Introduction to Genetics, Ethics, & Society

BIOS 232

Course overview

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

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

Taught by Daniel Cotter & Emily Greenwald

Guest lecture by
Dr. Jazlyn Mooney

Outline

- Brief overview of history of heredity pre-genetics
- Introduction to eugenics
  - Guest Speaker: Dr. Jazlyn Mooney
- History of genome editing and Recombinant DNA Advisory Committee
- Discussion Activity: Concept Map

Agreed Upon Group Norms

-Be respectful of conflicting opinions

-Commit to learning and growing

-Compassionate listening

-No talking over anyone

-Make space, take space

Sensitive Topics Acknowledgment

It’s okay to take a break or step away and take care of yourself.

Today will cover some difficult topics including slavery, racism, and the eugenics movement. Please prioritize your well-being and check in with yourself. Step outside, take a break, take a deep breath, do what is best for you in processing.

History of Heredity

(pre-genetics)

Hereditas — herencia — hérédité — *heredity*

- A legal term indicating the rules and rights of an heir and of succession.
- Many Roman legal cases were concerned with heredity and property inheritance.
- There are different systems around the world for determining heredity and family ties.

hereditas noun

Save Word

he·re·di·tas

variants: *or less commonly* **haereditas** \ hə ˈredə ˌtas \

plural **hereditates** \ ˌ ˈtāt(ˌ)ēz \

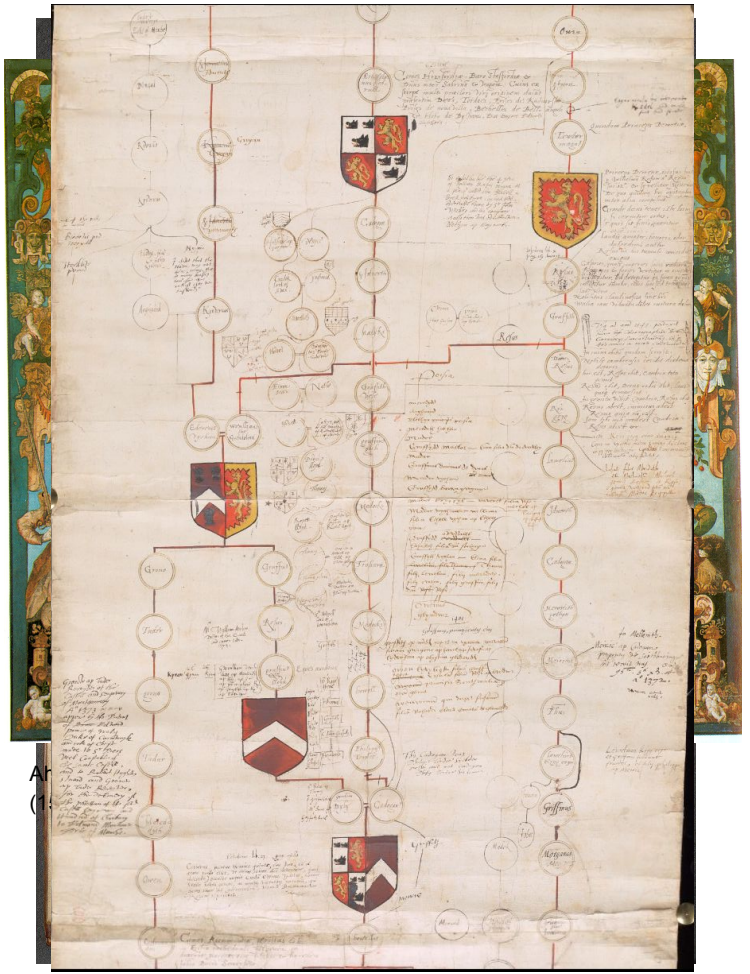
Definition of *hereditas*

Roman & civil law

: inheritance or succession : the rights and liabilities to which an heir succeeds : an estate of a deceased person regarded as a juridical person

Heredity becomes more important as time passes

- In Medieval Europe, families became more invested in tracking heredity.
- Royal families would write down detailed accounts of their ancestors.
- The shape of these stylized trees led to a small pronged symbol for “descent” which was dubbed “pié de grue” because it looked like the foot of a crane
    - Pié de grue → pedigree

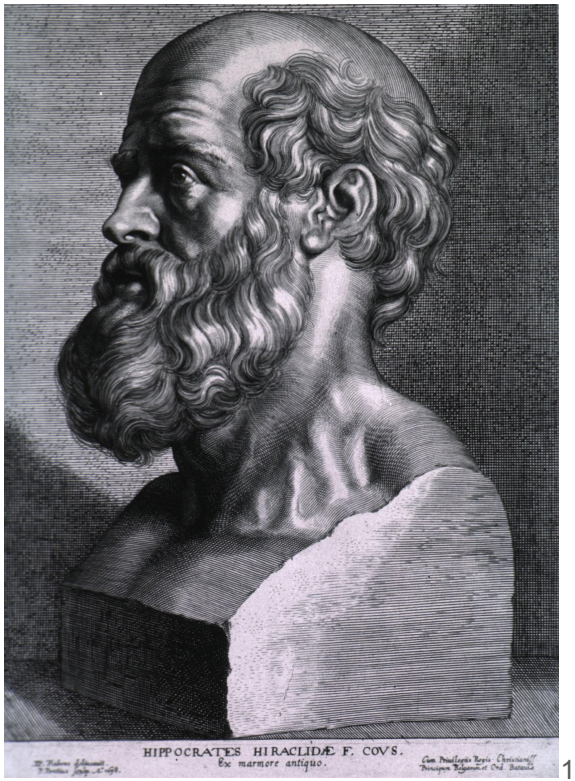


Cotton Ch XIV 1 f. 3r

King's 395 ff. 32v-33

How did heredity relate to physical traits?

- Greek and Roman thought
  - **Hippocrates (460 – 370 BCE)**
    - both parents produced “semen” or seminal fluids that intermingled to create the embryo
    - Mixed traits were explained by the blending of male and female seminal fluids



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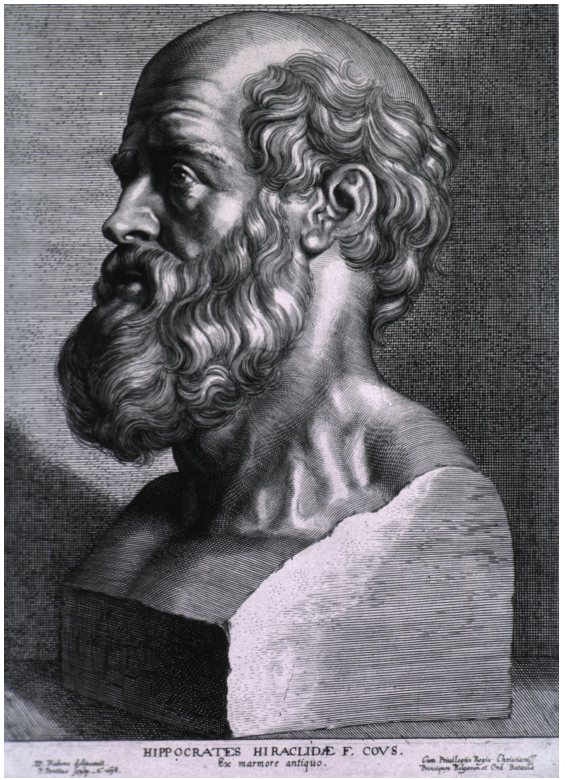
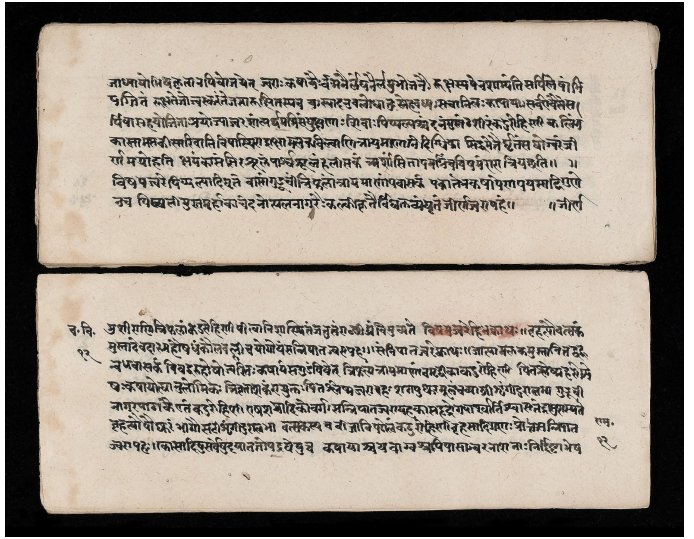
    - Mixed traits were explained by the blending of male and female seminal fluids
  - **Aristotle (384 – 322 BCE)**
    - germs in female menstrual blood were formed into a new living being by the movement of the paternal seed
    - environmental attributes in the womb (temperature, age, diet, etc…) affected the gender of the newborn



How did heredity relate to physical traits?

- Greek and Roman thought
  - Hippocrates
  - Aristotle
- Ancient Indian thought
  - In the Charaka Samhita (300CE), characteristics of the child are determined by four factors
    i. mother's reproductive material
    ii. the father's sperm
    iii. the diet of the pregnant mother
    iv. the soul which enters into the fetus



How did heredity relate to physical traits?

- Greek and Roman thought
  - Hippocrates
  - Aristotle
- Ancient Indian thought
- Arabic thought
  - Abu al-Qasim al-Zahrawi
    - describes the hereditary nature of haemophilia in his Al-Tasrif (1000CE)
  - Judah HaLevi
    - Describes dominant and recessive traits in The Kuzari (1140CE)

“Good” and “bad” blood

- In Medieval Europe, “blood” became the defining factor that related kinship between families.
- Nobles would pass their “good” blood onto their offspring and people with “bad” blood would do the same.
- Even animals had blood statuses. Falcons especially were renowned and could not be mated with lower birds at risk of tainting their good blood.

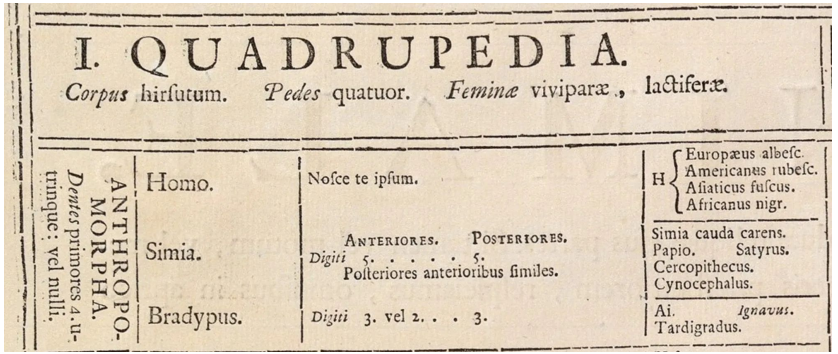
Groups of individuals or animals who shared the same blood were said to be a “race”

- The concept “race” came about to describe groups of individuals who shared the same kinship (or blood)
    - Was used to group individuals by nationality or ethnicity
- Early examples in the 1400s in Spain:
    - Non-christians, especially Jews were often persecuted and denied social status and land ownership.
    - *Sentencia-Estatuto* barred Jewish converts to Christianity who couldn’t prove four generations of affiliation from holding private or public office and receiving church land grants
        - “the first example in history of legalized racism” (Leon Poliakov)

“Retaule de Sant Bernardí i l'Àngel Custodi” - Jaume Huguet

Race and Classification

- The first uses of the word in English (in the 16th century) were used to categorize groups of humans
    - “Race of saints” or “race of bishops”
- With colonialism, groups around the world were classified into different races
- With the rise of taxonomic systems like those of Linnaeus and Blumenbach, racial hierarchies developed and became linked to science



I. QUADRUPEDIA.

Corpus hirſutum. *Pedes* quatuor. *Feminæ* viviparæ, lactiferæ.

ANTHROPOMORPHA. *Dentes primores* 4. utrinque: vel nulli.

Homo. Noſce te ipſum. H { Europæus albeſc. / Americanus rubeſc. / Aſiaticus fuſcus. / Africanus nigr.

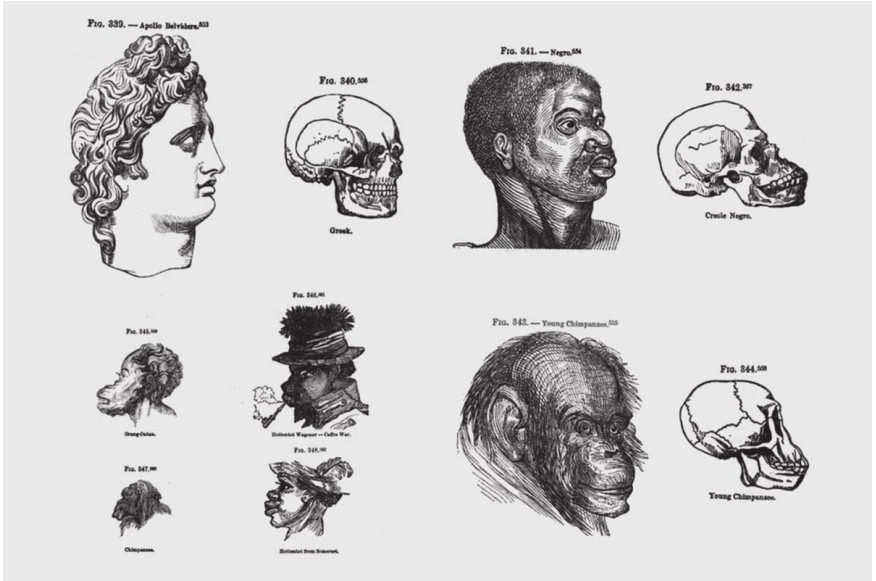
Simia. ANTERIORES. POSTERIORES. *Digiti* 5. . . . . 5. Poſteriores anterioribus ſimiles. Simia cauda carens. / Papio. Satyrus. / Cercopithecus. / Cynocephalus.

Bradypus. *Digiti* 3. vel 2. . . 3. Ai. *Ignavus*. / Tardigradus.

The order of Quadrupeds in *Systema naturae*, 1735

Activity 1: Small group discussion (5-7 min)

“Since the subject of ethnology was hierarchical classification of the races, absolute equality of them was out of the question.”



Discuss:

- How can classification occur without hierarchy?
- Are there any examples you can think of?

The historical linking of heredity and race is inextricably tied to Christian hegemony and colonialism

"If we are careful to situate Linnaean thought in the context of eighteenth-century theories of difference, we immediately recognise that Linnaeus' four primary taxonomic categories (…) are not functions of biology or morphology, but rather of geography."

– Ezra Tawil

The historical linking of heredity and race is inextricably tied to Christian hegemony and colonialism

- Before the 16th century, slavery was largely linked to religion (specifically non-Christian faiths)
- Over time, we see the legalization of a new hierarchy based on race
    - Race becomes linked to heredity as a justification for slavery

The historical linking of heredity and race is inextricably tied to Christian hegemony and colonialism

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The justification for black servitude changes from a religious status to a designation based on race

In parallel, mechanisms of heredity change from the 17-19th centuries, influencing view on malleability of heredity

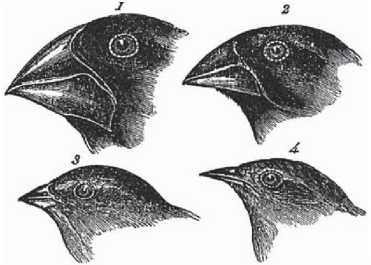
- Preformation
  - Humans were preformed and simply unfolded from either the egg or the sperm (spermist vs ovist)
- Epigenesis
  - Human form gradually emerges and is influenced by the environment

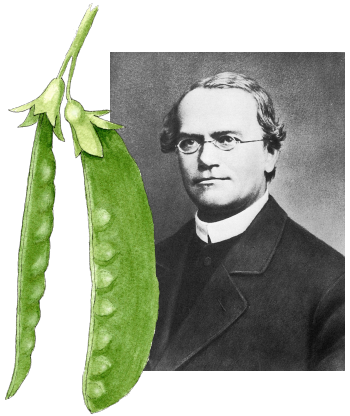
In parallel, heredity becomes inextricably linked to genetics

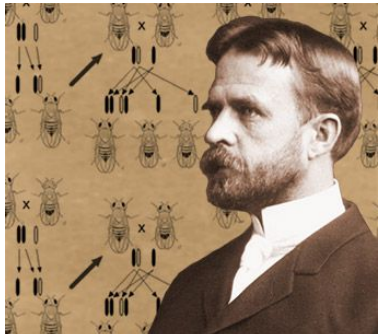
1859 - Darwin publishes *The Origin of Species,* describing a theory of natural selection

1865 - Mendel's experiments on peas demonstrate that heredity is transmitted in discrete units

1911 - Morgan's work with fruit flies shows that genes are carried on chromosomes







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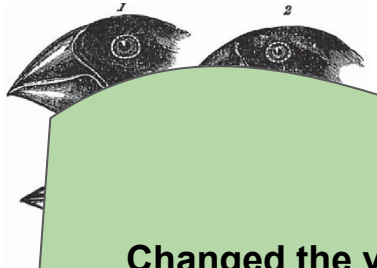
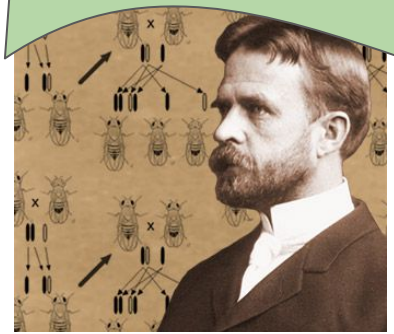


Changed the viewpoint on heredity largely from environmental to deterministic



History of Heredity

Eugenics

Eugenics: Brief reading discussion

Readings:

- *Eugenic Nation* (Alexandra Minna Stern)
  - Introduction
- *She has her mother's laugh* (Carl Zimmer)
  - Chapter 2

With a partner, please chat about for **5 minutes**:

- Did any part of the reading surprise you?
- Did any part of the reading make you uncomfortable?
- What questions did this bring up?

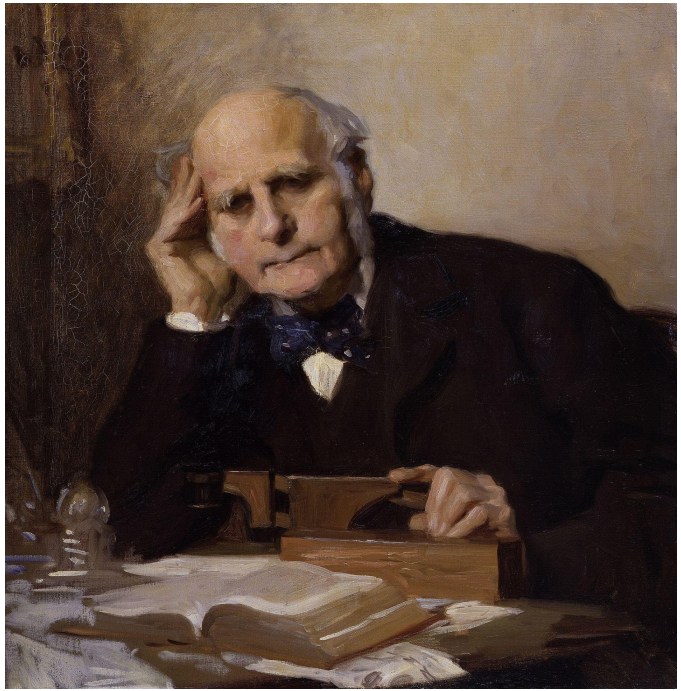
Guest Speaker

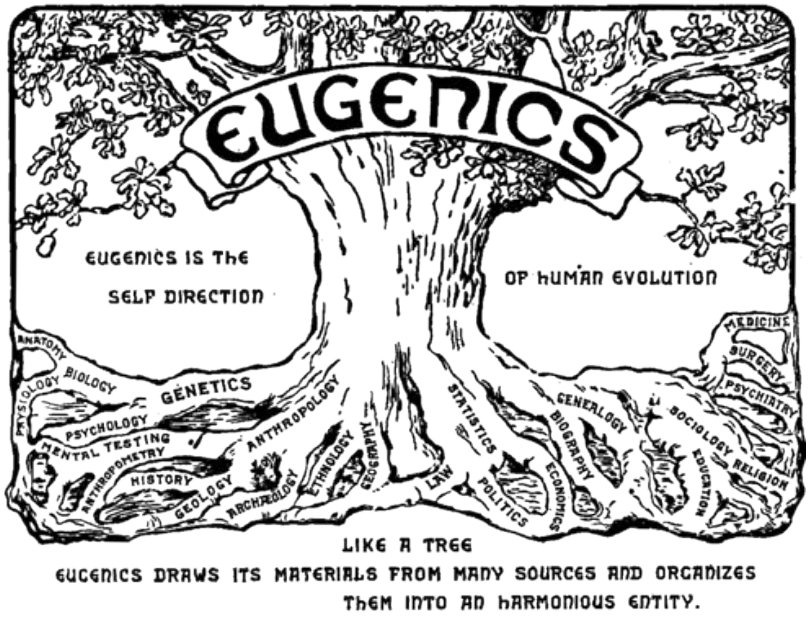
Dr. Jazlyn Mooney

Genetics and Racism in America: The 2020 Election

You have good genes. You know that, right? You have good genes. A lot of it is about the genes, isn't it, don't you believe? The racehorse theory. You think we're so different? You have good genes in Minnesota," Donald Trump, Minnesota, 9/18/20

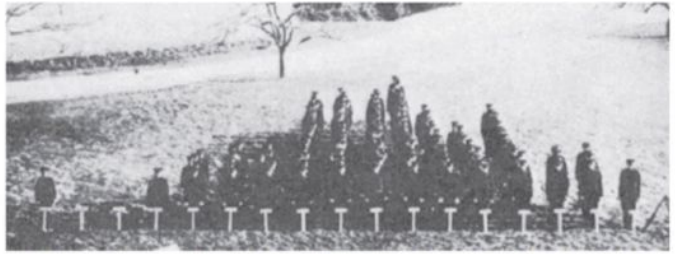
Did these ideas come from science?





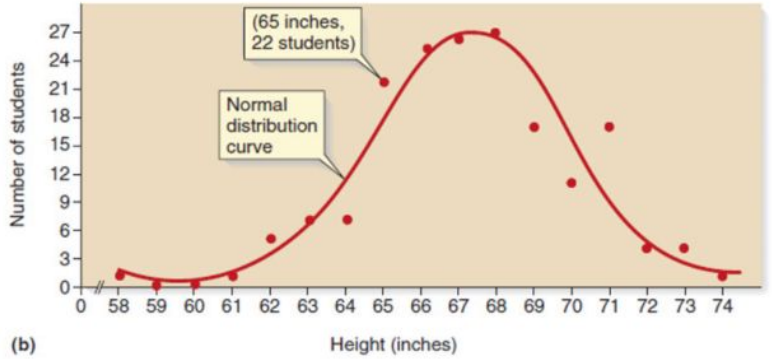
https://en.wikipedia.org/wiki/Eugenics

Height was one of the first complex traits to be studied by Galton



Number of students	1	0	0	1	5	7	7	22	25	26	27	17	11	17	4	4	1
Height (inches)	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74

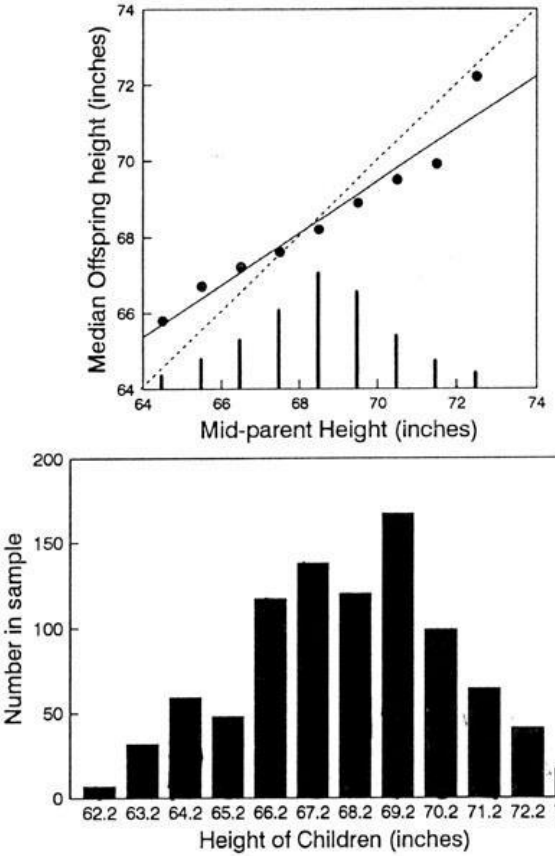
(a)



(b)

Figure 10-1. Human height was one of the earliest quantitative characters studied in detail. (a) Height distribution (inches) for 175 students in 1914 attending the Connecticut Agricultural College. (b) Graphical presentation of these student heights showing their close fit to a normal distribution. (a: Reprinted with permission from Albert and Blakeslee: Corn and Man. *Journal of Heredity*. 1914;5:51. Oxford University Press. b: Reprinted with permission from Brooker RJ: *Genetics: Analysis & Principles*, 3rd ed. New York: McGrawHill, 2008.)

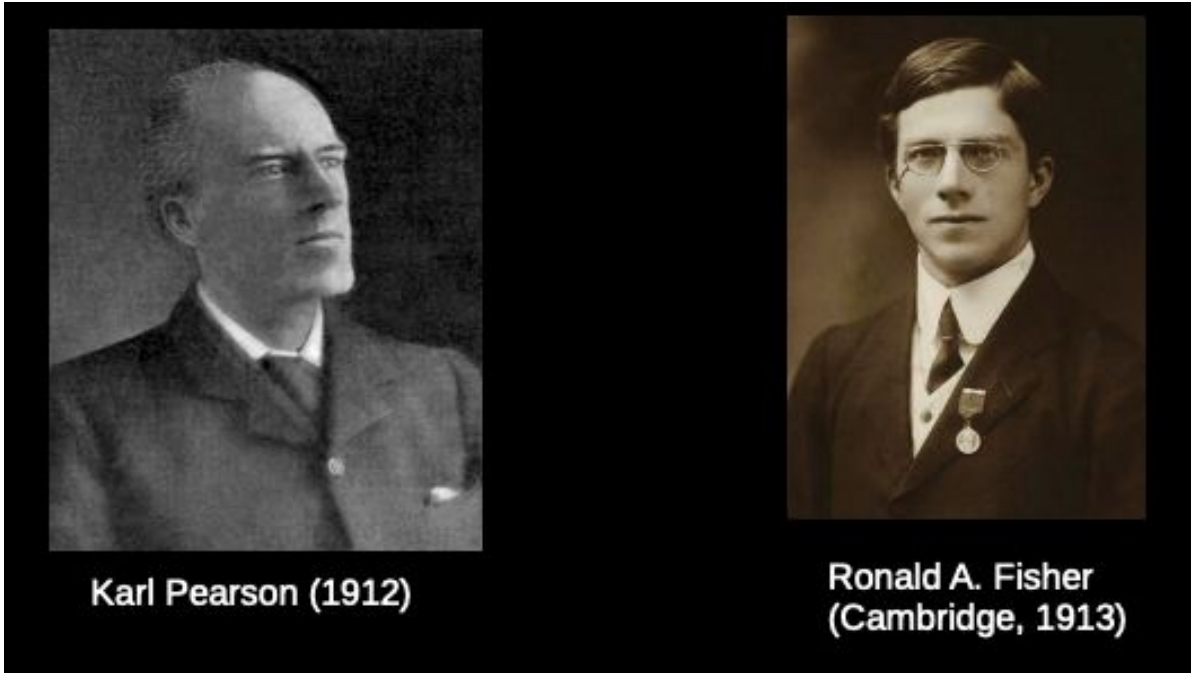
Galton's parent-offspring regression



Note: median offspring values regress toward the parental median

h^2 = heritability = slope of the regression of midoffspring on midparent

Galton and Leonard Darwin also went on to fund two of the pioneers of modern statistics



Slide from John Mcgowan

How did eugenics take root in California?

How did eugenics take root in California?

1. European immigrants saw themselves as settlers, who were spreading civilization throughout the untamed Pacific West
2. The rampant discrimination against Indigenous Americans built the foundation for scientific racism to take hold and permeate
3. Many organizations (educational, civic groups, medical societies etc.) already subscribed to eugenic philosophies and were aided by the State Department of Institutions which implemented anti-immigrant policies, intelligence testing, and mass sterilization

California has always been home to key players in the national eugenics movement

- Joseph P. Widney (doctor) and Luther Burbank (horticulturist) migrated to California from Europe
  - Both played large roles in using preservation of nature for eugenic purposes
- David Starr Jordan
  - President of Stanford and a founding member of the first American eugenics groups, the Eugenics Committee of the American Breeders' Association
  - This group was founded by a biologist from Cold Spring Harbor named Charles Davenport
    - Jordan was the chair of the eugenics committee
  - Spearheaded the (progressive) eugenics movement from its inception in the 1910s thru the 1930s
- Charles Goethe (realtor) and Samuel Holmes (Berkeley prof.)
  - Pressed Californian's to enforce an "immigrant cap"
  - Created a eugenics group in Northern California, which Lewis Terman and David Starr Jordan also joined

California carried out 20,000 sterilizations from 1920s-1950s

- Most of were carried out in “feebleminded homes” and mental institutions (which were determined by IQ tests)
- Dementia praecox (schizophrenia) was among the highest rates sterilized
- Higher likelihood of sterilization: Female, Spanish surname, younger than eighteen
- 55% of sterilizations in Sonoma were women (25% were there solely for sterilization)

Sterilizations in California

Superintendents of these institutions wielded an unwarrantable amount of power over the reproductive lives of patients

- Could approve without consent of patient or family
- “Improve standard of human race” “prevent unfit from reproducing their own kind”
- Overcrowding in institutions further encouraged more sterilizations
- Characterized as a revolving operating room

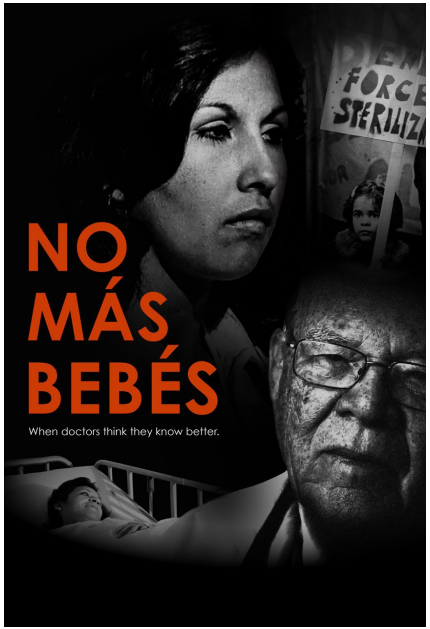
Extended into strategies of reproductive regulation; gave psychiatric diagnosis and used it as “hereditarian improvement”

Mass sterilizations of Mexicans in California

- High rate compared to other racial counterparts
  - 13%-29% → sterilized patients
  - >6.5% → state population

- Many of those sterilized were young adults/children
  - Officials used IQ, "criminal tendencies", and bad parenting to warrant sterilization

- Fred O. Butler → medical supervisor
  - Ordered many sterilizations under pretenses of: "low grade Mexican type [parenting]", "inferior stock", "involved in a gang of marauding Mexicans"



Madrigal V. Quilligan

- During the mid 1970s, the predominantly Latino Los Angeles district sued the Women's Hospital at University of Southern California/ Los Angeles County General Hospital
    - Working class Mexican women had non consensual sterilization performed (plaintiff)
    - Specifically postpartum tubal ligations after cesarean section
    - These procedures were supported by family planning initiatives of the War on Poverty
- The thousands of forced sterilizations on Mexican Women ranging from the late 1960s to mid 1970s allowed women of other minority groups to come forward

Madrigal V. Quilligan

- The plaintiffs were represented by Antonia Hernandez and Charles Nabarette
- A key witness, Karen Benker spoke against the doctors at the hospital
  - She recalls a conversation with Dr. Edward James Quilligan, where he said, “poor minority women in L.A. County were having too many babies; that it was a strain on society; and that it was good that they be sterilized”
  - His goal was to reduce the Negro and Mexican population with the money from a federal grant
- However, Judge Jesse Curtis did not view the witnesses evidence as vital to the ruling of the case
  - The judge ruled against the plaintiff stating the County Hospital “had acted in good faith”
  - He believed the defendant when they stated they would not perform surgery on a patient if they did not understand the procedure

- Advocacy against outdated sterilization laws grew during this period

- Birth Control benefited middle class white women while women of color were perceived as “destructive overbreadeers whose procreative tendencies needed to be managed”

- The Relf sisters (12 & 14) were sterilized after their mother unknowingly gave doctors consent because she could not read and thought she was giving consent to birth control.

★ Relf v. Weinberger concluded that large numbers of low income people have “been improperly coerced into accepting a sterilization operation”

  - Many other women from different ehtnic groups faces similar sterilization stories (Around 20-50% of Native American women had been forcibly sterilized)

California Law of 1986

“The right to choice over procreation is fundamental and may not be denied to any individual on the basis of disability...”

August Vollmer

- Vollmer emphasized the need to professionalize police agencies, using reliance on the scientific method to do so
    - Vollmer believed observation, clinical diagnosis, and rehabilitation provided a better alternative of rehabilitating criminals
- Vollmer insisted the starting point of evaluation of a criminal's mindset and motivations should be their genetic and constitutional makeup
    - Analogy of orange tree: "Environment plays an important role in developing all the potentialities of the tree, but that is all environment can do. It can add nothing to the tree that was not there at the beginning of its existence"
    - Extending analogy to humans: "A constitutionally defective individual will always be defective"
- "As a general rule, brilliant and talented persons usually are descendants of people of superior qualities while the stupid and insane are descendants of dull or defective forbears"

Vollmer's Philosophy

- Prevention!
  - "Crime should be combated by preventive measures in the same manner that diseases are fought by professional health officials"
- Vollmer was elected to the park board (local) and brought his philosophy to the industry
  - Access to recreation and nature areas was seen as a crucial component of maintaining a balanced and harmonious society
- Transformation of Vollmer's philosophy:
- National parks took Vollmer's philosophy and transformed it into something advantageous to them
  - National parks paired their interests for expansion with eugenicists' interests for increased access to nature to keep society's "criminals" at bay

An Alliance Between Eugenicists and California Landscapes

- In a general sense, both industries view exposure to nature as a method of containing the worst and bringing out the best of humans' environmental (evolutionary) and genetic (hereditary) predispositions
- Nature making in California:

1. Founded and financed environmental organizations
2. Fabricated justifications for expansion
    - "We can enter [wilderness] and relish it only because we have construed it as untamed and untrampled"
3. Named landmarks after European colonizers

The Sanctity of Trees

- Redwoods and Sequoias were seen as ancient and many had spiritual connections
  - "... a tree which was old when the first Egyptian conqueror penetrated to the valley of the Euphrates" -Roosevelt
  - "Sequoias were flourishing when dinosaurs roamed the earth" -Grant
  - "It has seen the rise and fall of civilization" -Jordan
- European Americans aligned their lives with the timeline of Redwood trees
  - Related it to conquest, domination, and racial supremacy
- Saw themselves as key figures in opinions towards Western settlement

Joseph P. Widney

- Western colonization was a triumph destined to happen and it began centuries ago in Eurasia
- Believed Los Angeles would become the “world capital of white domination”
  - Accomplished through the working of natural laws
  - “Teutons” (Germanic tribe) were to control the world, not Latins
- California would inevitably lose its Spanish and Mexican roots and survival of the fittest would give birth to a “hardier American race”
- Basically a white supremacist
  - Firmly believed in Aryan race supremacy
  - Advocated for these views for over 30 years

Luther Burbank

- Experimented with new methods of hybridization and cross fertilization
  - Shasta daisy, the Burbank rose, the Paradox walnut, and the Humboldt blackberry-raspberry
- He contributed to significant progress in the manipulation of nature and crossing of diverse plants
- Believed California had the best nature and was destined to head west
- Atypical eugenicist
  - Influenced by French naturalist Jean Baptiste de Lamarck
  - Traits were not completely predetermined
  - Environmental influences could become intrinsic to the organism
- Believed that the best characteristics from a “race” could be consciously combined to make a stronger “race”
  - Led him to become inviting of racial mixing and immigration
  - Saw it as an exciting opportunity
  - Was MUCH different than all prominent eugenicists who preceded him
  - Compared racial blending to the experiments that he performed on flowers and vegetables

David Starr Jordan

- Connected the “majesty of the mountains” and “abundance of coastal plains” to intrinsic superiority of Californians
  - They lived longer, were stronger, and larger than Easterns of the same age
  - Californians were individualistic, self-reliant, adaptable, etc.
  - The blood is what leads to these attributes
- Preservationist
  - Charter member of Sierra Club, helped organize the Sempervirens Club, and apart of Save-the-Redwoods League
- Believed in a pure-blood utopia (highly contrasted to Burbank)
  - Anglo-Saxons were at the top of the racial hierarchy
  - “Natural selection” mindset: strong races prevailed in hard times where weak races have become parasites to society
  - Immigration leads to hereditary unfitness; wanted to restrict South Europeans, Asians, and Mexicans

Charles Matthias Goethe

- Died on July 11, 1966
- Received praise in the San Francisco Chronicle and in the Sacramento Bee
- Renowned conservationist
- Passion for environmentalism was rooted in eugenics, selective breeding, and anti immigrant policy
- Believed that the progress of California was a direct result of the “white pioneer stock”
    - Compared the European-American migrants to the strength and hardiness of the cacti living in the deserts near California
    - Believed that those migrants were a “superlative biological strain whose purity demanded defense”
- Never had kids with his wife who he had to beg to marry him (asked her 9 times)
- Instead of having kids, funded youth programs for kids that seemed to fit their idea of an ideal race

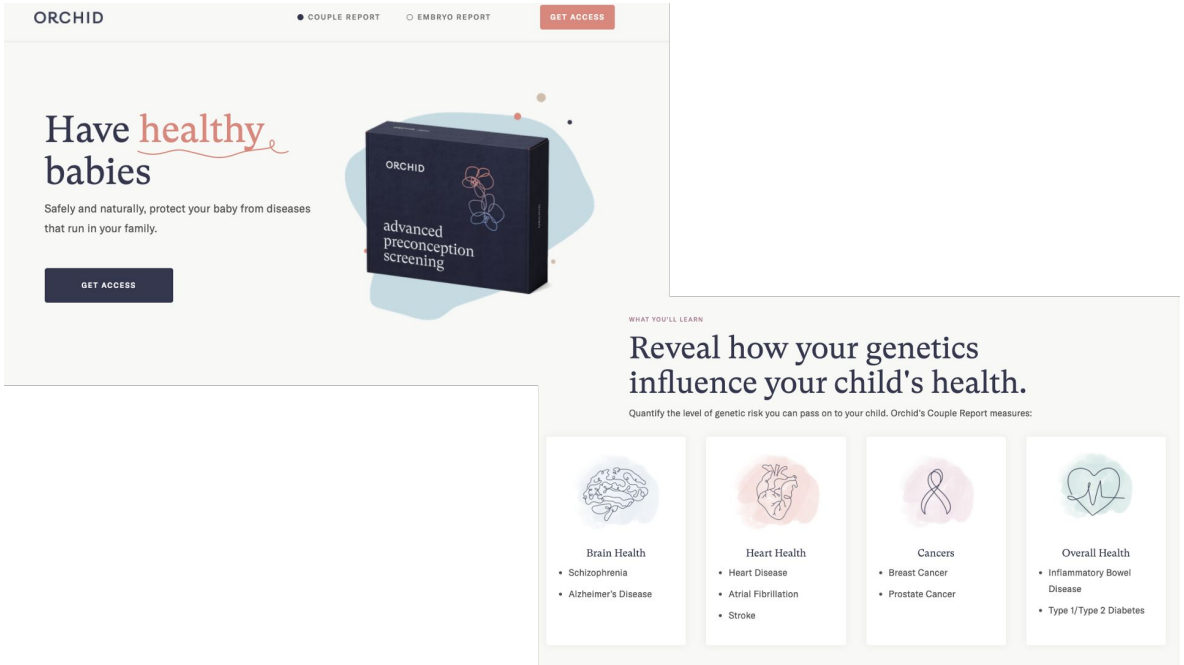
Goethe's Role in Politics

- Became vocal in political debates about immigrant restriction
  - Formed Immigration Study Commission which analyzed influx of "low powers" to California (Mexicans and Southern Europeans)
  - Talked about invading the "germ-plasm" and threatened race suicide
  - Wanted brokers to not sell to Mexicans due to "inferior intelligence"
  - Admired Germany in the late 1930s with sterilization and the beginning of the Nazi regime
  - Wanted to fight "biological illiteracy" aka people who were open to all races
  - Created pamphlets in the ESNC that discussed the "superior species"
  - Attempted to link nature and eugenics

Goethe's Legacy

- Very wealthy, $24 million worth of estates at his death
- Sponsored many Redwood forests to conserve the trees and funded scholarships
- Considered one of the most "outstanding citizens" in Sacramento
- In his book "What's in a Name" he said "Imagination, contemplation, discussion, some agitation, then finally Selection, Decision" which is similar to the "selection" of the colonists
    - "Those blue-eyed, blonde empire-building Nordics" that settled in California
- Built Yosemite Museum that helped teach future naturalists about California's past, including the pioneers that "paved the way"
    - "Learn to read the trailside as a book"
- Named nature with "pioneer" names to attempt to link white superiority with species, such as the Smith River or the Redwood reserves; showed a specific rendition of history
- He was famous but towards the end of his life, some began to critique him
    - Nevertheless, still had many supporters
    - Connected the outbreeding of "bad genes" to environmentalism and conservation

What about now?



Polygenic risk scores: a biased prediction?

Francisco M. De La Vega & Carlos D. Bustamante

Genome Medicine **10**, Article number: 100 (2018) | Cite this article

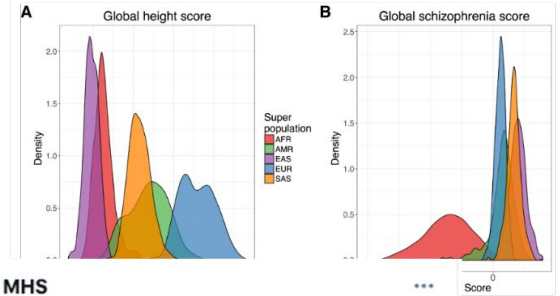
7060 Accesses | **24** Citations | **53** Altmetric | Metrics

A Research to this article was published on 14 November 2018

Abstract

A new study highlights the biases and inaccuracies of polygenic risk scores (PRS) when predicting disease risk in individuals from populations other than those used in their derivation. The design bias of workhorse tools used for research, particularly genotyping arrays, contributes to these distortions. To avoid
inclusion of diverse populations in research, unb
reduction in PRS are critical.

Martin A. et al. AJHG 2017



Genevieve Wojcik, PhD MHS
@genandgenes

The thing about current PRS for complex diseases is that they are complex and can capture modifiable environmental factors that reflect a broken society.

This is problematic on many levels but also reflects a fundamental misunderstanding of what many risk scores are telling us.

Activity 2: Small group discussions

Break into small groups and discuss these questions **(10 minutes)**.

- Taking what you learned about the history of heredity (pre-genetics), how did early thinking on these topics shape the study of eugenics?
- What were the different societal and scientific influences that shaped the study of eugenics?

5 Minute Break

History of Heredity

Genome Editing

History framing of genome editing

- The development of genome editing is a technology that makes it possible to individually alter the material of heredity

History framing of genome editing

- From the perspective of interaction between scientists and the public, recombinant DNA technology is genome editing’s conceptual precursor

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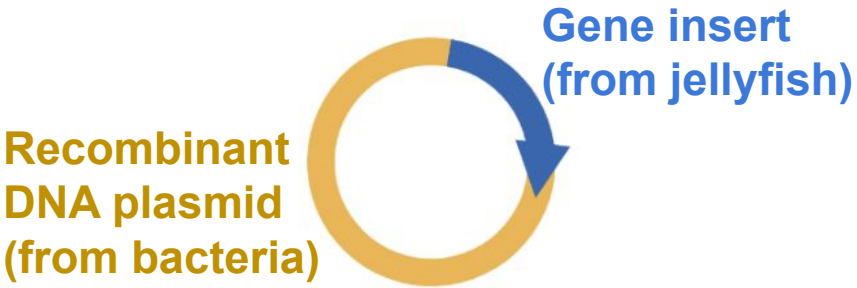
- From the perspective of interaction between scientists and the public, recombinant DNA technology is genome editing's conceptual precursor

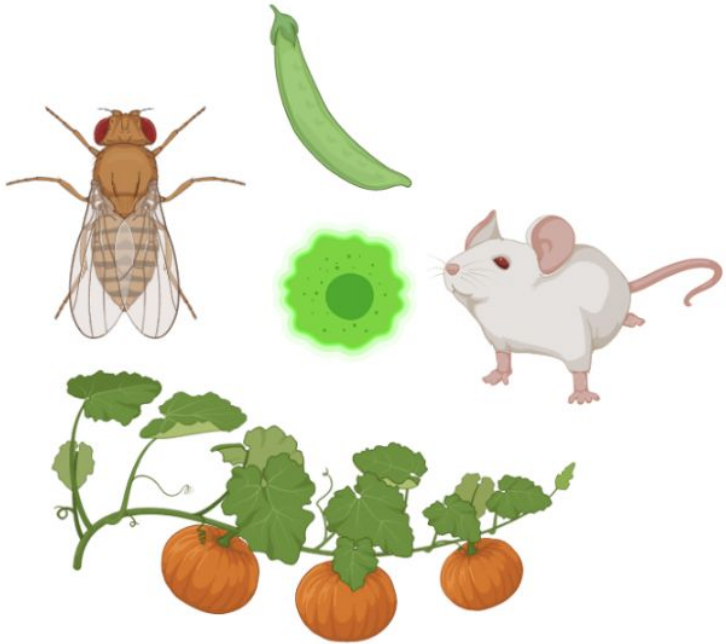
- Genome editing as a concept led to molecular biology interfacing with the public more than most other biological concepts

- Genome editing and recombinant DNA technology both led to social outcry from religious groups, policymakers, and environmentalists

Recombinant DNA is genetic material from different sources combined together



Recombinant DNA can be used to make genetically-modified organisms

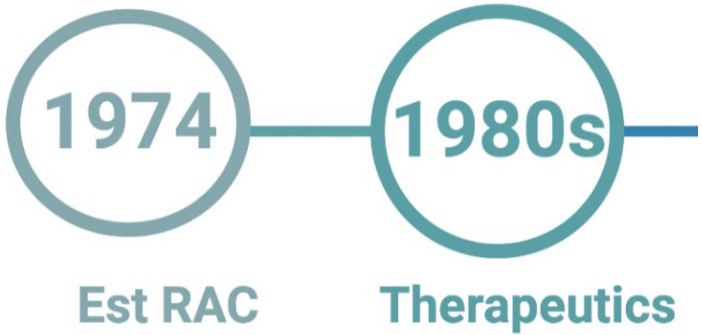


Recombinant DNA (rDNA) advisory committee (RAC)

Focus: rDNA & influence on environment

NIH Office of Science Policy Archives. Accessed Apr 2022.

Recombinant DNA (rDNA) advisory committee (RAC)



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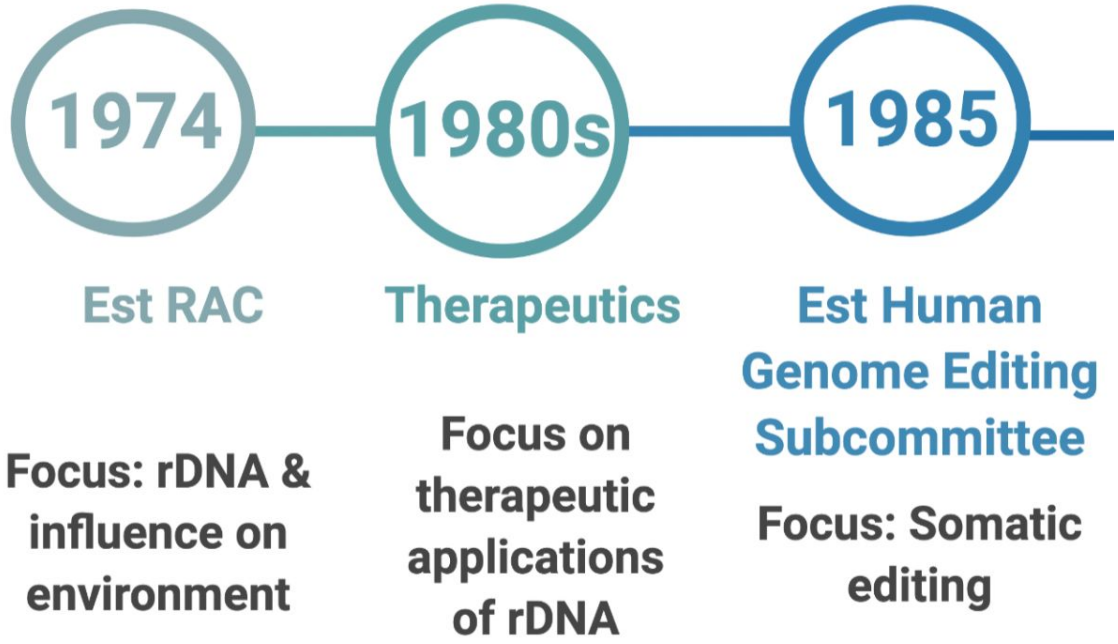

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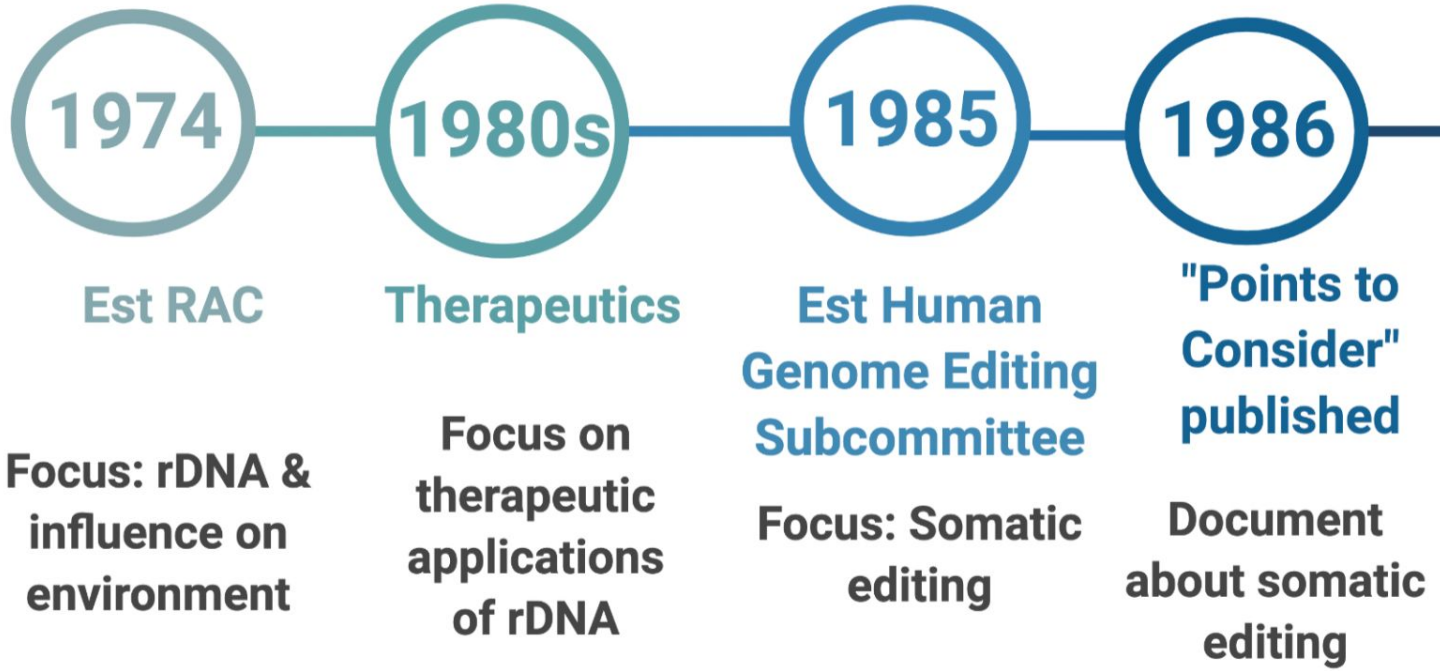

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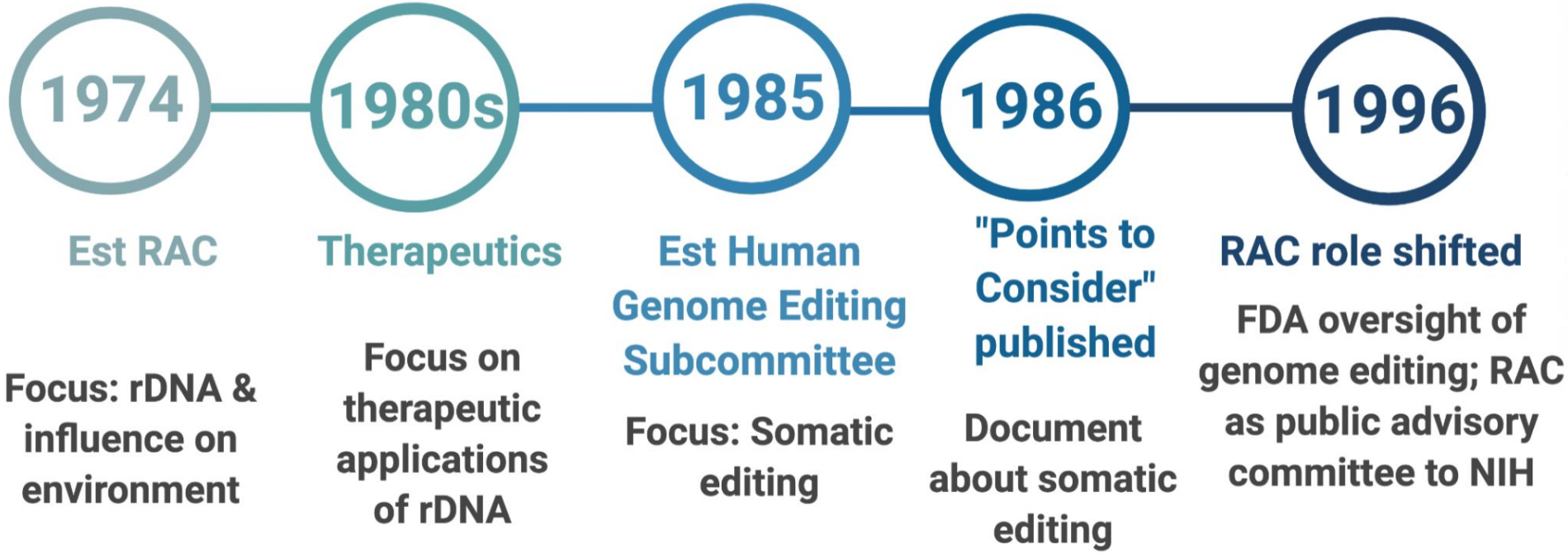


NIH Office of Science Policy Archives. Accessed Apr 2022.

Walters, Cook-Deegan, Adashi. 2021. *The CRISPR Journal.*

Human genome editing subcommittee

- Members: 4 lab scientists, 3 clinicians, 3 ethicists, 3 lawyers, 2 public policy experts
- Meetings were public
- Stance that germline genome editing should not be undertaken

Walters, Cook-Deegan, Adashi. 2021. *The CRISPR Journal.*

Human genome editing subcommittee disbanded

- 1996 - subcommittee was disbanded when the RAC stopped overseeing genome editing protocols

Walters, Cook-Deegan, Adashi. 2021. *The CRISPR Journal.*

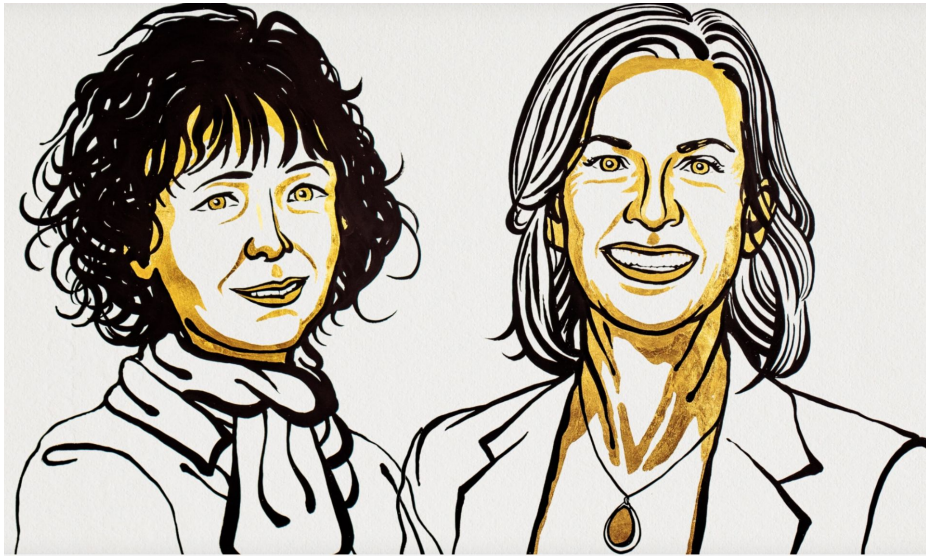
Human genome editing subcommittee disbanded

- 1996 - subcommittee was disbanded when the RAC stopped overseeing genome editing protocols

- 2019 - Recombinant DNA Advisory Committee (RAC) disbanded
  - There is currently no parallel or similar body

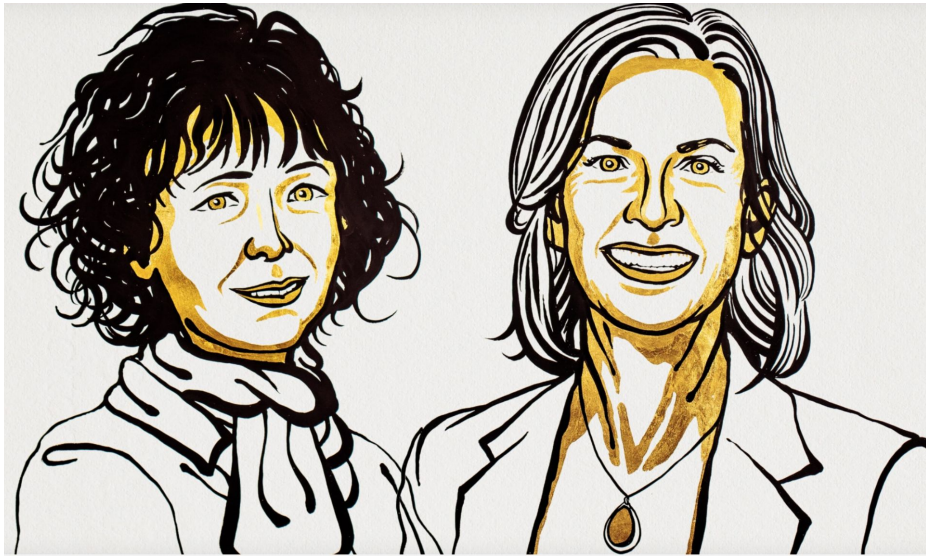
Walters, Cook-Deegan, Adashi. 2021. *The CRISPR Journal.*

CRISPR Discovery 2012



Emmanuelle Charpentier and Jennifer Doudna
2020 Nobel Laureates in Chemistry
Discovered CRISPR/Cas9 genome editing technology

CRISPR-Cas9 genome editing: efficient and specific



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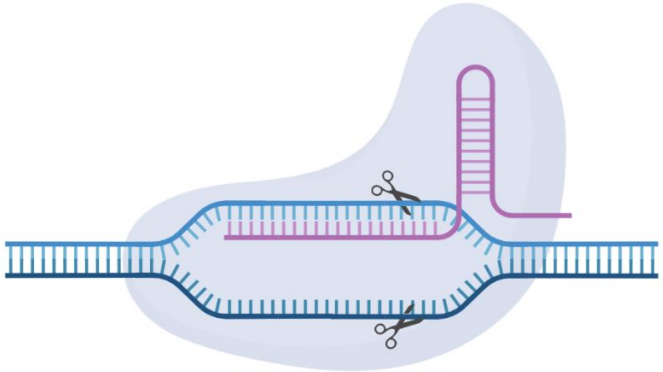

Cas9 enzyme makes a targeted double-stranded break in DNA

The RAC had little power by the discovery of CRISPR

- CRISPR/Cas9 discovery opened up the possibility of human genome editing

- By the time it was discovered, the RAC Human Genome Editing subcommittee had been disbanded, and the RAC had been demoted

Genome editing in humans

He Jiankui

Edited CCR5 locus using CRISPR/Cas9

(Image: Schmitz, R. 2019. *NPR.org.)*

Genome editing in humans

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BBC NEWS

China jails 'gene-edited babies' scientist for three years

30 December 2019

The Atlantic

SCIENCE

The CRISPR Baby Scandal Gets Worse by the Day

nature › news feature › article

NEWS FEATURE | 26 February 2019 | Clarification 11 March 2019

The CRISPR-baby scandal: what's next for human gene-editing

Genome editing in humans: 2018 He Jiankui

- The 2018 human genome editing case took place outside the US and outside the jurisdiction of the FDA or NIH

- By the time human genome editing had been done, there were no parallel advisory committees to interface with the public or develop a response

The RAC and human genome editing subcommittee

- Unique case study in history for scientists, ethicists and policymakers educating and interfacing with the public about a particular technology

- This historical oversight body and advisory board to funding agencies may inform your responses to ethical problems throughout the rest of this course

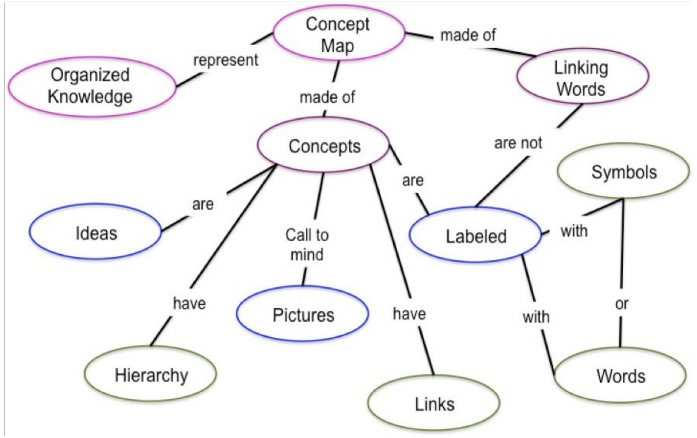
Activity 3: With your small groups, create a concept map

In what ways is modern-day research influenced by both the early history of heredity and the study of eugenics?

- Continue your thought process from the last activity, extending to more modern consequences

Ask yourself:

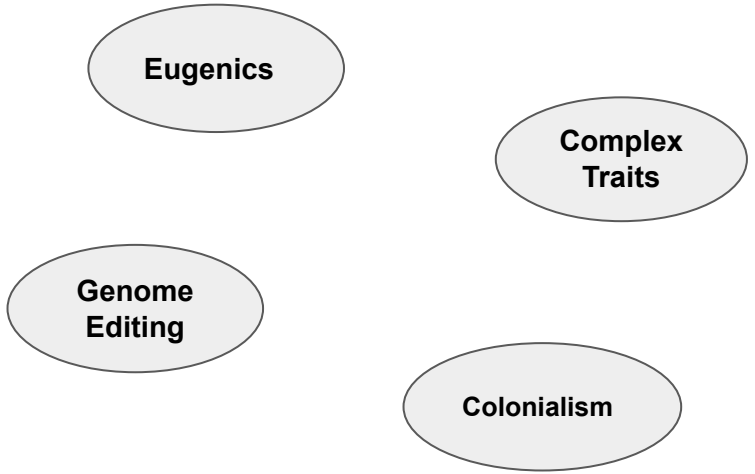
- Who from the 20th century do we still cite today?
- What sort of questions are asked?
- What recent papers have garnered significant backlash and why?



(Image: Sumeracki, M. *The Learning Scientists.)*

Activity 3: With your small groups, create a concept map

- What are historical and modern concepts of heredity and eugenics?



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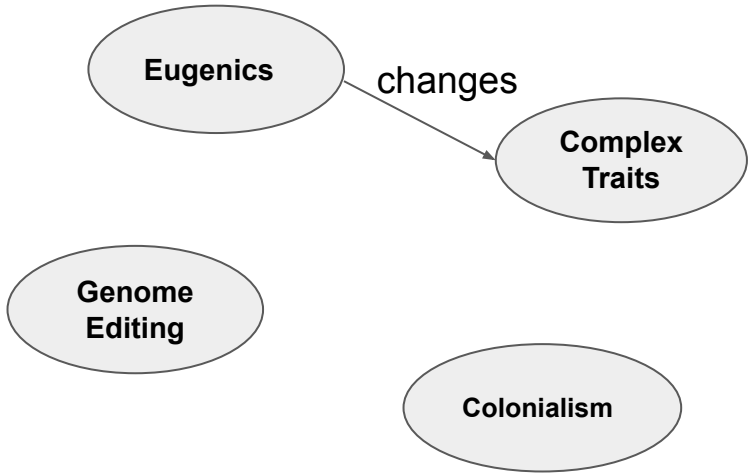
- How do these historical concepts link to modern genetics?



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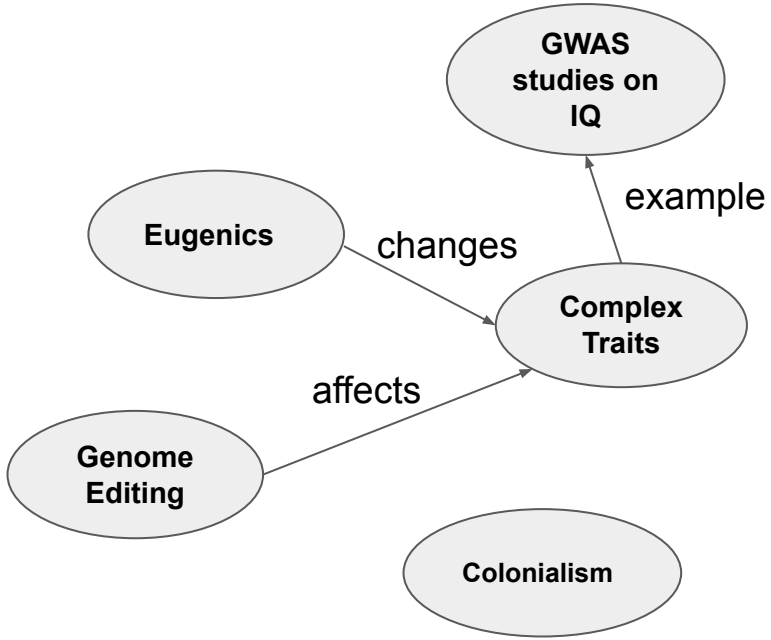

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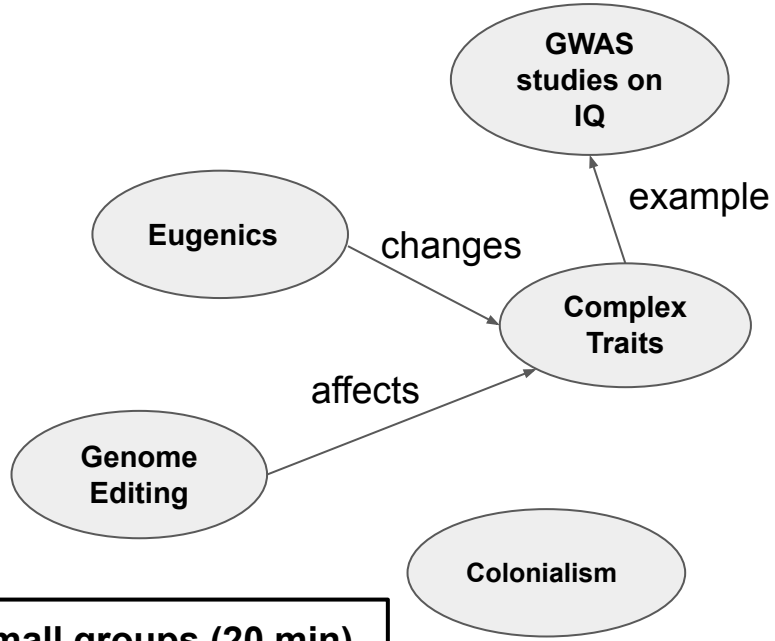

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Small groups (20 min)
Debrief (5 min)

Concept map examples

Heredity
Family
Law
Culture
Blood
Ancestors
Family trees
Pedigree
Physical traits

Good/bad
Race
Ethnic groups
Classification
Hierarchy
Christianity
Colonialism
Geography
Slavery

Consider:

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Racism
Eugenics
Genes
Complex traits
California
Sequoias

Intelligence tests
Forced sterilization
Polygenic risk scores
Embryo selection
GWAS of social traits
Genome editing

Session 3: Introduction to Human Genetic Data

Learning goals

- Identify limitations and concerns around the collection, use, and analysis of human genetic data
- Develop an understanding of the current landscape of genomic data stewardship
- Identify key stakeholders and conflicts of stakeholdership in the collection, use, and analysis of human genetic data

Please complete pre-class assignment in Canvas:
Ask 2-5 people in your life (friends, family, colleagues, community members, etc.) about their impressions of genetic studies and/or direct-to-consumer genetic testing.

Taught by Pagé Goddard, Meena Chakraborty, & Alanna Pyke

Session 3: Introduction to Human Genetic Data

Tuesday May 24, 2022

Facilitated by Pagé Goddard, Alanna Pyke, Meena Chakraborty

Learning objectives

- Students will be able to identify whether and how key stakeholders are involved in the collection, use, and analysis of human genetic data
- Students will examine the role of societal structures and norms in the collection, use, and analysis of human genetic data
- Students will connect historical context to reasons individuals choose to consent or decline into research studies today
- Students will be able to describe contemporary initiatives to make research on human genetic data more just and equitable



Session 3: Introduction to Human Genetic Data

Tuesday May 24, 2022

Facilitated by Pagé Goddard, Alanna Pyke, Meena Chakraborty

Assignment:

What does the landscape of attitudes towards genetics look like around you? Ask 2-5 people in your life (friends, family, colleagues, community members, etc.) about their impressions of genetic studies and/or direct-to-consumer genetic testing.