

HealthHIV™

SECOND ANNUAL

STATE OF
AGING
WITH HIV™

NATIONAL SURVEY

JULY 2021

healthhiv.org/positivelyaging

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INTRODUCTION AND BACKGROUND ON AGING WITH HIV

Modern-day HIV treatment, care coordination, and prevention services has revolutionized what living and aging with the virus has meant for people aging with HIV. Meanwhile, the world also marks the 40th anniversary of the first reports of HIV on June 1, 1981. Living with HIV can be challenging at any age. However, for older PWH, contending with the effects of aging and chronic inflammation issues can have a force multiplier effect. To further understand these experiences, the HealthHIV's Second Annual State of Aging with HIV™ National Survey was developed to provide a greater insight into the effects of aging with HIV.

2030

73%
of people
living with
HIV over
50

2020

60%
of people
living with
HIV over
50

As National HIV/AIDS & Aging Awareness Day nears on September 18th, this survey further underscores the ongoing needs and experiences of people aging, thriving, and sometimes struggling with HIV; many of whom are among the first generation of people diagnosed.

The Need to Address HIV among Persons Age 50 or Older

The number of people aging with HIV is rapidly increasing, and care coordination is vital to maintaining optimal health. The HealthHIV's Second Annual State of Aging with HIV™ National Survey was administered to capture the experiences and assess the needs of the following groups:

- » PWH over 50
- » PWH who are under 50 but have been living with HIV for 15 or more years.

The objective is to better inform the training needs of providers related to care coordination as part of HealthHIV's Positively Aging program.

Older people are the fastest growing group living with HIV in the US. New diagnoses of people over the age of 50 continues to increase, with the proportion of new diagnoses in this group almost doubling over the last decade, from just under 10% in 2007 to almost 23% in 2020. According to the *Lancet*, 73% of people with HIV (PWH) will be over age 50 by 2030.

Today, nearly six in 10 people living with HIV today are over the age of 50—making the state of successful aging with HIV among older people an equally expanding concern. To that, this population experiences unique health needs that are unmet. PWH over 50 face an intersection of general challenges associated with aging while also living with HIV, meaning they have 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 comorbid conditions associated with aging with HIV, and on the cumulative impacts of both comorbid conditions and frailty. This expanded training will need to increase as more and more people age with HIV.

Older people living with HIV are also often managing a number of other conditions or comorbidities—often a result of long-term inflamm-aging (chronic inflammation from HIV—even when virally suppressed) which can include: cardiovascular, dyslipidemia, hypertension, neuropathy, and the onset of type II diabetes, as well as lung and chronic kidney problems and bone-density loss. In fact, there is an average of three times the likelihood of as many long-term health conditions as compared with the general population. In particular, those who were diagnosed before the introduction of combination antiretroviral therapy were more likely to have more than three other co-occurring conditions.

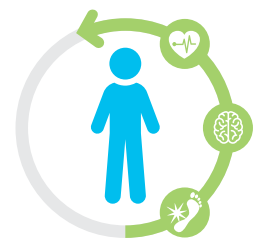
Factors that Influence Health for People Aging with HIV



Social Support



Insurance and Payer



Comorbidities



Health



Access



COVID-19



Mental Health and Substance Use



Medication and Pharmacy

ABOUT THE SURVEY



Methods

The survey consisted of **102 qualitative and quantitative questions**, which were drawn from validated measures published in the literature and the professional experience of our staff. An external Aging with HIV Community Advisory Board reviewed the survey to ensure coverage of all relevant issues and to pilot questions.

Distribution, Sampling, and Recruitment

The survey was distributed exclusively online using SurveyMonkey, from March 15, 2021 to June 16th, 2021. Participants were recruited through a purposive-stratified criterion sampling strategy that leveraged a sampling frame drawn from HealthHIV's constituent relationship management (CRM) database, SalsaLabs.

The CRM encompasses approximately 80,000 persons who reflect the diverse cross-section of populations disproportionately impacted by HIV in the U.S. since the epidemic began 40 decades earlier, in 1981. These include racial and ethnic minorities and sexual and gender minorities, across geographic and educational, and income levels. No incentive was provided for participation.

Data Analysis

Basic descriptive statistics were calculated in SurveyMonkey. Additional univariate, bivariate, and multivariate statistical analyses, including stratification of data, was calculated using Stata 17 and SAS 9.4 statistical software. Data tables for all relevant data can be found in the Appendix.

Eligibility Requirements

To be eligible to take the survey, participants had to indicate that they were 1) a person with HIV **age 50 or older**, or 2) a person living with HIV for **15 or more years**. A total of 596 participants started the survey. 479 respondents were eligible to participate; 420 have been living with HIV for 15 or more years and 59 were living with HIV 1 to 14 years.

OVERVIEW OF KEY FINDINGS



The following is an overview of key findings from HealthHIV’s Second Annual State of Aging with HIV survey. Since this is a “state of” report, respondents were asked how they would describe the state of aging with HIV in a word:



COVID-19 has altered the health care landscape for people aging with HIV.

- » According to the CDC, older age and comorbidities may put people living with HIV at increased risk for more severe illness if diagnosed with COVID-19. Therefore, HealthHIV’s Second Annual State of Aging with HIV National Survey examined the impact of COVID-19 on this population.
- » Survey respondents had **lower rates of COVID-19** than the general population, and COVID-19 **negatively impacted access** to care, mental health, social support, and other important protective factors.
- » People Aging with HIV in this survey reported **a decrease in service uptake** and a negative effect on the ability to access health care they need.
- » The pandemic may have been protective in terms of STIs.



Most people aging with HIV also have multiple comorbidities which require treatment/medication, highlighting an increasing need for care coordination for the whole person across the lifespan.

- » The average overall physical health score reported among participants was **3.4 out of 5**, graded on a self-report scale of 1 to 5 with 5 being excellent.
- » **High blood pressure** (57%), **high cholesterol** (57%), and **joint or back pain** (56%) were the three most reported co-occurring conditions.
- » **4 in 5** respondents indicated they have been prescribed medications for a chronic condition such as high blood pressure or high cholesterol.
- » More than a third of respondents expressed **mental health concerns**.

People aging with HIV were highly engaged in care, but their care provider is changing.

- » **4 of 5** respondents said they engaged in telehealth in 2020, as compared to less than one in ten in 2019.
- » People living with HIV longer (15+ years) were more likely to report that **they deferred visits or seeking care** versus those living with HIV for less than 15 years
- » **94% saw a provider** for HIV-related care in the last 12 months at least once, and **95%** responded that all of their healthcare providers know that they are living with HIV.
- » Nearly all respondents saw their PCP provider within the last 12 months, and more than half indicated that this provider was also their HIV provider.

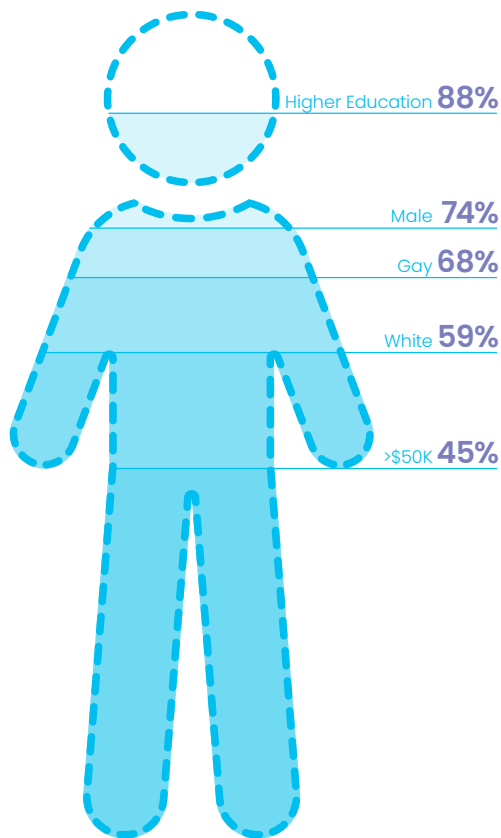
Aging with HIV not only affects one's physical health, but can have profound mental health ramifications as well:

- » Nearly **40 percent** reported being diagnosed with a mental health condition.
- » **More than a quarter** are in recovery from addiction and/or suffer post-traumatic stress disorder (PTSD).

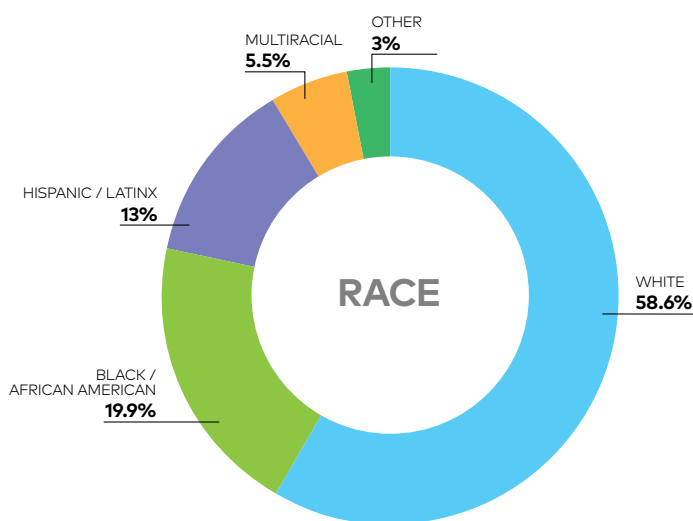
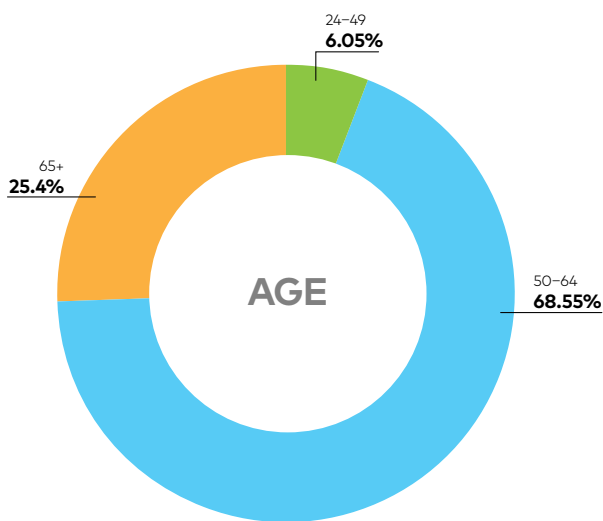
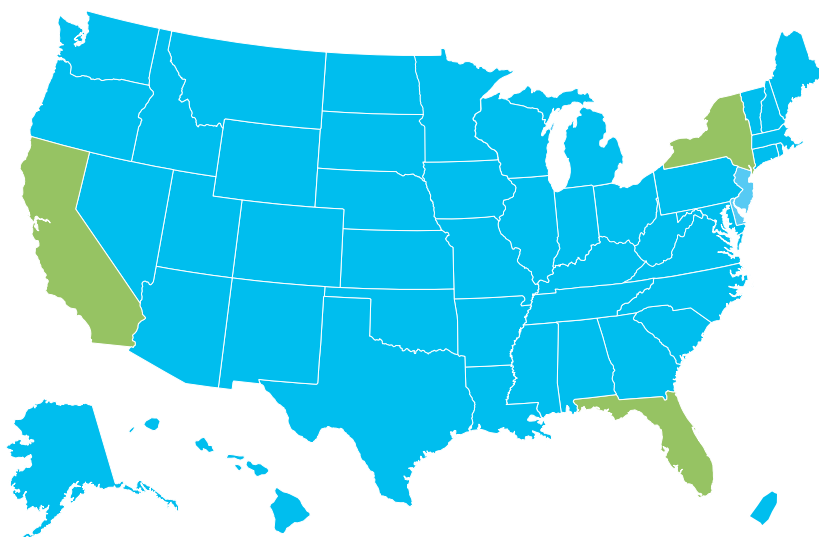
Discrimination remains a key barrier to accessing care:

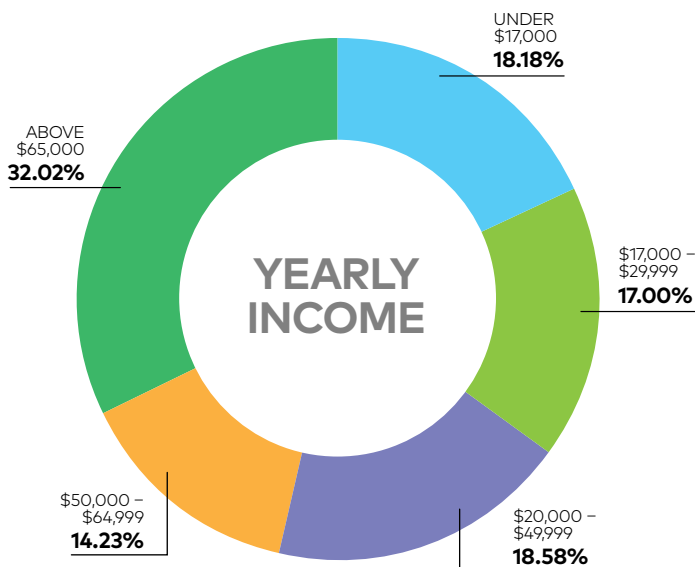
- » People aging with HIV experienced **stigma (28%), homophobia (19%), ageism (17%), and racism (10%)** when accessing care.
- » Respondents highlighted **a need for additional training** on cultural competency to providers and their staff, creating a more welcoming environment for all people with HIV.

DEMOGRAPHICS



Respondents were predominantly **male** (74%), **gay** (68%), and **white** (59%). Nearly half (45%) made less than \$50,000, and 88% had at least some level of higher education. Participants represented 38 U.S. states, the District of Columbia, Puerto Rico, and one location not in the U.S. The majority of responses came from California, followed by New York, and Florida.





Financial Status

While over 32% made above \$65,000 annually; just as many (36%) made below \$30,000 per year. Over 21% of respondents supported two or more people with an income below 65,000 per year.

More than 44% had no financial or retirement plan.

Differences by Age

There were differences when stratified by length of time living with HIV and age. Participants who reported living with HIV 15 or more years tended to be **older and more established** in terms of education and income than those living with HIV less than 15 years. Participants with HIV for 15 or more years were more likely to hold an advanced or professional degree, and to have a higher income. Nearly two-thirds (59%) of persons living with HIV less than 15 years reported incomes of \$30,000 per year or less, compared to 36% of those who have had HIV for 15+ years.

Housing

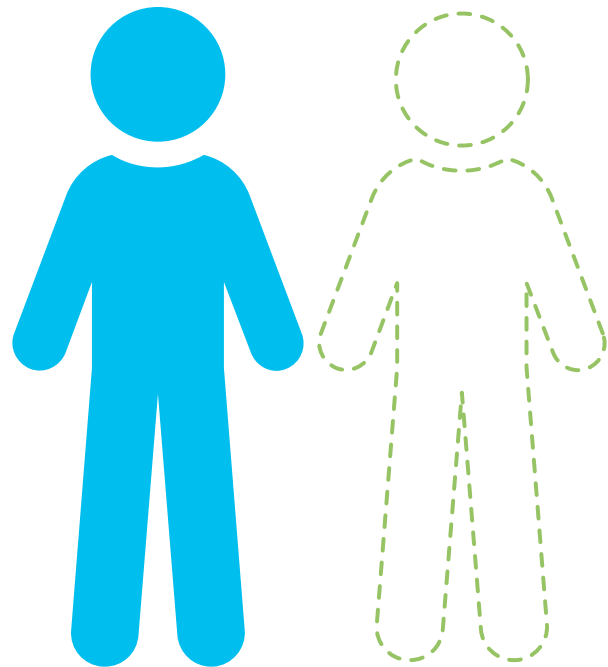
93% of respondents reported having stable housing, with little difference between those who had had HIV for under or over 15 years. Just under one-fifth of respondents received subsidized housing support.



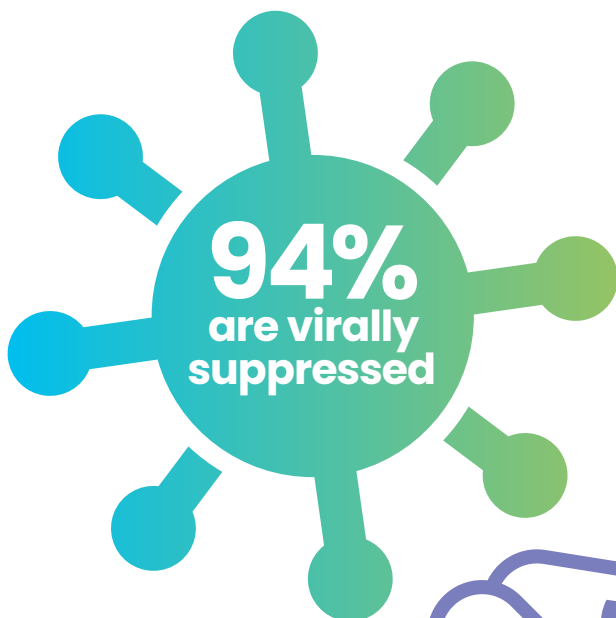
HIV AND HEALTH

Previous AIDS Diagnosis

56% of participants reported receiving an AIDS diagnosis in the past. These trends differed by age, with those 50 and older more likely to report a past AIDS diagnosis compared with those under the age of 50. A statistically significant number of those diagnosed with HIV for 15 or more years ago were more likely to report a past AIDS diagnosis than those diagnosed less than 15 years ago (58% vs. 31%).



1 in 2
participants have received
an AIDS diagnosis



99%
are taking
retrovirals



Viral Suppression

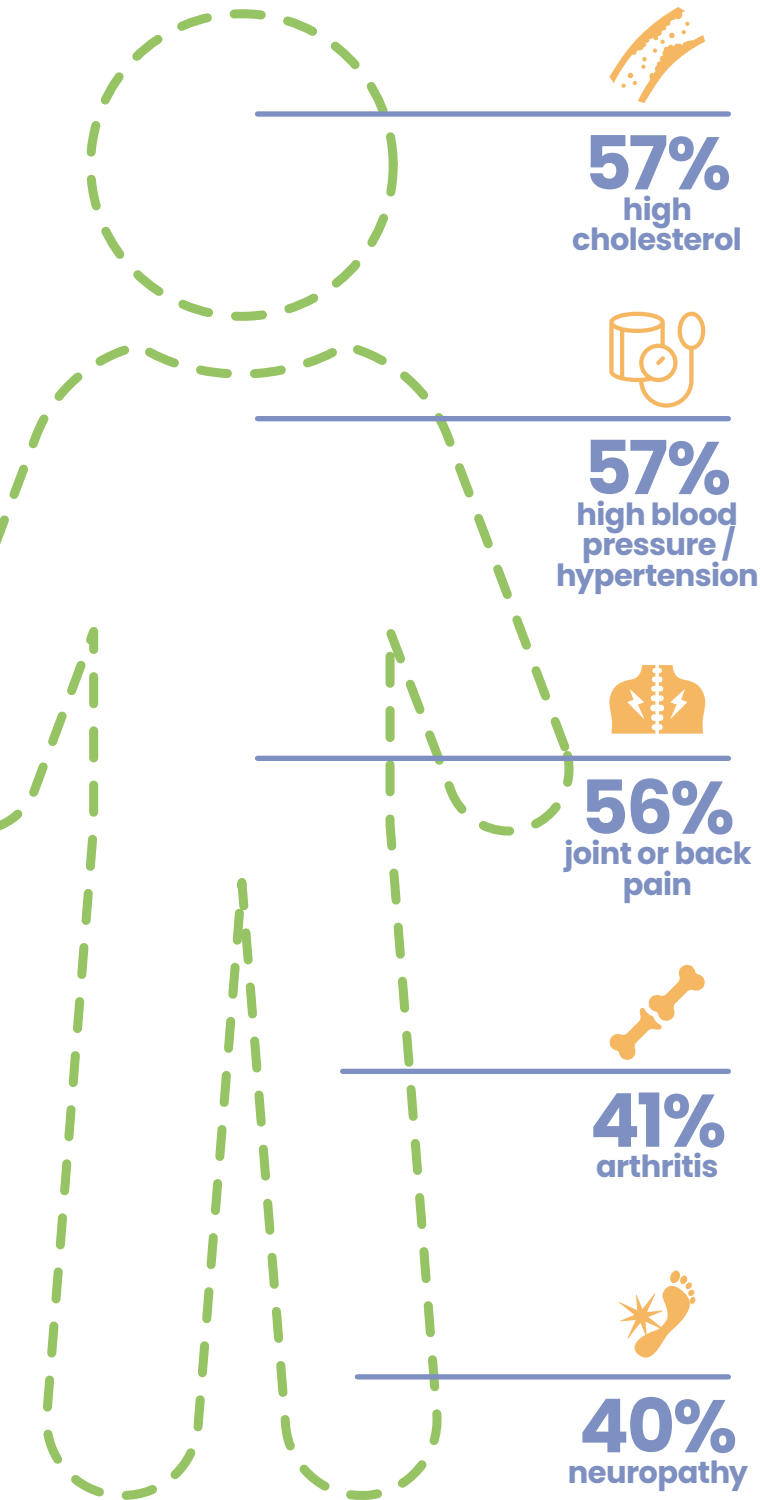
Results show that 99% of respondents are currently taking antiretrovirals. Approximately 94% of respondents reported having achieved viral suppression through adherence to an antiretroviral regimen.



11%
concerned
about viral
suppression
and
resistance

Despite this high-level of self-reported treatment adherence, over 11% of participants remained concerned about viral suppression or resistance to their current HIV regimen, while just under one-third of participants reported experiencing side effects of their medications.

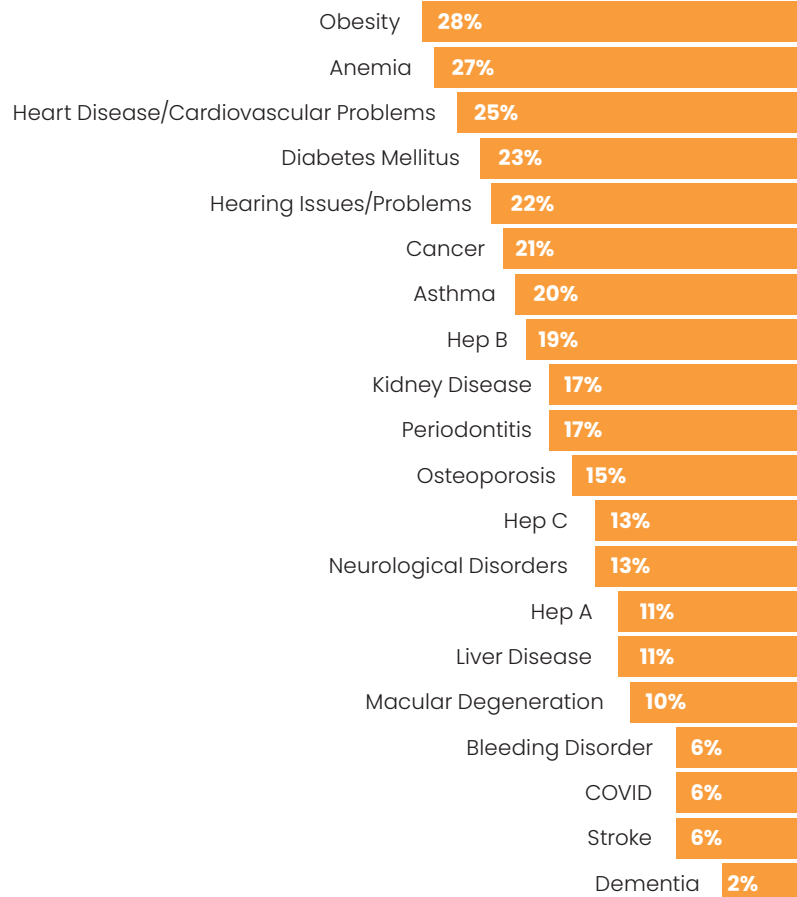
COMORBID CONDITIONS



The average overall physical health score reported among participants was 3.4 out of 5, graded on a self-report scale of 1 to 5, with 1 being poor and 5 being excellent. **Nearly 60% of all respondents reported having at least one comorbidity;** necessitating multiple medication prescriptions and providers.

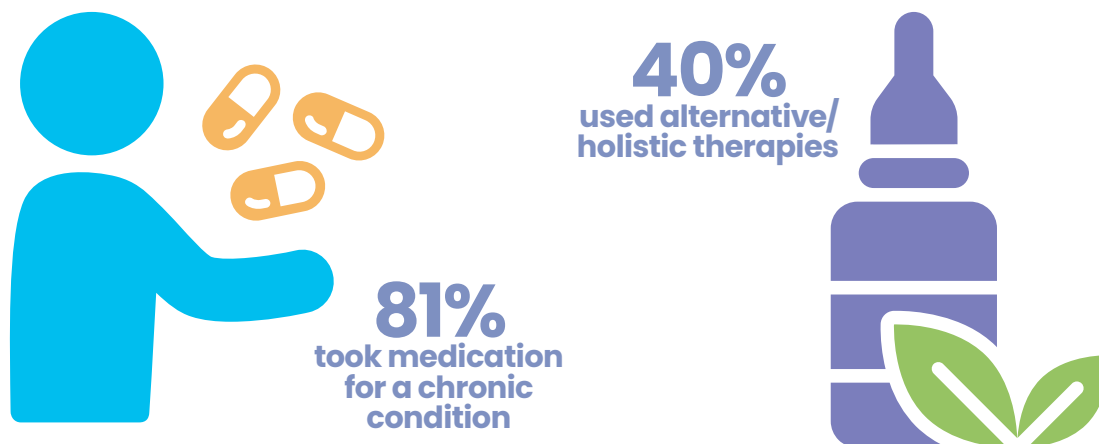
The most frequently named comorbid conditions were:

- » High cholesterol
- » Joint or back pain
- » High blood pressure/hypertension
- » Arthritis
- » Neuropathy



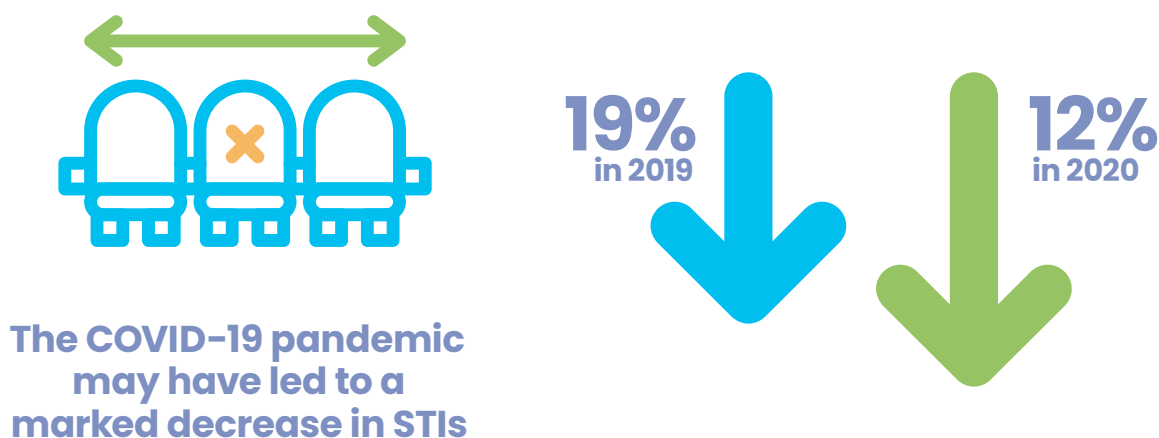
Medication and Comorbidities

81% of participants reported taking medication for a chronic condition, with those over age 65 being slightly more likely to do so (87%) than those under age 50 (66%). There was no marked difference by number of years living with HIV. **Over 40% of participants reported using alternative/holistic therapies**—a trend that was markedly higher among those under age 50 (60%) than those over age 65 (37%) and among those who had been living with HIV for 15 or more years.



STIs and Hepatitis

Approximately **12% of respondents reported being diagnosed or treated for a sexually transmitted infection (STI) or viral hepatitis** in the past 12 months, a marked decrease from 2019. This is most likely a result of social isolation due to the COVID-19 pandemic. These distributions were consistent across age groups and length of time living with HIV, with persons under the age of 50 reporting slightly fewer STIs. The majority of those with diagnosed STIs were between the ages of 50–64.



MENTAL HEALTH AND SUBSTANCE USE

Living and aging with HIV not only affects one's physical health but can have mental health implications as well. Living with HIV can lead to psychological difficulties such as increased rates of depression, a sense of lost agency and social positioning, and even poorer qualities of life.



39%
diagnosed with
mental health
condition

27%
in substance
abuse recovery

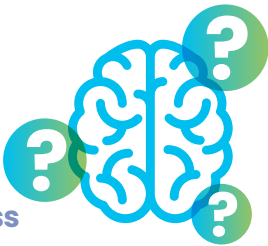
25%
reported PTSD

Participants ranked their mental health as a **3.2 out of 5** (1=poor, 5=excellent). Overall, 39% of participants reported experiencing mental illness. In the last 12 months, 35% stated that they have seen a mental health provider. Encouragingly, 89% of respondents felt that they can talk about their mental health with their provider.

Among participants:

- » 39% reported being diagnosed with a mental health condition
- » 25% of respondents have been diagnosed with PTSD

Nearly 60%
reported
memory loss
issues



Memory Loss

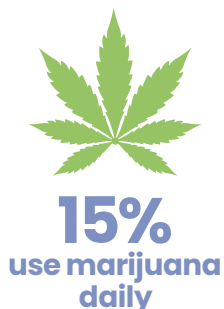
Nearly 6 out of 10 survey respondents reported memory loss issues. For those respondents who expressed concerns about memory loss, **only 64% indicated that their providers discussed memory loss** with them.



Substance Use

Substance use also was common among participants:

- » 10% use alcohol daily
- » 17% use tobacco daily
- » 15% use marijuana daily
- » 3% use opioids daily



Approximately 27% of participants reported being in recovery. Those who had been living with HIV for 15 or more years were more likely to be in recovery (28%) than those who had been living with HIV less than 15 years (20%). Persons living with HIV for 15 or more years were much more likely to report marijuana use, with 16% reporting daily use compared to 7% of persons who had been living with HIV less than 15 years. 15% of respondents said that they did not feel comfortable talking about substance use with their provider.

CARE COORDINATION



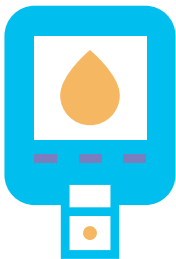
94%
have seen an HIV
care provider in
the last year

Responders are actively engaging with their providers, as 94% had seen an HIV care provider at least once in the last 12 months with over 73% having seen their HIV care provider 3 or more times. Approximately 62% of respondents across all age groups indicated that their primary care provider and HIV care provider are the same person. Seeing a primary care provider for HIV services, however, was more common among those living with HIV for 15 or more years (64%) compared to those living with HIV less than 15 years (44%). There are 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:

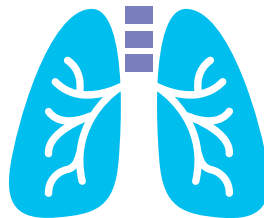
- » 59% of patients with Type 2 diabetes identified their HIV Care Providers as their PCPs.
- » 57% of patients with Asthma identified their HIV Care Providers as their PCPs.
- » 52% of patients with Kidney disease identified their HIV Care Providers as their PCPs.

Approximately 53% of respondents access services at a Ryan White Organization, and 42% reported that access their HIV medications through the Ryan White ADAP program.

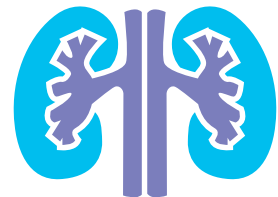
HIV care providers are also providing care for...



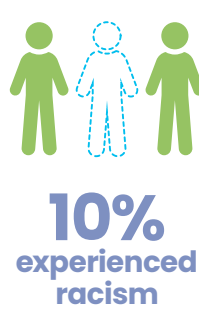
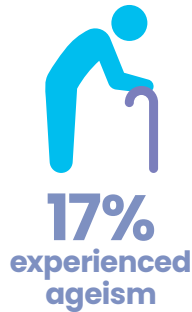
59%
of patients with Type 2
diabetes



57%
of patients with asthma



52%
of patients with kidney
disease



Barriers to Care

Participants report experiencing discrimination as a barrier to accessing medical care:

- » Stigma: 28%
- » Homophobia: 19%
- » Ageism: 17%
- » Racism: 10%



Respondents indicated that they experienced both environmental and logistical barriers when seeking and receiving care, such as not having transportation or being unable to access providers due to insurance restrictions. Other barriers included:

- » Long wait times: 16%
- » Cost of care: 16%
- » Cost of medications: 15%
- » Not being able to find a provider who is knowledgeable about aging with HIV: 14%
- » Not being able to find a provider covered by my insurance: 13%
- » Lack of convenient appointment times: 10%
- » Transportation: 9%

The trends that emerged as a result of the pandemic may reflect trends around health care engagement among this year's participants. 31% sought care at emergency departments, and 19% engaged urgent care, which indicates a lack of a medical home. Providers in these settings often are not HIV specialists and do not have access to the medical histories and unique needs of persons with both HIV and comorbid conditions associated with aging.



COVID-19, TELEHEALTH, AND HIV CARE



4 in 10
reported fewer visits to
providers during COVID

Respondents indicated that COVID-19 negatively impacted their ability to access services; with nearly **four in 10** reporting fewer visits to their providers than in previous years. These trends differed based on number of years living with HIV. 75% of those living with HIV less than 15 years indicating the pandemic had no impact on their HIV provider visits, with 19% indicating that the pandemic forced them to reduce the number of HIV provider visits.

Participants living with HIV for 15 or more years, however, were nearly **twice as likely** to report reducing their number of HIV provider visits during the pandemic.

In 2020, less than 7% of PWH over age 50 reported engaging in telehealth. In 2021, due to COVID-19 restrictions and new policies, 80% engaged in telehealth to meet with a healthcare provider and more than 73% said they had engaged in telehealth during the pandemic specifically for HIV-related care.



PAYER INFORMATION

More than 60% of respondents receive public insurance (Medicaid and/or Medicare), and more than 42% accessed HIV medications through their state's AIDS Drugs Assistance Program (ADAP)—a trend that was slightly more common among participants under age 50 and who had been living with HIV less than 15 years.

While over 97% of survey 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 for many aging with HIV, health insurance coverage may be insufficient.



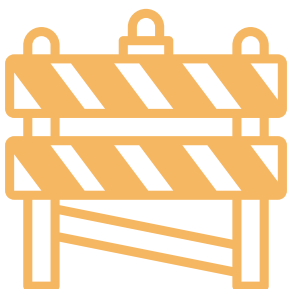
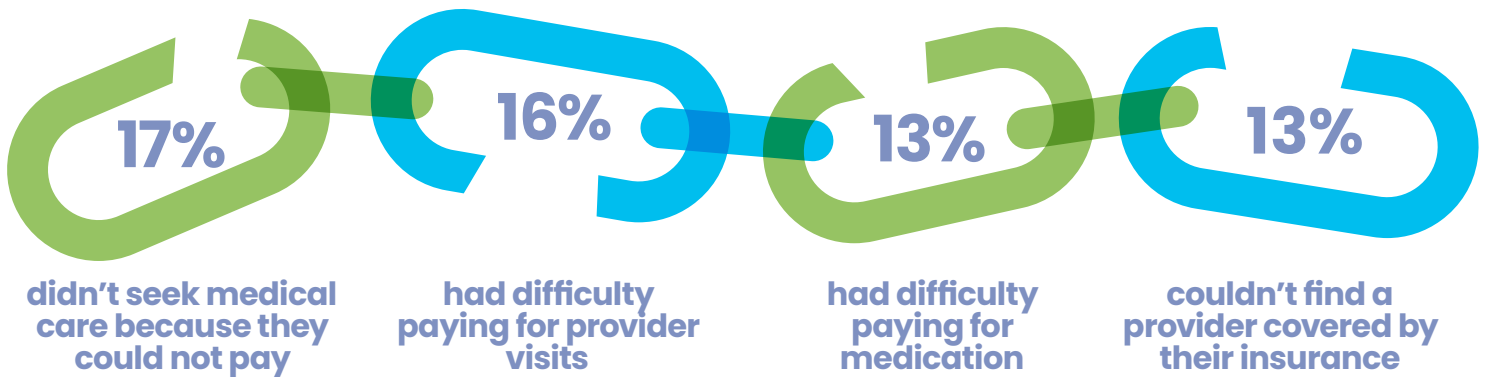
97% are insured



60% have public insurance



42% obtained medications through ADAP



There were indications that participants—especially those who were older and/or living with HIV for 15 or more years—needed additional support and wraparound services, such as transportation, to access care. 14% of those living with HIV for 15 or more years reported experiencing inadequate access to support services, compared to just 3% of those who had been living with HIV less than 15 years.

79% of respondents reported that they have adequate access to support services; those living with HIV for 15 or more years reported lower access to support services compared with those living with HIV less than 15 years (78%, 85% respectively).



57%
accessed
dental care



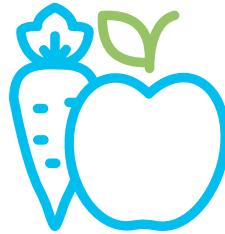
45%
accessed
vision care



39%
accessed
mental health
services

Support Services Accessed

- » Dental Care (57%)
- » Vision care (45%)
- » Mental Health Services (39%)
- » Food Assistance (23%)
- » Housing Assistance (15%)



23%
accessed food
assistance



15%
accessed
housing
assistance

Respondents indicated that they had trouble accessing these services:

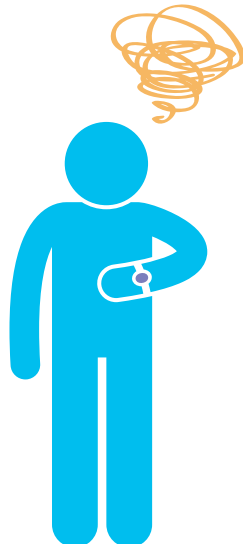
- » Dental Care (16%)
- » Mental Health Provider (11%)

Compared to those living with HIV for less time, those living with HIV for 15 or more years were more likely to have more medical expenses than they could afford. While no one living with HIV for less than 15 years reported changing their HIV medications due to insurance dictates, 5% of those living with HIV for 15 or more years indicated that they had been required to do so in the past year.

PHARMACY AND MEDICATIONS

Pharmacists play pivotal roles in maximizing HIV treatment outcomes for PWH in lots of ways—and they also serve as an impact model across many medical and non-clinical settings. Polypharmacy (or a concurrent use of multiple drugs or treatment regimens) is common in older persons with HIV, and because of that there is a greater risk of drug-drug interactions between antiretroviral drugs and associated medications.

Nearly
30%
experienced issues
with receiving their
medications on time



Overall, **timely acquisition of medication was an issue in 2020**. Almost 30% experienced issues with receiving their medications on time.

Just over 40% of participants reported that they had ever developed resistance to an HIV medication that caused their provider to change their medication. These results were generally the same across age groups and length of time with HIV.

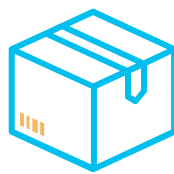
50% of respondents stated that they spoke with their pharmacist about their prescription; indicating a source of trust for their medical care.



TYPE OF PHARMACY USED



59%
retail
pharmacy



28%
mail order
pharmacy



17%
clinic
pharmacy



13%
other
pharmacy



12%
hospital
pharmacy

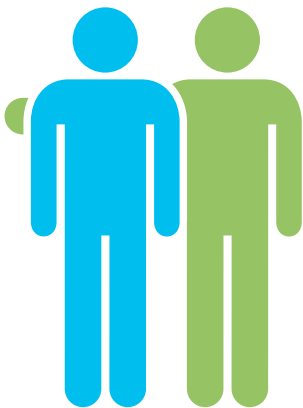
HIV-specific cofactors, like lower CD4 cell counts and longer ART exposure, are also identified risk factors for comorbid conditions for aging PWH. Our landscape survey indicated that nearly 81% of PWH take medications for comorbid conditions, and 93% use just one pharmacy. These data strongly support the need for earlier comprehensive panels and screening in HIV-positive patients—as well as enhanced care coordination between pharmacies and providers.

SOCIAL SUPPORT

Strong social support has been shown to be a protective factor resulting in better health outcomes for people living with HIV. Research has also documented the negative impacts that stigma has on health outcomes for PWH.



7%
do not have access
to social support



Nearly 50%
have care support
when sick or
injured

Overall, 7% of participants shared that they did not have access to social support, indicating an ongoing need for policies and interventions to help ensure engagement of OPWH in clinical and behavioral health care.

Daily Support

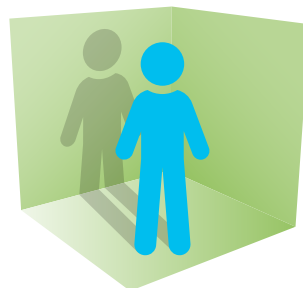
Approximately 32% of participants overall indicated that they went 24 hours without talking to a friend or family member in the past week—19% of participants ages 65 and older reported experiencing 24 hours of isolation from family and friends in the past week, compared to 33% of those under age 50, and 37% of those ages 50–64.

Assistance and Support

For daily support, respondents indicated that they were fairly independent with 68% reporting they do not need any assistance. When sick or injured, nearly one-half of participants indicated they had a friend, spouse/domestic partner or family members who could help care for them, regardless of years lived with HIV or age:

- » 30% have a spouse or domestic partner who can help
- » 22% have a family member who can help
- » 17% have a friend who can help

When looking across the age categories, the results demonstrated that those 65 and older were more likely to report requiring assistance for daily living activities compared with those in the younger age groups; indicating that social support is an important factor to address as PWH age.



32% experienced 24
hours of isolation
in the last week



33%
sought support
with daily tasks

Concerns about Support

Responses indicate that older PWH cited concerns with having enough income and social support as they grew older. This group also indicated needing help taking care of themselves and managing daily living. Roughly 33% of respondents said they sought outside or spousal, partner, friends or family support with those daily tasks.

Sex and Social Support

Among this year's survey participants, 41% indicated having sexual contact in the past year. While this trend held across years of living with HIV, participants under age 50 (73%) and age 50-64 (68%) were more likely to report having had sex than those over age 65 (35%). Condom use likewise varied, with 47% of participants under the age of 50 reporting never using condoms, compared to those ages 50-65 (52%) and those ages 65 and older (44%).



41%
had sexual contact
in the last year

IMPLICATIONS



HIV and Health

Acquiring and living with HIV can lead to psychological difficulties, reduced mental health, and resulting in poorer quality of life. To that end there is a need for: greater referrals to psychosocial support services; more questions asked by providers to assess neurocognitive impairment and memory loss issues; and, linkage to outpatient assistance for older PWH with managing all the specificity and levels of participation that comes with having multiple health conditions.



Care Coordination

There is a need for providers to build relationships with community-based organizations to coordinate along the HIV status neutral continuum. Also, there is an increase in reaching older PWH who live alone and/or take care of themselves when ill or injured. Telehealth outreach is a key tool for reaching the people who reported reducing their PCP visits due to COVID-19 and other social isolation.



Payer Information

Health insurance coverage is insufficient for many older adults with HIV. Older PWH also may need additional wraparound and navigation services, such as transportation, to access their providers.



Pharmacy

The interplay between polypharmacy and the high rates of comorbidities requiring medication is a concern because of risk of drug-drug interactions and extended use of medication showed a high rate of resistance. This report's findings also support the need for earlier comprehensive panels and screening in HIV-positive patients—as well as enhanced care coordination between pharmacies and providers.



Social Support

Social isolation was reported across age groups, so there's a need for more opportunities for PWH to socially engage especially given limitations and restrictions with COVID-19. There was a high health literacy of the participants in the study, most of whom are virally suppressed, making them unable to transmit the virus to their partners—so this raises the question of whether there's a relationship between viral suppression and health literacy.



Substance Use Disorder

Respondents identified higher than national average rates of substance use and engagement in recovery from substance use disorder. There is a need for expansive and inclusive substance use disorder treatment for people aging with HIV. There is also a need to integrate substance use care with both primary and mental and behavioral health providers, given that substance use disorder disproportionately affects PWH.



Stigma and Discrimination

More than a quarter of respondents reported experiencing stigma or other discrimination as a barrier to accessing care highlighting the need to support providers and their staff with competency training to provide a more welcoming environment for all PWH or at risk for HIV.



Medical Home

The disproportionately high rates of comorbid conditions coupled with an increased need to coordinate ongoing and long-term HIV care indicates that there is a large need for a medical home to consolidate care coordination for the whole person. Better care coordination could address comorbidities and the psychosocial issues that are impacting PWH and affecting their health outcomes.



Barriers to Access

COVID-19 installed a number of barriers to accessing care, but there exist other barriers such as structural barriers that need to be addressed to support medical visits, such as cost, wait times, and transportation; timely and affordable access to medication; increased insurance and payment navigation support; and culturally sensitive, stigma-free medical visits.



Telehealth

Telehealth emerged as a new vehicle for reaching PWH and its use and reach is likely to extend beyond the COVID-19 pandemic. Telehealth services need to be invested in as a viable and low barrier option for reaching PWH and coordinating care.

HEALTHHIV RESEARCH AND EVALUATION

HealthHIV, HealthHCV, and the National Coalition for LGBT Health conduct original and unique research. Their “State of” national surveys are conducted in Aging with HIV, HIV primary care, HCV care, LGBT health, ASOs and CBOS, and telehealth and HIV prevention, care, and treatment.



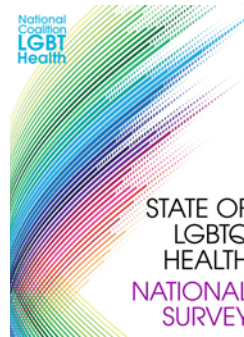
HealthHIV's Annual State of HIV Primary Care National Survey™



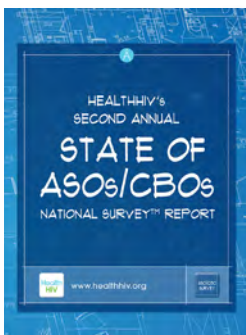
HealthHIV's Annual State of Aging with HIV National Survey™



HealthHCV's Annual State of HCV Care National Survey™



The National Coalition for LGBT Health's State of LGBT Health National Survey™



HealthHIV's Annual State of ASOs/CBOs National Survey™



HealthHIV's State of Telehealth and HIV Prevention, Care and Treatment™

GLOSSARY OF TERMS

AIDS Diagnosis (n.): AIDS-defining condition or having a CD4 count less than 200.

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.

Ageism (n.): Stereotyping, prejudice, and discrimination against people on the basis of their age.

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.

Comorbid (adj.) and **Comorbidity** (n.): The simultaneous presence of two chronic diseases or conditions in a patient.

Co-occurring Condition (n phrase): Refers to having one or more physical ill and behavioral health condition at the same time.

Dual-eligible (n.): Individuals who are eligible for both Medicare and Medicaid.

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.

HIV care provider (n.): Defined as the clinical provider who provides and supports the respondent with their HIV care and management.

Homophobia (n.): Irrational fear of, aversion to, or discrimination against homosexuality or homosexuals (or those perceived as such).

Inflammatory Aging / Imflamm-aging (n.): “inflamm-aging” refers to a general inflammatory process that involves the whole body and can result in diseases associated and exacerbated by aging, such as HIV.

Polypathology (n.): High occurrence of comorbidities

Polypharmacy Use (n.): Use of multiple pharmacies to fill prescriptions, often due to visiting multiple providers with different payers for varying conditions.

Primary Care Provider (PCP) (n.): A physician who provides the respondent their care for common medical problems, but not HIV care.

Ryan White HIV/AIDS Program (n.): First enacted in 1990 and administered by the Health Resources and Services Administration’s (HRSA), the Ryan White HIV/AIDS Program is the largest Federal program focused on providing HIV care and treatment services to low-income people with HIV who are uninsured or underserved.

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.

Social Support (n.): Provision of assistance or comfort to others, often in response to physical and psychosocial stressors. Support may be provided through interpersonal relationships created through a social network, involving support groups, family members, friends, neighbors, caregivers, and others. Support can be practical (e.g. providing advice or a ride), tangible (providing money or other tangible resources); and emotional (e.g. helping someone feel valued, accepted, and understood).

Telehealth or Telemedicine (n.): Describes the use of telephone, mobile devices, tablets, or computers to participate in a real-time, virtual health care appointment in place of an in-person visit. These engagements are sometimes called telemedicine.

Transphobia (n.): Irrational fear of, aversion to, or discrimination against transgender people (or those perceived as such).

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.

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APPENDIX

Table 1: Demographics by length of time living with HIV

	How long have you lived with HIV?		
	1-14 years ^a	15 or more years ^a	Total ^a
AGE			
26-49	7%	0%	6%
50-64	68%	71%	68%
65+	25%	29%	26%
GENDER IDENTITY			
Man	64%	75%	74%
Woman	31%	23%	23%
Other Gender Identity ^b	5%	2%	3%
SEXUAL ORIENTATION			
Gay/Lesbian	55%	70%	68%
Bisexual	18%	6%	7%
Heterosexual/Straight	23%	21%	21%
Other Orientation ^c	4%	3%	4%
RACE/ETHNICITY			
Asian	0%	0%	0%
Black	14%	20%	20%
Hispanic	19%	13%	13%
Multi-Race	10%	6%	6%
Native American	5%	0%	1%
Other	0%	1%	1%
White	52%	59%	59%
RESIDENCE			
Rural	12%	14%	12%
Suburban	60%	68%	61%
Urban	28%	18%	27%
HIGHEST LEVEL OF EDUCATION			
Advanced Degree (e.g. PhD, ScD/SD)	0%	3%	2%
Professional degree (e.g. JD, MD)	0%	4%	4%
Master's degree (e.g. MA, MS, MPH)	9%	20%	19%

Continued on page 29

How long have you lived with HIV?

	1-14 years ^a	15 or more years ^a	Total ^a
Undergraduate degree	36%	28%	29%
Some college but no degree	23%	22%	22%
Associate/Technical Degree	23%	10%	12%
High school diploma/GED	5%	11%	10%
Less than High School Diploma/GED	5%	2%	2%
HOUSEHOLD ANNUAL INCOME			
Less than \$17,000	45%	16%	19%
17,000 - 29,999	14%	17%	17%
30,000 - 49,999	14%	20%	19%
50,001 - 64,999	0%	15%	14%
More than 65,000	27%	32%	31%
NUMBER OF PERSONS SUPPORTED			
1	73%	54%	55%
2	23%	36%	35%
3 or more	4%	9%	9%
Prefer Not to Answer	0%	1%	1%
HOUSING STATUS			
Dwelling that I rent or own	91%	93%	93%
Car, shelter, other transitional housing	9%	1%	1%
With a friend, family member, group home	0%	6%	6%
SUBSIDIZED HOUSING STATUS			
Yes	82%	83%	83%
No	18%	17%	17%
FINANCIAL PLAN FOR RETIREMENT			
Yes	36%	52%	50%
No	55%	43%	44%
Prefer Not to Answer	9%	5%	6%

a = The percentages represent column percentages.

b = Other Gender Identity includes persons who identify as transgender, gender fluid, non-binary, and prefer not to answer.

c = Other Orientation includes queer, other, and prefer not to answer.

Table 2: Demographics by Age

	Age			
	26-49 ^a	50-64 ^a	65+ ^a	Total ^a
GENDER IDENTITY				
Man	64%	72%	84%	74%
Woman	29%	26%	16%	23%
Other Gender Identity ^b	7%	2%	0%	3%
SEXUAL ORIENTATION				
Gay/Lesbian	60%	69%	68%	68%
Bisexual	7%	7%	7%	7%
Heterosexual/Straight	26%	21%	19%	21%
Other Orientation ^c	7%	3%	6%	4%
RACE/ETHNICITY				
Asian	0%	1%	0%	0%
Black	40%	16%	19%	20%
Hispanic	27%	15%	5%	13%
Multi-Race	7%	7%	3%	6%
Native American	0%	1%	0%	1%
Other	0%	2%	2%	1%
White	26%	58%	71%	59%
RESIDENCE				
Rural	20%	14%	6%	12%
Suburban	60%	59%	60%	61%
Urban	20%	27%	34%	27%
HIGHEST LEVEL OF EDUCATION				
Advanced Degree (e.g. PhD, ScD/SD)	0%	1%	5%	2%
Professional degree (e.g. JD, MD)	0%	2%	9%	4%
Master's degree (e.g. MA, MS, MPH)	27%	20%	16%	19%
Undergraduate degree	20%	31%	30%	29%
Some college but no degree	13%	23%	22%	22%
Associate/Technical Degree	13%	10%	13%	12%
High school diploma/GED	27%	11%	3%	10%
Less than High School Diploma/GED	0%	2%	2%	2%
HOUSEHOLD ANNUAL INCOME				
Less than \$17,000	7%	22%	9%	19%
17,000 - 29,999	7%	17%	21%	17%
30,000 - 49,999	33%	18%	19%	19%
50,001 - 64,999	20%	13%	13%	14%
More than 65,000	33%	30%	38%	31%

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Age				
	26-49 ^a	50-64 ^a	65+ ^a	Total ^a
NUMBER OF PERSONS SUPPORTED				
1	40%	56%	57%	55%
2	40%	33%	38%	35%
3 or more	20%	9%	5%	9%
Prefer Not to Answer	0%	2%	0%	1%
HOUSING STATUS				
Dwelling that I rent or own	87%	93%	95%	93%
Car, shelter, other transitional housing	0%	1%	0%	1%
With a friend, family member, group home	13%	6%	5%	6%
SUBSIDIZED HOUSING STATUS				
Yes	7%	19%	13%	17%
No	93%	81%	87%	83%
FINANCIAL PLAN FOR RETIREMENT				
Yes	60%	48%	60%	50%
No	40%	48%	29%	44%
Prefer Not to Answer	0%	4%	11%	6%

a = The percentages represent column percentages.

b = Other Gender Identity includes persons who identify as transgender, gender fluid, non-binary, and prefer not to answer.

c = Other Orientation includes queer, other, and prefer not to answer.

Table 3: Pharmacy and medication by length of time living with HIV

How long have you lived with HIV?			
	1-14 years ^a	15 or more years ^a	Total ^a
VIRAL SUPPRESSED			
Yes	92%	94%	94%
No/Unsure/Don't Know	8%	6%	6%
FEEL VIRAL SUPPRESSION UNDER CONTROL			
Yes	86%	87%	87%
No/Unsure/Don't Know	14%	13%	13%
CURRENTLY TAKING ARVS			
Yes	100%	99%	99%
No	0%	1%	1%
FREQUENCY TAKING ARVS			
Every day	100%	97%	97%
Weekly or less often	0%	3%	3%
EXPERIENCE SIDE-EFFECTS			
Yes	30%	25%	30%
No	70%	75%	70%
EVER DEVELOPED RESISTANCE			
Yes	16%	42%	40%
No	78%	54%	56%
Unsure/Don't Know	6%	4%	4%
HAD TO SWITCH ARV IN PAST 12 MONTHS DUE TO SIDE EFFECTS			
Yes	0%	5%	5%
No	100%	95%	95%
TAKING MEDICATION FOR CHRONIC CONDITION			
Yes	84%	80%	81%
No	16%	20%	19%
USED ALTERNATIVE/HOLISTIC THERAPIES (E.G. YOGA) IN PAST 12 MONTHS			
Yes	38%	44%	44%
No	62%	56%	56%
HAVE YOUR MEDICAL PROVIDERS DISCUSSED MEMORY/RECALL/THINKING ISSUES WITH YOU?			
Yes	15%	33%	31%
No	82%	65%	67%
Unsure	3%	2%	2%

a = The percentages represent column percentages.

Table 4: Pharmacy and medication by age

	Age			
	26-49 ^a	50-64 ^a	65+ ^a	Total ^a
VIRAL SUPPRESSED				
Yes	86%	92%	95%	94%
No/Unsure/Don't Know	13%	8%	5%	6%
FEEL VIRAL SUPPRESSION UNDER CONTROL				
Yes	93%	87%	91%	87%
No/Unsure/Don't Know	7%	13%	9%	13%
CURRENTLY TAKING ARVS				
Yes	100%	98%	98%	99%
No	0%	2%	2%	1%
FREQUENCY TAKING ARVS				
Every day	87%	97%	97%	97%
Weekly or less often	13%	3%	3%	3%
EXPERIENCE SIDE-EFFECTS				
Yes	27%	35%	16%	30%
No	73%	64%	84%	70%
EVER DEVELOPED RESISTANCE				
Yes	40%	40%	27%	40%
No	53%	57%	67%	56%
Unsure/Don't Know	7%	3%	6%	4%
TAKING MEDICATION FOR CHRONIC CONDITION				
Yes	66%	78%	87%	81%
No	33%	22%	13%	19%
USED ALTERNATIVE/HOLISTIC THERAPIES (E.G. YOGA) IN PAST 12 MONTHS				
Yes	60%	44%	37%	44%
No	40%	56%	64%	56%
HAVE YOUR MEDICAL PROVIDERS DISCUSSED MEMORY/RECALL/THINKING ISSUES WITH YOU?				
Yes	20%	26%	41%	31%
No	80%	72%	53%	67%
Unsure	0%	2%	6%	2%

a = The percentages represent column percentages.

Table 5: Accessing care by length of time living with HIV

How long have you lived with HIV?			
	1-14 years ^a	15 or more years ^a	Total ^a
HIV AND PCP THE SAME PROVIDER			
Yes	44%	64%	62%
No/Don't Know	56%	36%	38%
NUMBER OF HEALTHCARE PROVIDERS SEEN IN THE LAST 6 MONTHS			
0 Providers	3%	7%	6%
1 Provider	18%	18%	18%
2 Providers	18%	23%	22%
3+ Providers	61%	53%	54%
ALL OF MY HEALTHCARE PROVIDERS KNOW THAT I AM LIVING WITH HIV OR AIDS.			
Yes	94%	96%	96%
No/Don't Know	6%	4%	4%
I FEEL THAT MY PROVIDER GIVES ME ENOUGH TIME TO ADDRESS MY CONCERNS AND QUESTIONS			
Yes	85%	73%	74%
Depends on the provider	6%	6%	6%
No	3%	4%	4%
Sometimes	6%	17%	16%
MY PROVIDER GIVES ME ENOUGH TIME TO DISCUSS OTHER THINGS OF IMPORTANCE TO ME			
Yes	79%	71%	71%
Depends on the provider	9%	5%	6%
No	6%	4%	4%
Sometimes	6%	20%	19%
USED TELEMEDICINE IN PAST 12 MONTHS			
Yes	79%	80%	80%
No	21%	20%	19%
HAS THE COVID-19 PANDEMIC IMPACTED YOUR ABILITY TO ACCESS HEALTHCARE SERVICES?			
Yes	29%	41%	40%
No	65%	55%	55%
Unsure/Don't Know	6%	4%	5%
HOW HAS COVID-19 IMPACTED THE FREQUENCY OF YOUR HIV-RELATED CARE (DOCTOR) VISITS			
The frequency has decreased (less visits)	19%	38%	36%
The frequency has increased (more visits)	6%	3%	3%
The frequency has not changed (no change in visits)	75%	59%	61%
WHO GIVES YOU HELP WITH DAILY LIVING ACTIVITIES?			
Family member	0%	5%	4%
Friend	13%	3%	4%
Health aide	7%	1%	2%
Spouse/partner	7%	18%	17%
I do not need any assistance.	70%	68%	68%
Other	3%	5%	5%
I EXPERIENCE STIGMA BASED ON MY HIV/AIDS STATUS			
Yes	8%	10%	90%
No	92%	90%	10%

a = The percentages represent column percentages.

Table 6: Accessing care by age

	Age			
	26-49 ^a	50-64 ^a	65+ ^a	Total ^a
HIV AND PCP THE SAME PROVIDER				
Yes	80%	66%	62%	62%
No/Don't Know	20%	34%	38%	38%
NUMBER OF HEALTHCARE PROVIDERS SEEN IN THE LAST 6 MONTHS				
0 Providers	7%	5%	6%	6%
1 Provider	33%	19%	11%	18%
2 Providers	33%	24%	29%	22%
3+ Providers	27%	52%	54%	54%
ALL OF MY HEALTHCARE PROVIDERS KNOW THAT I AM LIVING WITH HIV OR AIDS.				
Yes	93%	95%	98%	96%
No/Don't Know	7%	5%	2%	4%
I FEEL THAT MY PROVIDER GIVES ME ENOUGH TIME TO ADDRESS MY CONCERNS AND QUESTIONS				
Yes	73%	69%	82%	74%
Depends on the provider	7%	6%	8%	6%
No	0%	4%	2%	4%
Sometimes	20%	21%	8%	16%
MY PROVIDER GIVES ME ENOUGH TIME TO DISCUSS OTHER THINGS OF IMPORTANCE TO ME				
Yes	73%	66%	76%	71%
Depends on the provider	7%	6%	6%	6%
No	0%	6%	2%	4%
Sometimes	20%	22%	16%	19%
USED TELEMEDICINE IN PAST 12 MONTHS				
Yes	73%	78%	78%	80%
No	27%	22%	22%	19%
HAS THE COVID-19 PANDEMIC IMPACTED YOUR ABILITY TO ACCESS HEALTHCARE SERVICES?				
Yes	33%	40%	37%	40%
No	67%	54%	62%	55%
Unsure/Don't Know	0%	5%	1%	5%
HOW HAS COVID-19 IMPACTED THE FREQUENCY OF YOUR HIV-RELATED CARE (DOCTOR) VISITS				
The frequency has decreased (less visits)	33%	43%	29%	36%
The frequency has increased (more visits)	0%	3%	1%	3%
The frequency has not changed (no change in visits)	67%	54%	70%	61%
WHO GIVES YOU HELP WITH DAILY LIVING ACTIVITIES?				
Family member	13%	4%	3%	4%
Friend	7%	2%	5%	4%
Health aide	0%	1%	2%	2%
Spouse/partner	7%	14%	25%	17%
I do not need any assistance.	73%	74%	57%	68%
Other	0%	5%	8%	5%
I EXPERIENCE STIGMA BASED ON MY HIV/AIDS STATUS				
Yes	93%	89%	94%	90%
No	7%	11%	6%	10%

^a = The percentages represent column percentages.

Table 7: Ryan White and ADAP access by length of time living with HIV

How long have you lived with HIV?			
	1-14 years ^a	15 or more years ^a	Total ^a
ACCESS RYAN WHITE SERVICES			
Yes	50%	53%	53%
No/ Unsure/Don't Know	50%	47%	47%
ACCESS HIV MEDICATIONS THROUGH A STATE ADAP			
Yes	53%	41%	42%
No	41%	52%	51%
Unsure/Don't Know	6%	4%	4%
N/A	0%	3%	3%
ADEQUATE ACCESS TO SUPPORT SERVICES			
Yes	85%	78%	79%
No	3%	15%	13%
Unsure/Don't Know	12%	7%	8%

a = The percentages represent column percentages.

Table 8: Ryan White and ADAP access by Age

Age				
	26-49 ^a	50-64 ^a	65+ ^a	Total ^a
ACCESS RYAN WHITE SERVICES				
Yes	60%	38%	49%	37%
No/ Unsure/Don't Know	40%	62%	51%	53%
ACCESS HIV MEDICATIONS THROUGH A STATE ADAP				
Yes	27%	41%	41%	40%
No	60%	53%	49%	53%
Unsure/Don't Know	13%	5%	5%	5%
N/A	0%	1%	5%	2%
ADEQUATE ACCESS TO SUPPORT SERVICES				
Yes	67%	73%	87%	79%
No	20%	17%	18%	13%
Unsure/Don't Know	13%	11%	5%	8%

a = The percentages represent column percentages.

Table 9: Behavioral health and substance use by length of time living with HIV

How long have you lived with HIV?			
	1-14 years ^a	15 or more years ^a	Total ^a
IN THE LAST 12 MONTHS HAVE YOU HAD A SEXUAL CONTACT			
Yes	37%	42%	41%
No	56%	56%	56%
Prefer not to answer	7%	2%	4%
IN THE LAST 12 MONTHS, WHEN I HAD SEX, I USED A CONDOM:			
All of the time	23%	21%	21%
Most of the time	0%	3%	3%
Prefer not to answer	10%	5%	6%
Some of the time	23%	24%	24%
None of the time	44%	47%	46%
ARE YOU OR HAVE YOU EVER BEEN IN RECOVERY FROM SUBSTANCE USE?			
Yes	20%	28%	27%
No	76%	71%	72%
Prefer not to answer	3%	1%	1%
HOW MANY PEOPLE IN YOUR PERSONAL LIFE DO YOU FEEL YOU COULD "CALL ON" FOR SUPPORT.			
1 or 2	33%	30%	29%
2 or 3	30%	32%	31%
4 or more	30%	33%	33%
I do not have any people that I could call on.	7%	7%	7%
IN THE LAST WEEK, DID YOU GO 24 HOURS OR MORE WITHOUT MEETING OR TALKING TO A FRIEND OR FAMILY MEMBER?			
Yes	17%	33%	32%
No	83%	67%	68%

a = The percentages represent column percentages.

Table 10: Behavioral health and substance use by age

	Age			
	26-49 ^a	50-64 ^a	65+ ^a	Total ^a
IN THE LAST 12 MONTHS HAVE YOU HAD A SEXUAL CONTACT				
Yes	27%	41%	57%	41%
No	73%	58%	35%	56%
Prefer not to answer	0%	1%	8%	3%
IN THE LAST 12 MONTHS, WHEN I HAD SEX, I USED A CONDOM:				
All of the time	13%	19%	22%	21%
Most of the time	13%	2%	2%	3%
Prefer not to answer	7%	19%	30%	6%
Some of the time	20%	8%	2%	24%
None of the time	47%	52%	44%	46%
ARE YOU OR HAVE YOU EVER BEEN IN RECOVERY FROM SUBSTANCE USE?				
No	87%	73%	78%	72%
Prefer not to answer	0%	1%	2%	1%
Yes	13%	27%	21%	27%
HOW MANY PEOPLE IN YOUR PERSONAL LIFE DO YOU FEEL YOU COULD "CALL ON" FOR SUPPORT.				
1 or 2	20%	29%	27%	29%
2 or 3	40%	29%	37%	31%
4 or more	40%	35%	30%	33%
I do not have any people that I could call on.	0%	8%	6%	7%
IN THE LAST WEEK, DID YOU GO 24 HOURS OR MORE WITHOUT MEETING OR TALKING TO A FRIEND OR FAMILY MEMBER?				
Yes	33%	37%	19%	32%
No	67%	63%	81%	68%

a= The percentages represent column percentages.

ABOUT THE POZITIVELY AGING PROGRAM

HealthHIV's Pozitively Aging program improves access to services and care coordination for people with HIV (PWH) over 50. Health outcomes through enhancing care coordination/access, health literacy, and patient-provider communications.

Pozitively Aging offers consumer facing education materials to strengthen self-management of care and health literacy for people aging with HIV.

HealthHIV's National Resource Center for Care Coordination and Pozitively Aging with HIV

The National Resource Center from HealthHIV builds the capacity of HIV and primary care providers to coordinate care for people living and aging with HIV across a lifetime. This program enhances provider and patient knowledge related to the experiences of PWH over 50 and the comanagement of conditions associated with aging with HIV through data collection and medical education. Access the National Resource Center at AgingWithHIV.org.

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