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

Kurt Ragin Jr.

This lesson serves as an introduction to the prevalence and impact of healthcare stigma and medical mistrust on health outcomes for Black MSM. This includes, but is not limited to, treatment adherence, assessment practices, and accessibility to affirming healthcare services.

FORMAT	TIME
Workshop	90 minutes

Interdisciplinary Sexuality Research Collaborative

PREPARATION

The facilitator(s) should use this section to prepare for the lesson.

WHY THIS LESSON IS IMPORTANT FOR BLACK MEN

Gay, bisexual men, and other men who have sex with men (MSM) account for more than two thirds of new HIV infections in the U.S., with Black MSM experiencing the greatest burden *(Cahill, Taylor, Elsesser, Mena, Hickson, Mayer, 2017)***. Supporting treatment adherence through the accessibility of services that exhibit cultural competence, humility, and are culturally affirming through the engagement of practitioners who have non dominant cultural identities for BMSM is imperative to their wellbeing. Such supports have the power to build trust instead of reinforce the history of mistrust with the medical community and the Black community through incidences such as the Tuskegee Syphilis Trials and the case of Henrietta Lacks** *(Beskow, 2016; Powell, 2010)***. An increase in such trust also has the power to create relationships between BMSM and client experience contributors that may contribute to engaging in preventative care as well as treatment, and increase other positive help seeking behaviors, positively shifting the rates of HIV and other sexually transmitted infections that have been a burden to this community and increasing overall health and wellness** *(Eaton et al., 2015; Powell, 2010)***.**

GOAL

Participants will increase their knowledge and skills integral to the provision of care which reduces stigma and increases trust with BMSM clients.

OBJECTIVES

By the end of this lesson, participants will be able to:

- Understand what contributes to medical mistrust.
- Learn how to implement practices to develop trust with BMSM clients.

TIME

STEPS 1–5	Introductions and Opening Activity	25 min.
STEPS 6–9	Medical Mistrust Definitions and Context	15 min.
STEPS 6–9	Small Group Activity: A Moment to Imagine	15 min.
STEPS 10–14	Healthcare Discrimination and Its Impacts	10 min.
STEPS 6–9	Individual Activity: "It All Falls Down"	20 min.
STEPS 6–9	Break	5 min.
STEPS 6–9	Partner Activity: "Trust in Action Role Play"	15 min.
STEPS 10–14	Closing Activity	15 min.

REQUIRED BACKGROUND KNOWLEDGE FOR EDUCATORS

In order to effectively implement this lesson, the facilitator(s) should possess:

- A minimum of one year of working with LGBTQ+ populations.
- A minimum of one year of working within an LGBTQ+ healthcare agency.
- At least one year of experience providing adult education.
- Effective group management skills.
- Ability to expand on historical references involving healthcare institutions within the African-American community

This lesson references mistreatment of African Americans in the medical field. For further reading on the two examples used in this lesson, refer to these resources:

- Henrietta Lacks: nytimes.com/interactive/2018/obituaries/overlooked-henrietta-lacks.html
- Tuskegee Syphilis Study: cdc.gov/tuskegee/timeline.htm

FACILITATION PREP

The facilitator(s) should complete the following tasks before the lesson starts:

- ☐ This lesson includes a slide presentation, "Decreasing Healthcare Stigma and Medical Mistrust Among Black MSM," which can be found on the SWAG Toolkit website. Review the full presentation at least one day prior to the session to become familiar with its contents.
- ☐ Check your space 60 minutes in advance of the session to ensure that a computer, projector, and projector screen are available and in working order, and that the presentation can be seen and navigated properly. If you do not have access to technology, print out the presentation as a handout for each participant.

HANDOUTS

Each participant should be provided with the following printed materials:

- ☐ End-of-Session Evaluation

MATERIALS

The facilitator(s) should have the following materials for the lesson:

- ☐ Pens *(one for each participant)*
- ☐ Computer
- ☐ LCD projector, screen, and connector cables
- ☐ "Decreasing Healthcare Stigma and Medical Mistrust Among Black MSM" slide presentation
- ☐ Stopwatch
- ☐ 2- 8–16 oz bottles hand sanitizer
- ☐ 2 boxes Kleenex
- ☐ 200–700 toothpicks *(20 toothpicks per participant)*
- ☐ 2–3 bags of mini marshmallows
- ☐ Paper plates
- ☐ Small objects such as play dough, pipe cleaners, stress relief balls to go on tables to assist in concentration for participants

SPECIAL CONSIDERATIONS

This lesson is written to be delivered to groups of practicing client experience contributors ranging from 10 to 30 participants, with participants working in groups of five. If there are less than 10 participants there is no need to create small groups. The physical space needs to be able to accommodate 10–30 participants as one large group, accommodate small group break outs, and must be inviting for individuals with various abilities and accessibility needs. Space should also be equipped with a screen, projector, internet connection, computer, sound, and a dry erase board.

The lesson has been written for one facilitator, although it can be cofacilitated. Multiple facilitators can provide a variety of diverse perspectives. Be sure to assess the qualifications of each facilitator, including discussing in advance about sharing the training floor appropriately.

Lastly, in the case of emotional discomfort, having a licensed therapist or social worker accessible to help with unpacking emotions for any participant in need of emotional care is encouraged. Share with participants if they feel triggered by any words or experiences the facilitator should express they have the liberty to leave the space to honor their needs during the workshop.

KEY TERMS

Culture: a mark of disgrace associated with a particular circumstance, quality, or person.

Medical mistrust: circumspection of health care providers, fueled by painful experiences with racism that causes minorities to delay routine screenings and doctor's appointments, with potentially serious implications for their overall health.

Cultural humility: an approach to building relationships cross culturally in which privilege and power imbalances are brought to an awareness and suspended in exchange for a posture of humility which invites partnership, respect, reciprocity, and mutual learning and understanding across cultures.

PROCEDURE

The facilitator(s) should follow the steps in this section to facilitate the session, and use the margin for notes and prompts.

25

Introductions and Opening Activity

STEP 1

Welcome participants to your session, and thank them for coming. Conduct brief introductions (name, pronouns) with the group. Review all established group agreements and reaffirm consent from the group. If group agreements have not been completed, please create them at this time *(use the Community Agreements lesson, if necessary.)*

STEP 2

Introduce the session topic by informing the group the lesson will explore Stigma and Medical Mistrust and its impact on the health and wellness of Black men who have sex with men (BMSM).

STEP 3

Share with participants the next few minutes will be used to engage in an icebreaker. Instruct participants to get into groups of five in order to engage in the activity. After they are each in their small groups announce the icebreaker, "Two Truths and a Lie." Each participant should share two things about themselves that are true, and one that is a lie. The group members will want to guess which was the lie. Share they will have 15 minutes to complete this exercise. At the conclusion of the exercise ask participants to ponder whether or not their trust has increased or decreased based on what was shared with them.

15

Medical Mistrust Definitions and Context

STEP 4

Open the slide presentation included with this lesson, Slides S1, "Decreasing Healthcare Stigma and Medical Mistrust Among Black MSM". Proceed through the slides as follows:

SLIDE 1 Title Slide

Introduce that participants will be learning about the scope and impact of stigma and medical mistrust the sexual health and wellness of Black men who have sex with men, and skills to build trust with BMSM clients.

SLIDE 2 What Is Medical Mistrust?

Encourage participants to offer their own definitions of medical mistrust aloud.

SLIDE 3 Medical Mistrust Defined

To encourage continued engagement, **ask** for a participant to read the definition medical mistrust aloud. If no one volunteers, **read** the definition aloud.

Before moving on, **ask** participants if there is anything they would change to the definition provided. As you allow additional thoughts, **thank** them for sharing and **remind** them that this is the definition that will inform the workshop.

SLIDE 4 Medical Mistrust—Historical Context

Share with participants that understanding medical mistrust within the Black community in the United States can best be understood the history of medical mistreatment, starting with slavery. **Review** the bullet points aloud. *(You may choose to engage participants by having volunteers read the bullet points aloud.)*

SLIDE 5 Medical Mistrust—Historical Context (continued)

Review the bullet points aloud. *(You may choose to engage participants by having volunteers read the bullet points aloud.)*

SLIDE 6 Henrietta Lacks

Read the bullets aloud, or **read** the following points to highlight and reiterate the mistreatment of African Americans in the medical field.

- When samples were taken for biopsy, Lacks' cells were used in research without permission
- Tested thousands of patents for treatment; made millions of dollars in profit
- No credit given to Lacks or her family, who found out about the research 20 years later

SLIDE 7 Tuskegee Syphilis Study

Read the bullets aloud, or read the following points to highlight and reiterate the mistreatment of African Americans in the medical field.

- 600 black men in the study and 399 with syphilis, yet there was no informed consent for study participation.
- Individuals with syphilis were told they were being treated when they were not, despite treatment options like penicillin being available.
- The ethics of this study were not scrutinized until 1968, 36 years after it began.

Small Group Activity: A Moment to Imagine

STEP 5

Explain to participants that they will now take a moment to reflect on what has been shared thus far about the historical context of medical mistreatment and lack of transparency between the medical field and the Black community, and that they will work in their small group to answer a series of questions. Instruct them to identify a recorder to record the group's responses, and to identify a reporter to share their group's responses with the larger group.

SLIDE 8 A Moment to Imagine

Instruct participants to answer the questions on the slide. Share they will have five minutes to answer the following questions.

After five minutes, call the attention of the larger group back together. Instruct the reporter of the first group to share what their group discussed. Once shared, ask the larger group of participants if they have additions or clarifications on the first group's list. Repeat this process with the remaining groups. Modify accordingly. Allow 10 minutes for this portion of the activity.

STEP 6

Close the activity by reminding participants historical context is integral in understanding the pervasive and persistent nature of mistrust. While there are a host of ethical guidelines in place to prevent repeating things like the Tuskegee Syphilis Trial and Henrietta Lacks, today, there is still work to be done to build trust.

10

STEP 7

A

Healthcare Discrimination and Its Impacts

*(The following slides reference data that may bring up some questions among your participants. **Refer** to* Facilitator Resource A, "Slide Support" *for more information and data.)* Redirect participants' attention to the presentation, and **proceed** through the slides as follows:

SLIDE 9 Healthcare Discrimination: The Data

Review bullet points on slide aloud. *(You may choose to engage participants by having volunteers read the bullet points aloud.)*

Share with participants this data is not exhaustive, and is a combination of real experiences reported by African American medical patients and perceptions or fears of African American medical patients.

SLIDE 10 Impact of Healthcare Discrimination

Explain to participants discriminatory healthcare practices don't just occur in a patient meeting, nor do they stop there. Research has found there are disparities among treatment for White and Non-white patients, such as:

- Non-white patients are less likely to be prescribed pain medications
- Performance of cancer screenings and how early on they are performed
- Cancer treatment and Non-white patients being targeted less aggressively for treatment
- Non-white patients less likely to receive ART (antiretroviral therapy) for HIV

SLIDE 11 Impact of Healthcare Discrimination: Medical Mistrust and Healthcare Engagement

Explain to participants the experience of discrimination—or the perception of discrimination—by African Americans reinforces mistrust and also impacts healthcare engagement; the very engagement that can prove life saving for Black men and BMSM. Research has found:

- Lack of trust is associated with lower medication adherence and patient satisfaction among African Americans *(Cuevas, 2016)*

- For HIV positive and negative BMSM experiencing stigma-based discrimination, greater time elapsed time since their last healthcare examination *(Eaton, 2015)*
- Specific to emergency room dynamics it has been noted:
  - » Discrimination in the form of implicit biases that favor white patients over nonwhite patients are prevalent across healthcare providers' role or discipline
  - » Decisions that people make based on implicit biases are more likely to occur under time pressure/in times of cognitive overload
  - » According to Dehon (2017), this makes emergency departments a key place where discrimination through implicit biases influence how physicians provide care including pain medication dissemination which studies gave found are more likely to be prescribed to white patients more frequently than to nonwhite patients.

Individual Activity: "It All Falls Down"

STEP 8

Distribute paper plates, toothpicks, and marshmallows to participants. Instruct them to take the next five minutes to build a three dimensional foundation of their choosing, using no more than 20 toothpicks. Explain it can be as long, wide or high as they desire, and to use the materials provided at their table, constructing the foundation atop a paper plate.

Refer to Facilitator Resource B, "Statements for 'It All Falls Down' Activity" to complete the activity.

STEP 9

Once the activity is complete, proceed through the following discussion questions:

1. "What was it like to do this activity?"
2. "What surprised you as you went through the process of building a foundation and then had to dismantle it in response to the statements read aloud?"
3. "What do you think it is like for BMSM clients who have built foundations, relationships, with CECS in various human and health service organizations but to have one experience with one CEC that starts to dismantle all of that?"

Break

Ask participants to discard their foundations in the trashcan. Announce to the group that there will be a five-minute break. Encourage participants utilize the restrooms, stretch, etc. Remind them to return to the space in five minutes.

Partner Activity: "Trust in Action Role Play"

STEP 10

Welcome everyone back. Thank them for their hard work up until this point. Briefly recap what has been discussed thus far. Resume the slide presentation.

SLIDE 12 Building Trust: Considerations

Inform participants in order to establish trust with clients for whom there is not only a history of mistrust, but research maintains discrimination continues to reinforce the presence of mistrust today there are certain factors that must be considered. Proceed to ether read the points on the slide aloud or encouragement participation by asking participant to read the slide aloud.

SLIDE 13 Building Trust: Actions

Explain to participants building trust not only includes considerations or intentions, but their mist be behaviors, or actions that are used to build trust as well. Read the points on the slide aloud, or encourage participation by asking participant to read the slide aloud.

SLIDE 14 Trust in Action

Explain to participants they will spend the next couple of minutes practicing through role play how they would begin building rapport and establishing trust with their new client Caleb, using the scenario on the slide. Share with them that the scenario is a template and those on the role of Caleb may add to the character as they see fit.

Instruct them to find a partner for the role play. During the first two minutes, one person will assume the role of Caleb and the other will be the CEC. After two minutes, instruct them to switch roles thus allowing each person to serve as the client and the CEC.

STEP 11 After the appropriate time has elapsed, **call** the full group's attention to process the activity using the following questions:

1. "What did the CEC say or do that communicated they were listening to you openly and with empathy?"
2. "How did the CEC express respect for your expertise as the client and having a sense of either your needs and or thoughts on what care looks like for you?"
3. "What more would you like to know about Caleb to continue building trust and how would you go about learning this?"

Closing Activity

STEP 12 Ask if anyone has any outstanding questions about the lesson or session. Respond to these as necessary.

STEP 13 Distribute copies of the Session Evaluation to each participant. Allow participants 5-7 minutes to complete the evaluation, and **collect** them as they are completed. After five minutes, **invite** any participants who have not completed the evaluation to do so after the next activity.

STEP 14 Conclude by asking each participant to reflect upon their experience in this lesson. **Instruct** each participant to answer the following question:

- "What is one trust building consideration or action you will integrate into the way you engage BMSM?"

Encourage all participants to answer.

STEP 15 Once everyone has shared, **thank** all participants for participating, and then **adjourn** the session.

FACILITATOR RESOURCE A

SLIDE SUPPORT

Directions: See **STEP 7**.

Slide 9 Support:

African American patients' experience discrimination in healthcare on a variety of domains. These findings are from two studies involving focus groups of African American patients:

- discrimination might start at the beginning of the visit within the waiting room
- 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
- Black women in particular often feel they have to **repeat themselves constantly** in order to receive treatment *(Cuevas, 2016)*
- physicians can interact poorly with patient, have poor interpersonal skills
- some providers won't greet the patient, just begin providing care or writing a prescription *(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)*
- patients fear that providers are greedy, or like they want to experiment on the patient *(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)*
- many patients do believe that physicians are interested in experimenting on them
- patients referred to the Tuskegee study, and believed physicians wanted to test medications on them
- many perceive that providers are racist *(Jacobs, 2006)*
- don't trust physicians who seem to treat patients differently based on their race
- patients said some providers seem to care more about white patients' well-being
- these experiences make it stressful and uncomfortable to receive medical care

Slide 10 Support:

Multiple studies support these perceptions, and reveal that healthcare systems and individual providers discriminate against nonwhite patients.

- From a report of discrimination within 350 emergency departments nationwide *(Dehon, 2017)*
- Nonwhite patients are up to 30% less likely than white patients to receive pain medication when they present for abdominal pain
- Nonwhite patients are more likely to have longer wait times, less likely to be admitted to the emergency department
- Among patients with cardiovascular disease
- African Americans less likely than whites to receive beta-blockers, thrombolytic drugs, or aspirin, even when they are indicated for treatment *(Bustamante, 2014)*
- African Americans are less likely to receive advanced/expensive treatments and therapies for CVD conditions *(Bustamante, 2014)*
- Fewer cancer screenings and less appropriate care among minorities
- Fewer Native American, Asian, Latina, and African American women receive regular mammograms compared to non-Latina white women *(Bustamante, 2014)*
- African American women less likely than white to receive breast-conserving surgery and radiation
- Even after controlling for insurance, hospitals, and comorbidities: African Americans and Latinos are treated less aggressively for colorectal cancer than non-Latino whites *(Bustamante, 2014)*
- Less treatment for HIV
- African American and Latina women receive ART less often than white women (after controlling for confounders) *(Bustamante, 2014)*

Slide 11 Support:

Clients who do not trust the healthcare system, or their provider, are less likely to engage with the healthcare system.

- Many utilize the emergency department instead of primary care. From a 2016 study in Baltimore:
  - » **Population**
    - residents of neighborhoods with nearly equal proportion African American and white residents; no differences in socioeconomic status*(Arnett, 2015)*
  - » **Method**
    - interviews of residents
      - › assessed where they receive most healthcare
      - › assessed agreement with medical mistrust statements
      - › (e.g., "You'd better be cautious dealing with health care organizations", and "health care organizations don't always keep your information totally private")
  - » **Results**
    - African Americans are 1.43 as likely as whites to use the emergency department as their main source of care
    - This difference between the two racial groups was **based on higher medical mistrust in African American residents** (i.e. higher medical mistrust mediated the relationship)

- Lack of trust is associated with **lower medication adherence and patient satisfaction** *(Cuevas, 2016)*

- For those experiencing stigma, a greater elapsed time since last healthcare examination for HIV positive and negative black MSM *(Eaton, 2015)*

- **Additional note about emergency department use:**
  - » Implicit biases that favor white patients over nonwhite patients are prevalent across healthcare providers, regardless of their specific discipline
  - » Decisions that people make based on implicit biases are more likely to occur under time pressure/in times of cognitive overload
    - According to Dehon *(2017)*, this makes emergency departments a **key place where implicit biases can take over and influence how physicians provide care**
    - might lead providers to provide pain medication to white patients more frequently than to nonwhite patients

FACILITATOR RESOURCE B

STATEMENTS FOR "IT ALL FALLS DOWN" ACTIVITY

Directions: See **STEP 8**. Read each statement below out loud for your group, one statement at a time. Inform them that if their response to the statement is "yes", they need to remove a toothpick from their structure. If their response is "no," they don't need to do anything. Explain the statements may perpetuate stigma or be a form of bias, but all are factors that can perpetuate mistrust between them and their BMSM clients. Encourage them to reflect and respond honestly.

1. I am aware that the Black LGBTQ+ community may be viewed as a sexual deviant.
2. I am aware it is not uncommon for doctors to skip talking with BMSM about sexual health that specifically relates to their sexual orientation.
3. I am aware that BMSM have gone into healthcare facilities and felt uncomfortable for reasons specific to their BMSM identity.
4. BMSM may not initiate conversation with their physician about their sexual activities because they fear embarrassment, discrimination, or being shamed.
5. In my organization I have assumed the pronoun of a BMSM client before asking.
6. Some of the most salient data about BMSM is that they are often living with an STI or HIV.
7. My BMSM clients can readily engage staff that look like them or are a part of their community at my organization.
8. My organization receives funding that motivates targeting BMSM for services.
9. It is common practice at my organization to discuss masturbation and/or sex toys are discussed with my BMSM clients.
10. PREP (Pre exposure prophylaxis) is promoted primarily to Black MSM.
11. At my organization, health insurance determines the level of care and options discussed with BMSM clients.
12. I have heard front desk staff and/or security use non-inclusive language to refer to LGBTQ persons.
13. I have heard my colleagues (non front desk staff) use non-inclusive language to refer to LGBTQ persons.