



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 scenarios](#) is available to help public health professionals engage in deliberation using contemporary ethical questions. [Deliberative Scenario: MMR Vaccination Concerns within a Local Immigrant Community](#) with the accompanying [facilitator guide](#), and [Deliberative Scenario: Seasonal Influenza Vaccination Policy for a Local Public Health Department](#) with the accompanying [facilitator guide](#), present contemporary ethical challenges in public health.

Community Engagement

Public health practice and research often incorporates extensive community engagement. The [Community Engagement Background](#) module discusses various approaches to, ethical reasoning behind, and challenges to community engagement generally. The [Community Engagement in Moral Science](#) module builds upon the content of the Background module to address how community engagement fits into other aspects of human subjects research, including public health research, such as informed consent, and considers community engagement in both domestic and international contexts. The primer [Public Health Emergencies & the Media](#) presents a guide to spotting and responding to media hype surrounding public health emergencies.

Biotechnology and Public Health

New and emerging technologies, such as synthetic biology and whole genome sequencing techniques, have the potential to promote the health of populations, for example through new forms of pollution control, advances in vaccination development, and disease screening programs.

Community engagement is an important way for scientists and others to educate the public about new technologies and understand the concerns that affected communities might have about the development



and use of those technologies. The [Community Engagement in New Directions](#) module illustrates the importance of public and community engagement for research on emerging technologies including synthetic biology to provide opportunities for members of the public, researchers, and policy makers to share concerns, learn from each other, and work together to support safe and productive research. In addition, the [Community Engagement in Privacy and Progress](#) module considers how community engagement applies in the context of whole genomic sequencing and data storage and usage, and the [Privacy in Privacy and Progress](#) module addresses the importance of privacy in whole genome sequencing, and the inherent tension between protecting individuals' privacy and the supporting the progress of promising genomic research.

Public Health Preparedness

A collection of [Public Health Case Studies](#) describes cases based on the Bioethics Commission's reports that examine ethical questions and tensions that public health professionals might encounter in practice and research. Case study topics include the ethical use of liberty-restricting public health measures and communications during a public health emergency.

The [Classroom Discussion Guide on Ethics and Public Health Emergencies](#) provides structured questions to guide group discussion about ethical challenges that can arise during public health emergencies, focusing in particular on the 2014-2015 Ebola epidemic in western Africa.

The [Community Engagement in Ethics and Ebola](#) module provides an overview of the importance of community engagement as it relates to public health emergency planning, and ways in which community engagement can facilitate ethical public health planning.

The ethical considerations and regulatory requirements for pediatric medical countermeasure (MCM) research to prepare for potential future bioterrorist attacks are complex. The [Informed Consent in Safeguarding Children](#) and [Vulnerable Populations in Safeguarding Children](#) modules address ethical concerns and research regulations related to informed consent requirements and children as a vulnerable population, emphasizing both the importance of conducting pediatric MCM research that can inform preparedness efforts and protect children in the event of a bioterror attack, and the importance of ensuring robust protections for children who participate in the research.

Public health emergencies can provide important opportunities to conduct research. In some cases, such as the 2014-2015 Ebola epidemic in western Africa, a disease outbreak is the only opportunity to study critical aspects of the disease, such as its natural history, genetic features of the virus, factors associated with survival, or preventive and treatment interventions for the disease. Such research can help to protect populations in the event of future outbreaks.

Privacy

Public health activities such as surveillance or collection and storage of data encounter tension between protecting individuals' privacy and promoting public health. For example, some population-level screening programs, such as newborn screening, might in the future use whole genome sequencing, raising important and challenging ethical concerns about privacy protections. The [Privacy in Privacy and Progress](#) module addresses the importance of individual privacy in whole genome sequencing, and the



inherent tension between protecting that privacy and the supporting the progress of promising genomic research.

The [Privacy in Ethics and Ebola](#) module provides information and ethical principles to guide researchers and clinicians in the collection, storage, and international sharing of biospecimens, particularly in the context of a public health emergency such as the 2014-2015 Ebola epidemic in western Africa. This module highlights the importance of strong privacy protections for patients with Ebola who provide biospecimens, particularly given the stigma associated with the disease.

Historical Lessons and Contemporary Challenges in Research

The [Study Guide to “Ethically Impossible” STD Research in Guatemala from 1946 to 1948](#) provides an historical case study based on research conducted by U.S. Public Health Service personnel in Guatemala involving the intentional exposure of vulnerable populations to sexually transmitted diseases without their consent. The module identifies ethical breaches in design and conduct of the research, which sought to address a considerable public health problem at the time.

The [Vulnerable Populations Background](#) and [Vulnerable Populations in Safeguarding Children](#) modules address the concept of vulnerability for research participants, which can be a significant ethical concern in public health research, in which particular groups or populations participating in research might be vulnerable to stigma or discrimination, or their vulnerability might stem from circumstances related to a public health emergency.

The [Research Design Background](#) module highlights ethical and social considerations that can arise in the design of all scientific research, including public health research. Ethical principles that guide the conduct of research, such as public beneficence and justice, echo public health’s orientation towards promoting health for communities and populations and ensuring equitable access to key social determinants of health.