

## **AAC ETE Subcommittee Data Workgroup**

### **Implementation Strategy Focus Area 1: PrEP Data**

**Recommendation 1:** The AIDS Institute should explore the legality and potential for utilizing Regional Health Information Organizations (RHIOs) to establish systems of measurement related to the utilization of Pre-Exposure Prophylaxis (PrEP) and quality of PrEP related services. A pilot project with Healthix, Inc. should be initiated to assess the feasibility of this process, with the hopes of creating a scalable model that can be expanded across additional RHIOs within New York State. As the scale up of RHIOs progresses, Providers and Health Plans continue to sign on and begin sharing increasing amounts of data with their local RHIO. Important to note is the need for participant organizations (providers, health plans, MCOs) to transmit both prescription data and claims data to the RHIO. Healthix, Inc., being New York State's largest RHIO, has established relationships with over 200 participant organizations and contains information on over 10 million patients. Data contained within this system would provide invaluable information related to PrEP utilization, which will assist in providing measurement towards Ending the Epidemic in New York State.

**Recommendation 2:** The AIDS Institute, in conjunction with the NYCDOHMH and local health departments with capacity, should explore the possibility of creating uniform guidance to providers recommending a standard set of ICD-9/ICD-10 codes to be used for indicating Pre-Exposure Prophylaxis (PrEP). There is a great deal of variability in the provider community with regards to coding, efforts currently being made to analyze PrEP related activity are based on assumptions and proxies due to a lack of consistency in coding. A guidance document indicating codes to be used specifically for PrEP will greatly improve analytic capability when assessing data contained within Health Systems, EMRs, and RHIOs.

**Recommendation 3:** The AIDS Institute, NYCDOHMH, and local health departments with capacity should continue to collect parallel sources of PrEP related data within their respective surveillance systems to assist in measurement of PrEP utilization by including PrEP use history information at time of HIV diagnosis.

**Recommendation 4:** Initiatives are underway that look to characterize the size and features of the population that is in greatest need of PrEP, as well as data reviews to help identify individuals within healthcare systems who should be offered PrEP. We seek to facilitate the work of these groups and ensure that the results of these efforts are available publicly. There is a need to identify screening characteristics that can be used to identify individual patients who are in need of PrEP.

A verified screening tool that can be utilized for system-wide screens (EMRs, managed care plans, RHIOs) as well as in one-on-one screens for patients would facilitate the rapid identification of patients in need of PrEP.

The committee will reach out to NYSDOH to receive information on their process related to determining state-wide population size, as well as to Healthix to identify their methodology to determine if there are opportunities to meet this need under existing efforts.

## **AAC ETE Subcommittee Data Workgroup**

### **Implementation Strategy Focus Area 2: Data Systems and Analytics**

The focus of this workgroup was on the over-arching data systems and analytics that either need to be developed, or that need to be modified from existing sources, in order to meet the goals of the End the Epidemic (ETE) Campaign. Specific data issues related to individual ETE programs were the focus of other workgroups.

**Recommendation 1:** NYS DOH should under-take a review of the DOH controlled data systems (Surveillance, AIRS, eHIVQual, IPRO, etc.) to identify what information can be provided to clinical and non-clinical providers in a timely manner with the goal of supporting patient care, retaining patients in HIV treatment, and, conducting outreach for patients who drop of out care. The review should be inclusive of members of the surveillance teams of NYS and NYC departments of health, as well as clinical and non-clinical providers, consumers, and those who can provide guidance on the legality of different information sharing options. Additionally, the review should provide a tiered level of analysis that highlights the limitations of data provided in different timeframes to allow for a full understanding of what information can be available when, and the potential related limitations.

Recent approaches in NYC to give providers access to surveillance-related information to determine care status for patients who are no longer coming to clinic have been welcome. However, the data are not very timely. It has been noted that laboratories report CD4, VL and other HIV related tests on a daily basis, and it seems that more could be done to give providers access to more timely data around care status.

**Recommendation 2:** NYS DOH should facilitate a formal review investigating the value and plausibility of establishing a dedicated HIV patient information sharing portal. The goal would be to create a mechanism for clinical and non-clinical providers to share real-time information on individual patients, and the patient would maintain control of which providers are included in their personal information-sharing network. The review should include the patient portal currently developed within the RHIOs and the SHIN-NY and the capacity to utilize these existing systems or to build upon the existing infrastructure.

**Recommendation 3:** In an effort to capture essential information on the value of individual initiatives and activities, the NYS DOH should establish a mechanism to capture macro data on the ETE-related programmatic activities occurring across the State. The ETE Initiative currently does not have a systematic mechanism for tracking new programmatic implementation that is being implemented in support of the initiative's aims. This information exists in state and city health department databases, but there is no way to systematically disseminate it and overlay it with key epidemiological outcomes; such as number of people on PrEP, HIV incidence, late HIV diagnosis rates, prevalence, AIDS diagnoses, and death rates. Having this information would allow ETE Initiative stakeholders to see how implementation towards achieving the ETE Initiative's goals is being rolled out, to see where the implementation gaps are, and to assess the effectiveness of implementation on key outcomes. Given the scope of this initiative and the value not just to NYS's efforts, but to other municipalities seeking to learn from our efforts, a database of ETE initiatives linkable to standard outcome measures should be established. This database would be a required reporting element of any program receiving ETE related funds and/or implementing ETE-related activities (NY Links, OneStop, etc), and could be an encouraged reporting element for DSRIP projects and other community initiatives. It is recommended that the

reporting process be standard allowing limited – if any – free text options, along with a standard definitions set to maximize understanding of what programs are running and the outcomes of these programs. Program level information related to what services are occurring and where, can be provided to the public through the ETE Dashboard System ([www.etedashboardny.org](http://www.etedashboardny.org)).

**Recommendation 4:** NYS DOH should review the recent collaboration between the AIDS Institute and the largest health plans related to un-suppressed patients to identify any issues/concerns/obstacles related to these types of collaborations with the goal of expanding these data sharing arrangements. Initial, limited feedback has identified potential improvements related to sharing more patient specific information (i.e., actual lab results and dates as opposed to ranges of laboratory test results) and updated patient demographic data to help better match data within health plans with the data provided from the State. The goal of this effort would be to establish a model for increased data sharing between the State and health plans.

**Recommendation 5:** Working with the major health plans, NYS DOH should investigate the value in establishing standard reports that health plans share with front-end providers related to their patient/member panel. Information could mirror the types of utilization data common in ACO agreements. The goal would be to provide a more comprehensive view of care, and a standard across plans, allowing providers with multiple payers to have equal access to similar information across their panels of insured patients.

## AAC ETE Subcommittee Data Workgroup

### Implementation Strategy Focus Area 3: Housing Data

**Recommendation 1:** *Make the AIRS Housing Question a System “Hard Stop” Requirement for Regular Updates:* New York State Department of Health (NYSDOH) should routinely collect housing related data at visits by making the AIRS housing question a system “hard stop” requirement for regular updates. The housing question is currently required at intake, and an “at least annual” update of the Housing question is a programmatic requirement, but the recommendation is to make responding to the housing question a system requirement, with updates required at least semiannually.

**Recommendation 2:** *Align AIRS/eShare Housing-related Categories with NYS/Federal Housing Categories:* The current AIRS/eShare housing information should be aligned with housing categories utilized by other New York State and Federal housing programs. When possible, the AIRS/eShare categories should match common housing categories. If not, the AIRS/eShare categories should be able to “roll up” into common categories. This alignment should occur with as many NYS and Federal housing related programs as possible, specifically the Health and Recovery Plans (HARPs) assessment, the Ryan White Services Report (RSR), the NYC Department of Homeless Services (DHS) and Human Resources Administration (HRA) Division of HIV/AIDS Services (HASA), and CARES HMIS.

**Recommendation 3:** *Coordinate with State and City Agencies to Improve Housing Status Data Collection for People with HIV (PWH):* NYSDOH/AIDS Institute should work with other State agencies, including the Office of Temporary Disability Assistance (OTDA), to assess feasibility of obtaining housing-related data on a regular basis.

Information on HIV status within the Homeless Management Information System (HMIS) is highly incomplete, which could be a missed opportunity for data collection on individuals affected by both housing instability and HIV. Disclosure of HIV information is not and should not be required by applicants for homeless services, but as New York City has demonstrated by matching shelter and HIV surveillance data, administrative data matching provides an important tool for evaluating housing need by users of other public systems.

The AIDS Institute should explore matching state HIV surveillance system data with housing related information systems, such as the CARES HMIS, as well as data maintained by the Office of Temporary and Disability Assistance. The AIDS Institute should explore the feasibility of this match and analyze any potential legal obstacles.

**Recommendation 4:** *Establish Real-time Assessment of Centralized Housing Data Sets:* When NYC matched the DHS shelter system database with HIV surveillance data for the year 2013, the City Department of Health and Mental Hygiene (DOHMH) determined that approximately 1,300 unique persons diagnosed with HIV used the City shelters for at least one night during 2013; based on this match it can be estimated that approximately 800 persons with diagnosed HIV infection use the DHS shelter system on any given night. Although this type of data match provides historical information only, DOHMH and DHS have a current data sharing agreement that can be used to run daily matches of new DHS admissions against HIV surveillance data to identify HIV-positive clients in the DHS system.

Identification of an HIV-positive person entering the DHS system should trigger notification of Disease Intervention Specialist (DIS) staff to identify PWH in need of retention in care services or to engage the

identified person for referral to the HASA and/or other medical and social supports. The DOHMH/DHS data match should occur daily for now, with a view to moving as quickly as possible to use of a real time interface between the systems in order to maximize outreach, engagement and retention of homeless persons with HIV in care. It is important to note that implementing this recommendation is dependent upon changes in the NYS Public Health Law to allow sharing of HIV information with care coordination providers, and upon the expansion of HASA services to all income eligible people with HIV infection.

## **AAC ETE Subcommittee Data Workgroup**

### **Implementation Strategy Focus Area 4: Gender Identity/Data on Transgender New Yorkers**

The focus of this workgroup is to identify gender identity and transgender data gaps and needs, and propose recommendations to advance New York State's current data collection systems. The workgroup aims to propose implementation recommendations for the ETE initiative that will ultimately help to account for transgender New Yorkers living with HIV and at risk for HIV infection.

**Recommendation 1:** NYS DOH AIDS Institute should increase their efforts to capture data on currently diagnosed transgender people. Adding a "sex assigned at birth field" in AIRS, in addition to the already existing gender identity field, should allow for consistent identification and reporting of transgender people. Additionally, guidelines to assist the providers with inputting this data should be distributed.

#### *Background:*

There has been recent changes to the HIV Surveillance provider report form to reflect the above recommendation. The transgender options include: transgender MTF, transgender FTM, additional, or unknown. The unknown option should act to discourage providers from making an assumption if the provider is not aware of the patients' gender identity. The patient is not always in front of the provider when filling out the form. NYC and NYS use the same form, which is consistent with CDC.

The AIDS Institute has already started to make changes to AIRS. Previously, there was only a gender field, and no sex assigned at birth field. Programmers have started the process of adding the sex assigned at birth field to AIRS, which will bring some consistency to the changes on the HIV Surveillance provider report form. However, current gender options are: male, female, transgender male, and transgender female. There is no unknown or additional field option. Currently, inclusion of an unknown category is not necessary because the client is present when intake is happening which allows for self-identification. Also, there is concern that an unknown field would become the "default category", and would cause issues with data reliability and federal reporting.

Upgrades to AIRS occur on a quarterly basis. The next changes will not go into effect until April or May. Guidelines will be disseminated during the next upgrade. Future AIRS changes will consider a field that captures those who do not conform to the gender binary (e.g. gender non-conforming, gender fluid). Additionally, future AIRS changes will consider the gender identity reporting of other NYS systems and CDC (i.e. male, female, MTF, FTM, additional, unknown). The Medical Monitoring Project (MMP) records transgender data, and could be another source of information.

**Recommendation 2:** The NYS DOH AIDS Institute should retrieve an updated worksheet, detailing how gender identity and transgender data is collected in state systems. The goal would be to identify gaps, particularly in the Medicaid system, and propose that they specifically add transgender fields.

#### *Background:*

The AIDS Institute is trying to access an updated sheet from the Interagency LGBT Taskforce. The last version had no Medicaid information. The focus group is awaiting the result of conversations between Charles King and Jason Helgerson.

**Recommendation 3:** The NYS DOH AIDS Institute should collaborate with NYC DOHMH to estimate the population of transgender and gender non-conforming people in New York State. The goal would be to consider current research findings (e.g. Williams Institute) and the limitations that exist with the methodology, to calculate a range for the denominator that is reflective of the unique nature of NYS.

*Background:*

The [Williams Institute](#) proposes that transgender people make up 0.03% of the United States population. When that figure is applied to NYC, it yields 25,000 transgender people; however it is likely that a city like NYC would have a higher prevalence of transgender people since it is a “magnet” for this population. Beyond the [existing](#) limitations that exist with identifying transgender people, this method is based on social security records and name changes. Not all transgender people have access to the resources to achieve a gender marker change, and some may have gender ambiguous names. A range would be needed, with 25,000 on the lower end of this range. NYS DOH AIDS Institute and NYC DOHMH should research this issue further, and account for transgender people who were not able to get a name change. Ultimately, a starting point is needed for the potential denominator, and we can change it when more information becomes available.

**Recommendation 4:** The NYS DOH AIDS Institute should work with providers to streamline and best capture gender identity and transgender information. NYS and NYC Surveillance should collaborate with providers to update and provide complete and accurate information regarding transgender status for new and existing clients. The NYS DOH AIDS Institute should encourage and support the development of a second NYC study/assessment that will help to offer a systematic effort to capture transgender data.

*Background:*

NYC DOHMH conducted a project/study in the past, with specific providers that serve a high proportion of transgender individuals. There is interest to do this study again, since there is no systematic effort to try and collect this information. The reported number of transgender people living with HIV is perceived to be a low estimate. It is recommended that NYC and NYS DOH work collaboratively with providers to better collect data overtime. An AIRS and surveillance match is currently underway at the AIDS Institute.

## **AAC ETE Subcommittee Data Workgroup**

### **Implementation Strategy Focus Area: Other Focus Areas**

**Recommendation 1:** The AAC ETE Subcommittee should periodically, or as needed, reconvene the AAC ETE Subcommittee Data Workgroup to review and evaluate progress towards implementing the recommended strategies. The 2nd annual conference on ETE implementation and the ETE activities report cards will be additional mechanisms to assess which strategies have been implemented.

**Recommendation 2:** The AIDS Institute should continue to look at existing data systems for analysis and potential new survey development (e.g. CHAIN) to assess data on food insecurity, veteran status, disability status, and employment status among PLWHA.

**Recommendation 3:** Based on the information that is obtained from recommendation two, the AIDS Institute should pursue the development of standardized measures for each identified focus area.