

ETHICAL IMPLICATIONS OF EMERGING BIOTECHNOLOGY

M/W 3-4:20 PM, T-473

NOW REMOTE THRU 1/26

<https://washington.zoom.us/j/99668945938>

Stephanie “Malia” Fullerton | she/her | smflrtn@uw.edu

Land & Labor Acknowledgment

I acknowledge the peoples – past, present, and future – of the Dkhw’Duw’Absh, the Duwamish Tribe, the Muckleshoot Tribe, and other Coast Salish peoples on whose lands and waters I live and work.

I acknowledge that this country would not exist without the free and slave labor of Black people. I honor their knowledge and skills, stolen due to violence and white supremacy.

I take on the responsibility to continue to work towards justice in solidarity with Black and Indigenous people, and all whose labor and knowledge is unjustly marginalized.

Inclusivity & Diversity

This is a collaborative course. We will construct it together and learn from each other. As your instructor, I take on the responsibility of partnering and collaborating with all of you to ensure that this course actively supports diverse abilities, knowledges, and perspectives. Please never hesitate to let me know if there is more I can be doing to encourage inclusive learning in this course.

Course Overview

Scientific and technological innovation in biomedicine is advancing at breakneck speed, with exciting new developments ranging from precision medicine to gene editing to regenerative medicine being reported on a near daily basis. These emerging technologies and their application to disease prevention, treatment, and enhancement promise an array of individual and societal benefits; they also raise concerns related to the genetic manipulation of future generations, the automation of healthcare and medical decision-making, and the extension of human lifespan. AND, as the last 2 years have reminded us, no matter how good the science, biotechnology is subject to the effects of broader sociopolitical and historical phenomena. This course will introduce students to select biomedical innovations and invite sustained consideration of the diverse ethical and social implications surrounding their development and potential use.

Course Objectives

By the end of the course, students will be able to:

- Describe recent innovations in biotechnology with relevance to medicine and public health
- Identify applications of these innovations to disease prevention, therapy, and/or enhancement
- Recognize key contextual factors (including structural inequities) likely to impact the development and implementation of emerging biotechnologies
- Discuss implications of emerging technologies for individual autonomy and well-being, societal beneficence, public deliberation and oversight, and responsible scientific stewardship
- Anticipate, and propose solutions to address, potential harms of emerging biotechnologies

• [B&H Department Policies and Guidelines](#)

• [B&H Department Diversity Statement](#)

• [B&H Department Equity, Diversity and Inclusion Resources](#)

Contact Me

Email: smflrtn@uw.edu

Phone: 206-616-1864 (infrequently in the office due to COVID-19)

Web:
<https://depts.washington.edu/bhdept/stephanie-malia-fullerton-dphil>

Office hours: By appointment; please do not hesitate to reach out to schedule a time

Required Reading

All required readings are available at:

<https://canvas.uw.edu/courses/1514369>

Course Policies

PARTICIPATION. Engaged and thoughtful participation is expected every class session. This means coming to class having read all assigned materials and ready to discuss those readings with your fellow students and the instructor; you may also be asked to complete short writing assignments in class (which will count toward your 'participation' grade).

LATE ASSIGNMENTS. Online quizzes will NOT be accepted after the due date. Late writing assignments and/or papers WILL be accepted but will be penalized 5% per day late (including weekends). Exceptions made for students with documented disabilities or medical emergencies only.

Evaluation

Undergraduates. Undergraduates will be evaluated based on their performance on two online (closed book) exams, 5 online (open book) quizzes, and on the level and quality of classroom participation, including active engagement in the virtual classroom and completion of short (mostly in-class) writing assignments.

Graduates. Graduates will be evaluated based on the same assignments as undergraduates, as well as an 8-10 page research paper dealing in more depth with one of the topics discussed in class. Dr. Fullerton will meet separately with the graduate section to go over this assignment; please see Final Paper submission link on Canvas for expectations for the paper (a paper proposal/outline is due in Week 5).

The points breakdown in each case will be as follows:

	Exam 1	Exam 2	Quizzes	Participation	Final Paper
Undergraduates	30%	40%	10%	20%	--
Graduates	20%	30%	10%	15%	25%

Please consult the daily schedule (outlined below) to find dates and submission deadlines for exams, quizzes, and papers. All assigned readings are subject to change, please consult Canvas to find the truly final readings ahead of each class.

Quizzes will be online and must be completed outside of class time; use of notes, readings, and websites is allowed.

Please note scheduled dates for Exams 1 (Week 5) and 2 (Week 10) and notify the instructor EARLY in the quarter if you will need an alternate test date.

Course Schedule and Readings (all available on Canvas)

WEEK 1

January 3rd Introduction to the Course/ Emerging Biotechnology Thru an Anti-Racist Lens

- Harari, Y. V. (2015) "Chapter 1: The new human agenda", in *Homo Deus: A Brief History of Tomorrow*, Vintage Books: London, pp. 52-67 (excerpt of longer chapter).
- Callahan, D. (2018) Progress: its glories and pitfalls. *Hastings Center Report*, 48 (2): 18-21.
- Mithani, Z., et al. (2021) Race, power, and COVID-19: A call for advocacy within bioethics. *American Journal of Bioethics*, 21(2): 11-18.
- OPTIONAL (for those of you who may not already be familiar with the Belmont principles): Belmont Report (1979), Part B: *Basic Ethical Principles*. See link in Canvas.

January 5th Precision Medicine: For All or Only Some of Us?

- Ferryman, K. & Ptican, M. (2018) Fairness in precision medicine. *Data & Society*, read pp. 1-11 only (although longer document IS provided on Canvas, if interested).
- Schwartz, O. (2020) A geneticist's dilemma. *Washington Post Magazine*, November 23rd.
- Neuhaus, C. P. (2020) Does solidarity require "All of Us" to participate in genomics research? *Hastings Center Report*, 50(3): S62-S69.
- OPTIONAL: The All of Us Research Program Investigators (2019) The "All of Us" Research Program. *New England Journal of Medicine*, 381(7): 668-676. See also the link to the program website in Canvas (optional as well).

WEEK 2

January 10th Direct-to-Consumer Genetic Testing and Third-Party Tools – Guest: Sarah Nelson [ONLINE QUIZ 1 DUE]

- Marx, P. (2019) 23 and him. *The New Yorker*, May 20th.
- Molteni, M. (2019) The WIRED guide to genetic testing. *WIRED*, December 3rd.
- Nelson, S. C. (2019) Consumer genetic testing customers stretch their DNA data further with third-party interpretation websites. *The Conversation*, June 13th.

- Badalato, L. et al. (2017) Third party interpretation of raw genetic data: an ethical exploration. *Eur J Hum Genet*, 25: 1189–94.
- OPTIONAL: Nelson, S. C. et al. (2019) Third-party genetic interpretation tools: a mixed-methods study of consumer motivation and behavior. *American Journal of Human Genetics*, 105(1): 122-131.
- OPTIONAL: In Those Genes Podcast: ION Trust Dem People! (focus on 5:50 – 33:00)

January 12th Non-Invasive Prenatal Genetic Testing, Reproductive Autonomy, and Disability

- The Hastings Center (2018) Evolution of Prenatal Testing, February.
- Allyse, M. A. & Wick, M. J. (2018). Noninvasive prenatal genetic screening using cell-free DNA. *JAMA*, 320(6): 591-2.
- Ravitsky, V. (2017) The shifting landscape of prenatal testing: between reproductive autonomy and public health. *Hastings Center Report*, 47 Suppl 3, read pp. S34-S37 only.
- Zhang, S. (2020) The last children of Down Syndrome. *The Atlantic*, December.
- OPTIONAL: Gadsbøll, K. et al. (2020) Current use of noninvasive prenatal testing in Europe, Australia and the USA: A graphical presentation. *Acta Obstet Gynecol Scand*, 99: 722–30.

WEEK 3

January 17th NO CLASS (MLK Jr. Day): Precision Medicine Therapies and the Orphan Drug Problem [SEE WEBSITE FOR SHORT ASSIGNMENT LINKED TO READINGS]

- Luzzatto, L. et al. (2015). Rare diseases and effective treatments: Are we delivering? *The Lancet*. 385(9970): 750-2.
- Bear, C. E. (2020) A therapy for most with cystic fibrosis. *Cell*, 180: 211.
- Khamsi, R. (2020) How the cystic fibrosis miracle drug is playing out in real life. *Elemental*, March 31st.
- Gordon, A. (2021) Canada has universal health coverage. So why is a new 'miracle drug' so hard to get? *WHYY*, June 4th.

January 19th mRNA Vaccines – Guest: Deb Fuller

- Cabotaje, A. (2020) What to know about COVID-19 RNA vaccines. *Right as Rain by UW Medicine*, December 28th.

- Cohen, J. (2021) Omicron sparks a vaccine strategy debate. *Science*, 374(6575): 1544-5.
- Fuller, D. (2021) How can scientists update coronavirus vaccines for omicron? A microbiologist answers 5 questions about how Moderna and Pfizer could rapidly adjust mRNA vaccines. *The Conversation*, December 2nd.
- Morens, D.M., et al (2021) Universal coronavirus vaccines - an urgent need. *New England Journal of Medicine*, doi: 10.1056/NEJMp2118468.
- Jecker, N. S. (2021) Are COVID-19 boosters ethical, with half the world waiting for a first shot? A bioethicist weighs in. *The Conversation*, September 17th.
- OPTIONAL: Rubin, R. (2021) The search for a single vaccine against coronaviruses yet to come. *JAMA*, 326(2): 118-20.
- OPTIONAL: Kolata, G. & Mueller, B. (2022) Halting progress and happy accidents: how mRNA vaccines were made. *New York Times*, January 15th.

WEEK 4**January 24th Designing Babies with CRISPR-Cas9 [ONLINE QUIZ 2 DUE]**

- Genome editing with CRISPR-Cas9: <https://www.youtube.com/watch?v=2pp17E4E-O8>
- Baylis, F. (2019) "Babies by design," in *Altered Inheritance: CRISPR and the Ethics of Human Genome Editing*, Harvard University Press: Cambridge, MA, full chapter provided, but please focus most on pp. 42-56.
- Molteni, M. (2021) World Health Organization advisers urge global effort to regulate genome editing. *STAT News*, July 12th.
- Marx, V. (2021) The CRISPR children. *Nature Biotechnology*, 39: 1486–1490.
- OPTIONAL: Baylis, F. et al. (2020) Human germline and heritable genome editing: the global policy landscape. *The CRISPR Journal*, 3(5): 365-77.
- OPTIONAL: Gumer, J. M. (2019) When might human germline editing be justified? *Hastings Bioethics Forum*, September 26th.

January 26th CRISPR Health Applications: Ex Vivo and In Vivo Gene Therapy

- Johnson, E. (2019) Somatic genome editing - an overview. *PHG Foundation Policy Briefing*, May.
- Kaiser, J. (2020) Tweaking genes with CRISPR or viruses fixes blood disorders. *Science*, 370(6522): 1244-5.

- Stein, R. (2021) First sickle cell patient treated with CRISPR gene editing still thriving. *NPR*, December 31st.
- Kaiser, J. (2021) Gene editor injected into the body treats disease. *Science*, 373(6550): 16.
- OPTIONAL: Frangoul, H. et al. (2020) CRISPR-Cas9 gene editing for Sickle Cell Disease and β -Thalassemia. *New England Journal of Medicine*, Dec 5th.
- OPTIONAL: Scudellari, M. (2020) Hijacking evolution. *Nature*, 571: 160-2.

WEEK 5**January 31st Exam 1 Review [PAPER PROPOSALS DUE – Graduate Students Only]**

- Review Sheet (please come to class prepared to work through the review sheet in small groups)

February 2nd EXAM 1

- Exam will be completed in class but online – please bring a laptop with you to class! See Modules page for link; entry code will be provided in class.

WEEK 6**February 7th Mobile Technology for Continuous Health Surveillance**

- Stretchy electronics go wireless: <https://www.youtube.com/watch?v=Km1-LbqoHGJ>
- Parshley, L. (2020) Our phones can now detect health problems such as Parkinson's disease. Is that a good thing? *Vox*, February 12th.
- Horgan, J. (2021) Big data, questionable benefits and my girlfriend's magic ring. *Scientific American*, September 30th.
- Landau, S. (2021) Digital exposure tools: Design for privacy, efficacy, and equity. *Science*, 373(6560): 1202-4.
- OPTIONAL: Waltz, E. (2019) Sweet sensation. *Nature Biotechnology*, 37: 340-44.
- OPTIONAL: Joseph, N. (2021) Tracking your life. *UW College of Arts & Sciences*, July 9th.

PLEASE NOTE: ALL READINGS AFTER THIS POINT SUBJECT TO CHANGE – LOOK FOR UPDATED READINGS ON CANVAS!

February 9th Artificial Intelligence in Medicine [ONLINE QUIZ 3 DUE]

- Simonite, T. (2018) The WIRED guide to artificial intelligence. *WIRED*, February 1st.
- Heaven, W. D. (2020) Google's medical AI was super accurate in a lab. Real life was a different story. *MIT Technology Review*, April 27th.
- Anthes, E. (2020) Alexa, do I have COVID-19? *Nature*, 586: 22-25.
- Hao, K. (2020) We read the paper that forced Timnit Gebru out of Google. Here's what it says. *MIT Technology Review*, December 4th.
- OPTIONAL: Johnson, K. (2020) Ruha Benjamin on deep learning: Computational depth without sociological depth is 'superficial learning'. *VentureBeat*, April 29th.
- OPTIONAL: Callaway, E. (2020) 'It will change everything': AI makes gigantic leap in solving protein structures. *Nature*, 588: 203-4.
- OPTIONAL: Metz, C. (2020) Meet GPT-3. It has learned to code (and blog and argue). *New York Times*, Nov 24th.

WEEK 7**February 14th Emerging Neurotechnology: From Deep Brain Stimulation to Neuralink**

- Deep Brain Stimulation demonstration: <https://www.youtube.com/watch?v=wZZ4Vf3HinA>
- Lozano, A. M. et al. (2019) Deep brain stimulation: current challenges and future directions. *Nature Reviews Neurology*, 15(3): 148–160, focus on pp. 2-5 and 13-16 of the pdf.
- Willyard, C. (2019) First steps to a revolution. *Nature*, 572: 20-25.
- Regalado, A. (2020) Elon Musk's Neuralink is neuroscience theater. *MIT Technology Review*, August 30th
- OPTIONAL: Rao, R. P. N. (2019) Towards neural co-processors for the brain: combining decoding and encoding in Brain-Computer Interfaces. *Current Opinion in Neurobiology*, focus on pp. 2-7.

February 16th Ethics of Neurotechnology – Guest: Tim Brown [ONLINE QUIZ 4 DUE]

- Yuste, R., Goering, S., et al. (2017) Four ethical priorities for neurotechnologies and AI. *Nature*, 551(7679): 159-163.
- Hendriks et al. (2019) Ethical challenges of risk, informed consent, and posttrial responsibilities in human research with neural devices. *JAMA Neurology*, 76(12): 1506-1514.
- Khatchadourian, R. (2018) Degrees of freedom. *The New Yorker*, November 19th.

- OPTIONAL: Brown, T. (2020) Building intricate partnerships with neurotechnology: Deep Brain Stimulation and relational agency. *International Journal of Feminist Approaches to Bioethics*, 13(1): 134-154.

WEEK 8**February 21st NO CLASS (President's Day): DIY Biology [SEE WEBSITE FOR SHORT ASSIGNMENT LINKED TO READINGS]**

- Ravindran, S. (2020) How DIY technologies are democratizing science *Nature*, 587: 509-11.
- Gruber, K. (2019) Biohackers. *EMBO Reports*, 20: e48397 (pp. 1-3).
- Rasmussen, L. M. et al. (2020) Realizing present and future promise of DIY biology and medicine through a trust architecture. *Hastings Center Report*, 50 (6): 10-14.

February 23rd The Regenerative Medicine Gold Rush – Guest: David Mack

- Ball, P. (2019) "Twists of fate: how to reprogramme a cell," in *How to Grow a Human: Adventures in Who We Are and How We are Made*, William Collins: London, pp. 143-183.
- Clarke, G. (2018) Bench to bedside: Current advances in regenerative medicine. *Curr Opin in Cell Biology*, 55: 59–66.
- OPTIONAL: Cyranoski, D. (2019) Stem cells 2 go. *Nature*, 573: 482-5.

WEEK 9**February 28th Stem Cells, Cellular Reprogramming, and Brain Organoids, Oh My! [ONLINE QUIZ 5 DUE]**

- Collins, F. (2020) Mini-lungs in a lab dish mimic early COVID-19 infection. *NIH Director's Blog*, November 19th.
- Huff, C. (2020) Turbocharging dialysis. *Nature*, 579: 186-8.
- Reardon, S. (2020) Can lab-grown brains become conscious? *Nature*, 586: 658-61.
- OPTIONAL: Hyun, I. et al. (2020) Ethical issues related to brain organoid research. *Brain Research*, 1732:146653

March 2nd And Finally: Living Forever??

- Ledford, H. (2020) Reversal of biological clock restores vision in old mice. *Nature*, 588: 209.
- Davis, J. K. (2018) Want to live longer? Consider the ethics. *The Conversation*, August 31st.

- Fukuyama, F. (2002) "The prolongation of life" in *Our Posthuman Future: Consequences of the Biotechnology Revolution*, Farrar, Strauss, & Giroux, pp. 57-71.
- OPTIONAL: Notopoulos, K. (2020) When his mother died of COVID-19, this artist started tracking her online data. *BuzzFeed*, December 29th.

WEEK 10**March 7th Exam 2 Review [FINAL PAPER DUE – Graduate Students Only]**

- Review Sheet (please come to class prepared to work through the review sheet in small groups)

March 9th EXAM 2

- Exam will be completed in class but online – please bring a laptop with you to class! See Modules page for link; entry code will be provided in class.