



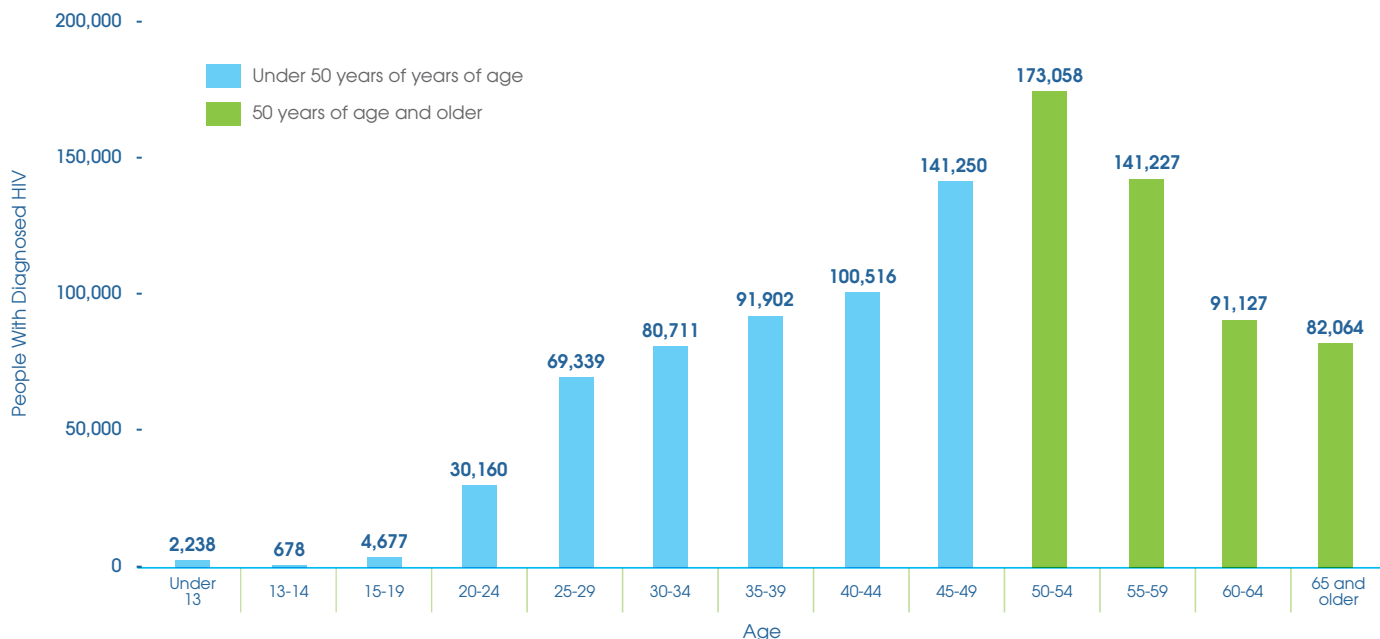
HealthHIV's INAUGURAL

# STATE OF AGING WITH HIV<sup>TM</sup>

NATIONAL SURVEY

[www.healthhiv.org/positivelyaging](http://www.healthhiv.org/positivelyaging)

## 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 often 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 comorbid conditions** associated with aging with HIV. This **expanded training** will need to increase as 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

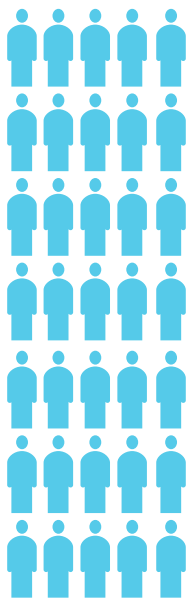
## Methodology

The survey instrument consisted of **76 qualitative and quantitative questions**, which were distributed online using Survey Monkey™. The survey data was collected from July 16th, 2019 to August 12th, 2019 through convenience sampling. No incentive was provided for participation.

The survey garnered **1,086 total responses** and included a qualification question **asking respondents if they were a person with HIV who is 50 years or older**. 160 respondents were disqualified, as they were 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 (PCP) is the physician who provides the respondent their care for common medical problems, but 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

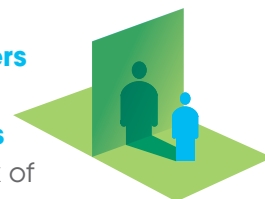


- Over half of the survey respondents **are living with at least one comorbid condition** -- the most prevalent are depression, high cholesterol, hypertension, and neuropathy.
- People aging with HIV are **engaged in routine care**, with nearly all having seen a provider in the last year, and **three 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**. 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 the respondent's insurance**.



- Respondents **struggle with lack of social support and isolation**. One third of respondents report 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 from substance use.

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

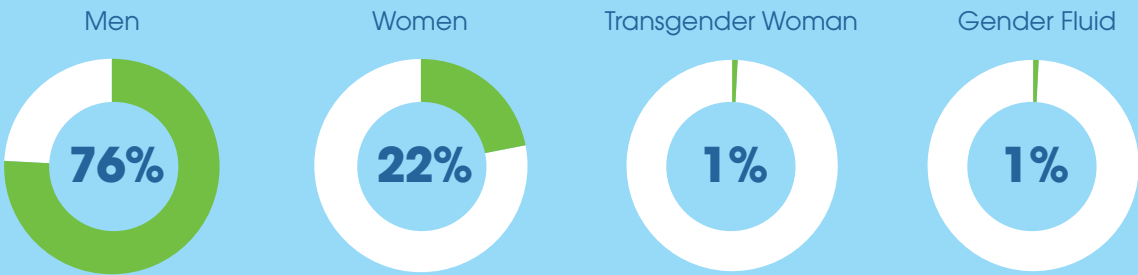


## Demographics

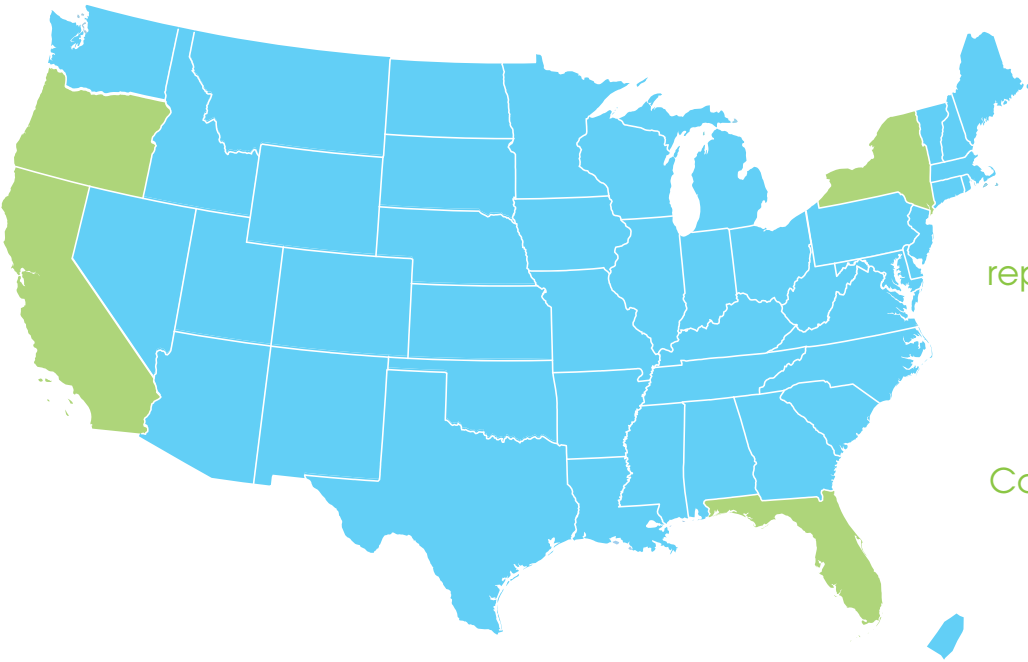
### Race



### Gender

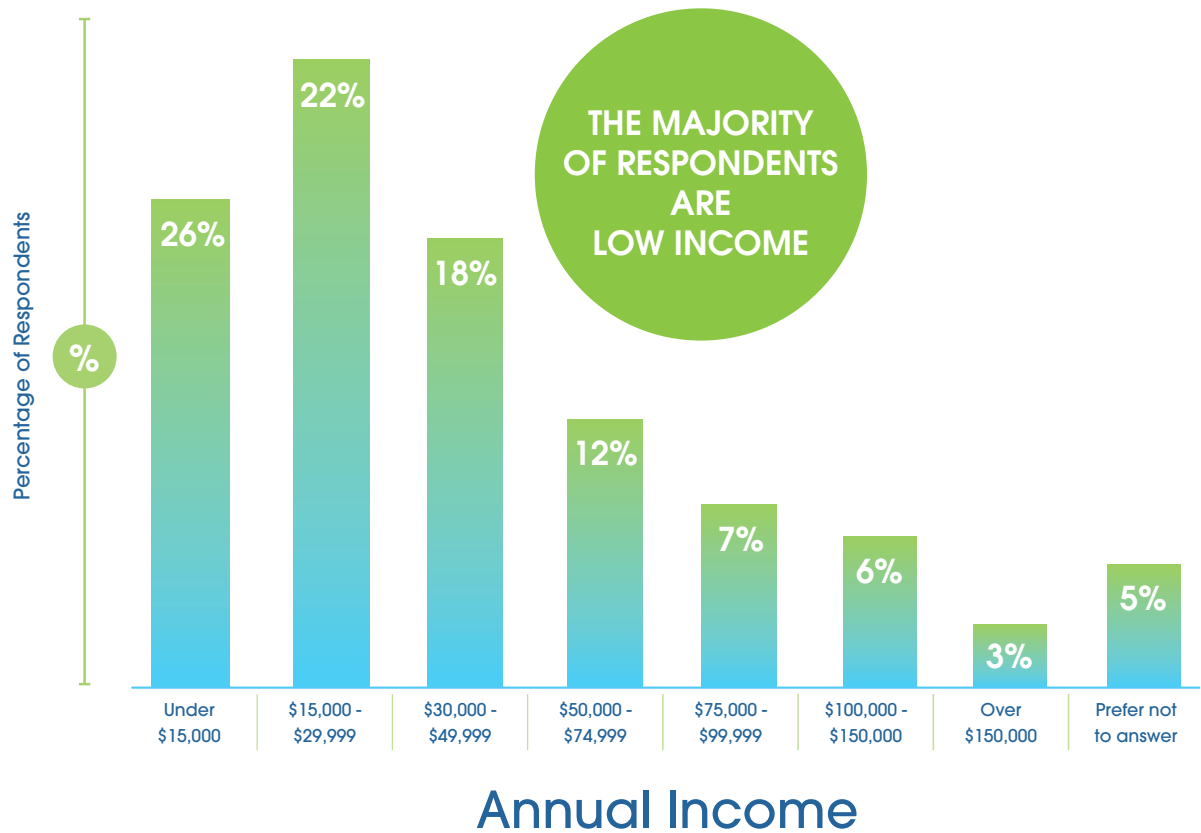


### Geography

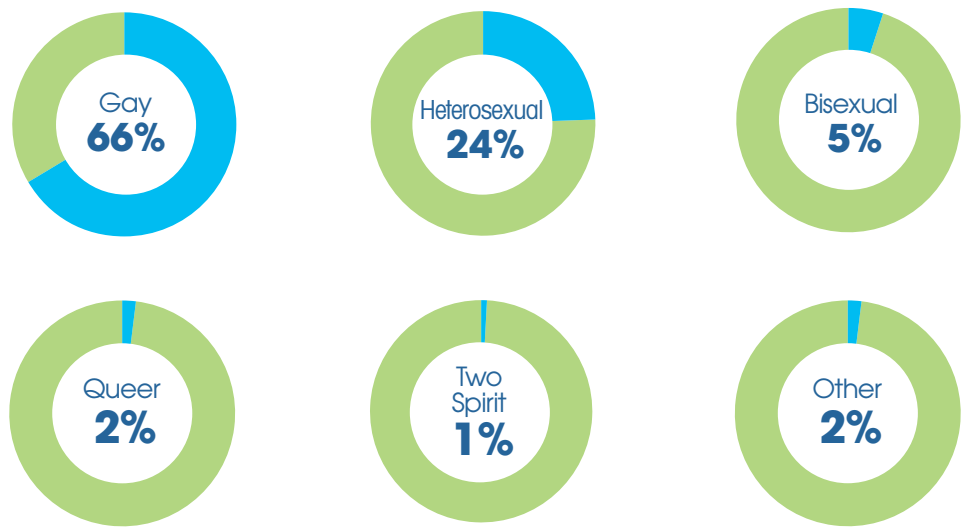


The respondents represented **39 U.S. states and Puerto Rico**. The highest response rates came from California, Florida, Oregon and New York.

## 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.

**92%**  
are virally  
suppressed

**97%**  
report  
taking their  
antiretrovirals (ARVs)  
every day

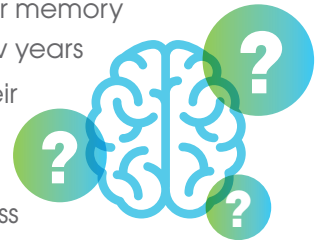
**Over 50%** have at least one comorbid condition:

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



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

- **72%** of respondents say 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)

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



Respondents also experience complications related to chronic inflammation

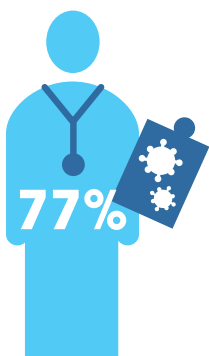
- **55%** have joint or back pain



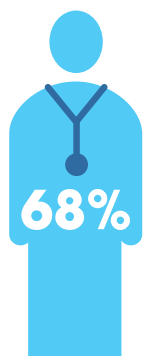
**19%** have been diagnosed or treated for a sexually transmitted infection (STI) over the last 12 months

## Interaction with Providers

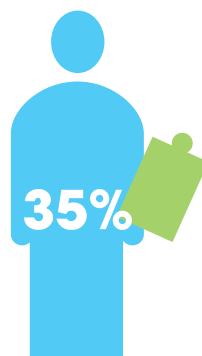
This cohort is actively engaging with their providers, as 77% had seen an HIV care provider within the last six months, and 99% have seen an HIV care provider at least once in the last 12 months. This cohort has high rates of satisfaction with their provider's care coordination, as 85% report feeling 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.



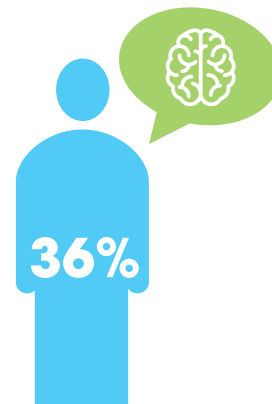
Had seen a HIV care provider in the last six months



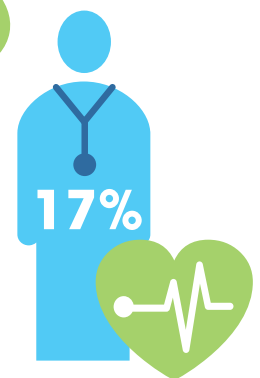
Had seen a primary care provider in the last six months



Had seen a case manager in the last six months



Had seen a mental health provider in the last six months

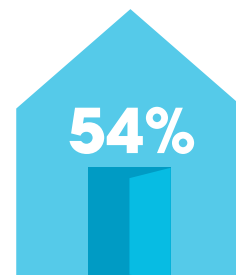


Had seen a cardiologist in the last six months



have seen their HIV care provider at least once during the past 12 months

- 8% had seen once
- 35% had seen twice
- 55% had seen more than three times



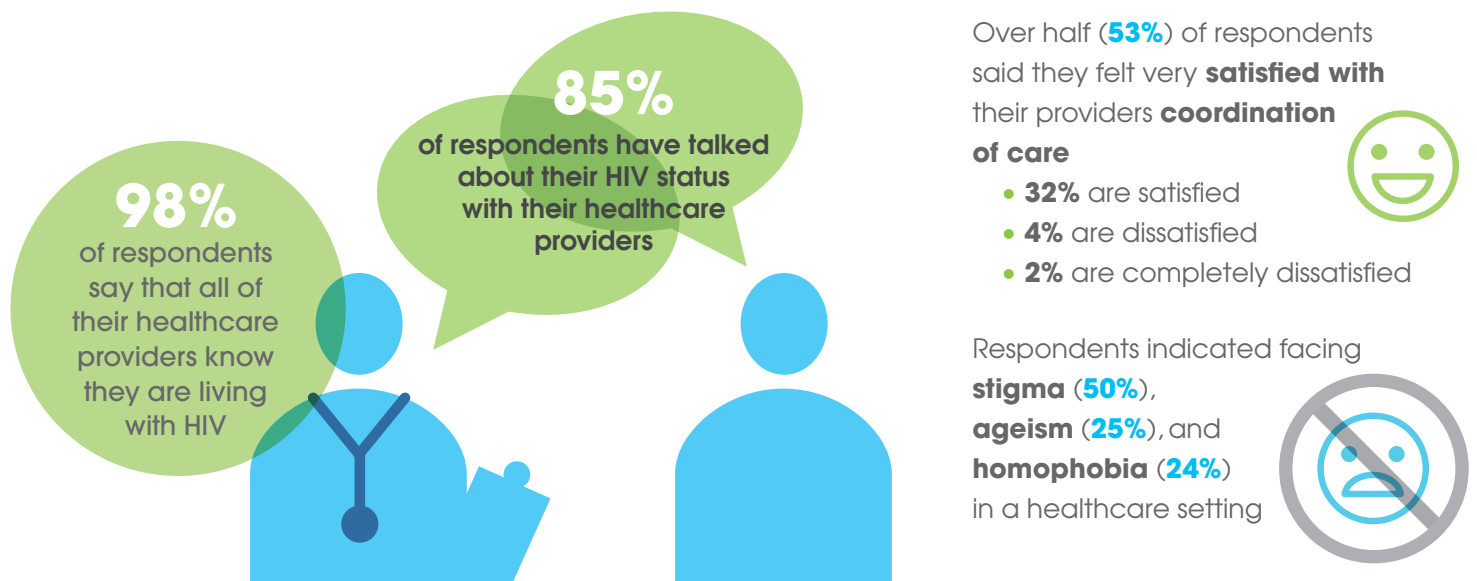
access services at a Ryan White funded program



## Interaction with Providers

Sixty-two percent (**62%**) of respondents stated that their primary care provider and HIV 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**.

Findings reveal 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.



Patients with **type 2 diabetes** who identified their HIV Care Provider as their PCP, only **10% receive medication** for their **type 2 diabetes**

- Patients who did not identify their HIV Care Provider as their PCP, **16% received medication** for their **type 2 diabetes**



Patients with **kidney disease** who identified their HIV Care Provider as their PCP, only **2% received medication** for **kidney disease**

- Patients who did not identify their HIV Care Provider as their PCP, **8% received medication** for **kidney disease**



Patients with **asthma** who identified their HIV Care Provider as their PCP, only **10% received medication** for their **asthma**

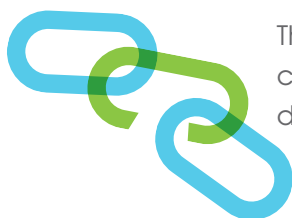
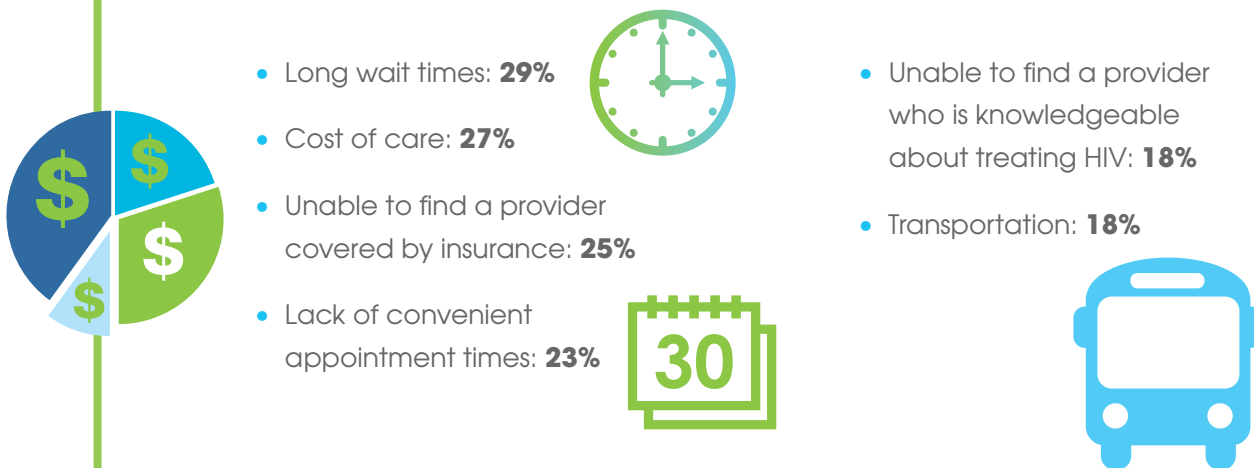
- Patients who did not identify their HIV Care Provider as their PCP, **17% received medication** for their **asthma**

## Care Coordination

Respondents indicate that they experience 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. Nearly 50% of respondents indicated that they take care of themselves when they are sick or injured.

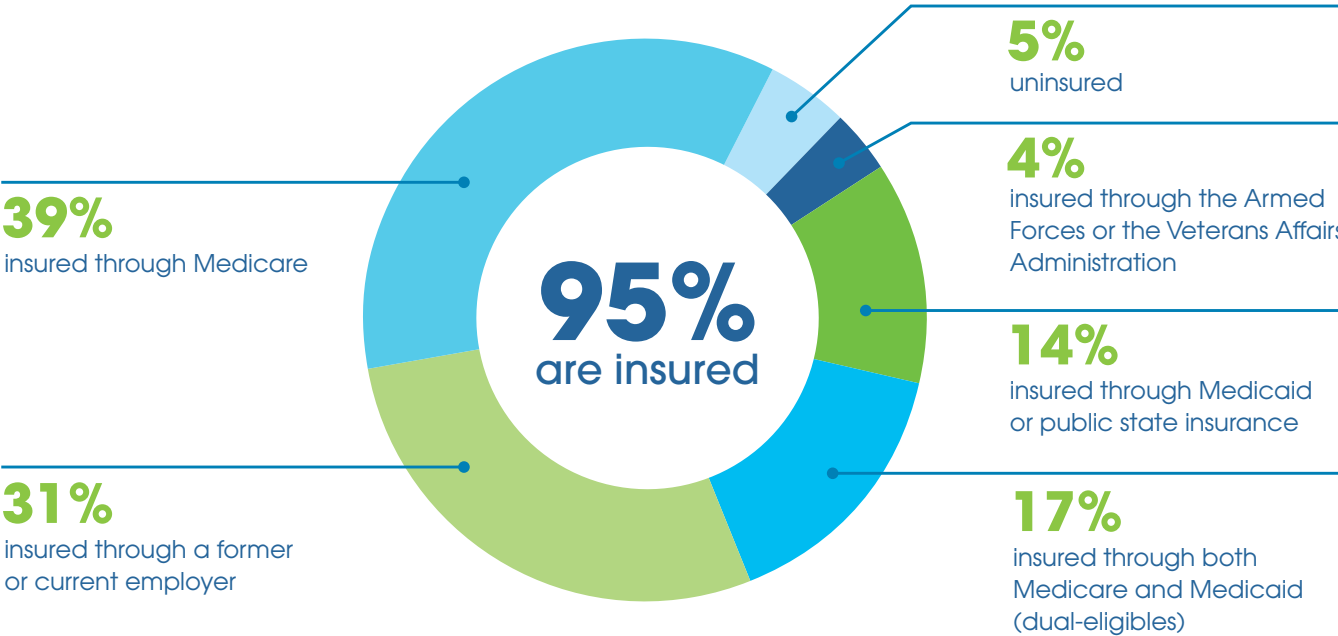
### Respondents reported the following barriers when seeking care:



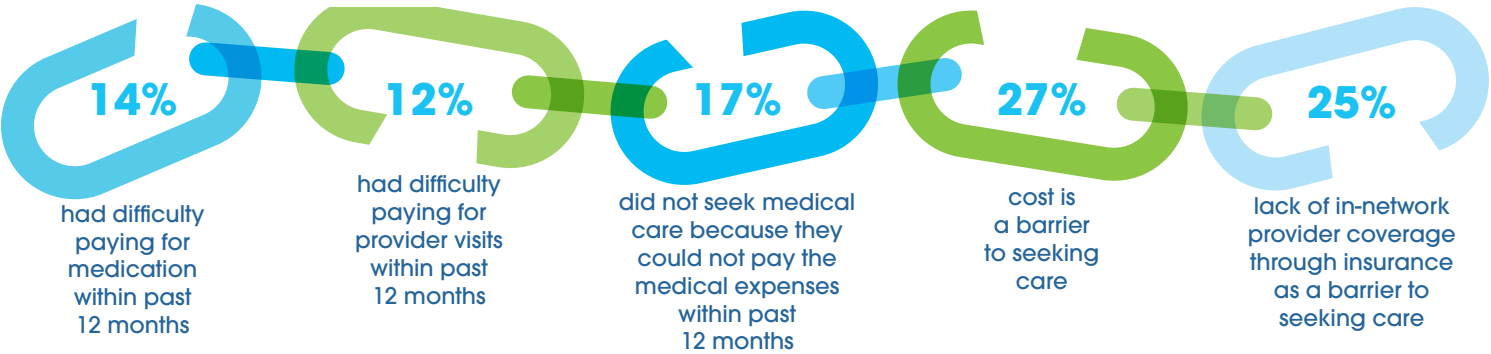
Thirty-six percent (**36%**) of respondents were never connected to government or community resources by their provider and were significantly more likely to be dissatisfied or very dissatisfied with their care coordination

## Healthcare Expenses

Ninety-five percent (**95%**) of respondents have health insurance, though many report 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 the respondent’s insurance, demonstrating that in-network provider coverage is insufficient for many older adults with HIV.

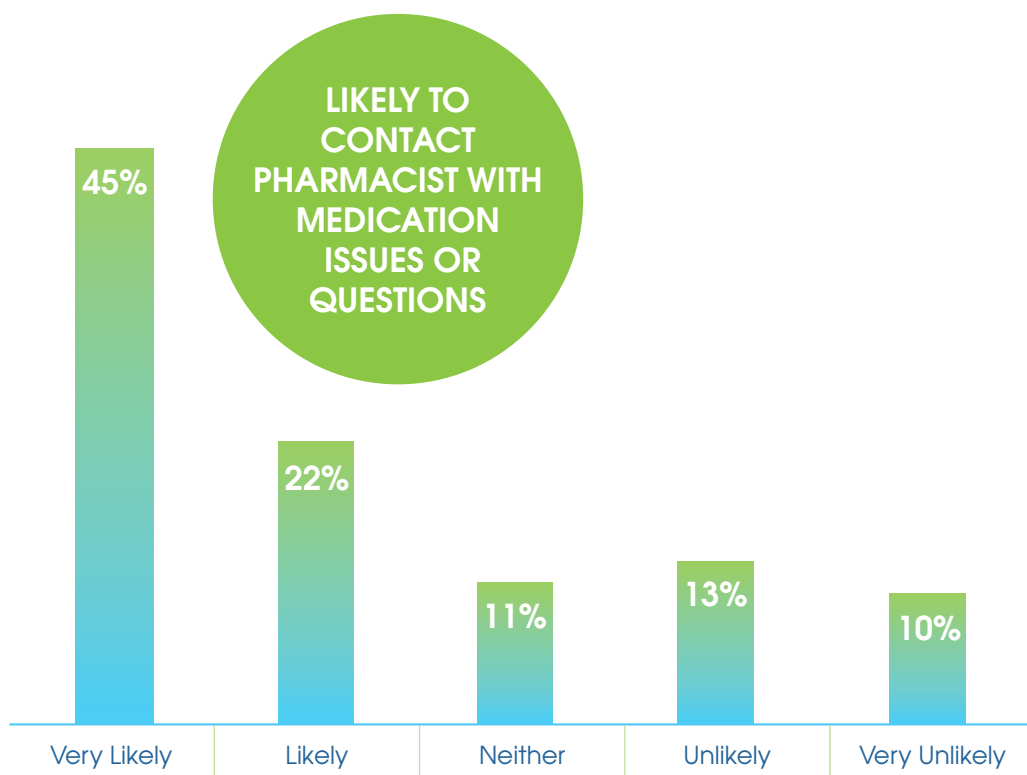


**35%**  
access their HIV medications through their state’s AIDS Drugs Assistance Program (ADAP)



## Pharmacy Usage

The majority of respondents consider their pharmacist to be an important part of their care team, and are likely to contact their pharmacist for medication counseling.



### Number of pharmacies used by respondents



## Aspects of Living with HIV

This cohort has similar needs to the general aging population, such as a lack of consistent emotional support and help with daily activities. 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, other than depression



**27%**

have been diagnosed with Post Traumatic Stress Disorder

**46%**

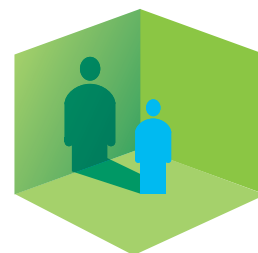
felt down or depressed

**39%**

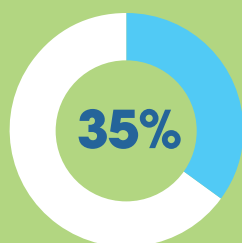
felt lonely or isolated within two weeks prior to taking the survey

**25%**

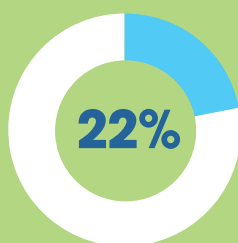
went 24 hours without interacting with another person



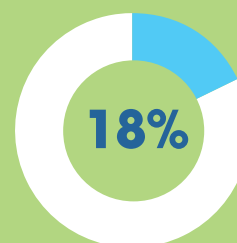
A quarter (**25%**) of the participants say they have no one to take care of them when they are sick or injured.



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

## Daily Substance Use

**23%**

use alcohol



**42%**

use tobacco



**50%**

use marijuana



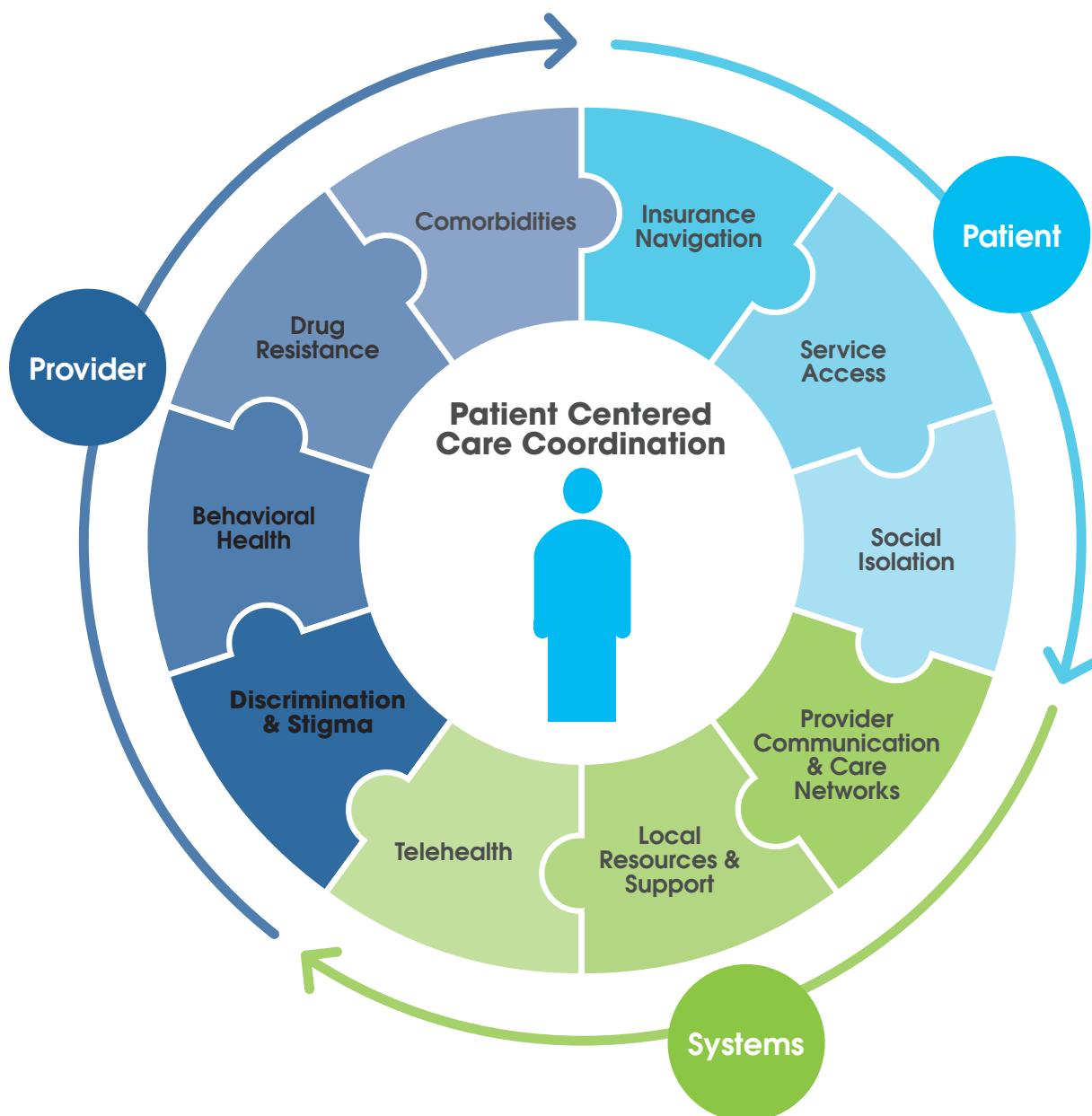
**4%**

use poppers



**ONE IN FOUR**  
have been in recovery from alcohol/substance use

# Implications on Patient Centered Care Coordination for those Aging with HIV



## Provider Implications

### Discrimination & Stigma

- Discrimination, stigma, ageism, and homophobia continue to impact service provision and outcomes; thus, a systems approach is necessary to address these issues.



### Behavioral Health

- To address significant concerns around social isolation and depression, clinical assessments should be routinely implemented to assess loneliness and isolation with appropriate referrals to social support services.
- High rates of daily tobacco and substance use inhibit optimal health outcomes. Providers need training on assessing and managing mental health and substance use in their aging patients with HIV.



### Drug Resistance

- Patients experiencing treatment-resistance need comprehensive assessment and treatment to achieve viral suppression; requiring expanded provider and patient education to identify treatment resistance and options.



### Comorbidities

- Clinicians providing both primary care and HIV care are less likely to prescribe or treat comorbid conditions beyond HIV. Providers need clinical training to address comorbid conditions as part of whole patient care.



## Patient Implications

### Insurance Navigation

- Patient education on insurance navigation may bolster access to medications, services, and in-network providers.



### Service Access

- Long wait times, lack of convenient appointment times, and transportation challenges remain significant barriers to care for patients aging with HIV.



### Social Isolation

- Patient engagement and provider relationship positively impact mental health and satisfaction of care coordination. Higher rates of satisfaction with healthcare providers result in decreased reports of depression and isolation.





## Systems Implications

### Provider Communication & Care Networks

- Building strong communication and coordination networks between primary care providers and HIV care providers is necessary to comprehensively address the health needs of people aging with HIV.



### Local Resources & Support

- To improve patient satisfaction with care coordination, providers require training on identifying and actively referring patients to local resources and support services to enhance care and health outcomes.



### Telehealth

- Clinics and healthcare providers should conduct comprehensive workflow assessments to streamline patient flow; including implementation of expanded treatment modalities such as telehealth.



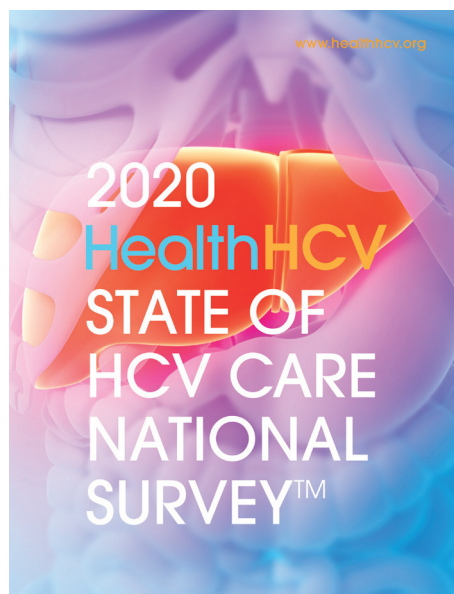
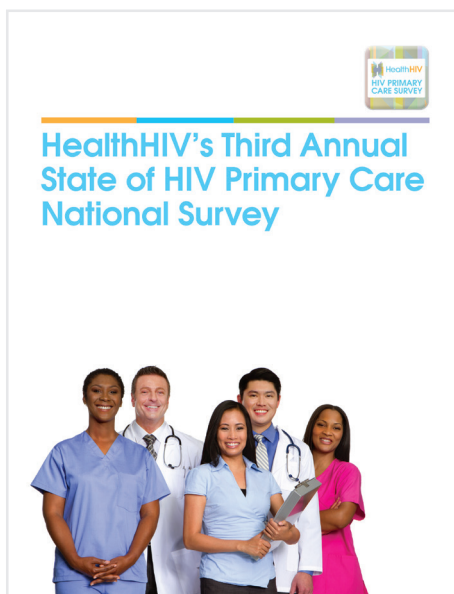


## About HealthHIV's Health Services Research

**HealthHIV** is known for its "State of" research in HIV and Hepatitis C prevention, care, and treatment, as well as in LGBT and STI health. HealthHIV's health services research uses original, distinct data analysis and evaluation methods.

The "State of" surveys are:

- The 4th Annual HIV Primary Care National Survey™
- The 2nd Annual HealthHCV State of HCV Care National Survey™
- The 2nd Annual HealthHIV State of ASOs/CBOs National Survey™
- The Inaugural HealthHIV State of Aging with HIV National Survey™
- The State of LGBT Health National Survey™ - Upcoming





## Glossary

**AIDS Drug Assistance Program (ADAP) (n.):** A state and territory-administered program authorized under Part B of the Ryan White HIV/AIDS Program – funded through HRSA. ADAP provides FDA-approved medications to low-income people living with HIV who have limited or no health coverage from private insurance, Medicaid, or Medicare.<sup>1</sup>

**Ageism (n.):** Stereotyping, prejudice, and discrimination against people on the basis of their age.<sup>2</sup>

**Bisexual (adj.):** A sexual orientation that describes a person who is emotionally and sexually attracted to people of their own gender and people of other genders.<sup>3</sup>

**Dual-eligible (n.):** Individuals who are eligible for both Medicare and Medicaid.<sup>4</sup>

**Comorbid, comorbidity (n.):** The simultaneous presence of two chronic diseases or conditions in a patient.<sup>5</sup>

**Genderqueer (adj.):** Describes a person whose gender identity falls outside of the traditional gender binary structure. Other terms for people whose gender identity falls outside the traditional gender binary include gender variant, gender expansive, etc.<sup>6</sup>

**Homophobia (n.):** Irrational fear of, aversion to, or discrimination against homosexuality or homosexuals (or those perceived as such).<sup>7</sup>

**Social Isolation (n.):** A state in which the individual lacks a sense of belonging socially, lacks engagement with others, has a minimal number of social contacts and, they are deficient in fulfilling, quality relationships.<sup>8</sup>

**Transphobia (n.):** Irrational fear of, aversion to, or discrimination against transgender people (or those perceived as such).<sup>9</sup>

**Two-Spirit (adj.):** Describes a person who embodies both a masculine and a feminine spirit. This is a culture-specific term used among some Native American, American Indian, and First Nations people.<sup>10</sup>

1. "Part B: AIDS Drug Assistance Program." HIV/AIDS Bureau, Health Resources and Services Administration, 25 Oct. 2019, [hab.hrsa.gov/about-ryan-white-hiv-aids-program/part-b-aids-drug-assistance-program](http://hab.hrsa.gov/about-ryan-white-hiv-aids-program/part-b-aids-drug-assistance-program).
2. "Ageism." World Health Organization, World Health Organization, 14 Mar. 2019, [www.who.int/ageing/ageism/en/](http://www.who.int/ageing/ageism/en/).
3. Originally published on 29 March, 2016. "LGBTQIA Glossary of Terms for Health Care Teams." National LGBT Health Education Center: A Program of the Fenway Institute, National LGBT Health Education Center, 2020, [www.lgbthealtheducation.org/publication/lgbtqia-glossary-of-terms-for-health-care-teams/](http://www.lgbthealtheducation.org/publication/lgbtqia-glossary-of-terms-for-health-care-teams/).
4. "Dual Eligible Beneficiaries Under Medicare and Medicaid." CMS, Centers for Medicare and Medicaid Services, May 2018, [https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/Medicare\\_Beneficiaries\\_Dual\\_Eligibles\\_At\\_a\\_Glance.pdf](https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/Medicare_Beneficiaries_Dual_Eligibles_At_a_Glance.pdf).
5. "Comorbid." Merriam-Webster, Merriam-Webster, [www.merriam-webster.com/dictionary/comorbid](http://www.merriam-webster.com/dictionary/comorbid).
6. Originally published on 29 March, 2016. "LGBTQIA Glossary of Terms for Health Care Teams." National LGBT Health Education Center: A Program of the Fenway Institute, National LGBT Health Education Center, 2020, [www.lgbthealtheducation.org/publication/lgbtqia-glossary-of-terms-for-health-care-teams/](http://www.lgbthealtheducation.org/publication/lgbtqia-glossary-of-terms-for-health-care-teams/).
7. "Homophobia." Merriam-Webster, Merriam-Webster, [www.merriam-webster.com/dictionary/homophobia](http://www.merriam-webster.com/dictionary/homophobia).
8. Nicholson, Nicholas R. "A Review of Social Isolation." The Journal of Primary Prevention, Medscape, 5 Sept. 2012, [www.medscape.com/viewarticle/769914](http://www.medscape.com/viewarticle/769914).
9. "Transphobia." Merriam-Webster, Merriam-Webster, [www.merriam-webster.com/dictionary/transphobia](http://www.merriam-webster.com/dictionary/transphobia).
10. Originally published on 29 March, 2016. "LGBTQIA Glossary of Terms for Health Care Teams." National LGBT Health Education Center: A Program of the Fenway Institute, National LGBT Health Education Center, 2020, [www.lgbthealtheducation.org/publication/lgbtqia-glossary-of-terms-for-health-care-teams/](http://www.lgbthealtheducation.org/publication/lgbtqia-glossary-of-terms-for-health-care-teams/).

## HealthHIV's POZITIVELY AGING

A PART OF



GILEAD

HIV<sup>+</sup>AGE<sup>™</sup>  
POZITIVELY

**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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