

School of Public Health
Department of Human Genetics
Ethical Issues in Clinical and Public Health Genetics
HUGEN 2052
MPH Public Health Genetics Section
Tuesday 1:00-1:50 PM, A719 Public Health
Credit Hours: 1.0
Spring 2023

Course Faculty and Contact Information

Course Directors and Lecturers:

Robin E. Grubs, PhD, LCGC

Office: 3138 Public Health

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Michael J. Deem, PhD

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Office hours: By appointment

Faculty Availability: We welcome your questions and suggestions. Please feel free to use email to set up an appointment with us. If you are having any problems with the course, please contact one of us as soon as possible.

Lecturers:

Brenda Diergaarde, PhD

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Jodie M. Vento, MGC, CGC

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Course Description

This course is designed to explore ethical and social issues as they relate to genetics and genomics in both clinical and public health contexts. Class sessions provide an ethical framework for analyzing arguments in the literature and cases arising in clinical, public health and research settings, and proceed 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 and social 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.

Course Format and Delivery

This class utilizes Canvas for class content and grading. Notifications will be sent regarding course content throughout the semester. Please make sure to set up your Canvas to receive email notifications from Canvas and please check for announcements and notifications on a regular basis. Should you need to communicate with the course instructors, please email them at their Pitt email addresses.

It is expected that class will take place in person. However, due to the shifting nature of the pandemic, it may be necessary to alter the delivery of the course. Any changes will be shared via announcements on Canvas. During this pandemic, it is extremely important that you abide by the public health regulations, the University of Pittsburgh's health standards and guidelines, and Pitt's Health Rules. These rules have been developed to protect the health and safety of all of us. The University's requirements for face coverings will at a minimum be consistent with CDC guidance and masks are required indoors (campus buildings and shuttles) on campuses in which COVID-19 Community Levels are High. This means that when COVID-19 Community Levels are High, you must wear a face covering that properly covers your nose and mouth when you are in the classroom. If you do not comply, you will be asked to leave class. It is your responsibility to have the required face covering when entering a university building or classroom. Masks are optional indoors for campuses in which county levels are Medium or Low. Be aware of your Community Level as it changes each Thursday. Read answers to frequently asked questions regarding face coverings. For the most up-to-date information and guidance, please visit the Power of Pitt site and check your Pitt email for updates before each class.

If you are required to isolate or quarantine, become sick, or are unable to come to class, contact us via email as soon as possible to discuss arrangements and we will determine the most appropriate make-up plan for class.

Course materials will be posted on Canvas. The course will employ readings and possibly videos depending on the content *to be reviewed prior to class*, and class discussions.

The goal of each class is to engage in ethical discussion, debate, and analysis. The class will not be recorded since recording has the potential to diminish engagement.

Requirements

To tailor content and enhance opportunity for engagement, the course is divided into two sections. One section is for the MPH public health genetics students and one section is for the MS genetic counseling students. The MPH section will take place on Tuesdays from 1:00 to 1:50 PM.

For each class there will be material to review prior to class. This will include items such as readings and may include short, recorded videos and/or podcasts. All students are expected to demonstrate that they completed the pre-class work and are expected to actively participate in the discussions.

Texts/assigned materials

Participants will need to read and be prepared to discuss assigned materials that will be posted on Canvas. There is no required textbook for this course.

Student Performance Evaluation and Grading

Grading is based on quality of contribution to the discussion. Each class covers critical material related to ethical and social issues in clinical, public health, and research settings. Therefore, your attendance and participation are important to your professional development and to the success of the course. We expect that each student will read the assigned materials and participate in class discussion. An online sign-in sheet will be available each week in Canvas between 11 AM to 5 PM to document attendance (*please do not forget to complete this attendance or you will be marked as absent*), and the instructors will provide feedback on discussion and participation. An S (satisfactory) grade is given when no more than 3 classes are missed and participation is adequate while attending. A NC (no credit) grade is given when there are 3 or more unexcused absences.

Academic Integrity

All students are expected to adhere to the school's standards of academic honesty. Cheating/plagiarism will not be tolerated. The 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.

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: <https://www.diversity.pitt.edu/civil-rights-title-ix/make-report/report-form>

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: <https://www.diversity.pitt.edu/civil-rights-title-ix-compliance/make-report>

Diversity Statement

The University of Pittsburgh 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 and promote social justice. 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 directors or course instructors;
- the Pitt Public Health Associate Dean for Diversity and Inclusion;
- the University of Pittsburgh Title IX Coordinator at 412-648-7860; or
- at <https://diversity.pitt.edu/civil-rights-title-ix/make-report/report-form>

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See [Library of Congress Copyright Office](#) and the [University Copyright Policy](#).

Schedule of Sessions

Date	Topic
January 10, 2023	Introduction to the course and public health ethics: Normative and conceptual research, Dr. Deem
January 17, 2023	Informed consent, capacity to consent, research and screening programs, Dr. Deem
January 24, 2023	Privacy and confidentiality, HIPAA and GINA, Dr. Deem
January 31, 2023	Population genetic screening, Dr. Grubs
February 7, 2023	Polygenic Risk Scores, Dr. Diergaarde
February 14, 2023	Consumer-driven genetic testing, Dr. Grubs
February 21, 2023	Community engagement for genetic research, Dr. Grubs
February 28, 2023	Return of individualized results and management of incidental findings of genetic research, Dr. Deem
March 7, 2023	Spring Break
March 14, 2023	Management of data and biological samples, Dr. Diergaarde
March 21, 2023	Ethical issues in public health research, Dr. Deem
March 28, 2023	Ethical and social issues in precision medicine, Dr. Deem
April 4, 2023	Disability studies and genetics, expressivist objection, selecting for disability, Dr. Grubs
April 11, 2023	Global Health and Biotechnology, Dr. Deem