GENE 220: Introduction to Genetics, Ethics, and Society

Syllabus Spring 2023

Primary Instructors: Roshni Patel (rpatel7) and Rachel Ungar (raungar) @stanford.edu
Secondary Instructors: Alanna Pyke, Alvina Adimoelja, Anjali Narain, Justin Gomez-Stafford, and Naiomi Hunter
Faculty Sponsor: Julie Baker
Class meetings: Wednesdays 1:30-3:20 pm, LKSC 209
Office hours: please email Roshni or Rachel to schedule

Syllabus Contents

Course Information

Course Overview

This mini-course will introduce concepts at the intersection of genetics, ethics, and society. This course will be composed of six sessions spread out over three weeks. Before each session, you can expect to spend approximately 30 minutes completing pre-class readings or other minor assignments. Each session will consist of short in-class lectures paired with both small-group and large-group discussions.

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.

Learning Goals

We hope this course will enable students to evaluate the ethical implications of scientific research and innovate just and equitable solutions. Specifically, by the end of this class, you will be able to:

1. Connect the historical context of genetics research to its modern-day practice
2. Evaluate the social and ethical implications of genetics research
3. Analyze how societal norms and structures, along with personal identities, biases, and responsibility, impact the conduct of scientific research

Course Materials

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

Grading

Our intention behind grades in this course is to encourage you to attend each session. This course is offered on a credit/no-credit basis, and attendance at 8 out of 10 sessions is required to pass. This grading allows for flexibility for you as a student in cases of emergency, but we expect that students will attend all classes.

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
- We will provide additional (optional) readings and other resources if you wish to continue thinking and learning about these topics
- We understand that you come from a variety of diverse backgrounds and commitments outside of class, and may have unforeseen circumstances that require you to miss class
- We will guide class 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

- Pre-class assignments - We will provide readings, and on occasion, exercises, to complete prior to each session. You will not be graded on completion, but the readings and exercises are crucial for participating in discussions and making the most of this course!
- Attendance - We ask that you attend every session, given how short this course is. In the event you are unable to attend a session due to unforeseen circumstances, please contact Rachel or Roshni.
- In-class participation - A significant portion of your learning will come from small group discussions. We expect everyone to participate in a manner that is consistent with the classroom norms we collectively establish in our first session.
- Honor code - We expect you to follow the Stanford Honor Code. For more information please see here.

Schedule

A list of our schedule is below. This is subject to potential changes prior to the course.

Session 1: Course Introduction and History of Genetics

Facilitated by Alanna Pyke and Justin Gomez-Stafford

Learning objectives

- Co-create ground norms for discussions throughout the course by sharing personal identities and experiences
- Understand how societal biases intersected with genetic research and medicine through the 20th century.

Session 2: Introduction to Bioethics, Social Responsibility, and Community Engagement

Facilitated by Alanna Pyke and Naiomi Hunter
Guest lecture by Dr. Daphne Martschenko

Learning objectives

- Describe the four principles of bioethics and apply them to case studies
- Identify shortcomings of the four principle of bioethics
- Understand the benefits of social responsibility and community-engaged research

Session 3: Race, Ancestry, Genetics Part 1

Facilitated by Anjali Narain, Justin Gomez-Stafford, and Roshni Patel

Learning objectives

- Distinguish between race, ethnicity, ancestry, and nationality.
- Differentiate between social identity and genetic ancestry, and in particular, understand how social identity is (often) discretized, while genetic ancestry is a continuum.
- Discuss the history of eugenics and medical mistrust among racial/ethnic groups through discussions of historical cases/events, such as the case of Henrietta Lacks.
- Understand how race/ethnicity becomes biological through the effects of racism and how this is relevant for genetic medicine and research.

Session 4: Race, Ancestry, Genetics Part 2

Facilitated by Anjali Narain, Justin Gomez-Stafford, and Roshni Patel

Learning objectives

- Describe societal perceptions of social identity (race, ethnicity, and nationality) and genetic ancestry, including racial essentialism.
- Examine the consequences that these societal perceptions of social identity and genetic ancestry have on individuals and society broadly.
- Critique scientific uses of social identity (race, ethnicity, and nationality) and genetic ancestry

Session 5: Behavior and Genetic Determinism

Facilitated by Naiomi Hunter and Alvina Adimoelja
Guest lecture by Dr. Daphne Martschenko

Learning objectives

- Recognize how genetics research can be weaponized to justify harmful (e.g. racist and ableist) viewpoints via genetic determinism and the associated harms
- Describe current efforts by the research community to combat the weaponization of research, and articulate strategies that individual scientists can employ

Session 6: Sex and Gender; Ability

Facilitated by Alvina Adimoelja and Justin Gomez-Stafford

Learning objectives

- Distinguish the relationship between biological sex, gender identity, and sexuality through discussion of the role genetics plays in these concepts.
- Examine the medicalization (called a disorder) of identities and how it impacts society, medicine, and research.
- Critique genetics studies and practices from a disability-rights perspective

Session 7: Screening and Selection

Facilitated by Anjali Narain and Alvina Adimoelja

Learning objectives

- Understand the role of eugenics in the development of the prenatal genetic testing field
- Summarize the current landscape of prenatal genetic testing, carrier screening, embryo selection and gene editing
- Extrapolate the current and future implications of the currently available technologies with a focus on reproductive choice and disability rights
- Evaluate how ethics can help guide society towards ethical application of these technologies

Session 8: Identification and Privacy

Facilitated by Alanna Pyke and Naiomi Hunter

Learning objectives

- Identify key stakeholders and evaluate conflicts of stakeholdership in the collection, use, and analysis of human genetic data
- Analyze the role that government and public databases play in the application of forensic genetics in the criminal justice system
- Examine risks and benefits of identification and privacy

Session 9: Self Reflection and Action

Facilitated by Naiomi Hunter and Alvina Adimoelja

Learning objectives

- Evaluate your own positionality and its relationship to your work as a scientist
- Construct and reflect on viewpoints that recognise and relate to different positionalities
- Ideate ways to make existing academic structures more equitable, inclusive, and just, and create actionable goals to do so

Session 10: Genetics in the Archives

Facilitated by Roshni Patel and Rachel Ungar

Learning objectives

- Understand how individuals acted to counter the misuse of genetics research to further racist and sexist ideologies
- Connect historical examples of ethical problems to the modern-day case studies presented in this course
- Analyze how scientists' ideologies impacted their interpretation of science

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 (Roshni or Rachel).
- Financial Resources and Assistance: https://biosciences.stanford.edu/current-students/resources/financial/