
User Guide for Public Policy 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 public policy educators to illustrate how they might be integrated into public policy education and curricula. This list is not exhaustive, rather, it is meant to serve as a quick reference to some of the most relevant materials.

Emerging Biotechnologies

Emerging technologies present novel challenges for policymakers. The Bioethics Commission has addressed the ethical dimensions of some emerging biotechnologies that warrant policy consideration, including whole genome sequencing technologies and synthetic biology.

The [Privacy in Privacy and Progress](#) module provides information on federal statutory protection for and state laws regarding genetic information, the role individual privacy concerns play in forming data protection policies, and the need to reconcile privacy concerns with the promotion of beneficial advances in whole genome sequencing.

The [Community Engagement in New Directions](#) module provides information and ethical analysis to support policymaking related to synthetic biology, and highlights the importance of public and community engagement when formulating policies regarding new and controversial technologies.

Public Health and National Security

Public health policies can intersect with national security priorities. As a result, it is helpful for policymakers and policy students to understand public health ethics and research ethics. A collection of [Public Health Case Studies](#) provides cases based on the Bioethics Commission's reports and examines 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, using examples such as the Ebola epidemic in western Africa in 2014-2015.

The Bioethics Commission addressed the ethical issues surrounding pediatric research on medical countermeasures (MCMs)—clinical interventions used in response to a bioterrorism attack—in its report *Safeguarding Children: Pediatric Medical Countermeasure Research*. The ethical considerations and regulatory requirements for pediatric MCM research 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.

The modules emphasize the importance of conducting ethical pediatric MCM research that can inform preparedness efforts and protect children in the event of a bioterror attack, as well as the importance of protecting children who participate in research from undue risk.

Historical Lessons in Human Subjects Research

When researchers and decision-makers overlook ethical considerations, injustices can occur. Policy students can understand and learn from past injustices to avoid future ethical failures. The [Study Guide to “Ethically Impossible”](#) provides information on the U.S. Public Health Service’s unethical STD studies that were conducted in Guatemala from 1946-1948. The study guide reflects on these studies to direct forward-looking standards and best practices for research with human participants.

Student Research: Ethical Research Design

Public policy students engaging in independent research should be aware of ethical research practices and policies. The [Research Design Background](#) module provides helpful information on the essential elements of ethical research design including categories of research, research risk, sample size, data collection and analysis, sharing of results, and validity and related concepts. In addition, it provides information on regulatory requirements for research including responsible conduct of research standards and human subjects research protections.

Student Research: Resources for Public Policy Research

The Bioethics Commission has made the following datasets available, which can be used for educating students and supporting the development of research and analytic skills.

The [Human Subjects Research Landscape Project Analysis Dataset](#) comprises project-level data about human subjects research supported by the federal government from 2006 to 2010.

The [Guatemala Subject Data Spreadsheet](#) includes a de-identified list of and information about the individual subjects involved in the STD research in Guatemala in the 1940s.