

Public Commentary on Ethical Issues in Public Health Genetics:

How are the Issues Addressed in Contemporary Criticism and Film?

PHG 525 | BH 515

Spring 2012 | Thursdays 1:30-4:20 | 3 credits | HSB T-635

Required Film Lab Mondays 3-5pm in HSB T-663

<https://catalyst.uw.edu/workspace/bh515/11120/56977>

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“Ethics is not only something to be studied or argued or analyzed, but exemplified in one’s daily actions. [This is] a notion so obvious and simple as to be, alas, utterly daunting for so many of us!” – Robert Coles

COURSE DESCRIPTION:

In this discussion-based seminar we will explore bioethical issues, with a focus on public health genetics, as portrayed through novels, popular non-fiction, film and contemporary criticism. Public Health Genetics examines the impact of genetic innovations on public health. As such, we will consider themes from both classic public health ethics (including social responsibility, communitarian ethics, and prevention) as well as ethics of genetics (including enhancements, problems of prediction, the question of normalcy, and unintended consequences of research and development). Using novels and film as our primary learning sources we will consider “*characters of geneticists (scientists), the plots of genetics, and the metaphors of genes (Van Dijck)*.” The goal of the seminar is to prepare students to be better readers and viewers of public media, and ultimately contribute to public discussions that impact science policy. Primary tools for our work are common frameworks from moral theory: deontology, consequentialist ethics, virtue ethics, and feminist ethics.

COURSE OBJECTIVES:

During this course, participants will:

1. Explore, debate, and critique ethical issues in public health genetics, as they appear in popular books, films and other public media;
2. Apply different ethical frameworks to the reading and viewing of public texts and film;
3. Contribute writing on bioethics and public health genetics issues at both the level of public debate and critical commentary.

“The limits of our language are the limits of our world.” – Wittgenstein

COURSE REQUIREMENTS

1. **CLASS PARTICIPATION**, including **regular contributions to the Course Blog and related science policy blogs** and engaged discussion in class (20%). At least one blog posting is required following each film lab and two readings prior to Wednesday evening (before class, total of **5 blogs for films, and at least 2 for readings**). Dialogue on the blog (responding to others, starting new threads) is encouraged and will result in a stronger evaluation of participation. We will focus on common questions for every story or film: What are the central arguments? How do the aesthetics or style work to support or motivate those arguments? What do you think the public would take away? What lessons are there for bioethics in general or public health genetics in particular? Additional threads or themes can be pursued each week, depending on faculty or student interest.

TIP: Prior to coming to class, read the assignments (book or blog) carefully and write down one or two interesting questions that were raised by the readings for that day. Be prepared to share your question(s) with the group 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. **CLASS PREPARATION AND FACILITATION** (15%)

Each student will have an opportunity to facilitate **an hour** of class discussion. Facilitation is expected to be interactive and creative. A **one-page handout** with focusing on key issues in the text or film along with questions for discussion will be expected in class.

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

There will be **three short writing assignments** due throughout the quarter (due **4/23-9am, 5/10, and 6/1**).

- Ethics analysis: Develop and justify an argument for a position, drawing explicitly on the ethical frameworks introduced in class (3 double-spaced pages).
- Contributing to a Wikipedia entry: With guidance from a Wikipedia editor, identify an issue that needs further refinement and extend the entry (minimum outlined in assignment page).
- Op-ed style essay: Writing as if for the NYT or The Scientist, or the Huffington Post, motivate your audience to care about your issue (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 drop-box on the course website by midnight of the due date, unless otherwise specified.

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 **June 7**). What are you taking away from this seminar? 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. Film lab attendance is also required. Watching films as a group for a course is a different experience than watching at home, alone. <u>If more than one class or lab is missed</u> , your participation grade will be docked 5 points (5 per class/lab per week) unless you provide a 1-2 page reflection paper based on the readings or film assigned for that day.
ELECTRONIC SUBMISSION	Students should submit papers electronically via the Collect-It tool on the course website. If you have finished with your paper before class, please bring a hardcopy to submit in addition to your online copy. 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. Specific events are listed in the syllabus; see also www.fosep.org for listings of events.
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.

COURSE TEXTS

Texts are available in through the usual outlets (in order of reading).

- Aldous Huxley, *Brave New World* (1932)
- Rebecca Skloot, *Immortal Life of Henrietta Lacks* (2010)
- Michael Berubé, *Life as We Know It* (2002)
- Mira Grant, *Feed* (2010)
- Richard Preston, *Demon in the Freezer* (2003)

COURSE READINGS: Supplementary course readings, sample op-ed and critical essay writings from public sources are available online at the course website.

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 are 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://bioethics.net/> and <http://www.thehastingscenter.org/bioethicsforum/>

Daily news related to ethics in science and medicine. Includes a link to [bioethics.blogspot](http://bioethics.blogspot.com).

<http://seattle.fosep.org/>

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

Week 1: Overview: Ethical Issues in Public Health Genetics

The history of science and medicine is a history of hope and discovery. The goals of science and medicine are, among other things, to alleviate human suffering and help improve the human condition. As our technologies progress, we have to ask the question: how far should we go toward enhancement and perfection? What is at stake? What are public concerns about scientific advancement? What should they be?

March 26: FILM: Gattaca (Andrew Niccol, 1997)

March 29: Discussion of Gattaca and Introduction to Ethics Frameworks

March 30-31: Husky Days at the Pacific Science Center. Optional participation in PHG booth (10-4, 3 hour shifts, 3 points extra credit). This is a great, real-time opportunity to practice and experience public engagement and outreach with science and genetics.

Week 2: Surveillance

A common theme in science fiction is the big brother experience of an omnipresent watcher, often exerting a high amount of control on human behavior. With growing interest in biobanks, genome-wide association studies, behavioral genetics, and pharmaceutical use, these concerns over privacy, elimination of variance, and conditioning toward a social “norm” are alive and well. Are there efficiencies that can be gained by large-scale monitoring? Are there some human behaviors that should be eliminated (either through genetic or pharmaceutical intervention)? What are the consequences of such actions?

April 2: No film lab

April 5: Discussion of Brave New World, with Lizzie Dorfman.

Week 3: Scientific Responsibility

With emerging technologies come impacts and unforeseen consequences. What role should scientists play regarding the ultimate uses and impacts of their discoveries? The publicly-funded research endeavor relies on public trust. Are scientists trustworthy? What can or should society expect of scientists?

Additional themes for this film: Many argue that because of unforeseen consequences we need to draw bright lines of caution around certain areas of technology development. Others argue that because human life is so unique and precious, we should not push boundaries that might smack of “playing god.” What responsibilities do we have as we move forward with technological developments? What safeguards or processes could we consider implementing to resolve these concerns, or will they always be present?

April 9: FILM LAB: Fat Man and Little Boy (Roland Joffe, 1989)

April 12: Discussion of FILM: Fat Man and Little Boy, with Alie Fohner and Ursula Schick

Additional Required READING: Ethics Frameworks Background (on website)

LP Pojman, “Moral Theories and Moral Character,” and (very) short stories from The Moral Life (2000).

Week 4: Research Ethics: Individual rights and the Common Good

Research ethics in Western cultures has been framed by the Belmont Report in 1974 and the Federal Regulations that guide Research with Human Subjects. These principles require researchers to conduct studies where the promise of benefit outweighs the risk of harm to participants (beneficence), to treat participants with respect, and to treat all people fairly within the study (justice). However, what is the most appropriate and effective way to show respect, especially in large-scale or tertiary studies that might be quite far removed from the original participant? What counts as sufficient benefit? Benefit for whom? Who decides? Are the current guidelines, regulations, and processes that provide ethical oversight in research sufficient in the context of a now rapidly changing, dynamic scientific enterprise?

April 16: No film lab.

April 19: Discussion of Immortal Life of Henrietta Lacks, with Leslie Mabry
Class ends at 3pm for Dr. Gil Omenn's Address.

April 19: DNA Day, PHG exhibit runs throughout April 21. Volunteer to staff the booth for extra credit.

**** First essay due 4/23 via Collect-It by 9am (ethics essay).**

Week 5: Research Ethics: Ethics of Collaboration

Increasingly NIH and other funding sources are recognizing the need to do research in partnership with communities. While this is a welcome development, there are many challenges with shifting the dominant research model to a more collaborative model. Even within interdisciplinary collaborations, we recognize that our collaborators have different sources of evidence, different ways of knowing, different values, different communication standards, different ways of showing respect, etc. Among the issues raised in this film, we see a battle between hierarchical or colonial ways of thinking and emerging, community-based and indigenous ways of being. What lessons are there for us in public health genetics research and practice?

April 23: Film: Avatar (James Cameron, 2009)

April 29: Discussion of Avatar, with Caitlin Scoville and Julie Weis
Additional required reading on the course website:

Goering, Holland & Fryer-Edwards, "Transforming Genetic Research Practices with Marginalized Communities," Hastings Center Report (2007).

Nisbet & Scheufele, "The Future Of Public Engagement," The Scientist (2007).

Week 6: Normalcy

With prenatal screening, pre-implantation genetic diagnosis, and discussions of genetic engineering, an unintended result is that some human conditions appear devalued. If someone is offering enhancement or choices, it presumes one of the choices is less desirable than another. For many of us, the question of 'what is normal?' is not so easily resolvable. In this story, we will take a look into the lived experiences of some of those considered 'undesirable'.

April 30: No film lab.

May 3: Discussion of Life as We Know It, with Kate West.

Week 7: Uncertainty and Hope

Of the many promises of genetic medicine and research, there is the hope and possibility that we can identify disease susceptibility before the disease manifests, and do something to prevent it.

Running alongside this great promise are dilemmas created because genetic information is inherently uncertain. How much risk are we willing to take when the possible outcomes are significant? How much evidence will we require before we should act? What should we require of others? How will the levels of evidence, and tolerance of uncertainty, change if we are talking about policy-level decisions rather than personal ones? And finally, how far should one go to hold on to hope?

May 7: FILM LAB: Lorenzo's Oil (George Miller, 1992)

May 10: Discussion of Lorenzo's Oil, with JD Fischer

Additional Readings: Zoloth, "Heroic Bioethics" and Terry&Terry, "Power to the People"

**** Wikipedia Assignment and Reflection due via Collect-It 5/10 midnight ****

Week 8: Unintended Consequences and the Collective Good

Scientific and technological advances have always depended upon a combination of hard work, creativity, innovation, and serendipity. There is a tension in current science/engineering circles about the limits of open source research. The Synthetic Biology community is an example of a group committed to open source and shares much with a computer hacker culture. Start-up companies are another. Are we putting science at risk? Will we miss out if we proceed otherwise? What kind of climate or culture is necessary to foster innovation and responsibility? Further difficulties arise when our extensive regulatory system for research ethics and research integrity is limited to federally-funded projects, leaving out most of industry, biotech, and garage biology projects. Is this a problem? How could we bridge this gap? Should we? What is at stake? Finally, how will we respond as a society when threatened?

May 14: No film lab

May 17: Discussion of Feed, with Laura Heath.

Week 9: Personal Identity and Free Will

How much of our obsession with genetic testing and innovation has to do with our interest in "conquering death"? Is it a responsibility of humans to advance our health and longevity, or are we in fact "playing god"? What makes innovations responsible versus irresponsible, acts of humility versus acts of arrogance? Does it matter what the researcher or innovator's intentions are, or is it only the consequences of our actions that matter?

Additional themes raised by this film: what does it mean to be human? What responsibilities do scientists have for the downstream consequences of their actions? Changes in biotechnology will result in changes in our understanding of what it means to be an individual person. Given the connection between personhood and freedom of the will this will further challenge our notion of individuality. The seat of these concerns will be the mind. To what extent is our individual identity bound to the structure of our minds? When our minds can be changed can our individuality be changed?

May 21: Film lab: Never Let Me Go (Mark Romanek, 2010 based on Kazuo Ishiguro's novel from 2005).

May 24: Discussion of Never Let Me Go, with Taryn Hall and Brenton Swenson

Additional Required Reading on Course Website: Guyer & Moreno, "Slouching toward Policy" (2004).

May 25: *Request for Public Comment from the President's Commission on Bioethics Due Today.* See "Request for Comments on Issues of Privacy and Access With Regard to Human Genome Sequence Data."

<http://bioethics.gov/cms/node/676>

Week 10: Drawing the Line

Many argue that because of unforeseen consequences we need to draw bright lines of caution around certain areas of technology development. What responsibilities do we have as we move forward with technological developments? What safeguards or processes could we consider implementing to resolve these concerns, or will they always be present?

Additional themes for this week: Running alongside this great promise are dilemmas created because genetic information is inherently uncertain. How much risk are we willing to take when the possible outcomes are significant? How much evidence will we require before we should act? How will the levels of evidence, and tolerance of uncertainty, change if we are talking about policy-level decisions rather than personal ones?

May 28: Holiday! No film lab.

May 31: Discussion of Demon in the Freezer, with Lorelei Walker

Additional readings recommended on course website: Including background on current “dual use” policies from NSABB and the Case study of Mouse-Pox and data release, found at:

http://www.fas.org/biosecurity/education/dualuse/FAS_Jackson/

**** June 1: FINAL PAPERS (op-eds) due by midnight via Collect It ****

June 7: Self-evaluations due via Collect It 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*