GENE 220: Introduction to Genetics, Ethics, and Society

Syllabus Spring 2024

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Faculty Sponsors: Dr. Julie Baker, Dr. Daphne Martschenko

Class meetings: Wednesdays 11:30am-1:20 pm, LKSC 308

Office hours: Please email one of the instructors to schedule.

Syllabus Contents

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Course Information

Learning Goals

By the end of this course, students will develop the skills to appreciate, articulate and address ethical, legal and social issues in genetics research and society.

Course Description

Focus is on examining the past, present, and future relationship between human genetics and society to evaluate the ethical implications of the research we conduct. Students will reflect on their personal roles and biases in order to develop the tools needed to conduct equitable, just, and inclusive research. Topics include the intersection between science and society; history of American eugenics; community-engaged research; race, ancestry, and identity; forensic genetics; behavioral genetics; and reproductive genetics. Preference to graduate students and postdocs working with genetic technologies or concepts. Formerly offered as BIOS 232.

Motivation

We are witnessing an astonishingly rapid development of technologies to measure, model, and manipulate our biological selves and environment, many of which are minimally regulated. We see a corresponding rise in powerful actors seeking to misuse genetic research to embolden racist, sexist, transphobic, and ableist ideology. Without formal training, students lack knowledge about the historical context and ethical frameworks of genetics research, both of which are key to enabling geneticists to interrogate their own biases, and responsibly conduct and communicate their research.

Course Materials

All course readings and content will be posted to Canvas; no materials will need to be purchased.

Grading

Our grading philosophy reflects our expectations of you: to show up, stay engaged, and help us create the best learning experience for you and your classmates. This course is offered on a credit/no-credit (CR/NC) basis; in order to receive credit, we expect that you:

- Attend at least 80% of the class sessions (8/10 classes)
- Complete at least 80% of all homework assignments
- Participate and complete the group project

This grading allows for flexibility for you as a student in cases of emergency, but we expect that students will attend all classes. If any extenuating circumstances arise, please reach out to us, and we will work with you to best accommodate your needs.

Expectations

What you can expect from us

- We will welcome questions, concerns, and general feedback.
- We will be responsive via email in a timely manner to students. Whenever you email us, please make sure to CC at least two instructors, so we can get back to you as soon as possible.
- We will provide additional (optional) readings and other resources if you wish to continue thinking and learning about these topics.
- We will guide class discussions in a manner that promotes compassionate, respectful, and open-minded discussion.
- We commit to ensuring an inclusive space and positive classroom environment.

What we expect from you

Attendance

 We ask that you attend every session. In the event you are unable to attend a session due to unforeseen circumstances, please contact two of the TA's by email.

• In-class participation

 A significant portion of your learning will come from class discussions. We expect everyone to participate in a manner that is consistent with the classroom norms we collectively establish in our first session.

Laptop policy

To promote active and engaged learning, we ask that you not use laptops or smartphones during class to limit distractions. All course materials will be posted to Canvas for you to review at your leisure so there is no need to take extensive notes. Notebooks and iPads are welcome for note taking.

Homework assignments

After each class, you will be expected to complete a short assignment asking you to: (1) comment on the reading for the next class, and (3) submit any questions you have about the next class's topic. Depending on the week you will also have a short reflection question on the previous class material or group project worksheets (but never both). The homework will be posted on Canvas by Wednesday, 5pm, and is due Mondays at 11:59pm. This homework will be graded on completion.

Group Project

 Everyone is expected to participate in the group project and work collaboratively with your classmates. For more details, see the Group Project section.

Honor code

 We expect you to follow the Stanford Honor Code. For more information please see here.

Group Project

- You will have an opportunity to further explore ethical considerations in a specific area of genetics research, or applications of genetics in society. In a group, you will identify a specific issue, formulate a potential solution, and craft a plan to implement that solution.
- This will be broken down into **3 worksheets** to be completed together by your group and submitted via Canvas, and **1 group presentation** to share your learnings over the 3 worksheets with the class.
- You are not expected to execute your solution over the course of the class. Rather, this
 group project is intended to be a tool for exploration to support your learning. If you
 wish to implement your group project after completion of this class, we are committed
 to providing support and directing you to further resources.

Communication with teaching team

- Please email us with any questions or concerns. To help us get back to you within 2 business days, please always email at least two instructors. Don't hesitate to follow up if you haven't heard from us!
- Please direct questions for the following topics to the following instructors:
 - Homework, readings, attendance, Canvas
 - Angela Hickey and Egor Lappo
 - Archives session
 - Alvina Adimoelja and Angela Hickey
 - Group project
 - Alvina Adimoelja and Tami Gjorgjieva
 - All other questions
 - Alvina Adimoelja and Tami Gjorgjieva

Schedule

Our current schedule is below. There may be minor changes if any circumstances arise.

Note: All reading/videos will be available on Canvas

Session 1: Course Introduction and Introduction to Genetics, Bioethics, and ELSI

April 3rd, 2024

Facilitated by Tami Gjorgjieva and Alvina Adimoelja

Learning objectives

- Develop a shared understanding of the class' scope, tone, learning objectives, and expectations, as well as a sense of collaboration in achieving learning objectives.
- Understand key concepts in genetics; get familiar with the four principles of bioethics; appreciate bioethical relativism; and get familiar with research methods in ethical, legal and social implications (ELSI) of genetics.

Pre-class reading: Science under the scope (Available on Canvas)

Homework: Homework Assignment 1 (Due April 8th, 2024 11:59PM)

Session 2: History of Eugenics

April 10th, 2024

Facilitated by Angela Hickey and Egor Lappo

Learning objectives

- Understand the timeline of the eugenics movement and appreciate the role of American eugenicists in legitimizing eugenic beliefs and actions.
- Interrogate eugenic beliefs perpetuated in present-day research and society.

Pre-class reading: The origins of eugenics in America clip from PBS

Homework: Homework Assignment 2 (Due April 15th, 2024 11:59PM)

Session 3: Race and Ethnicity, Introduction to Group Project

April 17th, 2024

Facilitated by Alvina Adimoelja

Guest lecture by Dr. Jonathan Rosa

Learning objectives

- Appreciate that race is socially constructed and scientifically fraudulent, yet has significant consequences in science and society.
- Understand the goals and expectations of the group project.

Pre-class reading: Graves & Goodman Introduction (pg3-7); Available on Canvas)

Homework: Homework Assignment 3 (Due April 22nd, 2024 11:59PM)

Session 4: Behavioral Genetics and Argumentation Workshop I

April 24th, 2024
Facilitated by Egor Lappo and Tami Gjorgjieva
Lecture by Dr. Daphne Martschenko

Learning objectives

- Examine the ELSI issues in behavioral genetics, as it relates to the field's past, present, and future.
- Develop skills for choosing, building and delivering strong, layered and compelling arguments.

Pre-class reading: Genomics, Behavior and Social Outcomes

Homework: Homework Assignment 4 (Due April 29th, 2024 11:59PM)

Session 5: Population Descriptors in Research

May 1st, 2024 Facilitated by Alvina Adimoelja Guest lecture by Dr. Gen Wojcik

Learning objectives

- Define genetic ancestry, and discuss how it is used in genetics research and consumer genetics.
- Appreciate the importance of studying diverse populations, and articulate best practices for the use of population descriptors in research studies.

Pre-class reading: The National Academies of Science, Engineering, and Medicine (NASEM) report (pg 1-5 only; Available on Canvas)

Homework: Homework Assignment 5; Group Project Worksheet 1 (May 6th, 2024 11:59PM)

Session 6: Community Engagement

May 8th, 2024 Facilitated by Angela Hickey Guest lecture by Dr. Joanne Tien

Learning objectives

- Discuss the value, opportunities, and downfalls of community engaged research, both generally and in human genetics.
- Learn how to consider various aspects and nuances of designing community-engaged research studies.

Pre-class reading: NYT Blood Journey (video)

Homework: Homework Assignment 6; Group Project Worksheet 2 (Due May 13th, 2024 11:59PM)

Session 7: Prenatal Testing and Direct-To-Consumer (DTC) Genetics

May 15th, 2024
Facilitated by Angela Hickey
Lecture by Dr. Daphne Martschenko

Learning objectives

- Summarize different types of routine prenatal genetic testing (including their timelines, results, and accessibilities), and explore the role of eugenics in this field.
- Describe the landscape and availability of consumer genetic products, and examine their ethical, legal and social implications.

Pre-class reading: The Last Children of Down Syndrome - Atlantic Article (Available on Canvas) Homework: Homework Assignment 7; Reading response (Due May 20th, 2024 11:59PM)

Session 8: CRISPR, Biotech, and Forensics

May 22nd, 2024 Facilitated by Paloma Ruiz and Egor Lappo

Learning objectives

- Understand how genetics is used in forensics, and discuss the main implications of using genetic evidence in forensics and privacy contexts.
- To reflect on how the "discovery" of revolutionary technologies, such as CRISPR, lead to ethical discussions on scientific ownership and the broad applications that such technologies can be utilized for.

Pre-class reading: <u>"The Creepy Genetics Behind the Golden State Killer Case" Wired Article</u> Homework: Homework Assignment 8; Group Project Worksheet 3 (Due May 27th, 2024 11:59PM)

Session 9: Genetics and Law, Argumentation Workshop II, and Closing Reflections

May 29th, 2024 Facilitated by Tami Gjorgjieva

Learning objectives

- Appreciate the relationship between genetics and the law, and be able to discuss examples from gene patenting, genetic discrimination and the use of genetic evidence in courts.
- Reflect on the learning arc and key takeaways from this class, and appreciate the abundance of topics that we didn't get a chance to cover.

Pre-class reading: <u>TED Talk by Tania Simoncelli, Should you be able to patent a human gene?</u> Homework: Homework Assignment 9 (Due June 3rd, 2024 11:59PM)

Session 10: Group Project Presentations

June 5th, 2024 Facilitated by Alvina Adimoelja and Tami Gjorgjieva

Learning objectives

Be inspired by the amazing work and ideas of your classmates!

Respect for Diversity and Commitment to Inclusion

Academic Accommodations

Stanford is committed to providing equal educational opportunities for disabled students. Disabled students are a valued and essential part of the Stanford community. We welcome you to our class, and we are committed to supporting your learning. If you experience disability, please register with the Office of Accessible Education (OAE). Professional staff will evaluate your needs, support appropriate and reasonable accommodations, and prepare an Academic Accommodation Letter for faculty. To get started, or to re-initiate services, please visit oae.stanford.edu.

If you already have an Academic Accommodation Letter, we invite you to share your letter with us. Academic Accommodation Letters should be shared at the earliest possible opportunity so we may partner with you and OAE to identify any barriers to access and inclusion that might be encountered in your experience of this course.

Content Considerations

As an ethics course, we will be discussing content that can be emotionally difficult. These topics can include, but are not limited to: race, class, and gender issues; genocide; eugenics; criminal justice; policing; prenatal testing; pregnancy termination; and forced sterilization. Being able to learn about and discuss uncomfortable topics is an important part of learning in this

course, but if engaging with specific content is so traumatic you cannot learn or be present, please let us know beforehand for accommodations. Likewise, if you become so distressed you need to leave a class, reach out to us afterwards for accommodations. We emphasize the importance of taking care of yourself and support you leaving a lesson that causes serious distress. Please reach out afterwards to let us know that you left class and so that we can check in on your well-being. In addition, we welcome feedback on how to better present this material or provide content warnings for students that may struggle in the future.

Name and Pronouns

If your name is different than on Canvas, feel free to reach out to us beforehand to notify us. We are committed to referring to you with the correct name and pronoun, and please feel free to correct us if we make a mistake or mispronounce your names. We promise during the first class to have everyone share their names and pronouns.

Additional Resources

These resources, primarily compiled by the Biosciences Department, are intended to show you further avenues of support. If you have any questions, or want help with further resources, please reach out to us, The Graduate Life Office (GLO: 650-723-7288), or the Biosciences Office of Graduate Education (OGE: oge-helpme@stanford.edu)

Diversity Resources

Diversity Resources and Organizations:
 https://biosciences.stanford.edu/current-students/diversity/diversity-resources-and-partnerships/

Academic Resources

 Academic Resources and Assistance: https://biosciences.stanford.edu/current-students/resources/academic-resources-and-assistance

Wellness Resources

- Health and wellness resources:
 https://biosciences.stanford.edu/current-students/resources/health-and-wellness-resources/
- Counseling & Psychological Services (CAPS) for urgent and non-urgent support: https://vaden.stanford.edu/caps (650-723-3785)
- National Suicide Prevention Lifeline: 1-800-273-8255 (24/7)

- The Trevor Project: 866-488-7386 (24/7)
- Crisis Text Line: Text SUPPORT to 741-741
- National Alliance on Mental Illness: 1-800-950-6264
- Native American Suicide Prevention Helpline operated by SAMHSA (800-273-8255)

Financial Resources

- Students should not have any financial costs associated with this class. If you notice
 there are any financial costs that arise related to this course, please reach out to a
 primary instructor.
- Financial Resources and Assistance: https://biosciences.stanford.edu/current-students/resources/financial/