



**SOUTHWESTERN PENNSYLVANIA  
REGIONAL HIV NEEDS ASSESSMENT  
2017/2019**

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## **SOUTHWESTERN PENNSYLVANIA REGIONAL HIV NEEDS ASSESSMENT**

### **SECTION A: INTRODUCTION**

#### **I. INTRODUCTION**

The Jewish Healthcare Foundation, as the lead agency in southwestern Pennsylvania, is tasked with conducting a needs assessment of the region's Ryan White HIV programs. This needs assessment serves to evaluate the implementation of HIV service models within the region; it can be used to assist with the regional planning process by providing a basis for priority setting and resource allocation.

Methods that were used in order to complete this needs assessment included the following:

- Literature and epidemiological data review
- Review of the region's HIV resources
- HIV consumer survey
- HIV provider interviews

The information within this document will illustrate the current delivery of HIV services, the distribution of Ryan White funds, and the gaps in services. This information may be used to guide stakeholders in making improvements to the care delivery system. It may also be used to advocate for people living with HIV at the state and federal levels to support increases or additions to their existing services.

#### **II. JEWISH HEALTHCARE FOUNDATION AND RYAN WHITE PROGRAMS**

The Jewish Healthcare Foundation (JHF) serves as the southwestern Pennsylvania (SWPA) lead agency for funding from the following programs: Ryan White Part B, State 656, AIDS Drug Assistance Program (ADAP), Emerging Communities, Minority AIDS Initiative (MAI), and Housing Opportunities for Persons with AIDS (HOPWA) in the 11-county southwestern Pennsylvania region. These funding streams facilitate the delivery of healthcare, supportive, and housing services to eligible individuals living with HIV/AIDS, as well as prevention and education services to at-risk populations.

JHF has served in this role since 1992 and is responsible for disbursing these grants annually, as well as helping the direct providers of services meet the federal and state requirements for program and fiscal management. JHF conducts monitoring and reporting to improve program efficiency and responsiveness; when possible, JHF helps streamline and standardize the work being done by the direct providers. Most importantly, the lead agency is responsible for strengthening the continuum of care and ensuring all eligible consumers receive services and medical support necessary to live a healthy life.

#### **III. PURPOSE, GOALS, AND SCOPE OF NEEDS ASSESMENT**

##### ***Purpose and Goals***

The purpose of this needs assessment is to collect information about the needs of People Living With HIV (PLWH)—both those receiving care and those who are not in care. The needs assessment will

ultimately determine where service gaps and where opportunities for improvements exist. This will provide a basis for planning future HIV/AIDS work in the region. The following goals were identified for the needs assessment:

1. To identify barriers that prevent PLWH from accessing services in SWPA
2. To characterize the challenges HIV providers face in delivering services for PLWH
3. To describe the strengths and weaknesses of the HIV service delivery system and related resources in SWPA
4. To describe HIV prevalence and incidence trends specific to SWPA

### *Scope*

This assessment focuses specifically on access and quality of services for HIV positive individuals. This needs assessment did not specifically assess prevention services, since Ryan White funds are primarily intended for individuals living with HIV. However, prevention did emerge as a concern in conversations with providers, so this report will include a limited discussion of related issues.

## **VI. KEY FINDINGS**

The following are the major themes that emerged from the needs assessment research. They include the key findings from the literature and epidemiological data review, the consumer survey, and the provider interviews. The last subheading, “overall themes” contains a synthesis of the major ideas that emerged through each method of data collection.

### *Literature and Epidemiological Data Review*

- HIV incidence in SWPA is remaining steady over time, rather than declining as it is nationally (2005-2014)
- Incidence of HIV is currently low in rural counties; however the increase in injection drug use and lack of access to syringe exchange may put rural areas at risk for HIV outbreaks in the future
- Rural counties in the region have high poverty rates and significant health professional shortages; therefore, access to health care is a concern
- Injection drug transmissions make up a smaller portion of new infections in SWPA compared to other regions in the state, as well as nationwide trends
- Similar to national trends, new infections in SWPA disproportionately occur in Black/African American and Multiracial populations; and Black/African Americans and Multiracial populations are overrepresented among total PLWH in SWPA
- Similar to national trends, SWPA incidence is steady or decreasing in all age groups except 20-29, in which it is increasing
- In comparison to Pennsylvania overall, a larger portion of the new infections in SWPA were in the 20-29 age group (2010-2015)
- Most of the increases in incidence during the past 10 years were in Allegheny County; other counties have remained fairly steady
- The capacity of behavioral health services in SPWA is inadequate, especially in rural counties

## *Consumer Survey*

### **Sample Characteristics**

- The sample was close but not entirely representative of people engaged in care in SWPA
  - Participants tended to be older than PLWH in SWPA
  - Sample approximated the rural/urban distribution of residency of PLWH in SWPA
  - Sample approximated the racial distribution of PLWH in SWPA
  - Sample approximated the gender distribution of PLWH in SWPA
- Large portion of sample had insurance through Medicaid (58.7%)
- 7 respondents use VA insurance
- 73.6% reported undetectable viral load
- 26.1% have received treatment for substance use
- 62.8% reported at least one mental health diagnosis

### **Findings**

- Generally positive perspectives on primary medical care, case management, and nonmedical support services
- This particular sample is very engaged in and interested in alternative therapies and wellness-focused activities
- Highest priorities in HIV care are:
  - Staff understand the needs of people living with HIV/AIDS
  - Can get to services easily
  - Easy to schedule appointments
  - Services are free/low cost or they take my insurance
  - I can get multiple services at the same location
- Concerns that emerged most often:
  - Getting and keeping affordable housing close to care
  - Burden of recertification and paperwork
  - Access from rural areas
  - Financial challenges
- A few consumers reported that they do not feel comfortable discussing their sexual health or drug use with providers
- Other consumers described their relationship with providers in very positive terms
- 13% of consumers reported that they had stopped taking HIV medications or missed doses in the past 6 months

**Provider Interviews**

<b>Individual-level barriers</b>	<b>Provider-level barriers</b>	<b>System &amp; policy-level barriers</b>
<p><i>Barriers that prevent diagnosed individuals from accessing HIV services, adhering to medication, and remaining in medical care</i></p> <ul style="list-style-type: none"> <li>• Treatment fatigue</li> <li>• Substance use</li> <li>• Mental illness</li> <li>• Burden of diagnosis</li> <li>• Burden of poverty</li> <li>• Literacy and communication</li> <li>• Unstable and unaffordable housing</li> <li>• Stigma/fear of disclosure</li> </ul>	<p><i>Barriers that prevent HIV service providers from optimally serving their consumers</i></p> <ul style="list-style-type: none"> <li>• Turnover</li> <li>• Lack of cultural competence</li> <li>• HIV medical provider shortage</li> <li>• Working with government agencies and non-HIV healthcare providers</li> <li>• Collaborations with other HIV service providers</li> <li>• Gathering consumer input</li> <li>• Staff development</li> <li>• Stigma</li> <li>• Connecting with younger clients</li> </ul>	<p><i>Barriers within the larger system or policies that prevent consumers from accessing services, adhering to medication, and remaining in care; or prevent providers from optimally serving their consumers</i></p> <ul style="list-style-type: none"> <li>• Behavioral health system capacity</li> <li>• MATP restrictions</li> <li>• Segregation of behavioral and physical health services</li> <li>• Lack of available subsidized housing close to medical care</li> <li>• Recertification requirements</li> </ul>

<b>Recommendations and Visions</b>
<ul style="list-style-type: none"> <li>• Better communication and information sharing between consumers and doctors</li> <li>• Integrated mental health in HIV-service organizations</li> <li>• More opportunities for peer connection and support in nontraditional ways; ex. congregate housing, outings, community meeting spaces</li> <li>• Staff development opportunities: case management training, cultural competency training</li> <li>• Age-specific programs and outreach</li> <li>• More opportunities for consumer input</li> <li>• Routinized/expanded testing and prevention activities</li> <li>• Stronger referral network and better relationships with non-HIV agencies</li> <li>• Messaging to educate the public and reduce stigma about HIV</li> <li>• More subsidized housing close to HIV care</li> <li>• More support for consumers seeking employment; ex. transportation assistance</li> <li>• More transparency from funders to organizations, and from organization staff to consumers</li> <li>• Expanded food access specific to the HIV community</li> <li>• Widespread adoption of harm reduction principles and programming</li> </ul>

<b>Strengths</b>
<ul style="list-style-type: none"> <li>• Consumer anonymity in organizations that are not HIV-specific</li> <li>• Variety of services offered at same organization</li> <li>• Strong collaborations and partnerships with other HIV service organizations</li> <li>• Utility of unrestricted funding sources to provide gap support</li> <li>• Resiliency of consumers</li> <li>• Strong Special Pharmaceutical Benefits Program (SPBP)</li> </ul>

## *Overall Themes*

### **Housing**

- Lack of affordable housing for low-income people in Pittsburgh
- Housing subsidy programs have long wait lists and can disqualify individuals on basis of criminal background and substance use history
- Low-income PLWH are being forced to move further away from care—access and transportation to medical care and supportive services become significant problems in these cases

### **Recertification and Paperwork**

- Recertification is burdensome for consumers and providers
- Information-sharing collaborations and strong partnerships can reduce the burden for providers
- Clarity and transparency in communication from funders to ASOs and ASO staff to consumers regarding requirements can help to reduce burden of recertification and other paperwork

### **Stigma**

- Stigma is still pervasive in the general public around HIV
- PLWH are often members of more than one marginalized group; as such, they may be particularly vulnerable to discrimination
- A history of mistreatment in medical settings may make PLWH hesitant to disclose personal information to providers

### **Rural Issues**

- Health professional shortages, rural PCP inexperience treating HIV, and transportation present access barriers for rural consumers
- Stigma is particularly pervasive in rural areas
- Opioid use is particularly prevalent in SWPA rural areas, and access to harm reduction services is low; as a result, rural areas of SWPA may be at risk for HIV outbreaks

### **Behavioral Health**

- There are not enough behavioral health providers to meet the demand across the region, and particularly in rural counties
- Behavioral health needs are particularly great among PLWH in SWPA
- Behavioral health services should be integrated into primary care

### **Communication and Consumer-Provider Relationships**

- Providers and consumers both noted communication challenges in their relationships with each other
- Consumers may have histories of being treated poorly by providers due to personal characteristics, including their HIV diagnosis; they may feel uncomfortable disclosing around sexual health and drug use as a result

- Lack of clarity, mistrust, staff turnover and cultural competency, and health literacy all impact the consumer-provider relationship

### **Youth and Aging Issues**

- Many providers believe that youth are less engaged with HIV-specific services other than primary medical care
- Individuals aging with HIV face unique challenges, such as treatment fatigue, isolation, and depression. Providers suggested age-specific programming and creative solutions to combat these issues
- Some providers work particularly well with young people, while other providers are less connected with this population; this may suggest a possible area for collaboration and learning

## **SECTION B: METHODS**

### **I. Consumer Survey Methods and Limitations**

#### ***Development***

The consumer survey was adapted primarily from the Massachusetts and Southern New Hampshire HIV/AIDS Consumer Survey, which was developed by JSI Research and Training Institute (2011). Adaptations were made to shorten the tool and incorporate input from the JHF HIV/AIDS team. The survey consisted of 47 questions across several topic areas; question type varied between multiple choice, dichotomous, rating scales, and open-ended.

JHF developed a paper version and identical online SurveyMonkey version of the survey. The paper version was 10 pages long and both versions took less than 15 minutes to complete. Subsections of the survey included the following (See Appendix A for the full survey tool):

- Demographics
- Primary Care
- HIV Medications and Adherence
- Housing
- Access
- Substance Use
- Mental Health
- Risk Reduction
- HIV Knowledge and Resources
- Aging
- Additional Information

#### ***Dissemination***

JHF utilized existing relationships with direct providers of services to disseminate the survey; thus the participants represent a convenience sample of consumers who are engaged in care. JHF provided paper surveys or links to the online version to direct provider staff for dissemination to consumers. Survey participation was voluntary and no incentives were provided for consumers who took the survey or the providers who disseminated it.

The only eligibility criteria were that participants must reside within the 11-county SWPA region and must be HIV-positive. The online survey automatically disqualified individuals who did not meet these eligibility criteria; paper survey responses from individuals who did not meet criteria were also removed.

Service providers individually decided how to disseminate the survey. Some providers offered the survey at meetings or group activities, while other providers offered the survey individually to consumers. Providers were instructed to verbally inform consumers of the survey disclosures and provide a summary of the instructions. Participation rates were not calculated, as organizations did not collect information on number of consumers who refused the survey.

There were several ways in which consumers could access and complete the survey. Consumers could access the survey by themselves online with a link; they could access the survey online using computers or tablets at certain provider locations; or they could complete a paper survey supplied by a service provider. Case managers, service provider staff, or JHF staff members were available to assist consumers with completing the survey if literacy or comprehension posed a barrier. The majority of participating organizations provided only the paper version of the survey. Consumers returned the survey directly to the provider organization, and most completed and returned the survey immediately.

### *Limitations*

The consumer survey was limited in a number of ways. First, the survey was long. The length was a consequence of the intention to capture a wide range of information; however, this naturally affected consumers' willingness to participate and resulted in a small sample size. Secondly, incentives were not available for participation, which also influenced consumers' willingness to participate and complete a lengthy survey.

In addition, the convenience sampling method significantly limits the generalizability of the results. The results best represent individuals living with HIV who are engaged in care and their experiences with services in this region. This assessment does not capture the experiences of HIV-positive individuals who are lost-to-care or undiagnosed, or those who never engaged in care after diagnosis. The experiences and opinions of these populations are important to capture, but were not feasible to include in this assessment considering the funding constraints. Future needs assessment opportunities might use incentives and other creative methods to include the feedback of hard-to-reach populations, for example, individuals living with HIV who are experiencing homelessness.

## **II. Provider Interview Methods & Limitations**

JHF staff conducted semi-structured interviews with staff of HIV service agencies using questions in five focus areas: background and experience, organizational barriers to providing services, consumer barriers to receiving services, and possible changes to existing service structures (See Appendix B for full interview guide).

JHF staff recruited interviewees by reaching out to organizations that are direct providers of HIV services; interviewees included all individuals who volunteered to participate. JHF staff interviewed 19 individuals representing nine different organizations within the region. All participants signed a disclaimer that described the manner in which responses would be used and ensured names and organizations would remain confidential (See Appendix C for full interview disclaimer). Participants received the question list by email before the interview to ensure time to consider their responses and query their databases if desired. The interviews were recorded, transcribed, and then coded using Dedoose 7.5.4.

As with the consumer survey, the results of these interviews are limited by the sample selection. JHF utilized existing relationships with direct providers of services to coordinate meetings with employees. While these organizations do represent a large portion of the HIV service organizations in the region, their selection on the basis of JHF funding may make them different from other organizations. In addition, interviews were conducted with three or fewer staff members from each organization who volunteered to participate. The perspectives and experiences of these staff members do not necessarily reflect those of the organization overall or the organization's other staff members.

## **SECTION C: LITERATURE REVIEW & EPIDEMIOLOGICAL REVIEW**

### **I. POPULATION, INCIDENCE, AND PREVALENCE**

#### *Population*

The SWPA region includes Allegheny, Armstrong, Beaver, Butler, Cambria, Fayette, Greene, Indiana, Somerset, Washington, and Westmoreland counties. Allegheny County, which includes the City of Pittsburgh, has the largest population and makes up 46% of the region's total population. The southwest region general population makes up about 21.1% of the state's total population (US Census Bureau, Census of Population and Housing, 2010).

<b>SWPA Population and Density, by County</b>				
<b>County</b>	<b>Population (2015)</b>	<b>Population Density** (2010)</b>	<b>Percent urban (2010)</b>	<b>Percent rural (2010)</b>
Allegheny	1,230,459	1,675.6	97.5	2.5
Armstrong*	67,052	105.5	32.5	67.5
Beaver	168,871	392.3	74.2	25.8
Butler*	186,818	233.1	58.0	42.0
Cambria*	136,411	208.7	68.0	32.0
Fayette*	133,628	172.8	52.1	47.9
Greene*	37,519	67.2	33.2	66.8
Indiana*	86,966	107.5	39.9	60.1
Somerset*	75,522	72.4	29.2	70.8
Washington*	208,261	242.5	69.2	30.8
Westmoreland	357,956	355.4	74.6	25.4
<b>REGION TOTAL</b>	<b>2,689,463</b>	<b>320.3</b>	<b>77.8</b>	<b>22.2</b>

Table 1: SWPA Population and Density, by County  
(United States Census Bureau, 2010)

\*Rural counties, as defined by a population density that is lower than the statewide density of 284 persons per square mile (The Center for Rural Pennsylvania, 2014)

\*\*Population Density is a measure of population per square mile, and indicates how rural or urban an area is.

**SWPA Population by County, 2015**

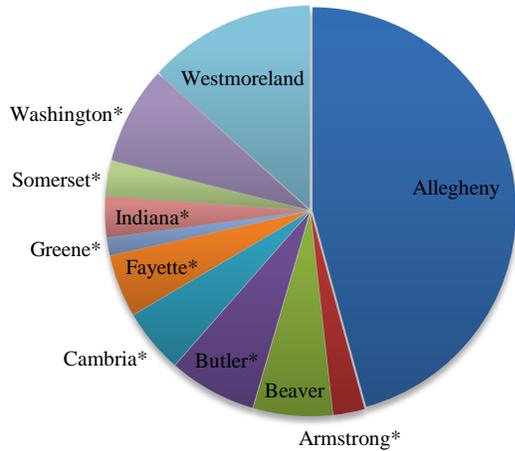


Figure 1: SWPA Population by County, 2015  
(United States Census Bureau, 2015)

***HIV Incidence and Prevalence***

The Southwest region makes up 10.63% of Pennsylvania’s population of people living with HIV. In 2015, 14.76% of Pennsylvania’s new HIV infections occurred in the region; in 2014, the region represented 14.25% of the state’s new infections (PA Department of Health, 2015).

Within the region, Allegheny County has the highest HIV incidence and prevalence, as it is the most populated county and contains the largest urban center in the region. In 2013,

2014, and 2015, the highest numbers of new diagnoses (after Allegheny) occurred in Washington, Westmoreland, and Butler

counties, respectively. Westmoreland has the second largest population of people living with HIV, although Somerset County has the second highest prevalence relative to the county’s population.

**HIV Prevalence in Southwest PA**

County	Presumed Alive (2015)	Prevalence per 100,000 people (2015)	Cumulative incidence per 100,000 people (2010-2015)
ALLEGHENY	2,830	230.0	63.9
ARMSTRONG	34	50.7	10.2
BEAVER	110	65.1	20.5
BUTLER	86	46.0	15.8
CAMBRIA	129	94.6	23.0
FAYETTE	94	70.3	19.8
GREENE	24	64.0	18.1
INDIANA	38	43.7	7.9
SOMERSET	87	115.2	14.2
WASHINGTON	111	53.3	13.0
WESTMORELAND	175	48.9	12.6
REGION TOTAL	3,718	138.2	37.4
STATE TOTAL	34,961	273.1	63.6

Table 2: HIV Prevalence in Southwest PA (Pennsylvania Department of Health, 2015)

Changes in the prevalence of HIV in SWPA over the past 10 years have mirrored nationwide trends. Prevalence has increased as treatment quality and access continue to improve, enabling HIV-positive individuals to live longer. However, incidence among the overall population in SWPA has remained fairly steady, contradicting a national decline by 19% between 2005 and 2014 (PA Department of Health, 2008-2015; CDC, 2016).

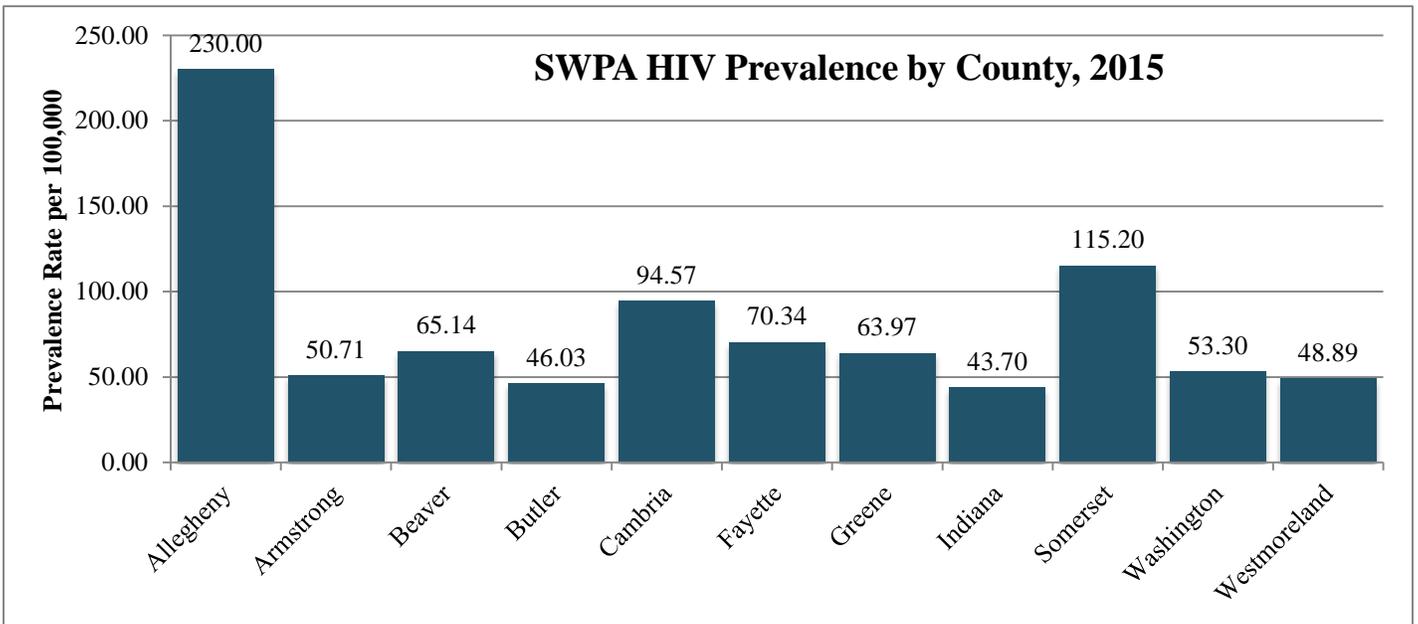


Figure 2: SWPA HIV Prevalence by County, 2015  
(Pennsylvania Department of Health, 2015)

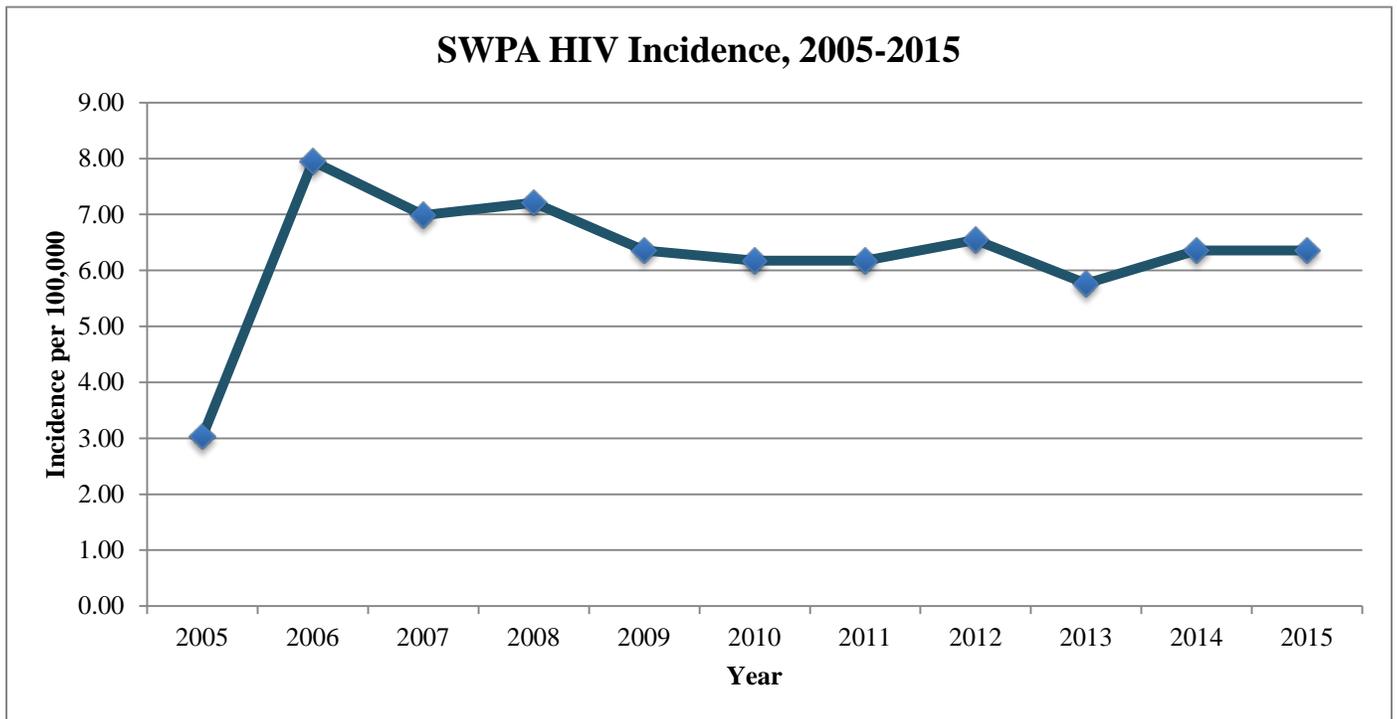


Figure 3: SWPA HIV Incidence, 2005-2015 (PA Department of Health, 2008-2015; US Census Bureau, 2010) Based on 2010 census population

## II. HIV IN RURAL AREAS

### *Rurality and Urbanity in Southwest Pennsylvania*

The SWPA region contains both rural and urban areas with large variations in density. Eight of the counties in this region are designated “rural,” according to the Center for Rural Pennsylvania: Armstrong, Butler, Cambria, Fayette, Greene, Indiana, Somerset, and Washington. These counties have a population density that is less than the statewide density of 284 persons per square mile (Center for Rural Pennsylvania, 2014).

The proportion of this region’s population that resides in rural areas is greater than the state or nation overall; because of this, the region must consider the unique needs of rural populations as well as those of the urban center. Pennsylvania overall is ranked among the top 10 states with the largest rural and small town population (Housing Assistance Council, 2011). The 2014 estimated population of the rural counties in the region is 935,500, which makes up 35% of the region’s total population (US Census Bureau). In comparison, 27% of Pennsylvania’s total population resides in rural areas (Center for Rural Pennsylvania, 2014), while 19.3% of the national population resides in rural areas (US Census Bureau, 2016).

### *Rural versus Urban HIV Care: Areas of Concern*

Rurality of a region factors greatly into access to care, treatment adherence, and health outcomes for HIV-positive individuals. HIV-positive individuals in rural areas overall have higher mortality than those in urban areas, even after adjusting for age, sex, race, risk factors, year of diagnosis, insurance, and receipt of antiretroviral treatment (Lahey et al., 2007; Ohl et al., 2010). The geographic isolation of rural areas often means poorer access, less public transportation options, and longer travel times to specialty healthcare (Cohn et al., 2001). Peer support resources and other HIV-specific psychosocial services may be rare or unavailable. Additionally, the social climate of the area may cause increased concerns over stigmatization and confidentiality (Cohn et al., 2001; Sutton, Anthony, Vila, McLellan-Lemal & Weidle, 2010).

- **Travel time to specialty care**

Unsurprisingly, there are fewer HIV specialists providing care in rural areas and long travel times to urban areas where specialty care is more available (Sutton, Anthony, Vila, McLellan-Lemal & Weidle, 2010; Sarnquist et al., 2011; Ohl et al., 2010). It is important to address this difference, as long travel times and transportation issues often lead to missed appointments, which in turn can lead to poorer health outcomes (Sarnquist et al., 2011).

- **Physician experience treating HIV**

Physician experience treating HIV also differs between rural and urban providers, since HIV is less prevalent in rural areas. Physician experience with HIV is strongly associated with patient outcomes. In cases where the patient exclusively saw a primary care physician (PCP) and did not have access to a specialist, the patients of physicians with less experience had poorer health outcomes (Kendall et al., 2015). This may be a reality for many people in rural areas who

cannot travel to specialists in urban areas. The lack of HIV-specific experience among rural physicians may also contribute to delayed detection; providers with less experience may be less likely to recognize risks or symptoms and suggest an HIV test (Ohl et al., 2010).

- **Delayed detection and entry to care**

One explanation for differential outcomes between rural and urban patients may be that rural individuals are diagnosed later in the course of the disease when compared to urban individuals (Weis, Liese, Hussey, Gibson & Duffus, 2010; Trepka et al., 2014; Ohl et al., 2010; Ohl et al., 2013). In a study of the veteran population, differences in rural and urban mortality were associated with delayed entry to care among rural individuals, which may or may not be caused by late detection (Ohl et al., 2010). Early detection of HIV is crucial, as late detection is associated with increased mortality, greater risk of transmission, and reduced response to medication treatment (Weis, Liese, Hussey, Gibson & Duffus, 2010).

- **Medication adherence**

Medication adherence is another factor strongly tied to health outcomes. There is limited research into whether rural and urban HIV-positive individuals differ in their medication adherence. VA studies of HIV-positive veterans show that rural residents adhere to medication even more consistently than urban veterans. However, the authors point out that this sample receives VA services and thus is not generalizable; the authors uphold this sample as evidence that rural individuals can achieve high adherence when provided with “resources to overcome distance and stigma-related barriers related to obtaining medication” (Ohl et al., 2013).

Another study suggested that the *reasons* for non-adherence did not differ between rural and urban HIV-positive populations (Heckman, Catz, Heckman, Miller, & Kalichman, 2004). Among rural, HIV-positive individuals, reasons given for missed doses were “simply forgot,” “had problems taking pills at specific times,” “felt sick from medication side effects,” “wanted to avoid negative side effects,” and “felt depressed or overwhelmed at the time.” The authors suggest that adherence issues in rural populations were related to lack of access to resources that help build skills and psychosocial support. Individuals with better adherence employed more coping strategies in response to stressors, had a good relationship with their primary care physician, and drank less alcohol. Interestingly, individuals who lived in the same area where they contracted HIV had better adherence. This might suggest that people who relocate to rural communities experience more social isolation, barriers to care, and confidentiality concerns that interfere with their adherence.

- **Stigma and confidentiality**

Stigma and perceived identifiability are other factors that may influence treatment adherence and outcomes in rural areas. Early studies suggested that the perception of discrimination and fear of discovery were greater among HIV-positive individuals in rural versus urban communities (Cohn et al., 2001). Another study correlated perception of HIV stigma with feelings of loneliness, which subsequently predicted sexual behavior (Hubach et al., 2015).

Feelings of loneliness were associated with a decrease in condom use. The authors suggest that loneliness and social isolation may be exacerbated in rural areas by systemic homophobia and geographical estrangement, which often means less support from HIV-positive peers and less access to psychosocial services. These results suggest that stigma is not only harmful to the psychological health of HIV-positive individuals, but may also indirectly increase risk of transmission in rural areas.

Aside from influencing risk behavior, the stigma that exists in rural areas may also discourage disclosure. This is important to examine because disclosure has been shown to mediate the relationship between social support and depression in certain populations. A study of rural African American women showed that HIV-positive participants with lower levels of social support had higher rates of depression. However, HIV status disclosure mediated this effect. One explanation is that in areas where HIV peer support resources are not available, disclosure allows friends and family to substitute for this important social support (Vyavaharkar et al., 2011).

Stigma in rural areas may be particularly salient among dually diagnosed individuals with both HIV and substance use disorders. In one study, rural HIV providers reported that their dual-diagnosis clients experienced stigma from referral sources, physicians, and specialists that made it difficult to access appropriate care (Yannessa, Reece, & Basta, 2008). Providers reported that referral source staff, physicians, and specialists present barriers to care and make excuses to avoid treating dual-diagnosis clients, preferring to refer them elsewhere. In addition, clients often have stigmatizing perspectives about certain types of treatment (for example, mental health counseling) that interfere with their own care; this further compounds the effects of stigma expressed by friends and family.

### ***HIV in Rural Southwest Pennsylvania***

Since rural counties represent different types of service needs and Allegheny County incidence is much greater than that of other counties in the region, it is beneficial to examine trends in rural areas separately from urban areas. When looking only at rural counties in the region, Somerset, Cambria, and Fayette have the highest prevalence rates. Cambria and Butler counties had the highest numbers of new infections from 2010-2015 out of all rural counties, at 33 and 29, respectively. Table 3 and Figure 5 provide comparisons of incidence trends over time between rural counties, Allegheny County, and the remaining urban counties, which include Beaver County and Westmoreland County. Figure 4 provides a comparison of incidence trends among the rural counties alone.

When comparing the combined the urban counties excluding Allegheny to the combined rural counties, incidence rates are nearly identical, at 15.38 and 15.98 respectively. From 2010-2015, the rural counties made up a larger portion of the region's new infections, at 14.64%.

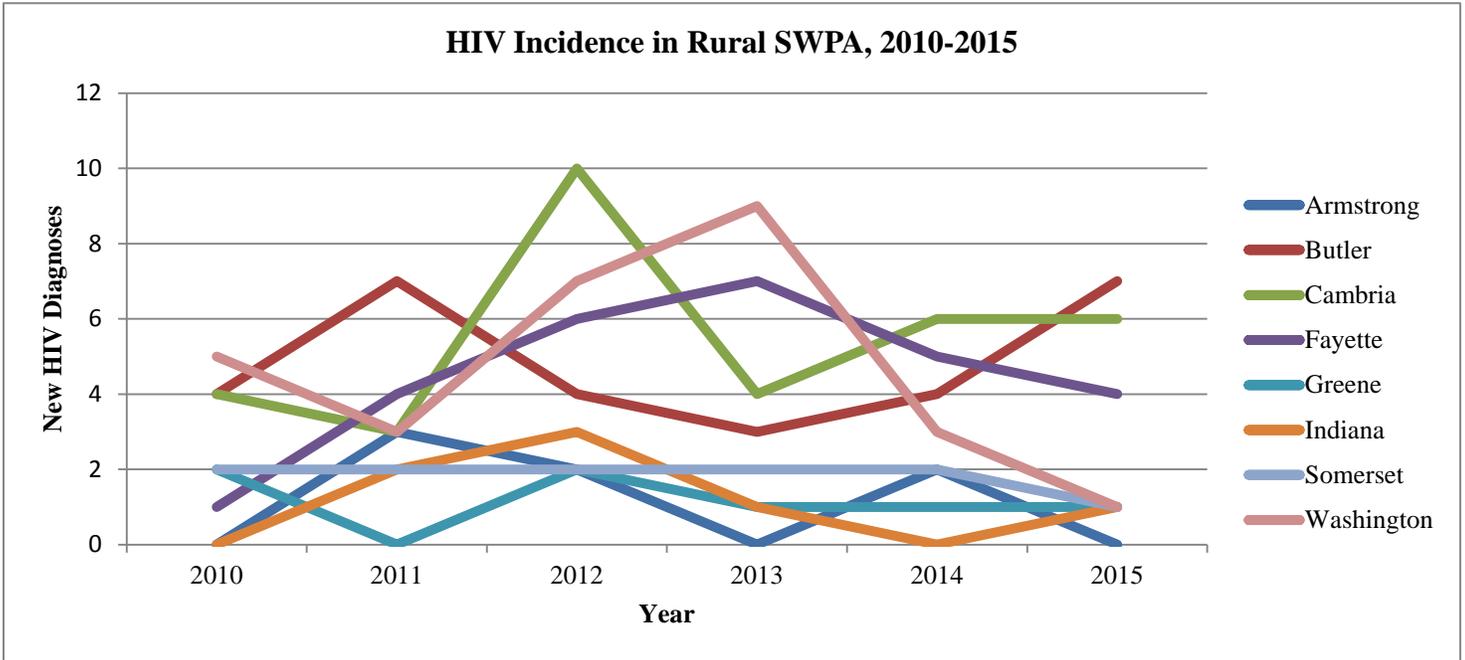


Figure 4: HIV Incidence in Rural SWPA, 2010-2015 (Pennsylvania Department of Health, 2015)

SWPA HIV New Diagnoses (2010-2015), Counties Grouped by Rurality			
	Percent of SWPA General Population (2015)	Percent of SWPA Cumulative Incidence (2010-2015)	Cumulative Incidence rate per 100,000 (2010-2015)
Urban counties excluding Allegheny	19.59	7.96	15.38
Allegheny County	45.75	77.41	64.04
Rural counties	34.66	14.64	15.98

Table 3: SWPA HIV New Diagnoses (2010-2015), Counties Grouped by Rurality (Pennsylvania Department of Health, 2015; US Census Bureau, 2015) Based on 2015 population estimate

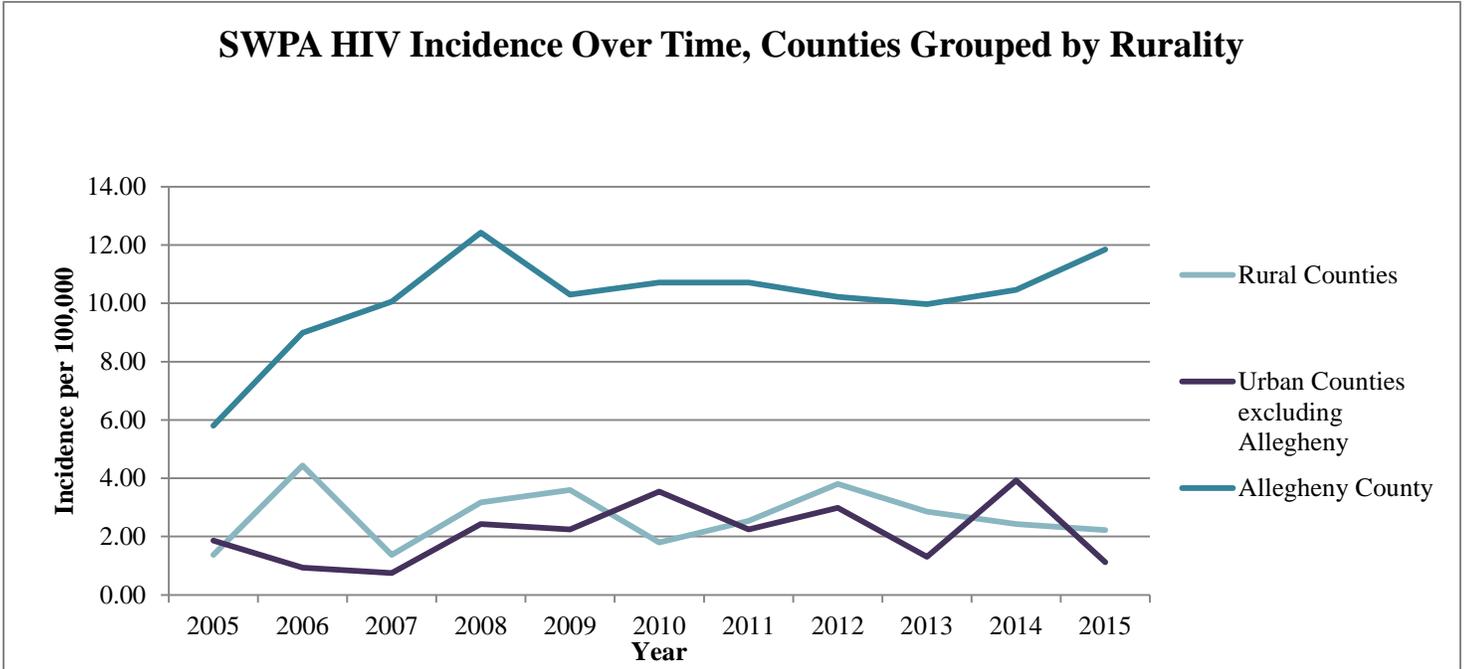


Figure 5: SWPA HIV incidence Over Time, Counties Grouped by Rurality (Pennsylvania Department of Health, 2007, 2013, 2014, 2015)

### III. SOCIOECONOMIC STATUS & HIV

#### *Background*

The association between HIV and socioeconomic status is well-documented (An, Prejean, McDavid Harrison, & Fang, 2013; Denning, DiNenno, Wiegand, 2011; Centers for Disease Control and Prevention, 2013). Studies have shown HIV diagnosis rates over four times higher in low-SES populations compared to high-SES populations (An, Prejean, McDavid Harrison, & Fang, 2013). Additionally, mortality rates of HIV-positive individuals differ based on socioeconomic status; HIV-positive individuals with no accumulated financial assets and with less education have a greater risk of death, even when use of services and Anti-Retroviral Therapy is accounted for (Cunningham et al., 2005). This gap in mortality between high and low SES populations has increased over time for HIV-positive individuals. The relative risk of HIV/AIDS mortality between the most-deprived group and most-affluent group went from 1.9 in 1987, to 2.9 in 1998, to 3.6 in 2009 (Singh, Aznuine, & Siahpush, 2013).

The increasing disparity in mortality among HIV-positive individuals may reflect general health disparities along socioeconomic lines. Studies have shown that the negative health effects due to the chronic stress of living in poverty also relate to lower levels of viral suppression among HIV positive individuals in care. Now that HIV is a chronic and manageable condition, mortality rates are as likely to be due to other health conditions, like heart disease or cancer, as to HIV-related infections (Sowah, Busse, & Amoroso, 2013). In the general population, income and education-level are clearly linked to health status (Braveman, Cubbin, Egerter, Williams, & Pamuk, 2010; Centers for Disease Control and Prevention, 2013). Medical care plays an important part in this linkage but is not the only factor.

Social determinants of health may also contribute to the disparities in mortality seen between HIV-positive individuals of low versus high socioeconomic status. The CDC and WHO define several social determinants of health that differ based on socioeconomic status, and thus contribute to health disparities. These include factors like access to healthy food, employment status, environmental hazards, access to healthcare and preventive services, and insurance coverage (Centers for Disease Control and Prevention, 2013). Social determinants of health also include behavioral factors like smoking, which has declined less among low-SES populations compared to the overall population (Sowah, Busse, & Amoroso, 2013).

Socioeconomic Indicators in SWPA Counties			
County	Education: Percent of people age 25+ with HS diploma (2010-2014)	Per capita income in past 12 months (2010-2014)	Percent of population in poverty
Allegheny	93.4	32,378	13.1
Armstrong	89.1	24,266†	13.8‡
Beaver	91.4	26,925†	11.7
Butler	93.2	31,818	8.9
Cambria	89	23,191†	15.3‡
Fayette	86.1*	21,319†	20.2‡
Greene	85.7*	22,847†	16.5‡
Indiana	88.6*	23,577†	17†
Somerset	86.4*	22,618†	13.5
Washington	90.8	29,816	10.7
Westmoreland	92.2	28,654†	10.1
PA OVERALL	89	28,912	13.6

Table 4: Socioeconomic Indicators in SWPA Counties (United States Census Bureau, 2010)

\*Lower educational attainment than the statewide proportion

†Lower income than the statewide average

‡Higher poverty than the statewide proportion

Education level, mean income per capita, and poverty as a percent of the population are three frequently used indicators of socioeconomic status. The above table shows these indicators for the 11 SWPA counties, as compared to Pennsylvania overall. Four of the counties in the region have a smaller proportion of people with a high school diploma than Pennsylvania overall; eight counties have a lower income per capita than the statewide average; and four counties have a higher percentage of people living in poverty than the statewide proportion.

Generally, the rural counties in the region fare much worse in terms of education attainment, income, and poverty level than the urban counties. All of the SWPA counties that fall both below the statewide numbers on education and above the statewide poverty are rural. In fact, Fayette and Greene counties are ranked in the top 10 poorest counties in the entire state when looking at per capita income. Fayette and Indiana rank at 4<sup>th</sup> and 6<sup>th</sup> statewide in terms of percentage of the population living below the poverty line.

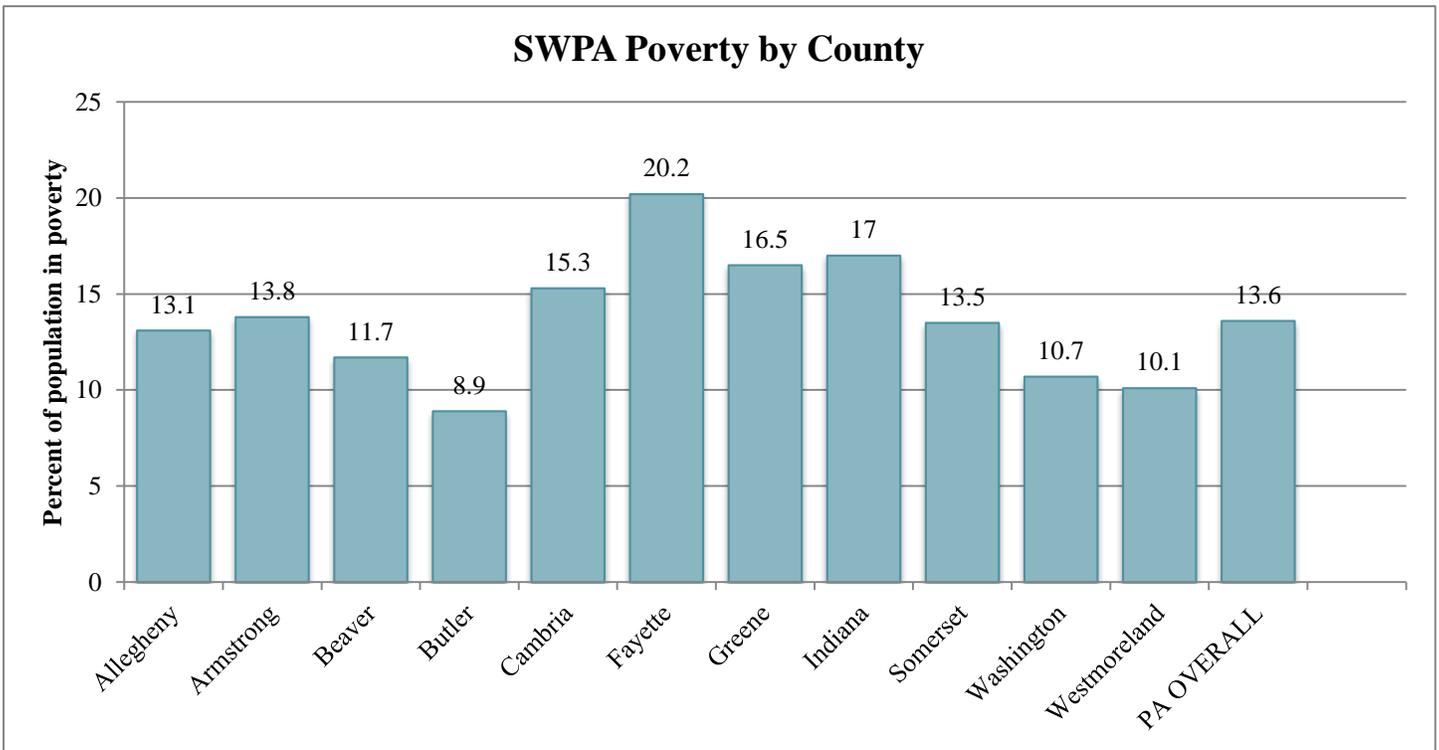


Figure 6: SWPA Poverty by County (US Census Bureau, 2016)

**IV. MODE OF TRANSMISSION**

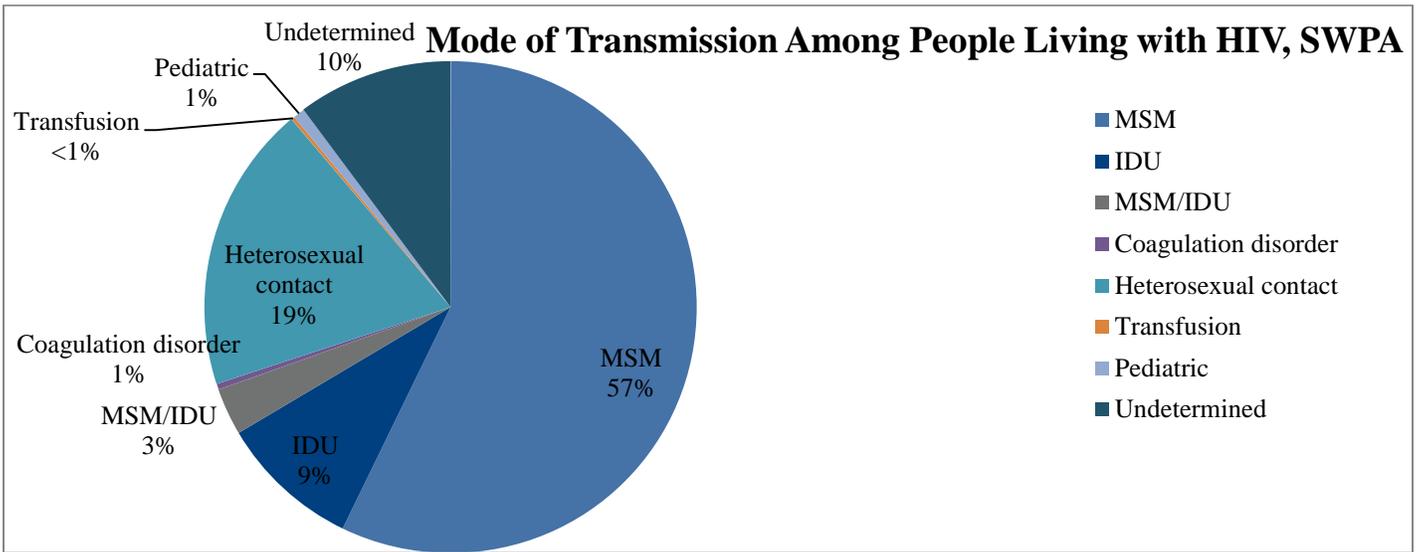


Figure 7: Mode of transmission Among People Living With HIV, SWPA (Pennsylvania Department of Health, 2014)

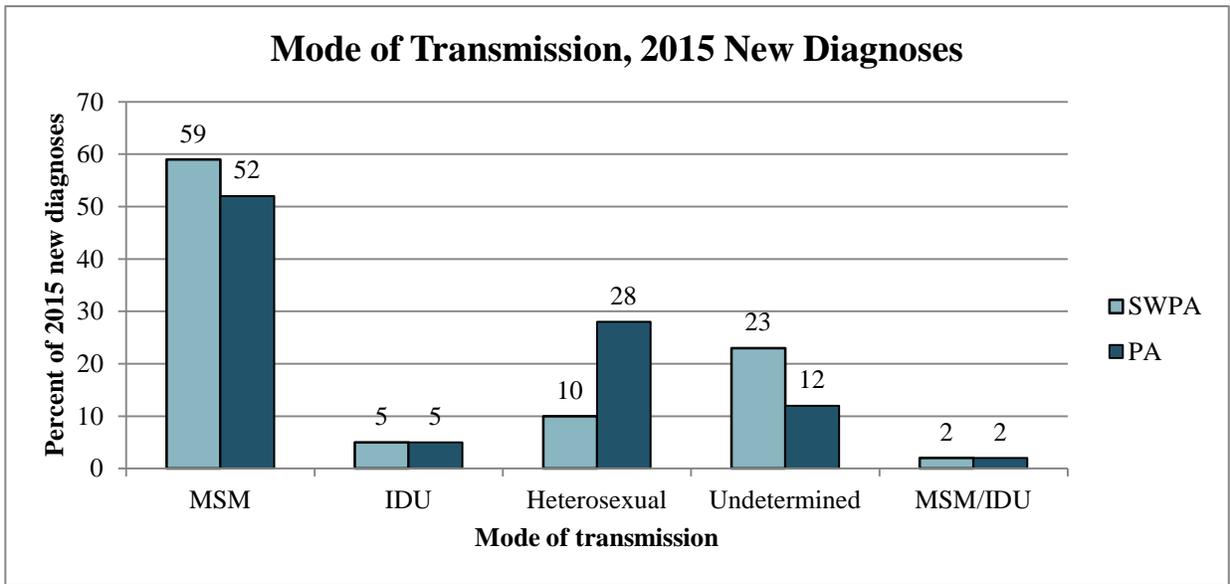


Figure 8: Mode of Transmission, 2015 New Diagnoses (Pennsylvania Department of Health, 2015)

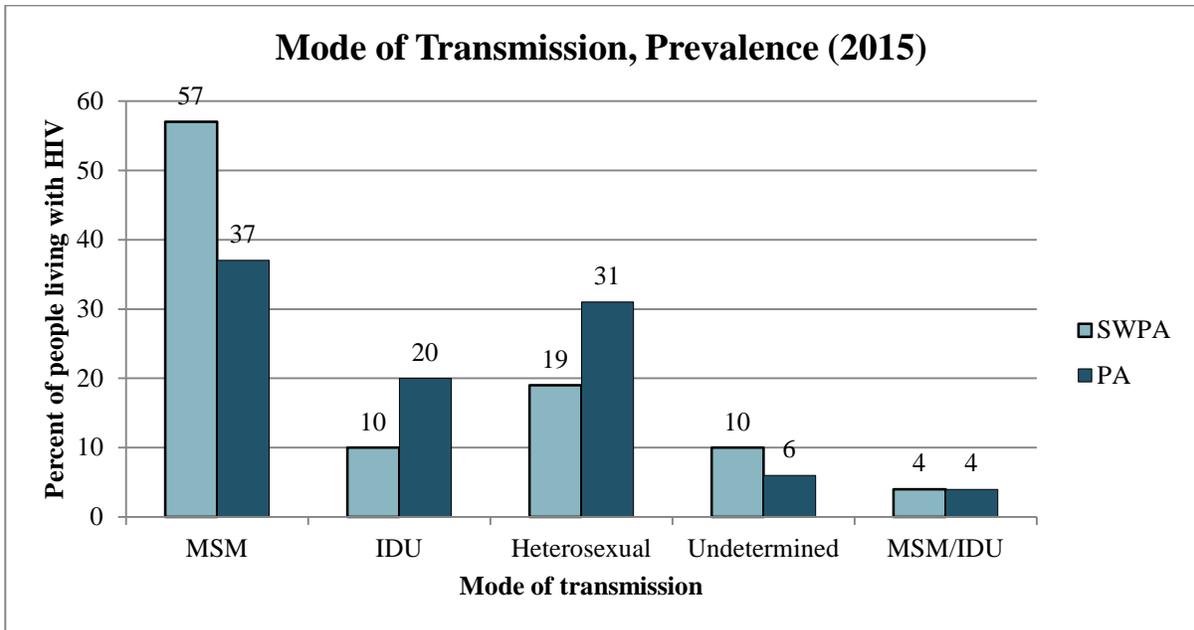


Figure 9: Mode of Transmission, Prevalence (2015) (Pennsylvania Department of Health, 2015)

Similar to national and statewide trends, the most common transmission pattern for HIV in the SWPA region is among men who have sex with men (MSM). 57% of individuals living with HIV in the region contracted HIV in this manner; similarly, MSM accounted for 59% of new HIV infections in SWPA in 2015. In SWPA, the next largest mode of transmission in 2015 was undetermined (23%), followed by heterosexual contact (10%).

In 2015, injection drug use (IDU) accounted for only 10% of transmissions among all people living with HIV in SWPA. This sharply contradicts the 20% of individuals statewide who contracted

HIV through injection drug use. This is also the lowest proportion among all the regions in the state. This may be due to the effectiveness of the region’s syringe access program, Prevention Point Pittsburgh, which began distributing sterile injection supplies in 1995. While the AACO region has a syringe access program, other regions of the state, particularly rural regions, do not have access to syringe exchange programs. Other regions are now also seeing low proportions of IDU transmission among new diagnoses, but the early establishment of needle exchange in the SWPA region may have ensured consistently low IDU transmission.

The SWPA region’s proportion of diagnoses attributable to MSM and heterosexual contact are larger than the statewide proportions, although new diagnoses attributable to MSM have declined since 2010. Heterosexual transmission shows a less consistent trend, fluctuating between 2010 and 2015, with the highest number of attributable diagnoses in 2014 (39) and the lowest in 2012 (15).

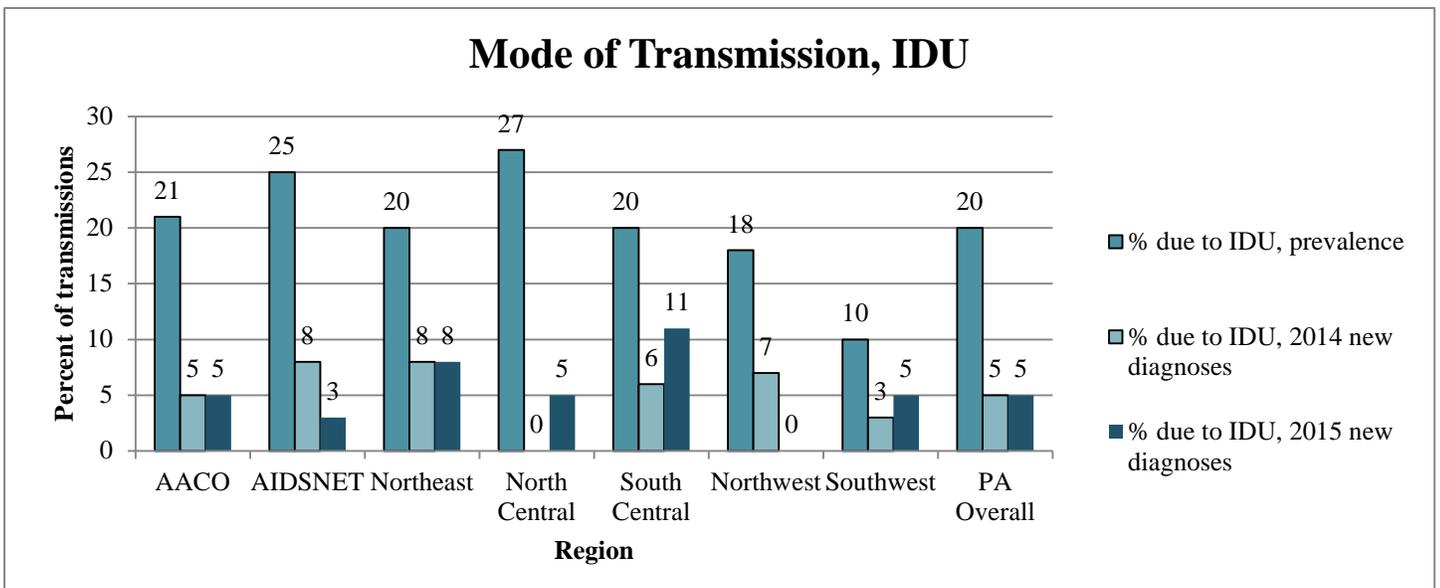


Figure 10: Mode of Transmission, IDU (Pennsylvania Department of Health, 2015)

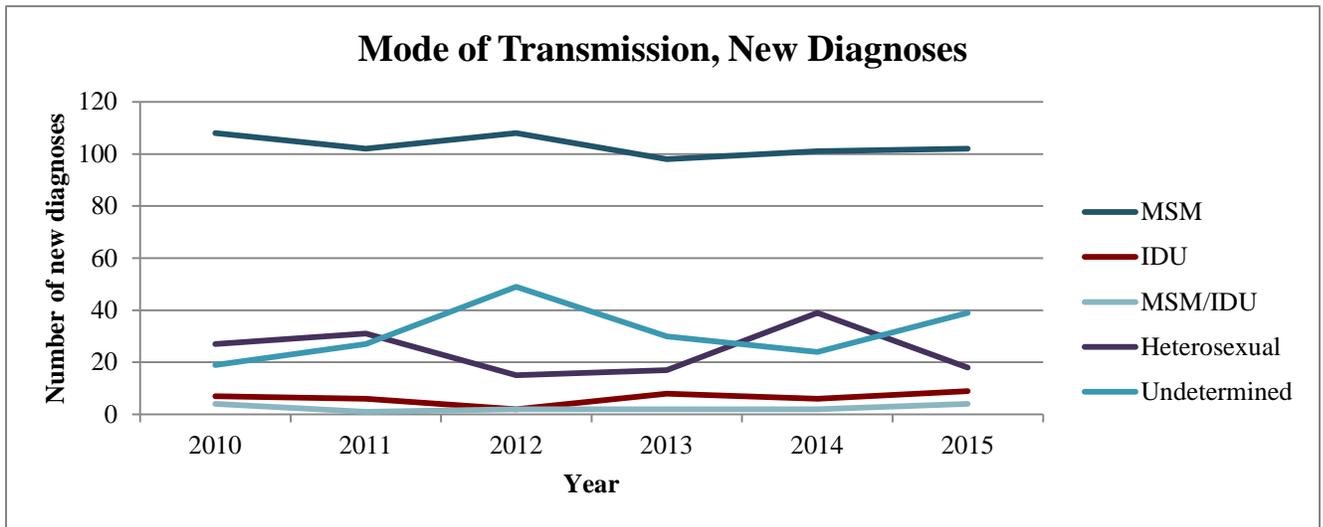


Figure 11: Mode of Transmission, New Diagnoses  
(Pennsylvania Department of Health, 2015)

## V. RACE AND ETHNICITY

Racial disparities in HIV exist in terms of incidence, treatment adherence, viral suppression, and health outcomes. Research suggests that these disparities are strongly linked to socioeconomic factors, but not exclusively. Nationally, Black/African-American men and women are disproportionately affected by HIV, despite a decline in diagnosis rates across all racial groups between 2005 and 2014. Incidence rates have increased in certain subgroups of the population. Men who have sex with men (MSM) are most impacted by HIV, nationally representing 67% of diagnoses in 2014, but only 2% of the population. Within the MSM population, rates among White men declined while rates among Latino and Black MSM continued to rise between 2005 and 2014. Rates stabilized for these populations within the last six years, with slower increases (CDC, 2016).

In addition to disparate incidence rates, outcomes like survival rates differ significantly by race. HIV/AIDS mortality rate ratios between Black and White individuals widened between 1987 and 2011; in 1987, Black/African American individuals had 3.1 times higher mortality rates from HIV, which increased to 4.7 in 1995 and 7.9 in 2011. In comparison to White individuals, mortality rates among Black/African-Americans rose faster between 1987 and 1995 and declined more slowly between 1995 and 2011. In particular, the HIV/AIDS mortality disparity is more significant between White and Black women compared to White and Black men. (Singh, Aznuine, & Siahpush, 2013). One study of survival in AIDS-diagnosed individuals showed that racial disparities peaked from 1996-1998, during early HAART implementation (Trepka et al., 2013); this was attributed to the initially disparate use of HAART in minority populations.

Explanations for outcome disparities are varied and have changed over time. Interestingly, VA studies have not seen significant racial disparities in survival rates, which suggest that survival differences largely result from healthcare access disparities (Giordano et al., 2006). Researchers have seen decreases in disparities when controlling for area-level socioeconomic status or neighborhood

deprivation, but these factors are not entirely responsible (Harrison, Ling, Song, & Hall, 2008). Other research has attributed disparities to late testing, which is more common among Black individuals than Whites (CDC, 2003). Additional reasons for survival differences may include ongoing disparities in ART use, access, and poor adherence related to discrimination, distrust of providers, conspiracy beliefs about HIV, and lack of knowledge about ART (Bogart, Wagner, Galvan, & Banks, 2010; Trepka et al., 2013).

<b>Southwest PA Race, by County (2015)</b>						
	Estimated Population	Percent White alone	Percent Black or African American alone	Percent Hispanic/Latino	Percent Asian alone	Percent Multirace
Allegheny	1,230,459	80.7	13.4	2.0	3.6	2.1
Armstrong	67,052	97.8	0.9	0.7	0.3	0.9
Beaver	168,871	91.0	6.4	1.5	0.5	1.9
Butler	186,818	96.3	1.3	1.4	1.2	1.1
Cambria	136,411	94.2	3.6	1.6	0.6	1.5
Fayette	133,628	92.9	4.8	1.1	0.4	1.6
Greene	37,519	94.6	3.6	1.5	0.4	1.2
Indiana	86,966	94.8	2.9	1.4	1.1	1.0
Somerset	75,522	95.9	2.9	1.4	0.4	0.7
Washington	208,261	93.9	3.2	1.6	1.0	1.7
Westmoreland	357,956	95.3	2.6	1.1	0.9	1.4
SWPA Region	2,689,463	88.2	7.9	1.6	2.1	1.7
Pennsylvania	12,784,227	82.6	11.7	6.8	3.4	1.9

Table 5: Southwest PA Race, by County (US Census Bureau, 2015)

Similar to national trends, the SWPA region experiences racial disparities with regards to HIV incidence and prevalence. In SWPA, Black and African American individuals made up only 7.9% of the general population in 2014 but accounted for 44.31% of new HIV diagnoses between 2010 and 2015. In addition, individuals identifying as Multirace represent only 2.39% of the general population in SWPA but make up 4.25% of new HIV diagnoses between 2010 and 2015. Disparities in the overall population of people living with HIV in SWPA are also significant. Black or African American individuals make up 40% of SWPA people living with HIV, while individuals identifying as Multirace make up 5%, and White individuals make up 50%.

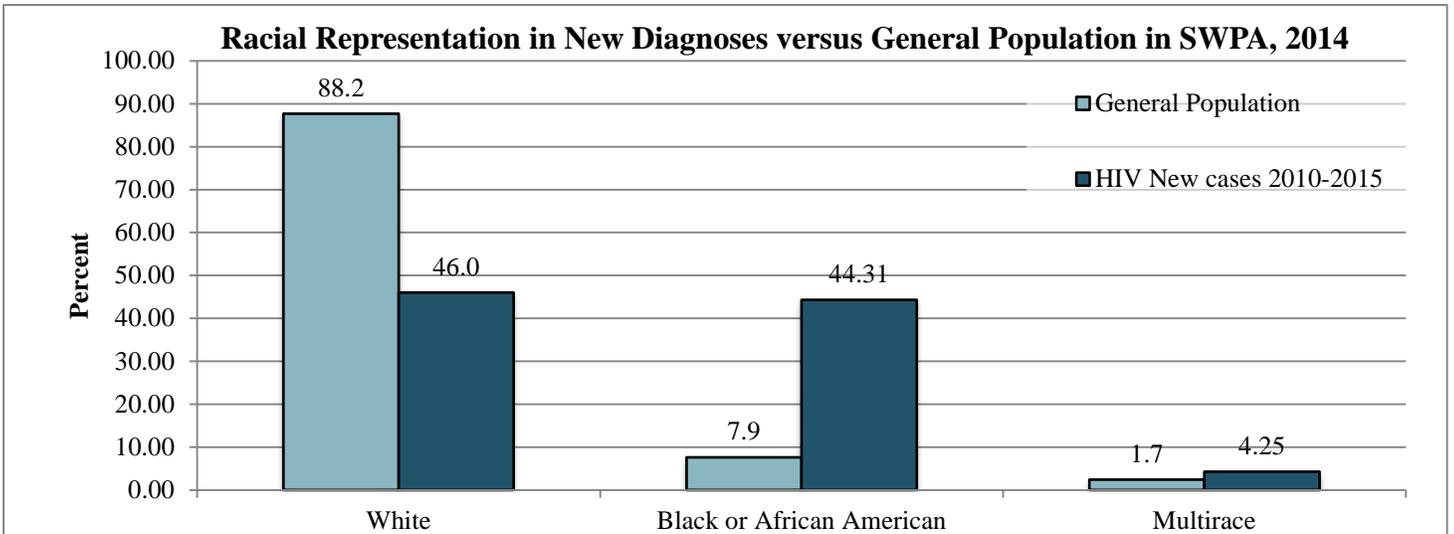


Figure 12: Racial Representation in New Diagnoses versus General Population in SWPA, 2014 (Pennsylvania Department of Health, 2014)

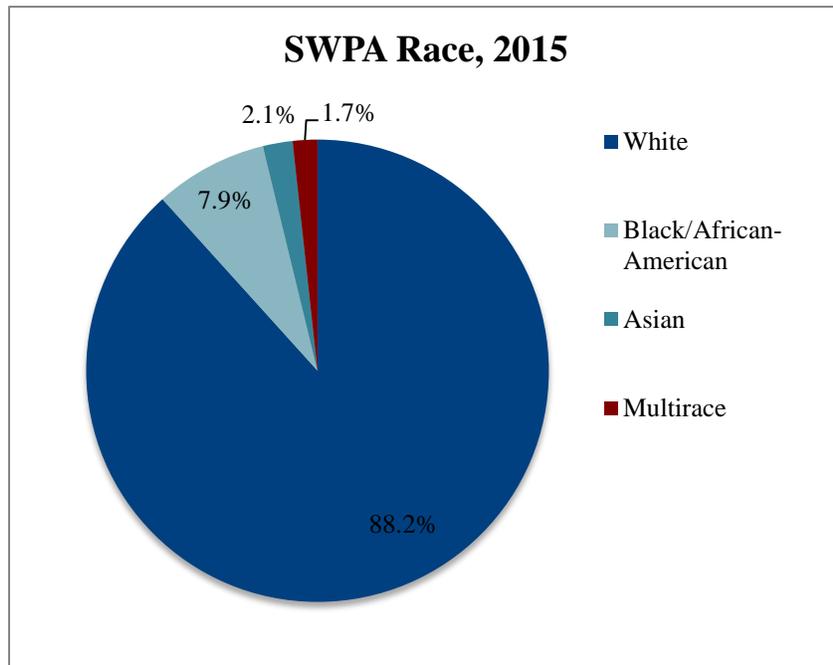


Figure 13: SWPA Race, 2015 (Pennsylvania Department of Health, 2014)

## VI. GENDER

HIV/AIDS cases in Southwest PA by Gender				
Gender	New HIV cases, 2015		People living with HIV/AIDS, 2015	
	Number	%	Number	%
Male	137	79.7	3,012	81.0
Female	32	20.4	706	19.0

Table 6: HIV/AIDS cases in Southwest PA by Gender (Pennsylvania Department of Health, 2015)  
 Note: Information on HIV cases among transgender individuals is not collected by the Department of Health

While men are disproportionately affected by HIV, the impact of HIV on women has increased over time. Between 1981 and 1987, women represented about 8% of new infections (UCSF Center for HIV Information, 2016). Today, women in the United States represent about 19% of new diagnoses (Centers for Disease Control and Prevention, 2016). SWPA diagnoses are similarly split, with 20.4% of new diagnoses in women in 2015; statewide, 22.9% of new infections occur among women (Pennsylvania Department of Health, 2015).

Similar to men, new diagnoses among women disproportionately affect minorities. Nationally, Black/African-American women represent 2/3<sup>rd</sup>s of new infections among women (Centers for Disease Control and Prevention, 2016). In Pennsylvania, Black/African-American women represented 60.4% of new infections among women between 2001 and 2015. Among men in Pennsylvania, 47.8% of new infections occur in Black/African-American individuals (Pennsylvania Department of Health, 2015).

Evidence suggests that disparities also exist between men and women living with HIV in terms of treatment quality and health outcomes. A 2013 study at the VA noted that after one year of treatment, women experienced less improvement in the burden of disease compared to men; these disparities were not entirely attributable to differences in adherence (Blackstock et al., 2013). A 2005 study of people living with HIV documented lower quality of life scores among women compared to men (Mrus et al.). In both samples, women were younger and more likely to be minorities compared to men. Disparities are also evident between men and women of the same race, suggesting that access and health status are affected by gender differences (Beer, Mattson, Bradley, & Skarbinski, 2016).

Mode of transmission differs between men and women as well. In Pennsylvania, 1,417 women contracted HIV through Injection Drug Use (IDU) between 2001 and 2015; this represents 19.6% of total new diagnoses among women during this time period. Among men in Pennsylvania, 2,838 contracted HIV through IDU between 2001 and 2015; this represents only 15.1% of new diagnoses during this time. Additionally, a larger portion of White women compared to Black/African-American women contracted HIV through IDU (28% versus 16%) (Pennsylvania Department of Health, 2015).

Women living with HIV also present unique health needs. Women with HIV are six times more likely than women without HIV to develop cervical cancer in their lifetimes; this is largely attributed to the immune system's decreased functioning and lessened ability to clear Human Papilloma Virus (Shiels et al., 2011; Grulich, van Leeuwen, Falster, & Vajdic, 2007). This public health concern is exacerbated

by the fact that many women with HIV do not get screened for cervical cancer as often as recommended. However, recent studies have demonstrated the success of cervical cancer screening interventions in low-income women, suggesting that the continued support of these efforts is crucial (Bynum et. al, 2016).

## VII. AGE

The United States has seen an increase in HIV among younger age groups in recent years, especially among minorities (Oster et al., 2014). Certain populations among youth face higher risk of acquiring HIV and greater burden of new infections; men who have sex with men (MSM), individuals who identify as transgender, people who inject drugs, people who engage in sex work, and racial minorities are particularly burdened by HIV (Bekker, Johnson, Wallace, & Hosek, 2015). In addition, young people experience unique challenges associated with accessing HIV testing and treatment services, including cost barriers, insurance, health literacy, and stigma (Kurth, Lally, Choko, Inwani, & Fortenberry, 2015).

While the largest portion of new HIV infections in recent years in SWPA have occurred in young people, the majority of individuals living with HIV/AIDS are over 30 years old. The largest portion of these individuals is between 30 and 39 years old, and a significant portion is between 40 and 49 years old. The age distribution of people living with HIV/AIDS in SWPA is comparable to Pennsylvania overall.

Recently diagnosed individuals are on average younger in the SWPA region than in Pennsylvania overall. The 20-29 age group makes up the largest percentage of new HIV diagnoses, both in the state and in the SWPA region. In 2015, the 20-29 age group accounted for 47% of new diagnoses in SWPA, the largest proportion in the past five years. The distribution of new HIV cases by age in SWPA is also similar to the state overall; however, a larger proportion of new cases in SWPA occurred in 20-29 year olds. The state overall sees a slightly higher proportion of new cases in the 40-49 and over 49 age groups.

<b>HIV Diagnoses by Age Group, PA versus SWPA (2010-2015)</b>						
<b>Age group</b>	<b>PA cumulative new diagnoses, 2010-2015</b>			<b>SWPA cumulative new diagnoses, 2010-2015</b>		
	Number	%	Diagnoses per 100,000	Number	%	Diagnoses per 100,000
<13	46	0.57	.36	4	0.40	.15
13-19	420	5.2	3.28	51	5.04	1.9
20-29	2511	31.09	19.61	361	35.71	13.42
30-39	1793	22.20	14.01	228	22.55	8.48
40-49	1721	21.31	13.44	189	18.69	7.03
>49	1585	19.63	12.38	179	17.61	6.62

Table 7: HIV Diagnoses by Age Group, PA versus SWPA, 2010-2015  
(Pennsylvania Department of Health, 2015)

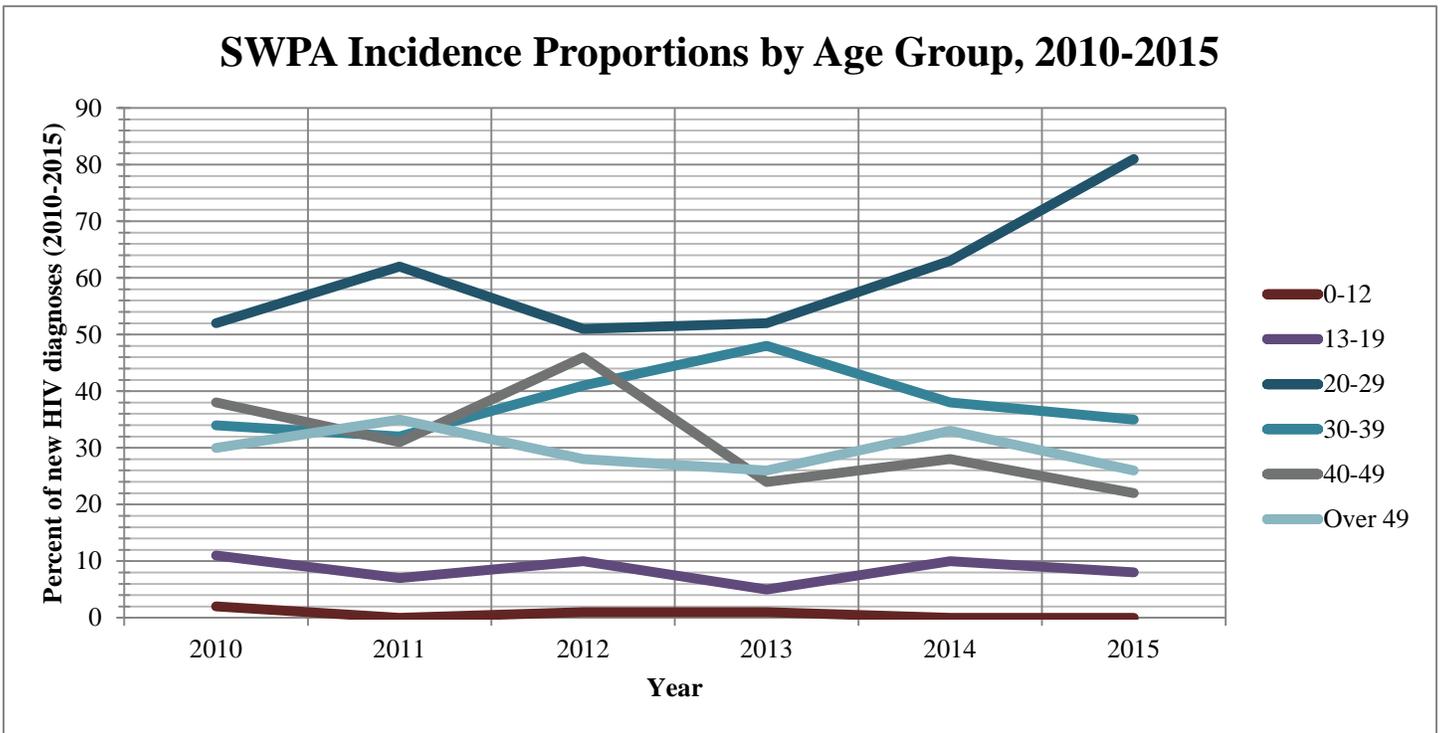


Figure 14: SWPA Incidence Proportions by Age Group, 2010-2015 (Pennsylvania Department of Health, 2015)

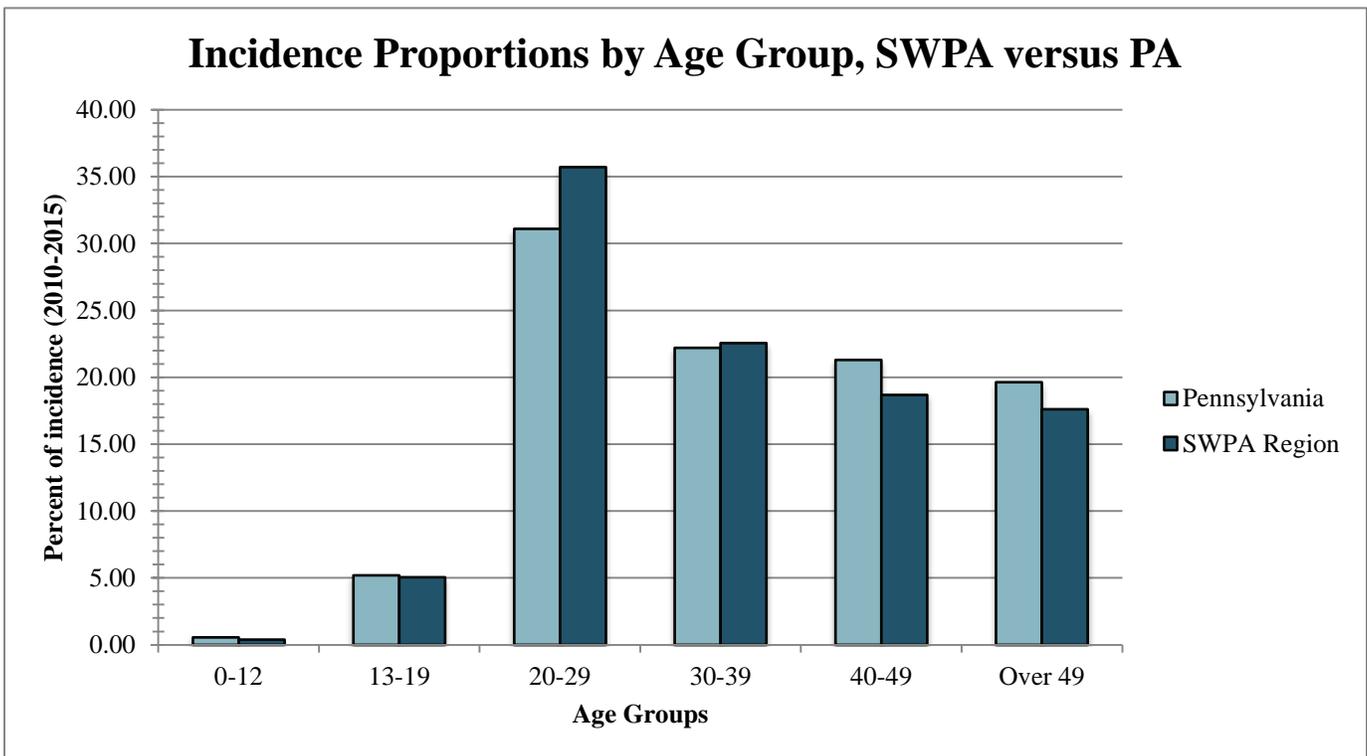


Figure 15: Incidence Proportions by Age Group, SWPA versus PA (Pennsylvania Department of Health, 2015)

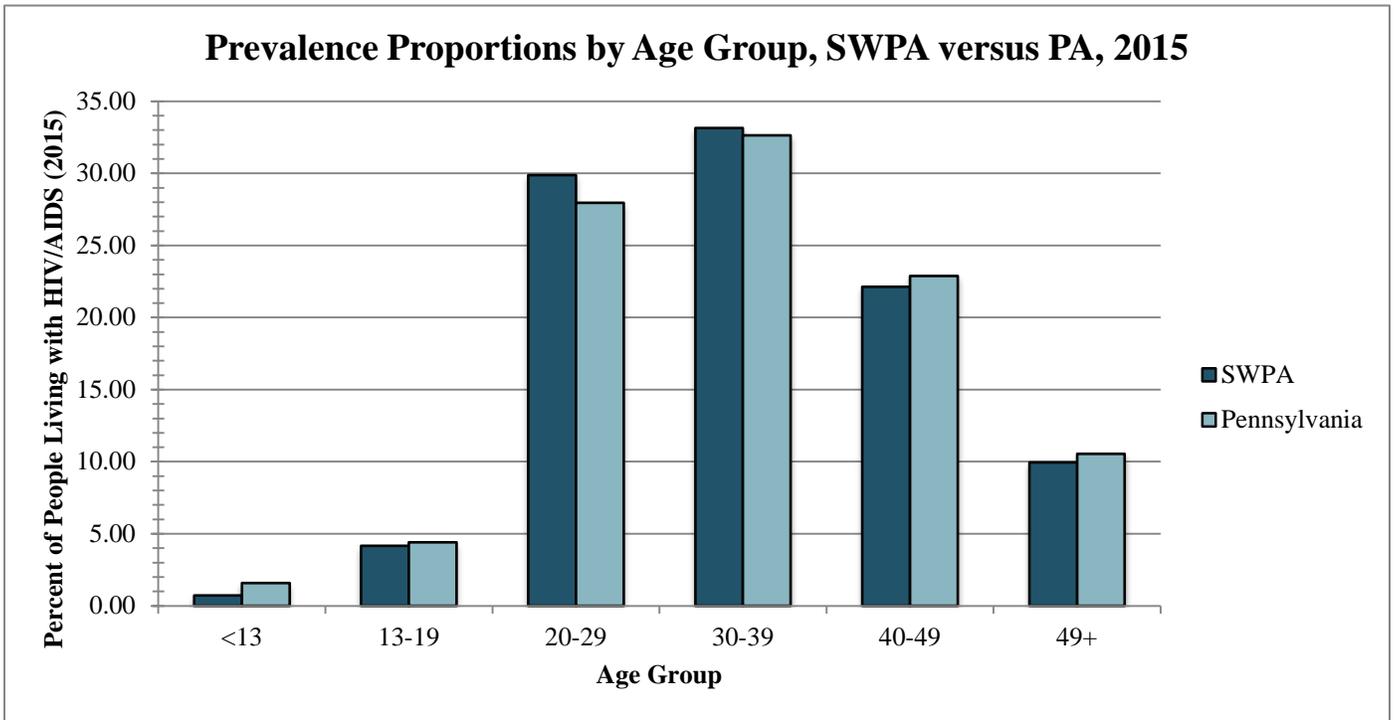


Figure 16: Prevalence Proportions by Age Group, SWPA versus PA, 2015 (Pennsylvania Department of Health, 2015)

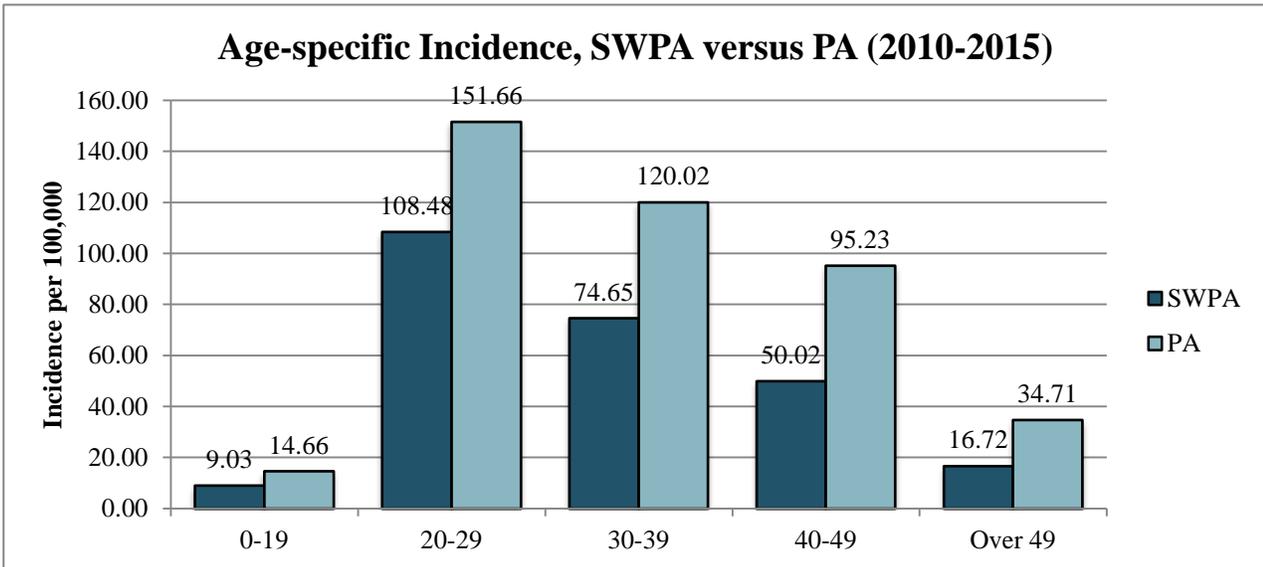


Figure 17: Age-specific Incidence, SWPA versus PA, 2010-2015 (Pennsylvania Department of Health, 2015; US Census Bureau, 2015)

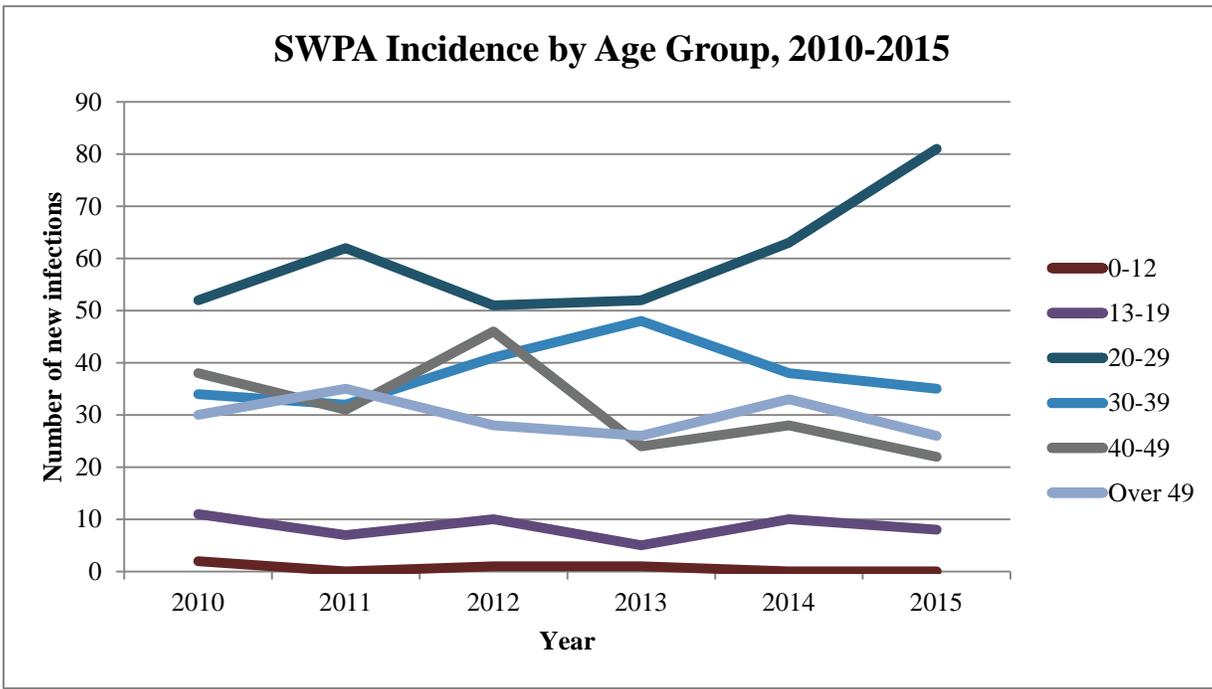


Figure 18: SWPA Incidence by Age Group, 2010-2015 (Pennsylvania Department of Health, 2015; US Census Bureau, 2015)

## SECTION D: HIV RESOURCES IN SWPA

### I. BACKGROUND

The Jewish Healthcare Foundation serves as the lead agency for the organizations shown below. This figure displays multiple funding streams, including some the Foundation administers and others the Foundation does not. The Foundation administers funding from Ryan White Part B, Ryan White Emerging Communities, HOPWA, the Minority AIDS Initiative (MAI), and the state. These organizations also utilize sources of revenue not listed above to provide other services and support the services provided by the below funding streams.

Organization	Type of service provided								
	Transportation	Case Management	Housing	Medical Care	Emergency Financial Assistance	Psychosocial: Peer support and groups	Prevention and/or testing	Food: meals or food bank	Insurance payment assistance
Adagio Health									
Center for Community Resources (CCR)									
Community Care Management (CCM)									
Macedonia Family And Community Enrichment (MFACE)									
Positive Health Clinic (PHC)									
Persad Center									
Pittsburgh AIDS Center for Treatment (PACT)									
Pittsburgh AIDS Task Force (PATF)									
Prevention Point Pittsburgh (PPP)									
Project Silk									
Senior Care Management (SCM)									
Shepherd Wellness Community (SWC)									
The Open Door, Inc.									

Figure 19: ASOs, Services, and Funding Streams in SWPA

There are many other organizations that also conduct important work around HIV in the region but do not receive Part B funding for services through the Jewish Healthcare Foundation. Some of these organizations include:

- AIDS Free Pittsburgh
- HIV Prevention and Care Project (University of Pittsburgh Graduate School of Public Health)
- Allegheny County Health Department STD & HIV/AIDS Clinic
- Central Outreach Wellness Center
- MidAtlantic AIDS Education and Training Center (MAAETC)
- AIDS Leadership for Prevention and Health Awareness (ALPHA) Pittsburgh

## **II. RYAN WHITE PART B ORGANIZATIONS**

The following includes information about the mission and services of each of the HIV service organizations that receive Ryan White Part B funding as provider agencies.

### ***Allegheny Health Network: The Positive Health Clinic***

The Positive Health Clinic (PHC) is a comprehensive HIV primary care clinic providing state-of-the-art care to HIV-positive persons. Their staffing consists of infectious disease physicians, a pharmacist, two nurse practitioners, two physician assistants as well as a multidisciplinary support team from Allegheny General Hospital. Additional support staff includes nurses and medical assistants, social workers, mental health therapists, psychiatrists, patient advocates, and clinical research coordinators. Their team treats more than 900 patients and has extensive experience with all aspects of HIV management. The clinic is open Monday through Friday and one evening each month. It is located on the Northside of Pittsburgh, with satellite clinics in Aliquippa and Monroeville. Below are some of the services provided within the program:

- Comprehensive HIV medical care to adult men and women and referral for additional specialized care
- Testing Services
- Medication adherence counseling and pharmacy support
- Gynecologic care
- Nutritional assessment and counseling by a Registered Dietitian
- Treatment for persons co-infected with HIV and Hepatitis C.
- Smoking cessation programs
- Mental health assessment, counseling and psychiatric support
- Medical case management
- Patient advocacy and Support groups
- Clinical trial unit to conduct and refer patients to clinical trials
- HIV wellness classes and other educational opportunities

The Ryan White Part B funds provide assistance to PHC for supportive services, medical transportation

assistance, and treatment adherence counseling.

### ***Center for Community Resources***

Center for Community Resources, or CCR, is a community-based organization that offers supportive services, resources, and referrals to help individuals and families navigate the human services system. Specifically around HIV, CCR offers a monthly support group for individuals living with HIV. They also provide services and referrals in the following areas:

- Community Education: Drug and alcohol, mental health
- Community Programs: Tax preparation, HIV+ support group, veterans' families supports
- Supports Coordination: Aging & disability, children, intellectual disabilities
- Emergency Support: Homelessness, crisis, utilities
- Home/School Support: Family and student support, behavioral health support
- Information
- Mental Health: Representative payee, drop-in center
- Recovery Support: Peer support, drug and alcohol case management

### ***Community Care Management***

Community Care Management (CCM) is co-located in Conemaugh Hospital's Family Medical Center, which has an HIV clinic and is a Family Medicine residency program in rural Cambria County. CCM serves Cambria, Indiana, Somerset, and Westmoreland counties. Family Medical Center's treatment team consists of an HIV specialist, an RN who coordinates the medical services, pharmacologists, psychologists, dietician, and social workers. Services provided are:

- Medical case management
- Emergency assistance
- Medical transportation assistance
- Food bank
- Health education/ risk reduction
- Health insurance premium and cost sharing
- Psychosocial support services
- Prevention
- Oral health

CCM's mission is to provide case management and support services to help HIV positive people and their families cope with HIV.

### ***Persad Center***

Persad Center is a human service organization whose mission is to improve the well-being of the Lesbian, Gay, Bisexual, Transgender, Queer and Questioning (LGBTQ) communities in Pittsburgh. Persad is also committed to the well-being of the HIV/AIDS community. Persad provides services across the region, with service centers in Pittsburgh, Washington, and Erie. Their services for HIV-

positive individuals include mental health services, treatment adherence counseling, substance abuse services, and secondary prevention services. They also conduct outreach, prevention, testing, and training and advocacy.

### ***Prevention Point Pittsburgh***

Prevention Point Pittsburgh (PPP) is a harm reduction organization that provides health empowerment services to injection drug users. PPP provides syringe exchange services and risk reduction counseling to prevent the spread of infectious diseases like HIV as well as allow people who inject drugs to keep themselves as healthy as possible. PPP also provides case management, referrals to treatment, health education, condom distribution, overdose prevention, and HIV and Hepatitis C screening.

### ***Project Silk***

Project Silk is a recreation-based community health space for LGBTQ youth of color in the Pittsburgh region modeling community-driven initiatives focused on holistic approaches to individuals' needs. Established in 2012 as a CDC-funded demonstration project, Project Silk is an innovative model that pairs recreational activities with HIV/STI prevention, testing, linkage to medical care, social services, therapeutic interventions, and social capital initiatives. The project's goals are: 1) to coordinate delivery of appropriate, culturally competent HIV and STI testing and linkage to medical care; 2) to increase access and uptake of HIV prevention services for the community of focus, which is routinely and predictably disenfranchised from services; 3) to build capacity across a broad spectrum within the Pittsburgh MSA to serve as a leader in the community for best-practice approaches to prevention programming in our region.

**Mission:** Project SILK provides a safe, healthy, supportive community environment for LGBT youth of color to grow, celebrate, and express themselves. With service providers and community partners, we advocate for our youth to determine the meaning and direction for their own lives.

**What We Do:** Project Silk is committed to member driven structures and offers unique pathways to service delivery on site at our youth drop in center. Project Silk provides STI/HIV testing on-site to increase knowledge of undiagnosed infections; implements behavioral interventions related to positive adult identity development and sexual health education; skills-based programming for youth to actualize their goals; and provides linkage to medical care and ancillary services to promote overall wellness within HIV positive as well as high risk negative communities.

- Medical case management.
- Mental health services.
- Healthy relationships/Life skills groups.
- HIV/ STI testing services.
- Outreach.
- Prevention education.
- Arts based recreation activities.
- Wellness workshops.

- Housing assistance services
- Social service coordination

***Macedonia Family and Community Enrichment Center (FACE)***

Macedonia FACE is a faith-based non-profit community outreach of Macedonia Church in the Hill District. Macedonia FACE is committed to supporting families in the community and addressing disparities that impact African-American families. Programs offered through Macedonia FACE include:

- HIV/AIDS prevention and education
- Medical case management
- Testing services
- Bullying prevention
- Teen dating violence prevention
- Girls' circle
- Families and community teaming
- Community Truancy Intervention Project (CTIP)
- Lifeline support services

***Presbyterian SeniorCare Network: SeniorCare Management Assistance Fund (SCMAF)***

Presbyterian SeniorCare Network is Western Pennsylvania's largest provider of aging services and senior living options, with several communities in the Pittsburgh region. They offer person-centered care, which means that residents are given all the choice and flexibility possible in their daily living. Their philosophy empowers residents and their families to be involved in making decisions that affect their lives.

The SeniorCare Management Assistance Fund has been established for over 15 years as the sole Housing Opportunities for Persons with AIDS (HOPWA) provider. These HOPWA funds, through the Pennsylvania Department of Health, provide Short-term Rent, Mortgage, and Utility (STRMU) Assistance as well as Tenant-Based Rental Assistance (TBRA) to eligible participants in the Southwest region. SCMAF also receives Emergency Financial Assistance through Ryan White Part B to assist consumers with emergent housing and utility related needs.

***Shepherd Wellness Community***

- **Wellness Dinners** improve nutrition, reduce isolation and provide social support.
- **Peer Counseling** phone calls connect members with HIV/AIDS services and offer a lifeline of help, support and hope.
- **Support Groups** boost mental and physical health. Groups guide members through the challenges of living with HIV/AIDS and help participants to deal with anxiety, depression and other relevant issues.
- **Health Education Programs** offer health and wellness guidance and provide information about HIV/AIDS treatment, HIV medications and the latest medical advances.

- **Complementary Therapy Classes** teach members how to improve health and wellness and strengthen their immune systems.
- **Treatment Adherence and Risk Reduction Programs** advise members on how to effectively maintain their HIV medical regimen and ways to decrease the risk of HIV transmission and reinfection.
- **Spiritual Life Programs** presented in an interfaith format offer insight, encouragement, inspiration, direction and guidance.
- **Social and Recreational Outings** combat isolation and loneliness and provide supportive community.
- **Wellness Classes** improve quality of life by addressing the Six Dimensions of Wellness (social, occupational, spiritual, physical, intellectual and emotional).
- **Transportation Assistance**, in the form of bus tickets or mileage reimbursement, helps our members attend programs and access services.

### *The Open Door*

The Open Door is a non-profit organization that provides affordable, safe, and supportive housing and related services for individuals living with HIV who are not eligible for more traditional housing programs. They also provide representative payee services, free of charge, to individuals who experience housing instability but may not need the additional supports of their housing program. They support and welcome high-risk individuals, including those with substance use, mental health diagnoses, and criminal histories to reside in their housing program as well as to access their representative payee services.

The Open Door, Inc. has provided services to over 175 people living with HIV. They currently house 15 individuals and provide representative payee services to about 60 clients, including residents, with hope to continue expansion. The Ryan White Part B funds provide assistance to the Open Door for outreach and non-medical case management services.

### *The Pittsburgh AIDS Center for Treatment*

The Pittsburgh AIDS Center for Treatment (PACT) is part of the University of Pittsburgh Medical Center for Care of Infectious Diseases. PACT is a medical provider that cares for more than 1,700 People Living with HIV; they are the region's largest HIV medical provider. PACT's care team is a multidisciplinary staff of physicians, social workers, nurses, and other health care and support staff. PACT also offers assistance with oral health care, health insurance premiums, medical transportation, and emergency financial assistance. Some of PACT's HIV treatment and support services include:

- HIV primary care
- Medical case management
- Gynecologic care
- Nutrition consults
- Clinical trials
- Pharmacy services

- Hepatitis C care
- Mental health care
- Pain management
- Support groups
- Testing services

### ***The Pittsburgh AIDS Task Force***

The Pittsburgh AIDS Task Force (PATF) is the largest AIDS Service Organization in the region. PATF is dedicated to supporting and empowering individuals living with HIV and preventing the spread of HIV. PATF aims to be a primary resource for HIV support, information, prevention, and testing. PATF's priorities include integrating the consumer's voice, collaborating with other providers, educating the public, providing a safe environment for those in need of a community, and combating stigma. Some of the services PATF offers:

- HIV primary care
- Food pantry
- Support groups
- Medical case management
- Medical transportation
- Housing assistance programs
- Legal services
- Emergency financial assistance

## **SECTION E: CONSUMER SURVEY RESULTS**

### ***Sample Demographics and Representativeness***

We received a total of 121 usable participant responses. We received 25 online responses, out of which two were disqualified because the participants did not meet the geographical or HIV status requirements. We received 98 paper surveys from six different organizations that distributed the survey to consumers.

We compared demographic characteristics such as county, gender, race, and age group of the participants and the overall population of people living with HIV in the region, as reported by the Pennsylvania Department of Health. We conducted tests of equality of proportions for each of these demographic characteristics. We used this comparison as a measure of our sample's representativeness of the region's HIV positive population.

The largest proportion of responses came from individuals living in Allegheny County, followed by Cambria and Westmoreland counties. We received responses from participants residing in all counties except Butler, Fayette, and Greene. The sample residence counties differed slightly from the overall population of people living with HIV. The sample was overly representative of individuals from Cambria and Westmoreland counties. These were the only two counties in which the sample differed significantly from the overall population. This likely reflects the manner in which the survey was distributed; an HIV service organization that operates out of Cambria County distributed the survey to their consumers. This

organization also serves individuals from neighboring Westmoreland County, which separates Cambria from Allegheny. Rural residents overall made up 19% of the survey responses; this proportion does not differ significantly from the region's overall rural representation (Table 9,  $p=.41$ ). See Table 8 and 9 for county proportions and  $p$  values of significance.

<b>County of Residence, Equality of Proportions</b>			
<b>County of residence</b>	<b>Region Percent of People Living with HIV/AIDS</b>	<b>Percent of Sample</b>	<b>p value</b>
Allegheny	76.1	68.6	.0578
Armstrong	.91	1.7	.3743
Beaver	3.0	.8	.1580
Butler	2.3	0	.0916
Cambria	3.5	12.4	.00932*
Fayette	2.5	0	.0783
Greene	.70	0	.3558
Indiana	1.0	1.7	.4513
Somerset	2.3	3.3	.4732
Washington	3.0	.8	.1580
Westmoreland	4.7	10.7	.0026*

Table 8: County of Residence Equality of Proportions  
\*Significant at  $\alpha=.05$

<b>County of Residence by Rurality, Equality of Proportions</b>			
<b>Rurality of residence</b>	<b>Region Percent of People Living with HIV/AIDS</b>	<b>Percent of Sample</b>	<b>p value</b>
Rural	16.2	19.0	.4118
Urban	83.8	81.0	.4118

Table 9: County of Residence, by Rurality, Equality of Proportions  
\*Significant at  $\alpha=.05$

In terms of racial representation, the sample reflected the regional population of people living with HIV, with the exception of one category. 1.7% of the sample identified as Native American/Alaskan Native; this proportion was higher than expected (See Table 10,  $p<.0001$ ). While not significant, the sample had a greater proportion of Black/African American participants, and a lower proportion of White participants as compared to the regional population of people living with HIV, as reported by the Pennsylvania Department of Health (See Table 10).

<b>Race/ethnicity, Equality of Proportions</b>			
<b>Race/ethnicity</b>	<b>Region Percent of People Living with HIV/AIDS</b>	<b>Percent of Sample</b>	<b>p value</b>
White	50.1	42.0	.0795
Black/African American	39.8	47.9	.0736
Hispanic	4.1	2.5	.3796
Asian/Pacific Islander	.9	0	.3030
Native American/Alaskan Native	0	1.7	<.0001*
Multirace	5.2	2.5	.1847
Other	3.4	n/a	

Table 10: Race and Ethnicity, Equality of Proportions  
 \*Significant at  $\alpha=.05$

The sample differed most with regards to distribution across age groups. The sample had an underrepresentation of individuals from the 13-19, 20-29, and 30-39 age groups ( $p=.0214$ ,  $p<.0001$ ,  $p<.0001$ ). The sample had an overrepresentation of individuals from the over 49 age group (See Table 11 for Age Group Representation). These differences may represent the age group distribution differences between those engaged in care and the overall population of individuals living with HIV. This could also result from a selection bias, through which older individuals may have been more willing to complete a survey for a variety of reasons. In any case, this difference should be kept in mind when considering the survey results.

<b>Age Groups, Equality of Proportions</b>			
<b>Age Group</b>	<b>Region Percent of People Living with HIV/AIDS</b>	<b>Percent of Sample</b>	<b>p value</b>
<13	.7	0	.3558
13-19	4.2	0	.0214*
20-29	29.9	6.1	<.0001*
30-39	33.1	10.2	<.0001*
40-49	22.1	21.4	.8551
>49	10	62.2	<.0001*

Table 11: Age Groups, Equality of Proportions  
 \*Significant at  $\alpha=.05$

The gender distribution of the sample participants was highly representative of the overall population of people living with HIV in SWPA. The proportions of males and females were not significantly different. Since the Pennsylvania Department of Health does not report on proportion of PLWH/A who identify as

transgender, JHF was unable to assess whether the transgender representation was reflective of the overall population. See Table 12 for the results of the equality of proportions tests for gender.

Gender, Equality of Proportions			
Gender	Region Percent of People Living with HIV/AIDS	Percent of Sample	p value
Male	81.0	79.3	.6394
Female	19.0	17.4	.6586
Transgender	n/a	2.5	n/a
Other	n/a	.8	n/a

Table 12: Gender, Equality of Proportions  
\*Significant at  $\alpha=.05$

Participants reported an average annual income of \$16,290 with a range from 0 to \$99,000. Participants reported a range of 1 to 4 adults in the household, including themselves, with an average of 1.38. Number of children living in the household ranged from 0-5.

The most commonly endorsed type of health insurance in the survey was Medicaid (58.7%), followed by Medicare (38%). Only 27.3% of respondents reported use of SPBP. 7 respondents reported VA insurance, 12 reported private insurance through an employer, and 9 reported private insurance through the marketplace. Only one participant reported having no insurance.

### **Primary Care**

In this section, participants reported where they go for primary medical care and the status of their viral load. The majority of respondents said they go to a hospital or hospital clinic (63.3%), while the second largest portion go to a private doctor's office (20.0%). 5 of the participants reported receiving care at a VA hospital or clinic.

In response to the question about viral load, 73.6% of participants reported that they are virally undetectable. 13.2% of participants did not remember the results of their most recent test. 9.9% were not undetectable.

Participants in the survey had generally positive views about their primary medical care. 93.2% of participants who answered the question regarding quality of HIV medical care rated their care as "Good" or better. 78.1% rated their care as "Very Good" or "Excellent."

The following responses to "My HIV provider..." had the lowest percentages of participants who answered "Always":

- "Seems to understand my culture or community." (72.4%)
- "Is easy to reach when I need to." (78%)

- “Spends enough time with me during visits.” (81.5%)
- “Seems to understand the needs of people my age.” (81.9%)
- “Is easy to schedule an appointment with.” (83.1%)

While these five prompts elicited the smallest proportions of “always” responses, these ratings were still fairly high. Respondents generally reported satisfaction with their HIV medical care.

Participants were also asked in this section to rate the overall quality of the HIV case management they have accessed and the overall quality of HIV non-medical support. 45.4% of respondents said that their case management services were excellent, while 26.1% rated them as “Very Good.” No respondents described their case management as “Poor.” 67.1% of respondents rated their non-medical HIV services as “Very Good” or “Excellent,” while only 2.5% rated these services as poor.

### ***HIV/AIDS Medications and Adherence***

96.6% of participants reported that they are currently prescribed HIV medications. This high rate likely reflects the participant pool of individuals currently engaged in care. Among those few who reported that they were not taking medication, reasons varied for each participant.

Participants were also asked if they had ever stopped taking HIV medications or missed doses in the past 6 months. 13% of respondents answered “Yes.” Open-ended reasons given for missing doses fell into the following categories:

- Illness and fatigue (3)
- Side effects (1)
- “Tired” of taking medication/treatment fatigue (2)
- Accidentally missed dose (2)
- Wasn’t home (1)
- Drug and alcohol abuse (4)
- Other (2)

In this section, participants were also asked about their use of alternative therapies to manage their HIV, such as herbal treatments, massage, or exercise. 76.9% of participants reported at least one type of alternative therapy, while many endorsed several. The most commonly endorsed therapies were “Vitamin/nutritional supplements” (51.2%), “Regular exercise” (45.5%), “A healthy diet” (41.3%), “Meditation” (26.4%), and “Massage” (19.8%). Participants on average endorsed 2 types of alternative therapy.

### ***Housing***

The survey asked participants about their current living situation. 12.2% of participants who responded said that they were living “In a family member, partner, or friend’s home (long-term);” 80.9% of respondents said that they were living in “My own home or apartment.” 4 survey respondents said they were living in a

residential program, while 2 said they were currently living “On the street, in a shelter, in a car, or some other temporary place.” 21.6% of respondents said they live in subsidized housing.

The survey also asked participants about problems they experienced when attempting to secure and keep their housing. The majority of respondents reported that they did not have trouble securing housing (60%). However, the most commonly endorsed problems experienced in securing housing were 1) Meeting eligibility requirements for subsidies or other public housing problems; 2) Waiting lists; 3) Criminal record information; and 4) Credit problems. Some of the responses to the open-ended prompt for more information included the following:

- *“I’ve been told I’m on the sec 8 list. But I think they forgot me.”*
- *“More needs to be done to place a cap on the price inflation of area property owners, especially those who own in Pittsburgh but do not live here themselves.”*

The responses to the question regarding problems *keeping* housing differed significantly. 87.6% of respondents reported “Difficulty paying rent, mortgage, or utilities.” Open-ended responses in this section included the following:

- *“My social security is only \$733.”*
- *“Gentrification forced me to find another apartment.”*
- *“I was in jail and that set me back.”*
- *“Used to be drug and alcohol, clean today.”*
- *“The high cost of maintaining the property.”*
- *“Short with money after paying rent, utilities, etc.”*

Overall, this particular sample of HIV-positive individuals does not experience significant problems securing housing, but do struggle to keep their housing. Financial challenges were the most commonly reported reasons respondents struggle to keep their housing.

### **Access**

In the Access section of the survey, JHF asked participants which features of HIV-related services were most important to them. This question was asked to gauge the aspects of services that consumers prioritize. The following responses were endorsed most frequently:

1. The staff understands the needs of people living with HIV/AIDS (49.6%)
2. I can get there easily (39.7%)
3. It is easy to schedule an appointment (38%)
4. Services are free or low cost (37.2%)/ They take my insurance (37.2%)
5. I can get multiple services at the same time (24.8%)

Participants were also asked what they find most difficult about accessing HIV services. 48.8% of respondents said they find it fairly easy to access the services they need. The following are responses participants most frequently endorsed as difficult about using HIV services:

1. Too much paperwork (21.5%)
2. Having to go to different places to get different services (12.4%)
3. Dealing with all of the things my different providers ask of me (10.7%)
4. Getting to and from appointments (9.9%)

This question also offered space for additional information in an open-ended format. The following are a selection of the responses:

- *“Medically too ill”*
- *“Bus tickets are so complicated to get to see my doctor or social workers, sometimes it is too much paperwork that I prefer to walk...”*
- *“SPBP/certify repetitive”*
- *“Some workers are insensitive of confidentiality”*
- *“Cabs won’t cross county lines”*
- *“Appointments are very difficult to get in the short-term...”*

### ***Substance Use and Mental Health***

Participants were asked about their current and past substance use. 10 participants did not respond to questions about substance use, but 10% of those who responded endorsed current use of nonprescription drugs; 6.3% endorsed current off-label use of prescription drugs. Of those who responded, 26.1% have received treatment for substance use in their lifetimes. Three participants answered “Yes” in response to “Was there ever a time when you wanted treatment for substance use, but were unable to get it?”

62.8% of participants reported at least one mental health diagnosis; 20.6% reported three or more diagnoses. The most common conditions reported were Depression (44.6%), Anxiety (40.5%), Bipolar Disorder (16.5%), and Post-Traumatic Stress Disorder (9.9%). 40.5% of participants reported current mental health treatment, 46.3% reported no current treatment, and 13.2% did not respond.

### ***Risk Reduction***

In the risk reduction section, participants were asked about their need for risk reduction education and help with disclosure. Participants were first asked whether they needed help figuring out ways to be sexually active while staying healthy. 18.3% of those who responded answered “Yes.” The next question asked participants whether they needed help figuring out ways to stay healthy while using drugs. 5.7% of respondents answered “Yes.” The final question in this section asked whether participants needed help with disclosing their HIV status; 16.5% of respondents answered “Yes.”

### ***HIV Knowledge and Resources***

The HIV Knowledge and Resources section intended to assess whether participants felt they had received enough information about HIV and which resources they rely on for information. 90.8% of respondents felt that their HIV providers had given them enough information about HIV/AIDS. The primary resources that participants reported accessing for HIV/AIDS education are as follows:

1. Medical care provider, HIV or primary (63.6%)
2. Case manager (50.4%)
3. HIV-positive peers (38.8%)
4. HIV literature, books, articles, pamphlets (35.5%)
5. Internet (23.1%)

The final question in this section asked, “Is there any information about HIV or services that providers have not discussed with you, that you wish they would?” Few participants responded to this open-ended question; the participants who did respond wanted more information about HIV/AIDS services, particularly dental services and housing assistance.

### ***Aging***

The survey asked participants to make three selections among six categories representing their biggest concerns about aging with HIV. The categories included relationships, health, access, housing, career, and end of life planning. The most commonly selected categories were as follows:

1. Health (56.2%)
2. Relationships (49.6%)
3. End of life planning (34.7%)

### ***Additional Information***

The final section asked participants three open ended questions that gave them the opportunity to share further information. The first question asked participants what services are missing or could be improved in the region. Responses generally fell into the following major categories: aging (4), peer/group support (4), access/transportation/rural coverage (4), wellness/alternative therapies (3), and education about new treatments (2). Additional responses noted the need for legal services, housing, food assistance, evening programming for individuals who work, life skills education, and services for mothers with children. The following are a small selection of the responses:

- *“Assistance with filling out forms for final life plans”*
- *“Bus service- living too far makes very difficult to see doctor and supporting groups”*
- *“Coverage to rural areas”*

- *“A place that can help people in household things”*
- *“Up to date education on current HIV treatments”*

Another open-ended question asked participants “Do you feel comfortable talking to your HIV service providers about your sexual health and/or drug use? Please explain.” 47.1% of those who responded said “Yes,” while 17.7% said “No.” The remaining responses were variable, including both positive and negative information. The following are a selection of responses to this open-ended question:

- *“No, because of past medical provider judgment of my drug use.”*
- *“They have always given me time, respect, and information for many years.”*
- *“Sometimes it is difficult to start or sometimes a certain provider is easier or more difficult to talk to.”*
- *“Generally so, unless I’ve had an unsafe encounter, which has occurred.”*
- *“Yes, been with my provider for four years and have a great relationship. They do not judge!”*

The final question was an open-ended question that asked for additional input about services or challenges accessing services. Responses generally fell in to the following categories: access to services in rural areas (3), privacy/confidentiality concerns (2), burden of recertification requirements (3), financial challenges (1), and challenges getting appointments (1). The following are a selection of responses to the question:

- *“Yes, we don’t have any service in my area about HIV so I always have to travel too far to get service and on top of that, very complicated to get bus tickets. However I never miss my doctor’s appointments.”*
- *“Recertification is burdensome in relationship to SPBP and other services. They have my SS# and thus have access to everything about me.”*
- *“It typically takes 2-3 months to get an appointment at any HIV clinic and diabetes offices. The dental process and coverage is overwhelming...”*
- *“I had to move...to be sure I had ease of care. I would love to move back...but am afraid to because of the lack of services in rural areas.”*

## **SECTION F: PROVIDER INTERVIEW RESULTS**

### *Barriers*

Provider interviews offered a more in-depth look at the state of HIV services in southwest Pennsylvania. Several major themes emerged in each topic area discussed during the interview. All interviews included a discussion about barriers at three levels. Individual level barriers are defined as those that prevent HIV positive individuals from accessing services or adhering to medication and care. Provider level barriers were considered those that prevented providers from optimally serving clients. Lastly, system and policy level barriers were macro-level issues that prevented the system from facilitating optimal care and access. The major barriers identified in the interviews are as follows:

<b>Key findings: Barriers</b>		
Individual-level barriers	Provider-level barriers	System & policy-level barriers
<p><i>Barriers that prevent diagnosed individuals from accessing HIV services, adhering to medication, and remaining in medical care</i></p> <ul style="list-style-type: none"> <li>• Treatment fatigue</li> <li>• Substance use</li> <li>• Mental illness</li> <li>• Burden of diagnosis</li> <li>• Burden of poverty</li> <li>• Literacy and communication</li> <li>• Unstable and unaffordable housing</li> <li>• Stigma/fear of disclosure</li> </ul>	<p><i>Barriers that prevent HIV service providers from optimally serving their consumers</i></p> <ul style="list-style-type: none"> <li>• Turnover</li> <li>• Lack of cultural competence</li> <li>• HIV medical provider shortage</li> <li>• Working with government agencies and non-HIV healthcare providers</li> <li>• Collaborations with other HIV service providers</li> <li>• Gathering consumer input</li> <li>• Staff development</li> <li>• Stigma</li> <li>• Connecting with younger clients</li> </ul>	<p><i>Barriers within the larger system or policies that prevent consumers from accessing services, adhering to medication, and remaining in care; or prevent providers from optimally serving their consumers</i></p> <ul style="list-style-type: none"> <li>• Behavioral health system capacity</li> <li>• MATP restrictions</li> <li>• Segregation of behavioral and physical health services</li> <li>• Lack of available subsidized housing close to medical care</li> <li>• Recertification requirements</li> </ul>

Table 13: Key findings, Barriers

### **Individual-level barriers**

Providers reported many factors that keep consumers from accessing care appropriately and generally agreed with each other about these factors. Providers talked extensively about the burden of poverty, the burden of HIV diagnosis, treatment fatigue, and how these three barriers intertwine. Often treatment fatigue was discussed in the context of older adults who were diagnosed early on and become exhausted with the medicalization of their lives. Providers discussed the burden of diagnoses both in terms of what consumers must do to access medical care and also in terms of living with a stigmatized disease that is not easily disclosed. Many consumers facing these barriers have the additional hardship of living in poverty; even when financial assistance is available for certain services, consumers may be unclear about what is covered and concerned about their inability to pay. Obviously financial concerns are tied to housing as well, and nearly every provider discussed unstable or unaffordable housing as a concern.

Most providers mentioned mental illness and substance use as major barriers as well. Providers noted that these factors can affect a consumer’s ability and willingness to adhere to medication and attend

appointments. Several providers mentioned that it is difficult to get consumers to follow through with referrals to mental health treatment.

### **Provider-level barriers**

Interviewees mentioned both internal and external barriers that challenge their ability to optimally serve consumers. Providers noted staff issues such as high turnover, lack of cultural competence, and a need for staff development. Some providers expressed a desire for re-establishment of a standard case management training, which they felt provided valuable training as well as opportunities to network and learn from each other. Providers noted a lack of training resources for new staff.

In terms of serving consumers, several providers noted the challenge of finding and keeping good candidates for peer advocate positions. Providers wanted guidance on this process and wanted to learn about other providers' experiences with this. In addition, providers expressed that they would like more consumer input and that existing methods of gathering input are inadequate; Consumer Advisory Boards in the past have not been inclusive enough or sustainable over the long term. In a similar vein, providers also expressed that it is challenging to reach and connect with the younger consumer base. Some providers expressed that these younger consumers seem less engaged with nonmedical services than older consumers.

Providers reported significant difficulties working with external agencies, particularly government agencies and providers that are not ASOs. In working with agencies outside of the HIV provider network, interviewees reported both sluggishness and stigma. Stigma was sometimes attributed to HIV and other times attributed to mental illness and substance use. Although each interviewee discussed stigma, providers in rural areas particularly noted that outreach in the community reveals heavy stigma around HIV.

### **Systemic & policy-level barriers**

Interviewees noted that recertification requirements are burdensome both for providers and for consumers; some providers noted that recertification often does not serve its intended purpose, as it may keep consumers from accessing care rather than keep them in care. Most interviewees also mentioned that the behavioral health system in the region poses a challenge in their work, specifically because the system lacks the capacity to provide for the significant need, and because it is starkly divided from the physical health system in many cases.

Lastly, providers specifically noted that the affordable and subsidized housing *close to care* is scarce. Providers noted that many consumers who seek subsidized or affordable housing are being forced to live further away from the urban center of Pittsburgh, some even moving outside of the county into rural areas. Transportation then becomes a challenge for these consumers; even when transportation is provided by the Medical Assistance Transportation Program (MATP) there are many restrictions and the burden of getting to appointments becomes significant. Rural consumers have the option to receive care from the single HIV medical provider in rural SWPA, if they live close enough; find a rural primary care physician willing and capable of treating HIV; or travel to Pittsburgh for medical appointments.

### ***Recommendations and Visions***

Providers were asked in several different questions about their ideas for expansions of existing programs, establishment of new programs, and suggestions for improvements in the region. These responses

were broadly grouped as recommendations and visions. The following list includes all suggestions made by at least two interviewees:

<b>Key findings: Recommendations and Visions</b>
<ul style="list-style-type: none"> <li>• Better communication and information sharing between consumers and doctors</li> <li>• Integrated mental health in HIV-service organizations</li> <li>• More opportunities for peer connection and support in nontraditional ways; ex. congregate housing, outings, community meeting spaces</li> <li>• Staff development opportunities: case management training, cultural competency training</li> <li>• Age-specific programs and outreach</li> <li>• More opportunities for consumer input</li> <li>• Routinized/expanded testing and prevention activities</li> <li>• Stronger referral network and better relationships with non-HIV agencies</li> <li>• Messaging to educate the public and reduce stigma about HIV</li> <li>• More subsidized housing close to HIV care</li> <li>• More support for consumers seeking employment; ex. transportation assistance</li> <li>• More transparency from funders to organizations, and from organization staff to consumers</li> <li>• Expanded food access specific to the HIV community</li> <li>• Widespread adoption of harm reduction principles and programming</li> </ul>

Table 14: Key findings, Recommendations and Visions

Providers had a number of recommendations, some specific and some general, about what could be done to improve the care of HIV-positive individuals in the region. Recommendations generally were around consumer programming, organizational and system functioning, and interaction with the public.

Providers had many suggestions for changes and expansions to consumer programming. Many providers want to expand opportunities for HIV-positive peers to connect, particularly in nontraditional settings outside of support groups. Providers also want to see age-specific programming and outreach, both for consumers in their later years and young people. Several providers mentioned that they would like to see more support for consumers who are seeking employment; in particular, consumers often need transportation assistance to employment opportunities. Many providers also want to see expanded food access and more opportunities for consumer engagement.

From an organizational and systems perspective, providers suggested changes in both the way organizations interact with consumers and with other organizations. Several interviewees wanted to see a widespread adoption of harm reduction principles to guide interactions with consumers. Providers would like to have better communication and information sharing both ways between doctors and consumers. Interviewees also suggested greater transparency to facilitate this communication, both between funders and organizations, and between the organizations and consumers. In response to the challenges in dealing with non-ASO agencies, providers mentioned they would like stronger referrals networks and improved relationships with these agencies. Within their own agencies, providers wanted to see more staff development opportunities to improve their abilities to serve consumers, and integrated mental health services. With regards to relationships with the public, nearly every provider recommended increased messaging to educate and reduce stigma, as well as routinizing and expanding testing and prevention activities.

**Strengths**

Providers were not asked specifically about strengths, but the topic emerged in nearly every interview. Providers discussed the strengths of consumers, the strengths of their own organizations, and the strengths of the particular service delivery system in southwest Pennsylvania. The following themes regarding strengths emerged throughout the interviews:

Key findings: Strengths	
Strengths identified by three or more interviewees	Selected quotes
<ul style="list-style-type: none"> <li>• Consumer anonymity in organizations that are not HIV-specific</li> </ul>	<p>“So the beauty of the fact that we are [organization] and that we offer different types of services is that when you come here, you could be getting any type of service.”</p>
<ul style="list-style-type: none"> <li>• Variety of services offered at same organization</li> </ul>	<p>“I think the way that we’ve managed to overcome a lot of those issues or mitigate those issues for people is to provide as many of those services as we can within our own walls. Because a lot of it is about self-disclosure of their HIV status or their substance use or their sexual orientation, gender identity, to providers who frankly don’t treat them well.”</p>
<ul style="list-style-type: none"> <li>• Strong collaborations and partnerships with other HIV service organizations</li> </ul>	<p>“...We have a very good certification collaboration with [organization], and we work with the barriers to information-sharing, but we do it very well.”</p>
<ul style="list-style-type: none"> <li>• Utility of unrestricted funding sources to provide gap support</li> </ul>	<p>“And so they provide an annual donation to the organization...and those are unrestricted dollars. And then also we do...our own fundraising. So we are able to support Ryan White consumers who—we call it gap support—who fall in a gap; we can tap into other revenue sources to support them.”</p>
<ul style="list-style-type: none"> <li>• Resiliency of consumers</li> </ul>	<p>“They’re very open regarding medications, what’s new out there. They educate each other.”</p> <p>“[Peer support] provides a lot of support from our consumers who can relate to each other. I’ve seen a lot of resiliency with that and that has seemed to be something has kept certain clients continuing in care, continuing to stay connected.”</p> <p>“I do think that clients are pretty resilient, and if we can give them a clear expectation of what we’re able to provide, they can work within those parameters.”</p> <p>“...The buddy system they created to take their pills. And we don’t have to remind them...Also they have the advisory board, where they come together and plan events...Even with all the barriers they’ve faced, they still can come together and do that.”</p>

Table 15: Key findings, strengths

Many interviewees were proud of their agency’s ability to preserve consumer anonymity; in other words, staff of organizations that were not explicitly HIV-service organizations felt that this feature made consumers more comfortable. Interviewees also felt that the large and varied offering of services at their agencies was a strong point, especially in terms of serving consumers who traveled far distances from rural areas. Interviewees placed a high value on the strong collaborations between their agencies and other ASOs.

Providers felt that these collaborations were key in overcoming barriers and giving consumers the best care possible. Providers often noted that unrestricted funding was crucial in providing gap support to overcome consumer barriers not covered by Ryan White funding. The flexibility of this funding allows providers to be creative in solving unique consumer problems that otherwise would keep consumers out of care. Lastly, nearly every provider talked about the resilience of consumers. Many interviewees were inspired by the challenges that consumers had overcome and the support that they provide for each other.

## **SECTION G: DISCUSSION**

Many congruent themes emerged through the provider interviews, consumer surveys, and literature review. The consumer and provider feedback consistently matched, with the provider interviews providing information that elaborated on the more concise consumer themes that emerged. The literature generally reinforced ideas presented by consumers and providers, especially with regards to the nuances of the southwestern Pennsylvania region.

### ***Housing***

Housing emerged as the largest concern across all the sources. Housing stability, as an important social determinant of health, plays a large role in the health outcomes of People Living With HIV (PLWH). Stable housing not only benefits the individual, but also benefits public health efforts by helping to decrease viral load and decrease risk behaviors, which reduces likelihood of transmission and new infections.

Access to stable, safe, affordable, and conveniently located housing is dependent on many factors, including individual income, subsidy programs, and housing market values. While housing in the region is considered relatively affordable compared to national standards, it is not affordable for those individuals living below 30% of the area's median income; Allegheny County has seen a major loss in the stock of affordable housing, especially in the past decade (University Center for Social and Urban Research, 2005). Individuals with lower incomes face a shortage of available units that appropriately match with their income level. As a result, 1/3<sup>rd</sup> of all households in Allegheny County spend more than 30% of their income on housing, a measure known as "rent burden". In addition, only 25% of the housing available to the lower income bracket (30% of median income) is subsidized or regulated, meaning that the majority is subject to fluctuations with the market (Institute of Politics, 2016). This is especially concerning for consumers who live in neighborhoods undergoing significant redevelopment.

Lack of affordable housing affects PLWH in a number of ways. Surveillance and literature suggest that HIV disproportionately affects people of lower socioeconomic status (An, Prejean, McDavid, Harrison, & Fang, 2013). The consumer sample reflected this knowledge, with a reported average annual income of \$16,290 and high enrollment rates in Medicaid (58.7%) and Medicare (38%). Consumers reported problems with getting housing and keeping housing. 87.6% of respondents reported that they have trouble paying for housing costs, and open-ended responses noted gentrification, minimal social security benefits, and property maintenance costs as related causes.

Even when housing assistance programs are available, many individuals are barred from consideration based on individual characteristics. A criminal background and history of drug possession can make someone ineligible for assistance through the Housing Choices Voucher program in Pittsburgh, for example (Housing

Authority of Pittsburgh, 2017). Consumers and providers both agreed that this is a major barrier to stable housing for many PLWH, and subsequently becomes a barrier to medication adherence and viral suppression.

ASOs and consumers have found several ways to deal with these challenges. Some case management ASOs have identified rural Primary Care Physicians capable of treating individuals with HIV, and have developed positive working relationships with these PCPs. Several ASOs have leveraged unrestricted funding in their organizations to transport rural individuals to medical care. Other ASOs that provide housing services have worked hard to develop relationships with landlords in rural areas.

Providers also offered many other suggestions to improve the availability of affordable housing for PLWH. The expansion of existing low-income subsidy programs available to the general public would certainly benefit PLWH. Policy changes to these subsidy programs could also place PLWH at high priority. There are also changes that could be made to existing housing programs that specifically serve PLWH. In terms of specific funding streams, the interviews suggested that there is not enough Tenant-Based Rental Assistance (TBRA) funding to meet the need, especially in rural areas. Interviewees favored an increase in funding for TBRA over Short Term Rental Mortgage, and Utility assistance (STRMU), which they felt fostered less stability in the long term. Continued and increased support for harm reduction housing models could also improve access to housing for individuals with criminal backgrounds.

#### Summary

**Problem:** Housing is unaffordable for low-income PLWH; subsidy programs have long wait lists and restrictions that can disqualify people with criminal background or history of drug use; these factors and others are forcing PLWH to live further from their HIV healthcare providers and supportive services.

**Solutions:** Expand low-income subsidy programs, change policies that bar people with criminal backgrounds from these programs, change policies to give priority in these programs to people living with HIV. Advocate for more funding for Tenant-Based Rental Assistance (TBRA). Advocate for and supports harm reduction housing models.

### *Recertification and Paperwork*

Providers and consumers consistently voiced concerns about the burden and repetitiveness of the recertification requirements. Providers noted that in addition to the extra burden on staff time and finances, recertification requirements also place cognitive burden on consumers. Consumers expressed frustration at being asked to submit the same documentation every six months or every year after they have already certified.

Recertification requirements are established by the Health Resources and Services Administration (HRSA) and enforced by the fiscal agents and HIV service providers. HRSA requires that after initial certification, consumers recertify every six months to maintain eligibility. This ensures that consumers continue to meet eligibility requirements and that Ryan White funding meets payer-of-last-resort requirements (HIV/AIDS Bureau, 2011; 2013).

The recertification requirement is established by HRSA and unlikely to change. However, there are steps providers can take to minimize the burden of the requirement as much as possible. Several providers reported that enhanced information sharing methods between ASOs were beneficial in reducing the burden of recertification. JHF has established an information-sharing recertification document to facilitate this and has

shared this document with all provider agencies. JHF will continue working with providers to nurture information-sharing relationships and reduce the burden of recertification on consumers and providers as much as possible.

### Summary

**Problem:** Recertification requirements are burdensome for consumers and providers.

**Solutions:** Continue to nurture information-sharing partnerships between ASOs and streamline the process as much as possible.

### *Stigma*

Stigma has emerged as a major concern from the literature, consumers, and providers. The stigma that PLWH experience is not limited to their HIV status, and often comes from providers as well as the general public. Stigma remains a major concern, as it can impact medication adherence as well as psychological well-being (Blake Helms, Turan, Atkins, 2017; Turan et. al, 2016). While the consumers who participated in the survey overall reported having a positive attitude in regards to the region's providers, many consumers noted that they had experienced stigma firsthand.

PLWH are often members of more than one marginalized group. HIV disproportionately affects people of color, men who have sex with men, transgender individuals, people of lower socioeconomic status, and people who inject drugs. These are all groups that experience discrimination, and therefore PLWH whose identities intersect these groups often experience even greater stigma. Research studies have shown this, and documented discrimination from medical providers toward dually diagnosed individuals who live with both HIV and substance use disorder (Yanessa, Reece, & Basta, 2008).

The HIV providers who were interviewed generally agreed that stigma around HIV status and other factors is a concern. Some providers noted that their organizations are particularly adept at treating people from marginalized populations; other providers were not as well-equipped, and voiced a need for cultural competency training for their staff and peers. Providers noted that discrimination or mistreatment can affect adherence over time; consumers may be hesitant to trust providers, follow through with referrals, or attend appointments. Several consumers corroborated this, reporting that they feel uncomfortable disclosing personal information to their providers because of past history of mistreatment.

While providers acknowledged this stigma as an issue, they were also eager to suggest tactics to address it. Several providers said that they want more training opportunities to increase the cultural competence of their staff. Nearly all providers suggested that more effort is needed to combat stigma in the general population; providers suggested media campaigns and normalizing testing as possible solutions.

Stigma related to HIV status is particularly salient in rural areas, as mentioned in the literature and reinforced by feedback from HIV providers. PLWH in rural areas may be less likely to disclose their status due to highly internalized stigma (Okellow et. al, 2015). Research suggests that disclosure for PLWH in rural areas may be important in combating depression by mitigating the effect of isolation (Vyavaharkar et. al, 2011). Since supportive psychosocial services for PLWH are less available, disclosure may be particularly crucial in this context.

### Summary

**Problem:** Stigma of HIV is still pervasive in the general population and among healthcare providers, social service agencies. Consumers whose identities intersect multiple marginalized groups are particularly subject to discrimination.

**Solutions:** More training opportunities; increase cultural competence among staff of ASOs; combat stigma in general population through media campaigns and normalizing testing.

### *Rural Issues*

Rural areas, which represent a significant portion of SWPA, present unique challenges in caring for PLWH and preventing the spread of HIV. About 15% of new HIV infections in SWPA were in rural counties in the past five years, and about 16% of the region's population of PLWH resides in rural counties. Rural areas typically have less access to quality HIV care due to health professional shortages, lower levels of provider knowledge about treating HIV, and are geographically farther from urban HIV medical care. PLWH in rural areas may experience isolation, especially related to stigma in rural areas. In addition, the high prevalence of injection drug use and low access to harm reduction services in many areas of rural SWPA may present a risk for future HIV outbreaks.

Access to HIV care in rural areas encompasses several issues. First, medical providers in general are scarcer. Twelve areas in SWPA's rural counties are designated as primary care Health Professional Shortage Areas. In addition, four out of the five counties in the region that are designated as mental health HPSAs are rural. Providers expressed concerns in the interviews that reflected this scarcity (Health Resources and Services Administration, 2017).

Second, health professionals—particularly Primary Care Physicians (PCPs)—who practice in rural areas may have less experience treating HIV. As a result, rural doctors may be less comfortable being the primary providers for PLWH. Rural consumers who want to seek care in their own counties may face challenges in locating an appropriate provider.

Given the scarcity of medical providers and rural physician's lack of experience treating HIV, many PLWH in rural areas of SWPA choose to access care in Pittsburgh. Consequently, transportation becomes the primary barrier. Public transportation in most rural areas is nonexistent, so consumers without vehicles or valid driver's licenses have limited options. Transportation through the Medical Assistance Transportation Program is available to individuals who are Medicaid eligible; however, as many providers pointed out in the interviews, there are often cumbersome restrictions on this program. Some providers are able to leverage other funding streams to pay for taxi services for rural consumers, but many ASOs do not have this kind of funding available.

Stigma and social isolation are other issues that arise for PLWH in rural areas. In addition to the absence of HIV-specific medical care, many rural areas also lack the same supportive psychosocial services available to PLWH in urban areas. Even when HIV-specific psychosocial services are available, stigma and fear of disclosure may keep people from accessing these supports. Since loneliness and stigma in rural PLWH have been linked to depression and increased risk behaviors, this is a potential area of concern (Hubach et. al, 2015; Bray Preston et. al, 2007).

Rural areas of the region have also been particularly affected by the opioid epidemic. Several consumers endorsed history of substance use, and nearly all providers mentioned it as a concern. As substance use—particularly injection drug use—increases in rural areas, providers are increasingly concerned about access to sterile injection equipment to prevent the spread of HIV. While individuals living close to Pittsburgh have access through needle exchange programs like Prevention Point Pittsburgh, a lack of access in rural areas may pose a risk of HIV outbreak. A 2016 study identified counties across the country in which key indicators suggest vulnerability for outbreak; Cambria County was identified as a county at particularly high risk (Van Handel et. al, 2016). Providers overwhelmingly recommended expanding needle exchange programs to rural areas and promoting widespread adoption of a harm reduction philosophy.

#### Summary

**Problem:** Medical providers in rural areas are scarcer and less knowledgeable about HIV; transportation to HIV care and supportive services in the city is a barrier. Stigma and social isolation are pervasive and access to harm reduction services is low.

**Solutions:** Continue work to expand treatment options in rural areas; leverage unrestricted funding to assist rural PLWH with getting to care; increase access to harm reduction services in rural areas.

### *Behavioral Health*

In both rural and urban areas, providers consistently mentioned behavioral health services as a concern. First, providers noted that the behavioral health system does not have the capacity to address the need in the region; this is especially true when considering the treatment of substance use disorder under the umbrella of behavioral health. This capacity problem typically presents as long wait times for appointments. Second, providers noted difficulty getting consumers to follow through with referrals to behavioral health care.

Providers, consumers, and the literature overwhelmingly depict behavioral health services as a need in the region. While the consumer survey did not ask specifically about the need for behavioral health treatment, the consumer sample did report a particularly high prevalence of mental health diagnoses. 62.8% of participants reported at least one mental health diagnosis and 40.5% reported that they were currently receiving some kind of mental health treatment, including psychiatric medications. Providers noted a spectrum of mental health concerns, from treatment fatigue and depression to severe and pervasive psychiatric conditions. In addition to reports from providers and consumers, the need for more behavioral health capacity is also evident in the literature. 5 of the 11 counties in the SWPA region are designated as mental health HPSAs (Health Resources and Services Administration, 2017).

While the behavioral health system capacity is a concern, consumers are resilient. Many consumers reported utilizing alternative therapies, for example, a healthy diet, exercise, or meditation (77%). Providers reported that consumers support each other, educate each other, and encourage each other to continue with care.

Providers suggested integrating behavioral health services into primary care as a potential way to address both the problem of capacity and the challenge of getting consumers to follow through with referrals. This agrees with recommendations from other health needs assessments in the region as well (Allegheny Health Network, 2015). In addition, incorporating a harm reduction philosophy into HIV services may improve follow-through with behavioral health referrals.

### Summary

**Problem:** Behavioral health system capacity is inadequate; many PLWH have significant behavioral health care needs.

**Solutions:** Integrate behavioral health services into primary care; advocate for increases to behavioral health system capacity.

### *Communication and Consumer-Provider Relationships*

The findings from this needs assessment identify communication challenges in the consumer-provider relationship as a potential area of concern. The assessment identified four primary contributing factors: lack of clarity, mistrust, staff issues, and health literacy challenges. This is an important topic of discussion, since patient-provider relationships have been associated with physical health indicators (Bankoff, McCullough, & Pantalone, 2013).

First, there is a lack of clarity on many levels about what services are available and the limitations on these services. In the same way that recertification requirements become frustrating to consumers, restrictions on services can become frustrating when they are not communicated clearly. These frustrations can further complicate the relationships between consumers and ASO staff and potentially cause consumers to disengage from services. Providers would like to see more transparency in the funder-ASO relationship, the ASO-staff relationship, and the staff-consumer relationship to improve communication about services.

Second, mistrust interferes with the consumer-provider relationship. Consumers expressed concerns about whether providers take their confidentiality seriously; some consumers reported feeling uncomfortable talking with providers about their sexual health or drug use because of bad experiences with providers in the past. Providers also discussed these concerns in interviews, saying that many consumers—especially those whose identities intersect multiple marginalized groups—have been treated poorly by providers in the past. As a result, they may be unwilling to disclose personal information and hesitant to trust provider recommendations.

Third, staff issues can contribute to this mistrust and overall consumer-provider relationship problems. The poor treatment consumers experience can result from a lack of cultural competence among staff. In addition, high turnover within agencies can contribute to mistrust; for example, consumers who are shuffled around among multiple case managers or other staff may find it difficult to establish trusting relationships with ASO staff.

Lastly, consumers may experience health literacy challenges that make it difficult to communicate with providers. Consumers may find it challenging to relate to doctors and may be self-conscious about their ability to communicate with providers, especially if they have low literacy. They may be less willing to ask questions, seek clarification, disclose personal information, and communicate their concerns to providers. Studies have found that 1/3<sup>rd</sup> of consumers do not know their CD4 count or viral load (Mooss, Brock-Getz, Ladner, & Fiaño, 2013). In the sample from this needs assessment, 13.2% of consumers did not know their viral load. While this is comparatively small, it speaks to the need for providers to keep health literacy issues in mind when communicating with consumers.

Although research does not agree about whether health literacy around HIV predicts adherence, low health literacy is predictive of incorrect beliefs about transmission (Mooss, Brock-Getz, Ladner, & Fiaño,

2013). A 1999 study showed that literacy was predictive of adherence, but a 2015 study showed no such relationship (Kalichman, Ramachandran, & Catz, 1999; Laws, Danielewicz, Rana, Kogelman, & Wilson, 2015). Providers should remain cognizant of the possibility that their consumers face health literacy barriers.

#### Summary

**Problem:** Communication barriers arise in the provider-consumer relationship as a result of mistrust, lack of clarity, staff issues (lack of cultural competence and high turnover), and literacy challenges.

**Solutions:** Increase transparency from funders to ASO, ASO to staff, staff to consumer; staff training around cultural competency.

#### *Youth and Aging Issues*

Age came up frequently in the literature and provider interviews. The bulk of PLWH in SWPA are between 20 and 49 years old, although new infections disproportionately occur in individuals in the 20-29 age group. New infections from 2010 to 2015 have affected 30-39, 40-49, and 49+ age groups similarly, however. Engaging youth is particularly important, as HIV-positive youth may be especially likely to delay or forgo medical care (Harper, G. W., Fernandez, I. M., Bruce, D., Hosek, S. G., & Jacobs, R. J., 2013). Youth also have poorer retention rates, and psychological distress in this population has been linked to nonadherence to medication (Harper, G. W., Fernandez, I. M., Bruce, D., Hosek, S. G., & Jacobs, R. J., 2013). These concerns are especially salient among youth whose identities intersect multiple marginalized groups.

Many providers expressed difficulty reaching out to youth and engaging them in services beyond primary medical care. Other providers said that they work particularly well with youth, whether through their HIV programming or other work. On the other side of the spectrum, there are particular organizations in SWPA that work particularly well with the aging population of PLWH. While these individuals are more engaged in services beyond their primary medical care, they have unique needs and challenges. This engaged and older population is the one best represented by the consumer survey sample. Consumers in the survey were asked to rate their biggest concerns about aging with HIV; the most frequently endorsed responses were “Health,” “Relationships,” and “End of life planning.”

There are many organizations in the region already doing effective work with either aging populations or youth populations. The concerns voiced by providers about working with these populations may suggest a potential area for creative collaborations and solutions that leverage the strengths of each organization to fill the gaps in others.

#### Summary

**Problem:** Many providers believe that youth are less engaged with HIV-specific services other than primary medical care. Individuals aging with HIV face unique challenges, such as treatment fatigue, isolation, and depression.

**Solutions:** Some providers work particularly well with young people, while other providers are less connected with this population; this may suggest a possible area for collaboration and learn. Age-specific programming and creative solutions to combat the issues experienced by the aging population.

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**SECTION I: APPENDICES**

Appendix A: Consumer Survey

Appendix B: Provider Interview

Appendix C: Provider Interview Disclaimer

Appendix D: Abbreviations

## **APPENDIX A: 2016 CONSUMER SURVEY**

### **Consumer Survey Instructions**

You are receiving this survey because Jewish Healthcare Foundation is conducting a needs assessment to evaluate HIV/AIDS services in Southwestern Pennsylvania. We want to hear about your experiences as someone who has used HIV/AIDS services in this region. Your feedback will help us assess which services are helpful, which services need improvement, and which services are missing from our region.

Your choice to participate in the survey is completely voluntary and will not affect the services you currently receive. Your answers are confidential and anonymous. Do **not** put your name anywhere on the survey. This survey should take between 10 and 20 minutes to complete.

If you need assistance taking the survey, your case manager or other staff members can help you complete the form. If you need assistance but prefer your case manager does not see your answers, you may have another person assist you, such as a friend or family member.

Please return the survey to your case manager or another staff member at the organization where you received it. The organization will return your survey to Jewish Healthcare Foundation, so your answers will remain confidential and your identity will remain anonymous.

Thank you for participating, we value your feedback.

**DEMOGRAPHICS**

1. In which Southwestern PA County do you reside?

- |                                 |   |
|---------------------------------|---|
| <input type="radio"/> Allegheny | <input type="radio"/> Greene                                      |
| <input type="radio"/> Armstrong | <input type="radio"/> Indiana                                     |
| <input type="radio"/> Beaver    | <input type="radio"/> Somerset                                    |
| <input type="radio"/> Butler    | <input type="radio"/> Washington                                  |
| <input type="radio"/> Cambria   | <input type="radio"/> Westmoreland                                |
| <input type="radio"/> Fayette   | <input type="radio"/> I do not live in the Southwestern PA region |

2. Are you HIV positive?

- Yes  
 No

3. In what year were you born? \_\_\_\_\_

4. What is your race and ethnicity? *(select all that apply)*

- |   |   |
|---|---|
| <input type="checkbox"/> American Indian/Alaskan Native   | <input type="checkbox"/> White                |
| <input type="checkbox"/> Asian                            | <input type="checkbox"/> Hispanic or Latino/a |
| <input type="checkbox"/> Black/African American           | <input type="checkbox"/> Other _____          |
| <input type="checkbox"/> Native Hawaiian/Pacific Islander |   |

5. How do you identify yourself in terms of gender?

- |  |  |
|--|--|
| <input type="radio"/> Male                         | <input type="radio"/> Transgender (female to male)             |
| <input type="radio"/> Female                       | <input type="radio"/> Gender nonbinary, nonconforming, neutral |
| <input type="radio"/> Transgender (male to female) | <input type="radio"/> Gender fluid or bigender                 |
|  | <input type="radio"/> Other _____                              |

6. What is your estimated annual household income?

\_\_\_\_\_

7. How many adults (18 years or older) including you live in your household?

\_\_\_\_\_

8. How many children (under 18 years old) live in your household?

\_\_\_\_\_

9. Which forms of health insurance do you have? *(select all that apply)*

- |  |   |
|--|---|
| <input type="checkbox"/> Medicaid or Medical Assistance        | <input type="checkbox"/> Special Pharmaceutical Benefits Program (SPBP) |
| <input type="checkbox"/> Medicare                              | <input type="checkbox"/> VA   |
| <input type="checkbox"/> Private insurance (employer provided) | <input type="checkbox"/> I don't have insurance                         |
| <input type="checkbox"/> Private insurance (marketplace)       | <input type="checkbox"/> Other _____                                    |

**PRIMARY CARE**

10. What were the results of your most recent viral load test

- Undetectable or less than 400
- 400 to 4,999
- 5,000 to 10,000
- Over 10,000
- I do not remember
- Other \_\_\_\_\_

11. What were the results of your most recent T-cell (CD4) test?

- Less than 200
- 200 to 350
- More than 350
- I do not remember
- Other \_\_\_\_\_

12. Where do you **primarily** go to get HIV medical care?

- Private doctor's office
- Hospital/hospital clinic
- Emergency room
- Community health center or clinic
- VA hospital/clinic
- I do not get medical care (*skip to question 16*)
- Other (*please specify*) \_\_\_\_\_

13. Did you keep your last HIV medical appointment

- Yes
- No → Why not?  
\_\_\_\_\_

14. My HIV medical provider...

	Always	Sometimes	Never	NA
Spends enough time with me during visits				
Listens to me during visits				
Is easy to reach when I need to				
Is easy to schedule an appointment with				
Encourages me to participate in my own care				

	Always	Sometimes	Never	NA
Makes sure I get the care I need, including referrals to specialty care				
Seems to understand the needs of people my age				
Seems to understand my culture or community				
Seems to understand how to treat HIV/AIDS				
Is able to help me deal with other health issues besides HIV/AIDS				
Offers me testing for other diseases like Hepatitis B or C, etc.				
Treats me with respect				
Works with me to help me keep my appointments				
Meets with my sexual and drug-using partners upon my request				
Refers me to mental health or substance abuse services if I need them				

15. How would you rate the overall quality of the **HIV medical care** you have accessed in Southwestern PA?

n/a	1	2	3	4	5
Did not access this service	Poor	Fair	Good	Very Good	Excellent

16. How would you rate the overall quality of the **HIV case management services** you have accessed in Southwestern PA?

n/a	1	2	3	4	5
Did not access this service	Poor	Fair	Good	Very Good	Excellent

17. How would you rate the overall quality of the **HIV non-medical support services (ex. Peer support, group meals, food pantry, transportation, etc.)** you have accessed in Southwestern PA?

n/a	1	2	3	4	5
Did not access this service	Poor	Fair	Good	Very Good	Excellent

**HIV/AIDS MEDICATIONS AND ADHERENCE**

18. Are you currently taking HIV medications (antiretrovirals) to treat HIV or AIDS?

- Yes
- No → 18.a. If you are **NOT** taking HIV medication, why not?

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19. During the **past 6 months**, have you ever stopped taking your HIV medications for more than a week or missed doses of your medication?

- Yes → 19. a. If yes, why did you stop taking your meds or miss doses?

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- No

20. Have you used any of the following therapies to help manage your HIV and/or side effects of medications? (*select all that apply*)

- |  |  |
|--|--|
| <input type="checkbox"/> Vitamin/nutritional supplements | <input type="checkbox"/> Massage                               |
| <input type="checkbox"/> Herbal treatments               | <input type="checkbox"/> Chiropractic care                     |
| <input type="checkbox"/> A healthy diet                  | <input type="checkbox"/> Acupuncture                           |
| <input type="checkbox"/> Regular exercise                | <input type="checkbox"/> Meditation                            |
|  | <input type="checkbox"/> Other ( <i>please specify</i> ) _____ |

**HOUSING**

21. Where are you living currently (past 30 days)?

- On the street, in a shelter, in a car, or some other temporary place
- In someone else's house or apartment for a short time because I have no place else to go
- In a family member, partner, or friend's home (long term)
- In a home or apartment of my own
- In a residential program
- Through Senior Care's assistance

Other (please specify) \_\_\_\_\_

22. Are you living in subsidized housing?

- Yes
- No
- I do not know

23. In the past 6 months, have you had any problems **getting** housing due to the following? (select all that apply)

- |   |   |
|---|---|
| <input type="checkbox"/> I have not had any problems getting housing  | <input type="checkbox"/> Finding a place to live that will accept my rental subsidy (Section 8) |
| <input type="checkbox"/> Criminal record information  | <input type="checkbox"/> Credit Problems  |
| <input type="checkbox"/> Waiting lists  | <input type="checkbox"/> History of drug or alcohol use   |
| <input type="checkbox"/> Meeting eligibility requirements for subsidies (e.g. Section 8) or other public housing programs | <input type="checkbox"/> Problems with my immigration status                                    |

Please share any additional challenges you have experienced with **getting** housing:

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24. In the past 6 months, have you had any problems **keeping** your housing due to any of the following? (select all that apply)

- |   |  |
|---|--|
| <input type="checkbox"/> I have not had any problems keeping my housing | <input type="checkbox"/> Credit problems                     |
| <input type="checkbox"/> Difficulty paying rent, mortgage, or utilities | <input type="checkbox"/> Eviction                            |
| <input type="checkbox"/> Drug or alcohol use                            | <input type="checkbox"/> Problems with my immigration status |
|   | <input type="checkbox"/> Legal problems                      |

Please share any additional challenges you have experienced with **keeping** your housing

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**ACCESS**

25. Which features are most important to you when receiving **HIV-related services**? (*select the 3 most important*)

- |   |  |
|---|--|
| <input type="checkbox"/> I do not use HIV-related services  | <input type="checkbox"/> They take my insurance  |
| <input type="checkbox"/> They are located OUTSIDE of my community so I will not see anyone I know there | <input type="checkbox"/> There are no waiting lists                                    |
| <input type="checkbox"/> They are located IN my community   | <input type="checkbox"/> I can get multiple services at the same location              |
| <input type="checkbox"/> I can get there easily   | <input type="checkbox"/> The staff understand the needs of people living with HIV/AIDS |
| <input type="checkbox"/> The staff speaks my language   | <input type="checkbox"/> None of these   |
| <input type="checkbox"/> The staff understands my culture and community                                 | <input type="checkbox"/> Other ( <i>please specify</i> )                               |
| <input type="checkbox"/> It is easy to schedule an appointment  | _____  |
| <input type="checkbox"/> Services are free or low cost  | _____  |
|   | _____  |

26. In general, what do you find **most difficult** about using **HIV-related services** in Southwestern PA? (*select the 3 most difficult*)

- |   |  |
|---|--|
| <input type="checkbox"/> Nothing- I find it fairly easy to use the services I need  | <input type="checkbox"/> Dealing with all of the things my different providers ask of me |
| <input type="checkbox"/> Too much paperwork   | <input type="checkbox"/> Getting services because of my immigration status               |
| <input type="checkbox"/> Getting to and from appointments                           | <input type="checkbox"/> I do not want people to see me getting HIV services             |
| <input type="checkbox"/> Finding time to go to appointments                         | <input type="checkbox"/> Feeling uncomfortable or unwelcome at some service providers    |
| <input type="checkbox"/> Having to go to different places to get different services |  |

*Please share any additional issues that you have encountered*

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27. Which HIV-related services do you use the most? *(select the 3 you use the most)*

- |   |   |
|---|---|
| <input type="checkbox"/> Case management          | <input type="checkbox"/> Medication adherence |
| <input type="checkbox"/> Food pantry/meals        | <input type="checkbox"/> SPBP                 |
| <input type="checkbox"/> Housing                  | <input type="checkbox"/> Insurance            |
| <input type="checkbox"/> Mental Health counseling | <input type="checkbox"/> Medical Care         |
| <input type="checkbox"/> Drug treatment           | <input type="checkbox"/> Support groups       |
| <input type="checkbox"/> Financial/Employment     | <input type="checkbox"/> Transportation       |
| <input type="checkbox"/> Dental/Oral Health       | <input type="checkbox"/> Other _____          |

**SUBSTANCE USE**

*Reminder: All of your responses are confidential and will not affect the services that you currently receive. Your responses will be used only to recommend improvements in the type and quality of services that are offered in the Southwestern PA region.*

28. **In the past 6 months**, have you used any nonprescription drugs, such as crack or heroin?

- Yes
- No

29. **In the past 6 months**, have you used any prescription drugs that were **not** prescribed to you?

- Yes
- No

30. Have you **ever** received treatment for substance use *(for example, counseling, peer support groups, detoxification, 12-step programs, methadone maintenance, suboxone)*?

- Yes
- No

31. Was there ever a time when you wanted treatment for substance use, but were unable to get it?

- Yes → 29.a. What prevented you from getting services?

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- No

32. **In the past 6 months**, have you injected drugs or hormones (not prescribed by your doctor)?

- Yes
- No (*skip to question 36*)

33. **In the past 6 months**, have you shared needles or works with someone else (including spouse/partners)?

- Yes
- No

34. Where do you get clean needles and works when you need them? (*select all that apply*)

- Needle exchange (e.g. Prevention Point Pittsburgh)
- Pharmacy
- Acquaintance/friend/family member
- Other \_\_\_\_\_

35. Please describe any challenges you have experienced in accessing clean needles and works

## MENTAL HEALTH

36. Has a mental health professional ever told you that you have any of the following conditions?

(*select all that apply*)

- |   |  |
|---|--|
| <input type="checkbox"/> Anxiety  | <input type="checkbox"/> Post-traumatic stress disorder (PTSD) |
| <input type="checkbox"/> Bipolar disorder                                       | <input type="checkbox"/> Schizophrenia                         |
| <input type="checkbox"/> Attention deficit/hyperactivity disorder (ADD or ADHD) | <input type="checkbox"/> Personality disorder                  |
| <input type="checkbox"/> Depression   | <input type="checkbox"/> Other ( <i>please specify</i> )       |
| <input type="checkbox"/> Panic disorder   | _____  |

37. Are you **currently** receiving mental health treatment (for example, talk therapy, medication, groups, partial hospitalization, IOP)?

- Yes
- No

**RISK REDUCTION**

38. **In the past 6 months**, have you needed help figuring out ways to be sexually active while staying healthy? *(for example, how to reduce the risk of transmitting HIV to your partner)*

- Yes
- No

39. **In the past 6 months**, have you needed help figuring out ways to stay healthy while using drugs? *(for example, how to keep your veins healthy or reduce the risk of an overdose)*

- Yes
- No

40. **In the past 6 months**, have you needed help figuring out if, when, and how to tell people about your HIV status?

- Yes
- No

**HIV KNOWLEDGE & RESOURCES**

41. Do you feel that your HIV service providers have given you enough information about HIV/AIDS?

- Yes
- No

42. What resources have been helpful to you in learning about HIV? *(select all that apply)*

- |  |   |
|--|---|
| <input type="checkbox"/> Medical care provider (HIV or primary)            | <input type="checkbox"/> HIV-positive peers                         |
| <input type="checkbox"/> Provider at the location where I was first tested | <input type="checkbox"/> Internet                                   |
| <input type="checkbox"/> Case manager                                      | <input type="checkbox"/> HIV literature, books, articles, pamphlets |
|  | <input type="checkbox"/> Other _____                                |

43. Is there any information about HIV or services that providers have **not** discussed with you, that you wish they would?

**AGING**

44. As you grow older living with HIV/AIDS, what are your concerns about accessing services and maintaining your health? *(select your 3 biggest concerns)*

- Relationships:** finding a partner, dating, having a family, taking care of significant others
- Health:** managing my HIV, long-term effects of medications, being a burden on friends/family
- Access:** finding medical providers or retirement homes that understand HIV, getting the HIV services I need
- Housing:** finding or having a place to live
- Career:** getting more education, going to work or having a job
- End of life planning:** making a will, long term care

**ADDITIONAL INFORMATION**

45. What HIV services do you feel are missing or could be improved in Southwestern PA? Explain

46. Do you feel comfortable talking to your HIV service providers about your sexual health and/or drug use? Please explain

47. Do you have any additional input about the HIV services in your area or the challenges you experience in accessing HIV services?

## **APPENDIX B: PROVIDER INTERVIEW**

Provider Agency Interviewed: \_\_\_\_\_

Provider Staff Interviewed: \_\_\_\_\_

### **Part I: Warm up and background information**

#### Experience:

What is your professional background? What field is the majority of your experience and educational background in?

How many years have you worked professionally in the HIV field?

#### Organization:

What types of services does your organization provide?

#### Role:

What is your role or position within the organization?

What percentage of your time is spent working directly with consumers?

### **Part II: Services**

#### Barriers to provision of services:

What do you see as the most significant barriers facing your *organization* in the provision of services?

What are some of the challenges in *your role/position specifically* around providing services to consumers?

Do you feel your *organization* has the capacity to provide quality services? Please explain.

#### Barriers to receiving services:

What do you see as some of the challenges for *consumers* accessing HIV services in your *organization*? Do these challenges differ in the *region* overall?

**Medical clinics only:** From your perspective, what reasons cause your consumers to miss medical or case management appointments? What reasons cause them to stop taking medications?

#### Possible changes to services:

What services or programs would you like to see *expanded or strengthened* in your *organization*? In the region?

What services or programs would you like to see *introduced* in your organization? In the region?

Are there any current services in the region (not necessarily provided by your organization) that you feel should be less of a *priority* now?

What kinds of training, technical assistance or other tools would improve your ability to serve your *consumers*?  
(Either as an individual or as an organization)

Based on what you've seen at this *organization*, what are your consumer's greatest unmet needs?

Additional input/comments:

Is there other information that you would like to add, or issues that you think should be taken into consideration as we conduct the regional needs assessment?

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## **APPENDIX C: PROVIDER INTERVIEW DISCLAIMER**

Jewish Healthcare Foundation is conducting a needs assessment to evaluate HIV/AIDS services in southwestern Pennsylvania. As part of this we will be interviewing the HIV/AIDS service providers who are currently contracted to provide Ryan White Part B services in the region. Your feedback will help us assess which services are helpful, which services need improvement, and which services are missing from our region.

This interview will be recorded and the information gathered from the questions will be included in the needs assessment. Your answers during the interview will have no effect or influence around your current Ryan White contracts and are only to be a source of information for the needs assessment. The names of the providers being interviewed *will not* be mentioned in the actual needs assessment document, but the types of agencies they represent will be.

If you agree to the terms of this disclaimer then please print and sign your name below. Thank you for participating, we value your feedback.

## **APPENDIX D: ABBREVIATIONS**

AACO	AIDS Activities Coordinating Office
ADAP	AIDS Drug Assistance Program
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ASOs	AIDS Service Organizations
CDC	Centers for Disease Control and Prevention
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
HOPWA	Housing Opportunities for Persons with AIDS
HRSA	Health Resources and Services Administration
HUD	Housing and Urban Development
IDU	Injection Drug Use
MATP	Medical Assistance Transportation Program
MSM	Men who have sex with men
PA	Pennsylvania
PCP	Primary Care Physician/Provider
PLWH	People/Persons Living with HIV
SES	Socioeconomic status
SPBP	Special Pharmaceutical Benefits Program
STD/I	Sexually Transmitted Disease/Infection
STRMU	Short-term Rental, Mortgage, and Utility
SWPA	Southwest Pennsylvania
TBRA	Tenant-Based Rental Assistance
WHO	World Health Organization