



Presidential Commission
for the Study of Bioethical Issues

TRANSCRIPT

Member Discussion

Meeting 24, Session 2
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Teleconference

SESSION 2: MEMBER DISCUSSION

DR. GUTMANN: Let's begin by discussing which bioethics topic or content areas we might want to prioritize as we develop additional materials in our remaining time. So we have this library of materials and disseminate them to various audiences.

I'm just going to open it up to whether there are particular topics or content areas that we might want to prioritize as we develop additional materials.

Should I just call on people? Dan, can I start with you?

DR. SULMASY: Sure. I'm not sure that anywhere we have a module, it may be buried in some of the other ones, but specifically on our principles. And because they're so broadly applicable to so many topics, and I just thought it might be nice, if we didn't have something. And I might have missed it, just on the principles for evaluating new technologies of any sort.

DR. GUTMANN: What would you think about having something on the principles which, like these others, which I like, illustrate with an example so students could actually grasp how we use the principle in a particular case.

DR. SULMASY: Right, there might be multiple examples under each of the principles, but I think sometimes cases are terrific and they're valuable, but I don't know that they're always sufficient as learning tools, and so this would be another take at it, start with some principles and then look at particular applications to cases.

DR. GUTMANN: You can go both directions, so you're suggesting it would be nice to highlight principles in some -- we need a material that highlights our principles and uses examples to illustrate the principles.

DR. SULMASY: Correct.

DR. GUTMANN: Great. Nelson, your thoughts.

DR. MICHAEL: I think I was struck by Steven's comments about how he used a fairly visceral example of the use of placebos in Ebola treatment. I mean I can't tell you how many times I've had that

discussion in the past year, and it is still a very hot debate. It just seems to take people that are, you know, steeped in bioethics and it really just turns them on their head.

And Barbara mentioned this earlier as well that all of us are now dealing with Zika, and the lessons learned with Ebola I have frequently found extremely helpful to apply to either Zika or to MERS-CoV, something that still remains a very significant threat.

I guess I'd ask whether or not we think that we have enough educational materials that basically would become interactive modules allowing an educator to teach to one point, take for example Guatemala or Tuskegee, or Guatemala it a man might apply to Tuskegee if you were living in that moment.

In the same fashion you could do with the lessons you learned for Ebola that don't completely convey to Zika, but I think there are lots of learnings there that could be useful.

I think that may be helpful for an educator to use, and there is no right answer, but I think it allows an educator to understand, and I think this is what Nita was driving at in her clarifying comments is what the uptake is; how else do students learn from this.

DR. GUTMANN: Right. Steve Hauser, topics that we should prioritize from your perspective?

DR. HAUSER: I would agree with what Nelson said. I wanted to ask a question about communication of new findings, but I think that might fit later in the hour, Amy, so perhaps I will hold for that.

DR. GUTMANN: Okay, make sure we get it before you have to leave, Steve.

DR. HAUSER: I'm able to stay, unfortunately, for many hours.

[Laughter.]

DR. GUTMANN: Okay, well, we don't want it to be many hours. We will end on time. Nita, what are your thoughts on topics?

DR. FARAHANY: I think the staff has already done a great job on the number of topics that they've taken on.

One area that I think would be useful to build on since it's a growing area of concern and touches on our privacy and progress report, is sharing of information, you know, how we kind of think about the balances of risks and benefits more sort of abstractly than just in a genomic context.

So much of information -- for research subjects, for clinical studies, for research studies, for health information, for all the consumer devices that are being captured -- cuts across a lot of the different topics that we've had and implicates sort of each and every one of the principles that we grapple with. Is it something that really focused on and expanded upon the concept of access to personal information, risks and benefits and tradeoffs, you know, how would one approach that and how would think through the complex issues that it touches upon.

DR. GUTMANN: Good. Barbara, any comments on this?

DR. ATKINSON: Yes, I was thinking about our synthetic biology work. We did it so early on that I don't think we've done a lot with it since, but I was particularly struck in those discussions by the environmental piece of it and whether there might not be something that could be done with maybe even updating it relative to all of the environmental consequences of different kinds of synthetic biology, not necessarily just the one we discussed, but that play together.

I think that would be a good one for teaching biology students and the ethical issues related to corn and things like that that are so much in the minds of some people but not others.

DR. GUTMANN: Yes, the principles there also relate to something that's become recently very controversial, this CRISPR so that would might be -- again, not with answers but with the critical questions that you have to ask.

DR. ATKINSON: Exactly.

DR. GUTMANN: And the principles that we've articulated. Jim, do you have anything to add?

DR. WAGNER: The only thing I have been -- I was really struck by Steven Kessler's part of his presentation, again, about the skepticism of ethics being a tag-on, an add-on, that actually could slow down or confuse the advancement of science.

How hard would it be to do a module that's at the high school level or even younger for that matter on the fundamentals of scientific method? Typically it's a couple or three pages in a high school textbook, so it's not big, but adding to that this obligation to ask is my process -- is both the topic and the process ethical, are they right?

And I just wonder if we should -- maybe we need to spend more creative time than we have in this hour, but I do -- it does trouble me that, you know, we're all bought into this because how we have grown up and then reinforced by our deliberations together.

But, in fact, we have a generation of both teachers and students who having one chapter good science design and in a second chapter ethical consideration. I think there's an opportunity to bring those together.

DR. GUTMANN: I like that idea. I would just add a friendly amendment, which is if we could do something on the scientific method and showing how the elements of the scientific method include their ethical elements, you know, the scientists who believe that they are doing something that's really serving the public good are talking ethics without really knowing it sometimes.

So it embeds within it -- there are some ethical issues that come outside of it, but the scientific method, so if you take the placebo-controlled trials it depends on what you're thinking about, but many aspects of the scientific method presuppose ethical principles.

DR. WAGNER: And we could highlight that.

DR. GUTMANN: Exactly. I think that would be -- before you bring in esoteric ethical issues, the scientific method itself as, you know, honorably practiced has ethical principles built into it.

DR. WAGNER: Agreed.

DR. GUTMANN: Showing that would be more than half the battle, actually.

DR. WAGNER: It would be terrific if we could come up with something crisp and a lesson, essentially, on that.

DR. GUTMANN: Lisa, any public comments that have come in?

DR. LEE: Thanks for asking and actually thanks to everybody for getting in the conversation. There's one comment, and I'd just like to read it briefly. I think it ends with a question.

In a prior meeting Dr. Gutmann mentioned the research that shows that contemporary society creates fewer and fewer opportunities and actually a diminished interest in gathering. You mentioned, for example, Robert Putnam's *Bowling Alone*.

So as we think about educational materials -- on the ethical issues that touch the lives of our population -- does the Bioethics Commission have any ideas about how to engage communities outside the academic setting?

DR. GUTMANN: That's a great question and I think one answer to that is as there are fewer and fewer civic associations gathering to do this, educational institutions become more important so that underscores the importance of educational communities.

Secondly, and we've heard from some people, workplaces become more important. Communities and workplaces including professionals, but not only professionals, become more important.

And then I think we have to come to terms with the way people communicate electronically through the internet, is virtual communities are really important. Because we, as the Commission, are not going to be able to stem the tide of the fact that people bowl alone more than they bowl on teams, which is the headline from Robert Putnam. But there are virtual communities, and getting ease of electronic access to educational materials is going to be important.

DR. LEE: Great, thank you. That was --

DR. GUTMANN: But our three presenters, let me put them on. Do they have anything to add to that because I think it is a great question. We can't fight how people now assemble less in voluntary organizations. We have to take advantage of where people do assemble. Any additions to that?

MR. KESSLER: Might I -- this is Steven Kessler.

DR. GUTMANN: Yes, please Steven.

MR. KESSLER: This is sort of a piggy-backing on something you said, Dr. Gutmann, a little while ago about creating an app that lives beyond the Commission. Sometimes, you know, I was thinking

even maybe a little less sophisticated than that, or less modern, contemporary, but some sort of package that can be put together and they might have to be tailored to different audiences.

And of course as a science teacher and educator I think, okay, what kind of package of materials would be great for undergraduate educators or high school educators. And it might be a physical package that's actually published, but it could also be a digital package that could potentially be disseminated in the year before the Commission sunsets.

And it might involve a package that is the discussion guides that are most relevant, but perhaps there also needs to be a small video presentation or something that goes along with it about how to use it or something to that effect, or even a short excerpt of an actual discussion, a live discussion, happening.

I'm not sure how easy or how feasible it is to put together a package like that, but that might be useful, and if it came from this Presidential Commission I think it would carry some weight and people would -- institutions would give it a serious look at. Thanks.

DR. GUTMANN: Good. So this goes back to what not so much the topic as the kind of -- what presentation will become most accessible in an educational way. So we should also consider a massively open online course, a MOOC.

MS. PIKE: This is Lizzie. The other thing I would say is that I think in some ways our modules have done a good job of targeting audiences to interact with the modules when they are in communities, so classrooms -- a lot of these are classroom activities which, MOOCs aside, still have groups of people in one place able to discuss.

The other thing I'd say is the primers for anticipate and communicate are really geared to inform people sort of on a one-on-one basis, either practitioners or potential recipients. So there are ways to get individuals engaged with the material even if they're not engaging with others.

DR. GUTMANN: But there's a practical issue we should come back to, I guess, which is when this Presidential Commission ceases to exist, our website ceases to exist, and the next Presidential Commission will have its own website. So how do we keep these educational materials in circulation and keep access to them?

DR. LEE: Amy, this is Lisa Lee speaking, and I just want to let you know that we are fortunate that the Georgetown Bioethics Resource Library has housed all of the materials from the previous Commissions since the 70's, and that includes as they went from paper copies of things to electronic copies of things.

So we are working with them to discuss how to maintain the electronic copies of the materials we will have available to keep them in circulation both electronically and in hard copy. So we do have that. I think the idea of some kind of app or something that can live without us is a fantastic one and that we certainly can explore that.

DR. GUTMANN: Yes, because that answers the question, "Will it be available somewhere?" It doesn't answer the question, "How will people know how to access it?" None of us except for you, Lisa, knew that we could get -- at least many of us -- didn't know we could access everything from previous Commissions through the Georgetown site.

Okay, so now we've begun to talk about various audiences we'd like to reach with our educational materials, and Steven Kessler's provided some really important insights about the community college setting. And Steve, I really admire what you're doing and it was very interesting to hear more from Maneesha about developing materials for public health professionals.

So let's consider what other stakeholders to focus on in developing new educational materials, or disseminating our existing ones. So this is about -- are there other stakeholders to focus on or stakeholders to focus on more when we develop new educational materials or disseminate our existing ones?

And I'll begin with Steve Hauser this time. Steve Hauser?

DR. HAUSER: Can you hear me?

DR. GUTMANN: Yes, now I can. What are your thoughts about other potential audiences or stakeholders?

DR. HAUSER: I'm not certain that I can add more, but would emphasize, especially given Steven's presentation in our earlier discussions, the importance of engaging senior potentially flexible as well as mid-career scientists of all types.

DR. GUTMANN: Good, good. Barbara?

DR. ATKINSON: I pass.

DR. GUTMANN: Nita?

DR. FARAHANY: Thanks, Amy. So looking at the user guides and the way in which we've gauged these, I think part of it is at what level we engage people, meaning at what educational level. So we talked a good bit in our previous meetings about the importance of really integrating this much earlier, high school, even younger potentially, the ethics bowl challenge as the people do, things like that.

So I think making clear that the materials are available to or even gearing them to a younger setting to be able to integrate it into middle school education, not just for science educators, but for kind of more general educators, government class, things like that. I think that would be great to be able to help introduce it into those younger settings.

DR. GUTMANN: Great. Dan?

DR. SULMASY: To the extent that they still do exist, civic organizations, even scouting, things like that, would be places where people can have both ethics education, education about science, and ethics education about science as well, religious organizations, even seminaries. The National Science Foundation is now working actively as a grant program for seminary faculty to teach about science and religion and there's going to be an opportunity to work with them to get to the faculty who are teaching clergy of the future.

DR. GUTMANN: Terrific. Nelson?

DR. MICHAEL: So I was thinking of either ethical groups that are based at the WHO Geneva or the regional offices, or certain large national ethical groups in countries where, since we are an advisory board to the President, perhaps targeting those nations where substantial amount of research is funded by the United States government occurs.

DR. GUTMANN: Terrific. Jim?

DR. WAGNER: I was wondering if it would make sense for us to have at least a small section available to advise patients and subjects.

DR. GUTMANN: Yes.

DR. WAGNER: Right, to be able to click to something and understand sort of what it means to be treated ethically as a patient or a subject.

DR. GUTMANN: Right, right, good.

So let me move on now to something that the staff presentations reviewed. They reviewed the types of educational materials we have now on and that are in the pipeline, and they're topic-based modules, case studies, primers, deliberative scenarios. They all take a kind of deliberative approach to education, which I think is appropriate for a deliberative commission.

Let's consider what types of educational materials work best in different contexts and for different audiences with an eye toward what type of education materials we should prioritize developing.

Are there new types of educational materials we should consider developing, or do you think we should continue more of the same of a particular type?

Nelson, I'll begin with you.

DR. MICHAEL: Maybe just because I'm so used to this in the countless hours of military training I have to take all the time, but what works for our constituency of 1.1 million people is scenario-based training where you would go through lessons, and then either in small groups or in interactive tools on the internet you would then apply your lessons to either other scenarios that have actually occurred or hypothetical scenarios. It would put you in a situation where you are forced to take your learnings and prove in fact that you've learned from them.

In many cases there's a pretest that's done before the training and then after you've had the training you then hopefully have demonstrated more insight into critical thinking given the scenarios that

you're faced. So I find that actually interesting for someone like me with my degree of education to do and pretty effective for 18-year-olds that we bring in as well.

So obviously it's not the same approach, perhaps, that might be best for certain highly educated groups or in an academic setting which is more didactic but I think the interactive approach resonates well with people that are young and it makes the training interesting.

DR. GUTMANN: Great. Barbara do you have anything to add?

DR. ATKINSON: Well, I like the scenario idea and that does work well especially when you do it with taped vignettes of things. We're doing a lot with problem-based learning for medical students so having problems that can incorporate scenarios, if you will, or ethical issues as part of real clinical experiences I think is really important, not just at the medical school level but probably even earlier. So I'd suggest maybe thinking about problem-based kinds of approaches.

DR. GUTMANN: Great. Nita?

DR. FARAHANY: Thanks Amy. So I think that the case studies have been quite useful that the Commission has already developed, but I'm going to -- case study examples are the most useful in the legal setting and in the types of classes that I teach -- but I wanted to pick up a methodology that you had mentioned the concept of a MOOC or something like that. That I think is something that thinking about innovative techniques for introducing case studies and for introducing concepts, you know, is becoming much more popular and much more engaging I think for students.

And what I have found is that the flipped classroom model is helping a lot of educators to rethink how they deliver content to individuals, and so it's not just the case study but how the case study is actually developed and how the case study is actually delivered.

And so I think to the extent that we can think about incorporating some of these innovations in the delivery of information rather than just the content of the information that that would work really well in both the settings that I teach in and I think in a kind of trend more generally of being able to disseminate knowledge more broadly.

DR. GUTMANN: Good, thanks. Steve? Steve Hauser?

DR. HAUSER: Can you hear me?

DR. GUTMANN: Yes.

DR. HAUSER: So I would like revisit a question that we've challenged, that we've discussed I think in at least three of our reports. It relates to the dynamic nature of modern science, the stunning progress, and also the sometimes overly optimistic ways that progress is communicated. And this is so central to bioethics education at all levels, of course, because the core of a decision has to be based on the facts.

And as we've spoken before, often interesting but possibly incrementally important discoveries are fueled and misinterpreted by the public and sometimes by experts by combinations of optimistic presentations to and by the media, by very hopeful patients and support groups, and as we all know, amplified by the internet. And we've spoken about internet sites that try to put new findings in perspective, things like FactCheck.org, Neuroskeptic, there are certainly others.

Just last month there was this very interesting genetic finding in autism showing that a gene of the immune system that is involved not only in the immune system but also in sculpting and recycling neural connections is a genetic contributor to autism. This is so very interesting, but what wasn't communicated is that the effect size was miniscule and that this has an important biological, but not a clinical relevance.

So I think that we are going to continue to see these kinds of very interesting discoveries that we want the public to be aware of and be interested in, and I'm just wondering what we might be able to do in this report that could promote an early layperson or general scientist oriented, perhaps video as well as audio, communication of the objective significance of this discovery, or advance, in a way that would be engaging and people would want to pick up.

I think if one looks at the many millions of hits that YouTube videos have over very short periods of time it's clear that interesting material will be accessed.

DR. GUTMANN: Right, to get something like a TEDx talk --

DR. HAUSER: Exactly, but shorter.

DR. GUTMANN: Yes, so good. You said another thing that raised in my mind and triggered an added educational material that we might develop which is us and it would be -- it's a communication of science in an ethical way, right?

DR. HAUSER: Yes.

DR. GUTMANN: And in an effective way, picking headlines or paragraphs of stories from various scientific discoveries, communications, breakthroughs, and asking -- doing it in a didactic way, I don't mean in a didactic way, an educational way -- that grabs people and asks them, "What does this make you think?" So some of the more spectacular headlines that we've discussed, whether in neuro or synthetic biology, but doing it educationally.

DR. HAUSER: Yes.

DR. GUTMANN: Jim, any final thoughts on this?

DR. WAGNER: Just that since we're talking about both --

DR. GUTMANN: I have Dan on the list.

DR. WAGNER: I'm sorry, go ahead Dan, I'm sorry.

DR. SULMASY: Next to last, perhaps. I think first what we had already stated that I think a module on principles rather than cases as a material would be good. But then following on Steve Hauser's final comments, I think some video materials, a compendium of them, perhaps not ones we produce ourselves, that points to examples of respectful deliberation and disagreement.

DR. GUTMANN: Great idea.

DR. SULMASY: Debates, friendly seminars, IQ squared debates, things like that, might be valuable. I'm constantly reminded that younger people learn best by seeing videos, things these days, in ways that I was not used to, and it might be a good idea.

DR. GUTMANN: That's a great idea. Jim?

DR. WAGNER: Just technical comment. So much of what we have is already wonderful, and we've mentioned this issue a little bit, but it's a technical comment about the discoverability of what we have. And as you mentioned earlier, Amy, particularly if this goes over to Georgetown or drops off the

gov website, you know, if you type in, if you google "bioethics Guatemala," okay, the first four things that pop up are our work. If you google "bioethics principles," please, I just did it right now, and my first page, which has 10 hits, we don't appear at all.

DR. GUTMANN: Right.

DR. WAGNER: And I know there are ways to ensure -- and by the way, I notice in general when I google us up the stuff that we have in PDF format is readily discovered, and maybe we should think about putting some of these educational materials in the PDF format so they'll be more discoverable.

But I would hope we'd think about other ways, this is getting back to Dan's earlier comment about -- I think it was Dan, you were talking about civic organizations and the Boy Scouts and religious organizations, wondering the kind of search terms that we would hope where we would pop up.

In other words, words like "dignity" or "aging" or whatever, where educational materials on bioethics might be a very welcome compliment. So in addition to adding more things, I'd really like to make sure we put a little bit of energy into what it will mean -- what can be done to help make what we already have more discoverable.

DR. GUTMANN: Right, and I would say let's do a lot of that because search optimization is really key to people being able to get access to us. So you'll be happy to know if you type in "bioethics education" we do pop up after the sponsored sites, which pay for it. We come up fifth I believe. Actually second, but that will not happen after we, you know, after Bioethics.gov -- that's because "Bioethics.gov" plus "education" we're there, the Presidential Commission for the Study of Bioethical Issues.

So how do we get a kind of secular immortality for our principles and focus on education?

I think that's a worthy high priority. We're way up there now on bioethics education when you type it in. We should do the same thing for bioethics deliberation.

So if we could charge the staff with working on that because it's one thing to develop new materials, but if not very many people can find them easily that wouldn't be good. If you type in "bioethics deliberation" we come up -- we're all over that which is great. We're the top four hits; top five; six. And Georgetown is right after us, after six of ours.

So I'm going to open it up to any additional ideas on our educational materials, either content or delivery, or I think delivery sounds like -- I would add to delivery, access, just access. We have less than a year to complete our suite of materials and we want them to live on long after we complete our work for the President. So because they're not -- while they are timely, they're also pretty timeless -- so any additional thoughts on this? I'm going to run down the list.

Barbara, I'll start with you.

DR. ATKINSON: No additional thoughts. Thank you.

DR. GUTMANN: Dan?

DR. SULMASY: None, thank you.

DR. GUTMANN: Nita?

DR. FARAHANY: None, thank you.

DR. GUTMANN: Hauser? Steve, I can hear you coming in.

DR. HAUSER: Can you hear me now?

DR. GUTMANN: Yes.

DR. HAUSER: No additional thoughts, thank you Amy.

DR. GUTMANN: Okay, thank you Steve. Nelson?

DR. MICHAEL: No, I'm good for now, thank you.

DR. GUTMANN: Jim?

DR. WAGNER: No thank you, Amy.

DR. GUTMANN: Okay, Lisa, any additional public comments?

DR. LEE: We do have one I'd like to share from Caroline Plunkett at NYU, and she made a comment that the deliberative modules and scenarios that Maneesha described and, Kessler's use of them in particular, do a great job at fostering independent thinking and grappling with uncertainty, taking different perspectives and the like.

And she's actually advocating for use in an educational setting, kinds of materials that help encourage deliberation, discussion, critical thinking and even potentially stoke dissent.

So I'm pleased to see that there's interest in that as our deliberative scenario, that suite of materials, will very much have that as their goal.

DR. GUTMANN: That's terrific. That's great to hear. Thank you for that comment. And that is a very important part of our educational mission to produce, to encourage, to model education through deliberative engagement, through mutually respectful argument.

So I thank you all for really engaging discussion about Bioethics Commission education materials. I particularly thank our three presenters who did a magnificent job under suboptimal conditions of doing it through teleconferencing but you really made the most of it. We have a lot of remaining work to do and it's really a privilege to contribute to bioethics education in this way and it's a legacy that we hope will live far past the end of our Commission's tenure.

CONCLUDING REMARKS

So let me close today by thanking you all again. I also want to reiterate that we invite everyone to write us with any comments at Info@Bioethics.gov.

The next Bioethics Commission meeting will be an in-person meeting May 3, 2016 in Washington, D.C. and at that meeting we anticipate a very engaging and fruitful discussion of our upcoming reflections project concerning the work and influence of bioethics advisory bodies past, present and future.

Jim, would you like add anything else?

DR. WAGNER: Other than my thanks to the staff and fellow commissioners and to you, nothing to add.

DR. GUTMANN: And thanks to you Jim and thank you again for attending this teleconference.