Introduction to Genetics, Ethics, & Society

BIOS 232

Personal Introductions

Share your name, pronouns, and favorite dessert

Acknowledgement Statement

I would like to begin by acknowledging that we meet today on the ancestral and unceded land of the Muwekma Ohlone Tribe. This land was and continues to be of great importance to the Ohlone people. As an uninvited guest on these lands, I am a beneficiary of the ongoing displacement of the Ohlone people. I pay my respects to the Native peoples, past and present.

I would like to acknowledge the suffering and resilience of all people whose lives and livelihoods were stolen by those with power, including but not limited to the millions of enslaved African American people. The devastating effects of these injustices continue to be felt today.

I would like to acknowledge everyone who has a lived experience of oppression, be it racism or sexism, classism or ableism, transphobia or homophobia, or any other form of oppression. To ignore oppression is to assent to oppression.

I appreciate and respect the knowledge and personal experience of everyone gathered here and I thank you for choosing to share your time and energy to be here today.

Session Outline

- Introduction to the course
- Creating ground norms
- Introduction to positionality
- Introduction to bioethics
- Science and society

Introduction to the course (!!)

Learning goals

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

Week 1: Principles of Bioethics Science and Society History of Heredity

Week 2: Human Genetic Data Race, Ancestry, Genetics, and Identity

Week 3: Reproductive Genetics Criminal Justice Reflections and Actions

Syllabus

- Expectations for us & expectations for you
- Content considerations
  - Please prioritize your well-being with regards to emotionally difficult content
- Grading/attendance
- Accommodations & other resources
- Anonymous feedback: bit.ly/bios232feedback

Grading

- Attendance of a session is 10 points
- You must get 40 points to pass
- Please reach out to Roshni or Rachel if you have any concerns, we will be accommodating of any unforeseen circumstances

Covid19 Ground Rules

- Please remained masked throughout the lectures and discussions
- Consider taking advantage of our free biweekly testing while in the course
- If you have covid, or any reason to believe you might have covid, please stay home!

Optional research survey (15 min)

This survey will be available for 24 hours to complete
(note: this might be easier to take on a laptop)

bit.ly/bios232-intro

Canvas > Pages >
Optional Research Study

Session 1: Introduction to Bioethics and Society

Learning goals

- Describe personal identities and use this to co-create ground norms for discussions throughout the course
- Evaluate different ethical frameworks by applying the four principles of bioethics to case studies
- Identify the ways in which societal structures and norms impact science

Taught by
Tim MacKenzie

Creating ground norms

Ground norms

We will co-create ground norms together. Take a moment to consider spaces where you have felt comfortable and empowered to engage. What about those spaces stands out to you? You are invited to make suggestions of how we will build a respectful space during this course.

Agreed Upon Group Norms

-Be respectful of conflicting opinions

-Commit to learning and growing

-Compassionate listening

-No talking over anyone

-Make space, take space

Introduction to positionality

Positionality, Intersectionality, and Privilege

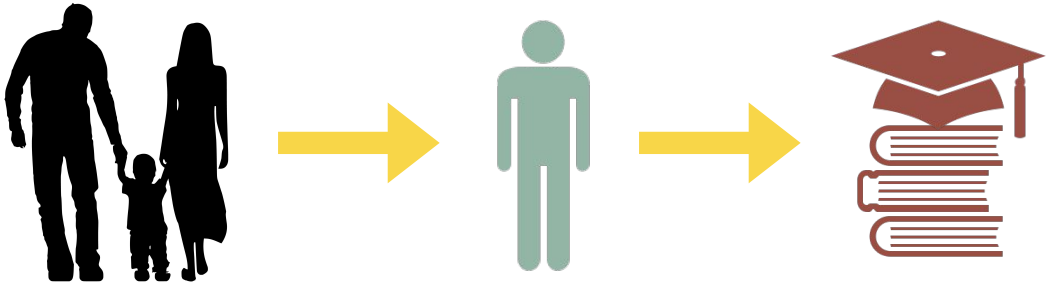
- Positionality
  - how our individual identities are constructed by cultural and political contexts
  - how these identities shape the way we see the world in relation to others
- Intersectionality
  - the complex, cumulative way in which the effects of multiple forms of discrimination combine, overlap, or intersect especially in the experiences of marginalized groups
- Privilege
  - an advantage that only one person or group of people has, usually because of their position or socioeconomic status

Conocimiento - Share Your Story

Conocimiento is a **place-based narrative** of where you and your ancestors are from. In pairs, share where you are from and begin thinking about how that shapes your positionality and identity.

In pairs

- What places are you and your ancestors from?
- How has that shaped your identity?
- How does this impact your positionality?



Who is in the Room?

Introduction to bioethics

Section Outline

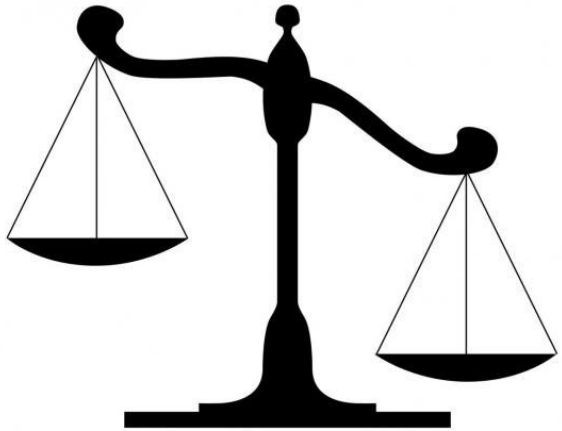
- Survey of Ethical Frameworks
- Four Principles of Bioethics
- Introduction of Case Study
- Group Activity

Ethical Frameworks

- Deontological (rule-based)
  - E.g Kantian ethics
  - Actions are moral if they conform to rules of conduct - the agent and outcomes do not matter, only the action itself
  - We have a moral duty to choose the action that follows the rules
    - Many deontological theories each with their own analysis of what rules for conduct are/should be

Ethical Frameworks

- Deontological (rule-based)
- Consequentialist (outcome-based)
  - E.g Utilitarianism
  - Actions are moral if they produce a beneficial/positive outcome - the action and agent do not matter, only what the end result is



Ethical Frameworks

- Deontological (rule-based)
- Consequentialist (outcome-based)
- Virtue Ethics (character-based)
  - E.g. Aristotelian ethics
  - The character of the moral agent is most important; focus is not on specific actions or decisions, but the way one lives their life
  - What is the Good Life?

Ethical Frameworks

- Social Contract Theory
  - Argues that limits on autonomy externally imposed (e.g. by the State) gain legitimacy because individuals in society have entered into an agreement
  - Focus is on the individual and their agency in agreeing (explicitly or implicitly) to the rules of society

Ethical Frameworks

- Social Contract Theory
- Communitarianism
  - Argues that individual sense of identity is molded by community relationships
  - Limits on autonomy are natural because the individual is a part of the whole
  - Focus is on the community and how those interactions shape the individual

Four Principles of the Belmont Report

- Autonomy
  - Respect for the individual
  - Making choices that are informed and in line with one's own beliefs and values

Four Principles of the Belmont Report

- Autonomy
- Beneficence
  - Promoting outcomes that are good for people

Four Principles of the Belmont Report

- Autonomy
- Beneficence
  - Promoting outcomes that are good for people

Ancient and modern genomics of the Ohlone Indigenous population of California

Alissa L. Severson[a], Brian F. Byrd[b], Elizabeth K. Mallott[c], Amanda C. Owings[d,e], Michael DeGiorgio[f], Alida de Flamingh[d,e], Charlene Nijmeh[g], Monica V. Arellano[g], Alan Leventhal[g,h], Noah A. Rosenberg[i,1], and Ripan S. Malhi[d,e,1]

[a]Department of Genetics, Stanford University, Stanford, CA 94305; [b]Far Western Anthropological Research Group, Davis, CA 95618; [c]Department of Anthropology, Northwestern University, Evanston, IL 60206; [d]Department of Anthropology, University of Illinois, Urbana, IL 61801; [e]Carl R. Woese Institute for Genomic Biology, University of Illinois, Urbana, IL 61801; [f]Department of Electrical Engineering and Computer Science, Florida Atlantic University, Boca Raton, FL 33431; [g]Muwekma Ohlone Tribe of the San Francisco Bay Area, Castro Valley, CA 94546; [h]Department of Anthropology, San Jose State University, San Jose, CA 95192; and [i]Department of Biology, Stanford University, Stanford, CA 94305

Four Principles of the Belmont Report

- Autonomy
- Beneficence
- Non-maleficence
  - “Doing no harm”
  - Avoiding outcomes that are bad for people

Four Principles of the Belmont Report

- Autonomy
- Beneficence
- Non-maleficence
- Justice
  - Fairness
  - Equity
  - Access

Justice(?) in Institutional Coronavirus Vaccine Distribution

On first day of vaccine rollout, UCSF immunized a custodial worker that had been employed for many years. At Stanford, over 100 of the ~1,300 residents protested because they were excluded from vaccine rollout in lieu of administrators working from home, even though the residents were treating COVID patients on the frontlines.

Case Study

Four scenarios

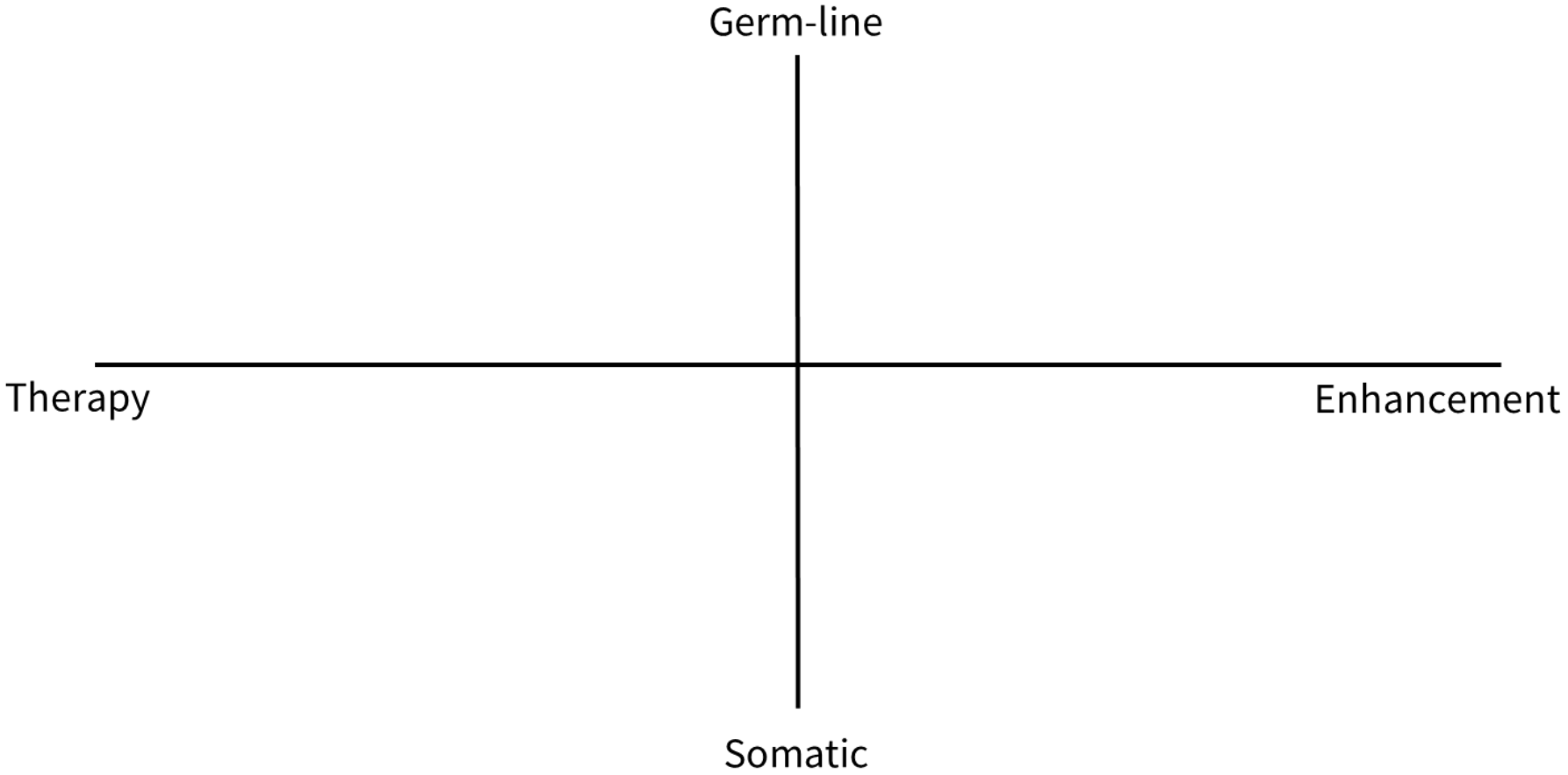
R Gillon

Promoting respect for the four principles remains of great practical importance in ordinary medicine

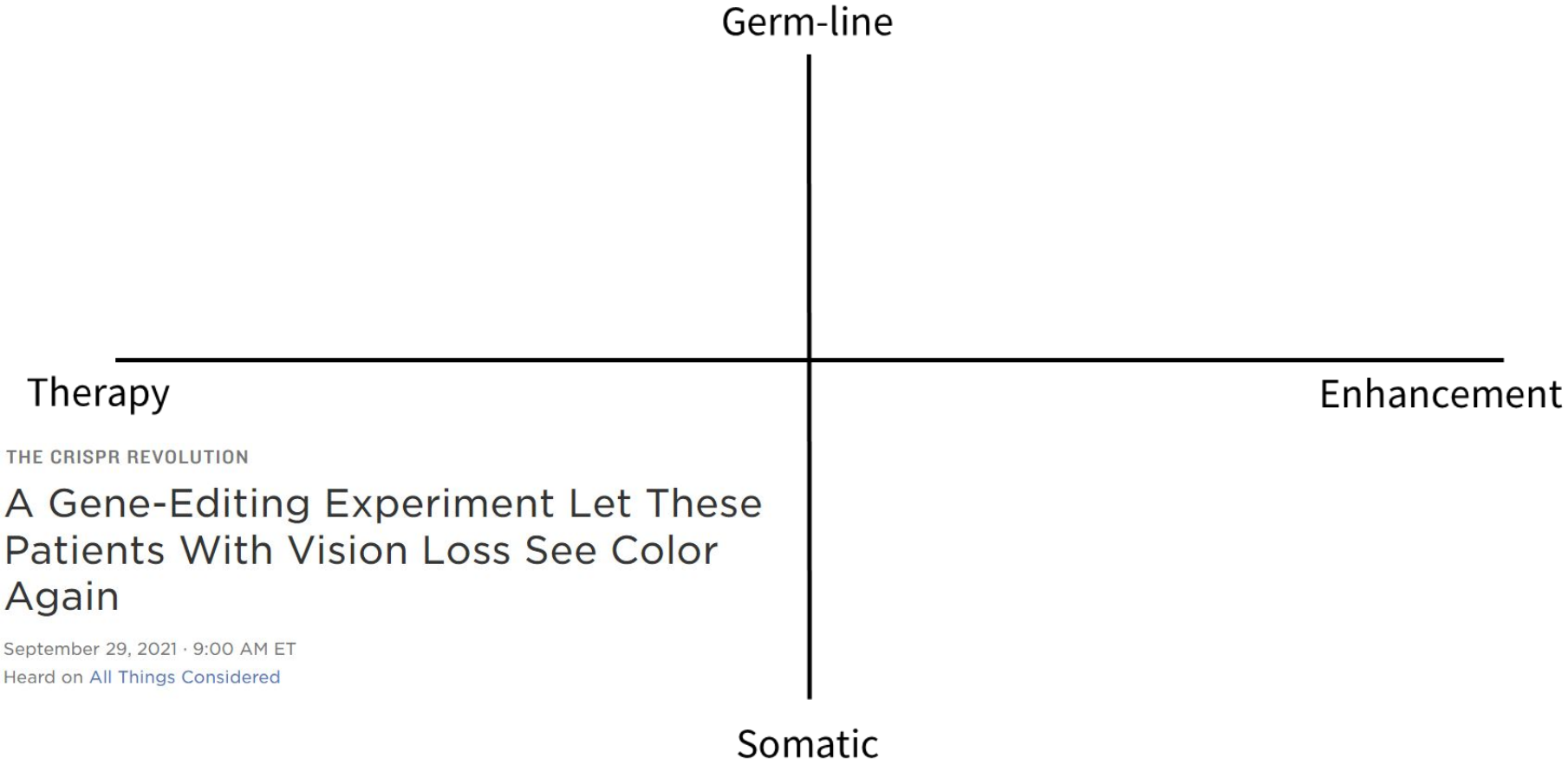
J Med Ethics 2003;**29**:267–268

GENETIC MANIPULATION TO PRODUCE GERMLINE TRANSMISSIBLE GENETIC ENHANCEMENT

Considerations in the Case Study



Considerations in the Case Study



THE CRISPR REVOLUTION

A Gene-Editing Experiment Let These Patients With Vision Loss See Color Again

September 29, 2021 · 9:00 AM ET

Heard on All Things Considered

Considerations in the Case Study

Michael Kalberer, a volunteer in the experiment, can now see colors and regained more peripheral vision.

Mass Eye and Ear

Therapy

THE CRISPR REVOLUTION

A Gene-Editing Experiment Let These Patients With Vision Loss See Color Again

September 29, 2021 · 9:00 AM ET

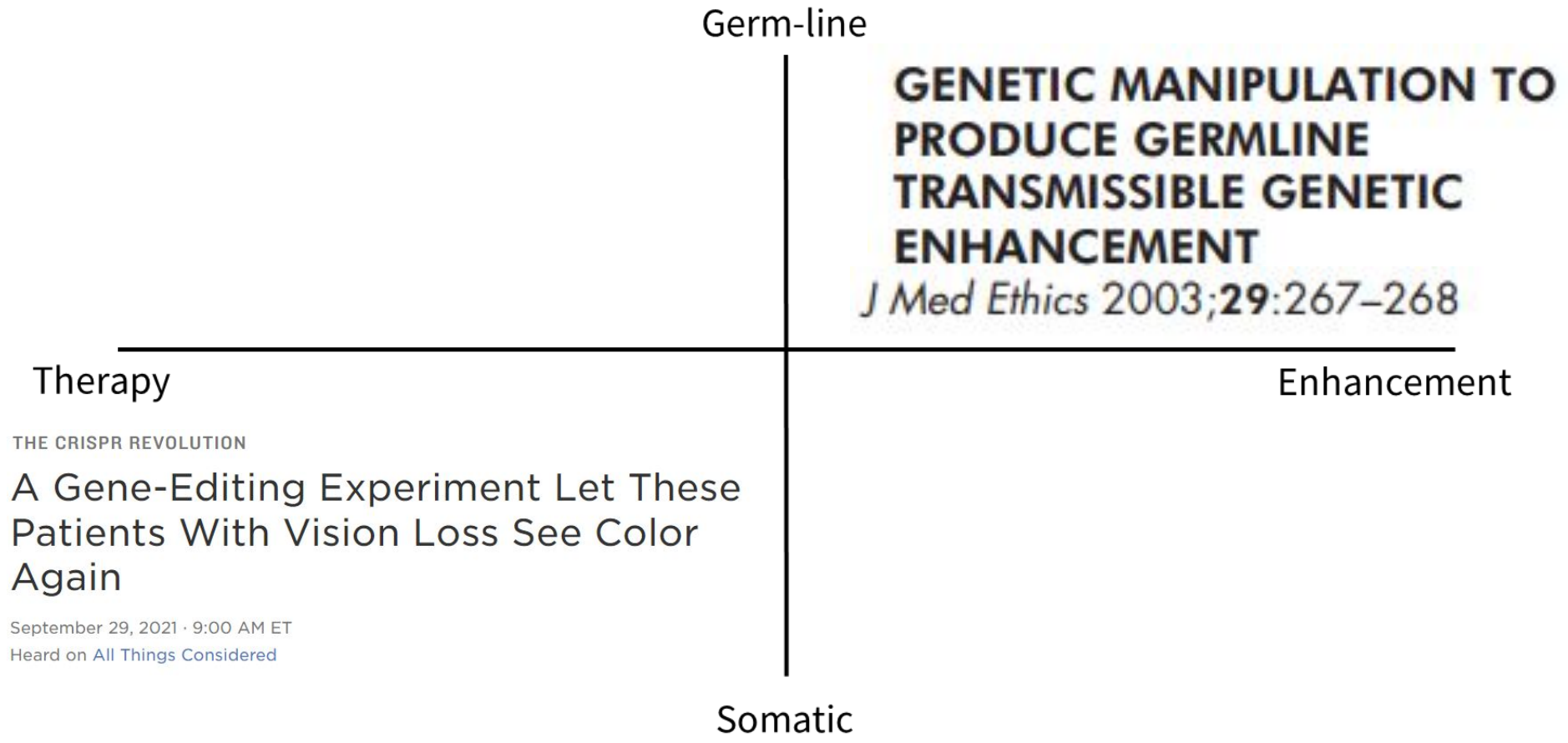
Heard on All Things Considered

Carlene Knight, who has a congenital eye disorder, volunteered to let doctors edit the genes in her retina using CRISPR.

Franny White/OHSU

Somatic

Considerations in the Case Study



From Thought Experiment to Reality

AP U.S. News World News Politics Sports Entertainment Business Technology Health Science

Chinese researcher claims first gene-edited babies

By MARILYNN MARCHIONE November 26, 2018

He Jiankui (HEH JEE'-an-qway), who goes by "JK," studied at Rice and Stanford universities in the U.S. before returning to his homeland to open a lab at Southern University of Science and Technology of China in Shenzhen

Ethical and Scientific Issues with Jiankui Experiment

FIRST OPINION

He Jiankui, embryo editing, CCR5, the London patient, and jumping to conclusions

By Henry T. Greely April 15, 2019

-Issues with informed consent (described research as looking for HIV vaccine)

-Failed to introduce the desired mutation

-Still potential for alternative strain of HIV to infect

Activity - Small Group Discussion (10 min)

Your group will be assigned one of the principles of bioethics. Discuss the case study through the lens of that principle. These are questions you may consider in your conversation:

- How do you view this scenario through the lens of your bioethics principle?
- How does your principle conflict with the analyses of other principles?
- How would you order the principles for this scenario?
- Any other thoughts on the most important questions/order?

Four principles: Autonomy, Beneficence, Non-maleficence, Justice

Large Group Share-out (5 min)

-Autonomy: individuals considered: potential/unborn children, parents; potential children do not have a choice - can't agree; concern with autonomy - risk/benefits, procedure not communicated accurately - is it truly an informed decision? Are there other actions that would give more choice/autonomy? How to handle autonomy of unborn children who cannot consent

-Beneficence: disagreement - some thought there was a weak case; if this was successful, would only give protection for one strain - is this a significant enough benefit medically to outweigh risks of CRISPR?; social behavioral interventions could be better to provide beneficence; on the other hand, greater good of society - if this paves the way for a preventative HIV treatment could be useful (but poor design indicates this specific case is not a great example) - the poor design makes it harder for next people who design experiment well

-Non-maleficence: a lot of focus on alternatives; sperm washing is a viable alternative - many things in best interest of children other than this; antiretorviral therapies have gotten much better, can take care of this issue in other ways - doesn't seem to have considered well-being of children given all the other proven ways of doing the stated goal

-Justice: this one is hard! This one is more contingent on how we respect autonomy of individuals and how we make the calculation of harms/benefits; comparison with covid vaccine where it is safe, proven, effective - compared with this experimental method which is risky and has other alternatives; who you decide to even ask to partake is going to change calculation - who will want to sign up for this?

Science and society

10 min independent reading
10 min small group discussion
10 min large group share-out

- What part of this reading surprised you?
- What part of this reading made you uncomfortable?
- What resonated with you?
- Where have you seen examples of society influencing science in your field of study?

Large Group Comic Shareout

-personal story of being susceptible to ‘cultural locatedness’ introduced in this comic; “let’s cure all the diseases! No more X!” - hadn’t considered some of the aspects based on cultural knowledge, working with positionality

-deafness is a go-to example; in hearing communities, people assume it is a disability, but deaf people don’t view it that way - it is an identity they value; highlights need to talk with people in community engages with them and their goals, what they want

-cystic fibrosis vs. sickle cell - what questions are asked, who benefits? Sickle cell has been ignored due to systemic racism; new research creating gene therapies for sickle cell, but they are very expensive and won’t necessarily be affordable/accessible those who need it

Session 2: History of Heredity

Learning goals

- Recall how the study of heredity and genetics has developed over time
- Understand how societal biases intersected with knowledge of heredity/genetics to justify early scientific thought and 19th/20th century eugenics movements
- Analyze how historical context impacts modern-day science through the specific examples of eugenics and genome editing

Please complete readings in Canvas before class.

Taught by Daniel Cotter & Emily Greenwald

Guest lecture by
Dr. Jazlyn Mooney