MEDICAL MISTRUST, RACISM, AND HIV- MUCH MORE THAN THE SYPHILIS STUDY IN TUSKEGEE

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OBJECTIVES

1. Discuss multiple definitions of medical mistrust
2. Improve understanding of the historical foundations of medical mistrust in Black communities
3. Negative impacts of medical mistrust on patients, healthcare behaviors and health outcomes
4. Provide skills and resources to interact with patients in a manner that encourages healthcare engagement and improves health outcomes.

TAKE CARE OF YOU

- I also want to acknowledge that many of the images and historical anecdotes which I'm are going to share with you might be triggering. I encourage you to prioritize your mental health during this time we have together:

✓If you feel the need to step away, please do so

✓Stop me at any time if you need to comment or process

✓This is a learning environment, where we will hear comments or perspectives that may be opposing to our own. We don't have to all agree, but we all have to be respectful to one another.

- Throughout this presentation, we will use the term "Black" to refer to people of the African diaspora both within and without the U.S.

ACROSS THE AFRICAN DIASPORA

WHAT IS RACE?

- Race is defined as " a class or group of people unified by shared customs and traits (Merriam Webster).
- The most common markers of race are physical characteristics- skin color, hair texture, bone structure.
- Today, we know that these traits have very little genetic significance, and race is largely a social construct.
- However, just because race is a social construct, that does not mean it does not have real life implications. We'll talk about how race has social impacts that influence health, as well as different racial disparities among health outcomes, especially in HIV.

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"

MEDICAL MISTRUST AND HEALTH

- Lower health care utilization including preventive health practices
- Lower adherence to medical treatment
- Poorer quality patient-provider relationships
- Higher likelihood of engaging in behaviors that place people at risk
- Lower rates of involvement in biomedical research

MEDICAL MISTRUST IN THE BLACK COMMUNITY

ACTIVITY: "IF YOU KEEP TALKING, THEY WILL KILL ME"

- List comments of mistrust you've heard from clients, family, friends or even yourself

ORIGINS OF MEDICAL MISTRUST

SLAVERY AND BLACK HEALTH

Slavery: Most Blacks were subjected to southern medicine and the South was/is an unhealthy region

1700: 20,000 Blacks

1860: 4,000,000 Blacks in slavery with a net worth of $4,000,000,000

Physicians dependent upon slaves for economic security and clinical materials that fed the medical research and training that led to physician's professional medical advancement

Slave owners had an interest in preserving the slave's health . Not out of concern for humanity but because of economic investment.

ORIGINAL SOCIAL DETERMINANTS OF HEALTH

- 1864 -4 million slaves freed BUT nothing came with it
  - No housing
  - No property
  - No financial resources
  - No tools to maintain good hygiene
  - No formalized healthcare

Former slaves are now dying in high numbers bodies are "littering the streets" and NOW it is a public health crisis because it is affecting the majority population so the first Federal healthcare program is established called the

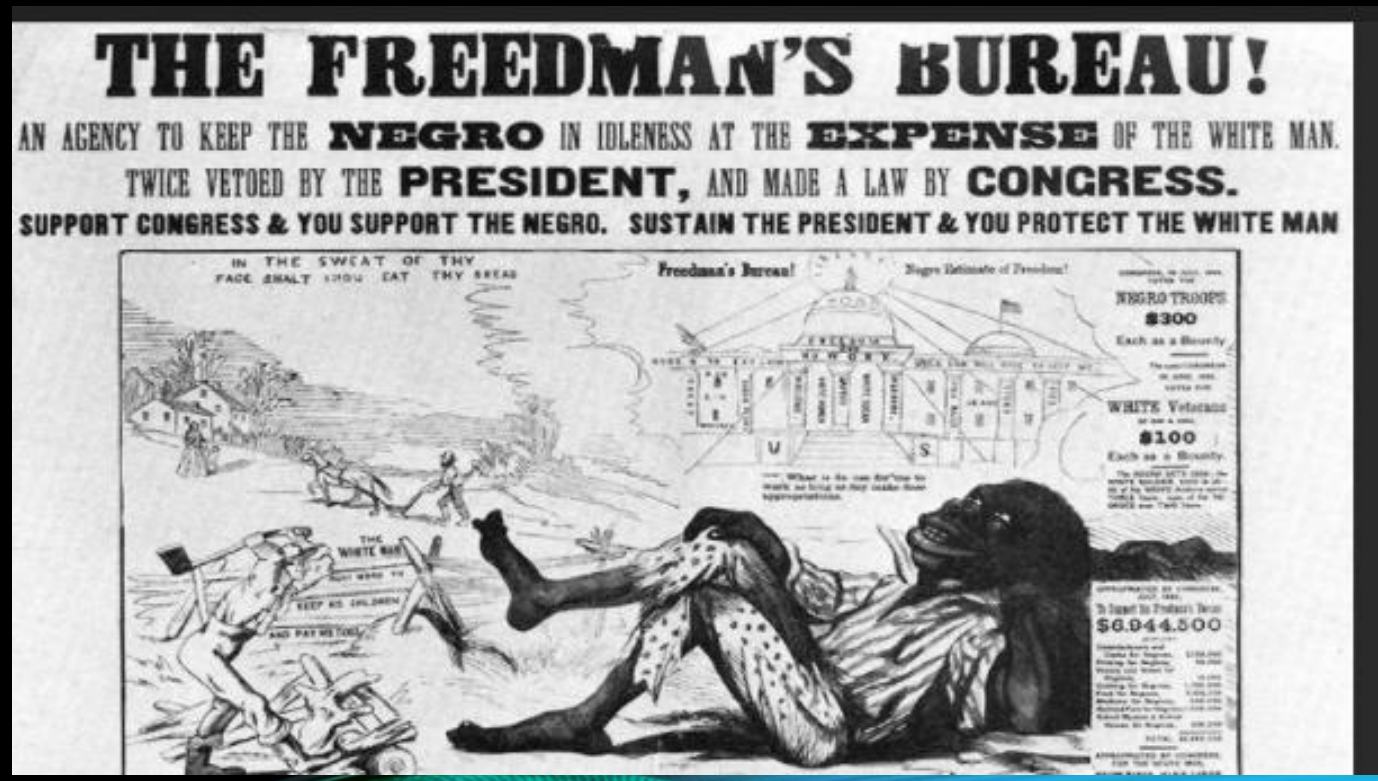
"Freedmen's Bureau

Medical Division."

Poorly staffed

Lack necessary supplies (bedding, medicine, enough small pox vaccines)

Lacked facilities for quarantine so that diseases don't spread



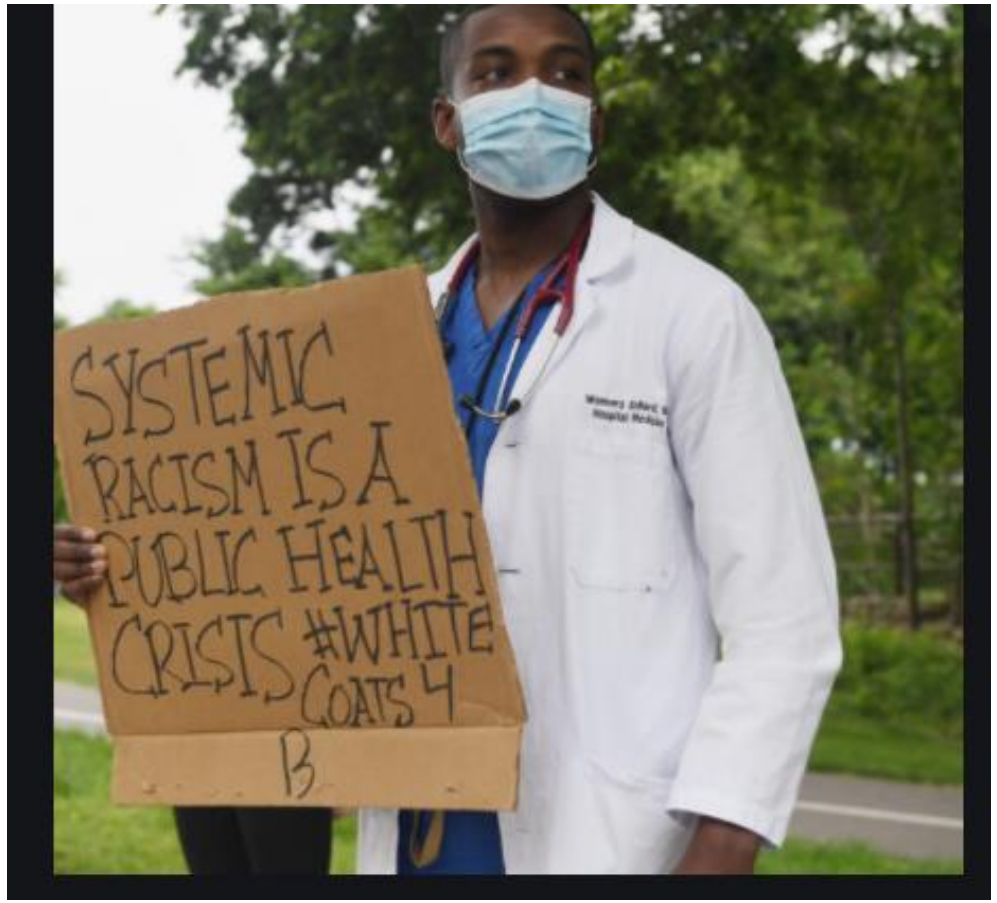
THEORY FOR POOR HEALTH AMONG BLACK COMMUNITIES RECEIVING GOVERNMENT SUPPORT

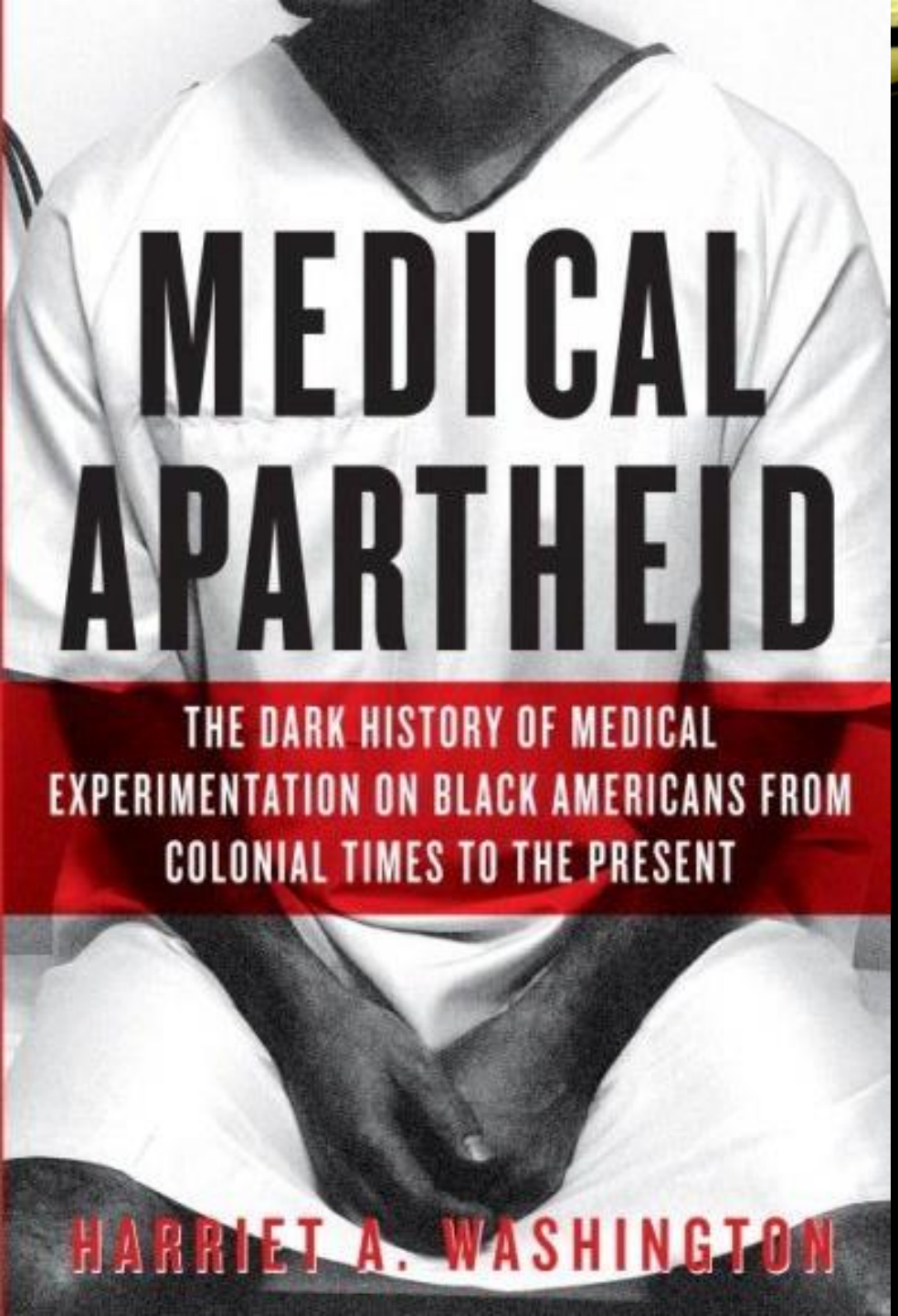
- "The high death rate is nature taking it's course. Black people are not dying from lack of basic necessity, they are dying because they are biologically inferior to white people and ill-suited for freedom. Black people are going extinct and to provide any resources to prevent that would be wasteful and foolish"
- The theory became mainstream and was argued in the house of representatives

ANY SIMILARITIES TO… ?

- Debates of Medicaid expansion?

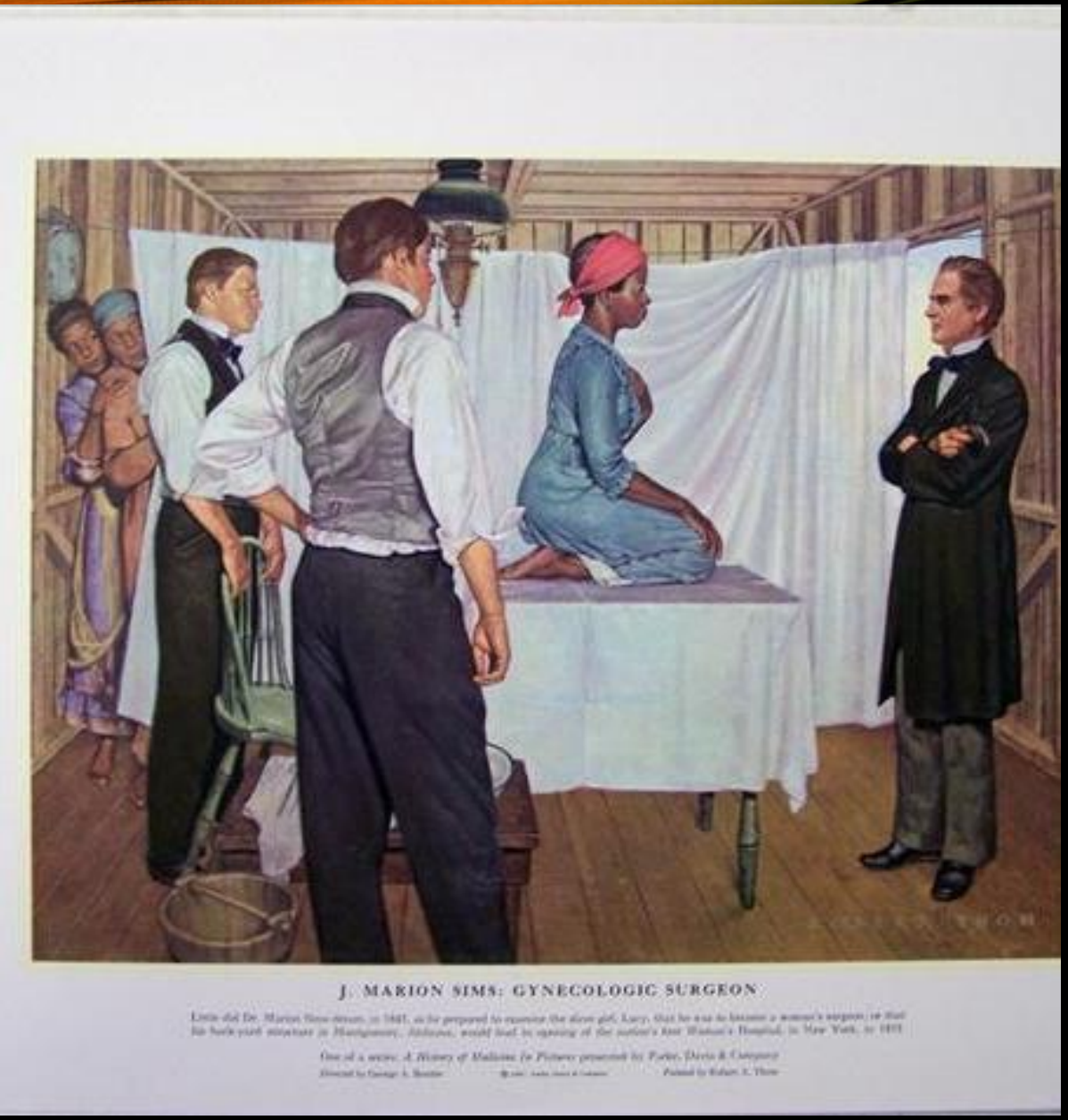
MEDICAL RACISM





HISTORY OF MEDICAL ABUSES

- During Antebellum period (1789- Civil War):
  - Medical abuses experienced by slaves were widespread and common
  - Included withholding of care, sub-standard care, and forced medical experimentation



MODERN GYNECOLOGY

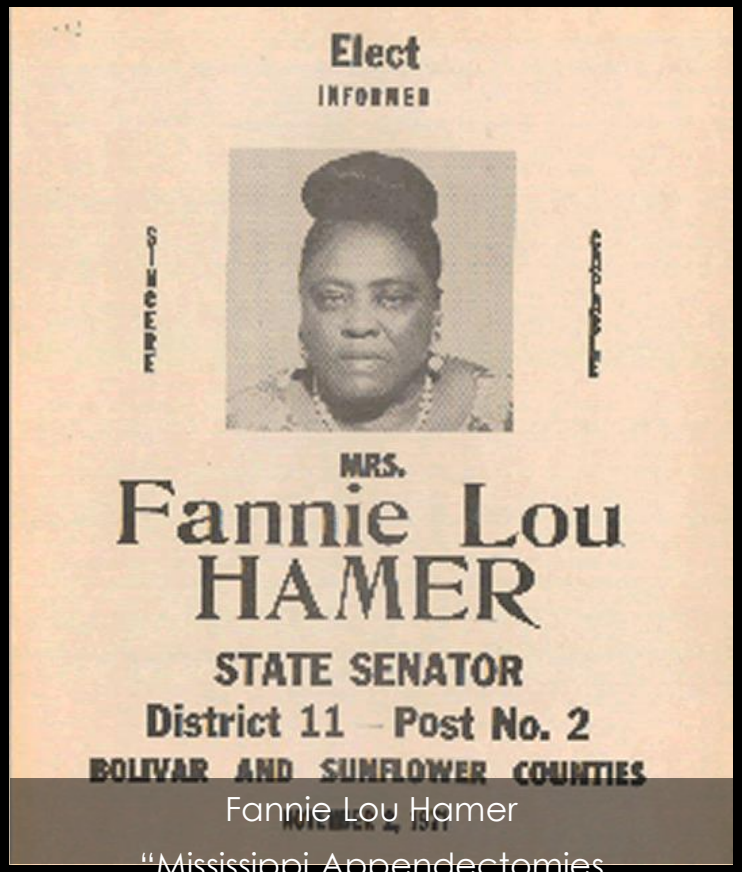
- Anarcha was a woman who had over 30 gynecological surgeries performed on her. She was one of at least 10 enslaved women who went through vesicovaginal fistula procedures
- As an enslaved woman, she was unable to consent to these surgeries
- J. Marion Sims, the doctor who performed these without anesthesia, is honored as the "father of gynecology" (1813-1883)

MOTHERS OF GYNECOLOGY

A new monument unveiled Friday in Montgomery aims to tell the other side of the Sims story by honoring the “Mothers of Gynecology,” -- Anarcha, Lucy and Betsey, three of eleven enslaved women who were the unwilling subjects of Sims’ experiments in the 1840s.

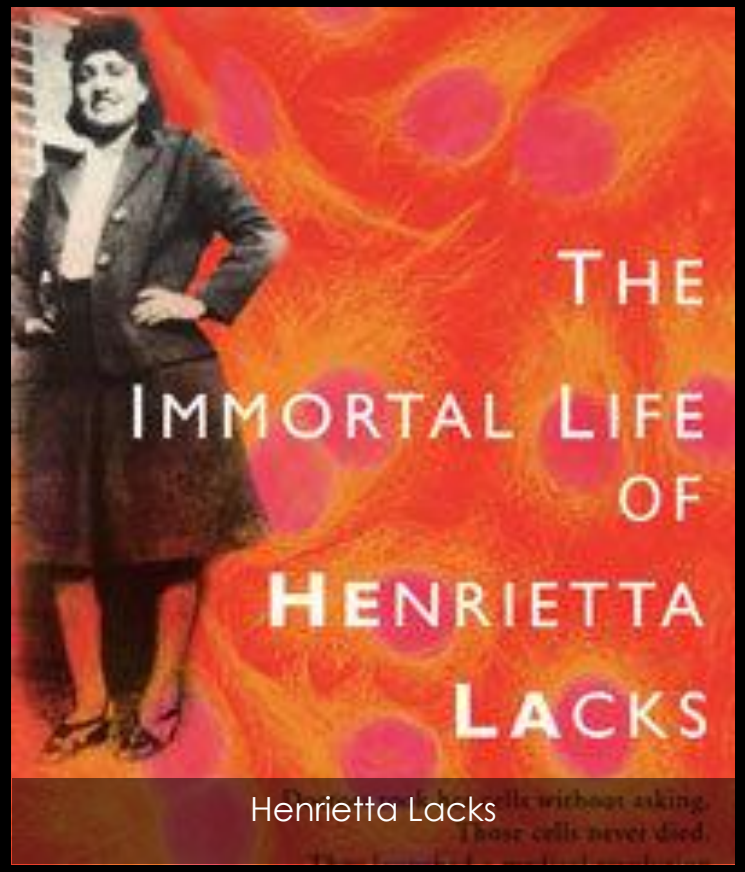
Statue created by Montgomery artist and activist Michelle Browder.

A new monument in Montgomery, Ala. honors the "Mothers of Gynecology," three enslaved Black women who were unwilling subjects in experiments that resulted in medical advances. The monument stands about 15 feet high. Kyle Sampson



Fannie Lou Hamer

"Mississippi Appendectomies



Henrietta Lacks

Birth control

"Negroes don't want children they can't take care of, but we are afraid to trust you when your offered help has so often turned out to be exploitation." –

Urelia Brown, a Black social worker speaking on family planning in 1972

PERSONAL STORY BIOMEDICAL RESEARCH

COVID-19 Vaccine Clinical Trials: One HIV Advocate's Experience as a Study Volunteer

By: HIV.gov | **Published:** September 14, 2021

Topics

COVID-19

Many in the HIV community continue to work tirelessly to respond to the COVID-19 public health crisis, including by stepping forward to participate in vaccine clinical trials.

Recently, national HIV/AIDS consultant Leisha McKinley-Beach spoke with us and shared with us her experience as a volunteer in the Novavax vaccine phase 3 clinical trial at a local university. Participants randomly received either the vaccine or placebo in two doses, 21 days apart. The study is supported through the National Institute of Allergy and Infectious Diseases.

Q: Why did you decide to get involved in a vaccine clinical trial?

A: When the trial was announced, I was approaching my 30th year of working as an HIV advocate. Before I retired, there was still something I wanted to do—participate in a clinical trial. I never fathomed that my first experience would be for COVID-19 rather than HIV.

Q: Did you have any reservations?

MEDICAL MISTRUST AND HIV

Medical Mistrust

"Social inequality drives mistrust; Mistrust drives disparities"

***Types of Medical Mistrust*:**

- Health care provider-level
- Clinic-level
- System-level: mistrust in the health care system or the government
- Research-related
- **HIV-Related Mistrust***:* holding certain beliefs regarding HIV ("conspiracy beliefs")

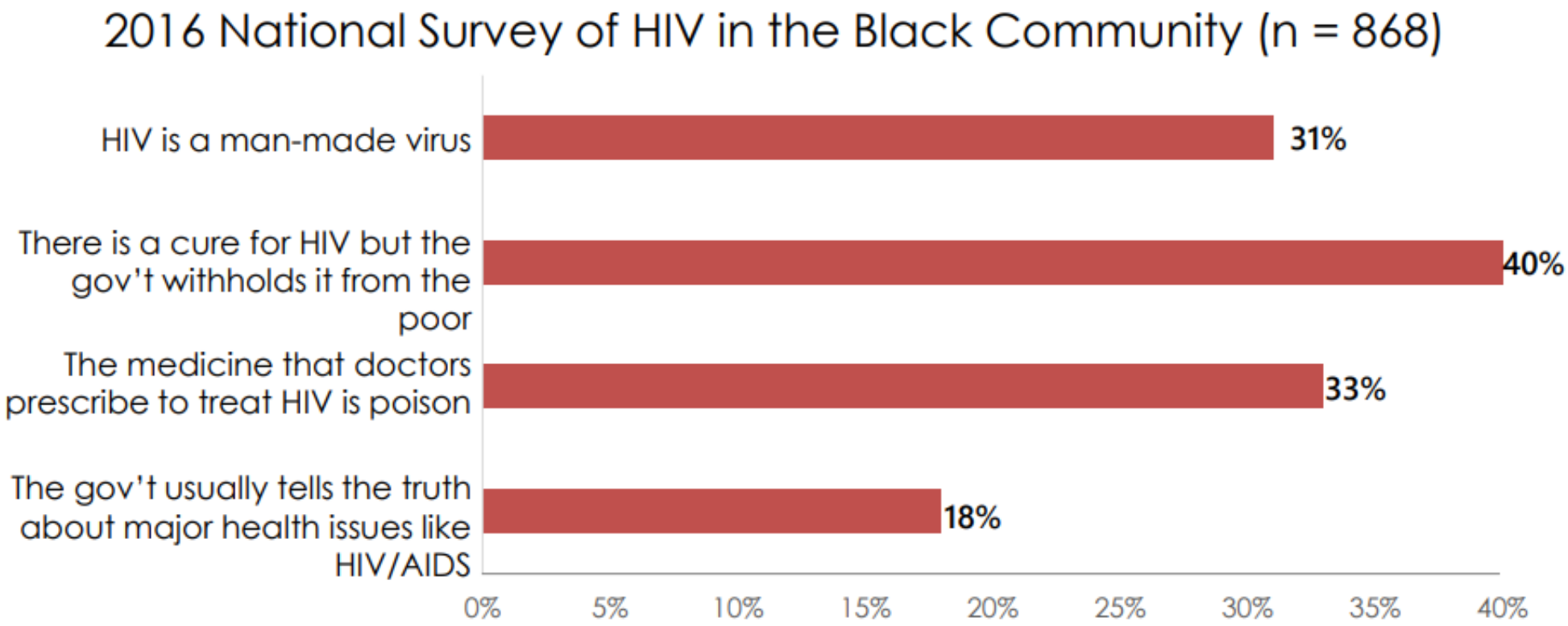
- Highest among Black and Latinx individuals

- Associated with lower ART adherence, decreased PrEP willingness, higher HIV testing

ACTIVITY: CONSPIRACY BELIEVES REGARDING HIV

- What are some of the conspiracy theories you've heard?

HIV-related mistrust remain common among many Black Americans



How does medical mistrust affect HIV outcomes?

Prevention Outcomes

- ✓ Condomless sex
- ✓ Lower comfort discussing PrEP with providers
- ✓ Lower PrEP awareness
- ✓ Lower intention to adopt PrEP
- ✓ Lower uptake of PrEP

Treatment Outcomes

- ✓ Lower adherence to ART
- ✓ Detectable viral load
- ✓ Weaker beliefs about the effectiveness of ART (which in turn is related to nonadherence)

ENGAGEMENT IN OUTPATIENT HIV CARE

- Medical mistrust is a factor in the relationships among HIV medication beliefs, HIV medication adherence, and/or serostatus disclosure to partners.

SOLUTIONS TO MEDICAL MISTRUST

How can medical mistrust be addressed?

- A few patient-level interventions focus on improving trust in HIV-related information and decreasing HIV-related mistrust
  - Community-based peer navigation, for peers to serve as a bridge to healthcare
  - Community-based peer counseling interventions that use motivational interviewing or cognitive behavior therapy strategies to acknowledge, validate, and discuss mistrust as a justified response to discrimination

RECOMMENDATIONS FOR PROVIDERS

- Raise provider awareness about the level of mistrust in communities and the origins of mistrust in system racism
- Provide psychoeducation about how mistrust is related to health inequities
- Discuss how to recognize mistrust (verbal/nonverbal cues)

SIGNS OF MISTRUST

Lack of engagement in healthcare interaction

– Doesn't ask questions or make eye contact, seems uncomfortable, doesn't verbally agree to recommended behavior

- Lack of healthcare engagement

  – Non-adherence, missed visits

- Direct statements

  – Says they don't like taking medication, or don't like or trust the medication

YOUR BILLBOARD TO ADDRESS MEDICAL MISTRUST

- What would you say to clients who have been out of HIV care because they don't trust the healthcare program but they are now visiting your clinic because they are symptomatic?

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WHAT CAN WE DO?

MOVING PAST MEDICAL MISTRUST

Trust in health care providers leads to better health outcomes and is associated with:

- Increase in HIV-related outpatient clinic visit
- Fewer emergency room visits
- Increased use of HIV therapy/adherence
- Improved physical and mental health

TACTICS FOR MOVING BEYOND MEDICAL MISTRUST

Community Empowerment:

- *Recruit and educate* "a social movement of Black healthcare and research activists"
- *Include* stakeholders with different perspectives when designing HIV interventions

Community Mobilization:

- *Empower and equip* communities to transform realities, decreasing the perception that other individuals and entities have control over Black health and well-being

TACTICS FOR MOVING MEDICAL MISTRUST

Cultural Competency:

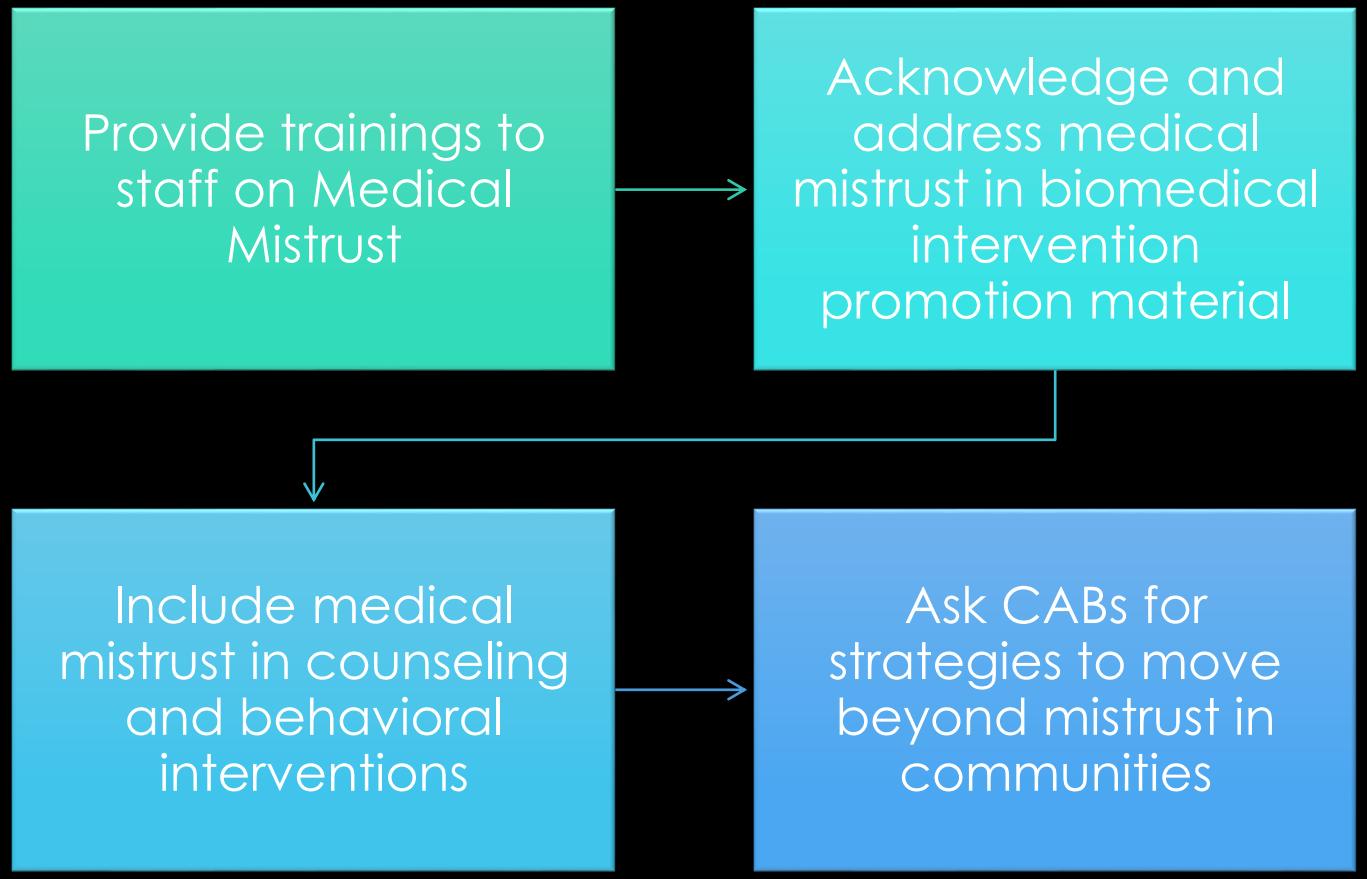
- *Recognize* that:
  - Fears of genocide and government suspicion are understandable and expected based off experiences of Black Americans
  - Medical mistrust should not be dismissed
- *Address* current discrimination Black people experience
- *Understand* that mistrust might also be tied to other parts of a patient's identity, i.e. Black MSM who have experienced stigma from a provider

TACTICS FOR MOVING BEYOND MEDICAL MISTRUST

Cultural Humility

- *Recognize* that you cannot reach a point at which you are ever finished learning and that cultural competency does not have an endpoint
- *Know* that mistrust and other cultural attitudes are ever-evolving given the political and social climate
- *Understand* that making assumptions about mistrust might actually lead to greater mistrust

TACTICS FOR MOVING BEYOND MEDICAL MISTRUST



RECOMMENDATIONS FOR PROVIDERS

1. Respond to mistrust in a sensitive manner, while conveying accurate information
2. Validate mistrust
3. Be non-judgmental and non-confrontational
4. Ask open-ended questions
5. Use reflection/reflective listening
6. Ask for permission before sharing information
7. Make eye contact,

- Use Validation:
  - – Acknowledge and affirm experiences of discrimination and expressions of mistrust
  - – Communicates that patients'/clients' thoughts, behaviors, or emotions are well-grounded, justifiable, relevant, and meaningful

RECOMMENDATIONS FOR PROVIDERS

VALIDATING MISTRUST

"We are trying to improve our relationships with patients. If there is anything that I do or say, or that someone at the clinic does or says that makes you feel uncomfortable, would you mind letting me know?

Whatever you tell me will not affect your treatment or healthcare. I can keep it confidential and covey your concerns anonymously to my supervisors, if you prefer."

TAKING CHARGE TO MITIGATE YOUR OWN BIAS

- **C-** Change your context: is there another perspective that is possible?
- **H-** Be Honest: with yourself, acknowledge and be aware
- **A-** Avoid blaming yourself: know that you can do something about it
- **R-** Realize when you need to slow down
- **G-** Get to know people you perceive as different than you
- **E-** Engage: remember why you are doing this
- **E-** Empower: your patients and peers

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