Ethical, Legal, & Social Issues in Public Health Genetics

PHG 512 | BH 514 | LAW H504
Winter 2014 | M/W 12-1:20pm | 3 credits | HSB T-474

Canvas Site URL:

Kelly Edwards, Associate Professor
Office: 221-6622 Email: edwards@uw.edu

Flavia Chen, PHG Graduate Student
Email: fhc@uw.edu

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.

“The limits of our language are the limits of our world.” – Wittgenstein
1. **CLASS PARTICIPATION**, including **weekly online responses to readings** 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** (40%)
   There will be two short writing assignments due throughout the quarter (due **February 3 and February 24**).
   - 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 PEER REVIEW** (25%) (Due March 10 – peer review by March 17)
   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 upload your narrated slide show using Panopto to our course website. 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). More guidance and demonstrations of the tools will be available later in the quarter.

4. **SELF EVALUATION** (5%)
   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. **If more than one class is missed**, 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 in original work and cite all sources that you use including websites, course handouts, texts, etc.

If a student needs accommodation for any health or ability reason, please contact me and we can discuss appropriate modifications to the requirement.

### Blogs to Watch:

- **http://scienceblogs.com/**
  Gateway to several science blogs and news sources, organized by discipline, sponsored by the Seed Media Group (makers of Seed magazine, dedicated to enhancing science literacy in popular culture). From their site:

  “Science is driving our conversation unlike ever before…New insights and discoveries in neuroscience, theoretical physics and genetics are revolutionizing our understanding of who we are, where we come from and where we’re heading. Launched in January 2006, ScienceBlogs is a portal to this global dialogue, a digital science salon featuring the leading bloggers from a wide array of scientific disciplines. Today, ScienceBlogs is the largest online community dedicated to science… We believe that science literacy is a pre-condition for progress in the 21st century. At a time when public interest in science is high but public understanding of science remains weak, we have set out to create innovative media ventures to improve science literacy and to advance global science culture.”

  **Check out a number of reputable public health and science blogs** that were consolidated onto this portal a few years ago: Effect Measure, Pharyngula, Aetiology, and Chris Mooney. Find others that interest you.

- **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://seattlefossep.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)

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 final part of class applying or making visible different ethical, legal, social, and policy frameworks and stakeholder values at play in the cases and issues presented.

January 6: 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/](http://www.bioethics.net/2013/11/the-fda-and-home-dna-testing/)

Background reading:
- Ethics Primer, from the Northwest Association for Biomedical Research.

January 8: Tara Coffin, MEd, PhC
Prenatal genetic testing and disability rights
*Reading questions due before class

January 13: Lou Garrison, PhD
Drug Development and the Economics of Personalized Medicine
*Reading questions due before class

January 15: Matt Seymour, MPHc
Infectious disease

January 20: MLK Day (no class)

January 22: Katherine Kwong, MPHc
Classic legal cases and analytic approaches in public health genetics
*Reading questions due before class

January 27: Andrew Serafini, PhD
The Myriad case. Lessons about intellectual property and precedent for genetic research and practice.

January 29: Joon-Ho Yu, PhD
Race and genetics.
*Reading questions due before class

February 3: Cyan James, PhC
Participant-centric initiatives
*Essay 1 (Ethics Analysis) due by midnight

February 5: Lorelei Walker, PhC
Epigenetics
*Reading questions due before class

February 10: Kate West, PhC
Food ethics and policy issues
February 12: Flavia Chen, MPHc
Risk assessment and emerging technology
*Reading questions due before class

February 17: President’s Day (no class)

February 19: Deb Lochner-Doyle, MS, CGC
The Art of Policy Development. Perspectives from the State Genetics Program.
*Reading questions due before class

February 24: Josh Carlson, MPH, PhD
Cost-benefit decision analysis and pharmacogenetics
*Essay 2 (Op-Ed) due by midnight

February 26: Wylie Burke, MD PhD
Clinical integration of genetics and clinical guideline development
*Reading questions due before class

March 3: John Thompson, PhD, MPH, MPA
State newborn screening program (NOTE: Optional site visit to the Washington State NBS program TBD)

March 5: Mercy Laurino, MS, CGC, PhC
Genetic counseling issues and global health
*Reading questions due before class

March 10: Holly Tabor, PhD
Integrated ethicist and exome sequencing
*Digital story uploaded to course website by 5pm.

March 12: Class Wrap-Up
Final digital story highlights and discussion. In-class evaluations.


“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