HUMAN EXPERIMENTATION/ . . . / EMBRYOS AND FETUSES

Lott, Jason P.; Savulescu, Julian. 2 Towards a global human embryonic stem cell bank. 3 American Journal of Bioethics 4 2007 August 5; 7(8): 37-44. 27 refs. 8 NRCBL: 18.5.4; 15.1; 19.5; 14.5; 9.3.19. SC: an10.

Keywords: *embryonic stem cells; *tissue banks; cell lines; cloning; donors; embryo disposition; ethnic groups; economics; financial support; in vitro fertilization; incentives; informed consent; international aspects; justice; mandatory programs; minority groups; moral policy; nuclear transfer techniques; organ transplantation; policy analysis; racial groups; remuneration; resource allocation; scarcity; social discrimination; standards; stem cell transplantation; transplant recipients;15 Proposed Keywords: embryo donation; haplotypes; tissue typing16.

Abstract: An increasingly unbridgeable gap exists between the supply and demand of transplantable organs. Human embryonic stem cell technology could solve the organ shortage problem by restoring diseased or damaged tissue across a range of common conditions. However, such technology faces several largely ignored immunological challenges in delivering cell lines to large populations. We address some of these challenges and argue in favor of encouraging contribution or intentional creation of embryos from which widely immunocompatible stem cell lines could be derived. Further, we argue that current immunological constraints in tissue transplantation demand the creation of a global stem cell bank, which may hold particular promise for minority populations and other sub-groups currently marginalized from organ procurement and allocation systems. Finally, we conclude by offering a number of practical and ethically oriented recommendations for constructing a human embryonic stem cell bank that we hope will help solve the ongoing organ shortage problem.18.

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This volume of the *Bibliography of Bioethics*

is dedicated to the memory of
our dear colleague and friend

**Frances Amitay Abramson**
January 13, 1933 - August 10, 2007

Associate Editor of the
*Bibliography of Bioethics, 1980-2007*
Library and Information Services
Kennedy Institute of Ethics
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INTRODUCTION
INTRODUCTION

The Field of Bioethics

Bioethics can be defined as the systematic study of value questions that arise in health care delivery and in biomedicine. Specific bioethical issues that have recently received national and international attention include euthanasia, assisted suicide, new reproductive technologies, cloning, human experimentation, genetic engineering, the neurosciences, abortion, informed consent, acquired immunodeficiency syndrome (AIDS), organ donation and transplantation, and managed care and other concerns in the allocation of health care resources.

As this list of topics suggests, the field of bioethics includes several dimensions. The first is the ethics of the professional patient relationship. Traditionally, the accent has been on the duties of health professionals—duties that, since the time of Hippocrates, have frequently been delineated in codes of professional ethics. In more recent times the rights of patients have also received considerable attention. Research ethics, the study of value problems in biomedical and behavioral research, constitutes a second dimension of bioethics. During the 20th century and the start of the 21st century, as both the volume and visible achievements of such research have increased, new questions have arisen concerning the investigator-subject relationship and the potential social impact of biomedical and behavioral research and technology. In recent years a third dimension of bioethics has emerged—the quest to develop reasonable public policy guidelines for both the delivery of health care and the allocation of health care resources, as well as for the conduct of research.

No single academic discipline is adequate to discuss these various dimensions of bioethics. For this reason bioethics has been, since its inception in the late 1960s, a cross-disciplinary field. The primary participants in the interdisciplinary discussion have been physicians and other health professionals, biologists, psychologists, sociologists, lawyers, historians, and philosophical and religious ethicists.

During the past thirty-three years there has been a rapid growth of academic, professional, and public interest in the field of bioethics. One evidence of this interest is the establishment of numerous research institutes and teaching programs in bioethics, both in the United States and abroad. Professional societies, federal and state legislatures, and the courts have also turned increasing attention to problems in the field. In addition, there has been a veritable explosion of literature on bioethical issues.

The literature of bioethics appears in widely scattered sources and is reported in diverse indexes which employ a bewildering variety of subject headings. This annual Bibliography is the product of a unique information retrieval system designed to identify the central issues of bioethics, to develop a subject classification scheme appropriate to the field, and to provide comprehensive, cross-disciplinary coverage of current English-language materials on bioethical topics.

Volume 34 of the Bibliography contains one year’s worth of the literature garnered by this comprehensive information system. Specifically, it includes selected citations that were acquired in 2007 by two projects at the Kennedy Institute of Ethics: the National Reference Center for Bioethics Literature (NRCBL) and the National Information Resource on Ethics & Human Genetics (NIREHG).

The Table of Contents includes a list of subject headings used to arrange the citations. Most citations are listed once, under their primary subject heading. Classification numbers at the end of each citation represent additional topics covered by the publication. These classification numbers are drawn from the NRCBL’s Classification Scheme, reproduced on the inside front cover. The inside back cover offers a key to going from brief citations in Section II to more complete citations in Section I.
The Scope of the Bibliography

This thirty-fourth volume of the *Bibliography of Bioethics* includes materials which discuss the ethical aspects of the following major topics and subtopics:

**BIOETHICS, MEDICAL ETHICS, AND PROFESSIONAL ETHICS**
- Codes of Ethics
- Commissions
- Education
- Ethicists and Ethics Committees
- History
- Nursing Ethics and Philosophy
- Philosophy of Medicine
- Professional Ethics
- Quality and Value of Life

**DEATH AND DYING**
- Advance Directives
- Assisted Suicide
- Attitudes to Death
- Capital Punishment
- Determination of Death
- Euthanasia and Allowing to Die
- Terminal Care

**GENETICS AND GENOMICS**
- Behavioral Genetics
- Chimeras and Hybrids
- Eugenics
- Gene Therapy
- Genetic Counseling
- Genetic Databases and Biobanks
- Genetic Engineering and Biotechnology
- Genetic Enhancement
- Genetic Privacy
- Genetic Research
- Genetic Screening
- Genetically Modified Organisms and Food
- Genetics and Human Ancestry
- Genome Mapping and Sequencing
- Patents
- Pharmacogenetics

**HEALTH CARE AND PUBLIC HEALTH**
- AIDS
- Blood Banking, Donation and Transfusion
- Care for Specific Groups
- Drug Industry
- Health, Concept of
  - Mental Health, Concept of
- Health Care
  - Health Care Economics
- Health Care Quality
- Organ and Tissue Transplantation
- Public Health
- Resource Allocation
- Right to Health Care
- Sexuality
- Telemedicine and Informatics

**MENTAL HEALTH THERAPIES AND NEUROSCIENCES**
- Behavior Control
- Electroconvulsive Therapy
- Involuntary Commitment
- Psychopharmacology
- Psychotherapy

**PATIENT RELATIONSHIPS**
- Confidentiality
- Informed Consent
- Treatment Refusal
- Truth Disclosure

**REPRODUCTION AND REPRODUCTIVE TECHNOLOGIES**
- Abortion
- Artificial Insemination and Surrogate Mothers
- Cloning
- Contraception
- Cryobanking of Sperm, Ova, and Embryos
- In Vitro Fertilization
- Sex Determination

**RESEARCH**
- Animal Experimentation
- Behavioral Research
- Biomedical Research
- Enhancement
- Human Experimentation
- Nanotechnology
- Research Ethics and Scientific Misconduct
- Social Control of Science and Technology
- Stem Cell Research

**SOCIOLGY OF MEDICINE**
- Cultural Pluralism
- Journalism and Publishing
- Malpractice and Professional Misconduct
- Medical Education
- Professional Professional Relationship
INTRODUCTION

WAR AND HUMAN RIGHTS ABUSES
International Health and Human Rights
International Migration of Health Care Professionals

This volume of the Bibliography cites 5,955 documents (primarily in English) that discuss ethical and related public policy aspects of the topics and subtopics listed above. Documents cited in this volume include journal and newspaper articles, laws, court decisions, monographs, and chapters in books. Most of the documents listed were published since 2004. In the Periodical Literature and Essays section, for example, 3,037 of the 5,201 entries were published in 2007; 1,316 in 2006; and 373 in 2005; therefore, 91 per cent of the literature cited in Section I was published from 2005 to 2007.

A cross-disciplinary monitoring system has been devised in an effort to secure documents falling within the subject-matter scope outlined above. Among the reference tools and databases searched for pertinent citations are the following:

AGRICOLA
All England Law Reports (subject index)
ATLA Religion Database
Choice
Cumulative Index to Nursing and Allied Health Literature (CINAHL)
Current Contents: Social and Behavioral Sciences
Digital Dissertations and Theses (UMI Proquest)
Dominion Law Reports (subject index)
ERIC
GPO Access
Library Journal
Mental and Physical Disability Law Reporter

In addition, the Bibliography staff directly monitors hundreds of web sites on an ongoing basis as well as 184 journals and newspapers for articles falling within the scope of bioethics. Those preceded by an asterisk (*) have given permission for abstracts to be included in this volume. It is important to note that the journal articles cited in this volume are actually drawn from many more journals than those listed below.

Academic Medicine
*Accountability in Research
Agriculture and Human Values
AIDS and Public Policy Journal
America
*American Journal of Bioethics
*American Journal of Law and Medicine
American Journal of Nursing
American Journal of Psychiatry
*American Journal of Public Health
Annals of Health Law
*Annals of Internal Medicine
APA Newsletter on Philosophy and Medicine
*Archives of Internal Medicine
ATLA: Alternatives to Laboratory Animals
*Bioethics
Bioethics Forum
BMC Medical Ethics [electronic resource]
*BMJ (British Medical Journal)

British Journal of Nursing
*Cambridge Quarterly of Healthcare Ethics
Canadian Medical Association Journal
CCAR Journal
Cerebrum
*Christian Bioethics
Christian Century
Community Genetics
Criminal Justice Ethics
DePaul Journal of Health Care Law
Developing World Bioethics
Dolentium Hominum
Environmental Ethics
Ethical Human Psychology and Psychiatry
Ethical Perspectives
Ethical Theory and Moral Practice
*Ethics
*Ethics and Behavior
Ethics and Intellectual Disability
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European Journal of Health Law
First Things: A Monthly Journal of Religion and Public Life
Formosan Journal of Medical Humanities
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*Hastings Center Report
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*Health Care Analysis
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Health Progress
*HEC Forum
Human Genome News
Human Life Review
Human Reproduction
Human Reproduction and Genetic Ethics
Human Research Report
Humane Health Care [electronic resource]
Hypatia
IDHL: International Digest of Health Legislation [online]
Indian Journal of Medical Ethics
International Journal of Applied Philosophy
*International Journal of Bioethics (Journal International de Bioéthique)
International Journal of Health Services
International Journal of Law and Psychiatry
International Journal of Technology Assessment in Health Care
IRB: Ethics and Human Research
Issues in Law and Medicine
Issues in Science and Technology
*JAMA
Jewish Medical Ethics and Halacha
JONA's Healthcare Law, Ethics, and Regulation
Journal of Advanced Nursing
Journal of Applied Animal Welfare Science
Journal of Applied Philosophy
*Journal of Bioethical Inquiry
Journal of Biowalt and Business
*Journal of Clinical Ethics
Journal of Contemporary Health Law and Policy
Journal of Ethics
Journal of General Internal Medicine
Journal of Genetic Counseling
Journal of Halacha and Contemporary Society
Journal of Health Care Law and Policy
*Journal of Health Politics, Policy and Law
Journal of Information Ethics
Journal of Intellectual Disability Research
Journal of Law and Health
Journal of Law and Religion
*Journal of Law, Medicine and Ethics
Journal of Legal Medicine
*Journal of Medical Ethics
Journal of Medical Genetics
*Journal of Medical Humanities
*Journal of Medicine and Philosophy
Journal of Moral Education
Journal of Nursing Administration
Journal of Nursing Law
Journal of Palliative Care
Journal of Philosophy, Science and Law
Journal of Professional Nursing
Journal of Psychiatry and Law
Journal of Public Health Policy
Journal of Religion and Health
Journal of Religious Ethics
Journal of Social Philosophy
Journal of the American Academy of Psychiatry and the Law
Journal of the American College of Dentists
Journal of the American Geriatrics Society
Judaism
*Kennedy Institute of Ethics Journal
*Lancet
Law and the Human Genome Review (Revista de Derecho y Genoma Humano)
Legal Medical Quarterly
Linacre Quarterly
Literature and Medicine
Medical Ethics & Bioethics (Medicinska Etika & Bioetika)
Medical Humanities
Medical Humanities Review
Medical Law International
Medical Law Review
Medicine and Law
Medicine, Conflict and Survival
Medicine, Health Care and Philosophy
Mental Retardation [ISSN 0047-6765]
*Milbank Quarterly
Minnesota Medicine
Monash Bioethics Review
Nanoethics
*National Catholic Bioethics Quarterly
*Nature
Nature Biotechnology
Nature Medicine
NCEHR Communiqué (National Council on Ethics in Human Research)
New Atlantis
*New England Journal of Medicine
New Genetics and Society
New Scientist
New York Times
Newsweek
Notizie de Politeia
Notre Dame Journal of Law, Ethics and Public Policy
*Nursing Ethics
Omega: Journal of Death and Dying
Online Journal of Issues in Nursing
Origins
Perspectives in Biology and Medicine
Perspectives on the Professions: Ethical & Policy Issues
Pharos
*Philosophy and Public Affairs
Philosophy and Public Policy Quarterly
Politics and the Life Sciences
Professional Ethics Report
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Public Affairs Quarterly
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Social Philosophy and Policy
*Social Science and Medicine
Social Theory and Practice
Society and Animals
*Theoretical Medicine and Bioethics
Tradition
Update (Loma Linda University Ethics Center)
U.S. News and World Report
Virtual Mentor: Ethics Journal of the American Medical Association [electronic resource]
Washington Post
Women's Health Issues
Yale Journal of Health Policy, Law, and Ethics

All documents cited by the Bibliography are in the collection of the NRCBL.

Arrangement of the Bibliography

This volume of the Bibliography of Bioethics is divided into five parts:
1. Introduction
2. Section I: Periodical Literature and Essays — Subject Entries
3. Section II: Periodical Literature and Essays — Author Index
4. Section III: Monographs — Subject Entries
5. Section IV: Monographs — Title Index.
Sections 2 and 4 constitute the core of the Bibliography.

Section 1: Periodical Literature and Essays — Subject Entries

This Section, one of the two main parts of the Bibliography, contains usually one entry for each of the documents selected by the bioethics information retrieval system during the preceding year. In Volume 34 of the Bibliography, entries for 5,201 documents have been included in the Section. The format of these documents is as follows:

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<td>Newspaper articles</td>
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</table>

Section I is organized under 78 major subject headings, of which 14 are further divided by subheadings. Each subheading is separated from the major subject term by a slash.
BIBLIOGRAPHY OF BIOETHICS

Readers of the Bibliography should first scan the alphabetic list of subject headings in the Table of Contents to determine where citations of interest to them are likely to be found.

Section I includes cross references of two types. See cross references lead the reader from terms that are not used as subject headings to terms that are used. See also cross references suggest additional subject headings where the reader may find citations of related interest.

Citations appear alphabetically by author, with anonymous citations at the beginning of the section, sorted alphabetically by title. Entries with both corporate and personal authors are sorted by the corporate author. As explained below, the citations are accompanied by NRCBL Classification Scheme numbers as well as, in some cases, Subject Captions denoting approach or content. Subject Caption definitions can be found on page footers. Abstracts are again included in this volume. Several optional fields provide additional information: identifiers (such as persons, places, organizations, acronym equivalents), conference information, comments regarding related publications, and general notes.

With the support of a grant from the U.S. National Human Genome Research Institute, bibliographers began indexing the genetics literature early in 2007 using the Bioethics Thesaurus for Genetics (see http://bioethics.georgetown.edu/nirehg/index.htm), a controlled vocabulary developed specifically for this project, using the Bioethics Thesaurus, originally developed for the BIOETHICSLINE database, as its foundation. The indexed citations are accompanied by keywords, proposed keywords, and keyword identifiers (usually proper nouns) in Section I. In addition to enhancing the representation of the content of each indexed citation, the keywords are used to generate more precise subject categories for the genetics literature. New subject headings appearing in this volume are: CHIMERAS AND HYBRIDS, GENETIC DATABASES AND BIOBANKS, GENETIC ENGINEERING AND BIOTECHNOLOGY, GENETIC ENHANCEMENT, GENETICALLY MODIFIED ORGANISMS AND FOOD, and PHARMACOGENETICS.

Now eighteen data elements may appear in a citation. A sample subject heading and entry for a journal article follow:

**HUMAN EXPERIMENTATION/ . . . / EMBRYOS AND FETUSES**

**Lott, Jason P.; Savulescu, Julian.** Towards a global human embryonic stem cell bank. *American Journal of Bioethics* 2007 August; 7(8): 37-44. NRCBL: 18.5.4; 15.1; 19.5; 14.5; 9.3.1. SC: an.

Keywords: *embryonic stem cells; *tissue banks; cell lines; cloning; donors; embryo disposition; Proposed Keywords: embryo donation; haplotypes; tissue typing.

Abstract: An increasingly unbridgeable gap exists between the supply and demand of transplantable organs. Human embryonic stem cell technology could solve the organ shortage problem by restoring diseased or damaged . . . .

1. Subject heading: **HUMAN EXPERIMENTATION/ . . . / EMBRYOS AND FETUSES** [Note: the ellipsis indicates that an intervening phrase of an exceptionally long subject heading has been omitted.]
2. Author(s): **Lott, Jason P.; Savulescu, Julian.**
3. Title of article: Towards a global human embryonic stem cell bank.
4. Title of journal: *American Journal of Bioethics*
5. Date of publication: 2007 August
6. Volume and issue number (if available): 7(8)
7. Pagination: 37-44
8. References: 27 refs. (optional)
9. NRCBL (all classification numbers): 18.5.4; 15.1; 19.5; 14.5; 9.3.1
10. SC (Subject Captions): an [analytical] (optional; not present here)
11. Identifiers: (optional; not present here)
12. Note: additional information (optional; not present here)
13. Conference: (optional; not present here)
14. Comments: information about related publications (optional; not present here)
15. Keywords: *embryonic stem cells; *tissue banks; . . . (optional)
INTRODUCTION

16. Proposed Keywords: embryo donation; haplotypes; tissue typing (optional)
17. Keyword Identifiers: (optional; not present here)
18. Abstract: An increasingly unbridgeable gap . . . . (optional)

The journal article is the most prevalent publication type. The title field may be augmented by terms in square brackets which indicate additional aspects of the document, such as: letter, editorial, and news. The complete NRCBL Classification Scheme can be found on the inside front cover, and the Subject Captions equivalents are on alternating footers in Section I. The inside back cover displays the Subject Heading Key for Section II, leading the reader from the primary, i.e. first, NRCBL number to the corresponding Subject Heading(s) in Section I. Most citations appear only once in this volume.

Section II: Periodical Literature and Essays — Author Index

Citations in the Author Index are followed by the primary NRCBL Classification Number (Subject). Citations that have no personal or corporate author are listed at the end of the Author Index for Periodical Literature and Essays under ANONYMOUS. The two-page SUBJECT HEADING KEY FOR SECTION II appears on the inside back cover; it provides subject heading equivalents in Section I for the subject numbers appearing at the end of each citation in Section II.

Section III: Monographs — Subject Entries

These records have been derived from the annual publication of the NRCBL’s New Titles in Bioethics, and cite monographs added to the collection in 2007 that cover bioethics and related areas of ethics and applied ethics. The NRCBL Classification Scheme (reproduced in full on the inside front cover) provides the arrangement for these citations. The Monographs section includes 754 records for books, reports, audiovisuals, special issues of journals, and new periodical subscriptions. Only subject headings actually occurring in Volume 34 are included on this list.

The monograph citations are arranged according to the primary subject category of the volume, and then, under subject category, by author, editor, producer, or title. Each citation in the Section usually appears only once. Classification numbers at the end of each citation represent additional bioethics topics covered by the publication. Monograph entries also include acquisition information, especially important for the so-called “gray literature.” Monographs in foreign languages are included in the Bibliography.

Section IV: Monographs — Title Index

This Section provides a title index to all the entries in the Monographs Section. The title is followed by the subject section and author within which the complete citation can be found.

The Bibliography of Bioethics: History and Current Availability on the World Wide Web

Through December 2000, the entries in all of the annual volumes of the Bibliography of Bioethics were available online in BIOETHICSLINE, a database produced for the National Library of Medicine (NLM) by the Bioethics Information Retrieval Project at the Kennedy Institute of Ethics, Georgetown University. As of 2001, NLM incorporated its subject-oriented databases—like BIOETHICSLINE—into two large databases, PubMed/MEDLINE for journal articles and related documents, and LOCATORplus/NLM Catalog for books and related documents.

Citations from the Bibliography of Bioethics are available on the World Wide Web via the ETHXWeb and GenETHX databases, maintained by NRCBL. Access to these databases, along with searching information, is available through the Web gateway of the Kennedy Institute of Ethics at http://bioethics.georgetown.edu. In addition, a comprehensive NRCBL publication provides advice for database searchers: Bioethics Searcher’s Guide to Online Information Resources. (See “Distribution” paragraph below for ordering information.)
ACKNOWLEDGMENTS

It is a pleasure to acknowledge the assistance of several people and organizations who played significant roles in the production of this thirty-fourth volume of the Bibliography of Bioethics. Although this publication is not a direct product of federal funding, it depends upon critical support from the National Library of Medicine and the National Human Genome Research Institute, both at the National Institutes of Health. We wish to thank, in particular, our NLM Project Officers, Sara Tybaerts, Martha Cohn, and Susan Von Braunberg; our NLM Contracting Officer, Alex Navas; and Joy Boyer, Program Director, The Ethical, Legal, and Social Implications Program, National Human Genome Research Institute, for their interest and support. Other support is provided by the National Endowment for the Humanities, the Anderson Partnership, Max M. and Marjory B. Kampelman, and many publishers and individuals who contributed copies of books and journal articles to NRCBL.

Patricia Milmoe McCarrick, former reference librarian at NRCBL, continues as a library volunteer. Mark Rosetti, a Georgetown University student, carried out document acquisition and data entry tasks.

DISTRIBUTION OF THE BIBLIOGRAPHY OF BIOETHICS AND RELATED PUBLICATIONS

Inquiries about purchasing Volumes 10-34 of the Bibliography or the current edition of Bioethics Searcher’s Guide to Online Information Resources should be directed to Library Publications, Kennedy Institute of Ethics, Georgetown University, Box 571212, Washington, DC 20057-1212, telephone 202-687-3885 or 888-BIO-ETHX (outside the Washington, DC metropolitan area); fax 202-687-6770, e-mail: bioethics@georgetown.edu.

INTERNATIONAL BIOETHICS EXCHANGE PROJECT (IBEP)

IBEP, a project of the Kennedy Institute of Ethics, promotes research and education in bioethics in the developing world by donating multiple volumes of the Bibliography to libraries abroad in order to encourage the development of bioethics reference resources in those countries. In turn, IBEP is eager to collect documents about bioethics from the exchange participants. Any books, policy statements, periodicals and other materials about bioethical issues in the participant countries that are donated to IBEP are added to the NRCBL collection and considered for inclusion in the Bibliography. This project relies upon the support of donors to underwrite the transport of the volumes to the developing country library.

To date libraries in the following countries have become participants in the project: Argentina, Belarus, Brazil, Burkina Faso, Cameroon, China, Congo, Costa Rica, Croatia, Eritrea, Gabon, Grenada, Israel, Jamaica, Kenya, Korea (South), Liberia, Lithuania, Madagascar, Mexico, Nigeria, Papua New Guinea, Philippines, Poland, Portugal, Romania, Rwanda, Saint Lucia, Sierra Leone, Slovakia, Slovenia, South Africa, Sri Lanka, Sudan, Thailand, Trinidad and Tobago, Turkey, Uzbekistan, Venezuela, Yemen, and Zambia.

Contributions in support of an IBEP library or donations of bioethics books, reprints, audiovisual materials, and other documents should be sent to Lucinda Fitch Huttlinger, Acquisitions Librarian, Kennedy Institute of Ethics, Georgetown University, Box 571212, Washington, DC 20057-1212; Telephone: +202-687-6433; Toll-free telephone: 1-888-BIO-ETHX (U.S. and Canada); FAX +202-687-6770; e-mail: bioethics@georgetown.edu. All donations are reviewed for inclusion in the NRCBL collection as well as for this Bibliography.

The staff welcomes suggestions for the improvement of future volumes of the Bibliography of Bioethics. Please send all comments to:

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Kennedy Institute of Ethics, Box 571212
Georgetown University
Washington, DC 20057-1212

July 22, 2008
SECTION I:
PERIODICAL LITERATURE
AND ESSAYS

SUBJECT ENTRIES
SECTION I: PERIODICAL LITERATURE AND ESSAYS

SUBJECT ENTRIES

ABORTION


Cole, Andrew. Botched abortions kill more than 66,000 women each year [news]. BMJ: British Medical Journal 2007 October 27; 335(7625): 845. NRCBL: 12.1; 9.5.5; 9.8; 20.1.


Horst, Jason M. The meaning of “life”: the morning-after pill, the question of when life begins, and judicial review. Texas Journal of Women and the Law 2007 Spring; 16(2): 205. NRCBL: 12.1; 9.7; 4.4. SC: le.


ABORTION/ LEGAL ASPECTS


Bodger, Jessica Ansley. Taking the sting out of reporting requirements: reproductive health clinics and the constitutional right to informational privacy. Duke Law Journal 2006 November; 56(2): 583-609. NRCBL: 12.4.2; 8.4; 8.3.2; 9.5.5; 10. SC: an; le.

NRCBL: National Reference Center for Bioethics Literature Classification Scheme

See inside front cover for terms.

Caplan, Arthur; Marino, Thomas A. The role of scientists in the beginning-of-life debate: a 25-year retrospective. Perspectives in Biology and Medicine 2007 Autumn; 50(4): 603-613. NRCBL: 12.4.2; 1.3.5; 1.3.9; 4.4; 5.1; 15.1; 18.5.4; 2.2. SC: le.


Abstract: Based on the case of Rosa, a nine-year-old girl who was denied a therapeutic abortion, this article analyzes the role played by the social in medical practice. For that purpose, it compares the different application of two similar pieces of legislation in Costa Rica, where both the practice of abortion and sterilization are restricted to the protection of health and life by the Penal Code. As a concept subject to interpretation, a broad conception of medical necessity could enable an ample use of the therapeutic exception and a liberal use of both surgeries. The practice of therapeutic sterilization has been generalized in Costa Rica and has become the legitimate way to distribute contraceptive sterilization. In contrast, therapeutic abortion is very rarely practiced. The analysis carried out proposes that it is the difference in social acceptance of abortion and sterilization that explains the different use that doctors, as gatekeepers of social morality, make of medical necessity.


Cook, R.J.; Ortega-Ortiz, A.; Romans, S.; Ross, L.E. Legal abortion for mental health indications. International Journal of Gynecology and Obstetrics 2006 November; 95(2): 185-190. NRCBL: 12.4.2; 17.1; 8.1; 7.1.


Abstract: The South African Choice on Termination of Pregnancy Act (Act 92 of 1996) (CTOP) passed by parliament ten years ago, aims to promote female reproductive autonomy through legitimising free access to abortion up to 20 weeks of gestation. The article critically evaluates CTOP and highlights three societal concerns: the effect of CTOP on the self-esteem of nurses who perform abortion; the effect on general societal morality, and its desirability. CTOP has enjoyed mixed success. On the plus side, it has furthered female reproductive autonomy, has decreased early pregnancy maternal mortality and has advanced non-racialism through equal access to safe abortion. On the minus side, it remains controversial; the majority of the population opposes abortion on request, predominantly based on religiously-informed intuitions on the value of ante-natal life. Officials and managers of public health care facilities are often obstructive, and TOP personnel victimised and socially stigmatised. An unacceptably high rate of unsafe abortion prevails, particularly in rural areas and amongst adolescents, but also in certain urban areas. The prime causes are inadequate public education, attitudinal problems, and lack of psychological support for TOP personnel, the segregation of ante-natal care and abortion services, inadequate training, research, communication and contraceptive services, absence of incentives for TOP personnel and “traditional” gender roles and male power-based domination in reproductive choices. Corrective measures include a goal directed educational programme and initiatives like value clarification workshops which have been effective in changing negative attitudes of participants, and may thus address stigmatisation, improve working conditions of TOP personnel, promote societal tolerance and acceptance, and informed consent. Of particular concern are the questions of informed consent, minors, promotion of counselling and contraceptive services (particularly for adolescents), conscientious objection and the protection of compliant (and non-compliant) personnel.


SECTION I

ABORTION/Legal Aspects

Diniz, Deborra. Selective abortion in Brazil: the anencephaly case. Developing World Bioethics 2007 August; 7(2): 64-67. NRCBL: 12.4.1; 11.3; 12.5.1. SC: le. Abstract: This paper discusses the Brazilian Supreme Court ruling on the case of anencephaly. In Brazil, abortion is a crime against the life of a fetus, and selective abortion of non-viable fetuses is prohibited. Following a paradigmatic case discussed by the Brazilian Supreme Court in 2004, the use of abortion was authorized in the case of a fetus with anencephaly. The objective of this paper is to analyze the ethical arguments of the case, in particular the strategy of avoiding the moral status of the fetus, the cornerstone thesis of the Catholic Church.


Dzier, Clare. Girl carrying anencephalic fetus is granted right to travel. BMJ: British Medical Journal 2007 May 19; 334(7602): 1026. NRCBL: 12.4.2; 20.5.2. Identifiers: Ireland.


European Commission of Human Rights. Brüggemann v. Germany [Date of Decision: 12 July 1977]. European Human Rights Reports 1977; 3: 244-258. NRCBL: 12.4.4; 12.4.3. SC: le. Abstract: Two German women, Brüggemann and Scheuten, assert that German law on abortion interferes with their right to respect for their private life under the European Convention on Human Rights. Specifically, they allege that they are not free to abort an unwanted pregnancy. In 1975, the German constitutional court voided a 1974 law allowing abortion during the first twelve weeks of pregnancy without any particular reason; thus German law remained as banning any abortion except in the case of medical grounds, i.e. saving the mother’s life or health. After that decision, in the next year, 1976, a new law was passed, which continued to hold abortion as a criminal offence, but allowed that in situations of distress, a doctor may perform an abortion with the woman’s consent after consultation. The European Commission on Human Rights found that German abortion law did not interfere with a woman’s right to respect for her private life, because Article 8(1) of the European Convention on Human Rights “cannot be interpreted as meaning that pregnancy and its termination are, as a principle, solely a matter of the private life of the mother.” The Commission reasoned that “pregnancy cannot be said to pertain uniquely to the sphere of private life.” Earlier jurisprudence held that “the claim to respect for private life is automatically reduced to the extent that the individual himself brings his private life into contact with public life or into close connection with other protected interests”.


Gornall, Jonathan. Where do we draw the line? Numerous attempts have been made to change the rules on abortion since it was legalised 40 years ago. BMJ: British Medical Journal 2007 February 10; 334(7588): 285-289. NRCBL: 12.4.1; 12.3; 12.5.1; 21.1. Identifiers: Great Britain (United Kingdom).


Hatzivramidis, Katie. Parental involvement law for abortion in the United States and the United Nations conventions on the rights of the child: Can international law secure the right to choose for minors? Texas Journal of Women and the Law 2007 Spring; 16(2): 185-204. NRCBL: 12.4.2; 8.3.2; 21.1. SC: le.


Hunter, Nan D. Justice Blackmun, abortion, and the myth of medical independence. Brooklyn Law Review 2006 Fall; 72(1): 147-197. NRCBL: 12.4.2; 1.1; 4.1.2; 9.5.5; 10. SC: le.


Kolenc, Antony B. Easing abortion’s pain: can fetal pain legislation survive the new judicial scrutiny of legislative fact-finding? Texas Review of Law and Politics 2005 Fall; 10(1): 171-228. NRCBL: 12.4.2; 9.5.8; 4.4. SC: le.


McAllister, Marc Chase. Human dignity and individual liberty in Germany and the United States as examined through each country’s leading abortion cases. Tulsa Journal of Comparative and International Law 2004 Spring; 11(2): 491-520. NRCBL: 12.4.2; 12.4.1; 4.4; 21.1.

Miller, Suellen; Billings, Deborah L. Abortion and postabortion care: ethical, legal, and policy issues in developing countries. Journal of Midwifery and Women’s Health 2005 July-August; 50(4): 341-343. NRCBL: 12.4.1; 12.5.3; 21.1; 12.3; 4.1.3. SC: cs.


Abstract: In Japan abortion is categorized into two types by law; one is illegal feticide and the other is legal abortion. The present criminal law forbids feticide in principle and the life of a fetus is protected. However, abortion can be practiced under the “Eugenic Protection Act” established in 1948 (currently referred to as the “Maternal Protection Act”), and is readily available in Japan. In this paper, I have traced the historical origins of abortion law and attempted to clarify the problems related to the current laws relating to artificial abortion. As a result, the existence of contradictions between attitudes toward the life of the fetus and that of the mother, women’s right to self determination, and women’s rights under current legislation has been clarified.


O’Toole, Leslie C.; Sobel-Read, Kevin B. Pharmacist refusals: a new twist on the debate over individual autonomy. Gender Medicine 2006 March; 3(1): 13-17. NRCBL: 12.4.3; 12.3; 8.1; 9.7; 1.1.


Pozgar, George D. Issues of procreation. In his: Legal Aspects of Health Care Administration. 9th edition. Sudbury,
MA: Jones and Bartlett Publishers, 2004: 345-364. NRCBL: 12.4.2; 12.4.3; 11.3; 11.4. SC: le; cs.


Statham, H.; Solomou, W.; Green, J. Late termination of pregnancy: law, policy and decision making in four English fetal medicine units. *BJOG: An International Journal of Obstetrics and Gynaecology* 2006 December; 113(12): 1402-1411. NRCBL: 12.4.2; 12.5.2.


**ABORTION/ MORA L AND RELIGIOUS ASPECTS**


Breger, Marshall. Freedom to choose. For Jewish women, a pro-choice stance on abortion often reflects their political values and culture as much as their views on reproductive freedom. *Moment* 1999 August; 24(4): 28-29. NRCBL: 12.3; 12.5.1; 1.2.


Eberl, Jason T. Issues at the beginning of human life: abortion, embryonic stem cell research, and cloning. In *his:* Thomistic Principles and Bioethics. London; New York: Routledge, 2006: 62-94. 19 fn. NRCBL: 12.3; 1.1; 4.4; 14.5; 18.5.4; 15.1. SC: an. Keywords: *abortion; beginning of life; cloning; embryryo research; embryos; moral status; abortifacients; adult stem cells; embryo disposition; fetal stem cells; in vitro fertilization; moral complicity; natural law; personhood; philosophy; reproductive technologies; Proposed Keywords: blastocysts; Keyword Identifiers: *Thomas Aquinas

NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.
Abstract: I argue that David Boonin has failed in his attempt to undermine Donald Marquis’s future-like-ours argument against abortion. I show that the ethical principle advanced by Boonin in his critique to that argument is unable, contrary to what he claims, to account for the wrongness of infanticide. Then I argue that Boonin’s critique misrepresented Marquis’s argument. Although there is a way to restate his critique in order to avoid the misrepresentation, the success of such restatement is precluded by the wrongness of infanticide.


Lustig, B. Andrew. The church and the world: are there theological resources for a common conversation? Christian Bioethics 2007 May-August; (13)2: 225-244. NRCBL: 12.3; 1.2; 7.1. SC: an.
Abstract: Abortion is an especially salient issue for considering the general problematic of religiously based conversation in the public square. It remains deeply divisive, fully thirty-four years after Roe v. Wade. Such divisiveness cannot be interpreted as merely an expression of profound differences between “secular” and “religious” voices, because differences also emerge among Christian denominations, reflecting different sources of moral authority, different accounts of moral discernment, and different judgments about the appropriate relations between law and morality in the context of pluralism. As this paper explores, however, despite those differences, a generally identifiable “Christian” position concerning the moral status of abortion can be distinguished from secular philosophical judgments on the issue, which is important for Christian engagement with public policy debate.


Abstract: Lee claims that foetuses and adult humans are phases of the same identical substance, and thus have the same moral status because: first, foetuses and adults are the same physical organism, and second, the development from foetus to adult is quantitative and thus not a change of substance. Versus the first argument, I contend that the fact that foetuses and adults are the same physical organism implies only that they are the same thing but not the same substance, much as living adults and their corpses are the same thing (same body) but not the same substance. Against Lee’s second argument, I contend that Lee confuses the nature of a process with the nature of its result. A process of quantitative change can produce a change in substance. Lee also fails to show that foetuses are rational and thus have all the essential properties of adults, as required for them to be the same substance. Against the pro-choice argument from asymmetric value (that only the fact that a human has become conscious of its life and begun to count on its continuing can explain human life’s asymmetric moral value, i.e. that it is vastly worse to kill a human than not to produce one), Lee claims that foetus’s lives are asymmetrically valuable to them before consciousness. This leads to counterintuitive outcomes, and it confuses the goodness of life (a symmetric value that cannot account for why it is worse to kill a human than not produce one) with asymmetric value.


ABORTION/ SOCIAL ASPECTS


Hashiloni-Dolev, Yael. Abortions on embryopathic grounds: policy and practice in Israel and Germany. *In her: A Life (Un)Worthy of Living: Reproductive Genetics in Israel and Germany*. Dordrecht: Springer, 2007: 83-104. 24 fn. NRCBL: 12.5.1; 15.2. SC: em. Keywords: *congenital disorders;* fetal development; *genetic counseling;* selective abortion; attitude of health personnel; cross cultural comparison; eugenics; fetuses; genetic disorders; historical aspects; interviews; Jewish ethics; legal aspects; males; prenatal diagnosis; professional role; public opinion; religion; Roman Catholic ethics; statistics; value of life; viability; women’s rights; wrongful life; Keyword Identifiers: *Germany;* Israel; Twentieth Century

Hashiloni-Dolev, Yael. Sex chromosome anomalies (SCAs) in Israel and Germany: assessing “birth defects” and medical risks according to the importance of fertility. *In her: A Life (Un)Worthy of Living: Reproductive Genetics in Israel and Germany*. Dordrecht: Springer, 2007: 105-117. 3 fn. NRCBL: 12.5.1; 15.2. SC: em. Keywords: *chromosome abnormalities;* genetic counseling; *selective abortion;* attitude of health personnel; child-birth; cross cultural comparison; culture; infertility; prenatal diagnosis; public opinion; reproductive technologies; risk; Keyword Identifiers: *Germany;* Israel; Klinefelter syndrome; Turner syndrome


Sedgh, Gilda; Henshaw, Stanley; Singh, Susheela; Ahman, Elizabeth; Shah, Iqbal H. Induced abortion: estimated rates and trends worldwide. *Lancet* 2007 October 13-19; 370(9595): 1338-1345. NRCBL: 12.5.2. SC: em. Abstract: BACKGROUND: Information on incidence of induced abortion is crucial for identifying policy and programmatic needs aimed at reducing unintended pregnancy. Because unsafe abortion is a cause of maternal morbidity and mortality, measures of its incidence are also important for monitoring progress towards Millennium Development Goal 5. We present new worldwide...
estimates of abortion rates and trends and discuss their implications for policies and programmes to reduce unintended pregnancy and unsafe abortion and to increase access to safe abortion. METHODS: The worldwide and regional incidences of safe abortions in 2003 were calculated by use of reports from official national reporting systems, nationally representative surveys, and published studies. Unsafe abortion rates in 2003 were estimated from hospital data, surveys, and other published studies. Demographic techniques were applied to estimate numbers of abortions and to calculate rates and ratios for 2003. UN estimates of female populations and livebirths were used as denominators for rates and ratios, respectively. Regions are defined according to UN classifications. Trends in abortion rates and incidences between 1995 and 2003 are presented. FINDINGS: An estimated 42 million abortions were induced in 2003, compared with 46 million in 1995. The induced abortion rate in 2003 was 29 per 1000 women aged 15-44 years, down from 35 in 1995. Abortion rates were lowest in western Europe (12 per 1000 women). Rates were 17 per 1000 women in northern Europe, 18 per 1000 women in southern Europe, and 21 per 1000 women in northern America (USA and Canada). In 2003, 48% of all abortions worldwide were unsafe, and more than 97% of all unsafe abortions were in developing countries. There were 31 abortions for every 100 livebirths worldwide in 2003, and this ratio was highest in eastern Europe (105 for every 100 livebirths). INTERPRETATION: Overall abortion rates are similar in the developing and developed world, but unsafe abortion is concentrated in developing countries. Ensuring that the need for contraception is met and that all abortions are safe will reduce maternal mortality substantially and protect maternal health.

ADVANCE DIRECTIVES

See also DEATH AND DYING; TREATMENT REFUSAL


Baumrucker, Steven J. Durable power of attorney versus the advance directive: who wins, who suffers? American Journal of Hospice and Palliative Care 2007 February-March; 24(1): 68-73. NRCBL: 20.5.4; 20.5.1; 8.3.3; 9.4.

Bianchi, Susan B. Living will for a handicapped child [letter]. Health Affairs 2007 September-October; 26(5): 1507. NRCBL: 20.5.4; 20.5.2.

Birnbacher, Dieter; Dabrock, Peter; Taupitz, Jochen; Vollmann, Jochen. Wie sollen Ärzte mit Patientenverfügungen umgehen? Ein Vorschlag aus interdisziplinärer Sicht [How should physicians deal with advance directives? A proposal from an interdisciplinary point of view].


Bockenheimer-Lucius, Gisela. Behandlungsbegrenzung durch eine Patientenverfügung - im individuellen Fall auch mit Blick auf neue therapeutische Möglichkeiten! = Limitation of treatment by an advanced directive - in the individual case also with regard to the therapeutic possibilities! Ethik in der Medizin 2007 March; 19(1): 5-6. NRCBL: 20.5.4; 20.5.1. SC: le. Identifiers: Austria; Germany.


Dyer, Clare. Patients win right to have their advance decisions honoured by medical staff [news]. BMJ: British Medical Journal 2007 October 6; 335(7622): 688-689. NRCBL: 20.5.4. SC: le. Identifiers: Great Britain (United Kingdom); Mental Capacity Act 2005.

Ehrlich, Joseph B. Schiavo: cold justice. Did the courts pursue, in view of the high court’s decision in Troxell v. Granville, the correct conclusion to the Schiavo case? The Journal of Law in Society Wayne State University Law School 2005 Fall; 7(1): 1-15. NRCBL: 20.5.4; 4.4; 8.3.3; 20.3.3; 20.5.1. SC: le.


For the past 15 years, hospitals have been providing these written materials, yet advance directives are still not adequately directing end-of-life care. Barriers and facilitators to implementation of this law are discussed, as well as the role of nursing management in meeting its true intent.


Michalowski, Sabine. Advance refusal of life-sustaining medical treatment: the relativity of an absolute right. Modern Law Review 2005 November; 68(6): 958-982. NRCBL: 20.5.4; 8.3.3; 8.3.4; 1.1; 1.2. SC: le. Identifiers: Great Britain (United Kingdom); Mental Capacity Act of 2005.


Nakashima, David Y. Your body, your choice: how mandatory advance health-care directives are necessary to protect your fundamental right to accept or refuse medical treatment. University of Hawai‘i Law Review 2004 Winter; 27(1): 201-231. NRCBL: 20.5.4; 8.3.4; 8.4; 20.5.1. Identifiers: Patient Self Determination Act; Uniform Health Care Decisions Act.


Abstract: Advance directives promise patients a say in their future care but actually have had little effect. Many experts blame problems with completion and implementation of the advance directive concept itself may be fundamentally flawed. Advance directives simply presuppose more control over future care than is realistic. Medical crises cannot be predicted in detail, making most prior instructions difficult to adapt, irrelevant, or even misleading. Furthermore, many proxies either do not know patients’ wishes or do not pursue those wishes effectively. Thus, unexpected problems arise often to defeat advance directives, as the case in this paper illustrates. Because advance directives offer only limited benefit, advance care planning should emphasize not the completion of directives but the emotional preparation of patients and families for future crises. The existentialist Albert Camus might suggest that physicians should warn patients and families that momentous, unforeseeable decisions lie ahead. Then, when the crisis hits, physicians should provide guidance; should help make decisions despite the inevitable uncertainties; should share responsibility for those decisions; and, above all, should courageously see patients and families through the fearsome experience of dying.


Samanta, Ash; Samanta, Jo. Advance directives, best interests and clinical judgement: shifting sands at the end of life. Clinical Medicine 2006 May-June; 6(3): 274-278. NRCBL: 20.5.4; 20.5.1; 9.4; 7.1; 8.1.


Stocking, C.B.; Hougham, G.W.; Danner, D.D.; Patterson, M.B.; Whitehouse, P.J.; Sachs, G.A. Speaking of research advance directives: planning for future research participation. Neurology 2006 May 9; 66(9): 1361-1366. NRCBL: 20.5.4; 18.2; 8.3.3.


Volandes, Angelo E.; Abbo, Elmer D. Flipping the default: a novel approach to cardiopulmonary resuscitation in end-stage dementia. Journal of Clinical Ethics 2007 Summer; 18(2): 122-139. NRCBL: 20.5.4; 9.5.2; 9.5.1; 20.4.1; 8.3.3; 17.1. SC: em.


ADVISORY COMMITTEES ON BIOETHICS
See BIOETHICS AND MEDICAL ETHICS/COMMISSIONS

AFRICAN AMERICANS AS RESEARCH SUBJECTS See HUMAN EXPERIMENTATION/SPECIAL POPULATIONS

AGED See CARE FOR SPECIFIC GROUPS/AGED; HUMAN EXPERIMENTATION/SPECIAL POPULATIONS/AGED AND TERMINALLY ILL

AGRICULTURE See GENETICALLY MODIFIED ORGANISMS AND FOOD

AIDS


Bennett, Rebecca. Routine antenatal HIV testing and informed consent: an unworkable marriage? Journal of Medical Ethics 2007 August; 33(8): 446-448. NRCBL: 9.5.6; 8.3.1; 9.5.5. Abstract: This paper considers the ethics of routine antenatal HIV testing and the role of informed consent within such a policy in order to decide how we should proceed in this area—a decision that ultimately rests on the relative importance we give to public health goals on the one hand and respect for individual autonomy on the other.


Christie, Timothy; Asrat, Getnet A.; Jiwani, Bashir; Maddix, Thomas; Montaner, Julio S.G. Exploring disparities between global HIV/AIDS funding and recent tsunami relief efforts: an ethical analysis. Developing World Bioethics 2007 April; 7(1): 1-7. NRCBL: 9.5.6; 9.4; 21.1. Abstract: Objective: To contrast relief efforts for the 26 December 2004 tsunami with current global HIV/AIDS relief efforts and analyse possible reasons for the disparity. Methods: Literature review and ethical analysis. Results: Just over 273,000 people died in the tsunami, resulting in relief efforts of more than US$10 bn, which is sufficient to achieve the United Nation’s long-term recovery plan for South East Asia. In contrast, 14 times more people died from HIV/AIDS in 2004, with UNAIDS predicting a US$8 bn funding gap for HIV/AIDS in developing nations between now and 2007. This disparity raises two important ethical questions. First, what is it that motivates a more empathic response to the victims of the tsunami than to those affected by HIV/AIDS? Second, is there a morally relevant difference between the two tragedies that justifies the difference in the international response? The principle of justice requires that two cases similarly situated be treated similarly. For the difference in the international response to the tsunami and HIV/AIDS to be justified, the tragedies have to be shown to be dissimilar in some relevant respect. Are the tragedies of the tsunami disaster and the HIV/AIDS pandemic sufficiently different, in relevant respects, to justify the difference in scope of the response by the international community? Conclusion: We detected no morally relevant distinction between the tsunami and the HIV/AIDS pandemic that justifies the disparity. Therefore, we must conclude that the international response to HIV/AIDS violates the fundamental principles of justice and fairness.

Coombes, Rebecca. Bad blood. *BMJ: British Medical Journal* 2007 April 28; 334(7599): 879-880. NRCBL: 9.5.6; 8.3.1; 19.4. Identifiers: haemophilia; factor VIII; hepatitis; HIV.

de Zulueta, Paquita; Boulton, Mary. Routine antenatal HIV testing: the responses and perceptions of pregnant women and the viability of informed consent. A qualitative study. *Journal of Medical Ethics* 2007 June; 33(6): 329-336. NRCBL: 9.5.6; 1.3.5; 8.3.1; 9.1; 9.5.5. SC: em. Abstract: This qualitative cross-sectional survey, undertaken in the antenatal booking clinics of a hospital in central London, explores pregnant women’s responses to routine HIV testing, examines their reasons for declining or accepting the test, and assesses how far their responses fulfil standard criteria for informed consent. Of the 32 women interviewed, only 10 participants were prepared for HIV testing at their booking interview. None of the women viewed themselves as being particularly at risk for HIV infection. The minority (n = 6) of the participants who declined testing differed from those who accepted, by interpreting test acceptance as risky behaviour, privileging the negative outcomes of HIV positivity and expressing an inability to cope with these, should they occur. Troublingly, only a minority of women (n = 9) had a broad understanding of the rationale for the test, and none fulfilled the standard criteria for informed consent. This study suggests that, although routine screening combined with professional recommendation may be successful in increasing uptake, this may be at the cost of eroding informed consent. Protecting third parties (notably fetuses) from a preventable disease may outweigh the moral duty of respecting autonomy, enshrined in Western bioethical tradition. Nevertheless, such a policy should be made transparent, debated in the public domain and negotiated with women seeking antenatal care.


Fielder, Odicie; Altice, Frederick L. Attitudes toward and beliefs about prenatal HIV testing policies and mandatory HIV testing of newborns among drug users. *AIDS and Public Policy Journal* 2005 Fall-Winter; 20(3-4): 74-91. NRCBL: 9.5.6; 9.1; 7.1; 9.5.7; 9.5.9. SC: em.


Patton, Cindy. Bullets, balance, or both: medicalisation in HIV treatment. *Lancet* 2007 February 24-March 2; 369(9562): 706-707. NRCBL: 9.5.6; 7.3; 7.1; 8.1; 4.1.1; 4.2.


Abstract: We analyzed the ethical and policy issues surrounding mandatory HIV testing of pregnant women in areas with high HIV prevalence rates. Through this analysis, we seek to demonstrate that a mandatory approach to testing and treatment has the potential to significantly reduce perinatal transmission of HIV and defend the view that mandatory testing is morally required if a number of conditions can be met. If such programs are to be introduced, continuing medical care, including highly active antiretroviral therapy, must be provided and pregnant women must have reasonable alternatives to compulsory testing and treatment. We propose that a liberal regime entailing abortion rights up to the point of fetal viability would satisfy these requirements. Pilot studies in the high-prevalence region of southern African countries should investigate the feasibility of this approach.

Smith, Charles B.; Battin, Margaret P.; Francis, Leslie P.; Jacobson, Jay A. Should rapid tests for HIV infection now be mandatory during pregnancy? Global differences in scarcity and a dilemma of technological advance. Developing World Bioethics 2007 August; 7(2): 86-103. NRCBL: 9.5.6; 9.5.5.

Abstract: Since testing for HIV infection became possible in 1985, testing of pregnant women has been conducted primarily on a voluntary, ‘opt-in’ basis. Faden, Geller and Powers, Bayer, Wilfert, and McKenna, among others, have suggested that with the development of more reliable testing and more effective therapy to reduce maternal-fetal transmission, testing should become either routine with ‘opt-out’ provisions or mandatory. We ask, in the light of the new rapid tests for HIV, such as OraQuick, and the development of antiretroviral treatment that can reduce maternal-fetal transmission rates to 1%, whether that time is now. Illustrating our argument with cases from the United States (US), Kenya, Peru, and an undocumented Mexican worker in the US, we show that when testing is accompanied by assured multi-drug therapy for the mother, the argument for opt-out or mandatory testing for HIV in pregnancy is strong, but that it is problematic where testing is accompanied by adverse events such as spousal abuse or by inadequate intrapartum or follow-up treatment. The difference is not a ‘double standard’, but reflects the presence of conflicts between the health interests of the mother and the fetus – conflicts that would be abrogated by the assurance of adequate, continuing multi-drug therapy. In light of these conflicts, where they still occur, careful processes of informed consent are appropriate, rather than opt-out or mandatory testing.


AIDS/ CONFIDENTIALITY


AIDS/ HUMAN EXPERIMENTATION

SECTION I AIDS/ LEGAL ASPECTS


Garber, Mandy; Hanusa, Barbara H.; Switzer, Galen E.; Mellors, John; Arnold, Robert M. HIV-infected African Americans are willing to participate in HIV treatment trials. JGIM: Journal of General Internal Medicine 2007 January; 22(1): 17-42. NRCBL: 9.5.6; 18.5.1. SC: em.


Moodley, Kaymanthri. Microbicide research in developing countries: have we given the ethical concerns due consideration? BMC Medical Ethics 2007; 8(10): 7 p. [electronic]. Accessed: http://www.biomedcentral.com/content/pdf/1472-6939-8-10.pdf [2007 December 18]. NRCBL: 9.5.6; 18.5.9; 9.7; 18.5.2; 18.5.3.


Slomka, Jaquelyn; McCurdy, Sheryl; Ratliff, Eric A.; Timpson, Sandra; Williams, Mark L. Perceptions of financial payment for research participation among African-American drug users in HIV studies. JGIM: Journal of General Internal Medicine 2007 October; 22(10): 1403-1409. NRCBL: 9.5.6; 18.5.1; 9.3.1. SC: em.


AIDS/ LEGAL ASPECTS


Halpern, Scott D.; Metkus, Thomas S.; Fuchs, Barry D.; Ward, Nicholas S.; Siegel, Mark D.; Luce, John M.; Curtis, J. Randall. Nonconsented human immunodeficiency virus testing among critically ill patients: intensivists’ practices and the influence of state laws. Archives of Internal Medicine 2007 November 26; 167(21): 2323-2328. NRCBL: 9.5.6; 8.3.3; 9.1. SC: le. Abstract: BACKGROUND: Human immunodeficiency virus (HIV) testing can improve care for many critically ill patients, but state laws and institutional policies may
impede such testing when patients cannot provide consent. METHODS: We electronically surveyed all US academic intensivists in 2006 to determine how state laws influence intensivists’ decisions to perform nonconsented HIV testing and to assess intensivists’ reliance on surrogate markers of HIV infection when unable to obtain HIV tests. We used multivariate logistic regression, clustered by state, to identify factors associated with intensivists’ decisions to pursue nonconsented HIV testing. RESULTS: Of 1026 responding intensivists, 765 (74.6%) had encountered decisionally incapacitated patients for whom HIV testing was wanted. Of these intensivists, 168 pursued testing without consent and 476 first obtained surrogate consent to testing. Intensivists who believed nonconsented HIV testing was ethical (odds ratio, 3.8; 95% confidence interval, 2.2-6.5) and those who believed their states allowed nonconsented testing when medically necessary (odds ratio, 2.3; 95% confidence interval, 1.6-3.4) were more likely to pursue nonconsented HIV tests; actual state laws were unrelated to testing practices. Of the intensivists, 72.7% had ordered tests for perceived surrogate markers of HIV infection in lieu of HIV tests; more than 90% believed these tests were sufficiently valid to base clinical decisions on. CONCLUSIONS: Most US intensivists have encountered decisionally incapacitated patients for whom HIV testing may improve care. Intensivists’ decisions to pursue nonconsented testing are associated with their personal ethics and often erroneous perceptions of state laws, but not with the laws themselves. Uniform standards enabling nonconsented HIV testing may minimize inappropriate influences on intensivists’ decisions and reduce intensivists’ reliance on perceived surrogate markers of immunodeficiency.


Reidpath, D.D.; Chan, K.Y. HIV discrimination: integrating the results from a six-country situational analysis in the Asia Pacific. AIDS Care 2005 July; 17(Supplement 2): S195-S204. NRCBL: 9.5.6; 9.5.4; 21.1. SC: em; le. Identifiers: China; India; Indonesia; Philippines; Thailand; Vietnam.


ALLOCATION See ORGAN AND TISSUE TRANSPLANTATION/ ALLOCATION; RESOURCE ALLOCATION

ALLOWING TO DIE See EUTHANASIA AND ALLOWING TO DIE

ANIMAL EXPERIMENTATION

NIH to make chimpanzee breeding moratorium permanent [news]. ATLA: Alternatives to Laboratory Animals 2007 June; 35(3): 300. NRCBL: 22.2; 5.3.


American Association for Laboratory Animal Science. AAALAS position statement on the humane care and use of laboratory animals. Comparative Medicine 2006 December; 56(6): 534. NRCBL: 22.2; 6.


Baldwin, Ann; Bekoff, Marc. Too stressed to work: scientists must provide lab animals with decent living conditions or accept that their results could be useless [com-
SECTION I

ANIMAL EXPERIMENTATION


Chandna, Alka; Stephens, Martin L.; Runkle, Deborah; Pippin, John J.; Greek, Ray; Perry, Seth. What have we learned from the use of animals in scientific research? [letters and reply]. Chronicle of Higher Education 2007 March 23; 53(29): B17-B18. NRCBL: 22.2; 22.1.


Cohen, Andrew I. Contractarianism, other-regarding attitudes, and the moral standing of nonhuman animals. Journal of Applied Philosophy 2007 May; 24(2): 188-201. NRCBL: 22.1. SC: an. Abstract: Contractarianism roots moral standing in an agreement among rational agents in the circumstances of justice. Critics have argued that the theory must exclude nonhuman animals from the protection of justice. I argue that contractarianism can consistently accommodate the notion that nonhuman animals are owed direct moral consideration. They can acquire their moral status indirectly, but their claims to justice can be as stringent as those among able-bodied rational adult humans. Any remaining criticisms of contractarianism likely rest on a disputable moral realism; contractarianism can underwrite the direct moral considerability of nonhuman animals by appealing to a projectivist quasi-realism.

Cohen, Jon. NIH to end chimp breeding for research [news]. Science 2007 June 1; 316(5829): 1265. NRCBL: 22.2.


Douglas, Kate. Just like us. Humans have rights, other animals don’t — no matter how human-like they are. New Scientist 2007 June 2-8; 194(2606): 46-49. NRCBL: 22.1; 22.2.


land; Burlington, VT: Ashgate, 2006: 543-559. 86 fn. NRCBL: 22.1; 15.1; 19.1; 22.2. SC: an; le.

Keywords: *animal welfare; *genetically modified animals; *legal aspects; animal experimentation; animal organs; biotechnology; ethical theory; organ transplantation; speciesism; suffering. Proposed Keywords: *harm; laboratory animals; Keyword Identifiers: Great Britain; Nuffield Council on Bioethics


Keywords: *animal rights; animal welfare; *commodification; *genetically modified animals; *moral policy; animal experimentation; biotechnology; genetic patents; Proposed Keywords: laboratory animals

Abstract: What’s wrong – fundamentally wrong – with the way animals are treated (...) isn’t the pain, the suffering, isn’t the deprivation. (...) The fundamental wrong is the system that allows us to view animals as our resources, here for us – to be eaten, or surgically manipulated, or exploited for sport or money.” Tom Regan made this claim 20 years ago. What he maintains is basically that the fundamental wrong is not the suffering we inflict on animals but the way we look at them. What we do to them, what we believe we are allowed to do to them, is dependent on how we perceive or conceptualize them. We not only treat them as resources but prior to this we already think of them as resources, and when we look at them, all we tend to see is resources. In our perception of them they exist not for themselves but ‘for us’. But obviously it can only be fundamentally wrong in a moral sense to view them that way if it is wrong in a factual sense, that is, if animals are in fact not ‘for us’. But is it wrong?


Keywords: *animal cloning; animal welfare; biotechnology; *genetically modified animals; agriculture; animal experimentation; animal organs; attitudes; focus groups; food; genetically modified organisms; interviews; public opinion; risk; wedge argument; Proposed Keywords: *domestic animals; laboratory animals; Keyword Identifiers: *Denmark; European Union


Perel, Pablo; Roberts, Ian; Sena, Emily; Wheble, Philipa; Briscoe, Catherine; Sandercok, Peter; Macleod, Malcolm; Mignini, Luciano E.; Jayaram, Predeep; Khan, Khalid S. Comparison of treatment effects between animal experiments and clinical trials: systematic review. *BMJ: British Medical Journal* 2007 January 27; 334(7586): 197-200. NRCBL: 22.2; 18.1. SC: em.

Abstract: OBJECTIVE: To examine concordance between treatment effects in animal experiments and clinical trials. Study design Systematic review. DATA SOURCES: Medline, Embase, SIGLE, NTIS, Science Citation Index, CAB, BIOSIS. STUDY SELECTION: Animal studies for interventions with unambiguous evidence of a treatment effect (benefit or harm) in clinical trials: head injury, antifibrinolytics in haemorrhage, thrombolysis in acute ischaemic stroke, tirilazad in acute ischaemic stroke, antenatal corticosteroids to prevent neonatal respiratory distress syndrome, and bisphosphonates to treat osteoporosis. Review methods Data were extracted on study design, allocation concealment, number of randomised animals, type of model, intervention, and out-
come. RESULTS: Corticosteroids did not show any benefit in clinical trials of treatment for head injury but did show a benefit in animal models (pooled odds ratio for adverse functional outcome 0.58, 95% confidence interval 0.41 to 0.83). Antifibrinolytics reduced bleeding in clinical trials but the data were inconclusive in animal models. Thrombolysis improved outcome in patients with ischaemic stroke. In animal models, tissue plasminogen activator reduced infarct volume by 24% (95% confidence interval 20% to 28%) and improved neurobehavioural scores by 23% (17% to 29%). Tirilazad was associated with a worse outcome in patients with ischaemic stroke. In animal models, tirilazad reduced infarct volume by 29% (21% to 37%) and improved neuro-behavioural scores by 48% (29% to 67%). Antenatal corticosteroids reduced respiratory distress and mortality in neonates whereas in animal models respiratory distress was reduced but the effect on mortality was inconclusive (odds ratio 4.2, 95% confidence interval 20% to 28%) and improved neurobehavioural scores by 23% (17% to 29%).

SECTION I ANIMAL EXPERIMENTATION


Abstract: Following the publication of the Weatherall report on the use of non-human primates in research, this paper reflects on how to provide appropriate and ethical models for research beneficial to humankind. Two of the main justifications for the use of non-human primates in biomedical research are analysed. These are the “least-harm/greatest-good” argument and the “capacity” argument. This paper argues that these are equally applicable when considering whether humans are appropriate subjects of biomedical research.


Rayasam, Renuka. Cloning around. An FDA ruling could spur growth at a Texas company that has the leg up on duplicating animals. *U.S. News and World Report* 2007 January 8; 142(1): 46-47. NRCBL: 22.3; 14.5; 5.3. SC: po.


Rollin, Bernard E. Animal mind: science, philosophy, and ethics. *Journal of Ethics* 2007; 11(3): 253-274. NRCBL: 22.1; 22.2; 1.3.11; 1.1; 4.4.


Abstract: Ethicists such as Peter Singer argue that consciousness and self-consciousness are the principal considerations in discussing the use of animals by humans, such as in medical experiments. This paper raises an additional consideration to factor into this ethical discussion. Ethics deal with the intentional impact of subjects on each other. This assumes a meta-representational ability of subjects to represent states of mind of others, which may be termed other-consciousness. The moral weight of other-consciousness is manifest in the notion of responsibility, where humans lacking in other-consciousness (such as individuals with autism) may not be held responsible for their harmful actions towards others. As responsibility implies not only duties but also rights and more generally high moral status, it follows that other-consciousness grants high moral status, other things being equal — recognizing that other factors grant moral status too. Other-consciousness also increases the capacity for suffering, both due to increased freedom (and consequently increased possibility of restriction of freedom) and to increased empathy (with suffering of others). Hence, the more an animal is other-conscious, the more it deserves high moral status and the more it can suffer, other things being equal, and consequently, the less it should be used for human purposes. Further study is required to elucidate to what extent animals used by humans, such as in medical experiments, particularly primates and other highly evolved mammals, are other-conscious.

Schiermeier, Quirin. Primate work faces German veto [news]. *Nature* 2007 April 26; 446(7139): 955. NRCBL: 22.2. Identifiers: Germany


ARTIFICIAL INSEMINATION AND SURROGATE MOTHERS

See also REPRODUCTIVE TECHNOLOGIES


Keywords: *preimplantation diagnosis; *public policy; legal aspects; prenatal diagnosis; embryos; advisory committees; moral status; international aspects; disabled persons; selective abortion; social discrimination; beginning of life; government regulation; motivation; value of life; Keyword Identifiers: *Austria


Keywords: *preimplantation diagnosis; *public policy; legal aspects; international aspects; prenatal diagnosis; embryos; moral status; advisory committees; beginning of life; government regulation; motivation; value of life; disabled persons; eugenics; social discrimination

Bahadar, Guido. Till death do us part: to be or not to be . . . a parent after one’s death? In: Shenfield, Françoise; Sureau, Claude, eds. Contemporary Ethical Dilemmas in Assisted Reproduction. Abingdon: Informa Healthcare, 2006: 29-42. NRCBL: 14.2; 8.3.3; 19.5; 20.1. SC: cs.


Abstract: Brazil has not yet approved legislation on assisted reproduction. For this reason, clinics, hospitals and semen banks active in the area follow Resolution 1358/92 of the Conselho Federal de Medicina, dated 30 September 1992. In respect to semen donation, the object of this article, the Resolution sets out that gamete donation shall be anonymous, that is, that the donor and recipients (and the children who might subsequently be born) shall not be informed of each other’s identity. Thus, since recipients are unaware of the donor’s identity, semen banks and the medical teams involved in assisted reproduction become the intermediaries in the process. The objective of this article is to show that, in practice, this represents disrespect for the ethical principles of autonomy, privacy and equality. The article also stresses that the problem is compounded by the racial question. In a country like Brazil, where racial classification is so flexible and goes side by side with racist attitudes, the intermediary role played by semen banks and medical teams is conditioned by their own criteria of racial classification, which are not always the same as those of donors and semen recipients. The data presented in this paper were taken from two semen banks located in the city of São Paulo (Brazil). At the time of my research, they were the only semen banks in the state of São Paulo and supplied semen to the capital (São Paulo city), the state of São Paulo, and to cities in other Brazilian states where semen banks were not available.


Hersberger, Patricia; Klock, Susan C.; Barnes, Randall B. Disclosure decisions among pregnant women who received donor oocytes: a phenomenological study. *Fertility and Sterility* 2007 February; 87(2): 288-296. NRCBL: 14.2; 9.5.5; 8.4; 13.1. SC: em.


Mavroforou, A.; Koumantakis, E.; Mavrophoros, D.; Michalodimitrakis, E. Medically assisted human reproduction: the Greek view. *Medicine and Law: The World Association for Medical Law* 2007 June; 26(2): 339-347. NRCBL: 14.2. SC: le. Abstract: Medically assisted human reproduction is a controversial issue that has attracted heated debate over the last two decades. In December 2002 the Greek Parliament passed a law with major social and scientific impact: the Medically Assisted Human Reproduction Act 3089/02. This law establishes the parameters of so-called surrogate motherhood, protects the anonymity of semen donors and sets the legal framework through which a woman’s artificial fertilization after her husband’s death is allowed. This article aims to discuss the legal ramifications of medically assisted human reproduction and especially the moral and social issues concerning the introduction of surrogate motherhood in Greece.


Abstract: In this paper, we will look at the development and the current status of the laws in France (and to some extent other EU nations) and the United States. In doing so, many differences will emerge about the views and values of assisted reproductive technology in the two countries. We will try to articulate some of those underlying moral, political, and legal differences.


Robertson, John A. Compensation and egg donation for research. *Fertility and Sterility* 2006 December; 86(6): 1573-1575. NRCBL: 14.2; 14.4; 9.3.1; 18.2; 18.5.4. SC: le.


**ARTIFICIAL NUTRITION AND HYDRATION** See EUThANASIA AND ALLOWING TO DIE

NRCBL: National Reference Center for Bioethics Literature Classification Scheme  See inside front cover for terms.
ASSISTED SUICIDE

See also EUTHANASIA AND ALLOWING TO DIE


Banerjee, Albert; Birenbaum-Carmeli, Daphna. Ordering suicide: media reporting of family assisted suicide in Britain. Journal of Medical Ethics 2007 November; 33(11): 639-642. NRCBL: 20.7; 13.7; 20.5.1. SC: em. Abstract: OBJECTIVE: To explore the relationship between the presentation of suffering and support for euthanasia in the British news media. METHOD: Data was retrieved by searching the British newspaper database LexisNexis from 1996 to 2000. Twenty-nine articles covering three cases of family assisted suicide (FAS) were found. Presentations of suffering were analysed employing Heidegger’s distinction between technological ordering and poetic revealing. FINDINGS: With few exceptions, the press constructed the complex terrain of FAS as an orderly or orderable performance. This was enabled by containing the contradictions of FAS through a number of journalistic strategies: treating degenerative dying as an aberrant condition, smoothing over bodched attempts, locating the object of ethical evaluation in persons, not contexts, abbreviating the decision making process, constructing community consensus and marginalising opposing views. CONCLUSION: The findings of this study support the view that news reporting of FAS is not neutral or inconsequential. In particular, those reports presenting FAS as an orderly, rational performance were biased in favor of technical solutions by way of the legalisation of euthanasia and/or the involvement of medical professionals. In contrast, while news reports sensitive to contradiction did not necessarily oppose euthanasia, they were less inclined to overtly support technical solutions, recognising the importance of a trial to address the complexity of FAS.


Battin, Margaret P.; van der Heide, Agnes; Ganzini, Linda; van der Wal, Gerrit; Onwuteaka-Philipsen, Bregje D. Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in “vulnerable” groups. Journal of Medical Ethics 2007 October; 33(10): 591-597. NRCBL: 20.7; 20.5.1; 8.1. SC: em; le. Abstract: Background: Debates over legalisation of physician-assisted suicide (PAS) or euthanasia often warn of a “slippery slope”, predicting abuse of people in vulnerable groups. To assess this concern, the authors examined data from Oregon and the Netherlands, the two principal jurisdictions in which physician-assisted dying is legal and data have been collected over a substantial period. Methods: The data from Oregon (where PAS, now called death under the Oregon Death with Dignity Act, is legal) comprised all annual and cumulative Department of Human Services reports 1998–2006 and three independent studies; the data from the Netherlands (where both PAS and euthanasia are now legal) comprised all four government-commissioned nationwide studies of end-of-life decision making (1990, 1995, 2001 and 2005) and specialised studies. Evidence of any disproportionate impact on 10 groups of potentially vulnerable patients was sought. Results: Rates of assisted dying in Oregon and in the Netherlands showed no evidence of heightened risk for the elderly, women, the uninsured (inapplicable in the Netherlands, where all are insured), people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations. The only group with a heightened risk was people with AIDS. While extralegal cases were not the focus of this study, none have been uncovered in Oregon; among extralegal cases in the Netherlands, there was no evidence of higher rates in vulnerable groups. Conclusions: Where assisted dying is already legal, there is no current evidence for the claim that legalised PAS or euthanasia will have disproportionate impact on patients in vulnerable groups. Those who received physician-assisted dying in the jurisdictions studied appeared to enjoy comparative social, economic, educational, professional and other privileges.


Bergner, Daniel. Death in the family: Booth Gardner, a former governor of Washington State who has Parkinson’s, is urgently lobbying for a doctor-assisted-suicide law. His son is among those fighting him every step of the
way. *New York Times Magazine* 2007 December 2; p. 38-45, 60, 76, 78, 80. NRCBL: 20.7; 20.5.1; 20.5.4; 20.3.3. SC: po; le.


**Craig, Alexa; Cronin, Beth; Eward, William; Metz, James; Murray, Logan; Rose, Gail; Suess, Eric; Vergara, Maria E.** Attitudes toward physician-assisted suicide among physicians in Vermont. *Journal of Medical Ethics* 2007 July; 33(7): 400-403. NRCBL: 20.7; 20.5.1; 20.3.2. SC: em; le.

Abstract: Background: Legislation on physician-assisted suicide (PAS) is being considered in a number of states since the passage of the Oregon Death With Dignity Act in 1994. Opinion assessment surveys have historically assessed particular subsets of physicians. Objective: To determine variables predictive of physicians’ opinions on PAS in a rural state, Vermont, USA. Design: Cross-sectional mailing survey. Participants: 1052 (48% response rate) physicians licensed by the state of Vermont. Results: Of the respondents, 38.2% believed PAS should be legalised, 16.0% believed it should be prohibited and 26.0% believed it should not be legislated. 15.7% were undecided. Males were more likely than females to favour legalisation (42% vs 34%). Physicians who did not care for patients through the end of life were significantly more likely to favour legalisation of PAS than physicians who do care for patients with terminal illness (48% vs 33%). 30% of the respondents had experienced a request for assistance with suicide. Conclusions: Vermont physicians’ opinions on the legalisation of PAS is sharply polarised. Patient autonomy was a factor strongly associated with opinions in favour of legalisation, whereas the sanctity of the doctor–patient relationship was strongly associated with opinions in favour of not legislating PAS. Those in favour of making PAS illegal overwhelmingly cited moral and ethical beliefs as factors in their opinion. Although opinions on legalisation appear to be based on firmly held beliefs, approximately half of Vermont physicians who responded to the survey agree that there is a need for more education in palliative care and pain management.


Abstract: In this paper, I examine the arguments against physician assisted suicide (PAS). Many of these arguments are consequentialist. Consequentialist arguments rely on empirical claims about the future and thus their strength depends on how likely it is that the predictions will be realized. I discuss these predictions against the backdrop of Oregon’s Death with Dignity Act and the practice of PAS in the Netherlands. I then turn to a specific consequentialist argument against PAS – Susan M. Wolf’s feminist critique of the practice. Finally, I examine the two most prominent deontological arguments against PAS. Ultimately, I conclude that no anti-PAS argument has merit. Although I do not provide positive arguments for PAS, if none of the arguments against it are strong, we have no reason not to legalize it.


**Dyer, Clare.** Dignitas is forced to offer its services from a former factory [news]. *BMJ: British Medical Journal* 2007 December 8; 335(7631): 1176. NRCBL: 20.7; 20.5.1.


Abstract: Several events that took place during recent years, such as the French Act on the rights of patients and the end of life, the Terri Schiavo case and Lord Joffe’s proposal for an Assisted Dying Bill in the United Kingdom, have triggered the debate on euthanasia more than ever. It is therefore opportune to revisit basic notions related thereto and to make a comparative analysis of the legal regime of euthanasia in several countries in Europe and elsewhere, as well as to try to see how the public awareness of the problem has of late developed. There seems to be a clear trend in many legal systems towards an increasing respect for the patient’s right to self-determination. However, we are still looking at a complex social game, where legal and medical terminology are manipulated and euphemisms are invented in order to accommodate bad moral consciences and avoid political unrest.

**Fish, Mark.** The health professional and the dying patient. In: Gunning, Jennifer; Holm, Søren, eds. Ethics, law, and society. Volume 1. Aldershot, Hants, England; Burlington,
Ganz, Freda DeKeyster; Musgrave, Catherine F. Israeli critical care nurses’ attitudes toward physician-assisted dying. *Heart and Lung* 2006 November-December; 35(6): 412-422. NRCBL: 20.7; 20.5.1; 4.1.3; 20.3.2. SC: em.

Ganzini, Linda; Beer, Tomasz M.; Brouns, Matthew C. Views on physician-assisted suicide among family members of Oregon cancer patients. *Journal of Pain and Symptom Management* 2006 September; 32(3): 230-236. NRCBL: 20.7; 20.5.1; 8.1; 9.5.1.


Guevin, Benedict M. Extraordinary treatment or suicide? *Ethics and Medics* 2007 May; 32(5): 1-2. NRCBL: 20.7; 20.5.1; 8.1; 1.2. Identifiers: Italy; Piergiorgio Welby.


Kamm, F.M. Ending life. In: Rhodes, Rosamond; Francis, Leslie P.; Silvers, Anita, eds. The Blackwell Guide to Medical Ethics. Malden, MA: Blackwell Pub., 2004: 387-422. NRCBL: 20.7; 20.5.1; 19.5; 20.2.1; 20.5.4; 8.3.3. SC: le; cs.


McAneely, Lindsay N. Physician assisted suicide: expanding the laboratory to the state of Hawai’i. *University of Hawai’i Law Review* 2006 Winter; 29(1): 269-299. NRCBL: 20.7; 1.1; 8.1; 20.5.1. SC: le.


Pozgar, George D. Health care ethics. In *his*: Legal Aspects of Health Care Administration. 9th edition. Sudbury, MA: Jones and Bartlett Publishers, 2004: 387-422. NRCBL: 20.7; 20.5.1; 19.5; 20.2.1; 20.5.4; 8.3.3. SC: le; cs.


Quill, Timothy E. Physician assisted death in vulnerable populations [editorial]. *BMJ: British Medical Journal* 2007 September 29; 335(7621): 625-626. NRCBL: 20.7; 20.5.1; 9.5.1. Identifiers: Oregon; Netherlands.


Tuff, Annette. Swiss hospitals admit to allowing assisted suicide on their wards under guidelines [news]. *BMJ: Brit-

Abstract: BACKGROUND: In 2002, an act regulating the ending of life by a physician at the request of a patient with unbearable suffering came into effect in the Netherlands. In 2005, we performed a follow-up study of euthanasia, physician-assisted suicide, and other end-of-life practices. METHODS: We mailed questionnaires to physicians attending 6860 deaths that were identified from death certificates. The response rate was 77.8%. RESULTS: In 2005, of all deaths in the Netherlands, 1.7% were the result of euthanasia and 0.1% were the result of physician-assisted suicide. These percentages were significantly lower than those in 2001, when 2.6% of all deaths resulted from euthanasia and 0.2% from assisted suicide. Of all deaths, 0.4% were the result of the ending of life without an explicit request by the patient. Continuous deep sedation was used in conjunction with possible hastening of death in 7.1% of all deaths in 2005, significantly increased from 5.6% in 2001. In 73.9% of all cases of euthanasia or assisted suicide in 2005, life was ended with the use of neuromuscular relaxants or barbiturates; opioids were used in 16.2% of cases. In 2005, 80.2% of all cases of euthanasia or assisted suicide were reported. Physicians were most likely to report their end-of-life practices if they considered them to be an act of euthanasia or assisted suicide, which was rarely true when opioids were used. CONCLUSIONS: The Dutch Euthanasia Act was followed by a modest decrease in the rates of euthanasia and physician-assisted suicide. The decrease may have resulted from the increased application of other end-of-life care interventions, such as palliative sedation.

Watson, Katie; Quill, Timothy. A conversation with Dr. Timothy Quill [interview]. Atrium 2007 Summer; 4: 18-20. NRCBL: 20.7; 20.5.1.


ATTITUDES TO DEATH See DEATH AND DYING/ ATTITUDES TO DEATH

BEHAVIOR CONTROL

See also CARE FOR SPECIFIC GROUPS/ MENTALLY DISABLED; ELECTROCONVULSIVE THERAPY; INVOLUNTARY COMMITMENT; MENTAL HEALTH THERAPIES AND NEUROSCIENCES; PSYCHOPHARMACOLOGY; PSYCHOTHERAPY


Abstract: Restraint as an intervention in the management of acute mental distress has a long history that predates the existence of psychiatry. However, it remains a source of controversy with an ongoing debate as to its role. This article critically explores what to date has seemingly been only implicit in the debate surrounding the role of restraint: how should the concept of validity be interpreted when applied to restraint as an intervention? The practice of restraint in mental health is critically examined using two post-positivist constructions of validity, the pragmatic and the psychopolitical, by means of a critical examination of the literature. The current literature provides only weak support for the pragmatic validity of restraint as an intervention and no support to date for its psychopolitical validity. Judgements regarding the validity of any intervention that is coercive must include reference to the psychopolitical dimensions of both practice and policy.


BEHAVIORAL GENETICS


Keywords: *behavioral genetics; *genetic information; *self-concept; clinical genetics; eugenics; genetic determinism; genetic research; mental disorders; right not to know


Keywords: *behavioral genetics; *neurosciences; behavioral research; brain; emotions; employment; genetic privacy; genetic screening; law enforcement; marketing; politics; Proposed Keywords: *brain imaging; personality


Keywords: *genetic determinism; *obligations of society; *socioeconomic factors; *values; disadvantaged persons; eugenics; intelligence; justice; men; sex factors; sociobiology; women

Hamer, Ian. Pastor, the gene made me do it! Concordia Journal 1997 January; 23: 18-26. NRCBL: 15.6; 1.2; 15.1.


Keywords: *aggression; *behavioral genetics; *genetic screening; *violence; behavior disorders; eugenics; racial groups; social problems; XYY chromosome; Proposed Keywords: *antisocial behavior; *crime; attention deficit disorder with hyperactivity; forensic genetics


Keywords: *behavioral genetics; *criminal law; *genetic determinism; *violence; adolescents; aggression; behavior control; behavior disorders; behavioral research; dangerousness; DNA fingerprinting; genetic predisposition; genetic research; genetic screening; law enforcement; legal liability; philosophy; socioeconomic factors; Proposed Keywords: *culpability; Keyword Identifiers: Great Britain; United States

Abstract: The idea of individual responsibility for action is central to our conception of what it is to be a person. Behavioural genetic research may seem to call into question the idea of individual responsibility with possible implications for the criminal justice system. These implications will depend on the understandings of the various agencies and professional groups involved in responding to violent and anti-social behaviour, and, the result of negotiations between them over resulting practice. The paper considers two kinds of approaches to the question of responsibility and ‘criminal genes’ arising from a sociological and philosophical perspective respectively. One is to consider the social context and possible practical implications of research into ‘criminal genes’ which will later be examined through interviews and discussions with a range of experts including lawyers and social workers. A second and different kind of approach is to ask whether the findings of behavioural genetics ought to have implications for attributions of responsibility. Issues of genetic influence are central to both approaches.


Keywords: *behavioral genetics; *genetic research; eugenics; genetic determinism; mental disorders; risks and benefits; social discrimination; stigmatization


BEHAVIORAL RESEARCH

See also BIOMEDICAL RESEARCH; HUMAN EXPERIMENTATION

Ashcraft, Mark H.; Krause, Jeremy A. Social and behavioral researchers’ experiences with their IRBs. Ethics and Behavior 2007; 17(1): 1-17. NRCBL: 18.4; 18.2; 1.3.9; 7.1. SC: em.

Abstract: A national survey on researchers’ experiences with their institutional review boards (IRBs) is presented, focused exclusively on social and behavioral researchers. A wide range of experiences is apparent in the data, especially in terms of turnaround time for submitted protocols, incidence of data collection without prior IRB approval, and stated reasons for “going solo.” Sixty-two percent felt that the turnaround time they typically experience is “reasonable,” and 44% said they had not exper-
enced long delays in obtaining approval. However, 48% of respondents reported either conducting a project without IRB approval or modifying an existing project without IRB approval, with anticipated time for approval being the dominant reason offered for doing so. This adds a new dimension to the widely discussed “national IRB crisis” (e.g., Illinois White Paper, 2005). The article concludes with 2 preliminary recommendations for IRB reform.


Burke, John; Diehl, Dawn; Durosinmi, Brenda; McGinnis, Troy A. The privacy of stigmatized persons. *Journal of Empirical Research on Human Research Ethics* 2007 March; 2(1): 65-67. NRCBL: 18.4; 18.5.1; 8.4; 10; 18.5.5.

Fischer, Henry W. Protecting human subjects from themselves... after the disaster. *Protecting Human Subjects* 2007 November (15): 20-21. NRCBL: 18.4; 18.2; 18.5.9; 18.3.


Abstract: It has been shown that properly conducted interviews in sensitive clinical contexts are negligibly stressful. The present study sought to extend these results and determine the perception of stress by research participants in nonclinical settings. Students enrolled in first year psychology courses typically have the option to receive class credit for research participation in studies assumed to pose minimal risk to participants. The perceptions of 101 student volunteers were examined to determine if they felt that research participation was stressful and, if so, what components of the process caused their stress. Participants completed a short survey indicating the reasons they served as research participants and the degree to which participation was stressful. They indicated that research participation was a valuable learning experience and the majority felt no stress associated with participation. Stress was reported by some due to concerns about confidentiality and evaluation by others of their personal performance. In addition, the majority of students reported having no knowledge of the ethical review process that preceded their participation. It is suggested that students should be informed of the ethical review process.

Holm, Søren; Bortolotti, Lisa. Large scale surveys for policy formation and research—a study in inconsistency. *Theoretical Medicine and Bioethics* 2007; 28(3): 205-220. NRCBL: 18.4; 9.1; 18.3; 21.1. SC: an. Identifiers: Europe. Abstract: In this paper we analyse the degree to which a distinction between social science and public health research and other non-research activities can account for differences between a number of large scale social surveys performed at the national and European level. The differences we will focus on are differences in how participation is elicited and how data are used for government, research and other purposes. We will argue that the research / non-research distinction does not account for the identified differences in recruitment or use and that there are no other convincing justifications. We argue that this entails that eliciting participation by coercion or manipulation becomes very difficult to justify.


Kilpatrick, Dean G. The ethics of disaster research: a special section. *Journal of Traumatic Stress* 2004 October; 17(5): 361-362. NRCBL: 18.4; 18.2; 18.5.1.


North, Carol S.; Pfefferbaum, Betty; Tucker, Phebe. Ethical and methodological issues in academic mental health research in populations affected by disasters: the Oklahoma City experience relevant to September 11, 2001. *CNS Spectrums* 2002 August; 7(8): 580-584. NRCBL: 18.4; 4.3; 18.2; 18.5.2; 18.5.6.


Abstract: This study examines the effectiveness of a new debriefing procedure designed specifically to address possible negative consequences of participation in deceptive research. The new debriefing includes an extended educational procedure that enables participants to gain insight into relevant deceptive practices and how to recognize and deal effectively with them, and thus end their participation with a positive and beneficial learning experience. The usefulness of the new tool was analyzed in a suggestibility study in which we compared the effects of the standard debriefing and the new procedure in terms of participants’ mood, self-esteem, and attitudes toward psychological experiments. The most important result was that at the end of the study subjects who received the new debriefing system expressed more positive mood.
and more positive attitudes toward research than those who received the standard debriefing system. The implications of these results for generalizing to other kinds of deception research are discussed.

Ohrstrom, Peter; Dyhrberg, Johan. Ethical problems inherent in psychological research based on Internet communication as stored information. *Theoretical Medicine and Bioethics* 2007; 28(3): 221-241. NRCBL: 18.4; 1.3.12; 8.4; 18.3.

Abstract: This paper deals with certain ethical problems inherent in psychological research based on Internet communication as stored information. Section 1 contains an analysis of research on Internet debates. In particular, it takes into account a famous example of deception for psychology research purposes. In section 2, the focus is on research on personal data in texts published on the Internet. Section 3 includes an attempt to formulate some ethical principles and guidelines, which should be regarded as fundamental in research on stored information.

Owen, Michael. Ethical review of social and behavioral science research. *In: Kulakowski, Elliott C.; Chronister, Lynne U., eds. Research Administration and Management. Sudbury, MA: Jones and Bartlett, 2006; 543-556. NRCBL: 18.4; 18.2; 18.3; 18.5.1; 18.5.9.


Abstract: A growing body of empirical literature has systematically documented the reactions to research participation among participants in trauma focused research. To date, the available data has generally presented an optimistic picture regarding participants’ ability to tolerate and even find benefit from their participation. However, this literature has been largely limited to cross-sectional designs. No extant literature has yet examined the perceptions of participants with psychiatric illness who are participating in randomized clinical trials (RCTs) designed to evaluate the efficacy or effectiveness of novel trauma treatments. The authors posit that negative experiences of, or poor reactions to, the research experience in the context of a trauma-focused RCT may elevate the risk of participation. Indeed, negative reactions may threaten to undermine the potential therapeutic gains of participants and promoting early drop out from the trial. Empirically assessing reactions to research participation at the pilot-study phase of a clinical trial can both provide investigators and IRB members alike with empirical evidence of some likely risks of participation. In turn, this information can be used to help shape the design and recruitment methodology of the full-scale trial. Using data from the pilot study of the Women’s Self-Defense Project as a case illustration, we provide readers with concrete suggestions for empirically assessing participants’ perceptions of risk involved in their participation in behaviorally oriented clinical trials.


**BIOBANKS** See GENETIC DATABASES AND BIOBANKS

**BIOETHICISTS** See ETHICISTS AND ETHICS COMMITTEES

**BIOETHICS AND MEDICAL ETHICS**

*See also CODES OF ETHICS; ETHICISTS AND ETHICS COMMITTEES; NURSING ETHICS AND PHILOSOPHY; PROFESSIONAL ETHICS*


Abstract: The Universal Declaration on Bioethics and Human Rights adopted by the United Nations Educational, Scientific, and Cultural Organisation (UNESCO) on 19 October 2005 is an important step in the search for global minimum standards in biomedical research and clinical practice. As a member of UNESCO International Bioethics Committee, I participated in the drafting of this document. Drawing on this experience, the principal features of the Declaration are outlined, before responding to two general charges that have been levelled at UNESCO’s bioethical activities and at this particular document, are outlined. One criticism is to the effect that UNESCO is exceeding its mandate by drafting such bioethical instruments — in particular, the charge is that it is trespassing on a topic that lies in the responsibility of the World Health Organization. The second criticism is that UNESCO’s reliance on international human rights norms is inappropriate.

SECTION I BIOETHICS AND MEDICAL ETHICS


Abstract: The IAB Presidential Address was delivered by Alexander Capron to the internationally gathered audience at the Closing Ceremony of the 8th World Congress of Bioethics, Beijing on 9th August 2006.


Christopher, Myra J. “Show me” bioethics and politics. American Journal of Bioethics 2007 October; 7(10): 28-33. NRCBL: 2.1; 21.1. Comments: American Journal of Bioethics 2007 October; 7(10): 34-44. NRCBL: 2.1; 34-44. Abstract: Missouri, the “Show Me State,” has become the epicenter of several important national public policy debates, including abortion rights, the right to choose and refuse medical treatment, and, most recently, early stem cell research. In this environment, the Center for Practical Bioethics (formerly, Midwest Bioethics Center) emerged and grew. The Center’s role in these “cultural wars” is not to advocate for a particular position but to provide well researched and objective information, perspective, and advocacy for the ethical justification of policy positions; and to serve as a neutral convener and provider of a public forum for discussion. In this article, the Center’s work on early stem cell research is a case study through which to argue that not only the Center, but also the field of bioethics has a critical role in the politics of public health policy.

De Vries, Raymond G.; Turner, Leigh; Orfali, Kristina; Bosk, Charles L. Social science and bioethics: morality from the ground up. Clinical Ethics 2007 March; 2(1): 33-35. NRCBL: 2.1; 7.1.


Dyer, Clare. GMC guidance on conscience goes too far, says BMA [news]. BMJ: British Medical Journal 2007 October 6; 335(7622): 688. NRCBL: 2.1; 11.1; 12.1; 20.5.1. Identifiers: Great Britain (United Kingdom); General Medical Council; British Medical Association.


English, Veronica; Hamm, Danielle; Harrison, Caroline; Sheather, Julian; Sommerville, Ann. Ethics briefings. Journal of Medical Ethics 2007 February; 33(2): 123-124. NRCBL: 2.1; 9.3.1; 9.4; 9.5.1; 12.4.1; 21.1. Identifiers: abortion; conflicts of interests; HPV vaccine; patient non-compliance; medical tourism.


Hansson, Mats G.; Kihlbom, Ulrik; Tuveson, Torsten; Olsen, Leif A.; Rodriguez, Alina. Ethics takes time, but not that long. BMC Medical Ethics [electronic] 2007; 8.6. 7 p. NRCBL: 2.1; 8.1.

Abstract: Background: Time and communication are important aspects of the medical consultation. Physician behavior in real-life pediatric consultations in relation to ethical practice, such as informed consent (provision of information, understanding), respect for integrity and patient autonomy (decision-making), has not been subjected to thorough empirical investigation. Such investigations are important tools in developing sound ethical praxis. Methods: 21 consultations for inguinal hernia were video recorded and observers independently assessed global impressions of provision of information, understanding, respect for integrity, and participation in decision making. The consultations were analyzed for the occurrence of specific physician verbal and nonverbal behaviors and length of time in minutes. Results: All of the consultations took less than 20 minutes, the majority consisting of 10 minutes or less. Despite this narrow time frame, we found strong and consistent association between increasing time and higher ratings on all components of ethical practice: information, (β = .43), understanding (β = .52), respect for integrity (β = .60), and decision making (β = .43). Positive nonverbal behaviors by physicians during the consultation were associated particularly with respect for integrity (β = .36). Positive behaviors by physicians during the physical examination were related to respect for children’s integrity. Conclusion: Time was of essence for the ethical encounter. Further, verbal and nonverbal positive behaviors by the physicians also contributed to higher ratings of ethical aspects. These results can help to improve quality of ethical practice in pediatric settings and are of relevance for teaching and policy makers.


Hennig, Wolfgang. Bioethics in China: although national guidelines are in place, their implementation remains difficult. EMBO Reports 2006 September; 7(9): 850-854. NRCBL: 2.1; 2.2; 2.4; 18.2. SC: rv.


Lindemann, Hilde. Obligations to fellow and future bioethicists: publication. In: Eckenwiler, Lisa A.; Cohn, Felicia G., eds. The Ethics of Bioethics: Mapping the
Moral Landscape. Baltimore, MD: Johns Hopkins University Press, 2007: 270-277. NRCBL: 2.1; 1.3.7; 7.3.


Lorenz, Rolf J. NRCBL: 2.1; 8.1; 9.4; 8.3.3.


Keywords: *bioethical issues; *bioethics; *databases; *genetics; *information dissemination; *literature; *terminology; eugenics; genetic patents; human experimentation; professional organizations; publishing; Proposed Keywords: *abstracting and indexing; *information services; publications; Keyword Identifiers: *Bioethics Thesaurus for Genetics; *ETHXWeb; *GenETHX; *National Information Resource on Ethics and Genetics; *National Reference Center for Bioethics Literature; *Bioethics Thesaurus; *Kennedy Institute of Ethics


Keywords: *bioethical issues; *bioethics; *databases; *genetics; *information dissemination; *literature; *terminology; eugenics; genetic patents; human experimentation; professional organizations; publishing; Proposed Keywords: *abstracting and indexing; *information services; publications; Keyword Identifiers: *Bioethics Thesaurus for Genetics; *ETHXWeb; *GenETHX; *National Information Resource on Ethics and Genetics; *National Reference Center for Bioethics Literature; *Bioethics Thesaurus; *Kennedy Institute of Ethics


Keywords: *bioethical issues; advisory committees; chimeras; cloning; contraception; embryo research; embryonic stem cells; federal government; government financing; government regulation; legal aspects; politics; preimplantation diagnosis; research support; siblings; tissue typing; value of life; Keyword Identifiers: Great Britain; Human Fertilisation and Embryology Authority; President’s Council on Bioethics; United States


Abstract: In October 2005, the United Nations Educational, Scientific and Cultural Organization adopted the Universal Declaration on Bioethics and Human Rights (UDBHR). A concept of central importance in the declaration is that of “human dignity”. However, there is lack of clarity about its scope, especially concerning the question of whether prenatal human life has the same dignity and rights as born human beings. This ambiguity has im-
applications for the interpretation of important articles of the declaration, including 2(3), 4, 8, 10 and 11. The paper applies relevant provisions of the UDHR to specific cases, addresses problems of internal consistency and considers attempts at clarifying the scope of “human dignity” by the negotiating parties. An analysis of the important relationship between the UDHR and the Universal Declaration of Human Rights, to which the UDHR refers in its title and elsewhere, shows that because of a crucial emphasis on the broad reading according to which the UDHR must be understood to ascribe human rights and dignity to prenatal life is untenable. However, the view that the UDHR confers human rights and dignity on humans from the moment of birth onwards is robust and defensible. This conclusion is important for a proper understanding of the declaration and its use, as stated in Articles 1(2) and 22, the latter urging states “...to give effect to the principles... in this declaration”. Similarly, it has implications for the use of the declaration in the wider context of bioethics-related law and policy, as well as in academic and other discussions where increasing reference to the UDHR is likely.

Sharpe, Virginia A. Strategic disclosure requirements and the ethics of bioethics. In: Eckenwiler, Lisa A.; Cohn, Felicia G., eds. The Ethics of Bioethics: Mapping the Moral Landscape. Baltimore, MD: Johns Hopkins University Press, 2007: 170-180. NRCBL: 2.1; 5.3; 7.3; 1.3.2; 9.7; 9.3.1.


ten Have, H.; Ang, T.W. UNESCO’s Global Ethics Observatory. Journal of Medical Ethics 2007 January; 33(1): 15-16. NRCBL: 2.1; 1.3.9; 1.3.12; 2.2. Abstract: The Global Ethics Observatory, launched by the United Nations Educational, Scientific, and Cultural Organization in December 2005, is a system of databases in the ethics of science and technology. It presents data on experts in ethics, on institutions (university departments and centres, commissions, councils and review boards, and societies and associations) and on teaching programmes in ethics. It has a global coverage and will be available in six major languages. Its aim is to facilitate the establishment of ethical infrastructures and international cooperation all around the world.


**BIOETHICS AND MEDICAL ETHICS/COMMISSIONS**

*See also ETHICISTS AND ETHICS COMMITTEES*


**Dzur, Albert W.; Levin, Daniel.** The primacy of the public: in support of bioethics commissions as deliberative forums. Kennedy Institute of Ethics Journal 2007 June; 17(2): 133-142. NRCBL: 2.4; 5.1; 1.3.5; 2.1; 1.1; 7.1. SC: an. Abstract: In a 2004 article, we argued that bioethics commissions should be assessed in terms of their usefulness as public forums. A 2006 article by Summer Johnson argued that our perspective was not supported by the existing literature on presidential commissions, which had not previously identified commissions as public forums and that we did not properly account for the political functions of commissions as instruments of presidential power. Johnson also argued that there was nothing sufficiently unique about bioethics commissions to make the public forum perspective particularly applicable. We respond by arguing that analysis of commissions’ work as public forums fits well within the literature on commissions, especially on their agenda-setting functions, and that the political functions of commissions are often compatible with their functioning as public forums. We also demonstrate how the origins and concerns of bioethics
make public forum analysis particularly applicable to bioethics commissions.


Keywords: *advisory committees; *embryo research; *public policy; *reproductive technologies; bioethical issues; cloning; decision making; embryonic stem cells; federal government; fetal research; genetic intervention; historical aspects; human experimentation; organization and administration; policy making;* Key word Identifiers: *United States; Biomedical Ethics Advisory Committee; Ethics Advisory Board; Human Fetal Tissue Transplantation Research Panel; National Bioethics Advisory Commission; National Commission for the Protection of Human Subjects; President’s Commission for the Study of Ethical Problems; President’s Council on Bioethics; Twentieth Century


Abstract: Bioethics commissions have been critiqued on the basis that they are not sufficiently public or are too reliant upon expertise to have legitimacy or authority in regard to public policy debates. Adequately assessing the legitimacy and authority of commissions requires thinking clearly about the “publics” these commissions serve, the primary tasks of public bioethics, and how those tasks might be performed with a certain kind of ethical expertise and limited authority that makes them legitimate players in public policy debates concerning bioethics.


Riley, Margaret Foster; Merrill, Richard A. Regulating reproductive genetics: a review of American bioethics commissions and comparison to the British Human Fertilisation and Embryology Authority. *Columbia Science and Technology Law Review* 2005; 6(1): 1-64. 363 fn. NRCBL: 2.4; 14.1; 14.4; 18.5.4; 15.1; 18.2. SC: 1e.

Keywords: *advisory committees; *government regulation; *regulation; *reproductive technologies; bioethical issues; biotechnology; comparative studies; legislation; organization and administration; preimplantation diagnosis; Key word Identifiers: *Great Britain; *Human Fertilisation and Embryology Authority; *United States; Biomedical Ethics Advisory Commission; Ethics Advisory Board, Human Embryo Research Panel; Human Fertilisation and Embryology Act 1990 (Great Britain); President’s Council on Bioethics; President’s Commission for the Study of Ethical Problems

Sherlock, Richard. Bioethics in liberal regimes: a review of the President’s Council. *Ethics and Medicine: An International Journal of Bioethics* 2007 Fall; 23(3): 169-188. 10 fn. NRCBL: 2.4; 2.2; 2.1; 1.2; 9.1; 14.1; 15.1; 15.2; 9.5.4; 10; 5.1. SC: rv.

Keywords: *advisory committees; *bioethical issues; *bioethics; biomedical enhancement; biotechnology; cloning; cultural pluralism; democracy; embryo research; embryonic stem cells; eugenics; euthanasia; genetic engineering; historical aspects; human dignity; human experimentation; morality; preimplantation diagnosis; public policy; religion; reproductive technologies; Proposed Keywords: publications; Keyword Identifiers: *President’s Council on Bioethics; *United States; National Bioethics Advisory Commission; National Commission for the Protection of Human Subjects and Biomedical and Behavioral Research; President’s Commission for the Study of Ethical Problems in Biomedical and Behavioral Research; Twentieth Century; Twenty-First Century


Abstract: Toi te Taiao: the Bioethics Council was established in 2002 to enhance New Zealand’s understanding of the cultural, ethical and spiritual aspects of biotechnology and ensure that the use of biotechnology has regard for the values held by New Zealanders. In 2005, the Bioethics Council focused on xenotransplantation. A series of dialogue events were held, the public had the opportunity to participate in an online discussion forum and were able to make written submissions. There is worldwide interest in the potential of this biotechnology to cure or alleviate a number of serious health conditions. However, there are concerns about the risks, especially the potential for cross species infection. Such risks have not yet been reliably quantified, but any decision about safety and effectiveness is also about cultural, ethical and spiritual factors. This paper considers some of the outcomes from the dialogue process and the reflections of the Bioethics Council on these. It contrasts the process with that of classic consultation and concludes that, although the process may be more costly and time consuming than the traditional consultative approach, it enables the role of science to be appreciated in its full context, including appreciation of the uncertainties of natural systems and the relevance of cultural, ethical and spiritual human values. It will be suggested that the public are able to interweave ethical concerns with scientific knowledge to engage in meaningful dialogue, resulting in useful recommendations.

**BIOETHICS AND MEDICAL ETHICS/EDUCATION**

See also MEDICAL EDUCATION

**Beckmann, Jan P.** Ethik in der Medizin in Aus- und Weiterbildung aus der Sicht der Philosophie [Ethics in medicine in education and continuing education from the philosophical point of view]. *Ethik in der Medizin* 2006 December; 18(4): 369-373. NRCBL: 2.3; 1.1; 7.2.

**Benatar, D.** Moral theories may have some role in teaching applied ethics. *Journal of Medical Ethics* 2007 November; 33(11): 671-672. NRCBL: 2.3; 1.1. SC: an.

Abstract: In a recent paper, Rob Lawlor argues that moral theories should not be taught in courses on applied ethics. The author contends that Dr Lawlor’s arguments overlook at least two important roles that some attention to ethical theories may play in practical ethics courses. The conclusion is not that moral theory must be taught, but rather that there is more to be said for it than Dr Lawlor’s arguments reveal.


**Claudot, Frédérique; Alla, François; Ducrocq, Xavier; Coudane, Henry.** Teaching ethics in Europe. *Journal of Medical Ethics* 2007 August; 33(8): 491-495. NRCBL: 2.3; 7.2; 21.1. SC: em.

Abstract: AIM: To carry out an appropriate overview and inventory of the teaching of ethics within the European Union Schools of Medicine. METHODS: A questionnaire was sent by email to 45 randomly selected medical schools from each of 23 countries in the European Union in February 2006. RESULTS: 25 schools of medicine from 18 European countries were included (response rate = 56%). In 21 of 25 medical schools, there was at least one ethics module. In 11 of 25 medical schools, the teaching of ethics was transversal. Only one of the responding schools did not teach ethics. The mean time invested in ethics teaching was 44 h during the overall curriculum. CONCLUSIONS: Ethics now has an established place within the medical curriculum throughout the European Union. However, there is a notable disparity in programme characteristics among schools of medicine.


**Daher, Michel.** Current trends in medical ethics education. *Journal Medical Libanais* 2006 July-September; 54(3): 121-123. NRCBL: 2.3.


**Kipnis, Kenneth.** The expert ethics witness as teacher. In: Rasmussen, Lisa, ed. Ethics Expertise: History, Contemporary Perspectives, and Applications. Dordrecht: Springer, 2005: 269-279. NRCBL: 2.3; 2.1; 7.3; 1.3.5. SC: le.


Abstract: It is argued, in this paper, that moral theories should not be discussed extensively when teaching applied ethics. First, it is argued that, students are either presented with a large amount of information regarding the various subtle distinctions and the nuances of the theory and, as a result, the students simply fail to take it in or, alternatively, the students are presented with a simplified caricature of the theory, in which case the students may understand the information they are given, but what they have understood is of little or no value because it is merely a caricature of a theory. Second, there is a methodological problem with appealing to moral theories to solve particular issues in applied ethics. An analogy with science is appealed to. In physics there is a hope that we could discover a unified theory of everything. But this is, of course, a hugely ambitious project, and much harder than, for example, finding a theory of motion. If the physicist wants to understand motion, he should try to do so directly. We would think he was particularly misguided if he thought that, to answer this question, he first needed to construct a unified theory of everything.

**Leget, Carlo; Olthuis, Gert.** Compassion as a basis for ethics in medical education. *Journal of Medical Ethics* 2007 October; 33(10): 617-620. NRCBL: 2.3; 7.2; 8.1.

Abstract: The idea that ethics is a matter of personal feeling is a dogma widespread among medical students. Because emotivism is firmly rooted in contemporary culture, the authors think that focusing on personal feeling can be an important point of departure for moral education. In this contribution, they clarify how personal feelings can be a solid basis for moral education by focusing on the analysis of compassion by the French phenomenologist Emmanuel Housset. This leads to three important issues regarding ethics education: (1) the necessity of a continuous attention for and interpretation of the meaning of language, (2) the importance of examining what aspect of “the other” touches one and what it is that evokes the urge to act morally and (3) the need to relate oneself to the community, both to the medical community
and to collectively formulated rules and laws. These issues can have a place in medical education by means of an ethical portfolio that supports students in their moral development. First, keeping a portfolio will improve their expression of the moral dimension of medical practice. Second, the effects of self-knowledge and language mastery will limit the pitfalls of emotivism and ethical subjectivism and will stimulate the inclination to really encounter the other. Third, it will show medical students from the start that their moral responsibility is more than following rules and that they are involved personally.


Moodley, Kaymanthri. Teaching medical ethics to undergraduate students in post-apartheid South Africa, 2003-2006. Journal of Medical Ethics 2007 November; 33(11): 673-677. NRCBL: 2.3; 7.2; 21.1. Abstract: The apartheid ideology in South Africa had a pervasive influence on all levels of education including medical undergraduate training. The role of the health sector in human rights abuses during the apartheid era was highlighted in 1997 during the Truth and Reconciliation Commission hearings. The Health Professions Council of South Africa (HPCSA) subsequently realised the importance of medical ethics education and encouraged the introduction of such teaching in all medical schools in the country. Curricular reform at the University of Stellenbosch in 1999 presented an unparalleled opportunity to formally introduce ethics teaching to undergraduate students. This paper outlines the introduction of a medical ethics programme at the Faculty of Health Sciences from 2003 to 2006, with special emphasis on the challenges encountered. It remains one of the most comprehensive undergraduate medical ethics programmes in South Africa. However, there is scope for expanding the curricular time allocated to medical ethics. Integrating the curriculum both horizontally and vertically is imperative. Implementing a core curriculum for all medical schools in South Africa would significantly enhance the goals of medical education in the country.


Parker, Michael. Deliberation and moral courage: the UK Genetics Club as a case study. Notizie di Politia 2006; 22(81): 78-83. 11 refs. NRCBL: 2.3; 2.1; 15.1; 9.6; 15.2; 15.3. Keywords: *clinical genetics; *ethics; *ethicists; *ethics; *morality; *professional role; *teaching methods; case studies; cultural pluralism; genetics; health personnel; interdisciplinary communication; interprofessional relations; researchers; science; Proposed Keywords: character; Keyword Identifiers: *UK Genetics Club; Causing Death and Saving Lives (Glover, Jonathan); Great Britain

Pegoraro, Renzo; Putoto, Giovanni. Findings from a European survey on current bioethics training activities in hospitals. Medicine, Health Care and Philosophy 2007 March; 10(1): 91-96. NRCBL: 2.3; 7.2; 21.1. SC: em. Abstract: While much work has been done on improving undergraduate education in bioethics, particularly in medicine, less has been said about continuing education of health care workers, particularly non-medical and nursing personnel. Hospitals bring together a variety of professional and non-professional groups in the place where clinical dilemmas are daily events, and would seem ideal places to conduct an ongoing bioethics dialogue. Yet evidence that this is being achieved is sparse. The European Hospital (-Based) Bioethics Program (EHBP) brings together both current and aspirant members of the EU as partners in a project that aims to assess the current situation with regard to bioethics education in hospitals, identify shortfalls, and address these. In order to achieve the first objective of the EHBP a survey of the current training activities (focused on activities in hospitals) in clinical bioethics in Europe was carried out. The results are presented in this paper, along with a discussion about the implications for the EHBP to address these issues.


Roberts, Laura Weiss; Warner, Teddy D.; Dunn, Laura B.; Brody, Janet L.; Hammond, Katherine A. Green; Roberts, Brian B. Shaping medical students’ attitudes toward ethically important aspects of clinical research: results of a randomized, controlled educational intervention. Ethics and Behavior 2007; 17(1): 19-50. NRCBL: 2.3; 7.2; 18.1; 1.3.9; 7.1; 18.3. SC: em. Abstract: The effects of research ethics training on medical students’ attitudes about clinical research are examined. A preliminary randomized controlled trial evaluated 2 didactic approaches to ethics training compared to a no-intervention control. The participant-oriented intervention emphasized subjective experiences of research participants (empathy focused). The criteria-oriented intervention emphasized specific ethical criteria for analyzing protocols (analytic focused). Compared to controls, those in the participant-oriented intervention group exhibited greater attunement to research participants’ attitudes related to altruism, trust, quality of relationships with researchers, desire for information, hopes about participation and possible therapeutic misconception, importance of consent forms, and deciding quickly about participation. The participant-oriented group also agreed more strongly that seriously ill people are capable of making their own research participation decisions. The criteria-oriented intervention did not affect learners’ attitudes about clinical research, ethical duties of investigators, or research participants’ decision making. An empathy-focused approach affected medical students’ at-
tunement to research volunteer perspectives, preferences, and attributes, but an analytically oriented approach had no influence. These findings underscore the need to further examine the differential effects of empathy-versus analytic-focused approaches to the teaching of ethics.


Yalisove, Daniel. From the ivory tower to the trenches: teaching professional ethics to substance abuse counselors. In: Kleing, John; Einstein, Stanley, eds. Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 507-527. NRCBL: 2.3; 9.5.9; 17.1; 1.1; 1.3.1.

**BIOETHICS AND MEDICAL ETHICS/ HISTORY**

Carson, Ronald A. Engaged humanities: moral work in the precincts of medicine. Perspectives in Biology and Medicine 2007 Summer; 50(3): 321-333. NRCBL: 2.2; 2.1; 4.1.2; 7.1. SC: rv.


Sass, Hans-Martin. Fritz Jahr’s 1927 concept of bioethics. Kennedy Institute of Ethics Journal 2007 December; 17(4): 279-295. NRCBL: 2.2; 1.1; 22.1; 16.1; 2.3. Abstract: In 1927, Fritz Jahr, a Protestant pastor, philosopher, and educator in Halle an der Saale, published an article entitled “Bio-Ethics: A Review of the Ethical Relationships of Humans to Animals and Plants” and proposed a “Bioethical Imperative,” extending Kant’s moral imperative to all forms of life. Reviewing new physiological knowledge of his times and moral challenges associated with the development of secular and pluralistic societies, Jahr redefines moral obligations towards human and nonhuman forms of life, outlining the concept of bioethics as an academic discipline, principle, and virtue. Although he had no immediate long-lasting influence during politically and morally turbulent times, his argument that new science and technology requires new ethical and philosophical reflection and resolve may contribute toward clarification of terminology and of normative and practical visions of bioethics, including understanding of the geoethical dimensions of bioethics.


**BIOETHICS AND MEDICAL ETHICS/ LEGAL ASPECTS**

Ethics briefings. Journal of Medical Ethics 2007 April; 33(4): 247-248. NRCBL: 2.1; 8.3.3; 8.4; 9.5.6; 9.5.7; 10; 11.3; 12.4.1; 14.1; 20.5.1. SC: le. Identifiers: Great Britain (United Kingdom); Portugal.


English, Veronica; Hamm, Danielle; Harrison, Caroline; Mussell, Rebecca; Sheather, Julian; Sommerville, Ann. Ethics briefings. Journal of Medical Ethics 2007 July; 33(7): 433-434 [see correction Journal of Medical Ethics 2007 October, 33(10): 620]. NRCBL: 2.1; 8.3.2; 8.3.3; 8.4; 9.1; 10; 12.4.1; 17.1; 17.7; 20.5.1. SC: le. Identifiers: euthanasia; mental health law; confidentiality; abortion.
Fossett, James W.; Ouellette, Alicia R.; Philpott, Sean; Magnus, David; McGee, Glenn. Federalism and bioethics: states and moral pluralism. Hastings Center Report 2007 November-December; 37(6): 24-35. 45 fn. NRCBL: 2.1; 1.3.5; 18.6; 18.5.4; 15.1; 11.1; 9.7. SC: cs; an; le. Keywords: *bioethical issues; *cultural pluralism; *federal government; *government regulation; *political systems; *state government; advisory committees; attitudes; bioethics; constitutional law; contraindication; democracy; embryo research; embryonic stem cells; empirical research; ethicists; judicial role; government financing; legal aspects; policy analysis; politics; policy making; public opinion; research support; Supreme Court decisions; Keyword Identifiers: *United States

Abstract: Bioethicists are often interested mostly in national standards and institutions, but state governments have historically overseen a wide range of bioethical issues and share responsibility with the federal government for still others. States ought to have an important role. By allowing for multiple outcomes, the American federal system allows a better fit between public opinion and public policies.

Fry-Revere, Sigrid. Legal trends in bioethics. Journal of Clinical Ethics 2007 Spring; 18(1): 72-90. NRCBL: 2.1; 2.5.3; 12.4.4; 18.5.4; 15.1; 19.5; 8.3.5; 8.4; 15.3; 20.4.1; 8.1. SC: le.

Fry-Revere, Sigrid. Legal trends in bioethics. Journal of Clinical Ethics 2007 Summer; 18(2): 162-188. NRCBL: 2.1; 1.3.8; 12.4.4; 8.3.5; 19.5; 8.4; 9.5.6. SC: le.

Fry-Revere, Sigrid; Koshy, Sheeba. Legal trends in bioethics. Journal of Clinical Ethics 2007 Fall; 18(3): 294-328. NRCBL: 2.1; 14.1; 14.5; 12.4.4; 15.1; 18.5.4; 21.1; 9.7; 8.3.5; 19.5; 20.5.3. SC: le. Keywords: *bioethical issues; *legal aspects; *state government; *trends; *abortion; access to information; cloning; confidentiality; conscience; embryo research; embryonic stem cells; euthanasia; government regulation; health disparities; immunization; informed consent; international aspects; investigative drugs; mandatory programs; mentally ill persons; Supreme Court decisions; terminally ill; Keyword Identifiers: *United States

Fry-Revere, Sigrid; Koshy, Sheeba; Leppard, IV, John. Legal trends in bioethics. Journal of Clinical Ethics 2007 Winter; 18(4): 404-424. NRCBL: 2.1; 9.1; 9.7; 12.4.4; 14.1; 21.1; 9.3.2; 19.5; 8.3.1; 20.5.3; 9.5.6. SC: le.


Mauler, Valerie. Improving public health: balancing ethics, culture, and technology. Georgetown Journal of Legal Ethics 2007 Summer; 20(3): 817-833. 113 fn. NRCBL: 2.1; 21.7; 18.5.4; 15.1. SC: le. Keywords: *bioethics; *cultural pluralism; *embryo research; *embryonic stem cells; *human rights; *international aspects; *legal aspects; *non-Western World; public health; regulation; values; *Western World; Keyword Identifiers: *United States

McPhee, John; Stewart, Cameron. Recent developments. Journal of Bioethical Inquiry 2006; 3(3): 125-131. NRCBL: 2.1; 20.7; 20.5.3; 14.6. SC: cs; le.


Riley, Margaret Foster; Merrill, Richard A. Regulating reproductive genetics: a review of American bioethics commissions and comparison to the British Human Fertilisation and Embryology Authority. Columbia Science and Technology Law Review 2005; 6(1): 1-64. 363 fn. NRCBL: 2.4; 14.1; 14.4; 18.5.4; 15.1; 18.2. SC: le. Keywords: *advisory committees; *government regulation; *regulation; *reproductive technologies; *bioethical issues; *biotechnology; *comparative studies; *legislation; *organization and administration; *preimplantation diagnosis; *Keyword Identifiers: *Great Britain; *Human Fertilisation and Embryology Authority; *United States; *Biomedical Ethics Advisory Commission; *Ethics Advisory Board; *Human Embryo Research Panel; *Human Fertilisation and Embryology Act 1990 (Great Britain); *President’s Council on Bioethics; *President’s Commission for the Study of Ethical Problems


NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.
Abstract: Toi te Taiho: the Bioethics Council was established in 2002 to enhance New Zealand's understanding of the cultural, ethical and spiritual aspects of biotechnology and ensure that the use of biotechnology has regard for the values held by New Zealanders. In 2005, the Bioethics Council focused on xenotransplantation. A series of dialogue events were held, the public had the opportunity to participate in an online discussion forum and were able to make written submissions. There is worldwide interest in the potential of this biotechnology to cure or alleviate a number of serious health conditions. However, there are concerns about the risks, especially the potential for cross species infection. Such risks have not yet been reliably quantified, but any decision about safety and effectiveness is also about cultural, ethical and spiritual factors. This paper considers some of the outcomes from the dialogue process and the reflections of the Bioethics Council on these. It contrasts the process with that of classic consultation and concludes that, although the process may be more costly and time consuming than the traditional consultative approach, it enables the role of science to be appreciated in its full context, including appreciation of the uncertainties of natural systems and the relevance of cultural, ethical and spiritual human values. It will be suggested that the public are able to interweave ethical concerns with scientific knowledge to engage in meaningful dialogue, resulting in useful recommendations.

BIOETHICS AND MEDICAL ETHICS/ PHILOSOPHICAL ASPECTS


Baker, Robert B.; McCullough, Laurence B. The relationship between moral philosophy and medical ethics reconsidered. Kennedy Institute of Ethics Journal 2007 September; 17(3): 271-276. NRCBL: 2.1; 1.1; 4.1.2; 1.3.1; 2.2. SC: an.

Abstract: Medical ethics often is treated as applied ethics, that is, the application of moral philosophy to ethical issues in medicine. In an earlier paper, we examined instances of moral philosophy’s influence on medical ethics. We found the applied ethics model inadequate and sketched an alternative model. On this model, practitioners seeking to change morality “appropriate” concepts and theory fragments from moral philosophy to valorize and justify their innovations. Goldilocks-like, five commentators tasted our offerings. Some found them too cold, since they had already abandoned applied ethics; others too hot, since they still find the applied ethics model to their taste. We reply that the appropriation model offers an empirically testable account of the historical relationship between moral philosophy and medical ethics that explains why practitioners appropriate concepts and fragments from moral philosophy. In contrast, the now fashionable common morality theory neither explains moral change nor why practitioners turn to moral philosophy.

Baker, Robert; McCullough, Laurence. Medical ethics’ appropriation of moral philosophy: the case of the sympathetic and the unsympathetic physician. Kennedy Institute of Ethics Journal 2007 March; 17(1): 3-22. NRCBL: 2.1; 1.3.1; 2.2; 1.1; 7.1; 9.5.3; 21.4; 4.1.2; 20.5.1. SC: an. Identifiers: Alfred Hoche; Karl Binding.

Abstract: Philosophy textbooks typically treat bioethics as a form of “applied ethics”—i.e., an attempt to apply a moral theory, like utilitarianism, to controversial ethical issues in biology and medicine. Historians, however, can find virtually no cases in which applied philosophical moral theory influenced ethical practice in biology or medicine. In light of the absence of historical evidence, the authors of this paper advance an alternative model of the historical relationship between philosophical ethics and medical ethics, the appropriation model. They offer two historical case studies to illustrate the ways in which physicians have “appropriated” concepts and theory fragments from philosophers, and demonstrate how appropriated moral philosophy profoundly influenced the way medical morality was conceived and practiced.


Beauchamp, Tom L. History and theory in “applied ethics”. Kennedy Institute of Ethics Journal 2007 March; 17(1): 55-64. NRCBL: 2.1; 1.3.1; 2.2; 1.1; 7.1; 4.1.2. SC: an.
SECTION I BIOETHICS AND MEDICAL ETHICS/ PHILOSOPHICAL ASPECTS

Abstract: Robert Baker and Laurence McCullough argue that the “applied ethics model” is deficient and in need of a replacement model. However, they supply no clear meaning to “applied ethics” and miss most of what is important in the literature on methodology that treats this question. The Baker-McCullough account of medical and applied ethics is a straw man that has had no influence in these fields or in philosophical ethics. The authors are also on shaky historical grounds in dealing with two problems: (1) the historical source of the notion of “practical ethics” and (2) the historical source of and the assimilation of the term “autonomy” into applied philosophy and professional ethics. They mistakenly hold (1) that the expression “practical ethics” was first used in a publication by Thomas Percival and (2) that Kant is the primary historical source of the notion of autonomy as that notion is used in contemporary applied ethics.


Beckmann, Jan P. Ethik in der Medizin in Aus- und Weiterbildung aus der Sicht der Philosophie [Ethics in medicine in education and continuing education from the philosophical point of view]. Ethik in der Medizin 2006 December; 18(4): 369-373. NRCBL: 2.3; 1.1; 7.2.

Bedford-Strohm, Heinrich. Justice and long-term care: a theological ethical perspective. Christian Bioethics 2007 September-December; (13)3: 269-285. NRCBL: 2.1; 1.2; 1.1; 9.5.1; 9.5.2; 9.5.10.

Abstract: The relevance of justice for the current debate on long-term care is explored on the basis of demographic and economic data, especially in the U.S. and Germany. There is a justice question concerning the quality and availability of long-term care for different groups within society. Mapping the justice debate by discussing the two main opponents, John Rawls and Robert Nozick, the article identifies fundamental assumptions in both theories. An exploration of the biblical concept of the “option for the poor” and its influence on a new “ecumenical social teaching from below” leads to the conclusion that a Christian ethical account of long-term care will argue for a system that guarantees decent care to every citizen. The German model of Soziale Pflegeversicherung is presented as one possible option for putting this ethical guideline into political practice. In a final reflection, the role of religious affiliation for long-term care is discussed by looking at empirical data and by naming seven dimensions of faith-driven long-term care.

Benatar, D. Moral theories may have some role in teaching applied ethics. Journal of Medical Ethics 2007 November; 33(11): 671-672. NRCBL: 2.3; 1.1. SC: an.

Abstract: In a recent paper, Rob Lawlor argues that moral theories should not be taught in courses on applied ethics. The author contends that Dr Lawlor’s arguments overlook at least two important roles that some attention to ethical theories may play in practical ethics courses. The conclusion is not that moral theory must be taught, but rather that there is more to be said for it than Dr Lawlor’s arguments reveal.


Capaldi, Nicholas. How philosophy and theology have undermined bioethics. Christian Bioethics 2007 January-April; (13)1: 53-66. NRCBL: 2.1; 1.2; 1.1; 7.1.

Abstract: This essay begins by distinguishing among the viewpoints of philosophy, theology, and religion; it then explores how each deals with “sin” in the bioethical context. The conclusions are that the philosophical and theological viewpoints are intellectually defective in that they cripple our ability to deal with normative issues, and are in the end unable to integrate Christian concepts like “sin” successfully into bioethics. Sin is predicated only of beings with free will, though only in Western Christianity must all sins be committed with knowledge and voluntarily. Without the notions of free will, sin, and a narrative of redemption, bioethics remains unable to provide itself with an adequate normative framework. Bioethics, and morality in general, remain a morass precisely because there has been a failure to translate Christian morality into fully secular and scientific terms.

Carson, Ronald A. Engaged humanities: moral work in the precincts of medicine. Perspectives in Biology and Medicine 2007 Summer; 50(3): 321-333. NRCBL: 2.2; 2.1; 4.1.2; 7.1. SC: rv.


Abstract: Moral decision procedures such as principilism or casuistry require intuition at certain junctures, as when a principle seems indeterminate, or principles conflict, or we wonder which paradigm case is most relevantly similar to the instant case. However, intuitions are widely thought to lack epistemic justification, and many ethicists urge that such decision procedures dispense with intuition in favor of forms of reasoning that provide discursive justification. I argue that discursive justification does not eliminate or minimize the need for intuition, or constrain our intuitions. However, this is not a problem, for intuitions can be justified in easy or obvious cases, and decision procedures should be understood as heuristic devices for reaching judgments among harder cases that approximate the justified intuitions we would have about cases under ideal conditions, where hard cases become easy. Similarly, the forms of reasoning which provide discursive justification help decision procedures perform this heuristic function not by avoiding intuition, but by making such heuristics more accurate. Nonetheless, it is possible to demand too much justification; many clinical ethicists lack the time and philosophical training to reach the more elaborate levels of discursive justification. We should keep moral decision procedures simple and user-friendly so that they will provide what justification can be achieved under clinical conditions, rather than trying to maximize our epistemic justification out of an overstated concern about intuition.


Delkeskamp-Hayes, Corinna. Resisting the therapeutic reduction: on the significance of sin. Christian Bioethics 2007 January-April; (13)1: 105-127. NRCBL: 2.1; 1.2; 4.2; 1.1; 7.1; 21.7.

Abstract: Sin-talk, though politically incorrect, is indispensable. Placing human life under the “hermeneutic of sin” means acknowledging that one ought to aim flawlessly at God, and that one can fail in this endeavor. None of this can be appreciated within the contemporary post-Christian, mindset, which has attempted to reduce religion to morality and culture. In such a secular context, the guilt-feelings connected with the recognition of sin are considered to be harmful; the eternal benefit of a repentance is disregarded. Nevertheless, spirituality appears to have therapeutic benefits. Therefore attempts are made to re-locate within healthcare a religion shorn of its transcendent claims, so as then to harvest the benefits of a spirituality “saved from sin”. This reduction of religiosity to its therapeutic function is nourished by a post-modern constructivist construal of religion. This article critically examines the dis-ingenuity marring such recasting, as well as the incoherence of related attempts to reduce transcendence to solidarity, and to re-shape the significance of religious rituals.


Dikova, Rossitza. Introduction [to issue on Philanthropy, Caritas, Diakonita — European approaches to Christians’ service in the world]. Christian Bioethics 2007 September-December; (13)3: 245-250. NRCBL: 2.1; 1.2; 9.5.1; 9.5.2; 9.5.10; 1.1.

Dzur, Albert W.; Levin, Daniel. The primacy of the public: in support of bioethics commissions as deliberative forums. Kennedy Institute of Ethics Journal 2007 June; 17(2): 133-142. NRCBL: 2.4; 5.1; 1.3.5; 2.1; 1.1; 7.1. SC: an.

Abstract: In a 2004 article, we argued that bioethics commissions should be assessed in terms of their usefulness as public forums. A 2006 article by Summer Johnson argued that our perspective was not supported by the existing literature on presidential commissions, which had not previously identified commissions as public forums and that we did not properly account for the political functions of commissions as instruments of presidential power. Johnson also argued that there was nothing sufficiently unique about bioethics commissions to make the public forum perspective particularly applicable. We respond by arguing that analysis of commissions’ work as public forums fits well within the literature on commissions, especially on their agenda-setting functions, and that the political functions of commissions are often com-
patible with their functioning as public forums. We also demonstrate how the origins and concerns of bioethics make public forum analysis particularly applicable to bioethics commissions.

**Ebbesen, Mette; Pedersen, Birthe D.** Using empirical research to formulate normative ethical principles in biomedicine. *Medicine, Health Care and Philosophy* 2007 March; 10(1): 33-48. NRCBL: 2.1; 1.1. SC: an; em. Abstract: Bioethical research has tended to focus on theoretical discussion of the principles on which the analysis of ethical issues in biomedicine should be based. But this discussion often seems remote from biomedical practice where researchers and physicians confront ethical problems. On the other hand, published empirical research on the ethical reasoning of health care professionals offers only descriptions of how physicians and nurses actually reason ethically. The question remains whether these descriptions have any normative implications for nurses and physicians? In this article, we illustrate an approach that integrates empirical research into the formulation of normative ethical principles using the moral-philosophical method of Wide Reflective Equilibrium (WRE). The research method discussed in this article was developed in connection with the project ‘Bioethics in Theory and Practice’. The purpose of this project is to investigate ethically reasoning in biomedical practice in Denmark empirically. In this article, we take the research method as our point of departure, but we exclusively discuss the theoretical framework of the method, not its empirical results. We argue that the descriptive phenomenological hermeneutical method developed by Lindseth and Norberg (2004) and Pedersen (1999) can be combined with the theory of WRE to arrive at a decision procedure and thus a foundation for the formulation of normative ethical principles. This could provide health care professionals and biomedical researchers with normative principles about how to analyse, reason and act in ethically difficult situations in their practice. We also show how to use existing bioethical principles as inspiration for interpreting the empirical findings of qualitative studies. This may help researchers design their own empirical studies in the field of ethics.

**Elliott, Carl.** The tyranny of expertise. *In: Eckenwiler, Lisa A.; Cohn, Felicia G., eds. The Ethics of Bioethics: Mapping the Moral Landscape. Baltimore, MD: Johns Hopkins University Press, 2007: 43-46. NRCBL: 2.1; 4.1.1; 7.3.*


**Engelhardt, H. Tristram.** Why ecumenism fails: taking theological differences seriously. *Christian Bioethics* 2007 January-April; (13)1: 25-51. NRCBL: 2.1; 1.2; 1.1. Abstract: Contemporary Christians are separated by foundational dis-parate understandings of Christianity itself. Christians do not share one theology, much less a common understanding of the significance of sin, suffering, disease, and death. These foundational disagreements not only stand as impediments to an intellectually defensible ecumenism, but they also form the underpinnings of major disputes in the culture wars, particularly as these are expressed in healthcare. There is not one Christian bioethics of sin, suffering, sickness, and death. In this article, the character of the moral-theological visions separating the various Christianities and thus their bioethics is examined. Particular emphasis is placed on the differences that set contemporary Western theology at odds with the theology of the Christianity of the first millennium. As is shown, the ground for this gulf lies in the divide between traditional and post-traditional views of the appropriate role of philosophy in theology, a difference rooted in disparate understandings of the meaning of church and of the meaning of the logos, the Son of God.


**Fox, Daniel M.** Selective appropriation, medical ethics, and health politics: the complementarity of Baker, McCullough, and me. *Kennedy Institute of Ethics Journal* 2007 March; 17(1): 23-30. NRCBL: 2.1; 1.3.1; 2.2; 1.1; 7.1; 4.1.2. SC: an. Abstract: Baker and McCullough (2007) criticize a 1979 article by this author for insufficiently appreciating how physicians have appropriated ideas from moral philosophy. This rejoinder argues that the two articles are complementary. The 1979 article summarized evidence that leading physicians in the nineteenth and twentieth centuries appropriated ideas from moral philosophy and re-
lated disciplines that reinforced their political goals of self-regulation and dominance of the allocation of resources for health. In retrospect the 1979 article also urged bioethicists to appropriate ideas from other disciplines, including moral philosophy, which would contribute to improving the health of populations.


**Gentry, Glenn.** Rawls and religious community: ethical decision making in the public square. *Christian Bioethics* 2007 May-August; (13)2: 171-181. NRCBL: 2.1; 1.2; 7.1; 1.1. SC: an.

Abstract: While most people may initially agree that justice is fairness, as an evangelical Protestant I argue that, for many religious comprehensive doctrines, the Rawlsian model does not possess the resources necessary to sustain tolerance in moral decision making. The weakness of Rawls's model centers on the reasonable priority of convictions that arise from private comprehensive doctrines. To attain a free and pluralistic society, people need resources sufficient to provide reasons to tolerate actions that are otherwise intolerable. In addition to arguing for the deficiency of the Rawlsian political model, I sketch out a preliminary model of ambassadorship that offers religious communities, and in particular Protestant evangelicals, the necessary resources to engage the broader society tolerantly while maintaining their religious convictions. As a citizen of the church and a member of another kingdom, Christians serve as ambassadors to those who are not of the heavenly kingdom. I take this model to be more ambitious than that of a sojourner who lives in the land but is isolated as much as possible from society, while more modest than that of reconstructionists who seek to implement their own sacred law on all others.


Abstract: Two pro-technology arguments, the “hopeful principle” and the “automatic escalator”, often used in bioethics, are identified and critically analysed in this paper. It is shown that the hopeful principle is closely related to the problematic precautionary principle, and the automatic escalator argument has close affinities to the often criticised empirical slippery slope argument. The hopeful principle is shown to be really hopeless as an argument, and automatic escalator arguments often lead nowhere when critically analysed. These arguments should therefore only be used with great caution.


**Johnson, Summer.** A rebuttal to Dzur and Levin: Johnson on the legitimacy and authority of bioethics commissions. *Kennedy Institute of Ethics Journal* 2007 June; 17(2): 143-152. NRCBL: 2.4; 5.1; 1.3.5; 2.1; 1.1; 7.1. SC: an.


Abstract: Bioethics commissions have been critiqued on the basis that they are not sufficiently public or are too reliant upon expertise to have legitimacy or authority in regard to public policy debates. Adequately assessing the legitimacy and authority of commissions requires thinking clearly about the “publics” these commissions serve, the primary tasks of public bioethics, and how those tasks might be performed with a certain kind of ethical expertise and authority that makes them legitimate in public policy debates concerning bioethics.

**Jonsen, Albert R.** How to appropriate appropriately: a comment on Baker and McCullough. *Kennedy Institute of Ethics Journal* 2007 March; 17(1): 43-54. NRCBL: 2.1; 1.3.1; 2.2; 1.1; 7.1; 4.1.2. SC: an.

Abstract: The article by Baker and McCullough in this issue posits that bioethics has generally applied moral theories to practical problems. They propose that, rather than this “application,” bioethicists should “appropriate” aspects of ethical theory. This article disagrees that bioethical writing is primary “application.” It agrees that “ap-
proprietation” is the most suitable approach to bioethical analysis but claims that the description of appropriation provided by Baker and McCullough is inadequate. It must be supplemented by the rhetorical concept of “invention.”


Abstract: In an attempt to be rational and objective, and, possibly, to avoid the charge of moral relativism, ethicists seek to categorise and characterise ethical dilemmas. This approach is intended to minimise the effect of the confusing individuality of the context within which ethically challenging problems exist. Despite and I argue partly as a result of this attempt to be rational and objective, even when the logic of the argument is accepted — for example, by healthcare professionals — those same professionals might well respond by stating that the conclusions are unacceptable to them. In this paper, I argue that an interpretative approach to ethical analysis, involving an examination of the ways in which ethical arguments are constructed and shared, can help ethicists to understand the origins of this gap between logic and intuition. I suggest that an argument will be persuasive either if the values underpinning the proposed argument accord with the reader’s values and worldview, or if the argument succeeds in persuading the reader to alter these. A failure either to appreciate or to acknowledge those things that give meaning to the lives of all the interested parties will make this objective far harder, if not impossible, to achieve. If, as a consequence, the narratives ethicists use to make their arguments seem to be about people living in different circumstances, and faced with different choices and challenges, from those the readers or listeners consider important or have to face in their own lives, then the argument is unlikely to seem either relevant or applicable to those people. The conclusion offered by the ethicist will be, for that individual, counterintuitive. Abortion, euthanasia and cadaveric organ donation are used as examples to support my argument.


Abstract: It is argued, in this paper, that moral theories should not be discussed extensively when teaching applied ethics. First, it is argued that, students are either presented with a large amount of information regarding the various subtle distinctions and the nuances of the theory and, as a result, the students simply fail to take it in or, alternatively, the students are presented with a simplified caricature of the theory, in which case the students may understand the information they are given, but what they have understood is of little or no value because it is merely a caricature of a theory. Second, there is a methodological problem with appealing to moral theories to solve particular issues in applied ethics. An analogy with science is appealed to. In physics there is a hope that we could discover a unified theory of everything. But this is, of course, a hugely ambitious project, and much harder than, for example, finding a theory of motion. If the physicist wants to understand motion, he should try to do so directly. We would think he was particularly misguided if he thought that, to answer this question, he first needed to construct a unified theory of everything.


London, Alex John. Clinical equipoise: foundational requirement or fundamental error? In: Steinbock, Bonnie,


McKay, Angela. Publicly accessible intuitions: “neutral reasons” and bioethics. Christian Bioethics 2007 May-Aug; (13)2: 183-197. NRCBL: 2.1; 1.2; 7.1; 1.1; 4.4; 20.7; 20.5.1; 8.1. SC: an.

Abstract: This article examines Leon Kass’s contention that a choice for physician-assisted suicide is “undignified.” Although Kass is Jewish rather than Christian, he argues for positions that most Christians share, and he argues for these positions without presupposing the truth of specific religious claims. I argue that although Kass has some important intuitions, he too readily assumes that these intuitions will be shared by his audience, and that this assumption diminishes the force of his argument. An examination of the limitations of Kass’s argument is helpful insofar as it illustrates the real challenge faced by religious believers who wish to defend their beliefs in the “public forum.” For it illustrates that what needs to be made “accessible” is the Judeo-Christian understanding of man and his place in the world. While I do not wish to claim that this task is impossible, I do think that it is far more difficult than most realize. Like all important tasks, however, unless we wrestle with the difficulties it raises, our arguments will strike many as unconvincing.

Moreno, Jonathan D. The triumph of autonomy in bioethics and commercialism in American healthcare. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Fall; 16(4): 415-419. NRCBL: 2.1; 2.2; 1.1; 9.3.1; 7.3; 1.3.2. SC: an.

Müller, Denis. The original risk: overtheologizing ethics and undertheologizing sin. Christian Bioethics 2007 January-April; (13)1: 7-23. NRCBL: 2.1; 1.2; 1.1.

Abstract: The project of articulating a theological ethics on the basis of liturgical anthropology is bound to fail if the necessary consequence is that one has to quit the forum of critical modern rationality. The risk of Engelhardt’s approach is to limit rationality to a narrow vision of reason. Sin is not to be understood as the negation of human holiness, but as the negation of divine holiness. The only way to renew theological ethics is to understand sin as the anthropological and ethical expression of the biblical message of the justification by faith only. Sin is therefore a secondary category, which can only by interpreted in light of the positive manifestation of liberation, justification, and grace. The central issue of Christian ethics is not ritual purity or morality, but experience, confession and recognition of our own injustice in our dealing with God and men.


Abstract: Modern medical practice is becoming increasingly pluralistic and diverse. Hence, cultural competency and awareness are given more focus in physician training seminars and within medical school curricula. A renewed interest in describing the varied ethical constructs of specific populations has taken place within medical literature. This paper aims to provide an overview of Islamic Medical Ethics. Beginning with a definition of Islamic Medical Ethics, the reader will be introduced to the scope of Islamic Medical Ethics literature, from that aimed at developing moral character to writings grounded in Islamic law. In the latter form, there is an attempt to derive an Islamic perspective on bioethical issues such as abortion, gender relations within the patient-doctor relationship, end-of-life care and euthanasia. It is hoped that the insights gained will aid both clinicians and ethicists to better understand the Islamic paradigm of medical ethics and thereby positively affect patient care.

Parker, C. Perspectives on ethics. Journal of Medical Ethics 2007 January; 33(1): 21-23. NRCBL: 2.1; 1.1; 8.1; 18.5.4; 21.7.

Abstract: In his recent paper about understanding ethical issues, Boyd suggests that traditional approaches based on principles or people are understood better in terms of perspectives, especially the perspective-based approach
of hermeneutics, which he uses for conversation rather than controversy. However, we find that Boyd’s undefined contrast between conversation and controversy does not point to any improvement in communication: disputes occur during conversation and controversy may be conducted in gentle tones. We agree with Boyd, that being prepared to listen and learn are excellent attitudes, but his vague attempts to establish these and similar virtues in hermeneutic theory are not plausible. Additionally, the current controversy about the use of human embryos in stem cell therapy research shows Boyd missing the opportunity to illustrate how conversation would improve understanding.


Abstract: Bioethics uses various theories, methods and institutions for its decision-making. Lately, a dialogical, i.e., dialogue-based, approach has been argued for in bioethics. The aim of this paper is to explore some of the decision-making processes that may be involved in this dialogical approach, as well as related pitfalls that may have to be addressed in order for this approach to be helpful, particularly in clinical ethics. Using informal logic, an analysis is presented of the notion of dialogue and of the stages of dialogical decision-making, and then processes and related pitfalls associated with these stages in the context of clinical ethics are examined. The results of this exploration are expected to facilitate the implementation and empirical testing of dialogical bioethics.

Sass, Hans-Martin. Fritz Jahr’s 1927 concept of bioethics. Kennedy Institute of Ethics Journal 2007 December; 17(4): 279-295. NRCBL: 2.2; 1.1; 22.1; 16.1; 2.3. Abstract: In 1927, Fritz Jahr, a Protestant pastor, philosopher, and educator in Halle an der Saale, published an article entitled “Bio-Ethics: A Review of the Ethical Relationships of Humans to Animals and Plants” and proposed a “Biomedical Imperative,” extending Kant’s moral imperative to all forms of life. Reviewing new physiological knowledge of his times and moral challenges associated with the development of secular and pluralistic societies, Jahr redefines moral obligations towards human and nonhuman forms of life, outlining the concept of bioethics as an academic discipline, principle, and virtue. Although he had no immediate long-lasting influence during politically and morally turbulent times, his argument that new science and technology requires new ethical and philosophical reflection and resolve may contribute toward clarification of terminology and of normative and practical visions of bioethics, including understanding of the geoethical dimensions of bioethics.


Schmidt, Ulf. Turning the history of medical ethics from its head onto its feet: a critical commentary on Baker and McCullough. Kennedy Institute of Ethics Journal 2007 March; 17(1): 31-42. NRCBL: 2.1; 1.3.1; 2.2; 1.1; 7.1; 4.1.2; 20.5.1; 21.4. SC: an. Identifiers: Karl Brandt.

Abstract: The paper provides a critical commentary on the article by Baker and McCullough on Medical Ethics’ Appropriation of Moral Philosophy. The author argues that Baker and McCullough offer a more “pragmatic” approach to the history of medical ethics that has the potential to enrich the bioethics field with a greater historical grounding and sound methodology. Their approach can help us to come to a more nuanced understanding about the way in which medical ethics has connected, disconnected, and reconnected with philosophical ideas throughout the centuries. The author points out that Baker and McCullough’s model can run the danger of overemphasizing the role of medical ethicists whilst marginalizing the influence of philosophers and of other historical actors and forces. He critically reviews the two case studies on which Baker and McCullough focus and concludes that scholars need to bear in mind the levels of uncertainty and ambivalence that accompany the process of transformation and dissemination of moral values in medicine and medical practice.


Abstract: The notion of ‘playing God’ frequently comes to fore in discussions of bioethics, especially in religious contexts. The phrase has always been analyzed and discussed from Christian and secular standpoints. Two interpretations exist in the literature. The first one takes ‘God’ seriously and playing ‘playfully’. It argues that this concept does state a principle but invokes a perspective on the world. The second takes both terms playfully. In the Islamic Intellectual tradition, the Sufi concept of ‘adopting divine character traits’ provides a legitimate paradigm for ‘playing God’. This paradigm is interesting because here we take both terms ‘God’ and ‘playing’ seriously. It is significant for the development of biomedical
ethics in contemporary Islamic societies as it can open new vistas for viewing biotechnological developments.


Spiess, Christian. Recognition and social justice: a Roman Catholic view of Christian bioethics of long-term care and community service. Christian Bioethics 2007 September-December. 13(3): 287-301. NRCBL: 2.1; 1.2; 1.1; 9.5.1; 9.5.2; 9.5.10.

Abstract: Contemporary Christian ethics encounters the challenge to communicate genuinely Christian normative orientations within the scientific debate in such a way as to render these orientations comprehensible, and to maintain or enhance their plausibility even for non-Christians. This essay, therefore, proceeds from a biblical motif, takes up certain themes from the Christian tradition (in particular the idea of social justice), and connects both with a compelling contemporary approach to ethics by secular moral philosophy, i.e. with Axel Honneth’s reception of Hegel, as based on Hegel’s theory of recognition. As a first step, elements of an ethics of recognition are developed on the basis of an anthropological recourse to the conditions of intersubjective encounters. These conditions are then brought to bear on the idea of social justice, as developed in the social-Catholic tradition, and as systematically explored in the Pastoral Letter of the United States Conference of Catholic Bishops, Economic Justice For All (1986). Proceeding from this basis, aspects of a Christian ethics of community service with regard to long-term care can be defined.


Abstract: Strong arguments support the notion that much of modern bioethics is a result of appropriation rather than strict application of traditional moral philosophy. Nevertheless, it is important to recognize these sources and approaches associated with them, even when working with appropriated theories, since traditional ethical theory does and should influence modern bioethics.


Tollesen, Christopher. Religious reasons and public healthcare deliberations. Christian Bioethics 2007 May-August; (13)2: 139-157. NRCBL: 2.1; 1.2; 7.1; 1.1.

Abstract: This paper critically explores the path of some of the controversies over public reason and religion through four distinct steps. The first part of this article considers the engagement of John Finnis and Robert P. George with John Rawls over the nature of public reason. The second part moves to the question of religion by looking at the engagement of Nicholas Wolterstorff with Rawls, Robert Audi, and others. Here the question turns specifically to religious reasons, and their permissible use by citizens in public debate and discourse. The third part engages Jürgen Habermas’s argument that while citizens must be free to make religious arguments, still, there is an obligation of translation, and a motivational constraint on lawmakers. The final section argues that even though Habermas’s proposal fails, nevertheless he recognizes a key difficulty for religious citizens in contemporary liberal polities. Restoration of a full role for religiously grounded justificatory reasons in public debate is one part of an adequate solution to this problem, but a second plank must be added to the solution: recognition that religious reasons can enter into public deliberation not just as first-order justifications of particular policies, but as second-order reasons, to be considered by any polity that respects its religious citizens and, more broadly, the good of religion.


Veatch, Robert M. Is bioethics applied ethics? Kennedy Institute of Ethics Journal 2007 March; 17(1): 1-2. NRCBL: 2.1; 1.3.1; 2.2; 1.1; 7.1; 4.1.2.


Yalisove, Daniel. From the ivory tower to the trenches: teaching professional ethics to substance abuse counselors. In: Kleimig, John; Einstein, Stanley, eds. Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 507-527. NRCBL: 2.3; 9.5.9; 17.1; 1.1; 1.3.1.


BIOETHICS AND MEDICAL ETHICS/ RELIGIOUS ASPECTS


Bedford-Strohm, Heinrich. Justice and long-term care: a theological ethical perspective. Christian Bioethics 2007 September-December; (13)3: 269-285. NRCBL: 2.1; 1.2; 1.1; 9.5.1; 9.5.2; 9.5.10.

Abstract: The relevance of justice for the current debate on long-term care is explored on the basis of demographic and economic data, especially in the U.S. and Germany. There is a justice question concerning the quality and availability of long-term care for different groups within society. Mapping the justice debate by discussing the two main opponents, John Rawls and Robert Nozick, the article identifies fundamental assumptions in both theories. An exploration of the biblical concept of the “option for the poor” and its influence on a new “ecumenical social teaching from below” leads to the conclusion that a Christian ethical account of long-term care will argue for a system that guarantees decent care to every citizen. The German model of Soziale Pflegeversicherung is presented as one possible option for putting this ethical guideline into political practice. In a final reflection, the role of religious affiliation for long-term care is discussed by looking at empirical data and by naming seven dimensions of faith-driven long-term care.


Burton, Olivette R. Why bioethics cannot figure out what to do with race. American Journal of Bioethics 2007 February; 7(2): 6-12. 20 refs. 9 fn. NRCBL: 2.1; 1.2; 13.1; 15.5.

Keywords: *bioethical issues; *bioethics; *blacks; *racial groups; capitalism; culture; eugenics; historical aspects; population control; religion; scientific misconduct; social discrimination; whites; Proposed Keywords: slavery; Keyword Identifiers: Seventeenth Century; Eighteenth Century; Nineteenth Century; Twentieth Century; Twenty-First Century; United States

Abstract: Race and religion are integral parts of bioethics. Harm and oppression, with the aim of social and political control, have been wrought in the name of religion against Blacks and people of color as embodied in the Ten Commandments, the Inquisition, and in the history of the Holy Crusades. Missionaries came armed with Judeo/Christian beliefs went to nations of people of color who had their own belief systems and forced change and caused untold harms because the indigenous belief systems were incompatible with their own. The indigenous people were denounced as ungodly, pagan, uncivilized, and savage. Hence, laws were enacted because of their perceived need to structure a sense of morality and to create and build a culture for these indigenous people of color. To date bioethics continues to be informed by a Western worldview that is Judeo/Christian in belief and orientation. However, missing from bioethical discourse in America is the historical influence of the Black Church as a cultural repository, which continues to influence the culture of Africans and Blacks. Cultural aspects of peoples of color are still largely ignored today. In attempting to deal with issues of race while steering clear of the religious and cultural impact of the Black Church, bioethics finds itself in the middle of a distressing situation: it simply cannot figure out what to do with race.

Capaldi, Nicholas. How philosophy and theology have undermined bioethics. Christian Bioethics 2007 January-April; (13)1: 53-66. NRCBL: 2.1; 1.2; 1.1; 7.1.

Abstract: This essay begins by distinguishing among the viewpoints of philosophy, theology, and religion; it then explores how each deals with “sin” in the bioethical context. The content is that the philosophical and theological viewpoints are intellectually defective in that they cripple our ability to deal with normative issues, and are in the end unable to integrate Christian concepts like “sin” successfully into bioethics. Sin is predicated only of beings with free will, though only in Western Christianity must all sins be committed with knowledge and voluntarily. Without the notions of free will, sin, and a narrative of redemption, bioethics remains unable to provide itself with an adequate normative framework. Bioethics, and morality in general, remain a morass precisely because there has been a failure to translate Christian morality into fully secular and scientific terms.
Cherry, Mark J. Traditional Christian norms and the shaping of public moral life: how should Christians engage in bioethical debate within the public forum? Christian Bioethics 2007 May-August; (13)2: 129-138. NRCBL: 2.1; 1.2; 7.1; 4.4. SC: an.


Abstract: On the basis of a definition of God as “love”, human philanthropy is derived from Divine philanthropy, and therefore extends to all human beings. Because Divine philanthropy is most centrally expressed in Christ’s incarnation and resurrection, Christ’s identification with all who suffer presents the strongest motivation for human philanthropy. After a short review of the Romanian Orthodox Church’s development after 1989, the author turns to his special case study, the Social-Medical Day-Care Christian Centre for older citizens. He describes the way in which Church-based philanthropy can integrate social-medical with Christian pastoral care, and how this work draws the local communities into assuming a shared responsibility.


Delkeskamp-Hayes, Corinna. Resisting the therapeutic reduction: on the significance of sin. Christian Bioethics 2007 January-April; (13)1: 105-127. NRCBL: 2.1; 1.2; 4.2; 1.1; 7.1; 21.7.

Abstract: Sin-talk, though politically incorrect, is indispensable. Placing human life under the “hermeneutic of sin” means acknowledging that one ought to aim flawlessly at God, and that one can fail in this endeavor. None of this can be appreciated within the contemporary post-Christian, mindset, which has attempted to reduce religion to morality and culture. In such a secular context, the guilt-feelings connected with the recognition of sin are considered to be harmful; the eternal benefit of a repentance is disregarded. Nevertheless, spirituality appears to have therapeutic benefits. Therefore attempts are made to relocate within healthcare a religion shorn of its transcendent claims, so as then to harvest the benefits of a spirituality “saved from sin”. This reduction of religiosity to its therapeutic function is nourished by a post-modern constructivist construal of religion. This article critically examines the dis-ingenuity marring such recasting, as well as the incoherence of related attempts to reduce transcendence to solidarity, and to re-shape the significance of religious rituals.

Dikova, Rossitza. Introduction [to issue on Philanthropy, Caritas, Diakonia — European approaches to Christians’ service in the world]. Christian Bioethics 2007 September-December; (13)3: 245-250. NRCBL: 2.1; 1.2; 9.5.1; 9.5.2; 9.5.10; 1.1.


Abstract: Contemporary Christians are separated by foundationally disparate understandings of Christianity itself. Christians do not share one theology, much less a common understanding of the significance of sin, suffering, disease, and death. These foundational disagreements not only stand as impediments to an intellectually defensible ecumenism, but they also form the underpinnings of major disputes in the culture wars, particularly as these are expressed in healthcare. There is not one Christian bioethics of sin, suffering, sickness, and death. In this article, the character of the moral-theological visions separating the various Christianities and thus their bioethics is examined. Particular emphasis is placed on the differences that set contemporary Western theology at odds with the theology of the Christianity of the first millennium. As is shown, the ground for this gulf lies in the divide between traditional and post-traditional views of the appropriate role of philosophy in theology, a difference rooted in disparate understandings of the meaning of church and of the meaning of the logos, the Son of God.


Abstract: While most people may initially agree that justice is fairness, as an evangelical Protestant I argue that, for many religious comprehensive doctrines, the Rawlsian model does not possess the resources necessary to sustain tolerance in moral decision making. The weakness of Rawls’s model centers on the reasonable priority of convictions that arise from private comprehensive doctrines. To attain a free and pluralistic society, people need resources sufficient to provide reasons to tolerate actions that are otherwise intolerable. In addition to arguing for the deficiency of the Rawlsian political model, I sketch out a preliminary model of ambassadorship that offers religious communities, and in particular Protestant evangelicals, the necessary resources to engage the broader society tolerantly while maintaining their religious convictions. As a citizen of the church and a member of another kingdom, Christians serve as ambassadors to those who are not of the heavenly kingdom. I take this model to be more ambitious than that of a sojourner who lives in the land but is isolated as much as possible from
society, while more modest than that of reconstructionists who seek to implement their own sacred law on all others.


Abstract: Statements on issues in biomedical ethics, purporting to represent international interests, have been put forth by numerous groups. Most of these groups are composed of thinkers in the tradition of European secularism, and do not take into account the values of other ethical systems. One fifth of the world’s population is accounted for by Islam, which is a universal religion, with more than 1400 years of scholarship. Although many values are held in common by secular ethical systems and Islam, their inferences are different. The question, “Is it possible to derive a truly universal declaration of biomedical ethics?” is discussed here by examining the value and extent of personal autonomy in Western and Islamic biomedical ethical constructs. These constructs are then tested vis-à-vis the issue of abortion. It is concluded that having a universal declaration of biomedical ethics in practice is not possible, although there are many conceptual similarities and agreements between secular and Islamic value systems, unless a radical paradigm shift occurs in segments of the world’s deliberative bodies. The appellation “universal” should not be used on deliberative statements unless the ethical values of all major schools of thought are satisfied.


McKay, Angela. Publicly accessible intuitions: “neutral reasons” and bioethics. *Christian Bioethics* 2007 May-August; (13)2: 183-197. NRCBL: 2.1; 1.2; 7.1; 1.1; 4.4; 20.7; 20.5.1; 8.1. SC: an.

Abstract: This article examines Leon Kass’s contention that a choice for physician-assisted suicide is “undignified.” Although Kass is Jewish rather than Christian, he argues for positions that most Christians share, and he argues for these positions without presupposing the truth of specific religious claims. I argue that although Kass has some important intuitions, he too readily assumes that these intuitions will be shared by his audience, and that this assumption diminishes the force of his argument. An examination of the limitations of Kass’s argument is helpful insofar as it illustrates the real challenge faced by religious believers who wish to defend their beliefs in the “public forum.” For it illustrates that what needs to be made “accessible” is the Judeo-Christian understanding of man and his place in the world. While I do not wish to claim that this task is impossible, I do think that it is far more difficult than most realize. Like all important tasks, however, unless we wrestle with the difficulties it raises, our arguments will strike many as unconvincing.

Müller, Denis. The original risk: overtheologizing ethics and undertheologizing sin. *Christian Bioethics* 2007 January-April; (13)1: 7-23. NRCBL: 2.1; 1.2; 1.1.

Abstract: The project of articulating a theological ethics on the basis of liturgical anthropology is bound to fail if the necessary consequence is that one has to quit the fo-
rum of critical modern rationality. The risk of Engelhardt’s approach is to limit rationality to a narrow vision of reason. Sin is not to be understood as the negation of human holiness, but as the negation of divine holiness. The only way to renew theological ethics is to understand sin as the anthropological and ethical expression of the biblical message of the justification by faith only. Sin is therefore a secondary category, which can only by interpreted in light of the positive manifestation of liberation, justification, and grace. The central issue of Christian ethics is not ritual purity or morality, but experience, confession and recognition of our own injustice in our dealing with God and men.

Orr, Robert D. The role of Christian belief in public policy. *Christian Bioethics* 2007 May-August; (13)2: 199-209. NRCBL: 2.1; 1.2; 7.1; 20.7; 20.5.1; 8.1; 12.3. SC: an.

Abstract: It seems intuitive to the believer that God intended through instruction in the Law to define morality, intended to lead humankind to “the right and the good.” Further, God’s love for humankind, exemplified by the incarnation, atonement and teachings of Jesus, and empowered by the Holy Spirit, should lead to a better world. Indeed, the Christian worldview is a coherent and valid way to look at bioethical issues in public policy and at the bedside. Yet, as this paper explores, in a pluralistic society such as the United States, it is neither possible nor desirable for Christians to try to force their views on others. Still, it is obligatory for Christians to stand up and articulate their views in the public square. We should try to persuade others using either prudential or moral arguments. While we must be willing to live with “the will of the people,” at the same time, we must not be intimidated into accepting the position that our voice is not valid because it has a religious basis.


Abstract: Modern medical practice is becoming increasingly pluralistic and diverse. Hence, cultural competency and awareness are given more focus in physician training seminars and within medical school curricula. A renewed interest in describing the varied ethical constructs of specific populations has taken place within medical literature. This paper aims to provide an overview of Islamic Medical Ethics. Beginning with a definition of Islamic Medical Ethics, the reader will be introduced to the scope of Islamic Medical Ethics literature, from that aimed at developing moral character to writings grounded in Islamic law. In the latter form, there is an attempt to derive an Islamic perspective on bioethical issues such as abortion, gender relations within the patient-doctor relationship, end-of-life care and euthanasia. It is hoped that the insights gained will aid both clinicians and ethicists to better understand the Islamic paradigm of medical ethics and thereby positively affect patient care.


Abstract: The notion of ‘playing God’ frequently comes to fore in discussions of bioethics, especially in religious contexts. The phrase has always been analyzed and discussed from Christian and secular standpoints. Two interpretations exist in the literature. The first one takes ‘God’ seriously and playing ‘playfully’. It argues that this concept does state a principle but invokes a perspective on the world. The second takes both terms playfully. In the Islamic Intellectual tradition, the Sufi concept of ‘adopting divine character traits’ provides a legitimate paradigm for ‘playing God’. This paradigm is interesting because here we take both terms ‘God’ and ‘playing’ seriously. It is significant for the development of biomedical ethics in contemporary Islamic societies as it can open new vistas for viewing biomedical developments.

Sherlock, Richard. Bioethics in liberal regimes: a review of the President’s Council. *Ethics and Medicine: An International Journal of Bioethics* 2007 Fall; 23(3): 169-188. 10 fn. NRCBL: 2.4; 2.2; 1.2; 9.1; 14.1; 15.1; 15.2; 9.5.4; 10; 5.1. SC: rv.

Keywords: *advisory committees; *bioethical issues; *bioethics; biomedical enhancement; biotechnology; cloning; cultural pluralism; democracy; embryo research; embryonic stem cells; eugenics; euthanasia; genetic engineering; historical aspects; human dignity; human experimentation; morality; preimplantation diagnosis; public policy; religion; reproductive technologies; Proposed Keywords: publications; Keyword Identifiers: *President’s Council on Bioethics; *United States; National Bioethics Advisory Commission; National Commission for the Protection of Human Subjects and Biomedical and Behavioral Research; President’s Commission for the Study of Ethical Problems in Biomedical and Behavioral Research; Twentieth Century; Twenty-First Century


Spiess, Christian. Recognition and social justice: a Roman Catholic view of Christian bioethics of long-term care and community service. *Christian Bioethics* 2007 September-December; (13)3: 287-301. NRCBL: 2.1; 1.2; 1.1; 9.5.1; 9.5.2; 9.5.10.

Abstract: Contemporary Christian ethics encounters the challenge to communicate genuinely Christian normative orientations within the scientific debate in such a way as to render these orientations comprehensible, and to maintain or enhance their plausibility even for non-Christians. This essay, therefore, proceeds from a biblical motif, takes up certain themes from the Christian tradition (in particular the idea of social justice), and connects both with a compelling contemporary approach to ethics by secular moral philosophy, i.e. with Axel Honneth’s reception of Hegel, as based on Hegel’s theory of recognition. As a first step, elements of an ethics of recognition are developed on the basis of an anthropological recourse
to the conditions of intersubjective encounters. These conditions are then brought to bear on the idea of social justice, as developed in the social-Catholic tradition, and as systematically explored in the Pastoral Letter of the United States Conference of Catholic Bishops, Economic Justice For All (1986). Proceeding from this basis, aspects of a Christian ethics of community service with regard to long-term care can be defined.

Tham, Joseph. Bioethics and anointing of the sick. *Linacre Quarterly* 2007 August; 74(3): 253-257. NRCBL: 2.1; 1.2; 4.4; 20.5.1.


Abstract: This paper critically explores the path of some of the controversies over public reason and religion through four distinct steps. The first part of this article considers the engagement of John Finnis and Robert P. George with John Rawls over the nature of public reason. The second part moves to the question of religion by looking at the engagement of Nicholas Wolterstorff with Rawls, Robert Audi, and others. Here the question turns specifically to religious reasons, and their permissible use by citizens in public debate and discourse. The third part engages Jürgen Habermas’s argument that while citizens must be free to make religious arguments, still, there is an obligation of translation, and a motivational constraint on lawmakers. The final section argues that even though Habermas’s proposal fails, nevertheless he recognizes a key difficulty for religious citizens in contemporary liberal politics. Restoration of a full role for religiously grounded justificatory reasons in public debate is one part of an adequate solution to this problem, but a second plank must be added to the solution: recognition that religious reasons can enter into public deliberation not just as first-order justifications of particular policies, but as second-order reasons, to be considered by any polity that respects its religious citizens and, more broadly, the good of religion.

Vantsos, Miltiadis; Kiroudi, Marina. An Orthodox view of philanthropy and Church diaconia. *Christian Bioethics* 2007 September-December; (13)3: 251-268. NRCBL: 2.1; 1.2; 7.1; 9.5.10.

Abstract: According to Orthodox theology, philanthropy refers to the love of God toward man, which man is called to imitate by loving his neighbor as himself. This love consists not just in emotions but requires specific acts of philanthropy toward our fellow man in need. The church, in keeping the commandments of Christ, has developed throughout her history a rich philanthropic work. The diaconia of the church has taken many forms, thus responding to historical change and to the specific human needs at different times. Concentrating on diaconia for those who are in need of long-term care, this article presents the Orthodox view of the diaconia of the church, as realized through her own philanthropic organizations as well as through her very specific contribution to the diaconia offered by state sponsored charitable institutions.


**BIOETHICS COMMISSIONS** See BIOETHICS AND MEDICAL ETHICS/ COMMISSIONS

**BIOLOGICAL WARFARE** See WAR AND TERRORISM

**BIOMEDICAL RESEARCH**

See also BEHAVIORAL RESEARCH; HUMAN EXPERIMENTATION; JOURNALISM AND PUBLISHING; NANOTECHNOLOGY


Abstract: The rapid fertility decline in most advanced industrial nations, coupled with secularization and the disintegration of the family, is a sign that Western Civilization is beginning to collapse, even while radical religious movements pose challenges to Western dominance. Under such dire circumstances, it is pointless to be cautious about developing new Converging Technologies. Historical events are undermining the entire basis of ethical decision-making, so it is necessary to seek a new basis for ethics in the intellectual unification of science and the power to do good inherent in the related technological convergence. This article considers the uneasy relations between science and religion, in the context of fertility decline, and the prospects for developing a new and self-sustaining civilization based in a broad convergence of science and technology, coalescing around a core of nanotechnology, biotechnology, information technology, and cognitive technologies. It concludes with the suggestion that the new civilization should become interstellar.

Bauer, Keith A. Wired patients: implantable microsensors and biosensors in patient care. *CQ: Cambridge Quarterly of Healthcare Ethics* 2007 Summer; 16(3): 281-290. NRCBL: 5.1; 9.7; 9.5.1; 4.4; 4.5; 8.1.


Burchell, Kevin. Boundary work, associative argumentation and switching in the advocacy of agricultural biotechnology. Science as Culture 2007 March; 16(1): 49-70. NRCBL: 5.1; 15.1; 1.3.11; 7.1. SC: em.

Campbell, Courtney S.; Clark, Lauren A.; Loy, David; Keenan, James F.; Matthews, Kathleen; Winograd, Terry; Zoloth, Laurie. The bodily incorporation of mechanical devices: ethical and religious issues (Part 1). CQ: Cambridge Quarterly of Healthcare Ethics 2007 Spring; 16(2): 229-239. NRCBL: 5.1; 4.4; 1.2; 5.4.

Campbell, Courtney S.; Clark, Lauren A.; Loy, David; Keenan, James F.; Matthews, Kathleen; Winograd, Terry; Zoloth, Laurie. The bodily incorporation of mechanical devices: ethical and religious issues (Part 2). CQ: Cambridge Quarterly of Healthcare Ethics 2007 Summer; 16(3): 268-280. NRCBL: 5.1; 9.7; 9.5.1; 4.4; 1.1; 1.2; 21.7. SC: rv.


Abstract: If such a thing as nanoethics is possible, it can only develop by confronting the great questions of moral philosophy, thus avoiding the pitfalls so common to regional ethics. We identify and analyze some of these pitfalls: the restriction of ethics to prudence understood as rational risk management; the reduction of ethics to cost/benefit analysis; the confusion of technique with technology and of human nature with the human condition. Once these points have been clarified, it is possible to take up some weighty philosophical and metaphysical questions which are not new, but which need to be raised anew with respect to nanotechnologies: the artificialization of nature; the question of limits; the role of religion; the finiteness of the human condition as something with a beginning and an end; the relationship between knowledge and know-how; the foundations of ethics.


Keywords: *economics; *genomics; *government financing; *public policy; *research priorities; *research support; entrepreneurship; genetic patents; industry; international aspects; policy making; politics; science; trends; universities; Proposed Keywords: technology transfer; Keyword Identifiers: *Canada; *Great Britain

Gillick, Muriel R. The technological imperative and the battle for the hearts of America. Perspectives in Biology and Medicine 2007 Spring; 50(2): 276-294. NRCBL: 5.2; 9.3.1; 9.5.2; 9.5.1; 9.1. Identifiers: Left Ventricular Assist Device.


Hansson, Sven Ove. The ethics of enabling technology. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Summer; 16(3): 257-267. NRCBL: 5.1; 9.7; 9.5.1; 4.4; 1.1; 9.4. SC: an.

Harvey, Matthew. Citizens in defence of something called science. Science as Culture 2007 March; 16(1): 31-48. NRCBL: 5.1; 1.1; 15.1; 1.3.11; 1.3.9. SC: em.


Hivon, Myriam; Lehoux, Pascale; Denis, Jean-Louis; Tailliez, Stéphanie. Use of health technology assessment in decision making: coresponsibility of users and producers? International Journal of Technology Assessment in Health Care 2005 Spring; 21(2): 268-275. NRCBL: 5.2; 9.1; 5.3; 7.1. SC: em.


Abstract: After historically situating NBIC Convergence in the context of earlier bioethical debate on genetics, ten questions are raised in areas related to the ethics of Convergence, indicating where future research is needed.


McGee, Ellen M.; Maguire, Gerald Q., Jr. Becoming borg to become immortal: regulating brain implant technologies. *CQ: Cambridge Quarterly of Healthcare Ethics* 2007 Summer; 16(3): 291-302. 13 fn. NRCBL: 5.1; 9.7; 9.5.1; 4.4; 17.1; 4.5; 14.5; 5.3. SC: rv.

Keywords: *biomedical enhancement;* biomedical technologies; *brain;* government regulation; *guidelines;* medical devices; autonomy; cloning; freedom; informed consent; international aspects; investigational therapies; neurosciences; policy making; privacy; reproductive technologies; risks and benefits; science; self concept; technology assessment; Proposed Keywords: *implants; cybernetics;* Keyword Identifiers: Food and Drug Administration; United States


Peterson, M. Should the precautionary principle guide our actions or our beliefs? *Journal of Medical Ethics* 2007 January; 33(1): 5-10. NRCBL: 5.2; 1.1.

Abstract: Two interpretations of the precautionary principle are considered. According to the normative (action-guiding) interpretation, the precautionary principle should be characterised in terms of what it urges doctors and other decision makers to do. According to the epistemic (belief-guiding) interpretation, the precautionary principle should be characterised in terms of what it urges us to believe. This paper recommends against the use of the precautionary principle as a decision rule in medical decision making, based on an impossibility theorem presented in Peterson (2005). However, the main point of the paper is an argument to the effect that decision theoretical problems associated with the precautionary principle can be overcome by paying greater attention to its epistemic dimension. Three epistemic principles inherent in a precautionary approach to medical risk analysis are characterised and defended.

Roongrengsukoe, Siriypua; Phornprapha, Sarote. Perceptions of issues in biotechnology management in Thailand. *Eubios Journal of Asian and International Bioethics* 2007 November; 17(6): 185-190. NRCBL: 5.1; 1.3.2; 5.3; 15.1; 1.3.11. SC: em.


**BIOMEDICAL RESEARCH/RESEARCH ETHICS AND SCIENTIFIC MISCONDUCT**

See also MALPRACTICE AND PROFESSIONAL MISCONDUCT

How to be good? Mentoring and training for ethical behaviour aren’t all their cracked up to be [editorial]. *Nature* 2007 October 11; 449(7163): 638. NRCBL: 1.3.9; 7.2.


Science at WHO and UNICEF: the corrosion of trust [editorial]. *Lancet* 2007 September 22-28; 370(9592): 1007. NRCBL: 1.3.9; 1.3.7; 5.3; 1.3.6.


Adrian, Manuella. Decisions involving research and ethics: misusing drug use(r) statistics. In: Kleinig, John; Einstein, Stanley, eds. Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 217-258. NRCBL: 1.3.9; 9.5.9; 18.2; 7.1; 9.3.1.


Abstract: Norms of behavior in scientific research represent ideals to which most scientists subscribe. Our analysis of the extent of dissonance between these widely espoused ideals and scientists’ perceptions of their own and others’ behavior is based on survey responses from 3,247 mid- and early-career scientists who had research funding from the U.S. National Institutes of Health. We found substantial normative dissonance, particularly between espoused ideals and respondents’ perceptions of other scientists’ typical behavior. Also, respondents on average saw other scientists’ behavior as more counter-normative than normative. Scientists’ views of their fields as cooperative or competitive were associated with their normative perspectives, with competitive fields showing more counter-normative behavior. The high levels of normative dissonance documented here represent a persistent source of stress in science.


Abstract: This study examined basic personality characteristics, narcissism, and cynicism as predictors of ethical decision-making among graduate students training for careers in the sciences. Participants completed individual difference measures along with a scenario-based ethical decision-making measure that captures the complex, multifaceted nature of ethical decision-making in scientific research. The results revealed that narcissism and cynicism (individual differences influencing self-perceptions and perceptions of others) showed consistently negative relationships with aspects of ethical decision-making, whereas more basic personality characteristics (e.g., conscientiousness, agreeableness) were less consistent and weaker. Further analyses examined the relationship of personality to metacognitive reasoning strategies and social behavioral response patterns thought to underlie ethical decision-making. The findings indicated that personality was associated with many of these social-cognitive mechanisms which might, in part, explain the association between personality and ethical decisions.


Abstract: University research administrators have been generally ignored in basic studies of research integrity. Hensley (1986) noted that research administrators are “essential to the achievement of the specific missions of postsecondary institutions and to science and the academic infrastructure” (p. 47, 48). The following study sought to extend the scope of research on research integrity to research administrative structures with a new instrument called the Research Environment Norm Inventory or RENI. University research administrators and their professional association were targeted for data collection. Evidence suggested that research administration in the United States supports integrity in the research
environment through: (1) respect for community; (2) respect for institutional boundaries; (3) professionalism; (4) respect for authority structures; (5) sensitivity to system conflicts. The study suggested that integrity structures are dictated largely by the institutional settings and environments (Meyer and Rowan, 2006).


**Böhme, Gernot.** Rationalizing unethical medical research: taking seriously the case of Viktor von Weizsäcker. *In*: LaFleur, William R.; Böhme, Gernot; Shimazono, Susumu, eds. Dark Medicine: Rationalizing Medical Research. Bloomington: Indiana University Press, 2007: 15-29. NRCBL: 1.3.9; 18.1; 20.5.1; 1.3.5; 2.2; 21.4.


Abstract: It is important to be able to offer an account of which activities count as scientific research, given our current interest in promoting research as a means to benefit humankind and in ethically regulating it. We attempt to offer such an account, arguing that we need to consider both the procedural and functional dimensions of an activity before we can establish whether it is a genuine instance of scientific research. By placing research in a broader schema of activities, the similarities and differences between research activities and other activities become visible. It is also easier to show why some activities that do not count as research can sometimes be confused with research and why some other activities can be regarded only partially as research. Although the concept of research is important to delimit a class of activities which we might be morally obliged to promote, we observe that the class of activities which are regarded as subject to ethical regulation is not exhausted by research activities. We argue that, whether or not research or not, all the activities that are likely to affect the rights and interests of the individuals involved and impact on the rights and interests of other individuals raise ethical issues and might be in need of ethical regulation.


**Brown, James Robert.** Self-censorship. *In*: Lemmens, Trudo; Waring, Duff R., eds. Law and Ethics in Biomedical Research: Regulation, Conflict of Interest and Liability. Toronto; Buffalo: University of Toronto Press, 2006: 82-94. NRCBL: 1.3.9; 7.3.

**Brumfiel, Geoff; Abbott, Alison; Cyranoski, David; Fuyuno, Ichiko; Giles, Jim; Oding-Smee, Lucy.** Misconduct? It’s all academic . . . [news]. *Nature* 2007 January 18; 445(7125): 240-214. NRCBL: 1.3.9; 1.3.3.

**Brunekeef, Bert.** He who pays the piper, calls the tune. . . . *Epidemiology* 2006 May; 17(3): 246-247. NRCBL: 1.3.9. SC: em.


**Camilleri, Michael; Dubnansky, Erin C.; Rustgi, Anil K.** Conflicts of interest and disclosures in publications. *Clinical Gastroenterology and Hepatology* 2007 March; 5(3): 268-273. NRCBL: 1.3.9; 7.3; 1.3.7.


Abstract: Scientific fraud and misconduct appear to be on the rise throughout the scientific community. Whatever the reasons for fraud and whatever the number of cases, it is important that the academic research community consider this problem in a cool and rational manner, ensuring that allegations are dealt with through fair and impartial procedures. Increasingly, governments have either sought to regulate fraud and misconduct through legislation, or they have left it to universities and research institutions to deal with at the local level. The result has been less than uniform understanding of what constitutes scientific fraud and misconduct and a great deal of variance in procedures used to investigate such allegations. In this paper, we propose a standard definition of scientific fraud and misconduct and procedures for investigation based on natural justice and fairness. The issue of fraud and misconduct should not be left to government regulation by default. The standardized definition and procedures presented here should lead to more appropriate institutional responses in dealing with allegations of scientific fraud and misconduct.


Abstract: This paper examines how current legislative and regulatory models do not adequately govern the pharmaceutical industry towards ethical scientific conduct. In the context of a highly profit-driven industry, governments need to ensure ethical and legal standards are not only in place for companies but that they are enforceable. We demonstrate with examples from both industrialized and developing countries how without sufficient controls, there is a risk that corporate behaviour will transgress ethical boundaries. We submit that there is a critical need for urgent drug regulatory reform. There must be robust regulatory structures in place which enforce corporate governance mechanisms to ensure that pharmaceutical companies maintain ethical standards in drug research and development and the marketing of pharmaceuticals. What is also needed is for the pharmaceutical industry to adopt authentic “corporate social responsibility” policies as current policies and practices are insufficient.

Corneliussen, Filippa. Adequate regulation, a stop-gap measure, or part of a package? Debates on codes of conduct for scientists could be diverting attention away from more serious questions. *EMBO Reports* 2006 July; 7 Special No: S50-S54. 19 refs. NRCBL: 1.3.9; 5.3; 6; 15.1.

Keywords: *biological sciences; biological warfare; bio-terrorism; codes of ethics; professional ethics; regulation; researchers; self regulation; biotechnology; disclosure; government regulation; guidelines; industry; international aspects; microbiology; policy making; professional organizations; public participation; public policy; recombinant DNA research; research ethics; review committees;* Keywords Identifiers: National Institutes of Health; NIH Guidelines; United States


Abstract: I summarize my experience with scientific misconduct and breach of publication ethics during my 10 year term as Editor-in-Chief and my first 3 years as Scientific Integrity Advisor for Neurology, the official publication of the American Academy of Neurology. I describe in some detail the highly publicized, lengthy saga involving the accusation from a former colleague that James Abbs falsified data in an article published in Neurology. Nine years later, after numerous investigations and law suits, Abbs was found to have engaged in scientific misconduct which prompted the retraction of the article. Most of the problems I encountered were less complex and involved claims of plagiarism (regarded as “scientific misconduct”) and self plagiarism (regarded as a “breach of publication ethics”). I conclude by providing helpful sources for editors in dealing with these infractions.


Dyer, Owen. GMC hearing against Andrew Wakefield opens [news]. *BMJ: British Medical Journal* 2007 July 14; 335(7610): 62-63. NRCBL: 1.3.9; 18.3; 18.5.3. Identifiers: Great Britain (United Kingdom); General Medical Council.

Dyer, Owen. Researcher accused of breaching research ethics faces GMC [news]. *BMJ: British Medical Journal
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2007 June 9; 334(7605): 1185. NRCBL: 1.3.9; 18.2. Identifiers: Great Britain (United Kingdom); General Medical Council; Tommoy Sharma.

Epstein, Richard A. Conflicts of interest in health care: who guards the guardians? Perspectives in Biology and Medicine 2007 Winter; 50(1): 72-88. NRCBL: 1.3.9; 5.3; 7.3; 9.7; 1.3.2.


Abstract: Whistleblowing in relation to scientific research misconduct, despite the benefits of increased transparency and accountability it often has brought to society and the discipline of science itself, remains generally regarded as a pariah activity by many of the most influential relevant organizations. The motivations of whistleblowers and those supporting them continued to be questioned and their actions criticised by colleagues and management, despite statutory protections for reasonable disclosures appropriately made in good faith and for the public interest. One reason for this paradoxical position, explored here, is that whistle blowing concerning scientific misconduct lacks the policy support customarily derived from firm bioethical and jurisprudential foundations. Recommendations are made for altering this situation in the public interest.

Federation of American Societies for Experimental Biology [FASEB]; Brockway, Laura M.; Furcht, Leo T. Conflicts of interest in biomedical research — the FASEB guidelines. FASEB Journal 2006 December; 20(14): 2435-2438. NRCBL: 1.3.9; 7.3; 9.3.1; 6.

Finkel, Elizabeth. New misconduct rules aim to minister to an ailing system [news]. Science 2007 August 31; 317(5842): 1159. NRCBL: 1.3.9; 7.4. Identifiers: Australia.


Abstract: In science, the data are supposed to speak for themselves. However, investigators have great latitude in how they report their results in the medical literature, even in an era of research protocols, pre-specified endpoints, reporting guidelines, and rigorous peer review. Authors’ personal agendas, such as financial, personal, and intellectual conflicts of interest, can and sometimes do color how research results are described. Articles in peer-reviewed medical journals are the evidence base not only for the care of patients but also for legal decisions and the scientific record may be tailored for legal reasons as well. Journal editors preside over where and how the results of scientific research are published. We therefore suggest some actions that editors can take to foster a more trustworthy evidence base both for the care of patients and for legal decisions.

Friedberg, Errol C. Fraud in science — reflections on some whys and wherefores. DNA Repair 2006 March 7; 5(3): 291-293. NRCBL: 1.3.9; 1.3.7.

Funk, Carolyn L.; Barrett, Kirsten A.; Macrina, Francis L. Authorship and publication practices: evaluation of the effect of responsible conduct of research instruction to postdoctoral trainees. Accountability in Research 2007 October-December; 14(4): 269-305. NRCBL: 1.3.9; 1.3.7; 2.3.


Hanawalt, Philip C. Research collaborations: trial, trust, and truth. Cell 2006 September 8; 126(5): 823-825. NRCBL: 1.3.9; 1.3.7; 7.1; 7.3; 18.2.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme  See inside front cover for terms.

Abstract: The science/non-science distinction has become increasingly blurred. This paper investigates whether recent cases of fraud in science can shed light on the distinction. First, it investigates whether there is an absolute distinction between science and non-science with respect to fraud, and in particular with regards to manipulation and fabrication of data. Finding that it is very hard to make such a distinction leads to the second step: scrutinizing whether there is a normative distinction between science and non-science. This is done by investigating one of the recent internationally famous frauds in science, the Sudbo case. This case demonstrates that moral norms are not only needed to regulate science because of its special characteristics, such as its potential for harm, but moral norms give science its special characteristics. Hence, moral norms are crucial in differentiating science from non-science. Although this does not mean that ethics can save the life of science, it can play a significant role in its resuscitation.


Hunter, Jennifer M. Plagiarism — does the punishment fit the crime? *Veterinary Anaesthesia and Analgesia* 2006 May; 33(3): 139-142. NRCBL: 1.3.9; 1.3.7.


Joly, Pierre-Benoît; Rip, Arie. A timely harvest. The public should be consulted on contentious research and development early enough for their opinions to influence the course of science and policy-making. *Nature* 2007 November 8; 450(7167): 174. NRCBL: 1.3.9; 5.3; 15.1; 1.3.11.


Kaiser, Jocelyn. Privacy policies take a toll on research survey finds [news]. *Science* 2007 November 16; 318(5853): 1049. NRCBL: 1.3.9; 8.4.


Kanungo, R. Ethics in research [editorial]. *Indian Journal of Medical Microbiology* 2006 January; 24(1): 5-6. NRCBL: 1.3.9; 18.2; 18.5.9.


Krimsky, Sheldon. The ethical and legal foundations of scientific ‘conflict of interest’. In: Lemmens, Trudo; Waring, Duff R., eds. *Law and Ethics in Biomedical Research: Regulation, Conflict of Interest and Liability*. Toronto; Buffalo: University of Toronto Press, 2006: 63-81. NRCBL: 1.3.9; 7.3. SC: le.


Abstract: Under the guidelines adopted by the United States (U.S.) Office of Research Integrity (ORI), scientific misconduct is defined by one or more of three activities: fabrication of data, falsification of results, and plagiarism or the improper appropriation of other people’s ideas or written work. This paper discusses whether three other breaches in scientific ethics, namely ghost
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writing, fabricating credentials, and failure to disclose conflicts of interest, rise to the level of scientific misconduct. After discussing the funding effect in science, the paper argues that, like ghost writing and fabricated credentials, conflicts of interest can bias the outcome of research. Thus, lack of transparency to reviewers, journals and readers for conflicts of interest should be considered a form of scientific misconduct.

Krumholz, Harlan. What have we learnt from Vioxx? BMJ: British Medical Journal 2007 January 20; 334(7585): 120-123. NRCBL: 1.3.9; 5.3; 9.7; 18.1; 7.3; 1.3.7; 9.3.1.

Kubiak, Erik N.; Park, Samuel S.; Egol, Kenneth; Zuckerman, Joseph D.; Koval, Kenneth J. Increasingly conflicted: an analysis of conflicts of interest reported at the annual meetings of the Orthopaedic Trauma Association. Bulletin (Hospital for Joint Diseases (New York, N.Y.)) 2006; 63(3-4): 83-87. NRCBL: 1.3.9; 1.3.7; 1.3.2; 9.3.1. SC: em.


Laine, Christine; Goodman, Steven N.; Griswold, Michael E.; Sox, Harold C. Reproducible research: moving toward research the public can really trust. Annals of Internal Medicine 2007 March 20; 146(6): 450-453. NRCBL: 1.3.9; 1.3.7. Abstract: A community of scientists arrives at the truth by independently verifying new observations. In this time-honored process, journals serve 2 principal functions: evaluative and editorial. In their evaluative function, they winnow out research that is unlikely to stand up to independent verification; this task is accomplished by peer review. In their editorial function, they try to ensure transparent (by which we mean clear, complete, and unambiguous) and objective descriptions of the research. Both the evaluative and editorial functions go largely unnoticed by the public—the former only draws public attention when a journal publishes fraudulent research. However, both play a critical role in the progress of science. This paper is about both functions. We describe the evaluative processes we use and announce a new policy to help the scientific community evaluate, and build upon, the research findings that we publish.


Lexchin, Joel. The secret things belong unto the Lord our God: secrecy in the pharmaceutical arena. Medicine and Law: The World Association for Medical Law 2007 September; 26(3): 417-430. NRCBL: 1.3.9; 7.3; 9.7. Abstract: Secrecy in the pharmaceutical arena has taken on more importance in the recent past as the pharmaceutical industry has assumed greater prominence in the funding of clinical research and has also become a funder of the agencies that are charged with regulating it. Governments have adopted a neo-liberal agenda that prioritizes private profit over public health and are therefore willing to let industry set the research agenda. As a result, secrecy, to protect intellectual property rights, is a major feature of clinical research. Secrecy also leads to biases in the published literature that conceal significant safety problems. Because regulators are now partially dependent on the pharmaceutical industry for their existence regulators are unwilling to challenge industry. By treating data on efficacy and safety as commercially confidential information they effectively collude with industry in denying health professionals and the public access to essential information to be able to use drugs appropriately.

Lind, Rebecca Ann; Lepper, Tammy Swenson. Sensitivity to research misconduct: a conceptual model. Medicine and Law: The World Association for Medical Law 2007 September; 26(3): 585-598. NRCBL: 1.3.9; 18.1. Abstract: Ethical sensitivity research suggests techniques for assessing people’s sensitivity to research misconduct (RM). Based on our prior work in assessing ethical sensitivity, we present a conceptual model for assessing RM sensitivity. We propose conceptual and operational definitions of RM sensitivity (RMsen), and consider how the construct could be measured. RMsen is conceptualized as a cognitive ability, a skill which can be learned and assessed. RMsen involves an awareness that the research situation presents the possibility for misconduct to occur, and that one may have to decide what is right or wrong in the situation. Indicators of RMsen can take many forms and represent multiple content domains and dimensions. Four main content domains of RMsen are situational characteristics, RM issues, consequences, and stakeholders. In addition, linkages are potential connections made among elements in the different content domains. Three dimensions applicable to assessing RMsen include time, breadth, and depth. Although our focus is on RMsen, we believe that our model and methods may be extended to assessing sensitivity to the responsible conduct of research.


Abstract: Scientific journals have a central place in protecting research integrity because published articles are the most visible documentation of research. We used SWOT analysis to audit (S)trengths and (W)eaknesses as internal and (O)pportunities and (T)hreats as external factors affecting journals’ responsibility in addressing research integrity issues. Strengths include editorial independence, authority and expertise, power to formulate editorial policies, and responsibility for the integrity of published records. Weaknesses stem from having no mandate for legal action, reluctance to get involved, and lack of training. Opportunities for editors are new technologies for detecting misconduct, policies by editorial organization or national institutions, and greater transparency of published research. Editors face threats from the lack of legal regulation and culture of research integrity in academic communities, lack of support from stakeholders in scientific publishing, and different pressures. Journal editors cannot be the policing force of the scientific community but they should actively ensure the integrity of the scientific record.


Abstract: The increasing globalization of scientific research lends urgency to the need for international agreement on the concepts of scientific misconduct. Universal spiritual and moral principles on which ethical standards are generally based indicate that it is possible to reach international agreement on the ethical principles underlying good scientific practice. Concordance on an operational definition of scientific misconduct that would allow independent observers to agree which behaviour constitutes misconduct is more problematic. Defining scientific misconduct to be universally recognized and universally sanctioned means addressing the broader question of ensuring that research is not only well-designed and addresses a real need for better evidence - but that it is ethically conducted in different cultures. An instrument is needed to ensure that uneven ethical standards do not create unnecessary obstacles to research, particularly in developing countries.

more favorable clinical interpretation of such findings. Disclosure of conflicts of interest should be strengthened for a more balanced opinion on the safety of drugs.


Normile, Dennis. Osaka University researchers reject demand to retract Science paper. Science 2007 June 22; 316(5832): 1681. NRCBL: 1.3.9; 1.3.7. Identifiers: Japan.

Novack, Gary D. Research ethics. The Ocular Surface 2006 April; 4(2): 103-104. NRCBL: 1.3.9; 1.3.7. SC: rv.

Odling-Smee, Lucy; Giles, Jim; Fuyuno, Ichiko; Cyranoski, David; Marris, Emma. Where are they now? [news]. Nature 2007 January 18; 445(7125): 244-245. NRCBL: 1.3.9.


Okike, Kanu; Kocher, Mininder S.; Mehlman, Charles T.; Bhandari, Mohit. Conflict of interest in orthopaedic research. An association between findings and funding in scientific presentations. Journal of Bone and Joint Surgery: American volume 2007 March; 89(3): 608-613. NRCBL: 1.3.9; 7.1; 1.3.2; 9.3.1; 9.8; 7.3.


Pang, Ching Ling. A code of ethics for scientists. Lancet 2007 March 31-April 6; 369(9567): 1068. NRCBL: 1.3.9; 7.3.

Pascal, Chris B. Beyond the federal definition: other forms of misconduct. In: Kulakowski, Elliott C.; Chronister, Lynne U., eds. Research Administration and Management. Sudbury, MA: Jones and Bartlett, 2006: 523-530. NRCBL: 1.3.9; 5.3; 18.2.


Pryor, Erica R.; Habermann, Barbara; Broome, Marion E. Scientific misconduct from the perspective of research coordinators: a national survey. Journal of Medical Ethics 2007 June; 33(6): 365-369. NRCBL: 1.3.9. SC: em. Abstract: OBJECTIVE: To report results from a national survey of coordinators and managers of clinical research studies in the US on their perceptions of and experiences with scientific misconduct. METHODS: Data were collected using the Scientific Misconduct Questionnaire-Revised. Eligible responses were received from 1645 of 5302 (31%) surveys sent to members of the Association of Clinical Research Professionals and to subscribers of Research Practitioner, published by the Center for Clinical Research Practice, between February 2004 and January 2005. Findings: Overall, the perceived frequency of misconduct was low. Differences were noted between workplaces with regard to perceived pressures on investigators and research coordinators, and on the effectiveness of the regulatory environment in reducing misconduct. First-hand experience with an incident of misconduct was reported by 18% of respondents. Those with first-hand knowledge of misconduct were more likely to report working in an academic medical setting, and to report that a typical research coordinator would probably do nothing if aware that a principal investigator or research staff member was involved in an incident of misconduct. CONCLUSION: These findings expand the knowledge on scientific misconduct by adding new information from the perspective of research coordinators. The findings provide some data supporting the influence of workplace climate on misconduct and also on the perceived effectiveness of institutional policies to reduce scientific misconduct.


Revill, James; Dando, Malcolm R. A Hippocratic oath for life scientists. A Hippocratic-style oath in the life sciences could help to educate researchers about the dangers of dual-use research. EMBO Reports 2006 July; 7 Special No: S55-S60. NRCBL: 1.3.9; 6.


Abstract: We argue that two ambiguities in [U.S.] Public Health Service (“PHS”) misconduct regulations make them so vague that they are unconstitutional and unfair: (1) they provide no guidance concerning when one can be held responsible for others’ actions; and (2) they simultaneously are intended to allow misconduct findings only when there are “significant departure[s] from established practices of the relevant research community” but even if one complied with customary standards of practice in her research community, thus providing confusion rather than guidance. The effect of these ambiguities is not only to leave researchers without notice as to proscribed or prescribed conduct but also to give officials discretion to apply the regulations arbitrarily and discriminatorily. The regulations’ effect is illustrated by applying them, hypothetically, to facts relating to the central charge in the misconduct case pressed by the University of Arizona in 1997 through 2003 against then Arizona Regents’ Professor Marguerite Kay.


Abstract: This article traces the regulation of [U.S.] Public Health Service (“PHS”)-funded research from changes begun with the proposal (1999) and then adoption (2000) of a basic, Uniform Federal (“research misconduct”) Policy. It argues that the PHS misconduct regulations deny due process of law and are fundamentally unfair because they fail to specify the level of culpability for guilt, force accused researchers to prove that they are innocent, and, although admittedly quasi-criminal, adopt a standard of proof that tolerates nearly a 50 percent probability of false convictions. The regulations’ infirmities will be demonstrated by applying them to facts relating to the central charge in the misconduct case pressed by the University of Arizona in 1997 through 2003 against then Arizona Regents’ Professor Marguerite Kay.
rite Kay, which facts are set forth in our companion piece in this theme issue.


**Spitzer, Walter O.** Minimizing bias and prejudice: special challenges for contractual research by academicians. *In: Shapiro, S.; Dinger, J.; Scriba, P., eds. Enabling Risk Assessment in Medicine: Farewell Symposium for Werner-Kari Raff. New Brunswick, NJ: Transaction Publishers, 2004: 31-49. NRCBL: 1.3.9; 1.3.2; 5.3; 9.7; 18.5.3.

**Stollorz, Volker.** Öffentlich und Industrie-geförderte Studien in der Perzeption der Medien — ein Dilemma. *Studien in der Perzeption der Medien — ein Di lemma.* Stollorz, Volker. Öffentlich und Industrie-geförderte Studien in der Perzeption der Medien — ein Dilemma. 2004: 31-49. NRCBL: 1.3.9; 1.3.2; 5.3; 9.7; 18.5.3.


**Tanne, Janice Hopkins.** Investigators to review conflicts of interest at NIH [news]. *BMJ: British Medical Journal* 2007 April 14; 334(7597): 767. NRCBL: 1.3.9; 7.3.


**Thrush, Carol R.; Vander Putten, Jim; Rapp, Carla Gene; Pearson, L. Carolyn; Berry, Katherine Simms; O’Sullivan, Patricia S.** Content validation of the Organizational Climate for Research Integrity (OCRI) Survey. *Journal of Empirical Research on Human Research Ethics* 2007 December; 2(4): 35-52. NRCBL: 1.3.9; 1.3.2; 18.2. SC: em.

Abstract: The purpose of this study was to develop and establish content validity of an instrument designed to measure the organizational climate for research integrity in academic health centers. Twenty-seven research integrity scholars and administrators evaluated 64 survey items for relevance and clarity, as well as overall comprehensiveness of the constructs that are measured (organizational inputs, structures, processes and outcomes). Both quantitative and qualitative methods were used, particularly content validity indices (CVI) and analyses of respondents’ comments. The content validity index for the overall survey was initially high (CVI = .83) and improved (CVI = .90) when 17 marginal-to-poor items were removed. This study resulted in the Organizational Climate for Research Integrity (OCRI) survey, a 43-item fixed-response survey with established content validity.

**Tierney, John.** Are scientists playing God? It depends on your religion. *New York Times* 2007 November 20; p. F1, F2. NRCBL: 1.3.9; 14.5; 1.2; 15.1; 18.5.4.

Keywords: *cloning; embryo research; genetic engineering; international aspects; non-Western World; religious ethics; secularism; Western World; biotechnology; Buddhist ethics; Christian ethics; embryonic stem cells; embryo; government regulation; Hindu ethics; legal aspects; public policy; reproductive technologies; Keyword Identifiers: Asia; Europe; North America; South America

**Twombly, Renee.** Goal of maintaining public’s trust brings research groups together on conflict-of-interest guidelines [news]. *Journal of the National Cancer Institute* 2005 November 2; 97(21): 1560-1561. NRCBL: 1.3.9; 7.3; 5.3.


**van den Belt, Henk.** Comments on Bulger: the responsible conduct of research, including responsible authorship and publication practices. *In: Korthals, Michiel; Bogers, Robert J., eds. Ethics for Life Scientists. Dordrecht, The Netherlands: Springer, 2004: 63-66. NRCBL: 1.3.9; 1.3.7.

**Van Der Weyden, Martin B.** Preventing and processing research misconduct: a new Australian code for responsible research: it all depends on compliance. *Medical Journal of Australia* 2006 May 1; 184(9): 430-431. NRCBL: 1.3.9; 1.3.7; 6.


**van Haselen, Robbert.** Misconduct in CAM research: does it occur? *Complementary Therapies in Medicine* 2006 June; 14(2): 89-90. NRCBL: 1.3.9; 4.1.1; 7.1. Identifiers: complementary alternative medicine.


Wager, Elizabeth. What do journal editors do when they suspect research misconduct? *Medicine and Law: The World Association for Medical Law 2007 September*, 26(3): 535-544. NRCBL: 1.3.9; 1.3.7. SC: em. Abstract: Several published guidelines urge journal editors to ensure that cases of suspected scientific misconduct are properly investigated. Using cases submitted to the Committee on Publication Ethics (COPE) I tried to discover what editors actually do when faced with such cases. Of the 79 cases referred to COPE between 1998 and 2003 relating to author misconduct, 35 related to redundant publication, 16 to unethical research, 13 to fabrication, 10 to clinical misconduct and 7 to plagiarism. Outcomes were reported in 49 cases. Authors were exonerated in 16 cases and reprimanded in another 17. An impasse (no or an unsatisfactory response) was reached in 16. Editors contacted the authors’ institutions in 24 cases. Nearly half the cases (36) lasted over a year. This small survey highlights the difficulties faced by editors in pursuing cases of suspected misconduct and the need for better training and guidance for editors and more cooperation from institutions.

Watts, Geoff. Croatian academic is found guilty of plagiarism. *BMJ: British Medical Journal* 2007 May 26; 334(7603): 1077. NRCBL: 1.3.9; 1.3.7.


White, Caroline. Cancer expert attacks research paper [news]. *BMJ: British Medical Journal* 2007 September 8; 335(7618): 469. NRCBL: 1.3.9; 9.5.1; 9.7.


Willyard, Cassandra. Allegations of bias cloud conflicting reports on bisphenol A’s effects [news]. *Nature Medicine* 2007 September; 13(9): 1002. NRCBL: 1.3.9; 1.3.5; 7.3.


**BIOMEDICAL RESEARCH/ SOCIAL CONTROL OF SCIENCE AND TECHNOLOGY**

California dreaming: universities should draw the line at certain types of support from the drug industry [editorial]. *Nature* 2007 July 26; 448(7152): 388. NRCBL: 5.3; 1.3.9; 7.3; 7.2; 9.7. Identifiers: University of California, San Francisco.

Federal funding for embryo research unlikely to rise after Bush. *BioEdge* 2007 August 22; 262: 4. NRCBL: 5.3; 18.5.4; 15.1.

Abelson, Julia; Giacomini, Mita; Lehoux, Pascale; Gauvin, Francois-Pierre. Bringing ‘the public’ into health technology assessment and coverage policy decisions: from principles to practice. *Health Policy* 2007 June; 82(1): 37-50. NRCBL: 5.3; 5.2; 9.4; 9.1. Identifiers: Canada.


Abstract: This paper examines medicine’s use of technology in a manner from a standpoint inspired by Heidegger’s thinking on technology. In the first part of the paper, I shall suggest an interpretation of Heidegger’s thinking on the topic, and attempt to show why he associates modern technology with danger. However, I shall also claim that there is little evidence that medicine’s appropriation of modern technology is dangerous in Heidegger’s sense, although there is no prima facie reason why it mightn’t be. The explanation for this, I claim, is ethical. There is an initial attraction to the thought that Heidegger’s thought echoes Kantian moral thinking, but I shall dismiss this. Instead, I shall suggest that the considerations that make modern technology dangerous for Heidegger are simply not in the character - the ethos - of
medicines properly understood. This is because there is a distinction to be drawn between chronological and historical modernity, and that even up-to-date medicine, empowered by technology, retains in its ethos crucial aspects of a historically pre-modern understanding of technology. A large part of the latter half of the paper will be concerned with explaining the difference.

**Brody, Baruch. Intellectual property and biotechnology: the European debate. Kennedy Institute of Ethics Journal 2007 June; 17(2): 69-110. 48 refs. NRCBL: 5.3; 15.8; 4.4; 15.1; 22.2; 18.5.4; 21.1. SC: rv.**  
Keywords: *biotechnology; *genetic patents; *moral policy; *patents; *policy making; *advisory committees; body parts and fluids; commodification; cryopreservation; embryoresearch; embryonic stem cells; genetic research; genetic screening; genetically modified animals; historical aspects; industry; human body; human dignity; legal aspects; life; methods; property rights; public policy; sex preselection; sperm; trends; Proposed Keywords: mice;  
Keyword Identifiers: *European Patent Organization; *European Union; Europe; Council of Europe; European Parliament; Twenty-First Century

**Calabrese, Edward J. Elliott’s ethics of expertise proposal and application: a dangerous precedent. Science and Engineering Ethics 2007 June; 13(2): 139-145. NRCBL: 5.3; 1.3.9; 1.3.7; 5.2; 8.3.1.**

**Campbell, Eric G.; Weissman, Joel S.; Ehringhaus, Susan; Rao, Sowmya R.; Moy, Beverly; Feibelmann, Sandra; Goold, Susan Dorr. Institutional academic-industry relationships. JAMA: The Journal of the American Medical Association 2007 October 17; 298(15): 1779-1786. NRCBL: 5.3; 7.3; 7.2. SC: em.**  
Abstract: CONTEXT: Institutional academic-industry relationships have the potential of creating institutional conflicts of interest. To date there are no empirical data to support the establishment and evaluation of institutional policies and practices related to managing these relationships. OBJECTIVE: To conduct a national survey of department chairs about the nature, extent, and consequences of institutional-academic industry relationships for medical schools and teaching hospitals. DESIGN, SETTING, AND PARTICIPANTS: National survey of department chairs in the 125 accredited allopathic medical schools and the 15 largest independent teaching hospitals in the United States, administered between February 2006 and October 2006. MAIN OUTCOME MEASURE: Types of relationships with industry. RESULTS: A total of 459 of 688 eligible department chairs completed the survey, yielding an overall response rate of 67%. Almost two-thirds (60%) of department chairs had some form of personal relationship with industry, including serving as a consultant (27%), a member of a scientific advisory board (27%), a paid speaker (14%), an officer (7%), a founder (9%), or a member of the board of directors (11%). Two-thirds (67%) of departments as administrative units had relationships with industry. Clinical departments were more likely than nonclinical departments to receive research equipment (17% vs 10%, P = .04), unrestricted funds (19% vs 3%, P = .001), residency or fellowship training support (37% vs 2%, P = .001), and continuing medical education support (65% vs 3%, P = .001). However, nonclinical departments were more likely to receive funding from intellectual property licensing (27% vs 16%, P = .01). More than two-thirds of chairs perceived that having a relationship with industry had no effect on their professional activities, 72% viewed a chair’s engaging in more than 1 industry-related activity (substantial role in a start-up company, consulting, or serving on a company’s board) as having a negative impact on a department’s ability to conduct independent unbiased research. CONCLUSION: Overall, institutional academic-industry relationships are highly prevalent and underscore the need for their active disclosure and management.

**Corbellini, Gilberto. Scientists, bioethics and democracy: the Italian case and its meanings. Journal of Medical Ethics 2007 June; 33(6): 349-352. 4 refs. NRCBL: 5.3; 1.3.5; 1.3.9; 14.1; 15.1. SC: le.**

**Farhat,劍草. A discussion on the use of anesthetic gases: perspective and ethical considerations. Journal of Clinical Anesthesia 2007 June; 19(3): 141-146. 10 refs. NRCBL: 5.3; 1.3.7; 7.2.2. SC: cm.**

**Galen, Galen. On the use of anesthetic gases: perspective and ethical considerations. Journal of Clinical Anesthesia 2007 June; 19(3): 141-146. 10 refs. NRCBL: 5.3; 1.3.7; 7.2.2. SC: cm.**

**Gomberg, Marcia. The role of ethics committees in the regulation of human research. Journal of Medical Ethics 2007 June; 33(6): 349-352. 4 refs. NRCBL: 5.3; 1.3.5; 1.3.9; 14.1; 15.1. SC: le.**

**Katz, Albert. The role of ethics committees in the regulation of human research. Journal of Medical Ethics 2007 June; 33(6): 349-352. 4 refs. NRCBL: 5.3; 1.3.5; 1.3.9; 14.1; 15.1. SC: le.**

**Kigawa, Kenji. The role of ethics committees in the regulation of human research. Journal of Medical Ethics 2007 June; 33(6): 349-352. 4 refs. NRCBL: 5.3; 1.3.5; 1.3.9; 14.1; 15.1. SC: le.**

**Lippman, Philip. The role of ethics committees in the regulation of human research. Journal of Medical Ethics 2007 June; 33(6): 349-352. 4 refs. NRCBL: 5.3; 1.3.5; 1.3.9; 14.1; 15.1. SC: le.**

**McGonnell, George. The role of ethics committees in the regulation of human research. Journal of Medical Ethics 2007 June; 33(6): 349-352. 4 refs. NRCBL: 5.3; 1.3.5; 1.3.9; 14.1; 15.1. SC: le.**

**McGonell, George. The role of ethics committees in the regulation of human research. Journal of Medical Ethics 2007 June; 33(6): 349-352. 4 refs. NRCBL: 5.3; 1.3.5; 1.3.9; 14.1; 15.1. SC: le.**

**McGonell, George. The role of ethics committees in the regulation of human research. Journal of Medical Ethics 2007 June; 33(6): 349-352. 4 refs. NRCBL: 5.3; 1.3.5; 1.3.9; 14.1; 15.1. SC: le.**

**NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.**
Dixon, Bernard. What do we need to say to each other? *New Science* 2007 January 6-12; 193(2585): 46-47. NRCBL: 5.3; 15.1.

Eaton, Lynne. Medical school accepts tobacco company funding for research [news]. *BMJ: British Medical Journal* 2007 March 10; 334(7592): 496. NRCBL: 5.3; 9.3.1; 1.3.9; 1.3.2; 9.5.9. Identifiers: University of Virginia.


Fossett, James W. Medicine and industry: a necessary but conflicted relationship. *Perspectives in Biology and Medicine* 2007 Winter; 50(1): 1-6. NRCBL: 5.3; 7.1; 9.7; 1.3.2; 1.3.9; 4.1.2.


Keywords: *embryo research; *embryonic stem cells; *government financing; *private sector; *research support; *state government; federal government; government regulation; public policy; statistics; stem cells; Keyword Identifiers: United States


Keywords: *biotechnology; *human characteristics; advisory committees; autonomy; biethical issues; biomedical enhancement; embryo research; evolution; forecasting; genetic determinism; genetic engineering; philosophy; public health; public policy; regulation; risks and benefits; science; stem cells; theology; uncertainty; values; Keyword Identifiers: New York State Task Force on Life and the Law; United States

Grimm, David. UC balks at campus-wide ban on tobacco money for research [news]. *Science* 2007 January 26; 315(5811): 447-448. NRCBL: 5.3; 1.3.3; 9.5.9. Identifiers: University of California.

Hoffmann, George R. Letter to the editor on ethics of expertise, informed consent, and hormesis. *Science and Engineering Ethics* 2007 June; 13(2): 135-137. NRCBL: 5.3; 8.3.1; 1.3.9.


Jizba, Laurel. Ethics in grant funded academia: issues and questions. *Journal of Information Ethics* 2007 Spring; 16(1): 42-52. NRCBL: 5.3; 1.3.9; 1.3.3.


Keywords: *democracy; *professional autonomy; *research priorities; *researchers; *science; *social control; biomedical research; decision making; economics; freedom; genetic research; government regulation; international aspects; policy making; self regulation; technical expertise; Keyword Identifiers: United States

Moran, Gordon. Rubber stamp-type decisions for funding of academic research: paradigms and conflicts of interest. *Journal of Information Ethics* 2007 Spring; 16(1): 53-58. NRCBL: 5.3; 1.3.9; 9.5.6.


SECTION I

BLOOD BANKING, DONATION, AND TRANSFUSION

Stossel, Thomas P. Regulation of financial conflicts of interest in medical practice and medical research: a damaging solution in search of a problem. Perspectives in Biology and Medicine 2007 Winter; 50(1): 54-71. NRCBL: 5.3; 1.3.2; 1.3.9.

Keywords: *biomedical research; *embryo research; *embryonic stem cells; *industry; *research support; *researchers; *authorship; *biotechnology; cell lines; *embryo disposition; *entrepreneurship; *genetic materials; *genetic patents; *moral implications; *politics; *professional autonomy; *property rights; *research ethics committees; *universities; *Proposed Keywords: *technology transfer; *Keyword Identifiers: *Sweden; *Cell Therapeutics; *Ovacell

Abstract: In this article two inter-related issues concerning the ongoing commercialisation of biomedical research are analyzed. One aim is to explain how scientists and clinicians at Swedish public institutions can make profits, both commercially and scientifically, by controlling rare human biological material, like embryos and embryonic stem cell lines. This control in no way presupposes legal ownership or other property rights as an initial condition. We show how ethically sensitive material (embryos and stem cell lines) have been used in Sweden as a foundation for a commercial stem cell enterprise — despite all official Swedish restrictions against commercialisation in this area. We also show how political decisions may amplify the value of controlling this kind of biological material. Another aim of the article is to analyze and discuss the meaning of this kind of academic commercial enterprise in a wider context of research funding strategies. A conclusion that is drawn is that the academic turn to commercial funding sources is dependent on the decline of public funding.

Tanne, Janice Hopkins. Group asks US institutes to reveal industry ties [news]. BMJ: British Medical Journal 2007 January 20; 334(7585): 115. NRCBL: 5.3; 7.3; 1.3.9; 9.7; 9.3.1.

Tucker, Jonathan B.; Hooper, Craig. Protein engineering: security implications; the increasing ability to manipulate protein toxins for hostile purposes has prompted calls for regulation. EMBO Reports 2006 July; 7 Special No: S14-S17. NRCBL: 5.3; 21.3; 1.3.9.

van Aken, Jan. When risk outweighs benefit. Dual-use research a scientifically sound risk-benefit analysis and legally binding biosecurity measures. EMBO Reports 2006 July; 7 Special No: S10-S13. 16 refs. NRCBL: 5.3; 21.3; 15.1.

Keywords: *biological sciences; *biological warfare; *bioterrorism; *genomics; *government regulation; *influenza; *international aspects; *microbiology; *publishing; *recombinant DNA research; *review committees; *risk; *risks and benefits; *Proposed Keywords: *crime; *Keyword Identifiers: *Biological and Toxin Weapons Convention


Keywords: *biotechnology; *legal aspects; *patents; *Supreme Court decisions; *industry; *universities; *Proposed Keywords: *licensure; *Keyword Identifiers: *MedImmune v. Genentech; *United States


Keywords: *embryo research; *embryonic stem cells; *legislation; *research support; *government financing; *politics; *public policy; *embryo; *federal government; *Keyword Identifiers: *United States; *U.S. House of Representatives

BIOMEDICAL TECHNOLOGIES See ENHANCEMENT; GENETIC ENGINEERING AND BIOTECHNOLOGY; ORGAN AND TISSUE TRANSPLANTATION; REPRODUCTIVE TECHNOLOGIES

BLACKS AS RESEARCH SUBJECTS See HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS

BLOOD BANKING, DONATION, AND TRANSFUSION

See also ORGAN AND TISSUE TRANSPLANTATION


Abstract: The National Blood Policy in India relies heavily on voluntary blood donors, as they are usually assumed to be associated with low levels of transfusion-transmitted infections (TTIs). In India, it is mandatory to test every unit of blood collected for hepatitis B, hepatitis C, HIV/AIDS, syphilis and malaria. Donors come to the blood bank with altruistic intentions. If donors test positive to any of the five infections, their blood is discarded. Although the blood policy advocates disclosure of TTI status, donors are not, in practice, informed about their results. The onus is on the donor to contact the blood bank. Out of approximately 16 000 donations in the past 2 years, 438 tested positive for TTI, including 107 for HIV. Only 20% of the donors contacted the blood bank; none of them were HIV positive. Disclosure by blood banks of TTI status by telephone or mail has resulted in serious consequences for some donors. Health providers face an ethical dilemma, in the absence of proper mechanisms in place for disclosure of test results, regarding notification to donors who may test positive but remain ignorant of...
their TTI status. Given the high cost of neglecting to notify infected donors, the authors strongly recommend the use of rapid tests before collecting blood, instead of the current practice, which takes 3 h to obtain results, and disclosure of results directly to the donor by a counsellor, to avoid dropouts and to ensure confidentiality.


Gunning, Jennifer. Umbilical cord cell banking: an issue of self-interest versus altruism. Medicine and Law: The World Association for Medical Law 2007 December; 26(4): 769-780. NRCBL: 19.4; 19.5; 4.4. Abstract: Stem cells from umbilical cord blood probably now form one of the most commonly banked types of human tissue. Originally stored for the treatment of haematological disorders these stem cells have now been found to be more versatile, even pluripotent, with potential for use in the treatment of a broader range of disorders and diseases and may be particularly valuable in cell therapy and regenerative medicine. This has led to the promotion of private storage of cord blood cells for autologous or family use and a rapidly growing private sector involvement. There is a growing tension between public and private banking and a number of ethical issues continue to be debated involving questions of regulation and quality assurance, ownership and commercialisation, and patenting. This paper aims to investigate some of these issues.


Kharaboyan, Linda; Knoppers, Bartha Maria; Avard, Denise; Nisker, Jeff. Understanding umbilical cord blood banking: what women need to know before deciding [editorial]. Women's Health Issues 2007 September-October; 17(5): 277-280. NRCBL: 19.4; 19.5; 9.5.5; 18.5.4; 8.4; 8.3.1.


Plant; Margo; Knoppers, Bartha Maria. Umbilical cord blood banking in Canada: socio-ethical and legal issues. Health Law Journal 2005; 13: 187-212. NRCBL: 19.4; 9.5.7; 8.3.2; 18.3; 9.5.4. SC: le; an.


CAPITAL PUNISHMENT


Abstract: In a recent issue of this journal, David Silver and Gerald Dworkin discuss the physicians’ role in execution by lethal injection. Dworkin concludes that discussion by stating that, at that point, he is unable to think of an acceptable set of moral principles to support the view that it is illegitimate for physicians to participate in execution by lethal injection that would not rule out certain other plausible moral judgements, namely that euthanasia is under certain conditions legitimate and that organ-donation surgery is sometimes permissible. This article draws attention to some problems in the views of Silver and Dworkin and suggests moral principles which support the three moral views just mentioned.


**CARE FOR SPECIFIC GROUPS**

*See also HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS*


Abel, Gregory A.; Penson, Richard T.; Joffe, Steven; Schapira, Lidia; Chabner, Bruce A.; Lynch, Thomas J., Jr. Direct-to-consumer advertising in oncology. *Oncologist* 2006 February; 11(2): 217-226. NRCBL: 9.5.1; 9.7; 1.3.2; 8.1; 5.3.


Abstract: Tensions exist between the disability rights movement and the work of many bioethicists. This book defends certain genetic policies against criticisms from disability rights advocates, in part by arguing that it is possible to accept both the genetic policies and the rights of people with impairments. However, a close reading of the book reveals a series of direct moral criticisms of the disability rights movement. The criticisms go beyond a defense of genetic policies from the criticisms of disability rights advocates. The disability rights movement is said not to have the same moral legitimacy as other civil rights movements, such as those for women or “racial” minorities. This paper documents, and in some cases shows the flaws within, these challenges to the disability rights movement.


Berlin, Jordan; Bruinooge, Suanna S.; Tannock, Ian F. Ethics in oncology: consulting for the investment industry. *Journal of Clinical Oncology* 2007 February 1; 25(4): 444-446. NRCBL: 9.5.1; 9.6; 7.1; 9.3.1; 18.2.

Bhandari, Mohit; Jönsson, Anders; Bühren, Volker. Conducting industry-partnered trials in orthopaedic surgery. *Injury* 2006 April; 37(4): 361-366. NRCBL: 9.5.1; 1.3.2; 9.7; 9.3.1.

Bowers, Libby. Ethical issues along the cancer continuum. *In: Carroll-Johnson, Rose Mary; Gorman, Linda M.; Bush, Nancy Jo, eds. Psychosocial Nursing Care Along the Cancer Continuum. 2nd edition. Pittsburgh, PA: Oncology Nursing Society, 2006: 551-564. NRCBL: 9.5.1; 8.1; 20.5.1; 20.7; 9.4; 4.1.3.


Chou, Ann F.; Brown, Arleen F.; Jensen, Roxanne E.; Shih, Sarah; Lawson, Greg; Scholle, Sarah Hudson. Gender and racial disparities in the management of diabetes mellitus among Medicare patients. *Women’s Health Is-
sues 2007 May-June; 17(3): 150-161. NRCBL: 9.5.1; 9.5.4; 9.5.5; 9.3.2. SC: em.


Abstract: The UK government has recently taken steps to exclude certain groups of migrants from free treatment under the National Health Service, most controversially from treatment for HIV. Whether this discrimination can have any coherent ethical basis is questioned in this paper. The exclusion of migrants of any status from any welfare system cannot be ethically justified because the distinction between citizens and migrants cannot be an ethical one.

Daneault, Serge; Lussier, Véronique; Mongeau, Suzanne; Hudon, Eveline; Paillé, Pierre; Dion, Dominique; Yelle, Louise. Primum non nocere: could the health care system contribute to suffering? In-depth study from the perspective of terminally ill cancer patients. Canadian Family Physician 2006 December; 52(12): 1575 e1-5. NRCBL: 9.5.1; 20.5.1; 4.4. Note: Abstract in French.


Abstract: People who are paid to provide basic care for others are frequently undervalued, exploited and expected to reach often unrealistic standards of care. I argue that appropriate social recognition, support and fair pay for people who provide care for those who are disabled, frail and aged, or suffering ill health that impedes their capacity to negotiate daily activities without support, depends on a reconsideration of the paradigm of the citizen or moral agent. I argue that by drawing on the ideas of human vulnerability and dependency as central to our personhood, a more realistic conception of selves, citizens and persons can be developed that better recognises the inevitability of human dependency and the social value of care work. I also indicate the significance of this vulnerability-focused view for ethical evaluation of the emotional aspects of care relationships.


Abstract: A number of commentators claim their disability to be a part of their identity. This claim can be labelled ‘the identity claim’. It is the claim that disabling characteristics of persons can be identity-constituting. According to a central constraint on traditional discussions of personal identity over time, only essential properties can count as identity-constituting properties. By this constraint, contingent properties of persons (those they might not have instanced) cannot be identity-constituting. Viewed through the lens of traditional approaches to the problem of personal identity over time, disability is most likely to be regarded as a contingent property of a person and not an essential one. Hence, on traditional approaches, the identity claim must be false. An alternative account of identity is sketched here. It is one which exploits the idea of narrative identity, and points to five basic features of personal existence. When accounts of identity are structured in relation to these five features, it is argued, disablement can be shown to be identity-constituting, and hence the identity claim can be accepted.


Fiege, Angela B. Resident portfolio: a tale of two women. Academic Emergency Medicine 2006 September; 13(9): 989-990; discussion 990-992. NRCBL: 9.5.1; 9.5.5; 14.1; 12.5.1.


Gostin, Lawrence O.; DeAngelis, Catherine D. Mandatory HPV vaccination: public health vs. private wealth [editorial]. JAMA: The Journal of the American Medical Association 2007 May 2; 297(17): 1921-1923. NRCBL: 9.5.1; 9.5.5; 9.5.7; 9.7. SC: an.

Greif, Karen F.; Merz, Jon F. Emerging diseases: SARS and government responses. In their: Current Controversies


Hinchley, Geoff; Patrick, Kirsten. Is infant male circumcision an abuse of the rights of the child? [debate]. BMJ: British Medical Journal 2007 December 8; 335(7631): 1180-1181. NRCBL: 9.5.1; 1.2; 10; 21.1; 1.2.


Infante, Peter F. The past suppression of industry knowledge of the toxicity of benzene to humans and potential bias in future benzene research. International Journal of Occupational and Environmental Health 2006 July-September; 12(3): 268-272. NRCBL: 9.5.1; 1.3.2; 8.3.1; 8.2; 16.1.


Jones, James W.; McCullough, Laurence B.; Richman, Bruce W. Other people’s money: ethics, finances, and bad outcomes. Journal of Vascular Surgery 2006 April; 43(4): 863-865. NRCBL: 9.5.1; 9.3.1; 1.3.2.


Liao, Lih Mei; Creighton, Sarah M. Requests for cosmetic genitoplasty: how should healthcare providers respond? BMJ: British Medical Journal 2007 May 26; 334(7603): 1090-1092. NRCBL: 9.5.1; 4.5; 10.


Lyren, Anne; Leonard, Ethan. Vaccine refusal: issues for the primary care physician. Clinical Pediatrics 2006 June; 45(5): 399-404. NRCBL: 9.5.1; 9.7; 8.3.2; 8.3.4.


McGee, Glenn; Johnson, Summer. Has the spread of HPV vaccine marketing conveyed immunity to common sense? [editorial]. American Journal of Bioethics 2007 July; 7(7): 1-2. NRCBL: 9.5.1; 9.3.1; 1.3.2; 9.1; 9.7.


Nelson, W.; Pomerantz, A.; Howard, K.; Bushy, A. A proposed rural healthcare ethics agenda. Journal of Medical Ethics 2007 March; 33(3): 136-139. NRCBL: 9.5.1. SC: em. Identifiers: Coalition for Rural Health Care Ethics. Abstract: The unique context of the rural setting provides special challenges to furnishing ethical healthcare to its approximately 62 million inhabitants. Although rural communities are widely diverse, most have the following common features: limited economic resources, shared values, reduced health status, limited availability of and accessibility to healthcare services, overlapping professional-patient relationships and care giver stress. These rural features shape common healthcare ethical issues, including threats to confidentiality, boundary issues, professional-patient relationship and allocation of resources. To date, there exists a limited focus on rural healthcare ethics shown by the scarcity of rural healthcare ethics literature, rural ethics committees, rural focused ethics training and research on rural ethics issues. An interdisciplinary group of rural healthcare ethicists with backgrounds in medicine, nursing and philosophy was convened to explore the need for a rural healthcare ethics agenda. At the meeting, the Coalition for Rural Health...
Care Ethics agreed to a definition of rural healthcare ethics and a broad-ranging rural ethics agenda with the ultimate goal of enhancing the quality of patient care in rural America. The proposed agenda calls for increasing awareness and understanding of rural healthcare ethics through the development of evidence — informed, rural-attuned research, scholarship and education in collaboration with rural healthcare professionals, healthcare institutions and the diverse rural population.


Abstract: Patient self-management (SM) of chronic disease is an evolving movement, with some forms documented as yielding important outcomes. Potential benefits from proper preparation and maintenance of patient SM skills include quality care tailored to the patient’s preferences and life goals, and increase in skills in problem solving, confidence and success, generalizable to other parts of the patient’s life. Four central ethical issues can be identified. 1) insufficient patient/family access to preparation that will optimize their competence to SM without harm to themselves, 2) lack of acknowledgement that an ethos of patient empowerment can mask transfer of responsibility beyond patient/family competency to handle that responsibility, 3) prevailing assumptions that preparation for SM cannot result in harm and that its main purpose is to deliver physician instructions, and 4) lack of standards for patient selection, which has the potential to exclude individuals who could benefit from learning to SM. Technology assessment offers one framework through which to examine available data about efficacy of patient SM and to answer the central question of what conditions must be put in place to optimize the benefits of SM while assuring that potential harms are controlled.


Shiao, Judith Shu-Chu; Koh, David; Lo, Li-Hua; Lim, Meng-Kin; Guo, Yueliang Leon. Factors predicting nurses’ consideration of leaving their job during the SARS outbreak. Nursing Ethics 2007 January; 14(1): 5-17. NRCBL: 9.5.1; 8.1; 7.1. SC: em. Identifiers: severe acute respiratory syndrome.

Abstract: Taiwan was affected by an outbreak of severe acute respiratory syndrome (SARS) in early 2003. A questionnaire survey was conducted to determine (1) the perceptions of risk of SARS infection in nurses; (2) the proportion of nurses considering leaving their job; and (3) work as well as non-work factors related to nurses’ consideration of leaving their job because of the SARS outbreak. Nearly three quarters (71.9%) of the participants believed they were ‘at great risk of exposure to SARS’, 49.9% felt ‘an increase in workload’, and 32.4% thought that people avoided them because of their job; 7.6% of the nurses not only considered that they should not care for SARS patients but were looking for another job or considering resignation. The main predictors of nurses’ consideration of leaving their job were shorter tenure, increased work stress, perceived risk of fatality from SARS, and affected social relationships. The findings are important in view of potential impending threats of pandemics such as avian influenza.


Tupasela, A. When legal worlds collide: from research to treatment in hereditary cancer prevention. European Journal of Cancer Care 2006 July; 15(3): 257-266. NRCBL: 9.5.1; 18.2; 18.5.9; 8.4; 18.3.


Vernick, William J. How long to postpone an operation after a myocardial infarction? When perioperative consultants contradict the literature, leaving the anesthesiologist in the middle. Journal of Clinical Anesthesia 2006 August; 18(5): 325-327. NRCBL: 9.5.1; 8.1; 8.3.1.

SECTION I CARE FOR SPECIFIC GROUPS/AGED

Organos Oficiales de la Sociedad Española de Patología Digestiva 2006 February; 98(2): 101-111. NRCBL: 9.5.1; 8.3.1.


CARE FOR SPECIFIC GROUPS/AGED


Abstract: This article accepts the proposition that old people want to be treated with dignity and that statements about dignity point to ethical duties that, if not independent of rights, at least enhance rights in ethically important ways. In contexts of policy and law, dignity can certainly have a substantive as well as rhetorical function. However, the article questions whether the concept of dignity can provide practical guidance for choosing among alternative approaches to the care of old people. The article explores the paradoxical relationship between the apparent lack of specific content in many conceptions of dignity and the broad utility that dignity appears to have as a concept expressive of shared social understandings about the status of old people.


Basta, Lofty L. Ethical issues in the management of geriatric cardiac patients: a 91-year old patient insists on an advance care plan that does not make sense. American Journal of Geriatric Cardiology 2004 September-October; 13(5): 276-277. NRCBL: 9.5.2; 9.6; 9.5.1.

Beaulieu, Marie; Leclerc, Nancy. Ethical and psycho-social issues raised by the practice in cases of mistreatment of older adults. Journal of Gerontological Social Work 2006 May; 46(3-4): 161-186. NRCBL: 9.5.2; 9.1; 4.1.2; 1.3.1; 8.1.


Abstract: Houston, Texas, is a major U.S. city with, like many, a growing aging population. The purpose of this study and ultimate book chapter is to explore the views and perceptions of long-term care (LTC) residents, family members and health care providers. Individuals primarily in independent living and group residential settings were interviewed and studied. Questions emphasized the concepts of personal autonomy, dignity, quality and location of care and decision making. Although a small sample of participants were involved, consistency was noted. Keeping the elderly in caring and loving home situations (their or family) was most preferred. Personal choice and independence were emphasized by residents, but family members needed to act as advocates. We also noted that the legal system emphasizes family control over individual decision making as competency declines with aging. Optimal personal decision making in the residents’ best interest also became more difficult with loss of individual mental capacity.


Abstract: This article reveals the outcome of a study on the perceptions of elders, family members, and healthcare professionals and administration providing care in a range of different long-term care facilities in Hong Kong with primary focus on the concepts of autonomy and dignity of elders, quality and location of care, decision making, and financing of long term care. It was found that aging in place and family care were considered the best approaches to long term care insofar as procuring and balancing the values of dignity, autonomy, family integrity and social sustainability were concerned. An elder having the final say was generally accepted. The results also initiated the importance of sharing of financial responsibility among elders, children and government although the emphasis was placed on individuals. Furthermore, dignity of elders was not considered purely a synonym of autonomy, but it had also to do with respect, family and social connections.

Cohen, Eric; Kass, Leon R. Cast me not off in old age. Commentary 2006 January; 121(1): 32-39. NRCBL: 9.5.2; 20.5.1; 20.5.4; 9.4; 20.3.3. Identifiers: euthanasia; assisted suicide.

Duhigg, Charles. At many homes, more profit and less nursing: insulated from lawsuits, private investors cut costs and staff. New York Times 2007 September 23; p. A1, A34, A35. NRCBL: 9.5.2; 9.3.1; 1.3.2. SC: po.

Elson, Paul. Do older adults presenting with memory complaints wish to be told if later diagnosed with Alzheimer’s disease? International Journal of Geriatric Psychiatry 2006 May; 21(5): 419-425. NRCBL: 9.5.2; 8.3.1; 8.2; 17.1.


Abstract: Long-term care is controversial because it involves foundational disputes. Some are moral-economic, bearing on whether the individual, the family, or the state is primarily responsible for long-term care, as well as on how one can establish a morally and financially sustainable long-term-care policy, given the moral hazard of people over-using entitlements once established, the political hazard of media democracies promising unfundable entitlements, the demographic hazard of relatively fewer workers to support those in need of long-term care, the moral hazard to responsibility of shifting accountability to third parties, and the bureaucratic hazard of moving from individual and family choice to bureaucratic oversight. These disputes are compounded by controversies regarding the nature of the family (Is it to be regarded primarily as a socio-biological category, a fundamental ontological category of social reality, or a construct resulting from the consent of the participants?), as well as its legal and moral autonomy and authority over its members. As the disputes show, there is no common understanding of respect and human dignity that will easily lead out of these disputes. The reflections on long-term care in this issue underscore the plurality of moralities defining bioethics.


Identifiers: China.

Abstract: Across the world, socio-economic forces are shifting the locus of long-term care from the family to institutional settings, producing significant moral, not just financial costs. This essay explores these costs and the distortions in the role of the family they involve. These reflections offer grounds for critically questioning the extent to which moral concerns regarding long-term care in Hong Kong and in mainland China are the same as those voiced in the United States, although family resemblances surely exist. Chinese moral values such as virtue and filial piety embedded in a Confucian moral and social context cannot be recast without distortion in terms of modern Western European notions. The essay concludes that the Confucian resources must be taken seriously in order to develop an authentic Chinese bioethics of long-term care and a defensible approach to long-term care policy for contemporary society in general and Chinese society in particular.


Abstract: The aim of the present study was, by means of discussion highlighting ethical questions and moral reasons, to increase understanding of the situations of caregivers and relatives of older persons living in a public nursing home in Sweden. The findings show that these circumstances can be better understood by considering two different perspectives: an individual perspective, which focuses on the direct contact that occurs among older people, caregivers and relatives; and a societal perspective, which focuses on the norms, values, rules and laws that govern a society. Relatives and caregivers thought that the politicians were sending out mixed messages: they were praising caregivers and relatives for their efforts, but at the same time the public health care sector was subjected to significant cutbacks in resources. Both caregivers and relatives were dissatisfied and frustrated with the present situation regarding the care of older persons in public nursing homes.


Pérez-Cárceles, M.D.; Lorenzo, M.D.; Luna, A.; Osuna, E. Elderly patients also have rights. *Journal of Medical Ethics* 2007 December; 33(12): 712-716. NRCBL: 9.5.2; 8.3.1; 8.4; 8.2. SC: em. Identifiers: Spain. Abstract: BACKGROUND: Sharing information with relatives of elderly patients in primary care and in hospital has to fit into the complex set of obligations, justifications and pressures concerning the provision of information, and the results of some studies point to the need for further empirical studies exploring issues of patient autonomy, privacy and informed consent in the day-to-day care of older people. OBJECTIVES: To know the frequency with which “capable” patients over 65 years of age receive information when admitted to hospital, the information offered to the families concerned, the person who gives consent for medical intervention, and the degree of satisfaction with the information received and the healthcare provided. Method: A descriptive questionnaire given to 200 patients and 200 relatives during the patients’ stay in hospital. RESULTS: Only 5% of patients confirmed that they had been asked whether information could be given to their relatives. A significantly higher proportion of relatives received information on the successive stages of the care offered than did patients themselves. As the age of the patients increased, so the number who were given information, understood the information and were asked for their consent for complementary tests decreased. The degree of satisfaction with the information offered was high for both patients and relatives (86.5% and 84%, respectively), despite the irregularities observed. CONCLUSIONS: The capacity of elderly patients to participate in the decision-making process is frequently doubted simply because they have reached a certain age and it is thought that relatives should act as their representatives. In Spain, the opinion of the family and doctors appears to play a larger role in making decisions than does the concept of patient autonomy.


Proot, Ireen M.; ter Meulen, Ruud H.J.; Abu-Saad, Huda Huijer; Crebolder, Harry E.J.M. Supporting stroke patients’ autonomy during rehabilitation. *Nursing Ethics* 2007 March; 14(2): 229-241. NRCBL: 9.5.2; 1.1. SC: em. Identifiers: Netherlands. Abstract: In a qualitative study, 22 stroke patients undergoing rehabilitation in three nursing homes were interviewed about constraints on and improvements in their autonomy and about approaches of health professionals regarding autonomy. The data were analysed using grounded theory, with a particular focus on the process of regaining autonomy. An approach by the health professionals that was responsive to changes in the patients’ autonomy was found to be helpful for restoration of their autonomy. Two patterns in health professionals’ approach appeared to be facilitatory: (1) from full support on admission through moderate support and supervision, to reduced supervision at discharge; and (2) from paternalism on admission through partial paternalism (regarding treatment) to shared decision making at discharge. The approach experienced by the patients did not always match their desires regarding their autonomy. Support and supervision were reduced over time, but paternalism was often continued too long. Additionally, the patients experienced a lack of information. Tailoring interventions to patients’ progress in autonomy would stimulate their active participation in rehabilitation and in decision making, and would improve patients’ preparation for autonomous living after discharge.


Sammet, Kai. Autonomy or protection from harm? Judgements of German courts on care for the elderly in nursing homes. *Journal of Medical Ethics* 2007 September; 33(9): 534-537. NRCBL: 9.5.2; 1.1; 17.3; 9.3.1. SC: le; cs. Abstract: The increase in life expectancy in developed countries has lead to an increase in the number of elderly people cared for in nursing homes. Given the physical frailty and deterioration of mental capacities in many of these residents, questions arise as to their autonomy and to their protection from harm. In 2005, one of the highest German courts, the Bundesgerichtshof (BGH) issued a seminal judgement that dealt with the obligations of nursing homes and with the preserving of autonomy and privacy in nursing home residents. An elderly woman had sustained a fracture of the neck of the femur during a fall. The health insurance company held that the nursing home
had breached its obligations to protect her from falling and sued the home for the hospital costs of her treatment. However, the BGH maintained that the case of the health insurance was not justified. It held that obligations of nursing homes have to be limited to normal arrangements within reasonable financial and personal effort, and that the autonomy of residents had to be protected from unnecessary interference. Permanent control or even restraining measures to reduce each risk would deprive the patient fully of her autonomy, and must therefore be hindered. Other judgments of other courts have emphasised the “protectionist” approach. The article deals with these different approaches and comments on both rationales. It will be shown that both approaches must be differentiated to establish fully autonomy and protection for nursing home residents.


Sloane, Peter; DeRenzo, Evan G. The case of Mr. A.B. *Journal of Clinical Ethics* 2007 Winter; 18(4): 399-401. NRCBL: 9.5.2; 8.3.1; 8.3.3; 20.3.3; 8.2. SC: cs.


Abstract: This article opens by reviewing the state of the knowledge on the most current worldwide facts about suicide in older people. Next, a number of values that have a role in this problem are considered. Having a clear and current understanding of suicide and of the related self-held and social values forms the framework for a number of clinical–ethical recommendations for care practice. An important aspect of caring for older people with suicidal tendencies is to determine whether their primary care fosters self-esteem and affirms their dignity. In addition to providing a timely and appropriate diagnosis and treatment of suicidality, the caregiver is responsible for helping the patient to cope with stressful conditions, and for treating the patient with respect and consideration, thereby supporting the patient's dignity and giving the patient a reason to live. Paying attention to these central points will foster caring contact with suicidal older people.


Werntoft, Elisbet; Hallberg, Ingalill R.; Edberg, Anna-Karin. Older people’s reasoning about age-related prioritization in health care. *Nursing Ethics* 2007 May; 14(3): 399-412. NRCBL: 9.5.2; 9.4. SC: em. Identifiers: Sweden. Abstract: The aim of this study was to describe the reasoning of people aged 60 years and over about prioritization in health care with regard to age and willingness to pay. Healthy people (n = 300) and people receiving continuous care and services (n = 146) who were between 60 and 101 years old were interviewed about their views on prioritization in health care. The transcribed interviews were analysed using manifest and latent qualitative content analysis. The participants’ reasoning on prioritization embraced eight categories: feeling secure and confident in the health care system; being old means low priority; prioritization causes worries; using underhand means in order to be prioritized; prioritization as a necessity; being averse to anyone having precedence over others; having doubts about the distribution of resources; and buying treatment requires wealth.


Zhai, Xiaomei; Qiu, Ren Zong. Perceptions of long-term care, autonomy, and dignity, by residents, family and care-
Abstract: This article examines historical and ideological trajectories that have made looking at the fetus via ultrasound a normal part of being pregnant for many women around the world. How did looking into so unlit a bodily space as the uterus become so natural? So everyday? So habit-forming? The answers lie in the convergence over time of technological hardware with knowledge practices that moved from medical to public domains. Germany serves as a site for an interrogation of how learned ways of thinking about anatomy, the development of technologies that “look,” a privileging of the visual in medical domains, and seeing as metaphor for truth about health reinforced and normalized prenatal ultrasound use.

Ethics Group of the Newborn Drug Development Initiative; Baer, Gerri R.; Nelson, Robert M. Ethical challenges in neonatal research: summary report of the ethics group of the newborn drug development initiative. *Clinical Therapeutics* 2006 September; 28(9): 1399-1407. NRCBL: 9.5.8; 9.7; 18.2; 18.5.4.


#### CARE FOR SPECIFIC GROUPS/ MENTALLY DISABLED

*See also BEHAVIOR CONTROL; ELECTROCONVULSIVE THERAPY; INVOLUNTARY COMMITMENT; MENTAL HEALTH THERA-

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**Addelson, Kathryn Pyne.** The emergence of the fetus. In: Mui, Constance L.; Murphy, Julien S., eds. Gender Struggles: Practical Approaches to Contemporary Feminism. Lanham, MD: Rowman & Littlefield Pub., 2002: 118-136. NRCBL: 9.5.8; 9.5.5; 10; 12.5.1.

American Pediatric Surgical Association Ethics and Advocacy Committee; Fallat, Mary E.; Caniano, Donna A.; Fecteau, Annie H. Ethics and the pediatric surgeon. *Journal of Pediatric Surgery* 2007 January; 42(1): 129-136; discussion 136. NRCBL: 9.5.8; 8.3.2; 9.5.1. SC: em.

Casper, Monica J. Fetal surgery then and now: there is too much emphasis on the fetus and not enough on the woman. *Conscience* 2007 Autumn; 28(3): 24-27. NRCBL: 9.5.8; 9.5.5.

Erikson, Susan L. Fetal views: histories and habits of looking at the fetus in Germany. *Journal of Medical Humanities* 2007 December; 28(4): 187-212. 28 refs. 34 fn. NRCBL: 9.5.8; 9.5.5; 7.1; 4.4; 14.1; 15.2.

Keywords: *fetuses; *historical aspects; *obstetrics; *prenatal diagnosis; *attitudes; *biomedical technologies; *international aspects; *mandatory programs; *mass screening; *metaphor; *medicine; *National Socialism; *pregnant women; *trends; *Proposed Keywords: *anatomy; *photography; *ultrasoundography; Keyword Identifiers: *Germany; *Fifteenth Century; *Sixteenth Century; *Seventeenth Century; *Eighteenth Century; *Nineteenth Century; *Twentieth Century; *Twenty-First Century
Ashley’s treatment: unethical or compassionate? [editorial]. Lancet 2007 January 13-19; 369(9556): 80. NRCBL: 9.5.3; 8.3.2; 4.4.


Treatments to keep disabled girl small stir debate. Washington Post 2007 January 5; p. A2. NRCBL: 9.5.3; 8.3.2; 4.4. SC: po. Identifiers: Ashley; growth attenuation therapy.


Abstract: This article looks at how mental health issues are conceptualized from the lens of Aboriginal world views. It refers to the legacy of colonization and the resulting historical trauma as the root of mental health “illnesses.” But it also raises questions on how definitions of “mental illnesses” are arrived at by one’s world view or lens. What may be seen as a mental health problem from one world view can be seen as a positive, healing spiritual experience from another.


Abstract: This article explores how ethics are framed for both Aboriginal and non-Aboriginal helpers. It examines both the challenges and the possibilities of working in the area of mental health, particularly if one is looking at the world through only a Western lens. It finishes with a brief exploration of how the two groups of helpers – Aboriginal and Western - might be able to work together ethically.

Bersani, Hank, Jr.; Rotholz, David A.; Eidelman, Steven M.; Pierson, Joanna L.; Bradley, Valerie J.; Gomez, Sharon C.; Havercamp, Susan M.; Silverman, Wayne P.; Yeager, Mark H.; Morin, Diane; Wehmeyer, Michael L.; Carabello, Bernard J.; Croser, M. Doreen.

Unjustifiable non-therapy: response to the issue of growth attenuation for young people on the basis of disability. Intellectual and Developmental Disabilities 2007 October; 45(5): 351-353. NRCBL: 9.5.3; 4.4; 8.3.2.


Coombes, Rebecca. Ashley X: a difficult moral choice. Did the doctors and parents responsible for a severely disabled girl have the right to keep her small? BMJ: British Medical Journal 2007 January 13; 334(7584): 72-73. NRCBL: 9.5.3; 9.5.7.

Dawson, John; Szmucler, George. Fusion of mental health and incapacity legislation. British Journal of Psychiatry 2006 June; 188: 504-509. NRCBL: 9.5.3; 8.3.3; 17.7; 1.3.5.


SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
SECTION I

CARE FOR SPECIFIC GROUPS/ MENTALLY DISABLED

Law 2007; 35(4): 533-534. NRCBL: 9.5.3; 1.3.5; 17.7. SC: le.


Metzner, Jeffrey L.; Tardiff, Kenneth; Lion, John; Reid, William H.; Recupero, Patricia Ryan; Schetky, Diane H.; Edenfield, Bruce M.; Mattson, Marlin; Janofsky, Jeffrey S. Resource document on the use of restraint and seclusion in correctional mental health care. Journal of the American Academy of Psychiatry and the Law 2007; 35(4): 417-425. NRCBL: 9.5.3; 1.3.5; 17.1; 6.

Newsom, Robert W. Seattle syndrome: comments on the reaction to Ashley X. Nursing Philosophy 2007 October; 8(4): 291-294. NRCBL: 9.5.3; 9.5.7; 4.4.


Patfield, Martyn. The ‘mentally disordered’ provisions of the New South Wales Mental Health Act 1990: their ethical standing and effect on services. Australasian Psychiatry 2006 September; 14(3): 263-266. NRCBL: 9.5.3; 17.7; 17.8. SC: ie.


Robertson, Michael. Part I: psychiatrists and social justice — the concept of justice. Journal of Ethics in Mental Health [electronic] 2007 November; 2(2): 5 p. Accessed: http://www.jemh.ca [2008 January 24]. NRCBL: 9.5.3; 1.1; 1.3.1; 4.1.2; 9.4. Abstract: These two papers consider the concept of social justice and the ethical obligations psychiatrists may have in its regard. In this first paper, the concept of social justice is defined in terms of the successful function of the social contract. Basic conceptions of justice are then considered.

Robertson, Michael. Part II: psychiatrists and social justice — when the social contract fails. Journal of Ethics in Mental Health [electronic] 2007 November; 2(2): 4 p. Accessed: http://www.jemh.ca [2008 January 24]. NRCBL: 9.5.3; 1.1; 1.3.1; 4.1.2; 9.4. Abstract: This second paper explores psychiatrists’ ethical obligations in the face of the failure of the social contract — inherent failures in distributive justice, the failure of the sovereign and the reconstitution of the social contract in post-conflict societies. Such situations present many sources of ethical tension between the professional ethical obligations of psychiatrists to their individual patients and to their society.

Sales, Becky; McKenzie, Nigel. Time to act on behalf of mentally disordered offenders. BMJ: British Medical Journal 2007 June 9; 334(7605): 1222. NRCBL: 9.5.3; 1.3.5.

Schmidt, Eric B. Making someone child-sized forever: ethical considerations in inhibiting the growth of a developmentally disabled child. Clinical Ethics 2007 March; 2(1): 46-49. NRCBL: 9.5.3; 4.4; 8.3.2; 9.5.7. SC: an. Abstract: In a recent case, parents of a profoundly developmentally disabled child asked physicians to use high-dose oestrogen to inhibit the growth of their child in the interests of allowing better care of her as she ages. The physicians asked whether such an intervention would be ethically acceptable. Such an intervention would seem to violate the rights of the child to bodily integrity and to normal growth, making the intervention ethically objectionable. But in this paper, I argue that in some rare instances, a developmentally disabled child may have only a minimal right against interference with her growth. In those instances, parents may be acting ethically if they use medical interventions to inhibit the growth of their child for the purposes of facilitating better care. But they may so intervene only when the child’s disabilities are so profound that the child has no personal interest in developing an adult size and when the intervention is the least intrusive means available for facilitating the care of the child.


Stansfield, Alison J.; Holland, A.J.; Clare, I.C.H. The sterilisation of people with intellectual disabilities in England and Wales during the period 1988 to 1999. Journal of Intellectual Disability Research 2007 August; 51(8): 569-570. NRCBL: 9.5.3; 11.3; 8.3.3; 2.2.


Wong, Sophia Isako. The moral personhood of individuals labeled “mentally retarded”: a Rawlsian response to
CARE FOR SPECIFIC GROUPS/ MINORITIES


Abstract: OBJECTIVES: We examined the racial/ethnic and geographic variation in distrust of physicians in the United States. METHODS: We obtained data from the Community Tracking Study, analyzing 20 sites where at least 5% of the population was Hispanic and 5% was Black. RESULTS: In univariate analyses, Blacks and Hispanics reported higher levels of physician distrust than did Whites. Multivariate analyses, however, suggested a complex interaction among sociodemographic variables, city of residence, race/ethnicity, and distrust of physician. In general, lower socioeconomic status (defined as lower income, lower education, and no health insurance) was associated with higher levels of distrust, with men generally reporting more distrust than women. But the strength of these effects was modified by race/ethnicity. We present examples of individual cities in which Blacks reported consistently higher mean levels of distrust than did Whites, consistently lower mean levels of distrust than did Whites, or a mixed relationship dependent on socioeconomic status. In the same cities, Hispanics reported either consistently higher mean levels of distrust relative to Whites or a mixed relationship. CONCLUSIONS: Racial/ethnic differences in physician distrust are less uniform than previously hypothesized, with substantial geographic and individual variation present.

Bailey, James E.; Sprabery, Laura R. Inequitable funding may cause health care disparities [editorial]. Archives of Internal Medicine 2007 June 25; 167(12): 1226-1228. NRCBL: 9.5.4; 9.3.1.


Duster, Troy. Medicalisation of race. Lancet 2007 February 24-March 2; 369(9562): 702-704. NRCBL: 9.5.4; 15.9; 9.7; 5.3; 7.1; 4.2.


Hasnain-Wynia, Romana; Baker, David W.; Nerenz, David; Feinglass, Joe; Beal, Anne C.; Landrum, Mary Beth; Behal, Raj; Weissman, Joel S. Disparities in health care are driven by where minority patients seek care. Archives of Internal Medicine 2007 June 25; 167(12): 1233-1239. NRCBL: 9.5.4; 9.8. SC: em.

Abstract: BACKGROUND: Racial/ethnic disparities in health care are well documented, but less is known about whether disparities occur within or between hospitals for specific inpatient processes of care. We assessed racial/ethnic disparities using the Hospital Quality Alliance Inpatient Quality of Care Indicators. METHODS: We performed an observational study using patient-level data for acute myocardial infarction (5 care measures), congestive heart failure (2 measures), community-acquired pneumonia (2 measures), and patient counseling (4 measures). Data were obtained from 123 hospitals reporting to the University HealthSystem Consortium from the third quarter of 2002 to the first quarter of 2005. A total of 320,970 patients 18 years or older were eligible for at least 1 of the 13 measures. RESULTS: There were consistent unadjusted differences between minority and non-minority patients in the quality of care across 8 of 13 quality measures (from 4.63 and 4.55 percentage points for angiotensin-converting enzyme inhibitors for acute myocardial infarction and congestive heart failure [P01] to 14.58 percentage points for smoking cessation counseling for pneumonia [P=.02]). Disparities were most pronounced for counseling measures. In multivariate models adjusted for individual patient characteristics and hospital effect, the magnitude of the disparities decreased substantially, yet remained significant for 3 of the 4 counseling measures; acute myocardial infarction (unadjusted, 9.00 [P01]; adjusted, 3.82 [P01]), congestive...
heart failure (unadjusted, 8.45 [P=.02]; adjusted, 3.54 [P=.02]), and community-acquired pneumonia (unadjusted, 14.58 [P=.02]; adjusted, 4.96 [P=.01]). CONCLUSIONS: Disparities in clinical process of care measures are largely the result of differences in where minority and nonminority patients seek care. However, disparities in services requiring counseling exist within hospitals after controlling for site of care. Policies to reduce disparities should consider the underlying reasons for the disparities.


Rogers, Naomi. Race and the politics of polio: Warm Springs, Tuskegee, and the March of Dimes. American Journal of Public Health 2007 May; 97(5): 784-795. NRCBL: 9.5.4; 7.1; 21.1. Abstract: The Tuskegee Institute opened a polio center in 1941, funded by the March of Dimes. The center’s founding was the result of a new visibility of Black polio survivors and the growing political embarrassment around the policy of the Georgia Warm Springs polio rehabilitation center, which Franklin Roosevelt had founded in the 1920s before he became president and which had maintained a Whites-only policy of admission. This policy, reflecting the ubiquitous norm of race-segregated health facilities of the era, was also sustained by a persuasive scientific argument about polio itself: that Blacks were not susceptible to the disease. After a decade of civil rights activism, this notion of polio as a White disease was challenged, and Black health professionals, emboldened by a new integrationist epidemiology, demanded that in polio, as in American medicine at large, health care should be provided regardless of race, color, or creed.
ethical obligations incumbent on disciplines traditionally recognised as purely academic.

**CARE FOR SPECIFIC GROUPS/ MINORS**


Brabin, Loretta; Roberts, Stephen A.; Kitchener, Janet; Maxwell, Gabrielle. The key to the gatekeepers: passive consent and other ethical issues surrounding the rights of children to speak on issues that concern them. *Child Abuse and Neglect* 2006 September; 30(9): 979-989. NRCBL: 9.5.7; 8.3.2; 9.1.

Coleman, Gerald D. The irreversible disabling of a child: the “Ashley treatment”. *National Catholic Bioethics Quarterly* 2007 Winter; 7(4): 711-728. 63 fn. NRCBL: 9.5.7; 9.5.1; 4.4; 2.4; 8.3.2; 1.2; 15.5. SC: cs; le.

Keywords: *children; *disabled persons; *human dignity; *patient care; brain pathology; choice behavior; clinical ethics committees; decision making; eugenics; parental consent; parents; physicians; quality of life; Roman Catholic ethics; sterilization; surgery;* Proposed Keywords: *body height; *developmental disabilities; *growth attenuation;* Key Word Identifiers: Children’s Hospital (Seattle, WA)

Abstract: The controversial growth attenuation therapy for a severely disabled girl named Ashley is about intentional and deliberate medical acts of crippling. Does crippling children amount to a fundamental violation of their dignity and the oath of physicians to first do no harm? The way we formulate the dilemma, the picture we draw of its salient features, largely determines the conclusions we reach and the choices we make. It is intellectually important to try to view the events as the major participants view them.


Davies, Glanville; Poole, Richard F.; Akerman, Beverly R.; Gogol, Manfred. Reflections on the birth of conjoined twins [letters]. *CMAJ/JAMC: Canadian Medi-

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**SC (Subject Captions):** an=analytical cs=case studies em=empirical le=legal po=popular rv=review
SECTION I  CARE FOR SPECIFIC GROUPS/ MINORS

Kumra, Sanjiv; Ashtari, Manzar; Anderson, Britt; Cervellione, Kelly L.; Kan, Li. Ethical and practical considerations in the management of incidental findings in pediatric MRI studies. Journal of the American Academy of Child and Adolescent Psychiatry 2006 August; 45(8): 1000-1006. NRCBL: 9.5.7; 18.2; 18.5.2; 9.8; 17.1.

Kuz, Kelly M. Young teenagers providing their own surgical consents: an ethical-legal dilemma for perioperative registered nurses. Canadian Operating Room Nursing Journal 2006 June; 24(2): 6-8, 10-11, 14-15. NRCBL: 9.5.7; 8.3.2.


Larcher, Vic. Ethical issues in child protection. Clinical Ethics 2007 December; 2(4): 208-212. NRCBL: 9.5.7; 9.1; 8.4; 1.3.5.

Abstract: The management of child protection concerns arouses strong emotions and controversies and creates ethical tensions for all concerned. This paper provides a rational analysis of some of the issues involved and suggests responses to them. The ethical and legal duties of health-care professionals are to act in the best interests of the child by safeguarding children and reporting concerns. But this may involve conflicts with parents and produce reluctance of professionals to become involved, especially in controversial types of abuse. Mandatory reporting of concerns might overcome such reluctance, but may be ineffective in the face of diagnostic uncertainties. Assembly of a stronger diagnostic evidence base would seem ethically justified, but organization of the necessary case controlled studies might be problematic. Even with a comprehensive evidence base, individual diagnoses of abuse will always involve value judgements that should be underpinned by effective training and assessment of core competencies of professionals. These manoeuvres are unlikely to prevent both justified and vexatious complaints, often in relation to breaches in professional duties or concerning professional misconduct. The tendency to blame experts may have contributed to a reluctance of other professionals to become involved, despite proposals for reforms in the expert witness and court systems. Current approaches to child protection may neither promote greater understanding nor be in the best interests of children. A revised social contract for the effective protection of children could include: a duty of care that adequately addresses the primacy of the child’s welfare; the acquisition of a sound evidence base; professional transparency and accountability (but with protection from malicious and vexatious complaints); and a shift emphasis towards a more inquisitorial system that embraced the principles of truth and reconciliation.


Abstract: Oestrogen treatment for girls, to prevent psychosocial problems due to extreme tallness, has been available for almost 50 years but uncertainty about its position prevails. The ethical problems of this treatment are focused on in this paper. After a brief overview on historical and medical aspects, ethical issues such as the general justification of oestrogen treatment, evaluation of its success and ethical concerns related to research in this subject are dealt with in detail.


Abstract: Human dignity is grounded in basic human attributes such as life and self-respect. When people cannot stand up for themselves they may lose their dignity towards themselves and others. The aim of this study was to elucidate if dignity remains intact for family members during care procedures in a children’s hospital. A qualitative approach was adopted, using open non-participation observation. The findings indicate that dignity remains intact in family-centred care where all concerned parties encourage each other in a collaborative relationship. Dignity is shattered when practitioners care from their own perspective without seeing the individual in front of them. When there is a break in care, family members can restore their dignity because the interruption helps them to master their emotions. Family members’ dignity is shattered and remains damaged when they are emotionally overwhelmed; they surrender themselves to practitioners’ care, losing their self-esteem and self-respect.


Moss, Ralph W. Health checks, not shots: blanket vaccination against a sexually transmitted virus is the wrong way to protect women’s health. New Scientist 2007 February 24-March 2; 193(2592): 20. NRCBL: 9.5.7; 9.5.1; 9.5.5; 10; 9.7.


Ogilvie, Gina S.; Remple, Valeria P.; Marra, Fawziah; McNell, Shelly A.; Naus, Monika; Pielak, Karen L.; Ehlen, Thomas G.; Dobson, Simon R.; Money, Deborah M.; Patrick, David M. Parental intention to have daughters receive the human papillomavirus vaccine [letters and reply]. CMAJ/JAMC: Canadian Medical Association Journal 2007 December 4; 177(12): 1506-1512. NRCBL: 9.5.7; 9.5.1; 9.7; 9.5.5; 8.3.2. SC: em. Identifiers: Canada.


Roy, Elizabeth; Samuels, Sumerlee. Ethical debating: therapy for adolescents with eating disorders. Journal of Pediatric Nursing 2006 April; 21(2): 161-166. NRCBL: 9.5.7; 17.2; 4.1.3.


Spinney, Laura. Therapy for autistic children causes outcry in France [comment]. Lancet 2007 August 25-31; 370(9588): 645-646. NRCBL: 9.5.7; 17.2; 17.3; 18.5.2; 18.4.

Udesky, Laurie. Push to mandate HPV vaccine triggers backlash in USA. Lancet 2007 March 24-30; 369(9566): 979-980. NRCBL: 9.5.7; 9.5.1; 10; 9.7; 9.3.1; 8.4; 9.1. SC: le.

Wright, C.M.; Waterston, A.J.R. Relationships between paediatricians and infant formula milk companies. Archives of Disease in Childhood 2006 May; 91(5): 383-385. NRCBL: 9.5.7; 7.3; 1.3.2.

CARE FOR SPECIFIC GROUPS/ SUBSTANCE ABUSERS

Baumrucker, Steven J. Ethics roundtable. Hospice and alcoholism. American Journal of Hospice and Palliative Care 2006 March-April; 23(2): 153-156. NRCBL: 9.5.9; 20.4.1; 8.1. SC: cs; le.

Benoit, Ellen; Magura, Stephen. Disability and substance user treatment/rehabilitation: ethical considerations. In: Kleinig, John; Einstein, Stanley, eds. Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 153-170. NRCBL: 9.5.9; 9.4; 9.1; 4.2; 4.3; 9.3.1. SC: le.

Caplan, Arthur L. Ethical issues surrounding forced, mandated, or coerced treatment. Journal of Substance Abuse Treatment 2006 September; 31(2): 117-120. NRCBL: 9.5.9; 9.7; 8.3.4; 13.5; 1.1.


Abstract: Attendance at 12-step programs has become part of the orthodoxy of treating clients with substance abuse disorders. However, concerns have been raised about the assumptions on which 12-step programs are based. I argue that antirepresentationalism is the moral principle that underpins such concerns. After clarifying the principle of antirepresentationalism, I explore strategies for reconciling antirepresentationalism with 12-step programs. However, all the strategies I try fail. Consequently, I adopt an alternative way of thinking about antirepresentationalism that leaves mental health professionals free to refer clients to 12-step programs. However, such referrals can continue only at the cost of accepting objectionable assumptions about motivation, spirituality and human agency. Therefore, it might well be time to find an alternative to 12-step programs.

Cohen, Elliot D. Conceptualizing the professional relationship in drug user and alcohol misuser counseling. In: Kleinig, John; Einstein, Stanley, eds. Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 367-382. NRCBL: 9.5.9; 8.1; 17.2; 8.4;

SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
SECTION I  CARE FOR SPECIFIC GROUPS/ SUBSTANCE ABUSERS

8.3.1. Identifiers: Alcoholics Anonymous; fiduciary model.

Coleman, Stephen. Ethical issues raised by non-punitive drug user policies. In: Kleining, John; Einstein, Stanley, eds. Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 99-119. NRCBL: 9.5.9; 9.1; 1.3.5.


Einstein, Stanley. Drug users can’t be treated, people can be! The creation and maintenance of ethical travesties, or at least dilemmas. In: Kleining, John; Einstein, Stanley, eds. Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 565-623. NRCBL: 9.5.9; 4.2; 7.1.


Gorman, Dennis M. Conflicts of interest in the evaluation and dissemination of drug use prevention programs. In: Kleining, John; Einstein, Stanley, eds. Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 171-187. NRCBL: 9.5.9; 9.1; 18.2; 9.7; 9.3.1.


Higgs, Peter; Moore, David; Aitken, Campbell. Engagement, reciprocity and advocacy: ethical harm reduction practice in research with injecting drug users. Drug and Alcohol Review 2006 September; 25(5): 419-423. NRCBL: 9.5.9; 7.1; 8.1.


Abstract: Background: Current anti-doping in competitive sports is advocated for reasons of fair-play and concern for the athlete’s health. With the inception of the World Anti Doping Agency (WADA), anti-doping effort has been considerably intensified. Resources invested in anti-doping are rising steeply and increasingly involve public funding. Most of the effort concerns elite athletes with much less impact on amateur sports and the general public. Discussion: We review this recent development of increasingly severe anti-doping control measures and find them based on questionable ethical grounds. The ethical foundation of the war on doping consists of largely unsubstantiated assumptions about fairness in sports and the concept of a ‘level playing field’. Moreover, it relies on dubious claims about the protection of an athlete’s health and the value of the essentialist view that sports achievements reflect natural capacities. In addition, costly antidoping efforts in elite competitive sports concern only a small fraction of the population. From a public health perspective this is problematic since the high prevalence of uncontrolled, medically unsupervised doping practiced in amateur sports and doping-like behaviour in the general population (substance use for performance enhancement outside sport) exposes greater numbers of people to potential harm. In addition, anti-doping has pushed doping and doping-like behaviour underground, thus fostering dangerous practices such as sharing needles for injection. Finally, we argue that the involvement of the medical profession in doping and anti-doping challenges the principles of non-maleficence and of privacy protection. As such, current anti-doping measures potentially introduce problems of greater impact than are solved, and place physicians working with athletes or in anti-doping settings in an ethically difficult position. In response, we argue on behalf of enhancement practices in sports within a framework of medical supervision. Summary: Current anti-doping strategy is aimed at eradication of doping in elite sports by means of all-out repression, buttressed by a war-like ideology similar to the public discourse sustaining international efforts against illicit drugs. Rather than striving for eradication of doping in sports, which appears to be an unattainable goal, a more pragmatic approach aimed at controlled use and harm reduction may be a viable alternative to cope with doping and doping-like behaviour.

Kene t t, Je annette; Matthe ws, Stephen. The moral goal of treatment in cases of dual diagnosis. In: Kleining, John; Einstein, Stanley, eds. Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 409-436. NRCBL: 9.5.9; 17.1. SC: an.
CARE FOR SPECIFIC GROUPS/ SUBSTANCE ABUSERS  
SECTION I

Kleinig, John. Thinking ethically about needle and syringe programs. In: Kleinig, John; Einstein, Stanley, eds. Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 9.5.6; 9.5.9; 8.3.1; 1.3.5. SC: an.

Kleinig, John. Thinking ethically about needle and syringe programs. Substance Use and Misuse 2006; 41(6-7): 815-825. NRCBL: 9.5.9; 9.1; 9.5.6.


Morse, Stephen J. Medicine and morals, craving and compulsion. In: Kleinig, John; Einstein, Stanley, eds. Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 9.5.9; 4.3; 4.2; 1.3.5. SC: an.

Mukherjee, Raja; Eastman, Nigel; Turk, Jeremy; Hollins, Sheila. Fetal alcohol syndrome: law and ethics. Lancet 2007 April 7-13; 369(9568): 1149-1150. NRCBL: 9.5.9; 9.5.5; 9.5.8; 8.1. SC: le.


Presenza, Louis J. Naltrexone as a “mandate” or as a choice: comments on “Judicially mandated naltrexone use by criminal offenders: a legal analysis”. Journal of Substance Abuse Treatment 2006 September; 31(2): 129-130. NRCBL: 9.5.9; 9.7; 8.3.4; 1.3.5. SC: le.


Rosenberg, Tina. Doctor or drug pusher? Pain is difficult to measure, and those who treat pain sufferers have to make highly subjective decisions about dosage levels of drugs that can be abused or even resold. When a doctor gets it wrong, is that bad medicine — or a drug felony? New York Times Magazine 2007 June 17; p. 48-55, 64, 68-71. NRCBL: 9.5.9; 4.4; 8.1; 9.7; 1.3.5. SC: po.

Schomerus, G; Matschinger, H.; Angermeyer, M.C. Alcoholism: illness beliefs and resource allocation preferences of the public. Drug and Alcohol Dependence 2006 May 20; 82(3): 204-210. NRCBL: 9.5.9; 9.2; 9.3.1; 9.4.


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Walsh, Adrian; Lynch, Tony. Drug user counseling renumeration and ethics. In: Kleinig, John; Einstein, Stanley, eds. Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 453-466. NRCBL: 9.5.9; 17.1; 9.3.1. SC: an.

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Wiechelt, Shelly A. Ethical issues surrounding access to treatment for substance misuse. In: Kleinig, John; Einstein, Stanley, eds. Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 553-563. NRCBL: 9.5.9; 9.4; 6; 9.3.1; 9.3.2.

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Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 341-365. NRCBL: 9.5.9; 8.1; 17.7; 1.3.5; 1.3.10. SC: an; le.

Zadunayski, Anna; Hicks, Matthew; Gibbard, Ben; Godlovitch, Glenys. Behind the screen: legal and ethical considerations in neonatal screening for prenatal exposure to alcohol. *Health Law Journal* 2006; 14: 105-127. NRCBL: 9.5.9; 9.5.8; 9.5.7; 8.3.4; 2.1. SC: po.

**CARE FOR SPECIFIC GROUPS/ WOMEN**


Identifiers: human papillomavirus vaccine (HPV).

**CARE FOR SPECIFIC GROUPS/ WOMEN**

Brown, Stephen D.; Truog, Robert D.; Johnson, Judith A.; Ecker, Jeffrey L. Do differences in the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists positions on the ethics of maternal-fetal interventions reflect subtly divergent professional sensitivities to pregnant women and fetuses? *Pediatrics* 2006 April; 117(4): 1382-1387. NRCBL: 9.5.5; 9.5.8; 8.3.1; 8.3.4; 9.5.1. SC: le.


Chou, Ann F.; Scholle, Sarah Hudson; Weisman, Carol S.; Bierman, Arlene S.; Correa-de-Araujo, Rosaly; Mosca, Lori. Gender disparities in the quality of cardiovascular disease care in private managed care plans. *Women's Health Issues* 2007 May-June; 17(3): 120-130. NRCBL: 9.5.5; 9.5.1; 9.3.2. SC: em.

Chou, Ann F.; Wong, Lok; Weisman, Carol S.; Chan, Sophia; Bierman, Arlene S.; Correa-de-Araujo, Rosaly; Scholle, Sarah Hudson. Gender disparities in cardiovascular disease care among commercial and Medicare managed care plans. *Women's Health Issues* 2007 May-June; 17(3): 139-149. NRCBL: 9.5.5; 9.5.1; 9.3.2. SC: em.


Dixon-Woods, Mary; Williams, Simon J.; Jackson, Clare J.; Akkad, Andrea; Kenyon, Sara; Habiba, Marwan. Why do women consent to surgery, even when they do not want to? An interactionist and Bourdieusian analysis. *Social Science and Medicine* 2006 June; 62(11): 2742-2753. NRCBL: 9.5.5; 8.3.1; 9.5.1; 1.1.

Dixon-Woods, Mary; Young, Bridget; Ross, Emma. Researching chronic childhood illness: the example of childhood cancer. *Chronic Illness* 2006 September; 2(3): 165-177. 68 refs. NRCBL: 9.5.5; 15.1; 18.5.2; 18.3.

Keywords: *cancer; *children; *chronically ill; *human experimentation; age factors; behavioral research; clinical trials; genetic research; informed consent; researcher subject relationship; risk; tissue donors

**FIGO Committee for the Ethical Aspects of Human Reproduction and Women’s Health.** Ethical guidelines on obstetric fistula. *International Journal of Gynecology*
and Obstetrics 2006 August; 94(2): 174-175. NRCBL: 9.5.5; 14.1.


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Fremont, Allen M.; Coreea-de-Araujo, Rosaly; Hayes, Sharon. Gender disparities in managed care: it’s time for action. Women’s Health Issues 2007 May-June; 17(3): 116-119. NRCBL: 9.5.5; 9.3.2.

Gannon, Susanne; Müller-Rockstroh, Babette. In memory: women’s experiences of (dangerous) breasts. Philosophy in the Contemporary World 2004 Spring-Summer; 11(1): 53-64. NRCBL: 9.5.5; 4.2; 4.4; 10.

Gass, C.W.J. It is the right of every anaesthetist to refuse to participate in a maternal-request caesarean section. International Journal of Obstetric Anesthesia 2006 January; 15(1): 33-35. NRCBL: 9.5.5; 9.5.8; 9.5.1; 8.1. SC: an.


Leavine, Barbara Ann. Court ordered cesareans: can a pregnant woman refuse? Houston Law Review 1992 Spring; 29(1): 185-213. NRCBL: 9.5.5; 1.1; 8.3.3; 8.3.4; 9.5.8. SC: le; rv.

Levy, Daniel R. The maternal-fetal conflict: the right of a woman to refuse a caesarean section versus the state’s interest in saving the life of the fetus. West Virginia Law Review 2005 Fall; 108(1): 97-124. NRCBL: 9.5.5; 9.5.8; 8.3.4; 1.3.5.


Macauley, Robert C. The role of substituted judgment in the aftermath of a suicide attempt. Journal of Clinical Ethics 2007 Summer; 18(2): 111-118. NRCBL: 9.5.5; 20.7; 20.5.4; 8.1; 8.3.3. SC: cs.

Mansi, James A.; Franco, Eduardo L.; de Pokomandy, Alexandra; Spence, Andrea R.; Burchell, Ann N.; Trottier, Helen; Mayrand, Marie-Hélène; Lau, Susie; Ferenczy, Alex; Brophy, James M.; Cassels, Alan K.; Nisker, Jeff; Lippman, Abby; Boscoe, Madeline; Shimmin, Carolyn. Vaccination against human papillomavirus. CMAJ/JAMC: Canadian Medical Association Journal 2007 December 4; 177(12): 1524-1528. NRCBL: 9.5.5; 9.5.1; 9.5.7; 9.7.

Morris, Kelly. Issues on female genital mutilation/cutting — progress and parallels. Lancet 2006 December; 368(special issue): S64-S66. NRCBL: 9.5.5; 9.5.7; 10; 21.7; 21.1; 4.2; 9.5.1.


Patni, Shalini; Wagstaff, John; Tosazzal, Nasima; Bonduelle, Myriam; Moselhi, Marsham; Kevelighan, Euan; Edwards, Steve. Metastatic unknown primary tumour presenting in pregnancy: a rarity posing an ethical dilemma. Journal of Medical Ethics 2007 August; 33(8): 442-443. NRCBL: 9.5.5; 9.5.1; 12.4.2. SC: cs.

Abstract: This brief report raises the ethical dilemma encountered by an obstetrician involved in the care of a pregnant woman with life-threatening disease. This is a particularly difficult issue if the maternal well-being is in conflict with the survival of the unborn child.


Abstract: In researching the biomedically-engineered drug Neulasta (filgrastim), a breast cancer patient becomes aware of the extent to which knowledge about the development and marketing of drugs influences her decisions with regard to treatment. Time spent on understanding the commercial interests of insurers and pharmaceutical companies initially thwarts but ultimately aids the healing process. This first-person narrative calls for physicians to recognize that the alignment of commercial interests transgresses the patient’s humanity.

Schwartz, Linda; Woloshin, Steven. Participation in mammography screening: Women should be encouraged to decide what is right for them, rather than being told what to do. BMJ: British Medical Journal 2007 October 13; 335(7623): 731-732. NRCBL: 9.5.5; 8.1; 1.1.


Szumacher, Ewa. The feminist approach in the decision-making process for treatment of women with breast cancer. Annals of the Academy of Medicine, Singapore 2006 September; 35(9): 655-661. NRCBL: 9.5.5; 9.5.4; 8.1; 10; 4.5; 9.5.1; 18.3. SC: rv.

Tong, Rosemarie. Gender-based disparities east/west: rethinking the burden of care in the United States and Taiwan. Bioethics 2007 November; 21(9): 488-499. NRCBL: 9.5.5; 9.5.2; 21.1; 9.3.1. SC: rv.

Abstract: When feminist bioethicists express concerns about health-related gender disparities, they raise considerations about justice and gender that traditional bioethicists have either not raised or raised somewhat weakly. In this article, I first provide a feminist analysis of long-term healthcare by and for women in the United States and women in Taiwan. Next, I make the case that, on average, elderly US and Taiwanese women fare less well in long-term care contexts than do elderly US and Taiwanese men. Finally, I explore some suggested practical remedies to reduce gender disparities in long-term care contexts.


Abstract: Despite global and local attempts to end female genital mutilation (FGM), the practice persists in some parts of the world and has spread to non-traditional countries through immigration. FGM is of varying degrees of invasiveness, but all forms raise health-related concerns that can be of considerable physical or psychological severity. FGM is becoming increasingly prohibited by law, both in countries where it is traditionally practised and in countries of immigration. Medical practice prohibits FGM. The Italian parliament passed a law prohibiting FGM, which has put in place a set of measures to prevent, to oppose and to suppress the practice of FGM as a violation of a person’s fundamental rights to physical and mental integrity and to the health of women and girls. The Italian law not only treats new offences but also wants to deal with the problem in its entirety, providing important intervention in all the sectors. Different kinds of interventions are considered, starting with the development of informative campaigns, training of health workers, institution of a tollfree number, international cooperation programmes and the responsibility of the institution where the crime is committed. Particularly, the law recognises that doctors have a role in eliminating FGM by educating patients and communities.


CARING See NURSING ETHICS AND PHILOSOPHY; PHILOSOPHY OF MEDICINE; PATIENT RELATIONSHIPS

CHIMERAS AND HYBRIDS


Keywords: *chimeras; *embryo research; *legal aspects; genetically modified animals; government regulation; legislation; public policy; Keyword Identifiers: *Great Britain; Human Fertilisation and Embryology Authority (Great Britain)

Animal-human hybrid-embryo research [editorial]. Lancet 2007 September 15-21; 370(9591): 909. NRCBL: 15.1; 18.5.4; 22.2; 5.3; 18.6; 18.1; 22.1.


Keywords: *chimeras; *embryo research; *stem cells; human dignity; nuclear transfer techniques; primates; regulation; risk; Keyword Identifiers: Great Britain

Chimera research should be lightly regulated, not banned [editorial]. Lancet 2007 January 20-26; 369(9557): 164. NRCBL: 18.5.4; 15.1; 18.1; 22.1; 5.3; 1.3.7.

Keywords: *chimeras; *embryo research; *embryonic stem cells; *government regulation; legal aspects; mass media; public policy; Keyword Identifiers: Great Britain; Human Fertilisation and Embryology Authority


Keywords: *chimeras; *embryo research; *embryonic stem cells; alternatives; embryos; ovum donors; private sector; regulation; remuneration; scarcity; Keyword Identifiers: Great Britain; United States

NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.
CHIMERAS AND HYBRIDS

Proyecto CHIMBRIDS: chimeras and hybrids in comparative European and international research-scientific, ethical, philosophical and legal aspects. Revista de Derecho y Genoma Humano = Law and the Human Genome Review 2007 July-December; (27): 227-243. 16 fn. NRCBL: 15.1; 18.1; 22.1; 21.1. SC: le; rv. Keywords: *chimeras; *international aspects; *moral policy; *public policy; animal experimentation; animal welfare; classification; comparative studies; embryo research; embryo transfer; embryos; ethical analysis; gene transfer techniques; genetic research; government regulation; legal aspects; moral status; nuclear transfer techniques; organ transplantation; research ethics; species specificity; stem cell transplantation; tissue transplantation; Keyword Identifiers: *European Union; Council of Europe; Europe

The use of human-animal hybrid embryos [news]. ATLA: Alternatives to Laboratory Animals 2007 March; 35(1): 8-9. 2 refs. NRCBL: 15.1; 18.1; 22.1; 18.5.4. SC: an. Keywords: *chimeras; *embryos; *research embryo creation; animal experimentation; biomedical research; embryonic stem cells; government regulation; Keyword Identifiers: Great Britain

Baylis, Françoise; Fenton, Andrew. Chimera research and stem cell therapies for human neurodegenerative disorders. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Spring; 16(2): 195-208. 71 fn. NRCBL: 15.1; 18.1; 22.1; 17.1; 4.4; 18.5.4. SC: an. Keywords: *chimeras; *embryonic stem cells; *ethical analysis; *human dignity; *moral policy; *moral status; *primates; *stem cell transplantation; animal welfare; clinical trials; guidelines; human characteristics; specieism; therapeutic research; risks and benefits; Proposed Keywords: *neurodegenerative diseases; Keyword Identifiers: National Academy of Sciences

Baylis, Françoise; Robert, Jason Scott. Part-human chimeras: worrying the facts, probing the ethics. American Journal of Bioethics 2007 May; 7(5): 41-45. 26 refs. NRCBL: 15.1; 18.1; 22.1. Comments: Comment on: Henry T. Greely, Mildred K. Cho, Linda F. Hogle, and Debra M. Satz. Thinking about the human neuron mouse. American Journal of Bioethics 2007 May; 7(5): 27-40. Keywords: *chimeras; animal experimentation; brain; human characteristics; moral status; personhood; research ethics; self concept; stem cell transplantation; wedge argument; Proposed Keywords: *cognition; mice

Cohen, Cynthia B. Beyond the human neuron mouse to the NAS guidelines. American Journal of Bioethics 2007 May; 7(5): 46-49. 12 refs. NRCBL: 15.1; 18.1; 22.1; 18.5.4. Comments: Comment on: Henry T. Greely, Mildred K. Cho, Linda F. Hogle, and Debra M. Satz. Thinking about the human neuron mouse. American Journal of Bioethics 2007 May; 7(5): 27-40. Keywords: *chimeras; *guidelines; *stem cell transplantation; advisory committees; animal experimentation; brain; embryonic stem cells; embryos; fetuses; human characteristics; moral policy; policy analysis; policy making; precautionary principle; primates; public policy; regulation; research ethics; risks and benefits; Proposed Keywords: blastocysts; mice; species specificity; Keyword Identifiers: National Academies of Sciences; Stanford University; United States

Cole, Andrew. Scientists plead for right to create interspecies embryos [news]. BMJ: British Medical Journal 2007 June 23; 334(7607): 1294. NRCBL: 15.1; 18.1; 22.1; 18.5.4. Keywords: *chimeras; *research embryo creation; embryonic stem cells; government regulation; organizational policies; professional organizations; public policy; researchers; Keyword Identifiers: *Great Britain; Academy of Medical Sciences (Great Britain)


Day, Michael. UK may use hybrid embryos for research [news]. BMJ: British Medical Journal 2007 May 26; 334(7603): 1074. NRCBL: 18.5.4; 15.1; 18.1; 22.1. Keywords: *chimeras; *embryo research; *embryos; *legal aspects; *public policy; government; legislation; Proposed Keywords: *Great Britain; Department of Health (Great Britain); *Human Tissue and Embryos Bill (Great Britain)

Eberl, Jason T. Creating non-human persons: might it be worth the risk? American Journal of Bioethics 2007 May; 7(5): 52-54. 11 refs. NRCBL: 15.1; 18.1; 22.1; 1.1; 4.4. Comments: Comment on: Henry T. Greely, Mildred K. Cho, Linda F. Hogle, and Debra M. Satz. Thinking about the human neuron mouse. American Journal of Bioethics 2007 May; 7(5): 27-40. Keywords: *chimeras; *moral status; *personhood; animal experimentation; brain; double effect; ethical analysis; human characteristics; philosophy; research ethics; risk; self concept; stem cell transplantation; Proposed Keywords: cognition; species specificity

Greely, Henry T.; Cho, Mildred K.; Hogle, Linda F.; Satz, Debra M. Response to open peer commentaries on “thinking about the human neuron mouse”. American
SECTION I

CHIMERAS AND HYBRIDS

NRCBL: 15.1; 18.1; 22.1; 4.4.  
Keywords: *chimeras; animal experimentation; animal rights; bioethics; brain; ethical analysis; human characteristics; moral status; personhood; research ethics; stem cell transplantation; wedge argument; Proposed Keywords: mice

Keywords: *chimeras; aborted fetuses; advisory committees; animal behavior; animal experimentation; animal welfare; biomedical research; body parts and fluids; brain; embryonic stem cells; embryos; fetal stem cells; government financing; guidelines; human characteristics; human dignity; legal aspects; moral policy; moral status; policy analysis; public policy; research ethics; research support; risks and benefits; stem cell transplantation; terminology; Proposed Keywords: cognition; mice; species specificity; Keyword Identifiers: Great Britain; National Academies of Science; National Institutes of Health; Stanford University; United States

Hoeyer, Klaus; Koch, Lene. The ethics of functional genomics: same, same, but different? Trends in Biotechnology 2006 September; 24(9): 387-389. 17 refs. NRCBL: 15.1; 18.1; 22.1;22.2; 4.4. SC: le.  
Keywords: *chimeras; *genomics; *species specificity; animal experimentation; animal organs; animal rights; deontological ethics; DNA sequences; genetic engineering; genetically modified animals; human dignity; utilitarianism

Keywords: *chimeras; *embryo research; legal aspects; embryonic stem cells; government regulation; Keyword Identifiers: *Great Britain

Keywords: *chimeras; *research embryo creation; *stem cells; *terminology; embryo research; editorial policies; public policy; Proposed Keywords: pluripotent stem cells; Keyword Identifiers: *Great Britain; Nature Medicine


Kmietowicz, Zosia. Public support for hybrid embryos rises, poll shows [news]. BMJ: British Medical Journal 2007 September 8; 335(7618): 466-467. NRCBL: 15.1; 18.1; 18.5.4; 22.1. SC: em.  
Keywords: *chimeras; *public opinion; *research embryo creation; embryos; survey; Keyword Identifiers: Great Britain


Keywords: *chimeras; animal experimentation; animal rights; brain; emotions; human characteristics; moral status; personhood; philosophy; research ethics; stem cell transplantation; Proposed Keywords: mice

Loike, John D.; Tendler, Moshe D. Ethical dilemmas in stem cell research: human-animal chimeras. Tradition 2007 Winter; 40(4): 28-49. 65 fn. NRCBL: 18.5.4; 15.1; 1.2; 18.1; 22.1.  
Keywords: *brain; *chimeras; *embryonic stem cells; *Jewish ethics; *stem cell transplantation; embryo research; embryos; human dignity; species specificity


Keywords: *chimeras; *embryo research; *regulation; public policy; Keyword Identifiers: *Great Britain; *Human Fertilisation and Embryology Authority

Keywords: *cloning; *embryo research; *embryonic stem cells; *government regulation; *nuclear transfer techniques; *political activity; *public policy; *religion; embryos; criminal law; legislation; moral status; politics; reproductive technologies; Keyword Identifiers: *Canada; Right to Life Movement; United States

Keywords: *chimeras; *cloning; *embryo research; *government regulation; *legal aspects; *legislation; *nuclear transfer techniques; *ovum donors; *women's health; criminal law; embryonic stem cells; embryos; reproductive technologies; women; Keyword Identifiers: *Canada

O'Dowd, Adrian. MPs back creation of hybrid embryos [news]. BMJ: British Medical Journal 2007 April 14; 334(7597): 764. NRCBL: 15.1; 18.1; 22.2; 18.5.4.

Keywords: *chimeras; *embryo research; *embryonic stem cells; government regulation; legal aspects; public policy; Keyword Identifiers: *Great Britain; Department of Health (Great Britain); House of Commons Select Committee on Science and Technology (Great Britain); Human Fertilisation and Embryology Authority

O'Dowd, Adrian. UK may allow creation of “cybrids” for stem cell research [news]. BMJ: British Medical Journal 2007 March 10; 334(7592): 495. NRCBL: 18.5.4; 15.1; 22.2; 14.5; 18.1; 22.1. SC: le.

Keywords: *chimeras; *embryo research; *embryonic stem cells; government regulation; public policy; Keyword Identifiers: *Great Britain

Pergament, Eugene. Controversies and challenges of array comparative genomic hybridization in preclinical genetic diagnosis. Genetics in Medicine 2007 September; 9(9): 596-599. NRCBL: 15.2; 15.3; 15.5.

Robert, Jason Scott. The science and ethics of making part-human animals in stem cell biology. FiSEB Journal: Official Publication of the Federation of American Societies for Experimental Biology 2006 May; 20(7): 838-845. 50 refs. NRCBL: 15.1; 18.1; 22.1; 18.5.4; 5.3. SC: rv.

Keywords: *chimeras; *embryonic stem cells; brain; embryo research; ethical review; fetal stem cells; guidelines; historical aspects; human dignity; moral policy; moral status; primates; public policy; regulation; research design; research ethics; review committees; risks and benefits; species specificity; stem cell transplantation; terminology; Proposed Keywords: mice; Keyword Identifiers: National Academy of Sciences; Nineteenth Century; Twentieth Century; United States


Keywords: *chimeras; animal cloning; animal experimentation; animal rights; brain; emotions; ethical analysis; genetically modified animals; human characteristics; moral status; personhood; public opinion; research ethics; stem cell transplantation; Proposed Keywords: mice; species specificity


Keywords: *chimeras; animal behavior; animal experimentation; animal rights; brain; emotions; human characteristics; literature; moral status; neurosciences; personhood; research ethics; stem cell transplantation; Proposed Keywords: mice


Keywords: *chimeras; animal organs; embryos; emotions; organ transplantation; political activity; stem cells; Proposed Keywords: species specificity; Keyword Identifiers: United States

Tabor, Holly K.; Cho, Mildred K. Ethical implications of array comparative genomic hybridization in complex phenotypes: points to consider in research. Genetics in Medicine 2007 September; 9(9): 626-631. NRCBL: 15.3; 15.1; 15.2; 18.2; 18.3.

CIVIL COMMITMENT See INVOLUNTARY COMMITMENT

CLINICAL ETHICISTS See ETHICISTS AND ETHICS COMMITTEES

CLINICAL ETHICS See BIOETHICS AND MEDICAL ETHICS; ETHICISTS AND ETHICS COMMITTEES; NURSING ETHICS AND PHILOSOPHY; PROFESSIONAL ETHICS

CLINICAL ETHICS COMMITTEES See ETHICISTS AND ETHICS COMMITTEES

CLINICAL TRIALS See BIOMEDICAL RESEARCH; HUMAN EXPERIMENTATION

CLONING

See also HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ EMBRYOS AND FETUSES; REPRODUCTIVE TECHNOLOGIES


Keywords: *cloning; *international aspects; embryo research; embryonic stem cells; human dignity; human experimentation; human rights; legal aspects; reproductive technologies; standards; Keyword Identifiers: Council of Europe; Declaration of Helsinki; European Convention on Human Rights and Biomedicine; European Union; Germany; International Convention Against the Reproductive Cloning of Human Beings; Universal Declaration on the Human Genome and Human Rights; United Nations; World Health Organization

Keywords: *animal cloning; cloning; human dignity; mass media; reproductive technologies; risk; risks and benefits; stem cells; trends; Proposed Keywords: research; sheep

Replicator review: Nature has implemented a peer-reviewed policy for strong claims [editorial]. *Nature* 2007 November 22; 450(7169): 457-458. NRCBL: 14.5; 1.3.7; 18.5.4; 15.1; 22.2.

Keywords: *cloning; nuclear transfer techniques; peer review; editorial policies; embryos; primates; Keyword Identifiers: *Nature


Keywords: *cloning; embryonic stem cells; *Islamic ethics; reproductive technologies; Keyword Identifiers: *Iran


Keywords: *cloning; international aspects; *policy making; consensus; cultural pluralism; dissent; embryo research; government regulation; human rights; legal aspects; reproductive technologies; Proposed Keywords: *negotiating; Keyword Identifiers: United Nations


Keywords: *cloning; autonomy; embryo research; ethical analysis; government regulation; human dignity; international aspects; reproductive technologies


Keywords: *cloning; embryonic stem cells; *policy analysis; *policy making; advisory committees; cultural pluralism; embryo research; ethical analysis; ethics committees; federal government; government financing; government regulation; industry; international aspects; legal aspects; moral policy; nuclear transfer techniques; ovum donors; organizational policies; politics; professional organizations; research priorities; research support; resource allocation; state government; values; Keyword Identifiers: United States


Keywords: *cloning; cultural pluralism; ethical analysis; *regulation; *beneficence; children; embryo research; embryonic stem cells; embryos; human dignity; human rights; international aspects; motivation; principle-based ethics; policy analysis; reproductive technologies; utilitarianism; values; Proposed Keywords: *harm


Keywords: *cloning; embryonic stem cells; motivation; reproductive technologies; stem cell transplantation; twinning; Proposed Keywords: blastocysts


Keywords: *cloning; autonomy; embryo research; ethical analysis; government regulation; human dignity; international aspects; reproductive technologies


Keywords: *cloning; cultural pluralism; *embryo research; *genetic techniques; *policy making; *public opinion; *public policy; *regulation; *reproductive technologies; advisory committees; biotechnology; consensus; criminal law; dissent; embryonic stem cells; embryos; focus groups; government regulation; human dignity; international aspects; legal aspects; moral status; nuclear transfer techniques; policy analysis; religion; religious ethics; risks and benefits; survey; values; Keyword Identifiers: *United States; Canada; United Nations


Keywords: *animal cloning; adverse effects; methods; stem cells; trends; Proposed Keywords: sheep
Heng, Boon Chin; Tong, Guo Qing; Stojkovic, Miodrag. The egg-sharing model for human therapeutic cloning research: managing donor selection criteria, the proportion of shared oocytes allocated to research, and amount of financial subsidy given to the donor. Medical Hypotheses 2006; 66(5): 1022-1024. 13 refs. NRCBL: 14.5; 14.4; 18.1.

Keywords: *cloning; *embryo research; *financial support; *incentives; *ovum; *ovum donors; *remuneration; *reproductive technologies; *resource allocation; age factors; patients; scarcity; standards


Holden, Constance. Former Hwang colleague faked monkey data, U.S. says [news]. Science 2007 January 19; 315(5810): 317. NRCBL: 14.5; 1.3.9; 15.1; 18.5.4; 22.2.

Keywords: *animal cloning; *embryonic stem cells; *scientific misconduct; embryos; government regulation; nuclear transfer techniques; research institutes; researchers; universities; Keyword Identifiers: *Park, Jong Hyuk; Hwang, Woo Suk; Korea; Office of Research Integrity; Schatten, Gerald; United States; University of Pittsburgh


Keywords: *Buddhist ethics; *cloning; family relationship; reproductive technologies; Keyword Identifiers: Asia


Keywords: *cloning; *embryonic stem cells; *gene therapy; *risks and benefits; adverse effects; animal cloning; chimeras; embryo disposition; embryo research; embryonic development; gene transfer techniques; human experimentation; nuclear transfer techniques; reproductive technologies


Keywords: *cloning; *human dignity; embryonic stem cells; genetic engineering; germ cells; human rights; preimplantation diagnosis; reproductive technologies; research embryo creation


Identifiers: James A. Thomson.

Keywords: *adult stem cells; *embryonic stem cells; *methods; embryo research; researchers; Keyword Identifiers: *Thomson, James A.; University of Wisconsin; United States


Keywords: *autonomy; *children; *cloning; *ethical analysis; *future generations; *genetic engineering; biotechnology; choice behavior; genetic determinism; genetic enhancement; moral obligations; parents; reproductive rights; reproductive technologies; self concept

Abstract: Some authors have argued that the human use of reproductive cloning and genetic engineering should be prohibited because these biotechnologies would undermine the autonomy of the resulting child. In this paper, two versions of this view are discussed. According to the first version, the autonomy of cloned and genetically engineered people would be undermined because knowledge of the method by which these people have been conceived would make them unable to assume full responsibility for their actions. According to the second version, these biotechnologies would undermine autonomy by violating these people’s right to an open future. There is no evidence to show that people conceived through cloning and genetic engineering would inevitably or even in general be unable to assume responsibility for their actions; there is also no evidence for the claim that cloning and genetic engineering would inevitably or even in general rob the child of the possibility to choose from a sufficiently large array of life plans.


Keywords: *cloning; *public policy; freedom; legal aspects; reproductive technologies; risks and benefits
Keywords: *animal cloning; *food; *political activity; government regulation; mandatory programs; risks and benefits; *Keywords Identifiers: Food and Drug Administration; United States

Keywords: *cloning; *government regulation; *nuclear transfer techniques; *professional autonomy; *researchers; *self regulation; biomedical research; chimera; *criminal law; embryo research; guidelines; legal aspects; professional ethics; public opinion; reproductive technologies; research ethics; scientific misconduct; *Keywords Identifiers: People for the Ethical Treatment of Animals (PETA)

Keywords: *animal cloning; *cloning; animal experimentation; domestic animals; historical aspects; methods; moral policy; political activity; public opinion; *Keywords Identifiers: People for the Ethical Treatment of Animals (PETA)

Keywords: *cloning; eugenics; family relationship; genetic engineering; genetic enhancement; methods; moral policy; public policy; reproductive technologies; research embryo creation; risks and benefits

Identifiers: Italy. 
Keywords: *cloning; *mass media; morality; public opinion; reproductive technologies; self concept; *Proposed Keywords: hyperbole; *Keywords Identifiers: *Italy; *Raelians; *Clonaid


Keywords: *cloning; *Jewish ethics; embryo research; reproductive technologies


Keywords: *cloning; embryo research; embryonic stem cells; moral policy; recombinant DNA research; reproductive technologies; stem cell transplantation; *Proposed Keywords: regenerative medicine


Keywords: *Buddhist ethics; *cloning; embryo research; human dignity; reproductive technologies; *Keywords Identifiers: Asia


Keywords: *animal cloning; *food; adverse effects; animal welfare; genetic diversity; genetically modified animals; genetically modified plants; government regulation; industry; mandatory programs; nuclear transfer techniques; *Keywords Identifiers: Food and Drug Administration; United States

SECTION I  CLONING

101-123. 47 fn. NRCBL: 14.5; 1.1; 1.2; 4.4; 15.1; 18.5.4. SC: an.
  Keywords: *cloning; *embryos; *genetic identity; *personhood; *philosophy; *theology; embryo research; ethical analysis; genetic engineering; human characteristics; human genome; Human Genome Project; nuclear transfer techniques; research priorities; social impact; twinning; Proposed Keywords: species specificity; Keyword Identifiers: Scotus, John Dunn

  Keywords: *cloning; *reproductive technologies; embryonic stem cells; international aspects; legal aspects; ovum donors; public policy; research embryo creation; value of life; terminology; Keyword Identifiers: *Europe; European Group on Ethics in Science and New Technologies; European Society of Human Reproduction and Embryology; United Nations

  Keywords: *cloning; *embryo research; *embryos; *political activity; embryonic stem cells; international aspects; legislation; ovum donors; patents; public policy; terminology; Keyword Identifiers: *United States; Asia; Europe

  Keywords: *cloning; *international aspects; *policy making; biotechnology; consensus; embryo research; government regulation; legal aspects; reproductive technologies; standards; Proposed Keywords: negotiating; Keyword Identifiers: European Union; United Nations

  Keywords: *Christian ethics; *cloning; embryo research; genetic intervention; human dignity; personhood; reproductive technologies

  Keywords: *embryo research; embryos; human dignity; legal aspects; personhood; reproductive technologies; Keyword Identifiers: Germany


  Keywords: *cloning; *embryo research; *embryonic stem cells; *embryos; *ethical analysis; *moral status; *philosophy; beginning of life; in vitro fertilization; personhood; reproduction; Proposed Keywords: technology; Keyword Identifiers: *Heidigger, Martin; Habermas, Jürgen; Kant, Immanuel

Abstract: Debates about the legitimacy of embryonic stem-cell research have largely focused on the type of ethical value that should be accorded to the human embryo in vitro. In this paper, I try to show that, to broaden the scope of these debates, one needs to articulate an ontology that does not limit itself to biological accounts, but that instead focuses on the embryo’s place in a totality of relevance surrounding and guiding a human practice. Instead of attempting to substantiate the ethical value of the embryo exclusively by pointing out that it has potentiality for personhood, one should examine the types of practices in which the embryo occurs and focus on the ends inherent to these practices. With this emphasis on context, it becomes apparent that the embryo’s ethical significance can only be understood by elucidating the attitudes that are established towards it in the course of specific activities. The distinction between fertilized embryos and cloned embryos proves to be important in this contextual analysis, since, from the point of view of practice, the two types of embryos appear to belong to different human practices: (assisted) procreation and medical research, respectively. In my arguments, I highlight the concepts of practice, technology, and nature, as they have been analyzed in the phenomenological tradition, particularly by Martin Heidegger. I come to the conclusion that therapeutic cloning should be allowed, provided that it turns out to be a project that benefits medical science in its aim to battle diseases. Important precautions have to be taken, however, in order to safeguard the practice of procreation from becoming perverted by the aims and attitudes of medical science when the two practices intersect. The threat in question needs to be taken seriously, since it concerns the structure and goal of practices which are central to our very self understanding as human beings.

Swift, Jennifer. Eggs don’t come cheap. New Scientist 2007 December 8-14; 196(2633): 22. NRCBL: 14.5; 14.2; 19.5; 18.5.3; 18.5.4; 15.1; 9.5.5.
  Keywords: *cloning; *ovum donors; *research embryo creation; *risk; *stem cells; adverse effects; conflict of interest; hormones; nontherapeutic research; remuneration; risks and benefits; women; Proposed Keywords: pluripotent stem cells

  Keywords: *cloning; *moral policy; autonomy; beginning of life; cultural pluralism; embryo research; embryonic development; embryonic stem cells; ethical analysis; motivation; mother fetus relationship; reproductive technologies
Keywords: *cloning; human characteristics; human dignity; informal social control; regulation; reproductive technologies

Keywords: *animal cloning; *cloning; *historical aspects; *research embryo creation; embryo research; embryonic stem cells; international aspects; mass media; public opinion; reproductive technologies; trends; Proposed Keywords: sheep; Keyword Identifiers: Twentieth Century; Twenty-First Century

Keywords: *animal cloning; *cloning; *historical aspects; *research embryo creation; embryo research; embryonic stem cells; international aspects; mass media; public opinion; reproductive technologies; trends; Proposed Keywords: Sheep; Keyword Identifiers: Twentieth Century; Twenty-First Century

Keywords: *cloning; adolescents; adults; animal cloning; embryos; genes; government regulation; international aspects; legislation; moral policy; morality; nuclear transfer techniques; public opinion; public policy; reproductive technologies; research embryo creation; state government; stem cells; Keyword Identifiers: United States

Keywords: *cloning; *human dignity; *human rights; *international aspects; embryos; freedom; government regulation; legal aspects; reproductive technologies; standards; Keyword Identifiers: Germany; United Nations; Universal Declaration of Human Rights

**CLONING/LEGAL ASPECTS**

Keywords: *cloning; genetic engineering; *germ cells; *international aspects; *regulation; human rights; legal aspects; nuclear transfer techniques; reproductive technologies; Keyword Identifiers: Convention on the Preservation of the Human Species; United States


Keywords: *cloning; *embryo research; *legal aspects; *reproductive technologies; *wedge argument; criminal law; biomedical technologies; genetic engineering; government regulation; nuclear transfer techniques; risks and benefits; Proposed Keywords: Logic; Keyword Identifiers: *Canada


Keywords: *cloning; *embryo research; *embryonic stem cells; *embryos; *legal aspects; advisory committees; chimeras; government regulation; legislation; politics; public policy; research embryo creation; Keyword Identifiers: *Australia

Keywords: *cloning; *legal aspects; constitutional law; federal government; government regulation; legislation; reproductive technologies; state government; Keyword Identifiers: *United States

Keywords: *cloning; *embryo research; *embryonic stem cells; *government regulation; *legal aspects; *nuclear transfer techniques; *policy making; commodification; criminal law; cultural pluralism; embryos; international aspects; legislation; moral status; public opinion; public pol-
icy; reproductive technologies; Keyword Identifiers: *Canada

Abstract: Somatic cell nuclear transfer (SCNT) remains a controversial technique, one that has elicited a variety of regulatory responses throughout the world. On March 29, 2005, Canada’s Assisted Human Reproduction Act came into force. This law prohibits a number of research activities, including SCNT. Given the pluralistic nature of Canadian society, the creation of this law stands as an interesting case study of the policy-making process and how and why a liberal democracy ends up making the relatively rare decision to use a statutory prohibition, backed by severe penalties, to stop a particular scientific activity. In this article, we provide a comprehensive and systematic legal analysis of the legislative process and parliamentary debates associated with the passage of this law.

Keywords: *cloning; *human dignity; *legal aspects; embryo research; moral status; reproductive technologies; Keyword Identifiers: *Germany

Keywords: *cloning; *legal aspects; embryo research; embryos; genetic engineering; human dignity; reproductive technologies; Keyword Identifiers: *Germany


Keywords: *cloning; *international aspects; *legal aspects; government regulation; human experimentation; informed consent; moral policy; reproductive technologies; risks and benefits; Keyword Identifiers: United Nations


Keywords: *cloning; *embryo research; *embryonic stem cells; *government regulation; *nuclear transfer techniques; *political activity; *public policy; *religion; embryos; criminal law; legislation; moral status; politics; reproductive technologies; Keyword Identifiers: *Canada; Right to Life Movement; United States


Keywords: *chimeras; *cloning; *embryo research; *government regulation; *legal aspects; *legislation; *nuclear transfer techniques; *ovum donors; *women’s health; criminal law; embryonic stem cells; embryos; reproductive technologies; women; Keyword Identifiers: *Canada

Keywords: *cloning; *embryo research; *government regulation; *legal aspects; *legislation; *morality; *public policy; *socioeconomic factors; *state government; abortion; biotechnology; comparative studies; government regulation; policy analysis; policy making; politics; religion; reproductive technologies; survey; Proposed Keywords: demography; Keyword Identifiers: *Canada


Keywords: *cloning; *criminal law; *embryo research; *government regulation; *morality; *nuclear transfer techniques; *public policy; legal aspects; public opinion; Keyword Identifiers: Canada

CODES OF ETHICS


American Association of Electrodiagnostic Medicine. Guidelines for ethical behavior relating to clinical practice issues in electrodiagnostic medicine. Muscle and Nerve

African Organization for Medical Sciences [IOMS]. Islamic code of medical ethics: doctor’s duty in war time. SC (Subject Captions): cs=case studies em=empirical le=legal po=popular rv=review


Abstract: INTRODUCTION: Consultation methods differ between medical practitioners depending on the individual setting. However, the central tenet to the doctor-patient relationship is the issue of confidentiality. This prospective survey highlights patient attitudes towards consultation methods in the setting of an ophthalmic outpatient department. METHOD: Questionnaires were completed by 100 consecutive patients, who had been seen by an ophthalmologist in a single room, which had a joint doctor-patient consultation occurring simultaneously. RESULTS: Each question of all 100 questionnaires was completed. 58% of patients were not concerned about sharing a consultation room with another patient or doctor. However, this did not equate to the 49% of patients who were indifferent to discussing issues in the joint consultation room. The most common factor was the general issue of confidentiality. DISCUSSION: Ensuring total patient confidentiality may be deemed more necessary for certain medical specialities than for others, as seen in the practice of separate medical records in genitourinary medicine, for instance. However, with regard to patient consultations, the same level of confidentiality should be afforded across all specialties, and such factors should be borne in mind when planning outpatient clinics.


Coombes, Rebecca. Medical records: are patients’ secrets up for grabs? BMJ: British Medical Journal 2007 January 6; 334(7583): 16-17. NRCBL: 8.4; 1.3.12; 8.2. Identifiers: Great Britain (United Kingdom).


Draper, Heather; MacDiarmad-Gordon, Adam; Strumilo, Laura; Teuten, Bea; Update, Eleanor. Virtual Clinical Ethics Committee, case 5: can we give a son access to his mother’s psychiatric notes? Clinical Ethics 2007 March; 2(1): 8-14. NRCBL: 8.4; 17.1; 9.6. SC: cs.


Haynes, Charlotte L.; Cook, Gary A.; Jones, Michael A. Legal and ethical considerations in processing patient-identifiable data without parental consent: lessons learnt from developing a disease register. Journal of Medical Ethics 2007 May; 33(5): 302-307. NRCBL: 8.4; 18.2; 18.3. SC: le. Identifiers: Great Britain (United Kingdom). Abstract: The legal requirements and justifications for collecting patient-identifiable data without patient consent were examined. The impetus for this arose from legal and ethical issues raised during the development of a population-based disease register. Numerous commentaries and case studies have been discussing the impact of the Data Protection Act 1998 (DPA1998) and Caldicott principles of good practice on the uses of personal data. But uncertainty still remains about the legal requirements for processing patient-identifiable data without patient consent for research purposes. This is largely owing to ignorance, or misunderstandings of the implications of the common law duty of confidentiality and section 60 of the Health and Social Care Act 2001. The common law duty of confidentiality states that patient-identifiable data should not be provided to third parties, regardless of compliance with the DPA1998. It is an obligation derived from case law, and is open to interpretation. Compliance with section 60 ensures that collection of patient-identifiable data without patient consent is lawful despite the duty of confidentiality. Fears regarding the duty of confidentiality have resulted in a common misconception that section 60 must be complied with. Although this is not the case, section 60 support does provide the most secure basis in law for collecting such data. Using our own experience in developing a disease register as a backdrop, this article will clarify the procedures, risks and potential costs of applying for section 60 support.


Abstract: This survey set out to explore occupational health professionals’ courses of action with respect to privacy in a situation of dual loyalty between employees and employers. A postal questionnaire was sent to randomly selected potential respondents. The overall response rate was 64%; 140 nurses and 94 physicians returned the questionnaire. Eight imaginary cases involving an ethical dilemma of privacy were presented to the respondents. Six different courses of action were constructed within the set alternatives proposed. The study indicated that privacy as an absolute value is not in the interest of either employees or employers. It also showed that, where dual loyalty is concerned, the most valid course of action in dealing with sensitive subjects such as drug and work community problems, sexual harassment and sick leave is to rely on tripartite co-operation. If they maintain their professional independence and impartiality, health professionals are well placed to succeed in this challenging task; if not, there are bound to be severe violations of privacy.


SECTION I  CONFIDENTIALITY


Keywords: *genetic privacy; *nurse’s role; genetic information; organizational policies; professional organizations


Abstract: Electronic medical record keeping has led to increased interest in analyzing historical patient data to improve care delivery. Such research use of patient data, however, raises concerns about confidentiality and institutional liability. Institutional review boards must balance patient data security with a researcher’s ability to explore potentially important clinical relationships. We considered the issues involved when patient records from health care institutions are used in medical research. We also explored current regulations on patient confidentiality, the need for identifying information in research, and the effectiveness of deidentification and data security. We will present an algorithm for researchers to use to think about the data security needs of their research, and we will introduce a vocabulary for documenting these techniques in proposals and publications.


Miller, Seumas. Privacy, confidentiality, and the treatment of drug addicts. In: Kleinig, John; Einstein, Stanley, eds. Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 467-483. NRCLB: 8.4; 9.5.9; 4.2; 1.1; 9.5.6.

Abstract: Paper-based privacy policies fail to resolve the new changes posed by electronic healthcare. Protecting patient privacy through electronic systems has become a serious concern and is the subject of several recent studies. The shift towards an electronic privacy policy introduces new ethical challenges that cannot be solved merely by technical measures. Structured Patient Privacy Policy (S3P) is a software tool assuming an automated electronic privacy policy in an electronic healthcare setting. It is designed to simulate different access levels and rights of various professionals involved in healthcare in order to assess the emerging ethical problems. The authors discuss ethical issues concerning electronic patient privacy policies that have become apparent during the development and application of S3P.

Moore, Ilene N.; Snyder, Samuel Leason; Miller, Cynthia; An, Angel Qi; Blackford, Jennifer U.; Zhou, Chuan; Hickson, Gerald B. Confidentiality and privacy


Abstract: CONTEXT: Anecdotal reports suggest that the Health Insurance Portability and Accountability Act Privacy Rule (HIPAA Privacy Rule) may be affecting health research in the United States. OBJECTIVE: To survey epidemiologists about their experiences with the HIPAA Privacy Rule. DESIGN, SETTING, AND PARTICIPANTS: Thirteen societies of epidemiology distributed a national Web-based survey: 2805 respondents accessed the survey Web site and 1527 eligible professionals anonymously answered questions. MAIN OUTCOME MEASURES: Responses related influences such as research delays and added cost after Privacy Rule implementation, frequency and type of Privacy Rule-related institutional review board modifications, level of difficulty obtaining deidentified data and waivers, experiences with multisite studies, and perceived participant privacy benefits under the rule. Respondents ranked their perceptions of Privacy Rule influence on 5-point Likert scales. RESULTS: A total of 875 (67.8%) respondents reported that the HIPAA Privacy Rule has made research more difficult at a level of 4 to 5 on a Likert scale, in which 5 indicates a great deal of added cost and time to study completion. A total of 684 (52.1%) of respondents identified a “most affected” protocol. Respondents indicated that the proportion of institutional review board applications in which the Privacy Rule had a negative influence on human subjects (participants) protection was significantly greater than the proportion in which it had a positive influence (P .001). CONCLUSION: In this national survey of clinical scientists, only a quarter perceived that the rule has enhanced participants’ confidentiality and privacy, whereas the HIPAA Privacy Rule was perceived to have a substantial, negative influence on the conduct of human subjects health research, often adding uncertainty, cost, and delay.


Keywords: *access to information; *confidentiality; *death; *disclosure; *medical records; family members; genetic information; legal aspects; physician patient relationship; privacy; professional family relationship; Proposed Keywords: harm; Keyword Identifiers: United States

Rothstein, Mark A.; Talbott, Meghan K. Compelled authorizations for disclosure of health records: magnitude and implications. American Journal of Bioethics 2007 March; 7(3): 38-45. NRCBL: 8.4; 1.3.12. Abstract: Each year individuals are required to execute millions of authorizations for the release of their health records as a condition of employment, applying for various types of insurance, and submitting claims for bene-
fits. Generally, there are no restrictions on the scope of information released pursuant to these compelled authorizations, and the development of a nationwide system of interoperable electronic health records will increase the amount of health information released. After quantifying the extent of these disclosures, this article discusses why it is important to limit disclosures of health information for nonmedical purposes as well as how it may be possible to do so.


Stirewalt, Karolyn. To release or not to release? When is it all right for physicians who treat injured workers to release medical information without their consent? Minnesota Medicine 2007 September; 90(9): 52-53. NRCBL: 8.4; 16.3.


Thomas, N.; Murray, E.; Rogstad, K.E. Confidentiality is essential if young people are to access sexual health services. International Journal of STD and AIDS 2006 August; 17(8): 525-529. NRCBL: 8.4; 9.5.7; 10.


Whiddett, Richard; Hunter, Inga; Engelbrecht, Judith; Handy, Jocelyn. Patients’ attitudes towards sharing their health information. International Journal of Medical Informatics 2006 July; 75(7): 530-541. NRCBL: 8.4; 1.3.12; 1.3.5; 21.1.

Wolff, Katharina; Brun, Wibecke; Kvale, Gerd; Nordin, Karin. Confidentiality versus duty to inform — an empirical study on attitudes towards the handling of genetic information. American Journal of Medical Genetics. Part A 2007 January 15; 143(2): 142-148. NRCBL: 8.4; 15.3; 8.3.1; 8.2.

Wynia, Matthew K. Breaching confidentiality to protect the public: evolving standards of medical confidentiality for military detainees. American Journal of Bioethics 2007 August; 7(8): 1-5. NRCBL: 8.4; 9.5.1; 1.3.5. Abstract: Confidentiality is a core value in medicine and public health yet, like other core values, it is not absolute. Medical ethics has typically allowed for breaches of confidentiality when there is a credible threat of significant harm to an identifiable third party. Medical ethics has been less explicit in spelling out criteria for allowing breaches of confidentiality to protect populations, instead tending to defer these decisions to the law. But recently, issues in military detention settings have raised the profile of decisions to breach medical confidentiality in efforts to protect the broader population. National and international ethics documents say little about the confidentiality of detainee medical records. But initial decisions to use detainee medical records to help craft coercive interrogations led to widespread condemnation, and might have contributed to detainee health problems, such as a large number of suicide attempts several of which have been successful. More recent military guidance seems to reflect lessons learned from these problems and does more to protect detainee records. For the public health system, this experience is a reminder of the importance of confidentiality in creating trustworthy, and effective, means to protect the public’s health.

CONTRACEPTION


Catholic hospitals will comply with flawed law [news]. America 2007 October 15; 197(11): 7. NRCBL: 11.1; 9.7; 1.2; 9.1.
Connecticut Catholic hospitals will comply with Plan B law. Origins 2007 October 11; 37(18). NRCBL: 11.1; 1.2; 9.7; 9.5.5.


Austriaco, Nicanor Pier Giorgio. Is Plan B an abortifacient? A critical look at the scientific evidence. National Catholic Bioethics Quarterly 2007 Winter; 7(4): 703-707. NRCBL: 11.1; 9.7; 12.3. Abstract: On September 27, 2007, the Catholic bishops of Connecticut announced that they would allow the four Catholic hospitals in their state to comply with the state’s emergency contraception law. The statement has generated much controversy and criticism from those who are convinced that Plan B is an abortifacient. This essay summarizes and critically reviews the scientific studies that have attempted to uncover the mechanism of action of levonorgestrel, the active drug in the contraceptive commonly known as Plan B. Mounting and recent evidence suggests that this emergency contraceptive has little or no effect on post-fertilization events.


Dailard, Cynthia; Richardson, Chinué Turner. Teenagers’ access to confidential reproductive health services. Guttmacher Report on Public Policy 2005 November; 8(4): 6-11. NRCBL: 11.2; 12.4.1; 8.3.2; 8.4. SC: le.


Douglas, Joshua A. When is a “minor” also an “adult”?: an adolescent’s liberty interest in accessing contraceptives from public school distribution programs. Willamette Law Review 2007 Summer; 43(4): 545-576. NRCBL: 11.2; 8.3.1. SC: le.


Gast, Kristen Marttila. Cold comfort pharmacy: pharmacist tort liability for conscientious refusals to dispense emergency contraception. Texas Journal of Women and the

SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
SECTION I

CONTRACEPTION

Law 2007 Spring; 16(2): 149-184. NRCBL: 11.1; 9.7; 7.1; 11.4. SC: le.

Guilhem; Dirce; Azevedo, Anamaria Ferreira. Brazilian public policies for reproductive health: family planning, abortion and prenatal care. Developing World Bioethics 2007 August; 7(2): 68-77. NRCBL: 11.1; 9.5.5; 12.4.1; 12.5.1.

Abstract: This study is an ethical reflection on the formulation and application of public policies regarding reproductive health in Brazil. The Integral Assistance Program for Women’s Health (PAISM) can be considered advanced for a country in development. Universal access for family planning is foreseen in the Brazilian legislation, but the services do not offer contraceptive methods for the population in a regular and consistent manner. Abortion is restricted by law to two cases: risk to the woman’s life and rape. This reality favors the practice of unsafe abortion, which is the third largest cause of maternal death in Brazil. Legal abortion is regulated by the State and the procedure is performed in public health centers. However, there is resistance on the part of professionals to attend these women. Prenatal care is a priority strategy for promoting the quality of life of these women and of future generations. Nonetheless, it is still difficult for these women to access the prenatal care services and to have the required number of consultations. Moreover, managers and health professionals need to be made aware of the importance of implementing the actions indicated by the public policies in the area of sexual and reproductive health, favoring respect for autonomy in a context of personal freedom.


Abstract: The problem of feeling guilty about a pregnancy loss is suggested to be primarily a moral matter and not a medical or psychological one. Two standard approaches to women who blame themselves for a loss are first introduced, characterised as either psychologistic or deterministic. Both these approaches are shown to under-determine the autonomy of the mother by depending on the notion that the mother is not culpable for the loss if she “could not have acted otherwise”. The inability to act otherwise is explained as not being as strong a determinant of culpability as it may seem at first. Instead, people’s culpability for a bad turn of events implies strongly that they have acted for the wrong reasons, which is probably not true in the case of women who have experienced a loss of pregnancy. The practical conclusion of this paper is that women who feel a sense of guilt in the wake of their loss have a good reason to reject both the psychologistic and the deterministic approaches to their guilt—that they are justified in feeling upset about what has gone wrong, even responsible for the life of the child, but are not culpable for the unfortunate turn of events.


Ranney, Megan L.; Gee, Erin M.; Merchant, Roland C. Nonprescription availability of emergency contraception

**Schneider, A. Patrick.** Emergency contraception (EC) for victims of rape: ten myths. *Linacre Quarterly* 2007 August; 74(3): 181-203. NRCBL: 11.1; 9.7; 1.2; 12.1.


**Wilan, Ken.** Susan Wood. *Nature Biotechnology* 2007 May 25(5): 495. NRCBL: 11.1; 5.3; 1.3.5.

**Williams, Anne.** The morning-after pill. *Human Reproduction and Genetic Ethics: An International Journal* 2007; 13(1): 8-36. NRCBL: 11.1; 9.7; 12.1; 9.5.1; 10; 8.3.2; 1.1.

**Zezima, Katie.** Not all are pleased at plan to offer birth control at Maine middle school. *New York Times* 2006 August 9.


Keywords: *cryopreservation; *dissent; *embryo disposition; *embryos; *ethical analysis; *genetic materials; *genetic relatedness ties; *in vitro fertilization; *parents; *property rights; donors; embryo transfer; genetic information; germ cells; informed consent; legal aspects; philosophy; reproductive rights; Proposed Keywords: exceptionism; Keyword Identifiers: Evans v. Americus Healthcare Ltd.; Great Britain

Abstract: Recent ethical and legal challenges have arisen concerning the rights of individuals over their IVF embryos, leading to questions about how, when the wishes of parents regarding their embryos conflict, such situations ought to be resolved. A notion commonly invoked in relation to frozen embryo disputes is that of reproductive rights: a right to have (or not to have) children. This has sometimes been interpreted to mean a right to have, or not to have, one’s own genetic children. But can such rights legitimately be asserted to give rise to claims over embryos? We examine the question of property in genetic material as applied to gametes and embryos, and whether rights over genetic information extend to grant control over IVF embryos. In particular we consider the purported right not to have one’s own genetically related children from a property-based perspective. We argue that even if we concede that such (property) rights do exist, those rights become limited in scope and application upon engaging in reproduction. We want to show that once an IVF embryo is created for the purpose of reproduction, any right not to have genetically-related children that may be based in property rights over genetic information is ceded. There is thus no right to prevent one’s IVF embryos from being brought to birth on the basis of a right to avoid having one’s own genetic children. Although there may be reproductive rights over gametes and embryos, these are not grounded in genetic information.


**Heng, Boon Chin.** Donation of surplus frozen embryos for stem cell research or fertility treatment — should medical professionals and healthcare institutions be allowed to exercise undue influence on the informed decision of their former patients? *Journal of Assisted Reproduction and Genetics* 2006 September-October; 23(9-10): 381-382. NRCBL: 14.6; 15.1; 18.5.4; 7.1; 8.3.1.

CULTURAL PLURALISM


Widdows, Heather. Is global ethics moral neo-colonialism? An investigation of the issue in the context of bioethics. Bioethics 2007 July; 21(6): 305-315. NRCBL: 21.7; 1.1. Abstract: This paper considers the possibility and desirability of global ethics in light of the claim that ‘global ethics’ in any form is not global, but simply the imposition of one form of local ethics – Western ethics – and, as such, a form of moral neo-colonialism. The claim that any form of global ethics is moral neo-colonialism is outlined using the work of a group of ‘developing world bioethicists’ who are sceptical of the possibility of global ethics. The work of virtue ethicists is then introduced and compared to the position of the developing world bioethicist in order to show that the divide between ‘Western’ and ‘non-Western’ ethics is exaggerated. The final section of the paper turns to the practical arena and considers the question of global ethics in light of practical issues in bioethics. The paper concludes that practical necessity is driving the creation of global ethics and thus the pertinent question is no longer ‘Whether global ethics?’, but ‘Why global ethics?’.

DEATH AND DYING


Garment, Ann; Lederer, Susan; Rogers, Naomi; Boult, Lisa. Let the dead teach the living: the rise of body bequeathal in 20th century America. Academic Medicine 2007 October; 82(10): 1000-1005. NRCBL: 20.1; 8.3.3; 19.5; 2.2; 7.1.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme
DEATH AND DYING/ATTITUDES TO DEATH

See also ADVANCE DIRECTIVES; ASSISTED SUICIDE; EUTHANASIA AND ALLOWING TO DIE

Ackerman, Felicia Nimue. Patient and family decisions about life-extension and death. In: Rhodes, Rosamond; Francis, Leslie P.; Silvers, Anita, eds. The Blackwell Guide to Medical Ethics. Malden, MA: Blackwell Pub., 2007: 52-68. NRCBL: 20.3.3; 20.5.1; 4.4; 20.5.4.

Bito, Seiji; Matsumura, Shinji; Singer, Marjorie Kagawa; Meredith, Lisa S.; Fukushima, Shunichi; Wenger, Neil S. Acculturation and end-of-life decision making: comparison of Japanese and Japanese-American focus groups. Bioethics 2007 June; 21(5): 251-262. NRCBL: 20.3.3; 21.7; 20.4.1; 20.5.1. SC: em.

Abstract: Variation in decision-making about end-of-life care among ethnic groups creates clinical conflicts. In order to understand changes in preferences for end-of-life care among Japanese who immigrate to the United States, we conducted 18 focus groups with 122 participants: 65 English-speaking Japanese Americans, 29 Japanese-speaking Japanese Americans and 28 Japanese living in Japan. Negative feelings toward living in adverse health states and receiving life-sustaining treatment in such states permeated all three groups. Fear of being meiwaku, a physical, psychological or financial caregiving burden on loved ones, was a prominent concern. They preferred to die pokkuri (popping off) before they become end stage or physically frail. All groups preferred group-oriented decision-making with family. Although advance directives were generally accepted, Japanese participants saw written directives as intrusive whereas Japanese Americans viewed them mainly as tools to reduce conflict created by dying person’s wishes and a family’s kazoku no jo — responsibility to sustain the dying patient. These findings suggest that in the United States Japanese cultural values concerning end-of-life care and decision-making process are largely preserved.


Hsin, Dena Hsin-Chen; Macer, Darryl. Comparisons of life images and end-of-life attitudes between the elderly in Taiwan and New Zealand. Journal of Nursing Research 2006 September; 14(3): 198-208. NRCBL: 20.3.1; 1.2; 20.4.1; 21.1.

SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
DEATH AND DYING/DETERMINATION OF DEATH


Bagheri, A. Individual choice in the definition of death. Journal of Medical Ethics 2007 March; 33(3): 146-149. NRCBL: 20.2.1; 19.5; 1.1. SC: le. Identifiers: Japan. Abstract: While there are numerous doubts, controversies and lack of consensus on alternative definitions of human death, it is argued that it is more ethical to allow people to choose either cessation of cardio-respiratory function or loss of entire brain function as the definition of death based on their own views. This paper presents the law of organ transplantation in Japan, which allows people to decide whether brain death can be used to determine their death in agreement with their family. Arguably, Japan could become a unique example of individual choice in the definition of death if the law is revised to allow individuals choose definition of death independently of their family. It suggests that such an approach is one of the reasonable policy options a country can adopt for legislation on issues related to the definition of death.


Bernat, James L. Ethical issues in brain death and multiorgan transplantation. Neurologic Clinics 1989 November; 7(4): 715-728. NRCBL: 20.2.1; 19.5; 9.5.5; 1.2; 18.5.7.


Doig, Christopher James; Young, Kimberly; Teitelbaum, Jeannie; Shemie, Sam D. Brief survey: determining brain death in Canadian intensive care units = Enquête ponctuelle: la détermination de la mort encéphalique dans les units de soins intensifs au Canada.


Eberl, Jason T. Dualist and animalist perspectives on death: a comparison with Aquinas. National Catholic Bioethics Quarterly 2007 Autumn; 7(3): 477-489. NRCBL: 20.2.1; 1.1; 4.4; 1.2.


Grinziekakis, Archimandrite Makarios. Legal and ethical issues associated with brain death. Ethics and Medicine: An International Journal of Bioethics 2007 Summer; 23(2): 113-117. NRCBL: 20.2.1; 20.2.2; 20.5.4; 8.3.3; 19.5; 1.1; 4.4. SC: le.


Machado, Calixto; Korein, Julius; Ferrer, Yazmina; Portela, Liana; de la C. García, María; Manero, José M. The concept of brain death did not evolve to benefit organ transplants. Journal of Medical Ethics 2007 April; 33(4): 197-200. NRCBL: 20.2.1; 19.5; 2.2.

Abstract: Although it is commonly believed that the concept of brain death (BD) was developed to benefit organ transplants, it evolved independently. Transplantation owed its development to advances in surgery and immunosuppressive treatment; BD owed its origin to the development of intensive care. The first autotransplant was achieved in the early 1900s, when studies of increased intracranial pressure causing respiratory arrest with preserved heartbeat were reported. Between 1902 and 1950, the BD concept was supported by the discovery of EEG, Crile’s definition of death, the use of EEG to demonstrate abolition of brain potentials after ischaemia, and Crafoord’s statement that death was due to cessation of blood flow. Transplantation saw the first xenotransplant in humans and the first unsuccessful kidney transplant from a cadaver. In the 1950s, circulatory arrest in coma was identified by angiography, and the death of the nervous system and coma dépassé were described. Murray performed the first successful kidney transplant. In the 1960s, the BD concept and organ transplants were instantly linked when the first kidney transplant using a brain-dead donor was performed; Schwab proposed to use EEG in BD; the Harvard Committee report and the Sydney Declaration appeared; the first successful kidney, lung and pancreas transplants using cadaveric (not brain-dead) donors were achieved; Barnard performed the first human heart transplant. This historical review demonstrates that the BD concept and organ transplantation arose separately and advanced in parallel, and only began to progress together in the late 1960s. Therefore, the BD concept did not evolve to benefit transplantation.


Abstract: On 5 August 1968, publication of the Harvard Committee’s report on the subject of “irreversible coma” established a standard for diagnosing death on neurological grounds. On the same day, the 22nd World Medical Assembly met in Sydney, Australia, and announced the Declaration of Sydney, a pronouncement on death, which is less often quoted because it was overshadowed by the impact of the Harvard Report. To put those events into present-day perspective, the authors reviewed all papers published on this subject and the World Medical Association web page and documents, and corresponded with Dr. A G Romualdez, the son of Dr. A Z Romualdez. There was vast neurological expertise among some of the Harvard Committee members, leading to a comprehensive and practical clinical description of the brain death syndrome and the way to diagnose it. This landmark account had a global medical and social impact on the issue of human death, which simultaneously lessened reception of the Declaration of Sydney. Nonetheless, the Declaration of Sydney faced the main conceptual and philosophical issues on human death in a bold and forthright manner.
This statement differentiated the meaning of death at the cellular and tissue levels from the death of the person. This was a pioneering view on the discussion of human death, published as early as in 1968, that should be recognised by current and future generations.


DEATH AND DYING/ TERMINAL CARE


Barilan, Y. Michael. The new Israeli law on the care of the terminally ill: conceptual innovations waiting for implementation. Perspectives in Biology and Medicine 2007 Autumn; 50(4): 557-571. NRCBL: 20.4.1; 1.2; 20.5.3; 20.5.2; 20.5.4; 1.2. SC: le.


Bentley, Philip J. The shattered vessel: the dying person in Jewish law and ethics. Loyola University Chicago Law Journal 2006 Winter; 37(2): 433-454. NRCBL: 20.4.1; 1.2; 4.4; 20.51.


Casarett, David J.; Quill, Timothy E. “I’m not ready for hospice”: strategies for timely and effective hospice decisions. Annals of Internal Medicine 2007 March 20; 146(6): 443-449. NRCBL: 20.4.1. Abstract: Hospice programs offer unique benefits for patients who are near the end of life and their families, and growing evidence indicates that hospice can provide high-quality care. Despite these benefits, many patients do not enroll in hospice, and those who enroll generally do so very late in the course of their illness. Some barriers to hospice referral arise from the requirements of hospice eligibility, which will be difficult to eliminate without major changes to hospice organization and financing. However, the challenges of discussing hospice create other barriers that are more easily remedied. The biggest communication barrier is that physicians are often unsure of how to talk with patients clearly and directly about their poor prognosis and limited treatment options (both requirements of hospice referral) without depriving them of hope. This article describes a structured strategy for discussing hospice, based on techniques of effective communication that physicians use in other “bad news"
situations. This strategy can make hospice discussions both more compassionate and more effective.


Engström, Joakim; Bruno, Erik; Holm, Birgitta; Hellzén, Ove. Palliative sedation at end of life — a systematic literature review. *European Journal of Oncology Nursing* 2007 February; 11(1): 26-35. NRCBL: 20.4.1; 4.4; 4.1.3.


Griffith, Richard. Controlled drugs and the principle of double effect. *British Journal of Community Nursing* 2006 August; 11(8): 352, 354-357. NRCBL: 20.4.1; 9.7; 4.4; 1.1; 4.1.3.

Han, Sung-Suk. Ethical issues in nursing care at the end of life. *Dolentiun Hominiun* 2007; 22(2): 28-32. NRCBL: 20.4.1; 4.1.3; 4.4; 1.1.


Kmietowicz, Zosia. Dying patients are often not told of the closeness of death [news]. *BMJ: British Medical Journal* 2007 December 8; 335(7631): 1176. NRCBL: 20.4.1; 8.2.


Linder, John F.; Meyers, Frederick J. Palliative care for prison inmates: “don’t let me die in prison”. *JAMA: The Journal of the American Medical Association* 2007 August 22-29; 298(8): 894-901. NRCBL: 20.4.1; 9.5.1. Abstract: The number of older inmates in US correctional facilities is increasing and with it the need for quality palliative health care services. Morbidity and mortality are high in this population. Palliative care in the correctional setting includes many of the challenges faced in the free-living community and several unique barriers to inpatient care. Successful models of hospice care in prisons have been established and should be disseminated and evaluated. This article highlights why the changing demographics of prison populations necessitates hospice in this setting and highlights many of the barriers that correctional and consulting physicians face while providing palliative care. Issues specific to palliative care and hospice in prison include palliative care standards, inmate-physician and inmate-family relationships, confidential-

SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
ience, interdisciplinary care, do-not-resuscitate orders and advance medical directives, medical parole, and the use of inmate volunteers in prison hospice programs. We also include practical recommendations to community-based physicians working with incarcerated or recently released prisoners and describe solutions that can be implemented on an individual and systems basis.


Abstract: The aim of this paper is to present and discuss nurses’ and physicians’ comments in a questionnaire relating to patients’ transition from curative treatment to palliative care. The four-page questionnaire relating to experiences of and attitudes towards communication, decision-making, documentation and responsibility of nurses and physicians and towards the competence of patients was developed and sent to a random sample of 1672 nurses and physicians of 10 specialties. The response rate was 52% (n = 844), and over one-third made comments. The respondents differed in their comments about three areas: the concept of palliative care, experiences of unclear decision-making and difficulties in acceptance of the patient’s situation. The responses are analysed in terms of four ethical theories: virtue ethics, deontology, consequentialism and casuistry. Many virtues considered to be appropriate for healthcare personnel to possess were invoked. Compassion, honesty, justice and prudence are especially important. However, principles of medical ethics, such as the deontological principle of respect for self-determination and the consequence of avoidance of harm, are also implied. Casuistry may be particularly helpful in analysing certain areas of difficulty—namely, what is meant by “palliative care”, decision-making and accepting the patient’s situation. Keeping a patient in a state of uncertainty often causes more suffering than necessary. Communication among the staff and with patients must be explicit. Many of the staff have not had adequate training in communicating with patients who are at the end of their life. Time for joint reflection has to be regained, and training in decision-making is essential. In our opinion, palliative care in Sweden is in need of improvement.

Malakoff, Marion. Palliative care/physician-assisted dying: alternative or continuing care? *Care Management Journals* 2006 Spring; 7(1): 41-44. NRCBL: 20.4.1; 20.7; 20.5.1; 8.1. SC: le.


Muller, David. GOMER. *Health Affairs* 2007 May-June; 26(3): 831-835. NRCBL: 20.4.1. Identifiers: “Get Out of My Emergency Room”.


Abstract: This article discusses the relationship between personal and professional qualities in hospice nurses. We examine the notion of self-esteem in personal and professional identity. The focus is on two questions: (1) what is self-esteem, and how is it related to personal identity and its moral dimension? and (2) how do self-esteem and personal identity relate to the professional identity of nurses? We demonstrate it is important that the moral and personal goals in nurses’ life coincide. If nurses’ personal view of the good life is compatible with their experiences and feelings as professionals, this improves their performance as nurses. We also discuss how good nursing depends on the responses that nurses receive from patients, colleagues and family; they make nurses feel valued as persons and enable them to see the value of the work they do.


Terry, W.; Olson, L.G.; Ravenscroft, P.; Wilss, L.; Boulton-Lewis, G. Hospice patients’ views on research in palliative care. Internal Medicine Journal 2006 July; 36(7): 406-413. NRCBL: 20.4.1; 8.3.1; 18.5.7. SC: em.

Tuffrey-Wijne, Irene; Bernal, Jane; Butler, Gary; Hollins, Sheila; Curfs, Leopold. Using nominal group technique to investigate the views of people with intellectual disabilities on end-of-life care provision. Journal of Advanced Nursing 2007 April; 58(1): 80-89. NRCBL: 20.4.1; 9.5.3. SC: em.


DEATH AND DYING/ TERMINAL CARE/ MINORS


Abstract: BACKGROUND: Despite a gradual shift in the focus of medical care among terminally ill patients to a palliative model, studies suggest that many children with life-limiting chronic illnesses continue to die in hospital after prolonged periods of inpatient admission and mechanical ventilation. OBJECTIVES: To (1) examine the characteristics and location of death among hospitalised children, (2) investigate yearwise trends in these characteristics and (3) test the hypothesis that professional ethical guidance from the UK Royal College of Paediatrics and Child Health (1997) would lead to significant changes in the characteristics of death among hospitalised children. METHODS: Routine administrative data from one large tertiary-level UK children’s hospital was examined over a 7-year period (1997-2004) for children aged 0-18 years. Demographic details, location of deaths, source of admission (within hospital vs external), length of stay and final diagnoses (International Classification of Diseases-10 codes) were studied. Statistical significance was tested by the Kruskal-Wallis analysis of ranks and median test (non-parametric variables), chi(2) test (proportions) and Cochran-Armitage test (linear trends). RESULTS: Of the 1127 deaths occurring in hospital over the 7-year period, the majority (57.7%) were among infants. The main diagnoses at death included congenital malformations (22.2%), perinatal diseases (18.1%), cardiovascular disorders (14.9%) and neoplasms (12.4%). Most deaths occurred in an intensive care unit (ICU) environment (85.7%), with a significant increase over the years (80.1% in 1997 to 90.6% in 2004). There was a clear increase in the proportion of admissions from in-hospital among the ICU cohort (14.8% in 1998 to 24.8% in 2004). Infants with congenital malformations and perinatal conditions were more likely to die in an ICU (OR 2.42, 95% CI 1.65 to 3.55), and older children with malignancy outside the ICU (OR 6.5, 95% CI 4.4 to 9.6). Children stayed for a median of 13 days interquartile range 4.0-23.25 days) on a hospital ward before being admitted to an ICU where they died. CONCLUSIONS: A greater proportion of hospitalised children are dying in an ICU environment. Our experience indicates that professional ethical guidance by itself may be inadequate in reversing the trends observed in this study.

DELIVERY OF HEALTH CARE See CARE FOR SPECIFIC GROUPS

DETERMINATION OF DEATH See DEATH AND DYING/DETERMINATION OF DEATH

DISCLOSURE See CONFIDENTIALITY; INFORMED CONSENT; HUMAN EXPERIMENTATION/INFORMED CONSENT; TRUTH DISCLOSURE

DISTRIBUTIVE JUSTICE See RESOURCE ALLOCATION

DIVERSITY See CULTURAL PLURALISM

DNA FINGERPRINTING See GENETIC PRIVACY

DONATION See BLOOD BANKING, DONATION, AND TRANSFUSION; ORGAN AND TISSUE TRANSPLANTATION/DONATION AND PROCUREMENT

DRUG INDUSTRY

Addicted to secrecy: sealed drug documents should be opened up [editorial]. Nature 2007 April 19; 446(7138): 832. NRCLB: 9.7; 1.3.2; 18.6. SC: le.


Flogging Gardasil. In its rush to market its human papillomavirus vaccine, Merck forgot to make a strong and compelling case for compulsory immunization [editorial]. Nature Biotechnology 2007 March; 25(3): 261. NRCLB: 9.7; 9.5.1; 9.5.5; 9.5.7.


Ausman, James I. I told you it was going to happen . . . Part II [editorial]. Surgical Neurology 2006 May; 65(5): 520-521. NRCLB: 9.7; 1.3.2; 9.3.1. Identifiers: Medtrons.


Bibbins-Domingo, Kirsten; Fernandez, Alicia; Kahn, Jonathan D.; Temple, Robert; Stockbridge, Norman L. BiDil for heart failure in black patients [letters and responses]. Annals of Internal Medicine 2007 August 7; 147(3): 214-216. 15 refs. NRCLB: 9.7; 9.5.4; 15.11. Keywords: *blacks; *drugs; *heart diseases; biomedical research; drug industry; genetic ancestry; government regulation; patents; pharmacogenetics; racial groups; selection for treatment; Proposed Keywords: *drug approval; *drug therapy; *Keyword Identifiers: *BiDil; *Food and Drug Administration; United States


Burton, Bob. Roche fined over “extravagant” meals for doctors [news]. BMJ: British Medical Journal 2007 Feb-
uary 24; 334(7590): 384. NRCBL: 9.7; 1.3.2; 9.3.1. SC: le. Identifiers: Australia.

Cahana, Alex; Mauron, Alexandre. The story of Vioxx — no pain and a lot of gain: ethical concerns regarding conduct of the pharmaceutical industry. *Journal of Anesthesia* 2006; 20(4): 348-351. NRCBL: 9.7; 4.4; 1.3.5; 1.3.9.

Campbell, Eric G. Doctors and drug companies — scrutinizing influential relationships. *New England Journal of Medicine* 2007 November 1; 357(18): 1796-1797. NRCBL: 9.7; 1.3.2; 7.3; 9.3.1.


Abstract: BACKGROUND: Relationships between physicians and pharmaceutical, medical device, and other medically related industries have received considerable attention in recent years. We surveyed physicians to collect information about their financial associations with industry and the factors that predict those associations. METHODS: We conducted a national survey of 3167 physicians in six specialties (anesthesiology, cardiology, family practice, general surgery, internal medicine, and pediatrics) in late 2003 and early 2004. The raw response rate for this probability sample was 52%, and the weighted response rate was 58%. RESULTS: Most physicians (94%) reported some type of relationship with the pharmaceutical industry, and most of these relationships involved receiving food in the workplace (83%) or receiving drug samples (78%). More than one third of the respondents (35%) received reimbursement for costs associated with professional meetings or continuing medical education, and more than one quarter (28%) received payments for consulting, giving lectures, or enrolling patients in trials. Cardiologists were more than twice as likely as family practitioners to receive payments. Family practitioners met more frequently with industry representatives than did physicians in other specialties, and physicians in solo, two-person, or group practices met more frequently with industry representatives than did physicians practicing in hospitals and clinics. CONCLUSIONS: The results of this national survey indicate that relationships between physicians and industry are common and underscore the variation among such relationships according to specialty, practice type, and professional activities.

Cardarelli, Robert; Licciardone, John C.; Taylor, Lockwood G. A cross-sectional evidence-based review of pharmaceutical promotional marketing brochures and their underlying studies: is what they tell us important and true? *BMC Family Practice* 2006 March 3; 7: 13-18. NRCBL: 9.7; 1.3.2; 7.3; 7.1.

Carlat, Daniel. Dr. drug rep: during a year of being paid to give talks to doctors about an antidepressant, a psychiatrist comes to terms with the fact that taking pharmaceutical money can cloud your judgment. *New York Times Magazine* 2007 November 25; p. 64-69. NRCBL: 9.7; 1.3.2; 9.3.1. SC: po.


Coombes, Rebecca. Life saving treatment or giant experiment. *BMJ: British Medical Journal* 2007 April 7; 334(7596): 721-723. NRCBL: 9.7; 9.5.1; 9.5.7.

Cooper, R.J.; Bissell, P.; Wingfield, J. A new prescription for empirical ethics research in pharmacy: a critical review of the literature. *Journal of Medical Ethics* 2007 February; 33(2): 82-86. NRCBL: 9.7; 4.1.1. SC: em; rv. Abstract: Empirical ethics research is increasingly valued in bioethics and healthcare more generally, but there remain as yet under-researched areas such as pharmacy, despite the increasingly visible attempts by the profession to embrace additional roles beyond the supply of medicines. A descriptive and critical review of the extant empirical pharmacy ethics literature is provided here. A chronological change from quantitative to qualitative ap-
proaches is highlighted in this review, as well as differing theoretical approaches such as cognitive moral development and the four principles of biomedical ethics. Research with pharmacy student cohorts is common, as is representation from American pharmacists. Many examples of ethical problems are identified, as well as commercial and legal influences on ethical understanding and decision making. In this paper, it is argued that as pharmacy seeks to develop additional roles with concomitant ethical responsibilities, a new prescription is needed for empirical ethics research in pharmacy-one that embraces an agenda of systematic research using a plurality of methodological and theoretical approaches to better explore this under-researched discipline.


Davis, Joel J. Consumers’ preferences for the communication of risk information in drug advertising. *Health Affairs* 2007 May-June; 26(3): 863-870. NRCBL: 9.7; 1.3.2; 8.3.1. SC: em.


DeMaria, Anthony N. Your soul for a pen? *Journal of the American College of Cardiology* 2007 March 20; 49(11): 1220-1222. NRCBL: 9.7; 1.3.2; 9.3.1.


Falcón, M.; Martínez-Cánovas, F.J.; Pérez-Carceles, M.D.; Osuna, E.; Luna, A. Ethical problems related to information and pharmaceutical care in Spain. *Medicine and Law: The World Association for Medical Law* 2007 March; 26(1): 85-93. NRCBL: 9.7. SC: ie. Abstract: This paper represents a reflection on the limits and objectives of the information pharmacists should offer in pharmacies. The obligation of a pharmacist to follow the patient’s therapeutic progress makes it necessary to integrate this figure into an ethical-legal framework and to define the objective of the health-related information offered, taking into account the patient’s welfare and constitutional rights.

Ferris, Lorraine E.; Naylor, C. David. Promoting integrity in industry-sponsored clinical drug trials: conflict of interest for Canadian academic health sciences centres. *In: Lemmens, Trudo; Waring, DuFtR., eds. Law and Ethics in Biomedical Research: Regulation, Conflict of Interest and Liability. Toronto; Buffalo: University of Toronto Press, 2006: 95-131. NRCBL: 9.7; 18.2; 1.3.9; 7.3.

Finucane, Thomas E.; Peterson, Eric D.; Boyce, Kurt; Overstreet, Karen; Sapers, Benjamin L.; Steinman, Michael A.; Chren, Mary-Margaret; Landefeld, C. Seth; Bero, Lisa A. The promotion of Gabapentin [letters and reply]. *Annals of Internal Medicine* 2007 February 20; 146(4): 312-314. NRCBL: 9.7; 1.3.2; 1.3.7; 1.3.9.


Giles, Jim. Say no to lunch [commentary]. *New Scientist* 2007 April 28-May 4; 194(2601): 18. NRCBL: 9.7; 1.3.2; 7.3.


Abstract: Surveillance of physicians’ prescribing patterns and the accumulation and sale of these data for pharmaceutical marketing are currently the subjects of legislation in several states and action by state and national medical associations. Contrary to common perception, the growth of the health care information organization industry has not been limited to the past decade but has been building slowly over the past 50 years, beginning in the 1940s when growth in the prescription drug market fueled industry interest in understanding and influencing prescribing patterns. The development of this surveillance system was not simply imposed on the medical profession by the pharmaceutical industry but was developed through the interactions of pharmaceutical salesmen, pharmaceutical marketers, academic researchers, individual physicians, and physician organizations. Examination of the role of physicians and physician organizations in the development of prescriber profiling is directly relevant to the contemporary policy debate surrounding this issue.


Kahn, Jeffrey. What vaccination programs mean for research [editorial]. American Journal of Bioethics 2007 March; 7(3): 5-10. NRCBL: 9.7; 9.1; 18.5.2; 18.6.


Lesser, Eugene A.; Starr, Jennifer; Kong, Xuan; Meegerian, J. Thomas; Gozani, Shai N. Point-of-service nerve conduction studies: an example of industry-driven disruptive innovation in health care. Perspectives in Biology and Medicine 2007 Winter; 50(1): 40-53. NRCBL: 9.7; 7.4; 7.3.


Magrini, Nicola; Font, Maria. Direct to consumer advertising of drugs in Europe [editorial]. BMJ: British Medical Journal 2007 September 15; 335(7619): 526. NRCBL: 9.7; 1.3.2; 1.3.7; 21.1.


McCarty, Michael. US campaign tackles drug company influence over doctors. Lancet 2007 March 3-9; 369(9563): 730. NRCBL: 9.7; 1.3.2; 9.3.1; 9.8; 1.3.9.


Metzl, Jonathan M. If direct-to-consumer advertisements come to Europe: lessons from the USA. Lancet 2007 February 24-March 2; 369(9562): 704-706. NRCBL: 9.7; 1.3.2; 4.2; 7.1; 8.1; 21.1.

NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.


Moynihan, Ray. Direct to consumer advertising should not come to Europe. BMJ: British Medical Journal 2007 May 19; 334(7602): 1025. NRCBL: 9.7; 1.3.2.


Mueller, Paul S.; Hook, C. Christopher; Litin, Scott C. Physician preferences and attitudes regarding industry support of CME programs. American Journal of Medicine 2007 March; 120(3): 281-285. NRCBL: 9.7; 7.1; 7.2; 9.3.1; 1.3.2. SC: em.


Oldani, Michael. Can doctors take back the script? Understanding the total system of prescription generation. Atrium 2007 Summer; 4: 15-17, 28. NRCBL: 9.7; 1.3.2; 9.3.1.


Pinto, Sharrel L.; Lipowski, Earlene; Segal, Richard; Kimberlin, Carole; Algina, James. Physicians’ intent to comply with the American Medical Association’s guidelines on gifts from the pharmaceutical industry. Journal of Medical Ethics 2007 June; 33(6): 313-319. NRCBL: 9.7; 1.3.2; 7.3; 9.3.1. SC: em. Abstract: OBJECTIVE: To identify factors that predict physicians’ intent to comply with the American Medical Association’s (AMA’s) ethical guidelines on gifts from the pharmaceutical industry. METHODS: A survey was designed and mailed in June 2004 to a random sample of
850 physicians in Florida, USA, excluding physicians with inactive licences, incomplete addresses, addresses in other states and pretest participants. Factor analysis extracted six factors: attitude towards following the guidelines, subjective norms (eg, peers, patients, etc), facilitating conditions (eg, knowledge of the guidelines, etc), profession-specific precedents (eg, institution’s policies, etc), individual-specific precedents (physicians’ own discretion, policies, etc) and intent. Multivariate regression modelling was conducted. RESULTS: Surveys were received from 213 physicians representing all specialties, with a net response rate of 25.5%. 62% (n = 133) of respondents were aware of the guidelines; 50% (n = 107) had read them. 48% (n = 102) thought that following the guidelines would increase physicians’ credibility and professional image; 68% (n = 145) agreed that it was important to do so. Intent to comply was positively associated with attitude, subjective norms, facilitators, and sponsorship of continuing medical education (CME) events, while individual-specific precedents had a negative relationship with intent to comply. Predictors of intent (R(2) = 0.52, p ) were attitude, subjective norms, the interaction term (attitude and subjective norms), sponsorship of CME events and individual-specific precedents.

CONCLUSIONS: Physicians are more likely to follow the AMA guidelines if they have positive attitudes towards the guidelines, greater subjective norms, fewer expectations of CME sponsorship and fewer individual-specific precedents. Physicians believing that important individuals or organisations expect them to comply with the guidelines are more likely to express intent, despite having fewer beliefs that positive outcomes would result through compliance.


Abstract: CONTEXT: Recent legislation in 5 states and the District of Columbia mandated state disclosure of payments made to physicians by pharmaceutical companies. In 2 of these states, Vermont and Minnesota, payment disclosures are publicly available. OBJECTIVES: To determine the accessibility and quality of the data available in Vermont and Minnesota and to describe the prevalence and magnitude of disclosed payments. DESIGN AND SETTING: Cross-sectional analysis of publicly available data from July 1, 2002, through June 30, 2004, in Vermont and from January 1, 2002, through December 31, 2004, in Minnesota. MAIN OUTCOME MEASURES: Accessibility and quality of disclosure data and the number, value, and type of payments of $100 or more to physicians. RESULTS: Access to payment data required extensive negotiation with the Office of the Vermont Attorney General and manual photocopying of individual disclosure forms at Minnesota’s State Board of Pharmacy. In Vermont, 61% of payments were not released to the public because pharmaceutical companies designated them as trade secrets and 75% of publicly disclosed payments were missing information necessary to identify the recipient. In Minnesota, 25% of companies reported in each of the 3 years. In Vermont, among 12,227 payments totaling $2.18 million publicly disclosed, there were 2416 payments of $100 or more to physicians; total, $1.01 million; median payment, $177 (range, $100-$20,000). In Minnesota, among 6946 payments totaling $30.96 million publicly disclosed, there were 6238 payments of $100 or more to physicians; total, $22.39 million; median payment, $1000 (range, $100-$922,239). Physician-specific analyses were possible only in Minnesota, identifying 2388 distinct physicians who received payment of $100 or more; median number of payments received, 1 (range, 1-88) and the median amount received, $1000 (range, $100-$1,178,203). CONCLUSIONS: The Vermont and Minnesota laws requiring disclosure of payments do not provide easy access.
access to payment information for the public and are of limited quality once accessed. However, substantial numbers of payments of $100 or more were made to physicians by pharmaceutical companies.


Sade, Robert M.; Grande, David; Gorske, Arnold L.; Campbell, Eric G. A national survey of physician-industry relationships [letters and reply]. New England Journal of Medicine August 2; 357(5): 507-508. NRCBL: 9.7; 1.3.2; 9.3.1; 7.3.


Selgelid, Michael J. Ethics and drug resistance. Bioethics 2007 May; 21(4): 218-229. NRCBL: 9.7; 1.3.2; 7.1; 9.5.1. SC: an.

Abstract: This paper reviews the dynamics behind, and ethical issues associated with, the phenomenon of drug resistance. Drug resistance is an important ethical issue partly because of the severe consequences likely to result from the increase in drug resistant pathogens if more is not done to control them. Drug resistance is also an ethical issue because, rather than being a mere quirk of nature, the problem is largely a product of drug distribution. Drug resistance results from the over-consumption of antibiotics by the wealthy; and it, ironically, results from the under-consumption of antibiotics, usually by the poor or otherwise marginalized. In both kinds of cases the phenomenon of drug resistance illustrates why health (care) — at least in the context of infectious disease — should be treated as a (global) public good. The point is that drug resistance involves ‘externalities’ affecting third parties. When one patient develops a resistant strain of disease because of her over- or under-consumption of medication, this more dangerous malady poses increased risk to others. The propriety of free-market distribution of goods subject to externalities is famously dubious — given that the ‘efficiency’ rationale behind markets assumes an absence of externalities. Market failure in the context of drug resistance is partly revealed by the fact that no new classes of antibiotics have been developed since 1970. I conclude by arguing that the case of drug resistance reveals additional reasons — to those traditionally appealed to by bioethicists — for treating health care as something special when making policy decisions about its distribution.


Soreth, Janice; Cox, Edward; Kweder, Sandra; Jenkins, John; Galson, Steven. Ketek — the FDA perspective. New England Journal of Medicine 2007 April 19; 356(16): 1675-1676. NRCBL: 9.7; 1.3.5; 1.3.9. Identifiers: Food and Drug Administration.


Tanne, Janice Hopkins. US campaign aims to end industry gifts and speaking fees [news]. BMJ: British Medical Journal 2007 February 24; 334(7590): 385. NRCBL: 9.7; 1.3.2; 9.3.1.

Tanne, Janice Hopkins. US guidelines often influenced by industry [news]. BMJ: British Medical Journal 2007 January 27; 334(7586): 171. NRCBL: 9.7; 18.2; 9.8; 1.3.9; 7.3.
SECTION I  ELECTROCONVULSIVE THERAPY


Triggle, David J. Treating desires not diseases: a pill for every ill and an ill for every pill? Drug Discovery Today 2007 February; 12(3-4): 161-166. NRCBL: 9.7; 1.3.2; 4.2; 4.3; 1.3.7; 9.3.1.


DURABLE POWER OF ATTORNEY See ADVANCE DIRECTIVES

ECONOMICS See GENETIC SCREENING/ECONOMIC ASPECTS; HEALTH CARE ECONOMICS; ORGAN AND TISSUE TRANSPLANTATION/ DONATION AND PROCUREMENT/ECONOMIC ASPECTS

EDUCATION See BIOETHICS AND MEDICAL ETHICS/ EDUCATION; MEDICAL EDUCATION

ELECTROCONVULSIVE THERAPY See also BEHAVIOR CONTROL; CARE FOR SPECIFIC GROUPS/ MENTALLY DISABLED; MENTAL HEALTH THERAPIES AND NEUROSCIENCES

Illes, Judy; Gallo, Marisa; Kirsch, Matthew P. An ethics perspective on transcranial magnetic stimulation (TMS) and human neuromodulation. Behavioural Neurology 2006; 17(3-4): 149-157. NRCBL: 17.5; 8.3.1; 8.3.3.


Newell, Elizabeth R. Competency, consent, and electroconvulsive therapy: a mentally ill prisoner’s right to refuse invasive medical treatment in Oregon’s criminal justice system. Lewis and Clark Law Review 2005 Winter; 9(4): 1019-1045. NRCBL: 17.5; 17.8; 1.3.5; 8.3.3; 8.3.4; 9.5.1. SC: le.

Racine, Eric; Waldman, Sarah; Palmour, Nicole; Risse, David; Illes, Judy. “Currents of hope”: neurostimulation techniques in U.S. and U.K. print media. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Summer; 16(3): 312-316. NRCBL: 17.5; 21.1; 1.3.7. SC: em.

EMBRYOS See CARE FOR SPECIFIC GROUPS/ FETUSES; CRYOBANKING OF SPERM, OVA AND EMBRYOS; HUMAN EXPERIMENTATION/SPECIAL POPULATIONS/ EMBRYOS AND FETUSES
ENHANCEMENT

Enhancing, not cheating. A broad debate about the use of drugs that improve cognition for both the healthy and the ill is needed [editorial]. Nature 2007 November 15; 450(7168): 320. NRCBL: 4.5; 9.7; 17.4.


Abstract: Our knowledge of the human brain and the influence of pharmacological substances on human mental functioning is expanding. This creates new possibilities to enhance personality and character traits. Psycho-pharmacological enhancers, as well as other enhancement technologies, raise moral questions concerning the boundary between clinical therapy and enhancement, risks and safety, coercion and justice. Other moral questions include the meaning and value of identity and authenticity, the role of happiness for a good life, or the perceived threats to humanity. Identity and authenticity are central in the debate on psychopharmacological enhancers. In this paper, I first describe the concerns at issue here as extensively propounded by Carl Elliott. Next, I address David DeGrazia’s theory, which holds that there are no fundamental identity-related and authenticity-related arguments against enhancement technologies. I argue, however, that DeGrazia’s line of reasoning does not succeed in settling these concerns. His conception of identity does not seem able to account for the importance we attach to personal identity in cases where personal identity is changed through enhancement technology. Moreover, his conception of authenticity does not explain the reason why we find inauthentic values objectionable. A broader approach to authenticity can make sense of concerns about changes in personal identity by means of enhancement technologies.

Burke, Michael. What would happen if a ‘woman’ outpaced the winner of the gold medal in the ‘men’s’ one hundred meters? female sport, drugs and the transgressive cyborg body. Philosophy in the Contemporary World 2004 Spring-Summer; 11(1): 33-41. NRCBL: 4.5; 5.1; 9.5.1; 10; 4.1.1. SC: an.


Abstract: Recent advances in cognitive science and cognitive neuroscience open up new vistas for human enhancement. Central to much of this work is the idea of new human-machine interfaces (in general) and new brain-machine interfaces (in particular). But despite the increasing prominence of such ideas, the very idea of such an interface remains surprisingly under-explored. In particular, the notion of human enhancement suggests an image of the embodied and reasoning agent as literally extended or augmented, rather than the more conservative image of a standard (non-enhanced) agent using a tool via some new interface. In this essay, I explore this difference, and attempt to lay out some of the conditions under which the more radical reading (positing brand new integrated agents or systemic wholes) becomes justified. I adduce some empirical evidence suggesting that the radical result is well within our scientific reach. The main reason why this is so has less to do with the advancement of our science (though that certainly helps) than with our native biological plasticity. We humans, I shall try to show, are biologically disposed towards literal (and repeated) episodes of sensory re-calibration, of bodily re-configuration and of mental extension. Such potential for literal and repeated re-configuration is the mark of what I shall call “profoundly embodied agency,” contrasting it with a variety of weaker (less philosophically and scientifically interesting) understandings of the nature and importance of embodiment for minds and persons. The article ends by relating the image of profound embodiment to some questions (and fears) concerning converging technologies for improving human performance.


Hughes, James; Bostrum, Nick; Agar, Nicholas. Human vs. posthuman [letters and reply]. Hastings Center Report


Keywords: *enhancement technologies; *ethical analysis; *moral policy; adults; biotechnology; children; doping in sports; drugs; freedom; hormones; human characteristics; justice; moral complicity; motivation; parents; public policy; regulation; Proposed Keywords: body height; therapeutics


Sahakian, Barbara; Morein-Zamir, Sharon. Professor’s little helper. The use of cognitive-enhancing drugs by both ill and healthy individuals raises ethical questions that should not be ignored. Nature 2007 December 20-27; 450(7173): 1157-1159. NRCBL: 4.5; 17.2.


Tuffs, Annette. German doctors may have to report patients who have piercings and beauty treatments [news]. BMJ: British Medical Journal 2007 November 3; 335(7626): 905. NRCBL: 4.5; 8.4; 9.3; 1.


Wilson, James. Transhumanism and moral equality. Bioethics 2007 October; 21(8): 419-425. NRCBL: 4.5; 1.1. Conference: Eighth World Congress of Bioethics: A Just and Healthy Society; Beijing, China; 2006 August 9. Abstract: Conservative thinkers such as Francis Fukuyama have produced a battery of objections to the transhumanist project of fundamentally enhancing human capacities. This article examines one of these objections, namely that by allowing some to greatly extend their capacities, we will undermine the fundamental equal morality of human beings. I argue that this objection is groundless: once we understand the basis for human equality, it is clear that anyone who now has sufficient capacities to count as a person from the moral point of view will continue to count as one even if others are fundamentally enhanced; and it is mistaken to think that a creature which had even far greater capacities than an unenhanced human being should count as more than an equal from the moral point of view.

**ETHICISTS AND ETHICS COMMITTEES**

See also BIOETHICS AND MEDICAL ETHICS/COMMISSIONS


Abstract: Clinical ethics teams exist in various forms and have assisted care providers for several decades. Our clinical ethics service at an urban, tertiary, teaching hospital provides ethics consultation to care providers, patients, and their family members. Scenarios prompting an ethics consultation may be complex, often involving social, cultural, and fiscal components. Because patients who receive an ethics consultation often require a lengthy hospital stay, our group searched for unique identifiers in a patient's presentation to facilitate earlier and, potentially, more effective interventions. Of particular interest to our group was the presentation of these patients to our institution from the emergency department (ED). Our group's subjective experience indicated that factors requiring ethics consultation were often present very early during hospitalization. A retrospective medical record review of a convenience sample of 50 records of patients who had received a formal clinical ethics consult within a 14-month timeframe was done. Those patients who were admitted to the hospital via the ED and subsequently received an ethics consultation were identified. The critical issues prompting the ethics consult were then evaluated. Eighteen (35%) of the study patients were originally admitted through the ED. Results showed that the ethical issue(s) that prompted the clinical ethics consult was regularly identifiable in the ED. Our study results indicate that issues prompting ethics consults may potentially be identified as patients present to the ED. Rapid and effective interventions proscribed through institutional policy guidelines could greatly assist nurses and other ED...
providers in identifying these at-risk patients upon entry of the ED. Such a policy would ultimately benefit both patient and provider.


Chwang, Eric; Landy, David C.; Sharp, Richard R. Views regarding the training of ethics consultants: a survey of physicians caring for patients in ICU. *Journal of Medical Ethics* 2007 June; 33(6): 320-324. NRCBL: 9.6; 7.3; 9.1. SC: em. Abstract: BACKGROUND: Despite the expansion of ethics consultation services, questions remain about the aims of clinical ethics consultation, its methods and the expertise of those who provide such services. OBJECTIVE: To describe physicians’ expectations regarding the training and skills necessary for ethics consultants to contribute effectively to the care of patients in intensive care unit (ICU). DESIGN: Mailed survey. PARTICIPANTS: Physicians responsible for the care of at least 10 patients in ICU over a 6-month period at a 921-bed private teaching hospital with an established ethics consultation service. 69 of 92 (75%) eligible physicians responded. Measurements: Importance of specialised knowledge and skills for ethics consultants contributing to the care of patients in ICU; need for advanced disciplinary training; expectations regarding formal-training programmes for ethics consultants. RESULTS: Expertise in ethics was described most often as important for ethics consultants taking part in the care of patients in ICU, compared with expertise in law (p.03), religious traditions (p.001), medicine (p.001) and conflict-mediation techniques (p.001). When asked about the formal training consultants should possess, however, physicians involved in the care of patients in ICU most often identified advanced medical training as important. CONCLUSIONS: Although many physicians caring for patients in ICU believe ethics consultants must possess non-medical expertise in ethics and law if they are to contribute effectively to patient care, these physicians place a very high value on medical training as well, suggesting a “medicine plus one” view of the training of an ideal ethics consultant. As ethics consultation services expand, clear expectations regarding the training of ethics consultants should be established.


Cranford, Ronald E. The neurologist as ethics consultant and as a member of the institutional ethics committee: the neuroethicist. *Neurologic Clinics* 1989 November; 7(4): 697-713. NRCBL: 9.6; 17.1; 20.2.1; 20.5.1.


Dörries, Andrea; Hespe-Jungesblut, Katharina. Die Implementierung klinischer Ethikberatung in Deutschland
The response rate was 87.4%. Ethics consultation services (ECSs) were found in 81% of all general hospitals in the U.S., and in 100% of hospitals with more than 400 beds. The median number of consults performed by ECSs in the year prior to survey was 3. Most individuals performing ethics consultation were physicians (34%), nurses (31%), social workers (11%), or chaplains (10%). Only 41% had formal supervised training in ethics consultation. Consultation practices varied widely both within and between ECSs. For example, 65% of ECSs always made recommendations, whereas 6% never did. These findings highlight a need to clarify standards for ethics consultation practices.


Hurst, Samia A.; Reiter-Theil, Stella; Perrier, Arnaud; Forde, Reidun; Slowther, Anne-Marie; Pegoraro, Renzo; Danis, Marion. Physicians’ access to ethics support services in four European countries. *Health Care Analysis: An International Journal of Health Philosophy and Policy* 2007 December; 15(4): 321-335. NRCBL: 9.6; 21.1. SC: em. Identifiers: Italy; Norway; Switzerland; Great Britain (United Kingdom).

Abstract: Clinical ethics support services are developing in Europe. They will be most useful if they are designed to match the ethical concerns of clinicians. We conducted a cross-sectional mailed survey on random samples of general physicians in Norway, Switzerland, Italy, and the UK, to assess their access to different types of ethics support services, and to describe what makes them more likely to have used available ethics support. Respondents reported access to formal ethics support services such as
clinical ethics committees (23%), consultation in individual cases (17.6%), and individual ethicists (8.8%), but also to other kinds of less formal ethics support (23.6%). Access to formal ethics support services was associated with work in urban hospitals. Informal ethics resources were more evenly distributed. Although most respondents (81%) reported that they would find help useful in facing ethical difficulties, they reported having used the available services infrequently (14%). Physicians with greater confidence in their knowledge of ethics (P=0.001), or who had had ethics courses in medical school (P=0.006), were more likely to have used available services. Access to help in facing ethical difficulties among general physicians in the surveyed countries is provided by a mix of at least two ethics support services and other resources. Developing ethics support services may benefit from integration of informal services. Development of ethics education in medical school curricula could lead to improved physicians sensitivity to ethical difficulties and greater use of ethics support services. Such support services may also need to be more proactive in making their help available.


Abstract: BACKGROUND: Ethics support services are growing in Europe to help doctors in dealing with ethical difficulties. Currently, insufficient attention has been focused on the experiences of doctors who have faced ethical difficulties in these countries to provide an evidence base for the development of these services. METHODS: A survey instrument was adapted to explore the types of ethical dilemmas faced by European doctors, how they ranked the difficulty of these dilemmas, their satisfaction with the resolution of a recent ethically difficult case and the types of help they would consider helpful. The questionnaire was translated and given to general internists in Norway, Switzerland, Italy and the UK. RESULTS: Survey respondents (n=656, response rate 43%) ranged in age from 28 to 82 years, and averaged 25 years in practice. Only a minority (17.6%) reported having access to ethics consultation in individual cases. The ethical difficulties most often reported as being encountered were uncertain or impaired decision-making capacity (94.8%), disagreement among caregivers (81.2%) and limitation of treatment at the end of life (79.3%). The frequency of most ethical difficulties varied among countries, as did the type of issue considered most difficult. The types of help most often identified as potentially useful were professional reassurance about the decision being correct (47.5%), someone capable of providing specific advice (41.1%), help in weighing outcomes (36%) and clarification of the issues (35.9%). Few of the types of help expected to be useful varied among countries. CONCLUSION: Cultural differences may indeed influence how doctors perceive ethical difficulties. The type of help needed, however, did not vary markedly. The general structure of ethics support services would not have to be radically altered to suit cultural variations among the surveyed countries.


McLean, Sheila A.M. What and who are clinical ethics committees for? [editorial]. Journal of Medical Ethics


Abstract: Clinical ethical consultants are subject to an unavoidable conflict of interest. Their work requires that they be independent, but incentives attached to their role chip relentlessly at independence. This is a problem without any solution, but it can at least be ameliorated through careful management.


**Morreim, E. Haavi.** Ties without tethers: bioethics corporate relations in the AbioCor artificial heart trial. *In: Eckenwiler, Lisa A.; Cohn, Felicia G., eds. The Ethics of Bioethics: Mapping the Moral Landscape. Baltimore, MD: Johns Hopkins University Press, 2007: 181-190. NRCBL: 9.6; 1.3.2; 9.7; 9.3.1; 18.5.1; 19.2. SC: cs.


Sokol, Daniel K. No patient is an island. *BMJ: British Medical Journal* 2007 September 15; 335(7619): 568. NRCBL: 9.6; 1.3.7; 17.1; 8.3.3; 8.3.4. Identifiers: Inside the Ethics Committee, BBC Radio 4 series.


Abstract: The need to evaluate the performance of clinical ethics services is widely acknowledged although work in this area is more developed in the United States. In the USA many studies that assess clinical ethics services have utilized empirical methods and assessment criteria. The value of these approaches is thought to rest on their ability to measure the value of services in a demonstrable fashion. However, empirical measures tend to lack ethical content, making their contribution to developments in ethical governance unclear. The steady increase of clinical ethics committees in the UK must be accompanied by efforts to evaluate their performance. As part of this evaluative work it is important to examine how the practice of clinical ethics committees can be informed by empirical measures.

Yarborough, Mark; Sharp, Richard R. Bioethics consultation and patient advocacy organizations; expanding the dialogue about professional conflicts of interest. *CQ: Cambridge Quarterly of Healthcare Ethics* 2007 Winter; 16(1): 74-81. NRCBL: 9.6; 1.3.1; 9.3.1; 7.1; 7.3.


**ETHICS COMMITTEES** See ETHICISTS AND ETHICS COMMITTEES; HUMAN EXPERIMENTATION/ ETHICS COMMITTEES AND POLICY GUIDELINES

**EUGENICS**


Keywords: *eugenics; *historical aspects; *involuntary sterilization; mentally disabled persons; National Socialism; prisoners; Keyword Identifiers: *United States; Germany; Indiana; Twentieth Century


Keywords: *eugenics; genetic intervention; germ cells; historical aspects; Keyword Identifiers: Europe; United States; Nineteenth Century; Twentieth Century


Keywords: *anthropology; *eugenics; behavioral genetics; culture; genetic determinism


Keywords: *eugenics; *psychiatry; attitude of health personnel; evolution; historical aspects; human characteristics; mental disorders; National Socialism; philosophy; physicians; racial groups; Proposed Keywords: Darwinism; Keyw ord Identifiers: Germany; Twentieth Century

Abstract: The hypothesis that anatomically modern hominids could have undergone changes akin to those observed in domesticated animals has been contemplated in the biological sciences for at least 150 years. The idea had already plagued philosophers such as Rousseau, who considered the civilisation of man as going against human nature, and eventually “sparked over” to the medical sciences in the late 19th and early 20th century. At that time, human “self-domestication” appealed to psychiatry, because it served as a causal explanation for the alleged degeneration of the “erbgut” (genetic material) of entire populations and the presumed increase of mental disorders. Consequently, Social Darwinists emphasised preventing procreation by people of “lower genetic value” and positively selecting favourable traits in others. Both tendencies culminated in euthanasia and breeding programs (“Lebensborn”) during the Nazi regime in Germany. Whether or not domestication actually plays a role in some anatomical changes since the late Pleistocene period is, from a biological standpoint, contentious, and the currently resurrected debate depends, in part, on the definitional criteria applied. However, the example of human self-domestication may illustrate that scientific ideas, especially when dealing with human biology, are prone to misuse, particularly if “is” is confused with “ought”, i.e., if moral principles are deduced from biological facts. Although such naturalistic fallacies appear to be banned,

SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review

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modern genetics may, at least in theory, pose similar ethical problems to medicine, including psychiatry. In times during which studies into the genetics of psychiatric disorders are scientifically more valued than studies into environmental causation of disorders (which is currently the case), the prospects of genetic therapy may be tempting to alter the human genome in patients, probably at costs that no-one can foresee. In the case of “self-domestication”, it is proposed that human characteristics resembling domesticated traits in animals should be labelled “domestication-like”, or better, objectively described as genuine adaptations to sedentism.

Keywords: *eugenics; *historical aspects; famous persons; involuntary sterilization; physicians; prisoners; professional misconduct; Keyword Identifiers: *Galton, Francis; *Sharp, Harry Clay; Twentieth Century; United States

Keywords: *eugenics; *historical aspects; famous persons; genetics; involuntary sterilization; researchers; Keyword Identifiers: *Davenport, Charles; *Laughlin, Harry; Eugenics Record Office; Twentieth Century; United States

Cleminson, Richard. “A century of civilization under the influence of eugenics”: Dr. Enrique Diego Madrazo, socialism and scientific progress. Dynamis 2006: 26: 221-251. NRCBL: 15.5; 1.3.5; 21.1.

Keywords: *economics; *eugenics; political systems; Proposed Keywords: *sociology

Keywords: *eugenics; *historical aspects; clinical genetics; international aspects; involuntary sterilization; National Socialism; politics; population genetics; public policy; researchers; terminology; Keyword Identifiers: Germany; Great Britain; Latin America; Scandinavia; United States

Dolan, Deborah V. Psychiatry, psychology, and human sterilization then and now: “therapeutic” or in the social interest? Ethical Human Psychology and Psychiatry 2007; 9(2): 99-108. NRCBL: 15.5; 11.3; 17.1; 2.2.


Keywords: *eugenics; attitudes; behavioral genetics; congenital disorders; disabled persons; Down syndrome; homosexuality; intelligence; population genetics; prenatal diagnosis; racial groups; researchers; selective abortion; trends; Keyword Identifiers: United States; Watson, James


Keywords: *eugenics; *literature; blacks; metaphor; mothers; sex factors; social discrimination; whites; Keyword Identifiers: *Seraph on the Suwanee (Hurston. Z.N.); Hurston, Zora Neale

Kirby, David A. The devil in our DNA: a brief history of eugenics in science fiction films. Literature and Medicine 2007 Spring; 26(1): 83-108. NRCBL: 15.5; 7.1; 15.11; 5.3; 3.2; 15.7.

Keywords: *eugenics; *historical aspects; involuntary sterilization; child abuse; dissent; family; famous persons; females; international aspects; legal liability; mass media; mental competence; mentally disabled persons; minors; mothers; parent-child relationship; parental consent; physicians; public opinion; public policy; professional organizations; sexuality; social control; state government; values; Keyword Identifiers: *Cooper Hewitt, Ann; *United States; American Eugenics Society; California; Hoover, Herbert; Roosevelt, Franklin; San Francisco; Twentieth Century

Keywords: *eugenics; *historical aspects; international aspects; National Socialism; Keyword Identifiers: Germany; Great Britain; Nineteenth Century; Twentieth Century; United States

NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.


Keywords: *eugenics; reproductive rights; reproductive technologies; regulation; reproduction; disabled persons;* Keyword Identifiers: Universal Declaration of Human Rights


Keywords: *abortion; eugenics; prenatal diagnosis; reproductive technologies; women’s rights; attitudes; disabled persons; family planning; feminist ethics; historical aspects; informal social control; international aspects; legal aspects; legislation; physicians; political activity; preimplantation diagnosis; reproductive rights; statistics; surrogate mothers; trends;* Keyword Identifiers: *Eugenic Protection Act (Japan); Japan; Twentieth Century; Twenty-First Century; World War II

Parker, Michael. The best possible child. *Journal of Medical Ethics* 2007 May; 33(5): 279-283. 21 refs. NRCBL: 15.5; 14.1; 1.1; 15.2; 14.4; 15.3; 9.5.1. SC: an.

Keywords: *beneficence; embryo transfer; ethical analysis; preimplantation diagnosis; prenatal diagnosis; quality of life; reproduction; autonomy; choice behavior; disabled persons; ethical relativism; genetic disorders; genetic enhancement; in vitro fertilization; moral obligations; parents; refusal to treat; uncertainty

Abstract: Julian Savulescu argues for two principles of reproductive ethics: reproductive autonomy and procreative beneficence, where the principle of procreative beneficence is conceptualised in terms of a duty to have the child, of the possible children that could be had, who will have the best opportunity of the best life. Were it to be accepted, this principle would have significant implications for the ethics of reproductive choice and, in particular, for the use of prenatal testing and other reproductive technologies for the avoidance of disability, and for enhancement. In this paper, it is argued that this principle should be rejected, and it is concluded that while potential parents do have important obligations in relation to the foreseeable lives of their future children, these obligations are not best captured in terms of a duty to have the child with the best opportunity of the best life.


Keywords: *eugenics; genetic engineering; freedom; historical aspects; informal social control; reproductive technologies; values; autonomy; attitudes; coercion; contraception; directive counseling; disabled persons; feminism; genetic services; public policy; reproduction; reproductive rights; researchers; sterilization; trends; voluntary programs; women; Proposed Keywords: ectogenesis; transhumanism;* Keyword Identifiers: Twentieth Century; Twenty-First Century


Rafter, Nicole H. Claims-making and socio-cultural context in the first U.S. eugenics campaign. *Social Problems* 1992 February; 39(1): 17-34. NRCBL: 15.5; 9.5.5; 9.5.3.


Keywords: *eugenics; historical aspects; animal experimentation; attitudes; euthanasia; famous persons; human experimentation; involuntary sterilization; mass media; mentally disabled persons; National Socialism; physicians; researchers; social discrimination; socioeconomic factors;* Keyword Identifiers: *Man, the Unknown (Carrel, Alexis); Lindbergh, Charles; Rockefeller Institute; Twentieth Century; United States

Revie, Linda. “More than just boots! The eugenic and commercial concerns behind A. R. Kaufman’s birth controlling activities”. *Canadian Bulletin of Medical History* 2006; 23(1): 119-143. NRCBL: 15.5; 11.1; 1.3.2; 11.3.

Rydell, Robert; Cogdoll, Christina; Largent, Mark. The Nazi eugenics exhibit in the United States, 1934-43. *In:* Currell, Susan; Cogdoll, Christina, eds. Popular Eugenics: National Efficiency and American Mass Culture in the
1930s. Athens, OH: Ohio University Press, 2006: 359-384.7 fn. NRCBL: 15.5; 11.3; 8.3.4; 21.4; 1.3.5; 2.2. Keywords: *eugenics; *historical aspects; *National Socialism; involuntary sterilization; legal aspects; mentally disabled persons; prisoners; professional organizations; state government; Proposed Keywords: *exhibits; museums; Keyword Identifiers: *United States; Germany; Twentieth Century

Savulescu, Julian. In defence of procreative beneficence. Journal of Medical Ethics 2007 May; 33(5): 284-288. 17 refs. NRCBL: 15.5; 1.1; 14.1; 14.4; 15.2; 15.3; 9.5.1. SC: an.

Weiss, Sheila Faith. Human genetics and politics as mutually beneficial resources: the case of the Kaiser Wilhn Institute for Anthropology, Human Heredity and Eugenics during the Third Reich. Journal of the History of Biology 2006 Spring; 39(1): 41-88. NRCBL: 15.5; 1.3.5; 15.11; 2.2.


Selgelid, Michael J. Neugenics? Monash Bioethics Review 2000 October; 19(4): 9-33. NRCBL: 15.5; 15.2; 15.3; 5.3; 2.2; 15.10. SC: an.

Weiss, Sheila Faith. Human genetics and politics as mutually beneficial resources: the case of the Kaiser Wilhn Institute for Anthropology, Human Heredity and Eugenics during the Third Reich. Journal of the History of Biology 2006 Spring; 39(1): 41-88. NRCBL: 15.5; 1.3.5; 15.11; 2.2.


Euthanasia and allowing to die

See also ADVANCE DIRECTIVES; ASSISTED SUICIDE; DEATH AND DYING


Euthanasia in Belgium up by 10% [news]. BMJ: British Medical Journal 2007 April 7; 334(7596): 714. NRCBL: 20.5.1.


Bendiane, Marc-Karim; Bouhnik, Anne-Deborah; Favre, Roger; Galinier,Anne; Obadia, Yolande; Moatti, Jean-Paul; Peretti-Watel, Patrick. Morphine prescription in end-of-life care and euthanasia: French home nurses’ opinions. Journal of Opioid Management 2007 January-February; 3(1): 21-26. NRCBL: 20.5.1; 20.4.1; 9.7; 4.4.


Abstract: BACKGROUND: Evidence concerning how Japanese physicians think and behave in specific clinical situations that involve withholding or withdrawal of medical interventions for end-of-life or frail elderly patients is yet insufficient. METHODS: To analyze decisions and actions concerning the withholding/withdrawal of life-support care by Japanese physicians, we conducted cross-sectional web-based internet survey presenting three scenarios involving an elderly comatose patient following a severe stroke. Volunteer physicians were recruited for the survey through mailing lists and medical journals. The respondents answered questions concerning attitudes and behaviors regarding decision-making for the withholding/withdrawal of life-support care, namely, the initiation/withdrawal of tube feeding.
and respirator attachment. RESULTS: Of the 304 responses analyzed, a majority felt that tube feeding should be initiated in these scenarios. Only 18% felt that a respirator should be attached when the patient had severe pneumonia and respiratory failure. Over half the respondents felt that tube feeding should not be withdrawn when the coma extended beyond 6 months. Only 11% responded that they actually withdrew tube feeding. Half the respondents perceived tube feeding in such a patient as a “life-sustaining treatment,” whereas the other half disagreed. Physicians seeking clinical ethics consultation supported the withdrawal of tube feeding (OR, 6.4; 95% CI, 2.5-16.3; P<0.001). CONCLUSION: Physicians tend to harbor greater negative attitudes toward the withdrawal of life-support care than its withholding. On the other hand, they favor withholding invasive life-sustaining treatments such as the attachment of a respirator over less invasive and long-term treatments such as tube feeding. Discrepancies were demonstrated between attitudes and actual behaviors. Physicians may need systematic support for appropriate decision-making for end-of-life care.


Boz, Bora; Acar, Kemalettin; Ergin, Ahmet; Kurtulús, Ayse; Ergin, Nesrin; Oguzhanoglu, Nalan. Effect of locus of control on acceptability of euthanasia among medical students and residents in Denizli, Turkey. *Journal of Palliative Care* 2007 Winter; 23(4): 286-290. NRCBL: 20.5.1; 7.2. SC: em.


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Canadian Researchers at the End of Life Network; Heyland, Daren K.; Frank, Chris; Groll, Dianne; Pichora, Deb; Dodek, Peter; Rocker, Graeme; Gafni, Amiram. Understanding cardiopulmonary resuscitation decision making: perspectives of seriously ill hospitalized patients and family members. *Chest* 2006 August; 130(2): 419-428. NRCBL: 20.5.1; 9.4; 8.3.1; 9.5.2; 1.


Clarkson, Frederick. Tragedy on the national stage: conservative intervention into the Terri Schiavo case was a disservice to everybody. *Conscience* 2007 Autumn; 28(3): 35-38. NRCBL: 20.5.1; 7.1.


Cosgriff, JoAnne Alissi; Pisani, Margaret; Bradley, Elizabeth H.; O’Leary, John R.; Fried, Terri R. The association between treatment preferences and trajectories of care at the end-of-life. *JGIM: Journal of General Internal Medicine*...
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De Gendt, Cindy; Bilsen, Johan; Stichele, Robert Vandcr; Van Den Noortgate, Nele; Lambert, Margareta; Deliens, Luc. Nurses’ involvement in ‘do not resuscitate’ decisions on acute elder care wards. Journal of Advanced Nursing 2007 February; 57(4): 404-409. NRCBL: 20.5.1; 7.1; 9.5.2. SC: em. Identifiers: Belgium.

Doig, Christopher; Murray, Holt; Bellomo, Rinaldo; Kuiper, Michael; Costa, Rubens; Azoulay, Elie; Crippen, David. Ethics roundtable debate: patients and surrogates want ‘everything done’ — what does ‘everything’ mean? Critical Care 2006; 10(5): 231. NRCBL: 20.5.1; 9.4; 8.1; 9.5.1; 21.1. SC: cs. Identifiers: Canada; Australia; Netherlands; France; Brazil.


Eliot, Jaklin; Olver, Ian. Autonomy and the family as (in)appropriate surrogates for DNR decisions: a qualitative analysis of dying cancer patients’ talk. Journal of Clinical Ethics 2007 Fall; 18(3): 206-218. NRCBL: 20.5.1; 8.3.3; 20.5.4; 20.3.3. SC: cs. Identifiers: Australia.


Abstract: In this paper, the ethical and legal issues raised by the deactivation of implantable cardioverter-defibrillators (ICDs) in patients with terminal cancer is considered. It is argued that the ICD cannot be well described either as a treatment or as a non-treatment option, and thus raises complex questions regarding how rules governing deactivation should be framed. A new category called “integral devices” is proposed. Integral devices require their own special rules, reflecting their position as a “halfway house” between a form of treatment and a part of the body. The practical problems faced by doctors working in palliative medicine with regard to the deactivation of ICDs are also considered.

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Friedman, Sandra; Gilmore, Dana. Factors that impact resuscitation preferences for young people with severe developmental disabilities. *Intellectual and Developmental Disabilities* 2007 April; 45(2): 90-97. NRCBL: 20.5.1; 8.3.3. SC: em. Note: Abstract in French.


Abstract: Eugenios Voulgaris (Corfu, Greece, 1716; St Petersburg, Russia, 1806) was an eminent theologian and scholar, and bishop of Kherson, Ukraine. He copiously wrote treatises in theology, philosophy and sciences, greatly influenced the development of modern Greek thought, and contributed to the perception of Western thought throughout the Eastern Christian world. In his Treatise on euthanasia (1804), Voulgaris tried to moderate the fear of death by exalting the power of faith and trust in the divine providence, and by presenting death as a universal necessity, a curative physician and a safe harbour. Voulgaris presented his views in the form of a consoling sermon, abundantly enriched with references to classical texts, the Bible and the Church Fathers, as well as to secular sources, including vital statistics from his contemporary England and France. Besides euthanasia, he introduced terms such as dysthanasia, etoimothanasia and prothanasia. The Treatise on euthanasia is one of the first books, if not the very first, devoted to euthanasia in modern European thought and a remarkable text for the study of the very early European attitudes towards “good death”. In the Treatise, euthanasia is clearly meant as a spiritual preparation and reconciliation with dying rather than a physician-related mercy killing, as the term progressed to mean during the 19th and the 20th centuries. This early text is worthy of study not only for the historian of medical ethics or of religious ethics, but for everybody who is trying to courageously confront death, either in private or in professional settings.


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Jennings, Beth. The politics of end-of-life decision-making: computerised decision-support tools, physicians’ jurisdiction and morality. *Sociology of Health and Illness* 2006 April; 28(3): 350-375. NRCBL: 20.5.1; 9.4; 8.1; 1.3.12; 7.1; 5.3. SC: cs; em.


Kimsma, Geritt K.; van Leeuwen; Evert. The role of family in euthanasia decision making. *HEC (Healthcare Ethics Committee) Forum* 2007 December; 19(4): 365-373. NRCBL: 20.5.1; 8.3.3.


Kwok, Timothy; Twinn, Sheila; Yan, Elsie. The attitudes of Chinese family caregivers of older people with dementia towards life sustaining treatments. *Journal of Advanced Nursing* 2007 May; 58(3): 256-262. NRCBL: 20.5.1; 8.1; 17.1; 9.5.2; 20.3.3. SC: em. Identifiers: Hong Kong.

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Lemiengre, Joke; de Casterlé, Bernadette Dierckx; Van Craen, Kathleen; Schotsmans, Paul; Gastmans, Chris. Institutional ethics policies on medical end-of-life decisions: a literature review. *Health Policy* 2007 October; 83(2-3): 131-143. NRCBL: 20.5.1; 7.1; 9.1. SC: em.

Lemiengre, Joke; Dierckx de Casterlé, Bernadette; Verbeke, Geert; Guisson, Catherine; Schotsmans, Paul; Gastmans, Chris. Ethics policies on euthanasia in hospitals — a survey in Flanders (Belgium). *Health Policy* 2007 December; 84(2-3): 170-180. NRCBL: 20.5.1; 9.1; 7.1. SC: em.


Level of Care Study Investigators; Canadian Critical Care Trials Group; Cook, Deborah; Rocker, Graeme; Marshall, John; Griffith, Lauren; McDonald, Ellen; Guyatt, Gordon. Levels of care in the intensive care unit: a research program. *American Journal of Critical Care* 2006 May; 15(3): 269-379. NRCBL: 20.5.1; 20.5.4; 4.4; 7.1; 8.1.


McCarron, Mary; McCallion, Philip. End-of-life care challenges for persons with intellectual disability and dementia: making decisions about tube feeding. *Intellectual and Developmental Disabilities* 2007 April; 45(2): 128-131. NRCBL: 20.5.1; 8.3.3; 9.5.3.


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Mohindra, Raj. Obligations to treat, personal autonomy, and artificial nutrition and hydration. *Clinical Medicine* 2006 May-June; 6(3): 271-273. NRCBL: 20.5.1; 7.1; 8.1; 8.3.4.

Abstract: This paper introduces the medical factual matrix as a new and potentially valuable tool in medical ethical analysis. Using this tool it demonstrates the idea that a defined medical intervention can only be meaningfully declared futile in relation to a defined goal(s) of treatment. It argues that a declaration of futility made solely in relation to a defined medical intervention is inchoate. It recasts the definition of goal futility as an intervention that cannot alter the probability of the existence of the important outcome states that might flow from a defined intervention. The idea of value futility and the extent of physician obligations in futile situations are also addressed. It also examines the source of substantive conflicts which commonly arise within the doctor-patient relationship and the ensuing power relations that operate between doctor and patient when questions of futility arise.


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Keywords: *disabled persons; *eugenics; *involuntary euthanasia; *Killing; *National Socialism; historical aspects; involuntary sterilization; legal aspects; moral complicity; physicians; quality of life; value of life; Keyword Identifiers: *Germany; Twentieth Century


Abstract: OBJECTIVES: To discover the current state of opinion and practice among doctors in Victoria, Australia, regarding end-of-life decisions and the legalisation of voluntary euthanasia. Longitudinal comparison with similar 1987 and 1993 studies. Design and PARTICI-
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Peiffer, Jürgen. Phases in the postwar German reception of the “Euthanasia Program” (1939-1945) involving the killing of the mentally disabled and its exploitation by neuroscientists. Journal of the History of the Neurosciences 2006 September; 15(3): 210-244. NRCBL: 20.5.1; 21.4; 1.3.5; 2.2; 9.5.3.

Pence, Gregory E. Is there a duty to die? In his: The Elements of Bioethics. Boston: McGraw-Hill, 2007: 233-262. NRCBL: 20.5.1; 9.4; 9.3.1; 9.5.2; 17.1; 20.5.4. SC: cs.


Rietjens, Judith A.C.; Bilsen, Johan; Fischer, Susanne; Van Der Heide, Agnes; Van Der Maas, Paul J.; Miccinessi, Guido; Norup, Michael; Onwuteaka-Philipsen, Bregje D.; Vrakking, Astrid M.; Van Der Wal, Gerrit. Using drugs to end life without an explicit request of the patient. Death Studies 2007 March; 31(3): 205-221. NRCBL: 20.5.1; 8.1; 9.7. SC: em. Identifiers: Belgium; Denmark; Sweden; Netherlands.

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Rubin, Susan B. If we think it’s futile, can’t we just say no? HEC (Healthcare Ethics Committee) Forum 2007 March; 19(1): 45-65. NRCBL: 20.5.1; 8.1; 7.3; 20.3.2; 20.3.3.


Schaffer, Marjorie A. Ethical problems in end-of-life decisions for elderly Norwegians. Nursing Ethics 2007 March; 14(2): 242-257. NRCBL: 20.5.1; 9.5.2. SC: em. Abstract: Norwegian health professionals, elderly people, and family members experience ethical problems involving end-of-life decision making for elders in the context of the values of Norwegian society. This study used ethical inquiry and qualitative methodology to conduct and analyze interviews carried out with 25 health professionals, six elderly people and five family members about the ethical problems they encountered in end-of-life decision making in Norway. All three participant groups experienced ethical problems involving the adequacy of health care for elderly Norwegians. Older people were concerned about being a burden to their families at the end of their life. However, health professionals wished to protect families from the burden of difficult decisions regarding health care for elderly parents at the end of life. Strategies are suggested for dialogue about end-of-life decisions and the integration of palliative care approaches into health care services for frail elderly people.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme

See inside front cover for terms.
Abstract: OBJECTIVES: To study the attitudes of both medical and non-medical students towards the do-not-resuscitate (DNR) decision in a university in Hong Kong, and the factors affecting their attitudes. METHODS: A questionnaire-based survey conducted in the campus of a university in Hong Kong. Preferences and priorities of participants on cardiopulmonary resuscitation in various situations and case scenarios, experience of death and dying, prior knowledge of DNR and basic demographic data were evaluated. RESULTS: A total of 766 students participated in the study. There were statistically significant differences in their DNR decisions in various situations between medical and non-medical students, clinical and preclinical students, and between students who had previously experienced death and dying and those who had not. A prior knowledge of DNR significantly affected DNR decision, although 66.4% of non-medical students and 18.7% of medical students had never heard of DNR. 74% of participants from both medical and non-medical fields considered the patient’s own wish as the most important factor that the healthcare team should consider when making DNR decisions. Family wishes might not be decisive on the choice of DNR. CONCLUSIONS: Students in medical and non-medical fields held different views on DNR. A majority of participants considered the patient’s own wish as most important in DNR decisions. Family wishes were considered less important than the patient’s own wishes.

Shapiro, Dvorah S.; Friedmann, Reuven. To feed or not to feed the terminal demented patient — is there any question? Israel Medical Association Journal 2006 July; 8(7): 507-508. NRCBL: 20.5.1; 17.1; 9.5.2.


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Keywords: *active euthanasia; *historical aspects; *killing; *mentally disabled persons; *National Socialism, adults; attitude of health personnel; children; eugenics; public opinion; religion; Keyword Identifiers: *Germany; *Twentieth Century

White, Douglas B.; Braddock, Clarence H., III; Bereknyei, Sylvia; Curtis, J. Randall. Toward shared decision making at the end of life in intensive care units: opportunities for improvement. Archives of Internal
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Brock, Dan W.; Truog, Robert D.; Brett, Allan S.; Frader, Joel; Downie, Jocelyn. Withholding and withdrawing life-sustaining treatment. In: *Baylis, François; Downie, Jocelyn; Freedman, Benjamin; Hoffmaster, Barry; Sherwin, Susan, eds. Health Care Ethics in Canada*. Toronto: Harcourt Brace Canada, 1995: 487-525. NRCBL: 20.5.1; 9.4; 8.1; 20.5.4. SC: le. Note: Section includes: Introduction — Forgoing life-sustaining food and water: is it killing? / Dan W. Brock — The problem with futility / Robert D. Truog, Allan S. Brett and Joel Frader — “Where there is a will, there may be a better way”: legislating advance directives / Jocelyn Downie.


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2007 July 12-25; 16(13): 816-818. NRCBL: 20.5.1; 8.3.3. SC: le. Identifiers: Great Britain (United Kingdom).

Hall, Mark A.; Bobinski, Mary Anne; Orentlicher, David. The right and “duty” to die. In their: Bioethics and Public Health Law. New York: Aspen Publishers, 2005: 221-338. NRCBL: 20.5.1; 20.7; 20.5.2; 8.3.3. SC: le; cs.


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Long, Robert Emmet. Nancy Cruzan and the “right to die”. In his: Suicide. New York: H.W. Wilson, 1995: 54-75. NRCBL: 20.5.1; 8.3.3; 8.3.4; 2.2. SC: le.


Naudts, Kris; Ducatelle, Caroline; Kovacs, Jozsef; Laurens, Kristin; van den Eynde, Frederique; van Heereningen, Cornelis. Euthanasia: the role of the psychiatrist. British Journal of Psychiatry 2006 May; 188: 405-409. NRCBL: 20.5.1; 4.3; 17.1; 21.1. SC: le.


Perry, Joshua E. Biopolitics at the bedside: proxy wars and feeding tubes. Journal of Legal Medicine 2007 April-June; 28(2): 171-192. NRCBL: 20.5.1; 8.3.2; 2.1; 2.4. SC: le.


SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review

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Sheperd, Lois. Terri Shiavo: unsettling the settled. Loyola University Chicago Law Journal 2006 Winter; 37(2): 297-341. NRCBL: 20.5.1; 8.3.3; 8.3.4; 20.5.4. SC: le.


Spurgeon, Brad. Clipped Decision-making. Dordrecht: Springer, 2005: 297-341. NRCBL: 20.5.1; 8.3.3; 8.3.4; 20.5.4. SC: le.

Shepherd, Lois. Euthanasia and allowing to die/ minors. University Chicago Law Journal 2006 Winter; 37(2): 297-341. NRCBL: 20.5.1; 8.3.3; 8.3.4; 20.5.4. SC: le.


Starks, Helene; Back, Anthony L.; Pearlman, Roberta A.; Koenig, Barbara A.; Hsu, Clarissa; Gordon, Judith R.; Bharucha, Ashok J. Family member involvement in hastened death. Death Studies 2007 February; 31(2): 105-130. NRCBL: 20.5.1; 9.4; 20.3.3; 1.1. SC: cs; le.


Wilcockson, Michael. Euthanasia and doctors’ ethics. In his: Issues of Life and Death. London: Hodder and Stoughton Educational, 1999: 57-71. NRCBL: 20.5.1; 20.5.2; 20.7; 8.1; 1.1; 1.2. SC: cs; le.


EUTHANASIA AND ALLOWING TO DIE/ MINORS


Carnevale, Franco A. The birth of tragedy in pediatrics: a phronetic conception of bioethics. Nursing Ethics 2007 September; 14(5): 571-582. NRCBL: 20.5.2; 1.1; 2.1; 8.3.2; 9.6. Abstract: Accepted standards of parental decisional autonomy and child best interests do not address adequately the complex moral problems involved in the care of critically ill children. A growing body of moral discourse is calling for the recognition of ‘tragedy’ in selected human problems. A tragic dilemma is an irresolvable dilemma with forced terrible alternatives, where even the virtuous agent inescapably emerges with ‘dirty hands’. The shift in moral framework described here recognizes that the form of conduct called for by tragic dilemmas is the practice of phronesis. The phronetic agent has acquired a capacity to discern good agency in tragic circumstances. This discernment is practiced through the artful creation of moral narratives: stories that convey that which is morally meaningful in a particular situation; that is, stories that are ‘meaning making’. The phronetic agent addresses tragic dilemmas involving children as a narrator of contextualized temporal embodied human (counter) stories.


Cremer, R.; Binoche, A.; Noizet, O.; Fourier, C.; Leteurte, S.; Moutel, G; Leclerc, F. Are the GFRUP’s...

Abstract: OBJECTIVE: To evaluate feasibility of the guidelines of the Groupe Francophone de Réanimation et Urgence Pédiatriques (French-speaking group of paediatric intensive and emergency care; GFRUP) for limitation of treatments in the paediatric intensive care unit (PICU). DESIGN: A 2-year prospective survey. SETTING: A 12-bed PICU at the Hôpital Jeanne de Flandre, Lille, France. PATIENTS: Were included when limitation of treatments was expected. RESULTS: Of 967 children admitted, 55 were included with a 2-day median delay. They were younger than others (24 v 60 months), had a higher paediatric risk of mortality (PRISM) score (14 v 4), and a higher paediatric overall performance category (POPC) score at admission (2 v 1); all p<0.002. 34 (50% of total deaths) children died. A limitation decision was made without meeting for 7 children who died: 6 received do-not-resuscitate orders (DNRs) and 1 received withholding decision. Decision-making meetings were organised for 31 children, and the following decisions were made: 12 DNRs (6 deaths and 6 survivals), 4 withholding (1 death and 3 survivals), with 14 withdrawing (14 deaths) and 1 continuing treatment (survival). After limitation, 21 (31% of total deaths) children died and 10 survived (POPC score 4). 13 procedures were interrupted because of death and 11 because of clinical improvement (POPC score 4). Parents’ opinions were obtained after 4 family conferences (for a total of 110 min), 3 days after inclusion. The first meeting was planned for 6 days after inclusion and held on the 7th day after inclusion; 80% of parents were immediately informed of the decision, which was implemented after half a day. CONCLUSIONS: GFRUP’s procedure was applicable in most cases. The main difficulties were anticipating the correct date for the meeting and involving nurses in the procedure. Children for whom the procedure was interrupted because of clinical improvement and who survived in poor condition without a formal decision pointed out the need for medical criteria for questioning, which should lead to a formal decision-making process.


Friedman, Sandra L. Parent resuscitation preferences for young people with severe developmental disabilities. *Journal of the American Medical Directors Association* 2006 February; 7(2): 67-72. NRCBL: 20.5.2; 20.5.4; 8.3.2; 9.5.3. SC: em.

Howe, Edmund G. When family members disagree. *Journal of Clinical Ethics* 2007 Winter; 18(4): 331-339. NRCBL: 20.5.2; 20.3.3; 20.4.2; 20.5.4; 9.6. SC: cs.

Isaacs, David; Kilham, Henry; Gordon, Adrienne; Jeffery, Heather; Tarnow-Mordi, William; Woolnough, Janet; Hamblin, Julie; Tobin, Bernadette. Withdrawal of neonatal mechanical ventilation against the parents’ wishes. *Journal of Paediatrics and Child Health* 2006 May; 42(5): 311-315. NRCBL: 20.5.2; 8.3.2; 9.4; 8.1; 1.1.

Jaing, Tang-Her; Tsay, Pei-Kwei; Fang, En-Chen; Yang, Shu-Ho; Chen, Shih-Hsiang; Yang, Chao-Ping; Hung, lou-Jih. “Do-not-resuscitate” orders in patients with cancer at a children’s hospital in Taiwan. *Journal of Medical Ethics* 2007 April; 33(4): 194-196. NRCBL: 20.5.2; 9.5.7; SC: em.

Abstract: OBJECTIVES: To quantify the use of do-not-resuscitate (DNR) orders in a tertiary-care children’s hospital and to characterise the circumstances in which such orders are written. DESIGN: Retrospective study conducted in a 500-bed children’s hospital in Taiwan. PATIENTS: The course of 101 patients who died between January 2002 and December 2005 was reviewed. The following data were collected: age at death, gender, disease and its status, place of death and survival. There were 59 males and 42 females with a median age of 103 months (range 1-263 months). 50 children had leukaemias, and 51 had malignancies other than leukaemia. The t test and the chi(2) test were applied as appropriate. RESULTS: The study found that 44% of patient deaths occurred in the paediatric oncology ward; 29% of patient deaths occurred in the intensive care unit; and 28% of patients died in their home or at another hospital. Other findings included the following: 46 of 101 (46%) patients died after attempted cardiopulmonary resuscitation and 55 (54%) died with a DNR order in effect. The
mean age at death was 9.8 years in both groups with or without DNR orders. CONCLUSIONS: From the study of patient deaths in this tertiary-care children’s hospital, it was concluded that an explicit DNR order is now the rule rather than the exception, with more DNR orders being written for patients who have been ill longer, who have solid tumours, who are not in remission and who are in the ward.


Jonas, Monique. The Baby MB case: medical decision making in the context of uncertain infant suffering. *Journal of Medical Ethics* 2007 September; 33(9): 541-544. NRCBL: 20.5.2; 8.3.2; 4.4. SC: an. Identifiers: Great Britain (United Kingdom).

Kaposy, Chris. Can infants have interests in continued life? *Theoretical Medicine and Bioethics* 2007; 28(4): 301-330. NRCBL: 20.5.2; 1.1; 4.4; 12.3; 22.1. SC: an. Abstract: The philosophers Peter Singer and Jeff McMahan hold variations of the view that infant interests in continued life are suspect because infants lack the cognitive complexity to anticipate the future. Since infants cannot see themselves as having a future, Singer argues that the future cannot have value for them, and McMahan argues that the future can only have minimal value for an infant. This paper critically analyzes these arguments and defends the view that infants can have interests in continuing to live. Even though infants themselves lack a strong psychological connection to the future, others who are involved in an infant’s life can anticipate, on an infant’s behalf, the kind of future that awaits the infant, and on the basis of this insight judge that continuing to live would be in the infant’s interests. After defending this position, I argue that this position on the interests of infants in continued life does not commit one to opposing abortion, and it does not commit one to the view that our ethical obligations to protect the lives of sentient animals are the same as our ethical obligations to protect infant lives.

Kipnis, Kenneth. Harm and uncertainty in newborn intensive care. *Theoretical Medicine and Bioethics* 2007; 28(5): 393-412. NRCBL: 20.5.2; 8.3.2; 8.3.4. Abstract: There is a broadly held view that neonatologists are ethically obligated to act to override parental non-treatment decisions for imperiled premature newborns when there is a reasonable chance of a good outcome. It is argued here that three types of uncertainty undercut any such general obligation: (1) the vagueness of the boundary at which an infant’s deficits become so intolerable that death could be reasonably preferred; (2) the uncertainty about whether aggressive treatment will result in the survival of a reasonably healthy child or, alternatively, the survival of a child with intolerable deficits; and (3) the inability to determine an acceptable ratio between the likelihoods of those two outcomes. It is argued that the broadly held view accords insufficient weight to the fact that newborn intensive care increases the likelihood of harm to the child by effecting survival with intolerable deficits. Though treatment may offer a reasonable chance of a good outcome, it is argued that there are situations in which neonatologists should nonetheless defer to parental non-treatment decisions.

Kon, Alexander A. Neonatal euthanasia is unsupportable: the Groningen Protocol should be abandoned. *Theoretical Medicine and Bioethics* 2007; 28(5): 453-463. NRCBL: 20.5.2; 4.4. SC: an. Identifiers: Netherlands. Abstract: The growing support for voluntary active euthanasia (VAE) is evident in the recently approved Dutch Law on Termination of Life on Request. Indeed, the debate over legalized VAE has increased in European countries, the United States, and many other nations over the last several years. The proponents of VAE argue that when a patient judges that the burdens of living outweigh the benefits, euthanasia can be justified. If some adults suffer to such an extent that VAE is justified, then one may conclude that some children suffer to this extent as well. In an attempt to alleviate the suffering of extremely ill neonates, the University Medical Center Groningen developed a protocol for neonatal euthanasia. In this article, I first present the ethical justifications for VAE and discuss how these arguments relate to euthanizing ill neonates. I then argue that, even if one accepts the justification for VAE in adults, neonatal euthanasia cannot be supported, primarily because physicians and parents can never accurately assess the suffering of children. I argue that without the testament of the patient herself as to the nature and magnitude of her suffering, physicians can never accurately weigh the benefits and burdens of a child’s life, and therefore any such system would condemn to death some children whose suffering is not unbearable. I conclude that because the primary duty of physicians is to never harm their patients, neonatal euthanasia cannot be supported.


McGraw, Melanie P.; Perlman, Jeffrey; Chervenak, Frank A.; McCullough, Laurence B. Clinical concepts of futility and ethically justified limits on neonatal care: a case presentation of an infant with Apgar scores of 0 at 1, 5, and 10 minutes. *American Journal of Perinatology* 2006 April; 23(3): 159-162. NRCBL: 20.5.2; 9.4; 7.1. SC: cs.

Mercurio, M.R. Parental authority, patient’s best interest and refusal of resuscitation at borderline gestational age. *Journal of Perinatology* 2006 August; 26(8): 452-457. NRCBL: 20.5.2; 9.5.8; 8.3.2; 8.3.4.


Abstract: Court Decision: 641 New York Supplement, 2d Series 989; 28 Feb 1996 (date of decision). The Supreme Court of New York authorized a hospital to withdraw artificial respiratory support from a brain-dead infant. After several days of care and testing, two hospital physicians certified the five-month-old baby on artificial respiratory support was brain dead. A medical expert retained by the infant’s parents, an anesthesiologist father and an attorney mother, concurred with that medical assessment. The court held that the conclusion of all three medical experts was consistent with the definition of death set forth under state law. The court also held that the hospital adequately notified the parents of their baby’s status, and that the hospital fulfilled its obligations as set forth in the hospital’s administrative manual. However, because the hospital did not have a written policy regarding “reasonable accommodation” of the individual’s religious or moral objection, the court reviewed the facts to determine this issue. Finding that the hospital did, in fact, reasonably accommodate parents’ religious and moral beliefs, the court granted an order authorizing the hospital’s withdrawal of the baby’s artificial respiratory support.


Abstract: In the twenty-first century, decisions to withhold or withdraw life-supporting measures commonly precede death in the neonatal intensive care unit without major ethical controversy. However, caregivers often feel much greater turmoil with regard to stopping medical hydration and nutrition than they do when considering discontinuation of mechanical ventilation or circulatory support. Nevertheless, forgoing medical fluids and food represents a morally acceptable option as part of a carefully developed palliative care plan considering the infant’s prognosis and the burdens of continued treatment. Decisions to stop any form of life support should focus on the clinical circumstances, not the means used to sustain life.


Richards, N. Life or death decisions in the NICU. *Journal of Perinatology* 2006 April; 26(4): 248-251. NRCBL: 20.5.2; 8.3.2; 4.4; 9.4. Identifiers: neonatal intensive care unit.


Abstract: This paper discusses the persistent devaluation of the girl child in India and the link between the entrenched perception of female valuelessness and the actual practice of infanticide of girl babies or foetuses. It seeks to place female infanticide, or ‘gendericide,’ within the context of Western-derived conceptions of ethics, justice and rights. To date, current ethical theories and internationally purveyed moral frameworks, as well as legal and political declarations, have fallen short of an adequate moral appraisal of infanticide. This paper seeks to rethink the issue.

Singer, Peter. Treating (or not) the tiniest babies. *Free Inquiry* 2007 June-July; 27(4): 20-21. NRCBL: 20.5.2; 9.5.7; 8.3.2; 9.4.

Steger, Florian. Neuropathological research at the “Deutsches Forschungszentrum fuer Psychiatrie” (German Institute for Psychiatric Research) in Munich (Kaiser-Wilhelm-Institute). Scientific utilization of children’s organs from the “Kinderfachabteilungen” (Children’s Special Departments) at Bavarian State Hospitals. *Journal of the History of the Neurosciences* 2006 September; 15(3): 173-185. NRCBL: 20.5.2; 9.5.3; 9.5.7; 21.4; 1.3.5; 2.2.


Abstract: With the rapid development of biotechnology, the physician is now more able to keep a patient’s life going indefinitely on a life support system. The question of
whether we should switch off the machine often arises when, according to the medical prognosis, there is no hope of recovery, or in a no-win situation where you are ‘damned if you do and damned if you don’t’. In a case which seems without hope, the dilemma of whether to prolong a life or let it go disturbs many people, including health professionals as well as the family of the patient. In this painful situation, an ethics consultant who has received intensive training can help the concerned parties to arrive at what may be the best decision. How do Asians, especially those living in countries influenced by Confucian teachings, reach their answers? Three aspects are usually considered: (1) motivation and situation; (2) reasonableness and propriety; and (3) lawfulness and legality. More specifically, three questions are deliberated, as follows. (1) Where an action has already been taken, what motivated it and in what situation? Or, where a decision has still to be made, what should motivate it, and what are the relevant features of the situation? (2) Was the attempted resolution of the dilemma, or its prospective resolution, reasonable and in accordance with traditional principles of ethical behaviour? (3) Was the action taken lawful, or would the intended action be lawful? This approach to finding an answer has been practised for centuries in Confucian society. But what is legal may not always be reasonable, what is reasonable may not always be compassionate, and what is compassionate may not always be either legal or reasonable. Principles to guide decision-making are therefore called for. This article, written by Michael Cheng-tek Tai in collaboration with Donald Hill, discusses the Confucian method of solving a problem and examines its principal features and how they are applied in ethics consultations. The article is followed by a series of questions and answers and a commentary by Donald Hill.


Thomas, Florian P.; Beres, Alana; Shevell, Michael I. “A cold wind coming”: Heinrich Gross and child euthanasia in Vienna. Journal of Child Neurology 2006 April; 21(4): 342-348. NRCBL: 20.5.2; 18.5.2; 1.3.9; 15.5; 2.2.


Veatch, Robert M. Court authorizes withdrawing of ventilator and nutrition. Ethics and Intellectual Disability 2006 Spring; 9(2): 1, 3-4. NRCBL: 20.5.2; 9.5.3. SC: le.


EUTHANASIA AND ALLOWING TO DIE/ PHILOSOPHICAL ASPECTS


Abstract: Applied ethics engages with concrete moral issues. This engagement involves the application of philosophical tools. When the philosophical tools used in applied ethics are problematic, conclusions about applied problems can become skewed. In this paper, I focus on problems with the idea that comparison cases must be exactly alike, except for the moral issue at hand. I argue that this idea has skewed the debate regarding the moral distinction between killing and letting die. I begin with problems that can arise from attempts to produce comparison cases that are exactly alike, except for the moral issue at hand. I then argue that attempts to produce such examples are doomed to failure. Finally, I argue that abandoning concerns about similarity advances the debate regarding the moral distinction between killing and letting die.

Ball, Susan C. Nurse-patient advocacy and the right to die. Journal of Psychosocial Nursing and Mental Health Services 2006 December; 44(12): 36-42. NRCBL: 20.5.1; 4.1.3; 8.1.


Abstract: OBJECTIVES: To assess French district nurses’ opinions towards euthanasia and to study factors associated with these opinions, with emphasis on attitudes towards terminal patients. DESIGN AND SETTING: An anonymous telephone survey carried out in 2005 among a national random sample of French district nurses. PARTICIPANTS: District nurses currently delivering home care who have at least 1 year of professional experience. Of 803 district nurses contacted, 602 agreed
to participate (response rate 75%). MAIN OUTCOME MEASURES: Opinion towards the legalisation of euthanasia (on a five-point Likert scale from “strongly agree” to “strongly disagree”), attitudes towards terminal patients (discussing end-of-life issues with them, considering they should be told their prognosis, valuing the role of advance directives and surrogates). RESULTS: Overall, 65% of the 602 nurses favoured legalising euthanasia. Regarding associated factors, this proportion was higher among those who discuss end-of-life issues with terminal patients (70%), who consider competent patients should always be told their prognosis (81%) and who value the role of advance directives and surrogates in end-of-life decision-making for incompetent patients (68% and 77% respectively). Women and older nurses were less likely to favour legalising euthanasia, as were those who believed in a god who masters their destiny. CONCLUSIONS: French nurses are more in favour of legalising euthanasia than French physicians; these two populations contrast greatly in the factors associated with this support. Further research is needed to investigate how and to what extent such attitudes may affect nursing practice and emotional well-being in the specific context of end-of-life home care.

**Activities**

**Benedict, Susan; Caplan, Arthur; Page, Traute Lefrenz.** Duty and ‘euthanasia’: the nurses of Meseritz-Obrawalde. Nursing Ethics 2007 November; 14(6): 781-794. NRCBL: 20.5.1; 4.1.3; 21.4; 2.2. Identifiers: Germany.

**Bosek, Marcia Sue DeWolf; Stammer, Karen.** Ethical commitments during desperate times. JONA’s Healthcare Law, Ethics, and Regulation 2006 October-December; 8(4): 123-128. NRCBL: 20.5.1; 4.1.3. Identifiers: Hurricane Katrina; Louisiana.

**Carmel, Sara; Werner, Perla; Ziedenberg, Hanna.** Physicians’ and nurses’ preferences in using life-sustaining treatments. Nursing Ethics 2007 September; 14(5): 665-674. NRCBL: 20.5.1; 4.1.2; 4.1.3. SC: em.

**Abstract:** This study examined why intensive care unit (ICU) nurses experience difficulties in respecting the wishes of patients in end-of-life care in Japan. A questionnaire survey was conducted with ICU nurses working in Japanese university hospitals. The content of their narratives was analyzed concerning the reasons why the nurses believed that patients’ wishes were not respected. The most commonly stated reason was that patients’ wishes were impossible to realize, followed by the fact that decision making was performed by others, regardless of whether the patients’ wishes were known, if the death was sudden, and time constraints. Many nurses wanted to respect the wishes of dying patients, but they questioned how patients die in ICUs and were therefore faced with ethical dilemmas. However, at the same time, many of the nurses realized that respecting patients’ wishes about end-of-life care in an ICU would be difficult and that being unable to respect these wishes would often be unavoidable. The results thus suggest that there has been insufficient discussion about respecting the wishes of patients undergoing intensive care.


**Cook, Deborah; Rocker, Graeme; Giacomini, Mita; Sinuff, Tasnim; Heyland, Daren.** Understanding and changing attitudes toward withdrawal and withholding of life support in the intensive care unit. Critical Care Medicine 2006 November; 34(11, Supplement): S317-S323. NRCBL: 20.5.1; 20.3.2; 1.1; 8.1; 9.4.

**Dennis, William J.** What is death with dignity? Ethics and Medicine 2007 August; 32(8): 1-2. NRCBL: 20.5.1; 4.4; 4.2; 1.1. Identifiers: Jack Kevorkian.

**Ferrell, Betty R.** Understanding the moral distress of nurses witnessing medically futile care. Oncology Nursing Forum 2006 September 1; 33(5): 922-930. NRCBL: 20.5.1; 4.1.3; 7.1; 1.1.


**Abstract:** This essay rebuts Gary Seay’s efforts to show that committing euthanasia need not conflict with a physician’s professional duties. First, I try to show how his misunderstanding of the correlativity of rights and duties and his discussion of the foundation of moral rights undermine his case. Second, I show aspects of physicians’ professional duties that clash with euthanasia, and that attempts to avoid this clash lead to absurdities. For professional duties are best understood as deriving from professional virtues and the commitments and purposes with which the professional as such ought to act, and there is no plausible way in which her death can be seen as advancing the patient’s medical welfare. Third, I argue against Prof. Seay’s assumption that apparent conflicts among professional duties must be resolved through “balancing” and argue that, while the physician’s duty to extend life is continuous with her duty to protect health, any duty to relieve pain is subordinate to these. Finally, I show what is morally determinative here, as throughout the moral life, is the agent’s intention and that Prof. Seay’s implicitly preferred consequentialism threatens not only to distort moral thinking but would altogether undermine the medical (and any other) profession and its internal ethics.


**Gavrin, Jonathan R.** Ethical considerations at the end of life in the intensive care unit. Critical Care Medicine 2007 February; 35(2, Supplement): S85-S94. NRCBL: 20.5.1; 1.1; 20.4.1; 7.1; 9.4.
SECTION I  EUTHANASIA AND ALLOWING TO DIE/ PHILOSOPHICAL ASPECTS


Abstract: The right to refuse medical intervention is well established, but it remains unclear how best to respect and exercise this right in life support. Contemporary ethical guidelines for critical care give ambiguous advice, largely because they focus on the moral equivalence of withholding and withdrawing care without confronting the very real differences regarding who is aware and informed of intervention options and how patient values are communicated and enacted. In withholding care, doctors typically withhold information about interventions judged too futile to offer. They thus retain greater decision-making burden (and power) and face weaker obligations to secure consent from patients or proxies. In withdrawing care, there is a clearer imperative for the doctor to include patients (or proxies) in decisions, share information and secure consent, even when continued life support is deemed futile. How decisions to withhold and withdraw life support differ ethically in their implications for positive versus negative interpretations of patient autonomy, imperatives for consent, definitions of futility and the subjective evaluation of (and submission to) benefits and burdens of life support in critical care settings are explored. Professional reflection is required to respond to trends favouring a more positive interpretation of patient autonomy in the context of life support decisions in critical care. Both the bioethics and critical care communities should investigate the possibilities and limits of growing pressure for doctors to disclose their reasoning or seek patient consent when decisions to withhold life support are made.

Hov, Reidun; Hedelin, Birgitta; Athlin, Elsy. Being an intensive care nurse related to questions of withdrawing or curative treatment. *Journal of Clinical Nursing* 2007 January; 16(1): 203-211. NRCBL: 20.5.1; 7.1; 4.1.3; 8.1.


Abstract: The Dutch case of Brongersma presents novel challenges to the definition and evaluation of voluntary euthanasia since it involved a doctor assisting the suicide of an individual who was (merely?) ‘tired of life’. Legal officials had called on the courts to ‘set a principled boundary’, excluding such cases from the scope of permissible voluntary euthanasia, but they arguably failed. This failure is explicable, however, since the case seems justifiable by reference to the two major principles in favour of that practice, respect for autonomy and beneficence. Ultimately, it will be argued that those proponents of voluntary euthanasia who are wary of its use in such circumstances may need to draw upon ‘practical’ objections, in order to erect an otherwise arbitrary perimeter. Furthermore, it will be suggested that the issues raised by the case are not peculiarly Dutch in nature and that, therefore, there are lessons here for other jurisdictions too.


Kaczor, Christopher. Philosophy and theology: the authority of Pope John Paul II allocation; is ANH required for PVS patients?; papal allocution and Catholic tradition; human life as intrinsic good; *National Catholic Bioethics Quarterly* 2007 Autumn; 7(3): 595-605. NRCBL: 20.5.1; 1.1; 1.2; 4.4. Identifiers: artificially administered nutrition and hydration; persistent vegetative state.


Abstract: This study examined why intensive care unit (ICU) nurses experience difficulties in respecting the wishes of patients in end-of-life care in Japan. A questionnaire survey was conducted with ICU nurses working in Japanese university hospitals. The content of their narratives was analyzed concerning the reasons why the nurses believed that patients’ wishes were not respected. The most commonly stated reason was that patients’ wishes were impossible to realize, followed by the fact that decision making was performed by others, regardless of whether the patients’ wishes were known, if the death was sudden, and time constraints. Many nurses wanted to respect the wishes of dying patients, but they questioned how patients die in ICUs and were therefore faced with ethical dilemmas. However, at the same time, many of the nurses realized that respecting patients’ wishes about end-of-life care in an ICU would be difficult and that being unable to respect these wishes would often be unavoidable. The results thus suggest that there has been insufficient discussion about respecting the wishes of patients undergoing intensive care.


Kumas, Gulsah; Óztunc, Gürsel; Alparslan, Z. Nazan. Intensive care unit nurses’ opinions about euthanasia.
EUTHANASIA AND ALLOWING TO DIE/ PHILOSOPHICAL ASPECTS

SECTION I


Abstract: This study was conducted to gain opinions about euthanasia from nurses who work in intensive care units. The research was planned as a descriptive study and conducted with 186 nurses who worked in intensive care units in a university hospital, a public hospital, and a private not-for-profit hospital in Adana, Turkey, and who agreed to complete a questionnaire. Euthanasia is not legal in Turkey. One third (33.9%) of the nurses supported the legalization of euthanasia, whereas 39.8% did not. In some specific circumstances, 44.1% of the nurses thought that euthanasia was being practiced in our country. The most significant finding was that these Turkish intensive care unit nurses did not overwhelmingly support the legalization of euthanasia. Those who did support it were inclined to agree with passive rather than active euthanasia (P = 0.011).


McCabe, Helen. Nursing involvement in euthanasia: how sound is the philosophical support? Nursing Philosophy 2007 July; 8(3): 167-175. NRCBL: 20.5.1; 1.1; 4.1.3.


Pijnenburg, Martien A.M.; Leget, Carlo. Who wants to live forever? Three arguments against extending the human lifespan. Journal of Medical Ethics 2007 October; 33(10): 585-587. NRCBL: 20.5.1; 1.1; 4.4; 4.5. SC: an. Abstract: The wish to extend the human lifespan has a long tradition in many cultures. Optimistic views of the possibility of achieving this goal through the latest developments in medicine feature increasingly in serious scientific and philosophical discussion. The authors of this paper argue that research with the explicit aim of extending the human lifespan is both undesirable and morally unacceptable. They present three serious objections, relating to justice, the community and the meaning of life.

Ray, Ratna; Raju, Mohan. Attitude towards euthanasia in relation to death anxiety among a sample of 343 nurses in India. Psychological Reports 2006 August; 99(1): 20-26. NRCBL: 20.5.1; 20.3.2; 4.1.3. SC: em.

Reiter-Theil, Stella; Mertz, Marcel; Meyer-Zehnder, Barbara. The complex roles of relatives in end-of-life decision-making: an ethical analysis. HEC (Healthcare Ethics Committee) Forum 2007 December; 19(4): 341-364. NRCBL: 20.5.1; 8.3.3; 1.1; 20.3.3. SC: em; cs.


Scherer, Yvonne.; Jezewski, Mary Ann; Graves, Brian; Wu, Yow-Wu; Bu, Xiaoyan. Advance directives and end-of-life decision making: survey of critical care nurses’ knowledge, attitude, and experience. Critical Care Nurse 2006 August; 26(4): 30-40. NRCBL: 20.5.1; 20.5.4; 7.1; 4.1.3; 20.3.2. SC: em.


Spurgeon, Brad. Doctors sign petition calling for euthanasia to be decriminalised [news]. *BMJ: British Medical Journal* 2007 March 17; 334(7593): 555. NRCBL: 20.5.1; 4.1.2; 20.3.2. SC: le. Identifiers: France.

Starks, Helene; Back, Anthony L.; Pearlman, Roberta A.; Koenig, Barbara A.; Hsu, Clarissa; Gordon, Judith R.; Bharucha, Ashok J. Family member involvement in hastened death. *Death Studies* 2007 February; 31(2): 105-130. NRCBL: 20.5.1; 9.4; 20.3.3; 1.1. SC: cs; le.

Strouth, Rael D. Hitler’s psychiatrists: healers and researchers turned executioners and its relevance today. *Harvard Review of Psychiatry* 2006 January-February; 14(1): 30-37. NRCBL: 20.5.1; 4.1.2; 17.1; 2.2; 21.4; 7.4.


Tsaloglidou,aret; Rammos, Kyriakos; Kiriklidis, Konstantinos; Zourladani, Athanasia; Matziari, Chrysoula. Nurses’ ethical decision-making role in artificial nutritional support. *British Journal of Nursing* 2007 September 13-27; 16(16): 996-998. NRCBL: 20.5.1; 4.1.3. SC: em.


**EUTHANASIA AND ALLOWING TO DIE/ RELIGIOUS ASPECTS**


Vatican clarifies position on artificial nutrition [news]. *America* 2007 October 1; 197(9): 6. NRCBL: 20.5.1; 1.2.


Bayley, Carol; Cardone, Joseph; Harvey, John Collins; O’Brien, Daniel; Panicola, Michael; Repenshek, Mark; Sheehan, Myles; Worsley, Stephen. Sampling of responses to the CDF statement on nutrition and hydration. *Health Care Ethics USA* 2007 Fall; 15(4): 8-14. NRCBL: 20.5.1; 1.2. Identifiers: Congregation for the Doctrine of the Faith.


Daly, Daniel J. Prudence and the debate on death and dying; in the Catholic theological tradition, temporal life is not the highest good. *Health Progress* 2007 September-October; 88(5): 49-54. NRCBL: 20.5.1; 1.2.


Dennis, William J. What is death with dignity? *Ethics and Medics* 2007 August; 32(8): 1-2. NRCBL: 20.5.1; 4.4; 1.2; 1.1. Identifiers: Jack Kevorkian.

Diamond, Eugene F. Catholic health care decision making [editorial]. *Linacre Quarterly* 2007 May; 74(2): 92-93. NRCBL: 20.5.1; 1.2.


Gesundheit, Benjamin; Steinberg, Avraham; Glick, Shimon; Or, Reuven; Jotkovitz, Alan. Euthanasia: an overview and the Jewish perspective. *Cancer Investigation* 2006 October; 24(6): 621-629. NRCBL: 20.5.1; 1.2; 7.2. SC: rv.


Hong, Suk Young. Patients in a vegetative state and the quality of life. *Dolentium Hominum* 2007; 22(2): 22-27. NRCBL: 20.5.1; 1.2; 2.2; 4.4.


Kaczor, Christopher. Philosophy and theology: the authority of Pope John Paul II allocution; is ANH required for PVS patients?; papal allocution and Catholic tradition; human life as intrinsic good. *National Catholic Bioethics Quarterly* 2007 Autumn; 7(3): 595-605. NRCBL: 20.5.1; 1.1; 1.2; 4.4. Identifiers: artificially administered nutrition and hydration; persistent vegetative state.

Kaplan, Kalman J. Zeno, Job and Terry Schiavo: the right to die versus the right to life. *Ethics and Medicine: An In-
SECTION I  EUTHANASIA AND ALLOWING TO DIE/ RELIGIOUS ASPECTS

international Journal of Bioethics 2007 Summer; 23(2): 95-102. NRCBL: 20.5.1; 1.2; 4.4; 20.7. SC: an.


Linacre Institute. Catholic medical decision-making on the concept of futility. Linacre Quarterly 2007 August; 74(3): 258-262. NRCBL: 20.5.1; 1.2; 9.4.


O’Rourke, Kevin D. Artificial nutrition and hydration and the Catholic tradition: the Terri Schiavo case had even members of Congress debating the issue. Health Progress 2007 May-June; 88(3): 50-54. NRCBL: 20.5.1; 1.2.


Providence Center for Health Care Ethics. A primer for understanding the CDF’s Responses regarding ANH for the PVS patient. Health Care Ethics USA 2007 Fall; 15(4): 15-9. NRCBL: 20.5.1; 1.2. Identifiers: Congregation for the Doctrine of the Faith; artificial nutrition and hydration; persistent vegetative state.


Abstract: In the Roman Catholic tradition the nature of the ordinary/extraordinary means distinction is best understood in light of its historical development. The moralist tradition that reared and nurtured this distinction implicitly developed a set of general criteria to distinguish the extraordinary from the ordinary. These criteria, conjoined with the context within which they were understood, can play an important role in refocusing the contemporary debate over the aggressiveness of medical treatment and the extent of one’s moral obligation.


FETUSES See CARE FOR SPECIFIC GROUPS/ FETUSES; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ EMBRYOS AND FETUSES

FOREIGN NATIONALS See HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ FOREIGN NATIONALS

GENE THERAPY


Keywords: *gene therapy; advisory committees; Christian ethics; clinical trials; cloning; embryonic stem cells; ethical analysis; fetal therapy; future generations; gene transfer techniques; genetic disorders; genetic engineering; genetic enhancement; germ cells; pharmacogenetics; risks and benefits; virtues; Proposed Keywords: transhumanism; Keyword Identifiers: Great Britain; Human Fertilisation and Embryology Authority


Keywords: *clinical trials; gene therapy; guidelines; legal aspects; federal government; government regulation; Keyword Identifiers: *Food and Drug Administration; *United States


Gelsinger, Paul L. Uninformed consent: the case of Jesse Gelsinger. In: Lemmens, Trudo; Waring, Duff R., eds. *Law and Ethics in Biomedical Research: Regulation, Conflict of Interest and Liability*. Toronto; Buffalo: University of Toronto Press, 2006: 12-32. 14 refs. NRCBL: 15.4; 18.3; 1.3.9; 7.3; 8.5; 18.6.

Keywords: *clinical trials; gene therapy; informed consent; adverse effects; altruism; conflict of interest; legal liability; nontherapeutic research; research related injuries; research subjects; Keyword Identifiers: *Gelsinger, Jesse; *University of Pennsylvania; Food and Drug Administration; United States


Keywords: *adverse effects; clinical trials; gene therapy; risks and benefits; death; gene transfer techniques; government regulation; industry; informed consent; international aspects; research subjects; research support; therapeutic misconception; Proposed Keywords: rheumatoid arthritis; Keyword Identifiers: *Mohr, Jolee; Targeted Genetics Corp.; United States


Keywords: *adverse effects; clinical trials; gene therapy; death; gene transfer techniques; industry; research subjects; selection of subjects; Proposed Keywords: arthritis; Keyword Identifiers: Mohr, Jolee; Targeted Genetics Corp.; United States


Keywords: *adverse effects; clinical trials; gene therapy; research subjects; advisory committees; death; industry; Keyword Identifiers: *Mohr, Jolee; Recombinant DNA Advisory Committee; Targeted Genetics Corp.

Keywords: *adverse effects; *clinical trials; *gene therapy; death; drugs; industry; informed consent; research subjects; Proposed Keywords: arthritis; Keyword Identifiers: *Mohr, Jolee; Targeted Genetics Corp.


Keywords: *feminist ethics; *fetal therapy; *gene therapy; *genetic intervention; *government regulation; *legal aspects; chimeras; cloning; embryos; family; freedom; gene pool; genetic determinism; germ cells; human experimentation; preimplantation diagnosis; prenatal diagnosis; public policy; reproduction; reproductive technologies; social impact; women; Keyword Identifiers: *Australia; *Canada


Keywords: *adverse effects; *clinical trials; *conflict of interest; *ethical review; *gene therapy; *research ethics committees; consent forms; death; evaluation; industry; research design; research subjects; research support; Keyword Identifiers: Mohr, Jolee; Targeted Genetics Corp.; United States

Nycum, Gillian; Reid, Lynette. The harm-benefit trade-off in “bad deal” trials. *Kennedy Institute of Ethics Journal* 2007 December; 17(4): 321-350. 80 refs. 11 fn. NRCBL: 15.4; 18.2; 5.2; 1.1. SC: an.

Keywords: *clinical trials; *evaluation; *gene therapy; *gene transfer techniques; *nontherapeutic research; *risks and benefits; adverse effects; altruism; biomedical research; cancer; emotions; ethical review; human experimentation; motivation; prognosis; research design; research ethics committees; research ethics; research subjects; selection of subjects; terminally ill; therapeutic misconception; uncertainty; vulnerable populations; Proposed Keywords: *phase I clinical trials; glioblastoma

Abstract: This paper examines the nature of the harm-benefit trade-off in early clinical research for interventions that involve remote possibility of direct benefit and likelihood of direct harms to research participants with fatal prognoses, by drawing on the example of gene transfer trials for glioblastoma multiforme. We argue that the appeal made by the component approach to clinical equi-
Keywords: *disabled persons; *gene therapy; *genetic engineering; *germ cells; *morality; *self concept; choice behavior; chronically ill; culture; ethical analysis; genetic diversity; hearing disorders; moral policy parents; patient participation; reproduction; suffering; wedge argument


Thomson, Mary M. Bringing research into therapy: liability anyone? In: Lemmens, Trudo; Waring, Duff R., eds. Law and Ethics in Biomedical Research: Regulation, Conflict of Interest and Liability. Toronto; Buffalo: University of Toronto Press, 2006: 183-205. 54 fn. NRCBL: 15.4; 18.3; 1.3.9; 7.3; 8.5; 18.6. SC: le.
Keywords: *clinical trials; *gene therapy; *legal liability; adverse effects; conflict of interest; death; disclosure; gene transfer techniques; informed consent; negligence; research ethics committees; research institutes; research subjects; research support; researchers; risk; Keyword Identifiers: *Canada; *United States; Dent, James; Gelsinger, Jesse

Keywords: *gene therapy; *feminist ethics; *genetic engineering; *moral policy; bioethics; choice behavior; disadvantaged persons; embryos; ethical analysis; fetal therapy; gene transfer techniques; genetic services; health services accessibility; pregnant women; preimplantation diagnosis; risks and benefits; treatment refusal; women

Keywords: *adverse effects; *clinical trials; *gene therapy; *research design: death; drugs; research subjects; uncertainty; Proposed Keywords: rheumatoid arthritis; Keyword Identifiers: *Mohr, Jolee; Targeted Genetics Corp.; United States

Keywords: *gene therapy; *genetic intervention; *Roman Catholic ethics; *theology; cancer; genetic enhancement; germ cells; human genome; natural law; risks and benefits

Keywords: *adverse effects; *phase I clinical trials; *gene therapy; *research subjects; consent forms; contracts; death; industry; investigational drugs; physicians; remuneration; research ethics committees; selection of subjects; Keyword Identifiers: *Mohr, Jolee; Targeted Genetics Corp.

Keywords: *adverse effects; *clinical trials; *gene therapy; advisory committees; consent forms; death; disclosure; ethical review; industry; methods; nontherapeutic research; research subjects; risk; Proposed Keywords: arthritis; Keyword Identifiers: *Mohr, Jolee; Recombinant DNA Advisory Committee; Targeted Genetics Corp.; United States

GENETIC COUNSELING
See also GENETIC SCREENING; SEX DETERMINATION

Mohler would favor altering ‘gay’ fetus [news]. Christian Century 2007 April 3; 124(7): 15. NRCBL: 15.2; 10; 9.5.8. Identifiers: R. Albert Mohler, Jr.; Southern Baptist Theological Seminary.


Keywords: attitudes; *genetic disorders; parents; *prenatal diagnosis; *selective abortion; fathers; mothers; questionnaires; survey; Keyword Identifiers: *Saudi Arabia


Keywords: *prenatal diagnosis; autonomy; consensus; decision making; legal aspects; pregnant women; risks and benefits; selective abortion; Keyword Identifiers: Austria


Keywords: *genetic counseling;* mentally ill persons; family members; genetic predisposition; patient care team; patient education; referral and consultation; stigmatization

Autti-Rämö, Ilona; Mäkelä, Marjukka. Screening for fetal abnormalities: from a health technology assessment report to a national statute. *International Journal of Technology Assessment in Health Care* 2007 Fall; 23(4): 436-442. 17 refs. NRCBL: 15.2; 15.3; 5.2; 9.1; 7.1. SC: em.

Keywords: *chromosome abnormalities;* congenital disorders; *mass screening;* policy making; *prenatal diagnosis;* public policy; *technology assessment;* attitudes; genetic services; government regulation; health services; survey accessibility; .; Key word Identifiers: *Finland


Keywords: *beneficence;* ethical analysis; *eugenics;* genetic intervention; *moral policy;* reproduction; autonomy; choice behavior; ecology; deontological ethics; genetic disorders; genetic screening; growth disorders; homosexuality; moral obligations; parents; preimplantation diagnosis; prenatal diagnosis; quality of life; reproductive rights; teleological ethics; value of life

Barfield, Raymond C.; Kodish, Eric. Pediatric ethics in the age of molecular medicine. *Pediatric Clinics of North America* 2006 August; 53(4): 639-648. NRCBL: 15.2; 15.3; 9.5.7; 18.5.4


Keywords: *prenatal diagnosis;* Down syndrome; organizational policies; professional organizations; obstetrics and gynecology; selective abortion; practice guidelines; Proposed Keywords: mental retardation; Key word Identifiers: American College of Obstetricians and Gynecologists

Beeson, Diane; Lippman, Abby. Egg harvesting for stem cell research: medical risks and ethical problems. *Reproductive Biomedicine Online* 2006 October; 13(4): 573-579. 50 refs. NRCBL: 15.2; 18.5.4; 9.5.5; 14.4; 14.5. Keywords: *embryonic stem cells;* oovum donors; *research embryo creation;* risk; cloning; conflict of interest; remuneration; reproduction; researchers; women’s health; Proposed Keywords: tissue harvesting


Braude, Peter; Flinter, Frances. Use and misuse of preimplantation genetic testing. *BMJ: British Medical Journal* 2007 October 13; 335(7623): 752-754. NRCBL: 15.2; 14.4.


Keywords: *cancer;* genetic counseling; *genetic predisposition;* adults; autonomy; beneficence; clinical genetics; duty to warn; family members; genetic screening; justice; minors; moral obligations; physician patient relationship; primary health care; professional family relationship; truth disclosure; uncertainty


Keywords: *preimplantation diagnosis;* legal aspects; children; embryos; family members; genetic disorders; legislation; regulation; siblings; value of life; Proposed Keywords: tissue typing; Key word Identifiers: *Great Britain;* Human Fertilisation and Embryology Act 1990 (Great Britain); Human Fertilisation and Embryology Authority


Keywords: *eugenics;* prenatal diagnosis; congenital disorders; genetic counseling; genetic disorders; preimplantation diagnosis; risk; selective abortion; social impact

Case, Amy P.; Ramadhani, Tunu A.; Canfield, Mark A.; Wicklund, Catherine A. Awareness and attitudes regarding prenatal testing among Texas women of childbearing age. *Journal of Genetic Counseling* 2007 October; 16(5): 655-661. NRCBL: 15.2. SC: em.


Keywords: *genetic disorders;* methods; *prenatal diagnosis;* costs and benefits; genetic screening; health insurance; insurance coverage; pregnant women; risks and benefits; selective abortion; social impact; standards; Proposed Keywords: predictive value of tests; prenatal care; Key word Identifiers: Medicaid; United States


Keywords: *embryonic stem cells; *preimplantation diagnosis; *moral policy; *stem cells; *tissue typing; adverse effects; classification; family members; ethical analysis; forecasting; motivation; reproduction; research embryo creation; risks and benefits; stem cell transplantation; trends. Proposed Keywords: *hematopoietic stem cells


Keywords: *genetic counseling; Christian ethics; disabled persons; precautionary principle; preimplantation diagnosis; prenatal diagnosis; reproductive technologies; risk; selective abortion; trust. Keyword Identifiers: Great Britain; Human Fertilisation and Embryology Authority


Keywords: *attitude of health personnel; *attitudes; *comparative studies; *pregnant women; *prenatal diagnosis; congenital disorders; Jews; patient satisfaction; questionnaires; socioeconomic factors. Keyword Identifiers: *Israel

Doerflinger, Richard M. Washington insider: House passes amended Genetic Nondiscrimination Bill; continued impasse on stem cell legislation, new executive order; defeat of deceptive human cloning bill; Supreme Court decision on partial-birth abortion. National Catholic Bioethics Quarterly 2007 Autumn; 7(3): 455-463. 21 fn. NRCBL: 15.2; 8.4; 18.5.4; 14.5. SC: le.

Keywords: *cloning; *embryo research; *embryonic stem cells; *genetic discrimination; *legislation; abortion; adult stem cells; cell lines; federal government; government financing; government regulation; politics; reproductive technologies; research support. Key word Identifiers: *U. S. Congress; *United States; Genetic Information Nondiscrimination Act; Human Cloning Prohibition Act; Partial Birth Abortion Ban Act; Stem Cell Research Enhancement Act

Ehrlich, Kathryn; Farsides, Bobbie; Williams, Clare; Scott, Rosamund. Testing the embryo, testing the fetus. Clinical Ethics 2007 December; 2(4): 181-186. 40 refs. NRCBL: 15.2; 7.1; 12.1; 14.4. SC: em.

Keywords: *attitude of health personnel; *beginning of life; *embryos; *fetuses; *moral status; *preimplantation diagnosis; *prenatal diagnosis; attitudes; comparative studies; embryo disposition; embryo transfer; embryonic development; genetic counseling; genetic disorders; in vitro fertilization; interviews; researchers; selective abortion; survey; value of life. Keyword Identifiers: Great Britain

Abstract: This paper stems from an ethnographic, multidisciplinary study that explored the views and experiences of practitioners and scientists on social, ethical and clinical dilemmas encountered when working in the area of pre-implantation genetic diagnosis for serious genetic disorders. We focus here on staff perceptions and experiences of working with embryos and helping women/couples to make choices that will result in selecting embryos for transfer and disposal of ‘affected’ embryos, compared to the termination of affected pregnancies following prenatal diagnosis. Analysis and discussion of our data led us to consider the possible advantages of pre-implantation genetic diagnosis and whether a gradualist account of the embryo’s and fetus’s moral status can account for all of these, particularly since a gradualist account concentrates on the significance of time (developmental stage) and makes no comment as to the significance of place (in vitro, in utero).


SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
Keywords: *ethical analysis; *preimplantation diagnosis; *reproduction; *siblings; *tissue typing; autonomy; commodification; directed donation; embryo transfer; legal aspects; moral obligations; parents; reproductive rights; risks and benefits; tissue donors; wedge argument; Keyword Identiﬁers: Australia; Great Britain; R (Quintavalle) v. Human Fertilisation and Embryology Authority

Gavaghan, Colin. Right problem, wrong solution: a pro-choice response to “expressivist” concerns about preimplantation genetic diagnosis. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Winter; 16(1): 20-34. 50 fn. NRCBL: 15.2; 9.5.1; 4.2; 12.5.1; 14.4. SC: an. Keywords: *disabled persons; *preimplantation diagnosis; autonomy; ethical analysis; eugenics; genetic disorders; genetic predisposition to disease; genetic screening; health care delivery; obligations of society; public policy; regulation; prenatal diagnosis; reproductive rights; selective abortion; social impact; Keyword Identiﬁers: Great Britain; Human Fertilisation and Embryology Authority

Gilbar, Roy. Communicating genetic information in the family: the familial relationship as the forgotten factor. Journal of Medical Ethics 2007 July; 33(7): 390-393. 29 refs. NRCBL: 15.2; 8.4; 1.1; 8.1. Keywords: *communication; *disclosure; *duty to warn; *family members; *family relationship; *genetic counseling; *genetic privacy; conﬁdentiality; informed consent; physician patient relationship; professional family relationship; right not to know; utilitarianism

Abstract: Communicating genetic information to family members has been the subject of an extensive debate recently in bioethics and law. In this context, the extent of the relatives’ right to know and not to know is examined. The mainstream in the bioethical literature adopts a liberal perception of patient autonomy and offers a utilitarian mechanism for solving familial tensions over genetic information. This reﬂects a patient-centred approach in which disclosure without consent is justiﬁed only to prevent serious harm or death to others. Based on a legal and bioethical analysis on the one hand, and an examination of empirical studies on the other, this paper advocates the adoption of a relational perception of autonomy, which, in the context of genetics, takes into account the effect that any decision—whether to disclose or not to disclose—will have on the familial relationship and the dynamics of the particular family. Adding this factor to the criteria usually advocated by lawyers and ethicists will facilitate reaching a sensitive decision, which recognises the various interests of family members beyond the risk to physical health. Taking this factor into account will require a process of deliberation both between doctors and patients, and in the family. It will also require a relaxation of medical conﬁdentiality, as the family rather than the patient is gradually perceived as the unit of care. Moreover, adopting such a relational approach will accord with current views of doctors and patients who base their decision primarily on the nature of the familial relationship.

Goldman, Bruce. The ﬁrst cut. Nature 2007 February 1; 445(7127): 479-480. 7 refs. NRCBL: 15.2; 14.4. SC: em. Keywords: *preimplantation diagnosis; *risks and beneﬁts; chromosome disorders; embryo transfer; empirical research; in vitro fertilization

Godden, Roger. Genetic test may lead to waste of healthy embryos [letter]. Nature 2007 March 22; 446(7134): 372. NRCBL: 15.2; 14.4. Keywords: *preimplantation diagnosis; chromosome abnormalities; embryo transfer; genetic screening; risks and beneﬁts; Proposed Keywords: predictive value of tests


Gruen, Lori; Grabel, Laura. Concise review: scientiﬁc and ethical roadblocks to human embryonic stem cell therapy. Stem Cells 2006 October; 24(10): 2162-2169 [Online]. Accessed: http://stemcell.alphamedpress.org/cgi/content/full/24/10/2162 [2007 December 4]. 72 refs. NRCBL: 15.2; 18.5.4; 5.3; 18.6. SC: rv. Keywords: *embryo research; *embryonic stem cells; *stem cell transplantation; advisory committees; cell lines; federal government; research support; state government; Proposed Keywords: altered nuclear transfer; blastocysts

Guilam, Maria Cristina R.; Corrêa, Marilena C.D.V. Risk, medicine and women: a case study on prenatal genetic counselling in Brazil. Developing World Bioethics 2007 August; 7(2): 78-85. 19 fn. NRCBL: 15.2; 12.4.1. Keywords: *congenital disorders; *genetic counseling; *prenatal diagnosis; *selective abortion; anencephaly; autonomy; communication; decision making; developing countries; Down syndrome; genetic services; illegal abortion; legal aspects; physician’s role; pregnant women; public hospitals; reproductive rights; risk; women’s rights; Keyword Identiﬁers: *Brazil; Rio de Janeiro

Abstract: Genetic counselling is an important aspect of prenatal care in many developed countries. This tendency has also begun to emerge in Brazil, although few medical centres offer this service. Genetic counselling provides prenatal risk control through a process of individual decision-making based on medical information, in a context where diagnostic and therapeutic possibilities overlap. Detection of severe foetal anomalies can lead to a decision involving possible termination of pregnancy. This paper focuses on medical and legal consequences of the detection of severe foetal anomalies, mainly anencephaly and Down syndrome, and in light of the fact that abortion is illegal in Brazil. The discussion is based on the literature and empirical research at a high-complexity public hospital in Rio de Janeiro.

Harrel, T. Recontacting former patients regarding BRCA1/2 rearrangement testing: opinions and practices of genetics professionals. Journal of Genetic Counseling 2007 December; 16(6): 670. NRCBL: 15.2; 15.3; 9.5.5. SC: em.

Harvey, Erin K.; Fogel, Chana E.; Peyrot, Mark; Christensen, Kurt D.; Terry, Sharon F.; McInerney, Joseph D. Providers’ knowledge of genetics: a survey of 5915 individuals and families with genetic conditions. Ge-

Keywords: *attitude of health personnel; *genetic counseling; *professional ethics; *professional competence; evaluation studies; family members; genetic disorders; medical education; patient education; patients; primary health care; survey

Hashiloni-Dolev, Yael. Genetic counselors’ moral practices. In her: A Life (Un)Worthy of Living: Reproductive Genetics in Israel and Germany. Dordrecht: Springer, 2007: 63-81. 4 fn. NRCBL: 15.2; 4.1.1; 1.3.1; 12.5.1; 21.1. SC: em.

Keywords: *attitude of health personnel; *genetic counseling; *professional ethics; *selective abortion; age factors; congenital disorders; cross cultural comparison; directive counseling; disabled persons; eugenics; interviews; medical specialties; prenatal diagnosis; religion; sex factors; statistics; Keyword Identifiers: *Germany; *Israel

Hashiloni-Dolev, Yael. The conflicts between individuals, families and society, as well as between different family members, embodied in reproductive genetics. In her: A Life (Un)Worthy of Living: Reproductive Genetics in Israel and Germany. Dordrecht: Springer, 2007: 131-146. 1 fn. NRCBL: 15.2; 12.5.1; 14.4; 8.1; 21.1.

Keywords: *attitude of health personnel; *genetic counseling; *preimplantation diagnosis; *preimplantation genetic testing of human embryos: ethical challenges and policy choices. Part A. Journal of Clinical Ethics 2007 Summer; 18(2): 99-110. 43 fn. NRCBL: 15.2; 14.4; 5.3. SC: rv.

Keywords: *preimplantation diagnosis; *selective abortion; age factors; congenital disorders; cross cultural comparison; culture; disabled persons; eugenics; interviews; medical specialties; prenatal diagnosis; religion; sex factors; statistics; Keyword Identifiers: *Germany; *Israel

Heyman, Bob; Hundt, Gillian; Sandall, Jane; Spencer, Kevin; Williams, Clare; Grellier, Rachel; Pitson, Laura. On being at higher risk: a qualitative study of prenatal screening for chromosomal anomalies. Social Science and Medicine 2006 May; 62(10): 2360-2372. NRCBL: 15.2; 8.3.1; 9.5.5.

Hiraki, Susan; Ormond, Kelly E.; Kim, Katherine; Ross, Lainie F. Attitudes of genetic counselors towards expanding newborn screening and offering predictive genetic testing to children. American Journal of Medical Genetics. Part A 2006 November 1; 140(21): 2312-2319. NRCBL: 15.2; 15.3; 9.5.7.


Keywords: *genetic counseling; *prenatal diagnosis; chromosomal disorders; communication; Hispanic Americans; socioeconomic factors; Keyword Identifiers: New York City


Howe, Edmund G. "I’m still glad you were born" — careproviders and genetic counseling. Journal of Clinical Ethics 2007 Summer; 18(2): 99-110. 43 fn. NRCBL: 15.2; 8.1; 8.2; 8.4.

Keywords: *directive counseling; *genetic counseling; *professional patient relationship; caring; choice behavior; communication; emotions; empirical research; family members; genetic screening; health personnel; parents; preimplantation diagnosis; prenatal diagnosis; psychological stress; risks and benefits


Keywords: *preimplantation diagnosis; *embryo transfer; *embryos; *evaluation studies; federal government; government regulation; insurance; legal aspects; moral policy; motivation; *policy making; public participation; public policy; risks and benefits; self regulation; standards; social impact; state government; value of life; Proposed Keywords: insurance coverage; Keyword Identifiers: Food and Drug Administration; United States


Keywords: *genetic counseling; *nurse’s role; *vulnerable populations; codes of ethics; nursing ethics; organizational policies; Proposed Keywords: societies

Iredale, Rachel; Longley, Marcus; Thomas, Christian; Shaw, Anita. What choices should we be able to make about designer babies? A Citizens’ Jury of young people in South Wales. Health Expectations 2006 September; 9(3): 207-217. NRCBL: 15.2; 15.3; 19.5; 14.3.

Kaimal, Girija; Steinberg, Annie G.; Ennis, Sara; Harasink, Sue Moyer; Ewing, Rachel; Li, Yuelin. Parental narratives about genetic testing for hearing loss: a one year follow up study. Journal of Genetic Counseling

SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
2007 December; 16(6): 775-787. NRCBL: 15.2; 9.5.7. SC: em.

Klitzman, Robert; Thorne, Deborah; Williamson, Jennifer; Chung, Wendy; Marder, Karen. Decision-making about reproductive choices among individuals at-risk for Huntington’s disease. Journal of Genetic Counseling 2007 June; 16(3): 347-362. NRCBL: 15.2; 14.1; 15.3; 15.1; 14.4. SC: em.


Krones, Tanja; Schlüter, Elmar; Neuwohner, Elke; El Ansari, Susan; Wisnner, Thomas; Richter, Gerd. What is the preimplantation embryo? Social Science and Medicine 2006 July; 63(1): 1-20. NRCBL: 15.2; 14.4.


Keywords: *genetic counseling; *parents; *patient participation; *professional family relationship; children; choice behavior; congenital disorders; diagnosis; parental consent; pedigree; professional role; reproduction; uncertainty

Abstract: The paper presents findings from an ethnography of dysmorphology, a specialism in genetic medicine, to explore genetic counselling as a process through which parents ‘become informed.’ Current professional and policy debate over the use of genetic technology in medicine emphasises the need for informed choice making, and for genetic services that provide parents with what is referred to as ‘non-directive genetic counselling.’ In the paper the process of becoming informed is shown to be very specific and to have its own effects. Specifically, genetics is performed in dysmorphology as a space of ambiguity and uncertainty. In addition, parents are engaged by the clinic as participants in the very processes through which their child, and perhaps their family, are clinically classified. The paper examines the effects of parents’ immersion in this clinical space of deferral to suggest how the need for reproductive choice, and calculation, is predicated upon clinical processes that shift parents between the experience of definition and uncertainty. The paper thus troubles simple stories about autonomous and informed choice, particularly reproductive choice, as icons of contemporary versions of what it is to be fully human.

Lenhard, Wolfgang; Breitenach, Erwin; Ebert, Harald; Schindelhauer-Deutscher, H. Joachim; Zang, Klaus D.; Henn, Wolfram. Attitudes of mothers towards their child with Down syndrome before and after the introduction of prenatal diagnosis. Intellectual and Developmental Disabilities 2007 April; 45(2): 98-102. 12 refs. NRCBL: 15.2; 8.1; 9.5.3. SC: em. Note: Abstract in French.

Keywords: *attitudes; *Down syndrome; *mothers; *parent child relationship; *prenatal diagnosis; children; emotions; questionnaires; time factors

Leroi, Armand Marie. The future of neo-eugenics: now that many people approve the elimination of certain genetically defective fetuses, is society closer to screening all fetuses for all known mutations? EMBO Reports 2006 December; 7(12): 1184-1187. NRCBL: 15.2; 15.1; 15.5; 12.1; 9.5.8.

Lisker, Rubén; Carnevale, Alessandra. Changing opinions of Mexican geneticists on ethical issues. Archives of Medical Research 2006 August; 37(6): 794-803. NRCBL: 15.2; 8.4; 8.3.1; 9.2; 15.3. SC: em.


Abstract: A brief discussion of how relational autonomy, phenomenological theories of embodiment and narrative approaches to clinical ethics can open up the space for more subtle feminist ethical reflection about genetic termination.


Keywords: *counseling; *preimplantation diagnosis; *pre-natal diagnosis; *reproduction; *women; autonomy; beneficence; cystic fibrosis; disabled persons; disclosure; embryos; fetuses; genetic disorders; genetic predisposition; genetic screening; moral status; paternity; phenylketonuria; professional patient relationship; racial groups; reproductive technologies; sex determination; spousal consent; Proposed Keywords: preconception care

Mahowald, Mary B. Prenatal testing for selection against disabilities. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Fall; 16(4): 457-462. NRCBL: 15.2; 4.4; 1.1. SC: an.


Keywords: *breast cancer; *communication; *genetic information; *information dissemination; genetic counseling; risk; survey; women; Keyword Identifiers: Great Britain

Paonessa, Louis. Straightening out your heir: on the constitutionality of regulating the use of preimplantation technologies to select preembryos or modify the genetic profile thereof based on expected sexual orientation. Rutgers Computer and Technology Law Journal 2007; 33(2): 331-366. NRCBL: 15.2; 14.3; 14.4; 5.3.


Keywords: *directed donation; *legal aspects; *preimplantation diagnosis; *reproduction; *siblings; *tissue donors; tissuetype; *tissue typing; anemia; Keywords Identifiers: *Great Britain; Human Fertilization and Embryology Authority


Keywords: *constitutional law; *legal aspects; *preimplantation diagnosis; *reproductive technologies; Keywords Identifiers: *Italy


Perry, Sandy; Woodall, Angela L.; Pressman, Eva K. Association of ultrasound findings with decision to continue Down syndrome pregnancies. Community Genetics 2007; 10(4): 227-230. 5 refs. NRCBL: 15.2; 12.5.2. SC: em.

Keywords: *childbirth; *choice behavior; *Down syndrome; *pregnant women; *prenatal diagnosis; *selective abortion; *decision making; *evaluation studies; Proposed Keywords: *retrospective studies; *ultrasoundography


Keywords: *females; *informed consent; *prenatal diagnosis; *sex determination; *sex preselection; *autonomy; *coercion; *comprehension; *congenital disorders; *disclosure; genetic counseling; *genetic screening; *legal aspects; *physician patient relationship; *pregnant women; *preimplantation diagnosis; selective abortion; standards; wrongful life; Keywords Identifiers: *Canada


Keywords: *genetic counseling; *knowledge; *attitudes; *practice; *spirituality; *health personnel; *professional patient relationship


Sawyer, Susan M.; Cerritelli, Belinda; Carter, Lucy S.; Cooke, Mary; Glazner, Judith A.; Massie, John. Changing their minds with time: a comparison of hypothetical and actual reproductive behaviors in parents of children with cystic fibrosis. Pediatrics 2006 September; 118(3): e649-e656. NRCBL: 15.2; 12.5.2.


Keywords: *genetic disorders; *genetic techniques; *methods; *prenatal diagnosis; *technology assessment; *autonomy; costs and benefits; *decision making; *disclosure; *eugenics; *fetuses; genetic counseling; *genetic screening; *informed consent; *justice; *normality; *philosophy; *parents; *physicians; *predictive value of tests; *preimplantation diagnosis; *public policy; *risks and benefits; *selective abortion; *standards; *trends; *values; *wrongful life


Keywords: *clinical genetics; *genetic research; *genetic services; *government financing; *research support; *scarcity; *education; *health personnel; *professional patient relationship;
Soini, S. Genetic diagnosis in New Zealand. University of New South Wales Law Journal 2007; 4(3): 207-215. NRCBL: 15.2; 15.3; 12.5.2; 12.3. Abstract: Genetic diagnosis is a widespread support for some degree of liberalization of the law, particularly where this relates to serious genetic conditions which can be identified prenatally. Tension emerges out of a publicly maintained conservatism on issues of abortion on the one hand and a growing disconnection from unregulated practices of termination in the private sector on the other. Social science approaches have much to contribute when understanding the ‘therapeutic gap’ that opens up and, in particular, the way that local ideas of fate, destiny and how suffering might be ameliorated become blended with the predictive power of genetic testing.

Skene, Loane. Should the law limit genetic tests on embryos and foetuses? University of New South Wales Law Journal 2006; 29(2): 250-253. 4 fn. NRCBL: 15.2; 15.5; 5.3; 1.3.5. SC: le. Keywords: *legal aspects; *preimplantation diagnosis; *prenatal diagnosis; eugenics; genetic screening; international aspects; legislation; Keyword Identifiers: Australia; Germany; Italy


Soini, S. Preimplantation genetic diagnosis (PGD) in Europe: diversity of legislation a challenge to the community and its citizens. Medicine and Law: The World Association for Medical Law 2007 June; 26(2): 309-323. 40 fn. NRCBL: 15.2; 14.4; 21.1. SC: le. Keywords: *international aspects; *legal aspects; *preimplantation diagnosis; cross cultural comparison; decision making; embryos; eugenics; genetic counseling; genetic disorders; guidelines; motivation; regulation; risk; sex preselection; Proposed Keywords: tissue typing; Keyword Identifiers: *Europe; European Union

Abstract: Preimplantation genetic diagnosis (PGD) aims to safeguard the reproductive confidence of couples who have an increased risk of having a child with a serious hereditary disease. Non-directive genetic counselling is an essential part of PGD. Lately, performance of PGD for some new and non-medical indications, such as selecting for a tissue-matching embryo for a saviour sibling, or sex-selection for family-balancing, has raised ethical concerns. Who decides when to perform PGD, and for which conditions? The European member states have very diverse regulation on PGD. Some countries totally ban PGD, while the others keep close track of the new applications. The people in need of PGD seek it in the other member states. These cross-border treatments cause psychological stress and pose many so far unresolved legal questions. The individuals need more information about all the aspects of PGD. This article analyses contemporary indications for PGD in Europe and relevant ethical discussion, and second, shows the diversity in regulation and reflects the consequences thereof.

Streton, Dean. Harriton v Stephens; Waller v James: wrongful life and the logic of non-existence. Melbourne University Law Review 2006 December; 30(3): 972-1001. 208 fn. NRCBL: 15.2; 1.1; 8.4; 12.4.2. SC: le. Keywords: *congenital disorders; *legal aspects; *legal liability; *negligence; *wrongful life; duty to warn; genetic disorders; physicians; prenatal diagnosis; rubella; Keyword Identifiers: *Australia; *Harriton v. Stephens; *Waller v. James

Thachuk, Angela. The space in between: narratives of silence and genetic terminations. Bioethics 2007 November; 21(9): 511-514. NRCBL: 15.2; 15.3; 1.1; 12.5.1. SC: an. Abstract: In North America, prenatal testing and genetic terminations are becoming clinically normalized. Yet despite this implied social acceptance, open discussions surrounding genetic terminations remain taboo and silenced. Women are socially isolated, their experiences kept secret, and their grief disenfranchised. The lack of social consensus regarding genetic terminations, the valorization of scientific knowledge, and the bioethical framing of the issue as a matter of personal choice and autonomy collectively serve to reify this silence. In many respects genetic screening offers a form of technological surveillance procuring security from the unwanted kind of child. Yet the manner in which ‘the unwanted kind of child’ is understood varies from context to context. While we carry with us the consequences of decisions made elsewhere, the institutionalized discourses upon which these decisions are made are not always so readily transportable. One must somehow reconcile ‘the unwanted kind of child’ of the biomedical model with ‘the unwanted kind of child’ who was to be a member of one’s family. In this paper, my intention is not to engage in the broader debate surrounding prenatal testing and genetic terminations. Rather, I employ my clinical encounters with these practices to illustrate the absence of an ethical language that might do justice to the experiences such practices construct. The limitations of a bioethical discourse that remains abstracted from lived experience are discussed.

Tonti-Filippini, Nicholas. Reproductive discrimination. University of New South Wales Law Journal 2006; 29(2): 254-260. 12 fn. NRCBL: 15.2; 15.5; 21.1. SC: le. Keywords: *disabled persons; *genetic intervention; *reproductive rights; *social discrimination; eugenics; genetic disorders; guidelines; international aspects; preimplantation diagnosis; prenatal diagnosis; reproductive technologies; Keyword Identifiers: Australia; Europe; European Convention on Human Rights and Biomedicine; National Health and Medical Research Council (Australia); United Nations; Universal Declaration on the Human Genome and Human Rights
Tuohey, John F. Screening for aneuploidy: a complex ethical issue. *Health Care Ethics USA* 2007 Spring; 15(2): 4-8. 25 refs. NRCBL: 15.2; 1.2; 9.5.5; 9.5.8.

Keywords: *chromosome abnormalities; prenat al diagnosis; Down syndrome; fetal development; moral obligations; pregnant women; Roman Catholic ethics; risk*


**Wasserman, David; Asch, Adrienne.** Reply to Nelson. *CQ: Cambridge Quarterly of Healthcare Ethics* 2007 Fall; 16(4): 478-482. NRCBL: 15.2; 4.4; 1.1; 7.1; 12.1. SC: an. Identifiers: prenatal testing for selection against disabilities.


**Zeiler, Kristin.** Shared decision-making, gender and new technologies. *Medicine, Health Care and Philosophy* 2007 September; 10(3): 279-287. 21 refs. 5 fn. NRCBL: 15.2; 14.4; 1.1; 8.1; 10. SC: an.

Keywords: *autonomy; clinical genetics; decision making; embryo transfer; ethical analysis; in vitro fertilization; interpersonal relations; men; preimplantation diagnosis; reproductive medicine; women; choice behavior; dissent; empirical research; genetic counseling; genetic disorders; genetic screening; health personnel; intention; married persons; philosophy; physician patient relationship; prenatal diagnosis; professional role; reproductive technologies; selective abortion; Proposed Keywords: *sex factors; cooperative behavior*

Abstract: Much discussion of decision-making processes in medicine has been patient-centred. It has been assumed that there is, most often, one patient. Less attention has been given to shared decision-making processes where two or more patients are involved. This article aims to contribute to this special area. What conditions need to be met if decision-making can be said to be shared? What is a shared decision-making process and what is a shared autonomous decision-making process? Why make the distinction? Examples are drawn from the area of new reproductive medicine and clinical genetics. Possible gender-differences in shared decision-making are discussed.

**GENETIC DATABASES AND BIOBANKS**


Keywords: *biological specimen banks; biomedical research; genetic databases; genetic research; legal aspects; legislation; advisory committees; cloning; economics; embryo research; embryonic stem cells; genetic engineering; human dignity; nuclear transfer techniques; Key word Identifiers: *Spain; Council of Europe*

Genome abuse [editorial]. *Nature* 2007 September 27; 449(7161): 377. NRCBL: 15.1; 1.3.5; 1.3.12. Identifiers: France; Great Britain (United Kingdom).

**Aray-Blais, Christiane; Patenaude, Johane.** Biobanking primer: down to basics [letter]. *Science* 2007 May 11; 316(5826): 830. NRCBL: 15.1; 1.3.12; 18.2.

Keywords: *biological specimen banks; genetic databases; ethical review; genetic research; informed consent; population genetics; research ethics committees; research subjects*


Keywords: *databases; genetic databases; advisory committees; biological specimen banks; committee membership; confidentiality; conflict of interest; donors; genetic research; government; health services research; guidelines; informed consent; interinstitutional relations; legislation; medical records; pedigree; population genetics; presumed consent; privacy; public health; public policy; regulation; research ethics; research subjects; standards; Key word Identifiers: *Iceland; Declaration of Helsinki; deCode Genetics; Health Sector Database (Iceland); National Bioethics Committee (Iceland); Nuremberg Code*


Keywords: *biological specimen banks; genetic databases; access to information; altruism; autonomy; blood specimen collection; confidentiality; databases; decision making; disclosure; ethical review; industry; informed consent; interna-


Keywords: *biological specimen banks;* genetic databases; *population genetics; benefit sharing; biotechnology; commerce; genetic materials; genetic patents; genomics; human genome; industry; international aspects; private sector; property rights; public opinion; public participation; public sector; regulation; Proposed Keywords: genetic resources; Keyword Identifiers: Myriad Genetics Inc.


Keywords: *biological specimen banks;* genetic databases; *population genetics; benefit sharing; biotechnology; commerce; genetic materials; genetic patents; genomics; human genome; industry; international aspects; private sector; property rights; public opinion; public participation; public sector; regulation; Proposed Keywords: genetic resources; Keyword Identifiers: *Iceland;* deCode Genetics


Keywords: *biological specimen banks;* genetic databases; *population genetics; benefit sharing; biomedical research; confidentiality; genetic information; informed consent; international aspects; organization and administration; property rights; regulation; tissue donors

Gamero, Joaquin J.; Romero, Jose-Luis; Peralta, Juan-Luis; Carvalho, Mónica; Corte-Real, Francisco. Spanish public awareness regarding DNA profile databases in forensic genetics: what type of DNA profiles should be included? *Journal of Medical Ethics* 2007 October; 33(10): 598-604. 52 refs. NRCBL: 15.1; 1.3.5; 1.3.12; 1.3.5; 8.4; 18.3. SC: em.

Keywords: *biological specimen banks;* DNA fingerprinting; *forensic genetics;* genetic databases; *public opinion;* public policy; genetic privacy; government regulation; informed consent; law enforcement; legislation; policy making; predictive value of tests; prisoners; public participation; survey; Keyword Identifiers: *Spain;* European Union

Abstract: The importance of non-coding DNA polymorphism for the administration of justice is now well known. In Spain, however, this type of test has given rise to questions in recent years: (a) Should consent be obtained before biological samples are taken from an individual for DNA analysis? (b) Does society perceive these techniques and methods of analysis as being reliable? (c) There appears to be lack of knowledge concerning the basic norms that regulate databases containing private or personal information and the protection that information of this type must be given. This opinion survey and the subsequent analysis of the results in ethical terms may serve to reveal the criteria and the degree of information that society has with regard to DNA databases. In the study, 73.20% (SE 1.12%) of the population surveyed was in favour of specific legislation for computer files in which DNA analysis results for forensic purposes are stored.


Keywords: *DNA fingerprinting;* genetic databases; legislation; public policy; Keyword Identifiers: *Canada


Keywords: *genetic databases;* DNA fingerprinting; genetic information; genetic privacy; genetic research; genetic screening; law enforcement; private sector; property rights; public sector; refusal to participate; registries; regulation; research subjects; Proposed Keywords: classification; tissue donors; Keyword Identifiers: *Australia


Keywords: *biological specimen banks;* genetic databases; family members; government regulation; guidelines; human experimentation; informed consent; legal aspects; research subjects; Proposed Keywords: tissue donors; Keyword Identifiers: *European Convention on Human Rights and Biomedicine;* Europe

SECTION I

GENETIC DATABASES AND BIOBANKS

NRCBL: National Reference Center for Bioethics Literature Classification Scheme

See inside front cover for terms.
GENETIC DATABASES AND BIOBANKS

SECTION I


Keywords: *genetic databases; *genetic research; *population genetics; *public participation; communication; confidentiality; genetic diversity; genomics; information dissemination; public opinion; research design; research subjects; selection of subjects; trust; Proposed Keywords: research findings; Keyword Identifiers: *Identifiers: Quebec

Godard, Béatrice; Marshall, Jennifer; Laborge, Claude. Community engagement in genetic research: results of the first public consultation for the Quebec CARTaGENE project. Community Genetics 2007; 10(3): 147-158. 28 refs. NRCBL: 15.1; 1.3.12; 18.1. SC: em.

Keywords: *genetic databases; *genetic research; *public opinion; *public participation; biological specimen banks; choice behavior; confidentiality; donors; duty to recontact; ethnic groups; focus groups; genetic privacy; knowledge, attitudes, practice; public sector; private sector; questionnaires; research subjects; researcher subject relationship; risks and benefits; Proposed Keywords: research findings; Keyword Identifiers: *Quebec; *Quebec CARTaGENE


Keywords: *biological specimen banks; *genetic databases; *genetic research; *guidelines; advisory committees; comparative studies; genetic information; informed consent; international aspects; organizational policies; public policy; research subjects; tissue donors; Keyword Identifiers: *Europe; Council of Europe; European Group on Ethics in Science and New Technologies; German National Ethics Council; Human Genetics Commission (Great Britain)


Keywords: *attitudes; *biological specimen banks; *biomedical research; *donors; *genetic materials; *informed consent; *patients; cancer; privacy; racial groups; research subjects; survey; time factors; Proposed Keywords: *tissue donors; Keyword Identifiers: Indiana University Cancer Center

Abstract: The policy debate concerning informed consent for future, unspecified research of stored human biological materials (HBM) would benefit from an understanding of the attitudes of individuals who contribute tissue specimens to HBM repositories. Cancer patients who contributed leftover tissue to the Indiana University Cancer Center Tissue Bank under such conditions were recruited for a mail survey study of their attitudes. Our findings suggest that a clear majority of subjects would permit unlimited future research on stored HBMs without re-contact and reconsent, and a significant minority appear to desire ongoing control over future research uses of their tissue. These differences merit further investigation and suggest that a policy of blanket consent for all future, unspecified research would be premature.

Helgeson, Gert; Dillner, Joakim; Carlson, Joyce; Bartram, Claus R.; Hansson, Mats G. Ethical framework for previously collected biobank samples [letter]. Nature Biotechnology 2007 September; 25(9): 973-976. 16 refs. NRCBL: 15.1; 1.3.12.

Keywords: *biological specimen banks; *biomedical research; *genetic research; *informed consent; *presumed consent; *standards; *tissue donors; access to information; confidentiality; duty to recontact; ethical review; genetic databases; guidelines; legal aspects; refusal to participate; regulation; research findings; research subjects; time factors


Keywords: *biological specimen banks; *genetic databases; *genetic information; *moral policy; biomedical research; common good; confidentiality; genetic discrimination; genetic privacy; genetic research; historical aspects; informed consent; international aspects; moral obligations; policy analysis; property rights; public health; public policy; research subjects; risks and benefits; tissue donors; trends; Proposed Keywords: exceptionalism

Jayaraman, K.S. Database targets Parsi genes [news]. Nature 2007 March 29; 446(7135): 475. NRCBL: 15.1; 1.3.12; 15.11. Identifiers: India.

Keywords: *ethnic groups; *genetic databases; *population genetics; access to information; commerce; industry; informed consent; international aspects; medical records; pedigree; research subjects; Keyword Identifiers: *India; *Parsi


Keywords: *biotechnology; *democracy; *decision making; *ethical analysis; *genetically modified organisms; *policy analysis; *policy making; *public policy; advisory committees; consensus; cultural pluralism; ethics committees; genetically modified food; guidelines; international aspects; public participation; risks and benefits; standards; technology assessment; theoretical models; Proposed Keywords: stakeholders

SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review

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SECTION I

GENETIC DATABASES AND BIOBANKS


Keywords: *DNA fingerprinting; *genetic databases; *legal aspects; *biological specimen banks; blood specimen collection; family members; *genetic privacy; genetic research; government regulation; law enforcement; prisoners; research subjects; Keyword Identifiers: *Landry v. Attorney General; *Massachusetts; Federal Policy (Common Rule) for the Protection of Human Subjects 1991; Nuremberg Code; United States


Keywords: *DNA fingerprinting; *genetic databases; *legal enforcement; *legal aspects; *biological specimen banks; constitutional law; costs and benefits; criminal law; *genetic privacy; justice; population genetics; prisoners; public opinion; racial groups; Supreme Court decisions; Keyword Identifiers: *United States


Keywords: *genetic databases; *genetic research; access to information; advisory committees; benefit sharing; *biological specimen banks; cloning; disclosure; duty to warn; economics; ethical review; family members; gene therapy; genetic patents; *genetic privacy; germ cells; guidelines; human rights; informed consent; international aspects; legal aspects; property rights; regulation; research ethics; research subjects; right not to know; trends; Proposed Keywords: tissue donors


Keywords: *genetic databases; *genetic research; access to information; advisory committees; benefit sharing; biological specimen banks; cloning; disclosure; duty to warn; economics; ethical review; family members; gene therapy; genetic patents; *genetic privacy; germ cells; guidelines; human rights; informed consent; international aspects; legal aspects; property rights; regulation; research ethics; research subjects; right not to know; trends; Proposed Keywords: tissue donors

Mc Fleming, Jennifer. The governance of human genetic research databases in mental health research. *International Journal of Law and Psychiatry* 2007 May-June; 30(3): 182-190. 45 refs. NRCBL: 15.1; 1.3.12; 15.6; 8.4; 17.1; 18.3. SC: le.

Keywords: *genetic databases; *genetic research; *mental health; *biological specimen banks; confidentiality; disclosure; empirical research; genetic information; *genetic privacy; guidelines; informed consent; legal aspects; mentally ill persons; property rights; regulation; research subjects; schizophrenia; stigmatization; vulnerable populations; Proposed Keywords: clinical utility; exceptionalism; research findings; Keyword Identifiers: Australia


Keywords: *access to information; *biological specimen banks; *genetic databases; *genetic materials; *interinstitutional relations; *institutional policies; benefit sharing; biomedical research; clinical genetics; contracts; genetic research; hospitals; industry; interviews; interprofessional relations; laboratories; organization and administration;

Merlo, D.F.; Knudsen, L.E.; Matusiewicz, K.; Niebrój, L.; Vähäkangas, K.H. Ethics in studies on children and environmental health. *Journal of Medical Ethics* 2007 July; 33(7): 408-413. 58 refs. NRCBL: 18.5.2; 16.1; 18.2; 18.3; 18.5.4; 15.1; 1.3.12.

Keywords: *adolescents; *biological specimen banks; *children; *nontherapeutic research; age factors; autonomy; biomedical research; consent forms; genetic databases; genetic research; guidelines; health hazards; informed consent; minors; parental consent; public health; refusal to participate; research ethics committees; research subjects; standards; tissue donors; vulnerable populations; Proposed Keywords: *environmental health; Keyword Identifiers: Europe

Abstract: Children, because of age-related reasons, are a vulnerable population, and protecting their health is a social, scientific and emotional priority. The increased susceptibility of children and fetuses to environmental (including genotoxic) agents has been widely discussed by the scientific community. Children may experience different levels of chemical exposure than adults, and their sensitivity to chemical toxicities may be increased or decreased in comparison with adults. Such considerations also apply to unborn (fetal exposure) and newborn (neonatal exposure) children. Therefore, research on children is necessary in both clinical and environmental fields, to provide age-specific relevant data regarding the efficacy and safety of medical treatments, and regarding the assessment of risk from unintended environmental exposure. In this context, the stakeholders are many, including children and their parents, physicians and public health researchers, and the society as a whole, with its ethical, regulatory, administrative and political components. The important ethical issues are information of participants and consent to participate. Follow-up and protection of data (samples and information derived from samples) should be discussed in the context of biobanks, where children obtain individual rights when they become adults. It is important to realise that there are highly variable practices within European countries, which may have, in the past, led to differences in practical aspects of research in children. A number of recommendations are provided for research with children and environmental health. Environmental research with children should be scientifically justified, with sound research questions and valid study protocols of sufficient statistical power, ensuring the autonomy of the child and his/her family at the time of the study and later in life, if data and samples are used for follow-up studies. When children are enrolled, we recommend a consent dyad, including (1) parental (or legal guardian) informed consent and (2) the child’s assent and/or informed consent from older minors. For evaluation of the studies including children, a paediatrician should always be involved in the research ethics committee.

NRCBL: National Reference Center for Bioethics Literature Classification Scheme  See inside front cover for terms.
Genetic Databases and Biobanks

Section I

Abstract: Key activities in biomedicine and related research rely on collections of biological samples and related files. Access to such resources in industry and in academic contexts has become strategic and represents a central issue in the general framework of rising patenting practices and in debates about the knowledge economy. It raises important issues concerning the organisation of scientific and medical work, the outline of data-sharing guidelines, and science policy’s contribution to the elaboration of an adapted framework. This paper presents an ethnographic study of three French human biobanks. Building on field work (participant observation and in-depth interviews), the study focuses on data access in the concrete practices in biobanks. The paper develops a perspective based on an analysis of different exchange regimes. We argue that access practices are submitted to the different regimes that can coexist and be articulated within the daily activities of each biobank. We also discuss how this perspective can further our understanding of biomedical research, and how it might inform data access policy.

Moluk, Alison. Crisis of trust over sperm bank errors: a new register of DNA from donors and their offspring is Exposure. New Scientist 2007 August 11-17; 195(2616): 6-7. NRCBL: 14.6; 14.2; 15.3.

Keywords: *biological specimen banks; *genetic screening; *sperm donors; *sperm; *standards; artificial insemination; industry; informed consent; medical errors; registries; regulation; Keyword Identifiers: *United States; Great Britain


Keywords: *genetic databases; *policy making; *public participation; *social control; *technical expertise; democracy; deontological ethics; focus groups; genetic research; international aspects; methods; politics; science; technology; trust; Proposed Keywords: stakeholders

Abstract: Key to concerns about public involvement in technology governance is the concept of lay expertise, the idea that lay people possess some kind of special knowledge that neither trained experts in technology, ethics and social sciences nor professional politicians possess. There are at least four different meanings of “lay expert”: (1) Lay people who are educated into quasi-experts on a particular issue or technology; (2) Lay people who turn themselves into experts in order to challenge scientific experts; (3) Lay people with particular knowledge based on tradition and experience; (4) Lay people who represent an alternative perspective to expert views because they are non-experts. The challenge is that lay people are often ignorant in the relevant matters and wish to leave governance to experts. Still, there are normative reasons for lay engagement, either as stakeholders or as citizens in a deliberative democracy. According to the second approach, political decisions should be based on an inclusive open debate aimed at the better argument, providing lay people a crucial role in governance. In order to include lay people without making them hostage to experts, politicians or interest groups, we can engage them in focus group interviews which are analysed by social scientists and included in the interdisciplinary debate in journals and political forums.

National Institutes of Health [NIH] (United States).

Petersen, Alan. ‘Biobanks’ “engagements”: engendering trust or engineering consent? Genomics, Society and Policy 2007 April; 3(1): 31-43. 56 fn. NRCBL: 15.1; 1.3.12; 5.1.

Keywords: *genetic databases; *international aspects; *policy making; *public participation; *trust; administrators; biotechnology; genetic research; genetically modified organisms; informed consent; population genetics; nanotechnology; politics; presumed consent; program descriptions; researchers; risk; science; social control; Keyword Identifiers: *UK Biobank; Great Britain

Abstract: The rapid development of biobanks internationally reflects the considerable expectations attached to the exploitation of genetics knowledge. However, establishing consent and legitimacy for the new generation of biobanks is not without its challenges because they tend to be prospective in nature, involving the collection of DNA, personal medical and lifestyle data generally held over a very long period of time for unspecified research purposes. Thus far, biobanks have tended to be established ahead of wide-ranging debate about their broad implications. Making specific reference to the ‘engagement’ processes employed by UK Biobank during its establishment phase, this article focuses on the politics of ‘public engagement’. It examines the context of arguments for ‘public engagement’, drawing attention to how
particular approaches to ‘engagement’ within biobank projects may serve to limit debate on substantive questions arising from their development. Unless biobanks’ ‘engagements’ substantially involve publics in deliberations about their development, it is argued, publics are likely to become distrustful of projects and perhaps resist other similar population-based health initiatives in the future.


Roche, Patricia A.; Annas, George J. Privacy concerns: DNA donors may give up more than they realize. GeneWatch 2007 January-February; 20(1): 14-17. NRCBL: 15.1; 1.3.12.


Keywords: *embryo transfer; *remuneration; commodification; ovum donors; semen donors; cryopreservation; *embryo; eugenics; *biological specimen banks

Swede, Helen; Stone, Carol L.; Norwood, Alyssa R. National population-based biobanks for genetic research. Genetics in Medicine 2007 March; 9(3): 141-149. 73 refs. NRCBL: 15.1; 1.3.12; 19.5; 21.1; 18.3. SC: rv.

Keywords: *biological specimen banks; *genetic databases; *population genetics; *international aspects; *public policy; *standards; confidentiality; donors; federal government; genetic privacy; genetic research; guidelines; informed consent; policy making; public health; public participation; research subjects; research support; state government; trends; Keyword Identifiers: *United States


UK Biobank. The UK National DNA Database. Balancing crime detection, human rights and privacy. EMBO Reports 2006 July; 7 Special No: S26-S30. 24 refs. NRCBL: 15.1; 1.3.5; 1.3.12; 8.4.


Watts, Geoff. UK Biobank gets 10% response rate as it starts recruiting volunteers in Manchester [news]. BMJ: British Medical Journal 2007 March 31; 334(7595): 659. NRCBL: 15.1; 1.3.12.
Keywords: *biological specimen banks; *genetic databases; donors; genetic research; informed consent; research design; research subjects; selection of subjects; statistics; Proposed Keywords: *pilot projects; Keyword Identifiers: *Great Britain; *UK Biobank; Manchester

Wylie, Jean E.; Mineau, Geraldine P. Biomedical databases: protecting privacy and promoting research. Trends in Biotechnology 2003 March; 21(3): 113-116. 23 refs. NRCBL: 15.1; 1.3.12; 1.3.9; 15.10; 8.4.

Keywords: *biomedical research; *databases; *genetic research; biological specimen banks; computers; confidentiality; epidemiology; genetic databases; industry; medical records; privacy; regulation; standards; Keyword Identifiers: deCode Genetics; Iceland; United States; Utah

GENETIC ENGINEERING AND BIO TECHNOLOGY


Keywords: *biotechnology; *cloning; *genetic information; *guidelines; *human genome; *human rights; *international aspects; *social control; *genetic databases; genetic research; genetic screening; reproductive technologies; Keyword Identifiers: *Draft International Convention on the Prohibition of All Forms of Human Cloning; *European Convention on Human Rights and Biomedicine; *International Declaration on Human Genetic Data; *Universal Declaration on the Human Genome and Human Rights; UNESCO


Keywords: *biotechnology; *developing countries; *genomics; *international aspects; *access to information; government; health priorities; industry; justice; international relations; policy making; public health; regulation; research priorities; risks and benefits; universities; Proposed Keywords: biodiversity; stakeholders; technology transfer; Keyword Identifiers: *Global Genomics Initiative


Keywords: *agriculture; *biotechnology; *genetically modified plants; developing countries; ecology; genetic engineering; industry; international aspects; property rights; risks and benefits; Proposed Keywords: biodiversity


Keywords: *cloning; *genetic engineering; *germ cells; *international aspects; *regulation; human rights; legal aspects; nuclear transfer techniques; reproductive technologies; Keyword Identifiers: Convention on the Preservation of the Human Species; United States


Keywords: *animal welfare; *biotechnology; *genetically modified animals; agriculture; animal experimentation; animal rights; ethical analysis; methods; regulation; researchers; risks and benefits; suffering; utilitarianism; Proposed Keywords: domestic animals; laboratory animals


Keywords: *biotechnology; *ethical analysis; *gene therapy; *genetic engineering; *genetic enhancement; *genetic screening; *moral policy; autonomy; confidentiality; diagnosis; eugenics; future generations; genetic information; genetic predisposition; germ cells; human characteristics; medicine; philosophy; physician patient relationship; population genetics; professional family relationship; prenatal diagnosis; principle-based ethics; right not to know; risks and benefits; social impact


Keywords: *genetic engineering; anthropology; chimeras; evolution; future generations; gene therapy; genetic enhancement; genetic intervention; germ cells; human experimentation; human genome; pedigree; risks and benefits; social impact


Keywords: *bioethics; *clinical genetics; *ethical analysis; *genetic engineering; *policy making; behavioral genetics; biotechnology; choice behavior; coercion; common good; decision making; deontological ethics; eugenics; genetic disorders; germ cells; hearing disorders; historical aspects;

Keywords: *biotechnology; *economics; *genetic research; *genetic screening; *policy making; blood banks; commerce; cord blood; diagnosis; disclosure; embryo research; embryonic stem cells; entrepreneurship; genetic databases; genetic discrimination; genetic disorders; genetic information; genetic predisposition; genomics; government financing; government regulation; industry; insurance; legal aspects; patents; pharmacogenetics; policy analysis; public policy; regulation; research support; researchers; science; trends; Keyword Identifiers: Australia

Betta, Michela. Looking back, looking beyond: revisiting the ethics of genome generation. Journal of Biosciences 2006 March; 31(1): 167-176. 42 refs. NRCBL: 15.1; 1.3.11; 2.1; 15.3; 15.10; 15.5. SC: rv.

Keywords: *biotechnology; *genetic engineering; *genetic research; *genomics; benefit sharing; bioethics; cloning; developing countries; economics; embryo research; ethical analysis; genes; genetic determinism; genetic information; genetic patents; genetic screening; genetically modified food; genetically modified plants; Human Genome Project; international aspects; Proposed Keywords: exceptionalism; genetic resources; stakeholders


Keywords: *clinical genetics; *genetic engineering; *Roman Catholic ethics; gene therapy; human dignity; risks and benefits; theology; Keyword Identifiers: *Pope John Paul II; *Pope Pius XII


Keywords: *biotechnology; *genetic patents; *moral policy; *patents; *policy making; advisory committees; body parts and fluids; commodification; cryopreservation; embryo research; embryonic stem cells; genetic research; genetic screening; genetically modified animals; historical aspects; industry; human body; human dignity; legal aspects; life; methods; property rights; public policy; sex preselection; sperm; trends; Proposed Keywords: mice; Keyword Identifiers: *European Patent Organization; *European Union; Europe; Council of Europe; European Parliament; Twentieth Century; Twenty-First Century

Abstract: The European patent system allows for the introduction of moral issues into decisions about the granting of patents. This feature has greatly impacted European debates about the patenting of biotechnology. This essay explores the European experience, in both the European Union and the European Patent Organization.

It argues that there has been great confusion surrounding these issues primarily because the Europeans have not developed a general theory about when exclusion from patentability is the best social mechanism for dealing with morally offensive technologies.


Keywords: *biotechnology; *genetic research; *policy making; *social control; ethical analysis; focus groups; genomics; government; industry; international aspects; political activity; public participation; regulation; research priorities; researchers; risks and benefits; Proposed Keywords: consumer advocacy; stakeholders


Keywords: *biotechnology; *government regulation; *public policy; *reproductive technologies; advisory committees; bioethical issues; chimeras; common good; embryo research; embryonic stem cells; federal government; freedom; genetic engineering; legal aspects; ovum donors; policy making; public participation; remuneration


Keywords: *biotechnology; *mass media; genetic research; risks and benefits; Proposed Keywords: *hyperbole


Keywords: *animal welfare; *genetically modified animals; agriculture; animal behavior; animal cloning; animal experimentation; attitudes; guidelines; researchers; Proposed
**GENETIC ENGINEERING AND BIOTECHNOLOGY**

**SECTION I**

Keywords: domestic animals; laboratory animals; Keyword Identifiers: Canada; Canadian Council on Animal Care

**Corbellini, Gilberto.** Scientists, bioethics and democracy: the Italian case and its meanings. *Journal of Medical Ethics* 2007 June; 33(6): 349-352. 4 refs. NRCBL: 5.3; 1.3.5; 1.3.9; 14.1; 15.1. SC: le.

Keywords: *biotechnology; *democracy; *freedom; *government regulation; *politics; *science; animal cloning; bioethical issues; bioethics; embryo research; embryonic stem cells; evolution; genetic engineering; genetically modified organisms; information dissemination; legal aspects; political systems; preimplantation diagnosis; reproductive technologies; social impact; values; Western World; Proposed Keywords: technology; Keyword Identifiers: *Italy

Abstract: In June 2005, Italy held a referendum on repealing the law on medically assisted fertilization (Law 40/2004), which limits access to artificial reproduction to infertile couples, and prohibits the donation of gametes, the cryopreservation of embryos, preimplantation genetic diagnosis (PGD), and research on human embryos. The referendum was invalidated, and the law remained unchanged. The Italian political bioethical debate on assisted reproduction was manipulated by the Catholic Church, which distorted scientific data and issues at stake with the help of Catholic politicians and bioethicists. What happened in Italy shows that some perverse sociocultural political mechanisms are spreading the absurd and anti-historical view that scientific and technological advancements are threatening democracy and personal freedom. Scientists should not only contrast the political attempts at limiting freedom of scientific research, but also tell politicians, humanists and citizens that the invention of Western science with its view of scientific community as an “open society”, contributed and still contributes, through scientific education, to the construction and maintaining of the moral and political values underlying Western democracies.

**Deane-Drummond, Celia.** Biotechnology and theology.


Keywords: *biotechnology; *theology; animal cloning; genetic engineering; genetic research; genetically modified organisms; human genome

**Deane-Drummond, Celia.** Genetics and environmental concern.

*In her: Genetics and Christian Ethics. Cambridge: Cambridge University Press, 2006: 220-244. 70 fn. NRCBL: 15.1; 1.2; 16.1; 22.2.

Keywords: *animal rights; *ecology; *genetic engineering; *genetically modified animals; *theology; agriculture; Christian ethics; covenant; genetically modified plants; philosophy; specieism; virtues

**Egorova, Yulia.** ‘Up in the sky’: human and social sciences’ responses to genetics.


Keywords: *biotechnology; *genetic research; *social impact; cloning; culture; genetic identity; genetic intervention; genetic patents; human genome; metaphor; philosophy; postmodernism; reproductive technologies; social sciences; Proposed Keywords: transhumanism

**Ehrenfeld, David.** Unethical contexts for ethical questions.

*In: Galston, Arthur W.; Peppard, Christiana Z., eds. Expanding Horizons in Bioethics. Dordrecht; Norwell, MA: Springer, 2005: 19-34. 41 refs. 42 fn. NRCBL: 15.1; 5.3; 15.7; 22.1.

Keywords: *biotechnology; agriculture; animal welfare; cloning; ecology; genetic engineering; genetic patents; industry; genetically modified animals; genetically modified food; genetically modified plants; reproductive technologies; science; technology; values

**Einsiedel, Edna.** Telling technological tales: the media and the evolution of biotechnology.


Keywords: *biotechnology; *mass media; cloning; genetic research; genetically modified food; industry; information dissemination; international aspects; Internet; marketing; public opinion; risks and benefits; social impact; Keyword Identifiers: Great Britain; United States

**Eischen, Kyle.** Commercializing Iceland: biotechnology, culture, and the information society.


Keywords: *genetic databases; *genetic research; *social impact; biotechnology; culture; genetic ancestry; genetic privacy; geographic factors; industry; legal aspects; population genetics; socioeconomic factors; Proposed Keywords: commerce; Keyword Identifiers: *Iceland; *deCode Genetics

**Fiester, Autumn.** Casuistry and the moral continuum: evaluating animal biotechnology.


Keywords: *animal cloning; *animal organs; *casuistry; *ethical analysis; *genetically modified animals; animal rights; animal welfare; biotechnology; drugs; organ transplantation; risks and benefits; teleological ethics; Proposed Keywords: biodiversity; goats; species specificity; swine; zoonoses


Keywords: *biotechnology; *democracy; *policy making; *public participation; *reproductive technologies; accountability; bioethical issues; cloning; cultural pluralism; embryo research; embryonic stem cells; freedom; genetic engineering; government financing; government regulation;
policy analysis; preimplantation diagnosis; public policy; regulation; Keyword Identifiers: *United States


Keywords: *biotechnology; *cultural pluralism; *government regulation; *public policy; *reproductive technologies; bioethical issues; cloning; decision making; democracy; dissent; embryo research; embryonic stem cells; embryos; federal government; moral status; policy analysis; preimplantation diagnosis; reproductive medicine; self regulation; state government; Keyword Identifiers: *United States; Great Britain


Keywords: *animal cloning; *biotechnology; *genetic engineering; *industry; *stem cells; *capitalism; cell lines; embryo research; embryonic stem cells; gene therapy; genetically modified food; genetically modified organisms; nuclear transfer techniques; patents; stem cell transplantation; trust; Proposed Keywords: domestic animals; regenerative medicine; sheep; Keyword Identifiers: *Geron Corp.; Great Britain; United States


Keywords: *biotechnology; *government regulation; *reproductive technologies; accountability; biomedical research; cloning; commerce; embryo research; embryonic stem cells; embryos; freedom; genetic engineering; germ cells; guidelines; industry; judicial role; legal aspects; political activity; policy analysis; politics; preimplantation diagnosis; public participation; public policy; quality of health care; standards; Keyword Identifiers: *United States


Keywords: *cloning; *genetic engineering; *human dignity; *Roman Catholic ethics; *technology; embryo research; embryos; eugenics; genetic research; international aspects; personhood; quality of life; regulation; reproductive technologies; value of life; Proposed Keywords: biological sciences; Keyword Identifiers: Germany


Keywords: *DNA fingerprinting; *genetic databases; legislation; public policy; Keyword Identifiers: *Canada


Keywords: *biotechnology; *genes; genetically modified animals; genetic patents; hyperbole; industry; literature; universities; Keyword Identifiers: *Next (Crichton, Michael)


Keywords: *biotechnology; *human characteristics; advisory committees; autonomy; bioethical issues; biomedical enhancement; embryo research; evolution; forecasting; genetic determinism; genetic engineering; philosophy; public health; public policy; regulation; risks and benefits; science; stem cells; theology; uncertainty; values; Keyword Identifiers: *New York State Task Force on Life and the Law; United States


Keywords: *biomedical enhancement; *Christian ethics; *genetic engineering; *theology; *technology; human dignity; personhood; philosophy; values; Proposed Keywords: *technology; *transhumanism


Keywords: *genetic engineering; *human characteristics; *technology; genetic enhancement; human genome; life extension; philosophy; precautionary principle; religious ethics; risks and benefits; sociobiology; theology; Proposed Keywords: transhumanism


Keywords: *ethical analysis; *ethical theory; *genetic therapy; *genetic engineering; *genetic enhancement; *philosophy; *autonomy; freedom; future generations; germ cells; government regulation; human dignity; moral obligations; moral policy; paternalism; public policy; risks and benefits; socioeconomic factors; Proposed Keywords: *happiness;Keyword Identifiers: *Kant, Immanuel
Abstract: It is tempting to argue that Kantian moral philosophy justifies prohibiting both human germ-line genetic engineering and non-therapeutic genetic engineering because they fail to respect human dignity. There are, however, good reasons for resisting this temptation. In fact, Kant’s moral philosophy provides reasons that support genetic engineering—even germ-line and non-therapeutic. This is true of Kant’s imperfect duties to seek one’s own perfection and the happiness of others. It is also true of the categorical imperative. Kant’s moral philosophy does, however, provide limits to justifiable genetic engineering.

Henaghan, Mark. The ‘do no harm’ principle and the genetic revolution in New Zealand. In: McLean, Sheila A.M., ed. First Do No Harm: Law, Ethics, and Healthcare. Aldershot, England; Burlington, VT: Ashgate, 2006: 511-526. 68 fn. NRCBL: 15.1; 14.4; 15.3; 21.1. Keywords: *genetic engineering; *genetic services; *preimplantation diagnosis; *public policy; *regulation; advisory committees; beneficence; biotechnology; clinical trials; cloning; common good; embryos; ethical analysis; ethics committees; genetic screening; genetically modified organisms; germ cells; government regulation; guidelines; legal aspects; precautionary principle; reproductive technologies; risks and benefits; sex preselection; tissue typing. Keyword Identifiers: *New Zealand; National Ethics Committee on Assisted Human Reproduction (New Zealand)

Hohlfeld, Rainer. Politische Ökonomie und Bio-Medizin. In: Neuer-Miebach, Therese; Wunder, Michael, eds. Bio-Ethik und die Zukunft der Medizin. Bonn: Psychiatrie-In: 511-526. 68 fn. NRCBL: 15.1; 14.1; 15.2; 14.4; 15.3; 21.1. Keywords: *genetic engineering; *genetic services; *preimplantation diagnosis; *public policy; *regulation; advisory committees; beneficence; biotechnology; clinical trials; cloning; common good; embryos; ethical analysis; ethics committees; genetic screening; genetically modified organisms; germ cells; government regulation; guidelines; legal aspects; precautionary principle; reproductive technologies; risks and benefits; sex preselection; tissue typing. Keyword Identifiers: *Novartis

Holland, Suzanne. Market transactions in regeneprogenetics: a case for regulation. In: Knowles, Lori P.; Kaebrick, Gregory E., eds. Reprogenetics: Law, Policy, and Ethical Issues. Baltimore: Johns Hopkins University Press, 2007: 89-104. 20 refs. 6 fn. NRCBL: 14.1; 15.2; 14.4; 5.3. SC: an. Keywords: *commerce; *freedom; *genetic engineering; *genetic services; *germ cells; *ovum donors; *public policy; *regulation; *remuneration; *reproductive technologies; commodification; common good; democracy; embryo research; embryos; federal government; genetic relatedness ties; government financing; health facilities; in vitro fertilization; industry; justice; moral policy; policy analysis; politics; preimplantation diagnosis; private sector; public opinion; reproductive rights; socioeconomic factors; surrogate mothers; values; women. Keyword Identifiers: *United States; Canada; Great Britain

Indigenous Peoples Council on Biocolonialism. Indigenous people, genes and genetics: what indigenous people should know about biocolonialism: a primer and resource guide. Nixon, NV: Indigenous Peoples Council on Biocolonialism, 2000 June; 25 p. [Online]. Accessed: http://www.ipcb.org/publications/primers/htmls/ipgg.html 2 refs. NRCBL: 15.11; 18.5.9. Keywords: *American Indians; *genetic engineering; *genetic research; *indigenous populations; agriculture; biological specimen banks; biotechnology; commerce; eugenics; genes; genetic ancestry; genetic databases; genetic discrimination; genetic materials; genetic patents; genetically modified organisms; genetics; health hazards; Human Genome Diversity Project; informed consent; international aspects; political activity; population genetics; public policy; research ethics; research priorities; research subjects; Proposed Keywords: *genetic resources; biodiversity; colonialism


Johnston, Josephine; Wasunna, Angela A. Patents, biomedical research, and treatments: examining concerns, canvassing solutions. Hastings Center Report 2007 January-February; 37(1): S2-S35. 183 fn. NRCBL: 15.8; 21.1; 14.1; 15.1; 18.5.2; 18.5.4; 5.3. SC: an; iv. Keywords: *biomedical research; *biotechnological; *biotechnology; *biomedical technologies; germ cells; *genetic materials; *international aspects; *patents; *public policy; *privacy rights; genetic screening; government financing; guidelines; health care delivery; health services accessibility; historical aspects; HIV infections; incentives; legal aspects; moral policy; polio; private sector; public policy; public sector; research support; trends; Proposed Keywords: licensure; vaccines. Keyword Identifiers: National Institutes of Health; Organization for Economic Cooperation and Development; South Africa; Trade-Related Aspects of Intellectual Property Rights (TRIPS); United States

Juengst, Eric T. “Alter-ing” the human species? Misplaced essentialism in science policy. In: Rasko, John E.J.; O’Sullivan, Gabrielle M.; Ankeny, Rachel A., eds. The Ethics of Inheritable Genetic Modification: A Dividing Line? Cambridge: Cambridge University Press, 2006: 149-158. 30 fn. NRCBL: 15.1. SC: an. Keywords: *genetic engineering; *moral policy; future generations; gene pool; gene therapy; genetic enhancement; genetic research; germ cells; human characteristics; human experimentation; human genome; human rights; international aspects; policy analysis; risks and benefits; social control. Proposed Keywords: *species specificity


Kaiser, Matthias. Practical ethics in search of a toolbox: ethics of science and technology at the crossroads. In:


Kleinman, Daniel Lee; Kinchy, Abby J. Against the neoliberal steamroller? The Biosafety Protocol and the social regulation of agricultural biotechnologies. *Agriculture and Human Values* 2007 Summer; 24(2): 195-206. 46 refs. NRCBL: 15.7; 1.3.11; 15.1.


Mackie, Jocelyn E.; Taylor, Andrew D.; Finegold, David L.; Daar, Abdallah S.; Singer, Peter A. Lessons on ethical decision making from the bioscience industry. *PLoS Medicine* 2006 May; 3(5): e129. 4 refs. NRCBL: 15.1; 1.3.2; 2.1. SC: em.


Keywords: *biotechnology; *business ethics; *ethics consultation; *industry; *institutional ethics; *organizational policies; administrators; advisory committees; agriculture; case studies; conflict of interest; decision making; disclosure; drug industry; employment; entrepreneurship; ethicists; evaluation; interinstitutional relations; interviews; organization and administration; Proposed Keywords: stakeholders

Abstract: Some authors have argued that the human use of reproductive cloning and genetic engineering should be prohibited because these biotechnologies would undermine the autonomy of the resulting child. In this paper, two versions of this view are discussed. According to the first version, the autonomy of cloned and genetically engineered people would be undermined because knowledge of the method by which these people have been conceived would make them unable to assume full responsibility for their actions. According to the second version, these biotechnologies would undermine autonomy by violating these people’s right to an open future. There is no evidence to show that people conceived through cloning and genetic engineering would inevitably or even in general be unable to assume responsibility for their actions; there is also no evidence for the claim...
that cloning and genetic engineering would inevitably or even in general rob the child of the possibility to choose from a sufficiently large array of life plans.

Marks, Stephen P. Tying Prometheus down: human rights issues of human genetic manipulation. In: Gruskin, Sofia; Grodin, Michael A.; Annas, George J.; Marks, Stephen P., eds. Perspectives on Health and Human Rights. New York: Routledge. 2005: 163-178, 57 fn. NRCBL: 15.1; 4.4; 21.1. Keywords: *genetic engineering; *human rights; *international aspects; *autonomy; *cloning; human dignity; legal aspects; regulation


Keywords: *genetic engineering; *human genome; biotechnology; commodification; dehumanization; embryo research; future generations; genes; genetic resources; justice; love; moral obligations; personhood; theology


Keywords: *biotechnology; *genetic materials; *genetic patents; *legal aspects; developing countries; genetic research; genetic resources; industry; international aspects; Proposed Keywords: Turkey; European Union


Keywords: *biotechnology; *food; *ethical analysis; *genetically modified organisms; agriculture; animal welfare; autonomy; beneficence; ecology; justice; theoretical models; Proposed Keywords: biodiversity

Novas, Carlos. What is the bioscience industry doing to address the ethical issues it faces? PLoS Medicine 2006 May; 3(5): e142. 5 refs. NRCBL: 15.1; 1.3.2. SC: *em.

Keywords: *biotechnology; *business ethics; *drug industry; *industry; *institutional ethics; *organizational policies; administrators; ethicists; ethics consultation; interinstitutional relations


Keywords: *animal welfare; *genetic engineering; *genetically modified animals; *risks and benefits; animal cloning; animal experimentation; ethical analysis; human experimentation; moral policy; trends; Proposed Keywords: species specificity

Obasogie, Osagie. Racial alchemy. It may not be long before genetic skin-lightening treatments are on sale, so it’s time to stop pretending colour prejudice isn’t a problem.


Keywords: *biotechnology; *genetic ancestry; *racial groups; population genetics; social discrimination; Proposed Keywords: *cosmetic techniques; *skin pigmentation


Keywords: *federal government; *freedom; *gene therapy; *genetic engineering; *government regulation; *historical aspects; *public policy; adverse effects; advisory committees; biotechnology; clinical trials; cloning; decision making; embryo research; ethical review; eugenics; germ cells; guidelines; human experimentation; justice; parents; recombinant DNA research; research priorities; research subjects; researchers; reproductive technologies; resource allocation; rights; self regulation; social worth; Keyword Identifiers: *United States; Asilomar Conference; Department of Health and Human Services; Federal Policy (Common Rule) for the Protection of Human Subjects; Food and Drug Administration; National Commission for the Protection of Human Subjects; National Institutes of Health; Points to Consider in Human Somatic Cell Therapy and Gene Therapy; President’s Commission for the Study of Ethical Problems; Recombinant DNA Advisory Committee; Twentieth Century; Twenty-First Century; Working Group on Human Gene Therapy


Keywords: *embryo research; *genetic engineering; *policy making; *public policy; *regulation; *reproductive technologies; adverse effects; advisory committees; cloning; embryonic stem cells; embryos; federal government; freedom; government regulation; historical aspects; human experimentation; international aspects; ovum donors; preimplantation diagnosis; professional organizations; recombinant DNA research; risk; social impact; state government; Proposed Keywords: tissue typing; Keyword Identifiers: Canada; Ethics Advisory Board; Food and Drug Administration; Great Britain; Human Embryo Research Panel; National Bioethics Advisory Commission; Recombinant DNA Advisory Committee; Reprogenetics Technology Board; Twentieth Century; Twenty-First Century; United States; Warnock Committee


Keywords: *eugenics; *genetic engineering; *freedom; *historical aspects; *informal social control; *reproductive technologies; *values; *voting autonomy; *attitudes; *coercion; *contraception; *directive counseling; disabled persons; feminism; *genetic services; *public policy; *reproduction; *reproductive rights; researchers; sterilization; trends; voluntary programs; women; Proposed Keywords: ectogenesis,
SECTION I

TRANSHUMANISM

Keywords: *gene therapy; *genetic engineering; *germ cells; adverse effects; clinical trials; ethical analysis; future generations; gene transfer techniques; historical aspects; human experimentation; reproductive technologies; scientific misconduct; terminology; Keyword Identifiers: Twentieth Century


Keywords: *genetic engineering; *mass media; adverse effects; chimeras; cloning; eugenics; gene therapy; genetic identity; germ cells; human genome; Human Genome Project; literature; philosophy; public opinion; Keyword Identifiers: *The Island of Dr. Moreau (motion picture); Frankenstein (Shelley, M.);Gattaca (motion picture); The Sixth Day (motion picture)


Keywords: *biotechnology; *policy making; *reproductive technologies; advisory committees; cultural pluralism; democracy; dissent; federal government; freedom; genetic engineering; government regulation; policy analysis; preimplantation diagnosis; public participation; public policy; Keyword Identifiers: *United States


Keywords: *animal cloning; *animal welfare; *genetically modified animals; *moral policy; *organ transplantation; political activity; public opinion; utilitarianism; Keyword Identifiers: *Italy; Anti-Vivisection League (Italy); Centre for Animal Aid (Italy); National Foundation for the Protection of Animals (Italy)


Keywords: *animal rights; *animal welfare; *attitudes; *biotechnology; *genetically modified animals; animal experimentation; animal organs; emotions; focus groups; moral policy; organ transplantation; political activity; public opinion; utilitarianism; Keyword Identifiers: *Italy; Anti-Vivisection League (Italy); Centre for Animal Aid (Italy)

Pollack, Andrew. Round 2 [two] for biotech beets; after delay over safety fears, engineered crop will be planted [news]. New York Times 2007 November 27; p. C1, C2. NRCBL: 15.1; 1.3.11. SC: po.

Keywords: *genetically modified plants; agriculture; genetically modified food; industry; trends; Keyword Identifiers: United States


Keywords: *autonomy; *eugenics; *genetic engineering; *genetic enhancement; *human characteristics; freedom; parent child relationship; parents; Keyword Identifiers: *The Future of Human Nature (Habermas, Jürgen)


Keywords: *gene therapy; *genetic engineering; *germ cells; adverse effects; clinical trials; ethical analysis; future generations; gene transfer techniques; historical aspects; human experimentation; reproductive technologies; scientific misconduct; terminology; Keyword Identifiers: Twentieth Century

SECTION II

GENETIC ENGINEERING AND BIOTECHNOLOGY

Keywords: *bio medical technologies; *biotechnology; *nanotechnology; genetic screening; genetic services; genomics; marketing; pharmacogenetics; policy making; public participation; risks and benefits; social impact; values


Keywords: *biomedical technologies; *biotechnology; *nanotechnology; genetic screening; genetic services; genomics; marketing; pharmacogenetics; policy making; public participation; risks and benefits; social impact; values

NRCBL: National Reference Center for Bioethics Literature Classification Scheme

See inside front cover for terms.

Keywords: *genetic engineering; genetically modified food; genetically modified plants; genetically modified organisms; genetic patents; microbiology; public opinion; recombinant DNA research; risk. Keyword Identifiers: Europe; United States


Keywords: *biotechnology; cloning; genetic materials; genetic patents; legal aspects; stem cells; DNA sequences; embryo research; genes; genetic engineering; germ cells; international aspects; reproductive technologies. Keyword Identifiers: Europe; United States


Keywords: *biotechnology; freedom; science; abortion; advisory committees; cloning; embryo disposition; embryo research; embryonic stem cells; eugenics; federal government; fetal research; gene therapy; genetic discrimination; genetic engineering; genetic patents; genetic privacy; genetic research; genetic screening; genetically modified organisms; government regulation; legal aspects; politics; recombinant DNA research; reproductive technologies; Proposed Keywords: parthenogenesis; Keyword Identifiers: *United States; Diamond v. Chakrabarty; Great Britain; Human Fertilisation and Embryology Act 1990 (Great Britain); Patent and Trademark Office; President’s Council on Bioethics

Tierney, John. Are scientists playing God? It depends on your religion. *New York Times* 2007 November 20; p. F1, F2. NRCBL: 1.3.9; 14.5; 1.2; 15.1; 18.5.4.

Keywords: *cloning; embryo research; genetic engineering; international aspects; non-Western World; religious ethics; secularism; Western World; biotechnology; Buddhist ethics; Christian ethics; embryonic stem cells; embryos; government regulation; Hindu ethics; legal aspects; public policy; reproductive technologies; Keyword Identifiers: Asia; Europe; North America; South America


Keywords: *gene therapy; feminist ethics; genetic engineering; moral policy; bioethics; choice behavior; disadvantaged persons; embryos; ethical analysis; fetal therapy; gene transfer techniques; genetic services; health services accessibility; pregnant women; preimplantation diagnosis; risks and benefits; treatment refusal; women


Keywords: *evolution; forecasting; genetic engineering; biotechnology; eugenics; genetics; historical aspects; literature; philosophy; public opinion; risks and benefits; social impact. Proposed Keywords: *transhumanism; Keyword Identifiers: Nineteenth Century; Twentieth Century


Keywords: *animal welfare; genomics; agriculture; animal cloning; biodiversity; biotechnology; chimeras; economics; food; genetic databases; international aspects; regulation; social sciences; trends. Proposed Keywords: *animal production; domestic animals.

Abstract: How may emergent biotechnologies impact upon our relations with other animals? To what extent are any changes indicative of new relations between society and nature? This paper critically explores which sociological tools can contribute to an understanding of the technologisation of animal bodies. By drawing upon interview data with animal scientists I argue that such technologies are being partly shaped by broader changes in agriculture. The complexity of genomics trajectories in animal science is partly fashioned through the deligitimisation of the productivist paradigm but continue to sit in tension around particular conceptions of sustainability in farm animal production. In spite of this deligitimisation process genomics is now being framed in the context of a new productivism (termed the livestock revolution) bound up in projected global changes in animal consumption during the first half of the 21st century. This potentially jars against both social trends that seek to re-enchant animal life and sustainability discourses which include social and environmental contexts. Nevertheless the possibility of a new productivism is supported by various interconnected trends including the emergence of a discourse of the ‘bioeconomy’ and a liberal regulatory apparatus for farm animal breeding technologies. Ultimately an understanding of the possibility of emerging new bio-capitalisations on animal life should be set in a broader context of competing agricultural paradigms as well as ongoing tensions over ‘naturalness’ in human/animal relations.


Keywords: *biological warfare; biotechnology; bioterrorism; genetic engineering; historical aspects; public health; resource allocation; risk; social control; world health

Abstract: A recent approach for bioterrorism risk management calls for stricter regulations over biotechnology as a way to control subversion of technology that may be used to create a man-made pandemic. This approach is
largely unworkable given the increasing pervasiveness of molecular techniques and tools throughout society. Emerging technology has provided the tools to design much deadlier pathogens but concomitantly the ability to respond to emerging pandemics to reduce mortality has also improved significantly in recent decades. In its historical context determining just how ‘risky’ biological weapons is an important consideration for decision making and resource allocation. Management should attempt to increase capacity, share resources, provide accurate infectious disease reporting, deliver information transparency and improve communications to help mitigate the magnitude of future pandemics.


Keywords: *biotechnology; *clinical genetics; *Roman Catholic ethics; *theology; bioethics; cloning; eugenics; genetic engineering; genotype; health priorities; human dignity; Human Genome Project; justice; natural law; phenotype; recombinant DNA research; Keyword Identifiers: *Curran, Charles


Keywords: *biotechnology; *legal aspects; *patents; *Supreme Court decisions; industry; universities; Proposed Keywords: licenseure; Keyword Identifiers: *MedImmune v. Genentech; *United States


Keywords: *genetic engineering; *genetic research; *genetic screening; *public opinion; access to information; biotechnology; cloning; disclosure; employment; eugenics; genetic discrimination; genetic information; Human Genome Project; insurance selection bias; preimplantation diagnosis; prenatal diagnosis; reproductive technologies; research priorities; risks and benefits; social impact; survey; Keyword Identifiers: United States


Keywords: *biotechnology; *genetic engineering; *genetically modified food; *genetically modified plants; agriculture; DNA fingerprinting; doping in sports; ecology; gene therapy; genetic enhancement; health hazards; international aspects; nanotechnology; public opinion; recombinant DNA research; regulation; risks and benefits; stem cells; Proposed Keywords: forensic genetics; Keyword Identifiers: United States


NRCBL: National Reference Center for Bioethics Literature Classification Scheme

SECTION I

GENETIC ENHANCEMENT

Zwart, Hub. Statements, declarations and the problems of ethical expertise [editorial]. Genomics, Society and Policy 2007 April; 3(1); ii-iv. 2 refs. NRCBL: 15.1; 2.1; 5.1; 21.1.

Keywords: *bioethical issues; *bioethics; *biotechnology; *genetics; *guidelines; *international aspects; *policy making; *public participation; *social control; *technical expertise; cloning; ethicists; ethics committees; genetic databases; genetic research; human genome; human rights; Keyword Identifiers: Human Genome Organization (HUGO); UNESCO; Universal Declaration on Bioethics and Human Rights; Universal Declaration on the Human Genome and Human Rights


Keywords: *biotechnology; *embryo research; *Roman Catholic ethics; ecology; embryonic stem cells; eugenics; human dignity; quality of life; value of life; values; Proposed Keywords: altered nuclear transfer


Keywords: *biotechnology; *embryos; *human dignity; *research embryo creation; *Roman Catholic ethics; bioethics; biomedical technologies; embryonic stem cells; evolution; moral status; nuclear transfer techniques; quality of life; value of life

GENETIC ENHANCEMENT


Keywords: *biotechnology; *ethical analysis; *gene therapy; *genetic engineering; *genetic enhancement; *genetic screening; *moral policy; autonomy; confidentiality; diagnosis; eugenics; future generations; genetic information; genetic predisposition; germ cells; human characteristics; medicine; philosophy; physician patient relationship; population genetics; professional family relationship; prenatal diagnosis; principle-based ethics; right not to know; risks and benefits; social impact

GENETIC ENHANCEMENT

SECTION I

Keywords: *eugenics; *freedom; *genetic enhancement; *genetic intervention; *philosophy; children; ethical theory; future generations; genetic determinism; human identity; human characteristics; moral policy; parent child relationship; parents; preimplantation diagnosis; regulation; Proposed Keywords: Australia; Habermas, Jurgen


Key words: *beneficence; *disabled persons; *ethical analysis; *genetic intervention; *moral policy; *reproduction; *risks and benefits; choice behavior; congenital disorders; moral obligations; normality; parents; precautionary principle; preimplantation diagnosis; selective abortion; socioeconomic factors; Proposed Keywords: transhumanism

Elliott, Carl. The mixed promise of genetic medicine. New England Journal of Medicine 2007 May 17; 356(20): 2024-2025. 4 refs. NRCBL: 15.1; 4.5; 5.3; 15.5.

Key words: *biomedical enhancement; *genetic enhancement; attitudes; cosmetic surgery; eugenics; philosophy; Proposed Keywords: United States


Key words: *biomedical enhancement; *Christian ethics; *genetic engineering; *theology; biotechnology; human dignity; personhood; philosophy; values; Proposed Keywords: *technology; *transhumanism


Key words: *ethical analysis; *ethical theory; *gene therapy; *genetic engineering; *genetic enhancement; *philosophy; autonomy; freedom; future generations; germ cells; government regulation; human dignity; moral obligations; moral policy; paternalism; public policy; risks and benefits; socioeconomic factors; Proposed Keywords: happiness; Proposed Keywords: *Kant, Immanuel

Abstract: It is tempting to argue that Kantian moral philosophy justifies prohibiting both human germ-line genetic engineering and non-therapeutic genetic engineering because they fail to respect human dignity. There are, however, good reasons for resisting this temptation. In fact, Kant’s moral philosophy provides reasons that support genetic engineering—even germ-line and non-therapeutic. This is true of Kant’s imperfect duties to seek one’s own perfection and the happiness of others. It is also true of the categorical imperative. Kant’s moral philosophy does, however, provide limits to justifiable genetic engineering.


Key words: *biotechnology; *genomics; drug industry; economics; eugenics; genetic determinism; genetic enhancement; genetic predisposition; Human Genome Project; synthetic biology; Keyword Identifiers: Novartis


Key words: *ethical analysis; *genetic enhancement; *human characteristics; bioethics; biotechnology; disabled persons; gene therapy; germ cells; intelligence; philosophy; teleological ethics; Proposed Keywords: *transhumanism


Key words: *Christian ethics; *genetic enhancement; *theology; human characteristics; philosophy


Lock, Margaret. Utopias of health eugenics, and germ-line engineering. In: Nichte, Mark and Lock, Margaret, eds. New Horizons in Medical Anthropology: Essays in Honour of Charles Leslie. London: Routledge, 2002: 240-266. NRCBL: 15.1; 1.1; 4.5; 15.3; 15.4; 15.5. 15.10.


Key words: *Christian ethics; *genetic enhancement; *theology; attitudes to death; biomedical enhancement; gene therapy; health; justice; neurosciences; personhood; philosophy; Proposed Keywords: *transhumanism


Key words: *autonomy; *eugenics; *genetic engineering; *genetic enhancement; *human characteristics; freedom; parent child relationship; parents; Keyword Identifiers: *The Future of Human Nature (Habermas, Jurgen)
Keywords: *ethical analysis; *genetic enhancement; *moral policy; adults; autonomy; behavioral genetics; beneficence; decision making; enhancement technologies; eugenics; genetic discrimination; genetic engineering; guidelines; human characteristics; justice; minors; public policy; reproduction; risk and benefits

Keywords: *access to information; *brain; *exceptionalism; *government regulation; *neurosciences; *privacy; disclosure; federal government; genetic information; legislation; presumed consent; state government; Proposed Keywords: *brain imaging; magnetic resonance imaging; Keyword Identifiers: *United States; Health Insurance Portability and Accountability Act (HIPAA)

Keywords: *access to information; *brain; *exceptionalism; *government regulation; *neurosciences; *privacy; disclosure; federal government; genetic information; legislation; presumed consent; state government; Proposed Keywords: *brain imaging; magnetic resonance imaging; Keyword Identifiers: *United States; Health Insurance Portability and Accountability Act (HIPAA)

Barnoy, Sivia; Tabak, Nili. Israeli nurses and genetic information disclosure. Nursing Ethics 2007 May; 14(3): 280-294. 37 refs. NRCBL: 15.1; 4.1.3; 8.4; 8.1; 15.3. SC: em.
Keywords: *attitude of health personnel; *disclosure; *family members; *genetic information; *genetic privacy; *nurse's role *nurses; family relationship; genetic screening; interprofessional relations; international aspects; knowledge, attitudes, practice; legal aspects; nurse patient relationship; patients; professional family relationship; questionnaires; Proposed Keywords: self disclosure; Keyword Identifiers: *Israel
Abstract: The debate continues about whether people have a duty to pass on the positive results of their genetic tests to relatives who are at risk from the same disease, and, should they refuse, whether physicians and genetic counselors then have the duty to do so. To date, the role and views of nurses in this debate have not been investigated. In our study, a sample of Israeli nurses, untrained in genetics, were asked for their theoretical opinions and what practical steps they would take in the case of patients' refusal to disclose. The nurses were very sure that patients should inform their families but were equally sure that nurses must respect their decision to disclose or not. Few said they would take practical steps to disclose information if the patient objected. The authors believe that the most useful and appropriate role for nurses in this field is in working to bring about co-operation between patients and family members.


Gamero, Joaquin J.; Romero, Jose-Luis; Peralta, Juan-Luis; Carvalho, Mónica; Corte-Real, Francisco. Spanish public awareness regarding DNA profile databases in forensic genetics: what type of DNA profiles should be included? Journal of Medical Ethics 2007 October; 33(10): 598-604. 52 refs. NRCBL: 15.1; 1.3.5; 1.3.12; 18.3; 8.4; 18.3. SC: em.
Keywords: *biological specimen banks; *DNA fingerprinting; *forensic genetics; *genetic databases; *public opinion; *public policy; genetic privacy; government regulation; informed consent; law enforcement; legislation; policy making; predictive value of tests; prisoners; public participation; survey; Keyword Identifiers: *Spain; European Union
Abstract: The importance of non-codifying DNA polymorphism for the administration of justice is now well known. In Spain, however, this type of test has given rise to questions in recent years: (a) Should consent be obtained before biological samples are taken from an individual for DNA analysis? (b) Does society perceive these techniques and methods of analysis as being reliable? (c) There appears to be lack of knowledge concerning the basic norms that regulate databases containing private or personal information and the protection that information of this type must be given. This opinion survey and the subsequent analysis of the results in ethical terms may serve to reveal the criteria and the degree of information that society has with regard to DNA databases. In the study, 73.20% (SE 1.12%) of the population surveyed was in favour of specific legislation for computer files in which DNA analysis results for forensic purposes are stored.

Cohesion. Vancouver: UBC Press, 2005: 117-132. 40 refs. 2 fn. NRCBL: 15.1; 1.3.12; 1.3.5. Keywords: *DNA fingerprinting; *genetic databases; legislation; public policy; Keyword Identifiers: *Canada

Gilibar, Roy. Communicating genetic information in the family: the familial relationship as the forgotten factor. Journal of Medical Ethics 2007 July; 33(7): 390-393. 29 refs. NRCBL: 15.2; 8.4; 1.1; 8.1. Keywords: *communication; *disclosure; *duty to warn; *family members; *family relationship; *genetic counseling; *genetic privacy; confidentiality; informed consent; physician patient relationship; professional family relationship; right not to know; utilitarianism

Abstract: Communicating genetic information to family members has been the subject of an extensive debate recently in bioethics and law. In this context, the extent of the relatives’ right to know and not to know is examined. The mainstream in the bioethical literature adopts a liberal perception of patient autonomy and offers a utilitarian mechanism for solving familial tensions over genetic information. This reflects a patient-centred approach in which disclosure without consent is justified only to prevent serious harm or death to others. Based on a legal and bioethical analysis on the one hand, and an examination of empirical studies on the other, this paper advocates the adoption of a relational perception of autonomy, which, in the context of genetics, takes into account the effect that any decision—whether to disclose or not to disclose—will have on the familial relationship and the dynamics of the particular family. Adding this factor to the criteria usually advocated by lawyers and ethicists will facilitate reaching a sensitive decision, which recognises the various interests of family members beyond the risk to physical health. Taking this factor into account will require a process of deliberation both between doctors and patients, and in the family. It will also require a relaxation of medical confidentiality, as the family rather than the patient is gradually perceived as the unit of care. Moreover, adopting such a relational approach will accord with current views of doctors and patients who base their decision primarily on the nature of the familial relationship.


Abstract: One of the most difficult issues doctors face is a conflict between their professional duties. Such a conflict may arise when doctors know that information has implications not only for patients but also for family members but their duty of confidentiality prevents them from disclosing it. A comparative analysis of English and Israeli medical law reveals that the doctors’ duty is based on two principles: a liberal perception of patient autonomy and an overriding utilitarian principle of prevention of harm. However, socio-medical research indicates that these principles do not entirely reflect the views of patients and doctors and are too narrow to deal with the complex situations in practice. Thus, it is argued that the doctor’s legal duty of confidentiality should be reconsidered and qualified when it concerns the family. It is suggested that if medical law seeks to recognize the various interests family members have in genetic information then we should consider a different approach, founded on a relational interpretation of autonomy and communitarian notions of solidarity and moral responsibility. This approach perceives confidentiality and privacy as embracing the family unit, based on the view that close relatives are not entirely outside the private sphere of the individual but rather are integral to his or her identity. Thus, to the utilitarian mechanism available in medical law this approach adds a social criterion: The effect any decision (to disclose or not to disclose) will have on the familial relationship and on the dynamics of the particular family. This will provide a more flexible and workable alternative for doctors to resolve familial tensions over access to genetic information.


Keywords: *disclosure; *genetic information; *insurance; genetic discrimination; genetic privacy; genetic screening; government regulation; Keyword Identifiers: Great Britain


Keywords: *genetic privacy; *nurse’s role; genetic information; organizational policies; professional organizations


Keywords: *DNA fingerprinting; *genetic databases; *legal aspects; biological specimen banks; blood specimen collection; family members; genetic privacy; genetic research; government regulation; law enforcement; prisoners; research subjects; Keyword Identifiers: *Landry v. Attorney General; *Massachusetts; Federal Policy (Common Rule) for the Protection of Human Subjects 1991; Nuremberg Code; United States


Keywords: *DNA fingerprinting; *genetic databases; *law enforcement; *legal aspects; biological specimen banks; constitutional law; costs and benefits; criminal law; genetic
SECTION I: GENETIC PRIVACY

privacy; justice; population genetics; prisoners; public opinion; racial groups; Supreme Court decisions; Keyword Identifiers: *United States

Kohut, Kelly; Manno, Michael; Gallinger, Steven; Esplen, Mary Jane. Should healthcare providers have a duty to warn family members of individuals with an HDPCN-causing mutation? A survey of patients from the Ontario Familial Colon Cancer Registry. *Journal of Medical Genetics* 2007 June; 44(6): 404-407. 30 refs. NRCBL: 15.1; 8.4. SC: em. Identifiers: hereditary non-polyposis colorectal cancer.

Keywords: *duty to warn; family members; genetic information; genetic predisposition; genetic screening; health personnel; attitudes; genetic counseling; genetic privacy; informed consent; legal aspects; patients; registries; risk; self disclosure; survey; Proposed Keywords: colon cancer; Keyword Identifiers: Ontario


Keywords: *access to information; genetic databases; genetic privacy; genetic research; genomics; biological specimen banks; confidentiality; ethical review; government regulation; human experimentation; human genome; information dissemination; informed consent; international aspects; legal aspects; research subjects; Keyword Identifiers: Health Insurance Portability and Accessibility Act (HIPAA); United States

Lucassen, Anneke; Clarke, Angus. Should families own genetic information [debate]. *BMJ: British Medical Journal* 2007 July 7; 335(7609): 22-23. NRCBL: 15.8; 1.3.12; 8.4.

Keywords: *disclosure; family members; genetic information; genetic privacy; property rights; altruism; autonomy; confidentiality; genetic counseling; genetic screening; pedigree; professional family relationship; risk


Keywords: *disclosure; DNA sequences; famous persons; genetic privacy; genome mapping; human genome; access to information; genetic databases; genetic predisposition; industry; informed consent; researchers; Proposed Keywords: self disclosure; Keyword Identifiers: *Watson, James; Church, George; Venter, J. Craig

Mc Fleming, Jennifer. The governance of human genetic research databases in mental health research. *International Journal of Law and Psychiatry* 2007 May-June; 30(3): 182-190. 45 refs. NRCBL: 15.1; 1.3.12; 15.6; 8.4; 17.1; 18.3. SC: le

Keywords: *genetic databases; genetic research; mental health; biological specimen banks; confidentiality; disclosure; empirical research; genetic information; genetic privacy; guidelines; informed consent; legal aspects; mentally ill persons; property rights; regulation; research subjects; schizophrenia; stigmatization; vulnerable populations; Proposed Keywords: clinical utility; exceptionalism; research findings; Keyword Identifiers: Australia


Keywords: *DNA fingerprinting; genetic relatedness ties; immigrants; public policy; ethnic groups; family members; genetic ancestry; international aspects; legal aspects; pedigrees; politics; racial groups; social discrimination; Proposed Keywords: travel; Keyword Identifiers: *France

Moore, Solomon. DNA exonerations leads to change in legal system; states pass new laws; new police procedures — prisoners gain evidence access [news]. *New York Times* 2007 October 1; p. A1, A22. NRCBL: 15.1; 1.3.5; SC: le; po.

Keywords: *DNA fingerprinting; law enforcement; legal aspects; state government; access to information; laboratories; legislation; prisoners; standards; Proposed Keywords: *forensic genetics; Keyword Identifiers: *United States

Nyrhinen, Tarja; Hietala, Marja; Puukka, Pauli; Leino-Kilpi, Helena. Privacy and equality in diagnostic genetic testing. *Nursing Ethics* 2007 May; 14(3): 295-308. 37 refs. NRCBL: 15.3; 8.4; 9.5.7. SC: em.

Keywords: *attitudes; genetic privacy; genetic screening; adults; attitude of health personnel; children; comparative studies; diagnosis; evaluation studies; education; genetic counseling; genetic discrimination; genetic information; genetic services; justice; knowledge, attitudes, practice; nurses; parents; patients; physicians; questionnaires; Keyword Identifiers: *Finland

Abstract: This study aimed to determine the extent to which the principles of privacy and equality were observed during diagnostic genetic testing according to views held by patients or child patients’ parents (n = 106) and by staff (n = 162) from three Finnish university hospitals. The data were collected through a structured questionnaire and analysed using the SAS 8.1 statistical software. In general, the two principles were observed relatively satisfactorily in clinical practice. According to patients/parents, equality in the post-anaalytic phase and, according to staff, privacy in the pre-analytic phase, involved the greatest ethical problems. The two groups differed in their views concerning pre-analytic privacy. Although there were no major problems regarding the two principles, the differences between the testing phases require further clarification. To enhance privacy protection and equality, professionals need to be given more genetics/ethics training, and patients individual counselling by genetics units staff, giving more consideration to patients’ world-view, the purpose of the test and the test result.

Pirakitikulr, Darlyn; Bursztajn, Harold J. Pride and prejudice: avoiding genetic gossip in the age of genetic testing. *Journal of Clinical Ethics* 2007 Summer; 18(2): 156-161. 21 fn. NRCBL: 15.3; 8.1; 8.4.

Keywords: *genetic privacy; genetic screening; disclosure; employment; genetic discrimination; genetic information; informed consent; insurance; legal aspects; legislation;
medical records; Keyword Identifiers: Health Insurance Portability and Accountability Act 1996; United States

Preston, Julia. U.S. set to begin a vast expansion of DNA sampling; big effect on immigrants; law to cover most people detained or arrested by federal agents. New York Times 2007 February 5; p. A1, A15. NRCBL: 15.1; 1.3.5. SC: po; le.

Keywords: *DNA fingerprinting; *legal aspects; *law enforcement; *legislation; immigrants; genetic databases; federal government; Keyword Identifiers: *United States; Department of Justice; Federal Bureau of Investigation; Violence against Women Act


Keywords: *clinical genetics; *duty to recontact; *duty to warn; *family members; *genetic research; *research findings; *research subjects; confidentiality; disclosure; genetic counseling; genetic privacy; research ethics; Keyword Identifiers: Newfoundland


Keywords: *access to information; *confidentiality; *death; *disclosure; *medical records; family members; genetic information; legal aspects; physician patient relationship; privacy; professional family relationship; Proposed Keywords: harm; Keyword Identifiers: United States


Keywords: *genetic information; *genetic privacy; *genetic screening; *legal aspects; access to information; anonymous testing; autonomy; confidentiality; duty to warn; exceptionalism; family members; genetic counseling; genetic research; government regulation; informed consent; legal rights; medical records; public opinion; research subjects; right to not know; risks and benefits; Keyword Identifiers: *Europe; Council of Europe


Abstract: Developments in pharmacogenetics make it possible to determine the genetic factors that influence variations in response to medicine. Differences in response to medication may be related to the genetic characteristics of the individual, to the genetic make-up of the diseased tissue or to both. Advantages include optimal therapeutic effect, safe medication, minimised side-effects, and development of medication for small groups of patients. Strict adherence to patients’ rights and to the medical professional standard must prevent negative effects of pharmacogenetics on individual rights, notably the right (not) to know, to privacy and informed consent. Use of pharmacogenetics by third parties for non-health related purposes may bring about a disproportionate intrusion of the privacy of an individual; it may result in barriers for accessing primary social goods, and it may be a disincentive for the individual to have a pharmacogenetic analysis performed for individual health care purposes or to participate in a drug trial. Medical examinations before employment must be justified by the health requirements unavoidably inherent to the job (their objective being the protection of health and not the financial interests of the employer). In a system that relies on private insurance for having access to primary social goods (health, disability — and life insurance), the use and the outcome of a pharmacogenetic analysis for the purpose of differentiation between insurance candidates on the basis of their “risk-profile” must be restricted; where appropriate measures should take into account justified interests of the insurance company to prevent adverse selection. Current measures in several European countries are not effective enough to meet the concerns specifically inherent to pharmacogenetics [sic; pharmacogenetics]. Human rights principles must be at the basis of national and European policies for providing adequate protection against disproportionate intrusion into private life, for guaranteeing equity in access to health care and accessibility of other primary social goods.


Keywords: *DNA fingerprinting; *genetic databases; *law enforcement; *legislation; *minority groups; *social impact; *state government; adults; biological specimen banks; evaluation studies; federal government; legal aspects; legal rights; minors; racial groups; social discrimination; statistics; trends; Proposed Keywords: crime; Keyword Identifiers: *United States


Keywords: *DNA fingerprinting; *genetic databases; *genetic information; *genetic privacy; *genetic screening; *legal aspects; access to information; exceptionalism; family members; genetic ancestry; genetic predisposition; international aspects; law enforcement; medical records; pregnant women; rights; Keyword Identifiers: *Europe; United States


Keywords: *genetic privacy; *legislation; politics; Keyword Identifiers: *United States


SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review

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Keywords: *genetic discrimination; *genetic information; *genetic privacy; *genetic screening; *legal aspects; employment; family members; health insurance; government regulation; Keyword Identifiers: *United States


GENETIC RESEARCH

See also GENETICALLY MODIFIED ORGANISMS AND FOOD; GENOME MAPPING AND SEQUENCING


Animal-human hybrid-embryo research [editorial]. Lancet 2007 September 15-21; 370(9591): 909. NRCBL: 15.1; 18.5.4; 22.2; 5.3; 18.6; 18.1; 22.1.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.
Keywords: *chimeras; *international aspects; *moral policy; *public policy; animal experimentation; animal welfare; classification; comparative studies; embryo research; embryo transfer; embryos; ethical analysis; gene transfer techniques; genetic research; government regulation; legal aspects; moral status; nuclear transfer techniques; organ transplantation; research ethics; species specificity; stem cell transplantation; tissue transplantation; Keyword Identifiers: *European Union; Council of Europe; Europe

Keywords: *genetic patents; *genome; *synthetic biology; industry; microbiology; Keyword Identifiers: Celera Genomics; Venter, Craig

Arnason, Arnar; Simpson, Bob. Refractions through culture: the new genomics in Iceland. Ethnos 2003 December; 68(4): 533-553. 52 refs. 8 fn. NRCBL: 15.11; 15.1; 1.3.12; 13.1.
Keywords: *culture; *genetic databases; *genetic research; *industry; *information dissemination; attitudes; biological specimen banks; biotechnology; genetic identity; genomics; mass media; medical records; metaphor; pedigree; politics; population genetics; public opinion; public participation; presumed consent; public policy; regulation; research subjects; researchers; risks and benefits; Proposed Keywords: persuasive communication; Keyword Identifiers: *deCode Genetics; *Iceland

Baylis, Françoise; Fenton, Andrew. Chimera research and stem cell therapies for human neurodegenerative disorders. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Spring; 16(2): 195-208. 71 fn. NRCBL: 15.1; 18.1; 22.1; 17.1; 4.4; 18.5.4. SC: an.
Keywords: *chimeras; *embryonic stem cells; *ethical analysis; *human dignity; *moral policy; *moral status; *primates; *stem cell transplantation; animal welfare; clinical trials; guidelines; human characteristics; speciessim; therapeutic research; risks and benefits; Proposed Keywords: *neurodegenerative diseases; Keyword Identifiers: National Academy of Sciences

Keywords: *genetic research; *genetics; eugenics; genetic determinism; genetic identity; genetic intervention; genetic variation; genotype; historical aspects; human dignity; human genome; Human Genome Project; phenotype; population genetics; risks and benefits; spirituality; trends

Keywords: *biotechnology; *economics; *genetic research; *genetic screening; *policy making; blood banks; commerce; cord blood; diagnosis; disclosure; embryo research; embryonic stem cells; entrepreneurship; genetic databases; genetic discrimination; genetic disorders; genetic information; genetic predisposition; genomics; government financing; government regulation; industry; insurance; legal aspects; patents; pharmacogenetics; policy analysis; public policy; regulation; research support; researchers; science; trends; Keyword Identifiers: Australia

Bharadwaj, Minakshi. Looking back, looking beyond: revisiting the ethics of genome generation. Journal of Bioethics 2006 March; 31(1): 167-176. 42 refs. NRCBL: 15.1; 1.3.11; 2.1; 15.3; 15.10; 15.5. SC: rv.
Keywords: *biotechnology; *genetic engineering; *genetic research; *genomics; benefit sharing; bioethics; cloning; developing countries; economies; embryo research; ethical analysis; genes; genetic determinism; genetic information; genetic patents; genetic screening; genetically modified food; genetically modified plants; Human Genome Project; international aspects; Proposed Keywords: exceptionalism; genetic resources; stakeholders

Keywords: *clinical genetics; *genetic patents; *genetic research; *genetic screening; autonomy; case studies; chromosome abnormalities; commerce; common good; embryo research; gene therapy; genetic disorders; genetic engineering; genetic predisposition; genetically modified organisms; health care reform; human dignity; human genome; Human Genome Project; legal aspects; prenatal diagnosis; risks and benefits; selective abortion; Keyword Identifiers: Canada

Keywords: *genetic research; *mass media; biotechnology; conflict of interest; editorial policies; genetic determinism; genetic engineering; journalism; public opinion; researchers; risks and benefits; social impact; trust; Proposed Keywords: publication bias

Keywords: *biotechnology; *genetic research; *policy making; *social control; ethical analysis; focus groups; genomics; government; industry; international aspects; political activity; public participation; regulation; research priorities; researchers; risks and benefits; Proposed Keywords: consumer advocacy; stakeholders

SECTION I

GENETIC RESEARCH

Keywords: *genetic research; *genetic services; *marketing; *mass media; biomedical research; biotechnology; government financing; industry; journalism; policy making; public participation; research priorities; research support; researchers; science; technology assessment; Keyword Identifiers: Canada


Keywords: *animal welfare; *genetically modified animals; agriculture; animal behavior; animal cloning; animal experimentation; attitudes; guidelines; researchers; Proposed Keywords: domestic animals; laboratory animals; Keyword Identifiers: Canada; Canadian Council on Animal Care


Keywords: *genetic determinism; *genetic research; *mass media; *public opinion; alcohol abuse; behavioral genetics; comprehension; empirical research; genetic ancestry; genetic predisposition; genetics; racial groups; social impact


Keywords: *attitudes; *genetic ancestry; *genetic discrimination; *genetic research; *information dissemination; *public opinion; *racial groups; *social impact; *blacks; mass media; minority groups; social discrimination; survey; whites; Keyword Identifiers: United States


Keywords: *genetic markers; *genetic predisposition; *genetic research; *human genome; *methods; access to information; clinical genetics; federal government; genetic databases; genetic screening; genetic techniques; informed consent; population genetics; public policy; research design; research subjects; trends; Proposed Keywords: *genome-wide association studies; Keyword Identifiers: National Institutes of Health; United States


Keywords: *attitudes; *genetic research; *genetics; researchers; clinical genetics; culture; evolution; genetic determinism; genetic engineering; Human Genome Project; interdisciplinary communication; international aspects; interviews; mass media; personhood; philosophy; professional role; religion; science; secularism; self concept; technical expertise; Keyword Identifiers: Great Britain; Russia; United States

Abstract: It is often suggested in the mass media and popular academic literature that scientists promote a secular and reductionist understanding of the implications of the life sciences for the concept of being human. Is adhering to this view considered to be one of the components of the notion of being a good scientist? This paper explores responses of geneticists interviewed in the UK, the USA and Russia about the cultural meanings of their work. When discussing this question the interviewees distinguished between their 'personal' and 'professional' views. When talking as 'lay people' they demonstrated a wide range of opinions none of which was perceived as incompatible with scientific practice. When talking as 'scientists' the respondents stressed that the cultural implications of their research were not a matter of their professional concern. It is suggested that these two trends in their answers could be explained by scientists tending to relegate the implications of their work to the realm of the social which they construe as divorced from scientific practice.


Keywords: *genetic databases; *genetic research; *social impact; biotechnology; culture; genetic ancestry; genetic privacy; geographic factors; industry; legal aspects; population genetics; socioeconomic factors; Proposed Keywords: commerce; Keyword Identifiers: *Iceland; *deCode Genetics


Keywords: *commerce; *genetic patents; *genetic research; *government; *human genome; *industry; commodification; community consent; conflict of interest; economics; genetic databases; indigenous populations; interinstitutional relations; population genetics; private sector; property rights; public policy; public sector; research support; risks and benefits; social impact; trends; universities; utilitarianism; values

NRCBL: National Reference Center for Bioethics Literature Classification Scheme. See inside front cover for terms.
Keywords: *biological specimen banks; *genetic databases; family members; government regulation; guidelines; human experimentation; informed consent; legal aspects; research subjects; Proposed Keywords: tissue donors; Keyword Identifiers: *European Convention on Human Rights and Biomedicine; Europe

Keywords: *genetic databases; *genetic research; *population genetics; *public participation; communication; confidentiality; genetic diversity; genetics; information dissemination; public opinion; research design; research subjects; selection of subjects; trust; Proposed Keywords: research findings; Keyword Identifiers: *Cartagene Project; *Quebec

Godard, Béatrice; Marshall, Jennifer; Laberge, Claude. Community engagement in genetic research: results of the first public consultation for the Quebec CARTaGENE project. Community Genetics 2007; 10(3): 147-158. 28 refs. NRCBL: 15.1; 1.3.12; 18.1. SC: em.
Keywords: *genetic databases; *genetic research; *public opinion; *public participation; biological specimen banks; choice behavior; confidentiality; donors; duty to recontact; ethnic groups; focus groups; genetic privacy; knowledge, attitudes, practice; public sector; private sector; questionnaires; research subjects; researcher subject relationship; risks and benefits; Proposed Keywords: research findings; Keyword Identifiers: *Quebec; *Quebec CARTaGENE

Keywords: *comparative study; *genetic research; *neurosciences; biomedical enhancement; biomedical technologies; brain; coercion; diagnosis; DNA fingerprinting; ethical analysis; eugenics; family members; genetic determinism; genetic diversity; genetic identity; genetic information; genetic screening; Human Genome Project; informed consent; justice; normality; personhood; philosophy; prenatal diagnosis; privacy; research subjects; risks and benefits; terminology; uncertainty; Proposed Keywords: brain imaging

Hausman, Daniel M. Group risks, risks to groups, and group engagement in genetics research. Kennedy Institute of Ethics Journal 2007 December; 17(4): 351-369. 12 refs. 1 fn. NRCBL: 15.1; 18.2; 18.3; 5.2; 15.11. SC: an.
Keywords: *genetic research; *moral policy; *research subjects; *risk; *vulnerable populations; anthropology; classicification; community consent; ethical analysis; ethnic groups; genetic ancestry; genetic epidemiology; indigenous populations; moral obligations; policy making; public participation; racial groups; research findings; social discrimination; stigmatization; Proposed Keywords: *community participation; *harm; *population groups; *third-party research subjects

Keywords: *biological specimen banks; *genetic databases; *genetic research; *guidelines; advisory committees; comparative studies; genetic information; informed consent; international aspects; organizational policies; public policy; research subjects; tissue donors; Keyword Identifiers: *Europe; *Council of Europe; European Group on Ethics in Science and New Technologies; German National Ethics Council; Human Genetics Commission (Great Britain)

Helgesson, Gert; Dílner, Joakim; Carlson, Joyce; Bartram, Claus R.; Hansson, Mats G. Ethical framework for previously collected biobank samples [letter]. Nature Biotechnology 2007 September; 25(9): 973-976. 16 refs. NRCBL: 15.1; 1.3.12.
Keywords: *biological specimen banks; *biomedical research; *genetic research; *informed consent; *presumed consent; *standards; *tissue donors; access to information; confidentiality; duty to recontact; ethical review; genetic databases; guidelines; legal aspects; refusal to participate; regulation; research findings; research subjects; time factors

Hoedemaekers, Rogeer; Gordijn, Bert; Pijnenburg, Martien. Solidarity and justice as guiding principles in genomic research. Bioethics 2007 July; 21(6): 342-350. 25 fn NRCBL: 15.10; 15.1; 1.3.12; 1.1; 9.1; 18.3; 18.5.1. SC: an.
Keywords: *ethical analysis; *future generations; *genetic research; *justice; *moral obligations; *moral policy; *nontherapeutic research; *obligations to society; *presumed consent; *altruism; *autonomy; *biological specimen banks; *communitarianism; *ethical review; *financial support; *genetic databases; *genomics; *health priorities; *industry; *informed consent; *obligations of society; *public policy; *research design; *research priorities; *research subjects; *research support; *resource allocation; *risks and benefits; *theoretical models
Abstract: In genomic research the ideal standard of free, informed, and explicit consent is sometimes difficult to apply. This has raised concern that important genomic research will be restricted. Different consent procedures have therefore been proposed. This paper explicitly examines the question how, in genomic research,
the principles of solidarity and justice can be used to justify forms of diminished individual control over personal data and bio-samples. After a discussion of the notions of solidarity and justice and how they can be related to health care and genomic research, we examine how and in which situations these notions can form a strong moral basis for demanding certain financial sacrifices. Then we examine how these principles can justify consent procedures which diverge from the ideal standard. Because much genomic research is not expected to lead to immediate (clinical) benefits we also discuss the question of whether we can be obliged to make any sacrifices for future (not yet existing) patients. We conclude with the formulation of a number of conditions that have to be met before autonomy sacrifices can be reasonably demanded in genomic research.

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**Institute of Medicine (United States) [IOM]. Board on Health Sciences Policy. Committee on Assessing Interactions Among Social, Behavioral, and Genetic Factors in Health; Hernandez, Lyla M.; Blazer, Dan G.** Ethical, legal, and social implications. *In their: Genes, Behavior, and the Social Environment: Moving Beyond the Nature/Nurture Debate.* Washington, DC: National Academy Press, 2006: 202-218. 43 refs., 3 fn. NRCBL: 15.1; 9.1; 7.1; 15.6; 16.1. *Keywords: *genetic predisposition; *genetic research; *health promotion; access to information; behavioral genetics; confidentiality; decision making; disclosure; ecology; genetic disorders; genetic patents; genomics; informed consent; interdisciplinary communication; occupational exposure; policy making; population genetics; public participation; public policy; research ethics committees; research priorities; research subjects; risk; socioeconomic factors; vulnerable populations; Proposed Keywords: *genetic epidemiology; research findings; Keyword Identifiers: National Institutes of Health; United States

**Juengst, Eric T.** Population genetic research and screening: conceptual and ethical issues. In: Steinbock, Bonnie, ed. *The Oxford Handbook of Bioethics.* Oxford; New York: Oxford University Press, 2007: 471-490. 66 refs. NRCBL: 15.11. SC: an; rv. *Keywords: *genetic research; *genetic screening; *population genetics; autonomy; benefit sharing; clinical genetics; community consent; cultural pluralism; decision making; ethnic groups; eugenics; gene pool; genetic ancestry; genetic discrimination; genetic diversity; genetic information; genetic resources; genotype; genomics; goals; international aspects; justice; mass screening; moral policy; phenotype; policy analysis; preventive medicine; property rights; public health; public policy; racial groups; research subjects; values

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**Kettis-Lindblad, Åsa; Ring, Lena; Vibert, Eva; Hansson, Mats G.** Genetic research and donation of tissue samples to biobanks. What do potential sample donors in the Swedish general public think? *European Journal of Public Health* 2006 August; 16(4): 433-440. NRCBL: 15.1; 19.1; 18.5.1; 18.3.

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**Knoppers, Bartha Maria; Joly, Yoly; Simard, Jacques; Durocher, Francine.** The emergence of an ethical duty to...

Knoppers, Bartha Maria; Sallée, Clémentine. Ethical aspects of genome research and banking. In: Sensen, Christopher W., ed. Handbook of Genome Research: aspects of genome research and banking. Knoppers, Bartha Maria; Sallée, Clémentine. Journal of Human Genetics 2006 December; 14(12): 1170-1178 [see correction in: European Union; Hagahai; National Geographic Society; National Institutes of Health; Patent Act; United States

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Keywords: *access to information; *genetic databases; *genetic research; *genetic privacy; *genomics; biological specimen banks; confidentiality; ethical review; government regulation; human experimentation; human genome; information dissemination; informed consent; international aspects; legal aspects; research subjects; right not to know; trends; Proposed Keywords: tissue donors


Keywords: *genetic databases; *genetic diversity; *genetic materials; *genetic patents; *genetic research; *HapMap Project; *Human Genome Diversity Project; *indigenous populations; *informed consent; *international aspects; *population genetics; American Indians; anthropology; autonomy; benefit sharing; biological specimen banks; culture; ethnic groups; genetic identity; human rights; industry; legal aspects; moral policy; public policy; research subjects; Keyword Identifiers: *Genographic Project; Canada; European Union; Hagahai; National Geographic Society; National Institutes of Health; Patent Act; United States


Keywords: *behavioral genetics; *genetic research; eugenics; genetic determinism; mental disorders; risks and benefits; social discrimination; stigmatization


Keywords: *genetic research; *genetic techniques; *reproductive technologies; *research subjects; *risks and benefits; adverse effects; beneficence; children; disabled persons; donors; economics; ethnic groups; ethical analysis; evaluation; family members; future generations; gene therapy; genetic engineering; genetic information; germ cells; guidelines; human experimentation; innovative therapies; men; preimplantation diagnosis; regulation; research ethics committees; stigmatization; women; wrongful life; Proposed Keywords: *third-party research subjects

Abstract: Research protocols must have a reasonable balance of risks and anticipated benefits to be ethically and legally acceptable. This article explores three characteristics of research on reproductive genetic technologies that complicate the assessment of the risk-benefit ratio for such research. First, a number of different people may be affected by a research protocol, raising the question of who should be considered to be the subject of reproductive genetic research. Second, such research could involve a wide range of possible harms and benefits, making the evaluation and comparison of those harms and benefits a challenging task. Finally, the risk-benefit ratio for this type of research is difficult to estimate because such research can have unpredictable, long-term implications. The article aims to facilitate the assessment of risk-benefit ratios in research on reproductive genetic technologies by proposing and defending some guidelines for dealing with each of these complicating factors.


Keywords: *genetic research; *genetic screening; *risks and benefits; decision making; ethical analysis; ethnic groups; evaluation; exceptionalism; family members; gene therapy; genetic ancestry; genetic information; genetic materials; research subjects; right not to know; stigmatization; Proposed Keywords: harm; third-party research subjects


Keywords: *comprehension; *genetic research; *informed consent; *methods; *research subjects; comparative studies; consent forms; epidemiology; motivation; Proposed Keywords: *genetic epidemiology; Keyword Identifiers: Japan

Abstract: This study evaluated the effect on participant understanding and participation rates of two different ap-
proaches to obtaining informed consent, using 2,192 actual research subjects in a genetic cohort study. One group received the routine approach consisting of written materials and an oral explanation. The other group received a more intense approach consisting of educational lectures and group meetings in addition to the routine approach. Subjects in the intense approach group were relatively more likely to read some or all of the explanatory material. Those in the intense group who did not read the material were more likely than those in the routine group to express uncertainty about their understanding of the research. Those in the intense group who read the material perceived that they had a higher level of understanding of the research and this was associated with a higher frequency of volunteering to participate. In contrast, subjects in the routine group were less likely to read the written material, but ironically more likely to assume that they understood what the research was about. These rather paradoxical findings raised questions about what motivates potential research subjects to become sufficiently engaged to seek actual understanding of the research before volunteering.

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Keywords: *biomedical research; *databases; *genetic databases; *genetic research; *informed consent; *presumed consent; confidentiality; epidemiology; international aspects; medical records; registries; Keyword Identifiers: Great Britain; UK Biobank


Keywords: *chimeras; *embryo research; *regulation; public policy; Keyword Identifiers: *Great Britain; *Human Fertilisation and Embryology Authority


Keywords: *genetic databases; *genetic research; *mental health; biological specimen banks; confidentiality; disclosure; empirical research; genetic information; genetic privacy; guidelines; informed consent; legal aspects; mentally ill persons; property rights; regulation; research subjects; schizophrenia; stigmatization; vulnerable populations; Proposed Keywords: clinical utility; exceptionalism; research findings; Keyword Identifiers: Australia


Keywords: *genetic databases; *genetic research; *informed consent; *motivation; *population genetics; *research subjects; biological specimen banks; coercion; donors; genomics; questionnaires; researchers; Keyword Identifiers: Wisconsin


Keywords: *benefit sharing; *developing countries; *genetic research; *international aspects; advisory committees; genetic databases; genetic diversity; genomics; human experimentation; human genome; justice; population genetics; property rights; research ethics;; research support; Proposed Keywords: biodiversity; Keyword Identifiers: Convention on Biological Diversity; Human Genome Organization (HUGO); United States


Keywords: *BRCA2 genes; *cancer; *disclosure; *family members; *genetic counseling; *genetic predisposition; *genetic research; *research findings; *truth disclosure; breast cancer; death; genetic screening; informed consent; interviews; ovarian cancer; prostate cancer; qualitative research; research subjects

Paradies, Yin C.; Montoya, Michael J.; Fullerton, Stephanie M. Racialized genetics and the study of complex diseases: the thrifty genotype revisited. Perspectives in Biology and Medicine 2007 Spring; 50(2): 203-227. 143 refs. NRCBL: 15.1; 9.5.4; 15.11. SC: an; rv.

Keywords: *diabetes; *ethnic groups; *genetic ancestry; *genetic predisposition; *genetic research; *population genetics; *racial groups; genetic diversity; genotype; health status; Proposed Keywords: *genetic epidemiology


Keywords: *attitudes; *biological specimen banks; *biomedical research; *blacks; *cancer; *minority groups; *patients; *whites; body parts and fluids; comparative studies; confidentiality; consent forms; donors; duty to recontact; genetic databases; informed consent; refusal to participate; socioeconomic factors; survey; time factors; Proposed Keywords: *tissue donors; Keyword Identifiers: Georgia

Persson, Anders. Research ethics and the development of medical biotechnology. Xenotransplantation 2006 November; 13(6): 511-513. NRCBL: 15.1; 15.4; 5.3; 18.2; 19.1; 22.2.


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Rusnak, A.J.; Chudley, A.E. Stem cell research: cloning, therapy and scientific fraud. Clinical Genetics 2006 October; 70(4): 302-305. NRCBL: 15.1; 14.5; 1.3.9; 18.5.1.


SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
ated with the protection of group interests and argue that protectionist strategies developed in the context of genetic research will not be easily adapted to other types of research in which social groups are placed at risk. We suggest that it is this set of conceptual and practical issues that philosophers, ethicists, and others should focus on in their efforts to protect identifiable social groups from harm resulting from biomedical research.


Keywords: *attitudes; *blacks; *genetic ancestry; *genetic predisposition; *genetic research; *racial groups; behavioral genetics; ethnic groups; genetic disorders; intelligence; interviews; risks and benefits; questionnaires; social discrimination; social impact; stigmatization; trust; violence; whites; Keyword Identifiers: United States


Keywords: *American Indians; *genetic research; community consent; government; indigenous populations; informed consent; policy making; public participation; refusal to participate; research subjects; Keyword Identifiers: United States

Sherwood, Mylaina L.; Buchinsky, Farrel J.; Quigley, Matthew R.; Donfack, Joseph; Choi, Sukgi S.; Conley, Stephen F.; Derkay, Craig S.; Myer, Charles M., III; Ehrlich, Garth D.; Post, J. Christopher. Unique challenges of obtaining regulatory approval for a multicenter protocol to study the genetics of RRP and suggested remedies. *Otolaryngology and Head and Neck Surgery* 2006 August; 135(2): 189-196. NRCBL: 15.1; 18.2; 18.3; 18.5.1.


Keywords: *clinical genetics; *genetic research; *genetic services; *government financing; *research support; *scarcity; education; health personnel; internship and residency; referral and consultation; Proposed Keywords: waiting lists; Keyword Identifiers: *Canada

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Keywords: *genetic epidemiology; *genetic research; *genetic screening; *research priorities; databases; genetic disorders; genetic predisposition; literature; survey; technology assessment; Keyword Identifiers: Germany


Keywords: *biological specimen banks; *genetic databases; *population genetics; *international aspects; *public policy; *standards; confidentiality; donors; federal government; genetic privacy; genetic research; guidelines; informed consent; policy making; public health; public participation; research subjects; research support; state government; trends; Keyword Identifiers: *United States


Keywords: *attitudes; *genetic predisposition to disease; *genetic research; *motivation; *research subjects; donors; blood specimen collection; epidemiology; family members; genetic privacy; interviews; nontherapeutic research; women; Proposed Keywords: *endometriosis; *genetic epidemiology; pilot projects; Keyword Identifiers: Australia


Keywords: *genetic research; *genomics; *legal aspects; *pharmacogenetics; *public policy; advertising; biological specimen banks; drugs; genetic screening; guidelines; research support; standards; Keyword Identifiers: *United States

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Keywords: *access to information; *children; *confidentiality; *DNA sequences; *genetic databases; *genetic information; *genetic privacy; *genetic research; *publishing; adolescents; biological specimen banks; cancer; disclosure; donors; empirical research; federal government; genetic predisposition; government regulation; human genome; Internet; legal aspects; parental consent; research ethics committees; research subjects; risk; risks and benefits; state government; Proposed Keywords: genome-wide association studies; tissue donors; Keyword Identifiers: Health Insurance Portability and Accountability Act (HIPAA); United States
GENETIC SCREENING

See also DNA FINGERPRINTING; GENETIC COUNSELING; GENOME MAPPING AND SEQUENCING


Keywords: *attitudes; *biomedical research; *bioethics; *decision making; *democracy; *embryo research; *embryonic stem cells; *eugenics; *freedom; *genetically modified organisms; *mass media; *social impact; *technology; *voluntary programs; *medicine; *risk; Proposed Keywords: *man; *man with a mission; *man with a plan; *man with a purpose; *man with a vision; *man with a will; *man with a word.

Burr, Paul; Craig, Susan; Kastely, Steven; Malsberger, Peter; Weisen, Susan. An overview of genetic counseling services in minors: a systematic review of guidelines and position papers. Clinical Genetics 2006 November; 70(5): 374-381. NRCBL: 15.3; 9.5.7.

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Keywords: *drugs; *genetic screening; *government regulation; pharmacogenetics; Proposed Keywords: *drug prescriptions; drug labeling; Keyword Identifiers: *Food and Drug Administration; *Warfarin; United States


Keywords: *clinical genetics; *genetic predisposition; *genomics; genetic screening; preventive medicine; risk; trends; Proposed Keywords: *personalized medicine


Keywords: *genetic screening; *evaluation studies; *goals; classification; clinical genetics; decision making; genetic services; health care delivery; predictive value of tests; standards


Keywords: *chronically ill; *genetic screening; *knowledge, attitudes, practice; genetic counseling; genetics; patients; survey; Proposed Keywords: asthma; cardiovascular diseases; diabetes mellitus; follow-up studies; Keyword Identifiers: Netherlands


Chen, Lei-Shih; Goodson, Patricia. Factors affecting decisions to accept or decline cystic fibrosis carrier testing/screening: a theory-guided systematic review. Genetics in Medicine 2007 July; 9(7): 442-450. NRCBL: 15.3. SC: em.


Keywords: *age factors; *chromosome abnormalities; *genetic screening; *preimplantation diagnosis; genetic disorders; in vitro fertilization; pregnant women; risks and benefits; Proposed Keywords: pregnancy outcome

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Keywords: *genetic screening; advisory committees; children; genetic databases; genetic disorders; population genetics; preimplantation diagnosis; prenatal diagnosis; public policy; Keyword Identifiers: Great Britain; Human Genetics Commission (Great Britain); Human Fertilisation and Embryology Authority; UK Biobank


Duncan, R.E.; Delatycki, M.B. Predictive genetic testing in young people for adult-onset conditions: where is the empirical evidence? Clinical Genetics 2006 January;
69(1): 8-16; discussion 17-20. 46 refs. NRCBL: 15.3; 9.5.7.

Keywords: *genetic screening; *late-onset disorders; *minor; *adolescents; *children; *genetic counseling; genetic predisposition; empirical research; risks and benefits

Erde, Edmund L.; McCormack, Michael K.; Steer, Robert A.; Ciervo, Carmen A., Jr.; McAbee, Gary N.

Patient confidentiality vs disclosure of inheritable risk: a survey-based study. Journal of the American Osteopathic Association 2006 October; 106(10): 615-620. NRCBL: 15.3; 8.4; 8.2; 7.1; 5.3. SC: en.

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Keywords: *genetic screening; *public policy; *advertising; advisory committees; *federal government; *genetic services; *government regulation; industry; *Keyword Identifiers: *Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS); Food and Drug Administration; Department of Health and Human Services; United States

Freeman, Bradley D.; Kennedy, Carie R.; Cooper-Smith, Craig M.; Zehnbauer, Barbara A.; Buchman, Timothy G.

Genetic research and testing in critical care: surrogates’ perspective. Critical Care Medicine 2006 April; 34(4): 986-994. NRCBL: 15.3; 8.3.3; 18.2.

Gagen, Wendy Jane; Bishop, Jeffrey P.


Keywords: *attitudes; *prenatal diagnosis; spina bifida; attitude of health personnel; *authorship; *congenital disorders; costs and benefits; *disabled persons; *editorial policies; *ethical analysis; *eugenics; *historical aspects; mass screening; *methods; neural tube defects; *paternalism; *preventive medicine; *public health; *public policy; *risks and benefits; *selective abortion; *survey; *utilitarianism; *Keyword Identifiers: *Great Britain; Lancet; National Health Service; Twentieth Century

Abstract: During the 1970s, prenatal screening technologies were in their infancy, but were being swiftly harnessed to uncover and prevent spina bifida. The historical rise of this screening process and prevention programme is analysed in this paper, and the role of ethical debates in key studies, editorial and letters reported in the Lancet, and other related texts and governmental documents between 1972 and 1983, is considered. The silence that surrounded rigorous ethical debate served to highlight where discussion lay—namely, within the justifications offered for the prevention of spina bifida, and the efficacy and benefits of screening. In other words, the ethical justifications for screening and prevention of spina bifida, when the authors are not explicitly interested in ethics, is considered. These justifications held certain notions of disability as costly to society, with an imperative to screen and prevent spina bifida for the good of the society.


Keywords: *genetic screening; *government regulation; *federal government; *genetic services; laboratories; medical devices; *Keyword Identifiers: *Food and Drug Administration; *United States


Keywords: *attitudes; *genetic screening; *lawyers; *medical students; *parents; *physicians; *prenatal diagnosis; *selective abortion; *thalassemia; *children; choice behavior; *comparative studies; *costs and benefits; *genetic carriers; *genetic disorders; *mandatory programs; *mass screening; *prognosis; *quality of life; *survey; *voluntary programs; *Keyword Identifiers: *Pakistan

Godard, Béatrice; Pratte, Annabelle; Dumont, Martine; Simard-Lebrun, Adèle; Simard, Jacques. Factors associated with an individual’s decision to withdraw from genetic testing for breast and ovarian cancer susceptibility: implications for counseling. Genetic Testing 2007 Spring; 11(1): 45-54. 53 refs. NRCBL: 15.3; 15.2. SC: en.

Keywords: *breast cancer; *choice behavior; *genetic counseling; *genetic screening; *refusal to participate; *ethnic groups; genetic predisposition; motivation; *pedigree; *psychology; Proposed Keywords: *ovarian cancer; *BRCA1 genes; *BRCA2 genes


Abstract: Epidemiologists and geneticists claim that genetics has an increasing role to play in public health policies and programs in the future. Within this perspective, genetic testing and screening are instrumental in avoiding the birth of children with serious, costly or untreatable disorders. This paper discusses genetic testing and screening within the framework of eugenics in the health care context of India. Observations are based on literature review and empirical research using qualitative methods. I distinguish ‘private’ from ‘public’ eugenics. I refer to the practice of prenatal diagnosis as an aspect of private
eugenics, when the initiative to test comes from the pregnant woman herself. Public eugenics involves testing initiated by the state or medical profession through (more or less) obligatory testing programmes. To illustrate these concepts I discuss the management of thalassaemia which I see as an example of private eugenics that is moving into the sphere of public eugenics. I then discuss the recently launched newborn screening programme as an example of public eugenics. I use Foucault’s concepts of power and governmentality to explore the thin line separating individual choice and overt or covert coercion, and between private and public eugenics. We can expect that the use of genetic testing technology will have serious and far-reaching implications for cultural perceptions regarding health and disease and women’s experience of pregnancy, besides creating new ethical dilemmas and new professional and parental responsibilities. Therefore, culturally sensitive health literacy programmes to empower the public and sensitize professionals need attention.

Gustafson, Shanna L.; Gettig, Elizabeth A.; Watt-Morse, Margaret; Krishnamurti, Lakshmanan. Health beliefs among African American women regarding genetic testing and counseling for sickle cell disease. *Genetics in Medicine* 2007 May; 9(5): 303-310. 51 refs. NRCBL: 15.3; 9.5.4; 15.2; 9.5.5. SC: em. Keywords: *attitudes; *blacks; *genetic counseling; *genetic screening; *sickle cell anemia; *women; knowledge, attitudes, practice; population genetics, questionnaires; risks and benefits; survey; Keyword Identifiers: United States

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NRCBL: National Reference Center for Bioethics Literature Classification Scheme

See inside front cover for terms. 209
testing acceptability for Paget’s disease of bone): an interview study about genetic testing and preventive treatment: would relatives of people with Paget’s disease want testing and treatment if they were available? *BMC Health Services Research* 2006 June 8; 6: 71: 9 p. NRCBL: 15.3; 15.2.

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Lenzer, Jeannine. Advert for breast cancer gene test triggers inquiry [news]. *BMJ: British Medical Journal* 2007 September 22; 335(7620): 579. NRCBL: 15.3; 1.3.2; 1.3.7.

Keywords: *advertising; breast cancer; genetic screening; genetic predisposition; genetic services; industry; mass media; ovarian cancer; Keyword Identifiers: Myriad Genetics; United States

Levy, Douglas E.; Youatt, Emily J; Shields, Alexandra E. Primary care physicians’ concerns about offering a genetic test to tailor smoking cessation treatment. *Genetics in Medicine* 2007 December; 9(12): 842-849. NRCBL: 15.3; 9.5.9; 9.1. SC: em.


Keywords: *genetic screening; prenatal diagnosis; disabled persons; eugenics; feminist ethics; genetic counseling; genetic disorders; preimplantation diagnosis; selective abortion; social control; stigmatization; women; Keyword Identifiers: Canada


Keywords: *genetic screening; confidentiality; DNA fingerprinting; genetic counseling; genetic determinism; genetic disorders; informed consent; risks and benefits


Keywords: *autonomy; children; genetic screening; late-onset disorders; risks and benefits; adolescents; adoption; age factors; disclosure; genetic disorders; genetic predisposition; guidelines; international aspects; parental consent


Offit, Kenneth; Kohut, Kelly; Claggett, Barthold; Wadsworth, Eve A.; Lafaro, Kelly J.; Cummings, Shelly; White, Melody; Sag, Michal; Bernstein, Donna; Davis, Jessica G. Cancer genetic testing and assisted reproduction. *Journal of Clinical Oncology* 2006 October 10; 24(29): 4775-4782. NRCBL: 15.3; 9.5.1; 14.1; 15.2.


Keywords: *choice behavior; genetic carriers; genetic screening; informed consent; attitudes; communication; decision making; focus groups; genetic counseling; genetic disorders; knowledge; attitudes; practice; mass screening; questionnaires; parents; patients; pregnant women; prenatal diagnosis; selective abortion


Keywords: *genetic screening; children; ethnic groups; genetic counseling; genetic disorders; genetic intervention; genetic predisposition; genetic privacy; insurance; mass screening; methods; preimplantation diagnosis; prenatal diagnosis; selective abortion; social control; stigmatization; women; Keyword Identifiers: Australia

Phelps, Ceri; Wood, F.; Bennett, P.; Brain, K.; Gray, J. Knowledge and expectations of women undergoing cancer genetic risk assessment: a qualitative analysis of free-text questionnaire comments. *Journal of Genetic Counseling* 2007 August; 16(4): 505-514. 50 refs. NRCBL: 15.3; 15.2; 9.5.1; 9.5.5. SC: em.

Keywords: *breast cancer; genetic counseling; genetic predisposition; genetic screening; knowledge, attitudes, practice; ovarian cancer; women; mass screening; questionnaires; risk; Keyword Identifiers: Wales


Keywords: *attitudes; genetic screening; mothers; mass screening; newborns; parental consent; patient satisfaction; survey; Keyword Identifiers: Wales
SECTION I  GENETIC SCREENING


Keywords: *genetic screening; international aspects; psychological stress; comparative studies; mass screening; questionnaires; psychology;* Keyword Identifiers: *Canada; United States


Keywords: *attitudes; choice behavior; pregnant women; prenatal diagnosis; genetic carriers; genetic disorders; genetic screening; interviews; Jews; socioeconomic factors;* Keyword Identifiers: *Israel

Richards, F.H. Maturity of judgement in decision making for predictive testing for non-treatable adult-onset neurogenic conditions: a case against predictive testing of minors. *Clinical Genetics* 2006 November; 70(5): 396-401. NRCBL: 15.3; 7.1; 9.4; 9.5.7; 17.1.


Schaller, Jean; Moser, Hugo; Begleiter, Michael L.; Edwards, Janice. Attitudes of families affected by adrenoleukodystrophy toward prenatal diagnosis, presymptomatic and carrier testing, and newborn screening. *Genetic Testing* 2007 Fall; 11(3): 296-302. 40 refs. NRCBL: 15.3; 15.2; 9.5.7. SC: em.

Keywords: *attitudes; genetic carriers; genetic disorders; genetic screening; prenatal diagnosis; family members; newborns; preimplantation diagnosis; survey; sex factors

Schiltz, Elizabeth R. The disabled Jesus: a parent looks at the logic behind prenatal testing and stem cell research. *America* 2007 March 12; 196(9): 16-18. NRCBL: 15.3; 18.5.4; 1.2.

Keywords: *embryo research; embryonic stem cells; prenatal diagnosis; Roman Catholic ethics; value of life; adult stem cells; attitudes; choice behavior; congenital disorders; Down syndrome; embryos; eugenics; mentally disabled persons; preimplantation diagnosis; quality of life; risks and benefits; selective abortion; Proposed Keywords: autistic disorder


Keywords: *children; ethical analysis; genetic intervention; moral obligations; parents; autonomy; beneficence; decision making; congenital disorders; disabled persons; genetic disorders; freedom; genetic enhancement; hearing disorders; preimplantation diagnosis; reproduction; selective abortion; standards

Abstract: As parents become increasingly able to make genetic trait selections on behalf of their children, they will need ethical guidance in deciding what genetic traits to select. Dena Davis has argued that parents act unethically if they make selections that constrain their child’s range of futures. But some selections may expand the child’s range of futures. And other selections may shift the child’s range of futures, without either constraining or expanding that range. I contend that not only would parents act unethically if they make selections that constrain the range of their child’s futures, they would act unethically if they make selections that shift the range of their child’s futures, because selections that shift the range of the child’s futures would allow parents to over-determine their child’s futures. Thus, I contend that parents would act ethically only if they make selections that expand their child’s range of futures.

Scully, Jackie Leach; Porz, Rouven; Rehmann-Sutter, Christoph. ‘You don’t make genetic test decisions from one day to the next’ — using time to preserve moral space. *Bioethics* 2007, May; 21(4):208-217. 16 fn. NRCBL: 15.3; 15.2. SC: an.

Keywords: *decision making; empirical research; ethical analysis; genetic screening; patients; prenatal diagnosis; time factors; age factors; autonomy; cancer; choice behavior; emotions; genetic counseling; Huntington disease; informed consent; interviews; mental competence; narrative ethics; qualitative research; theoretical models; uncertainty;* Keyword Identifiers: Switzerland

Abstract: The part played by time in ethics is often taken for granted, yet time is essential to moral decision making. This paper looks at time in ethical decisions about having a genetic test. We use a patient-centred approach, combining empirical research methods with normative ethical analysis to investigate the patients’ experience of time in (i) prenatal testing of a foetus for a genetic condition, (ii) predictive or diagnostic testing for breast and colon cancer, or (iii) testing for Huntington’s disease (HD). We found that participants often manipulated their experience of time, either using a stepwise process of microdecisions to extend it or, under the time pressure of pregnancy, changing their temporal ‘depth of field’. We discuss the implications of these strategies for normative concepts of moral agency, and for clinical ethics.

Shostak, Sara; Ottman, Ruth. Ethical, legal, and social dimensions of epilepsy genetics. *Epilepsia* 2006 October; 47(10): 1595-1602. NRCBL: 15.3; 15.11; 8.2; 8.4.

Shute, Nancy. Unraveling your DNA’s secrets. Do-it-yourself genetic tests promise to reveal your risk of coming down with a disease. But do they really deliver?

NRCBL: National Reference Center for Bioethics Literature Classification Scheme  See inside front cover for terms.
GENETIC SCREENING

U.S. News and World Report 2007 January 8; 142(1): 50-54. 57-58. NRCBL: 15.3; 15.2; 9.7; 5.3; 7.1; 8.4.


Keywords: *genetic information; *genetic screening; *paternity; *property rights; access to information; children; DNA fingerprinting; genetic databases; genetic privacy; genetic relatedness ties; genetic research; mandatory testing; men; population genetics; Keyword Identifiers: Australia

Wakefield, Claire E.; Kasparian, Nadine A.; Meiser, Bettina; Homewood, Judi; Kirk, Judy; Tucker, Kathy. Attitudes toward genetic testing for cancer risk after genetic counseling and decision support: a qualitative comparison between hereditary cancer types. Genetic Testing 2007 Winter; 11(4): 401-411. 37 refs. NRCBL: 15.3; 15.2; 9.5.5; 15.1; 9.5.1. SC: em.

Keywords: *attitudes; *breast cancer; *cancer; *genetic predisposition; *genetic screening; *motivation; *ovarian cancer; *risks and benefits; decision making; genetic counseling; patients; questionnaires; risk; women; Proposed Keywords: *colon cancer; Keyword Identifiers: Australia


Keywords: *genetic counseling; *genetic screening; *uncertainty; decision making; directive counseling; genetic information; prenatal diagnosis; psychological stress; risk


Keywords: *genetic carriers; *genetic screening; *Jews; *statistics; genetic counseling; genetic disorders; genetic services; interviews; mass screening; prenatal diagnosis; risks and benefits; selective abortion; Proposed Keywords: *Gaucher disease; Keyword Identifiers: *Israel

Abstract: CONTEXT: The aim of carrier screening is to prevent severe, untreatable genetic disease by identifying couples at risk before the birth of an affected child, and providing such couples with options for reproductive outcomes for affected pregnancies. Gaucher disease (GD) is an autosomal recessive storage disorder, relatively frequent in Ashkenazi Jews. Carrier screening for GD is controversial because common type 1 GD is often asymptomatic and effective treatment exists. However, screening is offered to Ashkenazi Jews worldwide and has been offered in Israel since 1995. OBJECTIVE: To examine the scope and outcomes of nationwide GD screening. DESIGN, SETTING, AND PARTICIPANTS: All Israeli genetic centers provided data on the number of
individuals screened for GD, the number of carriers identified, the number of carrier couples identified, and the mutations identified in these couples between January 1, 1995, and March 31, 2003. Carrier couples were interviewed via telephone between January 21, 2003, and August 31, 2004, using a structured questionnaire for relevant outcome measures. MAIN OUTCOME MEASURES: Screening scope (number of testing centers, tested individuals, and carrier couples), screening process (type of pretest and posttest consultations), and screening outcomes (utilization of prenatal diagnosis and pregnancy terminations). RESULTS: Between January 1, 1995, and March 31, 2003, 10 of 12 Israeli genetic centers (83.3%) offered carrier screening. Carrier frequency was 5.7%, and 83 carrier couples were identified among an estimated 28,893 individuals screened. There were 82 couples at risk for offspring with type 1 GD. Seventy of 82 couples (85%) were at risk for asymptomatic or mildly affected offspring and 12 of 82 couples (15%) were at risk for moderately affected offspring. At postscreening, 65 interviewed couples had 90 pregnancies, and prenatal diagnosis was performed in 68 pregnancies (76%), detecting 16 fetuses with GD (24%). Prenancies were terminated in 2 of 13 fetuses (15%) predicted to be asymptomatic or mildly affected and 2 of 3 fetuses (67%) with predicted moderate disease. There were significantly fewer pregnancy terminations in couples who in addition to genetic counseling had medical counseling with a GD expert (1 of 13 [8%] vs 3 of 3 with no medical counseling [100%], P = .007). CONCLUSIONS: In this study of GD screening among Ashkenazi Jewish couples in Israel, most couples did not terminate affected pregnancies, although screening was associated with a few pregnancy terminations. The main possible benefit was providing couples with knowledge and control. The divergence of these outcomes from stated goals of screening programs is likely to confront carrier screening programs for low-penetration diseases.

GENETIC SCREENING/ LEGAL ASPECTS


Keywords: *genetic discrimination; *genetic screening; *government regulation; employment; genetic information; insurance; international aspects; legislation; Keyword Identifiers: *Genetic Information Nondiscrimination Act; *United States; European Union

Messing with home brews. Political moves to expand FDA oversight to home brews are a bad idea. [editorial]. Nature Biotechnology 2007 March; 25(3): 262. NRCBL: 15.3; 5.3. SC: le.

Keywords: *genetic screening; *government regulation; *nutrition; genetic services; marketing; nutrigenomics; standards; Proposed Keywords: predictive value of tests; quackery; Keyword Identifiers: *Food and Drug Administration; United States


Keywords: *genetic discrimination; *genetic screening; *government regulation; *legislation; employment; federal government; health insurance; organizational policies; professional organizations; state government; Keyword Identifiers: *American Society of Human Genetics; *United States

Ballard, Rebecca. You get a line, I’ll get a pole, we’ll go fish’n in the plaintiff’s gene pool. Defense Counsel Journal 2007 January; 74(1): 22-34. NRCBL: 15.3; 8.4. SC: le.


Keywords: *genetic screening; *government regulation; *standards; federal government; genetic services; laboratories; legal aspects; medical devices; state government; Keyword Identifiers: *Department of Health and Human Services; United States


Keywords: *genetic discrimination; *government regulation; *legal aspects; *legislation; employment; genetic information; genetic privacy; insurance; Keyword Identifiers: *Genetic Information Nondiscrimination Act; *United States; U.S. House of Representatives

NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.
Hudson, Kathy L. Prohibiting genetic discrimination. *New England Journal of Medicine* 2007 May 17; 356(20): 2021-2023. 5 refs. NRCBL: 15.3; 9.3.1; 8.4; 16.3. SC: le. Keywords: *genetic discrimination; genetic screening; *government regulation; *legislation; access to information; attitude of health personnel; employment; genetic privacy; federal government; genetic research; health insurance; legal aspects; public opinion; state government; trust; Keyword Identifiers: *Genetic Information Nondiscrimination Act; *United States; Americans with Disabilities Act 1990; Health Insurance Portability and Accountability Act 1996


Keywords: *genetic screening; government regulation; *standards; *exceptionalism; federal government; genetic services; industry; laboratories; legal aspects; legislation; medical devices; Keyword Identifiers: *Food and Drug Administration; United States

Kaye, Jane. Testing times: what is the legal situation when an adolescent wants a genetic test? *Clinical Ethics* 2007 December; 24(4): 176-180. 40 refs. NRCBL: 15.3; 9.5.7; 8.3.1; 4.3. SC: le. Identifiers: Gillick principles (assessment of competence).

Keywords: *adolescents; *competence; *genetic screening; informed consent; *legal aspects; age factors; decision making; diagnosis; genetic counseling; parental consent; professional family relationship; Keyword Identifiers: *England; Gillick v. West Norfolk and Wisbech AHA

Abstract: Clinicians, as well as other health-care professionals in genetics clinics, may find themselves in a position where they must consider whether it would be appropriate to offer a diagnostic genetic test to an adolescent. While a clinician’s decision to offer a diagnostic genetic test may be straightforward in clinical terms, the dynamics of family interaction and circumstances may make the decision-making process more complicated. Disagreement between parent and child place clinicians in a difficult position and they must be clear about the scope of their professional responsibility and obligations, to both parents and the adolescent. The purpose of this paper is to discuss the Gillick principles and statutory requirements regarding the genetic testing of adolescents. While I will discuss the clinician’s obligations, these legal requirements also have applicability to other healthcare professionals, such as genetic counsellors, working in genetics clinics.


Keywords: *genetic information; *genetic privacy; *genetic screening; *legal aspects; access to information; anonymous testing; autonomy; confidentiality; duty to warn; exceptionalism; family members; genetic counseling; genetic research; government regulation; informed consent; legal rights; medical records; public opinion; research subjects; right not to know; risks and benefits; Keyword Identifiers: *Europe; Council of Europe

Slaughter, Louise M. Your genes and privacy [editorial]. *Science* 2007 May 11; 316(5826): 797. NRCBL: 15.3; 9.3.1; 8.4; 16.3. SC: le.

Keywords: *employment; *genetic discrimination; *genetic information; *government regulation; *health insurance; *legislation; genetic predisposition; genetic privacy; genetic research; genetic screening; insurance selection bias; research subjects; Keyword Identifiers: *Genetic Information Nondiscrimination Act; *United States; U.S. House of Representatives


Keywords: *employment; *genetic discrimination; *genetic information; *genetic privacy; *genetic screening; health insurance; *legal aspects; confidentiality; family members; genetic privacy; genetic services; government regulation; Keyword Identifiers: *United States


Keywords: *genetic discrimination; *genetic information; *genetic privacy; *genetic screening; *legal aspects; employment; family members; health insurance; government regulations; Keyword Identifiers: *United States

Keywords: *genetic discrimination; *genetic information; *genetic predisposition; *genetic screening; *insurance; *insurance selection bias; *legislation; *risk; *self induced illness; *genetic privacy; government regulation; policy analysis; smoking; Proposed Keywords: *exceptionalism; *lifestyle; Keyword Identifiers: *Belgium

Abstract: Over the past years, one of the most contentious topics in policy debates on genetics has been the use of genetic testing in insurance. In the rush to confront concerns about potential abuses of genetic information, most countries throughout Europe and the US have enacted genetics-specific legislation for insurance. Drawing on current debates on the pros and cons of a genetics-specific legislative approach, this article offers empirical insight into how such legislation works out in insurance practice. To this end, ethnographic fieldwork was done in the underwriting departments of Belgian insurance companies. Belgium was one of the first European countries introducing genetics-specific legislation in insurance. Although this approach does not allow us to speak in terms of ‘the causal effects of the law’, it enables us to point to some developments in insurance practice that are quite different than the law’s original intentions. It will not only become clear that the Belgian genetics-specific legislation does not offer adequate solutions to the underlying issues it was intended for. We will also show that, while the legislation’s focus has been on the inadmissibility of genetic discrimination, at the same time differences are made in the insurance appraisal within the group of the asymptomatic ill. In other words, by giving exclusive legal protection to the group of genetic risks, other non-genetic risk groups are unintentionally being under-protected. From a policy point of view, studying genetics-specific legislation is especially valuable because it forces us to return to first principles: Which risks deserve our legal protection in insurance? Who do we declare our solidarity with?


Keywords: *genetic discrimination; *genetic information; *legislation; employment; federal government; genetic screening; government regulation; insurance; Keyword Identifiers: *Genetic Information Nondiscrimination Act; *U.S. Senate; *United States

GENETIC SCREENING/ SOCIOECONOMIC ASPECTS


Keywords: *genetic discrimination; *genetic screening; *government regulation; employment; genetic information; insurance; international aspects; legislation; Keyword Identifiers: *Genetic Information Nondiscrimination Act; *United States; European Union

Pulling rank: why should US military personnel be singled out for genetic discrimination? [editorial]. Nature 2007 August 30; 448(7157): 969. NRCLB: 15.3; 1.3.5.


Keywords: *genetic discrimination; *genetic screening; *government regulation; *legislation; employment; federal government; health insurance; organizational policies; professional organizations; state government; Keyword Identifiers: *American Society of Human Genetics; *United States


Keywords: *genetic screening; *mass screening; *newborns; *sickle cell anemia; diagnosis; disclosure; ethnic groups; genetic carriers; genetic counseling; genetic privacy; incidental findings; parental consent; policy making; prevalence; program descriptions; racial groups; risks and benefits; social discrimination


Keywords: *genetic screening; attitudes; cancer; confidentiality; genetic counseling; genetic discrimination; genetic predisposition; nurse’s role; prenatal diagnosis; psychological stress

Borry, Pascal; Fryns, Jean-Pierre; Schotsmans, Paul; Dierickx, Kris. Carrier testing in minors: a systematic review of guidelines and position papers. European Journal of Human Genetics: EJHG 2006 February; 14(2): 133-138. NRCLB: 15.3; 9.3.1; 8.3.1.


Keywords: *genetic information; *genetic predisposition; *genetic screening; *moral policy; autonomy; beneficence;
biology; choice behavior; disclosure; family members; genetic counseling; genetic discrimination; genetic disorders; genetic engineering; genetic research; genotype; phenotype; prenatal diagnosis; reproduction; reproductive technologies; right not to know; uncertainty; Proposed Keywords: *predictive value of tests

Keywords: *genetic information;*genetic screening; *moral obligations; *moral policy; *right not to know; autonomy; biology; choice behavior; comprehension; disabled persons; disclosure; family members; genetic carriers; genetic counseling; genetic services; justice; health services accessibility; minority groups; prenatal diagnosis; reproduction; social discrimination; social impact; women

English, Veronica; Gardner, Jessica; Romano-Critchley, Gillian; Sommervann, Ann. Genetics and insurance. Journal of Medical Ethics 2001 June; 27(3): 204. 8 refs. NRCBL: 15.3; 9.3.1; 8.4.
Keywords: *genetic information;*genetic screening; *insurance; advisory committees; international aspects; legal aspects; self regulation; Keyword Identifiers: *Great Britain; Association of British Insurers; Genetics and Insurance Committee (Great Britain); Human Genetics Commission (Great Britain)


Evans, James P. Health care in the age of genetic medicine. JAMA: The Journal of the American Medical Association 2007 December 12; 298(22): 2670-2672. 6 refs. NRCBL: 15.3; 15.1; 9.1.
Keywords: *clinical genetics; *health care delivery; economics; genetic discrimination; genetic predisposition; genetic screening; genomics; health insurance; insurance coverage; justice; pharmacogenetics; preventive medicine; public health; resource allocation; trends; Proposed Keywords: personalized medicine; universal coverage; KEYWORD IDENTIFIERS: United States

Keywords: *genetic ancestry;*genetic screening; *vulnerable populations; children; DNA fingerprinting; genetic discrimination; genetic relatedness ties; immigrants; indigenous populations; informed consent; parental consent; paternity; population genetics; public policy; racial groups; Keyword Identifiers: Australia


Keywords: *genetic information;*genetic screening; *insurance; *regulation; *standards; access to information; advisory committees; disclosure; government; industry; interinstitutional relations; public policy voluntary programs; Keyword Identifiers: *Association of British Insurers; *Great Britain; Genetics and Insurance Committee (Great Britain); Human Genetics Commission (Great Britain)

Keywords: *genetic discrimination; *government regulation; *legal aspects; *legislation; employment; genetic information; genetic privacy; insurance; Keyword Identifiers: *Genetic Information Nondiscrimination Act; *United States; U.S. House of Representatives

Keywords: *genetic discrimination; *genetic screening; *government regulation; *legislation; access to information; attitude of health personnel; employment; genetic privacy; federal government; genetic research; health insurance; legal aspects; public opinion; state government; trust; Keyword Identifiers: *Genetic Information Nondiscrimination Act; *United States; Americans with Disabilities Act 1990; Health Insurance Portability and Accountability Act 1996

Jamieson, Suzanne. Genetic information and the Australian labour movement. In: Betta, Michela, ed. The Moral,
SECTION I  GENETIC SCREENING/ SOCIOECONOMIC ASPECTS

Keywords: *employment; *genetic discrimination; *genetic information; *regulation; advisory committees; genetic screening; industry; Proposed Keywords: *labor unions.; Keyword Identifiers: *Australia; Australian Law Reform Commission

Keywords: *choice behavior; *genetic screening; *health insurance; breast cancer; decision making; economics; genetic predisposition; genetic privacy; risk; survey; women; Proposed Keywords: *BRCA1 genes; *BRCA2 genes; *insurance coverage; ovarian cancer

Keywords: *children; *decision making; *guideline adherence; *genetic screening; *late-onset disorders; *parental consent; *standards; autonomy; dementia; dissent; ethical analysis; genetic discrimination; genetic disorders; genetic predisposition; guidelines; Huntington disease; minors; moral policy; parent child relationship; physicians; policy analysis; professional organizations; risks and benefits; truth disclosure; Proposed Keywords: Alzheimer disease

Abstract: A new analysis of the Best Interests Standard is given and applied to the controversy about testing children for untreatable, severe late-onset genetic diseases, such as Huntington’s disease or Alzheimer’s disease. A professional consensus recommends against such predictive testing, because it is not in children’s best interest. Critics disagree. The Best Interests Standard can be a powerful way to resolve such disputes. This paper begins by analyzing its meaning into three necessary and jointly sufficient conditions showing it: 1. is an “umbrella” standard, used differently in different contexts, 2. has objective and subjective features, 3. is more than people’s intuitions about how to rank potential benefits and risks in deciding for others but also includes evidence, established rights, duties and thresholds of acceptable care, and 4. can have different professional, medical, moral and legal uses, as in this dispute. Using this standard, support is given for the professional consensus based on concerns about discrimination, analogies to adult choices, consistency with clinical judgments for adults, and desires to preserve of an open future for children. Support is also given for parents’ legal authority to decide what genetic tests to do.

Keywords: *attitudes; *cancer; *genetic predisposition; *genetic screening; *Jews; focus groups; genetic discrimination; genetic privacy; mass screening; risks and benefits; women; Proposed Keywords: BRCA1 genes; BRCA2 genes; Keyword Identifiers: New Jersey

Keywords: *children; *genetic screenings; *genetic services; *mass screening; *prenatal diagnosis; *public policy; cystic fibrosis; Down syndrome; eugenics; genetic carriers; genetic discrimination; genetic privacy; hearing disorders; human rights; late-onset disorders; newborns; risks and benefits; sickle cell anemia; thalassemia; Keyword Identifiers: *Great Britain; National Health Service

Nyhrinen, Tarja; Hietala, Marja; Puukka, Pauli; Leino-Kilpi, Helena. Privacy and equality in diagnostic genetic testing. Nursing Ethics 2007 May; 14(3): 295-308. 37 refs. NRCBL: 15.3; 8.4; 9.5.7. SC: em.
Keywords: *attitudes; *genetic privacy; *genetic screening; adults; attitude of health personnel; children; comparative studies; diagnosis; evaluation studies; education; genetic counseling; genetic discrimination; genetic information; genetic services; justice; knowledge, attitudes, practice; nurses; parents; patients; physicians; questionnaires; Keyword Identifiers: *Finland

Abstract: This study aimed to determine the extent to which the principles of privacy and equality were observed during diagnostic genetic testing according to views held by patients or child patients’ parents (n = 106) and by staff (n = 162) from three Finnish university hospitals. The data were collected through a structured questionnaire and analysed using the SAS 8.1 statistical software. In general, the two principles were observed relatively satisfactorily in clinical practice. According to patients/parents, equality in the post-analytic phase and, according to staff, privacy in the pre-analytic phase, involved the greatest ethical problems. The two groups differed in their views concerning pre-analytic privacy. Although there were no major problems regarding the two principles, the differences between the testing phases require further clarification. To enhance privacy protection and equality, professionals need to be given more genetic/ethics training, and patients individual counselling by genetics units staff, giving more consideration to patients’ world-view, the purpose of the test and the test result.

Keywords: *employment; *genetic screening; *occupational exposure; advisory committees; coercion; genetic discrimination; genetic predisposition; genetic privacy; regulation; Proposed Keywords: workers’ compensation; Keyword Identifiers: *Australia; Australian Law Reform Commission

Pennock, Robert T. Pre-existing conditions: genetic testing, causation, and the justice of medical insurance. In:

Piratikitkul, Darlyn; Burzstajn, Harold J. Pride and prejudice: avoiding genetic gossip in the age of genetic testing. *Journal of Clinical Ethics* 2007 Summer; 18(2): 156-161. 21 fn. NRCBL: 15.3; 8.1; 8.4. Keywords: *genetic privacy; genetic screening; disclosure; employment; genetic discrimination; genetic information; informed consent; insurance; legal aspects; legislation; medical records; Keyword Identifiers: Health Insurance Portability and Accountability Act 1996; United States

Pollack, Andrew. A genetic test that very few need, marketed to the masses. *New York Times* 2007 September 11; p. C3. NRCBL: 15.3; 9.7; 9.3.1. SC: po. Keywords: *advertising; genetic screening; industry; mass media; breast cancer; genetic services; women; Keyword Identifiers: *Myriad Genetics Inc.*

Quinlivan, Julie A.; Suriadi, Christine. Attitudes of new mothers towards genetics and newborn screening. *Journal of Psychosomatic Obstetrics and Gynaecology* 2006 March; 27(1): 67-72. 22 refs. NRCBL: 15.3; 9.5.5; 9.5.7. SC: em. Keywords: *attitudes; genetic screening; mass screening; mothers; newborns; genetic discrimination; interviews; parental consent; questionnaires; Keyword Identifiers: Australia


Rose, Nikolas S. At genetic risk. *In his*: Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-first Century. Princeton: Princeton University Press, 2007: 106-130, 280-283. 25 fn. NRCBL: 15.3; 1; 4.4; 15.2. SC: an. Keywords: *genetic identity; genetic predisposition; genetic screening; philosophy; risk; adults; autonomy; behavioral genetics; children; choice behavior; confidentiality; disclosure; education; employment; eugenics; family members; family relationship; genetic counseling; genetic information; genetic determinism; genetic discrimination; genetic disorders; genetic relatedness ties; government regulation; health; historical aspects; Huntington disease; international aspects; insurance; moral obligations; patient participation; patients; personhood; professional patient relationship; reproduction; rights; self concept; Keyword Identifiers: Great Britain; Internet; United States


Slaughter, Louise M. Your genes and privacy [editorial]. *Science* 2007 May 11; 316(5826): 797. NRCBL: 15.3; 9.3.1; 8.4; 16.3. SC: le. Keywords: *employment; genetic discrimination; genetic information; government regulation; health insurance; legislation; genetic predisposition; genetic privacy; genetic research; genetic screening; insurance selection bias; research subjects; Keyword Identifiers: *Genetic Information Nondiscrimination Act; United States; U.S. House of Representatives

Sui, Suli; Sleeboom-Faulkner, Margaret. Commercial genetic testing in mainland China: social, financial and ethical issues. *Journal of Bioethical Inquiry* 2007; 4(3): 229-237. NRCBL: 15.3; 1.3.2; 5.3; 15.2; 8.4; 9.3.1. Abstract: This paper provides an empirical account of commercial genetic predisposition testing in mainland China, based on interviews with company managers, regulators and clients, and literature research during fieldwork in mainland China from July to September 2006. This research demonstrates that the commercialization of genetic testing and the lack of adequate regulation have created an environment in which dubious advertising practices and misleading and unprofessional medical advice are commonplace. The consequences of these ethically problematic activities for the users of predictive tests are, as yet, unknown. The paper concludes with a bioethical and social science perspective on the social and ethical issues raised by the dissemination and utilization of genetic testing in mainland China.

UK Cystic Fibrosis Database Steering Committee; Sims, Erika J.; Mugford, Miranda; Clark, Allan; Aitken, David; McCormick, Jonathan; Mehta, Gita; Mehta, Anil. Economic implications of newborn screening for cystic fibrosis: a cost of illness retrospective cohort study. *Lancet* 2007 April 7-13; 369(9568): 1187-1195. NRCBL: 15.3; 9.5.7; 9.5.1; 9.3.1. SC: em. Abstract: BACKGROUND: Newborn screening for cystic fibrosis might not be introduced if implementation and running costs are perceived as prohibitive. Compared with clinical diagnosis, newborn screening is associated with clinical benefit and reduced treatment needs. We estimate the potential savings in treatment costs attributable to newborn screening. METHODS: Using the UK Cystic Fibrosis Database, we used a prevalence strategy to undertake a cost of illness retrospective snapshot cohort study. We estimated yearly costs of long-term therapies and intravenous antibiotics for 184 patients who were diagnosed as a result of screening as newborn babies, and 950 patients who were clinically diagnosed aged 1-9 years in 2002. Costs of adding cystic fibrosis screening to an established newborn screening service in Scotland were adjusted to 2002 prices and applied to the UK as a whole. Costs were recalculated in US$. FINDINGS: Cost of therapy for patients diagnosed by newborn screening was significantly lower than equivalent therapies for clinically diagnosed patients: mean ($7228 vs $12 008, 95% CI of difference -6376 to -2028, p.0001) and median ($352 vs $2442, -1916 to -180, p.0001). When we limited the clinically diagnosed group to only those diagnosable with a 31 cystic fibrosis transmembrane regulator muta-
tion assay and assumed similar disease progression in the clinically diagnosed group as in the newborn screening group, we showed that mean ($3,397,344) or median ($947,032) drug cost savings could have offset the estimated cost of adding cystic fibrosis to a UK national newborn screening service ($2,971,551). INTERPRETATION: Including indirect costs savings, newborn screening for cystic fibrosis might have even greater financial benefits to society than our estimate shows. Clinical, social, and now economic evidence suggests that universal newborn screening programmes for cystic fibrosis should be adopted internationally.


Keywords: *employment; *genetic discrimination; *genetic information; *genetic screening; *health insurance; *legal aspects; confidentiality; family members; genetic privacy; genetic services; government regulation; Keyword Identifiers: *United States


Keywords: *genetic discrimination; *genetic information; *genetic privacy; *genetic screening; *legal aspects; employment; family members; health insurance; government regulation; Keyword Identifiers: *United States

**Van Hoyweghen, Ine; Horstman, Klasien; Schepers, Rita.** Genetic ‘risk carriers’ and lifestyle ‘risk takers’. Which risks deserve our legal protection in insurance? *Health Care Analysis: An International Journal of Health Philosophy and Policy* 2007 September; 15(3): 179-193. 49 refs.; 7 fn. NRCBL: 15.3; 8.4; 9.3.1. SC: an; em; le. Identifiers: *genetic discrimination; *genetic information; *genetic predisposition; *genetic screening; *insurance; *insurance selection bias; *legislation; *risk; *self induced illness; genetic privacy; government regulation; policy analysis; smoking; Proposed Keywords: *exceptionalism; *life style; Keyword Identifiers: *Belgium


Keywords: *genetic discrimination; *genetic information; *legislation; employment; federal government; genetic screening; government regulation; insurance; Keyword Identifiers: *Genetic Information Nondiscrimination Act; *U.S. Senate; *United States


Keywords: *costs and benefits; *cystic fibrosis; *genetic carriers; *genetic screening; ethnic groups; mass screening; prenatal diagnosis; racial groups; statistics; women; Keyword Identifiers: Michigan


Keywords: *genetic discrimination; *genetic information; *insurance; *insurance selection bias; *legislation; advisory committees; disabled persons; genetic privacy; genetic screening; legal aspects; legislation; private sector; risk; Keyword Identifiers: *Australia; Australian Law Reform Commission

NRCBL: National Reference Center for Bioethics Literature Classification Scheme  See inside front cover for terms. 219

Keywords: *genetic screening; adults; advertising; children; genetic carriers; genetic counseling; genetic discrimination; genetic disorders; genetic predisposition; genetic services; government regulation; incidental findings; late-onset disorders; legislation; mass screening; newborns; population genetics; preimplantation diagnosis; prenatal diagnosis; psychological stress; Proposed Keywords: predictive value of tests

GENETIC TESTING See GENETIC SCREENING

GENETICALLY MODIFIED ORGANISMS AND FOOD

Directive action required: Europe’s handling of applications to grow genetically modified crops amounts to bad governance [editorial]. Nature 2007 December 13; 450(7172): 921. NRCBL: 15.1; 1.3.11; 5.3; 21.1.

Keywords: *genetically modified plants; *politics; agriculture; genetically modified food; industry; regulation; risks and benefits; Keyword Identifiers: *European Union; Europe

Abbott, Alison; Schiermeier, Quirin. Showdown for Europe. The European Union is set to make a landmark decision on genetically modified crops. Nature 2007 December 13; 450(7172): 928-929. NRCBL: 15.1; 1.3.11; 5.3; 21.1.

Keywords: *genetically modified plants; agriculture; genetically modified food; regulation; Keyword Identifiers: *European Union; Europe


Keywords: *agriculture; *biotechnology; *genetically modified plants; developing countries; ecology; genetic engineering; industry; international aspects; property rights; risks and benefits; Proposed Keywords: biodiversity

Andréé, Peter. The biopolitics of genetically modified organisms in Canada. Journal of Canadian Studies 2002 Fall; 37(3): 162-191. 76 refs. 15 fn. NRCBL: 15.1; 1.3.11; 5.3. SC: rv.

Keywords: *genetically modified food; *genetically modified plants; *government regulation; *politics; biotechnology; genetically modified organisms; policy making; precautionary principle; public policy; risk; science; Keyword Identifiers: *Canada


Keywords: *animal welfare; *biotechnology; *genetically modified animals; agriculture; animal experimentation; animal rights; ethical analysis; methods; regulation; researchers; risks and benefits; suffering; utilitarianism; Proposed Keywords: domestic animals; laboratory animals


Bharadwaj, Minakshi. Looking back, looking beyond: revisiting the ethics of genome generation. Journal of Biosciences 2006 March; 31(1): 167-176. 42 refs. NRCBL: 15.1; 1.3.11; 2.1; 15.3; 15.10; 15.5. SC: rv.

Keywords: *biotechnology; *genetic engineering; *genetic research; *genomics; benefit sharing; bioethics; cloning; developing countries; economics; embryo research; ethical analysis; genes; genetic determinism; genetic information; genetic patents; genetic screening; genetically modified food; genetically modified plants; Human Genome Project; international aspects; Proposed Keywords: exceptionalism; genetic resources; stakeholders


Keywords: *genetically engineered animals; *government regulation; *legal aspects; agriculture; commerce; ecology; federal government; risk; state government; Proposed Keywords: *fish; Keyword Identifiers: *Food and Drug Administration; *United States; Environmental Protection Agency; Fish and Wildlife Service; Food, Drug, and Cosmetic Act


Keywords: *genetically modified food; agriculture; industry; regulation; risk


Keywords: *developing countries; *genetically modified food; *genetically modified plants; *moral obligations; *precautionary principle; *risks and benefits; ecology; nutrition; Proposed Keywords: malnutrition


Keywords: *genetically modified plants; *legal aspects; agriculture; ecology; federal government; government regula-
SECTION I

GENETICALLY MODIFIED ORGANISMS AND FOOD

tion; risk; Keyword Identifiers: *United States; Department of Agriculture

Charles, Dan. U.S. courts say transgenic crops need tighter scrutiny [news]. Science 2007 February 23; 315(5815): 1069. NRCBL: 15.7; 15.1; 1.3.11.

Keywords: *animal cloning; *biotechnology; *genetic engineering; *industry; *stem cells; capitalism; cell lines; embryonic research; embryonic stem cells; gene therapy; genetically modified food; genetically modified organisms; nuclear transfer techniques; patents; stem cell transplantation; trust; Proposed Keywords: domestic animals; regenerative medicine; sheep; Keyword Identifiers: Geron Corp.; Great Britain; United States


Keywords: *genetically modified plants; *international aspects; agriculture; commerce; ecology; genetically modified food; genetically modified organisms; legal aspects; regulation; risks and benefits; Keyword Identifiers: Europe; United States


Keywords: *animal rights; *animal welfare; *commodification; *genetically modified animals; *moral policy; animal experimentation; biotechnology; genetic patents; Proposed Keywords: laboratory animals

Abstract: What’s wrong – fundamentally wrong – with the way animals are treated (…) isn’t the pain, the suffering, isn’t the deprivation. (…) The fundamental wrong is the system that allows us to view animals as our resources, here for us – to be eaten, or surgically manipulated, or exploited for sport or money.’ Tom Regan made this claim 20 years ago. What he maintains is basically that the fundamental wrong is not the suffering we inflict on animals but the way we look at them. What we do to them, what we believe we are allowed to do to them, is dependent on how we perceive or conceptualize them. We not only treat them as resources but prior to this we already think of them as resources, and when we look at them, all we tend to see is resources. In our perception of them they exist not for themselves but ‘for us’. But obviously it can only be fundamentally wrong in a moral sense to view them that way if it is wrong in a factual sense, that is, if animals are in fact not ‘for us’. But is it wrong?

Holloway, Lewis; Morris, Carol. Exploring biopower in the regulation of farm animal bodies: genetic policy interventions in UK livestock. Genomics, Society and Policy 2007 August; 3(2): 82-98. 60 fn. NRCBL: 15.1; 1.3.11; 1.3.2; 21.1. SC: an; cs.

Keywords: *animal welfare; *food; *genetically modified animals; agriculture; biotechnology; case studies; commerce; genetic resources; genomics; policy analysis; public policy; Proposed Keywords: *animal production; *domestic animals; Keyword Identifiers: Great Britain

Abstract: This paper explores the analytical relevance of Foucault’s notion of biopower in the context of regulating and managing non-human lives and populations, spe-
specifically those animals that are the focus of livestock breeding based on genetic techniques. The concept of biopower is seen as offering theoretical possibilities precisely because it is concerned with the regulation of life and of populations. The paper approaches the task of testing the ‘analytic mettle’ of biopower through an analysis of four policy documents concerned with farm animal genetics: the UK’s National Scrappie Plan (2003); the UK National Action Plan on Farm Animal Genetic Resources (2006); the Agriculture and Environment Biotechnology Committee’s report on Animals and Biotechnology (2002); and the Farm Animal Welfare Council’s report on the Welfare Implications of Animal Breeding and Breeding Technologies in Commercial Agriculture (2004). Of interest is whether and how the four policy case studies articulate a form of biopower in relation to human-livestock animal relations in the context of genetic approaches to livestock breeding, and how biopower is variably expressed in relation to the different policy issues addressed. In concluding, the paper considers the overall applicability and relevance of biopower in the context of regulating animal lives within livestock breeding, highlighting both possibilities and limitations, and offers suggestions for taking forward research on livestock populations from a neo-Foucaultian perspective.


Kleinman, Daniel Lee; Kinchy, Abby J. Against the neoliberal steamroller? The Biosafety Protocol and the social regulation of agricultural biotechnologies. Agriculture and Human Values 2007 Summer; 24(2): 195-206. 46 refs. 5 fn. NRCBL: 15.7; 1.3.11; 15.7.

Lassen, Jesper; Gjerris, Mickey; Sandoe, Peter. After Dolly — ethical limits to the use of biotechnology on farm animals. Theriogenology 2006 March 15; 65(5): 992-1004. 14 refs. NRCBL: 22.3; 14.5; 15.1. SC: em.


SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
Keywords: *genetically modified food; disclosure; ecology; genetic engineering; genetically modified organisms; moral policy; public policy; risks and benefits


Keywords: *animal welfare; *genetic engineering; *genetically modified animals; *risks and benefits; animal cloning; animal experimentation; ethical analysis; human experimentation; moral policy; trends; Proposed Keywords: species specificity

Pearce, David. Economics and genetic diversity. Futures 1987; 19(6): 710-712. 3 refs. NRCBL: 15.1; 16.1; 9.3.1; 1.3.11.

Keywords: *economics; *genetic diversity; *international aspects; commerce; developing countries; ecology; gene pool; property rights; Proposed Keywords: *biodiversity; *genetic resources; Resource Identifiers: United States


Keywords: *animal rights; *animal welfare; *attitudes; *biotechnology; *genetically modified animals; animal experimentation; animal organs; emotions; focus groups; moral policy; organ transplantation; political activity; public opinion; utilitarianism; Keyword Identifiers: *Italy; Anti-Vivisection League (Italy); Centre for Animal Aid (Italy); National Foundation for the Protection of Animals (Italy)

Pollack, Andrew. Round 2 [two] for biotech beets; after delay over safety fears, engineered crop will be planted [news]. New York Times 2007 November 27; p. C1, C2. NRCBL: 15.1; 1.3.11. SC: po.

Keywords: *genetically modified plants; agriculture; genetically modified food; industry; trends; Proposed Keywords: United States


Keywords: *animal cloning; *animal welfare; *genetically modified animals; *moral policy; agriculture; animal experimentation; biotechnology; cloning; commodification; ecology; ethical analysis; gene pool; genetic diversity; genetic engineering; genetic research; industry; literature; religion; risks and benefits; suffering; Proposed Keywords: animal production; domestic animals; laboratory animals


Keywords: *genetic engineering; *genetically modified food; *genetically modified plants; genetically modified organisms; genetic patents; microbiology; public opinion; recombinant DNA research; risk; Proposed Keywords: United States


Keywords: *animal welfare; *genomics; agriculture; animal cloning; biodiversity; biotechnology; chimeras; economics; food; genetic databases; international aspects; regulation; social sciences; trends; Proposed Keywords: *animal production; *domestic animals

Abstract: How may emergent biotechnologies impact upon our relations with other animals? To what extent are any changes indicative of new relations between society and nature? This paper critically explores which sociological tools can contribute to an understanding of the technologisation of animal bodies. By drawing upon interview data with animal scientists I argue that such technologies are being partly shaped by broader changes in agriculture. The complexity of genomics trajectories in animal science is partly fashioned through the deligitimisation of the productivist paradigm but continue to sit in tension around particular conceptions of sustainability in farm animal production. In spite of this deligitimisation process genomics is now being framed in the context of a new productivism (termed the livestock revolution) bound up in projected global changes in animal consumption during the first half of the 21st century. This potentially jars against both social trends that seek to re-enchant animal life and sustainability discourses which include social and environmental contexts. Nevertheless the possibility of a new productivism is supported by various interconnected trends including the emergence of a discourse of the ‘bioeconomy’ and a liberal regulatory apparatus for farm animal breeding technologies. Ultimately an understanding of the possibility of emerging new bio-capitalisations on animal life should be set in a broader context of competing agricultural paradigms as well as ongoing tensions over ‘naturalness’ in human/animal relations.

Van Dooren, Thom. Terminated seed: death, proprietary kinship and the production of (bio)wealth. Science as Culture 2007 March; 16(1): 71-93. NRCBL: 15.1; 5.3; 1.3.11; 21.1. Identifiers: Genetic Use Restriction Technologies.


Keywords: *genetically modified food; *public opinion; agriculture; animal welfare; choice behavior; ecology; focus groups; genetically modified organisms; health hazards; industry; information dissemination; knowledge, attitudes, practice; political activity; risks and benefits; survey; trust; Proposed Keywords: *Canada

Keywords: *animal welfare; genetically modified animals; advisory committees; ethical review; guidelines; Proposed Keywords: *mice; Keyword Identifiers: Great Britain


Keywords: *biotechnology; genetic engineering; genetically modified food; genetically modified plants; agriculture; DNA fingerprinting; doping in sports; ecology; genetic therapy; genetic enhancement; health hazards; international aspects; nanotechnology; public opinion; recombinant DNA research; regulation; risks and benefits; stem cells; Proposed Keywords: forensic genetics; Keyword Identifiers: United States


**GENETICS AND GENOMICS**

...but not as we know it. Synthetic life is on the way, and we need to think about the consequences [editorial]. *New Scientist* 2007 October 20-26; 196(2626): 5. NRCBL: 15.1.


Keywords: *human genome; human dignity; international aspects; genetic privacy; human rights; legal aspects; Proposed Keywords: Declaration on the Human Genome (UNESCO)


Keywords: *Roman Catholic ethics; chimera; eugenics; recombinant DNA research; sex preselection


Abstract: The New Testament, while rejecting any superficial connection between illness and sin, does not reject a possible connection between illness and a person’s relationship with God. An example can be seen in the story of the young blind man who was healed (St. John 9:3). His blindness does not result from any fault he or his parents had committed but apparently from God’s wish to reveal his own healing power. The inner blindness of the Pharisees is a different type of blindness far more difficult to heal. The blind young man was actually healed, not only in body but also in soul. Such miraculous healings are rare nowadays. However, if one takes a closer look at modern genetics and psycho-neuro-immunological findings, one may come to a better understanding of how miracle healings are linked to man’s inner life and therefore also to his religiousness. Many diseases have genetic backgrounds. Defective genes, however, do not necessarily lead to subsequent illness. Genes have to be switched on or off. Only activated genes trigger pathological change. The human brain and all of man’s thinking and feeling are intimately connected with such activations. We may thus conclude that both inner life and religious outlook on life are relevant to the origin and development of diseases.

Beene-Harris, Rosalyn Y.; Wang, Catharine; Bach, Janice V. Barriers to access: results from focus groups to identify genetic service needs in the community. *Community Genetics* 2007; 10(1): 10-17. NRCBL: 15.1; 9.3.1; 9.5.1; 9.5.4; 15.2; 15.3. SC: em.

Keywords: *genetic services; health services accessibility; focus groups; genetic counseling; genetic disorders; health facilities; health insurance; health personnel; knowledge; attitudes; practice; minority groups; parents; patient satisfaction; public opinion; public policy; state government; Proposed Keywords: *needs assessment; Keyword Identifiers: Michigan


Keywords: *genetic intervention; philosophy; self concept; autonomy; cloning; genetic enhancement; genetic screening; human body; sexuality; Proposed Keywords: aging; Keyword Identifiers: Foucault, Michel


Keywords: *genetic resources; influenza; international aspects; property rights; public policy; world health; benefit sharing; developing countries; industry; obligations to society; public health; vaccines; Proposed Keywords: *viruses; communicable disease control; Keyword Identifiers: Indonesia; World Health Organization
SECTION I: GENETICS AND GENOMICS

Castle, David; Cline, Cheryl; Daar, Abdallah S.; Tsamis, Charoula; Singer, Peter A. The ethics of nutrigenomic tests and information. In their: Science, Society, and the Supermarket: The Opportunities and Challenges of Nutrigenomics. Hoboken, NJ: Wiley-Interscience, 2007: 49-75. 46 refs. NRCBL: 15.1; 15.3.

Keywords: *genetic information; *nutrition; *adolescents; *health disparities; *nutrition genetic; *personalized medicine; *personhood; *public policy; *self-concept; *social sciences


Keywords: *genetics; *personhood; *self-concept


Keywords: *biomedical research; *genetic determinism; *personhood; "race"; *science


Keywords: *biomedical research; *genetic determinism; *personhood; *science


Harvey, Erin K.; Fogel, Chana E.; Peyrot, Mark; Christensen, Kurt D.; Terry, Sharon F.; McInerney, Joseph D. Providers’ knowledge of genetics: a survey of 5915 individuals and families with genetic conditions. Genetics in Medicine 2007 May; 9(5): 259-267. 16 refs. NRCBL: 15.2; 15.1; 7.2. SC: em.

Keywords: *biomedical research; *genetic counseling; *personnel; *professional competence; *secondary analysis; *social sciences; *survey


Keywords: *animal welfare; *biomedical research; *personhood; *social sciences; *survey

Abstract: Animals are commonplace in genomic research, yet to date there has been little direct interrogation...
of the position, role and construction of animals in the otherwise flourishing social science of genomics. Following a brief discussion of this omission, I go on to suggest that there is much of interest for the social sciences and the humanities in this field of science. I show that animal genomics not only updates and extends established debates about the use of animals in science and society, but also raises novel issues and promotes new ways of thinking about what animals are, and the social and biological relationships between animals and humans. Organising the science of interest into six themes (sameness, difference and classification; crossing boundaries; the maintenance of borders; farmyard supermodels; laboratory supermodels; knowing, relating and looking at animals), for each I review some of the science that is being done, some of the conceptual issues that are raised, and some of the social science that is or could be done. I conclude by briefly considering the development of socially responsive policies for animal genomics.


Keywords: *genetic discrimination; genetic information; government regulation; human dignity; human rights; justice; legal aspects; terminology; Keyword Identifiers: *European Convention on Human Rights and Biomedicine; Council of Europe; Europe


20 refs. NRCBL: 15.1; 9.3.1; 9.4; 12.5.1; 15.2.

Keywords: *economics; *genetic carriers; *genetic disorders; *prenatal diagnosis; *reproduction; *resource allocation; *selective abortion; children; coercion; health insurance reimbursement; legal aspects; parents; patient care; reproductive rights; Proposed Keywords: Gaucher disease; Keyword Identifiers: Germany


Keywords: *genetic services; *nurse’s role; codes of ethics; health services accessibility; nursing ethics; organizational policies; professional organizations; Keyword Identifiers: *International Society of Nurses in Genetics [ISONG]


King, Nancy M.P. Genes and Tourette syndrome: scientific, ethical, and social implications. Advances in Neurology 2006; 99: 144-147. NRCBL: 15.1; 15.3; 15.10.


Keywords: *genetics; *genomics; *human genome; advisory committees; autonomy; beneficence; commerce; disclosure; duty to warn; ethical theory; eugenics; family members; gene therapy; genetic ancestry; genetic databases; genetic discrimination; genetic enhancement; genetic information; genetic patents; genetic privacy; genetic research; genetic screening; Human Genome Project; human rights; justice; legal aspects; moral policy; pharmacogenetics; professional organizations; public health; public policy; regulation; social impact; Proposed Keywords: exceptionalism; Keyword Identifiers: United States


Keywords: *freedom; *ethical analysis; *justice; *genetic intervention; *prenatal diagnosis; *reproductive rights; *rights; *values; choice behavior; cultural diversity; disabled persons; feminist ethics; genetic disorders; genetic enhancement; genetic information; legal aspects; morality; parents; reproductive technologies; selective abortion; sex determination; social discrimination; social control; women’s rights; Proposed Keywords: deafness; Keyword Identifiers: *Robertson, John; United States


Keywords: *personal genomics; *family members; *genetic disorders; children; diagnosis; DNA sequences; fathers

Keywords: *genetic information; *legal aspects; cloning; employment; family members; gene therapy; genetic counseling; genetic discrimination; genetic disorders; genetic privacy; genetic research; genetic screening; insurance; prenatal diagnosis; right not to know; Keyword Identifiers: Great Britain

Keywords: *clinical genetics; *genome mapping; *genomics; costs and benefits; forecasting; genetic counseling; genetic predisposition; genetic screening; human genome; industry; justice; practice guidelines; risks and benefits; trends; Proposed Keywords: *personalized medicine

Keywords: *Alzheimer disease; *family members; *genetic predisposition; *genetic screening; *knowledge, attitudes, practice; focus groups; genetic research; survey; Proposed Keywords: pilot projects; Keyword Identifiers: Alabama; Massachusetts

Keywords: *bioethical issues; *bioethics; *databases; *genetics; *information dissemination; *literature; *terminology; *eugenic genetics; genetic patents; human experimentation; professional organizations; publishing; Proposed Keywords: *abstracting and indexing; *information services; publications; Keyword Identifiers: *Bioethics Thesaurus for Genetics; *ETHXWeb; *GenETHX; *National Information Resource on Ethics and Genetics; *National Reference Center for Bioethics Literature; Bioethics Thesaurus; Georgetown University; Kennedy Institute of Ethics


Proposed Keywords: *genetic engineering; *genetic research; eugenics; gene therapy; genetic enhancement; genetic patents; genetic screening; genetically modified organisms; germ cells; mass screening; moral policy; Human Genome Diversity Project; Human Genome Project; prenatal diagnosis; recombinant DNA research

Keywords: *genomics; attitudes; biotechnology; clinical genetics; economics; gene therapy; genetic determinism; genetic disorders; genetic intervention; genetic materials; genetic patents; genetic research; genetic screening; life; mass media; metaphor; patient advocacy; philosophy; quality of life; research priorities; researchers; stem cells; Proposed Keywords: foundations; hyperbole

Keywords: *DNA fingerprinting; *fathers; *parent child relationship; *paternity; artificial insemination; confidentiality; disclosure; genetic identity; genetic relatedness ties; married persons; methods; reproductive technologies; semen donors; single persons

Keywords: *classification; *genomics; *neurosciences; *psychiatric diagnosis; *philosophy; behavioral genetics; brain; genotype; mental disorders; phenotype; psychiatry; schizophrenia

Keywords: *ethical theory; *morality; *sociobiology; *utilitarianism; behavioral genetics; ethnic groups; evolution; family members; freedom; justice; moral obligations; philosophy; religion; rights; Proposed Keywords: species specificity

Keywords: *benefit sharing; *genetic materials; *guidelines; *international aspects; developing countries; ecology; indigenous populations; informed consent; regulation; voluntary programs; Proposed Keywords: *biodiversity; *genetic resources; stakeholders; Keyword Identifiers: *Convention on Biological Diversity

Keywords: *genetic determinism; *genetic information; *policy making; *public policy; attitudes; biotechnology;
genetic materials; genetic screening; genomics; government regulation; human genome; international aspects; legal aspects; risks and benefits; social impact; Proposed Keywords: exceptionalism


Keywords: *culture; *family relationship; *genetic relatedness ties; anthropology; ethic groups; genetic services; reproductive technologies; Keyword Identifiers: Great Britain; Pakistan


Keywords: *culture; *genetics; *non-Western World; anthropology; biotechnology; Buddhist ethics; developing countries; genetic determinism; genomics; knowledge, attitudes, practice; personhood; science; suffering; Keyword Identifiers: * Sri Lanka

Abstract: This paper addresses the issue of how the scientific discourse of genetics is expressed in local idioms. The examples used are taken from fieldwork conducted in Sri Lanka and relate principally to Sinhala Buddhist attempts to socialise 'big science.' The paper explores idioms of both nature and nurture in local imagery and narratives and draws attention to the rhetorical dimensions of genetic discourses when used in context. The article concludes with a preliminary attempt to identify the ways in which explanations of genetic causality are aligned with notions of karma in the explanation of illness and misfortune.


Keywords: *criminal law; *genetic information; *genetic materials; *legal liability; *property rights; advisory committees; commodification; DNA fingerprinting; genetic privacy; genetic screening; informed consent; publishing; Proposed Keywords: *theft; Keyword Identifiers: Australia; Australian Law Reform Commission; Great Britain; Human Genetics Commission (Great Britain)


Keywords: *genetics; *human rights; *international aspects; *political activity; organizational policies; private sector; public participation; Proposed Keywords: nongovernmental organizations (NGOs)


Keywords: *autonomy; *communitarianism; *genetics; *self concept; *philosophy; bioethics; community consent; confidentiality; ethical theory; family members; freedom; genetic information; genetic patents; genetic privacy; genetic research; informed consent; freedom; literature; morality; population genetics; theoretical models; Keyword Identifiers: Murdoch, Iris

Abstract: This paper addresses the impact of genetic advances and understandings on our concept of the self and the individual. In particular it focuses on conceptions of the ‘autonomous individual’ in the post-Enlightenment tradition and in bioethics. It considers the ascendancy of the autonomous individual as the model of the self and describes the erosion of substantial concepts of the self and the reduction of the self to “the will”—with the accompanying values of freedom, choice and autonomy. This conception of the self as an isolated, autonomous individual, characterised by acts of “will” is then critiqued

SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review 228
drawing on both theoretical sources, particularly the work of Iris Murdoch, and practical sources, namely the difficulties raised by genetics.


Abstract: What is the impact of genetics and genomics on issues of identity and what do we mean when we speak of identity? This paper explores how certain concepts of identity used in philosophy can be brought together in a multi-layered concept of identity. It discusses the concepts of numerical, qualitative, personal and genetic identity-over-time as well as rival concepts of genomic identity-over-time. These are all understood as layers in the multi-layered concept of identity. Furthermore, the paper makes it clear that our understanding of genomic identity and the importance attached to genomic same-ness-over-time matters for the ethical questions raised by certain new gene technologies.

**GENETICS AND HUMAN ANCESTRY**


Keywords: *culture; genetic databases; genetic research; industry; information dissemination; attitudes; biological specimen banks; biotechnology; genetic identity; genomics; mass media; medical records; metaphor; pedigree; politics; population genetics; public opinion; public participation; presumed consent; public policy; regulation; research subjects; researchers; risks and benefits; Proposed Keywords: persuasive communication; Keyword Identifiers: *deCode Genetics; *Iceland

Bibbins-Domingo, Kirsten; Fernandez, Alicia. BiDil for heart failure in black patients: implications for the U.S. Food and Drug Administration approval. *Annals of Internal Medicine* 2007 January 2; 146(1): 52-56. 49 refs. NRCBL: 15.11; 5.3; 9.5.4; 9.7.

Keywords: *blacks; pharmacogenetics; clinical trials; drugs; federal government; health disparities; heart diseases; public policy; racial groups; Proposed Keywords: *drug approval; Keyword Identifiers: *BiDil; *Food and Drug Administration; United States

Bolnick, Deborah A.; Fullwiley, Duana; Duster, Troy; Cooper, Richard S.; Fujimura, Joan H.; Kahn, Jonathan; Kaufman, Jay S.; Marks, Jonathan; Morning, Ann; Nelson, Alondra; Ossorio, Pilar; Reardon, Jenny; Reverby, Susan M.; TallBear, Kimberly. The science and business of genetic ancestry testing. *Science* 2007 October 19; 318(5849): 399-400. 21 refs. NRCBL: 15.11; 15.3.

Keywords: *commerce; genetic ancestry; genetic screening; ethnic groups; genetic diversity; industry; racial groups; risks and benefits; Proposed Keywords: haplotypes


Keywords: *attitudes; genetic ancestry; genetic discrimination; genetic research; information dissemination; public opinion; racial groups; social impact; blacks; mass media; minority groups; social discrimination; survey; whites; Keyword Identifiers: United States


Keywords: *genetic ancestry; genetic screening; paternity; pedigree; attitudes; confidentiality; disclosure; ethnic groups; family relationship; genetic counseling; genetic identity; genetic services; incidental findings; informed consent; Internet; population genetics; racial groups; risks and benefits; trends

Abstract: Advances in genetic research and technology can have a profound impact on identity and family dynamics when genetic findings disrupt deeply held assumptions about the nuclear family. Ancestry tracing and paternity testing present parallel risks and opportunities. As these latter uses are now available over the internet directly to the consumer, bypassing the genetic counselor, consumers need adequate warning when making use of these new modalities.


Keywords: *blacks; genetic diversity; genetic epidemiology; genomics; health disparities; human genome; genetic ancestry; genetic research; genetic services; genome mapping; health services accessibility; population genetics; racial groups; Keyword Identifiers: *United States; Africa; Genomic Research in the African Diaspora (GRAD) Project; National Human Genome Center; Howard University

bioethics.unm.edu/genetics_and_identity/docs/gen-
grant.pdf [2007 April 24]. 43 refs. NRCBL: 15.11; 15.10; 18.5.1.

Keywords: *ethnic groups; *genetic ancestry; *genetic di-
versity; *genetic identity; *genetic relatedness ties; *Hu-
man Genome Project; *population genetics; family; genetic
information; racial groups; self concept; social discrimina-
tion; Proposed Keywords: classification; Keyword
Identifiers: United States

Fausto-Sterling, Anne. Refashioning race: DNA and the
politics of health care. 2004: 137-151. 38 fn. NRCBL: 15.11; 9.5.4. Conference:
Identity. Washington, DC: Georgetown Uni-
versity Press, D., eds. *African American Bioethics: Cul-
ture, Race, and ethics. In: Prograis, Lawrence J.; Pellegrino, Edmund
D., eds. *African American Bioethics: Culture, Race, and
Identity. Washington, DC: Georgetown University Press,
2004: 137-151. 38 fn. NRCBL: 15.11; 9.5.4. Conference:
Symposium on African American Perspectives in
Bioethics and Second Annual Conference on Health Dis-
parities, held on September 23-24, 2004, at Georgetown
University.

Keywords: *genetic ancestry; *genomics; *racial groups;
biomedical research; blacks; drugs; ethnic groups; health
care delivery; health disparities; justice; pharmacogenetics;
social discrimination; Proposed Keywords: classification;
Keyword Identifiers: BiDil; United States

Fullwiley, Duana. The molecularization of race: institu-
tionalizing human difference in pharmacogenetics prac-
tice. *Science as Culture 2007 March; 16(1): 1-30. NRCBL:
15.11; 9.7; 9.5.4.

Harmon, Amy. In DNA era, new worries about prejudice.
15.11. SC: po.

Keywords: *genetic ancestry; *genetic discrimination; *ge-
netic diversity; *racial groups; behavioral genetics; genetic
determination; genetic research; intelligence; population
genetics; social impact

Harmon, Amy. My genome, myself: seeking clues in
NRCBL: 15.11; 15.3. SC: po.

Keywords: *DNA fingerprinting; *genetic ancestry; *ge-
netic predisposition; *genetic services; industry; pedigree;
self concept

Indigenous Peoples Council on Biocolonialism. Indige-
nous people, genes and genetics: what indigenous people
should know about biocolonialism: a primer and resource
http://www.ipcb.org/publications/primers/htmls/
ipgg.html [2007 April 23]. 2 refs. NRCBL: 15.11; 18.5.9.

Keywords: *American Indians; *genetic engineering; *ge-
netic research; *indigenous populations; agriculture; bio-
logical specimen banks; biotechnology; commerce;
eugenics; genes; genetic ancestry; genetic databases; ge-
netic discrimination; genetic materials; genetic patents;
genetically modified organisms; genetics; health hazards;
Human Genome Diversity Project; informed consent; inter-
national aspects; political activity; population genetics;
public policy; research ethics; research priorities; research
subjects; Proposed Keywords: *genetic resources;
biodiversity; colonialism

International HapMap Consortium; Rotimi, Charles;
Lepper, Mark; Matsuda, Ichiro; Zeng, Changqing;
Zhang, Houcan; Adebamowo, Clement; Ajayi, Ike;
Aniagwu, Toyin; Dixon, Missy; Fukushima,
Yoshimitsu; Macer, Darryl; Marshall, Patricia;
Nkwodimmah, Chibuzor; Peiffer, Andy; Royal,
Charmaine; Suda, Eiko; Zhao, Hui; Wang, Vivian Ota;
McEwen, Jean. Community engagement and informed
consent in the international HapMap project. *Community
Genetics* 2007; 10(3): 186-198. 20 refs. NRCBL: 15.11;
15.10; 18.3. SC: em.

Keywords: *genetic diversity; *HapMap Project; *in-
formed consent; *international aspects; *population genet-
ics; *public participation; blood specimen collection;
donors; genetic databases; genetic research; incentives;
program descriptions; public opinion; racial groups; research
subjects; risks and benefits; Keyword Identifiers: China; Ja-
pan; National Institutes of Health; Nigeria; United States

Juengst, Eric T. Population genetic research and screening:
NRCBL: 15.11; SC: an; rv.

Keywords: *genetic research; *genetic screening; *popu-
lation genetics; autonomy; benefit sharing; clinical genetics;
community consent; cultural pluralism; decision making;
ethnic groups; eugenics; gene pool; genetic ancestry; ge-
netic discrimination; genetic diversity; genetic information;
genetic resources; genotype; genomics; goals; international
aspects; justice; mass screening; moral policy; phenotype;
policy analysis; preventive medicine; property rights; pub-
lic health; public policy; racial groups; research subjects; values

Lee, S.S.-J. The ethical implications of stratifying by race
in pharmacogenomics. *Clinical Pharmacology and Ther-

Lillquist, Erik; Sullivan, Charles A. The law and genetic-
ees of racial profiling in medicine. *Harvard Civil Rights-

Keywords: *biomedical research; *genetic ancestry;
*health disparities; *legal aspects; *medicine; *racial
groups; *prejudice; *population based; *research ethics; *racial
groups; *science; *social discrimination; *socioeconomic factors; Proposed Keywords: classification;
environmental health; Keyword Identifiers: *United States;
First Amendment; Fourteenth Amendment

MacIntosh, Constance. Indigenous self-determination and
research on human genetic material: a consideration of
the relevance of debates on patents and informed consent,
and the political demands on researchers. *Health Law
**SECTION I**

**GENETICS AND HUMAN ANCESTRY**

*Journal of Science* 2003 December; 70(5): 1161-1172. 33 refs.

**Mangon, R.**


Keywords: *ethnic groups; genetic ancestry; medicine; racial groups; biomedical research; clinical trials; drug industry; drugs; genetic diversity; genetic predisposition; mortality; morbidity; pharmacogenetics; research design; selection of subjects; socioeconomic factors; Proposed Keywords: drug approval; Keyword Identifiers: Bill; Food and Drug Administration; United States

**Mastroianni, George R.**


**McMurray, David L., Jr.**


Keywords: *ethnic groups; genetic ancestry; genetic predisposition; health hazards; justice; public policy; ecology; genomics; government regulation; health disparities; indigents; minority groups; pharmacogenetics; population genetics; public health; social discrimination; toxicity; Proposed Keywords: *environmental health; toxicogenetics; genetic epidemiology; Keyword Identifiers: *Environmental Protection Agency; United States

**Nixon, Ron.**


Keywords: *blacks; DNA fingerprinting; genetic ancestry; genetic services; pedigree; economics; industry; methods; population genetics; Keyword Identifiers: *United States; Africa; Gates, Henry Louis

**Obasogie, Osagie.**

Racial alchemy. It may not be long before genetic skin-lightening treatments are on sale, so it’s time to stop pretending colour prejudice isn’t a problem. *New Scientist* 2007 August 18-24; 195(2617): 17.

NRCBL: 15.11; 9.7.

Keywords: *biotechnology; genetic ancestry; racial groups; population genetics; social discrimination; Proposed Keywords: *cosmetic techniques; skin pigmentation

**Pigliucci, Massimo; Kaplan, Jonathan.**


Keywords: *racial groups; biological sciences; ecology; evolution; genetic ancestry; genetic diversity; genotype; geographic factors; phenotype; population genetics

**Po, Alan I.**

Personalised medicine: who is an Asian? *Lancet* 2007 May 26 - June 1; 369(9575): 1770-1771. NRCBL: 15.11; 9.7; 9.5.4.

**Reardon, Jenny.**


**Rose, Nikolas S.**


**Rothstein, M.A.; Epps, P.G.**


Keywords: *genetic ancestry; genetic research; pharmacogenetics; racial groups; biomedical research; clinical genetics; ethnic groups; genetic diversity; historical aspects; research subjects; selection of subjects; trends; Proposed Keywords: classification

**Schwartz, John.**


Keywords: *genetic ancestry; racial groups; blacks; famous persons; genetic research; genetic screening; intelligence; researchers; social discrimination; whites; Proposed Keywords: predictive value of tests; Keyword Identifiers: *Watson, James D.

**Sharp, Richard R.; Foster, Morris W.**


Keywords: *genetic diversity; genetic research; Human Genome Diversity Project; research; biomedical research; community consent; cultural pluralism; decision making; dissent; donors; ethnic groups; genetic ancestry; genetic materials; guidelines; indigenous populations; international aspects; justice; population genetics; public participation; research design; research subjects; researcher subject relationship; risks and benefits; vulnerable populations; Proposed Keywords: *population groups; harm; social identification; third-party research subjects

Abstract: Strategies for protecting historically disadvantaged groups have been extensively debated in the context of genetic variation research, making this a useful

NRCBL: National Reference Center for Bioethics Literature Classification Scheme
starting point in examining the protection of social groups from harm resulting from biomedical research. We analyze research practices developed in response to concerns about the involvement of indigenous communities in studies of genetic variation and consider their potential application in other contexts. We highlight several conceptual ambiguities and practical challenges associated with the protection of group interests and argue that protectionist strategies developed in the context of genetic research will not be easily adapted to other types of research in which social groups are placed at risk. We suggest that it is this set of conceptual and practical issues that philosophers, ethicists, and others should focus on in their efforts to protect identifiable social groups from harm resulting from biomedical research.

Sheldon, Jane P.; Jayaratne, Toby Epstein; Feldbaum, Merle B.; DiNardo, Courtney D.; Petty, Elizabeth M. Applications and implications of advances in human genomics: perspectives from a group of Black Americans. Community Genetics 2007; 10(2): 82-92. 39 refs. NRCBL: 15.11. SC: em. Keywords: *attitudes; *blacks; *genetic ancestry; *genetic predisposition; *genetic research; *racial groups; behavioral genetics; ethnic groups; genetic disorders; intelligence; interviews; risks and benefits; questionnaires; social discrimination; social impact; stigmatization; trust; violence; whites; Keyword Identifiers: United States

Shelton, B.L. Consent and consultation in genetic research on American Indians and Alaskan Natives. Nixon, NV: Indigenous Peoples Council on Biocolonialism, 2002; 3 p. [Online]. Accessed: http://www.ipcb.org/publications/briefing_papers/files/consent.html [2007 April 24]. NRCBL: 15.11; 18.3; 18.5.9. Keywords: *American Indians; *genetic research; community consent; government; indigenous populations; informed consent; policy making; public participation; refusal to participate; research subjects; Keyword Identifiers: United States

Temple, Robert; Stockbridge, Norman L. BiDil for heart failure in black patients: the U.S. Food and Drug Administration perspective. Annals of Internal Medicine 2007 January 2; 146(1): 52-62. 28 refs. NRCBL: 15.11; 5.3; 9.5.4; 9.7. Keywords: *blacks; *pharmacogenetics; clinical trials; drugs; federal government; heart diseases; public policy; racial groups; Proposed Keywords: *drug approval; Keyword Identifiers: *BiDil; *Food and Drug Administration; United States

GENOCIDE See TORTURE, GENOCIDE, AND WAR CRIMES

GENOME MAPPING AND SEQUENCING
See also GENETIC RESEARCH; GENETIC SCREENING; GENETICALLY MODIFIED ORGANISMS AND FOOD

Aldhous, Peter. Your own book of life. New Scientist 2007 September 8-14; 195(2620): 8-11. NRCBL: 15.10; 8.4; 9.7. Keywords: *genetic services; *genome mapping; *trends; DNA sequences; genetic predisposition; genomes; human genome; industry; Proposed Keywords: *personalized medicine; Keyword Identifiers: Venter, Craig

Brenner, Steven E. Common sense for our genomes. Nature 2007 October 18; 449(7164): 783-784. 5 refs. NRCBL: 15.10; 1.3.12; 15.11. Keywords: *genetic databases; *genetic diversity; *personal genomics; famous persons; research support; researchers; Keyword Identifiers: *Genome Commons; Venter, J. Craig; Watson, James


Check, Erika. Celebrity genomes alarm researchers [news]. Nature 2007 May 24; 447(7143): 358-359. NRCBL: 15.10; 1.3.12. Keywords: *famous persons; *genome mapping; *human genome; *researchers; *selection of subjects; DNA sequences; family members; genetic databases; genetic privacy; genomics; government financing; Human Genome Project; medical records; private sector; public sector; research design; research subjects; research support; Proposed Keywords: personalized medicine; Keyword Identifiers: Church, George; National Human Genome Research Institute; Venter, J. Craig; Watson, James

Greif, Karen F.; Merz, Jon F. Big science: the Human Genome Project and the public funding of science. In their: Current Controversies in the Biological Sciences: Case Studies of Policy Challenges from New Technologies. Cambridge, MA: MIT, 2007: 17-34. 37 refs. NRCBL: 15.10. Keywords: *government financing; *Human Genome Project; *research support; federal government; genetic patients; historical aspects; industry; international aspects; private sector; program descriptions; public sector; Keyword Identifiers: *United States; National Institutes of Health; Twentieth Century


Hoedemaekers, Rooger; Gordijn, Bert; Pijnenburg, Martien. Solidarity and justice as guiding principles in genomic research. Bioethics 2007 July; 21(6): 342-350. 25 fn. NRCBL: 15.10; 15.1; 1.3.12; 1.1; 9.1; 18.3; 18.5.1. SC: an. Keywords: *ethical analysis; *future generations; *genetic research; *justice; *moral obligations; *moral policy; *nontherapeutic research; *obligations to society; *presumed consent; altruism; autonomy; biological specimen

SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
bank; communitarianism; ethical review; financial support; genetic databases; genomics; health priorities; industry; informed consent; obligations of society; public policy; research design; research priorities; research subjects; research support; resource allocation; risks and benefits; theoretical models

Abstract: In genomic research the ideal standard of free, informed, prior and explicit consent is sometimes difficult to apply. This has raised concern that important genomic research will be restricted. Different consent procedures have therefore been proposed. This paper explicitly examines the question how, in genomic research, the principles of solidarity and justice can be used to justify forms of diminished individual control over personal data and bio-samples. After a discussion of the notions of solidarity and justice and how they can be related to health care and genomic research, we examine how and in which situations these notions can form a strong moral basis for demanding certain financial sacrifices. Then we examine when these principles can justify consent procedures which diverge from the ideal standard. Because much genomic research is not expected to lead to immediate (clinical) benefits we also discuss the question of whether we can be obliged to make any sacrifices for future (not yet existing) patients. We conclude with the formulation of a number of conditions that have to be met before autonomy sacrifices can be reasonably demanded in genomic research.

Keywords: *disclosure; *DNA sequences; *famous persons; *genetic privacy; *genome mapping; *human genome; access to information; genetic databases; genetic predisposition; industry; informed consent; researchers; Proposed Keywords: self disclosure; Keyword Identifiers: *Watson, James; Church, George; Venner, J. Craig

Mayor, Susan. Genome sequence of one person is published for first time [news]. BMJ: British Medical Journal 2007 September 15; 335(7619): 530-531. NRCBL: 15.10.

Keywords: *Human Genome Project; genetic research; genetic screening; human dignity; pharmacogenetics; Keyword Identifiers: NIH-DOE Working Group on Ethical, Legal, and Social Implications (ELSI)

Keywords: *Human Genome Project; genetic diversity; genetic patents; genome; genomics; government financing; HapMap Project; historical aspects; international aspects; mass media; private sector; public sector; research support; researchers; Keyword Identifiers: Department of Energy; National Human Genome Research Institute; National Institutes of Health; Twentieth Century; United States

GENOME SEQUENCING See GENOME MAPPING AND SEQUENCING

GENOMICS See GENETICS AND GENOMICS

HEALTH CARE
See also CARE FOR SPECIFIC GROUPS; HEALTH CARE ECONOMICS; HEALTH CARE QUALITY; RESOURCE ALLOCATION; RIGHT TO HEALTH CARE


Abstract: Recent medical informatics and sociological literature has painted the image of a new type of patient — one that is reflexive and informed, with highly specified information needs and perceptions, as well as highly developed skills and tactics for acquiring information. Patients have been re-named “reflexive consumers.” At the same time, literature about the questionable reliability of web-based information has suggested the need to create both user tools that have pre-selected information and special guidelines for individuals to use to check the individual characteristics of the information they encounter. In this article, we examine suggestions that individuals must be assisted in developing skills for “reflexive consumerism” and what these particular skills should be. Using two types of data (discursive data from websites and promotional items, and supplementary data from interviews and ethnographic observations carried out with those working to sustain these initiatives), we examine how users are directly addressed and discussed. We argue that these initiatives prescribe skills and practices that extend beyond finding and assessing information on the internet and demonstrate that they include ideals of consumerism and citizenship.


**Battin, Margaret P.; Francis, Leslie P.; Jacobson, Jay A.; Smith, Charles B.** The patient as victim and vector: an = analytical cs = case studies em = empirical le = legal po = popular rv = review


**Cooper, Robert W.; Frank, Garry L.; Gouty, Carol Ann; Hansen, Mary C.** Key ethical issues encountered in healthcare organizations: perceptions of nurse executives. *JONA: The Journal of Nursing Administration* 2002 June; 32(6): 331-337. NRCBL: 9.1; 9.8; 1.3.2; 4.1.3.


**Darr, Kurt.** Virtue ethics: worth another look. *Hospital Topics* 2006 Fall; 84(4): 29-31. NRCBL: 9.1; 1.3.2; 1.1.

**de Melo-Martín, Immaculada.** The promise of the human papillomavirus vaccine does not confer immunity against ethical reflection. *Oncologist* 2006 April; 11(4): 393-396. NRCBL: 9.1; 9.5.1; 10; 9.5.7; 8.3.2.


**Dekkers, Wim; Gordijn, Bert.** Practical wisdom in medicine and health care [editorial]. *Medicine, Health Care and Philosophy* 2007 September; 10(3): 231-232. NRCBL: 9.1; 1.1; 4.1.1; 9.8; 20.1.

**Edmondson, Ricca; Pearce, Jane.** The practice of health care: wisdom as a model. *Medicine, Health Care and Philosophy* 2007 September; 10(3): 233-244. NRCBL: 9.1; 1.1; 9.8; 17.1.

Abstract: Reasoning and judgement in health care entail complex responses to problems whose demands typically derive from several areas of specialization at once. We argue that current evidence- or value-based models of health care reasoning, despite their virtues, are insufficient to account for responses to such problems exhaustively. At the same time, we offer reasons for contending that health professionals in fact engage in forms of reasoning of a kind described for millennia under the concept of wisdom. Wisdom traditions refer to forms of deliberation which combine knowledge, reflection and life experience with social, emotional and ethical capacities. Wisdom is key in dealing with problems which are vital to human affairs but lack prescribed solutions. Uncertainty and fluidity must be tolerated in seeking to resolve them. We illustrate the application of wisdom using cases in psychiatry, where non-technical aspects of problems are often prominent and require more systematic analysis than conventional approaches offer, but we argue that our thesis applies throughout the health care field. We argue for the relevance of a threefold model of reasoning to modern health care situations in which multifaceted teamwork and complex settings demand wise judgement. A model based on practical wisdom highlights a triadic process with features activating capacities of the self (professional), other (patient and/or carers and/or colleagues) and aspects of the problem itself. Such a framework could be used to develop current approaches to health care based on case review and experiential learning.


**Engström, Timothy H.; Richter, Gerd.** Citizens and customers: establishing the ethical foundations of the German and U.S. health care systems. *In:* Engström, Timothy H.; Robison, Wade L., eds. Health Care Reform: Ethics and


Holm, Soren. Can politics be taken out of the (English) NHS? [editorial]. Journal of Medical Ethics 2007 October; 33(10): 559. NRCBL: 9.1. Identifiers: Great Britain (United Kingdom); National Health Service.


Abstract: In this paper the coherence of the precautionary principle as a guide to public health policy is considered. Two conditions that any account of the principle must meet are outlined, a condition of practicality and a condition of publicity. The principle is interpreted in terms of a tripartite division of the outcomes of action (good outcomes, normal bad outcomes and special bad outcomes). Such a division of outcomes can be justified on either “consequentialist” or “deontological” grounds. In the second half of the paper, it is argued that the precautionary principle is not necessarily opposed to risk-cost-benefit analysis, but, rather, should be interpreted as suggesting a lowering of our epistemic standards for assessing evidence that there is a link between some policy and “special bad” outcomes. This suggestion is defended against the claim that it mistakes the nature of statistical testing and against the charge that it is unscientific or antiscientific, and therefore irrational.


May, Thomas; Silverman, Ross D. Free-riding, fairness and the rights of minority groups in exemption from mandatory childhood vaccination. Human Vaccines 2005 January-February; 1(1): 12-15. NRCBL: 9.1; 9.7; 8.3.2; 8.3.4; 9.5.4; 1.2; 9.5.7. SC: le.

McIntyre, Di; Whitehead, Margaret; Gilson, Lucy; Dahlgren, Göran; Tang, Shenglan. Equity impacts of neoliberal reforms: what should the policy responses be? International Journal of Health Services 2007; 37(4): 693-709. NRCBL: 9.1; 9.5.3.


Nuzzo, Jennifer B.; Henderson, Donald A.; O’Toole, Tara; Inglesby, Thomas V. Comments from the Center for Biosecurity of UPMC on proposed revisions to federal quarantine rules. Biosecurity and Bioterrorism 2006; 4(2): 204-206. NRCBL: 9.1; 1.3.5.


Rathert, Cheryl; Fleming, David A. Ethical climates of HCOs and end-of-life moral conflict in care terms. Organizational Ethics: Healthcare, Business, and Policy 2006 Fall-Winter; 3(2): 101-111. NRCBL: 9.1; 1.3.2; 20.4.1; 20.5.1.

SECTION I HEALTH CARE


Abstract: Most of the discussion in bioethics and health policy concerning social responsibility for health has focused on society’s obligation to provide access to healthcare. While ensuring access to healthcare is an important social responsibility, societies can promote health in many other ways, such as through sanitation, pollution control, food and drug safety, health education, disease surveillance, urban planning and occupational health. Greater attention should be paid to strategies for health promotion other than access to healthcare, such as environmental and public health and health research.


Abstract: Empowerment is a concept that has been much used and discussed for a number of years. However, it is not always explicitly clarified what its central meaning is. The present paper intends to clarify what empowerment means, and relate it to the goals of health promotion. The paper starts with the claim that health-related quality of life is the ultimate general goal for health promotion, and continues by briefly presenting definitions of some central concepts: “welfare”, “health” and “quality of life”. Several suggestions as to what empowerment is are then discussed: autonomy, freedom, knowledge, self-esteem, self-confidence, and control over health or life. One conclusion of this discussion is that empowerment can be seen as a complex goal which includes aspects of the three central concepts welfare, health and quality of life. To the extent that the empowerment goals aimed at are health-related, it is concluded that empowerment is a legitimate goal for health promotion. But empowerment is not only a goal, it can also be described as a process or as an approach. This process, or approach, in a fundamental way involves the participants in problem formulation, decision making and action, which means that the experts have to relinquish some of their control and power.


Abstract: In this paper, we describe the value and philosophy of lifeworld-led care. Our purpose is to give a philosophically coherent foundation for lifeworld-led care and its core value as a humanising force that moderates technological progress. We begin by indicating the timeliness of these concerns within the current context of citizen-oriented, participative approaches to healthcare. We believe that this context is in need of a deepening philosophy if it is not to succumb to the discourses of mere consumerism. We thus revisit the potential of Husserl’s
notion of the lifeworld and how lifeworld-led care could provide important ideas and values that are central to the humanisation of healthcare practice. This framework provides a synthesis of the main arguments of the paper and is finally expressed in a model of lifeworld-led care that includes its core value, core perspectives, relevant indicative methodologies and main benefits. The model is offered as a potentially broad-based approach for integrating many existing practices and trends. In the spirit of Husserl’s interest in both commonality and variation, we highlight the central, less contestable foundations of lifeworld-led care, without constraining the possible varieties of confluent practices.


HEALTH CARE/ HEALTH CARE ECONOMICS
See also RESOURCE ALLOCATION


Andereck, William S.; Jonsen, Albert R. Conclusion [commercialism in medicine]. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Fall; 16(4): 439-442. NRCBL: 9.3.1; 7.3; 1.3.2; 4.1.2; 1.3.1; 1.1; 8.1.


Abstract: In contemporary China, physicians tend to require more diagnostic work-ups and prescribe more expensive medications than are clearly medically indicated. These practices have been interpreted as defensive medicine in response to a rising threat of potential medical malpractice lawsuits. After outlining recent changes in Chinese malpractice law, this essay contends that the overuse of expensive diagnostic and therapeutic interventions cannot be attributed to malpractice concerns alone. These practice patterns are due as well, if not primarily, to the corruption of medical decision-making by physicians being motivated to earn supplementary income, given the constraints of an ill-structured governmental policy by the over-use of expensive diagnostic and therapeutic interventions. To respond to these difficulties of Chinese health care policy, China will need not only to reform the particular policies that encourage these behaviors, but also to nurture a moral understanding that can place the pursuit of profit within the pursuit of virtue. This can be done by drawing on Confucian moral resources that integrate the pursuit of profit within an appreciation of benevolence. It is this Confucian moral account that can formulate a medical care policy suitable to China’s contemporary market economy.

Churchill, Larry R. The hegemony of money: commercialism and professionalism in American medicine. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Fall; 16(4): 407-414. NRCBL: 9.3.1; 7.3; 1.3.2; 4.1.2; 1.3.1; 1.1. SC: an.


Fins, Joseph J. Commercialism in the clinic: finding balance in medical professionalism. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Fall; 16(4): 425-432. NRCBL: 9.3.1; 7.3; 1.3.2; 4.1.2; 1.3.1; 8.1. SC: an.

Graham, Jane H. Community care or therapeutic stalking: two sides of the same coin? Journal of Psychosocial Nursing and Mental Health Services 2006 August; 44(8): 41-47. NRCBL: 9.3.1; 7.1; 17.8.


Jonsen, Albert R. Guest editorial: a note on the notion of commercialism. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Fall; 16(4): 368-373. NRCBL: 9.3.1; 1.3.2; 1.1; 7.3; 4.1.2; 1.3.1.

Kassirer, Jerome P. Commercialism and medicine: an overview. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Fall; 16(4): 377-386. NRCBL: 9.3.1; 1.3.2; 7.3; 4.1.2; 1.3.1. SC: rv.


Lehmann, Lisa Soleymani; Swartz, Katherine; Chinn, Michael; Angell, Marcia; Daniels, Norman; Brock, Dan; Relman, Bud; Fein, Rash. Harvard Medical School public forum: insuring the uninsured: does Massachusetts have the right model? 17 May 2007. Journal of Clinical Ethics 2007 Fall; 18(3): 270-293. NRCBL: 9.3.1; 9.3.2; 9.2; 9.4. SC: em.


Needleman, Jacob. A philosopher’s reflection on commercialism in medicine. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Fall; 16(4): 433-438. NRCBL: 9.3.1; 7.3; 1.3.2; 4.1.2; 1.3.1; 1.1; 8.1. SC: an.

Nichols, Len M. The moral case for covering children (and everyone else): policy analysis and evaluation cannot rest until there is real health care justice throughout the entire land. Health Affairs 2007 March-April; 26(2): 405-407. NRCBL: 9.3.1; 9.5.7; 1.2.


Abstract: President Bush and his Council of Economic Advisors have claimed that the US shouldn’t adopt a national health program because doing so would slow innovation in health care. Some have attacked this argument by challenging its moral claim that innovativeness is a good ground for choosing between health care systems.
This reply is misguided. If we want to refute the argument from innovation, we have to undercut the premise that seems least controversial – the premise that our current system produces more innovation than a national health program would. I argue that this premise is false. The argument requires clarifying the concept ‘national health program’ and examining various theories of human well-being.


Relman, Arnold S. The problem of commercialism in medicine. *CQ: Cambridge Quarterly of Healthcare Ethics* 2007 Fall; 16(4): 375-376. NRCBL: 9.3.1; 1.3.2; 7.1; 7.3; 4.1.2; 1.3.1.

Rodwin, Marc A. Commercialized health market. *CQ: Cambridge Quarterly of Healthcare Ethics* 2007 Fall; 16(4): 387-397. NRCBL: 9.3.1; 7.3; 1.3.2; 7.1. SC: rv; le.

Ruger, Jennifer Prah. Entrepreneurialism, and conflicts of interest. *CQ: Cambridge Quarterly of Healthcare Ethics* 2007 Fall; 16(4): 420-424. NRCBL: 9.3.1; 1.3.2; 1.3.7; 1.3.8; 2.8.4. SC: an.


Snyder, Lois; Neubauer, Richard L. Pay-for-performance principles that promote patient-centered care: an ethics manifesto. *Annals of Internal Medicine* 2007 December; 147(11): 792-794. NRCBL: 9.3.1; 9.8; 8.1; 7.1. Abstract: Pay-for-performance programs are growing, but little evidence exists on their effectiveness or on their potential unintended consequences and effects on the patient-physician relationship. Pay-for-performance has the potential to help improve the quality of care, if it can be aligned with the goals of medical professionalism. Initiatives that provide incentives for a few specific elements of a single disease or condition, however, may neglect the complexity of care for the whole patient, especially the elderly patient with multiple chronic conditions. Such programs could also result in the deselection of patients, “playing to the measures” rather than focusing on the patient as a whole, and misalignment of perceptions between physicians and patients. The primary focus of the quality movement in health care should not be on “pay for” or “performance” based on limited measures, but rather on the patient. The American College of Physicians hopes to move the pay-for-performance debate forward with a patient-centered focus — one that puts the needs and interests of the patient first — as these programs evolve.


United States. Department of Health and Human Services [DHHS]; United States. Centers for Medicare and Medicaid Services. Medicare program; physicians referrals to health care entities with which they have financial relationships; exceptions for certain electronic prescribing and electronic health records arrangements; final rule. Federal Register 2006 August 8; 71(152): 45139-45171. NRCBL: 9.3.1; 9.5.2; 1.3.12; 5.3. SC: le.


HEALTH CARE/. . ./ MANAGED CARE PROGRAMS


Abstract: Physician organizations, policy makers, and patient advocates have expressed concern that health plans have contractually limited the freedom of physicians to communicate with their patients. In response, many states have adopted gag laws that limit the ability of managed care contracts to restrict patient-physician communication. We examine the impact of these laws on patient trust in the physician. We analyzed patients’ ratings of trust in their physicians in states before and after adoption of gag laws. Individuals in states that had such laws throughout the study period were used as the comparison group. The analysis is based on a nationally representative sample of adults obtained from the 1996-1997 and 1998-1999 Community Tracking Study Household Surveys. After adjustment for patient characteristics, it was estimated that the adoption of gag laws had no statistically significant impact on trust in the physician for the average patient. However, the adoption of gag laws is estimated to have increased trust in the physician by a modest amount (25 percent of a standard deviation) for health maintenance organization (HMO) enrollees who did not have a usual source of care. Gag laws may assure HMO enrollees without a usual source of care that their physicians are free to speak candidly about treatment options. This does not necessarily imply that physicians are prohibited from speaking freely in the absence of such laws, but gag laws indicate concerns (justified or not) that patients have about unrestricted communication with their health care providers.


HEALTH CARE/ HEALTH CARE QUALITY

Baumrucker, Steven J. A medical error leads to tragedy: how do we inform the patient? American Journal of Hospice and Palliative Care 2006 October-November; 23(5): 417-421. NRCBL: 9.8; 7.1; 8.1; 20.4.1. SC: cs.

Bird, Chloe E.; Fremont, Allen M.; Bierman, Arlene S.; Wickstrom, Steve; Shah, Mona; Rector, Thomas; Horstman, Thomas; Escarce, Jose J. Does quality of care for cardiovascular disease and diabetes differ by gender for enrollees in managed care plans? Women ‘s Health Issues 2007 May-June; 17(3): 131-138. NRCBL: 9.8; 10; 9.5.5; 9.5.1; 9.3.2. SC: em.

Blustein, Jeffrey. Doctoring and self-forgiveness. In: Walker, Rebecca L.; Ivanhoe, Philip J., eds. Working Vir-

Boyle, Dennis; O’Connell, Daniel; Platt, Frederic W.; Albert, Richard K. Disclosing errors and adverse events in the intensive care unit. Critical Care Medicine 2006 May; 34(5): 1532-1537. NRCBL: 9.8; 8.2; 9.5.1. SC: cs; rv.


Abstract: Increasing recognition of adverse events in health care is wide spread. Implementing improved system arrangements, which prevent adverse events taking place rather than focussing on individual culpability is increasingly being recognised as a more effective preventative strategy. But does such a perspective mean individual health practitioners remain accountable for their practice? This article explores the philosophical, psychological and professional contradictions inherent in attempting to understand where the responsibility for our actions lies and concludes by arguing that while the case for the system approach to adverse event reduction is strong, the notion of individual professional culpability needs to be maintained.

Callens, Stefaan; Volbragt, Ilse; Nys, Herman. Legal thoughts on the implications of cost-reducing guidelines for the quality of health care. Health Policy 2007 March; 80(3): 422-431. NRCBL: 9.8; 9.2; 9.3.1; 21.1; 8.5. Identifiers: Europe; Belgium; The Netherlands; France.


Gerber, Andreas; Hentzel, Frieder; Lauterbach, Karl W. Can evidence-based medicine implicitly rely on current concepts of disease or does it have to develop its own definition? Journal of Medical Ethics 2007 July; 33(7): 394-399. NRCBL: 9.8; 1.1; 4.2. Abstract: Decisions in healthcare are made against the background of cultural and philosophical definitions of disease, sickness and illness. These concepts or definitions affect both health policy (macro level) and research (meso level), as well as individual encounters between patients and physicians (micro level). It is therefore necessary for evidence-based medicine to consider whether any of the definitions underlying research prior to the hierarchisation of knowledge are indeed compatible with its own epistemological principles.


Abstract: Medical work is increasingly being subjected to objective assessment as those who pay for it seek to grasp the quality of that work and how best to improve it. While objective measures have a role in the assessment of health care, I argue that this role is currently overestimated and that no human practice such as medicine can be fully comprehended by objective assessment. I suggest that the character of practices, in which formalizations are combined with judgment, requires that valid assessment involve the perspective of the skilled practitioner. Relying exclusively on objective measures in assessing health care will not only distort our assessments of it but lead to damage as the incentives of health care workers are directed away from the important aspects of their work that are not captured by objective measures.


Jansen-van der Weide, Marijke Catharina; Onwuteaka-Philipsen, Bregje Dorien; van der Wal, Gerrit. Quality of consultation and the project ‘Support and Consultation on Euthanasia in the Netherlands’ (SCEN). *Health Policy* 2007 January; 80(1): 97-106. NRCBL: 9.8; 7.3; 20.7; 8.1; 20.5.1; 7.1. SC: em.


Lynn, Joanne; Baily, Mary Ann; Bottrell, Melissa; Jennings, Bruce; Levine, Robert J.; Davidoff, Frank; Casaret, David; Corrigan, Janet; Fox, Ellen; Wynia, Matthew K.; Agich, George J.; O’Kane, Margaret; Speroff, Theodore; Schyve, Paul; Batalden, Paul; Tunis, Sean; Berlinger, Nancy; Cronenwett, Linda; Fitzmaurice, J. Michael; Neveloff Dubler, Nancy; James, Brent. The ethics of using quality improvement methods in health care. *Annals of Internal Medicine* 2007 May 1; 146(9): 666-673. NRCBL: 9.8; 18.6.

Abstract: Quality improvement (QI) activities can improve health care but must be conducted ethically. The Hastings Center convened leaders and scholars to address ethical requirements for QI and their relationship to regulations protecting human subjects of research. The group defined QI as systematic, data-guided activities designed to bring about immediate improvements in health care delivery in particular settings and concluded that QI is an intrinsic part of normal health care operations. Both clinicians and patients have an ethical responsibility to participate in QI, provided that it complies with specified ethical requirements. Most QI activities are not human subjects research and should not undergo review by an institutional review board; rather, appropriately calibrated supervision of QI activities should be part of professional supervision of clinical practice. The group formulated a framework that would use key characteristics of a project and its context to categorize it as QI, human subjects research, or both, with the potential of a customized institutional review board process for the overlap category. The group recommended a period of innovation and evaluation to refine the framework for ethical conduct of QI and to integrate that framework into clinical practice.


Abstract: Today, health systems around the world are under pressure to create greater value for patients and society; increasing access, improving client orientation and responsiveness, reducing medical errors and safety, re-straining utilization via managed care, and implementing priority allocation of resources for high-burden health problems are examples of strategies towards this end. The quality paradigm by virtue of its strategic consumer focus and its methods for achieving operational excellence has proved an effective approach for creating higher value in many sectors. If applied in a deliberate and holistic manner, the quality paradigm can bring about a more cost-effective organization of the health systems. In this article, we apply quality concepts to healthcare in a conceptual format; we characterize the health system’s customers and outputs with their quality dimensions. The product of this effort is a blueprint for a customer-driven health system which identifies six types of customers, nine types of outputs and the associated operations. As a preliminary step, a new analysis and definition of health and disease is provided. Rethinking the structure of health system in this manner and the related conceptual model can guide medical research, health sciences education, and health services policy, and help the practitioner to integrate all modern trends in healthcare delivery.


Abstract: Compared to other health care professions such as medicine, nursing and pharmacy, few studies have been conducted to examine the nature of practice errors in occupational and physical therapy. In an ongoing study to determine root causes, typographies and impact of occupational and physical therapy error on patients, focus group interviews have been conducted across the United States. A substantial number of harmful practice errors and/or other patient safety events (deviations or accidents) have been identified. Often these events have had moral dimensions that troubled the therapist involved. In this article, six of these transcribed cases are analyzed, using predominant bioethical theories, ethical principles and professional codes of ethics. The cases and their analyses are intended to be exemplary, improving the readers’ ability to discern and critically address similar such events. Several patient safety strategies are suggested that might have prevented the events described in these cases.


HEALTH CARE RATIONING See RESOURCE ALLOCATION

HEALTH CARE RIGHTS See RIGHT TO HEALTH CARE

HEALTH, CONCEPT OF

See also MENTAL HEALTH, CONCEPT OF


Davis, Kathy. Rethinking “normal” [reviews of No Child Left Different, edited by Sharon Olm; Cutting to the Core: Exploring the Ethics of Contested Surgeries, edited by David Benatar; Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality, edited by Erik Parens]. *Hastings Center Report* 2007 May-June; 37(3): 44-47. NRCBL: 4.2; 9.5.7; 9.7; 9.5.9.


Tarzian, Anita J. Disability and slippery slopes [Perspective]. *Hastings Center Report* 2007 September-October; 37(5): inside back cover. NRCBL: 4.2; 8.3.2; 9.5.1.


Abstract: The starting point for the contemporary debate about theories of health should be the holistic theory of Lennart Nordenfelt, claims George Khushf, not the refuted theory of Christopher Boorse. The present paper is an attempt to challenge Nordenfelt and to present an alternative theory to his and other theories, including Boorse’s. The main problems with Nordenfelt’s theory are that it is relativistic, that it leads to counter-intuitive results as to what goals can count as healthy, that it focuses on the wrong kind of abilities, that it makes measuring health extra difficult, and that it does not give us a sufficient account of health, at most a necessary one. The alternative theory proposed is two-dimensional. First, health is to have developed the abilities and dispositions that members of one’s culture typically develop, and be able to use them, in acceptable circumstances; and second, health is to experience positive moods and sensations, the kinds that have internal causes. The theory solves the problems attached to Nordenfelt’s theory by not being individual relativistic, by eliminating the goals in the definition, by giving an alternative interpretation of “ability,” by making health easier to measure, and by adding the dimension of well-being that, together with health as ability, not only gives us a necessary, but also a sufficient, account of health.


HOSPITAL ETHICS COMMITTEES See ETHICISTS AND ETHICS COMMITTEES

HUMAN EXPERIMENTATION

See also AIDS/ HUMAN EXPERIMENTATION; BEHAVIORAL RESEARCH; BIOMEDICAL RESEARCH


Abstract: John Harris suggests that participation in or support for research, particularly medical research, is a moral duty. One kind of defence of this position rests on an appeal to the past, and produces two arguments. The first of these arguments is that it is unfair to accept the benefits of research without contributing something back in the form of support for, or participation in, research. A second argument is that we have a social duty to maintain those practices and institutions that sustain us, such as those which contribute to medical knowledge. This argument is related to the first, but it does not rely so heavily on fairness. Another kind of defence of the duty to research rests on an appeal to the future benefits of research: research is an effective way to discharge a duty to rescue others from serious illness or death, therefore we have a duty to research. I suggest that all three of Harris’ lines fail to provide a compelling duty to research and spell out why. Moreover, not only do the lines of argument fail in their own terms: in combination, they turn out to be antagonistic to the very position that Harris wants to defend. While it is not my intention here to deny that there might be a duty to research, I claim that Harris’ argument for the existence of such a duty is not the best way to establish it.


Decullier, Evelyne; Chapusis, François. Impact of funding on biomedical research: a retrospective cohort study.

NRCBL: National Reference Center for Bioethics Literature Classification Scheme

See inside front cover for terms.
Abstract: The recent TeGenero phase I trial of a novel monoclonal antibody in healthy volunteers produced a drastic inflammatory reaction in participants receiving the experimental agent. Commentators on the ethics of the research have focused considerable attention on the role of financial considerations: the for-profit status of the biotechnology company and Contract Research Organization responsible respectively for sponsoring and conducting the trial and the amount of monetary compensation to participants. We argue that these financial considerations are largely irrelevant and distort ethical appraisal of this tragic research. Except for administering the antibody to all 6 participants nearly simultaneously, the trial appears to fulfill all of the critical ethical requirements for clinical research—social value, scientific validity, fair subject selection, favorable risk-benefit ratio, independent review, informed consent, and respect for enrolled participants.


Frewer, Andreas. Medical research, morality, and history: the German journal Ethik and the limits of human experimentation. In: LaFleur, William R.; Böhme, Gernot; Shimazono, Susumu, eds. Dark Medicine: Rationalizing Medical Research. Bloomington: Indiana University Press, 2007: 30-45. NRCBL: 18.1; 2.2; 10; 18.2; 1.3.5; 15.5; 21.4.


Hardell, Lennart; Walker, Martin J.; Walhjalt, Bo; Friedman, Lee S.; Richter, Elihu D. Secret ties to industry and conflicting interests in cancer research. American Journal of Industrial Medicine 2007 March; 50(3): 227-233 [See correction: American Journal of Industrial Medicine 2007 March; 50(3): 234]. NRCBL: 18.1; 1.3.2; 9.5.1; 7.1; 9.3.1.


Abstract: “Therapeutic misconception” has been misconstrued, and some of the newer, mistaken interpretations are troublesome. They exaggerate the distinction between research and treatment revealing problems in the foundations of research ethics and possibly weakening informed consent.


Klitzman, Robert; Albala, Ilene; Siragusa, Joseph; Nelson, Kristen N.; Appelbaum, Paul S. The reporting of monetary compensation in research articles. Journal of Empirical Research on Human Research Ethics 2007 December; 2(4): 61-67. NRCBL: 18.1; 7.3; 9.3.1; 8.2; 1.3.7; 18.2. SC: em.

Abstract: Study participant compensation is of increasing concern, yet few investigations have explored it; none have examined whether published journal articles report it. Medline searches for articles in six areas—HIV, substance abuse (heroin and cocaine), depression, essential hypertension, and cardiac surgery—reveal very low mention of payment (0–32.1%). Of 207 articles, only 13.5% mentioned financial compensation in any way, and only 11.1% listed amounts. Of the 207 studies, 92 involved more than minimal risk interventions, but were not more likely to mention compensation. Studies that included substance users were significantly more likely than others to mention payment (p .001). These overall low rates are concerning as they can hamper evaluation of ethical issues, and impact study replicability. Publication requirements should consider discussion of compensation.


Liao, S. Matthew; Goldschmidt-Clermont, Pascal J.; Sugarman, Jeremy. Ethical and policy issues relating to progenitor-cell-based strategies for prevention of atherosclerosis. Journal of Medical Ethics 2007 November; 33(11): 643-646. NRCBL: 18.1; 9.1; 9.4; 19.5. Note: A report of the Working Group on Ethics of Progenitor Cell-based Strategies for Disease Prevention. Abstract: OBJECTIVE: To examine important ethical and societal issues relating to the use of progenitor-cell-based strategies for disease prevention, particularly atherosclerosis. BACKGROUND: Several nascent lines of evidence suggest the feasibility of using progenitor cells to reverse the health consequence of atherosclerosis. Such potential uses of progenitor cells are scientifically exciting, yet they raise important ethical and societal issues. METHOD: The Working Group on Ethics of Progenitor Cell-based Strategies for Disease Prevention met to discuss the relevant issues. Several drafts of a report were then circulated to the entire Working Group for comments until a consensus was reached. RESULTS: Scientific evidence suggests the appropriateness of using progenitor-cell-based strategies for some rare conditions involving atherosclerosis, but additional preclinical data are needed for other, more prevalent conditions before human trials begin. All such trials raise a set of ethical issues, especially since trials aimed at prevention rather than treatment may involve persons who do not yet have disease but will be exposed to the risks of interventions. In addition, enrolment in prevention trials may be hazardous and harmful if participants erroneously believe experimental interventions will necessarily prevent disease. Finally, given the high prevalence of atherosclerosis, there are some important public policy implications of taking such an approach to prevention, including the sources of progenitor cells for such interventions as well as the allocation of health resources. CONCLUSION: Potential uses of progenitor-cell-based strategies for preventing atherosclerosis must be considered in the context of a range of social and ethical issues.


Abstract: This article argues that lingering uncertainty about the normative foundations of research ethics is perpetuated by two unfounded dogmas of research ethics. The first dogma is that clinical research, as a social activity, is an inherently utilitarian endeavor. The second dogma is that an acceptable framework for research ethics must impose constraints on this endeavor whose moral force is grounded in role-related obligations of either physicians or researchers. This article argues that these dogmas are common to traditional articulations of the equipoise requirement and to recently articulated alternatives, such as the non-exploitation approach. Moreover, important shortcomings of these approaches can be traced to their acceptance of these dogmas. After highlighting these shortcomings, this article illustrates the benefits of rejecting these dogmas by sketching the broad outlines of an alternative called the “integrative approach” to clinical research.


Abstract: The attitudes of women patients with cancer were explored when they were invited to participate in one of three randomised trials that included chemotherapy at two university centres and a satellite centre. Fourteen patients participating in and 15 patients declining trials were interviewed. Analysis was based on the constant comparative method. Most patients voiced positive attitudes towards clinical research, believing that trials are necessary for further medical development, and most spontaneously argued that participation is a moral obligation. Most trial decliners, however, described a radical change in focus as they faced the actual personal choice. Almost no one got an impression of clinical equipoise between treatments in the trials, and most patients expressed discomfort with randomisation. A patient’s choice to participate was mainly determined by whether the primary focus was on treatment effect or on adverse effects. Both knowledge about and feelings towards trials originated mostly from the media, although paradoxically the media were largely seen as untrustworthy. Mistrust was shown towards the pharmaceutical industry, and although most patients originally trusted that doctors primarily pursued the interest of patients, they did not trust the adequacy of doctors or industry in maintaining self-regulation. Thus, public control measures were judged to be essential.


HUMAN EXPERIMENTATION

SECTION I


Shapshay, Sandra; Pimple, Kenneth D. Participation in biomedical research is an imperfect moral duty: a response to John Harris. Journal of Medical Ethics 2007 July; 33(7): 414-417. NRCBL: 18.1; 1.1; 1.3.9. SC: an. Comments: John Harris. Scientific research is a moral duty. Journal of Medical Ethics 2005; 31: 242-248. Abstract: In his paper “Scientific research is a moral duty”, John Harris argues that individuals have a moral duty to participate in biomedical research by volunteering as research subjects. He supports his claim with reference to what he calls the principle of beneficence as embodied in the “rule of rescue” (the moral obligation to prevent serious harm), and the principle of fairness embodied in the prohibition on “free riding” (we are obliged to share the sacrifices that make possible social practices from which we benefit). His view that biomedical research is an important social good is agreed upon, but it is argued that Harris succeeds only in showing that such participation and support is a moral good, among many other moral goods, while failing to show that there is a moral duty to participate in biomedical research in particular. The flaws in Harris’s arguments are detailed here, and it is shown that the principles of beneficence and fairness yield only a weaker discretionary or imperfect obligation to help others in need and to reciprocate for sacrifices that others have made for the public good. This obligation is discretionary in the sense that the individuals are free to choose when, where, and how to help others in need and reciprocate for earlier sacrifices. That Harris has not succeeded in claiming a special status for biomedical research among all other social goods is shown here.


**HUMAN EXPERIMENTATION/ ETHICS COMMITTEES AND POLICY GUIDELINES**


Abstract: BACKGROUND: Ethics committees and their system of research protocol peer-review are currently used worldwide. To ensure an international standard for research ethics and safety, however, data is needed on the quality and function of each nation’s ethics committees. The purpose of this study was to describe the characteristics and developments of ethics committees established at medical schools and general hospitals in Japan. METHODS: This study consisted of four national surveys sent twice over a period of eight years to two separate samples. The first target was the ethics committees of all 80 medical schools and the second target was all general hospitals with over 300 beds in Japan (n = 1457 in 1996 and n = 1491 in 2002). Instruments contained four sections: (1) committee structure, (2) frequency of annual meetings, (3) committee function, and (4) existence of a set of guidelines for the refusal of blood transfusion by Jehovah’s Witnesses. RESULTS: Committee structure was overall interdisciplinary. Frequency of annual meetings increased significantly for both medical school and hospital ethics committees over the eight years. The primary activities for medical school and hospital ethics committees were research protocol reviews and policy making. Results also showed a significant increase in the use of ethical guidelines, particularly those related to the refusal of blood transfusion by Jehovah’s Witnesses, among both medical school and hospital ethics committees. CONCLUSION: Overall findings indicated a greater recognized degree of responsibilities and an increase in workload for Japanese ethics committees.

American Association of University Professors. Protecting human beings: institutional review boards and social science research. *Academe* 2001 May/June; 87(3): 55-67. NRCBL: 18.2; 1.3.9; 1.3.3; 1.3.5.

Anderson, Melissa S.; Horn, Aaron S.; Risbey, Kelly R.; Ronning, Emily A.; De Vries, Raymond; Martinson, Brian C. What do mentoring and training in the responsible conduct of research have to do with scientists’ misbehavior? Findings from a national survey of NIH-funded scientists. *Academic Medicine* 2007 September; 82(9): 853-860. NRCBL: 18.2; 2.3; 1.3.9. SC: em.


Becker, Gary J. Financial relationships with industry and device research involving non-Food and Drug Administration-approved use: a perspective. *Radiology* 2006 June; 239(3): 626-628. NRCBL: 18.2; 9.3.1; 1.3.2; 7.3; 18.6.


Bramstedt, Katrina A.; Ford, Paul J. Protecting human subjects in neurosurgical trials: the challenge of psychogenic dystonia. *Contemporary Clinical Trials* 2006 April; 27(2): 161-164. NRCBL: 18.2; 18.3; 18.5.6; 7.1; 17.1.


Braunschweiger, Paul; Goodman, Kenneth W. The CITI program: an international online resource for educa-

NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms. 249
tion in human subjects protection and the responsible conduct of research. *Academic Medicine* 2007 September; 82(9): 861-864. NRCBL: 18.2; 2.3.

Brown, Stephen D.; Daly, Jennifer C.; Kalish, Leslie A.; McDaniel, Samuel A. Financial disclosures of scientific papers presented at the 2003 RSNA Annual Meeting: association with reporting of non-Food and Drug Administration-approved uses of industry products. *Radiology* 2006 June; 239(3): 849-855. NRCBL: 18.2; 9.3.1; 1.3.2; 7.3; 18.6; 1.3.7.


Bulger, Ruth Ellen; Heitman, Elizabeth. Expanding responsible conduct of research instruction across the university. *Academic Medicine* 2007 September; 82(9): 876-878. NRCBL: 18.2; 2.3; 1.3.9.


Abstract: Background: The Declaration of Helsinki, the World Medical Association’s (WMA) statement of ethical guidelines regarding medical research, is published in the three official languages of the WMA: English, French and Spanish. Methods: A detailed comparison of the three official language versions was carried out to determine ways in which they differed and ways in which the wording of the three versions might illuminate the interpretation of the document. Results: There were many minor linguistic differences between the three versions. However, in paragraphs 1, 6, 29, 30 and in the note of clarification to paragraph 29, there were differences that could be considered potentially significant in their ethical relevance. Interpretation: Given the global status of the Declaration of Helsinki and the fact that it is translated from its official versions into many other languages for application to the ethical conduct of research, the differences identified are of concern. It would be best if such differences could be eliminated but, at the very least, a commentary to explain any differences that are unavoidable on the basis of language or culture should accompany the Declaration of Helsinki. This evidence further strengthens the case for international surveillance of medical research ethics as has been proposed by the WMA.


Catholic Medical Association; National Catholic Bioethics Center. Catholic principles and guidelines for clinical research. *National Catholic Bioethics Quarterly* 2007 Spring; 7(1): 153-165. NRCBL: 18.2; 18.5.1; 1.2; 2.4.


Corbie-Smith, Giselle M.; Durant, Raegan W.; St George, Diane Marie M. Investigators’ assessment of NIH mandated inclusion of women and minorities in research. *Contemporary Clinical Trials* 2006 December; 27(6): 571-579. NRCBL: 18.2; 18.5.3; 1.3.5; 18.6.

Abstract: In 1798 Dr Edward Jenner published his famous account of “vaccination”. Some claim that a Research Ethics Committee, had it existed in the 1790s, might have rejected his work. I provide the historical context of his work and argue that it addressed a major risk to the health of the community, and, given the devastating nature of smallpox and the significant risk of variolation, the only alternative preventative measure, Jenner’s study had purpose, justification and a base in the practice of the day.


Abstract: Recent policy in relation to clinical research proposals in the UK has distinguished between two types of review: scientific and ethical. This distinction has been formally enshrined in the recent changes to research ethics committee (REC) structure and operating procedures, introduced as the UK response to the EU Directive on clinical trials. Recent reviews and recommendations have confirmed the place of the distinction and the separate review processes. However, serious reservations can be mounted about the science/ethics distinction and the policy of separate review that has been built upon it. We argue here that, first, the science/ethics distinction is incoherent, and, second, that REC’s should not only be permitted to consider a study’s science, but that they have an obligation to do so.


Abstract: Since 1996, U.S. federal regulations allow research without informed consent to study emergency conditions, if there is currently no satisfactory treatment for the condition, no time to obtain advance consent from the patient or representative, and if there is community involvement through a public disclosure and community consultation process. REB experiences since then are unknown. We surveyed REB chairpersons at the 126 United States medical schools to quantify reviewed protocols and identify attitudes about the rule, to better understand the rule’s impact on REBs. Sixty-nine surveys were returned (55%). Fifty-two respondents reviewing human research had heard of the Rule. Forty-eight percent (25/52) had reviewed such a study; 40% of those had rejected at least one. Seventy-eight percent believe the rule protects human subjects, and 88% feel prepared to implement them. REB views differed from public opinion on how best to enact notification and consultation.


Ding, Eric L.; Powe, Neil R.; Manson, JoAnn E.; Sherber, Noëlle S.; Braunstein, Joel B. Sex differences in perceived risks, distrust, and willingness to participate in clinical trials. *Archives of Internal Medicine* 2007 May 14; 167(9): 905-912. NRCBL: 18.2; 18.5.1; 18.5.3; 10. SC: em.

Abstract: Background: Multiple sex differences exist in cardiovascular disease burden and treatment efficacies; adequate participation of both sexes is crucial to clinical research. Methods: A multicenter, double-blind, randomized study evaluated sex and trial scenarios on willingness to participate (WTP) in cardiovascular prevention trials and examined sex differences in perceived risks and distrust. Hypothetical trial scenarios randomized multifactorial vignettes of adverse effects, trial durations, sponsors, financial incentives, and conflicts of interest. Results: With 783 participants across 13 clinical centers, women showed lower distrust of medical researchers, perceived greater risk of myocardial infarction, and perceived greater risk of harm from trial participation than men. Men had 15% greater WTP than women (33.1% vs 28.7%; relative risk [RR], 1.15; 95% confidence interval [CI], 1.02-1.31); adjusting for explanatory mediators, we found that sex differences in perceived risks and benefits explained the sex gap in WTP. Although greater perceived probability of harm (RR, 0.41; 95% CI, 0.23-0.72), health benefit (RR, 2.99; 95% CI, 1.63-5.46), and quality of care (RR, 1.71; 95% CI, 1.12-2.61) strongly predicted WTP (for perceived probabilities 80% vs %) similarly in both sexes, and perceptions of distrust and myocardial infarction risk predicted WTP differently between sexes (P.01 for interactions), age, history of coronary artery disease, hypertension, and diabetes mellitus increased WTP in men but not in women (P.05 for sex interactions). Compared with no financial conflict, disclosure of investigator patent ownership increased WTP in women, while it decreased WTP in men (P = .02 for sex interaction). Monetary incentives were overall more effective on WTP in women (P = .03 for sex interaction). Conclusions: In this multicenter study, women perceived greater risk of harm and myocardial infarction and showed lower WTP in cardiovascular prevention trials. Evidence underscores the importance of sex in influencing clinical trial enrollment.

193-194. NRCBL: 18.2; 5.3; 9.3.1; 9.2; 9.4. Identifiers: health services research.


Abstract: This paper introduces taxonomy of clinical uncertainties and argues that the choice of scientific method should match the underlying level of uncertainty. Clinical trial is one of these methods aiming to resolve clinical uncertainties. Whenever possible these uncertainties should be quantified. The paper further shows that the still ongoing debate about the usage of "equipoise" vs. "uncertainty principle" vs. "indifference" as an entry criterion to clinical trials actually refers to the question "whose uncertainty counts". This question is intimately linked to the control of research agenda, which is not quantifiable and hence is not solvable to equal acceptability to all interested parties. The author finally shows that there is a predictable relation between [acknowledgement of] uncertainty (the moral principle) on which trials are based and the ultimate outcomes of clinical trials. That is, [acknowledgement of] uncertainty determines a pattern of success in medicine and drives clinical discoveries.


Effa, Pierre; Massougbodji, Achille; Ntoumi, Francine; Hirsch, Francois; Debois, Henri; Vicari, Marissa; Derme, Assetou; Ndemanga-Kamoume, Jacques; Ngueombo, Joseph; Impouma, Benido; Akue, Jean-Paul; Elhounan, Armand; Dieye, Alioune; Kilama, Wen. Ethics committees in western and central Africa: concrete foundations. Developing World Bioethics 2007 December; 7(3): 136-142. NRCBL: 18.2; 18.5.9; 21.1.

Abstract: The involvement of developing countries in international clinical trials is necessary for the development of appropriate medicines for local populations. However, the absence of appropriate structures for ethical review represents a barrier for certain countries. Currently there is very little information available on existing structures dedicated to ethics in western and central Africa. This article briefly describes historical milestones in the development of networks dedicated to capacity building in ethical review in these regions and outlines the major conclusions of two workshops on this issue, which were held in September and October 2002 in Libreville, Gabon, and Paris, France. The workshops were the culmination of collaboration between the African Malaria Network Trust (AMANET) and the Pan African Bioethics Initiative (PABIN). They produced an update on ethics organizations with regard to mission, function, activities, members, and contact people, in eight countries within the regions discussed. As a result of the commitment of mandated delegates, a further prominent outcome followed these workshops: the creation of national structures, where none existed before, dedicated to the ethical review of clinical trials.


Abstract: The ethical review process is an important component of contemporary health research worldwide. Sudan started an ethical review process rather late in comparison with other countries. In this study, we evaluate the structure and functions of existing ethics review committees. We also explore the knowledge and attitudes of Sudanese researchers toward the ethical review process and their experience with existing ethics review committees. There are four ethics review committees in the country; these committees have no institutional regulations to govern their functions. Furthermore, Sudan also lacks national guidelines. Ethical reviews are carried out primarily for studies seeking international funding and are almost always governed by the funding agencies’ requirements. Nearly half of respondents (46.3%) knew about the existence of research ethics committees in Sudan. Researchers reported a variety of experiences with the ethical review process; most of them were unable to define ‘ethics committee’.

Emanuel, Ezekiel J.; Lemmens, Trudo; Elliot, Carl. Should society allow research ethics boards to be run as for-profit enterprises? PLoS Medicine 2006 July; 3(7): e309. NRCBL: 18.2; 9.3.1; 1.3.2.


Abstract: The recently published Report of the AHAG on the Operation of NHS Research Ethics Committees (the Warner Report) advocates major reforms of the NHS research ethics committees system. The main implications of the proposed changes and their probable effects on the major stakeholders are described.

SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
SECTION I  HUMAN EXPERIMENTATION/ ETHICS COMMITTEES AND POLICY GUIDELINES

Espirit Group; Pace, Christine; Grady, Christine; Wendler, David; Bebchuk, Judith D.; Tavel, Jorge A.; McNay, Laura A.; Forster, Heidi P.; Killen, Jack; Emanuel, Ezekiel J. Post-trial access to tested interventions: the views of IRB/REC chair, investigators, and research participants in a multinational HIV/AIDS study. *AIDS Research and Human Retroviruses* 2006 September; 22(9): 837-841. NRCBL: 18.2; 1.3.2; 9.7; 9.5.6.


Abstract: An ethics/institutional review board(IRB) was established according to International standards at the University of Ibadan in Nigeria. To achieve this, a private-public partnership was developed to support a review of prevailing practice and the development of necessary infrastructure for an effective IRB. An internationally registered and well-constituted IRB with a federal-wide assurance (FWA) from the National Institute of Health in the United States was established within a year. Over a 3-year period, the number of proposals reviewed increased by 150% while time to approval decreased by 62%. International collaboration and external research funding has increased substantially. These findings support our initial supposition that the development of a properly functioning IRB can be a catalyst for increased research productivity at academic centers in developing countries while ensuring the protection of vulnerable human research subjects. The University of Ibadan is now assisting other academic Institutions in Nigeria and sub-Saharan Africa with the establishment of their own IRBs.


Fernandez, Conrad V. Our moral obligations in caring for patients with orphan cancers [editorial]. *CMAJ/JAMC: Canadian Medical Association Journal* 2007 January 30; 176(3): 297, 299. NRCBL: 18.2; 18.5.2; 9.3.1; 9.5.7.


Fuchs, Thomas. Ethical issues in neuroscience. *Current Opinion in Psychiatry* 2006 November; 19(6): 600-607. NRCBL: 18.2; 18.5.1; 17.1; 17.6.


Abstract: As clinicians, researchers, bioethicists, and members of society, we face a number of moral dilemmas concerning randomized clinical trials. How we manage the starting and stopping of such trials — how we conceptualize what evidence is sufficient for these decisions — has implications for both our obligations to trial participants and for the nature and security of the resultant medical knowledge. One view of how this is to be done, “clinical equipoise,” recently has been given an extended defense by Paul Miller and Charles Weijer in their article “Rehabilitating Equipoise.” The present paper critiques this position and Miller and Weijer’s defense of it. I argue that their attempted rehabilitation fails. Their analysis suffers from a number of confusions, as well as a failure to make crucial distinctions, adequately to clarify key concepts, or to think through exactly what needs to be established to justify their claim. We are left with little reason to uphold the clinical equipoise criterion.


Abstract: In this article, I review and expand upon arguments showing that Freedman’s so-called “clinical equipoise” criterion cannot serve as an appropriate guide and justification for the moral legitimacy of carrying out randomized clinical trials. At the same time, I try to explain...
why this approach has been given so much credence despite compelling arguments against it, including the fact that Freedman’s original discussion framed the issues in a misleading way, making certain things invisible: Clinical equipoise is conflated with community equipoise, and several versions of each are also conflated. But a misleading impression is given that, rather than distinct criteria being arbitrarily conflated, a puzzle is solved and a number of features unified. Various issues are pushed under the rug, hiding flaws of the “clinical equipoise” approach and thus deceiving us into thinking that we have a solution when we do not. Particularly significant is the ignoring of the crucial distinction between the individual patient decision and the policy decision.


Gonzalez, Luis S., 3rd; Miller, Stephanie; Barnhart, Donna; Leifheit, Michael. Institutional review board approval of projects presented as posters at an ASHP midyear clinical meeting. American Journal of Health-System Pharmacy 2005 September 15; 62(18): 1890-1893. NRCBL: 18.2; 9.7; 9.8.


Goodman, Steven N. Stopping at nothing? Some dilemmas of data monitoring in clinical trials [commentary]. Annals of Internal Medicine 2007 June 19; 146(12): 882-887. NRCBL: 18.2; 7.1. Abstract: This commentary reviews the argument that clinical trials with data monitoring committees that use statistical stopping guidelines should generally not be stopped early for large observed efficacy differences because efficacy estimates may be exaggerated and there is minimal information on treatment harms. Overall, the average of estimates from trials that use these boundaries differs minimally from the true value. Estimates from a given trial that seem implausibly high can be moderated by using Bayesian methods. Data monitoring committees are not ethically required to precisely estimate a large efficacy difference if that difference differs convincingly from zero, and the requirement to detect harms and balance efficacy against harm depends on whether the nature of the harm is known or unknown before the trial.


Green, David; Cushman, Mary; Dermond, Norma; Johnson, Eric A.; Castro, Cecilia; Arnett, Donna; Hill, Joel; Manolio, Teri A. Obtaining informed consent for genetic studies: the multietnic study of atherosclerosis. American Journal of Epidemiology 2006 November 1; 164(9): 845-851. NRCBL: 18.2; 18.5.1; 15.3; 18.3; 8.3.4.

Greene, Sarah M.; Geiger, Ann M. A review finds that multicenter studies face substantial challenges but strategies exist to achieve Institutional Review Board approval. Journal of Clinical Epidemiology 2006 August; 59(8): 784-790. NRCBL: 18.2; 18.1; 18.6. SC: em.

Greene, Sarah M.; Geiger, Ann M.; Harris, Emily L.; Altschuler, Andrea; Neklyudov, Larissa; Barton, Mary B.; Rolnick, Sharon J.; Elmore, Joann G.; Fletcher, Suzanne. Impact of IRB requirements on a multicenter survey of prophylactic mastectomy outcomes. Annals of Epidemiology 2006 April; 16(4): 275-278. NRCBL: 18.2; 18.5.3; 9.5.1; 7.1.

Griffin, Joan M.; Struve, James K.; Collins, Dorothy; Liu, An; Nelson, David B.; Bloomfield, Hanna E. Long term clinical trials: how much information do participants retain from the informed consent process? Contemporary Clinical Trials 2006 October; 27(5): 441-448. NRCBL: 18.2; 18.3.


Hadskis, Michael R. Giving voice to research participants: should IRBs hear from research participant representatives? Accountability in Research 2007 July-September; 14(3): 155-177. NRCBL: 18.2; 18.6.

SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
Abstract: The current decision-making model for the review of human research contains inadequate mechanisms to ensure that the interests and perspectives of research participants are considered by Institutional Review Boards, whose decisions may profoundly affect the safety and well-being of participants. As a result, this model is far from being optimized to realize Institutional Review Boards’ principal mandate and undermines the credibility of the research review process. This article proposes a procedural mechanism that would ameliorate these systemic deficiencies by allowing “research participant representatives” to give voice to participants during the research review process.

Hardy, Pollyahanna.; Clemens, Felicity. Stopping a randomized trial early: from protocol to publication. Commentary to Thome et al.: outcome of extremely preterm infants randomized at birth to different PaCO2 targets during the first seven days of life (Biology of the Neonate 2006; 90: 218-225). Biology of the Neonate 2006; 90(4): 226-228. NRCBL: 18.2; 18.6.


Hausman, Daniel M. Third-party risks in research: should IRBs address them? IRB: Ethics and Human Research 2007 May-June; 29(3): 1-5. NRCBL: 18.2; 18.3.

Healing, Ben; Murtagh, Madeleine; Rapley, Tim; May, Carl; Graham, Ruth; Kaner, Eileen; Thomson, Richard. Patients or research subjects? A qualitative study of participation in a randomised controlled trial of a complex intervention. Patient Education and Counseling 2006 August; 62(2): 260-270. NRCBL: 18.2; 18.5.1; 18.3; 8.1.


Heitman, Elizabeth; Olsen, Cara H.; Anestidou, Lida; Bulger, Ruth Ellen. New graduate students’ baseline knowledge of the responsible conduct of research. Academic Medicine 2007 September; 82(9): 838-845. NRCBL: 18.2; 2.3. SC: em.


Huang, David T.; Hadian, Mehrnaz. Bench-to-bedside review: human subjects research — are more standards needed? Critical Care 2006; 10(6): 244. NRCBL: 18.2; 18.6; 18.3.

Hunter, David. Efficiency and the proposed reforms to the NHS research ethics system. Journal of Medical Ethics 2007 November; 33(11): 651-654. NRCBL: 18.2. Identifiers: Great Britain (United Kingdom); National Health Service.

Abstract: Significant changes are proposed for the research ethics system governing the review of the conduct of medical research in the UK. This paper examines these changes and whether they will meet the aimed-for goal of improving the efficiency of the research ethics system. The author concludes that, unfortunately, they will not and thus should be rejected.


Abstract: Presently, there is a movement in the UK research governance framework towards what is referred to as proportional ethical review. Proportional ethical review is the notion that the level of ethical review and scrutiny given to a research project ought to reflect the level of ethical risk represented by that project. Relatively innocuous research should receive relatively minimal review and relatively risky research should receive intense scrutiny. Although conceptually attractive, the notion of proportional review depends on the possibility of effectively identifying the risks and ethical issues posed by an application with some process other than a full review by a properly constituted research ethics committee. In this paper, it is argued that this cannot be achieved and that the only appropriate means of identifying risks and ethical issues is consideration by a full committee. This implies that the suggested changes to the National Health Service research ethics system presently being consulted on should be strenuously resisted.

Huntington Study Group. Event Monitoring Committee; Erwin, Cheryl; Hersch, Steven. Monitoring reportable events and unanticipated problems: the PHAROS and PREDICT studies of Huntington disease. IRB: Ethics and Human Research 2007 May-June; 29(3): 11-16. 18 fn. NRCBL: 18.2; 15.1. Identifiers: Prospective Huntington At Risk Observational Study; Neurobiological Predictors of Huntington Disease [PREDICT-HD].

Keywords: *adverse effects; *clinical trials; *data monitoring committees; *genetic research; *Huntington disease; *research subjects; *risk; government regulation; information dissemination; multicenter studies; nontherapeutic research; research design; research ethics committees; research findings; risks and benefits; Proposed Keywords: *observation; prospective studies; Keyword Identifiers: *Neurobiological Predictors of Huntington Disease [PREDICT-HD]; *Prospective Huntington At Risk Observational Study; United States

INSECT Study Group; Seiler, C.M.; Kellmeyer, P.; Kienle, P.; Büchler, M.W.; Knaebel, H.-P. Assessment of the ethical review process for non-pharmacological

Abstract: OBJECTIVE: To examine the current ethical review process (ERP) of ethics committees in a non-pharmacological trial from the perspective of a clinical investigator. DESIGN: Prospective collection of data at the Study Centre of the German Surgical Society on the duration, costs and administrative effort of the ERP of a randomised controlled multicentre surgical INSECT Trial (|interrupted or continuous Slowly absorbable sutures-Evaluation of abdominal Closure Techniques Trial, ISRCTN 24023541) between November 2003 and May 2005. SETTING: Germany. PARTICIPANTS: 18 ethics committees, including the ethics committee handling the primary approval, responsible overall for 32 clinical sites throughout Germany. 8 ethics committees were located at university medical schools (MSU) and 10 at medical chambers. Duration was measured as days between submission and receipt of final approval, costs in euros and administrative effort by calculation of the product of the total number of different types of documents and the mean number of copies required (primary approval acting as the reference standard). RESULTS: The duration of the ERP ranged from 1 to 176 (median 31) days. The median duration was 26 days at MSUs compared with 34 days at medical chambers. The total cost was euro2947. 1 of 8 ethics committees at universities (euro250) and 8 of 10 at medical chambers charged a median fee of euro162 (mean euro269.70). The administrative effort for primary approval was 30. Four ethics committees required a higher administrative effort for secondary approval (37, 39, 42 and 104). CONCLUSION: The ERP for non-pharmacological multicentre trials in Germany needs improvement. The administrative process has to be standardised: the application forms and the number and content of the documents required should be identical or at least similar. The fees charged vary considerably and are obviously too high for committees located at medical chambers. However, the duration of the ERP was, with some exceptions, excellent. A centralised ethics committee in Germany for multicentre trials such as the INSECT Trial can simplify the ERP for clinical investigators in and outside the country.


**Kalichman, Michael W.** Responding to challenges in educating for the responsible conduct of research. *Academic Medicine* 2007 September; 82(9): 870-875. NRCBL: 18.2; 2.3.

**Kalichman, Michael W.; Plemmons, Dena K.** Reported goals for responsible conduct of research studies. *Academic Medicine* 2007 September; 82(9): 846-852. NRCBL: 18.2; 2.3. SC: em.


**Kass, N.E.; Myers, R.; Fuchs, E.J.; Carson, K.A.; Flexner, C.** Balancing justice and autonomy in clinical research with healthy volunteers. *Clinical Pharmacology and Therapeutics* 2007 August; 82(2): 219-227. NRCBL: 18.2; 18.5.1; 1.1; 18.3.


**Khoo, Chong-Yew.** Ethical issues in ophthalmology and vision research. *Annals of the Academy of Medicine, Singapore* 2006 July; 35(7): 512-516. NRCBL: 18.2; 18.5.1; 8.4; 21.1; 18.6.


**Kojima, Somei; Waikagul, Jitra; Rojekittikhun, Wichit; Keicho, Naoto.** The current situation regarding the establishment of national ethical guidelines for biomedical research in Thailand and its neighboring countries. *Southeast Asian Journal of Tropical Medicine and Public Health* 2005 May; 36(3): 728-732. 11 refs. NRCBL: 18.2; 18.3; 15.1; 6. SC: rv. Keywords: *guidelines; *human experimentation; ethical review; ethics committees; genetic research; informed consent; international aspects; Keyword Identifiers: *Cambodia; *Myanmar; *Thailand
CHAPTER 1  HUMAN EXPERIMENTATION/ETHICS COMMITTEES AND POLICY GUIDELINES


Krishna, Anurag. The ethics of research in children [editorial]. *Indian Pediatrics* 2005 May; 42(5): 419-423. NRCBL: 18.2; 18.5.2; 18.5.9.


Kukla, Rebecca. Resituating the principle of equipoise: justice and access to care in non-ideal conditions. *Kennedy Institute of Ethics Journal* 2007 September; 17(3): 171-202. NRCBL: 18.2; 4.1.2; 1.1; 9.8; 9.5.6; 9.5.10; 18.5.9. SC: an.

Abstract: The principle of equipoise traditionally is grounded in the special obligations of physician-investigators to provide research participants with optimal care. This grounding makes the principle hard to apply in contexts with limited health resources, to research that is not directed by physicians, or to non-therapeutic research. I propose a different version of the principle of equipoise that does not depend upon an appeal to the Hippocratic duties of physicians and that is designed to be applicable within a wider range of research contexts and types—including health services research and research on social interventions. I consider three examples of ethically contentious research trials conducted in three different social settings. I argue that in each case my version of the principle of equipoise provides more plausible and helpful guidance than does the traditional version of the principle.


Ledford, Heidi. Trial and error: the ethics committees that oversee research done in humans have been attacked from all sides. *Nature* 2007 August 2; 448(7153): 530-532. NRCBL: 18.2; 1.3.2; 1.3.9; 18.6.


Lubowitz, James H. Randomize, then consent: a strategy for improving patient acceptance of participation in randomized controlled trials. *Arthroscopy* 2006 September; 22(9): 1007-1008. NRCBL: 18.2; 18.3; 18.5.1; 9.5.1.


Macduff, Colin; McKie, Andrew; Martindale, Sheelagh; Rennie, Anne Marie; West, Bernice; Wilcock, Sylvia. A novel framework for reflecting on the functioning of research ethics review panels. *Nursing Ethics* 2007 January; 14(1): 99-116. NRCBL: 18.2. SC: em.

Abstract: In the past decade structures and processes for the ethical review of UK health care research have undergone rapid change. Although this has focused users’ attention on the functioning of review committees, it remains rare to read a substantive view from the inside. This article presents details of processes and findings resulting from a novel structured reflective exercise undertaken by a newly formed research ethics review panel in a university school of nursing and midwifery. By adopting and adapting some of the knowledge to be found in the art and science of malt whisky tasting, a framework for critical reflection is presented and applied. This enables analysis of the main contemporary issues for a review panel that is primarily concerned with research into nursing education and practice. In addition to structuring the panel’s own literary narrative, the framework also generates useful visual representation for further reflection. Both the analysis of issues and the framework itself are presented as of potential value to all nurses, health care professionals and educationalists with an interest in ethical review.

MacNeil, S. Danielle; Fernandez, Conrad V. Attitudes of research ethics board chairs toward disclosure of research results to participants: results of a national survey.
Abstract: Background: The offer of aggregate study results to research participants following study completion is increasingly accepted as a means of demonstrating greater respect for participants. The attitudes of research ethics board (REB) chairs towards this practice, although integral to policy development, are unknown. Objectives: To determine the attitudes of REB chairs and the practices of REBs with respect to disclosure of results to research participants. Design: A postal questionnaire was distributed to the chairs of English-language university-based REBs in Canada. In total, 88 REB chairs were eligible. The questionnaire examined respondents’ attitudes towards offering participants completed study results, methods for delivering this information, and barriers to disclosing results. Findings: The response rate was 89.8%. Chairs were highly supportive (94.8%) of offering results to research participants. Only 19.5% of chairs responded that a policy or guideline that governed the return of research results to participants existed at their institution. Most chairs (72.0%) supported the idea of their REB instituting a set of guidelines recommending that researchers offer results to participants in a lay format. Chairs identified the major impediments to the implementation of programmes offering to return results to participants as being financial cost (57.5%) and retaining contact with research participants (78.1%). Conclusions: University-based REB chairs overwhelmingly support the offer of research results to participants. This is incongruent with the frequent lack of existing REB guidelines recommending this practice. REBs should support guidelines that diminish identified barriers and promote consistency in offering to return results.

Macrina, Francis L. Scientific societies and promotion of the responsible conduct of research: codes, policies, and education. Academic Medicine 2007 September; 82(9): 865-869. NRCBL: 18.2; 2.3; 7.3.


Maloney, Dennis M. Case study: university forms two new institutional review boards (IRBs) to rereview suspended studies. Human Research Report 2007 June; 22(6): 6-7. NRCBL: 18.2; 1.3.3; 18.6.

Maloney, Dennis M. Case study: university says it is doing what it can to earn right to resume research. Human Research Report 2007 July; 22(7): 6-7. NRCBL: 18.2; 1.3.3; 18.6.


Maloney, Dennis M. University explains how it will strengthen its support for institutional review boards (IRBs) [case study]. Human Research Report 2007 October; 22(10): 6-7. NRCBL: 18.2; 1.3.3. SC: cs.

Maloney, Dennis M. University says its institutional review board (IRB) policies and procedures were just misunderstood. Human Research Report 2007 January; 22(1): 6-7. NRCBL: 18.2; 18.5.5.


Mayer, Musa. Listen to all the voices: an advocate’s perspective on early access to investigational therapies. Clinical Trials 2006; 3(2): 149-153. NRCBL: 18.2; 18.5.1; 18.6; 9.7.

Mayers, Douglas L.; Chung, Jain; Kohlbrenner, Veronika M.; Hall, David B.; DeMasi, Ralph A.; Neubacher, Dietmar; Buss, Neil E.; Salgo, Miklos P. Seeking ethical designs for HIV clinical trials in treat-
ment-experienced patients: an industry perspective. *AIDS Research and Human Retroviruses* 2006 November; 22(11): 1110-1112. NRCBL: 18.2; 18.5.1; 1.3.2; 18.6.

McClure, Katie B.; Delorio, Nicole M.; Schmidt, Terri A.; Chiodo, Gary; Gorman, Paul. A qualitative study of institutional review board members’ experience reviewing research proposals using emergency exception from informed consent. *Journal of Medical Ethics* 2007 May; 33(5): 289-293. NRCBL: 18.2; 18.3. SC: em.

Abstract: BACKGROUND: Emergency exception to informed consent regulation was introduced to provide a venue to perform research on subjects in emergency situations before obtaining informed consent. For a study to proceed, institutional review boards (IRBs) need to determine if the regulations have been met. AIM: To determine IRB members’ experience reviewing research protocols using emergency exception to informed consent. METHODS: This qualitative research used semi-structured telephone interviews of 10 selected IRB members from around the US in the fall of 2003. IRB members were chosen as little is known about their views of exception to consent, and part of their mandate is the protection of human subjects in research. Interview questions focused on the length of review process, ethical and legal considerations, training provided to IRB members on the regulations, and experience using community consultation and notification. Content analysis was performed on the transcripts of interviews. To ensure validity, data analysis was performed by individuals with varying backgrounds: three emergency physicians, an IRB member and a layperson. RESULTS: Respondents noted that: (1) emergency exception to informed consent studies require lengthy review; (2) community consultation and notification regulations are vague and hard to implement; (3) current regulations, if applied correctly, protect human subjects; (4) legal counsel is an important aspect of reviewing exception to informed-consent protocols; and (5) IRB members have had little or no formal training in these regulations, but are able to access materials needed to review such protocols. CONCLUSIONS: This preliminary study suggests that IRB members find emergency exception to informed consent studies take longer to review than other protocols, and that community consultation and community notification are the most difficult aspect of the regulations with which to comply but that they adequately protect human subjects.

McDonald, Katherine; Hernandez, Bridget; Pleemmons, Dena; Simmerling, Mary. Privacy in organizational research. *Journal of Empirical Research on Human Research Ethics* 2007 March; 2(1): 69-73. NRCBL: 18.2; 8.4; 1.3.2; 18.5.1.


Merritt, Maria; Grady, Christine. Reciprocity and post-trial access for participants in antiretroviral therapy trials. *AIDS* 2006 September 11; 20(14): 1791-1794. NRCBL: 18.2; 9.2; 9.7; 9.5.6.


Abstract: The doctrine of clinical equipoise is appealing because it appears to permit physicians to maintain their therapeutic obligation to offer optimal medical care to patients while conducting randomized controlled trials (RCTs). The appearance, however, is deceptive. In this article we argue that clinical equipoise is defective and incoherent in multiple ways. First, it confounds the sound methodological principle that RCTs should begin with an honest null hypothesis with the questionable ethical norm that participants in these trials should never be randomized to an intervention known to be inferior to standard treatment. Second, the claim that RCTs preserve the therapeutic obligation of physicians misrepresents the patient-centered orientation of medical care. Third, the appeal to clinical equipoise as a basic principle of risk-benefit assessment for RCTs is incoherent. Finally, the difficulties with clinical equipoise cannot be resolved by viewing it as a prescriptive principle subject to exceptions. In the final sections of the article, we elaborate on the non-expropriation framework for the ethics clinical research and indicate issues that warrant further inquiry.

Miller, Franklin G.; Campbell, Eric G.; Vogeli, Christine; Weissman, Joel S. Financial relationships of institutional review board members [letter and reply]. *New England Journal of Medicine* 2007 March 1; 356(9): 965. NRCBL: 18.2; 5.3; 1.3.9; 9.3.1; 9.7.


Miller, Franklin G.; Wertheimer, Alan. Facing up to paternalism in research ethics. *Hastings Center Report* 2007 May-June; 37(3): 24-34. NRCBL: 18.2; 18.3; 9.1; 1.1.

Abstract: Franklin G. Miller and colleagues have stimulated renewed interest in research ethics through their work criticizing clinical equipoise. Over three years and some twenty articles, they have also worked to articulate a positive alternative view on norms governing the conduct of clinical research. Shared presuppositions underlie the positive and critical dimensions of Miller and colleagues’ work. However, recognizing that constructive contributions to the field ought to enjoy priority, we presently scrutinize the constructive dimension of their work. We argue that it is wanting in several respects.


Abstract: The authors respond to objections Fred Gifford has raised against their paper “Rehabilitating Equipoise.” They situate this exchange in the wider context of recent debate over equipoise, highlighting substantial points of agreement between themselves and Gifford. The authors offer a brief restatement of “Rehabilitating Equipoise” in which they amplify some of its core arguments. They then assess Gifford’s objections. Finding each to be unfounded, they argue that there is no justification for “pulling the plug” on clinical equipoise.

Miossec, Marie; Miossec, Pierre. New regulatory rules for clinical trials in the United States and the European Union: key points and comparisons. *Arthritis and Rheumatism* 2006 December; 54(12): 3735-3740. NRCBL: 18.2; 21.1; 1.3.5.


Moerman, C.J.; Haafkens, J.A.; Söderström, M.; Råsk, É.; Maguire, P.; Maschwetz-Schneider, U.; Norstedt, M.; Hahn, D.; Reinerth, H.; McKeavit, M. Gender equality in the work of local research ethics committees in Europe: a study of practice of five countries. *Journal of Medical Ethics* 2007 February; 33(2): 107-112. NRCBL: 18.2; 10; 18.5.5; 21.1. SC: em; rv. Identifiers: Austria; Germany; Ireland; Netherlands; Sweden.

Abstract: BACKGROUND: Funding organisations and research ethics committees (RECs) should play a part in strengthening attention to gender equality in clinical research. In the research policy of European Union (EU), funding measures have been taken to realise this, but such measures are lacking in the EU policy regarding RECs. OBJECTIVE: To explore how RECs in Austria, Germany, Ireland, The Netherlands and Sweden deal with gender equality issues by asking two questions: (1) Do existing procedures promote representation of women and gender expertise in the committee? (2) How are sex and gender issues dealt with in protocol evaluation? METHODS: Two RECs were selected from each country. Data were obtained through interviews with key informants and content analysis of relevant documents (regulations, guidelines and review tools in use in 2003). RESULTS: All countries have rules (mostly informal) to ensure the presence of women on RECs: gender expertise is not required. Drug study protocols are carefully evaluated, sometimes on a formal basis, as regards the inclusion of women of childbearing age. The reason for excluding either one of the sexes or including specific groups of women or making a gender-specific risk-benefit analysis are investigated by some RECs. Such measures are, however, neither defined in the regulations nor integrated in review tools. CONCLUSIONS: The RECs investigated in five European member states are found to pay limited attention to gender equality in their working methods and, in particular in protocol evaluation. Policy and regulations of EU are needed to strengthen attention to gender equality in the work of RECs.


Moran, Maureen B. Ethical issues in research with human subjects. *Journal of the American Dietetic Association* 2006 September; 106(9): 1346, 1348. NRCBL: 18.2; 18.3; 8.1; 8.4.

Moreno, Jonathan D. Stumbling toward bioethics: human experiments policy and the early Cold War. In: LaFleur, William R.; Böhme, Gernot; Shima, Susumu, eds. Dark Medicine: Rationalizing Medical Research. Bloomington: Indiana University Press, 2007: 138-146. NRCBL: 18.2; 18.3; 6; 18.5.1; 1.3.5; 16.2; 21.3; 2.2.


Abstract: Stopping randomized trials early because of an apparent benefit is becoming more common. To protect and promote the interests of trial participants, investigators may feel obligated to stop a trial early because of the apparent benefit of a study treatment (compared with placebo or other treatment). There are, however, serious ethical problems with doing so. Truncated trials systematically overestimate treatment effects; in cases where the number of accrued outcome events is small, the overestimation may be very large. Generating seriously inflated estimates of treatment effect violates the ethical research requirement of scientific validity. Subsequent use of inflated estimates to inform clinical decision making and practice guidelines violates the ethical requirements of social value and a favorable risk–benefit ratio. Researchers should ensure that a large number of outcome events accrues before stopping a trial and then continue recrui-
ment to assess whether positive trends continue. This can balance the need to protect research participants with the ethical requirements of scientific validity, social value, and a favorable risk–benefit ratio.


Abstract: Institutional review boards (IRBs) are legally required to determine whether the balance between the risks and benefits (the risk–benefit ratio or RBR) of a proposed study is “reasonable” or “proportional”. This obligation flows from their duty to protect the interests of research subjects. It has been argued that it is difficult, perhaps even impossible for IRBs to determine the RBR of studies, because the risks and benefits are not only heterogeneous, but also incommensurable. After arguing that the relevant meaning of incommensurability is in-comparability, we discuss whether the risks of participating in a trial and the benefits are comparable. We conclude that at least the risks and the benefits to participants are comparable. In the last section we show that the main problem of RBR analyses is that of interpersonal incommensurability. IRBs have to assume that risks to research subjects be compensated by benefits to others. The question is: To what extent? When does it become unreasonable to ask that patients accept the risks of participating in a trial for the benefit of science and/or future patients?


Newcombe, J.P.; Kerridge, I.H. Assessment by human research ethics committees of potential conflicts of interest arising from pharmaceutical sponsorship of clinical research. *Internal Medicine Journal* 2007 January; 37(1): 12-17. NRCBL: 18.2; 9.7; 1.3.2; 18.5.1.


Perlis, Clifford S.; Harwood, Michael; Perlis, Roy H. Extent and impact of industry sponsorship conflicts of interest in dermatology research. *Journal of the American Academy of Dermatology* 2005 June; 52(6): 967-971. NRCBL: 18.2; 1.3.7; 7.3; 9.7; 1.3.2. SC: em; rv.

Pimple, Kenneth D. Ethical issues in drug user treatment research. In: Kleinig, John; Einstein, Stanley, eds. *Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues*. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 205-216. NRCBL: 18.2; 1.3.9; 18.3; 9.5.9. Identifiers: Belmont Report.


Quest, Dale. Case vignette 1: a randomized double-blind double-dummy cross-over study of oral hexylinsulin monoconjugate 2 [PEGInsulin] versus insulin lispro for postprandial glycaemic control in adult patients with Type

NRCBL: National Reference Center for Bioethics Literature Classification Scheme

See inside front cover for terms.

SECTION I HUMAN EXPERIMENTATION/ETHICS COMMITTEES AND POLICY GUIDELINES

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**Quest, Dale.** Case vignette 3: a multi-centered trial to compare TCT vs Clozapine for treatment-resistant schizophrenia. *NCEHR Communique CNERH* 2005 Spring; 13(1): 11-12. NRCBL: 18.2; 7.2. SC: cs.

**Rabin, Cheryl; Tabak, Nili.** Healthy participants in phase I clinical trials: the quality of their decision to take part. *Journal of Clinical Nursing* 2006 August; 15(8): 971-979. NRCBL: 18.2; 18.3; 18.5.1.


**Robinson, Louise; Murdoch-Eaton, Deborah; Carter, Yvonne.** NHS research ethics committees — still need more common sense and less bureaucracy [editorial]. *BMJ: British Medical Journal* 2007 July 7; 335(7609): 6. NRCBL: 18.2. Identifiers: Great Britain (United Kingdom); National Health Service.

**Sade, Robert M.** Reports of clinical trials: ethical aspects. *Journal of Thoracic and Cardiovascular Surgery* 2006 August; 132(2): 245-246. NRCBL: 18.2; 18.5.1; 1.3.7.

**Saunders, John.** More guidelines on research ethics? With its new research ethics guidelines, the UK Royal College of Physicians continues a useful tradition of providing guidance to medical researchers. [editorial]. *Journal of Medical Ethics* 2007 December; 33(12): 683-684. NRCBL: 18.2. Identifiers: Great Britain (United Kingdom).


Abstract: Research ethics committees (RECs) are charged with providing an opinion on whether research proposals are ethical. These committees are overseen by a central office that acts for the Department of Health and hence the State. An advisory group has recently reported back to the Department of Health, recommending that it should deal with (excessive) inconsistency in the decisions made by different RECs. This article questions the desirability and feasibility of questing for consistent ethical decisions.


Abstract: Research ethics committees - animal ethics committees (AECs) for animal-based research and institutional research boards (IRBs) for human subjects - have a key role in research governance, but there has been little study of the factors influencing their effectiveness. The objectives of this study were to examine how the effectiveness of a research ethics committee is influenced by committee composition and dynamics, recruitment of members, workload, participation level and member turnover. As a model, 28 members of AECs at four universities in western Canada were interviewed. Committees were selected to represent variation in the number and type of protocols reviewed, and participants were selected to include different types of committee members. We found that a bias towards institutional or scientific interests may result from (1) a preponderance of institutional and scientist members, (2) an intimidating atmosphere for community members and other minority members, (3) recruitment of community members who are affiliated with the institution and (4) members joining for reasons other than to fulfill the committee mandate. Thoroughness of protocol review may be influenced by heavy workloads, type of review process and lack of full committee participation. These results, together with results from the literature on research ethics committees, suggested potential ways to improve the effectiveness of research ethics committees.


Sinclair, Andrew H.; Schofield, Peter R. Human embryonic stem cell research: an Australian perspective. *Cell* 2007 January 26; 128(2): 221-223. NRCBL: 18.2; 18.5.4; 15.1; 1.3.5.

Singer, Eleanor; Bossarte, Robert M. Incentives for survey participation when are they “coercive”? *American Journal of Preventive Medicine* 2006 November; 31(5): 411-418. NRCBL: 18.2; 18.3; 9.3.1; 18.6; 9.1.


Snowdon, Claire; Garcia, Jo; Elbourne, Diana. Making sense of randomization: responses of parents of critically ill babies to random allocation of treatment in a clinical trial. *Social Science and Medicine* 1997 November; 45(9): 1337-1355. NRCBL: 18.2; 18.5.2; 18.3; 9.4.


Society for Adolescent Medicine. Guidelines for adolescent health research. 1995. *Journal of Adolescent Health* 2003 November; 33(5): 410-415. NRCBL: 18.2; 18.5.2; 18.3; 8.3.2; 5.2.


Steneck, Nicholas H.; Bulger, Ruth Ellen. The history, purpose, and future of instruction in the responsible conduct of research. *Academic Medicine* 2007 September; 82(9): 829-834. NRCBL: 18.2; 18.6; 2.3; 2.2.


Turale, Sue. Reflections on the ethics involved in international research. *Nursing and Health Sciences* 2006 September; 8(3): 131-132. NRCBL: 18.2; 18.5.9; 21.7; 21.1.


United States. Department of Health and Human Services [DHHS]. Office of the Secretary. Protection of hu-


**Van Denend, Toni; Finlayson, Marcia.** Ethical decision making in clinical research: application of CELIBATE. *American Journal of Occupational Therapy* 2007 January-February; 61(1): 92-95. NRCBL: 18.2; 16.3; 9.4; 4.1.1.


**Vasgird, Daniel R.** Prevention over cure: the administrative rationale for education in the responsible conduct of research. *Academic Medicine* 2007 September; 82(9): 835-837. NRCBL: 18.2; 18.6; 2.3.

**Veatch, Robert M.** The irrelevance of equipoise. *Journal of Medicine and Philosophy* 2007 March-April; 32(2): 167-183. NRCBL: 18.2; 1.1; 18.3. SC: an. Abstract: It is commonly believed in research ethics that some form of equipoise is a necessary condition for justifying randomized clinical trials, that without it clinicians are violating the moral duty to do what is best for the patient. Recent criticisms have shown how complex the concept of equipoise is, but often retain the commitment to some form of equipoise for randomization to be justified. This article rejects that claim. It first asks for what one should be equally poised (scientific or clinical equipoise), then asks who should be equally poised (scientist, clinician, or subject), and finally asks why any of these players need be equally poised between treatment options. The article argues that only the subject’s evaluation of the options is morally relevant and that even the subject need not be equally poised or indifferent between the options in order to volunteer for randomization. All that is needed is adequately informed, free, and unexploited consent. It concludes equipoise is irrelevant.

**Weijer, Charles; Miller, P.B.** Refuting the net risks test: a response to Wendler and Miller’s “Assessing research risks systematically”. *Journal of Medical Ethics* 2007 August; 33(8): 487-490. NRCBL: 18.2. SC: an. Comments: D. Wendler and F.G. Miller. Assessing research risks systematically: the net risks test. *Journal of Medical Ethics* 2007 August; 33(8): 481-486. Abstract: Earlier in the pages of this journal (p 481), Wendler and Miller offered the “net risks test” as an alternative approach to the ethical analysis of benefits and harms in research. They have been vocal critics of the dominant view of benefit-harm analysis in research ethics, which encompasses core concepts of duty of care, clinical equipoise and component analysis. They had been challenged to come up with a viable alternative to component analysis which meets five criteria. The alternative must (1) protect research subjects; (2) allow clinical research to proceed; (3) explain how physicians may offer trial enrolment to their patients; (4) address the challenges posed by research containing a mixture of interventions and (5) define ethical standards according to which the risks and potential benefits of research may be consistently evaluated. This response argues that the net risks test meets none of these criteria and concludes that it is not a viable alternative to component analysis.


Carvalho, Fatima Lampreia. Regulation of clinical research and bioethics in Portugal. *Bioethics* 2007 June; 21(5): 290-302. NRCBL: 18.2; 9.6. SC: le. Abstract: This article presents an overview of the Portuguese transposition of the European Directive on Good Clinical Practice (2001/20/E) concerning scientific and academic debates on bioethics and clinical investigation. Since the Directive was transposed into Portuguese law by its National Assembly, the bureaucracy of clinical trials has been even more complex. Despite demands for swift application processes by the Pharmaceutical industry, supported by the European Parliament, the Directive’s transcription to the national law has not always delivered the expected outcome. However, this has led to an increased number of applications for clinical trials in Portuguese hospitals. In this article I revise bioethical publications and decree-laws enabling an informed appraisal of the anxieties and prospects for the implementation of the clinical trials Directive in Portugal. This article also places the European Directive in the field of sociology of bioethics, arguing that Portuguese bioethical institutions differ from those of the US, and also from Northern European counterparts. The main divergence is that those people in Portugal who claim expertise in ‘legal’ bioethics do not dominate either the bureaucratic structure of research or ethics committees for health. Even experts in the applied ethics field now claim that ‘professional bioethicists do not exist’. The recent creation of a national Ethics Committee for Clinical Investigation (CEIC) in line with the European Directive on Good Clinical Practice (GCP) will not change the present imbalance between different professional jurisdictions in the national bioethical debate in Portugal.


Douglas, Thomas M. Ethics committees and the legality of research. *Journal of Medical Ethics* 2007 December; 33(12): 732-736. NRCBL: 18.2. SC: an; le. Identifiers: New Zealand. Abstract: One role of research ethics committees (RECs) is to assess the ethics of proposed health research. In some countries, RECs are also instructed to assess its legality. However, in other countries they are explicitly instructed not to do so. In this paper, I defend the claim that...
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SECTION I

public policy should instruct RECs not to assess the legality of proposed research (“the Claim”). I initially defend a presumption in favour of the Claim, citing reasons for making research institutions solely responsible for assessing the legality of their own research. I then consider three arguments against the Claim which may over-ride this presumption-namely, that policy should instruct RECs to assess the legality of research because (1) doing so would minimise the costs of assessing the legality of research, (2) whether research is legal may partly determine whether it is ethical and (3) whether research is legal may constitute evidence for whether it is ethical. I reject the first two arguments and note that whether the third succeeds depends on the answer to a more fundamental question about the appropriate nature of REC ethical deliberation. I end with a brief discussion of this question, tentatively concluding that the third argument also fails.


Kesselheim, Aaron S.; Mello, Michelle M. Confidentiality laws and secrecy in medical research: improving public access to data on drug safety. Concealing clinical trial data from public scrutiny has implications for Americans’ health. Health Affairs 2007 March-April; 26(2): 483-491. NRCBL: 18.2; 8.4; 9.7. SC: le.


Maloney, Dennis M. Court says actions of institutional review board (IRB) members were ethically wrong. Human Research Report 2007 April; 22(4): 8. NRCBL: 18.2; 16.1; 18.5.2. SC: le. Identifiers: Grimes v. Kennedy Krieger Institute (KKI), (associated with Johns Hopkins University), (Part 6).

Maloney, Dennis M. Court says institutional review boards (IRBs) are not objective enough to protect human subjects. Human Research Report 2007 March; 22(3): 8. NRCBL: 18.2; 18.5.2; 18.3. SC: le. Identifiers: Grimes v. Kennedy Krieger Institute (KKI), (associated with Johns Hopkins University), (Part 5).


Moore, Mary E.; Berk, Stephen N.; Freedman, Benjamin; Salisbury, David A.; Schechter, Martin T. Research involving human subjects. In: Baylis, Françoise; Downie, Jocelyn; Freedman, Benjamin; Hoffmaster, Barry; Sherwin, Susan, eds. Health Care Ethics in Canada. Toronto: Harcourt Brace Canada, 1995: 319-364. NRCBL: 18.2; 18.3; 18.5.1; 9.5.6; 4.1.1. SC: le. Note: Section includes: Introduction — Halushka v. University of Saskatchewan et al. / Saskatchewan Court of Appeal — Ethical considerations encountered in a study of acupuncture — a reappraisal / Mary E. Moore and Stephen N. Berk — Equipoise and the ethics of clinical research / Benjamin Freedman — AIDS trials, civil liberties and the social control of therapy: should we embrace new drugs with open arms? / David A. Salisbury and Martin T. Schechter.


Society for Adolescent Medicine; Santelli, John S.; Smith Rogers, Audrey; Rosenfeld, Walter D.; DuRant, Robert H.; Dubler, Nancy; Morreale, Madlyn; English, Abigail; Lyss, Sheryl; Wimberly, Yolanda; Schissel, Anna. Guidelines for adolescent health research. A position paper of the Society for Adolescent Medicine. Journal of Adolescent Health 2003 November; 33(5): 396-409. NRCBL: 18.2; 18.5.2; 18.3; 8.3.2; 8.4; 18.4. SC: le.

Tonti-Filippini, Nicholas. The need for ethics committees, and their role and function. National Catholic Bioethics Quarterly 2007 Winter; 7(4): 749-769. NRCBL: 18.2; 1.2; 4.1.1; 18.6; 18.3; 18.3. SC: le. Abs tract: The search for truth is not the sole end of science. Science serves humanity, not humanity science. Science must never forget that the human being is not a mere means to scientific ends, but the reason for and goal of research. The central function of bioethics committees is to guide the development of medical science so that it genuinely seeks knowledge within the context of recog-
nizing that each human being is created in God’s own image and likeness and that no member of the human family may be used or treated merely as an object of use.


HUMAN EXPERIMENTATION/ INFORMED CONSENT

See also INFORMED CONSENT

Uninformed consent? The US should revamp rules on informed consent to ensure that people have all the information and support they need before deciding to enroll in clinical trials [editorial]. Nature Medicine 2007 September; 13(9): 999. NRCBL: 18.3; 18.6; 15.4.

Keywords: *clinical trials; *gene therapy; *government regulation; *informed consent; adverse effects; conflict of interest; consent forms; death; disclosure; industry; physicians; research ethics committees; research subjects; research support; researchers; risks and benefits; therapeutic misconception; Proposed Keywords: rheumatoid arthritis; Keyword Identifiers: *United States; Mohr, Jolee; Targeted Genetics Corp.


American College of Epidemiology Policy Committee; Ness, Roberta B. Biospecimen “ownership”: point. Cancer Epidemiology, Biomarkers and Prevention 2007 February; 16(2): 188-189. NRCBL: 18.3; 15.11; 18.6; 4.4.


Bradburn, Norman; Simon, Gayle; Bankowski, Susan Burner; Beattie, Elizabeth; Buckwalter, Kathleen; Clark, Laura; Diehl, Dawn. Informed consent. Journal
of Empirical Research on Human Research Ethics 2007 March; 2(1): 75-82. NRCBL: 18.3; 18.5.2; 18.5.6.


Abstract: To information on how persons from diverse backgrounds experience the informed consent process, we surveyed adults with a wide variety of educational levels and different primary languages (English, Spanish, or Vietnamese) who had recently enrolled in a study requiring written informed consent. Of the 100 participants, 62 were non-White, 43 had less than a high school education, and 60 had a primary language other than English. The median score for comprehension was 62% (IQR 50–76%); the median satisfaction score was 86% (IQR 71–100%). In multivariate analysis, only educational level was significantly associated with comprehension and satisfaction with the informed consent process (p = 0.001). Comprehension and satisfaction with the informed consent process were markedly lower among persons with lower educational levels.


Abstract: The study was designed to access differences in the content of HIPAA authorization forms now required for clinical research. Authorization forms were collected from 111 institutions, including academic medical centers and commercial Institutional Review Boards. The requirement for an element covering the use of information acquired was fulfilled in 95% of the forms, and 100% had a statement fulfilling the core requirement of a description of the data to be collected. However, only 19% distinguished between entities that could see personal identifiers versus aggregate data. Significant differences existed in how long the disclosure agreement would remain in effect, and complex legalistic language was common. Thus, while research authorization forms technically met the requirements, the complex language and confusion over personal identifiers may raise concerns in prospective research participants.


Cahana, Alex; Romagnoli, Simone. Not all placebos are the same: a debate on the ethics of placebo use in clinical trials versus clinical practice. Journal of Anesthesia 2007; 21(1): 102-105. NRCBL: 18.3; 18.2.


Abstract: The certificate of confidentiality (COC) provides additional protections to personal and sensitive research data. COC guarantees are not absolute and investigators are obligated to inform potential participants of COC limitations. The present study utilized qualitative and partnership methodology to examine participants’ (N = 24) perceptions of COC assurances and limitations in the context of a hypothetical study on depression. Although some participants were comforted by COC assurances, a majority of participants had confidentiality/privacy concerns specifically with COC passages concerning federal audits and legal reporting requirements. As one respondent noted, "Why is it that you guys don’t have to turn the records over to the court unless I say so . . . but you have to give them over to the government? . . . I don’t know about what is goin’ on." Our findings underscore the need for larger quantitative investigations to examine the negative and positive impact of COCs on research participation and response bias.

Chenaud, Catherine; Merlani, Paolo; Luyasu, Samuel; Ricou, Bara. Informed consent for research obtained during the intensive care unit stay. Critical Care 2006; 10(6): R170. NRCBL: 18.3; 9.5.1. SC: em.


Christopher, Paul P.; Foti, Mary Ellen; Roy-Bujnowski, Kristen; Appelbaum, Paul S. Consent form readability and educational levels of potential participants in mental health research. Psychiatric Services 2007 February; 58(2): 227-232. NRCBL: 18.3; 18.5.6. SC: em.


Cooper, Matthew. Sharing data and results in ethnographic research: why this should not be an ethical imperative. Journal of Empirical Research on Human Research Ethics 2007 March; 2(1): 3-19. NRCBL: 18.3; 8.2; 1.3.1; 18.6; 18.5.9. SC: cs; rv.

Abstract: Researchers recently have argued that offering to share research results with study participants should be
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an “ethical imperative.” This article considers that suggestion in light of the practice of ethnographic, particularly anthropological, research. Sharing results is discussed in relation to several issues, e.g., whether it occurs during or after completion of a project, whether the research is long-term, the complexities involved in depositing field materials in archives, the changing politics of ethnographic research, research not concerned with communities, situations in which participants and the anthropologist may be in danger, and changing styles of ethnographic research. I argue that, ideally, sharing should be a regular component of ethnographic research but should not be an ethical requirement. Given the complexity, variety and changing political contexts of ethnographic research, implementing such a requirement would often be practically impossible and sometimes would be inadvisable. I recommend instead that research ethics boards educate themselves about the nature of ethnographic research. Further, they should approach decision making on the issue of data or results sharing on a case-by-case basis. For researchers, I recommend that discussion of data and result sharing should become part of the education of all ethnographers and that discussion of the issue should be fostered.


Abstract: Previous research on informed consent for research in psychiatric patients has centered on disorders that affect comprehension and appreciation of risks. Little has been written about consent to research in those subjects with Borderline Personality Disorder, a prevalent and disabling condition. Discussion: Despite apparently intact cognition and comprehension of risks, a borderline subject may deliberately choose self-harm in order to fulfill abnormal psychological needs, or due to suicidality. Alternatively, such a subject may refuse enrollment due to transference or the desire to harm him or herself. Such phenomena could be precipitated or prevented by the interpersonal dynamics of the informed consent encounter. Summary: Caution should be exercised in obtaining informed consent for research from subjects with Borderline Personality Disorder. A literature review and recommendations for future research are discussed.


Abstract: Research in emergency settings (RES) has become a major public issue with urgent policy implications. Significant attention has focused recently on RES in response to the trial of PolyHeme, a synthetic blood substitute, in trauma victims in hemorrhagic shock. Unfortunately, the discussion of the PolyHeme trial in the popular and scholarly press leaves important questions unanswered. This paper articulates three important lessons from the PolyHeme trial that have significant policy implications. First, the RES regulations should be re-visited, particularly the requirement that existing treatments be unproven or unsatisfactory in order for research to be acceptable without consent. Second, further conceptual and empirical scholarship is needed to accomplish the goal of effectively involving communities. Third, a more subtle analysis is needed regarding how to balance the needs of maintaining public trust and protecting confidential trade information in the context of RES.


Feuchthaim, Lisa; Cunningham, George; Scioritno, Stan. Questioning the need for informed consent: a case study of California’s experience with a pilot newborn screening research project. Journal of Empirical Research on Human Research Ethics 2007 September; 2(3): 3-14. 31 refs. NRCBL: 18.3; 18.5.2; 15.3; 18.6; 8.3.2; 15.1. SC: cs; an; em.

Keywords: *genetic research; *genetic screening; *mandatory testing; *mass screening; *newborns; *public health; attitudes; autonomy; blood specimen collection; communitarianism; genetic disorders; interviews; moral policy; policy analysis; pregnant women; public policy; refusal to participate; risks and benefits; utilitarianism; Proposed Keywords: pilot projects; Keyword Identifiers: California

Abstract: California provides mandatory newborn screening for disorders that cause irreversible, severe disabilities if not identified and treated early in life. Parental consent is not required. In 2001, the Genetic Disease Branch was mandated to pilot test a new technology that could identify many additional disorders using the same blood specimen already collected. Study participation required informed consent, which was obtained for 47% of births during the study timeframe. The inability of hospitals to carry out the consent procedure for all newborns resulted in denial of testing and missed cases. If informed consent were waived, all newborns could have been tested. Several empirical questions are posed and each is examined from the perspective of society, the parents and the newborn. It is concluded that the legitimate needs of society and the interests of newborns should not be sacrificed to respond to the autonomy interests of the few parents who did not wish their infant to participate in the study, and that in the future, parental consent should be waived for projects evaluating new screening technologies.

HUMAN EXPERIMENTATION/ INFORMED CONSENT

SECTION I


Abstract: OBJECTIVES: (1) To investigate the quality of consent gained for the use in research of tissue that is surplus after surgery. (2) To compare the use of two consent forms: a simple locally introduced form and a more complex centrally instigated form. (3) To discuss the attitudes of patients towards the use of their surplus tissue in research. DESIGN: Data were collected through interviews and analysed with a combination of quantitative and qualitative analytical techniques. Participants and SETTING: Patients of the breast care unit at a teaching hospital were interviewed at home or in a quiet room at the hospital. RESULTS: 57 people were interviewed out of 81 approached, between October 2003 and March 2004. Most participants had a poor level of knowledge about the consent they had given, but reported being happy about having given it. The patients who had signed the locally introduced form had considerably more knowledge than those who had signed the centrally instigated form (z = -2.56; p < .05). Participants considered being well informed to be less important than believing that their opinions were valued and respected. CONCLUSIONS: The findings suggest that traditional models of informed consent are not universally applicable and, in this case, seem to overstate what people wish to know. The simple consent form achieved a better quality of informed consent and provided a better model of practice than the complex form, and it seemed that a focused approach to consent seeking is more effective and acceptable than more complex approaches.

Hem, Marit Helene; Heggen, Kristin; Ruyter, Knut W. Questionable requirement for consent in observational research in psychiatry. *Nursing Ethics* 2007 January; 14(1): 41-53. NRCBL: 18.3; 18.5.6; 8.3.3. SC: em. Identiﬁers: Norway.

Abstract: Informed consent represents a cornerstone of the endeavours to make health care research ethically acceptable. Based on experience of qualitative research on power dynamics in nursing care in acute psychiatry, we show that the requirement for informed consent may be practised in formalistic ways that legitimize the researcher’s activities without taking the patient’s changing perception of the situation sufficiently into account. The presentation of three patient case studies illustrates a diversity of issues that the researcher must consider in each situation. We argue for the necessity of researchers to base their judgement on a complex set of competen-

cies. Consciousness of research ethics must be combined with knowledge of the challenges involved in research methodology in qualitative research and familiarity with the therapeutic arena in which the research is being conducted. The article shows that the alternative solution is not simple but must emphasize the researcher’s ability to doubt and be based on an awareness of the researcher’s fallibility.

Huntington, Ian; Robinson, Walter. The many ways of saying yes and no: reflections on the research coordinator’s role in recruiting research participants and obtaining informed consent. *IRB: Ethics and Human Research* 2007 May-June; 29(3): 6-10. NRCBL: 18.3; 18.2.


Kimberly, Michael B.; Hoehn, K. Sarah; Feudtner, Chris; Nelson, Robert M.; Schreiner, Mark. Variation in standards of research compensation and child assent practices: a comparison of 69 institutional review board-approved informed permission and assent forms for 3 multicenter pediatric clinical trials. *Pediatrics* 2006 May; 117(5): 1706-1711. NRCBL: 18.3; 9.3.1; 18.2; 18.5.2. SC: em; rv.


Maloney, Dennis M. Case study: university says it will modify many human subject protection procedures. *Human Research Report* 2007 August; 22(8): 6-7. NRCBL: 18.3; 18.2; 18.5.5; 18.6. SC: cs.


Keywords: *informed consent; *legal aspects; *nontherapeutic research; disclosure; gene therapy; children; research subjects; researcher subject relationship; Keyword Identifiers: *Grimes v. Kennedy Krieger Institute; Gelsinger, Jesse

Maloney, Dennis M. In court: researchers didn’t tell subject’s mother of high lead levels in house until after blood tests. *Human Research Report* 2007 July; 22(7): 8. NRCBL: 18.3; 16.1; 18.5.2. SC: le. Identifiers: Grimes v Kennedy Krieger Institute (KKI), (associated with Johns Hopkins University), (Part 9).

Maloney, Dennis M. IRBs have some leeway on methods of informed consent. *Human Research Report* 2007 August; 22(8): 3. NRCBL: 18.3; 18.5.2; 18.2.

Marshall, Jennifer; Martin, Toby; Downie, Jocelyn; Malisza, Krisztina. A comprehensive analysis of MRI research risks: in support of full disclosure. *Canadian Journal of Neurological Sciences* 2007 February; 34(1): 11-17. NRCBL: 18.3; 18.5.1.

Matthews, Robert. Are you looking at me? Medical researchers keen to scour patients’ data for insights into disease should get consent first or risk seriously unstuck. *New Scientist* 2007 August 4-10; 195(2615): 18. NRCBL: 18.3; 8.4; 15.1; 1.3.12.

Keywords: *biomedical research; *databases; *genetic databases; *genetic research; *informed consent; *presumed consent; confidentiality; epidemiology; international aspects; medical records; registries; Keyword Identifiers: Great Britain; UK Biobank

May, Thomas; Craig, J.M.; Spelley, Ryan. IRBs, hospital ethics committees, and the need for “translational informed consent”. *Academic Medicine* 2007 July; 82(7): 670-674. NRCBL: 18.3; 18.2; 8.3.1; 9.6.

McCarty, Catherine A.; Nair, Anuradha; Austin, Diane M.; Giampietro, Philip F. Informed consent and subject motivation to participate in a large, population-based genomics study: the Marshfield Clinic Personalized Medicine Research Project. *Community Genetics* 2007; 10(1): 2-9. 23 refs. NRCBL: 18.3; 15.1; 15.11; 1.3.12. SC: em. Keywords: *genetic databases; *genetic research; *informed consent; *motivation; *population genetics; *research subjects; biological specimen banks; coercion; donors; genomics; questionnaires; researchers; Keyword Identifiers: Wisconsin


Abstract: Participants are often not informed by investigators who conduct randomised, placebo-controlled acupuncture trials that they may receive a sham acupuncture intervention. Instead, they are told that one or more forms of acupuncture are being compared in the study. This deceptive disclosure practice lacks a compelling methodological rationale and violates the ethical requirement to obtain informed consent. Participants in placebo-controlled acupuncture trials should be provided an accurate disclosure regarding the use of sham acupuncture, consistent with the practice of placebo-controlled drug trials.

Miller, Robin L.; Forte, Dracco; Wilson, Bianca Della; Greene, George J. Protecting sexual minority youth from research risks: conflicting perspectives. *American Journal of Community Psychology* 2006 June; 37(3-4): 341-348. NRCBL: 18.3; 8.3.2; 18.2; 18.5.2; 18.6; 10.


Abstract: Background: The doctrine of informed consent (IC) exists to protect individuals from exploitation or harm. This study into IC was carried out to investigate how different researchers perceived the process whereby researchers obtained consent. It also examined researchers’ perspectives on what constituted IC, and how different settings influenced the process. Methods: The study recorded in-depth interviews with 12 lecturers and five doctoral students, who had carried out research in devel-

NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.
opining countries, at a leading school of public health in the United Kingdom. A purposive, snowballing approach was used to identify interviewees. Results: Although the concept and application of the doctrine of IC should have been the same, irrespective of where the research was carried out, the process of obtaining it had to be different. The setting had to be taken into consideration and the autonomy of the subject had to be respected at all times. In areas of high illiteracy, and where understanding of the subject was likely to be a problem, there was an added responsibility placed on the researcher to devise innovative ways of carrying out the study, taking into consideration the peculiarities of the environment. Conclusion: The ethical issues for IC were the same, irrespective of where the research was conducted. However, because the backgrounds, setting, and knowledge of populations differed, there was the need to be similarly sensitive in obtaining consent. The problems of obtaining genuine IC were not limited to developing countries.


Abstract: We reported 164 researchers’ recommendations for information that should be included in the informed consent process. These recommendations were obtained during training workshops conducted in Africa, Europe, and the United States. The 8 elements of informed consent of the US Code of Federal Regulations were used to identify 95 items of information (“points”), most related to benefits and research description. Limited consensus was found among the 3 workshops: of the 95 points, only 27 (28%) were identified as useful by all groups. These points serve as a springboard for identifying information applicable in different geographic areas and indicate the need for involving a variety of individuals and stakeholders, with different research and cultural perspectives, in the development of informed consent, particularly for research undertaken in international settings.


Sammons, Helen M.; Atkinson, Maria; Choonara, Imti; Stephenson, Terence. What motivates British parents to consent for research? A questionnaire study. *BMC Pediatrics* 2007 March 9; 7: 12. NRCBL: 18.3; 18.5.2; 18.2.


Abstract: Reflections on my experience of conducting research in Botswana are used to highlight tensions and conflicts that arise from adhering to the western conceptualization of bioethics and the need to be culturally sensitive when carrying out research in one’s own culture. Cultural practices required the need to exercise discretionary judgement guided by respect for the culture and decision-making protocols of the research participants. Ethical challenges that arose are discussed. The brokerage role of nurse educators and leaders in contextualizing western bioethics is emphasized.


Slaughter, Susan; Cole, Dixie; Jennings, Eileen; Reimer, Marlene A. Consent and assent to participate in research from people with dementia. *Nursing Ethics* 2007 January; 14(1): 27-40. NRCBL: 18.3; 18.5.6; 18.5.7; 8.3.3.

Abstract: Conducting research with vulnerable populations involves careful attention to the interests of individuals. Although it is generally understood that informed consent is a necessary prerequisite to research participation, it is less clear how to proceed when potential research participants lack the capacity to provide this informed consent. The rationale for assessing the assent or dissent of vulnerable individuals and obtaining informed consent by authorized representatives is discussed. Practical guidelines for recruitment of and data collection from people in the middle or late stage of dementia are proposed. These guidelines were used by research assistants in a minimal risk study.

Snowden, Claire; Elbourne, Diana; Garcia, Jo. Declining enrolment in a clinical trial and injurious misconceptions: is there a flipside to the therapeutic misconception? *Clinical Ethics* 2007 December; 24(4): 193-200. NRCBL: 18.3; 18.5.2; 8.3.2; 7.1; 18.2. SC: em. Identifiers: CANDA Trial.

Abstract: The term ‘therapeutic misconception’ (TM) was introduced in 1982 to conceptualize how some psy-

Sugarman, Jeremy; Roter, Debra; Cain, Carole; Wallace, Roberta; Schmechel, Don; Welsh-Bohmer, Kathleen A. Proxies and consent discussions for dementia research. Journal of the American Geriatrics Society 2007 April; 55(4): 556-561. NRCBL: 18.3; 18.5.6; 18.5.7. SC: em.

Vaslef, Steven N.; Cairns, Charles B.; Falletta, John M. Ethical and regulatory challenges associated with the exception from informed consent requirements for emergency research: from experimental design to institutional review board approval. Archives of Surgery 2006 October; 141(10): 1019-1023; discussion 1024. NRCBL: 18.3; 18.6; 18.2; 9.5.1. SC: em.


HUMAN EXPERIMENTATION/REGULATION


Risk, consent and IRB models. Protecting Human Subjects 2007 November (15): 1, 4-5. NRCBL: 18.6; 18.2; 18.3.

 identifiers: U.S. Department of Health and Human Services Secretary’s Advisory Committee on Human Research Protections [SACHRP].


Emanuel, Ezekiel J.; Grady, Christine. Four paradigms of clinical research and research oversight. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Winter; 16(1): 82-96. NRCBL: 18.6; 2.2; 8.1.


Glass, Kathleen Cranley. Question and challenges in the governance of research involving humans: a Canadian perspective. In: Lemmens, Trudo; Waring, Duff R., eds. Law and Ethics in Biomedical Research: Regulation, Conflict of Interest and Liability. Toronto; Buffalo: University of Toronto Press, 2006: 35-46. NRCBL: 18.6; 1.3.9; 7.3.


Abstract: Contemporary Research Ethics Review Committees (REC's) are heavily influenced by the established academic or health care institutional frameworks in which they operate, sharing a cultural, methodological and ethical perspective on the conduct of research involving humans. The principle of autonomous choice carries great weight in what is a highly individualistic decision-making process in medical practice and research. This assumes that the best protection lies in the ability of patients or research participants to make competent, vol-
untary, informed choices, evaluating the risks and benefits from a personal perspective. Over the past two decades, North American and international indigenous researchers, policy makers and communities have identified key issues of relevance to them, but ignored by most institutional or university-based RECs. They critique the current research review structure, and propose changes on a variety of levels in an attempt to develop more community-sensitive research ethics review processes. In doing so, they have emphasized recognition of collective rights including community consent. Critics see alternative policy guidelines and community-based review bodies as challenging the current system of ethics review. Some view them as reflecting a fundamental difference in values. In this paper, we explore these developments in the context of the political, legal and ethical frameworks that have informed REC review. We examine the process and content of these frameworks and ask how this contrasts with emerging Aboriginal proposals for community-based research ethics review. We follow this with recommendations on how current REC review models might accommodate the requirements of both communities and RECs.


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Laine, Christine; Horton, Richard; DeAngelis, Catherine D.; Drazen, Jeffrey M.; Frizelle, Frank A.; Godlee, Fiona; Haug, Charlotte; Hébert, Paul C.; Kotzin, Sheldon; Marusic, Ana; Sahni, Peush; Schroeder, Torben V.; Sox, Harold C.; Van Der Weyden, Martin B.; Verheugt, Freek W.A. Clinical trial registration: looking back and moving ahead [editorial]. JAMA: The Journal of the American Medical Association 2007 July 4; 298(1): 93-94. NRCBL: 18.6; 1.3.7; 1.3.9; 1.3.12; 21.1.

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Laine, Christine; Horton, Richard; DeAngelis, Catherine D.; Drazen, Jeffrey M.; Frizelle, Frank A.; Godlee, Fiona; Haug, Charlotte; Hébert, Paul C.; Kotzin, Sheldon; Marusic, Ana; Sahni, Peush; Schroeder, Torben V.; Sox, Harold C.; Van Der Weyden, Martin B.; Verheugt, Freek W.A. Clinical trials registration: looking back and moving ahead [editorial]. New England Journal of Medicine 2007 June 28; 356(26): 2734-2736. NRCBL: 18.6; 1.3.7; 1.3.9; 1.3.12; 21.1.

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Abstract: Professors who include their students as subjects in classroom-based research projects typically must submit to a review by their university’s research ethics committee (REC) even in cases which present only minimal risks, and when the investigation is intended for evaluation of teaching approaches only, and not for publication. Results of a web-based survey with 378 respondents indicate that the perceived costs of the review process may outweigh the perceived benefits to subjects. A logistic regression analysis identifies the time it takes to complete the review application, the time it takes to receive a response, and the necessity of revising a project as significant factors in respondents viewing the REC process as a barrier to research. Instituting policies of expedited review for minimal-risk classroom research and exempting evaluations that are not to be published, both of which are permitted under the current regulations, would decrease burdens on both researchers and REC members, and foster improvement of teaching.


**Maloney, Dennis M.** Case study: university is allowed to resume its human subjects research projects. *Human Research Report* 2007 December; 22(12): 6-7. NRCBL: 18.6; 18.5.5; 18.3; 18.2.

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Abstract: Concerns about exploiting the poor or economically disadvantaged in clinical research are widespread in the bioethics community. For some, any research that involves economically disadvantaged individuals is de facto ethically problematic. The economically disadvantaged are thought of as “vulnerable” [sic; “vulnerable”] to exploitation, impaired decision making, or both, thus requiring either special protections or complete exclusion from research. A closer examination of the worries about vulnerabilities among the economically disadvantaged reveals that some of these worries are empirically or logically untenable, while others can be better resolved by improved study designs than by blanket exclusion of poorer individuals from research participation. The scientific objective to generate generalisable results and the ethical objective to fairly distribute both the risks and benefits of research oblige researchers not to unnecessarily bar economically disadvantaged subjects from clinical research participation.

**Dickinson, Frederick R.** Biohazard: Unit 731 in postwar Japanese politics of national “forgetfulness”. In: L'Flour, William R.; Böhme, Gernot; Shimazono, Susumu, eds. Dark Medicine: Rationalizing Medical Research. Bloomington: Indiana University Press, 2007: 85-104. NRCBL: 18.5.1; 18.5.8; 18.5.9; 21.3; 2.2; 1.3.5. SC: rv.

**Farmer, Deborah F.; Jackson, Sharon A.; Camacho, Fabian; Hall, Mark A.** Attitudes of African American and low socioeconomic status white women toward medical research. *Journal of Health Care for the Poor and Underserved* 2007 February; 18(1): 85-99. NRCBL: 18.5.1; 18.5.3; 8.1. SC: em.


Abstract: We administered debriefing probes to gauge respondent discomfort in reaction to sensitive questions. These probes assessed respondents’ own reactions to being asked to report on substance use (subjective discomfort), as well as their beliefs about the reaction of others (projective discomfort). We investigated whether a sample of men from the general population were more uncomfortable with questions about drug use than a sample
of men who have sex with men (MSM) surveyed from the same city (Chicago). We also investigated whether those who disclosed drug use on the survey experienced higher levels of discomfort. Contrary to opinions often expressed as research ethics committee (REC) recommendations, questions about drug use do not generate much subjective discomfort. MSM did not differ from the general population with respect to subjective discomfort. General population males did, however, report higher levels of “drug specific” projective discomfort. Respondents disclosing recent drug use reported higher levels of subjective discomfort. Implications for the REC practice, researcher and REC education, and directions for future research are discussed.

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Abstract: We explore the experience of Navajo communities living under the shadow of nuclear age fallout who were subjects of five decades of research. In this historical analysis of public health (epidemiological) research conducted in the Navajo lands since the inception of uranium mining from the 1950s until the end of the 20th century, we analyze the successes and failures in the research initiatives conducted on Navajo lands, the ethical breaches, and the harms and benefits that this research has brought about to the community. We discuss how scientific and moral uncertainty, lack of full stakeholder participation and community wide outreach and education can impact ethical decisions made in research.


Abstract: The dynamic and ever-evolving nature of neuroimaging research creates important ethical challenges. New domains of neuroscience research and improving technological capabilities in neuroimaging have expanded the scope of studies that probe the biology of the social and ethical brain, the range of eligible volunteers for research, and the extent of academic-industry relationships. Accordingly, challenges in informed consent and subject protection are surfacing. In this context, we provide an overview of the current landscape for neuroimaging and discuss specific research ethics topics arising from it. We suggest preliminary approaches to tackle current issues, and identify areas for further collaboration between neuroimagers and institutional review boards (research ethics committee).

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SECTION I  HUMAN EXPERIMENTATION/ . . . / AGED AND TERMINALLY ILL

HUMAN EXPERIMENTATION/ . . . / AGED AND TERMINALLY ILL

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HUMAN EXPERIMENTATION/ . . . / EMBRYOS AND FETUSES

See also CLONING


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Keywords: *embryonic stem cells; *tissue banks; *donors; incentives; mandatory programs; moral policy; organ transplantation; remuneration; resource allocation; risks and benefits; scarcity; standards; stem cell transplantation; utilitarianism; Proposed Keywords: embryo donation


Keywords: *embryo research; embryo disposition; embryonic stem cells; in vitro fertilization; informed consent; ovum donors; professional organizations; research embryo creation; Keyword Identifiers: International Federation of Gynecology and Obstetrics

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Keywords: *embryo disposition; *embryo research; *embryonic stem cells; *in vitro fertilization; biological specimen banks; cell lines; donors; economics; motivation; public policy; regulation; trends; Proposed Keywords: *embryo donation; Keyword Identifiers: Great Britain

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Keywords: *embryo research; *embryonic stem cells; *freedom; *public policy; *research support; biomedical research; cloning; democracy; government financing; government regulation; international aspects; legal aspects; religion; science; Keyword Identifiers: *European Union


Keywords: *embryo research; *regulation; *reproductive technologies; cloning; government regulation; physicians; preimplantation diagnosis; professional autonomy; reproduction; researchers; risk; self regulation; sexuality; Keyword Identifiers: Great Britain; Human Fertilisation and Embryology Act 1990 (Great Britain); Human Fertilisation and Embryology Authority

NRCBL: National Reference Center for Bioethics Literature Classification Scheme

See inside front cover for terms.

Keywords: *double effect;* embryonic stem cells; *embryo research;* embryonic stem cells; *ethical analysis;* government financing; *moral complicity;* moral policy; *public policy;* value of life; adult stem cells; allowing to die; beginning of life; cell lines; common good; embryos; federal government; guidelines; human dignity; killing; moral status; parental consent; personhood; Roman Catholic ethics; Keyword Identifiers: Bush, George; United States


Keywords: *embryonic stem cells;* organ transplantation; *property rights;* public policy; *social control;* biomedical technologies; body parts and fluids; cadavers; consensus; determination of death; embryo research; embryos; government regulation; kidneys; living donors; moral status; organ donors; policy making; remuneration; resource allocation; Proposed Keywords: stakeholders; Keyword Identifiers: United Network for Organ Sharing; United States


Keywords: *embryonic stem cells;* tissue banks; donors; incentives; international aspects; justice; minority groups; moral policy; remuneration; stem cell transplantation; Proposed Keywords: embryo donation


Keywords: *embryo research;* embryonic stem cells; *mass media;* biotechnology; editorial policies; genetic research; journalism; survey; Keyword Identifiers: Great Britain


Keywords: *stem cells;* chimeras; embryo research; embryonic stem cells; genetic techniques; methods; risk; Proposed Keywords: *pluripotent stem cells


Keywords: *embryonic stem cells;* embryo research; *public policy;* embryo; value of life; research support; government financing; Proposed Keywords: *United States


Keywords: *embryonic stem cells;* tissue banks; cell lines; cloning; donors; embryo disposition; ethnic groups; economies; financial support; in vitro fertilization; incentives; informed consent; international aspects; justice; mandatory programs; minority groups; moral policy; nuclear transfer techniques; organ transplantation; policy analysis; racial groups; remuneration; resource allocation; scarcity; social discrimination; standards; stem cell transplantation; transplant recipients; Proposed Keywords: embryo donation; haplotypes; tissue typing

Abstract: An increasingly unbridgeable gap exists between the supply and demand of transplantable organs. Human embryonic stem cell technology could solve the organ shortage problem by restoring diseased or damaged tissue across a range of common conditions. However, such technology faces several largely ignored immunological challenges in delivering cell lines to large populations. We address some of these challenges and argue in favor of encouraging contribution or intentional creation of embryos from which widely immunocompatible stem cell lines could be derived. Further, we argue that current immunological constraints in tissue transplantation demand the creation of a global stem cell bank, which may hold particular promise for minority populations and other sub-groups currently marginalized from organ procurement and allocation systems. Finally, we conclude by offering a number of practical and ethically oriented recommendations for constructing a human embryonic stem cell bank that we hope will help solve the ongoing organ shortage problem.

SECTION I  HUMAN EXPERIMENTATION/.../ EMBRYOS AND FETUSES

Keywords: *attitudes; *cryopreservation; *donors; *embryo disposition; *embryo research; *embryonic stem cells; *embryos; *patients; biomedical research; embryo transfer; in vitro fertilization; informed consent; moral status; public opinion; survey; Keyword Identifiers: *United States; Australia; Great Britain


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McLeod, Carolyn; Baylis, Françoise. Donating fresh versus frozen embryos to stem cell research: in whose interests. Bioethics 2007 November; 21(9): 465-477. NRCBL: 18.5.4; 10; 14.4; 14.6; 19.5.

Abstract: Some stem cell researchers believe that it is easier to derive human embryonic stem cells from fresh rather than frozen embryos and they have had in vitro fertilization (IVF) clinicians invite their infertility patients to donate their fresh embryos for research use. These embryos include those that are deemed ‘suitable for transfer’ (i.e. to the woman’s uterus) and those deemed unsuitable in this regard. This paper focuses on fresh embryos deemed suitable for transfer – hereafter ‘fresh embryos’ – which IVF patients have good reason not to donate. We explain why donating them to research is not in the self-interests specifically of female IVF patients. Next, we consider the other-regarding interests of these patients and conclude that while fresh embryo donation may serve those interests, it does so at unnecessary cost to patients’ self-interests. Lastly, we review some of the potential barriers to the autonomous donation of fresh embryos to research and highlight the risk that female IVF patients invited to donate these embryos will misunderstand key aspects of the donation decision, be coerced to donate, or be exploited in the consent process. On the basis of our analysis, we conclude that patients should not be asked to donate their fresh embryos to stem cell research.


Morris, Jonathan. Stem cell research. In his: The Ethics of Biotechnology. Philadelphia: Chelsea Publishers, 2006: 83-104. NRCBL: 18.5.4; 15.1. SC: po. Keywords: *embryo research; *embryonic stem cells; abortion; federal government; government financing; legal aspects; moral policy; religious ethics; risks and benefits; stem cell transplantation; Keyword Identifiers: United States

Murray, Fiona. The stem cell market — patents and the pursuit of scientific progress. New England Journal of Medicine 2007 June 7; 356(23): 2341-2343. 4 refs. NRCBL: 18.5.4; 15.1; 1.3.9; 15.8; 19.1.


Keywords: *biological specimen banks; *cell lines; *embryo research; *embryonic stem cells; *federal government; *government financing; *public policy; *research support; *guidelines; international aspects; registries; Keyword Identifiers: *National Institutes of Health; *United States

Onder, Robert. “People need a fairy tale”: the embryonic stem cell and cloning debate in Missouri. Missouri Medicine 2006 March-April; 103(2): 106-111. NRCBL: 18.5.4; 14.5; 15.1. SC: cm.


Keywords: *embryonic stem cells; *tissue banks; donors; embryos; health services accessibility; incentives; international aspects; justice; mandatory programs; minority groups; moral policy; moral status; organ transplantation; presumed consent; remuneration; required request; risks and benefits; scarcity; stem cell transplantation; voluntary programs; Proposed Keywords: embryo donation

NRCBL: National Reference Center for Bioethics Literature Classification Scheme  See inside front cover for terms.


Keywords: *biological specimen banks;* cell lines; *embryonic stem cells;* guidelines; *standards; embryo research;* ethical review; *fetal research;* informed consent; organizational policies; physicians; professional organizations; stem cells; Keyword Identifiers: *Royal College of Obstetricians and Gynaecologists (Great Britain);* Great Britain


Keywords: *cryopreservation;* embryo research; *embryonic stem cells;* embryos; in vitro fertilization; Proposed Keywords: blastomeres

Somerville, Margaret A. The importance of empirical research in bioethics: the case of human embryo stem cell research = Importance de la recherche empirique en bioéthique: cas de la recherche sur les cellules souches embryonnaires humaines [editorial]. *JOGC: Journal of Obstetrics and Gynaecology Canada = JOGC: Journal d’Obstétrique et Gynécologie du Canada* 2005 October; 27(10): 929-932. NRCBL: 18.5.4; 15.1; 18.3; 2.1.


Keywords: *biomedical research;* embryonic stem cells; *interprofessional relations;* beneficience; *biotechnology;* embryo research; genetic research; guidelines; industry; informed consent; international aspects; justice; obligations to society; patents; research ethics; research subjects; researchers; universities; Proposed Keywords: *cooperative behavior;* Keyword Identifiers: International Society for Stem Cell Research


Keywords: *embryo research;* cloning; fetal research; genetic engineering; guidelines; human dignity; human experimentation; in vitro fertilization; value of life; Keyword Identifiers: *Council of Europe;* Ad Hoc Committee of Experts on Progress in the Medical Sciences (CAHBI); Europe; European Convention on Human Rights and Biomedicine


Keywords: *embryonic stem cells;* *ovum donors;* remuneration; *embryo disposition; embryo research;* government regulation; in vitro fertilization; *indigents;* *ovum;* researchers; *scarcity;* women; Keyword Identifiers: Great Britain; United States


Keywords: *embryo research;* embryonic stem cells; *federal government;* *government financing;* *public policy;* research support; adult stem cells; advisory committees; cell lines; guidelines; Keyword Identifiers: *United States;* President’s Council on Bioethics


Keywords: *embryo research;* *legal aspects;* *public policy;* stem cells; adult stem cells; alternatives; cloning; embryo disposition; embryonic stem cells; federal government; government financing; methods; research support; value of life; Keyword Identifiers: *United States;* President’s Council on Bioethics


Wainwright, Steven; Williams, Clare; Michael, Mike; Farsides, Bobbie; Cribb, Alan. Remaking the body? Scientists’ genetic discourses and practices as examples of changing expectations on embryonic stem cell therapy for diabetes. *New Genetics and Society* 2007 December; 26(3): 251-268. NRCBL: 18.5.4; 15.1.


Keywords: *embryonic stem cells;* research embryo creation; *methods;* public policy; research support; government financing; Keyword Identifiers: United States

SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
SECTION I  HUMAN EXPERIMENTATION/ . . . / EMBRYOS AND FETUSES/ LEGAL ASPECTS


Yoshimura, Yasunori.  Bioethical aspects of regenerative and reproductive medicine.  *Human Cell* 2006 May; 19(2): 83-86.  NRCBL: 18.5.4; 14.5; 15.1; 18.2; 14.1.

Zycinski, J.  Bioethics, technology and human dignity: the Roman Catholic viewpoint.  *Acta Neurochirurgica Supplement* 2006; 98: 1-7.  25 refs.  NRCBL: 18.5.4; 15.1; 1.2; 4.4.  Keywords: *biotechnology; embryos; *human dignity; *research embryo creation; *Roman Catholic ethics; bioethics; biomedical technologies; embryonic stem cells; evolution; moral status; nuclear transfer techniques; quality of life; value of life

Zycinski, Joseph.  Ethics in medical technologies: the Roman Catholic viewpoint.  *Journal of Clinical Neuroscience* 2006 June; 13(5): 518-523.  20 refs.  NRCBL: 18.5.4; 15.1; 1.2; 4.4.  Keywords: *biotechnology; embryo research; *Roman Catholic ethics; ecology; embryonic stem cells; eugenics; human dignity; quality of life; value of life; values; Proposed Keywords: altered nuclear transfer

HUMAN EXPERIMENTATION/ . . . / EMBRYOS AND FETUSES/ LEGAL ASPECTS

See also CLONING

An unwieldy hybrid [editorial].  *Nature* 2007 May 24; 447(7143): 353-354.  NRCBL: 18.5.4; 15.1; 18.1; 22.1.  SC: le.  Keywords: *chimeras; embryo research; *legal aspects; genetically modified animals; government regulation; legislation; public policy; Keyword Identifiers: *Great Britain; Human Fertilisation and Embryology Authority (Great Britain)

German stem-cell law should change, says ethics council [news].  *Nature* 2007 July 26; 448(7152): 399.  NRCBL: 18.5.4; 15.1.  SC: le.  Keywords: *embryo research; embryonic stem cells; *government regulation; *legal aspects; advisory committees; cell lines; public policy; Keyword Identifiers: *Germany; National Ethics Council (Germany)

Burns, Lawrence.  Overstating the ban, ignoring the compromise.  *American Journal of Bioethics* 2007 February; 7(2): 65-66.  4 refs.  NRCBL: 18.5.4; 15.1; 14.5.  SC: le.  Comments: Timothy Caulfield and Tania Bubela.  Why a criminal ban?  Analyzing the arguments against somatic cell nuclear transfer in the Canadian parliamentary debate.  *American Journal of Bioethics* 2007 February; 7(2): 51-61.  Keywords: *cloning; embryo research; *legal aspects; *nuclear transfer techniques; *public policy; abortion; consensus; embryonic stem cells; embryos; government regulation; moral status; political activity; reproductive technologies; wedge argument; Keyword Identifiers: Canada


Green, Shane K.; Lott, Jason P.; Savulescu, Julian.  Is Canada’s stem cell legislation unwittingly discriminatory?  *American Journal of Bioethics* 2007 August; 7(8): 50-52; author reply W4-W6.  4 refs.  NRCBL: 18.5.4; 15.1; 19.5.  SC: le.  Comments: Jason P. Lott and Julian Savulescu.  Towards a global human embryonic stem cell bank.  *American Journal of Bioethics* 2007 August; 7(8): 37-44.  Keywords: *embryonic stem cells; *legislation; *tissue banks; cell lines; cloning; donors; government regulation; guidelines; in vitro fertilization; incentives; international aspects; justice; minority groups; moral policy; nuclear transfer techniques; public policy; remuneration; scarcity; social discrimination; Proposed Keywords: embryo donation; haplotypes; Keyword Identifiers: *Canada

Grubb, Andrew.  Regulating reprograming in the United Kingdom.  In: Knowles, Lori P.; Kaebnick, Gregory E., eds.  Reprogenetics: Law, Policy, and Ethical Issues.  Baltimore: Johns Hopkins University Press, 2007: 144-177.  30 refs., 31 fn.  NRCBL: 18.5.4; 15.1; 14.1; 14.5; 15.2; 14.4.  SC: le.  Keywords: *cloning; embryo research; *legislation; *policy making; *preimplantation diagnosis; *public policy; *regulation; *reproductive technologies; advisory committees; embryonic stem cells; embryos; nuclear transfer techniques; organization and administration; standards; Proposed Keywords: licensure; tissue typing; Keyword Identifiers: *Great Britain; *Human Fertilisation and Embryology Authority; *Human Fertilisation and Embryology Act 1990 (Great Britain); Warnock Committee

Guenin, Louis M.  A proposed stem cell research policy.  *Stem Cells* 2005 September; 23(8): 1023-1027.  NRCBL: 18.5.4; 15.1; 18.6.  SC: le.


Holt, Rush.  How should government regulate stem-cell research? Views from a scientist- legislator.  In: Santoro, Michael A.; Gorrie, Thomas M., eds.  Ethics and the Pharmaceutical Industry.  Cambridge; New York: Cambridge University Press, 2005: 109-122.  427-431.  53 refs.  NRCBL: 18.5.4; 15.1.  SC: le.  Keywords: *embryo research; *legal aspects; *stem cells; cloning; embryonic stem cells; federal government; government financing; in vitro fertilization; international aspects; legislation; public policy; reproductive technologies; state government; stem cell transplantation; Keyword Identifiers: *United States; Europe; Asia

Martínez, Jaime Vidal.  Biomedical research with human embryos: changes in the legislation on assisted reproduction in Spain.  *Revista de Derecho y Genoma Humano* =

Keywords: *embryo research; *legal aspects; *reproductive technologies; biomedical research; embryonic stem cells; embryos; fetal research; legislation; genetic engineering; legal rights; property rights; Keyword Identifiers: *Spain


Keywords: *embryo research; *embryonic stem cells; *government financing; *legislation; federal government; politics; public policy; research support; Keyword Identifiers: *Stem Cell Research Enhancement Act; *U.S. Congress; *United States

O'Dowd, Adrian. UK may allow creation of “cybroids” for stem cell research [news]. BMJ: British Medical Journal 2007 March 10; 334(7592): 495. NRCBL: 18.5.4; 15.1; 22.2; 14.5; 18.1; 22.1. SC: le.

Keywords: *chimeras; *embryo research; *embryonic stem cells; government regulation; public policy; Keyword Identifiers: *Great Britain


Keywords: *cloning; *embryo research; *embryonic stem cells; *embryos; *legal aspects; government regulation; Keyword Identifiers: *Australia


Keywords: *embryo research; *embryonic stem cells; *government regulation; *international aspects; cloning; cross-cultural comparison; embryos; ethical review; government financing; guidelines; legal aspects; public policy; reproductive technologies; research support; stem cells; Keyword Identifiers: *Canada; *Japan


Keywords: *embryo research; *embryonic stem cells; adult stem cells; cloning; international aspects; legal aspects; Keyword Identifiers: *France; *Great Britain; *Sweden; Switzerland

Spar, Debora; Harrington, Anna. Selling stem cell science: how markets drive law along the technological frontier. American Journal of Law and Medicine 2007; 33(4): 541-565. NRCBL: 18.5.4; 15.1; 18.6; 5.3; 11.1; 14.4. SC: le.

Takala, Tuja; Häyry, Matti. Benefiting from past wrongdoing, human embryonic stem cell lines, and the fragility of the German legal position. Bioethics 2007 March; 21(3): 150-159. 50 fn. NRCBL: 18.5.4; 15.1; 19.5; 1.1. SC: an; le.

Keywords: *cell lines; *embryo research; *embryonic stem cells; *ethical analysis; *legislation; *moral complicity; *moral policy; aborted fetuses; commerce; commodification; dehumanization; embryo disposition; embryos; government regulation; historical aspects; in vitro fertilization; international aspects; morality; National Socialism; ovum donors; policy analysis; public policy; scientific misconduct; Keyword Identifiers: *Germany; *Stem Cell Act 2002 (Germany)

Abstract: This paper examines the logic and morality of the German Stem Cell Act of 2002. After a brief description of the law’s scope and intent, its ethical dimensions are analysed in terms of symbolic threats, indirect consequences, and the encouragement of immorality. The conclusions are twofold. For those who want to accept the law, the arguments for its rationality and morality can be sound. For others, the emphasis on the uniqueness of the German experience, the combination of absolute and qualified value judgments, and the lingering questions of indirect encouragement of immoral activities will probably be too much.


Keywords: *embryos; *legal aspects; *stem cells; alternatives; cell lines; embryo research; methods; Keyword Identifiers: *United States


Keywords: *embryo research; *embryonic stem cells; *legal aspects; Keyword Identifiers: *United States


Keywords: *embryo research; *embryonic stem cells; *legal aspects; embryo disposition; Keyword Identifiers: *United States


Keywords: *cell lines; *legal aspects; *research embryo creation; *stem cells; alternatives; embryonic stem cells; public policy; Keyword Identifiers: *United States


Keywords: *legal aspects; *stem cells; alternatives; biomedical research; embryo research; embryos; guidelines; public policy; Keyword Identifiers: *United States


Keywords: *embryonic stem cells; *embryo research; *government financing; *legal aspects; *research support; *stem cells; adult stem cells; alternatives; cell lines; embryos; informed consent; research ethics committees; Keyword Identifiers: *United States

**Wadman, Meredith.** Stem-cell issue moves up the US agenda [news]. Nature 2007 April 19; 446(7138): 842. NRCBL: 18.5.4; 15.1. SC: le.

Keywords: *embryo research; *embryonic stem cells; *government financing; *legal aspects; *research support; cell lines; federal government; legislation; politics; Keyword Identifiers: *United States; Stem Cell Research Enhancement Act 2007; U.S. House of Representative; U.S. Senate

**HUMAN EXPERIMENTATION/ . . . / EMBR. & FETUSES/ PHIL. & RELIG. ASPECTS**

See also CLONING

**Agar, Nicholas.** Embryonic potential and stem cells. Bioethics 2007, May; 21(4): 198-207. 23 fn. NRCBL: 18.5.4; 1.1; 4.4; 15.1; 19.5. SC: an.

Keywords: *embryo research; *embryonic stem cells; *embryos; *ethical analysis; *moral status; beginning of life; cloning; embryo disposition; embryonic development; in vitro fertilization; intention; nuclear transfer techniques; philosophy; Proposed Keywords: *blastocysts

Abstract: This paper examines three arguments that use the concept of potential to identify embryos that are morally suitable for embryonic stem cell research (ESCR). According to the first argument, due to Ronald Green, the fact that they are scheduled for disposal makes embryos left over from IVF treatments morally appropriate for research. Paul McHugh argues that embryos created by somatic cell nuclear transfer differ from those that result directly from the meeting of sperm and egg in having potential especially conducive to the therapeutic use of their stem cells. I reject both of these arguments. According to the way of making distinctions in embryonic potential that I defend, it is the absence of a functional relationship with a womb that marks embryos morally suitable for ESCR.


**Barnes, Richard.** Stem cell research funding: testimony. Origins 2007 March 15; 36(39): 616-620. 10 refs. NRCBL: 18.5.4; 15.1; 1.2; 9.3.1.

Keywords: *embryo research; *embryonic stem cells; *government financing; *research support; *Roman Catholic ethics; *state government; adult stem cells; biotechnology; cloning; conflict of interest; economics; embryos; industry; legislation; public opinion; public policy; value of life; Keyword Identifiers: *New York; United States


Abstract: A higher order potential analysis of moral status clarifies the issues that divide Human Being Theorists who oppose embryo research from Person Theorists who favor embryo research. Higher order potential personhood is transitive if it is active, identity preserving and morally relevant. If the transition from the Second Order Potential of the embryo to the First Order Potential

NRCBL: National Reference Center for Bioethics Literature Classification Scheme

See inside front cover for terms.
of an infant is transitive, opponents of embryo research make a powerful case for the moral status of the embryo. If it is intransitive, then the Person Theorist can draw lines between levels of moral status that permit embryo research to proceed.


Condic, Maureen L.; Furton, Edward J. Harvesting embryonic stem cells from deceased human embryos. National Catholic Bioethics Quarterly 2007 Autumn; 7(3): 507-525. 35 fn. NRCBL: 18.5.4; 15.1; 19.5; 20.2.1; 14.4; 18.3; 1.2.
Keywords: *death; *determination of death; *embryo disposition; *embryonic stem cells; *embryos; *moral policy; cryopreservation; embryo research; human dignity; in vitro fertilization; methods; model legislation; moral complicity; parental consent; public policy; Roman Catholic ethics; Proposed Keywords: *embryo death

Decker, J. Why two arguments from probability fail and one argument from Thomson’s analogy of the violinist succeeds in justifying embryo destruction in some situations. Journal of Medical Ethics 2007 March; 33(3): 160-164. 10 refs. NRCBL: 18.5.4; 14.5; 1.1; 15.1; 4.4. SC: an.
Keywords: *embryo research; *embryos; *ethical analysis; *killing; *moral status; abortion; advisory committees; beginning of life; embryo disposition; legal aspects; philosophy; public policy; value of life; Proposed Keywords: probability; spontaneous abortion; Keyword Identifiers: Chief Medical Officer’s Expert Group (Great Britain), Great Britain; House of Lords Select Committee on Medical Ethics; Thomson, Judith

Abstract: The scope of embryo research in the UK has been expanded by the Human Fertilisation and Embryology (Research Purposes) Regulations 2001. Two advisory bodies — the Chief Medical Officer’s Expert Group and the House of Lords’ Select Committee — presented various arguments in favour of embryo research. One of these is the view that, just as lottery tickets have relatively little value before the draw because of the low probability of their being the winning ticket, early embryos have relatively little value because of the presumed low probability that they will mature into more developed embryos. This (first) argument from probability is questioned in this paper, as well as the contention that allowing embryo destruction is incompatible with the view that embryos have full moral status. Although I challenge Savulescu’s view that early embryos should be entered into a lottery in which they are subjected to the probability of being destroyed (the second argument from probability), a revised version of Thomson’s analogy of the famous violinist defies the view that the position that the embryo has full moral status is incompatible with qualified support for embryo destruction.


Hagen, John D., Jr. Bentham’s mummy and stem cells. America 2007 May 14; 196(17): 12-14. NRCBL: 18.5.4; 15.1; 1.1; 4.4.

Hurlbut, William B. Stem cells, embryos, and ethics: is there a way forward? Update (Loma Linda Center) 2007 January 21(3): 1-10. 5 refs. NRCBL: 18.5.4; 15.1; 4.4; 1.2.
Keywords: *beginning of life; *embryo research; *embryonic stem cells; *embryos; *moral policy; alternatives; cloning; government financing; in vitro fertilization; moral status; nuclear transfer techniques; public policy; twinning; value of life; Proposed Keywords: regenerative medicine; Keyword Identifiers: United States

Keywords: *embryonic stem cells; *embryos; *Protestant ethics; *value of life; beginning of life; embryo research; ethical analysis; moral status; personhood; Roman Catholic ethics; stem cell transplantation; theology

Keywords: *embryo research; *embryonic stem cells; *ethical theory; *moral policy; *war; embryos; intention; killing; moral status; rights

Abstrack: This paper responds to DW Brock's technically strong case for the use of human embryonic stem cells in medical research. His main issue in this context is the question of whether it is moral to destroy viable human embryos. He offers a number of reasons to support his view that it is moral to destroy them, but his use of conceptual arguments is not adequate to secure his position. The purpose and scope of this paper is wholly concerned with his arguments rather than with the conclusion that it is justifiable to destroy human embryos. The author proceeds through his variety of arguments and offers reasons for rejecting them. The author concludes that Brock has not shown that it is moral to destroy viable human embryos.


Takala, Tuija; Häyry, Matti. Benefitting from past wrongdoing, human embryonic stem cell lines, and the fragility of the German legal position. Bioethics 2007 March; 21(3): 150-159. 50 fn. NRCBL: 18.5.4; 15.1; 19.5; 1.1. SC: an; le.


Keywords: *embryo research; *embryonic stem cells; *Roman Catholic ethics; beginning of life; cloning; embryos; justice; moral status; personhood; value of life

Mauceri, Joseph M. Evolution and the embryo: the evidence for special creation. Linacre Quarterly 2007 February; 74(1): 30-49. NRCBL: 18.5.4; 3.2; 15.1; 14.5; 1.2.

Napier, Stephen. Human embryos as human subjects. Ethics and Medics 2007 September; 32(9): 3-4. NRCBL: 18.5.4; 15.1; 18.6; 1.2; 1.1.

Northcott, Michael S. In the waters of Babylon: the moral geography of the embryo. In: Deane-Drummond, Celia; Scott, Peter Manley, eds. Future Perfect?: God, Medicine and Human Identity. New York: T and T Clark International, 2006: 73-86. NRCBL: 18.5.4; 15.1; 14.4; 14.5; 4.4; 1.2.


Takala, Tuija; Häyry, Matti. Benefiting from past wrongdoing, human embryonic stem cell lines, and the fragility of the German legal position. Bioethics 2007 March; 21(3): 150-159. 50 fn. NRCBL: 18.5.4; 15.1; 19.5; 1.1. SC: an; le.

Keywords: *embryo research; *embryonic stem cells; *ethical analysis; *legislation; *moral complicity; *moral policy; aborted fetuses; commerce; commodification; dehumanization; embryo disposition; embryos; government regulation; historical aspects; in vitro fertilization; international aspects; morality; National Socialism; ovum donors; policy analysis; public policy; scientific misconduct; KeyWord Identifiers: *Germany; *Stem Cell Act 2002 (Germany)

Abstract: This paper examines the logic and morality of the German Stem Cell Act of 2002. After a brief description of the law’s scope and intent, its ethical dimensions are analysed in terms of symbolic threats, indirect consequences, and the encouragement of immorality. The conclusions are twofold. For those who want to accept the law, the arguments for its rationality and morality can be sound. For others, the emphasis on the uniqueness of the German experience, the combination of absolute and qualified value judgments, and the lingering questions of indirect encouragement of immoral activities will probably be too much.


Keywords: *embryonic stem cells; *embryos; *moral status; *value of life; beginning of life; cloning; embryonic development; ethical analysis; personhood; rights; value of life; Proposed Keywords: blastocysts

Abstract: This paper responds to DW Brock's technically strong case for the use of human embryonic stem cells in medical research. His main issue in this context is the question of whether it is moral to destroy viable human embryos. He offers a number of reasons to support his view that it is moral to destroy them, but his use of conceptual arguments is not adequate to secure his position. The purpose and scope of this paper is wholly concerned with his arguments rather than with the conclusion that it is justifiable to destroy human embryos. The author proceeds through his variety of arguments and offers reasons for rejecting them. The author concludes that Brock has not shown that it is moral to destroy viable human embryos.


have human status and a morally significant line cannot be drawn between human embryos and other human beings. What is morally at stake in stem cell research is therefore the question of the source of derivation or generation of the cells, not of the cells as such.


Keywords: *embryonic stem cells; *methods; *research embryo creation; advisory committees; alternatives; beginning of life; Christian ethics; dissent; embryos; Keyword Identifiers: *Hurlbut, William; President’s Council on Bioethics

Tong, Rosemary. Stem-cell research and the affirmation of life. Conscience 2007 Autumn; 28(3): 19-23. NRCBL: 18.5.4; 15.1; 4.4; 1.2; 7.1.


Keywords: *embryos; *legal aspects; *stem cells; alternatives; cell lines; embryo research; methods; Keyword Identifiers: *United States


**HUMAN EXPERIMENTATION/ . . . / FOREIGN NATIONALS**


Caniza, Miguela A.; Clara, Wilfrido; Maron, Gabriela; Navarro-Marín, Jose Ernesto; Rivera, Roberto; Howard, Scott C.; Camp, Jonathan; Barfield, Raymond C. Establishment of ethical oversight of human research in El Salvador: lessons learned. Lancet Oncology 2006 December; 7(12): 1027-1033. NRCBL: 18.5.9; 18.2; 2.4.


Dunbar, Terry; Scrimgeour, Margaret. Ethics in indigenous research — connecting with community. Journal of Bioethical Inquiry 2006; 3(3): 179-185. NRCBL: 18.5.9; 18.6; 18.2; 18.3.


Abstract: Considerable variation has been demonstrated in applying regulations across research ethics committees (RECs) in the U.S., U.K., and European nations. With the

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SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
rise of international research collaborations, REC's in developing countries apply a variety of international regulations. We conducted a qualitative descriptive pilot study with members of the national REC in Malawi to determine criteria they use to review research, and their views on international collaborations. Qualitative content analysis demonstrated that international guidelines are interpreted in light of local African conditions such that emphasis is placed on examining benefit to the community and ensuring the informed consent process translates concepts in locally-meaningful ways. Members suggest that REC's often must comply with regulations that do not fit local conditions. Recommendations are provided for improving such international collaborations.


Abstract: The concept of ‘vulnerability’ is well established within the realm of research ethics and most ethical guidelines include a section on ‘vulnerable populations’. However, the term ‘vulnerability’, used within a human research context, has received a lot of negative publicity recently and has been described as being simultaneously ‘too broad’ and ‘too narrow’. The aim of the paper is to explore the concept of research vulnerability by using a detailed case study - that of mineworkers in post-apartheid South Africa. In particular, the usefulness of Kipnis’s taxonomy of research vulnerability will be examined. In recent years the volume of clinical research on human subjects in South Africa has increased significantly. The HIV and TB pandemics have contributed to this increase. These epidemics have impacted negatively on the mining industry; and mining companies have become increasingly interested in research initiatives that address these problems. This case study explores the potential research vulnerability of mineworkers in the context of the South African mining industry and examines measures that can reduce this vulnerability.


Kilmarx, Peter H.; Ramjee, Gita; Kitayaporn, Dwip; Kunasol, Prayura. Protection of human subjects’ rights in HIV-preventive clinical trials in Africa and Asia: experiences and recommendations. AIDS 2001; 15 (suppl.5): S73-S79. NRCBL: 18.5.9; 9.5.6; 18.3; 18.6.


Keywords: *clinical trials; *developing countries; *disadvantaged; *gene therapy; *gene transfer techniques; drugs; economics; genetic disorders; guideline adherence; guidelines; health care delivery; hemophilia; HIV infections; international aspects; justice; nontherapeutic research; research design; research ethics; socioeconomic factors; standards; therapeutic misconception; Proposed Keywords: *phase I clinical trials; adenosine deaminase; severe combined immunodeficiency; Keyword Identifiers: Africa; Council for International Organizations of Medical Sciences; Declaration of Helsinki; Italy

Abstract: Relatively little has been written about the ethics of conducting early phase clinical trials involving subjects from the developing world. Below, I analyze ethical issues surrounding one of gene transfer’s most widely praised studies conducted to date: in this study, Italian investigators recruited two subjects from the developing world who were ineligible for standard of care because of economic considerations. Though the study seems to have rendered a cure in these two subjects, it does not appear to have complied with various international guidelines that require that clinical trials conducted in the developing world be responsive to their populations’ health needs. Nevertheless, policies devised to address large scale, late stage trials, such as the AZT short-course placebo trials, map somewhat awkwardly to early phase studies. I argue that interest in conducting translational research in the developing world, particularly in the context of hemophilia trials, should motivate more rigorous ethical thinking around clinical trials involving economically disadvantaged populations.

Lertsitichai, Panuwat. Health research, fair benefits and access to medicines. Journal of the Medical Association of Thailand = Chotmaihet Thangphaet 2006 April; 89(4): 558-564. NRCBL: 18.5.9; 9.2; 2.4; 18.2.


Newton, Sam K.; Appiah-Poku, John. Opinions of researchers based in the UK on recruiting subjects from developing countries into randomized controlled trials. Developing World Bioethics 2007 December; 7(3); 149-156. NRCBL: 18.5.9; 18.3. SC: em.

Abstract: BACKGROUND: Explaining technical terms in consent forms prior to seeking informed consent to recruit into trials can be challenging in developing countries, and more so when the studies are randomized controlled trials. This study was carried out to examine the opinions of researchers on ways of dealing with these challenges in developing countries. METHODS: Recorded in-depth interviews with 12 lecturers and five doctoral students, who had carried out research in developing countries, at a leading school of public health in the United Kingdom. A purposive, snowballing approach was used to identify interviewees. RESULTS: Researchers were divided on the feasibility of explaining technical trials in illiterate populations; the majority of them held the view that local analogies could be used to explain these technical terms. Others were of the opinion that this could not be done since it was too difficult to explain technical trials, such as randomized controlled trials,
even to people in developed countries. CONCLUSION: Researchers acknowledged the difficulty in explaining randomized controlled trials but it was also their perception that this was an important part of the ethics of the work of scientific research involving human subjects. These difficulties notwithstanding, efforts should be made to ensure that subjects have sufficient understanding to consent, taking into account the fact that peculiar situations in developing countries might compound this difficulty.

Rohter, Larry. In the Amazon, giving blood but getting nothing. *New York Times* 2007 June 20; p. A1, A4. NRCBL: 18.5.9; 19.4; 9.3.1; 1.3.9; 15.1; 15.11. SC: po. Keywords: *blood specimen collection;*commerce; *genetic materials;*genetic research; *indigenous populations; American Indians; culture; deception; informed consent; international aspects; population genetics; property rights; scientific misconduct; Proposed Keywords: tissue donors; Keyword Identifiers: *Brazil; Karitiana Indians

Salvi, Vinita; Damania, K. HIV, research and women. *Journal of Postgraduate Medicine* 2006 July-September; 52(3): 161-162. NRCBL: 18.5.9; 18.5.3; 18.3; 9.5.6.

Terrell White, Mary. A right to benefit from international research: a new approach to capacity building in less-developed countries. *Accountability in Research* 2007 April-June; 14(2): 73-92. NRCBL: 18.5.9; 18.2. Abstract: This article proposes a means by which benefits provided in international research collaborations might be employed to strengthen health care, research, and other capacities in less-developed countries. The Declaration of Helsinki and CIOMS Guidelines define certain expectations of benefits, but these requirements are ambiguous, logistically problematic, and studies suggest they are inconsistently upheld. Drawing on the principle of respect for persons, a right to benefit from hosting externally-sponsored research is proposed. This right guarantees host communities benefits of a certain value, the nature and use of which is controlled by indigenous personnel. Suggestions are made as to how implementation of this right, using structured incentives, may systematically promote capacity building in host communities.


**HUMAN EXPERIMENTATION/ . . . / MENTALLY DISABLED**

Anderson, Kelly K.; Mukherjee, Som D. The need for additional safeguards in the informed consent process in schizophrenia research. *Journal of Medical Ethics* 2007 November; 33(11): 647-650. NRCBL: 18.5.6; 18.3. Abstract: The process of obtaining informed consent to participate in a clinical study presents many challenges for research conducted in a population of patients with schizophrenia. Morally valid, informed consent must include information sharing, decisional capacity, and capacity for voluntarism. This paper examines the unique features of schizophrenia that may threaten each of these elements of informed consent, and it proposes additional safeguards in the process of gaining informed consent from individuals with schizophrenia in order to maximise the decision-making potential of this patient population.

Brashler, Rebecca. Ethics, family caregivers, and stroke. *Topics in Stroke Rehabilitation* 2006 Fall; 13(4): 11-17. NRCBL: 18.5.6; 9.5.1; 8.1.

Dewing, Jan. From ritual to relationship: a person-centered approach to consent in qualitative research with older people who have dementia. *Dementia: The International Journal of Social Research and Practice* 2002 June; 1(2): 157-171. NRCBL: 18.5.6; 4.4; 18.3; 18.5.7.

Hellström, Ingrid; Nolan, Mike; Nordenfelt, Lennart; Lundh, Ulla. Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics* 2007 September; 14(5): 608-619. NRCBL: 18.5.6; 18.5.7; 18.3. Abstract: People with dementia have previously not been active participants in research, with ethical difficulties often being cited as the reason for this. A wider inclusion of people with dementia in research raises several ethical and methodological challenges. This article adds to the emerging debate by reflecting on the ethical and methodological issues raised during an interview study involving people with dementia and their spouses. The study sought to explore the impact of living with dementia. We argue that there is support for the inclusion of people with dementia in research and that the benefits of participation usually far outweigh the risks, particularly when a ‘safe context’ has been created. The role of gatekeepers as potentially responsible for excluding people with dementia needs further consideration, with particular reference to the appropriateness of viewing consent as a primarily cognitive, universalistic and exclusionary event as opposed to a more particularistic, inclusive and context relevant process.


SECTION I HUMAN EXPERIMENTATION/ . . . / MINORS

Care Nursing 2006 March-April; 25(2): 89-92. NRCBL: 18.5.6; 4.1.3; 18.3; 18.6.


Maloney, Dennis M. Research with adult subjects who have impaired decision-making capacity. Human Research Report 2007 October; 22(10): 1-2. NRCBL: 18.5.6; 18.2.


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Savage, Teresa A. Ethical issues in research with patients who have experienced stroke. Topics in Stroke Rehabilitation 2006 Fall; 13(4): 1-10. NRCBL: 18.5.6; 18.3; 18.2.

Siegel, Paul E.; Ellis, Norman R. Note on the recruitment of subjects for mental retardation research. American Journal of Mental Deficiency 1985 January; 89(4): 431-433. NRCBL: 18.5.6; 18.2; 18.6.

HUMAN EXPERIMENTATION/ . . . / MINORS

Alderson, Priscilla. Ethics. In: Fraser, Sandy; Lewis, Vicky; Ding, Sharon; Kellett, Mary; Robinson, Chris, eds. Doing Research with Children and Young People. London; Thousand Oaks, CA: Sage Publications, 2004: 97-112. NRCBL: 18.5.2; 18.2; 18.3; 1.3.9.

Anand, K.J.S.; Aranda, Jacob V.; Berde, Charles B.; Buckman, ShaAvhrée; Capparelli, Edmund V.; Carlo, Waldemar A.; Hummel, Patricia; Lantos, John; Johnston, C. Celeste; Lehr, Victoria Tutag; Lynn, Anne M.; Maxwell, Lynne G.; Oberlander, Tim E.; Raju, Tonsie N.K.; Soriano, Sulpicio G.; Taddio, Anna; Walco, Gary A. Analgesia and anesthesia for neonates: study design and ethical issues. Clinical Therapeutics 2005 June; 27(6): 814-843. NRCBL: 18.5.2; 18.2; 18.6; 4.4. SC: rv.

Austin, Joan K. Ethical issues related to the increased emphasis on children participating in research. Chronic Illness 2006 September; 2(3): 181-182. NRCBL: 18.5.2; 18.2.

Banister, Elizabeth; Leadbeater, Bonnie; Benoit, Cecilia; Jansson, Michael; Marshall, Anne; Riecken, Ted. Ethical issues in community-based research with children and youth. NCEHR Communiqué CNERH 2006 Spring; 14(1): 23-24. NRCBL: 18.5.2; 18.3; 18.6. Identifiers: Canada.


Downie, Jocelyn; Schmidt, Matthias; Kenny, Nuala; D’Arcy, Ryan; Hadskis, Michael; Marshall, Jennifer. Paediatric MRI research ethics: the priority issues. Journal of Bioethical Inquiry 2007; 4(2): 85-91. NRCBL: 18.5.2; 8.3.2; 8.4; 5.3.

Abstract: Abstract In this paper, we first briefly describe neuroimaging technology, our reasons for studying magnetic resonance imaging (MRI) technology, and then provide a discussion of what we have identified as priority issues for paediatric MRI research. We examine the issues of respectful involvement of children in the consent process as well as privacy and confidentiality for this group of MRI research participants. In addition, we explore the implications of unexpected findings for paediatric MRI research participants. Finally, we explore the ethical issues concerning advances in functional MRI. This paper aims to provide a clear description of priority paediatric MRI research ethics issues to make some preliminary recommendations regarding next steps.

Dyer, Owen. Andrew Wakefield is accused of paying children for blood [news]. BMJ: British Medical Journal 2007 July 21; 335(7611): 118-119. NRCBL: 18.5.2; 1.3.9; 18.2; 19.5; 9.3.1. SC: le.


Abstract: United States federal regulations for pediatric research with no prospect of direct benefit restrict institutional review board (IRB) approval to procedures presenting: 1) no more than “minimal risk” (§ 45CFR46.404); or 2) no more than a “minor increase over minimal risk” if the research is commensurate with the subjects’ previous or expected experiences and intended to gain vitally important information about the child’s disorder or condition (§ 45CFR46.406) (DHHS 2001). During the 25 years since their adoption, these regulations have helped IRBs balance subject protections with the pursuit of scientific knowledge to advance children’s welfare. At the same time, inconsistency in IRB application of these regulations to pediatric protocols has been widespread, in part because of the ambiguity of the regulatory language. During the past decade, three federally-authorized committees have addressed these ambiguities: 1) the National Human Research Protections Advisory Committee (NHRPAC) (Washington, DC); 2) the Institute of Medicine (IOM) Committee on the Ethical Conduct of Clinical Research Involving Children (Washington, DC); and 3) the United States Department of Health and Human Services Secretary’s Advisory Committee for Human Research Protections (SACHRP) (Washington, DC). These committees have reached similar conclusions on interpretation of language within regulations § § 45CFR46.404 and 406; these conclusions are remarkably consistent with recent international recommendations and those of the original National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1977) report from which current regulations are based. Drawing on the committees’ public reports, this article identifies the ethical issues posed by ambiguities in regulatory language, summarizes the committees’ deliberations, and calls for a national consensus on recommended criteria.


Firth, Lucy. Researching chronic childhood illness: autonomy or beneficence? *Chronic Illness* 2006 September; 2(3): 178-180. NRCBL: 18.5.2; 18.3; 1.1. Identifiers: Great Britain (United Kingdom).


Abstract: Physicians’ presentation of treatment options in a non-coercive manner is critical for informed consent for participation in randomized clinical trials (RCTs). This study examined discrepancies between observer and physician report of treatment recommendations for pediatric leukemia RCTs. This study also assessed relationships between recommendations and decisions to participate in RCTs. Participants were 104 parents of children with leukemia and the treating physicians. Measures included observations of informed consent conferences (ICCs), physician report of treatment recommendations, and parent report of trial participation. Observation revealed that physicians recommended RCTs in 38% of ICCs, while physicians reported recommending RCTs in 73% of ICCs. Treatment recommendations were unrelated to decisions to participate in RCTs. Results highlight the importance of enhancing parent-physician communication regarding RCT participation.


Abstract: This paper looks at the issue of consent from children and whether the test of Gillick competency, applied in medical and healthcare practice, ought to extend to participation in research. It is argued that the relatively broad usage of the test of Gillick competency in the medical context should not be considered applicable for use in research. The question of who would and could determine Gillick competency in research raises further concerns relating to the training of the researcher to make such a decision as well as to the obvious issue of the researcher’s personal interest in the project and possibility of benefiting from the outcome. These could affect the judgment of Gillick competency if the researcher is charged with making this decision. The above notwithstanding, there are two exceptional research situations in which Gillick competency might be legitimately applied: (1) when the research is likely to generate significant advantages for the participants while exposing them to relatively minor risks, and (2) when it is likely to generate great societal benefit, pose minimal risks for the participants and yet raise parental objection. In both cases, to ensure that autonomy is genuinely respected and to protect against personal interest, Gillick competency should be assessed by an individual who has no interest or involvement in the research.

Joffe, Steven; Fernandez, Conrad V.; Pentz, Rebecca D.; Ungar, David R.; Mathew, N. Ajoy; Turner, Curtis W.; Alessandri, Angela J.; Woodman, Catherine L.; Singer, Dale A.; Kodish, Eric. Involving children with cancer in decision-making about research participation. *Journal of Pediatrics* 2006 December; 149(6): 862-868. NRCBL: 18.5.2; 9.5.1; 18.3; 8.1.

John, Jill E. The child’s right to participate in research: myth or misconception? *British Journal of Nursing* 2007 February 8-21; 16(3): 157-160. NRCBL: 18.5.2; 18.3; 8.3.2.

Johnson, Jeannette L.; Vandermark, Nancy R. Ethics in prevention research with children. In: Kleinig, John; Einstein, Stanley, eds. Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 259-279. NRCBL: 18.5.2; 9.5.9; 18.2; 18.3; 21.7.


Lynch, Margaret A.; Glaser, Danya; Prior, Vivien; Inwood, Vivien. Following up children who have been abused: ethical considerations for research design. *Child Psychology and Psychiatry Review* 1999 May; 4(2): 68-75. NRCBL: 18.5.2; 18.2; 18.3; 9.5.7; 9.1; 18.2. SC: rv; em. Identifiers: Great Britain (United Kingdom).


Maloney, Dennis M. In court: researchers and a history of unethical behavior. *Human Research Report* 2007 December; 22(12): 8. NRCBL: 18.5.2; 18.3; 18.4; 1.3.9. SC: le. Identifiers: Grimes v. Kennedy Krieger Institute (KKI), (associated with Johns Hopkins University), (Part 11); Wendell Johnson.

Maloney, Dennis M. Study’s children lived in housing with various levels of possible lead exposure. Human Research Report 2007 May; 22(5): 8. NRCBL: 18.5.2; 16.1; 18.3. SC: le. Identifiers: Grimes v. Kennedy Krieger Institute (KKI), (associated with Johns Hopkins University), (Part 7).


Merlo, D.F.; Knudsen, L.E.; Matusiewicz, K.; Niebrój, L.; Vähäkangas, K.H. Ethics in studies on children and environmental health. Journal of Medical Ethics 2007 July; 33(7): 408-413. 58 refs. NRCBL: 18.5.2; 16.1; 18.2; 18.3; 18.5.4; 15.1; 1.3.12.


Pasternak, Ryan H.; Geller, Gail; Parrish, Catherine; Cheng, Tina L. Adolescent and parent perceptions on youth participation in risk behavior research. Archives of Pediatrics and Adolescent Medicine 2006 November; 160(11): 1159-1166. NRCBL: 18.5.2; 17.3; 18.3.


Resnik, David B.; Wing, Steven. Lessons learned from the children’s environmental exposure research study. American Journal of Public Health 2007 March; 97(3): 414-418. NRCBL: 18.5.2; 16.1; 9.5.4; 18.3; 1.3.9.


Keywords: *chile; *clinical trials; *genetic disorders; *nontherapeutic research; *risk; *terminally ill; *brain; government regulation; informed consent; investigational therapies; parental consent; pediatrics; research ethics committees; research subjects; stem cell transplantation; therapeutic misconception; vulnerable populations; Proposed Keywords: Batten disease; Keyword Identifiers: United States

Abstract: Children, because of age-related reasons, are a vulnerable population, and protecting their health is a social, scientific and emotional priority. The increased susceptibility of children and fetuses to environmental (including genotoxic) agents has been widely discussed by the scientific community. Children may experience different levels of chemical exposure than adults, and their sensitivity to chemical toxicities may be increased or decreased in comparison with adults. Such considerations also apply to unborn (fetal exposure) and newborn (neonatal exposure) children. Therefore, research on children is necessary in both clinical and environmental fields, to provide age-specific relevant data regarding the efficacy and safety of medical treatments, and regarding the assessment of risk from unintended environmental exposure. In this context, the stakeholders are many, including children and their parents, physicians and public health researchers, and the society as a whole, with its ethical, regulatory, administrative and political components. The important ethical issues are information of participants and consent to participate. Follow-up and protection of data (samples and information derived from samples) should be discussed in the context of biobanks, where children obtain individual rights when they become adults. It is important to realise that there are highly variable practices within European countries, which may have, in the past, led to differences in practical aspects of research in children. A number of recommendations are provided for research with children and environmental health. Environmental research with children should be scientifically justified, with sound research questions and valid study protocols of sufficient statistical power, ensuring the autonomy of the child and his/her family at the time of the study and later in life, if data and samples are used for follow-up studies. When children are enrolled, we recommend a consent dyad, including (1) parental (or legal guardian) informed consent and (2) the child’s assent and/or informed consent from older minors. For evaluation of the studies including children, a paediatrician should always be involved in the research ethics committee.


Singh, Jerome Amir; Abdool Karim, Salim S.; Abdool Karim, Quarrisha; Mlisana, Koleka; Williamson, Carolyn; Gray, Clive; Govender, Michelle; Gray, Andrew. Enrolling adolescents in research on HIV and other sensitive issues: lessons from South Africa. *PLoS Medicine* 2006 July; 3(7): e180 (0984-0988). NRCBL: 18.5.2; 18.5.1; 9.5.6.

Slack, Catherine; Strode, Ann; Fleischer, Theodore; Gray, Glenda; Ranchod, Chitra. Enrolling adolescents in HIV vaccine trials: reflections on legal complexities from South Africa. *BMC Medical Ethics* 2007; 8:5; 8 p. [Online]. Accessed: http://www.biomedcentral.com/1472-6939/8/5 [2007 June 18]. NRCBL: 18.5.2; 9.5.6; 9.5.7; 18.3. SC: le.

Abstract: Background: South Africa is likely to be the first country in the world to host an adolescent HIV vaccine trial. Adolescents may be enrolled in late 2007. In the development and review of adolescent HIV vaccine trial protocols there are many complexities to consider, and much work to be done if these important trials are to become a reality. Discussion: This article sets out essential requirements for the lawful conduct of adolescent research in South Africa including compliance with consent requirements, child protection laws, and processes for the ethical and regulatory approval of research. Summary: This article outlines likely complexities for researchers and research ethics committees, including determining that trial interventions meet current risk standards for child research. Explicit recommendations are made for role-players in other jurisdictions who may also be planning such trials. This article concludes with concrete steps for implementing these important trials in South Africa and other jurisdictions, including planning for consent processes; delineating privacy rights; compiling information necessary for ethics committees to assess risks to child participants; training trial site staff to recognize when disclosures trig mandatory reporting response; networking among relevant ethics committees; and lobbying the National Regulatory Authority for guidance.


HUMAN EXPERIMENTATION/.../PRISONERS


Maloney, Dennis M. Impermissible research with prisoners and generally improper protocol reviews [case study]. *Human Research Report* 2007 April; 22(4): 6-7. NRCBL: 18.5.5; 18.2.

**HUMAN EXPERIMENTATION/.../WOMEN**


Abstract: **BACKGROUND**: The objective of this study was to identify factors motivating women to take part in endometriosis research and to determine if these factors differ for women participating in clinical versus basic science studies. **METHODS**: A consecutive series of 24 women volunteering for participation in endometriosis-related research were asked to indicate, in their own words, why they chose to volunteer. In addition, the women were asked to rate, on a scale of 0 to 10, sixteen potentially motivating factors. The information was gathered in the form of an anonymous self-administered questionnaire. **RESULTS**: Strong motivating factors (mean score 8) included potential benefit to other women’s health, improvement to one’s own condition, and participation in scientific advancement. Weak motivating factors (mean score 3) included financial compensation, making one’s doctor happy, and use of ‘natural’ products. No difference was detected between clinical and basic science study participants. **CONCLUSION**: This study is the first study to specifically investigate the factors that motivate women to take part in endometriosis research. Understanding why women choose to take part in such research is important to the integrity of the informed consent process. The factors most strongly motivating women to participate in endometriosis research related to improving personal or public health; the weakest, to financial compensation and pleasing the doctor.

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**Keywords**: *cloning; *human experimentation; *pregnant women; *women; cord blood; cryopreservation; embryo research; ethical review; fetal therapy; informed consent; ovum; paternalism; randomized clinical trials; reproductive technologies; research subjects; selection of subjects; stem cells

Manderson, Lenore; Kelaerh, Margaret; Williams, Gail; Shannon, Cindy. The politics of community: negotiation and consultation in research on women’s health. *Human Organization* 1998 Summer; 57(2): 222-229. NRCBL: 18.5.3; 18.6; 18.5.1. Identifiers: Australia.

McCullough, Laurence B.; Coverdale, John H.; Chervenak, Frank A. Preventive ethics for including women of childbearing potential in clinical trials. *American Journal of Obstetrics and Gynecology* 2006 May; 194(5): 1221-1227. NRCBL: 18.5.3; 18.3; 18.2; 18.5.2.


Shakur, Haleema; Roberts, Ian; Barnetson, Lin; Coats, Tim. Clinical trials in emergency situations [editorial]. *BMJ: British Medical Journal* 2007 January 27; 334(7586): 165-166. NRCBL: 18.5.3; 9.5.1.

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**HUMAN RIGHTS See INTERNATIONAL HEALTH AND HUMAN RIGHTS**

**HYBRIDS** See CHIMERAS AND HYBRIDS

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SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
**SECTION I  IN VITRO FERTILIZATION**

**IMMUNIZATION** See CARE FOR SPECIFIC GROUPS; DRUG INDUSTRY; PUBLIC HEALTH

**IN VITRO FERTILIZATION**

*See also REPRODUCTIVE TECHNOLOGIES*


Abstract: The author describes various risks to the foetus arising from assisted reproduction technology (ART). These risks are examined from the legal viewpoint, especially considering the rights of the foetus as interpreted in a number of jurisdictions. He distinguishes between the avoidable and inherent risks to the foetus resulting from ART and the potential hazards of ART relevant to criminal law. The basic internationally accepted conventions on foetal rights are compared relative to decisions in a number of cases heard and decided.


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SC: le. Identifiers: Australia; Canada; Ireland; New Zealand; Great Britain (United Kingdom).


Keywords: *biotechnology; *government regulation; *public policy; *reproductive technologies; advisory committees; bioethical issues; chimeras; common good; embryo research; embryonic stem cells; federal government; freedom; genetic engineering; legal aspects; ovum donors; policy making; public participation; recalibration


**Chung, Lisa Hird.** Free trade in human reproductive cells: a solution to procreative tourism and the unregulated Internet. *Minnesota Journal of International Law* 2006...
IN VITRO FERTILIZATION

SECTION I


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May; 87(5): 1001-1004. NRCBL: 14.4; 14.6; 9.3.1; 19.5; 9.5.5.

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cers: Great Britain (United Kingdom); Human Fertilisation
and Embryology Authority.

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Embryology [ESHRE]. Task Force on Ethics and Law:
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14.4; 10.

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77-99. NRCBL: 14.4; 5.3; 9.3.1; 14.1; 15.2. SC: le.

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14.6; 14.5; 4.4. SC: an.

Keywords: *beginning of life; *embryos; *moral status;
cloning; cryopreservation; embryo disposition; embryo re-
search; embryonic stem cells; in vitro fertilization; moral
obligations; moral policy; personhood; preimplantation di-
agnosis; reproductive technologies; value of life

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14.4; 18.5.3; 4.2.

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Keywords: *embryo research; *feminist ethics; *regulation; *reproductive technologies; *values; anthropology; advisory committees; biotechnology; commodification; decision making; donors; embryonic stem cells; genes; in vitro fertilization; legal aspects; surrogate mothers; value of life; women; Proposed Keywords: embryo donation; Keyword Identifiers: Great Britain; Warnock Committee

Abstract: This paper forms part of the feminist critique of the regulatory consequences of biomedicine’s systematic exclusion of the role of women’s bodies in the development of reprognetic technologies. I suggest that strategic use of notions of the sacred to decontextualise and delimit disagreement fosters this marginalisation. Here conceptions of the sacred and sacralisation afford a means by which pragmatic consensus over regulation may be achieved, through the deployment of a bricolage of dense images associated with cultural loyalties to solidify support or exclude contradictory elements. Hence an explicit renegotiation of the symbolic order structuring salient debates is necessary to disrupt and enrich the entrenched and exclusionary dominant discourse over reprognetic regulation. I draw upon previous analyses of strategic rhetoric associated with the regulation of infertility treatment and embryo research in the United Kingdom, the cultural anthropology of biomedicine and feminist ethnographies of reprognetics to illustrate these claims.


Mahowald, Mary Briody; Sherwin, Susan; Overall, Christine. Assisted reproductive technologies. In: Baylis, Françoise; Downie, Jocelyn; Freedman, Benjamin; Hoffmaster, Barry; Sherwin, Susan, eds. Health Care Ethics in Canada. Toronto: Harcourt Brace Canada, 1995: 449-485. NRCBL: 14.4; 14.2; 9.5.5; 10; 2.4. SC: le. Note: Section includes: Introduction — Fertility enhancement and the right to have a baby / Mary Briody Mahowald — New reproductive technologies / Susan Sherwin — Surrogate motherhood / Christine Overall — Proceed with care: final report of the Royal Commission on New Reproductive Technologies.

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Keywords: *embryonic stem cells; *in vitro fertilization; *incentives; *ovum donors; *remuneration; cloning; embryonic research; public policy; research support; Keyword Identifiers: *Medical Research Council (Great Britain); Great Britain; National Health Service; Newcastle Fertility Centre


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Keywords: *embryo transfer; remuneration; commodifi-
cation; ovum donors; semen donors; cryopreservation; *em-
bro; eugenics; *biological specimen banks

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problems who desires a multiple pregnancy. *JAMA: The
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Abstract: In-vitro fertilisation has been done for nearly
30 years; in developed countries at least 1% of births are
from assisted reproductive therapies (ART). These chil-
dren now represent a substantial proportion of the popu-
lation but little is known about their health. Some of the
morbidity associated with ART does not result from the
techniques but from the underlying health risks of being
subfertile. Much of the amplified risk associated with
ART is related to high birth order. However, risk of
intrauterine and subsequent perinatal complications is
enhanced after ART, and urogenital malformations can
be present in boys, even in singleton infants. No increase
in discord or other difficulties within families has been
recorded. Long-term follow-up of children born after
ART to reproductive age and beyond is necessary.

Takeshita, Naoki; Hanaoka, Kanako; Shibui, Yukihiro;
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and Genetics* 3 July; 20(7): 290-292. NRCBL: 14.4;
9.8. SC: le.

INCOMPETENTS See INFORMED CONSENT/
INCOMPETENTS

INDIGENTS See CARE FOR SPECIFIC
GROUPS/ INDIGENTS

INFANTICIDE See EUTHANASIA AND AL-
LOWING TO DIE/ MINORS

INFANTS See CARE FOR SPECIFIC GROUPS/
MINORS; EUTHANASIA AND ALLOWING TO DIE/
MINORS; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ MINORS

INFORMATICS See TELEMEDICINE AND IN-
FORMATICS

INFORMED CONSENT
See also HUMAN EXPERIMENTATION/ IN-
FORMED CONSENT; TREATMENT REFUSAL

Ågård, Anders; Löfmark, Rurik; Edvardsson, Nils;
Ekman, Inger. Views of patients with heart failure about
their role in the decision to start implantable cardioverter-
defibrillator treatment: prescription rather than participa-
tion. *Journal of Medical Ethics* September; 33(9):
514-518. NRCBL: 8.3.1; 9.5.1. SC: em.
Abstract: Background: There is a shortage of reports on
what potential recipients of implantable cardioverter-
defibrillators (ICDs) need to be informed about and what role they can and want to play in the decision-making process when it comes to whether or not to implant an ICD. Aims: To explore how patients with heart failure and previous episodes of malignant arrhythmia experience and view their role in the decision to initiate ICD treatment. Patients and methods: A qualitative content analysis of semistructured interviews was used. The study population consisted of 31 outpatients with moderate heart failure at the time of their first ICD implantation. Setting: The study was performed at Sahlgrenska University Hospital, Göteborg, Sweden. Results: None of the respondents had discussed the alternative option of receiving treatment with anti-arrhythmic drugs, the estimated risk of a fatal arrhythmia, or the expected time of survival from heart failure in itself. Even so, very little criticism was directed at the lack of information or the lack of participation in the decision-making process. The respondents felt that they had to rely on the doctors’ recommendation when it comes to such a complex and important decision. None of them regretted implatement of the ICD. Conclusions: The respondents were confronted by a matter of fact. They needed an ICD and were given an offer they could not refuse, simply because life was precious to them. Being able to give well-informed consent seemed to be a matter of less importance for them.


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Clarke, Steve; Levy, Neil. On the competence of substance users to consent to treatment programs. In: Kleinig, John; Einstein, Stanley, eds. Ethical Challenges for Inter-vening in Drug Use: Policy, Research and Treatment Issues. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 309-322. NRCBL: 8.3.1; 4.3; 9.5.9. SC: an.


Abstract: Autonomy is a concept that holds much appeal to social and legal philosophers. Within a medical context, it is often argued that it should be afforded supremacy over other concepts and interests. When respect for autonomy merely requires non-intervention, an adult’s right to refuse treatment is held at law to be absolute. This apparently simple statement of principle does not hold true in practice. This is in part because an individual must be found to be competent to make a valid refusal of consent to medical treatment, and capacity to decide is not an absolute concept. But further to this, I argue that there are three relevant understandings of autonomy within our society, and each can demand in differing cases that different courses of action be followed. Judges, perhaps inadvertently, have been able to take advantage of the equivocal nature of the concept to come tacitly to decisions that reflect their own moral judgments of patients or
decisions made in particular cases. The result is the inconsistent application of principle. I ask whether this is an unforeseen outcome or if it reflects a wilful disregard for equal treatment in favour of silent moral judgments in legal cases. Whatever the cause, I suggest that once this practice is seen to occur, acceptable justification of it in some cases is difficult to find.

Corfield, Lorraine F. To inform or not to inform: how should the surgeon proceed when the patient refuses to discuss surgical risk? *Journal of Vascular Surgery* 2006 July; 44(1): 219-221. NRCBL: 8.3.1; 9.5.1; 8.1. SC: cs.


Egonsson, Dan. Hypothetical approval in prudence and medicine. *Medicine, Health Care and Philosophy* 2007 September; 10(3): 245-252. NRCBL: 8.3.1; 1.1; 8.3.4; 17.1; 20.5.1. Abstract: We often assume that hypothetical approval - either in the form of preferences or consent - under ideal conditions adds to the legitimacy of an arrangement or act. I want to show that this assumption, reasonable as it may seem, will also give rise to ethical problems. I focus on three problem areas: prudence, euthanasia and coercive psychiatric treatment. If we are to count as prudentially or morally relevant those preferences you would have if you were informed and rational, we will run into difficulties in all these areas if your actual and rational preferences are at variance with each other. In the prudential sphere we may question the personal value of satisfying preferences that a person does not actually have. In this case our problem concerns the point of satisfying a rational preference in conflict with an actual one. In the cases of euthanasia and coercive care it concerns instead whether it would be morally right to do such a thing. I doubt there is a simple solution to our problem. In this paper at most I prepare the way for a solution or for wiser decisions in the hard cases, by pointing out what they will have to deal with.


Abstract: OBJECTIVE: To audit doctors’ knowledge of informed consent. DESIGN: 10 consent scenarios with “true”, “false”, or “don’t know” answers were completed by doctors who care for children at a large district general hospital. These questions tested clinicians’ knowledge of who could give consent in different clinical situations. SETTING: Royal United Hospital, Bath, UK. RESULTS: 51 doctors participated (25 paediatricians and 26 other clinicians). Paediatricians scored higher than other clinicians (average correct response 69% vs 49%). Only 36% (9/25) of paediatricians and 8% (2/26) of other clinicians realised that the biological father of a child born before 1 December 2003 needed a court order or a parental responsibility agreement to acquire parental responsibility, and thus be able to consent on behalf of his child, if he was not married to the child’s mother. Non-paediatric clinicians were unsure or incorrect when tested on situations where people with parental responsibility do not agree, or where young people (years), who are Fraser competent do not want to consult their parents. Most clinicians did not know that the parents of a 20-year-old man with severe learning difficulties are unable to consent to surgery on his behalf, and many non-paediatricians were unclear on who could give consent when a child lived with foster parents. CONCLUSION: Clinicians who obtain consent for the treatment of children need to increase their knowledge on who is able to give informed consent to ensure best (legal and safe) practice.


Fullbrook, Suzanne. Consent: the issue of rights and responsibilities for the health worker. *British Journal of Nursing* 2007 March 8-21; 16(5): 318-319. NRCBL: 8.3.1; 8.3.2; 8.3.3. SC: le. Identifiers: Great Britain (United Kingdom).


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SECTION I

INFORMED CONSENT

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González San Segundo, Carmen; Santos Miranda, Juan A. Informed consent in radiation oncology: is consenting easier than informing? Clinical and Translational Oncology 2006 November; 8(11): 802-804. NRCBL: 8.3.1; 8.2; 8.1; 9.5.1.


Hayes, Margaret Oot. Prisoners and autonomy: implications for the informed consent process with vulnerable populations. Journal of Forensic Nursing 2006 Summer; 2(2): 84-89. NRCBL: 8.3.1; 9.5.1; 1.3.5.

Hunt, Linda M.; de Voogd, Katherine B. Are good intentions good enough?: Informed consent without trained interpreters. JGIM: Journal of General Internal Medicine 2007 May; 22(5): 598-605. NRCBL: 8.3.1; 9.5.4; 15.2.


Abstract: For decades, the greater part of efforts to improve regulatory frameworks for research ethics has focused on informed consent procedures; their design, codification and regulation. Why is informed consent thought to be so important? Since the publication of the Belmont Report in 1979, the standard response has been that obtaining informed consent is a way of treating individuals as autonomous agents. Despite its political success, the philosophical validity of this Belmont view cannot be taken for granted. If the Belmont view is to be based on a conception of autonomy that generates moral justification, it will either have to be reinterpreted along Kantian lines or coupled with a something like Mill’s conception of individuality. The Kantian interpretation would be a radical reinterpretation of the Belmont view, while the Millian justification is incompatible with the liberal requirement that justification for public policy should be neutral between controversial conceptions of the good. This consequence might be avoided by replacing Mill’s conception of individuality with a procedural conception of autonomy, but I argue that the resulting view would in fact fail to support a non-Kantian, autonomy-based justification of informed consent. These difficulties suggest that insofar as informed consent is justified by respect for persons and considerations of autonomy, as the Belmont report maintained, the justification should be along the lines of Kantian autonomy and not individual autonomy.


Abstract: The large-scale change of Czech society since 1989 has involved the democratic transformation of the health system. To empower the patient was one important goal of the healthcare reform launched immediately after the Velvet Revolution. The process has been enhanced by the accession of the Czech Republic to the European Union and the adoption of important European conventions regulating the area. The concept of informed consent and a culture of negotiation are being inserted into a traditionally paternalistic culture. Our article describes the current situation on the issue of the communication of information on state of health and treatment, and on the question of the participation of the patient in decisions on treatment. We present empirical results of a public opinion survey on this issue. The results show a still prevailing submissive attitude towards the physicians, despite the fact that the concept of informed consent has become more and more publicly familiar (42% of respondents gave the completely correct answer regarding informed consent). The impact of age, education and sex on answers to the questionnaire was analysed. Men, younger and more educated respondents were more likely to show the autonomous attitude, whereas women, older and less educated people tended to show the traditional submissive attitude. Further, our article raises the question of the cultural and historical background within which the current ethically and legally binding norms (products of western democracies, in fact) are interpreted. The question is how far cultural modifications are tolerable in the practical implementation of universal ethical constructs (informed consent).


Abstract: The way patients make health care decisions is much more complicated than is often recognized. Patient autonomy allows both that patients will sometimes defer
to clinicians and that they should sometimes be active inquirers, ready to question their clinicians and do some independent research. At the same time, patients' active inquiry requires clinicians' support.


Mason, J.K.; Laurie, G.T. Consent to treatment. *In their:* Mason and McCall Smith's Law and Medical Ethics. 7th ed. Oxford; New York: Oxford University Press, 2005: 348-411. NRCBL: 8.3.1; 8.3.2; 8.3.3; 8.3.4; 9.5.5; 9.5.6. SC: em; le. Identifiers: Great Britain (United Kingdom).

Masood, Junaid; Hafeez, Azhar; Wiseman, Oliver; Hill, James T. Informed consent: are we deluding ourselves? A randomized controlled study. *BJU International* 2007 January; 99(1): 4-5. NRCBL: 8.3.1; 9.5.1; 8.1.


Mishra, Pankaj Kumar; Ozalp, Faruk; Gardner, Roy S.; Arangannal, Arul; Murday, Andrew. Informed consent in cardiac surgery: is it truly informed? *Journal of Cardiovascular Medicine* 2006 September; 7(9): 675-681. NRCBL: 8.3.1; 9.5.1; 7.1; 8.1.


Murphy, Dominic; Dandeker, Christopher; Horn, Oded; Hotopf, Matthew; Hull, Lisa; Jones, Margaret; Marteau, Theresa; Rona, Roberto; Wessely, Simon. UK armed forces responses to an informed consent policy for anthrax vaccination: a paradoxical effect? *Vaccine* 2006 April 12; 24(16): 3109-3114. NRCBL: 8.3.1; 9.1; 9.5.1.


O’Brien, C.M.; Thorburn, T.G.; Sibbel-Linz, A.; McGregor, A.D. Consent for plastic surgical procedures. *Journal of Plastic, Reconstructive and Aesthetic Surgery* 2006; 59(9): 983-989. NRCBL: 8.3.1; 8.2; 9.5.1; 5.2. SC: em; le. Identifiers: Great Britain (United Kingdom).

O’Connor, Annette M.; Wennberg, John E.; Legare, France; Llewellyn-Thomas, Hilary A.; Moulton, Benjamin W.; Sepucha, Karen R.; Sodano, Andrea G.; King, Jaime S. Toward the ‘tipping point’: decision aids and informed patient choice. *Health Affairs* 2007 May-June; 26(3): 716-725. NRCBL: 8.3.1; 5.2.


Ab abstract: BACKGROUND: More and more quantitative information is becoming available about the risks of complications arising from medical treatment. In everyday practice, this raises the question whether each and every risk, however low, should be disclosed to patients. What could be good reasons for doing or not doing so? This will increasingly become a dilemma for practitioners. OBJECTIVE: To report doctors’ views on whether to disclose or withhold information on low risks of complications. METHODS: In a qualitative study design, 37 respondents (gastroenterologists and gynaecologists or obstetricians) were included. Focus group interviews were held with 22 respondents and individual in-depth interviews with 15. RESULTS: Doctors have doubts about disclosing or withholding information on compli-
SECTION I INFORMED CONSENT


Triner, Wayne; Jacoby, Liva; Shelton, Wayne; Burk, Mathew; Imarenakhue, Samuel; Watt, James; Larkin, Gregory; McGee, Glenn. Exception from informed consent enrollment in emergency medical research: attitudes and awareness. Academic Emergency Medicine 2007 February; 14(2): 187-191. NRCBL: 8.3.1; 9.5.1.

van den Brink-Muinen, Atie; van Dulmen, Sandra M.; de Haes, Hanneke C.J.M.; Visser, Adriaan Ph.; Schellevis, F.G.; Bensing, J.M. Has patients’ involvement in the decision-making process changed over time? Health Expectations 2006 December; 9(4): 333-342. NRCBL: 8.3.1; 8.1; 9.5.1; 9.5.2.


Recupero, Patricia R.; Rainey, Samara E. Informed consent to e-therapy. American Journal of Psychotherapy 2005; 59(4): 319-331. NRCBL: 8.3.1; 17.1; 1.3.12; 8.1.

Reider, Alan E.; Dahlinghaus, Andrew B. The impact of new technology on informed consent. Comprehensive Ophthalmology Update 2006 November-December; 7(6): 299-302. NRCBL: 8.3.1; 8.2; 8.5; 9.5.1; 4.5. SC: le.

Parsons, Brian; Kennedy, Miriam. A review of recorded information given to patients starting to take clozapine and the development of guidelines on disclosure, a key component of informed consent. Journal of Medical Ethics 2007 October; 33(10): 564-567. NRCBL: 8.3.1; 8.3.3; 17.4. SC: em.

Abstract: Clozapine is a very effective drug with both significant benefits and significant risks in treatment-resistant schizophrenia. Informed consent is generally accepted as both desirable and necessary in order to ensure that the patient’s human rights and dignity are respected. Disclosure is a key element of informed consent. It is unclear if the adequate documentation of disclosure is standard practice before initiation of clozapine. The aim of this study was to assess the adequacy of the documentation of disclosure in consent to clozapine treatment in an adult mental health service and to develop guidelines on disclosure. The method was a retrospective analysis of charts of patients given clozapine who received the drug through the pharmacy of a single North Dublin psychiatric hospital. Results show that current practice has evident gaps. The professional, ethical and legal issues are discussed.


Weinstein, James N.; Clay, Kate; Morgan, Tamara S. Informed patient choice: patient-centered valuing of surgical risks and benefits. Health Affairs 2007 May-June; 26(3): 726-730. NRCBL: 8.3.1; 5.2.

Wilson, James. Is respect for autonomy defensible? Journal of Medical Ethics 2007 June; 33(6): 353-356. NRCBL: 8.3.1; 1.1. SC: an. Abstract: Three main claims are made in this paper. First, it is argued that Onora O’Neill has uncovered a serious problem in the way medical ethicists have thought about both respect for autonomy and informed consent. Medical ethicists have tended to think that autonomous choices are intrinsically worthy of respect, and that informed consent procedures are the best way to respect the autonomous choices of individuals. However, O’Neill convincingly argues that we should abandon both these thoughts. Second, it is argued that O’Neill’s proposed solution to this problem is inadequate. O’Neill’s approach requires that a more modest view of the purpose of informed consent procedures be adopted. In her view, the purpose of informed consent procedures is simply to avoid deception and coercion, and the ethical justification for informed consent derives from a different ethical principle, which she calls principled autonomy. It is argued that contrary to what O’Neill claims, the wrongness of coercion cannot be derived from principled autonomy, and so its credentials as a justification for informed consent procedures is weak. Third, it is argued that we do better to rethink autonomy and informed consent in terms of respecting persons as ends in themselves, and a characteristically liberal commitment to allowing individuals to make certain categories of decisions for themselves.

Wirtz, Veronika; Cribb, Alan; Barber, Nick. The use of informed consent for medication treatment in hospital: a qualitative study of the views of doctors and nurses. Clinical Ethics 2007 March; 2(1): 36-41. NRCBL: 8.3.1; 9.7; 7.1. SC: em; le. Abstract: The use of informed consent for surgery or research has been widely studied; however, its use in other areas of clinical practice has received less attention. This study investigates how doctors and nurses understand informed consent in relation to the prescription and administration of medicines in secondary care. It uses a qualitative analysis of semi-structured in-depth interviews with 19 doctors and 6 nurses recruited from various specialties in a teaching hospital. The results indicate a striking gap between official and actual standards of practice. Providing information, assuring adherence and communication about potential treatment harms were raised as key issues instead of the principal goals of informed consent. Rather than simply treating these findings as support for a ‘deficit’ account of professionalism, the paper concludes that we need a richer and more grounded account of exactly when hospital medication decisions need to be subjected to the highest standards of informed consent.

Woodrow, Susannah R.; Jenkins, Anthony P. How thorough is the process of informed consent prior to outpatient gastroscopy? A study of practice in a United Kingdom District Hospital. Digestion 2006; 73(2-3): 189-197. NRCBL: 8.3.1; 8.1; 9.5.1.

Yang, Julia A.; Kombarakaran, Francis A. A practitioner’s response to the new health privacy regulations. Health and Social Work 2006 May; 31(2): 129-136. NRCBL: 8.3.1; 8.2; 8.4; 1.3.5.

INFORMED CONSENT/ INCOMPETENTS


Appelbaum, Paul S. Assessment of patients’ competence to consent to treatment. New England Journal of Medicine 2007 November 1; 357(18): 1834-1840. NRCBL: 8.3.3; 8.3.4; 8.1. SC: cs; rv.


Brady Wagner, Lynne C.; Stein, Joel. Failure to achieve assent in a communicative patient: what are the caregiver’s

SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
obligations? *Topics in Stroke Rehabilitation* 2006 Fall; 13(4): 36-41. NRCBL: 8.3.3; 8.3.4. SC: cs.


**Brodström, Linus; Johansson, Mats; Nielsen, Morten Klemme.** "What the patient would have decided": a fundamental problem with the substituted judgment standard. *Medicine, Health Care and Philosophy* 2007 September; 10(3): 265-278. NRCBL: 8.3.3; 1.1.

Abstract: Decision making for incompetent patients is a much-discussed topic in bioethics. According to one influential decision making standard, the substituted judgment standard, the decision that ought to be made for the incompetent patient is the decision the patient would have made, had he or she been competent. Although the merits of this standard have been extensively debated, some important issues have not been sufficiently explored. One fundamental problem is that the substituted judgment standard, as commonly formulated, is indeterminate in content and thus offers the surrogate little or no guidance. What the standard does not specify is just how competent one should imagine the patient to be, and what else one ought to envision about the patient’s hypothetical outlook and the circumstances surrounding his or her decision making. The article discusses this problem of underdetermined decision conditions.

**Cherney, Leora Reiff.** Ethical issues involving the right hemisphere stroke patient: to treat or not to treat? *Topics in Stroke Rehabilitation* 2006 Fall; 13(4): 47-53. NRCBL: 8.3.3; 8.3.4; 4.4.

**Childress, James F.** Must we always respect religious belief? *Hastings Center Report* 2007 January-February; 37(1): 3. NRCBL: 8.3.3; 8.1; 1.2.


**Dimond, Bridgit.** The Mental Capacity Act 2005: the new Court of Protection. *British Journal of Nursing* 2007 November 22-December 12; 16(21): 1328-1330. NRCBL: 8.3.3; 20.5.4. SC: le. Identifiers: Great Britain (United Kingdom).

**Fraleigh, Anna Schork.** An alternative to guardianship: should Michigan statutorily allow acute-care hospitals to make medical treatment decisions for incompetent patients who have neither identifiable surrogates nor advance directives? *University of Detroit Mercy Law Review* 1999 Summer; 76(4): 1079-1134. NRCBL: 8.3.3; 8.4; 9.5.2; 17.1; 20.5.4. SC: le; an.


**Fullbrook, Suzanne; Sanders, Karen.** Consent and capacity 2: the Mental Capacity Act 2005 and ‘living wills’. *British Journal of Nursing* 2007 April 26-May 9; 16(8): 474-475. NRCBL: 8.3.3; 20.5.4. SC: le. Identifiers: Great Britain (United Kingdom).

**Fullbrook, Suzanne; Sanders, Karen.** Consent and capacity: other aspects of the Mental Capacity Act. *British Journal of Nursing* 2007 May 10-23; 16(9): 538-539. NRCBL: 8.3.3; 20.5.4. SC: le. Identifiers: Great Britain (United Kingdom).


NRCBL: National Reference Center for Bioethics Literature Classification Scheme


Abstract: In this theoretical review we examine the issue of informed consent in child psychiatry. We describe the development of the concept of informed consent in the history of medicine and review the limited research on its application in child psychiatry. We analyze special features of informed consent unique to our field, such as the capacity of the child to give consent, the status of the "mature minor", the special situation of the child within the family, the place of informed consent in psychotherapy, and the ability of child psychiatrists to give full information prior to consent. We conclude that children, even under the legal age, should be part of the process of giving consent to treatment. On the other hand the complex process of obtaining consent should be aimed at achieving real involvement of patients and families and not merely adhering to formal requirements.


Abstract: The Mental Capacity Act received Royal Assent on 7 April 2005, and it will be implemented in 2007. The Act defines when someone lacks capacity and it supports people with limited decision-making ability to make as many decisions as possible for themselves. The Act lays down rules for substitute decision making. Someone taking decisions on behalf of the person lacking capacity must act in the best interests of the person concerned and choose the options least restrictive of his or her rights and freedoms. Decision making will be allowed without any formal procedure unless specific provisions apply, such as a written advance decision, lasting powers of attorney or a decision by the court of protection.


Mendelson, Danuta. Roman concept of mental capacity to make end-of-life decisions. International Journal of Law and Psychiatry 2007 May-June; 30(3): 201-212. NRCBL: 8.3.3; 8.3.4; 20.5.1; 1.1; 2.2.


Stein, Joel; Brady Wagner, Lynne C. Is informed consent a “yes or no” response? Enhancing the shared decision-
making process for persons with aphasia. *Topics in Stroke Rehabilitation* 2006 Fall; 13(4): 42-46. NRCBL: 8.3.3; 8.3.4.

Stewart, Cameron. Recent developments. *Journal of Bioethical Inquiry* 2007; 4(2): 81-84. NRCBL: 8.3.3; 20.5.3; 14.5; 18.5.4. SC: le.


Abstract: The physician-patient relationship is a cornerstone of the medical encounter and has been analyzed extensively. But in many cases, this relationship is altered because patients are unable to make decisions for themselves. In such cases, physicians rely on surrogates, who are often asked to “speak for the patient.” This view overlooks the fundamental fact that the surrogate decision maker cannot be just a passive spokesperson for the patient but is also an active agent who develops a complex relationship with the physician. Although there has been much analysis of the ethical guidelines by which surrogates should make decisions, there has been little previous analysis of the special features of the physician-surrogate relationship. Such an analysis seems crucial as the population ages and life-sustaining technologies improve, which is likely to make surrogate decision making even more common. We outline key issues affecting the physician-surrogate relationship and provide guidance for physicians who are making decisions with surrogates.

Varma, Sumeeta; Wendler, David. Medical decision making for patients without surrogates. *Archives of Internal Medicine* 2007 September 10; 167(16): 1711-1715. NRCBL: 8.3.3.

Abstract: Patients who lose decision-making capacity and lack advance directives and next of kin present a quandary for physicians. Current mechanisms for making treatment decisions for these patients rely on decision makers, such as courts, public guardians, committees, and physicians, who typically do not have sufficient knowledge to predict the patients’ preferences. Thus, these mechanisms likely yield decisions that are inconsistent with patients’ treatment preferences in many cases. A population-based treatment indicator is a computer-based tool that predicts which treatment a given patient would prefer based on the treatment preferences of similar patients in similar situations. A recent analysis suggests that a population-based treatment indicator could predict patient preferences as accurately as patient-appointed surrogates and next of kin. This analysis suggests that a population-based treatment indicator may provide a mechanism to respect the treatment preferences of patients without surrogates and ensure that their treatment preferences are respected as much as the preferences of patients who have surrogates. Collection of data on patients’ treatment preferences, especially those without surrogates, incorporation of these data into a treatment indicator, and exploration of ways to implement this approach for patients without surrogates are called for.


Abstract: Background: Physicians in intensive care units have withdrawn life support in incapacitated patients who lack surrogate decision makers and advance directives, yet little is known about how often this occurs or under what circumstances. Objective: To determine the proportion of deaths in intensive care units that occur in patients who lack decision-making capacity and a surrogate and the process that physicians use to make these decisions. Design: Multicenter, prospective cohort study. Setting: Intensive care units of 7 medical centers in 2004 to 2005. Patients: 3011 consecutive critically ill adults. Measurements: Attending physicians completed a questionnaire about the decision-making process for each incapacitated patient without a surrogate or advance directive for whom they considered limiting life support. Results: Overall, 5.5% (25 of 451 patients) of deaths in intensive care units occurred in incapacitated patients who lacked a surrogate decision maker and an advance directive. This percentage ranged from 0% to 27% across the 7 centers. Physicians considered limiting life support in 37 such patients or would have considered it if a surrogate had been available. In 6 patients, there was prospective hospital review of the decision, and in 1 patient, there was court review. In the remaining 30 patients, the decision was made by the intensive care unit team alone or by the intensive care unit team plus another attending physician. The authors found wide variability in hospital policies, professional society guidelines, and state laws regarding who should make life-support decisions for this patient population. Thirty-six of 37 life-support decisions were made in a manner inconsistent with American College of Physicians guidelines for judicial review. Limitations: The results are based on physicians’ self-reported practices and may not match actual practices. The number of incapacitated patients without surrogates in the study is small. Conclusions: Incapacitated patients without surrogates accounted for approximately 1 in 20 deaths in intensive care units. Most life-support decisions were made by physicians without institutional or judicial review.
**Wilson, Naomi.** Professionals’ experiences of addressing ethical issues in services for people with intellectual disabilities: a brief report. *Ethics and Intellectual Disability* 2005 Winter; 8(2): 5-7. NRCBL: 8.3.3; 9.5.3; 1.1.


**Wrigley, A.** Proxy consent: moral authority misconceived. *Journal of Medical Ethics* 2007 September; 33(9): 527-531. NRCBL: 8.3.3. SC: an; le.

Abstract: The Mental Capacity Act 2005 has provided a unified scope in the British medical system for proxy consent with regard to medical decisions, in the form of a lasting power of attorney. While the intentions are to increase the autonomous decision making powers of those unable to consent, the author of this paper argues that the whole notion of proxy consent collapses into a paternalistic judgement regarding the other person’s best interests and that the new legislation introduces only an advisor, not a proxy with the moral authority to make treatment decisions on behalf of another. The criticism is threefold. First, there is good empirical evidence that people are poor proxy decision makers as regards accurately representing other people’s desires and wishes, and this is therefore a pragmatically inadequate method of gaining consent. Second, philosophical theory explaining how we represent other people’s thought processes indicates that we are unlikely ever to achieve accurate simulations of others’ wishes in making a proxy decision. Third, even if we could accurately simulate other people’s beliefs and wishes, the current construction of proxy consent in the Mental Capacity Act means that it has no significant ethical authority to match that of autonomous decision making. Instead, it is governed by a professional, paternalistic, best-interests judgement that undermines the intended role of a proxy decision maker. The author argues in favour of clearly adopting the paternalistic best-interests option and viewing the proxy as solely an advisor to the professional medical team in helping make best-interests judgements.

**INFORMED CONSENT/ MINORS**


**Cashmore, Judy.** Ethical issues concerning consent in obtaining children’s reports on their experience of violence. *Child Abuse and Neglect* 2006 September; 30(9): 969-977. NRCBL: 8.3.2; 9.5.7; 9.1; 18.2; 18.3; 18.5.2.

**Cohn, Felicia.** Real life informs consent. *Journal of Clinical Ethics* 2007 Winter; 18(4): 366-368. NRCBL: 8.3.2; 8.3.1; 9.6; 20.5.2.

**Furton, Edward J.** Morality is not a medical problem. *Ethics and Medicine* 2007 July; 32(7): 3-4. NRCBL: 8.3.2; 9.5.1; 9.7; 9.5.5; 9.5.7; 8.3.4; 1.2.


**Hester, D. Micah.** Interests and neonates: there is more to the story than we explicitly acknowledge. *Theoretical Medicine and Bioethics* 2007; 28(5): 357-372. NRCBL: 8.3.2; 9.5.7.

Abstract: Although there are many different moral arguments concerning the use of Best Interests in neonatal decision-making, there seems in practice a firm commitment to application of the concept. And yet, there is still little reflection given by practitioners about what employing a Best Interest determination means in infant care. The following lays out a comprehensive taxonomy of interest-sources in order to provide for more robust considerations of what constitutes best interests of/for neonates.

**Hickey, Kathryn.** Minors rights in medical decision making. *JONA’s Healthcare Law, Ethics, and Regulation* 2007 July-September; 9(3): 100-106. NRCBL: 8.3.2; 1.2; 8.3.4; 8.4; 18.5.2; 18.2.

Abstract: In the past, minors were not considered legally capable of making medical decisions and were viewed as incompetent because of their age. The authority to consent or refuse treatment for a minor remained with a parent or guardian. This parental authority was derived from the constitutional right to privacy regarding family matters, common law rule, and a general presumption that parents or guardians will act in the best interest of their incompetent child. However, over the years, the courts have gradually recognized that children younger than 18 years who show maturity and competence deserve a voice in determining their course of medical treatment. This article will explore the rights and interests of minors, parents, and the state in medical decision making and will address implications for nursing administrators and leaders.


**Kopelman, Loretta M.; Kopelman, Arthur E.** Using a new analysis of the best interests standard to address cultural disputes: whose data, which values? *Theoretical..."
SECTION I
INTERNATIONAL HEALTH AND HUMAN RIGHTS

Medicine and Bioethics 2007; 28(5): 373-391. NRCBL: 8.3.2; 8.3.4; 20.5.2; 21.7. SC: cs.

Abstract: Clinicians sometimes disagree about how much to honor surrogates’ deeply held cultural values or traditions when they differ from those of the host country. Such a controversy arose when parents requested a cultural accommodation to let their infant die by withdrawing life saving care. While both the parents and clinicians claimed to be using the Best Interests Standard to decide what to do, they were at an impasse. This standard is analyzed into three necessary and jointly sufficient conditions and used to resolve the question of how much to accommodate cultural preferences and how to treat this infant. The extreme versions of absolutism and relativism are rejected. Properly understood, the Best Interests Standard can serve as a powerful tool in settling disputes about how to make good decisions for those who cannot decide for themselves.

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Lo, Bernard.

Slonina, Mary Irene.

Sobsey, Dick.
Growth attenuation and indirect-benefit rationale. Ethics and Intellectual Disability 2007 Winter; 10(1): 1,2, 7-8. NRCBL: 8.3.2; 9.5.3; 1.1.

Stultiëns, Loes; Goffin, Tom; Borry, Pascal; Dierickx, Kris; Nys, Herman.

Wilfond, Benjamin S.

Wright, Wendy; Stabile, Nancy.
HPV mandates: parents trump politics. Ethics and Medics 2007 July; 32(7): 1-3. NRCBL: 8.3.2; 9.5.1; 9.7; 9.5.5; 9.5.7; 8.3.4. Identifiers: human papillomavirus.

INSTITUTIONAL REVIEW BOARDS See HUMAN EXPERIMENTATION/ ETHICS COMMITTEES AND POLICY GUIDELINES

INTERNATIONAL HEALTH AND HUMAN RIGHTS

See also TORTURE, GENOCIDE AND WAR CRIMES; WAR AND TERRORISM

Bennett, Belinda.

Bibeau, Gilles; Pedersen, Duncan.

Borst-Eisler, Els.

Charo, R. Alta.

DeCamp, Matthew.

Denniston, George C.

Fleck, Leonard M.
Can we trust “democratic deliberation”? Hastings Center Report 2007 July-August; 37(4): 22-25. 4 refs. NRCBL: 21.1; 14.1; 15.1; 5.3. SC: an; le. Comments: Franco Furger and Francis Fukuyama. A proposal for modernizing the regulation of human biotechnologies. Hastings Center Report 2007 July-August; 37(4): 16-20. Keywords: *biotechnology; *democracy; *policy making; *public participation; *reproductive technologies; accountability; bioethical issues; cloning; cultural pluralism; embryonic research; embryonic stem cells; freedom; genetic engineering; government financing; government regulation; policy analysis; preimplantation diagnosis; public policy; regulation; *Keyword Identiifers: *United States

Gadd, Elaine.


Jayasinghe, Saroj. Faith-based NGOs and healthcare in poor countries: a preliminary exploration of ethical issues. Journal of Medical Ethics 2007 November; 33(11): 623-626. NRCBL: 21.1; 1.2; 9.1. Abstract: An increasing number of non-governmental organisations (NGOs) provide humanitarian assistance, including healthcare. Some faith-based NGOs combine proselytising work with humanitarian aid. This can result in ethical dilemmas that are rarely discussed in the literature. The article explores several ethical issues, using four generic activities of faith-based NGOs: (1) It is discriminatory to deny aid to a needy community because it provides less opportunity for proselytising work. Allocating aid to a community with fewer health needs but potential for proselytising work is unjust, since it neither maximises welfare (utilitarianism) nor assists the most needy (egalitarianism). (2) Faith-based-NGOs may state that proselytising work combined with humanitarian assistance improves spiritual wellbeing and overall benefit. However, proselytising work creates religious doubts, which could transiently decrease wellbeing. (3) Proselytising work is unlikely to be perceived need of the population and, if carried out without consent, breaches the principle of autonomy. Such work also exploits the vulnerability of disaster victims. (4) Governments that decline the assistance of a faith-based NGO involved in proselytising work may deprive the needy of aid. Three strategies are proposed: (a) Increase knowledge to empower communities, individuals and governments; information on NGOs could be provided through an accessible register that discloses objectives, funding sources and intended spiritual activities. (b) Clearly demarcate between humanitarian aid from proselytising work, by setting explicit guidelines for humanitarian assistance. (c) Strengthen self-regulation by modifying the Code of Conduct of the Red Cross to state criteria for selecting communities for assistance and procedures for proselytising work.


Novotny, Thomas E.; Mordini, Emilio; Chadwick, Ruth; Pedersen, J. Martin; Fabbi, Fabrizio; Lie, Reidar; Thanachaiboot, Natapong; Mossialos, Elias; Permanand, Govin. Bioethical implications of globalization: an international consortium project of the European Commission. PLoS Medicine 2006 February; 3(2); e43: 0173-0176. 16 refs. NRCBL: 21.1; 9.1; 1.3.12; 15.1; 9.3.1; 21.3. Keywords: *communicable diseases; *international aspects; *policy making; *public health; *trends; access to information; biomedical research; bioterrorism; commerce; developing countries; genetic predisposition; genetic screening; genetically modified plants; genomics; health care delivery; immigrants; Internet; population genetics; property rights; resource allocation; social impact; social problems; Proposed Keywords: *technology; *world health; developed countries; genetic resources; travel; Key- word Identifiers: *Bioethical Implications of Globalization Project; *European Commission; Europe; European Union...
SECTION I  INTERNATIONAL MIGRATION OF HEALTH CARE PROFESSIONALS


Abstract: Legal instruments and litigation as a way to enforce the rights to life and to health is a relatively new strategy that is increasingly common. We show how legal measures have been used to attain health and human rights with case examples from India and South Africa that resulted in large public-health benefits.


Abstract: Human rights, considered as rights inherent to all human beings, must be respected unconditionally, especially during health care delivery. These rights became actually protected by International Law when the UN was created in 1945 and, later, when the Universal Declaration of Human Rights was issued in 1948, giving rise to various subsequent treaties. Based on the historical evolution of Human Rights in the international sphere, associated with the principles of constitutional, penal and civil law and psychiatric patient rights in Brazil, we aim to understand some dilemmas of psychiatric nursing care: individuals’ rights as psychiatric patients, hospitalization and nursing professionals’ practice. In their practice, nurses attempt to conciliate patients’ rights with their legal role and concerns with high-quality psychiatric care. In coping with these dilemmas, these professionals are active in three spheres: as health care providers, as employees of a health organization and as citizens.


INTERNATIONAL MIGRATION OF HEALTH CARE PROFESSIONALS


Abstract: When health care workers migrate from poor countries to rich countries, they are exercising an important human right and helping rich countries fulfill obligations of social justice. They are also, however, creating problems of social justice in the countries they leave. Solving these problems requires balancing social needs against individual rights and studying the relationship of social justice to international justice.

IN Voluntary COMMITMENT


Griffith, Richard. Authorizing the deprivation of liberty of incapable adults in institutions. *British Journal of Community Nursing* 2006 December; 11(12): 538-541. NRCBL: 17.7; 8.3.3; 17.8.


Kuosmanen, Lauri; Hätönen, Heli; Malkavaara, Heikki; Kyllmä, Jari; Välimäki, Maritta. Deprivation of liberty in psychiatry hospital care: the patient’s perspective. *Nursing Ethics* 2007 September; 14(5): 597-607. NRCBL: 17.7. SC: em. Identifiers: Finland. Abstract: Deprivation of liberty in psychiatric hospitals is common world-wide. The aim of this study was to find out whether patients had experienced deprivation of their liberty during psychiatric hospitalization and to explore their views about it. Patients (n = 51) in two acute psychiatric inpatient wards were interviewed in 2001. They were asked to describe in their own words their experiences of being deprived of their liberty. The data were analysed by inductive content analysis. The types of deprivation of liberty in psychiatric hospital care reported by these patients were: restrictions on leaving the ward and on communication, confiscation of property, and various coercive measures. The patients’ experiences of being deprived of their liberty were negative, although some saw the rationale for using these interventions, considering them as part of hospital care.


Pescosolido, Bernice A; Fettes, Danielle L.; Martin, Jack K.; Monahan, John; McLeod, Jane D. Perceived dangerousness of children with mental health problems and support for coerced treatment. *Psychiatric Services* 2007 May; 58(5): 619-625. NRCBL: 17.7; 4.3; 8.3.2. SC: em.


Zion, Deborah; Jureidini, Jon; Newman, Louise; Kyambi, Sarah; Zion, Deborah. Replication: in that case [case study and commentaries]. *Journal of Bioethical Inquiry* 2006; 3(3): 193-202. NRCBL: 17.7; 1.3.5; 9.5.4; 4.3; 4.1.1; 8.3.3; 10; 17.1; 17.8. SC: cs; le.

**JOURNALISM AND PUBLISHING**

See also BIOMEDICAL RESEARCH


Benítez-Bribiesca, Luis; Modiano-Esquenazi, Marcos. Ethics of scientific publication after the human stem cell scandal [editorial]. *Archives of Medical Research* 2006 May; 37(4): 423-424. NRCBL: 1.3.7; 1.3.9.

Bevan, Joan C.; Miller, Donald R. Medical journals and cross-cultural research ethics. *Canadian Journal of Anaesthesia = Journal Canadien d’anesthésie* 2005 December; 52(10): 1009-1016. NRCBL: 1.3.7; 21.7; 18.2.

Bogod, D.G. The editor as umpire: clinical trial registration and dispute resolution. *Anaesthesia* 2006 December; 61(12): 1133-1135. NRCBL: 1.3.7; 18.2; 18.6.


Abstract: This article examines some of the story conventions of network television news to explain the ways in which healthcare interest groups develop and maintain their presence in this medium - a process that has significant implications for public understanding of healthcare issues, and therefore to bioethics. The article is divided into three sections. The first section focuses on three major normative conventions of television news: adherence to a simple narrative structure, the balance ethic, and avoidance of the “think-piece” and outlines the basic strategies available to interest groups for exploiting these normative conventions. Section two introduces three case studies of organizations and individuals who have run high-profile media campaigns. Section three explores the implications for bioethics of the observations made in this article.


Keywords: *genetic research; *genetic services; *marketing; *mass media; biomedical research; biotechnology; government financing; industry; journalism; policy making; public participation; research priorities; research support; researchers; science; technology assessment; Keyword Identifiers: Canada


de Melo-Martín, Immaculada; Intemann, Kristen. Authors’ financial interests should be made known to manuscript reviewers. *Nature* 2007 July 12; 448(7150): 129. NRCBL: 1.3.7; 1.3.9; 7.3.

Derbyshire, Stuart W.G. Medical journals: past their sell by date? *BMJ: British Medical Journal* 2007 January 6; 334(7583): 45. NRCBL: 1.3.7; 1.3.9; 9.7.


Goldacre, Ben. Why don’t journalists mention the data? BMJ: British Medical Journal 2007 June 16; 334(7606): 1249. NRCBL: 1.3.7; 1.3.9; 18.1.


Holaday, Margot; Yost, Tracey E. Tobacco industry sponsorship of a book and conflict of interest. Addiction 2006 August; 101(8): 1202-1211. NRCBL: 1.3.7; 1.3.9; 9.3.1; 1.3.7.

Hren, Darko; Sambunjak, Dario; Ivanis, Ana; Marusic, Marko; Marusic, Ana. Permissions of authorship criteria: effects of student instruction and scientific experience. Journal of Medical Ethics 2007 July; 33(7): 428-432. NRCBL: 1.3.7; 1.3.9. SC: em. Abstract: Objective: To analyse medical students’/graduate students’/doctors’ and medical teachers’ perceptions of research contributions as criteria for authorship in relation to the authorship criteria defined by the International Committee of Medical Journal Editors (ICMJE). Design: Medical students with (n = 152) or without (n = 85) prior instruction on ICMJE criteria, graduate students/doctors (n = 125) and medical teachers (n = 112) rated the importance of 11 contributions as authorship qualifications. They also reported single contributions eligible for authorship, as well as acceptable combinations of two or three qualifying contributions. Results: Concept and design, Analysis and interpretation and Drafting of article formed the most important cluster in all four groups. Students without prior instruction rated Critical revision and Final approval lower than the other three groups. “Final approval” was a part of the least important cluster in all groups except among students with instruction. Conclusions: Concept and design, Analysis and interpretation and Drafting of article were recognized as the most important of the ICMJE criteria by all participants. They can be considered independent of previous instruction or experience. Final approval and Critical review should be actively taught as important authorship criteria to future scientists.


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SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
Luft, Harold S.; Flood, Ann Barry; Escaré, José J. New policy on disclosures at Health Services Research. *Health Services Research* 2006 October; 41(5): 1721-1732. NRCBL: 1.3.7; 7.3; 9.7; 1.3.2; 9.3.1.

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Vaithianathan, Rhema. Better the devil you know than the doctor you don’t: is advertising drugs to doctors more harmful than advertising to patients? *Journal of Health Services Research and Policy* 2006 October; 11(4): 235-239. NRCBL: 1.3.7; 7.1; 1.3.2; 9.7.

Woolley, Karen L. Goodbye Ghostwriters!: How to work ethically and efficiently with professional medical writers. *Chest* 2006 September; 130(3): 921-923. NRCBL: 1.3.7; 1.3.9.


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Keywords: *compensation; *deception; *DNA fingerprinting; *fathers; *fraud; *paternity; autonomy; children; financial support; genetic relatedness ties; legal aspects; marital relationship; mothers

Abstract: Claims for reimbursement of child support, the reversal of property settlements and compensation can arise when misattributed paternity is discovered. The ethical justifications for such claims seem to be related to the financial cost of bringing up children, the absence of choice about taking on these expenses, the hard work involved in child rearing, the emotional attachments that are formed with children, the obligation of women to make truthful claims about paternity, and the deception involved in infidelity. In this paper it is argued that there should not be compensation for infidelity and that reimbursement is appropriate where the claimant has made child support payments but has not taken on the social role of father. Where the claimant’s behaviour suggests a social view of fatherhood, on the other hand, claims for compensation are less coherent. Where the genetic model of fatherhood dominates, the “other” man (the woman’s lover and progenitor of the children) might also have a claim for the loss of the benefits of fatherhood. It is concluded that claims for reimbursement and compensation in cases of misattributed paternity produce the same distorted and thin view of what it means to be a father that paternity testing assumes, and underscores a trend that is not in the interests of children.

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Dyer, Clare. GMC to introduce “plea bargaining” for less serious misconduct cases. *BMJ: British Medical Journal* 2007 April 14; 334(7597): 763. NRCBL: 7.4. Identifiers: Great Britain (United Kingdom); General Medical Council.


Abstract: This paper argues that three salient corrupt practices that mark contemporary Chinese health care, namely the over-prescription of indicated drugs, the prescription of more expensive forms of medication and more expensive diagnostic work-ups than needed, and illegal cash payments to physicians-i.e., red packages-result not from the introduction of the market to China, but from two clusters of circumstances. First, there has been a loss of the Confucian appreciation of the proper role of financial reward for good health care. Second, misguided governmental policies have distorted the behavior of
physicians and hospitals. The distorting policies include (1) setting very low salaries for physicians, (2) providing bonuses to physicians and profits to hospitals from the excessive prescription of drugs and the use of more expensive drugs and unnecessary expensive diagnostic procedures, and (3) prohibiting payments by patients to physicians for higher quality care. The latter problem is complicated by policies that do not allow the use of governmental insurance and funds from medical savings accounts in private hospitals as well as other policies that fail to create a level playing field for both private and government hospitals. The corrupt practices currently characterizing Chinese health care will require not only abolishing the distorting governmental policies but also drawing on Confucian moral resources to establish a rightly directed appreciation of the proper place of financial reward in the practice of medicine.


Magnavita, Nicola. The unhealthy physician. Journal of Medical Ethics 2007 April; 33(4): 210-214. NRCBL: 7.4; 16.3; 9.1; 8.1. Abstract: BACKGROUND: Physicians, if affected by transmissible or impairing diseases, could be hazardous for third persons. AIM: To solve the apparent chasm between patient’s and sick worker’s rights, a consensus-building process leading to hospital-wide policies is the better alternative to individual decision making. CONCLUSIONS: Policies have to balance the rights of the sick worker, the right of the other workers, patients and customers, and society’s expectations.


MANAGED CARE PROGRAMS See HEALTH CARE/ HEALTH CARE ECONOMICS/ MANAGED CARE PROGRAMS

MASS SCREENING See PUBLIC HEALTH

MEDICAL EDUCATION
See also BIOETHICS AND MEDICAL ETHICS/ EDUCATION

Educational advantage. Journal of Empirical Research on Human Research Ethics 2007 March; 2(1): 47-48. NRCBL: 7.2; 18.2; 18.6; 1.3.1; 8.4. SC: ie. Abstract: The research articles in the March 2007 issue of JERHRE explore two major topics: • Research methods wherein the investigator does not have unilateral control over the setting, as in ethnography and community-based participatory research, raise special problems of ethical oversight and problem solving. • Introducing new ethical oversight, whether developing an effective ethics committee in a developing country or implementing HIPAA requirements in human research, call for mindfulness of ethical objectives rather than simple rule following. JERHRE has an advantage in the ethics education arena. Lecturing about what should be done is an ineffective way to change people’s hearts and minds, much less their behavior. In contrast, JERHRE provides concepts and methods that learners can use to discover for themselves what should be done. In the process, learners discover that what they should do is synergistic with what is in their best interests. Such is the persuasive power of evidence-based ethical problem solving.

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Austin, Zubin; Collins, David; Remillard, Alfred; Kelcher, Sheila; Chui, Stephanie. Influence of attitudes toward curriculum on dishonest academic behavior. American Journal of Pharmaceutical Education 2006 June 15; 70(3): 50. NRCBL: 7.2; 7.4; 9.7.

NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.

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Elcin, Melih; Odabasi, Orhan; Gokler, Bahar; Sayek, Isender; Akova, Murat; Kiper, Nural. Developing and evaluating professionalism. *Medical Teacher* 2006 February; 28(1): 36-39. NRCBL: 7.2; 4.1.2; 1.3.1.


Finkel, Alan G. Conflict of interest or productive collaboration? The pharma: academic relationship and its implications for headache medicine. *Headache* 2006 July-August; 46(7): 1181-1185. NRCBL: 7.2; 9.7; 1.3.2; 9.3.1.

Fitz, Matthew M.; Homan, David; Reddy, Shalini; Griffith, Charles H.; Baker, Elizabeth; Simpson, Kevin P. The hidden curriculum: medical students’ changing opinions toward the pharmaceutical industry. *Academic Medicine* 2007 October; 82(10, Supplement): S1-S3. NRCBL: 7.2; 9.7; 1.3.2; 9.3.1. SC: em.

SECTION I MEDICAL EDUCATION


Goodman, Robert L. Medical education and the pharmaceutical industry. Perspectives in Biology and Medicine 2007 Winter; 50(1): 32-39. NRCBL: 7.2; 9.7; 1.3.3.

Görgülü, Refia Selma; Dinç, Leyla. Ethics in Turkish nursing education programs. Nursing Ethics 2007 November; 14(6): 741-752. NRCBL: 7.2; 2.3; 9.1.


Hamilton, Patricia. Ethical dilemmas in training tomorrow’s doctors. Paediatric Respiratory Reviews 2006 June; 7(2): 129-134. NRCBL: 7.2; 8.1; 9.5.7; 9.8.


Abstract: In a recent paper published in the Journal of Medical Ethics, Le Morvan and Stock claim that the kantian ideal of treating people always as ends in themselves and never merely as a means is in direct and insurmountable conflict with the current medical practice of allowing practitioners at the bottom of their “learning curve” to “practise their skills” on patients. In this response, I take up the challenge they issue is and try to reconcile this conflict. The kantian ideal offered in the paper is an incomplete characterisation of Kant’s moral philosophy, and the formula of humanity is considered in isolation without taking into account other salient kantian principles. I also suggest that their argument based on “necessary for the patient” assumes too narrow a reading of “necessary”. This reply is intended as an extension to, rather than a criticism of, their work.


Abstract: This article aims to present 10 years of experience of teaching ethics in a Masters Program in Public Health in Lithuania, and to discuss the content, skills, teaching approach and tools of this programme. In addition, the article analyses the links between ethics and law, identifies the challenges of the teaching process and suggests future teaching strategies. The important role of teaching ethics in countries that are in transition owing to a radically changing value system is emphasised.

Johnston, Carolyn; Haughton, Peter. Medical students’ perceptions of their ethics teaching. Journal of Medical Ethics 2007 July; 33(7): 418-422. NRCBL: 7.2; 2.3; SC: em.

Abstract: The teaching of ethics in UK medical schools has recently been reviewed, from the perspective of the teachers themselves. A questionnaire survey of medical undergraduates at King’s College London School of Medicine provides useful insight into the students’ perception of ethics education, what they consider to be the value of learning ethics and law, and how engaged they feel with the subject.

Kanter, Steven L.; Wimmers, Paul F.; Levine, Arthur S. In-depth learning: one school’s initiatives to foster integration of ethics, values, and the human dimensions of medicine. Academic Medicine 2007 April; 82(4): 405-409. NRCBL: 7.2; 2.1; 2.3; 4.1.2; 1.3.1.


Langone, Melissa. Promoting integrity among nursing students. Journal of Nursing Education 2007 January; 46(1): 45-47. NRCBL: 7.2; 4.1.3.

Leino-Kilpi, Helena. [Education in nursing ethics research] [editorial]. Nursing Ethics 2007 July; 14(4): 443-444. NRCBL: 7.2; 4.1.3.


Lipscomb, Martin; Snelling, Paul C. Moral content and assignment marking: an exploratory study. Nurse Education Today 2006 August; 26(6): 457-464. NRCBL: 7.2; 1.1; 4.1.3; 7.1; 7.3.

Lown, Beth A.; Chou, Calvin L.; Clark, William D.; Haidet, Paul; White, Maysel Kemp; Krupat, Edward; Pelletier, Stephen; Weissmann, Peter; Anderson, M. Brownell. Caring attitudes in medical education: perceptions of deans and curriculum leaders. JGIM: Journal of General Internal Medicine 2007 November; 22(11): 1514-1522. NRCBL: 7.2; 4.1.1; 4.1.2; 8.1. SC: em.


Shapiro, Johanna; Rucker, Lloyd; Robitshek, Daniel. Teaching the art of doctoring: an innovative medical student elective. Medical Teacher 2006 February; 28(1): 30-35. NRCBL: 7.2; 4.1.2; 1.3.1.


Abstract: A cross-sectional study explored the moral judgement competence and moral attitudes of 310 Czech and Slovak and 70 foreign national students at the Medical Faculty of Charles University in Hradec Králové, Czech Republic. Lind’s Moral Judgement Test was used to evaluate moral judgement competence and moral attitudes depending on factors such as age, number of semesters of study, sex, nationality and religion. Moral judgement competence decreased significantly in the Czech and Slovak medical students as they grew older; in medical students from other countries it did not significantly increase. The influence of other factors (sex, nationality and religion) on moral judgement competence was not proven in either the Czech and Slovak or the foreign national medical students. Moral attitudes do not change; the Czech and Slovak as well as the foreign students preferred the post-conventional levels of moral judgement (Kohlberg’s 5th and 6th stages). The fact that the Czech and Slovak students’ moral judgement competence decreased with age and number of semesters of study completed is not an optimistic sign: medical students who had undergone a lower number of semesters of study were morally more competent.


Talbott, John A.; Mallott, David B. Professionalism, medical humanism, and clinical bioethics: the new wave — does psychiatry have a role? Journal of Psychiatric Practice 2006 November; 12(6): 384-390. NRCBL: 7.2; 4.1.2; 1.3.1; 17.1; 7.1.

Toliušiene, Jolanta; Peicius, Eimantas. Changes in nursing ethics education in Lithuania. Nursing Ethics 2007 November; 14(6): 753-757. NRCBL: 7.2; 2.3; 4.1.3.

van Hooft, Stan. Socratic dialogue: an example. In: Tschudin, Verena, ed. Approaches to Ethics: Nursing Be-
Vanlaere, Linus; Gastmans, Chris. Ethics in nursing education: learning to reflect on care practices. *Nursing Ethics* 2007 November; 14(6): 758-766. NRCBL: 7.2; 2.3; 1.1; 4.1.3.


Vezeau, Toni M. Teaching professional values in a BSN program. *International Journal of Nursing Education Scholarship* 2006; 3: Article 25. NRCBL: 7.2; 4.1.3; 8.1.

Whiting, Demian. Inappropriate attitudes, fitness to practise and the challenges facing medical educators. *Journal of Medical Ethics* 2007 November; 33(11): 667-670. NRCBL: 7.2; 9.8; 2.3.

Abstract: The author outlines a number of reasons why morally inappropriate attitudes may give rise to concerns about fitness to practise. He argues that inappropriate attitudes may raise such concerns because they can lead to harmful behaviours (such as a failure to give proper care or treatment), and because they are often themselves harmful (both because of the offence that they can cause and because of the unhealthy pall that they may cast over relations between healthcare practitioners and patients). He also outlines some of the challenges that the cultivation and assessment of attitudes in students raise for medical educators and some of the ways in which those challenges may be approached and possibly overcome.


Abstract: Definition of the problem: The regulation of residents’ work hours involves several ethical conflicts which need to be systematically analysed and evaluated. Arguments and conclusion: The most important ethical principle when regulating work hours is to avoid the harm resulting from the over-work of physicians and from an excessive division of labour. Additionally, other ethical principles have to be taken into account, in particular the principles of nonmaleficence and beneficence for future patients and for physicians. The article presents arguments for balancing the relevant ethical principles and analyses the structural difficulties that occur unavoidably in any regulation of the complex activities of physicians.

Wolfberg, Adam J. The patient as ally — learning the pelvic examination. *New England Journal of Medicine* 2007 March 1; 356(9): 889-890. NRCBL: 7.2; 9.5.5; 8.3.1; 8.1.


Abstract: The population of most non-dominant ethnic groups in the USA is growing dramatically. Faculty members are challenged to develop curricula that adequately prepare our future nurses. An increased focus on clinical ethics has resulted from the use of sophisticated technology, changes in health care financing, an increasing elderly population and the shift of care from inpatient to outpatient settings. Nurses frequently face situations demanding resolution of ethical dilemmas involving cultural differences. Nursing curricula must include content on both ethics and cultural sensitivity. Active student participation is an important element providing a foundation for ethical practice. A proposed educational format was introduced with graduating baccalaureate students. In a pilot study, curricular content on cultural sensitivity and ethical practice was taught in separate modules. Students were then asked to identify and problem solve an ethical dilemma involving patients and professional caregivers from vastly different cultures. Course faculty members provided discussion questions to guide the students’ thinking.

**MEDICAL ERRORS** See HEALTH CARE/HEALTH CARE QUALITY

**MEDICAL ETHICS** See BIOETHICS AND MEDICAL ETHICS

**MENTAL HEALTH, CONCEPT OF**

*See also* MENTAL HEALTH THERAPIES AND NEUROSCIENCES

Barry, Colleen L. The political evolution of mental health parity. *Harvard Review of Psychiatry* 2006 July-August; 14(4): 185-194. NRCBL: 4.3; 9.3.1; 1.3.2; 1.3.5.


Rosen, Jeffrey. The brain on the stand: how neuroscience is transforming the legal system. *New York Times Magazine* 2007 March 11; p. 48-53, 70, 77, 82, 83. NRCBL: 4.3; 17.1; 1.3.8; 1.3.5. SC: po; le.
Mental Health Therapies and Neurosciences


**MENTAL HEALTH THERAPIES AND NEUROSCIENCES**

See also BEHAVIOR CONTROL; CARE FOR SPECIFIC GROUPS/ MENTALLY DISABLED; ELECTROCONVULSIVE THERAPY; HUMAN EXPERIMENTATION/SPECIAL POPULATIONS/MENTALLY DISABLED; INVOLUNTARY COMMITMENT; MENTAL HEALTH, CONCEPT OF; PSYCHOPHARMACOLOGY; PSYCHOTHERAPY


Keywords: *access to information;* brain; *exceptionalism;* government regulation; *neurosciences;* privacy; disclosure; federal government; genetic information; legislation; presumed consent; state government; Proposed Keywords: *brain imaging; magnetic resonance imaging;* Keyword Identifiers: *United States; Health Insurance Portability and Accountability Act (HIPAA)*


Keywords: *drug abuse;* neurosciences; autonomy; behavior control; behavioral genetics; biomedical enhancement; coercion; confidentiality; genetic engineering; genetic research; genetic screening; immunization; informed consent; preimplantation diagnosis; psychoactive drugs


**Blank, Robert H.** Policy implications of the new neuroscience. *CQ: Cambridge Quarterly of Healthcare Ethics* 2007 Spring; 16(2): 169-180. NRCBL: 17.1; 4.4; 5.3; 17.3.


**SC (Subject Captions):** an=analytical cs=case studies em=empirical le=legal po=popular rv=review

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Burke, Greg F. Medicine: mental health and war; dementia and vasectomy; oocyte donation and sale; pedophilia; benefits of rest; diabetes mellitus; abortion and breast cancer; spirituality and health; euthanasia in the Netherlands; the Supreme Court decision on partial-birth abortion. *National Catholic Bioethics Quarterly* 2007 Autumn; 7(3): 579-594. NRCBL: 17.1; 21.2; 14.4; 10; 12.1; 20.7.

Canli, Turhan; Brandon, Susan; Casebeer, William; Crowley, Philip J.; DuRousseau, Don; Greely, Henry T.; Pascual-Leone, Alvaro. Neuroethics and national security. *American Journal of Bioethics* 2007 May; 7(5): 3-13. NRCBL: 17.1; 5.1; 1.3.8; 1.3.5; 21.3.


Chatterjee, Anjan. Cosmetic neurology and cosmetic surgery: parallels, predictions, and challenges. *CQ: Cambridge Quarterly of Healthcare Ethics* 2007 Spring; 16(2): 129-137. NRCBL: 17.1; 4.4; 4.5; 5.2; 7.1; 9.5.1.


Abstract: The idea of enhancing our mental functions through medical means makes many people uncomfortable. People have a vague feeling that altering our brains tinkers with the core of our personalities and the core of ourselves. It changes who we are, and doing so seems wrong, even if the exact reasons for the unease are difficult to define. Many of the standard arguments against neuroenhancements—that they are unsafe, that they violate the distinction between therapy and enhancements, that they undermine equality, and that they will be used coercively—fail to show why the use of any such technologies is wrong in principle. Two other objections—the arguments that such changes undermine our integrity and that they prevent us from living authentic lives—will condemn only a few of the uses that are proposed. The result is that very few uses of these drugs are morally suspect and that most uses are morally permissible.
Dowine, Jocelyn; Marshall, Jennifer. Pediatric neuroimaging ethics. *Cambridge Quarterly of Healthcare Ethics* 2007 Spring; 16(2): 147-160. NRCBL: 17.1; 4.4; 9.5.7; 5.2; 8.4; 9.4.


Dyer, Clare. Mental health act becomes law after concessions are made [news]. *BMJ: British Medical Journal* 2007 July 14; 335(7610): 65. NRCBL: 17.1; 1.3.5; 17.7. SC: le.

Eaton, Margaret L.; Illes, Judy. Commercializing cognitive neurotechnology — the ethical terrain. *Nature Biotechnology* 2007 April; 25(4): 393-397. NRCBL: 17.1; 4.4; 8.4; 5.1; 9.3.1.


Ellilä, Heikki; Välimäki, Maritta; Warne, Tony; Sourander, Andre. Ideology of nursing care in child psychiatric inpatient treatment. *Nursing Ethics* 2007 September; 14(5): 583-596. NRCBL: 17.1; 9.5.7; 4.1.3; 8.1. SC: em. Identifiers: Finland. Abstract: Research on nursing ideology and the ethics of child and adolescent psychiatric nursing care is limited. The aim of this study was to describe and explore the ideological approaches guiding psychiatric nursing in child and adolescent psychiatric inpatient wards in Finland, and discuss the ethical, theoretical and practical concerns related to nursing ideologies. Data were collected by means of a national questionnaire survey, which included one open-ended question seeking managers’ opinions on the nursing ideology used in their area of practice. Questionnaires were sent to all child and adolescent psychiatric inpatient wards (n = 69) in Finland; 61 ward managers responded. Data were analysed by qualitative and quantitative content analysis. Six categories — family-centred care, individual care, milieu-centred care, integrated care, educational care and psychodynamic care — were formed to specify ideological approaches used in inpatient nursing. The majority of the wards were guided by two or more approaches. Nursing models, theories and codes of ethics were almost totally ignored in the ward managers’ ideological descriptions.


Farah, Martha J.; Heberlein, Andrea S. Personhood and neuroscience: naturalizing or nihilating? *American Journal of Bioethics* 2007 January; 7(1): 37-48. NRCBL: 17.1; 4.4; 1.1. Abstract: Personhood is a foundational concept in ethics, yet defining criteria have been elusive. In this article we summarize attempts to define personhood in psychological and neurological terms and conclude that none manage to be both specific and non-arbitrary. We propose that this is because the concept does not correspond to any real category of objects in the world. Rather, it is the product of an evolved brain system that develops innately and projects itself automatically and irresponsibly onto the world whenever triggered by stimulus features such as a human-like face, body, or contingent patterns of behavior. We review the evidence for the existence of an autonomous person network in the brain and discuss its implications for the field of ethics and for the implicit morality of everyday behavior.


Abstract: Since 1998, several attempts have been made to reform the existing mental health legislation - the Mental Health Act 1983. However, all efforts thus far have been resoundingly rejected by mental health charities, psychiatrists and related professions. Following the Government’s decision to abandon the draft Mental Health Bill in March 2006, plans to introduce new legislation designed to amend the existing 1983 Act have been published. This shorter bill was introduced before Parliament in November 2006. The amendments focused on six key policy areas including supervised community treatment, the nearest relative, the definition of mental disorder and detention criteria. It is also intended that the Mental Capacity Act 2005 will be amended to bridge the present ‘Bournewood’ gap.


Abstract: There continues to be a debate on whether addiction is best understood as a brain disease or a moral condition. This debate, which may influence both the stigma attached to addiction and access to treatment, is often motivated by the question of whether and to what extent we can justly hold addicted individuals responsible for their actions. In fact, there is substantial evidence for a disease model, but the disease model per se does not resolve the question of voluntary control. Recent research at the intersection of neuroscience and psychology suggests that addicted individuals have substantial impairments in cognitive control of behavior, but this “loss of control” is not complete or simple. Possible mechanisms and implications are briefly reviewed.


Jones, Dan. The depths of disgust. Is there wisdom to be found in repugnance? Or is disgust ‘the nastiest of all emotions’, offering nothing but support to prejudice? Nature 2007 June 14; 447(7146): 768-771. NRCBL: 17.1; 2.1; 3.1.


Abstract: The extended mind thesis is the claim that mental states extend beyond the skulls of the agents whose states they are. This seemingly obscure and bizarre claim has far-reaching implications for neuroethics, I argue. In the first half of this article, I sketch the extended mind thesis and defend it against criticisms. In the second half, I turn to its neuroethical implications. I argue that the extended mind thesis entails the falsity of the claim that interventions into the brain are especially problematic just because they are internal interventions, but that many objections to such interventions rely, at least in part, on this claim. Further, I argue that the thesis alters the focus of neuroethics, away from the question of whether we ought to allow interventions into the mind, and toward the question of which interventions we ought to allow and under what conditions. The extended mind thesis dramatically expands the scope of neuroethics: because interventions into the environment of agents can count as interventions into their minds, decisions concerning such interventions become questions for neuroethics.


Mason, J.K.; Laurie, G.T. Mental health and human rights. In: their: Mason and McCall Smith’s Law and Medi-


Racine, Eric; van der Loos, HZ Adriaan; Illes, Judy. Internet marketing of neuroproducts: new practices and healthcare policy changes. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Spring; 16(2): 181-194. NRCBL: 17.1; 4.4; 1.3.12; 1.3.2; 5.3; 8.1. SC: em.


Keywords: *classification; *genomics; *neurosciences; *psychiatric diagnosis; *philosophy; behavioral genetics; brain; genotype; mental disorders; phenotype; psychiatry; schizophrenia.

Roberts, Laura Weiss; Coverdale, John; Louie, Alan K. Philanthropy, ethics, and leadership in academic psychiatry. Academic Psychiatry 2006 July-August; 30(4): 269-272. NRCBL: 17.1; 1.3.3; 9.3.1.


Abstract: Utilitarianism is one of the “grand Enlightenment” moral philosophies. It provides a means of evaluating the ethical implications of common and unusual situations faced by psychiatrists, and offers a logical and ostensibly scientific method of moral justification and action. In this first of our two papers, we trace the evolution of utilitarianism into a contemporary moral theory and review the main theoretical critiques. In the second paper we contextualize utilitarianism in psychiatry and con-
sider its function within the realm of the professional ethics of psychiatrist as physician, before applying it to two dilemmas faced by psychiatrists as individuals and as members of a profession. We conclude that psychiatry must search beyond utilitarianism in grappling with everyday clinical scenarios.

Robertson, Michael; Walter, Gary. A critical reflection on utilitarianism as the basis for psychiatric ethics. Part II: Utilitarianism and psychiatry. Journal of Ethics in Mental Health 2007 April; 2(1): 4 p. Accessed: http://www.jemh.ca [2007 July 31]. NRCBL: 17.1; 2.1; 4.1.2. Abstract: In this second paper we contextualize utilitarianism to the craft of psychiatry and consider its function within the realm of the professional ethics of psychiatrists as physicians. We then apply it to two dilemmas faced by psychiatrists as individuals and as members of a profession. We conclude that psychiatry must search beyond utilitarianism in grappling with everyday clinical scenarios.


Schmidt, Charles. Putting the brakes on psychosis. Science 2007 May 18; 316(5827): 976-977. NRCBL: 17.1; 17.3; 17.4.

Sen, Piyal; Gordon, Harvey; Adshen, Gwen; Irons, Ashley. Ethical dilemmas in forensic psychiatry: two illustrative cases. Journal of Medical Ethics 2007 June; 33(6): 337-341. NRCBL: 17.1; 1.3.1; 1.3.5; 2.1; 4.1.2; 6; 8.1; 8.3.3; 8.3.4; 17.3. SC: cs. Abstract: One approach to the analysis of ethical dilemmas in medical practice uses the “four principles plus scope” approach. These principles are: respect for autonomy, beneficence, non-malefice and justice, along with concern for their scope of application. However, conflicts between the different principles are commonplace in psychiatric practice, especially in forensic psychiatry, where duties to patients often conflict with duties to third parties such as the public. This article seeks to highlight some of the specific ethical dilemmas encountered in forensic psychiatry: the excessive use of segregation for the protection of others, the ethics of using mechanical restraint when clinically beneficial and the use of physical treatment without consent. We argue that justice, as a principle, should be paramount in forensic psychiatry, and that there is a need for a more specific code of ethics to cover specialised areas of medicine like forensic psychiatry. This code should specify that in cases of conflict between different principles, justice should gain precedence over the other principles.


Srebnik, Debra S.; Russo, Joan. Consistency of psychiatric crisis care with advance directive instructions. Psychiatric Services 2007 September; 58(9): 1157-1163. NRCBL: 17.1; 8.3.3; 8.3.4. SC: em.


Abstract: Operational psychology is an emerging subdiscipline that has enhanced the U.S. military’s combat capabilities during the Global War on Terrorism. What makes this subdiscipline unique is its use of psychological principles and skills to improve a commander’s decision making as it pertains to conducting combat (or related operations). Due to psychology’s expanding role in combat support, psychologists are being confronted with challenges that require the application of their professional ethics in areas in which little if any guidance has been provided. Operational psychologists are at the forefront of this expansion. Accordingly, they need a decision model to assist them in this complex dynamic environment. To this end, this article reviews various decision models and ethical frameworks, selects the most appropriate, and then applies it to the challenges faced by operational psychologists. A naturalistic decision model that integrates rational and intuitive elements is recommended.


Stocking, Carol B.; Hougham, Gavin W.; Danner, Deborah D.; Patterson, Marian B.; Whitehouse, Peter J.; Sachs, Greg A. Empirical assessment of a research advance directive for persons with dementia and their proxies. Journal of the American Geriatrics Society 2007 October; 55(10): 1609-1612. NRCBL: 17.1; 8.3.3; 8.3.4; 18.5.6; 18.3. SC: em.

Swartz, Marvin S.; Swanson, Jeffrey W. Psychiatric advance directives and recovery-oriented care. Psychiatric Services 2007 September; 58(9): 1164. NRCBL: 17.1; 8.3.3; 8.3.4.


Van Citters, Arica D.; Naidoo, Umadevi; Foti, Mary Ellen. Using a hypothetical scenario to inform psychiatric advance directives. Psychiatric Services 2007 November; 58(11): 1467-1471. NRCBL: 17.1; 8.3.3; 8.3.4. SC: em.


Abstract: Coercion and pressure in mental healthcare raise moral questions. This article focuses on moral questions raised by the everyday practice of pressure and coercion in the care for the mentally ill. In view of an example from literature—the story of Ulysses and the Sirens—several ethical issues surrounding this practice of care are discussed. Care giver and patient should be able to express feelings such as frustration, fear and powerlessness, and attention must be paid to those feelings. In order to be able to evaluate the intervention, one has to be aware of the variety of goals the intervention can aim at. One also has to be aware of the variety of methods of intervention, each with its own benefits and drawbacks. Finally, an intervention requires a context of care and responsibility, along with good communication and fair treatment before, during and after the use of coercion and pressure.


Wilder, Christine M.; Elbogen, Eric B.; Swartz, Marvin S.; Swanson, Jeffrey W.; Van Dorn, Richard A. Effect of patients’ reasons for refusing treatment on implementing psychiatric advance directives. Psychiatric Services 2007 October; 58(10): 1348-1350. NRCBL: 17.1; 8.3.3; 8.3.4. SC: em.

SECTION I  NANOTECHNOLOGY


MENTALLY DISABLED See CARE FOR SPECIFIC GROUPS/ MENTALLY DISABLED; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ MENTALLY DISABLED; INFORMED CONSENT/ INCOMPETENTS

MENTALLY HANDICAPPED See CARE FOR SPECIFIC GROUPS/ MENTALLY DISABLED; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ MENTALLY DISABLED; INFORMED CONSENT/ INCOMPETENTS

MENTALLY ILL See CARE FOR SPECIFIC GROUPS/ MENTALLY DISABLED; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ MENTALLY DISABLED; INFORMED CONSENT/ INCOMPETENTS; TREATMENT REFUSAL/ MENTALLY ILL

MERCY KILLING See EUTHANASIA AND ALLOWING TO DIE

MIGRATION OF HEALTH CARE PROFESSIONALS See INTERNATIONAL MIGRATION OF HEALTH CARE PROFESSIONALS

MINORITIES See CARE FOR SPECIFIC GROUPS/ MINORITIES

MINORS See CARE FOR SPECIFIC GROUPS/ MINORS; DEATH AND DYING/ TERMINAL CARE FOR MINORS; EUTHANASIA AND ALLOWING TO DIE/ MINORS; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ MINORS; INFORMED CONSENT/ MINORS

MISCONDUCT See BIOMEDICAL RESEARCH/ RESEARCH ETHICS AND SCIENTIFIC MISCONDUCT; MALPRACTICE AND PROFESSIONAL MISCONDUCT

MORAL AND RELIGIOUS ASPECTS See ABORTION/ MORAL AND RELIGIOUS ASPECTS; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ EMBRYOS AND FETUSES/ PHILOSOPHICAL AND RELIGIOUS ASPECTS

NANOTECHNOLOGY

Enough talk already: governments should act on researchers’ attempts to engage the public over nanotechnology [editorial]. Nature 2007 July 5; 448(7149): 1-2. NRCBL: 5.4; 5.3.

Allhoff, Fritz. On the autonomy and justification of nanoethics. NanoEthics 2007 December; 1(3): 185-210. NRCBL: 5.4; 1.1; 1.3.2; 2.1; 16.1; 17.1. SC: an; rv.

Bowman, Diana M.; Hodge, Graeme A. Editorial - governing nanotechnology: more than a small matter? NanoEthics 2007 December; 1(3): 239-241. NRCBL: 5.4; 5.3.

Bruce, Donald. Ethical and social issues in nanobiotechnologies: Nano2Life provides a European ethical ‘think tank’ for research in biology at the nanoscale. EMBO Reports 2006 August; 7(8): 754-758. NRCBL: 5.4; 4.4; 21.1; 15.1.


Dorbeck-Jung, Bärbel R. What can prudent public regulators learn from the United Kingdom government’s nanotechnological regulatory activities? NanoEthics 2007 December; 1(3): 257-270. NRCBL: 5.4; 5.3.


Edwards, Steven A. Fear of nano: dangers and ethical challenges. In his: The Nanotech Pioneers: Where Are They Taking Us? Weinheim: Wiley-VCH, 2006: 197-229. NRCBL: 5.4; 5.3; 5.1; 16.1; 20.5.1; 4.4; 21.3.


Grunwald, Armin; Julliard, Yannick. Nanotechnology — steps toward understanding human beings as technology? *NanoEthics* 2007 August; 1(2): 77-87. NRCBL: 5.4; 1.1; 4.4; 4.5. SC: an; le.


Kjølberg, Kamilla; Wickson, Fern. Social and ethical interactions with nano: mapping the early literature. *NanoEthics* 2007 August; 1(2): 89-104. NRCBL: 5.4; 1.1; 5.2. SC: em; rv.


Abstract: Nanomedicine plays a prominent role among emerging technologies. The spectrum of potential applications is as broad as it is promising. It includes the use of nanoparticles and nanodevices for diagnostics, targeted drug delivery in the human body, the production of new therapeutic materials as well as nanorobots or nanoprotheses. Funding agencies are investing large sums in the development of this area, among them the European Commission, which has launched a large network for life-sciences related nanotechnology. At the same time government agencies as well as the private sector are putting forward reports of working groups that have looked into the promises and risks of these developments. This paper will begin with an introduction to the central ethical themes as identified by selected reports from Europe and beyond. In a next step, it will analyse the most frequently invoked ethical concerns-risk assessment and management, the issues of human identity and enhancement, possible implications for civil liberties (e.g. nanodevices that might be used for covert surveillance), and concerns about equity and fair access. Although it seems that the main ethical issues are not unique to nano- technologies, the conclusion will argue against shrugging them off as non-specific items that have been considered before in the context of other biomedical technologies, such as gene therapy or xenotransplantation. Rather, the paper will call on ethicists to help foster a rational, fair and participatory discourse on the different potential applications of nanotechnologies in medicine, which can form the basis for informed and responsible societal and political decisions.

Lin, Patrick. Nanotechnology bound: evaluating the case for more regulation. *NanoEthics* 2007 August; 1(2): 105-122. NRCBL: 5.4; 5.2; 5.3; 16.1. SC: an; le.


Abstract: Nanotechnology is a term derived from the Greek word nanos, meaning dwarf. It is used to describe activities at the level of atoms and molecules. The application of this technology is aimed at controlling and manipulating the physical properties of materials with single molecule precision. Scientists use the technology to build working devices, systems and materials, molecule by molecule. This enables them to exploit the unique and powerful electrical, physical and chemical properties found at that scale. Nanotech holds the potential to revolutionise medicine, electronics and chemistry. Nanomedicine would facilitate the repair and improvement of the human body from the inside out, with a precision and delicacy far greater than the finest surgical instruments permit. Problem areas stemming from the technology include the following:- Who will benefit - just the rich or the poor as well? This paper will explore the role of law, ethics and suitable control mechanisms to limit the dangers and maximise the benefits of nanotechnology for society, especially in the field of medicine.


Petersen, Alan; Anderson, Alison. A question of balance or blind faith?: scientists' and science policymakers’ representations of the benefits and risks of nanotechnologies. *NanoEthics* 2007 December; 1(3): 243-256. NRCBL: 5.4; 5.2. SC: em.


Abstract: *biomedical technologies; *biotechnology; *nanotechnology; genetic screening; genetic services; genomics; marketing; pharmacogenetics; policy making; public participation; risks and benefits; social impact; values


Sheremeta, Lorraine. Nanotechnologies and the ethical conduct of research involving human subjects. In: Hunt, Geoffrey; Mehta, Michael D., eds. Nanotechnology: Risk,
SECTION I

NURSING ETHICS AND PHILOSOPHY


Thurs, Daniel Patrick. No longer academic: models of commercialization and the construction of a nanotech industry. Science as Culture 2007 June; 16(2): 169-186. NRCBL: 5.4; 5.3; 1.3.2.


van den Hoven, Jeroen; Vermaas, Pieter E. Nanotechnology and privacy: on continuous surveillance outside the panopticon. Journal of Medicine and Philosophy 2007 May-June; 32(3): 283-297. NRCBL: 5.4; 1.1; 8.4. Abstract: We argue that nano-technology in the form of invisible tags, sensors, and Radio Frequency Identity Chips (RFIDs) will give rise to privacy issues that are in two ways different from the traditional privacy issues of the last decades. One, they will not exclusively revolve around the idea of centralization of surveillance and concentration of power, as the metaphor of the Panopticon suggests, but will be about constant observation at decentralized levels. Two, privacy concerns may not exclusively be about constraining information flows but also about designing of materials and nano-artifacts such as chips and tags. We begin by presenting a framework for structuring the current debates on privacy, and then present our arguments.

NATIVE AMERICANS AS RESEARCH SUBJECTS See HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS

NEUROSCIENCES See MENTAL HEALTH THERAPIES AND NEUROSCIENCES

NONTHERAPEUTIC HUMAN EXPERIMENTATION See HUMAN EXPERIMENTATION

NURSE PATIENT RELATIONSHIP See NURSING ETHICS AND PHILOSOPHY; PATIENT RELATIONSHIPS

NURSING CARE See CARE FOR SPECIFIC GROUPS; DEATH AND DYING/ TERMINAL CARE; NURSING ETHICS AND PHILOSOPHY

NURSING ETHICS AND PHILOSOPHY See also BIOETHICS AND MEDICAL ETHICS; CODES OF ETHICS; PROFESSIONAL ETHICS

Arman, Maria; Rehnfeldt, Arne. The presence of love in ethical caring. Nursing Forum 2006 January-March; 41(1): 4-12. NRCBL: 4.1.3; 1.1; 8.1.


Badger, James M.; O’Connor, Bonnie. Moral discord, cognitive coping strategies, and medical intensive care unit nurses: insights from a focus group study. Critical Care Nursing Quarterly 2006 April-June; 29(2): 147-151. NRCBL: 4.1.3; 1.1; 7.3; 8.1.


Abstract: This article is a first assessment of the Italian Code of deontology for nurses (revised in 1999) on the basis of data collected from focus groups with nurses taking part in the Ethical Codes in Nursing (ECN) project. We illustrate the professional context in which the Code was introduced and explain why the 1999 revision was necessary in the light of changes affecting the Italian nursing profession. The most remarkable findings concern professional autonomy and responsibility, and how the Code is thought of as a set of guidelines for nursing practice. We discuss these issues, underlining that the 1999 Code represents a valuable instrument for ethical reflection and examination, a stimulus for putting the moral sense of the nursing profession into action, and that it represents a new era for professional nursing practice in Italy. The results of the analysis also deserve further qualitative study and future consideration.


Dahlgqvist, Vera; Eriksson, Sture; Glasberg, Ann-Louise; Lindahl, Elisabeth; Lützén, Kim; Strandberg, Gunilla; Söderberg, Anna; Sörlie, Venke; Norberg,

Abstract: Health care often involves ethically difficult situations that may disquiet the conscience. The purpose of this study was to develop a questionnaire for identifying various perceptions of conscience within a framework based on the literature and on explorative interviews about perceptions of conscience (Perceptions of Conscience Questionnaire). The questionnaire was tested on a sample of 444 registered nurses, enrolled nurses, nurses’ assistants and physicians. The data were analysed using principal component analysis to explore possible dimensions of perceptions of conscience. The results showed six dimensions, found also in theory and empirical health care studies. Conscience was perceived as authority, a warning signal, demanding sensitivity, an asset, a burden and depending on culture. We conclude that the Perceptions of Conscience Questionnaire is valid for assessing some perceptions of conscience relevant to health care providers.


Dobrowolska, Beata; Wronska, Irena; Fidecki, Wysokinski, Mariusz. Moral obligations of nurses based on the ICN, UK, Irish and Polish codes of ethics for nurses. *Nursing Ethics* 2007 March; 14(2): 171-180. NRCBL: 4.1.3; 6; 21.1. Identifiers: International Council of Nurses [ICN]; Great Britain (United Kingdom); Iceland; Poland.

Abstract: A code of professional conduct is a collection of norms appropriate for the nursing profession and should be the point of reference for all decisions made during the care process. Codes of ethics for nurses are formulated by members of national nurses’ organizations. These codes can be considered to specify general norms that function in the relevant society, adjusting them to the character of the profession and enriching them with rules signifying the essence of nursing professionalism. The aim of this article is to present a comparative analysis of codes of ethics for nurses: the ICN’s Code of ethics for nurses, the UK’s Code of professional conduct, the Irish Code of professional conduct for each nurse and midwife, and the Polish Code of professional ethics for nurses and midwives. This analysis allows the identification of common elements in the professional ethics of nurses in these countries.


SECTION I  NURSING ETHICS AND PHILOSOPHY


Fullbrook, Suzanne. Best interests: a review of issues that affect nurses’ decision making. British Journal of Nursing 2007 May 24 - June 13; 16(10): 600-601. NRCBL: 4.1.3; 8.1; 8.3.3. SC: le.


Abstract: Respect is much referred to in professional codes, in health policy documents and in everyday conversation. What respect means and what it requires in everyday contemporary nursing practice is less than clear. Prescriptions in professional codes are insufficient, given the complexity and ambiguity of everyday nursing practice. This article explores the meaning and requirements of respect in relation to nursing practice. Fundamentally, respect is concerned with value: where ethical value or worth is present, respect is indicated. Raz has argued that the two ways of encountering value are to respect and to engage with it. The former requires acknowledgement and preservation. Respect in nursing practice necessarily requires also engagement. Respect is an active value and can be conceptualized within the context of virtue ethics as a hybrid virtue having both intellectual and ethical components. Examples from the literature are provided to illustrate situations where the respectful nurse requires these components or capabilities.


Abstract: Every day situations arising in health care contain ethical issues influencing care providers’ conscience. How and to what extent conscience is influenced may differ according to how conscience is perceived. This study aimed to explore the relationship between perceptions of conscience and stress of conscience among care providers working in municipal housing for elderly people. A total of 166 care providers were approached, of which 146 (50 registered nurses and 96 nurses’ aides/enrolled nurses) completed a questionnaire containing the Perceptions of Conscience Questionnaire and the Stress of Conscience Questionnaire. A multivariate canonical correlation analysis was conducted. The first two functions emerging from the analysis themselves explained a noteworthy amount of the shared variance (25.6% and 17.8%). These two dimensions of the relationship were interpreted either as having to deaden one’s conscience relating to external demands in order to be able to collaborate with coworkers, or as having to deaden one’s conscience relating to internal demands in order to uphold one’s identity as a ‘good’ health care professional.


Kim, Yong-Soon; Park, Jin-Hee; Han, Sung-Suk. Differences in moral judgment between nursing students and qualified nurses. Nursing Ethics 2007 May; 14(3): 309-319. NRCBL: 4.1.3; 1.3.1; 7.2. SC: em. Identifiers: Korea.
Abstract: This longitudinal study examined how nursing students’ moral judgment changes after they become qualified nurses working in a hospital environment. The
sample used was a group of 80 nursing students attending a university in Suwon, Korea, between 2001 and 2003. By using a Korean version of the Judgment About Nursing Decisions questionnaire, an instrument used in nursing care research, moral judgment scores based on Ketefian’s six nursing dilemmas were determined. The results were as follows: (1) the qualified nurses had significantly higher idealistic moral judgment scores than the nursing students; (2) the qualified nurses showed significantly higher realistic moral judgment scores than the nursing students; and (3) when comparing idealistic and realistic moral judgment scores, both the qualified nurses and the nursing students had higher scores for idealistic moral judgment. Further study is recommended to examine changes in moral judgment.


Abstract: Communalization of health care refers to the increasing responsibility of citizens to look after their ill or handicapped fellow members of society and to provide care to them. Governments in Western Europe more and more develop health care policies directed at communalization of health care. The article discusses the care responsibilities of individuals based on the views of the philosophers Buber, Levinas, and Ricoeur and on the views of the family therapist Nagy. The care responsibilities of states are discussed in terms of the views of the political philosophers Rawls and Daniels and these are linked to right liberal, left liberal, and Christian-democrat views on care responsibilities of states. Thereupon, four criteria for a proper communalization of health care are proposed and different forms of health care policies with respect to communalization of care are assessed. In the last section, we look closely at several measures in the just reformed Dutch health care system and discuss how far these measures meet our criteria for a proper communalization. We focus in this section on the effects of these measures on family care because more and more family care plays an important role in good functioning of the health care system.


Leners, Debra Woodward; Roehrs, Carol; Piccone, Adam Vincent. Tracking the development of professional values in undergraduate nursing students. Journal of Nursing Education 2006 December; 45(12): 504-511. NRCBL: 4.1.3; 7.2. SC: em.


Abstract: This article reports a study exploring the meaning of the complex phenomenon of moral responsibility in nursing practice. Each of three focus groups with a total of 14 student nurses were conducted twice to gather their views on moral responsibility in nursing practice. The data were analysed by qualitative thematic content analysis. Moral responsibility was interpreted as a relational way of being, which involved guidance by one’s inner compass composed of ideals, values and knowledge that translate into a striving to do good. It was concluded that, if student nurses are to continue striving to do good in a way that respects themselves and other people, it is important that they do not feel forced to compromise their values. Instead they should be given space and encouragement in their endeavours to do good in a relational way that advances nursing as a moral practice.

fortune - and to argue that feeling it in the course of health care work, as elsewhere, is evidence of a deficient character. In order to show that Schadenfreude is an objectionable emotion in health care work, I first offer some conceptual remarks about emotions generally and their differential treatment in Kantian and Aristotelian thought. Second, I argue that an appreciation of the rationality of the emotions is crucial to our self-understanding as persons in general and nurses in particular. Third, I present a critique of Portmann’s (2000, When Bad Things Happen to Other People. London: Routledge) defence of Schadenfreude with examples from both nursing and medical scenarios. Specifically, I show how his exculpation of the emotion in terms of low self-esteem and a commitment to justice are not compelling. I argue that we are active in the construction of our emotional experiences of Schadenfreude, how we may indeed, nurse the emotion, and thus become culpable for them in ethical terms.


Abstract: It is imperative to understand the factors that influence clinical competency. Consequently, it is essential to study those that have an impact on the process of attaining clinical competency. A grounded theory approach was adopted for this study. Professional competency empowers nurses and enables them to fulfill their duties effectively. Internal and external factors were identified as affecting clinical competency. A total of 36 clinical nurses, nurse educators, hospital managers and members of the Nursing Council in Tehran participated in this research. Data were obtained by semistructured interviews. Personal factors and useful work experience were considered to be significant, based on knowledge and skills, ethical conduct, professional commitment, self-respect and respect for others, as well as from effective relationships, interest, responsibility and accountability. Effective management, education systems and technology were named as influential environmental factors. Personal and environmental factors affect clinical competency. Ethical persons are responsible and committed to their work, acquiring relevant work experience. A suitable work environment that is structured and ordered also encourages an ethical approach by nurses.


Solomon, Margot R.; DeNatale, Mary Lou. Academic dishonesty and professional practice: a convocation. *Nurse Educator* 2000 November-December; 25(6): 270-271. NRCBL: 4.1.3; 1.3.1; 2.3; 7.2; 8.2; 1.3.3.


Tang, Ping Fen; Johansson, Camilla; Wadensten, Barbro; Wenneberg, Stig; Ahlström, Gerd. Chinese nurses’ ethical concerns in a neurological ward. *Nursing Ethics* 2007 November; 14(6): 810-824. NRCBL: 4.1.3; 9.5.1; 9.8. SC: em.


Abstract: Ten nurses at a university hospital in Norway were interviewed as part of a comprehensive investigation into the narratives of nurses and physicians about being in ethically difficult situations in surgical units. The transcribed interview texts were subjected to a phenomenological-hermeneutical interpretation. The main theme in the narratives was being close to and moved by the suffering of patients and relatives. The nurses’ responsibility for patients and relatives was expressed as a commitment to act, and they needed to ask themselves whether their responsibility had been fulfilled, that nothing had been left undone, overlooked or neglected, before they could leave the unit. When there was confirmation by the patients, relatives, colleagues and themselves that the needs of patients and relatives had been attended to in a morally and professionally satisfying manner, this increased the nurses’ confidence and satisfaction in their work, and their strength to live with the burden of being in ethically difficult situations.


Abstract: This article examines clinical wisdom, which has emerged from a broader study about nurse managers’ influence on proficient registered nurse turnover and retention. The purpose of the study was to increase understanding of proficient nurses’ experience and clinical practice by giving voice to the nurses themselves, and to look for differences in their practice. This was a qualitative study based on semistructured interviews followed by analysis founded on Gadamerian hermeneutics. The article describes how proficient nurses experience their practice. Proficient practice constitutes clinical wisdom based on responsibility, thinking and ethical discernment, and a drive for action. The study showed that poor working conditions cause proficient nurses to regress to non-proficient performance. Further studies are recommended to allow deeper searching into the area of working conditions and their relationship to lack of nurse proficiency.


Abstract: Registered nurses (RNs) employed in an urban medical center in the USA identified moral distress as a practice concern. This study describes RNs’ moral distress and the frequency of morally distressing events. Data were collected using the Moral Distress Scale and an open-ended questionnaire. The instruments were distributed to direct-care-providing RNs; 100 responses were returned. Morally distressing events included: working with staffing levels perceived as ‘unsafe’, following families’ wishes for patient care even though the nurse disagreed with the plan, and continuing life support for patients owing to family wishes despite patients’ poor prognoses. One high frequency distressing event was carrying out orders for unnecessary tests and treatments. Qualitative data analysis revealed that the nurses sought support and information from nurse managers, chaplaincy services and colleagues. The RNs requested further information on biomedical ethics, suggested ethics rounds, and requested a non-punitive environment surrounding the initiation of ethics committee consultations.

**ORGAN AND TISSUE TRANSPLANTATION**

*See also BLOOD BANKING, DONATION, AND TRANSFUSION*


Botkin, Jeffrey R.; Munger, Mark A.; Shea, Patrick A.; Coffin, Cheryl; Mineau, Geraldine P. Management of human tissue resources for research in academic medical centers: points to consider. In: Kulakowski, Elliott C.; Chronister, Lynne U., eds. Research Administration and Management. Sudbury, MA: Jones and Bartlett, 2006: 567-575. NRCBL: 19.1; 19.5; 18.3.


Charatan, Fred. Organ recipients may die when insurance for drugs runs out [news]. *BMJ: British Medical Journal* 2007 March 17; 334(7593): 556. NRCBL: 19.3; 9.5.7; 9.3.1; 9.7; 20.1.

Cheema, Puneet; Mehta, Paulette. Pediatric stem cell transplantation ethical concerns. In: Mehta, P., ed. Pediatric Stem Cell Transplantation. Sudbury: Jones and Bartlett Publishers, 2004: p. 91-98. NRCBL: 19.1; 8.3.2; 19.4; 19.5; 18.5.4; 9.5.7; 1.1.


Fortin, Marie-Chantal; Roigt, Delphine; Doucet, Hubert. What should we do with patients who buy a kidney overseas? *Journal of Clinical Ethics* 2007 Spring; 18(1): 23-34. NRCBL: 19.3; 19.5; 8.1; 21.1; 9.3.1. SC: le.


Abstract: Should face transplants be undertaken? This article examines the ethical problems involved from the perspective of the recipient, looking particularly at the question of identity, the donor and the donor’s family, and the disfigured community and society more generally. Concern is expressed that full face transplants are going ahead.


Abstract: The use of human tissue raises ethical issues of great concern to health care professionals, biomedical researchers, ethics committees, tissue banks and policy makers because of the heightened importance given to informed consent and patient autonomy. The debate has been intensified by high profile scandals such as the “baby hearts” debacle and revelations about the retention of human brains in neuropathology laboratories worldwide. Respect for patient’s rights seems, however, to impede research and development of clinical knowledge in contemporary health care. The Common clinical endeavour argument and a Presumption for beneficial use suggest that the use of tissues for research and teaching in contemporary health care can respect patients and their values in multicultural communities where there are provisions for oversight and for opting not to contribute, both of which should respect the diverse views of different ethnic or cultural groups.


Meckler, Laura. More kidneys for transplants may go to young; policy to stress benefit to patient over length of time on wait list. Wall Street Journal 2007 March 10; p. A1, A7. NRCBL: 19.3; 19.6; 9.5.7. SC: po.


Northern Ireland Targeting Social Need Renal Group; Kee, Frank; Reaney, Elizabeth; Savage, Gerard; O’Reilly, Dermot; Patterson, Chris; Maxwell, Peter; Fogarty, Damian. Are gatekeepers to renal services referring patients equitably? Journal of Health Services Research and Policy 2007 January; 12(1): 36-41. NRCBL: 19.3; 9.5.1; 9.2; 9.4.


Ringel, Steven P. Autonomy and ars moriendi. Neurology 2006 September 26; 67(6): 1101-1102. NRCBL: 19.2; 8.3.1; 8.3.2; 8.3.4; 20.5.1.

Rohrich, Rod J.; Longaker, Michael T.; Cunningham, Bruce. On the ethics of composite tissue allotransplantation (facial transplantation) [editorial]. Plastic and Reconstructive Surgery 2006 May; 117(6): 2071-2073. NRCBL: 19.1; 9.7; 8.3.1.


Swindell, J.S. Facial allograft transplantation, personal identity and subjectivity. Journal of Medical Ethics 2007 August; 33(8): 449-453. NRCBL: 19.1; 1.1; 4.4. SC: an. Abstract: An analysis of the identity issues involved in facial allograft transplantation is provided in this paper. The identity issues involved in organ transplantation in general, under both theoretical accounts of personal identity and subjective accounts provided by organ recipients, are examined. It is argued that the identity issues involved in facial allograft transplantation are similar to those involved in organ transplantation in general, but much stronger because the face is so closely linked with personal identity. Recipients of facial allograft transplantation have the potential to feel that their identity is a mix between their own and the donor’s, and the donor’s family is potentially likely to feel that their loved one “lives on”. It is also argued that facial allograft transplantation allows the recipients to regain an identity, because they can now be seen in the social world. Moreover, they may regain expressivity, allowing for them to be seen even more by others, and to regain an identity to an even greater extent. Informing both recipients and donors about the role that identity plays in facial allograft
transplantation could enhance the consent process for facial allograft transplantation and donation.


Thamer, Mae; Zhang, Yi. Dialysis facility ownership and epoetin dosing in patients receiving hemodialysis: the authors respond. American Journal of Kidney Diseases 2007 October; 50(4): 538-541. NRCBL: 19.3; 5.3; 9.7; 9.3.1. SC: em.


**ORGAN AND TISSUE TRANSPLANTATION/ ALLOCATION**


**de Beaufort, Inez; Meulenberg, Frans.** The dangers of triage by television. BMJ: British Medical Journal 2007 June 9; 334(7605): 1194-1195. NRCBL: 19.5; 1.3.7; 9.4.

**Draper, Heather; MacDiarmaid-Gordon, Adam; Strumilod, Laura; Teuten, Bea; Update, Eleanor.** Virtual clinical ethics committee, case 8/case 4 vol 2: should non-medical circumstances determine whether a child is placed on the transplant register when there is a risk of wasting a scarce organ? Clinical Ethics 2007 December; 2(4): 166-172. NRCBL: 19.6; 20.5.2; 19.2; 9.6. SC: cs.


**Magnus, David; Tabor, Holly; Karkazis, Katrina.** Transplants for developmentally delayed children. Ethics and Intellectual Disability 2007 Winter; 10(1): 3-4. NRCBL: 19.6; 9.5.3; 7.2.

**Neuberger, James; Gimson, Alexander.** Selfless adults and split donor livers [comment]. Lancet 2007 July 28-August 3; 370(9584): 299-300. NRCBL: 19.6; 19.5; 1.1; 9.5.7. SC: em.

**Pennings, Guido.** Directed organ donation: discrimination or autonomy? Journal of Applied Philosophy 2007; 24(1): 41-49. NRCBL: 19.6; 1.1; 19.5. Abstract: Numerous measures have been proposed to change the collection procedure in order to increase the supply of organ donations. One such proposal is to give the candidate donors the right to direct their organs to groups of recipients characterised by specific features like sex, age, disease and geographic location. Four possible justifications for directed donation of organs are considered: the utilitarian benefit, the egalitarian principle of justice, the maximin principle of justice and the autonomy principle. It is concluded that none of these principles justifies the acceptance of designated donations. When potentially life-saving resources are distributed, only a pure egalitarian distribution is in agreement with the principle of justice.

**Tuffs, Annette.** Media claim allocations of organs to Saudi patients was unfair [news]. BMJ: British Medical Journal 2007 September 29; 335(7621): 634. NRCBL: 19.6; 19.1; 19.3; 21.1.


Abstract: The allocation of cadaveric organs for transplantation in the United States is governed by a process of private regulation. Through the Organ Procurement and Transplantation Network (OPTN), stakeholders and public representatives determine the substantive content of allocation rules. Between 1994 and 2000 the U.S. Department of Health and Human Services conducted a rule making to define more clearly the public and private roles in the determination of organ allocation policy. Several prominent liver transplant centers that were losing market share as a result of the proliferation of transplant centers used the rule making as a vehicle for challenging the local priority for organ allocation inherent in the OPTN rules. The process leading to the final rule provides a window on the politics of organ allocation. It also facilitates an assessment of the strengths and weaknesses of private rule making. Overall, private rule making appears to be relatively effective in tapping the technical expertise and tacit knowledge of stakeholders to allow for the adaptation of rules in the face of changing technology and information. However, the particular system of representation employed may give less influence to some stakeholders than they would have in public regulatory arenas, giving them an incentive to seek public rule making as a remedy for their persistent losses within the framework of private rule making.

ORGAN AND TISSUE TRANSPANTATION/ DONATION AND PROCUREMENT


Presumed consent. ATLA: Alternatives to Laboratory Animals 2007 August; 35(4): 379. NRCBL: 19.5; 8.3.1. Identifiers: Great Britain (United Kingdom).


Canova, Daniele; De Bona, Manuela; Ruminati, Rino; Ermani, Mario; Naccarato, Remo; Burra, Patrizia. Understanding of and attitudes to organ donation and transplantation: a survey among Italian university students. Clinical Transplantation 2006 May-June; 20(3): 307-312. NRCBL: 19.5; 19.1. SC: em.


DuBois, James M.; Anderson, Emily E. Attitudes toward death criteria and organ donation among healthcare personnel and the general public. Progress in Transplantation 2006 March; 16(1): 65-73. NRCBL: 19.5; 8.3.1; 20.2.1; 20.3.1; 20.3.2. SC: rv.


Dyer, Clare. UK considers moving to new system to increase organ donation [news]. BMJ: British Medical Journal 2007 September 29; 335(7621): 634-635. NRCBL: 19.5.


Fujita, Misao; Akabayashi, Akira; Slingsby, Brian Taylor; Kosugi, Shinji; Fujimoto, Yasuhiro; Tanaka, Koichi. A model of donors’ decision-making in adult-to-adult living donor liver transplantation in Japan: having no choice. Liver Transplantation 2006 May; 12(5): 768-774. NRCBL: 19.5; 9.4; 8.3.1.

Gallagher, John A. Donation after cardiac death: an ethical reflection on the development of a protocol. Health Care Ethics USA 2007 Summer; 15(3): 5-6. NRCBL: 19.5; 20.2.1; 8.3.1; 1.2; 9.7.


Grasser, Phyllis L. Donation after cardiac death: major ethical issues. National Catholic Bioethics Quarterly 2007 Autumn; 7(3): 527-543. NRCBL: 19.5; 9.6; 1.2; 20.2.1; 20.3.3.


Healy, G.W. Moral and legal aspects of transplantation: prisoners or death convicts as donors. Transplantation Proceedings 1998 November; 30(7): 3653-3654. NRCBL: 19.5; 1.3.5; 9.5.1.


Keywords: *attitudes; *biological specimen banks; *biomedical research; *donors; *genetic materials; *informed consent; *patients; cancer; privacy; racial groups; research subjects; survey; time factors; Proposed Keywords: *tissue donors; Keyword Identifiers: Indiana University Cancer Center

Abstract: The policy debate concerning informed consent for future, unspecified research of stored human biological materials (HBM) would benefit from an understanding of the attitudes of individuals who contribute tissue specimens to HBM repositories. Cancer patients who contributed leftover tissue to the Indiana University Cancer Center Tissue Bank under such conditions were recruited for a mail survey study of their attitudes. Our findings suggest that a clear majority of subjects would permit unlimited future research on stored HBMs without re-contact and reconsent, and a significant minority appear to desire ongoing control over future research uses of their tissue. These differences merit further investigation and suggest that a policy of blanket consent for all future, unspecified research would be premature.

Helft, Paul R.; Daugherty, Christopher K. Are we taking without giving in return? The ethics of research-related biopsies and the benefits of clinical trial participation. Journal of Clinical Oncology 2006 October 20; 24(30): 4793-4795. NRCBL: 19.5; 18.1; 18.2; 18.3; 9.5.1.

Abstract: Living kidney donation provides a promising opportunity in situations where the scarcity of cadaveric kidneys is widely acknowledged. While many patients and their relatives are willing to accept its benefits, others are concerned about living kidney programs; they appear to feel pressured into accepting living kidney transplantations as the only proper option for them. As we studied the attitudes and views of patients and their relatives, we considered just how actively health care professionals should encourage living donation. We argue that active interference in peoples’ personal lives is justified - if not obligatory. First, we address the ambiguous ideals of non-directivity and value neutrality in counselling. We describe the main pitfalls implied in these concepts, and conclude that these concepts cannot account for the complex reality of living donation and transplantation. We depict what is required instead as truthful information and context-relative counselling. We then consider professional interference into personal belief systems. We argue that individual convictions are not necessarily strong, stable, or deep. They may be flawed in many ways. In order to justify interference in peoples’ personal lives, it is crucial to understand the structure of these convictions. Evidence suggests that both patients and their relatives have attitudes towards living kidney donation that are often open to change and, accordingly, can be influenced. We show how ethical theories can account for this reality and can help us to discern between justified and unjustified interference. We refer to Stephen Toulmin’s model of the structure of logical argument, the Rawlsian model of reflective equilibrium, and Thomas Nagel’s representation of the particularistic position.


Howard, R.J. We have an obligation to provide organs for transplantation after we die. *American Journal of Transplantation* 2006 August; 6(8): 1786-1789. NRCBL: 19.5; 20.1; 1.1.


Mandell, M. Susan; Zamudio, Stacy; Seem, Debbie; McGaw, Lin J.; Wood, Geri; Liehr, Patricia.; Ethier, Angela; D’Alessandro, Anthony M. National evaluation of healthcare provider attitudes toward organ donation after cardiac death. *Critical Care Medicine* 2006 December; 34(12): 2952-2958. NRCBL: 19.5; 7.1; 20.3.2.

Mayer, Susan. HFEA allows women to donate their eggs for research [news]. *BMJ: British Medical Journal* 2007 March 3; 334(7591): 445. NRCBL: 19.5; 14.6; 14.5; 1.3.9; 18.1. Identifiers: Great Britain (United Kingdom); Human Fertilisation and Embryology Authority.


Abstract: Research collaboration beyond national jurisdiction is one aspect of the globalisation of health research. It has potential to complement researchers in terms of research skills, equipment and lack of adequate numbers of potential research subjects. Collaboration at an equal level of partnership though desirable, may not be practicable. Sometimes, human research specimens must be transported from one country to other. Where this occurs, there should be clear understanding between the collaborating research institutions regarding issues of access and control of the specimens as well as the duration of storage of specimens. The researchers have the duty to inform the research participants about specimen storage and transport across national boundaries. While obtaining informed consent from study subjects if specimens are to be stored beyond the life of the present study could be the ideal, there still remains significant challenges in a multi-cultural world.


SECTION I

ORGAN AND TISSUE TRANSPLANTATION/DONATION AND PROCUREMENT


Abstract: In 1975 John Harris envisaged a survival lottery to redistribute organs from one to a greater number in order to reduce number of deaths as a consequence of organ failure. In this paper I reach a conclusion about when running a survival lottery is permissible by looking at the reason prospective participants have for allowing the procedure from a contractual perspective. I identify three versions of the survival lottery. In a National Lottery, everyone within a jurisdiction is a candidate for being a donor for everyone else, disregarding all differences between individuals’ eventual possibility of needing an organ. In a Group Specific Lottery, it is a question of running a lottery among members of a specific group who share the same probability of getting organ failure. In a Local Lottery one randomises among individuals who are already in need of a new organ but who happen to be compatible and in need of different organs. While the first is vulnerable to considerations of fairness, it is difficult to perceive a feasible way to implement the second option that does not come with a host of unwelcome consequences. I argue, however, that it is permissible to run Local Lotteries.


Abstract: This paper argues that the new commercial and quasi-commercial activities of medicine, scientists, pharmaceutical companies and industry with regard to human tissue has given rise to a whole new way of valuing our bodies. It is argued that a property framework may be an effective and constructive method of exploring issues arising from this. The paper refers to A M Honoré’s theory of ownership and aims to show that we have full liberal ownership of our own bodies and as such can be considered to be self-owners.


Abstract: As of September 2006, non-directed donation of kidneys and other tissues and organs is permitted in the UK under the new Human Tissue Acts. At the same time as making provision for psychiatric and clinical assessment of so-called “altruistic” donations to complete strangers, the Acts intensify assessments required for familial, genetically related donations, which will now require the same level as genetically unrelated but “emotionally” connected donations by locally based independent assessors reporting to the newly constituted Human Tissue Authority. But there will also need to be considerable reflection on the criteria for “stranger donation”, which may lead us to a new understanding of the moral economy of altruistic organ donation, no matter how mixed the motives of the donor may be. This paper looks at some of the issues that will have to be accommodated in such a framework.

Ross, Lainie Friedman; Siegler, Mark; Thistlethwaite, J. Richard, Jr. We need a registry of living kidney donors. Hastings Center Report 2007 November-December; 37(6): Inside back cover. NRCBL: 19.5; 19.3.


Sanner, Margareta A. People’s attitudes and reactions to organ donation. Mortality 2006 May; 11(2): 133-150. NRCBL: 19.5; 7.1; 20.3.1. SC: em.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.

Keywords: *access to information;* children; *confidentiality;* DNA sequences; *genetic databases;* genetic information; *genetic privacy;* *genetic research;* publishing: adolescents; biological specimen banks; cancer; disclosure; donors; empirical research; federal government; genetic predisposition; government regulation; human genome; Internet; legal aspects; parental consent; research ethics.

Abstract: This paper examines, from a philosophical point of view, the ethics of the role of the family and the deceased in decisions about organ retrieval. The paper asks: Who, out of the individual and the family, should have the ultimate power to donate or withhold organs? On the side of respecting the wishes of the deceased individual, the paper considers and rejects arguments by analogy with bequest and from posthumous bodily integrity. It develops an argument for posthumous autonomy based on the liberal idea of self-development and argues that this establishes a right of veto over donation. It claims, however, that whether the family's power to veto would conflict with posthumous autonomy rights depends on how it comes about. On the side of respecting the family's wishes, the paper first considers an argument from family distress. This supports a contingent, non-rights-based reason for the family's power that is trumped by the deceased’s rights. It then outlines and criticises an argument based on family autonomy. The conclusion is that the individual has the right to veto the family's wish to donate and that, while the family has no right to veto the individual's wishes to donate, it can legitimately acquire this power and has done so in practice.

Wilson, Penelope; Sexton, Wendy; Singh, Andrea; Smith, Melissa; Durham, Stephanie; Cowie, Anne; Fritschi, Lin. Family experiences of tissue donation in Australia. *Progress in Transplantation* 2006 March; 16(1): 52-56. NRCBL: 19.5; 8.3.3; 20.1; 8.1. SC: an.


**ORGAN AND TISSUE TRANSPLANTATION/.../ECONOMIC ASPECTS**


Arnold, Robert; Bartlett, Steven; Bernat, James; Colonna, John; Dafoe, Donald; Dubler, Nancy; Gruber, Scott; Kahn, Jeffrey; Luskin, Richard; Nathan, Howard; Orloff, Susan; Prottas, Jeffrey; Shapiro, Robyn; Ricordi, Camillo; Youngner, Stuart; Delmonico, Francis L. Financial incentives for cadaver organ donation: an ethical reappraisal. *Transplantation* 2002 April 27; 73(8): 1361-1367. NRCBL: 19.5; 4.4; 9.3.1; 19.1; 20.1.


Baylis, Françoise; McLeod, C. The stem cell debate continues: the buying and selling of eggs for research. *Journal of Medical Ethics* 2007 December; 33(12): 726-731. 41 refs. NRCBL: 19.5; 14.5; 1.3.9; 18.5.4; 15.1; 18.5.3; 9.3.1. SC: an. Keywords: *embryo research; embryonic stem cells; *guidelines; *ovum donors; *remuneration; cloning; embryo disposition; ethical analysis; disadvantaged persons; in vitro fertilization; incentives; international aspects; organizational policies; ovum; patients; professional organizations; research subjects; risk; socioeconomic factors; women; *ISSCR Guidelines; *International Society for Stem Cell Research.


Brown, Susan; Glenn, David. The true price of a human organ: economists and surgeons debate on whether legalizing the sale of body parts will help or harm. *Chronicle of Higher Education* 2007 March 23; 53(29): A12-A15. NRCBL: 19.5; 9.3.1; 21.1; 1.3.2; 9.3.1. SC: le.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme

See inside front cover for terms.

Dykstra, Alyssa. Should incentives be used to increase organ donation? Plastic Surgical Nursing 2004 April-June; 24(2): 70-74. NRCBL: 19.5; 1.1; 9.3.1.

Epstein, Miran. The ethics of poverty and the poverty of ethics: the case of Palestinian prisoners in Israel seeking to sell their kidneys in order to feed their children. Journal of Medical Ethics 2007 August; 33(8): 473-474. NRCBL: 19.5; 9.5.1; 19.3; 9.3.1. Abstract: Bioethical arguments conceal the coercion underlying the choice between poverty and selling one's organs.


Garden, Rebecca; Murphree, Hyon Joo Yoo. Class and ethnicity in the global market for organs: the case of Korean cinema. Journal of Medical Humanities 2007 December; 28(4): 213-229. NRCBL: 19.5; 4.4; 7.1; 21.1; 9.3.1. Abstract: While organ transplantation has been established in the medical imagination since the 1960s, this technology is currently undergoing a popular re-imagination in the era of global capitalism. As transplantation procedures have become routine in medical centers in non-Western and developing nations and as organ sales and transplant tourism become increasingly common, organs that function as a material resource increasingly derive from subaltern bodies. This essay explores this development as represented in a Korean filmmaker Park Chan-wook’s 2002 Sympathy for Mr. Vengeance, focusing on the ethnic and class characteristics of the global market in organs and possible modes of counter-logic to transplant technologies and related ethical discourses.


Taylor, J.S. A “queen of hearts” trial of organ markets: why Scheper-Hughes’s objections to human or-
gans fail. *Journal of Medical Ethics* 2007 April; 33(4): 201-204. NRCBL: 19.5; 9.3.1; 19.3; 1.1. SC: an.

Abstract: Nancy Scheper-Hughes is one of the most prominent critics of markets in human organs. Unfortunately, Scheper-Hughes rejects the view that markets should be used to solve the current (and chronic) shortage of transplant organs without engaging with the arguments in favour of them. Scheper-Hughes’s rejection of such markets is of special concern, given her influence over their future, for she holds, among other positions, the status of an adviser to the World Health Organization (Geneva) on issues related to global transplantation. Given her influence, it is important that Scheper-Hughes’s moral condemnation of markets in human organs be subject to critical assessment. Such critical assessment, however, has not generally been forthcoming. A careful examination of Scheper-Hughes’s anti-market stance shows that it is based on serious mischaracterisations of both the pro-market position and the medical and economic realities that underlie it. In this paper, the author will expose and correct these mischaracterisations and, in so doing, show that her objections to markets in human organs are unfounded.


Waltz, Emily. The body snatchers: rising demand has created a thriving market for human body parts — and not all of it above ground [news]. *Nature Medicine* 2006 May; 12(5): 487-488. NRCBL: 19.5; 4.4; 9.3.1; 18.1; 20.1. SC: le.


Zarocostas, John. UN calls for tougher rules to prevent sale of children’s organs [news]. *BMJ: British Medical Journal* 2007 March 31; 334(7595): 656. NRCBL: 19.5; 19.2; 9.5.7; 9.3.1; 21.1.

**ORGAN AND TISSUE TRANSPLANTATION/.../LEGAL ASPECTS**


Arnold, Brent. Legal solutions to Ontario’s organ shortage: redrawing the boundaries of consent. *Health Law Journal* 2005; 13: 139-163. NRCBL: 19.5; 8.3.1; 8.3.3; 20.3.1. SC: le.


Bucklin, Leonard H. Woe unto those who request consent: ethical and legal considerations in rejecting a deceased’s anatomical gift because there is no consent by the survivors. *North Dakota Law Review* 2002 October; 78: 323-354. NRCBL: 19.5; 20.1; 8.3.1; 8.3.3. SC: le.


Abstract: In 2006, the National Conference of Commissioners on Uniform State Laws rewrote the Uniform Anatomical Gift Act. To overcome the problem of family members prohibiting organ donation from their deceased loved ones even when a donor card existed, the commissioners modified the act to prevent end-of-life care from precluding organ donation. An unintended consequence of the new wording creates the potential for end-of-life care that prioritizes care of the potential donor organs over care and comfort of the dying person. The commissioners have now revised the act, but the original version has already been legislated in many states, with others poised to follow. To protect dying patients’ wishes about their end-of-life care, states that have legislated or are considering the original act must replace it with the re-
vised version. A long-term and important ethical precept must stand: Care of dying patients takes precedence over organs. Another laudable goal must be promoted as well: Organ donation is an important part of end-of-life care.

Feifer, Jason. Paying big to be a donor; gifting an organ can be costly. Would a tax break cross a moral line? Washington Post 2007 March 20; p. F1, F4. NRCBL: 19.5; 9.3.1. SC: po; le.


Keywords: *cord blood; *fetal stem cells; *legal aspects; *parental consent; biomedical research; DNA; legislation; newborns; property rights; stem cell transplantation; Proposed Keywords: *South Africa

Abstract: The author develops a thorough analysis of current and proposed South African law in relation to the harvesting and use of stem cells. He begins with the question of ownership of the umbilical cord at birth and afterwards. The problems of informed consent in these situations are discussed. Changes in the law in South Africa, now in progress, should ameliorate some of the difficulties.


Mertes, Heidi.; Pennings, G. Oocyte donation for stem cell research. Human Reproduction 2007 March; 22(3): 629-634. NRCBL: 19.5; 14.6; 9.5.5; 18.5.4; 15.1; 4.4; 18.3. SC: le.


Abstract: This paper provides a legal overview of key issues associated with donation of genetic samples and information from a donor perspective. In particular, it addresses the property status of samples as well as issues in respect of consent, privacy, commercialisation and benefit sharing. The paper highlights the need for appropriate protection and safeguards for individuals, but also, importantly, for understanding what donors actually think and want in terms of genetic research and the use of their samples and information. The paper seeks to emphasise the importance of transparency and accountability in the conduct of research in order to maximise donor participation and confidence and public trust in general.


Abstract: In this article, the author defines and discusses various concepts of consent in relation to organ transplantation. Beginning with the law of the Russian Federation, he highlights the benefits and shortcomings of basic provisions and parameters of consent in Russian law. The
situation is [sic; in] some other countries is reviewed from a comparative aspect. With the object of making transplantation more widespread, liberal interpretations of the rules are to be encouraged.


Abstract: In an attempt to increase the number of organs available for transplantation, section 43 of the Human Tissue Act 2004 provides, for the first time, a statutory basis for the non-consensual preservation of organs. However, several issues arise out of the terminology of the section relating to where the preservation steps can be carried out and, indeed, what preservation steps can be performed which may affect the success of this attempt to increase the organ donor pool.

Sarig, Merav. Israeli surgeon is arrested for suspected organ trafficking [news]. *BMJ: British Medical Journal* 2007 May 12; 334(7601): 973. NRCBL: 19.5. SC: le. Keywords: Israel


Tuffs, Annette. German council demands opt-out system for transplants [news]. *BMJ: British Medical Journal* 2007 May 12; 334(7601): 973. NRCBL: 19.5. SC: le. Keywords: Germany

Underwood, J.C.E. The impact on histopathology practice of new human tissue legislation in the UK. *Histopathology* 2006 September; 49(3): 221-228. NRCBL: 19.5; 19.1; 20.1; 18.3. SC: le.
our attention in contexts of technological innovation and scientific uncertainty. Xenotransplantation, the transplantation of organs or tissues from animals to humans, has the potential to save or improve the lives of many patients but gives rise to the possibility of infectious agents being transferred from donor animals into the human population. As well as being an important ethical issue in its own right it therefore provides a useful vehicle for exploring the more general question of how to balance the benefits of a practice against the risks to third parties. This paper focuses on the Rawlsian, justice-based analysis of the risks of xenotransplantation proposed by Robert Veatch. It argues that Veatch is right to take considerations of distributive justice into account, but that his particular approach is flawed. It is hoped that consideration of Veatch’s arguments, and of the underlying assumptions will suggest better ways of executing a justice-based approach.


ORGAN DONATION See ORGAN AND TISSUE TRANSPLANTATION/ DONATION AND PROCUREMENT

OVA See CRYOBANKING OF SPERM, OVA AND EMBRYOS

OVUM DONORS See REPRODUCTIVE TECHNOLOGIES

PAIN AND PAIN CARE See QUALITY AND VALUE OF LIFE

PALLIATIVE CARE See DEATH AND DYING/ TERMINAL CARE

PARENTAL CONSENT See EUTHANASIA AND ALLOWING TO DIE/ MINORS; CARE FOR SPECIFIC GROUPS/ MINORS; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ MINORS; INFORMED CONSENT/ MINORS

PATENTS


Keywords: *international aspects; *patents; *stem cells; access to information; databases; embryonic stem cells; industry; interinstitutional relations; private sector; public sector; research institutes; statistics; universities; Proposed Keywords: *technology transfer; licensure; Keyword Identifiers: United States


Keywords: *genes; *patents; *property rights; legal aspects; industry; biotechnology

Caulfield, Timothy; Bubela, Tania; Murdoch, C.J. Myriad and the mass media: the covering of a gene patent controversy. Genetics in Medicine 2007 December; 9(12): 850-855. NRCBL: 15.8; 1.3.7; 1.3.2; 9.5.5; 21.1. SC: em.


Keywords: *embryonic stem cells; *legal aspects; biomedical research; biotechnology; economics; methods; public policy; research support; researchers; social impact; state government; universities; Proposed Keywords: licensure; technology transfer; Keyword Identifiers: *Patent and Trademark Office; *United States; *Wisconsin; *Wisconsin Alumni Research Foundation; California


Keywords: *DNA; *genetic patents; *legal aspects; *risks and benefits; biotechnology; DNA sequences; guidelines; human genome; industry; legislation; policy analysis; public policy; recombinant DNA research; Keyword Identifiers: *Patent and Trademark Office; *United States; Patent Act

Commission on Intellectual Property Rights [CIPR]; Thambisetty, Sivaramjani. Human genome patents and

Keywords: *developing countries; *genetic materials; *genetic patents; benefit sharing; community consent; donors; genetic research; human genome; industry; informed consent; international aspects; legal aspects; research subjects; Western World; Proposed Keywords: genetic resources


Keywords: *genetic patents; benefit sharing; Christian ethics; common good; genetic materials; embryonic stem cells; international aspects; justice; legal aspects; philosophy; theology; virtues; Keyword Identifiers: Europe; European Biotechnology Patent Directive; Human Genome Organization (HUGO); United States


Gold, E. Richard; Bubela, Tania; Miller, Fiona A.; Nicol, Dianne; Piper, Tina. Gene patents — more evidence needed, but policymakers must act [letter]. Nature Biotechnology 2007 April; 25(4): 388-389. NRCBL: 15.8. Comments: Timothy Caulfield, Robert M. Cook-Deegan, F. Scott Kieff, and John P. Walsh. Evidence and anecdotes: an analysis of human gene patenting controversies Nature Biotechnology 2006 September; 24(9): 1091-1094. Keywords: *access to information; *biomedical research; *genes; *genetic patents; *interinstitutional relations; empirical research; guidelines; industry; international aspects; justice; legal aspects; organizational policies; policy making; Proposed Keywords: licensure; technology transfer


Keywords: *genetic patents; *legal aspects; biomedical research; cell lines; clinical genetics; genes; genetic research; genetic screening; genetic services; international aspects; patients; patients’ rights; physicians; property rights; recombinant DNA research; research subjects; researchers; Supreme Court decisions; Proposed Keywords: Canavan disease; licensure; tissue donors; Keyword Identifiers: *United States; Diamond v. Chakrabarty; Greenberg v. Miami Children’s Hospital Research Institute; Moore v. Regents of the University of California; Patent and Trademark Office


Keywords: *cell lines; *embryonic stem cells; biomedical research; embryo research; industry; interinstitutional relations; organizational policies; property rights; research support; universities; Proposed Keywords: *licensure; foundations; technology transfer; Keyword Identifiers: *Wisconsin Alumni Research Foundation; United States; University of Wisconsin

Hansson, Mats G; Helgesson, Gert; Wessman, Richard; Jaenisch, Rudolf. Commentary: isolated stem cells — patentable as cultural artifacts? Stem Cells 2007 June; 25(6): 1507-1510 [Online]. Accessed: http://www.StemCells.com/cgi/content/full/25/6/1507 [2007 December 3]. 31 refs. NRCBL: 15.8; 15.1; 18.5.4; 1.1. Comments: Timothy Caulfield, Robert M. Cook-Deegan, F. Scott Kieff, and John P. Walsh. Evidence and anecdotes: an analysis of human gene patenting controversies Nature Biotechnology 2006 September; 24(9): 1091-1094. Keywords: *access to information; *biomedical research; *genes; *genetic patents; *interinstitutional relations; empirical research; guidelines; industry; international aspects; justice; legal aspects; organizational policies; policy making; Proposed Keywords: licensure; technology transfer

Holden, Constance. Prominent researchers join the attack on stem cell patents [news]. Science 2007 July 13; 317(5835): 187. NRCBL: 15.8; 18.5.4; 15.1. Identifiers: Wisconsin Alumni Research Foundation; United States; University of California; Patent and Trademark Office; Thomson, James; University of Wisconsin; United States

Holden, Constance. U.S. Patent Office casts doubt on Wisconsin stem cell patents [news]. Science 2007 April 13; 316(5822): 182. NRCBL: 15.8; 15.1; 18.5.4. Identifiers: Wisconsin Alumni Research Foundation. Keywords: *cell lines; *embryonic stem cells; *patents; industry; legal aspects; universities; Proposed Keywords: foundations; licensure; technology transfer; Keyword Identifiers: *Patent and Trademark Office; *Wisconsin Alumni Research Foundation; United States

Hopkins, Michael M.; Mahdi, Surya; Patel, Pari; Thomas, Sandy M. DNA patenting: the end of an era? Nature Biotechnology 2007 February; 25(2): 185-188. 18 refs. NRCBL: 15.8; 21.1 SC: em.


Klein, Roger D. Gene patents and genetic testing in the United States. As genetic testing moves into mainstream medicine, its restriction by gene patent holders will have far-reaching, detrimental effects on the healthcare system. *Nature Biotechnology* 2007 September; 25(9): 989-991. 23 refs. NRCBL: 15.8; 15.3.


Lucassen, Anneke; Clarke, Angus. Should families own genetic information [debate]. *BJP: British Medical Jour- nal* 2007 July 7; 335(7609): 22-23. NRCBL: 15.8; 1.3.12; 8.4.


SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review


Van Overwalle, Geertrui; van Zimmeren, Esther; Verbeure, Birgit; Matthijs, Gert. Models for facilitating access to patents on genetic inventions. *Nature Reviews Genetics* 2006 February; 7(2): 143-148. 47 refs. NRCBL: 15.8; 5.3.


PATERNALISM See PATIENT RELATIONSHIPS

PATIENT ACCESS TO RECORDS See CONFIDENTIALITY; TRUTH DISCLOSURE

PATIENT CARE See CARE FOR SPECIFIC GROUPS; DEATH AND DYING/ TERMINAL CARE; PATIENT RELATIONSHIPS

PATIENT RELATIONSHIPS

See also CARE FOR SPECIFIC GROUPS; PROFESSIONAL ETHICS


Berlinger, Nancy. Martin Luther at the bedside: conscientious objection and community. Hastings Center Report 2007 March-April; 37(2): inside back cover. NRCBL: 8.1; 4.1.2; 11.1; 12.3; 20.4.1; 20.7.

Berry, Philip A. The absence of sadness: darker reflections on the doctor-patient relationship. Journal of Medical Ethics 2007 May; 33(5): 266-268. NRCBL: 8.1; 20.4.1. Abstract: Recognising a diminution in his emotional response to patients’ deaths, the author analyses in detail his internal reactions in an attempt to understand what he believes is a common phenomenon among doctors. He identifies factors that may erode the connection between patient and physician: an instinct to separate oneself from another’s suffering, professional unease in the case of therapeutic failure, the atrophying effect of perceived hopelessness, insincerities in the establishment of the initial relationship, and an inability to imbue the sedated or unconscious patient with human qualities. He concludes that recognition of these negative influences, without necessarily changing behaviours that are natural, may be a first step towards protecting doctors against what might be an otherwise insidious process of dehumanisation.


Bowers, Len. On conflict, containment and the relationship between them. Nursing Inquiry 2006 September; 13(3): 172-180. NRCBL: 8.1; 8.3.4; 17.2; 4.3.


Burns, Tom; Shaw, Joanne. Is it acceptable for people to be paid to adhere to medication?[forum]. BMJ: British Medical Journal 2007 August 4; 335(7613): 232-233. NRCBL: 8.1; 9.3.1; 17.8; 17.4.

Camann, William. It is the right of every anaesthetist to refuse to participate in a maternal-request caesarean section. International Journal of Obstetric Anaesthesis 2006 January; 15(1): 35-37. NRCBL: 8.1; 9.5.5; 9.5.8; 9.5.1. SC: an.


Cochrane, Thomas I. Religious delusions and the limits of spirituality in decision-making. American Journal of


Coulter, Angela; Ellins, Jo. Effectiveness of strategies for informing, educating, and involving patients. BMJ: British Medical Journal 2007 July 7; 335(7609): 24-27. NRCBL: 8.1; 9.5.1; 9.8.

Curlin, Farr A.; Chin, Marshall H.; Sellergren, Sarah A.; Roach, Chad J.; Lantos, John D. The association of physicians’ religious characteristics with their attitudes and self-reported behaviors regarding religion and spirituality in the clinical encounter. Medical Care 2006 May; 44(5): 446-453. NRCBL: 8.1; 1.2. SC: em.


Detmer, Don E.; Singleton, Peter; Ratzan, Scott C. The need for better health information: advancing the informed patient in Europe. In: Santoro, Michael A.; Gorrie, Thomas M., eds. Ethics and the Pharmaceutical Industry. Cambridge; New York: Cambridge University Press, 2005: 196-205. NRCBL: 8.1; 8.2; 9.7; 1.3.2.


Duggan, Patrick S.; Geller, Gail; Cooper, Lisa A.; Beach, Mary Catherine. The moral nature of patient-centeredness: is it “just the right thing to do”? Patient Counselling and Health Education 2006 August; 62(2): 271-276. NRCBL: 8.1; 7.1; 1.1.

Ehrenstein, Boris P.; Hanses, Frank; Salzberger, Bernd. Influenza pandemic and professional duty: family or patients first? A survey of hospital employees. BMC Public Health 2006 December 28; 6: 311. NRCBL: 8.1; 1.1; 9.2; 16.3.


Epstein, Miran. Legal and institutional fictions in medical ethics: a common, and yet largely overlooked, phenomenon: a theoretical platform for a much-needed change in the provision of healthcare based on restoring the autonomy of doctor-patient relationships. Journal of Medical Ethics 2007 June; 33(6): 362-364. NRCBL: 8.1; 2.1; 5.3; 8.3.1; 18.1; 19.5; 20.5.1.

Evans, H.M. Do patients have duties? Journal of Medical Ethics 2007 December; 33(12): 689-694. NRCBL: 8.1; 1.1; 9.1; 18.1; SC: an. Abstract: The notion of patients’ duties has received periodic scholarly attention but remains overwhelmed by attention to the duties of healthcare professionals. In a previous paper the author argued that patients in publicly funded healthcare systems have a duty to participate in clinical research, arising from their debt to previous patients. Here the author proposes a greatly extended range of patients’ duties grounding their moral force distinctively in the interests of contemporary and future patients, since medical treatment offered to one patient is always liable to be an opportunity cost (however justifiable) in terms of medical treatment needed by other patients. This generates both negative and positive duties. Ten duties-enjoining obligations ranging from participation in healthcare schemes to promoting one’s own earliest recovery from illness-are proposed. The characteristics of these duties, including their basis, moral force, extent and enforceability, are considered. They are tested against a range of objections—principled, societal, epistemological and practical—and found to survive. Finally, the paper suggests that these duties could be thought to reinforce a regrettably adversarial characteristic, shared with rights-based approaches, and that a pref-
erable alternative might be sought through the (here unexplored) notion of a “virtuous patient” contributing to a problem-solving partnership with the clinician. However, in defining and giving content to that partnership, there is a clear role for most, if not all, of the proposed duties; their value thus extends beyond the adversarial context in which they might first be thought to arise.

Fioriglio, Gianluigi; Szolovits, Peter. Copy fees and patients’ rights to obtain a copy of their medical records: from law to reality. *AMIA Annual Symposium Proceedings* 2005: 251-255. NRCBL: 8.1; 9.2; 9.3.1; 1.3.12.

Fontana, Nicholas. A question of professionalism: are we treating patients as people or procedures? *Journal of the Michigan Dental Association* 2006 October; 88(10): 28-30. NRCBL: 8.1; 7.1; 4.1.1.


Groopman, Leonard C.; Miller, Franklin G.; Fins, Joseph J. The patient’s work. *CQ: Cambridge Quarterly of Healthcare Ethics* 2007 Winter; 16(1): 44-52. NRCBL: 8.1; 8.3.1; 4.1.2; 4.2; 1.1.


Henderson, Amanda; Van Eps, Mary Ann; Pearson, Kate; James, Catherine; Henderson, Peter; Osborne, Yvonne. ‘Caring for’ behaviours that indicate to patients that nurses ‘care about’ them. *Journal of Advanced Nursing* 2007 October; 60(2): 146-153. NRCBL: 8.1; 4.1.3. SC: em.


Abstract: A pandemic due to the avian flu virus (H5N1) is possible, and if it occurs, the event will not be unfamiliar to health care workers. History provides us with numerous examples. In the twentieth century alone, there were three pandemics, the largest being the 1918 “Spanish” influenza pandemic, in which forty to fifty million people died worldwide within one year. Five hundred thousand persons died in the United States alone. Such crises have generated heroic responses by health care workers. The question that arises today is whether such heroism will prevail in the face of varying perceptions concerning the duty of health care workers to care.


SECTION I PATIENT RELATIONSHIPS


Abstract: Turkey has a complex character, which has differences from the Western world or Eastern Asia as well as common points. Even after more than a century of efforts to modernise and integrate with the West, Turkish society has values that are different from those of the West, as well as having Western values. It is worth questioning whether ordinary Turkish people show an individualistic character. The principle of respect for individual autonomy arises from a perception of oneself as an individual, and the person’s situation may affect the applicability of the principle. Patients who perceive themselves to be members of a community rather than free persons and who prefer to participate in the common decisions of the community and to consider the common interest and the common value system of the community concerning problems of their life (except healthcare or biomedical research) rather than to decide as independent, rational individuals may not be competent to make an autonomous choice. Expectations that such patients will behave as autonomous individuals may be unjustified.

The family, rather than the patient, may take a primary role in decisions. A flexible system considering cultural differences in the concept of autonomy may be more feasible than a system following strict universal norms.


Abstract: In this paper several reasons as to why framing issues should be of greater interest to both medical ethicists and healthcare professionals are suggested: firstly, framing can help in explaining health behaviours that can, from the medical perspective, appear perverse; secondly, framing provides a way of describing the internal structure of ethical arguments; and thirdly, an understanding of framing issues can help in identifying clinical practices, such as non-directive counselling, which may, inadvertently, be failing to meet their own stated ethical aims. The effect of framing on how individuals interpret information and how healthcare choices are influenced by framing are described. Next, the role of framing in ethical discourse is discussed with specific reference to Judith Jarvis Thomon’s philosophical mind experiment about abortion and the violinist. Finally, the implications of this analysis are examined for the practice of non-directive counselling, which aims at communicating information in a neutral, value-free way and thereby protecting patient autonomy.


Abstract: Spirituality or religion often presents as a foreign element to the clinical environment, and its language and reasoning can be a source of conflict there. As a result, the use of spirituality or religion by patients and families seems to be a solicitation that is destined to be unanswered and seems to open a distance between those who speak this language and those who do not. I argue that there are two promising approaches for engaging such language and helping patients and their families to productively engage in the decision-making process. First, patient-centered interviewing techniques can be employed to explore the patient’s religious or spiritual beliefs and successfully translate them into choices. Second, and more radically, I suggest that in some more recalcitrant conflicts regarding treatment plans, resolution may require that clinicians become more involved, personally engaging in discussion and disclosure of religious and spiritual worldviews. I believe that both these approaches are supported by rich models of informed consent such as the transparency model and identify considerations and circumstances that can justify such personal disclosures. I conclude by offering some
considerations for curbing potential unprofessional excesses or abuses in discussing spirituality and religion with patients.


Abstract: The essence of a patient’s rights and legislation framework requires an answer to the question on how legislation can work towards better defining, respecting, protecting and effectiveness of these rights. First, it is necessary to give a short introduction to patients’ rights, their definition and different classifications. In the long list of human rights, patients’ rights obviously take one of the very important places. Human life and health are the values, which, in comparison with all other human values, are considered as values of the highest rank. Patients’ rights represent a legal expression of something, which every person basically and naturally expects from a doctor, medical staff, and from a health care system in general. The subject of the second part of this paper presents the intention, scope and conception of necessary legislation. How should it be considered - in a wider sense or as a special law? Some theoretical and practical questions regarding interaction between medical ethics regulation, confidentiality, and legislation are discussed as well. In the European context there are numerous examples of laws with the specific purpose of protecting patients’ rights. Special attention and critical review will be paid to the situation of patients’ rights in Serbia. The paper concludes with the point that the role of legislation is evidently important, but the traditional view should be replaced with a new one, due to the reason that modern [sic; modern] health law puts the protection of patients’ rights on a higher level. De lege lata, the whole system of health law in its diversity (civil, penal and administrative) is characterized by better understanding of rights, duties and legal relations, either through regulation or the protection of patients’ rights.


SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
SECTION I

PATIENT RELATIONSHIPS

jm&year=2005&vol=4&num=01&keys=V4N1 [2008 February 14]. NRCBL: 8.1; 1.1; 20.5.1; 20.2.1. SC: cs.


Abstract: Stewart and DeMarco’s economic theory of patient decision-making applied to the case of diabetes is flawed by clinical inaccuracies and an unrealistic depiction of patients as rational traders. The theory incorrectly represents patients' struggles to optimize their management as calculated trade-offs against the costs of care, and gives an unrealistic, inflexible account of such costs. It imputes to physicians the view that their patients’ lack of compliance is unreasonable, but physicians are accustomed to the variety of human factors which contribute to suboptimal compliance, and work with patients to minimize their influence. By depicting patients as rational traders rather than human beings with a range of motivations and burdens, the economic theory distorts the proper function of informed consent.


Abstract: The term “callous” has not, to this point, been studied empirically or considered philosophically in the context of healthcare professionalism. It should be, however, because its uses seem peculiar. Sometimes “callous” is used to suggest that becoming callous confers a benefit of some protection against emotional distress, which might be considered expedient in the healthcare work environment. But, “callous” also refers to a person’s unappealing demeanor of hardened insensitivity. The tension between these different moral connotations of “callous” prompts several empirical, psychological, and moral questions; I introduce and entertain a few here. I also suggest a distinction between callousness and inurement and argue for why this distinction is important to appreciate and uphold in health professions education.


Rosenthal, M. Sara. Patient misconceptions and ethical challenges in radioactive iodine scanning and therapy. Journal of Nuclear Medicine Technology 2006 September; 34(3): 143-150; quiz 151-152. NRCBL: 8.1; 1.3.12; 9.7; 8.3.1; 8.4; 2.1; 16.2.


Abstract: Advocates of “concordance” describe it as a new model of shared decision-making between physicians and patients based on a partnership of equals. “Concordance” is meant to make obsolete the notion of “compliance,” in which patients are seen as, ideally, following doctors’ orders. This essay offers a critical view of concordance, arguing that the literature itself on concordance, including materials at the web site of Medicines Partnership, the implementation arm in Great Britain of the concordance model, is full of contradiction; concordance, in fact, harbors an ideology of compliance. The essay suggests that an improvement in patient medication use will more likely come from a frank consideration of the relation of compliance issues and commercial ones.
and that a key question across domains is, “how are patients/health agents/consumers persuaded to acquire certain drugs and take them as directed?”


Wirtz, Veronika; Cribb, Alan; Barber, Nick. Patient-doctor decision-making about treatment within the consultation — a critical analysis of models. Social Science and Medicine 2006 January; 62(1): 116-124. NRCBL: 8.1; 7.3.


PATIENTS’ RIGHTS See CARE FOR SPECIFIC GROUPS; CONFIDENTIALITY; INFORMED CONSENT; RIGHT TO HEALTH CARE; TREATMENT REFUSAL; TRUTH DISCLOSURE
PERSONHOOD See QUALITY AND VALUE OF LIFE

PHARMACOGENETICS

Bibbins-Domingo, Kirsten; Fernandez, Alicia. BiDil for heart failure in black patients: implications of the U.S. Food and Drug Administration approval. *Annals of Internal Medicine* 2007 January 2; 146(1): 52-56. 49 refs. NRCBL: 15.1; 5.3; 9.5.4; 9.7.

Keywords: *blacks; *pharmacogenetics; clinical trials; drugs; federal government; health disparities; heart diseases; public policy; racial groups; Proposed Keywords: *drug approval; Keyword Identifiers: *BiDil; *Food and Drug Administration; United States


Keywords: *clinical trials; *ethnic groups; *pharmacogenetics; *racial groups; *culture; drug industry; drugs; genetic ancestry; health hazards; minority groups; public policy; Keyword Identifiers: BiDil; United States


Keywords: *moral policy; *pharmacogenetics; clinical genetics; clinical trials; community consent; confidentiality; drugs; economics; ethical analysis; ethnic groups; genetic ancestry; genetic databases; genetic diversity; genetic information; genetic research; genetic screening; genetic services; health services accessibility; informed consent; justice; marketing; property rights; population genetics; privacy; racial groups; regulation; research subjects; risks and benefits; standards; Proposed Keywords: community participation; exceptionalism


Keywords: *developing countries; *drug industry; *ethical analysis; *international aspects; *justice; *pharmacogenetics; *regulation; clinical genetics; clinical trials; economics; health care delivery; informed consent; marketing; risks and benefits; social impact; trends; Proposed Keywords: world health


Keywords: *pharmacogenetics; *organizational policies; access to information; clinical genetics; drugs; ethics committees; family members; genetic research; genetic services; goals; international aspects; justice; population genetics; public participation; research priorities; risks and benefits; social impact; standards; Proposed Keywords: stakeholders; Keyword Identifiers: *Human Genome Organization (HUGO)


Keywords: *pharmacogenetics; drug industry; forecasting; marketing; social impact; trends


Pato wary, S. Pharmacogenomics — therapeutic and ethical issues. *Kathmandu University Medical Journal (KUMJ)* 2005 October-December; 3(4): 428-430. NRCBL: 15.1; 9.7; 15.11.


Abstract: Developments in pharmacogenetics make it possible to determine the genetic factors that influence variations in response to medicine. Differences in response to medication may be related to the genetic characteristics of the individual, to the genetic make-up of the diseased tissue or to both. Advantages include optimal therapeutic effect, safe medication, minimised side-effects, and development of medication for small groups of patients. Strict adherence to patients’ rights and to the medical professional standard must prevent negative effects of pharmacogenetics on individual rights, notably the right (not) to know, to privacy and informed consent. Use of pharmacogenetics by third parties for non-health related purposes may bring about a disproportionate intrusion of the privacy of an individual; it may result in barriers for accessing primary social goods, and it may be a disincentive for the individual to have a pharmacogenetic analysis performed for individual health care purposes or to participate in a drug trial. Medical examinations before employment must be justified by the health requirements unavoidably inherent to the job (their objective being the protection of health and not the financial interests of the employer). In a system that relies on private insurance for having access to primary social goods (health, disability — and life insurance), the use and the outcome of a pharmacogenetic analysis for the purpose of differentiation between insurance candidates on the basis of their “risk-profile” must be restricted; where appropri-
ate measures should take into account justified interests of the insurance company to prevent adverse selection. Current measures in several European countries are not effective enough to meet the concerns specifically inherent to pharmacogenetics [sic; pharmacogenetics]. Human rights principles must be at the basis of national and European policies for providing adequate protection against disproportionate intrusion into private life, for guaranteeing equity in access to health care and accessibility of other primary social goods.


Keywords: *genetic ancestry; *genetic research; *pharmacogenetics; *race; *race groups; biomedical research; clinical genetics; ethnic groups; genetic diversity; historical aspects; research subjects; selection of subjects; trends; Proposed Keywords: classification

Temple, Robert; Stockbridge, Norman L. BiDil for heart failure in black patients: the U.S. Food and Drug Administration perspective. Annals of Internal Medicine 2007 January 2; 146(1): 52-62. 28 refs. NRCBL: 15.11; 5.3; 9.5.4; 9.7.

Keywords: *blacks; *pharmacogenetics; clinical trials; drugs; federal government; heart diseases; public policy; racial groups; Proposed Keywords: *drug approval; Keyword Identifiers: *BiDil; *Food and Drug Administration; United States


Keywords: *genetic research; *genomics; *legal aspects; *pharmacogenetics; *public policy; advertising; biological specimen banks; drugs; genetic screening; guidelines; research support; standards; Keyword Identifiers: *United States

PHARMACOGENOMICS See PHARMACOGENETICS

PHILOSOPHICAL ASPECTS See BIOETHICS AND MEDICAL ETHICS/ PHILOSOPHICAL ASPECTS; EUTHANASIA AND ALLOWING TO DIE/ PHILOSOPHICAL ASPECTS

PHILOSOPHY See BIOETHICS AND MEDICAL ETHICS/ PHILOSOPHICAL ASPECTS; EUTHANASIA AND ALLOWING TO DIE/

PHILOSOPHY OF MEDICINE


Abstract: BACKGROUND: The prospect of improving care through increasing professionalism has been gaining momentum among physician organizations. Although there have been efforts to define and promote professionalism, few data are available on physician attitudes toward and conformance with professional norms. OBJECTIVE: To ascertain the extent to which practicing physicians agree with and act consistently with norms of professionalism. DESIGN: National survey using a stratified random sample. SETTING: Medical care in the United States. PARTICIPANTS: 3504 practicing physicians in internal medicine, family practice, pediatrics, surgery, anesthesiology, and cardiology. MEASUREMENTS: Attitudes and behaviors were assessed by using
indicators for each domain of professionalism developed by the American College of Physicians and the American Board of Internal Medicine. Of the eligible sampled physicians, 1662 responded, yielding a 58% weighted response rate (adjusting for noneligible physicians).

RESULTS: Ninety percent or more of the respondents agreed with specific statements about principles of fair distribution of finite resources, improving access to and quality of care, managing conflicts of interest, and professional self-regulation. Twenty-four percent disagreed that periodic recertification was desirable. Physician behavior did not always reflect the standards they endorsed. For example, although 96% of respondents agreed that physicians should report impaired or incompetent colleagues to relevant authorities, 45% of respondents who encountered such colleagues had not reported them.

LIMITATIONS: Our measures of behavior did not capture all activities that may reflect on the norms in question. Furthermore, behaviors were self-reported, and the results may not be generalizable to physicians in specialties not included in the study.

CONCLUSION: Physicians agreed with standards of professional behavior promulgated by professional societies. Reported behavior, however, did not always conform to those norms.


Epstein, Ronald M. Mindful practice and the tacit ethics of the moment. In: Kenny, Nuala; Shelton, Wayne, eds. Lost Virtue: Professional Character Development in Medical Education. Amsterdam; Oxford: Elsevier, 2006: 115-144. NRCBL: 4.1.2; 7.2; 8.1.


Genuis, S.J. Dismembering the ethical physician. Postgraduate Medical Journal 2006 April; 82(966): 233-238. NRCBL: 4.1.2; 18.6; 2.1.


Kinghorn, Warren A.; McEvoy, Matthew D.; Michel, Andrew; Balboni, Michael. Professionalism in modern medicine: does the emperor have any clothes? Academic Medicine 2007 January; 82(1): 40-45. NRCBL: 4.1.2; 1.3.1; 7.2.


Le Coz, Pierre; Tassy, Sebastien. The philosophical moment of the medical decision: revisiting emotions felt, to improve ethics of future decisions. *Journal of Medical Ethics* 2007 August; 33(8): 470-472. NRCBL: 4.1.2; 1.1; 8.1.

Abstract: The present investigation looks for a solution to the problem of the influence of feelings and emotions on our ethical decisions. This problem can be formulated in the following way. On the one hand, emotions (fear, pity and so on) can alter our sense of discrimination and lead us to make our wrong decisions. On the other hand, it is known that lack of sensitivity can alter our judgment and lead us to sacrifice basic ethical principles such as autonomy, beneficence, non-maleficence and justice. Only emotions can turn a decision into an ethical one, but they can also turn it into an unreasonable one. To avoid this contradiction, suggest integrating emotions with the decisional factors of the process of “retrospective thinking”. During this thinking, doctors usually try to identify the nature and impact of feelings on the decision they have just made. In this retrospective moment of analysis of the decision, doctors also question themselves on the feelings they did not experience. They do this to estimate the consequences of this lack of feeling on the way they behaved with the patient.


Petrova, Mila; Dale, Jeremy; Fulford, Bill (KWM). Values-based practice in primary care: easing the tension between individual values, ethical principles and best evidence. *British Journal of General Practice* 2006 September; 56(530): 703-709. NRCBL: 4.1.2; 8.1; 7.1.


Sox, Harold C. Medical professionalism and the parable of the craft guilds [editorial]. *Annals of Internal Medicine* 2007 December; 147(11): 809-810. NRCBL: 4.1.2; 1.3.1; 7.2.

Stark, Patsy; Roberts, Chris; Newble, David; Bax, Nigel. Discovering professionalism through guided reflection. *Medical Teacher* 2006 February; 28(1): e25-e31. NRCBL: 4.1.2; 1.3.1; 7.2.


**PHILOSOPHY OF NURSING** See NURSING ETHICS AND PHILOSOPHY

**PHYSICIAN PATIENT RELATIONSHIP** See BIOETHICS AND MEDICAL ETHICS; PATIENT RELATIONSHIPS

**PREIMPLANTATION DIAGNOSIS** See GENETIC COUNSELING; GENETIC SCREENING

**PRENATAL DIAGNOSIS** See GENETIC COUNSELING; GENETIC SCREENING; SEX DETERMINATION

**PRIORITIES IN HEALTH CARE** See RESOURCE ALLOCATION

**PRISONERS** See HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ PRISONERS; TREATMENT REFUSAL

**PRIVACY** See CONFIDENTIALITY; GENETIC PRIVACY

**PRIVILEGED COMMUNICATION** See CONFIDENTIALITY

**PROCUREMENT** See ORGAN AND TISSUE TRANSPLANTATION/ DONATION AND PROCUREMENT

**PROFESSIONAL ETHICS** See also BIOETHICS AND MEDICAL ETHICS; CODES OF ETHICS; NURSING ETHICS AND PHILOSOPHY

Arman, Maria; Rehnsfeldt, Arne; Oberle, Kathleen. The ‘little extra’ that alleviates suffering. *Nursing Ethics* 2007 May; 14(3): 372-384; discussion: 384-386. NRCBL: 4.1.1; 4.1.3; 8.1; 4.4. SC: em.

Abstract: Nursing, or caring science, is mainly concerned with developing knowledge of what constitutes ideal, good health care for patients as whole persons, and how to achieve this. The aim of this study was to find clinical empirical indications of good ethical care and to investigate the substance of ideal nursing care in praxis. A hermeneutic method was employed in this clinical study, assuming the theoretical perspective of caritative caring and ethics of the understanding of life. The data consisted of two Socratic dialogues: one with nurses and one with nursing students, and interviews with two former patients. The empirical data are first described from a phenomenological approach. Observations of caregivers offering ‘the little extra’ were taken to confirm that patients were ‘being seen’, not from the perspective of an ideal nursing model, but from that of interaction as a fellow human being. The study provides clinical evidence that, as an ontological response to suffering, ‘symbolic acts’ such as giving the ‘little extra’ may work to bridge gaps in human interaction. The fact that ‘little things’ have the power to preserve dignity and make patients feel they are valued offers hope. Witnessing benevolent acts also paves the way for both patients and caregivers to increase their understanding of life.

Beemsterboer, Phyllis L. Developing an ethic of access to care in dentistry. *Journal of Dental Education* 2006 November; 70(11): 1212-1216. NRCBL: 4.1.1; 7.2.


Catalanotto, Frank A.; Patthoff, Donald E.; Gray, Carolyn F. Ethics of access to oral health care: an introduction to the special issue. *Journal of Dental Education* 2006 November; 70(11): 1117-1119. NRCBL: 4.1.1; 9.2.


Cohen, Michael H. Legal and ethical issues relating to use of complementary therapies in pediatric hematology/oncology. *Journal of Pediatric Hematology/Oncology* 2006 March; 28(3): 190-193. NRCBL: 4.1.1; 8.1; 8.3.2; 9.5.1. SC: le; rv.


Abstract: There is a prevailing conviction that if traditional medicine (TRM) or complementary and alternative medicine (CAM) are integrated into healthcare systems, modern scientific medicine (MSM) should retain its principal status. This paper contends that this position is misguided in medical contexts where TRM is established and remains vibrant. By reflecting on the Chinese policy on three entrenched forms of TRM (Tibetan, Mongolian and Uighur medicines) in western regions of China, the paper challenges the ideology of science that lies behind the demand that all traditional forms of medicine be evaluated and reformed according to MSM standards. Tibetan medicine is used as a case study to indicate the falsity of a major premise of the scientific ideology. The conclusion is that the proper integrative system for TRM and MSM is a dual standard based system in which both TRM and MSM are free to operate according to their own medical standards.

Henley, Lesley D.; Frank, Denise M. Reporting ethical protections in physical therapy research. *Physical Therapy* 2006 April; 86(4): 499-509. NRCBL: 4.1.1; 18.2; 18.3; 1.3.7. SC: em.


Abstract: Ten new graduate speech pathologists recounted their experiences in managing workplace ethical dilemmas in semi-structured interviews. Their stories were analysed for elements that described the nature and management of the ethical dilemmas. Ethical reasoning themes were generated to reflect the participants’ approaches to managing these dilemmas. Finally, a conceptual model, the Dynamic Model of Ethical Reasoning, was developed. This model incorporates the elements of awareness, independent problem solving, supported problem solving, and decision and outcome evaluation. Features of the model demonstrate the complexity of ethical reasoning and the challenges that new graduates encounter when managing ethical dilemmas. The results have implications for preparing new graduates to manage ethical dilemmas in the workplace.


Largent, Beverly A. When is it proper to refer a patient receiving public aid to another dentist? *Journal of the American Dental Association* 2006 March; 137(3): 395-396. NRCBL: 4.1.1; 9.3.1; 9.5.10; 7.3.


Abstract: In recent years the literature on bioethics has begun to pose the sociological challenge of how to explore organisational processes that facilitate a systemic response to ethical concerns. The present discussion seeks to make a contribution to this important new direction in ethical research by presenting findings from an Australian pilot study. The research was initiated by the Clinical Ethics Committee of Redland Hospital at Bayside Health Service District in Queensland, Australia, and explores health professionals’ understanding of the nature of ethics and their experience with ethical decision-making within an acute medical ward. This study focuses on the actual experience, understanding and attitudes of clinical professionals in a general medical ward. In particular, the discussion explores the specific findings from the study concerned with how a multi-disciplinary team of health professionals define and operationalise the notion of ethics in an acute ward hospital setting. The key issue reported is that health professionals are not only able to clearly articulate notions of ethics, but that the notions expressed by a multi-disciplinary diversity of participants share a common definitional concept of ethics as patient-centred care. The central finding is that all professional groups indicated that there is a guiding principle to address their ethical sense of the ‘good’ or the ‘ought’ and that is to act in a way that furthered the interests of patients and their families. The findings affirm the importance of a sociological perspective as a productive new direction in bioethical research.


Abstract: With the prevalence of complementary and alternative medicine (CAM) increasing in western societies, questions of the ethical justification of these alternative health care approaches and practices have to be addressed. In order to evaluate philosophical reasoning on this subject, it is of paramount importance to identify and analyse possible arguments for the ethical justification of CAM considering contemporary biomedical ethics as well as more fundamental philosophical aspects. Moreover, it is vital to provide adequate analytical instruments for this task, such as separating, CAM as belief system’ and ‘CAM as practice’. Findings show that beneficence and non-maleficence are central issues for an ethical justification of CAM as practice, while freedom of thought and religion are central to CAM as belief system. Many justification strategies have limitations and qualifications that have to be taken into account. Singularly descriptive premises in an argument often prove to be more problematic than universal ethical principles. Thus, non-ethical issues related to a general philosophical underpinning - e.g. epistemology, semantics, and ontology - are highly relevant for determining a justification strategy, especially when strong metaphysical assumptions are involved. Even if some values are shared with traditional biomedicine, axiological differences have to be considered as well. Further research should be done about specific CAM positions. These could be combined with applied qualitative social research methods.

Newburger, Amy E.; Caplan, Arthur L. Taking ethics seriously in cosmetic dermatology. Archives of Dermatology 2006 December; 142(12): 1641-1642. NRCBL: 4.1.1; 7.1; 1.3.2; 7.2; 9.3.1.


Abstract: It has been estimated that more than 80% of people in Africa use traditional medicine (TM). With the HIV/AIDS epidemic claiming many lives in Africa, the majority of people affected rely on TM mainly because it is relatively affordable and available to the poor populations who cannot afford orthodox medicine. Whereas orthodox medicine is practiced under stringent regulations and ethical guidelines emanating from The Nuremberg Code,1 African TM seems to be exempt from such scrutiny. Although recently there have been calls for TM to be incorporated into the health care system, less emphasis has been placed on ethical and regulatory issues. In this paper, an overview of the use of African TM in general, and for HIV/AIDS in particular, is given, followed by a look at: (i) the relative laxity in the application of ethical standards and regulatory requirements with regards to TM; (ii) the importance of research on TM in order to improve and demystify its therapeutic qualities; (iii) the need to tailor-make intellectual property laws to protect traditional knowledge and biodiversity. A framework of partnerships involving traditional healers’ associations, scientists, policy makers, patients, community leaders, members of the communities, and funding organizations is suggested as a possible method to tackle these issues. It is hoped that this paper will stimulate objective and constructive debate that could enhance the protection of patients’ welfare.

O’Toole, Brian. Four ways we approach ethics. Journal of Dental Education 2006 November; 70(11): 1152-1158. NRCBL: 4.1.1; 2.1.


Patthoff, Donald E. How did we get here? Where are we going? Hopes and gaps in access to oral health care. *Journal of Dental Education* 2006 November; 70(11): 1125-1132. NRCBL: 4.1.1; 9.2; 9.3.1.


Schwab, Abraham. Getting rid of heroes. *Atrium* 2007 Summer; 4: 25-28. NRCBL: 1.3.1; 4.1.2; 18.4; 18.5.2.

Smith, Jayne L.; Cervero, Ronald M.; Valentine, Thomas. Impact of commercial support on continuing pharmacy education. *Journal of Continuing Education in the Health Professions* 2006 Fall; 26(4): 302-312. NRCBL: 4.1.1; 7.2; 1.3.2; 7.3. SC: em.

Tangwa, Godfrey B. How not to compare western scientific medicine with African traditional medicine. *Developing World Bioethics* 2007 April; 7(1): 41-44. NRCBL: 4.1.1; 9.5.6; 21.7; 21.1. Comments: Aceme Nyika. Ethical and regulatory issues surrounding African traditional medicine in the context of HIV/AIDS. *Developing World Bioethics* 2007 April; 7(1): 25-34. Abstract: In his commentary on Aceme Nyika’s paper ‘Ethical and Regulatory Issues Surrounding African Traditional Medicine in the Context of HIV/AIDS’, Godfrey B. Tangwa charges the author with inappropriately using expressions, terminology and criteria of evaluation appropriate in Western scientific medicine to judge African traditional medicine (TM). He seriously frowns on Nyika’s suggestion that African TM needs to be incorporated into, and subjected to the canons of Western scientific medicine. Such a suggestion, he believes, is a prescription for invasion, colonization and exploitation so characteristic of the relationship between Africa and the Western world. However, he thinks that African TM is quite compatible with Western scientific medicine.

Van Bogaert, Donna Knapp. Ethical considerations in African traditional medicine: a response to Nyika. *Developing World Bioethics* 2007 April; 7(1): 35-40. NRCBL: 4.1.1; 9.5.6; 21.7. Comments: Aceme Nyika. Ethical and regulatory issues surrounding African traditional medicine in the context of HIV/AIDS. *Developing World Bioethics* 2007 April; 7(1): 25-34. Abstract: Like other so-called ‘parallel’ practices in medicine, traditional medicine (TM) does not avoid criticism or even rejection. Nyika’s article ‘Ethical and Regulatory Issues Surrounding African Traditional Medicine in the Context of HIV/AIDS’ looks at some of the issues from a traditional Western ethical perspective and suggests that it should be rejected. I respond to this article agreeing with Nyika’s three major criticisms: lack of informed consent, confidentiality and paternalism. However, as traditional healers are consulted by over 70% of South Africans before any other type of healthcare professional, a blanket negation of TM is not possible, nor is it politically feasible. A pragmatic approach would be to work within the current structures for positive change. I point out that, as all cultural practices do, TM will change over time. Yet, until some regulations and change occur, the problem of harm to patients remains a major concern.

Weaver, Kathryn. Ethical sensitivity: state of knowledge and needs for further research. *Nursing Ethics* 2007 March; 14(2): 141-155. NRCBL: 1.3.1; 4.1.3. SC: em; rv. Abstract: Ethical sensitivity was introduced to caring science to describe the first component of decision making in professional practice; that is, recognizing and interpreting the ethical dimension of a care situation. It has since been conceptualized in various ways by scholars of professional disciplines. While all have agreed that ethical sensitivity is vital to practice, there has been no consensus regarding its definition, its characteristics, the conditions needed for it to occur, or the outcomes to professionals and society. The purpose of this article is to explore the meaning of the concept of ethical sensitivity based on a review of the professional literature of selected disciplines. Qualitative content analysis of the many descriptors found within the literature was conducted to enhance understanding of the concept and identify its essential characteristics. Ethical sensitivity is considered to be an emerging concept with potential utility in research and practice.

Weaver, Kathryn; Morse, Janice M. Pragmatic utility: using analytical questions to explore the concept of ethical sensitivity. *Research and Theory for Nursing Practice* 2006 Fall; 20(3): 191-214. NRCBL: 4.1.1; 1.1; 4.4.


**PROFESSIONAL MISCONDUCT** See BIOMEDICAL RESEARCH/ RESEARCH ETHICS AND SCIENTIFIC MISCONDUCT; MALPRACTICE AND PROFESSIONAL MISCONDUCT
PROFESSIONAL PATIENT RELATIONSHIP
See CARE FOR SPECIFIC GROUPS; NURSING ETHICS AND PHILOSOPHY; PATIENT RELATIONSHIPS; PROFESSIONAL ETHICS

PROFESSIONAL PROFESSIONAL RELATIONSHIP

Caldicott, Catherine V. “Sweeping up after the parade”: professional, ethical, and patient care implications of “turfing”. Perspectives in Biology and Medicine 2007 Winter; 50(1): 136-149. NRCBL: 7.3; 8.1; 7.2.

Chervenak, Frank A.; McCullough, Laurence B.; Baril, Thomas E., Sr. Ethics, a neglected dimension of power relationships of physician leaders. American Journal of Obstetrics and Gynecology 2006 September; 195(3): 651-656. NRCBL: 7.3; 7.1; 1.3.2.

Cosgrove, Lisa; Krimsky, Sheldon; Vijayaraghavan, Manisha; Schneider, Lisa. Financial ties between DSM-IV panel members and the pharmaceutical industry. Psychotherapy and Psychosomatics 2006; 75(3): 154-160. NRCBL: 7.3; 17.1; 9.7; 9.3.1.

Cram, Peter; Rosenthal; Gary E. Physician-owned specialty hospitals and coronary revascularization utilization: too much of a good thing? JAMA: The Journal of the American Medical Association 2007 March 7; 297(9): 998-999. NRCBL: 7.3; 9.3.1; 9.5.1.


Abstract: This article, written from research data, focuses on the possible meaning of the data rather than on detailed statistical reporting. It defines whistleblowing as an act of the international nursing ethical ideal of advocacy, and places it in the larger context of professional responsibility. The experiences, actions, and ethical positions of 24 Japanese nurses regarding whistleblowing or reporting a colleague for wrongdoing provide the data. Of these respondents, similar in age, educational level and clinical experience, 10 had previously reported another nurse and 12 had reported a physician for a wrongful act. These data raise questions about overt actions to expose a colleague in a culture that values group loyalty and saving face. Additional research is needed for an in-depth understanding of whistleblowing, patient advocacy and professional responsibility across cultures, especially those that value group loyalty, saving face and similar concepts to the Japanese. The value is on implicit understanding requiring indirect communication. Usually, being direct and openly discussing sensitive topics is not valued in Japan because such behavior disrupts the most fundamental value, harmony (wa).


Duvall, David G. Conflict of interest or ideological divide: the need for ongoing collaboration between physicians and industry. Current Medical Research and Opinion 2006 September; 22(9): 1807-1812. NRCBL: 7.3; 1.3.2; 9.7.


Komesaroff, P. Ethical issues in the relationships involving medicine and industry: evolving problems require evolving. Internal Medicine Journal 2005 April; 35(4): 203-205. NRCBL: 7.3; 1.3.2; 9.3.1; 9.7. Identifiers: Australia.


McKnealy, Martin F. Beyond disclosure: managing conflicts of interest to strengthen trust in our profession. Journal of Thoracic and Cardiovascular Surgery 2007 February; 133(2): 300-302. NRCBL: 7.3; 8.2; 9.3.1; 9.5.1; 1.3.7.

Parker, Lisa S.; Satkoske, Valerie B. Conflicts of interest: are informed consent an appropriate model and disclosure an appropriate remedy? Journal of the American College of Dentists 2007 Summer; 74(2): 19-26. NRCBL: 7.3; 4.1.1; 1.3.1; 8.2.

Rentmeester, Christy A. "Why aren’t you doing what we want?" Cultivating collegiality and communication between specialist and generalist physicians and residents. Journal of Medical Ethics 2007 May; 33(5): 308-310. NRCBL: 7.3.

Abstract: Developing residents’ communication skills has been a goal of residency training programmes since the Accreditation Council for Graduate Medical Education codified it as a core competency. In this article, a case that features problematic communication between a generalist and specialist physician is drawn upon, and it is suggested how their communication might become open and effective through a practice of reason exchange. This is a practice of giving reasons, listening to reasons given...
by others, evaluating reasons and deciding which particulars of situations constitute reasons to act and reasons how to act. Drawing on recent literature in teaching communication to radiology residents, it is proposed that practices of reason exchange are part of the skill set generally referred to as “negotiation skills” that should be cultivated in all residents. Particularly, in cases in which generalist and specialist physicians disagree about the reasons to do something, not do something or do something this way or that way, how well physicians are trained to practice reason exchange depends on whether they can communicate effectively and negotiate disagreement collegially.

Rich, Karen L. Using Buddhist Sangha as a model of communitarianism in nursing. *Nursing Ethics* 2007 July; 14(4): 466-477. NRCBL: 7.3; 1.2; 1.3.1; 4.1.3.

Abstract: In spite of a continuing long and rich history of caring for patients, many nurses have not been satisfied with their work. One cause among others for this dissatisfaction is that nurses often do not care for one another. The philosophy of a Buddhist Sangha, or community, is similar to the philosophy of western communitarian ethics. Both philosophies emphasize the importance of people working together harmoniously towards a common good. In this article, unsatisfactory nurse-nurse relationships have been considered and a model for communitarian nursing practice has been suggested based on a Buddhist Sangha.


Standridge, John B. Of doctor conventions and drug companies. *Family Medicine* 2006 July-August; 38(7): 518-520. NRCBL: 7.3; 9.7; 9.3.1; 1.3.2.


Abstract: Physicians and nurses need to sustain their unique strengths and work in true collaboration, recognizing their interdependence and the complementarity of their knowledge, skills and perspectives, as well as their common moral commitments. In this article, challenges often faced by both nurses and physicians in working collaboratively are explored with a focus on the ways in which each profession’s preparation for practice has differed over time, including shifts in knowledge development and codes of ethics guiding their practice. A call for envisioning their practice as shared moral work as well as practical strategies to begin that work are offered as a basis for reflection towards enhanced nurse-physician relationships.


PROLON GATION OF LIFE See EUTHANASIA AND ALLOWING TO DIE

PROXY DECISION MAKING See ADVANCE DIRECTIVES; EUTHANASIA AND ALLOWING TO DIE; INFORMED CONSENT/ INCOMPETENTS; INFORMED CONSENT/ MINORS

**PSYCHOPHARMACOLOGY**

*See also* BEHAVIOR CONTROL; CARE FOR SPECIFIC GROUPS/ MENTALLY DISABLED; MENTAL HEALTH THERAPIES AND NEUROSCIENCES


Abstract: BACKGROUND: Giving money as a direct incentive for patients in exchange for depot medication has proved beneficial in some clinical cases in assertive outreach (AO). However, ethical concerns around this practice have been raised, and will be analysed in more detail here. Method: Ethical concern voiced in a survey of all AO teams in England were analysed regarding their content. These were grouped into categories. RESULTS: 53 of 70 team managers mentioned concerns, many of them serious and expressing a negative attitude towards giving money for depot adherence. Four broad categories of ethical concern following Christensen’s concept were distinguished: valid consent and refusal (n = 5), psychiatric paternalism (n = 31), resource allocation (n = 4), organisational relationships (n = 2), with a residual category others and unspecified (n = 11). DISCUSSION: The main concerns identified are discussed on the background of existing ethical theories in healthcare and the
specific problems of community mental health and AO. Points for practice are derived from this discussion. A way forward is outlined that includes informed consent and an operational policy in the use of incentives, further randomised controlled trials and qualitative studies, and continuing discussions with all stakeholders, especially service users.

Cosgrove, Lisa; Bursztajn, Harold J. Undoing undue industry influence: lessons from psychiatry as psychopharmacology. Organizational Ethics: Healthcare, Business, and Policy 2006 Fall-Winter; 3(2): 131-133. NRCBL: 17.4; 1.3.2; 7.3; 17.1.


Dekkers, Wim; Rikkert, Marcel Olde. Memory enhancing drugs and Alzheimer’s disease: enhancing the self or preventing the loss of it? Medicine, Health Care and Philosophy 2007 June; 10(2): 141-151. NRCBL: 17.4; 1.1; 4.5; 4.4; 9.5.2. SC: an.

Abstract: In this paper we analyse some ethical and philosophical questions related to the development of memory enhancing drugs (MEDs) and anti-dementia drugs. The world of memory enhancement is coloured by utopian thinking and by the desire for quicker, sharper, and more reliable memories. Dementia is characterized by decline, fragility, vulnerability, a loss of the most important cognitive functions and even a loss of self. While MEDs are being developed for self-improvement, in Alzheimer’s Disease (AD) the self is being lost. Despite this it is precisely those patients with AD and other forms of dementia that provide the subjects for scientific research on memory improvement. Biomedical research in the field of MEDs and anti-dementia drugs appears to provide a strong impetus for rethinking what we mean by ‘memory’, ‘enhancement’, ‘therapy’, and ‘self’. We conclude (1) that the enhancement of memory is still in its infancy, (2) that current MEDs and anti-dementia drugs are at best partially and minimally effective under specific conditions, (3) that ‘memory’ and ‘enhancement’ are ambiguous terms, (4) that there is no clear-cut distinction between enhancement and therapy, and (5) that the research into MEDs and anti-dementia drugs encourages a reductionistic view of the human mind and of the self.


Hawthorne, Susan. ADHD drugs: values that drive the debates and decisions. Medicine, Health Care and Philosophy 2007 June; 10(2): 129-140. NRCBL: 17.4; 17.3. SC: an.

Abstract: Use of medication for treatment of ADHD (or its historical precursors) has been debated for more than forty years. Reasons for the ongoing differences of opinion are analyzed by exploring some of the arguments for and against considering ADHD a mental disorder. Relative to two important DSM criteria - that a mental disorder causes some sort of harm to the individual and that a mental disorder is the manifestation of a dysfunction in the individual - ADHD’s classification as a mental disorder is found to be contentiously value-laden. The disagreements spill over to reasoning regarding appropriate management, because justification for a drug prescription is in part predicated on the idea that the drugs manage mental disorders. These debates do not appear to be nearing resolution, so individuals offering advice, or trying to decide whether ADHD drugs are appropriate for themselves or their children, may find it helpful to compare the values underlying various perspectives with their own.

Abstract: The National Institute of Mental Health (Bethesda, MD) reports that approximately 5.2 million Americans experience post-traumatic stress disorder (PTSD) each year. PTSD can be severely debilitating and diminish quality of life for patients and those who care for them. Studies have indicated that propranolol, a beta-blocker, reduces consolidation of emotional memory. When administered immediately after a psychic trauma, it is efficacious as a prophylactic for PTSD. Use of such memory-altering drugs raises important ethical concerns, including some futuristic dystopias put forth by the President’s Council on Bioethics. We think that adequate informed consent should facilitate ethical research using propranolol and, if it proves efficacious, routine treatment. Clinical evidence from studies should certainly continue to evaluate realistic concerns about possible ill effects of diminishing memory. If memory-attenuating drugs prove effective, we believe that the most immediate social concern is the over-medicalization of bad memories, and its subsequent exploitation by the pharmaceutical industry.


Abstract: The clinical ethics literature is striking for the absence of an important genre of scholarship that is common to the literature of clinical medicine: systematic reviews. As a consequence, the field of clinical ethics lacks the internal, corrective effect of review articles that are designed to reduce potential bias. This article inaugurates a new section of the annual “Clinical Ethics” issue of the Journal of Medicine and Philosophy on systematic reviews. Using recently articulated standards for argument-based normative ethics, we provide a systematic review of the literature on concealed medication for the management of psychiatric disorders. Four steps are completed: identify a focused question; conduct a literature search using key terms relevant to the focused question; assess the adequacy of the argument-based methods of the papers identified; and identify conclusions drawn in each paper and whether they apply to the focused question. We identified seven papers and provide an assessment of them. While none of the papers fully meet the standards of argument-based ethics, they did provide rationales for the use of concealed medications, with the important requirement such a practice be accountable in explicit organizational policy to prevent abuse of patients with mental illness or dementia.


Sade, Robert M.; Henry, Michael; Fishman, Jennifer R.; Youngner, Stuart J. On moralizing and hidden agendas: the pot and the kettle in political bioethics. *American Journal of Bioethics* 2007 September; 7(9): 42-43; author reply W1-W3. NRCBL: 17.4; 2.4; 1.3.2. Comments: Mi-


Abstract: Aldous Huxley’s Brave New World is a familiar dystopia, frequently called upon in public discussions about new biotechnology. It is less well known that 30 years later Huxley also wrote a utopian novel, called Island. This paper will discuss both novels focussing especially on the role of psychopharmacological substances. If we see fiction as a way of imagining what the world could look like, then what can we learn from Huxley’s novels about psychopharmacology and how does that relate to the discussion in the ethical and philosophical literature on this subject? The paper argues that in the current ethical discussion the dystopian vision on psychopharmacology is dominant, but that a comparison between Brave New World and Island shows that a more utopian view is possible as well. This is illustrated by a discussion of the issue of psychopharmacology and authenticity. The second part of the paper draws some further conclusions for the ethical debate on psychopharmacology and human enhancement, by comparing the novels not only with each other, but also with our present reality. It is claimed that the debate should not get stuck in an opposition of dystopian and utopian views, but should address important issues that demand attention in our real world: those of evaluation and governance of enhancing psychopharmacological substances in democratic, pluralistic societies.


Abstract: In this paper, I explore the questions of how and to what extent new antidepressants (selective serotonin-reuptake inhibitors, or SSRIs) could possibly affect the self. I do this by way of a phenomenological approach, using the works of Martin Heidegger and Thomas Fuchs to analyze the roles of attunement and embodiment in normal and abnormal ways of being-in-the-world. The nature of depression and anxiety disorders - the diagnoses for which treatment with antidepressants is most commonly indicated - is also explored by way of this phenomenological approach, as are the basic structures of self-being. Special attention is paid in the analysis to the moods of boredom, anxiety and grief, since they play fundamental roles in depression and anxiety disorders and since their intensity and frequency appear to be modulated by antidepressants. My conclusion is that the effect of these drugs on the self can be thought of in terms of changes in self-feeling, or, more precisely, self-vibration of embodiment. I present the idea of a spectrum of bodily resonance, which extends from the normal resonance of the lived body, in which the body is able to pick up a wide range of different moods; continuing over various kinds of sensitivities, preferences and idiosyncrasies, in which certain moods are favored over others; to cases that we unreservedly label pathologies, in which the body is severely out of tune, or even devoid of tune and thus useless as a tool of resonance. Different cultures and societies favor slightly differently attuned self-styles as paradigmatic of the normal and good life, and the popularity of the SSRIs can therefore be explained, not only by defects of embodiment, but also by the presence of certain cultural norms in our contemporary society.


Tovino, Stacey A. Functional neuroimaging and the law: trends and directions for future scholarship. American Journal of Bioethics 2007 September; 7(9): 44-56. NRCBL: 17.4; 4.4; 1.3.2; 1.3.5; 5.3; 8.4. SC: le. Comments: American Journal of Bioethics 2007 September 7(9): 57-75.

Abstract: Under the umbrella of the burgeoning neurotransdisciplinary, scholars are using the principles and research methodologies of their primary and secondary fields to examine developments in neuroimaging, neuromodulation and psychopharmacology. The path for
advanced scholarship at the intersection of law and neuroscience may clear if work across the disciplines is collected and reviewed and outstanding and debated issues are identified and clarified. In this article, I organize, examine and refine a narrow class of the burgeoning neurotransdiscipline scholarship; that is, scholarship at the interface of law and functional magnetic resonance imaging (fMRI).


PSYCHOTHERAPY

See also CARE FOR SPECIFIC GROUPS/MENTALLY DISABLED; INVOLUNTARY COMMITMENT; MENTAL HEALTH THERAPIES AND NEUROSCIENCES

Arboleda-Flórez, Julio E. The ethics of forensic psychiatry. *Current Opinion in Psychiatry* 2006 September; 19(5): 544-546. NRCBL: 17.2; 4.3; 1.3.5. SC: le.


Danzinger, Paula R.; Welfel, Elizabeth Reynolds. The impact of managed care on mental health counselors: a survey of perceptions, practices, and compliance with ethical standards. *Journal of Mental Health Counseling* 2001 April; 23(2): 137-150. NRCBL: 17.2; 1.3.2; 8.3.1; 6; 8.4. SC: em.


Fennig, Silvana; Secker, Aya; Treves, Ilan; Ben Yakar, Motti; Farina, Jorje; Roe, David; Levkovitz, Yechiel; Fennig, Shmuel. Ethical dilemmas in psychotherapy: comparison between patients, therapists and laypersons. *Israel Journal of Psychiatry and Related Sciences* 2005; 42(4): 251-257. NRCBL: 17.2; 8.4; 8.1. SC: em; cs.

Gottdiener, William H. Is harm reduction psychotherapy ethical? In: Kleinig, John; Einstein, Stanley, eds. *Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues*. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 91-98. NRCBL: 17.2; 9.5.9.


Hajdin, Mane. The prohibition of sexual relationships between drug users and their counselors: is it justified? In: Kleinig, John; Einstein, Stanley, eds. *Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues*. Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 437-452. NRCBL: 17.2; 10; 7.4; 9.5.9; 1.3.5. SC: an.

Johnson, W. Brad; Bacho, Roderick; Heim, Mark; Ralph, John. Multiple-role dilemmas for military mental health care providers. *Military Medicine* 2006 April; 171(4): 311-315. NRCBL: 17.2; 7.3; 1.3.5; 8.4.

Lowe, Jennifer; Pomerantz, Andrew M.; Pettibone, Jon C. The influence of payment method on psychologists’ diagnostic decisions: expanding the range of present-
**SECTION I  PUBLIC HEALTH**


Clancy, Anne; Svensson, Tommy. 'Faced' with responsibility: Levinasian ethics and the challenges of responsibility in Norwegian public health nursing. *Nursing Philosophy* 2007 July; 8(3): 158-166. NRCBL: 9.1; 1.1; 4.1.3.


Hall, Mark A.; Bobinski, Mary Anne; Orentlicher, David. Public health law. *In their: Bioethics and Public Health Law. New York: Aspen Publishers, 2005: 519-588. NRCBL: 9.1; 8.3.4; 8.4; 17.8; 9.5.6; 9.7. SC: le; cs.


Hodge, James G. Jr; Gostin, Lawrence O.; Vernick, Jon S. The Pandemic and All-Hazards Preparedness Act:


Abstract: The history of motorcycle helmet legislation in the United States reflects the extent to which concerns about individual liberties have shaped the public health debate. Despite overwhelming epidemiological evidence that motorcycle helmet laws reduce fatalities and serious injuries, only 20 states currently require all riders to wear helmets. During the past 3 decades, federal government efforts to push states toward enactment of universal helmet laws have faltered, and motorcyclists’ advocacy groups have been successful at repealing state helmet laws. This history raises questions about the possibilities for articulating an ethics of public health that would call upon government to protect citizens from their own choices that result in needless morbidity and suffering.


Abstract: Responses to public health emergencies can entail difficult decisions about restricting individual liberties to prevent the spread of disease. The quintessential example is quarantine. While isolating sick patients tends not to provoke much concern, quarantine of healthy people who only might be infected often is controversial. In fact, as the experience with severe acute respiratory syndrome (SARS) shows, the vast majority of those placed under quarantine typically do not become ill. Efforts to enforce involuntary quarantine through military or police powers also can backfire, stoking both panic and disease spread. Yet quarantine is part of a limited arsenal of options when effective treatment or prophylaxis is not available, and some evidence suggests it can be effective, especially when it is voluntary, home-based and accompanied by extensive outreach, communication and education efforts. Even assuming that quarantine is medically effective, however, it still must be ethically justified because it creates harms for many of those affected. Moreover, ethical principles of reciprocity, transparency, non-discrimination and accountability should guide any implementation of quarantine.

PUBLISHING See JOURNALISM AND PUBLISHING

QUALITY AND VALUE OF LIFE


Abstract: Various debates in bioethics have been focused on whether non-persons, such as marginal humans or non-human animals, deserve respectful treatment. It has been argued that, where we cannot agree on whether these individuals have moral status, we might agree that they have symbolic value and ascribe to them moral value in virtue of their symbolic significance. In the paper I resist the suggestion that symbolic value is relevant to ethical disputes in which the respect for individuals with no intrinsic moral value is in conflict with the interests of individuals with intrinsic moral value. I then turn to moral status and discuss the suitability of personhood as a criterion. There some desiderata for a criterion for moral status: it should be applicable on the basis of our current scientific knowledge; it should have a solid ethical justification; and it should be in line with some of our moral intuitions and social practices. Although it highlights an important connection between the possession of some psychological properties and eligibility for moral status, the criterion of personhood does not meet the desiderata above. I suggest that all intentional systems should be credited with moral status in virtue of having preferences and interests that are relevant to their well-being.


Briggs, Sheila. The ethics of life: medical advances have exposed inconsistencies in the Roman Catholic hierarchy’s position on life. *Conscience* 2007 Autumn; 28(3): 14-18. NRCBL: 4.4; 1.2; 20.5.1; 20.1. Identifiers: Terri Schiavo; natural death.


Cooper, Rachel. Can it be a good thing to be deaf? *Journal of Medicine and Philosophy* 2007 November-December; 32(6): 563-583. NRCBL: 4.4; 1.1; 9.5.1; 18.4. SC: an. Abstract: Increasingly, Deaf activists claim that it can be good to be Deaf. Still, much of the hearing world remains unconvinced, and continues to think of deafness in negative terms. I examine this debate and argue that to determine whether it can be good to be deaf it is necessary to examine each claimed advantage or disadvantage of being deaf, and then to make an overall judgment regarding
the net cost or benefit. On the basis of such a survey I con-
clude that being deaf may plausibly be a good thing for
some deaf people but not for others.

De Graeff, Alexander; Dean, Mervyn. Palliative seda-
tion therapy in the last weeks of life: a literature review and
recommendations for standards. Journal of Palliative
20.4.1; 9.

De Grazia, David. Must we have full moral status
throughout our existence? A reply to Alfonso Gomez-
Lobo. Kennedy Institute of Ethics Journal 2007 Decem-
ber; 17(4): 297-310. NRCBL: 4.4; 1.1; 12.3; 22.1. SC: an.
Abstract: Those who are morally opposed to abortion
generally make several pivotal assumptions. This paper
focuses on the assumption that we have full moral status
throughout our existence. Coupled with the assumption
that we come into existence at conception, the assump-
tion about moral status entails that all human fetuses have
full moral status, including a right to life. Is the assump-
tion about moral status correct? In addressing this
question, I respond to several arguments advanced, in this
journal and other venues, by Alfonso Gómez-Lobo.
Gómez-Lobo’s reasoning resolves into two basic argu-
ments: (1) an appeal to the practical necessity of early
moral protection and (2) an appeal to our kind member-
ship and potentiality. I respond to these in turn before
offering further reflections.

Deckers, Jan. Are those who subscribe to the view that
early embryos are persons irrational and inconsistent? A
reply to Brock. Journal of Medical Ethics 2007 February;
33(2): 102-106. NRCBL: 4.4; 1.1. SC: an. Comments:
D.W. Brock. Is a consensus possible on stem cell research?
Abstract: Dan Brock has asserted that those who claim
that the early embryo has full moral status are not consis-
tent, and that the rationality of such a position is dubious
when it is adopted from a religious perspective. I argue
that both claims are flawed. Starting with the second
claim, which is grounded in Brock’s moral absolutist po-

tion, I argue that Brock has provided no argument on
why the religious position should be less rational than the
secular position. With regard to the first claim, I argue
that those who hold the view that the early embryo has
full moral status can be consistent even if they do not op-
pose sexual reproduction, even if they do not grieve as
much over the loss of embryos as over the loss of other
humans, even if they prefer to save one child instead of
100 embryos in the event of fire, and even if they do not
accept racism and sexism.

Deckers, Jan. Why Eberl is wrong. Reflections on the be-


ginning of personhood. Bioethics 2007 June; 21(5):
270-282. NRCBL: 4.4; 1.1. SC: an. Comments: Jason T.
Eberl. A Thomistic perspective on the beginning of
Abstract: In a paper published in Bioethics, Jason Eberl
has argued that early embryos are not persons and should
not be granted the status possessed by them. Eberl bases
this position upon the following claims: (1) The early em-


bryo has a passive potentiality for development into a
person. (2) The early embryo has not established both
‘unique genetic identity’ and ‘ongoing ontological iden-
tity’, which are necessary conditions for ensoulment. (3)
The early embryo has a low probability of developing
into a more developed embryo. This paper examines
these claims. I argue against (1) that a plausible view is
that the early embryo has an active potentiality to grow
into a more developed embryo. Against (2), I argue that
neither ‘unique genetic identity’ nor ‘ongoing ontologi-
cal identity’ are necessary conditions for ensoulment, and
that ‘ongoing ontological identity’ is established between
early embryos and more developed embryos. Against (3),
I argue that the fact that the early embryo has a low prob-
ability of developing into a more developed embryo, if
ture, does not warrant the conclusion that the early em-


bryo is not a person. If Eberl is right that the human soul is
that which organises the activities of a human being and
that ensouled humans are persons, embryos are persons
from conception.

Diamond, Sheila M. Response to Todd Bindig’s “Confu-
sion about speciesism and moral status”. Linacre Quar-
terly 2007 May; 74(2): 156-158. NRCBL: 4.4; 1.2;
22.1. Comments: Todd S. Bindig. Confusion about speciesism
and moral status. Linacre Quarterly 2007 May; 74(2):
156-158.

Dolgin, Janet L. New terms for an old debate: embryos, dying,
and the “culture wars”. Houston Journal of Health
Law and Policy 2006; 6(2): 249-273. NRCBL: 4.4; 12.5.1;
12.3; 20.5.1; 20.3.1. SC: le; an.

Conscience 2007 Autumn; 28(3): 30-33. NRCBL:
4.4; 1.2; 20.5.1; 22.1.

Durante, Chris. Persons, identities, and medical ethics [review of
Human Identity and Bioethics, by David DeGrazia]. Hastings Center Report 2007 March-April;
37(2): 47. NRCBL: 4.4; 2.1.

Eberl, Jason T. A Thomistic perspective on the beginning
283-289. NRCBL: 4.4; 1.1. SC: an. Comments: Jan
Deckers. Why Eberl is wrong. Reflections on the be-


ginning of personhood. Bioethics 2007 June; 21(5):
270-282. NRCBL: 4.4; 1.1. SC: an. Comments: Jason T.


Eberl. A Thomistic perspective on the beginning
283-289. Abstract: In a paper published in Bioethics, Jason Eberl
has argued that early embryos are not persons and should
not be granted the status possessed by them. Eberl bases
this position upon the following claims: (1) The early em-


bryo has a passive potentiality for development into a
person. (2) The early embryo has not established both
‘unique genetic identity’ and ‘ongoing ontological iden-
tity’, which are necessary conditions for ensoulment. (3)
The early embryo has a low probability of developing
into a more developed embryo. This paper examines
these claims. I argue against (1) that a plausible view is
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into a more developed embryo. Against (2), I argue that
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cal identity’ are necessary conditions for ensoulment, and
that ‘ongoing ontological identity’ is established between
early embryos and more developed embryos. Against (3),
I argue that the fact that the early embryo has a low prob-
ability of developing into a more developed embryo, if
ture, does not warrant the conclusion that the early em-


bryo is not a person. If Eberl is right that the human soul is
that which organises the activities of a human being and
that ensouled humans are persons, embryos are persons
from conception.

Gibson, Susanne. Uses of respect and uses of the human
NRCBL: 4.4; 1.1; 18.5.4. SC: an; le. Identifiers: Great
Britain (United Kingdom); Human Fertilisation and Em-


bryology Act (HFEA) 1990; Report of the Committee of
Inquiry into Human Fertilisation and Embryology (Warnock Report).
Abstract: In most parts of the world, research on the hu-


man embryo is subject to tight controls. In the United
SECTION I
QUALITY AND VALUE OF LIFE

Hirskyj, Peter. QALY: an ethical issue that dare not speak its name. Nursing Ethics 2007 January; 14(1): 72-82. NRCBL: 4.4; 9.4; 4.1.3. Identifiers: Great Britain (United Kingdom).

Abstract: The current British Government’s policy towards resource allocation for health care has been informed by the commissioned Wanless Report. This makes a case for the use of quality adjusted life years (QALYs) to form a rationale for resourcing health care and has implications for the staff and patients who work in and use the health service. This article offers a definition of the term ‘QALY’ and considers some of the strengths and weaknesses of this approach to resource distribution. An account is also given of an alternative formula, the DALY (disability adjusted life years), which can address some of the problems that are associated with QALYs. The values of the public, patients and nurses are identified and linked to the potential effect of a QALY formula. The implications of QALY use are applied to the health care of patients and a discussion is offered with regard to whether this method of resource allocation can be considered as just.


Janvier, Annie; Bauer, Karen Lynn; Lantos, John D. Are newborns morally different from older children? Theoretical Medicine and Bioethics 2007; 28(5): 413-425. NRCBL: 4.4; 8.3.2; 20.5.2.

Abstract: Policies and position statements regarding decision-making for extremely premature babies exist in many countries and are often directive, focusing on parental choice and expected outcomes. These recommendations often state survival and handicap as reasons for optional intervention. The fact that such outcome statistics would not justify such approaches in other populations suggests that some other powerful factors are at work. The value of neonatal intensive care has been scrutinized far more than intensive care for older patients and suggests that neonatal care is held to a higher standard of justification. The relative value placed on the life of newborns, in particular the preterm, is less than expected by any objective medical data or any prevailing moral frameworks about the value of individual lives. Why do we feel less obligated to treat the premature baby? Do we put newborns in a special and lesser moral category? We explore this question from a legal and ethical perspective and offer several hypotheses pertaining to personhood, reproductive choices, “precious children,” and probable evolutionary and anthropological factors.


Abstract: This paper starts from three assumptions: that we are essentially human organisms, that we start to exist at conception, and that we retain our identity throughout our lives. The identity claim provides the background to argue that it is irrational for a person to claim that it would be impermissible to kill her now but permissible to have killed her at an earlier age. The notion of “full moral status” as an ascertainable property is questioned and shown to be dependent on previously accepted moral norms. It is concluded that the exclusion of the very young from the scope of the norm of common morality that prohibits the killing of the innocent amounts to discrimination on the basis of age.


Kingdom it is restricted by means of both a fourteen-day time limit and the permitted purposes of the research. One of the ways in which the argument for these restrictions has been put is in terms of respect. That is, the human embryo is said to be the kind of thing that is worthy of a measure of respect such that there are limits to what can be done to it. This paper considers some of the ways in which this principle of respect has been understood as well as some objections to the very idea that research resulting in the destruction of the human embryo can claim to show that embryo respect. It will be argued that an account of ‘respectful destruction’ can be articulated on the grounds of our shared finitude as human moral agents, and in particular on the grounds of our shared lack of certainty regarding the moral status of the embryo.


Abstract: This paper starts from three assumptions: that we are essentially human organisms, that we start to exist at conception, and that we retain our identity throughout our lives. The identity claim provides the background to argue that it is irrational for a person to claim that it would be impermissible to kill her now but permissible to have killed her at an earlier age. The notion of “full moral status” as an ascertainable property is questioned and shown to be dependent on previously accepted moral norms. It is concluded that the exclusion of the very young from the scope of the norm of common morality that prohibits the killing of the innocent amounts to discrimination on the basis of age.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme   See inside front cover for terms. 385
QUALITY AND VALUE OF LIFE

SECTION I


Abstract: Consideration of the potentiality of human embryos to develop characteristics of personhood, such as intellect and will, has figured prominently in arguments against abortion and the use of human embryos for research. In particular, such consideration was the basis for the call of the US President’s Council on Bioethics for a moratorium on stem cell research on human embryos. In this paper, I critique the concept of potentiality invoked by the Council and offer an alternative account. In contrast to the Council’s view that an embryo’s potentiality is determined by definition and is not affected by external conditions that may prevent certain possibilities from ever being realized, I propose an empirically grounded account of potentiality that involves an assessment of the physical and decisional conditions that may restrict an embryo’s possibilities. In my view, some human embryos lack the potentiality to become a person that other human embryos have. Assuming for the sake of argument that the potential to become a person gives a being special moral status, it follows that some human embryos lack this status. This argument is then used to support Gene Outka’s suggestion that it is morally permissible to experiment on ‘spare’ frozen embryos that are destined to be destroyed.


SC: le. Identifiers: Great Britain (United Kingdom); The Nuffield Report.

Mclachlan, Hugh V.; Swales, J. Kim. Embryology and human cloning. In their: From the Womb to the Tomb: Issues in Medical Ethics. Glasgow, Scotland: Humming Earth, 2007: 21-83. 50 refs. 35 fn. NRCBL: 4.4; 1.2; 14.5; 18.5.4; 15.1.

Keywords: *cloning; *embryo research; *embryos; advisory committees; beginning of life; embryonic stem cells; genetic diversity; human dignity; legal aspects; moral status; personhood; Protestant ethics; public policy; reproductive technologies; twinning; value of life; Keyword Identifiers: Church of Scotland; European Union; Great Britain; Human Fertilisation and Embryology Act 1990 (Great Britain); Quintavalle v. Human Fertilisation and Embryology Authority; Warnock Committee.


Abstract: The dominant account of welfare in medicine is an objective one; welfare consists of certain favoured health states, or in having needs satisfied, or in certain capabilities and functionings. By contrast, I present a subjective account of welfare, suggested initially by LW Sumner and called “authentic happiness”. The adoption of such an account of welfare within medicine offers several advantages over other subjective and objective accounts, and systematises several intuitions about patient-centredness and autonomy. Subjective accounts of welfare are unpopular because of their implications for justice and the autonomy of the healthcare professional. This account of welfare, however, seems to have the resources to resist these criticisms.


Abstract: Three of the articles included in this issue of the Journal of Medicine and Philosophy - Ron Amundson and Shari Tresky’s “On a Bioethical Challenge to Dis-
ability Rights”; Rachel Cooper’s “Can It Be a Good Thing to Be Deaf?”; and Mark T. Brown’s “The Potential of the Human Embryo” - interact (in various ways) with the concepts of disability, humanity, and personhood and their normative dimensions. As one peruses these articles, it becomes apparent that terms like “disability,” “human being,” and “person” carry with them great normative significance. There is, however, much disagreement concerning both the definition and the extension of such terms. This is significant because different terms and definitions are associated with different sets of normative requirements. In what follows we reconstruct the argument of each of the articles, and then offer some brief critical analysis intended to stimulate further thought about and discussion of the issues that each raises.


Abstract: In the context of research and reproduction, the status of the human in vitro embryo ranges from being regarded as a person to being regarded as mere property. As regards the first view, one extreme of the spectrum for offering possible legal protection considers that the embryo constitutes a legal person from the moment of conception. For opponents of this view life is a continuum that runs from conception until death. In this process one of the most important stages is birth, the reason being that birth represents the transition between a potential person and a person. The term “embryo” is used to express the being that exists after fusion of the egg and a spermatozoon during the process of embryogenesis until it reaches eight weeks, after which time it is termed a foetus. The embryo’s life is recognized as a constitutional value which deserves juridical protection, but not as a person. It only becomes a person with birth.


Keywords: *embryos; *fetuses; *legal rights; abortion; biotechnology; embryo research; genetic intervention; Key-word Identifiers: Europe; United States


Steinberg, Douglas. Consciousness is missing — and so is research. After the Schiavo controversy in the USA, obstacles still hinder the study of people with little or no awareness. EMBO Reports 2005 November; 6(11): 1009-1011. NRCBL: 4.4; 20.5.1; 7.1; 9.4; 18.5.6.


Keywords: *embryo research; *embryonic stem cells; *embryos; *moral policy; *moral status; abortion; beginning of life; cadavers; ethical analysis; human characteristics; killing; nuclear transfer techniques; personhood; public policy; research embryo creation; species specificity; stem cells; twinning; values; Proposed Keywords: altered nuclear transfer; embryo death; pluripotent stem cells; sentence


NRCBL: National Reference Center for Bioethics Literature Classification Scheme

See inside front cover for terms.

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Abstract: It is commonly held that respect for autonomy is one of the most important principles in medical ethics. However, there are a number of interpretations as to what that respect actually entails in practice and a number of constraints have been suggested even on our self-regarding choices. These limits are often justified in the name of autonomy. In this paper, it is argued that these different interpretations can be explained and understood by looking at the discussion from the viewpoints of positive and negative liberty and the various notions of a “person” that lay beneath. It will be shown how all the appeals to positive liberty presuppose a particular value system and are therefore problematic in multicultural societies.

Talseth, Anne-Grethe; Gilje, Fredricka. Unburdening suffering: responses of psychiatrists to patients’ suicide deaths. *Nursing Ethics* 2007 September; 14(5): 620-636. NRCBL: 4.4; 20.7; 17.1; 8.1. SC: em. Identifiers: Norway. Abstract: The research questions was: ‘How do psychiatrists describe their responses to patients’ suicidal deaths in the light of a published model of consolation?’ The textual data (n = 5) was a subset of a larger (n = 19) study. Thematic analysis showed a main theme, ‘unburdening grief’, and six themes. Embedded in the results is a story about suffering that reveals that, through ethical reflectiveness, a meaning of suffering can be recreated that unburdens grief and opens up new understandings with and among disciplines. This can help to prepare health professionals to respond to people who suffer because of suicidal death.

Taylor, Joseph G. NICE, Alzheimer’s and QALY. *Clinical Ethics* 2007 March; 2(1): 50-54. NRCBL: 4.4; 9.4; 17.1; 9.5.2; 1.1. SC: National Institute for Health and Clinical Excellence; quality-adjusted life year. Abstract: The introduction of National Institute for Health and Clinical Excellence (NICE) guidance on Alzheimer’s medication in November 2006 will have a significant effect on the treatment of patients, and is opposed by the Royal College of Psychiatrists and many charities dealing with the elderly. The use of the Quality-Adjusted Life Year (QALY) in the guidance formulation is much debated due to questions of ageism. This article seeks to examine the basis of these accusations and whether NICE can be justified using a utilitarian calculation in a principally egalitarian system such as the NHS.


Watt, Helen. Embryos and pseudoembryos: parthenotes, reprogrammed oocytes and headless clones. *Journal of Medical Ethics* 2007 September; 33(9): 554-556. 9 refs. NRCBL: 4.4; 14.5; 18.1; 18.5.4; 15.1; 19.1; 22.1. SC: an. Keywords: *cloning; *embryos; *moral status; *ovum; *research embryo creation; anencephaly; chimeras; embryonic stem cells; genetic engineering; human dignity; methods; nuclear transfer techniques; Proposed Keywords: *parthenogenesis; altered nuclear transfer


Yu, Erika; Fan, Ruiping. A Confucian view of personhood and bioethics. *Journal of Bioethical Inquiry* 2007; 4(3): 171-179. NRCBL: 4.4; 1.1; 1.2; 2.1; 8.3.1; 21.7. Abstract: This paper focuses on Confucian formulations of personhood and the implications they may have for bioethics and medical practice. We discuss how an appreciation of the Confucian concept of personhood can provide insights into the practice of informed consent and, in particular, the role of family members and physicians in medical decision-making in societies influenced by Confucian culture. We suggest that Western notions of informed consent appear ethically misguided when viewed from a Confucian perspective.


RATIONALING OF HEALTH CARE See RESOURCE ALLOCATION

RECOMBINANT DNA RESEARCH See GENETICALLY MODIFIED ORGANISMS AND FOOD

REGULATION See ABORTION/LEGAL ASPECTS; BIOETHICS AND MEDICAL ETHICS/LEGAL ASPECTS; CLONING/LEGAL ASPECTS; EUTHANASIA AND ALLOWING TO DIE/LEGAL ASPECTS; GENETIC SCREENING/LEGAL ASPECTS; HUMAN EXPERIMENTATION/ETHICS COMMITTEES AND POLICY GUIDELINES/LEGAL ASPECTS; HUMAN EXPERIMENTATION/REGULATION; ORGAN AND TISSUE TRANSPLANTATION/DONATION AND PROCUREMENT/LEGAL ASPECTS

RELIGIOUS ASPECTS See ABORTION/MORAL AND RELIGIOUS ASPECTS; BIOETHICS AND MEDICAL ETHICS/RELIGIOUS ASPECTS; EUTHANASIA AND ALLOWING TO DIE/RELIGIOUS ASPECTS; HUMAN EXPERIMENTATION/SPECIAL POP-
ULATIONS/ EMBRYOS AND FETUSES/ PHILOSOPHICAL AND RELIGIOUS ASPECTS

RENAI DIALYSIS See ORGAN AND TISSUE TRANSPLANTATION

REPRODUCTION See REPRODUCTIVE TECHNOLOGIES

REPRODUCTIVE TECHNOLOGIES
See also ARTIFICIAL INSEMINATION AND SURROGATE MOTHERS; CLONING; CRYOBANKING OF SPERM, OVA, AND EMBRYOS; IN VITRO FERTILIZATION; SEX DETERMINATION


American Society for Reproductive Medicine [ASRM]. Practice Committee. Definition of “experimental”. Fertility and Sterility 2006 November; 86(5; Supplement): S123. NRCBL: 14.1; 1.3.7; 1.3.9.


Keywords: *public policy; *regulation; *reproductive technologies; advisory committees; cloning; embryo research; federal government; genetic engineering; historical aspects; justice; legislation; policy making; public participation; religion; surrogate mothers; values; Proposed Keywords: licensure; Keyword Identifiers: *Canada; Royal Commission on New Reproductive Technologies (Canada); Twentieth Century; United States


Abstract: In his review of my book, Better never to have been, Len Doyal suggests, contrary to my view, that rational beings in the original position might prefer coming into existence to the alternative of never existing, if their lives were to include enough good and not too much bad. I argue, in response, that Professor Doyal dis to make his case.


Keywords: *embryo research; *historical aspects; *regulation; *reproductive technologies; advisory committees; cloning; embryonic stem cells; ethical review; federal government; gene therapy; government regulation; guidelines; human experimentation; legal aspects; nuclear transfer techniques; policy making; preimplantation diagnosis; professional organizations; recombinant DNA research; self regulation; state government; standards; Keyword Identifiers: *United States; Department of Health and Human Services; Department of Health, Education, and Welfare; Food and Drug Administration; Human Embryo Research Panel; Twentieth Century; U.S. Congress


Cannold, Leslie. Women, ectogenesis, and ethical theory. In: Gelfand, Scott; Shook, John R., eds. Ectogenesis: Artificial Womb Technology and the Future of Human Repro-


Abstract: Benatar argues that it is better never to have been born because of the harms always associated with human existence. Non-existence entails no harm, along with no experience of the absence of any benefits that existence might offer. Therefore, he maintains that procreation is morally irresponsible, along with the use of reproductive technology to have children. Women should seek termination if they become pregnant and it would be better for potential future generations if humans become extinct as soon as humanly possible. These views are challenged by the argument that while decisions not to procreate may be rational on the grounds of the harm that might occur, it may equally rational to gamble under certain circumstances that future children would be better-off experiencing the harms and benefits of life rather than never having the opportunity of experiencing anything. To the degree that Benatar's arguments preclude the potential rationality of any such gamble, their moral relevance to concrete issues concerning human reproduction is weakened. However, he is right to emphasise the importance of foreseen harm when decisions are made to attempt to have children.


Keywords: *biotechnology; *cultural pluralism; *government regulation; *public policy; *reproductive technologies; bioethical issues; cloning; decision making; democracy; dissent; embryo research; embryonic stem cells; embryos; federal government; moral status; policy analysis; preimplantation diagnosis; reproductive medicine; self regulation; state government; Keyword Identifiers: *United States; Great Britain


Keywords: *biotechnology; *government regulation; *reproductive technologies; accountability; biomedical research; cloning; commerce; embryo research; embryonic stem cells; embryos; freedom; genetic engineering; germ cells; guidelines; industry; judicial role; legal aspects; political activity; policy analysis; politics; preimplantation diagnosis; public participation; public policy; quality of health care; standards; Keyword Identifiers: *United States

Gelfand, Scott. Ectogenesis and the ethics of care. In: Gelfand, Scott; Shook, John R., eds. Ectogenesis: Artificial Womb Technology and the Future of Human Repro-


Keywords: *government regulation; *legal aspects; *legal rights; *reproductive rights; *reproductive technologies; abortion; cesarean section; cloning; constitutional law; contraception; drug abuse; embryo disposition; eugenics; federal government; fetuses; gene therapy; genetic counseling; genetic disorders; genetic engineering; genetic predisposition; genetic screening; in vitro fertilization; informed consent; involuntary sterilization; living wills; mental competence; mentally retarded persons; minors; ovum donors; parent-child relationship; personhood; pregnant women; prisoners; privacy; spousal consent; state government; Supreme Court decisions; surrogate mothers; treatment refusal. Keyword Identifiers: *United States; Buck v. Bell; Griswold v. Connecticut; Ferguson v. City of Charleston; In re A.C.; Planned Parenthood of Southeastern Pennsylvania v. Casey; Roe v. Wade; Skinner v. Oklahoma; Stenberg v. Carhart; Whitmer v. South Carolina


Heng, B.C. Should fertility specialists refer local patients abroad for shared or commercialized oocyte donation? Fertility and Sterility 2007 January; 87(1): 6-7. NRCBL: 14.1; 21.1; 8.1; 7.1; 9.3.1.


Keywords: *embryo disposition; *embryo research; *embryos; *germ cells; *reproductive technologies; age factors; beginning of life; cryopreservation; embryo transfer; embryonic stem cells; freedom; genetic materials; in vitro fertilization; informed consent; legal aspects; moral status; oocyte donation; preimplantation diagnosis; public opinion; regulation; selection for treatment; sex preselection; Proposed Keywords: blastocysts; Keyword Identifiers: Germany; Embryo Protection Act (Germany)

Hitchen, Lisa. Keeping the scientists in step with society [news]. BMJ: British Medical Journal 2007 May 26; 334(7603): 1079. NRCBL: 14.1; 2.4; 14.4; 15.1; 15.2; 22.2. Identifiers: Great Britain (United Kingdom).


Keywords: *commerce; *freedom; *genetic engineering; *genetic services; *germ cells; *ovum donors; *public policy; *regulation; *remuneration; *reproductive technologies; commodification; common good; democracy; embryo research; embryos; federal government; genetic relatedness ties; government financing; health facilities; in vitro fertilization; industry; justice; moral policy; policy analysis; politics; preimplantation diagnosis; private sector; public opinion; reproductive rights; socioeconomic factors; surrogacy mothers; values; women. Keyword Identifiers: *United States; Canada; Great Britain


Keywords: *biotechnology; *genetic relatedness ties; *government regulation; *reproductive technologies; cloning; family relationship; genetic techniques; moral policy; ovum donors; policy analysis; public policy. Keyword Identifiers: United States

Kabir, M.; az-Zubair, Banu. Who is a parent? Parenthood in Islamic ethics. Journal of Medical Ethics 2007 October; 33(10): 605-609. 33 refs. NRCBL: 14.1; 1.2; 15.1. Keywords: *Islamic ethics; *parent child relationship; *reproductive technologies; adoption; beginning of life; bioethical issues; cross-cultural comparison; embryo transfer; fathers; fetuses; genetic relatedness ties; in vitro fertilization; minors; mothers; ovum donors; paternity; rights; Western World; Proposed Keywords: marriage


Kaczor, Christopher Robert. Moral absolutism and ectopic pregnancy. In his: The Edge of Life: Human Dign-
nity and Contemporary Bioethics. Dordrecht: Springer, 2005: 97-103. NRCBL: 14.1; 1.1; 9.5.5.

Kennedy, Holly P.; Renfrew, Mary J.; Madi, Banyana C.; Opoku, Dora; Thompson, Joyce B. The conduct of ethical research collaboration across international and culturally diverse communities. Midwifery 2006 June; 22(2): 100-107. NRCBL: 14.1; 9.5.5; 18.2; 18.5.3; 21.7; 21.1.


Keywords: *embryo research; *international aspects; *public policy; *regulation; *reproductive technologies; advisory committees; biotechnology; chimeras; cloning; consensus; cross cultural comparison; dissent; donors; embryonic stem cells; embryos; genetic engineering; government regulation; human dignity; in vitro fertilization; informed consent; legal aspects; legislation; moral status; policy making; public opinion; trends; Proposed Keywords: organizational models; Keyword Identifiers: Asia; Australia; Canada; Europe; Human Fertilisation and Embryology Authority; United States


Abstract: In this paper I explore the potential of virtue ethical ideas to generate a new way of thinking about the ethical questions surrounding the creation of children. Applying ideas from neo-Aristotelian virtue ethics to the parental sphere specifically, I develop a framework for the moral assessment of reproductive actions that centres on the concept of parental virtue. I suggest that the character traits of the good parent can be used as a basis for determining the moral permissibility of a particular reproductive action. I posit three parental virtues and argue that we can see the moral status of a reproductive action as determined by the relationship between such an action and (at least) these virtues. Using a case involving selection for deafness, I argue that thinking in terms of the question ‘would a virtuous parent do this?’ when morally assessing reproductive action is a viable and useful way of thinking about issues in reproductive ethics.


Keywords: *eugenics; *freedom; *government regulation; *preimplantation diagnosis; *reproductive technologies; embryos; genetic intervention; genetic services; legislation; prenatal diagnosis; public policy; reproductive rights. Keyword Identifiers: *Great Britain; *House of Commons Select Committee on Science and Technology (Great Britain); Human Fertilisation and Embryology Act 1990 (Great Britain); Human Fertilisation and Embryology Authority


Keywords: *autonomy; *congenital disorders; *ethical analysis; *moral obligations; *reproduction; choice behavior; decision making; disabled persons; ethical relativism; future generations; genetic disorders; genetic screening; obligations to society; parents; prenatal diagnosis; quality of life; reproductive rights; reproductive technologies; selective abortion; suffering; wrongful life; Proposed Keywords: harm

Abstract: Advances in reproductive technologies continue to present ethical problems concerning their implementation and use. These advances have preoccupied bioethicists in their bid to gauge our moral responsibili-

SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
ties and obligations when making reproductive decisions. The aim of this discussion is to highlight the importance of a sensibility to differences in moral perspective as part of our ethical inquiry in these matters. Its focal point is the work of John Harris, who has consistently addressed the ethical issues raised by advancing reproductive technologies. The discussion is aimed at a central tenet of Harris’s position on reproductive decision-making—namely, that in some instances, giving birth to a worthwhile life may cause harm and will therefore be morally wrong. It attempts to spell out some of the implications of Harris’s position that the author takes to involve a misplaced generality. To support this claim, some examples are explored that demonstrate the variety of ways in which concepts (such as harm) may manifest themselves as moral considerations within the context of reproductive decision-making. The purpose is to demonstrate that Harris’s general conception of the moral limits of reproductive autonomy obscures the issues raised by particular cases, which in themselves may reveal important directions for our ethical inquiry.


Keywords: *legal aspects; *reproductive technologies; cloning; embryo disposition; genetic engineering; genetic screening; informed consent; Keyword Identifiers: *Italy


Keywords: *embryo research; *genetic engineering; *pol icy making; *public policy; *regulation; *reproductive technologies; adverse effects; advisory committees; cloning; embryonic stem cells; embryos; federal government; freedom; government regulation; historical aspects; human experimentation; international aspects; ovum donors; preimplantation diagnosis; professional organizations; recombination DNA research; risk; social impact; state government; Proposed Keywords: tissue typing; Keyword Identifiers: Canada; Ethics Advisory Board; Food and Drug Administration; Great Britain; Human Embryo Research Panel; National Bioethics Advisory Commission; Recombinant DNA Advisory Committee; Reprogenetics Technology Board; Twentieth Century; Twenty-First Century; United States; Warnock Committee


Abstract: In this paper I examine the prevailing assumption that there is a right to procreate and question whether there exists a coherent notion of such a right. I argue that we should question any and all procreative activities, not just alternative procreative means and contexts. I suggest that clinging to the assumption of a right to procreate prevents serious scrutiny of reproductive behavior and that, instead of continuing to embrace this assumption, attempts should be made to provide a proper foundation for it. I argue that the focus of procreative activities and discourse on reproductive ethics should be on obligations instead of rights, as rights talk tends to obfuscate recognition of obligations toward others, particularly those who bear the most significant burdens of the procreative process. I examine some possible foundations of a right to procreate as well as John Robertson’s thoughtful account of “procreative liberty” but conclude that at the present time there exists no compelling account of a right to procreate. Finally, I conclude that in the absence of a satisfactory account of a right to procreate, we should refrain from grounding practices or polices on the assumption that there is such a right.


Keywords: *biotechnology; *policy making; *reproductive technologies; advisory committees; cultural pluralism; democracy; dissent; federal government; freedom; genetic engineering; government regulation; policy analysis; preimplantation diagnosis; public participation; public policy; Keyword Identifiers: *United States


Schneider, Ingrid. Oocyte donation for reproduction and research cloning — the perils of commodification and the need for European and international regulation. Revista de Derecho y Genoma Humano – Law and the Human Genome Review 2006 July-December; (25): 205-241. 79 refs. NRCBL: 14.1; 14.5; 18.3.1; 21.1; 5.3; 9.3.1. SC: le.

Keywords: *cloning; *commodification; *embryo research; *genetic research; *ovum donors; *regulation; *remuneration; *reproductive technologies; *advertising; *embryo disposition; *germ cells; *in vitro fertilization; *informed consent; *international aspects; *nuclear transfer techniques; *therapeutic misconception; Keyword Identifiers: Europe


Shields, Wayne C.; Jordan, Beth. Adding value to reproductive health research: communicating about the moral dimensions of science. Contraception 2006 September; 74(3): 199-200. NRCBL: 14.1; 1.3; 9; 1.1; 5.3.

Shildrick, Margrit. Reconfiguring the bioethics of reproduction. Philosophy in the Contemporary World 2004 Spring-Summer; 11(1): 75-83. NRCBL: 14.1; 10; 2.1; 1.1.


Smajdor, Anna. The moral imperative for ectogenesis. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Summer; 16(3): 336-345. NRCBL: 14.1; 1.1; 9.2; 9.4; 9.5.5; 5.2; 9.5.7; 19.1. SC: an.


Soini, Sirpa; Ibarreta, Dolores; Anastasiadou, Violetta; Aymé, Ségolène; Braga, Suzanne; Cornel, Martina; Coviello, Domenico A.; Evers-Kiebooms, Gerry; Geraedts, Joep; Gianaroli, Luca; Harper, Joyce; Kosztolanyi, György; Lundin, Kersti; Rodrigues-Cerezo, Emilio; Sermon, Karen; Sequeiros, Jorge; Tranebaerg, Lisbeth; Kääriäinen, Helena. The interface between assisted reproductive technologies and genetics: technical, social, ethical, and legal issues. European Journal of Human Genetics 2006 May; 14(5): 588-645. NRCBL: 14.1; 15.3; 15.2; 21.1.


Keywords: *autonomy; *beginning of life; *cloning; *embryos; *ethical analysis; *ethical theory; *fetuses; *moral policy; *personhood; *philosophy; *reproduction; *reproductive technologies; *abortion; *childbirth; *chimeras; *common good; *contraception; *deontological ethics; *embryo disposition; *embryo research; *embryonic stem cells; *feminist ethics; *fetal research; *freedom; *genetic engineering; *intention; *justice; *killing; *marriage; *moral status; *mother fetus relationship; *pregnant women; *principle-based ethics; *preimplantation diagnosis; *reproductive rights; *sexuality; *utilitarianism; *wedge argument; *value of life; *values


Keywords: *policy making; *public policy; *regulation; *reproductive technologies; advisory committees; cross-cultural comparison; genetic intervention; guidelines; public participation; Proposed Keywords: licensure; Keyword Identifiers: *United States; Great Britain; Human Fertilisation and Embryology Authority; President's Council on Bioethics


Keywords: *cloning; *Islamic ethics; *reproduction; *reproductive technologies; beginning of life; embryo research; embryo transfer; in vitro fertilization; infertility; posthumous conception; surrogate mothers


Keywords: *legal aspects; *policy making; *public policy; *regulation; *reproductive technologies; advisory committees; cloning; contracts; cross-cultural comparison; genetic intervention; government regulation; guidelines; mass media; surrogate mothers; torts; Keyword Identifiers: *United States; Canada


Keywords: *embryo research; *legal aspects; *preimplantation diagnosis; *reproductive technologies; bioethical issues; cloning; embryonic stem cells; embryos; human dignity; legal rights; value of life; values; Keyword Identifiers: *Germany

RESEARCH ETHICS COMMITTEES See HUMAN EXPERIMENTATION/ETHICS COMMITTEES AND POLICY GUIDELINES

RESOURCE ALLOCATION

See also HEALTH CARE ECONOMICS


Abstract: Application of egalitarian and prioritarian accounts of health resource allocation in low-income countries have both been criticized for implying distribution outcomes that allow decreasing/undermining health gains and for tolerating unacceptable standards of health care and health status that result from such allocation schemes. Insufficient health care and severe deprivation of health resources are difficult to accept even when justified by aggregative efficiency or legitimized by fair deliberative process in pursuing equality and priority oriented outcomes. I affirm the sufficiencist argument that, given extreme scarcity of public health resources in low-income countries, neither health status equality between populations nor priority for the worse off is normatively adequate. Nevertheless, the threshold norm alone need not be the sole consideration when a country’s total health budget is extremely scarce. Threshold considerations are necessary in developing a theory of fair distribution of health resources that is sensitive to the lexically prior norm of sufficiency. Based on the intuition that shares must not be taken away from those who barely achieve a minimal level of health, I argue that assessments based on standards of minimal physical/mental health must be developed to evaluate the sufficiency of the total resources of health systems in low-income countries prior to pursuing equality, priority, and efficiency based resource allocation. I also begin to examine how threshold sensitive health resource assessment could be used in the Philippines.


Baxter, Nancy N. Equal for whom? Addressing disparities in the Canadian medical system must become a national
RESOURCE ALLOCATION

priority. CMA/JAMC: Canadian Medical Association Journal 2007 December 4; 177(12): 1522-1523. NRCBL: 9.4; 9.2; 9.5.5; 9.5.2; 9.5.4; 10.


Brindle, David. Seeing red [interview]. BMJ: British Medical Journal 2007 May 12; 334(7601): 976-977. NRCBL: 9.4; 9.3.2; 18.5.1. Identifiers: Great Britain (United Kingdom); National Health Service; Julian Tudor Hart.


Abstract: Harris’ reply to our defence of the National Institute for Clinical Excellence’s (NICE) current cost-effectiveness procedures contains two further errors. First, he wrongly draws a conclusion from the fact that NICE does not and cannot evaluate all possible uses of healthcare resources at any one time and generally cannot know which National Health Service (NHS) activities would be displaced or which groups of patients would have to forgo health benefits: the inference is that no estimate is or can be made by NICE of the benefits to be forgone. This is a non-sequitur. Second, he asserts that it is a flaw at the heart of the use of quality-adjusted life years (QALYs) as an outcome measure that comparisons between people need to be made. Such comparisons do indeed have to be made, but this is not a consequence of the choice of any particular outcome measure, be it the QALY or anything else.


Engelman, Michal; Johnson, Summer. Population aging and international development: addressing competing claims of distributive justice. Developing World Bioethics 2007 April; 7(1): 8-18. NRCBL: 9.4; 9.5.2; 21.1. SC: an. Abstract: To date, bioethics and health policy scholarship has given little consideration to questions of aging and intergenerational justice in the developing world. Demographic changes are precipitating rapid population aging in developing nations, however, and ethical issues regarding older people’s claim to scarce healthcare resources must be addressed. This paper posits that the traditional arguments about generational justice and age-based rationing of healthcare resources, which were developed primarily in more industrialized nations, fail to adequately address the unique challenges facing older persons in developing nations. Existing philosophical approaches to age-based resource allocation underemphasize the importance of older persons for developing countries and fail to adequately consider the rights and interests of older persons in these settings. Ultimately, the paper concludes that the most appropriate framework for thinking about generational justice in developing nations is a rights-based approach that allows for the interests of all age groups, including the oldest, to be considered in the determination of health resource allocation.


SC (Subject Captions): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
SECTION I

RESOURCE ALLOCATION


Abstract: This paper examines the law relating to healthcare resource allocation in England. The National Health Service (NHS) Act 1977 does not impose an absolute duty to provide specified healthcare services. The courts will only interfere with a resource allocation decision made by an NHS body if that decision is frankly irrational (or where the decision infringes the principle of proportionality when a right under the European Convention on Human Rights (ECHR) is engaged). Such irrationality is very difficult to establish. The ECHR has made no significant contribution to domestic English law in the arena of healthcare provision. The decision of the European Court in the Yvonne Watts case establishes that, in relation to the question of entitlement to seek treatment abroad at the expense of the NHS, a clinical judgment about the urgency of treatment trumps an administrative decision about waiting list targets. That decision goes against the grain of domestic law about healthcare allocation, but is not likely to have wide ramifications in domestic law.

Fowler, Robert A.; Sabur, Natasha; Li, Ping; Juurlink, David N.; Pinto, Ruxandra; Hladunewich, Michelle A.; Adhikari, Neill K.J.; Sibbald, William J.; Martin, Claudio M. Sex- and age-based differences in the delivery and outcomes of critical care. *CMAJ/JAMC: Canadian Medical Association Journal* 2007 December 4; 177(12): 1513-1519. NRCBL: 9.4; 9.2; 9.5.2; 9.5.5; 10. SC: em.

Francis, Leslie P. Discrimination in medical practice: justice and the obligations of health care providers to disadvantaged patients. In: Rhodes, Rosamond; Francis, Leslie P.; Silvers, Anita, eds. The Blackwell Guide to Medical Ethics. Malden, MA: Blackwell Pub., 2007: 162-179. NRCBL: 9.4; 11.1; 9.5.2; 9.5.3; 9.5.4; 9.5.5; 9.5.7; 9.5.10.


Abstract: Since distribution of health resources involves various aspects of ethics, the evaluation of ethical problems should be emphasized in health decisions using criteria of fairness and fundamental principles of ethics correctly understood and chosen in order to solve the real conflicts evident in the distribution of health resources and to enable fair and reasonable distribution of health resources.


Howe, Edmund G. How should careproviders respond when the medical system leaves a patient short? *Journal of Clinical Ethics* 2007 Fall; 18(3): 195-205. NRCBL: 9.4; 8.1; 8.2; 8.4.


Abstract: At the 5th International Conference on Priorities in Health Care in Wellington, New Zealand, 2004, one resonating theme was that for priority setting to be effective, it has to include clinicians in both decision making and the enforcement of those decisions. There was, however, a disturbing undertone to this theme, namely that doctors, in particular, were unjustifiably thwarting good systems of prioritising scarce healthcare resources. This undertone seems unfair precisely because doctors may, and in some cases do, feel obligated by their professional ethics to remain unininvolved either in deciding priorities and in some cases in enforcing them. I will argue that the professional role of a doctor ought not be considered inconsistent with the role of a priority setter or enforcer, as long as one crucial element is in place, a rationally coherent and broadly justifiable regime for prioritising healthcare. Given this I conclude both that prioritisation and doctoring are not incompatible under certain conditions, and that the education of healthcare professionals ought to include material on distributive justice in healthcare.


Abstract: Although rationing by clinical judgment is controversial, its acceptability partly depends on how it is practiced. In this paper, rationing by clinical judgment is defined in three different circumstances that represent increasingly wider circles of resource pools in which the rationing decision takes place: triage during acute shortage, comparison to other potential patients in a context of limited but not immediately strained resources, and determination of whether expected benefit of an intervention is deemed sufficient to warrant its cost by reference to published population based thresholds. Notions of procedural justice are applied along with an analytical framework of six minimal requisites in order to facilitate fair bedside rationing: (1) a closed system that offers reciprocity, (2) attention to general concerns of justice, (3) respect for individual variations, (4) application of a consistent process, (5) explicitness, and (6) review of
decisions. The process could be monitored for its applicability and appropriateness.


Abstract: Rationing healthcare is a difficult task, which includes preventing patients from accessing potentially beneficial treatments. Proponents of implicit rationing argue that politicians cannot resist pressure from strong patient groups for treatments and conclude that physicians should ration without informing patients or the public. The authors subdivide this specific programme of implicit rationing, or “hidden rationing”, into local hidden rationing, unsophisticated global hidden rationing and sophisticated global hidden rationing. They evaluate the appropriateness of these methods of rationing from the perspectives of individual and political autonomy and conclude that local hidden rationing and unsophisticated global hidden rationing clearly violate patients’ individual autonomy, that is, their right to participate in medical decision-making. While sophisticated global hidden rationing avoids this charge, the authors point out that it nonetheless violates the political autonomy of patients, that is, their right to engage in public affairs as citizens. A defence of any of the forms of hidden rationing is therefore considered to be incompatible with a defence of autonomy.


Abstract: Healthcare package decisions are complex. Different judgements about effectiveness, cost-effectiveness and disease burden influence the decision-making process. Moreover, different concepts of justice generate different ideas about fair distribution of healthcare resources. This paper presents a decision model that is used in medical school in order to familiarise medical students with the different concepts of justice and the ethical dimension of making concrete choices. The model is based on the four-stage decision model developed in the Netherlands by the Dunning Committee and the discussion that followed its presentation in 1991. Having to deal with 10 medical services, students working with the model learn to discern and integrate four different ideas of distributive justice that are integrated in a flow chart: libertarian, communitarian, egalitarian and utilitarian.


Marcus, Robert; Firth, John. Should you tell patients about beneficial treatments that they cannot have? [debate]. BMJ: British Medical Journal 2007 April 21; 334(7598): 826-827. NRCBL: 9.4; 8.2; 9.3.2; 9.7; 7.3.


Abstract: A response is given to the claim by Claxton and Culyer, who stated that the policies of the National Institute for Health and Clinical Excellence (NICE) do not evaluate patients rather than treatments. The argument is made that the use of values such as quality of life and
life-years is ethically dubious when used to choose which patients ought to receive treatments in the National Health Service (NHS).


Abstract: In this paper, I want to scrutinise the value of utilising the concept of disease for a theory of distributive justice in health care. Although many people believe that the presence of a disease-related condition is a prerequisite of a justified claim on health care resources, the impact of the philosophical debate on the concept of disease is still relatively minor. This is surprising, because how we conceive of disease determines the amount of justified claims on health care resources. Therefore, the severity of scarcity depends on our interpretation of the concept of disease. I want to defend a specific combination of a theory of disease with a theory of distributive justice. A naturalist account of disease, together with sufficientarianism, is able to perform a gate-keeping function regarding entitlements to medical treatment. Although this combination cannot solve all problems of justice in health care, it may inform rationing decisions as well.


Task Force on Values, Ethics, and Rationing in Critical Care (VERICC); Truog, Robert D.; Brock, Dan W.; Cook, Deborah J.; Danis, Marion; Luce, John M.; Rubenfeld, Gordon D.; Levy, Mitchell M. Rationing in the intensive care unit. Critical Care Medicine 2006 April; 34(4): 958-963; quiz 971. NRCBL: 9.4; 9.5.1; 7.2.


Abstract: Samia Hurst and Marion Danis provide a thoughtful framework for how to judge the morality of bedside rationing decisions. In this commentary, I applaud Hurst and Danis for advancing the level of debate about bedside rationing. But when I attempt to apply the framework to my own clinical practice, I conclude that the framework comes up short.

Vannelli, Alberto; Battaglia, Luigi; Poiasina, Elia; Belli, Filiberto; Bonfanti, Giuliano; Gallino, Gianfrancesco; Vitellaro, Marco; De Dosso, Sara; Leo, Ermanno. The art of decision-making in surgery. To what extent does economics influence choice? Chirurgia Italiana 2006 November-December; 58(6): 717-722. NRCBL: 9.4; 9.3.1; 9.5.1.


RESUSCITATION ORDERS See EUTHANASIA AND ALLOWING TO DIE

RIGHT TO DIE See ASSISTED SUICIDE; EUTHANASIA AND ALLOWING TO DIE

RIGHT TO HEALTH CARE


Beyer, Crist; Villar, Juan Carlos; Suwanvanichkij, Voravit; Singh, Sonal; Baral, Stefan D.; Mills, Edward J. Neglected diseases, civil conflicts, and the right to

NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.
NRCBL: 9.2; 21.1; 7.1.

Abstract: Neglected diseases remain one of the largest causes of disease and mortality. In addition to the difficulties in provision of appropriate drugs for specific diseases, many other factors contribute to the prevalence of such diseases and the difficulties in reducing their burden. We address the role that poor governance and politically motivated oppression have on the epidemiology of neglected diseases. We give case examples including filariasis in eastern Burma and vector-borne diseases (Chagas’ disease, leishmaniasis, and yellow fever) in Colombia, we show the links between systematic human rights violations and the effects of infectious disease on health. We also discuss the role of researchers in advocating for and researching within oppressed populations.


Corsino, Bruce V.; Patthoff, Donald E., Jr. The ethical and practical aspects of acceptance and Universal Patient Acceptance. _Journal of Dental Education_ 2006 November; 70(11): 1198-1201. NRCBL: 9.2; 2.1; 4.1.1.

Crall, James J. Access to oral health care: professional and societal considerations. _Journal of Dental Education_ 2006 November; 70(11): 1133-1138. NRCBL: 9.2; 9.5.7; 9.5.2; 4.1.1.


Abstract: The post-Communist countries in Central Europe, including the Czech Republic, underwent a rapid transformation of their legal systems, within which the concept of patient rights passed through revolutionary changes. This process however often left significant gaps in patient rights protection. There are practical difficulties for patients in defending their rights before the courts, such as problems with obtaining evidence and independent expert opinions, long delays and high costs of court proceedings, strict burden of proof rules and low compensation levels. Modern patient rights often collide with the systems of health care provision that are still unprepared for patient autonomy and responsibility. The experience gained in the transition process might be applicable also to other countries that undergo changes from traditional to modern system of patient rights protection.


Forman, Lisa. Trade rules, intellectual property, and the right to health. _Ethics and International Affairs_ 2007 Fall; 21(3): 337-357. NRCBL: 9.2; 5.3; 21.1.


Abstract: Individuals and populations suffer violations of their rights that affect health and wellbeing. Health professionals have a part to play in reduction and prevention of these violations and ensuring that health-related policies and practices promote rights. This needs efforts in terms of advocacy, application of legal standards, and public-health programming. We discuss the changing views of human rights in the context of the HIV/AIDS epidemic and propose further development of the right to health by increased practice, evidence, and action.


Kisely, Stephen; Smith, Mark; Lawrence, David; Cox, Martha; Campbell, Leslie Anne; Maaten, Sarah. Inequitable access for mentally ill patients to some medically necessary procedures. **CMAJ/JAMC: Canadian Medical Association Journal** 2007 March 13; 176(6): 779-784. NRCBL: 9.2; 9.3.1; 17.1. SC: em.


Loewy, Erich H.; Loewy, Roberta Springer. Framing issues in health care: do American ideals demand basic health care and other social necessities for all? **Health Care Analysis: An International Journal of Health Philosophy and Policy** 2007 December; 15(4): 261-271. NRCBL: 9.2; 1.1; 1.3.1; 1.3.5. SC: an. Abstract: This paper argues for the necessity of universal health care (as well as universal free education) using a different argument than most that have been made heretofore. It is not meant to conflict with but to strengthen the arguments previously made by others. Using the second paragraph of the Declaration of Independence and the Preamble to the Constitution we argue that universal health care in this day and age has become a necessary condition if the ideals of life, liberty and the pursuit of happiness are to be more than an empty promise and if the discussion of “promoting of general welfare” in the preamble is to have any meaning.


Niveau, Gérard. Relevance and limits of the principle of “equivalence of care” in prison medicine. **Journal of Medical Ethics** 2007 October; 33(10): 610-613. NRCBL: 9.2; 1.3.5; 9.5.1. SC: rv. Abstract: The principle of “equivalence of care” in prison medicine is a principle by which prison health services are obliged to provide prisoners with care of a quality equivalent to that provided for the general public in the same country. It is cited in numerous national and international directives and recommendations. The principle of equivalence is extremely relevant from the point of view of normative ethics but requires adaptation from the point of view of applied ethics. From a clinical point of view, the principle of equivalence is often insufficient to take account of the adaptations necessary for the organization of care in a correctional setting. The principle of equivalence is cost-effective in general, but has to be overstepped to ensure the humane management of certain special cases.

Nys, Herman; Stultiëns, Loes; Borry, Pascal; Goffin, Tom; Dierickx, Kris. Patient rights in EU Member States after the ratification of the Convention on Human Rights and Biomedicine. **Health Policy** 2007 October; 83(2-3): 223-235. NRCBL: 9.2; 21.1. SC: le.

O’Toole, Brian. Promoting access to oral health care: more than professional ethics is needed. **Journal of Dental Education** 2006 November; 70(11): 1217-1220. NRCBL: 9.2; 4.1.1.


Ozar, David T. Ethics, access, and care. **Journal of Dental Education** 2006 November; 70(11): 1139-1145. NRCBL: 9.2; 4.1.1; 2.1.
SEX DETERMINATION

SECTION I


Welles, J.A. Making access a priority: ethics has a vital role in fostering collaboration in health care. Health Progress 2007 March-April; 88(2): 67-72. NRCBL: 9.2; 9.3.1; 1.2.


Werhane, Patricia H. Access, responsibility, and funding: a systems thinking approach to universal access to oral health. Journal of Dental Education 2006 November; 70(11): 1184-1195. NRCBL: 9.2; 4.1.1; 9.1; 1.3.2.


RIGHTS See INTERNATIONAL HEALTH AND HUMAN RIGHTS; RIGHT TO HEALTH CARE

SCIENCE AND TECHNOLOGY See BIOMEDICAL RESEARCH/ RESEARCH ETHICS AND SCIENTIFIC MISCONDUCT

SEX DETERMINATION

See also GENETIC COUNSELING; GENETIC SCREENING


sex selection and the balance of the sexes: empirical evidence from Germany, the UK, and the US. *Journal of Assisted Reproduction and Genetics* 2006 July-August; 23(7-8): 311-318. NRCBL: 14.3; 15.2; 21.1.


Keywords: *sex preselection; methods; organizational policies; professional organizations; international aspects; attitude of health personnel; Keyword Identifiers: American College of Obstetricians and Gynecologists; American Society for Reproductive Medicine


Abstract: Sex selection, which refers to the attempt to choose or control the sex of a child prior to its birth, has become the subject of increasing ethical scrutiny and many jurisdictions have criminalized it except for serious sex-linked diseases or conditions that cannot easily be ameliorated or remedied. This paper argues that such a blanket prohibition is ethically unwarranted because it is based on a flawed understanding of the difference between sexist values and mere sex-oriented preferences. It distinguishes between ethics and public policy, and suggests a way of allowing preference-based sex selection as a matter of public policy without permitting value-based sex selection. It further argues that medically-based sex selection should be publicly funded but that preference-based sex selection should not be paid for by society, and that the prohibition against value-based sex selection should be enforced through legislation that controls the licensing of health care facilities and through disciplinary procedures against health care professionals.


Keywords: *criminal law; females; justice; legal aspects; sex determination; sex preselection; attitudes; advisory committees; freedom; infanticide; international aspects; justice; legal rights; males; moral policy; preimplantation diagnosis; prenatal diagnosis; selective abortion; social discrimination; Keyword Identifiers: *Canada; Assisted Human Reproduction Act (Canada); Canadian Charter of Rights and Freedoms; Royal Commission on New Reproductive Technologies (Canada)

Rogers, Wendy; Ballantyne, Angela; Draper, Heather. Is sex-selective abortion morally justified and should it be prohibited? *Bioethics* 2007 November; 21(9): 520-524. NRCBL: 14.3; 12.5.1. SC: an.

Abstract: In this paper we argue that sex-selective abortion (SSA) cannot be morally justified and that it should be prohibited. We present two main arguments against SSA. First, we present reasons why the decision for a woman to seek SSA in cultures with strong son-preference cannot be regarded as autonomous on either a narrow or a broad account of autonomy. Second, we identify serious harms associated with SSA including perpetuation of discrimination against women, disruption to social and familial networks, and increased violence against women. For these reasons, SSA should be prohibited by law, and such laws should be enforced. Finally, we describe additional strategies for decreasing sex-preference. Some of these strategies rely upon highlighting the disadvantages of women becoming scarce, such as lack of brides and daughters-in-law to care for elderly parents. We should, however, be cautious not to perpetuate the view that the purpose of women is to be the consorts for, and carers of, men, and the providers of children. Arguments against SSA should be located within a concerted effort to ensure greater, deeper social and cultural equality between the sexes.


Keywords: *sex determination; sex preselection; moral obligations; advertising; ethical analysis; females; industry; males; methods; moral policy; parents; preimplantation diagnosis; prenatal diagnosis; public policy; reproductive technologies; selective abortion; sexuality; Western World
Zilberberg, Julie. Sex selection and restricting abortion and sex determination. *Bioethics* 2007 November; 21(9): 517-519. NRCBL: 14.3; 1.1; 10; 15.2; 12.4.2; 12.5.1. Abstract: Sex selection in India and China is fostered by a limiting social structure that disallows women from performing the roles that men perform, and regulates women to a lower status level. Individual parents and individual families benefit concretely from having a son born into the family, while society, and girls and women as a group, are harmed by the widespread practice of sex selection. Sex selection reinforces oppression of women and girls. Sex selection is best addressed by ameliorating the situations of women and girls, increasing their autonomy, and elevating their status in society. One might argue that restricting or prohibiting abortion, prohibiting sex selection, and prohibiting sex determination would eliminate sex selective abortion. But this decreases women’s autonomy rather than increases it. Such practices will turn underground. Sex selective infanticide, and slower death by long term neglect, could increase. If abortion is restricted, the burden is placed on women seeking abortions to show that they have a legally acceptable or legitimate reason for a desired abortion, and this seriously limits women’s autonomy. Instead of restricting abortion, banning sex selection, and sex determination, it is better to address the practice of sex selection by elevating the status of women and empowering women so that giving birth to a girl is a real and positive option, instead of a detriment to the parents and family as it is currently. But, if a ban on sex selective abortion or a ban on sex determination is indeed instituted, then wider social change promoting women’s status in society should be instituted simultaneously.

**SEX PRESELECTION** See SEX DETERMINATION

**SEXUALITY**

See also MALPRACTICE AND PROFESSIONAL MISCONDUCT


Gurney, Karen. Sex and the surgeon’s knife: the family court’s dilemma... informed consent and the specter of iatrogenic harm to children with intersex characteristics. *American Journal of Law and Medicine* 2007; 33(4): 625-661. NRCBL: 10; 8.3.2; 9.5.7. SC: le.


Wiesen, Jonathan; Kulak, David. “Male and female He created them.” revisiting gender assignment and treatment in intersex children. *Journal of Halacha and Contemporary Society* 2007 Fall; (54): 5-29. NRCBL: 10; 9.5.7.

**SOCIAL ASPECTS** See ABORTION/ SOCIAL ASPECTS

**SOCIAL CONTROL OF SCIENCE AND TECHNOLOGY** See BIOMEDICAL RESEARCH/ SOCIAL CONTROL OF SCIENCE AND TECHNOLOGY
SOCIAL JUSTICE See RESOURCE ALLOCATION; RIGHT TO HEALTH CARE

SOCIOECONOMIC ASPECTS See GENETIC SCREENING/ SOCIOECONOMIC ASPECTS

SOCIOLOGY OF MEDICINE


Bouknight, Heyward H., III. Between the scalpel and the lie: comparing theories of physician accountability for misrepresentations of experience and competence. Washington and Lee Law Review 2003 Fall; 60(4): 1515-1560. NRCBL: 7.1; 8.3.1; 8.1; 9.8; 8.5. SC: le.


Endacott, Ruth; Wood, Anita; Judd, Fiona; Hulbert, Carol; Thomas, Ben; Grigg, Margaret. Impact and management of dual relationships in metropolitan, regional and rural mental health practice. Australian and New Zealand Journal of Psychiatry 2006 November-December; 40(11-12): 987-994. NRCBL: 7.1; 7.3; 8.1; 17.1.


King, Patricia A.; Areen, Judith; Gostin, Lawrence O. Private control of science and medicine. In their: Law, Medicine and Ethics. New York: Foundation Press, 2006: 112-207. NRCBL: 7.1; 6; 8.2; 8.3.1; 18.2; 16.3; 2.1. SC: le.


McLean, Michelle; Naidoo, Soornarain S. Medical students’ views on the white coat: a South African perspective on ethical issues. Ethics and Behavior 2007 December; 17(4): 387-402. NRCBL: 7.1; 7.2. SC: em. Abstract: There is a debate regarding the use of the white coat, a traditional symbol of the medical profession, by students. In a study evaluating final-year South African medical students’ perceptions, the white coat was associated with traditional symbolic values (e.g., trust) and had practical uses (e.g., identification). The coat was generally perceived to evoke positive emotions in patients, but some recognized that it may cause anxiety or mistrust. Donning a white coat generally implied a responsibility to the profession. For a few, without the coat, patients would not cooperate, resulting in some perceiving no need to be distinguished from qualified practitioners. There was thus some evidence of entitled (vs. earned) respect. In the light of the underresourced health care setting in which these students learn clinical medicine, we recommend that students be able to recognize the potential for unprofessional or unethical behavior. Students should also be able to identify role models.


Abstract: The unprofessional behaviour of medics is explored through their depiction in two physician-authored books—the novel Bodies and the autobiography Bedside stories: confessions of a junior doctor. Using the Integrative Model of Behavioural Prediction, not only the range and nature of professionalism lapses outlined in these books but also the reasons behind such unprofessional behaviours are examined. The books contained examples of lapses in professionalism outlined in research investigating the unprofessional behaviour of medical students, such as communication violations, objectification of patients and causing harm to patients. More interestingly, various reasons behind lapses in professionalism were found. Most examples of unprofessional behaviour were unintentional acts and therefore due to environmental constraints and skill deficits. Seemingly intentional acts were largely influenced by normative beliefs—that is, people feeling pressurised to act unprofessionally. Further research is needed to examine the depiction of lapses in professionalism in a wider range of physician-authored prose.


Williams, Hywel C.; Naldi, Luigi; Paul, Carle; Vahlquist, Anders; Schroter, Sara; Jobling, Ray. Conflicts of interest in dermatology. *Acta Dermato-Venereologica* 2006; 86(6): 485-497. NRCBL: 7.1; 1.3.2; 9.3.1; 1.3.7.


**SPECIAL POPULATIONS** See CARE FOR SPECIFIC GROUPS; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS

**SPERM** See CRYOBANKING OF SPERM, OVA AND EMBRYOS

**STEM CELL RESEARCH**


Keywords: *adult stem cells;* *embryo research;* *embryonic stem cells;* international aspects; regulation


Keywords: *chimeras;* *embryo research;* *stem cells;* human dignity; nuclear transfer techniques; primates; regulation; risk; Keyword Identifiers: Great Britain


Keywords: *embryonic stem cells;* *pluripotent stem cells;* *public policy;* *registries;* adult stem cells; cell lines; embryo research; federal government; research support; Keyword Identifiers: United States; National Institutes of Health


Keywords: *embryo research;* *embryonic stem cells;* *government regulation;* *legal aspects;* advisory commit-
SECTION I

STEM CELL RESEARCH

New Jersey Catholic hospitals support stem cell research, promote cord blood donation. Health Care Ethics USA 2007 Winter; 15(1): 15. NRCBL: 18.5.1; 15.1; 19.4; 9.5.7; 1.2.

Keywords: *adult stem cells; *cord blood; *institutional policies; *religious hospitals; biomedical research; blood banks; blood donation; Roman Catholic ethics; Keyword Identifiers: *New Jersey

Time out, not the final buzzer, in the stem cell debate [editorial]. Lancet 2007 December 1-7; 370(9602): 1802. NRCBL: 18.5.1; 15.1; 18.5.4.


Keywords: *embryo research; *embryonic stem cells; *embryos; *ethical analysis; *moral status; beginning of life; cloning; embryonic disposition; embryonic development; in vitro fertilization; intention; nuclear transfer techniques; philosophy; Proposed Keywords: *blastocysts

Abstract: This paper examines three arguments that use the concept of potential to identify embryos that are morally suitable for embryonic stem cell research (ESCR). According to the first argument, due to Ronald Green, the fact that they are scheduled for disposal makes embryos left over from IVF treatments morally appropriate for research. Paul McHugh argues that embryos created by somatic cell nuclear transfer differ from those that result directly from the meeting of sperm and egg in having potential especially conducive to the therapeutic use of their stem cells. I reject both of these arguments. According to the way of making distinctions in embryonic potential that I defend, it is the absence of a functional relationship with a womb that marks embryos morally suitable for ESCR.


Keywords: *embryo research; *embryonic stem cells; *stem cells; advisory committees; government financing; organizational policies; professional organizations; public policy; Keyword Identifiers: United States


Keywords: *cloning; *embryo research; *embryonic stem cells; *Islamic ethics; reproductive technologies; Keyword Identifiers: *Iran


Keywords: *stem cells; embryonic stem cells; embryo research; federal government; pluripotent stem cells; research support; Keyword Identifiers: United States


Barnes, Richard. Stem cell research funding: testimony. Origins 2007 March 15; 36(39): 616-620. 10 refs. NRCBL: 18.5.4; 15.1; 1.2; 9.3.1.

Keywords: *embryo research; *embryonic stem cells; *government financing; *research support; *Roman Catholic ethics; *state government; adult stem cells; biotechnology; cloning; conflict of interest; economics; embryos; industry; legislation; public opinion; public policy; value of life; Keyword Identifiers: *New York; United States

Baylis, François; Fenton, Andrew. Chimera research and stem cell therapies for human neurodegenerative disorders. CQ: Cambridge Quarterly of Healthcare Ethics 2007 Spring; 16(2): 195-208. 71 fn. NRCBL: 15.1; 18.1; 22.1; 17.1; 4.4; 18.5.4. SC: an.

Keywords: *chimeras; *embryonic stem cells; *ethical analysis; *human dignity; *moral policy; *moral status; *primates; *stem cell transplantation; animal welfare; clinical trials; guidelines; human characteristics; speciessism; therapeutic research; risks and benefits; Proposed Keywords: *neurodegenerative diseases; Keyword Identifiers: National Academy of Sciences

Baylis, François; McLeod, C. The stem cell debate continues: the buying and selling of eggs for research. Journal of Medical Ethics 2007 December; 33(12): 726-731. 41 refs. NRCBL: 19.5; 14.5; 1.3.9; 18.5.4; 15.1; 18.5.3; 9.3.1. SC: an.

Keywords: *embryo research; *embryonic stem cells; *guidelines; *ovum donors; *remuneration; cloning; embryo disposition; ethical analysis; disadvantaged persons; in vitro fertilization; incentives; international aspects; organizational policies; ovum; patients; professional organizations; research subjects; risk; socioeconomic factors; women; Keyword Identifiers: *ISSCR Guidelines; *International Society for Stem Cell Research


Beeson, Diane; Lippman, Abby. Egg harvesting for stem cell research: medical risks and ethical problems. Reproductive Biomedicine Online 2006 October; 13(4): 573-579. 50 refs. NRCBL: 15.2; 18.5.4; 9.5.5; 14.4; 14.5.

NRCBL: National Reference Center for Bioethics Literature Classification Scheme

See inside front cover for terms.

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Bell, Leanne; Devaney, Sarah. Gaps and overlaps: improving the current regulation of stem cells in the UK. *Journal of Medical Ethics* 2007 November; 33(11): 621-622. NRCBL: 18.5.4; 15.1; 19.1. SC: le.

Benítez-Bribiesca, Luis; Modiano-Esquenazi, Marcos. Ethics of scientific publication after the human stem cell scandal [editorial]. *Archives of Medical Research* 2006 May; 37(4): 423-424. NRCBL: 1.3.7; 1.3.9.


Keywords: *international aspects; *patents; *stem cells; access to information; databases; embryonic stem cells; industry; interinstitutional relations; private sector; public sector; research institutes; statistics; universities; Proposed Keywords: *technology transfer; licensure; Keyword Identifiers: United States

Bobbert, Monika. Ethical questions concerning research on human embryos, embryonic stem cells and chimeras. *Biotechnology Journal* 2006 December; 1(12): 1352-1369. NRCBL: 18.5.4; 15.1; 22.1; 15.8; 4.4.


Brainard, Jeffrey. California stem-cell researchers ponder next steps after court victory. *Chronicle of Higher Education* 2007 June 1; 53(39): A20. NRCBL: 18.5.4; 15.1; 1.3.9.

Keywords: *government financing; *research support; *state government; *stem cells; *universities; biomedical research; conflict of interest; embryo research; laboratories; legal aspects; patient advocacy; politics; public policy; research institutes; Keyword Identifiers: *California; Stanford University; University of California, San Francisco


Keywords: *embryo research; *embryonic stem cells; *government financing; *public policy; *research support; cell lines; government regulation; Keyword Identifiers: *United States; *Zerhouni, Elias; National Institutes of Health

Brown, Susan. China challenges the west in stem-cell research: unconstrained by public debate, cities like Shanghai and Beijing lure scientists with new laboratories and grants. *Chronicle of Higher Education* 2007 April 13; 53(32): A14-16, A18. NRCBL: 18.5.4; 15.1; 21.1; 1.3.9.


Burke, William; Pullicino, Patrick; Richard, Edward J. The biological basis of the oocyte assisted reprogramming (OAR) hypothesis: is it an ethical procedure for making embryonic stem cells? *Linacre Quarterly* 2007 August; 74(3): 204-212. NRCBL: 18.5.4; 15.1.


Keywords: *embryo research; *embryonic stem cells; *government financing; *guidelines; *public policy; *research support; cell lines; commerce; confidentiality; disclosure; ethical review; germ cells; informed consent; policy making; public participation; review committees; standards; stem cell transplantation; stem cells; Keyword Identifiers: *Canada; *Canadian Institutes of Health Research


Keywords: *biomedical research; *cell lines; *embryo research; *embryonic stem cells; *guidelines; *public policy; *stem cells; confidentiality; conflict of interest; directed donation; donors; ethical review; fetal research; industry; informed consent; international aspects; registries; remuneration; refusal to participate; research embryo creation; research support; researchers; Keyword Identifiers: *Canada; *Canadian Institutes of Health Research; Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans


Keywords: *cloning; *embryo research; *embryonic stem cells; motivation; reproductive technologies; stem cell transplantation; twinning; Proposed Keywords: blastocysts


Keywords: *cloning; *embryo research; *genetic techniques; *policy making; *public opinion; *public policy; *regulation; *reproductive technologies; advisory committees; biotechnology; consensus; criminal law; dissent; embryonic stem cells; embryos; focus groups; government regulation; human dignity; international aspects; legal aspects; moral status; nuclear transfer
techniques; policy analysis; religion; religious ethics; risks and benefits; survey; values; Keyword Identifiers: *United States; Canada; United Nations

Cheema, Puneet; Mehta, Paulette. Pediatric stem cell transplantation ethical concerns. In: Mehta, P., ed. Pediatric Stem Cell Transplantation. Sudbury: Jones and Bartlett Publishers, 2004: p. 91-98. NRCBL: 19.1; 8.3.2; 19.4; 19.5; 18.5.4; 9.5.7; 1.1.


Cibelli, Jose. Is therapeutic cloning dead? The ability to generate pluripotent stem cells directly from skin fibroblasts may render ethical debates over the use of human oocytes to create stem cells irrelevant. *Science* 2007 December 21; 318(5858): 1879-1880. 17 refs. NRCBL: 14.5; 18.5.4; 15.1.

Keywords: *cloning; *stem cells; embryonic stem cells; genetic techniques; methods; nuclear transfer techniques; Proposed Keywords: *pluripotent stem cells


Keywords: *cell lines; *embryo research; *embryonic stem cells; beginning of life; cloning; donors; embryo disposition; genetic diversity; government regulation; informed consent; research support; stem cell transplantation; Key word Identifiers: *United States


Keywords: *chimeras; *guidelines; *stem cell transplantation; advisory committees; animal experimentation; brain; embryonic stem cells; embryos; fetuses; human characteristics; moral policy; policy analysis; policy making; precautionary principle; primates; public policy; regulation; research ethics; risks and benefits; Proposed Keywords: blastocysts; mice; species specificity; Keyword Identifiers: National Academies of Sciences; Stanford University; United States

Condic, Maureen L. What we know about embryonic stem cells. *First Things* 2007 January; (169): 25-29. NRCBL: 18.5.4; 15.1; 14.5; 18.5.1; 22.2; 19.1.

Condic, Maureen L.; Furton, Edward J. Harvesting embryonic stem cells from deceased human embryos. *National Catholic Bioethics Quarterly* 2007 Autumn; 7(3): 507-525. 35 fn. NRCBL: 18.5.4; 15.1; 19.5; 20.2.1; 14.4; 18.3; 1.2. Keywords: *death; *determination of death; *embryo disposition; *embryonic stem cells; *embryos; *moral policy; cryopreservation; embryo research; human dignity; in vitro fertilization; methods; model legislation; moral complicity; parental consent; public policy; Roman Catholic ethics; Proposed Keywords: *embryo death


Keywords: *cloning; *embryonic stem cells; *methods; adult stem cells; embryo research; nuclear transfer techniques; primates; stem cell transplantation; Proposed Keywords: *pluripotent stem cells; regenerative medicine

Cyranoski, David. Stem-cell fraudster ‘is working in Thailand’ [news]. *Nature* 2007 September 27; 449(7161): 387. NRCBL: 18.5.4; 15.1; 14.5; 18.1; 22.1. Identifiers: Woo Suk Hwang.

Daley, George Q.; Ahrlund-Richter, Lars; Auerbach, Jonathan M.; Benvenisti, Nissim; Charo, R. Alta; Chen, Grace; Deng, Hong-kui; Goldstein, Lawrence S.; Hudson, Kathy L.; Hyun, Insoo; Jann, Sung Chull; Love, Jane; Lee, Eng Hin; McLaren, Anne; Mummery, Christine L.; Nakatsuji, Norio; Racekowsky, Catherine; Rokee, Heather; Rossant, Janet; Schöler, Hans R.; Solbakk, Jan Helge; Taylor, Patrick; Trounson, Alan O.; Weissman, Irving L.; Wilmut, Ian; Yu, John; Zoloth, Laurie. The ISSCR guidelines for human embryonic stem cell research. *Science* 2007 February 2; 315(5812): 603-604. 12 refs. NRCBL: 18.5.4; 15.1. Identifiers: International Society for Stem Cell Research.

Keywords: *embryo research; *embryonic stem cells; *guidelines; *professional organizations; access to information; chimeras; cloning; donors; editorial policies; ethical review; germ cells; guideline adherence; informed consent; international aspects; regulation; remuneration; researchers; Proposed Keywords: pluripotent stem cells; Keyword Identifiers: *International Society for Stem Cell Research; National Academy of Sciences; United States

de Melo-Martín, Immaculada; Rosenwaks, Zev; Fins, Joseph J. New methods for deriving embryonic stem cell lines: are the ethical problems solved? *Fertility and Sterility* 2006 November; 86(5): 1330-1332. NRCBL: 15.2; 18.5.4; 15.3.

2167 [2007 December 4]. 47 refs. NRCBL: 15.2; 14.4; 18.5.4.

Keywords: *embryonic stem cells; *preimplantation diagnosis; *moral policy; *stem cells; *tissue typing; adverse effects; classification; family members; ethical analysis; forecasting; motivation; reproduction; research embryo creation; risks and benefits; stem cell transplantation; trends; Proposed Keywords: *hematopoietic stem cells


Doerflinger, Richard M. Washington insider: House passes amended Genetic Nondiscrimination Bill; continued impasse on stem cell legislation, new executive order; defeat of deceptive human cloning bill; Supreme Court decision on partial-birth abortion. National Catholic Bioethics Quarterly 2007 Autumn; 7(3): 455-463. 21 fn. NRCBL: 15.2; 8.4; 18.5.4; 14.5. SC: le. Keywords: *embryo research; *embryonic stem cells; *genetic discrimination; *legislation; abortion; adult stem cells; cell lines; federal government; government financing; government regulation; politics; reproductive technologies; research support; Keyword Identifiers: *U. S. Congress; *United States; Genetic Information Nondiscrimination Act; Human Cloning Prohibition Act; Partial Birth Abortion Ban Act; Stem Cell Research Enhancement Act

Doerflinger, Richard M. Washington insider: 2006 in Congress; Senate Hearing on Misrepresentations in stem cell research; Opening battle of 2007; Genetic Nondiscrimination Bill may see action. National Catholic Bioethics Quarterly 2007 Spring; 7(1): 15-21. NRCBL: 18.5.4; 15.1; 18.5.1; 1.2; 15.3. SC: le. Identifiers: H.R. 810 — Stem Cell Research Enhancement Act


Keywords: *embryo research; *embryonic stem cells; *policy making; *public policy; advisory committees; biomedical research; cloning; democracy; government financing; government regulation; guidelines; historical aspects; international aspects; legal aspects; legislation; patient advocacy; political activity; research support; researchers; Proposed Keywords: *stakeholders; lobbying; Keyword Identifiers: *Canada; Canadian Institutes of Health Research; Royal Commission on New Reproductive Technologies; Right to Life Movement; Twentieth Century


Keywords: abortion; *beginning of life; *cloning; *embryo research; *embryos; *moral status; abortifacients; adult stem cells; embryo disposition; fetal stem cells; in vitro fertilization; moral complexity; natural law; personhood; philosophy; reproductive technologies; Proposed Keywords: blastocysts; Keyword Identifiers: *Thomas Aquinas


Keywords: *embryonic stem cells; *tissue banks; donors; incentives; mandatory programs; moral policy; organ transplantation; remuneration; resource allocation; risks and benefits; scarcity; standards; stem cell transplantation; utilitarianism; Proposed Keywords: embryo donation


Keywords: *embryo research; *embryonic stem cells; *government financing; *private sector; *research support; *state government; federal government; government regulation; public policy; statistics; stem cells; Keyword Identifiers: *United States

Franklin, Sarah. Embryonic economies: the double reproductive value of stem cells. Biosocieties 2006 March; 1(1): 71-90. 97 refs. NRCBL: 18.5.4; 15.1; 19.5; 14.1; 18.3.

Keywords: *embryo disposition; *embryo research; *embryonic stem cells; *in vitro fertilization; biological specimen banks; cell lines; donors; economics; motivation; public policy; regulation; trends; Proposed Keywords: *embryo donation; Keyword Identifiers: Great Britain


Keywords: *animal cloning; *biotechnology; *genetic engineering; *industry; *stem cells; capitalism; cell lines; embryonic research; embryonic stem cells; gene therapy; genetically modified food; genetically modified organisms;
nuclear transfer techniques; patents; stem cell transplantation; trust; Proposed Keywords: domestic animals; regenerative medicine; sheep; Keyword Identifiers: Geron Corp.; Great Britain; United States

Genetics Committee of the Society of Obstetricians and Gynaecologists of Canada; Wilson, R. Douglas; Desilets, Valerie; Gagnon, Alain; Summers, Anne; Wyatt, Philip; Allen, Victoria; Langlois, Sylvie. Present role of stem cells for fetal genetic therapy = Rôle actuel des cellules souches en matière de thérapie génique fœtale. JOG: Journal of Obstetrics and Gynaecology Canada = JOG: Journal d’Obstétrique et Gynécologie du Canada 2005 November; 27(11): 1038-1047. NRCBL: 18.5.4; 15.1; 15.4; 19.5.

Giacomini, Mita; Baylis, Françoise; Robert, Jason. Banking on it: public policy and the ethics of stem cell research and development. Social Science and Medicine 2007 October; 65(7): 1490-1500. NRCBL: 18.5.4; 15.1; 18.5.1; 5.2; 5.3.

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Keywords: *cloning; *stem cell transplantation; adult stem cells; embryonic stem cells; reproductive technologies


Keywords: *embryonic stem cells; *legislation; *tissue banks; cell lines; cloning; donors; government regulation; guidelines; in vitro fertilization; incentives; international aspects; justice; minority groups; moral policy; nuclear transfer techniques; public policy; remuneration; scarcity; social discrimination; Proposed Keywords: embryo donation; haplotypes; Keyword Identifiers: *Canada

Keywords: *cloning; *embryo research; *embryonic stem cells; *public policy; *recombinant DNA research; *regulation; advisory committees; government regulation; reproductive technologies; self regulation; Keyword Identifiers: *United States; Asilomar Conference; President’s Council on Bioethics; Recombinant DNA Advisory Committee

Keywords: *embryo research; *embryonic stem cells; *stem cell transplantation; advisory committees; cell lines; federal government; research support; state government; Proposed Keywords: altered nuclear transfer; blastocysts

Guennin, Louis M. A proposed stem cell research policy. Stem Cells 2005 September; 23(8): 1023-1027. NRCBL: 18.5.4; 15.1; 18.6. SC: le.

Hagen, John D., Jr. Bentham’s mummy and stem cells. America 2007 May 14; 196(17): 12-14. NRCBL: 18.5.4; 15.1; 1.1; 4.4.

Hall, Vanessa J.; Stojkovic, Petra; Stojkovic, Miodrag. Using therapeutic cloning to fight human disease: a conundrum or reality? Stem Cells 2006 July; 24(7): 1628-1637. 99 refs. NRCBL: 14.5; 18.5.4; 15.1; 18.2.
Keywords: *cloning; *embryonic stem cells; *stem cell transplantation; adult stem cells; adverse effects; beginning of life; cell lines; commodification; in vitro fertilization; international aspects; legislation; ovum donors; reproductive technologies; research support; Proposed Keywords: parthenogenesis; Keyword Identifiers: Australia; Canada; Europe; Japan; Mexico

Keywords: *embryonic stem cells; *patents; adult stem cells; commodification; donors; embryo research; embryos; informed consent; international aspects; legal aspects; moral status; public policy; Keyword Identifiers: Europe

Heng, Boon Chin. Donation of surplus frozen embryos for stem cell research or fertility treatment — should medical professionals and healthcare institutions be allowed to exercise undue influence on the informed decision of their former patients? Journal of Assisted Reproduction and Genetics 2006 September-October; 23(9-10): 381-382. NRCBL: 14.6; 15.1; 18.5.4; 7.1; 8.3.1.


Keywords: *beginning of life; *embryos; *moral status; cloning; cryopreservation; embryo disposition; embryo research; embryonic stem cells; in vitro fertilization; moral obligations; moral policy; personhood; preimplantation diagnosis; reproductive technologies; value of life

Holden, Constance. Prominent researchers join the attack on stem cell patents [news]. Science 2007 July 13; 317(5835): 187. NRCBL: 15.8; 18.5.4; 15.1.

Keywords: *cell lines; *embryonic stem cells; *legal aspects; *patents; attitudes; researchers; universities; Proposed Keywords: consumer advocacy; Keyword Identifiers: *Wisconsin Alumni Research Foundation; Patent and Trademark Office; Thomson, James; University of Wisconsin; United States


Keywords: *cell lines; *embryonic stem cells; *patents; industry; legal aspects; universities; Proposed Keywords: foundations; licensure; technology transfer; Keyword Identifiers: *Patent and Trademark Office; *Wisconsin Alumni Research Foundation; United States


Keywords: *embryo research; *legal aspects; *stem cells; cloning; embryonic stem cells; federal government; government financing; in vitro fertilization; international aspects; legislation; public policy; reproductive technologies; state government; stem cell transplantation; Keyword Identifiers: *United States; Europe; Asia

Hurlbut, William B. Stem cells, embryos, and ethics: is there a way forward? Update (Loma Linda Center) 2007 January 21(3): 1-10. 5 refs. NRCBL: 18.5.4; 15.1; 4.4; 1.2. Note: Adapted from the Health and Faith Forum: Bioethics and Wholeness Grand Rounds presentation, 2007 January 10.

Keywords: *beginning of life; *embryo research; *embryonic stem cells; *embryos; *moral policy; alternatives; cloning; government financing; in vitro fertilization; moral status; nuclear transfer techniques; public policy; twinning; value of life; Proposed Keywords: regenerative medicine; Keyword Identifiers: United States


Keywords: *chimeras; *research embryo creation; *stem cells; *terminology; *embryo research; editorial policies; public policy; Proposed Keywords: pluripotent stem cells; Keyword Identifiers: *Great Britain; Nature Medicine


Keywords: *cloning; *embryonic stem cells; *gene therapy; *risks and benefits; adverse effects; animal cloning; chimeras; embryo disposition; embryo research; embryonic development; gene transfer techniques; human experimentation; nuclear transfer techniques; reproductive technologies


Keywords: *embryonic stem cells; *embryos; *Protestant ethics; *value of life; beginning of life; embryo research; ethical analysis; moral status; personhood; Roman Catholic ethics; stem cell transplantation; theology


Keywords: *embryo research; *embryonic stem cells; *ethical theory; *moral policy; *war; *embryos; *intention; killing; moral status; rights


Keywords: *double effect; *embryo research; *embryonic stem cells; *ethical analysis; *government financing; *moral complicity; *moral policy; *public policy; *value of life; adult stem cells; allowing to die; beginning of life; cell lines; common good; embryos; federal government; guidelines; human dignity; killing; moral status; parental consent; personhood; Roman Catholic ethics; Keyword Identifiers: Bush, George; United States


Keywords: *embryonic stem cells; *organ transplantation; *property rights; *public policy; *social control; biomedical technologies; body parts and fluids; cadavers; consensus; determination of death; embryo research; embryos; government regulation; kidneys; living donors; moral status; organ
SECTION I

STEM CELL RESEARCH


Key words: *embryonic stem cells; tissue banks; donors; incentives; international aspects; justice; minority groups; moral policy; remuneration; stem cell transplantation; Proposed Keywords: embryonic donation.


Key words: *cord blood; fetal stem cells; legal aspects; parental consent; biomedical research; DNA; legislation; newborns; property rights; stem cell transplantation; Proposed Keywords: South Africa.

Abstract: The author develops a thorough analysis of current and proposed South African law in relation to the harvesting and use of stem cells. He begins with the question of ownership of the umbilical cord at birth and afterwards. The problems of informed consent in these situations are discussed. Changes in the law in South Africa, now in progress, should ameliorate some of the difficulties.


Keywords: *embryo research; embryonic stem cells; mass media; biotechnology; editorial policies; genetic research; journalism; survey; Keyword Identifiers: Great Britain.


Keywords: *adult stem cells; embryonic stem cells; methods; embryo research; researchers; Keyword Identifiers: Thomson, James A.; University of Wisconsin; United States.

Kolata, Gina. Scientists bypass need for embryo to get stem cells; method using human skin is seen as defusing the debate over ethics [news]. *New York Times* 2007 November 21; p. A1, A23. NRCBL: 18.5.1; 15.1; 19.1; 18.5.4. SC: po. Identifiers: Japan; Wisconsin; Shinya Yamanaka; James A. Thomson.

Keywords: *adult stem cells; methods; cloning; embryonic stem cells; politics; researchers; Keyword Identifiers: Japan; Thomson, James A.; United States; Yamanaka, Shinya.


Keywords: *stem cells; chimeras; embryo research; embryonic stem cells; genetic techniques; methods; risk; Proposed Keywords: pluripotent stem cells.


Keywords: *embryonic stem cells; embryo research; public policy; embryo; value of life; research support; government financing; Keyword Identifiers: United States.

Little, Melissa; Hall, Wayne; Orlandi, Amy. Delivering on the promise of human stem-cell research. What are the real barriers? *EMBO Reports* 2006 December; 7(12): 1188-1192. NRCBL: 18.5.4; 15.1; 18.6.


Keywords: *brain; chimeras; embryonic stem cells; Jewish ethics; stem cell transplantation; embryo research; embryos; human dignity; species specificity.


Keywords: *embryonic stem cells; tissue banks; cell lines; cloning; donors; embryo disposition; ethnic groups; economics; financial support; in vitro fertilization; incentives; informed consent; international aspects; justice; mandatory programs; minority groups; moral policy; nuclear transfer techniques; organ transplantation; policy analysis; racial groups; remuneration; resource allocation; scarcity; social discrimination; standards; stem cell transplantation; transplant recipients; Proposed Keywords: embryo donation; haplotypes; tissue typing.

Abstract: An increasingly unbridgeable gap exists between the supply and demand of transplantable organs. Human embryonic stem cell technology could solve the organ shortage problem by restoring diseased or damaged tissue across a range of common conditions. However, such technology faces several largely ignored immunological challenges in delivering cell lines to large populations. We address some of these challenges and argue in favor of encouraging contribution or intentional creation of embryos from which widely immunocompatible stem cell lines could be derived. Further, we argue that current immunological constraints in tissue transplantation demand the creation of a global stem cell bank, which may hold particular promise for minority populations and other sub-groups currently marginalized from organ procurement and allocation systems. Finally, we conclude by offering a number of practical and ethically
Lysaught, M. Therese. Making decisions about embryonic stem cell research. *In: Hamel, Ronald, ed. Making Health Care Decisions: A Catholic Guide. Liguori, MO: Liguori Publications, 2006: 19-36. 7 refs. NRCBL: 18.5.4; 1.2; 15.1. Keywords: *embryo research; *embryonic stem cells; Roman Catholic ethics; beginning of life; cloning; embryos; justice; moral status; personhood; value of life

Master, Zubin; McLeod, Marcus; Mendez, Ivar. Benefits, risks and ethical considerations in translation of stem cell research to clinical applications in Parkinson’s disease. *Journal of Medical Ethics* 2007 March; 33(3): 169-173. 30 refs. NRCBL: 18.5.1; 18.5.4; 15.1; 19.1. SC: an. Keywords: *clinical trials; *research subjects; *risks and benefits; *stem cell transplantation; adverse effects; embryonic stem cells; ethical review; therapeutic research; placebo; research design; surgery; Proposed Keywords: sham surgery; Keyword Identifiers: *Parkinson disease

Abstract: Stem cells are likely to be used as an alternate source of biological material for neural transplantation to treat Parkinson’s disease in the not too distant future. Among the several ethical criteria that must be fulfilled before proceeding with clinical research, a beneficial risk to benefit ratio must be obtained. The potential benefits to the participant and to society are evaluated relative to the risks in an attempt to offer the participants a reasonable choice. Through examination of preclinical studies transplanting stem cells in animals and the transplantation of fetal tissue in patients with Parkinson’s disease, a current set of potential benefits and risks for neural transplantation of stem cells in clinical research of Parkinson’s disease are derived. The potential benefits to research participants undergoing stem cell transplantation are relief of parkinsonian symptoms and decreasing doses of parkinsonian drugs. Transplantation of stem cells as a treatment for Parkinson’s disease may benefit society by providing knowledge that can be used to help determine better treatments in the future. The risks to research participants undergoing stem cell transplantation include tumour formation, inappropriate stem cell migration, immune rejection of transplanted stem cells, haemorrhage during neurosurgery and postoperative infection. Although some of these risks are general to neurosurgical transplantation and may not be reduced for participants, the potential risk of tumour formation and inappropriate stem cell migration must be minimised before obtaining a favourable potential benefit to risk calculus and to provide participants with a reasonable choice before they enroll in clinical studies.

McKneally, Martin. Controversies in cardiothoracic surgery: should therapeutic cloning be supported to provide stem cells for cardiothoracic surgery research and treatment? [debate]. *Journal of Thoracic and Cardiovascular Surgery* 2006 May; 131(5): 937-940. NRCBL: 18.5.4; 15.1; 14.5; 9.5.1.

Abstract: Some stem cell researchers believe that it is easier to derive human embryonic stem cells from fresh rather than frozen embryos and they have had in vitro fertilization (IVF) clinicians invite their infertility patients to donate their fresh embryos for research use. These embryos include those that are deemed ‘suitable for transfer’ (i.e. to the woman’s uterus) and those deemed unsuitable in this regard. This paper focuses on fresh embryos deemed suitable for transfer – hereafter ‘fresh embryos’ – which IVF patients have good reason not to donate. We explain why donating them to research is not in the self-interests specifically of female IVF patients. Next, we consider the other-regarding interests of these patients and conclude that while fresh embryo donation may serve those interests, it does so at unnecessary cost to patients’ self-interests. Lastly, we review some of the potential barriers to the autonomous donation of fresh embryos to research and highlight the risk that female IVF patients invited to donate these embryos will misunderstand key aspects of the donation decision, be coerced to donate, or be exploited in the consent process. On the basis of our analysis, we conclude that patients should not be asked to donate their fresh embryos to stem cell research.

SECTION I

STEM CELL RESEARCH

629-634. NRCBL: 19.5; 14.6; 9.5.5; 18.5.4; 15.1; 4.4; 18.3. SC: le.

Keywords: *embryo research; *embryonic stem cells; *government financing; *legislation; federal government; politics; public policy; research support; Keyword Identifiers: *Stem Cell Research Enhancement Act; *U.S. Congress; *United States

Murray, Fiona. The stem cell market — patents and the pursuit of scientific progress. New England Journal of Medicine 2007 June 7; 356(23): 2341-2343. 4 refs. NRCBL: 18.5.4; 15.1; 1.3.9; 15.8; 19.1.;
Keywords: *biomedical research; *embryonic stem cells; *patents; *research support; *universities; access to information; cell lines; commerce; contracts; embryo research; industry; legal aspects; private sector; publishing; science; Proposed Keywords: technology transfer; Keyword Identifiers: *Wisconsin Alumni Research Foundation; United States; University of Wisconsin

Keywords: *biological specimen banks; *cell lines; *embryo research; *embryonic stem cells; *federal government; *government financing; *public policy; *research support; guidelines; international aspects; registries; Keyword Identifiers: *National Institutes of Health; *United States


Keywords: *embryo research; *embryonic stem cells; *embryos; *Jewish ethics; *moral policy; *moral status; *philosophy; *public policy; *religion; *biomedical research; *embryonic stem cells; *natural law; *personhood; *politics; *secularism; *value of life; Proposed Keywords: embryo death; embryonic development

O’Dowd, Adrian. UK may allow creation of “cybrids” for stem cell research [news]. BMJ: British Medical Journal 2007 March 10; 334(7592): 495. NRCBL: 18.5.4; 15.1; 22.2; 14.5; 18.1; 22.1. SC: le.
Keywords: *chimeras; *embryo research; *embryonic stem cells; *government regulation; public policy; Keyword Identifiers: *Great Britain

Keywords: *cloning; *embryo research; *embryonic stem cells; *embryos; *federal regulations; *government regulation; Key word Identifiers: *Australia

Okarma, Tom. Adult stem cells won’t do. New Scientist 2007 March 10-16; 193(2594): 20. NRCBL: 18.5.1; 15.1; 19.1; 18.5.4.
Keywords: *embryo research; *embryonic stem cells; *government financing; *research support; adult stem cells; federal government; government regulation; industry; politics; public policy; stem cell transplantation; Keyword Identifiers: *United States; National Institutes of Health


Keywords: *embryonic stem cells; *tissue banks; donors; embryos; health services accessibility; incentives; international aspects; justice; mandatory programs; minority groups; moral policy; moral status; organ transplantation; presumed consent; remuneration; required request; risks and benefits; scarcity; stem cell transplantation; voluntary programs; Proposed Keywords: embryo donation

Parry, Sarah. (Re)constructing embryos in stem cell research: exploring the meaning of embryos for people involved in fertility treatments. Social Science and Medicine 2006 May; 62(10): 2349-2359. NRCBL: 18.5.4; 15.1; 14.1; 9.5.5; 18.3.

Keywords: *biomedical research; *embryo research; *embryonic stem cells; *industry; *research support; *researchers; *authorship; *biotechnology; *cell lines; *embryo disposition; *entrepreneurship; *genetic materials; *genetic
patents; motivation; politics; professional autonomy; property rights; research ethics committees; universities; Proposed Keywords: technology transfer; Keyword Identifiers: *Sweden; Cell Therapeutics; Ovacell

Abstract: In this article two inter-related issues concerning the ongoing commercialisation of biomedical research are analyzed. One aim is to explain how scientists and clinicians at Swedish public institutions can make profits, both commercially and scientifically, by controlling rare human biological material, like embryos and embryonic stem cell lines. This control in no way presupposes legal ownership or other property rights as an initial condition. We show how ethically sensitive material (embryos and stem cell lines) have been used in Sweden as a foundation for a commercial stem cell enterprise — despite all official Swedish strictures against commercialisation in this area. We also show how political decisions may amplify the value of controlling this kind of biological material. Another aim of the article is to analyze and discuss the meaning of this kind of academic commercial enterprise in a wider context of research funding strategies. A conclusion that is drawn is that the academic turn to commercial funding sources is dependent on the decline of public funding.


Keywords: *beginning of life; *nuclear transfer techniques; *philosophy; *research embryo creation; *pluripotent stem cells; *Roman Catholic ethics; embryos; methods; personhood; theology; Proposed Keywords: *altered nuclear transfer; Keyword Identifiers: *Aristotle; *Thomas Aquinas

Abstract: The leaders of the resistance against not only ANT-OAR and ANT-Cdx2 but any ANT procedure are two editors of Communio, David Schindler and Adrian Walker. Both scholars offer what they hold to be an Aristotelian-Thomistic objection to any ANT procedure. While many of their intuitions resonate with Aristotelians and Thomists, I do not believe they have represented either the Philosopher or the Common Doctor accurately. This article focuses almost exclusively on the Schindler’s reading of Aristyle and St. Thomas Aquinas to show why his reading of them cannot be used to mount an effective objection against ANT on strictly Aristotelian-Thomistic grounds.

Pittman, Larry J. Embryonic stem cell research and religion: the ban on federal funding as a violation of the establishment clause. University of Pittsburgh Law Review 2006 Fall; 68(1): 131-190. NRCBL: 18.5.4; 15.1; 1.2; 5.3.

Prentice, David A. The whole truth about stem cells and relevant therapies. Today’s Christian Doctor 2007 Summer; 38(2): 21-24. NRCBL: 18.5.1; 18.5.4; 15.1; 14.5.

Keywords: *adult stem cells; *embryo research; *embryonic stem cells; *stem cell transplantation; cloning

Prentice, David A.; Tarne, Gene. Treating diseases with adult stem cells [letter]. Science 2007 January 19; 315(5810): 328. 8 refs. NRCBL: 18.5.1; 15.1; 5.3.

Keywords: *adult stem cells; cancer; clinical trials; embryonic stem cells; government regulation; stem cell transplantation; treatment outcome; Proposed Keywords: *therapeutics; Keyword Identifiers: Food and Drug Administration; United States

Rao, Mahendra S. Are there morally acceptable alternatives to blastocyst derived ESC? Journal of Cellular Biochemistry 2006 August 1; 98(5): 1054-1061. NRCBL: 15.1; 18.5.4; 9.3.1; 19.1.

Rao, Mahendra S. Mired in the quagmire of uncertainty: The “catch-22” of embryonic stem cell research. Stem Cells and Development 2006 August; 15(4): 492-496. NRCBL: 18.5.4; 15.1; 15.8; 5.3; 18.2; 9.3.1.


Keywords: *embryonic stem cells; *human dignity; *moral policy; *moral status; *patents; beginning of life; biotechnology; embryos; ethical analysis; genetic patents; genetically modified organisms; guidelines; historical aspects; human characteristics; legal aspects; natural law; stem cells; terminology; value of life; Proposed Keywords: *multipotent stem cells; *pluripotent stem cells; *totipotent stem cells; blastocysts; classification; Keyword Identifiers: Europe; Twentieth Century; United States

Abstract: This article examines the assertion that human embryonic stem cells patents are immoral because they violate human dignity. After analyzing the concept of human dignity and its role in bioethics debates, this article argues that patents on human embryos or totipotent embryonic stem cells violate human dignity, but that patents on pluripotent or multipotent stem cells do not. Since patents on pluripotent or multipotent stem cells may still threaten human dignity by encouraging people to treat embryos as property, patent agencies should carefully monitor and control these patents to ensure that patents are not inadvertently awarded on embryos or totipotent stem cells.


Keywords: *embryonic stem cells; *government regulation; *international aspects; cloning; cross-cultural comparison; embryos; ethical review; government financing; guidelines; legal aspects; public policy; reproductive technologies; research support; stem cells; Keyword Identifiers: *Canada; *Japan

Robert, Jason Scott. The science and ethics of making part-human animals in stem cell biology. FASEB Journal: Official Publication of the Federation of American Societies for Experimental Biology 2006 May; 20(7): 838-845. 50 refs. NRCBL: 15.1; 18.1; 22.1; 18.5.4; 5.3. SC: rv.
Key words: *chimeras; *embryonic stem cells; brain; embryo research; ethical review; fetal stem cells; guidelines; historical aspects; human dignity; moral policy; moral status; primates; public policy; regulation; research design; research ethics; review committees; risks and benefits; species specificity; stem cell transplantation; terminology; Proposed Keywords: mice; Keyword Identifiers: National Academy of Sciences; Nineteenth Century; Twentieth Century; United States

Romano, Gaetano. Perspectives and controversies in the field of stem cell research. Drug News and Perspectives 2006 September; 19(7): 433-439. NRCBL: 18.5.4; 15.1; 18.5.1; 18.2.


Keywords: *biological specimen banks; *cell lines; *embryonic stem cells; *guidelines; *standards; embryo research; ethical review; fetal research; informed consent; organizational policies; physicians; professional organizations; stem cells; Keyword Identifiers: *Royal College of Obstetricians and Gynaecologists (Great Britain); Great Britain

Rusnak, A.J.; Chudley, A.E. Stem cell research: cloning, therapy and scientific fraud. Clinical Genetics 2006 October; 70(4): 302-305. NRCBL: 15.1; 14.5; 1.3.9; 18.5.1.


Keywords: *embryonic stem cells; *legal aspects; *patents; *regulation; international aspects; Keyword Identifiers: *Europe; European Group on Ethics in Science and New Technologies; European Patent Convention; European Patent Office; European Union


Schiltz, Elizabeth R. The disabled Jesus: a parent looks at the logic behind prenatal testing and stem cell research. America 2007 March 12; 196(9): 16-18. NRCBL: 15.3; 18.5.4; 1.2.

Keywords: *embryo research; *embryonic stem cells; *pre-natal diagnosis; *Roman Catholic ethics; *value of life; adult stem cells; attitudes; choice behavior; congenital disorders; Down syndrome; embryos; eugenics; mentally disabled persons; preimplantation diagnosis; quality of life; risks and benefits; selective abortion; Proposed Keywords: autistic disorder


Keywords: *cryopreservation; *embryo research; *embryonic stem cells; *embryos; in vitro fertilization; Proposed Keywords: blastomeres


Keywords: *biotechnology; *cloning; *genetic materials; *genetic patents; *legal aspects; *stem cells; DNA sequences; embryo research; genes; genetic engineering; germ cells; international aspects; reproductive technologies; Keyword Identifiers: Europe; United States

Sinclair, Andrew H.; Schofield, Peter R. Human embryonic stem cell research: an Australian perspective. Cell 2007 January 26; 128(2): 221-223. NRCBL: 18.2; 18.5.4; 15.1; 1.3.5.

Smith, Shane; Neaves, William; Teitelbaum, Steven; Prentice, David A.; Tarne, Gene. Adult versus embryonic stem cells: treatments [letter and reply]. Science 2007 June 8; 316(5830): 1422-1423. 22 refs. NRCBL: 18.5.1; 15.1; 18.5.4; 18.2.
Keywords: *adult stem cells; *embryonic stem cells; *stem cell transplantation; *treatment outcome; clinical trials; embryonic research; Proposed Keywords: *therapeutics

**Somerville, Margaret A.** The importance of empirical research in bioethics: the case of human embryonic stem cell research = Importance de la recherche empirique en bioéthique: cas de la recherche sur les cellules souches embryonnaires humaines [editorial]. *JOGC: Journal of Obstetrics and Gynaecology Canada* = *JOGC: Journal d’Obstétrique et Gynécologie du Canada* 2005 October; 27(10): 929-932. NRCBL: 18.5.4; 15.1; 18.3; 2.1.


**Spar, Debora; Harrington, Anna.** Selling stem cell science: how markets drive law along the technological frontier. *American Journal of Law and Medicine* 2007; 33(4): 541-565. NRCBL: 18.5.4; 15.1; 18.6; 5.3; 11.1; 14.4. SC: le.


Keywords: *embryo research; *embryonic stem cells; *embryos; *moral policy; *moral status; abortion; beginning of life; cadavers; ethical analysis; human characteristics; killing; nuclear transfer techniques; personhood; public policy; research embryo creation; species specificity; stem cells; twinning; values; Proposed Keywords: altered nuclear transfer; embryo death; pluripotent stem cells; sentence

**Swift, Jennifer.** Eggs don’t come cheap. *New Scientist* 2007 December 8-14; 196(2633): 22. NRCBL: 14.5; 14.2; 19.5; 18.5.3; 18.5.4; 15.1; 9.5.5.

Keywords: *cloning; *ovum donors; *research embryo creation; *risk; *stem cells; adverse effects; conflict of interest; hormones; nontherapeutic research; remuneration; risks and benefits; women; Proposed Keywords: pluripotent stem cells

**Takala, Tuja; Häyry, Matti.** Benefiting from past wrongdoing, human embryonic stem cell lines, and the fragility of the German legal position. *Bioethics* 2007 March; 21(3): 150-159. 50 fn. NRCBL: 18.5.4; 15.1; 19.5; 1.1. SC: an; le.

Keywords: *cell lines; *embryo research; *embryonic stem cells; *ethical analysis; *legislation; *moral complicity; *moral policy; aborted fetuses; commerce; commodification; dehumanization; embryo disposition; embryos; government regulation; historical aspects; in vitro fertilization; international aspects; morality; National Socialism; ovum donors; policy analysis; public policy; scientific misconduct; Keyword Identifiers: *Germany; *Stem Cell Act 2002 (Germany)

Abstract: This paper examines the logic and morality of the German Stem Cell Act of 2002. After a brief description of the law’s scope and intent, its ethical dimensions are analysed in terms of symbolic threats, indirect consequences, and the encouragement of immorality. The conclusions are twofold. For those who want to accept the law, the arguments for its rationality and morality can be sound. For others, the emphasis on the uniqueness of the German experience, the combination of absolute and qualified value judgments, and the lingering questions of indirect encouragement of immoral activities will probably be too much.


Keywords: *embryonic stem cells; *embryos; *moral status; *value of life; beginning of life; cloning; ethical analysis; embryo research; morality; non-Western World; personhood; teleological ethics; wedge argument; Proposed Keywords: blastocysts; Keyword Identifiers: Africa


Keywords: *embryonic stem cells; *methods; *research embryo creation; advisory committees; alternatives; beginning of life; Christian ethics; dissent; embryos; Keyword Identifiers: *Hurlbut, William; President’s Council on Bioethics

**Tong, Rosemary.** Stem-cell research and the affirmation of life. *Conscience* 2007 Autumn; 28(3): 19-23. NRCBL: 18.5.4; 15.1; 4.4; 1.2; 7.1.

**Trivedi, Bijal.** Researchers detour around stem-cell rules. *Chronicle of Higher Education* 2007 October 3; 54(6): A12-A15. NRCBL: 18.5.4; 15.1; 18.6; 19.5.

Keywords: *embryos; *legal aspects; *stem cells; alternatives; *cell lines; *embryo research; *methods; *Keyword Identifiers: *United States


Keywords: *embryo research; *embryonic stem cells; *legal aspects; *Keyword Identifiers: *United States


Keywords: *embryos; *legal aspects; *stem cells; alternatives; *cell lines; *embryo research; *methods; *Keyword Identifiers: *United States


Keywords: *legal aspects; *stem cells; alternatives; *embryos; *legal aspects; *research ethics; *informed consent; *research ethics committees; *Keyword Identifiers: *United States


Keywords: *embryonic stem cells; *embryo research; *government financing; *legal aspects; *research support; *stem cells; adult stem cells; alternatives; *cell lines; *embryos; *informed consent; *research ethics; *Keyword Identifiers: *United States


Keywords: *embryo research; *embryonic stem cells; *adult stem cells; *research ethics; *government financing; *public policy; *research ethics; *Keyword Identifiers: *United States

Keywords: *embryo research; *legal aspects; *public policy; *stem cells; adult stem cells; alternatives; cloning; embryonic stem cell; embryonic stem cells; federal government; government financing; methods; research support; value of life; Keyword Identifiers: *United States; President’s Council on Bioethics


Wadman, Meredith. Stem-cell issue moves up the US agenda [news]. *Nature* 2007 April 19; 446(7138): 842. NRCBL: 18.5.4; 15.1. SC: le.

Keywords: *embryo research; embryonic stem cells; *government financing; *legal aspects; *research support; cell lines; federal government; legislation; politics; Keyword Identifiers: *United States; Stem Cell Research Enhancement Act 2007; U.S. House of Representative; U.S. Senate

Wainwright, Steven; Williams, Clare; Michael, Mike; Farsides, Bobbie; Cribb, Alan. Remaking the body? Scientists’ genetic discourses and practices as examples of changing expectations on embryonic stem cell therapy for diabetes. *New Genetics and Society* 2007 December; 26(3): 251-268. NRCBL: 18.5.4; 15.1.


Keywords: *embryo research; embryonic stem cells; Roman Catholic ethics; embryos; government financing; moral status; public policy; research support; theology


Keywords: *embryo research; embryonic stem cells; *government financing; *public policy; research support; government financing; politics; Keyword Identifiers: *Roman Catholic ethics; embryos; government financing; moral status; public policy; research support; theology


Keywords: *embryonic stem cells; research embryo creation; *methods; public policy; research support; government financing; Keyword Identifiers: United States

Hoglada

Huang, Nicole; Shih, Shu-Fang; Chang, Hsing-Yi; Chou, Yiing-Jeng. Record linkage research and informed consent: who consents? BMC Health Services Research 2007 February 12; 7: 18. NRCBL: 1.3.12; 8.3.1. Identifiers: Great Britain (United Kingdom).


McCubbin, Caroline N. Legal and ethical-legal issues in e-healthcare research projects in the UK. Social Science and Medicine 2006 June; 62(11): 2768-2773. NRCBL: 1.3.12; 18.2; 18.6. Identifiers: Great Britain (United Kingdom).


TERMINAL CARE. See DEATH AND DYING/ TERMINAL CARE

TERMINALLY ILL. See DEATH AND DYING/ TERMINAL CARE; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ AGED AND TERMINALLY ILL

TERRORISM. See WAR AND TERRORISM

TEST TUBE FERTILIZATION. See IN VITRO FERTILIZATION

THERAPEUTIC RESEARCH. See HUMAN EXPERIMENTATION
TREATMENT REFUSAL

Section I

Right to refuse treatment: prisoner’s claim that conditioning eligibility for parole on taking potentially medically inappropriate medication violated his due process rights is not frivolous. Journal of the American Academy of Psychiatry and the Law 2007; 35(2): 260-262. NRCBL: 8.3.4; 17.4; 1.3.5; 20.5.1; 7.1. Identifiers: Hans Münch.


Crosby, Sondra S.; Apovian, Caroline M.; Grodin, Michael A. Hunger strikes, force-feeding, and physicians’ responsibilities. JAMA: The Journal of the American Medical Association 2007 August 1; 298(5): 563-566. NRCBL: 8.3.4; 17.4; 4.1.2; 8.1.


Hord, Jeffrey D.; Rehman, Waqas; Hannon, Patricia; Anderson-Shaw, Lisa; Schmidt, Mary Lou. Do parents have the right to refuse standard treatment for their child with favorable-prognosis cancer? Ethical and legal concerns. Journal of Clinical Oncology 2006 December 1; 24(34): 5454-5456. NRCBL: 8.3.4; 8.3.2; 9.5.1; 9.5.7. SC: le.


Levins, Susan. Teen leaves “his only hope” behind in U.S. After 20 months, 14-year-old with leukemia returns home, saying no more chemotherapy or bone marrow transplants. Washington Post 2007 January 11; p. B1, B5. NRCBL: 8.3.4; 9.5.7. SC: po. Identifiers: Kabir Sekhri; India.


Orr, Robert D.; Craig, Debra. Old enough [case study and commentaries]. Hastings Center Report 2007 November-December; 37(6): 15-16. NRCBL: 8.3.4; 8.3.2; 19.4; 8.1; 1.2. SC: cs; le.


Abstract: When there is a conflict between parents and the physician over appropriate care due to an infant whose decision prevails? What standard, if any, should guide such decisions?This article traces the varying standards articulated over the past three decades from the proposal in Duff and Campbell’s 1973 essay that these decisions are best left to the parents to the Baby Doe Regs of the 1980s which required every life that could be salvaged be continued. We conclude with support for the policy articulated in the 2007 guidelines of the American
Academy of Pediatrics on non-intervention or withdrawal of intensive care for high-risk newborns.


Pence, Gregory E. The refusal of treatment in anorexia nervosa. Journal of the American Academy of Psychiatry and the Law 2007; 35(1): 118-120. NRCBL: 17.8; 1.3.5; 8.3.3; 8.3.4; 9.5.3; 17.1. SC: em.


Kaplan, This S. The refusal of treatment in anorexia nervosa, an ethical conflict with three characters: “the girl, the family and the medical profession”. Discussion in a French legislative context. Diabetes and Metabolism 2006 September; 32(4): 306-311. NRCBL: 8.3.4; 8.3.2; 20.5.2; 8.1; 4.1.2; 1.1. SC: le. Note: Abstract in French.

White, Ben; Willmott, Lindy. Will you do as I ask? Compliance with instructions about health care in Queensland. Queensland University of Technology Law and Justice Journal 2004; 4(1): 77-87. NRCBL: 8.3.4; 8.3.3; 20.5.4. SC: le.

TRUTH DISCLOSURE


Ambrose, Ella Grace. Placebos: the nurse and the iron pills. Journal of Medical Ethics 2007 June; 33(6): 325-328. NRCBL: 8.2; 4.1.3; 21.1. Identifiers: Africa. Abstract: In sub-Saharan Africa, a nurse gives iron pills as placebos to terminally ill patients. She tells them, act-
ing in what she believes is in their best interests; “these will make you feel better”. The patients believe it will help their AIDS and their well-being improves. Do the motive and the patient’s positive outcome in well-being make the deceit justifiable when other issues such as consent, autonomy and potential consequences regarding the patient and the wider community are considered? Is there a difference between lying and non-lying deception when the end result is the same? The patients feel better, but at what cost if the deceit was found out? It will be argued that although the actions of the nurse are understandable and to some extent defensible, they are unethical. It is not ethically acceptable to take away the patient’s autonomy and risk the health of the community even though the risk of deceit being discovered is a small one.

Ausman, James I. Trust, malpractice, and honesty in medicine: should doctors say they are sorry? Surgical neurology 2006 July; 66(1): 105-106. NRCBL: 8.2; 8.1; 8.5.

Ayers, Tressie A. Dutchyn. A partnership in like-minded thinking generating hopefulness in persons with cancer. Medicine, Health Care and Philosophy 2007 March; 10(1): 65-80. NRCBL: 8.2; 9.5.1; 1.1; 8.1; 20.4.1.

Abstract: A conceptual model of a partnership in ‘like-minded thinking’ consists of the following components: a relationship, a shared goal with mutual agreement to work toward that goal, and reciprocal encouragement between two people. A like-minded alliance is a relationship that offers support while at the same time encourages hope and establishes a reciprocating emotional attitude of hopefulness. The discussion focuses on the principles of such a model that is designed primarily as a lay intervention for anyone who has a close friend with cancer and who wants to assist the friend in maintaining a hopeful attitude in the face of illness. While this model is not directed at healthcare professionals it may be transferable into psychosocial interventions to assist persons toward sustaining hopefulness in the context of the cancer trajectory. Much has been written in the literature about how hopelessness spawns despair for individuals who have cancer and in those near the end of life; it may even create a desire for hastened death (Breitbart W., Heller K.S.: 2003, “Reframing Hope: Meaning-Centered Care for Patients Near the End of Life”. Journal of Palliative Medicine 6, 979-988; Jones J.M., Huggins M.A., Rydall A.C., Rodin G.M.: 2003, “Symptomatic distress, hopelessness, and the desire for hastened death in hospitalized cancer patients”, Journal of Psychosomatic Research 55, 411-418). Therefore, the aim of this paper is to explore how like-minded thinking for a person with cancer and his or her support person provides a framework for a personal shared worldview that is hope-based, meaningful and coherent.

Back, Anthony L.; Arnold, R.M. Discussing prognosis: “how much do you want to know?” talking to patients who do not want information or who are ambivalent. Journal of Clinical Oncology 2006 September 1; 24(25): 4214-4217. NRCBL: 8.2; 8.1; 9.5.1.


Derksen, E.; Vernooij-Dassen, M.; Gillissen, F.; Olde Rikkert, M.; Scheltens, P. Impact of diagnostic disclosure in dementia on patients and carers: qualitative case series analysis. Aging and Mental Health 2006 September; 10(5): 525-531. NRCBL: 8.2; 8.3.3; 9.5.2; 8.1; 17.1.


Abstract: Using a fictional but representative general practice consultation, involving the diagnosis of irritable bowel syndrome in a patient who is anxious for some relief from the discomfort his condition entails, this paper argues that when both (a) a drug fails to out-perform placebo and (b) the condition in question is a functional illness with no demonstrable underlying pathology, then the action of the drug is not only no better than placebo, and it is also no different from it either. The paper also argues that, in the circumstances of the consultation described, it is striking that current governance deems it unethical for a practitioner to prescribe either a drug or a placebo, both of which appear to rely for their effectiveness on a measure of concealment on the part of the doctor, yet deems it unethical for a practitioner openly to prescribe a harmless and enjoyable substance which (in equivalent conditions of transparency and information) is likely to be no less effective than either drug or placebo and is also likely to be better-tolerated and cheaper than the drug.

SECTION I

TRUTH DISCLOSURE

Helgesson, Gert; Eriksson, Stefan; Swartling, Ulrica. Limited relevance of the right not to know — reflections on a screening study. *Accountability in Research* 2007 July-September; 14(3): 197-209. NRCBL: 8.2; 9.5.7; 18.5.2; 9.1. SC: an; em. Identifiers: Sweden.

Abstract: The right not to know personal health-related information has been included in prominent human rights documents and subsequently in national legislation since the middle of the 1990s. Apart from situations where another life is at stake, the right not to know has in these documents been formulated as if it should have precedence over other interests. This article argues against giving the right not to know such a prominent position. It does so by questioning the ethical relevance of the concept for both theoretical and empirical reasons. The main focus of the article is on empirical data from a prospective population screening for Type I diabetes. Data indicate that researchers are not as autonomous as is generally assumed by the defenders of the right not to know.


Jotkowitz, A.; Glick, Shimon; Gezundheit, B. Truth-telling in a culturally diverse world. *Cancer Investigation* 2006 December; 24(8): 786-789. NRCBL: 8.2; 8.1; 7.1; 21.7.

Kendall, Sharon. Being asked not to tell: nurses’ experiences of caring for cancer patients not told their diagnosis. *Journal of Clinical Nursing* 2006 September; 15(9): 1149-1157. NRCBL: 8.2; 9.5.1; 7.1; 8.1; 21.7.


Abstract: This paper examines the potential role of metaphors in helping healthcare professionals to communicate honestly with patients and in helping patients gain a richer and more nuanced understanding of what is being explained. One of the ways in which doctors and nurses may intentionally, or unintentionally, avoid telling the truth to patients is either by using metaphors that obscure the truth or by failing to deploy appropriately powerful and revealing metaphors in their discussions. This failure to tell the truth may partly account for the observation by clinicians that patients sometimes make decisions that, from the perspective of their clinician, and given all that the clinician knows, seem unwise. For example, patients with advanced cancer may choose to undergo further, aggressive, treatment despite the fact that they are likely to accrue little or no benefit as a result. While acknowledging that the immediate task of telling patients the truth can be difficult for all those concerned, I argue that the long-term consequences of denying patients autonomy at the end of life can be harmful to patients and can leave doctors and nurses distressed and confused.


Lee, A.; Wu, H.Y. Diagnosis disclosure in cancer patients — when the family says “no!”. *Singapore Medical Journal* 2002 October; 43(10): 533-538. NRCBL: 8.2; 8.1; 20.3.1; 20.3.3; 21.1. SC: rv.

Mack, Jennifer W.; Wolfe, Joanne; Grier, Holcombe E.; Cleary, Paul D.; Weeks, Jane C. Communication about prognosis between parents and physicians of children with cancer: parent preferences and the impact of prognostic information. *Journal of Clinical Oncology* 2006 November 20; 24(33): 5265-5270. NRCBL: 8.2; 8.3.2; 9.5.1; 9.5.7. SC: em.


Nelson, William A.; Campfield, Justin. Ethical implications of transparency. Valid justification is required when withholding information. *Healthcare Executive* 2006 November-December; 21(6): 33-34. NRCBL: 8.2; 7.1; 8.3.1; 9.3.1.


Rockwell, Lindsay E. Truth telling. *Journal of Clinical Oncology* 2007 February 1; 25(4): 454-455. NRCBL: 8.2; 9.5.1; 20.3.2.

Sheu, Shuh-Jen; Huang, Shu-He; Tang, Fu-In; Huang, Song-Lih. Ethical decision making on truth telling in terminal cancer: medical students' choices between patient autonomy and family paternalism. *Medical Education* 2006 June; 40(6): 590-598. NRCBL: 8.2; 7.2; 8.1; 9.5.1.


Sokol, Daniel K. How the doctor’s nose has shortened over time; a historical overview of the truth-telling debate in the doctor-patient relationship. *Journal of the Royal Society of Medicine* 2006 December; 99(12): 632-636. NRCBL: 8.2; 8.1; 2.2.


Wright, Linda; MacRae, Susan; Gordon, Debra; Elliot, Esther; Dixon, David; Abbey, Susan; Richardson, Robert. Disclosure of misattributed paternity: issues involved in the discovery of unsought information. *Seminars in Dialysis* 2002 June; 15(3): 202-206. NRCBL: 8.2; 19.5. SC: cs.

**UMBILICAL CORD BLOOD** See BLOOD BANKING, DONATION, AND TRANSFUSION

**VALUE OF LIFE** See QUALITY AND VALUE OF LIFE

**WAR AND TERRORISM**

See also TORTURE, GENOCIDE, AND WAR CRIMES


Green, Colin; Khan, Asad; Karmi, Ghada; Burns-Cox, Chris; Birnstingl, Martin; Halpin, David; Summerfield, Derek. Medical ethical violations in Gaza. *Lancet* 2007 December 22-2008 January 4; 370(9605): 2102. NRCBL: 21.2; 21.4; 7.4; 7.3.


Kaebnick, Gregory E. Secrets and open societies [editorial]. *Hastings Center Report* 2007 May-June; 37(3): 2. NRCBL: 21.3; 1.3.9; 1.3.7; 5.3. Identifiers: national security.


SECTION I WAR AND TERRORISM


Keywords: *biological sciences; biomedical research; bioterrorism; ethical analysis; moral policy; biological warfare; decision making; freedom; genetically modified organisms; government regulation; guidelines; information dissemination; international aspects; microbiology; philosophy; policy analysis; property rights; public health; public policy; publishing; researchers; risk; risks and benefits; science; self regulation; synthetic biology; Proposed Keywords: viruses; Keyword Identifiers: Biological Weapons Convention; National Biodefense Analysis and Countermeasures Center, United States


Tyshenko, Michael G. Management of natural and bioterrorism induced pandemics. *Bioethics* 2007 September; 21(7): 364-369. 31 fn. NRCBL: 21.3; 9.1; 15.1; 5.3.

Keywords: biological warfare; biotechnology; bioterrorism; genetic engineering; historical aspects; public health; resource allocation; risk; social control; world health

Abstract: A recent approach for bioterrorism risk management calls for stricter regulations over biotechnology as a way to control subversion of technology that may be used to create a man-made pandemic. This approach is largely unworkable given the increasing pervasiveness of molecular techniques and tools throughout society. Emerging technology has provided the tools to design much deadlier pathogens but concomitantly the ability to respond to emerging pandemics to reduce mortality has also improved significantly in recent decades. In its historical context determining just how ‘risky’ biological weapons is an important consideration for decision making and resource allocation. Management should attempt to increase capacity, share resources, provide accurate infectious disease reporting, deliver information transparency and improve communications to help mitigate the magnitude of future pandemics.


WITHHOLDING TREATMENT See EUTHANASIA AND ALLOWING TO DIE

WOMEN See CARE FOR SPECIFIC GROUPS/ WOMEN; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ WOMEN

WRONGFUL BIRTH See CONTRACEPTION

XENOTRANSPLANTATION See ORGAN AND TISSUE TRANSPLANTATION/ XENOTRANSPLANTATION

NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.
SECTION II:
PERIODICAL LITERATURE
AND ESSAYS

AUTHOR INDEX
Section II: Periodical Literature and Essays
Author Index

A

Aagaard-Hansen, Jens; Johansen, Maria Vang; Riis, Pols. Research ethical challenges in cross-disciplinary and cross-cultural health research: the diversity of codes. *Danish Medical Bulletin* 2004 February; 51(1): 117-120. Subject: 18.2


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Acquavella, John F. Why focus only on financial interests? *Epidemiology* 2006 May; 17(3): 248-249. Subject: 1.3.9


Adams, Jared R.; Drake, Robert E.; Wolford, George L. Shared decision-making preferences of people with severe mental illness. *Psychiatric Services* 2007 September; 58(9): 1219-1221. Subject: 8.1


Adams, Karen E. What’s “normal”: female genital mutilation, psychology, and body image. *Journal of the American Medical Women’s Association* 2004 Summer; 59(3): 168-170. Subject: 9.5.5


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Addelson, Kathryn Pyne. The emergence of the fetus. *In:* Mui, Constance L.; Murphy, Julien S., eds. *Gender Struggles: Practical Approaches to Contemporary Feminism.* Lanham, MD: Rowman & Littlefield Pub., 2002: 118-136. Subject: 9.5.8

Adkins, Jason A. Meet me at the (West Coast) hotel: the Lochner Era and the demise of Roe v. Wade. *Specialty Law Digest: Health Care Law* 2007 July; (339): 9-43. Subject: 12.4.1


Adrian, Manuella. Decisions involving research and ethics: misusing drug use(r) statistics. *In:* Kleinig, John; Einstein, Stanley, eds. *Ethical Challenges for Intervening in Drug Use: Policy, Research and Treatment Issues.* Huntsville, TX: Office of International Criminal Justice; Criminal Justice Center, Sam Houston State University, 2006: 217-258. Subject: 1.3.9


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Subject = NRCBL Primary Classification Number; see inside front cover.


Alonzi, Andrew; Pringle, Mike. Mental Capacity Act 2005 should guide doctors to help protect vulnerable people [editorial]. BMJ: British Medical Journal 2007 November 3; 335(7626): 898. Subject: 8.3.3


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Subject = NRCBL Primary Classification Number; see inside front cover.


Anand, K.J.S.; Aranda, Jacob V.; Berde, Charles B.; Buckman, ShaAvhreé; Capparelli, Edmund V.; Carlo, Waldemar A.; Hummel, Patricia; Lantos, John; Johnston, C. Celeste; Lehr, Victoria Tutag; Lynn, Anne M.; Maxwell, Lynne G.; Oberlander, Tim F.; Raju, Tonse N.K.; Soriano, Sulipcio G.; Taddio, Anna; Walco, Gary A. Analgesia and anesthesia for neonates: study design and ethical issues. *Clinical Therapeutics* 2005 June; 27(6): 814-843. Subject: 18.5.2


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Arnold, Robert; Bartlett, Steven; Bernat, James; Colonna, John; Dafoe, Donald; Dubler, Nancy; Gruber, Scott; Kahn, Jeffrey; Luskin, Richard; Nathan, Howard; Orloff, Susan; Pottas, Jeffrey; Shapiro, Robyn; Ricordi, Camillo; Youngner, Stuart; Delmonico, Francis L. Financial incentives for cadaver organ donation: an ethical reappraisal. Transplantation 2002 April 27; 73(8): 1361-1367. Subject: 19.5


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Messing with home brews. Political moves to expand FDA oversight to home brews are a bad idea. [editorial]. *Nature Biotechnology* 2007 March; 25(3): 262. Subject: 15.3

Mohler would favor altering ‘gay’ fetus [news]. *Christian Century* 2007 April 3; 124(7): 15. Subject: 15.2


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NIH to make chimpanzee breeding moratorium permanent [news]. *ATLA: Alternatives to Laboratory Animals* 2007 June; 35(3): 300. Subject: 22.2


Timeout, not the final buzzer, in the stem cell debate [editorial]. *Lancet* 2007 December 1-7; 370(9602): 1802. Subject: 18.5.1


Uninformed consent? The US should revamp rules on informed consent to ensure that people have all the information and support they need before deciding to enroll in clinical trials [editorial]. *Nature Medicine* 2007 September; 13(9): 999. Subject: 18.3


Vatican clarifies position on artificial nutrition [news]. *America* 2007 October 1; 197(9): 6. Subject: 20.5.1

When in doubt, disclose [editorial]. *Lancet* 2007 February 3-9; 369(9559): 344. Subject: 1.3.9


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SUBJECT ENTRIES

1.1 PHILOSOPHICAL ETHICS


1.2 RELIGIOUS ETHICS


Sorajjako, Siroj. WHEN SICKNESS HEALS: THE PLACE OF RELIGIOUS BELIEF IN HEALTHCARE. Philadelphia:
1.3.1 APPLIED AND PROFESSIONAL ETHICS: GENERAL


1.3.1 APPLIED AND PROFESSIONAL ETHICS: GENERAL


Pritchard, Michael S. PROFESSIONAL INTEGRITY: THINKING ETHICALLY. Lawrence: University Press of Kansas, 2006. 195 p. ISBN 0-7006-1446-X. [BJ1725 .P752 2006] (1.3.1; 1.3.2; 1.3.4; 4.1.1; 6)

1.3.2 APPLIED AND PROFESSIONAL ETHICS: BUSINESS


1.3.3 APPLIED AND PROFESSIONAL ETHICS: EDUCATION


1.3.4 APPLIED AND PROFESSIONAL ETHICS: ENGINEERING


1.3.5 APPLIED AND PROFESSIONAL ETHICS: GOVERNMENT/ CRIMINAL JUSTICE


1.3.6 APPLIED AND PROFESSIONAL ETHICS: INTERNATIONAL AFFAIRS


1.3.7 APPLIED AND PROFESSIONAL ETHICS: JOURNALISM/ MASS MEDIA


1.3.9 APPLIED AND PROFESSIONAL ETHICS: SCIENTIFIC RESEARCH

Eaton, Margaret L. and Kennedy, Donald. INNOVATION IN MEDICAL TECHNOLOGY: ETHICAL ISSUES AND CHALLENGES. Baltimore, MD: Johns Hopkins University Press, 2007. 155 p. ISBN 978-0-8018-8526-4. (Gift of the publisher.) [R855.3 .E28 2007] (1.3.9; 2.2; 5.1; 5.2; 9.7; 14.1; 18.1)


Oliver, Paul. THE STUDENT’S GUIDE TO RESEARCH ETHICS. Maidenhead, UK/New York: Open University Press, 2003. 156 p. ISBN 0-335-21087-2. [Q180.55 .M67 O38 2003] (1.3.9; 1.3.7; 5.3; 8.4; 18.2; 18.3)

Wagner, Wendy and Steinhorn, Rena, eds. RESCuing SCIENCE FROM POLITICS: REGULATION AND THE DISTORTION OF SCIENTIFIC RESEARCH. Cambridge/New York: Cambridge University Press, 2006. 304 p. ISBN 0-521-54009-7. (Gift of the publisher.) [Q125 .R4178 2006] (1.3.9; 1.3.5; 1.3.7; 5.3; 9.7; 16.1; 21.1)
1.3.10 APPLIED AND PROFESSIONAL ETHICS: SOCIAL WORK


1.3.11 APPLIED AND PROFESSIONAL ETHICS: AGRICULTURE


1.3.12 APPLIED AND PROFESSIONAL ETHICS: INFORMATION TECHNOLOGY


Pourciau, Lester. ETICS AND ELECTRONIC INFORMATION IN THE TWENTY-FIRST CENTURY. West Lafayette, IN: Purdue University Press, 1999. 334 p. ISBN 1-55753-138-2. [T58.5 .E77 1999] (1.3.12; 1.1; 1.3.2; 5.3; 8.4; 15.10)


2.1 BIOETHICS (GENERAL)


2.1 BIOETHICS (GENERAL) SECTION III


Gunning, Jennifer and Holm, Søren, eds. ETHICS, LAW AND SOCIETY, VOLUME I. Aldershot, England/Burlington, VT: Ashgate, 2005. 280 p. ISBN 0-7546-4583-5. [BJ1581.2 .E85 2005 v.1] (2.1; 1.3.2; 1.3.7; 1.3.9; 1.3.11; 1.3.12; 9.3.1; 9.6; 9.8; 14.1; 14.5; 15.8; 16.1; 17.1; 19.5; 20.1; 21.1)

Gunning, Jennifer and Holm, Søren, eds. ETHICS, LAW AND SOCIETY, VOLUME II. Aldershot, England/Burlington, VT: Ashgate, 2006. 326 p. ISBN 978-0-7546-4881-9; ISBN 0-7546-4881-8. (Gift of the publisher.) [BJ1581.2 .E85 2005 v.2] (2.1; 1.3.1; 1.3.2; 1.3.7; 1.3.9; 1.3.11; 5.3; 9.5.7; 9.7; 14.1; 15.1; 17.1; 18.1; 18.5.1; 19.2; 21.1; 21.3; 21.4)

Hall, Mark A.; Bobinski, Mary Anne; and Orentlicher, David. BIOETHICS AND PUBLIC HEALTH LAW. New York: Aspen Publishers, 2005. 601 p. ISBN 0-7355-5205-3. [KF3775 .A7 H34 2005] (2.1; 8.1; 8.3.1; 9.1; 9.4; 14.1; 15.1; 19.6; 20.5.1)


Hervé, Christian; Knoppers, Bartha Maria; Molinari, Patrick A.; and Moutel, Grégoire, eds. PLACE DE LA BIOÉTHIQUE EN RECHERCHE ET DANS LES SERVICES CLINIQUES. Paris: Dalloz , 2005. 215 p. ISBN 2-247-06003-X. (Themes & commentaires series. Actes series. Institut international de recherche en éthique biomédicale [IIREB], Séminaire d’experts, Université René-Descartes (Paris V), held 4-5 December 2003 in Paris.) (2.1; 8.1; 18.1; 18.2)


Howard, Philip and Bogle, James. MEDICAL LAW AND ETHICS. Malden, MA: Blackwell, 2005. 204 p. ISBN 1-4051-1868-7. (Lecture Notes series.) [R724 .H69 2005] (2.1; 4.3; 7.3; 8.3.1; 8.4; 12.4.1; 14.2; 20.5.1)

2.1 BIOETHICS (GENERAL)


Jackson, Julia. ETHICS, LEGAL ISSUES, AND PROFESSIONALISM IN SURGICAL TECHNOLOGY. Clifton Park, NY: Delmar Learning, 2007. 368 p. ISBN 978-1-4018-5793-6; ISBN 1-4018-5793-0. (Gift of the publisher.) [RD32.3 .J33 2007] (2.1; 1.1; 1.3.1; 2.3; 4.2.1; 6; 9.1)


Lo, Bernard. RESOLVING ETHICAL DILEMMAS: A GUIDE FOR CLINICIANS. Philadelphia: Lippincott Williams & Wilkins, 2005. 309 p. ISBN 0-7817-5357-0. (Third edition.) [RD32.3 .L59 2005] (2.1; 4.3; 7.4; 8.1; 8.2; 8.3; 8.3.3; 8.4; 9.1; 9.4; 9.6; 9.7; 15.3; 17.1; 19.1; 20.2.1; 20.5.1; 20.7)


Mahowald, Mary Briody. BIOETHICS AND WOMEN: ACROSS THE LIFE SPAN. Oxford/New York: Oxford University Press, 2006. 272 p. ISBN 978-0-19-517617-9; ISBN 0-19-517617-0. (Gift of the publisher.) [R725 .M34 2006] (2.1; 1.1; 8.1; 9.5.2; 9.5.5; 9.5.7; 14.1; 15.2; 15.3; 18.5.3; 20.4.1)


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Spilman, Bethany J. BIOETHICS IN LAW. Totowa, NJ: Humana Press, 2007. 181 p. ISBN 978-1-58829-434-0; ISBN 1-58829-434-X. [KF3821 .S687 2007] (2.1; 1.3.5; 1.3.7; 1.3.8; 2.3; 2.4; 9.6; 18.2)


3.1 PHILOSOPHY OF BIOLOGY (GENERAL)


3.2 EVOLUTION AND CREATION


4.1.1 PHILOSOPHY OF THE HEALTH PROFESSIONS (GENERAL)


4.1.2 PHILOSOPHY OF MEDICINE


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4.3 CONCEPT OF MENTAL HEALTH


4.4 QUALITY/ VALUE OF LIFE/PERSONHOOD


4.4 QUALITY/ VALUE OF LIFE/PERSONHOOD


Deane-Drummond, Celia and Scott, Peter Manley, eds. FUTURE PERFECT? GOD, MEDICINE AND HUMAN IDENTITY. London/New York: T&T Clark International, 2006. 219 p. ISBN 0-567-03079-2. (Gift of the publisher.) [QH438.7 .L68 2006] (4.4; 1.2; 2.1; 4.5; 5.1; 9.5.2; 15.1; 17.1; 18.5.4)


5.1 SCIENCE, TECHNOLOGY AND SOCIETY (GENERAL)


Altner, Günter. LEBEN IN DER HAND DES MENSCHEN: DIE BRISANZ DES BIOTECHNISCHEN FORTSCHRITTS. Darmstadt: Primus, 1998. 234 p. ISBN 3-89678-077-8. (5.1; 1.1; 1.2; 1.3.11; 2.1; 4.4; 5.3; 9.5.2; 14.5; 15.7; 15.8; 19.1; 20.5.1; 20.7; 22.2; 22.3)


Carlson, Elof Axel. TIMES OF TRIUMPH, TIMES OF DOUBT: SCIENCE AND THE BATTLE FOR PUBLIC TRUST. Cold Spring Harbor, NY: Cold Spring Harbor Laboratory Press, 2006. 227 p. ISBN 0-87969-805-5. [Q175.35 .C37 2006] (5.1; 1.3.9; 2.1; 5.3; 9.7; 14.1; 15.5; 15.7; 15.8; 16.1; 16.2; 18.5.4; 21.2)


5.2 TECHNOLOGY ASSESSMENT


5.3 SOCIAL CONTROL OF SCIENCE/TECHNOLOGY


Kulakowski, Elliott C. and Chronister, Lynne U. RESEARCH ADMINISTRATION AND MANAGEMENT. Boston: Jones and Bartlett, 2006. 916 p. ISBN 0-7637-3277-X. (Gift of the publisher.) [Q180 .U5 R3816 2006] (5.3; 1.3.9; 1.3.11; 1.3.12; 9.5.6; 14.1; 15.8; 15.10; 19.1)


5.4 NANOTECHNOLOGY


Numbers in ( ) = NRCBL Classification Numbers

Hall, J. Storrs. NANO FUTURE: WHAT'S NEXT FOR NANOTECHNOLOGY. Amherst, NY: Prometheus Books, 2006. 296 p. ISBN 978-1-84407-358-0; ISBN 1-84407-358-0. (Science and Society Series.) [T174.7 .N375 2006] (5.4; 1.3.2; 1.3.9; 5.2; 5.3; 15.1; 16.1; 18.1; 21.1)


6 CODES OF/ POSITION STATEMENTS ON PROFESSIONAL ETHICS


7.1 SOCIOLOGY OF HEALTH CARE (GENERAL)


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7.2 EDUCATION FOR HEALTH CARE PROFESSIONALS

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American Research Advanced Seminar Series.) [QP81 .R45 2003] (7.1; 14.5; 15.1; 18.5.4; 19.5; 20.3.1)


Levy, Barry S. and Sidel, Victor W., eds. SOCIAL INJUSTICE AND PUBLIC HEALTH. Oxford/New York: Oxford University Press, 2006. 529 p. ISBN 978-0-19-517185-3; ISBN 0-19-517185-3 (Published in cooperation with the American Public Health Association.) [RA418 .S6423 2006] (7.1; 9.1; 9.5.1; 9.5.2; 9.5.4; 9.5.7; 9.5.10; 10; 16.3; 17.1; 21.1; 21.2)


Woodward, John and Jütte, Robert, eds. COPING WITH SICKNESS: HISTORICAL ASPECTS OF HEALTH CARE IN A EUROPEAN PERSPECTIVE. Sheffield: European Association for the History of Medicine and Health Publications, 1995. 224 p. ISBN 0-9527045-0-1. (History of Medicine, Health and Disease Series.) (7.1; 4.1.1; 4.1.3; 9.3.1; 9.5.1; 9.5.6)


7.2 EDUCATION FOR HEALTH CARE PROFESSIONALS


Numbers in ( ) = NRCBL Classification Numbers
Rhodes, Teresa [Ann Reitsma]. IDENTIFICATION OF CURRICULAR AND EDUCATIONAL NEEDS FOR PRIMARY CARE PHYSICIANS IN DEALING WITH THE CLINICAL APPLICATION OF GENOMIC MEDICINE. Ann Arbor, MI: University Microfilms International [UMI], 2001. 97 p. (Publication No. AAT-3005661. Dissertation, (Ph.D.)—Medical University of South Carolina, College of Health Professionals, 2001.) (7.2; 7.1; 15.1)

7.4 PROFESSIONAL MISCONDUCT


8.2 TRUTH DISCLOSURE


8.3.1 INFORMED CONSENT (GENERAL)


8.3.4 RIGHT TO REFUSE TREATMENT


8.4 CONFIDENTIALITY


Herdmann, Roger and Moses, Harold L. EFFECT OF THE HIPAA PRIVACY RULE ON HEALTH RESEARCH: PROCEED-
8.5 MALPRACTICE


9.1 HEALTH CARE (GENERAL)


Balint, John; Philpott, Sean; Baker, Robert; and Strosberg, Martin, eds. ETHICS AND EPIDEMICS. Amsterdam/Boston: JAI Press/Elsevier, 2006. 253 p. ISBN 978-0-7623-1311-2; ISBN 978-0-7623-1311-0. (Advances in Bioethics series; Vol. 9. ISSN 1479-3709.) (9.1; 2.2; 7.1; 8.1; 9.5.1; 9.5.6; 9.7; 18.5.9; 21.1; 21.3)


Flood, Colleen M., ed. JUST MEDICARE: WHAT’S IN, WHAT’S OUT, HOW WE DECIDE. Toronto/Buffalo, NY: University of Toronto Press, 2006. 458 p. ISBN 978-0-8020-8002-8; ISBN 0-8020-8002-2. [KE3404 .J87 2006] (9.1; 1.3.5; 1.3.7; 9.3.1; 9.4; 9.5.4; 9.5.6; 11.1; 12.4.1; 15.1; 17.1)


Pozgar, George D. LEGAL ASPECTS OF HEALTH CARE ADMINISTRATION. Boston: Jones and Bartlett, 2004. 560 p. ISBN 978-0-7637-3182-X. (Ninth edition.) [KF3821 .P69 2004] (9.1; 1.3.5; 1.3.12; 2.1; 7.4; 8.3.1; 8.5; 9.3.2; 9.5.6; 9.8; 14.1)

Pozgar, George D. and Santucci, Nina M. STUDENT CASE LAW RESOURCE GUIDE TO ACCOMPANY LEGAL ASPECTS OF HEALTH CARE ADMINISTRATION. Boston: Jones and Bartlett, 2006. 64 p. ISBN 0-7637-4093-4. (Ninth edition.) [KF3821 .P69 2004 suppl.] (9.1; 1.3.5; 1.3.12; 2.1; 7.4; 8.3.1; 8.5; 9.3.2; 9.5.6; 9.8; 14.1)


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9.3.1 HEALTH CARE ECONOMICS (GENERAL)

**HEALTH CARE ISSUES AND POLICY SOLUTIONS**


9.3.1 HEALTH CARE ECONOMICS (GENERAL)


Ryder, Bruce, guest ed. Symposium on Chaoulli. OSGOOD HALL LAW JOURNAL 2006 Summer; 44(2): 249-375. (ISSN 0030-6185.) [RA413 .U53 H434 2004] (9.3.1; 7.1; 9.2; 21.1)


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9.3.2 MANAGED CARE


9.4 ALLOCATION OF HEALTH CARE RESOURCES


9.5.1 HEALTH CARE FOR SPECIFIC DISEASES/GROUPS (GENERAL)


Carroll-Johnson, Rose Mary; Gorman, Linda M.; and Bush, Nancy Jo, eds. PSYCHOSOCIAL NURSING CARE ALONG THE CANCER CONTINUUM. Pittsburgh, PA: Oncology Nursing Society, 2006. 670 p. ISBN 978-1-890504-57-1; ISBN 1-890504-57-2. (Second edition.) [RC266 .P79 2006] (9.5.1; 1.1; 1.2; 4.4; 7.1; 8.1; 9.5.9; 15.3; 17.1; 19.1; 20.7; 21.7)


Denniston, George C.; Gallo, Pia Grassivaro; Hodges, Frederick M.; Milos, Marilyn Fayre; and Viviani, Franco, eds. BODILY INTEGRITY AND THE POLITICS OF CIRCUMCIS-

SECTION III

9.3.2 MANAGED CARE


9.4 ALLOCATION OF HEALTH CARE RESOURCES


9.5.1 HEALTH CARE FOR SPECIFIC DISEASES/GROUPS (GENERAL)


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9.5.2 HEALTH CARE FOR THE AGED

San Francisco: American Academy of Ophthalmology, 2005. 352 p. ISBN 1-56055-494-0. (Publisher’s address: 655 Beach Street, Suite 300, Box 7424, zip 94109-1336.) [RE72 .P76 2005] (9.5.1; 2.1; 4.1.2; 6; 9.3.1)


9.5.2 HEALTH CARE FOR THE AGED SECTION III


Livingston, Ivor Lensworth, ed. PRAEGER HANDBOOK OF BLACK AMERICAN HEALTH: POLICIES AND ISSUES BEHIND DISPARITIES IN HEALTH. Westport, CT: Praeger, 2004. 2 volumes. [911 p.]. ISBN 0-313-32477-8 (set). (Foreword by David Satcher.) [RA448.5 .N4 H364 2004] (9.5.4; 7.1; 9.1; 9.5.6; 9.5.9; 10; 15.11; 17.1)


9.5.5 HEALTH CARE FOR WOMEN


9.5.6 HIV INFECTION AND AIDS


9.5.7 HEALTH CARE FOR MINORS

Freeman, Michael, ed. CHILDREN’S HEALTH AND CHILDREN’S RIGHTS. Leiden/Boston: Martinus Nijhoff, 2006. 337 p. ISBN 978-90-04-14894-9; ISBN 90-04-14894-9. (Rose Fitzgerald Kennedy Collection on Women, Infants and Children.) [HQ789 .C453 2006] (9.5.7; 1.1; 8.3.2; 8.3.3; 9.5.1; 9.5.3; 9.5.6; 10; 15.3; 17.1; 18.5.2; 20.5.2; 21.1)


9.5.8 HEALTH CARE FOR EMBRYOS AND FETUSES


9.5.9 HEALTH CARE FOR SUBSTANCE ABUSERS/ USERS OF CONTROLLED SUBSTANCES


Kleinig, John and Einstein, Stanley, eds. ETHICAL CHALLENGES FOR INTERVENTION IN DRUG USE: POLICY, RESEARCH AND TREATMENT ISSUES. Huntsville, TX: Office of International Criminal Justice [OMICJ], Sam Houston State University, Criminal Justice Center, 2006. 770 p. ISBN 978-0-942511-65-9; ISBN 0-942511-65-4. (The Uncertainty Series; Vol. 5.) [HV4998 .E74 2006] (9.5.9; 1.3.9; 2.3; 4.3; 6; 8.1; 8.3.1; 8.4; 10; 17.2; 18.5.1; 18.5.2)

9.5.10 HEALTH CARE FOR INDIGENTS

Engel, Jonathan. POOR PEOPLE’S MEDICINE: MEDICAID AND AMERICAN CHARITY CARE SINCE 1965. Durham, NC: Duke University Press, 2006. 318 p. ISBN 0-8223-3695-2. [RA412.4 .E54 2006] (9.5.10; 7.1; 9.1; 9.3.1; 9.3.2; 9.5.2; 9.5.4; 9.5.6)


9.6 ETHICS COMMITTEES/CONSULTATION

Post, Linda Farber; Blustein, Jeffrey; and Dubler, Nancy Neveloff. HANDBOOK FOR HEALTH CARE ETHICS COMMITTEES. Baltimore, MD: Johns Hopkins University Press, 2007. 327 p. ISBN 0-8018-8448-9. (Gift of the publisher.) [R725.3 .P67 2007] (9.6; 2.1; 4.3; 8.2; 8.3.1; 9.2; 9.4; 9.5.7; 20.5.1)

9.7 DRUGS AND PHARMACEUTICAL INDUSTRY


9.8 QUALITY OF HEALTH CARE

Santoro, Michael A. and Gorrie, Thomas M., eds. ETHICS AND THE PHARMACEUTICAL INDUSTRY. Cambridge/New York: Cambridge University Press, 2005. 492 p. ISBN 978-0-521-85496-2; ISBN 0-521-85496-2. [HD9665.5.E85 2005] (9.7; 1.3.5; 5.3; 8.3.1; 9.2; 9.3.1; 9.4; 9.5.6; 9.5.7; 18.2; 18.5.2; 18.5.4; 21.1)

Schacter, Bernice. THE NEW MEDICINES: HOW DRUGS ARE CREATED, APPROVED, MARKETED, AND SOLD. Westport, CT: Praeger, 2006. 267 p. ISBN 0-275-98141-X. [9.7; 1.3.2; 1.3.5; 9.3.1; 9.4; 9.5.6; 18.2; 18.5.4; 21.1]


9.8 QUALITY OF HEALTH CARE


Meulen, Ruud ter; Biller-Andorno, Nikola; Lenk, Christian; and Lie, Reidar, K., eds. EVIDENCE-BASED PRACTICE IN MEDICINE AND HEALTH CARE: A DISCUSSION OF THE ETHICAL ISSUES. Berlin/New York: Springer, 2005. 184 p. ISBN 3-540-22239-1. [R723.7 .E96 2005] (9.8; 1.3.5; 1.3.9; 7.1; 7.2; 8.1; 9.1; 9.3.2; 9.5.1; 9.5.2; 9.5.4; 17.1; 21.1)


10 SEXUALITY/GENDER


11.1 CONTRACEPTION (GENERAL)


Muir, Constance L. and Murphy, Julien S., eds. GENDER STRUGGLES: PRACTICAL APPROACHES TO CONTEMPORARY FEMINISM. Lanham, MD: Rowman & Littlefield, 2002. 369 p. ISBN 0-7425-1255-X. (Feminist Constructions series.) [HQ1190 .G473 2002] (10; 9.5.3; 9.5.5; 9.5.7; 9.5.8)


11.1 CONTRACEPTION (GENERAL)


12.1 ABORTION (GENERAL)


12.3 ABORTION: MORAL AND RELIGIOUS ASPECTS


12.4.1 ABORTION: LEGAL ASPECTS (GENERAL)

Dellapenna, Joseph W. DISPELLING THE MYTHS OF ABORTION HISTORY. Durham, NC: Carolina Academic Press, 2006. 1283 p. ISBN 0-89089-509-0. [KF3771 .D45 2005] (12.4.1; 4.4; 7.1; 12.3; 12.4.2; 12.5.1; 15.5; 20.5.2)


12.5.1 ABORTION: SOCIAL ASPECTS (GENERAL)


12.5.2 ABORTION: SOCIAL ASPECTS—DEMOGRAPHIC SURVEYS


13.1 POPULATION (GENERAL)


13.2 POPULATION GROWTH


13.3 POPULATION POLICY


14.1 REPRODUCTION/ REPRODUCTIVE TECHNOLOGIES (GENERAL)


Hodges, Sarah, ed. REPRODUCTIVE HEALTH IN INDIA: HISTORY, POLITICS, CONTROVERSIES. Hyderabad, India: Orient Longman, in association with the Wellcome Trust Centre for the History of Medicine, 2006. 264 p. ISBN 978-81-250-2939-7; ISBN 81-250-2939-7. (New Perspectives in South Asian History series; Vol. 13. Publisher’s address: 3-6-752 Himayatnagar, Hyderabad 500 029 (A.P.), India.) [HQ766.5 .J5 2006] (14.1; 1.2; 7.1; 9.5.5; 10; 13.3; 15.5; 21.1)


Shenfield, Françoise and Sureau, Claude, eds. CONTEMPORARY ETHICAL DILEMMAS IN ASSISTED REPRODUCTION. Abingdon, Oxon, UK: Informa Healthcare; Distributed in North and South America by: Boca Raton, FL: Taylor & Francis, 2006. 120 p. ISBN 978-0-415-37131-5; ISBN 0-415-37131-7. (Gift of the publisher.) [RG133.5 .C668 2006] (14.1; 1.2; 4.4; 9.5.7; 14.5; 15.2; 21.1)


14.2 ARTIFICIAL INSEMINATION AND SURROGACY


14.3 SEX PREDETERMINATION/SELECTION


14.4 IN VITRO FERTILIZATION AND EMBRYO TRANSFER

Creating Life? Examining the Legal, Ethical and Medical Issues of Assisted Reproductive Technologies [Part I]. JOURNAL OF GENDER, RACE AND JUSTICE 2005 Fall; 9(1): 1-136. (ISSN 1550-7815.) (14.4; 1.2; 4.4; 8.4; 9.5.5; 10; 14.2; 14.6; 15.3; 18.5.4)


14.5 CLONING


Roezt, Heiner, ed. CROSS-CULTURAL ISSUES IN BIOETHICS: THE EXAMPLE OF HUMAN CLONING. Amsterdam/New York: Rodopi, 2006. 470 p. ISBN 90-420-1609-4. (At the Interface / Probing the Boundaries series; Vol. 27. “A volume in the Making Sense Of: project ‘Health, Illness and Disease.’”) [QH442.2 .C768 2006] (14.5; 1.2; 2.1; 4.4; 5.3; 15.1; 18.5.4; 21.7)


15.1 GENETICS, MOLECULAR BIOLOGY AND MICROBIOLOGY (GENERAL)


Numbers in ( ) = NRCBL Classification Numbers
Crichton, Michael. NEXT: A NOVEL. New York: HarperCollins, 2006. 431 p. ISBN 978-0-06-087298-4; ISBN 0-06-087298-5. (“We live in a time of momentous scientific leaps; a time when it’s possible to sell our eggs and sperm online for thousands of dollars or test our spouses for genetic maladies. We live in a time when one fifth of all our genes are owned by someone else, and an unsuspecting person and his family can be pursued cross-country because they happen to have certain valuable genes within their chromosomes.”) [PS3553 .R48 N48 2006] (15.1; Fiction)

Deane-Drummond, Celia. GENETICS AND CHRISTIAN ETHICS. Cambridge/New York: Cambridge University Press, 2006. 281 p. ISBN 978-0-521-53637-0; ISBN 0-521-53637-5. (Gift of the publisher.) [QH438.7 .D43 2006] (15.1; 1.1; 1.2; 9.5.5; 10; 15.2; 15.3; 15.4; 15.5; 15.7; 15.8)


Entine, Jon, ed. LET THEM EAT PRECAUTION: HOW POLITICS IS UNDERMINING THE GENETIC REVOLUTION IN AGRICULTURE. Washington, DC: AEI Press, 2006. 203 p. ISBN 0-8447-4200-7. [SB106 .B56 L48 2006] (15.1; 1.3.11; 1.3.7; 1.3.11; 1.3.12; 5.3; 5.4; 18.5.4; 22.2)

Flaman, Paul. GENETIC ENGINEERING, CHRISTIAN VALUES AND CATHOLIC TEACHING. New York: Paulist Press, 2002. 138 p. ISBN 0-8091-4089-6. [QH442 .F525 2002] (15.1; 1.2; 1.3.11; 2.3; 4.5; 8.4; 14.5; 15.2; 15.3; 15.5; 18.5.4; 19.1; 21.3; 22.2)


Mitchell, C. Ben; Pellegrino, Edmund D.; Elshtain, Jean Bethke; Kilner, John F.; Rae, Scott B. BIOTECHNOLOGY
15.2 GENETIC COUNSELING/ PRENATAL DIAGNOSIS


Stephenson, Frank H. DNA: HOW THE BIOTECH REVOLUTION IS CHANGING THE WAY WE FIGHT DISEASE. Amherst, NY: Prometheus Books, 2007. 333 p. (Gift of the publisher.) [TP248.215 .S74 2007] (15.1; 9.5.1; 9.5.2; 9.5.6; 14.5; 15.4; 15.10; 15.5; 21.3)


15.2 GENETIC COUNSELING/ PRENATAL DIAGNOSIS


15.3 GENETIC SCREENING/ TESTING
15.4 GENE THERAPY/TRANSFER

Fuchs, Michael; Lanzerath, Dirk; and Schmidt, Matthias C., eds. PRÄDIKTIVE GENETISCHE TESTS: "HEALTH PURPOSES" UND INDIKATIONSTELLUNG ALS KRITERIEN DER ANWENDUNG. Bonn: Institut für Wissenschaft und Ethik, 2004. 158 p. ISBN 3-936020-01-9. (Ethik in Biowissenschaften und Medizin Forschungsbeiträge, Reihe A series; Bd. 2. ISSN 1617-8742. Gift of DRZE.) (15.3; 1.1; 7.1; 8.3.1; Reference)


15.5 EUGENICS


15.6 BEHAVIORAL GENETICS


15.8 GENETIC PATENTS


Jaenicke, Hans-Rainer; McDonell, Leslie A.; Haley, James F.; and Hosoda, Yoshinori. FROM CLONES TO CLONES: THE EUROPEAN PATENT OFFICE’S CASE LAW ON THE PATENTABILITY OF BIOTECHNOLOGY INVENTIONS IN COMPARISON TO THE UNITED STATES AND JAPANESE PRAC-


15.9 SOCIOBIOLOGY


16.1 ENVIRONMENTAL QUALITY

(GENERAL)


Numbers in ( ) = NRCBL Classification Numbers
SECTION III 17.1 THE NEUROSCIENCES AND MENTAL HEALTH THERAPIES (GENERAL)


Andrews, Jonathan and Digby, Anne, eds. SEX AND SECLUSION, CLASS AND CUSTODY: PERSPECTIVES ON GENDER AND CLASS IN THE HISTORY OF BRITISH AND IRISH PSYCHIATRY. Amsterdam/New York: Rodopi, 2004. 338 p. ISBN 90-420-1176-9. (The Wellcome Series in the History of Medicine, Clio Medica; No. 73. ISSN 0045-7183.) [RC455.4 .S45 S49 2004] (17.1; 4.3; 7.1; 9.5.5; 10; 15.5; 17.7)


Bersoff, Donald N. ETHICAL CONFLICTS IN PSYCHOLOGY. Washington, DC: American Psychological Association, 2003. 573 p. ISBN 1-59147-050-1. (Third edition.) [BF76.4 .E814 2003] (17.1; 1.3.12; 2.3; 4.3; 6; 7.3; 7.4; 8.1; 8.4; 9.3.2; 9.5.6; 9.5.7; 10; 17.2; 18.2; 18.3; 18.4; 22.2)


Ford, Gary G. ETHICAL REASONING FOR MENTAL HEALTH PROFESSIONALS. Thousand Oaks, CA: SAGE Publications, 2006. 393 p. ISBN 0-7619-3094-9. [RC455.2 .E8 F67 2006] (17.1; 1.1; 1.3.1; 1.3.2; 1.3.12; 4.3; 6; 7.2; 8.1; 9.6; 18.5.6)


17.1 THE NEUROSCIENCES AND MENTAL HEALTH THERAPIES (GENERAL) SECTION III


Green, Stephen A. and Bloch, Sidney, eds. AN ANTHOLOGY OF PSYCHIATRIC ETHICS. Oxford/New York: Oxford University Press, 2006. 498 p. ISBN 978-0-19-856488-1; ISBN 0-19-856488-0. (Gift of the publisher.) [RC455.2 .E8 A58 2006] (17.1; 1.1; 1.3.5; 2.1; 4.3; 7.3; 8.1; 8.3.1; 8.4; 9.4; 17.4; 18.3; 18.5.6; 20.6)

Guimón, José. INEQUITY AND MADNESS: PSYCHOSOCIAL AND HUMAN RIGHTS ISSUES. New York: Kluwer Academic/Plenum Publishers, 2001. 225 p. ISBN 0-306-46674-0. [RC455.2 .E8 G85 2001] (17.1; 1.1; 1.2; 1.3.3; 6; 8.1; 8.3.1; 9.5.4; 9.5.7; 20.7; 21.7)


Jones, Caroline (contributing editor); Shillito-Clarke, Carol; Syme, Gabrielle; Hill, Derek; Casemore, Roger; and Murdin, Lesley. QUESTIONS OF ETHICS IN COUNSELING AND THERAPY. Buckingham, UK/Philadelphia: Open University Press, 2000. 190 p. ISBN 978-0-19-856721-9; ISBN 0-19-856721-9. (Foreword by Arthur Caplan. Gift of the publisher.) [RC343 .N44 2006] (17.1; 1.2; 1.3.3; 4.5; 7.1; 15.1; 17.5; 18.2)


Linhorst, Donald M. EMPOWERING PEOPLE WITH SEVERE MENTAL ILLNESS: A PRACTICAL GUIDE. Oxford/New York: Oxford University Press, 2006. 353 p. ISBN 978-0-19-517187-7; ISBN 0-19-517187-X. (“Presents a model of empowerment and then applies it to seven areas that have potential to empower people with severe mental illness, including treatment planning, housing, employment, and others. Provides practitioners, administrators, and policymakers with specific guidelines and actions to promote empowerment.”) [HV3006 .A4 L56 2006] (17.1; 7.1; 9.1; 18.5.6)


17.2 PSYCHOTHERAPY


17.3 BEHAVIOR MODIFICATION


17.4 PSYCHOPHARMACOLOGY


Vuckovich, Paula K. JUSTIFYING COERCION: NURSES’ EXPERIENCES MEDICATING INVOLUNTARY PSYCHIATRIC PATIENTS. Ann Arbor, MI: ProQuest Information and Learning/UMI, 2003. 184 p. (Publication No. AAT-3088677. Dissertation (Ph.D. in Nursing)—University of San Diego, 2003.) [RC440 .V8 2003](17.4; 8.3.4; 17.3; 17.7; 17.8)

17.5 ELECTRICAL STIMULATION OF THE BRAIN


18.1 HUMAN EXPERIMENTATION (GENERAL)


Gallin, John I. and Ognibene, Frederick P., eds. PRINCIPLES AND PRACTICE OF CLINICAL RESEARCH. Amster-
18.2 HUMAN EXPERIMENTATION: POLICY GUIDELINES/IRB


18.2 HUMAN EXPERIMENTATION: POLICY GUIDELINES/IRB


18.3 HUMAN EXPERIMENTATION: INFORMED CONSENT


18.4 BEHAVIORAL RESEARCH


18.5.1 RESEARCH ON SPECIAL POPULATIONS (GENERAL)


18.5.2 RESEARCH ON NEWBORNS AND MINORS

Alderson, Priscilla and Morrow, Virginia. ETHICS, SOCIAL RESEARCH AND CONSULTING WITH CHILDREN AND YOUNG PEOPLE. Ilford: Barnado’s, 2004. 171 p. ISBN 1-904659-07-1. (Revised and updated from: Listening to Children: Children, Ethics and Social Research; Barnardo’s, 1995. Rose Fitzgerald Kennedy Collection on Women, Infants and Children.) (18.5.2; 8.4; 9.3.1; 18.2; 18.3)


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18.5.4 RESEARCH ON EMBRYOS AND FETUSES

Cohen, Cynthia B. RENEWING THE STUFF OF LIFE: STEM CELLS, ETHICS, AND PUBLIC POLICY. Oxford/New York: Oxford University Press, 2007. 311 p. ISBN 978-0-19-530524-1. [QH588 .S83 C46 2007] (18.5.4; 1.2; 14.5; 15.1; 15.8; 18.1; 18.6; 20.7) [HQ767.85 .R435 2004] (18.5.2; 1.3.2; 4.4; 9.3.1; 15.1; 15.8)


18.5.5 RESEARCH ON PRISONERS


18.5.6 RESEARCH ON MENTALLY ILL AND DISABLED PERSONS


18.6 SOCIAL CONTROL OF HUMAN EXPERIMENTATION


19.1 ARTIFICIAL AND TRANSPLANTED ORGANS OR TISSUES (GENERAL)


19.2 ARTIFICIAL AND TRANSPLANTED HEARTS

19.5 DONATION/ PROCUREMENT OF ORGANS/TISSUES

Shannon, Joyce Brennfleck, ed. DEATH AND DYING SOURCEBOOK: BASIC CONSUMER HEALTH INFORMATION ABOUT END-OF-LIFE CARE AND RELATED PERSPECTIVES AND ETHICAL ISSUES, INCLUDING END-OF-LIFE SYMPTOMS AND TREATMENTS, PAIN MANAGEMENT, QUALITY-OF-LIFE CONCERNS, THE USE OF LIFE SUPPORT, PATIENTS' RIGHTS AND PRIVACY ISSUES, ADVANCE DIRECTIVES, PHYSICIAN-ASSISTED SUICIDE, CAREGIVING, ORGAN AND TISSUE DONATION, AUTOPSIES, FUNERAL ARRANGEMENTS, AND GRIEF, ALONG WITH STATISTICAL DATA, INFORMATION ABOUT THE LEADING CAUSES OF DEATH, A GLOSSARY, AND DIRECTORIES OF SUPPORT GROUPS AND OTHER RESOURCES.

[20.1; 7.1; 7.2; 9.3.1; 9.5.1; 19.5; 20.4.1; 20.4.2; 20.5.1; 20.5.4; 20.7; Reference]

20.2.1 DEFINITION OR DETERMINATION OF DEATH (GENERAL)


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20.3.2 ATTITUDES TOWARD DEATH: HEALTH PERSONNEL


20.4.1 CARE OF THE DYING PATIENT (GENERAL)


[20.4.1; 7.1; 8.1; 10]

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Numbers in ( ) = NRCBL Classification Numbers
END-OF-LIFE CARE: AN EXPLORATORY STUDY. Ann Arbor, MI: ProQuest Information and Learning/UMI, 2003. 141 p. (Publication No. AAT-3073662. Dissertation, (Ph.D. of Health Administration)—Medical University of South Carolina, College of Health Professions, 2003.) (20.4.1; 7.1)

Hurwitz, Peter Joel; Picard, Jacques; and Steinberg, Avraham, eds. JEWISH ETHICS AND THE CARE OF END-OF-LIFE PATIENTS: A COLLECTION OF RABBINICAL, BIOETHICS, PHILOSOPHICAL, AND JURISTIC OPINIONS. Jersey City, NJ: KTAV, in association with the Institute for Jewish Studies, University of Basel, Basel, Switzerland, 2006. 254 p. ISBN 0-88125-921-7. (Gift of Max M. and Marjorie B. Kampelman.) [BM635.4 .J384 2006] (20.4.1; 1.2; 4.4; 8.1; 20.3.1; 20.4.2; 20.5.1; 20.7)

Pharaoh, Gill. CARING FOR THE DYING AT HOME: A PRACTICAL GUIDE. London: Free Association Books, 2004. 168 p. ISBN 1-85343-739-5. (Foreword by Tony Benn.) [R726.8 .W657 2007] (20.4.1; 1.2; 4.4; 2.2; 4.1.2; 8.1.5; 15.5; 20.3.2)

Rowe, Charles. THE DI OCESAN BISHOP’S PASTORAL RESPONSIBILITY FOR THE ETHICALLY CORRECT CARE OF CRITICALLY ILL PATIENTS AT CATHOLIC HEALTH CARE FACILITIES IN THE UNITED STATES. Rome: [s.n.], 2006. 375 p. (Dissertation, [Doctoratum in Theologie Morali]—Pontificia Universitas Lateranensis Academia Alfonsiana, Institutum Superius Theologiae Moralis, 2006. Gift of the author.) [RC86.95 .R69 2006] (20.4.1; 1.2; 1.3.2; 2.2; 4.1.2; 8.1; 9.1; 20.5.1)


20.4.2 CARE OF THE DYING CHILD


20.5.1 PROLONGATION OF LIFE AND EUTHANASIA (GENERAL)


Csikai, Ellen L. and Jones, Barbara, ed. TEACHING RESOURCES FOR END OF LIFE AND PALLIATIVE CARE COURSES. Chicago: Lyceum Books, 2007. 324 p. ISBN 978-1-933478-10-4. (Gift of the publisher.) [HV687 .T43 2007] (20.5.1; 1.2; 1.3.10; 2.3; 7.2; 9.5.6; 17.1; 20.1; 20.4.2; 21.7; Reference)

20.5.2 ALLOWING MINORS TO DIE

Humboldt-Universität zu Berlin and the Union Theological Seminary in New York.” Gift of LeRoy Walters.) [R726 .D524 2005] (20.5.1; 1.2; 1.3.5; 2.2; 11.3; 15.5; 21.4)

Greve, Michael. DIE ORGANISIERTE VERNICHTUNG "LEBENSUNWERTEN LEBENS" IM RAHMEN DER "AKTION T4": DARGESTELLT AM BEISPIEL DES WIRKENS UND DER STRAFRECHTLICHEN VERFOLGUNG AUSGEGEWÄHLTER NS-TÖTUNGSSÄRZTE. Herbolzheim: Centaurus Verlag, 2006. 145 p. ISBN 978-3-8255-0123-5; ISBN 3-8255-0123-X. (Second edition. Reihe Geschichte-wissenschafts-series; Bd. 43. ISSN 0177-2767.) [R726 .G75 1998] (20.5.1; 1.3.5; 2.2; 4.1.2; 21.2; 21.4; Biography)


Hübener, Kristina, ed. and Heinze, Martin. BRANDENBURGSCHER HEIL- UND PFLEGEANSTALTEN IN DER NS-ZEIT. Berlin: Be.bra Wissenschaft, 2002. 480 p. ISBN 978-3-88840-221-0; ISBN 3-88840-221-2. (Schriftenreihe zur Medizin-Geschichte des Landes Brandenburg series; Bd. 10. ISSN 1611-8456.) [R726 .K497 2004] (20.5.1; 1.3.5; 2.2; 11.3; 15.5; 21.4)


Kaul, Friedrich Karl. DIE PSYCHIATRIE IM STRUDEL DER "EUTHANASIE": EIN BERICHT ÜBER DIE ERSTE INDUSTRIEMÄßIG DURCHGEFÜHRTE MORDAKTION DES NAZIREGIMES. Köln/Frankfurt am Main: Europäische Verlagsanstalt, 2004. 205 p. ISBN 978-3-937233-14-8. (Schriftenreihe zur Medizin-Geschichte des Landes Brandenburg series; Bd. 10. ISSN 1611-8456.) [R726 .K497 2004] (20.5.1; 1.3.5; 2.2; 15.5; 21.4)


Tolmein, Oliver. SELBSTBESTIMMUNGSRECHT UND EINWILLIGUNGSFÄHIGKEIT: DER ABBRUCH DER KÜNSTLICHEN ERNÄHRUNG BEI PATIENTEN IM VEGETATIVEN STATE IN RECHTSVERGLEICHENDER SICHT: DER KEMPTEER FALL UND DIE VERFAHREN CRUZAN UND BLAND. Frankfurt am Main: Mabuse-Verlag, 2004. 311 p. ISBN 3-95964-73-0. (Mabuse-Verlag Wissenschaft series; Bd. 81.) [K3611 .E95 T65 2004] (20.5.1; 1.3.5; 8.3.1; 8.3.3; 20.2.1; 20.4.1)

Tuchel, Johannes. KEIN RECHT AUF LEBEN: BEITRÄGE UND DOKUMENTE ZUR ENTRECHTUNG UND VERNICHTUNG "LEBENSUNWERTEN LEBENS" IM NATIONALSOZIALISMUS. Berlin: Wissenschaftlicher Autoren-Verlag, 1984. 122 p. ISBN 978-3-88840-221-0; ISBN 3-88840-221-2. [KK8364 .K45 1984] (20.5.1; 1.3.5; 2.2; 15.5; 21.4)


20.5.2 ALLOWING MINORS TO DIE

Beddies, Thomas and Hübener, Kristina, eds. KINDER IN DER NS-PSYCHIATRIE. Berlin-Brandenburg: Be.bra Wissenschaft, 2004. 205 p. ISBN 3-937233-14-8. (Schriftenreihe zur Medizin-Geschichte des Landes Brandenburg series; Bd. 10. ISSN 1611-8456.) [R726 .K497 2004] (20.5.1; 1.3.5; 2.2; 9.5.7; 15.5; 21.1; 21.4)

Bhatnagar, Rashmi Dube; Dube, Renu; and Dube, Reena. FEMALE INFANTICIDE IN INDIA: A FEMINIST CULTURAL HISTORY. Albany: State University NewYork Press, 2005. 320 p. ISBN 0-7914-6328-1. [HV6541 .I5 B53 2005] (20.5.1; 7.1; 9.3.1; 9.5.7)

SECTION III

20.5.4 LIVING WILLS/ ADVANCE DIRECTIVES


20.6 CAPITAL PUNISHMENT


20.7 SUICIDE/ ASSISTED SUICIDE


21.1 INTERNATIONAL AND POLITICAL DIMENSIONS OF BIOLOGY AND MEDICINE (GENERAL)


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21.4 TORTURE AND GENOCIDE


21.4 TORTURE AND GENOCIDE


22.1 ANIMAL WELFARE (GENERAL)

Armstrong, Susan J. and Botzler, Richard G., eds. THE ANIMAL ETHICS READER. London/New York: Routledge, 2003. 588 p. ISBN 0-415-27589-X. (Gift of Peter Imman.) [HV4708 .A54 2003] (22.1; 1.3.12; 14.5; 15.1; 19.5; 22.2; 22.3; Reference)


22.2 ANIMAL EXPERIMENTATION


22.3 ANIMAL PRODUCTION


NEW JOURNAL SUBSCRIPTIONS

NANOETHICS 2007 March; 1(1). Quarterly. ISSN 1871-4757. Publisher's address: Springer Netherlands,
NEW PUBLICATIONS FROM THE KENNEDY INSTITUTE OF ETHICS

Walters, LeRoy; Kahn, Tamar Joy; and Goldstein, Doris Mueller, eds. BIBLIOGRAPHY OF BIOETHICS, VOLUME 33. Washington, DC: Kennedy Institute of Ethics, Georgetown University, 2007. 848 p. ISBN 978-1-883913-14-4. (ISSN 0363-0161. Pricing and availability from: Mara Snyder, Kennedy Institute of Ethics, Georgetown University, Box 571212; tel: 1-888-BIO-ETHX [U.S. and Canada only] [or] 202-687-6689; fax: 202-687-6770; email: mrm37@georgetown.edu.) [Z6675 .E8 W34 v.33] (2.1; Reference)

BIOETHICS SEARCHER'S GUIDE TO ONLINE INFORMATION RESOURCES. Washington, DC: National Reference Center for Bioethics Literature [and] National Information Resource on Ethics and Human Genetics, Kennedy Institute of Ethics, Georgetown University, 2008. 173 p. (May 2008. Pricing and availability from: Mara Snyder, Kennedy Institute of Ethics, Georgetown University, Box 571212; tel: 1-888-BIO-ETHX [U.S. and Canada only] [or] 202-687-6689; fax: 202-687-6770; email: mrm37@georgetown.edu.) (2.1; Reference)
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Absolute Convictions: My Father, a City, and the Conflict That Divided America. Section III: 12.1 —Press, Eyal.

ACA Ethical Standards Casebook. Section III: 17.1 —Herlihy, Barbara and Corey, Gerald, [eds.].


Access to Care, Access to Justice: The Legal Debate Over Private Health Insurance in Canada. Section III: 9.3.1 —Flood, Colleen M.; Roach, Kent; and Sossin, Lorne, eds.

Achieving Excellence in Medical Education. Section III: 7.2 —Gunderman, Richard B.


African American Bioethics: Culture, Race, and Identity. Section III: 2.1 —Prograis, Lawrence J. and Pellegrino, Edmund D., eds.


AIDS and Power: Why There Is No Political Crisis—Yet. Section III: 9.5.6 —de Waal, Alex.

AIDS in Latin America. Section III: 9.5.6 —Frasca, Tim.

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And Life Is Changed Forever: Holocaust Childhoods Remembered. Section III: 21.4 —Glassner, Martin Ira and Krell, Robert, eds.


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Autonomy & Paternalism: Reflections on the Theory and Practice of Health Care. Section III: 2.1 —Nys, Thomas; Denier, Yvonne; and Vandevelde, Toon, eds.


Bad Medicine: Doctors Doing Harm Since Hippocrates. Section III: 7.1 —Wootton, David.

Bad Medicine: Misconceptions and Misuses Revealed, from Distance Healing to Vitamin O. Section III: 4.1.1 —Wanjek, Christopher.

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Beauty Junkies: Inside Our $15 Billion Obsession with Cosmetic Surgery. Section III: 9.5.1 —Kuczynski, Alex.

Becoming Culturally Oriented: Practical Advice for Psychologists and Educators. Section III: 21.7 —Fouda, Nadya A. and Arredondo, Patricia.


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Better But Not Well: Mental Health Policy in the United States Since 1950. Section III: 17.1 —Frank, Richard G. and Glied, Sherry A.

Beyond the DSM Story: Ethical Quandaries, Challenges, and Best Practices. Section III: 4.3 —Eriksen, Karen and Kress, Victoria E.

Beyond the Hippocratic Oath: A Memoir of the Rise of Modern Medical Ethics. Section III: 2.2 —Dossetor, John B.

Bibliography of Bioethics, Volume 33. Section III: 2.1 —Walters, LeRoy; Kahn, Tamar Joy; and Goldstein, Doris Mueller, eds.


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| 20.3.1, 20.3.2, 20.3.3 | Death and Dying/ Attitudes Toward Death |
| 20.4.1 | Death and Dying/ Terminal Care |
| 20.4.2 | Death and Dying/ Terminal Care/ Minors |
| 20.5.1 | Euthanasia and Allowing to Die or its subdivisions: /Legal, /Philosophical, or /Religious Aspects |
| 20.5.2 | Euthanasia and Allowing to Die/ Minors |
| 20.5.3 | Euthanasia and Allowing to Die or its subdivisions: /Legal, /Philosophical, or /Religious Aspects |
| 20.5.4 | Advance Directives |
| 20.6 | Capital Punishment |
| 20.7 | Assisted Suicide |
| 21.1 | International Health and Human Rights |
| 21.2, 21.3 | War and Terrorism |
| 21.4 | Torture, Genocide, and War Crimes |
| 21.5 | Treatment Refusal |
| 21.6 | International Migration of Health Care Professionals |
| 21.7 | Cultural Pluralism |
| 22.1, 22.2, 22.3 | Animal Experimentation |