



Stigma Update

Kelly Hancock
Program Assistant, AIDS Institute



Patient Experience with Stigma in NYS

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%

Internalized HIV-Related Stigma

Almost 8 in 10 HIV patients in the United States report feeling internalized HIV-related stigma.

What is internalized HIV-related stigma?

It is when a person living with HIV experiences negative feelings or thoughts about their HIV status. Here, it is defined as someone agreeing with one or more of the following statements:



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 that being HIV-positive makes them feel dirty or worthless.

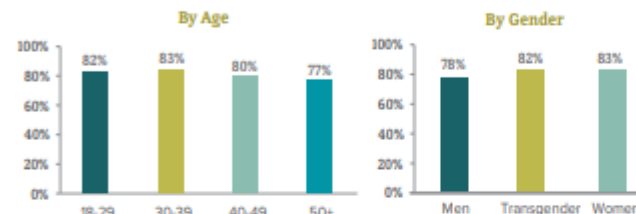
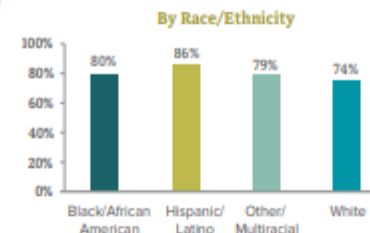


National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
Division of HIV/AIDS Prevention



Which groups are most affected by internalized HIV-related stigma?

Percentage reporting internalized stigma:



Learn more about the Medical Monitoring Project:
www.cdc.gov/hiv/statistics/systems/mmp

SOURCE:
Baugher, AR et al. Prevalence of internalized HIV-related stigma among HIV-infected adults in care, United States, 2011–2013. *AIDS Behav* 2017;21(9):2600–2608.

ADDITIONAL RESOURCES FOR REDUCING STIGMA:

Let's Stop HIV Together Campaign
www.cdc.gov/together

National Prevention Information Network (NPIN)
<https://npin.cdc.gov/search/all/stigma>



How can people living with HIV reduce internalized stigma?



Think about the negative beliefs you may have about yourself. Ask yourself if they are really true.



Find a counselor who can help you deal with any negative thoughts and feelings about your HIV status.



Take HIV medicine as prescribed to keep an undetectable viral load—that means the level of HIV in your body is so low that a test can't detect it. Getting and keeping an undetectable viral load can reduce internalized stigma by keeping you healthy and protecting your partner.



Join support groups and organizations that help people living with HIV. These groups offer a safe environment and can help you overcome the challenges of living with HIV.

Live Well With HIV



Take HIV medicine as prescribed



Stay in HIV care



Share your status



Protect your partners



HIV TREATMENT CAN KEEP YOU HEALTHY AND PROTECT OTHERS

If you are living with HIV, get in care and start treatment as soon as possible. The sooner you start treatment, the more you benefit. Taking HIV medicine as prescribed can make the level of HIV in your blood very low (called *viral suppression*) or even undetectable. Getting and keeping an undetectable viral load is the best thing you can do to stay healthy. Also, if you stay undetectable, you have effectively no risk of transmitting HIV to an HIV-negative partner through sex. Learn more about living with HIV at www.cdc.gov/hiv/treatmentworks.

For More Information

Call 1-800-CDC-INFO (232-4636)
Visit www.cdc.gov/hiv

CDC
Resources

Status of Stigma Activities

At this time:

72 organizations participating in the QoC review have surveyed staff and received feedback from consumers

- *~3,032 staff members surveyed*
- *~2,119 consumers surveyed*

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

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

Stigma Reduction Action Plan *Themes*

- Increasing staff education
 - HIV-related stigma and discrimination trainings, key population trainings (TGNC, STI screening for 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