



Presidential Commission
for the Study of Bioethical Issues

TRANSCRIPT

Roundtable Discussion and Concluding Remarks

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SESSION 4: ROUNDTABLE DISCUSSION AND CONCLUDING REMARKS

DR. GUTMANN: This will be a round-table discussion. So I'll ask a big question, but ask you to give one focused answer to it which will then -- then when we go down, we will -- we can have a discussion about it. So if we as a Commission are -- let me preface it. We as a Commission are undertaking a capstone project to talk about and make some recommendations about how we as a society can improve public dialogue deliberation about bioethics and improve bioethics education and the connection between improved deliberation about bioethics and improved education about bioethics.

So my question to you on behalf of the Commission is if there is one thing you would like us to recommend, what would it be, or one thing you would like us to with laser-like focus key in on, what would it be?

I'll start with Jim because Jim has laser-like focus on deliberative polling, so...

DR. FISHKIN: Well, yes. And I appreciate the chance to talk, and I also build on the suggestion that I think Nelson Michael made in the last session.

Look, watching is one thing; doing is another. So recommending -- in the best of all possible worlds, which we normally don't live in, I -- for years I've been saying a Commission -- and there are Commissions all over the world that have the same -- Royal Commissions in Britain -- Commissions all over the world have the same problem. How do they hear from the people or do they hear from the people? And you've got the -- you've got the policymakers, you've got the expert community and stakeholders, which this Commission has many good examples of, and then you've got the public.

And it seems to me that all you would need to do -- at the very least, you could recommend an agenda of ripe public issues, issues that are ripe for balanced and thoughtful and maybe even urgent deliberation.

I don't know how long this Commission will last, whether this Commission has the capacity to actually do something or just recommend. If it's just recommending, you ought to do -- some subset of the people involved in this Commission ought to be constituted to actually do an exemplary project.

And that exemplary project would, in my view, consist in developing materials for public deliberation, both written and video and -- or supervising the production, not doing, but supervising, and suitable for the schools, as well, and then maybe an agenda, a fairly broad agenda.

You know, in -- by the way, in a weekend deliberative poll, we often do many issues, related issues. We did a thing on the future of California which had something like 36 policy options in four different areas. You can do a lot in one -- that's a weekend deliberation.

You've got online capacity to do deliberation. You've got local capacities. There's not just one menu that's a question of what the issues are and who should be consulted and why.

And, of course, there are other models than deliberative polling. I happen to argue that, for certain reasons, that deliberative polling solves the problems better than the others, but, you know, let there be variety.

Just like the Japanese did -- I was mentioning in Fukushima they did various things, but, you know, they -- I -- so I think that -- that it wouldn't be hard. You're a Presidential Commission. You've been thinking for five years or you --

DR. GUTMANN: We've been doing more than thinking.

DR. FISHKIN: Yeah, you've been thinking -- well, no, you've been thinking, deliberating, discussing, learning.

DR. GUTMANN: We've made many recommendations.

DR. FISHKIN: That's fine.

DR. GUTMANN: Some of which have been acted on, yes.

DR. FISHKIN: That's good. That's good. That's good.

All I'm saying is that -- is that, you know, there was a moment in my life years ago, in 1988, when I thought of the deliberative poll and I wrote it up in the Atlantic and I was meeting with a friend of mine, a very influential Washington figure, and he said to me, "That's not just an idea. You could do that. You could do that. In fact, all you need is a television network. I've got somebody for you to talk to. But you could do that. You ought to do that. Don't just talk. You could do that." And that moment changed my life. It was very good for me because I learned a lot from the doing.

Well, as a Commission, if you did something or sponsored something or spawned something or created -- or the progeny of this Commission was some other group -- and they don't all have to be Presidential Commissions. I was on the Penn National Commission for whatever it was some years ago that Judy wrote in, a very excellent experience, you know, you can have Commissions of different kinds.

You could -- you could do an exemplary series of deliberations sponsored in the schools, in local communities, online and nationally or maybe state by state and nationally and I'm sure -- you know, I deal with foundations all the time. You must deal with foundations of -- there's so many bad ideas out there. A good idea, if you could set an example for other Commissions, there are all kinds of problems in the world where there are Commissions and they don't know how to bring the people in.

And the reason to do it this way, with scientific sampling, evidence-based discussion, balanced, vetted materials, evidence, qualitative and quantitative data collected, control groups if budget permit, the reason to do it in a scientific way is it has credibility. It has credibility and you have - you could know exactly that it's not been swamped by some group of intense activists who try to take it over and capture it or -- and you can get the reasoning of the public.

And if you -- and I even have a media partner. I mean, we've done all these things with Jim -- with the NewsHour. You know, it used to be NewsHour with Jim. They're -- we're discussing possible projects all the time with PBS. They're perfect because they have no agenda, they're credible, and a coalition.

I mean, I'm not an expert on bioethics, though I am a little bit. I mean, I have published some, but it's not my field. But we're doing a big project on Internet governance. I'm not an expert on Internet governess, but they -- there's -- the substantive people are partnering. Everything I do is collaborative. But if -- we would love to be involved, but lots of other people. You've got great experts on this right here at Penn.

In any case, I think you should go from thinking to doing. That suggestion -- or thinking to sponsoring the doing or exploring, at least, the doing. Because it's not hard because every value involved, balanced material, identification of key issues, involving the public in a representative and thoughtful way, exemplifying the same process in the classroom, using technology to radiate and enhance the process, these are all things that, if you do it right, other Commissions could follow in your footsteps on other urgent issues facing the country.

DR. GUTMANN: Thanks. Dan. Dan, I hope you have an opinion because Jim just can't really manage to get his opinion out there.

DR. DAVIS: He set a tough precedent.

DR. GUTMANN: Right, right.

DR. DAVIS: I'm going to focus on education and I'm going to try to pull together a couple of threads, one with Maggie's description of Ethics Lab, and Dan's comments on virtue education.

I think if you were to make recommendations about bioethics education, I think one of the ways in which we may have shot ourselves in our feet is with an overly theoretical emphasis in some settings. And so I think the more practical the better.

And I'm thinking of something that we're just now toying with in my institution; and that is, we have this big, large problem in this country of medical error, adverse events. Now supposedly the third leading cause of death. We know that it's related to psychological safety in healthcare teams, and we know psychological safety is related to respect between and among healthcare professionals.

And so we've started to work with surgical residents. And this always gets a chuckle, so we'll see if it does. And we've begun by using assessments of emotional intelligence in surgical

residents to begin to develop self-awareness about emotional regulation and so on and so forth, but as sort of what we hope will be the foundation for a few other steps, 360s where we have the residents who evaluated by their peers, nursing, all the members of the OR team, even by the patients, so that we can sort of begin to throw into relief for them not just what are the ethical issues at stake in harm prevention, but also how do they operationalize that ethical knowledge and do so in a virtuous way.

So I think practical education in bioethics and that -- that -- that I think with Maggie's work, that applies across the board, not just to nurses and to physicians, etcetera, but to ethics education in probably any sphere. So there's mine.

DR. GUTMANN: Thank you. Jason.

DR. SCHWARTZ: So I think I'll come back to the deliberation topic to an area we didn't get a chance to talk about during the session this morning, but something I've been thinking a lot about, and I'd love to see you say something to the effect that the kinds of public deliberation about bioethics and regarding bioethics within the Government is not and cannot and should not be restricted to groups with bioethics in their name or bioethics in their mandates; that these kinds of questions are present throughout the Government's day-to-day work in health and medicine and not just in the obvious issues around genetics and pandemic preparedness and things like that, but how the FDA weighs the risks and benefits of individual pharmaceuticals, how we debate the quality of evidence regarding preventative strategies, how we think about prioritizing vaccines as part of the recommended vaccination schedule.

There are obvious ethical dimensions to all of those decisions that expert panels like this one and the agencies that support them make every day, but those ethical dimensions are largely either ignored or cast aside or reshaped as if they are exclusively technical or scientific questions and -- and I don't think that's a good thing.

So I think to call attention to the fact that -- that bioethics need not be the domain of bioethicists and bioethics Commissions alone within the Government, but to shine light on all the ways in which it informs how we think about health and disease would be a very good thing.

DR. GUTMANN: Connie.

DR. ULRICH: I also agree that for bioethics education in the health professions, that it needs to be much more from a pragmatic perspective so that we can readily address those issues within the clinical arena.

And the other issue that I've been thinking a lot about is the issue of communication. I don't know if we really have really good communication skills. And I think many times that's where the ethical conflict seems to arise, when we do not communicate in a good way. And I think training in communication would absolutely help in bioethics education so that we can help clinicians feel more confident to address the ethical issues that they face.

DR. GUTMANN: Maggie.

DR. LITTLE: I think it would be really potentially potent for the Commission to recommend something like the following, and it's not a conventional form of recommendation. One is saying why it's so important that we have education and deliberation; and then to say we don't know how to do it well and what we need is a series of experiments. And so to fund -- I mean, I think you fund hack-a-thon on this, you know, whatever way you want to do it. But, you know, fund different experiments at different scales in different places. Some could be at universities, but should be in communities, you know, that have nothing to do with academics, but just fund experiments and innovation in bioethics education and deliberation and community and have a prize.

So it's a great model that's out there that's used in many places. Like right now there's an energy prize, \$5 million to a community that figures out how to reduce its carbon footprint. So it's just crowd source it with incentives and an aspirational mandate.

DR. GUTMANN: Steven.

DR. JOFFE: So I want to promote a modest idea thinking about the sort of public audience or public education aspect, which is simply to promote respectful conversations about these difficult issues.

Actually, the model that I have in mind is -- you may laugh -- Presidential debates, but not the -- not the primary debates and not the kind of debates where all the questions are asked by the moderators, but the debates where the questions are asked by citizens who sit around in a big circle and ask questions of the candidates. The candidates acquit themselves variably well, but the citizens acquit themselves incredibly well time after time after time.

And those sorts of discussions, debates, conversations, engaging the public about bioethical issues I think would be -- televised, publicized, on the radio, whatever -- would be incredibly powerful tools to promote the kind of conversations that we want to have.

DR. GUTMANN: Let's open this up now that you've thrown out some really good suggestions. Let's open it up for Commission members, any members of our audience and members of the panelists who want to engage one another.

Nelson.

DR. MICHAEL: Are you describing what in other fields we would call implementation science? In other words, do you believe that democratic deliberation is important, but we're not really sure how to use that tool? We've got it; we're not sure how to use it? Declare the fact that we, as you said -- we know that we need bioethics training or education, multiple sectors of society, so that part we know. We're just not exactly sure how precise it is to do it, so we need some way to learn how to implement that tool.

DR. LITTLE: No. I think I don't mean that. So "implementation science" is a new term to me. But I think I mean something closely related. But when I say we don't know how to do it, I

really mean let's throw open the box. I don't think we know what it should look like and we're not sure how to implement to get there. There could be models out there, again, that might not even be university based.

So to me this is more of a design challenge where design, you say here's the broad prompt and aspiration, but we don't know if what we want to make is a building or -- so I think implementation is part of it, but it really is about what are -- what are new designs in this that -- and even an expert body bringing in other wonderful experts might not be the best designers. They might be the people to commission the design.

DR. GUTMANN: Can I just follow up on Nelson's follow up? There are -- what about the cases where we do know that, for example, I mean, just to say we do know that public -- some kinds of public deliberation yield more informed electorates. There are examples, you know, in British Columbia of citizen deliberations on issues that have yielded, you know, really excellent results and so on.

So are you saying that we should throw open the box -- I guess I'm a little concerned. There are some things we know about this and it just doesn't -- we're not a very deliberative democracy right now.

So what do we do with the things we do know that aren't being enacted is, I guess, the follow up. I mean, there are some things we don't know, but there are other -- there's a lot we do know that we don't act upon.

DR. LITTLE: I really agree. So I overstated it by saying that the prompt is we don't know how to do it. What I should have said was we don't know what the possibility spacefully looks like.

So, really, there are two -- there's a parallel charge. One is -- so I loved the way you put it. How do we -- how do you all take the things we do know, which include a lots of things that were experiments, right? That we do know and figure out ways to implement, and then how do we keep that experimental space tilled and fed? I'm mixing my metaphors. Do you see what I mean?

And so I think I was speaking more -- so it's not a no to your question. It's an and.

DR. WAGNER: I'd like to -- I'm having a little technical difficulty.

DR. GUTMANN: Dan, you go and then Jim wants to say something, too. But you go first.

DR. WAGNER: Now, it'll probably dovetail. I'd like to spend -- have her spend just a moment - - and it doesn't need to be much longer than a moment -- on the zeroth order question. You know, as I ran down your comments, there were, Nelson, a bunch of tools suggested, you know, deliberative polling, more practical than theoretical educational processes, bioethics throughout the Government-- you know, through -- more than just with people who have ethics in their title, training and communication skills, experimentation to admit what we don't know.

But, Maggie, you and Steven both said we need to declare why it is that we need ethics education or, Steve, your -- Steven, your words were "promote respect for discussions." The zeroth order question, we do have a bit of a bully pulpit, Jim, that is still -- has some value even to say. Okay?

Do we as a Commission feel as though we have an obligation and responsibility and enough ammunition to say that this is important in the first place in a time where, I will tell you -- I mentioned it earlier -- virtuous education is not something that our public school systems or our state institutions of higher education are going to jump all over.

Zeroth order question. Now, maybe it's a question for the Commission. Do we have -- do we want to assert it? For you, should we assert it? And how do we assert it?

DR. GUTMANN: Go ahead, Jim.

DR. FISHKIN: So, look, technology, change, there -- we're constantly being confronted with difficult and sometimes almost unprecedented questions. Designer genes. I don't know. We could come up with a whole list. Right? These raise ethical issues. These raise policy issues. The public -- like most complicated issues, the public is often ill-prepared for them, but that doesn't mean they wouldn't be -- they wouldn't really have something to say if you created good conditions for them to think about the tradeoffs and engage them in the discussion.

So it seems to me that you -- far be it for me to really tell you what to do, but since you asked, I mean, my advice is to seize the fact that the country and, indeed, the world -- countries around the world are facing these urgent problems and they're only going to increase in terms of the unexpected issues that arise, particularly in this area of bioethics.

So what do we do? The -- in Thailand when we did that project, the people were initially saying, "Oh, let the priest decide." And priest said, "Oh, no, we don't want the responsibility." And then the policymakers said, "Well, we need to hear the values of the people in order to -- we can tell you that if you do this, these will be the consequences; we do that, those will be the consequences, but we really need to hear the value of the people."

I think that in order to lay the groundwork for consulting the people, you either need something like what we've been doing or something very much like it. So I think the idea of an agenda of experimentation, well, we're not -- an agenda of experimentation and consulting the people in a scientifically based, representative and thoughtful way based upon good information would -- should be legitimated. Whether you can actually do it or not or some successor group can do it, but I think it's -- it's well worth doing because the issues are urgent.

DR. GUTMANN: But, Jim, just to be clear about this, there are some issues where -- and we'd have to think about what the issues are -- where a deliberative poll would actually move the policy ball forward. But, generally speaking, a deliberative poll is thinking, not doing, just as we have been -- you've accused us of thinking and not doing. And that sense is a deliberative poll comes to a recommendation. We've come to a series of recommendations, some of which have actually been acted upon.

So in our deliberations on testing anthrax vaccine on children, the Government actually took our recommendation. On the question of databases, making databases more open, the Government, in fact, the Department of Defense, actually took our recommendation.

What we could look at, apropos of your suggestion, is the places where deliberative polling might do more to move the policy ball forward, but it's really important not to say that deliberation of the Commission is thinking, not doing, because this exact same thing holds for deliberative polls. They yield a recommendation.

And the question we need to ask ourselves, and I think you've really helped us here, is where is it that it would be useful in moving a policy ball forward in a more informative way and moving public education forward in a more respectful way by doing something, you know, that's more public -- engaging the public more in deliberation.

I want to hear what others --

DR. FISHKIN: But let me just say you said what I meant to say, maybe better.

DR. GUTMANN: Thank you. You do it, so that's -- we'll admire it. But other answers to Jim's question, Steven.

DR. JOFFE: So I don't think that you would be cramming this down the throat of an unwilling public or a reluctant public. I think there's a demand and a market for this. As bioethics-related issues sort of hit the public attention, hit the media, they're sort of objects of fascination, objects of interest, objects that get people to care. And so, again, I don't think you'd be -- you'd find the public unwilling. I think they're looking for this.

DR. WAGNER: They certainly are popular among our students right now, these subjects.

DR. JOFFE: I do -- I do want -- it just gives me the opportunity to mention a stakeholder in all of our discussions today that has not come up yet, which is the media, which is a critical conduit for the kinds of discussions that we're talking about. I just want to sort of put them on the radar screen.

DR. GUTMANN: Yeah.

AUDIENCE MEMBER: I have a comment.

DR. WAGNER: Yeah, please do write it down for us so we can -- we can insert it here.

AUDIENCE MEMBER: I was told that I would be able to make a public comment.

DR. WAGNER: Yeah, we have a mechanism for that. We sure do.

AUDIENCE MEMBER: So you're not taking public comments?

DR. WAGNER: Yes, we are. She's going to help you out right now. Dan, you had your hand up?

AUDIENCE MEMBER: So I can't deliver it to you?

DR. GUTMANN: Yeah, Dan. Once we get it up here, we'll read it and we'll engage with it. Dan.

DR. SULMASY: Yeah, I have a question sitting here and thinking about, you know, democratic deliberation is a kind of process which doesn't really have a content, and the content we're going to add to it might be bioethics of variable kinds of substance. And I wonder whether even that is sufficient for the kind of work that we really want to do, or whether we don't need either as part of our bioethics education or elsewhere an ethics education in general to be ramped up so that people might actually have content full, comprehensive views they could bring to the table, which might often converge on particular issues of bioethics, can sometimes diverge, but would give us the kind of citizens who could participate in deliberative democracy. Part of what you were suggesting is sort of missing, Jim.

DR. FISHKIN: Exactly.

DR. SULMASY: Because otherwise I'm afraid if we don't have that, if we just have deliberative democracy and, you know, the polling mechanisms, we kind of privilege a sort of collective preference maximization or consensus without, you know, the real content that's necessary.

DR. GUTMANN: Would someone like to respond to that? I'm actually reaching for my sunglasses, so when I look at it, you're, like -- sure.

DR. FISHKIN: So, look, if you want the values of the people when they're really thinking, you have to ask the people. Now, it would be great, and I'm a big proponent of spreading ethics education as far and wide as you can spread it, but we're a society of -- what is it -- 360 million people or something. It's going to be hard to spread it to the whole mass public.

If you ask people -- if you give them a concrete problem, dilemma -- oh, and the real protection for doing any of these projects is that it be balanced, that it not -- that the outcome not be predetermined, that anybody could read the materials and see that they're the strongest possible cases for any of several options and it's really going to be interesting and a surprise to see how it comes out. Well, the public actually can bring a lot to these issues, particularly if they're ethical issues.

Now, that's not incompatible, it's synergistic with spreading ethics education because, in fact, the same materials and issues can be used to dramatize issues that can be spread in communities and schools and the rest of it. So it's -- but I wouldn't -- I wouldn't dismiss the views of the people if you really do the hard work to prepare the agenda so that they can really understand the nature of an ethical problem about end of life or risks to health or all the kinds of issues we've been talking about.

DR. SULMASY: I'm certainly not dismissing the views of the public, but I -- and I sort of anticipated the kind of response you might have, but I'm wondering if others have a -- you know, sort of understood what I was trying to get at in terms of, you know, what's brought to the table actually and whether you just sort of give people, you know -- you know, a bit of an education in, you know, a half hour, two-hour sessions about something absent a kind of, you know, robust sort of view -- set of views they would bring to the table so there could actually be critical differences where people could exercise respect and transparency and actually deliberate at a deeper level. And I think that might improve the process, but maybe -- maybe everyone agrees with Jim. I don't know.

DR. GUTMANN: Any responses?

DR. FISHKIN: A two-day deliberation, it gets pretty deep. I think you'd be impressed.

DR. GUTMANN: But, Jim, let me respond, then, because I really appreciate what Jim does and I think it is an important addition to what we or any commission do.

But I also think that Dan is absolutely right in suggesting that the more robust we can make education relative to bioethics, the better all deliberations will be; and even those of us who defend deliberative democracy make it very clear that just as constitutional democracy -- deliberative democracy is a form of constitutional democracy. And when you modify democracy by constitutionalism or deliberation, you're not suggesting that everything is decided by deliberation or everything is decided by our constitution.

They're frameworks within which people live -- we want people to be able to live good lives by their own light and in order to do that, Dan's suggestion is extremely important. We have to have a kind of education that allows people when they're not thinking about policy to be able to live good lives and be able to think about the decisions they want to make, whether it be in getting their genome mapped, sequenced or, you know, end-of-life care.

So I think -- I think some of you already answered Dan's question and you might want to take the opportunity to elaborate on your answers because we really want to be able to make a set of recommendations that are if not comprehensive, at least hitting important issues of education. So I see Jason.

DR. SCHWARTZ: Yeah, just briefly, I liked Jim's use of "synergistic." And, Dan, your original question asked whether it was sufficient, the tools of democratic deliberation, and I think that would be a tough case to make for the kinds of questions here, but synergistic, a part of the conversation, as Dan and I talked about earlier this morning, seems right to me, that it provides useful information and insights both to the deliberation around bioethics and I think more broadly as Dr. Gutmann suggested. So I think synergistic does better work than sufficient would in terms of making the case for why it can be valuable, at least in my mind.

DR. GUTMANN: I have Steve?

DR. HAUSER: Thank you.

So I'm going to go back, as Jim did, to this concept of ethical stress, Connie, and thinking just from a bedside perspective where -- where -- at least one of the many areas where I'm sure that you could enumerate where the stress exists.

But one area is how we think about risk/reward, and we have at our -- at all of our centers wonderful people who understand medical decision making, who know data, who can enunciate the likely outcomes and the unlikely outcomes from any intervention, yet have dramatically different thoughts about risk/reward.

We are, as we all know, bracketed by recent events in our lives that can override our data, limbic system overrides our cortex often in all things that we do.

And my question is: How do we think about education for these kinds of issues? For example, when there's a very unlikely possibility of a horrific or a wonderful consequence for something that we -- that we take on, is this an area where maybe the variance could -- the differences of opinion could decrease, or is it always going to be an area where we all -- reasonable people will disagree and we need to air the sources of the disagreements?

DR. ULRICH: Thank you for your question. I think, as I've indicated, this ethics stress is very profound within the clinical arena and it creates much dissatisfaction and concern and individuals do want to leave the clinical arena because of this ethics stress.

I think it's a complex issue. And I think, as you said, that there is much room for variation, and I believe that ethics education allows a forum for us to have that disagreement. So it allows students to better understand various different opinions or differing opinions associated with a particular issue, whether it's end of life or disagreements among the physician and the nurse or disagreements among the physician and the patient.

And I also use case-based reasoning, so I provide actual cases that have occurred within the clinical arena to show students different ways of formulating their ethical judgment related to that particular case.

So I think it's very complex. I think, as I said earlier, we need much more of a pragmatic approach. There is room for divergent opinions, and we have to come to that recognition and respect that those views.

DR. LITTLE: I love that you brought up the question about reasoning around risk because when we talk about what are the constitutive literacies that we all want when we're teaching bioethics, that's one of them. So getting people, again, even just some fluency, to use Dr. Gutmann's phrase, around how humans reason around risk, which is, roughly speaking, really poorly, but we actually know more about the architecture of predictable irrationalities and naming for people framing biases and stuff.

And one of the things that I do with my bioethics students is they each do a research project on a different cognitive bias around risk. And then how can we communicate well with that risk? Then we can surface better true disagreements about should we have a precautionary principle here on this one. Some people really will feel that. That's a great debate to have, but only after you get through to just, you know, pass the here's the number that is supposed to be dispositive.

DR. GUTMANN: Barbara. Oh, Steve.

DR. JOFFE: I also just want to flag -- this notion of ethical stress is, I think, really important. And I want to flag the fact that it's not just professionals, healthcare professionals, scientists, whatever, who have ethical stress, but patients and family members run into all kinds of -- many of the situations that they deal with are, in part, characterized by ethical stress.

Think about the position of being a parent or an adult child making decisions for your -- you know, your parent with dementia. Those decisions are some of the hardest decisions we make. Christine's colleagues at the NIH have shown that they are lasting adverse effects on people from wondering whether they did the right thing for their loved one.

And so in thinking about ways in which we use ethics education, ethics conversations to address ethics stress, you should remember not just the professionals, but also the patients and their families.

There's a wonderful article going back more than 20 years by Margaret Urban Walker called, "Keeping Moral Spaces Open," talking about the role of ethics consultation services, ethics committees within healthcare institutions. And I think we can use that metaphor more broadly to think about the kinds of conversations we've been talking about, keeping moral spaces open in all kinds of areas of public and professional life.

DR. GUTMANN: Terrific. Barbara.

DR. ATKINSON: I think it's on now.

DR. GUTMANN: Yes.

DR. ATKINSON: I wanted to talk about what ages. We've spent most of our time -- not all of it, but most of it talking about university level, maybe community college level. Going down, is there some time that we should say we should try to get kids earlier and earlier and earlier? It seems to me that the more you can teach them when they're really young, the more they'll really get involved in it. And it's not just the bioethics. It's the ethics piece, too, and how do you sort of see integrating all of that.

And I think of bullying and some of those problems that happen really young and maybe if you can start doing ethical things right from then on, maybe it would be better for everybody; although that's something that gets very tricky because parents have all different opinions on how you handle those ethical issues in children that are young. So I'm interested in what you think about that.

DR. WAGNER: Is anybody here familiar with the KIPP Schools?

DR. GUTMANN: Yeah, yeah.

DR. WAGNER: K-I-P-P. Are they not trying to do what Barbara's talking about? Yeah.

DR. LITTLE: Yes. It's not my area of expertise, but I do know, in part because of my own kids' experience with public schools, there is a big resurgence of interest in ethics education even in public schools starting very early on. So they do tend to be the consensus values, like respect, self-respect, community, truth telling, integrity, but it's awesome. And it is, it's introducing moral language as part of the fabric of all language and ways of seeing reality and talking with one another. So I think it's great.

And I think it would be wonderful to introduce some headline issues into -- you know, very early that might be bioethics or something else, but just to make the connection it's not just about community respect; it's also about the things that are happening in the world.

DR. GUTMANN: So we heard presentation -- a presentation by Diana Hess -- I have Dan down. I just want to -- by Diana Hess, and she and Paula McAvoy have done empirical research, controlled experiments in schools, in public schools, that show when deliberative -- deliberations -- now, they're deliberations in a pedagogical way. They're as if you were deliberating on controversial issues -- actually works to educate students better. Where the better is they respect each other's opposing positions more. They feel that they understand their own position better. And they've actually learned more about the issues than they have in controlled experiment education that's more didactic.

So there is and they've been able to introduce these into public school systems, and Jim is absolutely right that there are some charter schools, like the knowledge is power program, KIPP, that are more dedicated to integrating this early on. So there is movement in this direction. It's not universal, but it is as a consequence of some scholars actually doing what you've recommended, being more pragmatic about taking theory, putting it into practice and doing it in a as controlled an experiment as you can do with -- ethically with human -- with human beings. And it's worked quite well for the more robust deliberative approach.

And there are qualifications to it. If you're in a very homogeneous school district, you have to teach differently. It's harder to do a robust deliberation, but there's still ways of doing it.

So go ahead, Barbara.

DR. ATKINSON: Could I just follow up? I was actually wondering, too, whether it was a way to get students more interested in the STEM things, too, to move it to the bioethics and use it as a pipeline kind of an issue.

DR. GUTMANN: So we don't know that. I'm putting my sunglasses on, so -- but now the sun is behind, so I can actually look out and see you rather than shadows.

The -- it would be something we could recommend. It hasn't, to my knowledge, been done specifically with bioethical issues and it would -- there's a groundwork to think it would work there, but it -- that's something we could recommend.

Dan.

DR. SULMASY: Just wanted to, in the interest of keeping our vocabulary clear, make sure that we're keeping things distinct in our discussions about stress. Because I think when Connie first spoke about it, she used a -- sort of a term of art in the literature now with moral distress, which really is something that we ought to think about, which is the experience that nurses and sometimes medical students have of being totally disemboweled and being forced to do things in the clinical setting that they don't think are morally proper. Right? And that's different from the stress of ethical decision making, which is a big problem in lots of other ways for clinicians, for family members, as well. But I just want to make sure that we keep those problems distinct. They're both important, so, yeah. . .

DR. GUTMANN: We'll break this tie. Connie, please speak.

DR. ULRICH: No, you're absolutely correct. Moral distress has been in the literature now for about over 30 years. It was originally defined by a philosopher and originally was found to be significant within the nursing profession. But we do see now that that is also relevant with physicians and other healthcare providers, and it's a serious issue that we need much more thought and dialogue on.

Ethical stress is also clearly important with regards to ethical decision making, how we make decisions and the stress related to that. Also has serious outcomes with regards to clinicians, such as dissatisfaction and leaving their position. So thank you for the clarification.

DR. GUTMANN: Christine.

DR. GRADY: I was going to say a little bit of what Connie said. I think two really important things about moral distress is that although most of the literature has been in nursing, there is an increasing literature that shows it's present in all kind of disciplines; social workers, respiratory therapists, medical physicians, residents, etcetera.

And it's also not limited to things that people feel forced to do. It's a -- it's a byproduct of the fact that many decisions that are made in the medical setting are made by one person and there's a whole team involved in the care of somebody, so you may not entirely agree with the decision that was made or there are system constraints or whatever it is that make the decision in something that you would have done differently if it was all up to you and it's never all up to you.

DR. SULMASY: For the latter, it sounds like deliberative democracy of the bedside might be a good solution.

DR. GUTMANN: Yeah.

DR. GRADY: Well, it's certainly -- there's evidence to show that one of the things that does work is letting people voice their concern, so it is.

DR. GUTMANN: Dan. Well put, Dan.

DR. DAVIS: Just want to add one other comment about moral distress. It's structural in nature. And I think that's important to keep in mind when we think about ethics education. And it's not just about processes of reasoning and deliberation; it's also about developing that sort of broader awareness of what is systemic in nature, what may be ad hoc in nature. But moral distress, I think is a great example of a culture structural issue throughout healthcare that will require those sorts of solutions.

DR. ULRICH: But that is why I think ethics education is so key, so that they can better understand what those structural constraints actually are within the healthcare system and the resources that they need and that they take advantage of within that system to help mitigate that stress or moral distress that they're facing.

DR. GUTMANN: So I began way back with a rhetorical question. This is the opposite of that. It's really something that I've been concerned about without any clear answer ever since we took up the Ebola and how to best respond to the next public health emergency question.

So we know based on vast amounts of evidence and now neuroscience is showing us what goes on in the brain that supports this, but we knew it even before we saw the brain that fear, that the emotion of fear drives out a lot of the ability of the prefrontal lobe to make rational decisions and to factor in all the evidence.

And once a public health emergency happens, and in the case of Ebola, a few public officials, you know, called for quarantines, it's almost -- it's -- so much is already determined about how there's going to be a response.

So what I've been concerned about -- in this Commission, we've made recommendations on it -- but we don't feel like we have the keys to how to get this, you know, moving. And I'd be happy for any Commission members to answer, but we have you here just for a limited time. What are the best mechanisms ahead of time for whether citizens or public or you name it, how do you prepare with education and/or deliberation ahead of time for the next public health emergency?

Because you've been talking -- we've been talking an awful lot about doctor/patient and things like this, but we know that thousands of lives can be saved or lost depending on whether -- this is a big ethical issue -- depending on whether we prepare well for the next emergency. And we don't know what the next emergency is, but we know what possibility is there -- what the probabilities are there.

Do you have any general or specific recommendations for us because -- what we can say? You can't have -- it's too late to have a deliberative poll when Ebola hits our shores. It's, you know --

that just takes too long. It's too late to start a new course. So all those things are important. We'll deliberate about those recommendations and say something, no doubt, about them.

But what about mitigating fear? What Nita Farahany was suggesting as we were talking, prudent vig-- so we have stood behind something that we can call prudent vigilance, which is doing things ahead of time that foresee what we're going to have to do as a society. So what would prudent vigilance call for in education or deliberation or anything to get our society to focus on the fact that we have to do things before these public health emergencies happen? I don't know the answer to this question.

DR. FISHKIN: Well, I think you need to think with the best expert groups you can about what things, and then you need to think about -- and then I would do the deliberation to see which of those things the public would accept or would not.

I was in Ghana in -- which is in West Africa, as you know. Has no Ebola. It's surrounded by countries with Ebola. And I wanted to insert in our deliberative poll in Tamale, which is a very poor city in the northern part of Ghana, which is the worst -- the poorest part of Ghana, the discussion of Ebola, and the public health experts from the University of Development studies, UDS, refused. They said, "We have so much death here from malaria, from cholera, from dysentery. These are real problems. We don't have any Ebola."

So I said -- I finally got them to accept some options about communicable diseases and etcetera, but they said, "We have all these other problems we have to deal with right now." And so we did and we -- we're writing that up now. It was great.

But the Ebola thing was a -- was a -- but I've been telling the African partners we should be doing Ebola preparedness all over Africa and exactly that, that we should be -- because the burial practices spread the Ebola. They are various things that spread it. And there's so much fear and suspicion of, you know, even that the westerners and the doctors are spreading it. No, they don't.

So you need -- you need to coordinate a public education campaign with the -- with the good information, but also to clearly think ahead of time of the policies that could be implemented that would actually do some good beforehand. So I agree with you completely, but -- and other disasters.

We have a partner which is the Tulane Disaster preparedness -- goodness. A guy named Kelu (ph), who used to be a high official at USAID. Anyway, I'd recommend you talk to him because he's been dealing with disaster preparedness all over the world. But he's proposing to work with us on deliberation for disaster preparedness, but he's got his own independent center, much bigger than my center, but that's the kind of thing that has to be done, I think.

DR. GUTMANN: Steve. Yeah.

DR. JOFFE: I wonder, you know, it's the job of the first responders, and I don't only mean the healthcare system and, you know, people involved in burial or the people involved in government. But everybody who's involved in this, of communications and all the things that

need to happen to have those kinds of preparation. But in terms of engaging the public, I actually wonder whether there isn't a role for just-in-time, even in the public health emergency context.

So just like there are clinical trials that you would want to do for Ebola or whatever the sort of pandemic disease might be, but you can't do between the epidemics, so you need to have the sort of protocols up and ready to sort of go in a just-in-time way.

It seems to me like there are public engagement strategies, ideally evidence-based ones, which is part of what the challenge is, that can't really do beforehand in this case because the issue is --

DR. GUTMANN: But you can prepare to do them beforehand --

DR. JOFFE: Precisely.

DR. GUTMANN: -- that's --

DR. JOFFE: Precisely. And then the moment the issue hits and the moment you go the public's attention --

DR. GUTMANN: The moment it hits, you have to do it.

DR. JOFFE: -- you roll -- you roll it out. And that kind of just-in-time approach seems to me more effective than thinking that you can do it in advance when you don't have people's attention.

DR. GUTMANN: Yeah.

Anita.

DR. ALLEN: I think that's great, Steve. But it seemed to me there's even like something before that. So if people aren't already of the mindset that the moral community extends beyond their borders, if people had not been able to overcome their xenophobia and their prejudices, just-in-time is not going to be enough. Right?

So I would say just-in-time, great, let's do that; but let's also take a step backwards and just make as much of what we can do to keep fighting against xenophobia and limited visions of justice and belonging as we can. It's a little bit idealistic, but I think if we don't do that, then there's little we can do when the time comes that's going to be effective.

DR. JOFFE: I completely agree.

And I also want to add to my comment about just-in-time and endorse, obviously, what Anita said. But also the potential to debrief, okay, what are the lessons learned in the immediate aftermath? That may be a real teachable moment.

DR. GUTMANN: Yeah, I think we actually have learned something through the Ebola. I think we have reason to believe WHO is in the process of doing some real structural reorganization. We have reason to believe that CDC and other public officials who are expert in this area and realized how the quarantine was very counterproductive, I think they're more prepared to do a just-in-time response. Now, it may not be Ebola, so you have to take the facts into account, but I think there is -- there's been some learning here.

That said, I also am sure from the evidence that our society cares more -- weighs one American life, alas, more than thousands of lives on the -- you know, in West Africa, and that's more than sobering. That's a depressing fact. And we have to -- we do have to work on educa-- deep educa-- if you want to call it deep education and deep character development to overcome that.

And we're not unusual. I mean, I say that not to cast particular aspersion against my fellow Americans. It's just nationalism and racism are pretty pervasive in our world and we're fortunate to have a peaceful way of dealing with that in a constitutional democracy; where other parts of the world are killing -- actively killing people. What we suffer from is not doing what we can to save people when it would be of -- the prudent as well as moral thing to do.

So I don't want to end on that note, so we do want to --

DR. WAGNER: Too late.

DR. GUTMANN: Too late? But is there any other -- yeah, Connie.

DR. ULRICH: I agree with you. I do think Ebola was an example for us. And it set the example for us to think about in the future how might we respond, especially from a health professional perspective, and what are our professional and moral obligations to patients? So it's much of a preventative type of ethics that it set the example for us in going forward.

DR. WAGNER: Patients and the public, it was, right?

DR. ULRICH: And the public, yes.

DR. WAGNER: That, I think --

DR. ULRICH: Absolutely.

DR. WAGNER: --- is one of the big lessons of Ebola --

DR. ULRICH: Absolutely.

DR. WAGNER: -- is -- is public protection --

DR. ULRICH: Right.

DR. WAGNER: -- as well as patient care.

DR. GUTMANN: Yes.

DR. WAGNER: Right.

DR. ULRICH: Yes.

DR. GUTMANN: So I do want to thank all of our presenters for being truly -- truly illuminating, edifying and forthcoming in your comments and definitely extremely helpful to our Commission's work. So with that, let us thank our panelists.

Let me just say that we will -- people who submit comments, we will respond to them. You can submit comments on our website, bioethics.gov. I want to thank my fellow Commission members and our Vice Chair, Jim Wagner, and I --

DR. WAGNER: And thanks to our Chair, as well. You never get -- you always leave yourself out of that list.

DR. GUTMANN: Well, it's my honor and privilege to serve. And thank you, all. And we stand adjourned. Thanks.

(Meeting adjourned at 3:59 p.m.)