HCOL 185M: Controversies in Modern Genomics
Tamara Williams, Ph.D.
Fall 2014 Syllabus

Mondays, Wednesdays 4:05-5:20pm
North Complex 016

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Course Summary and Goals
Following completion of the Human Genome Project, Genomics has proven a rich source of controversy. As the applications and implications of rapid, inexpensive, and reliable whole-genome sequencing become clearer, complex ethical, moral, and practical questions emerge. Misuse and misunderstanding of the science behind Genomics has clouded conversations in the public forum and polarized topics that warrant many shades of gray. This course will focus on thoughtful, engaging, and open-minded discussions of current controversies involving Genomics (the study of the structure, function, and evolution of an organism’s entire genome) and Genetics (the study of specific gene function and inheritance). Students are expected to actively participate and prepare for each class through critical review of assigned scientific literature, documentaries, public policy reports and documents, news articles, and other media. There is no pre-requisite knowledge of Genetics or Genomics. Evaluation will include preparing for and actively engaging in class discussions and projects, composing thoughtful reflection papers and a midterm paper, and crafting a well-sourced final research report and presenting findings as part of an expert team panel to the class for discussion.

Course Learning Objectives
Throughout this course, students will:
• Engage in thought-provoking discussions with classmates and instructor
• Increase familiarity and awareness of controversies in Genomics/Genetics
• Develop skills to critically interpret scientific literature, policy documents, and mass media coverage of topics in Genomics/Genetics
• Expand appreciation for the ways in which science affects society and society affects science
• Practice working in groups to dissect a topic of interest into its scientific, ethical, and social implications
Skills developed in this course include:
- Articulate an argument or position and respectfully listen to and understand arguments or positions of others
- Write concise and thoughtful prose reflecting on complex topics spanning science, ethics, and society
- Conduct literature research to form and support positions
- Work individually and collaboratively to complete projects
- Increase comfort and skill with oral presentation
- Challenge previous notions and impressions held through curious learning

**Required Text**

(available through most online book sellers including amazon.com and bn.com and in e-book format)

**Blackboard**
Assigned reading and viewing materials, excluding text chapters, will be provided on Blackboard either by PDF attachment or web link. Please use Blackboard for updated reading/viewing materials as changes may occur to the listed course schedule included in this syllabus. Assignments must be uploaded to Blackboard by the listed deadline. Please contact me prior to the deadline if you are not able to upload an assignment to Blackboard so we can make other arrangements.

**Attendance Policy**
Given the importance of active discussion in attaining the goals of the class, attendance is mandatory. Students must notify me of any University-approved absences prior to class when possible. Any student with three or more unexcused absences will receive a failing grade.

**Grading Criteria**
100 points total shall be earned as follows:
- 20 points- Class participation
- 20 points- 4 Reflection papers
- 20 points- Midterm paper
- 5 points- Research report proposal (25% individual score, 75% team score)
- 5 points- Participation in peer review of report proposals
- 10 points- Panel presentation and discussion (50% team score, 50% individual score)
- 20 points- Final research report (75% individual score, 25% team score)
Assignments

- Reflection Papers: Four, 2-3 page papers (excluding cover page and bibliography) summarizing the student's thoughts, perceptions, and lingering questions on any topic discussed in class within its section (Life, Health, Ethics, and Society). Must cite at least 3 relevant and legitimate sources.
- Midterm Paper: 4-6 page paper (excluding cover page and bibliography) citing reputable sources exploring the science, ethics, and social implications of a controversy in Genomics/Genetics. Must cite at least 5 relevant and legitimate sources.
- Final Project: Students will work in teams of 3 to research a controversial Genomics/Genetics topic with each student taking the lead in one aspect of the controversy. Groups must cover the science and technology involved, ethical considerations, and its impact on society. Individual and team grades will be given for the proposal, the final report and the panel presentation. Individual grades will be given for providing peer review of other teams’ proposals.
  - **Report Proposal:** Each team will submit a proposal for their report in outline format, identifying the key aspects that will be covered in the final report and presentation (details provided in the assignment description).
  - **Peer Review:** Proposals will be reviewed by the instructor but also will be reviewed by classmates as part of a peer review process. Each student will review and provide feedback on the other teams’ proposals.
  - **Final Report:** Each student will independently contribute a 4-6 page section of the final report based on the aspect of the controversy he or she researched for the team project, citing at least 5 relevant and legitimate sources. The team will collaboratively write the Executive Summary, Introduction, and Conclusion sections.
  - **Panel Presentation:** Each team will form an expert panel and lead a class discussion on the scientific, ethical, and societal considerations of the selected topic. Students will receive copies of each team's final report to read prior to the class discussion to enable an engaging and well-informed dialogue.

Classroom Environment Expectations

Each student is expected to:
- Actively and thoughtfully participate in class discussions
- Treat others in the class with respect and dignity
- Complete assigned reading materials prior to class
- Turn in assignments on time
- Seek out assistance from me or from classmates when needed
- Behave with academic honesty and honor
- Show up for class on time
- Silence cell phones and put away laptops while in class
UVM Libraries Liaison for Honors College Students

For assistance with library services and for support in research for Honors College courses, please contact Patricia Mardeusz.

Patricia Mardeusz
Library Associate Professor
Information & Instruction Services
802.656.5718
patricia.mardeusz@uvm.edu
Course Schedule
- Subject to change- please reference Blackboard for updates and links to reading/viewing materials
- All assignments will be turned in via Blackboard unless otherwise instructed

INTRODUCTION
- **Monday, August 25**: Course Introduction
  *Objectives*
  - Introductions by students and professor
  - Discuss syllabus, course objectives and expectations

- **Wednesday, August 27**: The American Eugenics Movement- Historical Misuse of Genetics
  *Objectives*
  - Provide context for modern controversies in genomics by exploring the history of American eugenics
  - Discuss impact and influence of the American Eugenics Movement

  *Required Reading / Viewing (completed prior to class)*
  - *Handbook of genetics and society: Mapping the new genomic era.*
    - Chapter 30 Eugenics (Koch, L.); pp 437-447.
  - Review the site hosting Vermont Eugenics: A Documentary History <http://www.uvm.edu/~eugenics/>.

LIFE
- **Wednesday, September 3**: Cloning
  *Objectives*
  - Review briefly the basic science of cloning
  - Discuss the pros and cons of human cloning
  - Consider ethical and moral issues
  - Discern fact from fiction in popular perceptions of cloning

  *Required Reading/ Viewing (completed prior to class)*
- *Handbook of genetics and society: Mapping the new genomic era.*
  - Chapter 15 Human genetics and cloning in the media - Mapping the research field (Haran, J. and Kitzinger, J.); pp 203-221.

**Assignment Due**
- (Optional and ungraded) Practice Reflection Paper - Students wishing for ungraded feedback on writing may submit a Reflection Paper on Eugenics

- **Monday, September 8:** Designed Life and Synthetic Life
  **Objectives**
  - Review basics of the science of synthetic life
  - Continue discussion on cloning with respect to “designer babies” concept
  - Discuss impact of synthetic life on science and society
  **Required Reading/ Viewing (completed prior to class)**
  - TED Talk (November 2010). “Paul Root Wolpe: It's time to question bio-engineering”.
  - TED Talk (May 2010). “Craig Venter unveils ‘synthetic life’”.
  - Executive Summary pages 1-18 of The Presidential Commission for the Study of Bioethical Issues (December 2010) "NEW DIRECTIONS- The Ethics of Synthetic Biology and Emerging Technologies". Washington, D.C.

- **Wednesday, September 10:** Genetically Modified Organisms (GMO)
  **Objectives**
  - Review basics of the technologies and applications of genetic modification of organisms
  - Describe scientifically-based pros and cons to GMOs
  - Discuss both popular and personal perceptions of GMOs
  **Required Reading/ Viewing (completed prior to class)**
  - *Handbook of genetics and society: Mapping the new genomic era.*
    - Chapter 9 Making Europe unsafe for agbiotech (Levidow, L.); pp 110-126.
World Health Organization "20 Questions on Genetically Modified (GM) Foods".

- **Monday, September 15**: Genetically Modified Organisms (GMO) II, Guest Speaker

  **Objectives**
  - Engage with speaker on the pros and cons of labeling GM foods in Vermont
  - Understand the broader implications of Vermont's labeling law nationwide
  - Learn about the process of political and social advocacy

  **Required Reading/Viewing (completed prior to class)**

**HEALTH**

- **Wednesday, September 17**: Genomics and the Healthcare Industry- Guest Lecturer

  Mr. Alan French, Vice President Campbell Alliance

  **Objectives**
  - Engage with guest lecturer on genetics and the pharmaceutical industry
  - Discuss drug development and pricing for the niche of genetic diseases

  **Required Reading/Viewing (completed prior to class)**
  - *Handbook of genetics and society: Mapping the new genomic era.*
    - Chapter 11 On a critical path: genomics, the crisis of pharmaceutical productivity and the search for sustainability (Martin, P., et al.); pp 145-162.
  - Cracking Your Genetic Code. NOVA Special documentary, Air date 03/28/12 http://www.pbs.org/wgbh/nova/body/cracking-your-genetic-code.html

  **Assignment Due**
  - Reflection Paper #1 (Life) due September 17 by 3pm

- **Monday, September 22**: Genomics and Healthcare

  **Objectives**
  - Review the role of genomics in disease diagnosis and treatment
  - Discuss the potential and limitations of personalized medicine
  - Discuss cultural and social stigma of genetic disease
  - Five students present 5-minute Executive Summary of Reflection Paper #1
Required Reading/Viewing (completed prior to class)
- *Handbook of genetics and society: Mapping the new genomic era.*
  - Chapter 6 Localising genetic testing and screening in Cyprus and Germany: contingencies, continuities, ordering effects, and biocultural intimacy (Beck, S. and Niewohner, J.); pp 76-93.
- TEDMED (2010) “Greg Lucier, CEO Life Technologies”

- **Wednesday, September 24:** Genetic Testing, Guest Speaker Dr. Leah Burke, Clinical Geneticist, Director, Vermont Regional Genetics Center, Fletcher Allen Healthcare
  **Objectives**
  - Understand the differences between genetic disease and genetic susceptibility
  - Discuss the impact and implications of increasing genetic testing on disease diagnosis, treatment, and prevention
  - Discuss issues related to genetic testing interpretation and cost

Required Reading/Viewing (completed prior to class)
  http://www.wbur.org/npr/149804404/n-y-preschool-starts-dna-testing-for-admission
- TEDMED (2009) “Anne Wojcicki, CEO of 23andMe”

Assignment Due
- **One page brief outline for Midterm Paper topic due no later than September 24 by 3pm**

- **Monday, September 29:** Personal Genomics
  **Objectives**
  - Review concepts of personal genomics and how it is being used today
Discuss what personal genomics does and does not tell us about ourselves

**Required Reading/Viewing (completed prior to class)**

- Handbook of genetics and society: Mapping the new genomic era.
  - Chapter 7: Nutrigenomics (Chadwick, R.); pp 94-104.
- Nordgren, A. (2012). Neither as harmful as feared by critics nor as empowering as promised by providers: risk information offered direct to consumer by personal genomics companies. *Journal of Community Genetics* 22 March 2012.

### Wednesday, October 1: Final Report Proposal Workshop

**Objectives**

- Five students present 5-minute Executive Summary of Reflection Paper #2
- Work in Final Report teams to develop proposals

**Assignment Due**

- Reflection Paper #2 (Health) due October 1 by 3pm

### ETHICS

**Monday, October 6: Politics and Public Policy of Genomics**

**Objectives**

- Introduce public policy and laws designed to protect genetic rights
- Discuss the impact of GINA on society
- Discuss the ethical implications of genetic testing in criminal justice

**Required Reading/Viewing (completed prior to class)**

- (For use as a reference only, no need to read in its entirety) House Resolution (HR-493): Genetic Nondiscrimination Act of 2008.
- Genetic Alliance, the Genetics and Public Policy Center at the Johns Hopkins University, and the National Coalition for Health Professional Education in Genetics. (2010). “Understanding GINA”.
• **Wednesday, October 8**: Use of Genetic Information I, Guest Speaker, Dr. Robert Macauley, Medical Director, Clinical Ethics, Fletcher Allen Health Care

*Objectives*
- Understand how genetic information could be used in other contexts outside of healthcare planning
- Discuss the ethics behind current and potential uses of genetic information
- Understand the importance of genetic information privacy, issues of confidentiality, stigmatization, and the psychological impact of learning about your own genetic makeup

*Required Reading/Viewing (completed prior to class)*

*Assignment Due*
- **Midterm Paper due October 8 by 3pm**

• **Monday, October 13**: Use of Genetic Information II

*Objectives*
- Continue discussion on the ethics behind current and potential uses of genetic information
- Discuss the implications of genetic information in sports and in criminal justice

*Required Reading/Viewing (completed prior to class)*
- Handbook of genetics and society: Mapping the new genomic era.
  - Chapter 20 Forensic DNA databases and biolegality: the co-production of law, surveillance technology and suspect bodies (Lynch, M. and McNally, R.); pp 283-301.

• **Wednesday, October 15**: Genetic "Enhancement"
Objectives
- Review the basic science behind inheritable genetic modification
- Discuss the potential impact of genetic modification on society
- Discuss the ethical concerns related to genetic “enhancement”

Required Reading/Viewing (completed prior to class)
- *Handbook of genetics and society: Mapping the new genomic era.*
  - Chapter 24 Bioethics and human genetic engineering (Evans, J. and Schairer, C.); pp 349-366.
  - http://www.genome.gov/10004767
- Center for Genetics and Society (2006). "Inheritable Genetic Modification Basic Science".
- Center for Genetics and Society (2006). "Inheritable Genetic Modification Arguments Pro and Con".

Assignment Due
- Final Report Proposal due October 15 by 3pm

Monday, October 20: Peer Review of Research Panel Proposals I

Objective
- Engage in groups to review research panel proposals

Required Reading/Viewing (completed prior to class)
- Read assigned set #1 team research proposals posted on Blackboard

Assignment Due
- Come to class with at least 2 questions or comments for each proposal in set #1

Wednesday, October 22: Peer Review of Research Panel Proposals II

Objective
- Engage in groups to review research panel proposals

Required Reading/Viewing (completed prior to class)
- Read assigned set #2 team research proposals posted on Blackboard

Assignment Due
- Come to class with at least 2 questions or comments for each proposal in set #2
• **Monday, October 27:** Genetic Influence of Human Behavior

*Objectives*
- Review evidence of genetic influence of behavior
- Discuss the implications of genetic influence on mental illness, addiction, and personality
- Five students present 5-minute Executive Summary of Reflection Paper #3

*Required Reading/Viewing (completed prior to class)*
- Videos of Kay Jamison in DNAinteractive Chronicle “Living with Eugenics”.

*Assignment Due*
- **Reflection Paper #3 (Ethics) due October 27 by 3pm**

• **Wednesday, October 29:** Human Evolution

*Objectives*
- Discuss implications of evolution and natural selection on society
- Discuss the role of positive selection in characterizing human-ness

*Required Reading/Viewing (completed prior to class)*
- TEDMED Talk (2012) “Dr. Jay Lombard”

• **Monday, November 3:** Human Evolution II and Genetic Influence of Human Behavior

*Objectives*
- Engage with class regarding human evolution and the genetics of addiction
- Discuss the role of positive selection in characterizing human-ness
- Discuss the implications of genetic influence of addiction

*Required Reading/Viewing (completed prior to class)*
• TED Talk (April 2012). “Juan Enriquez: Will our kids be a different species?”.

**Wednesday, November 5:** Genetic Influence of Human Behavior II

**Objectives**
- Review evidence of genetic influence of behavior
- Discuss the implications of genetic influence on sexual orientation, risk-taking, musical ability, and political beliefs

**Required Reading/Viewing (completed prior to class)**

**Monday, November 10:** Workshop on Final Reports

**Objectives**
- Work in teams to finalize report
- Check in with instructor for guidance on any questions related to the final report
- Four students present 5-minute Executive Summary of Reflection Paper #4

**Assignment Due**
- **Reflection Paper #4 (Society) due November 10 by 3pm**

**CONCLUSIONS**

**Wednesday, November 12:** Panel Presentations (Groups 1-2)

**Objectives**
- Groups 1-2 present final report findings
- Engage with students in expert panels to deepen discussion

**Required Reading**
- Final reports from Groups 1-2

**Assignment Due**
- **Create at least one question to ask each of the expert panels presenting**
- **Final Report due November 11 by 11:59pm**

**Monday, November 17:** No class session
• **Wednesday, November 19:** Panel Presentations (Groups 3-4)
  
  **Objectives**
  - Groups 3-4 present final report findings
  - Engage with students in expert panels to deepen discussion
  
  **Required Reading**
  - Final reports from Groups 3-4
  
  **Assignment Due**
  - **Create at least one question to ask each of the expert panels presenting**

• **Thanksgiving Break November 24-28**

• **Monday, December 1:** Panel Presentations (Group 5-6)
  
  **Objectives**
  - Groups 5-6 present final report findings
  - Engage with students in the expert panel to deepen discussion
  
  **Required Reading**
  - Final report from Groups 5-6
  
  **Assignment Due**
  - **Create at least one question to ask the expert panel presenting**

• **Wednesday, December 3:** Class Conclusion
  
  **Objectives**
  - Review course
**Student Learning Accommodations:** In keeping with University policy, any student with a documented disability interested in utilizing accommodations should contact ACCESS, the office of Disability Services on campus. ACCESS works with students to create reasonable and appropriate accommodations via an accommodation letter to their professors as early as possible each semester. Contact ACCESS: A170 Living/Learning Center; 802-656-7753; access@uvm.edu; www.uvm.edu/access

UVM’s policy on disability certification and student support:
www.uvm.edu/~uvmppg/ppg/student/disability.pdf

**Religious Holidays:** Students have the right to practice the religion of their choice. If you need to miss class to observe a religious holiday, please submit the dates of your absence to me in writing by the end of the second full week of classes. You will be permitted to make up work within a mutually agreed-upon time.

**Academic Integrity:** The policy addresses plagiarism, fabrication, collusion, and cheating. www.uvm.edu/~uvmppg/ppg/student/acadintegrity.pdf

**Grade Appeals:** If you would like to contest a grade, please follow the procedures outlined in this policy: www.uvm.edu/~uvmppg/ppg/student/gradeappeals.pdf

**Code of Student Rights and Responsibilities:**
www.uvm.edu/~uvmppg/ppg/student/studentcode.pdf

**FERPA Rights Disclosure:** The purpose of this policy is to communicate the rights of students regarding access to, and privacy of their student educational records as provided for in the Family Educational Rights and Privacy Act (FERPA) of 1974. http://www.uvm.edu/~uvmppg/ppg/student/ferpa.pdf

**Promoting Health & Safety:**
The University of Vermont's number one priority is to support a healthy and safe community:

- **Center for Health and Wellbeing** http://www.uvm.edu/~chwb/
- **Counseling & Psychiatry Services (CAPS)** Phone: (802) 656-3340
- **C.A.R.E.** If you are concerned about a UVM community member or are concerned about a specific event, we encourage you to contact the Dean of Students Office (802-656-3380). If you would like to remain anonymous, you can report your concerns online by visiting the Dean of Students website at http://www.uvm.edu/~dos/