

D. Assessing Needs, Gaps, and Barriers

Addendum - July 2018¹

The following needs assessment demonstrates that rising HIV prevalence significantly increases demand on available resources and highlights the disproportionate impact on vulnerable populations. Multiple primary and secondary data sources were used to assess jurisdictional needs, including quantitative and qualitative research conducted by Office of HIV Planning (OHP) and Philadelphia Department of Public Health (PDPH). These data provide compelling evidence that, despite the availability of high quality outpatient ambulatory medical care and other medical and social services, health disparities persist for people living with HIV (PLWH) and other vulnerable communities. Although HIV incidence is stable or decreasing for most populations, men who have sex with men (MSM) and youth populations experience disproportionate risk of acquiring HIV. The HIV prevention system, which includes routine and targeted testing, preexposure prophylaxis (PrEP), non-occupational post exposure prophylaxis (nPEP), condom distribution, partner services, and linkage navigation services, is positioned to address the disparities experienced by these populations.

This discussion will summarize the service needs and barriers in both the HIV prevention and care systems in the EMA. The processes and data used to identify service needs, gaps, and barriers will be followed by an updated description of those identified needs, gaps and barriers.

a. Needs Assessment Process

Community input into the planning process is assured through multiple means. Membership of the Philadelphia HIV Integrated Planning Council (HIPC) and committees reflect the demographics of the local HIV/AIDS epidemic. Community participation is encouraged; all meetings are open to the public. Members and guests receive transportation reimbursement and refreshments at meetings. Language interpretation services are provided whenever requested within reasonable timeframes. Members and participants regularly receive training and data reports necessary to make planning decisions from OHP and PDPH staff and other local experts. HIPC actively recruits members to meet any gaps in representation. The Positive Committee represents the needs of PLWH in formal and informal processes throughout integrated planning cycles.

The Office of HIV Planning (OHP) supports the HIPC in their assessment of service needs, gaps and barriers by providing data collected from other sources, as well as conducting original studies on current community needs. Major needs assessment activities conducted by OHP since 2012 include the 2016 Ryan White consumer survey, focus groups with young MSM and heterosexuals of low socio-economic status, an online survey of medical case managers about consumer need for local pharmaceutical assistance, and surveys of both PLWH and providers about transportation access for PLWH. Information

¹ To be read as an addendum to Section ID in the Philadelphia EMA Integrated Prevention and Care Plan. <https://www.hivphilly.org/plan/>

collected in these activities informs all planning processes, including development of this integrated plan, and service priorities and regional allocations of Ryan White Part A funding.

OHP Needs Assessment Activities

Ryan White consumers were surveyed on their access to services and barriers to care in the 2017 consumer survey. Similar surveys were conducted in 2012, 2007 and 2002. OHP worked with the EMA's Ryan White providers to distribute the survey in English and Spanish. The survey included questions about demographics, health outcomes, barriers to services, co-morbidities, and service utilization. OHP received and analyzed 392 responses from the 2,915 surveys distributed. The majority of the respondents were long-term survivors who were retained in care and had a suppressed viral load. These data tend to reflect the needs of consumers who are accessing services². Consumer survey data provide the EMA information on service needs at the retained in care, on ART, and virally suppressed stages in the Continuum. The survey asks consumers if there were services they needed but did not receive and why they didn't receive those services. These responses help RWPC and PDPH mitigate service gaps and barriers. Results from the survey informed the Ryan White Part A service priorities and regional allocations.

As a part of stakeholder engagement, OHP conducted focus groups in 2014 with MSM aged 18-30 and heterosexuals of low socio-economic status aged 25-65.^{3,4} The discussions focused on the participants' experiences with primary and HIV specialty healthcare and HIV testing. OHP shared the analysis with the planning bodies, HIV service providers, federal partners, and community members through formal and informal means.

OHP has used geography to analyze social determinants of health for over a decade. In 2011, OHP requested Public Health Management Corporation conduct a multinomial logistic regression analysis of the relationships between HIV risk and 15 indicators of severe need in Philadelphia census tracts.⁵ In 2018, OHP updated maps of over 60 social determinants for each of the EMA's counties.⁶ These maps are used by HIPC to explore how social determinants like income, education, race/ethnicity, racial segregation, and disease and crime prevalence affect HIV risk and access to HIV care.

In fall 2015, PDPH requested that OHP conduct an online survey of medical case managers to better understand how the Local Pharmaceutical Assistance Program (LPAP) was used in the EMA. Case managers were asked about the situations in which clients rely on the program and barriers to accessing medications through other payers. These data informed the RW Part A grant application and the RW regional allocations for the service in FY2016/2017.

² The consumer survey analysis, *Philadelphia EMA Ryan White Consumer Survey 2016-2017* is available at: <http://hivphilly.org/data-and-statistics/consumer-survey/>

³ The focus group analysis, *Experiences with HIV testing and Health Care in Philadelphia: Young men who have sex with men*, is available for download: <http://hivphilly.org/data-and-statistics/focus-groups/>

⁴ The focus group analysis, *Experiences with HIV testing and Health Care in Philadelphia: High Risk Heterosexuals*, is available for download: <http://hivphilly.org/data-and-statistics/focus-groups/>

⁵ The 2011 Geographic Risk Analysis is available at <http://www.hivphilly.org/Documents/2011GeoReport.pdf>

⁶ Data availability varies by county so not every county has data on every factor. The 2018 social determinant maps for each of the EMA's counties are available for download <http://www.hivphilly.org/data-and-statistics/maps/>

OHP conducted another online survey of RW medical case managers about PLWH access to medical transportation in 2016. The short survey asked how the provider organizations assisted clients attending medical appointments and what barriers providers and consumers experienced in accessing RW and Medicaid medical transportation. A similar survey was conducted with the members of the Positive Committee in 2015. Those results informed the survey for case managers and discussions within the Needs Assessment, Positive, and Comprehensive Planning Committees.

PDPH and National Data Sources

Client Services Unit data measure client needs at PDPH Ryan White medical case management intake. Presenting needs will be high and generally unmet, because most of the clients calling are not currently retained in HIV care, even if they were so previously. These data give the EMA information on service needs at the HIV diagnosed and linked to care stages in the Continuum. These data are used to determine RW service priorities and regional allocations.

PDPH conducts ongoing evaluation and research activities to identify service gaps, barriers, and opportunities to improve service delivery and quality. In August 2017, AACO staff conducted appointment availability calls to collect data on the HRSA systems-level measure that monitors waiting time for initial access to outpatient/ambulatory health services. PDPH also uses CAREWare, HIV surveillance, and other available local data to evaluate and assess the RW service system. This update includes evaluations from the CDC-funded data-to-care initiative CoRECT, the RW Prison Linkage Project, and EMA's RW system.

Medical Monitoring Project is a nationally representative, population-based surveillance system to assess clinical outcomes, behaviors, and the quality of HIV care. Data on 191 persons interviewed for MMP from Philadelphia for 2013 produced information about met and unmet needs for HIV care and care-related services. These data give the EMA information on service needs at the linked to care, retained in care, and on ART stages in the Continuum. These data are used to determine RW service priorities and regional allocations and inform HIPC about the service needs for PLWH who may not be RW clients.

National HIV Behavioral Surveillance (NHBS) is conducted in rotating, annual cycles, in three different populations at increased risk for HIV: men who have sex with men (MSM), people who inject drugs (PWID), and heterosexuals at increased risk for HIV infection. NHBS collects data in 22 project areas with high prevalence of HIV, of which Philadelphia is one. These data inform HIPC on risk behaviors, testing patterns, general demographics, HIV prevalence, and substance use of local at-risk populations.

b. Identified Service Needs of PLWH and Those at Most Risk

Poverty is a significant factor driving the needs of people at risk for and living with HIV (PLWH) in the EMA. Poverty reduces access to healthcare. Living in poverty limits individuals' abilities to make health-promoting choices and adhere to treatment. Even "nominal costs" can prevent a person living in poverty from accessing care and medications. Most of the EMA's Ryan White clients are living in or near poverty and are insured by public insurance (like Medicare or Medicaid) or are uninsured. The EMA's coordinated and comprehensive HIV service continuum cannot meet all the needs of all PLWH and those at-risk. Service gaps exist because of lack of adequate funding, limited human resources, competing

political priorities, and other factors. PDPH, OHP, and the HIPC work together to identify and address the service needs, gaps, and barriers with the resources available.

PDPH and HIPC regularly assess needs and service gaps due to the implementation of the ACA. The expansion of Medicaid eligibility within the EMA was sporadic and inconsistent due to political factors. As of 2015, both Pennsylvania and New Jersey expanded eligibility to all adults under 138% FPL. Considering the prevalence of poverty within the local population and particularly in PLWH, the EMA expects to see a decrease in the number of uninsured PLWH over the next five years. PDPH and HIPC will work together to ensure that all the resources available target the current and emerging needs related to any potential changes in health insurance systems and eligibility of PLWH, and that RW funds remain the payer of last resort.

High Quality HIV and Primary Care

In an on-going effort to measure waiting time for initial access to Outpatient Ambulatory Health Services (OAHS), staff from PDPH's AIDS Activities Coordinating Office calls all PDPH funded RW ambulatory outpatient care providers (39) to collect appointment availability by posing as an uninsured PLWH who has been lost to care. The purpose of the calls are to collect appointment availability data in order to calculate the HIV/AIDS Bureau systems-level measure assessing waiting times for initial access to outpatient ambulatory care and to conduct a qualitative assessment of the system to identify policies, processes, or gaps between policies and implementation by front-line staff that can promote or impede access to care. For the reporting period ending in December 2017, 27 of the 39 providers met the HAB measure of having the third available appointment within 15 days of the call. There was no improvement from calls conducted in December 2016 where a significant decline in performance was identified. Nine programs failed to meet the measure because the third offered appointment was more than 15 days from the time of the call. Callers were unable to schedule appointments with three other providers. There were issues about communicating fees and other costs and callers encountered schedulers who behaved in an unprofessional manner at three locations. The mean wait time for the third available appointment was 10.9 business days with the median of 9.5 days. The poor outcomes over the previous two years demonstrate a need for improvement around access to care in the system, and both PDPH and HIPC have taken measures to improve the deficiencies identified in this evaluation. See Section II for more information on strategies and activities.

Almost all of the respondents to the 2017 Ryan White Consumer Survey reported they received HIV medical care regularly at the same place (98.3%). Most of the respondents reported seeing their HIV provider 3 or more times in the previous 12 months (83.2%), while 16.2% had seen their provider once or twice in the past year. Two respondents reported not seeing their HIV provider in the previous 12 months. In addition, 86.9% of respondents said that their HIV medical provider had always taken time to explain their lab results, diagnoses, treatment plans and answer their questions. Another 8.9% said that their doctor did this "most of the time", while 3% said "some of the time", and 1.2% said "never". Almost three-quarters of respondents (71.2%) said that they always feel comfortable talking to their HIV medical provider about personal or sensitive issues; another 11.7% said that they felt comfortable "most of the time", 6.1% said "some of the time", and 4.5% said that they "never" feel comfortable discussing sensitive issues with their medical provider.

Of the survey respondents, 91.3% did not experience problems accessing HIV medical care. People who experienced problems were more likely to be younger than the mean age of the sample (52) and more likely to be Hispanic/Latinx. From the analysis, people who were marginally housed or homeless, were without medical insurance, and/or had a history of incarceration since HIV diagnosis were more likely to have problems accessing HIV medical care.

Table 1: Gaps in Service as Reported by PLWH by Percent

Service Reported as Needed	PDPH Client Services Unit Need at MCM Intake (n=1,887)	Medical Monitoring Project (n=152)	EMA Consumer Survey (n=392)
Medical Care	23.9	5.9	3.8
Medications	22.7	3.7	3.8
Treatment Adherence	36.8	1.0	9.9
Dental	3.4	48.1	11.2
Home Health Care	2.4	0	11.2
Mental Health	25.5	17.2	10.5
Case Management	N/A	13.4	5.9
Substance Abuse Treatment	6.0	2.3	8.7
Food	26.8	5.5	9.9
Housing	51.5	12.3	15.1
Transportation	25.2	12.3	11.2
Support Groups/Peer Support	6.9	3.1	9.4
HIV Education/Risk Reduction	13.4	N/A	N/A
Benefits Assistance	46.0	19.2	11.7
Language Translation	1.8	0.0	10.5
Patient Navigation	N/A	2.9	7.9

Service gaps among PLWH who are not in care

PDPH is one of three health departments participating in CoRECT, a CDC-funded data-to-care initiative. This project generates out-of-care lists using HIV laboratory surveillance data while collaborating clinics concurrently generate out-of-care lists using appointment data. The combined out-of-care list are reconciled by the health department and clinics. Barriers to HIV care are collected from out-of-care individuals identified through this process. The primary barriers identified are summarized in **Table 2**. Overall, the barriers identified were quite varied with the most common falling into the domains of time management, challenges with the medical facilities and socio-economic status factors. The barriers that PLWH cite as reasons for being out of care are addressed through multiple services throughout the EMA, including outpatient ambulatory care, medical case management, housing assistance, benefits assistance, and transportation. Participants in the CoRECT project are given a specialized re-engagement intervention to remove any specific barriers to care in order to re-link and retain those individuals in care.

Persons Under-Represented in Care

Each year the EMA conducts an analysis of persons under-represented in care to determine if there are any system-level disparities in accessing the RW system which would create service gaps based on socio-demographic variables. Whites, males, persons 50 years of age and older, and people who inject drugs (PWID) are under-represented in Ryan White primary medical care when compared to the proportion of the total PLWH population. The EMA’s analysis has shown that the disparity for whites, males and persons 50 years and older would largely disappear if availability of private insurance were taken into consideration. There may be some misclassification of former PWIDs into the heterosexual transmission category within Ryan White services, but PWID likely remain underrepresented even after these circumstances are taken into consideration.

Table 2: Primary Barriers to HIV Care among PLWH Out of Care, Philadelphia CoRECT (2016-2017) (n=168)		
Barrier Domain	Percent PLWH	Specific Barrier Examples
Time Management/ Organization	20.1%	Couldn’t get time off from work or school Had other more important responsibilities
Challenge with the Medical Facility	18.0%	Not sure when to follow up Too long to get an appointment with provider of choice Hours inconvenient
Socio-Economic Status Factors	16.5%	Unemployment Transportation Housing
Attitudes/Perceptions about HIV Health	12.7%	Felt good Felt sick
Insurance and Access to Care	10.9%	No health insurance Co-pay too high; afraid of cost
Mental Health/Substance Abuse	9.4%	Felt depressed Was too drunk or high
Other Barriers	12.4%	Stigma Disclosure Communication issues

Medical Case Management

The majority (82.1%) of respondents to the 2017 RW consumer survey had a case manager and almost all of them were satisfied with their case managers (96.6%). The results showed that those who had detectable viral loads or an AIDS diagnosis were more likely to have a medical case manager. This is to be expected because medical case management is intended to help PLWH access medical care, improve

health outcomes, and achieve viral suppression. People who need the extra support will be referred to medical case management.

In 2018-2019, PDPH is implementing a new medical case management model which will better meet the diversity of need in the RW client population. One type of MCM will address acute/short term needs and the other type will be a comprehensive long-term relationship to address persistent needs and barriers to improved health outcomes like homelessness, mental health disorders, substance use disorder, and significant co-morbidities.

Transportation

RW consumer survey respondents reported transportation as a significant barrier to both clinical and supportive services. Transportation problems were a barrier to medical care in the previous 12 months for 53% of the uninsured. Transportation was also a barrier for 37% of the respondents who get their insurance through an employer, 40% of the self-insured, 50% of people with ACA Marketplace plans, 19% of those with Medicare coverage, 38% for those with Medicaid coverage, and 36% of PLWH with “other insurance”. Interestingly, none of the respondents covered by the Veterans Administration reported transportation problems in the previous 12 months. The uninsured, people with Marketplace plans, and people covered by Medicaid and Medicare were significantly more likely to have transportation challenges that prevented them from attending medical appointments in the previous 12 months.

Dental Care

Dental care was reported as the most-used service in the RW consumer survey (after medical care), 63% of respondents reported having had dental services in the previous 12 months. However, 11% of respondents reported needing but not receiving dental services. The need for dental services is more heavily identified after consumers are in RW services (as compared to those entering or returning to the RW system), this could be because other needs are a priority and identifying dental issues only after more pressing medical conditions have stabilized.

Mental Health

RW consumer survey respondents were asked whether a doctor ever told them that they had a mental health disorder (they were provided a list to choose from). Overall, 63.5% respondents reported having ever being diagnosed with at least one mental health disorder. Prevalence of lifetime mental health disorders are as follows: 51.5% depression, 43.3% anxiety disorder, 19.2% bipolar disorder, 10.4% substance use disorder, 8.3% schizophrenia or schizoaffective disorder, 10.9% Post Traumatic Stress Disorder, 13% mood disorder, 3.4% Obsessive Compulsive Disorder, 2.8% eating disorder, and 1% dementia. Prevalence of lifetime mental disorders did not differ significantly by gender, age, race/ethnicity, income or education levels. However, people who were employed or retired were less likely to report a mental disorder, while those who were unemployed or disabled were more likely to report one.

Opioid dependency and other substance use

Although syringe exchange services in Philadelphia have had a dramatic impact on new cases of HIV among PWID in the EMA over the last two decades, there is deep concern about a potential resurgence of the HIV epidemic in PWID due to the escalating opioid epidemic. In 2016 there were over 900 fatal overdoses related to opioids in Philadelphia alone. For 2017, Philadelphia had 1,217 opioid overdose deaths⁷. Philadelphia County had the second highest overdose death rate in the country, with 46 deaths per 100,000⁸. In response to the increasing number of non-fatal and fatal overdoses, the Mayor of Philadelphia appointed a task force to receive community and stakeholder feedback on the opioid epidemic. In May 2017, the task force released their 18 recommendations, which included expanding access to medication-assisted treatment, exploration of comprehensive user engagement sites, and expanding naloxone access throughout the community⁹. PDPH and other city departments and community stakeholders are exploring and implementing many of these recommendations as outlined in the status report from March 2018.¹⁰

This epidemic is not just a Philadelphia problem. The opioid epidemic is a significant public health challenge for the whole EMA. In the four suburban PA counties, police and EMS workers are reversing overdoses at alarming rates (in Delaware County the police reversed 532 overdoses in 2017¹¹), and yet many people are dying from overdose. In 2016, Montgomery County had 230 deaths (rate of 28.75 per 100,00), Delaware County had 206 deaths by overdose (rate of 36.85), Bucks County 168 deaths, and Chester County had 97 deaths. In the suburban New Jersey counties, we see similar numbers in overdose deaths. There were 96 deaths in Burlington County, 200 in Camden County, 88 in Gloucester County, and 18 in Salem County¹². EMS and law enforcement in NJ reversed thousands of overdoses in 2017: Burlington County 914, Camden County 2,493, Gloucester County 797, and Salem County 147¹³.

Meanwhile, opioid overdoses and deaths only tell one aspect of the story regarding the EMA's opioid epidemic. There were also approximately 14,000 persons in treatment for opioid dependence in publicly funded facilities in 2016. In terms of drug use, there were approximately 55,000 heroin users and approximately 55,000 persons who misused/abuse prescription opioids in 2016 in Philadelphia. Approximately 150,000 adults in Philadelphia received >1 opioid prescription in the last year.

⁷Philadelphia Department of Public Health. Fatal Drug Overdoses in Philadelphia, 2017. CHART 2018;3(1):1-4. <http://www.phila.gov/health/pdfs/chart%20v3e1.pdf>

⁸ Eichel, Karry & Pharis, Meagan. (February 2018). *Philadelphia's Overdose Death Rate Among Highest in Nation*. <http://www.pewtrusts.org/en/research-and-analysis/articles/2018/02/15/philadelphias-drug-overdose-death-rate-among-highest-in-nation>

⁹ The Mayor's Task Force to Combat the Opioid Epidemic in Philadelphia Final Report and Recommendations: <https://dbhids.org/opioid>

¹⁰The Opioid Epidemic in Philadelphia Implementation of the Mayor's Task Force Recommendations https://dbhids.org/wp-content/uploads/2018/03/OTF_StatusReport_March2018.pdf

¹¹ Data on police and EMS overdose reversals by county can be found at the Pennsylvania Opioid Data Dashboard: <https://data.pa.gov/stories/s/Rescue/dji6-fb2x>

¹² Overdose deaths in NJ by County and Drug <http://www.nj.gov/oag/njcares/pdfs/2016-DRUG-RELATED-DEATHS.pdf>

¹³EMS and Law Enforcement Overdose Reversals in NJ in 2017 by County <http://www.nj.gov/oag/njcares/pdfs/2017-NJ-Naloxone-Administrations-web.pdf>

According to Philadelphia NHBS data in 2015, approximately half of PWID used prescription opioids prior to their first injection but only 23% continued to use prescription opioids at the time of their NHBS interview which confirms that prescription opioid use is a gateway to injection drug use. The median time between the start of using prescription opioids to their first injection was 3 years. In the 2015 Medical Monitoring Project (Philadelphia), 2.0% of PLWH surveyed injected drugs in the last 12 months and 2.0% of PLWH surveyed took a prescription opioid that was not prescribed to them or was prescribed and they took more than directed.

While HIV prevalence in PWID has decreased dramatically based on Philadelphia NHBS data to 4.8% as of 2015, HCV prevalence is high at 81% among HIV positive PWID. Due to high rates of sharing of syringes and works, high rates of exchange sex, low rates of HIV and HCV testing and high rates of HCV transmission, re-introduction of HIV into these high-risk networks could easily lead to an HIV outbreak in Philadelphia as was previously observed in other jurisdictions in the United States. Young white people are the most affected by the opioid epidemic in EMA, in contrast to the older, largely racial/ethnic minority population that comprises the majority of PLWH with PWID transmission.

As of October 2018, PDPH has identified a significant increase in new HIV infections within people who inject drugs, 48% in the previous 12 months¹⁴. PDPH has formed a response team and experienced community-based organizations and clinical providers are collaborating with PDPH for a robust response.

Housing Insecurity and Homelessness among PLWH

According to PDPH, more than 10.6% (1,779 individuals) of PLWH receiving Ryan White services in the EMA are reported to have unstable or temporary housing. PDPH estimates that there are 2,675 PLWH experiencing homelessness in 2015. Over half of the RW consumer survey respondents (61.6%) reported that they were renting or owned a house or apartment at the time of the survey. However, a substantial proportion of the sample was homeless or marginally housed: 14.5% of the sample were staying with friends or family, 2.1% lived in a shelter, 1.1% said they were in transitional housing (halfway houses or drug treatment program), and 0.8% lived on the street. Rental subsidies supported another 16.4% of respondents: 9% relied on Housing Opportunities for People with AIDS (HOPWA) and 7.4% reported participating in the Housing Choice Voucher Program or living in public housing. Respondents from New Jersey were more likely to rent or own their own home than respondents from Philadelphia and the PA Counties.

¹⁴ Philadelphia Department of Public Health. HIV Spread Among People Who Inject Drugs. October 2018. <https://www.phila.gov/health/pdfs/commissioner/chart/chart%20v3e4.pdf>

Populations at Risk

Men who have Sex with Men (MSM)

MSM of color have extremely high HIV prevalence in the community, high incidence, and high unaware rates that dramatically increase transmission in this population. In 2016, 227 new diagnoses of HIV among MSM of color were reported, and there were 4,697 prevalent cases in the EMA. Among members of this population a unique confluence of stigmas – racism, homophobia, and HIV stigma – vastly complicate identification, linkage and retention in care. Once in care, disparities in health outcomes are significantly reduced, and MSM of color exhibit no disparities in achieving and sustaining viral load suppression.

While studies confirm that MSM of color do not engage in behaviors with greater risk than white MSM, as discussed above, the high prevalence of HIV among MSM of color means that they face a greater risk of being exposed to HIV. For young black MSM in particular, partnering with older black men (where HIV prevalence is high) leads to increased risk. Transmission of HIV is also compounded by the higher percentage of those MSM (in relation to other populations) who are unaware of their status. As per the CDC, especially for MSM of color, social and economic factors, including homophobia, stigma, poverty, lack of health insurance may increase risk and/or act as a deterrent to receiving needed social services. Finally, the use of alcohol and drugs in MSM of color may increase the acquisition of HIV through engaging in unprotected sex while under the influence or sharing needles or other injection equipment

In 2017, the majority of participants in the NHBS MSM cycle were less than 30 years of age (54.1%) consistent with the population of MSM at greatest risk for HIV. The majority were black (69.6%) followed by white (13.9%) and Hispanic (12.3%). There was evidence of high risk behaviors in the MSM population with an average of 9 sexual partners in the last 12 months and high use of non-injection drugs (57%) in the last 12 months. Although 85% of MSM in the sample had an HIV test in the last 12 months, only 35% of participants knew the HIV status of their last sexual partner. Of those tested for HIV through NHBS, 37.6% (N=212) were HIV positive which included 42 newly diagnosed individuals. These data highlight that MSM in Philadelphia have high rates of ongoing HIV risk behaviors, lower than optimal HIV testing rates, and high rates of being unaware of their own and their partner's HIV status.

People Who Inject Drugs (PWID)

In 2015, the average age of participants in the NHBS PWID cycle was 37 (range 19-70), consistent with the underlying population of PWID. The majority of participants were white (65%) followed by Hispanic (20%), and black/African American (13%). Eighty-eight percent of participants injected more than once a day and 97% injected more than once per week. HIV related risk was high with only 37% always using a new sterile needle, 62% using works (i.e. cookers, cottons, or water) after at least one other person and 43% used drugs divided up with a used syringe. Of those that reported sharing needles or works, only 44% and 46% knew their last injecting partner's HIV and HCV status, respectively. Over 40% of female participants and 25% of male participants exchanged sex for money, drugs or other goods in the past 12 months. Despite high HIV risk behaviors, only 55% of participants reported having an HIV test in the past 12 months. Of those tested through NHBS, 4.8% were HIV positive (N=32) which included 14 new positives. By comparison, 81% of participants tested for HCV through NHBS were HCV positive with nearly a quarter being unaware of their HCV status. In summary, PWID in Philadelphia have high rates of

sharing of syringes and works, high rates of exchange sex, low rates of HIV testing and high rates of being unaware of sex/needle sharing partners' HIV and HCV status.

Heterosexuals at high risk of HIV transmission (HET)

Women of Color: Women of color experience all of the challenges of deep poverty and stigma, frequently compounded by child care or other caregiver responsibilities. Taken together, these factors lead to a significant disparity in access to health care, and a higher than expected HIV incidence. Due to extensive HIV testing in perinatal healthcare settings in the Philadelphia EMA, many women of child bearing age, get tested for HIV, and once in the Ryan White care system experience higher than average positive health outcomes including viral suppression.

Heterosexual Men of Color: The major challenge in heterosexual men of color is that they do not perceive that they are at risk for HIV infection. The PDPH conducted NHBS among heterosexuals at risk of HIV infection in 2016. CDC defines heterosexuals at high risk of HIV infection as persons who have had sex with a person of the opposite sex in the last 12 months and are of a low socioeconomic status. During this cycle, PDPH completed interviews with 292 heterosexual men of color of which 82.5% reported that they perceived their risk of becoming HIV infected in the next 12 months as low. In contrast, data show that the prevalence of HIV in this population was high at 1.7% and testing in the last 12 months was low at 39.3% even though 78.6% had been seen by a medical provider in the last 12 months. This is likely due to a combination of generally poor access to health care and HIV stigma and homophobia.

In 2016, average age of participants of the NHBS heterosexual cycle was 39 years of age, also consistent with the underlying at-risk population. The majority of those interviewed were black (92.5%), followed by Hispanic (4%) or white (1.3%). A third of the participants, 33.8%, reported 4 or more partners in the preceding 12 months. An estimated 45% of participants reported non-injection drug use in the past 12 months. Again, despite high risk behaviors only 49.7% of participants had been tested for HIV in the last 12 months. Of those tested for HIV through NHBS, <3% (N=12) were HIV positive which included 5 newly diagnosed individuals. Heterosexuals have high rates of poverty, high rates of sexual and drug use behaviors that increase their risk of HIV but have low rates of HIV testing since they do not perceive themselves to be at risk.

Minority Youth

The main challenge for addressing HIV among racial and ethnic minority youth is the high rates of STIs, high rates of new HIV infections and high rates of unaware status resulting from a high prevalence of risky sexual behaviors.

According to the CDC, among U.S. high school students surveyed in 2017 in the Youth Risk Behavior Survey¹⁵:

- Nationally 39.5% had ever had sexual intercourse. In Philadelphia, among Black or African Americans, the percent was 48.6.9%, among Hispanics, 44.2%.
- Nationally, 28.7% had sexual intercourse during the previous 3 months, and, of these, 46.2% did not use a condom the last time they had sex. In Philadelphia, 33.6% of Black or African American, 29.5% of Hispanics report having a sexual experience within 3 months of taking the questionnaire. Of these 43.2% of Black or African Americans report not using a condom.
- Nationally, 9.3% of all students have ever been tested for HIV. In Philadelphia, due to an aggressive testing program by the Philadelphia Department of Health, coupled with educational and social media campaigns, 43.3% of Black or African Americans, and 37.4% of Hispanics had ever had an HIV test.

Minority youth newly diagnosed with HIV are 90.6% male and 9.4% female in Philadelphia. Among the males, 84.4% are MSM only, 3.1% heterosexual only, and 9.4% who reported sex with men and women. Among minority young women newly diagnosed with HIV, 100% were infected through heterosexual transmission. MSM transmission is driving the epidemic in minority youth and crossover transmission to young minority young women is likely.

Other challenges in serving minority youth include, unstable living situation, difficulty in maintaining treatment adherence which results in lower viral suppression, unsafe conditions or abuse at home or rejection from home and homelessness. Minority youth also suffer disproportionately from trauma-induced depression and other mental health issues.

Transgender persons who have Sex with Men (TSM):

A significant challenge for the EMA in responding to the HIV epidemic among TSM is the unreliability of data. TSM may avoid treatment related to stigma and poor treatment. Names and genders of individual TSM may be reported differently in medical care and supportive services sites. Some reporting sources may only collect sex at birth or current gender so that transgender persons are not reported accurately in either surveillance or RW program data. In addition, gender identity was not available in Philadelphia surveillance data until 2009 and is still not collected by the HIV surveillance program in the PA counties. As a result, there is a significant undercounting of transgender persons in both the EMA surveillance program and RW program data.

An estimated 256 TSM are diagnosed and living with HIV in Philadelphia and NJ portions of the EMA. No data is available from the PA counties on TSM living with HIV. 17.1% of TSM who are infected are unaware of their status which is significantly higher than the overall unaware estimate of 7.4% for the EMA.

¹⁵ Centers for Disease Prevention and Control, Youth Risk Behavior Surveillance System: <https://www.cdc.gov/healthyyouth/data/yrbs/index.htm>

The 2015 U.S. Transgender Survey (USTS), the largest survey examining the experiences of transgender people in the United States, with 27,715 respondents nationwide was conducted by the National Center for Transgender Equality in the summer of 2015. This survey highlights the challenges faced nationally by transgender individuals. Of respondents in the USTS, 550 were New Jersey residents, and 1,171 were Pennsylvania residents. Transgender persons in both states experienced high levels of unemployment, poverty, low levels of education and homelessness. Transgender individuals report difficulty in accessing appropriate care, harassment, sexual assault, and mistreatment, and difficulty or confusion over identity documents. Transgender individuals experience high levels of trauma, stress and other behavioral and mental health issues. In New Jersey, 41% of respondents and in Pennsylvania 36% of respondents reported experiencing serious psychological distress in the one-month period preceding the survey.

Although transgender individuals make up only a small percentage of the Philadelphia EMA population, their socialization spans across many spectrums, and the potential for infection is increased. Many within the transgender community experience low self-esteem, a lack of family support systems, and discrimination. This is compounded by the lack of education, social capital, community and economic opportunity, and discrimination in housing, employment and public services.

Pre-Exposure Prophylaxis (PrEP)

According to local NHBS data, PrEP awareness among MSM is high, but use is low. In the most recent MSM cycle, 73.5% of MSM had heard of PrEP, 35% had discussed with a physician, 54.6% have considered it, and 51.7% thought it was a good option for them. However, 26.5% of MSM had taken PrEP, and 59% of those men took it every day¹⁶. Most common reasons reported for PrEP not being a good option were: person doesn't like taking medicine, consistent condom use, and not a lot of sexual partners. There were differences in attitudes between men who self-reported being HIV-positive and those that did not. Men who did not report being HIV-positive were less likely to believe that PrEP would reduce their risk of contracting HIV (69.6%) than men who reported being HIV positive (79.3%). More men who reported being HIV-positive (82.4%) would recommend PrEP than men who didn't report being HIV positive (46.4%).

PrEP awareness among heterosexuals and PWID was much lower. Only 4.5% of the heterosexuals in the 2016 NHBS cycle were aware of PrEP. Less than 1% had spoken with a doctor about PrEP or taken it themselves. In the PWID cycle in 2015, 12% had heard about PrEP, 4% had spoken to a doctor about PrEP and less than one percent had taken PrEP.

Identified Barriers to HIV Prevention and Care Services

Barriers to HIV prevention, screening, and care services are myriad and vary from individual psychosocial factors to systemic factors like poverty and HIV stigma. The EMA utilizes every available resource to mitigate these barriers, yet many persist. Individuals at high risk for HIV and PLWH face competing pressures that complicate and compromise their abilities to practice risk reduction behaviors, access prevention services, get an HIV test, attend medical appointments, and adhere to treatment regimens.

¹⁶ Presentation by Dr. Kathleen Brady: "Philadelphia National HIV Behavioral Surveillance <https://www.slideshare.net/HIVPhilly/philadelphia-national-hiv-behavioral-surveillance-2018>

For these reasons, the EMA ensures access to medical care and a wide variety of support services through a coordinated and comprehensive system of services funded through local, state, private, and federal grants.

The following lists offer brief descriptions of the most important barriers and challenges to the EMA achieving the national goals to reduce new infections and increase viral suppression among PLWH.

Social and Structural Barriers¹⁷

- Poverty, especially entrenched deep poverty
- Racism, often in conjunction with and/or because of poverty, is one of the drivers of health disparities among Black and Latinx populations in the EMA. Racism manifests in racial segregation, which impacts individuals' and communities' abilities to access services and resources. Structural and interpersonal racism threatens the physical safety of black and brown people which increases stress responses and degrades health over time.
- Gender inequality limits women and girls' ability to negotiate condom use and practice other harm reduction strategies. Many women with HIV and those at high risk for HIV, are survivors of interpersonal violence and sexual trauma. These traumatic experiences may interfere with their abilities to engage in healthcare and practice health promoting behaviors.
- LGBTQIA stigma and discrimination pervade society, even with the legal advances of the last decade. Fear of stigma and discrimination based on one's sexual orientation or gender presentation can be a powerful barrier to accessing healthcare. This stigma is institutionalized in many regards, especially considering Pennsylvania does not have a legal protection against employment, housing, or other discrimination for LGBTQIA individuals. There are also the threats to previously secured and protected legal rights with changes at the federal level.
- HIV stigma prevents people from accessing HIV testing and prevention services and from engaging in appropriate health care. HIV stigma manifests in interpersonal, familiar, medical and other public settings.
- Mass incarceration affects community and individual-level risk for HIV on multiple levels that include limiting the number of adult males within a community, concentrating HIV within the incarcerated and recently incarcerated populations, practicing risk behaviors while incarcerated due to policies banning or limiting access to condoms and other harm reduction tools, and

¹⁷ The social and structural barriers listed in this section are powerful and intersecting forces in HIV risk and health disparities. This section has been kept brief in order to aid readability. It is assumed the reader has a basic understanding of how social determinants influence HIV risk and health. For more information about social determinants of HIV risk refer to: Centers for Disease Control and Prevention. Social determinants of health among adults with diagnosed HIV in 11 states, the District of Columbia and Puerto Rico, 2013. HIV Surveillance Supplemental Report 2015;20(No. 5): <http://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillancereport-vol20-no5.pdf> Published November 2015. Dean, H. and Fenton, K. Addressing the social determinants of health in the prevention and control of HIV/AIDS, viral hepatitis, sexually transmitted infections, and tuberculosis. Public Health Reports. 2010. 125(Suppl 4): 1–5. Retrieved from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2882967/> Office of HIV Planning. Where we live matters: Social determinants of HIV risk. 2013 <http://www.slideshare.net/HIVPhilly/where-we-live-matters-january-2013-update-57848626> Maps of many of the social determinants for the 9 counties of the EMA can be found on the Office of HIV Planning website on the Documents page: <https://www.hivphilly.org/data-and-statistics/maps/>

policies and laws denying individuals employment and other opportunities due to criminal history. Mass incarceration harms black and Latinx communities disproportionately.

- Lack of affordable housing within the City of Philadelphia and other EMA's communities is a pervasive problem. There is also a lack of federal, state, and local resources to combat the problem. The entrenched nature of poverty makes this lack of housing resources even more acute to the most vulnerable communities.
- Lack of perceived risk of HIV can be found in various subpopulations, including minority heterosexual communities. Lack of perceived risk often leads to lax condom use, other sexual risk behaviors, and not seeking HIV screening.
- Medical mistrust is common among Black, Latinx and other minority communities. Medical mistrust leads to individuals not seeking primary care and prevention services, as well as not adhering to treatment regimens.
- Lack of community knowledge about pre-exposure prophylaxis (PrEP) and other HIV prevention services impedes the full implementation of this biomedical intervention.

Legislative and Policy Barriers

- Sexuality education varies in the EMA's public school systems, and often focuses on abstinence and contraception with little to no information relevant to students who do not identify as heterosexual or are gender non-conforming/transgender. In both New Jersey and Pennsylvania, sexually transmitted infections and HIV/AIDS education is required, but the methods and curriculum are decided by the local school board and individual schools. Sexuality education is required in New Jersey but not Pennsylvania.
- Syringe access barriers exist in the EMA because of state laws and federal funding restrictions on the purchase of syringes. In New Jersey and Pennsylvania, syringe distribution for the purpose of use of illicit drugs is illegal. Within the EMA, there are only two syringe exchange programs, a multi-site program in Philadelphia (city-funded) and Camden city. Syringes can be purchased in pharmacies without a prescription (at the discretion of the pharmacist) throughout the EMA.
- Federal funding restrictions limit the EMA's ability to provide PrEP to appropriate high-risk individuals. Ryan White funds and CDC HIV prevention funds cannot pay for medications for PrEP use or the accompanying laboratory tests. Pharmaceutical patient assistance programs do not provide funds for laboratory tests required for PrEP management. This limits the EMA's ability to ensure PrEP access to the most at-risk population. Patients wanting to start PrEP often have burdensome paperwork, waiting, and "red tape" to deal with before insurance will cover medications.
- Different laws about HIV laboratory reporting requirements hinder PDPH's ability to properly plan for the whole EMA, compare outcomes geographically, and to target programs and resources appropriately. There are also significant reporting delays, which prevent planning in real time.
- Pennsylvania's "super protected data" policies, which cover mental health status, HIV status, and drug and alcohol treatment, hinder coordination within the state's various programs.
- Pennsylvania law considers it a felony for a person living with HIV to engage in sex work, even when using condoms and/or the activity cannot transmit HIV. New Jersey law criminalizes "an

act of sexual penetration without the informed consent of the other person” by anyone who knows they are HIV positive. These laws impact the decisions PLWH make around disclosure and sexual behaviors. Sex workers may be reluctant to be tested for HIV because knowledge of their status can have legal ramifications. Neither state laws consider whether the intent was malicious or if transmission occurred or was likely to occur.

- Law enforcement may consider an individual carrying condoms as a sign of prostitution. This discourages sex workers from using/carrying condoms.
- Federal laws like SESTA and FOSTA are making sex work less safe for sex workers and making it difficult for service providers to engage with this vulnerable population for fear of legal repercussions. Driving sex workers offline and on the streets makes them less safe and more open to predators and violence.
- The increased activity of I.C.E. within the EMA has led to fear and insecurity in immigrant communities. Providers report a reluctance of clients/patients to attend appointments or to seek out services and healthcare for fear of being separated from family due to deportation or being taken into custody. Even immigrants with documented status are fearful of interaction with government and other “officials”. These fears and reluctance to engage with providers causes lack of access to necessary resources and care.

Health Department Barriers

- PDPH experiences challenges in coordinating between several health departments. These challenges range from differences in the type of surveillance data collected and timing of release of those data to differences in priorities, laws, and policies between jurisdictions. The differences in the types of data collected limit the ability of PDPH to develop EMA-wide Care Continuums and to compare the outcomes across the regions.

Program Barriers

- Due to PA and NJ confidentiality laws and differences in reporting requirements and methods, real time coordination of services on the client and provider levels are hindered. Written releases are required for any HIV-related information to be shared between providers.
- Lack of adequate funding to provide affordable short-term and permanent housing for PLWH and those at high risk for HIV. Federal, state, and local funds cannot meet the demand.
- Some medical providers are uninformed about PrEP, which leads to reluctance to prescribe PrEP to their patients. Many medical practices do not know how to bill for PrEP-related services and advocate for patients who want to initiate PrEP.
- Medical providers’ reluctance to offer routine HIV testing to their patients is a barrier to full implementation of routine testing. Providers’ reluctance stems from lack of perceived risk for patients, reluctance to discuss sexuality and risk behaviors, perception that HIV testing will be time consuming, and lack of knowledge about third-party billing.

Service Provider Barriers

- Lack of participation of insurers and state Medicaid offices in planning prevents a full understanding of how the public and private insurance programs provide for the needs of PLWH

and those at risk. Coordination and integration of services would improve with participation from these payers.

Client Barriers

- Most of the EMA's PLWH and individuals most at risk for HIV are living in or near poverty. Poverty affects every aspect of an individual's life and well-being, including limiting access to healthcare and prevention services.
- Lack of reliable transportation is a common problem for people throughout the EMA. Transit does not run in many suburban and rural parts of the EMA. Those who live near transit lines may not have the money to pay fares. The Medicaid transportation providers are often unreliable. Travel times to appointments via transit or Medicaid transportation can take hours, which limits individuals' abilities to keep appointments.
- Many PLWH and those at-risk lack access to needed behavioral and mental health services due to lack of insurance coverage for needed treatment, workforce capacity issues, shortage of inpatient and outpatient treatment slots, and lack of integration of these services in primary care.
- Non-English proficiency is a barrier for various cultural and ethnic communities within our diverse EMA. Even if language interpretation and translation are available at service providers, many people are unaware or do not feel comfortable seeking services outside of their own communities. Printed health education materials are often only distributed in English.
- Many of the individuals at greatest risk for HIV experience stigma, discrimination and violence due to their gender, race, sexual orientation, and/or socio-economic status. Populations most vulnerable to the compounding impact of these intersectional identities are young men of color who have sex with men, Black men and women living in poverty, Latinx individuals, sex workers, people who inject drugs and Trans women of color. The trauma experienced by these individuals and communities must be addressed in order to provide comprehensive healthcare. These experiences of trauma impact the individual's ability to trust providers, access health care, and protect themselves from HIV and other health risks.
- Many PLWH and those at high risk are living with chronic and complex health concerns like diabetes, asthma, heart disease, viral hepatitis, mental health diagnoses, and substance use dependency. These co-morbidities require holistic and comprehensive care. Co-morbidities can also complicate HIV treatment through physiology and an individual's behaviors and health literacy about their various conditions.
- Housing instability and homelessness affect many PLWH and those at risk. Without adequate housing, it is difficult to maintain HIV treatment and continue health promoting behaviors. Those who are insecurely housed may engage in risky sexual behaviors to secure housing.
- Low health literacy affects individuals' abilities to understand and adhere to treatment regimens.
- Fear of law enforcement and or other federal, state or local authorities prevents some individuals from seeking healthcare and other services; for example, undocumented immigrants, sex workers, drug users, and individuals with a history of incarceration.