The Acadia Institute Project on Bioethics in American Society

November 11, 1999. Interview with Patricia A. King, JD, Carmack Waterhouse Professor of Law, Medicine, Ethics and Public Policy, Georgetown University, Washington, DC. The interview is being conducted by Judith P. Swazey, PhD at Professor King’s office at Georgetown.

Swazey: Let’s start with a little about your family background, where you were raised and what your parents did.

King: Okay. I was born in Norfolk, Virginia in 1942. My mother was the secretary to the publisher of a black newspaper. My father worked, I don’t know where, in the same newspaper. And pretty shortly, maybe three or four years later, he went to work for the Pittsburgh Courier, which was also a black newspaper, in advertising. So that was the early form of the commuting marriage. My parents separated when I was six and my mother basically raised my sister and I, by herself after that time. I know very little about my father, which will be clear as I’m talking about this, but he was diagnosed with tuberculosis about four months after they separated and spent maybe the next five years in a sanitarium. At least I don’t remember him being out for visits until I was twelve or thirteen.

Norfolk was a segregated port city. My mother left the Norfolk Journal and went to work for the city. The two parts of city government that were duplicated were the education system and the recreation system, and she
went to work as a secretary to the then Negro head of Parks and Recreation. That was the job that she retired from, although it went through several cycles after desegregation. I went to public segregated schools in Norfolk, and when I graduated in 1959, schools were still segregated. *Brown v. Board of Topeka* had come down in 1954, but Virginia engaged in forms of massive resistance and desegregation was very slow.

Swazey: Then you went to Wheaton?

King: I went to Wheaton College in Norton Massachusetts for four years.

Swazey: What did you major in at Wheaton?

King: Religion and Philosophy.

Swazey: What attracted you to those?

King: Well, I just think I was a rebel. I just don’t think I knew it at the time. And I went to college and it had, Wheaton had distribution requirements and I decided to take a course in Biblical studies, just because it sounded
like the best in that area, and I fell in love with it. I thought it was wonderful.

Swazey: I minored in Biblical History at Wellesley.

King: Well it was wonderful. I loved it.

Swazey: Did you have a religious upbringing?

King: We were Episcopalian, and you know, as you know, the African-American community actually is quite religious. The Southern African-American community is very much so. The only unusual thing about my upbringing is that we were Episcopalian rather than Baptist. Half my family was Baptist but my mother became Episcopalian because my father was. I just liked it, and it was the cause of great consternation in my family that I decided to major in religion and philosophy. The philosophy I didn’t love, but Wheaton did not have a religion major. You had to major in Religion and Philosophy. It was all right. The religion part I did truly enjoy. In those days, we’re talking ’59 to ’63, women didn’t do much except teach school or some few women went on to get graduate degrees. But that wasn’t sort of the career path or way for women and that certainly was not
a path for black women. And my view was, well, then I shouldn’t worry about it. I’m in college. I should do what I want to do. That’s what I mean when I say I was an early rebel.

When I graduated, of course, I had not a clue where I would find a job, and my mother wanted me to become a lay worker in the church. I will never forget. It precipitated a big argument when I said I would never go work anywhere where I couldn’t rise to the top. And women could not be priests in those days so that ended that thought. When I graduated from Wheaton, I went home and stayed home for six months while I tried to figure out where I was going to get a job. I finally got a job in Department of State. So I moved to Washington. I was in an intern program. It was quite a good job and I did that for two years. But it was in a very difficult department, because State had a long history of elitism. It had a long history of really paying very little attention to women, and even more a long history of not paying very much attention to African-Americans or other minorities. So I stayed in State for two years, actually trying to figure out what to do next. I had a friend of mine that was at Law School at Yale and I went up to visit him and I took a look at his class and said, I can do this. It didn’t seem special. So I came to Georgetown Law School as a night student while I worked the third year at State. I decided that I really did like Law School, so I quit my job and went to Harvard. I had to
start over because I had been a night student and so I went for three years and graduated in 1969. I was a House Mother at Wellesley, by the way, the first year that Wellesley had young House Mothers. It was the time of the Vietnam Conflict. Lots of rebellion. The students at Wellesley had demanded a greater diversity and youth, including age, and four of us were hired that year. It was quite an experience.

Swazey: Yes. When I was there the House Mothers still poured tea with a full tea service. I graduated in '61. The House Mother still had a very traditional role.

King: Well, I was supposed to pour tea on Wednesday afternoons. I must say, I don’t think they knew what they were getting when they were getting me. Because the first thing I did was I rebelled against the pouring of tea. Somehow it did not fit with my image of myself to pour tea and so I delegated it on a rotating basis to the students, and then we all gathered on the floor to play bridge and things like that. Wheaton had been a much more informal place without all of those kinds of trappings.

Swazey: Which dorm were you in?
King: Davis. Hilary Clinton was a senior in my dorm. As was Elizabeth, I mean to say Betsy, Griffith, who did the biography of Elizabeth Cady Stanton that’s currently showing on film, on public television. Betsy is Head Mistress at Madeira. I got along very well with the seniors at Wellesley, many of whom I talked to over a long period of time. I had two who wanted to go to Law School and this was still fairly early in the period in which women were going to Law School. So it was an interesting experience.

Swazey: When you went to law school did you have an idea as to what you wanted to do with it?

King: Well, I actually thought that I was going to be doing public interest law, specifically, civil rights law. But I put myself through law school and it turned out to be an experience that left me not with very much money by the time I got through. And although I interviewed, public interest law was then like it is now: it doesn’t pay very much and so I had serious problems. But I did go work for the Federal Government. I worked at the Equal Employment Opportunity Commission as a Special Assistant to the Chair. Then I went to the Office of Civil Rights at HEW and I was Deputy Director. It was a Republican Administration. I am not a Republican. It
had been okay to be Deputy, because that was an office that was then one
of the most controversial offices in government. It is not now. But
because it was in charge of school desegregation it was very controversial,
and the director and I had an arrangement, which was that I did no school
desegregation issues because I objected to the stance of the Nixon
Administration and I didn’t want to be a part of it. So I did affirmative
action. It was the beginning of affirmative action and higher education.
When the director left to become Assistant Attorney General at Justice,
they did offer me the job of Director but I turned it down. But you know,
when you turn down a job like that, you have to leave too. Because it’s
not fair to anybody coming in.

So I took a year’s leave to see if I liked teaching at Georgetown. I
liked it very much. Georgetown offered me a tenure track position the
following year and I left HEW. It was that decision that got me into
bioethics. Cap Weinberger was the Secretary of HEW and I was very
lucky because his top assistant was one of my law school classmates,
William Taft IV, whom I’d actually known pretty well in law school.
When they realized I really was not going to come back, the Secretary
asked me would I like to work on this new commission that was being
established and I thought that would be a great idea. I think I got asked,
although I don’t know this for sure, because the Tuskegee Commission
had just finished its work. And Tuskegee was one of the forces that led to
the creation of the National Commission for the Protection of Human
Subjects. Because I had a Civil Rights background, and because I’m
black, you know, I fit, even without a background in medicine or
philosophy. It was a good niche. And that sort of changed me. Changed
my whole focus. I loved it. I loved being on the National Commission. I
loved the work we were doing. The people were really interesting. So
I’ve been at Georgetown and doing this kind of work ever since.

Swazey: The element of serendipity in our lives is amazing.

King: Isn’t it incredible? It really is.

Swazey: What did you love about the Commission and its work?

King: I liked the process, though I didn’t understand that then. There was
something very attractive about people deliberating about hard issues in
good faith, not being advocates one way or the other. I mean, today the
field is filled with a lot of controversies marked with advocacies in a way
that it wasn’t in the early ‘70’s. So I liked that. It was a thoughtful
development of policy, I thought. Mind you, I never thought of it as an
ethics commission and that shouldn’t be surprising. I kept thinking of it as
a public policy-making body. And for me it always was. But it was a very
special kind of public policy making. It was one where you could take a
lot of the political issues out of it and really try to struggle together
through hard issues. So it was the process I was really attracted to, I think.
But I was also attracted to the subject matter. It was a relatively new area.
Things were not in concrete. For lawyers, you think of always dealing
with what has come before. This was an area which has long antecedents
but what has come before was quite different than what I was used to
working with. I had always been attracted to medicine and had given
some thought early on in my life about going to med school, because I like
science. I had given up that thought in college, mostly I think because I
wasn’t sure about career patterns. Law was easier to figure out. And so I
was very attracted to the science and to the medical questions. We were
dealing with research on human subjects, so you could really be attracted
to the science aspect. The basic science questions of fetal tissue research,
for example. It was also the medicine as well, but I focused less on the
medicine then. I was very accepting of the paradigms that people were
operating with, about doctor-patient relationships for example, without a
great deal of questioning about it. In hindsight because I never made a lot
of it at the time, the only unease I ever felt at the National Commission
was when we spent a lot of time talking about questions of consent. That focus was very troublesome for me and it did come to a head in some ways when we were doing research with prisoners. There were big Commission debates about whether this (research on prisoners) was an issue of the voluntariness of consent or whether this was an issue of social justice. I knew so little that I didn’t know then I had really come down on this side of social justice. I was making my arguments about prisoner research being a question of exploitation, taking advantage of people in a disadvantaged situation. But I didn’t think it was because they couldn’t consent. I thought they were extraordinarily knowledgeable about the constraints of their own lives, and they understood very well what options they had. They understood participation in research. Many of them saw it as an avenue to obtain what they otherwise could not obtain. They were quite pragmatic about it and to my liberal “do gooder” approach, many prisoners, particularly black prisoners, to my amazement said, “I wish you’d get out of here, we really don’t need you, I’m doing just fine. My problem is that we don’t get access to the research that we would like to participate in.” Not “we were afraid of participation,” because in prison, unlike the external world, participation in research was, for those who wanted to participate, a plum. Because it gave them other things. It gave them access to a health system, for one thing. What I always heard was
that they got a health examination, etc. and it was true. The medical
facilities in most prisons then, and I assume now, are not very good. So
that’s what I took away with me: this nagging view that the theoretical
formulations about autonomy and informed consent were fine, but it
wasn’t working for me. And I think that’s who I am. I think that was my
life experience speaking. I think that was my gut that I should have paid a
lot more attention to, but I was young. That emphasis on autonomy and
consent didn’t resonate with what I understood about growing up about the
choices people have to make and how they make those choices. How
much time they have for self-education, how they really understand or
cannot understand.

Swazey: On that Commission you were surrounded by bioethicists, which was a
fairly identification, and the focus on autonomy so overwhelming.

King: Oh, it still is.

Swazey: Renée and I have long pondered and talked to people like Norm Daniels
and others about why bioethics has virtually ignored social justice issues in
health care. There have been very few people who have dealt with that
and the reasons are....
I think one of the reasons, because I see it in law all the time, is that our whole frame of thinking is in terms of individualism. It is in terms of individual rights. When we do Constitutional Law that is what we are interested in. I raise this with my students all the time: when it comes to issues of family, for example, that you can’t neatly place into an individual rights framework. Part of it also is not because people don’t think about it and it’s not a part of peoples’ experience, but it is very hard to develop philosophically or theoretically. To have an emphasis on a unit as distinct from the individual. The only place where people in my experience have been comfortable talking about units, be it the family, local community, or maybe the broadest society, is when they operate with some religious framework as the backdrop. If you look at the early history of the family in the United States, for example, many of the values that permeated that area were derived from backgrounds in Christianity and Judaism. We see it all the time -- all the moral concerns that found their way into family law. So I suspect that bioethics is very similar: that we work best when we deal with that unit, the individual, that Western philosophy’s been concerned about for the last 300 years. But ultimately I really find it quite cold; it does not reflect what I consider a good life. It doesn’t take account of what for me has been the best of living and that is interactions with other people. Dependency on others, growing with others, which is why I
think that the beginning of feminism, for example, in law and the academy
generally, and in bioethics has been a good thing. Because it’s forced us to
start looking at some issues in a different way. I would like to live long
enough to see this also take place with non-majority people. In other
words, I really would like to see, and I’d like to be part of it myself, except
I’m pretty old at this point, not just the introduction of a cultural emphasis
or appreciation of trying to thinking about culture in bioethics, but
specifically to take on some of the issues in the United States. We’ve
never dealt very well with race in bioethics. Although Tuskegee is a
defining event in bioethics in the United States, we’ve been very slow.
My example is we still think of Tuskegee as an informed consent problem.
In my way of thinking, informed consent is at the bottom of what kind of
problems Tuskegee was. We should have gotten to it last. It’s not that it’s
not important, it’s just that it seems to me in thinking about Tuskegee,
whether or not those men consented is at the end of a long list of problems
that they were encountering in their lives and as participants in that
particular experiment, or study. So you’re right about looking back. I
know I was surrounded by bioethicists, and boy was I young. But I’ve
been back through some of the National Commission transcripts recently,
through prisoner research, for example, and the transcripts of the Belmont
Swazey: Hmm, and Karen’s coming from the religious tradition you talked about...

King: Yes, and so did Al Jonsen. It just got lost. I mean, when I looked back I said to myself when I was reading these transcripts, how did I let this go by? Why didn’t I grab hold of that statement that Karen just made? And latch on to that and see if we could develop something with that?

Swazey: As you probably know, when the President’s Commission discussed doing a report on access to health care there was a fairly vigorous fight about it, because some of the staff and Commissioners said that’s not an ethical issue, that’s economics and so forth. There still is that sense that all those social justice/access types of issues belong someplace else, and I think it’s a sad or bizarre view of bioethics.

King: Well, I think that the field’s not going to go anyplace unless it grows. That I’m convinced.

Swazey: But it also, I think is connected with the extent to which analytic philosophy has dominated bioethics...

King: That’s true.
... and it’s wonderful fit with our American jurisprudence.

That’s exactly right.

If bioethics had bioethicists who had more exposure to Continental philosophy and some of the European notions like solidarity, things might have taken a very different turn.

Let me back track. The second explanation for the focus on autonomy and individualism is the kinds of issues that presented themselves at the time. One of the first issues was research on human subjects and the second one was dying and death, and also the area that you worked in a great deal, organ transplantation. Those issues lent themselves to a focus on individuals and rights. You could look at them from other directions; there’s nothing about death that makes it a solitary experience only. But they’re also so easy to pull into this individualistic autonomy framework. Even organ transplantation, where you’re really making a connection with somebody else, can still be talked about in terms of the rights of the persons giving up the organ. Or the rights of the former person giving up the organ. Reproduction, once we get past abortion, offers I think the prospect of being different. Because reproduction and all the technologies
coming down the pike dealing with everything from stem cell research to
embryo research to cloning, lends itself more -- I hope I’m right on this
one -- more to having to take a look at the family. It’s very hard to look at
the family or creation of the family in just the frame of individuals. It’s
such a shock to people to have to think about pregnant women issues, or
creation of children issues, as my decision to do this without going further.

Swazey: Is that one of the reasons you focused a lot of your work on reproduction?

King: Yes. And I hope actually that in my career I’ll also focus a lot of my work
on race, because I’ve come full circle. I always was a big fan of Renée’s
because she made more sense to me than anybody else. She would say
things that resonated. I knew her outside of bioethics contacts as well.
But I’m not a sociologist and I did not have a lot of background in social
sciences either. I took one course in race relations and it was actually one
of the best courses I had in college, but for some reason in my mind race
relations was not sociology. I don’t know why I got myself into that box.
But until I retire I actually would like to spend, my time on questions
about race, culture and health. It makes me happier. That’s the best thing
I can think of. It’s not a struggle to have to do the reading, or to think
through some of the issues and so I sort of realized that I’m at home. It’s
one of those self awareness things.

Swazey: Personally and professionally?

King: Personally and professionally, and it takes me into public health much
more so than thinking about private health care problems that arise in the
medical as distinct from the public health arenas. It’s very hard to stay in
public health -- though people do -- and just talk about individuals. You
really are forced to move out of that and I get excited. The book, *The
Spirit Catches You and You Fall Down*, the Anne Fadiman book on the
Hmong, when I read that I was so excited, even though that’s not public
health, because finally we were talking about very hard issues in terms of
both the people who want to provide care and the people who seek care.
Misunderstandings, problems of communications. I just found that much
more interesting for example than a lot of things I had read or engaged in,
or done before, if you must know the truth. And I’ve served on a lot of
panels and a lot of commissions, and I’d like to think I’ve done well. But I
can’t...

Swazey: Your CV is overwhelming, Professor King!
I never was excited, you know, and this is different. I just wish I had sort of understood some of these things about myself earlier. I've taken a long time getting here.

Well, we get into our tracks and it's hard to step out.

Yeah, it is. It really is.

But, you know, I think another unfortunate cleavage has been the fact that public health has been over here... And medicine has been over here.

And it's one reason why bioethics, or bioethics, or biomedical ethics has not been involved in public health.

That's right. And one of the concerns, well, this goes back to when I say I sort of feel at home. I rediscovered things. I had long repressed memories. That's the best way I can explain it. I mean, I hadn't thought about some things in years. Something special that triggered all of this was to write about Tuskegee. When my father had tuberculosis, even
though we didn’t live with him when he was identified, it didn’t matter.

We lived in public housing and the requirement was that there was a

family, because they were not divorced, with a communicable disease.

Then you had to be regularly screened in the public health system. I know

of no experiences that I can come up with in my personal life that were

worse than having to go to the TB screening clinics in a segregated city. It

was so bad. My mother, in her own way, is a very special person. She did

understand this. It was so bad as a teenage girl, to go and sit all day in this

little tiny place and wait for a chest x-ray and the same test they do now,

the screening test. They served both black and white people, but it was

segregated so the black people went off to their own little waiting area.

Men, women, teenagers, kids, people brought their kids because they were

going to be there all day, sitting in a tiny room, with a little top on. Like

they do the hospital things now -- you had to take off everything from the

waist up. Small room, close quarters, smells, and there would be a teenage

girl who is really upset about bodies. Well, it was without a doubt the

worst experience I ever had in my whole life. And I went for several

years. We had to go, all of us, and my sister kept testing positive. She

didn’t have TB but she did test positive so they really made us come back.

Finally one year I just couldn’t take it and cried and cried and said, Mom I

just can’t go. I cannot deal with this. So she and my sister went and
because I didn't show up they threatened to evict us. They said if I didn’t
go submit to the public screening, I could go to a private clinic as a private
patient and get the chest x-ray and the screening and pay for it, but that
was the only alternative. We were very poor. My mother was struggling
to keep all of us together. She sent me to a private hospital. She is a very
special person because she understood exactly. But you know, until I
actually allowed myself to think about some of those early experiences, I
hadn’t thought about the connection between public health needs, the
living conditions of people, the connections between for example, public
housing and public health. And how many ways you could affect peoples
lives under a health umbrella. And as far as I’m concerned it may be
some of those early experiences that I didn’t think about for many years
that really turned me on when I was dealing with the National
Commission. Some things you never know. But once I allowed myself to
really think about those things again, and think about what it was like to
get health care when I was growing up, they came back in a flood and I
said, this is why I’m interested, and while things have changed
enormously, they haven’t changed all that much. If I write about HIV, for
example, it really takes me back to a lot of things when I think about
screening for, particularly for women and children, the area that I’m really
interested in. It takes me back to a lot of those times in my life. And I’ve
decided they’re really quite important and so what I’m concerned about in public health is the turn that public health is taking to human rights. It’s not that I’m not a good liberal. In other parts of my life I do things about human rights issues in other parts of the world, but to make this a rights issue just sort of really gets my gut. Because once again we’re going to ignore the social justice issues in either this country, or in other countries. I just came back from 10 days in South Africa, and looking at health facilities, reproductive facilities there. I said it would be a shame to think about some of these health issues, and AIDS is a big issue, in human rights terms. The only way you can think about it is in justice terms, in terms of the society’s obligation to provide services for people who are affected and for their families. That’s what really hit me in South Africa. It was very much a family issue. It is not an individual issue.

Swazey: I was talking to Bob Veatch a couple of days ago about this move to globalize American bioethics, which creates a lot of unease with Renée and me.

King: For good reason.
Philosophical bioethicists like Ruth Macklin would think we’re, cultural relativists.

That’s right. She thinks I am too.

But, we see the validity of including both culture differences and ethical principles. That they shouldn’t be mutually exclusive. Bob commented to me that as much as he was sympathetic to Ruth’s book, and wrote a very good review of it, the Universal Declaration of Human Rights is not the US Bill of Rights. I thought that was a very trenchant summary of this overweening focus on individualism...

That’s exactly right. I’ve probably gone on too long. You probably have other questions...

No, this is wonderful. It’s just the type of thing we want. Do you consider yourself a bioethicist?

No. I’ve had a lot of discussions with other people. For me the question always arises when I have to do radio or TV interviews and they want to put a tag underneath and I always say that I’m a law professor. And that’s
the way I see myself because I've never been quite sure what an ethicist was. It's a convenient term to use.

Swazey: Sexier than law professor.

King: Right, it's true. But the large part of that is imposed from the outside.

And I've always thought it was very important to do accurate self-identification. I am not a philosopher. I am not a doctor. I don't come out of public health or those arenas, but I think that my niche is the development of public policy in the health and medicine area. And for that, lawyers I think are well suited. Probably political scientists are too in terms of where you locate certain kinds of decisions, what process you employ to reach certain ends. I don't like that extra attention that comes when I'm introduced as an ethicist, because I think it continues the confusion about the issues that you are talking about. That's been my take on it. From my perspective, we have a series of problems and we bring different areas of expertise to bear on those problems. Some are more practically oriented, some are more theoretically oriented, and you identify yourself by your first field. I'm very tough on my students about this.
Swazey: How would you characterize bioethics? What is this creature that you’ve been working in almost since it started?

King: I always talk about this as a series of problems. Watershed is the way I sort of think of the issues. They are pushed by developments in biology, although all of them are not. But the rapid advances, technological and basic science advances, make us focus in different ways. I say that hesitantly. I know Alex Capron defines it as the life sciences, and I think in some ways that’s a very good term because we actually have dropped off the environment. And I’m not sure that at least even from the health and medicine perspective we should have dropped it off. There’s a part of the environment that is critical. Maybe had we kept public health we would have included some of the environmental questions that naturally link up with public health questions. But, life sciences is a good term and I actually think in law schools there is also a distinction between what I do and the people who work in law and psychiatry and law and psychology. They see themselves as a separate breed. So to some extent, when we think of ourselves in bioethics as life sciences and those kinds of issues, the big social issues -- having to do research with human beings, all of the huge ones, on the beginning of life, like abortion, like embryo research -- to some extent we’ve cut off the mental health side. I’ve been guilty of
that too. So bioethics for me, even though I may start with the broad term,
if I really examine it I know I’ve left a lot off. I realize that I’ve left off
certain areas. Does it include health policy which has also been an
interesting new area for me. When Clinton was elected and set up his
health care task force and decided to have an ethics cluster... For the first
time I had to come to grips with, did bioethics include health and health
issues rather than this narrower focus on doctor-patient, maybe hospital-
patient issues? I concluded that it did. But, in asking myself how far I
was willing to go with what I thought were the bioethics issues, the
gambling commission was proposed. I said to myself, now why isn’t the
question on gambling a bioethics issue? In the way that issue was posed it
didn’t involve human health and disease, although it might, because we
may come to discover that gambling addiction may be very much a
biological issue or a health issue. But it certainly isn’t now in the way
most people think about it. My definition, as you can tell, my evolution is
away from thinking about the issues that arise in this context of
doctor/patient/research subject to access; abortion was somewhat of an
access issue as well as a philosophical issue. Humans are still at the
center, but it concerns those issues that affect human health and well-
being, I think is what I am really starting to come to even though I have
problems at the edges. They are not all technologically driven for me
anymore. In many ways, organ transplantation, death, reproduction, and
the Clinton Task Force helped me really focus on that. And it also made
clear to me what lawyers could contribute. When you talk about
individual rights lawyers always can make a contribution, but when we
talk about health policies there is an ignored area of law too, and that is the
role that lawyers can play in the development of any public policy, and
how good we are at it actually. It made it clear that the public policy
effects of health care sort of fell within what I was doing. So my
definition of bioethics is broader. In personal terms I still don't like
dealing with issues of privacy and confidentiality, and the reason I don't is
because they just take me back to that individual. They are important
issues, they are very important issues, but I still don't gravitate towards
those.

Once I gave a speech in which I described thinking about what I
meant by bioethics, and I described it both as a process and as a focus on
sensitive areas. The weirdest part of the process was an-all-things
considered approach, taken from the public radio show. Because it is a
different process and I don't think that should be lost. It is not purely a
political process so I object to all those people who talk about it as being
crass politics. I am trying to remember the man who actually has written
some pieces about distinguishing consensus from majority vote. I think it
was Martin Benjamin. I have been very attracted to the little bit of work that has been done to explain this area, how this field of bioethics can contribute to the way public decisions are made. I find that intriguing. The reason I find it intriguing is because if we take an issue like embryo research, and this does intersect with our political science, what strikes me about that issue is you will never get agreement among all parts of the sectors of the population. It is an area where it is very difficult to take a traditional liberal stance about governmental neutrality -- let the private sector work its will because we don't want government to put its thumb down on either side of the scale. It provides an opportunity to think about what is at stake, what interests are on the table for the American population in focusing on embryo research or stem cell research. I have always and I still maintain that we haven't talked enough about the stance that you have on abortion doesn't necessarily have to carry you over to the same stance on embryo research. We have made people lazy in not teasing out the concerns that they have in different contexts. When I wrote a dissent to the embryo research report the Washington Post did something very unusual. It named me in the lead editorial. That is very unusual. The editorial writer agreed with the positions I had taken in the dissent. She didn't want to label the Post, so they used me as the stalking horse, I will never forget that. Nobody believed that I could be pro-choice and object
to some research that was done on embryos, but it was a no-brainer for me.

It never occurred to me that because I felt a certain way about choice that I then had to say that any research you want to do with a human embryo, anything goes. This never occurred to me. And it never occurred to me that because I was willing to argue fairly fiercely for a woman's right, in this case not to become a parent, or issues with respect to her bodily integrity, that I meant that the fetus was a nothing or the embryo was a nothing because it didn't have a special significance to me, or that human attempts to control their environment and human attempts to control the development of future humans wouldn't raise enormous problems for many people. It was raising problems for me. When I say I am into the process, it is the fault of some of our processes that we have gotten ourselves into this position. In other words, in making a public policy consensus is important. We make much of the fact that there is consensus, but we spend very little time showing how the consensus was possible. Because in showing how the consensus was possible we undermine the thrust of what we said initially, that there was consensus, that people got to this end by multiple routes, and ultimately what they agreed on was only the product, the recommendation or the goal. They disagreed along the way about many things, but I happen to think that that is fine. I don't think that we loose anything by recognizing both our differences and our
similarities, and if you know anything about me the differences and the
similarities are very important. Because it's recognition of the fact that I
am different because I am African American, and recognition of the fact
that I am also American that I find the significant factors in all of this. I
mean I don't look like people who came from Ireland or whatever, that is a
different culture. You may want to dance differently, eat different things,
go to a different church. I don't have any problem with that. Why can't we
celebrate the differences and celebrate our similarities? That is what I
come to bioethics with. It is okay that we got there by different streets.

Swazey: A consensus doesn't mean unanimity.

Right, and why should it? Why should we want to send a signal that
consensus is important. It is important, but it is the fact that we all came
down together that is so significant. The other areas was when we were
doing the brief for the Supreme Court on physician's assisted suicide. I
was working with women's groups about getting them involved in the case
because they didn't exactly want to be involved in it. They didn't see it
immediately as a woman's issue. And someone said to me, “well I can't be
opposed to the Supreme Court finding a right to die,” which I was. I did
not want the Court to find such a Constitutional right. She said, “when I
look on your side I see a lot of people that I don't like, pro-life advocate

that I have fought with on other issues, and my view is that when in doubt

it is best to be with my friends.” I didn't object to people being pro or

anti-physician assisted suicide, I just was very struck by what for her had

become definitive, and I started thinking, “why do we do that? Why do we

feel that we have agreement, that our policies have to be that consistent?

Why can't we look at the issues that are really tough issues and think them

through?”

So I have wandered far field, but we were talking about what is

bioethics and I see it as a substantive area of issues that has expanded, but

I also see it -- lawyers would use due process terms -- as making a

contribution and process by the way. It is not radically different. There

are other commissions in government that dealt with other kinds of

problems like Three Mile Island, but in the beginning bioethics did also

emphasize a different approach to reaching some conclusions that might

affect us all.

Swazey: Has it maintained that approach?

King: No, it has been captured I think. But that is my public policy side saying

“no new public policy initiative or approach or process gets to last long in
its pure state.” When I was on the Advisory Committee on Human Radiation Experiments this fact really struck me. The same thing occurred to me on the NIH Human Embryo Research Panel, how much bioethics process has become subject to lobbying. And the press pays attention now. Advocacy groups existed at the time of the National Commission, but you used to be able to deliberate in public about very sensitive things. I never worried with the National Commission about anything I ever said about fetal research or abortion or...Well, I want to tell you all that has changed, because now if you are not careful you end up worrying about what is going to be in the newspapers and how what you’re saying is going to be characterized; that is all new.

Swazey: And you said it has been captured. Do you mean captured by the political process?

King: By the political process, yes. And it appears in who gets to go on a commission, who is represented. When I was on the National Commission I thought I represented myself. The thing I was supposed to do was come and be as open as I could be, work very hard, think very hard, listen carefully to other people, and we would all move where we were moving to. It was not preordained. I am sure that a lot of thought
went into the composition of the National Commission and who was going
to be selected, because it was a very controversial commission, I
understand. Before I got involved, I didn't know about the pre-history.
But now it is what groups are represented...

Swazey: Noah's Ark...

King: Yes. It is very different and so the deliberations are to some extent
different or affected by that. It's not that they can't do good work. That is
possible, but I think they do good work in a less controversial area. It is
very hard to be a commission and be handed cloning; it is not even an
issue that is ripe for people to think about seriously. It is very hard
because it is all future possibilities rather than having some real concrete
facts to work with. I felt a great deal of sympathy for NBAC having to
deal with cloning. On the other hand, stem cell research was a very
controversial issue that I thought they might actually be able to make a
major contribution to, and from my point of view they have in the way
they talked about it. But it is much more of an immediate issue. It was an
issue where they could at least take the science that they had and deliberate
about it. It was not so shocking, so enticing to the press. It was to some
extent obviously, but they still had opportunity in that area and other areas
they have dealt with. They actually had a lot of opportunity to make a
difference in dealing with the issues. So it is not that I am saying those
kind of bodies are useless. It's just that they are not likely to be as useful
as perhaps they would have been in an earlier stage. Nobody will be able
to do what the President's Commission did. You stop and look back at
what they did and what they were able to produce...

Swazey: Both the National Commission and the President's Commission issued an
astounding array of reports. One thing that intrigued me about the cloning
report, quite apart from all the “gee whiz” reasons it was mandated by the
President, was that it was one of the few times a bioethics commission has
explicitly called in people from different religious traditions to testify. I
think it was the nature of the issue, but that is another thread of bioethics
that Renée and Carla and I fascinated about -- the role that religion or
thinking religiously has and hasn't had in the development of bioethics.
We think it is very complicated, and we don't think it is enough to say
bioethics went to Washington and got secularized.

King: Now remember something that Alex Capron did have in the splicing life
report -- they did actually talk to religious leaders.
That was another sort of “us playing God,” topic.

Right. I don't consider myself a very religious person, but I have to say that, I was the one who argued in our textbook *Law Science and Medicine* that we had to pay more attention to religion. I don't know if I come at that question the way you all come at it, but I come at it because I think religion is part of culture and that you ignore it at your peril. I cannot tell you the number of people who have come back and said to me, you were so right about embryo research -- the nicest of whom was John Fletcher; he almost made me weep because I took so much grief. The panel went too far and we undermined the whole report by the stance we took on creating embryos for research. I don't think I was smarter than everyone else on the panel by a long shot. I just think I was more in tune to peoples’ religious beliefs. We have ignored religion and appreciation of the fact that a large part of the country is still quite religious. The vast majority of people in the country are affiliated and it is getting more and more so and not less so. We ignore the thinking and the complexity of the thinking because it is no longer just “we are going to be neutral” or “it is going to be Christian and Jew.” It is not that at all. We have multiple religions, multiple variations.
Swazey: You can't even say "Protestant" now...

King: That's exactly right, it doesn't mean anything anymore, and so not to take account of that and to ignore that area of peoples' experience I just think is extraordinarily short-sighted, and it is the influence again of American philosophy.

Swazey: The religious dimensions and other social and cultural dimensions just have not been that important to the bioethical dialogue.

King: But from my view the successes "bioethics" has had in the public arena is what has made analytical philosophy. I know this is not their view, but it has been my view that bioethics would have stayed in an area in the academy in the philosophy department, and biologists would have stayed in the biology department, but for the enormous public interest in some of these matters. It is the public dimension that from my point of view rescued philosophy...I don't know what the philosophers think but that has long been my view. If philosophers would think more broadly about their field they would see the necessity of having some dimension to what they do that captures the human experiences. I just don't know how to frame it any other way. It is like economics, that has this vision of human behavior
that bears no resemblance to anything, but at least some economists know
that their assumption about rational actors is just that, an assumption. In
fact, a lot of them do work to show that people don't necessarily act
rationally when they are making economic decisions, but I don't see that
happening in philosophy. Maybe I am wrong about that.

Swazey: A lot of the philosopher-bioethicists that we’ve interviewed absolutely
avowed that yes, there used to be tensions between social science and
philosophy and bioethics, but now they are really incorporating social
science perspectives and methods. But I think there still is a gulf, and I
think religion gets into that too -- the human dimensions.

King: The best place to study the tensions in bioethics I think was Clinton's Task
Force on health care.

Swazey: I was going to ask you about your expectations of that group or what it
could do....

King: Actually my expectations were high through the first meeting of the group.
Then after that they went rapidly down hill, for lots of reasons. One
reason is that most people who are in Washington are policy junkies and it
didn't take me long to figure out that the task force was a disaster. My husband, Roger, who is somewhat of a policy junkie too, kept saying when I came home, “well Pat you exaggerate. No, you are not seeing what you are seeing.” It took me a while to convince him what I was seeing. First of all it was a major disaster in political terms. And so...

Swazey: Now do you mean people in the ethics cluster or...

King: No, the whole thing. And it didn't take long if you had been around Washington for a while, or if you had been through your phase of Potomac fever, to see that that was happening. It was just a nightmare. But within the ethics cluster itself, the tensions were unbelievable. First of all there was the tension between the intellectual elites and the those they considered not the intellectual elites. You couldn't even make the cut between “this is a smart person vs this person has a role to play but may not be as smart.” There was a split between analytical philosophers and the religious group. William May from Texas used to trigger such animosity. He got such a reaction that it was just unbelievable to me. As I said, I am not a religious person myself, but my view is that he had something to contribute and it was not getting anywhere because people were not open to listening to what he had to say. There was enormous
tension between minorities and non-minorities, which I felt keenly,
because it was the one time in a long time where I felt I was caught
between two worlds again, where I was supposed to choose sides on racial
grounds rather than choose sides on some other bases. Within the group,
when we got past those bioethics splits, there was little appreciation for
people who came from the different bioethics’ arenas. I like Dan
Callahan's classification about theoretical and public and regulatory
because it helps me understand some of the issues and cultures because
there was really no appreciation between all these groups: philosophers,
lawyers, people who worked in hospitals. Sometimes the lawyers worked
in hospitals too. People came from all these different perspectives, and it
was very hard for them to talk to each other. That is what let me know
that “bioethics” was a name up there that covered up a lot of other things
underneath. I stopped going. I didn't find that the meetings were very
productive.

Swazey: And Roger couldn't believe it was that bad?

King: I could not believe it was that bad. I used to tell Roger what we do when
he came home and he said, “Oh Patricia, you're kidding me.” I said, “no
I'm not kidding you.” I told him about how they set up toll gates, and I
told him Bernie Lo could not believe what he was seeing. I will never forget when we went to the first meeting with the person in charge of the task force and Bernie asked a question. I believe the question dealt with rationing. Bernie didn’t believe the answer he got to the question, so he tried again and he got the same answer. Walking around Dupont Circle after we got out of that meeting; Bernie said, “I'm going back to San Francisco and I don't think I am coming back because this is ridiculous.” I said, “I hate to confirm what you're saying but I would suggest to you that it is ridiculous because nobody is really serious.” Then it became clear that what they really wanted to do with this ethics group was to try to do something like a declaration or statement of values like the Declaration of Independence or the Constitution and the Preamble. We were never going to be able to agree on that, not this group anyway. It was really an unfortunate experience.

Swazey: What had you thought it could do before that first meeting?

King: Well, what I thought it could do would be if we had a something to work with, which was one of the problems -- we did not have something to focus on. I thought it would have been useful for us to tease out the values that were embedded in that health plan and to give the values some sort of
substance. Not a preamble, but to help clarify for people and Congress what was at stake. Because we were making a series of trade-offs.

Swazey: You thought you were back at the National Commission.

King: I sure did. And was I wrong. I mean from a lot of points of view I was wrong. The ethics cluster, I think, because of the tensions within the group, would have been unable to do that because there would have been no respect for the different members of the cluster. One of the things that had happened in the other bodies was that people got past that and they started listening to each other. That really wasn't happening in the bioethics cluster. And I must say that there are some people who are very smart, really good people, who are completely out of their league in terms of understanding that they were not in their academic offices, that this really was a government program and that it wasn't all academics who were going to create this program. The one person I came away with who I had an enormous respect for after having been in the ethics cluster was Art Caplan.

Swazey: Art took it very seriously.
Yes, I know he did. Like a lot of people I’ve said that if Art would just
keep his mouth shut and not comment on everything, when he did
comment then more people would listen when he had something to say.
But I came away from that experience with a great deal more respect for
him.

Well, Art, probably more than other philosopher/bioethicists, really cares
about and works with the social sciences, and I think he learned a lot about
the political process.

He was probably the best political person and...

And he really felt very strongly, at least he has told me, that he felt it was
essential to incorporate religious perspectives into the ethics cluster
document, and that was fought tooth and nail.

It was fought tooth and nail and it was very...that is what I said about
William May.

Probably Larry O'Connell too.
He gave up earlier. Bill May hung in there a lot longer and he just took a lot of punishment. I don't know how he could hang in there so long. It was so obvious to him that these religious perspectives were important, but he couldn't make other people understand that as well. He took a lot of it as a given.

Maybe he thought it was self-evident.

Yes, but it is only self-evident to those of us who are already there. It just doesn't seem self-evident to other people at all.

I remember Art saying, laughingly, “we knew our work was done the day our magnetic parking lot cards wouldn't open the gate.” He said there was no great ceremony in the Rose Garden!

There was a reception that I did not go to and Roger could not believe it. He said, “You're not going to this reception on the White House Lawn?” I said, no I actually have some work to do in the office so I am going to go to the office. I talked to people who had gone afterwards and they had been given -- I should have kept a diary -- M&M's! I went home and I told Roger that and he said, “you're right, I give up.” But he said to me many
times after that, because we watched the early days of the Clinton
Administration, “you know, I just should have paid attention to you. I just
never paid any attention to what you were saying.” I think Al Gore did
that because he was interested in ethics but he did it as a politician, not as
somebody who has...

Swazey: You mean the ethics cluster?

King: Right, and he did it as a politician rather than the person who had gotten it
involved in ethics in the first place. But the good outcome, I think, is that
it made more people understand that health care had a value dimension
that we were really not willing to appreciate before. That is my view of it
anyway, and I think that the changes in the health care system after 1992
have served to make this more important. I have to tell you that I am one
of the few people I know who still reacts to the Patient Bill of Rights
negatively. I start with the name negatively, and have gotten in a lot of
trouble with a lot of my friends. There are very few parts of the bill that I
like and I've shut up because when I raise this with some of my friends,
people who ordinarily think like I do, they just say “how can you?” I am
clearly not making my concerns understood. It's the Bill of Rights I don't
like. I don't like the language. I hate to see Congress have to legislate
about what particular elements of access to care we should be entitled to. I can live with that, but the system of appeals in getting...the money is going to go into the system. It is not going to go for peoples’ health care and that has got me so upset. The one point I haven’t been able to get across is that if we give the middle class the Patient Bill of Rights, we will take the political pressure off of doing anything about the uninsured, some of whom are also middle class. It will take all pressure off keeping our eye on Medicare and Medicaid. And I think to be engaged in this and to think of it as incremental is short-sighted. I understand as a policy person that you often have to do things in incremental steps. But too not also understand simultaneously where the pressure points are, I think, is insanity.

Well, Judy, this is not my interview but what were your objections to the Patient Bill of Rights? I am just curious.

Swazey: I think much like you do. It’s focusing on the middle class who have insurance, and I don’t like the language. And you are right, it has been a deflective strategy. I still think we have to have a massive reform and my view is that the bill is not reform, it’s tinkering. It’s reform without change, like medical education has undergone. I gather it is dead for this session.
Looks like it. I am hoping that it will be dead for this session because it gives me more time to try to get the attention of some people out there who are working for the Bill. If you can keep their attention long enough they would pick up some of these problems. If we gave them enough time to think about it they would try to do something about it. I am on the board of the Kaiser Family Foundation and the one thing that Kaiser does that I can deal with is they spend as much time trying to get the Bill of Rights passed as they spend on Medicaid, as they spend on the uninsured. At least they have the broad outlines of the right approach. And I think that people at Kaiser are susceptible to understanding some of the deficiencies in the Bill of Rights approach. I think that is true across a large spectrum of people.

You know, I can also argue myself into the corner of thinking “well, it's better than nothing.”

I have learned my lesson about that. I’ve lived long enough now to figure out that is not where I want to go. Because often, it is sort of living through the Civil Rights movement. You say, well, this is better than we had before and some of the things turned out to be big boomerangs. I don't mean recent civil rights; I mean some of the early decisions on school
desegregation. I learned tough lessons about where the burdens eventually fall.

Swazey: Talk to me a little bit about what you see as the reciprocal influences or non-reciprocal influences between law and bioethics, which we touched on. Has law influenced bioethics in its approaches, process, topics?

King: Yes. The obvious place where that is so is informed consent and our understanding of it. That substantively has had an influence, some of the legal developments that have influenced the conceptual developments of informed consent. Sometimes I think badly; I mean, that the impact has not been a good one. No matter what we lawyers say, people still think of informed consent as the form, not the process. And they still think of it as disclosure and nothing else. That is a long legal influence. That said, the fact that the law itself seemed to require that we move in this direction was a good thing because of the impetus to the need to involve the other. I think in the dying area the developments would not have evolved in the way they did but for courts and legal traditions endorsing certain approaches. So I think that law was very important in terms of legitimation of some of the developments. But in many areas I think that law has really lagged behind. That has always been my view: law has
spent a lot of time trying to catch up and learn from bioethics. When I look at legal decisions now, the extent to which bioethicists are cited or law review articles that cite bioethicists, or bioethics journals or works...is absolutely amazing. The most amazing thing is to think that Dworkin filed a philosophers’ brief in the Supreme Court in Washington v Glucksberg. I actually teach that in my law and bioethics seminar. And I ask why would there be a philosophers’ brief? But I could just as easily ask, why would there be a bioethics brief? I think that some of the interactions, if I were to summarize, has been good. I think some of it has been not good but maybe that’s due to the fact that the broader public, including judges, think of lawyers who work in bioethics and even physicians as experts, so that we bring something very special to the table. I have never been convinced that we were all that special in what we bring to the table.

Swazey: You mean bioethics?

King: Yes. And I have asked myself often what is gained from a person who is a physician or a lawyer or an academic when they testify in court, when they are called an expert witness. What exactly do they bring? If we are lucky they bring common sense. You know, I have never been able to figure out
what it is. What do we bring? I have never been a consultant to a
corporation and I have never been a witness. I have signed some of our
briefs in the Supreme Court. Part of it is not because I am not willing to
be paid for my work like everybody else. It is because I can't figure out
what my role is supposed to be.

Swazey: Other than a lawyer...

King: Right. And so it makes me wonder what kind of interaction really does
take place. I obviously think that lawyers make the best contribution, in
some ways, in policy development because that is where I have been most
of the time. But you can certainly see that if you read enough court
decision and if you look at enough pieces of legislation in the areas where
they overlap, the two areas influence each other. Privacy and
confidentiality is one area where there is a great deal of overlap.

Swazey: So if I were to sit down and read court decisions on privacy and
confidentiality would I find bioethicists’ views in the decisions?

King: I haven't read them. I find them more when we do death and some of
those issues. I don't read a lot of privacy cases. But yes, you might.
I have read the landmark court decisions on treatment, like *Cruzan*, and there is not much reference to bioethics.

What I really remember is that *Cruzan* cited a *JAMA* articles by Judy Arena, and she considered herself a bioethicist. When she did the *JAMA* article about what was happening in all the states she was very much influenced by the fact she was doing bioethics work. She was on the RAC’S, gene therapy working group.

What *Cruzan* cited most was the President’s Commission report on *Life Sustaining Treatment* about artificial feeding and hydration, it was just their technical material in there and has nothing...

But the President’s Commission report is cited in lots of places and the New York State Task Force on Life in the Law is cited. I think there is a reliance by lawyers on the much more comprehensively developed work in bioethics. They like that, but commissions are the best. I also think that it’s the time the judge thinks they are not dealing with advocates. That is the expert part of it that; what you're getting is somebody who has carefully looked at the issues, who is not being paid by either side, no axes to grind. This is not all true of course, but what you are getting is carefully
considered reflections on the subject. I would say that probably in the surrogacy cases as they keep being developed we are likely to see interaction if these issues are dealt with by people who are bioethics. Davis v. Davis, the embryo storage case, the first one that came out through the Tennessee courts. The trial was really interesting. They had John Robertson there. He played a big role, but he was there basically for the work he does in bioethics. He certainly wasn't testifying as a law professor with some expert knowledge of the law. So when you look at a trial court level where we don't get lots of opinions, what we are getting are people who have spent their lives in bioethics, often lawyers, coming in and testifying, and that's what I mean about reliance. The other area I can think about is In Re AC, the big pregnancy case in the District of Columbia, the first of the maternal C-section cases: the people who were involved in that at the lower stages like Barbara Mishkin, for example, was involved as an advocate. But what Barbara was doing was what she learned in bioethics. She had just basically graduated from law school at that time. So I see that kind of influence where judges are out of their league, and they understand it, because I work with a lot of judges on these issues. They are out of their league and they are called upon to rule in areas that are not traditional for them, and when I say not traditional I mean the subject matter. They issue declaratory judgments, which is not
something the courts do a lot of. And they are issuing declaratory
judgements where they are not sure that the advocacy system works. That
is because we have a funny kind of dispute in these areas. In the dying
cases it was hospitals saying “I got to get a court order.” In the
reproductive cases it was the same thing. The hospital saying “I am afraid
of legal liability and I am not going any further.” But it is not the kind of
case that courts are used to. Judges get upset because I don't think judges
think they have any greater expertise in this area than anybody else. The
Supreme Court's expertise and the Circuit’ expertise is in understanding
what the Constitution requires. All the rest of it is judges not being very
much different from other well informed people in the society. That is
where the work people will do in bioethics is important, and I did go
through a lot of the briefs, for example, in the physician assisted suicide
case. It is really interesting how much of the lawyer briefs rely on work
that has been done not only by bioethicists, but by advocacy organizations
in general. But if you look at the roster, at who participated, you can really
start to see the cross-over. Maybe that is a better development in terms of
thinking about the law and bioethics. The other area that I have done some
work in is I have trained judges. I did this for the National Women Judges
Association, who were very concerned about the kinds of cases they were
seeing at a trial court level, petitions for declarations to let somebody die,
or food and hydration, or the C-section cases. They wanted conferences and that is what I did. Sometimes I called in lawyers, sometimes I got political scientists, sometimes I got physicians, basic scientists. They wanted people to come in and talk to them about their areas, and what some of the issues were because they were having a really tough time dealing with it. I just got a call recently, actually from the National Women Judges Association. They must be having difficulty with some of the new genetics cases because that is what they asked me about. They said can you tell us people who can put together workshops and conferences for us about some of the issues in genetics. Because the expertise, even how to think about some of the privacy and confidentiality issues, is all new to them.

Swazey: You would almost worry if they weren't having difficulties.

King: Yes, you would.

Swazey: I think I am at the point with privacy and confidentiality of saying we don't have any left, so lets...
It is amazing how much you and I think alike! You know Larry Gostin, who does law work in privacy and confidentiality, is here, and I’ve said to him, Larry I don't know how you do it. Every call I ever get I just send over to Larry, saying this is just totally out of my ball park. Because I have such a cynical attitude about it, and the attitude is “privacy, what’s that? It’s all gone.” If we’ve got to do anything the only thing we can do is to put in place penalties for having breached confidentiality, but that’s about it. If there’s anything that somebody wants to know about me, if they want to know it badly enough they will find it out. When I am cynical about an issue I just turn the other direction and leave the field to others and maybe I shouldn't do that. Maybe I should spend more time about trying to write about it.

I don’t want to keep you all morning, but let me ask you to reflect on where you think bioethics is going. We’ve interviewed some people like Art Caplan and Tom Murray who recalled that when they got their first jobs in bioethics, at Hastings, they thought this new field probably was just a craze and would not be a lasting thing. They hoped they might have a job for 5 to 10 years, but I didn’t think it could be a career route. Then they said, "So far we have been really wrong about that!”
I think it is clearly going to still exist because health is a major dimension of Americans’ life right now, probably elsewhere too, but we are conscious of it and it has taken a long time to get health up there with education, for example, which has been a real major part of American life. There are probably reasons why it has taken health so long but...

Is it public policy levels or more concerns about...

I think everything, not only the public policy part but how you get access to health care, what kind of health care or medical care you receive. And each one of those issues, each one of those levels will continue to be of such importance to Americans that we bioethicists or whatever we are will stay in business, and it is going to increase rather than decrease. We are going to be dealing with the health aspect for a long time. The other side is that research in the United States is just booming along at every level. Basic biological research, genetic research, clinical research. The research itself generates the kinds of issues that bioethicists have grappled with, but the applications will too. So I don't see bioethics going away. Physics and chemistry have had their heyday. We are very much in an era like that in biology now, and while I am sure there will be some point at which it will start to slack off too, you certainly can't see it now. As long
as that continues, and it is now beyond government-funded -- when you
can make lots of money for the applications of research, which is what's
happening with drug companies, and the biotech companies, we are going
to be in business for a long time. I am not sure if it is going to be good or
bad but we are going to be in business for a long time. The third area, I
think, and I have been watching this one is public health. Public health
has had a very narrow meaning in this country. It has been communicable
disease, more recently it is sexually transmitted communicable diseases
like AIDS. But it's more than AIDS, it is having hepatitis C, for example,
that causes people a different kind of worry. What the evening news now
does is disease transmission around the world. I watched one last night
which was about how a Japanese mosquito got to the United States, in
Texas, and how it has spread, and this mosquito can carry certain kinds of
diseases. What I think we are also going to get with this new emphasis on
health is a broader attention to the public health aspects, which we ethicist
are going to have to start dealing with, which places like Hastings has
already started to deal with. It is being driven, I think, by the awareness
that we are not safe behind our own borders, so that we have to deal with
some of the questions of international issues in health and disease in ways
we have not had to do before. One part of that is communicable disease.
The other part of that is the human rights drive, and a part of that is
coming from women's groups, for example, being concerned about women
in other parts of the world, their reproductive freedom, their access to
health care. So that an international dimension is going to give us a whole
new arena to think about and to grapple with. That is the value side of
what I see as globalism. In law school we are very enamored of this but it
is all the business side -- it's international trade, the global corporation, but
that is just one dimension. There is going to be the value health disease
and relationship among human beings that I think is also going to emerge.
It will be interesting to see how it emerges, but I think that's what we are in
business for.

Swazey: Can you throw into that equation academic medicines, and it's ideology
about being responsible for the health of the community? I am not sure I
know what that means given what doctors do as opposed to what public
health people do, but it certainly has been a big push for several years.

King: I have some sympathy with their rhetoric because they have in fact been
serving people who would otherwise go unserved. I actually worry about
what is going to happen when they no longer decide that they can do that,
and some of them are deciding. The optimistic side of me says that what's
happening in the academic health care means that the public is going to
have to start looking more closely at things that they avoid examining.

Health care for the uninsured, health care for the poor, the connections
between the fact that HIV is in an inner city community does not mean that
the suburbs can say that is not my problem. That is the optimistic side of
me -- that it will be a force for making us focus on the community and the
good health of the community. The jaded side of me says that is not going
to happen, but if you say jaded and cynical all the time you are not going
to get anyplace. So I am going to be positive about this one, and that is
that these problems have got to go beyond being the problems for the
academic health center, and the fact that they no longer can carry it is
going to be good for making the rest of us have to focus on it. I'm not
sure. I think that the dynamic here is the business of health and probably
what you are talking about in the academic health center is that for a long
time we like to think about health in professional terms. And that is
changing rapidly.

Swazey: Carla and I just finished a 5 year study of the Allegheny Health Care
System and its merger of the MCP and Hahnemann medical schools.

King: And what did you conclude?
Swazey: It turned out to be an absolutely horrible story, but when you factor out all
the evil things that were done by Allegheney corporate management, so
many of the patterns are endemic to what has become the business ethos of
academic medicine and are not just about Sherif Abdelhak.

Swazey: That is not a side of the enterprise that I actually love getting involved in,
but it’s real and I think that some of bioethics work will have to go on in
that area. For some reason people call ethicists, about HMO issues, and
this goes back to our prior conversation, to have credibility. Some of us
bristle at what that implies about credibility, but there will be work to do
in terms of deliberating about how we can deal with some of these
problems.

Swazey: There will be, and as you probably know there is a big move now among
clinical bioethics consultants to move into organizational ethics. They are
starting conferences and so forth, and we find that a little scary because
they don’t seem to make sense, except for a few people, a need to have
competence in areas like the sociology of organizations. I don’t think you
can just leap from the clinical bedside to dealing with organizations and
business ethics. So I can’t quite decide how much it is a genuine
commitment or an effort to get a new market niche. I think work on
organizational ethics in health care is needed, but I hope they recognize the need to know something about organizations.

King: Maybe the generations that come, the younger people, will have a better appreciation of it because they won't be so mired down and only looking at what older generations have looked at. I remember when I used to lecture every summer at the Kennedy Institute, one of the points I made about bioethics was the disciplines that were not represented that needed to be represented. At that time I was focused mostly on economics. At another place I argued for the need to include political scientists because there is a very narrow focus of who can be at the table, that is what we were talking about, who can be at the table. Actually, because of you and Renée, and you should never underestimate this, while the back biting against social scientists may be there, whether social scientists should be at the bioethics table wasn't the issue.

Swazey: Well people will always say, “oh yes that is important.”

King: But at least I think you got to the table; there are some people who weren't at the table...I understand that. It is like being African American...
Swazey: I think Renée and I have a different sense than you do about how receptive bioethics has been to social science. We can remember when we came back from China and wrote “Medical Morality Is Not Bioethics.” It was published in Perspectives in Biology and Medicine because Dan Callahan said Hastings would publish the part on China but wanted to cut out the part on bioethics in the United States. And we said, we don't think so.

King: I love that article, and it was a classic at the time.

Swazey: We were called bioethics bashers in the literature as; the paper was not well received.

King: I wish I had known you both better, because in 1978 I went to China with a group of bioethicists from the Kennedy...

Swazey: Were you with Tris’ group?

King: Right. I came back and I never wrote about it, but my commentary to people was that I was dismayed at the behavior of our group. And the reason I was dismayed at their behavior was that when we would have meetings with people we were always trying to tell them about the values
of autonomy. We never listened to them talk about community, we never
listened to them talk about the importance of the whole. That was because
we were still busy saying “you can't have the reproductive policy that you
have and that you can do this group pressure about...” I was really upset,
because everything comes from exposure, even though I didn't have one
personally, to a larger kinship system which has always been important. I
said, “you know, I am missing everything. And who are we to come to
one of the oldest civilizations in the world and tell them that you have it all
backwards?” And I loved the way the Chinese handled it, which I have
never gotten over. They too understood they were one of the world's
oldest civilizations. It was the first time I had seen people treat some
Americans that way, because Japan had not been the same way when we
had been in Japan. But the Chinese were different, they were much more
aware of their culture, so when your article came out you made enormous
sense to me. I said this is incredible. You must have picked up some of
the same things I picked up. That we were so willing to criticize the
Chinese and not willing to learn anything from them.

I never had the courage that you all had to write the kind of piece
you wrote about China, to write about bioethics, and it's for a lot of
reasons. But I think there is still time for me to do something about that,
and I think I am ready to figure how I am going to do that. In fact I have
felt myself easing up on this because there is a certain something that comes with age and feeling established that is liberating. I finally feel I'm at the point where I can really start to say and write about some of the things that I have long thought, particularly when it comes to racial issues.

I have spoken to Susan Wolf and I told her she was quite courageous to do the book on feminism and bioethics. Although there is law and feminism work more broadly outside of health, which was very helpful to her, there is not the same kind of background on race although at least in the law there is some. I realize how quiet I have been all these years; people don't think of me as quiet, but I think of me as quiet. I realize I didn't get to say all the things I probably should have been saying.

Swazey: You’ve have been on a lot of task forces and other advisory bodies. Do you have writing inhibitions?

King: Yes, that is exactly it.

Swazey: You sound like most of the nurses I have known! They get convinced in their training that they can't write.
King: I too suffer from that and I think in a way I am very fortunate that I am very good at one-on-one or in oral discussions or on my feet, and I am very good at consensus building. But lasting contributions, as I have always said to Roger, requires that you put them down on a piece of paper.

Swazey: That’s not always true. As a teacher you make a contribution through your students.

King: That’s also true. But I would feel this more if I were at a public health school, or a medical school because that’s the area that I’ve worked in and it is going to be more direct. You know health is becoming a big legal field, so we get a lot of health students at the law school, but they know and I know that law is all about going into the fields where the money is, and in the health areas the money is not out there yet. There may be in the future, but now they are very small health advocacy organizations or public interest organizations, so primarily the health law students are going into law firms...

Swazey: This is a great discussion, but I should get out of your hair now, and head for the airport.
King: Well, I have enjoyed this.

END OF INTERVIEW