



Presidential Commission
for the Study of Bioethical Issues

TRANSCRIPT

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WELCOME AND OPENING REMARKS

DR. GUTMANN: Thank you. Good afternoon. I'm Amy Gutmann. I'm president at the University of Pennsylvania and chair of the Presidential Commission for the Study of Bioethical Issues. On behalf of myself and my vice-chair, Jim Wagner, who is the president of Emory University, I welcome you to our 24th public meeting.

Let me begin by noting the presence of our designated federal official Bioethics Commission executive director Lisa M. Lee. Lisa, would you please verbally acknowledge your presence?

DR. LEE: Good afternoon. Thank you, I'm here.

DR. GUTMANN: Great. Because today's meeting is being held by teleconference there'll be a few differences in process from our in-person meetings. Public comment will be taken by email. The address is Info@Bioethics.gov. Again, Info@Bioethics.gov. Staff will monitor incoming comments during the teleconference and Lisa will read any public questions and comments relating to the discussion at hand as time and the flow of our discussion permits. All comments, whether they're read aloud here today or not, are reviewed and logged as public input. So thank you in advance for participating in our discussion.

I'd also like to remind the Bioethics Commission members and speakers presenting today, identify yourselves by name when you speak. It's important for those listening to the call today as well for the person preparing the meeting transcript. And since I can't see everyone, and to minimize our talking over one another, I'll be calling on Bioethics Commission members and speakers at certain points during the discussion to ensure that all those with a question or comment have an opportunity to speak.

I'd also like to ask Commission members to mute their phones when they're not speaking, and you can use the mute button or *6 to mute and unmute. So thank you. I'd also like to ask Bioethics Commission members to introduce yourselves, and for teleconference purposes we'll call on each of you one by one.

So first let me ask Barbara to introduce herself.

DR. ATKINSON: Hi, I'm Barbara Atkinson. I'm the founding dean for the UNLV School of Medicine in Las Vegas.

DR. GUTMANN: Thank you, Barbara. Nita? Nita? We lost Nita. She'll come back on. Nelson?

DR. MICHAEL: Yeah, Nelson Michael at the Walter Reed Army Institute of Research in the Washington, D.C. area.

DR. GUTMANN: Thank you, Nelson. Dan?

DR. SULMASY: Dan Sulmasy, the Department of Medicine and Divinity School at the University of Chicago.

DR. GUTMANN: Steve? Don't have Steve. Nita? We'll reconnect with them. Since we have audio only today I'm going to refer to everybody by -- I'm going to refer to the Steves by full name because we have a Steve Hauser and a Steve Kessler. So welcome everybody. During this meeting we're going to focus on the Bioethics Commission's educational materials, and these materials reflect our efforts to put our commitments into practice by developing useful and acceptable tools to facilitate the integration of bioethics in classrooms and professional context.

And now I'd like to ask our vice-chair to say a few words. Jim?

DR. WAGNER: Hello. Hello to all of you. In fact, I miss our face-to-face encounters. I can't read expressions and body language --

DR. GUTMANN: Right.

DR. WAGNER: -- but this is the next best thing. You know, education, I think, has been mentioned in most, if not all, right, of our studies over the years, and we have ended up building up quite an extensive library so I think it's very appropriate that we're spending some time thinking about how best to compliment and use that library, what are the gaps and what are the ranges of audiences and stakeholders that we want to be able to address, and in what formats.

So I'm looking forward to this conversation, Amy. Thank you very much.

DR. GUTMANN: Well, Jim, I'd like you to begin our first session, so this is the perfect segue. Why don't you just take it away from here?

DR. FARAHANY: Sorry, Amy, may I introduce myself. I'm sorry, I had some technical difficulties, but it's Nita Farahany.

DR. GUTMANN: Terrific, thank you, Nita.

DR. HAUSER: And may I also, I'm Stephen Hauser, UC San Francisco Neurology. Technical difficulties also, apologies.

DR. GUTMANN: Thank you, Steve. Great to have Steve Hauser and Nita Farahany on. Jim, take it away.

SESSION 1: BIOETHICS COMMISSION EDUCATIONAL MATERIALS

DR. WAGNER: Sure, we're going to have a single panel today, and we're pleased to be able to feature and learn from our Bioethics Commission staff. At the end -- we'll do the same as we normally do. We'll hear from all three of our speakers, and then go to questions.

Again, it's being suggested that since we're doing this by teleconference and we

want to make sure everybody gets a voice that I might essentially ask for questions at the end in a rollcall format. And I've been noting people here, well, and it works well. Nelson, I think you have the most reliable connection of anyone so I'll probably go to you first and then work my way through the membership.

Our first speaker we'll hear from is Elizabeth Pike. We know her as Lizzie. She joined Bioethics Commission staff in 2012; senior policy and research analyst and was staff lead for our secondary and incidental findings piece -- *Anticipate and Communicate: Ethical Management of Incidental and Secondary Findings in Clinical, Research, and Direct-to-Consumer Contexts*.

Lizzie has contributed extensively to the development of the Bioethics Commission's education materials, and received her B.A. at Swarthmore College, J.D. from Georgetown University Law Center, LL.M. in Global Health Law from Georgetown University Law Center.

Prior to the Commission work, she was a post-doctoral fellow in the NIH Department of Bioethics where she focused on compensation for research related injury and incidental findings in genetics research. Her scholarship has been published in the *Georgetown Law Journal*, *Cardozo Law Journal* and *Nebraska Law Review*, among others.

Lizzie, thanks for joining us today.

MS. PIKE: Thank you so much for this opportunity to begin today's important discussion of the Bioethics Commission's educational materials, the materials that we, the staff, and members of the Bioethics Commission have developed thus far, and the new materials that we plan on prioritizing as the Commission approaches the end of its tenure.

As you know, we have devoted considerable effort to developing bioethics educational materials for a variety of audiences reflecting the importance the Bioethics Commission has placed since its inception on helping students, professionals and the public grapple with challenging, contemporary issues in bioethics.

These materials take the content of the work that the Bioethics Commission did in its reports, and repackages the substance into formats that are intended to be more accessible to a wider range of audiences. In today's presentation, I'll describe the current inventory of educational materials freely available for download on the Bioethics Commission's website, bioethics.gov, and my colleague, Maneesha Sakhuja, will then discuss educational materials currently in development.

Turning to the first part -- our analysis of the current inventory of materials. There are currently 56 educational tools available on bioethics.gov. The largest number of existing materials are what we call "topic-based modules," which explore key issues in bioethics that have been considered in Bioethics Commission reports. These topics include community engagement, compensation, informed consent, privacy, research design, and vulnerable populations.

In considering these topic-based modules let us consider as an example -- the module on *Privacy and Progress in Whole Genome Sequencing*. This module adapts the contents of the Commission's report -- including background information about whole genome sequencing, definitions of privacy, and guiding ethical principles. It highlights specific recommendations from the report and suggests selected additional readings from the report.

The background section is followed by different types of exercises designed to help students come to a better understanding of the topic and the way that the Bioethics

Commission has interpreted or treated the topic and its work.

The discussion questions, which include prompts for teachers or discussion leaders, are intended to reinforce key aspects of the Commission's ethical analysis related to the topic. For example, in the privacy module, one discussion question asks: “What are the three facets of privacy and confidentiality protection recognized by the Bioethics Commission?”

The problem-based learning sections of the topic modules feature scenarios that help students analyze different cases. In the privacy module, for example, students are presented with a scenario, based on real world events, in which an artist collected strands of hair, chewing gum, and cigarette butts she found on the street; sequenced the DNA found on these specimens; and created portrait sculptures based on the DNA profiles. The module then asks a series of questions including: “How do the Bioethics Commission’s ethical principles apply to this scenario?” and “What are some practical considerations that this scenario raises?” The module includes some starting points for discussion.

The final section of these topic-based modules, Exercises, encourages students to research and conduct an independent piece of work related to the topic. One exercise included in this module raises questions about the privacy protections afforded to Henrietta Lacks’s genetic sequence. The exercise includes additional topical readings and poses questions designed to foster more open-ended consideration of the issues.

This first category of educational material, topic-based modules, is designed to give instructors in a variety of settings a resource that they can use to introduce either the topic or the Bioethics Commission report in their classroom, using up as much or as little space in the curriculum as is needed. A module could be used to supplement one

class session on a topic, or a series of modules on that topic could form a larger section of a course curriculum. The modules are designed to be as self-contained as possible so that teachers can pick out only what is most useful to them.

The topic-based modules initially formed the backbone of the Bioethics Commission's suite of educational materials. More recently, however, in an effort to reach specific audiences relevant to particular reports, staff have developed materials in a range of different formats.

Following the release of *Anticipate and Communicate*, staff developed a series of primers targeting the audiences most likely to have an interest in the Commission's analysis and recommendations regarding incidental findings. These audiences include: researchers, IRB members, clinicians, research participants, patients, providers of direct-to-consumer tests, and consumers.

The primers for practitioners—including researchers, clinicians, and DTC providers—are designed to help practitioners understand and implement the Bioethics Commission's recommendations, and are written to engage the audience through a series of frequently asked questions. For recipients of incidental findings, we developed the Conversation Series primers—primers that are one-page information sheets designed to make the content of the Bioethics Commission's report accessible to lay audiences.

To further the goal of reaching specific audiences, staff launched a third category of educational materials, the Public Health Case Studies following the release of *Ethics and Ebola*. The cases in this series include one with a focus on communication during a public health emergency and one on the use of liberty-restricting public health interventions—both key themes of the report. These case studies were designed

specifically with an audience of public health professionals in mind, aiming to distill the Bioethics Commission's analysis and the pertinent ethical considerations into a case that could, for example, serve as a lunch time or hour-long training session for global health students and professionals. The cases could also be used to form the basis of a lesson in a public health ethics curriculum. We were pleased to have worked on these two cases with doctors Howard Markel and Seema Yasmin, who presented to the Bioethics Commission at Meeting 20. Dr. Markel, a physician and historian of medicine, reviewed the case study on restrictive measures lending a historical perspective, and Dr. Yasmin provided insight on the communication case study drawn from her expertise as a public health physician and journalist. As we think about developing additional materials, we hope to be able to continue to engage other speakers, as well as members of the Commission, in developing more case studies to add to this series.

One final product to highlight is the classroom discussion guide, which Steven Kessler will discuss in more detail later in this panel. The discussion guides are intended to encapsulate the Bioethics Commission's work on this topic for use by science or social science classroom teachers who might be engaging students in ethics for the first time, or who might want a prompt that they can use to supplement a lesson on a related topic. These are the educational materials most directly targeting high school teachers or non-ethics teachers, and so can potentially be used to reach a much wider audience.

Turning our focus away from specific modules, there are some bigger picture takeaways about the Bioethics Commission's work on educational materials that I would like to mention briefly. First, the educational materials cover a broad range of topics or themes that appear throughout the Commission's reports. Some of these topics—such as informed consent, privacy, and vulnerable populations—are common in

bioethics syllabi or curricula. Others, however, such as communication, research design, and compensation, might be found less frequently. These educational materials therefore make a distinctive contribution to bioethics education.

Second, the materials encompass a wide range of practice areas. Although human subjects research is the most common, the materials also address areas as diverse as clinical practice, law, and communications, among others. These materials are intended for a wide range of audiences that include researchers, public health professionals, IRB members, and educators in a wide range of disciplines.

Finally, the Bioethics Commission's educational materials are targeted at a range of educational levels, including high school, undergraduate, and graduate education, and even at professionals in a range of careers.

Thank you.

DR. WAGNER: Lizzie, thank you very much. Let's move along now to Maneesha Sakhuja.

Maneesha, am I pronouncing your last name correcting?

MS. SAKHUJA: Yes, you are, thank you.

DR. WAGNER. Thank you. Maneesha joined the Bioethics Commission's staff in 2013 and she is a research analyst; has been instrumental in the development of Bioethics Commission's public health case studies, as well as many other education materials. She earned an M.H.S., Master of Health Sciences, from Johns Hopkins Bloomberg School of Public Health, and B.S. in biological sciences from Carnegie Mellon University.

She has a background in public health ethics and basic science research, including research in opioid addiction and malaria vaccine development.

Maneesha, we're looking forward to hearing from you.

MS. SAKHUJA: Great. Thank you, Dr. Wagner. I'm excited to speak with the Bioethics Commission today about the development of additional educational materials. As Lizzy described, the Commission and its staff members are invested in developing educational materials that can be valuable tools for a variety of groups on all the topics that the Commission has addressed. In order to broaden the Bioethics Commission's educational scope, the staff is working to round out our materials, both in topic and in type.

In this presentation, I will outline the materials that are currently under development, delving into some detail about what each of these materials aims to offer. Currently the Commission staff plan to develop additional educational materials in the content areas of law, science communication, incidental findings, cognitive enhancement, and public health ethics, among others.

These materials will take three different forms. The first will be case studies; the second will be a new type of educational material that we are calling deliberative scenarios; and the third will be classroom discussion guides. I will describe the case studies and the deliberative scenarios here, and Steven Kessler will discuss the classroom discussion guides in the next presentation.

As Lizzy discussed, the staff began creating case studies following the release of *Ethics and Ebola*. These cases were specific to public health and were aimed to provide public health professionals opportunities to explore ethical issues that might arise in the course of their work. These cases can be used as educational tools to teach public health professionals and students to recognize and address ethical aspects of their work and understand how deliberation can inform ethical decisions. They are appropriate for use

in professional training, individual study or reflection, and traditional classroom settings. Staff members are developing cases aimed at other audiences and on a variety of topics, including incidental findings and cognitive enhancement.

In general, these case studies include a case scenario, an analysis of the case, and questions for discussion which include twists in the case to encourage “real time” consideration of new information. The case scenario presents a background of the case and a task for the learner to complete. The analysis section provides an overview of the ethical dimensions of the case, including a brief overview of the Bioethics Commission’s analysis and recommendations on the topic. The questions for discussion can be used to facilitate additional analysis or create a twist in the scenario.

As an example, the Case Study on Communication During a Public Health Emergency—which is in the briefing material and also available on the Commission’s website, bioethics.gov—presents a scenario related to the 2014-2015 Ebola epidemic. In this case, the learner is a Public Information Office who is working at a city health department during an international public health emergency. The city is home to a large community of immigrants from affected countries and the health department must respond to calls about what is being done to protect the residents. The scenario presents a few different perspectives and asks the learner to draft a press release and talking points for answering questions from the public and the media.

The Case Analysis section then describes various ethical considerations that the learner should be aware of. These include anticipating the public’s need for information while also using effective communication strategies to mitigate stigma and discrimination. The analysis goes on to describe what the Bioethics Commission considered in its deliberations surrounding the Ebola epidemic in western Africa. This

section includes insights and recommendations that are particularly relevant to this case.

Following this section are questions for discussion. Specifically, in the communication case these questions are tailored to formulating a communications plan and responding to problems that might arise throughout the course of a public health crisis. For example, one question asks the learner “what groups have a stake in the situation presented in the case?” Another asks how public health officials and institutions can “sustain ongoing public engagement and education in emergency planning and response measures.”

As Lizzy discussed, in developing this case study, staff members worked with Dr. Yasmin, who had just started working for the *Dallas Morning News* when Ebola arrived in Dallas. She was particularly helpful in determining what questions would be most useful for public health professionals to contemplate.

While case studies serve as a very effective educational tool, the staff has also begun development of scenarios that incorporate skill-building for deliberation—these are the deliberative scenarios. These deliberative scenarios are aimed to be used in high-school and undergraduate classrooms to help students develop deliberative skills and facilitate deliberation on a variety of topics.

The deliberative scenario will present a situation in which there is an open question asking students to come up with a policy or recommendations to address a specific problem. An accompanying teacher companion will provide instructors with a step-by-step process for facilitating the deliberation based in part on the work of Diana Hess, who spoke before the Commission at Meeting 19 in Salt Lake City. This manual will include readings to provide background and context, examples of roles for students that would help facilitate effective deliberation, strategies to focus and improve the

deliberative process and content, and guidance for assessment and reflection.

Additionally, the staff is working to create a general Guide to Classroom Deliberation that will provide instructors and students with a condensed overview of how to conduct deliberation in the classroom and include information about what is key to the deliberative process. As an example of one of these materials, staff members are currently working to develop a deliberative scenario on the use of prescription stimulants for enhanced academic performance which could be well-suited for a science or health class in high-school or college.

We aim to release two deliberative scenarios concurrently with the release of the report on deliberation and education. As we look toward putting these materials to use in high school, we might think about the ways in which the Commission's educational materials can be connected to the Common Core, as we look toward putting our materials to use in high-schools.

For example, at the last meeting, you heard from Dr. Laura Bishop from the Kennedy Institute of Ethics who said that bioethics education quote "would help meet many of the new education standards, both in sciences and in literacy in the Next Generation Science Standards and in the Common Core" unquote. At the same meeting Dr. David Steiner from the Johns Hopkins Institute for Education Policy suggested that quote "when we support bioethics materials for high schools, they have to come with sophisticated structures that enable them to be put into Common Core classrooms" unquote. Engaging with the Common Core is something the Bioethics Commission could think about as they continue to develop these materials.

We hope that these efforts to round out the Bioethics Commission's educational materials will provide a wide array of stakeholders with the tools they need to tackle

complex topics in bioethics and provide an alternative way to get the Commission's body of work into the hands of current and future bioethicists, policymakers, scientists, and technology professionals. We look forward to hearing your thoughts on these content areas, types of materials, and stakeholders. Thank you.

DR. WAGNER: Thank you, Maneesha. And our final panel speaker is Steven Kessler. Steven was a visiting fellow with the Bioethics Commission while on sabbatical during the Spring of 2015, and with the Bioethics Commission staff he spearheaded the development of bioethics educational materials for biology teachers at the undergraduate and high school level.

Steve first developed an interest in bioethics as an undergraduate at Wesleyan University where he studied both biology and science in society, and from there he completed a master's degree in molecular and cell biology from the University of California Berkeley. After finishing his graduate work in 1999 he began teaching biology at several community colleges in the San Francisco Bay area.

Steven joined the faculty of City College of San Francisco in 2005 where he now teaches courses in microbiology, genetics, and introductory biology, and also developed and teaches a bioethics course.

In addition to the dedicated bioethics course, he has a strong interest in the integration of ethics into the basic science curriculum. In the fall of 2016 Steven will join the biology faculty of Santa Rosa Junior College where he will continue to integrate ethics into the biology curriculum.

Steven, welcome.

MR. KESSLER: Thank you very much. It is a pleasure and an honor to be addressing you all today.

Working with the Commission staff as a visiting fellow last spring was an amazing and rewarding experience. I learned so much from them and received a lot of inspiration while there. Participating in today's meeting is an opportunity to close a loop on the work I did while in Washington last spring even though I'm actually in the early stages of a work-in-progress, both in my own classroom and especially in terms of promoting the incorporation of ethics into basic science education.

For most of my career I have integrated ethical and social issues into my teaching both as a way of stimulating interest in the material and because I view these issues as integral to many scientific concepts. I have written today's remarks with three main sections.

First, I will share with you some background about where I teach and about my students. Second, I will tell you about how I have been using the discussion guides that the Commission staff and I created last spring. And I'd like to say that while I was a visiting fellow with the Commission staff I worked most closely with Misti Anderson, Elizabeth Fenton and Maneesha Sakhuja. Finally, in my third section I would like to touch upon ways to promote these discussion guides and to promote the very notion of addressing ethical issues in basic science classes.

Now before I go into these sections I just want to be clear. I am confident that these discussion guides are a wonderful and valuable resource for science educators, and I realize that I do not need to convince you all of the value of ethics-based education.

As I mentioned a moment ago, I have been integrating ethical and social issues into my classes throughout the career, and my personal goals in working with the Commission staff last year were to develop more formal materials for this integration and also to potentially have a wider impact beyond just my classroom.

Now my first section is brief and covers the environment in which I teach. I've been teaching at City College of San Francisco as a fulltime faculty member since 2005, and prior to that I had been an adjunct faculty member at a variety of SF Bay area colleges.

City College is a very large community college with tens of thousands of students attending each semester. The students, including those who take my classes, run a wide spectrum. Many of our students already have a bachelor's degree, or instead they might be the first in their family to attend college and they are just at the beginning of their college career.

Many of our students are immigrants or the children of immigrants and English is their second language. There are typically students with many different levels of preparation for college coursework in the very same classroom, and I truly enjoy the challenge of reaching all of these folks at once.

I generally teach in two tracks each semester. One track is aimed towards Pre-Allied Health students, and they are mostly pre-nursing students, and I teach their microbiology course. The other track I teach in consists of general education courses for non-majors.

Occasionally I also teach introductory level courses for prospective majors. In all of these courses I direct significant amount of attention to ethical and social issues, and based on my experiences I'm strongly compelled to do so -- to continue to do so, excuse me.

Now for my second section I would like to describe how I use the discussion guides that have been referred to earlier in the previous talks. The two finished classroom discussion guides which are up on the Commission's website are based on the

two reports, *Ethics and Ebola*" and *Gray Matters* Volume II.

I will speak today about the guide for *Ethics and Ebola* as I have used it more. It is applicable to both my general education courses and to my microbiology course. Both discussion guides -- for *Ethics and Ebola*" and for *Gray Matters* -- offer a good variety of questions for teachers to choose from. I find that only one question, however, can be addressed well during a typical 90-minute class meeting.

The question I have most strongly emphasized concerns the use of placebo controlled trials for potentially life-saving anti-Ebola drugs during a large Ebola outbreak. I find that questions such as this one are a great place to start for those teachers who are unsure of how to integrate ethics into their teaching because at the core of this question is the design of a scientific study.

Science educators often wrestle with how to effectively teach their introductory students about experimental design. One way in, perhaps surprisingly, may be through a discussion of ethics.

Also importantly I have found that many students, regardless of their educational background, engage meaningfully with this issue of placebos in an anti-Ebola drug trial when we discuss it in class.

It is exciting to me and I hope it would be to many of my colleagues in science education that the students find meaning in discussing the ethics of how to treat human research participants. They are discussing the value of placebos as a research control and hence the design of a research study.

Another aspect of the discussions that has been exciting to me is that many of the students seem to change their mind over the course of the 90-minute discussion. Presenting the question to the students elicits an initial gut-level response from many of

them that is different from their final response after a more careful reasoned discussion. Most of the students initially assume that the experimental drug should be given to all participants. However, after weighing the importance of the placebo as a control, a significant portion of them reconsider their initial position.

I want to mention that I do not tell them what I consider to be a correct answer although I do often play the role of devil's advocate. I have not yet been systematic in measuring this putative change of mind, however later this semester I will indeed start a quick before-and-after poll of the students.

I want to be clear that while I mention to my students that we are doing ethics, I do not explicitly emphasize philosophical ethical principles very much during the class. Rather, I give them the question and we approach it from a perhaps more lay perspective.

We do begin by covering background material, some of which is assigned as homework prior to the discussion, and next, without attempting to come up with a final answer, I have the students brainstorm pros and cons to the use of placebos in trials of potentially lifesaving anti-Ebola drugs. If they miss anything I consider to be important I might give some suggestions.

As we are brainstorming, of course, we are beginning to answer the question is how I have so far gauged their initial responses. After we have what I consider an exhaustive list I give them time to come up with a recommendation as an answer to the question, and I have them do this in small groups. I encourage them also to see if they can come to a consensus.

Now I've just presented to you the schemes that I use during the class because I think it might be a scheme that can easily be replicated. When promoting these

discussion guides it will be necessary to offer something very straightforward to science educators, and I think my scheme is straightforward enough. Facilitating this type of discussion would be new terrain for most science teachers, even those who are interested in incorporating ethics.

So to sum up the scheme we begin with an introduction to the question and any background for it. Then the students brainstorm pros and cons; and after generating a thorough list of these pros and cons I have them try to resolve the question as best they can.

Now before I move on to the third section of my remarks, I would like to quickly mention here that the other questions from the discussion guides are also intended to inspire both students and teachers. Perhaps that is an obvious intention.

In my classes I have also covered the question regarding the quarantining of healthcare workers returning to the U.S. following time in West Africa during the Ebola crisis. This question seems engaging to all of my students, however it covers a topic that is pertinent to the future professions of many of my Pre-Allied Health students. The possibility of finding connections to the students' intended careers is another great framework for incorporating these discussion guides into our science classrooms.

So the third and final section of my remarks I would like to turn to how we can ensure that science educators can access these discussion guides and find value in this work in general. Of course, posting them on the Commission's website is a great place for them.

When I began teaching a course in bioethics years ago I went to the website of your predecessor for resources. I hope other instructors are doing the same. And I also hope that speaking to you today will help in the promotion of these materials.

I have been having direct interactions with science educators. Recently I presented this work to some of my colleagues at City College of San Francisco. Many of them were interested and receptive, neither of which was a guarantee, even if they showed up for the presentation. After my presentation some of colleagues clearly expressed that they wished to use the discussion guides, which was very encouraging to me.

One did, however, voice skepticism stemming from his concern that discussing moral issues would muddy the students' ability to think about scientific study design. I attempted to convince him that the ethical discussion is, in part, an entrée into the consideration of scientific design, and that the students are, indeed, capable of weighing the importance of scientific controls even under these circumstances. I must admit that I am not sure what this skeptical colleague's final impression has been.

I hope to continue to engage with my City College colleagues, however, at the end of this semester I will be moving on to another college, Santa Rosa Junior College. This is a community college in Northern California in Sonoma County. I was very explicit throughout the hiring process that integrating ethics into my science teaching is my main passion and I described my experiences in doing so. The hiring committee and the administration at Santa Rosa have expressed their support for what I want to do and that is beyond simply hiring me. It is my expectation that I will have a good audience there for presenting this work further.

Still, these are only two colleges in one region of the country. Perhaps these Bioethics Commission materials can be presented at science education conferences. Perhaps a package of materials can be disseminated online or otherwise to educators around the country.

This package would have to include material that emphasizes the importance of integrating ethical discussions into the science curriculum, and it would also need to include a straightforward scheme for facilitating an ethics-based discussion. The scheme could be the one I described earlier. And I do realize that efforts along these lines are already underway, I'm just trying to emphasize them.

Based on my experiences so far I am confident that there are many science teachers who are interested in and willing to use these discussion guides such as the ones that Commission has posted. I am excited by the possibility of reaching as many of these teachers as we can.

And lastly, just to finish up, I am really excited by this opportunity you've just given me to address you today. It has been a wonderful honor and thank you so much.

DR. WAGNER: Steven, thank you. It's a wonderful account of how these materials can be used.

That concludes the remarks from our three panelists so I would like to have, as I say, I'll go through a roll call here to see if folks have any clarifying questions. Bear in mind that our next section that Amy's going to lead we're going to go into depth on several key questions. So I think at this point anything you might have that clarifies or addresses something that might be outside the scope of what we anticipate in the next hour.

Nelson, do you have anything you'd like to ask?

DR. MICHAEL: Yes, just a further clarifying point, now those were a wonderful series of presentations. Our hats really are off to all three speakers for presenting such an incredible impressive breadth of work.

But the one clarifying question I had is, are all of the materials that are available -

- and by my perusal quickly on our website it looks like I think I know the answer to this question -- are all the materials simply done in English?

In other words, would there be intent to translate or, in fact, are there already companion modules that would be in languages like Mandarin, Arabic, Russian, et cetera?

DR. WAGNER: How about asking -- Lizzie, would that be one you could field for us?

MS. PIKE: Certainly, yes, this is Lizzie here. Most of the educational modules are only in English, and as far as I can tell there aren't plans in place to get them translated. One exception to this is the "Ethically Impossible" study guide which is available on the website.

So if you go on our website and you get to the tab that's All Educational Resources by Bioethics Commission Report, if you scroll down there's a study guide for ethically impossible and there's a Spanish translation of that study guide. The goal here was, given that the research was conducted in Guatemala, the study guide should be accessible more broadly. But the other educational modules have not yet been translated.

DR. WAGNER: Any follow up Nelson?

DR. MICHAEL: No, no, I just was obviously would think, for example, for some of the Ebola materials having them available in French would be important for some of the affected countries.

DR. WAGNER: Great, great. Nita, how about you -- any questions, clarifying questions?

DR. FARAHANY: Just one which is so let me act on Nelson's comments.

These were fabulous presentations, so helpful, and the materials have been so helpful as well. I've enjoyed looking through them and incorporating some of them into our bioethics education here at Duke.

I wonder if any of three speakers could just talk to any of the challenges that they see about kind of uptake of these materials. What are some of the impediments that we may face in helping people to access, integrate, and really understand how to incorporate these materials into their curriculum.

DR. WAGNER: Probably start with Steven for that. Steven?

MR. KESSLER: Well, one of the challenges that I sort of mentioned it is actually a lot of science instructors are skeptical or just not interested in using ethics. And I don't know how much we need to address them, but during my presentation I actually enjoyed the exchange I had with the skeptical colleague that I referred to. Other than that, the main challenge is that instructors, my colleagues, they don't know what to do or how to do this. And I've been approached a number of times, I'm known as the ethics person in my department, and so they do ask me and I've helped provide materials, and sometimes I even find myself at a loss, and that's what's been really exciting over the last year having worked with the Commission staff, I feel now I have resources. And the challenge now is making sure people know about them.

And so I don't know how specific of a response I have, but some things I mentioned in my remarks were -- and I hopefully could do this or someone could make sure at education conferences, science education conferences and meetings that educators are made aware of these materials.

DR. WAGNER: Maneesha or Lizzie?

MS. SAKHUJA: Yes, this is Maneesha. I'll just echo Steven Kessler's

comments a little bit and add that I think that one of the greatest challenges is getting the materials into the hands of teachers in high school and colleges.

A lot of teachers don't know that these materials exist and that they're out there. And when they find out about them they're pleased to find them and they're pleased to use them in their classroom. But I think it's a pretty big challenge to get them into their hands.

DR. WAGNER: Anything to add, Lizzie?

MS. PIKE: Yes, the one thing I would add is that as the Commission members and staff continue to be so prolific in producing modules -- so now we're up to 56 and they're plans for many more -- I think it almost becomes harder to access what's most relevant.

So when you have just one it's clear, like, oh I can use that, I'll try to figure out how to incorporate that one thing. But when they're 56 I think someone who practiced in a particular area might have more trouble accessing it even if they were to know they were there.

I think the user guides do a good job of pointing people to the materials that would be most likely to be of use to them, but even so I can see if there's sort of initial -- if there's sort of a barrier to entry that that could be tricky.

DR. FARAHANY: Could I just ask a follow up to that, Jim?

DR. WAGNER: Sure.

DR. FARAHANY: Which is so that, I think, Lizzie, was one of the things I was worried about, you know, the embarrassment of riches is sometimes it becomes -- you lose in the kind of forest that we've established there, and that you guys have done such a good job of building up, how to access and which ones to access.

And so I'm wondering if the staff has talked about kind of developing a user's guide, an easy here's how to navigate the materials and here's how to find what you're looking for by category or a quick cheat sheet to help people and integrate it.

MS. PIKE: Yes, so there are some of those. So if you, on our education tab on the left there are some options and one of them is User Guides. And currently they're user guides for researchers, human subject's researchers, public health professionals, legal educators, public policy educators, and science educators.

I think there are ways in which to add more but also you run the risk of creating the problem, again, where the list becomes overwhelming and people back away. So I think it's a matter of striking that balance.

DR. WAGNER: Thank you. Dan, any thoughts or questions?

DR. SULMASY: Yes, this has been very helpful. One thing that I had thought during all three of the presentations, actually, but particularly after Mr. Kessler's, is the question of whether there's been any consideration to working with an external publisher to make these materials available, both in print and electronic format, to improve the access that people might have to these materials without having to, sort of, have somebody tell them you should go to the website and then try to navigate it there.

There's a precedent for this in our predecessor's Commission for different style. "Being Human" was a compendium of stories and myths, et cetera, which was then published by an independent publisher and used in bioethics courses; and I wonder if there's been any consideration among staff to trying to work with an outside publisher to create a compendium, a bioethics casebook, utilizing both print and electronic formats.

DR. WAGNER: Lizzie or Maneesha.

MS. PIKE: This is Lizzie. I'm happy to take a quick stab at answering this. As

far as I know there haven't been concrete discussions about moving this towards a hardcopy printed edition, although I might actually be wrong on that.

I think one thing the Commission has been really thoughtful and mindful about is how to keep these accessible after the Commission's sunsets, how the links can't be sort of updated or maintained in ways that allow us to make content changes, but when there's a transfer of the website how the information can remain accessible.

If there's someone else who can weigh in on the print edition issue someone else might have more insight on that.

DR. GUTMANN: Jim, this is Amy.

DR. WAGNER: Yes, Amy.

DR. GUTMANN: I think this is a really important issue about dissemination and access, and the problem with print is that any publisher will charge where it's now free. I think the history -- here's where history changes. I would love to see us create an app that could be accessed with, and we could perhaps hire somebody, and it would probably be some young person, to create an app which would live beyond the Commission, and would be able to access these since these are -- it could be an open access. And that's where a lot of people get their information now and it would be much easier for teachers and for the whole variety of people we have if it were a well-designed app.

DR. WAGNER: Fascinating. And I hope we're collecting all these good ideas for the end of the session. Let me go to Steve Hauser. Steve? Steve, are you muted perhaps? There you are.

DR. HAUSER: I would echo everyone's comments. I think this has been -- these are three extremely interesting presentations. Perhaps one follow up question for

Steven, and the others may want to weigh in also.

The skepticism that you described with respect to how scientists, presumably of various stripes, great embedding ethics in their thinking about clinical trials in the example that you used, but it certainly extends beyond this.

I wondered, because this is such an important area to the point of origin of how information is communicated to the public and as well as how the science is conducted, and I wonder if you have other ideas about how the Commission might be able to make an impact in this area.

MR. KESSLER: Yes, this is Steven Kessler, thank you. You know, so this is a great question and the way I've at least personally attempted to approach it -- and I imagine the Commission could emphasize this as well -- is that what I find is that the students are really engaging with the scientific process at the same time as considering the ethics of the trial design.

And to me that's just exciting -- that they really are doing these two parallel processes at the same time, two parallel intellectual processes, and I really do think the students are capable of that.

And what I see in my classroom is that the students take very seriously -- so I'm going to go back to the example I spoke about -- they do take very seriously the value of a placebo control even though that was counter to their gut response at the beginning. They thought everyone should have this drug, this life-saving drug, but then they realized well, first of all they don't know if it's life-saving, and they really did seem to understand that the placebo is an important scientific control, and I felt like that was very valuable just for the basic science, as well, for understanding a scientific method and trial design.

And I wonder if in trying to reach science educators, and especially the skeptical ones, emphasizing how this might be of benefit to their educational goals in terms of teaching about the scientific method.

DR. WAGNER: Jim Wagner here. You know, we repeat it often, Steve Hauser, through our deliberations that there is, in our view, no such thing as good science that isn't also moral science, and of course "Moral Science" is the title of one of our reports. Other than asserting that -- well, I should say it the other way around. One way is to make sure we assert that either in the introduction of these modules or throughout the content.

Other thoughts on that before I go to Barbara? Barbara?

DR. ATKINSON: Hi. I agree these were great talks. What I am interested in is maybe a little more than clarification, but I was interested in the Ebola discussion as it relates to the Zika problem that we're having now.

I was really interested as I watched the communications, the public health communications about Zika, and how much better people were at actually handling this. It's different and not fatal instantly, but it has very serious issues associated with it and I thought they did a much better job of handling it.

And I guess I really wondered as I was listening whether anything that we had done, particularly the communications part of Ebola, had had any impact, did we know if anybody had actually used our efforts to help form the communications better?

DR. WAGNER: Which of our staffers wants to try a shot at that. Do we have any way of knowing?

MS. SAKHUJA: This is Maneesha. I can take a stab at this.

DR. WAGNER: Sure.

MS. SAKHUJA: I'm actually not certain right now if we know that those materials or our "Ethics and Ebola" report got into the hands of journalists, communications experts, et cetera. But we have done our best to, with outreach, in terms of getting the report out there, getting these materials out there.

Commission staff actually just spoke at a conference in Reston, Virginia a couple weeks ago where we talked about these public health ethics case studies and they were very well-received by the individuals who were at the conference.

So our materials are getting out there. Finding out exactly whose hands they've gotten into it's a little bit difficult, but I'm not sure if anyone else can take a stab at or if they know anyone else who's received these materials.

DR. WAGNER: Silence seems deafening. So we'll hope and we'll assume that as we see better and better responses, Barbara, that we had some impact. I trust that we have.

Amy, anything on your mind?

DR. GUTMANN: So I just think Lizzie, Maneesha and Steve, each of your presentations was terrific and highlighted how important these materials are. My question is the theme I think of all of our statements and questions -- is how can we be more effective in disseminating them and getting more people to know about them, have access to them.

And I think Steve Hauser's question is really -- I would take a stab at answering Steve's question, but I throw the other question of how can we get it out there. I think, Steve, that it may be the case that these practical scientific problems that we tackle that have ethical -- strong ethical components like running a good scientific experiment with controls.

Posing those as big issues whether it's in an ethics class or a science class is really important and I think scientists would resonate with the fact that if you don't tackle those practical problems with ethical components you're not going to be able to get science to make progress.

At least that's a practical way in which we address ethical issues. I think scientists -- I don't know, I guess I'm asking Steve, do you think scientists would resonate with that?

I'm done, Jim.

DR. WAGNER: Thank you, Amy.

MR. KESSLER: Absolutely Amy, and think also that the question of how we maximize the dissemination of the reports particular the aspect of the reports that are geared to particular settings and groups is going to be so important as we think about this final legacy report.

DR. WAGNER: Thank you, and I hope we'll have a little more time in the next hour to discuss that.

I had a quick, quick clarifying question for you, Lizzie. In fact, it came to mind as I heard Steven Kessler speaking when he said that he hadn't dwelt much on the principles, that they kind of came out of discussions in brainstorming of the issues. The clarifying question is this: We include in our educational materials more issues than the Commission actually discussed, and I trust that, you know, we never discussed Henrietta Lacks. We never discussed an artist who picks up hair and cigarette butts and tries to base art work and sculpture on that.

But we are using those, I assume, to illustrate the principles that we have discussed early, and we are careful not to go too far down the road suggesting how the

Commission would have applied those principles to issues that we haven't actually discussed.

MS. PIKE: Yes, Jim, that's correct. So each of those modules that sort of introduces the new scenarios, before it gets to the scenarios sets forth the Commission's key principles at stake and how the Bioethics Commission has interpreted those principles. It talks about how the Bioethics Commission has applied those principles to the analysis at hand, whatever the consideration of the issues is.

It then offers multiple choice questions confirming the Bioethics Commission's definitions of various principles, or applications of various principles, to the extent those can be conveyed in multiple choice questions and answers. And then ultimately presents these new scenarios as open-ended -- "for your consideration" how might the -- and then it sort of has some open-ended questions.

It doesn't imply that the Bioethics Commission has tackled the particular issue. It doesn't weigh in on how the Commission would decide the particular issue. I'm not even sure, as someone who's drafted them, I could come down definitively one way or another. They're not designed for that.

DR. WAGNER: No.

MS. PIKE: So I think it charts a path of sort of introducing the Commission's work and then giving teachers a tool to bring that work into the classrooms in novel ways, in ways that, sort of, just the report on its own could not do because we sort of -- the Commission has sort of settled or landed on a position. And that's a little bit, I think, less conducive to classroom discussion.

DR. WAGNER: I agree, and so that answers my question. I wasn't suggesting we want to show people here's how we do it. In fact, quite the contrary. I wanted to

make sure that anything that we state in our education materials in a definitive way are matters that the Commission has actually discussed.

MS. PIKE: Yes, yes, that's absolutely the case.

DR. WAGNER: And you answered that.

MS. PIKE: That's absolutely the case.

DR. WAGNER: Perfect, thank you. Well, Lizzie, Maneesha, Steve Kessler, again, I'll echo what everybody else has said, just wonderful reports and leading to already some good discussion that I think is going to really be amplified in this next session.

So let's move onto that and for that, Amy, I'll turn it back to you.

DR. GUTMANN: Thank you, Jim.