Philadelphia EMA Ryan White Consumer Survey 2016-2017

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Office of HIV Planning

PHILADELPHIA DEPARTMENT OF PUBLIC HEALTH | AIDS ACTIVITIES COORDINATING OFFICE

Written by Nicole Johns and Dina Terloyeva with assistance by Stephen Budhu

Edited by Mari Ross-Russell and Briana Morgan

Data analysis by Dina Terloyeva

Survey tool developed by the Office of HIV Planning, in cooperation with the Philadelphia EMA HIV Integrated Planning Council and AIDS Activities Coordinating Office

Special thanks to the organizations that distributed the survey and all the people who took the time to share their thoughts and experiences with us.

We couldn't have done it without you.

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Purpose

Successful engagement and retention in HIV medical care requires meeting the medical, psychological, physical, and social needs of individuals. The purpose of this study is to assess the individual-level, provider-level, and system-level barriers to services experienced by Philadelphia EMA (Eligible Metropolitan Area) Ryan White HIV services consumers, in order to better understand how these barriers affect not only individual but population engagement along the HIV care continuum. This survey is part of the ongoing evaluation of the Philadelphia EMA Ryan White care system.

The Philadelphia EMA HIV Integrated Planning Council (HIPC) and the Philadelphia Department of Public Health's (PDPH) AIDS Activities Coordinating Office (AACO) will use these results and analysis to plan services, reduce barriers, and improve health outcomes for PLWH throughout the EMA. The Office of HIV Planning conducted similar surveys of Ryan White clients in 2002, 2007, and 2012 to inform service planning and evaluation. The Office of HIV Planning (OHP) conducts EMA-wide surveys of Ryan White clients to determine barriers to care, service gaps, level of satisfaction with services, and other key characteristics of the RW client population not collected through other means. These needs assessment data inform the legislatively required activities of the EMA and play a key role in service priority setting and allocations of funding for Ryan White services.

Philadelphia Eligible Metropolitan Area[1]

The Philadelphia Eligible Metropolitan Area (EMA) consists of 9 counties: Bucks, Chester, Delaware, Montgomery, and Philadelphia in Pennsylvania and Burlington, Camden, Gloucester, and Salem in New Jersey. The EMA's counties' demographics differ significantly in terms of race/ethnicity and income. In 2016, 63% of the EMA's population was non-Hispanic white, 20% was non-Hispanic black, 6% was non-Hispanic Asian, and 9% was Hispanic (all races).[2] Yet, in Philadelphia, only 35% of the general population was white, while 42% was black, 7% was Asian, and 14% was Hispanic. For some comparison, Camden County was 58% white, 18% black, 6% Asian, and 16% Hispanic, and Bucks County was 85% white, 4% black, 4% Asian, and 5% Hispanic.

As with many metropolitan areas, income varies greatly throughout the EMA. By county, the highest median household income was found in Chester County ($88,995 in 2016), while median household income in Coatesville (a city within Chester County) was only $36,212.[3] This is even lower than Philadelphia's median household income of $39,770. In Camden County, the median household income was $63,028, but in the City of Camden, median household income was only $26,214. Chester County is the highest-income county in Pennsylvania and one of the wealthiest counties in the United States,

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[1] The following sections about the EMA, PLWH, and Ryan White are informed by the EMA's Ryan White Part A FY 2018 application. All data concerning PLWH and the EMA's services are from the Philadelphia Department of Public Health's AIDS Activities Coordinating Office. More info about services and local surveillance data can be found: http://www.phila.gov/health/aaco/

[2] U.S. Census Bureau. (2016). DP05 Demographic and Housing Estimates [Data]. *2016 American Community Survey 5-Year Estimates*. Retrieved from http://factfinder.census.gov/.

[3] U.S. Census Bureau. (2016). S1901 Income in the Past 12 Months [Data]. *2016 American Community Survey 5-Year Estimates*. Retrieved from http://factfinder.census.gov/.

while Philadelphia has the highest rate of deep poverty (50% or less of the Federal Poverty Line) of any major city in the country. From these data we can see that there are urban centers within counties with concentrated poverty, and in some cases deep poverty. In the EMA, many of the communities with high rates of poverty are also majority-minority communities.

Description of the EMA's People Living with HIV/AIDS

As of 2016, an estimated 26,752 people were living with HIV/AIDS in the Philadelphia EMA. Of these, 12,012 (44.9%) were living with HIV (non-AIDS) and 14,740 (55.1%) were living with AIDS. In 2016, there were 721 new HIV diagnoses (regardless of AIDS status) within the EMA. The total number of people living with HIV/AIDS in the region has been growing over time, as new diagnoses now outpace deaths among people with HIV/AIDS.

HIV/AIDS prevalence rates are notably higher in Philadelphia compared to PA and NJ for the same period. Rates are highest among black men, followed by Hispanic men, black women, Hispanic women, white men, and white women. About 0.5% of all residents of the EMA are living with HIV/AIDS and aware of their status. However, the City of Philadelphia represents more than two-thirds of the EMA's epidemic. Within Philadelphia, the overall prevalence is 1.3%, and as high as 2.8% among black males, 2.3% among Hispanic males, 1.1% among black females and 1.0% among white males[4]. HIV prevalence is close to or over 10% for all racial/ethnic groups among both MSM (men who have sex with men) and PWID (people who inject drugs). Again, the prevalence of HIV infection is much higher in Philadelphia compared to the EMA overall for all racial/ethnic groups and modes of transmission.

People living with HIV/AIDS and people at risk for HIV infection in the EMA are overwhelmingly poor, dependent on public forms of assistance including insurance, tend to be unemployed with lower educational levels, and have higher levels of homelessness and incarceration than the general population.

EMA's Ryan White Care System

Most of the HIV care provided in the EMA is through the Ryan White care system[5]. PDPH estimates that in 2016, 71% of the PLWH in Philadelphia who received HIV medical care received their care in the EMA's Ryan White system. This is likely due to the better HIV-related outcomes in the Ryan White system compared to care outside of the system for measures like retention in care, viral suppression, and durable viral suppression. Figure 1 below compares the viral suppression and retention in care outcomes for the entire EMA, heterosexual men of color, women of color, individuals recently released from incarceration, and minority youth. For each population for which Ryan White data are available, a

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[4] Prevalence refers to the number of people living with a disease in a population of people within a specific timeframe. In this sentence, the percentage refers to the number of people within that group living with HIV in 2016. For example, 2.8% of all the black men in Philadelphia are living with HIV.

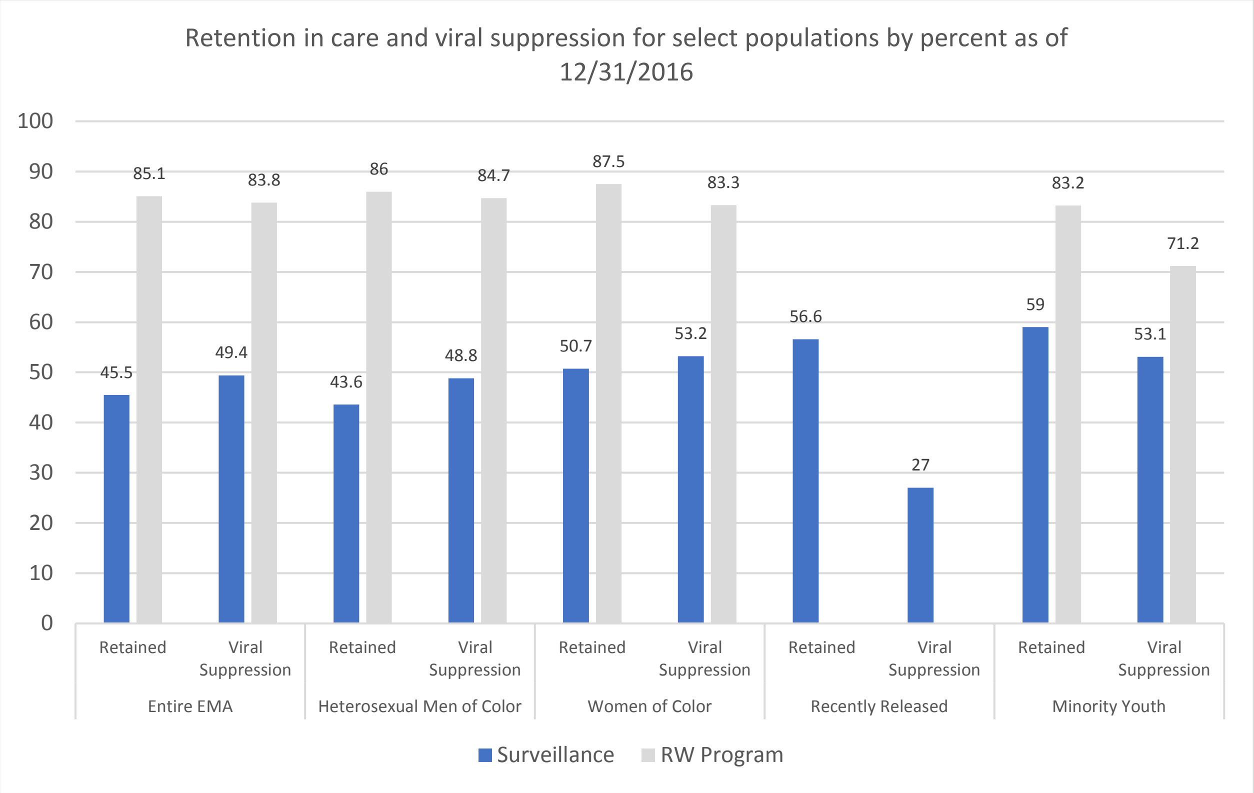
[5] The Ryan White HIV/AIDS Program is a Federal program that provides HIV-related health services. The program works with cities, states, and local community-based organizations to provide services to more than half a million people each year. The program is for those who do not have sufficient health care coverage or financial resources for coping with HIV disease. It fills gaps in care not covered by these other sources. https://hab.hrsa.gov/about-ryan-white-hivaids-program/about-ryan-white-hivaids-program

much higher percentage of people living with HIV/AIDS in the RW system are virally suppressed (49.4% vs. 83.8%) and retained in care (45.5% vs. 85.1%).

While many of the EMA's people living with HIV/AIDS are virally suppressed, they still require ongoing HIV care, treatment adherence services, and supportive services. Persons with extremely low incomes, low educational attainment, mental health conditions, and/or substance abuse issues may face significant challenges to maintaining their viral suppression and treatment adherence, according to local and national analyses. While deaths from AIDS have dropped dramatically, and we are beginning to see a drop in HIV transmissions among certain populations, the burden of HIV disease on the EMA continues to increase. This strains not only the Ryan White system, but the housing, mental health, and substance abuse treatment systems as well.

According to PDPH analyses, many of the EMA's PLWH are living on incomes at or below the federal poverty line. This renders them vulnerable to any number of challenges and emergencies that can lead them to falling out of care and becoming non-adherent to medications and other necessary treatments (including health conditions in addition to HIV). A change in or loss of housing, loss of Medicaid or other health insurance, a move to a new town, the death or illness of partner or loved one, or incarceration can leave individuals unable to meet their basic needs and continue to adhere to treatment.

Figure 1. Retention in care and viral suppression for select populations by percent as of 12/31/2016



Methodology

Survey Question Development

In summer 2016, Office of HIV Planning (OHP) staff met with the HIV Integrated Planning Council (HIPC)'s Comprehensive Planning Committee to develop the 2017 survey tool. OHP staff presented the committee with recommendations for changes, removals, and additions to the 2012 questionnaire, based on current policy, changes in clinical practice, and community feedback gathered at a local HIV summit earlier that summer. Special attention was given to the readability of the questions, to ensure a broad spectrum of respondents could participate and understand the questions. The HIPC was dedicated to ensuring the questions were not stigmatizing or triggering, and were inclusive of marginalized groups. The questions were developed over the course of three months through collaboration between OHP, AACO, and the HIPC. Members of the Positive Committee piloted the survey in November 2016 and offered feedback on the wording and order of some questions.

The survey included new questions about employment, sexual behaviors, sexual partners' HIV statuses, co-occurring conditions (physical and mental health), insurance status, and barriers to services. This survey includes four separate questions addressing sex at birth, gender identity, sexual orientation, and sexual partners' gender/sex. The survey was designed to be open to all adults, regardless of HIV status, with a section dedicated to HIV clinical outcomes and Ryan White services. The survey closed with an open-ended question asking what challenges respondents faced when accessing medical care or non-clinical support services in the last 12 months. There was a similarly worded open-ended question in the section of the survey that asked HIV-related questions. The questionnaire can be found in Appendix A.

Spanish Language Surveys

The survey was translated into Spanish by a contractor. Spanish-speaking HIPC members also helped tailor questions to appropriate language and reading abilities.

Distribution of Paper Surveys

In order to comply with the Health Insurance Portability and Accountability Act (HIPAA) and state confidentiality laws, OHP staff worked with RW providers to determine the best method of getting surveys to their clients, whether via mail, e-mail or in-person contacts. In order to reach the region's PLWH, OHP staff must rely on RW providers volunteering to distribute the survey to their clients. Agencies were asked to distribute the surveys via mail to a random 25% sample of their mailing list or in their waiting rooms and other common areas on-site. AACO encouraged provider agencies to help distribute the survey via a letter and an announcement at a quarterly meeting of directors of RW-funded service agencies in January 2017.

In total, 19 provider organizations (including HIV medical and non-medical providers) agreed to distribute the survey. Of these organizations, 3 were located in South Jersey, 2 were in the PA suburbs, and 14 were in Philadelphia. OHP staff provided 2,915 paper surveys to providers who agreed to distribute them between December 2016 and February 2017. Of the paper surveys, 2,405 were in English and 510 were in Spanish. OHP staff delivered the surveys and supplies to the agencies, including the postage for mailing surveys and return pre-paid self-addressed envelopes. The actual distribution of the surveys to clients happened at the discretion of provider staff. OHP staff had no control over when or how the surveys were given to clients, or if they were distributed at all. This is a major limitation to this study.

Online Survey

The survey was adapted for online use in both English and Spanish via the Survey Monkey platform with the highest level of security available, including HIPAA compliance. The anonymous survey did not collect IP addresses, email addresses, or any other identifiers from the respondents. The questions were only altered to reflect the respondents' ability to skip questions that were not applicable, and to include an opt-out selection in case respondents were under the age of 18. The online survey was tested by OHP staff and a few community members before it launched in honor of World AIDS Day on December 1, 2016.

Marketing of the Online Survey

OHP staff designed several versions of fliers for the online survey featuring varied photographs of people to appeal to a diverse consumer population. Fliers were distributed to providers in the packets of paper surveys, via email, by mail, and made available at community planning meetings. OHP staff created images to be used on social media platforms like Facebook and Twitter, and made those available to providers through a flash drive in all the survey packages that were distributed to providers, as well as through email.

Announcements about the survey were included in the OHP email newsletter. OHP staff used social media platforms from December 1, 2016 to April 30, 2017 to promote the survey to community members and provider agencies.

Limitations

This survey is an evaluation of the Philadelphia EMA Ryan White service system and not research. These results are not intended to be generalized to all Ryan White clients or all people living with HIV in the 9-county region. These results describe the sample who responded to the survey and can give readers an insight into common traits, experiences, and needs of individuals who use Ryan White services.

The distribution methods allowed by law and logistics prevented a wide and truly random sample of RW clients throughout the EMA. Providers mail information to their clients less often than they did five years ago, when the last RW consumer survey was conducted. Some providers no longer send mail at all. Having to rely on RW providers to distribute the survey is a significant challenge. This makes it difficult to ensure the survey distribution instructions are followed or that the survey is distributed at all. Providers have to fit survey distribution into their daily operations, and sometimes they don't have the capacity to distribute the surveys. Some agencies have more resources to devote to the distribution, and some agencies have a greater investment in and understanding of the Ryan White services planning process.

This distribution method favors people who are currently engaged in Ryan White services, people who have a mailing address, and people who visited a participating provider between December 2016 and February 2017.

Responses may be influenced by individuals' beliefs about what they should report in order to give the "right" answer. This is particularly a concern in situations when individuals answered the survey in the company of and/or with the assistance of a case manager or other person of authority.

There is also the effect of nonresponse bias of this sample. We do not know who didn't respond to the survey, and how they may differ from the sample. For example, people living with HIV who primarily speak Spanish or other languages aside from English were not adequately represented in the sample. Certain subpopulations and demographic characteristics are under or over-represented in the sample, compared to the EMA's Ryan White client population in 2016. By way of example, Black/African American PLWH and Hispanics were underrepresented. People with income below $1,000/month were underrepresented while those with income over $2,000/month were overrepresented. The mean age was 6-7 years higher for survey respondents than the RW client population. Consumers between 18-24 and under 39 years old were underrepresented and those over 50 years old were significantly overrepresented. See Appendix for a comparison between the Ryan White client data and the survey respondents' demographics.

Institutional Review Board

The survey tool, marketing materials, and methodology were submitted to the Philadelphia Department of Public Health's Institutional Review Board (IRB). The IRB Administrator deemed the survey to be exempt from the Department's IRB process because this activity is a part of the evaluation of the Ryan White Part A system, and therefore is not research.

Responses

By the close of survey collection on April 30, 2017, 392 valid surveys were returned. Of these, 28 were online surveys and 364 were paper surveys. Only 15 of the Spanish language paper surveys were returned. By region, the responses were not proportional to the distribution of the epidemic. Philadelphia was under-represented. Residents of Philadelphia represented 62% of the sample, New Jersey counties represented 19%, and the Pennsylvania counties represented 18%. The majority of respondents (62.7%) reported getting the survey at a provider agency. Of these, 41.3% obtained the survey from an individual, 20.9% got it in a waiting room, and 0.5% received it at a pharmacy. Some respondents reported receiving the survey from family and friends (2.6%), and 4.8% reported getting the survey from another source.

The online survey received 53 responses, of which 28 were valid surveys from HIV-positive respondents. No responses were received via the Spanish-language online survey. Only 1.8% (7) of online survey respondents reported they received the survey via email.

Table 1. Geographic Distribution Method and Responses n=372

Region	Mail English	Mail Spanish	Provider On-Site English	Provider On-Site Spanish	Responses Number	Responses % of Total	2015 EMA PLWH % of Total
PA Suburbs	110	0	90	10	68	18%	15.5%
NJ Suburbs	0	0	190	10	73	19%	12.5%
Philadelphia	695	280	1320	210	231	62%	72%
EMA Total	805	280	1600	230	372	100%	100%

Not all survey participants responded to the residence question

Description of Respondents

The majority of respondents were male, African-American, over 50, from Philadelphia, and/or had an income below the Federal Poverty Line (FPL). A description of the sample's demographics, co-morbidities, health care access, HIV clinical outcomes, and service access are included here.

Age

The respondents represent an aging population of PLWH, which mirrors the Ryan White client population served in our EMA. The median age of the respondents who gave their age was 54 years. The mean age was 52.76 years old. This was consistent throughout the three regions. Ages spanned from 18 to 89. Most respondents were aged 50 or older (72.2%). Only 53 respondents were aged 39 or younger (14.6%). 2.4% were between 18 and 24 years of age.

Sex at Birth

More individuals were assigned male than female at birth in the sample: 65.9% (249) vs 34.1% (129). In terms of how they now identify, 34.6% identify as female, 63.3% identify as male, 1.3% identify as transgender, and .3% identify as gender nonconforming.

Race/Ethnicity

The racial/ethnic composition of the sample was similar to previous consumer surveys. 62.1% of the respondents identified themselves as black, 25.3% said they were white, 6.3% were Hispanic or Latinx, and 6.3% indicated another race, which included biracial/multiracial, Native American/Alaskan native, and Asian. As shown in Figure 2, black men and women made up over half of the sample, at 38.7% and 23.3% respectively. The survey tool asked two separate questions about race and Hispanic/Latinx ethnicity. Some individuals wrote in Hispanic/Latinx as their race and selected Hispanic/Latinx as their ethnicity. This leads to two different data points regarding Hispanic/Latinx identity. We have provided both for your review. Figure 3 has the self-identified ethnic identity of Hispanic/Latinx or Non-Hispanic/Latinx by sex, 3% of the respondents identified as Hispanic/Latinx women and 12% as Hispanic/Latinx men. Individuals could choose any race in combination with either Hispanic/Latinx or non-Hispanic/Latinx ethnicity.

Figure 2. Survey Respondents’ Race and Sex at Birth n=279

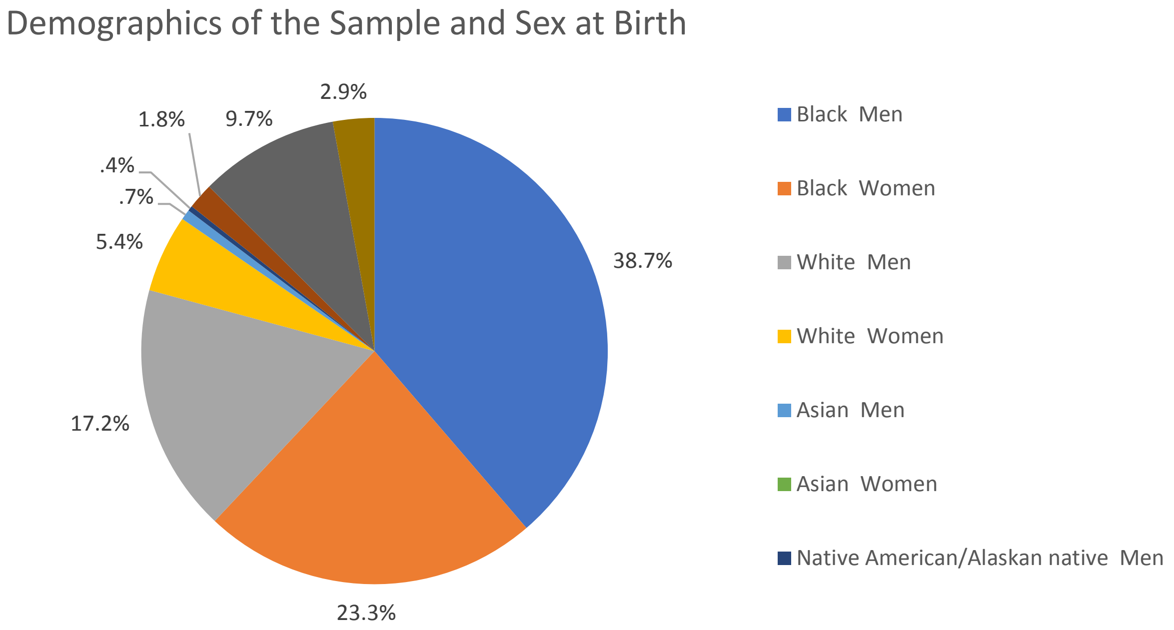
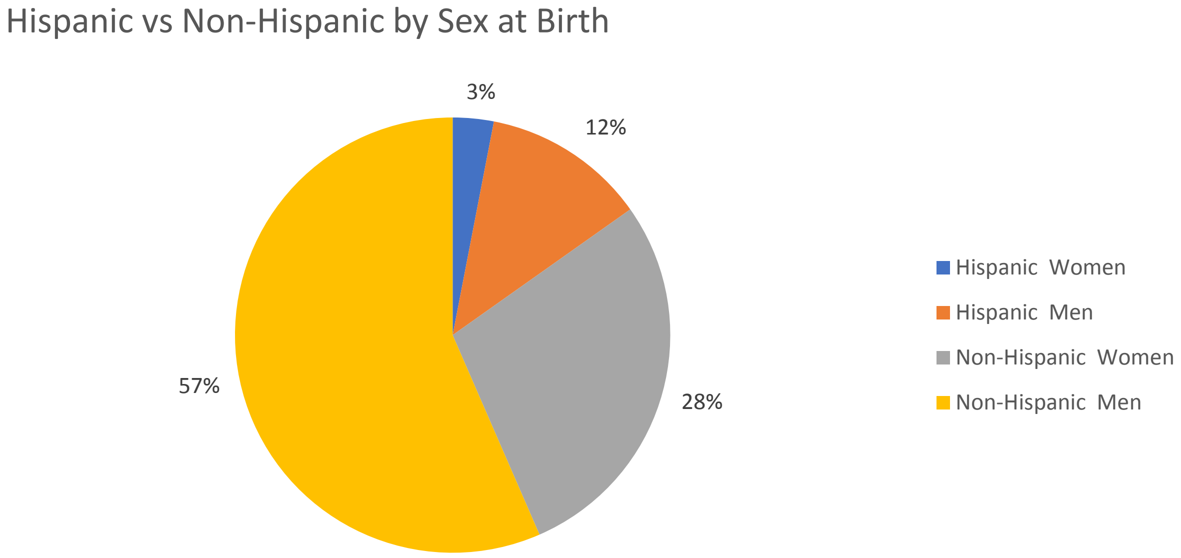


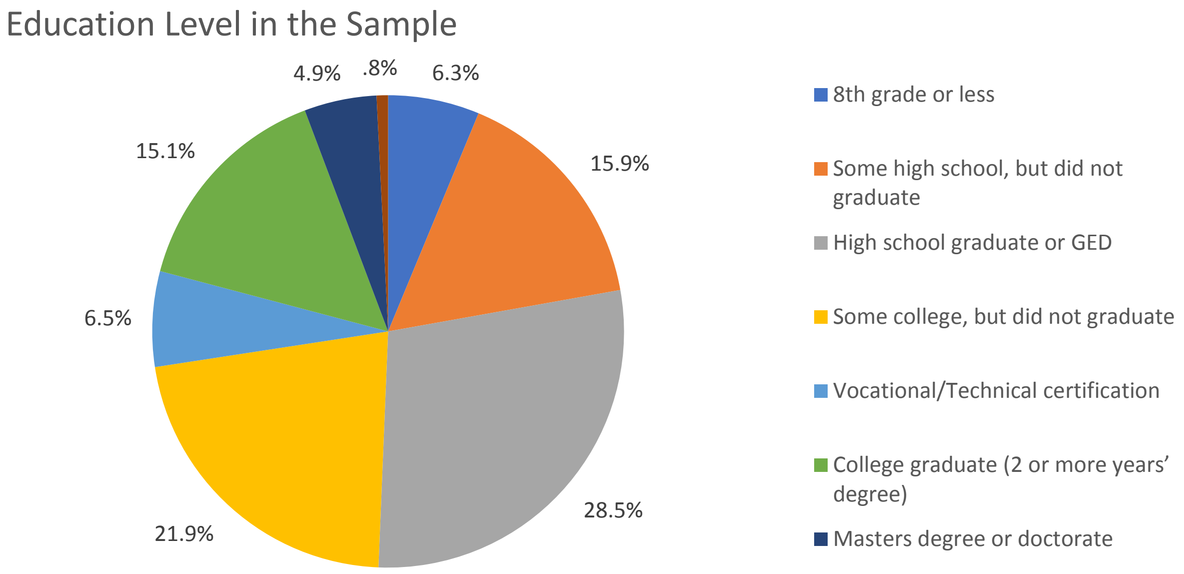
Figure 3. Survey Respondents' Ethnicity and Sex at Birth n=329



Educational Attainment

The majority of the participants reported having graduated from high school or having attained higher education. Within the sample, 22.7% had an education level below high school (8th grade or less plus some high school but did not graduate), 28.5% identified as high school graduates, when combined 28.4% had some college or vocational training, and 20% indicated they were college graduates (see Figure 4).

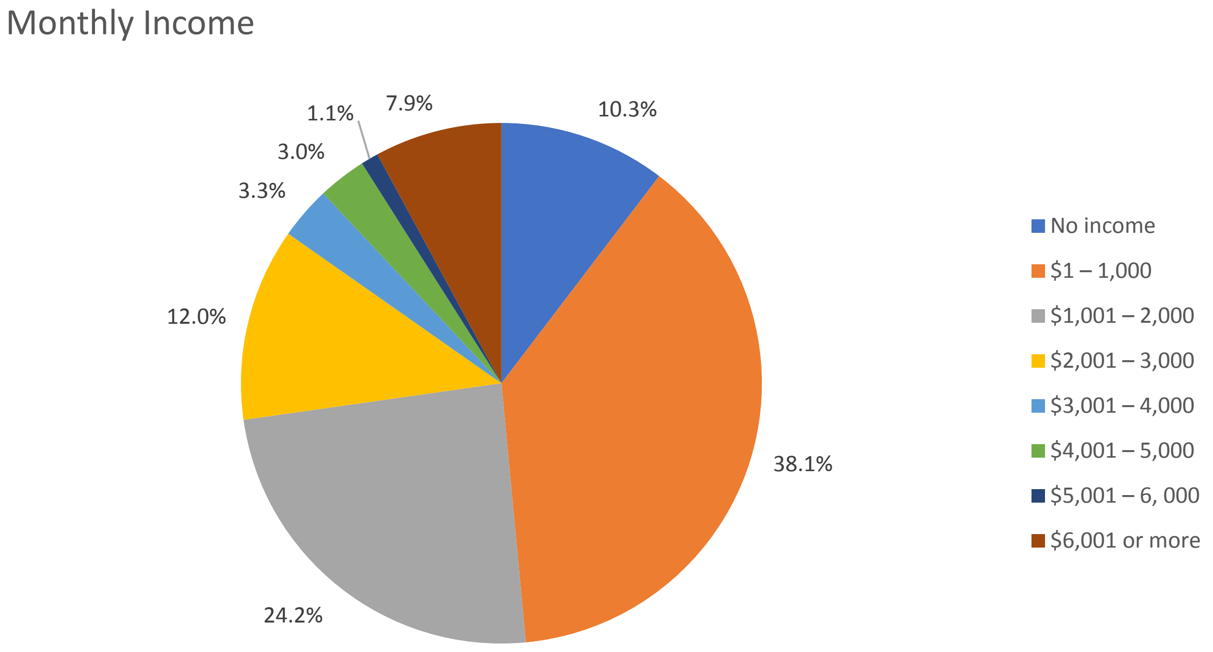
Figure 4. Survey Respondents' Education Completed n=383



Income/Employment

Almost half of the respondents indicated their personal income to be below $1,000 per month[6]. 10.3% of respondents said they earned no income at all, and another 38.1% earned below $1,000 per month. 24.2% of respondents earned between $1,001 and $2,000 per month, 12% earned between $2,001 and $3,000, and 15.3% earned more than $3,001 per month (Figure 5). Respondents from New Jersey were more likely to have an income higher than $1,000 per month (p<.001) than respondents from Philadelphia and the PA Counties. Males were more likely to have an income higher than $1,000 per month than females. Almost half of the sample (45.1%) were unemployed due to disability, while 17.8% were unemployed but not disabled, 10% were retired, and 27% were employed.

Figure 5. Survey Respondents' Income n=368



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[6] The Federal Poverty Guidelines for 2017 list an annual income of $12,060 (approximately $1000/month) as meeting the definition of poverty. https://www.federalregister.gov/documents/2017/01/31/2017-02076/annual-update-of-the-hhs-poverty-guidelines

Housing

Over half of the sample (61.6%) said 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 respondents said they stayed 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 (Figure 6). Respondents from New Jersey were more likely to rent or own their own home (p<.001) than respondents from Philadelphia and the PA Counties (Table 2).

People who were homeless or marginally housed were significantly younger than those who owned or rented (p=.020), were significantly more likely to have income below $1,000 or no income at all (p<.0001), and were more likely to be unemployed (p=.012).

Figure 6. Survey Respondents' Housing Status n=378

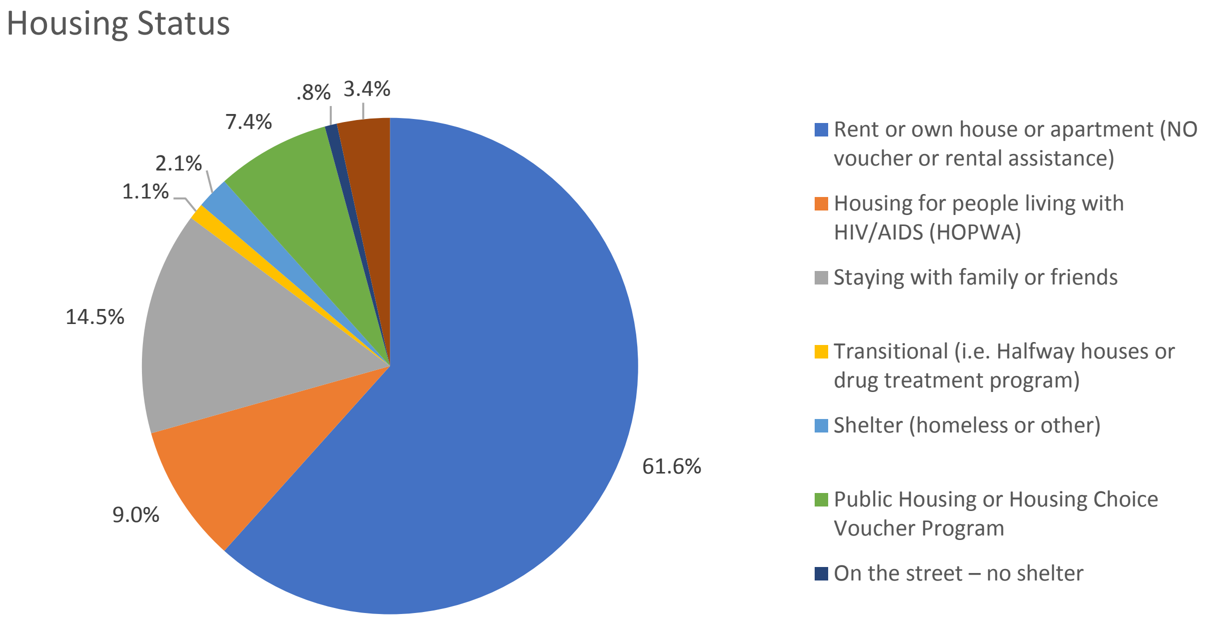

Table 2. Demographic Characteristics of the Survey Respondents

Predictors	Philadelphia	New Jersey	Pennsylvania	Total	p-value*
Age (Mean)	52.5	53.5	53.4		
Sex n=363					
Male	40.8%	12.9%	11.8%	**65.5%**	
Female	21.5%	6.4%	6.6%	**34.5%**	
Total	**62.3%**	**19.3%**	**18.4**	**100%**	
Race/Ethnicity n=349					
Black/African-American	44.7%	9.8%	8.3%	**62.8%**	***
White/Caucasian	9.7%	7.4%	8.3%	**25.4%**	
Hispanic/Latinx	4.0%	2.3%	0.3%	**6.6%**	
Other-race	2.9%	0.6%	1.7%	**5.2%**	
Total	**61.3%**	**20.1%**	**18.6%**	**100%**	
Personal monthly income n=352					
No income	7.4%	.7%	2.3%	**10.4%**	***
Below $1,000	26.1%	5.7%	6.3%	**38.1%**	
$1,001-2,000	13.1%	7.1%	4.5%	**24.7%**	
$2,001-3,000	6.0%	2.3%	3.1%	**11.4%**	
$3,001+	8.8%	4.3%	2.6%	**15.7%**	
Total	**61.4%**	**19.9%**	**18.8**	**100%**	
Education n=367					
Below High School	15.5%	4.4%	3.0%	**22.9%**	*
High School Graduate	20.4%	3.8%	4.6%	**28.8%**	
Some College /Vocational	15.5%	6.3%	6.5%	**28.3%**	
College graduate +	10.4%	5.1%	4.4%	**19.9%**	
Total	**61.8%**	**19.6%**	**18.5%**	**100%**	
Employment n=352					
Employed	14.2%	5.9%	7.1%	**27.2%**	
Unemployed	11.9%	4.0%	1.7%	**17.6%**	
Retired	6.2%	1.7%	2.0%	**9.9%**	
Disabled	28.8%	9.1%	7.4%	**45.3%**	
Total	**61.1%**	**20.7%**	**18.2%**	**100%**	
Housing n=363					
Rent or own a place	37.7%	14.3%	10.5%	**62.5%**	***
Housing for PLWH	5.5%	0.3%	2.2%	**8.0%**	
Staying with family/friends	8.6%	2.5%	3.9%	**15.0%**	
Other	10.5%	2.5%	1.6%	**14.6%**	
Total	**62.3%**	**19.6%**	**18.2%**	**100%**	

For p-values, * refers to $p < 0.1$, ** refers to $p < 0.05$, and *** refers to $p < .01$.

Incarceration

History of incarceration since HIV diagnosis was reported by 19.4% (75/364) of respondents. Those with and without incarceration history were of similar age and did not differ in racial/ethnic composition or employment status. A higher percentage of respondents who reported incarceration since their HIV diagnosis were male, as compared to those who had not been incarcerated (75% vs 65.2% respectively); however, this relationship was not statistically significant. Incarceration since HIV diagnosis was statistically associated with income and education, with people who had been incarcerated being more likely to report personal income below $1,000 per month (p<.0001) and less likely to have attained high school or above levels of education (p=.005) compared to those who did not report being incarcerated since their HIV diagnosis (Table 3).

Table 3. Comparison of Survey Respondents with and Without History of Incarceration Since HIV Diagnosis by Income and Education

	Incarceration since HIV diagnosis	No incarceration since HIV diagnosis
Personal monthly income	n=70	n=272
No income	24.3%	7.7%
Below $1,000	45.7%	35.3%
$1,001-2,000	8.6%	29.0%
$2,001-3,000	12.9%	12.1%
$3,001+	8.6%	15.8%
Total	**100%**	**100%**
Education	n=73	n=284
Below High School	37.0%	19.7%
High School Graduate	26.0%	27.5%
Some College/Vocational	27.4%	29.9%
College Graduate +	9.6%	22.9%
Total	**100%**	**100%**

Health Insurance

The majority of participants (95.9%) had some form of health insurance or medical services coverage. 46.4% had Medicaid or Medical Assistance, HealthChoices, or an ACCESS card. 31.4% said they had Medicare. 9.9% were insured through work or a union. 4.6% were insured through the Affordable Care Act health insurance marketplace. 10.7% said they were covered under Health Partners plans. 1.5% bought their insurance directly. 1.5% were insured through Veterans Affairs or military health care. Participants could pick more than one type of insurance. Therefore, the sum of the percentages in the text above exceeds 100%.

Of those who were uninsured (4.1%, n=16), 7 people said that their insurance status changed in the past year. This implies that they lost their coverage in the past year. Of those who were insured, 36 people said that their coverage changed in the last year. This implies that they gained or changed their insurance provider.

Co-occurring Conditions

Respondents were asked if a doctor had ever told them they had any of the health conditions in Table 4. Hypertension was the most commonly reported condition, with almost half of the participants reporting that they had high blood pressure (48.4%). This was followed by high cholesterol (30.8%), lung/breathing problems (19.2%), diabetes (19.2%), nerve issues such as epilepsy or neuropathy (18.1%), liver problems (15.3%), kidney problems (13.2%), cardiac problems or heart disease (12.7%), and cancer (8.5%).

Table 4. Ever Diagnosed with Common Chronic Disease and Health Conditions, n=386

Diseases and Conditions	Yes	Yes %
High Blood Pressure	187	48.4%
High Cholesterol	119	30.8%
Lung/Breathing Problems	74	19.2%
Diabetes	74	19.2%
Nerve Issues	70	18.1%
Liver Problems	59	15.3%
Kidney Problems	51	13.2%
Cardiac Problems	49	12.7%
Cancer	33	8.5%

Mental Health Disorders

Participants were asked whether a doctor ever told them that they had any of the following mental health disorders: depression, anxiety, bipolar disorder, dementia, schizophrenia/schizoaffective disorder, post-traumatic stress disorder (PTSD), obsessive compulsive disorder (OCD), eating disorder, substance use disorder, and/or mood disorder. Overall, 63.5% of participants reported having at least one mental health problem. Prevalence of lifetime mental disorders can be found in Table 5 below. 51.5% of respondents reported to have been diagnosed with depression, 43.3% with anxiety, 19.2% with bipolar disorder, 10.4% with substance use disorder, 8.3% with schizophrenia or schizoaffective disorder, 10.9% with PTSD, 13% with mood disorder, 3.4% with OCD, 2.8% with eating disorder, and 1% with 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 (p=.012).

Table 5. Survey Respondents Reporting Ever Diagnosed with Mental Health Disorders, n=386

Mental Health Disorders	Yes	Yes %
Depression	199	51.5%
Anxiety	167	43.3%
Bipolar Disorder	74	19.2%
Mood Disorders	50	12.9%
Post Trauma Stress Disorder	42	10.9%
Substance Use Disorder	40	10.4%
Schizophrenia/Schizoaffective Disorder	32	8.3%
Obsessive Compulsive Disorder	13	3.4%
Eating Disorders	11	2.8%
Dementia	4	1.0%

Hepatitis C (HCV)

The majority of respondents (61.1%) reported that they had never been diagnosed with hepatitis C (HCV). Other respondents said that they either had HCV but had been treated/cured (21.8%, n=84) or had HCV and had not been treated/cured (6.2%, n=24). There were no significant differences in gender and racial/ethnic composition of the HCV groups; however, there were differences in distribution of income, education, and employment between them. People with higher incomes were less likely to have ever had HCV compared to those with lower incomes. People with lower income were more likely to have a history of untreated HCV (p=.046), compared to other groups. People with the history of HCV were more likely to have lower education levels compared to those without a history of HCV (p=.011). People with histories of treated HCV were more likely to be disabled, retired, or unemployed compared to people with histories of untreated HCV or no HCV history. People with histories of untreated HCV were more likely to be employed (p=.012). See Table 6 for the demographics of respondents who had ever been diagnosed with HCV.

Table 6. Demographic Characteristics of Respondents with a History of HCV

Predictors	History Treated HCV n	History Treated HCV %	History of Untreated HCV n	History of Untreated HCV %
Age Mean (SD)	57.1 (8.1)		53.2 (10.9)	
Sex				
Male	59	73.7%	12	54.5%
Female	21	26.3%	10	45.5%
Total	**80**	**100%**	**22**	**100%**
Race/Ethnicity				
Black/African-American	50	64.1%	14	58.3%
White/Caucasian	17	21.8%	7	29.2%
Hispanic/Latinx	4	5.1%	1	4.2%
Other-race	7	9.0%	2	8.3%
Total	**78**	**100%**	**24**	**100%**
Income				
No income	9	11.8%	4	18.2%
Below $1,000	37	48.7%	11	50.0%
$1,001 - $2,000	16	21.1%	2	9.1%
$2,001 - $3,000	7	9.2%	3	13.6%
$3,001 +	7	9.2%	2	9.1%
Total	**76**	**100%**	**22**	**100%**
Education				
Below High School	22	27.2%	6	25.0%
High School Graduate	26	32.1%	11	45.8%
Some College/Vocational	24	29.6%	6	25.0%
College Graduate	9	11.1%	1	4.2%
Total	**81**	**100%**	**24**	**100%**
Employment				
Employed	10	13.5%	9	45.0%
Unemployed	16	21.6%	4	20.0%
Retired	11	14.9%	2	10.0%
Disabled	37	50.0%	5	25.0%
Total	**74**	**100%**	**20**	**100%**

HIV-related Health Outcomes and Service Access

The mean number of years with an HIV diagnosis among participants was 16 years (SD=9.9). About 10% of the participants received their HIV diagnosis within the last year. Most participants (81.3%) said that they received HIV medical care within 30 days of their HIV diagnosis. Almost half of participants (48.9%) said they had an AIDS diagnosis, 47.7% said they had not been diagnosed with AIDS, and 3.1% said that they do not know whether they had AIDS or not. Of those who had AIDS diagnoses, 110 (67.5%) people said that they were diagnosed with AIDS at the same time they received a diagnosis of HIV. The remaining 53 (32.5%) respondents were diagnosed with AIDS later.

Most participants said that their most recent viral load was undetectable (90.7%), while 6.8% said that their viral load was detectable but below 5,000 copies/ml. The remaining 2.5% had viral loads greater than 5,000 copies/ml. Almost all participants reported taking antiretroviral medications (95.1%).

Almost all respondents said that they get HIV medical care regularly at the same place (98.3%). Most of the respondents said that they have seen their HIV medical provider 3 times or more in the past year (83.2%), while 16.2% have seen their medical provider once or twice in the past year. Two respondents said they did not see an HIV medical provider in the previous 12 months.

In addition, the majority of the respondents (86.9%) 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 3.0% said “some of the time”, and 1.2% said “never”. Almost three-quarters of the respondents (71.2%) said that they always feel comfortable talking to their HIV medical provider about personal and 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.

Concurrent AIDS and HIV Diagnoses

For the purpose of this analysis, we defined concurrent HIV/AIDS diagnosis as reported AIDS diagnosis at the same time as initial HIV diagnosis. This is based on responses to the question: “When you were diagnosed with HIV, were you also told that you had an AIDS diagnosis?” We refer to the group that responded “yes” as “late testers”. Overall, 110 people (34.2%) reported that they received an AIDS diagnosis at the time they learned that they had HIV. Late testers were slightly older (p=.024) than those who received their HIV diagnosis earlier in the disease stage. Late testers were more likely to be men (p=.031) and more likely to have housing (p=.023) than those who did not fall into the late tester category. See Table 7 for demographic characteristics of those who did and did not have concurrent HIV/AIDS diagnoses.

Limited Access to HIV Services in the Past 12 Months

Fortunately, 91.3% did not experience problems in accessing HIV medical care in the previous 12 months. 8.8% said that they could not get the service/services they needed. People who experienced problems accessing HIV medical services were more likely to be younger than the mean age of the sample ($p < .05$) and more likely to be Hispanic/Latinx ($p < .01$). Although there were more male participants among those who experienced limited access to HIV care compared to those who did not, this relationship was marginally significant (p=.068). From our analysis, people who were marginally housed or homeless (p=.083), were without medical insurance (p=.001), and/or had a history of incarceration since HIV diagnosis (p=.008) were more likely to have problems accessing HIV medical care (Table 8).

HIV Case Management

Most respondents had an HIV case manager (82.1%), and most of those respondents were satisfied with their case managers (96.6%). Respondents who were female ($p < .05$), had a race/ethnicity other than white ($p < .05$), had incomes less than $1,000 per month ($p < .01$), had greater than a high school education ($p < .01$), and/or were unemployed ($p < .01$) were more likely to have a medical case manager (see Table 9). People who have HIV case manager are more likely to have slightly worse clinical characteristics compared to those who do not have a case manager. A higher percentage of respondents with case managers had AIDS diagnoses when compared to the group without case managers (53% vs 38.6% respectively, p=.05). There are more people with detectable viral loads in the group with case managers (18.2% vs. 7.5%, p=.013). This is to be expected, because medical case management is intended to help PLWH access medical care, improve health outcomes, and achieve viral suppression. Those who need more support to achieve these goals will be referred to medical case management.

Table 7. Characteristics of Respondents who Reported Concurrent HIV and AIDS Diagnoses

Predictors	**Concurrent HIV/AIDS dx**			**Independent HIV & AIDS dx**			**p-value***
	n	**%**	**Total Responses - Yes**	**n**	**%**	**Total Responses - No**	
Age Mean (SD)	55.1 (9.2)	NA	NA	52.1 (11.6)	NA	NA	**
Sex at Birth							
Male	83	76.8%		136	65.0%		**
Female	25	23.2%		73	35.0%		
Total		**100%**	**108**		**100%**	**209**	
Race/Ethnicity							
Black/African-American	58	59.2%		126	60.3%		
White/Caucasian	23	23.5%		61	29.2%		
Hispanic/Latinx	10	10.2%		12	5.7%		
Other-race	7	7.1%		10	4.8%		
Total		**100%**	**98**		**100%**	**209**	
Income							
Below $1,000	46	45.1%		95	46.8%		
$1,01-2,000	23	22.5%		58	28.6%		
$2,001-3,000	15	14.7%		22	10.8%		
$3,001+	18	17.7%		28	13.8%		
Total		**100%**	**102**		**100%**	**203**	
Education							
Below High School	25	23.1%		48	22.8%		
High School Graduate	31	28.7%		56	26.5%		
Some College/Vocational	34	31.5%		59	27.9%		
College Graduate +	18	16.7%		48	22.8%		
Total		**100%**	**108**		**100%**	**211**	
Employment							
Employed	26	25.2%		60	30.2%		
Unemployed	16	15.5%		33	16.6%		
Retired	11	10.7%		19	9.5%		
Disabled	50	48.6%		87	43.7%		
Total		**100%**	**103**		**100%**	**199**	
Homeless/marginally homeless	13	12.6%	103	49	23.5%	208	
Having no medical insurance	7	6.4%	110	9	4.2%	212	
Any mental disorder	71	64.5%	110	134	63.2%	212	
Hepatitis C	31	31.3%	99	60	31.2%	192	
Incarceration history	22	21.0%	105	46	22.1%	208	**

*p-values were obtained as a result of independent-sample t-test for age, and chi-square test or fisher's exact test for categorical variables. For p-values * refers to p < 0.1, ** refers to p < 0.05, and *** refers to p < .01.

Table 8. Characteristics of Respondents with and Without Experience of Limited Access to HIV Services

Survey question: In the past 12 months, did you ever need HIV medical care but could not get it?	Yes	No	p-value*
Age			
Mean (SD)	46.4 (13.8)	53.2 (11.1)	***
Sex at Birth	n=27	n=287	
Male	85.2%	68.3%	*
Female	14.8%	31.7%	
Total	**100%**	**100%**	
Race/Ethnicity	n=25	n=276	
Black/African-American	64.0%	60.9%	
White/Caucasian	8.0%	28.3%	**
Hispanic/Latinx	12.0%	6.2%	
Other-race	16.0%	4.7%	
Total	**100%**	**100%**	
Personal monthly income	n=20	n=282	
Below $1,000	45.0%	47.2%	
$1,001-2,000	15.0%	26.9%	
$2,001-3,000	20.0%	10.6%	
$3,001+	20.0%	15.3%	
Total	**100%**	**100%**	
Education	n=27	n=287	
Below High School	25.9%	23.9%	
High School Graduate	25.9%	25.3%	
Some College/Vocational	25.9%	29.4%	
College graduate +	22.2%	21.4%	
Total	**100%**	**100%**	
Employment	n=22	n=278	
Employed	22.7%	28.4%	
Unemployed	45.5%	15.5%	***
Retired	9.1%	9.0%	
Disabled	22.7%	47.1%	
Total	**100%**	**100%**	
Homeless/marginally homeless	33.3% (8/24)	18.7% (53/284)	*
Having no medical insurance	32.1% (9/28)	2.1% (6/292)	***

*p-values were obtained as a result of independent-sample t-test for age, and chi-square test or fisher's exact test for categorical variables. For p-values * refers to $p < 0.1$, ** refers to $p < 0.05$, and *** refers to $p < .01$.

Table 9. Characteristics of Respondents with and Without Medical Case Managers

Survey question: Do you have an HIV case manager?			
	Yes	**No**	**p-value***
Age			
Mean (SD)	53.1 (10.9)	51.7 (12.9)	
Sex at Birth	n=269	n=60	
Male	66.2%	80.0%	**
Female	33.8%	20.0%	
Total	**100%**	**100%**	
Race/Ethnicity	n=259	n=56	
African American/Black	62.6%	58.9%	
White/Caucasian	23.2%	39.3%	***
Hispanic/Latinx	7.7%	1.8%	
Other-race	6.5%	0	
Total	**100%**	**100%**	
Personal monthly income	n=256	n=60	
Below $1,000	50.4%	35.0%	
$1,001-3,000	26.5%	23.3%	**
$2,001-3,000	9.8%	23.3%	
$3,001+	13.3%	18.3%	
Total	**100%**	**100%**	
Education	n=271	n=60	
Below High School	25.8%	18.3%	
High School Graduate	28.4%	20.0%	***
Some College/Vocational	29.9%	21.7%	
College Graduate +	15.9%	40.0%	
Total	**100%**	**100%**	
Employment	n=255	n=58	
Employed	23.5%	44.8%	
Unemployed	18.8%	10.3%	***
Retired	9.8%	12.1%	
Disabled	47.8%	32.8%	
Total	**100%**	**100%**	
Homeless/marginally homeless	19.4% (51/263)	21.7% (13/60)	
Having no medical insurance	4.7% (13/275)	5.0% (3/60)	

*p-values were obtained as a result of independent-sample t-test for age, and chi-square test or fisher's exact test for categorical variables. For p-values * refers to $p< 0.1$, ** refers to $p < 0.05$, and *** refers to $p < .01$.

Gynecological Service Access

Out of 125 individuals who reported their sex at birth as female, only 54 answered the question: "In the last 12 months, has your primary medical provider asked you about family planning, birth control, or your pregnancy plans". Out of those who answered this question, 35.2% (n=19) said "yes" and 64.8% (n=35) said "no". As expected, women who were asked about family planning were significantly younger (mean age = 44.7) than those who were not asked about it (mean age = 52.5, p=.014).

Out of 125 individuals who reported they were assigned female at birth, 101 answered the question “Do you get gynecological or women’s health care (GYN) at the same place you get your other medical care or are you referred somewhere else?” Most respondents said that they get gynecological services at the same place (79.2%), 19.8% said that they get referred to somewhere else for gynecological services, and one person said that their medical provider does not refer them anywhere for gynecological services or take care of their reproductive health.

The majority of individuals who answered the questions “When was the last time you received GYN care?” answered “in the last 12 months” (80.4%). 13.1% answered that they received gynecologic services 1-2 years ago, and 6.5% said that they received these services more than 2 years ago. It is important to note that guidelines around cervical cancer screening changed in 2015 to screenings every 3 years if there has been a history of normal results[7]. The individuals who have not had an exam in the last 3 years may not have an unmet need for gynecological care.

Self-reported Service Utilization and Unmet Service Needs

Survey respondents were asked to indicate whether, in the previous 12 months, they had used or needed but did not receive the services listed in Table 10 below. If the respondent did not select either “I have used this service in the last 12 months” or “I needed this service but did not get it**”,** we interpreted this as the individual not needing the service. This assumption may not accurately reflect the individual’s true service needs. We also believe that some respondents interpreted the two columns as “needed” and “didn’t need” so they may have checked the “I needed this service but did not get it” in error. It is impossible to know the intentions of all the respondents, so the following results should be considered in context of all the other data about service needs and barriers presented in this report. Data collected from this particular question may under- or overrepresent true consumer need of services due to the suspected misunderstanding of the answers and the design of the question. See appendix for a comparison between the survey respondents self-reported service utilization and EMA system-wide service utilization.

Dental care was reported as the most-used service, with 63% of respondents reported having used the service in the last 12 months. Medical care and medical case management were the second and third most-used services, at 58% and 48% respectively. The services with the highest percentage of respondents who reported needing but not receiving them were direct emergency financial assistance (DEFA) at 18%, housing assistance (15%), financial assistance for health insurance premiums and co-pays (12%), and legal services (13%). Most services have a self-reported unmet need of 9-11%. The services with the least reported unmet need are medical care (4%) and medical case management (6%).

Unmet service needs were collected through questions about specific services like mental health, substance use treatment, and dental care. Mental health counseling and substance use treatment were

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[7] For more information on cervical cancer screening from Health and Human Services: https://www.hhs.gov/opa/reproductive-health/cancers/cervical-cancer/index.html

noted as unmet needs (“I needed but didn’t get”) in the last 12 months for 6.8% and 2.7%, respectively. A regular place for dental care was noted as an unmet need for 15.1% of respondents.

Of those who reported incarceration since HIV diagnosis, 52.4% reported that they were not offered “any assistance with planning for healthcare and other needs after release”. The survey did not capture when or where this incarceration occurred, only that it was after their HIV diagnosis.

Table 10. Self-reported Service Utilization and Unmet Need in the Previous 12 months, n= 392

Service Category	I have used these services in the past 12 months	I needed these services but was unable to access them	Total Responses n=392
Dental care	63%	11%	74%
Medical care	58%	4%	62%
Medical case management	48%	6%	54%
Mental health therapy/counseling	32%	10%	42%
Housing assistance services	26%	15%	41%
Food bank/home-delivered meals	30%	10%	40%
Nutritional counseling	30%	10%	40%
Support groups	30%	9%	39%
Medical transportation services	26%	11%	37%
Emergency medications	32%	4%	35%
Financial assistance for health insurance premiums & co-pays	19%	12%	31%
Legal services	18%	13%	30%
Direct emergency financial assistance	11%	18%	29%
Treatment adherence counseling	15%	10%	24%
Assistance with household tasks and self-care	11%	12%	23%
Home health care	11%	11%	23%
Physical rehabilitation after an accident, stroke or other health condition	11%	11%	22%
Substance use treatment	13%	9%	22%
Services to help you get HIV medical care or get back into care after time away	12%	8%	20%
Language translation and interpretation services	7%	10%	17%
Hospice services	5%	11%	16%
Adult daycare for a relative or other person you care for	3%	11%	14%
Child care	4%	10%	14%

Barriers to Medical Care and Other Services

Respondents reported transportation and health insurance co-payments/deductibles were barriers to HIV medical care. 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 their employer, 40% of the self-insured, 50% of people with marketplace plans, 19% of those with Medicare coverage, 38% of those with Medicaid coverage, 28% of those covered by Health Partners, and 36% of those who reported "other insurance" (see Table 11). None of the respondents covered by the VA reported any transportation challenges in the previous 12 months. As you can see in Table 11, the uninsured, people with marketplace plans, and people covered through Medicaid and Medicare were significantly more likely to have transportation challenges that prevented them from attending appointments.

As shown in Table 12, the uninsured (47%), those with employer-based coverage (37%), the self-insured (40%), people with ACA marketplace plans (44%), Medicare-covered individuals (7%), and those covered by Medicaid (9%) were significantly more likely to have challenges related to out-of-pocket costs than PLWH covered under other types of insurance. No one with VA coverage reported a cost barrier to medical care (n=5).

Both the English and Spanish language versions of the survey asked if language was a barrier to services. 4.1% of respondents replied "yes" to the following question: "In the last 12 months, have you had problems getting medical care or other services because of the language/s you speak?" This includes respondents who returned surveys in English and Spanish. It should be noted that the survey was not offered in languages other than English and Spanish, so there was no opportunity for readers of other languages to participate in the survey without translation/interpretation assistance. Therefore, these data may undercount the true need for language services in the RW client population.

Respondents were asked, "In the past 12 months, if you couldn't get the services you needed, what were the reasons?" The reasons reported were: "can't afford them" (4.1%), "don't know where to go" (2.8%), "don't have insurance" (2.3%), "I don't want to go" (2.6%), "I don't have transportation" (3.6%), "depression" (4.1%), and "denial" (2.3%). The majority (75.3%) reported "I got the services I needed".

Qualitative Responses about Barriers to Care

Respondents were asked to share any problems they had experienced in the last 12 months that prevented them from getting the medical and support services they needed. This open-ended question solicited rich qualitative data (a total of 74 responses) on the stresses of poverty, aging, and insecure housing. Quotations are included throughout this discussion to add depth and personal experiences to these quantitative data. Problems with health insurance (including affording co-payments and cost-sharing) and transportation were the most-often mentioned barriers to HIV medical and other services experienced in the last 12 months. As noted in the OHP focus groups in 2014, even nominal co-pays of a few dollars can be a barrier to services or medications for people living in poverty. Transportation is a common and recurring barrier for many people who rely on Medicare and Medicaid transportation.[8]

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[8] 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/

Many respondents praised their doctors and other providers. Most of the comments related to lack of money to meet basic expenses like rent, food, healthcare (co-payments), transportation, and utilities. Some of the respondents were living with friends or relatives, and expressed their desire to have their own place for their wellbeing. Many of the survey respondents own or rent their own homes, and face the high costs of rent, utilities, and upkeep/maintenance of properties. Several respondents said that they were lonely or depressed and needed a place for socialization and support. Some responses centered on the challenges of managing complex health conditions like lupus, COPD, and mental health diagnoses.

Table 11. Transportation Barriers to Medical Care in the Previous 12 Months by Insurance, n=326

Survey question: In the last 12 months have you missed a medical appointment because you had problems with transportation and you could not get there on time?						
Insurance type	**Issues with transportation number of responses**	**Issues with transportation %**	**No issues number of responses**	**No Issues %**	**Total responses**	**p-value***
Uninsured	8	53.3%	7	46.7%	15	**
Unionized Insurance	13	37.1%	22	62.9%	35	
Self-insured	2	40.0%	3	60.0%	5	
Affordable Care Act Marketplace Insurance	8	50.0%	8	50.0%	16	*
Medicare	22	19.5%	91	80.5%	113	***
Medicaid	64	37.9%	105	62.1%	169	***
Health Partners	10	27.8%	26	72.2%	36	
Veterans Affairs/ Military Health Care	0	0%	5	100%	5	
Other	16	35.5%	29	64.5%	45	
Total	**93**	**28.5%**	**233**	**71.5%**	**326**	

*p-values were obtained as a result of independent-sample t-test for age, and chi-square test or fisher's exact test for categorical variables. For p-values * refers to $p < 0.1$, ** refers to $p < 0.05$, and *** refers to $p < .01$.

Table 12. Co-pays and Deductibles as Barrier to Medical Care in the Previous 12 Months by Insurance Type, n=311

Survey question: In the last 12 months, have you not gotten medical care because you couldn't afford co-pay or deductible?						
Insurance type	**Unable to get care # of responses**	**Unable to get care %**	**Able to get care # of responses**	**Able to get care %**	**Total responses**	**p-value**
Uninsured	7	46.7%	8	53.3%	15	***
Employment-based Insurance	11	36.7%	19	63.3%	30	***
Self-insured	2	40.0%	3	60.0%	5	*
Affordable Care Act	7	43.7%	9	56.3%	16	***
Medicare	8	7.3%	101	92.7%	109	**
Medicaid	14	9.3%	137	90.7%	151	*
Health Partners	3	8.8%	31	91.2%	34	
Veterans Affairs/ Military Health Care	0	0%	5	100%	5	
Other	5	12.5%	35	87.5%	40	
Total	**39**	**12.5%**	**272**	**87.5%**	**311**	

*p-values were obtained as a result of independent-sample t-test for age, and chi-square test or fisher's exact test for categorical variables. For p-values * refers to p< 0.1, ** refers to p < 0.05, and *** refers to p < .01.

Intersection of Identities

To explore the different population groups and compare them to each other, we classified the respondents by different combinations of their race/ethnicity, gender, and sexual orientation. Respondents were classified into 6 groups (Table 13): "white men who have sex with men (MSM)" (n=55, 15.9%), "MSM of color" which includes Latinx and Black men (n=91, 26.4%), white heterosexual males (n=12, 3.5%), heterosexual males of color (n=74, 21.4%), heterosexual females of color (n=92, 26.7%), and white heterosexual females (n=21, 6.1%). Since there were only 3 white females and 5 women of color who identified as lesbian, these categories were not included.

Table 13 shows the distribution of demographic and clinical characteristics by the groups defined by sex, race, and sexual orientation. The mean age of MSM of color was younger than all other groups, and there was marginal significance using age as a predictor (p=0.06). Heterosexual males and females of color were more likely to report earning less than $1,000 a month, and all MSM and white heterosexual males were more likely to report earnings of at least $1,000 a month (p<.0001). White MSM tended to report higher levels of education than other groups, while greater proportions of heterosexual males of color reported lower levels of education (p<.0001). White MSM, heterosexual females of color, and white heterosexual males were more likely to have a disability. Heterosexual males of color were more likely to be unemployed. White heterosexual females were more likely to be employed (p=.023). MSM of all races reported more years since their HIV diagnosis than other groups (p=.01). Heterosexual males of all races and white heterosexual females had higher proportions of histories of Hepatitis C infection (p=.001). Heterosexual males of all races/ethnicities had the highest probability of reporting incarceration history compared to other groups (p<.0001).

Table 13. Distribution of Characteristics by Groups Defined by Sex, Race, and Sexual Orientation

Predictors	White MSM N=55	MSM of color N=91	White heterosexual males N=12	Heterosexual males of color N=74	Heterosexual females of color N=92	White heterosexual females N=21	p-value*
Age Mean (SD)	55.1 (9.3)	50.5 (14.6)	49 (10.5)	55.1 (8.9)	53.8 (10)	53.8 (9.7)	*
Income							
<$1,000	25.5%	34.1%	33.3%	62.9%	62.5%	60%	
$1,001-3,000	54.5%	51.1%	58.3%	25.7%	22.7%	25%	***
$3,001+	20.0%	14.8%	8.3%	11.4%	14.8%	15%	
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	
Education							
<High School	1.8%	14.3%	8.3%	36.5%	31.9%	14.3%	
High School grad	16.4%	25.3%	33.3%	41.9%	29.7%	33.3%	***
Some College/ Vocational	29.1%	35.2%	41.7%	17.6%	26.4%	42.9%	
College+	52.7%	25.3%	16.7%	4.1%	12.1%	9.5%	
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	
Employment							
Employed	26.9%	35.7%	41.7%	17.6%	21.2%	40.0%	
Unemployed	9.6%	14.3%	8.3%	30.9%	15.3%	10.0%	**
Retired	9.6%	15.5%	0%	5.9%	8.2%	10.0%	
Disabled	53.8%	34.5%	50.0%	45.6%	55.3%	40.0%	
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	
Homeless	18.5%	20.2%	33.3%	16.7%	16.7%	9.5%	
Years since HIV diagnosis	20.4 (9.3)	18 (10.3)	13 (10)	14.7 (10.1)	14.5 (8.3)	16.3 (11.1)	**
Uninsured	1.80%	6.6%	0%	4.1%	3.3%	0%	
Detectable viral load	11.5%	12.3%	18.2%	12.7%	6.2%	0%	
Hepatitis C	15.4%	26.9%	54.5%	46.4%	22.6%	44.4%	***
Incarceration history	3.6%	19.3%	45.5%	36.6%	13.1%	25.0%	***

*p-values were obtained as a result of independent-sample t-test for age, and chi-square test or fisher's exact test for categorical variables. For p-values * refers to p< 0.1, ** refers to p < 0.05, and *** refers to p < .01

Sexual Activity and Drug Use

Respondents were asked, “In the last 12 months, have you been sexually active (includes any kind of consensual sexual contact)?” Most respondents (57.1%) reported having sexual contact in the last 12 months. Respondents reported the sex/gender of their romantic and/or sexual partners. They could make more than one choice. 24% reported having female partners, 64.5% reported male partners, and 2.8% reported transgender and/or gender non-conforming partners. A separate question was asked about the respondent’s sexual orientation or identity. In that question, 7.6% of the sample identified as bisexual, 35.2% as gay or lesbian, 53.3% as straight/heterosexual, and 1% identified as an option not listed.

Respondents were asked if their partner/s were on antiretroviral therapy (ART) or pre-exposure prophylaxis (PrEP). Of the sample, 12.8% said that their partner was HIV-positive and taking antiretroviral medications (ART), while only 7 of them said that their partner was HIV-positive and did not take ART. 4.3% of sexually active participants said their HIV-negative partner was on PrEP, and 15.6% said that their HIV-negative partner was not taking PrEP. Some respondents (6.9%) replied “don’t know”. Another 7 people reported “other” answers, which included “we use condoms” (2), “partner not HIV-positive” (3), “she’s not taking her meds”, and the final respondent didn’t provide an answer.

Table 14. Prevention and Harm Reduction Services Offered by Medical Provider in the Previous 12 Months, N=392

Prevention/harm reduction services	Yes	Yes %	No	No %
Condoms or safer sex kits	137	34.9%	255	65.1%
STD testing including HCV	104	26.5%	288	73.5%
Info about PrEP	65	16.6%	327	83.4%
Info on disclosure	54	13.8%	338	86.2%
Info on HIV counseling for pregnant women	16	4.1%	376	95.9%
Partner services	15	3.8%	377	96.2%
Safer injection/bleach kits	10	2.6%	382	97.4%
Info on syringe access	8	2.0%	384	98.0%

As noted in Table 14 above, respondents reported prevention and harm reduction services offered to them in the previous 12 months by their medical providers. Respondents could select all the options that applied. Condoms and safer sex kits and STD testing were the most reported services at 34.9% and 26.5%, respectively. Information about PrEP was offered to 16.6% of the sample and disclosure support to 13.8%. Few respondents reported being offered harm reduction support for injection drug use. Ten people reported receiving safe injection kits/bleach kits, and 8 people received information on syringe access services. Only 29 respondents reported using street drugs other than marijuana, and only 3 individuals reported sharing injection equipment.

Reported Sexual and Drug Use Behaviors

A substantial proportion of the respondents reported engaging in one or more of the following behaviors in the last 12 months: having performed oral sex without a condom, dental dam, or other barrier (24.1%), having had vaginal sex without a condom (11.9%), having had anal sex without a condom (15.5%), and/or having used street drug other than marijuana (7.5%). 3 people reported having shared injection equipment in the last 12 months, and 6 individuals reported trading sex for money or drugs in the last 12 months. Respondents who reported having transactional sex and/or unprotected oral, vaginal, or anal sex in the last 12 months were combined into one group, which comprised 35.5% of the sample. It is important to note that we made this decision in this analysis to combine these factors into one group, even though that may conflate sexual behavior (condomless oral, vaginal or anal sex) with social context of the behavior (transactional sex). Considering the number of people who reported transactional sex (n=6), any effect on the outcomes in Table 15 are minimal. We do not know whether these sexual behaviors occurred in situations where there was a real possibility of HIV transmission, so we will not assign a risk value to the behaviors. Some of these behaviors might have been between PLWH with suppressed viral loads (most of the sample) or between PLWH with suppressed viral loads and HIV-negative partners (whether on PrEP or not)[9]. Serosorting and sero-positioning could also be present as tools for HIV risk reduction[10]. For the purpose of this analysis, the group of respondents who did not report any of the above sexual behaviors or contexts are described as the referent group.

People who reported any of these sexual behaviors were significantly younger (p<.0001), more likely to be male (p<.0001), more likely to identify as white/Caucasian (p=.027), and more likely to identify as homosexual or bisexual (p< .0001) than those who did not report any of those behaviors (Table 15). After we combined sexual identity, race, and gender into one variable, we found that more men, regardless of racial identity, who identify as homosexual or bisexual were likely to report any of these behaviors compared to the referent group (p< .0001).

Comparing the socioeconomic characteristics between the two groups, we found that people reporting any of these behaviors had higher levels of education than those in the referent group (p<.0001), and were more likely to be employed (p<.0001). People in the referent group were more likely to have health insurance than those who reported these sexual behaviors (p=.001).

We assessed access to HIV/STD prevention and treatment services between these two groups. Although respondents who reported any of these behaviors were more likely to receive a STD and Hepatitis C screening in the last 12 months compared to respondents in the referent group (p<.0001), over half of them (56.9%) did not get this referral. People who reported any of these behaviors were more likely to be offered condoms and safer sex kits by their HIV provider (p=.009); however, over half of them (56.2%) were not. Information about PrEP was more likely to be offered to people who reported any of these behaviors, although the proportion was low in both groups (26.3% vs 11.2%, p<.0001). For all the services, the group reporting these behaviors was more likely to be offered services or referrals; however, the proportions were low in both groups.

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[9] Centers for Disease Control and Prevention Dear Colleague Letter about the risk of sexual transmission of HIV of virally suppressed PLWH: https://www.cdc.gov/hiv/library/dcl/dcl/092717.html

[10] More information on serosorting: https://wwwn.cdc.gov/hivrisk/decreased_risk/communication/same_status.html

Table 15. Characteristics of Those who Reported Various Sexual Behaviors in the Last 12 Months

	Reported condom-less oral, anal, or vaginal sex and/or transactional sex in the previous 12 months		
Predictors	**Yes**	**No**	**P value**
Age	49.2 (*12.4*)	54.8 (*10.2*)	***
Sex	N=135	N=238	
Male	81.5%	57.0%	
Female	18.5%	42.0%	***
Total	**100%**	**100%**	
Race/Ethnicity	N=131	N=228	
African American/Black	53.4%	66.2%	
White/Caucasian	31.3%	22.4%	**
Hispanic/Latinx	5.3%	7.0%	
Other-race	9.9%	4.4%	
Total	**100%**	**100%**	
Sexual Orientation	N=167	N=167	
Homosexual/Bisexual	52.7%	47.3%	***
Gender* Race*Sexual Orientation	N=125	N=220	
White Homosexual Male	24.8%	11.4%	
Black/Other Homosexual Male	38.4%	19.5%	
White Heterosexual Male	4.8%	2.7%	
Black/Other Heterosexual Male	16.0%	24.6%	
Black/Other Heterosexual Female	14.4%	33.6%	
White Heterosexual Female	2.4%	8.2%	***
Total	**100%**	**100%**	
Personal monthly income	N=133	N=241	
Below $1,000	41.3%	53.5%	
$1,001-3,000	42.9%	32.0%	
$3,001+	15.8%	14.5%	*
Total	**100%**	**100%**	
Education	N=137	N=241	
Below High School	17.5%	25.7%	
High School Graduate	23.4%	31.1%	
Some College/Vocational	26.3%	30.3%	
College Graduate +	32.8%	12.9%	***
Total	**100%**	**100%**	
Employment	N=127	N=226	
Employed	40.1%	18.6%	
Unemployed	18.9%	17.2%	
Retired	8.7%	11.1%	
Disabled	32.3%	53.1%	***
Total	**100%**	**100%**	
Homeless/marginally homeless	17.3%(23/133)	20.3%(48/237)	
Having no medical insurance	8.8% (12/137)	1.6% (4/249)	***
Referred to STD and Hep C testing	43.1% (59/137)	17.7% (44/249)	***
Offered condoms or safer sex kits	43.8% (60/137)	30.5% (76/249)	***
Offered partner services	7.3% (10/137)	2.0% (5/249)	**
Offered information on disclosure	17.5% (24/137)	11.7% (29/249)	
Offered information on PrEP for participants/partners	26.3% (36/137)	11.2% (28/249)	***

*p-values were obtained as a result of independent-sample t-test for age, and chi-square test or fisher's exact test for categorical variables. For p-values * refers to $p< 0.1$, ** refers to $p < 0.05$, and *** refers to $p < .01$.

Discussion

Overall, respondents reported that the EMA's Ryan White system is meeting their HIV clinical needs. Most respondents reported having regular HIV medical care (98.3%), being prescribed ART (95.1%), and having an undetectable viral load (90.7%). The EMA is generally meeting the needs of the people who receive HIV care at RW providers. This analysis supports this assertion, as does data from other local studies by PDPH (see section: Other evaluations of the EMA's Ryan White system) and analysis of national samples of PLWH like the Medical Monitoring Project[11] (MMP) and Ryan White Program data.

The barriers to services reported by the sample generally were not any function of the Ryan White care system, but more likely to be individual-level barriers like low/no income, housing instability, incarceration history, chronic health conditions, mental health disorders, and lack of social support. Some systems and structures outside of the Ryan White system were noted as significant barriers, such as Medicaid/Medicare transportation processes and inconsistencies, eligibility requirements and resource limitations for public benefits and assistance, and lack of services in respondents' geographic areas. Throughout this discussion there are recommendations related to service provision and community planning, with the understanding that not all of the suggested activities can be supported with Ryan White funds. These were included as suggestions for provider agencies.

Poverty is the root cause of many of the challenges experienced by the respondents. Most of the EMA's PLWH are living on incomes at or below the federal poverty line, which renders them vulnerable to challenges and emergencies that can lead them to falling out of care and not adhering to medications and other necessary treatments (including chronic health conditions in addition to HIV). A loss of housing, loss of/change in health insurance coverage, a move, a death or illness of a loved one, or incarceration can render someone unable to meet their basic needs and stay adherent to treatment. Even though these barriers are not caused by the Ryan White system, they can be eased by using RW resources and funding to help meet basic needs. **The Philadelphia EMA HIV Integrated Planning Council should ease the burdens of poverty for vulnerable PLWH in the EMA by ensuring access to food, housing, emergency financial assistance, and help with health insurance co-pays and deductibles.**

Weiser et al. (2015) found that PLWH living in poverty were more likely to achieve viral suppression if they received care at a Ryan White facility compared to non-RW facilities. That analysis also showed that patients at the Ryan White facilities were more likely to receive medical case management, mental health treatment, substance abuse treatment, and other support services than PLWH who received care at non-RW facilities. Weiser et al. (2015) concluded that many RW clients have social determinants of poor health (like low/no income), and without RW facilities, these patients may have reduced access to services and poorer health outcomes.

Doshi et al. (2015) reviewed a national sample of PLWH who received at least

> "The only problem I have sometimes is transportation and I have emphysema and COPD and as a result I cannot walk long distances."

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[11] The Medical Monitoring Project (MMP) is a surveillance system designed to learn more about the experiences and needs of people who are living with HIV. It is supported by several government agencies and conducted by state and local health departments along with the Centers for Disease Control and Prevention (CDC). https://www.cdc.gov/hiv/statistics/systems/mmp/

> “Honestly, I have received excellent support in Philadelphia. This support extends from assistance with my down payment for housing, legal assistance to secure my SSI, education about the disease, Mental Health counseling and last, but not least, my primary health care. I truly am grateful to be a resident of Philadelphia. The support has been tremendous.”

one non-ADAP[12] Ryan White service in 2011. Of the sample, 61.8% were seen for at least 1 HIV medical visit, and of those, 82.2% were retained in care and 72.6% reached viral suppression. These outcomes are higher than other samples/estimates from the same time period. Another analysis of MMP data by Bradley et al. (2016) found that uninsured PLWH at RW facilities were more likely to be prescribed ART (94% vs. 52%) and virally suppressed (77% vs. 39%) than uninsured PLWH at non-Ryan White facilities. In that analysis, patients with private or Medicaid coverage with Ryan White services had better outcomes than those without Ryan White services (Bradley, et al., 2016).

As noted above, staying in care is challenging for people living at or below the poverty line. Poverty, housing instability, food insecurity, mental illness (specifically depression), competing life activities, expensive and unreliable transportation, insufficient insurance coverage, incarceration, lack of social support, and stigma are all documented barriers to retention in care for PLWH (Colasanti, Stahl, Farber, del Rio, & Armstrong, 2017, Iroh, Mayo, & Nijhawan, 2015, Yehia, et al., 2015, Yehia, et al., 2015). All of these challenges create the possibility of chaos and lack of control over their own circumstances, which can make keeping appointments or managing treatment extremely difficult. There are opportunities in the provision of services and in planning the EMA’s care system to lessen the effects of life circumstances on PLWH’s health and wellbeing. Evidence-based risk assessment tools and the use of data-to-care initiatives can help direct services to the PLWH who most need them.

Colasanti et al. (2017) interviewed PLWH who were continuously retained in care over 6 years (n = 32) and those who had recent gaps in care (n=27) to assess facilitators and barriers to retention. They found that PLWH with younger age, crack cocaine use, food insecurity, financial instability, housing instability, and phone number changes in the past year were significantly more likely to be unretained in HIV care. Unretained clients were more likely to report having run out of money for necessities like housing and food and to have unmet transportation needs than retained clients. A higher proportion of the unretained PLWH had been incarcerated in their lifetimes and in the last year. Colasanti recommended risk assessments to identify when a patient might be at risk of falling out of care or adherence due to chaotic life circumstances or other threats to stability.

Yehia et al. (2015) interviewed 51 PLWH to identify facilitators and barriers to retention in HIV care. Their analysis identified 12 barriers and 5 facilitators, including 3 common barriers for the retained group and 5 for the unretained group. Commonly discussed barriers were mental illness/depression, feeling sick, and competing life activities. The not retained group identified additional barriers to care,

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[12] The AIDS Drug Assistance Program (ADAP) is a state and territory-administered program authorized under Ryan White Part B that provides FDA-approved medications to low-income people living with HIV who have limited or no health coverage from private insurance, Medicaid, or Medicare. ADAP funds may also be used to purchase health insurance for eligible clients and for services that enhance access to, adherence to, and monitoring of drug treatments.

which included expensive or unreliable transportation, stigma (avoidance of disclosure), and insufficient insurance. Facilitators of retention in care included social support, patient-friendly clinic services (transportation, co-location of services, ease of scheduling/reminders), and positive relationships with providers and clinic staff (Yehia, et al., 2015).

Our respondents shared their own stories of financial distress, mental and physical health challenges, and housing insecurity that at times prevented them from attending appointments, accessing needed services, and adhering to treatment for HIV and other health conditions. Although the sample was retained in care (98.3% reported a regular place for HIV medical care), there is a risk of a change in life circumstances making it more difficult to make appointments and adhere to treatment. Measures the RW providers and AACO can take to identify and support PLWH who may be in danger of falling out of care should be explored. Some options include Enhanced Personal Contact, an evidence-based intervention and using risk assessments to identify PLWH at risk of falling out of care[13]. **RW Providers should use targeted risk assessments to predict which patients are at risk for poor retention. PLWH should receive appropriate supports and interventions before they are lost to care rather than interventions after they have missed appointments or are no longer adherent to ART.**

Syed et al. (2013) found that those who have the highest burden of disease face greater transportation barriers. Addressing barriers to transportation for the most vulnerable can lead to cost savings over time, because missed appointments and poorly managed health conditions can trigger visits to emergency departments and declining health (Syed, Gerber, & Sharp, 2013). Transportation barriers cause appointments to be missed or rescheduled, which can lead to poor management of HIV and other health conditions.

> "I never have extra money at the end of the month because of my bills. I have no transportation. I need more insurance to get in a day program. I can't afford to pay 20% of my medical bills every month."

Transportation problems were often cited as barriers to healthcare access for respondents; 28.5% of respondents reported transportation problems as the reason they missed a HIV medical appointment in the previous 12 months. Challenges with transportation varied by insurance coverage: 53.3% of the uninsured, 50% of with Affordable Care Act coverage, 37.9% of Medicaid covered respondents, and 19.5% of Medicare covered respondents. Medicaid and Medicare both provide transportation to HIV medical care appointments for eligible individuals, so these results are cause for concern. **The HIPC and AACO should explore ways for Ryan White Medical transportation to provide transportation for PLWH who experience barriers due to Medicaid or Medicare transportation.**

The EMA can help PLWH manage and navigate these common barriers to retention and adherence through direct material services like transitional and short-term housing, food banks and home-delivered meals, alternatives to unreliable transportation like on-demand and ride-sharing services, and financial assistance for health insurance costs like premiums, cost-sharing, and deductibles.

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[13] Retention through Enhanced Personal Contacts intervention description: https://www.cdc.gov/hiv/pdf/research/interventionresearch/compendium/lrc/cdc-hiv-lrc-retention-through-enhanced-personal-contacts.pdf

> I never accessed housing assistance because I don’t know where to go, and I was never told. I don’t go to the orthodontist due to financial issues. I don’t use mental health therapy services because of the cost with my current insurance provider some of my other non-HIV medications are not covered due to me having no prescription drug coverage.

Homelessness and housing insecurity are significant barriers to care for the EMA’s PLWH. Alost 15% of the sample were staying with family and friends. The qualitative answers to the survey shared how challenging and unstable such arrangements can be for individuals. Homelessness affects 4% of the sample. Even people who own or rent are vulnerable to losing their homes because costs are high and incomes are low. Almost half of the sample reported monthly incomes below $1,000 per month, with 10.3% of them reporting no income. There are not enough housing subsidies to meet current needs in Philadelphia. The wait lists for both Housing Opportunities for People with AIDS (HOPWA) and Philadelphia Housing Choice voucher program are both 8 to 10 years for people not currently homeless. **The HIV Integrated Planning Council should explore how Ryan White funds can best be leveraged to prevent homelessness and provide housing for PLWH. The HIPC should consider options which include Housing First models, emergency financial assistance, and other interventions to prevent homelessness. Such efforts maybe require reallocating resources and adjusting service priorities.**

Lack of stable, secure, affordable housing is a well-documented barrier to consistent HIV medical care, access and adherence to antiretroviral medications, and sustained viral suppression. A systematic review of the evidence of the association between housing status and HIV health outcomes found that interventions that meet the housing needs of PLWH can significantly improve their connection to HIV care, adherence to treatment, and health outcomes (Aidala, et al., 2016). Aidala et al. (2016) asserted that meeting the housing needs of PLWH is a necessary component of efforts to achieve individual and population-level HIV medical care, health and prevention goals, including reducing disparities. Housing First is a cost-effective best practice for reducing homelessness among PLWH and other vulnerable populations (Aidala, et al., 2016).

> “Housing is healthcare.
> I need permanent housing!!!”

Below in Table 16, we have presented the self-reported service needs for the EMA’s PLWH from three sources at potentially different stages along the care continuum: Medical Monitoring Project, PDPH’s Client Services Unit Medical Case Management Intake, and this consumer survey[14]. For the most part, the CSU

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[14] *Client Services Unit Data* measure client presenting need at medical case management intake. These data give the EMA information on service needs at the HIV diagnosed and linked to care stages in the Continuum. While clients typically access case management services after they have had a medical visit, these data are a reasonable surrogate for consumers out of care, since needs have not yet been addressed. *Medical Monitoring Project* is a nationally representative, population-based surveillance system to assess clinical outcomes, behaviors, and the quality of HIV care. These data give the EMA information on service needs at the linked to care, retained in care and on ART stages in the Continuum.

Intake sample has a higher proportion of unmet need for these categories than the other two samples. This is consistent with our understanding of the needs and characteristics of people who are newly diagnosed or returning to care, compared to those retained in care. For example, dental care is at 3.4% for the CSU group and 48.1% for the MMP. The CSU group reported a need for medications 22.7% of the time, compared to 3.7% of the MMP sample. In general, the survey sample and the MMP sample have similar unmet service needs. Considering both the MMP and survey sample are more likely to be in care and receiving services than the CSU Intake group.

Table 16. Gaps in Service as Reported by EMA PLWH by Percent

Service reported as needed	PDPH Client Services Unit 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	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	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	19.2	11.7

Considering the high prevalence of depression in our sample and in PLWH in general, special consideration should be made to support PLWH in managing their mental health and wellbeing. Do et al. (2014) used MMP and Behavior Risk Factor Surveillance System[15] data to determine the prevalence of depression among PLWH and the general population. They found that the prevalence ratio of current major depression between PLWH and the general population was 3.1, meaning PLWH were three times more likely to be diagnosed with major depression than the general population. The difference was associated with differences in annual income. In the MMP sample, 12.4% had a current diagnosis of major depression in 2009, whereas 4.1% of the general population had major depression (Do, et al., 2014). The high prevalence of depression (51.6% in our sample) in the EMA's RW client population is particularly concerning because depression has been associated with non-adherence and poor health outcomes for PLWH. Gonzalez et al. (2011) found that depression was significantly associated with non-adherence to antiretroviral therapies. Leserman (2008) found that chronic depression, stressful events,

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[15] 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. https://www.cdc.gov/brfss/index.html

and trauma may negatively impact the progression of HIV disease. This may include a decrease in CD4 counts, an increase in viral load, and greater risk of clinical decline and death.

Depression and other mental health disorders can be as debilitating as physical ailments. Respondents shared that their depression can be a barrier to care and is harmful to their health and wellbeing. Integration of mental and behavioral health into all HIV clinical settings should a priority in the EMA, because of the documented need for these services in the consumer population and the association between mental health and adherence and viral suppression. In a meta-analysis in 2014, treatment of depression and psychological distress were associated with improvements in antiretroviral adherence (Sin & DiMatteo, 2014). Integrated services should include nonclinical services, such as support groups, peer navigators, and social activities. These services can provide the social support and purpose that some of our respondents said they needed.

> “I would not be stable without drug pay assistance. I would have lost my home because I could not afford what Medicare does not cover.”

The EMA’s RW client population is aging, and many older PLWH have been living with HIV for decades. Age-related non-infectious comorbidities are more common among PLWH than the general population (Guaraldi, et al., 2011). These differences were statistically significant after adjusting for sex, age, and hypertension. Risk factors included prolonged ART exposure and lower nadir CD4 cell count (Guaraldi, et al., 2011). Weiss et al. (2010) found that 84% of PLWH at an urban health clinic reported at least one comorbid condition, while 92% of them had at least one chart-documented condition aside from HIV. The highest prevalence conditions were hepatitis C (51.5%), pulmonary disease (28.5%), high blood pressure (27%), high cholesterol (24.5%), and obesity (22.5%). A high number of co-morbidities was associated with older age, being female, and injection drug use as reported mode of HIV transmission.

A study of comorbidities among older PLWH found that patients over 60 years old had an average of 4.52 comorbidities (Vance, Mugavero, Willig, Raper, & Saag, 2011). That study also looked at differences in comorbidities and HIV health outcomes between PLWH aged 50-59 and 60 and older. They found that using the age group 50 and older confounded some important differences between the 50-59 years group and 60 and older groups. The number of medications often increases as PLWH get older. This adds complexity to managing their healthcare. However, in this study, older patients had better health outcomes than younger patients, despite complicated treatments (Vance, Mugavero, Willig, Raper, & Saag, 2011).

Advancements in HIV treatment mean that people are living decades with HIV, well into old age. Older PLWH are more likely to experience mental health and neurocognitive impairment than their HIV-negative peers. They are also more likely to experience social isolation as a result of decreased social participation and engagement due to social factors like stigma and declining health and mobility (Rueda, Law, & Rourke, 2014). **The EMA's service system has to adjust to meet the needs of our aging population. Examples of possible changes in the RW delivery system include home visits by case managers, enhanced personal contact like follow-up phone calls and check-ins about current needs, support groups for older PLWH, and a focus on holistic care.**

As noted above, PLWH, especially those over 65, often face complicated treatment plans for numerous chronic conditions. Some PLWH need extra support to manage their complex health conditions. Special attention should be paid to designing materials that meet the health literacy and resource needs of communities. **Educational campaigns for PLWH to assist with health literacy, access, and adherence to treatment are recommended to help PLWH manage complex treatment** (Weiss, Osorio, Ryan, Marcus, & Fishbein, 2010).

> "I feel that I would not be eligible for housing assistance due to my background and income level even though it is not enough to support myself on. I have had to make hard decisions like living with my parents and not affording certain necessities on my own, such as dental care and vision care (i.e. new glasses)."

In addition to comorbidities and mental health disorders, a history of incarceration since HIV diagnosis (19.4% of our sample) was a significant barrier to services. Nasrallah et al. (2016) reviewed MMP data for 2009-2010 to determine the prevalence of recent incarceration (previous 24 months) among PLWH. They found that 5.4% of PLWH receiving care were recently incarcerated. Being 50 years or older, having a high school education or less, being homeless, income at or below poverty guidelines, and using drugs in the last 12 months were associated with recent incarceration. Those who were recently incarcerated were less likely to achieve viral suppression. Recent incarceration independently predicted worse health outcomes and greater use of emergency departments for PLWH in HIV care. The researchers and the current guidelines recommend that release planning include pre-enrollment in healthcare coverage to help reduce barriers to care upon release (Nasrullah, Frazier, Fagan, Hardnett, & Skarbinski, 2016).

Iroh et al. (2015) reviewed health outcomes for recently released PLWH and found that outcomes were worse after release than during or before incarceration. Incarceration can be a time for PLWH to be diagnosed, linked, and retained in HIV care. Iroh et al. found that all the stages along the care continuum increased during incarceration. Incarceration is a prime time for re-engagement in care for many PLWH. Iroh's analysis identified specific facilitators for linkage and engagement upon release: education about HIV, release planning, transportation, and stable housing. The significant barriers to care and adherence were mental illness, stigma, lack of social support, and unemployment. Successful interventions included opiate replacement therapy, enhanced case management, and patient navigation. Iroh et al. recommended following the guidelines for release planning for PLWH, including making an appointment at a community health provider, assistance with entitlement enrollment, and providing a copy of the medical record and HIV medications to the individual upon release to facilitate retention in care and ART adherence (Iroh, Mayo, & Nijhawan, 2015).

PDPH conducted a study that matched data from the Philadelphia Department of Prisons with Philadelphia HIV surveillance data to 1) identify previous persons who were newly diagnosed with HIV at prison intake and evaluate the HIV care continuum after release; and 2) identify persons with known HIV infection who became incarcerated to evaluate the HIV care continuum after release. Results indicated that persons who were linked to the funded prison linkage program during incarceration were significantly more likely to re-engage in care within 90 days after release, be retained in care in the year after release and achieve viral suppression within 1 year after release as compared to persons who were not linked to this program in both populations.

PLWH incarcerated in institutions outside the Philadelphia Jail System do not have access to this Linkage Program, but they do have access to other services/supports. These services vary depending on the county and correctional system. 52.4% of respondents reported not receiving any assistance with planning for healthcare or other services at release. We do not know when or where these individuals were incarcerated, so we cannot make any conclusions about gaps in services, other than they exist.

The HIPC should assess access to and the quality of linkage programs and release planning for PLWH who are incarcerated in the EMA's county jails and New Jersey and Pennsylvania state correctional institutions. Recently incarcerated PLWH are vulnerable to falling out of care and having worsened health outcomes. Pre-enrollment in health insurance and other benefits should be a part of release planning for all incarcerated PLWH regardless of correctional institution. The EMA should work with the correctional systems to get needed services and support to PLWH, including telehealth when necessary.

STD/HIV prevention counseling from HIV medical providers is an effective intervention and supported by current standards of practice guidelines, and yet an analysis of MMP data found that 39% of PLWH who reported sexual risk behaviors did not receive any HIV/STD risk reduction intervention (Mizuno, et al., 2014). Another analysis of data from HIV medical providers in the Houston area found that prevention counseling, HIV risk reduction, and disease screening was more likely to be offered to newly diagnosed versus established patients (Mgbere, et al., 2014). Biases about who is or isn't at risk are a factor in PLWH's access to prevention and risk reduction services.

People over 55 are sexually active. Lindau et al. (2007) conducted a survey of 3,005 Americans aged 57 to 84 and found that 73% of those ages 57 to 64, 53% of those 65 to 74, and 26% of those aged 75 to 85 had sexual activity with a partner in the previous 12 months. Sexual problems and behaviors are common for older adults, but these are rarely discussed with physicians (Tessler Lindau, et al., 2007).

In our sample, we saw that even for respondents who reported behaviors that potentially could have transmission risk (35.5% of the sample), HIV medical providers were not offering screening or other prevention services like partner services or PrEP at rates we would hope to see. Providers are reporting that risk reduction counseling is happening almost all the time (95-98% according to Ryan White performance measures for Outpatient Ambulatory Care). Our survey respondents are reporting different experiences. Of the people who self-reported any condomless sex or transactional sex, over half did not report receiving STI screening (56.9%) and/or being offered condoms or safer sex kits (56.2%). Information about PrEP was only offered to 26.3% of those reporting these sexual behaviors and to 11.2% of those who did not report any of the behaviors. Providers are making assumptions about older and established patients that leave them vulnerable to STIs and possible transmission risks. This is troubling because most of our respondents reported feeling comfortable talking to their HIV medical provider about sex and other sensitive issues, 71.2% said "always" and 11.7% said "sometimes". If our results are reflective of what's happening in the exam rooms, there is a significant lack of communication about sexuality in Ryan White clinical care**. At a minimum, our results speak to a need for training and technical assistance about discussing sexuality, STIs and PrEP for Ryan White clinical**

providers. Further evaluation about how sexuality and sexual risk is addressed by Ryan White clinical providers is required to fully understand training needs and provider-patient interactions.

Conclusion

The EMA's Ryan White clients are generally retained in care and achieving viral suppression. Barriers to HIV medical care and other services are largely due to life circumstances and structural barriers like entrenched poverty and lack of affordable housing. The most common barriers to care were unreliable and or unaffordable transportation, insecure housing/homelessness, cost-sharing/deductibles for health care, and co-morbidities like depression and decreased mobility. The EMA's Ryan White system must ensure we use our resources efficiently and cost-effectively to meet the basic needs of the PLWH we serve. Meeting basic needs like food and housing, as well as psychosocial support and integrated mental and behavioral health care, should be EMA priorities because need for these services is high, especially among the EMA's most vulnerable PLWH. Some further assessment of the barriers experienced by returning citizens and the provision of HIV prevention and harm reduction services to PLWH by Ryan White clinical providers are necessary to ensure the EMA's population and individual-level health outcomes are met.

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Appendix

Table A: Comparison of Consumer Survey Respondent Self-reported Service Utilization and FY 2016 Ryan White Part A Service Utilization Data

Service Category	Survey respondents reporting use of the service in last 12 months	Ryan White Part A clients use of service in FY 2016 N= 16,760**
Dental care	63%	10%
Medical care	58%	67%
Medical case management	48%	36%
Mental health therapy/counseling	32%	13%
Housing assistance services	26%	5%
Food bank/home-delivered meals	30%	18%
Nutritional counseling	30%	2%
Support groups	30%	NA
Medical transportation services	26%	14%
Emergency medications	32%	3%
Financial assistance for health insurance premiums & co-pays	19%	NA
Legal services	18%	6%
Direct emergency financial assistance	11%	1%
Treatment adherence counseling	15%	NA
Assistance with household tasks and self-care	11%	NA
Home health care	11%	NA
Physical rehabilitation after an accident, stroke or other health condition	11%	NA
Substance use treatment	13%	1%
Services to help you get HIV medical care or get back into care after time away	12%	NA
Language translation and interpretation services	7%	NA
Hospice services	5%	NA
Adult daycare for a relative or other person you care for	3%	NA
Child care	4%	NA

Data source: CAREWare financial reports for 3/1/2016-2/28/2017. * Survey respondents were not asked where they received these services or how they were paid for. Not all the services reported are funded under Ryan White Part A in the EMA but are funded through health insurance, Medicaid, Medicare, or other local, state, federal, or private funding. The survey responses include services not funded under Ryan White Part A in FY 2016. **Only includes clients of Ryan White Part A services.

Table B. Comparison between Consumer Survey Respondents’ Demographics and Ryan White Part A Client Demographics.

Demographics	**Consumer Survey Respondents**	**2016 Ryan White Part A clients**
Sex		*
Male	**65.5%**	**66.1%**
Female	**34.5%**	**32.3%**
Transgender	**<1%**	**1.6%**
Total	**100%**	**100%**
Race/Ethnicity		**
Black/African-American	**62.8%**	**68.8%**
White/Caucasian	**25.4%**	**26.6%**
Hispanic/Latinx	**6.6%**	**14.8%**
Other-race	**5.2%**	**12.3%**
Personal monthly income***		*
No income	**10.4%**	**13%**
Below $1,000	**38.1%**	**50.1%**
$1,001-2,000	**24.7%**	**18%**
$2,001-3,000	**11.4%**	**7.1%**
$3,001+	**15.7%**	**5.1%**
Health Insurance		**
Medicaid	**46.3%**	**50.2%**
Medicare	**31.4%**	**15.9%**
Private/Employer/ACA	**16.5%**	**20.5%**
VA/Tricare/other military	**1.5%**	**.1%**
No insurance	**4.1%**	**9.4%**
Age		*
18-24	**2.4%**	**4.8%**
<+39	**14.6%**	**30.8%**
50+	**72.2%**	**45.5%**
<1 year since diagnosis****	**10%**	**10.3%**

Data Sources are *2016 Ryan White Database (PDE data,) n=16,760 and **CAREWare Medical Clients for 2016, n=14,032. *** CAREWARE data showed 5.1% of clients were missing income data. Percentages may add up to more than 100.

Community Health Survey 2017

PLEASE READ THIS BEFORE ANSWERING THE SURVEY QUESTIONS

Please help us with an important community effort.

This survey is for any adult (over 18) who would like to take it. There is a section of questions specifically for people living with HIV, but the rest of the questions are for everyone. If you are not HIV+, you can just skip that section.

The Office of HIV Planning (part of the Philadelphia Department of Public Health) is conducting this survey. The survey will help us understand your health care needs. **The Ryan White Health Services Planning Council and the others who deliver healthcare and HIV services use this valuable information to decide which services are most needed in our communities.** The Ryan White Health Services Planning Council is responsible for planning services for people living with HIV throughout the Philadelphia region. For information about the Office of HIV Planning or the Council go to **hivphilly.org**

This survey asks questions about your medical history, services you use, and things that may prevent you from getting the services you need. It also asks for some personal information, such as sexual orientation and income. **Your answers are secure and confidential.** Your name will not be attached to the survey.

It is your choice to take the survey. No one will know whether you do or not. Your ability to get care and services will not be affected. There are no right or wrong answers. It is important that you answer as honestly as you can and as many questions as you can. **If you do not want to answer a question, you can skip it.**

It will take 15 to 30 minutes to complete the survey.

- For help answering the survey, please contact the service agency listed on the cover letter.
- If you need medical care or other services, call the Health Information line at 215-985-2437
- If you have any questions about this survey, please contact the Office of HIV Planning at (215) 574-6760.

If you complete the survey, **please return it to the Office of HIV Planning within two weeks in the envelope provided.**

We have included a small gift as a thank you for your time. Thank you for your thoughtful answers. Your feedback is important.

You may also take this survey on our secure and confidential website: www.research.net/r/HIVTalkBack

This survey tool may be reproduced as a whole or in part. The Office of HIV Planning encourages anyone considering the use of any part of the survey to contact us, in order to discuss any lessons learned. Several of the questions presented challenges either for the respondents or during analysis.

Email us at info@hivphilly.org or call 215-574-6760

1. How did you get this survey? *(check one)*
   - ☐ In the mail
   - ☐ Someone at an agency gave it to me
   - ☐ In a waiting room
   - ☐ At my pharmacy
   - ☐ Through an email
   - ☐ A link on social media
   - ☐ A friend or relative gave it to me
   - ☐ Another source not listed above *(please specify)*: ______________________________

2. What is your age? __________

3. What sex were you assigned at birth, on your original birth certificate? *(check one)*
   - ☐ Female
   - ☐ Male

4. How do you identify? *(check one)*
   - ☐ Female
   - ☐ Male
   - ☐ Transgender
   - ☐ Gender non-conforming
   - ☐ Another answer not listed above *(please specify)*: ______________________________
   - ☐ Do not want to answer

5. What is your race? *(check one)*
   - ☐ Asian
   - ☐ African American/Black
   - ☐ Caucasian/ White
   - ☐ Native American/Alaskan Native
   - ☐ Native Hawaiian/Pacific Islander
   - ☐ Biracial/Multiracial *(please specify):* ______________________________
   - ☐ Another race not listed above *(please specify)*: ______________________________

6. Are you Hispanic/Latinx? *(check one)*
   - ☐ Hispanic/Latinx
   - ☐ Non-Hispanic/Non-Latinx

7. Do you think of yourself as? *(check all that apply)*
   - ☐ Bisexual
   - ☐ Gay or lesbian
   - ☐ Straight
   - ☐ Another answer not listed above *(please specify)*: ______________________________

8. What is the highest degree or level of school you completed? *(check one)*
   - ☐ 8th grade or less
   - ☐ Some high school, but did not graduate
   - ☐ High school graduate or GED
   - ☐ Some college, but did not graduate
   - ☐ Vocational/Technical certification
   - ☐ College graduate (2 or more years' degree)
   - ☐ Masters degree or doctorate
   - ☐ Another answer not listed above *(please specify)* ______________________________

9. Do you have internet access when you want it? *(check one)*
   - ☐ Yes, I have my own computer or smart phone
   - ☐ Yes, I have a place I can go to access the internet (friend's house, library, etc.)
   - ☐ No, I don't have any way to access the internet
   - ☐ No, it is too difficult to access the internet. I only use it when I really need to.
   - ☐ Don't know
   - ☐ Another answer not provided *(please specify):* ______________________
   - ☐ Does not apply

10. What kind of housing do you have now? *(check one)*
    - ☐ Rent or own house or apartment (NO voucher or rental assistance)
    - ☐ Housing for people living with HIV/AIDS (HOPWA)
    - ☐ Staying with family or friends
    - ☐ Transitional (i.e. Halfway houses or drug treatment program)
    - ☐ Shelter (homeless or other)
    - ☐ Public Housing or Housing Choice Voucher Program
    - ☐ On the street – no shelter
    - ☐ Another type of housing not listed above *(please specify)* ______________________

11. What is your monthly income? *(check one)*
    - ☐ No income
    - ☐ $1 – 1,000
    - ☐ $1,001 – 2,000
    - ☐ $2,001 – 3,000
    - ☐ $3,001 – 4,000
    - ☐ $4,001 – 5,000
    - ☐ $5,001 – 6, 000
    - ☐ $6,001 or more

12. Do you support anyone else with your income? *(check one)*
    - ☐ Yes
    - ☐ No

13. Which of the following categories best describes your employment status? *(check all that apply)*
   - ☐ Employed, working 40 or more hours per week
   - ☐ Employed, working 1-39 hours per week
   - ☐ Self-employed or contract worker
   - ☐ Not employed, looking for work
   - ☐ Not employed, NOT looking for work
   - ☐ Retired
   - ☐ Disabled, not able to work
   - ☐ Another answer not provided (please specify):

   ____

14. What county do you live in now? *(check one)*
   - ☐ Burlington County
   - ☐ Camden County
   - ☐ Gloucester County
   - ☐ Salem County
   - ☐ Bucks County
   - ☐ Chester County
   - ☐ Delaware County
   - ☐ Montgomery County
   - ☐ Philadelphia County
   - ☐ Another county not listed above *(please specify)*:

   ____

15. What is your Zip Code? _____________

The next 3 questions are about sexual and drug use behaviors.

16. In the last 12 months, have you been sexually active? (includes any kind of consensual sexual contact) (*check one)*
   - ☐ Yes
   - ☐ No

17. Your sexual partners are: *(check all that apply)*
   - ☐ Female
   - ☐ Male
   - ☐ Transgender female
   - ☐ Transgender male
   - ☐ Gender non-conforming
   - ☐ Another answer not listed above (*please specify*):

   ____

18. In the last 12 months, have you….? (*check all that apply*)
   - ☐ Performed oral sex without a condom, dental dam, or other barrier
   - ☐ Had vaginal sex without a condom
   - ☐ Had anal sex without a condom
   - ☐ Shared injection equipment
   - ☐ Used a street drug other than marijuana (pot)
   - ☐ Traded sex for money, drugs, or any other item/service
   - ☐ None of the above

The next 2 questions are about the last time you got a test to see if you have HIV. If you are HIV+, this would be the time you got tested and found out your diagnosis.

19. When was your last HIV test? *(check one)*
   - ☐ Within the last 12 months
   - ☐ 1-2 years ago
   - ☐ 3-5 Years ago
   - ☐ Longer than 5 years ago
   - ☐ I have never had an HIV test (*skip to #40*)
   - ☐ Don't know if I have been tested (*skip to #40*)
   - ☐ Don't remember when I was tested

20. Where did you get your most recent HIV test? (*check one*)
   - ☐ Doctor's office
   - ☐ Public/community health center
   - ☐ Emergency Department
   - ☐ Inpatient at a hospital
   - ☐ Health fair
   - ☐ Testing van
   - ☐ Community organization
   - ☐ Pharmacy
   - ☐ Prenatal care
   - ☐ At labor and delivery in the hospital
   - ☐ At home
   - ☐ Jail or prison
   - ☐ Another place not listed (please specify):

   ____

21. Have you ever received a HIV+ test result?
   - ☐ Yes – What year? _________________
   - ☐ No
   - ☐ I don't know

If you do not use HIV services, please skip to question #40.

The following questions are about living with HIV and HIV-related services. <u>If you do not use HIV services, please skip to question #40</u>

22. When you were diagnosed with HIV, were you also told that you had an AIDS diagnosis? *(check one)*
    - ☐ Yes
    - ☐ No, that was later
    - ☐ No, I have not been diagnosed with AIDS
    - ☐ Don't know
    - ☐ Does not apply

23. Did you get HIV medical care within 30-days of your HIV diagnosis? *(check one)*
    - ☐ Yes
    - ☐ No
    - ☐ Don't know
    - ☐ Does not apply

24. What is your most recent viral load? *(check one)*
    - ☐ Undetectable
    - ☐ Detectable but less than 5,000 viral copies/ml
    - ☐ 5,000 to 100,000 viral copies/ml
    - ☐ Greater than 100,000 viral copies/ml
    - ☐ Never received a viral load test
    - ☐ Don't know
    - ☐ Does not apply

25. Do you regularly go to the same place to get your HIV medical care (such as physical exams, labs, and medications)? *(check one)*
    - ☐ Yes
    - ☐ No
    - ☐ Don't know
    - ☐ Does not apply

26. If you don't regularly go to the same provider, what is the reason? *(check all that apply)*
    - ☐ I <u>do</u> have a regular place for care
    - ☐ Can't afford it
    - ☐ Don't know where to find it
    - ☐ Could not get regular appointments anywhere
    - ☐ Don't think it is needed
    - ☐ Didn't want to get care
    - ☐ Don't know where to find someone who speaks my language
    - ☐ Another reason not listed above *(please specify):* ______________________
    - ☐ Does not apply

27. In the past 12 months, how many times did you see your HIV medical provider? *(check one)*
    - ☐ 1
    - ☐ 2
    - ☐ 3-5
    - ☐ 6 or more
    - ☐ Did not see an HIV doctor
    - ☐ Does not apply

28. In the past 12 months, did you ever need HIV medical care but could not get it? *(check one)*
    - ☐ Yes
    - ☐ No
    - ☐ Does not apply

29. Do you have an HIV case manager? (*check one*)
    - ☐ Yes
    - ☐ No
    - ☐ Don't know
    - ☐ Does not apply

30. Are you satisfied with your HIV case management services? (*check one*)
    - ☐ Yes, please explain: ______________________
    - ☐ No, please explain: ______________________
    - ☐ Don't know
    - ☐ Does not apply

31. Are you currently taking any antiretroviral medicines to treat your HIV? (*check one*)
- ☐ Yes
- ☐ No
- ☐ Does not apply

32. Is your sexual partner/s on PrEP (taking HIV meds to prevent HIV)? (*check all that apply*)
- ☐ I am not sexually active
- ☐ My partner is on PrEP
- ☐ My partner is <u>not</u> on PrEP
- ☐ My partner is HIV+ and on HIV meds
- ☐ My partner is HIV+ and not on HIV meds
- ☐ Don't know
- ☐ Does not apply
- ☐ Another option not listed: (please specify):

____

33. Over the last 12 months, has your HIV medical provider taken the time to explain your lab results, diagnoses, treatment plans and answer all your questions? (*check one*)
- ☐ Always
- ☐ Most of the time
- ☐ Some of the time
- ☐ Never
- ☐ Does not apply

34. In the last 12 months, have you felt comfortable talking to your HIV medical provider about personal issues, including sexual matters, family and relationship challenges, and other personal matters related to your health and well-being? (*check one*)
- ☐ Always
- ☐ Most of the time
- ☐ Some of the time
- ☐ Never
- ☐ Does not apply

35. In the past 12 months, if you couldn't get services you needed, what are the reasons? (*please check all that apply*)
- ☐ I got the services I needed
- ☐ Can't afford them
- ☐ Don't know where to go
- ☐ I don't have insurance
- ☐ I don't know where to go where they speak my language
- ☐ I have responsibilities that prevent me from going (caring for children or family members, work, etc.)
- ☐ I don't want to go
- ☐ I don't have transportation to get there
- ☐ Depression
- ☐ Denial
- ☐ Another reason/s not listed (*please specify*):

____

36. Since your HIV diagnosis, have you served a prison or jail sentence? (*check one*)
- ☐ Yes
- ☐ No (*<u>skip to #38</u>*)

37. During the most recent time you were in jail or prison, were you offered any assistance with planning for healthcare and other needs after your release? (*check one*)
- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Does not apply
- ☐ Another answer not listed (*please specify*):

____

38. *Please review the list of services below and check all the services* you used in the last 12 months and the services you needed but did not get *for any reason.* *<u>You only need to check the services you used or needed.</u> You can skip any services you didn't use or didn't need.*

	I have used this service in the last 12 months	*I needed this services but <u>did not get it</u>*
Emergency Medications	☐	☐
Dental Care	☐	☐
Direct Emergency Financial Assistance (DEFA)	☐	☐
Food Bank/Home Delivered Meals	☐	☐
Financial Assistance for Health Insurance Premiums and Co-pays	☐	☐
Housing Assistance Services	☐	☐
Legal Services	☐	☐
Medical Case Management	☐	☐
Nutritional Counseling	☐	☐
Medical Care	☐	☐
Medical Transportation Services	☐	☐
Mental Health Therapy/ Counseling	☐	☐
Substance Use Treatment	☐	☐
Treatment Adherence Counseling	☐	☐
Home health care (professional nurse provides medical care in your home)	☐	☐
Assistance with household tasks and self-care from professional service provider	☐	☐
Support groups	☐	☐
Hospice services	☐	☐
Physical rehabilitation after an accident, stroke or other health condition	☐	☐
Adult daycare for a relative or other person you care for	☐	☐
Child care	☐	☐
Services to help you get HIV medical care or get back into care after a time away	☐	☐
Language translation and interpretation services	☐	☐

39. Did you experience problems getting the services in #38? (*check one*)

☐ Yes
☐ No
☐ Not applicable

If yes, please explain the problems you had getting services:

____
____
____
____
____
____

The remaining questions are for everyone. They are about your health insurance and health conditions you may have.

40. What type of health insurance do you have? *(check all that apply)*
- ☐ Uninsured
- ☐ Through work or union (employer-based)
- ☐ Bought directly and paid in total by yourself or your family (self-insured)
- ☐ Obamacare/Affordable Care Act (healthcare.gov)
- ☐ Medicare (for people who are 65+ years old or disabled)
- ☐ Medicaid or Medical Assistance (MA), Health Choices or Access Card
- ☐ Health Partners (Medicaid or Medicare)
- ☐ Veterans Affairs (VA) or military health care
- ☐ Another insurance type not listed above *(please specify):*

____

If you are uninsured, please describe your situation:

____

____

____

41. Has your insurance status changed in the last 2 years? (*check one*)
- ☐ Yes (please explain):

____

- ☐ No
- ☐ Don't know

42. How do you pay for medications? (*check all that apply*)
- ☐ SPBP or ADDP
- ☐ Medicare Part D supplemental
- ☐ Patient Assistance program from drug company
- ☐ Other type of insurance
- ☐ I pay for them myself
- ☐ Don't know
- ☐ Answer not provided above (please specify):

____

43. Do you have dental insurance? (*check one*)
- ☐ Yes
- ☐ No
- ☐ Don't know

44. Has a doctor ever told you that you have any of the following conditions? (*check all that apply*)
- ☐ High blood pressure
- ☐ Diabetes
- ☐ Cardiac problems/heart disease
- ☐ Cancer
- ☐ Nerve issues (epilepsy, neuropathy)
- ☐ High cholesterol
- ☐ Kidney problems
- ☐ Liver problems
- ☐ Lung/breathing problems
- ☐ Don't know
- ☐ None of the above

45. Has a doctor ever told you that you have any of the following? (*check all that apply*)
- ☐ Depression
- ☐ Anxiety
- ☐ Bipolar Disorder
- ☐ Dementia
- ☐ Schizophrenia/Schizoaffective disorder
- ☐ Post-Traumatic Stress Disorder (PTSD)
- ☐ Obsessive Compulsive Disorder (OCD)
- ☐ Eating Disorder (Anorexia, Bulimia, etc.)
- ☐ Substance Use Disorder
- ☐ Mood Disorder
- ☐ Don't know
- ☐ None of the above

46. Has a doctor ever told you that you have Hepatitis C? (*check one*)
- ☐ No
- ☐ Yes, and I have been treated/cured for Hepatitis C
- ☐ Yes, and I have not been treated for Hepatitis C
- ☐ Don't know
- ☐ Does not apply
- ☐ Another answer not listed above (*please specify*):

____

The next section is about medical care and other services you may use and problems you might have had.

47. Is there a place you usually go for dental care? (*check one*)
    - ☐ Yes
    - ☐ No
    - ☐ Does not apply

48. In the last 12 months, did you need mental health care or counseling services? *(check one)*
    - ☐ Yes, and I got the mental health care I needed
    - ☐ Yes, and <u>I did not get</u> the mental health care I needed
    - ☐ No, I did not need mental health care

49. In the last 12 months, did you need drug or alcohol treatment services? *(check one)*
    - ☐ Yes, and I got the drug or alcohol treatment I needed
    - ☐ Yes, and <u>I did not get</u> the drug or alcohol treatment services I needed
    - ☐ No, I did not need drug or alcohol treatment services

50. In the last 12 months, has your medical provider offered any of the following services to you? (*check all that apply*)
    - ☐ STD testing including hepatitis C
    - ☐ Condoms or safer sex kits
    - ☐ Safer injection/bleach kits
    - ☐ Information on syringe access programs
    - ☐ Information on HIV counseling for pregnant women
    - ☐ Partner services (assistance contacting previous sex partners after positive diagnosis)
    - ☐ Information on how to tell someone about your HIV status (disclosure)
    - ☐ Information about PrEP (taking HIV meds to prevent HIV) for you or your partner/s
    - ☐ None of the above
    - ☐ Does not apply

51. In the last 12 months, have you had problems getting medical care or other services because of the language/s you speak? (*check one*)
    - ☐ Yes
    - ☐ No
    - ☐ Does not apply

52. In the last 12 months, have you not gotten medical care because you couldn't afford a co-pay or deductible? (*check one*)
    - ☐ Yes
    - ☐ No
    - ☐ Does not apply

53. In the last 12 months, have you missed a medical appointment because you had problems with transportation and you could not get there on time? (*check one*)
    - ☐ Yes
    - ☐ No
    - ☐ Does not apply

These next 3 questions are about women's health and gynecological care. Skip to #57 if you do not need these services.

54. In the last 12 months, has your primary medical provider asked you about family planning, birth control, or your pregnancy plans? (*check one*)
    - ☐ Yes
    - ☐ No
    - ☐ Don't know
    - ☐ Does not apply

55. Do you get gynecological or women's health care (GYN) at the same place you get your other medical care or are you referred somewhere else? (GYN care includes PAP smears and pelvic exams.) *(check one)*
    - ☐ Yes, I get my GYN care at my medical provider
    - ☐ No, I get referred somewhere else
    - ☐ My medical provider does not refer me or take care of my GYN care
    - ☐ Don't know
    - ☐ Does not apply
    - ☐ Another answer not given above: (*please specify*): ________________________________

56. When was the last time you received GYN care? (*check one*)
    - ☐ Within the last 12 months
    - ☐ Between 1 and 2 years ago
    - ☐ More than 2 years ago
    - ☐ Don't know
    - ☐ Does not apply

57. Please share any problems you have experienced in the last 12 months that have prevented you from getting the medical and support services you need. *These problems might include things like not having transportation, not having money for co-pays, not having a place to live, not knowing where to go, no health insurance, or family responsibilities.*

Please be as honest as you can.

Is there anything else you would like for us to know?

Thank you so much for your thoughtful answers.
To be notified when we release the results of this survey, you can follow us on Twitter and Facebook @HIVPhilly

Please return the survey in the postage-paid envelope provided.

OFFICE OF HIV PLANNING FOR THE HIV INTEGRATED PLANNING COUNCIL