Ethical Frameworks of Public Health Genetics
PHG 522/BH 516 (3 Credits)

University of Washington
Winter Quarter 2011

Mondays & Wednesdays 1:30-2:50 p.m.

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Office Hours: By Appointment

Summary of Course

This course introduces students to frameworks for understanding ethical principles, concepts and their application in public health genetics. This approach allows for detailed examination and discussion of ethical issues in genetics that arise in research, practice and policy affecting both individuals and populations. Part I focuses on foundational issues, including: (a) introduction and review of approaches to and tools for understanding ethics and ethical analysis, and (b) early approaches to ethical issues arising in genetics, particularly the historical experience with early screening programs and counseling practices, and genetic engineering. Part II explores the application of ethical frameworks in the context of public health genetics. The potential for tension between individual and societal perspectives is considered throughout the course. Of particular focus will be issues that arise in thinking about how advances in genetic technology can benefit or pose a threat to public health, particularly in the areas of health promotion and disease prevention.

Course Objectives

Through lectures, class discussions, and oral and written presentations, students will: further develop basic skills in ethical analysis; be able to recognize, research, and analyze ethical issues arising in the context of public health genetics; and increase the competence with which they make ethical decisions as issues arise in their practice and professional training.

Required Course Materials

There are two required “texts” for this course:

1. The Course Materials consist of a compilation of medical, scientific, legal, policy and public health journal articles, book excerpts, miscellaneous legal materials, and articles from the popular press. They are available online for downloading via Catalyst CommonView: https://catalyst.uw.edu/workspace/kschuda/17823/
2. Mary Shelley, *Frankenstein* (any unabridged edition). This book is available for purchase at the Health Sciences branch of the University Bookstore. You are expected to have read the book by the date of class discussion, January 26.

Scientific and medical advancements with potential ethical implications are being reported practically every day. From time to time throughout the course I will email news items of potential relevance to the class. Unless specifically identified as *required* reading for the course, these news items are *optional* readings.

**Course Policies**

**Attendance:** Because this class will use a seminar format to discuss the readings, your attendance and participation are critical to the success of the class. Two excused absences will be allowed (you must notify me in advance either by email, phone/voice mail, or in person); you will lose participation points for other absences.

**Class participation:** This course provides an opportunity for students to discuss potentially controversial issues in a seminar format. Active participation by students is crucial to the success of this class. It is important that students prepare for class, having both read the materials and thought about the issues.

**Electronic submissions:** Written assignments will be accepted as an electronic copy using Catalyst Drop box. All submissions must be received by the due date and time.

**Late assignments:** In the interest of fairness to other students, any assignments received after the due date and time will receive 2 points off for each day late. If you have extenuating circumstances that will require renegotiating deadlines, please give the instructor as much warning as possible. You must have prior approval to avoid late penalties.

**Quality of your writing:** High-quality writing is the standard for graduate education. Thus, I expect that you will have proof-read your papers for spelling and grammatical errors before turning them in. I will pay attention to style as well as content. In general, you will lose points for sloppiness and gain points for eloquence. If you know you have trouble in these areas, please let me know so I can take that into consideration as I grade your papers. Your best strategy is to have someone else review and proof your papers. For guidance, please refer to *The Elements of Style*, by William Strunk, Jr., ([http://www.bartleby.com/141/](http://www.bartleby.com/141/)) and *Style: Ten Lessons in Clarity & Grace (7th ed)*, by Joseph M. Williams. Both are excellent references for organizing and improving your writing. In addition, a free consultation service is available through the UW’s Odegaard Writing and Research Center [http://depts.washington.edu/owrc/]. Please consult their website for policies, contact information and hours. In addition, the following webpage has links to useful resources in multidisciplinary communication: [http://depts.washington.edu/phgen/resources/writing.shtml](http://depts.washington.edu/phgen/resources/writing.shtml).
Disability Accommodation: If you would like to request academic accommodations due to a disability, please contact Disability Resources for Students (DRS), 448 Schmitz, 543-8924 (V/TDD), http://www.washington.edu/students/drs/. If you have a letter from DRS indicating you have such a disability, please present the letter to me so that we can discuss appropriate accommodations.

Feedback, suggestions, assessment and summative evaluations: Seminar members are encouraged to suggest alternative readings and topics for seminar discussion and otherwise recommend ways to maximize our study time together. I welcome continual feedback and assessment of seminar substance and process. A formal course evaluation will be collected and assessed by the Educational Assessment Center during the last class session. Participation in the evaluation process is voluntary.

**Course Assignments and Grading**

Course assignments are described below. Your course grade will be based upon the following:

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<tr>
<th>Assignment</th>
<th>Weight in Final Grade (%/points)</th>
<th>Due Date/Time</th>
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<tbody>
<tr>
<td>Critique—Article Selection from Part II</td>
<td>CR/NC</td>
<td>January 10, hard copy to class or email instructor in advance of class</td>
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<td>(3 choices, ranked, include class date and author name)</td>
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<tr>
<td>Written Critique (3-4 pages)</td>
<td>20%/80 points</td>
<td>Draft written critique: 1 copy to class for personal reference on date material covered in class/beginning of class</td>
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<td>Oral Brief Presentation of Critique (3-5 minutes)</td>
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<td>Final written critique: by 2:30 pm the day following student presentation</td>
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<td>In class presentation on date material covered</td>
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<tr>
<td>Catalyst Go Post (Blog) Response on Frankenstein</td>
<td>5%/20 points</td>
<td>No later than January 24, 1:30 pm</td>
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<tr>
<td>Ethical Analysis Essay and Annotated Bibliography Topic Description</td>
<td>CR/NC</td>
<td>January 19, hard copy to class or email instructor in advance of class</td>
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Annotated Bibliography 20%/80 points  First draft: February 10, 9:30 am
Final: March 10, 9:30 am

Ethical Analysis Essay(4-5 pages) 30%/120 points  First Draft: February 24, 9:30 am
Final: March 10, 9:30 am

Class Participation 25%/100 points  Total of two excused absences permitted without penalty. See course policies for details.

Total 100%/400 points

Other important due dates:
Frankenstein Discussion—January 26

Important instructions for all papers: Format, Submission and Late Papers

All papers should be typed, double-spaced in 12-point Times New Roman font, with 1-inch margins, and must include page numbers. Unless otherwise indicated, written papers are to be delivered by Catalyst Collect-It dropbox submission at https://catalyst.uw.edu/collectit/dropbox/parkervt/13308. Points will be deducted for formatting and length, as well as spelling and grammar errors, if appropriate. In fairness to all other students, papers will receive a 2-point deduction for each day late (calculated in 24-hour periods following due date and time). Students must abide by the stated page limits to avoid penalty.

Assignments

Catalyst Go Post (Blog) Response on Frankenstein.
This assignment requires that you read Mary Shelley’s Frankenstein and join the Discussion Board [https://catalyst.uw.edu/gopost/board/amastroi/19836/] in thoughtfully responding to the question posted as well as to posted comments by at least two of your classmates. Your response is valued at 5% of your grade and is due no later than January 24 at 1:30 PM.

Critique and Brief Presentation

This assignment is a short paper that critiques one of the assigned readings. In the second class, students will each select one assigned reading from Part II of the course to critique. Final selection is subject to instructor’s permission. Papers should be at least 3 pages, and should not exceed 4 pages. The paper should consist of a very brief (no more than one short paragraph) summary of the article followed by a critique. The paper should reflect your ability to analyze critically the data and arguments presented by the author(s).

Important: Please do not conduct any additional research. You should plan on reading the article several times before writing your essay. The critique is due on the date the material is covered in class. The student is expected to make a brief (3-5 minutes) presentation of the critique to the class. As you should assume that the other students have read the material, the summary of the article should be quite brief, i.e., the focus of the paper and presentation should be your critique. This critique and brief presentation will constitute 20% of your grade (12% for written essay, 8% for oral presentation). Students may revise the written critique after class discussion and turn in the final version of the critique by 2:30 PM on the day following class discussion.
Ethical Analysis Essay

In this writing assignment, you will use either the Beauchamp and Childress principles or the Belmont Report principles, as appropriate, to analyze an ethical issue arising in public health genetics. You may select a topic of your choice arising in public health genetics or alternatively, a topic that we have discussed in class that presents an ethical dilemma. In this 4-5 page essay, you will describe the relevant facts, specify the ethical issue, describe each principle and its application to the relevant facts, discuss any areas of conflict, anticipate counter arguments, and arrive at a conclusion. If you choose an issue we have discussed in class, you may draw on readings and class discussions in developing your own argument, but you should not summarize the readings or class discussions. Refer to the “Guidelines for Ethical Analysis Essay and Annotated Bibliography” posted on the course web site for additional guidance. The Ethical Analysis Essay will constitute 30% of your grade. You must (1) identify a topic by January 19; (2) submit a first draft by Feb. 24, 9:30 AM; and (3) submit your final draft by March 10, 9:30 AM.

Annotated Bibliography

The Annotated Bibliography should present a review of the published ethics literature on an ethical issue arising in a current topic of interest in public health genetics or a topic we have discussed in class. Grading will be based on evidence of facility with diverse sources of ethics literature, ability to identify ethical issues related to the topic, and proper citation of literature. Because of the many disciplinary perspectives represented in this course, the student may choose the reference or citation format customarily used within his or her discipline, but must use it consistently. Please identify your chosen reference/citation style in your topic proposal. The Bibliography should have 8-15 cited sources. Refer to the “Guidelines for Ethical Analysis Essay and Annotated Bibliography” posted on the course web site for additional guidance. The Annotated Bibliography will constitute 20% of your grade. You must (1) identify a topic by January 19, which must be the same topic selected for the Ethical Analysis Essay; (2) submit a first draft by Feb. 10, 9:30 AM; and (3) submit your final draft by March 10, 9:30 AM.

Class Participation

This course is designed to engender active discussion of the issues. An essential component of this course will be your attendance in class and your active and voluntary participation in class discussion. The expectation is that you will attend all classes, have read the assigned readings and be prepared to engage fully in the discussion. Class participation will constitute 25% of your grade. Two excused absences will be allowed (you must notify the instructor in advance either by email, phone/voice mail, or in person); you will lose points for other absences.

COURSE OUTLINE

PART I: FOUNDATIONS—APPROACHES AND TOOLS

A. Introduction to Course
B. In-Class Exercise
D. Ethics in the Evolution of Genetics in Science and Medicine
1. Early Experiences with Testing, Screening and Counseling
2. Confronting New Technologies: Genetic Engineering

PART II: APPLICATIONS

A. Recognizing, Respecting and Protecting Interests: Individuals, Families, Communities and Populations
   1. Privacy and Confidentiality: Definitions, Limitations and Applications
   2. Genetic Counseling and Nondirectiveness
   3. Family Issues
   4. Communities, Populations and Research
   5. Challenges to Informed Consent: Testing and Children
   6. Enhancement and Prevention

B. Accounting for “Difference” in Access and Impact
   1. Gender
   2. Disability
   3. Class
   4. Race and Ethnicity

COURSE SYLLABUS

The following syllabus outlines the course and reading assignments and sets forth a preliminary timetable. It is possible that the timetable and reading assignments will be amended during the course, depending on our pace and new developments in public health genetics. However, this outline should serve as a rough guide as you plan your reading and study schedule. Please note that the reading assignments should be read prior to our coverage of that portion of the outline in class.

PART I: FOUNDATIONS—APPROACHES AND TOOLS

January 3  No Class Meeting

January 5

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<thead>
<tr>
<th>Introduction to Course</th>
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<tr>
<td>Breakout Exercise</td>
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<tr>
<td>Introduction to Bioethics Research in Public Health Genetics</td>
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<tr>
<td>Law Library Research Guide: Health Care – Substantive Medical Research</td>
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January 10 & 12


Reading Assignment:


**January 17** [No class: MLK Holiday]

**January 18**  Make-up Class (for Jan. 3)  4:00-5:00 pm  Turner Auditorium, HSD 209
2011 Charles W. Bodemer Lecture:  
**Ruth R. Faden**, PhD, MPH, Johns Hopkins Berman Institute of Bioethics  
Henrietta Lacks: Ethics at the Intersection of Health Care and Biomedical Science

Reading Assignment:

**January 19**
Ethics in the Evolution of Genetics in Science and Medicine  
Early Experiences with Testing, Screening and Counseling  
Confronting New Technologies: Genetic Engineering

Reading Assignment:

**PART II: APPLICATIONS**

**January 24**
Recognizing, Respecting and Protecting Interests: Individuals, Families, Communities and Populations  
Privacy and Confidentiality: Definitions, Limitations and Applications  
Families and Confidentiality

Reading Assignment:
You are required to read the Target article and will be assigned up to three of the commentaries (you may read all the commentaries if you are interested).  


Comment in:

- Deven McGraw, Data Identifiability and Privacy, Am J Bioeth. 2010 Sep;10(9):30-1.

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**January 26**  
Guest Discussion Leader: Kelly Edwards PhD, Dept. of Bioethics & Humanities, School of Medicine  
Applying a narrative ethics framework: Discussion of Mary Shelley’s **Frankenstein**  
Reading Assignment:

Mary Shelley’s Frankenstein  
Other Writing Assignment: **No later than January 24, 1:30 pm**, post a response to the following question and respond to at least two other student comments on the Catalyst Go Post Discussion Board  
https://catalyst.uw.edu/gopost/board/amastroi/19836/: **What lessons can researchers learn today from Frankenstein regarding ethical research practices?**
### January 31 & February 2

**Communities, Populations and Research**

**Reading Assignment:**


### February 7

**Challenges to informed consent**

**Genetic testing and children**

**Reading Assignment:**


*Each student will be assigned two of the following six position statements*

**February 9 & 14**

Enhancement and Prevention

Reading Assignment:

  - Ch. 1, section V (The Limitations of the “Therapy vs. Enhancement” Distinction) http://bioethics.georgetown.edu/pcbe/reports/beyonddiagnosis/chapter1.html#section5
  - Ch. 1, section VI (Beyond Natural Limits: Dreams of Perfection and Happiness) http://bioethics.georgetown.edu/pcbe/reports/beyonddiagnosis/chapter1.html#section6
  - Ch. 2 (Better Children) http://bioethics.georgetown.edu/pcbe/reports/beyonddiagnosis/chapter2.html

**February 16** [No class February 21: President’s Day Holiday]

Accounting for “Difference” in Access and Impact

Gender

Reading Assignment:


**February 23 & 28**

Accounting for “Difference” in Access and Impact (cont’d)

Disability

Race and Ethnicity

Reading Assignment:

- King, PA, The dangers of difference, revisited, in *The Story of Bioethics: From...*

| **March 2**  |
| Instructor-Student Meetings: Advance Sign-up |

| **March 7 & 9**  |
| In class discussions of Ethical Analysis Essays |