Everyday Ethics: Problem Solving Day-to-Day Questions That Give Us Pause

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Learning Objectives

By the end of this session, you will be able to:

• Reflect upon potential ethical concerns in your everyday work
• Recognize when potential ethical concerns become ethical dilemmas
• Understand when to elevate a situation to the principal investigator
What is Ethics?
Good Clinical Practice

Ethical Conduct

Intuition
Overview

Background
- Ethical principles
- Informed consent

Case studies
- Privacy and confidentiality
- Recruitment and subject selection
- Informed consent

Research ethics consultations
Four Ethical Principles

Respect for persons

- *Are we treating people how they want to be treated?*

Beneficence

- *Are we maximizing benefits?*

Nonmaleficence

- *Are we minimizing harms?*

Justice

- *Are we treating people fairly?*

Belmont Report 1979; Beauchamp & Childress *Principles of Biomedical Ethics*
Informed Consent

“The voluntary consent of the human subject is absolutely essential.”
– Nuremberg Code

…but consenting participants raises a lot of ethical questions

• Informed consent was an issue in half of research ethics consults across a national collaborative
• Other ethical issues:
  • Privacy and confidentiality
  • Recruitment
  • Risks and benefits
  • Sharing results with participants
How do we work through these “everyday ethics” questions?
Case Studies

- What gives you pause?
- What is the ethical question?
- What might change to make you feel differently?
- What would you do?
- Do you want to include anyone else in the discussion?
You are conducting a chart review to collect clinical information on patients who have been diagnosed with sleep apnea. You open a chart and see that the patient is a physician at your institution.
Case Study: Privacy/Confidentiality

You are coordinating a study that investigates how people prefer to receive lab test results. One arm of the study is for participants to receive these health results by email. A requirement for participation is that people have an email address.

A young woman would like to participate in the study. She does not have her own email account, but shares an account with her sister.
You are enrolling healthy volunteers in a study that involves frequent blood draws, several overnight urine collections, and keeping a food diary.

Someone who is homeless is interested in participating. The PI does not think it is ethical to enroll someone who is homeless.
You are implementing a study that investigates neurodevelopment in typically-developing kids. Study procedures include standard psychological assessments, questionnaires for the participant and parent, and an MRI scan. The PI of the study would like to enroll one of his kids.
Case Study: Informed Consent

You are in a clinic waiting to talk to a patient about participating in a study that consists of a blood draw and a medical records review.

When you go into the exam room there’s a strong smell of marijuana. Should you be concerned about the patient’s ability to give consent?
What situations have given you pause?
What if a case is more than just “everyday” ethics?
You are part of a study team trying to learn whether young adults (age 18+) who contracted herpes simplex virus (HSV) as newborns are currently experiencing genital shedding. The IRB has approved a plan to ask parents of children who were in an HSV study as infants if the study team can interview their now adult children.

However, the team hasn’t been able to recruit a single participant because parents are reluctant to tell their children about the previous study and/or their child’s HSV status. But parents are very interested in learning the study results and anything that might be relevant to their child’s health.

Is it ethical for the study team to directly contact the now adult children instead of going through their parents?
Additional Information


Case Study: Beyond Everyday Ethics:

Commentaries:
The ITHS Research Bioethics program provides a forum for discussion and analysis of ethical issues in clinical and translational research.

The Consultation Process

ITHS offers research bioethics consultations to researchers, trainees, research staff, and personnel involved in the protection of human subjects. Discussions with consultants can take place by telephone or in person. There is generally no charge.

Bioethics consults are advisory and provide a forum for in-depth conversation and analysis of ethical issues in clinical and translational research. Recommendations are supplemental to the authority and oversight of review groups such as an Institutional Review Board or Data Monitoring Committee.

To ensure a balanced understanding of the facts or to facilitate resolution of a conflict, the consultant is available to talk with others involved in the issue if the requestor so desires.
To request a consultation with the ITHS Bioethics Consult Service:

Phone: (206) 616-3875
Email: ithsnav@uw.edu
Web: iths.org/bioethics