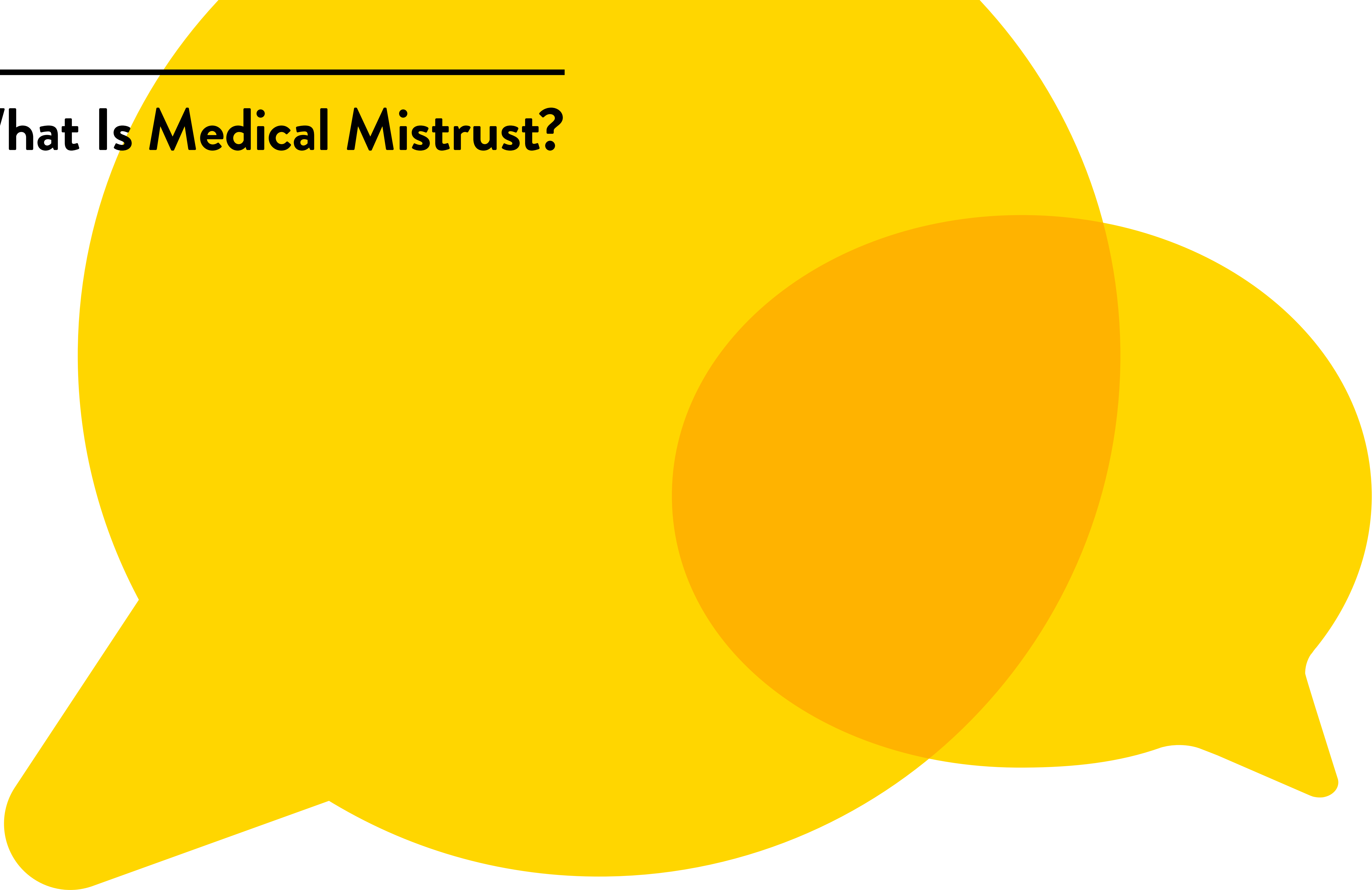
SWAG: LESSONS IN
SEXUAL WELLNESS AND GROWTH

CEC LESSON *This lesson is designed specifically for Client Experience Contributors (CECs).*

DECREASING HEALTHCARE STIGMA AND MEDICAL MISTRUST AMONG BLACK MSM

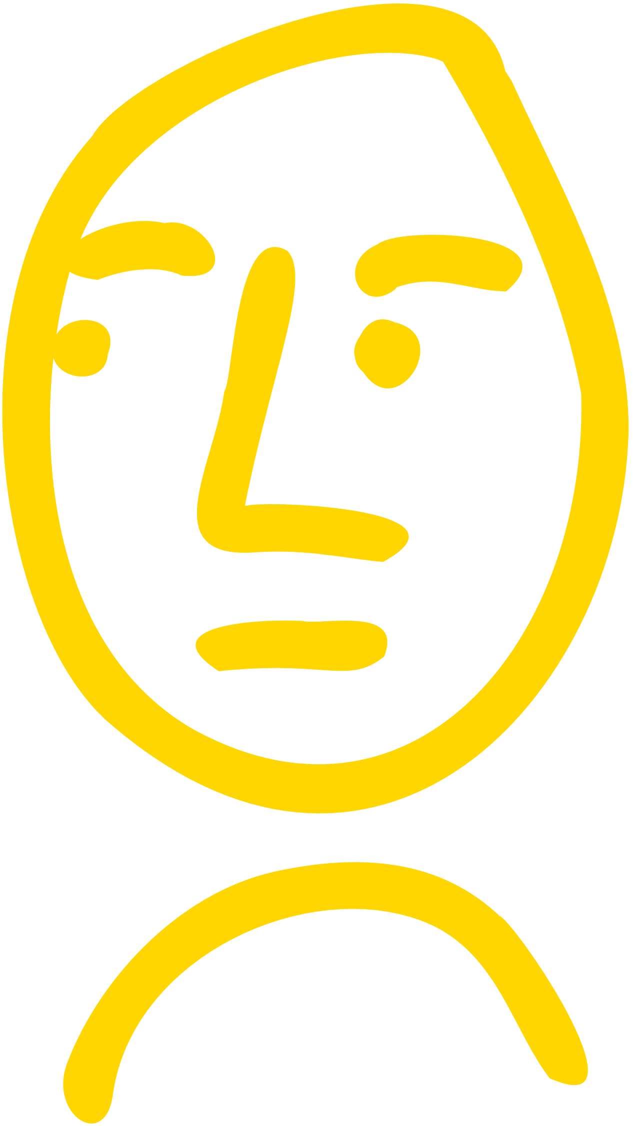
Interdisciplinary
Sexuality Research
Collaborative

What Is Medical Mistrust?



Medical Mistrust Defined

- A suspicion or lack of trust in medical organizations, practices, and institutions, including medical schools or research organizations and pharmaceutical companies.



Medical Mistrust—Historical Context

In the 18th and 19th centuries, enslaved African Americans could only receive medical care from slave hospitals.

If treated, it was by White doctors, paid for by their owners, and often without the enslaved person's consent, regard for their pain, or treatment preferences.

In the early 20th century, African Americans were excluded from the professional medical schools and societies, and the public health service did not take their health into account *(Bustamante, 2014)*

When the health of African Americans jeopardized the health of White Americans did public services start to take action *(Bustamante, 2014)*

Medical Mistrust—Historical Context (continued)

- Medical mistrust is the result of past and continuing medical mistreatment of blacks and African Americans by the United States medical and healthcare systems.
- Two of the most salient examples of medical mistreatment are:
  - HeLa cells from Henrietta Lacks
  - Tuskegee Syphilis Study

Henrietta Lacks

- Henrietta Lacks was a 30 year old African American wife and mother of five who sought treatment for what would be diagnosed as an aggressive form of cervical cancer
- When samples were taken for biopsy Lacks' cells were used in research without permission
- This happened at Johns Hopkins Hospital in 1951
- Her cancer cells multiplied and thrived
- Cells were named "HeLa" cells
- Tested thousands of patents for treatment
- Millions of dollars made in profits
- No credit given to Lacks or her family
- Family found out about research in 1973

Henrietta Lacks.
(Credit: Lacks Family;
source: History.com)

Tuskegee Syphilis Study

- 1932 Public Health Service study
- 600 black men—399 with syphilis
- No informed consent
- Men told they were being treated
- Even after penicillin was approved, no treatment offered
- Ethics were not questioned until 1968

Source: cdc.org

A Moment to Imagine

Source: washingtonpost.com

- What kind of messages does this history communicate about the value of Black bodies?
- What kind of messages does this history communicate about medical institutions and practitioners?
- How could a foundation of trust been laid in these scenarios, allowing the medical field to advance and Black people to be valuable contributors?
- How do you currently build trust with your clients?

Healthcare Discrimination: The Data

- Research notes African Americans have found or feared the following as part of their healthcare experiences:

African American participants felt the front desk staff were more inclined to be friendly and chat with white patients

Front desk staff seemed to skip over black patients and provide care to white patients first

Some providers won't greet the patient, just begin providing care or writing a prescription *(Jacobs, 2006)*

Physicians focused on profit rather than care "if they don't see where they can get paid, they are not really interested in you" *(Jacobs, 2006)*

does not allow patient to discuss their care

Some patients expressed that doctors seemed afraid to touch them, or acted like they couldn't see that anything was wrong *(Cuevas, 2016)*

Impact of Healthcare Discrimination

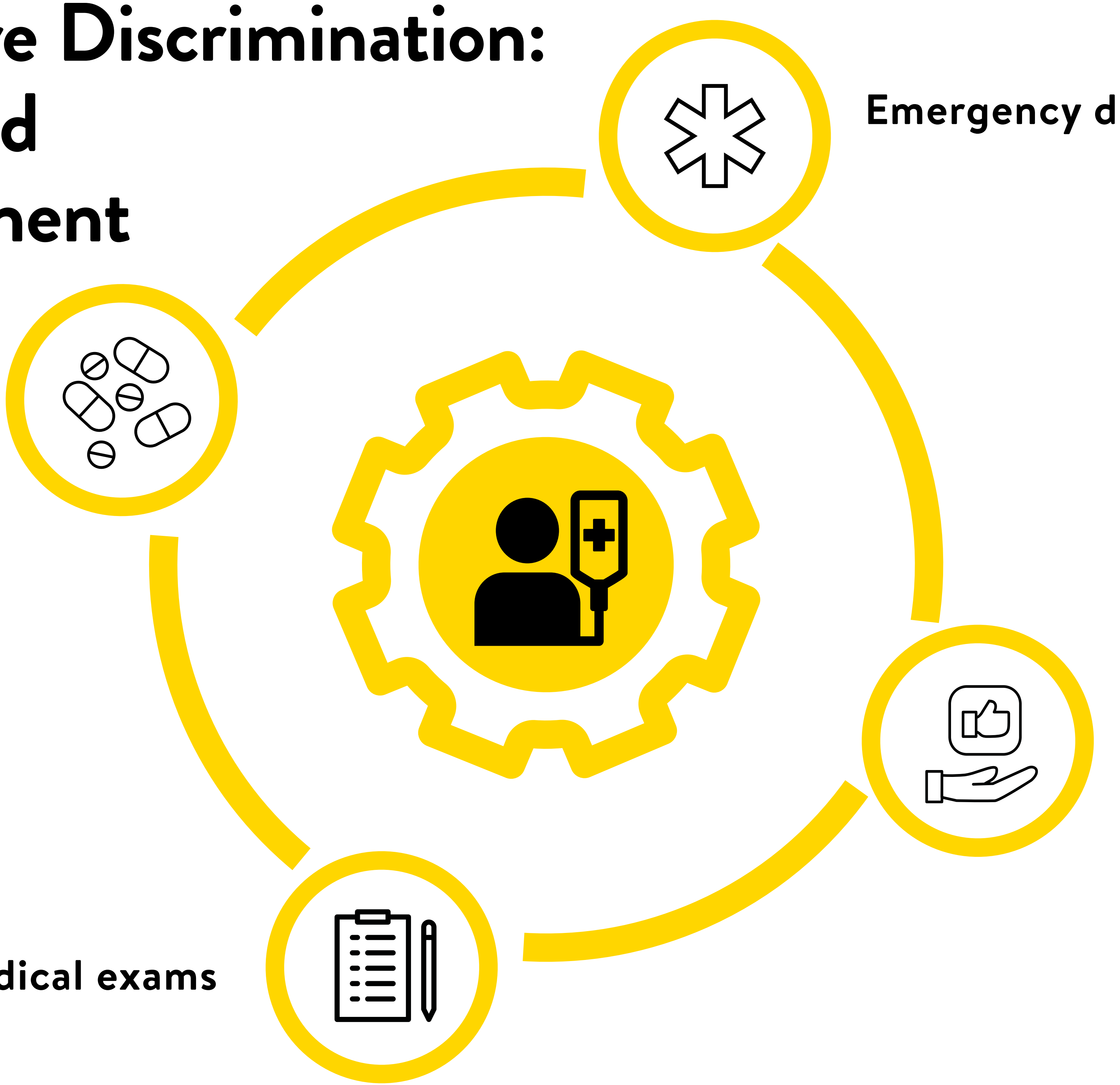
Pain medication

Cancer screening

Vigorous cancer treatment

Anti- retroviral treatment
(ART) for HIV/AIDS

Impact of Healthcare Discrimination: Medical Mistrust and Healthcare Engagement



Emergency department use

Medication adherence

Patient satisfaction

Medical exams

Building Trust: Considerations

Trust must be built and earned, starting with your first interaction with the client.

Clients have a right to be informed about ALL care options, even trials.

Clients maintain the expertise about their life and circumstances, which can be used to help determine the best method of care. Honor their expertise as you expect them to honor yours.

Client involvement in treatment planning, especially for populations such as BMSM, is powerful. Such power can increase their trust in your care.

Client involvement in treatment planning communicates respect for their autonomy and life circumstances which may make one treatment option more preferable than another.

Patients may want to discuss treatment options with their partner(s), family, or friends before making a final decision.

Building Trust: Actions

- Introduce yourself
- Communicate (speak and listen) with
  - Openness
  - Honesty
  - Empathy
- Keep patients' best interest front and center
- Involve the patient in their care

Trust in Action

CALEB

How would you begin building rapport and establishing trust with Caleb?

- Caleb is a 46 year old BMSM who is new to your city and your organization. Caleb shares you came recommended from a friend who expressed enjoying the services you provide, although they weren't particularly happy with their experiences with your organization overall. Caleb also shares they don't "do docs" but they're getting older and considering settling down with the partner who also relocated with them and wants to make sure that as they start life in this city, all is well. Caleb says "I usually have a good sense of what my body needs and if I'm sick I still call my mom for a quick remedy."