Report: Recommendations from the Second 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 second annual joint meeting of the NYS HIV Quality of Care Clinical and Consumer Advisory Committees. The meeting focused on three topics: Improving the Ending the Epidemic (ETE) Dashboard; Measuring and Addressing HIV/AIDS Related Stigma in Healthcare Facilities; and Improving the Quality of STI Care in NYS.

**Key Recommendations:**

**Ending the Epidemic Dashboard:**
- Develop a mobile application and link the dashboard to different forms of social media.
- Adjust color schemes in the dashboard to make it more accessible for individuals who are visually impaired, and make the dashboard available in additional languages, especially Spanish.
- Provide practical hyperlinks to help consumers find PrEP and HIV providers throughout the State as well as information on STI clinics, pharmacies, and other peer related services.
- Incorporate vignettes, social media, photos, and testimonials of HIV+ individuals and PrEP users.
- Draw upon additional data from regional health information organizations, the veteran affairs healthcare system, the community health center association of NYS, NYSDOH and NYCDOHMH field service units, immunization and vaccination databases, and private insurance companies.
- Include additional measures on: nPEP/PrEP; STI incidence; HCV prevalence, treatment, and HIV coinfection; CD4 count at Diagnosis; HIV testing data; rates of Homelessness; Prescription Data; Missed clinical Visits; Insurance Status; Patient Satisfaction Surveys; and HIV/AIDS related stigma.

**Measuring and Addressing HIV/AIDS Related Stigma in Healthcare Facilities**
- Implement continuous stigma reduction education for all facility staff and volunteers, including receptionists, security guards and peers. Educational efforts should go beyond the HIV clinic.
- Address secondary stigma related to insurance status.
- Require that facilities funded by the AIDS Institute assess and address stigma; develop a domain in the NYS Quality of Care Organizational Assessment to measure facility level efforts to address stigma and publish a best practices guide on how to measure and reduce HIV/AIDS related stigma.
- Empower Consumer Advisory Boards (CABs) to address HIV/AIDS related stigma. Consumer groups should conduct stigma reduction campaigns and carry out patient satisfaction surveys.
- Incorporate sex positive messaging into PrEP implementation.
- Measure stigma through validated quantitative surveys and qualitative research; pilot the stigma scale developed by the Health Policy Project and Dr. Laura Nyblade throughout NYS.

**Improving the Quality of STI Care in NYS**
- Encourage healthcare settings with high volumes of STI testing, including emergency rooms, GYN clinics and HIV clinics, to focus on the quality of STI care and treatment.
- Prioritize efforts to monitor STI drug resistance, assure that patients are receiving appropriate treatments, and confirm that patients have been cured.
- Incentivize the provision of high quality STI care and publish quality data for different sites.
- Encourage facilities to improve and standardize the coordination of care for STI patients.
- Provide higher reimbursements for facilities that conduct extra genital testing.
- Increase efforts to link young MSM to primary care from STI screening.
- Support providers who conduct expedited partner therapy.
- Routinize sexual health screenings, and integrate HPV vaccinations into STI screenings.
- Provide increased education on testing practices to pharmacists.
- Integrate STI care with PrEP care.
- Use prescription data, diagnostic lab data, data from RHIOs, HIV SNPs, Managed Care Plans, and Medicaid, and chart reviews to measure the quality of STI care.
- Develop metrics to monitor the quality of STI care on topics including: risk assessments; 3-site NAAT testing; incidence of STIs; Partner Notification Services; offer of and/or linkage to PrEP and other prevention tools; and routine testing for Hepatitis A, B, and C.
**Introduction**

The New York State Department of Health (NYSDOH) AIDS Institute (AI) Office of the Medical Director convened the second annual joint meeting of the HIV Quality of Care Clinical and Consumer Advisory Committees on Tuesday, September 8th, 2015. The meeting was attended by more than 80 clinicians and HIV+ consumers and focused on three topics: Improving the Ending the Epidemic (ETE) Dashboard, Measuring and Addressing HIV/AIDS Related Stigma in Healthcare Facilities, and Improving the Quality of STI Care in New York State. Committee members spent the majority of the meeting discussing these topics in small breakout groups. Dan O’Connell, Director of the AIDS Institute, and Dr. Demetre Daskalakis, Assistant Health Commissioner of the New York City Department of Health and Mental Hygiene Bureau of HIV/AIDS Prevention and Control, also provided an update on the ETE Initiative.

The meeting began with a memorial tribute to Johanna Buck, a quality consultant with the AIDS Institute for fifteen years. She played a critical role in the development of the AIDS Institute’s Quality of Care program. She was the architect of the State’s quality learning network, and launched its first one, focusing on retention with HHC hospitals, over a decade ago.

Dr. Bruce Agins, Medical Director of the NYSDOH AI, provided an update on work since the last joint meeting in September of 2014.2

- The Ending the Epidemic (ETE) subcommittee has developed a domain for the Quality of Care Organizational Assessment to evaluate each clinic’s capacity to follow through on the goals of the ETE Initiative.
- The Tobacco Cessation subcommittee has developed screening indicators, and is actively planning an improvement campaign for 2016.
- The Access to Medication subcommittee conducted an informal survey at the AIDS Walk and is planning to conduct a facility level survey in January. They also developed a palm card to provide guidance for patients when they have problems accessing their medications. The AIDS Institute has since convened a formal technical work group with pharmacists, providers, and consumers to address medication access issues.

Dr. Agins also announced the launch of an ETE specific 2014 eHIVQUAL performance data review, as well as a launch of HEPQUAL, a quality improvement program for viral hepatitis indicators.

Dan O’Connell provided committee members with an update on the ETE initiative. The initiative is gaining momentum through the rollout of a media campaign, and increased funding from the State legislature, but it will take time to develop many of the larger, systematic endeavors related to the initiative. O’Connell reported that the AI has corrected the NYS cascade to account for individuals who died or moved out of state. This correction has reduced the number of PLWH in NYS from 152,000 to 129,000. The State is using new software to track PLWH more effectively. Additionally, the State has successfully linked the correctional system with statewide surveillance data, and can confirm that 95-97 percent of known HIV+ inmates are virally suppressed. A number of inmates have not disclosed their status, but the State is aware of whom those individuals are, and plans to link these individuals with HIV care and treatment services.

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O’Connell discussed the need to focus on improving testing rates at emergency rooms. Hospitals are good at documenting that they have offered a test, but very few tests are actually being administered. Most hospitals have a testing rate of about 3%. The most successful testing hospital has a rate of 17% of all patients. They improved their rate after they received a visit from the NYSDOH Office of Health System Management to investigate complaints about their practices.

O’Connell noted recent work to improve PrEP uptake. In August, OMD convened a PrEP implementation forum which presented efforts from numerous providers across the state. He highlighted Callen-Lorde’s work with PrEP enrollment. There has been a 400% increase in PREP use at Callen-Lorde. O’Connell stressed the need to increase uptake amongst the African-American population.

Dr. Daskalakis informed the committee that the City DOHMH has been working closely with AI to align State and City initiatives. He discussed the NYC HIV cascade of care in the context of ETE, noting that the remaining individuals who are out of care are the toughest to reach.

Dr. Daskalakis introduced the concept of an “HIV neutral cascade” which includes a prevention care cascade. All individuals, including high-risk negative people need to be involved in reducing the incidence of HIV. Every negative HIV test should be a call to action, an opportunity to engage individuals in preventive care, and reduce HIV/AIDS related stigma. He reviewed the work of the NYKNOWS testing initiative. The Bronx has been very successful since the establishment of BRONX KNOWS in the mid-2000s. The city is developing best practices for improving testing rates in the ER. NYKNOWS is currently coordinating work with NYLINKS to implement testing and linkage programs across the other boroughs.

The City is implementing PrEP/PEP media campaigns, and is preparing to roll out the “Play Safe Campaign,” a broader prevention campaign. The City is also focused on helping LGBT organizations coordinate their activities to carry out work related to the ETE initiative.

The City is developing clinical care guidance for target populations. MSM and transwomen guides have already been published on the city website, and a transmen guide is under review. To access the guides, follow this link: http://www.nyc.gov/html/doh/html/data/chi.shtml.
Denis Nash, Professor of Epidemiology and Biostatistics at CUNY Hunter, presented an overview of the Ending the Epidemic Dashboard, a public, outward facing website designed by CUNY Hunter to track and report the progress of the Ending the Epidemic Initiative. The dashboard serves as an accessible set of information, ranging from high-level to detailed, on key metrics and unifies data from wide array of realms and data sources. It integrates previously siloed data relevant to the ETE initiative, making it accessible to a wide range of stakeholders. The dashboard was launched in mid-September and can be viewed at: www.etedashboardny.gov. Geographic information, and interactive maps and cascades will be available in December 2015. Nash and CUNY Hunter are considering adding information on funding for HIV care and prevention, and utilizing Regional Health Information Organizations as a data source.

Committee members were asked to comment on the layout and overall display of data on the dashboard as well as provide recommendations to make the dashboard more accessible for all audiences, regardless of data literacy level, and inclusive of language barriers. They were also asked to comment on existing data sets utilized and recommend additional data sets and indicators for HIV care and prevention that should be measured and displayed by the dashboard. Providers and consumers also considered whether or not the dashboard reflected key population demographics and whether or not the dashboard was user friendly for all audiences.³

Accessibility

Committee members recommended a number of changes to make the dashboard more accessible for the general population. They suggested developing the dashboard in different languages (including Spanish), and adjusting the color schemes of the dashboard to make it more accessible for individuals who are visually impaired. Increased contrast in the foreground and background is critical for improving visibility of the site.

To cater to younger populations, Hunter should seek to develop a mobile application for the dashboard, and link the dashboard to different forms of social media. A logo with a hyperlink to the dashboard should be developed and disseminated to public health organizations and healthcare facilities so that they can post it on their own websites, thus increasing public access to the dashboard.

To make the dashboard more user friendly, CUNY Hunter should place data at the top of the dashboard. Users should not have to scroll down to view data. Search engines should be added to the dashboard to help users find specific data they wish to view more quickly. The dashboard should also have easily accessible information on various projects and initiatives related to ETE, and different ways for individuals and organizations to get involved in these projects.

Consumer Engagement

To make the dashboard more consumer friendly, it should include practical hyperlinks to valuable patient resources. This section of the dashboard should help patients and individuals interested in PrEP find providers throughout the State, and help them access information about ADAP. A list of facilities with peer related services and holistic therapies should be included as well as a provider directory, a list of STI Clinics, and pharmacies. This section should not take away from, or overwhelm, the central focus

³ For more information on the ETE Dashboard and group discussion questions, please see Appendix 1 and 2.
of the dashboard, which is to track the progress of the ETE initiative. The dashboard should also provide a consumer specific data dictionary section that provides definitions of measures and explanations about how to understand data.

The dashboard should also incorporate vignettes, social media, and qualitative data to more effectively engage youth and consumers. Photos and testimonials of HIV+ individuals and individuals on PrEP would help to combat stigma and make the dashboard more relatable for consumers. The blog section of the dashboard should be promoted and more interactive components should be developed. CUNY Hunter should conduct consumer satisfaction surveys and develop feedback mechanisms for the dashboard so that they can analyze and improve how it is being used.

**Website Design**

Committee members recommended simplifying the opening page of the dashboard by removing the changing image at the top of the web-page and providing a snapshot of three key data points that are being used to measure ETE progress. The front page should have a link to a video overview of the ETE initiative that is addressed to all New Yorkers. Users should be able to customize their dashboard so that they can review data they have specific interests in, and they should be able to receive notifications when new content related to specific topics is available. CUNY Hunter should also develop an interactive tool that allows users to compare data sources simultaneously across sub-populations. A pop-up button for different measures and features to explain each component should be incorporated into the design of the dashboard. Benchmarks and goals for each indicator should be clearly articulated throughout the dashboard.

**Metrics and Data Literacy**

Committee members recommended numerous additional measures and data sources that the dashboard should seek to incorporate. Additional sources include Regional Health Information Organizations, Veteran Affairs Healthcare System, the NYSDOH and NYCDOHMH Field Service Units, Immunization and Vaccination Databases, and private insurance companies. Additional measures and topics for measurement recommended by the committee include:

- nPEP/PrEP related measures
- STI incidence
- HCV Prevalence and Treatment
- HCV/HIV Co-infection Rates
- Intravenous Drug Use Data
- Distribution of CD4 Count at Diagnosis (to demonstrate how quickly infected individuals are getting diagnosed and linked to care)
- VLS disaggregated by sub-populations and zip codes
- ER HIV testing data and HIV testing in the general population
- Rates of Homelessness/Unstably Housed
- Data Sets on patients over the age of 50 should be developed
- Prescription data (% prescribed, % filled, % suppressed)
- Missed clinical visits
- Collect data on “Waiting Time Before Appointment”
- Insurance Status
- HIV/AIDS Related Stigma Measures
- Use data from patient satisfaction surveys such as Consumer Assessment of Healthcare Providers and Systems (CAHPS) and Clinician and Group Consumer Assessment of Healthcare Providers and Systems (CGCAPS).
- Implement a qualitative component to collect consumer stories.
In addition to these recommendations, consumers and providers suggested that the dashboard should include de-identified, site specific data that allows for viewers to get a better sense of how each facility is doing. Facilities that are scoring well should be highlighted on the dashboard.\(^4\) Data should be presented geographically. The dashboard should draw upon facility level data from NYLINKS and Medicaid. De-identified data from Medicaid can show which hospitals have high ER admission rates for HIV patients. Providers and public health officials should use this data to re-engage patients in care. Medicaid data can also provide information on disabled individuals who are HIV positive.

Committee members also recommended developing more educational components for display on the dashboard to account for gaps in data literacy amongst the general population. HIV guidelines, and standards of HIV care should be referenced. Basic epidemiology and technical language should be incorporated into the educational components. The dashboard should also provide updates on ART initiation research and developments with HIV/AIDS policy.

**Next Steps**

CUNY Hunter will focus on incorporating these recommendations into the development of the ETE dashboard. To provide additional feedback on the dashboard, follow this link: [http://etedashboardny.org/contact-us/](http://etedashboardny.org/contact-us/).

\(^4\) One committee member suggested not being critical of facilities with poor statistics because there may be extenuating circumstances that explain why certain facilities have lower rates. Other members suggested that providers should be able to compare their own performance to the general data. Providers are motivated to avoid the bottom quartile, and public displays of data could push providers to work on improvement.
Measuring and Addressing HIV/AIDS Related Stigma in Healthcare Facilities

Despite a widespread consensus that HIV/AIDS related stigma both inhibits access to prevention, care, and treatment services, and has a deleterious effect on the personal lives of individuals, efforts to measure and address stigma on a global, national, and local level are under developed. These efforts often lack funding, and are hindered by the complexity of measuring levels of stigma in different cultural settings.

In recent years, global institutions including PEPFAR, WHO, UNAIDS and the Global Fund have released guidance on how to more effectively reduce HIV/AIDS stigma. In New York State, the Ending the Epidemic Initiative Blueprint calls for an “anti-stigma media campaign” to reduce the barriers that inhibit individuals from remaining in care. The Blueprint also calls for health care providers “to increase their cultural competency and reduce the stigma that patients experience while in care.”

Acting on these recommendations, the AIDS Institute Office of the Medical Director solicited feedback from the clinical and consumer advisory committees on a variety of issues related to HIV/AIDS related stigma. Committee members provided recommendations on how facility-based quality management programs can reduce stigma, and how healthcare organizations can effectively measure stigma. They were asked to brainstorm specific measures to assess the presence of stigma in healthcare facilities and different ways that assessments of patient experience can be used to capture experiences with stigma. They discussed more effective strategies for coordinating stigma reduction activities between providers and impacted communities across all departments in each healthcare facility. Committee members were also asked to determine whether or not healthcare facilities should be required to implement quality improvement projects to reduce stigma in their facilities, and what types of stigma (anticipated, enacted, internalized, and secondary) the NYS HIV Quality of Care Program should seek to address.

Facility Wide Educational Efforts

Committee members agreed that facility wide educational efforts should be continuous for all staff in order to prioritize stigma reduction. Consumers noted that secondary stigma as a result of race, ethnicity, gender and/or sexuality is often discussed, but insurance status and poverty are less of a focus. Individuals who are on Medicaid, Medicare, or ADAP often experience HIV/AIDS related stigma. Their care often gets delayed in high volume facilities compared with individuals who have private insurance. Low-income individuals on Medicaid often feel unwelcome and become frustrated while waiting to see a doctor. Committee members recommended that receptionists and security guards, in addition to all other facility staff, should receive training on insurance status, so that they can be more sensitive to the needs of low income consumers. Staff should also receive education about sexual orientation and gender identity. EMRs should be updated to account for gender identity.

7 Mahajan AP, Sayles JN, Patel VA, et al. 2008
8 Nyblade L. What Works for Reducing Stigma and Discrimination in Health Services. NYS HIV Quality of Care Clinical Advisory Committee Quarterly Meeting; 2015 June 11th, 2015; NY.
9 Ending the Epidemic Blue Print: New York State Department of Health AIDS Institute; 2015.
10 For more information on HIV/AIDS related stigma and group discussion questions, please see Appendix 1 and 2.
Providers and facility staff should be given an opportunity to self-reflect on their feelings towards HIV+ patients. It is important that educational efforts address the root causes of subtle stigmatization and micro-aggression that consumers experience in the clinic. Facilities should provide stigma sensitivity training for patient navigators and medical case managers to help them do a more effective job when they meet patients at medical appointments, and follow up with patients if they miss their visits. Peer-to-peer training should also be incorporated into educational efforts.

Committee members also expressed concerns that segmenting an HIV/AIDS clinic from the rest of the hospital adds to internalized stigma, and recommended integrating HIV/AIDS care. Other members expressed the opposing perspective, and suggested that centralizing or integrating the clinic could decrease patient privacy. Members agreed that HIV/AIDS trainings, and stigma reduction efforts need to be provided outside of the HIV/AIDS clinic in each facility in order to develop a broader, more excepting environment.

Reducing Stigma through facility-based quality management programs

Committee members recommended that facilities that receive funding from the AIDS Institute should be required to assess and address stigma. To implement this recommendation, the AIDS Institute should develop a domain in the NYS Quality of Care Organizational Assessment to measure facility level efforts to address HIV/AIDS related stigma. The NYS QOC program should publish a best practices guide on how to reduce HIV/AIDS related stigma, speak with patients about stigma, and measure stigma. Facilities should incorporate quality improvement into stigma reduction interventions, and report progress to the AIDS Institute. Facilities should implement individual stigma assessments, to help both consumers and providers evaluate their own relationships with HIV/AIDS related stigma. Providers, consumers and public health officials should examine existing language in the Ryan White Act to make sure it includes addressing stigma. If it does not, they should advocate for it to be added to federal requirements.

Role of Consumers in Addressing Stigma

Consumer Advisory Boards (CABs) should be empowered to address HIV/AIDS related stigma throughout their facilities. Committee members recommended that CABs and other consumer groups help to conduct facility level, patient satisfaction surveys and develop targeted action plans to address the issues uncovered in the survey. Peer navigators and peer support staff should play a prominent role in assessing and interviewing patients about HIV/AIDS related stigma in each clinic. Facilities should ensure that consumers are comfortable reporting experiences. They should display signs and images throughout clinics announcing that patients are in a “stigma free zone,” and also address other diseases such as HCV, in addition to HIV. Stigma reduction campaigns should be conducted throughout facilities, including non-HIV specific areas.

Support for Consumers

Committee members discussed ways to provide increased support for consumers dealing with stigma and different stigma-related issues consumers face on a daily basis. Facilities should be sure to provide

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11 Committee members suggested that there could be a number of problems with requiring facilities to address HIV/AIDS related stigma. Providers could be frustrated and belittled by the requirement, which could result in stigma. Staff might feel pressure to fast track patients who complain more to satisfy them faster, and neglect to help patients who do not advocate for themselves as well. Other committee members felt that many providers would be open to increased education about stigma, and would respond positively to increased emphasis on reducing stigma.
consumers with easy access to social workers and psychologists, and also share stories and photos throughout each clinic to create a more comfortable environment. Committee members emphasized the need to address stigma related to PrEP and HIV prevention. Members were concerned about sex shaming, and the stereotype that PrEP is for white gay men. Implementation of PrEP should incorporate sex positive messaging for different key populations including MSM of Color. Committee members also noted that individuals who test positive for HIV can be afraid of the social consequences related to unknowingly infecting a partner. To increase HIV testing rates, it is critical that the providers, consumers, and public health officials address anticipated stigma.

Measuring Stigma in Healthcare Organizations

Committee members engaged in an intensive discussion about the value of collecting both quantitative and qualitative research on HIV/AIDS related stigma in healthcare settings. Qualitative research on the patient experience is critical for understanding how stigma manifests in the healthcare setting. Providers should ask patients about experiences with stigma as part of the standard patient history.

Committee members recommended measuring stigma through qualitative analyses. Different populations experience stigma in different ways, and each facility may engender different kinds of provider-based stigma. Stigma may be assessed and experienced differently at stand-alone clinics versus large networks and facilities. Committee members suggested convening a yearly focus group of consumers to design an annual intervention to reduce stigma, and carrying out patient satisfaction surveys to understand how stigma manifests itself in each clinic.

Committee members felt that quantitative research is necessary for stigma reduction efforts to have a significant impact on the development of laws, regulations, and guidelines. Experiences of enacted stigma and compound stigma should be quantified. Internalized stigma should be collected through qualitative research.

Facilities should develop feedback mechanisms to monitor and address stigma complaints from patients. These complaints should be used for staff education and improvement activities. Committee members cautioned that using feedback from patients is not comprehensive; it is limited to individuals who are not afraid to advocate for themselves. Facilities should implement additional safeguards in the clinic to protect consumers and help them feel comfortable reporting negative experiences. Facilities should also be careful to differentiate between HIV/AIDS related stigma and other types of stigma experienced by consumers.

Committee members agreed on the importance of integrating a rigorous mechanism for measuring stigma in the care system. The NYSDOH should pilot the stigma scale developed by Health Policy Project (HPP) and Dr. Laura Nyblade in healthcare facilities throughout New York State. A rigorous client self-monitoring tool that consumers can use to score a facility on should be developed, and the results of this tool should be compared with the facility level tool developed by HPP. This would help to confirm whether or not facility level scores match with client perceptions. Facilities should consider using the Stigma Index tool to measure individual level stigma of clients in different facilities. Committee members recommended developing measures on the following topics:

- Missed Visits (Patient navigators or medical case managers should evaluate whether or not)
- Implementation of positive, safe sex messaging and peer-to-peer work
not HIV/AIDS related Stigma played a role in the missed visit.
- Impact of payor status on stigma
- Documentation of stigma reduction training
- Staff diversity
- Stigma assessments of surrounding communities
- The frequency with which patients use resources
- Existing conceptions of PLWH among facility staff
- Impact of stigma reduction interventions on retention rates

Next Steps
To implement the recommendations outlined in this section, the NYSDOH AI OMD will:
1. Pilot the Health Policy Project’s facility level stigma tool at select clinics throughout NYS.
3. Provide educational resources on stigma that facilities can use to train their staff and help them become more sensitive.
4. Create a domain in the quality of care organizational assessment to measure stigma reduction efforts in quality management programs.
5. Encourage facilities to develop feedback mechanisms to monitor stigma in healthcare settings. Facilities should receive additional support to implement “The Healthcare Stories Project” and other forms of qualitative analysis to collect data on HIV/AIDS related stigma.
6. Facilitate peer trainings on managing and reducing stigma.
7. Support CABs and other consumer advocacy groups to carry out patient satisfaction surveys and anti-stigma campaigns in their respective facilities.
**Improving the Quality of STI Care in NYS**

The AIDS institute is uniquely positioned to measure and improve the quality of STI care in NYS, but no formal system and no resources specifically designed to monitor the quality of STI care in healthcare institutions exists in NYS. The HIV Quality of Care Clinical and Consumer Advisory Committee convened an STI care subcommittee to explore strategies to measure quality of care and examine existing data sources measuring incidence and prevalence to identify areas of priority for clinical education and improvement. The joint meeting served as a platform for the entire committee to further investigate these issues.

Committee members discussed the complications related to monitoring and improving STI care throughout NYS. The incidence of STIs is much larger than HIV, and STI care is managed in a variety of different healthcare settings including primary care sites, urgent care sites, emergency departments, OB-GYNs, and STD Clinics. Committee members were asked to identify key measurement sources as well as key measures to capture the quality of STI care for all New Yorkers, New Yorkers living with HIV, and MSM and Transwomen. They were also asked to suggest best practices for measuring sexual history taking in patient records and data systems, as well as ways to engage health facility – both hospital and CHC – programs in integrating STI quality, including diagnosis, treatment and follow-up, into their quality improvement programs, quality committees and measurement systems. Providers and consumers also considered how healthcare facilities can engage with communities to address rising rates of STIs, what additional resources should be provided to assure that standards of STI care are met, and how to more effectively increase provider awareness and competency to manage STIs. Lastly, committee members discussed how to most effectively engage and train providers who are not STI practitioners, and how to define the challenges and opportunities for STI diagnosis and care that exist following the implementation of PrEP across the State.  

**Healthcare Facility Engagement and Communication**

Committee members discussed the most effective ways to engage a broad range of healthcare providers and facilities in STI monitoring and improvement efforts. A major barrier to systematically monitoring the quality of STI care is the fragmentation of STI care across different departments. Committee members emphasized focusing on healthcare settings with high volumes of testing, including the emergency room, GYN clinics, and HIV clinics. Physicians should be encouraged to prioritize efforts to monitor STI drug resistance, assure that patients are receiving appropriate treatments, and confirm that they have been cured.

To encourage an increased focus on STI care, the NYSDOH should find ways to incentivize the provision of high quality STI care, and publish records on the quality of STI care at different sites. The NYSDOH should emphasize the business angle of providing good care, and provide technical assistance and site visits. The department should develop NYS specific guidelines based CDC STI guidelines for 2015. Committee members recommended developing population specific guidance for the treatment of STIs in the MSM and Transgender communities. They also suggested paying close attention to older populations, especially men diagnosed with erectile dysfunction.

The NYSDOH should encourage facilities to improve and standardize the coordination of care for STI patients. There is a problematic disconnect between STI clinics and other providers. Many MSM who use

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12 For more information on STI Care and group discussion questions, please see Appendix 1 and 2.
PrEP use county STI clinics as a stop in between scheduled medical appointments with their primary care providers. Urgent care centers should be encouraged to provide comprehensive care for individuals diagnosed with STIs. Oftentimes primary care providers are not aware that their patient was diagnosed with an STI at these clinics or in the emergency room. This gap in communication needs to be fixed to ensure that patients receive proper care. Regional Health Information Organizations (RHIOs) will play a key role in plugging these communication gaps between providers. Patients should be consistently asked to sign release of information forms so that anonymous treatment at clinics can be passed on to their primary care providers. Committee members recommended expanding anonymous STD clinics and coordination efforts between these clinics and primary care providers. Committee members felt that individuals should have the opportunity to be screened any time they engage with a healthcare provider. Home testing should also be made available.

To encourage more comprehensive STI testing, facilities that screen a large number of non-urethral specimens should receive higher reimbursements facilities that only provide genital screening. Private insurance companies should be encouraged to increase their support of STI screening, prevention and treatment efforts. Committee members identified lack of reimbursement as a barrier for primary care providers to provide testing. Institutions should implement standing orders to free up time for treatment and testing. Multi-disciplinary teams should be organized to facilitate an increase in testing rates.

Clinics should be prepared to treat penicillin-resistant strains of gonorrhea. Many clinics do not stock the alternative antibiotics for these people. NYS should address of appropriate resources and supplies, and seek to resolve any insurance related problems.

Pharmacists should receive additional education on STI care. Some pharmacists are reluctant to fill a prescription for someone other than the index patient, even though they are legally protected to do so.

Community Engagement

Committee members discussed key priorities and strategies for mobilizing and engaging the broader community in efforts to reduce STI incidence and improve care. Members felt that it was critical to focus on young MSM populations and focus on linking them to primary care from STI screening. Peers and community advocates should play a critical role in conducting community outreach to MSM and other populations and addressing STI related stigma. The Department of Health should collaborate with peer educators, and school programs to improve STI health literacy throughout the State.

Consumers should be empowered and encouraged to ask providers why they do not provider certain types of screenings or services. Consumers can play a critical role in helping facilities to move towards providing more comprehensive, integrated STI care.

Partner Testing

Consumers and providers also addressed the need to develop more effective avenues for expediting partner notification and treatment. Sites that are providing STI treatment and conducting expedited partner therapies should receive increased levels of support. Many primary care providers outside of the realm of infectious diseases do not know that they can conducted expedited partner therapy, and should be encouraged to do so.
Sexual Health Screening

Committee members focused on ways to measure and improve sexual health screenings. According to committee members, sexual history risk assessments are consistently considered inadequate in most healthcare facilities. Sexual history taking and risk assessments should be measured through chart reviews and open ended questions in EMRs, and providers should be required to interview patients about the 5 “Ps,” (partners, practices, pregnancies, protection and past history). Consumers recommended asking questions about sexual history prior to testing. This will make the questions seem less judgmental and make patients more comfortable. Primary care providers should consistently update patient history by asking patients about their sexual identity. The frequency of screening should be dependent on the specific to the patient. HIVQUAL guidelines require screening a minimum of once a year, even if an individual is not sexually active. Screening serves as an important opportunity for facilities to educate consumers and provide resources.

Screening should be as routine as complete blood count (CBC) or any other standard test. Committee members recommended that programs should standardize STI screenings, and err on the side of screening more people than necessary. HPV vaccination should be integrated into STI care and testing sites, and at risk women should consistently receive chlamydia screenings. Sites should also integrate standardized post-STI diagnosis counseling. HIV clinics should be encouraged to have more conversations with patients about Herpes Simplex Virus. Clinics that conduct extra-genital testing should be aware that PCR is not approved for oral and anal site testing. Cultures are much less sensitive and cases can be missed. PCR could be used, but facilities would need to do a validation test.

Pharmacists should receive increased education on testing practices. STI testing could happen at pharmacy based quick clinics like CVS, and Walgreens. Insurance issues related to pharmacy testing would need to be resolved.

STI screening should be incorporated into school programs, and work and athletic physicals. Youth coming in for athletic physicals should have conversations about steroid use, and self-done tattoos. Committee members also recommended ensuring that deaf, hard of hearing, and blind patients, as well as patients over the age of 60 are screened consistently.

STIs and PrEP

Committee members discussed ways to use PrEP care as an opportunity to expand STI care throughout NYS. PrEP guidelines were identified as a critical opportunity for the scale up of STI screening and increasing efforts to monitor the quality of STI care. PrEP and STI education should be a focal point of Statewide CME programs. Providers should seek to integrate PrEP and STI care.

Primary care physicians should be encouraged to provide comprehensive sexual care with their patients. HIV testing, PrEP, PEP, sexual risk assessments, should all be conducted together and should not be confined to a single component of the healthcare system. PrEP navigators and STD clinics should develop relationships to coordinate care for patients. Providers should measure the number of patients they discuss PrEP and STIs with.

Metrics and Data Sources

Committee members discussed different metrics and data sources that the NYSDOH should use to monitor the quality of STI care in NYS. In order to more effectively engage health facilities in monitoring
the quality of STI care and utilizing QI to improve rates, the NYSDOH, and CABs and consumers, should push facilities to incorporate STI care into their quality programs. Quality measures and efforts to improve the quality of STI care should focus on ensuring continuity of care for people with STIs, so that they have routine check-ups and have discussions about PrEP with their providers.

Key Metrics and Measures Recommendations:

| - Incidence of STIs | - Develop screening measures for the MSM and Transgender communities, including anal STI screening rates for MSM and Trans (Female to Male) patients |
| - Risk Assessments and Sexual History: emphasize the need for action and sensitive care | - Generate comprehensive information on gender identity, sexual activity, sexual orientation. |
| - STI/HIV screenings and follow up tests for positives (3 month re-testing for STIs) | - Differentiate quality measures for each STI. |
| - Partner Notification Services | - Test for Hepatitis A, B, and C routinely |
| - 3-Site NAAT testing | - HPV Vaccination |
| - Offer of and/or linkage to PrEP and other prevention tools | |

STI Measurement Sources:

| - Surveillance data from NYSDOH and NYCDOHMH | - Managed Care Plans |
| - Chart extraction | - Medicaid |
| - Prescription data from pharmacies | - STI care in the ED |
| - Diagnostic lab data | - Develop a continuum of care for STI care. |
| - Regional Healthcare Information Organizations | - Use the Health Electronic Response Data System (HERDS) to remind providers about monitoring and improving the quality of STI care. |
| - HIV Special Needs Plans | |

Next Steps

To implement the recommendations outlined in this section, the NYSDOH AI OMD will work with the Quality of Care STI subcommittee to:

1. Identify and implement ways to effectively collect data on the quality of STI care in NYS; investigate the feasibility of collecting data through a new data platform.
2. Promote sexual health history taking and risk assessments as key components in improving the quality of STI care, and develop clinical measures to monitor usage.
3. Support the adoption of 3-site NAAT testing throughout NYS, and identify and validate NAAT labs.
4. Develop measures to monitor STI drug resistance, assure that patients are receiving appropriate treatments, and confirm that they have been cured.
5. Encourage different departments within healthcare facilities and systems to coordinate STI care.
6. Educate pharmacists about STI screening and educate primary care providers about expedited partner testing and therapy.
7. Develop interventions to engage young MSM in primary care.
9. Encourage sites to integrate HPV vaccinations into STI care and provide increased education about HSV.
Appendix 1: Briefs

Brief: Ending the Epidemic Dashboard

A key recommendation included in the New York State's Ending the Epidemic (EtE) Initiative’s Task Force Blueprint is to extend and enhance the use of data to track and report progress on ending the epidemic in New York, including “The creation of a web-based, public facing, Ending the Epidemic Dashboard system is recommended to broadly disseminate information to stakeholders on the [EtE] initiative’s progress.”

Designed and developed by Hunter College and The CUNY School of Public Health, the purpose of the ETE Dashboard System is to measure, track and disseminate actionable information on progress towards achieving goals to all interested stakeholders. Additionally, key metrics aligned with the ETE Blueprint Aims will be developed and disseminated via the Dashboard. To fully characterize this complex topic, the Dashboard system incorporates aggregate data from multiple data content realms and data sources. The Dashboard is designed to create a visual and interactive experience that allows stakeholders (users) to get the information they want in visual and tabular format, which is both content and geographically-driven. Using aggregate data, Version 1.0 of the dashboard includes static content and key metrics summarizing the current state of the HIV epidemic in New York State. Version 2.0, planned for release in the Fall 2015, will feature an interactive dashboard and incorporate additional EtE-priority metrics. Users will be able to stratify and filter maps, graphs, and other visualizations according to the sub-group (e.g gender, age-group, risk) or geographic area of interest.

Current Data Content Realms
- Prevention
- New Infections
- HIV Testing
- New Diagnoses and Linkage
- Prevalence and Care
- AIDS Diagnoses
- Deaths among PLWHI

Current Data Sources

<table>
<thead>
<tr>
<th>Data Source</th>
<th>Description</th>
</tr>
</thead>
</table>
| NYSDOH HIV/AIDS Surveillance and NYC DOHMH HIV/AIDS Surveillance | HIV/AIDS surveillance activities in New York are conducted by the Bureau of HIV/AIDS Epidemiology within the New York State Department of Health, and by the HIV Epidemiology & Field Services Program of the NYC Department of Health and Mental Hygiene. Both release annual detailed reports on the HIV/AIDS epidemiology within NYS and NYC. Surveillance data includes information on new HIV/AIDS diagnoses (date, test and values, ordering provider), as well as all CD4 and VL laboratory test results following diagnosis that have been reported to the NYS Department of Health. From this information, we can use surveillance data to follow the number of new diagnoses and the number of persons living with HIV/AIDS in New York, as well as trends in linkage to care rates, retention in care rates, and viral load suppression data. Surveillance data can further assist in looking at this data by specific demographic or high-risk subpopulations. New York State and New York
City are also funded by the Centers for Disease Control and Prevention (CDC) to assess incidence data, or estimated new HIV infections, using a method developed by CDC known as stratified extrapolation approach (SEA). Annual incidence estimates are an essential benchmark in tracking progress towards reducing new infections to 750 by the end of 2020.

The New York State Department of Health (NYSDOH) AIDS Institute HIV Quality of Care (QOC) Program overseen by the Office of the Medical Director (OMD) is committed to promoting the quality of HIV clinical care and supportive services delivered to people with HIV in New York State (NYS) and to building capacity for quality management in HIV programs throughout the region. The QOC Program promotes improvement in HIV care, using a framework to achieve its objectives that includes the following components: performance measurement of clinical care and services, improvement coaching and consultation, exchange of improvement resources, peer learning, and collaborative participation of clinical experts and consumer representatives. Performance measurement of HIV ambulatory care providers occurs through annual self-reporting as part of the New York State HIV QOC Program review process. The HIVQUAL framework, developed by the NYSDOH AIDS Institute, is based on the concept that quality management programs should reflect a balance between quality improvement and performance measurement activities and be built on a sustainable programmatic infrastructure with active support from the agency’s leadership.

The Behavioral Risk Factor Surveillance System (BRFSS) is the nation’s premier system of health-related telephone surveys that collect state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. Established in 1984 with 15 states, BRFSS now collects data in all 50 states as well as the District of Columbia and three U.S. territories. BRFSS completes more than 400,000 adult interviews each year, making it the largest continuously conducted health survey system in the world.

The New York City Community Health Survey (CHS) is an annual cross-sectional telephone survey conducted by the Bureau of Epidemiology Services at the New York City Department of Health and Mental Hygiene. The CHS provides data on the health of New York City residents. The annual sample includes approximately 8,500 adults ages 18 and older from all five city boroughs. All data collected are based on self-report. The CHS data is used to provide measures of HIV testing and prevention in New York City. CHS participants are asked a) if they have ever been tested for HIV and b) if they have been tested for HIV in the past 12 months. For data regarding condom use, participants are also asked whether they used a condom the last time they had sex.

NYLinks is a New York State Department of Health (NYS DOH), AIDS Institute initiative that focuses on improving linkage to and retention in HIV care to support the delivery of routine, timely, and effective care for Persons living with HIV/AIDS in New York State. HIV testing and care providers, supportive service groups and consumers participate in regional collaboratives (e.g. Upper Manhattan, Western NY, Hudson Region) with an aim to improve linkage and
| **NYLinks** | retention across their region and the state. The NYLinks measures aim to monitor the progress and impact of the New York State collaborative efforts to improve linkage to and retention in HIV clinical care. All sites participating in NYLinks are encouraged to routinely collect the data and to report aggregate results through a web application every two months. The data should capture all patients/clients with a diagnosis of HIV/AIDS, regardless of age or funding source of services. These data are used to set regional linkage and retention priorities and evaluate the effectiveness of interventions developed. You can find a description of the measures in detail here. NYLinks calculations for linkage, retention and viral suppression may differ from other NYS surveillance-based content. |
| **NYS Vital Statistics** | The New York State Department of Health (DOH) collects data on live births and deaths recorded in New York State. Through a cooperative agreement, the New York State DOH receives data on live births and deaths recorded in New York City from the New York City Department of Health and Mental Hygiene and on live births and deaths recorded outside of New York State to residents of New York State from other states and Canada. Vital statistics data are used to provide a measure of AIDS mortality. The cause of death reported is based on the underlying cause and is classified according to the International Classification of Diseases. |
Brief: Sexually Transmitted Infections in NYS: Addressing the Quality of Care

Based on the most recent data reported from CDC, New York ranked 11th in chlamydial infections (516.5 per 100,000 persons), 16th in gonorrheal infections (116 per 100,000 persons), and 7th in primary and secondary syphilis rates (6.3 per 100,000 persons) out of all 50 states in the U.S.1 Rates of chlamydia among women in 2012 were approximately twice the rate among men in NYS, with more than 681.1 cases per 100,000 women, compared with 340.8.1 Across NYS, rates of syphilis among men (12.5 cases per 100,000 men) were significantly higher than rates among women (0.4 cases per 100,000).1 Additionally, young adult populations (ages 15-24) account for 74% of Chlamydia infections and 64% of gonorrhea infections.2

2014 incidence data collected by the NYSDOH Bureau of STD Prevention and Epidemiology illustrates the extent of the STI burden across NYS (Table 1).

<table>
<thead>
<tr>
<th>County</th>
<th>Chlamydia #</th>
<th>Rate (per 100,000)</th>
<th>County</th>
<th>Gonorrhea #</th>
<th>Rate</th>
<th>County</th>
<th>Early Syphilis #</th>
<th>Rate</th>
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Janowski and colleagues surveyed all healthcare facilities in New York State to assess the extent of their services for monitoring the quality of STI care and treatment outcomes.3 Only 30% of facilities surveyed have an established process, and only 50% of facilities employ staff to track and report STI rates.3 A majority of STIs are diagnosed and treated at emergency rooms, women’s health clinics, and private practice providers, rather than local health department STI clinics.3

Additionally, 2013 eHIVQUAL data suggest that extragenital screening rates are alarmingly low for PLHIV. Clinic level mean scores for rectal testing for Chlamydia were 11% for MSM (n=2,990) and 14% for MtF (n=111). Clinic level mean scores for rectal gonorrhea testing were 12% for MSM (n=2,990) and 14% for MtF (n=111). Clinic level mean scores for pharyngeal gonorrhea testing were 10% for MSM (n=2,990) and 13% for MtF (n=111).4
Despite the high prevalence of STIs in NYS, and data indicating low extra-genital testing rates, no formal, standardized system exists to monitor the quality of STI care provided in healthcare facilities. The STI subcommittee of the Quality Advisory Committee has been convened to specifically address this issue.

According to their mission statement, the subcommittee is charged with advising the Institute “on issues related to the care of patients with sexually transmitted infections and promoting sexual health within clinical care settings. The subcommittee will review statewide STI data, endorse or develop guidelines for management of STIs and identify priorities for addressing the quality of STI care in New York State, and advise the Office of the Medical Director on matters of clinical policy pertaining to STIs.”

Specific issues identified by the STI quality of care subcommittee to improve the quality of STI care in NYS include: increasing the practice of extragenital NAAT testing for men who have sex with men and transgender women; in addition to a variety of educational programs. Other issues pertaining to the quality of STI care that have emerged as priorities through discussions and questions raised to the AIDS Institute STI Center of Excellence by providers include alternative treatment options for those with allergies, basic STI care in the rural setting, follow-up tests of cure and partner testing.

With the increasing pace of implementing PrEP throughout NYS and its key role as part of the End of Epidemic initiative, the incidence of STIs may increase, as a result of both detection frequency and the consequence of decreased condom use. Accordingly, the need for focusing on quality of STI diagnosis, treatment and follow-up becomes more critical within the community of PrEP providers.

Existing clinical education materials are available through the STI Center of Excellence. The Center delivers both in-person clinical education opportunities (which include intensive clinical preceptorships, an annual statewide STI conference and regional conferences) as well as distance learning opportunities (which include tele-consulting, webinars, webcasting, digital health and other emerging distance education technologies). Through this combined approach, the Center is able to reach areas that are designated as Health Provider Shortage Areas (HPSAs), rural areas and other areas where STI treatment providers are in short supply. However, educational programs are insufficient to fully address the quality of STI services, leading to the need to develop metrics, systems for assessing care and organizational quality management programs that will integrate STIs among their portfolios on a routine basis. In the absence of dedicated funding for STI review programs, consideration of how to use existing systems to analyze statewide and local data are among top priorities for addressing the quality of STI care in NYS.

Finally, and importantly, providing access to confidential, user-friendly STI services is essential for delivering quality STI services that meet standards of care. Working with consumers to define priorities and use experiences to drive quality is, like experiences with HIV care have shown us in New York, an important strategy for providing quality STI care.

**Brief: Measuring and Addressing HIV/AIDS Related Stigma**

Despite a widespread consensus that HIV/AIDS related stigma both inhibits access to prevention, care, and treatment services, and has a deleterious effect on the personal lives of individuals, efforts to measure and address stigma on a global, national, and local level are under developed.1,2 These efforts often lack funding, and are hindered by the complexity of measuring levels of stigma in different cultural settings.1

HIV/AIDS related stigma is defined by scholars 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: enacted stigma, where one experiences or has experienced discrimination, stereotyping, and/or prejudice as result of other people’s actions;4,5 anticipated stigma, when one expects to be discriminated against in the future because of one’s HIV;4,5 internalized stigma, when one develops low self-esteem and negative feelings about themselves because of one’s HIV;4,5 secondary stigma, the result of being associated with someone who is HIV+; and compound stigma, where the stigma of being HIV+ is coupled with stigma related to other personal attributes such as gender, poverty, class, race, geography, migrant status, and sexuality or sexual orientation.6

In recent years, global institutions including PEPFAR, WHO, UNAIDS and the Global Fund have released guidance on how to more effectively reduce HIV/AIDS stigma.6 In New York State, the Ending the Epidemic Initiative Blueprint calls for an “anti-stigma media campaign” to reduce the barriers that inhibit individuals from remaining in care. The Blueprint also calls for health care providers “to increase their cultural competency and reduce the stigma that patients experience while in care.”7

Laura Nyblade, an expert on HIV/AIDS related stigma in health care settings from the Health Policy Project, presented her work to develop a stigma measurement tool to the Quality of Care Clinical and Consumer Advisory Committees in June of 2015. Nyblade and colleagues assert that few institutions have attempted to scale-up “stigma reduction programs in service delivery” in part because they do not have a “brief, simple, standardized tool for measuring stigma among all levels of health facility staff that work across diverse HIV prevalence, language and healthcare settings.”2 Nyblade and colleagues argue that measuring stigma in healthcare facilities, followed by the implementation of stigma-reduction programs, is critical for improving the quality of care provided to PLWH. The tool developed by Nyblade and colleagues, which was field tested in China, Dominica, Egypt, Kenya, Puerto Rico, St. Christopher & Nevis, measures “three programmatically actionable drives of stigma within health facilities (worry about HIV transmission, attitudes towards people living with HIV, and health facility environment, including policies), and enacted stigma.” The domains of the comprehensive tool include infection control, health facility environment, health facility policies, and opinions about PLWH and key populations. The Health Policy Project offers this comprehensive tool, as well as a seven question monitoring tool on http://www.healthpolicyproject.com/index.cfm?id=stigmapackage.6

In addition to the Health Policy Project’s tool for measuring stigma in healthcare facilities, UNAIDS has developed “The People Living with HIV Stigma Index,” located at http://www.stigmaintdex.org/. More than 50,000 PLWH have been interviewed for the project since 2008, encompassing 50+ countries. UNAIDS has developed a PLWH Stigma Index questionnaire, which has been translated into more than 50 languages.8 Whereas the tool developed by Nyblade and the Health Policy Project focuses on measuring the levels of stigma present in health care facilities, the PLWH Stigma Index seeks to both measure the levels of stigma experienced by PLWH to shape the development of “programmatic
interventions and policy change” and empower PLWH to address HIV/AIDS related stigma as individuals and members of a larger community.

Similar to the UNAIDS PLWH Stigma Index, the HIV Stigma Scale (HSS), which was developed in the early 2000s and has recently been adapted for children living with HIV, serves to measure internal stigma, rather than HIV/AIDS related stigma present in a healthcare setting.\(^9\)\(^10\) The standard HSS has 40 items and is used to measure 4 components of internal stigma including: personalized stigma; disclosure concerns; negative self-image; and concerns with public attitudes.\(^9\)\(^10\) Earnshaw and colleagues recently used the HSS to measure how different types of stigma impact an individual’s health. According to their research, high levels of internalized HIV/AIDS related stigma are associated with negative health and well-being, and a “greater likelihood of ARV non-adherence.” Individuals with high levels of anticipated HIV/AIDS related stigma were more likely to have another chronic illness, and individuals with high levels of enacted HIV stigma were likely to have a CD4 count lower than 200.\(^5\)

At the June Advisory Committee meetings, Nyblade also discussed recent progress in the development of HIV/AIDS related stigma reduction interventions. “Stigma reduction interventions are based on three overarching principles: addressing immediately actionable drivers, placing affected groups at the center of the response, and creating partnerships between affected groups and opinion leaders. Contact strategies aim to put people experiencing stigma in contact with those who enact it, as the ability to empathize with each other reduces stigma.”\(^6\)

In 2013 Stangl and colleagues conducted a review of 48 HIV/AIDS related stigma reduction interventions, which built on the first ever review conducted by Brown and colleagues in 2003.\(^11\)\(^12\) As of 2013, most studies of stigma reduction interventions had been conducted outside of the United States and Western nations. Whereas 40 of the interventions identified by Stangl and colleagues were conducted in Africa and Asia, only 5 were conducted in North America, Western and Central Europe.\(^11\)

New stigma reduction interventions have been documented in the United States since 2013. In June, Nyblade referenced the ongoing work of Janet Turan at the University of Alabama at Birmingham, who has implemented an intervention targeting stigma reduction in healthcare settings. The intervention, based on intensive, multi-day workshops with consumers and healthcare workers, was found to reduce consumer scores on negative self-image, disclosure concerns, and enacted stigma and increase empathy scores for healthcare providers.\(^6\) In 2014, Barroso and colleagues published a randomized control trial of a stigma reduction intervention implemented in North Carolina. The intervention was targeted at improving “self-esteem, coping self-efficacy, and internalized stigma” in HIV+ women through the provision of an iPod Touch with a 45 minute motivational video that participants were required to watch every week for four weeks and then on a voluntary basis for another eight weeks.\(^4\) The authors found that the intervention resulted in an increase in self-esteem, coping self-efficacy, and lower levels of overall stigma.\(^4\)

Although Stangl and colleagues concluded that significant progress has been made in developing and implementing effective stigma reduction interventions since 2002, there are a number of outstanding issues that need to be addressed. The authors note that determining which interventions are most effective for reducing stigma in different settings is limited by the dearth of “standardized outcome measures for stigma and discrimination.”\(^11\) Measuring the impact of stigma-reduction interventions is further inhibited by the simultaneous implementation of multiple components, which makes conducting randomized control trials and establishing causality challenging.\(^11\) Additionally, Nyblade notes that
neither the cost effectiveness of stigma reduction interventions nor their effect on other simultaneously implemented interventions for issues like linkage and retention have yet to be properly measured.

As New York State works towards ending the HIV/AIDS epidemic by 2020, healthcare facilities should seek to measure and address HIV/AIDS related stigma. Reducing HIV/AIDS related stigma is an important component in improving access to prevention, treatment, and care services.¹

Appendix 2: Discussion Questions

Ending the Epidemic Dashboard

Purpose: In response to the recommendations of the Ending the Epidemic Initiative Taskforce Blueprint, Hunter College and The CUNY School of Public Health have developed an ETE Dashboard System to measure, track and disseminate actionable information on the progress of the Initiative. Data content realms include prevention, new infections, HIV testing, new diagnoses and linkage, prevalence and care, AIDS diagnoses, deaths among PLWHIV. The purpose of this discussion is to get feedback and recommendations on the use of data sources and visual presentation of the dashboard.

Questions:
1. What is your opinion of the layout and overall display of data on the dashboard? Would you recommend changes based on different literacy levels for different audiences?
2. What general comments do you have on existing data sets and are there any additional data sets or modifications to the data content that you would recommend be incorporated into the dashboard? Are there other aspects of HIV care and prevention that should be measured and displayed by the dashboard?
3. Which key metrics should be used for presenting information about the quality of HIV care and from which data sources?
4. Does the dashboard reflect key population demographics? How would you refine the dashboard to reflect key populations?
5. Is the dashboard user friendly and accessible for all audiences? Are there any additional features you would recommend?
6. Should a separate dashboard be developed in Spanish? What should the page on “communities” include?
HIV/AIDS Related Stigma

**Purpose:** Stigma remains a frequently identified barrier to achieving desired health outcomes. The Ending the Epidemic Blue Print calls for healthcare providers to “increase their cultural competency and reduce the stigma that patients experience while in care.” In order to address this recommendation we are seeking to integrate stigma reduction into the framework of the quality of care program. The purpose of this section is to gather input to achieve this goal that we believe will lead to reducing stigma in healthcare facility.

**Questions**

1. How should stigma reduction be addressed within facility-based quality management programs?
2. How can stigma be measured within healthcare organizations? Do the domains in the Nyblade framework (listed below) make sense? Which would be appropriate for New York State’s Quality of Care Program?
   a. Infection Control
   b. Health Facility Environment (observed and secondary stigma)
   c. Health facility policies (training, policies)
   d. Opinions about patients (willingness to treat; observed and secondary)
3. Which specific measures would you recommend to assess stigma present in healthcare facility settings?
4. How can assessment of patient experience be used to measure and address different types of HIV/AIDS related stigma?
5. How can providers effectively engage affected communities in addressing stigma as a driver of quality? How can all departments in the hospital or CHCs be involved?
6. Should healthcare facilities be required to implement quality improvement projects to reduce levels of stigma in their facilities?
7. What types of stigma (anticipated, enacted, internalized, etc...) should the Quality of Care program focus on addressing? How should the program address these different types of stigma?
Quality of STI Care

**Purpose:** The AIDS institute is uniquely positioned to measure and improve the quality of STI care in NYS, but no formal system to monitor the quality of STI care in healthcare institutions exists in NYS. The HIV Quality of Care Clinical and Consumer Advisory Committee and STI care subcommittees should explore strategies to measure quality of care while also examining existing data sources measuring incidence and prevalence to identify areas of priority for clinical education and improvement.

**Questions:**

1. In your opinion, what is the most important measure to capture the quality of STI care for all New Yorkers? For all New Yorkers living with HIV? For MSM/Transwomen?
2. What do you believe is the best measurement source for STI quality indicators? For the general population? For the HIV population?
3. Sexual history taking often comes up as an important quality of care measure? What do you think is the best way to measure this in patient records or data systems?
4. How would you suggest that we engage health facility – both hospital and CHC – programs in integrating STI quality, including diagnosis, treatment and follow-up into their quality improvement programs, quality committees and measurement systems? (How do we get past the focus on reporting cases to the health department?)
5. How do you think healthcare facilities should engage with communities to address the rising rates of STIs that are occurring and presenting to their facilities?
6. What additional resources do you think are needed to address the quality of STI Care and to assure that standards of care are met?
7. How can we increase provider awareness about and provider competency to manage STIs? (In addition to the STI Clinical Education Center of Excellence).
8. How do we engage and train providers who are not STI practitioners on quality STI care most effectively?
9. What challenges and opportunities does PrEP offer for STI diagnosis and care?
Appendix 3: Presentations
Ending the Epidemic in New York State
HIV Quality of Care
Clinical and Consumer Advisory Committee
Joint Meeting
September 8, 2015

November 25, 2015

Defining the End of AIDS
Goal
Reduce from 3,000 to 750 new HIV infections per year by the end of 2020.

Three Point Plan
1. Identify all persons with HIV who remain undiagnosed and link them to health care.
2. Link and retain those with HIV in health care, to treat them with anti-HIV therapy to maximize virus suppression so they remain healthy and prevent further transmission.
3. Provide Pre-Exposure Prophylaxis for persons who engage in high risk behaviors to keep them HIV negative.

Governor Andrew Cuomo announcing his new initiative to combat the AIDS epidemic before the 2014 NYC Gay Pride Parade.

Credit: Michael Appleton for The New York Times

New York State Cascade of HIV Care, 2013
Persons Residing in NYS at End of 2013

Estimated HIV Infected Persons
Persons Living w/ Diagnosed HIV Infection
Cases w/consecutive care during the year*
Cases w/ continuous care during the year**
Virologically suppressed (v.e. < 400 Copy/mL) at test closest to end of year***

* Any 6 to 12 tests in the year
** At least 2 tests, at least 3 months apart
*** At least one test at the end of the year

Overview
• Until this year, all NYS HIV Surveillance reporting of persons living with diagnosed HIV infection (PLWIDH) has been based on residence at HIV or AIDS diagnosis
• Accurate reporting of measures of success of care and effective program planning at the sub-state level require counts of persons actually resident in the area (e.g. county)
• The Bureau of HIV/AIDS Epidemiology has developed a method to report estimated PLWIDH by most recent known address and used it to produce Cascades of Care for 2013.
Rationale for the Change

- Through improved treatment PLWDH are living longer lives. Among PLWDH in NYS in 2013, mean time since diagnosis was 13 years. Residence at diagnosis may not reflect current residence.
- Persons diagnosed in other states but now resident in NYS are not included in the current method, which counts only cases with NYS or foreign country residence at diagnosis.
- For many NYS-diagnosed cases the surveillance system has no evidence of NYS residence in recent years.
- Some cases are likely no longer alive and/or resident in NYS.
- By continuing to count them we are likely overestimating the number of PLWDH and their service needs.
- Because we lack any lab data for them, they appear to be out of care, and we are underestimating performance measures such as continuity of care and viral suppression.
- Other surveillance jurisdictions (NHC, MA) have excluded such cases from some published statistics.

New and Expanded Programs

- NY Links, improve systems for linking to and retention in care.
- Expanded Partner Services Program (ExPS) uses HIV surveillance data to identify and re-engage individuals in medical care.
- The Linkage, Retention and Treatment Adherence Initiative facilitates patient entry into treatment, promotes adherence to antiretroviral treatment (ART), and viral suppression.
- Positive Pathways, working with HIV-positive incarcerated persons to encourage the initiation of medical care.
- Development of a Peer Certification program for persons with HIV/AIDS.
- Hospital review for HIV testing conducted by IRB.
- Utilize the new HIV testing algorithm to diagnose asymptomatic initial HIV infections.
- Use of surveillance data for both Medicaid and DOCCS enrollees.
- New syringe exchange program sites and use of peers to work with young injecting.
- Expand targeted health care services to young MO and transgender persons.
- ARV MHA to fund the linkage of up to 1,000 people from the populations at greatest risk for HIV/AIDS to ARV.
- January 1, 2015 start up of IPD – AP to provide reimbursement for necessary primary care services for eligible individuals.
- Use of targeted social marketing and messaging efforts to identify persons with HIV.

HIV Test Policy and Hospital Review Timeline of activities 11/1/14 – 6/30/15

DOH requested that all Article 28 healthcare settings in NYS, with an active medical Emergency Department (N=195) provide a copy of their HIV testing policy, promoting routine HIV testing in the hospital, including the Emergency Department and inpatient settings.

- Onsite chart review using standard tool - completed in May 2015
- Final reports received June 2015
- Comparative analysis of HIV testing policies and rates of HIV testing in Emergency Departments to assess successful strategies and areas for improvement
- Review of Emergency Department medical records at a sample of 27 hospitals, across NYS
- 200 cases at each site were sampled from SPARCS data provided by DOH, for record review
- Crystal chart review using standard tool - completed in May 2015

HIV Testing Documentation Findings

- Low performance of both HIV and Hepatitis C testing documented in EDs reviewed; however, the review period was prior to ‘ETE’.
- Expand review using 2015 Emergency Department visits to evaluate implementation of HIV testing policies and efforts to increase acceptance of HIV testing.
Current PrEP Initiatives

- PrEP Education Campaign: “HIV Prevention Just Got Easier”
- Implementation of a PrEP pilot in six sites
- Enhancements to 23 provider contracts to include on-site PrEP Specialists
- $1 Million to fund “One Stop STD Clinics” in NYC
- $3 million directed toward linking up to 1,000 people from the populations at greatest risk for HIV/AIDS to PrEP
- A Community Health Center survey on PrEP is underway
- PrEP Medicaid analysis shows a significant increase in PrEP utilization since the Governor’s announcement in June 2014

www.prepforsex.org

PrEP-AP is serving a younger, slightly higher income and predominantly uninsured group of people.

LGBT Health: Beyond the Epidemic

July 13-15, 2015
Hilton Garden Inn, Troy, New York

DOCCS Match

- Match between surveillance and DOCCS census data.
  - Confirmed 2.5% sero prevalence in NYS prisons.
  - Approximately 1,000 DOCCS inmates are linked to care.
  - Public health worker follow up with those individuals identified out of care.

Activities Report Card & Dashboard

The AIDS Institute will develop and post an annual ETE Activity Report Card to assist in sharing progress towards our stated goals as well as on recommendations included in the ending the epidemic Blueprint document.

Key metrics will be systematically tracked at the state and local levels, with publicly available results. The AIDS Institute will develop an ETE Dashboard which will assist in sharing progress towards our stated goals and share key metrics and data relevant to ending the epidemic in NYS.

ETE Dashboard

- Prevention
- Surveillance
- Case reporting
- HIV testing
- New diagnoses
- Acute infections
- Transmission
- Linkage to care
- New diagnoses and linkage to care
- New diagnoses and continued care
- Case reporting and care
- Quality of care
- Health and social services
-MAC
- Number of new AIDS diagnoses
- Number of deaths among persons with AIDS

DOCCS Match

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  - Public health worker follow up with those individuals identified out of care.
Implementation: AAC ETE Subcommittee

AIDS Advisory Council (AAC) Ending the Epidemic (ETE) Subcommittee:
The Subcommittee will ensure on-going formal involvement of the AAC in follow-up and recommendations on the implementation of the Ending the Epidemic Task Force (ETE TF) recommendations.

- 16 Members: The selection of members to the Subcommittee was conducted as part of the completion of the work of the ETE TF and is representative of each ETE TF Committee
- Bi-Monthly meetings
- Co-Chairs: Charles King, President and CEO, Housing Works, Inc.  
  Marjorie Hill, PhD, CEO, Joseph Addabbo Family Health Center
- Ending the Epidemic Website: https://health.ny.gov/EndingtheEpidemic

Gathering Implementation Strategies

The SurveyMonkey to collect implementation strategies in support of Blueprint Recommendations is currently being drafted and will be released publicly Thursday, October 22, 2015.

It will be available on the ETE webpage: https://health.ny.gov/EndingtheEpidemic

NYS Regional Discussions

- Receive updated information about HIV/AIDS in your region/borough.
- Provide input on identified service gaps in your region/borough.
- Participate in region/borough discussions about ending the epidemic.

<table>
<thead>
<tr>
<th>NYS Regional Discussion Dates</th>
<th>Locations</th>
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<td>November 13</td>
<td>Suffolk County</td>
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Dan O’Connell  
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November 25, 2015
**Ending the Epidemic:**
Making NYC the Epicenter of the End of AIDS

Demetre Daskalakis MD MPH
Assistant Commissioner
NYC Department of Health
Bureau of HIV Prevention & Control

**Bending the Curve=Making a Change**

Total New Yorkers living with HIV/AIDS

New HIV infections

HIV/AIDS deaths

**Number and Proportion of Persons with HIV in New York City Engaged in Selected Stages of the Continuum of HIV Care in 2013**

- 100% HIV tested
- 86% Diagnosed
- 79% Retained in care
- 74% Prescribed ART
- 64% Virally suppressed

**The New HIV Neutral Continuum of Care**

HIV Care and Prevention are the Same=Getting to HIV Neutral
Ending the Epidemic

• Identifying persons with HIV who remain undiagnosed and linking them to health care
• Linking and retaining persons with HIV to health care, getting them on antiretroviral therapy to improve their health and prevent transmission
• Providing Pre-Exposure Prophylaxis (PrEP) to high-risk persons to keep them HIV-negative.

Ending the Epidemic: The Challenge

• Identifying LGBTQ youth of color and other men and women not served by healthcare with HIV who remain undiagnosed and linking them to health care
• Linking and retaining LGBTQ youth of color and other men and women not served by healthcare with HIV to health care, getting them on antiretroviral therapy to improve their health and prevent transmission
• Providing Pre-Exposure Prophylaxis (PrEP) to LGBTQ youth of color and other men and women not served by healthcare at-risk to keep them HIV-negative

Our Goal

• To keep everyone in NYC undetectable
• People with HIV have a right to services and high quality care that promote VLS and general health
• People at risk of HIV have the right to access prevention so they DO NOT GET HIV.

HIV Testing is the key that unlocks the gateway of our new paradigm

In New York City we will make HIV negative and positive test results an equivalent call to action. Both require linkage to care and services

New York Knows Goals

✓ Provide a voluntary HIV test to every New York City resident who has never been tested
✓ Make HIV testing a routine part of health care in New York City
✓ Identify undiagnosed HIV-positive people in New York City and link them to medical care
✓ Connect people who test negative for HIV to prevention services, including PrEP
BeHIVSure Coalition

- Three summits to bring together LGBTQ focused organizations, HIV focused organizations and funders
- Almost 70 local organizations signed on to work together to end AIDS in NYC
- Steering committee formed

Transgender Health Guides

- Transgender Women’s Health guide—available on NYC DOHMH website
- Transgender Men’s Health guide—coming soon
- Transgender CHI—coming soon

City Health Information: Comprehensive Care for MSM and People of Trans Experience

- Provide a welcoming environment for MSM and Trans People
- Take a sexual history as a routine part of primary care
- Routinely screen for alcohol, drug use, depression, HIV and other STIs
- Counsel on consistent condom use as well as PEP and PrEP
- CME Credit—Clinical Symposium: Providing Comprehensive Health Care to Men who have Sex with Men

Viral Load Suppression NYC Clinics
HIV Care Continuum Dashboards (CCD)

- Facility-specific data provided to key members of the organization (CEO, CMO, Clinic Medical Director) regarding timely linkage to care of newly diagnosed patients and viral load suppression among patients in care for that particular facility.
- December 2012: first release of CCD to 21 sites; biannually since.
- 2014 releases: increase in number of sites receiving CCDs.
  - June: 35 sites
  - December: 46 sites (67% PLWHA in NYC)
- December 2015: public release.
- New position: Director of Clinical Operations and Provider Communications.

PrEP and PEP Detailing/Action Kit

- Increasing PrEP & PEP Awareness
  - Share the Night, Not HIV
  - We Share Everything but HIV
- Awareness of PrEP Among MSM*, NYC, 2012-14

Use of PrEP Among MSM*, NYC, 2012-14

- Medical Records Monitoring
  - PrEP Prescription per 100,000 Patients Seen at Ambulatory Care Practices (n=542), NYC, 2012-2014
  - Logarithmic scale
Thank You!

ddaskalakis@health.nyc.gov
Tracking and Disseminating Information on Progress Towards Ending the AIDS Epidemic in New York: A Dashboard System

Denis Nash, PhD, MPH
Hunter College, City University of New York

Outline

- Genesis of the EtE Dashboard System project
- Overview of the purposes of the EtE Dashboard System
- Demo of the system (hopefully live!)
- Plans for system launch
- Timeline going forward

Blueprint recommendation 29

- Extend and enhance the use of data to track and report progress
  - “The creation of a web-based, public facing, Ending the Epidemic Dashboard system is recommended to broadly disseminate information to stakeholders on the (EtE) initiative’s progress.”

Key Purposes of EtE Dashboard

- Measure, track and disseminate actionable information on progress towards achieving the Ending the Epidemic (EtE) initiative’s goals in NYS to all who need to know
- Disseminate key metrics aligned with the EtE blueprint aims:
  - Identify persons with HIV who remain undiagnosed and link them to care
  - Link and retain persons diagnosed with HIV in health care to maximize viral suppression on they remain healthy and prevent future transmission
  - Facilitate access to EtE for high-risk persons to keep them HIV negative
- Create a visual and interactive experience that allows stakeholders (users) to get the information they want in visual and tabular format
  - Content and geographically-driven
  - Integrated at the geographic level (GIS driven)
- E.g., access the most recently available data on new diagnoses, prevalence, and testing rates for a given county (or group of counties) side by side in one place.

Data sources, content, and functionality

- EtE-related aggregate data from different realms and data sources
  - Real-time: e.g., prevention, incidence, testing, new diagnoses, prevalence and care, AIDS diagnoses and deaths
  - Data sources: e.g., HIV surveillance, vital statistics, eHIVQual, eTransmission, STD surveillance, NY Links, Medicaid
  - ZIP/county-level aggregate “data streams”
  - Updated frequency (e.g., quarterly when available)
- Integrate by geography and calendar time
- Display high level EtE metrics on a splash page to allow stakeholders to assess status/progress ‘at a glance’
- Ability for users to ‘drill down’ for further detail across and within realms for specific geographic areas and population groups (e.g., gender, race/ethnicity, transmission risk)
Quality indicators

Key challenges

- Timeliness of some metrics
  - Significant lag time for some data sources (e.g., case surveillance)
- Data needs and gaps
  - E.g., PrEP and nPEP indicators; harm reduction, prevention cascade; supportive services, housing stability, vocational opportunity
- Availability of data at the county or ZIP code level with further ability to stratify
  - Small numbers may prevent inclusion of some data stratified by gender, race/ethnicity, transmission risk, etc due to confidentiality issues
- Trends: not all metrics will be available routinely

Key strengths

- Comprehensiveness
  - Wide array of relevant EtE indicators in one place, from prevention to HIV-related deaths
- Integration
  - Brings together previously siloed data across various realms and data sources
- Visual and interactive
  - Provides the potential to lead to new insights
- Accessibility
  - Content useful to a wide range of stakeholders with different data needs
- Tailored to the EtE initiative
  - Will help track and disseminate information about the EtE Initiative’s progress
  - Can help target resources, programmatic efforts, and advocacy where they are needed most
Plans for system launch

- Email blast announcing the system launch
  - Targeting about 700 persons
  - Task force members and affiliates,
  - Those who have submitted emails requesting notification
  - Other key stakeholders
- Describes purpose of the EtE Dashboard system, FAQs, and links to the site
- Ability to register to receive communications from the Dashboard system
  - Updates, new data sources, visualizations, blog posts, announcements, etc.
- Social media
  - Use Twitter hashtag (etedashboardny)
  - Follow the EtE Dashboard on Twitter and Facebook

NY EtE Dashboard Timeline

- Incorporate feedback from AIDS Institute staff
  - Committed to system
  - Ability to reflect ‘qualitative’ dashboard content from EtE Blueprint (e.g., legislative progress)
  - Ability to drill down on metrics from state to local level
- Receive and incorporate post-launch feedback on the EtE Dashboard System
  - Multiple stratifications for statewide and citywide annual numbers (e.g., time, gender, race-ethnicity, risk category)
- Curation of key additional streams and integration of data (ongoing)

Extra slides

Stratification (or sub setting)

- Stratifications by county for maps and trends:
  - Time*, gender, age
  - Time*, gender, risk category
  - Time*, gender, race-ethnicity
- Multiple stratifications for statewide and citywide annual numbers (e.g., time, gender, race-ethnicity, risk category)