

PHILADELPHIA EMA RYAN WHITE CONSUMER SURVEY 2021-2022

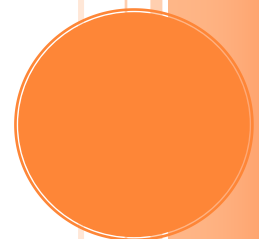
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Purpose

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) Division of HIV Health (DHH) formerly 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, 2012, and 2017 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

The Philadelphia Eligible Metropolitan Area (EMA) encompasses 3,855 square miles and consists of 9 counties in 2 states: 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.

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

The estimated total population is 5.4 million, of which 30% are people of color. At the end of 2021, a total of 27,421 individuals in the EMA were living with diagnosed HIV/AIDS. People of color continue to be severely disproportionately affected: 78.4% of people living with HIV/AIDS in the EMA are minorities. Cisgender women comprised more than one-fourth (27.6%) of prevalent HIV/AIDS cases. More than half of cases are among persons 50 years of age and older (56.9%). The major exposure categories are men who have sex with men (39.3%), heterosexual (33.1%), and injecting drug use (16.9%)

EMA's Ryan White Care System

The EMA's Comprehensive System of Care: Core medical and support services are located in and accessible to the EMA's highest need communities including: North, West, and Southwest Philadelphia; Chester City (Delaware County PA); Norristown (Montgomery County PA); and Camden City (Camden County NJ). In FY 2021, Philadelphia's RWHAP served 17,898 unduplicated clients of which 11,500 received ambulatory/outpatient health services. The EMA estimates that more than 8 in 10 PLWH in Philadelphia who receive care, received that care in the Ryan White HIV AIDS Program (RWHAP) system. All RWHAP services are comprehensive, decentralized, often co-located, and delivered by public and private non-profit settings, hospital outpatient clinics, and community-based organizations. The system

of care includes 44 medical care sites and 39 medical case management sites. People Living With HIV (PLWH) are supported in accessing and remaining in care through the EMA's comprehensive strategy for Early Identification of Individuals with HIV/AIDS, RWHAP-funded medical case management, active re-engagement services in the field, availability of key support services, and coordination with other service systems. Minority AIDS Initiative programs for minority youth and community-based medical case management for adult ethnic/racial minorities are provided as part of the continuum of care.

Viral Suppression: OHP received the 2021 viral suppression data from DHH and it was presented to the HIPC but it is only Philadelphia and NJ counties and not inclusive of the PA counties. Therefore, it was not included in this document and the 2019 data which includes the EMA in its entirety is used. Rates of viral suppression (VS) for RWHAP clients in 2019 was 87.6%, compared to 48.7% using population-based surveillance data. Disparities among subpopulations are: racial/ethnic minority persons who inject drugs (45.6%), transgender persons who have sex with men (46.9%), and racial/ethnic minority youth (37.8%).

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. As noted in the HIV Surveillance Report Philadelphia 2021, Qualitative data collected through the Data to Care and Field Services programs indicates that 54.5% of barriers faced by out-of-care individuals are provider/structural barriers, 44.9% are patient rights/education barriers, 32.4% are supportive services/SES barriers, and 9.7% are behavioral health barrier thus highlighting the significant challenges some in the EMA face to maintaining their viral suppression and treatment adherence. 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 a partner or loved one, or incarceration can leave individuals unable to meet their basic needs and continue to adhere to treatment.

Methodology

Survey Question and Process Description

In 2021, Office of HIV Planning (OHP) staff met with the HIV Integrated Planning Council (HIPC)'s Comprehensive Planning Committee to develop the 2022 survey tool. OHP staff presented the committee with recommendations for changes, removals, and additions to the 2017 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, DHH, and the HIPC. Members of the Positive Committee piloted the survey in early 2022 and offered feedback on the wording and order of some questions.

The survey included new questions about the impacts of COVID on housing, loss of income, access to medical care (missed doses, appointments, or delays in treatment). In addition to adding questions around tele-health vs in-person care. Like the previous surveys, this survey included 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.

Spanish Language Surveys

The survey was translated into Spanish by a contractor. Spanish-speaking staff and 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 Ryan White (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. DHH 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 total, 20 provider organizations (including HIV medical and non-medical providers) agreed to distribute the survey. Of these organizations, 3 were located in South Jersey, 5 were in the PA suburbs, and 12 were in Philadelphia. OHP staff provided 2,475 paper surveys to providers who agreed to distribute them between March 2022 and June 2022. Of the paper surveys, 1,745 were in English and 730 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 online 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 was launched.

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 and by mail. OHP staff created images to be used on social media platforms like Facebook and Instagram.

Announcements about the survey were included in the OHP email newsletter. OHP staff used social media platforms from March 1, 2022 to June 30, 2022 to promote the survey to community members and provider agencies. However, mail in responses were actively received through the end of September 2022.

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. Internal staff shortages at OHP impacted the process to distribute and analyze the data collected. Similar staff shortages were seen at the provider level for distribution. 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 with fewer providers in office due to COVID distribution patterns had to change, 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 March 2022 and June 2022.

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. People with income below \$1,000/month were underrepresented while those with income over \$3,000/month were overrepresented.

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 September 30, 2022, 272 surveys were returned and 236 surveys were deemed valid. Of these 236, 102 were online surveys and 134 were paper surveys. Only 7 of the Spanish language paper surveys and 1 online were returned. By region, the responses were not proportional to the distribution of the epidemic. Philadelphia was under-represented. Of the valid responses, residents of Philadelphia represented 57.6% of the sample, New Jersey (NJ) counties represented 30.5%, and the Pennsylvania (PA) counties represented 11%. In Table 1, Philadelphia is slightly lower in responses percentages and NJ counties are slightly higher. The table does not reflect the adjustment for validity. The majority of respondents (46.7%) reported getting the survey at a provider agency. 9.8% of respondents stated receiving it through the mail, 10.3% got it in a waiting room, and 0.4% received it at a pharmacy. Some respondents reported receiving the survey from family and friends (.8%), 15.4 % through an email, another 5.1% reported receiving a link via social media, and 11.6% reported getting the survey from another source.

Table 1: Geographic Distribution Method and Responses N=272

Region	Mail/Provider		Paper Responses		Online Responses		Total Responses		EMA PLWH
	English	Spanish	English	Spanish	English	Spanish	Total	% of Number	% Total
PA Suburbs	360	120	18	0	12	0	30	11.0%	20%
NJ Suburbs	260	85	28	*	60	0	89	32.7%	13%
Philadelphia	1,125	525	68	6	69	0	143	52.5%	67%
Other	0	0	0	0	9	*	10	3.6%	0
EMA Total	1,745	730	114	7	150	*	272	100%	100%

Notes: * indicates number is suppression because it is < 6. Not all survey participants responded to the residence question

Description of Respondents

The majority of respondents were male, African-American, over 50, identified as straight, and/or from Philadelphia. 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 mean age was 49.04 years old. This was consistent throughout the three regions. Ages spanned from 18 to 89. Most respondents were aged 50 or older (54.2%). Only 50 respondents were aged 39 or younger (21.1%). 4.2% were between 18 and 24 years of age.

Sex at Birth

More individuals were assigned male than female at birth in the sample: 58.1% (136) vs 41.4% (97). In terms of how they now identify, 41.8% identify as female, 53.8% identify as male, 1.2% identify as transgender, 1.2% identify as non-binary and .4% identify as gender nonconforming.

Race/Ethnicity

Figure 1 shows sex at birth and race/ethnicity. The racial/ethnic composition of the sample were as follows: 54.5% of the respondents identified themselves as Black, 33.7% said they were White, 16.2% were Hispanic or Latinx, and 11.6% indicated another race, which included biracial/multiracial, Native American/Alaskan native, and Asian. As shown in Figure 2, black men and women made up a huge proportion of the respondents. Black women accounted for 70% of all women respondents and black men accounted for 44% of all men sampled. 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 assigned at birth, of the 221 respondents to the question 36 individuals (16.2%) of the total. Of the 36 respondents 36.1% of those respondents identified as Hispanic/Latinx women and 63.9% as Hispanic/Latinx men. Conversely, 185 individuals did not identify as Hispanic/Latinx and of those respondents 40.5% were non-Hispanic women and 58.9% non-Hispanic men. Individuals could choose any race in combination with either Hispanic/Latinx or non-Hispanic/Latinx ethnicity.

Figure 1: Survey Respondents' Race and Sex at Birth n=230

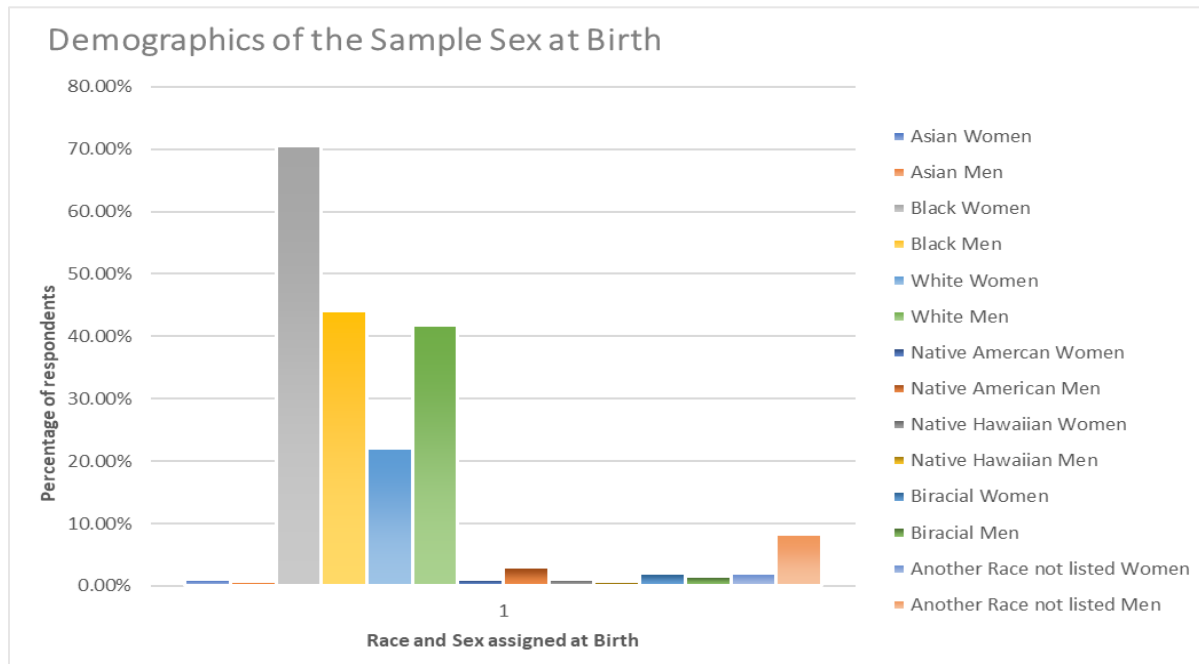
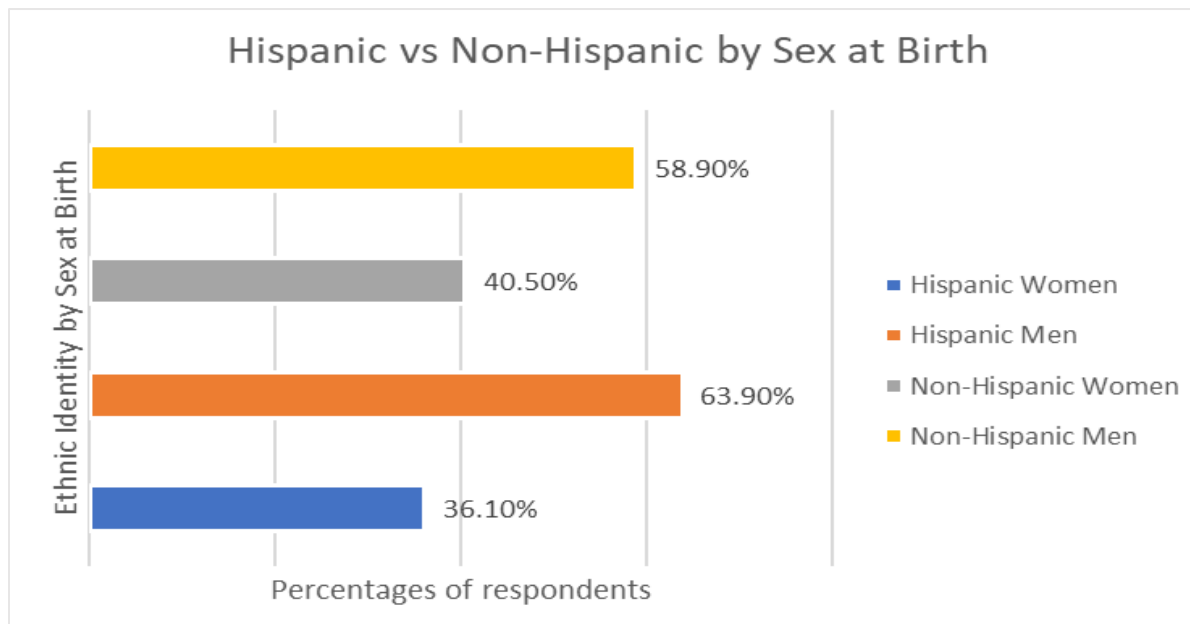


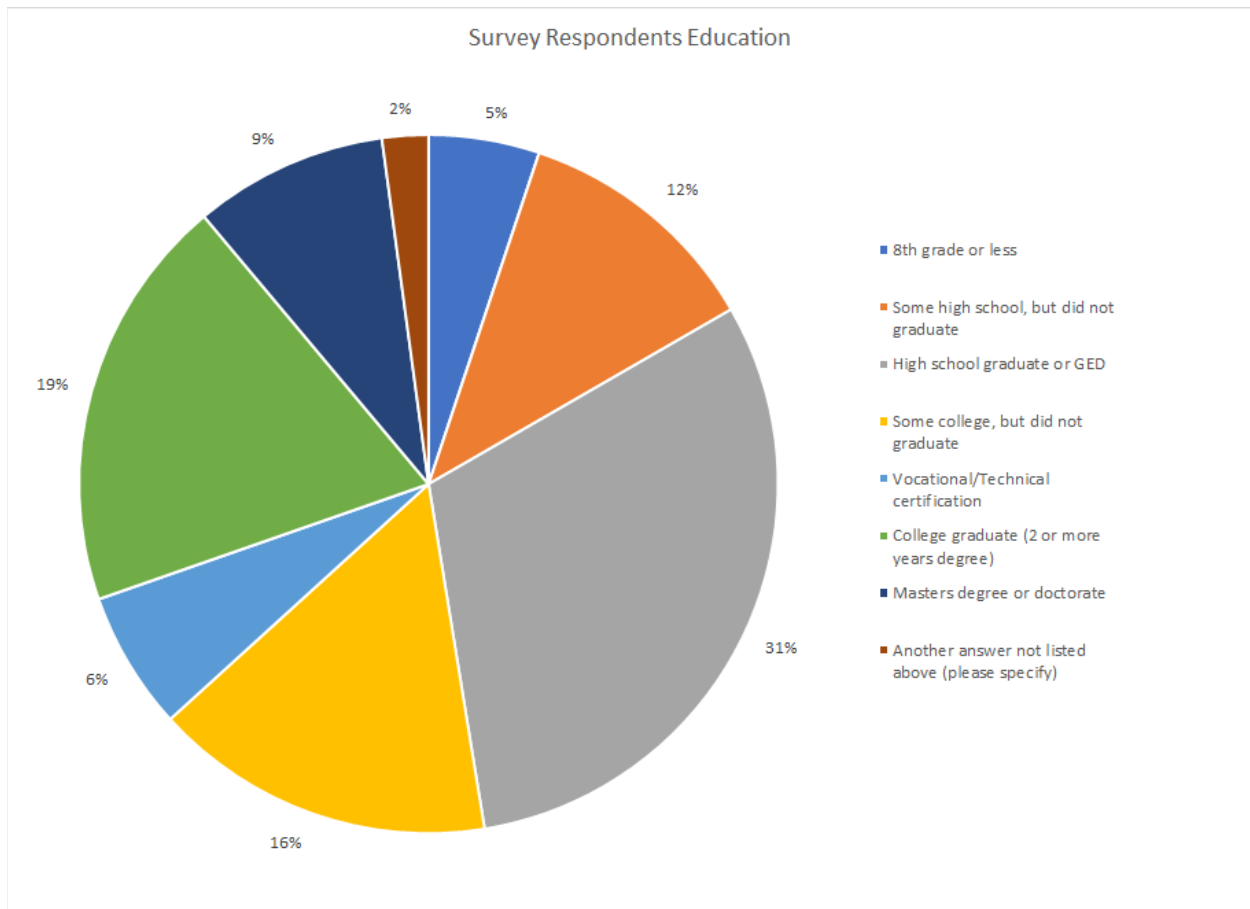
Figure 2: Survey Respondents' Ethnicity and Sex at Birth: n=221



Educational Attainment

The majority of the participants reported having graduated from high school or having attained higher education. Within the sample, 16.6% had an education level below high school (8th grade or less plus some high school but did not graduate), 30.7% identified as high school graduates, when combined 22.2% had some college or vocational training, and 28.2% indicated they were college graduates (see Figure 3) for a more detailed breakdown of educational status.

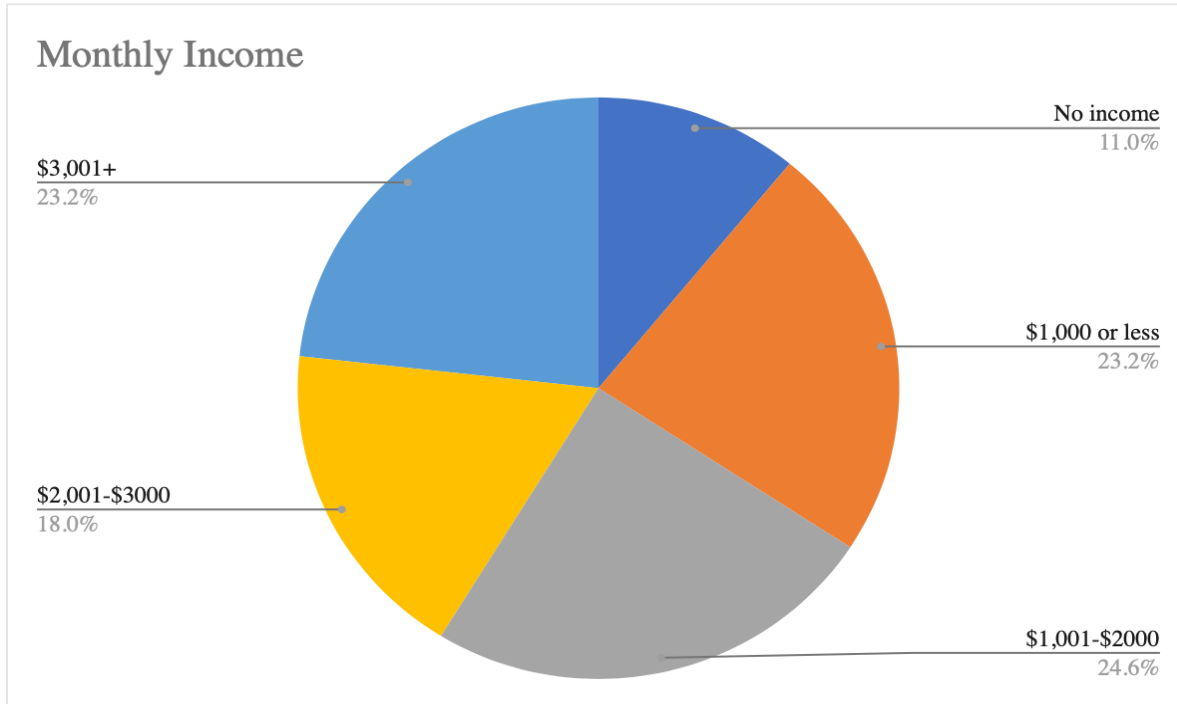
Figure 3: Survey Respondents' Education Completed n=236



Income/Employment

One third of the respondents indicated their personal income to be below \$1,000 per month. In previous surveys a half of respondents indicated having income below \$1,000 per month. 11% of respondents said they earned no income at all, and another 23.4% earned below \$1,000 per month. 24.6% of respondents earned between \$1,001 and \$2,000 per month, 18% earned between \$2,001 and \$3,000, and 23.2% earned more than \$3,001 per month (Figure 4). 35.3% indicated supporting someone else while 64.7% did not. Respondents from Philadelphia were more likely to have an income higher than \$1,000 per month than respondents from New Jersey and the PA Counties. Males were more likely to have an income higher than \$1,000 per month than females. Over half of the sample (51.4%) were employed, while 14.4% were unemployed but not disabled, 27% were disabled and 7.2% were retired.

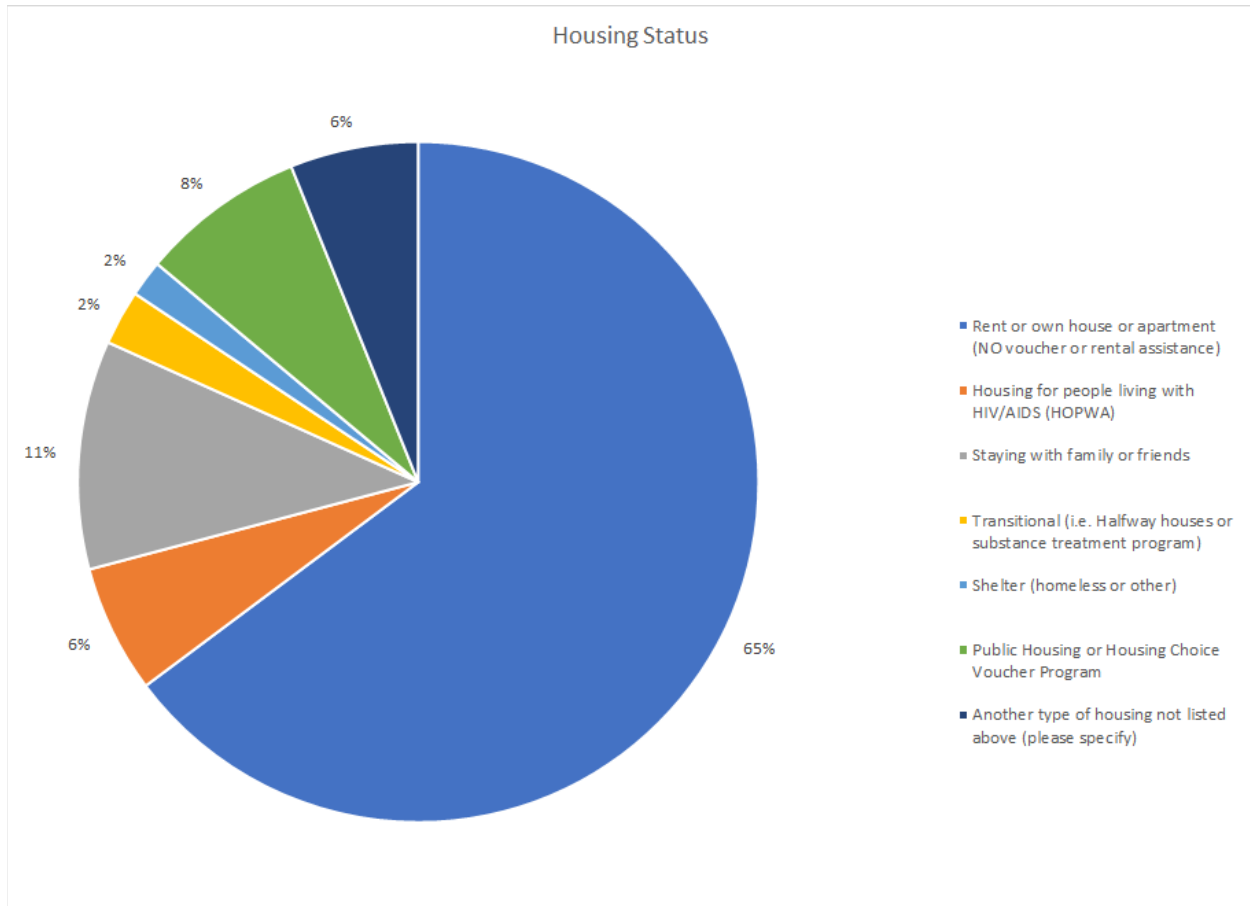
Figure 4: Survey Respondents' Income n= 236



Housing

Over half of the sample (64.7%) 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. 0.8% of respondents said they stayed with friends or family, 1.7% lived in a shelter, and 2.6% said they were in transitional housing (halfway houses or drug treatment program). Rental subsidies supported another 13.8% of respondents: 6% relied on Housing Opportunities for People with AIDS (HOPWA) and 7.8% reported participating in the Housing Choice Voucher Program or living in public housing. Another 6% indicated other housing not listed (Figure 5). Respondents from Philadelphia were more likely to rent or own their own home than respondents from New Jersey and the PA Counties (Figure 8).

Figure 5: Survey Respondents' Housing Status n= 236



Demographics by Region

The following figures show the demographic characteristics of the survey respondents by region. To highlight the similarities and regional differences of the sample. As seen in Figure 6 the majority of the respondents were employed in Philadelphia and New Jersey counties but with more disabled respondents than employed from the PA counties. Income status was well distributed across the region shown in Figure 7 with PA counties showing consistency in three of the four income brackets highlighted. Figure 8 examines housing status in all regions the majority of respondents were renting or own their own place. However, the number of people who identified other is greater than staying in housing for PLWH or staying with friends in all regions. Figure 9 shows Non-Hispanic respondents were the predominant participants in the survey for each region. In Figure 10, NJ counties have more white respondents than the other regions while Black respondents were the majority of respondents in Philadelphia in the PA counties. The primary sex at birth was male for respondents in each region seen in Figure 11.

Figure 6: Survey Participants' Employment Status by Region

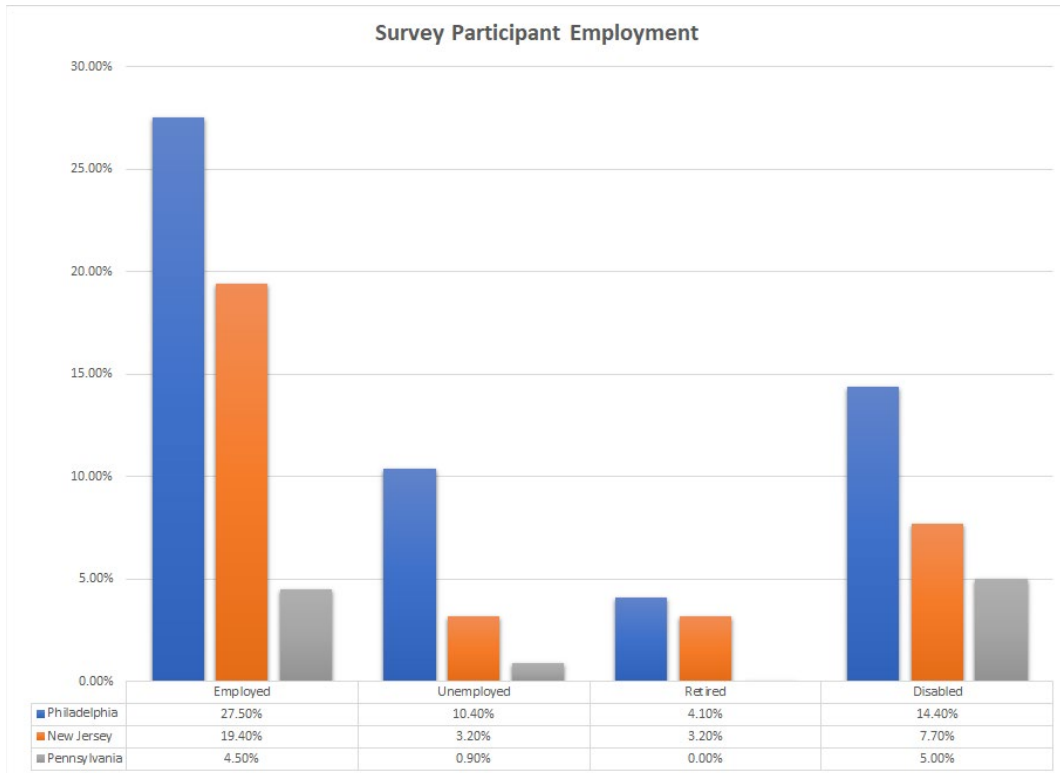


Figure 7: Survey Participants' Income by Region

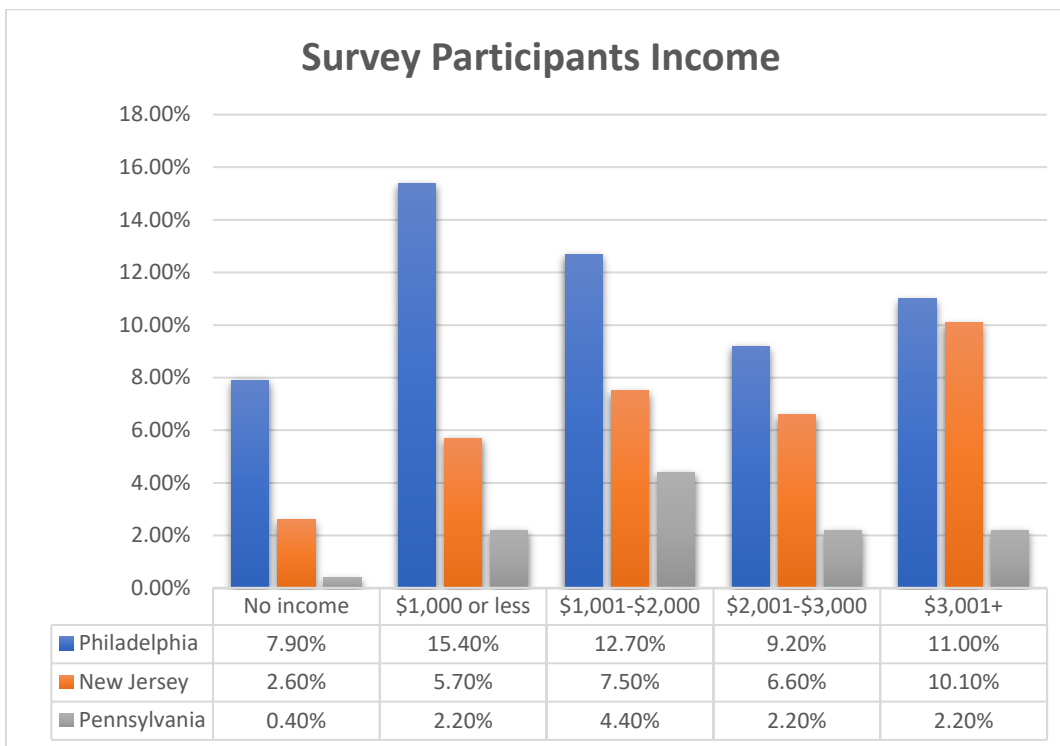


Figure 8: Survey Participants' Housing by Region

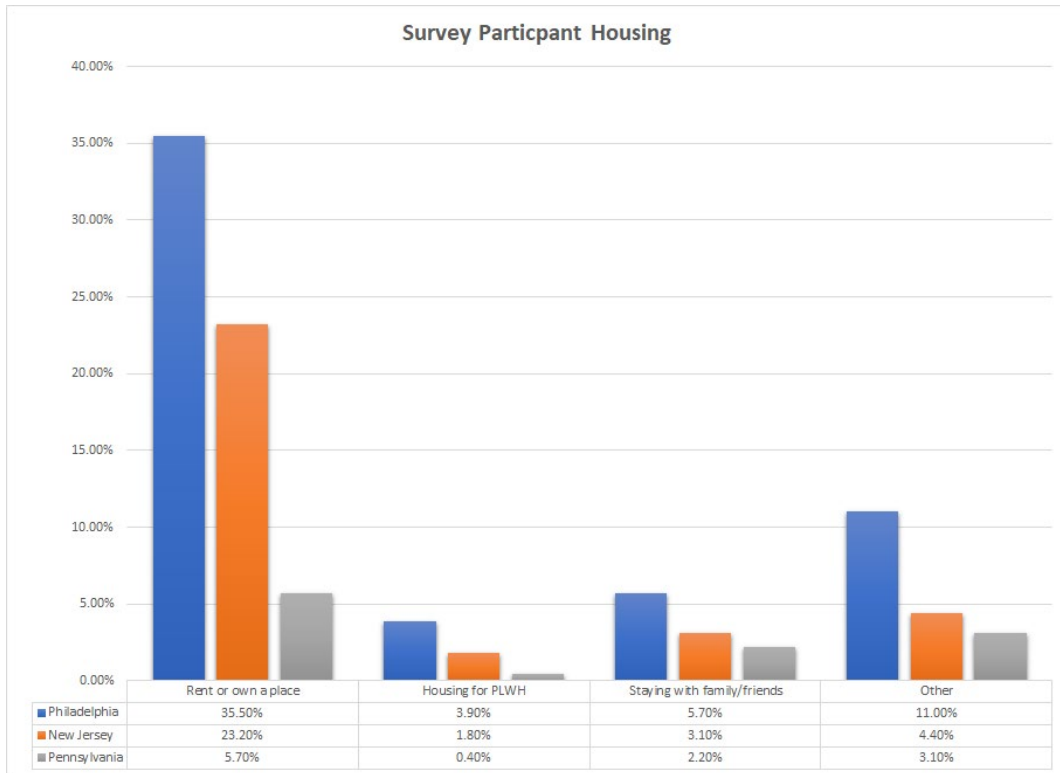


Figure 9: Survey Participants' Ethnicity Region

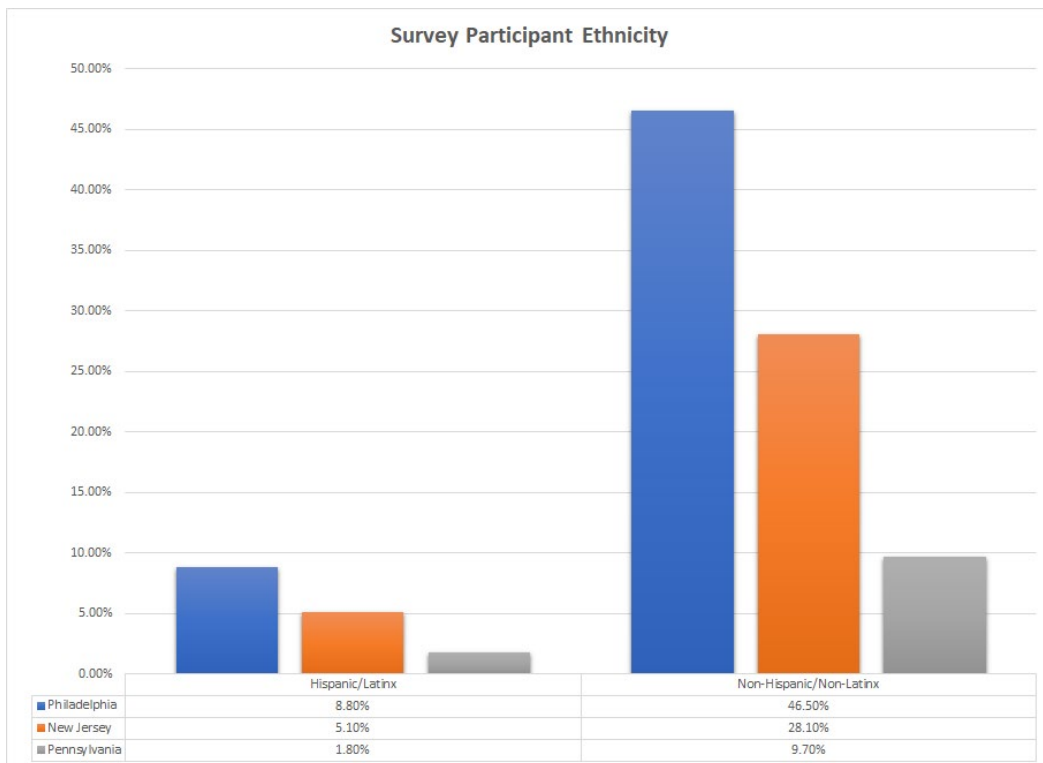


Figure 10: Survey Participants' Race by Region

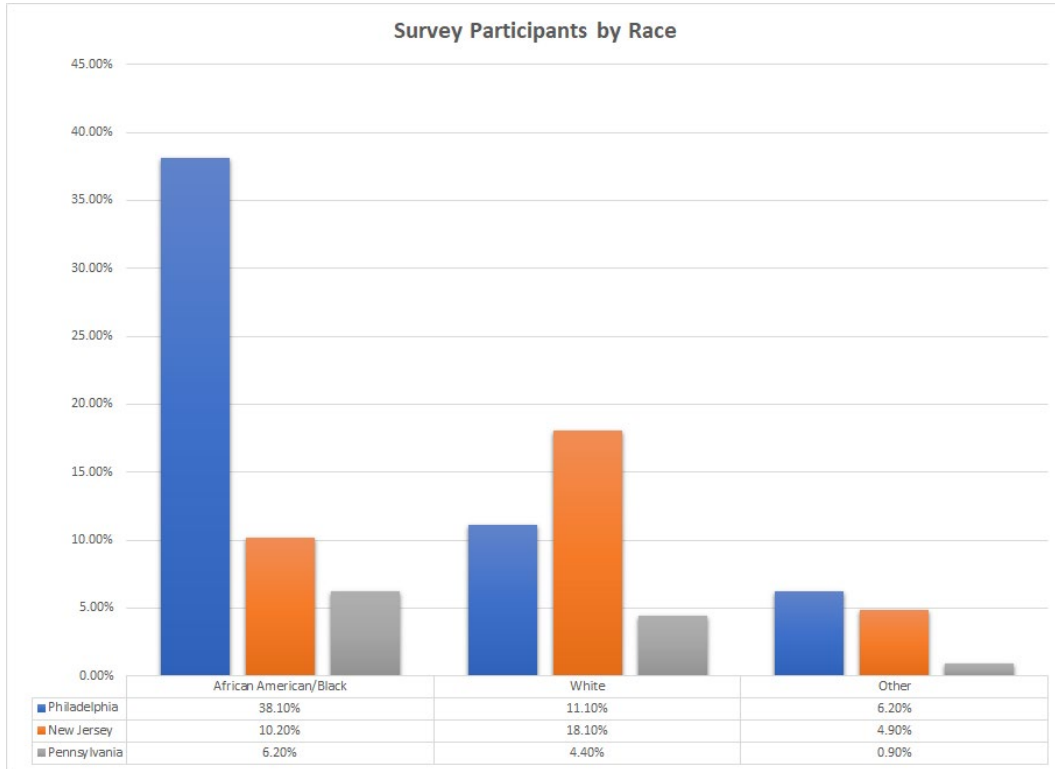
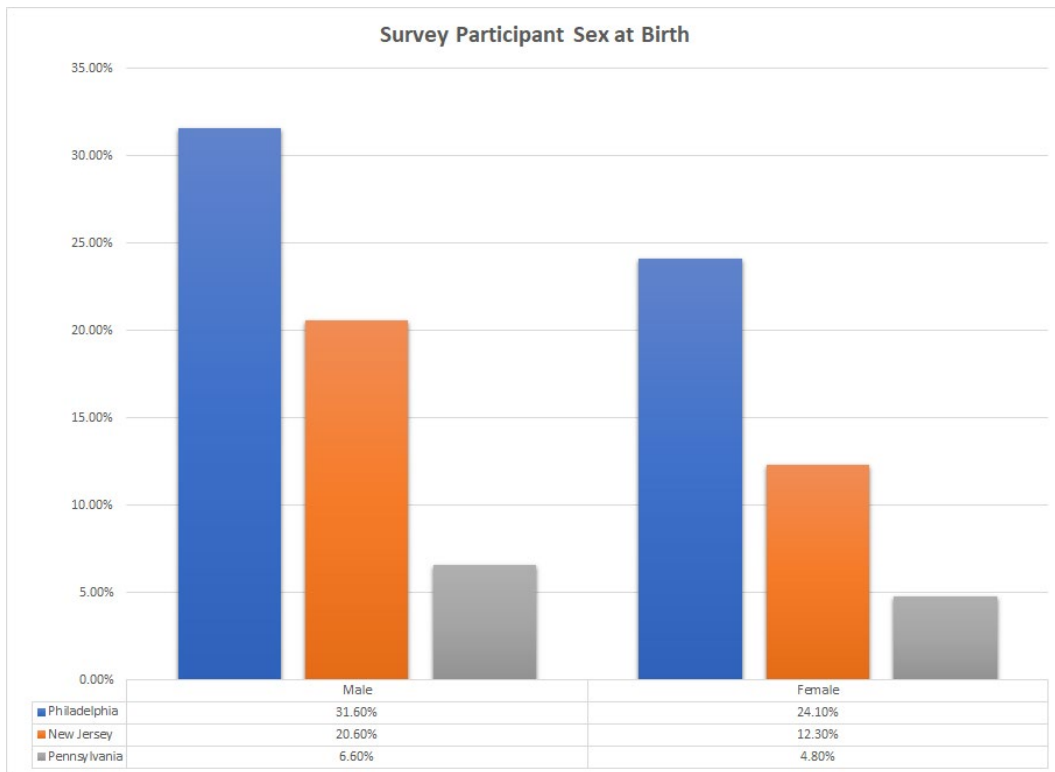


Figure 11: Survey Participants Sex at Birth by Region



Incarceration

History of incarceration since HIV diagnosis was reported by 20.6% (40/194) of respondents. A higher percentage of respondents who reported incarceration since their HIV diagnosis were male, as compared to those who had not been incarcerated (22.8% vs 17.9% respectively). Incarceration since HIV diagnosis was associated with income but not necessarily education, with people who had been incarcerated being more likely to report personal income below \$1,000 per month however their educational status crossed the education spectrum compared to those who did not report being incarcerated since their HIV diagnosis (Table 2).

Table 2: 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=40	n=150
No income	17.5%	8%
\$1-\$1,000	27.5%	22%
\$1,001- \$2000	15%	29.3%
\$2,001-\$3,000	22.5%	17.3%
\$3,001-\$4,000	5%	6%
\$4,001-\$5,000	5%	3.3%
\$5,001-\$6,000	2.5%	3.3%
\$6,001 - more	5%	10.7%
Total	100%	100%
Education	n=40	n=153
8th grade or less	7.5%	5.2%
Some high school, but did not graduate	12.5%	12.4%
High school graduate or GED	35%	28.8%
Some college, but did not graduate	17.5%	14.4%
Vocational/Training certification	2.5%	7.8%
College graduate (2 or more years' degree)	25%	17.6%
Master's degree or doctorate	0%	10.5%
Another answer not listed	0%	3.3%
Total	100%	100%

Health Insurance

The majority of participants (86.9%) had some form of health insurance or medical services coverage. 35.2% had Medicaid or Medical Assistance, Health Choices, or an ACCESS card. 22.9% said they had Medicare. 17.8% were insured through work or a union. 6.4% were insured through the Affordable Care Act health insurance marketplace. 9.3% said they were covered under Health Partners plans. 4.2% bought their insurance directly. 0.4% 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%.

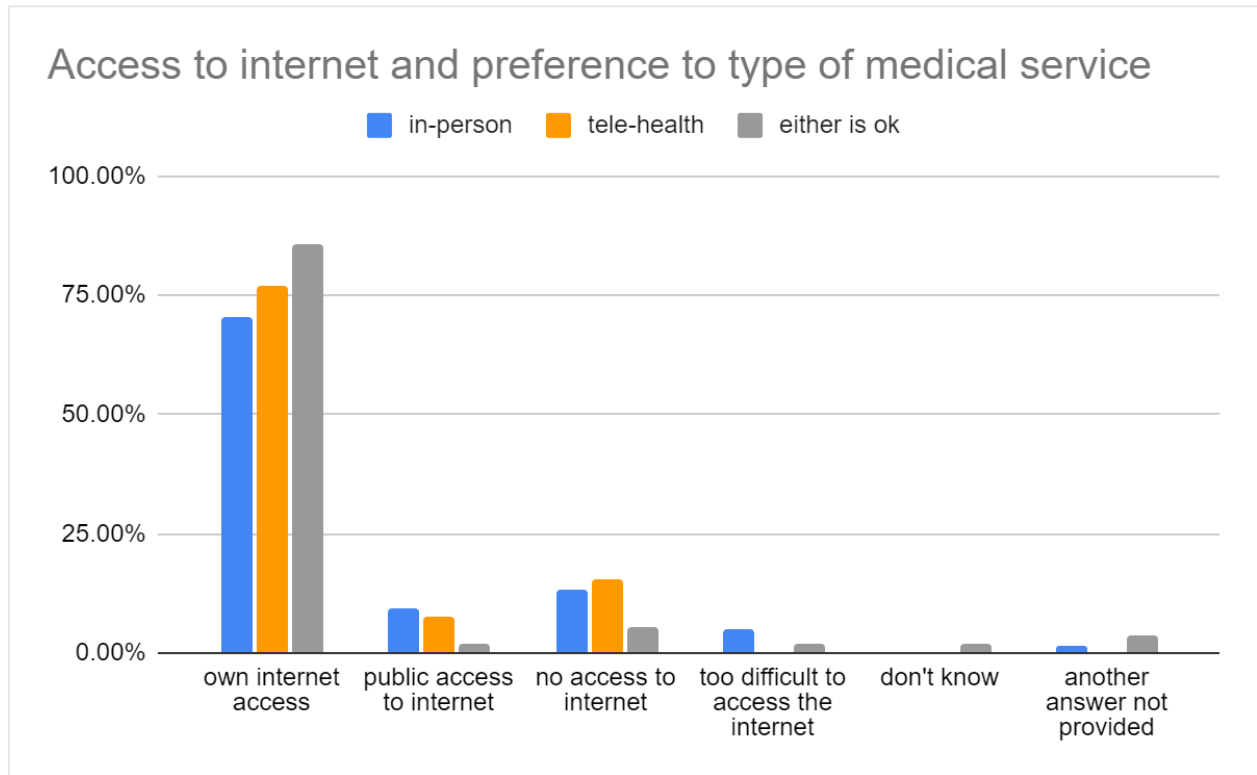
COVID-19

It was critical to examine the impact of COVID on the population. Therefore, the survey included several questions meant to ascertain what if any impact COVID had on housing, wages, and access to medical care. Respondents were asked if their housing had changed since the pandemic 73.5% of respondents said no and 25.5% had some housing changes. It is believed that the impact on housing may have been mitigated by the safeguards put in place during the height of the pandemic (moratorium on evictions, pandemic federal relief checks, etc.) 31.7% of respondents reported losing at least one week of wages or more due to the pandemic, while 55.5% did not indicate an impact on wages as a result of the pandemic. 10.5% of participants admitted to missing doses of HIV medications and 8.9% missed other essential non-HIV medicines. Conversely, 83.9% did not identify any disruption in doses of HIV medicines and 72% did not identify missing doses of other non-HIV medicines. Almost twenty percent (19.9%) of survey respondents missed a medical appointment due to COVID-19 and 74.6% did not miss a medical appointment because of COVID-19.

Tele-Health

When assessing tele-health versus in-person care preferences respondents were asked about their access to the internet when they want it. 74.9% of the respondents have their own computer or smartphone, 6.9% of respondents access the internet from a public place (friend, library, etc.); 14.8% of respondents do not have access to the internet or find it too difficult to access. Half of respondents (54.6%) prefer future in-person care visits, 5.9% prefer future telehealth visits, and 24.1% respondents stated either was fine. Respondents were asked why they prefer in-person visits 55.5% like seeing the provider face to face, 26.2% perceived better treatment in person, 16.5% feel it is more confidential in-person. When asked why they prefer tele-health visits 31.7% responded convenience, 15.6% not having to deal with transportation issues; 13.9% stated their health was good. Figure 12 demonstrates access to the internet and preference to the type of medical service provided.

Figure 12: Access to Internet and Preference to Type of Medical Services



Co-occurring Conditions

Respondents were asked if a doctor had ever told them they had any of the health conditions in Table 3. Hypertension was the most commonly reported condition, with almost half of the participants reporting that they had high blood pressure (39.4%). This was followed by high cholesterol (30.8%), lung/breathing problems (16.5%), diabetes (13.5%), nerve issues such as epilepsy or neuropathy (13.5%), cardiac problems or heart disease (12.2%), cancer (8.7%), kidney problems (8%), and liver problems (7.6%)

Table 3: Ever Diagnosed with Common Chronic Disease and Health Conditions, n=236

Diseases and Conditions	Yes	Yes %
High blood pressure	93	39.41%
High cholesterol	71	30.08%
Lung/breathing problems	39	16.53%
Diabetes	32	13.56%
Nerve issues (epilepsy, neuropathy)	32	13.56%
Cardiac problems/heart disease	29	12.29%
Cancer	23	9.75%
Kidney problems	19	8.05%
Liver problems	18	7.63%
Don't know	*	1.69%
None of the above	58	24.58%
No response	21	8.90%

Notes: * indicates number is suppression because it is < 6

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. As seen in Table 4 below 43.6% of respondents reported to have been diagnosed with depression, 43.6% with anxiety, 12.7% with bipolar disorder, 9.7% with substance use disorder, 4.6% with schizophrenia or schizoaffective disorder, 13.4% with PTSD, 10.5% with mood disorder, 5.9% with OCD, 2.1% with eating disorder, and 3.1% with dementia.

Table 4: Survey Respondents Reporting Ever Diagnosed with Mental Health Disorders, n=236

Mental Health	Yes	Yes %
Depression	103	43.64%
Anxiety	103	43.64%
Post-Traumatic Stress Disorder (PTSD)	31	13.14%
Bipolar Disorder	30	12.71%
Mood Disorder	25	10.59%
Substance Use Disorder	23	9.75%
Obsessive Compulsive Disorder (OCD)	14	5.93%
Schizophrenia/Schizoaffective disorder	11	4.66%
Dementia	8	3.39%
Eating Disorder (Anorexia, Bulimia, etc.)	*	2.12%
Don't know	7	2.97%
None of the above	69	29.24%
No response	21	8.90%

Notes: * indicates number is suppression because it is < 6

Hepatitis C (HCV)

A little over half of the respondents (57.6%) reported that they had never been diagnosed with hepatitis C (HCV). Other respondents said that they either had HCV but had been treated/cured (11.8%, n=28) or had HCV and had not been treated/cured (2.1%, n=5). There were (4.2%, n=10) and (10.1%, n=24) of respondents who reported having had Hepatitis A and Hepatitis B respectively. There were significant differences in gender and racial/ethnic composition of the HCV groups; in addition to differences in distribution of income, education, and employment between them. 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 had equal distribution of income levels. See Table 6 for the demographics of respondents who had ever been diagnosed with HCV. Note as seen in Figure 1 above, there was diversity in racial identity however the numbers of respondents who were non-Black, non-White, or Biracial was small and therefore categorized below as other race. Additionally, we asked respondents to identify their sex non-Binary is inclusive of six other identified genders too small to examine separately.

Table 5: Demographic Characteristics of Respondents with a History of HCV

Characteristics	History Treated HCV		History of Untreated HCV	
	N	%	N	%
Sex				
Male	17	61%	*	40%
Female	10	36%	*	60%
Non-binary	*	3%	0	0%
Total	28	100%	*	100%
Race/Ethnicity				
Black/African American	10	35.7%	*	40%
White/ Caucasian	11	39.3%	*	60
Biracial	*	3.6%	0	0%
Other-race	6	21.4%	0	0%
Total	28	100%	*	100%
Income				
No income	*	10%	0	0%
Below \$1,000	11	39%	0	0%
\$1,001-\$2000	*	18%	*	20%
\$2,001-\$3000	*	14%	*	20%
\$3,001-\$4000	*	4%	*	20%
\$,4,001-\$5,000	*	4%	*	20%
\$5,001-\$6,000	*	7%	0	0%
\$6,001 or more	*	4%	*	20%
Total	28	100%	*	100%
Education				
8th grade or less	*	17.9%	0	0%
Some high school, but did not graduate	*	14.3%	*	40%
High school graduate or GED	10	35.7%	*	20%
Some college, but did not graduate	*	7.1%	0	0%
Vocational/Training certification	*	3.6%	0	0%
College graduate (2 or more years' degree)	*	10.7%	*	40%
Master's degree or doctorate	*	7.1%	0	0%
Another answer not listed	*	3.6%	0	0%
Total	28	100%	*	100%
Employment				
Employed full time	*	17%	*	50%
Employed working part time	*	10%	0	0%
Self employed	0	0%	0	0%
Not employed looking for work	*	3%	0	0%
Not employed, not looking for work	*	7%	*	17%
Retired	*	7%	0	0%
Disabled	14	49%	*	33%
No response	*	7%	0	0
Total	29	100%	*	100%

Notes: * indicates number is suppression because it is < 6

HIV-Related Health Outcomes and Service Access

Most participants (80.7%) said that they received HIV medical care within 30 days of their HIV diagnosis. A majority of respondents said that their most recent viral load was undetectable (81.3%), while 8.8% said that their viral load was detectable but below 5,000 copies/ml. The remaining 2.9% had viral loads greater than 5,000 copies/ml and 3.4% were unsure of their viral load. Almost all participants reported taking antiretroviral medications (92%).

Respondents said that they have seen their HIV medical provider 3 times or more in the past year (57.3%), while 37.2% have seen their medical provider once or twice in the past year. Three respondents said they did not see an HIV medical provider in the previous 12 months.

Respondents (68.6%) said that their HIV medical provider had always taken time to explain their lab results, diagnoses, treatment plans and answer their questions. Another 8.4% said that their doctor did this “most of the time”, while 5.0% said “some of the time”, and 0.8% said “never”. Over half of the respondents (56.7%) said that they always feel comfortable talking to their HIV medical provider about personal and sensitive issues. Another 11.8% said that they felt comfortable “most of the time”, 12.2% said “some of the time”, and 1.2% said that they “never” feel comfortable discussing sensitive issues with their medical provider.

Limited Access to HIV Services in the Past 12 Months

Out of 201 respondents 82.6% (166) did not experience problems in accessing HIV medical care in the previous 12 months. 12% (24) said that they could not get the service/services they needed. Note: as seen in Figure 1, there was diversity in racial identity however the numbers of respondents who were non-Black, non-White, or Biracial was small and therefore categorized below in Table 6 and Table 7 as other race. Additionally, we asked respondents to identify their sex and non-Binary is inclusive of six other identified genders too small to examine separately.

Table 6: 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
Sex	n=24	n=166
Male	50%	55.4%
Female	45.8%	39.2%
Non-Binary	4.2%	4.2%
Total	100%	100%
Race/Ethnicity	n=24	n=163
Black/African American	45.8%	55.2%
White/ Caucasian	41.7%	32.5%
Biracial	4.2%	1.2%
Other-race	8.4%	11%
Total	100%	100%
Personal Monthly Income	n=24	n=162
No income	8.3%	10.5%
Below \$1,000	29.2%	23.5%
\$1,001-\$2000	20.8%	26.5%
\$2,001-\$3000	20.8%	18.5%
\$3,001-\$4000	4.2%	6.2%
\$4,001-\$5,000	4.2%	3.1%
\$5,001-\$6,000	0%	3.7%
\$6,001 or more	12.5%	8%
Total	100%	100%
Education	n=24	n=166
8th grade or less	4.2%	6.6%
Some high school, but did not graduate	25%	10.8%
High school graduate or GED	29.2%	28.3%
Some college, but did not graduate	12.5%	16.3%
Vocational/Training certification	8.3%	6.6%
College graduate (2 or more years' degree)	16.7%	19.9%
Master's degree or doctorate	4.2%	9%
Another answer not listed	0%	2.4%
Total	100%	100%

Table 6 continued: 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
	n= 25	n= 163
Employment		
Employed full time	24%	30%
Employed working part time	20%	12.8%
Self employed	4%	3.6%
Not employed looking for work	8%	8.5%
Not employed, not looking for work	8%	4.2%
Retired	8%	8%
Disabled	28%	30%
No response	0%	2.4%
Total	100%	100%
Homeless/ Marginally housed	0% (0/24)	1.9% (3/162)
Having no medical insurance	0% (0/24)	4.2% (7/166)

Case Management

Of the 182 respondents who responded to the question 84.6% (154) stated having a case manager. However, this is only 65.2% of the entire sample. Table 7 describes characteristics of those who do and do not have medical case management. 82.1% of respondents were satisfied with their case managers. Respondents affirming case management were more likely male (55.9%), black 59%, a third with a high school diploma and had an income of below \$1,000 a month or \$1,000-\$2,000 a month 24.7% and 28.7% respectively. Respondents who did not have a case manager 43% were male, 55% white, 41% were employed full time and identified an income of \$2,000-\$3,000 a month, and a third had a college degree.

Table 7: Characteristics of Respondents with or without Medical Case Managers n=182

Survey question: Do you have an HIV case manager?		
	Yes	No
Sex	n=152	n=30
Male	55.9%	43.3%
Female	39.5%	50%
Non-Binary	4.8%	3.3%
Prefer not to answer	.7%	3.3%
Total	100%	100%
Race/Ethnicity	n=151	n=29
Black/African American	59.6%	37.9%
White/ Caucasian	28.5%	55.2%
Biracial	1.3%	3.4%
Other-race	10.6%	3.4%
Total	100%	100%
Personal Monthly Income	n=150	n=29
No income	12%	10%
Below \$1,000	24.7%	13.8%
\$1,001-\$2000	28.7%	6.9%
\$2,001-\$3000	14.7%	41.4%
\$3,001-\$4000	5.3%	10.3%
\$4,001-\$5,000	4.0%	6.9%
\$5,001-\$6,000	3.3%	0%
\$6,001 or more	7.3%	20.7%
Total	100%	100%
Education	n=152	n=30
8th grade or less	6.6%	0%
Some high school, but did not graduate	11.8%	13.3%
High school graduate or GED	32.2%	13.3%
Some college, but did not graduate	15.1%	13.3%
Vocational/Training certification	4.6%	16.7%
College graduate (2 or more years' degree)	17.8%	33.3%
Master's degree or doctorate	8.6%	10%
Another answer not listed	3.3%	0%
Total	100%	100%

Table 7 continued: Characteristics of Respondents with or without Medical Case Managers

Survey question: Do you have an HIV case manager?			
	Yes	No	
	n= 149	n= 32	
Employment			
Employed full time	30%	41%	
Employed working part time	15%	6%	
Self employed	1%	12%	
Not employed looking for work	9%	3%	
Not employed, not looking for work	7%	0%	
Retired	7%	19%	
Disabled	30%	16%	
No response	1%	3%	
Total	100%	100%	
Homeless/ Marginally housed	1.3% (2/149)	0% (0/30)	
Having no medical insurance	3.9% (6/152)	3.2% (1/31)	

Gynecological Service Access

“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, 36.6% (n=41) said “yes” and 63.3% (n=71) said “no”

Out of the 92 participants that 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 (59.7%), 30.4% said that they get referred to somewhere else for gynecological services, and three people said that their medical provider does not refer them anywhere for gynecological services or take care of their reproductive health.

Just over half of the individuals who answered the question “When was the last time you received GYN care?” responded “in the last 12 months” (51.5%). 25.2% answered that they received gynecologic services 1-2 years ago, and 8% 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 results⁷. 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

In past iterations of the survey respondents were asked to indicate whether, in the previous 12 months, they had used or needed but did not receive the services. The question was expanded to include never heard of as well as never personally needed. The inclusion of these two additional responses as listed in Table 8 below provide a more illustrative examination of service utilization and unmet need. 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”, in the past we may have 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. With the inclusion of these two new options we hope to eliminate potential misunderstanding of the answers and the design of the question.

Medical care was reported as the most-used service, with 53% of respondents reported having used the service in the last 12 months. Dental care and medical case management were the second and third most-used services, at 50% and 46% respectively. The services with the highest percentage of respondents who reported needing but not receiving them were housing assistance (11%), direct emergency financial assistance (DEFA) at 9%, and legal services (8%). The services with the least reported unmet need are medical care, adult day care, and HIV care entry all at (2%). When examining the answers further it was possible to determine what if any regional differences existed in terms of knowledge of services. This difference can further compound the need of a service.

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 noted as unmet needs (“I needed but didn’t get”) in the last 12 months for 5.9% and 2.9%, respectively.

The top four services identified by respondents as having never heard of DEFA was represented 10.6% of respondents followed by treatment adherence (6.8%), legal (5.9%), and emergency medications at (5.1%).

Hospice services accounted for 57% of services personally never needing, followed by self-care assistance (51.3%), and pro-health nurse services (47.9%) were the top three services people did not personally need. It is important to note that some services that are typically believed to be services needed by populations such as child care also had high respondents stating that they did not need. In some of these instances we could not conclude definitively if the need does not exist but note that the majority of respondents were not of child bearing age and therefore the needs may vary in a different age group.

Of those who reported incarceration since their HIV diagnosis, 24.3% 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 8: Self-reported Service Utilization and Unmet Need Percentages in the Previous 12 months

Service Categories	I have used these services in the past 12 months	I have needed these services in the past 12 months but didn't get	I never heard of these services in the past 12 months	I never personally needed these services
Dental care	50.00%	7.63%	1.3%	14.8%
DEFA	24.15%	9.75%	10.6%	31.8%
Food bank/home delivered meals	32.63%	6.36%	4.7%	32.6%
HIPCP	29.24%	7.20%	4.7%	33.1%
Housing assistance	23.73%	11.44%	2.5%	36%
Legal	24.58%	8.90%	5.9%	36.9%
Medical Case Management	46.61%	5.93%	0.8%	20.8%
Nutritional Counseling	30.51%	6.78%	4.7%	29.7%
Medical Care	53.81%	2.12%	2.1%	15.3%
Emergency Medications	29.66%	3.39%	5.1%	40.3%
Transportation	36.44%	5.93%	2.1%	30.9%
Mental Health Counseling	37.71%	5.93%	2.1%	25%
Substance use counseling	20.76%	2.97%	4.2%	42.4%
Treatment adherence	22.03%	3.81%	6.8%	39.8%
Home Health (pro nurse)	16.10%	5.08%	4.2%	47.9%
Self-care assistance	11.86%	5.51%	4.2%	51.3%
Support groups	19.49%	8.05%	3.4%	41.9%
Hospice services	6.36%	2.97%	4.7%	57.6%
Physical Rehab	20.34%	2.97%	4.2%	46.6%
Adult day care	8.05%	2.54%	6.4%	55.5%
Child care	7.20%	4.24%	5.1%	56.4%
HIV care entry	21.19%	2.54%	3.8%	44.9%
Translation and Interpretation	8.47%	2.54%	3.8%	57.2%

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 42.9% of the uninsured. Transportation was also a barrier for 38.1% of the respondents who get their insurance through Medicaid, 50% of the self-insured, 18.2% of people with marketplace plans, 25% of those with coverage through an employer, 38% 20% of those covered by Health Partners, and 28% of those who reported “other insurance” (see Table 9). None of the respondents covered by the Veteran Affairs (VA) reported any transportation challenges in the previous 12 months. As you can see in Table 10, the uninsured, and people covered through Medicaid and Medicare were significantly more likely to have transportation challenges that prevented them from attending appointments.

Due to the COVID landscape, respondents were asked “have you not gotten medical care because you couldn’t afford the co-pay or deductible for both before February 2020 and after February 2020 to identify if there was disruption because of this factor. 12% of respondents stated having difficulty prior to February 2020 and 10.6% stated having difficulty after February 2020.

Table 9: Transportation Barriers to Medical Care in the Previous 12 Months by Insurance, n=202

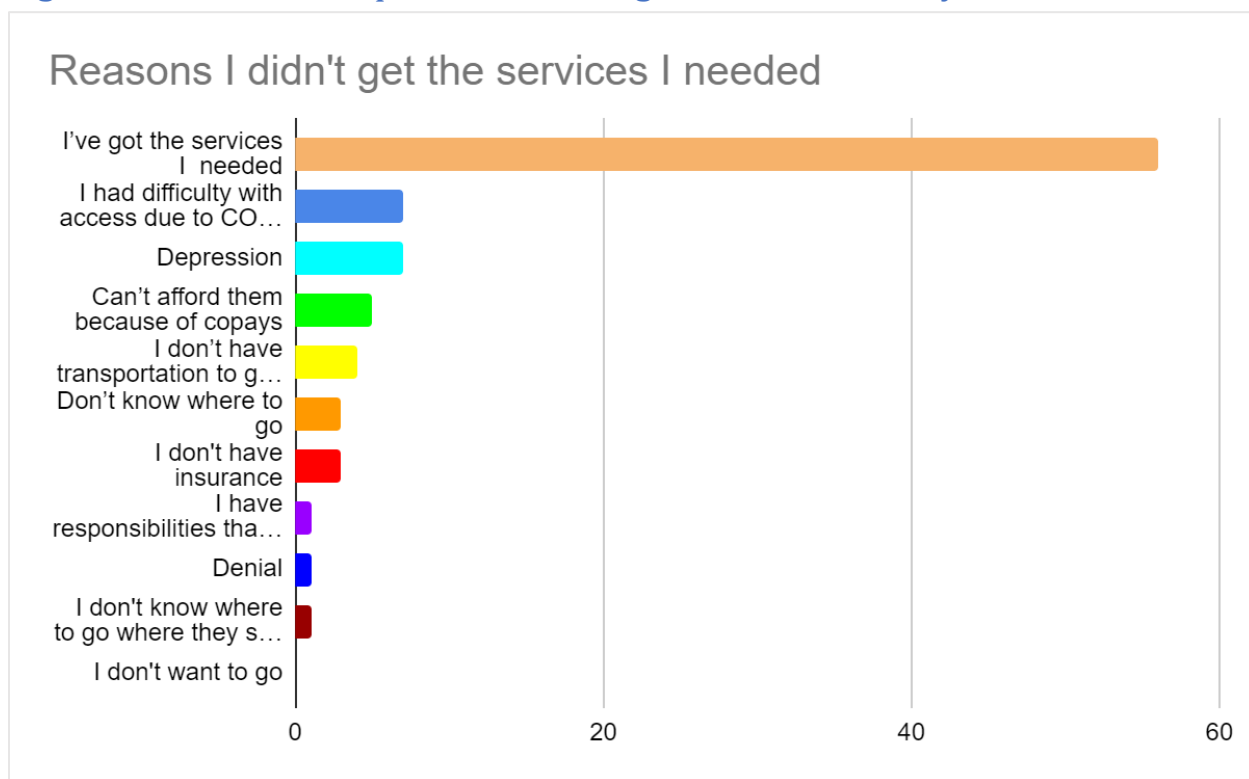
Insurance Type	Transportation Barrier					
	Yes			No		
	N	%		N	%	
Health Partners	*	20.0%		12	80.0%	
Medicaid, MA, HC, AC	24	38.1%		39	61.9%	
Medicare	12	23.5%		39	76.5%	
Other	*	28.6%		*	71.4%	
Self-insured	*	50.0%		*	50.0%	
Uninsured	*	42.9%		*	57.1%	
Work/union	10	25.0%		30	75.0%	
Total	60	29.7%		142	70.3%	

Notes: * indicates number is suppression because it is < 6

Both the English and Spanish language versions of the survey asked if language was a barrier to services. 1.2% 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: “I had difficulty with access due to COVID-19” (7.2%), “Depression” (6.7%), “Can’t afford them because of co-pays” (4.6%), “I don’t have transportation to get there” (3.8%), “Don’t know where to go” (2.9%), “I don’t have insurance” (2.9%), and “I have responsibilities that prevent me from going (caring for children or family members, work, etc.)” (1.2%) “denial” (1.2%), and under 1% of respondents stated “I don’t know where to go where they speak my language” (.85%) and “I don’t want to go” (.42%). Just over half the sample (55.9%) reported “I got the services I needed”.

Figure 13: Reasons Respondents didn’t get the services they 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 99 responses) on the stresses of poverty 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. 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.

Many respondents praised their doctors and other providers. With some often offering their years of lived experience being greater than 20 years and having a positive healthcare experience. Although there were a number of comments related to COVID-19 staffing issues, fear of getting COVID, or being able to afford basic necessities due to issues exacerbated by the pandemic. Additionally, transportation, lack of money to meet basic expenses like rent, food, healthcare (co-payments), and mental health were mentioned. Although most of the respondents were not incarcerated, those who experienced incarceration stated staff not being concerned about medications in jail or lack of access to care. Several respondents said that they were lonely or depressed and had difficulty coping.

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 11 groups Table 10a and Table 10b. “White men who have sex with men (MSM)” (n=31, 13.6%), “MSM of color” (n=52, 22.8%), white heterosexual males (n=15, 6.6%), heterosexual males of color (n=36, 15.8%), heterosexual females of color (n=69, 30.3%), white heterosexual females (n=12, 15.3%), and non-heterosexual female of color (n=8, 3.5%). However, four categories transgender females of color, white non-heterosexual females, white transgender females, and white transgender males were suppressed and will not be used in the comparison due to sample size.

Table 10a and Table 10b shows the distribution of demographic and clinical characteristics by the groups defined by sex, race, and sexual orientation. The people of color were slightly older than their white counterparts. Heterosexual men of color were less likely to be a college graduate or be employed in comparison to the remaining groups. Conversely white heterosexual females were more likely to be disabled in the sample followed by heterosexual men of color. All groups appear to be stably housed at 80% or more. Groups seem to be insured at greater than 90% with the exception of non-heterosexual females of color.

Table 10a: Distribution of Characteristics by Groups Defined by Sex, Race, and Sexual Orientation

	Heterosexual Female of Color		Heterosexual Male of Color		MSM of Color		Non-heterosexual Female of Color		Transgender Female of Color	
	N	%	N	%	N	%	N	%	N	%
	Total count	69	30.3%	36	15.8%	52	22.8%	8	3.5%	*
Age	49.3	67%	50	34%	47.66	50%	49.2	7%	54	1%
Income										
No income	*	3.0%	11	30.6%	*	10.0%	*	25.0%	0	0.0%
\$1,000 or less	20	30.3%	8	22.2%	11	22.0%	*	50.0%	*	100.0%
\$1,001-\$2,000	21	31.8%	7	19.4%	12	24.0%	*	12.5%	0	0.0%
\$2,001-\$3,000	12	18.2%	*	13.9%	12	24.0%	0	0.0%	0	0.0%
\$3,001+	11	16.7%	*	13.9%	10	20.0%	*	12.5%	0	0.0%
Total	66		36		50		8		*	
School										
Below High School	11	15.9%	10	27.8%	6	11.5%	*	37.5%	*	100.0%
High School Graduate	21	30.4%	15	41.7%	17	32.7%	*	25.0%	0	0.0%
Some College/Vocational	20	29.0%	7	19.4%	15	28.8%	0	0.0%	0	0.0%
College Graduate+	14	20.3%	*	11.1%	13	25.0%	*	37.5%	0	0.0%
Other	*	4.3%	0	0.0%	*	1.9%	0	0.0%	0	0.0%
Total	69		36		52		8		*	
Employment										
Employed	37	56.1%	8	24.2%	26	53.1%	*	42.9%	0	0.0%
Unemployed	8	12.1%	11	33.3%	*	8.2%	*	42.9%	*	100.0%
Retired	*	4.5%	*	3.0%	*	10.2%	*	14.3%	0	0.0%
Disabled	18	27.3%	13	39.4%	14	28.6%	0	0.0%	0	0.0%
Total	66		33		49		7		*	
Housing										
Stably housed	58	87.9%	31	86.1%	41	82.0%	7	87.5%	*	100.0%
Unhoused/marginally unhoused	8	12.1%	*	13.9%	9	18.0%	*	12.5%	0	0.0%
Total										
Insured										
Insured	58	93.5%	34	97.1%	45	93.8%	*	80.0%	*	100.0%
Uninsured	*	6.5%	*	2.9%	*	6.3%	*	20.0%	0	0.0%
Total										
Viral Load										
Undetectable	48	90.6%	23	85.2%	39	88.6%	6	85.7%	*	100.0%
Detectable	*	9.4%	*	14.8%	*	11.4%	*	14.3%	0	0.0%
Total										

Notes: * indicates number is suppression because it is < 6

Table 10b: Distribution of Characteristics by Groups Defined by Sex, Race, and Sexual Orientation

	White Heterosexual Female		White Heterosexual Male		White MSM		White Non-heterosexual Female		White Transgender Female		White Transgender Male	
	N	%	N	%	N	%	N	%	N	%	N	%
Total count	12	5.3%	15	6.6%	31	13.6%	*	0.9%	*	0.4%	*	0.4%
Age	42.7	12%	42.2	14%	42.2	29%	35	1%	60	1%	45	1%
Income												
No income	*	8.3%	*	13.3%	*	6.5%	0	0.0%	0	0.0%	0	0.0%
\$1,000 or less	*	33.3%	*	6.7%	*	3.2%	0	0.0%	0	0.0%	0	0.0%
\$1,001-\$2,000	*	25.0%	*	6.7%	10	32.3%	0	0.0%	0	0.0%	*	100%
\$2,001-\$3,000	*	25.0%	*	26.7%	*	9.7%	*	50.0%	*	100%	0	0.0%
\$3,001+	*	8.3%	7	46.7%	15	48.4%	*	50.0%	0	0.0%	0	0.0%
Total	12		15		31		*		*		*	
School												
Below High School	*	16.7%	*	13.3%	*	3.2%	*	100%	0	0.0%	0	0.0%
High School Graduate	*	41.7%	*	26.7%	*	12.9%	0	0.0%	0	0.0%	*	100%
Some College/Vocational	*	8.3%	*	13.3%	*	16.1%	0	0.0%	*	100%	0	0.0%
College Graduate+	*	33.3%	7	46.7%	21	67.7%	0	0.0%	0	0.0%	0	0.0%
Other	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Total	12		15		31		*		*		*	
Employment												
Employed	6	50.0%	9	60.0%	18	60.0%	*	50.0%	*	100%	0	0.0%
Unemployed	*	8.3%	*	6.7%	*	6.7%	*	50.0%	0	0.0%	0	0.0%
Retired	0	0.0%	*	6.7%	*	16.7%	0	0.0%	0	0.0%	0	0.0%
Disabled	*	41.7%	*	26.7%	*	16.7%	0	0.0%	0	0.0%	*	100%
Total	12		15		30		*		*		*	
Housing												
Stably housed	10	83.3%	12	80.0%	26	83.9%	0	0.0%	*	100%	*	100%
Unhoused/marginally unhoused	*	16.7%	*	20.0%	*	16.1%	*	100%	0	0.0%	0	0.0%
Total	12		15		31		*		*		*	
Insured												
Insured	11	100%	14	100%	28	100%	*	100%	*	100%	*	100%
Uninsured	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Total	11		14		28		*		*		*	
Viral Load												
Undetectable	7	77.8%	7	70.0%	28	93.3%	0	0.0%	*	100.0%	*	100%
Detectable	*	22.2%	*	30.0%	*	6.7%	*	100%	0	0.0%	0	0.0%
Total	9		10		30		*		*		*	

Notes: * indicates number is suppression because it is < 6

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 (58.5%) 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. 27.5% reported having female partners, 69% reported male partners, and 2.9% reported transgender and/or gender non-conforming partners. A separate question was asked about the respondent’s sexual orientation or identity.

Respondents were asked if their partner/s were on antiretroviral therapy (ART) or pre-exposure prophylaxis (PrEP). Of the sample, 13.5% said that their partner was HIV-positive and undetectable, while only 2 (0.8%) of them said that their partner was HIV-positive and has detectable viral load, another 4 (1.6%) said their partner was HIV-positive and not on meds. 8.4% of sexually active participants said their HIV-negative partner was on PrEP, and 14.8% said that their HIV-negative partner was not taking PrEP. Some respondents (8%) replied “don’t know”.

Table 11: Harm reduction services offered in last 12 months, n=236

Services Offered (location not identified)	N	%
STD testing including hepatitis C	44	18.64%
Condoms or safer sex kits	65	27.54%
Safer injection/bleach kits	*	1.69%
Information on syringe access programs	9	3.81%
Information on a colorectal cancer screening	26	11.02%
Information on a mammogram	28	11.86%
Information on HIV counseling for pregnancy	13	5.51%
Partner services (assistance contacting previous sex partners after positive diagnosis)	18	7.63%
Information on how to tell someone about your HIV status (disclosure)	27	11.44%
Information about PrEP (taking HIV meds to prevent HIV) for you or your partner/s	32	13.56%
Information about PEP (taking HIV meds after exposure to prevent HIV) for you or your partner/s	18	7.63%
None of the above	50	21.19%
Does not apply	43	18.22%
No response	23	9.75%

Notes: * indicates number is suppression because it is < 6

As noted in Table 11 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 27.5% and 18.6%, respectively. Information about PrEP was offered to 13.5% of the sample and disclosure support to 7.6%. Few respondents reported being offered harm reduction support for injection drug use. Four people reported receiving safe injection kits/bleach kits, and 9 people received information on syringe access services.

Reported Sexual and Drug Use Behaviors

A substantial proportion of the respondents reported engaging in one or more of the following behaviors before 2020 or after 2020 respectively: having performed oral sex without a condom, dental dam, or other barrier (36.8%, 33.9%), having had vaginal sex without a condom (26.2%, 25.8%), having had anal sex without a condom (26.6%, 23.3%), and/or having traded sex for money, drugs, or services (5.5%, 4.2%) and/or having used street drug other than marijuana (14.4%). When asked about substance use 28 respondents (11.9%) stated using substances other than marijuana during or before sexual activity. 11 people (4.7%) reported having shared injection equipment in the last 12 months, and 10 (4.2%) 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 29.5% 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=10), any effect on the outcomes is 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). Serosorting and sero-positioning could also be present as tools for HIV risk reduction.

Although respondents who reported transactional sex, condomless sex, or shared injection equipment were more likely to receive a STD and Hepatitis C screening in the last 12 months compared to respondents who did not state having condomless or transactional sex or shared injection equipment the referrals given were low in both groups.

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 (94.6%), being prescribed ART (92%), and having an undetectable viral load (81.3%). The EMA is generally meeting the needs of the people who receive HIV care at RW providers. This analysis supports this assertion.

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 impacts due to COVID mitigation strategies, transportation processes, housing costs, 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.

Many 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.

The negative effects of the pandemic could potentially be accounted by the structural barriers due to COVID-19 mitigation measures (e.g. lockdown, social distancing) and the subsequent underutilization of HIV care services, the patients' personal behavior (e.g. avoidance of accessing healthcare) (Yang et al 2023). Joseph et al. (2022) found that PLWH reported exacerbated mental health stressors (e.g., anxiety, depression, substance use) in correlation with the COVID-19 pandemic. Many of the participants expressed challenges related to mental health during the period. In addition to stating how COVID impacted their ability to receive care throughout the EMA during this period

"I have no money to see doctor because of the pandemic"

"Covid overwhelmed the infectious disease unit and ID doctors were too busy"

"Surgery for prostate cancer was delayed due to Covid and may have worsened the cancer"

"Transportation is not easy during the pandemic"

"Fear of getting covid"

Labisi et al (2022) remarks the success of telehealth in HIV care. However, the key findings were PLWH may be willing to use telehealth beyond the pandemic, but social determinants of health and demographic factors are important predictors of utilization and sustainability. This finding is not unlike what was seen in the Philadelphia EMA respondents with participants both highlighting the success and the difficulty around access and utilization.

"Appreciate everything my case manager does especially checking up on me"

"no internet"

The official emergency declaration is over for COVID however there are lessons to be learned from that moment which could be implemented to address the needs of the population within the Philadelphia EMA. Infrastructure to assist healthcare facilities as well as patient populations with access to the internet through entities outside of the confines of the Ryan White Program may possibly address some of the barriers mentioned by Labisi.

Persons 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.

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.

Dasgupta et al (2021) describes Barriers to HIV care may be categorized into domains, some of which include structural factors, such as provider availability and transportation; financial barriers, including health care coverage and poverty; personal circumstances, including co-occurring conditions (e.g., depression, substance use), incarceration, competing priorities, or personal health beliefs; and stigma and discrimination. Transportation continues to be one of the most salient barriers mentioned from respondents making Ebberhart et al (2014) examination of travel distance a critical factor when discussing transportation barriers because it not only means access and cost but also time and distance to care and how addressing all of the components for a client is necessary to overcome the barrier identified.

Transportation problems were often cited as “difficulty with transportation (too expensive)”

“Medical Transportation is an issue– either doesn’t show or is really late”

29.7% 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: 50% of the self-insured, 42.9% of the uninsured, 38.1% of Medicaid covered respondents, 23.5% of Medicare covered respondents and 18.2% with Affordable Care Act coverage. Medicaid and Medicare both provide transportation to HIV medical care appointments for eligible individuals, so these results are cause for concern. The HIPC and DHH 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.

Homelessness and housing insecurity are significant barriers to care for the EMA's PLWH. 10.8% 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 4.3% of the sample. Even people who own or rent are vulnerable to losing their homes because costs are high and incomes are low. 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 7 to 8 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 may 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). Aquino's 2021 study in DC continues to affirm this position that PLWH who have unstable housing or who are homeless may need additional support services for maintaining Retention in Care and Viral Suppression, as the proportion meeting those benchmarks was not at goal when they sought services at HCS.

"Housing instability caused me to move out but don't want to change provider..."

"My concern now is paying rent due to income I get help from ##### I'm worried about rent but not a high priority"

"Barrier to stable housing; 30-day rehab programs not long enough"

Lang et al. (2023) posits the prevalence of mental health disorder among PLWH was high, including mental health multimorbidity. Although retention and viral suppression were similar to people without mental health disorder, viral suppression was lower in those with bipolar disorder and mental health multimorbidity. Thus, highlighting a need to give more attention to PLWH and mental health. 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 be 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. 43.6% of the respondents to the Philadelphia EMA Consumer survey identified having depression; and 43.6% anxiety. Although unclear if

it is poly diagnoses. The implications to co-locate mental health services at primary care locations to facilitate better health outcomes and ART adherence.

The EMA's RW client population is aging, thus the need to examine how PLWH are cared for in the healthcare system. Kiplagat et al (2022) reviews the advantages and disadvantages of HIV care of older adults remaining in infectious disease units with and without specialized care to meet the needs of an aging population with comorbidities. It is argued that the number of ageing people with HIV, that is adults (aged 50 years and older) living with HIV, is increasing and their proportion among total people with HIV is estimated to rise from 28% in 2010, to 73% in 2030. As people age with HIV, however, their needs grow beyond sole management of HIV. Vance et al 2011 examined the differences of comorbidities and HIV health outcomes for 50-59 year olds and 60 and over PLWH. The study found on average 4.52 comorbidities among older PLWH over 60 years old. The number of medications often increases as PLWH get older. When examining the comorbidities of our sample in the EMA 39.4% experienced high blood pressure, 30% high cholesterol, 16.5% lung/breathing problems, 13.5% cardiac or nerve issues respectively.

With an aging population it is critical that we address multiple comorbidities as the population ages. As well as the isolation respondents feel. Loneliness was found to mediate the relationship between HIV-related stigma and depressive symptoms among older PLWH in the Yoo-Jeong 2022 study. HIV-related stigma was associated with loneliness, which was associated with depressive symptoms.

“Loneliness is biggest problem-other friends have died years ago and I’ve survived with my HIV diagnosis”

The above quote in addition to the previous data illuminates a holistic approach required that can meet the complex physical and mental health needs of the RW population.

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.

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).

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 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).

In our sample, we saw that even for respondents who reported behaviors that potentially could have transmission risk (29.5% 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. Of the people who self-reported any sex in the past 12 months, 18.6% report being offered STI screening (27.5%) and/or being offered condoms or safer sex kits. Information about PrEP was only offered to 13.5% of those reporting these sexual 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, 56.8% said "always", 11.9% said "most of the time", and another 12.3% 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 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, some of which was exacerbated by the pandemic. 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 individuals 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

Section 1: The following questions (#1-18) represent demographic-related questions. Please be aware that demographic-related questions are important to help us understand who is using the services.

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 year of birth? _____
3. What sex were you assigned at birth? *(check one)*
- Female
 - Male
 - Prefer not to answer
4. Intersex is someone with a physical, genetic and hormonal features of a male and female. Do you have an intersex variation?
- Yes
 - No
 - Don't know
 - Prefer not to answer
5. How do you identify? *(check one)*
- Female
 - Male
 - Transgender female
 - Transgender male
 - Gender non-conforming
 - Non-binary
 - Agender
 - Gender fluid
 - Gender queer
 - Another answer not listed above *(please specify)*:

 - Prefer not to answer
6. Are you Hispanic/Latinx? *(check one)*
- Hispanic/Latinx
 - Non-Hispanic/Non-Latinx
7. 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)*:

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

9. 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)*:

10. 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

11. 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 substance 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*)

12. Has your housing situation changed since February 2020 because of the COVID-19 pandemic?

- Yes
- No
- Don't know
- Prefer not to answer

If yes, please explain _____

13. 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

14. Do you support anyone else with your income? (*check one*)

- Yes
- No

15. Which of the following categories best describes your employment status? (*check all that apply*)

- Employed, working full time
- Employed, working part time
- Self-employed
- Not employed, looking for work
- Not employed, NOT looking for work
- Retired
- Disabled, not able to work
- Another answer not provided (please specify): _____

16. Have you lost wages from your work for one week or more because of COVID-19?

- No
- Yes
- Don't Know
- Prefer not to answer
- Not applicable – Not working

17. 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*):

18. What is your Zip Code? _____

Section 2: The next 7 questions (#19-25) are about sexual and substance use behaviors before and after the beginning of the COVID-19 pandemic.

19. **Before** February 2020, did you have vaginal, anal or oral sex with another person? (includes any kind of consensual sexual contact) (*check one*)

- Yes
- No

20. **After** February 2020, did you have vaginal, anal or oral sex with another person? (includes any kind of consensual sexual contact) (*check one*)

- Yes
- No

21. Your sexual partners are: (*check all that apply*)

- Female
- Male
- Transgender female
- Transgender male
- Gender non-conforming
- Another answer not listed above (*please specify*):

22. **Before** February 2020, have you....? (check all that apply)
- Had oral sex without a condom, dental dam, or other barrier
 - Had vaginal sex without a condom
 - Had anal sex without a condom
 - Traded sex for money, drugs, or any other item/service
 - None of the above
 - Another answer not listed above _____

23. **After** February 2020, have you....? (check all that apply)
- Had oral sex without a condom, dental dam, or other barrier
 - Had vaginal sex without a condom
 - Had anal sex without a condom
 - Traded sex for money, drugs, or any other item/service
 - None of the above
 - Another answer not listed above _____

24. **After** February 2020, have you...? (check all that apply)
- Other than marijuana (pot), used substances not prescribed to you
 - Had more than 8 (for women) or 15 (for men) alcoholic beverages in the past week
 - Shared injection equipment (for opioid use, methamphetamines, hormones, Botox, etc.)
 - Attended an event or party centered around substance use
 - Used substances (other than marijuana) during or before sexual activity
 - None of the above

25. **After** February 2020, if you have used a substance not prescribed to you other than marijuana, how?
- Orally
 - Injection/syringe
 - Inhalation/smoking
 - Anally
 - Not applicable
 - Prefer not to say
 - Another method not listed above (please specify): _____

SECTION 3: The following questions (#26-28) 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.

26. 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 Section 5 #58)
 - Don't know if I have been tested (skip to Section 5 #58)
 - Don't remember when I was tested
27. 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): _____

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

SECTION 4: The following questions (#) are SPECIFIC to people using HIV services. Those who do not use HIV services are asked to skip this section.

29. Did you get medical care within 30 days of your HIV diagnosis? (check one)
- Yes
 - No, that was later
 - No, I have not been diagnosed with AIDS
 - Don't know
 - Does not apply
30. Did you get HIV medical care within 30-days of your HIV diagnosis? (check one)
- Yes
 - No
 - Don't know
 - Does not apply
31. 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
32. Which of the following services are available to you at the same location where you receive your HIV medical care? (Check all that apply)
- Physical exams/office visit
 - Labs/bloodwork
 - Prescriptions/medications
 - Don't know
 - Does not apply

33. In the past 12 months, how many times did you see your medical provider for your HIV medical care needs? (check one)
- 1
 - 2
 - 3-5
 - 6 or more
 - Did not see an HIV doctor
 - Does not apply
34. If you don't go to the same provider for your HIV medical care, what is the reason? (check all that apply)
- I do have a regular place for care
 - Can't afford it
 - Don't know where to find it
 - Could not get regular appointments anywhere
 - Difficulty with access because of COVID-19
 - 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
35. Are you currently taking any antiretroviral medicines to treat your HIV? (check one)
- Yes
 - No
 - Don't know
 - Does not apply
36. Have you missed any doses of your HIV medicines because of COVID-19?
- No
 - Yes
 - Don't Know
 - Prefer not to Answer
- If yes, please explain the situation If yes, please explain _____

37. Have you had a problem getting a prescription or a refill for your HIV medicines due to COVID-19?
- No
 - Yes
 - Don't Know
 - Prefer not to Answer
- If yes, please explain the situation If yes, please explain _____

38. Have you missed doses of other essential medications (not HIV) because of COVID-19?

- No
- Yes
- Don't Know
- Prefer not to Answer

If yes, please explain the situation If yes, please explain_____

39. Have you missed a medical appointment because of COVID-19?

- No
- Yes
- Don't Know
- Prefer not to Answer

If yes, please explain the situation If yes, please explain_____

40. Have you skipped or delayed routine HIV-related laboratory tests (such as CD4 and viral load tests) due to COVID-19?

- No
- Yes
- Don't Know
- Prefer not to Answer

If yes, please explain the situation If yes, please explain_____

41. In the past 12 months, did you ever need HIV medical care but could not get it? (*check one*)

- Yes
- No
- Does not apply

42. For 2021 and beyond, how would you like to get your medical care for HIV? (**One visit per year must be in person.**)

- In person only
- Telehealth
- Either is OK with me
- Don't Know

43. If you want **in person only and not telehealth**, what are the reasons? (Check all that apply)

- I like face to face with my provider
- I feel I get better treatment in person
- I feel the quality in telehealth is not as good as an in person visit
- I feel there is more confidentiality in person
- I do not have internet
- I have internet but it keeps disconnecting
- It is too complicated to use telehealth
- I do not have a smart phone, tablet, or computer with video
- I do not know how to use the telehealth "apps"
- I do not feel comfortable using the telehealth "apps"
- I have no privacy where I live to conduct a medical visit by telehealth
- Other (please specify)_____

44. If you want **telehealth in addition to the annual in person visit**, what are the reasons? (Check all that apply.)

- I like convenience
- I do not have to deal with transportation issues
- My health is good
- I do not need many office visits
- I feel quality of treatment by telehealth is good
- My provider can take time with me
- I am comfortable with telehealth confidentiality
- I have privacy for telehealth visit
- I have internet
- I have a smart phone, tablet, or computer with video
- I feel comfortable using the telehealth "apps"
- Telehealth is safe from COVID
- Other (please specify)_____

45. Do you have an HIV case manager? (*check one*)

- Yes
- No
- Don't know
- Does not apply

46. Are you satisfied with your HIV case management services? (*check one*)
- Yes, please explain:
-
- No, please explain:
-
- Don't know
- Does not apply
47. Have you ever heard of U=U (undetectable = untransmittable)?
- Yes
- No
- Don't know
48. Have you ever heard of PrEP (Pre-exposure prophylaxis)?
- Yes
- No
- Don't know
49. Have you ever heard of PEP (Post-exposure prophylaxis)?
- Yes
- No
- Don't know
50. Is your sexual partner/s on PrEP (taking HIV meds to prevent HIV)? (*check all that apply*)
- I am not sexually active
- My partner/s is on PrEP
- My partner/s is not on PrEP
- My partner/s is HIV+ and undetectable
- My partner/s is HIV+ and has a detectable viral load
- My partner/s is HIV+ but I don't know their viral load
- My partner/s is HIV+ and not on HIV meds
- Don't know
- Does not apply
- Another option not listed: (please specify):
-

51. 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

52. 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

53. In the past 12 months, if you couldn't get HIV services you needed, what are the reasons? (*please check all that apply*)
- I got the services I needed
- Can't afford them because of co-pays
- Don't know where to go
- I had difficulty with access due to COVID-19
- 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*):
-

54. Since your HIV diagnosis, have you served a prison/jail sentence for more than 24 hours or been held in detention for another reason? (*check one*)
- Yes
- No (*skip to #56*)

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

56. Please review the list of services below and put an "X" in column (1) if you have **never personally needed** the service, (2) if you **ever personally needed the service and were able to receive it** (3) if you **ever personally needed but did not get the service** for any reason and (4) if you **never heard of the service**.

	(1) if you have never personally needed the service	(2) if you ever personally needed the service and were able to receive it	(3) if you ever personally needed but did not get the service for any reason	(4) if you never heard of the service
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				

57. Did you experience problems getting the services in #56? (*check one*)

- Yes
- No
- Not applicable

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

SECTION 5: *The remaining questions are for everyone. They are about your health insurance and health conditions you may have.*

58. 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:

59. Has your insurance status changed **since February 2020?** *(check one)*

- Yes (please explain):

- No
- Don't know

60. How do you pay for medications? *(check all that apply)*

- SPBP or ADDP (ADAP)
- 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):

61. Do you have dental insurance? *(check one)*

- Yes
- No
- Don't know

62. 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

63. 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

64. Has a doctor ever told you that you have Hepatitis? *(check all that apply)*

- Yes, and I have been treated/cured for Hepatitis C
- Yes, and I have not been treated for Hepatitis C
- Yes, Hepatitis A
- Yes, Hepatitis B
- No
- 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.

65. Is there a place you usually go for dental care? *(check one)*
- Yes
 - No
 - Does not apply
66. 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 I did not get the mental health care I needed
 - Yes, but I did not get it because the wait time was too long
 - Yes, but I stopped because I did not like/did not relate to my therapist/counselor
 - No, I did not need mental health care
67. In the last 12 months, did you need substance use or alcohol treatment services? *(check one)*
- Yes, and I got the substance use or alcohol treatment I needed
 - Yes, and I did not get the substance use or alcohol treatment services I needed
 - No, I did not need substance use or alcohol treatment services
68. In the last 12 months, has your medical provider or case manager 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 a colorectal cancer screening
 - Information on a mammogram
 - Information on HIV counseling for pregnancy
 - 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
 - Information about PEP (taking HIV meds after exposure to prevent HIV) for you or your partner/s
 - None of the above
 - Does not apply

69. Have you ever requested PrEP from a provider but were unable to receive it?
- Yes
 - No
 - Don't know
- If yes, please explain the situation If yes, please explain _____

70. 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
 - If yes, which language do you speak? *(please specify)*: _____

71. **Before** February 2020, have you not gotten medical care because you couldn't afford a co-pay or deductible? *(check one)*
- Yes
 - No
 - Does not apply

72. **After** February 2020, have you not gotten medical care because you couldn't afford a co-pay or deductible? *(check one)*
- Yes
 - No
 - Does not apply

73. 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 4 questions are about gynecological care. Skip to #78 if you do not need these services.

74. 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

75. In the last 12 months, has your primary medical provider offered you a mammogram (to check for tumors or lumps in breast tissue)? *(check one)*
- Yes
 - No
 - Don't know
 - Does not apply
76. Do you get gynecological (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):* _____
77. 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

