



# Medical Mistrust (System Trustworthiness)

Women and AIDS Conference

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# Disclaimer

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# Learning Objectives

- Define Trust, Distrust, and Mistrust
- Compare and Contrast Distrust and Mistrust
- Define Historical Trauma
- Explore Historical Events Leading to Medical Mistrust
- List Practices to Foster Trust and Trustworthiness

# Trust & Distrust

**Trust** - belief in a person's competence to complete a certain task

**Distrust** - Distrust is based on the assumption that providers or healthcare entities may not be trustworthy, that they may not have equal access to state-of-the-art care, that quality is variable at best, and that the patient is likely receiving lower quality than the typical standard of care.

# Mistrust

**Mistrust** - a general sense of unease or suspicion toward someone or something that is predicated either on the notion that the provider or healthcare entity may not act in the patient's best interest and they may actively work against the patient.

Mistrust may originate from **distinct historical experiences linked to group identity**, personal experience, vicarious experiences, and oral histories.

# Distrust and Mistrust

The terms distrust and mistrust are often used interchangeably, but **distrust** is most correctly based on a **specific experience or information**, while **mistrust** expresses a **general sense of unease toward someone or something**.

# Distrust & Mistrust

- Patients may **distrust** a provider, researcher, organization, or institution because they know or have heard specific things about what they have done
- Patients also may **mistrust** medical care, providers, researchers, health-related organizations, or institutions in general

# Medical Mistrust & HIV

- Medical Mistrust has been associated with decreased uptake of PrEP
  - A study of Black women in Planned Parenthood found higher rates of medical mistrust than in White women and resulted in less discomfort discussing PrEP with providers
- Qualitative studies of minority gay, bisexual, and other men who have sex with men sex workers showed high levels of medical mistrust
- One study of Black men with HIV reported that 90% of the respondents agreed with at least 1 medical mistrust statement and 80% with at least 1 racism-related mistrust statement
- One nationally representative sample of Black men with HIV, found lower levels of ART adherence were associated with distrust in one's provider
- Lastly, medical mistrust has been associated with detectable viral loads in Black sexual minority men with HIV

# Medical Mistrust

**Where**



**Why**



# Truth

The institution of medicine in the United States was built with the lives of black men and women.



Dr. Ephraim McDowell



Ephraim McDowell  
Health®



Dr. Ephraim McDowell perfected his dangerous and radical surgery on non-consenting slave women.



## Dr. Crawford Long

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Dr. Crawford Long is known as the discoverer of anesthesia. Since that time he has been recognized by medical bodies all over the world and has been memorialized by monuments, statues, paintings, and a U.S. postage stamp.

What he did:

Dr. Crawford Long conducted the majority of his early experiments on non-consenting slave men and women.



## John Brown

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John Brown was an escaped slave who fled to England and dictated his memoirs which were published under the title, *Slave Life in Georgia: A Narrative of the Life, Sufferings, and Escape of John Brown, a Fugitive Slave, Now in England*.

In his memoirs he recounts his experiences with Dr. Thomas Hamilton who used “heat therapy” as an experimental method to treat Brown after years of abuse as a slave. The method entailed forcing Brown to sit on a box while a fire burned beneath him to test the impact of extreme heat on the body.



## Dr. J Marion Sims

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Dr. J Marion Sims was an American physician and a pioneer in the field of surgery, known as the "father of modern gynecology". His most significant work was the development of a surgical technique for the repair of vesicovaginal fistula, a severe complication of obstructed childbirth.

What he did:

Dr. J Marion Sims performed his surgery on non-consenting slaves addicting them to narcotics to sedate and immobilize them post-operatively – he also performed the surgery repeatedly on the same women.



# The Tuskegee Study

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- In 1932, the Public Health Service, working with the Tuskegee Institute, began a study to record the natural history of syphilis called the “Tuskegee Study of Untreated Syphilis in the Negro Male.”
- The study was conducted without the benefit of patients’ informed consent.
- The men were never given adequate treatment for their disease. Even when penicillin became the drug of choice for syphilis in 1947, researchers did not offer it to the subjects.
- The study lasted until 1972.
- The last U.S. Public Health Service Syphilis Study at Tuskegee participant died on January 16, 2004.



Dr. Austin R. Stough



# Sickle-Cell Screening

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- In the 1970s large scale screening of African Americans for sickle-cell was used to change African-American “mating” behavior.
- States passed legislation requiring all African-American children be screened for sickle-cell even though there was no treatment for the disease.
- Insurance companies and employers used the screening data to deny or increase insurance rates or to fire employees – the US Army considered banning all African-Americans from service.
- African-Americans came to believe the screening efforts were disguised genocide.



# Family Planning and Involuntary Sterilization

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- Many early family planning initiatives were aimed at controlling and reducing the Black population.
- In 1939, the Birth Control Foundation of America planned a “Negro Project” designed to limit reproduction by Blacks.
- In the 1960s the government expanded the subsidization of family planning clinics as a way to reduce the number of persons on welfare – establishing clinics in proportion to the number of Black and Hispanics in a community.
- In the 1970s, some doctors would only deliver babies or perform abortions on pregnant African-American women if the women considered sterilization.

# Truth

The institution of medicine in the United States was built with the lives of black men and women.

# Historical Trauma

**Historical Trauma** refers to a complex and collective trauma experienced **over time and across generations** by a group of people who share an **identity, affiliation, or circumstance**.

# Mistrust

Mistrust is not merely the opposite of trust but is more negative than just the absence of trust; mistrust often refers to the belief that the entity that is the object of mistrust **is acting against one's best interest or well-being**

# Fostering Trust and Trustworthiness

- **Communications/Knowing Your Patient** – practices that emphasize communications tools, models and channels for understanding the lived experience of patients, clinicians and other providers
- **Conversations/Support** – practices that encourage trusting relationships and interactions through the ways in which those providing care and those receiving care engage with each other
- **Leadership** – practices that demonstrate, cultivate and support efforts to nurture trust in clinical practice and relationships throughout the health care system
- **Misinformation** – practices that attempt to counter misinformation in health care and/or work to disseminate accurate information about medicine and health care

# Fostering Trust and Trustworthiness

- **Patient-Centered Design** – practices that ensure consistency in clinical practice and focus on clinical practice approaches that position the varied interests/needs of patients as paramount
- **Transparency** – practices that reflect full disclosure of clinical and other information that would be important for good health care decision-making and effective health care delivery
- **Value/Affordability** – practices that promote awareness of and engagement involving the costs of health care and potential impact on patients and health systems

# Questions and Comments



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