Race, Ancestry, Identity & Genetics
Part 1

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Learning Goals

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

Ground norms

- Be respectful of conflicting opinions
- Commit to learning and growing
- Compassionate listening
- No talking over anyone
- Make space, take space
- What is said in the room, stays in the room (confidentiality)
- Use “I”statements for sensitive topics
- Don’t equate people with stereotypes
- Don’t rush to judge others

Overview

20 min: Discussion and didactic lesson on social identity
20 min: Discussion and didactic lesson on genetic ancestry
10 min: BREAK
10 mins: Dialysis video
10 mins: Dialysis video discussion + key points
30 min: Case examples and reflections in small groups

Genetic Ancestry & Social Identity

What comes to mind when you think about race?

What comes to mind when you think about ethnicity?

What comes to mind when you think about ancestry?

Discussion

What was your rationale for putting down certain words?

Are there words in these clouds that you disagree with?

Race and ethnicity in the US Census over time

1790

- Free white males, Free white females
- All other free persons
- Slaves

2020

- White [+]
- Black or African American [+]
- American Indian or Alaska Native
- Chinese
- Japanese
- Filipino
- Korean
- Asian Indian
- Vietnamese
- Other Asian
- Native Hawaiian
- Samoan
- Chamorro
- Other Pacific Islander
- Some other race
- Mexican, Mexican American, Chicano [+]
- Puerto Rican
- Cuban
- Another Hispanic, Latino, Spanish origin

What Census Calls Us
A Historical Timeline

This graphic displays the different race, ethnicity and origin categories used in the U.S. decennial census, from the first one in 1790 to the latest count in 2020. The category names often changed from one decade to the next, in a reflection of current politics, science and public attitudes. For example, "colored" became "black," with "Negro" and "African American" added later. The term "Negro" was dropped for the 2020 census. Through 1950, census-takers commonly determined the race of the people they counted. From 1960 on, Americans could choose their own race. Starting in 2000, Americans could include themselves in more than one racial category. Before that, many multiracial people were counted in only one racial category.

For the first time, people who check one or both of these boxes are asked to write more about their origins, for example German, African American, Jamaican, etc.

People could **choose** their own race

People could choose **two or more** races

CENSUS YEAR

1790 1800 1810 1820 1830 1840 1850 1860 1870 1880 1890 1900 1910 1920 1930 1940 1950 1960 1970 1980 1990 2000 2010 2020

Free white males, Free white females

White

All other free persons

Free colored males and females

Slaves

Black

Mulatto

Black Slaves

Mulatto Slaves

Quadroon

Octoroon

Black (Negro or of Negro descent)

Black

Mulatto

Negro

Negro, or Black

Black, or Negro

Black, African American, or Negro

Black or African American

Mulatto: Definitions varied from census to census, but this term generally means someone who is black and at least one other race. Mulattoes, octoroons and quadroons were counted as single-race black, but today could be counted as multiracial.

Quadroon: Someone with "one-fourth black blood," according to census-taker instructions.
Octoroon: Someone with "one-eighth or any trace of black blood."

Aleut: People who trace their ancestry to the Aleutian Islands in Alaska.

Aleut

Eskimo

Aleut

Eskimo

American Indian or Alaska Native

Multiracial: Two or more races

Indian

American Indian

Indian (American)

Although **American Indians** living in white society were included in the census before 1890, the 1890 census was the first to include a complete count of American Indians on tribal land as well.

Chinese

Japanese

Filipino

In 1910, the vast majority of the Other category were **Korean, Filipino and Asian Indian** (called Hindu).

Other

Korean

Hindu

Korean

Asian Indian

Vietnamese

Hindu: Referred to Asian Indians, regardless of religion.

Part Hawaiian

Other

Other Asian

Asian or Pacific Islander

Hawaiian

Native Hawaiian

Pacific Islanders and Hawaiians were grouped with Asians from 1960-1990. Starting with the 2000 census, they became their own group.

Samoa

Guamanian

Samoan

Guamanian, Chamorro

Guamanian

Chamorro

Other Pacific Islander

This category included smaller racial groups not specified on the census form.

Other

Other

Other race

Some other race

CLASSIFICATION BY **RACE**

Mexican

Central or So. Amer.

Chicano: A variation of "Mexican American" commonly used in Western and Southwestern states.

Mexicans were counted as a separate race in 1930 for the first and only time.

Mexican

Mexican, Mexican Amer., Chicano

Puerto Rican

Cuban

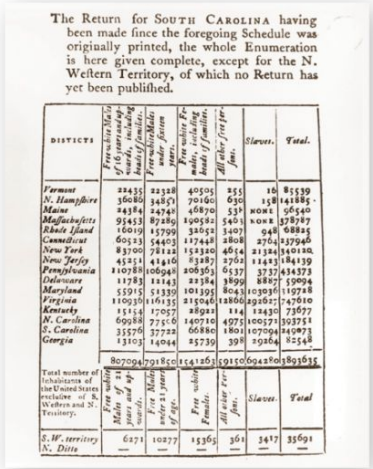
Other Spanish

Other Spanish/ Hispanic

Other Spanish/ Hispanic/ Latino

Another Hispanic, Latino, Spanish origin

CLASSIFICATION BY **HISPANIC ETHNICITY**



The Return for SOUTH CAROLINA having been made since the foregoing Schedule was originally printed, the whole Enumeration is here given complete, except for the N. Western Territory, of which no Return has yet been published.

DISTRICTS	Free white Males of 16 years and upwards, including heads of families.	Free white Males under 16 years.	Free white Females, including heads of families.	All other free persons.	Slaves.	Total.
Vermont	22435	22328	40505	255	16	85539
N. Hampshire	36086	34854	70160	630	158	142885
Maine	24384	24748	46870	538	NONE	96540
Massachusetts	95453	87289	190582	5463	NONE	378787
Rhode Island	16019	15799	32052	3407	948	68825
Connecticut	60523	54403	117448	2808	2764	237946
New York	83700	78122	152320	4654	21324	340120
New Jersey	45251	41416	83287	2762	11423	184339
Pennsylvania	110788	106948	206363	6537	3737	434373
Delaware	11783	12143	22384	3899	8887	59094
Maryland	55915	51339	101395	8043	103036	319728
Virginia	110936	116135	215046	12866	292627	747610
Kentucky	15154	17057	28922	114	12430	73677
N. Carolina	69988	77506	140710	4975	100572	393751
S. Carolina	35576	37722	66880	1801	107094	249073
Georgia	13103	14044	25739	398	29264	82548
	807094	791850	1541263	59150	694280	3893635

Total number of Inhabitants of the United States exclusive of S. Western and N. Western Territory.	Free white Males of 16 years and upwards.	Free Males under 16 years.	Free white Females.	All other free persons.	Slaves.	Total
S. W. territory	6271	10277	15365	361	3417	35691
N. Ditto	—	—	—	—	—	—

U.S. Census Bureau

The nation's first census was a count of the U.S. population as of Aug. 2, 1790. U.S. marshals and their assistants were supposed to visit each U.S. household and record the name of the head of the household and the number of people in each household in the following categories: Free white males ages 16 and older, free white males younger than 16, free white females, other free persons, and slaves. This is the first page of the publication containing the results.

Note: The U.S. Census Bureau does not consider Hispanic/Latino ethnicity to be a race. Hispanics also are asked to select one or more races to define themselves.

Source: U.S. Census Bureau

Definitions

Race: socio-political mechanism for classifying individuals; often tied to status, colonialism and power; relies on ideology or inequality. Similar physical or behavioral characteristics
Ethnicity: cultural construct often linked to community, religion, language, etc.
Ancestry: biological inheritance of DNA, can be traced through the genome using genotype data
Nationality: place of legal organization, ownership, citizenship, or lawful permanent residence (or equivalent immigration status to live and work on a continuing basis) of suppliers of commodities and services.

Popejoy, A. (2020, September). Information Disparities and Implications for Clinical Genetics. Lecture conducted from at Stanford University, United States.
Cornell Law (2023)

Racism and Its Effects

Racism: A system of structuring opportunity and assigning value based on the social interpretation of how one looks ("race"). It unfairly disadvantages some individuals/communities, unfairly advantages other individuals/ communities – Camara Jones, Phylon 2003

<u>Three Levels of Racism</u>:

1) **Institutional/ Structural Racism**
   - The unfair policies, practices and procedures of particular institutions and systems that routinely produce racially inequitable outcomes for people of color and advantages for white people
2) **Personally-Mediated/Individual/Interpersonal Racism**
   - Individual acts of discrimination and prejudice, stereotypes, hate
3) **Internalized Racism**
   - Acceptance by minority groups of negative messages about their own self worth; BIPOC adopt racially prejudiced attitudes and behaviors that lead to discrimination and stereotyping of their own racial group

Racism and Its Effects

1) **Implicit Bias:** Unconscious bias in favor of or against one person or group that affects our thoughts or actions in a certain way

2) **Microaggressions:** The everyday verbal, nonverbal, and environmental slights, snubs, or insults, whether intentional or unintentional, that communicate hostile, derogatory, or negative messages to target persons based solely upon their marginalized group membership (from Diversity in the Classroom, UCLA Diversity & Faculty Development, 2014)
   - “The most detrimental forms of microaggressions are usually delivered by well-intentioned individuals who are unaware that they have engaged in harmful conduct towards a socially devalued group”

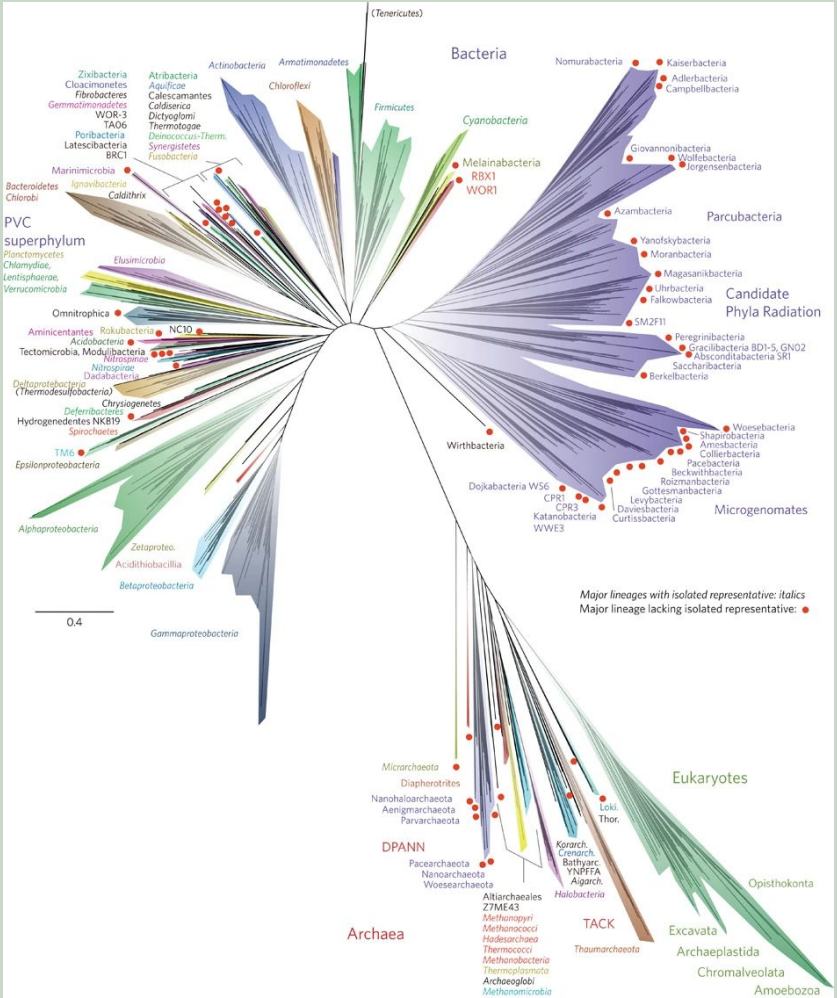
3) **White Privilege:** An unearned advantage white and white-passing people have in relation to power dynamics in social settings, simply because of their skin color and/or appearance.

Turner, J., Higgins, R., & Childs, E. (2021). Microaggression and implicit bias. *The American Surgeon*, *87*(11), 1727-1731.

Race is a product of racism, not the other way around.

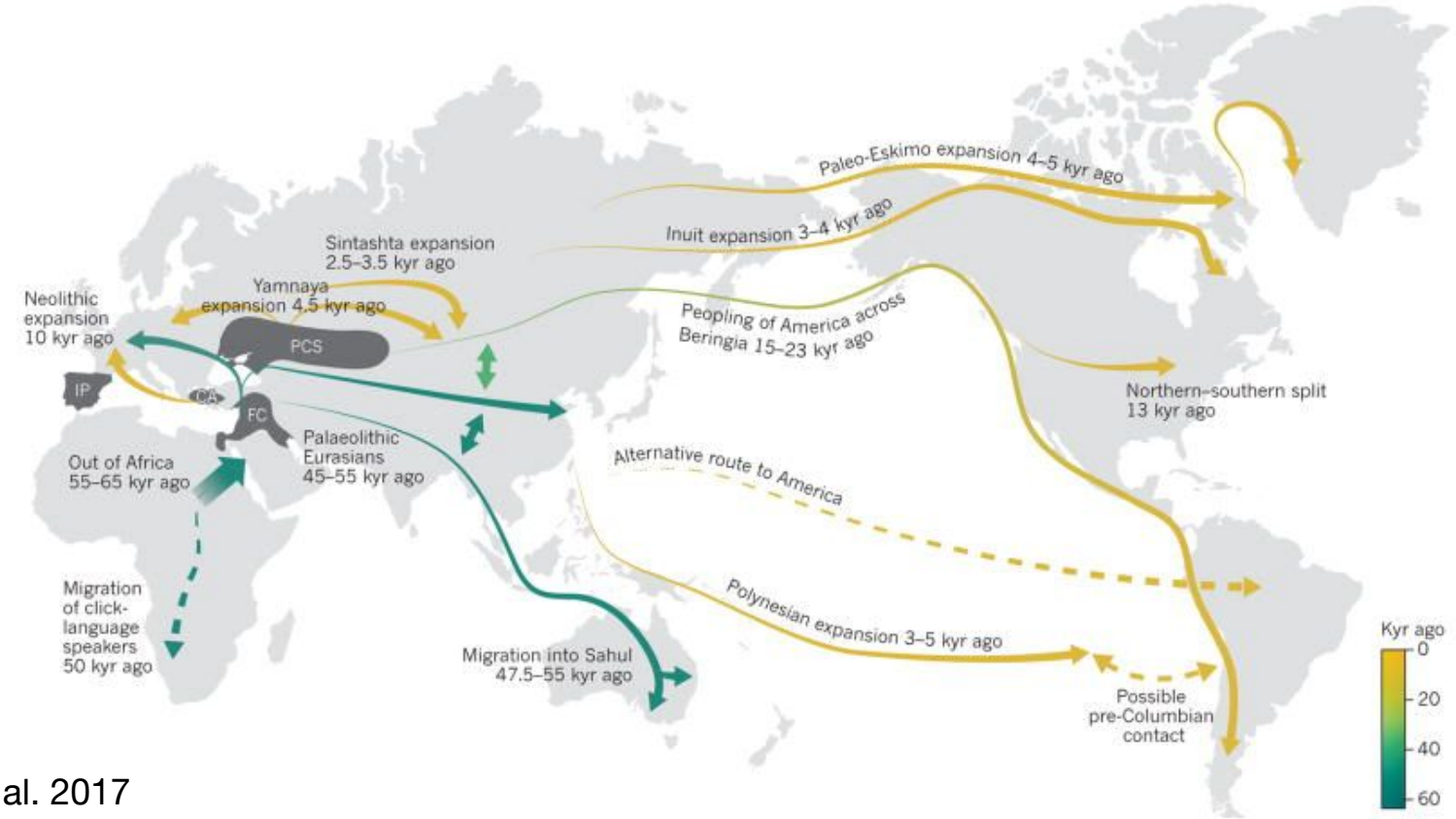
What do you think genetic ancestry means?

Tree of life



Hug et al. 2016

Human evolutionary history



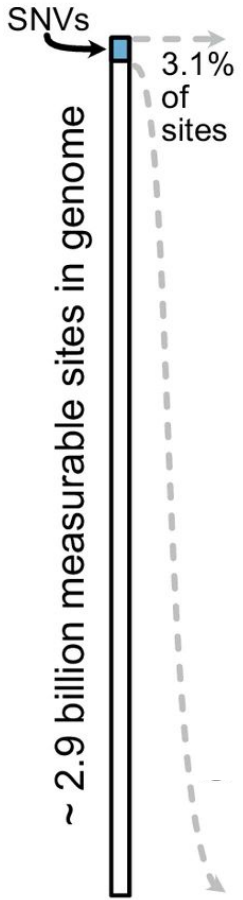
Nielsen et al. 2017

0.1% of the human genome differs between individuals

Total human genome: 3 billion base pairs

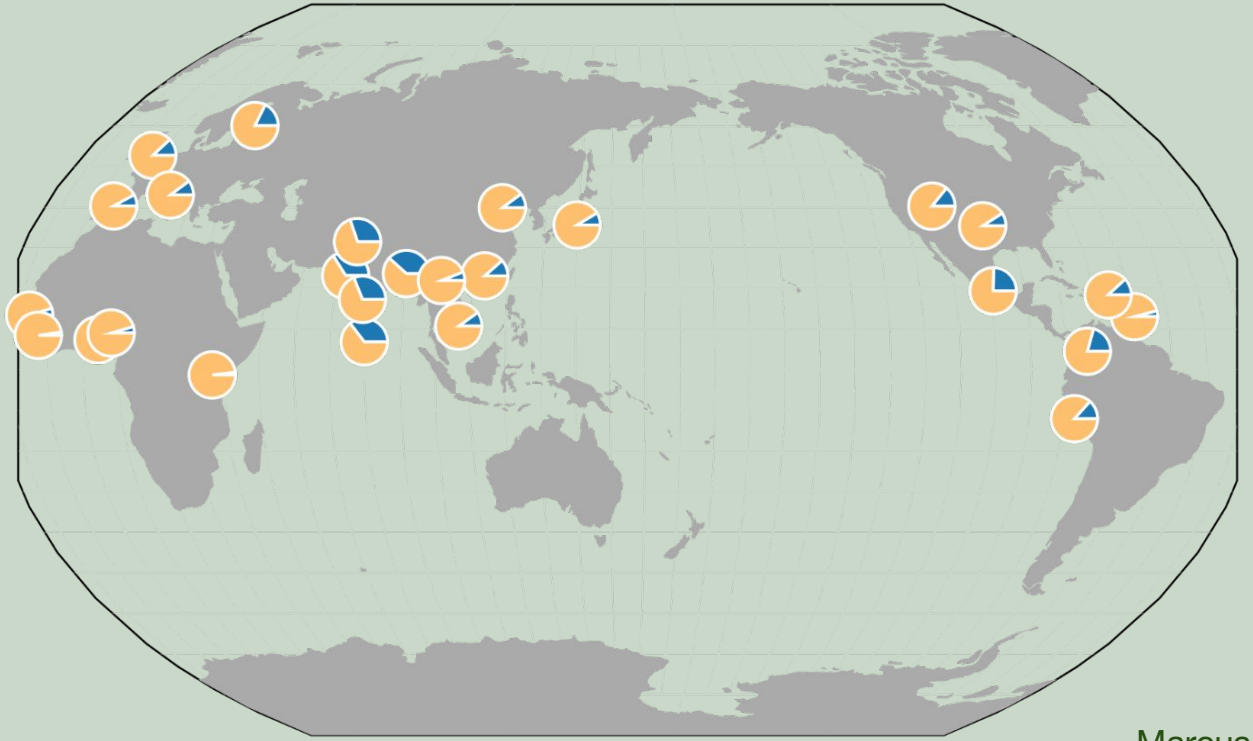
Average pairwise differences: 3 million base pairs

Variants that are common in one population are usually shared by multiple populations



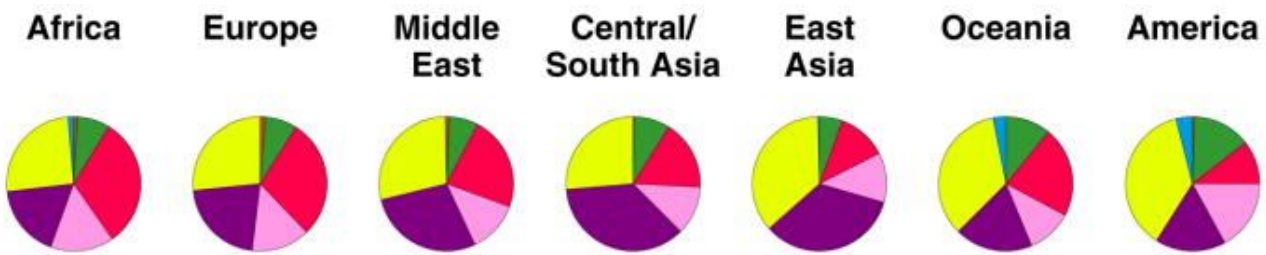
Biddanda et al. 2020

Allele frequencies vary continuously with geographic distance



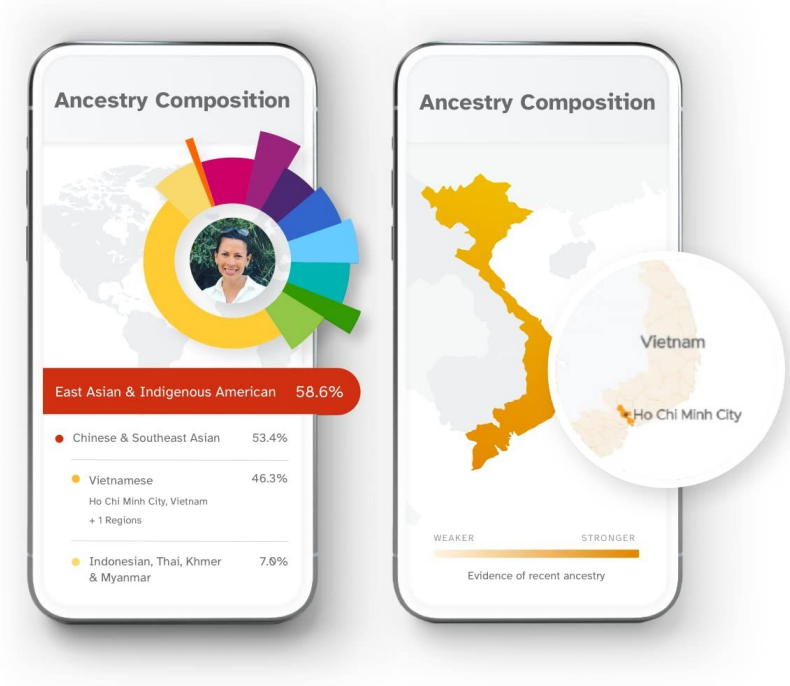
Chr12:113118612
Marcus & Novembre 2016

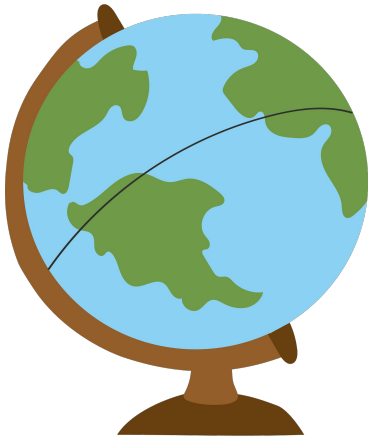
And yet... it is still possible to cluster individuals into groups based on genetic information



Rosenberg 2011

Genetic “ancestry” is usually estimated by computing genetic similarity to some reference population(s)

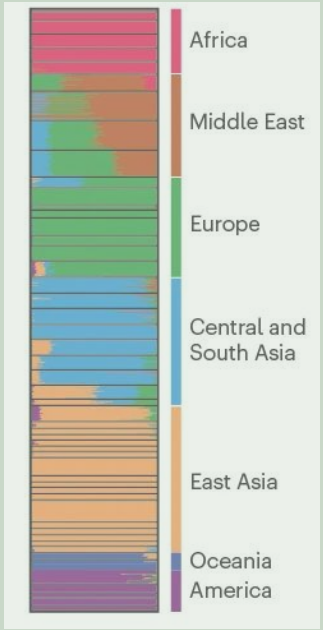




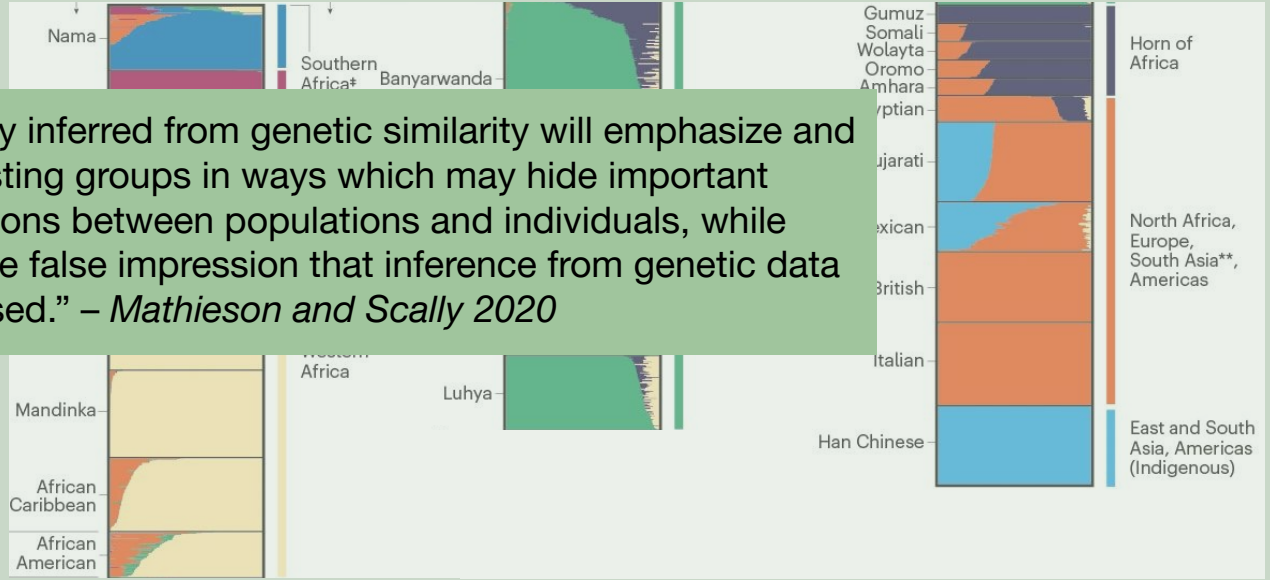
23andMe

In computing genetic similarity, our choice of reference populations matters... a lot

African populations are 13% of those sampled



African populations are 85% of those sampled



"Ancestry inferred from genetic similarity will emphasize and reify existing groups in ways which may hide important connections between populations and individuals, while giving the false impression that inference from genetic data is unbiased." – *Mathieson and Scally 2020*

Carlson et al 2022

Deconvoluting some terms

Genetic Similarity

Similarity of one's genetic variation, usually to some reference populations

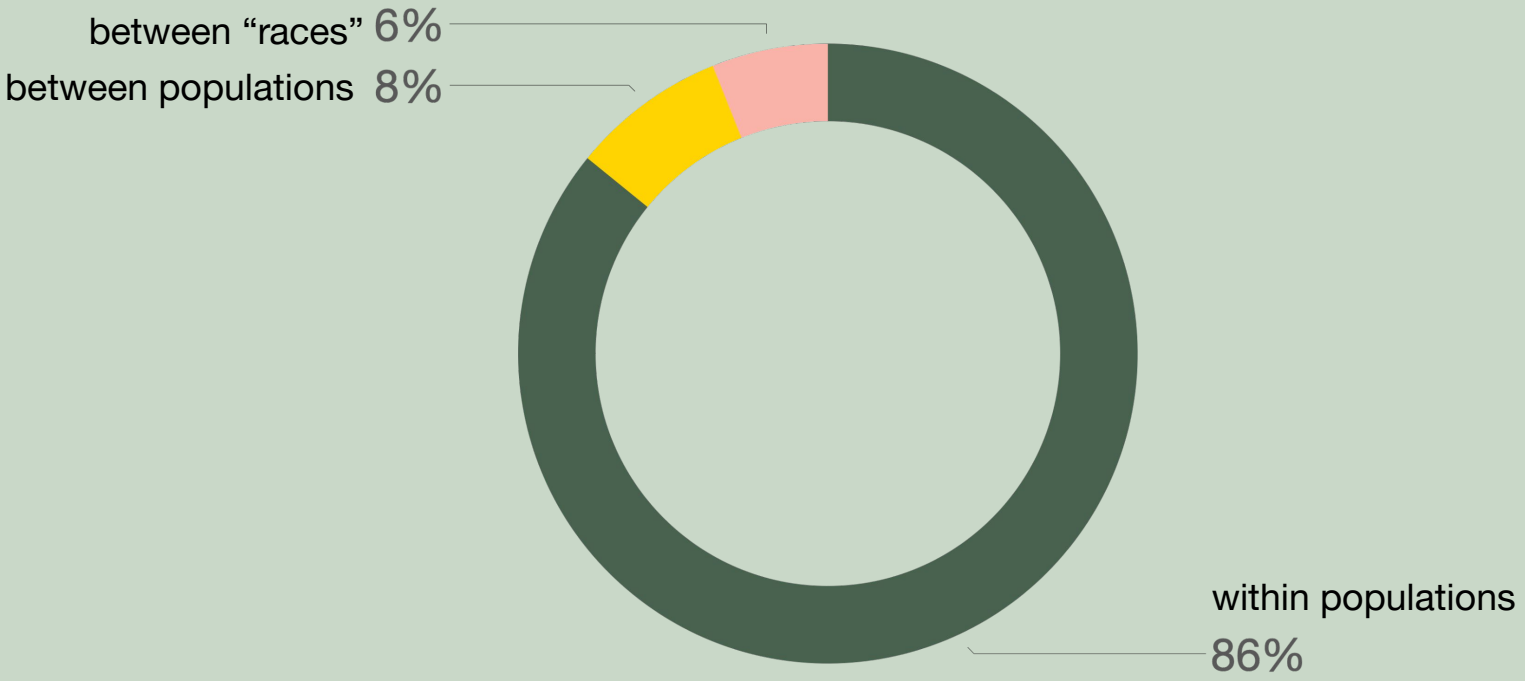
Genetic Ancestry

Biological inheritance of DNA, can be traced through the genome using genotype data

Geographic Ancestry

Region(s) of the world where portions of an individual's ancestors lived. As a result of migration of individuals and populations over time, an individual's genetic ancestry might not match their geographic ancestry.

Importantly, very little genetic variation can be attributed to differences between populations or “races”



Lewontin 1972

Importantly, very little genetic variation can be attributed to differences between populations or “races”

Human racial classifcation is of no social value and is positively destructive of social and human relations. Since such racial classification is now seen to be of virtually no genetic or taxonomic significance either, no justification can be offered for its continuance.

Lewontin 1972

Genetic Ancestry vs. Social Identity

1) **Genetic Ancestry:** biological inheritance of DNA, can be traced through the genome using genotype data

2) **Social Identity (Theory):** social categorization and self-conception that explains how people represent social categories and their associated attributes govern how they behave and how they conceive of themselves.

Popejoy, A. (2020, September). Information Disparities and Implications for Clinical Genetics. Lecture conducted at Stanford University, United States.
Hogg, M. A., & Rinella, M. J. (2018). Social identities and shared realities. Current opinion in psychology, 23, 6–10.

Discussion: Genetic Ancestry & Social Identity

How do race, ethnicity, ancestry, and nationality fall into social identity and genetic ancestry?

How do you see social identity interact with genetic research and healthcare?

BREAK - 10 minutes

Dialysis Video

Dialysis Video

http://docuseek2.com/cart/product/522

Dialysis Video Discussion

1. What are your immediate thoughts/reactions to this video?

2. In what ways do you see race/racism becoming biological?

Dialysis Video - Key Points

1. Tuskegee and other similar events have colored how people view medicine and research
    a. Medical/Research Mistrust
2. Racial thinking affects who is likely to qualify for organ transplants
    a. Stereotypes/stigmas of certain groups of people (often people of color) can affect clinical judgment of who is “deserving” of a kidney transplant
    b. Perceptions that certain people will “ruin” or “waste” the opportunity for a transplant, so why not give it to someone who is deemed “more deserving”
3. Person reported seeing more white people in line for a kidney than black patients
    a. Mentions differences in delays and misbeliefs about interracial organ transplant matching

Case Examples: Genetic Ancestry and Social Identity Interplay with Healthcare

Overview of activity

Case examples

1. Henrietta Lacks - Intro Video + Impact Video
2. Forced Sterilization - California Sterilization + Prison Sterilization
3. VUS Rates/Carrier Screening - Discussion Article

Activity timing

- 5 min small group discussion
- 15 min large group share-out
- 10 min large group discussion

10 minutes - small group discussions

Who benefitted and/or who was harmed in this case study?

What do you think is the impact on communities or society as a whole today?

What was ethical, controversial, impactful to you as an individual?

15 minutes - large group sharing

What are the key points you'd like to summarize about your case?

Did you agree/disagree with anything from the articles/video?

What was ethical, controversial, impactful to you as an individual?

Henrietta Lacks - Key Points

1. Black woman in Southern VA, diagnosed with cervical cancer in 1951
    a. Went to John Hopkins in Baltimore for treatment due to only place near her that was open to Black and/or poor people
2. W/o her knowledge, a cell sample was collected from tumor and sent to lab
    a. George Guy, head of tissue culture research, was trying to grow human cells outside of body and HL's cells didn't die for unknown reasons
3. HL's cells were shared with research community and used for:
    a. Vaccines, Cloning, IVF, Genomic Mapping, etc.
4. HL died in 1951 (age of 31) without knowing her impact or what was done
    a. Family + Advocacy was needed to honor HL and her family

Forced Sterilization - Key Points

1. California was “worst state” within Eugenics movement in US
    a. Both sexes were affected
    b. ⅓ of sterilizations in country
2. Nazis based their eugenics ideologies off of theories developed in California
    a. Scientists at Stanford promoted sterilizations as a way to improve society
3. 1970s = Sterilizations prohibited at all state institutions, unless found to be medically necessary
    a. More clearer laws came in 1995

Carrier Screening - Key Points

Carrier: An individual who has one copy of a disease-causing gene for an autosomal recessive condition, and has none or mild symptoms.

Carrier Screening

1. Identifies presumptuously healthy prospective couples in which both individuals are heterozygous for the same disorder, and are, therefore, at risk to have an affected child with a life-threatening, serious, or chronic disorder.
2. Couples are screened for multiple genetic conditions (ranging from a ~150-500)
3. All individuals are thought to be carriers of atleast one genetic condition

Discussion Article for Healthcare Disparities in Carrier Screening:
https://www.mdpi.com/2075-4698/12/2/33

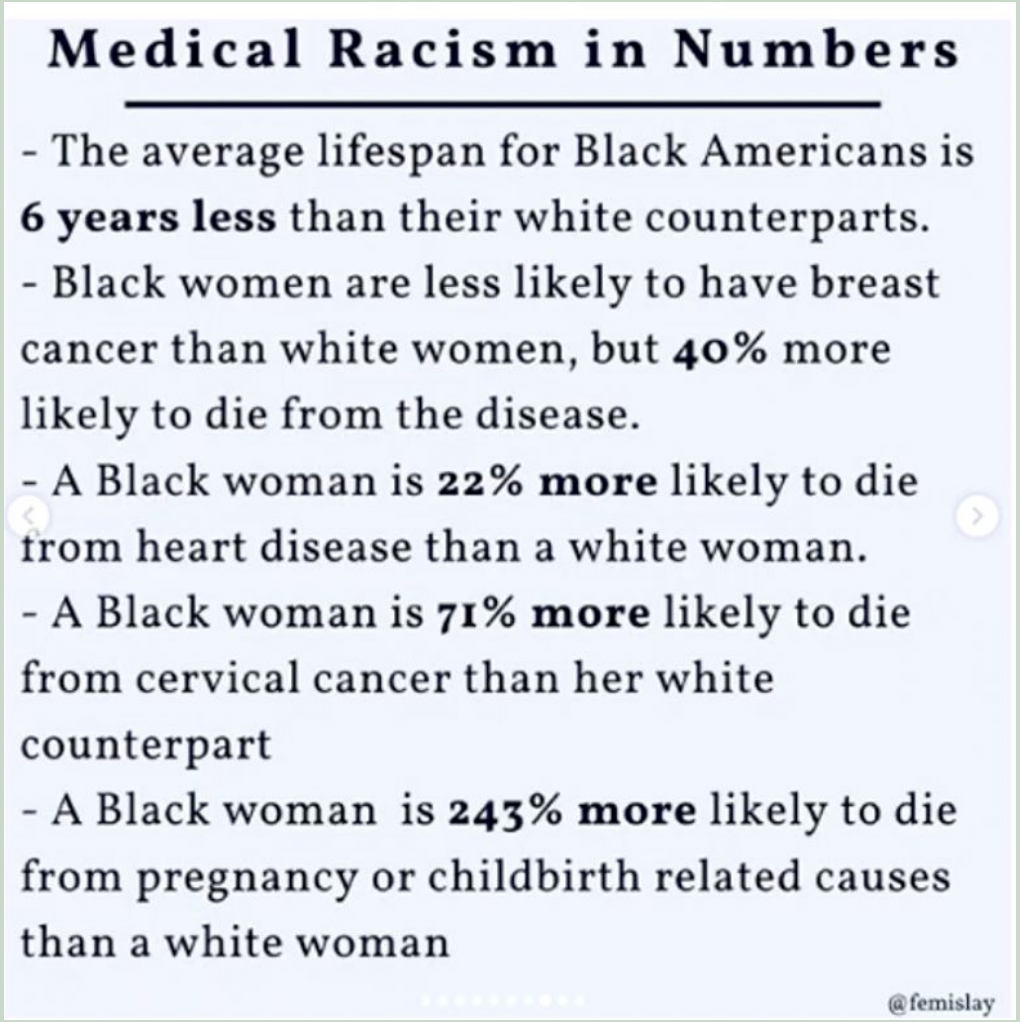
Carrier Screening - Key Points

1. Carrier screening, a nearly half-century old practice, aims to provide individuals and couples with information about their risk of having children with serious genetic conditions.
    a. Traditionally, the conditions for which individuals were offered screening depended on their self-reported race or ethnicity and which conditions were seen commonly in that population.
2. This process has led to disparities and inequities in care as the multi-racial population in the U.S. has grown exponentially, yet databases used to determine clinical practice guidelines are made up of primarily White cohorts.
    a. Technological advancements now allow for pan-ethnic expanded carrier screening (ECS), which screens for many conditions regardless of self-reported race or ethnicity.
3. ECS presents a unique opportunity to promote equitable genetic testing practices in reproductive medicine.
    a. However, this goal can only be achieved if we acknowledge and appreciate the innumerable inequities evidenced in reproductive medicine and other socio-legal practices in the United States, and if we intentionally work in concert with healthcare providers, policy makers, advocates, and community health champions to reduce current and future reproductive health disparities.

10 minutes - large group discussion on biological effects of racism

Based on historical examples discussed:

a. What impact might medical mistrust have on these racial ethnic groups?
b. How do you see racism generating racial health disparities?
c. How might these racial health disparities affect your research and/or practice?



" – the mortality penalty for Black newborns is 39% lower under the care of Black physicians than White physicians."

Greenwood et al. 2020

Session 4: Race, Ancestry, Identity, and Genetics Pt 2

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

Taught by
Justin Gomez-Stafford (he/they)

Taught by
Anjali Narain (she/her)