



**Presidential Commission**  
*for the Study of Bioethical Issues*

**TRANSCRIPT**

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Meeting 22, Session Two

August 31, 2016

Philadelphia, PA

## SESSION TWO: REFLECTING ON THE PAST, PRESENT, AND FUTURE IMPACT OF NATIONAL BIOETHICS ADVISORY BODIES

DR. GUTMANN: Great. Could we ask the first panel group to come on up? Great. So, I'm going to be very brief because I've already said what this – introduced this session as the past, present and future impact of national bioethics advisory bodies. We'll hear, first, from Dr. Robert Cook-Deegan, who is a Professor at Arizona State University School for the Future of Innovation in Society and the Consortium for Science Policy and Outcomes. Before his position at Arizona State, he served as Research Professor in the Sanford School of Public Policy at Duke University with secondary appointments in Internal Medicine and Biology. He was Founding Director for Genome Ethics, Law, and Policy in Duke University's Institute for Genome Sciences and Policy from 2002 to 2012. Dr. Cook-Deegan is the former director of the Robert Wood Johnson Foundation Health Policy Fellowship Program at the National Academy of Medicine and a former RWJ Health Policy Investigator at Georgetown University. His research focuses on policy implications of genomics, bioethics, intellectual policy and innovation. Dr. Cook-Deegan served as a member of the Biomedical Ethical Advisory Committee, which was established by the U.S. Congress. Welcome and we'll begin with you.

DR. COOK-DEEGAN: Sure. I have an instruction here to turn this on. Can you hear me? Okay. There we go. Thank you so much for having me. And I think I'm not here because of any of the stuff you just heard about. I think I'm here because, in this panel, we're going to begin to review some of the history of the purpose and function of bioethics commissions. And I have, I think, the unique distinction of having worked for two organizations that were killed by Congress, and so, I guess we're starting with – with things that didn't work out as anticipated, and I hope that we will move to some examples of things that worked out and actually did contribute and had huge impact. So, the two organizations that I was directly familiar with were the Office of Technology Assessment, which was a unit of the U.S. Congress that existed for about 20 years; and it was not a bioethics commission, but it did a lot of reports that were at the interface of science and technology and there were sections of many of those reports, particularly in the life sciences, that dealt with bioethical issues.

DR. COOK-DEEGAN: For example, Alta Charo was a big player in one of the reports on infertility. And we did reports on gene therapy and on whether there should be a human genome

project. OTA was systematically bipartisan and it was a creature of Congress. It's not clear, if it hadn't been killed, whether it would be able to function in the current political environment since over the last 20 years, it's – it's been really hard to live in that killing zone between the partisan poles. So, the systematic bipartisan processes that we used at OTA, I don't – I simply don't know if they would succeed in the current environment. One example of why that may be true, and was an early example, was the Biomedical Ethics Board and the Biomedical Ethics Advisory Committee. It was also – it was modeled, actually, on OTA.

DR. COOK-DEEGAN: It was supposed to have a board of 12 members of Congress. Alex and I shared the experience of trying to get this thing up and running. It had six senators, six members of the House, each picked from their respective parties. And in our particular case, it was also explicitly and carefully picked so that there were three pro-life and three pro-choice members of Congress on – on – from each House on the board. And that's probably the reason that it failed. So, I guess it's hard to take much of a lesson from such a complete and abject failure as the Biomedical Ethics Board, except to say that all of the other commissions all the way back to the Ford Administration, the Clintons – or, excuse me, the Carter to Reagan transition that I think Alex will be talking about, and the bioethics commission since have all been parts of the Executive Branch. And I think that has something to do with the fact that they've been – at least they have survived and have done good work.

DR. COOK-DEEGAN: So, I think there's something to be taken from that, which is perhaps housing something in the Executive Branch, is a good idea as opposed to trying to house it in Congress. But one other model that I wanted to float, and I don't know if you all have discussed it, is the Nuffield Council model, which is basically nonprofits, nongovernmental organizations sponsoring a bioethics commission that reports to government, but is not itself completely dependent on government, and I think that's a model that might work in the U.S. context. I think it's worked remarkably well in the U.K. context. One thing – and I understand there may be a special issue of Hastings Center Report that's going to come out of your deliberations about the past and future of bioethics commissions.

DR. COOK-DEEGAN: And I've discovered in doing some homework for the presentation today, I'm going to be hoping – I'm hoping to coauthor with Jenny Brian, who wrote her Ph.D. thesis on bioethics commissions, a piece for that, and we've discovered that there is one sense – and in

your description of what today's session is about was the word "impact." And it turns out that Jenny and I disagree pretty deeply about what is the underlying purpose of a bioethics commission.

DR. COOK-DEEGAN: You mentioned deliberation and education, which all of the bioethics commissions have had as goals. There is another goal that I actually think is quite important, but Jenny doesn't completely agree with me that it's important, and that is political change, political impact. And we do have examples of bioethics commissions that have had huge impact. The President's Commission, in its *Defining Death* report, within a year or two, every state had passed statutes. Amazing impact that I think would not have happened without the President's Commission. *Splicing Life* report from the President's Commission led very directly to the oversight of human gene therapy in the early clinical trials within the Recombinant DNA Advisory Committee at NIH Those are very high-impact reports that, really, you can trace a causal chain that goes from bioethics commission report to things happening in the real world.

DR. COOK-DEEGAN: And I actually think that if a commission is sanctioned by the U.S. Government, if it has a Presidential seal or a Congressional seal of approval, there should be something that connects it to the political apparatus and there should be something that you're doing that matters for real world activity. So, I actually think that that's a criterion that should be right on the table. Although I also think that Jenny's more of the Leon Kass sense of what's the purpose of a bioethics commission, which is a good place to have arguments in a conspicuous place and present the dilemmas that we face as a society in a place where you can yell at each other in a safe environment. And there is some value to that. Although I have to say I'm not sure that there's a great value in having that connected to the U.S. Government.

DR. COOK-DEEGAN: We can do that in academe without any help. And I wanted to finish with just an observation about the Nuffield model because I really do think it's a promising model of the kind of stable economic support that depends less on direct appropriations from the Federal Government. And I wanted to use the example of how they have managed the mitochondrial treatments issue, where I think the Nuffield Council did the deliberation and educational function extremely well, and their report maps very directly to the Human Fertilization Embryology Authority decisions to regulate the process of integrating mitochondrial treatments into clinical practice.

DR. COOK-DEEGAN: I think it demonstrates that you don't have to have government money to have government impact, but the Nuffield Council I think also illustrates the fact that it's the social network of which a bioethics commission is a part; that is, you aren't just sitting in a room having conversations; you're actually connected through staff and through your deliberative process to the people who are making the decisions and listening to the report that's going to come out at the back end. So, enough with history lessons and I'll just move on and, in fact, talk to somebody who actually accomplished something through a bioethics commission.

DR. GUTMANN: Thank you very much. So, now, we'll hear from Alex Capron, who is the Scott Bice Chair in Healthcare Law, Policy and Ethics at the University of Southern California, Gould School of Law. He's a professor of law and medicine at the USC Keck School of Medicine and co-director of the Pacific Center for Health Policy and Ethics. He was the first Director of Ethics Trade, Human Rights and Health Law at the WHO in Geneva from 2002 to 2006 and a past President of the International Association of Bioethics and the American Society of Law, Medicine and Ethics. On a personal note, I have to say that I first met Alex, he was already a wise person in bioethics when I was just a neophyte at The Hastings Center.

DR. GUTMANN: He's authored and edited 10 books and more than 300 articles and chapters and for 7 years, he was a Commissioner of the Joint Commission, a major U.S. accrediting body for hospitals and other healthcare organizations. He's a member of virtually every honorific society you can be a member of with his broad talent set. For our purposes most relevantly, with all of his skill and accomplishment, is the fact that from 1979 to 1983, he served as the Executive Director of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. I thought our group had the longest title, but I'm glad to see we – Not even close. We did not set the record. Professor Capron served as Chair of the Biomedical Ethics Advisory Committee of the U.S. Congress from 1988 to 1990 and as a member of the National Bioethics Advisory Commission from '95 to 2001. Welcome, Alex. Look forward to your comments.

PROF. CAPRON: Thank you very much, Amy. It's a pleasure to be back with you all and here at Penn. Penn has a very long history in this area. Eliot Stellar, provost of Penn, was a member of the National Bioethics Advisory Commission. Renée Fox, who I had hoped to see here today, was a member of the President's Commission. And, of course, on this commission, you have two

of your leaders playing the leading roles. So, I took the question for today as being: Do we need a bioethics commission and, if so, why? And asking that by looking at what we can learn from the past about issues, for example, authorization, appointment, location, about subject matter, objectives and functions and then looking to the future, as your chair said a moment ago.

PROF. CAPRON: And rather than beginning with my own views, I want to turn your attention to a report that came out in 1995 when Harvey Fineberg was still dean at the School of Public Health at Harvard, later, of course, was President of the Institute of Medicine, and that commission – that report, the committee on which I had the pleasure of serving under Harvey, concluded very definitely, yes, we do need these commissions. They talked about the value of having bioethics review at many levels, beginning with hospitals and research centers through professional associations, state governments and, of course, looking beyond that, at international bodies, but the focus was on the kinds of commissions of which this is an example at the national level.

PROF. CAPRON: And we can take note if you wanted to have a complete catalog, you'd be talking about a large variety of bodies. And most of the ones on this list had a particular time-limited function and many of them, including those that continue to exist, are using rules, some of which they shape to make individual decisions. So, they are [advisory] bodies just the same way an institutional review board or a stem cell research oversight committee or a biosafety committee at an institution would do. And then there are – in between those, there are committees looking at bioethics in many aspects through the National Academy structure and through professional bodies.

PROF. CAPRON: But what I want to focus on are these federal bioethics bodies. And I use the word "federal" rather than "national" because these are creatures of the Federal Government, which I think has some implications for us. And I've listed them here and I want to call your attention to the two columns called "Created By" and "Appointed By." And Bob has already given you a little bit of a sense of this, but I think he and I differ on this.

PROF. CAPRON: I actually think that if we were able to overcome some of the problems in our divided politics these days, we would be better served by having [an advisory] body that is generated by Congress to which Congress looks for advice. And the reports, for example, of the

President's Commission were addressed to the President, but they were also addressed to the President of the Senate and the Speaker of the House of Representatives. And it was really that sad story with the Biomedical Ethics Advisory Committee which had the misfortune not of being created by Congress, but being appointed by Congress, and that's where the problem arose.

PROF. CAPRON: Eventually, of course, when it was impossible to have a further legislative involvement, the President, through an executive order, created, first, the Advisory Committee on Human Radiation Experiments; and based on its conclusions, then appointed the bio- – the National Bioethics Advisory Committee, or NBAC. President Bush then followed with the President's Council, and President Obama with the Presidential Commission that's meeting here. What do we learn by some of this? Well, one of the things that having a congressionally-appointed [advisory] body can do is to have action-forcing power. And as I note on this slide, it's not a legal power.

PROF. CAPRON: It's more of a moral or symbolic power. But what it means, and which commissions since then, to the best of my knowledge, have not had, is the reports of the commission must be published and responded to within a given amount of time by the body to which they're addressed, if it's a federal agency. You can't order institutions and state governments to respond, but you can say if there's something that goes on in federal regulation, this needs attention.

PROF. CAPRON: In terms of topics, all the commissions have had a combination of something that they're mandated to do, something that the President has asked them to do, and some things that they've taken up on their own initiative. And that seems to me to be a good characteristic that I would hope would be followed through. Now, when I speak of diverse membership, many people from outside looking at the commissions, particularly those appointed by presidents in recent years, have thought maybe they aren't as diverse because maybe they come from a particular ideology. My sense is that, in fact, the commissions have had a wider range of ideology.

PROF. CAPRON: That was certainly true with the President's Commission, particularly as we transitioned from the Carter Administration to the Reagan Administration. And to remind you, of our dozen reports, there was one dissent by one commissioner on one report, even though

most of the reports, all of which have been begun under the Carter Administration, most of them were completed with the Reagan appointees and we were able to find the common ground and say something substantive and find that people could agree on that.

PROF. CAPRON: Another characteristic which I think was very valuable for the President's Commission was that unlike subsequent commissions, we were not located within a department and, administratively, this meant that we had liaisons from all federal departments that had anything to do with our area appointed to sit there and be with the Commission and we could go to them for information. They were mandated to provide it. But, administratively, they were not in charge of us.

PROF. CAPRON: It's already been mentioned, my involvement, I would say, beyond that with the National Commission, I was a consultant and wrote a report for them on fetal research. And I had the pleasure of appearing at the final commission meeting of the President's Council in a role very much like this, except I was asked to sit there all day and then comment at the end of the day about the themes that I had heard them raise, and I've had the pleasure once before of being with you all.

PROF. CAPRON: Now, in the rest of what I'm going to say, I'm going to drop out the Biomedical Ethics Advisory Committee because it was killed by the board to which it reported. Here is a list, and I'm going to go through this rather quickly, of gathering the reports of the bodies because I want to think about the ways in which we can tell what the subject matter of bioethics is and should be from these reports.

PROF. CAPRON: Not surprisingly, the one which has been characteristic of basically all of the commissions, save one, is the subject of research with human beings. And it's not surprising because national attention began with that subject in 1972 with the revelation of the Tuskegee study, but even before that, we're now celebrating the 50th anniversary of Henry Beecher's famous *New England Journal of Medicine* article cataloging 22 examples on unethical research. And, of course, the very act that created the national Commission also mandated the existence of IRBs at all institutions receiving federal research support.

PROF. CAPRON: This has been a fairly constant topic, except for the President's Council. The major focus has therefore been on federal agencies that support or regulate research. Your work,

it strikes me, has been less regulatory and more connected to the other two areas – two of the other areas that I highlighted there; that is to say, clinical practice and social impact. And I think this is – you set a good example because your reports have shown the ways in which ethical issues will move from the research stage through to the questions of what the effect on society will be and on clinical practice and healthcare.

PROF. CAPRON: Now, looking at another area, the impact of new science, the potential impact has been a major area. It's not surprising. This can focus on federal policymakers. And the report that we did on genetic engineering in human beings, the report that NBAC did on cloning and then on embryonic stem cells are examples of that. You can also focus on researchers in institutions, and it seems to me that your reports on brain science and synthetic biology were like that. Or there can be a very broad examination, and I think this is characteristic particularly during the period at which the President's Council was chaired by Leon Kass, of reports that are really addressed to the public and saying wake up and look at the kinds of things that these scientific developments could mean for all of us. It's less narrowly a regulatory or what can the Federal Government do about things.

PROF. CAPRON: Now, your report having to do with the Ebola is distinctive because despite the great importance of public health ethics, it's the only report that got into that area, and I would say that that is a topic which deserves further attention. You paved the way, but I really think that this is something that should get further attention. And, again, with your reports, you showed how that's connected to issues of research with human subjects. Likewise, one could say there has been another distinctive area, and that was the focus of the President's Commission. We were the Commission for the study of ethical problems in medicine as well as in research, and a number of our reports – four of our reports dealt with clinical medicine and then, of course, very uniquely, we had the only report, the only real attention that formal bioethics has given to a fundamental issue for society, which is access to healthcare.

PROF. CAPRON: It's hard to think of anything more basic than that, and it really substantiates the concern with justice, but that's what we did there and it could get more attention. Now, finally, this other area, and there are two types of things here. One is summaries of principles. The Belmont report was, of course, that summary report explaining the ethical principles that guided the conclusions in the other reports. We found ourselves with three extra months, the first

three months of 1983, so, I told the staff we were going to do another report, and we did one called, "Summing Up" both to do that and also to point the way towards topics that we hadn't gotten to and hadn't been able to deal with, and the two were privacy and the reproductive technologies.

PROF. CAPRON: You – you've shown another way of going about topics other than those that are narrowly technically focused; and that is your reports on deliberation and education and showing the importance of that. The President's Council did a very unique thing, again, I think influenced by Leon Kass as a teacher, and that was to issue a set of readings and then a set of essays on dignity. I gather there's some dispute that Bob is having with the coauthor as to whether or not that's a good function for a commission. In looking back on the President's Commission and in talking to the President's Council, I suggested that there were five general areas that – five functions that a commission can serve.

PROF. CAPRON: There are certain topics that are far enough advanced that they can be laid to rest and a consensus can be stated. There are others at the opposite extreme where there are highly different views and you really have a crucible in which these arguments come out, and then the purpose of the commission is to kind of try to define the agenda to articulate the implications and try to maybe find some common ground. If you're looking, as you were, at human subjects research and looking out of the Guatemala experience, there's a watch dog function.

PROF. CAPRON: There is also, of course, the occasion when something is sent to a commission in the hopes that it will go away and the President or the secretary of something won't have to deal with it. And then there are these areas which are closer to clinical medicine and therefore not just to what doctors do, but to what patients do, where the idea of the commission is to help people to see, to provide a light on the pathway of guidance for individuals. Not that you'll be determining what they do, but giving them some help in doing it.

PROF. CAPRON: Now, I want to just give you a summary of four of the things that that Institute of Medicine Committee said about the important way of judging whether or not these functions are being well carried out. There has to be intellectual integrity. There has to be sensitivity to democratic values. You have to measure the effectiveness in terms of the communication process

and speaking with authority. And then the results have to be judged. Do they really bring people together and is there a consensus?

PROF. CAPRON: And I suggested to the President's Council that one way of thinking about this is what I called the "H.E.A.R.D. model." There's the heritage; both what you inherited and what you bequeath. There's the environment; whether or not the issues are familiar or novel. There's the audience: professionals, public, peers; in the ethics sense, public officials, press. There's the response: Will you get legislation? Will you set new standards? Will you provide useful information? And then there's the dissemination and the mode of dissemination.

PROF. CAPRON: So, finally, looking to the future, I think that the two things that I would hope to see discussed today are the value of continuity. We can look to bioethics commissions in other countries that go on regime after regime. There's only been one queen during the Nuffield Council, but there have been any number of prime ministers. They don't appoint them, but they do get reports from them. The French have managed to have their national advisory committee for a long time. And then in terms of response: What are we aiming for? Obviously, intellectual integrity, democratic values and consensus. But is the only way to measure things is with this notion of laws and standards, or can there be other measurements? Thank you very much.

DR. GUTMANN: Thank you. We'll hear next from Dr. Thomas Murray, who I know very well, also from The Hastings Center. And I should underscore – I said it earlier, but we have great debt, I think, to The Hastings Center for bringing many of us together and also being in the forefront of this before it was a sexy area, but when it was clear, very important. And Tom is a senior research scholar and President Emeritus of The Hastings Center, who served in that capacity for 13 years, from 1999 to 2012. He was formerly the director of the Center for Biomedical Ethics at Case Western Reserve University School of Medicine, where he's also the Susan Watson professor of bioethics.

DR. GUTMANN: Dr. Murray's a past president of both the American Society for Bioethics and Humanities and the Society for Health and Human Values. And currently, he serves as chair of the Ethical Issues Review Panel for the World Anti-Doping Agency, a very hot topic, and as an international expert advisor to Singapore's Bioethics Advisory Committee. In 2004, he received an honorary Doctorate of Medicine from Uppsala University, and he's authored and edited many

books and many articles. And from 1995 to 2001, Tom Murray served on the National Bioethics Advisory Commission under President Clinton – I should say President Bill Clinton. Yes.

Welcome.

DR. MURRAY: Am I – yes. Good. Mic's on. Well, many thanks. Alex's – Alex's brilliant talk began reminiscing about his time at Penn, and I should note that I was born a few miles south of here in the middle of south Philadelphia and spent most of my childhood in south and west Philadelphia and in those years, Penn was terra incognita, but it's very nice to feel welcome here right now. So, thank you. I don't think it was ever Penn's fault that it felt that way. And thanks to Amy so much for that wonderful shout-out to The Hastings Center, where I also began my career in bioethics. And I remember Amy coming as a – this brilliant, energetic, young scholar coming up from – I guess you were at Princeton back then. And have followed with great – great satisfaction your career since then.

DR. MURRAY: Now, I'm going to take a more personal and anecdotal tone than my two predecessors on the panel reflecting on my time, really, at NBAC and what I think I've learned and what lessons, if any, I might be able to share with future commissions. Let me start with that. And I'm going to – I'm doing something, for me, very unusual. I'm actually reading, more or less, from a text. I almost always prefer to read from notes, but this one I thought I needed to write something. So, one of these things is not like the other. Now, you may recognize this from Sesame Street.

DR. MURRAY: The choices here include the United States, Australia, India, Mexico, Norway, Peru, South Africa, Trinidad and Tobago and the U.K. And the correct answer is the United States. Because all of the other countries I've mentioned, along with many more, have legislation that bans human reproductive cloning. We do not. Cloning was the issue that put NBAC on the map, I think it's fair to say. And there, I had the privilege to serve as a member of the Commission along with Alex and under the leadership of Harold Shapiro, who's – my admiration for Harold cannot be overstated.

DR. MURRAY: I think, Alex, we fit – that fit into the dumping ground lightning round category that you – that you brilliantly outlined there. So, our first clue was when each member of the Commission received terse facts from the White House, a letter noting that with the birth

of Dolly, mammalian cloning was now a reality, and it tasked NBAC with providing advice on the ethics of human cloning and on how the nation should respond.

DR. MURRAY: We were given 90 days. We met the deadline. Along the way, I learned some important lessons. My goal in this presentation is to share what I think I learned at the ramparts of what I will call, with apologies to George Lucas, "The Cloning Wars," along with some reflections on our other five reports. Lesson Number 1: Listen attentively to a variety of voices. 20 years on, I continued to believe that one of the best things we did at NBAC was open our first meeting on cloning with theologians representing conservative and liberal wings of the Protestant, Roman Catholic and Jewish faiths.

DR. MURRAY: When we had an opportunity to reprise our conversation with theologians later in our work on human embryonic stem cells, we were wise enough to include an expert on Islam as well. As I recall, fellow commissioner, Jim Childress, led the initiative to invite these religious spokespersons. Thanks, Jim. What I, at least, learned from them was the range of views within each broad tradition. That said, I don't recall any of our speakers being particularly enthused at the prospect of cloning people.

DR. MURRAY: Given that many Americans look to their religion for moral guidance on at least some matters, it was important to hear what sort of guidance they were likely to receive. And I hope the people who spoke felt they were listened to respectfully – respectfully even if, in the end, their particular views didn't prevail. Lesson Number 2: Know the audiences you mean to address. The principal audiences for NBAC varied according to the subject of that particular report. They included the public, professionals and professional organizations, researchers, scholars, international bodies, state governments, federal agencies and, particularly in our work on human cloning, the U.S. Congress.

DR. MURRAY: On seven – seven separate occasions, NBAC commissioners or senior staff testified before Senate and House panels holding hearings on human cloning. I participated in three of those hearings. Two memories seem worth sharing. First, in the rushed confusion following the announcement of Dolly's birth, many ideas about legislation were put forward, some of them quite sweeping. I recall reading draft language that I thought would prohibit any duplication of DNA. And if that language became law, we would be locking up most high school

biology teachers. Congress steered away from that language in the end. The second memory years later, 2001, came when Congress worried about a number of people at that point claiming that they either would or already had made a human baby by cloning. That was 15 years ago. Hard to believe.

DR. MURRAY: But some names may remain familiar: The aptly named Richard Seed; Panos Zavos; Severino Antinori; The Clone Rights United Front; and most notoriously, probably, the Raelians – I hope I'm pronouncing that correctly – led by Rael and his chief scientist, Brigitte Boisselier, an inorganic chemist, by the way. A committee of the House of Representatives asked me to testify, along with prominent scientists and various cloning enthusiasts. One of them, Boisselier, read a letter purporting to be from a father whose 11-month-old son had recently died.

DR. MURRAY: She quoted from the letter. "I decided then and there that I would never give up on my child. I would never stop until I could give his DNA, his genetic makeup, a chance." I should have been prepared for something like this, but I was not. Cynthia and I had lost our daughter, Emily, just five months before the hearing, so, I understood only too well the raging desire to escape from grief. But I also understood that the charlatans promising to recreate his son were exploiting him and, more importantly, that there were no detours around or shortcuts through grief. In a white, hot intensity of feeling, I felt compelled to write about this incident.

DR. MURRAY: I wasn't sure whether such deeply personal details should be shared beyond my family, but Cynthia and our surviving children urged me to publish the brief essay, which I did just over a week later in the "Washington Post." Nothing I've ever written elicited such an outpouring of responses from the public, from policymakers, from scholars, from scientists. In preparation for today's testimony, I reread that piece. The description of the science around cloning needs serious updating, but I wouldn't change a word about what it means to grieve over your child's death.

DR. MURRAY: In its six reports – and that did, I think, a good job of being mindful about its audiences. In our awkwardly but accurately titled, *1998 Report on Research Involving Persons With Mental Disorders That May Affect Decision-Making Capacity* – that may be the longest title for any commission report – we offered 21 recommendations divided among a variety of

audiences: investigators and IRBs, health professionals, state legislatures, federal agencies subject to the common rule and others bearing responsibility for protecting research participants.

DR. MURRAY: The '99 report on human biological materials and research had no fewer than 23 recommendations. They went to the Office of Protection from Research Risks, investigators, IRBs, tissue repositories, journals, research funders and state and federal legislators. So, if you conclude that something should change, identify who can make that change and direct your recommendation to them. Lesson Number 3: Understand that the attention your work receives is mostly a function of topicality, not quality.

DR. MURRAY: Alyssa Eisenmann's admirable history of NBAC analyzed its impact on public policy. One measure was the number of media reports. Now, the cutoff was June 2001, so, some later things wouldn't have been counted. But by then, she found 1,287 media reports on our work. More than half, 665, were on cloning. Stem cells came next with 276, oversight of human subject research clocking in at 108, with capacity at 33, human biological materials at 28, and international research bringing up the rear at 24. Now, another plausible measure is legislative activity. There were 13 bills introduced in Congress that cite NBAC as inspiration: four on cloning, eight on privacy of genetic and medical information, and one on protecting human research participants. The number made into law: zero.

DR. MURRAY: But to put this discouraging number into perspective, remember that the overwhelming bulk of NBAC's recommendations were directed at other audiences. The record there is complex, but far more encouraging. I urge you to look at Alyssa's detailed recounting of that impact. NBAC produced its cloning report in 90 days. We worked on the human biological materials report for two years. That extra time, needless to say, allowed us to gather far more relevant information, wrestle at length with complexities and craft recommendations. One could argue that this report was, in those respects, superior to the cloning report, but it doesn't matter.

DR. MURRAY: NBAC's report on cloning was an important marker in the evolving debate in the U.S. and internationally, so, I think it served its purpose honorably and well. Lesson 4: Don't confuse transactional relationships with friendships. This is really directed at me, I think. While we were working on cloning, I'm sure other commission members received lavish attention from journalists. There were weeks when had I wanted to return every call, I simply didn't have

enough hours in the day. A prominent science reporter writing for the "New York Times" called me frequently in the months leading up to the report's release. She was so congenial and chatty.

DR. MURRAY: We spoke about family, life, work. I think I'm seeing recognition here, yeah? When the report was finally completed, Harold Shapiro, our chair, asked us not to preempt its official release by revealing any details to the media. When my *New York Times* friend called eager to get the details in advance, I explained to her what Harold had asked and said I was going to honor his request. Friendliness soon turned to fury when she realized I was serious. I think I've heard from her a time – one or two times in the next 20 to 30 years in a purely businesslike way. 20 years.

DR. MURRAY: I've been blessed with many friends and I value those friendships enormously, including people I met who first – I first met when they were journalists. But as a Commission member, never forget that your position gives you voice and privileged access to important information and some people will want to use the illusion of friendship for transactional instrumental purposes. Lesson Number 5: There will be ripples. Alyssa's wonderful report was a joy for me to read.

DR. MURRAY: Don't know why I'd never read it before, but it brought back warm memories and it showed that NBAC's work resonated far more widely than I had realized. Our reports influenced how IRBs, regulators and researchers think about a variety of issues not just here in the U.S., but around the world. Our recommendations have been referenced, adopted and sometimes criticized by professional societies, scholars and religious organizations, among others.

DR. MURRAY: I had a recent glimpse of the ripples NBAC created when I was asked for advice on what to do with incidental findings from research that performed genetic analyses on stored tissue samples. I dove into the recent literature, and there's a lot of recent literature, surprisingly, only to discover that the foundational reference is still our report on human biological materials. To be sure, there have been refinements since then largely due to the increasing ease with which we can analyze DNA in that form, but the principles we articulated 17 years ago have shaped the debate in fundamental and, I think, helpful ways.

DR. MURRAY: So, yes, your work will have ripples that will likely last for many, many years. Lastly, Lesson Number 6: Be mindful of the third rail, but don't let it terrify you. Embryo politics is the third rail of bioethics. We've already heard how it completely derailed one commission and it's killed it in its birth, but that third rail was thrust into NBAC's hands in both the cloning and stem cell reports. The reason our country is unlike so many of our peer nations in not having national legislation to ban reproductive cloning is embryo politics. Just about everyone agreed that cloning to make babies should not be permitted.

DR. MURRAY: Scientists, though, wanted to be able to experiment with cloning human embryos, but were content to follow the prevailing international standard that such embryos should not be allowed to survive past 14 days' development. People committed to the belief that embryos are persons refuse to back any legislation that permitted creating embryos for research. They insisted that a ban on reproductive cloning must also include a ban on cloning for research.

DR. MURRAY: No one was able to craft a compromise and there was precious little appetite to stick one's head above the trench. Politicians were understandably reluctant to invest political capital and their careers in what they saw correctly, as I believe, as a no-win proposition. So, if I had one regret about the PCSBI, it was the decision not to use its resources to promote a respectful public conversation about the range of issues in embryo politics, especially the growth of reproductive technologies. I proposed such an initiative in an essay in "Science" a couple years back.

DR. MURRAY: But I hope you will take my disappointment as a compliment to you because your commission has done an extraordinary job of using media resources and the Internet to reach out to interested persons. Your admirable focus on creating lasting educational resources is matched by your patient devotion to the process of democratic deliberation. You have more tools and greater sophistication on how to use them well than any previous [advisory] body and use them well you most certainly have.

DR. MURRAY: Many thanks for the excellent, thoughtful work you've done. Many more thanks for showing the way forward for future national bioethics commissions on how to create new kinds of resources and new opportunities for dialogue. And who knows? Maybe a successor will grab hold of the third rail. Thank you.

DR. GUTMANN: Thank you, Tom. Thank you very much and thank you for joining us again in this meeting. So, we close the session, appropriately enough, with a final speaker who chairs the council that you have heard many people praise. I have had the honor, privilege of speaking with and seeing in operation on the ground, coming away with great admiration as well. Jonathan Montgomery, who chairs the Nuffield Council on Bioethics, is a Professor of Healthcare Law at University College, London, Chair of the Advisory Committee on Clinical Excellence Awards and Chair of the Health Research Authority, which is an organization that protects and promotes the interests of research participants. He was a member of the Medical Ethics Committee of the British Medical Association, the U.K.'s Organ Donation Task Force, and the U.K. Committee on the Ethics of Pandemic Influenza.

DR. GUTMANN: He's developed ethical guidance for public health practice, including the report on the genetic testing of children, 2010, and guidelines for the ethical conduct of research involving children. You can see how, just in that short summary, how much Jonathan's work has informed our work as a commission. And, indeed, one of the things we wanted to do to break from the immediate past commission was to learn from international bodies and, particularly, from the most successful ones, of which Nuffield Council is certainly up there.

DR. GUTMANN: Professor Montgomery has served as chair of the Human Genetics Commission, the U.K.'s National Advisory Body on New Developments in Human Genetics, and the U.K. Clinical Research Collaboration Working Party on a Strategy for Brain Tissue Banking. Welcome. We're really pleased and honored to have you here.

PROF. MONTGOMERY: Thank you. And it's a great privilege to be here. And thank you very much for joining us in London to join your lecture previously. I'm going to try and draw on that different range of experience, all of the national bioethics [advisory] bodies are different thoughts in the U.K., and also on my academic work and reflections. And I want to consider dimensions of three of the many roles that national ethics committees play across the world: Roles relating to representing ethics in government; roles relating to helping people – the people, perhaps I should say, in this country – reflect on their moral positions, support public thoughtfulness; and then, finally, elements of the roles of representing nations in a global governance context. Each of those areas raises questions about the nature of the authority to speak, the basis on which we can claim our opinion should be taken seriously, and also the way

in which we go about doing our business. And I'll try and use the patent of the U.K.'s approaches to draw some attention to issues that I see, and it is approaches in plural. As you'll see from my own biography, it's a relatively small country and a lot of opportunities that we pop up and meet our friends in. Obviously, you here can claim to have led the way with the initial presidential commission, but the whole world now thinks about national ethics committees. They're recognizing UNESCO's declaration.

PROF. MONTGOMERY: We were in Berlin, with 83 countries represented, at the Global Summit earlier in 2016. But that masks – that apparent consensus masks a very significant patent variation. I think we've heard some of that already in the presentations this morning. I see this commission as sort of located within the executive branch of the government. If you were looking for a model of a successful situation in the legislative branch, I would look to the French committee, which now has a statutory obligation to inform the legislature of bioethical issues that come before it and, also, actually, a well-developed regional network of spaces in which public ethics can be deliberated. The U.K. is pretty fragmented. It has a lot of bodies who work in that area.

PROF. MONTGOMERY: The Nuffield Council is probably the nearest we have to your sort of overarching responsibility. As has already been noted, it's a nongovernment organization. In terms of the taxonomy that Jason Schwartz offered you, I'd say this is arm's length plus-plus at the Nuffield Council. We have no positional authority. We have no constitutional right to speak to government. What that means is in order to hope to have some impact; we have to work on the basis of some form of relational authority built on reputation.

PROF. MONTGOMERY: Now, we've commissioned an evaluation of our work that you can read on our website published in 2015, and that looked at the perceptions of our stakeholders, who suggested that our work is influential in a quiet way; usually takes some time to come to fruition; that we have been reasonably successful in shaping thinking and culture among opinion formers, but are not necessarily very good at communicating accessibly to people.

PROF. MONTGOMERY: We were said to be reflective in our style rather than providing precise recommendations that get quickly taken up. So, that was the sort of feedback that we picked up. We, of course, think that we make very specific, targeted recommendations and we

follow them up very carefully and we engage in conversations with people; but, of course, responses are discretionary. And we were – I think it was a criticism from one policymaker in the evaluation that we sometimes wrote our recommendations like a parliamentary select committee even though we didn't have that authority.

PROF. MONTGOMERY: We don't see why the lack of formal authority should stop us having a go. And I think we can show that in some areas, we've had very specific impacts, and mitochondrial DNA is one of those. I'll say a little bit about that in these prepared remarks, but I'm very happy to explore more about that later on. I think we believe that our influence is based on a set of – a sense of our character ways of working and claims about the quality of outputs and set that out in our strategic plan for 2012 to 2016, which, again, you can read. But in a sense,

PROF. MONTGOMERY: I think you could see this as an attempt to set forward what would the virtues of an effective national ethics committee look like, because that's our only claim to have impact. We committed ourselves to a set of values, our version of inclusivity, which was that we should hear all voices, but then we should subject those voices to scrutiny to examine them for coherence, for rationality. We should develop a position on those which is intellectually rigorous, consistent with the best available evidence.

PROF. MONTGOMERY: And that's, if you like, the clues to a starting point about virtues, but I think there were three particular things I'd want to draw attention to in relation to this role addressing government. The first, and we say we think this is absolutely the core, is independence. Independence in the sense that we are not beholden to or under the influence of others in the conclusions that we reach or – and this is a little bit more sensitive – in the topics that we select for examination.

PROF. MONTGOMERY: I think if you're a government national bioethics commission, the position I was in when I was chairing the Human Genetics Commission, it's perfectly reasonable that government sets agendas it needs advice on and there's a process of negotiation about offering advice it doesn't think it needs but that the commission believes it does. We have a particular issue because two of our three funders also fund health research.

PROF. MONTGOMERY: So, we need to be really clear that the views that we reach are not colored by the fact that they're interested in the research that we are scrutinizing. If we can't

sustain our independence, we can be accused of providing false assurance on the ethics in relation to scientific advance. That sort of conflict of interest issues doesn't apply to our third funder, the Nuffield Foundation, from which we take our name.

PROF. MONTGOMERY: But I think there's a sense of independence that matters even to them and I'm sure matters to you, which is unless the deliberations of the Nuffield Council on Bioethics move from some degree of open mind to a conclusion, it's hard to see what value we have added in the process. And our topic selection criteria include the potential to add value. Secondly, I think it's crucial that we are courageous.

PROF. MONTGOMERY: We need to be able to speak our mind even when it's unpopular. And we have not shied away from criticizing the ways in which our government or our national health service operates. There's also an element here in relation to public opinion. It's not respectful of public opinion just to accept it at face value. It's respectful to engage it, take it seriously and have a conversation. We think that respecting people requires us to be courageous enough to challenge them even if we think we're not sure whether they're right or not.

PROF. MONTGOMERY: And then thirdly, and I'm not quite sure the right way of describing this, there's a virtue around practical engagement. You will see our reports. What you won't necessarily see is the conversations and the working groups and the lobbying that goes on around them. We try very hard when we're engaging with existing policy to understand how policymakers think about what they're doing and to engage in the discourses that they develop.

PROF. MONTGOMERY: That sometimes means developing a terminology that is somewhere between what we would have talked about and what they would have talked about. And we did that in our public health ethics report around the context of stewardship and the use of a framework taken from John Stuart Mill which was designed to bridge the gaps between the way we started and the way we thought public discourse and policy discourse operated.

PROF. MONTGOMERY: We're following up our reports with workshops and roundtables, encouraging people and helping them develop position statements. We see this sense of engagement as being a sort of conversation. And because we are a non-government [advisory] body, we can talk to whoever we like and we can use different methods for doing that. And, finally, in relation to that sort of activity, we don't limit our conversations to new projects. We

now have a significant body of historical work and we see ourselves in having a curator type responsibility to try and bring that to play.

PROF. MONTGOMERY: We did that in relation to your work on Ebola, where we looked back at our public health ethics report and asked ourselves what it could contribute to your thinking. So, those are some elements of that domain of the conscience of government, if you like. What about the engagement between national ethics committees and the thinking? Well, I'm very envious of your work on public deliberation.

PROF. MONTGOMERY: We've talked about doing it, but we haven't mapped out a good normative framework, and I think that's been a weakness of our thinking. I'm also envious of the benefits of openness that come with being a presidential commission. We've tried to move more of our work into the public domain, and much more of it's visible than it used to be, but we don't meet in public, we don't stream our meetings in the way that you do, and those, I think, are really valuable and important things.

PROF. MONTGOMERY: I want to reflect on two elements that are slightly different, but I don't want to downplay the value of those things. The first is around relationships with the past and the importance of a truth and reconciliation function and the virtue of nations being able to express contrition. That's how I saw the work you did on the Guatemala experiments. We have something similar in the U.K. around organ retention which came to light in the 1990s.

PROF. MONTGOMERY: We discovered that there had been significant retention of tissue samples, occasionally whole organs, and in one rather gruesome case, a whole head, and those had been kept from postmortem examinations on children without the consent or knowledge of parents. It needs to be said that in many of those cases, that probably would have been prevailing practice at the time. Well, they're not later on.

PROF. MONTGOMERY: But the way in which that's addressed use a number of different organizations. We had a major public inquiry with legal counsel and taking of witnesses. We had a task force type body, the Retained Organs Commission that oversaw the immediate institutional responses of our universities and our health systems. And then we had a statutory regulator, the Human Tissue Authority that administered the legislation that followed.

PROF. MONTGOMERY: Now, I've been not involved directly in that, but in other inquiries. They seem to me to be very different types of skills and resources, and whether or not they're a right thing for a bioethics commission is challenging. But what I do think we need to do is to be able to use the dignity that comes with being a state [advisory] body to express remorse and contrition about that. So, that's a bit about the past. The future, we're reflecting on this. I think the position from the point when the Nuffield Council was originally established and the future we see looks slightly different.

PROF. MONTGOMERY: We were established in 1991. We're established on a model that was worried about public anxiety about science and was worried about regulatory catch-up. But, actually, if you look at our experience of mitochondrial DNA, it really doesn't look like that at all. First of all, the scientists have been very open in the U.K. public discourse for about 15 years about the fact that this was coming and we needed to talk about it. Secondly, we had regulation already in place that we could use.

PROF. MONTGOMERY: The question was, were we going to use it? And thirdly, the desire to use the technology was driven bottom up. It was driven by the families wanting to have the chance to use it. I found myself cosigning a letter to the *London Times* which rather reframed the sort of job we asked ourselves. It said this: "The question the parliamentarians must consider is not whether they'd want to use the technology themselves, but whether there are good grounds to prevent affected families from using – from doing so.

PROF. MONTGOMERY: We believe that those who know what it's like to care for and sometimes lose an extremely sick child are people best placed to decide whether technology is right for them, with medical advice and within a strict regulatory framework proposed. They've been waiting for the science long enough. They shouldn't have to wait for the law to catch up."

PROF. MONTGOMERY: Now, that's a direct flip from the logic on which we were constituted. There are other elements that come with democratization of bioethics. There's a whole literature around participant-led research. There's a set of questions, then, about what are we seeking to justify. Is it regulation, or is it the use of the new science? Most of our activities have been looking at the ethics of the use of scientific advances.

PROF. MONTGOMERY: Maybe we need to have a focus on the justification of regulation. And we have a little spanner thrown into our works recently in the U.K. by the Supreme Court, which, like Canada, has rather challenged the idea that bioethics is part of either the Executive or the Legislative branch competence and maybe a human rights dimension means that we shouldn't interfere with people's choices. The human rights question then turns me to my third area about national ethics committees in the world order.

PROF. MONTGOMERY: And I want to raise questions about what we should do together and what we should do separately. There are, of course, many issues around health services which are very firmly rooted in local, national, social, economic and political context. Your Ebola report was a mixture of things that felt particularly American and which felt really important on the world stage in terms of talking about it. We're grappling at Nuffield with two issues which seem crying out for that sort of process.

PROF. MONTGOMERY: The question around germline therapies and the question about whether that's inconsistent with human dignity as recognized in the UNESCO convention, and the rule – I think the first one, I put "rule" in inverted commas – it's very definitely a rule about 14-day embryo research in the U.K. because it's a statutory rule – each of which raise questions about what's the nature of the moral foundation for those rules. Science, things like safety, we seem to be – we should be able to work on those together.

PROF. MONTGOMERY: I'm of the view that we can explore this, perhaps, more in discussion, that the 14-day rule emerged in the U.K. as a sort of political compromise that then became socially, scientifically, politically, legally acceptable. The question on the global stage is, well, who has to accept it for it to be able to operate on that sort of basis? I think we have a real challenge coming forward about how we can manage to work together and how we can use the considerable resources for national ethics committees to address that idea of a sense of global governance of bioethics. Thanks very much.

DR. GUTMANN: Thank you. We are open for discussion and, I think, questions or comments from members of the commission. Let me just preface it by saying that the range of insights you have provided is quite remarkable and I think very well-taken. I will not speak for the whole commission, but I'll just highlight a few things that you've covered without trying – I'm not going

to try to be comprehensive. But the beginning, with Bob, we – maybe these fall under Alex's lay to rest, but I don't think they will be laid to rest, but I think in our – at least speaking for our commission, I think we definitely view coming to decisions that had some practical hope of effect as a very – as the primary goal, and deliberation and education being means to those ends not just immediately, but in the long term.

DR. GUTMANN: Whether it be the anthrax or trying to lay to rest Guatemala – what the lessons of Guatemala were or the synthetic biology where we took great pains to underline the importance of intellectual freedom and responsibility and regulatory parsimony, along with making sure that unlike the supposed creator of life who brought synthetic biology to the fore, we were not endorsing the creation of life as a safe means, but neither were we calling on Congress to issue some new – which would have been crazy – regulations in light of this.

DR. GUTMANN: Definitely decision-making – being a strong advisor to decision-making – that gets to Alex [Alex's point], I thought, laying out of the different roles was – some of them you can do all together and others are mutually exclusive. So, I thought that was – we had those in mind, but you articulated them much better. While we articulated our five principles, you articulated these roles in a way that I think could inform the future.

DR. GUTMANN: Tom, in speaking personally, I thought it was – it really was important for our commission learning from the past in our deliberations to actually show the personal importance of what bioethics was. One of the things, Jonathan, of being, all of our meetings, in public, it was really important that we practice what we preached in being respectful to the wide range of views, and we had a wide range of views, some of which we couldn't possibly endorse, but all of which we listen to and try to understand.

DR. GUTMANN: And I think that was a very important part, not our goal, but a very important virtue, if you will, that we tried to demonstrate. No doubt imperfectly, but we certainly worked and took – worked very hard at it and took it to light. And, Jonathan, I think you raised, finally, bioethics is – most of the issues we undertook were not just national, but international, and how you respond to our constituents, our political constituents were the citizens of the United States and the President representing them. Our moral constituents include the whole world, and so,

that raises a very big issue. I just think – I just wanted to highlight those things as being very relevant to our thinking and our actions, and I'm now going to open it to – I'll start with Barbara.

DR. ATKINSON: Thank you. This is a wonderful panel and a very good way to be ending our discussions now. But I was particularly struck by the Nuffield experience being independent and you being able to do a strategic plan for five years. And you touched on one of the topics that you used to help you pick. I mean, we responded to the President in many cases and we picked a few things ourselves, but being able to look five years ahead and – I'm really interested in the criteria you used to do that.

PROF. MONTGOMERY: Okay. Well, thank you very much. I could, for the roundtable later on, actually pull them up and go through them in great detail, but they're on our website. We have a flow diagram. We start with the fact that we have an open call. Anybody who wishes to suggest that there are issues that come within our remit is entitled to e-mail us, let us know that. We maintain a long list, which is publically available, and then usually on an annual cycle, but it depends a little bit on the work plan we've got and how much of our resource is already tied up in other things, we hold what we call – describe a forward-look meeting.

PROF. MONTGOMERY: We usually identify – we were typically thinking about the ability to start one or maybe two projects. We usually identify four or five frontrunners. We commission papers and we make an open call. Some of those end up being written in house, some are written by people who respond to the call – invitation to do it, to write it. We publish those papers and we hold a workshop where we discuss what's rising.

PROF. MONTGOMERY: Our criteria for selection are partly driven by the scope of our terms of reference. So, we are not in a position to cover a number of things that needed covering. We don't cover issues around mainstream clinical ethics. We don't typically cover research ethics. We cover things that relate to emerging issues from science and technology that may end up being issues for what we would call "research ethics committees"; you would call "IRBs."

PROF. MONTGOMERY: But we have another body, the Health Research Authority, which I coincidentally chair, which is slightly ironic because when Nuffield was founded, I wrote to the director of the foundation saying, "Whatever you did, you must keep – not allow Nuffield Council bioethics to be seen as being a way in for researchers to" – so, we have a conflict of

interest policy. I step out of anything that relates to those things. So, first of all, this question of “What's our scope?”, and our scope essentially is around issues that emerge around advances in science and which are likely to cause public concern.

PROF. MONTGOMERY: We're just in the process of tweaking those slightly. They haven't changed since 1991. We'll then ask ourselves whether they raise complex ethical issues. There are many important issues on which the ethics are actually pretty obvious; it's just practice that's difficult. There are also issues which other people could deal with a less deliberative multi-disciplinary type of process, and we would tend not to do those.

PROF. MONTGOMERY: And we would tend not to do things that we think are already within the competence of other bodies. We would be asking ourselves the question: What is the value that we could see work from us could deliver? And those are our selection criteria. But we make available the background papers. They're already there for contribution to broader debate.

DR. GUTMANN: That's terrific. Let me – since I said – let me just say one thing that I don't know if you came to a conclusion, any of you, but my sense, and I speak with a kind of political scientist hat on, is I'm unlimited in my admiration for the Nuffield Council. I do not think that an independent-of-government, not-appointed-by-government commission in this country would get any visibility more than The Hastings Center or any number of other independently constituted commissions.

DR. GUTMANN: Do I think to the extent that our commission and previous commissions have had influence on government and public policy and gotten the visibility they've gotten in the practical deliberative or policy – it requires being commissioned by either the executive or, I mean, if – Alex, if – I think we could – you might be, like, waiting for the messiah to come now to wait for Congress to do this, but it would be even more – more effective if Congress and the President, but it requires in this – in our context – and I wish there were more like the New York State bodies at the state level to have that as well. Jim, I have next, and I think I'll probably have everybody on the list, so, I'm going to go around.

DR. WAGNER: Thank you, and my thanks to all of you. Remarkable – a remarkable panel and each of you representing in different ways. Amazing accomplishment and contribution. And so, I think it's fair, though, to do what you have done, focus on some of the areas we would like to

polish on these – on these processes. Tom, your comments in particular, and I'd like you to begin with your thoughts and, of course, if others have them, I would be interested in them. It seems to me that perhaps "frustration" is too large a word, too harsh a word to explain – to describe that particular facet around impact when we talk about the degree to which we have been able to get attention.

DR. WAGNER: Your third principle, I think, was – or, actually, I wrote it mathematically. I wrote that, "Attention is not proportional to quality," but I think what you meant, what you actually said, was just because we are doing wonderfully high quality work doesn't necessarily mean that it will have the kind of impact we would like to have. Yes, we will have ripples. We like to think that the principles this commission laid down, we'd like to think that the educational tools that we put together, we'd like to think that our own demonstration of democratic deliberation is something that will ripple.

DR. WAGNER: The question is this – and it's based on the observation, also, from your presentation. The question is: Can we do better at making others care? Do we have more levers to pull than just the positioning and the pathways and the funding, the independence of these groups? All of which I think anyone around here can figure out how to – how to improve. But what about the Steve Jobs' magic that identifies and convinces people of what they need with technology that already – that already exists?

DR. WAGNER: We had for a brief period a patient advocate. Should we have had someone from the fourth estate? Should we have had press? Should we have – are we, perhaps, victims of a longstanding problem in all of academia and academics – academic scholarship of being satisfied with the degree to which we impress our colleagues without having translated it to a level that actually makes it meaningful, exciting and concerning for others?

DR. WAGNER: You said you got the greatest – I think I wrote it down – outpouring of response from your op-ed piece because somehow you connected something vitally important in bioethics to something very personally meaningful to a public. Should we be changing our composition and maybe being very specific about how it is we engage public?

DR. MURRAY: Thanks for that question, Jim. It's not a simple one and I'm not going to attempt a simple-minded answer. But I think it's an important one. I don't know what your policy was.

Did you encourage members of your commission to write for the broader public? I would think that –

DR. WAGNER: We did, yeah.

DR. MURRAY: Yeah.

DR. WAGNER: Yeah.

DR. MURRAY: And, in fact, not just encourage or permit, but I would say it probably would be wise even to facilitate, encourage and help sponsor that for a future commission in the sense that –

DR. GUTMANN: Yeah.

DR. WAGNER: Uh-huh.

DR. MURRAY: – suppose –

DR. WAGNER: Uh-huh.

DR. MURRAY: – suppose I needed to do three days' background research before I could write that op-ed piece and I didn't have three days because of my other responsibilities, would the Commission have provided – could you provide one of your members? I think there are ways we can increase our impact in reaching much broader audiences. And absolutely, I mean, have a thoughtful journalist. I mean, I became very good friends with –

DR. GUTMANN: Find a thoughtful journalist.

DR. MURRAY: No, I know lots. I know – I –

DR. GUTMANN: No, there are.

DR. MURRAY: Yeah.

DR. GUTMANN: But there are not – but they don't get – I say that jokingly, but what I'm not – what I wouldn't say jokingly is don't underestimate the change in the media environment –

DR. MURRAY: Yeah.

DR. GUTMANN: – over the last five years, let alone ten years, let alone twenty years. The pressure on the media to do things that are sensational and can be repeated over and over again and that are not thoughtful and are not nuanced is enormous, and it – whatever it was twenty years ago, multiply it by a hundred.

DR. MURRAY: It would be commission malpractice not to pay attention to this trend that Amy's identified. But I'm remembering a conversation I had with a friend of mine, Nancy, whose last name skips my mind right now, but she was very senior at "Time." And she said, "Well, what does The Hastings Center do?" And I said, "Well, we just are interested in what happens at the beginning of life, at the end of life and a lot of the important stuff in between." I mean, so, if the public –

DR. WAGNER: You bounded it.

DR. MURRAY: That's our – if we can get the public to understand the connection between what they care about and the issues that this commission and previous commissions and I hope future ones will engage, that's what we do. And so, probably having a very sophisticated communication strategy would be a help. Engaging people from that community. I mean, I know there tends to be a self-selection. I still talk to lots of journalists because they call me, they contact me. But, it tends to be a winnowing-out practice. I don't continue to talk to the ones I think are shallow. And the ones who want to take deep dives and are willing to entertain complexity are the ones that I – and it may often end up being on background, right –

DR. WAGNER: Sure.

DR. MURRAY: – because they just want to be well-informed about the issue they're going to write about. And, to me, that has every bit as much value as getting my name in the paper. I would encourage every commission to have a – to really put a premium on that public communication.

PROF. CAPRON: I wanted to add two things, one of which builds on what I thought was Tom's original point when he made the contrast between intellectual quality and attention and said perhaps one of our later reports on impact actually –

DR. MURRAY: I said several of them.

PROF. CAPRON: Several of them, but you – I think you highlighted the human biological materials one compared to cloning because cloning was just the topic that everyone was going to cover. An anecdote about what happened with the President's Commission: Just as we were meeting for the commission to approve its first report, which was the *Determination of Death* report, the *New York Times* and the *Washington Post* basically ran the same story the day that the commission was meeting, which the basic headline of which was "Congress debates when life begins. Presidential commission decides when it ends."

PROF. CAPRON: The result of that was that that night, one of the commissioners and I were on "Nightline." This was when Ted Koppel had just transitioned it from being all about America held hostage, which was its origin of the Iran hostage crisis, and was going on to other topics. It proved to be a very difficult time because I was being called out of the meeting all day. They said, "We can't find anybody who disagrees with this report who disagrees with it." And as I said, that there were some topics we were more or less laying to rest.

PROF. CAPRON: We had all of the authorities who had published on the *Determination of Death* who were the medical consultants, and they had come up with their own report on the technical side, and the report addressed the way the law could respond. They ended up finding someone who was confused about what the report said, and that was the person who was on with us. The second suggestion is if you look back in the mid-1980s, Fred Friendly, who had run a series of programs called "The Constitution: That Delicate Balance" in which he had Arthur Miller principally, but a few other law professor-interlocutors leading a table of people like this with difficult situations.

PROF. CAPRON: It was the law professor's hypotheticals. And his producers came to me after the commission was done and said, "Is there anything we could do here in your area?" And they came up with a program, a whole series of programs, in the same format. And I think it is possible to use the media in a way that it is equally as thoughtful as the reports because in the right hands of the right producer, like Fred, and the right staff headed by someone like Arthur, it was possible to have really difficult conversations.

PROF. CAPRON: And his way of describing it was that you had to get to the point where there was no escape, but, you had to come down one way or the other and then see the conflicts that

were still there and that you were grappling with and you were making those decisions, but having people do that was very engaging television. And I think it –it was on public television. Doesn't reach the same number of people as some shows, probably.

PROF. CAPRON: But I know in light of your concern about education, that those programs were used for years. Some of the dilemmas now seem a little dated that they may be using; but for a long time, they were used not just at the college level, but at the high school level, with teachers wanting to introduce their students to these issues. And I think it is possible to have journalism in one form or another that is thoughtful.

DR. GUTMANN: No, I totally agree with that. We do and we've been very successful in having – there are ethics bowls now, which are institutionalized, for high school students. There are – I mean, Nita was on with Alan Alda on neuroscience. There are a lot – there have been a lot of journalistic legs here, and the science reporters have been phenomenal and they've covered us really thoughtfully.

DR. GUTMANN: But if you compare that to what makes – what gets the huge audiences, it's not the thoughtful stuff. We have to be realistic about what the difference between long-term impact and what makes the biggest news nightly. I think – when we count up, we're very impressed by how many reports we've got, how positive it's been, the education. But in the larger media landscape, it's a smaller part of the larger media landscape because the social media and cable news and the amount of media is just enormous –

PROF. CAPRON: Right, right.

DR. GUTMANN: – these days.

PROF. CAPRON: If I could –

DR. GUTMANN: Yeah.

PROF. CAPRON: One further avenue is, of course, entertainment. And I actually – I was actually on the Joint Commission for 18 years, so, I had a lot of experience seeing this. One time we felt we had the biggest impact on what happens in hospitals was when one of our standards

about time out, and this was before – these are time-outs before surgery starts and so forth. And this is long before Atul Gawande –

DR. GUTMANN: Yeah.

PROF. CAPRON: – and the checklist and so forth, and Peter –

DR. GUTMANN: Yeah.

PROF. CAPRON: – Pronovost. We got to Neal Baer through the group, Hollywood Health and Society, and they had an episode of "ER" in which that became crucial. And, of course, it was woven in by the clever writers in a way that someone found himself called back and not allowed to go ahead and then something happened, and so forth, to make it dramatic. And the response – the Joint Commission surveyors said when they were out at hospitals, everybody was talking about that. And compared to some revision of the standards, the Joint Commission standards, that had more impact. And, again, it's just a matter of creatively thinking about how to get into people's homes and before –

DR. WAGNER: Exactly. And from that point of view, I find myself wondering whether or not Craig Venter actually helped.

DR. GUTMANN: Oh, he did.

DR. WAGNER: But by making an outrageous statement that could focus people's attention, I think we never really pointed our finger at him, but I think if –

DR. GUTMANN: Well, we had him – he presented.

DR. WAGNER: I know, but he would say of course not.

DR. GUTMANN: And he wouldn't say it to us.

DR. WAGNER: Of course not.

DR. GUTMANN: He'd only say it –

DR. WAGNER: Yeah.

DR. GUTMANN: – to get attention and it got attention. And as a consequence, there are thousands, if not tens of thousands of people, who know what synthetic biology is now, who never knew before.

DR. WAGNER: That's my point.

DR. GUTMANN: Our recommendation was not to – don't be too – don't be afraid of it, let's watch it and let's ask the scientist, as they did in genetics, to self-regulate. That would be preferable to asking Congress or state legislatures to do it. So, it actually did –

DR. WAGNER: Yeah, that's my point.

DR. GUTMANN: There's a –

DR. WAGNER: It got us in a broader –

DR. GUTMANN: You know, there's joke about teaching. The – I don't know if it was a horse or something and to come to the water and the guy – it's an old bad joke – knocks him on the head first, which I – we would not approve. Why did you do that? You have to get their attention first. Well, Craig got their attention first, and then we helped actually give good sense to it.

DR. WAGNER: And it might be worth –

DR. GUTMANN: And it helped us. It definitely helped us and it helped the field. At the same time, if you don't bring the hype down, you get really bad results. We have to put the right impact first before the intent; and then if you can use the attention to get the right impact. Christine – oh, Jonathan.

PROF. MONTGOMERY: I just want to make a couple of observations around that scene in the U.K. When I was discussing our mitochondrial report with our daughter, I had said, "Well, one of the recommendations was we shouldn't talk about three-parent babies." And she said, "Well, that was a failure, then, wasn't it?" Because that was a headline across everything. Just a few things, though. I mean, we have developed as part of our idea of curation that we should be prepared to be a content partner with people who are skilled at doing these things.

PROF. MONTGOMERY: Secondly, we have always had a – I think, a way in my time to have a journalist on our council. You were interviewed by Jeff Watts when you came over, who's a very experienced print journalist. We've moved to a documentary maker, which has given us a different perspective. We've begun talking about how we can get a handle on social media and how that operates.

PROF. MONTGOMERY: We also have in the U.K. a number of examples of working with very specific deliberative processes. The Human Genetics Council had a Citizens Council. It also commissioned citizens jury work. Our Organ Donation Task Force had a tricky issue when the commissioned Citizens' Jury, which said it believed we should have presumed consent to organ donation, they believed it appeared because they thought it would increase donation rates, and the Organ Donation Task Force thought it would probably not increase the donation rates. We had to grapple with what is a respectful response to that voice.

DR. GUTMANN: Christine – Oh, Nelson.

COL. MICHAEL: Thank you. I was going to ask Bob to further a comment he made about connecting the work of [an advisory] body like this to the – you used the term "through the political process" or I would probably use the term "the governance process." We're fairly unique. I think we may be completely unique in that three of us from the beginning of the formation of this commission were employees of the Federal Government. And unlike a liaison, we were not selected for our affiliation; we were selected based on qualification to round out the diversity.

COL. MICHAEL: And now there are – two of us remain. And just as a side note, in the military, a liaison officer is always a spy for another agency – there's that. But in terms of your viewpoint on that relatively unique – we have our own view on how that could have been helpful. Do you think that could be one way to ensure – regardless of where the authority was grounded, either in the legislative or the executive branch or possibly elsewhere, do you think having federal employees sit on the Federal Advisory Commission, do you think that's – this experiment, do you think that was a reasonable one?

DR. COOK-DEEGAN: I think that's certainly one way to solve this problem. I actually don't share – I actually think most of the bioethics commissions that have had a big impact get that

impact by becoming credible, and I think it sometimes depends on having formal authority. I strongly endorse one of the points that Alex made early on, which is I think it was really important for the national commission initially, in particular, to have that forcing authority, that responding authority, and that means that it has to be built into statute.

COL. MICHAEL: There's no way around that. And I think that was really, really important for the national commission. If you've got that, I think it's a big advantage. The problems that we always come across – and I'm sure you guys have struggled with it more than the other commissions did – is all the rules about conflict of interest and who can do what, when, when there are federal officials because of all the body of federal law about what federal officials can do and cannot do, which you guys undoubtedly have memorized by now. But I think that's one way to solve that problem, but I actually –

DR. GUTMANN: We stayed sane by not memorizing, but that's okay.

DR. COOK-DEEGAN: I actually think the credibility of most of the bioethics councils comes from the process by which they go about their business. I'm not as despairing of having a private sector entity that would have sustained longevity and wouldn't have to keep coming back to government, still having credibility with the government precisely because it's independent. I could imagine that happening, but I can also imagine that failing, and I think it would really depend on the degree to which it builds credibility and the social networking function, of making sure that you're brokering the communications among the people who have to make decisions about the subject matter that you're covering.

DR. GUTMANN: It is important. I just want to make sure this is – see whether you – we felt and acted as if we had total independence as to what we said, what topics we took. As I said jokingly, but if the President or the Secretary of HHS asked us to take something on, the presumption is we'd say yes, unless – but if it were some crazy – if we thought it was wrong for us to do it, we wouldn't have.

DR. GUTMANN: We thought they were very good and timely topics. But everything else we picked, we picked with our independent judgment. Not oblivious to what we thought might have some influence and lasting effect, but to give you an example, previous commissions had all recommended compensation for harm, and it's never been adopted, and we thought we should do

the – when we were doing testing anthrax PDF, we did it in a more general report, but we thought that was a time to say if you're going to go ahead and do testing, responsible testing, minimal risk testing with HD escalation, you have to compensate – you have to find a way of compensating for harm.

DR. GUTMANN: We had no reason to believe we'd be successful where previous ones haven't; but, in fact, the government accepted in this limited area this way of moving forward because there was no other responsible way of moving forward when you combine vaccine, children, testing for – for anthrax immunity. I think the independence of if you are a political body, as a politically constituted body, being clearly independent is very important.

DR. GUTMANN: And it's interesting having insight into government with our two – two members now, is helped on the impact side, but it does raise the questions you raised, and I wouldn't want – with great respect for Christine and Nelson – I don't think they would want, either, to have a majority of our members government employees. That would be – that would be a mistake for, I think, the obvious reasons.

DR. COOK-DEEGAN: Just one really quick comment.

DR. GUTMANN: Yeah.

DR. COOK-DEEGAN: One other – I actually had three things that I was going to add to the list –

DR. GUTMANN: Go.

DR. COOK-DEEGAN: – and I'll send them to e-mail to you. But one of the issues that I think bioethics commissions has done is nagging.

DR. GUTMANN: Yeah.

DR. COOK-DEEGAN: And I think that –

DR. GUTMANN: That's good. Yeah, yeah.

DR. COOK-DEEGAN: – you just gave us a really good example of compensating for research injuries. And I think that's a really important function.

DR. GUTMANN: Dan and then Raju and then Anita.

DR. SULMASY: First, I'll, on behalf of our –

DR. GUTMANN: Yeah.

DR. SULMASY: – dear, dear departed colleague, John Arras, thank Alex for talking about access and justice.

DR. GUTMANN: Yeah.

DR. SULMASY: It was a theme very much at his heart. And with all due respect, we weren't totally independent in terms of what topics we could – we could take up. But the topic I did want to talk about among all of you, and I think, Alex, you had mentioned it first, but some of you have in other contexts, again is this question of continuity. And, first, does everybody agree that the advantages outweigh the disadvantages? Because there is the possibility that being within one President's ambit gives you more potential leverage.

DR. SULMASY: I'd like to see the pros and cons. And then, second, to hear all of your thoughts on if you do think that we should have continuity in this country instead of 'The Commission is dead, long live the Commission', which has been the U.S. standard, how we should do that. Should it be something independent?

DR. SULMASY: Should it be through Congress? Should it be through the executive branch? And, in fact, in New York State, I was on the Task Force on Life in the Law, it is actually through the executive branch and has survived multiple parties in the governorship. Your thoughts on continuity from all of you.

PROF. CAPRON: The French model began on the executive side and it was appointed by the president and continued. And I know when I've mentioned this to members of the present commission, there's sort of a sigh of saying, "Well, we're all kind of tired." And I think the idea is continuity with turnover and –

DR. GUTMANN: Definitely.

PROF. CAPRON: Yeah. And some idea that that would be occurring seriatim across the life of a commission, including under any particular President if a President has four or eight years. I agree with your chair that it is unlikely that the present Congress would be capable of having agreement on the establishment of a commission to then be appointed by the President, but you could never tell. It is possible.

PROF. CAPRON: The reason we got a Biomedical Advisory Board was Congress thought it was a good idea to have a body, but the people – the right thought that it was disappointing that the Reagan appointees to the Presidential Commission had not been conservative enough, and the people in the House on the left were worried that the new President would – the President would, going forward, appoint much more conservative people, so they gave themselves the job and then fell upon each other like a den of whatever. Maybe it's not possible, but maybe a compromise could be reached. Having a long-term continuity, it's like the Supreme Court, you gain credibility, you [develop] a way of working together. I think that the benefits outweigh the risks, to answer your question.

DR. GUTMANN: Jonathan.

PROF. MONTGOMERY: I think we believe we have both. We have a significant number of ad hoc bodies. We have committees that look at bioethical issues in both our House of Lords and our House of Commons. I gave evidence on behalf of Nuffield to a House of Lord's inquiry on genetically modified insects which we had turned down as a topic. It had been on our long list. We had looked at it and thought we weren't quite sure it was a big enough topic. We may or may not have been right about that.

PROF. MONTGOMERY: So, I mean, we have a slightly odd continuity in that our remit is, as I described earlier, not the full breadth of remit you would expect a bioethics advisory body to need to cover. We tend not to cover issues around resources because we have a National Institute of Clinical Excellence that looks at the ethics and the science of rationing. We were kept away from medical ethics at the original settlement because it was thought that, in a rather British sort of way, it was already covered by the professions.

PROF. MONTGOMERY: And our history of bioethics is very different from yours. Our early history is very collaborative, very collegiate, and we have a different mechanism for looking at

access to healthcare than you have here, which we wouldn't see as bioethical; we'd see as just part of our political settlement. We have turnover. We have – I have a fixed five-year term. We have – it looks as though I may need to extend slightly to induct the new chair in the next funding round.

PROF. MONTGOMERY: We have three-year terms which can be renewed once. We build in the expectation of turnover. I do think you can have both. There's nothing to stop specific task forces being set up for certain different things. And as I indicated with my comments, I think particularly for this little truth and reconciliation functions, and these are different skill sets, different type of resource. And I would not – we resist Nuffield being dragged in to some things. We turn down some invitations to collaborate because they think they would impair our core mission. Not because we don't think they're important, but because they're not for us.

DR. GUTMANN: Tom.

DR. MURRAY: On balance, it would be desirable to have a – some kind of [advisory] body that did have a longer life. And with all the kinds of transition arrangements that Jonathan just described, those are wise. My one concern would be – and this is not – this would not make me recommend against such [an advisory] body, but my concern would be that there are some issues that probably it couldn't take on just because they are so divisive.

DR. MURRAY: Some of the issues that resulted in the death of BEAB and BEAC – I called it the "third rail" – I think that really is the ultimate – the ultimate defeating – it's a self-defeating thing. That would make it – at least that [advisory] body would probably not have the capacity to tackle those issues in a meaningful way without destroying itself, which isn't a reason not to have it because there are other issues where – many issues where there could be broad agreement and wouldn't touch them.

DR. WAGNER: Is that a role for the ad hoc structure in Nuffield?

PROF. MONTGOMERY: One thing I didn't say about how Nuffield works is the relationship between the working parties, who produce the individual reports, and the overarching councils. I think we would deal with that type of problem by thinking very carefully about who was on the working party. A working party would have two members of the council. There would be a third

of the two members of the council who have a sort of watching oversight and keep a close view, but we would deliberately pick for our working party people we think are going to disagree, so [that] would sort of buffer the benefits of the general competence with the controversy in the specific bits by driving that work through a working process.

DR. GUTMANN: We had a recommendation at our last meeting which fixed the Occam's razor view of how to get continuity; which is if you look over the last 20 to 30 years, there's been a President – a commission that's just been differently named every time. And if you want turnover anyway, if you could keep the same name over time, I – I'm – it sounds – it may sound silly, but I don't think it is. I think because we all have different names, we talk about NBAC. This is what NBAC did and this is what the next commission whose name I can't recall – I know our commission.

DR. GUTMANN: Right. But if there were the same name of the commission, you can't prevent – if it's going to be government appointed, you can't prevent Congress and/or the President from charging it in different ways and so on. But if there were a continuity of name over time, it would be the simplest important change that you could make. Somebody recommended that last meeting and we all kind of nodded as it's really pretty silly that these – the names are not significant, the change of names, except that every administration changed the name.

DR. MURRAY: In preparation for meeting with you, I actually tried to find the mission statements –

DR. GUTMANN: Yeah.

DR. MURRAY: – and charges of each of the commissions –

DR. GUTMANN: Yeah.

DR. MURRAY: – that preceded. And you wouldn't be – you won't be surprised to know that there's more continuity than difference. There were differences –

DR. GUTMANN: Yeah.

DR. MURRAY: – right?

DR. GUTMANN: Absolutely.

DR. MURRAY: But I think your point is – your point is well taken.

DR. GUTMANN: You could do that, too, and keep the name. You know, you could even tweak the –

DR. MURRAY: You could bury – yeah.

DR. GUTMANN: Anyway, I want to go to Raju; you were next. And Anita.

DR. KUCHERLAPATI: Thank you, everybody, for a great – great session. One of the themes in this discussion is the topics that groups of this nation should consider. And many of the topics of these types of groups to consider are more reactive. Many of the examples that we have heard are because of something that happened. And in our case, it was like the synthetic biology, it was a paper, and the reports on Guatemala, the discovery of something like that. The other one which was really more proactive was the President asking us to look at grey matter in our report on brain initiative, and that was sort of proactive thinking about that.

DR. KUCHERLAPATI: I want to ask, do the kinds of the things that we – all of the commissions do, aren't they appropriately balanced in terms of these reactive and proactive things? I think about many, many very important issues that are out there that we have really either have – don't have the time or have not taken out. And then Jonathan really talked about an approach that Nuffield takes about how they were accumulated and how to prioritize issues and so on. But is it a right balance; if not, how do we address that balance?

PROF. CAPRON: I also looked over all the Commission's reports in preparation for being here today. And it seemed to me that the commission that was most likely to have carved out areas for itself was actually the one which I think has had, like, the least impact.

DR. GUTMANN: Yeah.

PROF. CAPRON: Although Rebecca Dresser is here and she –

DR. GUTMANN: Yeah.

PROF. CAPRON: – may take a different view of that. The President's Council took on a number of issues with, as far as I could see, the desire to get people to think about them, rather than to have Alyssa Eisenmann come along a few years later and say, "Here are all the actions that the profession or the government regulators or the state legislators have taken in response." And so, that's – in other words, it was generating those ideas.

PROF. CAPRON: I think that the Nuffield's approach of doing that in a systematic way and really asking the world what are the topics that most are on the minds of anyone who thinks they have a bioethics topic; let's hear it; let's filter them; let's have our four frontrunners and so forth –

DR. GUTMANN: Uh-huh.

PROF. CAPRON: – would be very desirable. But I don't think there's anything wrong with responding –

DR. GUTMANN: Yeah.

PROF. CAPRON: – to issues that are those lightning rods that something has gotten – or the crucibles –

DR. GUTMANN: Yeah.

PROF. CAPRON: – I called it, where everybody is storming in and you got to get some order and what really are the issues –

DR. GUTMANN: Yeah, yeah.

PROF. CAPRON: – and let's set the agenda. We're not going to resolve this forever, but we're going to get the discussion going. And I was very happy that Tom did the research on our "Biological Materials" report and found that it really is still very influential in the thinking. Not that we take – would take pride just in owning that, but just, okay, we did something that had lasting value. But at the time we were doing it, that wasn't as much a front-page issue.

DR. GUTMANN: Right, right.

PROF. CAPRON: In fact, most people were unaware that there were hundreds of millions of samples –

DR. GUTMANN: Yep.

PROF. CAPRON: – then in existence and many more now with the –

DR. GUTMAN: Yep.

PROF. CAPRON: – the methodology that is of importance. I think the combination works pretty well, but we – the commissions could be more orderly and I think taking a page from Nuffield would be useful.

DR. GUTMANN: Well said. Thank you. Anita.

DR. ALLEN: Well, one of my questions, slash, comments was about continuity and I think that you addressed continuity pretty well. My personal concern about continuity reached a head when I went to the World Summit of Bioethics Commissions in Berlin this past year and I felt great frustration and even sadness about the fact that for us, Election Day cuts a cord, and then there might be a six-month, twelve-month, eighteen-month hiatus when there's no conversation between the United States and other nations of the world.

DR. ALLEN: I think name continuity might be helpful, but also at least an administrative continuity, an office somewhere that's part of the executive branch or Congress, that keeps those connections alive and can communicate the priorities, the topics, the issues to the next commission. I think that would be very, very helpful by way of continuity. And I'm seeing from the nods that you guys agree, so, you don't need to answer that question.

DR. ALLEN: The other thing I wanted to talk about had to do with voice, perspective and style, and it was something I had never thought about until today and I think some of Alex's comments about speaking – the commission speaking to the public, and you asked were we encouraged to speak publically. The answer that Dr. Gutmann gave was yes, and we were encouraged to write op-eds and so forth.

DR. ALLEN: Yet I must say that I think that being a presidentially appointed public employee, special purpose public employee, has a constraining effect on those of us who are commissioners. I've been on "Fred Friendly," "Nightline," "Good Morning America," had a newspaper column, had a TV show, all that stuff before the commission, and the moment I

became a commissioner, I'm, like, 'Brooks Brothers'. I've thoroughly enjoyed every minute of the commission and I believe that my contributions here have been greater, actually, than the combined contributions of my public intellectual life before the commission.

DR. ALLEN: But I'd love you guys to comment on whether you think there is a constraining impact when the commission is tied so directly to the President or to Congress that might cause us to actually lose in the public context some of the perspective and voice of the people who are appointed as commissioners.

DR. MURRAY: No. No, I don't think there's anything about being a member of some kind of national or presidential commission that should feel at all restraining to you because you're responsible people. I mean, there are – there are folks I wouldn't want around the table because they would basically use this for their own celebrity. It's important to select people who are going to be thoughtful and responsible. But, I felt far more constrained as president of The Hastings Center in what I said and wrote than I ever did on NBAC. Because, there, I was representing an institution. And I'm sure Penn and –

DR. GUTMANN: Yeah.

DR. MURRAY: – Amy and Jim could speak to the same thing.

DR. GUTMANN: There, the rules do help. I mean, if we – I feel free to talk about bioethics in my own right, but I – as long as I chair this commission or were I a member of it, I would have to say I'm not speaking for the Commission. Now, I wouldn't – and when we're discussing take the anthrax vaccine or Guatemala, any – I wouldn't choose, before this commission completes its deliberations, to speak just as Amy Gutmann on this issue because even though I would say, "I'm not speaking for the commission," I'd be tying my own views prematurely to our – before our deliberations.

DR. GUTMANN: I can understand the feeling that Anita had, but I think the rules work in this regard. And I do – because you all nodded to what Anita said about not having that continuity of the commission, I do think – I want to speak my view from the perspective of the United States as a nation among nations and as a nation that wants to be a leader in areas of public ethics. I do

think it's a shame that the United States stands out as not having a continuity of a bioethics commission over time.

DR. COOK-DEEGAN: One other aspect –

DR. GUTMANN: I do not think it serves our country well.

DR. COOK-DEEGAN: One other aspect of continuity that may be worth mentioning is – and it relates, Raj, to your – to your comment about this balance of emerging issues versus reactive things – I think if what you want to find is impact, you're going to usually find that impact is associated with something where something happens in the world and it's reactive and somebody needs to fix it quickly and therefore there's going to be a logical train of political action that follows from that. It doesn't mean that the emerging issues things aren't really important.

DR. COOK-DEEGAN: And I remember going through two kind of self-inspections, one at the Office of Technology Assessment and another one at the National Academy of Sciences – and this bears on one of the points that you made, Anita – the single most powerful predictor of whether an individual report was actually going to matter in the real world was not the content of the report, but was whether there was a staff person who was permanently associated with and knowledgeable about a subject matter area and stuck around long enough after that to be a national expert or international expert in that thing; so, that when the event happens in the real world and the window of opportunity opens, you're ready to walk through it.

DR. COOK-DEEGAN: And that's where continuity really has a cost – the lack of continuity really has a cost because if you're – you guys have just closed your offices, right, or you're in the process of that? Somebody has to spend all that time and energy and money doing something – recreating something and the staff are going to have to be recollected again and you lose a lot, actually, when you terminate something.

DR. GUTMANN: Steve.

DR. HAUSER: Thank you, Amy. I would like to just speak a little bit about our discussion this morning just to comment and then ask a question. I thought that Robert started us – it was so useful for me to think about these dual roles that we have, the role of defining what – what is important, but then also having an impact and doing something with that and effecting change.

DR. HAUSER: And I think, Raju, that as we've tried to find topics that have both, it may be worth the role for future commissions to consider topics that may be signature important issues that are deserving of our , even if we think that our ability to impact change over the short term – sometimes the change may come longer, as you have told us – even if we think the long term – the short-term impact might be marginal, and to serve our role as a – as a deliberation body and as an – our educational role to all these stakeholders.

DR. HAUSER: I thought our discussion this morning about the role of media and having media-savvy individuals engaged on our commission is – would have been very helpful to us. And one additional example – you gave one, Alexander – from my career has been with the Dana Foundation, a very important neuroscience-related support and informational organization. When Bill Safire was running the Dana Foundation, we were rocking and rolling. And when he no longer did, the foundation lost its footing a little bit.

DR. HAUSER: And much of what he brought was the ability to connect to the outside world. I really think that that's an important issue. And then the question which grows from that a little bit – and, Jonathan, you spoke about our – the importance of our curator role or our – the legacy of the commissions and more – maybe in a more practical way, how we pass the baton, we are non-continuous. We aspire, perhaps, to be continuous down the road, but right now we – this may be our last public meeting. And I wonder if, as a commission, we might think of a practical way to briefly communicate advice that could be useful to the next commission, whatever their configuration is.

DR. GUTMANN: Tom.

DR. MURRAY: I feel like you have made powerful arguments. I mean, Bob's argument about the need to have – you develop an expertise, an embodied expertise – that can then continue to push forward for changes that you think are necessary. The idea, I think what you just said, it struck a chord with me.

DR. MURRAY: Basically, reports of previous commissions become orphans because – because I'm new, there's no continuity in staff, usually not in membership and we're doing our own stuff, and whatever happened by NBAC or any of the commissions represented here, it's history. And we may not denounce it, but we don't do anything to really keep it alive. There's so many good

reasons to try to encourage continuity. And then the – and Anita mentioned, we could have a year with nothing, right? And we're losing time and there might be important issues that arise that it would be great to have [an advisory] body like yours that could take it up. I mean, these are compelling so, please, whatever you can do to encourage that.

DR. GUTMANN: Yup.

DR. COOK-DEEGAN: Just to add one thing. Historically, I made mention of that action-forcing power and one of the things that existed for the President's Commission is we regarded our action-forcing power to insist on action – which we got on some, but not on all – of the national commission's reports on which there had been no action because action-forcing power is hard to exercise when you're dead, and the National Commission had gone out of business shortly after issuing the last couple of reports. And so, in that sense, continuity is important. I had the good fortune of having two sources for my staff where I was able to hire whoever I wanted.

DR. COOK-DEEGAN: And I chose a number of people who had worked for the national commission, so, I did have continuity and those were people who knew the ropes. Now, the national commission had been focused on what was then the Department of Health, Education and Welfare, and the President's Commission was created because Paul Rogers in the House wanted something that was going to be government-wide and get to healthcare. Teddy Kennedy in the Senate had his focus on research, and he agreed.

DR. COOK-DEEGAN: And so having those people brought in knowledge about H.E.W. and I was then able to hire young people who were working in the nascent field of bioethics and get them in for a year on leave from their universities. Those people didn't have the continuity, but then they had the continuity because they became the academic experts and continued to write and build on the things that had been done at the commission. I think we have to look at continuity and expertise in a slightly broader way.

DR. COOK-DEEGAN: It would be great if you could persuade the President, extend the charter a little and get the successor an opportunity to appoint people. Harold – I don't know if Harold Shapiro will say anything since so many – several of you have mentioned the Summit, but the Summit of National Bioethics Commissions was created because the NBAC invited the French commission to send out an invitation to the then-existing ethics bodies around the world, and we

got them to San Francisco at the time of the World Congress of Bioethics in 1996, and every couple of years since then, it's gone on to meet. I took it with me when I went to WHO, and WHO is now the convening body for it, but it's an independent group just of the commissions deciding that there is that value, Anita, to getting together. We had a hiatus, however, when the national – when the President's Council came in because Leon really was a little suspicious of that activity and really didn't want to send anybody to those –

DR. GUTMANN: Yeah.

DR. COOK-DEEGAN: – meetings.

DR. GUTMANN: We can't – we may be wringing our hands too much, then, because we can't – we – if there's diversity of views about engagement with international bodies, we happen to disagree with that; but if the next commission is more like the previous one, they won't engage, but we – you've had enormous influence, if not power, because we have – we have launched dozens of young staff people into bioethics.

DR. GUTMANN: We've gotten an amazing array of talent, and I was shocked at the size of the staff we were permitted to have and I realized, once we started our reports, that we needed them. I mean, we really needed them. And the quality of our Executive Directors, Valerie Bonham and now Lisa Lee, has been phenomenal and they will continue to – so, there's been an enormous de facto, if not de jure, continuity here, but the change of views of a commission will affect how engaged we are as a nation, internationally as well as domestically, in policy recommendations in addition to the educational part.

DR. GUTMANN: Whether the next commission believes in the deliberative view, which isn't just to discuss, it's to make decisions and recommendations that have some – is up in the air. This has been extremely, extremely helpful to us, enlightening both theoretically and practically. And we're going to take a lunch break until 12:30, but not before we thank you very much for your contributions.

[Whereupon, a lunch break was held].