

User Guide for Science Educators

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 science educators at the undergraduate and high school levels to illustrate how they might be integrated into science courses. This list is not exhaustive; rather, it is meant to serve as a quick reference to some of the most relevant materials.

The webinar [Multidisciplinary Implementation of Bioethics Commission Education Materials](#) demonstrates how topic-based modules can be employed in various disciplines, including the science classroom.

General Science Applications

Instructors in many science courses choose to address ethical considerations related to research and professionalism. Scientists in all disciplines share an obligation to employ scientifically and ethically sound research design. Research can be considered good science only if it is conducted ethically. Developing a sound research design is an essential first step in conducting ethical research.

Science educators teaching students how to design studies can use the [Research Design Background](#) module for helpful information about ethical research design across disciplines, including types of research, research risk, sample size, data collection and analysis, sharing of results, and validity and related concepts. In addition, the module provides information on certain regulatory requirements for research including responsible conduct of research standards and protection of research participants.

The [Research Design in Gray Matters](#) module addresses the ethical underpinnings of research design including researchers' professional ethics obligations, research ethics requirements for those conducting certain categories of research, and the obligation for all scientists to consider potential societal implications of their work. Integrating ethics early and throughout the course of research facilitates excellence in science and gives scientists a way to meet these obligations in their work.

Biology (General and Introductory)

For instructors discussing synthetic biology in their biology classes, 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 policymakers to share concerns, learn from each other, and work together to support safe and productive research.

The [Classroom Discussion Guide on Ethics and Public Health Emergencies](#) provides structured questions to guide student discussion about ethical questions that arise in public health emergency situations such as the Ebola outbreak in western Africa in 2014-15.

If instructors teach students about the importance of protecting human participants 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 content of this study guide is more appropriate for older students, such as undergraduates, since the historical research involved exposure to sexually transmitted diseases.)

Biotechnology

Biotechnology instructors might address synthetic biology techniques and relevant ethical and societal considerations. The [Community Engagement in New Directions](#) module illustrates the importance of public and community engagement for research on emerging technologies including synthetic biology and provides, for example, relevant problem-based learning scenarios including one about how engaging communities might help address concerns about potential ecological impacts of releasing engineered organisms.

In addition, other modules discuss ethical considerations relevant to whole genome sequencing, including how the informed consent process can address storing and sharing of data and related information ([Informed Consent in Privacy and Progress](#)), the importance of protecting individuals’ privacy while using whole genome sequencing data in research ([Privacy in Privacy and Progress](#)), and how community engagement can guide ethical policies for use and access of whole genome sequencing data ([Community Engagement in Privacy and Progress](#)).

Ecology

Ecology instructors might discuss synthetic biology and potential ecological impacts of biologically engineered organisms. The [Community Engagement in New Directions](#) module illustrates the importance of public and community engagement for research on emerging technologies including synthetic biology and provides, for example, relevant problem-based learning scenarios including one focused on how engaging communities can help address concerns about potential ecological impacts of releasing engineered organisms.

Genetics

Genetics instructors covering whole genome sequencing technologies might discuss related ethical concerns and questions with their students, including ethical informed consent processes and privacy protections for individuals when their whole genome sequence data is used for research.

The [Informed Consent in Privacy and Progress](#) module provides information and analysis about informed consent processes in the context of whole genome sequencing, 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 supporting the progress of promising genomic research. Large-scale genetic sequencing—whether conducted in the clinical, research, or direct to consumer contexts—can lead to the discovery of incidental or secondary findings. A set of primers about incidental

and secondary findings that can arise in various modalities, including large-scale genetic sequencing, discuss the ethical responsibilities of clinical, research, and direct-to-consumer professionals to plan for and adequately inform recipients of the possibility of incidental and secondary findings. These include primers written for [clinicians](#), [researchers](#), and [direct-to-consumer providers](#).

Health Sciences

Instructors in the health sciences might discuss clinical research with their classes. The [Research Design Background](#) module provides information about ethical research design generally—including types of research, research risk, sample size, data collection and analysis, sharing of results, and validity and related concepts—and examples specific to clinical and public health research. It provides information on certain regulatory requirements for research including responsible conduct of research standards and protection of research participants.

Class discussion about clinical trials and public health research also might include consideration of specific topics including informed consent and vulnerable populations in research. The informed consent process serves two primary purposes: to educate potential participants or patients about the potential benefits and risks of an intervention and to establish voluntary willingness to participate. The [Informed Consent Background](#) module describes the ethical underpinnings of informed consent, the history of informed consent in research and how it came to be regulated in the United States, and common implementation challenges for the informed consent process. Other modules provide examples, information, and analysis about informed consent processes in specific contexts such as whole genome sequencing ([Informed Consent in Privacy and Progress](#)), pediatric medical countermeasure research ([Informed Consent in Safeguarding Children](#)), research or other activities that could result in incidental and secondary findings ([Informed Consent in Anticipate and Communicate](#)), and neuroscience research that involves participants with potentially impaired consent capacity ([Informed Consent in Gray Matters](#)).

Discussion about clinical trials might include various conceptions of vulnerability and examples of vulnerable populations that are explained in the [Vulnerable Populations Background](#) module in addition to applicable regulations, guidelines, and related protections for vulnerable populations. The [Study Guide to “Ethically Impossible”](#) 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 content of this study guide is more appropriate for older students, such as undergraduates, since the historical research involved exposure to sexually transmitted diseases.) The [Vulnerable Populations in Safeguarding Children](#) module addresses children as a vulnerable population generally and within the context of medical countermeasure research specifically, in which there is a tension between the need to protect all children to the extent possible in the event of a future bioterrorist attack, and the obligation to protect children participating in research from which they stand to receive no direct benefit. In addition, the [Vulnerable Populations in Gray Matters](#) module discusses potentially vulnerable groups that might participate in neuroscience and other research, such as individuals with potentially impaired consent capacity

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. In addition, the collection of

[Public Health Case Studies](#) provides contemporary and relevant case studies that examine ethical implications of public health practice and research.

Microbiology

Microbiology instructors might address synthetic biology techniques involving microorganisms and relevant ethical and societal considerations. The [Community Engagement in New Directions](#) module illustrates the importance of public and community engagement for research on emerging technologies including synthetic biology. It provides, for example, relevant problem-based learning scenarios including one about how engaging communities might help address concerns about potential ecological impacts of releasing engineered organisms.

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.