

**Graduate School of Public Health
Department of Human Genetics
Ethical Issues in Clinical and Public Health Genetics
HUGEN 2052
Thursday 1:15-2:15PM
Location: A215
Credit Hours: 1.0
Spring 2020**

Instructors and Contact Information:

Lisa S. Parker, PhD

Office: 519 Barco Law Building

Phone: 412-648-7007; 412-361-5704

Email: lisap@pitt.edu

Office hours: By appointment

Robin E. Grubs, PhD, LCGC

Office: 3138 Parran Hall

Phone: 412-624-4695

Email: rgrubs@pitt.edu

Office hours: By appointment

Course Description

This course is designed to explore ethical issues as they relate to genetics and genomics in both the clinical and public health contexts. This seminar series provides an ethical framework for analyzing arguments in the literature and cases arising in clinical, public health and research settings, and proceeds throughout the semester with a discussion-based format that encourages students to assume responsibility for engaging in ethical analysis.

Learning Objectives:

At the end of the course, each student will be able to:

- (1) demonstrate critical reasoning about ethical issues;
- (2) present arguments in support of normative positions; and
- (3) identify ethical concerns and pertinent discussions in the bioethics literature, as well as in the clinical, public health genetics and scientific literature.

Requirements:

For all students: All students are required to attend class and participate in class discussion. All participants are expected to demonstrate that they have read the assigned readings and evidence development of critical reasoning skills.

Students seeking a degree in genetic counseling are required to take this class in both their first and second years, and to make class presentations. All other students take this class once and write a brief paper.

For students seeking a degree in genetic counseling: Students will be assigned to groups for their presentations.

Each group will submit for instructor approval a proposal including:

- a) an issue or topic on which they will lead the class discussion,
- b) relevant literature for the class to read in advance of the discussion,
- c) a list of the questions to be raised in class, and
- d) the points the class should take away from discussion.

The group coordinates discussion leadership with emphasis on facilitating analysis of the arguments presented by the assigned authors.

The instructors will review the topic and readings, inform the group when the proposal is approved, and help guide the discussion during class to ensure both accuracy of understanding and comprehensive attention to the issues. Please review the information at the end of the syllabus that addresses frequently raised questions about the presentation and provides assistance for selecting bioethics resources.

Proposals must be submitted at least two weeks in advance of the date of the group's discussion leadership. Proposals from each group should include: topic to be discussed, readings to be assigned, questions for discussion and points to be derived from the discussion.

Proposals **must** be submitted by email to the instructors with the following in the subject line: HUGEN 2052 – *assigned date of discussion (e.g., 2-14-17) – proposed topic (e.g., genetic testing in adoptions)*. So, the subject line will, for example, look like this: HUGEN 2052 – 2-14-17 – genetic testing in adoptions. Emails without a subject line formatted in this manner will be returned for reformatting. The volume of email received by the instructors makes this requirement necessary.

At the group's class meeting, or by email on the day of the class meeting, the group should provide a brief statement—similar to statements made at the end of some published articles—in which the “division of labor” of the group members is stated, for example:

Presenters discussed possible topics and chose this topic. Lisa used PubMed to identify possible articles. Robin reviewed the articles initially and followed up a couple of articles cited therein; she elected five possible articles as the best. Both read and discussed the articles, and chose two to assign and one to recommend. Robin outlined the 1st, 3rd, and 5th points to be discussed in class. Lisa outlined the 2nd and 4th points, as well as the session summary.

For all other students (i.e., those not seeking a degree in genetic counseling): Students may, but need not, work in pairs. By midnight on March 16, the student/pair will choose

an article for analysis. This may be an article that was provided for class discussion, or may be an article drawn from the bioethics, ELSI (ethical, legal, and social implications), or genetics and ethics literatures. The student/pair will write a brief (3-4 double-spaced pages) paper that discusses the public health dimension of the topic of the article chosen. This paper should either (a) provide a discussion of the public health dimension of the topic that was omitted from the article chosen, or (b) provide a critique of the article (and thus, the article's topic) from a public health genetics and public health ethics perspective.

The student/pair must submit the chosen article to the instructors for approval by midnight March 16. When submitting the chosen article for approval, and when submitting the paper, to the instructors by email, the following must be used in the subject line:

HUGEN 2052 – proposed article for critique – *your name(s)*

and

HUGEN 2052 –critique – *your name(s)*

Emails without a subject line formatted in this manner will be returned for reformatting. The volume of email received by the instructors makes this requirement necessary.

Required Texts

None. Readings are drawn from the current literature and classic texts on the course topics.

Student Performance Evaluation and Grading:

Grading is based on quality of participation in the discussion, and either the quality of preparation for discussion leadership or the quality of the article analysis. A sign-in sheet is available to document attendance, and the instructors provide feedback on discussion leadership, participation, and article analysis. An S (satisfactory) grade is given when no more than 3 seminars are missed and when participation and article analysis is adequate. A NC (no credit) grade is given when there are 3 or more unexcused absences.

CourseWeb/BlackBoard Instruction

This class utilizes CourseWeb for the class schedule and posting of required readings.

Academic Integrity

All students are expected to adhere to the school's standards of academic honesty. Cheating/plagiarism will not be tolerated. The Graduate School of Public Health's policy on academic integrity, which is based on the University policy, is available online in the Pitt Public Health Academic

Handbook www.publichealth.pitt.edu/home/academics/academic-requirements. The policy includes obligations for faculty and students, procedures for adjudicating violations, and other critical information. Please take the time to read this policy.

Accommodation for Students with Disabilities:

If you have a disability for which you are or may be requesting an accommodation, you are encouraged to contact both your instructor and Disability Resources and Services, 140 William Pitt Union, 412-648-7890 as early as possible in the term.

A comprehensive description of the services of that office can be obtained at www.drs.pitt.edu.

Diversity Statement

The University of Pittsburgh Graduate School of Public Health considers the diversity of its students, faculty, and staff to be a strength and critical to its educational mission. Pitt Public Health is committed to creating and fostering inclusive learning environments that value human dignity and equity. Every member of our community is expected to be respectful of the individual perspectives, experiences, behaviors, worldviews, and backgrounds of others. While intellectual disagreement may be constructive, no derogatory statements, or demeaning or discriminatory behavior will be permitted.

If you feel uncomfortable or would like to discuss a situation, please contact any of the following:

- the course instructor;
- the Pitt Public Health Associate Dean for Diversity at 412-624-3506 or nam137@pitt.edu;
- the University's Office of Diversity and Inclusion at 412-648-7860 or <https://www.diversity.pitt.edu/make-report/report-form> (anonymous reporting form).

Sexual Misconduct, Required Reporting and Title IX Statement

The University is committed to combatting sexual misconduct. As a result, you should know that University faculty and staff members are required to report any instances of sexual misconduct, including harassment and sexual violence, to the University's Title IX office so that the victim may be provided appropriate resources and support options. What this means is that as your professors, we are required to report any incidents of sexual misconduct that are directly reported to us, or of which we are somehow made aware.

There are two important exceptions to this requirement about which you should be aware: A list of the designated University employees who, as counselors and medical professionals, do not have this reporting responsibility and can maintain confidentiality, can be found here: www.titleix.pitt.edu/report/confidentiality

An important exception to the reporting requirement exists for academic work. Disclosures about sexual misconduct that are shared as part of an academic project, classroom discussion, or course assignment, are not required to be disclosed to the University's Title IX office.

If you are the victim of sexual misconduct, Pitt encourages you to reach out to these resources:

- Title IX Office: 412-648-7860
- SHARE @ the University Counseling Center: 412-648-7930 (8:30 A.M. TO 5 P.M. M-F) and 412-648-7856 (AFTER BUSINESS HOURS)

If you have a safety concern, please contact the University of Pittsburgh Police, 412-624-2121.

Other reporting information is available here: www.titleix.pitt.edu/report-0

Schedule of Sessions:

Date	Presenters and Topics
January 9, 2020	Introduction to the Course and Overview of Requirements
January 16, 2020	<i>No Class</i>
January 23, 2020	1 - Caroline Bong, Kaylee Williams
January 30, 2020	2 - Rose Venier, Julia Gerow, Trinity Sprague
February 6, 2020	3 - Andrew Fazenbaker, Michael Gosky
February 13, 2020	4 - Claire McDonald, Madeline Reding
February 20, 2020	No Class
February 27, 2020	5 - Alyson Evans, Chelsey Walsh
March 5, 2020	6 - Sarah McGee, Mariele Anneling
March 12, 2020	<i>Spring Break</i>
March 19, 2020	7 - Ashley Lahr, Ravella Raker
March 26, 2020	8 - Stephanie Betts, Kaitlyn Scola
April 2, 2020	9 - Pooja Solanki, Haley Kulas
April 9, 2020	10 - Christine Drogan, Megan Czekalski
April 16, 2020	<i>No Class</i>

Questions and Assistance Regarding Resources

Is a handout required for the seminar meeting? No, though most presenters prepare one. Be certain, however, that you do not simply read the handout during the seminar meeting. Instead, if you prepare a handout use it to present data, excerpt part of a reading (or other text) that you want to discuss, present facts of a case to be discussed, or augment your oral presentation in some other way.

Are recent articles necessarily better than older articles? No. Earlier articles (e.g., from the 1980s and 1990s) may present more foundational considerations and arguments, while more recent articles may present refinements, more specialized cases, and “quirky” arguments (in the author’s attempt to distinguish him/herself from others). Recent articles may update data and sociocultural facts (e.g., about legislation, frequency of problems), but foundational arguments may be what you need to assign in order to help establish initial sound understanding.

Resources available on-line are not necessarily superior to hard copy resources; they are only easier to obtain without walking.

Librarians are invaluable. They can help develop search strategies and know about resources beyond Ovid, PubMed, and Google. Relevant librarians and resources may be found at Falk, Hillman, and Barco Law Libraries.

Contact Carrie Iwema, PhD, MLS, AHIP (iwema@pitt.edu), the Falk Library Liaison for Basic Sciences, who has particular interest in personal genomics and precision medicine, or Helena VonVille, MLS, MPH, (HelenaVonVille@pitt.edu), the Pitt Public Health Sciences Library Liaison, for assistance with literature searches.

Search strategies.

- If you find one article on a topic, track down the other articles it cites.
- Figure out how to find those articles using keywords; the use of those keywords should then take you to additional articles beyond those used by your original author.
- Find other things written by that original author.
- Not everything of value will be published in journals; some will be in books. Again, pursue citations in articles to identify anthologies of relevance. Use PittCat and librarians to find books of relevance.

When considering an article, information, or data, consider the source.

- Is the article published in a peer-reviewed source or in a book by a well-respected publisher? Are the data or information from government sources? Partisan organizations?
- Search for other literature by the same author and/or look up the author’s cv. Has s/he published other work on this topic? (Maybe there is a better—i.e., clearer or more comprehensive—article by the same author.)
- Does the author have a particular ideological bias? Consider who published the work, where the author is employed or who funded the work, and the author’s

- affiliations or appointments (e.g. whether s/he is from President GW Bush's bioethics committee or that of Presidents Clinton or Obama).
- Where is the journal published, what are its goals, who is its target readership, and what are its publication practices? How do these affect content—e.g., consider the unique practices of *AJOB*, the *American Journal of Bioethics*.
 - Is the journal (or the article) focused on a particular country or part of the world? Is that the relevant context for your consideration? The UK, Australia, Canada, and the US have very different political climates, legislative and legal frameworks, healthcare contexts, and political structures. An argument about a healthcare issue that is the “right” one for the UK may not be the best one for the US, even though authors in all the journals share a version of English. Concerns in developing countries differ from those in the US, and while the concerns of the developing world or global health problems are important, in hour-long discussions pertinent to genetic counselors and public health practitioners in the US, it may be important to assign resources focused on the US context.

If you are finding articles by only one author or from only one source (e.g., the journal *Bioethics*), your search strategy may be too limited.

Journals in medicine, healthcare, and genetics publish articles of ethical relevance. In particular, consult:

NEJM

JAMA

Lancet

J of Genetic Counseling

Am J Human Genetics

Genetics in Medicine

Obstetrics & Gynecology

Clinical Genetics

Science

Nature

Two encyclopedias may be of particular assistance to you: *The Encyclopedia of Bioethics* and the *Stanford Encyclopedia of Philosophy* (plato.stanford.edu/).

The *New York Times* is an excellent source of topic ideas. Consult both the Science Times section and the news articles.