



Online Ethics Center
FOR ENGINEERING AND SCIENCE

Graduate Student Discussion

Description

Part of unit 7 of the [Course on Genomics, Ethics and Society](#), this graduate-level case study discusses issues of ethics, genomics, and privacy.

Body

Directions: Read the following scenario to prepare for the discussion.

Imagine you are a researcher conducting gene therapy research and you have been appointed to a committee that is charged with creating a standardized consent form for patients to decide how their genetic data will be used in the future. Suppose the committee has been asked to choose between an “opt-out” and an “opt-in” design. Under the opt-out design, patients’ data would automatically be included in a large international database, accessible by a wide range of researchers, and those researchers would determine how the data is used. Patients would have to explicitly ask for their data to be removed from this database, in which case their data would only be used by doctors in their healthcare system. Under the opt-in design, patients’ data would only be used by doctors in their own healthcare system unless patients explicitly ask to have their data included in a large international database. In both cases, each patient’s data will be anonymized as much as possible and then stored in a database of other patients’ genetic data.

In this discussion forum, create a thread telling your classmates which design (opt-out or opt-in) you would choose and why. Discuss the ethical issues raised by each design. We expect a lively discussion, not an essay, and it is OKAY to change your views more than once during the discussion or to stick to your views throughout the discussion. Post your brief initial

entry on the FIRST DAY so that everyone can respond to others' ideas throughout the discussion. You should contribute at least three times to the discussion. The [graduate discussion rubric](#) explains what we're looking for in this discussion: good writing quality, clarity and relevance, a response on the first day of discussion, then a collegial exchange with other members of the discussion; your posts should show knowledge and understanding of the readings, and you should try to develop an argument for which you provide support, and that engages critically and thoughtfully with the course materials.

[Continue to Case Analysis and Instructions](#)

Rights

Use of Materials on the OEC

Resource Type

Case Study / Scenario

Instructor Materials

Topics

Privacy and Surveillance

Informed Consent

Human Subjects Research

Discipline(s)

Genetics and Genomics

Life and Environmental Sciences