Human Genomics: Science, Ethics, and Society
Placing Recent Advances in Human Genetics and Genomics in Social Context

PHG 551 / B H 551 / GENOME 573 (3 credits)
Autumn 2014 | Thursdays 1:30-4:20 pm | Location T-663

https://canvas.uw.edu/courses/913526

Stephanie Malia Fullerton, DPhil
Associate Professor
Department of Bioethics & Humanities
Office: 616-1864
Email: smflrln@uw.edu
Office hours: By Appointment

"Disappointed love, not hatred or aversion, is the strongest motivation behind the urge
to make an argument sing, rather than shout. And that is why the screamers on every side leave me so cold.
They argue without love—and they are not true polemists." -- Lee Siegel

"In science it often happens that scientists say, 'You know that's a really good argument; my position is mistaken,'
and then they would actually change their minds and you never hear that old view from them again. They really do it.
It doesn't happen as often as it should, because scientists are human and change is sometimes painful. But it happens every day. I cannot recall the last time something like that happened in politics or religion."
— Carl Sagan

COURSE DESCRIPTION
This course aims to provide an overview of recent topics in human genetics and genomics while simultaneously placing those topics in a broader social and ethical context. The approach to learning is unstructured and collaborative. Students will explore, in a sustained manner, the science involved in recent research advances, ranging from next gen sequencing to mitochondrial gene transfer. They will also use a range of ethical arguments to assess the implications of such advances for scientists, clinicians, research participants, and society at large.

COURSE OBJECTIVES
At the end of this course, students should be able to:

1. Describe and discuss key genetic and genomic approaches to the identification of genes and genetic variants relevant to health and disease;

2. Identify the ways in which human genomic investigation both determines, and is determined by, prevailing social norms and values;

3. Apply scientific insights to the critical assessment of current ethical debates in human genetics and genomics.

COURSE PREREQUISITES
LAW H 504/B H 514/PHG 512 or permission of instructor.
COURSE REQUIREMENTS

1. CLASS PARTICIPATION (25%): including careful reading and engaged discussion

2. COMMENTARY OUTLINES (30%): three one-page bulleted outlines of a genomics research ethics-oriented argument, suitable for use as the basis of a full length commentary. Outlines will be due by 5 PM on the SUNDAY AFTER the class for which an outline has been assigned. Assignments will be determined by random draw on the first day of class.

3. FINAL COMMENTARY (40%): one 1500-2000 word essay, written in the form of a commentary appropriate for a general scientific audience. Please follow standard conventions for peer-reviewed publication, i.e. double-space throughout, adequately cite all sources, proof read your work, etc. This essay, which must be based on one of the three outlines submitted earlier in the quarter, is due MONDAY, DECEMBER 8th at 5 PM.

4. SELF EVALUATION (5%): write a 1-page statement of self-evaluation with respect to your course participation (while I welcome feedback on my performance, this is really supposed to be about YOU). What are you taking away from this experience? What helped your understanding the most? Due by WEDNESDAY, DECEMBER 10th at 5 PM.

COURSE TEXTS

Links to all readings (outlined in Course Schedule below) will be posted to the Syllabus page of the course website:

➢ https://canvas.uw.edu/courses/913526

COURSE POLICIES

<table>
<thead>
<tr>
<th>ATTENDANCE</th>
<th>Regular attendance is expected. If you must miss more than one class meeting you will be required to make up work through additional writing assignments. Advance notice of anticipated absence(s) is appreciated.</th>
</tr>
</thead>
<tbody>
<tr>
<td>ELECTRONIC SUBMISSION</td>
<td>I prefer to receive writing assignments electronically (via Assignments page). If access to, or regular engagement with, the website is likely to be a problem for you, please come see me so we can discuss alternative mechanisms for participation.</td>
</tr>
<tr>
<td>LATE ASSIGNMENTS</td>
<td>In the interest of fairness, late assignments (received after due dates/times noted above) will lose 5% of the final grade per late day.</td>
</tr>
</tbody>
</table>

Version September 23, 2014  2
WEEK 1 (9/25): Introduction to Course, Art of Argument

  http://www.youtube.com/watch?v=tAmgEa1B1vl&index=2&list=PLDF3C877967DFDEC6
- deLaplante, K. (2013). “What is a good argument? (Parts I & II)”
  http://www.youtube.com/watch?v=AlRYrBFoQqA
  http://www.youtube.com/watch?v=B2WWeWUBhKU
  http://www.youtube.com/watch?v=07mehbgE5jc

Optional


WEEK 2 (10/2): Genomic (Big) Data Sharing and Implications for Informed Consent


Optional

WEEK 3 (10/9): Return of “Incidental” Findings from Genomic Testing (J. Kocarnik)


Optional


WEEK 4 (10/16): Protecting Genomic Privacy in Research and Public Spaces


Optional

WEEK 5 (10/23): Addressing Kidney Disease Disparities with Genetic Testing


Optional


WEEK 6 (10/30): Epigenetics and Geneticists’ “Obsession” with Parents and Parenthood


Optional

WEEK 7 (11/6): RNA-guided “Gene Drives”: Applications and Concerns


Optional


WEEK 8 (11/13): The Perfect 46 (K. Edwards)

- [ThePerfect46.com](ThePerfect46.com)

Optional


WEEK 9 (11/20): Population-Based Screening for BRCA Mutations (W. Burke)


Optional


11/27: THANKSGIVING DAY HOLIDAY – NO CLASS

WEEK 10 (12/4): Genomic Surveillance in the 2014 Ebola Outbreak in West Africa


Optional


SELF-EVALUATIONS DUE 12/10 BY 5 PM

EQUAL OPPORTUNITY STATEMENT

The University of Washington reaffirms its policy of equal opportunity regardless of race, color, creed, religion, national origin, sex, sexual orientation, age, marital status, disability, or status as a disabled veteran or Vietnam-era veteran in accordance with University of Washington policy and applicable federal and state statutes and regulations.

DISABILITY ACCOMMODATION
The University of Washington is committed to providing access, equal opportunity and reasonable accommodation in its services, programs, activities, education and employment for individuals with disabilities. For information or to request disability accommodation contact: Disabled Students Services (Seattle campus) at (206) 543-8924/V, (206) 543-8925/TTY, (206) 616-8379/Fax, or e-mail at uwdss@u.washington.edu.

**ACADEMIC INTEGRITY**

Matters of academic integrity are handled by the Vice Provost for Student Relations and the Committee for Academic Misconduct. The Office of the Vice Provost for Student Relations assumes responsibility for investigating and resolving allegations of scientific and scholarly misconduct by faculty, students, and staff of the University of Washington. It coordinates, in consultation and cooperation with the Schools and Colleges, inquiries and investigations into allegations of scientific and scholarly misconduct. The Office of the Vice Provost for Student Relations is responsible for compliance with reporting requirements established by various Federal and other funding agencies in matters of scientific or scholarly misconduct. The Vice Provost maintains all records resulting from inquiries and investigations of such allegations. University rules (Handbook, Vol. II, Section 25-51, Executive Order #61) define scientific and scholarly misconduct to include the following forms of inappropriate activities: intentional misrepresentation of credentials; falsification of data; plagiarism; abuse of confidentiality; deliberate violation of regulations applicable to research. Students can report cases of scientific or scholarly misconduct either to the Office of the Vice Provost for Student Relations, to their faculty adviser, or the department Chair. The student should report such problems to whomever he or she feels most comfortable.