**Precision Medicine: Science, Ethics, and Culture**

**CPLS 3965**

**Fall 2024**

**Professors**: Dr. Rachel Adams (English), Dr. Maya Sabatello (Medicine, Medical Humanities & Ethics), Dr. Samuel Sternberg (Biochemistry and Molecular Biophysics)

**Class time:** Tuesday, 4:10-6:00 PM, 301 Fayerweather Hall

**Office Hours:**

Rachel Adams Monday 12:30-2:00 PM and Thursday 2:30-4:00 PM, 405 Philosophy Hall

Maya Sabatello By appointment

Sam Sternberg By appointment

**Overview:**

This seminar will cover the scientific foundations of precision medicine and its social and ethical dimensions, alongside fundamental humanistic questions and challenges raised by this discipline. It is designed as an introduction to precision medicine accessible to the non-scientist student, but will also explore issues relevant to students who are planning a career in science or medicine.

**Assignments and Grading:**

The three instructors have created specific assignments designed to assess students’ grasp of course themes, as well as to provide opportunities for independent work exploring some of these themes. There are five assignments as detailed in the course syllabus below, which include take-home short essays and a final project. *All written work must be completed in order to pass the course.*

**Grade breakdown:**

Participation and attendance: 25%

Five weekly assignments: 50%

Final paper: 25%

**Weekly preparation:**

Students should come to class having read the texts assigned in the syllabus, and be prepared to participate. Attendance at every class meeting is expected, as well as thoughtful and informed contribution to seminar discussions.

**Required texts:**

There are no textbooks. Articles listed on the syllabus and will be available on Courseworks. The following books are also required and are available from Book Culture (536 W. 112th St.):

Philippe Amouyel, Héloise Chochois, *Genetics at Heart* (ebook)

Brian Fries, *Mom’s Cancer*

Alice Wexler, *Mapping Fate*

**Disability policy:**

Columbia University is dedicated to facilitating equal access for students with disabilities, and to cultivating a campus culture that is sensitive and responsive to the needs of students. Please let us know, either through the Office of Disability Services or by contacting instructors individually, if you need special accommodations because of a disability.

**Preferred pronouns:**

Please share the name and gender pronouns you prefer for use throughout the semester.

**Policy on electronic devices in class:**

We do not ban the use of laptops and other electronic devices because some students need them as a disability accommodation.  However, there is strong evidence that the use of laptops impedes learning in many typical students.  The use of email, texting, and social media during class is strictly prohibited.

**Policy on generative AI:**

We may incorporate ChatGPT and other generative AI software during this course to generate ideas, study questions or paper topics, or research historical or literary references. Students will be informed about when, where, and how such tools are permitted to be used for class work and assignments, along with specific instructions for attribution. Outside of these approved uses, ChatGPT and other generative AI software are not permitted and must be specifically approved by the instructors. Any and all use of ChatGPT and other AI software at any stage of completing assignments for this course must be properly cited in your work; neglecting to do so may constitute a violation of Columbia College’s [Honor Code](https://www.cc-seas.columbia.edu/integrity#:~:text=Honor%20Code&text=I%20affirm%20that%20I%20will,assignments%2C%20papers%2C%20or%20examinations.).  If you have questions about what is permissible at any point in the semester, please reach out to one of the instructors. Please also note that this policy applies only to our class, and it is your responsibility to check with other instructors if ever you are unsure about what constitutes academic honesty in their class.

**Academic integrity:**

“The intellectual venture in which we are all engaged requires of faculty and students alike the highest level of personal and academic integrity. As students, you must be responsible for the full citations of others’ ideas in all of your research papers and projects and you must always submit your own work and not that of another student, scholar, or internet agent. Any breach of this intellectual responsibility is a breach of faith with the rest of our academic community. It undermines our shared intellectual culture, and it cannot be tolerated. Students failing to meet these responsibilities should anticipate being asked to leave Columbia.” (Excerpted from Columbia University *Faculty Statement on Academic Integrity*)

**COURSE SYLLABUS**

**Week 1 (09/03)**

**Introduction: What is ‘precision medicine’? (Adams/Sabatello/Sternberg)**

**Week 2 (09/10)**

**Human genetics and disease (Sternberg)**

We will take a crash course in molecular biology and human genetics: what constitutes the human ‘genome’ and how is it organized; how are genes ‘expressed’ in the cell; how can mutations in DNA cause disease; how is genetic information transmitted during reproduction; and more. Well-studied genetic diseases, including sickle cell disease, Tay-Sachs disease, and cystic fibrosis, will be used as case studies to explore these topics, and in particular, how genetic testing can provide actionable information about disease transmission.

**Readings**:

1. Lewis, R. (2017). How genes work (Chapter 2). In: *Human genetics: The basics*. New York, NY: Routledge.
2. Mukherjee, S. (2016). The hunger winter. In: *The gene: An intimate history*. New York, NY: Scribner.
3. Khatchadourian, R. (2021, November). How your family tree could catch a killer. *The New Yorker*. Retrieved from https://www.newyorker.com/magazine/2021/11/22/how- your-family-tree-could-catch-a-killer.
4. Zimmer, C. (2018, May 21). Every cell in your body has the same DNA. Except it doesn’t. *The New York Times*. Retrieved from https://www.nytimes.com/2018/05/21/ science/mosaicism-dna-genome-cancer.html.
5. Murphy, H. (2019, December 7). When a DNA test says you’re a younger man, who lives 5,000 miles away. *The New York Times.* Retrieved from https://www.nytimes.com/2019/ 12/07/us/dna-bone-marrow-transplant-crime-lab.html.

**Additional resources and reading (optional):**

1. Collins, F. (2010). The future has already happened (Chapter 1); When genes go wrong, it gets personal (Chapter 2). In: *The language of life: DNA and the revolution in personalized medicine.* New York, NY: HarperCollins.
2. “Help me understand genetics.” https://medlineplus.gov/genetics/understanding/
3. “About genomics.” https://www.genome.gov/about-genomics

**Week 3 (09/17)**

**Revolutions in reading, writing, and editing DNA (Sternberg)**

Scientists have dreamed of ‘cracking the genetic code’ ever since the discovery that DNA is the genetic material of the cell. The past half-century has witnessed phenomenal advances in our abilities to sequence and synthesize DNA, and now, with the advent of CRISPR technology, we can precisely modify DNA inside living cells and organisms. This week will highlight these technological developments by focusing on real-world implications. Some key discussion areas will include: what did (and didn’t) we learn from the Human Genome Project; the advent of direct-to-consumer genetic testing (e.g. 23andMe); synthetic biology and the ability to create new life forms from scratch; genome editing and a new era of precision genetic therapies.

**Readings:**

* + - 1. Goldstein, J. (2022, August 12). Hospital and drugmaker move to build vast database of New Yorkers' DNA. The New York Times. Retrieved from https://www.nytimes.com/2019/ 12/07/us/dna-bone-marrow-transplant-crime-lab.html.
      2. Gertner, J. (2021, March 25). Unlocking the COVID code. The New York Times Magazine. Retrieved from https://www.nytimes.com/2019/ 12/07/us/dna-bone-marrow-transplant-crime-lab.html.
      3. Regalado, A. (2016, June 2). Plans to fabricate a genome raises questions on designer humans. MIT Technology Review. Retrieved from https://www.nytimes.com/2019/ 12/07/us/dna-bone-marrow-transplant-crime-lab.html.
      4. Kahn, J. (2015, November 15). The CRISPR quandary. The New York Times Magazine. Retrieved from https://www.nytimes.com/2019/ 12/07/us/dna-bone-marrow-transplant-crime-lab.html.
      5. Molteni, M. (2020, August 1). The WIRED guide to CRISPR. WIRED. Retrieved from https://www.wired.com/story/wired-guide-to-crispr/
      6. Khullar, D. (2022, March). Are we about to cure sickle-cell disease? The New Yorker. Retrieved from https://www.newyorker.com/science/annals-of-medicine/are-we-about-to- cure-sickle-cell-disease.
      7. Hall, S. (2016, February 4). The embarrassing, destructive fight over biotech's big breakthrough. Scientific American. Retrieved from https://www.scientificamerican.com/article/the-embarrassing-destructive-fight-over-biotech-s-big-breakthrough/

**Assignment #1** (due at beginning of week 4): You will complete a series of short essay prompts, to explore the present-day application of new genome editing-based therapeutics to functionally cure patients of various genetic diseases. I will ask you to pay particular attention to the underlying genetic mutation(s) that cause the disease, and how these mutations constrain the kind of CRISPR-based drug that can be applied. How do these next-generation genetic medicines compare to the current standard of care, in terms of cost, administration, dosage, etc.?

**Week 4 (09/24)**

**Bioart, precision medicine, and personhood (Adams)**

Who counts as a person?  What is the scale of personhood?  How does the meaning of personhood change in an age of precision medicine? This week will focus on artists using some of the same technologies used by researchers and practitioners of precision medicine to create work that encourages viewers to think about the ethics, aesthetics and social implications of engineering or editing biological matter.  We will consider how bioart raises questions about personhood, subjectivity, and embodiment, while also drawing attention to ethical questions around access to healthcare, and environmental sustainability.  Among artists we could study are Caitlin Flannagan, Eduardo Kac, Kathy High, Sabrina Raff, Joana Ricou, Sonja Baumel, Gina Czarnecki and John Hunt, Charlotte Javis, Heather Dewey-Hagborg, Julia Reodica, and Kuang Yi-Ku. Flanagan, Kac, and High all have good essays on their art practices.

**​​Readings**:

1. Samuel Rodriguez and Nick Love, “The Precision Portrait”
2. Lori B. Andrews, “Art as a Public Policy Medium”
3. Evelyn Hawthorne and Paul Vanouse, “Race, the Jamaican Body, and Eugenics/Genomics”
4. Interview with Paul Vanouse
5. Ali K. Yetisen et. al., “Bioart”
6. Kathy High, “Tactical Biopolitics

**Assignment #2** (due at beginning of week 5): Pick a work of art and write a two-page reflection on how it employs, comments on, or innovates the scientific concepts introduced in weeks 2–3. “Reflection” means that you do not need to write a traditional, academic style paper. You may write in first person, but you should use proper grammar and develop your thoughts in a logical fashion.

**Week 5 (10/01)**

**Comics as a learning method and critical tool (Adams)\***

This week will introduce students to the rapidly expanding field of graphic medicine, which uses comics to tell stories of illness, as well as to train healthcare practitioners.  We will study examples of graphic narratives about illness, considering how the combination of print and visual texts works to create meaning, and we will also study comics used to teach readers about scientific concepts necessary to understand precision medicine. Students will be asked to produce two comics: i) a self-portrait, and ii) an explanation of a scientific concept introduced by Sam’s lectures. *\*Please note that NO drawing ability or experience is required to complete the assignments for this week!*

**Readings**:

1. Philippe Amouyel, Héloise Chochois, *Genetics at Heart*
2. Brian Fries, *Mom’s Cancer*
3. Michael J. Greene and Kimberly R. Myers, “Graphic Medicine: Use of Comics in Medical Education and Patient Care”

**Assignment #3 (due at the beginning of week 6):**

Create a comic of at least four panels either illustrating a scientific concept introduced in weeks 2–3 or about a medical encounter related to course material.

**Week 6 (10/08)**

**Using personalized genomics to inform patient care (Sternberg)**

Building on the past few weeks, we’ll explore how genetic analyses can be used to provide actionable information that guides decisions about patient care and disease treatment. In the context of cancer, tissue biopsies can yield information about which patients will or will not respond to certain drug treatments, based on the mutations present. A recent case study involving a patient treated by Timothy Yu offers a powerful example of how “N-of-1” clinical trials can be tailored to rare genetic disorders. And ‘genome-wide association studies’ (GWAS) offer the promise of genetic risk scores for more common conditions, but also call into question how actionable these probabilistic predictions will be. We will be joined by Dr. Juan-Manual Schvartzman, a medical oncologist at Columbia University Irving Medical Center who runs a research lab and treats patients with gastrointestinal malignancies.

**Readings:**

1. LeMieux, J. (2021). N-Lorem makes ultrarare disease treatment personal. *Gen Eng* *News*. Retrieved from https://www.genengnews.com/insights/n-lorem-makes-ultrarare-disease treatment-personal/.
2. Lohr, S. (2022). A gene sequencing pioneer battles over what it can buy. *The New York Times.* Retrieved from https://www.genengnews.com/insights/n-lorem-makes-ultrarare-disease-treatment-personal/.
3. Sagonowsky, E. (2017). At $475,000, is Novartis’ Kymriah a bargain—or another example of skyrocketing prices? *Fierce Pharma*. Retrieved from https://www.fiercepharma.com/pharma/at-475-000-per-treatment-novartis-kymriah-a-bargain-or-just-another-example-skyrocketing.
4. Muigai, A. (2022). Expanding global access to genetic therapies. *Nature Biotechnology*. Retrieved from https://www.nature.com/articles/s41587-021-01191-0.

**Additional resources and reading (optional):**

1. Graeber, C. (2018). Meet the carousing, harmonica-playing Texan who won a Nobel for his cancer breakthrough. *WIRED*. Retrieved from https://www.wired.com/story/meet-jim-allison-the-texan-who-just-won-a-nobel-cancer-breakthrough/.

**Assignment #4 (due at beginning of week 7):**

Write a ~2-3-page review that summarizes recent developments in cancer immunotherapy using so-called chimeric antigen receptor (CAR) T cells. Your review should provide a general description of how CAR T cells work: what kinds of ‘antigens’ have CARs been engineered to recognize; how the engineered T cells are sourced and manufactured; and what some ongoing challenges with this type of cellular therapy are. Your should specifically explain the distinction between autologous CAR T-cell therapy versus allogeneic (‘off-the-shelf’) CAR T-cell therapy, and I’d like you to also summarize the current commercial landscape involving biotechnology and pharmaceutical companies in this space.

**Week 7 (10/15)**

**Genomic ancestry and genetic counseling (Dr. Hila Milo Rasouly; Guest lecture)**

This session will consider the definitions and the utilization of genetic ancestry, race and ethnicity. We will discuss the genetic variation observed in humans, between and within group variation, and its utilization to calculate genetic ancestry. We will also discuss the role of genetic counselors and the idea of non-directive counseling.

**Readings**:

1. Stern AM. A quiet revolution: the birth of the genetic counselor at Sarah Lawrence College, 1969. J Genet Couns. 2009 Feb;18(1):1-11. doi: 10.1007/s10897-008-9186-8. Epub 2008 Nov 5. PMID: 18985445.
2. Rutherford A. Eugenics and the misuse of Mendel. Am J Hum Genet. 2024 Jul 11;111(7):1254-1257. doi: 10.1016/j.ajhg.2024.05.013. PMID: 38996467; PMCID: PMC11307615.
3. Ademuyiwa FO, Salyer P, Tao Y, Luo J, Hensing WL, Afolalu A, Peterson LL, Weilbaecher K, Housten AJ, Baumann AA, Desai M, Jones S, Linnenbringer E, Plichta J, Bierut L. Genetic Counseling and Testing in African American Patients With Breast Cancer: A Nationwide Survey of US Breast Oncologists. J Clin Oncol. 2021 Dec 20;39(36):4020-4028. doi: 10.1200/JCO.21.01426. Epub 2021 Oct 18. PMID: 34662201.
4. Borrell LN, Elhawary JR, Fuentes-Afflick E, Witonsky J, Bhakta N, Wu AHB, Bibbins-Domingo K, Rodríguez-Santana JR, Lenoir MA, Gavin JR 3rd, Kittles RA, Zaitlen NA, Wilkes DS, Powe NR, Ziv E, Burchard EG. Race and Genetic Ancestry in Medicine - A Time for Reckoning with Racism. N Engl J Med. 2021 Feb 4;384(5):474-480. doi: 10.1056/NEJMms2029562. Epub 2021 Jan 6. PMID: 33406325; PMCID: PMC8979367.

**Week 8 (10/22)**

**Return of genetic results from research in adult populations (Sabatello)**

Emerging technologies for genetic analyses have raised the possibility—and expectation—that genetic testing will be offered in clinical settings and/or that genetic results from research will be returned to research participants. Yet clinical and research settings are different, with each raising unique ethical, legal, and social challenges. These challenges are pronounced in pediatric populations. In this session, we will explore issues of consent and assent; differences between clinical and research settings; models for return of results from research; and the legal regulations for genetic testing and return of results. We will situate children (under 18yo) in genomic conversations; and focus on the unique legal, social and cultural challenges that arise for adolescents (ages 13-17yo).

**Readings**:

1. Mikat-Stevens NA, Larson IA, Tarini BA. Primary-care providers' perceived barriers to integration of genetics services: a systematic review of the literature. Genet Med. 2015 Mar;17(3):169-76. doi: 10.1038/gim.2014.101. Epub 2014 Sep 11. PMID: 25210938.
2. Koenig BA. Have we asked too much of consent? Hastings Cent Rep. 2014 Jul-Aug;44(4):33-4. doi: 10.1002/hast.329. PMID: 25043364; PMCID: PMC4249719.
3. Appelbaum PS, Parens E, Waldman CR, Klitzman R, Fyer A, Martinez J, Price WN 2nd, Chung WK. Models of consent to return of incidental findings in genomic research. Hastings Cent Rep. 2014 Jul-Aug;44(4):22-32. doi: 10.1002/hast.328. Epub 2014 Jun 11. PMID: 24919982; PMCID: PMC4107028.
4. Jarvik GP, Amendola LM, Berg JS, Brothers K, Clayton EW, Chung W, Evans BJ, Evans JP, Fullerton SM, Gallego CJ, Garrison NA, Gray SW, Holm IA, Kullo IJ, Lehmann LS, McCarty C, Prows CA, Rehm HL, Sharp RR, Salama J, Sanderson S, Van Driest SL, Williams MS, Wolf SM, Wolf WA; eMERGE Act-ROR Committee and CERC Committee; CSER Act-ROR Working Group; Burke W. Return of genomic results to research participants: the floor, the ceiling, and the choices in between. Am J Hum Genet. 2014 Jun 5;94(6):818-26. doi: 10.1016/j.ajhg.2014.04.009. Epub 2014 May 8. PMID: 24814192; PMCID: PMC4121476.

**Additional resources and reading (optional):**

1. Miller DT, Lee K, Abul-Husn NS, Amendola LM, Brothers K, Chung WK, Gollob MH, Gordon AS, Harrison SM, Hershberger RE, Klein TE, Richards CS, Stewart DR, Martin CL; ACMG Secondary Findings Working Group. ACMG SF v3.2 list for reporting of secondary findings in clinical exome and genome sequencing: A policy statement of the American College of Medical Genetics and Genomics (ACMG). Genet Med. 2023 Aug;25(8):100866. doi: 10.1016/j.gim.2023.100866. Epub 2023 Jun 22. PMID: 37347242; PMCID: PMC10524344.

**Week 9 (10/29)**

**Pediatric genomic testing and Sociogenomics (Sabatello)**

This week will build on the previous one by examining the possibility of returning so-called sociogenomic data to families and children. We will discuss the expansion of genetic testing to genetic screening in school settings and consider the potential uses and concerns related to behavioral genetics for educational attainment.

**Readings**:

1. Wright Clayton, How much control do children and adolescents have over genomic testing, parental access to their results, and parental communication of those results to others? *Law, Med Ethics* 2015; 43(3): 538-544
2. Garrett JR, Lantos JD, Biesecker LG, Childerhose JE, Chung WK, Holm IA, Koenig BA, McEwen JE, Wilfond BS, Brothers K; Clinical Sequencing Exploratory Research (CSER) Consortium Pediatrics Working Group. Rethinking the "open future" argument against predictive genetic testing of children. Genet Med. 2019 Oct;21(10):2190-2198. doi: 10.1038/s41436-019-0483-4. Epub 2019 Mar 21. PMID: 30894702; PMCID: PMC6754817.
3. May T, Strong KA, Zusevics KL, Jeruzal J, Farrell MH, LaPean Kirschner A, Derse AR, Evans JP, Grotevant HD. Does Lack of "Genetic-Relative Family Health History" Represent a Potentially Avoidable Health Disparity for Adoptees? Am J Bioeth. 2016 Dec;16(12):33-38. doi: 10.1080/15265161.2016.1240255. PMID: 27901440.
4. Hodapp, R. M., & Fisher, M. H. (2017). Using genetic etiology to intervene with students with intellectual disabilities. In S. Bouregy, E. L. Grigorenko, S. R. Latham, & M. Tan (Eds.), *Genetics, ethics and education* (pp. 183–201). Cambridge, UK: Cambridge University Press.
5. Robert Plomin and Sophie von Stumm.  The New Genetics of Intelligence.  *Nature Reviews Genetics* 19 (2018): 148-59.
6. K. Paige Harden.  Why Progressives Should Embrace the Genetics of Education. *New York Times*.  July 7, 2018 (posted)
7. Martschenko DO. Social Equality in an Alternate World. Hastings Cent Rep. 2021 Nov;51(6):54-55. doi: 10.1002/hast.1307. PMID: 34904740; PMCID: PMC9210985 (posted)

**Additional resources and reading (optional):**

1. Mostafavi H, Harpak A, Agarwal I, Conley D, Pritchard JK, Przeworski M. Variable prediction accuracy of polygenic scores within an ancestry group. Elife. 2020 Jan 30;9:e48376. doi: 10.7554/eLife.48376. PMID: 31999256; PMCID: PMC7067566.

**Assignment #5 (10%; due at the beginning of week 10):**

Students are required to write a **1000-1200-word commentary** on topics broadly relevant to the subject matter explored in the sessions on return of results and sociogenomics. Topics may be drawn from major online or print newspapers and magazines and major academic journals such as Genetics in Medicine, the Hastings Center Report, and the AJOB journals (including bioethics.net). Recently published sources are preferred. The commentary should explain the key issues, responses to the key dilemma, and reflection about the ELSI implications thereof.

**No class on 11/05 due to Academic Holiday**

**Week 10 (11/12)**

**Life writing and the some-body memoir (Adams)**

The late 20th century saw an outpouring of life writing about illness and disability, a genre that literary critic G. Thomas Couser calls “the some-body memoir.”  This week will ask what life writing can teach us about experiences of illness and disability, build humanistic skills for narrative analysis, and ask students to reflect on what illness memoirs can contribute to the development and administration of precision medicine.

**Readings**:

1. Alice Wexler, *Mapping Fate*
2. Emily Rapp, “Notes from a Dragon Mom”

**Assignment #6A (due at the beginning of week 11):**

2–3-page reflection on one of the readings, guided by prompts provided during the week. *If you plan to complete Assignment B (see below), you do not need to complete Assignment A.*

**Week 11 (11/19)**

**Who needs to be cured? (Adams)**

This week will continue to consider life writing, but shifting perspective to authors who see their illness/disability as a source of opportunity, and who offer alternatives to the medical view that they need to be fixed or cured.

**Readings**:

* 1. Harriet McBryde Johnson, “Unspeakable Conversations”
  2. Ben Mattlin, “SMA and Me”
  3. George Estreich, “An Open Letter to Medical Students”
  4. Riva Lehrer, from *Golem Girl*
  5. Watch video of “In my language” by Mel Baggs

**Assignment #6B (due at the beginning of week 12):**

2–3-page reflection on what you learned from putting one of the authors from this week’s reading in dialogue with your emerging understanding of precision medicine. *If you completed Assignment A (see above), you do not need to complete Assignment B.*

**Week 12 (11/26)**

**Psychiatric genetics and responsibility in courts (Sabatello):**

Although genomic data have great potential value in clinical care, their use in nonclinical settings such as courts raise a host of ELSI concerns. In this session, we will discuss the growing and potential uses of genetic information in criminal and civil litigation. We will consider the types of genetic data that are used, gene-environment interactions, the goals for their uses, and the challenges that arise.

**Readings:**

1. Caspi A, McClay J, Moffitt TE, Mill J, Martin J, Craig IW, Taylor A, Poulton R. Role of genotype in the cycle of violence in maltreated children. Science. 2002 Aug 2;297(5582):851-4. doi: 10.1126/science.1072290. PMID: 12161658.
2. NYT: *The Golden State Killer Is Tracked Through a Thicket of DNA, and Experts Shudder*, <https://www.nytimes.com/2018/04/27/health/dna-privacy-golden-state-killer-genealogy.html> (posted)
3. Forzano et al, Italian appeal court: a genetic predisposition to commit murder? *European J Hum Genet* 2010; 18: 519-521
4. Adacsi v Amin, Docket 1201-0330-AC, 2013 ABCA 315. 2013, Ct. App. Alberta, Canada.
5. Sabatello M, Appelbaum S. Psychiatric Genetics in Child Custody Proceedings: Ethical, Legal, and Social Issues. Curr Genet Med Rep. 2016 Sep;4(3):98-106. Doi: 10.1007/s40142-016-0093-2. Epub 2016 Jun 30. PMID: 27695660; PMCID: PMC5040211.

**Assignment #7, ELSI policy position paper (15%; due on December 13, 2024):**

Students are required to **write one policy position paper (1500-2000 words)** on a challenging ELSI issue in precision medicine or precision medicine research. Students will select 1 policy topic from among 4 potential policy descriptions that will be distributed in the middle of the semester. This paper should explore the ELSI issues encountered in the topic, identify the key scholarly views that have been taken on the issue, explore pros and cons of each argument, and result in a well-reasoned justification of a policy position taken by the student. The paper must go beyond class discussion and resources and include at least 15 scholarly books and journal articles. The guidelines for these papers and the grading rubric will be handed out separately.

**Week 13 (12/03)**

**The intersection of precision medicine and human reproduction (Sternberg)**

1-2% of all births in the US now occur via in vitro fertilization (IVF), and fertility clinics are increasingly offering additional services to parents, such as the genetic testing of fertilized embryos before implantation. When combined with our increasing knowledge of human genetics, will this lead to a future in which parents increasingly opt for IVF in order to choose the ‘best’ embryos? How are assisted reproductive technologies being commercialized, and what kinds of access and equality problems arise as a result? How might gene editing technologies further complicate this area? These issues will be explored, using both science fiction and actual scientific developments to inform the discussion.

**Readings**:

TBD