

Structural Racism in Genetics: Consequences and Plans for the Future

Racismo estructural en la Genética: Consecuencias y planes para el futuro

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Financial Disclosure

Jessica Gold, MD, PhD

Does not have any relevant disclosures.

Poll:

Please choose from the options:

- Strongly Disagree
- Disagree
- Neither Agree nor Disagree
- Agree
- Strongly Agree

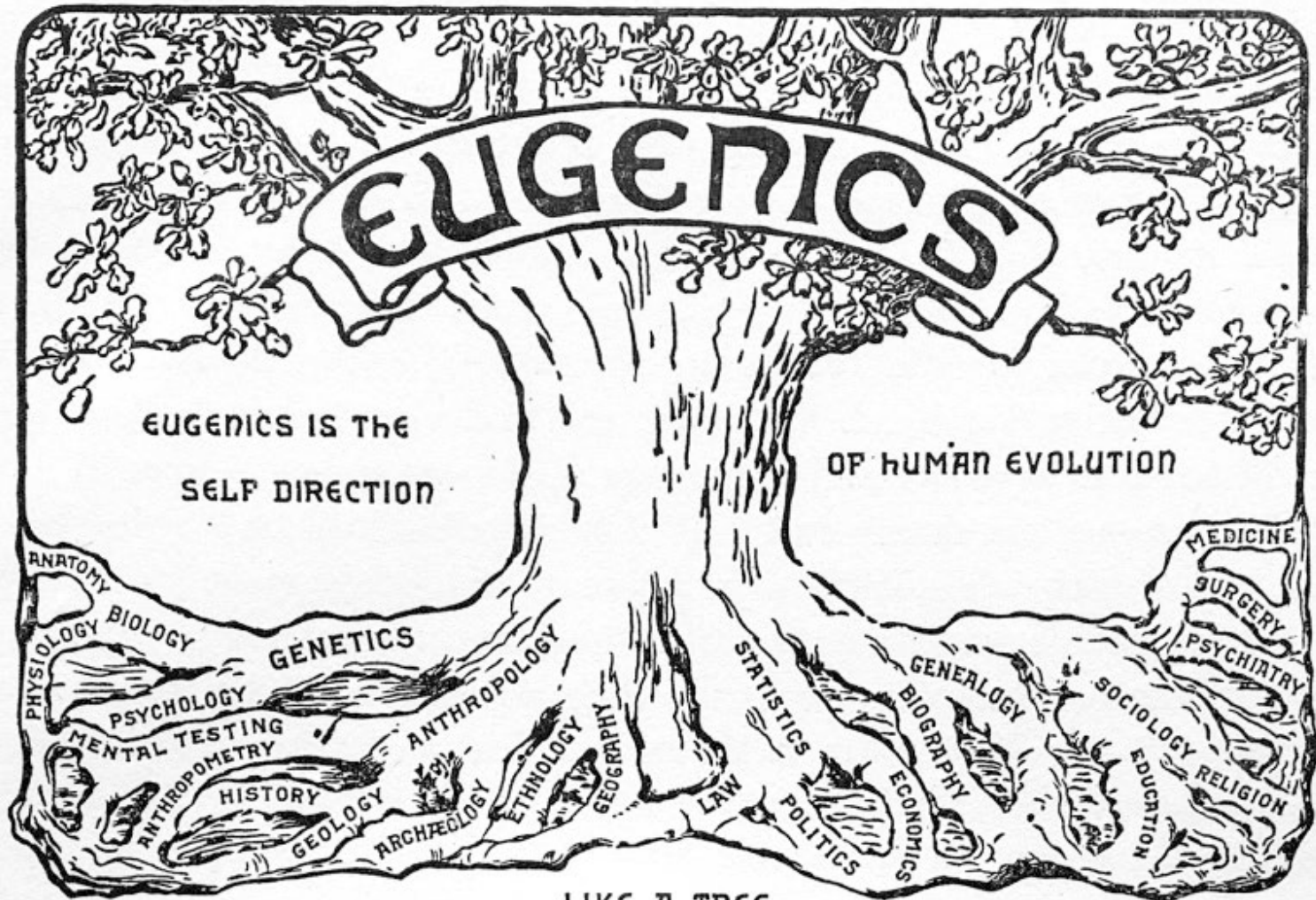
Encuesta:

Elija entre las opciones:

- Totalmente en desacuerdo
- En desacuerdo
- Ni de acuerdo ni en desacuerdo
- De acuerdo
- Totalmente de acuerdo

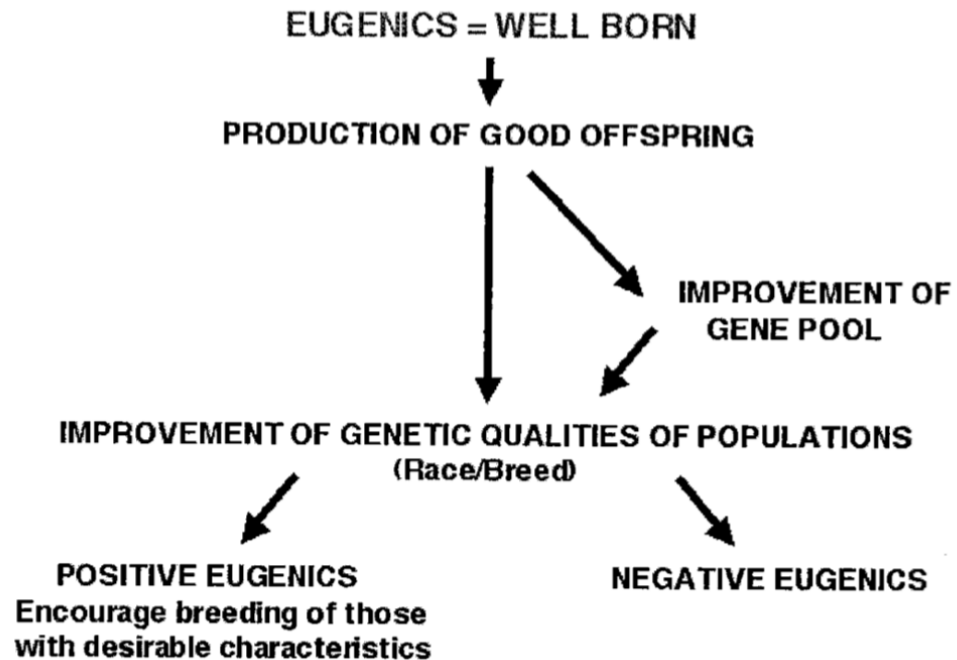
- I am concerned about structural racism in genetics
- Learning about structural racism in genetics is important
- There is a need for education on structural racism that is specifically dedicated to medical genetics
- Knowledge on structural racism in clinical genetics will change my personal clinical or lab practice

- Me preocupa el racismo estructural en genética.
- Aprender sobre el racismo estructural en la genética es importante.
- Hay una necesidad de educación sobre el racismo estructural que se dedique específicamente a la genética médica.
- El conocimiento sobre el racismo estructural en genética clínica cambiará mi práctica clínica o de laboratorio personal.

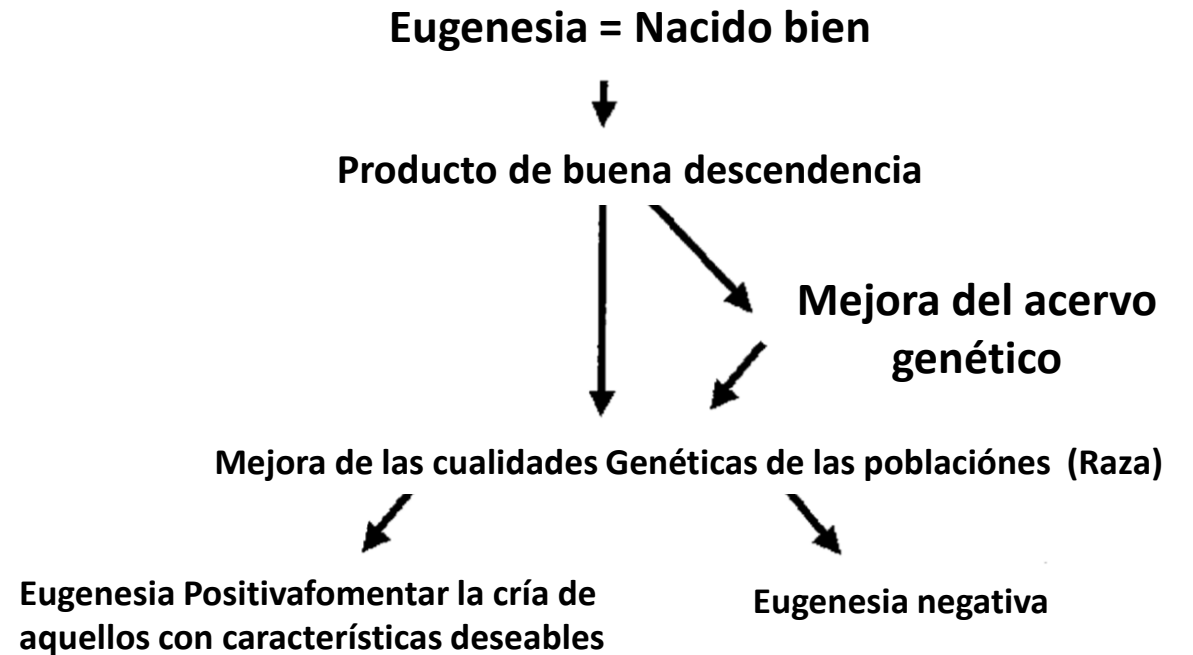


LIKE A TREE
EUGENICS DRAWS ITS MATERIALS FROM MANY SOURCES AND ORGANIZES
THEM INTO AN HARMONIOUS ENTITY.

Eugenics – Applying the Theory of evolution to society

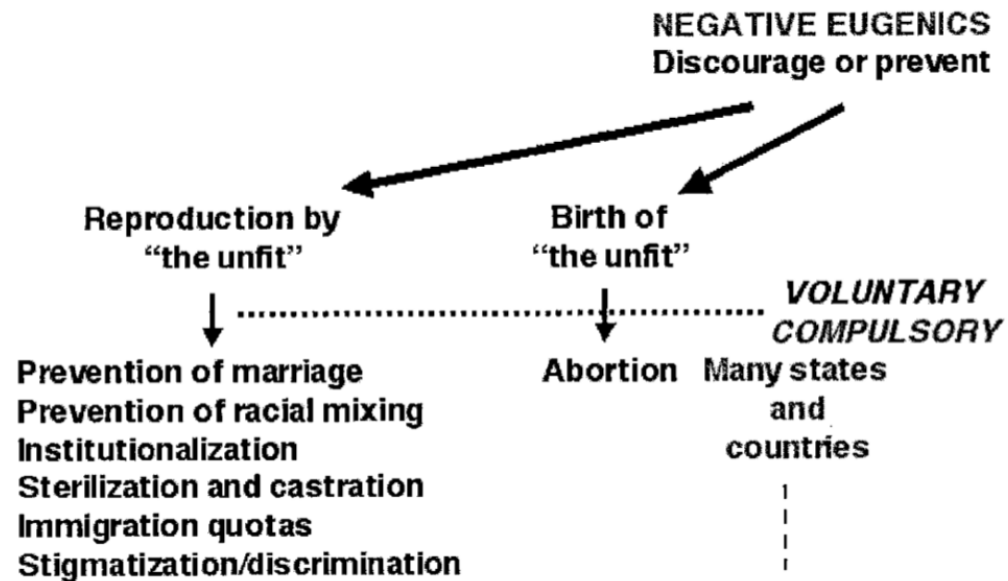


Eugenesia – Aplicando la Teoría de la evolución a la sociedad



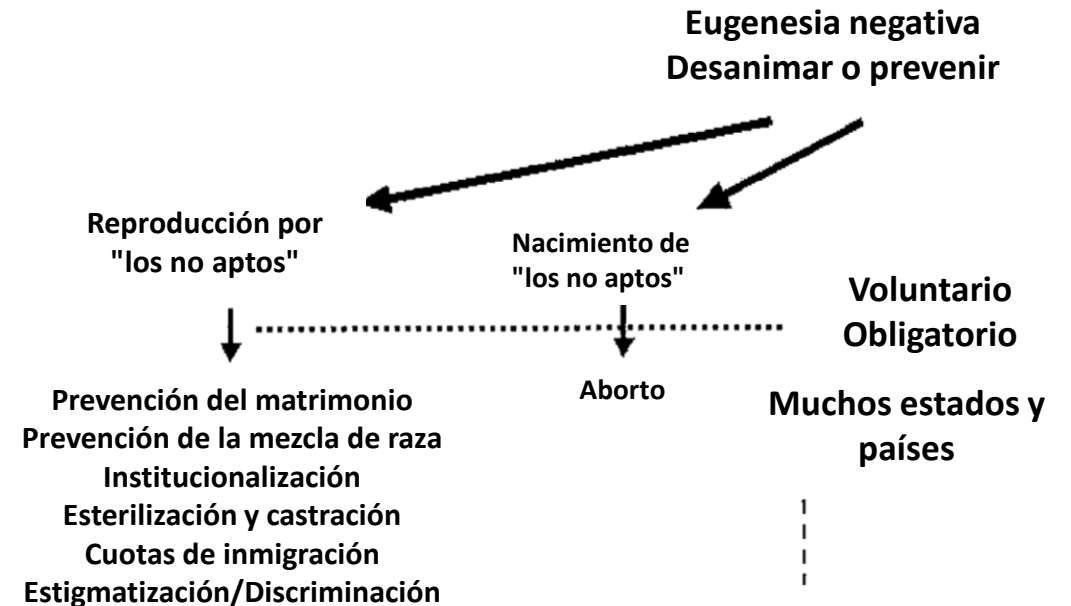
Negative Eugenics

- Cold Spring Harbor
- Margaret Sanger's birth control clinics
- Buck v Bell
- ASHG leadership



Eugenesia negativa

- Puerto de primavera fría
- Las clínicas de control de la natalidad de Margaret Sanger
- (Buck v Bell)
- Liderazgo ASHG





Francis Galton's Legacy


- Father of Eugenics
- Inventor of standard deviation and variance
- Creator of the Dysmorphology Exam including the use of dermatoglyphics

El legado de Francis Galton

- Padre de la eugenesia
- Inventor de la desviación estándar y la varianza.
- Creador del Examen de dismorfología que incluye el uso de dermatoglifos

MR. FRANCIS GALTON'S ANTHROPOMETRIC LABORATORY.

The Laboratory communicates with the "Western Gallery" in which the Scientific Collections of the South Kensington Museum are contained. The Western Gallery runs parallel to Queen's Gate, and is entered from the Imperial Institute Road. Admission is free.

Date of Measurement.			Initials.	Birthday.			Eye Color.	Sex.	Single, Married, or Widowed?	Page of Register.			
Day.	Month.	Year.		Day.	Month.	Year.							
19	5	94	Pa l	21	7	66	Brown grey	m	S	966 6600			
Head length, maximum	Head breadth, maximum.	Cheek bones, maximum breadth.	Height standing, less heels of shoes.	Span of arms from opposite finger tips in front of chest.	Weight in ordinary clothing.	Strength of grasp.		Breath capacity.	Color Sense.	Keeness of Eyesight.			
						Right hand.	Left hand.			Diamond Numerals, read at inches.		Smallest Snellen's type read at 6 metres.	
Millimetres.	Millimetres.	Millimetres	Inch. Tenths.	Inch. Tenths.	lbs.	lbs.	lbs.	Cubic inches.	? Normal.	Right eye.	Left eye.	Right Eye.	Left Eye.
195	156	131	66.6	69.3	130	75	75	225	Yes	16	14	No. 12	No. 12
Height sitting above seat of chair.	Length from elbow to finger tip.		Length of middle finger of left hand.	Keeness of hearing.	Highest audible note. (by whistle)	Reaction time, in hundredths of a second	Greatest speed of blow with fist.	NOTE.—Snellen's types are legible by normal eyes at as many metres distance as the numbers they severally bear.					
	Left arm	Right arm.						Left Thumb.			Right Thumb.		
Inch. Tenths.	Millimetres	Millimetres	Millimetres	? Normal.	Vibrations per second.	To Sight	To Sound	Feet per sec.					
34.9	445	446	117	Yes	21,000	22	20	—					

One page of the Register is assigned to each person, in which his measurements at successive periods are entered in successive lines. A copy of these made at any specified date may be obtained on application by the person measured, or by his or her representative, at the cost of sixpence and postage.

SPECIMENS OF COMPOSITE PORTRAITURE

PERSONAL AND FAMILY.



*Alexander the Great
From 6 Different
Medals.*



Two Sisters.



*From 6 Members
of same Family
Male & Female.*

HEALTH. DISEASE. CRIMINALITY.



*23 Cases.
Royal Engineers,
12 Officers,
11 Privates*



*6
Cases*



*9
Cases*

Tubercular Disease



*8
Cases*



*4
Cases*

*2 OF the many
Criminal Types*

CONSUMPTION AND OTHER MALADIES



I

*20
Cases*



II

*36
Cases*



56 Cases

Co-composite of I & II

Consumptive Cases.

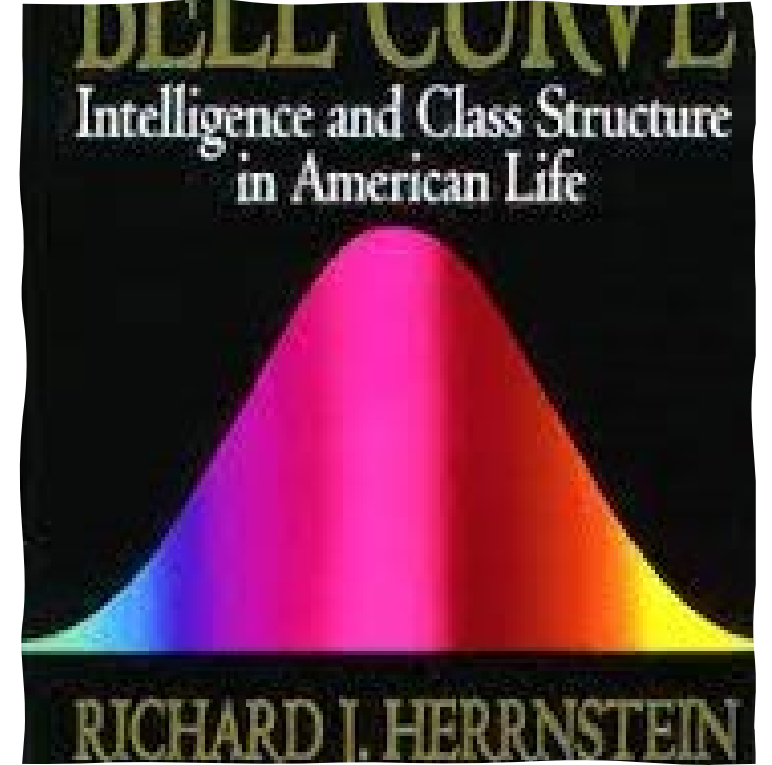


*100
Cases*



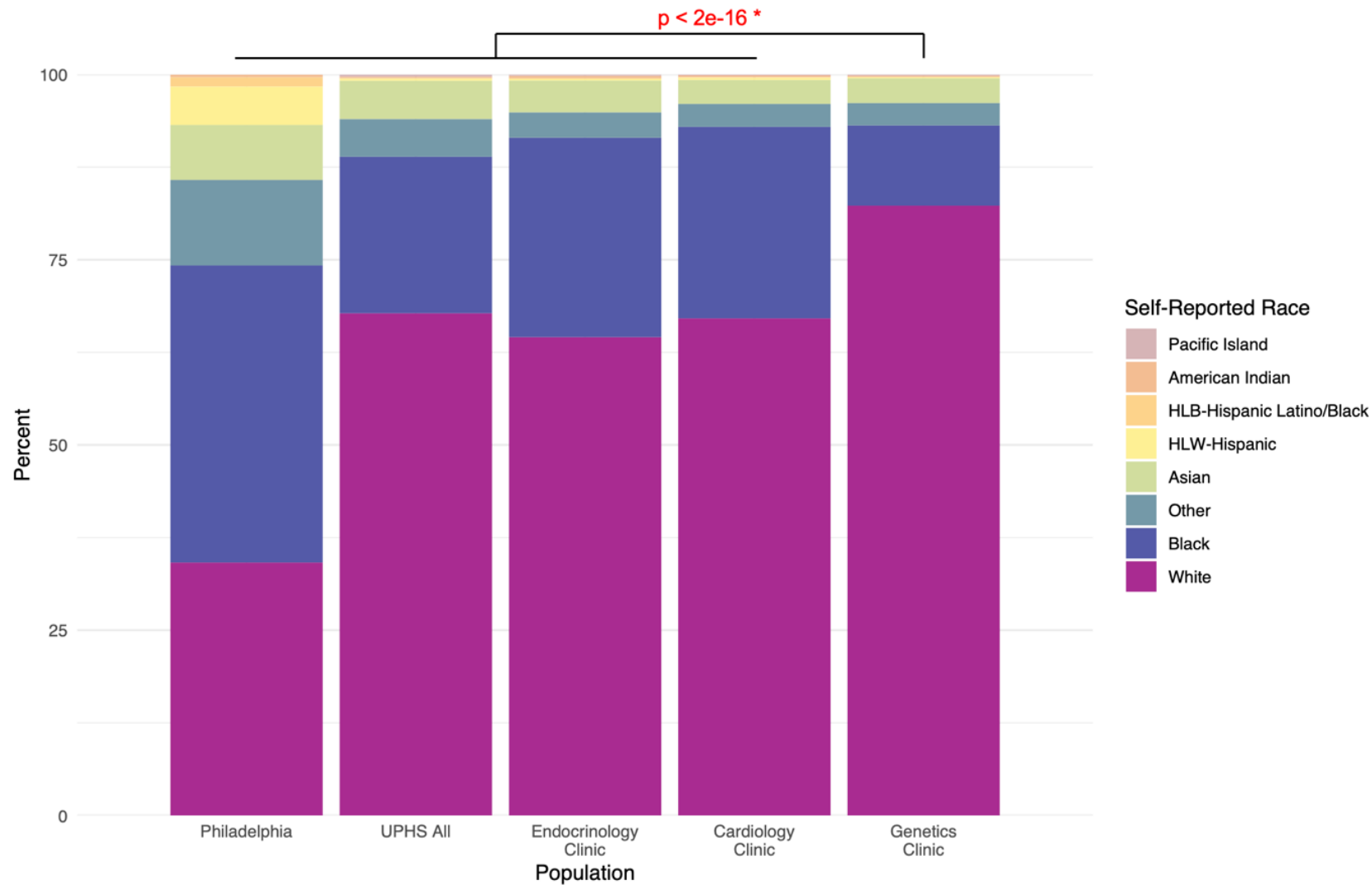
*50
Cases*

Not Consumptive.



Appropriating Genetics for White supremacy

Apropiación de la genética para la supremacía blanca



Race-based disparities in adult genetics

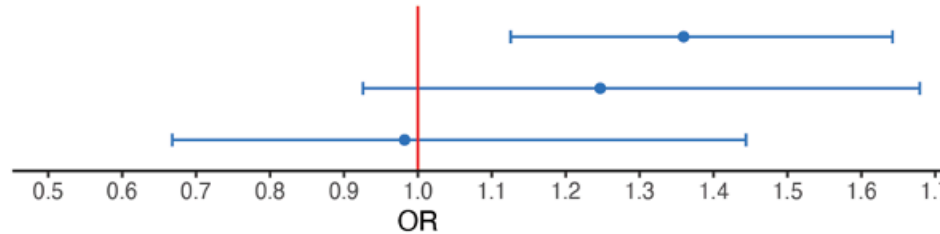
Disigualdades basadas en la raza en la genética adulta

Most genetic testing sent for URM

La mayoría de las pruebas genéticas enviadas para URM

A. Self-Reported Black/Hispanic Race/Ethnicity

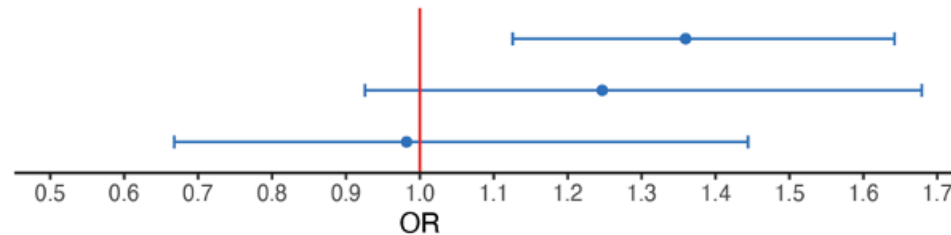
Genetic Testing Sent
Positive Testing Result
VUS Testing Result



OR [95% CI]	p-value
1.36 [1.13 - 1.64]	0.0014 *
1.25 [0.93 - 1.68]	0.1466
0.98 [0.67 - 1.44]	0.9264

A. Raza/Etnicidad Negra/hispana Autoinformada

Prueba genética enviada
Resultado positivo de la prueba
Resultado de la prueba Vus



OR [95% CI]	p-valor
1.36 [1.13 - 1.64]	0.0014 *
1.25 [0.93 - 1.68]	0.1466
0.98 [0.67 - 1.44]	0.9264

CHOP/Penn Diversity in Genetics Curriculum Initiative

CHOP/Penn Diversidad en la Iniciativa Curricular de Genética

Knowledge – Conocimiento

- Grand Rounds – Grandes rondas
- Fellow Lectures – Compañeros de conferencia

Reflection - Reflección

- Book Club – Club de libros
- Balint Group – Grupo Balint

Action- Acción

- Personal Practice- Práctica personal
- Quality Improvement – Mejora en la calidad

Curriculum Timeline

	2022						2023					
	July	August	September	October	November	December	January	February	March	April	May	June
Assessment	Pre-test										Post-Test	
Fellows' Didactics	Session 1			Session 2			Session 3			Session 4		
Genetics Grand Rounds			Lecture 1		Lecture 2		Lecture 3		Lecture 4			
Book Club Meeting				Superior				The Social Life of DNA				
Balint Group						Group 1						Group 2
Dissemination											APHMG	Grand Rounds

Cronología del plan de estudios

	2022						2023					
	Julio	Agosto	Septiembre	Octubre	Noviembre	Diciembre	Enero	Febrero	Marzo	Abril	Mayo	Junio
Evaluación	Prueba previa										Prueba posterior	
Didáctica de los compañeros	Sección 1			Sección 2			Sección 3			Sección 4		
Grandes rondas de genética			Clase 1		Clase 2		Clase 3		Clase 4			
Reunión del club de lectura				Superior				Vida social del ADN				
Brupo valiente						Grupo 1						Grupo 2
Diseminación											APHMG	Rondas

POLL: Pre-test Question Example

1. Historically, the term “Caucasian” has described people from the following regions (check all that apply):
 - a. Northern Europe
 - b. Mediterranean
 - c. Northern Africa
 - d. Sub-Saharan Africa
 - e. Middle East
 - f. India
 - g. China
 - h. Pacific Islands
 - i. America

ENCUESTA: Ejemplo de pregunta previa a la prueba

1. Históricamente, el término “caucásico” ha descrito a personas de las siguientes regiones (marque todo lo que corresponda):
 - a. Norte de Europa
 - b. Mediterráneo
 - c. Africa del Norte
 - d. Africa Sub-sahariana
 - e. Oriente Medio
 - f. India
 - g. China
 - h. Islas del pacifico
 - i. America

POLL: Pre-test Question Example

2. How many self-reported Black individuals were enrolled in the first cohort of the Human Genome project (total subjects = 60)?

- a. 0
- b. 2
- c. 6
- d. 11

ENCUESTA: Ejemplo de pregunta previa a la prueba

2. ¿Cuántos individuos negros auto informados se inscribieron en la primera cohorte del proyecto Genoma Humano (total de sujetos = 60)?

- a. 0
- b. 2
- c. 6
- d. 11

Curriculum in Progress

- Pre-test average knowledge score: $50.6 \pm 14.6\%$
- 88% felt that addressing structural racism in medical genetics is "very important"
- 100% reported that formalized learning would greatly impact their clinical practice

Currículo en progreso

- Puntaje promedio de conocimiento previo a la prueba: $50.6 + 14.6\%$ El
- 88% consideró que abordar el racismo estructural en la genética médica es "muy importante"
- El 100% informó que el aprendizaje formalizado tendría un gran impacto en su práctica clínica.

Curriculum in Progress

- Grand Rounds speakers
 - Shoumita Dasgupta, PhD
 - Ambroise Wonkam, MD
 - Aishwarya Arjunan, MSGC
 - Latrice Landry, PhD
- Book Club for Superior
- QI Project examining delays in whole exome sequencing for non-native English speakers

Currículo en progreso

- Oradores de grandes rondas
 - Shoumita Dasgupta, PhDDr.
 - Ambroise Wonkam
 - Aishwarya Arjunan, MSGC
 - Dra. Latrice Landry
- Club de lectura para-Superior
- Proyecto QI que examina los retrasos en la secuenciación del exoma completo para hablantes no nativos de inglés

CHAT: What topics would you include in a curriculum on structural racism in medical genetics?

CHAT: ¿Qué temas incluiría en un currículo sobre racismo estructural en genética médica?