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Data: Access, Sources, and Systems

Philadelphia EMA Integrated HIV Prevention and Care Plan

REGION	Northeast
PLAN TYPE	EMA, Integrated city/county-only prevention and care plan
JURISDICTIONS	Philadelphia EMA
HIV PREVALENCE	High

The Philadelphia EMA described in detail the data they used to develop the Integrated Plan and how it is used for HIV Planning. A major strength variety of datasets used including: United States Census Bureau, American Community Survey, Bureau of Justice Statistics, Pennsylvania Uniform Crime Reporting System, Youth Risk Behavior Survey, Behavioral Risk Factor Surveillance System: Survey, Wide-Ranging Online Data for Epidemiologic Research (WONDER), Health Professional Shortage Areas, Substance Abuse and Mental Health Services Administration, National Survey on Drug Use and Health, Treatment Episode Data Set, Philadelphia Housing Authority, Medical Monitoring Project, National HIV Behavioral Surveillance, as well as the state and local health departments for HIV surveillance and RSR data.

In addition to providing this data, this section also includes a description of how these data were used to inform the development of the Integrated Plan. There is also a description of their qualitative data collection activities including a consumer survey and focus groups about general access to healthcare with young men who have sex with men and heterosexuals of low socioeconomic status. The section also has a nice description of policy facilitators and challenges, such as the fact that the Philadelphia EMA falls under two state health departments and one city health department. Each health department has a different structure, collects different data, and reports on different variables.

SELECTION CRITERIA: DATA: ACCESS, SOURCES, AND SYSTEMS

Exemplary Data: Access, Sources, and Systems sections met the following criteria (based on the Integrated HIV Prevention and Care Plan Guidance):

- Description of the ways data was used to develop needs assessment and HIV Care Continuum, including:
 - ▶ Use of RSR data
 - ▶ Use of Surveillance data
 - ▶ Use of Qualitative data
- Description of data policies that acted as barriers to data access
- Description of data that jurisdictions were unable to access but that would be helpful to access as a way to develop stronger epidemiologic profile and HIV Care Continuum.



Additional exemplary plan sections are available online:
www.targetHIV.org/exemplary-integrated-plans

E: Data Access, Sources, and Systems

a. Data Sources and Systems

The data used in this plan, the integrated epidemiologic profile, and HIV planning draw on a wide variety of sources. Regular review of data is fully integrated into the planning process. For example, the annual RWPC allocations process draws on the most recent epidemiologic data, service cost data, local consumer survey data, and more. The integrated epidemiologic profile compiles much, but not all, of this data. This plan, including the epidemiologic overview, draws on that information and adds further contextual information when appropriate. The primary data sources included in local HIV planning needs assessments, as well as this plan, are below.

PDPH and National Data Sources

- United States Census Bureau
 - American Community Survey: Information regarding general population, race, ethnicity, poverty, insurance status, education, and employment
 - Research on Americans who are likely transgender
- Bureau of Justice Statistics: Information on state imprisonment rates and HIV/AIDS mortality
- Pennsylvania Uniform Crime Reporting System: Drug-related arrest data
- Centers for Disease Control and Prevention
 - Youth Risk Behavior Survey: Survey data on risk behaviors of high school students, including drug and alcohol use and sexual behaviors
 - Behavioral Risk Factor Surveillance System: Survey data on risk behaviors of adults, including drug and alcohol use and sexual behaviors
 - Wide-Ranging Online Data for Epidemiologic Research (WONDER): Deaths attributed to HIV disease
- Health Resources and Services Administration
 - Health Professional Shortage Areas: Data regarding employment and shortages of health professionals; used heavily in the Resource Inventory
- Substance Abuse and Mental Health Services Administration
 - National Survey on Drug Use and Health: Data on serious mental illness and drug use
 - Treatment Episode Data Set – Admissions: Data on drug of choice and method of administration by demographic for people admitted to rehabilitation programs
- Philadelphia Housing Authority: Information about housing, homeless, and HIV, including point-in-time counts and general estimates
- Medical Monitoring Project: Local data on the medical care and needs of people living with HIV
- National HIV Behavioral Surveillance: Local HIV behavioral risk data for men who have sex with men, people who inject drugs, and high-risk heterosexuals
- Local and state health departments
 - HIV surveillance: New diagnoses, prevalence, and demographic data
 - STD surveillance
 - PDPH/AACO Client Services Unit: Requests at client intake, barriers to service, client demographics

- HIV prevention
- Vital statistics
- CAREWare: Client-level data
- Unduplicated client-level service utilization data
- Ryan White Services Report data
- Incidence estimates (where available)
- Quality management reports
- HRSA/HAB and PDPH/AACO performance measures

These data sources are augmented by published peer-reviewed research and comprehensive reports from various organizations, including the National Alliance to End Homelessness and The Pew Charitable Trust.

OHP Research

OHP assesses access to services, gaps, and barriers through a consumer survey every five years. The survey relies on Ryan White providers to randomly sample 25% of their clients, and asks questions about demographics, health status, barriers to care, and service priorities. In 2012, 3,500 surveys were distributed, and there were 700 responses. The next consumer survey will be conducted in 2016/2017.

In 2014, OHP held focus groups about general access to healthcare with young men who have sex with men and heterosexuals of low socioeconomic status. These focus groups provided new contextual information about individual experiences with the healthcare system that impact target populations' access to and interactions with healthcare and HIV testing.

In addition, OHP regularly uses geographic analysis to illustrate social determinants of health, inform planning decisions, and augment other data sources. OHP also conducts small-scale exploratory surveys as necessary in order to identify needs for further investigation.

b. Policy Facilitators and Challenges

One of Philadelphia's greatest assets in HIV data availability is the coordination of HIV funding under PDPH's AIDS Activities Coordinating Office (AACO). As a RW Part A recipient, RW Part B regional sub-recipient, and a directly-funded CDC HIV prevention recipient, PDPH's AACO has access to a comprehensive compendium of information about people who use HIV-related services in the region. This enables a thorough view of people living with or at risk for HIV who are a part of PDPH's HIV service system.

In order to augment this information, the Planning Council and HPG use many different data sources. While this provides a broad basis for HIV planning that includes several social determinants of health, it also necessitates using sources with different methods, variables, classifications, reporting, and coverage areas.

When using outside data sources, the geographical area is often ambiguous. The Philadelphia Metropolitan Statistical Area (MSA) is defined in several ways, and may include 11 counties in 4 states, 9 counties in 2 states (as seen in the EMA), 5 counties in 1 state, or another variation, depending on the source. The definition used in any given report is not always clear. There are also situations where a

county within the EMA is excluded by a data source. For example, Behavioral Risk Factor Surveillance Survey data is available for the 5-county Philadelphia MSA and a 3-county Camden MSA, but the latter excludes Salem County. In other cases, additional counties are included, as seen in the 7-county Southern New Jersey region in the National Survey on Drug Use and Health. The lack of uniform aggregate data standards across federal data sources, particularly as they pertain to geographic area, creates a challenge to planning for the EMA.

In addition, the Philadelphia EMA falls under two state health departments and one city health department. Each health department has a different structure, collects different data, and reports on different variables. This is the case for both HIV data and other categories of data. Furthermore, each releases data on a different schedule, which often involves a lengthy reporting delay.

The most significant policy challenge in developing the HIV Care Continuum in particular is the lack of comparable data from Pennsylvania and New Jersey. The City of Philadelphia has full electronic reporting of CD4 and viral load data. However, Pennsylvania only requires reporting for CD4 counts below 200 and detectable viral loads. In Pennsylvania, CD4 counts over 200 and undetectable viral load reports are not reported. Meanwhile, New Jersey requires reporting for all viral loads as well as CD4 counts below 200, and it only recently implemented electronic lab reporting. Consequently, a comprehensive HIV Care Continuum for the entire EMA is not currently possible.

Finally, one of the biggest barriers to effective data-informed service planning is maintaining compliance with Pennsylvania's strict HIV confidentiality laws. Surveillance-driven interventions have been demonstrated as effective strategies in many jurisdictions, but the Philadelphia EMA must use workarounds to implement these types of interventions. However, PDPH has identified many strategies to implement surveillance-assisted programs while complying with confidentiality laws; this can be seen in START Care, CoRECT, and HIV surveillance-assisted Partner Services referrals.

c. Unavailable Data

There is limited information available on the general population of certain risk groups. For example, detailed data on factors like income and insurance is not available by sexual orientation, which makes it difficult to analyze differences between men who have sex with men and the general population. This is even more difficult for persons who are transgender, since data related to gender identity is rarely collected, and certainly not on a population level. The lack of availability of population estimates and demographics for those populations creates a major difficulty in planning services. Likewise, risk behaviors (such as illicit drug use) are often underreported. This impacts planning for prevention service delivery, but also affects available information on mode of HIV transmission. Additionally, there is limited information on PrEP uptake, particularly for privately-insured patients; data on patients on PrEP in the region would be useful in prevention service planning.