# **Ohio Integrated HIV Needs Assessment**

Ryan White Part A Cleveland Transitional Grant Area

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Prepared for the Ohio Department of Health by Ohio University's Voinovich School of Leadership and Public Affairs



Department of Health



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# Introduction

The Cleveland Transitional Grant Area (TGA) includes six northeastern Ohio counties: Ashtabula, Cuyahoga, Geauga, Lake, Lorain, and Medina. This group of counties has been designated by the U.S. Health Resources and Services Administration as a Ryan White Part A Transitional Grant Area (TGA), based on its population size and the severity of the impact of the HIV epidemic on the region. This report provides the results of a needs assessment carried out for the region from 2017 to 2020 as part of the statewide Ohio Integrated HIV Needs Assessment. Key findings from the needs assessment are listed in the following figure.



Map 1. The Ryan White Part A Cleveland TGA includes Ashtabula, Cuyahoga, Geauga, Lake, Lorain, and Medina counties.

#### Figure 1. Key Findings from Cleveland Part A TGA Needs Assessment



**PREVENTION**: Compared to other regions, the Cleveland Part A TGA (Region 3) has the lowest percentage of individuals who are at high risk for contracting HIV (PHR) who report that they worry about the risk of getting HIV. The most frequently reported risk factor was having sex while drunk or high. Health care professionals are an important source of sexual health information in the region, and knowledge related to HIV transmission among PHR in the region generally compares favorably to PHR in the state as a whole. Use of pre-exposure prophylaxis (PEP) and post-exposure prophylaxis (PEP), as well as interest in these preventative medications, is a bit lower in the region when compared to the whole state.



**DIAGNOSIS**: A higher percentage of PHR report that they have been tested for HIV when compared to the whole state. Testing rates are higher among PHR who are older, Black, and/or who identify as non-binary. Public health clinics and doctors' offices are the most common testing sites for PHR in the region, and mobile testing sites appear to be used in the Cleveland TGA more often than in other parts of the state. The main reason provided by those who have not been tested is that they do not believe themselves to be at risk.



**LINKAGE TO CARE:** Higher percentages of PHR in the Cleveland Part A TGA report unmet needs, which are associated with reduced incidence of linkage to care, when compared to other regions. The most frequently unmet basic need for PHR in the region is the need for utilities such as water, gas, or electricity. Lower percentages of PHR in the region report that they have access to trusted substance use services, compared to PHR in the state as a whole.



**RETENTION IN CARE:** Eight percent of surveyed people who are living with HIV or AIDS (PLWHA) were out of care at the time of the survey. Most of the out-of-care respondents identify as Black. More than in other regions, out-of-care PLWHA reported that a main reason for being out of care is that they do not feel sick and they do not like thinking about having HIV. Out-of-care respondents reported a need for support from friends and family more often than out-of-care PLWHA statewide. Many of those PLWHA in the region who are currently in care report a need for mental health services and social support services.



**ANTIRETROVIRAL THERAPY (ART) INITIATION:** One percent of PLWHA in the region report that they have not been prescribed HIV medication, and 2% report that they are not taking the prescribed medication for their HIV. When asked why they are not taking medication, these respondents most frequently reported that they feel healthy.



**VIRAL SUPPRESSION:** Eighty-eight percent of PLWHA in the region report that they have had viral load testing completed in the 12 months leading up to the survey. Eighty percent of those individuals report that they are virally suppressed. Twenty-nine percent of PLWHA taking HIV medications reported that they had missed a dose in the week before taking the survey. The most frequent reason provided for missing a dose was simply forgetting.

# About the Needs Assessment

In 2017, the Ohio Department of Health (ODH) contracted with Ohio University's Voinovich School of Leadership and Public Affairs (OU) to conduct the 2017-2020 Ohio HIV Needs Assessment (2017-2020 Integrated HIV Needs Assessment). The stated goal of the needs assessment was to "identify the service gaps and access barriers, among individuals at each stage of the HIV Care Continuum, and the variables that impact an individual's movement into and out of each stage of the continuum," (State of Ohio, 2017). Findings from the needs assessment are meant to support statewide efforts to reduce risk behaviors among persons who are at higher risk for contracting HIV (PHR), to encourage HIV testing among those at risk, to support linkage to care and retention in care of people who are living with HIV (PLWHA), and to promote viral suppression among PLWHA.

In addition to this statewide focus, researchers were tasked with preparing region-specific needs assessment reports for all Ryan White regions across the state, including the Cleveland Part A region. The needs assessment was guided by a needs assessment steering committee that included representatives from the Cleveland Part A TGA, the Columbus Part A TGA, and ODH.

For the Cleveland Part A TGA, the first phase of data collection for the needs assessment took place from June to August of 2018, during which time researchers from OU conducted seven focus groups and 18 interviews with a total of 111 PLWHA and five PHR. Findings from this phase of the multi-year research effort can be found in the *Integrated HIV Needs* Assessment *Year 1 Region 3 Report*, which is available from ODH's website at 2017-2020 Integrated HIV Needs Assessment. The second phase of data collection took place from February to June 2020 and consisted of a survey that was completed by 204 PLWHA and 173 PHR.

**377** individuals from the Cleveland Part A TGA responded to the survey.

### **Data Comparisons Included in This Report**

There are three types of comparison used in the regional reports. First, survey data collected in the Cleveland Part A TGA are compared to survey data collected in the whole State of Ohio (Figure 2).



# The wider **light gray bar** indicates the percentage of respondents across the whole **state** who agreed with the statement.

Second, the Cleveland Part A TGA's survey responses are compared across all Ryan White regions throughout Ohio, to demonstrate any meaningful differences across regions. The columns in the figure on the right present the different percentages for each region. Note that the Cleveland Part A TGA is designated as Region 3.

The map on this page depicts the Ryan White HIV Prevention and Care regions for the State of Ohio. In order to generate sufficient sample sizes needed to protect participants' privacy and conduct more robust

#### Figure 3. Sample Regional Comparison Figure

Compared to other regions, the Cleveland Part A TGA (Region 3) has the lowest percentage of PHR who worry about the risk of getting HIV.



Region 1 Regions 2 Region 3 Regions 4 Regions 6 Region 8 Region 9 Region 11 & 10 & 5 & 7

Data for Regions 3 and 11 are weighted by age and race.

analyses, some of the Ryan White regions have been combined for reporting purposes.

#### Map 2. Ryan White Regions Used for Regional Comparisons

The Cleveland Part A TGA is Region 3



Finally, the responses of different *subpopulations within the region* are compared, to identify whether there are patterns among participants who differ by race, gender identification, sexual orientation, income, etc. (Figure 4). For the small number of cases in which the data support a Chi-square test for independence, researchers conducted the analysis to determine if the difference between groups was statistically significant.



#### Figure 4. Sample Subpopulation Comparison Figure

Information about individuals who are identified as Black Men Who Have Sex with Men (Black MSM), which is a population of special interest because of the higher rates of HIV among this group, is included in the text and in call-out boxes throughout the report. This subpopulation is not represented in the percentage-based figures of this report due to the small sample sizes.

In addition to basic bar charts, this report also uses stacked bar charts. This chart type is primarily used to provide information about participants' needs for services. As with other figures, the horizonal axes in these figures indicate the *number* of respondents answering a question, and the labels on the bars indicate the *percentage* of respondents providing specific answers. Visualizing the responses in stacked bar charts allows for comparison across categories (for example, the percentage of respondents with unmet needs can be compared across different service areas) and comparison within categories (for example, the relative proportion of met and unmet needs can be assessed within each individual service area).

#### Sample Stacked Bar Figure

Needed and did not receive service/support
Did not need service /support
Peer navigation
9% 20% 72%
4%
An appointment with a doctor, nurse, or other provider as a part of my medical treatment

The total need for a service can be calculated by adding the **unmet need** to the **met need**. In this example, a larger percent of respondents reported a need for an appointment (71% of respondents) compared to the percentage of respondents reporting a need for peer navigation (29% of respondents). However, there is a larger unmet need for peer navigation (9% of respondents) compared to the unmet need for an appointment (4% of respondents).

# **Data Weighting**

Respondents were not randomly selected for the survey. Specific minimum survey response targets were set for regions and subpopulations to guide recruitment and to create as representative a sample as possible. However, in order to include as many PLWHA and PHR as possible, researchers did not cap participants once response quotas were met. Some hard-to-reach populations were also under-sampled. As a result, some subpopulations are overrepresented in the data while other subpopulations are underrepresented. To correct for this imbalance, researchers used poststratification weighting. Specifically, researchers weighted PHR responses by race and age, using population estimates from the National Center for Health Statistics. Researchers weighted the PLWHA responses by age and gender, using known population counts provided by ODH. The exception to this occurs when survey responses are broken down by subpopulations, in which case unweighted data are used because the data from different subpopulations are not being aggregated. For more information about this process, see Appendix 3 to this report.

# Survey Design, Recruitment, and Analysis

Information about the methods used to design the survey instrument, recruit participants, define key populations, and analyze survey data is available in the appendices to this report, as is a discussion of the strength and limitations of this survey research.

# **Structure of This Report**

This report begins with a description of select demographic characteristics of the individuals from the Cleveland Part A TGA who participated in the survey. After that, survey results related to the prevention of HIV transmission are provided in the section titled *Prevention*, and the remaining results of the survey are broken down by the stages of the HIV Care Continuum: *Diagnosis, Linkage to Care, Retention in Care, Antiretroviral Therapy (ART) Initiation,* and *Viral Suppression*. The survey instruments, survey frequencies, and explanations of data collection and analysis are included in appendices to the report.

# **Participant Profile**

This section provides an overview of select demographic characteristics of PHR and PLWHA in the Cleveland Part A TGA who responded to the survey.

# **PHR Sample**

**173** individuals who are at high risk for contracting HIV (PHR) responded to the prevention survey. The figure below summarizes select demographic characteristics of the individuals completing the survey. Data in the figure have not been weighted. Note that during survey analysis, data were weighted by race and age to make sure that neither of these subcategories was overrepresented.

#### Figure 5. Cleveland Part A TGA PHR Sample

Age	Over half of the individuals in the PHR sample (51%) are 18–29 years old. Thirty-five percent of respondents are in the 30–49 year old category, and 15% are 50 years and older.
Gender identity	A bit more than half (51%) of PHR respondents identify as female, 43% identify as male, 5% identify as non-binary, and 1% prefer not to say. Survey data were weighted by gender in order to reflect the actual incidence rates of HIV among those who identify as male and female. Population estimates are not available for those who identify as non-binary.
Sexual orientation	Members of the PHR sample for the Cleveland Part A region are largely heterosexual (70% of the sample identified as heterosexual or straight). Thirteen percent of respondents identify as bisexual, 3% as lesbian, and 2% as gay men. In addition, 9% of respondents preferred not to say, and 4% preferred to self-describe.
Race and ethnicity	Over half (63%) of PHR respondents in the Cleveland Part A region are white, 30% are Black, and 8% are of different race or multiple races. Six percent of the sample are Hispanic or Latinx.

Income	Over half (57%) of PHR respondents report annual incomes of less than \$15,000. Almost a quarter (24%) have annual incomes of \$15,000 to \$34,999. Nine percent report incomes of \$35,000 to \$49,999, 6% report incomes of \$50,000 to \$74,999, and 4% report incomes of \$75,000 and higher.		
Populations of special interest	Based on respondents' answers about their gender identity, sex assigned at birth, and sexual orientation, researchers identified those respondents who are identified as transgender and those who are identified as Black men who have sex with men (Black MSM). Four percent of the PHR sample are identified as transgender individuals, and the same percentage are identified as Black MSM. For more information about how these two groups were defined, see Appendix 3.		

# **PLWHA Sample**

**204** PLWHA in the Cleveland Part A region completed the survey. The figure below summarizes select demographic characteristics of the individuals completing the survey. Data in the table have not been weighted.

Age	Half of the survey respondents are 50 years and older. Forty-two percent are age 30–49, and 9% are 18–29 years old.
Gender identity	Sixty-seven percent of PLWHA respondents in the region identify as male, 27% as female, 6% as non-binary, and 0.5% prefer not to say.
Sexual orientation	Thirty-nine percent of PLWHA respondents are gay (men), while 16% are bisexual, 34% are heterosexual/straight, 6% prefer to self-describe, 4% prefer not to say, and 1% are lesbian/gay woman.
Race and ethnicity	Over half of the PLWHA sample for the region (58%) identify as Black. Thirty- seven percent are white, and 5% of PLWHA respondents report different races or multiple races. Thirteen percent of PLWHA respondents report that they are Hispanic or Latinx.

#### Figure 6. Cleveland Part A TGA PLWHA Sample

Income	Half (50%) of PLWHA respondents report annual incomes of less than \$15,000. A third (33%) report incomes of \$15,000 to \$34,999, while 8% report their annual incomes as \$35,000 to \$49,999, 7% report their annual incomes as \$50,000 to \$74,999, and 1.5% report their annual incomes as \$75,000 and higher.	
Payment for HIV medical care	51% use the Ryan White program to pay for their medical care.	
Years since diagnosis	Most respondents have been diagnosed in the last 20 years, with 17% diagnosed in the last five years and an additional 17% diagnosed in the last 6-10 years.	
Retention in care	Eight percent of respondents are not currently in care for their HIV.	
Medication adherence	92% of respondents are taking medication.	
Viral suppression	86% of respondents report that they have had a viral load test in the last 12 months. Of these individuals, 74% report that their viral load is less than 200 copies per milliliter, meaning that 59% of all PLWHA respondents report that they are virally suppressed.	
Populations of special interest	Twenty-eight percent of the PLWHA respondents are identified as Black MSM. Three percent of PLWHA respondents are identified as transgender.	

# **Key Findings**

# × Prevention

The literature on HIV prevention identifies a variety of factors that influence an individual's perception of their risk for HIV, their risk behaviors, and their overall likelihood for contracting HIV. These factors include health literacy, risk behaviors, risk perceptions, substance use, mental health, unmet needs, and stigma (Aaron et al., 2018; Franks et al., 2018; Krueger et al., 2020). This section discusses health literacy, risk factors, and risk perceptions in detail. Substance use, mental health, unmet needs, and stigma are discussed in more detail in the Linkage to Care section of this report. Data for this section are taken from the PHR survey.

## **Risk Factors**

The main risk factors reported by PHR respondents in the Cleveland Part A TGA are related to sexual activity, as shown in Figure 7. The most frequently reported risk factor was having sex while drunk or high. When compared to other regions, the Cleveland Part A region is the locality with the highest percentages of PHR reporting that they have had an STI and that they have been incarcerated.

Figure 7.	<b>Risk Factors</b>	Among PHR
		,



Risk Factors (continued)	% Agreeing*
Have you experienced sex without your consent?	<b>21%</b> 19%
Have you had a sexually transmitted infection (STI/STD) such as syphilis, gonorrhea, or chlamydia?	<b>19%</b> 16%
Have your sexual partner(s) injected street drugs or street hormones?	15%
Have you had sex with someone who asked you to trust them about their HIV status?	<b>10%</b> 16%
Have you or your sexual partner(s) shared needles or works with another person?	<b>6%</b> 10%
Have you had sex with a person who is living with HIV?	<b>4%</b> 4%

\* Data have been weighted by age and race. *Region 3*=170 respondents, *State*=661 respondents

When answers to these questions are broken down by subpopulation, some differences emerge between respondents of different demographic groups.<sup>1</sup>

- Age: Overall risk tends to be higher for respondents who are 30–49 years old, as they report risk factors more frequently than all other age groups (with the exception of sex without consent, which is reported by equal percentages of 30–49-year-olds and those 50 and older). Figure 8 presents responses to these items broken out by age groups.
- *Race:* Higher percentages of respondents who identify as Black report that they have had a sexually transmitted infection, that they or their partners have shared needles or works with another person, and that they have had sex with someone who asked them to trust them about their HIV status. Higher percentages of white respondents report that they have had sex with someone because they or their partner were drunk or high, and that they have had sex with someone because they are afraid of losing them. Higher percentages of respondents who are of a different race or multiple races report that they have had sex to feel good when

<sup>&</sup>lt;sup>1</sup> Chi-square tests for independence cannot be performed for these particular survey items because the distribution of responses does not meet minimum cell count requirements.

lonely or depressed, that they have been incarcerated, that they have experienced sex without their consent, and that they have had sex with someone who is living with HIV. Figure 9 presents responses to these items broken out by race.

- Black MSM: The two most commonly selected risk factors for individuals who are identified as Black MSM are having sex when they or their partner are drunk or high, and having a partner who injects drugs or hormones. Both of these items were selected by half of the six respondents identified as Black MSM in the Cleveland Part A sample.
- *Transgender*: The most frequently selected risk factor for individuals who are identified as transgender are having sex while they or their partner are drunk or high. This item was selected by four of the six respondents identified as transgender PHR in the Cleveland Part A sample.

#### Figure 8. Risk Factors by Age

Higher percentages of 30–49-year-olds reported risk factors, compared to respondents in other age groups.





#### Figure 9. Risk Factors by Race

# **Risk Perceptions**

Eighty percent of PHR in the region (80%) report that they know how HIV is transmitted, which is a slightly lower percentage than seen in the statewide sample. The biggest difference between responses from the Cleveland Part A TGA and the state are seen for the item "I worry about the possibility of getting HIV," which 21% of respondents in the region agreed with, compared to 32% of respondents statewide. This is also the item for which there is the greatest difference between the Cleveland TGA and other individual regions across the state (Figures 10 and 11).

#### Figure 10. Worry About HIV Across Regions

Compared to other regions, the Cleveland Part A TGA (Region 3) has the lowest percentage of PHR who worry about the risk of getting HIV.



Region 1 Regions 2 Region 3 Regions 4 Regions 6 Region 8 Region 9 Region 11 & 10 & 5 & 7

Data for Regions 3 and 11 are weighted by age and race.

#### Figure 11. Risk Perceptions Among PHR

Risk Perception	% Agreeing
I know how HIV is transmitted	Region 3: 80% State : 85%
HIV and AIDS can be taken care of pretty easily with medication.	<b>26%</b> 31%
I am at risk for getting HIV.	<b>24%</b> 29%
I worry about the possibility of getting HIV.	<b>21%</b> <i>32%</i>
If I get HIV or am diagnosed with AIDS, it is not a big problem. I could handle it.	14% 15%

\* Data have been weighted by age and race. *Region* 3= 172 respondents; State=664 respondents

When answers to these questions are broken down by demographic groups, some differences emerge between respondents from different groups.

Age: Chi-square tests for independence were possible for age groups for all risk perception items except "I know how HIV is transmitted."<sup>2</sup> The only item with a statistically significant relationship with age was "If I get or am diagnosed with HIV or AIDS, it is not a big problem. I could handle it."<sup>3</sup> For that item, a higher percentage (22%) of respondents age 30–49 years old agreed that HIV or AIDS would not be a big deal, compared to the percentage of respondents in the 18–29-year-old age category (13%) and the 50 years and older category (20%).

In the Cleveland Part A TGA, as in the state, a higher percentage of 30–49- yearold respondents agreed that a diagnosis of HIV or AIDS would be "not a big problem," compared to respondents of other ages.

*Race:* A higher percentage of respondents who are Black

(33%) report that being diagnosed with HIV or AIDS would not be a big problem, when compared to 9% of respondents who are white and 15% of respondents of other or multiple races who gave the same answer. More details about differences among respondents of different races are included in the figure below.

*Gender:* Higher percentages of PHR who are non-binary report that being diagnosed with HIV or AIDS would not be a big problem. More information about differences across PHR with different gender identities is provided in the figure below.

*Black MSM:* Three of the six respondents who are identified as Black MSM responding to the survey agreed that they were at risk for getting HIV, and the remainder chose the neutral response; none disagreed with the statement "I am at risk for getting HIV."

*Transgender:* Half of the six respondents identified as transgender reported that they know how HIV is transmitted, compared to 80% of PHR in the region. Half indicated that they are at risk for HIV. Two-thirds reported that an HIV diagnosis would not be a big problem. Half reported that HIV and AIDS are easily taken care of with medication.

<sup>&</sup>lt;sup>2</sup> Chi-square tests for association were run on *unweighted* data.

 $<sup>{}^{3}\</sup>chi^{2}(4, N = 172) = 10.881, p = .028$ 



#### Figure 12. Risk Perception by Race and Gender

### **Negotiating Safe Sexual Experiences**

Most statewide survey respondents reported that they are comfortable buying condoms and discussing condom use with their partners (Figure 13), and this pattern holds for the Cleveland Part A TGA as well.

#### Figure 13. Negotiating Safe Sexual Experiences, PHR



Survey Item (continued)	% Selecting Yes*
I feel comfortable talking with my partner about when, when not, and how I want to have sex	<b>79%</b> 83%
l feel comfortable asking my partners about their sexual history	<b>73%</b>
l feel pausing to put on a condom ruins the sexual mood	<b>16%</b> 22%
I feel comfortable having sex with someone who is HIV positive and is undetectable	<b>8%</b> 12%

\* Data have been weighted by age and race. *Region* 3=170 respondents, *State*= 659 respondents

When answers to these questions are broken down by demographic groups, some differences emerge between respondents from different groups.

Age: Lower percentages of individuals age 50 years and older (64%) agree that they are comfortable talking about how and when to have sex, compared to respondents who are 18–29 years old (81%) and 30–49 years old (81%).

Four of the six individuals who are identified as Black MSM (67%) agreed that pausing for a condom ruins the sexual mood, compared to 16% of all Cleveland Part A respondents.

*Black MSM*: Five of the six individuals who are identified as Black MSM (83%) reported that they are not comfortable

around someone who is living with HIV, compared to 16% of all Cleveland Part A respondents. In contrast, four of the six (67%) reported that they are comfortable having sex with someone if they are HIV-positive and undetectable, compared to 8% of all respondents in the region. Finally, as indicated in the callout box, a higher percentage of the small sample of those identified as Black MSM also reported that pausing for a condom ruins the sexual mood.

*Transgender:* Five out of six respondents identified as transgender report that they are comfortable asking about their partner's sexual history. Half of respondents who are identified as trangender report that they are comfortable buying condoms, discussing condom use, and stopping their partner if their partner starts to do something unsafe. A third of those identifed as transgender PHR report that they are comfortable talking about how and when to have sex and that they are comfortable having sex with a person who has HIV and is virally suppressed. One-third also report agreement with the statement that pausing for condom usage ruins the sexual mood; none of the respondents who are identifed as transgender disagrees with this statement.

## **HIV-Related Knowledge**

As indicated previously in Figure 11, 80% of PHR in the region report that they know how HIV is transmitted. The main source PHR cite for this type of information is health care professionals, and PHR in the region generally demonstrated a higher level of HIV-transmission knowledge than PHR statewide (Figure 14).

#### Information Sources

Health care professionals are a main source of sexual-health-related information in Region 3; PHR in the region turn to providers for this type of information more frequently than PHR as a whole across the state. Fewer Region 3 PHR turn to the internet compared to all respondents statewide, though the internet is still the second most frequently selected information source in the region. The most frequently selected information source selected by individuals who are identified as Black MSM is the internet.

The most frequently selected information source selected by individuals who are identified as transgender is health care professionals.



#### Figure 14. Sources of Sexual Health Information for PHR

Information Sources (continued)	% Reporting*	
Religious advisor	6% <i>3%</i>	

\* Data for this figure have been weighted by age and race. *Region* 3=172 respondents; *State*=664 respondents

The most frequent write-in response in the "other" category is schools.

#### Knowledge Related to HIV Transmission

When asked a series of questions designed to gauge HIV-related knowledge (Figure 15), PHR in the Cleveland Part A TGA provided correct answers to most questions *as often or more often than PHR statewide*. In particular PHR in the region demonstrated a higher level of awareness of the potential to contract HIV through oral sex and the fact that using Vaseline or baby oil in conjunction with condoms does *not* reduce the risk of HIV transmission. PHR in the Cleveland Part A region also demonstrated slightly higher levels of awareness of the fact that a person living with HIV whose viral load is undetectable cannot transmit HIV.

HIV Knowledge Items	% Selecting Yes*
A person can get HIV from sharing needles and/or works (equipment)(Answer: True)	Part A: State: 85% 89%
Showering, or washing one's genitals/private parts, after sex keeps a person from getting HIV (Answer: False)	88% 82%
Using Vaseline or baby oil with condoms lowers the chance of getting HIV (Answer: False)	87% 73%
Pulling out the penis before climaxing/cumming keeps your partner from getting HIV during sex (Answer: False)	83% 86%
People who have been infected with HIV will quickly show serious signs of being infected (Answer: False)	83% 79%
A person can't get HIV if they are the insertive (top) partner (Answer: False)	82% 80%
Coughing and sneezing spreads HIV (Answer: False)	81% 78 <i>%</i>

#### Figure 15. Self-Reported Knowledge of HIV Transmission among PHR

HIV Knowledge Items (continued)	% Selecting Yes*
A person can get HIV from oral sex (Answer: True)	65%
A person can get HIV by sharing a glass of water with someone who has HIV (Answer: False)	<b>73%</b> 74%
There is a vaccine that can stop people from getting HIV (Answer: False)	55% 53%
A natural skin condom works better against HIV than does a latex condom (Answer: False)	<b>44%</b> 45%
There is an internal condom that can help decrease chances of getting HIV (Answer: True)	<b>33%</b> 44%
A person can't get HIV if their partner is HIV positive and virally suppressed (undetectable) (Answer: True)	<b>25%</b> 20%

\* Data have been weighted by age and race. *Region* 3= 172 respondents, *State* = 664 respondents

When answers to these questions are broken down by demographic groups, some differences emerge between respondents in different demographic categories.

Age: Compared to respondents of other ages, a *lower* percentage of 18–29-year-old respondents (24%) could not correctly identify the statement "Showering, or washing one's genitals/private parts, after sex keeps a person from getting HIV" as false. Twelve percent of 30–49-year-olds and the same percentage of those 50 years and older responded to this item incorrectly. On the other hand, a *higher* percentage of 18–29-year-olds (39%) knew that an internal condom can reduce the risk of HIV, compared to 32% of 30–49-year-olds and 20% of those age 50 and older. This difference is statistically significant.<sup>4</sup> Although significance tests were not possible for the item "A person can get HIV from oral sex," there were notable differences among the responses from different age groups. Eighty-eight percent of those 50 years and older correctly reported that this statement is true, which was a larger percentage than the 70% of 30–49-year-olds and 59% of 18–29-year-olds who also identified the statement as true.

*Black MSM*: Respondents who are identified as Black MSM once again demonstrate a higher level of awareness of U=U, with half of the six respondents identifying the statement, "A person can't get

 $<sup>^{4}\</sup>chi^{2}(4, N = 172) = 13.174, p = .010$ 

HIV if their partner is HIV positive and virally suppressed (undetectable)" as true. By comparison, a quarter of all respondents in the region identified this statement as true.

*Transgender:* Respondents who are identified as transgender also demonstrate a high level of awareness of U=U, with two-thirds of the six respondents identified as transgender correctly identifying the statement, "A person can't get HIV if their partner is HIV positive and virally suppressed (undetectable)" as true.

# PrEP and PEP

As Figure 16 indicates, a little more than a third of PHR in the region have heard of PrEP, and 3% are currently taking the preventative medication. Eighteen percent of PHR in the region have heard of PEP, and 4% have taken it. These percentages are lower than the percentages for the whole state. Levels of interest in PEP and PrEP among PHR in the Cleveland Part A region are also lower than statewide levels of interest. **PrEP** (pre-exposure prophylaxis) is a daily medication that can significantly reduce the risk of acquiring HIV.

**PEP** (post-exposure prophylaxis) is a medication taken after a suspected exposure to HIV, which reduces the risk of acquiring HIV.



#### Figure 16. Awareness of PrEP and PEP among PHR

\* Data have been weighted by age and race. "Have you heard of PrEP?" *Region 3*= 164 respondents, *State*= 645 respondents; "Do you currently take PrEP?" *Region 3* =72 respondents, *State* = 288 respondents; "Would you be interested in PrEP?" *Region 3*= 160 respondents, *State*= 619 respondents; "Have you heard of PEP?" *Region 3*=164

respondents, *State*=645 respondents; "Have you ever used PEP?" *Region 3*= 38 respondents, *State*= 197 respondents; "Would you be interested in PEP?" *Region 3*= 164 respondents, *State*= 644 respondents

When answers to these questions are broken down by demographic groups, some differences emerge between respondents in different demographic categories.

*Age:* Respondents in the 50-years-and-older age category generally reported lower rates of awareness of PrEP and PEP. There is a statistically significant relationship between age and interest in PEP: 46% of those 30–49 years old are interested in PEP, compared to 56% of those 50 years and older and 69% of those age 18–29.<sup>5</sup>

*Black MSM*: Half of respondents who are identified as Black MSM reported that they have heard of PrEP, though only one individual reported that they are currently taking PrEP. Only one individual who is not taking PrEP indicated that they would be interested in taking PrEP. Two individuals indicated interested in PEP, and the same number had heard of PEP before the survey.

*Transgender:* Half of the six respondents who are identified as transgender reported that they have heard of PrEP, and one respondent identified as transgender is taking PrEP. Only one of the respondents who is not taking PrEP would be interested in taking the medication. Only one respondent identified as transgender had heard of PEP, and two would be interested in taking PEP if they thought they had been exposed to HIV.

 $<sup>^{5}\</sup>chi^{2}$  (4, N = 164) = 20.289, p <.001

# Diagnosis

HIV testing is a crucial component of HIV prevention and care efforts. In the Cleveland Part A region, a higher percentage of PHR report that they have been tested for HIV when compared to the whole state. Testing rates are higher among PHR who are older, Black, and/or who identify as non-binary. Public health clinics and doctors' offices are the most common testing sites for PHR in the region, and mobile testing sites appear to be used in the Cleveland TGA more often than in other parts of the state. The main reason for not testing provided by respondents is that they do not believe themselves to be at risk. Data for this section are taken from the PHR survey.

# **Testing Behaviors**

Three-quarters of PHR respondents in the Cleveland Part A TGA have been tested for HIV (Figure 17). This is a larger percentage than the 50% of statewide respondents who report having been tested.

A higher percentage of Cleveland Part A survey respondents have been tested for HIV, compared to respondents statewide.

75%

50%

#### Figure 17. HIV Testing Experiences among PHR

Have you ever been tested for HIV?

\* Data have been weighted by age and race. *Region* 3 = 172 respondents, *State*= 664 respondents

When answers to these questions are broken down by demographic groups, some differences emerge between respondents in different demographic categories. More details are provided in Figure 18.

*Age:* A much smaller percentage of 18–29-year-olds has been tested for HIV compared to respondents who are older.

*Race:* Higher percentages of PHR who are Black report that they have been tested for HIV compared to other respondents.

*Income:* Higher percentages of individuals reporting annual incomes between \$15,000 and \$75,000 reported that they have been tested, compared to individuals with higher and lower incomes.

*Gender:* Respondents who are non-binary report much higher rates of testing compared to participants identifying as male and those identifying as female.

*Sexual orientation:* Smaller percentages of heterosexual and bisexual participants reported having been tested compared to those who are gay, are lesbian, or describe their sexual orientation in a different way.

*Black MSM:* Five of the six (83%) individuals who are identified as Black MSM have been tested for HIV.

*Transgender:* All of the six PHR who are identified as transgender have been tested for HIV. These individuals were tested at clinics, mobile testing sites, a doctor's office, and a special event.

Figure 18. HIV Testing by Age, Income, Race, Sexual Orientation, and Gender Identity



Lower percentages of respondents who are bisexual and heterosexual report having been tested for HIV.



A higher percentage of PHR who are Black report having been tested for HIV.



A higher percentage of respondents who are non-binary report having been tested.



Higher percentages of PHR with incomes between \$15k and \$50k have been tested.



## **Reasons for HIV Testing**

When asked why they had been tested for HIV, the most frequently selected reason was a desire to know their status, followed by having been offered a test (Figure 19). These were also the most frequently selected reasons in the statewide sample.

Figure 19. Reasons for HIV Testing among PHR

Testing Reasons	% Reporting
l wanted to know my status	Cleveland Part A: 53% 66%
l was offered a test	40% 39%
l thought l might be at risk	<b>26%</b> 21%
I have shared needles/works	15% 11%
l'm in a new relationship	14% 12%
Other	9% 9%
My partner asked me to be tested	<b>8%</b> 7%
I was tested as part of my PrEP care	<b>6%</b> 9%
I was diagnosed with an STI/STD	<b>6%</b> 7%
I had symptoms that made me or a health provider think I might have HIV	<b>5%</b> 1%
Someone I know was diagnosed with HIV	■ <b>3%</b> 4%
Don't know	<b>1%</b> 1%

\* Data have been weighted by age and race. Region 3=107 respondents, State= 323 respondents

#### **Testing Locations**

Those who responded that they had been tested for HIV were asked where they have been tested in the last 12 months, as shown in Figure 20. The top two most frequent responses, a clinic or private doctor's office, are the same as the top two testing locations reported by statewide respondents. The Cleveland Part A region, however, has a higher percentage of PHR who report having been tested via a street outreach program or at a mobile site compared to the state. A higher percentage of the region's respondents report having been tested in a correctional facility and at community events as well.

#### Figure 20. HIV Testing Sites Used by PHR



Category (continued)	% Reporting*	
During a hospital stay	3% 4%	
l took an at-home test	1% 0%	

\* Data have been weighted by age and race. *Region* 3=107 respondents, *State*= 323 respondents

#### Reasons for Not Being Tested

As shown in Figure 21, the main reason reported for *not* being tested in the Cleveland Part A TGA is "I don't think I'm at risk for HIV." Only very small percentages of participants reported they have not been tested because they don't know about or have access to a testing site, though a small number of participants wrote in responses that indicated a lack of accessibility.

#### Figure 21. Reasons for Not Being Tested for HIV among PHR

Reasons	% Reporting*
l don't think I'm at risk for HIV	<b>66%</b>
I'm not concerned about my HIV status	<b>8%</b> 27%
l don't have health insurance or can't afford an HIV test	<b>8%</b> 5%
My partner tested negative	<b>6%</b>
l've never been offered an HIV test	<b>5%</b> 19%
l don't want to be seen at a clinic	<b>3%</b> 5%
l don't know where to get tested	<b>2%</b> 10%
Other	<b>2%</b> 4%

Reasons (continued)	% Reporting*
There is no HIV testing site near me	<b>  1%</b> 3%
l don't like needles	<b>0%</b> 7%
I'm worried about the cost of treatment	<b>0%</b> 4%
l am afraid to find out whether I have HIV	<b>0%</b> 2%
My partner is on PrEP	<b>0%</b> 0%

\* Data have been weighted by age and race. *Region* 3 = 65 respondents; *State*=341 respondents

#### Facilitators of HIV Testing

When asked what would make them more likely to be tested for HIV, most respondents reported that an increase in their risk would prompt them to be tested. "If a girl I had sex with said she was HIV," "If I knew my partner wasn't faithful," and "If I had unprotected sex with someone whose sexual history I am not familiar with" are some of the write-in responses in this category. A smaller number of PHR reported that they would be more likely to be tested if their access to testing was improved. Responses of this type included, "Easier access, knowing where to go, and how much testing costs," "If it was more accessible," and "More available testing sites near where I live."



This section discusses the survey results that have implications for several of the factors associated with linkage to care (stigma, unmet needs, substance use, mental health) as identified in peer-reviewed literature on HIV care and the focus group findings from the previous phase of this needs assessment (Brewer et al., 2018; Giles et al., 2019; Herce et al., 2019; Monroe et al., 2019; Rebeiro et al., 2018). Data for this section are taken from both the PHR and the PLWHA survey. Figures are labeled to indicate which population's data they are reporting.

### Stigma

Stigma is associated with reduced rates of linkage to care. Sixteen percent of PHR in the Cleveland Part A TGA sample reported that they do not feel comfortable around someone with HIV (Figure 22). This was slightly less than the overall percentage for the state sample.

#### Figure 22. HIV-Related Stigma among PHR

Survey Item	% Agreeing
I do not feel comfortable around someone with HIV.	<b>16%</b> 23%

\* Data have been weighted by age and race. *Region 3* =170 respondents; State =659 respondents

When answers to this question are broken down by demographic groups, some differences emerge between respondents in different demographic categories.

*Gender:* Higher percentages of respondents who identify as male reported that they are not comfortable around someone with HIV. Over a third (34%) of those who identify as male reported this, compared to 19% of those who identify as female and 18% of those who identify as non-binary.

*Black MSM:* 83% of the individuals who are identified as Black MSM in the region indicated that they do not feel comfortable around someone with HIV.

*Transgender*: A third of the PHR who are identified as transgender report that they do not feel comfortable around someone with HIV.

### **Basic Needs**

Unmet needs for basic resources such as food, housing, and utilities are associated with decreased linkage to care. The percentage of PHR reporting unmet basic needs is higher than the statewide percentage for every item in the figure below. When the Cleveland Part A TGA is compared against the other Ryan White regions, PHR report the highest levels of unmet needs for all items in this graphic except for food. PLWHA report higher levels of unmet need for food compared to PWLHA statewide, but do not exceed state rates for the other types of needs in the figure.

Areas of Need	% PHR Agreeing*	%PLWHA Agreeing
Utilities such as water, gas, or electricity	Cleveland Pa State: 22% A: 38%	art 28%
Rent or mortgage	23%	<b>32%</b> 33%
Transportation	<b>34%</b> 20%	18% 22%
Food	<b>31%</b> 23%	<b>39%</b> 35%
Phone	<b>29%</b> 18%	<b>15%</b> 25%
Place to sleep	<b>25%</b> 14%	<b>13%</b> 17%
Child care	16% 7%	<b>4%</b> 9%

#### Figure 23. Unmet Basic Needs Among PHR and PLWHA in Last 30 or 90 Days

\*Data for this section have been weighted by age and race. The percentages listed are the combined percentage of respondents who answered "yes, in the last 30 days" or "yes, in the last 90 days". *PHR Region 3*= 164 respondents, *PHR State*= 643 respondents, *PLWHA Region 3*= 98 respondents, *PLWHA State* = 570 respondents

When answers to this question are broken down by demographic groups, some differences emerge between respondents in different demographic categories.

• *Black MSM*: Four of six of those PHR identified as Black MSM reported trouble paying for utilities and rent/mortgage in the last 30 or 90 days. Half report that they have been unable to obtain food, transportation, childcare, and a place to sleep in the same time period.

• *Transgender:* Half of the PHR who are identified as transgender reported that they have been unable to access transportation in the last 30 or 90 days, and a third reported that they have had trouble paying for food, utilities, rent or mortgage, a regular place to sleep, and a phone in the last 30 or 90 days.

### Substance Use

Substance use is associated with difficulties linking to care. In the Cleveland Part A TGA, a slightly lower percentage of PHR report that they have trusted resources for stopping substance use when compared to PHR statewide (Figure 24).

#### Figure 24. Trusted Resources for Stopping Substance Use Among PHR



There is a statistically significant association between age and responses to this question. A much lower percentage (24%) of those age 50 and older report that they have trusted resources for substance use treatment compared to PLWHA who are 18–29 (60% of whom report having these resources) and those who are 30-49 (64%). <sup>6</sup>

The percentages of PHR in the region who report concerns about their drug or alcohol use is similar to statewide percentages (Figure 25).

#### Figure 25. Substance Use Indicators Among PHR

Survey Items	% Agreeing
Family and friends have been worried about my drug/alcohol use (in the past 30 or 90 days)	Cleveland Part A: 21% State: 22%
l have been worried about my drug/alcohol use (in the past 30 or 90 days)	21% 21%

\* Data have been weighted by age and race. *Region* 3=164 respondents; *State*=643 respondents

 $^{6}\chi^{2}(4, N = 164) = 13.642, p = .009$ 

When answers to this question are broken down by demographic groups, some differences emerge between respondents in different demographic categories.

*Black MSM*: A third of those identified as Black MSM in the PHR sample report that they have worried about their drug or alcohol use in the past 30 or 90 days, and the same proportion report that their families or friends have had this concern.

*Transgender:* None of the PHR who are identified as transgender report that they or their family and friends have been worried about their drug/alcohol use.

### **Mental Health**

#### Mental Health Among PHR

A much lower percentage of PHR in the region report that it would be helpful if they were to see a counselor, compared to the percentage of PHR statewide who reported this need. A similar percentage of PHR reported that they are currently receiving counseling (Figure 26).

#### Figure 26. Mental Health Needs Among PHR



\* Data for this section have been weighted by age and race. The percentages listed are the combined percentage of respondents who answered "yes, in the last 30 days" or "yes, in the last 90 days." "It would be helpful if I saw a counselor" *Region 3*=164 respondents, *State*=643 respondents; "I am currently receiving counseling" *Region 3*=163 respondents, *State*= 642 respondents

#### Mental Health Among PLWHA

When PLWHA were asked about their perceptions of counseling and seeing a counselor, the highest percentage of PLWHA (41%) agreed with the statement "I could not afford a counselor," followed by "The wait time to see a counselor is too long" (38% of PLWHA agreed with this statement), and then "I don't want anyone to know," and "I have not considered seeing a counselor" (which earned agreement from 34% and 35% of PLWHA in the region, respectively).

*Race:* Higher percentages of non-white respondents provided answers consistent with stigmatizing beliefs about mental health care, and this relationship between mental health stigma and race is statistically significant.<sup>7</sup> Figure 27 provides details.

Age: As Figure 28 indicates, higher percentages of 30–49-year-old PLWHA respondents provided answers consistent with stigmatizing beliefs about mental health care, and the relationship is statistically significant.<sup>8</sup>

*Sexual orientation:* There are also statistically significant differences between responses by individuals reporting different sexual orientations.<sup>9</sup> These are detailed in Figure 29.

Figure 27. Perceptions of Mental Health Care Among PLWHA by Race



<sup>&</sup>lt;sup>7</sup> "I would not want anyone to know I saw a counselor, therapist, or psychologist."  $\chi^2$  (2, N = 201) = 7.964, p = .019. The relationship between race and "The wait time to see a counselor is too long" is also statistically significant.  $\chi^2$  (2, N = 201) = 6.700, p = .035.

<sup>&</sup>lt;sup>8</sup> "I would not want anyone to know I saw a counselor, therapist, or psychologist."  $\chi^2$  (2, N = 199) = 15.677, p < .001; "I would not know how to find a counselor."  $\chi^2$  (2, N = 199) = 15.728, p < .001; "The wait time to see a counselor is too long."  $\chi^2$  (2, N = 199) = 12.881, p = .002; "I could not afford a counselor."  $\chi^2$  (2, N = 199) = 11.032, p = .004; "There aren't any counselors, therapists, or psychologists close enough to where I live."  $\chi^2$  (2, N = 199) = 20.056, p < .001.

<sup>&</sup>lt;sup>9</sup> "It would probably be helpful if I were to see a counselor."  $\chi^2$  (4, N = 201) = 16.779, p = .002; I would not want anyone to know if I saw a counselor."  $\chi^2$  (4, N = 201) = 15.312, p = .004; "I would not know how to find a counselor."  $\chi^2$  (4, N = 201) = 10.044, p = .040; "I would not have transportation to a counselor."  $\chi^2$  (4, N = 201) = 11.896, p = .018.



#### Figure 28. Perceptions of Mental Health Care Among PLWHA by Age

#### Figure 29. Perceptions of Mental Health Care Among PLWHA by Sexual Orientation




## **Care Status of Survey Respondents**

Ninety-two percent of PLWHA in the region have seen a medical care provider for their HIV in the year leading up to the survey. This is very similar to the statewide percentage for PLWHA (Figure 30). For more information about how care status is defined, see Appendix 3.

#### Figure 30. The Last Time Respondents Saw a Medical Care Provider for HIV

Survey Item	% Agreeing*
0 to 6 months ago	Region 3: 795
	State : 82%
7 to 12 months ago	13%
Over a year ago but less than 2 years	5% 3%
Over 2 years ago	<b>3%</b> 1%
I have never seen a medical care provider for my HIV	<b>0%</b> 1%

\*Region 3 data in this figure are unweighted. State data are weighted by age and gender. *Region* 3=204 respondents, *State*=594 respondents

## **Out-of-Care Respondents**

Sixteen PLWHA respondents (8%) were out of care at the time of the survey. Eighty-one percent of these individuals are Black, while 13% are white and 6% are other or multiple races. Almost a third (31%) are Hispanic or Latinx. Half (50%) of these individuals identify as male, 31% identify as female and 19% identify as non-binary. Over half (56%) are age 30–49, while 38% are 50 years or older and 6% are 18–29. Half of the individuals who are out of care are heterosexual, while 31% prefer to self-describe/prefer not to answer, 13% are bisexual, and 6% are lesbian. Three individuals (19%) are identified as transgender.

## **Factors Affecting Care Status**

When the PLWHA who reported that they had *not* seen a medical care provider for their HIV in the last year were asked about their reasons for remaining out of care, the most frequently selected reason was that they did not feel sick (Figure 31). Much higher percentages of PLWHA in the Cleveland Part A TGA gave this answer compared to PLWHA across the whole state. This speaks to a need for improved health literacy among some PLWHA, which was a theme in the focus groups that took place in the region during the earlier phase of the needs assessment. The second most frequently selected reason for not seeing a medical care provider was that they do not like thinking about having HIV. Once again, higher percentages of PLWHA in the region gave this answer compared to PLWHA across the state. These two reasons are consistent with focus group and interview findings from this region, which identified depression and denial as the main reasons for delaying linkage to care in the region.



#### Figure 31. Reasons for Not Seeing a Medical Care Provider

Reasons (continued)	% Agreeing
Can't get transportation	<b>6%</b> 13%
Can't get an appointment	<b>0%</b> 20%
Don't know where to go	<b>0%</b> 16%
Substance use prevented me	<b>0%</b> 13%
Released from incarceration, not re-established care	<b>0%</b> 7%
Can't get child care	0 <mark>%</mark> 5%

State-level data in this figure have been weighted by age and race. Because of the small number of responses at the regional level, Region 3 data in this figure are unweighted. *Region 3*=16 respondents, *State*=40 respondents

Over half of those who selected "other" indicated that they did not believe that they have HIV, reporting, "I believe the test is bad," "I think the test was inaccurate," and "The test was wrong, I think."

## **Supports for Entering Care**

When asked what would help support a return to care, the most frequently selected support was "support from my family" (Figure 32). "Support from friends," and "A steady source of income" tied for the second-most frequently selected support. Compared to PHR respondents statewide, higher percentages of PHR who are out of care in the Cleveland Part A area reported that support from family and friends would be an important part of returning to care, as would be assistance with coming to terms with their HIV diagnosis. Compared to out-of-care PLWHA across the state, out-of-care PLWHA in the Cleveland Part A TGA more frequently reported a need for these social and psychological supports. When asked what would facilitate their return to care, one PLWHA who is identified as transgender responded:

"A more open HIV community that understands the trans experience...the black trans experience."

Supports Needed	% Agreeing*
Support from family	Region 3: 44% State: 35%
Steady source of income	<b>38%</b> 57%
Support from friends	<b>38%</b> 11%
Coming to terms with my diagnosis	<b>3</b> 1% 17%
Other	31% 6%
Financial assistance for care	<b>19%</b> 43%
Housing services	<b>19%</b> 32%
Mental health services	<b>13%</b> <i>38%</i>
Transportation assistance	<b>13%</b> 27%
Job training or employment services	<b>13%</b> 27%
More education on what HIV means to me	<b>6</b> % 10%
Substance use treatment services	<b>0%</b> 21%

\* State-level data have been weighted by age and race. Because of the small number of responses at the regional level, Region 3 data in this figure are unweighted. *Region 3*=16 respondents, *State=*40 respondents

## **Unmet Needs for Services**

Maintaining overall health and addressing substance use are both important contributors to retention in care. In the Cleveland TGA, the most frequently identified unmet needs are for mental health care services and dental care (Figure 33).

#### Figure 33. Needed Services



Data have been weighted by age and race. N = 99

For those who said they were not receiving needed services, the most common reasons cited were that they did not know the services existed, and that they cannot afford them.

Ryan White Payment for Care: PLWHA who use the Ryan White program to pay for medical care report better access to mental health care compared to those who do not use Ryan White to pay for care. Seven percent of all PLWHA who use Ryan White to pay for care report that they need but do not receive mental health care, while 9% of those using other types of payment report the same unmet need. This difference is statistically significant.<sup>10</sup> When those who do not need mental health services are removed from the sample, 15% of those who

PLWHA who use Ryan White to pay for medical care report better access to mental health care compared to those who do not use Ryan White to pay for medical care.

need mental health services and use Ryan White to pay for care have an unmet need for mental

 $<sup>^{10}\</sup>chi^2$  (2, N = 203) = 6.957, p = .031

health care, compared to 28% of those who need mental health services and do not use Ryan White to pay for care.

*Age:* Higher percentages of respondents who are 30–49 years old often report unmet needs for services compared to older and younger respondents. For example, 23% of those 30–49-year-olds who report a need for case management services indicated that this need is not met, compared to 10% of 18–29-year-olds and 8% of those 50 and older. Similarly 30% of those 30–49-year-olds who report a need for dental care report that this need is unmet, compared to 10% of 18–29-year-olds and 22% of those 50 years and older.

Years Since Diagnosis: PLWHA who have been diagnosed in the five years before the survey generally reported higher levels of unmet needs compared to those who have been diagnosed for six or more years.

## Interactions with HIV Care Providers

An individual's relationship with their provider is another factor associated with retention in care (Anderson et al., 2020). When asked about their interactions with their main HIV medical care providers and their staffs, PLWHA in the region responded mostly favorably, in a pattern similar to that seen statewide (Figure 34).

#### Figure 34. Perceptions of Care from Main HIV Medical Care Provider and Staff

Category	% Reporting*
The doctor or medical staff treat me with courtesy and respect	Region 3: 90% State: 92%
The doctor or medical staff listen carefully to me	90% 88%
The doctor or medical staff explain things in a way l understand	<b>87%</b> 87%
The nursing staff treat me with courtesy and respect	<b>88%</b> 87%
The nursing staff listen carefully to me	88% 86%
The nursing staff explain things in a way l understand	<b>88%</b> 87%



\* State-level data have been weighted by age and race. Because of the small number of responses at the regional level, Region 3 data in this figure are unweighted. *Region 3*=183–186 respondents, *State*=541–546 respondents

*Age:* Respondents who are 30–49 tended to report slightly lower levels of agreement with the positive statements about care providers. This was especially true for questions about office staff. Respondents over 50 years old tended to express more agreement with the statements. Figure 35 provides more details.

*Ryan White Medical Coverage:* Higher percentages of those PLWHA who use Ryan White to pay for their medical care agree with the statements in the figure above, compared to those PLWHA who do not use Ryan White to pay for their care. The biggest differences are seen when respondents are asked about their treatment by office staff. Data for only one item in this question panel supported Chi-square testing, and a Chi-square test for independence identified a statistically significant difference in responses to the item "The doctor or medical staff treat me with courtesy and respect."<sup>11</sup> Figure 36 gives more details about the differences between those paying for care with Ryan White and those using other forms of payment.

<sup>&</sup>lt;sup>11</sup>  $\chi^2$  (1, N = 184) = 14.334, p = < 0.01



#### Figure 35. Perception of Care from Main HIV Medical Provider, by Age

#### Figure 36. Perception of Care from Main HIV Medical Provider, by Use of Ryan White Payment



## **Ryan White Case Managers**

Ryan White case managers play an important role is supporting retention in care (Parnell et al., 2017). Most respondents agreed with the positive statements about Ryan White case managers listed in the figure below, though at least 20% of PLWHA did *not* agree that their Ryan White case managers listen carefully to them, provide them with support navigating the Ryan White program, help them to get needed medical care, or help them to get needed non-medical care.

#### Figure 37: Perceptions of Ryan White Case Managers



Data have been weighted by age and race. Region 3=88 respondents, State=485 respondents

## **Social Support and Related Needs**

During the previous phase of the needs assessment, focus group and interview data indicated a need for increased social interaction with other PLWHA. This is reinforced by survey findings, in which opportunities to get together with other PLWHA is the largest unmet social-support-related need (Figure 38). It should be noted that this need emerged most strongly in the more rural regions

of the Cleveland Part A TGA during the prior needs assessment research. In order to protect participants' privacy, the survey asked participants only for their region of residence, so these results cannot be disaggregated into responses from PLWHA in urban areas and PLWHA in suburban and rural areas.

Mental health diagnoses and symptoms are also associated with retention in care (Byrd et al., 2020; Fuller et al., 2019). A counselor or therapist is the second most often reported unmet need in this category, after socialization opportunities. Nineteen percent of PLWHA report that they need but do not receive services from a counselor or therapist. This is slightly larger than the 18% of PLWHA statewide who report this unmet need.

#### **Figure 38: Social Support and Related Needs**



Data have been weighted by age and race. *Region 3*= 98 respondents

Years Since Diagnosis: For all but one item, higher percentages of those individuals who were diagnosed between 11 and 20 years ago reported an unmet need for the social support or related service, compared to respondents who have been diagnosed in the last 10 years and those diagnosed over 20 years ago. The sole exception is the need for a counselor or therapist, which was reported by a higher percentage of individuals who have been diagnosed 6–10 years ago.

### **Substance Use-Related Needs**

As with other stages of the HIV care continuum, substance use is associated with decreased retention in care (Fojo et al., 2019; Kraemer et al., 2019). Thirty-one percent of PLWHA report that they use unprescribed medication or substances, which is very close to the 30% of PLWHA statewide who report this. Thirty-two percent of white respondents report using unprescribed medications or substances, compared to 29% of respondents who are Black and 27% of respondents reporting other or multiple races.

Five percent of PLWHA in the region report that they have been diagnosed with a substance use disorder. Five percent of PLWHA in the region also report that they have missed medication because of substance use, and 18% of those who are out of care report that substance use got in the way of seeing an HIV car provider.

Relapse prevention services	12% 13%	75%
Substance use treatment	8% 19%	73%
A counselor or therapist for me to focus on my substance use	6% 25%	69%
Medication-Assisted Treatment, such as methadone or suboxone	4% 11%	85%
Harm reduction education and strategies (such as needle exchange)	4% 15%	81%
Detoxification (detox) in a residential setting	4% 13%	83%
12-step program, such as Narcotics Anonymous or Alcoholics Anonymous	2% 15%	83%
Need and do NOT receive	I and DO receive	Do not need

#### Figure 39: Substance-Use-Related Needs

Data for this figure have been weighted by age and race. *Region* 3=32 respondents

Higher percentages of PLWHA in the Cleveland TGA report unmet needs for relapse prevention services compared to PLWHA statewide (Figure 39). Eight percent of PLWHA statewide report an unmet need for this service, compared to 12% of PLWHA in the Cleveland Part A TGA.

*Race: All* of the individuals reporting an unmet need for a counselor or therapist, detox in a residential setting, medication-assisted treatment, harm reduction services, and a 12-step program identify as Black.

While a higher percentage of respondents who are white report that they use substances, those who have unmet needs for substance use-related services overwhelmingly identify as Black.

## **Comorbid Conditions**

The main comorbid condition reported by PLWHA in the region is high blood pressure, followed by a mental health diagnosis and sexually transmitted infections (Figure 40).

Figure 40. Comorbid Conditions Among PLWHA

Category	% Reporting
High blood pressure	Region 3: 26% State: 27%
Mental health diagnosis	<b>17%</b> 21%
Sexually transmitted infection (STI)	<b>12%</b> 11%
Heart disease	<b>8%</b> 9%
Substance use disorder	<b>8%</b> 8%
Diabetes	<b>7%</b> 9%
Kidney disease	<b>7%</b> 7%
Cancer	<b>5%</b> 4%
Hepatitis C	<b>3%</b> 5%
Hepatitis A	<b>2%</b> 2%

\* State-level data have been weighted by age and race. Because of the small number of responses at the regional level, Region 3 data in this figure are unweighted. *Region 3=*201 respondents, *State=*570 respondents



The initiation of ART is an important milestone on the way to viral suppression and has been found to be associated with unmet needs, stigma, substance use, competing life activities, perceived health, mental health, trust in care providers, health literacy, and other factors (Beattie et al., 2019; Lesko et al., 2019; Hollingdrake et al., 2019). Based upon input from the steering committee during the survey design process, the decision to initiate ART was not a specific focus of the survey. Instead, the survey explored reasons for engaging in care and reasons for adhering to medication regimens, both of which can shed light on ART initiation. This section provides a brief overview of the reasons some PLWHA answering the survey are not taking HIV medication. Their responses touch on perceived health, competing life activities, unmet needs, stigma, and health literacy. Relationships with providers have already been discussed in the Retention in Care section of this report.

Just 1% of PLWHA in the region report that they have not been prescribed HIV medication, and 2% more report that they are not taking medication for their HIV. When asked why they are not taking medication, these respondents most frequently reported that they feel healthy (Figure 41). Fifty-six percent of those not taking medication reported that it is because they feel healthy, which is more than the 46% of PLWHA statewide who provide that reason. This is consistent with findings from focus groups and interviews in the region, in which denial was identified as a barrier to ART initiation and medication adherence.



#### Figure 41. Reasons for Not Taking Any Medications

Reasons (continued)	% Reporting*
I don't want to take HIV medication	<b>25%</b> 33%
I can't afford my medication	<b>19%</b> 31%
l don't know how to get my HIV medication in a way that protects my privacy	19% 14%
I don't know where to get my HIV medication	<b>6%</b> 10%
l am worried that someone will see me taking my medication	<b>6%</b> 5%
I have trouble remembering to take my medication	<b>6%</b> 14%
l don't have a pharmacy I feel comfortable with	<b>0%</b> 5%

\* State-level data have been weighted by age and race. Because of the small number of responses at the regional level, Region 3 data in this figure are unweighted. *Region 3*=16 respondents, *State*=22 respondents

Two-thirds of the six respondents identified as transgender report that they are not taking medication for their HIV. Two of these respondents indicated that the side effects of the medications prevent them from working. The responses written in by these two respondents are: "Side effects don't work well for my work that I have to do to make ends meet," and "Doing sex work, the meds give me diarrhea."



Eighty-eight percent of PLWHA in the region report that they have had viral load testing completed in the 12 months leading up to the survey. Eighty percent of those individuals report that they are virally suppressed. Factors associated with viral suppression include routine viral load testing, stigma, unmet needs, health literacy, perceived health, side effects from medication, relationship with prescribing provider, pharmacy characteristics, mental health, and more (Engler et al., 2018; Rintamaki et al., 2019). Many of these factors have been discussed in previous sections. This section discusses participants' responses to questions about viral load testing and medication regimen adherence.

#### Viral Suppression Among Populations of Special Interest

Black MSM: Rates of viral load testing and viral suppression among respondents identified as Black MSM are very similar to overall regional rates. Eighty-nine percent of those identified as Black MSM have had viral load testing done in the last 12 months, and of those individuals, 73% report that they are virally suppressed. Overall, 65% of those identified as Black MSM in the PLWHA sample for the region are virally suppressed.

*Transgender*: Only three PLWHA identified as transgender answered the survey question about viral load testing, and two of these individuals report a viral load test in the past 12 months. Both of these individuals report that they are virally suppressed.

## Viral Load Testing

Figure 42. Viral Load Testing in Last 12 Months



\* Data have been weighted by age and race. *Region* 3=98 respondents, *State*=553 respondents

Eighty-eight percent of PLWHA in the region report that they have had a viral load test completed in the 12 months before taking the survey. Of these individuals, 80% report that they are virally suppressed. This is a slightly higher percentage than seen in the statewide PLWHA sample.

## **Viral Suppression**

#### Figure 43. Viral Suppression Among PLWHA

Category	% Reporting <sup>*</sup>	
Less than 200 copies per mL		Region 3: 80%

\* Data have been weighted by age and race. *Region* 3=84 respondents, *State*=470 respondents

In general, higher percentages of older respondents reported that they are virally suppressed, and lower percentages of wealthier respondents reported that they are virally suppressed. Rates of viral suppression are also higher among those who use Ryan White to pay for their care.

### **Medication Adherence**

Along with viral load testing, adherence to ART regimens is vital for achieving viral suppression. When PLWHA in the region were asked about whether they missed a dose of their medication in the week prior to the survey, 29% of those who have been prescribed HIV medications reported that they had missed at least one dose in the previous week. The main reason provided for missed doses was simply forgetting to take a dose.

#### Category % Reporting\* Region 3: 57% I forgot to take medication State: 57% 19% I ran out of my medication 19% 13% My medication makes me feel sick (bad side effects) 17% My substance use got in the way of taking my 13% medications 10% 13% Other 12% 9% I feel healthy 8%

#### Figure 44. Reasons for Missing Doses

Category (continued)	% Reporting
l was experiencing mental health issues, which got in the way of taking my medications	10% 11%
I can't afford medication	<b>6%</b>
l was in police custody/jail and did not have access to medication	<b>6%</b> 5%
l don't have access to insurance	<b>4%</b> 6%

\* State-level data have been weighted by age and race. Because of the small number of responses at the regional level, Region 3 data in this figure are unweighted.

*Region 3*=54 respondents, *State*=128 respondents

## Conclusion

Some of the challenges facing PHR in the Cleveland Part A TGA include high levels of unmet needs, lower levels of concern about contracting HIV compared to their counterparts across the state, and slightly lower levels of interest in PrEP and PEP. On the other hand, PHR in the region also demonstrate more knowledge of HIV transmission and more have been tested for HIV when compared to PHR across the state. Higher percentages of PHR who are older, Black, and/or non-binary are being tested in the region, compared to PHR from other demographic groups. Related to testing, a much higher percentage of PHR report that they have been tested at mobile testing sites compared to PHR statewide.

Among PHR, specific subpopulations demonstrated increased need. As was seen in the statewide sample, PHR who are 30–49 years old report more risk behaviors, less appreciation for the burden imposed by HIV, and less interest in prophylactic medications than PHR in other age groups. PHR who are 18–29 years old did not report being tested for HIV at the same rate as older PHR. PHR who are identified as Black MSM demonstrated higher levels of HIV-related stigma, indicated more agreement with the idea that pausing for condom use ruins the sexual mood, and showed lower levels of interest in PrEP. PHR who are identified as transgender reported lower levels of concern about contracting HIV and lower levels of interest in PEP and PrEP. Due to low sample sizes for PHR who are identified as transgender and PHR who are identified as Black MSM, these findings should be considered tentative.

The vast majority of PLWHA in the region have successfully been linked to care, but barriers to linkage to care remain. PHR in the region report less access to substance use resources than others across the state, and higher unmet needs for basic necessities. Those PLWHA who are not linked to care report that they have not seen a provider because they do not feel sick and they do not like to think about having HIV, suggesting a need for both improved health literacy and improved access to mental health care. In fact, the most frequently reported unmet need for services among PLWHA is the need for mental health care. Barriers to mental health care include the perceived cost of services, the wait times for these services, and the stigma associated with seeking mental health care. Respondents who are not white and/or who are 30–49 years old expressed higher levels of mental-health-care-related stigma. Perceived health and health literacy also play a role in retention in care and ART initiation. Although most PLWHA report that they are in care, most of the out-of-care respondents report that they have not seen a provider for their HIV because they do not feel sick. Those PLWHA who are not taking medication most frequently explained that this is because they feel healthy.

Finally, the need for increased social support that was originally identified during the focus group phase of the research emerged strongly in the survey research as well. When asked what would support a return to care, out-of-care respondents indicated a need for support from family and friends at higher percentages than out-of-care PLWHA statewide. PLWHA who are in care

reported unmet needs for social supports, especially opportunities to interact socially with other PLWHA in the region.

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## Appendix 1. Strengths and Limitations

### Dependability of findings

In an effort to make sure survey items were as up-to-date as possible, and phrased in ways that would resonate with clients, the HIV Needs Assessment Steering Committee decided not to use validated question batteries to measure HIV-related knowledge, risk perception, mental health, and other phenomena. Instead, validated items were adjusted by the steering committee, and other items were created from scratch to query respondents about concepts of interest. To increase the dependability of survey findings, researchers provided guidance grounded in best practices for question construction, in order to maximize the likelihood that respondents would interpret the questions as intended, and that the questions would measure the intended phenomena. Researchers also piloted the survey with PLWHA and with PHR, holding discussions with these initial respondents about their understandings of survey questions.

#### Representativeness of findings

Respondents were not randomly selected for the survey. Specific minimum survey response targets were set for regions and subpopulations to guide recruitment and to create as representative a sample as might be possible. However, in order to include as many PLWHA and PHR as possible, researchers did not cap participants once response quotas were met. Some hard to reach populations were also under-sampled. As a result, some subpopulations are overrepresented in the data while other subpopulations are underrepresented. To correct for this imbalance, researchers used poststratification weighting. Specifically, researchers weighted PHR responses by race and age, using population estimates from the National Center for Health Statistics. Researchers weighted the PLWHA responses by age and gender, using known population counts provided by ODH.

Researchers also used chi-square tests for independence to look for statistically significant differences between subgroups (e.g., differences between respondents who identify as male versus those who identify as female or those who identify as non-binary). For example, when assessing risk perceptions among PHR, researchers are able to say that a higher percentage of persons who identify as non-binary report that they think that being diagnosed with HIV "would not be a big deal," compared to participants with other gender identities, and that the difference between these groups is statistically significant.

### Accuracy of findings

There are many factors that affect an individual's movement among the stages of the HIV care continuum, and these factors exist at various socioecological levels (i.e., within an individual, between an individual and their social support system, within a community, within a system of care, etc.). The particular survey items used for this needs assessment are best suited to uncover information about those factors that occur at the level of the individual, and to learn about individuals' *perceptions* of those factors as they exist at other socioecological levels. Perceptions

are valid regardless of whether they match reality, and the research study was not intended or designed to test the extent of drift between perceptions and reality. As a result, the findings reported here should be interpreted in their proper context. For example, this survey can report that 5% of respondents say they cannot find a pharmacy at which to get their medications in a suitably confidential way, but it cannot document whether there are in fact pharmacies with adequate privacy practices available to those individuals.

#### Comprehensiveness of findings

The core motivating task of the Ohio HIV Needs Assessment was a broad one: to assess the state of HIV prevention and care among all Ohioans at all stages of the HIV care continuum. To do this, researchers drew on peer-reviewed literature to identify those factors that influence an individual's HIV-related behaviors and outcomes. The Ohio HIV Needs Assessment Steering Committee further refined the focus of the needs assessment to specific factors of interest, such as health literacy, prevention behaviors, and access to specialty services, through discussions with researchers and revisions of the survey instrument.

## **Appendix 2. Data Collection**

#### Survey development

The Ohio HIV Needs Assessment survey was developed in partnership with the Ohio HIV Needs Assessment Steering Committee, which is composed of representatives from The Ohio Department of Health (ODH) including Ryan White Part B and HIV Prevention, Ryan White Cleveland Part A (administered by the Cuyahoga County Board of Health), and the Ryan White Columbus Part A (administered by Columbus Public Health). As a first step in the process, the steering committee identified constructs of interest for the survey, such as HIV risk factors or reasons for missing doses of antiretroviral therapy (ART). Ohio University (OU) also received feedback from the Combined Community Planning Group on their preferred survey items. Keeping the various partners' differing inputs in mind, OU then researched and collected validated survey items to explore these constructs of interest. ODH and the two Part A's then provided extensive revisions to the survey–including question wording adjustments, the removal of some questions, and the addition of other questions–in order to tailor the survey items to their specific interests and clients.

Once revisions made by the steering committee were largely completed, OU tested the survey with individuals from the Ohio University Lesbian, Gay, Bisexual, and Transgender (LGBT) Center and a group of people living with HIV/AIDS (PLWHA) from the Cleveland Part A Planning Council. OU additionally sent the draft survey to internal consultants (including the director of the LGBT center and public health researcher Dr. Caroline Kingori) for further review. When these processes were completed, OU made final revisions and submitted the survey to the steering committee. Once the steering committee approved the survey, OU submitted the survey to ODH's Institutional Review Board, which provided approval for the survey research to commence (ODH IRB 2018-22).

ODH then had the survey translated into Somali and Spanish, at which point OU contracted with native Somali and Spanish speakers to check the translations for clarity before programming the surveys into Qualtrics in Somali and Spanish, respectively.

The full text of the surveys is available in Appendix 4.

#### Recruitment

OU engaged in a wide variety of recruitment efforts, which included in-person discussions with key contacts, communication through social media, snowball sampling of out-of-care respondents, and collaboration with agencies that serve the populations of interest. The activities OU carried out during the recruitment phase include the following:

• OU attended meetings and conferences, such as the Transforming Care Conference in October 2019 and pre-exposure prophylaxis (PrEP)-related discussions hosted by Equitas

Health, both to connect with and to distribute survey information to representatives of organizations that serve the populations of interest.

- OU researchers also reconnected with key contacts who had assisted with recruiting for the first-year focus groups to ask them for help with distributing the survey.
- OU created a comprehensive contact list with extensive assistance from the steering committee, which was used to make calls and send emails to secure assistance with survey distribution. This extensive list included (but was not limited to) the following:
  - harm reduction clinics, community groups that serve PLWHA and youth who are at higher risk, health departments;
  - ODH-funded subgrantees providing Ryan White case management services, such as Equitas agencies and Caracole;
  - o clinics providing medical services to PLWHA;
  - advocacy and support groups serving the transgender community, such as TransOhio and MOZAIC;
  - groups serving young Black men, such as Brothers in Unity and the MPowerment Program;
  - LGBTQ+ support groups and advocacy organizations across the state, including Equality Ohio, Community AIDS Network Akron Pride Initiative, and local support groups.
- OU researchers then telephoned and emailed contacts on the list to explain the survey and ask for help distributing the survey to potential respondents. Members of the steering committee also established connections with key contacts to encourage these contacts' participation in the recruitment process.
- OU researchers developed a social media plan in very close collaboration with the steering committee and used Facebook, Twitter, and Instagram to publicize the survey.
- ODH and the Cleveland TGA provided a list of HIV medical care providers across the state. Using case counts, OU developed a list of clinics of interest and began contacting clinics to arrange in-person visits to clinics to administer the survey to consenting clients and to engage clinic staff in recruitment efforts. As this process was underway, Ohio Governor Mike DeWine issued a stay-at-home order because of the COVID-19 pandemic. Independently of this order, Ohio University simultaneously implemented travel restrictions for its employees. As a result of these developments, and recognizing not only the vulnerability of the population researchers needed to reach but also the strain on health clinics and other health care facilities during the pandemic, researchers abandoned previously agreed-upon plans for in-person visits to clinics.
- Researchers developed a list of individuals with contacts to out-of-care PLWHA. This list was based on contacts made during the focus group phase, as well as contacts made as recruitment efforts were underway for the survey. These contacts were given information to provide to potential out-of-care respondents to recruit them for the survey.

#### Survey distribution

The survey launched on February 19, 2020 and closed on June 30, 2020. All survey links led to one survey, at which point screening questions directed respondents either to questions for those who had been diagnosed with HIV or to questions for those who had not been diagnosed with HIV. The initial launch of the survey on social media resulted in 1,423 surveys that were completed overnight from IP addresses that were largely out of the United States. After careful analysis and

consultation with representatives from Qualtrics (the maker of the software used for the survey deployment), it was determined that these responses were the result of bot activity. These survey responses were eliminated, and a new anonymized survey link generated.

Researchers and collaborating recruiters distributed these new anonymous survey links via text, email, and private messaging in social media. A QR code was also generated for distribution. Technical safety protocols were applied so that the survey could not be taken twice on the same device and browser. A link that did not include these protections was given to collaborating Ryan White case workers and other professionals, so that they could complete the survey multiple times on one device with their clients.

Due to an accidental posting of the link to social media by a recruiter, a second round of bot activity occurred, but researchers again eliminated surveys originating from IP addresses located outside of Ohio and the surrounding states for a two-day span of time when it was known that the survey link was posted on a Facebook page. After the incident, mail-only options for incentives were enforced on survey links that would be available to a wide audience, and a CAPTCHA was added to the survey.

If a respondent wished to complete the survey over the phone, they were provided with a phone number to call that connected them with a researcher who was available to administer the survey verbally. Respondents or organizations could also request hard copies of the surveys, along with pre-paid envelopes for returning them.

#### Incentives

Each respondent who completed the survey and provided either a postal mailing address or an email address received a \$15 gift card. Respondents could choose from among 17 types of gift cards, including cards for Walmart, Target, Aldi, Starbucks, and Marathon. The list of gift cards was developed in consultation with ODH and was in full accordance with Health Resources and Services Administration (HRSA) guidelines. The information respondents provided in order to receive their earned gift card was isolated from their survey responses.

In addition, individuals who were tapped to recruit respondents who are out-of-care were provided with a code to give the individuals they were recruiting. When these individuals then took the survey and entered their code, the recruiter was provided with a \$5 gift card. There was a 10-person (\$50) limit on incentives for recruiting respondents who are out-of-care.

## Appendix 3. Data Analysis

At the time the survey was closed, there were 2,764 respondents, not including the first removed batch of 1,423 bot responses that were generated when the first link to the survey was released on social media. The first step in data cleaning was to remove the additional batch of 1,096 bot responses. After these responses were eliminated, cases where respondents only answered demographic questions were eliminated. If respondents progressed beyond the demographic section, their responses were retained. After eliminating incomplete surveys, 1,382 remained. The surveys were then split by whether the respondent had been diagnosed with HIV or had not been diagnosed. The resulting data set included 620 responses from PLWHA and 762 responses from HIV-negative participants.

Next, focusing on respondents who were not HIV positive, researchers reviewed a series of questions on behaviors within the last 12 months that served as a screening mechanism to identify those respondents who engage in behaviors that might lead to a higher risk of contracting HIV. If respondents did not engage in any of the behaviors in the series of questions, and if they identified as "heterosexual or straight," they were not included in this reporting. This brought the number of cases down from 762 to 695, eliminating 67 responses. The screening questions covered situations like sharing needles or works, sex without consent, STI contraction, and incarceration.

Data tables with complete responses to the PLWHA survey and the PHR survey are available in Appendix 5 and 6, respectively, including write-in responses.

#### Weighting

Initial discussions about the likelihood of low responses, particularly from certain demographic groups and certain HIV Prevention Planning regions for both the PLWHA and the PHR surveys indicated a need to poststratify the survey data we were likely to end up with once the surveys closed. For an explanation of this process see the following breakout box.

## Poststratification of Survey Data

Non-representative data typically present the single largest threat to the validity of survey research. The samples one usually ends up with may underrepresent some respondent groups while overrepresenting other respondent groups, and hence distort the inferences that can be drawn from the respondents' answers to survey questions. A common technique used to deal with this threat is reliance on poststratification weighting—a post hoc statistical procedure used to correct for sampling bias in surveys How do these weights work? Here is a simple, popular example (Royal, 2019).

Assume that we are trying to survey an adult population and know that this population is split equally between males and females. Let us also assume that we know the population size is 100 adults, and that we also know the race/ethnicity of these 100 adults. The population and sample data are shown below, along with the derived weights where the weight for each unique combination of gender and race/ethnicity is calculated as the population fraction divided by the sample fraction (for example, 0.100 divided by 0.140 yields 0.714). As a result, and simply put, undersampled groups count more while oversampled groups count less, all in proportion to their calculated poststratification weight.

Gender x Race/Ethnicity	Population N (fraction)	Sample <i>n</i> (fraction)	Weight
Black Female	10 (0.100)	8 (0.140)	0.714
Black Male	10 (0.100)	5 (0.088)	1.136
White Female	35 (0.350)	25 (0.439)	0.797
White Male	35 (0.350)	15 (0.263)	1.330
Other Female	5 (0.050)	3 (0.053)	0.943
Other Male	5 (0.050)	1 (0.018)	2.777
Total	100 (1.000)	57 (1.000)	

After much deliberation, researchers decided to utilize two sources of population-level data to create the poststratification weights necessary for each survey. Weighting for the PLWHA survey was carried out as follows. First, the Ohio Department of Health provided known population counts of the number of persons living with HIV/AIDS in Ohio as of 2018, by HIV Prevention Planning region, age-group, gender, race, and mode of transmission (for example, individuals who identify as males who have sex with males, people who inject drugs, and so on). However, it would have been impractical to create poststratification weights with this level of detail, as that would leave very few respondents in a particular demographic category in a particular region. After several discussions with the Ohio Department of Health and Part As, a decision was made to create weights by broad age and gender categories: Male 18–29, Female 18–29, Male 30–49, Female 30–49, Male 50+, and Female 50+. In addition, it was also decided that poststratification weights would be used for the statewide analysis, and for regions 3 and 11, respectively, but not for the other HIV Prevention Planning regions given the expected low sample sizes.

Researchers employed a different data source to create the poststratification weights for the PHR survey: the intercensal bridged race population estimates released by the National Center for Health Statistics (NCHS). These population-level data were collapsed into six combinations of age group and race: Black 18–29, White 18–29, Other 18–29, Black 30–49, White 30–49, Other 30–49, and

Black 50+, White 50+, and Other 50+. Poststratification weights were then created for these six groups. Again, it was decided that poststratification weights would be used for the statewide analysis, and for regions 3 and 11, respectively. Note that the 2019 bridged race estimates were unavailable when we began the weighting and hence, we were forced to rely on the 2018 estimates.

#### Analysis Plan

The plan of analysis was designed with an eye on the ultimate goal motivating the surveys: determine patterns of health behaviors, attitudes, and opinions in the two populations of interest those living with HIV/AIDS, and those who engage in behavior that put them at a higher risk for contracting HIV. Researchers analyzed the data at multiple levels, starting with statewide weighted (where poststratification weights were used to make the survey responses more representative of the population) and unweighted (where survey responses were not adjusted in any shape or form) frequency tabulations. In the report, researchers present the weighted percentages to illustrate general patterns we see in the survey data, but also utilize simple chisquare ( $\chi$ 2) tests with the unweighted data to identify situations where the responses are statistically significant.

Researchers also disaggregated the survey responses along specific dimensions (for example, self-reported sexual orientation) and then relied on unweighted frequency crosstabulations supplemented by appropriate chi-square ( $\chi$ 2) tests to distinguish between instances where responses to a question vary (or not), for example, by sexual orientation. The specific dimensions of interest we used to disaggregate most—but not all—PLWHA survey questions include the following: if the respondent has been out of care, if the respondent identifies as a Black male who has sex with males, if the respondent identifies as transgender, the respondent's experience with their Ryan White case manager, if the respondent engages in substance use, the respondent's viral load levels, years since the respondent uses Ryan White services or not. In addition, the PLWHA survey questions were disaggregated by income, gender, age, self-reported sexual orientation, and race. The PHR survey questions were, in turn, disaggregated by the following: whether the individual self-identified as transgender, if the respondent engaged in high-risk behavior, if the respondent identified as a Black male who had sex with males, by race, sexual orientation, income, gender, and age. Table 1 lists the disaggregations used per survey.

#### Table 1. Disaggregations by Survey

PHR Survey
Age
Income
Race
Gender
Sexual orientation
Black MSM
Transgender
Risk behavior

#### PLWHA Survey Ryan White case manager relationship Provider experience Substance use Viral load Years since diagnosis

Both the PLWHA and the PHR surveys include several questions that allowed respondents to select multiple responses. For example, one of the survey questions asked respondents "Why haven't you seen a medical care provider for your HIV in the last year or more? Select all that apply." Their response options included such reasons as "I don't like thinking about having HIV," "I don't know where to go," "I can't get an appointment," and so on. Because respondents could pick more than one option, and these options may not necessarily be independent, chi-square tests ( $\chi$ 2) would be inappropriate in the case of multiple response questions. Hence these tests were not carried out for the PLWHA and PHR surveys, respectively.

#### Defining key population variables

*Race:* Both surveys asked respondents to select as many of the following as described their race: American Indian or Alaska Native; Asian; Black/African American; Native Hawaiian or Pacific Islander; and White/Caucasian. Due to small sample sizes of some categories, for the purposes of examining data by race, the following categories were created: Black, white, and a grouping for those who reported multiple races or a different race from Black or white. The last category represents the following: those who chose multiple races, American Indian or Alaska Native, Asian, and Native Hawaiian or Pacific Islander.

*Gender*: Both surveys provide the following gender categories and ask respondents to choose one: female; male; non-binary; prefer not to say; and prefer to self-describe in the box below (with the option to write in a description). Due to small sample sizes of some categories, for the purposes of examining gender data, the following categories were created: male, female, and non-binary. Nonbinary includes those who self-describe their gender. Transgender respondents were included with non-binary respondents. See below for how researchers created the transgender category.

*Age:* Respondents reported their year of birth. Those under 18 were not permitted to continue the survey. The following age categories were created to be consistent with weighting categories: 18–29; 30–49; and 50+.

*Transgender:* A variable identifying individuals who identify as transgender was created. A respondent was included if their selection for "what sex were you assigned at birth, such as on an original birth certificate" was male, and they identified their gender as female, or if their sex at birth was female, and they identified their gender as male. Those who identified as non-binary were not included, and those who wrote in their gender description were assigned to the transgender category on a case-by-case basis.

*Income Level:* Both surveys provide the following categories and asked respondents to choose one to describe their individual yearly income range: less than \$15,000; \$15,000 to \$34,999; \$35,000 to \$49,999; \$50,000 to \$74,999; \$75,000 to \$99,999; and over \$100,000. Due to the smaller sizes of higher income groups, the data was collapsed into the following categories: Less than \$15,000; \$15,000 to \$34,999; \$35,000 to \$49,999; \$50,000 to \$74, 999; and \$75,000 and over.

Black Men Who Have Sex with Men (Black MSM): A variable identifying individuals who are Black MSM was created. First, those who report male assignment at birth were identified. Of those, respondents who chose Black race, or Black as one of multiple races were identified. Of that group, all who identify as a bisexual or gay man were assigned to the variable. Those who self-described their orientation were assigned on a case-by-case basis, and those who identified as transgender female were excluded.

Years Since Diagnosis with HIV: ODH identified meaningful categories for this variable. Respondents selected the year they were diagnosed from a dropdown menu. From there, years were collapsed into the following categories: Past 5 years; 6 to 10 years ago; 11 to 20 years ago; 21 to 25 years ago; 26 to 30 years ago; 31 or more years ago. Table 2 lists the years since diagnosis based on when the survey was conducted:

#### **Table 2. Years Since Diagnosis Variable Creation**

Years
2019 - 2015
2014 - 2010
2009 - 2000
1999 - 1995
1994 – 1990
1989 or earlier

# Appendix 4. HIV Needs Assessment Surveys

Start of Block: Introduction to All

By starting this survey you are giving your consent to participate in this research. For information about the research, including its risks and benefits and your rights as a participant, please click the link below. If you consent to participate in the research, please select "I agree to consent" and continue to the first question.

Click here to download information about the research.

- lagree to consent
- I do not agree
  Skip To: End of Survey If = I do not agree

There are some questions in this survey that we absolutely need you to answer in order to make sure we are hearing from a diverse group of people. If you skip one of those questions, we will ask you to answer that question before continuing.

Are you 18 years old or older?

- Yes
- No

Display This Question:

If Are you 18 years old or older? = No

Skip To: End of Survey If We're sorry, this survey is for individuals who are 18 and over. Thanks for your time. Is Displayed

• We are doing two surveys - one for people who are living with HIV, and one for people who are not. Answering this question will tell us which survey to give you.

Have you ever been diagnosed with HIV? Yes

• No

End of Block: Introduction to All

Start of Block: PLWHA Survey

*Ohio HIV Needs Assessment Survey for People Living With HIV.* This survey is to help us learn more about people living with HIV in Ohio and what they need. This will help program planners to better serve you. Your answers are confidential and will go directly to researchers at Ohio University. After the survey is done, the research report will be available here: <u>www.odh.ohio.gov/hiv</u>.

Each person should only take the survey one time. Taking the survey more than once keeps us from being able to provide an accurate and complete picture of the needs of everyone who is living with HIV in the state of Ohio. If you want information about resources for people living with HIV, please look on the last page of the survey for a list of resources. If you have questions about how to complete the survey, please contact Natalie Wilson at <u>wilsonn3@ohio.edu</u> or (740) 593-2343. Some questions on the survey may make you feel uncomfortable. You may choose neutral options or stop taking the survey at any time.

What year were you diagnosed with HIV?

Select year:

▼ 1984 ... 2019

We are asking the next questions because it is important to capture the experiences of all our respondents.

Please select the year you were born.

▼ 1939 ... 2001

How do you describe your gender?

- Female
- Male
- Non-binary
- Prefer not to say
- Prefer to self-describe in the box below

What sex were you assigned at birth, such as on an original birth certificate?

- Female
- Male
- Prefer not to say

Do you consider yourself to be:

- Bisexual
- Gay man
- Heterosexual or straight
- Lesbian/Gay woman
- Prefer to self-describe in the box below
- Prefer not to say

How would you describe your race? Select all that apply.

- American Indian or Alaska Native
- Asian
- Black/African American
- Native Hawaiian or Pacific Islander
- White/Caucasian

Do you consider yourself to be Hispanic/Latinx?

- Yes
- No

Which of the following best describes your individual yearly income range?

- Less than \$15,000
- \$15,000 to \$34,999
- \$35,000 to \$49,999
- \$50,000 to \$74,999
- \$75,000 to \$99,999
- Over \$100,000

Please look at the map. In which region do you live? Select from the drop down menu.

▼ Region 1... I don't live in Ohio, but I receive services in Ohio.

When is the last time you saw a medical care provider for your HIV?

- 0 to 6 months ago
- 7 to 12 months ago
- Over a year ago but less than 2 years
- Over 2 years ago
- I have never seen a medical care provider for my HIV Display This Question:

If When is the last time you saw a medical care provider for your HIV? = Over a year ago but less than 2 years

Or When is the last time you saw a medical care provider for your HIV? = Over 2 years ago

Or When is the last time you saw a medical care provider for your HIV? = I have never seen a medical care provider for my HIV

Why haven't you seen a medical care provider for your HIV in the last year or more? Select all that apply.

- I don't like thinking about having HIV
- Other things are more important to me

- I don't know where to go
- I can't get an appointment
- I don't have time
- I can't afford it
- I can't get transportation
- I don't want anyone to know that I have HIV
- I don't feel sick
- I haven't felt like going to my appointments
- My substance use has prevented me from scheduling and/or attending appointments
- I have been incarcerated and was not able to see a provider while in jail or prison
- I was released from incarceration and have not reestablished care
- I can't get child care
- Other, use the box below \_\_\_\_\_\_ Display This Question:

If When is the last time you saw a medical care provider for your HIV? = 0 to 6 months ago

Or When is the last time you saw a medical care provider for your HIV? = 7 to 12 months ago

Have you had a viral load done in the last 12 months?

- Yes
- No
- I don't know/Not sure

Display This Question:

If Have you had a viral load done in the last 12 months? = Yes

What were the results of your most recent viral load test?

- Less than 200 copies per mL (virally suppressed/undetectable)
- Over 200 copies per mL (not virally suppressed/undetectable)
- I prefer not to say
- I don't know/not sure Display This Question:

If When is the last time you saw a medical care provider for your HIV? = 0 to 6 months ago

Or When is the last time you saw a medical care provider for your HIV? = 7 to 12 months ago
For the next set of questions, please think about your main HIV medical care provider and their office staff.

	Agree	Neither Agree nor Disagree	Disagree	Not Applicable
The <b>doctor or medical staff</b> treat me with courtesy and respect				
The doctor or medical staff listen carefully to me				
The <b>doctor or medical staff</b> explains thing in a way I understand				
The <b>nursing staff</b> treat me with courtesy and respect				
The <b>nursing staff</b> listen carefully to me				
The <b>nurse staff</b> explains thing in a way l understand				
The <b>office staff (registration, scheduling, etc.)</b> treat me with courtesy and respect				
The <b>office staff (registration, scheduling, etc.)</b> listen carefully to me				
The <b>office staff (registration, scheduling, etc.)</b> explains thing in a way I understand				

### Display This Question:

If When is the last time you saw a medical care provider for your HIV? = Over a year ago but less than 2 years

Or When is the last time you saw a medical care provider for your HIV? = Over 2 years ago

Or When is the last time you saw a medical care provider for your HIV? = I have never seen a medical care provider for my HIV

What would support you getting back into care (or beginning care) for your HIV? Select all that apply.

- More education on what HIV means to me
- Coming to terms with my HIV diagnosis
- Financial assistance for medical care
- Mental health services
- Substance use treatment services
- Housing services
- A steady source of income
- Support from family
- Support from friends
- Assistance with transportation
- Job training or employment services

• Other, use the box below

Over the last week, have you skipped/missed taking one or more of your HIV medication (ARTs) doses in a day?

- Yes
- No
- I have not been prescribed HIV medication
- I am not taking HIV medication

Display This Question:

If Over the last week, have you skipped/missed taking one or more of your HIV medication (ARTs) dose... = Yes

What has caused you to miss a dose of your HIV medication(s)? Select all that apply.

- My medication makes me feel sick (bad side effects)
- I ran out of my medication
- I forgot to take my medication
- I was in police custody/jail and did not have access to medication
- I can't afford my medication
- I don't have access to insurance
- My substance use got in the way of taking my medications
- I was experiencing mental health issues which got in the way of taking my medications
- I feel healthy
- Other, use the box below

Display This Question:

If Over the last week, have you skipped/missed taking one or more of your HIV medication (ARTs) dose... = I have not been prescribed HIV medication

Or Over the last week, have you skipped/missed taking one or more of your HIV medication (ARTs) dose... = I am not taking HIV medication

Please complete the following sentence: I'm not currently taking HIV medication because: (select all that apply)

- The medication makes me feel sick (bad side effects)
- I can't afford my HIV medication
- I don't know where to get my HIV medication
- I don't know how to get my HIV medication in a way that protects my privacy
- I feel healthy

- My life situation prevents me from taking medication as prescribed (i.e. my work schedule gets in the way)
- I don't want to take HIV medication
- I'm worried that someone will see me taking my medication
- I don't have a pharmacy I feel comfortable with
- I have trouble remembering to take my medication
- I'm tired of taking my meds
- I am taking the medication currently prescribed to me
- Other, use the box below

Display This Question:

If Over the last week, have you skipped/missed taking one or more of your HIV medication (ARTs) dose... = Yes

Or Over the last week, have you skipped/missed taking one or more of your HIV medication (ARTs) dose... = No

How do you pay for your HIV medical care? Select all that apply.

- Medicaid
- Medicare
- Ryan White services
- Private insurance
- ACA/Obamacare insurance
- VA health insurance
- I do not access HIV medical services
- I pay for my own medical care

Have you <u>ever</u> used any of the following Ryan White services? Select all that apply.

- Ryan White Case Management
- Ryan White Emergency Medications Assistance
- Ryan White Financial Assistance for Medical Services (i.e. copay assistance or paying for medical bills or labs)
- Ryan White Housing Case Management
- Ryan White Medical Transportation
- Ryan White Dental Services
- Ryan White Mental Health Services
- Ohio AIDS Drug Assistance Program (ADAP)
- Other, use the box below
- I have not used any Ryan White services
- I don't know
- I have not heard of Ryan White

The following is a list of services available through the Ryan White program. Please tell us whether you had a <u>need</u> for any of the services in the last 12 months and whether you <u>received</u> the service.

	Did not need	Needed and RECEIVED service/support	Needed but DID NOT receive service/support
An appointment with a doctor, nurse, or other provider as part of your HIV treatment. (Outpatient medical care)			
Dental Care			
Medication program (to help pay for HIV medications)			
Mental health care			
Peer navigation (someone else living with HIV who can help you with information and support)			
Case management (someone to help with medical appointments, scheduling, transportation, and getting public assistance)			
Outpatient substance use treatment (when you make an appointment)			
Inpatient substance use treatment (when you are admitted)			

If you needed any of the above services and did not receive them, why not? Select all that apply.

- There is no provider near me
- I cannot afford this service
- I did not know this service existed
- I did not have transportation to get to this service
- I didn't have time to go to an appointment
- Office hours are inconvenient for my schedule
- I never received a call back
- Other

Display This Question:

If Have you ever used any of the following Ryan White services? Select all that apply. != I have not used any Ryan White services

And Have you ever used any of the following Ryan White services? Select all that apply. != I don't know

And Have you ever used any of the following Ryan White services? Select all that apply. != I have not heard of Ryan White

Thinking about your most recent Ryan White case manager and the staff in their office, how much do you agree with the statements below?

	Agree	Neither Agree nor Disagree	Disagree
Provides me with up to date information about services available to me			
Helps me to re-enroll in Ryan White services on time			
Provides me support navigating the Ryan White program			
Helps me to get the medical care/services I need			
Helps me to get the non-medical services I need			
Treats me with courtesy and respect			
Listens carefully to me			
Explains things in a way I can understand			

In the last 12 months, have you been diagnosed with any of the following?

	Yes	No	Prefer not to
Sexually Transmitted Infection (STI) such as syphilis, gonorrhea, chlamydia, herpes, and/or genital warts			say
Hepatitis A			
Hepatitis C			
Cancer			
Heart Disease			
Kidney Disease			
Mental Health Diagnosis			
Substance Use Disorder			
Diabetes			
High Blood Pressure			

Have you used unprescribed medications or substances in the last 12 months (e.g. unprescribed medications, alcohol, marijuana, meth, crack, heroin, etc.)?

- Yes
- No
- Prefer not to say

Display This Question:

If Have you used unprescribed medications or substances in the last 12 months (e.g. unprescribed med... = Yes

Please read the following list of services related to substance use treatment, and tell us whether you need each support and whether you are receiving each support.

	Do not need	Need and RECEIVE service/support	Need and DO NOT receive service/support
A counselor or therapist for me to focus on my			
substance use			
Detoxification (detox) in a residential setting			
Medication-Assisted Treatment, such as			
methadone or suboxone			
Relapse prevention services			
Harm reduction education and strategies (such as needle exchange)			
12-step program, such as Narcotics Anonymous or Alcoholics Anonymous			

In the past 30 or 90 days, have you been unable to get or pay for any of the following when it was really needed? Please select if this happened in the last 30 or 90 days.

	Yes, past 30 days	Yes, past 90 days	Did not happen
Food			
Utilities such as water, gas, or electricity			
Pay my rent or mortgage			
A regular place to sleep			
Child care			
Transportation to medical care providers			
Phone			

Please tell us whether you agree or disagree with the following statements.

	Agree	Disagree
It would probably be helpful if I saw a counselor, therapist, or psychologist.		
l would not want anyone to know if I saw a counselor, therapist, or psychologist.		
I would not know how to find a counselor, therapist, or psychologist.		
The wait time to see a counselor, therapist, or psychologist is too long.		
I could not afford to see a counselor, therapist, or psychologist.		
There aren't any counselors, therapists, or psychologists close enough to where I live.		
I have not considered going to see a counselor, therapist, or psychologist.		
I would not have transportation to a counselor, therapist, or psychologist.		

Please read the following list of possible supports for people living with HIV, and tell us whether you need each support and whether you are receiving each support.

	Do	Need and	Need but DO
	not	RECEIVE	NOT receive
	need	service/support	service/support
A support group for people living with HIV			
A support group for my friends and family			
A counselor or therapist for me			
Opportunities to get together with other people who			
are living with HIV to do activities or go on trips			
Peer Navigation (someone else living with HIV who			
can help you with information and support)			
Substance use treatment			

Thinking about the medical staff (such as nurses/doctors) at your HIV Care Provider in the last 12 months, please answer the following questions about how you think they have treated you. You may select more than one reason. If you do not feel that you have been treated the way described, select "This has not happened to me."

	HIV Status	Race	Gender/Gender Presentation	Sexual Orientation	Ethnicity/ National Origin	Age	Financial Status	This has not happened to me
My doctor/nurse has treated me with less respect than other people because of								
My doctor/nurse has acted as if they think I am not smart because of								
My doctor/nurse has acted as if they are afraid of me because of								
My doctor/nurse has acted as if they think I am dishonest because of								
My doctor/nurse has acted as if they are better than me because of								
My doctor/nurse has threatened or harassed me because of								

Is there anything else you would like us to know, that we haven't asked about?

Where did you hear about this survey?

End of Block: PLWHA Survey

Start of Block: HIV Prevention Survey

Sexual Health Survey

The purpose of this survey is to find out what people know and think about sexual health. The information gathered through the survey will be used to tell service providers what needs are being met and what needs are not being met. Survey results are confidential. When the research is complete, findings will be available at www.odh.ohio.gov/hiv.

► Each person should only take the survey one time.
► If you have questions about how to complete the survey, please contact Natalie Wilson at wilsonn3@ohio.edu or (740) 593-2343.
► Some questions on the survey may make you feel uncomfortable. You may choose neutral options or stop taking the survey at any time.

We are asking the next questions because it is important to capture the experiences of all our respondents.

How do you describe your gender?

- Female
- Male
- Non-binary
- Prefer not to say
- Prefer to self-describe-use the box below

#### Age:

Please select the year you were born.

▼ 1939 ... 2001

What sex were you assigned at birth, such as on an original birth certificate?

- Female
- Male
- Prefer not to say

Do you consider yourself to be:

- Bisexual
- Gay man
- Heterosexual or straight
- Lesbian/Gay woman
- Prefer not to say
- Prefer to self-describe-use the box below

How would you describe your race? Select all that apply.

- American Indian or Alaska Native
- Asian
- Black/African American

- Native Hawaiian or Pacific Islander
- White/Caucasian

Do you consider yourself to be Hispanic/Latinx?

- Yes
- No

Which of the following best describes your <u>yearly</u> income range?

- Less than \$15,000
- \$15,000 to \$34,999
- \$35,000 to \$49,999
- \$50,000 to \$74,999
- \$75,000 to \$99,999
- Over \$100,000

Please look at the map below. In which region do you live? Select from the drop down menu.

▼ Region 1... I don't live in Ohio but I receive services in Ohio.

Where do you go to learn about sexual health? Select all that apply.

- Friend
- Family member
- Internet
- Social media (Twitter, Instagram, Tumblr, Grindr, Reddit, Facebook)
- Health care professional
- Brochure/pamphlet
- Religious or spiritual advisor
- Other, use the box below

Please tell us whether you agree with the following statements.

	Agree	Neither Agree nor Disagree	Disagree
I am at risk for getting HIV			
I worry about the possibility of getting HIV			
If I get HIV or am diagnosed with AIDS, it is not a big problem. I could handle it			
HIV and AIDS can be taken care of pretty easily with medication			
I know how HIV is transmitted			

We are asking the next set of questions to better understand any experiences that may affect your risk for getting HIV.

Thinking about the last 12 months, please answer yes or no to the following questions. *If a question does not apply to you, please select no.* 

	Yes	No	Prefer not to say
Have you had oral, anal, or vaginal sex? (If you have not had sex in the past year, select No)			
Have you had a sexually transmitted infection (STI/STD) such as syphilis, gonorrhea or chlamydia?			
Have your sexual partner(s) injected street drugs or street hormones? (If you have not had sex in the past year, select No)			
Have you or your sexual partner(s) shared needles or works with another person?			
Have you had sex with a partner who identifies as a gay male, bisexual male or a transgender woman?			
Have you had sex with a person who is living with HIV?			
Have you experienced sex without your consent?			
Have you been incarcerated?			
Have you had sex to feel good when lonely or depressed?			
Have you had sex when you or your partner are drunk or high?			
Have you had sex with someone because you were afraid of losing them?			
Have you had sex with someone who asked you to trust them about their HIV status?			

Please tell us whether you agree or disagree with the following statements.

	Agree	Neither Agree nor Disagree	Disagree
I feel comfortable buying condoms.			
I feel comfortable discussing condom use with a casual sex partner.			
I feel pausing to put on a condom ruins the sexual mood.			
I feel comfortable stopping my sexual partner if they start to do something unsafe while we're having sex.			
I feel comfortable asking my partners about their sexual history.			
I do not feel comfortable around someone with HIV.			
I feel comfortable talking with my partner about when, when not, and how I want to have sex.			
I feel comfortable having sex with someone who is HIV positive and is undetectable.			

Please tell us whether you think the following statement are true or false. You may select "I don't know" if you do not know.

	True	False	Don't know
Coughing and sneezing spreads HIV			
A person can get HIV by sharing a glass of water with someone who has HIV			
Pulling out the penis before climaxing/cumming keeps your partner from getting HIV during sex			
Showering, or washing ones genitals/private parts, after sex keeps a person from getting HIV			
People who have been infected with HIV will quickly show serious signs of being infected			
There is a vaccine that can stop people from getting HIV			
There is an internal condom that can help decrease chances of getting HIV			
A natural skin condom works better against HIV than does a latex condom			
Taking a test for HIV one week after having sex will tell a person if they have HIV			
A person can get HIV from oral sex			
Using Vaseline or baby oil with condoms lowers the chance of getting HIV			
A person can't get HIV if they are the insertive (top) partner			
A person can't get HIV if their partner is HIV positive and virally suppressed (undetectable)			
A person can get HIV from sharing needles and/or works (equipment)			

Do you personally know anyone who is living with HIV, or who has passed away from complications related to HIV or AIDS?

- Yes
- No

Thinking about the last 12 months, please answer the following questions about how you think people have treated you. You may select more than one reason for how people treat you. If you do not feel that you have been treated the way described, select "This has not happened to me."

	Race	Gender/Gender Presentation	Sexual Orientation	Ethnicity/National Origin	Age	Other	This hasn't happened to me
I have been treated with less respect than other people because of							
I have been treated unfairly at restaurants or stores because of							
People criticized my accent or the way I speak because of							

People acted as if they think I am not smart because of			
People acted as if they are afraid of me because of			
People acted as if they think I am dishonest because of			
People acted as if they are better than me because of			
I have been threatened or harassed because of			

Have you ever been tested for HIV?

- Yes
- No
- I don't know

Display This Question:

If Have you ever been tested for HIV? = Yes

What was the reason you were tested for HIV?

- I wanted to know my status
- My partner asked me to be tested
- Someone I know was diagnosed with HIV
- I thought I might be at risk
- I have shared needles/works
- I had symptoms that made me or a health provider think I might have HIV
- I'm in a new relationship
- I was offered a test
- I was diagnosed with an STI/STD
- I was tested as part of my PrEP care
- Don't know
- Prefer not to answer
- Other, please specify in the box below:

Display This Question:

If Have you ever been tested for HIV? = Yes

Where have you been tested for HIV in the last 12 months?

- An HIV counseling and testing site/a free testing site
- A public health clinic, community health clinic, or sexually transmitted disease clinic
- A street outreach program or mobile unit
- A private doctor's office
- The emergency room
- During a hospital stay
- A correctional facility (jail or prison)
- Blood or plasma center
- Substance use treatment center
- I took an at-home test
- Community or special event (PRIDE, National HIV Testing Day, World AIDS Day)
- I was not tested in the last 12 months
- Other, please specify in the box below:

Display This Question:

If Have you ever been tested for HIV? = No

Or Have you ever been tested for HIV? = I don't know

If you have not been tested in the last 12 months, why not?

- I don't think I'm at risk for HIV
- There is no HIV testing site near me
- I don't want to be seen at a clinic
- I'm not concerned about my HIV status
- I've never been offered an HIV test
- I don't have health insurance or can't afford an HIV test
- I don't like needles
- I am afraid to find out whether I have HIV
- I'm worried about the cost of treatment
- I don't know where to get tested
- My partner is on PrEP
- My partner tested negative
- I have been tested for HIV in the last 12 months
- Other reason, please specify in the box below:

Display This Question:

If Have you ever been tested for HIV? = No

Or Have you ever been tested for HIV? = I don't know

What would make you more likely to be tested for HIV?

## PrEP/PEP Questions

Have you ever heard of PrEP?

- Yes
- No

Display This Question:

If PrEP/PEP Questions Have you ever heard of PrEP? = Yes

Do you currently take PrEP (also known as Truvada)?

- Yes
- No

Display This Question:

If Do you currently take PrEP (also known as Truvada)? = Yes

I experienced the following while taking PrEP. Select all that apply.

- I no longer worry about HIV
- I worry less about sex
- I find sex more pleasurable
- I have had more sex
- I have had less sex
- I am more aware of my sexual health
- I have engaged in sex I wouldn't have before taking PrEP
- I think about HIV more than I did before
- I worry more about STIs

PrEP is a daily pill that is prescribed by a health care provider. If you take PrEP 4 times a week, it can be highly effective in reducing the risk of getting HIV. It does not protect against other sexually transmitted infections.

Would you be interested in taking PrEP?

- Yes
- I already take PrEP
- No
- Not Sure

Have you heard about PEP?

- Yes
  - No Display This Question:

If Have you heard about PEP? = Yes

Have you ever used PEP?

- Yes
- No

PEP is medication that can be taken to reduce the risk of HIV infection <u>after</u> someone thinks they have been exposed to HIV. It must be started within 72 hours of exposure, and it is taken for 28 days. If you thought there was a chance you had been exposed to HIV, would you be interested in taking PEP?

- Yes
- No
- Not sure

Do you currently receive any counseling, therapy, or see a psychologist?

- Yes
- No
- Prefer not to say

I have trusted resources for support if I want to stop using substances (like alcohol, or street drugs).

- Yes
- No
- I do not use substances

In the past 30 or 90 days, have you been unable to get or pay for any of the following when it was really needed? Please select if this happened in the last 30 or 90 days.

	Yes, past 30 days	Yes, past 90 days	Has not happened
Food			
Utilities such as water, gas, or electricity			
Rent or mortgage			
A regular place to sleep			
Child care			

Transportation		
Phone		

During the past 30 or 90 days, did you experience any of the following?

	Yes, past 30 days	Yes, past 90 days	No
I thought it would be helpful if I saw a counselor, therapist, or psychologist.			
My family or friends were worried about my drug or alcohol use.			
I was worried about my drug or alcohol use.			

Where did you hear about this survey?

End of Block: HIV Prevention Survey

Start of Block: Gift Card Page

**You are now done with the survey!** Thank you for taking the time to answer our questions. Your information will help inform health services at the Ohio Department of Health. We would like to offer you a \$15 gift card to thank you for the time you took to answer our questions.

I do not wish to receive a gift card.

Mail my gift card (An envelope from Ohio University will be sent to you, along with a letter thanking you for your help with research. We will not specify what type of research you participated in) Available gift cards: WalMart, Aldi, Target, Kroger, Uber, Speedway, Marathon, Starbucks, Panera, Subway, Taco Bell, Tim Hortons, White Castle, Burger King, Arby's, Steak 'n Shake, McDonalds.

Which card would you like to receive?

- Walmart Note: By checking this box I understand that this card is not to be used for clothing, alcohol, or tobacco.
- Kroger Note: By checking this box I understand that this card is not to be used for clothing, alcohol, or tobacco.
- Aldi Note: By checking this box I understand that this card is not to be used for clothing, alcohol, or tobacco.
- Target Note: By checking this box I understand that this card is not to be used for clothing, alcohol, or tobacco.
- Uber
- Speedway
- Marathon
- Starbucks
- Panera

- Subway
- Taco Bell
- Tim Hortons
- White Castle
- Burger King
- Arby's
- Steak 'n Shake
- McDonalds

Please enter your mailing address and who you would like your envelope sent to.

Name on envelope
Address
City
State
Postal code

End of Block: Gift Card Page

Start of Block: Resources for people living with HIV

Display This Question:

If We are doing two surveys - one for people who are living with HIV, and one for people who are not... = Yes

**Resources for people living with HIV** <u>Click here to download</u> . Ohio HIV/AIDS Hotline: (800) 332-2437 http://ohiv.org/ . CDC health information hotline: 1-800-CDC-INFO (232-4636) In English, en Español, 8 am to 8 pm ET, Monday through Friday . 2018 Ryan White Case Manager contact list (sorted by region): https://odh.ohio.gov/wps/portal/gov/odh/know-our-programs/ryan-white-part-b-hiv-client-services/resources/2018cmprimarycontacts . HIV care locators: https://hivcare.org/ https://locator.hiv.gov/ . Equitas Health: https://equitashealth.com/

Caracole (Southwest Ohio): https://www.caracole.org 513-761-1480 hello@caracole.org
CANAPI (Summit and Portage counties) http://www.canapi.org/. Cleveland Ryan White

Part A https://www.ccbh.net/ryan-white/ . Columbus Ryan White Part A: https://www.columbus.gov/publichealth/programs/HIV-Testing-and-Care/

End of Block: Resources for people living with HIV

Start of Block: Prevention Assistance Program Interventions

Display This Question:

If We are doing two surveys - one for people who are living with HIV, and one for people who are not... = No

PAPI (Prevention Assistance Program Interventions) is an HIV prevention program created by the Ohio Department of Health. It is for HIV-negative Ohioans who have or are seeking a PrEP prescription. PAPI pays for PrEP-related medical costs. To find out more about PAPI, PrEP, or to be linked to a PrEP Health Navigator visit Ohiv.org

End of Block: Prevention Assistance Program Interventions

# Appendix 5. Region 3 PLWHA Survey Frequencies

Region 3 = 204

Years since HIV diagnosis.

	Frequency	Percent
Past 5 years	34	16.7
6 to 10 years	35	17.2
11 to 20 Years	71	34.8
21 to 25 years	17	8.3
26 to 30 years	28	13.7
31 or more years	19	9.3
Total	204	100.0

Age categories of respondents.

	Frequency	Percent
18-29	18	8.9
30-49	84	41.6
50+	100	49.5
Total	202	100.0

#### How do you describe your gender?

	Frequency	Percent
Female	54	26.5
Male	136	66.7
Non-Binary	13	6.4
Prefer not to say/Prefer to self-describe	1	0.5
Total	204	100.0

Sex assigned at birth, such as on an original birth certificate?

	Frequency	Percent
Female	54	26.5
Male	148	72.5
Prefer not to say	2	1.0
Total	204	100.0

	Frequency	Percent
Gay man	79	38.7
Heterosexual	70	34.3
Bisexual	32	15.7
Prefer to self-describe	13	6.4
Prefer not to say	8	3.9
Lesbian/Gay woman	2	1.0
Total	204	100.0

Orientation: Do you consider yourself to be:

How would you describe your race? Select all that apply.

	Frequency	Percent
White/Caucasian	75	36.8
Black/African American	118	57.8
Multiple selected	5	2.5
American Indian or Alaska Native	5	2.5
Asian	1	0.5
Native Hawaiian or Pacific Islander	0	0.0
Total	204	100.0

Do you consider yourself to be Hispanic/Latinx?

	Frequency	Percent
Hispanic	27	13.2
Not Hispanic	177	86.8
Total	204	100.0

Which of the following best describes your yearly income?

	Frequency	Percent
Less than \$15,000	102	50.0
\$15,000 to \$34,999	67	32.8
\$35,000 to \$49,999	17	8,3
\$50,000 to \$74,999	15	7.4
\$75,000 to \$99,999	3	1.5
0ver \$100,000	0	0.0
Total	204	100.0

When is the last time you saw a medical care provider for your HIV?

	Frequency	Percent
O to 6 months ago	161	78.9
7 to 12 months ago	27	13.2
Over a year ago but less than 2 years	10	4.9
Over 2 years ago	6	2.9

I have never seen a medical care provider for my HIV	0	0.0
Total	204	100.0

Why haven't you seen a medical care provider for your HIV in the last year or more? Select all that apply.

Note: Only those responding that they have not seen a provider in over 12 months see this question.

	Frequency	Percent	Percent of Respondents
Don't feel sick	8	18.2	50.0
Don't like thinking having about HIV	7	15.9	43.8
Don't have time	6	13.6	37.5
Haven't felt like going to appointments	6	13.6	37.5
Don't want anyone to know I have HIV	5	11.4	31.3
Other	5	11.4	31.3
Other things are more important to me	3	6.8	18.8
Can't afford it	2	4.5	12.5
Can't get transportation	1	2.3	6.3
I have been incarcerated	1	2.3	6.3
Don't know where to go	0	0.0	0.0
Substance use prevented me	0	0.0	0.0
Can't get an appointment	0	0.0	0.0
Released from incarceration, not reestablished care	0	0.0	0.0
Can't get child care	0	0.0	0.0

Have you had a viral load done in the last 12 months?

Note: Only those responding that they have seen a provider in over 12 months see this question.

	Frequency	Percent
Yes	162	86.2
No	17	9.0
l don't know/Not sure	9	4.8
Total	188	100.0

What were the results of your most recent viral load test?

Note: Only those responding that they had a viral load test done in the last 12 months see this question.

	Frequency	Percent
Less than 200 copies per mL	120	74.1
Over 200 copies per mL	24	14.8
I prefer not to say	1	.6
l don't know/Not sure	17	10.5

Total 162	100.0
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For the next set of questions, please think about your main HIV medical care provider and their office staff.

Only those responding that they have not seen a provider in the past 12 months see this question.

	Number Who Agree	Percent Who Agree
The doctor or medical staff		
treat me with courtesy and respect (n = 184)	165	89.7
listen carefully to me (n = 186)	167	89.8
explain things in a way I understand (n = 186)	161	86.6
The nursing staff		
treat me with courtesy and respect (n = 184)	161	87.5
listen carefully to me (n = 183)	161	88.0
explain things in a way I understand (n = 185)	163	88.1
The office staff (registration, scheduling)		
treat me with courtesy and respect (n = 184)	157	85.3
listen carefully to me (n = 183)	152	83.1
explain things in a way I understand (n = 182)	155	85.2

What would support you getting back into care (or starting care) for your HIV? Select all that apply. *Note: Only those responding that they have not seen a provider in over 12 months see this question.* 

	Frequency	Percent	Percent of Respondents
Support from family	7	16.7	43.8
Steady source of income	6	14.3	37.5
Support from friends	6	14.3	37.5
Coming to terms with my diagnosis	5	11.9	31.3
Other	5	11.9	31.3
Financial assistance for medical care	3	7.1	18.8
Housing services	3	7.1	18.8
Mental health services	2	4.8	12.5
Job training or employment services	2	4.8	12.5
Transportation assistance	2	4.8	12.5
More education on what HIV means to me	1	2.4	6.3
Substance use treatment	0	0.0	0.0

Over the last week, have you skipped/missed taking one or more of your HIV medication (ARTs) doses in a day?

	Frequency	Percent
Yes	54	26.5
No	134	65.7
I have not been prescribed HIV medication	2	1.0
I am not taking HIV medication	14	6.9
Total	204	100.0

	Frequency	Percent	Percent of Respondents
Forgot to take medication	31	38.3	57.4
Ran out of medication	10	12.3	18.5
Makes me feel sick (bad side effects)	7	8.6	13.0
Substance use got in the way	7	8.6	13.0
Other	7	8.6	13.0
I feel healthy	5	6.2	9.3
Mental health issues got in the way	6	7.4	11.1
Can't afford medication	3	3.7	5.6
In police custody/jail, no access to medication	3	3.7	5.6
No access to insurance	2	2.5	3.7

What has caused you to miss a dose of your HIV medication(s)? Select all that apply. *Note: Only those who answer yes to missing medication doses see this question.* 

Write-in responses for those who chose "other" to the question above follow:

- "At emergency room"
- "Fell asleep"
- "I'm unemployed and don't have transportation to go to the doctor's office to sign up for ODAP and no money for transportation so I go without medication often until I'm able to secure employment then I start back on my medication."
- "It's not important to me, I don't see the need"
- "Really not that concerned with it"
- "Spent the night over at a friend's house and forgot my dosage"
- "Was confused because of COVID-19"

Please complete the following sentence: I'm not currently taking HIV medication because: Select all that apply.

Note: Only those who respond that they have not been prescribed or are not taking HIV medication see this question.

	Frequency	Percent	Percent of Respondents
Feel healthy	9	18.8	56.3
Other	8	16.7	50.0
Makes me feel sick (bad side effects)	7	14.6	43.8
Tired of taking my meds	6	12.5	37.5
Life situation prevents taking meds as prescribed	5	10.4	31.3
Don't want to take HIV medication	4	8.3	25.0
Don't know how to get meds in a way that protects privacy	3	6.3	18.8
I can't afford my HIV medication	3	6.3	18.8
I'm worried that someone will see me taking my medication	1	2.1	6.3
Don't know where to get medication	1	2.1	6.3
Trouble remembering to take medication	1	2.1	6.3
Ran out of medication	0	0.0	0.0
Taking medication currently prescribed to me	0	0.0	0.0
Don't have a pharmacy I feel comfortable with	0	0.0	0.0

How do you pay for your HIV medical care? Select all that apply.

Note: Only those who answer they have OR have not missed medication doses see this question. Only those who access medical services are included.

	Frequency	Percent	Percent of Respondents
Medicaid	99	32.2	52.7
Ryan White services	96	31.3	51.1
Medicare	56	18.2	29.8
Private insurance	30	9.8	16.0
ACA/Obamacare	15	4.9	8.0
Pay for my own care	6	2.0	3.2
VA health insurance	5	1.6	2.7

	Frequency	Percent	Percent of Respondents
Case management	122	20.7	62.2
ADAP	108	18.4	55.1
Financial assistance for medical services	76	12.9	38.8
Dental services	69	11.7	35.2
Housing case management	49	8.3	25.0
Emergency medications assistance	48	8.2	24.5
Medical transportation	48	8.2	24.5
Mental health services	32	5.4	16.3
Don't know	31	5.3	15.8
Other	5	0.9	2.6

Have you ever used any of the following Ryan White services? Select all that apply.

Write-in responses for those who chose "other" to the question above follow:

- "Assistance with utilities"
- "At the University Hospital"
- "Eyeglasses" (2)

The following is a list of services available through the Ryan White program. Please tell us whether you had a need for any of the services in the last 12 months and whether you received the service.

	Did not need	Needed and RECEIVED service/support		Needed but DID NOT receive service/support	
	Ν	Ν	%	Ν	%
Inpatient substance use treatment (when you are admitted)	165	30	78.9	8	21.1
Outpatient substance use treatment (when you make an appointment)	158	30	66.7	15	33.3
Peer navigation (someone else living with HIV who can help you with information and support)	135	42	61.8	26	38.2
Mental health care	120	66	79.5	17	20.5
Dental care	78	94	75.2	31	24.8
Case management (someone to help with medical appointments, scheduling, transportation, and getting public assistance)	65	117	84.8	21	15.2
An appointment with a doctor, nurse, or other provider as part of your HIV treatment (outpatient medical care)	51	138	90.8	14	9.2
Medication program (to help pay for HIV medications)	48	138	89.0	17	11.0

If you needed any of the above services and did not receive them, why not? Select all that apply.

	Frequency	Percent	Percent of
			Respondents
I did not know this service existed	26	22.0	38.2
Other	25	21.2	36.8
I never received a call back	19	16.1	27.9
I cannot afford this service	15	12.7	22.1
l didn't have time to go to an appointment	11	9.3	16.2
Office hours are inconvenient for my schedule	10	8.5	14.7
I did not have transportation to get to this service	9	7.6	13.2
There is no provider near me	3	2.5	4.4

Thinking about your most recent Ryan White case manager and the staff in their office, how much do you agree with the statements below?

Note: Only those who report using Ryan White services see this question.

	Number Who Agree	Percent Who Agree
Explains things in a way I can understand	142	87.7
Treats me with courtesy and respect	140	86.4
Listens carefully to me	139	85.8
Helps me to re-enroll in Ryan White services on time	135	83.3
Helps me to get the medical care/services I need	127	78.4
Provides me support navigating the Ryan White program	127	78.4
Provides me with up-to-date information about services available to me	123	75.9
Helps me to get the non-medical services I need	120	74.1

In the last 12 months, have you been diagnosed with any of the following? (n = 201)

	Number Yes	Percent Yes
High blood pressure	53	26.4
Mental health diagnosis	35	17.4
Sexually transmitted infection (STI)	24	11.9
Heart disease	16	8.0
Substance use disorder	15	7.5
Kidney disease	14	7.0
Diabetes	13	6.5
Cancer	9	4.5
Hepatitis C	6	3.0
Hepatitis A	3	1.5

Have you used unprescribed medications or substances in the last 12 months (e.g., unprescribed medications, alcohol, marijuana, meth, crack, heroin, etc.)?

	Frequency	Percent
Yes	61	30.3
No	120	59.7
Prefer not to say	20	10.0
Total	201	100.0

Please read the following list of services related to substance use treatment, and tell us whether you need each support and whether you are receiving each support.

Note: Only those who report using unprescribed substances see this question.

	Did not need	Needed and RECEIVED service/support		Needed but DID NOT receive service/support	
	Ν	Ν	%	Ν	%
Detoxification (detox) in a residential setting	53	6	75.0	2	25.0
Harm reduction education and strategies (such as needle exchange)	54	6	85.7	1	14.3
Medication-assisted treatment, such as methadone or suboxone	53	6	75.0	2	25.0
12-step program, such as Narcotics Anonymous or Alcoholics Anonymous	49	10	83.3	2	16.7
Relapse prevention services	50	7	63.6	4	36.4
A counselor or therapist for me to focus on my substance use	40	17	81.0	4	19.0

In the past 30 or 90 days, have you been unable to get or pay for any of the following when it was really needed? Please select if this happened in the last 30 or 90 days. (n = 201)

	Yes, Pa	Yes, Past 30 Days Yes, Past 9		: 90 Days Did N		Not Happen	
	Ν	%	Ν	%	N	%	
Food	38	18.9	33	16.4	130	64.7	
Pay my rent or mortgage	37	18.4	30	14.9	134	66.7	
Utilities such as water, gas, or electricity	38	18.9	31	15.4	132	65.7	
Phone	36	17.9	24	11.9	141	70.1	
Transportation to medical care providers	30	14.9	22	10.9	149	74.1	
A regular place to sleep	12	6.0	13	6.5	176	87.6	
Child care	6	3.0	5	2.5	190	94.5	

Please tell us whether you agree or disagree with the following statements:

( <i>n</i> = 201)	Number Who Agree	Percent Who Agree
It would probably be helpful if I saw a counselor, therapist, or psychologist.	100	49.8
I would not want anyone to know if I saw a counselor, therapist, or psychologist.	87	43.3
I could not afford to see a counselor, therapist, or psychologist.	84	41.8
I have not considered going to see a counselor, therapist, or psychologist.	81	40.3
The wait time to see a counselor, therapist, or psychologist is too long.	65	32.3
I would not know how to find a counselor, therapist, or psychologist.	62	30.8
I would not have transportation to a counselor, therapist, or psychologist.	50	24.9
There aren't any counselors, therapists, or psychologists close enough to where I live.	44	21.9

	Do not need	Need and RECEIVED service/support		Need but DO NOT receive service/support	
	Ν	Ν	%	Ν	%
Substance use treatment	160	29	70.7	12	29.3
A support group for my friends and family	143	34	58.6	24	41.4
Peer navigation (someone else living with HIV who can help you with information and support)	108	46	49.5	47	50.5
A support group for people living with HIV	86	79	68.7	36	31.3
A counselor or therapist for me	105	64	66.7	32	33.3
Opportunities to get together with other people who are living with HIV to do activities or go on trips	79	63	51.6	59	48.4

Thinking about the medical staff (such as nurses/doctors) at your HIV Care Provider in the last 12 months, please answer the following questions about how you think they have treated you. You may select more than one reason. If you do not feel that you have been treated the way described, select "This has not happened to me."

	HIV Status	Race	Gender/ Presentation	Sexual Orientation	Ethnicity/Nat Origin	Age	Financial Status	Has not happened	:
	Ν	Ν	Ν	Ν	Ν	Ν	Ν	Ν	%
Threatened or harassed me	2	6	2	7	1	3	0	169	92.3
Acted as if they think I am dishonest	7	5	3	3	2	1	3	169	92.3
Acted as if they are better than me	9	5	2	4	2	2	5	163	89.1
Acted as if they are afraid of me	7	9	4	5	1	2	1	164	89.6
Acted as if they think I am not smart	7	8	3	5	1	5	2	162	88.5
Treated me with less respect than other people	8	9	3	9	3	4	4	159	86.9

# Appendix 6. Region 3 PHR Survey Frequencies

Region 3 = 173

Age categories of respondents.

	Frequency	Percent
18-29	87	50.6
30-49	60	34.9
50+	25	14.5
Total	172	100.0

How do you describe your gender?

	Frequency	Percent
Female	90	52.0
Male	76	43.9
Non-Binary	2	1.2
Prefer not to say/self-describe	5	2.9
Total	173	100.0

Sex assigned at birth, such as on an original birth certificate?

	Frequency	Percent
Female	90	52.0
Male	80	46.2
Prefer not to say/Prefer to self-describe	3	1.7
Total	173	100.0

Orientation: Do you consider yourself to be:

	Frequency	Percent
Heterosexual	121	69.9
Bisexual	22	12.7
Prefer not to say	15	8.7
Prefer to self-describe	6	3.5
Lesbian/Gay woman	5	2.9
Gay man	4	2.3
Total	173	100.0

How would you describe your race? Select all that apply.

	Frequency	Percent
White/Caucasian	109	63.0
Black/African American	51	29.5
Multiple selected	8	4.6
Native Hawaiian or Pacific Islander	4	2.3
Asian	1	0.6
American Indian or Alaska Native	0	0.0
Total	173	100.0

Do you consider yourself to be Hispanic/Latinx?

	Frequency	Percent
Hispanic	11	6.4
Not Hispanic	162	93.6
Total	173	100.0

Which of the following best describes your yearly income?

	Frequency	Percent
Less than \$15,000	99	57.2
\$15,000 to \$34,999	42	24.3
\$35,000 to \$49,999	16	9.2
\$50,000 to \$74,999	10	5.8
\$75,000 to \$99,999	1	.6
0ver \$100,000	5	2.9
Total	173	100.0

Where do you go to learn about sexual health? Select all that apply.

	Frequency	Percent	Percent of Respondents
Internet	113	24.0	65.3
Health care professional	105	22.3	60.7
Friend	77	16.3	44.5
Family member	63	13.4	36.4
Other	11	2.3	6.4
Brochure/pamphlet	52	11.0	30.1
Social media (Twitter, Instagram, Tumblr, Grindr, Reddit,	42	8.9	24.3
Facebook)			
Religious or spiritual advisor	8	1.7	4.6

Following are write-in responses provided from the question above:

- AA support group/ lgbtq center
- Books and magazines
- I don't really go looking to learn about sexual health
- School
- School health class
- School, health class
- Self

Please tell us whether you agree with the following statements.

	Number Who Agree	Percent Who Agree
I know how HIV is transmitted	138	79.8
I am at risk for getting HIV	59	34.1
I worry about the possibility of getting HIV	51	29.5
HIV and AIDS can be taken care of pretty easily with medication	50	28.9
If I get HIV or am diagnosed with AIDS, it is not a big problem. I could handle it	29	16.8

Thinking about the last 12 months, please answer yes or no to the following questions. If a question does not apply to you, please select no. (n = 171)

	Number yes	Percent yes
Have you had oral, anal, or vaginal sex? (If you have not had sex in the past year, select No)	146	85.4
Have you had sex when you or your partner is drunk or high?	118	69.0
Have you had sex to feel good when lonely or depressed?	86	50.3
Have you had sex with someone because you were afraid of losing them?	51	29.8
Have you experienced sex without your consent?	33	19.3
Have you had sex with a partner who identifies as a gay male, bisexual male, or a _transgender woman?	24	14.0
Have you had a sexually transmitted infection (STI/STD) such as syphilis, gonorrhea, or chlamydia?	34	19.9
Have you had sex with someone who asked you to trust them about their HIV status?	19	11.1
Have you been incarcerated?	39	22.8
Have your sexual partner(s) injected street drugs or street hormones? (If you have not had sex in the past year, select No)	29	17.0
Have you or your sexual partner(s) shared needles or works with another person?	16	9.4
Have you had sex with a person who is living with HIV?	10	5.8

Please tell us if you agree or disagree with the following statements.

( <i>n</i> = 171)	Number Who Agree	Percent Who Agree
I feel comfortable buying condoms.	146	85.4
I feel comfortable discussing condom use with a casual sex partner.	143	83.6
I feel comfortable talking with my partner about when, when not, and how I want to have sex.	134	78.4
I feel comfortable stopping my sexual partner if they start to do something unsafe while we're having sex.	132	77.2
I feel comfortable asking my partners about their sexual history.	129	75.4
I do not feel comfortable around someone with HIV.	43	25.1
I feel pausing to put on a condom ruins the sexual mood.	41	24.0
I feel comfortable having sex with someone who is HIV positive and is undetectable.	23	13.5

Please tell us whether you think the following statements are true or false. You may select "I don't know" if you do not know.

	Number Answering Correctly	Percent Answering Correctly
Pulling out the penis before climaxing/cumming keeps your partner from getting HIV during sex (false)	148	85.5
A person can get HIV from sharing needles and/or works (equipment)(true)	146	84.4
Showering, or washing ones genitals/private parts, after sex keeps a person from getting HIV (false)	142	82.1
People who have been infected with HIV will quickly show serious signs of being infected (false)	140	80.9
Using Vaseline or baby oil with condoms lowers the chance of getting HIV (false)	134	77.5
A person can't get HIV if they are the insertive (top) partner (false)	130	75.1
Coughing and sneezing spreads HIV (false)	131	75.7
A person can get HIV by sharing a glass of water with someone who has HIV (false)	129	74.6
A person can get HIV from oral sex (true)	116	67.1
There is a vaccine that can stop people from getting HIV (false)	97	56.1
Taking a test for HIV one week after having sex will tell a person if they have HIV (false)	92	53.2
A natural skin condom works better against HIV than does a latex condom (false)	83	48.0
There is an internal condom that can help decrease chances of getting HIV (true)	58	33.5
A person can't get HIV if their partner is HIV positive and virally suppressed (undetectable)(true)	34	19.7

Do you personally know anyone who is living with HIV, or who has passed away from complications related to HIV or AIDS?

	Frequency	Percent
Yes	64	38.1
No	104	61.9
Total	168	100.0

Thinking about the last 12 months, please answer the following questions about how you think people have treated you. You may select more than one reason for how people treat you. If you do not feel that you have been treated the way described, select "This has not happened to me."

	Race	Gender/ Presentation	Sexual Orientation	Ethnicity/Nat Origin	Age	Other	Has not happened	Percent Has not happened
	Ν	Ν	Ν	Ν	Ν	Ν	N	%
People criticized my accent or the way l speak	22	12	4	15	5	6	115	69.7
People acted as if they are afraid of me	25	10	4	10	3	12	112	67.9
l have been treated unfairly at restaurants or stores	26	17	3	6	20	7	101	61.2
People acted as if they think I am dishonest	28	14	7	10	11	11	103	62.4
I have been threatened or harassed	30	30	7	4	11	7	106	64.2
People acted as if they think I am not smart	29	40	1	12	27	13	80	48.5
People acted as if they are better than me	41	41	9	11	30	18	66	40.0
I have been treated with less respect than other people	44	48	18	18	44	18	59	35.8

Have you ever been tested for HIV?

	Frequency	Percent
Yes	108	62.4
No	52	30.1
l don't know	13	7.5
Total	173	100.0

What was the reason you were tested for HIV? Select all that apply. Note: Only those who responded that they have been tested for HIV see this question.

	Frequency	Percent	Percent of Respondents
I wanted to know my status	62	35.2	57.4
I was offered a test	37	21.0	34.3
I thought I might be at risk	22	12.5	20.4
I'm in a new relationship	11	6.3	10.2
I have shared needles/works	10	5.7	9.3
Other	9	5.1	8.3
My partner asked me to be tested	8	4.5	7.4
Someone I know was diagnosed with HIV	6	3.4	5.6
I was diagnosed with an STI/STD	4	2.3	3.7
I was tested as part of my PrEP care	4	2.3	3.7
I had symptoms that made me or a health provider think I might have HIV	2	1.1	1.9
Don't know	1	0.6	0.9
Prefer not to answer	0	0.0	0.0

Where have you been tested for HIV in the last 12 months?

Note: Only those who responded that they have been tested for HIV see this question. Only those who have been tested in the past 12 months are displayed.

	Frequency	Percent	Percent of Respondents
A public health clinic, community health clinic, or sexually	31	23.5	34.4
transmitted disease clinic			
A private doctor's office	24	18.2	26.7
An HIV counseling and testing site/a free testing site	20	15.2	22.2
A street outreach program or mobile unit	15	11.4	16.7
A correctional facility (jail or prison)	10	7.6	11.1
Community or special event (PRIDE, National HIV Testing Day, World AIDS Day)	7	5.3	7.8
Other	5	3.8	5.6
Blood or plasma center	5	3.8	5.6
Substance use treatment center	5	3.8	5.6
During a hospital stay	5	3.8	5.6
The emergency room	5	3.8	5.6
l took an at-home test	0	0.0	0.0

If you have not been tested in the last 12 months, why not? Note: Only those who respond that they have not been tested or don't know see this question.

	Frequency	Percent	Percent of Respondents
l don't think I'm at risk for HIV	34	47.2	61.8
I'm not concerned about my HIV status	12	16.7	21.8
l've never been offered an HIV test	8	11.1	14.5
l don't know where to get tested	5	6.9	9.1
l don't want to be seen at a clinic	3	4.2	5.5
My partner tested negative	3	4.2	5.5
Other reason	3	4.2	5.5
There is no HIV testing site near me	3	4.2	5.5
I don't have health insurance or can't afford an HIV test	1	1.4	1.8
l don't like needles	0	0.0	0.0
I'm worried about the cost of treatment	0	0.0	0.0
I am afraid to find out whether I have HIV	0	00	0.0
My partner is on PrEP	0	0.0	0.0

Have you ever heard of PrEP?

	Frequency	Percent
Yes	72	43.6
No	93	56.4
Total	165	100.0

Do you currently take PrEP (also known as Truvada)? Note: Only those who have heard of PrEP see this question.

	Frequency	Percent
Yes	4	5.6
No	68	94.4
Total	72	100.0

I experienced the following while taking PrEP. Select all that apply. Note: Only those who report they take PrEP see this question.

	Frequency	Percent	Percent of Respondents
I no longer worry about HIV	3	30.0	75.0
I am more aware of my sexual health	2	20.0	50.0
I have had less sex	1	10.0	25.0
l worry less about sex	1	10.0	25.0
I have engaged in sex I wouldn't have before taking PrEP	1	10.0	25.0
I think about HIV more than I did before	1	10.0	25.0
l find sex more pleasurable	1	10.0	25.0
I have had more sex	0	0.0	0.0
I worry more about STIs	0	0.0	0.0

### Would you be interested in taking PrEP?

	Frequency	Percent
Yes	25	15.2
l already take PrEP	4	2.4
No	76	46.1
Not sure	60	36.4
Total	165	100.0

Have you heard about PEP?

	Frequency	Percent
Yes	39	23.6
No	126	76.4
Total	165	100.0

Have you ever used PEP?

Note: Only those who report they have heard of PEP see this question.

	Frequency	Percent		
Yes	3	7.7		
No	36	92.3		
Total	39	100.0		

If you thought there was a chance you had been exposed to HIV, would you be interested in taking PEP?

	Frequency	Percent
Yes	98	59.4
No	30	18.2
Not sure	37	22.4
Total	165	100.0

Do you currently receive any counseling or therapy, or see a psychologist?

	Frequency	Percent
Yes	26	15.9
No	135	82.3
Prefer not to say	3	1.8
Total	164	100.0

I have trusted resources for support if I want to stop using substances (like alcohol, or street drugs).

	Frequency	Percent
Yes	93	56.4
No	33	20.0
l do not use substances	39	23.6
Total	165	100.0

In the past 30 or 90 days, have you been unable to get or pay for any of the following when it was really needed? Please select if this happened in the last 30 or 90 days. (*n* = 165)

	Yes, Past 30 Days		Yes, Past 90 Days		Did Not	t Happen
	Ν	%	Ν	%	Ν	%
Child care	10	6.1	12	7.3	143	86.7
A regular place to sleep	25	15.2	12	7.3	128	77.6
Phone	29	17.6	14	8.1	122	73.9
Transportation to medical care providers	32	19.4	23	13.9	110	66.7
Utilities such as water, gas, or electricity	29	17.6	24	14.5	112	67.9
Pay my rent or mortgage	33	20.0	16	9.7	116	70.3
Food	28	17.0	22	13.3	115	69.7

During the past 30 or 90 days, did you experience any of the following? (n = 165)

	Yes, Past 30 Days		Yes, Past 90 Days		No	
	Ν	%	Ν	%	Ν	%
I thought it would be helpful if I saw a counselor, therapist, or psychologist.	39	23.6	23	13.9	103	62.4
My family or friends were worried about my drug or alcohol use.	23	13.9	13	7.9	129	78.2
I was worried about my drug or alcohol use.	23	13.9	16	9.7	126	76.4