



HealthHIV's INAUGURAL NATIONAL SURVEY

STATE OF AGING WITH HIV™

POZITIVELY AGING

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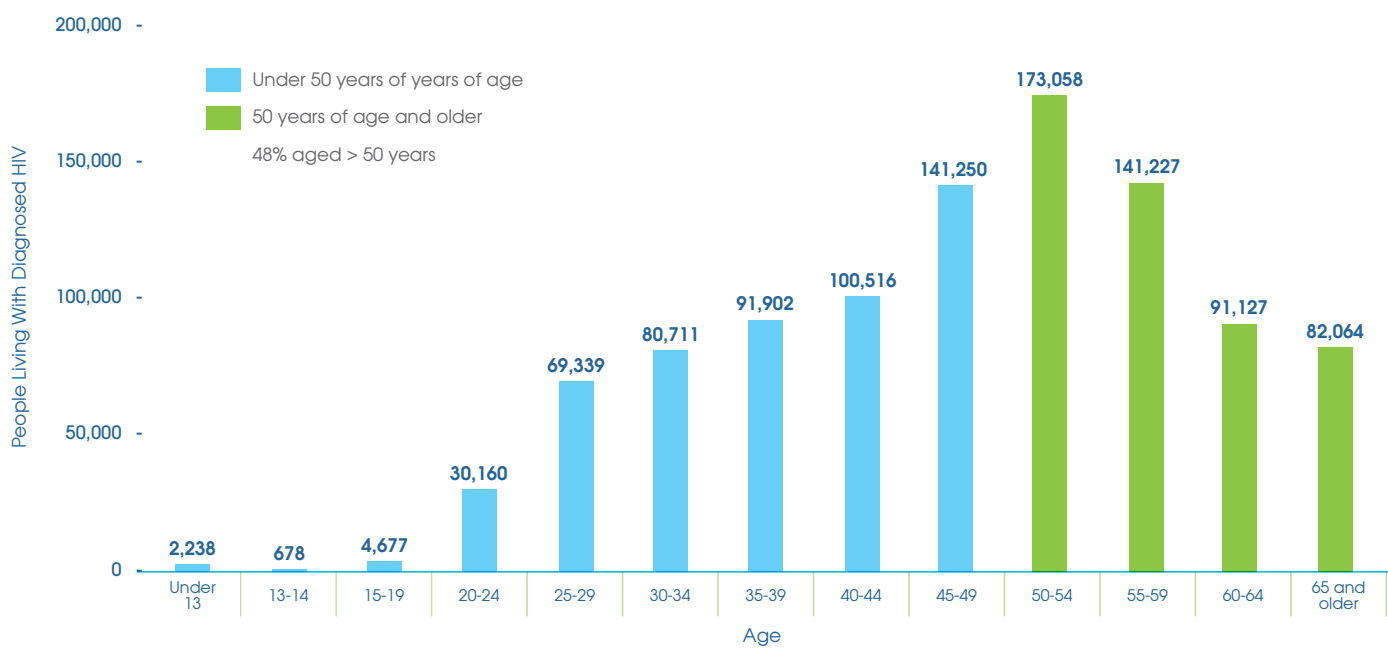
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NATIONAL SURVEY



Why Is This Survey Needed?



According to the CDC, **nearly half of the people with HIV (PWH) are 50 years of age or older**, and they face unique health challenges that are going unmet. **PWH over 50** are at the intersection of facing general challenges associated with aging while living with HIV, facing a number of **risk factors** for **comorbidities, mental health issues,** and social needs.

While medical providers are adept at addressing HIV or addressing people as they age, there is a greater need for **enhanced training** and **medical education** on how to **treat co-morbid conditions** associated with aging with HIV, and on the **cumulative impacts** of both co-morbid conditions and frailty. This **expanded training** will need to increase as more and more people age with HIV.

The number of people aging with HIV is **rapidly increasing**, and **care coordination** is vital in **maintaining optimal health**. The inaugural **HealthHIV State of Aging with HIV™** national survey was developed to **capture the experiences** and **assess the needs** of PWH over 50 and **better inform training needs** for providers as it relates to care coordination as part of HealthHIV’s Pozitively Aging program.

48%
of people with HIV (PWH) in the United States are 50 years or older



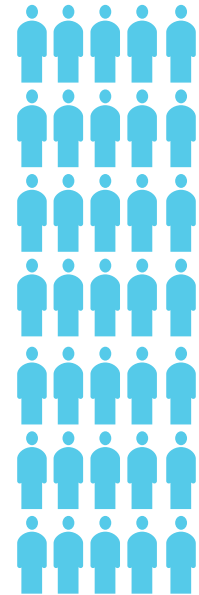
Methodology

HealthHIV developed the survey instrument with input from advocates and people who work with people with HIV (PWH) 50 years of age. The survey instrument consisted of **76 questions**, both qualitative and quantitative. The survey was distributed online using Survey Monkey™. HealthHIV recruited respondents through open invitations using targeted email lists and social media postings. The survey opened on July 16th, 2019 and data was collected through August 12th, 2019. The survey was a convenience sample and no incentive was provided for participation.

The survey garnered **1,086 total responses**. The survey included a qualification question **asking respondents if they were a person with HIV who is 50 years or older**. 160 respondents were disqualified from as they are under 50 years of age. Of the 931 respondents who qualified, 831 participated in the survey.

For the purposes of this survey and report, an HIV care provider is defined as the clinical provider who provides and supports the respondent with their HIV care and management. A primary care provider is the physician who provides the respondent their care for common medical problem, not HIV care.

1,086
total responses



The survey addressed the following topics:

HIV Management	Interactions with Providers	Care Coordination	Healthcare Expenses	Pharmacy Usage	Aspects of Living with HIV
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Overview of Key Findings



- Over half of the survey respondents **are living with at least one co-morbid condition** -- the most prevalent are depression, high cholesterol, hypertension, and neuropathy.

- People aging with HIV are **engaged in routine care**, with nearly all having seen a provider in the last year, and **three quarters having seen an HIV care provider in the last six months**.



- The majority of respondents **report feeling satisfied or very satisfied with their care coordination**. However, **dissatisfaction was much higher among respondents who had not been linked by their providers to government or community resources**, indicating a need for increased provider engagement.

- Respondents **report experiencing discrimination when seeking healthcare services** and over half report experiencing stigma, and approximately a quarter of respondents report experiencing ageism and/or homophobia.



- Nearly **all respondents have health insurance** and many are accessing services through Ryan White funded programs and utilizing their state's Aids Drug Assistance program (ADAP). However, over a quarter of **respondents cited cost of care as a barrier to seeking care**.

- The most **frequently cited barriers** to care are **cost of care**, lack of **transportation**, lack of **providers knowledgeable about HIV**, lack of convenient **appointment times**, and not being able to find a provider who **accepts their insurance**.



- Respondents **struggle with lack of social support and isolation**, with one third of respondents reporting not having any emotional support system, and almost half of participants care for themselves when they are sick or injured.



- Approximately **half of respondents use at least one substance on a daily basis**, with alcohol, tobacco and marijuana as the most frequently used substances. A quarter of respondents also indicated they are or have been in recovery for substance use.

- The majority of **respondents currently have stable housing**, with 90% living in a house or apartment that they have owned or rented for at least one year.



Demographics

Race

60%
White

21%
Black or African American

12%
Latino

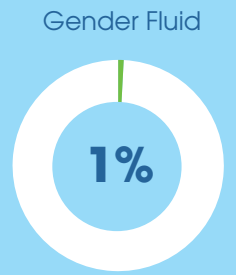
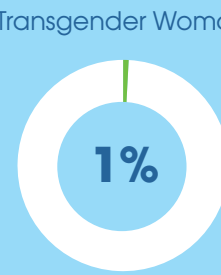
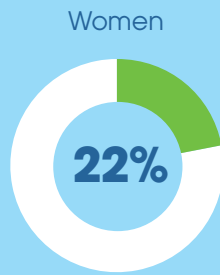
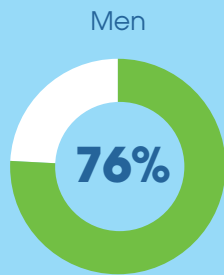
.02%
Asian or Asian American

1%
American Indian or Alaska Native

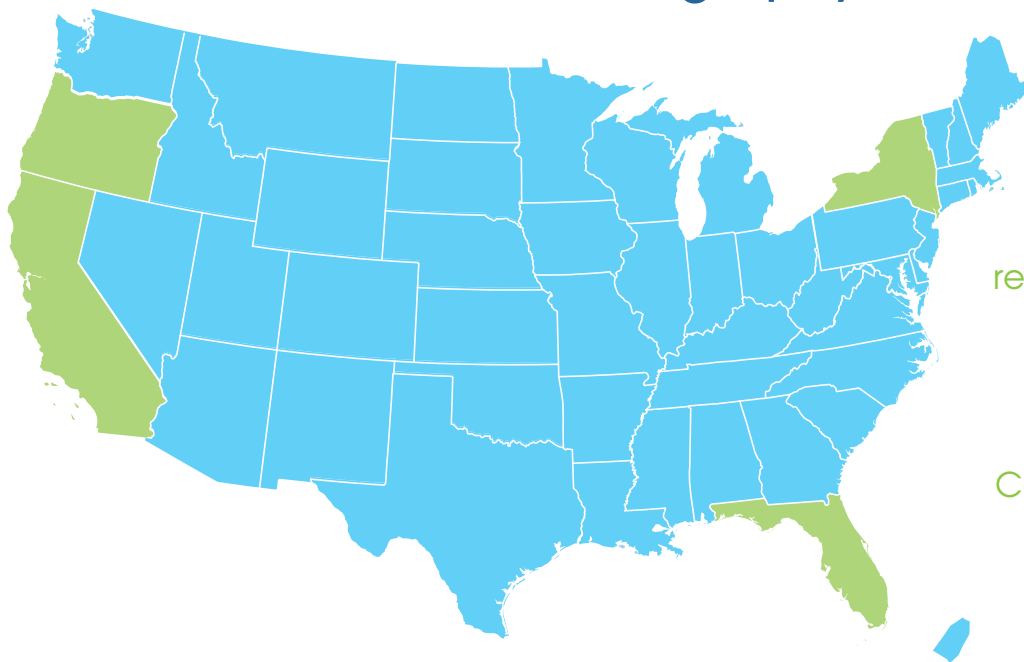
.02%
Native Hawaiian or Pacific Islander

6%
Multi Racial

Gender

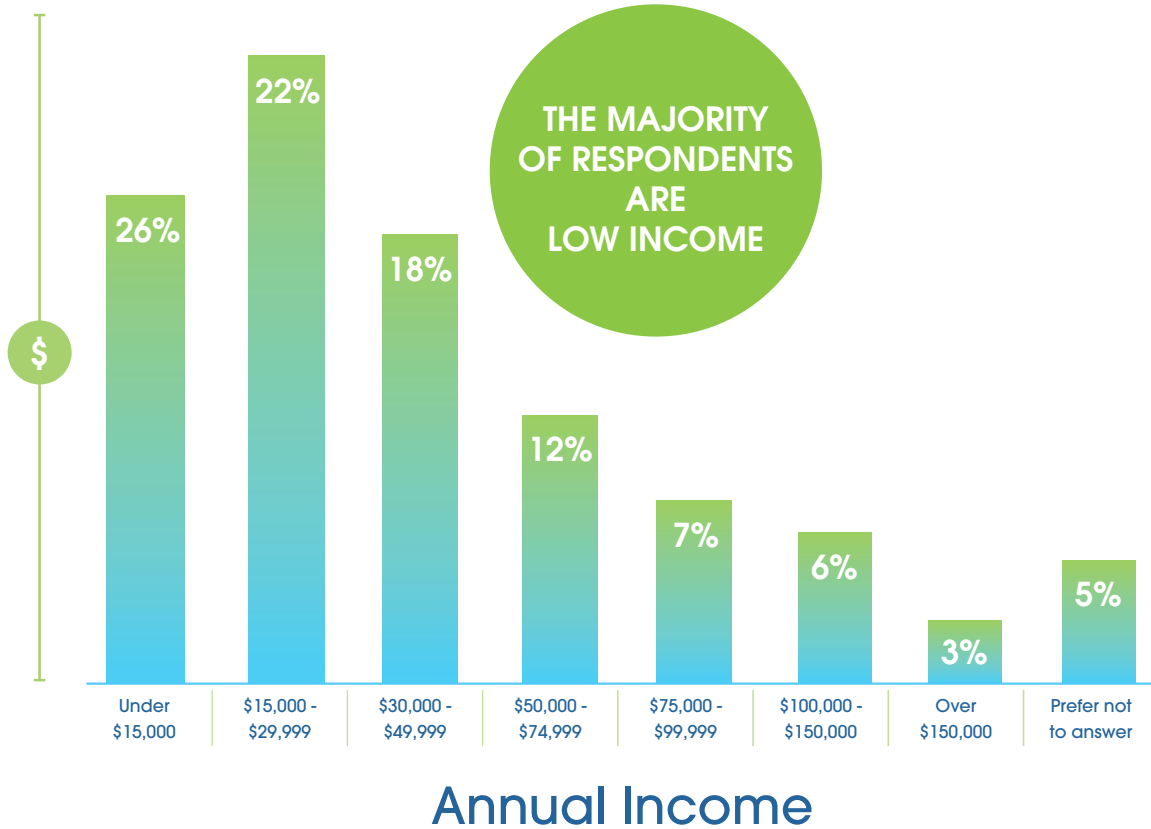


Geography

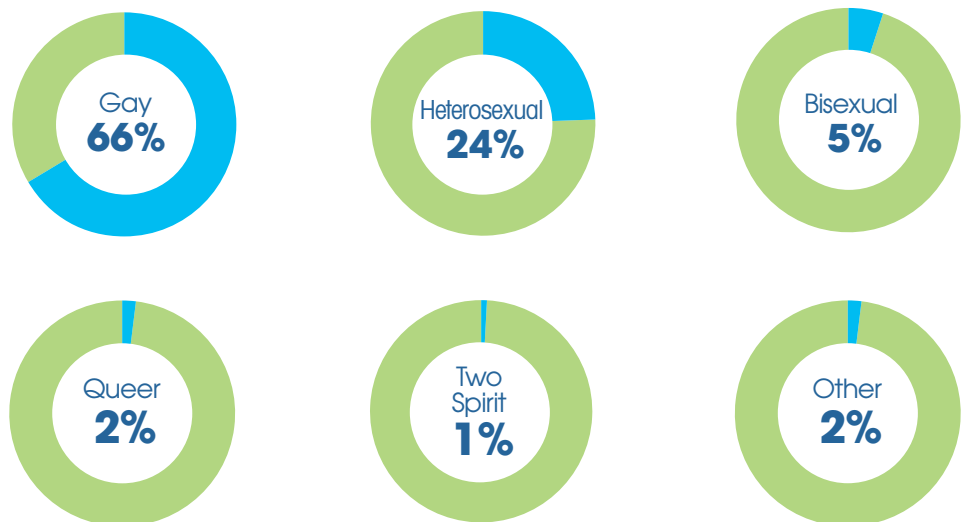


The respondents represented **39 U.S. states and Puerto Rico**. The highest response rates came from California, Florida, Oregon and New York.

Demographics

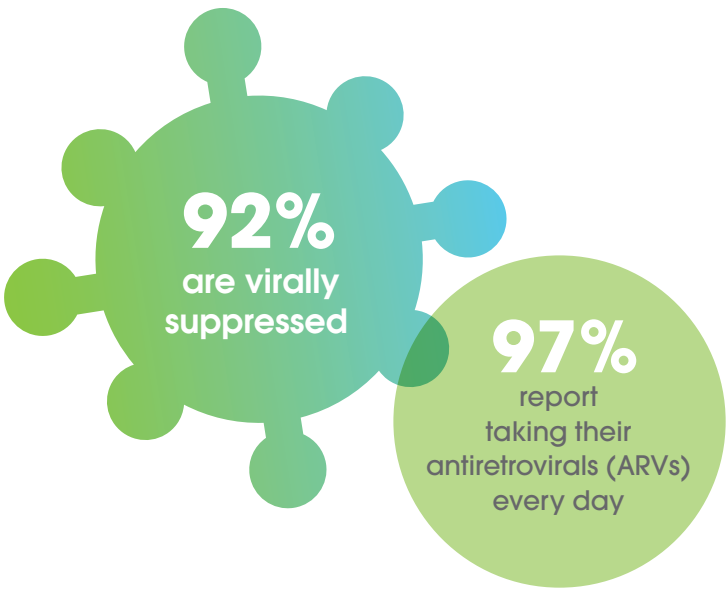


Sexual Orientation



HIV Management

This cohort is overwhelmingly virally suppressed and adherent to medication, demonstrating consistent retention in care and access to antiretroviral therapy (ART). Over half of the cohort is living with at least one comorbid condition, necessitating multiple medication prescriptions and providers. One of the most common comorbid conditions is depression, which is indicative of a need for greater referrals to psychosocial support services.



58% were concerned that their memory had worsened in the past few years

- **72%** of respondents have said their HIV care provider has not asked them about any issues related to memory loss



60% have received an AIDS diagnosis (AIDS-defining condition or having a CD4 count less than 200)

Over 50% have at least one comorbid condition:



- **56%** have high cholesterol
- **51%** have high blood pressure/hypertension
- **45%** have neuropathy

36% have developed a resistance to an HIV medication that caused their doctor to change their medication



Respondents also experienced complications related to chronic inflammation

- **55%** have joint or back pain

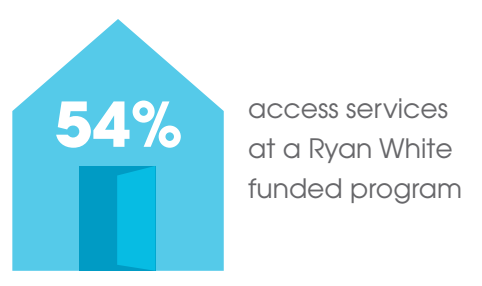
19% have been diagnosed or treated for a sexually transmitted infection (STI) over the last 12 months



Interaction with Providers

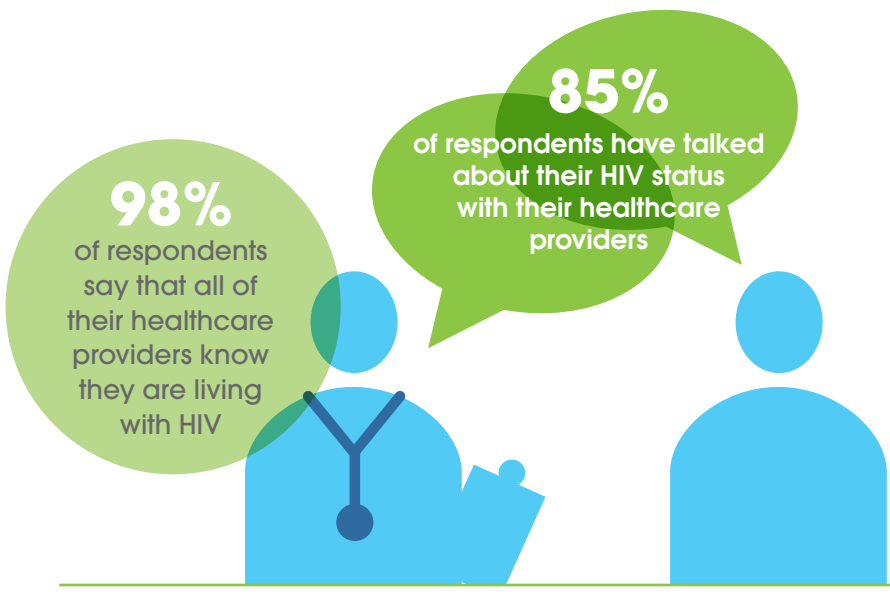
This cohort is actively engaging with their providers, as 76% have seen an HIV care provider within the last six months, and 99% have seen an HIV care provider at least once in the last 12 months. This cohort has high rates of satisfaction with their provider’s care coordination, as 85% report feeling satisfied or very satisfied with their care coordination. Despite rates of high satisfaction, 50% of respondents report facing stigma when seeking healthcare, 25% report facing ageism, and 24% report facing homophobia.

Over half of respondents indicated that their primary care provider and HIV care provider are the same person. Finding revealed statistically significant differences in the rates of medication prescription for multiple conditions among this group in comparison to individuals who have separate primary care and HIV care providers.



Interaction with Providers

62% of respondents stated that their HIV care provider and primary care provider are the same person. These respondents were less likely to be prescribed medication for their comorbid conditions, with the most stark differences found in **type 2 diabetes, asthma, and kidney disease**.



Over half (**53%**) of respondents said they felt very **satisfied with their providers coordination of care**

- **32%** are satisfied
- **4%** are dissatisfied
- **2%** are completely dissatisfied

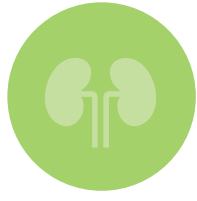


Respondents indicated facing **stigma (52%), ageism (26%), and homophobia (25%)** in a healthcare setting



Of patients with **type 2 diabetes** who identified their HIV Care Providers as their PCPs, only **10% receive medications** for their **type 2 Diabetes**

- Of the patients who did not identify HIV Care Providers as their PCPs, **16% received medication** for their **type 2 Diabetes**



Of patients with **Kidney Disease** who identified their HIV Care Providers as their PCPs, only **2% received medication** for **Kidney Disease**

- Of the patients who did not identify HIV Care Providers as their PCPs, **8% received medications** for **Kidney Disease**



Of patients with **Asthma** who identified their HIV Care Providers as their PCPs, only **10% received medication** for their **Asthma**

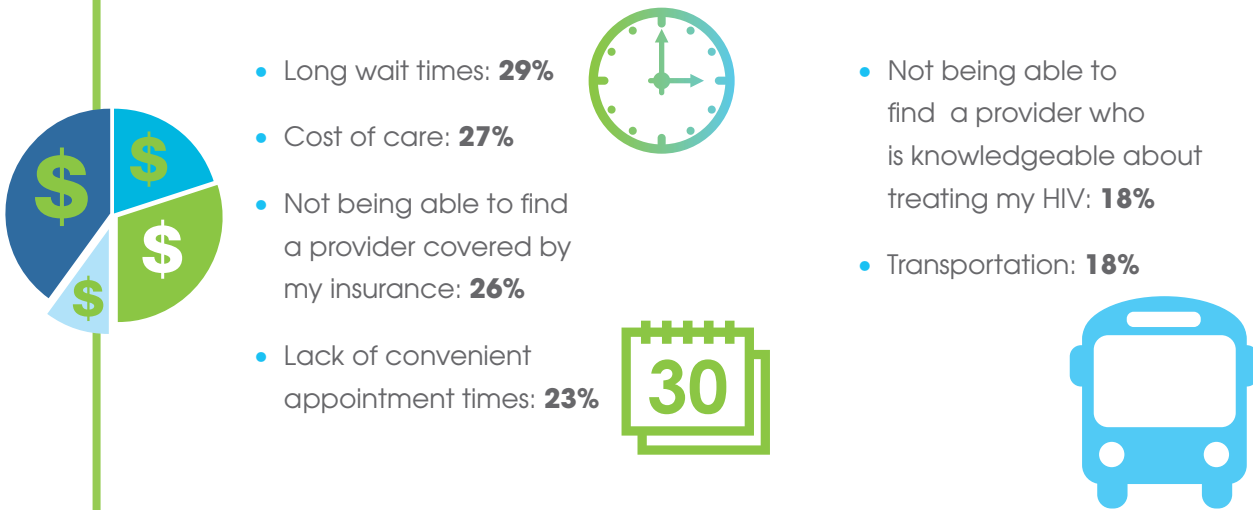
- Of the patients who did not identify HIV Care Providers as their PCPs, **17% received medications** for their **Asthma**

Care Coordination

Respondents indicated that they experienced both environmental and logistical barriers when seeking and receiving care. These barriers range from experiencing discrimination as a consequence of their intersectional identities to encountering structural challenges, such as not having transportation or being unable to access providers due to insurance restrictions.

In looking at acquisition of community based resources, those who had providers who referred them to non-clinical, community-based resources felt more satisfied with their care than those who were not referred to resources, indicating that there may be a need for providers to build Relationships with community based organizations. Further, nearly 50% of respondents indicated that they take care of themselves when they are sick or injured.

Respondents reported the following barriers when seeking care:



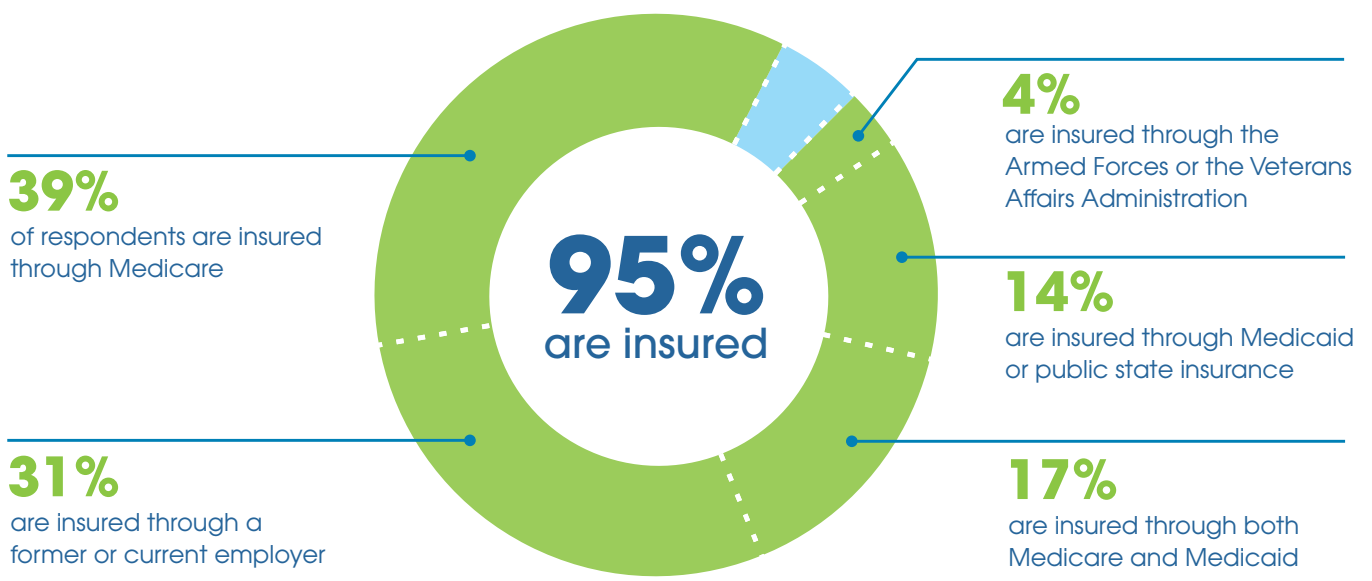
Respondents who were never connected to state or community resources by their provider were significantly more likely to be dissatisfied or very dissatisfied with their care coordination



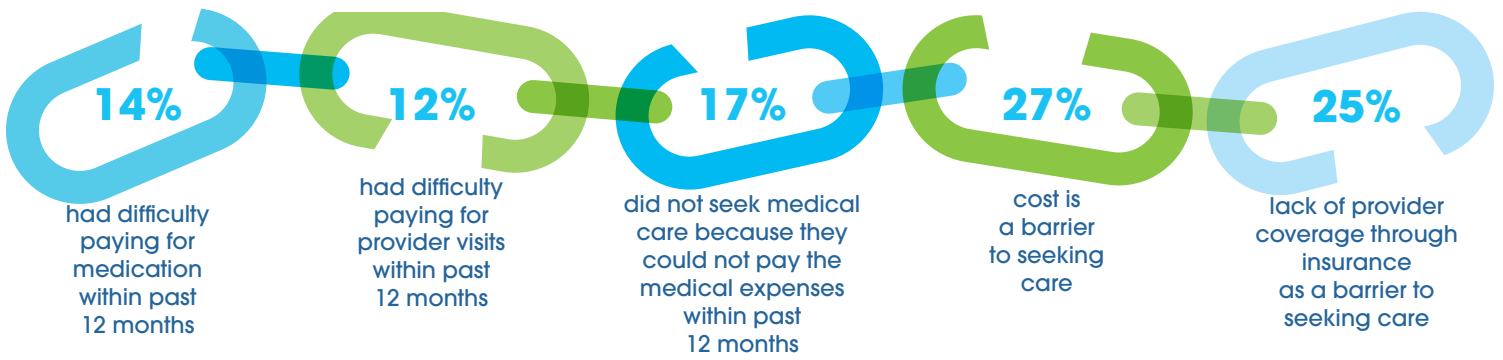
- **36%** of respondents indicated that their provider had never connected them state or community resources

Healthcare Expenses

While nearly 100% of respondents have health insurance, many had issues paying for services. One of the most commonly cited barriers to not seeking care was not being able to find a provider who is covered by insurance, demonstrating that health insurance coverage is insufficient for many older adults with HIV.

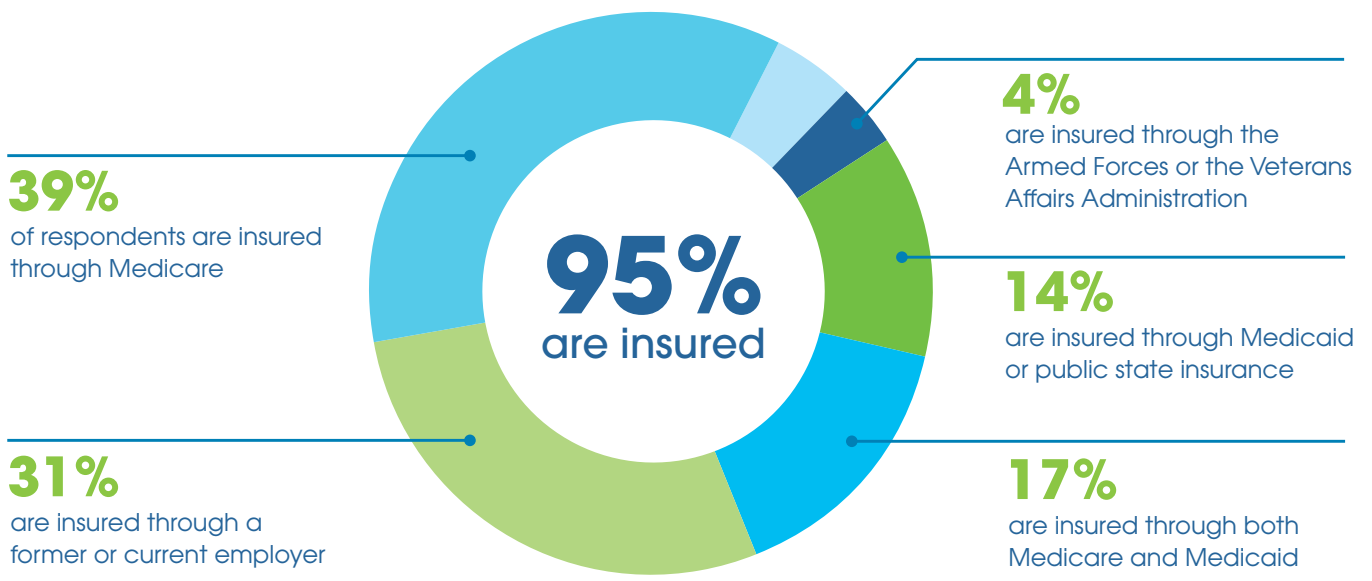


35%
of respondents access their HIV medications through their state's AIDS Drugs Assistance Program

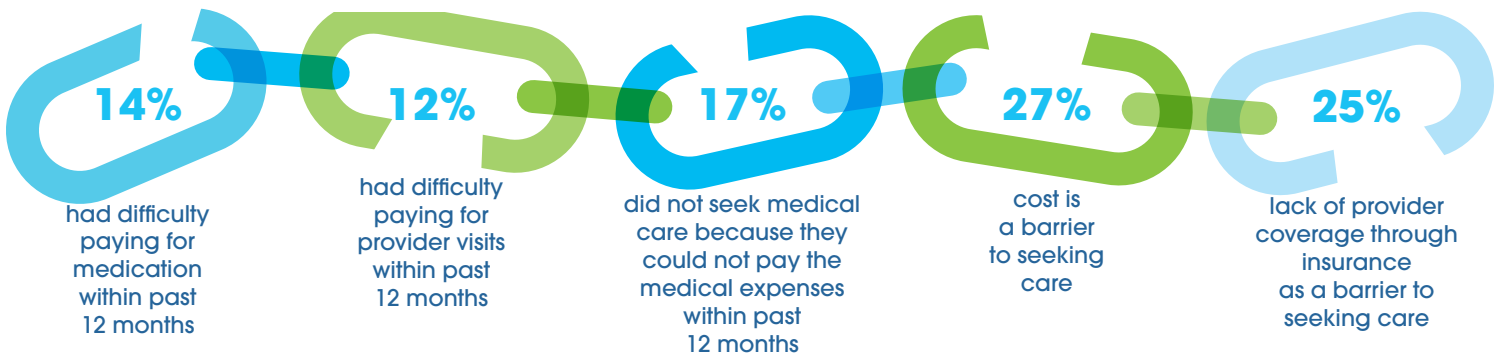


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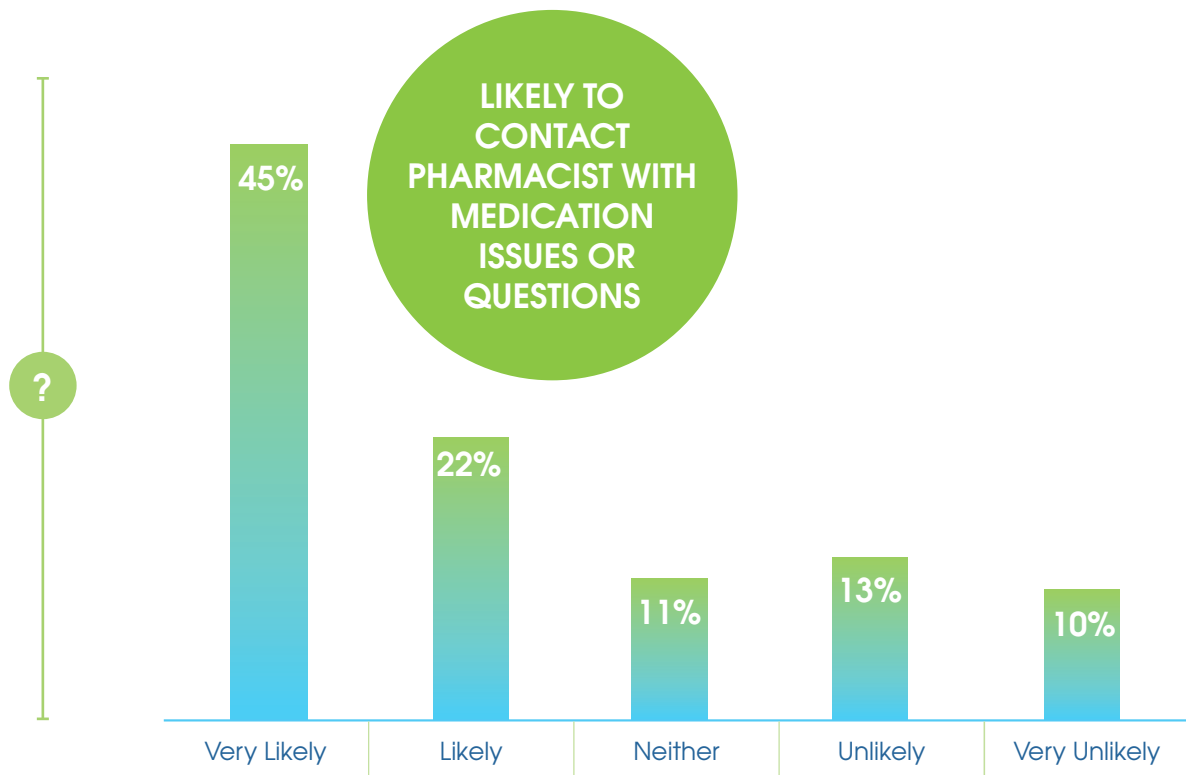


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Pharmacy Usage

The majority of respondents consider their pharmacist to be an important part of their care team, citing a high likelihood of contacting a pharmacist as a resource for medication counseling.



Number of pharmacies used



Aspects of Living with HIV

This cohort has similar needs to general aging population, such as lack of consistent emotional support and help with daily activities, but these needs are often exacerbated by living with HIV. In general, those aging with HIV face higher rates of depression and mental health issues than their HIV-negative counterparts due to higher rates of isolation, lack of familial support, and lack of social support--30% of respondents indicated that they do not have an emotional support system.

56%

have been diagnosed with depression

31%

have been diagnosed with a mental health issue



27%

have been diagnosed with Post Traumatic Stress Disorder

46%

felt down or depressed

39%

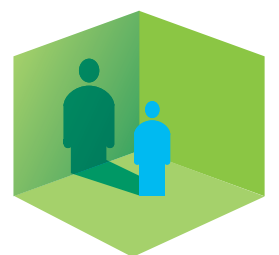
felt lonely or isolated

39%

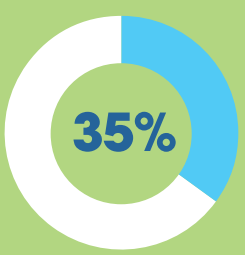
felt lonely or isolated within two weeks of taking the survey

25%

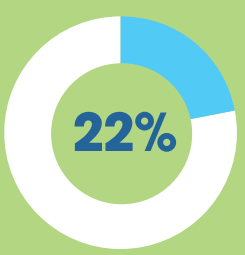
went 24 hours without interacting with another person.



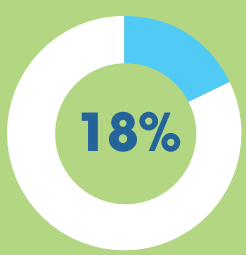
Almost half of the participants said they take care of themselves when they are sick or injured



have a spouse or domestic partner take care of them



have a family member take care of them



have a friend take care of them

Substance Use

23%

use alcohol daily



42%

use tobacco daily



50%

use marijuana daily



4%

use poppers daily

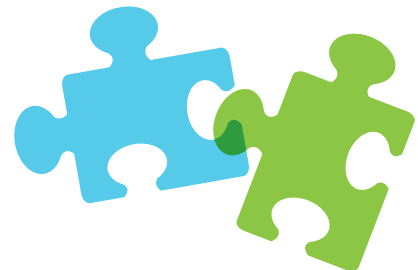


ONE IN FOUR

indicated that they either are or have been in recovery from alcohol/substance use

Implications Moving Forward

- Further research is needed to explore and better understand the relationship between aging with HIV and mental health.
- Focusing on improved patient-provider interactions can positively impact mental health, since higher rates of satisfaction with healthcare providers results in lower rates of feelings of depression and isolation.
- Social support systems are needed to foster more socialization and connection among people aging with HIV.
- Care providers would benefit significantly from education on the intersection of ageism, stigma and homophobia and their impact on health outcomes.
- Providers need to address memory issues more frequently, considering significant patient concern about memory loss.
- Care coordination efforts should involve building connections between primary care providers and HIV care providers to comprehensively address the health needs of people aging with HIV.
- The patient experience can be improved through increased provider engagement, including increased referrals and enhanced connections to outside resources.





**NOTE:
WE HAVE AN EXTRA PAGE
IS THERE ANYTHING YOU WAN
TO PUT HERE?**

HealthHIV's POZITIVELY AGING

A PART OF



HealthHIV's Pozitively Aging program seeks to improve access to services and care coordination for people with HIV (PWH) over 50. Health outcomes can be improved and sustained for PWH over 50 by enhancing care coordination/access, health literacy, and patient-provider communications. This program seeks to enhance provider knowledge related to the experiences of PWH over 50 and the co-management of conditions associated with aging with HIV through data collection and medical education. Additionally, Pozitively Aging will offer consumer education materials to strengthen self-management of care and health literacy.

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