

Measuring and Addressing Stigma in Healthcare Settings:

Reducing Stigma in HIV Primary Care



June 6th, 2018

Overview

- Overview of stigma and discrimination
 - What it is, what it looks like, and ways to combat it
- NYS HIV Quality of Care Program Review
 - “Measuring and Addressing Stigma in Healthcare Settings”
- Time for Q&A

To begin...

Cultural Humility

- The approach of cultural humility goes beyond the concept of cultural competence to encourage individuals to *identify their own biases and to acknowledge that those biases must be recognized.*
- Cultural competency implies that one can function with a thorough knowledge of the mores and beliefs of another culture.
- Cultural humility acknowledges that it is impossible to be adequately knowledgeable about cultures other than one's own.

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What is stigma and
discrimination?

Definition of Stigma

- Depends on the convergence of interrelated components

- Consisting of the following elements:

Labeling – *human differences*

Stereotyping – “*undesirable*” characteristics

Separation – “*us*” from “*them*”

Status Loss

Discrimination

Process of Stigma

1. People distinguish and label human differences
2. Dominant cultural beliefs link labeled persons to undesirable characteristics (negative stereotypes)
3. Labeled persons are placed in distinct categories to accomplish some degree of separation of “us” from “them”
4. Labeled persons experience status loss and discrimination

Stigma VS Discrimination

Stigma

- Mark
- In the person
- Recipient of behavior



Discrimination

- Focused on the producers of rejection and exclusion
- Those who do the “discriminating” rather than the recipients of the behaviors

Role of Power in Stigma

**“Stigmatization is entirely contingent on
access to social, economic, and
political power
that allows the identification of
differentness, the construction of
stereotypes,
the separation of labeled persons into
distinct categories,
and the full execution of disapproval,
rejection, exclusion, and discrimination”**

What is HIV-related stigma?

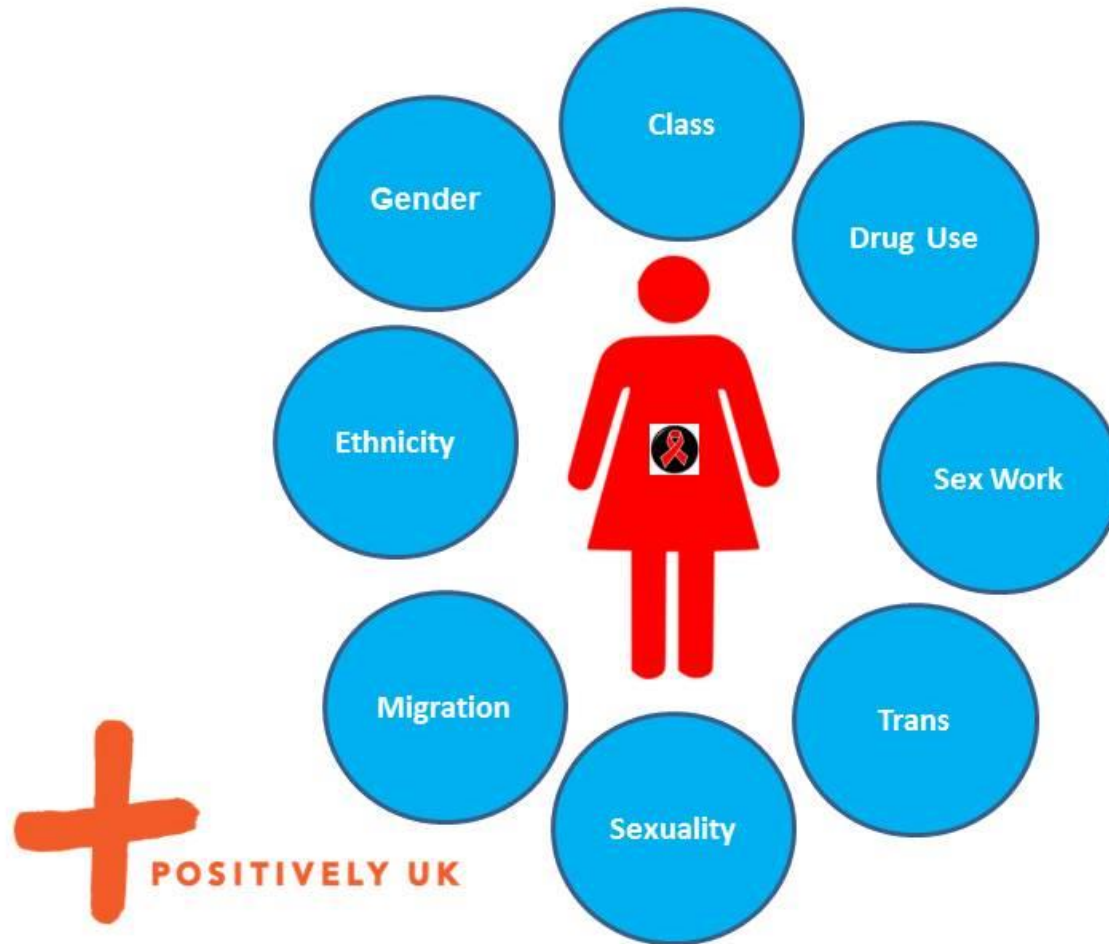
**HIV-related stigma is defined as
“prejudice, discounting,
discrediting, and discrimination
directed at people perceived to
have HIV.”**

Types of Stigma

- **Internalized** stigma (self)
 - “I feel ashamed of having HIV”
- **Anticipated** stigma (fear of)
 - “If I go in for an appointment, healthcare workers will treat me with less respect”
- **Enacted** stigma (discrimination)
 - “At my appointment, my doctor did not touch me without gloves on”

Stigma & Identity

Intersectional Stigma



What does discrimination look like?

- **Physical**
 - Isolation
 - Violence
- **Social**
 - Isolation
 - Loss of identity/role
- **Language/Verbal**
 - Gossip
 - Insults
 - Expressions of blame and shame
 - Labeling and use of derogatory words to describe PLWH
 - Microaggressions
- **Institutional**
 - Differential treatment in health care settings
 - Differential treatment in public spaces
 - Media and public health messages and campaigns

Microaggressions

Brief and commonplace daily verbal, behavioral, or environmental indignities, whether *intentional or unintentional*, that communicate hostile, derogatory, or negative slights and insults toward members of oppressed groups

“He’s really handsome for a trans guy”

“I don’t see color”

“You don’t look like you have HIV at all”

“He’s so hot, but he’s positive”

“You act white”

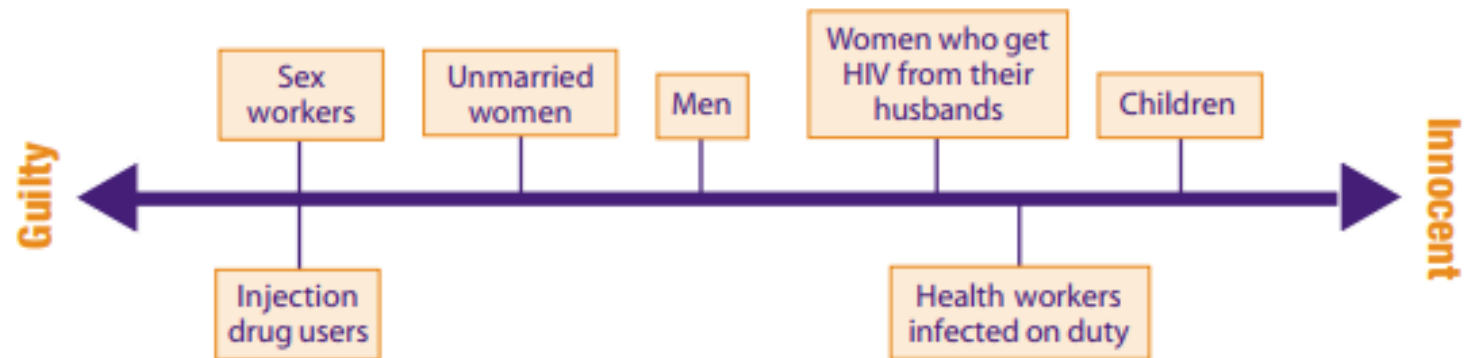
“I’m clean”

“You’re a single mom? But your daughter is so well behaved”

Root Causes of Stigmatizing Behavior

- Knowledge
 - Lack of knowledge on transmission
 - I.e. casual contact, unlikely modes of transmission
 - Doubt
 - Fear-based public messaging
- Morality
 - Divide between “us” (moral/innocent) and “them” (immoral/guilty)
 - Role of gender

Box 3: Schematic of “Innocence-to-Guilt” Continuum



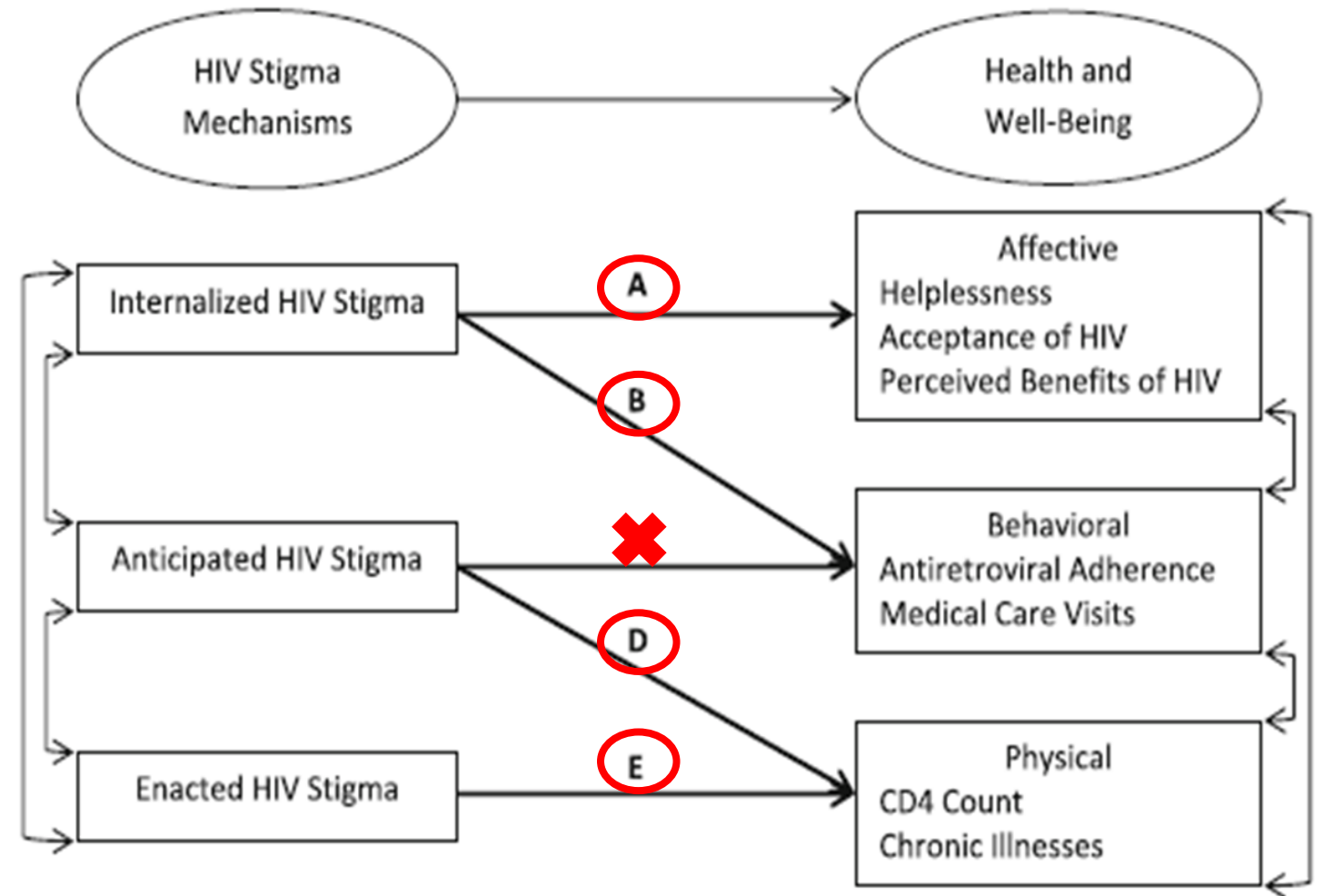
Patient Experience with Stigma in NYS

18

According to the Medical Monitoring Project (MMP), a population-based surveillance system that assesses clinical outcomes and behaviors of PLWH receiving care in the US between 2009-2014, in NYS (excluding NYC) and NYC:

MMP Statement	NYS (excluding NYC) (N=421)	NYC (N=1,577)
<i>Perceived Stigma</i>		
“I hide my HIV status from others”	67%	47%
“It is difficult to tell people about my HIV infection”	74%	58%
<i>Discrimination Experiences</i>		
Reported healthcare providers exhibited hostility or a lack of respect during a healthcare visit	26%	13%
Reported said discrimination occurred because of HIV infection	92%	69%

A framework for the effects of stigma on health



Negative Health Effects of Stigma on PLWH

Stigma Health. 2017 Aug;2(3):216-228. doi: 10.1037/sah0000051. Epub 2016 Aug 8.

Moment-to-moment within-person associations between acts of discrimination and internalized stigma in people living with HIV: An experience sampling study.

Fazeli PL¹, Turan JM², Budhwani H², Smith W², Raper JL³, Mugavero MJ³, Turan B⁴.

AIDS Behav. 2018 Feb;22(2):522-530. doi: 10.1007/s10461-017-2005-1.

Anticipated HIV Stigma and Delays in Regular HIV Testing Behaviors Among Sexually-Active Young Gay, Bisexual, and Other Men Who Have Sex with Men and Transgender Women.

Gamarel KE^{1,2,3}, Nelson KM^{4,5,6}, Stephenson R^{7,8,9}, Santiago Rivera OJ¹⁰, Chiaramonte D¹⁰, Miller RL¹⁰; Adolescent Medicine Trials Network for HIV/AIDS Interventions.

J Acquir Immune Defic Syndr. 2016 Jun 1; 72(2): 198–205.

Published online 2016 May 16. doi: [10.1097/QAI.0000000000000948](https://doi.org/10.1097/QAI.0000000000000948)

PMCID: PMC4868649

NIHMSID: NIHMS756224

Mechanisms for the Negative Effects of Internalized HIV-Related Stigma on Antiretroviral Therapy Adherence in Women: The Mediating Roles of Social Isolation and Depression

Bulent Turan, PhD,[✉] Whitney Smith, MPH,[†] Mardge H. Cohen, MD,[‡] Tracey E. Wilson, PhD,[§] Adaora A. Adimora, MD,^{||} Daniel Merenstein, MD,[¶] Adebola Adedimeji, PhD, MPH, MBA,[#] Eryka L. Wentz,^{**} Antonina G. Foster, NP, MSN, MPH,^{††} Lisa Metsch, PhD,^{‡‡} Phyllis C. Tien, MD,^{§§} Sheri D. Weiser, MD, MPH,^{|||} and Janet M. Turan, PhD, MPH[†]

J Acquir Immune Defic Syndr. 2018 Mar 1;77(3):257-263. doi: 10.1097/QAI.0000000000001590.

Experienced HIV-Related Stigma in Health Care and Community Settings: Mediated Associations With Psychosocial and Health Outcomes.

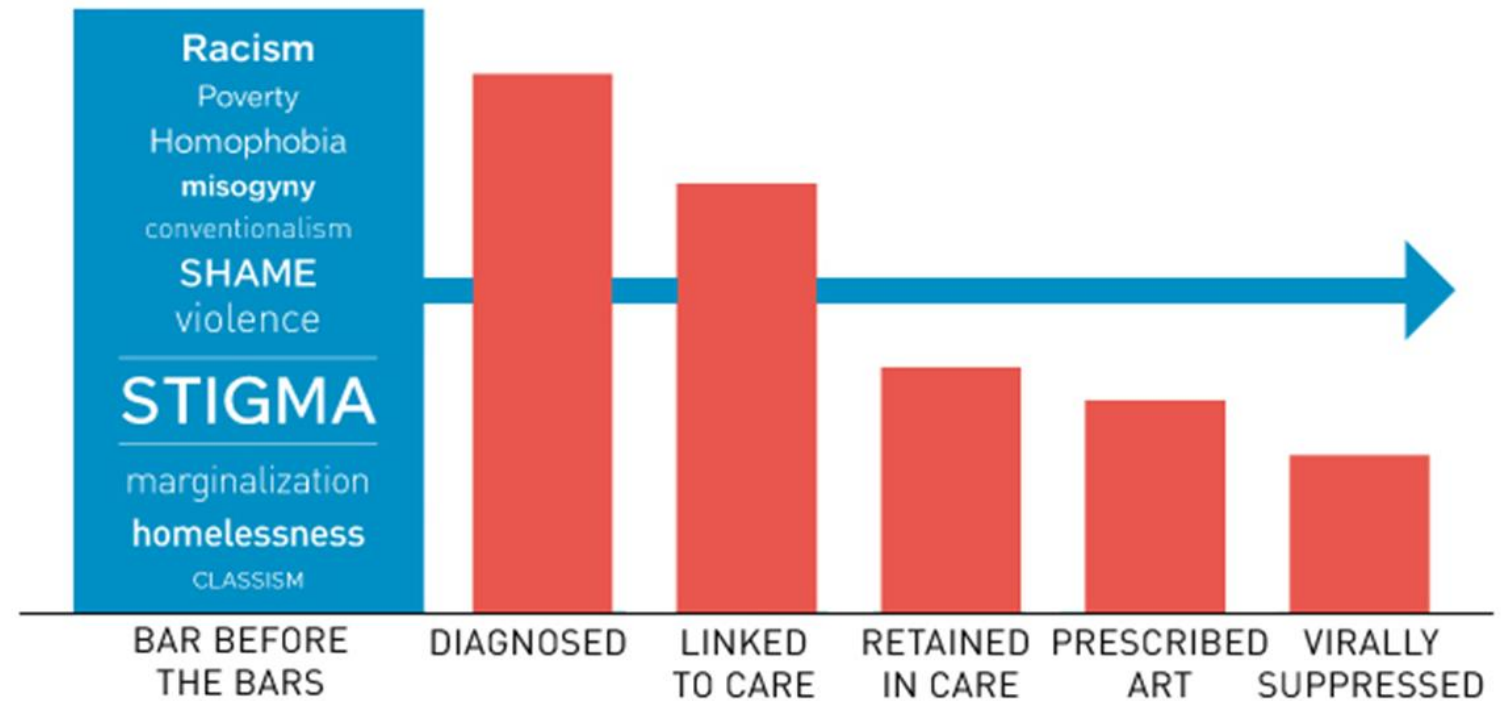
Kay ES¹, Rice WS, Crockett KB, Atkins GC, Batey DS², Turan B.

Prev Med. 2018 Feb;107:36-44. doi: 10.1016/j.ypmed.2017.12.018. Epub 2017 Dec 22.

HIV-related stigma, racial discrimination, and gender discrimination: Pathways to physical and mental health-related quality of life among a national cohort of women living with HIV.

Logie CH¹, Wang Y², Lacombe-Duncan A³, Wagner AC⁴, Kaida A⁵, Conway T⁶, Webster K⁷, de Pokomandy A⁸, Loutfy MR⁹.

Why stigma reduction now?



- Impacts of stigma lead to negative health outcomes
 - PLWH avoid getting care or disclosing status because of fears of discrimination

Principles for Stigma Reduction Programming

Address Immediately Actionable Drivers

Raise awareness
Discuss and challenge the shame and
blame
Address HIV transmission fears and
misconceptions

Create partnerships between affected groups and opinion leaders

“Contact strategies”
Model desirable behaviors
Recognize and reward role models

Affected groups at the center of the response

Develop and strengthen networks
Empower and strengthen capacity
Address self-stigma

Stigma Reduction Examples

**Education, education,
education!**

HIV-Related Stigma in Health Care Settings

Publish date: October 20, 2016

[Adam Thompson](#) (Presenter)

AETC source: [Albany Medical College](#)

PCDC Hosts 'Culturally Responsive Health Care for LGBTQ Communities' Webinar Series

November 15, 2017

Categories: Capacity Building, Other, PCDC News

Treatment Implications of the Triple Threat - HIV, Mental Illness and Substance Use

Monday, November 27, 2017 - 12:30pm to 1:30pm EST (Open Event)

[Southeast AETC](#)

[Florida South AIDS Education and Training Center](#)

Dr. Marisa Echenique, Assistant Professor of Clinical Psychiatry at the University of Miami will be presenting "Treatment Implications of the Triple Threat: HIV, Mental Illness and Substance Use".



Stigma Reduction Examples

Language

Stigmatizing Language ("Try not to use")	Preferred Language ("Use this instead")
HIV infections	HIV transmissions; diagnosed with HIV
HIV infected	Living with HIV; diagnosed with HIV
Became infected	Contracted or acquired; diagnosed with
Serodiscordant couple	Serodifferent, magnetic, mixed-status couple
Mother-to-child transmission	Vertical transmission or perinatal transmission
Victim, innocent victim, sufferer, contaminated, infected	Person living with HIV; survivor; warrior Again, never use the term "infected" when referring to a person

Stigmatizing Language ("Try not to use")	Preferred Language ("Use this instead")
HIV-infected person	Person living with HIV; PLHIV
HIV or AIDS patient, AIDS or HIV carrier Positives or HIVers	Never use "infected" when referring to a person
Died of AIDS, to die of AIDS	Died of AIDS-related illness, AIDS-related complications, end-stage HIV
AIDS virus	HIV (AIDS is a diagnosis, not a virus; it cannot be transmitted)
Full-blown AIDS	There is no medical definition for this phrase; simply use "AIDS," or "Stage 3 HIV"
HIV virus	This is redundant; simply use "HIV"
Zero new infections	Zero new HIV transmissions

'I got HIV from pasta. Said no one ever': Toronto pop-up serves meals made by HIV- positive chefs

Stigma Reduction Examples

One on one interaction
“Contact Strategies”



Stigma Reduction Examples

Welcoming, inclusive
environment

LOOK PAST
PINK AND BLUE

Alisha,
The Bronx

USE THE RESTROOM CONSISTENT
WITH WHO YOU ARE

IN NYC, IT'S THE LAW.
NO QUESTIONS ASKED.

If you face discrimination based on your gender identity and expression, contact the NYC Commission on Human Rights today by calling 311. For more information, visit NYC.gov/HumanRights

NYC Commission on Human Rights
Bill de Blasio, Mayor
Carmelyn P. Malalis, Commissioner/Chair
@NYCCHR
#BeYouNYC

**TREATMENT
CHANGES
EVERYTHING**

Medications transform our lives by making the virus undetectable, keeping us healthy and reducing the risk of infecting someone else.

Treatment helps me reveal my truth
—Joshua, Positive since 2001

HIV STOPS WITH ME.ORG
Call 800-541-AIDS for services near you. New York State Department of Health

WE STAY SURE
DAILY PrEP + CONDOMS

#PLAYSURE

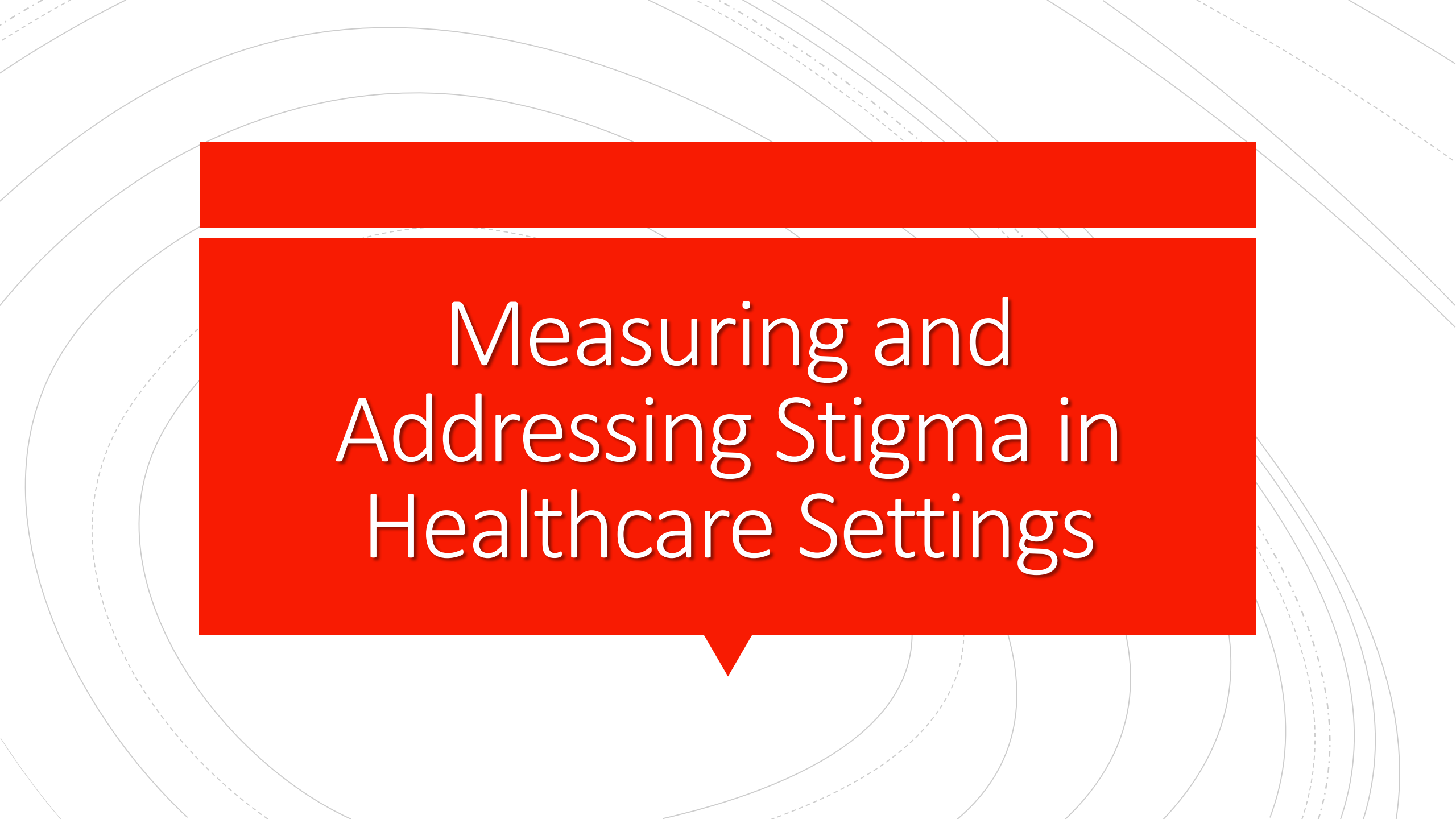
BE SURE, PLAY SURE, STAY SURE.
If you're HIV negative, PrEP is a daily pill that protects you from HIV. Condoms offer additional protection against HIV and other STIs.

STAY SURE: Call 311 or visit nyc.gov/health/staysure to design the right HIV and STI prevention combination for you.

NYC Health Department
Don't Spread HIV

U=U

UNDETECTABLE = UNTRANSMITTABLE

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Measuring and Addressing Stigma in Healthcare Settings

ETE Blueprint

“In response to presenting barriers that may influence a patient's retention and adherence, **quality indicators should be expanded to include stigma and discrimination.** Stigma measures will provide a baseline for providers and health plans to use to **improve a patient's health care experience.**”

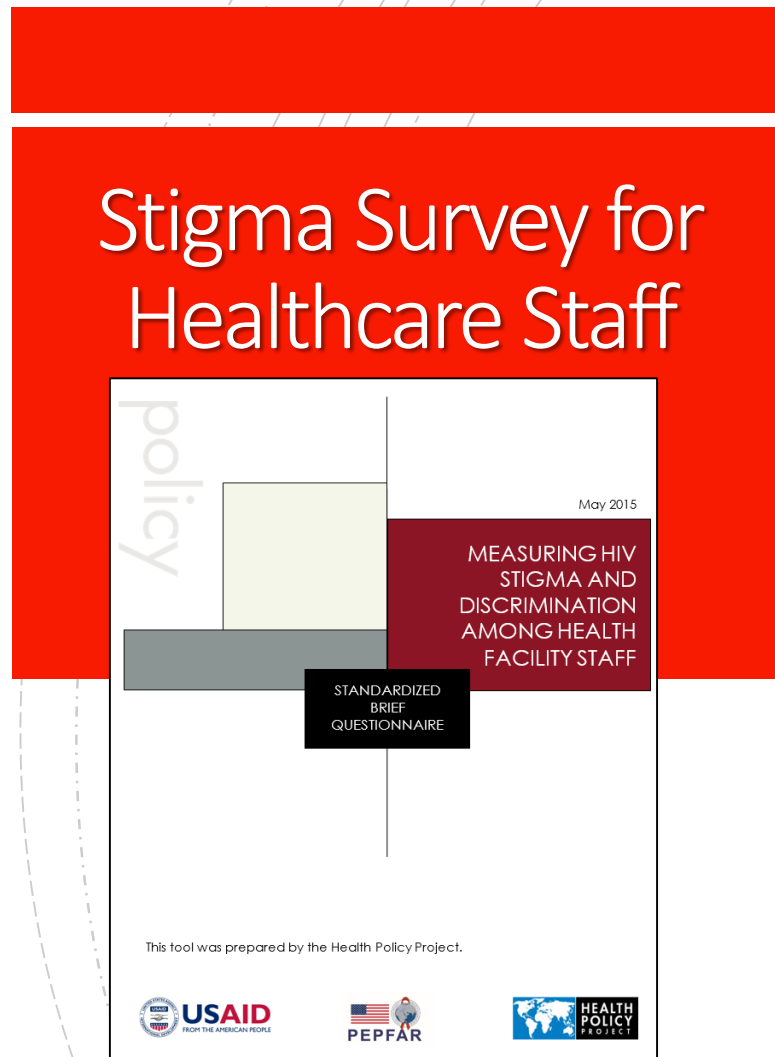
- *BP7: Use client-level data to identify and assist patients lost to care or not virally suppressed*

Stigma Survey Origins

- *June 2015* – Quality of Care Clinical Advisory Committee (QAC)
 - Presentation from Laura Nyblade on work to develop a stigma measurement tool in healthcare settings
- *Early 2016*- Stigma-Subcommittee first convened
 - Consisted of members of the Quality of Care Clinical Advisory Committee (QAC) and members of the Consumer Advisory Committee (CAC)

Health Policy Project's "Measuring HIV Stigma and Discrimination Among Health Facility Staff"

- Background Information
 - Collecting demographics
- Health facility environment and health facility policies
 - Questions on practices and experiences in the health facility
 - Questions on facility policy and work environment
- Opinions about people living with HIV
 - Attitudes and willingness to care
- Questions on key populations (*not found in original tool*)
 - Men Who Identify as Gay or Bisexual, People of Transgender and Gender Non-Conforming Experience, Women, People with a Mental Health Diagnosis, People of Color



**NYS HIV
Quality of
Care Program
Review**

Measuring and Addressing Stigma in Healthcare Settings

Three Components:

- 1. Administer the stigma survey to staff members**
- 2. Solicit feedback from consumers**
- 3. Create a stigma reduction action plan based off of results**

Results

New York City vs New York State

Stigma Staff Survey *Findings/Themes*

In general, survey respondents:

- Have not received training on HIV-related stigma and discrimination
- Did not have knowledge of policy against discrimination of key populations
- Agreed that infection occurs due to irresponsible behavior, and PLWH have had many sexual partners
- Observed people talking badly about:
 - Women
 - People of color
 - **People with a mental health diagnosis**
 - TG/GNC individuals
- Have lack of training:
 - Women's health
 - TG/GNC individuals
 - **People with a mental health diagnosis**
 - People who use drugs

Stigma Staff Survey *NYC vs ROS*

	Hospitals	Health centers	Total
NYC	13	14	27
ROS	13	10	23
Total	26	24	50

In general, survey respondents in NYC more frequently:

- Have a lack of training noted for:
 - Healthcare of TGNC individuals, people with a mental health diagnosis, and gay and bisexual men
- Have a lack of knowledge of policies against discrimination against PLWH and key populations
- Agreed that people get HIV due to irresponsible behavior and agreed that PLWH have had many sexual partners

Consumer Feedback *Findings/Themes*

In general, consumers:

■ In the healthcare setting:

- Have feelings of discomfort in waiting room/front desk area
 - Lack of welcoming environment
 - Staff behavior, intake forms, loud talking
- Experienced stigma in other areas of healthcare center (ER, dental, specialty providers, inpatient units)
- Experienced staff providing extra infection control procedures
- Observed staff talking badly about PLWH, TGNC folks, and people with a mental health diagnosis
- Clinic location and name cause for concern for confidentiality and privacy

■ In the community and personally:

- Experience more stigma in the community than in the healthcare setting
 - Have worries about telling others about HIV status, worries about discrimination, and hide their status from others
 - Lack of knowledge in the community

Consumer Feedback *NYC vs ROS*

	Hospitals	Health centers	Total
NYC	10	14	24
ROS	12	10	22
Total	22	24	46

In general, consumers in NYC more frequently:

- Reported the front desk area being unwelcoming (staff behavior, intake forms, posters/resources)
- Reported staff taking extra infection control procedures (*mainly in hospitals*)

Stigma Reduction Action Plan *Themes*

- Increasing staff education
 - HIV-related stigma and discrimination trainings, key population trainings (TGNC, STI screening for the LGBT population, mental health)
 - Train staff outside of clinics
- Welcoming, inclusive environment
 - Posters and resources for all populations (women, TGNC, PLWH), U=U
- Updating policies
 - Stigma and discrimination, sexual orientation and gender identity (SOGI) use
- Creation of stigma reduction work groups (consumers and staff)
- Creation of support groups for key populations