

Ethical, Legal, & Social Issues in Public Health Genetics

PHG 512 | BH 514 | LAW H504
Winter 2015 | W 12-2pm | 3 credits | A204

Canvas Site URL: <https://canvas.uw.edu/courses/945209>

"Ethics is about our interdependency as well as our freedom, our emotions as well as our reason, and our unique situation as well as our human commonalities."

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COURSE DESCRIPTION:

This core course offered by the Institute for Public Health Genetics provides an introduction to the legal, ethical, and social issues arising as genetic knowledge and technologies are developed and made available to individuals and populations. Students will learn to identify and anticipate potential ethical, legal, social, and policy concerns that arise with emerging technologies when applied in public health contexts. In this course, we will gain familiarity with the analytic tools used to examine public health genetics issues from diverse disciplinary perspectives and traditions.

COURSE OBJECTIVES:

Through active participation in reading, discussion, and activities, students will:

1. Learn and apply different ethical, legal, social, and policy frameworks to key issues in public health genetics.
2. Explore, debate, and critique key issues in public health genetics.
3. Critically analyze readings and issues and express positions in writing and discussion.
4. Identify and present unique issues in public health genetics as identified throughout real-world experiences.

COURSE REQUIREMENTS

1. **CLASS PARTICIPATION**, including **weekly online responses to readings, films**, and engaged discussion in class (30%).

TIP: Prior to coming to class, read the assignments carefully and post one or two interesting questions that were raised by the readings for that day. Be prepared to share your question(s) with the group and guest speaker in class. Come to class every week, do the readings, and engage thoughtfully in discussion by raising one or two points and by responding to points made by others. Be a good listener and follow the line of discussion. At times perhaps point out what the group is failing to consider, thus alter the course of discussion. This will help you keep on track with consistent, high-quality participation.

2. **SHORT PAPERS (60%)**

There will be **three short writing assignments** due throughout the quarter (due **January 29, February 18, and March 17**).

- Identify the argument: Choose a controversial issue in PHG and interview 5 people about the issue. Ask what they believe, and why. Outline the arguments, identify them, and then take and justify your own position (3 double-spaced pages).
- Ethics analysis: Develop and justify an argument for a position, drawing explicitly on the ethical frameworks introduced in class (3 double-spaced pages).
- Op-ed style essay: Writing as if for the NYT or The Scientist, or the Huffington Post, make a case for your issue to a public/general audience (3 double-spaced pages).

Each assignment can be on a public health genetics issue of your choosing (can be the same or different). Details will be provided under “Assignments” page on course website. All assignments should be submitted via the course website by midnight of the due date, unless otherwise specified.

3. **DIGITAL STORY AND ORAL PRESENTATION (10%) (Due March 11)**

An important skill to develop is awareness and recognition of issues. For the final project in this course, you will compile a digital story – a composite of images set to a narrative and theme of your choosing – and present your story in class. Your digital story should highlight themes in public health, public health genetics, ethics, legal, social, or policy implications, as you choose. The slide show and narration should be 5 minutes in length when final. Consider using the “ignite” style approach with 20 slides viewed for 15 seconds each (repeats are permissible).

4. **SELF EVALUATION (Required)**

At the end of the course, you must also write a 1-page statement of your own personal lessons from the course (due **March 17**). What are you taking away from this course? What surprised you? What helped your understanding the most?

COURSE POLICIES

ATTENDANCE	Regular attendance is important, because classroom discussion is a central part of the course. <u>If more than one class is missed</u> , your participation grade will be docked 5 points (5 per class per week) unless you provide a 1-2 page reflection paper based on the readings assigned for that day. Please let the TA know in advance if you will be missing a class and your plan for making up the missed class and content.
REQUIRED READINGS	Readings are posted on the course canvas site by week and should be completed in advance of class. Once a week, an assignment will open requesting submissions of questions in advance of class. These will seed the discussion with the guest speaker and are required.
ELECTRONIC SUBMISSION	Students should submit papers electronically via the course website. Feedback will be given electronically.
LATE ASSIGNMENTS	In the interest of fairness, late assignments (received after time on the due date) will receive 2 points off for each day late.
EXTRA CREDIT	If you attend talks, films, or other public events related to our course topic (other than those assigned), you can earn 1 point for attending and up to 5 points for writing a reflection paper on the event.
PLAGIARISM	Plagiarism on any of the writing assignments is grounds for failing the course. You must turn original work and cite all sources that you use including websites, course handouts, texts, etc.
ACCOMMODATION	If a student needs accommodation for any health or ability reason, please contact me and we can discuss appropriate modifications to the requirement.

REQUIRED READINGS:

- Margaret Atwood, *Oryx and Crake*. New York: Anchor Books, 2003.
- Mary Shelley, *Frankenstein*. Originally published in 1816. Any edition will work (but read the Preface).
- Larry Gostin, *Public Health Law: Reader*. <http://www.publichealthlaw.net/Reader/toc.htm>
- NWABR, *Ethics Primer*.

REQUIRED FILMS:

- *Gattaca* (1997)
- *Contagion* (2011)
- *Perfect 46* (2014)

CASES:

- **23&Me and FDA:** <http://www.fda.gov/ICECI/EnforcementActions/WarningLetters/2013/ucm376296.htm>
<http://www.bioethics.net/2013/11/the-fda-and-home-dna-testing/>
- **Valley Medical Wrongful Birth Suit:**
http://seattletimes.com/html/localnews/2022438460_geneticverdictxml.html
http://seattletimes.com/html/opinion/2022593411_joshaasengopedgenetictesting04xml.html
- **Myriad Supreme Court Case:** http://www.supremecourt.gov/opinions/12pdf/12-398_1b7d.pdf
<http://www.genomicslawreport.com/index.php/2013/06/18/myriad-finally-supreme-court-surprises-by-not-surprising/>

BLOGS TO WATCH:

- <http://scienceblogs.com/>.
- <http://www.humanosphere.org/> focuses on global health issues.
- <http://bioethics.net/> and <http://www.thehastingscenter.org/bioethicsforum/> Daily news related to ethics in science and medicine. **Check out the “genetics” threads.**
- <http://seattlefosep.wordpress.com/> UW Graduate Student-run organization: Promoting dialogue among scholars, policy experts, and the public about the role of science in society. They have a running blog, reading group, happy hour nights to discuss science policy, and good postings of events around campus town.

Find your own blogs or public information portals and let us know about them!

COURSE SCHEDULE (subject to some revision – see Canvas Modules for most current assignments)

NOTE: Class format is structured around case studies presented by guest speakers coming from a variety of disciplinary and professional perspectives. A number of the class speakers are Public Health Genetics senior students, alumni, or faculty, as the students themselves are defining this emerging field. After each hour conversation with a guest, we will spend the next hour class applying or making visible different ethical, legal, social, and policy frameworks and stakeholder values at play in the cases and issues presented.

Week 1: Outside Work

- Watch Sam Harris, “Science can answer moral questions” (including post lecture Q&A) http://www.ted.com/talks/sam_harris_science_can_show_what_s_right. Contribute at least twice to the online discussion thread in response to the argument Harris makes.
- Submit a short response (2 paragraphs) as an assignment regarding “What is Public Health Genetics?”

January 7: Kelly Edwards, PhD

Introduction to ELSI approaches to Public Health Genetics. As an interdisciplinary class and program, we will begin by examining our own lenses, assumptions, and ways of knowing to help prepare for on-going engagement and layering on frameworks for our decisionmaking toolkit. Our first case discussion will focus on the FDA shutdown of 23&Me: <http://www.bioethics.net/2013/11/the-fda-and-home-dna-testing/>

Background reading:

- Beauchamp T. et al. Moral dilemmas and disagreements. 2008.
- Fullerton SM, Knerr S, Burke W. Finding a place for genomics in health disparities research. Public Health Genomics. 2012;15(3-4):156-63.
- Khoury MJ, Bowen MS, Burke W, Coates RJ, Dowling NF, Evans JP, Reyes M, St Pierre J. Current priorities for public health practice in addressing the role of human genomics in improving population health. Am J Prev Med. 2011 Apr;40(4):486-93.

Week 2: Outside Work

- Utilize the decision analysis worksheet and reflect upon what counts as a cost or benefit. Who decides, and can you imagine others would include different risks or outcomes of value? Contribute your ideas to the canvas online discussion board.
http://www.smartrecovery.org/resources/library/Tools_and_Homework/Quick_Reference/CBA_Worksheet.pdf
- Watch Daniel Ariely, “Our Buggy Moral Code,” http://www.ted.com/talks/dan_ariely_on_our_buggy_moral_code#t-4416 Contribute and respond at least twice to the online course discussion in response to this talk.
- Identify issue for Essay 1 interviews – post your draft interview question (by January 16)
- Optional: GO-MAP Power Hour (small group workshop) Power, Privilege and Difference: Microaggressions Facilitated by Geneva Gay, College of Education January 13 | 12-1:30pm ECC

January 14: Josh Carlson, MPH, PhD

Cost-benefit decision analysis and pharmacogenetics

- Radiolab podcast: Worth (linked on Canvas module)
- Conceptualizing a model: Report

Week 3: Outside Work

- Watch: Susan Etlinger, “What do we do with all this big data” and contribute to Discussion Board.
http://www.ted.com/talks/susan_etlinger_what_do_we_do_with_all_this_big_data.
- Read: Wang (PHG alum) and Watts, “The Role of Genetics in the Provision of Public Health Services”
- Read: Katz and Thompson, “The Role of Public Policy in Health Care Market Change”

January 21: Deb Lochner-Doyle, MS, CGC

The Art of Policy Development. Perspectives from the State Genetics Program.

Week 4: Outside Work/Advance Preparation

- Watch film Contagion. Track the ELSI issues in the film. Assess the portrayal of socio-cultural response to infectious disease. Contribute to the discussion thread on the canvas online board.
- Watch Seth Berkley TED talk:
http://www.ted.com/talks/seth_berkley_hiv_and_flu_the_vaccine_strategy. Discussion thread on the canvas online discussion board.
- Watch Ed.TED module on How Pandemics Spread and complete the short answer questions (under “Think”). <http://ed.ted.com/lessons/how-pandemics-spread>
- Watch Ed.TED module on Ebola virus and complete the short answer questions.
<http://ed.ted.com/lessons/what-we-know-and-don-t-know-about-ebola-alex-gendler>
- Read: Gupta et al. “Can the infectious disease genome project predict and prevent the next pandemic?” PLOS Biology (2009).
- Read: Colgrove & Bayer, “The legacy of Jacobson v. Massachusetts” AJPH (2005).

January 28: Matthew Seymour, MPH

What does genetics have to do with infectious disease?

Week 5: Outside Work/Advance Preparation

- Read the blogspot and watch selected videos highlighted there (particularly 1, 2, 7, 9)
<http://ideas.ted.com/2014/12/17/fresh-smart-ways-to-think-about-racism-and-injustice-in-the-u-s-today/>
- Read Weiss & Fullerton. Racing around, going nowhere (2005).
- Watch Gattaca (first) and then Perfect 46

February 4: S. Malia Fullerton, DPhil

Race and genetics.

Week 6: Outside Work/Advance Preparation

- Read Frankenstein
- Read Oryx & Crake
- Review background for Frankenstein and Oryx & Crake regarding the speculative fiction, dystopia, and transhumanism.

February 11: Truth is Stranger than Fiction

Lessons from Frankenstein and Oryx & Crake

Week 7: Outside Work/Advance Preparation

- Review themes from narrative films and novels for opening discussion.
- Watch CEEH epigenetics film:
- Recommended: Woolf & Braveman, “Where health disparities begin: The role of social and economic determinants,” Health Affairs (2011).
- Read: Thayer & Kuwaza, “Biological memories of past environments,” Epigenetics (2011).

February 18: Lorelei Walker, PhC

Epigenetics and public education

Week 8: Outside Work/Advance Preparation

- Read: Riedel: Human right to health.
- Read: Universal Declaration of Human Rights
- Read: UNESCO Declaration of Human Genome and Human Rights

February 25: Global health, Human Rights, and Collective Impact

Part 1: Beth Rivin, MD, MPH

Global health, public health law, and human rights

Part 2: Sahil Kejriwal, MGC, PhD student

Global public health and collective impact approaches to policy development

Readings:

Atul Gawande, The Cost Conundrum, The New Yorker (2009).

<http://www.newyorker.com/magazine/2009/06/01/the-cost-conundrum>

Week 9: Outside Work/Advance Preparation

March 4: John Thompson, PhD, MPH, MPA

State newborn screening program

Week 10: Outside Work/Advance Preparation

- Watch Sandal: “Putting a pricetag on life” (first 24 minutes of lecture)

March 11: Class Presentations and Course Wrap-Up

FINALS WEEK

March 17: Final Essay Due. Self-assessment uploaded by midnight.

“The challenge is not to get narrative and storytelling out of policy making. They are the oxygen to the process and cannot be eliminated. We might as well try to ban conversation. The challenge is to raise everyone’s skill level – officials and citizens alike – to be more intelligent consumers of stories.”

– JE McDonough (former health committee chairman in the Massachusetts House of Representatives)

*“Knowing is not enough; we must apply.
Willing is not enough; we must do. – Goethe*