

***Report: Recommendations from the Third Annual HIV Quality of Care Joint Clinical and Consumer Advisory Committee Meeting***

*New York State Department of Health AIDS Institute, Office of the Medical Director*

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This report describes key discussions and recommendations from the third annual joint meeting of the New York State HIV Quality of Care Clinical and Consumer Advisory Committees. The meeting focused on three topics: Addressing Open Patients Through Quality Improvement, Measuring Patient Experience, and Drug User Health.

### **Key Recommendations:**

#### Addressing Open Patients Through Quality Improvement

- Encourage collaboration within and among healthcare organizations to identify and ascertain the care status of open patients.
- Encourage collaboration between healthcare organizations and pharmacies, community-based organizations, and insurance providers to help identify and ascertain the care status of open patients.
- Incentivize identifying and ascertaining the care status of open patients.
- Ascertain the care status of open patients in real-time while the patient is receiving care from an organization.
- Tailor engagement strategies to the needs of subpopulations.
- Encourage the use of peers to (re)engage open, non-active patients in ongoing HIV care.
- Make better use of electronic medical records (EMRs) and other patient databases to identify and ascertain the care status of open patients.
- Improve understanding of the benefits of Regional Health Information Organizations (RHIOs), among providers and consumers.
- Align New York City and New York State expectations and databases.

#### Drug User Health

- Develop, implement, and assess quality measures for the care of people who use drugs.
- Improve access to medical services for people who use drugs, particularly mental health treatment.
- Improve documentation of, and follow-up on, referrals to mental health and drug treatment facilities and other specialty services for people who use drugs.
- Improve documentation of substance use in routine HIV clinical visits and build trusting relationships between patients and providers to address substance use.
- Continue to address stigma in the healthcare setting.
- Incorporate harm reduction principles into clinical settings, and provide training on harm reduction and pain management for clinicians.
- Include people with experience on the spectrum of drug use in conversations about quality of care.
- Gather information on the quality of care for people who use drugs from other NYS offices, including the Office of Alcoholism and Substance Abuse Services (OASAS).

#### Measuring Patient Experience

- Begin to routinely utilize PREMs, as opposed to satisfaction surveys, for QI work.
- Collect PREMs at the site-level at least annually.
- Share QI projects informed by PREMs with patients.
- Ensure PREMs are accessible for all patients.
- Include consumers in the development and review of PREMs and PREMs data at a state- and site-level.

## **Introduction**

The New York State Department of Health (NYSDOH) AIDS Institute Office of the Medical Director convened the third annual joint meeting of the HIV Quality of Care Clinical and Consumer Advisory Committees on Thursday, December 14, 2017. The meeting was attended by 33 QAC members and 27 CAC members. The meeting was focused on three topics: Addressing Open Patients Through Quality Improvement, Drug User Health, and Measuring Patient Experience. Committee members spent the majority of the day discussing these topics in small breakout groups.

Lyn Stevens, acting director of the Office of the Medical Director, provided opening remarks. She discussed initiatives that have resulted from previous joint meetings, as well as successes of the past year, including the Organizational HIV Treatment Cascades and Measuring and Addressing Stigma in Healthcare Settings. In the future, the AIDS Institute will identify best practices for tobacco cessation.

She noted the absence for the first time of Dr. Bruce Agins from these meetings, and reminded the audience of his consistent enjoinders to seek every opportunity to improve the quality of care provided to patients, and how the Quality Advisory Committee and Consumer Advisory Committee have built and expanded the conception of quality in NYS.

Johanne Morne, Director of the AIDS Institute, also gave remarks on statewide progress. At the Ending the Epidemic Summit in December 2017, data were released that demonstrated improvements in both New York City (NYC) and New York State (NYS). While new diagnoses of HIV fell in 2016 to below 3,000 for the first time, disparities remain in the diagnosis and treatment for women of color, MSM, and young persons. In 2018, in addition to an emphasis on continuing quality initiatives, including stigma and tobacco, priorities will include:

- Increasing services to American Indians/Alaska Natives
- Recognizing educational awareness initiatives specific to Asians and Pacific Islanders
- Improving data efficiency and ensuring that data are reflective of all communities served, including transgender individuals

Johanne Morne concluded by emphasizing that New York State will not end the epidemic if any population is left behind, and that the joint meeting has the potential to help ensure that every population receives the highest quality of care.

Allan Clear, Director of the Office of Drug User Health, gave the plenary presentation. He started by introducing the Office of Drug User Health, which was created last year to bring together the disparate drug user health initiatives that the AIDS Institute supports, including syringe exchange, the Opioid Overdose Prevention Program, Drug User Health Hubs, and programs to expand access to buprenorphine. The Office of Drug User Health does not oversee New York State-funded healthcare at methadone clinics or hepatitis C programs.

Clear then discussed the importance of (1) examining how we approach drugs and people who use drugs in general and (2) incorporating drug user voices and expertise into drug use programs. He also emphasized that, when considering drug user health, it is useful to look beyond specific drug-related issues, such as overdoses or a rise in crack cocaine usage, and look more broadly at how we approach drugs and people who use drugs. He emphasized that there is a spectrum of drug usage, from non-problematic to problematic usage.

In addition, Clear argued that drug users had critical expertise that should be drawn upon to develop interventions to improve drug user health. He noted that, often, the expertise of drug users has not been sought due to negative perceptions of drugs and of people who use drugs. He underscored this unfortunate neglect because, historically, the most successful interventions have been those that were implemented in collaboration with those who use drugs. For example, syringe exchange programs were spearheaded by people who injected drugs. Similarly, people who inject drugs have been critical to the success of naloxone programs. They are often the ones on the scene of overdoses, and many have already saved the lives of others in their community by using naloxone.

## ***Addressing Open Patients Through Quality Improvement***

As part of New York State’s annual HIV Quality of Care Program Review in 2017, HIV ambulatory care organizations submitted Organizational HIV Treatment Cascades, which included counts of “open, non-active patients” or “patients of unknown disposition;” that is, of people living with HIV (PLWH) who had received some services from a healthcare organization, but who did not receive HIV care from that organization, and were not confirmed to be in HIV care elsewhere, incarcerated, or deceased. Nearly 24,000 open, non-active patients were reported by the 97 organizations in the 2017 review, with organizations reporting anywhere between 0 and 4,288 open patients.

The 2017 Organizational HIV Treatment Cascades confirmed that many PLWH are touching the healthcare system outside of HIV programs, including at emergency departments, dental clinics, and as inpatients. A clear opportunity exists to (re)engage these individuals in HIV care whenever they touch the healthcare system. The joint meeting served as a forum for providers and consumers to brainstorm how to identify open patients and (re)engage them in care.

Meeting participants were asked to share challenges faced and successful strategies for identifying and ascertaining the care status of open patients. They were also asked to consider how HIV providers can successfully engage emergency departments, inpatient units, substance use, and behavioral health programs in identifying and ascertaining the care status of open patients. Finally, they considered the role of consumers in addressing open patients.

### *Current strategies and challenges*

Organizations are using a variety of strategies to ascertain care status, including making modifications to EMR systems; querying databases, such as the NYS HIV/AIDS Provider Portal, the NYC Care Status Reports system, and prison databases; and sending care coordinators or HIV clinic staff to visit PLWH who are patients in the ED. Some participants reported contacting social workers at insurance companies for updated contact information for open patients. Others used the Prescription Monitoring Database to find patients who also use Schedule II, III, or IV controlled substances.

Providers cited multiple challenges to identifying and ascertaining the care status of open patients. Many organizations lack standard practices to identify and ascertain the care status of open patients. Asking patients with HIV if they are in care for HIV, regardless of their presenting complaint, is often not standard practice across an organization. Providers also noted a lack of coordination among various care providers, as well the fact that ascertaining the care status of open patients is often not a priority outside of HIV programs.

In addition, various technical challenges relating to EMRs, including a lack of standardized data fields and the presence of multiple EMRs systems within one organization that do not interface well, limit the data that is readily available to providers. The technical challenges can mean that, even when HIV care status is ascertained by providers, an organization may lack a standardized way to record and retrieve this information. Resource limitations – particularly on staff time of HCW from the HIV program – were also identified as a significant barrier to identifying and ascertaining the care status of open patients receiving services outside of their programs but within their organizations.

Challenges related to communication with patients about care status were also reported by providers and consumers. When patients are asked, some choose not to disclose their HIV status to healthcare providers for a range of reasons, including denial and stigma. Providers reported significant challenges to contacting patients to ascertain care status days or weeks after a non-HIV-related encounter. Contact information may quickly become outdated, particularly for those who move frequently and those whose phones may be out of service depending on the time of the month. Meeting participants thought phone calls to ascertain HIV care status could be problematic. Some participants expressed skepticism that phone calls have a sufficient likelihood of success to warrant the time and resources involved, since privacy laws limit the ability of organizations to leave voicemails or messages with other individuals with sufficient detail to trigger the patient to contact them. Others thought phone messages risked alienating patients and raised privacy concerns.

### *Regional Health Information Organizations*

Participants repeatedly mentioned the potential of Regional Health Information Organizations (RHIOs), as well as the current limitations of the RHIOs and the Statewide Health Information Network for New York (SHIN-NY) to identify and ascertain the care status of open patients. There is a need for greater education, for both consumers and providers, on RHIOs. Many organizations are not enrolled in RHIOs, and even when organizations are enrolled, many providers do not know how to use them to help identify open patients. Some participants reported finding RHIOs to be of limited utility to identify open patients due to the currently insufficient levels of patient consent and organizational participation.

Many patients do not know about the RHIOs and do not have adequate information to consent to participation. Participants noted that to increase affirmative patient consent to RHIOs, there needed to be trust that private patient information would be shared securely and conscientiously. Noting that some EMR systems shared large amounts of health information somewhat indiscriminately (e.g., providing a podiatrist with the complete sexual and drug use history of a patient), some participants expressed concern and skepticism that RHIOs would adequately protect patient privacy.

### *Recommendations for providers*

- Ascertain the care status of open patients in real-time as the patient is receiving care from an organization. Whenever PLWH receive services from any part of a healthcare organization, they should be asked whether they are in ongoing care.
- Tailor engagement strategies to the needs of various subpopulations, including those with comorbidities. For example, younger people may respond better to messages inquiring about their care status via text or messaging via Facebook or other social media platforms.
- Ask patients to provide a back-up contact, whom healthcare organizations would be authorized to contact if the patient cannot be reached.
- Encourage and pursue greater coordination within and among healthcare organizations, and between healthcare organizations and pharmacies, community-based organizations, and insurance providers to help identify and ascertain the care status of open patients.
- Encourage the use of peers to (re)engage open, non-active patients in ongoing HIV care.
- Make better use of electronic medical records and other patient databases to identify and ascertain the care status of open patients.

### *Policy Recommendations*

- Incentivize identifying and ascertaining the care status of open patients.
- Improve understanding of RHIOs and the SHIN-NY among providers and consumers.
- Align New York City and New York State expectations and patient databases.

### *Outstanding questions*

Substantive discussion of how HIV providers can successfully engage emergency departments, inpatient units, substance use, and behavioral health programs in identifying and ascertaining the care status of open patients did not occur. While participants recommended greater cooperation within organizations, specific recommendations for how to engage each of these departments and programs, which tend to have large numbers of open patients, were not produced.

### *Action Steps*

1. Compile examples of what organizations have done to successfully identify and ascertain the care status of open patients and share with providers across NYS, with a particular focus on productive collaborations between departments and among providers.
  - Use QAC meetings as a forum to disseminate these examples.

2. Consider how the AIDS Institute can encourage an expanded use of peers to reengage non-active patients, such as offering specific peer certification coursework on addressing open patients.
  - QAC and CAC members should encourage PLWH to pursue AIDS Institute peer certification.
3. Develop and provide educational resources on RHIOS and the SHIN-NY, tailored to both providers and consumers.
4. Begin conversations to align NYS and NYC expectations with regard to open patients, and augment data sharing.
5. Return, in future QAC meetings, to the question of how HIV providers can successfully engage with emergency departments, inpatient units, and substance use and behavioral health programs to identify and ascertain the care status of open patients.

## ***Drug User Health***

While NYS and the AI continue to support innovative ways of caring for the health of people who use drugs, this population has historically been overlooked and excluded from conversations about quality health care. In light of the current opioid crisis, a rigorous review of the quality of care for people who use drugs, as well as new programs to continually improve the quality of primary and substance use care, is necessary. How to achieve these goals and implement changes in the absence of dedicated funding remains a major challenge.

Much of the committees' discussion centered on bringing people with lived experience of drug use to the table, considering the plenary presentation highlighting the exclusion of people who use drugs from conversations about their own health and the AI's commitment to include consumers in quality improvement. Participants agreed that one approach to care does not work for all people who use drugs.

Healthcare services should have standard quality measures across the board, but should also address the specific needs of clients on the spectrum of drug use. As of now, a robust set of data measures has not been developed for people who use drugs, which hinders quality improvement. However, the group did not reach consensus on whether a small-scale, site-level approach or a systems-level, statewide approach would be more effective and appropriate in the development of quality measures and in engaging in quality improvement for the care of drug users.

Conversation on which organizations should be measured generated several suggestions of the types of facilities that could be incorporated into the quality management program: OASAS-funded organizations, community-based organizations, substance use residential programs, "detox" programs, and other drug treatment programs. At present, substance abuse treatment programs (such as methadone clinics) with HIV care services supported by NYS submit data to eHIVQUAL. Although OASAS-funded organizations perform HIV and HCV testing and link individuals to primary care, committee members suggested beginning a quality review of OASAS-funded healthcare organizations and CBOs, which would benefit all people who receive care there.

## ***Stigma***

Stigma was overwhelmingly one of the most discussed themes at the meeting. Both providers and consumers underscored the fact that stigma – both internalized and experienced – keeps people who use or have used drugs from accessing care and from being transparent with providers about their drug use. Conversations focused on how providers can best open the door to conversations about drug use with patients. It was noted that, within the HIV community, people who use drugs are among the most stigmatized, but that stigma toward people who use drugs is more prevalent outside of HIV settings. It was emphasized that current and former drug users should feel comfortable with providers regardless of type or frequency of drug use. Members of both committees discussed instances in which a person under the influence of a substance is denied care in a medical setting. Providers should develop skills to manage disruptive patients and ensure that patients who are under the influence receive necessary care.

The group noted that current language used with relation to drug use can be stigmatizing for people with experience using drugs, including words like "addiction" and "abuse." Removing the term "addiction" is not feasible within medical settings because of its diagnostic specificity and relationship to interventions, compared to the broader "substance use disorder." Furthermore, there are formal clinical distinctions between levels of drug use and differing treatment modalities for people who occasionally use drugs, who have a dependency on drugs, and those who are addicted. However, consistent with policies promoted by the AI, using person-centered language (such as "a person with addiction disorder," as opposed to the stigmatizing "addict") offers an important strategy to use language that de-stigmatizes substance use disorders and is more patient-friendly. It was also recommended that clinical providers, in addition to other primary care staff, law enforcement, and community members who work with people with substance use disorders receive sensitivity training. Additionally, it was recommended that people with lived experience using drugs could be offered empowerment training.

## *Mental Health*

As substance use disorders and mental health disorders are often co-occurring, the quality of mental health services for people who use drugs was discussed. Both consumers and providers brought up the desire for an integrated “one stop shop” model for care for substance use and mental health (and perhaps also HIV primary care). While mental health services are sometimes offered at drug treatment centers, drug treatment is rarely offered within mental health treatment centers. The treatment of mental health disorders along with substance use disorders should be considered a quality issue.

Referrals for other services for substance use disorder treatment were brought up as a way to measure the quality of care for people who use drugs. However, it was cautioned that “passive referrals,” or those made without any documentation of follow-up from the provider (and consumer) are not a helpful measure of quality. However, follow-up or engagement in care could be quality measures.

## *Consumer engagement*

Robust examples of consumer involvement, particularly involvement in quality management teams or CABs, do not exist for people who use drugs the same as they do for consumers of HIV health services. It was widely agreed that people who use or have used drugs – within and outside of HIV health care– should be meaningfully included on advisory bodies, in quality management programs, and as peer educators. It was suggested that substance abuse treatment programs and Drug User Health Hubs be required to have CABs as part of their quality program (as HIV programs are required). Furthermore, CABs should not only be composed of former users, but of people on the spectrum of use and of substance use disorders, to be fully representative of lived experiences.

## *Measurement*

Several recommendations of potential quality measurement items were made.

- Appropriate treatment of actively using or currently intoxicated patients
- Follow up on referrals to services (to drug treatment, mental health, specialty, etc.)
- Appointment availability
- Accessibility of medication – i.e., buprenorphine or naloxone
- Linkage to mental health services
- Linkage to drug treatment programs
- Retention in care for active users

## *Recommendations for Providers*

- Providers should routinely ask patients about their **history of substance use**. Some consumers brought up the possibility of patients not feeling comfortable disclosing their substance use to providers, and recommended instead the use of surveys or disclosure to peers or drug counselors. However, these recommendations do not lessen the importance of providing stigma-free care and development of a trusting relationship between providers and consumers.
- Providers should receive training to **incorporate harm reduction principles** in the clinical setting to “meet all patients where they are” and provide the most appropriate health care. Additionally, considering the current opioid epidemic, providers should be trained in **pain management** but also understand the challenges of living with chronic pain – particularly when choosing to label a patient as “drug-seeking.”
- **Expanding access to buprenorphine** was a topic of discussion. Participants felt that more providers, especially HIV providers, should be trained and waived to prescribe buprenorphine, and that more people would begin buprenorphine treatment if a provider whom they already know is eligible to prescribe.



- **Referrals** made by HIV primary care physicians outside of the facility – such as to drug treatment facilities, mental health services, or a buprenorphine provider – should be documented, as should the follow-up.

### *Key Recommendations*

- Quality measures for this population should be developed, implemented, and assessed. Measurement categories include access to treatment and medication, referrals, linkage, and retention to specialty services.
- Quality of care for people who use drugs can begin to be measured in HIV primary care organizations under the purview of the AI, including Drug User Health Hubs, but it was recommended that quality improvement also take place in OASAS-funded sites.
- Access to medical services for people who use drugs should be prioritized and expanded. It was recommended that mental health treatment be incorporated into treatment for substance use disorders, and indeed into HIV primary care treatment when possible.
- Stigma should continue to be addressed in the healthcare setting for former and active substance users.
- People who have experience on the spectrum of substance use – former users to current users, regardless of substance – should be involved in conversations and policy-making about the quality of care they receive.

### *Outstanding Questions*

Many recommendations fell outside of the AI's current purview. It was recommended that the State clarify what requirements and policies are in place to address management of intoxicated patients who present to healthcare facilities. It was also recommended that drug treatment centers and OASAS-funded sites begin a more robust quality review program, such as those implemented in AI-funded sites. Finally, there was no consensus on which kinds of healthcare and community-based organizations should undertake quality measurement for people who use drugs. However, drug user health quality measurement could be piloted within HIV primary care and expanded at a later time.

### *Action Steps*

1. Develop quality measurements for people who use drugs to be used in HIV primary care settings
2. Expand access to buprenorphine by having more HIV primary care physicians become waived to prescribe
3. Facilitate the completion of pain management training for HIV primary care providers
4. Facilitate harm reduction and trauma-informed care training for HIV primary care providers
5. Form a Drug User Health subcommittee within the QAC
6. Include people with lived experience of substance use (not necessarily HIV+) on the CAC
7. Encourage HIV primary care organizations to include people with experience with substance use on consumer advisory bodies
8. Collaborate with OASAS and other organizations through the Interagency AIDS Task Force (IATF) and at the AI/OASAS quarterly meetings to discuss quality of care requirements and policy.

## ***Measuring Patient Experience***

The standard method of collecting information about patient experience is in the form of patient satisfaction surveys. However, the literature shows that measurements of satisfaction are not particularly meaningful nor are they reliable as data upon which to build quality improvement initiatives. Utilizing Patient Reported Experience Measures, or PREMs, has been shown to be an objective and meaningful way to measure the patient experience of their health care and have been shown to be effective in improving the quality of health care. The importance of patient experience measures, as opposed to satisfaction measures, should be communicated to patients, leadership, and key stakeholders as the new paradigm in quality of care.

The Clinical and Consumer Quality Advisory Committees discussed ways that the patient experience is currently assessed in their respective healthcare organizations and brainstormed ways for PREMs to be integrated into existing quality management programs. Committee members also discussed how PREMs for the HIV primary care setting should look and what PREMs should measure.

Although PREMs are not routinely utilized in the HIV primary care setting in NYS, healthcare organizations still routinely collect data from their patients. Current methods of soliciting the patient experience include: satisfaction surveys (including Press Ganey), routine collection of feedback from CABs and focus groups, suggestion boxes, the AIDS Institute stigma survey, and structured interviews upon a patient rescheduling or leaving the clinic. Some committee members brought up the AI's Healthcare Stories Project, which uses patients' own words and experiences of quality, visit flow, and co-production to improve QI, as an experience measurement tool. This example solicits patient experience for QI purposes, but PREMs tend to solicit more concrete data and are more reliable as a measurement tool. Some committee members, though, felt that qualitative data (such as that gleaned from HCSP, interviews, and focus groups) was more robust than data collected from surveys and should be collected in tandem with PREMs.

One issue that committee members raised was the timeliness and impact of PREMs. It was stressed that patients are asked to fill out so many forms and surveys that they would not want to also complete a PREMs survey. If another patient survey or form is introduced, the patient should be able to see the impact of their participation as soon as possible. It was recommended that PREMs be collected more than annually, and that patients should be informed of any changes or QI plans that emerge from the analysis of PREMs as soon as they have been made.

Committee members brainstormed experiences that can be addressed and improved through the use of PREMs. These included:

- Wait time
- Did your provider adequately address all of your concerns?
- Did you understand everything your provider told you today?
- Prescription access
- Insurance difficulties
- Visit flow and structure
- Follow-up
- Interactions with providers
- Interactions with frontline staff
- Trauma-informed care
- Labs and other test results communicated and understood
- Do you feel safe at this healthcare facility?

Committee members raised several challenges in implementing the routine collection of PREMs for QI. One challenge is how to collect PREMs from people who are not engaged or active in their health care, as these may be some of the most

important experiences to collect to understand the quality of care at an organization. Another challenge of PREMs lies in the length of the survey – they must be short enough for patients to complete during their visit but long enough to gather pertinent information. Additionally, PREMs should be customizable and adaptable. One major complaint with the widely-used Press Ganey satisfaction survey is the inability to adapt the questions to the specificity of the organization. It was also recommended that PREMs be developed corresponding to the cascade to better address gaps.

Committee members suggested that CABs and other consumers help develop the PREMs for their organizations. They also suggested that CAB members or peers be instrumental in the collection of PREMs from other patients. Opinions varied on whether PREMs could be completed through a patient portal or EHR, or whether collecting PREMs in the office (on paper or on a tablet) would get better response rates. Conversations centered on accessibility of the survey for people without internet access and on making PREMs surveys accessible to varying literacy levels. It was also suggested that consumers, an organization's quality management team, and the clinical team all review patient experience data collected.

### *Key Recommendations*

- PREMs should be collected from patients at least annually, and patients should be informed of any quality improvement projects or changes that are informed by PREMs data.
- PREMs should address the entirety of the patient experience, including interactions with providers, other staff, and insurance and prescription access.
- PREMs must be distinct from satisfaction surveys and should focus on the experience of care instead of the perception of the quality of care.
- The experiences of unengaged or hard-to-reach patients are some of the most meaningful for QI, and strategies to engage these patients should be developed.
- PREMs should be fast and easy to complete, and should be accessible for consumers across the board. Accessibility includes offering PREMs in multiple languages, making sure they are at an accessible literacy level, and offering multiple ways of completing PREMs (for example, by hand, on a tablet, or through a secure patient portal).
- Consumers should be included in the development of PREMs (at the site and state level) and in the review of PREMs data on the site level.

### *Action Steps*

1. Form a joint QAC and CAC PREMs subcommittee
2. Continue education on the value of PREMs in QI
3. Identify organizations in NYS currently utilizing PREMs for quality improvement
4. Identify or develop PREMs to be used in HIV quality management
5. Identify methods to have unengaged patients complete PREMs