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Scope Note 34

## Bioethics Commissions: Town Meetings with a "Blue, Blue Ribbon"

[Susan Cartier Poland](#)

Town meetings are characteristic of New England. In theory, a quorum of registered voters in a small municipality meets annually to decide local public policy. In fact, special interests and the town bureaucracy control the meeting.

Like a town meeting, a commission (or committee or council) comes into being, whether on an ad hoc or permanent basis, to direct a government function. Bioethics commissions specialize in one area: the intersection of public policy with developments, either real or anticipated, in the basic and applied sciences.

That specialization of commissions carries over into the selection of the members. More often than not commission members are appointed on the basis of expertise in a specific area. Although some commissions are still made up entirely of one kind of expert, usually medical, the majority of these government bodies seek breadth between the fields of law, religion, ethics, and science (including medicine and the social sciences).

In the words of Mrs. Rigenbach, the law clerk to Chief Judge Carl B. Rubin of the United States District Court for the Southern District of Ohio, selection of persons "knowledgeable in the field" constitutes a "blue, blue ribbon" jury. In contrast, a "blue ribbon" jury is composed of those persons having "the greatest amount of formal education" (*In re Richardson-Merrill, Inc.* (Bendectin litigation), 624 Federal Supplement 1212 at 1217 (1985)). The problem with persons knowledgeable in the field is that their minds may have already been made up. For a jury, this is a disaster; for a bioethics commission, this directs and shapes the research, investigation, and discussion, or, in short, it makes for more efficient decision making.

For this Scope Note, the definition of commission begins with the Bioethicsline description of its index term "advisory committees" as committees or commissions set up to advise government bodies on public policy. Furthermore, a commission [**End Page 91**] (or committee) receives government funding and support in exchange for its expertise in research, investigation, reporting, and recommendations.

Six functions served by bioethics commissions have been clearly and succinctly described by LeRoy Walters (Commissions and Bioethics. *Journal of Medicine and Philosophy* 14 (4): 363-68, August 1989). The functions are: (1) to legitimize action; (2) to delay action or resolution; (3) to identify duplication; (4) to be representative; (5) to do research and find facts; and (6) to provide education and support (pp. 364-65). Since 1989, however, another government function has moved to the forefront. Instead of remaining within the legislative arena, government commissions serve the judiciary as well, in cases involving complex and technical questions. The now defunct Law Reform Commission of Canada recognized this use when it included in its annual reports a section on its "Influence on Law Reform through Judicial Decisions."

In mid-1997, the United States Supreme Court in its consolidated cases on assisted suicide used extensively the writings from a state commission, the New York State Task Force on Life and the Law, to support its rationale. Not only did the Court make use of the Task Force's work, but in so doing the Court extended the efforts of the commission beyond its jurisdiction of New York into another jurisdiction on the opposite coast, Washington state. Furthermore, although the commission was chartered by one state, through the federal court system, its influence became national.

Outside the U.S., the United Nations recently adopted its first bioethics text on the ethics of genetic research, and Canada is reworking its human research guidelines into a single set of guidelines that will apply to research in both the natural sciences and the social sciences.

This Scope Note attempts to compile for the researcher and the reference librarian those commissions, existing and defunct, that have addressed bioethics issues. Only one other such attempt is known to the author, an Office of Technology Assessment [OTA] Background Paper, *Biomedical Ethics in U.S. Public Policy* (1993). Due to space limitations, not all publications could be listed; the selections included represent the range of topics from a particular group or the more frequently cited sources. Future updates of this compilation are planned, so please notify the National Reference Center for Bioethics Literature regarding any omissions or additions (1-800-MED-ETHX or medethx@gunet.georgetown.edu).

Obviously given the proliferation of bioethics commissions at the national level, the commission is not about to disappear. Like citizens eligible to vote at a town meeting, commission membership will probably remain exclusive. Unlike the town meeting, however, the commission seems destined not to be confined to a single jurisdiction. In its decision on assisted suicide, the Supreme Court has given the nod to the states to act. Whether or not more state commissions come forth to take up that challenge and other issues in bioethics is a question that remains to be answered. **[End Page 92]**

## **I. International/World Bodies**

Steering Committee for Bioethics [Comité Directeur de Bioéthique (CDBI)], Division I, Directorate of Legal Affairs, Council of Europe [Conseil de l'Europe], F-67075 Strasbourg Cedex, France.

CDBI is a multidisciplinary ad hoc group created by the now 40 member states of the Council of Europe to study issues in medical ethics. Committee members are experts in law, medicine, science, ethics, or human rights. Its work may result in binding treaties, guidelines, or recommendations for policy and legislation for the Council members. The Council itself was established in 1949 to encourage intergovernmental cooperation based on a common heritage on human rights issues. Its Parliamentary Assembly recommended in 1982 the creation of a Committee of Ministers. That Committee is made up of the foreign ministers of the member states. It set up the Ad Hoc Committee on Genetics Experts (CAHGE) in 1983. In 1985, the Committee changed its name to the Ad Hoc Committee for Progress of Biomedical Sciences (CAHBI) until 1993 when it acquired its present name. The first international treaty on bioethics was adopted by CDBI in 1996 and since 1997 undergoing ratification by the member states.

Resolution 613(1976) on the Rights of the Sick and Dying

Recommendation 779(1976) on the Rights of the Sick and Dying

Recommendation 818(1977) on the Situation of the Mentally Ill

Resolution (78)29 Relating to Removal, Grafting and Transplantation of Human Substances

Recommendation R(79)5 Concerning International Exchange and Transportation of Human Substances

Recommendation 934(1982) on Genetic Engineering

Recommendation R(83)2 Concerning the Legal Protection of Persons Suffering from Mental Disorder Placed as Involuntary Patients

Recommendation R(84)16 Concerning Notification of Work Involving Recombinant Deoxyribonucleic Acid (DNA)

Recommendation 1046(1986) on the Use of Human Embryos and Foetuses for Diagnostic, Therapeutic, Scientific, Industrial and Commercial Purposes

Recommendation R(87)25 Concerning a Common European Public Health Policy to Fight the Acquired Immunodeficiency Syndrome (AIDS)

Recommendation 1100(1989) on the Use of Human Embryos and Foetuses in Scientific Research

Recommendation R(89)14 on the Ethical Issues of HIV Infection in the Health Care and Social Settings

Human Artificial Procreation (CAHBI, Legal Affairs) (1989)

Recommendations Adopted by the Committee of Ministers and the Parliamentary Assembly of the Council of Europe on Bioethical Questions (CAHBI, Legal Affairs) (1989) **[End Page 93]**

Recommendation R(90)3 Concerning Medical Research on Human Beings

Recommendation R(90)13 on Prenatal Genetic Screening, Prenatal Genetic Diagnosis and Associated Genetic Counselling

Recommendation R(90)8 on the Impact of New Technologies on Health Services, Particularly Primary Health Care

Recommendation 1153(1991) on Concerted European Policies for Health

Recommendation 1160(1991)(1) on the Preparation of a Convention on Bioethics

Recommendation R92(1) on the Use of Analysis of Deoxyribonucleic Acid (DNA) Within the Framework of the Criminal Justice System

Recommendation R92(3) on Genetic Testing and Screening for Health Care Purposes

Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine (1997)

European Commission [Commission Européenne], Directorate-General XII for Science, Research and Development, Directorate E for Life Sciences and Technologies, Unit 5 on Ethical and Legal Aspects, 200 rue de la Loi, B-1049 Brussels, Belgium.

The Commission of the European Community (EC) has established working groups on bioethics issues. These groups include the Working Group on Human Embryos and Research and the Working Group on Ethical, Social, and Legal Aspects of Human Genome Analysis. The Working Party on Ethical and Legal Issues Raised by New Reproductive Technology is also known as the Glover Commission. Its report was not published by the Commission but by various academic presses and consequently can be found under different titles. The research program in bioethics under the life sciences and technologies directorate funds investigators in general bioethics research.

Ethics of New Reproductive Technologies: The Glover Report to the European Commission (1989)

United Nations Educational, Scientific and Cultural Organization (UNESCO), International Bioethics

Committee (IBC) [Comité International de Bioéthique (CIB)], 1 rue Miollis, 75015 Paris, France.

The IBC is the only ethics committee within the U.N. It has no international counterpart. It was established in 1993 with a mandate from UNESCO to consider the possibility of establishing an international legal framework for the protection of the human genome. Its 55 members come from 40 countries and a range of disciplines. The IBC Legal Commission is much smaller and narrower in focus; its 20 members are either law professors or judges from constitutional and supreme courts.

Universal Declaration on the Human Genome and Human Rights (1997)

Holy See (Vatican). Congregation for the Doctrine of the Faith, Mission Permanente du Saint-Siege auprès du Conseil de l'Europe, 2 rue Le Notre, 67000 Strasbourg, France. **[End Page 94]**

Declaration on Euthanasia (1980)

Instruction on Respect for Human Life in Its Origin and on the Dignity of Procreation: Replies to Certain Questions of the Day (1987)

Responses to Questions Proposed Concerning "Uterine Isolation" and Related Matters (1994)

## **II. National Bodies**

AUSTRALIA. Australian Law Reform Commission (ALRC), GPO Box 3708, Sydney NSW 2001 or GPO Box 1995, Canberra ACT 2601.

Established by 1973 legislation to recommend changes in laws of the Australian Commonwealth and Territories, the ALRC can only act on matters referred by the federal Attorney-General and then reports back to Parliament through the same federal office.

Human Tissue Transplants (1977)

Informed Decision-Making in Medical Procedures (1989)

National Health and Medical Research Council (NHMRC), Australian Health Ethics Committee (AHEC), GPO Box 9848, Canberra ACT 26001.

NHMRC falls under the Minister for Health and Family Services. The Medical Research Ethics Committee (MERC) of the NHMRC was established in 1981 and finished its work in 1990. Its replacement, AHEC, started in 1992 as a merger of the National Bioethics Consultative Committee and MERC. As a principal committee of NHMRC, AHEC advises on ethical issues related to health, develops guidelines for medical research involving humans, and monitors institutional ethics committees. Chaired by a lawyer, the committee is made up of experts in law, religion, philosophy, medical research, public health research, social science, clinical medical practice, nursing or allied health practice, regulation of the medical professions, and consumer health issues.

First Report: Research on Humans (Working Party on Ethics in Medical Research) (1982)

Ethics in Medical Research (1983)

Ethics in Medical Research Involving the Human Fetus and Human Fetal Tissue (1983)

Report on Ethics in Epidemiological Research (1985)

Embryo Donation by Uterine Flushing (1985)

Report on Workshops on the Constitution and Functions of Institutional Ethics Committees in Australia (1988-1990)

In Vitro Fertilisation Centres in Australia: Their Observance of the National Health and Medical Research Council Guidelines (1986)

Consideration by Institutional Ethics Committees of Research Protocols Involving Frozen-Thawed Human Ova (1987)

Ethical Aspects of Research on Human Gene Therapy (1987)

Discussion Paper on the Ethics of Limiting Life Sustaining Treatment (1988) **[End Page 95]**

Report of the Round Table Conference on Human Gene Therapy (1988)

Discussion Paper on Ethics and Resource Allocation in Health Care--Discussion Paper (1990)

Guidelines for the Use of Genetic Registers in Medical Research (1991)

Guidelines for the Protection of Privacy in the Conduct of Medical Research (1991)

Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research (1991)

The Clinical Trial Notification Scheme: Interim Guidelines for Institutional Ethics Committees (1992)

NHMRC Statement on Human Experimentation and Supplementary Notes (1992)

Guidelines for the Monitoring of Research by Institutional Ethics Committees (1992)

The Place of Ethics in Health Care Resource--Where to Now? (1992)

Human Gene Therapy and Related Procedures (1993)

Ethical Considerations Relating to Health Care Resource Allocation Decisions (1993)

Aspects of Privacy in Medical Research (1995)

Report on Compensation, Insurance and Indemnity Arrangements for Institutional Ethics Committees (1995)

Donating Organs After Death: Ethical Issues (1996)

Ethical Aspects of Qualitative Methods in Health (1996)

Ethical Guidelines on Assisted Reproductive Technology (1996)

Ethical Issues in Donating Organs and Tissues by Living Donors (1996)

Ethical Issues Raised by Allocation of Transplant Resources (1996)

Certifying Death: The Brain Function Criterion (1996)

CANADA. Ministry of Health [Ministère de la Santé], Ottawa, Ontario.

New Reproductive and Genetic Techniques; Setting Boundaries, Enhancing Health [Les Nouvelles Techniques de Reproduction et de Génétique; Fixer des Limites et Protéger la Santé] (1996)

Law Reform Commission of Canada (LRC), 130 Albert Street, Ottawa, Ontario.

Established by the federal government in 1971 and concluded in 1992, the LRC reviewed federal laws and recommended reform on a continuing basis as modernization. The Protection of Life Project dealt with issues in biomedical ethics.

Criteria for Determination of Death (1979)

Sterilization: Implications for Mentally Retarded and Mentally Ill Persons (1979)

Sanctity of Life or Quality of Life (1979) (Study Paper by E.W. Keyserlingk)

Medical Treatment and Criminal Law (1980)

Consent to Medical Care (1980) (Study Paper by Margaret A. Somerville) **[End Page 96]**

Criteria for Determination of Death (1981)

Euthanasia, Aiding Suicide and Cessation of Treatment (1983)

Behaviour Alteration and the Criminal Law (1985)

Obtaining Forensic Evidence: Investigative Procedures in Respect of the Person (1985)

Some Aspects of Medical Treatment and Criminal Law (1986)

Options for Abortion Policy Reform (1986)

Crimes Against the Foetus (1989)

Biomedical Experimentation Involving Human Subjects (1989)

Medical Research Council of Canada (MRC), Communications and Information Branch, 5th Floor, Tower B, 1600 Scott Street, Ottawa, Ontario K1A 0W9.

The federal government grant-funding agency for basic, applied, and clinical research in health sciences, the MRC appointed a Working Group on Human Experimentation, which produced a set of guidelines. In 1984, the MRC established a Standing Committee on Ethics in Experimentation, which had as its first priority a review of the guidelines set up by the first group. This Standing Committee formed another Working Group to develop guidelines on somatic cell gene therapy.

Ethics in Human Experimentation (1978)

Revised Guidelines on Research Involving Human Subjects (1987)

Guidelines on Research on Somatic Cell Gene Therapy in Humans (1990)

National Council on Bioethics in Human Research (NCBHR) [Conseil National de la Bioéthique en Recherche chez les Sujets Humains (CNBRH)], 774 Echo Drive, Ottawa, Ontario K1S 5N8.

Founded in 1989 by the Medical Research Council of Canada (MRC), the Royal College of Physicians and Surgeons of Canada (RCPSC), and Health Canada (HC), NCBHR's original mandate was "to support the interpretation and implementation of ethical guidelines on research involving human subjects." That included an advisory role to local institutional Research Ethics Boards. In 1994, NCBHR broadened its mission beyond biomedical research into the ethics of health and social science research involving human beings. Membership will expand beyond the original 20 members from the health professions, ethics,

philosophy, law, humanities, and the lay communities to reflect the addition of the Natural Sciences and Engineering Research Council of Canada (NSERC) and the Social Sciences and Humanities Council of Canada (SSHRC).

NCBHR Communiqué (1990--date)

Ethical Aspects of Pharmaceutically-Based Clinical Investigations (1990)

Ethics of Clinical Trials for Research Ethics Board: Proceedings of a National Workshop (1991)

Legal Aspects of Research and Clinical Practice with Children (1992) **[End Page 97]**

Legal Aspects of Research and Clinical Practice with Human Beings (1992)

Report on Research Involving Children (1993 revised; 1997 reprint)

Proceedings of the Workshop on the Ethics of Research with Children (1993)

Bioethics of Research with Human Subjects in the Health Sciences (1995)

Protecting and Promoting the Human Research Subject: A Review of the Function of Research Ethics Boards in Canadian Faculties of Medicine (1995)

Facilitating Ethical Research: Promoting Informed Choice (1996)

Royal Commission on New Reproductive Technologies [Commission Royale sur les Nouvelles Techniques de Reproduction].

The Commission was established in 1989 as an ad hoc group to report on issues surrounding the new reproductive technologies, including preconception arrangements, gene therapy and genetic alteration, use of fetal tissue in research, and judicial intervention in pregnancy and birth.

Proceed with Care: Final Report (1993)

Research Studies: New Reproductive Technologies; Ethical Aspects (1994)

Social Values and Attitudes Surrounding New Reproductive Technologies (1994)

Overview of Legal Issues in New Reproductive Technologies (1994)

Legal and Ethical Issues in New Reproductive Technologies; Pregnancy and Parenthood (1994)

New Reproductive Technologies and the Science, Industry, Education and Social Welfare Systems in Canada (1994)

The Prevalence of Infertility in Canada (1994)

Understanding Infertility Risk Factors Affecting Fertility (1994)

Prevention of Infertility (1994)

Treatment of Infertility Assisted Reproductive Technologies (1994)

Treatment of Infertility Current Practices and Psychosocial Implications (1994)

New Reproductive Technologies and the Health Care System: The Case for Evidence-Based Medicine



(1994)

Prenatal Diagnosis Background and Impact on Individuals (1994)

Current Practice of Prenatal Diagnosis in Canada (1994)

Technologies of Sex Selection and Prenatal Diagnosis (1994)

Background and Current Practice of Fetal Tissue and Embryo Research in Canada (1994)

CZECH REPUBLIC. Central Ethical Commission (CEC) [Centralni Eticka Komise], Ministry of Health, Palaokeo nem.4, 128 01 Praha 2.

Created in 1990 after the 1989 revolution, the CEC acts as an advisory board to the Ministry of Health. Its 28 members are appointed by the president of the Scientific Council of the Minister of Health, and consist of 3 lawyers, 2 priests, 2 psychologists, a pharmacist, **[End Page 98]** and medical specialists. Among its works are a report to the Minister of Health on drugging athletes; publication of the Rights of Sick Persons in medical journals and daily papers and of the Principles of Assessment of Clinical Trials for support of local ethics committees; investigations into the quality of medical care in prisons and the problem of political hunger strikers; discussion on the refusal of treatment by Jehovah's Witnesses; discussion of euthanasia and the conclusion that it was not an ethical problem, but that attention should be paid to the social problem of euthanasia and medical service; no recommendation on methadone due to lack of a national drug problem; and the national mapping of the 18 local commissions in hospitals.

DENMARK. Danish Council of Ethics [Det Ethiske Råd], Ravnsborggade 2-4, DK-2200, Copenhagen N.

Founded in 1987, the Council secures information and advice on ethical problems arising from developments in the health service and from biomedicine. It reports annually to the Parliament in addition to publishing reports and statements for public authorities and the public in general. Of its 17 members, 9 are appointed by Parliamentary committee with none being members of Parliament or regional or local councils, and 8 are designated by the Minister of Health based on knowledge of the social, ethical, and cultural issues. Membership is split evenly by gender.

The Death Criteria: A Report (1989)

Protection of Human Gametes, Fertilized Ova, Embryos and Fetuses: A Report (1990)

Fetal Diagnosis and Ethics: A Report (1991)

Public Discussion about Bioethics (1992)

Protection of Sensitive Personal Information: A Report (1993)

Genetic Screening: A Report (1993)

Genetic Testing in Appointments, etc. (1993)

Patenting Human Genes: A Report (1994)

Extreme Prematurity, Ethical Aspects: Debate Outline (1995)

Assisted Reproduction: A Report (1996)

Health Science Information Banks: Biobanks (1996)

Working Paper on Cloning (1997)

Priority Settings in the Health Service (1997)

Euthanasia: Summary of a Report for Use in Public Debate (1997)

Late, Induced Abortions (1997)

FRANCE. National Consultative Committee on Ethics in the Biological and Medical Sciences [Comité Consultatif National d'Éthique pour les Sciences de la Vie et de la Santé (CCNE)], 71 rue Saint-Dominique, 75007 Paris Cedex 13.

Created in 1983, the CCNE is a permanent agency that succeeds the Ethics Committee of the Institut National de la Santé et de la Recherche Scientifique (INSERM). Its mission is to give opinions on ethical problems raised by advances in biology, medicine, and health and to publish recommendations. Besides a president and [End Page 99] honorary president, its 39 members include 19 in ethics, 15 in scientific research, and 5 in religion. An independent, consultative body, CCNE is linked to the Ministers for Research and Health. INSERM through the Centre de Documentation et d'Information en Éthique de l'Institut National de la Santé et de la Recherche Médicale (CDEI) provides technical and administration support.

Avis sur les Prélèvements de Tissus d'Embryons ou de Foetus Humains Morts a des Fins Thérapeutiques, Diagnostiques et Scientifiques (1984)

Avis sur les Problèmes Éthiques Nes des Techniques de Reproduction Artificielle (1984)

Problemes d'Éthique Posées par les Essais chez l'Homme, Nouveaux Traitements (1984)

Lettre du Comité Consultatif National d'Éthique pour les Sciences de la Vie et de la Santé (1985)

Avis sur les Registres Médicaux pour Études Épidémiologiques et de Prévention (1985)

Avis concernant les Problèmes Éthique Posées par l'Appréciation des Risques du SIDA par la Recherche d'Anticorps Spécifiques chez les Donneurs de Sang (1985)

Génétique, Procréation et Droit (1985, INSERM)

Avis de Recherche sur l'Embryon (1987)

Recherche Médicale et Respect de la Personne Humaine (1988)

Éthique Médicale et Droits de l'Homme (1988, INSERM)

Avis sur la Thérapie Génétique (1990)

Éthique et Connaissance (1990)

Avis sur la Non Commercialisation de Genome Humain (1992)

Avis sur la Transfusion Sanguine au Regard de la Non Commercialisation du Corps Humain (1992)

Questions Éthiques Posées par l'Obligation de Tests Génétiques pour les Concurrentes des Jeux d'Alberville (1992)

Éthiqué et Pédiatrie (1992)

Avis sur le Dépistage de l'Infection par le Virus du SIDA (1993)

Avis Relatif aux Comités d'Éthique (1993)

Génétiq e et M decine: de la Pr diction   la Pr vention (1997)

GERMANY. Central Commission for the Observance of Ethical Principles in Reproductive Medicine, Research on Human Embryos and Gene Therapy, Bundesministerium f r Gesundheit, Deutscherstr. 87, 5300 Bonn 2.

The Benda Commission. Arbeitsgruppe IVF, Genomanalyse und G ntherapie (1985)

Enquetekommission des Deutschen Bundestages. Bericht: Chancen und Risiken der Gentechnologie (1987)

GREAT BRITAIN. Human Genetics Advisory Commission (HGAC), Office of Science and Technology, Room G/12, Albany House, 94-98 Petty France, London SW1H 9ST.

In response to the second report on human genetics by the House of Commons Science and Technology Select Committee, the government established **[End Page 100]** HGAC in December 1996. As an independent group, HGAC will consider the broad social, ethical, and economic consequences of developments in human genetics, such as insurance, employment, patents, and public health. Its future reports will go to the Industry and Health Ministers. Members include the chairs of the Advisory Committee on Genetic Testing, the Gene Therapy Advisory Committee, and the Nuffield Council on Bioethics.

Department of Health and Human Services, The Peel Commission.

This Advisory Group chaired by John Peel was an interdisciplinary group appointed in 1970 to consider the ethical, medical, social, and legal implications of using fetuses and fetal material for research. Members were five doctors (including the chair), three lawyers, two nurses, and a social worker.

The Use of Fetuses and Fetal Material for Research; Report of the Advisory Group (1972)

Department of Health and Human Services, The Warnock Commission.

Chaired by philosopher Mary Warnock, the Committee consisted of 15 other members: 6 medical practitioners, 3 lawyers, 2 social workers, a nurse, a charitable trust director, a research scientist, and a theologian. Its charge was to examine the social, ethical, and legal implications of recent and potential developments in assisted reproduction. Its report is a landmark because of its different treatment of moral issues and explanation of the difficulties in seeking consensus in ethics.

Report of the Committee of Enquiry into Human Fertilisation and Embryology (1984)

Department of Health and Human Services, The Polkinghorne Commission.

The Rev. Dr. John Polkinghorne, who currently chairs the Advisory Committee on Genetic Testing and is a member of the Human Genetics Advisory Commission, chaired this Commission.

Review of the Guidance on the Research Use of Fetuses and Fetal Material (1989)

Department of Health and Human Services, The Clothier Commission.

Report of the Committee on the Ethics of Gene Therapy (1992)

HUNGARY. Scientific and Research Ethics Committee.

Set up by the Scientific Health Council in 1987, the Committee is made up of 20 members, which include physicians, theologians, ethicists, and lawyers. It oversees human subjects research and coordinates the

regional research ethics committees.

Bioethics Commission.

This Commission was established in 1990 by the Parliament Committee on Social, Health and Family Welfare as an advisory body to legislators and on legislation. Its 16 members include health professionals, sociologists, and philosophers.

ITALY. National Ethics Committee [Comitato Nazionale di Bioetica], Via dei Villini 13-15, 00161 Rome.  
**[End Page 101]**

Created in 1990 by the president of Council of Ministers, the Committee advises Parliament on ethical and legal issues connected with research in the life and health sciences or with clinical therapies. Of its 40 members, 36 come from various disciplines and the remaining 4 represent professional organizations, including the Italian Medical Association.

Donazione d'Organo a Fini di Trapianto (1991)

Problemi della Raccolta e Trattamento del Liquido Seminale Umano per Finalita Diagnostiche (1991)

Terapia Genica (1991)

I Comitato Etici (1992)

Diagnosi Prenatali (1992)

Informazione e Consenso All'atto Medico (1992)

JAPAN. Ad Hoc Committee on Brain Death and Organ Transplantation, House of Representatives [Dai-ichi Giin-kaikan], 2-2-1 Nagata-cho, Chiyoda-ku, Tokyo 100.

Dr. Taro Nakayama, a former Minister of Health Affairs, now chairs this Diet Committee.

Report on Brain Death (1992)

LUXEMBOURG. National Consultative Committee on Ethics in the Biological and Medical Sciences [Commission Consultative Nationale d'Éthique pour les Sciences de la Vie et de la Santé], 12-14 avenue Emile Reuter, 2919 Luxembourg.

Established in 1988, the Commission falls under the Ministry of the State as an advisory agency on ethical issues of the life and health sciences.

Avis concernant la Brevetabilité des Inventions Biotechnologiques (1992)

MALTA. Bioethics Consultative Committee, Ministry for Home Affairs and Social Development, Casa Leoni, St. Joseph High Road, Santa Venera HMR 18.

MEXICO. National Bioethics Commission [Comision Nacional de Bioetica].

Begun in 1992, the Commission reports to the Ministry of Health on medical and environmental issues. The 10 members and executive secretary are health professionals appointed by the Secretary of Health, who acts as the Commission's president.

NETHERLANDS. Commission on Health Ethics and Health Law (CHEHL), Health Council [Gezondheidsraad], P.O. Box 90517, 2509 LM The Hague.

Since 1977, CHEHL has operated under the Health Council, which is the government advisory board on public and environmental health, to transmit to the government findings on specific topics of ad hoc committees set up by the Health Council.

Interim Consultative Committee on the Ethical Aspects of Medical Research [Kerncommissie Ethiek Medisch Onderzoek (KEMO)], Ministry of Welfare, Health and Cultural Affairs, Postbus 5406, 2280 HK Rijswijk.

This Committee, as the national advisory commission on medical research and related legal, ethical, and social issues, makes nonbinding recommendations to local ethics boards. It was established in 1989 by the Minister [**End Page 102**] of Welfare, Health and Cultural Affairs.

NEW ZEALAND. Health Research Council of New Zealand, Ethics Committee, P.O. Box 5541, Wellesley Street, Auckland.

The Council is the major government-funded agency for purchasing and coordinating health research. The Committee was set up in 1990 to create guidelines on health research ethics and to accredit other ethics committees.

HRC Guidelines on Ethics in Health Research [From the HRC Handbook] (revised 1997)

NORWAY. Ministry of Health and Social Affairs, P.O. Box 8011 Dep., 0030 Oslo 1.

Biotechnology as Related to Human Beings (1993)

National Biotechnology Advisory Board [Bioteknologi Nemnda], P.O. Box 8027, N-0030 Oslo.

The National Committees for Research Ethics [National Committee for Medical Research Ethics (NEM); National Committee for Research Ethics in Science and Technology (NENT); National Committee for Research Ethics in the Social Sciences and the Humanities (NESH)], The Research Council of Norway, Gaustadalleen 21, N-0371 Oslo 3.

The three national committees were established by Parliament in 1990. Unlike NENT and NESH, NEM had existed prior to legislative passage. NEM's mandate covers research ethics in medicine and health and the life sciences. NENT's responsibility for research ethics lies in the natural sciences and technology; industrial, agricultural, and fisheries research; and biotechnology and gene technology not covered by medicine. NESH's area concerns research ethics in the social sciences and the humanities, including law and theology. At the minimum, each committee has nine members, with two of those being lay members and the rest having competency in the fields relevant to the committee's scope.

PHILIPPINES. National Ethics Committee.

Created in 1987 along with institutional review committees when the Council for Health Research and Development published national guidelines on human subjects research, the Committee by law has a greater number of public members than physicians. Members include a homemaker, a lawyer, an environmentalist, a social scientist, a medical researcher, a Philippine Medical Association member, and a religious representative.

POLAND. Ministry of Health and Social Welfare, National Committee for the Supervision of Human Research.

Founded in 1982, this Committee addresses policy on human subjects research. The chair is a physician coming from the parent ministry, and the Minister appoints the members.

PORTUGAL. National Council for Biological Sciences.

Since its creation in 1990, the Council has reported to the Prime Minister on the applications and implications of new technologies to human life. Half of its 20 members are medical professors [End Page 103] or specialists; 4 judges, 3 philosophers, a biologist, an engineer, and a Catholic theologian or priest make up the remaining 10 members. Each member serves a five-year term. The Prime Minister appoints the chair. Parliament elects six members; ministries and scientific or professional organizations appoint the others.

Avis sur les Greffes d'Organes et de Tissus (1991)

RUSSIA. National Committee on Bioethics, Volkhonka 14, Moscow 119842.

Formed by the Russian Academies of Sciences and of Medical Sciences in 1992, the Committee primarily advises on ethical issues arising from new research or practice and makes reports or recommendations, although it can draft new laws or guidelines.

SWEDEN. National Council on Medical Ethics, Ministry of Health and Social Affairs, S-103 33 Stockholm.

Since 1985, the Council has been advising the government through the Ministry of Health and Social Affairs. The 18 member group, 7 of whom are Parliament members with the others coming from ethics, the arts, religion, and various organizations, selects its own topics and usually meets in closed sessions unless it wants to bring a particular bioethics issue to public attention. Its duties are to monitor research and to perform problem analysis, not investigation.

Committee on Transplantation.

Appointed in 1987 by the Minister of Health and Social Affairs, this ad hoc Committee was assigned to report specifically on the topic of transplantation prior to preparation of a legislative bill.

SWITZERLAND. Expert Commission on Human Genetics and Reproductive Medicine [Expertenkommission Humangenetik und Reproduktionsmedizin].

A joint commission of the Swiss Departments of the Interior and of Justice and Police, the 21 member Commission met from 1986 to 1988 to discuss new reproductive technologies and the legal, ethical, and social implications of them before advising the government in a report popularly known as the Amstad Report.

Botschaft zur Volksinitiative "gegen Missbrauche der Fortpflanzungsund Gentechnologie beim Menschen" (1989)

TURKEY. Higher Council of Health, Représentation Permanente de Turquie auprès du Conseil de l'Europe, 23 boulevard de l'Orangerie, 67000 Strasbourg, France.

The nine health care professionals who make up this Council, which was created by legislation in 1930, are chosen by the Minister of Health. The Council's scope includes bioethical issues, but its work is not published.

UNITED STATES. Office of Technology Assessment (OTA).

OTA was created by Congress in 1972 to provide legislators with independent and timely (within two years of the request) information about the effects of technological applications. The Health Program assessed specific clinical and general health care technologies, studied broader issues of health policy with technology implications, [End Page 104] and studied applications of the biological and behavioral sciences to human health in particular. The OTA was closed in 1995 due to federal budget cuts.

Human Gene Therapy (1984)

Reproductive Health Hazards in the Workplace, Volume I: Selected Ethical Issues in the Management of Reproductive Health Hazards in the Workplace (1986)

New Developments in Biotechnology: Ownership of Human Tissues and Cells (1987)

Mapping Our Genes: Genome Projects: How Big, How Fast? (1988)

New Developments in Biotechnology: Patenting Life (1989)

Genetic Tests and Health Insurance: Results of a Survey (1992)

Protecting Privacy in Computerized Medical Information (1993)

Biomedical Ethics in U.S. Public Policy (1993)

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.

The first public national body to shape bioethics policy in the United States, the National Commission was created by Congress in 1974 and ran under the Department of Health, Education and Welfare until 1978. Its final report, The Belmont Report, outlines the moral principles underlying research: autonomy, beneficence, and justice.

Research on the Fetus (1975)

Research Involving Prisoners (1976)

Research Involving Children (1977)

Psychosurgery (1977)

Disclosure of Research Information Under the Freedom of Information Act (1977)

Research Involving Those Institutionalized as Mentally Infirm (1978)

Ethical Guidelines for the Delivery of Health Services by DHEW (1978)

Institutional Review Boards (1978)

Implications of Advances in Biomedical and Behavioral Research (1978)

The Belmont Report: Ethical Principles and Guidelines for Protection of Human Subjects of Biomedical and Behavioral Research (1978)

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.

This Congressionally mandated group succeeded the National Commission when it was authorized in 1978. The group worked independently from January 1980 to March 1983.

Defining Death (1981)

Protecting Human Subjects (1981)

Whistleblowing in Biomedical Research (1981)

IRB Guidebook (1982)

Compensating for Research Injuries (1982)

Splicing Life (1982)

Making Health Care Decisions (1982-83)

Deciding to Forego Life-Sustaining Treatment (1983)

Implementing Human Research Regulations (1983) **[End Page 105]**

Screening and Counseling for Genetic Conditions (1983)

Securing Access to Health Care (1983)

Summing Up (1983)

Ethics Advisory Board (EAB).

This group began in 1978 under the auspices of the Department of Health, Education and Welfare. Its pronouncement on human embryo research in 1979 followed by the EAB dissolution began a 15-year moratorium on such research.

HEW Support of Research Involving Human In Vitro Fertilization and Embryo Transfer: Report and Conclusions (1979)

Human Embryo Research Panel.

The National Institutes of Health formed this panel in January 1994 after Congress nullified the federal regulations that required review by a non-existent Ethics Advisory Board on human embryo research. The 19 members were selected not for their moral views but for their individual expertise in basic and clinical sciences, ethics, law, and public policy. The group classified human embryo research into three categories: acceptable, needing additional review, and unacceptable; it also drafted guidelines for the review and conduct of acceptable research. The Advisory Committee to the Director of NIH unanimously approved the report, but President Clinton issued a statement saying "I do not believe that federal funds should be used to support the creation of human embryos for research purposes, and I have directed that NIH not allocate any resources for such research." Consequently the moratorium on human embryo research funding essentially continues.

Report of the Human Embryo Research Panel: Final Draft (1994)

Biomedical Ethics Advisory Committee.

The 14 initial members of this Committee were selected by the Biomedical Ethics Board, which was made up of 6 senators and 6 congressmen. The group functioned only briefly from late 1988 to early 1989 and had two meetings before its parent group became politically deadlocked due to abortion politics, its appropriations were frozen, and finally its term expired in 1990.

National Bioethics Advisory Commission (NBAC).

NBAC met for the first time in October 1996, a year after it was created by Executive Order. Its initial two-year term has been extended two more years to October 1999. Originally assigned two priority areas on human subjects research and genetic information, after the announcement of the cloning of the sheep Dolly, at President Clinton's request NBAC produced a report on cloning, its first report under its advisory duties.



The maximum number of members is 18, with at least one member coming from each of the areas of philosophy or theology, social or behavioral science, law, medicine or the allied health professions, and biological research, in addition to three members from the public.

#### Cloning Human Beings (1997)

Advisory Commission on Consumer Protection and Quality in the Health Care Industry. **[End Page 106]**

Assigned to develop a "Consumer Bill of Rights" under the 1996 Executive Order creating it, the 32-member Commission is co-chaired by the Secretaries of Labor and Health and Human Services. The Commission's concern focuses on patient protections including the appeals and grievances processes and the quality of health care as measured by real outcomes and consumer satisfaction. A final report is due by 30 March 1998 for review by Vice President Gore before submission to the president.

#### Proposed Consumer Bill of Rights and Responsibilities in Health Care (1997)

Advisory Committee on Human Radiation Experiments.

Created in January 1994 and dissolved in October 1995, the 14-member Committee was charged with the investigation of and to report on the use of human beings as subjects of federally funded research using ionizing radiation. To maximize public access as required under the Federal Advisory Committee Act, the Committee created for the first time a gopher site on the World Wide Web, which is now under the National Security Agency Archives at [www.seas.gwu.edu/nsarchive/radiation](http://www.seas.gwu.edu/nsarchive/radiation).

#### Interim Report (1994)

#### Final Report (1995)

NIH-DOE Joint Working Group on Ethical, Legal and Social Implications (ELSI) of Human Genome Research, U.S. Department of Energy (DOE), 19901 Germantown Road, Germantown, MD 20874, and U.S. Department of Health and Human Services, National Institutes of Health (NIH), National Human Genome Research Institute (NHGRI), 31 Center Drive, Building 31, Room 4B09, MSC 2152, Bethesda, MD 20892.

ELSI is the largest bioethics initiative funded by the government, where a percentage of the research budgets within two executive departments is set aside to study the ethical, legal, and social implications of research on the human genome. Begun in 1989, a Joint Working Group between the two departments, more popularly known as the ELSI Working Group, analyzes critical issues and provides guidance. Currently ELSI focuses on four priority areas: (1) the use and interpretation of genetic information; (2) clinical integration of genetic technologies; (3) issues surrounding genetics research; and (4) public and professional education and training on those issues.

U.S. Congress. Senate. Committee on Labor and Human Resources.

#### Biomedical Ethics and U.S. Public Policy; Hearing (1993)

#### Recombinant DNA Advisory Committee (RAC).

RAC was created in 1976 in the original NIH Guidelines for Recombinant DNA Research. Its purpose is threefold: to provide a public forum for debate over issues involving recombinant DNA; to make recommendations to the Director of NIH on changes in the research guidelines; and to review individual research protocols as need be. **[End Page 107]**

### **III. State/Provincial**

AUSTRALIA. New South Wales, Law Reform Commission.

Human Artificial Insemination: Report (1986)

Surrogate Motherhood: Australian Public Opinion, Research Report (1986)

Discussion Paper 2: In Vitro Fertilization (1987)

Report on In Vitro Fertilization (1988)

Queensland.

Report of the Special Committee Appointed by the Queensland Government to Enquire into the Laws Relating to Artificial Insemination, In Vitro Fertilization and Other Related Matters (1984)

South Australia.

Report of the Select Committee of the Legislative Council on Artificial Insemination by Donor, In Vitro Fertilization and Embryo Transfer Procedures and Related Matters in South Australia (1987)

Tasmania.

Committee to Investigate Artificial Conception and Related Matters: Final Report (1985)

Victoria. Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization.

Known as the Waller Committee, for its chair, law professor Louis Waller, the nine-member committee also included two theologians, a former schoolteacher, two professors of medicine, one general medical practitioner, a family lawyer, and a social worker. It operated between 1982 and 1984.

Interim Report of the Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization (1982)

Report on Donor Gametes in IVF (1984)

Report on the Disposition of Embryos Produced by In Vitro Fertilization (1984)

Western Australia.

Report of the Committee Appointed by the Western Australian Government to Enquire into the Social, Legal and Ethical Issues Relating to In Vitro Fertilization and its Supervision (1986)

CANADA. Alberta. Human Tissue Procurement Task Force.

Report (1985)

Ontario. Ontario Law Reform Commission (OLRC).

The Ontario Law Reform Commission worked from 1982 to 1985. Although all five commissioners were legal scholars, the Commission retained an expert in medical law and ethics, who then appointed an advisory board with expertise in law, medicine, social work, philosophy, and ethics.

Report on Human Artificial Reproduction and Related Matters (1985)

UNITED STATES. New Jersey. Commission on Legal and Ethical Problems in the Delivery of Health Care (formerly **[End Page 108]** New Jersey Bioethics Commission), CN061, Trenton, NJ 08625-0061.

Proposed New Jersey Advance Directives for Health Care Act (1988)

Policy Statement for Triennial Report (1988)

Problems and Approaches in Health Care Decisionmaking: The New Jersey Experience: A Report (1990)

Advance Directives for Health Care: Planning Ahead for Important Health Care Decisions (1991)

The New Jersey Advance Directives for Health Care and Declaration of Death Acts: Statutes, Commentaries and Analyses (1991)

The New Jersey Declaration of Death Act Statute and Commentary (1991)

Policy Recommendations on Surrogacy (1991)

After Baby M: The Legal, Ethical and Social Dimensions of Surrogacy (1992)

The New Jersey Advance Directives for Health Care Act (and the Patient Self-Determination Act): A Guidebook for Health Care Professionals (1992)

New York. New York State Task Force on Life and the Law, 5 Penn Plaza, 3rd Floor New York, NY 10001-1803. Tel. 212-613-4303.

This ongoing multidisciplinary 25-member group began in 1985 with a broad mandate to recommend public policy issues guided by medical advances.

The Required Request Law (1986)

The Determination of Death (1986)

Life-Sustaining Treatment: Making Decisions and Appointing a Health Care Agent (1987)

Fetal Extrauterine Survivability (1988)

Transplantation in New York State: The Procurement and Distribution of Organs and Tissues (1988)

Surrogate Parenting: Analysis and Recommendations for Public Policy (1988)

Do Not Resuscitate Orders, 2nd edition (1988)

When Others Must Choose: Deciding for Patients Without Capacity (1992)

When Death Is Sought: Assisted Suicide and Euthanasia in the Medical Context (1994)

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