

The background is a vibrant, abstract composition. It features a dark blue base with a fine, repeating pattern of small white dots. Overlaid on this are several large, organic, wavy shapes in bright colors: a large pink shape on the left, a teal shape at the top right, and a yellow shape at the bottom right. These shapes are decorated with various patterns: the pink shape has white squiggly lines, the teal shape has a white dotted pattern, and the yellow shape has a white grid of plus signs. There are also white dashed lines in a circular pattern on the left and white wavy lines on the right.

# *Tackling racial and ethnic bias when translating research into policy*

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A black silhouette of a person's profile, facing right, occupies the left side of the slide. The word "Agenda" is written in a white, italicized serif font over the silhouette.

# *Agenda*

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There is no race without racism

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Racial and ethnic categories do not approximate genetic risk

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Racism harms health and biases healthcare

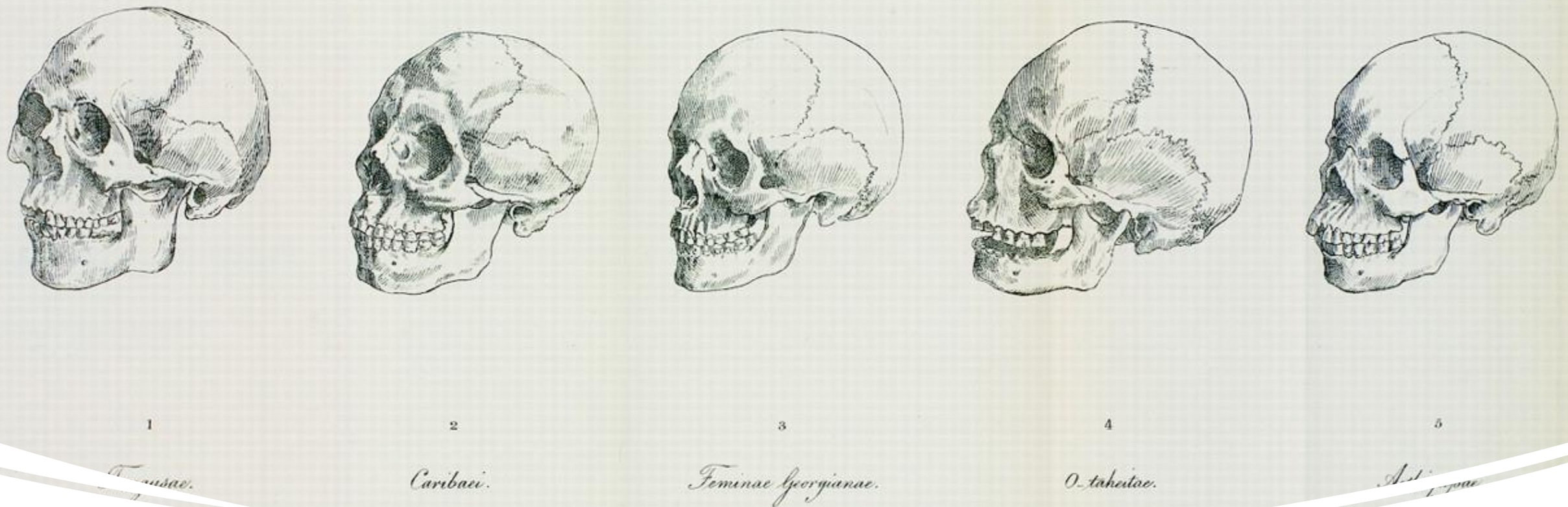
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Race-conscious medicine counteracts racism



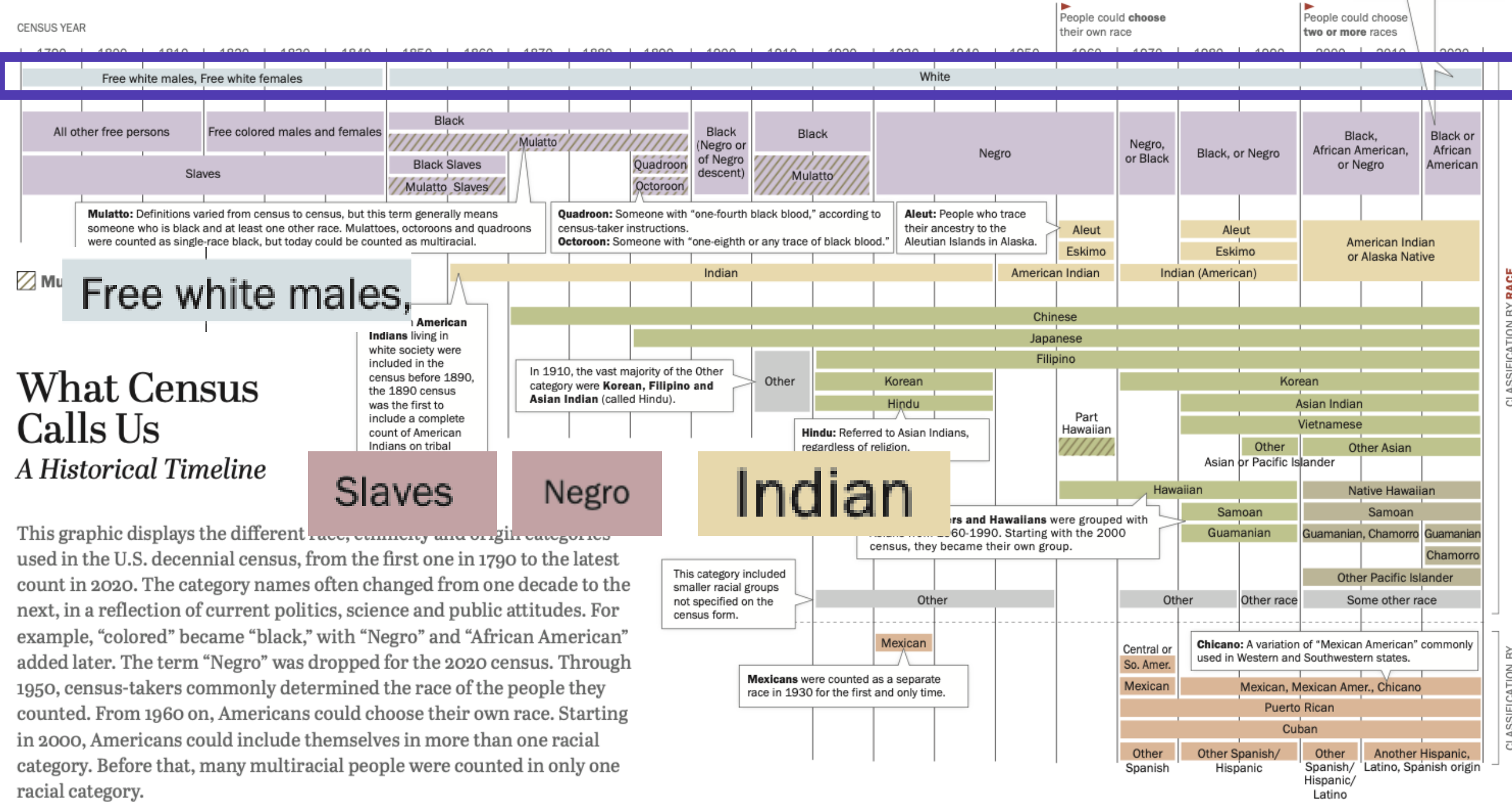
***There is no  
race without  
racism***

THE ORIGIN OF RACIAL  
HIERARCHIES IN  
MEDICINE



***Race is a sociopolitical construct inferred to have biological meaning***

- Convergence of Enlightenment and Imperialism Eras
- Tool to divide and conquer populations
  - Assert biological inferiority of dark-skinned populations
  - Meaning shifts to suit goals of dominant group



# 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.

**Slaves**

**Negro**

**Indian**

CLASSIFICATION BY RACE

CLASSIFICATION BY

# *Race is constructed relative to White hegemony*

| “slaves”                                    | “Indian”                               | “free white” |
|---|--|--------------|
| “free colored persons”                      | “American Indian”                      | “White”      |
| “Black”/“Mulatto”/<br>“Quadroon”/“Octoroon” | “Aleut”/“Eskimo”/<br>“American Indian” |              |
| “Negro”                                     | “American Indian” /<br>“Alaska Native” |              |
| “Black”/“African American”                  |  |              |

**What is your race or ethnicity?**

Select all that apply **AND** enter additional details in the spaces below.

Note, you may report more than one group.

**WHITE** – Provide details below.

German  Irish  English

Italian  Polish  French

Enter, for example, Scottish, Norwegian, Dutch, etc.

**HISPANIC OR LATINO** – Provide details below.

Mexican or Mexican American  Puerto Rican  Cuban

Salvadoran  Dominican  Colombian

Enter, for example, Guatemalan, Spaniard, Ecuadorian, etc.

**BLACK OR AFRICAN AMERICAN** – Provide details below.

African American  Jamaican  Haitian

Nigerian  Ethiopian  Somali

Enter, for example, Ghanaian, South African, Barbadian, etc.

**ASIAN** – Provide details below.

Chinese  Filipino  Asian Indian

Vietnamese  Korean  Japanese

Enter, for example, Pakistani, Cambodian, Hmong, etc.

**AMERICAN INDIAN OR ALASKA NATIVE** – Enter, for example, Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barrow Inupiat Tribal Government, Tlingit, etc.

**MIDDLE EASTERN OR NORTH AFRICAN** – Provide details below.

Lebanese  Iranian  Egyptian

Syrian  Moroccan  Israeli

Enter, for example, Algerian, Iraqi, Kurdish, etc.

**NATIVE HAWAIIAN OR PACIFIC ISLANDER** – Provide details below.

Native Hawaiian  Samoan  Chamorro

Tongan  Fijian  Marshallese

Enter, for example, Palauan, Tahitian, Chuukese, etc.

Example initial proposal for combining race-ethnicity question for Office of Management and Budget Statistical Standards

***Changing racial categories show political nature***

*Treating race  
as a clinical  
category or  
research  
variable is  
engaging in  
racism*

COLOR IS  
NOT  
A CRIME

End  
of  
the  
Day  
of  
the  
Day  
of  
the  
Day



*Racial and  
ethnic categories  
do not  
approximate  
genetic risk*

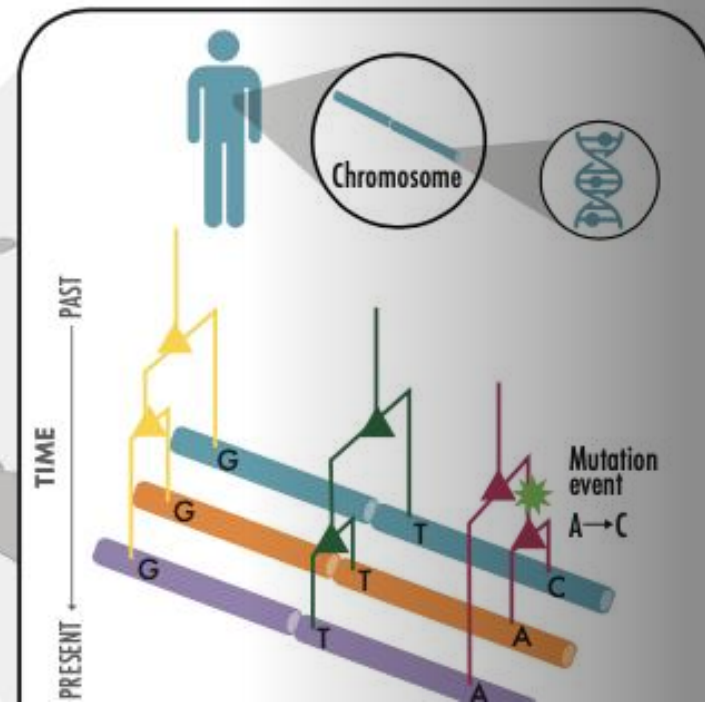
DISENTANGLING RACE  
FROM GENETICS

*race*  $\neq$   
*ethnicity*  $\neq$   
*ancestry*  $\neq$   
*genetics*

TIME

PRESENT

-  Living Individual at Present
-  Genetic Ancestors for Specific Loci
-  Genealogical Ancestors
-  Common Genetic Ancestor Event





*Imagine treating  
a White Swiss  
patient with gout*

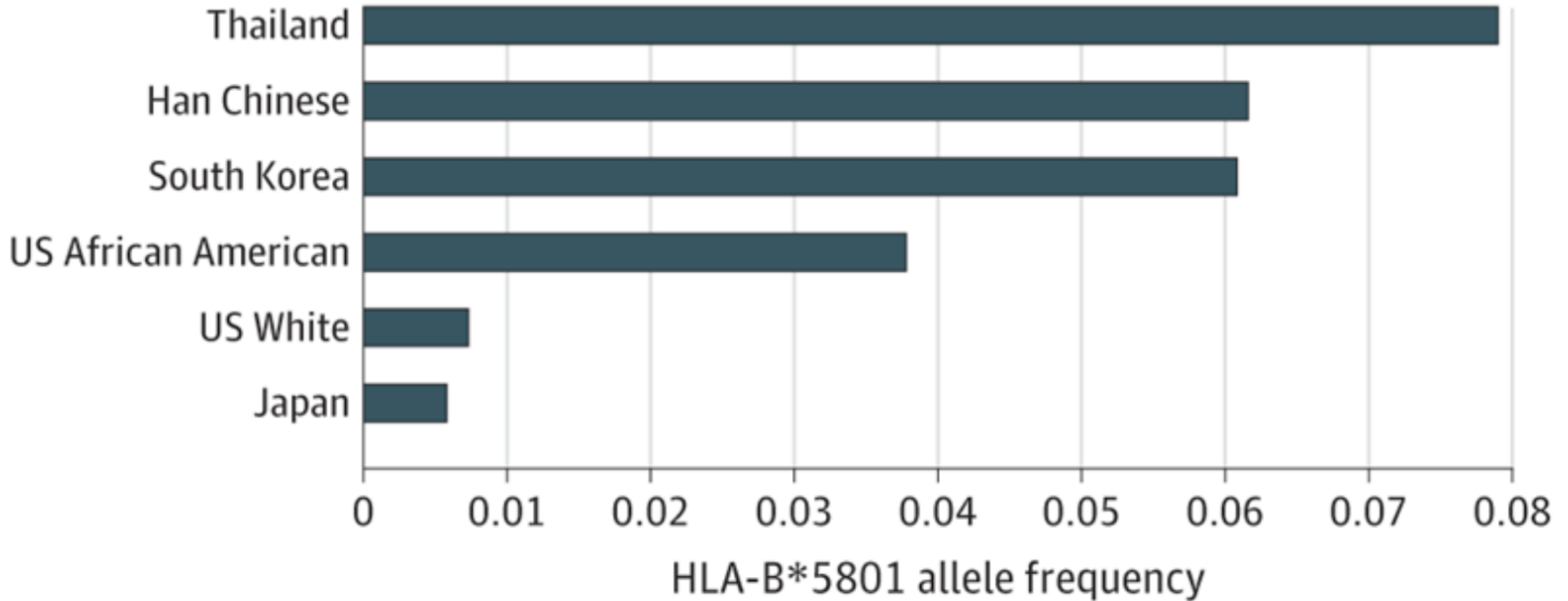
AMERICAN COLLEGE  
of RHEUMATOLOGY  
*Empowering Rheumatology Professionals*

Testing for the HLA-B\*5801 allele prior to starting allopurinol is conditionally recommended for patients of Southeast Asian descent (e.g., Han Chinese, Korean, Thai) and for African American patients, over not testing for the HLA-B\*5801 allele.

Universal testing for the HLA-B\*5801 allele prior to starting allopurinol is conditionally recommended *against* in patients of other ethnic or racial background over testing for the HLA-B\*5801 allele.

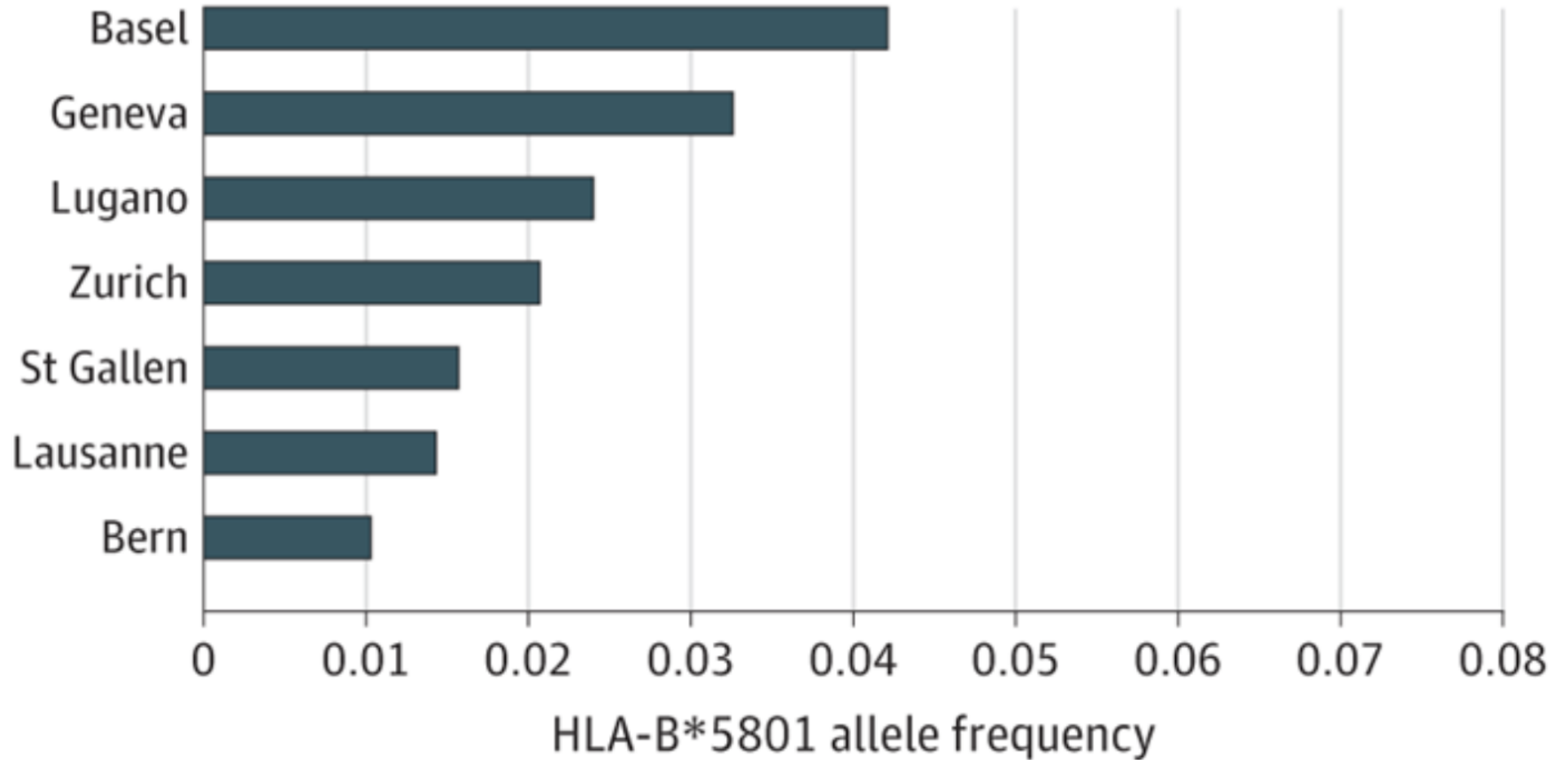
Screen African American but not White people?

**A** US and Asian populations



Screen Swiss people from Basel,  
not Bern?

**B** Cities in Switzerland

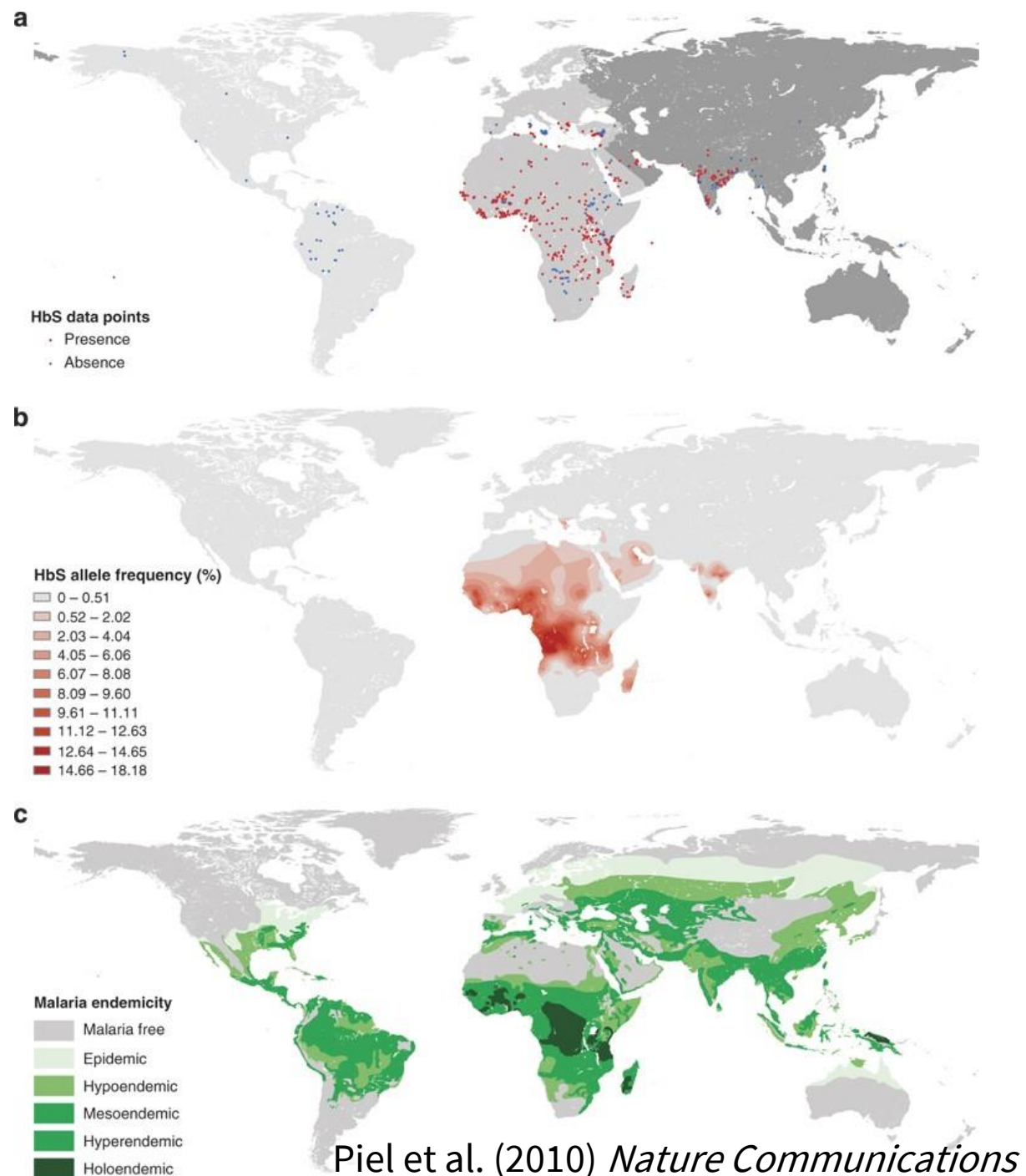




***Racial & ethnic  
categories  
influence data  
interpretation***

## *What about Tay Sachs? Sickle cell?*

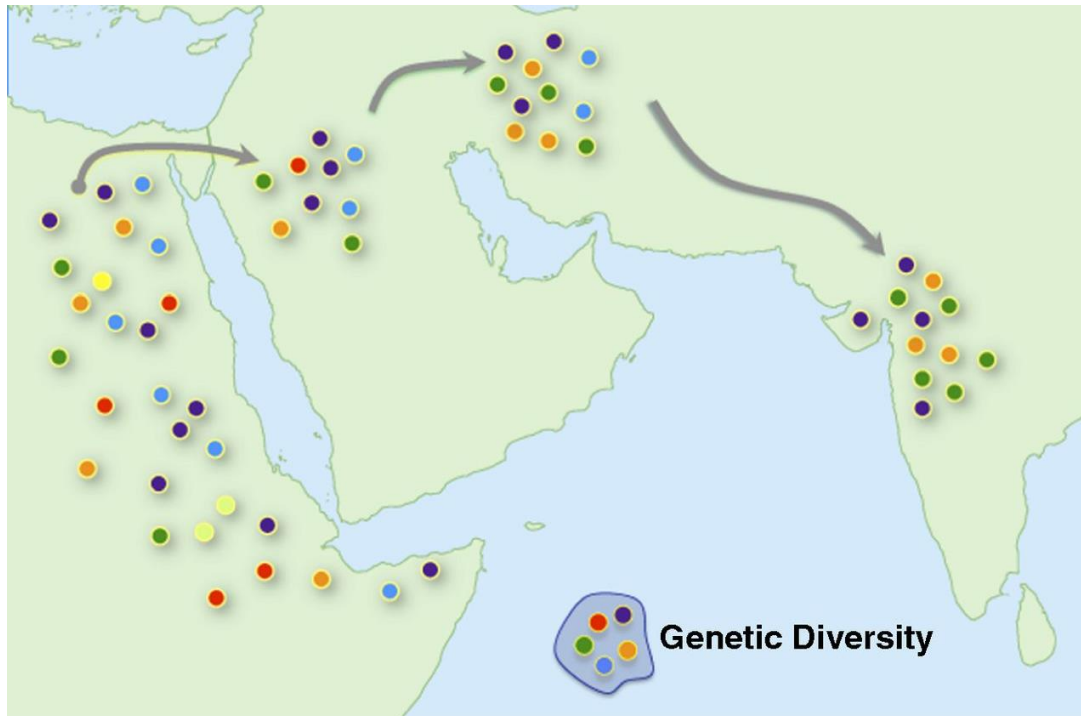
- Few diseases driven by single point mutations
- Mendelian diseases occur more frequently in restricted gene pools patterned by social and reproductive isolation
- Common diseases less influenced by selection



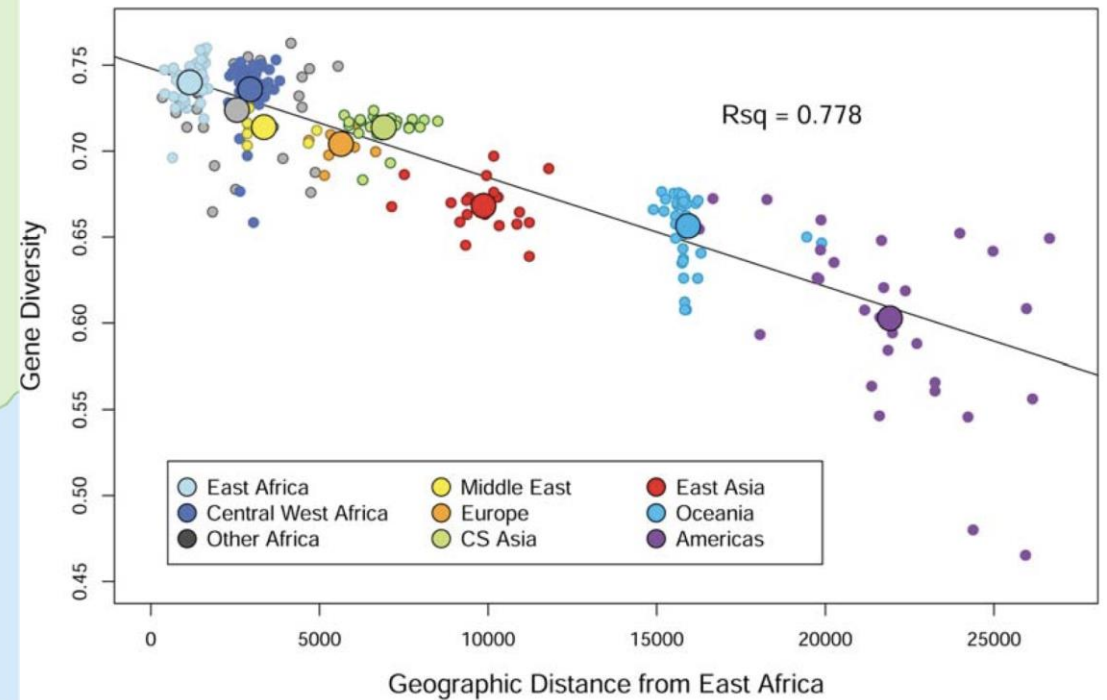
# *Genetic diversity derives from serial founder effects*

Recurrent "bottlenecks" reduce genetic diversity with increasing distance from East Africa

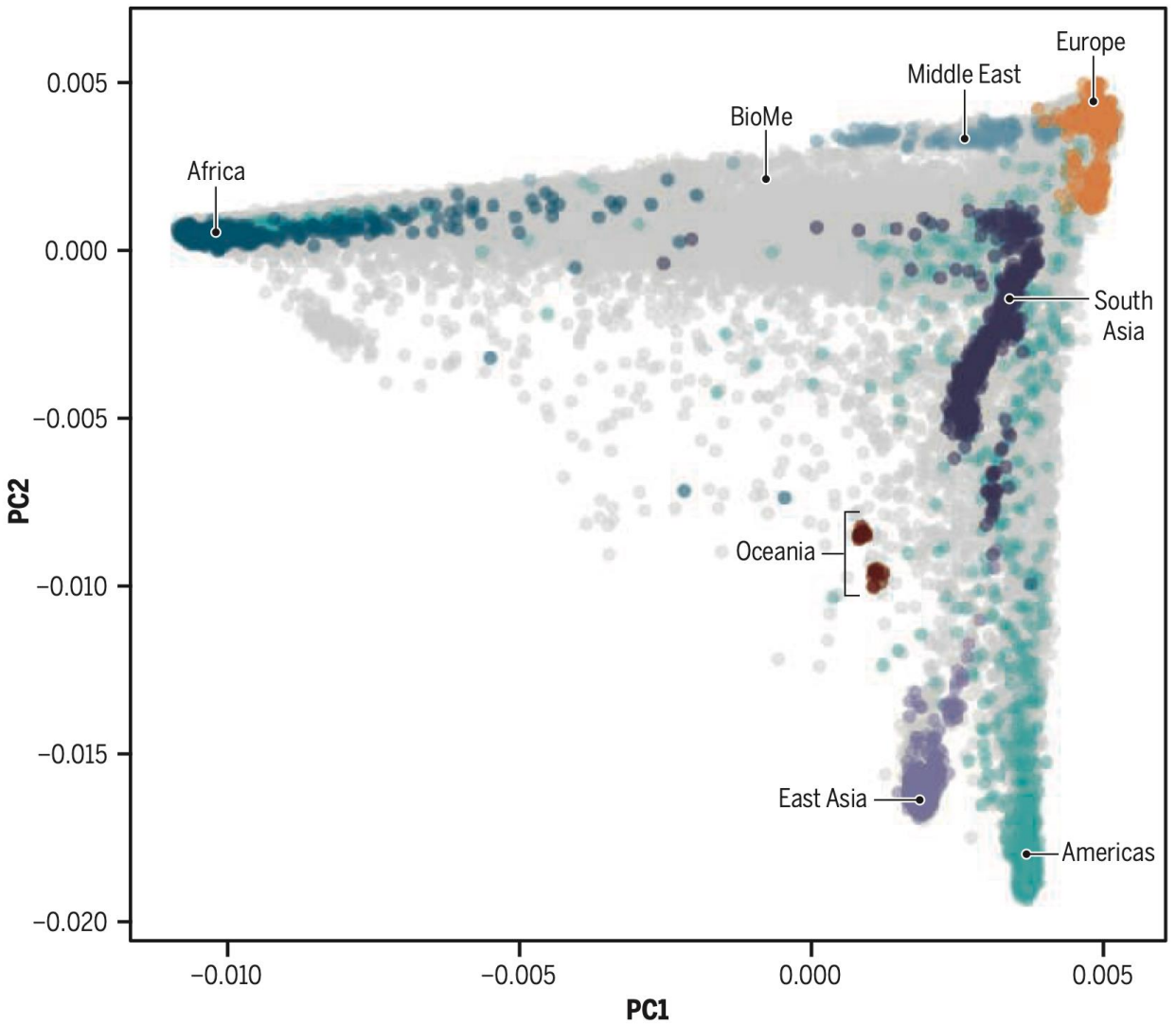
Henn et al. (2012). *PNAS*.



Hunley and Cabana. (2016). *Human Biology*.





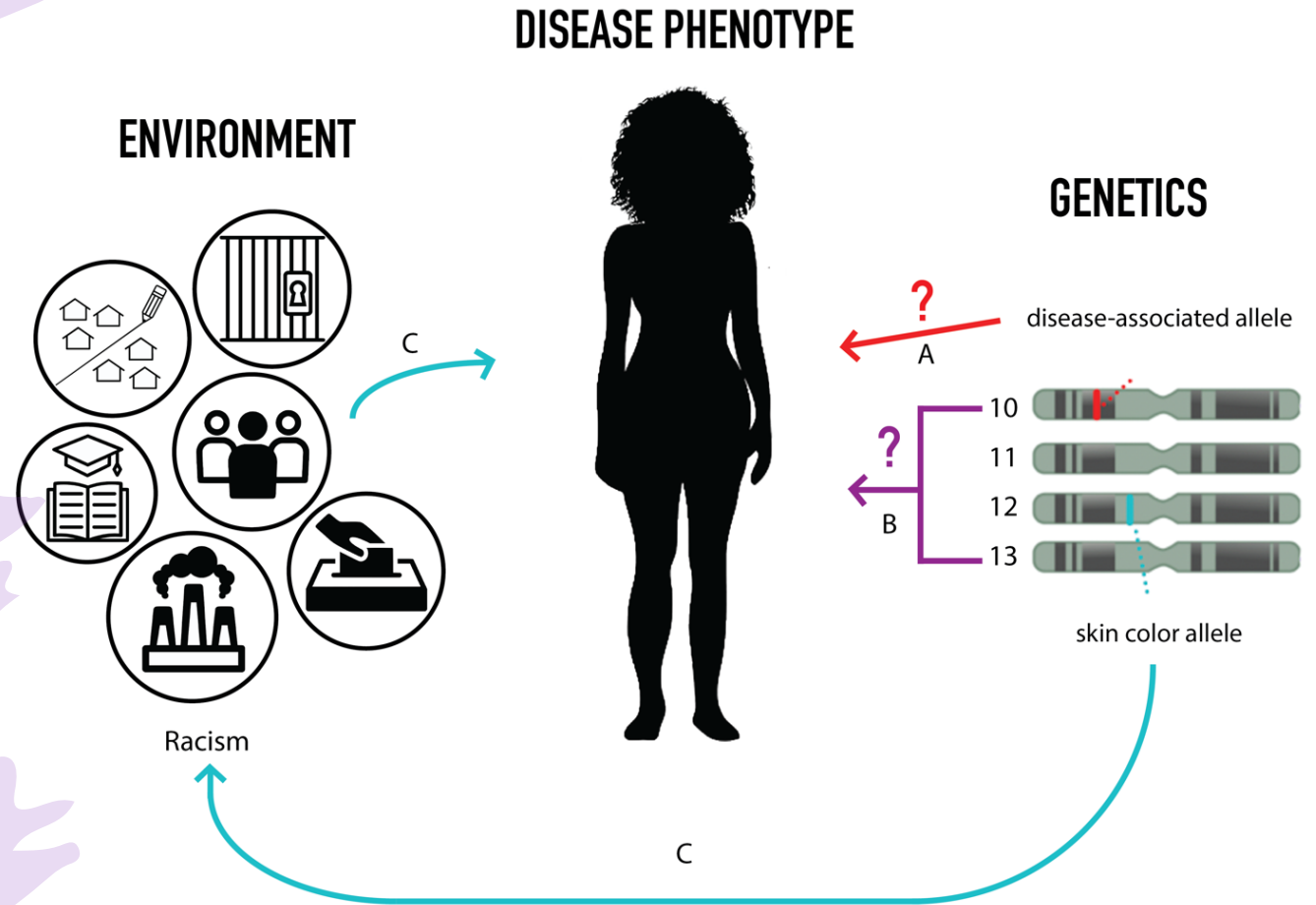


*There is no “African”  
or “European”  
ancestry*

Lewis et al. (2022). *Science*.

# *Diseases may be associated with ancestry, but better explained by racism*

CERDEÑA, GRUBBS, NON. (2022).  
THE LANCET.



**Pathway A:** gene linked to disease → “it’s genetic”


**Pathway B:** dark skin gene + disease gene → “it’s ancestry”


**Pathway C:** dark skin ↑ racism ↑ disease → “it’s racism”


# *We should measure genetic similarity & social environment*




































## LEGEND

 Preferred population descriptor(s)

 Should not be used

 In some cases; refer to Ch. 5 text and the decision tree in Appendix D

 Descriptors could be used if appropriate proxies for environmental, not genetic, effects

| GENOMICS STUDY TYPE                      | Race  | Ethnicity/Indigeneity   | Geography   | Genetic Ancestry  | Genetic Similarity  | Notes   |
|--|---|---|---|---|---|---|
| 1: Gene Discovery - Mendelian Traits     |    |    |    |    |    | Similarity suffices as a genetic measure; at fine-scale, other variables may be useful                                    |
| 2: Trait Prediction - Mendelian Traits   |    |    |    |    |    | No population descriptors may be necessary for analysis   |
| 3: Gene Discovery - Complex Traits       |    |    |    |    |    | Similarity suffices as a genetic measure  |
| 4: Trait Prediction - Complex Traits     |    |    |    |    |    | Similarity suffices as a genetic measure  |
| 5: Cellular and Physiological Mechanisms |    |    |    |    |    | No population descriptors may be necessary for analysis   |
| 6: Health Disparities with Genomic Data  |  |  |  |  |  | Not all health disparities studies rely on descent-associated population groupings, so none may be necessary for analysis |
| 7: Human Evolutionary History            |  |  |  |  |  | Reconstructing genetic ancestry may be of central interest  |



***Racism harms  
health and  
biases  
healthcare***

THE DANGERS OF RACE-  
BASED MEDICINE

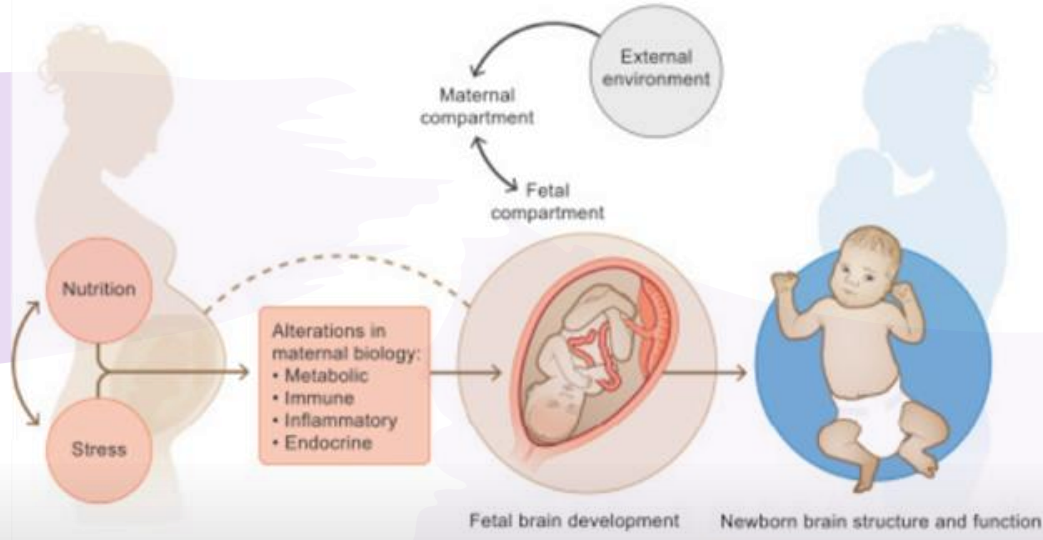
***Race is not genetic,  
but racism affects  
health***

**RACE ≠ GENETICS**

Biomedicine often believes this

**RACISM → RACE →→→  
BIOLOGY**

This is what's happening

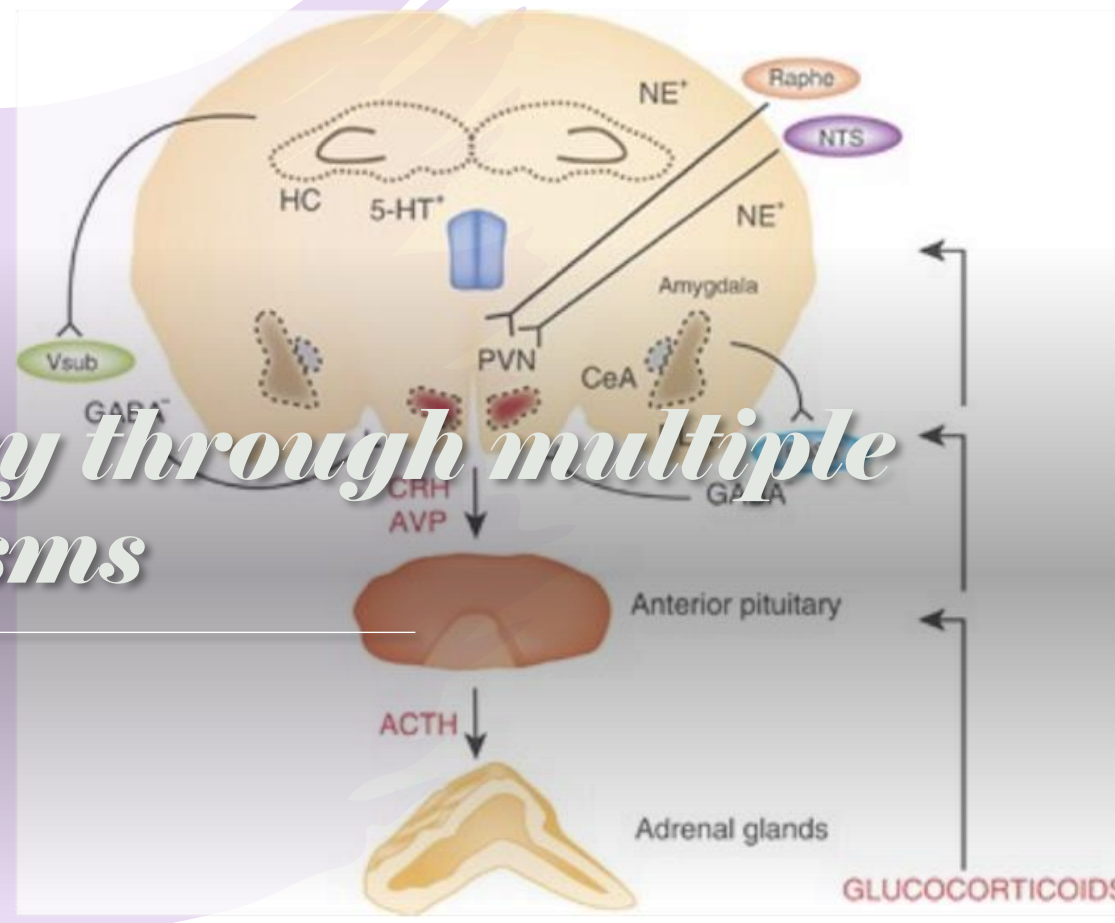


**FETAL PROGRAMMING**

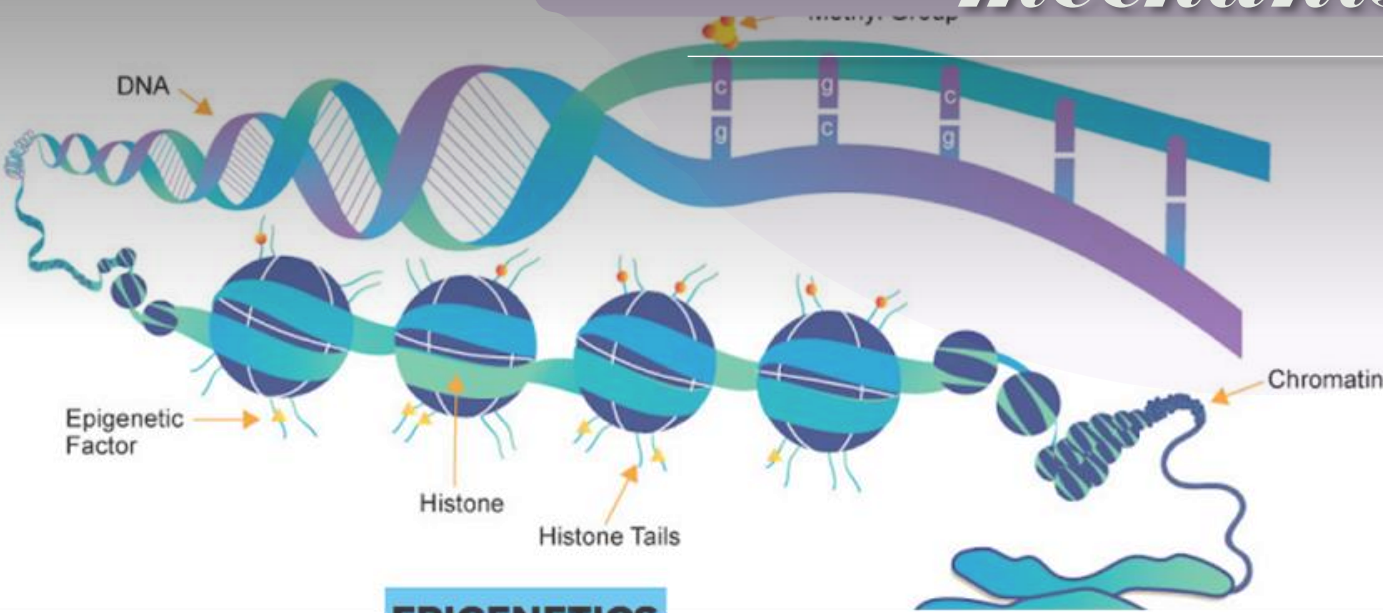
*Racism influences biology through multiple mechanisms*

- Infant feeding
- Child diet, physical activity
- Postnatal stress exposure
- Maternal parenting behavior
- Maternal mental health

Neurodevelopmental disorders, mood, cognition



**HYPOTHALAMIC-PITUITARY-ADRENAL (HPA) AXIS**



**EPIGENETICS**



***Racism***  
***shapes the***  
***way we collect***  
***and interpret***  
***data***

research questions & hypotheses

sampling methods and sample size size  
variability

terminology

- conflation of race, ethnicity, ancestry, and geography

analytical methods

- descriptive, covariate, stratification

conclusion & recommendation

clinicians only see  
this

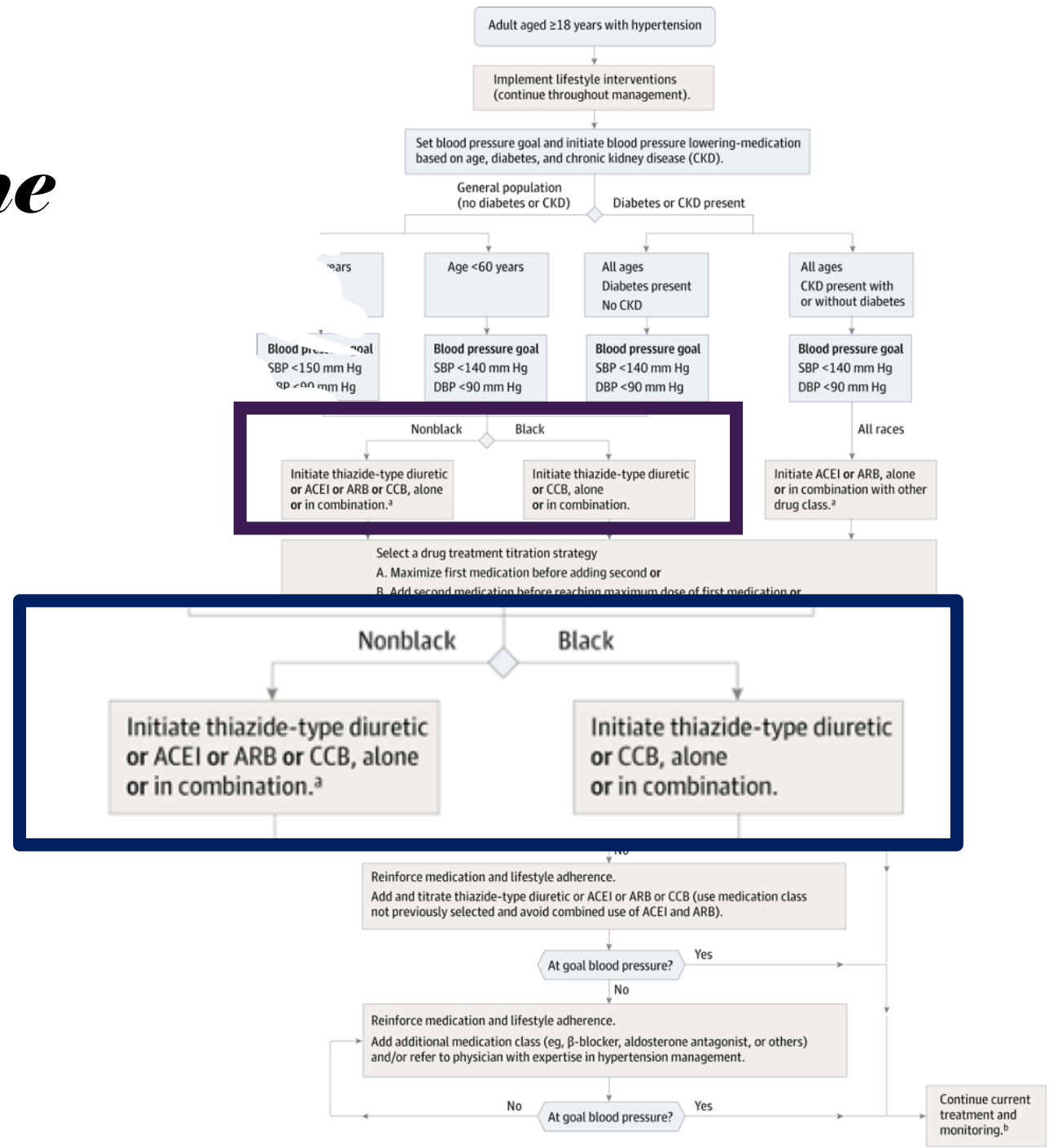


# *Race-based guidelines undermine patient autonomy*

“Hypertension in Blacks is a salt disease,” Dr. Anderson explained. “We’ll start her on a diuretic and see how she does.”

“Doc, I’m a bus driver,” our patient said. “I don’t want to be on something that’s going to make me have to go to the bathroom. I don’t get breaks.”

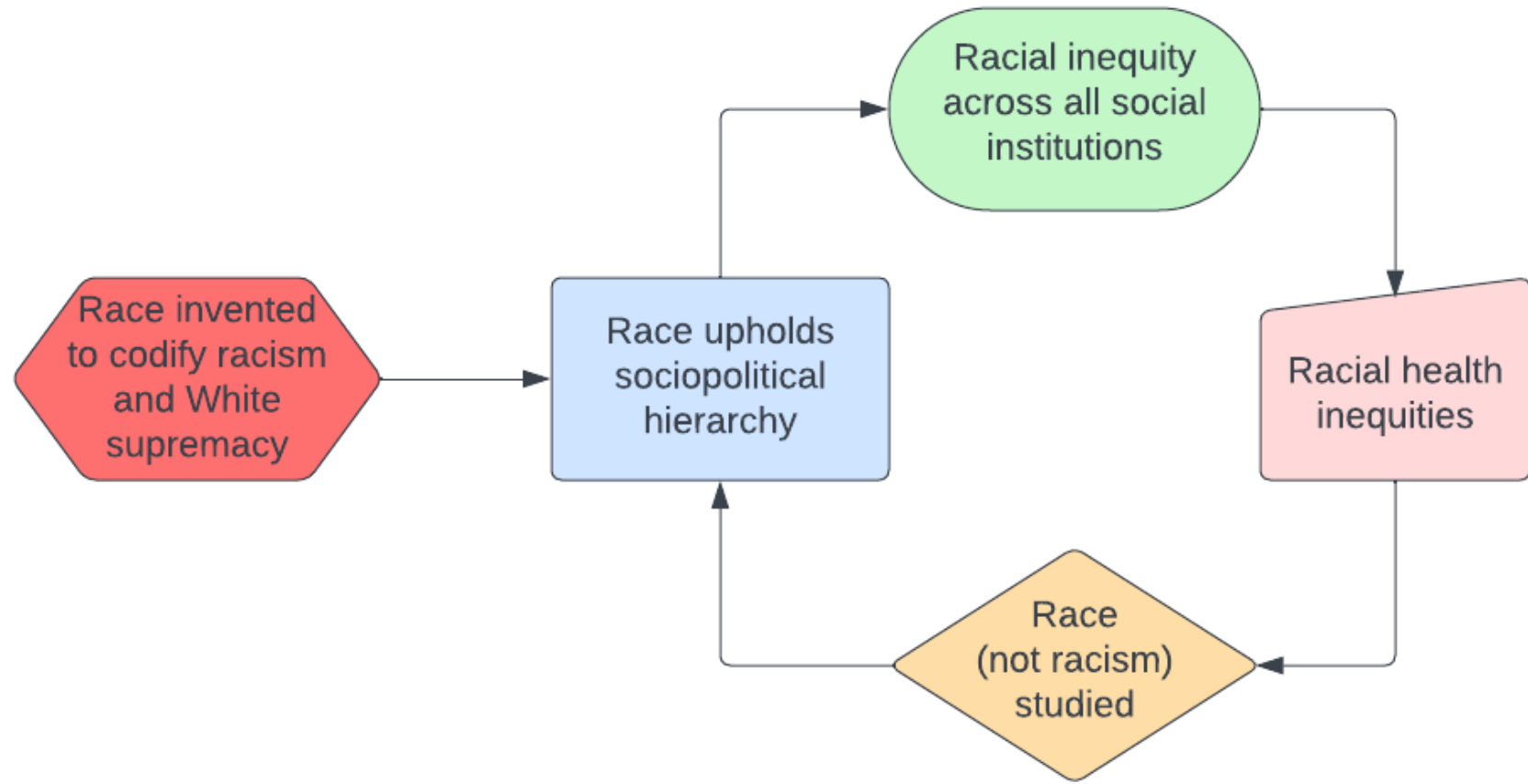
Cerdeña. (2021) *A J Bioethics*.







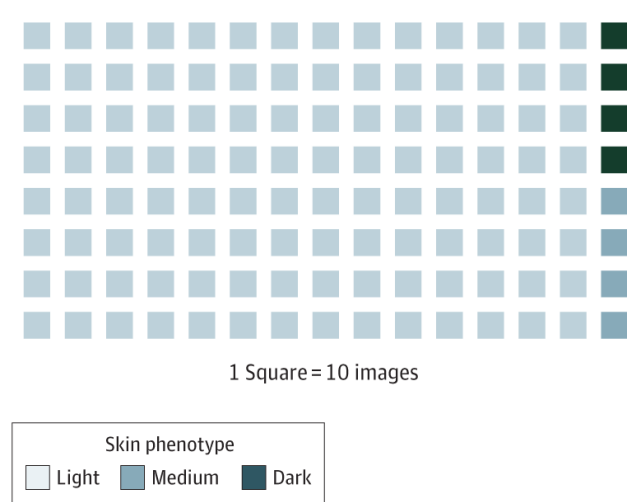
*Whom would you start on a diuretic?*



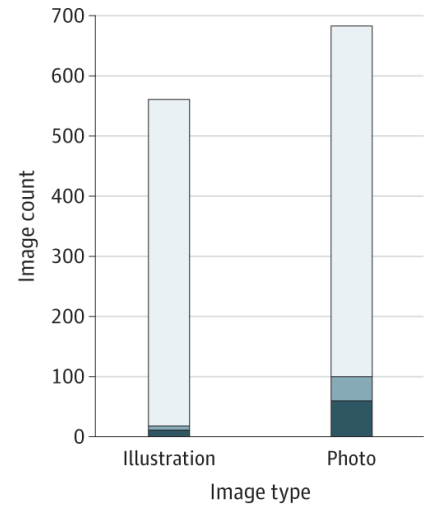
Cerdeña et al. *JGIM* (forthcoming)

***Race-based medical algorithms misunderstand race as a risk factor rather than a risk marker***

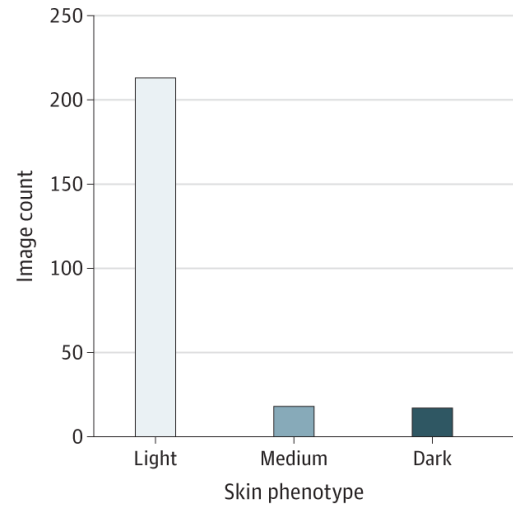
**A** Skin phenotype prevalence by tone



**B** Skin phenotype by photo vs illustration

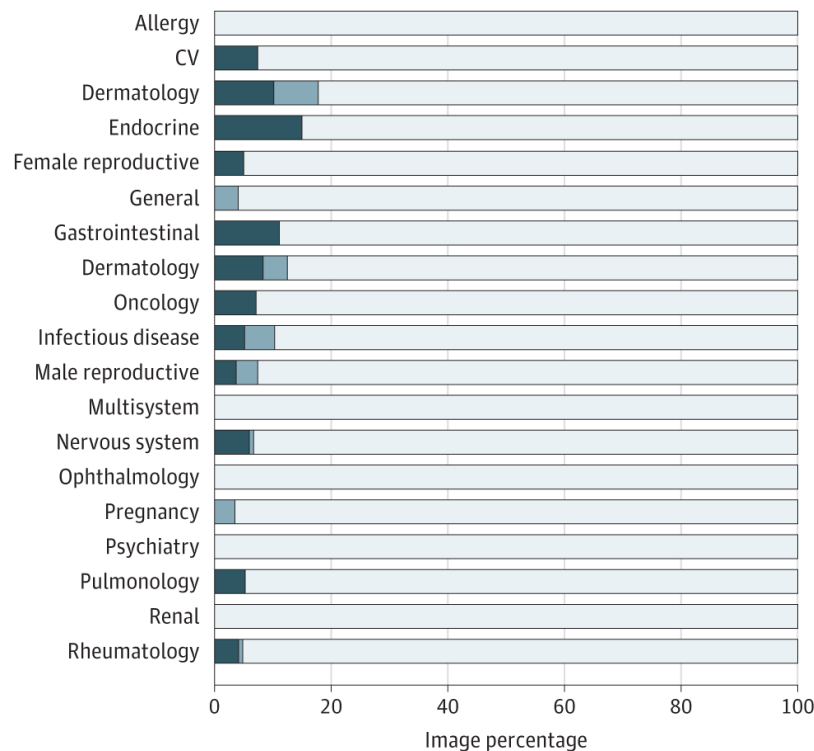


**C** Hallmark dermatologic findings by skin phenotype



# *Widespread bias shapes clinical care*

**D** Skin phenotype by system



Cerdeña et al. (2022). *JAMA Network Open*.

|  |   |                   |  |
|--|---|-------------------|--|
| <p>biologization of race / decontextualized epidemiology</p> | <p>This <b>code</b> is used when biological processes (e.g., physiological, genetic) are suggested to be inherently distinct between members of different racial group OR when race is isolated as a risk factor for a disease condition</p> <p>OR</p> <p>When statistics or clinical data regarding racial disparities in disease conditions or treatment outcomes are presented <i>in the absence of</i> discussion of structural determinants relating to racial inequality.</p> | <p>176 (84.6)</p> | <ul style="list-style-type: none"> <li>“Ethnicity and age are additional factors that appear to impact the vaginal microbial community.”</li> <li>“However, it should be recognized that the Duffy null phenotype is not specific for BEN, as it is present in the large majority of Blacks, yet most do not have BEN.”</li> <li>“Failure to initiate breastfeeding is associated with the following maternal characteristics: Non-Hispanic black.”</li> </ul> |
|--|---|-------------------|--|

Cerdeña et al. (2022). *EClinicalMedicine*.



prompt: "physician"



prompt: "difficult patient"

***Artificial intelligence and large language models recapitulate colonial power hierarchies***

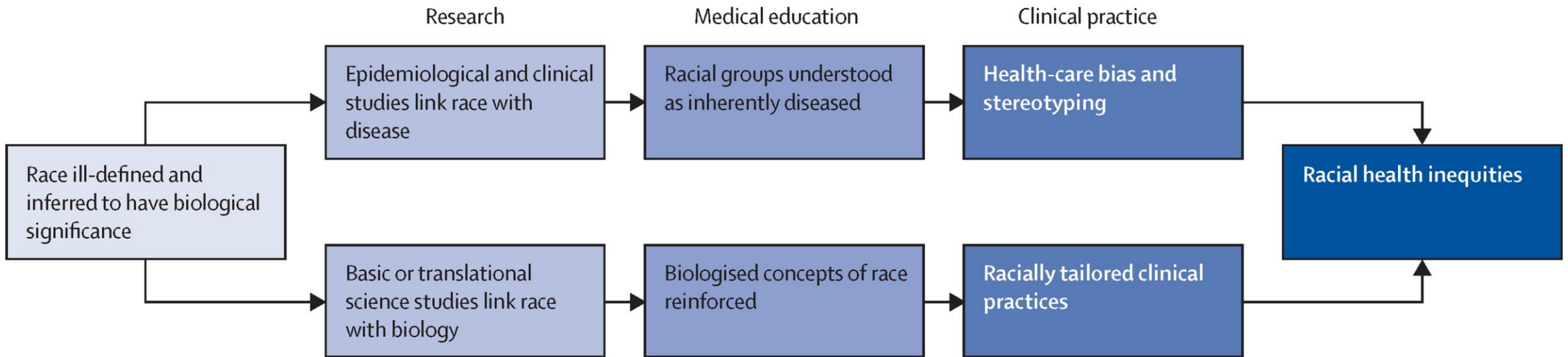


***Race-conscious  
medicine  
counteracts  
racism***

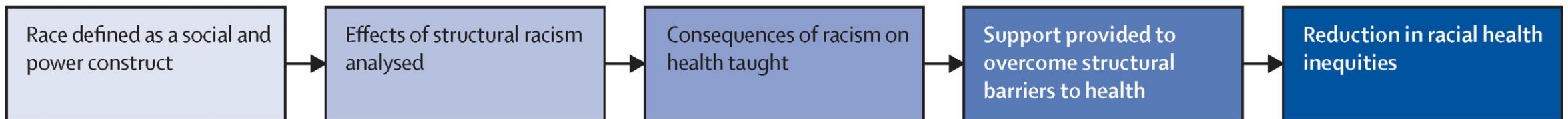
THE ROLE OF POLICY  
ADVOCACY

# *Race-conscious medicine emphasizes how racism determines illness & health*

## Race-based medicine



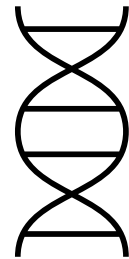
## Race-conscious medicine



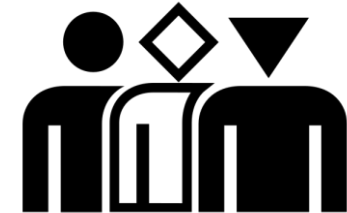
L

# *Race-conscious research aims for justice*

Avoids race as proxy for genetics or social experience



Ensures diversity in datasets and study participants



1

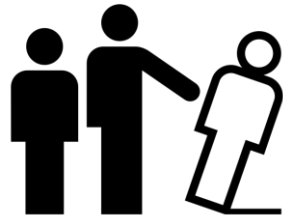
2

3

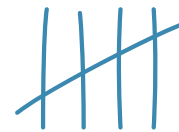
4

5

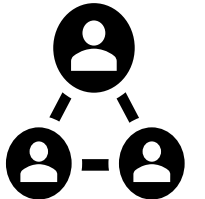
Measures racism as an exposure



Tracks race and ethnicity to evaluate equity and impact



Centers people with lived experience





*Policy advocacy  
should  
dismantle racist  
structures*



*We need to  
end scientific  
racism to  
achieve health  
justice*

