Measuring and Addressing Stigma in Healthcare Settings
Guidance for Stigma Survey Administration and the Stigma Reduction Action Plan

Introduction

As a part of the 2016 HIV Quality of Care Program Review submission, all sites providing medical care to HIV-positive patients in New York State are expected to complete activities focusing on stigma reduction. This document provides guidance on the various components of the initiative, including:

- Administration of a **survey to healthcare workers** designed to measure levels of HIV-related and key population-related stigma in the healthcare practice site
- Solicitation of **consumer feedback** on stigmatizing experiences in the healthcare practice site
- Development of an **action plan** to address stigma that incorporates consumer input and feedback

The timeline for submission of the different components can be found on page 7 of this document.

This initiative aligns with Governor Andrew Cuomo's Ending the Epidemic (ETE) Blueprint, which states: "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."[1] The central activity of the initiative includes a survey adapted from the Health Policy Project and a consequent action plan based on the findings generated following the survey's administration.

Stigma measurement was first discussed at the HIV Quality of Care Advisory Committee (QAC) meeting in June 2015 when Dr. Laura Nyblade presented her work in the field of stigma reduction in healthcare facilities. In response to this presentation and the goals of the ETE blueprint, a stigma subcommittee composed of representatives of both QAC and the HIV Quality of Care Consumer Advisory Committee (CAC) first convened in early 2016 with the purpose of adapting Nyblade's healthcare facility assessment tool[2] to the context of HIV care in NYS. The HIV Quality of Care Advisory Committee recommended that the survey be integrated into the 2016 Quality of Care Program Review. This guidance was developed based on the recommendations of the Stigma subcommittee, which were supported by both HIV Quality of Care Advisory Committees.

Background

What is HIV-related Stigma?

HIV/AIDS-related stigma is defined as "prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV."[3,4] This definition can be disaggregated into a variety of different types of stigma including:
- *Internalized stigma*: when oneself develops low self-esteem and negative feelings about themselves because of oneself's HIV status[4,5]
- *Anticipated stigma*: when one expects to be discriminated against in the future because of one's HIV status[4,5]
- *Enacted stigma*: when one experiences or has experienced discrimination, stereotyping, and/or prejudice as result of other people's actions[4,5]
- *Intersectional stigma*: when the stigma of being HIV-positive is coupled with stigma related to other personal attributes such as gender, poverty, class, race, geography, migrant status, drug use, mental health diagnosis and sexuality or sexual orientation[6]

This initiative focuses on enacted stigma, specifically stigma experienced in a healthcare setting.

HIV-related Stigma and Health Outcomes

Research has shown that stigmatized groups experience greater disparities in HIV care and health outcomes. For example, social fragmentation, income inequality, and racial composition are all associated with higher rates of late HIV diagnosis.[7] New York City neighborhoods with a high concentration of black residents predict late HIV diagnosis for residents[8] and after HIV diagnosis, on average, black patients take longer to initiate treatment than white patients.[9] People who inject drugs (PWID), have a lower probability of retention in HIV care, ART use, and viral suppression compared to people who do not inject drugs.[10] The experience of discriminatory behaviors can put a person at an increased risk of HIV. For example, the unfair treatment of a person belonging to a stigmatized group, based on perceived differences, can lead a stigmatized individual to engage more frequently in high risk behaviors (substance use, risky sexual practice) as a coping strategy.[11]

The Medical Monitoring Project (MMP) is a population-based surveillance system that assessed clinical outcomes and behaviors of PLWH receiving care in the US between 2009-2014. In NYS, excluding NYC, and NYC substantial stigma related to HIV status is perceived by PLWH, and the majority of healthcare related discrimination experienced is reported to be due to their HIV status:

MMP Statement	NYS (excluding NYC) (N=421)	NYC (N=1,577)
Perceived Stigma		
"I hide my HIV status from others"	67%	47%
"It is difficult to tell people about my HIV infection"	74%	58%
Discrimination Experiences		
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%

Fears of stigmatization and discrimination can dissuade people living with HIV (PLWH) from seeking care and disclosing their HIV status.[12] Unfortunately, some PLWH can report feeling discriminated against by the very people who work in their places of care.[13] A growing body of research is examining the influence of stigma on physical and mental health outcomes in PLWH. Internalized HIV stigma, anticipated HIV stigma, and enacted HIV stigma have each been found to be associated with negative effects on the health and well-being of PLWH, including a greater likelihood of chronic illness comorbidity, longer gaps in medical care and greater likelihood of ART non-adherence.[14,15] This occurs because stigma and discrimination disrupt a patient's access to health resources and social support.[16] The compounding health disparities that PLWH experience are rooted in the multifaceted and intersectional stigmas encountered on a daily basis both in the community and in healthcare settings.

The potential impact of stigma on achieving the goals of the NYS ETE has been identified by both healthcare providers and consumers. Actionable drivers, such as manifestations of stigma at healthcare facilities, can be addressed to improve healthcare systems to reduce stigma. To provide inclusive and accessible quality of care to all PWLH in NYS, the barriers that stigma engenders should be identified, addressed, and broken down. The figure below, adapted from a presentation by Dr. Laura Nyblade, illustrates the relationship of stigma to adverse HIV health outcomes, including testing, linkage and adherence, showing potential pathways that result in gaps in the HIV treatment cascade.[17]
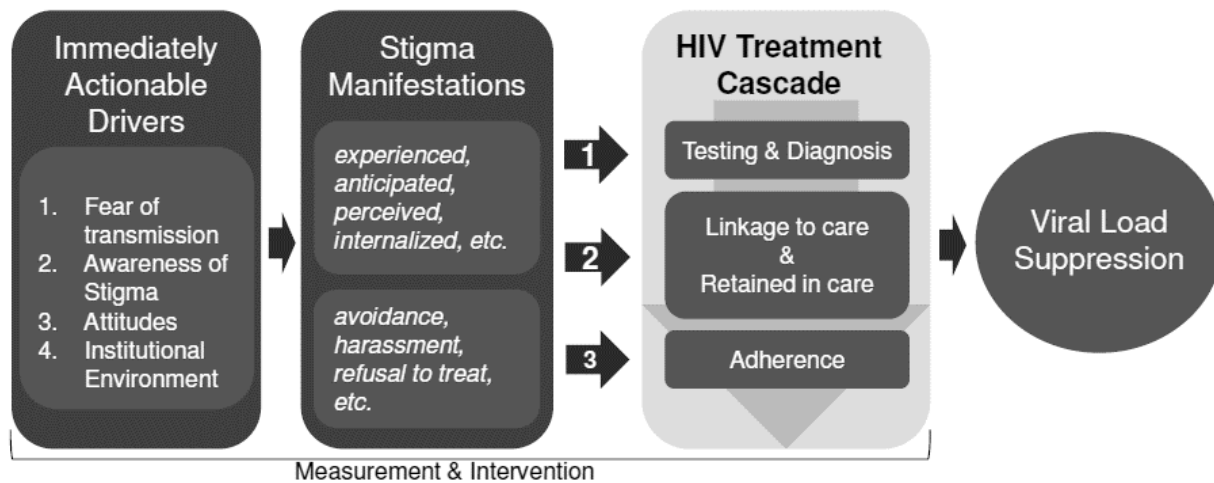
Sources: HIV Treatment Cascade Reference Literature:
1. Testing: (Musheke et al., 2013)
2. Linkage to & Retained in care: (Govindasamy et al., 2012, Alvarez-Uria et al., 2013)
3. Adherence: (Katz et al., 2013)

Stigma Reduction - 2016 HIV Quality of Care Program Review

HIV care practice sites participating in the 2016 HIV Quality of Care Program Review will be expected to complete the survey, solicit feedback from consumers, and develop an action plan based on their findings. The Sub-Committee adapted Health Policy Project's (RTI) "Measuring HIV Stigma and Discrimination Among Health Facility Staff: Comprehensive Questionnaire" for HIV clinics in NYS to administer to healthcare workers.[2] The survey contains questions that address both facility-level and personal-level HIV-related stigma with an additional section containing questions about stigma relating to key populations (regardless of HIV status). The key populations, chosen by members of the HIV Quality of Care Advisory Committees, include:

- **People of transgender/gender non-conforming experience**
- **Women**
- **Men who have sex with men (MSM)/men who identify as gay or bisexual**
- **People of color**
- **People living with a mental health diagnosis.**

To align with the ETE initiatives, the 2016 New York State HIV Quality of Care Program Review has included the adapted stigma assessment as part of the required submission. Addressing the facility environment within the healthcare institution will require careful thought about the pathways patients take within the hospital or clinic, particularly for services not located within the HIV clinic.

Stigma Survey and Stigma Reduction Action Plan

Stigma Survey for Healthcare Workers

Practice sites are expected to administer the survey to healthcare workers with whom a PLWH may interact during their visit to the healthcare practice site. Examples might include clinicians, nurses, people in billing offices or at registration desks, among others. Each practice site has the discretion to determine how the survey will be administered. Ideas for administration include but are not limited to administering a paper survey during a staff meeting or creating a link to an online survey platform. PDF and Word document versions of the survey will be provided to practice sites to use for survey administration. In total, the whole survey is nine pages long and should take less than 20 minutes to complete.

Consumer Feedback

An important component of the assessment of stigma in healthcare settings is eliciting input from consumers. Feedback should be solicited from consumers about stigma experienced at the practice site as well as how consumers can be involved in stigma reduction programming. Programs should underscore in their approach that stigma may be experienced anywhere in the institution, especially outside of the HIV clinic or service areas. Examples of consumer feedback include:

- Interviews with patients to discuss experiences of stigma at the healthcare practice site
- Surveys with open-ended questions to consumers about stigmatizing experiences at their healthcare site (ensuring confidentiality in survey administration)
- Discussions involving patients and case managers that explain stigma and elicit experiences of stigma in the healthcare practice site
- Focus group with patients
- Meeting with the consumer advisory body (CAB) about experiences of stigma

Stigma Reduction Action Plan

After survey administration to healthcare workers, the practice site will then tabulate the results from the survey and discuss the findings with healthcare workers. Survey results should be confidential and no healthcare worker should be punished for their views/beliefs; rather, this should open a discussion about HIV-related and key population-related stigma within the practice site and the subsequent stigma reduction action plan.

Using the results from the survey and consumer feedback, each practice site is expected to develop an action plan that focuses on stigma reduction programming and submit it with their survey results. Important aspects of stigma reduction programming include incorporating feedback from PLWH, creating partnerships between PLWH and healthcare workers, and addressing key drivers of both HIV-related and key population-related stigma.[6] Stigma reduction interventions could focus on different levels of the healthcare site. Examples include:

- Individual Level
    - From the results of the healthcare worker survey, identify a specific area/belief that could lead to stigmatizing actions, and create a plan to raise awareness (e.g. hold meetings with staff and members of the stigmatized populations).
- Environment Level

- o Based on the consumer feedback, identify an area that is identified by patients that makes them feel stigmatized, and create a plan to address this area and remove the barrier to care (e.g. a separate waiting area for people who are receiving HIV-services).
- Policy Level
  - o Identify areas from the consumer feedback that resulted in stigmatizing behaviors (e.g. healthcare workers were overheard speaking badly about PLWH), and develop policies that will discourage this type of behavior.
  - o Identify certain populations that did not receive adequate care, and conduct staff trainings about this population (e.g. people of transgender/gender non-conforming experience) to design strategies to improve the quality of care they receive.

Example: Stigma Reduction Initiatives in New York State

<u>Montefiore AIDS Center</u>

In 2016, leadership of the Montefiore AIDS Center recognized that HIV-positive transgender and gender-nonconforming (TGNC) patients experience significant stigma, preventing them from linking to and being retained in care. A subcommittee of the Montefiore AIDS Center's QI Committee was formed and named the Trans Health Committee (THC). The THC was charged with addressing stigmatizing attitudes and practices and improving cultural sensitivity among staff and in the environment of care at the Center for Positive Living/I.D. (CPL/ID) Clinic, the AIDS Center's outpatient HIV clinic. The THC is also involved with a Montefiore-wide LGBTQ working group, sharing strategies and brainstorming to improve efforts throughout the medical center.

At the THC's first meeting, the group undertook a broad discussion of the issue of stigma and TGNC patients, and reviewed literature on best practices regarding care of this group. The group agreed to focus on TGNC clients, but when appropriate, to extend efforts to LGB clients as well. By April 2017, the THC, with the full support and involvement of Montefiore AIDS Center leadership, had initiated multiple positive changes based on recommendations of six key areas for improvement, including:

1. The physical environment at CPL/ID clinic
   a. Addition of positive and confirming images of TGNC and LGB individuals, a new resource center at the entrance to the clinic, with a prominent section for TGNC- and LGB-related educational, support, and community services, and new icons for TGNC and LGB resources on clinic computers available to consumers
2. Staff training
   a. Staff meeting presented by two members of the TGNC consumer group, and AIDS Center-wide and small group trainings in progress
3. Improving use of TGNC patients' preferred name and pronouns through adjustments to the EMR (Epic)
4. Bathroom signage and access
   a. Designation of certain bathrooms as gender neutral, with new signage as well as signage directing TGNC clients to other similar bathrooms throughout the building and nearby if needed
5. Patient and staff knowledge of access to TGNC-focused community resources and support services
6. Development of a TGNC consumer group to provide input on and assist directly in the initiative

<u>Harlem United</u>

Harlem United is tackling HIV-related stigma in New York City with the help of AIDS United's Positive Organizing Project grant by launching their Peer Empowerment Leaders Program. With this program, they hope to empower their clients to address HIV-related stigma through civic engagement and knowledge. Four Harlem United community members were chosen and trained in advocacy, policy, and activism to become Peer Empowerment Leaders. With this training, the Peer Empowerment Leaders worked specifically with clients in Harlem United's advocacy program to help empower fellow clients to learn and share about policy issues affecting themselves and their communities. A recent example includes a Peer Empowerment Leader facilitating a screening and discussion of the documentary *Gender Revolution: A Journey with Katie Couric* to a group of Harlem United clients. To measure the efficacy of the intervention, Harlem United created their own HIV-stigma index derived from the literature assessing experienced stigma in the healthcare site and the community. It was administered pre- and post-program to the Peer Empowerment leaders and the clients with whom they worked. The goal of this stigma reduction program is to increase self-esteem, agency, and the overall health and well-being of clients by involving them in their own advocacy. Visit www.harlemunited.org to learn more about this ongoing program.

Example: Stigma Reduction Initiative from Literature

An example of a successful stigma reduction initiative from the literature is the *Finding Respect and Ending Stigma around HIV (FRESH) Study* completed by the University of Alabama – Birmingham (UAB) to address HIV-related stigma in healthcare settings in the southeastern United States. Although this is a formal investigation of measuring stigma and stigma reduction programming, it provides examples and insights that can be used when thinking of stigma reduction programming. The FRESH study used an adapted version of the Health Policy Project questionnaire and administered it to various health care organizations throughout Alabama and Mississippi. The results from the questionnaire administered by UAB revealed that many health care workers still held significant negative beliefs and opinions about patients who were living with HIV. Using the results from the questionnaire and the principles for stigma reduction programming, the researchers at UAB created the FRESH workshop intervention. The intervention consisted of intensive, multi-day workshops with consumers and healthcare workers. The participants were led through topics such as understanding how stigma works, the outcomes of stigma, why stigma is hard to change, and stigma reduction strategies. The FRESH intervention was found to reduce consumer scores on negative self-image, disclosure concerns, and enacted stigma as well as increase empathy scores for healthcare providers.[18] Visit http://alphtc.org/fresh to learn more and access resources from this initiative. Resources include the surveys used during the FRESH Study and a facilitators' manuals for stigma reduction programming.

Resources for Assistance

To assist practice sites in thinking about stigma in healthcare settings and in how to implement stigma reduction programming, a stigma "toolkit" will be made available. The "toolkit" is divided into types of resources: general HIV-related stigma, key population stigma, stigma reduction programming ideas, stigma reduction examples from successful programs, and consumer resources. "Toolkit" resources will be sent in future correspondence or can be requested from qocreviews@health.ny.gov. In addition to the "toolkit" resources, there will be periodic webinars with leaders in the HIV-related stigma field to share their knowledge and experience.

Timeline for Component Submission

All submissions should be sent to qocreviews@health.ny.gov. HIV Quality of Care Program coaches and staff will review plans throughout the process and provide feedback.

FIRST SUBMISSION - By July 31, 2017:
- Return a detailed plan of how the stigma survey will be administered to healthcare workers and how feedback will be solicited from consumers, including:
    1. Stigma Survey Planning
        - A detailed plan of how the survey will be administered to healthcare workers
            - To whom the survey will be administered
            - How the survey will be administered (paper, online, staff meeting, etc.)
        - Initial plan of how results with be aggregated and analyzed
    2. Consumer Feedback Planning
        - A detailed plan of how consumer feedback will be solicited
            - How information will be collected and reported (qualitatively or quantitatively)
    3. If there is a specific contact person working on the stigma survey
- *Please note that survey results and consumer feedback are not expected in this phase of submission*

SECOND SUBMISSION - By October 31, 2017:
- Return a summary of the survey methodology and results and a stigma reduction action plan, including:
    1. Stigma Survey Results
        - A summary of the survey methodology
            - How it was administered
            - To which healthcare workers the survey was given
        - Aggregate practice site survey results (with aggregate demographics data, if applicable)
        - Key findings from the survey data
    2. Consumer Feedback Results
        - A summary of the consumer feedback methodology
        - How it was solicited
        - How many consumers were consulted
        - Results from consumer feedback and key findings
    3. Stigma Reduction Action Plan
        - How stigma reduction will be addressed/how programming will be implemented
        - How consumers will be involved in stigma reduction practices

THIRD SUBMISSION - By January 31, 2018:
- Return a summary of the stigma reduction action plan project, including:
    1. Overview of stigma reduction action plan
        - What stigma reduction programming was implemented at the healthcare practice site
        - How consumers were involved in the stigma reduction programming
        - How the stigma reduction programming was received by healthcare workers and consumers
        - What changes will be made to the stigma reduction programming for future quality improvement/how stigma reduction will be incorporated into future work

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