

SOUTHWESTERN PENNSYLVANIA REGIONAL HIV NEEDS ASSESSMENT

2019–2022



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INTRODUCTION

Background

The Jewish Healthcare Foundation (JHF) serves as the lead fiscal agent for Ryan White Part B (RWPB), Emerging Communities, Minority AIDS Initiative (MAI), and Housing Opportunities for Persons with AIDS (HOPWA) funding in the 11-county (Allegheny, Armstrong, Beaver, Butler, Cambria, Fayette, Greene, Indiana, Somerset, Washington, and Westmoreland counties) region of southwestern Pennsylvania (SWPA). These funding streams facilitate the delivery of healthcare, supportive, and housing services to eligible individuals living with human immunodeficiency virus (HIV), as well as prevention and education services to other key populations impacted by the HIV epidemic.

JHF has served as the SWPA lead fiscal agent since 1992 and is responsible for disbursing these grants to direct service providers in the region annually, as well as, helping to ensure the service providers meet federal and state requirements for the program. JHF conducts monitoring and reporting to improve program efficiency and responsiveness and, when possible, helps to coordinate, streamline, and standardize efforts across the region. Most importantly, JHF is responsible for strengthening the HIV continuum of care and ensuring all eligible consumers receive services and medical support necessary to live a healthy life.

JHF is tasked with conducting a needs assessment of the region's Ryan White HIV program. This needs assessment serves to evaluate the implementation of HIV service models within the region. The information presented within the 2019–2022 needs assessment illustrates the current HIV epidemiologic landscape and existing HIV services offered, as well as identifies gaps and needs in medical and supportive services of people living with HIV (PLWH) in SWPA.

Methods that were used in order to complete the 2019–2022 needs assessment included the following:

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

The information found in this report can be used to guide key audiences in making improvements to the HIV continuum of care delivery system, as well as, to advocate for PLWH at the local, state, and federal levels to support expansions in funding and services. Furthermore, it can be used to assist with regional planning processes by providing a basis for priority setting and resource allocation.

Purpose, Goals, and Scope of Needs Assessment

The purpose of this needs assessment is to collect information about the needs of PLWH – both those receiving care and those who are not in care. The needs assessment will ultimately determine service gaps and opportunities for improvements. It will also serve as a basis for planning future HIV-related programming in the region. The following specific goals were identified for the needs assessment:

- To identify barriers that prevent PLWH from accessing services in SWPA
- To characterize the challenges HIV providers face in delivering services for PLWH
- To describe the strengths and weaknesses of the HIV service delivery system and related resources in SWPA
- To describe HIV epidemiologic trends specific to SWPA

This assessment focuses specifically on access and quality of services for PLWH. This needs assessment did not assess prevention services, since Ryan White funds are primarily intended for PLWH. However, prevention is often related to the care of PLWH and therefore this report will include a limited discussion of prevention issues.

Key Findings

Literature/Epidemiologic Review

- In 2021, there were 121 newly reported HIV diagnoses in SWPA, an increase from the 109 newly reported HIV diagnoses in 2020
- A breakdown of risk factors in 2021 for the 121 newly diagnosed were as follows: male-to-male sexual contact (MSM) accounted for 60.3%, heterosexual contact accounted for 27.3%, MSM and injection drug use (IDU) combined accounted for 5.0%, IDU accounted 2.5%
- Allegheny County comprised 73.6% of newly reported HIV diagnoses in SWPA in 2021
- In 2021, an estimated 4,755 people in SWPA were living with HIV

HIV Resources in Southwestern Pennsylvania

- There are currently 15 agencies in SWPA that provide Ryan White medical or supportive services
- Ryan White HIV services provided in the region include ambulatory medical services, emergency financial assistance, food bank and congregate meals, legal services, medical and non-medical case management, mental health services, psychosocial support, health insurance premiums assistance, medical transportation, home and community-based services, outreach, health education/risk reduction, early intervention services, substance abuse support, oral health care, and housing services

Consumer Survey

- The top three services that consumers valued included medical services, housing services, and prescription drug services
- Experiences when seeking care and overall needs of PLWH substantially varied by demographic characteristics across SWPA
- Consumers generally rated the quality of HIV medical care, case management, and supportive services received in the region as good, but room for improvement remains
- Significant barriers, including but not limited to access to mental health and access to quality food, remain prevalent across the southwest region of Pennsylvania

Provider Interviews

- Individual-level barriers included the burden of acquiring documentation for RWPB certification, the burden of poverty, having unstable housing, having a substance use disorder, and limited access to transportation throughout the 11-county region
- Provider-level barriers included staff fatigue and turnover, challenges in fulfilling different requirements for local, regional, and state governments/organizations which leads to spending less time with consumers living with HIV, and a lack of regional standardized case management training
- System and policy-level barriers included lack of available and affordable apartments due to current Fair Market Rent (FMR) rates, limited funding for programs (and how funding is related to who holds political office), the limited capacity of the behavioral health system, the lack of

availability of a regional transportation system, and limitations of what the RWPB grant can pay for

- Recommendations included providing educational classes and trainings for consumers, providing increased staff development for subgrantees, expanding outreach to high-risk communities like those who are incarcerated, expanding telehealth, and increasing availability of more affordable housing
- Strengths included the harm reduction focus present in the SWPA RWPB organizations, the presence of Ryan White Learning sessions, the strong collaborative partnership between RWPB subgrantees, and the high rates of retention in care and viral suppression in the region

METHODS

Literature/Epidemiologic Review

A multi-media literature search was conducted to obtain the most current HIV epidemiologic and social-based data and trends for SWPA. The following questions were used to guide the literature review:

1. What is the current epidemiology of HIV in the region (e.g., incidence, prevalence, trends by demographics, HIV-related death trends)?
2. What are the additional HIV priority topics of interest or other HIV topics that particularly impact or relate to SWPA, and what does current data indicate about these topics (e.g., COVID-19, stigma, aging, harm reduction)?

This search was conducted using Google's search engine, Google Scholar, and PubMed. Multimedia resources utilized and incorporated into the review included state and county health department data reports, news articles, United States Census Bureau reports, other government-based reports, and published peer reviewed research articles. When specific information pertaining to the region was unavailable, information from the state of Pennsylvania or other parts of the United States was used as a proxy.

HIV Resources in Southwestern Pennsylvania

A list of HIV-related resources, with a focus on Ryan White funded programs, was compiled for inclusion in this needs assessment.

Consumer Survey

The Ryan White Consumer Survey was conducted in order to collect information on the medical and supportive service needs of PLWH in the 11-county region of southwest Pennsylvania. The goals of this survey were to (1) assess service utilization and (2) identify barriers to care and unmet needs among PLWH in the region overall and by geographic area of residence and demographic characteristics.

Survey development

JHF staff designed and implemented a 54-question anonymous consumer survey which included questions about demographic characteristics, HIV and primary care medical services, HIV medications and barriers to medication adherence, barriers to accessing or maintaining affordable housing, substance use and treatment, access to mental health services, aging with HIV, and access to support systems. The survey was estimated to take approximately 20 minutes. Appendix B includes a copy of the survey questionnaire.

Respondent recruitment and survey completion

The survey was voluntarily offered from August 2019 through January 2020 to consumers, defined as PLWH receiving Ryan White Part B services who resided within the 11-county region of southwest Pennsylvania. Medical and supportive service agencies in the region that provided care for PLWH and that were receiving Ryan White Part B funding during the 2019–2020 fiscal year assisted with survey distribution to consumers. Agency staff (e.g., HIV support group leaders, case managers, etc.) identified eligible consumers and facilitated their survey completion.

Both paper and online (using SurveyMonkey) options were available for completion. Case managers or other staff at the service agencies provided respondents with assistance completing the survey upon request. Respondents were also informed that they could utilize assistance from a friend or family

member if they preferred their case managers to not view their responses. All paper copies were either entered into the SurveyMonkey tool by case managers or JHF staff members.

Data analysis

Data cleaning and analysis were completed using SAS version 9.4 (Cary, NC). Data were downloaded from SurveyMonkey into an Excel file and uploaded into SAS. Responses for each question were analyzed overall, as well as, by demographic characteristics including geographic area of residence, birth year, race, and gender identity. Due to small samples sizes when stratifying data in some of the rural counties in the region, geographic area of residence was in some cases analyzed as Allegheny County versus non-Allegheny County (with the latter including Armstrong, Beaver, Butler, Cambria, Fayette, Greene, Indiana, Somerset, Washington, and Westmoreland counties). Similarly, birth year was analyzed as those born before 1970 versus those born in 1970 or after. Pearson's chi square tests were conducted to determine if any significant relationship existed between responses and demographic characteristics (a p-value of <0.05 was considered significant). Not all questions were required and therefore some questions had missing responses. Missing responses were excluded in Pearson's chi square tests.

Provider Interviews

Two JHF staff members conducted semi-structured interviews with the staff of Ryan White Part B subgrantee recipients. Questions were focused on five subject areas: background and experience, organizational barriers to providing services, consumer barriers to receiving services, and possible changes to existing service structures (See Appendix C for full interview questions).

JHF staff recruited organizations in the SWPA region that are Ryan White Part B recipients and provide direct services to PLWH. Two members of the JHF staff interviewed 25 employees representing eight different organizations throughout the region. Interviewees volunteered and were not compensated for their time. JHF asked that each subgrantee provide at least two employees at the administrative and executive level, as well as at least two case managers, when possible. Not every organization contains at least two administrative or executive employees. In those cases, one or no executive staff members were interviewed. Interviews between the administrative and executive level staff and the case managers were held together, though one organization had a separate interview for each due to the number of employees who volunteered to be interviewed. An average of three individuals per organization were interviewed. All participants signed a disclaimer that described the way responses would be used and ensured names and organizations would remain confidential. Participants received the question list by email before the interview to ensure time to consider their responses. The interviews were recorded and transcribed before analyzation.

LITERATURE/EPIDEMIOLOGIC REVIEW

Population, Incidence, Prevalence, and Death

Population

The 2020 United States Census (the most recent comprehensive measure of population size to date) estimated that in 2020, 13,002,700 people lived in the state of Pennsylvania. This number represented a 2.4% increase (300,321 people) in Pennsylvania’s total population between 2010 and 2020 [1].

The region of southwest Pennsylvania is comprised of Allegheny, Armstrong, Beaver, Butler, Cambria, Fayette, Greene, Indiana, Somerset, Washington, and Westmoreland counties [2]. In 2020, this eleven-county region was estimated to have a population of 2,697,731 people, which represented a 0.3% decrease (7,541 people) in the region’s total population between 2010 and 2020. Notably, only three counties in the region (Allegheny, Butler, and Washington) experienced a net growth in population between 2010 and 2020 (Table 1) [1]. In 2020, the southwest region accounted for approximately 20.7% of the state’s total population [1].

Allegheny County, which includes the City of Pittsburgh, had the largest crude population compared to all other counties in the southwest region, representing nearly half (46.4%) of the region’s total population. Allegheny County also had at least 4.3 times the population density of each of the other counties in the region (Table 1) [1].

Table 1: 2020 Population, Density, and Percent Change by County¹

County	2020 Population	2020 Population Density (per square mile) ²	2010–2020 Percent Change in Population
Allegheny	1,250,578	1,676	2.2%
Armstrong ³	65,558	106	-4.9%
Beaver	168,215	392	-1.4%
Butler ³	193,763	233	5.4%
Cambria ³	133,472	209	-7.1%
Fayette ³	128,804	173	-5.7%
Greene ³	35,954	67	-7.1%
Indiana ³	83,246	107	-6.3%
Somerset ³	74,129	72	-4.6%
Washington ³	209,349	243	0.7%
Westmoreland	354,663	355	-2.9%

¹Source: United States Census Bureau, 2020 [1]

²Population density is a measure of an area’s population per square mile [3]

³Rural counties are characterized by a population density that is lower than the statewide density of 284 persons per square mile [3]

HIV Incidence

In 2021, 121 (13.7%) of Pennsylvania’s 886 new HIV diagnoses were among people residing in the southwest region of Pennsylvania, which is a slight decrease in the proportion of statewide diagnoses recorded in the region compared to the prior year (in 2020, the region represented 14.0% of the state’s new diagnoses) [2]. After Allegheny County, which comprised 89 (73.6%) of the 121 new diagnoses in

the region, the largest number of new HIV diagnoses in 2021 occurred in Westmoreland, Washington, Cambria, and Fayette counties, respectively (Table 2, Figure 1) [2].

Due to the nature in which the Pennsylvania Department of Health calculates HIV incidence rates, 2021 rates are not yet available [2]. The HIV incidence rate in 2020 by county in the southwest region ranged from 0.0 to 6.5 cases per 100,000 population (Figure 2). Allegheny County and Beaver County had the highest 2020 HIV incidence rates with 6.5 cases per 100,000 population and 5.5 cases per 100,000 population, respectively [2]. Aside from Allegheny County, all counties in the southwest region experienced a decrease in their incidence rate from 2019 to 2020. Allegheny County’s incidence rate increased from 6.1 to 6.5 cases per 100,000 population [2, 4].

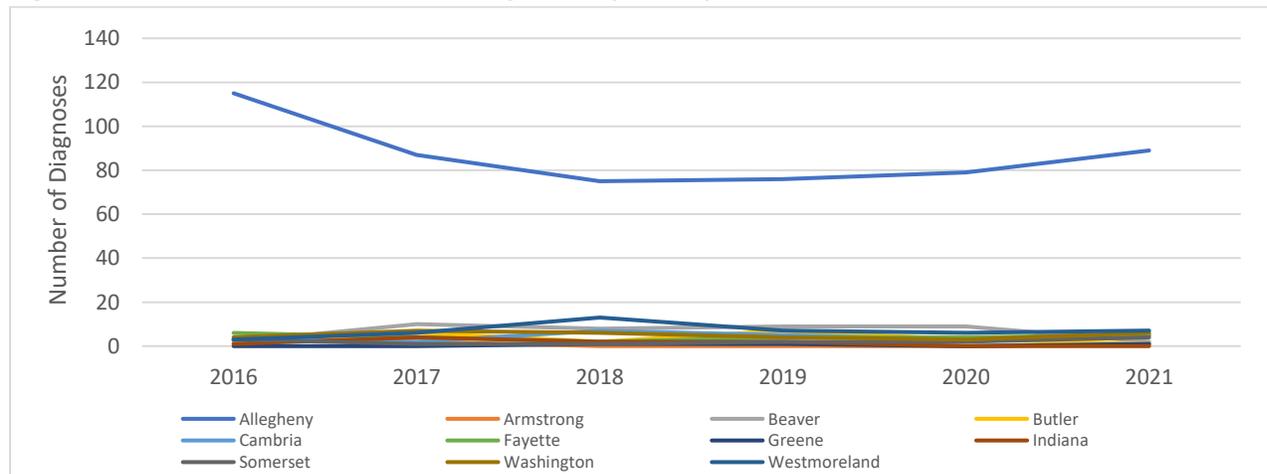
It is important to note that these measures represent new diagnoses and not new infections. Data collection methodologies at the state and county level only report the number of new diagnoses confirmed through testing and do not capture those living with undiagnosed HIV.

Table 2: Annual Number of New HIV Diagnoses by County, 2016–2021¹

County	2016	2017	2018	2019	2020	2021
Allegheny	115	87	75	76	79	89
Armstrong	3	2	0	0	0	1
Beaver	2	1	8	9	9	2
Butler	1	1	2	7	3	1
Cambria	3	2	7	5	3	5
Fayette	6	4	2	4	4	5
Greene	0	0	1	1	0	1
Indiana	1	1	2	2	0	0
Somerset	3	2	1	2	2	4
Washington	4	3	6	4	3	6
Westmoreland	3	2	13	7	6	7
Region Total	141	129	117	117	109	121
State Total	1,132	1,090	1,006	989	777	886

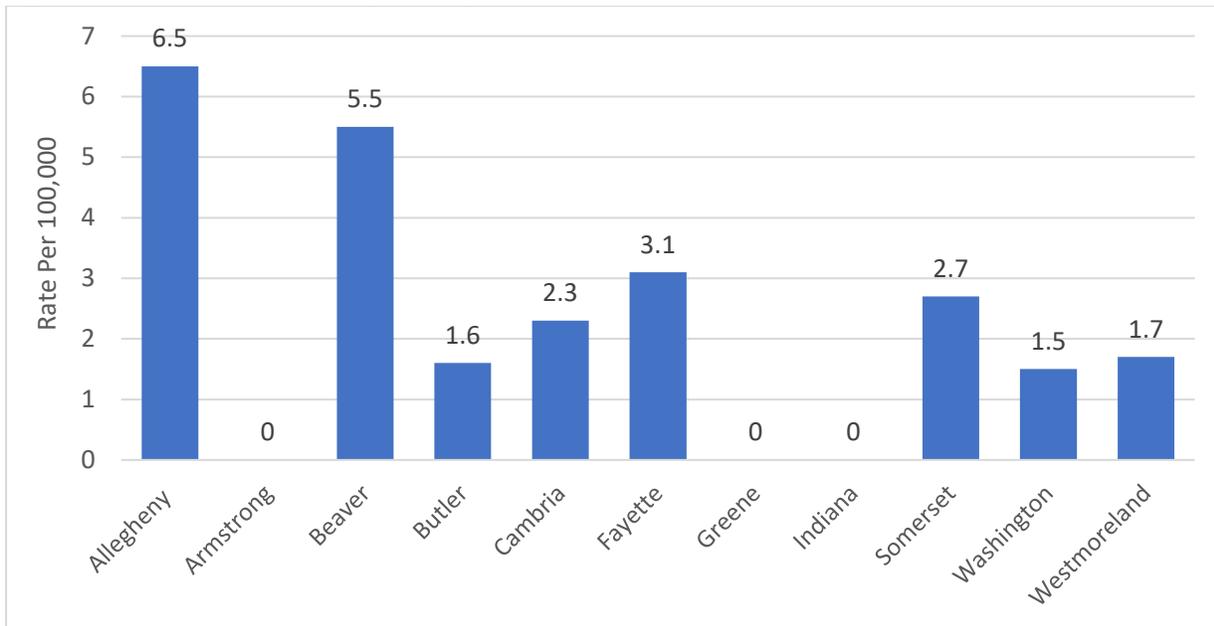
¹Source: Pennsylvania Department of Health, 2022 [2]

Figure 1. Annual Number of New HIV Diagnoses by County, 2016–2021¹



¹Source: Pennsylvania Department of Health, 2022 [2]

Figure 2. HIV Incidence Rate by County, 2020



¹Source: Pennsylvania Department of Health, 2022 [2]

Concurrent (or late) HIV/AIDS diagnoses represent individuals who receive a diagnosis of AIDS within 90 days after an initial HIV diagnosis. In 2021, there were 31 concurrent diagnoses in the region (25.6% of all new diagnoses) [2]. The majority of these concurrent cases were among residents of Allegheny County, in which 24 (27.0%) of the 89 new HIV diagnoses in the county were concurrently diagnosed with AIDS. For Allegheny County, this represented a decrease in the number of concurrent cases compared to 2020, but an increase in the proportion of all diagnoses (Table 3) [2].

Table 3: Concurrent HIV/AIDS Diagnoses by County, 2019–2021¹

County	2019 Number of Concurrent Diagnoses	2019 Percent of All Diagnoses	2020 Number of Concurrent Diagnoses	2020 Percent of All Diagnoses	2021 Number of Concurrent Diagnoses	2021 Percent of All Diagnoses
Allegheny	30	39.5%	19	24.1%	24	27.0%
Armstrong	0	0%	0	0%	0	0%
Beaver	2	22.2%	5	55.6%	2	100.0%
Butler	1	14.3%	1	33.3%	0	0%
Cambria	1	20.0%	2	66.7%	1	20.0%
Fayette	2	50.0%	1	25.0%	1	20.0%
Greene	0	0%	0	0%	0	0%
Indiana	0	0%	0	0%	0	0%
Somerset	0	0%	0	0%	2	50.0%
Washington	2	50.0%	0	0%	0	0%
Westmoreland	4	57.1%	3	50.0%	1	14.3%
Region Total	42	35.9%	31	28.4%	31	25.6%
State Total	231	23.4%	184	23.7%	206	23.3%

¹Source: Pennsylvania Department of Health, 2022 [2]

HIV Prevalence

At the end of 2021, approximately 4,755 people were estimated to be living with HIV in the southwest region of Pennsylvania, which represented 11.7% of all PLWH in the state [2]. Approximately 82.1% of PLWH in the region were male (38.3% female) and 47.8% were of white race (38.3% Black/African American, 6.1% Hispanic/Latinx, 1% Asian/Hawaiian/Pacific Islander, and 6.7% multiple or unknown race). Half (50.5%) were between the ages of 45–64 years old (0.1% 0–12 years, 2.0% 13–24 years, 34.3% 25–44 years, 13.0% 65+ years). Allegheny County had the highest prevalence in the region in recent years, comprising 76.0% of all PLWH in the region in 2021 (Tables 4–6, Figures 3–5) [2].

Table 4: HIV Prevalence by County and Sex, 2021¹

County	Total	Males	Females
Allegheny	3,616	2,947	669
Armstrong	48	40	8
Beaver	169	139	30
Butler	103	91	12
Cambria	181	145	36
Fayette	148	125	23
Greene	35	33	2
Indiana	53	42	11
Somerset	76	74	2
Washington	141	111	30
Westmoreland	185	155	30
Region Total	4,755	3,902	853
State Total	40,609	29,600	11,009

¹Source: Pennsylvania Department of Health, 2022 [2]

Table 5: HIV Prevalence by County and Race, 2021¹

County	Total	White	Black/ African American	Hispanic/ Latinx	Asian/ Hawaiian Native/Pacific Islander	Native American	Multiple Races or Unknown
Allegheny	3,616	1,548	1,560	197	41	1	269
Armstrong	48	41	4	1	0	0	2
Beaver	169	105	49	9	0	0	6
Butler	103	81	8	8	1	0	5
Cambria	181	95	61	17	1	0	7
Fayette	148	95	37	10	0	0	6
Greene	35	16	10	7	0	0	2
Indiana	53	36	12	4	0	0	1
Somerset	76	37	21	13	0	0	5
Washington	141	84	34	13	2	0	8
Westmoreland	185	136	24	13	4	0	8
Region Total	4,755	2,274	1,820	292	49	1	319
State Total	40,609	11,998	18,876	7,443	393	52	1,847

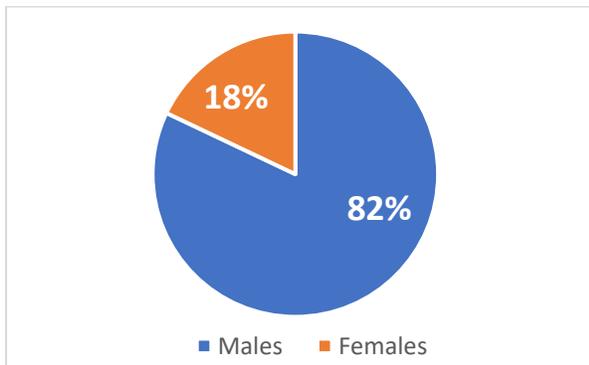
¹Source: Pennsylvania Department of Health, 2022 [2]

Table 6: HIV Prevalence by County and Age (years), 2021¹

County	Total	0–12	13–24	25–44	45–64	65+
Allegheny	3,616	6	82	1,267	1,784	477
Armstrong	48	0	0	8	31	9
Beaver	169	0	6	60	80	23
Butler	103	0	4	30	58	11
Cambria	181	0	0	58	101	22
Fayette	148	0	2	58	76	12
Greene	35	0	0	12	18	5
Indiana	53	0	0	19	30	4
Somerset	76	0	0	20	45	11
Washington	141	0	2	42	80	17
Westmoreland	185	0	1	59	100	25
Region Total	4,755	6	97	1,633	2,403	616
State Total	40,609	41	943	12,666	21,053	5,906

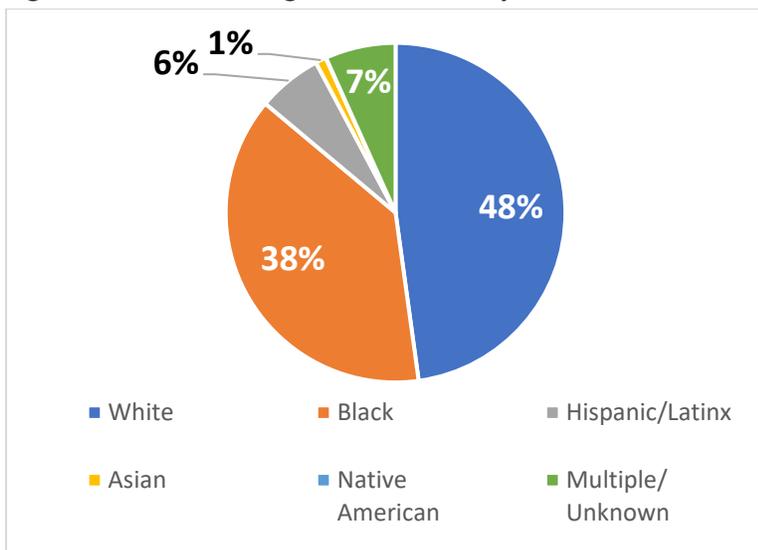
¹Source: Pennsylvania Department of Health, 2022 [2]

Figure 3. Southwest Region Prevalence by Sex, 2021¹



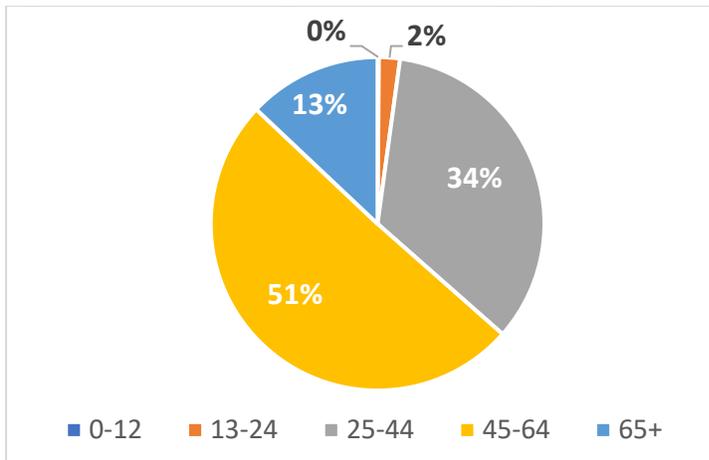
¹Source: Pennsylvania Department of Health, 2022 [2]

Figure 4. Southwest Region Prevalence by Race, 2021¹



¹Source: Pennsylvania Department of Health, 2022 [2]

Figure 5. Southwest Region Prevalence by Age, 2021¹



¹ Source: Pennsylvania Department of Health, 2022 [2]

Death

Death data for 2021 is not yet available. In 2020, the Pennsylvania Department of Health estimated that 14 HIV-related deaths (defined as the number of persons with a diagnosed HIV infection who died in a given time period) occurred in the southwest region, which represents an increase in the number of HIV-related deaths recorded from the prior year (in 2019, there were 12 HIV-related deaths) [6]. However, generally, the number of HIV-related deaths has trended downwards since 2010 (20 HIV-related deaths in 2010, 13 of which occurred in Allegheny County) [5, 6]. Table 7 presents a breakdown of 2020 deaths by county and demographics.

It is important to interpret these numbers with caution, as deaths of persons with a diagnosis of HIV may be due to any cause (i.e., the death may or may not be related to HIV) [6]. These numbers may also represent an undercount as HIV information on death certificates is not routinely captured.

Table 7: HIV-Related Deaths in Southwestern Pennsylvania, 2020

County	Deaths ^{1,2} (2020)	Additional Details
Allegheny	6	Three white males (ages 40–44, ages 65–59, and ages 80–84), and three black males (ages 40–44, 65–69, and 75–79)
Armstrong	0	-
Beaver	1	One white male (ages 55–59)
Butler	0	-
Cambria	2	One white female (ages 55–59) and one black male (ages 65–69)
Fayette	1	One white male (ages 40–44)
Greene	0	-
Indiana	1	One white male (ages 75–79)
Somerset	1	One white male (ages 55–59)
Washington	0	-
Westmoreland	2	Two white males (ages 40–44 and 55–59)
Region Total	14	-

¹ Source: Pennsylvania Department of Health, Division of Health Informatics, 2020 [6]

² Definition: HIV-related deaths were defined as the number of persons with a diagnosed HIV infection who died in a given time period [6]

Risk Factors

The most common HIV transmission category reported among new diagnoses in the southwest region of Pennsylvania during 2016–2021 was MSM, which accounted for 63.2% of new diagnoses during this time period (Figure 6) [2]. These patterns observed in SWPA somewhat differ from statewide 2016–2021 trends, in which MSM accounted for only 52.0% percent of all new diagnoses [2].

In 2021, 73 (60.3%) of the 121 new HIV diagnoses in the region were reported as MSM. The remaining cases in the region were classified with a mode of transmission as follows: 33 (27.3%) heterosexual contact, 6 (5.0%) both MSM and IDU, 3 (2.5%) IDU only, 6 (5.0%) unknown [2]. It is important to note that the proportion of persons with heterosexual contact reported as their mode of transmission has been steadily increasing since 2016, whereas the proportion of persons reporting MSM has generally declined over the same time period (Table 8, Figure 6) [2].

Few cases per year reported IDU in in the region from 2016–2021. In contrast, IDU accounted for a substantially higher proportion of cases across the state [2]. Of note, this difference may be due to the effectiveness of programs in Allegheny County like Prevention Point Pittsburgh, which has established a county-authorized needle exchange site. Over 5,000 PWID have enrolled in this critical prevention service in the region, which has contributed to lower IDU-related transmission of HIV [7, 8, 9]. Other regions of the state, particularly rural regions, do not have access to syringe exchange programs.

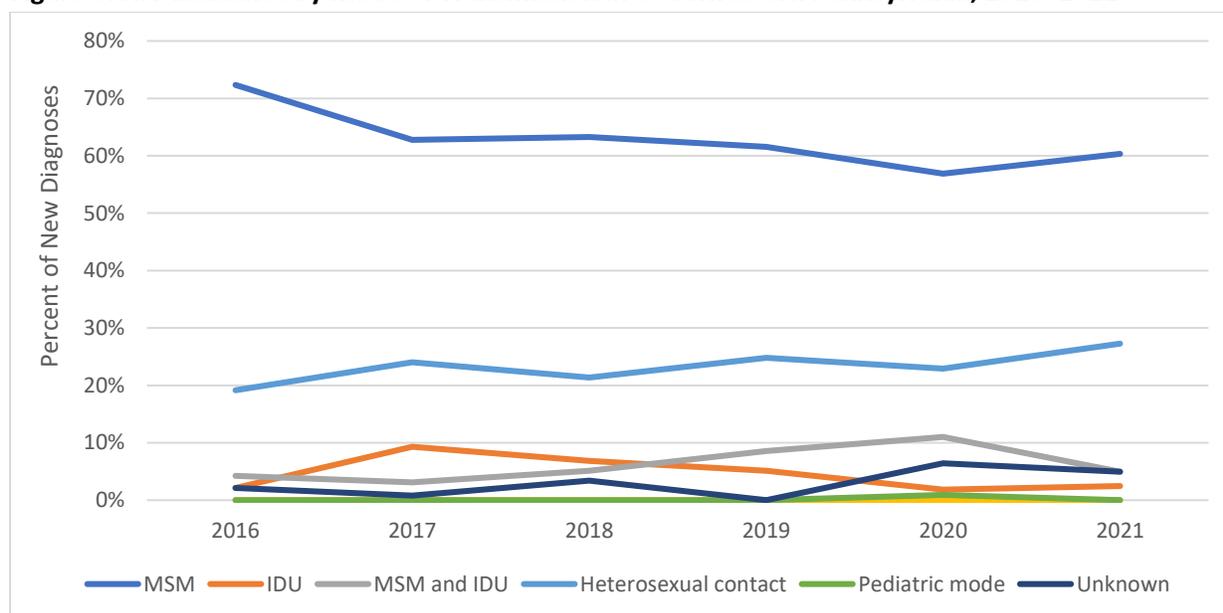
It is important to note that mode of transmission data were self-reported and, as a result, must be interpreted with caution. Additionally, stigma associated with these factors may have impacted how individuals self-reported their responses.

Table 8: HIV Incidence by Mode of Transmission in Southwestern Pennsylvania, 2016–2021¹

Mode of Transmission	2016	2017	2018	2019	2020	2021
Male-to-male (MSM) sexual contact	102	81	74	72	62	73
Injection drug use (IDU)	3	12	8	6	2	3
MSM and IDU	6	4	6	10	12	6
Heterosexual contact	27	31	25	29	25	33
Pediatric transmission	0	0	0	0	1	0
Unknown	3	1	4	0	7	6

¹Source: Pennsylvania Department of Health, 2022 [2]

Figure 6: HIV Incidence by Mode of Transmission in Southwestern Pennsylvania, 2016–2021¹



¹Source: Pennsylvania Department of Health, 2022 [2]

Race and Ethnicity

Black and African American individuals are disproportionately impacted by the HIV epidemic across the state and within the southwest region. These individuals comprised the largest proportion (45.4%) of new diagnoses in the southwest region from 2016–2021, followed by those of white race (44.0%) [2]. These patterns observed in SWPA were similar to statewide 2016–2021 trends, in which Blacks/African Americans accounted for 47.8% percent of all new diagnoses [2].

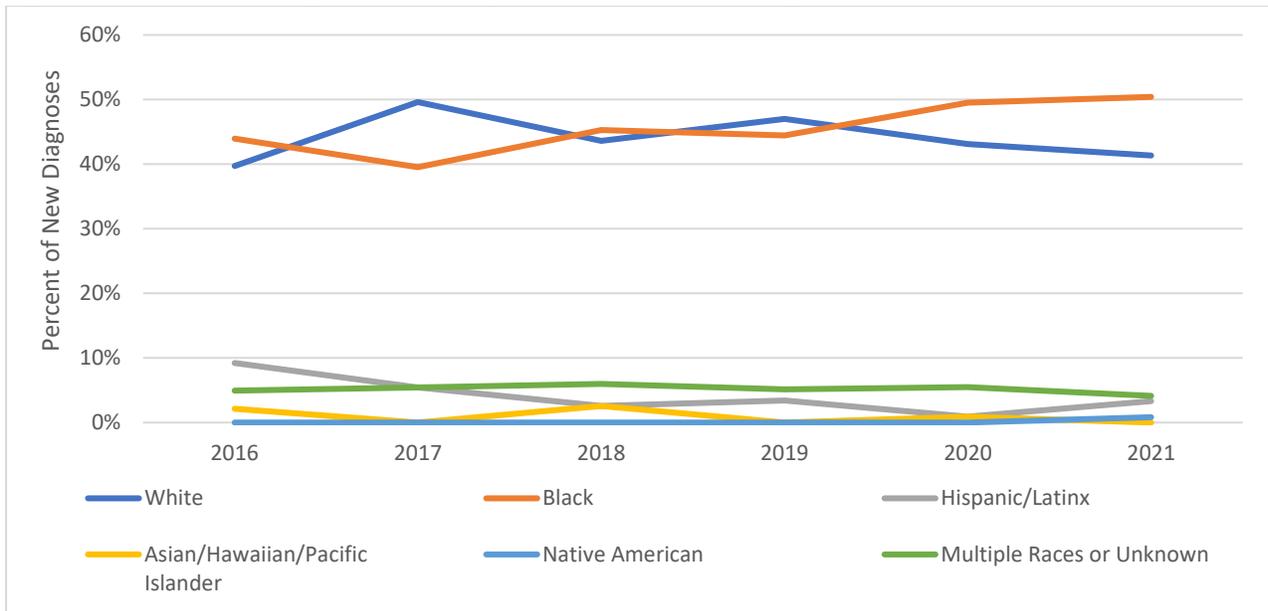
In 2021, Blacks/African Americans accounted for 61 (50.4%) of the 121 new HIV diagnoses in the region [2]. White individuals represented the second highest number of new HIV diagnoses with 50 (41.3%) of the 121 cases in the region [2]. Except for the years 2017 and 2019, Black and African American individuals have represented the highest number of new HIV diagnoses in the southwest region annually from 2016–2021. It is important to note in recent years, the proportion of cases among those of Black/African American race has been increasing (Table 9, Figure 7) [2].

Table 9: HIV Incidence by Race/Ethnicity in Southwestern Pennsylvania, 2016–2021¹

Race/Ethnicity	2016	2017	2018	2019	2020	2021
White	56	64	51	55	47	50
Black/African American	62	51	53	52	54	61
Hispanic/Latinx	13	7	3	4	1	4
Asian/Hawaiian Native/Pacific Islander	3	0	3	0	1	0
Native American/Alaskan Native	0	0	0	0	0	1
Multiple or Unknown	7	7	7	6	6	5

¹Source: Pennsylvania Department of Health, 2022 [2]

Figure 7: HIV Incidence by Race/Ethnicity in Southwestern Pennsylvania, 2016–2021¹



¹Source: Pennsylvania Department of Health, 2022 [2]

Gender

Males comprised the majority (85.0%) of new diagnoses in the southwest region from 2016–2021, which is slightly higher than statewide 2016–2021 trends, in which males accounted for 78.0% percent of all new diagnoses [2]. In 2021, 102 (84.3%) of the 121 new HIV diagnoses in the region occurred among males; the remaining 19 (15.7%) occurred among females. These trends have remained relatively stable throughout the past five-year period (Table 10, Figure 8) [2].

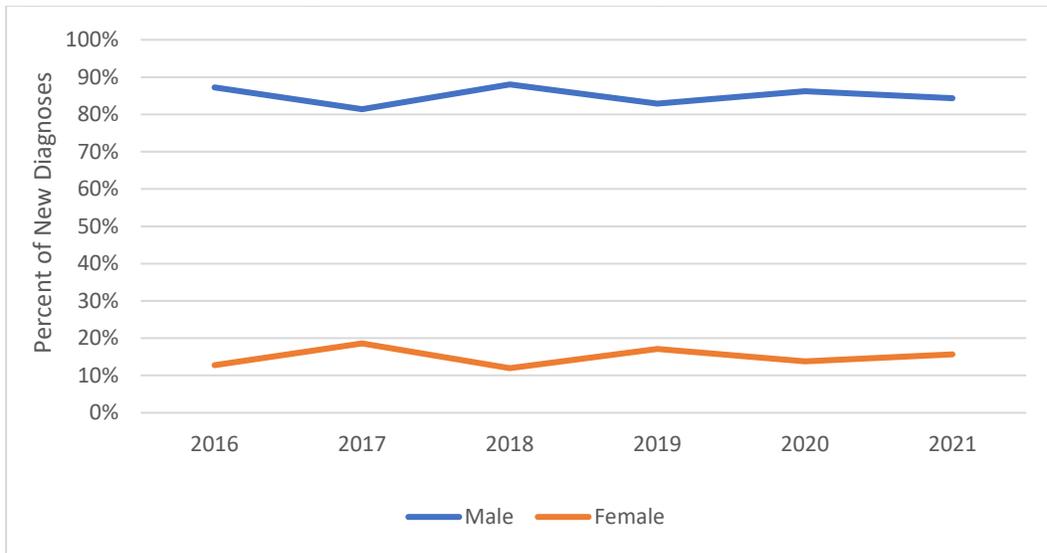
It is important to note that data collection methodologies are not comprehensive of all genders [2]. Therefore, the only two genders that are represented in this report are male and female, which eliminates the opportunity to consider how other genders are impacted by HIV.

Table 10: HIV Incidence by Sex in Southwestern Pennsylvania, 2016–2021¹

Sex	2016	2017	2018	2019	2020	2021
Male	123	105	103	97	94	102
Female	18	24	14	20	15	19

¹Source: Pennsylvania Department of Health, 2022 [2]

Figure 8: HIV Incidence by Sex in Southwestern Pennsylvania, 2016–2021¹



¹ Source: Pennsylvania Department of Health, 2022 [2]

Age

Persons 25–34 years old comprised the largest proportion (35.4%) of new diagnoses in the southwest region from 2016–2021, which is similar to statewide 2016–2021 trends, in which persons 25–34 years old accounted for 35.0% percent of all new diagnoses [2]. There was one diagnosis between 2016–2021 in a person <13 years old in the region [2].

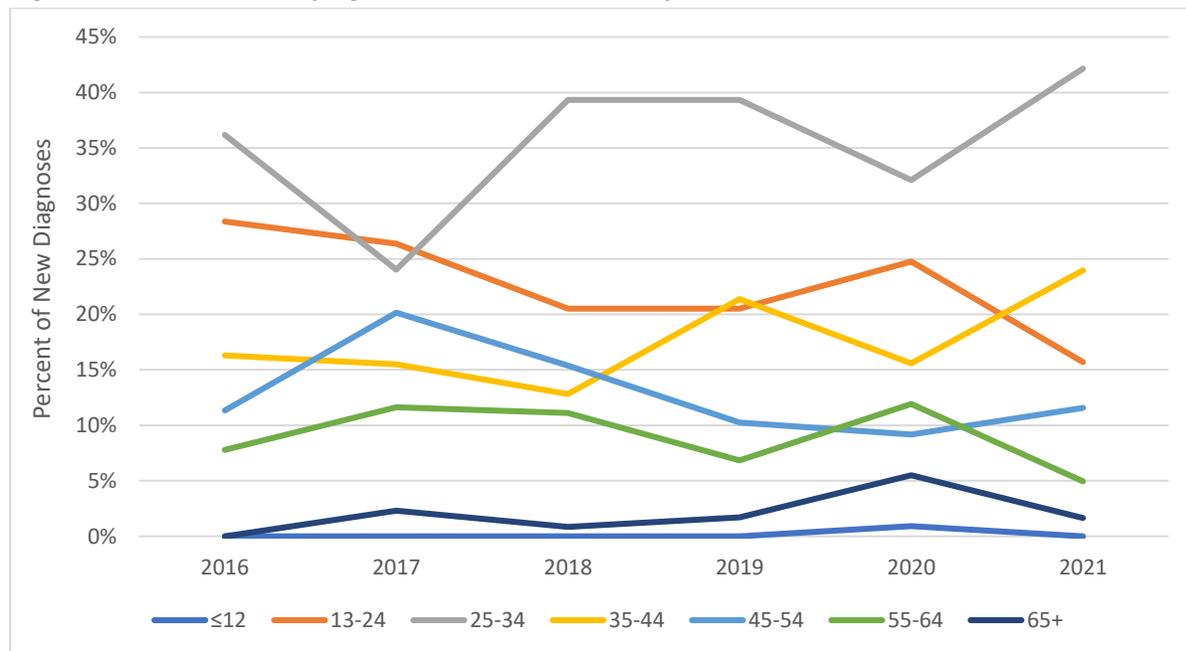
In the southwest region of Pennsylvania in 2021, 51 (42.1%) new HIV diagnoses were reported in persons ages 25–34 years old [2]. Compared to 2020, the proportion of new diagnoses in 2021 among those 25–54 years old increased, whereas the proportion of those 13–24 years old and 55–64 years old decreased (Table 11, Figure 9) [2].

Table 11: HIV Incidence by Age in Southwestern Pennsylvania, 2016–2021¹

Age (years)	2016	2017	2018	2019	2020	2021
≤12	0	0	0	0	1	0
13–24	40	34	24	24	27	19
25–34	51	31	46	46	35	51
35–44	23	20	15	25	17	29
45–54	16	26	18	12	10	14
55–64	11	15	13	8	13	6
65+	0	3	1	2	6	2

¹ Source: Pennsylvania Department of Health, 2022 [2]

Figure 9: HIV Incidence by Age in Southwestern Pennsylvania, 2016–2021¹



¹ Source: Pennsylvania Department of Health, 2022 [2]

Rural versus Urban

Rurality and Urbanity in Southwest Pennsylvania

The southwest region of Pennsylvania is comprised of both rural and urban areas. The Center for Rural Pennsylvania classifies eight SWPA counties as rural: Armstrong, Butler, Cambria, Fayette, Greene, Indiana, Somerset, and Washington [3]. The remaining three are classified as urban counties [3].

The proportion of SWPA’s population that resides in rural areas is greater than both statewide and national proportions [3]. The combined population of the rural counties in the region is 924,275, which represents approximately 34.3% of the region’s total population [1]. In comparison, 26.0% of the statewide total population resides in rural areas and 20.0% of the national population resides in rural areas [1,3]. Therefore, it is critical to consider the unique needs of PLWH in both rural and urban areas when planning for and providing services within the region.

Rural versus Urban HIV Care: Areas of Concern

Barriers to care among PLWH in rural communities are well-documented. Studies show that PLWH in rural areas report unique challenges, including the need to travel long distances to medical facilities (which is often coupled with limited personal or public transportation options related to geographical isolation), limited access to quality medical care (including shortages of trained medical and mental health professionals), and increased stigma toward PLWH [10, 11]. These problems have persisted across the past three decades despite significant advancements in HIV-related care over the same time period. In contrast, studies indicate that PLWH in urban areas are more likely to disclose their positive status (potentially indicating lower levels of stigma), have better access to HIV service organizations and social support (due to more options, less required travel time, and more accessible public transportation), and participate in advocacy efforts. Ultimately, social and community contexts that result from residing in rural versus urban landscapes shape opportunities, decisions, and behaviors of PLWH [11].

Furthermore, unique barriers to HIV testing are present in rural settings. For instance, rural residents are often diagnosed with HIV later compared to urban residents due to fewer providers and resources for HIV testing, greater distances between residents and services, and HIV-related stigma [12]. These barriers are particularly pronounced among communities of color in rural settings, highlighting the need to identify innovative, community-driven methods for HIV testing and care that reflect the experiences of people residing in rural regions [12].

HIV in Rural Southwest Pennsylvania

Given that people living in rural counties experience different service needs and barriers, it is critical to examine trends in rural SWPA separately from trends in the region's urban areas. Data from 2021 show that Cambria, Fayette, and Washington have the highest HIV prevalence rates of the rural counties in the southwest region, respectively [2]. Additionally, among the region's rural counties, Washington, Cambria, and Fayette have the highest number of new HIV diagnoses, respectively [2].

Socioeconomic Status

Researchers have sought to characterize the HIV epidemic in low-income areas of the United States. One study suggested that HIV prevalence rates are inversely related to annual household income in urban areas – meaning that areas with a lower median income were often also identified as having higher HIV prevalence rates. Furthermore, results showed that this inverse relationship also existed between HIV prevalence and education, employment, and housing status [13]. The same study found that the HIV prevalence rate among persons living below the poverty threshold in urban areas was high (2.1%) relative to the generic definition of an HIV epidemic in the United States (1% prevalence) [13].

Poverty-related stigma is also associated with suboptimal outcomes for PLWH, with some studies linking this stigma to poor adherence to medications resulting in unsuppressed viral loads, poor HIV medical appointment attendance, and increased HIV-related mortality [14]. Lastly, it is also important to note that the implications of socioeconomic status in the HIV epidemic are deeply intertwined with race and ethnicity [14, 15, 16].

Harm Reduction

Condom Use and PrEP/PEP

Consistent and correct use of condoms is a highly effective harm reduction strategy in preventing sexual transmission of HIV [17]. Condom programming serves as a structural intervention that involves wide-scale equitable distribution and education on proper usage [17, 18, 19]. Effective condom distribution programs require determining appropriate venues (e.g., STD clinics) that are both accessible and acceptable to community members, ensuring distribution occurs in key priority communities, and strong social marketing campaigns [18, 19]. Supply considerations are also important, as condom use is directly correlated with supply – areas where it is difficult to access condoms report low levels of use, whereas areas with a larger supply report higher levels of condom use [18].

Secondly, pre-exposure prophylaxis (PrEP), which is a course of antiretroviral therapy (ART) that protects people from developing HIV if exposed when taken as prescribed, is also a method of HIV harm reduction [20]. PrEP is most commonly offered in pill form, but a long-acting injection and vaginal ring are newly available routes of delivery in some countries [20]. Studies estimate that oral PrEP reduces the risk of HIV infection by 99% when used correctly and consistently [20]. Healthcare providers are recommended to provide PrEP as an option to people who are at an increased risk of HIV infection, including people whose partners are living with HIV and have a detectable viral load, people who do not use condoms, and people who inject drugs [20].

Additionally, post-exposure prophylaxis (PEP) is a short course of HIV medications that are prescribed after possible exposure to HIV and is considered an additional HIV harm reduction tool [21]. People who use PEP take a combination of pills at the same time each day for four weeks to prevent HIV infection following a potential exposure. PEP is highly effective at reducing a person's risk of contracting HIV if initiated within 72 hours of possible exposure [21]. However, PEP's success as a prevention method requires education about both the importance of early initiation and how to access to the medication when needed [21].

Housing

Housing is also a key HIV harm reduction strategy. Aidala et al. (2016) examined the association between housing status, medical care, and health outcomes among PLWH and found that a lack of stable, secure, and adequate housing presents a significant barrier to appropriate and consistent HIV medical care, access and adherence to antiretroviral medications, and sustained viral suppression – ultimately leading to an increased risk of transmission [22]. Galárraga et al. (2018) also identified unstable housing and homelessness as public policy concerns for PLWH [23]. Galárraga et al. (2018) noted that unstable housing dramatically reduced HIV viral suppression by 51.0% and CD4 cell count by 53.0%, worsening clinical outcomes and health disparities [23].

In San Francisco, approximately 72-88% of PLWH achieve viral suppression. However, only 40% of women with a history of housing instability achieved viral suppression during a three-year study conducted by Riley et al. (2019) [24]. Most participants reported recent outpatient healthcare and case management, but it is important to note that neither of these services predicted viral suppression. Furthermore, factors that are known to predict viral suppression in PLWH, including higher income, consistent health insurance, and consistent access to food were not significantly associated with viral suppression in this study. Instead, the lack of stable housing and incarceration were found to be predictors of future unsuppressed viral loads [24]. Additionally, Towe et al. (2019) analyzed the association between rapid re-housing interventions and viral suppression [25]. Results from this study suggest that the implementation of a rapid-rehousing program in combination with immediate case management can positively impact health outcomes among PLWH [25]. These results demonstrate how strategies like case management alone are insufficient in ensuring sustained viral suppression and ultimately suggest that healthcare delivery interventions that do not integrate housing needs are unlikely to achieve optimal clinical outcomes among PLWH [22, 24].

Drug Use Harm Reduction and Syringe Services Programs

People who inject drugs are at a higher risk of HIV exposure when needles, syringes, or other injection equipment are shared [8]. Drug use-related harm reduction programs aim to prevent HIV transmission, as well as reduce other risks associated with drug use. Drug use-related harm reduction approaches include Syringe Services Programs (SSP), opioid agonist therapy, ensuring safe spaces to use drugs, and overdose prevention education [18, 26]. The basic premise of these programs is to provide support and services to people who use drugs instead of punishing them. However, many areas of the United States enforce punitive laws against people who use drugs, which makes it difficult to promote these harm reduction services [18].

SSPs specifically are community-based prevention programs that provide a range of services, including linkage to substance use disorder treatment, access to and safe disposal of sterile syringes and injection equipment, and vaccination, testing, linkage to care, and treatment for certain infectious diseases [26]. Comprehensive SSPs are safe, effective, and cost saving, as well as do not increase illegal substance use or crime and play a key role in reducing the transmission of HIV [26]. The Centers for Disease Control and Prevention recently published a report in 2019 that highlights the effectiveness of SSPs, which

reported that SSPs are associated with an approximate 50% reduction in HIV incidence and an increase in linkage to HIV care and treatment [26].

Substance Use

Alcohol use has been associated with a lack of HIV testing, as well as poor linkage and retention in care, medication adherence, and viral suppression among PLWH. Additionally, high alcohol use among PLWH is associated with numerous mental and physical health conditions including anxiety, hypertension, diabetes, liver disease, and cardiovascular disease [27].

Furthermore, Crawford and Thornton (2018) demonstrated a significant association between alcohol use and multimorbidity (defined as the occurrence of at least two chronic health conditions) among PLWH [27]. Participants who reported current alcohol use had an increased risk of multimorbidity compared to participants who had never used alcohol. Consistent with existing literature, the most common conditions reported included mental health conditions, hypertension, diabetes, cancer, and cardiovascular disease [27]. The researchers concluded that PLWH are more likely to develop comorbid conditions in combination with alcohol use; therefore, suggesting that alcohol use is a modifiable risk factor and decreasing alcohol use when needed may improve quality of life, result in fewer hospitalizations, enhance functional status, and reduce overall mortality among PLWH [27].

Health-related Quality of Life

Health-related quality of life (HRQOL) refers to how physical health, social health, and mental health all impact both one's ability to function in daily life and their overall perceived well-being. Previous studies have shown that HIV and its related physical symptoms, as well as perceived stigma are associated with a lower HRQOL [28, 29, 30]. Furthermore, higher HRQOL scores are directly associated with improved clinical outcomes for PLWH, including better treatment adherence and viral suppression [28, 30].

Aging

The prevalence of HIV among older adults in the United States is increasing due to the many biomedical advances that allow PLWH to live longer and healthier lives [2, 31]. Advances in clinical care and ART have significantly decreased morbidity and mortality among PLWH and transformed HIV from a terminal illness into a chronic disease requiring self-management and long-term care [31, 32]. In 2021, more than 65% of all PLWH in Pennsylvania were 45 years or older, and 15% were 65 years or older [2].

Yet, older adults with HIV face complex health and psychosocial challenges. With increasing age, comorbidities become increasingly prevalent among PLWH [32]. Yet studies show that though a high comorbidity burden among those aging and living with HIV is present, adherence to risk assessment and management programs remains low (e.g., cardiovascular and bone density screenings and interventions) [32]. Older PLWH may also face mental health challenges including depression, substance use, and loneliness. These medical and mental health factors are further complicated by environmental and psychosocial issues including poor nutrition, poverty, and limited physical and social resources [32].

Quinn et al. (2017) examined the intersection of aging and HIV to identify factors that affect overall health, engagement in care, and medication adherence [31]. Findings show that physicians' inability to attribute symptoms definitively to HIV or aging can contribute to doubts about the effectiveness of HIV medications, misunderstandings about the progression of HIV, patient frustration, and poor patient-provider communication [31].

Dental Care

Given that incidence and severity of dental disease in PLWH is greater than in the general population, available and accessible oral health care is especially critical. It is estimated that over 90% of PLWH will have at least one oral manifestation attributed to HIV during their lives [33]. Poor oral health can compromise overall well-being in a variety of ways, such as contributing to a higher risk of opportunistic infections, preventing proper swallowing of prescribed antiretroviral medications, and impairing speaking ability [33]. Impacts to PLWH's oral health are also significantly higher among women, people who are unemployed, people living in temporary housing, and people who smoke cigarettes [34].

One study examined barriers and facilitators of obtaining dental care through qualitative interviews with PLWH who had not received dental services in the prior 12 months. Respondents identified barriers including dental anxiety and fear, cumbersome administrative procedures, long wait times at the dental office, dismissal of the importance of preventive dental care, transportation difficulties, dentists' reluctance to treat PLWH (stigma), and psychological issues [33]. Factors associated with successfully obtaining dental care included adequate dental insurance coverage, being treated with respect and acceptance, and having an assigned case manager or social worker [33].

Polypharmacy

Polypharmacy, typically defined as having prescriptions for five or more medications, is a growing issue in healthcare [35, 36]. Polypharmacy among PLWH is associated with organ system injury, hospitalization, geriatric syndromes (falls, fractures, and cognitive decline), and mortality [35]. It is also a strong predictor of adverse drug events and drug-drug interactions, which is especially concerning for PLWH.

With the adoption of combination ART, PLWH in care are often prescribed five or more medications and therefore are at risk of harm from polypharmacy, a risk that increases with the number of medications, age, and physiologic frailty [35, 36]. For instance, Kim et al. (2017) examined the association between polypharmacy and the risk of falls and fractures among PLWH [36]. Findings indicated that a higher number of medications, specifically sedating medications, was associated with an increase in falls that required medical attention [36]. Other studies have shown that the likelihood of viral suppression among PLWH who reported using more than 15 medications decreased compared to PLWH who reported using fewer medications [37].

Stigma

HIV-related stigma occurs when individuals are discredited or socially devalued because they are living with HIV [38]. Fekete et al. (2018) reported that most PLWH experience HIV-related stigma, whether it is perceived, enacted, internalized, or anticipated [38]. The well-recognized HIV-Stigma Framework suggests that stigma mechanisms are an individual's psychological responses to the knowledge that people treat PLWH negatively due to their HIV status. Stigma mechanisms can negatively impact psychological, behavioral, and health outcomes, including mental health, support seeking behaviors, and HIV-related symptoms [38].

Stigma often manifests in the form of social discrimination. Previous research has reported a relationship between social discrimination, marginalization, and negative health outcomes among PLWH. In the Multicenter AIDS Cohort Study, Herrick et al. (2013) investigated the relationship between forms of adversity—namely discrimination, marginalization, and general life satisfaction—and psychosocial health outcomes among MSM living with HIV [39]. The researchers noted that greater

social discrimination and marginalization significantly predicted depressive symptoms, stress, stimulant use, sexual compulsivity, and intimate partner violence [39].

Furthermore, studies have shown that PLWH are more likely to experience loneliness due to a history of stigma and discrimination. Higher levels of loneliness and social isolation result in greater negative health outcomes, including a higher likelihood of smoking, alcohol, or substance use; high rates of depression; and lower quality of life [40].

Engagement in Care

HIV is now characterized as a chronic illness due to treatment advances in recent years that allow people to live longer [2]. Many people who are diagnosed with HIV manage their illness through a complex regimen of antiretroviral medications. ART requires strict adherence to prevent illness progression, viral mutations, and drug resistance among PLWH [41]. However, in some individuals, a high level of adherence is difficult. Evidence suggests that the likelihood of adherence decreases as the length of a prescription increases [41]. Erlen et al. (2002) assessed self-reported adherence to medication among a sample of 61 women living with HIV [41]. Adherence ranged from 60% to 75%, indicating the need to develop, implement, and evaluate interventions that promote better adherence to ART among PLWH [41].

In 2020, it was estimated that approximately 85% of PLWH in care were virally suppressed nationwide, and two-thirds of PLWH had maintained viral suppression for over a year [42]. However, disparities persist and viral suppression rates remain exceptionally low for groups that are not consistently engaged in care, including vulnerable youth, people with unstable housing, people who actively use substances, and people with untreated mental illnesses. Supportive funding structures and low-threshold, team-based care that promotes harm reduction philosophies is needed to improve engagement in care among PLWH [43].

COVID-19

Krier et al. (2020) examined how the COVID-19 pandemic impacted PLWH [40]. Researchers asked participants to respond to questions regarding their health seeking behaviors and future healthcare needs and concerns related to the COVID-19 pandemic. Respondents noted the following concerns: increased avoidance of healthcare services due to the risk of COVID-19 infection, social isolation, unexpected changes in routine, potential mortality, limited access to healthcare services, and challenges with management of comorbidities (specifically cancer). Concerns regarding utilization of telemedicine and trusting in practitioners' advice also emerged [40].

Schmalzle et al. (2021) specifically explored how COVID-19 impacted people aging with HIV (PAWH) disproportionately compared to the general population due to increased age-related mortality risks and policies that limited in-person interaction and access to certain healthcare staff or facilities [44]. PAWH in this study echoed the concerns that Krier et al. (2020) reported: social isolation and loneliness, difficulty accessing healthcare resources, increased mortality risk, and difficulties with management of comorbidities [44].

The Pennsylvania Department of Health explored characteristics of PLWH diagnosed with COVID-19 in Pennsylvania from March 2020 through May 2021. Findings indicated that residents of Pennsylvania living with HIV were less likely to test positive for COVID-19 compared to the overall Pennsylvania population [4]. Yet results also highlighted how individuals aged 55 years and older, African Americans, and MSM were disproportionately impacted by the pandemic [4].

Policy

Many states have laws in place that prosecute and punish PLWH. The CDC reports that 35 states currently have laws that criminalize HIV exposure, as of when this report was published in 2022 [45]. Some of these laws are not rooted in current science and criminalize biting, spitting, or other behaviors that cannot transmit HIV. HIV criminalization laws also often disproportionately affect communities of color, transgender women, and sex workers [45].

At the national scale, CDC launched its “Ending the HIV Epidemic in the U.S.,” or EHE, initiative in 2019. The EHE initiative aims to reduce new HIV infections in the U.S. by 90% by 2030 by focusing on the following four strategies: diagnose, treat, prevent, and respond [46]. The initiative also focusses on addressing health disparities, including racial, ethnic, and geographic disparities. The initiative provides resources and support to 50 local areas that account for more than half of new HIV diagnoses and seven states with a substantial rural burden. However, at the time of this report, the only location in Pennsylvania receiving EHE support from the CDC is Philadelphia County [46].

Locally, on November 18, 2021, Pittsburgh Mayor Bill Peduto designated Pittsburgh as a Fast-Track City, making Pittsburgh the latest and only city in Pennsylvania to join a global network committed to ending the HIV epidemic by 2030. Through the Fast-Track City Initiative, the City of Pittsburgh has pledged to work toward zero new HIV infections, zero AIDS-related deaths, and zero stigma against PLWH [47].

HIV RESOURCES IN SOUTHWESTERN PENNSYLVANIA

Background

The table below displays service organizations that serve PLWH in the southwest region for which JHF is the lead fiscal agent. Funding through JHF for these organizations includes Ryan White Part B, Ryan White Emerging Communities, HOPWA, and MAI funding. These organizations also utilize additional sources of revenue to provide services to PLWH and other key populations.

It is important to note that there are many other organizations that also conduct important work around HIV in the region but do not receive funding for services through JHF. 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)
- Positive Health Clinic

Southwest Region Service Organizations

Organization	HIV-related Service Provided (funded through Jewish Healthcare Foundation)																
	Medical Case Management	Non-medical Case Management	Mental Health	Food Bank	Legal	Emergency Financial Assistance	Psychosocial Services	Medical Transportation	Health Insurance Premium Assistance	Ambulatory Medical Services	Home and Community-based Services	Health Education/Risk Reduction	Substance Abuse Outpatient Care	Outreach	Oral Health Care	Early Intervention Services	Housing
Allies for Health + Wellbeing	Orange	Yellow	Orange	Orange	Orange	Orange	Orange	Orange	Orange	Orange	Orange	Green		Green			
Center for Community Resources		Orange		Orange		Orange	Orange	Orange									
Community Care Management	Orange	Orange		Orange		Orange	Orange	Orange			Orange	Green		Green			
Central Outreach Resource and Referral Center		Orange				Orange		Orange									
Hugh Lane Wellness Foundation				Orange		Orange	Orange										
Macedonia Family and Community Enrichment		Orange	Orange	Orange		Orange	Orange						Orange	Orange			
Persad Center			Orange										Orange				
Pittsburgh Area Center for Treatment						Orange		Orange	Orange						Orange		
Planned Parenthood of Western Pennsylvania																Orange	
Prevention Point Pittsburgh																Orange	
Project Silk																Orange	
Senior Care Management		Orange															Orange
Shepherd Wellness Community				Orange			Orange	Orange				Orange					
The Open Door, Inc.		Orange						Orange									
True T PGH																Orange	

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

Allies for Health + Wellbeing

Allies for Health + Wellbeing (Allies) provides integrated medical care, supportive human services, and community-based education for individuals living with or otherwise impacted by HIV, viral hepatitis, and other sexually transmitted infections. Allies is dedicated to supporting and empowering PLWH and preventing the spread of HIV. Allies aims to be a primary resource for HIV support, information, prevention, and testing. Allies' priorities include integrating the consumer voice, collaborating with other providers, educating the public, providing a safe environment for those in need of a community, and combatting stigma.

Center for Community Resources

Center for Community Resources (CCR) is a community-based organization that offers supportive services, resources, and referrals to help individuals and families navigate the human services system. CCR connects people to a network of supports and services essential for actively learning, working, and living in the community. In addition to the Ryan White Part B services included in the chart above, CCR also provide services and referrals in the following areas: community education (drug and alcohol, mental health), community programs (tax preparation, veterans' family support), supports coordination (aging and disability, children, intellectual disabilities), emergency support (homelessness, crisis, utilities), home/school support (family and student support, behavioral health support), mental health (representative payee, drop-in center), and recovery support (peer support, drug/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, a dietician, and social workers. Part of CCM's mission is to provide case management and support services to help PLWH and their families.

Central Outreach Resource and Referral Center

Central Outreach Resource and Referral Center (CORRC) provides assistance to persons affected by drug and alcohol addiction and/or HIV/STIs through grassroots community-based services that promote healthy living through outreach and education. Services offered by CORRC include but are not limited to inpatient and outpatient rehabilitation, aftercare, HIV/STI testing, medical referrals, mental health referrals, community outreach, and educational programs.

Hugh Lane Wellness Foundation

The Hugh Lane Wellness Foundation works to improve the health of the lesbian, gay, bisexual, transgender, queer/questioning, intersex, asexual, plus (LGBTQIA+) community and communities impacted by HIV. They offer a variety of services and resources such as legal services (which includes a legal aid program that was created to provide free, need-based civil legal aid services specifically tailored to the LGBTQIA+ community), creative and engaging programming for LGBTQIA+ youth to build supportive connections, caregiver support trainings to better support LGBTQIA+ youth, and a food pantry, as well as, expert training for organizations to improve their capacity to serve LGBTQIA+ clients and staff.

Macedonia Family and Community Enrichment Center

Macedonia Family and Community Enrichment Center (FACE) is a faith-based non-profit in the Hill District of Pittsburgh. Macedonia FACE is committed to supporting and addressing disparities that impact African American families. Programs and services offered through Macedonia FACE include HIV/AIDS prevention and education, testing services, bullying prevention, teen dating violence prevention, Girls' circle, family and community teaming, Community Truancy Intervention Project (CTIP), and lifeline support services.

Persad Center

Persad Center is a human service organization whose mission is to improve the well-being of the LGBTQIA+ communities in Pittsburgh. Persad Center is also committed to the well-being of the HIV/AIDS community. Persad Center offers treatment adherence counseling and secondary prevention services, as well as conducts outreach, prevention, testing, training, and advocacy.

Pittsburgh Area Center for Treatment

The Pittsburgh Area Center for Treatment (PACT) is a 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 PLWH. PACT's care team includes a multidisciplinary staff of physicians, social workers, nurses, and other health care and support staff. In addition to the Ryan White Part B services included in the chart above, PACT also offers additional HIV treatment and support services including HIV primary care, medical case management, gynecologic care, nutrition consultations, pharmacy services, hepatitis C care, mental health care, pain management, and support groups.

Planned Parenthood of Western Pennsylvania

Planned Parenthood of Western Pennsylvania's (PPWP) mission is to provide high-quality reproductive health care services, comprehensive sexuality education, and strategic advocacy. PPWP operates seven family planning centers in the region with the largest center located in downtown Pittsburgh. These centers provide complete gynecological care, STI testing and treatment services, well person exams, and cancer screenings.

Prevention Point Pittsburgh

Prevention Point Pittsburgh (PPP) is a harm reduction organization that provides health empowerment services to people who inject drugs. PPP provides syringe exchange services and risk reduction counseling to prevent the spread of infectious diseases like HIV and allow people who inject drugs to keep themselves as healthy as possible. PPP 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 LGBTQIA+ youth of color in the Pittsburgh region. Project Silk pairs recreational activities with HIV/STI prevention, testing, linkage to medical care, social services, therapeutic interventions, and social capital initiatives. Project Silk provides STI/HIV testing, behavioral interventions related to positive adult identity development and sexual health education, skills-based programming for youth, and linkage to medical care and ancillary services.

Presbyterian SeniorCare Network: SeniorCare Management Assistance Fund

Presbyterian SeniorCare Network's SeniorCare Management Assistance Fund (SCMAF) 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 in which residents are given choice and flexibility

when possible, in their daily living. SCMAF has been established for over 15 years as the sole HOPWA provider in the region. These HOPWA funds provide Short-term Rent, Mortgage, and Utility (STRMU) Assistance, Tenant-Based Rental Assistance (TBRA), and Permanent Housing Placement (PHP) to eligible participants.

Shepherd Wellness Community

Shepherd Wellness Community's mission is to help PLWH improve their wellness through providing services and a supportive community. Services provided include wellness dinners, peer counseling phone calls which connect members with HIV-related services, support groups which boost mental and physical health, health education programming, therapy classes, treatment adherence and risk reduction programming, spiritual life programming presented in an interfaith format, social and recreational outings which provide community, wellness classes, and transportation assistance.

The Open Door

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

True T Pittsburgh

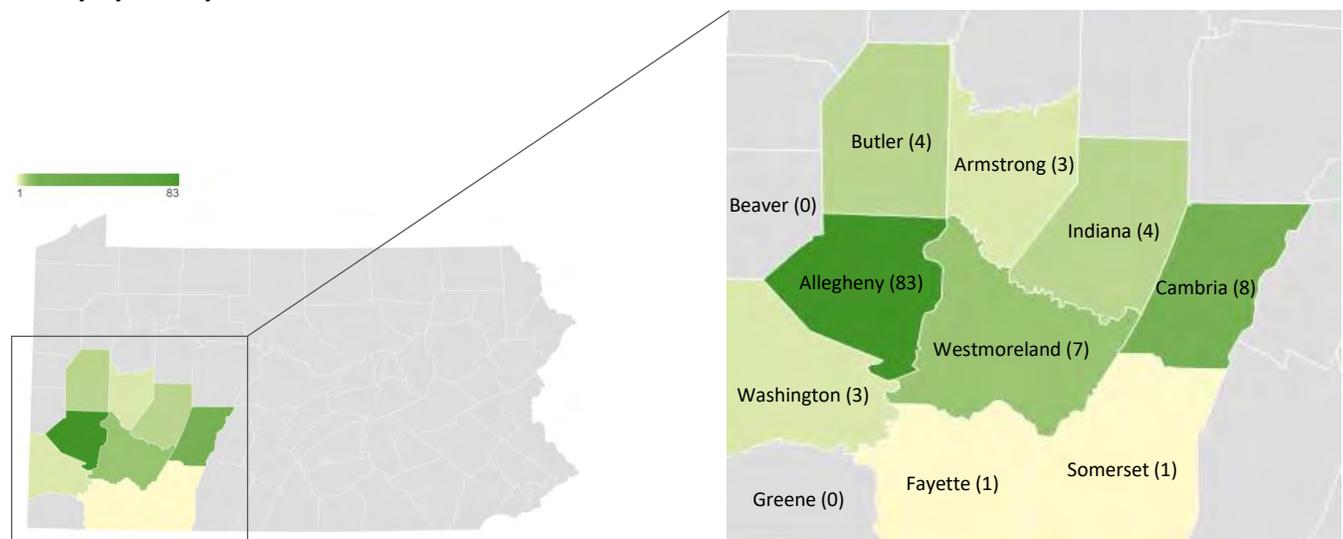
True T Pittsburgh is a community space for LGBTQIA+ resource sharing, queer arts, activism, and entertainment. True T is a community arts and wellness center that provides meaningful resources to improve the quality of life for LGBTQIA+ people of color. They also offer LGBTQIA+ short-term and emergency housing.

CONSUMER SURVEY RESULTS

Demographics

A total of 117 responses were received. Appendix A – Table 1 presents a detailed summary of respondent demographics. The majority of respondents (n=83, 70.9%) resided in Allegheny County at the time of the survey (Figure 1). Over half (n=64, 54.7%) were of white race and nearly one third (n=34, 29.1%) of Black race. Only 4.3% (n=5) of respondents were Hispanic or Latino/Latina/Latinx. Most respondents were born before 1980 (n=84, 71.8%), and median age was approximately 52 years old (interquartile range: 46–61 years). In terms of gender identify, 79.5% (n=93) were male, 15.4% (n=18) were female, and 1.7% (n=2) were transgender (male to female).

Figure 1. Number of respondents to the 2019–2020 southwest¹ Pennsylvania Ryan White consumer survey by county of residence



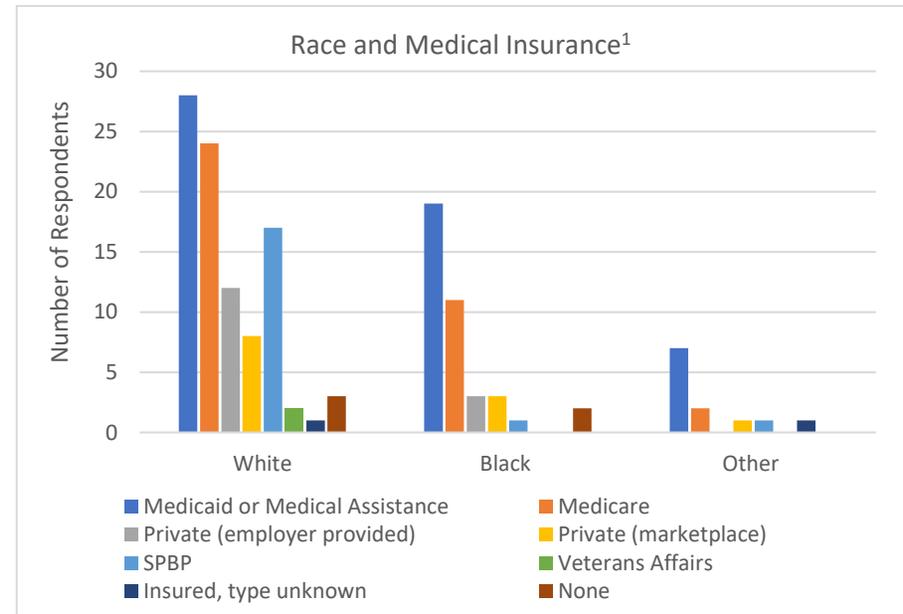
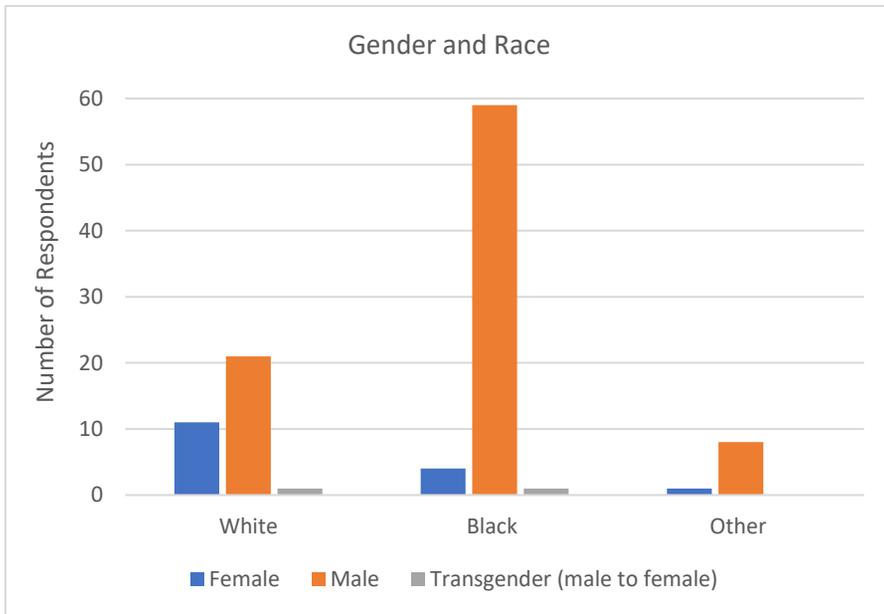
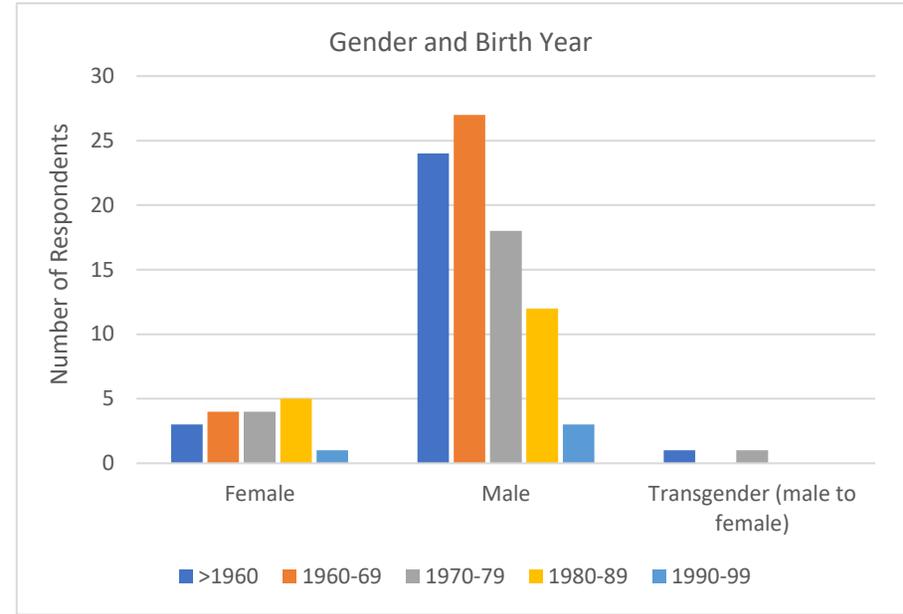
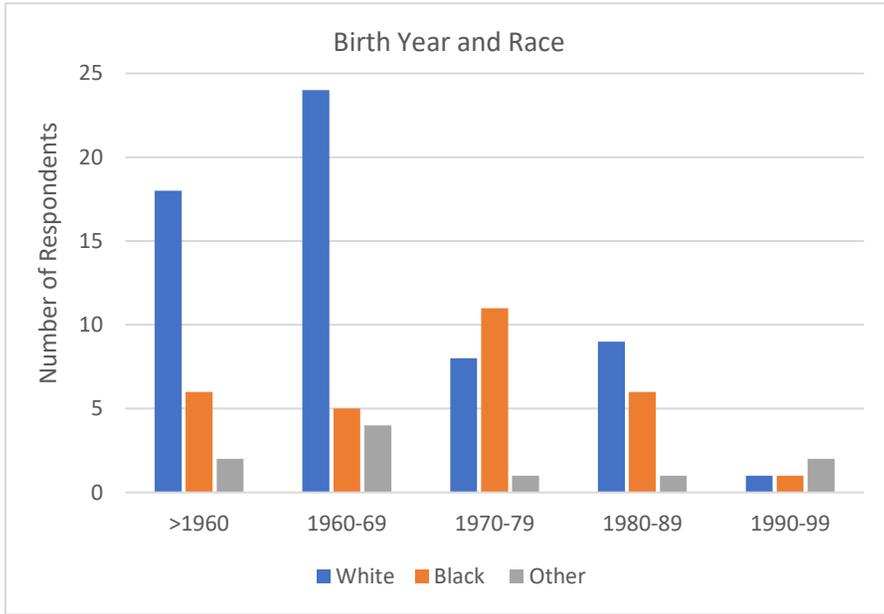
¹ Counties not labeled are not a part of the southwest region of Pennsylvania

Almost half lived alone (n=50, 42.7%) and most had a median household annual income of less than \$40,000. Nearly all (n=111, 94.9%) reported having health insurance, with the most common types being Medicaid/Medical Assistance (n=59, 50.4%) and Medicare (n=41, 35.0%).

It is important to note that respondents from Allegheny County were more likely to be Black (33.7%) and live alone (48.2%) compared to those who resided in the other 10 counties in the region (19.4% of Black race, 29.0% lived alone). Older respondents (those born before 1970) were also more commonly white compared to younger respondents (68.9% versus 40.9%, respectively), as well as, were more likely to live alone compared to younger respondents (49.2% versus 38.6%, respectively).

Furthermore, although male was the most common gender identity reported by both Black and white respondents, a larger proportion of white respondents compared to Black respondents identified as male (92.2% versus 61.8%, respectively). Females also tended to have lower income and not live alone compared to males. Non-Allegheny County, younger, of black race, and female respondents were more likely to have Medicaid/Medical Assistance than their respective counterparts. Figure 2 and Appendix A – Table 1 display the intersection of age, race, gender identity, and insurance status in further detail.

Figure 2. Demographic characteristics of respondents to the 2019–2020 southwest Pennsylvania Ryan White consumer survey



¹Medical insurance not mutually exclusive (respondents could select more than one option)

Table 1 compares the survey demographics to the number of PLWH in the southwest region in 2020 (the same year the survey response collection ended). Overall, the survey respondent demographics were largely representative of PLWH with some exceptions. Most notable, (1) those of white or Native American/Alaskan Native were overrepresented whereas those of Black race were underrepresented, (2) older persons were overrepresented whereas younger persons were underrepresented, and (3) Beaver County residents were underrepresented whereas Cambria and Indiana County residents were overrepresented in the survey when compared to regional demographics.

Table 1. Comparison of 2019–2020 southwest Pennsylvania Ryan White consumer survey demographics to 2020 regional HIV demographics

Characteristic	People Living with HIV in Southwest Region of Pennsylvania in 2020 ¹	2019–2020 Ryan White Consumer Survey Respondents	P-value ²
	N (%)	N (%)	
	N=3913	N=117	
Sex ³			
Male	3196 (81.7)	93 (79.5)	0.5485
Female	717 (18.3)	18 (15.4)	0.4179
Race			
White	1829 (48.4)	64 (54.7)	0.0891
Black/African American	1570 (40.1)	34 (29.1)	0.0160
Asian/Pacific Islander	42 (1.1)	1 (0.9)	0.8181
Native American/Alaskan Native	0	3 (2.6)	<0.0001
Biracial/multiracial	238 (6.1)	6 (5.1)	0.3843
Hispanic ⁴	171 (4.4)	5 (4.3)	0.9601
Age ⁵			
<13	26 (0.7)	0	0.3789
13–19	173 (4.4)	0	0.0203
20–29	1264 (32.3)	4 (3.4)	<0.0001
30–39	1248 (31.9)	15 (12.8)	<0.0001
40–49	787 (20.1)	20 (17.1)	0.4237
>49	415 (10.6)	66 (56.4)	<0.0001
County of residence			
Allegheny	2982 (76.2)	83 (70.9)	0.1868
Armstrong	37 (0.9)	3 (2.6)	0.0819
Beaver	130 (3.3)	0	0.0455
Butler	96 (2.5)	4 (3.4)	0.5093
Cambria	120 (3.1)	8 (6.8)	0.0220
Fayette	100 (2.6)	1 (0.9)	0.2460
Greene	22 (0.6)	0	0.4179
Indiana	41 (1.0)	4 (3.4)	0.0164
Somerset	89 (2.3)	1 (0.9)	0.3077
Washington	111 (2.8)	3 (2.6)	0.8572
Westmoreland	185 (4.7)	7 (6.0)	0.5287

¹ Source: Pennsylvania Department of Health [4]

² Equality of proportions, bold indicates significant at $\alpha < 0.05$

³ The Pennsylvania Department of Health records sex, whereas the Ryan White Consumer Survey recorded gender identity

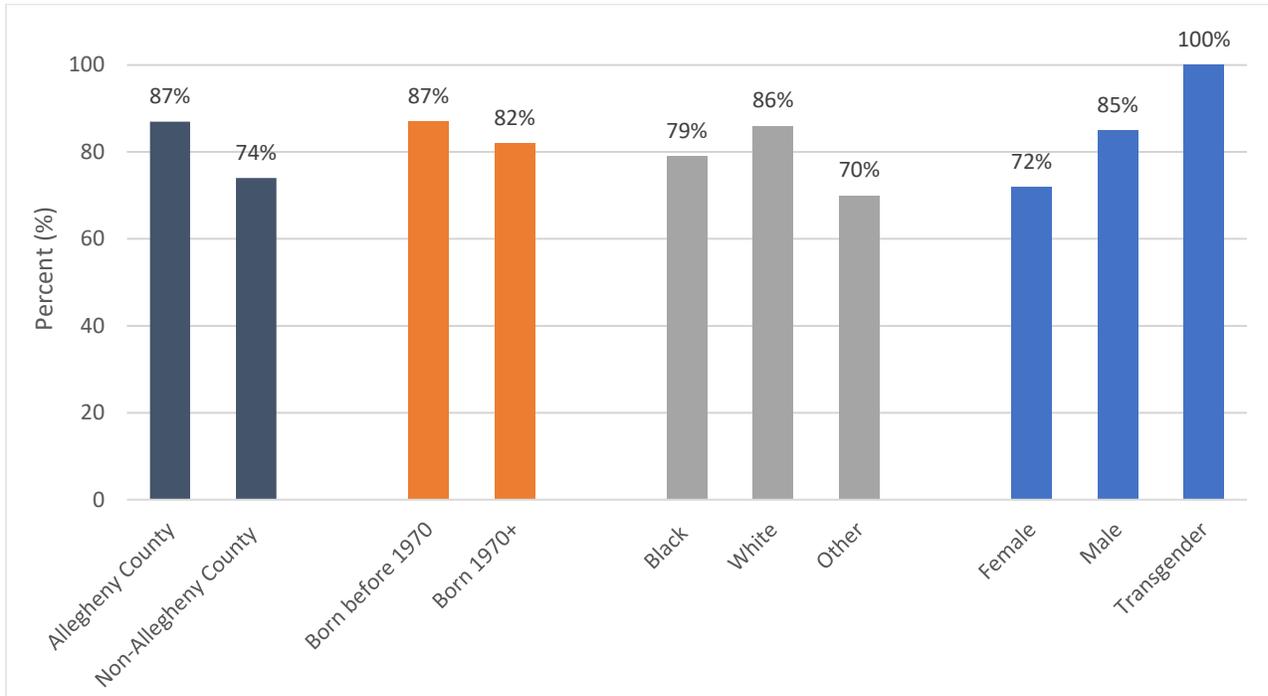
⁴ The Pennsylvania Department of Health classifies Hispanic as a race category, whereas the Ryan White Consumer Survey recorded Hispanic as mutually exclusive from other race categories

⁵ The Ryan White Consumer Survey recorded birth year and then calculated the age of respondents assuming they were born January 1 of their respective year and took the survey on January 1, 2020 (likely resulting in small discrepancies)

HIV and Primary Care

Appendix A – Table 2 presents data on HIV medical care and primary care. The majority (n=98, 83.8%) of respondents self-reported an undetectable (defined as <200 copies/ml) result from their most recent HIV viral load test. An undetectable result was more commonly reported among Allegheny County residents versus residents of the other 10 counties combined (86.8% versus 74.2%), those born before 1970 versus those born in 1970 or after (86.9% versus 81.8%), those of white versus black race (85.9% versus 79.4%), and those who identified as male versus female (85.0% versus 72.2%, Figure 3).

Figure 3. Proportion of respondents who reported undetectable recent viral load (<200 copies/ml), by demographic characteristic

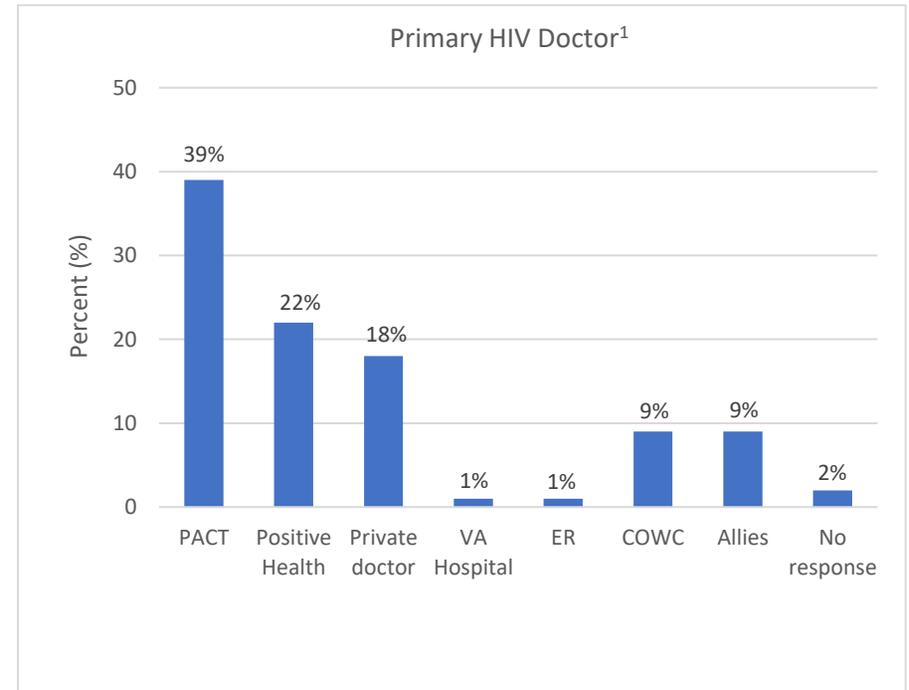
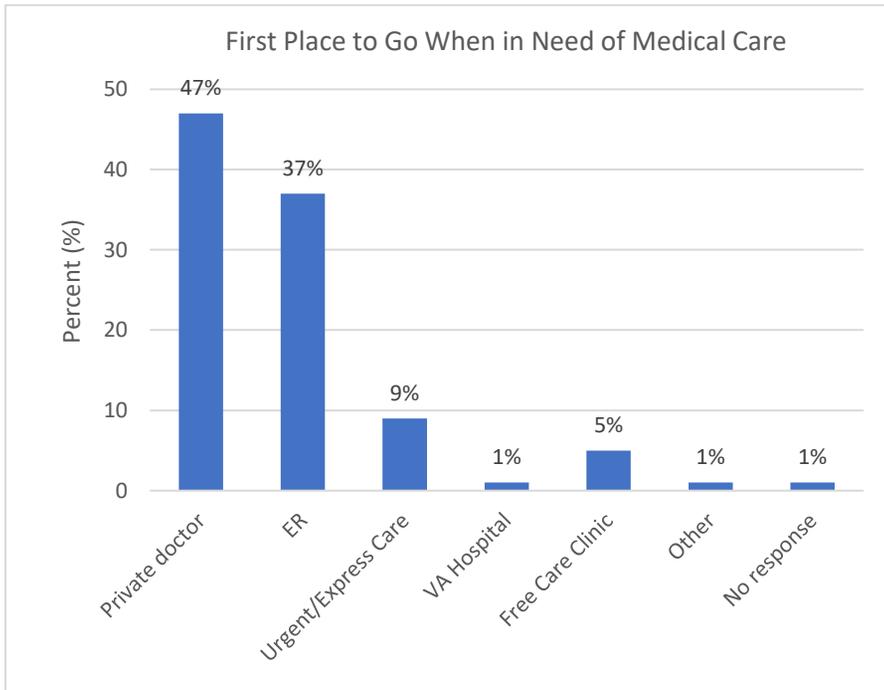


Overall, the most common first location respondents reported going to when in need of medical care was a private doctor's office (n=55, 47%), followed by the emergency room (n=43, 36.8%). However, it is important to note responses varied by demographic characteristic. Persons not residing in Allegheny County, those born in 1970 or after, those of Black race, and those who identify as female were more likely to seek care at an emergency room.

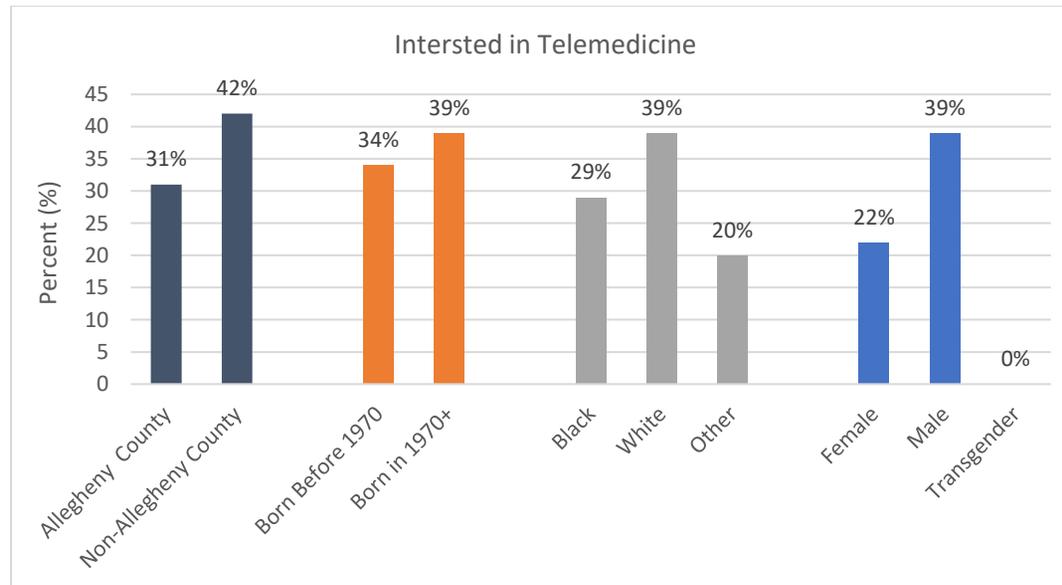
Most respondents reported that they see their primary HIV medical provider at Pittsburgh Area Center for Treatment (PACT; n=45, 38.5%), Positive Health Clinic (n=26, 22.2%), or a private doctor's office (n=21, 18.0%, Figure 4); however, this varied by demographic characteristic (e.g., a larger proportion of non-Allegheny County residents reporting going to a private doctor versus Allegheny County residents and a larger proportion of older respondents reported going to PACT compared to younger respondents).

Almost all (n=110, 94.0%) reported attending their last HIV medical appointment. About one third (n=41, 35.0%) of respondents noted interest in telemedicine, with higher interest among those not residing in Allegheny County, those born in 1970 or after, those of white race, and those who identify as male.

Figure 4. Location for seeking medical and HIV care among respondents to the 2019–2020 southwest Pennsylvania Ryan White consumer survey



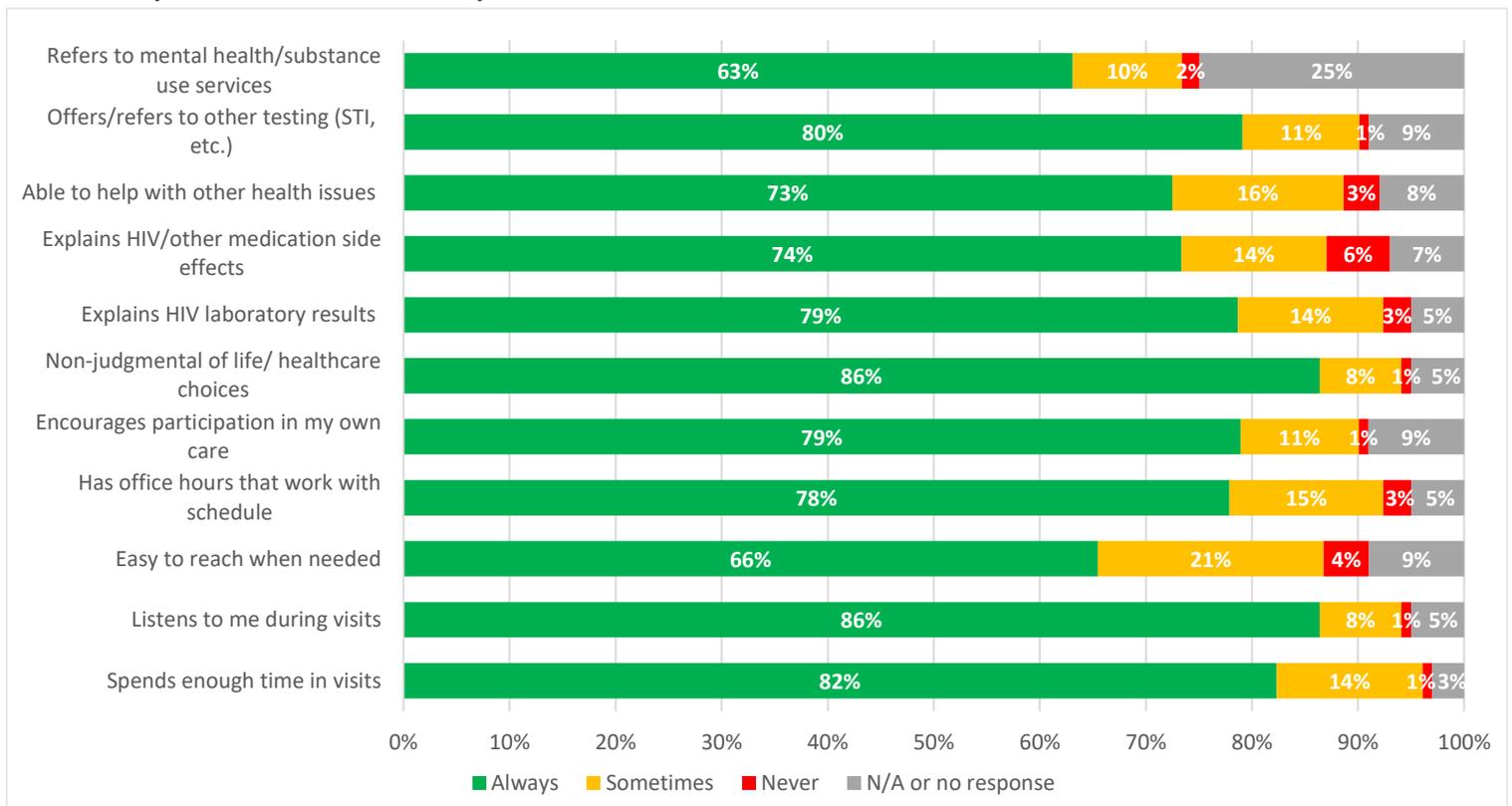
¹ PACT: Pittsburgh Area Center for Treatment, COWC: Central Outreach Wellness Center, Allies: Allies for Health +Wellbeing



Ninety-eight respondents (83.8%) felt their medical provider ensured confidentiality of their HIV status, yet this feeling of confidentiality was lower among those residing in Allegheny County, those born in 1970 or after, and those of Black race. A large proportion (n=101, 86.3%) reported that they felt their doctor was always non-judgmental of their life and healthcare choices. Yet 21.4% (n=25) noted that only sometimes was their doctor easy to reach when they needed to speak with them. Figure 5 provides a complete depiction of respondents' ratings of their HIV medical provider.

Over one third of respondents (n=44, 37.6%) reported having experienced discrimination when seeking healthcare, with the most common types being HIV stigma (n=36, 30.6%) and homophobia (n=20, 17.1%).

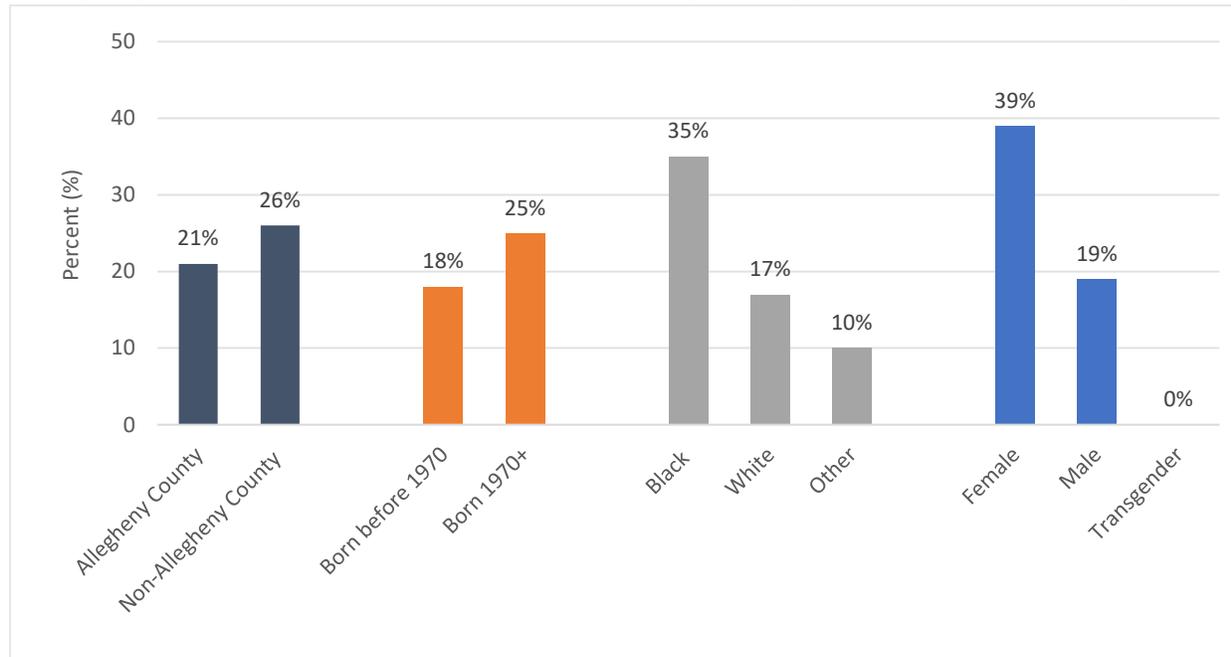
Figure 5. Rating of medical provider among respondents to the 2019–2020 southwest Pennsylvania Ryan White consumer survey



HIV Medication and Adherence

Appendix A – Table 3 presents data on HIV medication and medication adherence characteristics. Almost all (n=112, 95.7%) reported taking HIV medications at the time of the survey. Yet one fifth (n=25, 21.4%) reported having missed doses for >1 week within the prior six months, citing reasons including forgetting, inability to take the medications due to mental health conditions (e.g., depression, stress), no availability of medications at a local pharmacy while traveling, and negative side effects. Missed doses were more commonly reported among those born in 1970 or later compared those born before 1970 (18.0% versus 25.0%), those of black race compared to white race (35.5% versus 17.2%), and among those who identify as female versus male (38.9% versus 19.4%, Figure 6).

Figure 6. Proportion that missed or stopped taking HIV medications for >1 week in past six months among respondents to the 2019–2020 southwest Pennsylvania Ryan White consumer survey



Many (n=87, 74.4%) persons reported using additional/alternative therapies to manage HIV and/or the side effects of HIV medications (the most common being vitamins/nutritional supplements, ensuring a healthy diet, regular exercise, massage, and meditation/yoga), of which 78.2% (n=68) reported these as being helpful.

Housing

Appendix A – Table 4 presents data on housing access. Eighty-two (70.1%) respondents reported living in their own home or apartment at the time of the survey, whereas another 7.7% (n=9) reported either living short-term in someone else’s house or living in another temporary location (i.e., street, shelter, car). Short-term or temporary living arrangements were more common among those residing in Allegheny County, younger respondents, those of Black race, and males. Nearly one third (n=34, 29.1%) reported living in subsidized housing, which was more common among those living in Allegheny County, those of Black race, and those who identify as female.

One fifth of respondents reported having trouble getting housing in the past 6 months (n=25, 21.4%) and keeping housing the past 6 months (n=28, 23.9%). Those who struggled to get housing cited barriers such as long wait lists, credit problems that prevented approval, and having a criminal record history and were more likely to reside in Allegheny County. Conversely, those who struggled to keep their housing reported their primary barrier as difficulty paying rent, mortgage, and utility bills and were more likely to be younger and identify as female.

Access to Care and Support Services

Appendix A – Table 5 presents responses regarding access to care and support services. Over half of respondents (n=64, 54.7%) preferred having HIV services located in their own neighborhood. Notably, this was preferred more often by those of white race relative to those of Black race (65.6% versus

41.2%). Those residing in Allegheny County, males, and older respondents also tended to prefer services in their own neighborhood. Many of those who reported not wanting to receive services in their own neighborhood cited concerns over privacy and discrimination. However, regardless of the location, most (n=89, 76.1%) preferred the ability to receive multiple HIV services in one place.

One quarter (n=30, 25.6%) reported having concerns about where their next meal would come from within the past 90 days, with this being more commonly reported among those living in Allegheny County, those born in 1970 or after, and those of white race.

Thirteen (11.1%) respondents reported needing help with everyday activities, with over half of these persons born before 1970. Of these 13 respondents, only six reported being able to get the help they needed.

Approximately two thirds (n=75, 64.1%) reported having a social/emotional support system, with those of white race and those who identify as male more commonly reporting access to a support system relative to those of Black race and those who identify as female or transgender.

Substance Use

Appendix A – Table 6 presents substance use characteristics of respondents. Fifteen (12.8%) persons reported use of non-prescription drugs, 10 (8.6%) persons reported use of prescription drugs not as prescribed, and six (5.1%) persons reported injecting drugs or hormones in the past six months (not mutually exclusive). Among the six people who injected drugs/hormones, two reported sharing needles or works in the past six months. One person reported obtaining needles/works at a needle exchange location, whereas others reported obtaining them from people they knew.

Out of the 117 respondents, 23.1% (n=27) reported ever receiving treatment for substance use, with another 6.8% (n=8) reporting having wanted treatment but was unable to access it (citing reasons including fear that disability benefits would be jeopardized, lack of transportation, and being young and in the foster care system).

Mental Health

Appendix A – Table 7 presents mental health characteristics of respondents. Eighty-one (69.2%) respondents reported having been diagnosed with a mental health condition by a medical professional. The most common diagnoses included depression (n=64, 54.7%), anxiety (n=61, 52.1%), post-traumatic stress disorder (n=31, 26.5%), and bi-polar disorder (n=19, 16.2%).

Fifty-two (44.4%) respondents reported receiving mental health treatment at the time of the survey. Ninety-one persons (77.8%) reported having ever received mental health treatment, of which 81.3% (n=74) found the treatment to be helpful. Common barriers reported for not receiving treatment included struggling to find a provider who understood them, availability of providers near residence, and high costs. It is important to note that that barrier of “not available close to home” was more commonly reported by those residing outside of Allegheny County compared to Allegheny County residents (17.7% versus 0%). Those residing outside of Allegheny County also reported a high rate of struggling to find a provider (17.7%).

Of the 91 respondents who reported ever receiving treatment, most reported receiving the services at PACT (n=26, 28.6%) or other locations (n=26, 28.6%), which included private practices, psychiatric hospitals, and community support groups.

Aging

Figures 7a and 7b present ratings of how respondents felt about how their medical provider addresses issues of aging and how concerned respondents are about certain aspects of aging with HIV. About half (n=54, 46.2%) reported that their medical provider “always” helps to explain differences between symptoms of normal aging, HIV symptoms, and side effects of medication. Respondents reported being “very” concerned about the long-term effects of medication as they age (n=62, 53.0%), managing HIV as they age (n=53, 45.3%), having multi-morbidity (multiple chronic illnesses and daily medications; n=52, 44.4%), and finding a place to live as they age (n=50, 42.7%).

Figure 7a. Rating of activities medical provider completed regarding aging with HIV

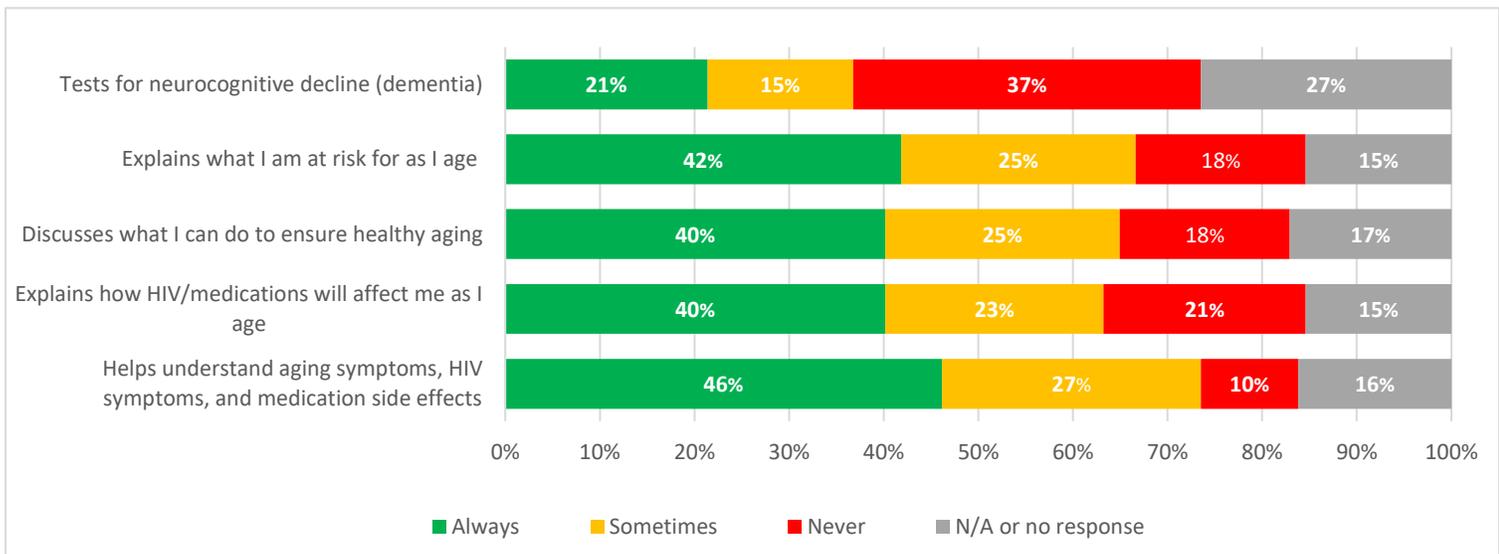
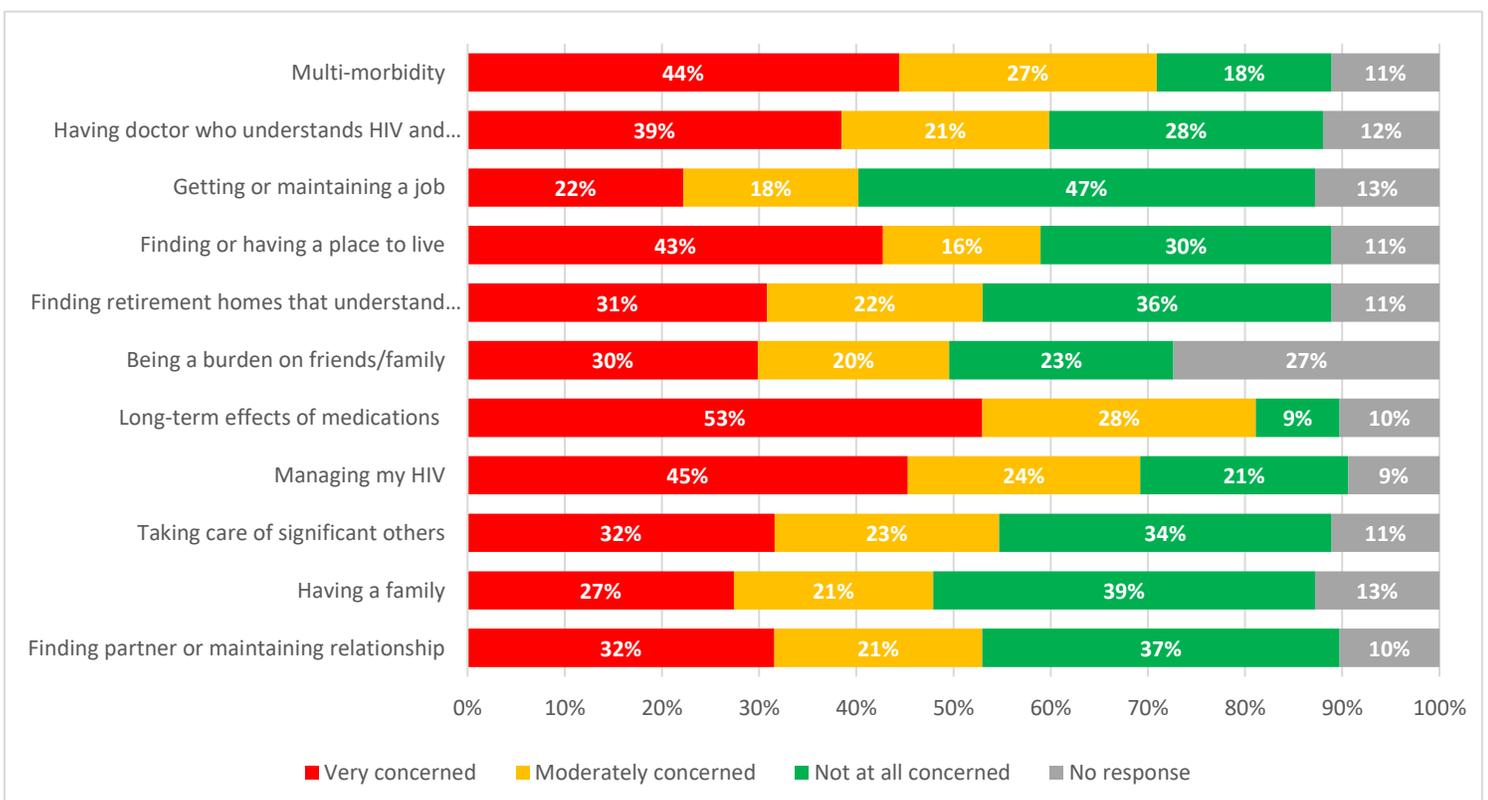


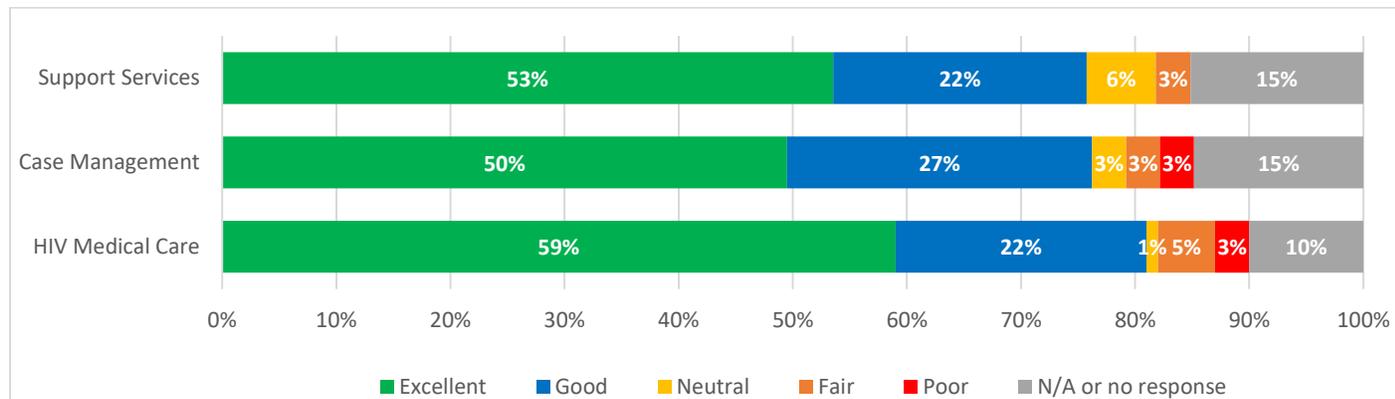
Figure 7b. Rating of concern by respondents about certain aspects of aging with HIV



Overarching Measures

Figure 8 provides overall respondent ratings on the quality of HIV non-medical support services, HIV case management services, and HIV medical care in the region. In terms of HIV non-medical support services, 75.2% (n=88) rated the quality as excellent or good. Ninety (n=76.9%) respondents rated HIV case management services as excellent or good; 81.2% (n=95) rated HIV medical care as excellent or good.

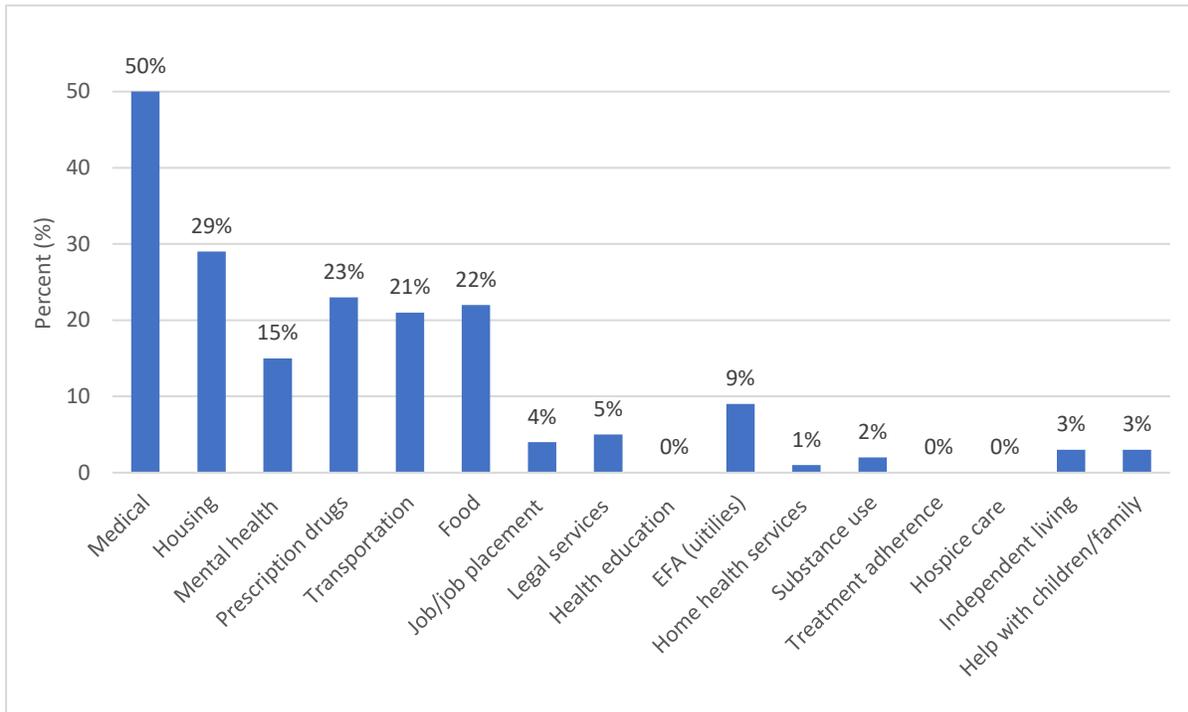
Figure 8. Overall rating of quality of services in region by respondents to the 2019–2020 southwest Pennsylvania Ryan White consumer survey



Altogether respondents ranked the top three services most valuable to them as medical services, housing services, and prescription drug services (Figure 9). Yet these top three varied by demographic, as shown here and in Figure 10:

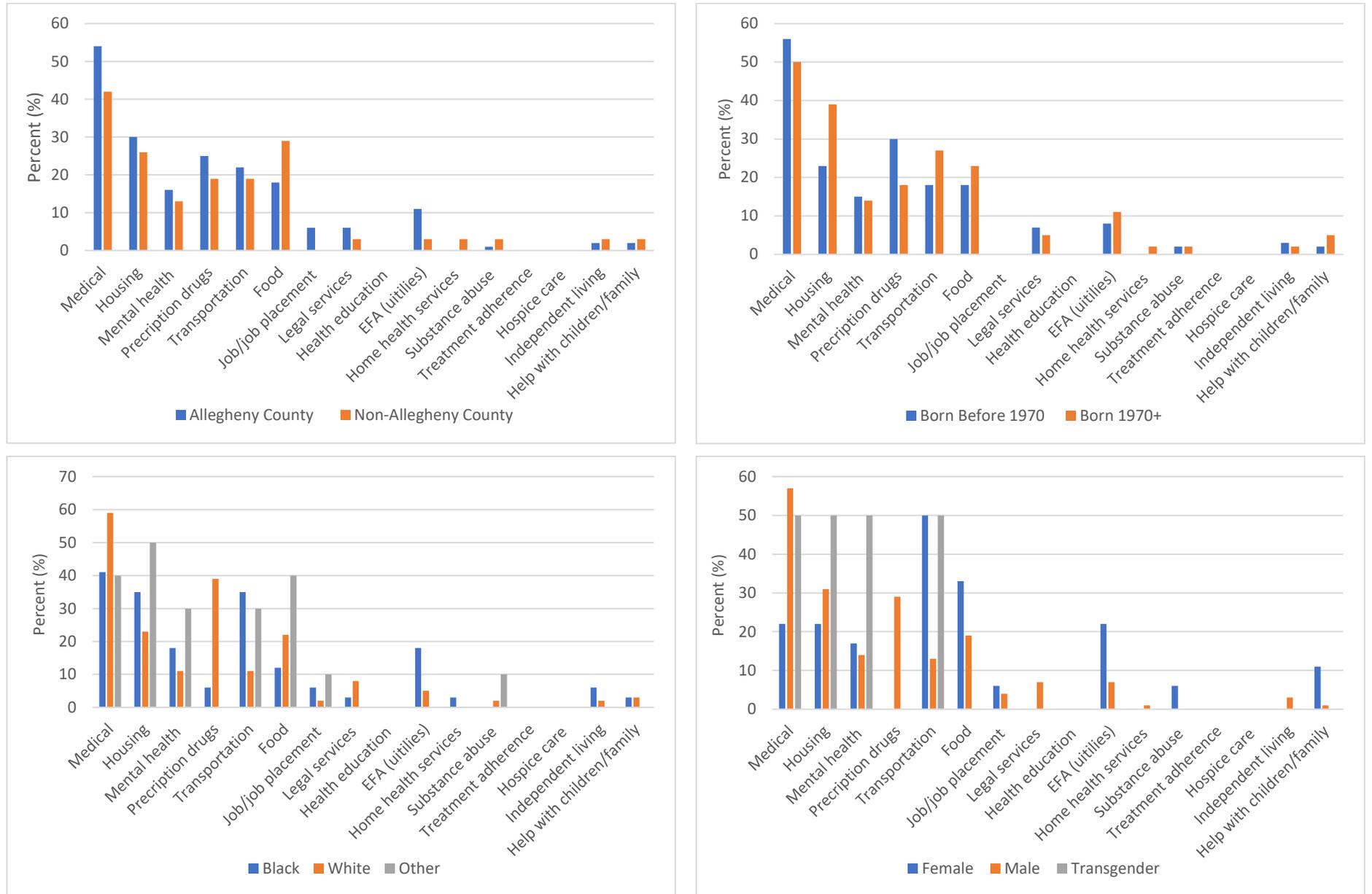
- Allegheny County resident: (1) medical, (2) housing, (3) prescription drugs
- Non-Allegheny County resident: (1) medical, (2) food, (3) housing
- Born before 1970: (1) medical, (2) prescription drugs, (3) housing
- Born 1970+: (1) medical, (2) housing, (3) transportation
- Black: (1) medical, (2–3) transportation, housing (tied)
- White: (1) medical, (2) prescription drugs, (3) housing
- Other: (1) housing, (2–3) medical, housing (tied)
- Female: (1) transportation, (2) food, (3) medical, housing, emergency financial assistance (tied)
- Male: (1) medical, (2) housing, (3) prescription drugs
- Transgender: (1–3) medical, housing, mental health, transportation (tied)

Figure 9. Ranking¹ of value of medical and supportive services by respondents to the 2019–2020 southwest Pennsylvania Ryan White consumer survey



¹ Respondents were asked to rank top two priorities as a “1” and “2.” However, many selected two options without denoting rank order, so this question was analyzed as if each person could choose two options without consideration of ranking

Figure 10. Ranking of value of medical and supportive services by respondents to the 2019–2020 southwest Pennsylvania Ryan White consumer survey



PROVIDER INTERVIEW RESULTS

Barriers

Key Findings: Barriers		
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"> • Burden of acquiring documentation to receive services • Burden of poverty • Unstable housing/homelessness • Stigma/fear of disclosure • Mental illness • Misunderstanding of the services available • Disability • Aging related diagnoses taking priority • Employment for people with limited education • Substance use • Transportation throughout the 11-county region • Reliable internet service in rural areas • Health literacy 	<p><i>Barriers that prevent HIV service providers from optimally serving their consumers</i></p> <ul style="list-style-type: none"> • Collaborations with other HIV organizations (both a barrier and a strength) • Turnover and fatigue • Getting lab results back from healthcare providers • Connecting with younger clients • Having to fulfill different requirements for local, regional, and state governments/organizations, leading to less time spent with consumers • Lack of regional standardized case management training • Gathering community and consumer input • Landlords not maintaining housing and having very little accountability and enforcement • Lack of cultural competence 	<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"> • Available affordable housing – FMR <ul style="list-style-type: none"> ○ Housing for older people living with HIV (OPLWH), older LGBTQIA+ individuals ○ Housing close to services • Recertification requirements • Politics and who is in power threatening the available funding (not only for Ryan White funds, but for SNAP, WIC, SSI, SSDI, etc.) • Systems like CAREWare not being updated to be more gender and sexual orientation inclusive • Behavioral health system capacity • What the RWPB grant can pay for (and what it cannot) • Transportation

Provider interviews offered an in-depth look at the state of HIV services in southwest Pennsylvania. Interviews included discussions of barriers at three levels: individual level barriers which are defined as those that prevent PLWH from accessing services or adhering to medication and care; provider-level

barriers which are defined as those that prevent providers from optimally serving clients; and system and policy level barriers which are defined as macro-level issues that prevent the system from facilitating optimal care and access. Several major themes emerged across providers.

Individual-level Barriers

Providers reported several factors that continuously keep consumers from accessing care appropriately, and generally agreed with each other about these factors. There was frequent discussion around the burden of acquiring documentation to receive care through the Ryan White Part B grant, with many providers stating that the amount of work needed to be done to get consumers the legal documents they need often prevented consumers from accessing services quickly, or at all. Many providers shared that consumers struggled to get speedy and convenient transportation to a case manager, a provider's office, or another qualifying Ryan White Part B program. This barrier, intertwined with the burden of poverty and unstable housing, led to many consumers receiving less care than they qualified for, or receiving care infrequently. The misunderstanding of what Ryan White Part B funding covered, according to providers, often made consumers feel as if their needs weren't being met, that funding was being withheld, or led to confusion about what services were available to consumers. Several providers mentioned that health literacy played into this barrier.

Furthermore, mental illness and substance use were also frequently listed as barriers to care. It was noted that these factors can affect a consumer's ability and willingness to adhere to medication, attend appointments, and stay in contact with their case managers.

Provider-level Barriers

Providers experienced both internal and external barriers that affected their ability to optimally serve consumers. Frequently noted was staff turnover and fatigue, lack of regional standardized case management training, and lack of cultural competence. Providers felt that it was often difficult to collaborate with other HIV providers in the region, though collaboration was also listed as a strength. The need to have the appropriate paperwork and releases signed often led to consumers waiting to receive assistance, as well as trying to maintain constant contact with other Ryan White Part B providers that are just as overworked and lacking time. Furthermore, it was mentioned that it was often hard to know if a consumer was certified at one agency and therefore did not need to be certified again; several providers explained that they had consumers who went through a certification process up to three times a year because it was happening with multiple providers. It was particularly noted that labs were difficult to work with and rarely sent lab results quickly.

Tied in with staff fatigue and turnover was the amount of time it took to complete regional and state reporting requirements, which often took case managers away from working one-on-one with consumers. Many felt that a larger staff would remedy this issue but struggled to bring on new case managers either due to a small job market or an inability to provide a highly competitive pay.

Many providers expressed an interest in increasing community input, but noted that existing methods of collecting this information are inadequate. For example, nearly every provider mentioned survey fatigue from consumers, that Consumer Advisory Boards are difficult to maintain long-term and often disregard a large portion of consumers who are unable to participate in something that requires a large time commitment, and that grant restrictions not allowing incentives makes it more difficult to get consumers to willingly offer their knowledge, expertise, and time.

System & policy-level barriers

The most mentioned macro-level barriers were available and affordable housing, recertification requirements, and what the Ryan White Part B grant can and cannot pay for.

Fair market rent was mentioned as being unreasonable and unaffordable, and far lower than the actual cost of average rent in neighborhoods that individuals live in or are looking to live in. Providers mentioned this led to consumers having to make a choice between leaving their preferred neighborhood where all their supports were and choosing to live in more unsafe or unhealthy situations. Several interviewees mentioned that they knew of consumers who chose unstable housing or being unhoused over leaving their support systems. Furthermore, affordable housing was rarely close to services, making living there a barrier to receiving care. Lastly, there was a need for more specialized housing, such as housing for older people living with HIV, or housing specifically for older LGBTQIA+ individuals. It was cited that housing like this would build community, decrease stigma, and promote a healthier lifestyle.

Recertification requirements were cited as being more of a frustration than a help, and often deterred consumers from receiving assistance because of the difficulties and annoyances of recertifying so frequently. Several providers explained that some consumers chose to have their certification lapse, and their care discontinue, rather than going through the recertification process.

Many providers explained that their consumers were often unsure of what the Ryan White Part B grant could and could not pay for, therefore feeling as if all their needs were not being met. Bed bug abatement, in particular, was mentioned several times as a need for consumers who felt as if the grant should pay for it. Furthermore, providers stated clothing needs as also being a source of funding that consumers felt was or should be included as part of the grant. Health literacy was stated as a possible barrier to not understanding the funds available, as well as a lack of easy-to-read and understand pamphlets and marketing materials for this grant specifically.

Another frequently mentioned barrier was access to transportation, particularly for those living in more rural areas. Though transportation is a covered funding stream, it was still described as being difficult to obtain (especially for those in rural areas), often unreliable or late, and incredibly time consuming. The lack of a regional transportation system is a barrier to connecting people in more rural areas to services, programs, and medical assistance they may benefit from.

Lastly, the behavioral health system in this region was mentioned as lacking the capacity to provide adequate care for the large number of individuals who would benefit from it. Its frequent separation from the physical health system leads to burdening consumers, and the stigma associated with mental health was mentioned as being rather large.

Recommendations and Visions

Multiple times throughout the interviews, providers were asked questions and given the opportunity to discuss their recommendations and visions for improving care in the southwest Pennsylvania region. This includes, but is not limited to, suggestions for revamping old programs, introducing new programs, and suggestions for improvements in the region. The table below includes the most mentioned suggestions:

Key Findings: Recommendations and Visions
<ul style="list-style-type: none"> • Budgeting classes, employment education, and other educational opportunities for consumers • Staff development opportunities: standardized regional case management training, CPR/First Aid & active shooter training, process-mapping and other quality improvement trainings, Medicaid/Medicare/health insurance training, aging with HIV education, medication updates, transgender health education

- Providing HIV training to non-HIV organizations, such as skilled nursing facilities, dental offices etc. to increase knowledge and lower stigma and discrimination
- More affordable and subsidized housing close to HIV services
 - Senior housing for OPLWH and older LGBTQIA+ adults
- Better communication and information sharing between sub-grantees
 - Including more information on what services each subgrantee provides, including non-Ryan White programs and services available
- Drop-in medical centers operating in rural areas, expanded food pantry access in rural areas
- Increased funding for outreach to those who are unhoused or unstably housed
- Expanding in-home medical services for people with disabilities and people choosing to age in place
- Expanding outreach to jails and to communities in the region not currently being actively engaged, like the Latinx community
- Social opportunities for consumers to build a community, such as an annual BBQ
- Expanding telehealth
- Getting Ryan White Learning Session trainings approved for Continuing Education Credits for those with a License in Social Work

Providers had several suggestions, both specific and general, about what can be done to improve the care of PLWH in the region. Generally, these suggestions were around training and education opportunities for AIDS Service Organizations' (ASO) staff, consumers living with HIV, and non-ASOs, as well as improving organizational and system functioning.

Regarding expanding consumer programming, many providers wanted more funding available so they could hold trainings for consumers. It was stated that being able to provide consumers with education on budgeting and employment training could better assist them and prevent recidivism into jail or unstable housing. Creating funding for more social activities was also suggested, as it was believed this could help build a community. There was also a recommendation to expand outreach to jails and to those who are unstably housed. Providers hoped that increased funding in these areas could help connect people to medication and services and lead to a quicker end to the HIV epidemic.

From an organization and systems-level perspective, providers suggested increasing HIV training at non-HIV organizations, such as skilled nursing facilities, dental offices, and other places where PLWH often frequent and face stigma. They also promoted the idea of there being more drop-in centers in rural areas, along with expanded food pantry access, which could alleviate some of the issues related to a lack of regional transportation. Lastly, providers saw a need for expanded telehealth options, which could potentially alleviate some of the acute needs for transportation to HIV medical providers and case management offices. It was noted that utilizing telehealth could have positive benefits for consumers, who would not have to spend as much time traveling to appointments, as well for case managers, who would also spend less time traveling and therefore be able to spend more time with consumers and completing notes and other paperwork. Within the organizations, or on a larger regional level, providers wanted to see more staff development trainings and education, especially if it could come with Continuing Education Credits for those with a License in Social Work. Examples of staff development included, but are not limited to, standardized regional case management training, CPR/First Aid & active shooter training, process-mapping and other quality improvement trainings, Medicaid/Medicare/health insurance training, aging with HIV education, medication updates, and transgender health education.

The purpose of advocating for these trainings, it was stated, was to better service delivery to consumers by ensuring case managers are aware of and understand up-to-date best practices.

Strengths

While there was no specific question asked about strengths, the topic emerged in nearly every provider interview. Strengths included the inherent strength of PLWH and the community they create for themselves, regional unity and a core set of regional beliefs, and the individual strengths of the provider offices and staff. The following themes provide a more in-depth look at the strengths that were discussed:

Key Findings: Strengths	
Strengths identified by three or more interviewees	Selected Quotes
Ryan White Learning Sessions	<ul style="list-style-type: none"> • The Learning Sessions have “brought everybody together in a new way, and it’s relieved a lot of tension and stress between the providers... I feel like all of the providers are very supportive of one another.” • “The communication with me and other agencies that I met at the collaborative has helped immensely. Even giving a scenario and someone being able to help something.”
Variety of services offered at a single location	<ul style="list-style-type: none"> • “Being able to provide healthcare on site is really huge for me...the idea of providing integrated care and then being able to add to that integrated care model behavioral healthcare.” • “The world has always shown that one stop shopping has just always been really successful if you can have it.” • Regarding consumers utilizing mental services (both RWPB services and non-HIV services): “And they do all the time. And it’s interesting because sometimes I find out by accident and it’s just like a mental aha.”
Strong collaborative partnership with other RWPB providers	<ul style="list-style-type: none"> • “We’re very collaborative with the other providers. And I know that it wasn’t always that way. I think seeing some changes organizationally in other orgs. [organizations] as well as this one in terms of leadership and participating in the regional collaborative, participating in AFP [AIDS Free Pittsburgh], really just getting the organizations to know each other better, know what everyone’s roles are. There’s not a whole lot of ego involved, we all do our different thing and do it differently.”
Harm Reduction	<ul style="list-style-type: none"> • “I think we do a really good job of meeting our patients where they’re at. And again, it’s taking that harm reduction approach and extending that into the clinic, too,”

Retention in Care and Viral Suppression	<ul style="list-style-type: none"> • “The vast majority of our patients are suppressed, 90 some percent just like everywhere else now.” • “We have lots of things in place. If a patient misses an appointment or hasn’t been in care for a while, we have several different retention care projects to try to get these folks rescheduled. What are their barriers to getting in here, trying to really facilitate them coming in.”
Resiliency and Community of Consumers	<ul style="list-style-type: none"> • People will ask “the neighbor down the street [for help or ask if they need help], things like that. There’s dignity in that. People want to be able to take care of themselves as well and not always depend on somebody else.” • “[A consumer] was asking about resources, and he was just like, ‘I want to know where there are people like me.’ • “What’s always interesting is even patients who have other comorbid conditions that maybe there’s other things going on, they’re still taking their ARTs no matter what.” • “And the thing of it is that we’ll get calls from people...our clients refer their friends.” • “Like [redacted consumer] who reached out to me that I bike ride with now.” • “I see a greater community, I guess a bond with our long-term survivors”

Most notable is the strength of the region as a whole, which includes networking, regional training and education provided through the Ryan White Learning Sessions, the strong collaborative partnerships between providers, and the core belief in harm reduction methods that providers unanimously share. Providers felt that the SWPA region had cohesion in its HIV services and belief systems, which ultimately helps consumers overcome the barriers they face. These strong relationships in this region are especially potent as it was noted that many consumers receive services from multiple ASOs.

High retention in care rates and high viral suppression were also pointed out as a moment of pride within individual provider organizations. Several providers stated the importance of the work they do and the benefits they provide through the RWPB grant in allowing PLWH to focus on maintaining their health and taking their medications to obtain an undetectable viral load. The ability to offer multiple services at a single location was also stated as a benefit for consumers, allowing them to meet more of their needs quicker and more affordably.

Lastly, the resiliency of the community of PLWH was highly regarded. Interviewees noted several instances in which consumers created a community for themselves, reached out when they needed assistance, and worked to provide for themselves so they would not need to rely on others and could gain a sense of independence. The community created has crossed the boundaries of providers, as many consumers receive services from multiple providers, and therefore are exposed to a greater number of community members and community events. The resiliency to continue taking ARTs even when facing other health issues or personal issues was mentioned as a strength, as well.

LIMITATIONS

Literature/Epidemiologic Review

This literature and epidemiologic review had several limitations. First, region specific information and data were not always available and therefore information from other areas was reported as a proxy. However, it is important to note that the experiences and barriers of PLWH in southwest Pennsylvania may differ from other parts of the United States. Furthermore, data and information regarding the needs of PLWH in rural areas of the southwest region are sparse and often lacking. This review also relied on published literature and publicly available reports, which may limit the types of data utilized and the information included.

Consumer Survey

First off, all laboratory values (e.g., HIV viral load) were self-reported and were not confirmed with medical records for accuracy. Secondly, not all questions were required and not all respondents completed all questions. Additionally, small sample sizes within certain demographics prevented further stratification of some measures (e.g., only able to compare Allegheny versus non-Allegheny counties).

Given that recruitment was conducted through service agencies, it is also important to note that this survey only included respondents likely in routine care. Survey responses may have differed if PLWH not in care were included. Lastly, this survey was conducted in 2019 and 2020, prior to the COVID-19 pandemic, and only represents a snapshot in time. However, the pandemic substantially altered the healthcare and supportive services systems and therefore not all results may be representative of the present time.

Provider Interviews

The results of these surveys are limited by the sample selection; subgrantees chose the interview subjects but were asked to provide both administrative and executive leadership, as well as case managers. Meetings took place in person at the subgrantee office, which affected which case managers were able to attend, as many work in the field and were not able to be in the office on that specific interview day. Not every case manager or administrative and executive staff member was interviewed, which limits the number of voices who participated. Some organizations were able to provide more employees to be interviewed than others, though the perspective and experiences of these staff members does not necessarily reflect those of the organization or other staff members. Furthermore, due to internal changes in staff, one RWPB subgrantee was unable to participate in the interview at the time it was being held. It was rescheduled, though the COVID-19 pandemic began and the subgrantee organization was ultimately unable to participate in the interview.

Furthermore, while these organizations represent a large portion of the HIV services available in the Southwest Pennsylvania region, their funding through JHF may make them differ from other AIDS Service Organizations or organizations working with PLWH.

DISCUSSION

In conclusion, overall this needs assessment revealed multiple gaps and opportunities for improvement, most notably around housing access, transportation assistance, food access, prescription drug access, and medical care. However, the assessment also further revealed that the southwest region of Pennsylvania is not homogenous and that the specific needs of PLWH vary by demographic characteristics such as county (or rural versus urban setting), race, ethnicity, gender identify, and age. Particularly for the latter, epidemiologic data indicates an aging population of PLWH in the southwest region, highlighting the need to proactively develop programming and supportive services that meet the needs of those aging with HIV. Ultimately, it is critical to understand the nuanced needs throughout the region when conducting priority settings to ensure the unique needs of all PLWH are adequately addressed and met.

Stigma and discrimination also emerged as overarching factors that are known to persist as major barriers among PLWH. Though scientific advancements have provided us with the tools to prevent the spread of HIV, not everyone currently benefits from these advancements due in part to the stigma and discrimination surrounding the disease. Stigma and discrimination must concurrently be addressed alongside efforts to increase access to care and supportive services to ensure continued progress in supporting PLWH.

Lastly, it is important to note that the COVID-19 pandemic had a negative impact on HIV outcomes and services for PLWH, which is not captured in this report as the interviews and consumer survey were conducted prior to the pandemic. Therefore, responses to the consumer survey and provider interviews do not reflect experiences related to the ongoing pandemic. Yet, the pandemic had a profound impact on the HIV landscape as it disrupted services for PLWH and prevention efforts. The COVID-19 pandemic also further exacerbated racial and ethnic disparities and highlighted the need for prevention and treatment efforts to focus on social determinants of health. Though HIV testing and other HIV metrics have in many cases returned to pre-pandemic levels, it is critical to continue to monitor the impact of COVID-19 on the HIV epidemic to mitigate any residual impacts.

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ACRONYMS

ART – Antiretroviral therapy

ASO – AIDS Service Organization

FMR – Fair market rent

HIV – Human immunodeficiency virus

HOPWA – Housing Opportunities for Persons with AIDS

HRQOL – Health-related quality of life

IDU – Injection drug use

JHF – Jewish Healthcare Foundation

LGBTQIA+ - Lesbian, gay, bisexual, transgender, queer/questioning, intersex, asexual, plus

MAI – Minority AIDS Initiative

MSM – Male-to-male sexual contact, can also refer to men who have sex with men

OPLWH – Older people living with HIV

PAWH – People aging with HIV

PEP – post-exposure prophylaxis

PLWH – People living with HIV

PrEP – Pre-exposure prophylaxis

PWID – People who inject drugs

RWPB – Ryan White Part B

SES – Socioeconomic status

SWPA – Southwest Region of Pennsylvania

SSP – Syringe Services Programs

APPENDICES

Appendix A: Consumer Survey

Consumer Survey Instructions

You are receiving this survey because the 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 this 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 this survey. This survey should take between 10 and 20 minutes to complete.

If you need assistance taking this survey, your case manager or other staff members can help you. 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 this survey to your case manager or another staff member at the organization where you received it. The organization will return your survey to the 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 any of these counties (<i>please do not complete this survey</i>)

2. Are you HIV positive?

<input type="radio"/> Yes
<input type="radio"/> No (<i>please do not complete this survey</i>)

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"/> Biracial / Multi-racial
<input type="checkbox"/> Black/African American	<input type="checkbox"/> Other: _____
<input type="checkbox"/> Native Hawaiian/Pacific Islander	

5. Are you Hispanic or Latino/Latina/Latinx?

<input type="radio"/> Yes
<input type="radio"/> No

6. What gender do you identify with?
- Female
 - Male
 - Transgender (Male to Female)
 - Transgender (Female to Male)
 - Genderqueer, nonbinary, nonconforming, agender
 - Bigender
 - Other: _____
7. How many people live in your household? _____
8. What is your estimated annual household income?
- \$0 - \$11,999
 - \$12,000 - \$24,999
 - \$25,000 - \$39,999
 - \$40,000 - \$59,999
 - \$60,000 - \$74,999
 - \$75,000 or greater
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"/> Veterans Affairs (the 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 200
 - 200 to 4,999
 - 5,000 to 10,000
 - More than 10,000
 - I do not remember
11. What were the results of your most recent T-cell (CD4) test?
- Less than 200
 - 200 to 499
 - More than 500
 - I do not remember
12. Where is the **first** place you would go when you are sick and in need of medical care? *(Select one)*
- | | |
|---|---|
| <input type="radio"/> Private doctor's office | <input type="radio"/> VA Hospital |
| <input type="radio"/> Emergency room | <input type="radio"/> Free Care Clinic |
| <input type="radio"/> Pharmacy/Minute Clinic | <input type="radio"/> I do not get medical care |
| <input type="radio"/> Urgent/Express Care | <input type="radio"/> Other: _____ |
13. Did you go to your last HIV medical appointment as scheduled?
- Yes
 - No

14. If no, why not? _____

15. Would you be interested in using telemedicine/virtual doctor visits (having a doctor’s appointment by using video and audio on a cell phone or computer from your own home)?

- Yes
- No

16. Where do you see your primary HIV doctor/medical provider?

- PACT (UPMC)
- Positive Health Clinic (AHN)
- Private doctor’s office
- VA Hospital
- Emergency Room
- Central Outreach Wellness Center
- Allies for Health + Wellbeing
- I do not get medical care
- Other:

17. My HIV doctor/medical provider...

	Always	Sometimes	Never	N/A
Spends enough time with me during visits				
Listens to me during visits				
Is easy to reach when I need to speak with them				
Has office hours that work well with my schedule				
Encourages me to participate in my own care				
Is accepting and non-judgmental of my life and healthcare choices				
Explains what my HIV lab results (viral load and CD4 count) mean for my health				
Explains the side effects of the HIV medication and other medications I take so that I can understand				
Is able to help me deal with other health issues besides HIV				
Offers me testing for other diseases like Hepatitis B or C, sexually transmitted infections (STIs), etc., or refers me to places that offer these tests, if necessary				
Refers me to mental health or substance abuse services, if I need them				

18. I feel that my doctor keeps my HIV-status and medical care confidential.

- Yes
- No

19. How would you rate the overall quality of...

	Poor	Fair	Neither good nor poor (neutral)	Good	Excellent	N/A
the HIV medical care you have accessed in Southwestern PA						
the HIV case management services you have accessed in Southwestern PA						
the HIV non-medical support services (ex. Peer support, group meals, food pantry, transportation, etc.) you have accessed in Southwestern PA						

20. Which of the following types of discrimination have you experienced when seeking health care? (*Select all that apply*)

- | | |
|--------------------------------------|---------------------------------------|
| <input type="checkbox"/> Ageism | <input type="checkbox"/> Racism |
| <input type="checkbox"/> Sexism | <input type="checkbox"/> Classism |
| <input type="checkbox"/> HIV Stigma | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Transphobia | <input type="checkbox"/> None |
| <input type="checkbox"/> Homophobia | |

HIV/AIDS MEDICATIONS AND ADHERENCE

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

- Yes
- No

22. If you are **NOT** taking HIV medication, why not? _____

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

- Yes
- No

24. If yes, why? _____

25. 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"/> Chiropractic care |
| <input type="checkbox"/> Herbal treatments | <input type="checkbox"/> Acupuncture |
| <input type="checkbox"/> A healthy diet | <input type="checkbox"/> Meditation/Yoga |
| <input type="checkbox"/> Regular exercise | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Massage | <input type="checkbox"/> None |
| | <input type="checkbox"/> |

26. If you checked any of the above, have you found these alternate therapies to be helpful in managing your HIV and/or side effects of medication?

- Yes
- No

HOUSING

27. Where are you currently living (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
 - Through SeniorCare Management’s assistance (HOPWA Housing)
 - In a residential program
 - Other: _____
28. Are you currently living in subsidized housing?
- Yes
 - No
 - I do not know
29. In the past 6 months, have you had any problems **getting** housing due to any of the following? *(Select all that apply)*
- | | |
|---|---|
| <input type="checkbox"/> Criminal record information | <input type="checkbox"/> Finding a place to live that will accept my rental subsidy (Section 8) |
| <input type="checkbox"/> Waiting lists | <input type="checkbox"/> Problems with my immigration status |
| <input type="checkbox"/> Credit problems | <input type="checkbox"/> Meeting eligibility requirements |
| <input type="checkbox"/> History of drug or alcohol use | <input type="checkbox"/> I have not had any problems getting housing |
| <input type="checkbox"/> Meeting eligibility requirements for subsidies (e.g. Section 8) or other public housing programs | |

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

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

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

ACCESS

31. Do you prefer that the HIV-related services you receive be located **within** your neighborhood?
- Yes, I prefer they be located **within** my neighborhood
 - No, I prefer that they are **not** located within my neighborhood
32. If no, please explain: _____

33. Is it important for you to be able to receive multiple HIV-related services at **one** location?
- Yes
- No
34. Within the last 90 days, have you been concerned about where your next meal would come from?
- Yes
- No
35. What two services do you need the most? (*Write 1 & 2 only*)
- | | |
|---|---|
| <input type="checkbox"/> Medical | <input type="checkbox"/> Health Education |
| <input type="checkbox"/> Housing | <input type="checkbox"/> Emergency Financial Assistance (utilities) |
| <input type="checkbox"/> Mental Health | <input type="checkbox"/> Home Health Services |
| <input type="checkbox"/> Prescription Drugs | <input type="checkbox"/> Substance Use Assistance |
| <input type="checkbox"/> Transportation | <input type="checkbox"/> Treatment Adherence |
| <input type="checkbox"/> Food | <input type="checkbox"/> Hospice Care |
| <input type="checkbox"/> Job/Job Placement | <input type="checkbox"/> Independent Living |
| <input type="checkbox"/> Legal Services | <input type="checkbox"/> Help with children/family |

SUBSTANCE USE

Reminder: All of your responses are confidential and anonymous 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 Pennsylvania region.

36. **In the past 6 months**, have you used any nonprescription drugs, such as crack or heroin?
- Yes
- No
37. **In the past 6 months**, have you used any prescription drugs that were **not** prescribed to you?
- Yes
- No
38. Have you **ever** received treatment for substance use (*for example, counseling, peer support groups, detoxification, methadone maintenance, suboxone*)?
- Yes
- No
39. Was there ever a time when you wanted treatment for substance use, but were unable to get it?
- Yes
- No
40. What prevented you from getting services? _____
41. **In the past 6 months**, have you injected drugs or hormones (not prescribed to you by your doctor)?
- Yes
- No
42. **In the past 6 months**, have you shared needles or works with someone else (including spouse/partners)?
- Yes
- No

43. Where do you get sterile needles and works when you need them? *(Select all that apply)*

- Needle exchange (e.g., Prevention Point Pittsburgh)
- Pharmacy
- Acquaintance/friend/family member
- Other: _____

MENTAL HEALTH

44. Have you **ever** received mental health services (for example, talk therapy, medication, groups, partial hospitalization, IOP)?

- Yes
- No

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

- Yes
- No

46. 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"/> Panic disorder |
| <input type="checkbox"/> Attention deficit/hyperactivity disorder (ADD or ADHD) | <input type="checkbox"/> Personality disorder |
| <input type="checkbox"/> Bipolar disorder | <input type="checkbox"/> Post-traumatic stress disorder (PTSD) |
| <input type="checkbox"/> Borderline personality disorder (BPD) | <input type="checkbox"/> Schizophrenia |
| <input type="checkbox"/> Depression | <input type="checkbox"/> None/I have not been diagnosed with any condition |
| <input type="checkbox"/> Other: _____ | |

47. If you are currently or have ever received mental health treatment, where did you receive it? *(Select all that apply)*

- VA Hospital
- Allies for Health + Wellbeing
- Persad Center
- Positive Health Clinic (AHN)
- PACT (UPMC)
- Other: _____
- I have never received mental health treatment

48. Is/Was your mental health treatment helpful?

- Yes
- No

49. If you are not currently receiving mental health treatment, why? *(Select all that apply)*

- It is not available close to where I live
- I have struggled to find a mental health provider who understands me and my needs
- The available hours do not work for me
- The office has not called me back
- I am concerned about the stigma of needing mental health treatment
- The cost of mental health treatment is too much
- Other: _____
- I do not currently need mental health treatment

AGING

50. My doctor/medical provider...

	Always	Sometimes	Never	N/A
Helps me understand the difference between symptoms of normal aging, HIV symptoms, and side effects of medication				
Explains to me how HIV and the medication I take will affect me as I age				
Discusses with me what I can do to ensure healthy aging				
Explains to me what I am at risk for as I age (for example: cardiovascular disease, osteoporosis, neurocognitive decline)				
Tests me for neurocognitive decline (dementia)				

51. How concerned are you about the following aspects of aging?

	Very	Moderately	Not at all
Finding a partner or maintaining a relationship through the years			
Having a family			
Taking care of significant others			
Managing my HIV			
Long-term effects of medications			
Being a burden on friends and family			
Finding retirement homes that understand HIV			
Finding or having a place to live			
Getting or maintaining a job			
Having a doctor who understands how HIV will affect me as I age			
Multi-Morbidity – having to live with multiple chronic illnesses and take multiple daily medications			

SUPPORTS

52. Do you need help with your everyday activities (bathing, preparing meals, shopping, and/or getting dressed)?

- Yes
- No

53. If yes, do you get the help you need with your everyday activities?

Yes

No

54. Do you have a social (emotional) support system?

Yes

No

*Thank you for completing this survey. Please return this survey to your case manager or another staff member at the organization where you completed this survey. Your responses will remain **confidential**, and your identity will remain **anonymous**. If you have any questions about Ryan White Part B services available in the Southwestern Pennsylvania region, please contact the Jewish Healthcare Foundation at 412-594-2550, and ask for the HIV/AIDS Program.*

Appendix B: Breakdown of Consumer Survey Responses by Demographics

Table 1. Demographic characteristics of respondents to the 2019–2020 southwest Pennsylvania Ryan White consumer survey

Characteristic	N (%)	BY COUNTY		BY BIRTH YEAR		BY RACE			BY GENDER IDENTITY		
		Allegheny	Other	<1970	1970+	Black	White	Other	Female	Male	Transgender
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
	N=117	N=83	N=31	N=61	N=44	N=34	N=64	N=10	N=18	N=93	N=2
County											
Allegheny	83 (70.9)			44 (72.1)	31 (70.5)	28 (82.4)	41 (64.1)	9 (90.0)	15 (83.3)	66 (71.0)	1 (50.0)
Armstrong	3 (2.6)			3 (4.9)	0	0	3 (4.7)	0	0	3 (3.2)	0
Butler	4 (3.4)			2 (3.3)	1 (2.3)	0	3 (4.7)	1 (10.0)	1 (5.6)	2 (2.2)	0
Cambria	8 (6.8)			2 (3.3)	5 (11.4)	3 (8.8)	5 (7.8)	0	0	8 (8.6)	0
Fayette	1 (0.9)			1 (1.6)	0	0	0	0	0	1 (1.1)	0
Indiana	4 (3.4)			3 (4.9)	1 (2.3)	0	4 (6.3)	0	0	4 (4.3)	0
Somerset	1 (0.9)			0	1 (2.3)	0	1 (1.6)	0	0	1 (1.8)	0
Washington	3 (2.6)			1 (1.6)	2 (4.6)	2 (5.9)	1 (1.6)	0	1 (5.6)	2 (2.2)	0
Westmoreland	7 (6.0)			4 (6.6)	3 (6.8)	1 (2.9)	5 (7.8)	0	1 (5.6)	5 (5.4)	1 (50.0)
No response	3 (2.6)			1 (1.6)	0	0	1 (1.6)	0	0	1 (1.1)	0
Birth year											
Before 1960	28 (23.9)	20 (24.1)	8 (25.8)			6 (17.7)	18 (28.1)	2 (20.0)	3 (16.7)	24 (25.8)	1 (50.0)
1960–1969	33 (28.2)	24 (28.9)	8 (25.8)			5 (14.7)	24 (37.5)	4 (40.0)	4 (22.2)	27 (29.0)	0
1970–1979	23 (19.7)	18 (21.7)	5 (16.1)			11 (32.4)	8 (12.5)	1 (10.0)	4 (22.2)	18 (19.4)	1 (50.0)
1980–1989	17 (14.5)	10 (12.1)	7 (22.6)			6 (17.7)	9 (14.1)	1 (10.0)	5 (27.8)	12 (12.9)	0
1990–1999	4 (3.4)	3 (3.6)	1 (3.2)			1 (2.9)	1 (1.6)	2 (20.0)	1 (5.6)	3 (3.2)	0
No response	12 (10.3)	8 (9.6)	2 (6.5)			5 (14.7)	4 (6.3)	0	1 (5.6)	9 (9.7)	0
Race											
American Indian/Alaskan											
Native	3 (2.6)	2 (2.4)	1 (3.2)	2 (3.3)	1 (2.3)				1 (5.6)	1 (1.1)	0
Asian	1 (0.9)	1 (1.2)	0	1 (1.6)	0				0	1 (1.1)	0
Black/African American	34 (29.1)	28 (33.7)	6 (19.4)	11 (18.0)	18 (40.9)				11 (61.1)	21 (22.6)	1 (50.0)
White	64 (54.7)	41 (49.4)	22 (71.0)	42 (68.9)	18 (40.9)				4 (22.2)	59 (63.4)	1 (50.0)
Biracial/multiracial	6 (5.1)	6 (7.2)	0	3 (4.9)	3 (6.8)				0	6 (6.5)	0
No response	9 (7.7)	5 (6.0)	2 (6.5)	2 (3.3)	4 (9.1)				2 (11.1)	5 (5.4)	0
Ethnicity											
Hispanic or Latino/a/x	5 (4.3)	3 (3.6)	2 (6.5)	4 (6.6)	1 (2.3)	1 (2.9)	0	2 (20.0)	0	5 (5.4)	0
Not Hispanic or Latino/a/x	105 (89.7)	76 (91.6)	28 (90.3)	57 (93.4)	40 (90.9)	31 (91.2)	64 (100)	7 (70.0)	16 (88.9)	85 (91.4)	2 (100)
No response	7 (6.0)	4 (4.8)	1 (3.2)	0	3 (6.8)	2 (5.9)	0	1 (10.0)	2 (11.1)	3 (3.2)	0
Gender identity											
Female	18 (15.4)	15 (18.1)	3 (9.7)	7 (11.5)	10 (22.7)	11 (32.4)	4 (6.3)	1 (10.0)			
Male	93 (79.5)	66 (79.5)	26 (83.9)	51 (83.6)	33 (75.0)	21 (61.8)	59 (92.2)	8 (80.0)			
Transgender ¹	2 (1.7)	1 (1.2)	1 (3.2)	1 (1.6)	1 (2.3)	1 (2.9)	1 (1.6)	0			

No response	4 (3.4)	1 (1.2)	1 (3.2)	2 (3.3)	0	1 (2.9)	0	1 (10.0)			
Household size											
1 person (lives alone)	50 (42.7)	40 (48.2)	9 (29.0)	30 (49.2)	17 (38.6)	13 (38.2)	28 (43.8)	6 (60.0)	5 (27.8)	42 (45.2)	1 (50.0)
2 persons	26 (22.2)	15 (18.1)	11 (35.5)	19 (31.2)	6 (13.6)	2 (5.9)	22 (34.4)	1 (10.0)	4 (22.2)	22 (23.7)	0
3 persons	9 (7.7)	6 (7.2)	3 (9.7)	2 (3.3)	7 (15.9)	5 (14.7)	3 (4.7)	1 (10.0)	2 (11.1)	7 (7.5)	0
4+ persons	8 (6.8)	8 (9.6)	0	1 (1.6)	7 (15.9)	5 (14.7)	2 (3.1)	0	4 (22.2)	4 (4.3)	0
No response	24 (20.5)	14 (16.9)	8 (25.8)	9 (14.8)	7 (15.9)	9 (26.5)	9 (14.1)	2 (20.0)	3 (16.7)	18 (19.4)	1 (50.0)
Household income											
\$0–\$11,999	48 (41.0)	34 (41.0)	13 (41.9)	21 (34.4)	22 (50.0)	17 (50.0)	21 (32.8)	6 (60.0)	12 (66.7)	34 (36.6)	1 (50.0)
\$12,000–\$24,999	31 (26.5)	25 (30.1)	6 (19.4)	17 (27.9)	11 (25.0)	10 (29.4)	16 (25.0)	3 (30.0)	2 (11.1)	27 (29.0)	1 (50.0)
\$25,000–\$39,999	20 (17.1)	11 (13.3)	9 (29.0)	10 (16.4)	8 (18.2)	4 (11.8)	15 (23.4)	1 (10.0)	2 (11.1)	18 (19.4)	0
\$40,000–\$59,999	8 (6.8)	7 (8.4)	1 (3.2)	7 (11.5)	1 (2.3)	1 (2.9)	7 (10.9)	0	1 (5.6)	7 (7.5)	0
\$60,000–\$74,999	2 (1.7)	2 (2.4)	0	1 (1.6)	1 (2.3)	1 (2.9)	1 (1.6)	0	0	2 (2.2)	0
\$75,000+	4 (3.4)	3 (3.6)	1 (3.2)	4 (6.6)	0	0	4 (6.3)	0	0	4 (4.3)	0
No response	4 (3.4)	1 (1.2)	1 (3.2)	1 (1.6)	1 (2.3)	1 (2.9)	0	0	1 (5.6)	1 (1.1)	0
Medical insurance ²											
Medicaid/Medical Assistance	59 (50.4)	36 (43.4)	21 (67.7)	29 (47.5)	28 (63.6)	19 (55.9)	28 (43.8)	7 (70.0)	10 (55.6)	46 (49.5)	1 (50.0)
Medicare	41 (35.0)	26 (31.3)	13 (41.9)	28 (45.9)	6 (13.6)	11 (32.4)	24 (37.5)	2 (20.0)	4 (22.2)	35 (37.6)	0
Private (employer provided)	15 (12.8)	13 (15.7)	2 (6.5)	10 (16.4)	4 (9.1)	3 (8.8)	12 (18.8)	0	1 (5.6)	14 (15.1)	0
Private (marketplace)	12 (10.3)	11 (13.3)	1 (3.2)	11 (18.0)	0	3 (8.8)	8 (12.5)	1 (10.0)	0	11 (11.8)	1 (50.0)
SPBP ³	20 (17.1)	16 (19.3)	4 (12.9)	15 (24.6)	2 (4.6)	1 (2.9)	17 (26.6)	1 (10.0)	1 (5.6)	19 (20.4)	0
Veterans Affairs	2 (1.7)	2 (2.4)	0	1 (1.6)	0	0	2 (3.1)	0	0	2 (2.2)	0
Insured, type unknown	4 (3.4)	2 (2.4)	2 (6.5)	2 (3.3)	2 (4.6)	0	1 (1.6)	1 (10.0)	2 (11.1)	1 (1.1)	0
None	5 (4.3)	5 (6.0)	0	1 (1.6)	4 (9.1)	2 (5.9)	3 (4.7)	0	1 (5.6)	4 (4.3)	0
No response	1 (0.9)	0	0	0	0	0	0	0	0	0	0

¹ N=2 for male to female

² Not mutually exclusive

³ Special Pharmaceutical Benefits Program

Table 2. HIV medical care and primary care characteristics of respondents to the 2019–2020 southwest Pennsylvania Ryan White consumer survey

Characteristic	N (%)	BY COUNTY		BY BIRTH YEAR		BY RACE			BY GENDER IDENTITY		
		Allegheny N (%)	Other N (%)	<1970 N (%)	1970+ N (%)	Black N (%)	White N (%)	Other N (%)	Female N (%)	Male N (%)	Transgender N (%)
	N=117	N=83	N=31	N=61	N=44	N=34	N=64	N=10	N=18	N=93	N=2
Recent viral load (copies/ml)											
<200	98 (83.8)	72 (86.8)	23 (74.2)	53 (86.9)	36 (81.8)	27 (79.4)	55 (85.9)	7 (70.0)	13 (72.2)	79 (85.0)	2 (100)
200–4,999	8 (6.8)	4 (4.8)	4 (12.9)	3 (4.9)	3 (6.8)	2 (5.9)	5 (7.8)	1 (10.0)	1 (5.6)	7 (7.5)	0
5,000–10,0000	2 (1.7)	1 (1.2)	1 (3.2)	0	2 (4.6)	1 (2.9)	0	1 (10.0)	0	2 (2.2)	0
>10,000	1 (0.9)	0	1 (3.2)	1 (1.6)	0	0	1 (1.6)	0	0	1 (1.1)	0
Unknown/no response	8 (6.8)	6 (7.2)	2 (6.5)	4 (6.6)	3 (6.8)	4 (11.8)	3 (4.7)	1 (10.0)	4 (22.2)	4 (4.3)	0
Recent T-cell (CD4)											
<200	18 (15.4)	12 (14.5)	6 (19.4)	10 (16.4)	8 (18.2)	6 (17.7)	9 (14.1)	2 (20.0)	3 (16.7)	15 (16.1)	0
200–499	26 (22.2)	19 (22.9)	6 (19.4)	13 (21.3)	7 (15.9)	9 (26.5)	12 (18.8)	4 (40.0)	1 (5.6)	24 (25.8)	0
>500	42 (35.9)	30 (36.1)	11 (35.5)	25 (41.0)	13 (29.6)	5 (14.7)	32 (50.0)	2 (20.0)	1 (5.6)	38 (40.9)	2 (100)
Unknown/no response	31 (26.5)	22 (26.5)	8 (25.8)	13 (21.3)	16 (36.4)	14 (41.2)	11 (17.2)	2 (20.0)	13 (72.2)	16 (17.2)	0
First place to go when need medical care											
Private doctor's office	55 (47.0)	41 (49.4)	13 (41.9)	33 (54.1)	15 (34.1)	10 (29.4)	36 (56.3)	3 (30.0)	7 (38.9)	47 (50.5)	0
Emergency room	43 (36.8)	27 (32.5)	14 (45.2)	16 (26.2)	24 (54.6)	23 (67.7)	14 (21.9)	3 (30.0)	9 (50.0)	29 (31.2)	2 (100)
Urgent/Express Care	10 (8.6)	7 (8.4)	3 (9.7)	6 (9.8)	3 (6.8)	1 (2.9)	9 (14.1)	4 (40.0)	1 (5.6)	9 (9.7)	0
Veterans Affairs hospital	1 (0.9)	1 (1.2)	0	0	0	0	1 (1.6)	0	0	1 (1.1)	0
Free care clinic	6 (5.1)	5 (6.0)	1 (3.2)	4 (6.6)	2 (4.6)	0	2 (3.1)	0	1 (5.6)	5 (5.4)	0
Other	1 (0.9)	1 (1.2)	0	1 (1.6)	0	0	1 (1.6)	0	0	1 (1.1)	0
No response	1 (0.9)	1 (1.2)	0	1 (1.6)	0	0	1 (1.6)	0	0	1 (1.1)	0
Attended last HIV medical appointment											
Yes	110 (94.0)	78 (94.0)	29 (93.6)	55 (90.2)	44 (100)	31 (91.2)	60 (93.8)	10 (100)	16 (88.9)	88 (94.6)	2 (100)
No ¹	3 (2.6)	2 (2.4)	1 (3.2)	3 (4.9)	0	1 (2.9)	2 (3.1)	0	0	3 (3.2)	0
No response	4 (3.4)	3 (3.6)	1 (3.2)	3 (4.9)	0	2 (5.9)	2 (3.1)	0	2 (11.1)	2 (2.2)	0
Interested in telemedicine											
Yes	41 (35.0)	26 (31.3)	13 (41.9)	21 (34.4)	17 (38.6)	10 (29.4)	25 (39.1)	2 (20.0)	4 (22.2)	36 (38.7)	0
No	71 (60.7)	52 (62.7)	18 (58.1)	38 (62.3)	24 (54.6)	21 (61.8)	38 (59.4)	7 (70.0)	13 (72.2)	53 (57.0)	2 (100)
No response	5 (4.3)	5 (6.0)	0	2 (3.3)	3 (6.8)	3 (8.8)	1 (1.6)	1 (10.0)	1 (5.6)	4 (4.3)	0
Primary HIV doctor											
Pittsburgh Area Center for Treatment	45 (38.5)	31 (37.4)	12 (38.7)	30 (49.2)	12 (27.3)	13 (38.2)	28 (43.8)	2 (20.0)	10 (55.6)	32 (34.4)	1 (50.0)
Positive Health Clinic	26 (22.2)	22 (26.5)	4 (12.9)	13 (21.3)	10 (22.7)	9 (26.5)	13 (20.3)	4 (40.0)	4 (22.2)	20 (21.5)	1 (50.0)
Private doctor's office	21 (18.0)	11 (13.3)	9 (29.0)	9 (14.8)	8 (18.2)	6 (17.7)	10 (15.6)	1 (10.0)	2 (11.1)	18 (19.4)	0
Veterans Affairs hospital	1 (0.9)	1 (1.2)	0	0	0	0	1 (1.6)	0	0	1 (1.1)	0
Emergency room	1 (0.9)	0	1 (3.2)	0	1 (2.3)	1 (2.9)	0	0	0	1 (1.1)	0
Central Outreach Wellness Center	10 (8.6)	8 (9.6)	2 (6.5)	7 (11.5)	3 (6.8)	2 (5.9)	5 (7.8)	2 (20.0)	1 (5.6)	9 (9.7)	0
Allies for Health + Wellbeing	11 (9.4)	8 (9.6)	3 (9.7)	1 (1.6)	9 (20.5)	2 (5.9)	6 (9.4)	1 (10.0)	1 (5.6)	10 (10.8)	0

No response	2 (1.7)	2 (2.4)	0	1 (1.6)	1 (2.3)	1 (2.9)	1 (1.6)	0	0	2 (2.2)	0
Feels doctor keeps HIV status confidential											
Yes	98 (83.8)	68 (81.9)	28 (90.3)	54 (88.5)	34 (77.3)	26 (76.5)	58 (90.6)	8 (80.0)	16 (88.9)	78 (83.9)	2 (100)
No	2 (1.7)	2 (2.4)	0	0	2 (4.6)	1 (2.9)	1 (1.6)	0	1 (5.6)	1 (1.1)	0
No response	17 (14.5)	13 (15.7)	3 (9.7)	7 (11.5)	8 (18.2)	7 (20.6)	5 (7.8)	2 (20.0)	1 (5.6)	14 (15.1)	0
Discrimination when seeking healthcare ²											
Ageism	5 (4.3)	3 (3.6)	2 (6.5)	3 (4.9)	0	0	5 (7.8)	0	0	5 (5.4)	0
Sexism	1 (0.9)	1 (1.2)	0	1 (1.6)	0	1 (2.9)	0	0	0	1 (1.1)	0
HIV stigma	36 (30.8)	25 (30.1)	10 (32.3)	20 (32.8)	11 (25.0)	6 (17.7)	23 (35.9)	3 (30.0)	5 (27.8)	30 (32.3)	1 (50.0)
Transphobia	1 (0.9)	0	1 (3.2)	0	1 (2.3)	0	1 (1.6)	0	0	0	1 (50.0)
Homophobia	20 (17.1)	14 (16.9)	5 (16.1)	9 (14.8)	8 (18.2)	2 (5.9)	16 (25.0)	1 (10.0)	3 (16.7)	16 (17.2)	1 (50.0)
Racism	5 (4.3)	3 (3.6)	2 (6.5)	3 (4.9)	2 (4.6)	3 (8.8)	1 (1.6)	1 (10.0)	0	4 (4.3)	0
Classism	5 (4.3)	3 (3.6)	2 (6.5)	3 (4.9)	2 (4.6)	1 (2.9)	3 (4.7)	1 (10.0)	0	4 (4.3)	0
None	60 (51.3)	42 (50.6)	16 (51.6)	31 (50.8)	25 (56.8)	18 (52.9)	35 (54.7)	3 (30.0)	8 (44.4)	48 (51.6)	1 (50.0)
Other ³	1 (0.9)	1 (1.2)	0	0	0	0	1 (1.6)	0	0	1 (1.1)	0
No response	13 (11.1)	10 (12.1)	3 (9.7)	7 (11.5)	5 (11.4)	6 (17.7)	3 (4.7)	3 (30.0)	4 (22.2)	9 (9.7)	0

¹ Reason for no (n=3): "family emergency," "forgot," "I became sick and went to E.R. instead"

² Not mutually exclusive

Table 3. HIV medication and medication adherence characteristics of respondents to the 2019–2020 southwest Pennsylvania Ryan White consumer survey

Characteristic	N (%)	BY COUNTY		BY BIRTH YEAR		BY RACE			BY GENDER IDENTITY		
		Allegheny	Other	<1970	1970+	Black	White	Other	Female	Male	Transgender
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
	N=117	N=83	N=31	N=61	N=44	N=34	N=64	N=10	N=18	N=93	N=2
Currently taking HIV medications											
Yes	112 (95.7)	79 (95.2)	30 (96.8)	59 (96.7)	41 (93.2)	32 (94.1)	63 (98.4)	9 (90.0)	17 (94.4)	89 (95.7)	2 (100)
No	1 (0.9)	1 (1.2)	0	0	1 (2.3)	1 (2.9)	0	0	1 (5.6)	4 (4.3)	0
No response	4 (3.4)	3 (3.6)	1 (3.2)	2 (3.3)	2 (4.6)	1 (2.9)	1 (1.6)	1 (10.0)	0	0	0
In past 6 months, missed/stopped taking HIV medication for >1 week											
Yes	25 (21.4)	17 (20.5)	8 (25.8)	11 (18.0)	11 (25.0)	12 (35.3)	11 (17.2)	1 (10.0)	7 (38.9)	18 (19.4)	0
No	86 (73.5)	62 (74.7)	21 (67.7)	48 (78.7)	29 (65.9)	20 (58.8)	51 (79.7)	8 (80.0)	10 (55.6)	70 (75.3)	2 (100)
Not on medication	1 (0.9)	1 (1.2)	0	0	1 (2.3)	1 (2.9)	0	0	1 (5.6)	0	0
No response	5 (4.3)	3 (3.6)	2 (6.5)	2 (3.3)	3 (6.8)	1 (2.9)	2 (3.1)	1 (10.0)	0	5 (5.4)	0
Therapies used to manage HIV or medication side effects ¹											
Vitamins/nutrition supplements	55 (47.0)	39 (47.0)	14 (45.2)	33 (54.1)	17 (38.6)	9 (26.5)	35 (54.7)	8 (80.0)	2 (11.1)	50 (53.8)	1 (50.0)
Herbal treatments	12 (10.3)	8 (9.6)	4 (12.9)	8 (13.1)	2 (4.6)	1 (2.9)	8 (12.5)	2 (20.0)	1 (5.6)	11 (11.8)	0
A healthy diet	50 (42.7)	35 (42.2)	13 (41.9)	28 (45.9)	16 (36.4)	10 (29.4)	30 (46.9)	5 (50.0)	4 (22.2)	44 (47.3)	1 (50.0)
Regular exercise	47 (40.2)	35 (42.2)	10 (32.3)	24 (39.3)	17 (38.6)	14 (41.2)	25 (39.1)	3 (30.0)	3 (16.7)	41 (44.1)	1 (50.0)
Massage	21 (18.0)	14 (16.9)	7 (22.6)	9 (14.8)	10 (22.7)	7 (20.6)	10 (15.6)	1 (10.0)	3 (16.7)	17 (18.3)	1 (50.0)
Chiropractic care	9 (7.7)	4 (4.8)	5 (16.1)	5 (8.2)	4 (9.1)	1 (2.9)	8 (12.5)	0	1 (5.6)	7 (7.5)	1 (50.0)
Acupuncture	2 (1.7)	1 (1.2)	1 (3.2)	2 (3.3)	0	0	2 (3.1)	0	0	2 (2.2)	0
Meditation/yoga	27 (23.1)	20 (24.1)	6 (19.4)	16 (26.2)	8 (18.2)	7 (20.6)	15 (23.4)	3 (30.0)	2 (11.1)	24 (25.8)	0
Other therapies ²	5 (4.3)	3 (3.6)	2 (6.5)	3 (4.9)	2 (4.6)	0	5 (7.8)	0	1 (5.6)	4 (4.3)	0
None	22 (18.8)	14 (16.9)	8 (25.8)	10 (16.4)	12 (27.3)	6 (17.7)	13 (20.3)	2 (20.0)	8 (44.4)	13 (14.0)	0
No response	8 (6.8)	6 (7.2)	2 (6.5)	6 (9.8)	1 (2.3)	4 (11.8)	3 (4.7)	0	4 (22.2)	4 (4.3)	0
Alternative therapies helpful (n=87)											
Yes	68 (78.2)	49 (77.8)	16 (76.2)	38 (84.4)	21 (67.7)	14 (58.3)	42 (87.5)	7 (87.5)	4 (66.7)	61 (80.3)	0
No	8 (9.2)	5 (7.9)	3 (14.3)	3 (6.7)	5 (16.1)	3 (12.5)	4 (8.3)	0	1 (16.7)	7 (9.2)	0
No response	11 (12.6)	9 (14.5)	2 (9.5)	4 (8.9)	5 (16.1)	7 (29.2)	2 (4.2)	1 (12.5)	1 (16.7)	8 (10.5)	2 (100)

¹ Not mutually exclusive

² Other: marijuana (n=3), medications (e.g., Gabapentin for neuropathy; n=1), walks with dog and member of Alcoholic Anonymous (n=1)

Table 4. Housing access characteristics of respondents to the 2019–2020 southwest Pennsylvania Ryan White consumer survey

Characteristic	N (%)	BY COUNTY		BY BIRTH YEAR		BY RACE			BY GENDER IDENTITY		
		Allegheny	Other	<1970	1970+	Black	White	Other	Female	Male	Transgender
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
	N=117	N=83	N=31	N=61	N=44	N=34	N=64	N=10	N=18	N=93	N=2
Residence in past 30 days											
Temporary place ¹	4 (3.4)	4 (4.8)	0	1 (1.6)	2 (4.6)	2 (5.9)	0	0	0	4 (4.3)	0
Someone's house, short term	5 (4.3)	3 (3.6)	2 (6.5)	0	4 (9.1)	1 (2.9)	2 (3.1)	2 (20.0)	1 (5.6)	4 (4.3)	0
Someone's house, long term	13 (11.1)	12 (14.5)	1 (3.2)	3 (4.9)	8 (18.2)	2 (5.9)	8 (12.5)	1 (10.0)	2 (11.1)	11 (11.8)	0
Own home or apartment	82 (70.1)	54 (65.1)	25 (80.7)	49 (80.3)	25 (56.8)	23 (67.7)	50 (78.1)	5 (50.0)	12 (66.7)	64 (68.8)	2 (100)
HOPWA housing	4 (3.4)	2 (2.4)	2 (6.5)	1 (1.6)	3 (6.8)	2 (5.9)	1 (1.6)	1 (10.0)	0	4 (4.3)	0
Residential program	3 (2.6)	3 (3.6)	0	2 (3.3)	1 (2.3)	2 (5.9)	0	1 (10.0)	1 (5.6)	2 (2.2)	0
Other	2 (1.7)	2 (2.4)	0	1 (1.6)	1 (2.3)	1 (2.9)	1 (1.6)	0	1 (5.6)	1 (1.1)	0
No response	4 (3.4)	3 (3.6)	1 (3.2)	4 (6.6)	0	1 (2.9)	2 (3.1)	0	1 (5.6)	3 (3.2)	0
Currently in subsidized housing											
Yes	34 (29.1)	26 (31.3)	5 (16.1)	14 (23.0)	13 (29.6)	18 (52.9)	8 (12.5)	3 (30.0)	10 (55.6)	20 (21.5)	1 (50.0)
No	72 (61.5)	47 (56.6)	25 (80.7)	41 (67.2)	27 (61.4)	11 (32.4)	53 (82.8)	6 (60.0)	5 (27.8)	65 (69.9)	1 (50.0)
Unknown	11 (9.4)	10 (12.1)	1 (3.2)	6 (9.8)	4 (9.1)	5 (14.7)	3 (4.7)	1 (10.0)	3 (16.7)	8 (8.6)	0
Problems getting housing in past 6 months ³											
Criminal record information	8 (6.8)	8 (9.6)	0	2 (3.3)	5 (11.4)	2 (5.9)	5 (7.8)	1 (10.0)	1 (5.6)	7 (7.5)	0
Waiting list	14 (12.0)	13 (15.7)	1 (3.2)	7 (11.5)	6 (13.6)	5 (14.7)	6 (9.4)	2 (20.0)	2 (11.1)	12 (12.9)	0
Credit problems	15 (12.8)	14 (16.9)	1 (3.2)	3 (4.9)	11 (25.0)	5 (14.7)	8 (12.5)	1 (10.0)	2 (11.1)	13 (14.0)	0
History of drug or alcohol use	5 (4.3)	5 (6.0)	0	0	4 (9.1)	1 (2.9)	3 (4.7)	0	1 (5.6)	4 (4.3)	0
Eligibility for subsidies	3 (2.6)	3 (3.6)	0	1 (1.6)	2 (4.6)	1 (2.9)	1 (1.6)	1 (10.0)	1 (5.6)	2 (2.2)	0
Finding place that accepts subsidy (Section 8)	6 (5.1)	6 (6.0)	1 (3.2)	3 (4.9)	3 (6.8)	2 (5.9)	3 (4.7)	1 (10.0)	1 (5.6)	5 (5.4)	0
Meeting eligibility requirements	6 (5.1)	6 (7.2)	0	2 (3.3)	3 (6.8)	1 (2.9)	4 (6.3)	0	1 (5.6)	5 (5.4)	0
No problems	71 (60.7)	44 (53.0)	24 (77.4)	40 (65.6)	22 (50.0)	18 (52.9)	45 (70.3)	3 (30.0)	10 (55.6)	57 (61.3)	1 (50.0)
Other ²	8 (6.8)	8 (9.6)	0	3 (4.9)	4 (9.1)	2 (5.9)	5 (7.8)	1 (10.0)	3 (16.7)	5 (5.4)	0
No response	21 (18.0)	15 (18.1)	6 (19.4)	12 (19.7)	8 (18.2)	7 (20.6)	7 (10.9)	5 (50.0)	4 (22.2)	15 (16.1)	1 (50.0)
Problems keeping housing in past 6 months ²											
Difficulty paying rent, mortgage, or utilities	25 (21.4)	20 (24.1)	5 (16.1)	9 (14.8)	16 (36.4)	7 (20.6)	13 (20.3)	2 (20.0)	7 (38.9)	16 (17.2)	1 (50.0)
Drug or alcohol use	3 (2.6)	3 (3.6)	0	1 (1.6)	2 (4.6)	1 (2.9)	2 (3.1)	0	2 (11.1)	1 (1.1)	0
Credit problems	3 (2.6)	3 (3.6)	0	0	3 (6.8)	1 (2.9)	2 (3.1)	0	1 (5.6)	2 (2.2)	0
Eviction	5 (4.3)	2 (2.4)	3 (9.7)	1 (1.6)	4 (9.1)	1 (2.9)	4 (6.3)	0	1 (5.6)	3 (3.2)	1 (50.0)
Legal problems	1 (0.9)	1 (1.2)	0	1 (1.6)	0	0	1 (1.6)	0	0	1 (1.1)	0
No problems	68 (58.1)	46 (55.4)	19 (61.3)	41 (67.2)	17 (38.6)	20 (58.2)	41 (64.1)	3 (30.0)	8 (44.4)	56 (60.2)	1 (50.0)
Other ²	7 (6.0)	7 (8.4)	0	2 (3.3)	5 (11.4)	0	4 (6.3)	2 (20.0)	2 (11.1)	5 (5.4)	0
No response	21 (18.0)	15 (18.1)	6 (19.4)	10 (16.4)	9 (20.5)	6 (17.7)	9 (14.1)	4 (40.0)	3 (16.7)	18 (19.4)	0

¹ E.g., car, street, shelter, or other temporary location

² Not mutually exclusive

Table 5. Services and support access characteristics of respondents to the 2019–2020 southwest Pennsylvania Ryan White consumer survey

Characteristic	N (%)	BY COUNTY		BY BIRTH YEAR		BY RACE			BY GENDER IDENTITY		
		Allegheny N (%)	Other N (%)	<1970 N (%)	1970+ N (%)	Black N (%)	White N (%)	Other N (%)	Female N (%)	Male N (%)	Transgender N (%)
	N=117	N=83	N=31	N=61	N=44	N=34	N=64	N=10	N=18	N=93	N=2
Preferred location of HIV services											
Within own neighborhood	64 (54.7)	47 (56.6)	15 (48.4)	36 (59.0)	22 (50.0)	14 (41.2)	42 (65.6)	4 (40.0)	8 (44.4)	53 (57.0)	1 (50.0)
Outside own neighborhood ¹	40 (34.2)	26 (31.3)	13 (41.9)	15 (24.6)	20 (45.5)	16 (47.1)	16 (25.0)	5 (50.0)	8 (44.4)	30 (32.3)	0
No response	13 (11.1)	10 (12.1)	3 (9.7)	10 (16.4)	2 (4.6)	4 (11.8)	6 (9.4)	1 (10.0)	2 (11.1)	10 (10.8)	1 (50.0)
Important to receive multiple HIV services at one location											
Yes	89 (76.1)	64 (77.1)	22 (71.0)	45 (73.8)	34 (77.3)	24 (70.6)	49 (76.6)	9 (90.0)	12 (66.7)	72 (77.4)	1 (50.0)
No	20 (17.1)	14 (16.9)	6 (19.4)	10 (16.4)	8 (18.2)	8 (23.5)	10 (15.6)	1 (10.0)	5 (27.8)	14 (15.1)	1 (50.0)
No response	8 (6.8)	5 (6.0)	3 (9.7)	6 (9.8)	2 (4.6)	2 (5.9)	5 (7.8)	0	1 (5.6)	7 (7.5)	0
Concern about next meal, in past 90 days											
Yes	30 (25.6)	23 (27.7)	5 (16.1)	11 (18.0)	14 (31.8)	5 (14.7)	18 (28.1)	5 (50.0)	5 (27.8)	24 (25.8)	0
No	80 (68.4)	56 (67.5)	23 (74.2)	45 (73.8)	28 (63.6)	28 (82.4)	42 (65.6)	5 (50.0)	13 (72.2)	62 (66.7)	2 (100)
No response	7 (6.0)	4 (4.8)	3 (9.7)	5 (8.2)	2 (4.6)	1 (2.9)	4 (6.3)	0	0	7 (7.5)	0
Need help with everyday activities											
Yes	13 (11.1)	7 (8.4)	6 (19.4)	7 (11.5)	3 (6.8)	4 (11.8)	7 (10.9)	1 (10.0)	1 (5.6)	11 (11.8)	1 (50.0)
No	89 (76.1)	65 (78.3)	22 (71.0)	45 (73.8)	36 (81.8)	27 (79.4)	49 (76.6)	8 (80.0)	17 (94.4)	69 (74.2)	0
No response	15 (12.8)	11 (13.3)	3 (9.7)	9 (14.8)	5 (11.4)	3 (8.8)	8 (12.5)	1 (10.0)	0	13 (14.0)	1 (50.0)
Able to access help with everyday activities when needed (n=13)											
Yes	6 (46.2)	3 (42.9)	3 (50.0)	3 (42.9)	2 (66.7)	2 (50.0)	3 (42.9)	0	0	5 (45.5)	1 (100)
No	7 (53.8)	4 (57.1)	3 (50.0)	4 (57.1)	1 (33.3)	2 (50.0)	4 (57.1)	1 (100)	1 (100)	6 (54.6)	0
Have social/emotional support system											
Yes	75 (64.1)	52 (62.7)	21 (67.7)	40 (65.6)	26 (59.1)	19 (55.9)	45 (70.3)	7 (70.0)	8 (44.4)	64 (68.8)	0
No	26 (22.2)	19 (22.9)	7 (22.6)	11 (18.0)	13 (29.6)	11 (32.4)	11 (17.2)	2 (20.0)	9 (50.0)	16 (17.2)	1 (50.0)
No response	16 (13.7)	12 (14.5)	3 (9.7)	10 (16.4)	5 (11.4)	4 (11.8)	8 (12.5)	1 (10.0)	1 (5.6)	13 (14.0)	1 (50.0)

¹ Reasons (if provided) for outside neighborhood: privacy (n=9), discrimination/fear of hate attacks (n=2), no services in neighborhood or dislikes how they are set-up (n=4), enjoys getting out of neighborhood to meet people (n=1)

Table 6. Substance use characteristics of respondents to the 2019–2020 southwest Pennsylvania Ryan White consumer survey

Characteristic	N (%)	BY COUNTY		BY BIRTH YEAR		BY RACE			BY GENDER IDENTITY		
		Allegheny	Other	<1970	1970+	Black	White	Other	Female	Male	Transgender
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
	N=117	N=83	N=31	N=61	N=44	N=34	N=64	N=10	N=18	N=93	N=2
Use of nonprescription drugs in past 6 months											
Yes	15 (12.8)	13 (15.7)	2 (6.5)	8 (13.1)	6 (13.6)	5 (14.7)	6 (9.4)	3 (30.0)	3 (16.7)	11 (11.8)	0
No	94 (80.3)	64 (77.1)	27 (87.1)	47 (77.1)	37 (84.1)	26 (76.5)	54 (84.4)	7 (70.0)	15 (83.3)	75 (80.7)	1 (50.0)
No response	8 (6.8)	6 (7.2)	2 (6.5)	6 (9.8)	1 (2.3)	3 (8.8)	4 (6.3)	0	0	7 (7.5)	1 (50.0)
Use of prescription drugs (not as prescribed) in past 6 months											
Yes	10 (8.6)	6 (7.2)	3 (9.7)	4 (6.6)	5 (11.4)	2 (5.9)	5 (7.8)	2 (20.0)	0	9 (9.7)	0
No	99 (84.6)	71 (85.5)	26 (83.9)	51 (83.6)	38 (86.4)	29 (85.3)	55 (85.9)	8 (80.0)	18 (100)	77 (82.8)	1 (50.0)
No response	8 (6.8)	6 (7.2)	2 (6.5)	6 (9.8)	1 (2.3)	3 (8.8)	4 (6.3)	0	0	7 (7.5)	1 (50.0)
Injected drugs or hormones in past 6 months											
Yes	6 (5.1)	6 (7.2)	0	1 (1.6)	4 (9.1)	1 (2.9)	3 (4.7)	1 (10.0)	1 (5.6)	5 (5.4)	0
No	102 (87.2)	71 (85.5)	28 (90.3)	54 (88.5)	39 (88.6)	30 (88.2)	56 (87.5)	9 (90.0)	17 (94.4)	80 (86.0)	1 (50.0)
No response	9 (7.7)	6 (7.2)	3 (9.7)	6 (9.8)	1 (2.3)	3 (8.8)	5 (7.8)	0	0	8 (8.6)	1 (50.0)
Ever received substance use treatment											
Yes	27 (23.1)	19 (22.9)	8 (25.8)	15 (24.6)	10 (22.7)	8 (23.5)	14 (21.9)	3 (30.0)	4 (22.2)	21 (22.6)	0
No	82 (70.1)	58 (69.9)	21 (67.7)	40 (65.6)	33 (75.0)	23 (67.7)	46 (71.9)	7 (70.0)	14 (77.8)	65 (69.9)	1 (50.0)
No response	8 (6.8)	6 (7.2)	2 (6.5)	6 (9.8)	1 (2.3)	3 (8.8)	4 (6.3)	0	0	7 (7.5)	1 (50.0)
Ever wanted substance use treatment but unable to access											
Yes ¹	8 (6.8)	5 (6.0)	3 (9.7)	4 (6.6)	3 (6.8)	2 (5.9)	3 (4.7)	3 (30.0)	1 (5.6)	6 (6.5)	0
No	93 (79.5)	65 (78.3)	26 (83.9)	47 (77.1)	38 (86.4)	27 (79.4)	54 (84.4)	6 (60.0)	16 (88.9)	74 (79.6)	1 (50.0)
No response	16 (13.7)	13 (15.7)	2 (6.5)	10 (16.4)	3 (6.8)	5 (14.7)	7 (10.9)	1 (10.0)	1 (5.6)	13 (14.0)	1 (50.0)

¹ Reasons for inability to access: fear that disability benefits would be jeopardized, lack of transportation, young age and being in foster care programs

Table 7. Mental health characteristics of respondents to the 2019–2020 southwest Pennsylvania Ryan White consumer survey

Characteristic	N (%)	BY COUNTY		BY BIRTH YEAR		BY RACE			BY GENDER IDENTITY		
		Allegheny N (%)	Other N (%)	<1970 N (%)	1970+ N (%)	Black N (%)	White N (%)	Other N (%)	Female N (%)	Male N (%)	Transgender N (%)
	N=117	N=83	N=31	N=61	N=44	N=34	N=64	N=10	N=18	N=93	N=2
Mental health conditions¹											
Anxiety	61 (52.1)	42 (50.6)	17 (54.8)	32 (52.5)	25 (56.8)	11 (32.4)	40 (62.5)	6 (60.0)	10 (55.6)	49 (52.7)	1 (50.0)
Attention deficit/hyperactivity disorder	10 (8.6)	6 (7.2)	3 (9.7)	2 (3.3)	8 (18.2)	1 (2.9)	8 (12.85)	1 (10.0)	2 (11.1)	8 (8.6)	0
Bipolar disorder	19 (16.2)	14 (16.9)	4 (12.9)	11 (18.0)	8 (18.2)	7 (20.6)	11 (17.2)	0	4 (22.2)	14 (15.1)	0
Borderline personality disorder	4 (3.4)	2 (2.4)	2 (6.5)	3 (4.9)	0	1 (2.9)	3 (4.7)	0	0	4 (4.3)	0
Depression	64 (54.7)	45 (54.2)	17 (54.8)	32 (52.5)	24 (54.6)	14 (41.2)	39 (60.9)	6 (60.0)	12 (66.7)	48 (51.6)	2 (100)
Panic disorder	11 (9.4)	9 (10.8)	2 (6.5)	5 (8.2)	5 (11.4)	0	9 (14.1)	1 (10.0)	0	10 (10.8)	1 (50.0)
Personality disorder	2 (1.7)	0	2 (6.5)	2 (3.3)	0	0	2 (3.1)	0	0	2 (2.2)	0
Post-traumatic stress disorder	31 (26.5)	20 (24.1)	10 (32.3)	11 (18.0)	17 (38.6)	4 (11.8)	22 (34.4)	2 (20.0)	5 (27.8)	24 (25.8)	1 (50.0)
Schizophrenia	2 (1.7)	2 (2.4)	0	1 (1.6)	1 (2.3)	1 (2.9)	0	0	0	2 (2.2)	0
None	17 (14.5)	9 (10.8)	8 (25.8)	9 (14.8)	6 (13.6)	5 (14.7)	9 (14.1)	1 (10.0)	2 (11.1)	15 (16.1)	0
Other ²	5 (4.3)	4 (4.8)	1 (3.2)	5 (8.2)	0	0	4 (6.3)	1 (10.0)	0	5 (5.38)	0
No response	19 (16.2)	15 (18.1)	4 (12.9)	10 (16.4)	7 (15.9)	10 (29.4)	6 (9.4)	1 (10.0)	3 (16.7)	15 (16.1)	0
Ever received mental health services											
Yes	91 (77.8)	67 (80.7)	21 (67.7)	50 (82.0)	32 (72.3)	23 (67.7)	53 (82.8)	10 (100)	16 (88.9)	69 (74.2)	2 (100)
No	18 (15.4)	10 (12.1)	8 (25.8)	5 (8.2)	10 (22.7)	10 (29.4)	6 (9.4)	0	2 (11.1)	16 (17.2)	0
No response	8 (6.8)	6 (7.2)	2 (6.5)	6 (9.8)	2 (4.6)	1 (2.9)	5 (7.8)	0	0	8 (8.6)	0
Currently receiving mental health treatment											
Yes	52 (44.4)	38 (45.8)	12 (38.7)	28 (45.9)	18 (40.9)	12 (35.3)	34 (53.1)	4 (40.0)	8 (44.4)	41 (44.1)	2 (100)
No	58 (49.6)	40 (48.2)	17 (54.8)	28 (45.9)	24 (54.6)	21 (61.8)	26 (40.6)	6 (60.0)	10 (55.6)	45 (48.4)	0
No response	7 (6.0)	5 (6.0)	2 (6.5)	5 (8.2)	2 (4.6)	1 (2.9)	4 (6.3)	0	0	7 (7.5)	0
Location of mental health treatment, if ever/currently receiving¹ (n=91)											
Veterans Affairs Hospital	2 (2.2)	2 (3.0)	0	1 (2.0)	0	1 (4.4)	1 (1.9)	0	1 (6.3)	1 (1.5)	0
Allies for Health + Wellbeing	12 (13.2)	10 (14.9)	2 (9.5)	6 (12.0)	6 (18.8)	4 (17.4)	6 (11.3)	2 (20.0)	4 (25.0)	8 (12.0)	0
Persad Center	13 (14.3)	11 (16.4)	1 (4.8)	8 (16.0)	3 (9.4)	1 (4.4)	12 (22.6)	0	0	13 (18.8)	0
Positive Health Clinic	12 (13.2)	11 (16.4)	1 (4.8)	5 (10.0)	7 (21.9)	4 (17.4)	5 (9.4)	3 (30.0)	2 (12.5)	9 (13.0)	0
Pittsburgh Area Center for Treatment	26 (28.6)	20 (29.9)	5 (23.8)	14 (28.0)	8 (25.0)	7 (30.4)	15 (28.3)	2 (20.0)	7 (43.8)	18 (26.1)	0
Other ³	26 (28.6)	17 (25.4)	9 (42.9)	16 (32.0)	8 (25.0)	6 (26.1)	18 (34.0)	2 (20.0)	3 (16.7)	21 (33.3)	1 (50.0)
No response	8 (8.8)	6 (9.0)	1 (4.8)	5 (10.0)	2 (6.3)	4 (17.4)	2 (3.8)	1 (10.0)	3 (18.8)	3 (4.4)	0
Was mental health treatment helpful, if ever/currently receiving (n=91)											
Yes	74 (81.3)	54 (80.6)	19 (90.5)	41 (82.0)	27 (84.4)	16 (69.6)	46 (86.8)	9 (90.0)	11 (68.8)	60 (87.0)	1 (50.0)
No	9 (9.9)	7 (10.5)	1 (4.8)	4 (8.0)	3 (9.4)	3 (13.0)	5 (9.4)	0	2 (12.5)	6 (8.7)	0
No response	8 (8.8)	6 (9.0)	1 (4.8)	5 (10.0)	2 (6.3)	4 (17.4)	2 (3.8)	1 (10.0)	3 (18.8)	3 (4.4)	1 (50.0)

Reason for not receiving mental health treatment, if not currently (n=58)

Not available close to home	3 (5.2)	0	3 (17.7)	2 (7.1)	1 (4.2)	0	3 (11.5)	0	0	3 (6.7)	0
Struggled to find provider	5 (8.6)	2 (5.0)	3 (17.7)	2 (7.1)	3 (12.5)	0	3 (11.5)	1 (16.7)	1 (10.0)	4 (8.9)	0
Available hours do not work	2 (3.5)	1 (2.5)	1 (5.9)	2 (7.1)	0	0	2 (7.7)	0	0	2 (4.4)	0
Office did not call back	2 (3.5)	2 (5.0)	0	0	2 (8.3)	0	0	1 (16.7)	1 (10.0)	1 (2.2)	0
Concerned about stigma	2 (3.5)	1 (2.5)	1 (5.9)	0	2 (8.3)	0	1 (3.9)	1 (16.7)	0	2 (4.4)	0
Too costly	3 (5.2)	3 (7.5)	0	0	3 (12.5)	1 (4.8)	2 (7.7)	0	0	3 (6.7)	0
Do not currently need treatment	26 (44.8)	18 (45.0)	8 (47.1)	15 (53.6)	7 (29.2)	11 (52.4)	9 (34.6)	4 (66.7)	5 (50.0)	19 (42.2)	0
Other ⁴	3 (5.2)	3 (7.5)	0	1 (3.6)	2 (8.3)	1 (4.8)	2 (7.7)	0	1 (10)	2 (4.4)	0
No response	18 (31.0)	13 (32.5)	4 (23.5)	8 (28.6)	8 (33.3)	8 (38.1)	7 (26.9)	1 (16.7)	3 (30.0)	14 (31.1)	0

¹ Not mutually exclusive

² Other conditions listed: agoraphobic, brain damage, early dementia, encephalitis, word finding challenges, self-esteem concerns

³ Other responses: private practice, psychiatric hospital, local HIV support groups

⁴ Other: confidentiality concerns, discharged preemptively, will continue in future

Table 8. Ratings of services and needs by respondents to the 2019–2020 southwest Pennsylvania Ryan White consumer survey

Characteristic	N (%)	BY COUNTY		BY BIRTH YEAR		BY RACE			BY GENDER IDENTITY		
		Allegheny N (%)	Other N (%)	<1970 N (%)	1970+ N (%)	Black N (%)	White N (%)	Other N (%)	Female N (%)	Male N (%)	Transgender N (%)
	N=117	N=83	N=31	N=61	N=44	N=34	N=64	N=10	N=18	N=93	N=2
Quality of HIV medical care services											
Poor	3 (2.6)	3 (3.6)	0	0	3 (6.8)	0	2 (3.1)	1 (10.0)	0	3 (3.2)	0
Fair	6 (5.1)	2 (2.4)	4 (12.9)	4 (6.6)	1 (2.3)	0	6 (9.4)	0	0	5 (5.4)	1 (50.0)
Neutral	1 (0.9)	0	1 (3.2)	0	1 (2.3)	0	1 (1.6)	0	0	1 (1.1)	0
Good	26 (22.2)	17 (20.5)	8 (25.8)	13 (21.3)	12 (27.3)	7 (20.6)	15 (23.4)	3 (30.0)	4 (22.2)	20 (21.5)	1 (50.0)
Excellent	69 (59.0)	52 (62.7)	15 (48.4)	39 (63.9)	22 (50.0)	22 (64.7)	36 (56.3)	5 (50.0)	11 (61.1)	55 (59.1)	0
N/A or no response	12 (10.3)	9 (10.8)	3 (9.7)	5 (8.2)	5 (11.4)	5 (14.7)	4 (6.3)	1 (10.0)	3 (16.7)	9 (9.7)	0
Quality of HIV case management											
Poor	3 (2.6)	3 (3.6)	0	1 (1.6)	2 (4.6)	0	3 (4.7)	0	0	3 (3.2)	0
Fair	3 (2.6)	2 (2.4)	1 (3.2)	3 (4.9)	0	0	3 (4.7)	0	0	3 (3.2)	0
Neutral	4 (3.4)	4 (4.8)	0	2 (3.3)	2 (4.6)	2 (5.9)	2 (3.1)	0	0	4 (4.3)	0
Good	32 (27.4)	23 (27.7)	8 (25.8)	16 (26.2)	13 (29.6)	7 (20.6)	19 (29.7)	5 (50.0)	3 (16.7)	27 (29.0)	2 (100)
Excellent	58 (49.6)	36 (43.4)	20 (64.5)	29 (47.5)	22 (50.0)	19 (55.9)	28 (43.8)	5 (50.0)	11 (61.1)	43 (46.2)	0
N/A or no response	17 (14.5)	15 (18.1)	2 (6.4)	10 (16.4)	5 (11.4)	6 (17.6)	9 (14.1)	0	4 (22.2)	13 (14.0)	0
Quality of HIV non-medical support services											
Poor	0	0	0	0	0	0	0	0	0	0	0
Fair	4 (3.4)	2 (2.4)	1 (3.2)	3 (4.9)	1 (2.3)	0	4 (6.3)	0	0	4 (4.3)	0
Neutral	7 (6.0)	4 (4.8)	3 (9.7)	2 (3.3)	4 (9.1)	1 (2.9)	6 (9.4)	0	0	7 (7.5)	0
Good	26 (22.2)	20 (24.1)	6 (19.4)	13 (21.3)	10 (22.7)	5 (14.7)	15 (23.4)	5 (50.0)	3 (16.7)	21 (22.6)	2 (100)
Excellent	62 (53.0)	44 (53.0)	16 (51.6)	34 (55.7)	22 (50.0)	21 (61.8)	30 (46.9)	5 (50.0)	11 (61.1)	47 (50.5)	0
N/A or no response	18 (15.4)	13 (15.6)	5 (16.1)	9 (14.8)	7 (15.9)	7 (20.6)	9 (14.1)	0	4 (22.2)	14 (15.1)	0
Top valued services ¹											
Medical	59 (50.4)	45 (54.2)	13 (41.9)	34 (55.7)	22 (50.0)	14 (41.2)	38 (59.4)	4 (40.0)	4 (22.2)	53 (57.0)	1 (50.0)
Housing	35 (29.0)	25 (30.1)	8 (25.8)	14 (23.0)	17 (38.6)	12 (35.3)	15 (23.4)	5 (50.0)	4 (22.2)	29 (31.2)	1 (50.0)
Mental health	17 (14.5)	13 (15.7)	4 (12.9)	9 (14.8)	6 (13.6)	6 (17.7)	7 (10.9)	3 (30.0)	3 (16.7)	13 (14.0)	1 (50.0)
Prescription drugs	27 (23.1)	21 (25.3)	6 (19.4)	18 (29.5)	8 (18.2)	2 (5.9)	25 (39.1)	0	0	27 (29.0)	0
Transportation	24 (20.5)	18 (21.7)	6 (19.4)	11 (18.0)	12 (27.3)	12 (35.3)	7 (10.9)	3 (30.0)	9 (50.0)	12 (12.9)	1 (50.0)
Food	26 (22.2)	15 (18.1)	9 (29.0)	11 (18.0)	10 (22.7)	4 (11.8)	14 (21.9)	4 (40.0)	6 (33.3)	18 (19.4)	0
Job/job placement	5 (4.3)	5 (6.0)	0	0	4 (9.1)	2 (5.9)	1 (1.6)	1 (10.0)	1 (5.6)	4 (4.3)	0
Legal services	6 (5.1)	5 (6.0)	1 (3.2)	4 (6.6)	2 (4.6)	1 (2.9)	5 (7.8)	0	0	6 (6.5)	0
Emergency financial assistance (utilities)	10 (8.6)	9 (10.8)	1 (3.2)	5 (8.2)	5 (11.4)	6 (17.7)	3 (4.7)	0	4 (22.2)	6 (6.5)	0
Home health services	1 (0.9)	0	1 (3.2)	0	1 (2.3)	1 (2.9)	0	0	0	1 (1.1)	0
Substance use treatment	2 (1.7)	1 (1.2)	1 (3.2)	1 (1.6)	1 (2.3)	0	1 (1.6)	1 (10.0)	1 (5.6)	0	0
Independent living	3 (2.6)	2 (2.4)	1 (3.2)	2 (3.3)	1 (2.3)	2 (5.9)	1 (1.6)	0	0	3 (3.2)	0
Help with children/family	3 (2.6)	2 (2.4)	1 (3.2)	1 (1.6)	2 (4.6)	1 (2.9)	2 (3.1)	0	2 (11.1)	1 (1.1)	0

¹ Respondents were asked to rank their top two priorities for services needed in the region as a “1” and “2.” However, many respondents selected two options without denoting which one ranked higher, so this question was analyzed as if each person could choose two options without consideration of ranking.

Appendix C: Provider Interviews

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.

Print Name: _____

Signature: _____

Print Name: _____

Signature: _____

2020 Needs Assessment 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?