The Journey of the STigma And Resilience (STAR) Coalition to End Intersectional Stigma in HIV Settings

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NATIONAL
RYAN WHITE
CONFERENCE
ON HIV CARE & TREATMENT

Conflicts of Interest

- None to declare

Learning Objectives

- Understand the nature of intersectional stigma
- Learn the effects of intersectional stigma on healthcare for PLWH
- Share approaches to reduce HIV-related stigma in healthcare settings

Stigma and Resilience (STAR) Project

Our Team

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What is stigma?

Stigma is the disapproval of or discrimination against a person based on perceivable social characteristics that serve to distinguish them from other members of society.

Social stigmas are commonly related to culture, gender, race, age, intelligence, and health.

Intersectional stigma occurs when people have multiple stigmatized identities that intersect (i.e., race, sexual identity, HIV status, etc.)
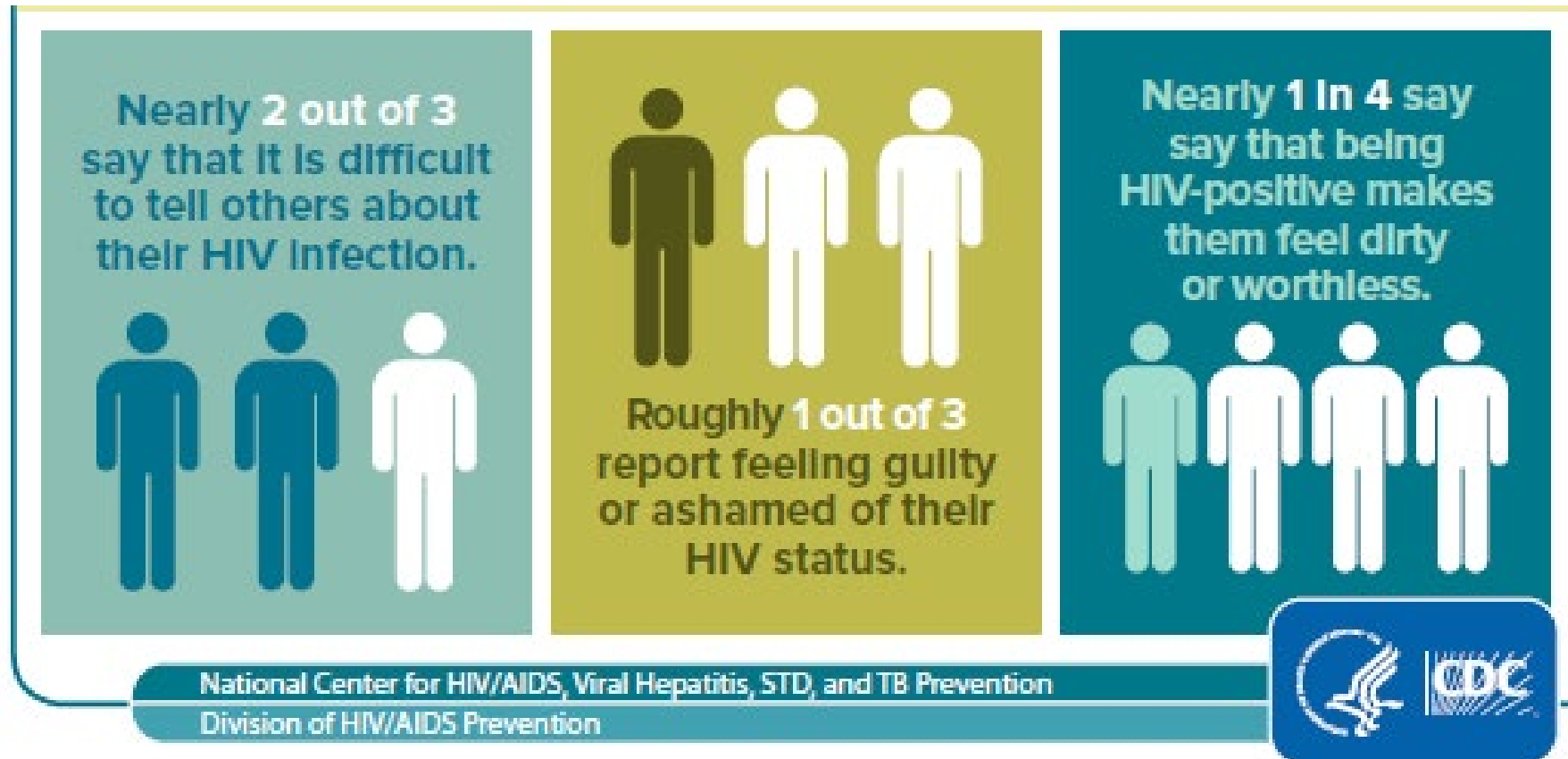
Intersectional Stigma

https://youtu.be/8tbwIImrt1E

HIV Stigma is Common in the US

CDC found HIV stigma to be very common among PWH nationally
https://www.cdc.gov/hiv/pdf/statistics/mmp/cdc-hiv-internalized-stigma.pdf

Nearly **2 out of 3** say that it is difficult to tell others about their HIV infection.

Roughly **1 out of 3** report feeling guilty or ashamed of their HIV status.

Nearly **1 in 4** say say that being HIV-positive makes them feel dirty or worthless.

National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
Division of HIV/AIDS Prevention

CDC
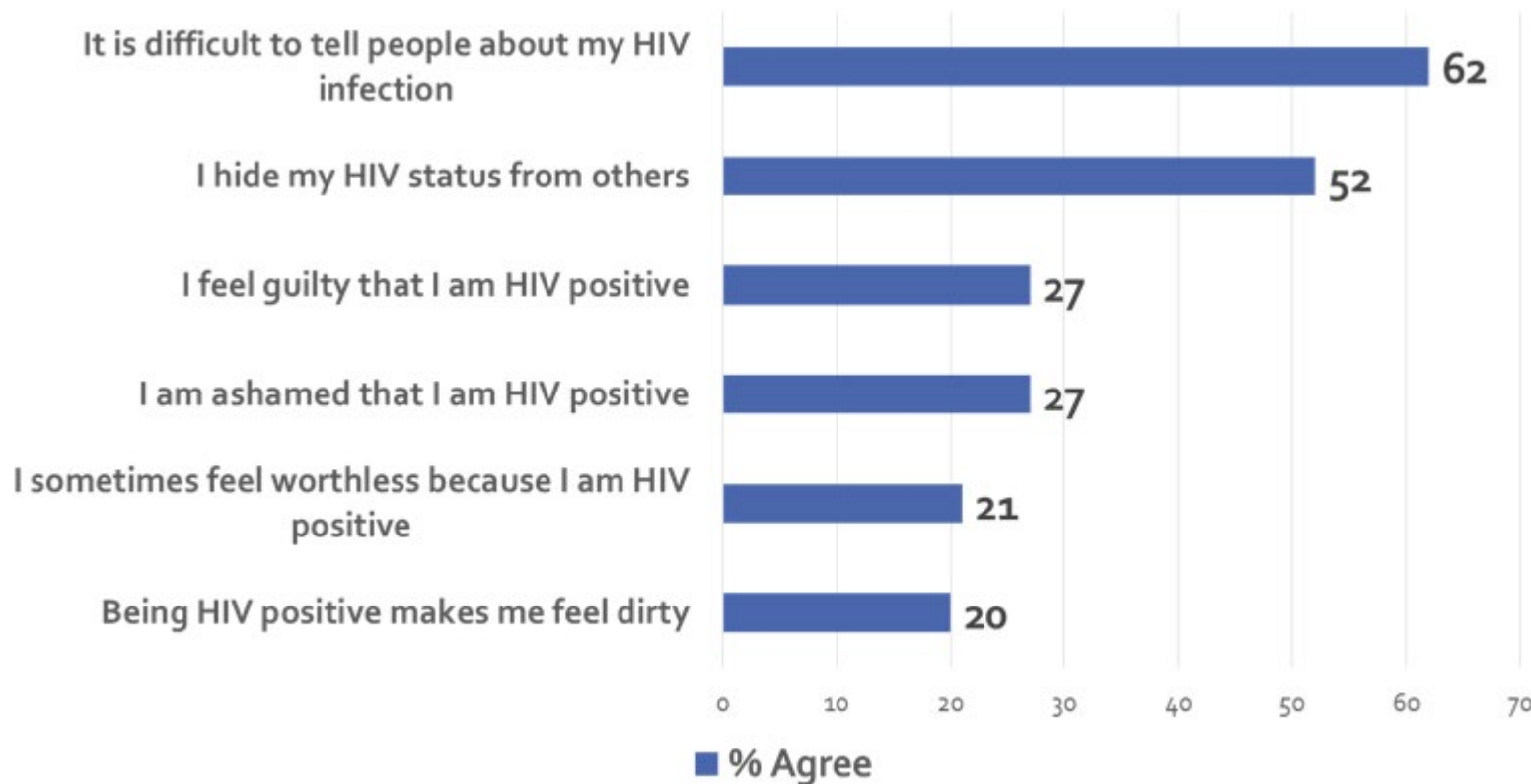
HIV Stigma is Common in New York

Stigma reported by HIV organizations surveyed by the AIDS Institute. Stigma was highest towards people with a mental health diagnosis, transgender persons, and PWH.

From Ahmed et al. poster at 2018 National Ryan White Conference on HIV Care & Treatment

Healthcare staff…	%
Have not received training on HIV-related stigma and discrimination and key populations	**36%**
Did not have knowledge of policy against discrimination of key populations	**17%**
Agreed that infection occurs due to irresponsible behavior	**26%**
Agreed that PLWH have had many sexual partners	**16%**
Expressed lack of comfort working with patients with a mental health diagnosis	**18%**

HIV Stigma is Common in NYC

Stigma among PWH in HIV Care in NYC Medicaid Monitoring Project, 2011-2014 (N=1,321)

It is difficult to tell people about my HIV infection — 62

I hide my HIV status from others — 52

I feel guilty that I am HIV positive — 27

I am ashamed that I am HIV positive — 27

I sometimes feel worthless because I am HIV positive — 21

Being HIV positive makes me feel dirty — 20

■ % Agree

75% of PWH receiving HIV care in NYC agreed with at least one HIV stigma statement.

Stigma was highest for:
- Latinos
- Queens
- those born outside of the US
- those diagnosed <5 years ago
- those with depression
- those who binge drink

Why focus on stigma?

- Stigma in NYC interferes with access to prevention and health care, but it has not been adequately addressed until now

- Uncertainty about how what works to eliminate stigma. There are many programs and initiatives, but little evaluation

Intersectional stigma

- We focus on other stigmas that intersect with HIV stigma (substance use, mental health, demographic characteristics)
- The STAR Coalition brings together groups and individuals in NYC who want to unite to address stigma

Our Goals

Coalition of HIV-related organizations, affected communities, non-traditional partners, public health officials, academic researchers to guide work of the planning year.

Map & assess the evidence base (compendium) underlying current stigma-reduction activities using surveys and interviews of organizations and analyze existing data on stigma drivers (e.g., poverty, crime, HIV status, race/ethnicity, same-sex households). Same for resiliency promotion.

Identify sites where stigma reduction/resiliency-promotion interventions are most needed, feasible, and with whom they are best implemented to address EHE.

The STAR Coalition

- Conduct activities to identify where and how stigma-reduction and resilience promotion interventions might optimally be implemented in NYC

- Partners Include:
  - NYC Department of Health and Mental Hygiene
  - New York State Department of Health
  - CBOs
  - Healthcare organizations
  - Members of affected communities
  - AETC
  - Columbia University

STAR Coalition Organizations

1. AIDS Healthcare Foundation (Bk,Bx,M,Q)
2. Amida Care (Bk,Bx,M,Q)
3. APICHA (Bk,Bx,M,Q)
4. Callen Lorde Community Health Center (Bx,M)
5. CAMBA (Bk)
6. Center for Public Health Education, Stony Brook University (Q)
7. Community Healthcare Network (Bk,Bx,M,Q)
8. CUNY School of Medicine (Bk,Bx,M,Q)
9. DOH-AIDS Institute (Bk,Bx,M,Q)
10. DOHMH (Bk,Bx,M,Q)
11. FACES NY INC (Bk,Bx,M)
12. Gay Men's Health Crisis-GM (Bk,Bx,M,Q)
13. Harlem United (Bk,Bx,M)
14. Harm Reduction Coalition (Bk,Bx,M,Q)
15. Healthfirst (Bk,Bx,M,Q)
16. HIV Planning Council (Bk,Bx,M,Q)
17. Housing Works (Bk,Bx,M)

18. Interfaith Medical Center (Bk,Bx,M,Q)
19. Jacobi Medical Center (Bx)
20. La Nueva Esperanza, Inc (Bk)
21. LGBT Network (Q)
22. Mount Sinai Institute (M)
23. National Black Leadership Commission on Health (Bk,Bx,M,Q)
24. New York-Presbyterian Hospital (Bk,Bx,M,Q)
25. NYC H +H (Bk,Bx,M,Q)
26. NY Links Upper Manhattan & Lower Manhattan Regional Group (M)
27. Ryan Center (M)
28. Sunset Park Family Health Centers @ NYU Langone (Bk)
29. The Alliance (Bx,M)
30. The Brooklyn Hospital – PATH Center (Bk)
31. The Institute for Family Health (Bk,Bx,M)
32. The Queens ETE Regional Steering Committee (Q)

STAR Project Components

Mapping Stigma Drivers
Integrated data from multiple sources to explore the distribution of HIV-related stigma and potential drivers across neighborhoods/communities in NYC to focus stigma reduction on communities most in need

STAR Consensus Process
Findings reported to STAR Coalition during a final Consensus Meeting and member priorities elicited:
- **Structural interventions** at the community and health care levels that use **media, education, storytelling, and peer health workers**
- Focus on **racism, stigma of living with HIV, and sexual and gender minority stigma**
- Focus on **transgender people, African-Americans, youth, and MSM**
- Focus on **HIV testing, PrEP use, and mental health care seeking**

Stigma Activities Mapping
Mapped activities in HIV organizations to reduce HIV and intersectional stigma and promote resilience, assess evidence, and characterize barriers/facilitators
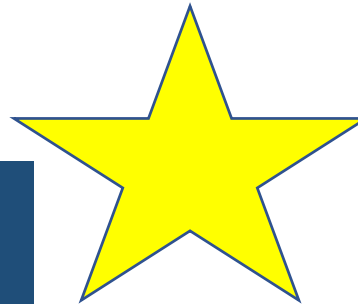
STAR Compendium
Conducted a literature review to identify evidence-based interventions that reduce HIV-related intersectional stigma in healthcare settings in the US

STAR Townhalls
Brought together members of affected communities to learn about their experiences with intersectional stigma and gather their recommendations for reducing stigma in healthcare settings

STAR Project Townhalls with PWH

- Four sessions
  - Townhall Session 1: September 18th (21 people)
  - Townhall Session 2: September 25th (28 people)
  - Focus Group with small sample of prior townhall participants: October 9th (8 people)
  - Spanish Townhall: October 16th (3 people)

Townhall Topics for Discussion

- How does intersectional stigma impact peoples' experiences in healthcare settings?
    - What makes for a positive experience in a healthcare setting?
    - What makes for a negative experience in a healthcare setting?
- What can be done to reduce stigma in the healthcare setting?
    - What has or hasn't worked?

Intersectional Stigma in Healthcare

If the ideal is a white cisgender heterosexual man, the further away you get from that, the more oppressed you are. People live at the intersection of poverty, homophobia, xenophobia. It becomes challenging to say that people are getting stigmatized because of their HIV status – is it because they are trans, is it because they exhibit mental illness symptoms?

Racism and Sexual Identity Expression
In this place where I see LGBT decals, I've been treated as a hoodlum because of how I dress. I am categorized by the way I dress and the color of my skin, and I become invisible to Caucasians. LGBTQ are all different sizes, smell, scents, we all grow and speak differently.. Listen to how I articulate, don't judge me by my appearance.

Aging and HIV
There's a level of anxiety not knowing if health-related issues are because of aging or because of HIV. The health risks associated with HIV create an additional level of anxiety .

Intersectional Stigma in Healthcare

Racism and Substance Use

On the intake form, I checked off black, I checked off that I used drugs in the past, and then I checked off HIV status, so it was 3 for 3! They treated me like I had the plague.

Mental Health and HIV

I was getting help for mental illness, and when I told them I was HIV positive, they put me in the aisles with the addicts. They thought I was using drugs because I had HIV and was having a breakdown.

Immigration status, language barriers, and HIV

When I first got my diagnosis, the doctor told me laughing that if I wanted to learn more about HIV, I should come back when I learn to speak English so he can tell me more about it. Where I'm from, people don't even know what HIV is…I'm still afraid I could be locked up by immigration and my medication would be withheld.

Positive Healthcare Experiences

- When clinics connect clients to support groups or interventions such as Healthy Relationships, the Positive Life Workshop, Harlem United, or Voces Latinas

- When doctors use accessible language and take the time to check in personally, remember details about your life, answer questions and give clear explanations.

They speak in a way that respects peoples' boundaries while recognizing who they are, explain things in terms you can understand. They make you feel human and that you can be what you want to be and it's ok to ask for help.

- Posters and flyers welcoming every group

- Feeling your confidentiality is taken seriously

- Clinic for trans population where even the security staff enforces respect

- Warm greetings and courteous service, being offered water or alerted if there is a delay, like your time is valuable

*People who talk **to** me, as opposed to at me. Like talking with a friend, as opposed to them just simply doing their job.*

Negative Healthcare Experiences

- When there is one clinic for infectious diseases or HIV only, so everyone knows why you are there

One of the biggest stigmas is that people know in their neighborhood which are the HIV clinics – and they think once I start getting care over there, everyone will know.

- When staff make you feel less, by doubling up gloves, whispering behind your back, keeping distant, no eye contact

- Not feeling heard, not feeling human

- Separate staff and client bathrooms

- Being made to wait a long time for appointments

- Having your medical history taken multiple times in one visit

The interns came in first, asking a thousand questions about why you're there, it was traumatizing and frustrating.

Townhall Recommendations: Strategies

- Strategies for reducing HIV-related stigma in healthcare settings
  - Community Advisory Boards
  - Anti-stigma skits and theater groups
  - Inserting anti-stigma ads on YouTube, Facebook or Instagram, especially targeting areas with high HIV prevalence
  - Peer certification program at DOH could include PLWHIV
  - Help people navigate insurance

Recommendations for Provider Training and Accountability

- Teach providers to use person-centered language, conduct trainings on making daily language empathetic, including body language
  - Training should include PLWHIV who tell stories about times they were stigmatized and how it made them feel and help people see their biases

- *There should be a peer-delivered intervention so that providers can learn from the people they serve (mis-gendering/providers not looking them in eye but typing the whole time) - reverse role play to drive the point home – a peer conducting an "exam" of a provider and not looking them in the eye, for example.*

- Beyond training, there should be accountability, including a suggestion box

- *There needs to be accountability – client concerns and satisfaction needs to reach the funders, because until we impact funding, we don't impact the situation.*

STAR Project Consensus Meetings

- STAR Coalition members were presented with findings from STAR projects focused on:
    - Mapping activities in HIV organizations to reduce stigma and promote resilience
    - Exploring the distribution of HIV and potential drivers of stigma across NYC neighborhoods
    - Identifying evidence-based interventions to reduce HIV-related intersectional stigma based on the literature
    - Bringing together members of affected communities to discuss stigma and gather recommendations (townhalls)

STAR Project Consensus Process

- Members voted on:
  - Which interventions would make the strongest contribution to ending the HIV epidemic in NYC?
  - Where are these interventions most needed?
  - Which ones are most likely to work in a real-world setting?
  - Which will likely have the strongest impact on ending the epidemic?
  - Who could best implement these interventions?

Consensus Findings

- Structural interventions at the community and healthcare levels that use media, education, story telling, and peer health workers

"If the community isn't destigmatizing HIV, they will not come into the healthcare setting."

**Where** would interventions have **the most impact**?
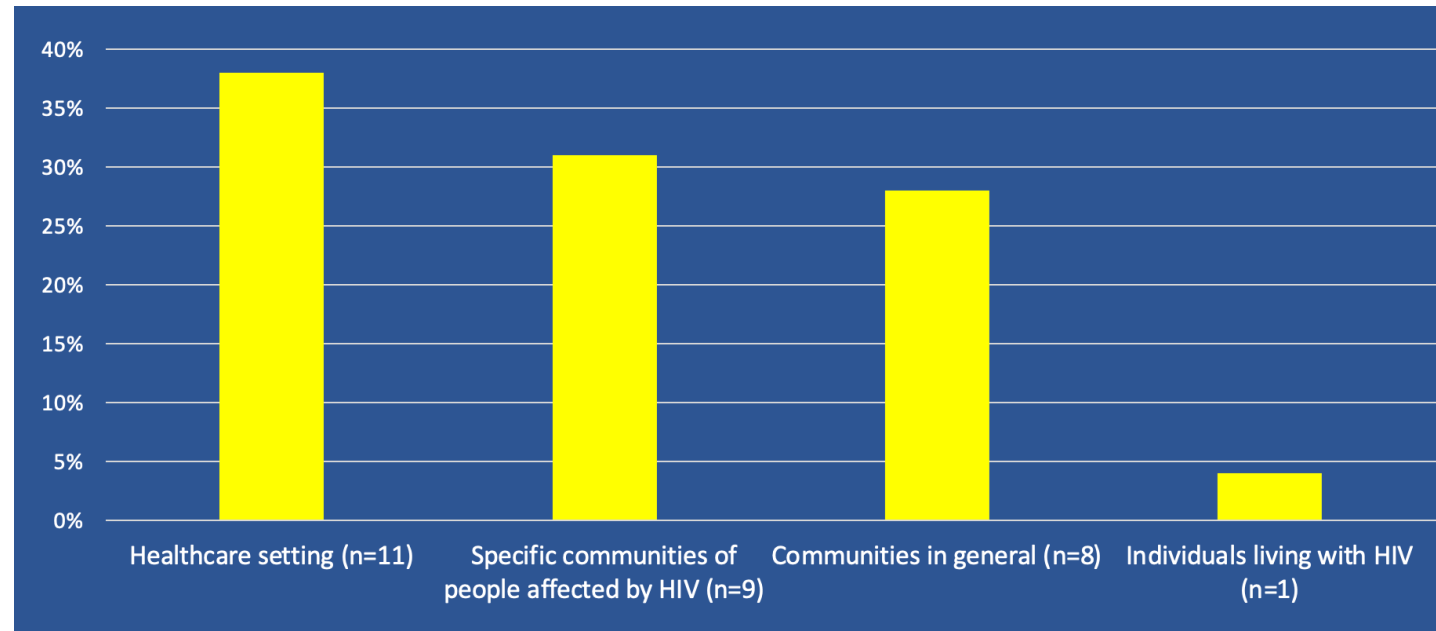
Consensus Findings

- Focus on racism, stigma of living with HIV, and sexual and gender minority stigma

"Many clinics now have rainbow flags in the waiting room and other visible ways to be LGBT inclusive, but there is not much being done about race. It's not being addressed explicitly."

When is it not feasible in an intervention to address different stigmas at the same time, which stigma would be the most important to address to end the HIV epidemic?
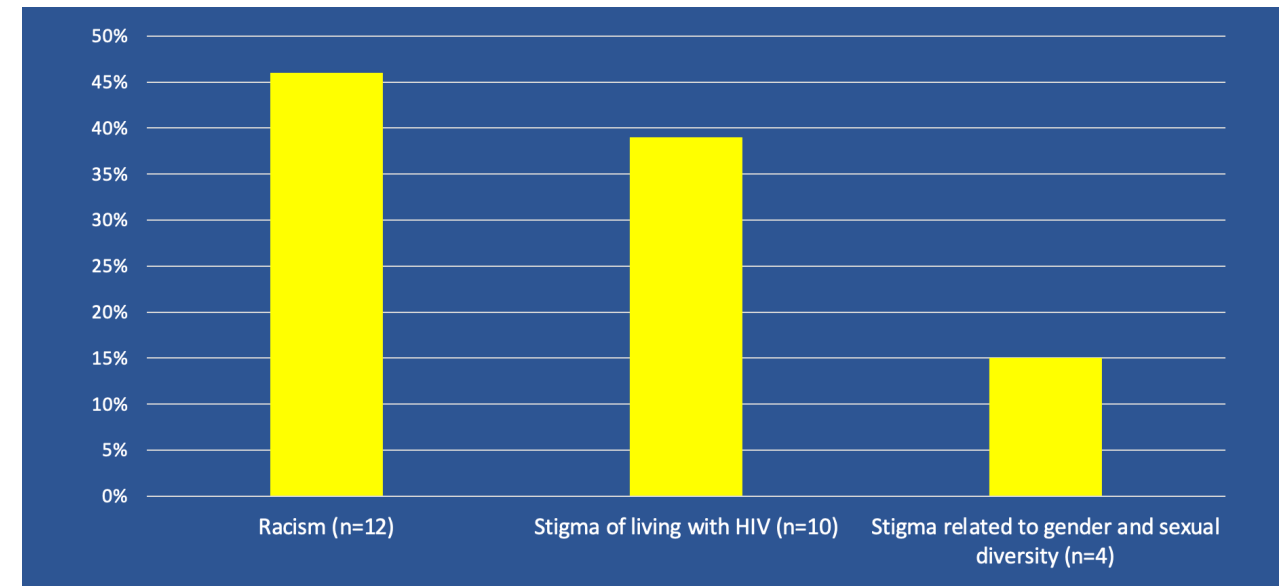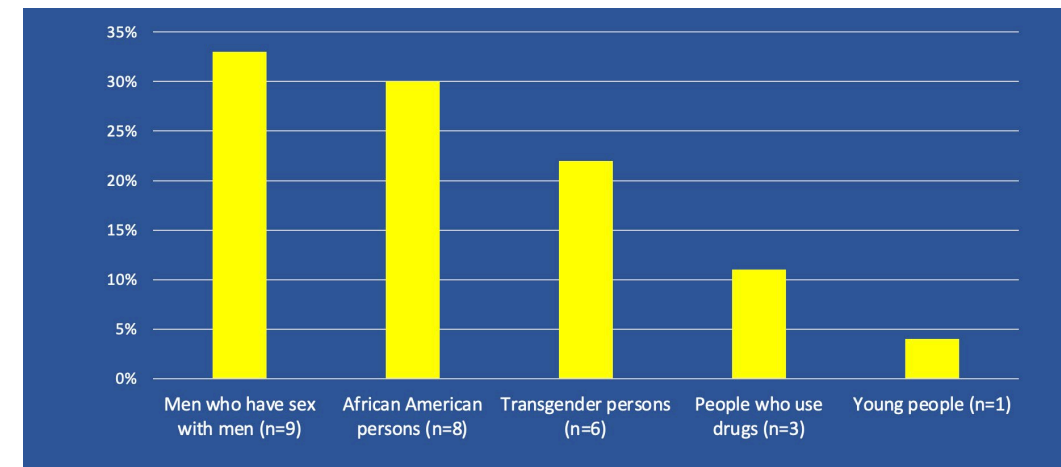
Consensus Findings

- Focus on transgender people, African-Americans, youth, people who use drugs, and MSM

"African Americans are an overarching population that includes men who have sex with men, transgender people, younger people, and people who use drugs. African Americans have experienced stigma throughout their lifetimes in different ways, so it's internalized and anticipated in almost every aspect of their life. If we start there, it will have a ripple down effect in other communities like men who have sex with men, and they would all benefit from this focus."

If an intervention were to address internalized or anticipated stigma and promote resilience among **persons living with HIV**, which population would benefit the most?
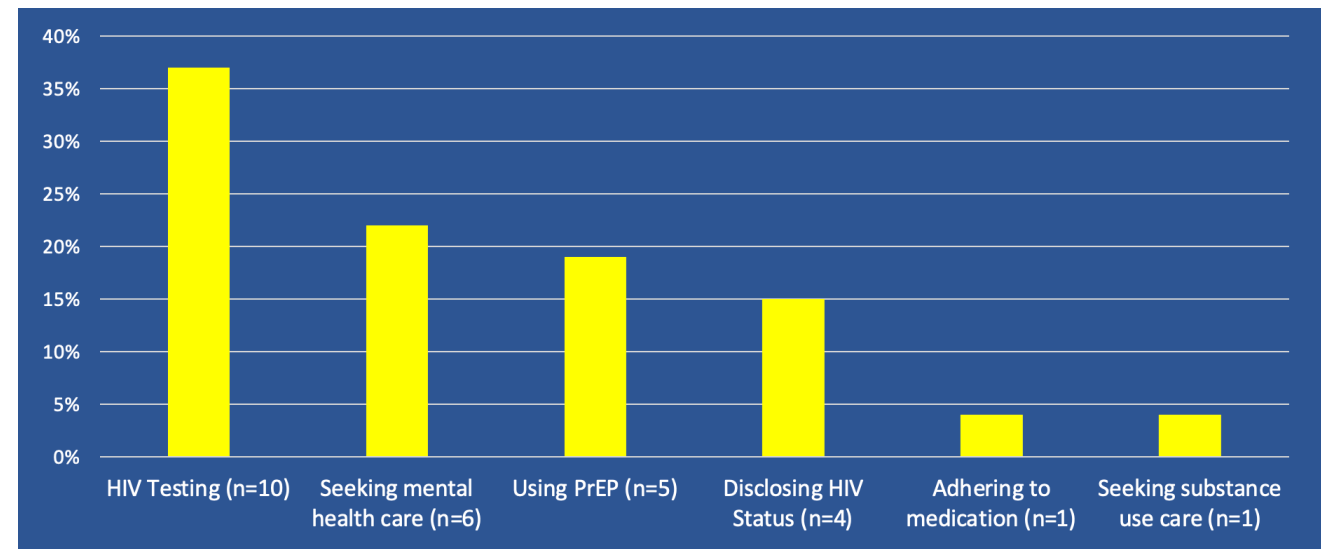
Consensus Findings

- Focus on HIV testing, PrEP use, and mental health care seeking

"The concept is making testing routine and regular as opposed to a stigmatized behavior."

Imagine that the intervention addresses a specific stigmatized behavior. Which behavior would you prioritize as the most important to address?

Recommendations for Interventions

- Media campaigns
  - Similar to PrEP campaigns, broad, upbeat, U=U, showing how you can live a normal life with HIV,
  - City-wide anti-stigma media campaign
  - Prominent women of color encouraging PrEP use and announcing their own PrEP use
  - Partnering with CBOs and ARV pharma to conduct outreach events
- Role-play and storytelling
  - Clients, social workers, doctors, frontline admin staff, nurses, etc. spending a week playing the role of someone else to understand different perspectives
  - Storytelling among young MSM and transwomen with healthcare providers

Recommendations for Interventions

- Structural interventions at community level
  - Address systemic power imbalances such as poverty, equality, housing, economic empowerment
- Education
  - Education, training and support for healthcare teams
  - Workshops in schools, prisons, clinics, places of worship

Recommendations for Interventions

- Peer health workers
  - Peers and the DOH working together to increase client-centeredness
  - Appointing ambassadors and peers to help initiate conversations
- Structural changes at the healthcare level
  - Improve system of healthcare and social services
  - Structural approach across many organizations involving staff, clients, and community
  - Engagement of providers
  - Ongoing evaluation and consumer surveys to inform quality improvement

Considerations

- Stigma doesn't exist in a vacuum, and we don't live single issue lives, so a one size fits all approach will not work

- Addressing intersectional stigmas that people experience will work best by allowing us to find common ground and promote understanding

- Intersectional stigma is at the core of the problem – one stigmatizing event can lead to catastrophe at the individual and community levels

It has to be a joint effort between people who are living with HIV and people who aren't.