

ASPPH Presents Webinar Series

***Bioethics for Every Generation –
Incorporating Bioethics
Education into Curricula***

Thursday, October 20, 2016
1:00 pm-2:00 pm Eastern

ASPPH.ORG

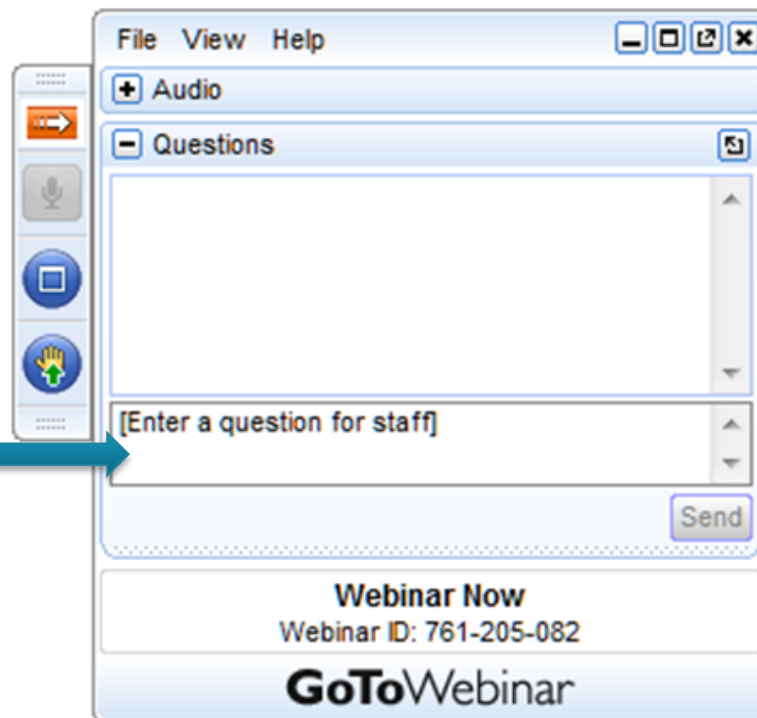
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 **WEBINAR**

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ASPPH Presents
WEBINAR

Moderator



Tony Mazzaschi
Senior Director of Policy and Research
ASPPH

Today's Presenter



Lisa M. Lee, PhD, MA, MS
Executive Director, Presidential Commission
for the Study of Bioethical Issues



Presidential Commission *for the* Study of Bioethical Issues

ASPPH Presents:

*Bioethics for Every Generation:
Incorporating Bioethics Education into
Curricula*

ASPPH Webinar
October 20, 2016

Lisa M. Lee, PhD, MA, MS
Executive Director



W.D. Hamilton

"And it was so typically brilliant of you to have invited an epidemiologist."



Presentation Outline

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- Opportunity for Public Health in the 21st Century
- The Presidential Bioethics Commission
- Public Health Topics
- Ethical Justification for Public Health Action
- Democratic Deliberation for Public Health Decision Making
- Facilitating Practice by Integrating Ethics into Policymaking




Exciting Time in Public Health




Public Health Now

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Public Health 3.0

A Call to Action to Create a 21st Century Public Health Infrastructure

 Office of the Assistant Secretary for Health
U.S. Department of Health and Human Services

PUBLIC HEALTH 3.0



Presidential Commission *for the Study of Bioethical Issues*



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Welcome to the Public Health Accreditation Board

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PHNCI Local Public Health Departments

A local health department is the governmental body serving a jurisdiction or group of jurisdictions geographically smaller than a state, and recognized as having primary statutory authority to promote and protect the public's health and prevent disease in humans. >>





The Bioethics Commission



Creation of the Bioethics Commission ¹¹

“As our nation invests in science and innovation and pursues advances in biomedical research and health care, it’s imperative that we do so in a responsible manner.”

62671	
Federal Register Vol. 74, No. 228 Monday, November 30, 2009	Presidential Documents
Title 3— The President	Executive Order 13521 of November 24, 2009 Establishing the Presidential Commission for the Study of Bioethical Issues By the authority vested in me as President by the Constitution and the laws of the United States of America, it is hereby ordered as follows: Section 1. Establishment. There is established within the Department of Health and Human Services the Presidential Commission for the Study of Bioethical Issues (Commission). Sec. 2. Mission. (a) The Commission shall advise the President on bioethical issues that may emerge as a consequence of advance of science and technology. The Commission shall have as its goal the goal of identifying and promoting scientific research, healthcare delivery, conducted in an ethically responsible manner. The Commission shall: (i) identify and examine specific bioethical issues and their potential impacts on healthcare delivery, or other areas of science and technology; and (ii) recommend any legal, regulatory, or policy guidance with respect to address these issues; and (iii) critically examine diverse perspectives on bioethical issues, including but not limited to useful international collaboration on these issues. (b) In support of its mission, the Commission shall identify and promote specific technologies, including but not limited to: intellectual property rights, biomarkers, and other screening technologies; the application of neuro- and robotic science issues not linked to specific technologies; protection of human research participants; of interest in research; and the intersection of these issues. (c) The Commission shall not be responsible for specific projects. (d) The Commission may accept suggestions from executive departments and agencies in support of its mission. (e) In establishing priorities for its activities among other things, the Commission shall take into account the significance of policy, regulatory, and policy guidance with respect to the issues to the goal of Federal advancement and the availability of other appropriate resources on the issues. (f) The Commission is authorized to conduct original empirical and conceptual research, commission papers and studies, hold hearings, and establish committees and subcommittees, as necessary. The Commission is authorized to develop reports or other materials. Sec. 3. Membership.

l. 74, No. 228 / Monday, November 30, 2009 / Presidential Documents

(a) The Commission shall be an expert panel composed of not more than 13 members appointed by the President, drawn from the fields of bioethics, science, medicine, technology, engineering, law, philosophy, theology, or other areas of the humanities or social sciences, at least one and not more than three of whom may be bioethicists or scientists drawn from the executive branch, as designated by the President.

(b) The President shall designate a Chair and Vice Chair from among the members of the Commission. The Chair shall convene and preside at meetings of the Commission, determine its agenda, and direct its work. The Vice Chair shall perform the duties of the Chair in the absence or disability of the Chair and shall perform such other functions as the Chair may from time to time assign.

(c) Members shall serve for a term of 2 years and shall be eligible for reappointment. Members may continue to serve after the expiration of their terms until the appointment of a successor.

Sec. 4. Administration.

(a) The Department of Health and Human Services shall provide funding and administrative support for the Commission to the extent permitted by law and within available appropriations.

“...shall be an expert panel... drawn from fields of bioethics, science, medicine, technology, engineering, law, philosophy, theology, or other areas of the humanities or social sciences.”

- President Barack Obama

(e) This order is not intended to, and does not, create any right or benefit, substantive or procedural, enforceable at law or in equity by any party against the United States, its departments, agencies, or entities, its officers, employees, or agents, or any other person.



The Bioethics Commission

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AMY GUTMANN, PhD, Chair

JAMES W. WAGNER, PhD, Vice Chair

NELSON L. MICHAEL, MD, PhD

STEPHEN L. HAUSER, MD

NITA A. FARAHANY, JD, PhD

CHRISTINE GRADY, RN, PhD

RAJU S. KUCHERLAPATI, PhD

DANIEL P. SULMASY, MD, PhD



ANITA L. ALLEN, JD, PhD

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JOHN D. ARRAS, PhD*

ALEXANDER G. GARZA, MD, MPH*

YOLANDA ALI, MBA*

Lisa M. Lee, PhD, MS, Executive Director

* Former member



Bioethics Commission Reports

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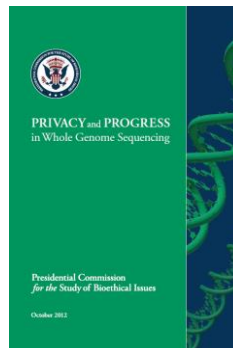
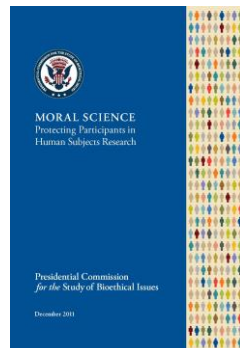
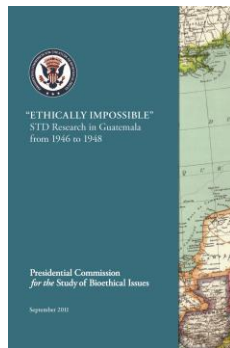
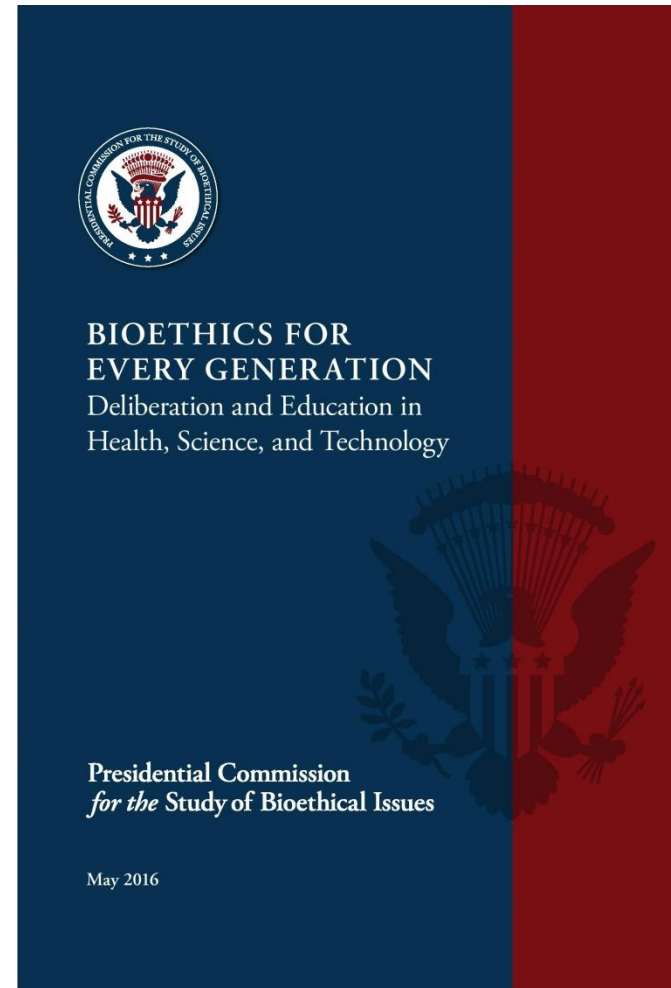
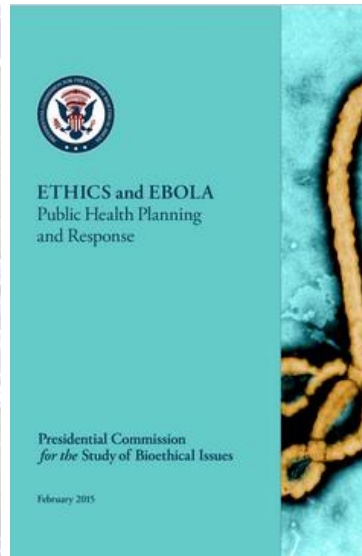
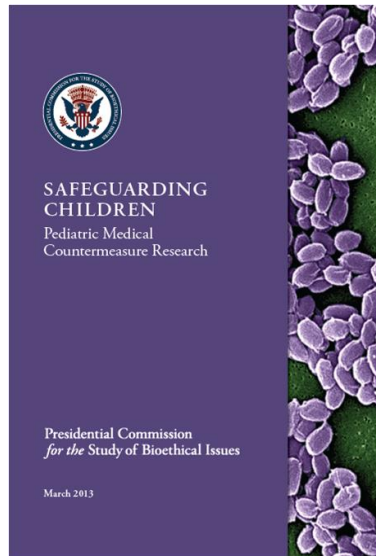
Current Project: Reflections on Impact of National Bioethics Commissions



Public Health Topics



Ethics, Public Health, & the Bioethics Commission ¹⁵

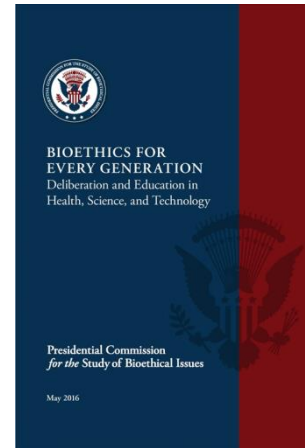




Democratic Deliberation & Bioethics Education¹⁶

Why are these topics relevant?

- As public health professionals we face numerous bioethical issues in our work
- Public health policy decisions are often complex and deal with deeply held often opposing values
- Democratic deliberation provides a method for policy making that embodies constructive public engagement
- Ethics education fosters ethical literacy and grounds deliberation about bioethical topics in reasoning skills





Ethical Justification for Public Health Action



Deliberation & Education Facilitate PH

- Dealing with a *public good*
 - Shift from individual to collective
 - Shift from personal moral compass to a process of ethical decision making





Operating Ethical Principles in Public Health

- **Wide array of tangible expectations that guide what public health practitioners *should* do**
 - Use evidence-based interventions
 - Focus on fundamental causes of disease
 - Be transparent and accountable
 - Reduce inequities
 - Reduce harms & burdens
 - Interfere with liberty as little as possible
 - Infringe on autonomy only as necessary
 - Respect privacy & confidentiality
 - Ensure benefits outweigh infringement



- **Public Health Accreditation Board (PHAB) requires a process for managing ethical issues**
 - Measure 11.1.2.A “The purpose of this measure is to assess the health department’s policies and process for the *identification* and *resolution* of ethical issues that arise from the department’s program, policies, interventions, or employee/employer relations (emphasis added).”



Deliberation & Education Facilitate PH

- Transparent decision making and communication
 - Provide public with useful, clear, accurate, and accessible justification for public policies
 - Provide those most affected by public health policies and programs with appreciation of values reflected in, and reasoning behind, their implementation
 - Mitigate stigmatization and discrimination that can accompany public health interventions



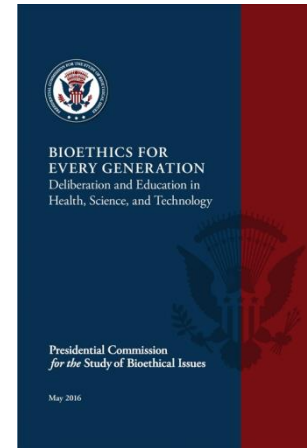
Democratic Deliberation



Democratic Deliberation

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What is it? How does it work?





Democratic Deliberation

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Deliberation for Better Health, Science, and Technology Policy: Five Steps for Effective Deliberation¹ Presidential Commission *for the Study of Bioethical Issues*

The process of democratic deliberation is especially useful for the types of questions we face in bioethics, in which solutions have complex empirical as well as moral bases and about which reasonable people can disagree. This method of decision making can be used by bodies at all levels—institutional, local, state, national, and international—to inform policy development.



Step I. Begin with an open policy question

Choose an open question and consider distinct points of view. The question should have an applied component, including questions about how to move forward and what should be done.



Step II. Time deliberation for maximum impact

Allow ample lead time for deliberation before a decision becomes absolutely necessary. In the case of an ongoing emergency situation, conduct deliberation simultaneously, and apply results as soon as possible.



Step III. Invite input from experts and the public

Use sound and relevant information to inform the deliberation. If new information emerges, integrate it into the deliberation. Evaluate evidence through an established and reliable mechanism before and during deliberation. Make established facts, in the form of accessible background materials, available to all participants.



Step IV. Foster open discussion and debate

Cultivate an environment that encourages participants in the deliberation to practice mutual respect and reason-giving.



Step V. Develop detailed, actionable recommendations

Feed decisions back into the policymaking process whenever possible, either by making the results of deliberation binding or by asking participants to develop a set of recommendations that policymakers can use to guide their decisions.

¹Presidential Commission for the Study of Bioethical Issues (PCSEI). (2016, May). *Bioethics for Every Generation: Deliberation and Education in Health, Science, and Technology*. PCSEI: Washington, DC, adapted from Appendix I.



Democratic Deliberation

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Deliberation for Better Health, Science,
and Technology Policy:
Five Steps for Effective Deliberation
Presidential Commission for the Study of Bioethical Issues

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Democratic Deliberation

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Democratic Deliberation

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Democratic Deliberation

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Democratic Deliberation

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Preparing Public Health Professionals: Facilitating Practice by Integrating Ethics into Policymaking



Integrating Ethics into Public Health Practice

Ethics in all policies: Getting there

- Infusing ethics early and explicitly from program conceptualization through implementation
 - A collective prioritization of ethical practice
 - Goal of improving human flourishing
- Creating ethics resources for public health professionals





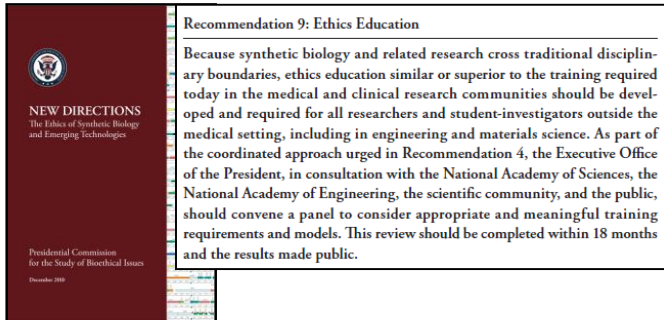
Ethics education

- Integrating ethics through all levels of education
 - Pre-K to undergraduate to professional training
 - Transformational learning
 - Dual understanding of science and ethics
- Understanding the ethical implications of our work
- Ethical decision making: four areas of competence
 - Identify ethical dimensions
 - Articulate dimensions and areas of concern
 - Deliberate possible paths forward
 - Implement and evaluate



Ethics Education Recommendations

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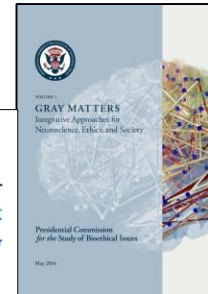
Recommendation 9: Ethics Education

Because synthetic biology and related research cross traditional disciplinary boundaries, ethics education similar or superior to the training required today in the medical and clinical research communities should be developed and required for all researchers and student-investigators outside the medical setting, including in engineering and materials science. As part of the coordinated approach urged in Recommendation 4, the Executive Office of the President, in consultation with the National Academy of Sciences, the National Academy of Engineering, the scientific community, and the public, should convene a panel to consider appropriate and meaningful training requirements and models. This review should be completed within 18 months and the results made public.

Recommendation 3:

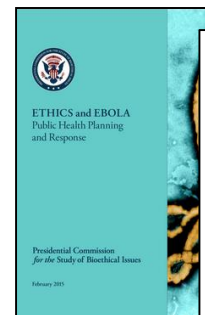
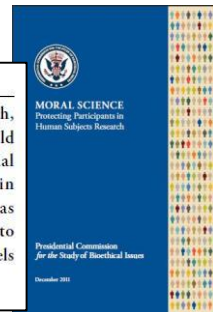
Integrate Ethics and Science through Education at All Levels

Government agencies and other research funders should initiate and support research that develops innovative models and evaluates existing and new models for integrating ethics and science through education at all levels.



Recommendation 7: Expand Ethics Discourse and Education

To ensure the ethical design and conduct of human subjects research, universities, professional societies, licensing bodies, and journals should adopt more effective ways of integrating a lively understanding of personal responsibility into professional research practice. Rigorous courses in bioethics and human subjects research at the undergraduate as well as graduate and professional levels should be developed and expanded to include ongoing engagement and case reviews for investigators at all levels of experience.



Recommendation 3

Public officials have a responsibility to support public education and communication regarding the nature and justification of public health responses. Communication efforts should serve the following three interrelated purposes: (1) to provide the public with the information needed to make informed decisions about their health; (2) to provide the public with the information needed to understand the policies and programs that are being implemented; and (3) to provide the public with the information needed to understand the reasoning behind, and the justification for, public health actions and discrimination.

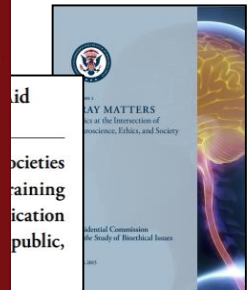
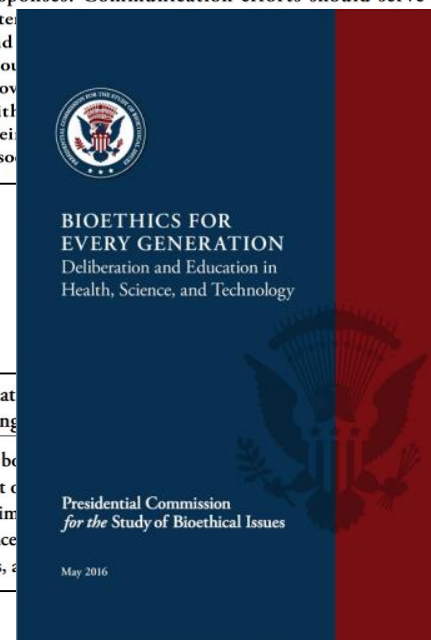


Recommendation 4

Public and private entities should prepare educational materials to inform all stakeholders—including practitioners, institutional review boards, and potential recipients—about the ethical, practical, and legal considerations raised by incidental and secondary findings.

Recommendation 1: Understanding

Government bodies and nonprofit organizations should develop resources, primarily for the training of neuroscience researchers, judges, jurors, judges, and





Beyond RCR, IRB, and compliance

- Foundational ethics education to promote bioethics literacy for our personal *and* professional lives
- Bioethics for all science, health, and technology professionals





Getting There

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- Broad range of ethical areas in public health
 - Professional ethics
 - Research ethics
 - Clinical ethics
 - Environmental ethics
 - Public health ethics



Training educators

- Educators at all levels must be prepared to raise and address ethical dimensions of their subject
- Integrate into teacher training programs at all levels
- Address obstacles
- Resources for instructors
 - NIH Curriculum, NWABR
 - Bioethics Commission's educational materials



Resources for Public Health Educators³⁷

Bioethics.gov



Presidential Commission
for the Study of Bioethical Issues

Amy Gutmann, Ph.D.
Commission Chair



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- All Educational Resources by Bioethics Commission Report

To support ethics education and facilitate the integration of bioethics into traditional and non-traditional educational and professional settings, the Presidential Commission for the Study of Bioethical Issues (Bioethics Commission) has developed pedagogical materials to facilitate easy access to the material in its reports by professors, instructors, practitioners, and the public.

User Guides are organized by field and serve as quick reference documents to help professionals and educators identify relevant Bioethics Commission educational materials. Current guides address:

Researchers
Human Subjects Researchers
Public Health Professionals
High School Educators

Public Policy Educators
Legal Educators
Science Educators
Medical Educators

Primers target specific audiences to support practical application of some of the Bioethics Commission's recommendations. Audiences include professionals (e.g., clinicians, researchers

Featured Video



Representatives of the Bioethics Commission share their views on the importance of bioethics education.



education@bioethics.gov for
comments and questions about
educational materials



Resources for Public Health Educators³⁸



Presidential Commission
for the Study of Bioethical Issues

Last Updated: September 30, 2016

User Guide for Public Health Professionals

Bioethics Commission Educational Materials

The Presidential Commission for the Study of Bioethical Issues (Bioethics Commission) has developed educational materials for use in traditional and nontraditional educational settings to provide educators with contemporary examples of real-life ethical challenges addressed by a presidential commission. The materials are designed to be applicable to a wide variety of disciplines at the undergraduate, graduate, and professional levels as well as continuing education and professional training courses, graduate or professional school seminars, workplace discussions, and other settings.

The purpose of this guide is to highlight the most relevant materials for public health educators and to illustrate how they might be integrated into public health classes, seminars, and workshops. This list is not exhaustive; rather, it is meant to serve as a quick reference to some of the most relevant materials.

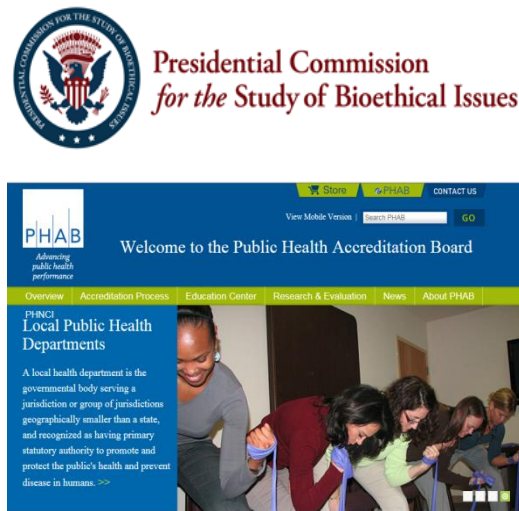
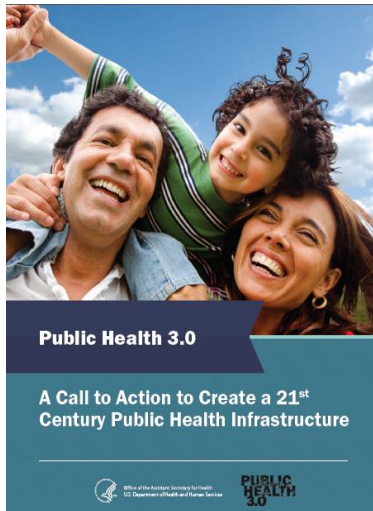
Democratic Deliberation

Democratic deliberation is an inclusive method of decision making used to address open policy questions. The [Guide to Democratic Deliberation for Public Health Ethics Professionals](#) provides an overview of how public health professionals can conduct democratic deliberation. A collection of [deliberative](#)



Public Health Next

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Connect with the Bioethics Commission¹⁰

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Thank you!

Thank you to today's Presenter

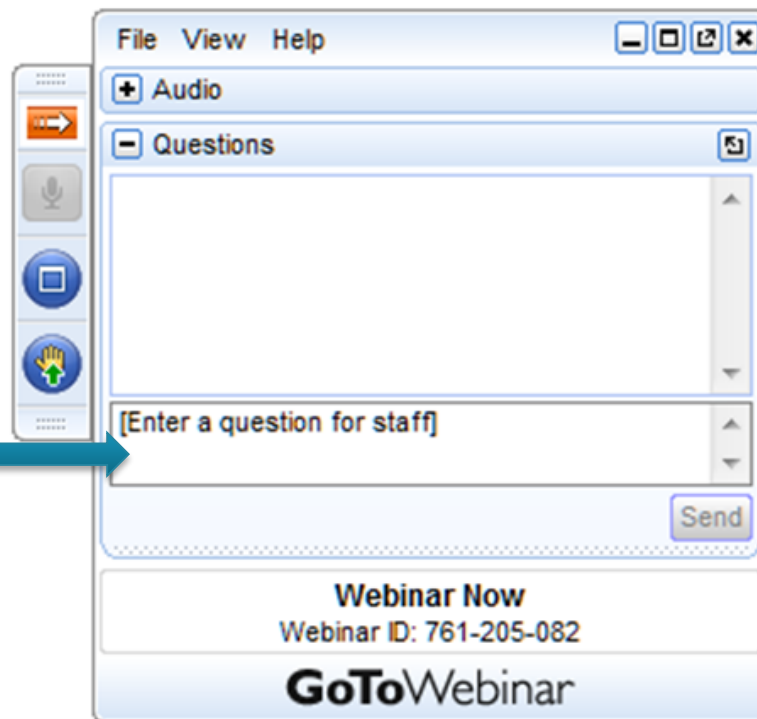


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ASPPH Presents
WEBINAR

Today's Presenter

Now taking questions.



Lisa M. Lee, PhD, MA, MS
Executive Director, Presidential Commission
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Thank You!

See the webinar event page on the ASPPH website for a link to the **archived webinar**:

<http://www.aspph.org/event/aspph-presents-bioethics-for-every-generation-incorporating-bioethics-education-into-curricula/>

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Coming Attractions...

ASPPH Presents



WEBINAR

ASPPH Presents: Graduate School Financial Aid for Beginners

Tuesday, October 25, 1:00 pm – 2:00 pm Eastern

ASPPH Presents: Public Health Associate Program (PHAP) Program and BEST FIT Candidate Model Overview

Tuesday, November 15, 12:30 pm - 1:30 pm Eastern

For more information about and to register for upcoming webinars, visit the
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Coming Attractions...



2017 ASPPH
ANNUAL MEETING
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Thank you!