# How did we get here? – Historical perspectives

Oni J. Blackstock, MD, MHS

Founder and Executive Director, Health Justice, New York, NY

Attending Physician, Harlem Hospital, New York, NY

Clinical Assistant Professor, Montefiore Medical Center, Bronx, NY

"Addressing Medical Mistrust in Black Communities: Implications for COVID-19, HIV, Hepatitis, STIs and Other Conditions"

August 29, 2020

# Learning Objectives

- Define medical mistrust
- Understand the racist policies and practices that have contributed to medical mistrust in the Black community
- Characterize the relationship between medical mistrust and select health care outcomes

# Presentation Roadmap

- Brief Overview of Medical Mistrust
- Origins of Medical Mistrust in the Black community
- Provider Bias – the Role of “Implicit Bias”
- Health Care and Health Inequities
- Medical Mistrust and Health Care
  - HIV, Reproductive Health and COVID-19

# Presentation Roadmap

- Brief Overview of Medical Mistrust
- Origins of Medical Mistrust in the Black community
- Provider Bias – the Role of “Implicit Bias”
- Health Care and Health Inequities
- Medical Mistrust and Health Care
  - HIV, Reproductive Health and COVID-19

# Case Vignette

- 65 year old Black man with hypertension presents with fever, cough and shortness of breath for several days
- Lives with his son who is a bus driver and who recently had a viral illness
- Respiratory and heart rate are elevated and he is hypoxic
- You are certain that he has COVID-19 and you tell him you think he needs to go to the ED, but he says *“I don’t trust that hospital to take care of me. The staff there haven’t treated me well in the past. I’d rather go home until I really have to go.”*

# Health Care: A Social Determinant of Health

| Economic Stability | Neighborhood and Physical Environment | Education | Food | Community and Social Context | Health Care System |
|---|---|---|---|---|---|
| Employment | Housing | Literacy | Hunger | Social integration | Health coverage |
| Income | Transportation | Language | Access to healthy options | Support systems | Provider availability |
| Expenses | Safety | Early childhood education | | Community engagement | Provider linguistic and cultural competency |
| Debt | Parks | Vocational training | | Discrimination | Quality of care |
| Medical bills | Playgrounds | Higher education | | Stress | |
| Support | Walkability | | | | |
| | Zip code / geography | | | | |

**Health Outcomes**
Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations

https://www.kff.org/disparities-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/

# Side Note: Health Disparities vs. Health Inequities

Health **disparities** are differences in health, health outcomes, access to care, etc.

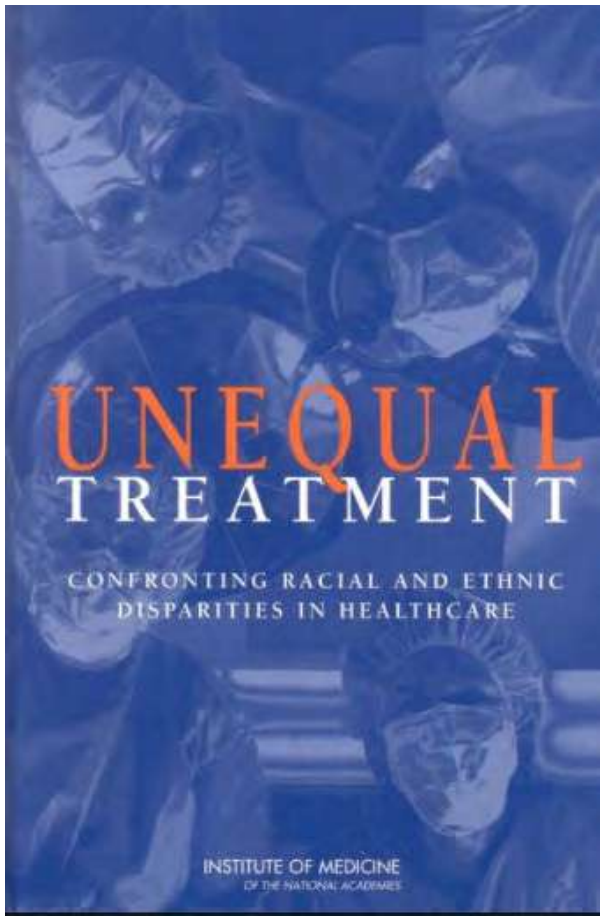
"difference", "lack of parity"

Health **inequities** are when these differences are the result of systems of oppression and structural factors that do disproportionate harm to certain groups vs. other groups.

"state of being unfair"

Adapted from Meghani et al. Pain Medicine. 2008

# Unequal Treatment: Health Care Inequities




- In 1999, U.S. Congress commissioned a report on racial/ethnic inequities in health care
- Released in 2002, the report's findings recognized the pervasiveness of these inequities, that they occur within a broader context of historic and contemporary inequities, and the ways in which the health care system contributes to these inequities
- Medical mistrust was called out in the report as a consequence of systemic racism

Institute of Medicine. 2003.

# What is Medical mistrust?

- Not just a lack of trust in the medical system & personnel (dominant culture), *but the belief that they are acting/will act with ill intent towards a certain individual or group (marginalized)*
- Often extends to the pharmaceutical industry and to government
- Considered "an active response to direct or vicarious (e.g., intergenerational or social network stories) marginalization"[1]
- "A phenomenon created by and existing within a system that creates, sustains and reinforces **racism, classism, homophobia** and **transphobia**, and **stigma"** (also known as inequality-driven mistrust)[2]

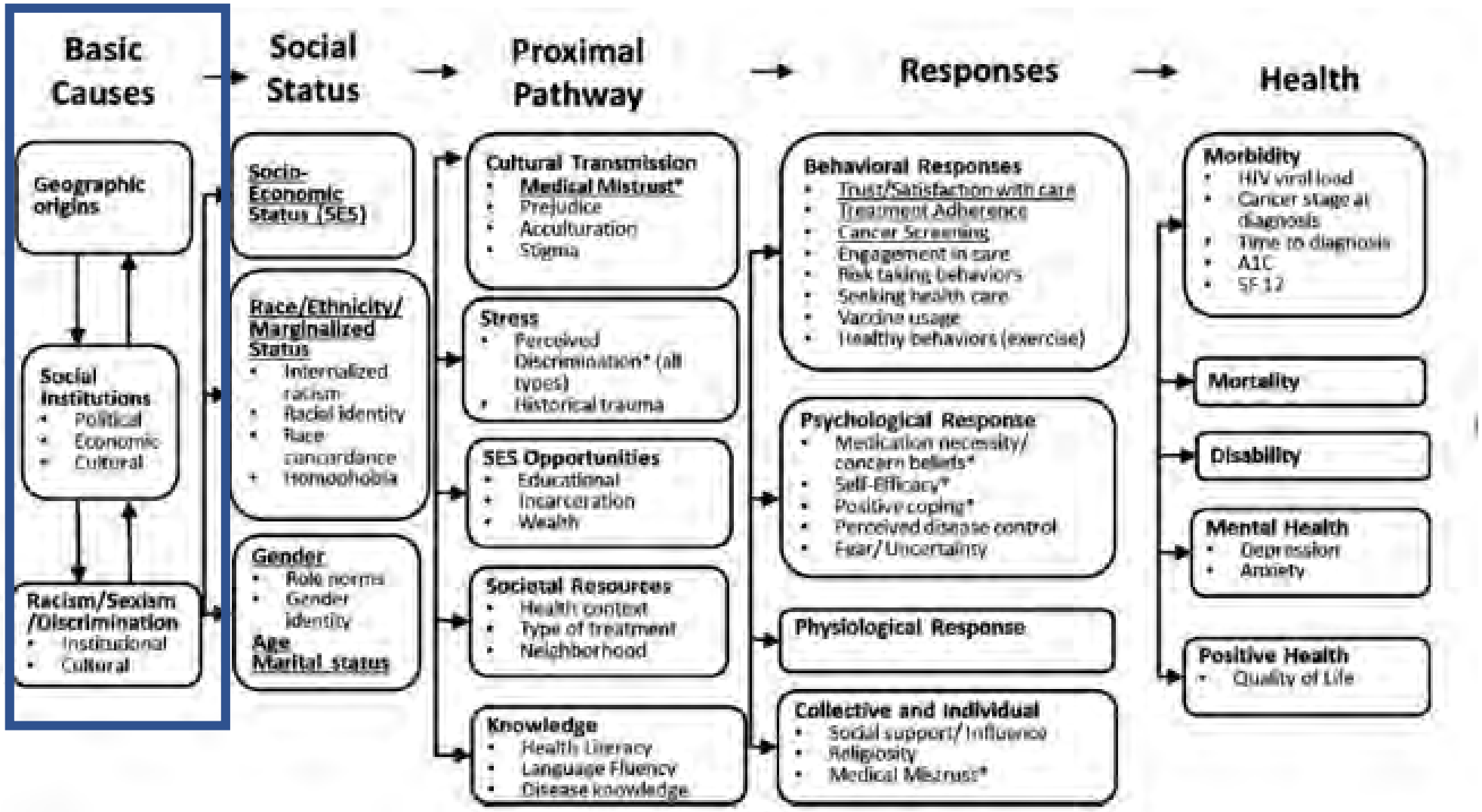
[1]Benkert et al. Behav Med. 2019.; [2]Jaiswal et al. Behav Med. 2019

# Medical Mistrust& Health

- Lower health care utilization including preventive health practices[1-5]
- Lower adherence to medical treatment[6-9]
- Poorer quality patient-provider relationships[10,11]
- Higher likelihood of engaging in behaviors that place people at risk[12]
- Lower rates of involvement in biomedical research[13,14]

[1]Eaton et al. AJPH. 2015; [2]Brenick et al. LGBT Health. 2017.; [3]LaVeist et al. Health Serv Res. 2009; [4]Arnett et al. J Urban Health. 2016; [5]Powell et al. Behav Med. 2019; [6]Dale et al. J Health Psych. 2016.; [7]Kalichman et al. Behav Med. 2016; [8]Bogart et al. Soc Sci Med 2016; [9]Bickell et al. J Clin Oncol. 2009; [10]Tekeste et al. AIDS Behav. 2019; [11]Benkert et al. J Nurs Scholarsh. 2009; [12]Bogart et al. AIDS Behav. 2011; [13]George et al. AJPH. 2014; [14]Smirnoff et al. AJOB Empir Bioeth. 2018

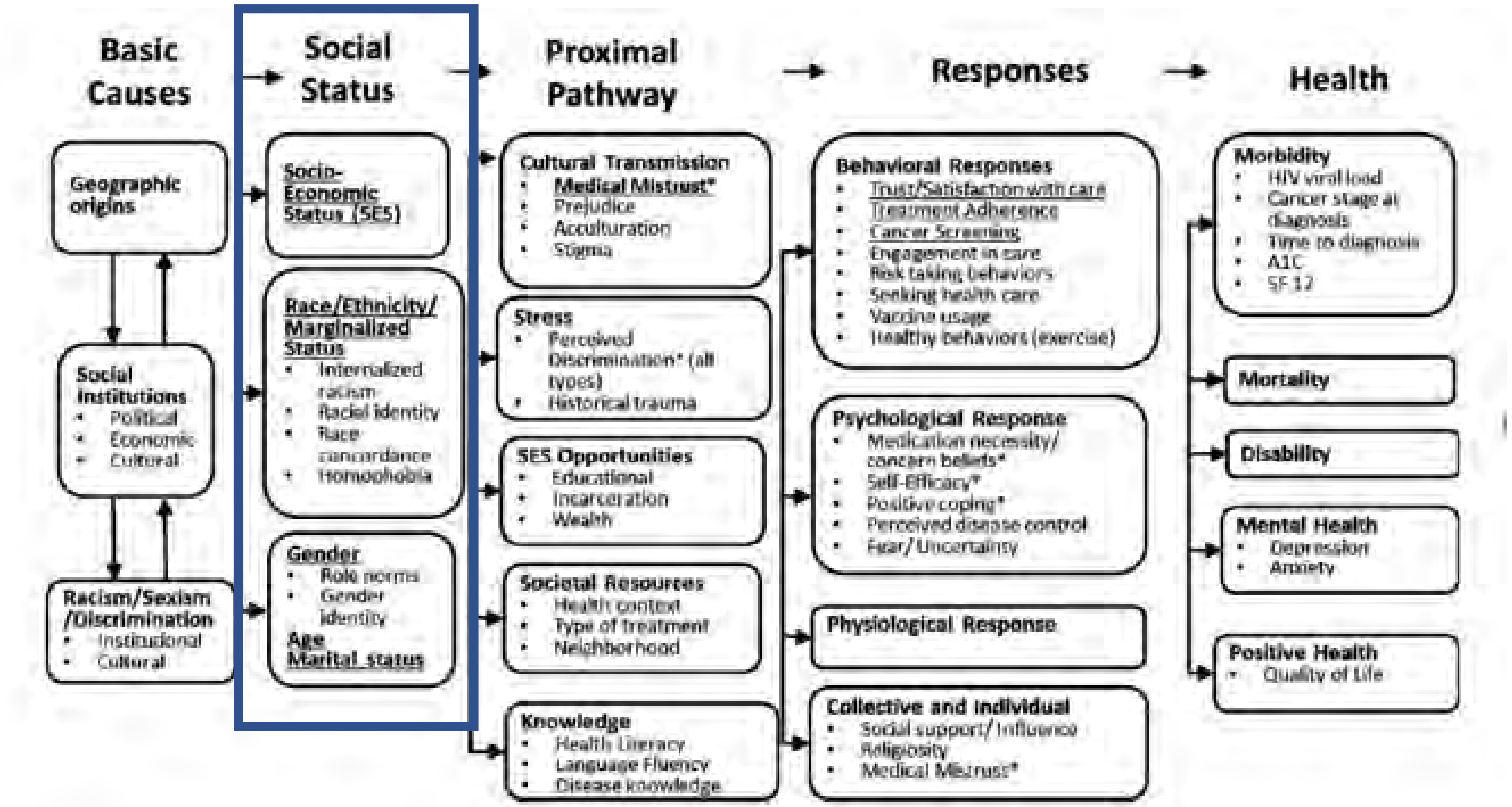
# How might Medical Mistrust impact health?




Racism and Health Framework for the study of medical mistrust and health.
Adapted from Williams and Mohammed, 2013.

Benkert et al. Behav Med. 2019

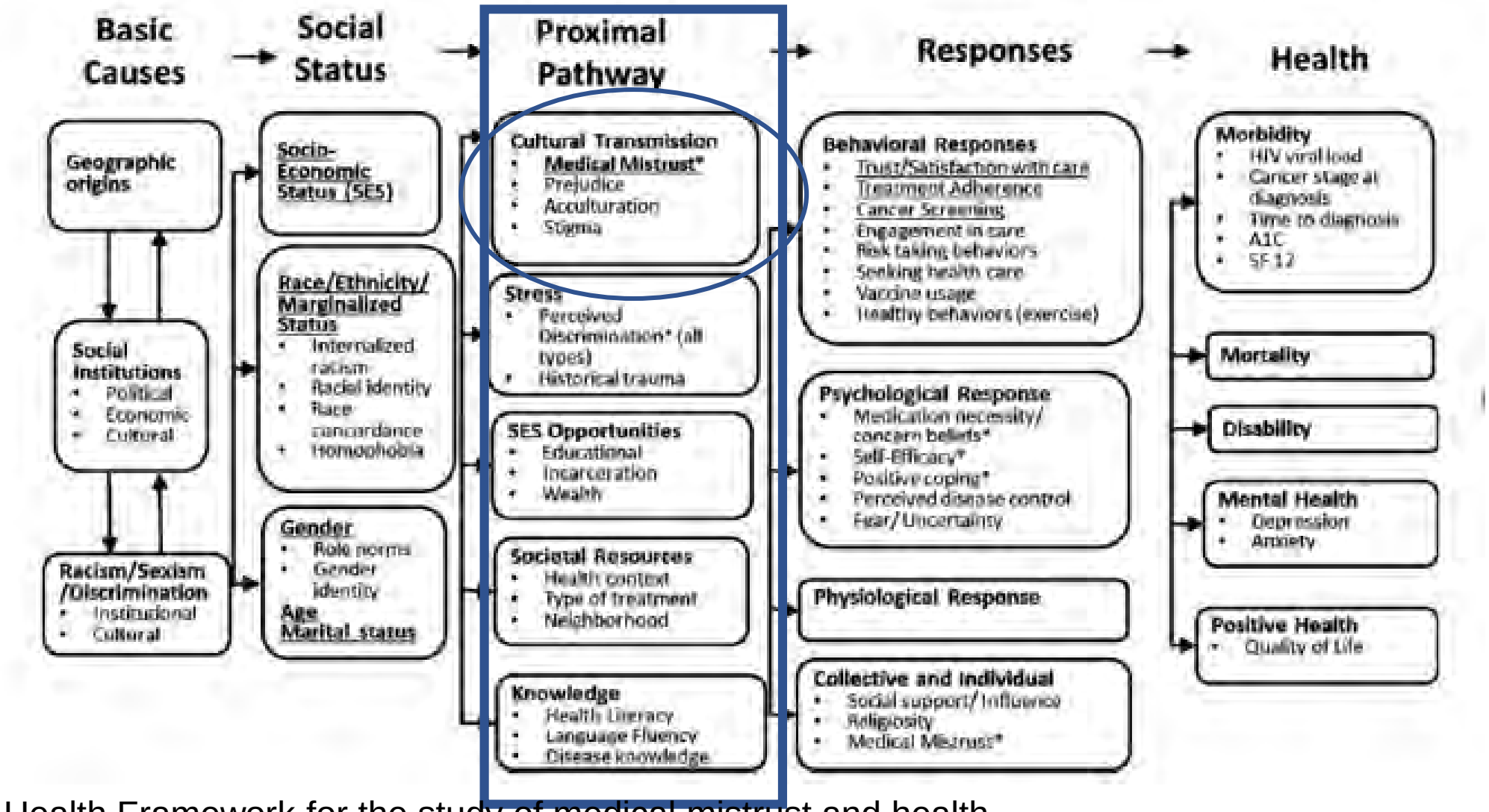
# How might Medical Mistrust impact health?




Racism and Health Framework for the study of medical mistrust and health.
Adapted from Williams and Mohammed, 2013.

Benkert et al. Behav Med. 2019

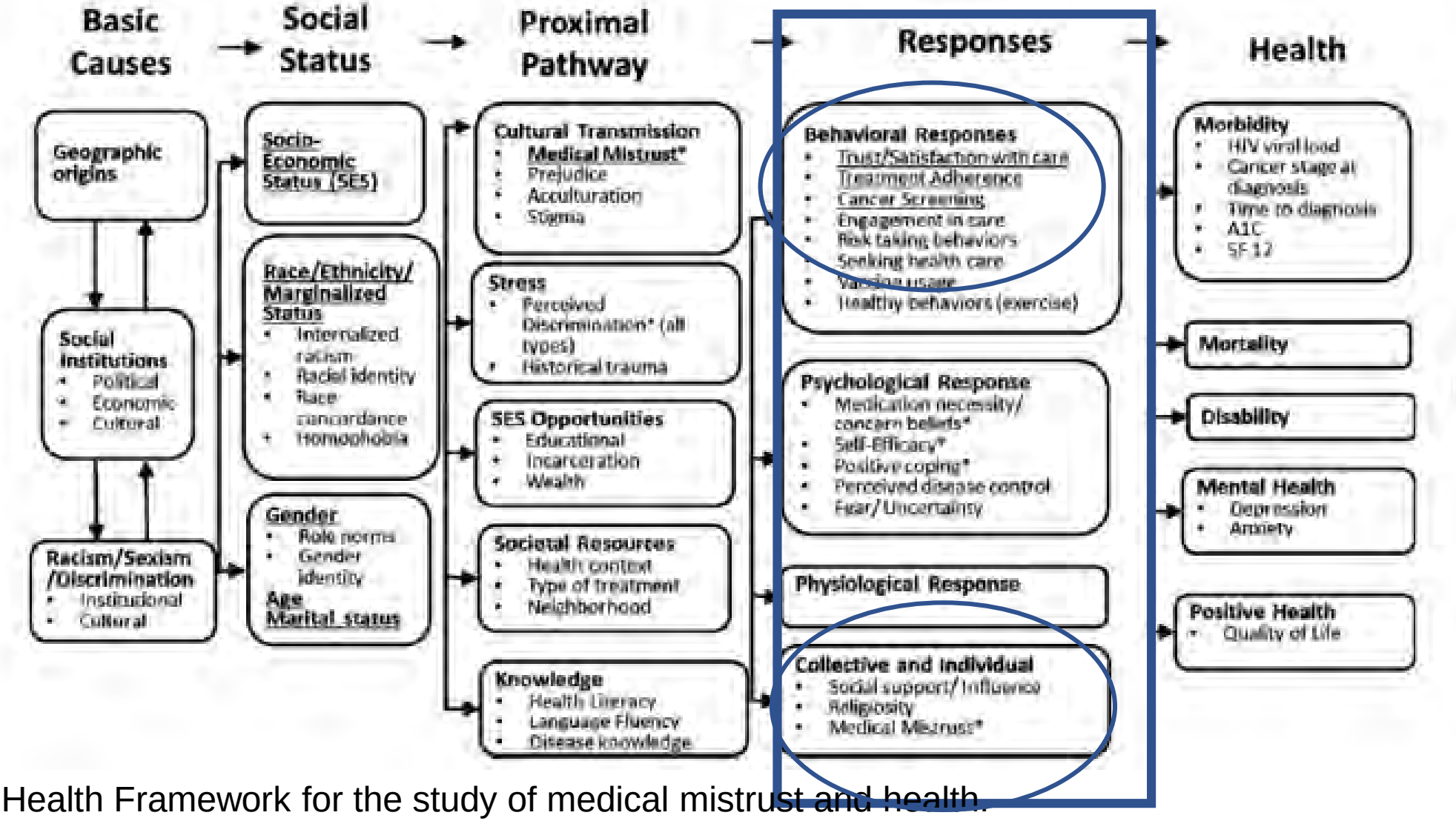
# How might Medical Mistrust impact health?




Racism and Health Framework for the study of medical mistrust and health.
Adapted from Williams and Mohammed, 2013.

Benkert et al. Behav Med. 2019

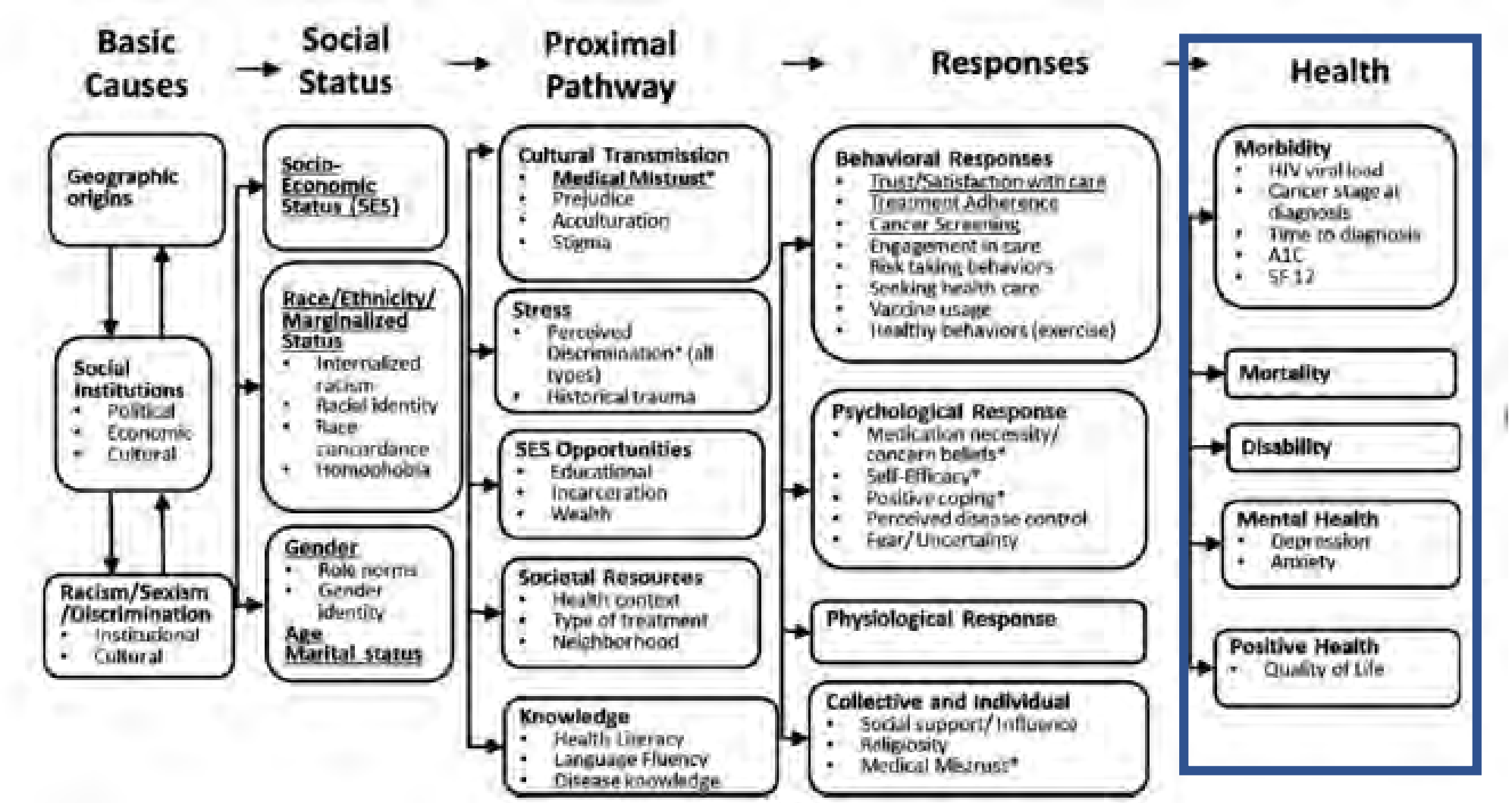
# How might Medical Mistrust impact health?




Racism and Health Framework for the study of medical mistrust and health.
Adapted from Williams and Mohammed, 2013.

Benkert et al. Behav Med. 2019

# How might Medical Mistrust impact health?



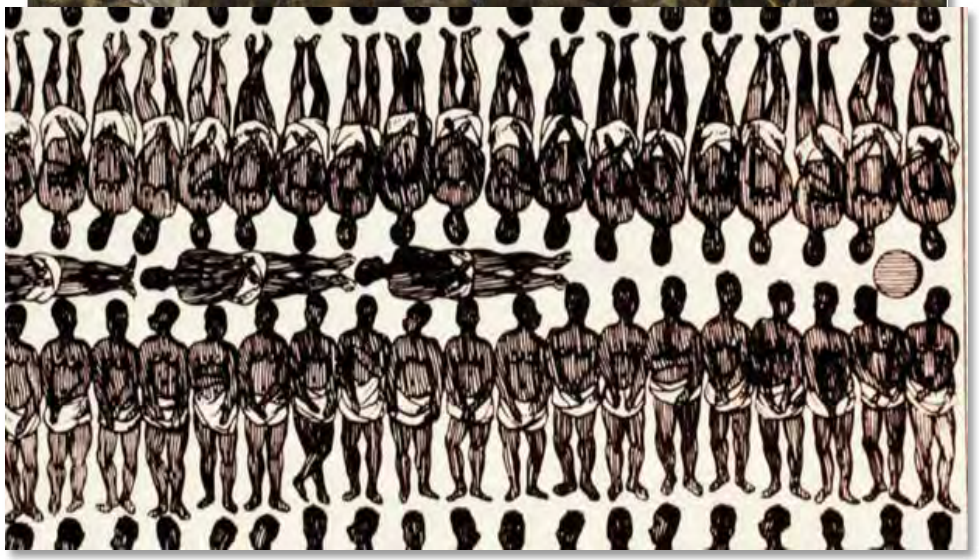

Racism and Health Framework for the study of medical mistrust and health.
Adapted from Williams and Mohammed, 2013.

Benkert et al. Behav Med. 2019

# Presentation Roadmap

- Brief Overview of Medical Mistrust
- Origins of Medical Mistrust in the Black community
- Implicit Bias
- Health Care and Health Inequities
- Medical Mistrust and Health Care
  - HIV, Reproductive Health and COVID-19

# “Medical practice” during the Transatlantic Slave Trade



- “Medically managed enterprise”
- Doctors inspected enslaved people before they were forcibly taken to slave ships; hired to ensure the “cargo” remained alive and healthy during transport
- Compensated with money as well as with enslaved people
- Passage of the Dolben Act (aka the Slave Carrying Bill) in 1788 mandated all English slave ships to have a doctor on board

Lee et al. Yale Daily News. 2019; Halperin. The Pharos. Winter 2013.

# “Medical practice” during the Transatlantic Slave Trade

TO BE SOLD on board the Ship *Bance-Island*, on tuesday the 6th of *May* next, at *Afbley-Ferry*; a choice cargo of about 250 fine healthy

NEGROES,

just arrived from the Windward & Rice Coaft. —The utmoft care has already been taken, and ſhall be continued, to keep them free from the leaſt danger of being infected with the SMALL-POX, no boat having been on board, and all other communication with people from *Charles-Town* prevented.

*Auſtin, Laurens, & Appleby.*

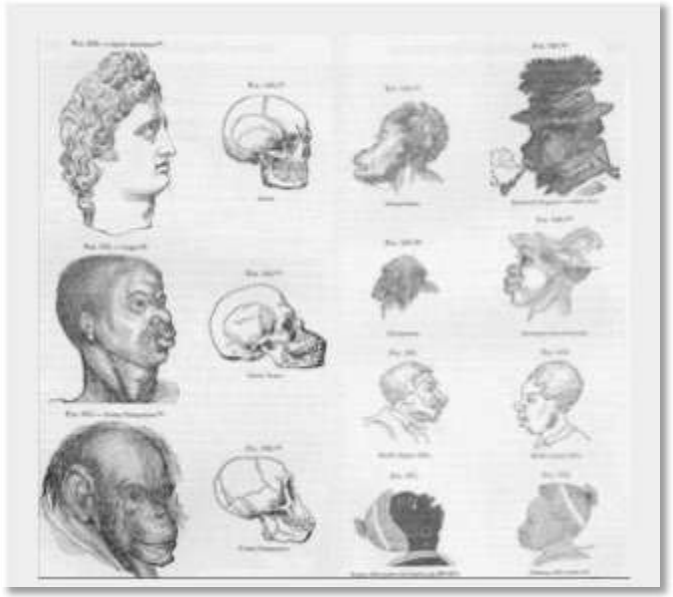
*N. B.* Full one Half of the above Negroes have had the SMALL-POX in their own Country.

“The more you preserve of them for the Plantations the more Profit you will have, and also the greater Reputation and Wages another voyage.

Besides it’s a Case of Conscience to be careful of them as the White Men. For although they are Heathens yet have they a rational Soul as well as us, and God knows whether it may not be more tolerable for them in the latter Day than for many who profess themselves Christians.”

Halperin. The Pharos. Winter 2013.

# The birth of “race”



- Evolved in the 18th century driven, in part, by an increased awareness about animal subspecies as a result of animal breeding
- Occurred as the slave trade was growing
- People of African descent categorized as Homo sapiens *afer* (“ruled by caprice”)
- Associated with innate inferiority – creating a “hierarchy of humanity”
- Reified by what Europeans said where physical and mental defects of Black people (e.g., cranium size [phrenology], drapetomania, Hebetude (“laziness”), **different manifestations of syphilis**)

Washington. Medical Apartheid. P. 25-51
https://pages.vassar.edu/realarchaeology/2017/03/05/phrenology-and-scientific-racism-in-the-19th-century/

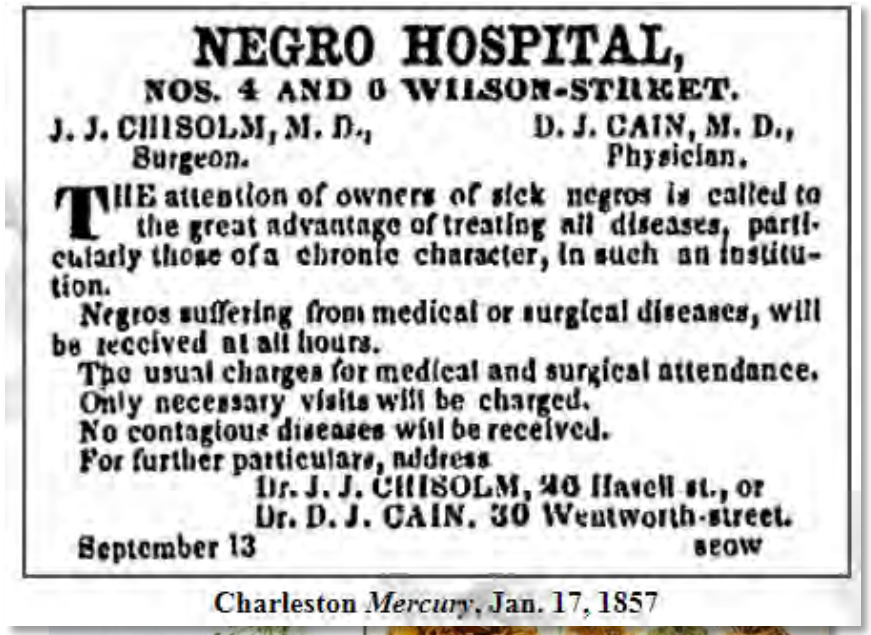
# “Medical practice” during slavery: A medical partnership between doctor & slaveowner


DEALERS INSPECTING A NEGRO AT A SLAVE AUCTION IN VIRGINIA,—FROM A SKETCH BY OUR SPECIAL ARTIST.

- Played a key role in establishing “soundness” at the auction block
- Partnership between slave owner and doctor
- If an enslaved person became ill or died, it was considered a significant financial loss for the owner
- Because enslaved people were often hospitalized at their owner’s expense, owners did what they could do to avoid professional medical care

Washington. Medical Apartheid. p 46-47; Halperin. The Pharos. Winter 2013

# The care of enslaved persons



**NEGRO HOSPITAL,**

**NOS. 4 AND 6 WILSON-STREET.**

J. J. CHISOLM, M. D., Surgeon. D. J. CAIN, M. D., Physician.

THE attention of owners of sick negros is called to the great advantage of treating all diseases, particularly those of a chronic character, in such an institution.

Negros suffering from medical or surgical diseases, will be received at all hours.

The usual charges for medical and surgical attendance.

Only necessary visits will be charged.

No contagious diseases will be received.

For further particulars, address

Dr. J. J. CHISOLM, 46 Havell st., or

Dr. D. J. CAIN, 30 Wentworth-street.

September 13 sscow

Charleston *Mercury*, Jan. 17, 1857

- When an enslaved person became sick, they were often first attended to by other enslaved people who used traditional methods passed down over generations
- Enslaved people often avoided often harsh "treatments" from their owners
- Then a physician called; if not able to help, then was admitted to poorly resourced "slave hospitals"
- **Black midwives**: Most plantations designated women who attended births of both enslaved women and slaveowners' wives/mistresses alike, as well as caring for their babies and children.

Halperin. The Pharos. Winter 2013; Washington. Medical Apartheid. p. 46-51; https://blackmidwivesalliance.org/

# Medical experimentation on enslaved people: the Case of Dr. J. Marion Sims


- Father of modern gynecology; founded the New York Women's Hospital
- Owned enslaved people and did experiments on them without anesthesia
- Surgical experimentation on babies to learn about "newborn" tetanus
- Purchased 11 Black women to develop and refine repair of vesicovaginal fistula

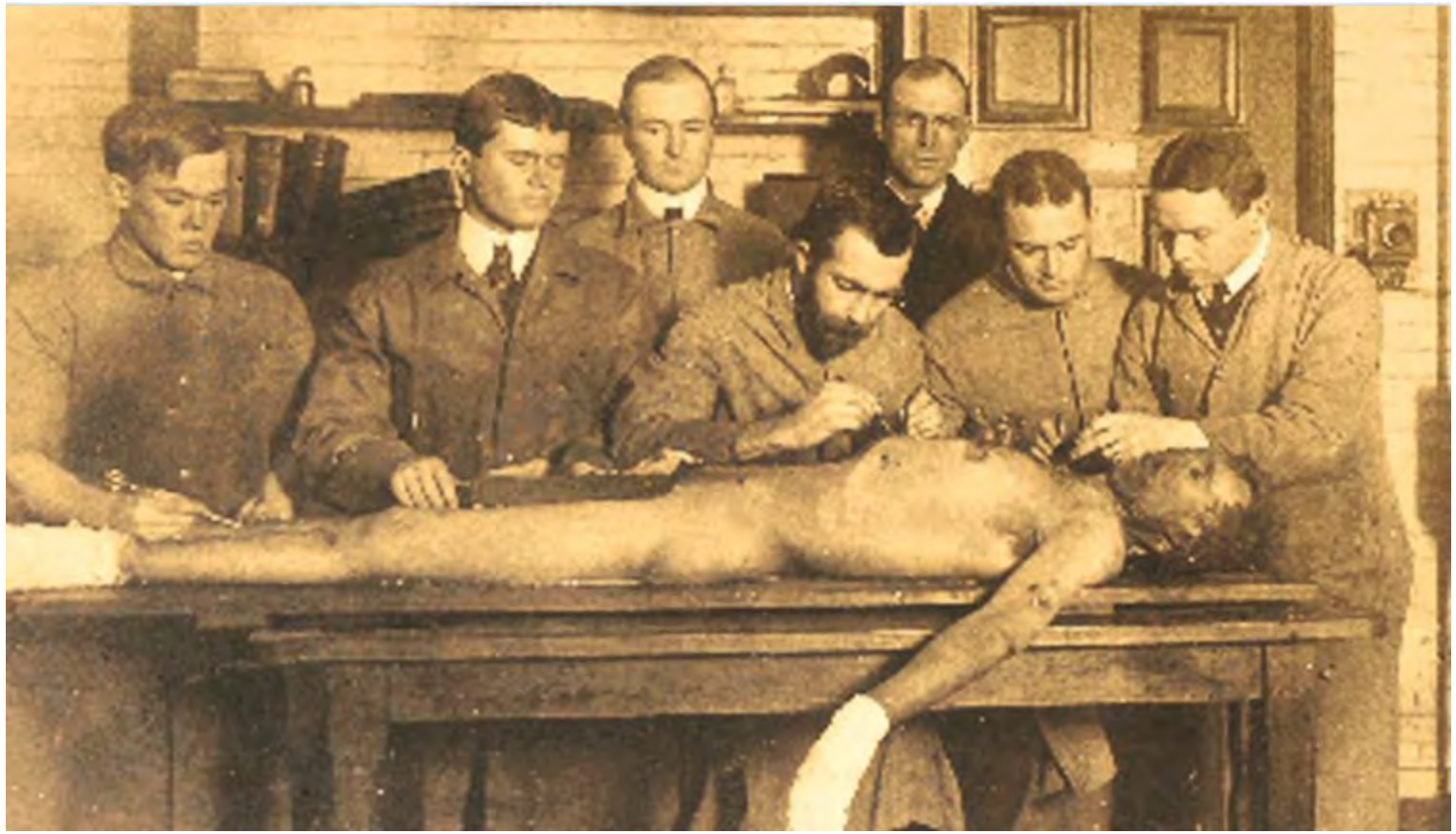
Washington. Medical Apartheid. p. 61-74

# Abuse to Black bodies after death by the medical establishment

- Frenzied need for bodies to practice anatomy and various procedures
- This made Black and poor White people wary about going to hospitals – that they would be unnecessarily experimented or allowed to die so they could be practiced upon
- “Grave robbing” and worry about the “night doctors” emerged
- Bodies often shipped to medical schools in the North as well - schools advertised that they had “dissecting material”

Clark SJ. The Linacre Quarterly. 1998; Washington. Medical Apartheid. P. 115-142

- Content warning for the next four slides: Images from the documentary ““Until The Well Runs Dry: Medicine & the Exploitation of Black Bodies” by Shawn Utsey, PhD demonstrating examples of the ways in which Black people’s bodies were used in anatomy classes at Medical College of Virginia



Screenshot from “Until The Well Runs Dry: Medicine & the Exploitation of Black Bodies” directed by Shawn Utsey Ph.D.

https://vimeo.com/28188054


Screenshot from “Until The Well Runs Dry: Medicine & the Exploitation of Black Bodies” directed by Shawn Utsey Ph.D.

https://vimeo.com/28188054


Screenshot from “Until The Well Runs Dry: Medicine & the Exploitation of Black Bodies” directed by Shawn Utsey Ph.D.

https://vimeo.com/28188054

Screenshot from “Until The Well Runs Dry: Medicine & the Exploitation of Black Bodies” directed by Shawn Utsey Ph.D.

https://vimeo.com/28188054

# Segregated Hospitals


- Up until the 1960s, hospitals were rigidly segregated by race
- In the South, as per Jim Crow laws, separate hospitals for Black patients and where Black doctors could train
- In the North, training opportunities and staff privileges at historically white institutions were offered only to Whites, helping ensure an almost equivalent degree of separate and unequal care

https://guides.mclibrary.duke.edu/blackhistorymonth

# Emergence of Black Hospitals: "The Black Hospital movement" (1865-1960s)

- Freedmen's Hospital established in 1862 in Washington, DC – would later become Howard University Hospital
- Established by the Medical Division of the Freedmen's Bureau
- At its peak, the Black Hospital movement had 90 new hospitals for Black people throughout the U.S.
- Represented "the move from exclusion to segregation in hospital care"

https://guides.mclibrary.duke.edu/blackhistorymonth/hospitals

# Hospital Desegregation Happened Quietly

- With the passage of the Medicare program, desegregation of hospitals was swift
- Hospitals could receive funding only if they integrated
- Johnson administration's Office of Equal Health Opportunity—five staff – and 1,000 employees from federal agencies and 10,000 Civil Rights organizers became inspectors on the ground who fanned out to hospitals to make sure they were in compliance with the law and thus eligible for federal funds.

https://www.usnews.com/news/articles/2015/07/30/desegregation-the-hidden-legacy-of-medicare
https://khn.org/news/1965-the-year-that-brought-civil-rights-to-the-nations-hospitals/

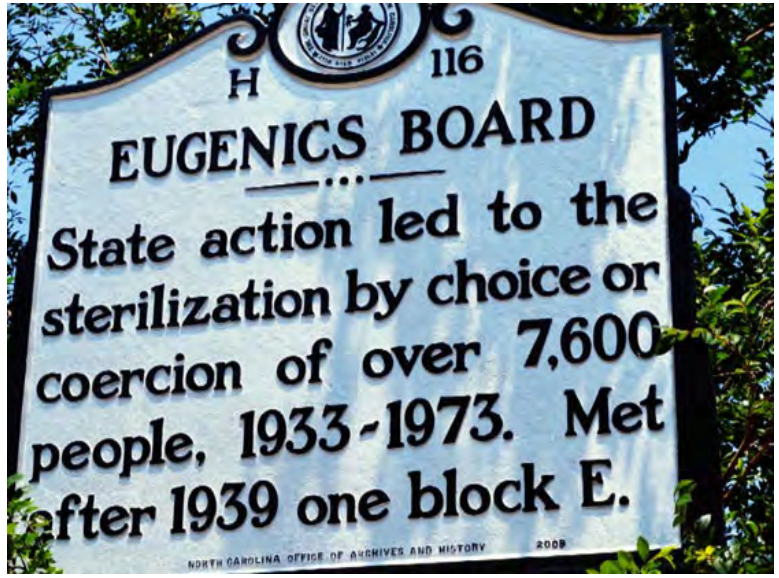
# A legacy of Medical Experimentation Without Informed Consent



- 1932-1972: “Tuskegee Study of Untreated Syphilis in the Negro Male”
- 1940s: Untreated syphilis on Guatemalan prison inmates and psychiatric patients
- 1951: Henrietta Lacks’s cervical cancer cells taken without her consent becoming 1st immortalized cell line
- 1955: “The Pill” studies in Puerto Rico
- 1974: The National Research Act established Institutional Review Boards

Washington. Medical Apartheid. P.157-185; p. 355; https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html https://www.reuters.com/article/us-usa-guatemala-syphilis/u-s-researchers-broke-rules-in-guatemala-syphilis-study-idUSTRE77S3L120110829; https://www.pbs.org/wgbh/americanexperience/features/pill-puerto-rico-pill-trials/

# Eugenics (“well-born”) & Government-sanctioned programs




- Throughout most of the 20th century, compulsory surgical sterilizations of communities considered “unfit” to reproduce – disproportionately Black women – were legal
- North Carolina **Eugenics** Commission sterilized 8,000 mentally disabled persons through the 1930s, 5,000 were Black
- South Poverty Law Center estimates 100K to 150K women using federal funds, ½ were Black
- However, many sterilizations happened outside of the law at the discretion of physicians (“Mississippi appendenctomy”)
- Governmental public assistance programs also linked sterilizations to welfare benefits

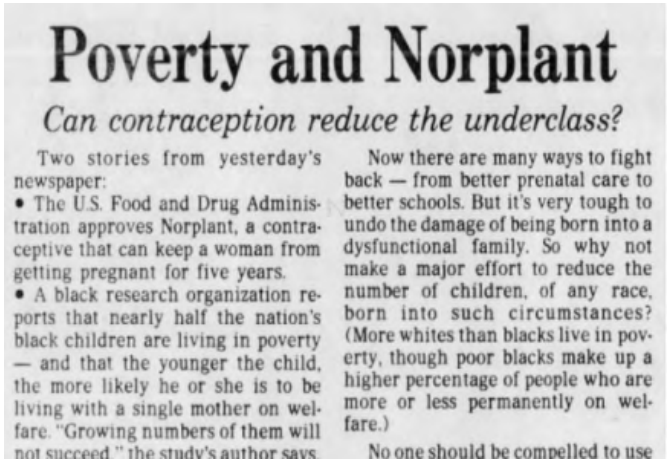
Washington. Medical Apartheid. p.189-215

# Reproductive coercion

- Margaret Sanger, founder of Planned Parenthood, moved from women's reproductive rights to eugenics
- Her American Birth Control League merged with another organization and developed up the "Negro Project" which set up birth control clinics in Black neighborhoods around the country
- The Pill as well as other contraceptive methods were made available to Black women w/ low-incomes for free or at low cost through government-sponsored Planned Parenthood clinics
- Raised community concerns about genocide in these clinics

Washington. Medical Apartheid. p. 195-202.

# Reproductive coercion



**Poverty and Norplant**

*Can contraception reduce the underclass?*

Two stories from yesterday's newspaper:

• The U.S. Food and Drug Administration approves Norplant, a contraceptive that can keep a woman from getting pregnant for five years.

• A black research organization reports that nearly half the nation's black children are living in poverty — and that the younger the child, the more likely he or she is to be living with a single mother on welfare. "Growing numbers of them will not succeed," the study's author says.

Now there are many ways to fight back — from better prenatal care to better schools. But it's very tough to undo the damage of being born into a dysfunctional family. So why not make a major effort to reduce the number of children, of any race, born into such circumstances? (More whites than blacks live in poverty, though poor blacks make up a higher percentage of people who are more or less permanently on welfare.)

No one should be compelled to use

- First new contraceptive on the market in 25 years made (1990)
- Many bills proposed to “incentivize” Norplant use for people on public assistance and even to mandating it for women on Medicaid who had an abortion (North Carolina)
- Lawmakers also made Norplant expensive to remove
- Medicaid only reimbursed providers if Norplant was in for five years
- Promoted throughout urban areas, groundswell of opposition by advocates and community groups
- Eventually discontinued 2002 after multiple class action lawsuits and concerns about its adverse side effects

Jekanowski. Berkeley Public Policy Journal. Fall 2018.

# Presentation Roadmap

- Brief Overview of Medical Mistrust
- Origins of Medical Mistrust in the Black community
- Provider Bias – the role of “Implicit Bias”
- Health Care and Health Inequities
- Medical Mistrust and Health Care
  - HIV, Reproductive Health and COVID-19

# Provider Bias: The Role of “Implicit Bias”

- Implicit bias refers to attitudes or stereotypes that affect our understanding, actions, and decisions in an unconscious manner
- Thought to be activated involuntarily and without an individual’s awareness or intention control
- Considered different from explicit biases and to form from very early ages influenced by early life experiences, media, etc.
- Concerns for potential impact on health outcomes

http://kirwaninstitute.osu.edu/research/understanding-implicit-bias/

# Implicit Bias & Health Care Professionals

- Systematic review by Hall et al. of studies looking of health care professionals (HCPs) examining association between implicit bias and health care outcomes (n=15)
- Found low to moderate levels of racial/ethnic bias among HCPs
  - Scores similar to those in the general population
  - Levels of implicit bias against Black, Latinx and dark-skinned relatively similar across groups
- Results showed trends towards implicit bias being significantly and negatively associated with:
  - **Patient-provider interactions** (e.g. dominant communication styles)
  - **Treatment decisions** (e.g., Black patients less likely to be referred for thrombolysis)
  - **Treatment adherence** (Blk patient of pro-White bias providers less likely to fill scripts)
  - **Patient health outcomes** (Black patients reporting worse psychosocial outcomes).

Hall et al. AJPH. 2015.

# Presentation Roadmap

- Brief Overview of Medical Mistrust
- Origins of Medical Mistrust in the Black community
- Provider Bias – “Implicit Bias”
- Health Care and Health Inequities
- Medical Mistrust and Health Care
  - HIV, Reproductive Health and COVID-19

# Racial inequities in health care

- Access to and receipt of health care
  - Preventive services, sease management[1-3]
- Quality of health car
  - People of color less s with health care providers[4]
  - Dominant communic ed positive emotions, infrequent requests for input about treatment decisions, and less patient-centered care seem to characterize patient–provider interactions involving people of color[5,6]

HEALTH INEQUITIES

[1]CDC. MMWR. 2013;62(S3):1-187. [2]Fiscella et al. JAMA. 2000; [3]Mayberry et al. Med Care Res Rev. 2000; [4]AHRQ. US DHHS. 2014; [5]Beckman et al. Ann Intern Med. 1984. [6]Johnson et al. AJPH. 2004

# Health Care Inequities

- Thrombolytic therapy[1,2]
- Automatic implantable cardioverter-defibrillators (AICD) implantation[3,4]
- Cardiac resynchronization therapy with defibrillation (CRT-D)[5,6]
- Limb-preserving mechanical revascularization procedures like balloon angioplasty, stent placement, or bypass surgery[7,8]
- Limb amputation[7,8]

[1]Manhapra et al. Am Heart J. 2001; [2]Peterson et al. JAMA. 1994; [3]Groenenveld et al. Am Heart J. 2007; [4]Hernandez et al. JAMA 2007; [5]Eapen et al. JACC. 2012; [6]Farmer et al. Heart Rhythm. 2009; [7]Guadagnoli et al. Arch Surg. 1995; [8]Eslami et al. J Vasc Surg. 2007.

# Health Care Inequities: Pain Treatment

- Compared to White people, Black people are less likely to receive pain treatment[1-10]
- If Black people do receive pain treatment, the amount/quantity is lower than that of received by White people
  - A study found that Black patients were significantly less likely than White patients to receive analgesics for extremity fractures in the emergency room (57% vs. 74%), despite having similar self-reports of pain.[6]
  - In a study of appendicitis among children, Black patients received opioid analgesia significantly less frequently than white patients (12.2%  vs 33.9%)[10]

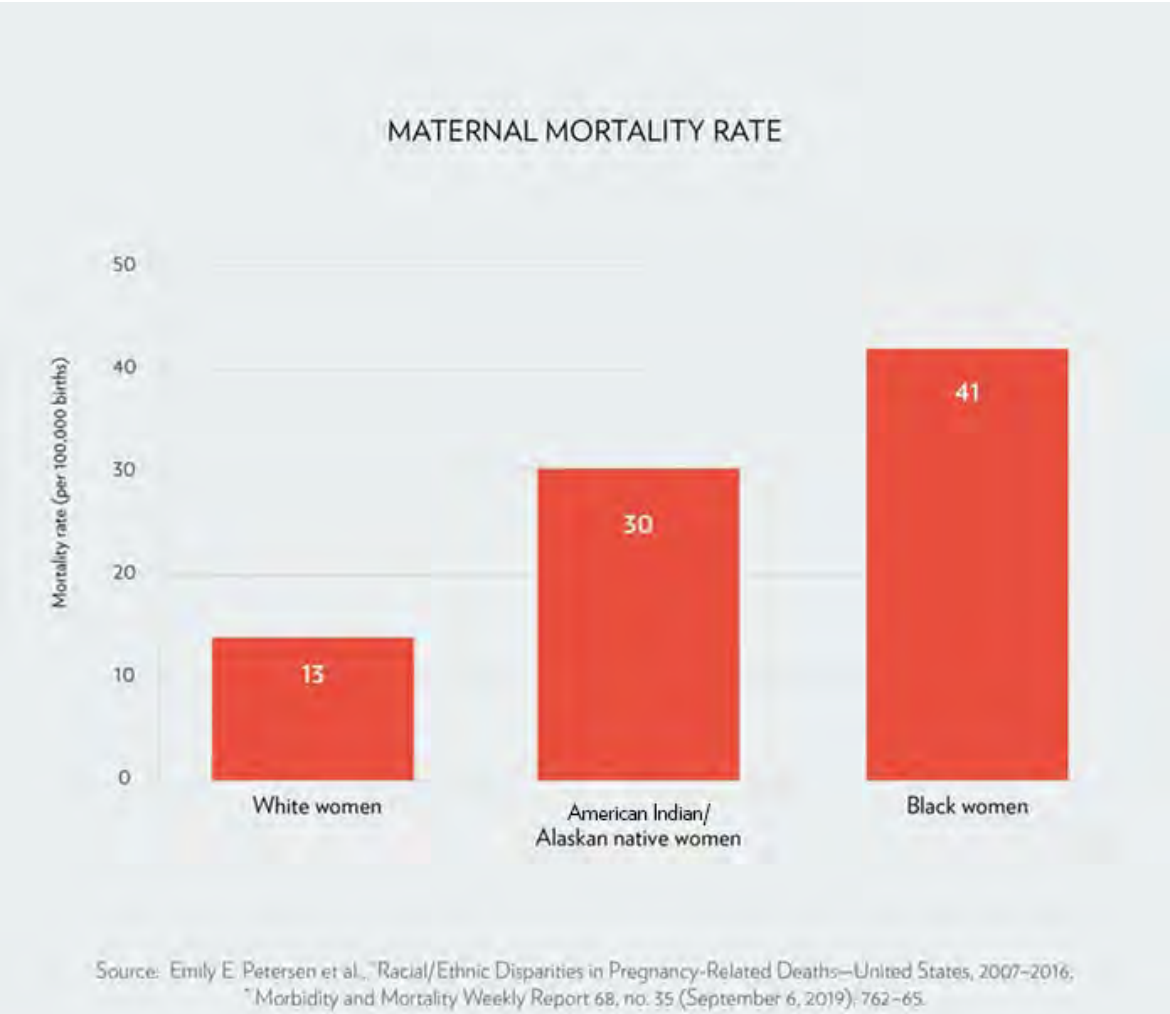
[1]Anderson et al. J Pain. 2009; [2]Bonham et al. J Law Med Ethics. 2001; [3]Cintron et al. J Palliat Med. 2006; [4]Cleeland et al. Ann Intern Med. 1997; [5]Freeman et al. NEJM. 2000; [6]Todd et al. Ann Emerg Med. 2000; [7]Green et al. Pain Med. 2003; [8]Shavers et al. J Health Care Poor Underserved. 2010; [9]Smedley et al. National Academies Press. 2013; [10]Goyal et al. JAMA Pediatr. 2015

# Health Care Inequities: Pain Treatment

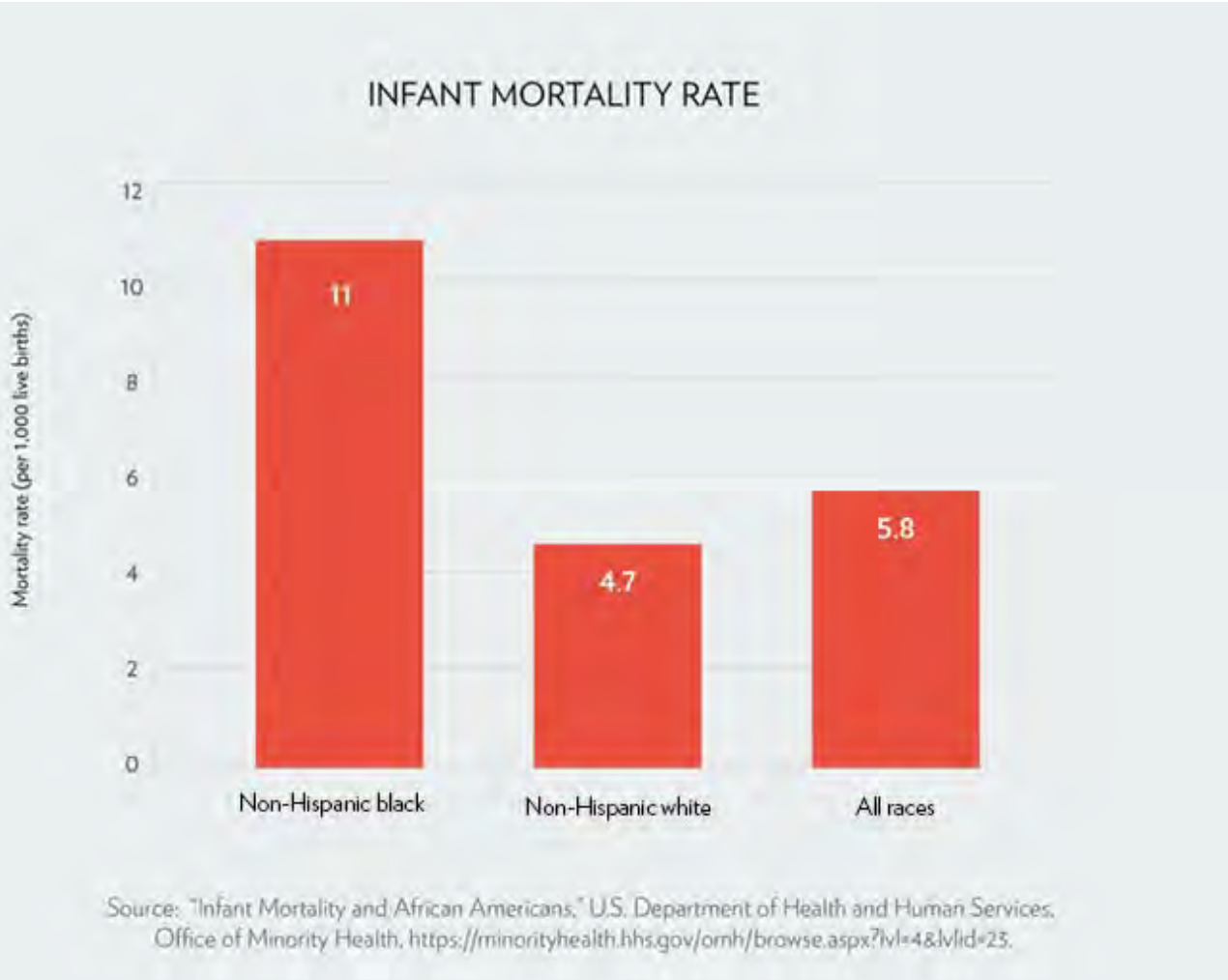
- Study of false beliefs in “biological differences” between Black and White people
  - “Blacks age more slowly than whites”; “Blacks’ nerve endings are less sensitive than whites”; “Blacks’ blood coagulates more quickly than whites”; “Whites have larger brains than blacks”
- 14-58% of White people in the study endorsed false beliefs about Black people
  - Including 58% of white people who believed that “Blacks’ skin is thicker than Whites”
  - False beliefs were associated with lower ratings for pain in Black people (vs White people)
- Similar findings among medical students and trainees and, in addition, those with false beliefs were more likely to make less appropriate treatment recommendations

Hoffman et al. PNAS. 2016.

# Health Inequities: Maternal & Infant Mortality



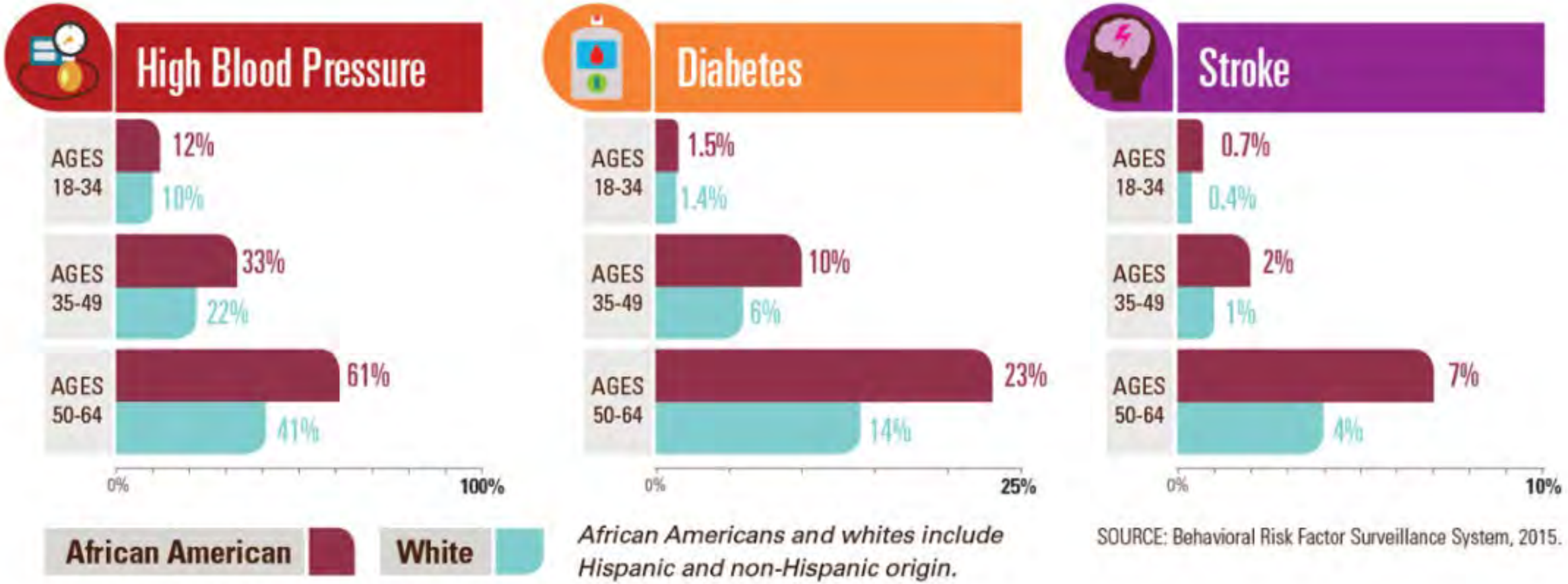

Source: Emily E. Petersen et al., "Racial/Ethnic Disparities in Pregnancy-Related Deaths—United States, 2007–2016," Morbidity and Mortality Weekly Report 68, no. 35 (September 6, 2019): 762–65.




Source: "Infant Mortality and African Americans," U.S. Department of Health and Human Services, Office of Minority Health, https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=23.

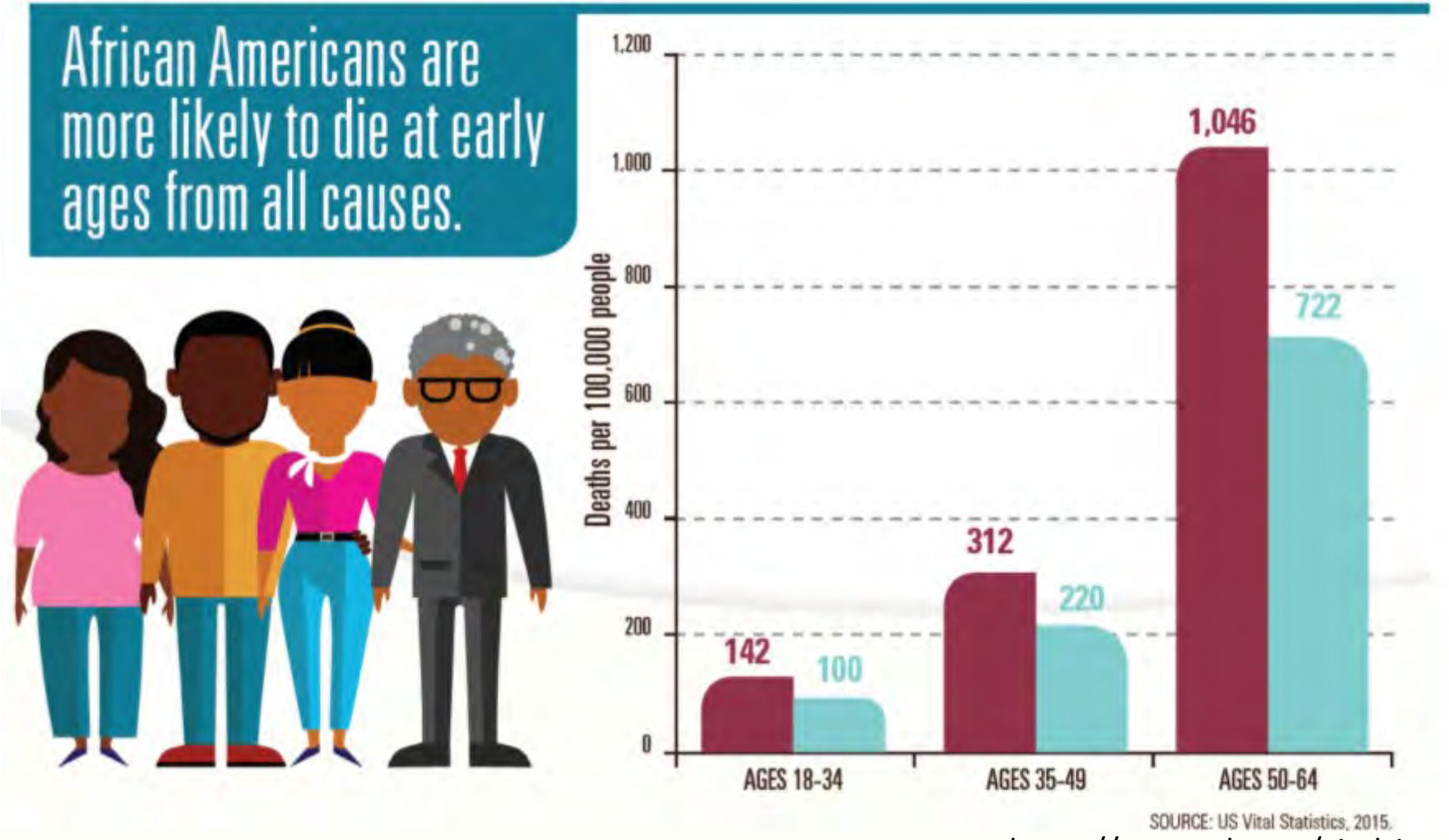
https://tcf.org/content/report/racism-inequality-health-care-african-americans/?agreed=1

# Health Inequities: Hypertension, Diabetes & Stroke




https://www.cdc.gov/vitalsigns/aahealth/index.html

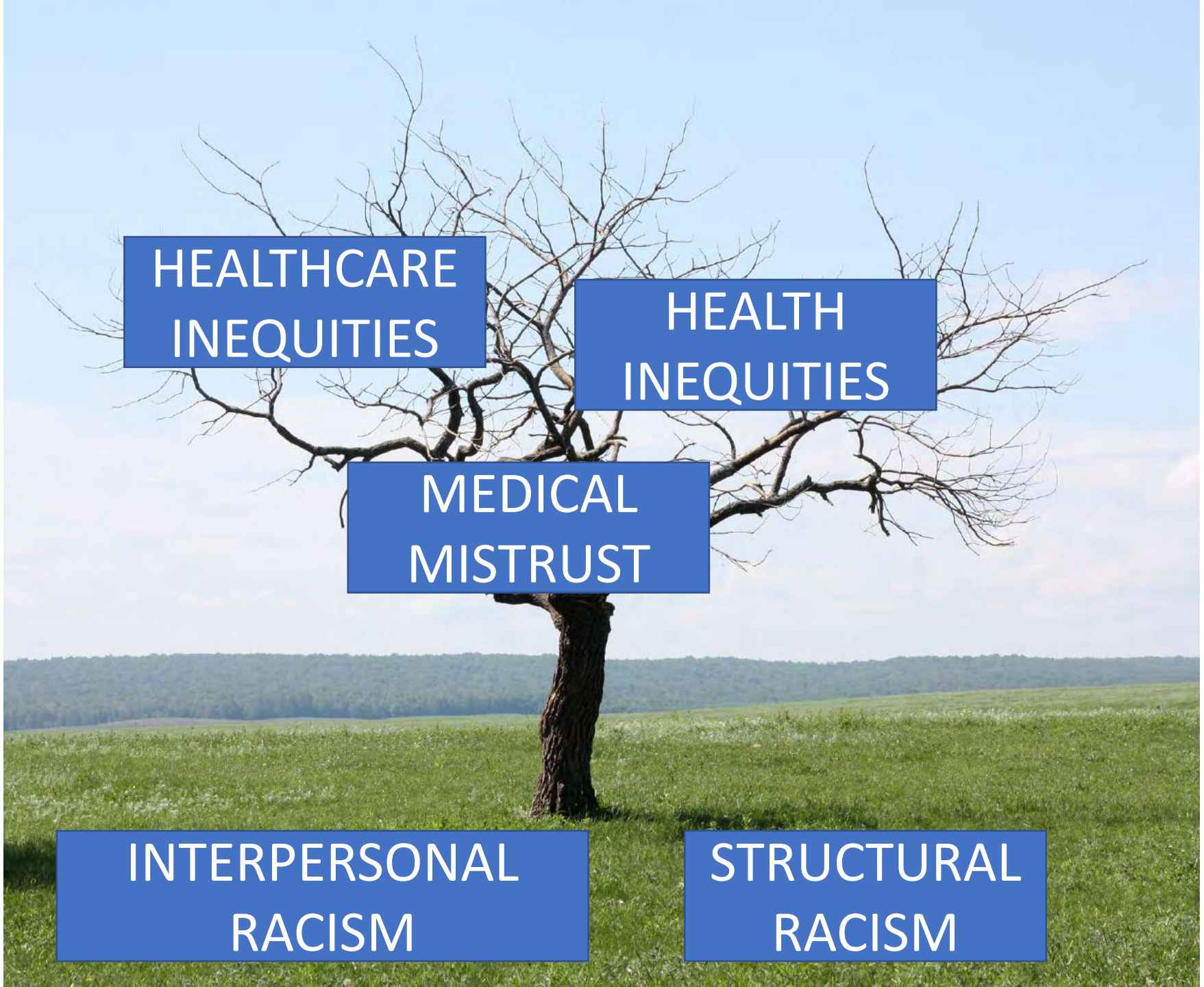
# Health Inequities: Mortality




https://www.cdc.gov/vitalsigns/aahealth/index.html

# Presentation Roadmap

- Brief Overview of Medical Mistrust
- Origins of Medical Mistrust in the Black community
- Provider Bias – the role of “Implicit Bias”
- Health Care and Health Inequities
- Medical Mistrust and Health Care
  - HIV, Reproductive Health and COVID-19


HEALTHCARE INEQUITIES
HEALTH INEQUITIES
MEDICAL MISTRUST
INTERPERSONAL RACISM
STRUCTURAL RACISM

# What is Medical mistrust?

- Not just a lack of trust in the medical system & personnel (dominant culture), *but the belief that they are acting/will act with ill intent towards a certain individual or group (marginalized)*
- Often extends to the pharmaceutical industry and to government
- Considered "an active response to direct or vicarious (e.g., intergenerational or social network stories) marginalization"[1]
- "A phenomenon created by and existing within a system that creates, sustains and reinforces **racism, classism, homophobia** and **transphobia**, and **stigma"** (also known as inequality-driven mistrust)[2]

[1]Benkert et al. Behav Med. 2019.; [2]Jaiswal et al. Behav Med. 2019

# How is medical mistrust measured?

- The Group-Based Medical Mistrust Scale[1]
- Medical Mistrust Index[2]
- Health Care System Distrust Scale[3]
- Corbie-Smith Distrust Index[4]
- Cultural Mistrust Inventory[5]
- HIV Conspiracy Beliefs[6]

[1]Thompson et al. Prev Med. 2004; [2]LaVeist et al. Med Care Res Rev. 2000; [3]Rose et al. JGIM. 2004; [4]Corbie-Smith et al. Arch Intern Med. 2002; [5]Terrell et al. Handbook of test and measurements for black populations. 1996; [6]Bogart et al. JAIDS. 2005.

## The Group-Based Medical Mistrust Scale

**Instructions:** Below is a list of statements dealing with your general feelings about the healthcare system. Read each item carefully and circle whether you strongly agree, agree, feel neutral, disagree, or strongly disagree with each statement.

| Item | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|---|---|---|---|---|---|
| 1. Doctors and healthcare workers sometimes hide information from patients who belong to my ethnic group. | 1 | 2 | 3 | 4 | 5 |
| 2. Doctors have the best interests of people of my ethnic group in mind. | 1 | 2 | 3 | 4 | 5 |
| 3. People of my ethnic group should not confide in doctors and healthcare workers because it will be used against them. | 1 | 2 | 3 | 4 | 5 |
| 4. People of my ethnic group should be suspicious of information from doctors and healthcare workers. | 1 | 2 | 3 | 4 | 5 |
| 5. People of my ethnic group cannot trust doctors and healthcare workers. | 1 | 2 | 3 | 4 | 5 |
| 6. People of my ethnic group should be suspicious of modern medicine. | 1 | 2 | 3 | 4 | 5 |

Thompson et al. Prev Med. 2004

## The Group-Based Medical Mistrust Scale

**Instructions:** Below is a list of statements dealing with your general feelings about the healthcare system. Read each item carefully and circle whether you strongly agree, agree, feel neutral, disagree, or strongly disagree with each statement.

| Item | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|---|---|---|---|---|---|
| 1. Doctors and healthcare workers sometimes hide information from patients who belong to my ethnic group. | 1 | 2 | 3 | 4 | 5 |
| 2. Doctors have the best interests of people of my ethnic group in mind. | 1 | 2 | 3 | 4 | 5 |
| 3. People of my ethnic group should not confide in doctors and healthcare workers because it will be used against them. | 1 | 2 | 3 | 4 | 5 |
| 4. People of my ethnic group should be suspicious of information from doctors and healthcare workers. | 1 | 2 | 3 | 4 | 5 |
| 5. People of my ethnic group cannot trust doctors and healthcare workers. | 1 | 2 | 3 | 4 | 5 |
| 6. People of my ethnic group should be suspicious of modern medicine. | 1 | 2 | 3 | 4 | 5 |

Thompson et al. Prev Med. 2004

| Item | Strongly Disagree | Disagree | Neutral | Agree | Strongly Disagree |
|---|---|---|---|---|---|
| 7. Doctors and healthcare workers treat people of my ethnic group like "guinea pigs". | 1 | 2 | 3 | 4 | 5 |
| 8. People of my ethnic group receive the same medical care from doctors and healthcare workers as people from other groups. | 1 | 2 | 3 | 4 | 5 |
| 9. Doctors and healthcare workers do not take the medical complaints of people of my ethnic group seriously. | 1 | 2 | 3 | 4 | 5 |
| 10. People of my ethnic group are treated the same as people of other groups by doctors and healthcare workers. | 1 | 2 | 3 | 4 | 5 |
| 11. In most hospitals, people of different ethnic groups receive the same kind of care. | 1 | 2 | 3 | 4 | 5 |
| 12. I have personally been treated poorly or unfairly by doctors or healthcare workers because of my ethnicity. | 1 | 2 | 3 | 4 | 5 |

Thompson et al. Prev Med. 2004

# Medical mistrust & Reproductive Health

- Long history of the dominant culture controlling Black women's ability to reproduce
- Thoburn & Bogart's study about relationships between beliefs and contraceptive attitudes and use
  - Among Black men and women, stronger Black genocide "conspiracy" beliefs and stronger contraceptive safety conspiracy beliefs were negatively associated with contraceptive attitudes
  - Men with stronger contraceptive safety conspiracy beliefs were less likely to be currently using birth control.
  - Among current birth control users, women with stronger contraceptive safety conspiracy beliefs were less likely to be using contraceptive methods that must be obtained from a health care provider.

Thoburn & Bogart. Health Education & Behavior. 2005.

Table 1. Endorsement of Birth Control Conspiracy Beliefs, Overall and by Gender

| Conspiracy Belief | % Agree | | |
|---|---|---|---|
| | Total ($N = 500$) | Men ($n = 174$) | Women ($n = 326$) |
| The government is trying to limit the Black population by encouraging the use of condoms. (F1) | 14.4 | 17.2 | 12.9 |
| Birth control is part of a White plot to eliminate Blacks. (F1) | 5.8 | 9.8 | 3.7* |
| Birth control is a form of Black genocide. (F1) | 8.4 | 13.8 | 5.5** |
| Whites want to keep the numbers of Black people down. (F1) | 33.6 | 36.8 | 31.9 |
| The government's family planning policies are intended to control the number of Black people. (F1) | 22.4 | 27.6 | 19.6* |
| Abortion is Black genocide. (F1) | 12.8 | 21.3 | 8.3*** |
| Black women can trust what medical and public health professionals say about birth control methods. (F2)[a] | 61.8 | 54.0 | 66.0** |
| The government tells the truth about the safety and side effects of new birth control methods. (F2)[a] | 50.0 | 43.7 | 53.4 |
| Medical and public health institutions use poor and minority people as guinea pigs to try out new birth control methods. (F2) | 37.4 | 42.5 | 34.7** |
| The government makes certain that birth control methods are safe before they come onto the market. (F2)[a] | 59.2 | 58.0 | 59.8 |
| Poor and minority women are sometimes forced to be sterilized by the government.[b] | 24.8 | 31.0 | 21.5** |
| Having children is the key to the survival of the Black population.[b] | 44.2 | 54.0 | 39.0** |
| Access to safe and effective birth control methods can improve Black women's lives.[a,b] | 71.2 | 70.1 | 71.8 |
| Blacks can trust what Whites say about pregnancy prevention programs.[a,b] | 55.6 | 54.0 | 56.4 |

Thoburn & Bogart. Health Education & Behavior. 2005.

Table 1. Endorsement of Birth Control Conspiracy Beliefs, Overall and by Gender

| Conspiracy Belief | % Agree | | |
|---|---|---|---|
| | Total ($N = 500$) | Men ($n = 174$) | Women ($n = 326$) |
| The government is trying to limit the Black population by encouraging the use of condoms. (F1) | 14.4 | 17.2 | 12.9 |
| Birth control is part of a White plot to eliminate Blacks. (F1) | 5.8 | 9.8 | 3.7* |
| Birth control is a form of Black genocide. (F1) | 8.4 | 13.8 | 5.5** |
| Whites want to keep the numbers of Black people down. (F1) | 33.6 | 36.8 | 31.9 |
| The government's family planning policies are intended to control the number of Black people. (F1) | 22.4 | 27.6 | 19.6* |
| Abortion is Black genocide. (F1) | 12.8 | 21.3 | 8.3*** |
| Black women can trust what medical and public health professionals say about birth control methods. (F2)[a] | 61.8 | 54.0 | 66.0** |
| The government tells the truth about the safety and side effects of new birth control methods. (F2)[a] | 50.0 | 43.7 | 53.4 |
| Medical and public health institutions use poor and minority people as guinea pigs to try out new birth control methods. (F2) | 37.4 | 42.5 | 34.7** |
| The government makes certain that birth control methods are safe before they come onto the market. (F2)[a] | 59.2 | 58.0 | 59.8 |
| Poor and minority women are sometimes forced to be sterilized by the government.[b] | 24.8 | 31.0 | 21.5** |
| Having children is the key to the survival of the Black population.[b] | 44.2 | 54.0 | 39.0** |
| Access to safe and effective birth control methods can improve Black women's lives.[a,b] | 71.2 | 70.1 | 71.8 |
| Blacks can trust what Whites say about pregnancy prevention programs.[a,b] | 55.6 | 54.0 | 56.4 |

Thoburn & Bogart. Health Education & Behavior. 2005.

Table 1. Endorsement of Birth Control Conspiracy Beliefs, Overall and by Gender

| Conspiracy Belief | % Agree | | |
|---|---|---|---|
| | Total ($N = 500$) | Men ($n = 174$) | Women ($n = 326$) |
| The government is trying to limit the Black population by encouraging the use of condoms. (F1) | 14.4 | 17.2 | 12.9 |
| Birth control is part of a White plot to eliminate Blacks. (F1) | 5.8 | 9.8 | 3.7* |
| Birth control is a form of Black genocide. (F1) | 8.4 | 13.8 | 5.5** |
| Whites want to keep the numbers of Black people down. (F1) | 33.6 | 36.8 | 31.9 |
| The government's family planning policies are intended to control the number of Black people. (F1) | 22.4 | 27.6 | 19.6* |
| Abortion is Black genocide. (F1) | 12.8 | 21.3 | 8.3*** |
| Black women can trust what medical and public health professionals say about birth control methods. (F2)[a] | 61.8 | 54.0 | 66.0** |
| The government tells the truth about the safety and side effects of new birth control methods. (F2)[a] | 50.0 | 43.7 | 53.4 |
| Medical and public health institutions use poor and minority people as guinea pigs to try out new birth control methods. (F2) | 37.4 | 42.5 | 34.7** |
| The government makes certain that birth control methods are safe before they come onto the market. (F2)[a] | 59.2 | 58.0 | 59.8 |
| Poor and minority women are sometimes forced to be sterilized by the government.[b] | 24.8 | 31.0 | 21.5** |
| Having children is the key to the survival of the Black population.[b] | 44.2 | 54.0 | 39.0** |
| Access to safe and effective birth control methods can improve Black women's lives.[a,b] | 71.2 | 70.1 | 71.8 |
| Blacks can trust what Whites say about pregnancy prevention programs.[a,b] | 55.6 | 54.0 | 56.4 |

Thoburn & Bogart. Health Education & Behavior. 2005.

# Medical Mistrust & HIV


The idea that the government created HIV as a form of genocide against Black people and other marginalized groups


The idea that HIV treatment (antiretrovirals) are used to experiment on or kill those who take or that a cure is available, but is being withheld by the government and/or pharmaceutical company for profit

Jaiswal. Journal of Racial and Ethnic Health Disparities. 2018.

# Medical mistrust is negatively associated with many HIV-related measures and outcomes

- HIV testing
- Condom and birth control use
- HIV vaccines
- Participation in HIV-related clinical research
- Antiretroviral adherence
- Engagement in HIV care?

Jaiswal. Journal of Racial and Ethnic Health Disparities. 2018.

# Mistrust and engagement in HIV care

- Qualitative study
- Focused on people who were not engaged in HIV care
- 27 participants, 78% Black
- HIV-related beliefs are common, but may not necessarily be a barrier to care. Participants in various stages of engagement insisted that these beliefs did not play  a central role in how they managed their health

*"I mean, I do, but I don't. I think they experiment with a lot of stuff and things happen, and the stuff just starts forming. I can't be thinking about all that. I got other stuff to think about…"*

Jaiswal. Journal of Racial and Ethnic Health Disparities. 2018.

# Medical mistrust: COVID-19 origins and vaccines


# Medical mistrust:
# COVID-19 origins & vaccines

## Study: Nearly a third of Americans believe a conspiracy theory about the origins of the coronavirus

A new Pew study finds 30 percent of Americans believe scientists created Covid-19. That isn't what happened.

By Aja Romano | @ajaromano | Apr 12, 2020, 9:30am EDT

HEALTH

## 'Tuskegee always looms in our minds': Some fear black Americans, hardest hit by coronavirus, may not get vaccine

Jayne O'Donnell USA TODAY

Published 7:00 a.m. ET Apr. 19, 2020 | **Updated 10:09 a.m. ET Apr. 20, 2020**

## Nearly one-third of Americans believe a coronavirus vaccine exists and is being withheld, survey finds

Joey Garrison USA TODAY

Published 5:00 a.m. ET Apr. 24, 2020 | **Updated 11:05 a.m. ET May 12, 2020**

https://www.vox.com/covid-19-coronavirus-us-response-trump/2020/4/12/21217646/pew-study-coronavirus-origins-conspiracy-theory-media
https://www.usatoday.com/story/news/politics/2020/04/24/coronavirus-one-third-us-believe-vaccine-exists-is-being-withheld/3004841001/
https://www.usatoday.com/story/news/health/2020/04/19/coronavirus-vaccine-black-americans-prevention/5146777002/

# Potential Provider-level Interventions to Address Mistrust

- Patient-centered approach
  - Ask open-ended questions about patient's beliefs (e.g., those related to medication)
  - Elicit from patient their priorities related to their health
  - Understand their competing priorities/concerns
  - Utilize shared decision-making
- Longitudinal anti-racism training for health care professionals and institutional leadership

Jaiswal. Behav Med. 2019; Jaiswal. J Racial Ethnic Health Disparities. 2018.

# Potential  Systems-level Interventions to Address Mistrust

- Having staff that reflects the patient population
  - Increasing underrepresented group representation among medical providers
- Using community workers or peer navigators
- Working with faith-based organizations
- Commitment to and work towards becoming a fully inclusive anti-racist organization

Jaiswal. Behav Med. 2019; Jaiswal. J Racial Ethnic Health Disparities. 2018.

# Questions?

@DrOniBee