HealthHIV
POZITIVELY
AGING

HealthHIV STATE OF Aging with HIV™

Fourth Annual National Survey

Report on Findings

JANUARY 2025

Introduction

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In 2022, individuals aged 50 and older comprised over 54% of those living with HIV in the United States.[1] For the purposes of this report, People Aging With HIV (PAWH) are defined as individuals aged 50 and older who are living with HIV. This group includes Long-Term Survivors, Lifetime Survivors ("dandelions"), and Older People with HIV. PAWH face a disproportionate burden of chronic conditions, with those over 65 requiring specialized clinical care and quality-of-life improvements. The group also includes individuals under 50 who began antiretroviral therapy (ART) before 2006 and are now experiencing aging-related complications due to older, more toxic treatments. These conditions often include cardiovascular disease, diabetes and metabolic complications, COPD, liver and kidney disease, neuropathy and motor function issues, lower bone density, cognitive decline and neurocognitive disorders, and higher cancer risk—many of which manifest 10–15 years earlier than in the general population.[2]

In addition to physical health challenges, PAWH frequently experience significant social isolation and loneliness, which increases their risk for depression and anxiety. Robust social support systems are crucial for improving their mental health and overall quality of life.[3] As the PAWH population continues to grow, there is an increasing urgency for a reimagined care framework—one that addresses the accelerated aging process and the complex health needs unique to this group. This shift also highlights the importance of training healthcare providers in both HIV care and geriatric care to meet these emerging demands.[4]

About the Survey

HealthHIV's Fourth Annual State of Aging with HIV™ National Survey examines crucial issues facing long-term survivors and adults aging with HIV. For the first time, this survey has two population focuses—one that reached the PAWH community and one that reached the workforce that provides health and human services to the population. The survey data was collected between August and September 2024 and included responses from 907 participants.

In coordination with HealthHIV's Pozitively Aging program, the survey is dedicated to improving access to services and care coordination for People with HIV—particularly Lifetime Survivors of HIV and those over 50. Findings from this survey will be used in the creation of vital education and training materials for the HIV care workforce and will inform advocacy and research priorities for the coming year surrounding those aging with HIV.

Since its inception, the survey has highlighted the unique challenges faced by PAWH, including stigma, social isolation, and long-term treatment concerns, often exacerbated by insufficient support services. The past three surveys reveal a shift from initial concerns about access to care—particularly in the immediate aftermath of the COVID-19 pandemic—to a broader focus on how stigma, discrimination, mental health challenges, and the lack of age-appropriate services collectively strain quality of life. Additionally, the number of people using telehealth in the past year fell by 12% from the previous survey, suggesting a potential barrier to accessing remote care. For the second consecutive year, participants listed "**complicated**," "**difficult**," and "**challenging**" as the top three words to describe aging with HIV, underscoring the persistent struggles they face daily. Mental health concerns remain significant, with approximately 80% reporting moderate to high levels of stress and over 60% having received diagnoses for depression or anxiety, as reflected in both the 2023 and 2024 surveys.

When asked to describe aging with HIV in one word, participants most frequently said, "challenging," followed by the descriptors "difficult" and "complicated," — for the second year in a row. Providers and community members were completely aligned, with both groups selecting the same three top words.

Key Findings

HealthHIV's Fourth Annual State of Aging with HIV National Survey sheds light on critical issues affecting PAWH and the workforce that supports them. The findings reveal four interconnected challenges: financial precarity and persistent insurance gaps that block access to essential care, declining quality of life driven by widespread mental health challenges, a shortage of aging-focused services leaving caregivers and communities unsupported, and rising frustration with the healthcare system and insufficient government protections. Together, these findings underscore the urgent need for targeted interventions, enhanced advocacy, and systemic changes to better address the complex and evolving needs of PAWH.

Financial precarity and persistent insurance gaps impact the vast majority of PAWH and block access to essential care

Nearly half of respondents lack a financial plan for retirement, and the majority of those who have one are unsure if it will cover potential long-term care needs. Over three-quarters avoided or delayed seeking medical care in the last year due to concerns about insurance coverage or out-of-pocket costs.

The gap is widening between aging services and the specific needs of PAWH, leaving them and their caregivers unsupported and without tailored resources, training, or support

Most organizations recognize the need for aging-focused services, but many haven't implemented them. More than half of providers believe that informal caregivers of older persons with HIV lack necessary support. Broader aging services are fragmented from HIV-specific programs like Ryan White, especially with transitions to Medicare.

Continued decline in quality of life for many PAWH, largely driven by mental health challenges such as depression and anxiety

More than three-quarters (76%) of PAWH experienced moderate to high mental health stress over the last six months, and mental health diagnoses, like depression or anxiety, were the second most common comorbidity impacting PAWH.

Increasing discontent and anger with the health care system reflects widespread community fatigue and insufficient government protections

Most PAWH (72%) feel the government isn't adequately addressing their needs, and the vast majority of all respondents—97% of providers and 88% of community members—call for enhanced advocacy efforts for the aging HIV community.

> *"Our systems are not designed to support people living and aging with HIV. Even though my husband and I are financially doing relatively well and retiring soon, like everyone else I'm worried that I'm one catastrophic illness away from poverty. If something happens to me or my spouse, who is going to look after, help and support the one who's left behind? We need long-term care facilities and more housing for PLWH who cannot live independently, and we need more training for compassionate and stigma-free care for PLWH and LGBTQ+ people over 50."*
>
> — SURVEY RESPONDENT, PERSON WITH HIV

Participant Profiles

Description and Eligibility: Community Participants

Community members answered questions about psychosocial needs, healthcare needs, and financial challenges from the perspectives of people living with HIV (PAWH) in 2024. The community survey also focused on access to care and quality of life for older people with HIV (OPWH). Eligibility for this survey includes individuals aged 50 and older who are living with HIV and/or who have been living with HIV for 15+ years, regardless of their current healthcare access or socioeconomic status, to assure applicability to the general population.

Community Participant Profile

Community respondents were primarily gay men living in urban settings. About half were employed full-time and 92% had at least some level of higher education. Participants represented 40 states, Puerto Rico and the District of Columbia. The majority of responses came from New York, California, Florida, and Georgia.

92% with higher education

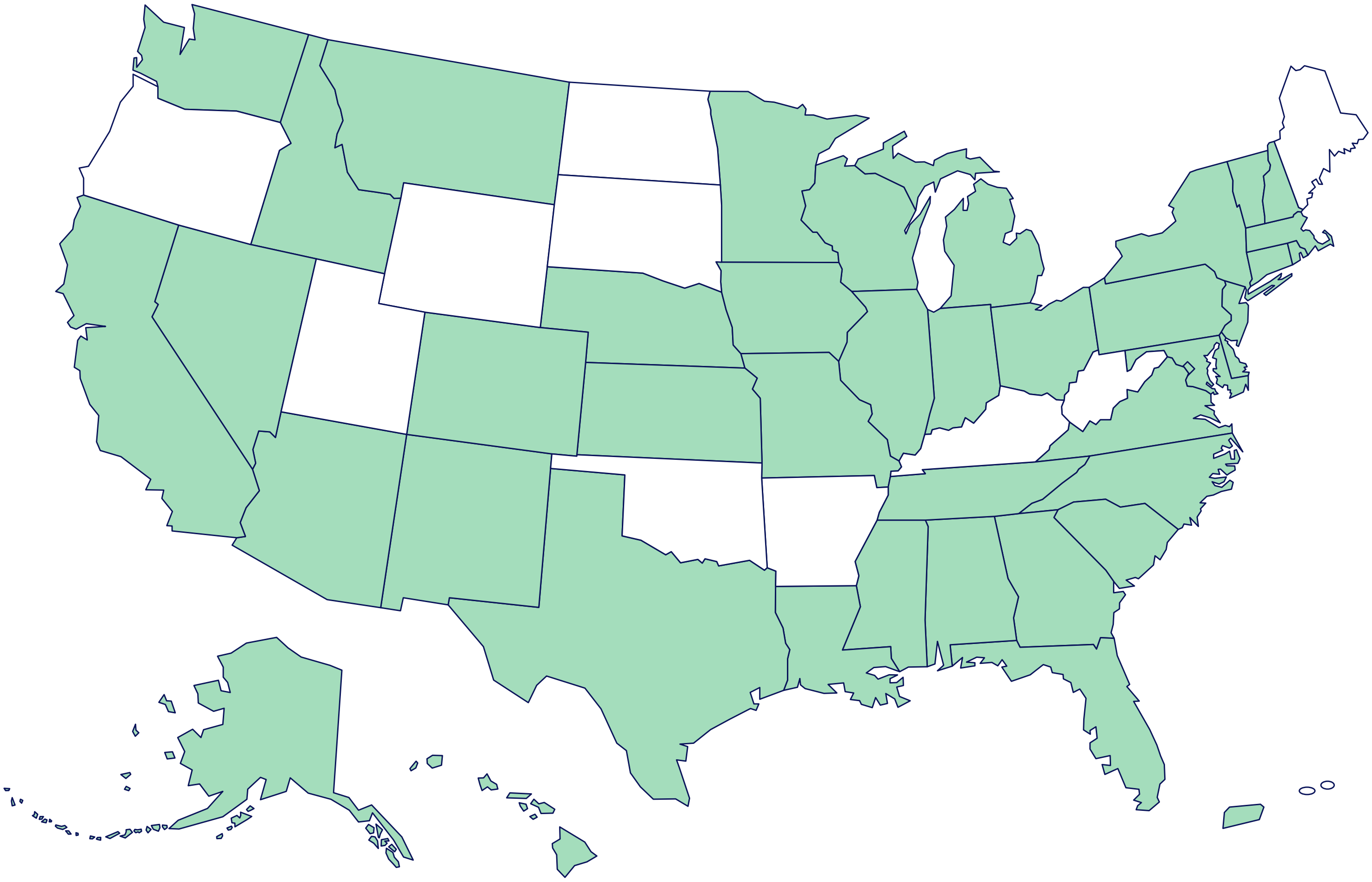
56% lesbian or gay

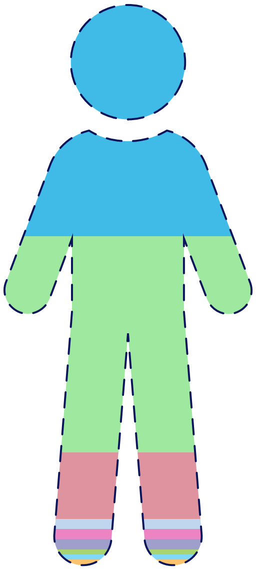
65% male

55% live in an urban area

95% are virally suppressed

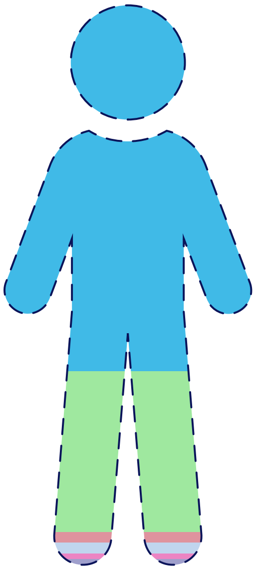
All were 50 years or older and/or have been living with HIV for 15+ years. More than half (54%) have received an AIDS diagnosis, and of those, about half (51%) were considered late diagnoses. Almost all respondents are currently virally suppressed (95%).





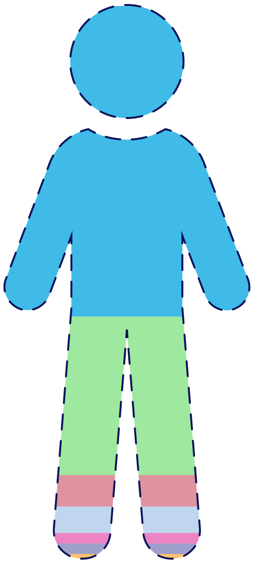
Race

Black or African American	41.3%
White or Caucasian	38.5%
Hispanic or Latino/a/x	11.9%
Native American or Alaska Native	1.8%
Middle Eastern or North African	1.8%
Other	1.8%
Asian or Southeast Asian	.9%
Prefer not to say	.9%
Native Hawaiian or Pacific Islander	.9%



Gender Identity

Male/man	65.4%
Female/woman	28.8%
Nonbinary	1.9%
Transgender female/woman	1.9%
Genderqueer, or not exclusively female or male	1.0%
Another gender	1.0%



Sexual Orientation

Lesbian/Gay	56.2%
Straight/heterosexual	28.6%
Bisexual	5.7%
Queer	4.8%
Something else	1.9%
Prefer not to answer	1.8%
Pansexual	1.0%

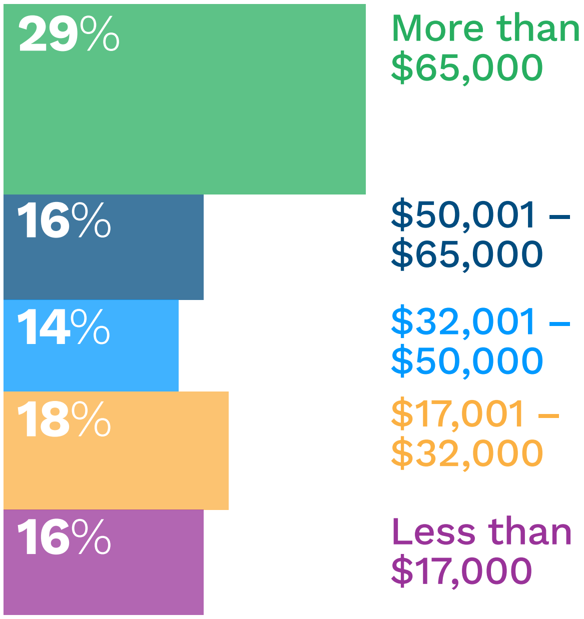
Geographic Setting

55% Urban

27% Suburban

18% Rural

Annual Household Income



While nearly a third of respondents (30%) made over $65,000 annually, just as many (34%) made below $32,000 annually.

Description and Eligibility: Workforce Participants

Providers answered questions about psychosocial needs, healthcare needs, and financial challenges from the perspectives of the HIV workforce in 2024. Topics also included barriers to providing care, training needs, and strategies surrounding HIV treatment and prevention for the aging population. Eligible participants included healthcare providers, case managers, community health workers, and policy advocates who work with people aging with HIV. The participants in the workforce survey were both non-clinical and clinical professionals who all have diverse perspectives on their patients/clients aging with HIV.

Workforce Participant Profile

Respondents were primarily white and black women who perform non-clinical roles in urban settings. Case managers were the most common professional type, followed by administrators and physicians. The majority of respondents worked at non-profit organizations, Ryan White HIV/AIDS Clinics, Community Based Organizations (CBOs), 340B HRSA Ryan White Covered Entities, AIDS Service Organizations (ASOs) or Federally Qualified Health Centers (FQHCs). Participants represented 41 states, Puerto Rico, the U.S. Virgin Islands, and the District of Columbia.

72% women

65% non-clinical roles

40% white/caucasian

30% black/African American

Years in the Role

12% <2 years

21% 2–4 years

24% 5–10 years

21% 11–20 years

22% 21+ years

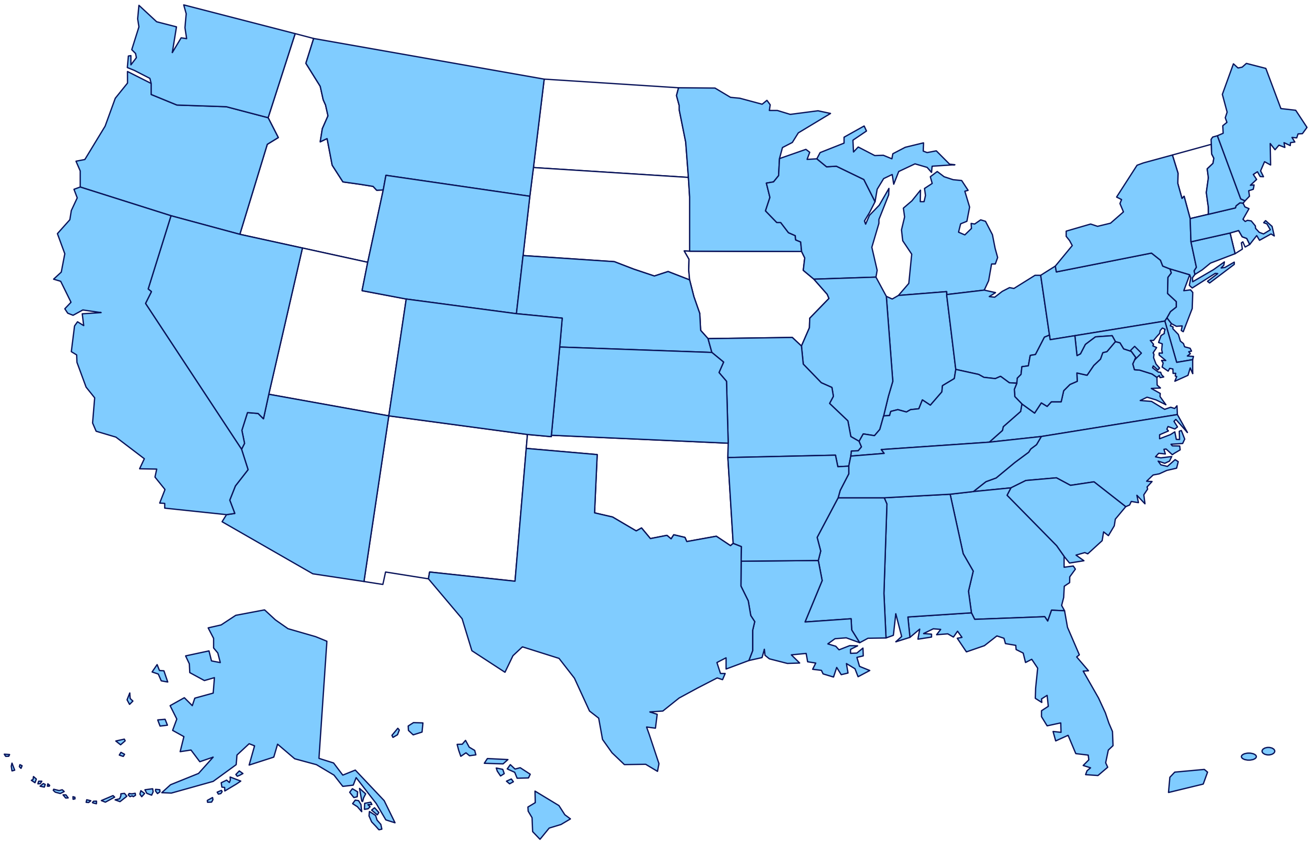
Geographic Setting

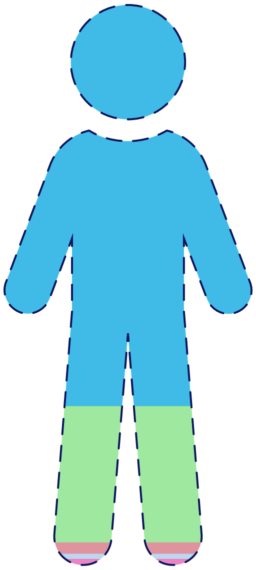
60.4% Urban

22.8% Rural

15.8% Suburban

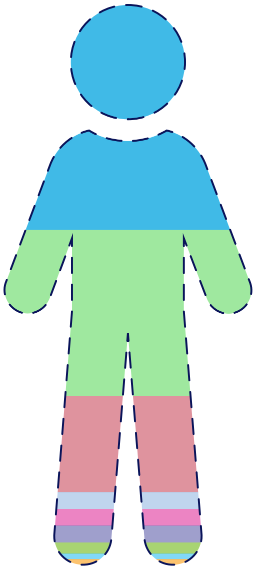
1.0% Tribal





Gender Identity

Female/woman	71.7%
Male/man	24.2%
Nonbinary, genderqueer, or not exclusively female or male	2.0%
Transgender female/woman	1.0%
Prefer not to answer	1.0%



Race

White or Caucasian	40.4%
Black or African American	29.8%
Hispanic or Latino/a/x	17.3%
Asian and/or Asian American	2.9%
Multiracial	2.9%
Prefer not to disclose	2.9%
Native American or Alaska Native	1.9%
Middle Eastern or North African	1.0%
Native Hawaiian or Pacific Islander	1.0%

Professional Role

Case Manager/Medical Case Manager	20.8%
Other	14.2%
Administrator	9.3%
Physician (MD/DO)	8.1%
Community Health Worker	7.2%
Registered Nurse (RN)	5.8%
Data Manager	2.9%
Licensed Clinical Social Worker (LCSW)	2.6%
Disease Intervention Specialist	2.6%
Health Navigator	2.3%
Outreach Worker	2.3%
Nurse Practitioner (NP)	2.3%
Harm Reductionist/Risk Reductionist	2.0%
Peer Counselor	1.7%
Medical Assistant (MA)	1.7%
Licensed Practical Nurse (LPN)	1.5%
Physician Associate (PA)	1.5%
Patient Coordinator	1.5%
Training and Development Specialist	1.2%
Pharmacist	1.2%
Dietitian/Nutritionist, Psychologist, Certified Nursing Assistant (CNA), Administrative Assistant, Caregiver, Health Education Specialist, Patient Advocate, Substance Use Counselor, Dentist, Optometrist, Pharmacy Technician, Psychiatrist, Billing Specialist, Finance/Fiscal Manager, IT Specialist	Less than 1%

Organization Type

Non-Profit Organization	10.9%
Ryan White HIV/AIDS Clinic	10.4%
Community-Based Organization	9.1%
340B HRSA Ryan White Covered Entity	8.7%
AIDS Service Organization (ASO)	5.2%
Federally Qualified Health Center (FQHC)	5.2%
Health Department Clinic	4.4%
Medical Center	4.4%
STD Clinic 330 Provider	3.9%
Government Entity (Local, State, Federal)	3.5%
Mental Health Services	3.5%
Health Department Non-Clinic	3.5%
Housing Services	3.0%
340B Contract Pharmacy	3.0%
LGBTQ+ Health Center	2.6%
University or College Health Service Center	2.6%
AIDS Drug Assistance Program (ADAP)	2.6%
Behavioral Health Organization	2.2%
Addiction Services Provider/Clinic	1.7%
Advocacy Organization	1.7%
Reproductive or Sexual Health Clinic	1.3%
Substance Use Treatment Facility	1.3%
Other	1.3%
Community Hospital, Private Practice, Independent Pharmacy, Faith-Based Organization, Private Hospital or Clinic, Veterans Health Administration (VA)	Less than 1%

Survey Findings

Part One: Community

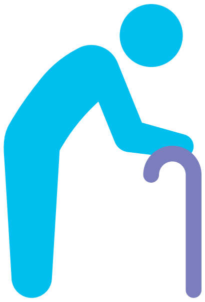
Overall Health and Quality of Life

PHYSICAL HEALTH

Survey findings on the physical health of participants reflect the significant physical and emotional toll of aging with HIV. Participants expressed concerns about long-term health and quality of life, and noted gaps in frailty prevention and early intervention.

⅓ experience difficulty with balance, mobility or physical activities due to HIV, but three-quarters say they have not been screened for frailty or fall risk in the past year (32%).

> *"Mobility is definitely being challenged as joint stiffness and pain increase."*
>
> —SURVEY RESPONDENT, PERSON WITH HIV



- **Frailty is defined as the presence of three or more of the following criteria:** unintentional weight loss, self-reported exhaustion/fatigue, weakness (grip strength), slow walking speed, and low level of physical activity.[5]
- Screening older people with HIV and HIV long-term survivors for frailty is critical because it allows early identification of and prevention of declining health.

Nearly a third of respondents had their last dental check-up over a year ago.

Dental check-ups are recommended every six months for older individuals.[6] In 2023, the Federal Reserve reported that dental care was the service most commonly skipped by Americans due to lack of insurance coverage.[7]

Almost half of respondents (47%) experienced significant body changes (e.g. weight gain or loss) that have caused them to become concerned about their health in the last year.

> *"I'm aging faster than my peers: hearing problems, vision problems, joint pain, foot pain, belly fat, loss of motivation, loss of sex drive, memory issues..."*
>
> — SURVEY RESPONDENT, PERSON WITH HIV

The vast majority of respondents are proactive with vaccinations:

86% get an annual flu shot

72% have received one or both shingles vaccines

72% are up to date on their COVID-19 boosters

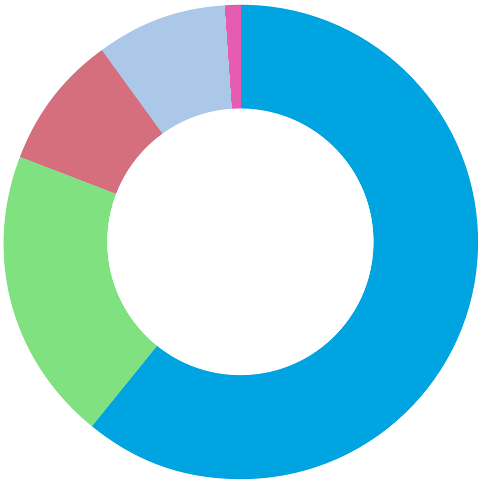
81% are up to date on their pneumonia vaccinations

- ▶ **Less than half (48%) are aware of the new FDA-approved Pneumonia vaccination, called PCV20.**

This October, the CDC lowered the recommended age for the PCV20 pneumonia vaccine to 50 years.[8] This is significant for older people with HIV, as they are at a higher risk for complications from pneumococcal pneumonia and access to this non-invasive vaccine can help prevent serious infections, improve overall health outcomes, and address health disparities.

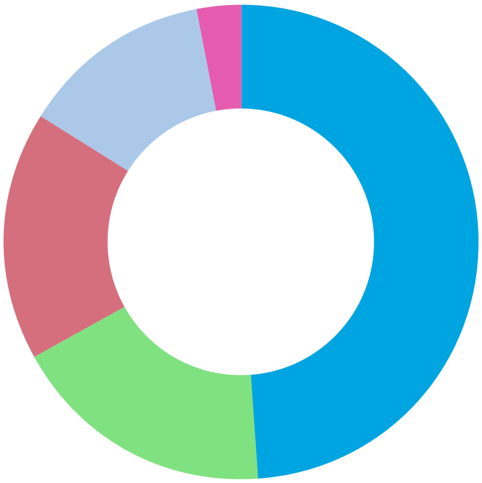
Many respondents (60%) rated their overall physical health as "good," but less than half rated it as "good" when asked to compare it to people their age who are not living with HIV.

How would you rate your overall physical health?



Good	60.9%
Neutral	20.0%
Poor	9.1%
Excellent	9.1%
Very Poor	0.9%

How would you rate your health in comparison to people your age who aren't living with HIV?

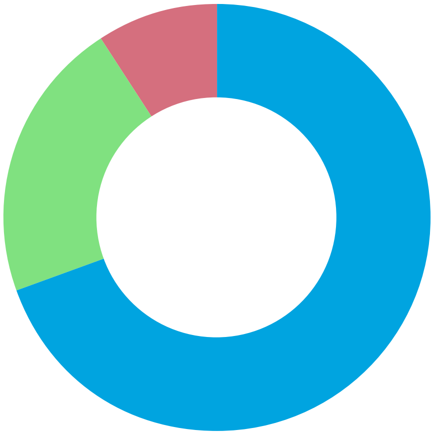


Good	49.0%
Poor	18.0%
Neutral	17.0%
Excellent	13.0%
Very Poor	3.0%

Social and Mental Health

Findings reveal a population that values social connections and faces varying degrees of isolation and mental distress, with substance use being relatively common. While many are socially engaged and have support networks, mental health and substance use may be important areas to address in efforts to improve their overall well-being.

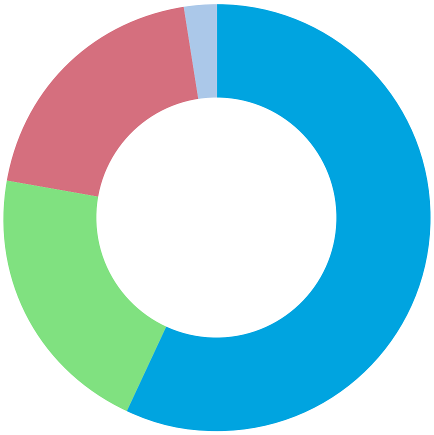
How would you rate your overall quality of life?



Good	69.7%
Neutral	21.2%
Poor	9.1%

> *"There needs to be a greater support system in nearly every community to counter loneliness, stigma, and cognitive decline."*
> — SURVEY RESPONDENT,
> PERSON WITH HIV

What is your current housing status?

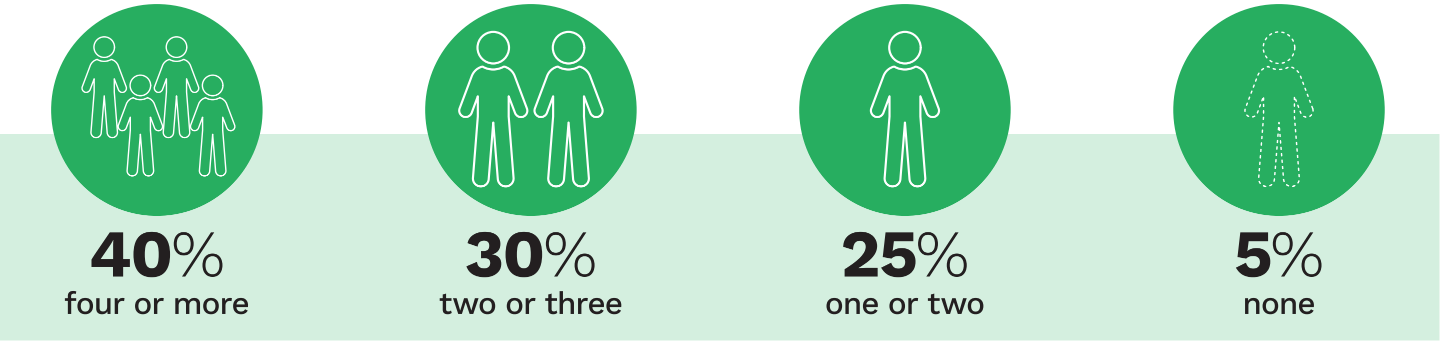


Live alone in my own home	49.0%
Live with others in my own home	18.0%
Temporarily staying with a relative or friend	17.0%
Unstably housed or staying in a shelter	2.0%

> *"I [have] no support if I get sick or incapacitated because I have somehow outlived all of the people in my support network."*
> — SURVEY RESPONDENT,
> PERSON WITH HIV

The vast majority say **participation in social groups or community organizations is important to their well-being** (85%) and many are active participants in such groups (70%).

Number of people in your personal life you could call on if you had an immediate need:

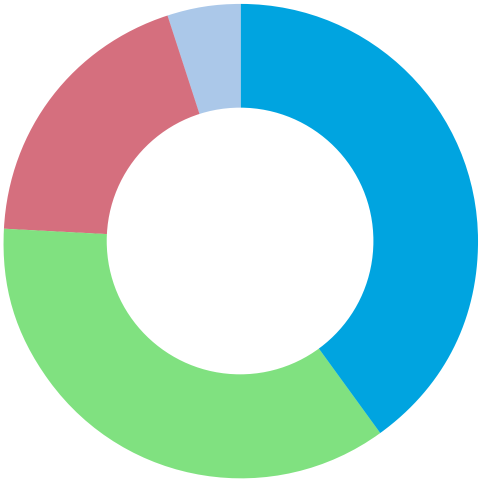


40%	30%	25%	5%
four or more	two or three	one or two	none

More than half of respondents have experienced a lot or a moderate amount of mental health stress in the past six months.

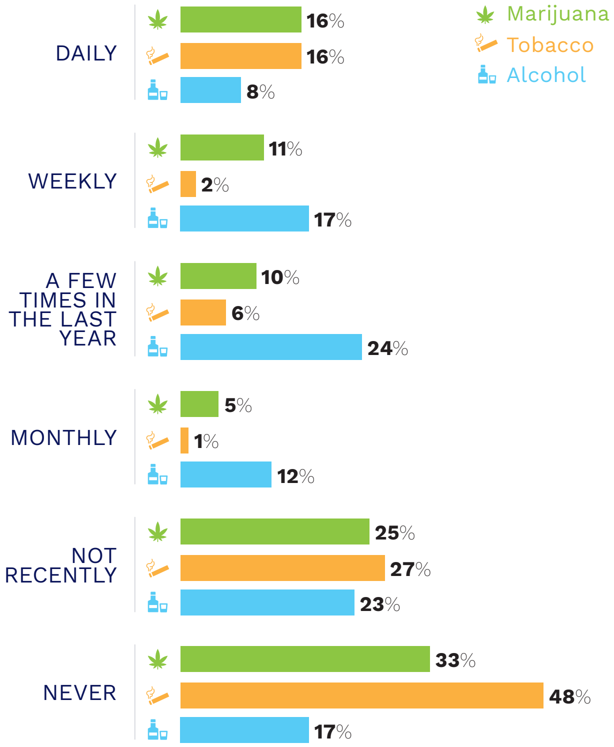
> *"For me, the aspects of daily living most impacted by HIV are mental health and social interactions, particularly navigating stigma and managing stress related to long-term treatment."*
>
> — SURVEY RESPONDENT, PERSON WITH HIV

In the past six months, how much mental health stress have you experienced?



A moderate amount of stress	40.0%
A lot of stress	36.0%
Relatively little stress	19.0%
Almost no stress at all	5.0%

Frequency of substance use



> *"HIV has left a "scar" on my mental health that has interfered with me having close relationships."*
>
> — SURVEY RESPONDENT, PERSON WITH HIV

Financial Security

Concerns about healthcare costs are pervasive, leading to delays in seeking medical attention. Assistance programs are widely utilized, but many still struggle with basic expenses like housing and utilities and there is notable dissatisfaction with insurance providers. Many feel unsupported by their insurance provider in managing their HIV and aging needs, which could result in decreased access to necessary treatments and increased vulnerability to financial hardship.

Almost half (45%) **do not have a financial plan for retirement** and even among those who do, the vast majority (76%) **do not feel it is enough if they ever need long-term or supportive care.**

These findings underscore the critical need for sustained support through assistance programs like the AIDS Drug Assistance Program (ADAP), the Ryan White Program (RWP), and co-pay assistance. These programs play an essential role in bridging the affordability gap, ensuring that aging individuals with HIV can access the medications and care they require. Yet, the significant reliance on these programs and the high rates of delayed or avoided care due to cost reveal persistent vulnerabilities in the system. As newer medications become available and cost challenges continue, it's crucial to advocate.

Many respondents are avoiding or delaying seeking medical care in the last year due to concerns about insurance coverage or out-of-pocket costs (79%), underscoring how restrictive formularies in Medicare Part D contribute to financial strain, impeding older PAWH from accessing essential medications consistently. Research shows that in 2023, 27% of American adults avoided medical care due to prohibitive costs.[7] The significantly higher rate found by State of Aging survey respondents reflects the considerable financial burden facing long-term HIV survivors.

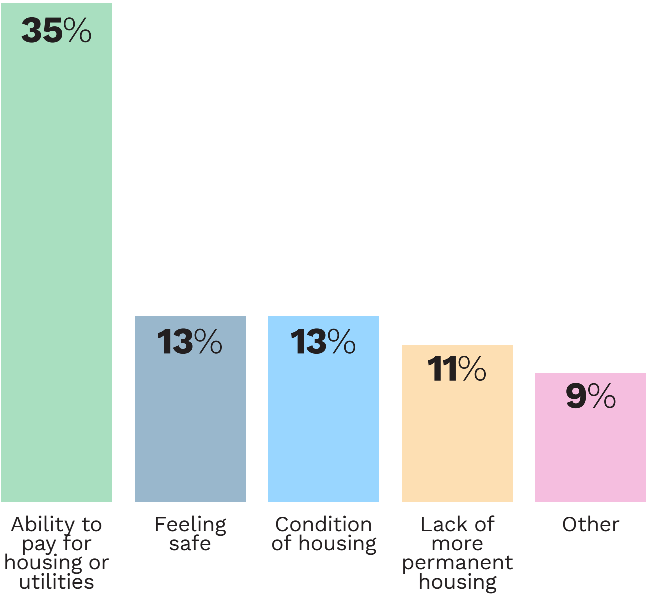
Patient assistance programs or co-pay assistance for their HIV medications were **used by 60% of respondents** in the last year.

Ability to pay for housing or utilities listed as top concern about living situation

In the last year...

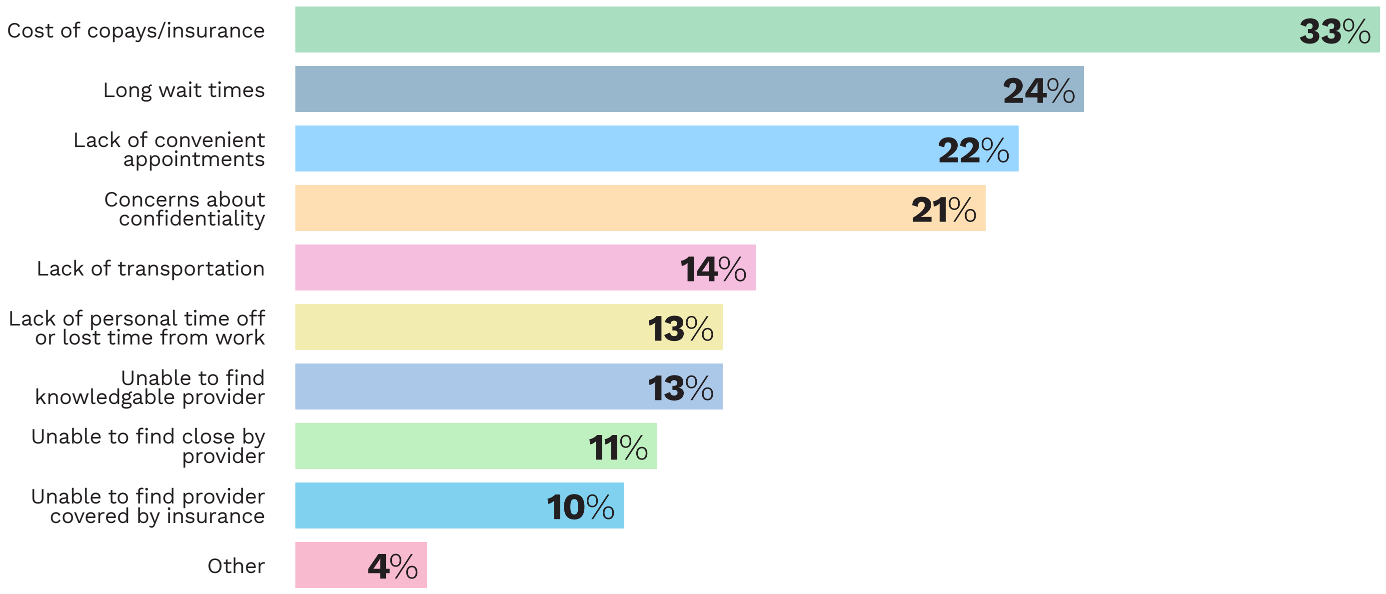
- 33% had trouble paying debts
- 32% had trouble paying for food
- 27% had trouble paying for housing
- 23% had trouble paying for heat and electricity

Top concerns about living situation



Cost of copays named as the greatest barrier to seeking healthcare

Top barriers faced when seeking healthcare



INSURANCE EXPERIENCES

- **Nearly half feel their health insurance provider is not doing enough to support their HIV and aging needs (47%)**
- **A quarter of respondents have had to switch pharmacies due to insurance plan or formulary changes**
- **Too many are not confident that their insurance would cover necessary HIV-related medical expenses in case of an emergency (22%)**

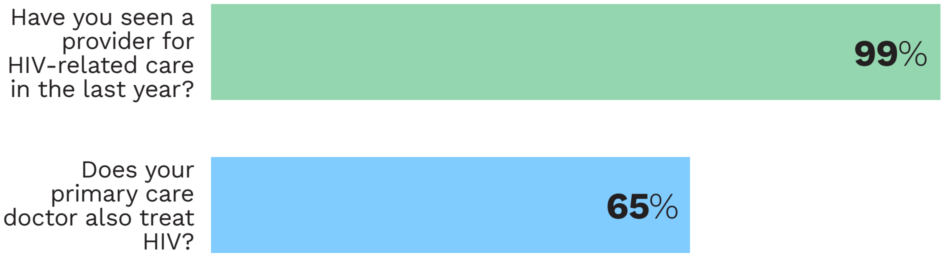
Restrictive insurance practices pose significant barriers to treatment continuity, especially for PAWH managing multiple comorbidities. Medicare Part D plans are mandated to cover “all or substantially all” drugs in specific protected classes, such as antiretrovirals used for HIV treatment. However, research from the University of Southern California has documented a significant increase in drug exclusions and utilization restrictions from 2011 to 2020, with coverage exclusions rising from 20.4% to 30.4%. Additionally, the share of drugs subject to utilization management, such as prior authorization or step therapy, increased by over 20%, impacting 14.4% of covered medications.[9]

It is evident that policy adjustments are crucial for ensuring reliable and comprehensive drug coverage under Medicare Part D. Addressing utilization management practices and fostering an inclusive formulary are essential for supporting medication adherence and improving health outcomes for PAWH. The new Medicare Part D Prescription Payment Plan (M3P), effective in January 2025, enables older adults with HIV to spread their out-of-pocket prescription costs over the year, capped at $2,000 annually. While the program aims to ease financial burdens and improve medication adherence, concerns include hidden copays for specialty drugs and potential delays due to increased utilization management, such as prior authorizations. CMS plans to release educational materials, but additional advocacy is essential to ensure that older adults fully understand enrollment and cost implications.

Clinical Care for Older People With HIV

HIV TREATMENT

Most respondents are actively engaged in HIV-related care, with many seeing a primary care doctor who manages both their general health and HIV treatment. However, many note that providers are not always knowledgeable about their specific needs as PAWH.

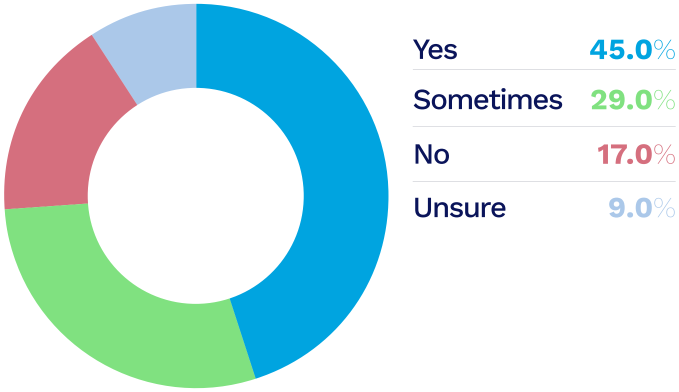


All participants are taking ARV medications to treat their HIV, and **the majority (79%) do not have treatment concerns**, like viral blips or having acquired treatment resistance.

A small number are currently experiencing side-effects from their HIV medications (12%), but **nearly three quarters of those who are**, said the side effects **negatively impact their quality of life** (72%).

> *"I've been on a half-dozen or more regimens, each of which got changed due to side effects: AZT lowered my white count, d4T gave me wasting and neuropathy, Sustiva gave me vivid dreams at a time when I was already having mental health issues, abacavir perhaps gave me a coronary artery blockage, Odefsey needed to be taken with food…"*
>
> — SURVEY RESPONDENT, PERSON WITH HIV

Are healthcare providers knowledgable about the specific needs of older persons with HIV?



- **More than a third of respondents** shared their provider does not talk to them about new approaches to long term care or developments in HIV treatment practices (34%)
- Too many say their provider **does not ask them about their sexual history** (22%)

> *"HIV does not exist in isolation … [it] is an inextricable part of living and aging with HIV. HIV specialists need to consider how aging affects health and treatment, and how HIV treatment affects aging with HIV. Gerontologists need to become more knowledgeable about HIV. This training needs to start in medical school."*
>
> — SURVEY RESPONDENT, PERSON WITH HIV

CARE COORDINATION

The vast majority of respondents (86%) have not had problems getting their HIV medications on time in the last year, up 6% from the last State of Aging survey. However, **coordinating HIV care with primary care and treatment of chronic illness continues to pose significant barriers to the aging community**, a significant portion of whom are living with at least one other comorbid condition.

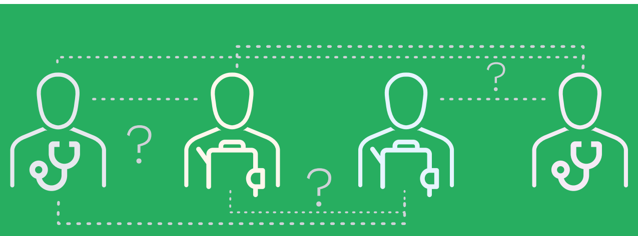
Most say they would go to a private doctor's office or health center first if they needed medical care for HIV, but almost one third have gone to an urgent clinic or emergency department (ED) for non-urgent primary care in the last year (30%).

- This reliance on EDs is notable for a chronic condition like HIV, which typically requires ongoing management in outpatient settings. Several factors may contribute to this trend: some PAWH may lack access to local specialized services or face transportation challenges that make reaching clinics difficult, leading them to use EDs as the most accessible option. Others might experience urgent health needs requiring immediate attention or encounter long wait times for appointments at clinics and private practices. Additionally, concerns about stigma or past negative experiences in traditional care settings might deter some PAWH from seeking routine care elsewhere.

About a third of respondents currently receive case management services at a community-based organization or clinic; the majority do not (63%).

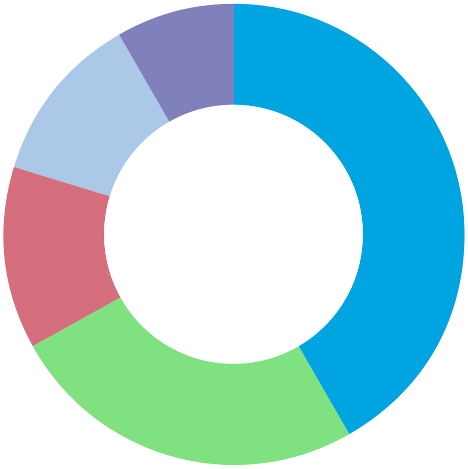
- Several factors could contribute to this lack of engagement. Some PAWH might feel confident in managing their health independently and prefer to make decisions without assistance from a case manager. Others may not qualify for medical case management services due to income levels or insurance status, as eligibility criteria can sometimes exclude those who could benefit from additional support.

More than a quarter of participants say their providers **do NOT coordinate or communicate** with one another about their care and prevention needs (27%).



> *"My primary concerns about aging with HIV in the next 5-10 years include the potential for increased health complications, such as cardiovascular disease, cognitive decline, and other comorbidities that may be exacerbated by long-term HIV and its treatments."*
>
> — COMMUNITY MEMBER

Most only have to use one pharmacy to fill their prescriptions, but as much as 30% have to use two or three pharmacies.



What types of pharmacies do you use to fill your prescriptions?

Retail pharmacy	41.8%
Mail order	25.4%
Community clinic	12.7%
Hospital pharmacy	11.9%
Community-based organization	8.2%

Most respondents (81%) are taking medication for a chronic medical condition other than HIV, and too many (17%) have had to adjust their HIV medication regimen due to interactions with medications for other age-related conditions.

> *"Being a long-term survivor is becoming more challenging because of resistance, and lack of available regimens that I can take effectively. This is complicated by the fact of secondary conditions of kidney, liver and limits what new meds I can take. Also, I have serious allergies to compounds that worsen the available choices."*
>
> — SURVEY RESPONDENT, PERSON WITH HIV

Comorbidities Reported

High cholesterol	62%
Mental health (depression, anxiety, other)	61%
COVID-19	60%
High blood pressure/hypertension	59%
Joint or back pain/injury	58%
Sex drive (loss of, etc.)	43%
Lipodystrophy, wasting, and weight gain	37%
Neuropathy/nerve damage	36%
Periodontitis	36%
High triglycerides	34%
Heart/cardiovascular issues	33%
Pre-diabetes	31%
Osteoporosis/bone loss/bone density	28%
Hearing problems	23%
Precancerous condition	22%
Type 2 onset diabetes	20%
Kidney disease	19%
Cancer	19%
Hepatitis B	17%
Hepatitis C	15%
Anal dysplasia	15%
Lung disease/pulmonary/COPD	15%
Neurocognitive changes	15%
Neurological conditions	11%
Liver disease	9%

These findings raise questions about the impact of care fragmentation. Using multiple pharmacies can lead to medication errors, duplications, and difficulty managing complex treatment regimens. This fragmentation can adversely affect medication adherence and overall health outcomes. Pharmacy deserts—areas with limited access to retail pharmacies—also pose significant challenges for consistent medication access. Limited pharmacy access worsens difficulties for those in underserved areas, creating barriers to continuous treatment and effective health management. Furthermore, when patients obtain medications from multiple sources, it becomes more challenging for community-based organizations, Ryan White Program (RWP) clinics, and AIDS Service Organizations (ASOs) to coordinate care effectively. These organizations often rely on close relationships with patients and integrated pharmacy services to monitor adherence, manage drug interactions, and provide personalized support.

Just over half (56%) have used telehealth in the last year.

- 44% have not, primarily citing a preference for meeting with healthcare providers in-person.

CURRENT HEALTH ISSUES

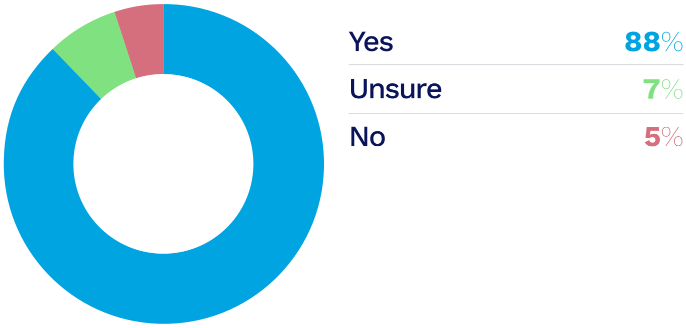
Nearly half of respondents rarely or never undergo non-invasive diagnostic tests for cardiovascular disease. This represents a critical gap that HIV and aging advocacy must focus on. Non-invasive diagnostic tests are valuable for older people with HIV because they enable early detection of cardiovascular disease and frailty without the discomfort and risks associated with invasive procedures and are typically reimbursed by insurance.

More than half of respondents would participate in clinical medication/treatment trials if they were made more aware of them.

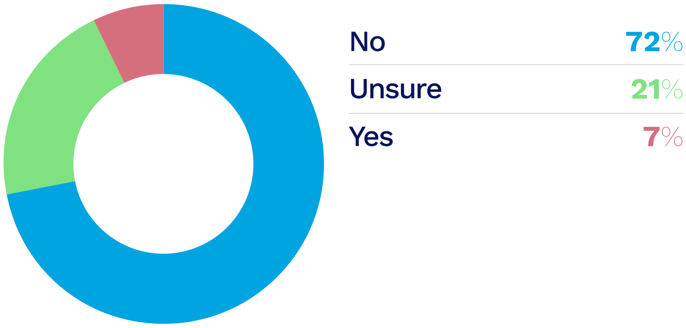
Less than a quarter of respondents are concerned about contracting the mpox virus (20%). This is trending downward 11% from last year.

- However, more than half have not received either dose of the JYNNEOS vaccine for mpox.

Are more advocacy efforts needed to address the needs of people aging with HIV?



Is the U.S. government doing enough to support your HIV and aging needs?



With most respondents expressing the need for increased advocacy to address PAWH (88%), it is clear that policy needs to be more responsive to the changing face of HIV. The Older Americans Act (OAA) is one policy intervention that has historically provided vital support through a variety of social services and programs for individuals aged 60 or older, including supportive services, nutrition programs, home-delivered meals, caregiver assistance, community service employment, and protective measures against abuse and exploitation. However, the OAA's reauthorization remains uncertain amid changing legislative focus, which raises significant concerns for PAWH. The lapse of this essential legislation could result in reduced access to services such as meals, transportation, and health screenings, and may impact the distribution of resources, potentially stalling progress on inclusive, patient-centered care frameworks.

> *"I live in a pretty rural and conservative state. Long term care facilities are not ready for our populations and they [don't] ... have their own internal Ryan White Part B and case management to support [those who] do not have retirement or other plans other than Social security."*
>
> — COMMUNITY MEMBER

Part Two: Workforce

Geriatric HIV Care

The healthcare workforce, particularly in HIV care, faces significant stress with increasing retirements, shortages, and burnout among providers, impacting care continuity for PAWH. The retirement of experienced providers leaves long-standing patients at risk of fragmented care, which can affect their quality of life. These workforce challenges emphasize the need for sustained capacity-building efforts, specialized training, and multidisciplinary support to meet the complex needs of PAWH. This section explores key challenges and gaps in providing specialized care for people aging with HIV, based on provider perspectives. Although most respondents agree their organizations recognize the need for age-focused services, implementation remains limited. Barriers like provider shortages in HIV and geriatric expertise, legal issues, and insufficient support for advanced care planning complicate the care experience, while high rates of patient loneliness and caregiver support inadequacies further underscore the need for comprehensive, patient-centered strategies.

90%

of all respondents believe their organization recognizes the need for services geared towards an aging population but **only 78%** said their organization is actively implementing changes to better serve an aging population.

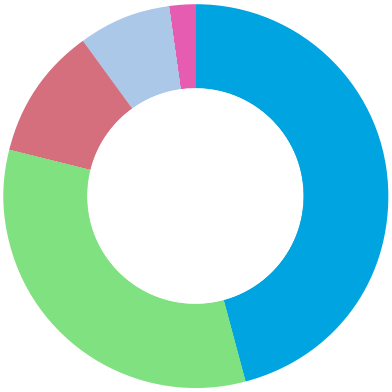
Less than a third of providers (27%) offer end-of-life or advanced care planning services.

This reflects a widespread issue, as studies have repeatedly indicated that end-of-life planning, critical to aging individuals and their families, is often overlooked and/or inaccessible in traditional care settings, particularly to people of color and people.[10]

“Shortage of healthcare providers with expertise in both HIV and geriatric care”

The #1 barrier providers think their aging patients face when trying to access HIV care.

Do patients/clients encounter legal barriers to care, such as issues with guardianship or power of attorney?



Sometimes	46%
Rarely	33%
Often	11%
Never	8%
All the time	2%

The majority of providers say their patients have experienced stigma or discrimination from healthcare providers due to their HIV status or age (59%).

Providers say their older patients/clients with HIV feel lonely or isolated...

49%	39%	11%
often or all of the time	sometimes	rarely

More than half say they do not think the informal caregivers of older people with HIV have adequate access to the support, resources, and training needed to provide care (51%).

Do the informal caregivers of older people with HIV have adequate access to the support, resources, and training needed to provide care?

✓	✗	?
16% yes	**51%** no	**33%** unsure

> *"Isolation and cognitive decline is HUGE for our patients and more information on how to address this would be helpful to receive as a provider."*
>
> — LCSW AT A MICHIGAN MEDICAL CENTER

Almost half have specific policies to ensure appointment flexibility for patients/clients who face transportation challenges (46%).

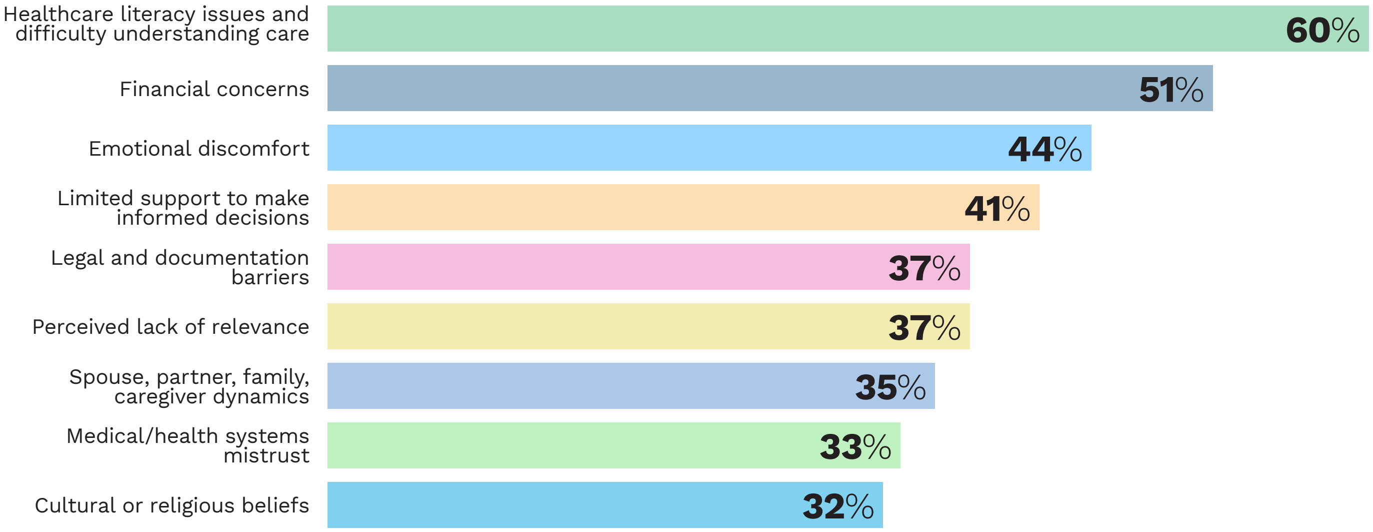
- 36% help informally or on a case-by-case basis
- 13% do not have any policies in place

Almost half say their patients face delays in accessing specialized HIV care due to unreliable transportation services, such as Medicaid transport, often or all the time (40%).

- 36% say sometimes
- 18% say rarely

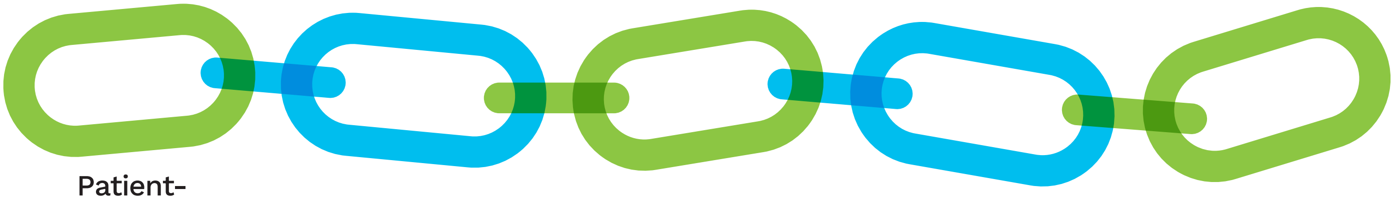
> *"Many clients diagnosed in the 1980-90s Era have expressed that they didn't plan on living so long. Many don't have financial saving because they were not expecting to be here, they have no retirement plans or future ideas"*
>
> — CASE MANAGER AT A PENNSYLVANIA 340B HRSA RYAN WHITE COVERED ENTITY

What barriers do patients face when engaging in advanced care planning?



Engaging in coordinated care, including external referrals and multidisciplinary collaboration, is common among 75% of providers. This approach is essential for addressing the complex needs of older patients with HIV, especially given the high rates of comorbidities in this population. By collaborating across disciplines and connecting patients to appropriate resources, providers can offer more comprehensive care and improve health outcomes.

Strengthening the Chain: Respondents Identified What is Most Needed to Improve Care Coordination



Patient-Centered Approaches	Cross-Sector Collaboration	Incorporation of Social Determinants of Health	Data-Driven Adjustments	Provider Engagement
42%	**19**%	**19**%	**7**%	**7**%

With the complexities of polypharmacy—experienced by 75% of respondents taking at least two daily medications—as well as widespread multimorbidity, mental health concerns, housing instability, and food insecurity, comprehensive care coordination and specialized training for providers is essential. Without these enhancements, gaps in support could widen, affecting health outcomes and limiting access to needed resources. Strengthening provider training and expanding roles for Peer Service Navigators are crucial to ensuring that PAWH receive person-centered care that incorporates mental health, social determinants of health, and advanced care planning, fostering better health and quality of life.

> *"Clients are experiencing age-related illnesses and cancer etc., and are struggling with engaging with medical providers to get the best care when those providers aren't familiar with the needs of the HIV-positive population."*
>
> —ADMINISTRATOR AT A PENNSYLVANIA AIDS SERVICE ORGANIZATION

Financial Landscape and Insurance Barriers

Survey findings highlight the pervasive financial insecurity and systemic barriers impacting access to HIV care for aging patients. Financial stress, including housing and healthcare affordability, is a top concern, with many patients struggling to engage in essential advanced care planning. Transportation and insurance limitations, such as prior authorizations and out-of-pocket costs, frequently delay access to specialized care and medications. The administrative burden of insurance requirements adds strain on providers, while ongoing issues with Medicaid transport and proposed Medicare fee reductions threaten the sustainability of HIV care services for disproportionately impacted populations.

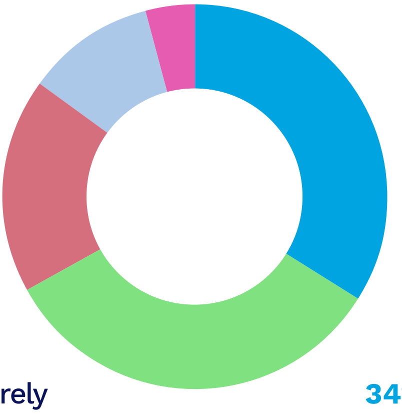
The Financial Landscape of Aging With HIV

Financial insecurity identified as the second greatest issue facing patients/clients aging with HIV.

Housing affordability and healthcare costs ranked in top three barriers to accessing healthcare for patients/clients aging with HIV.

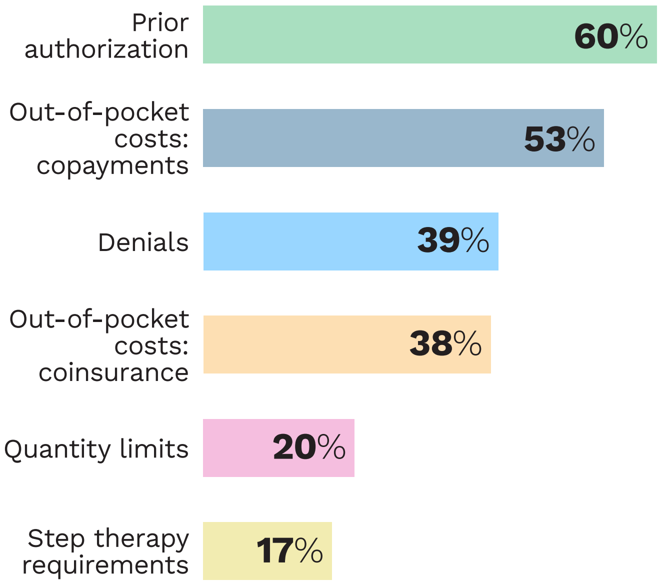
Financial concerns identified as a major barrier to engaging in advanced care planning by over half of respondents.

How often do insurance restrictions delay or prevent patients/clients from accessing necessary HIV medications?



Rarely	34%
Sometimes	33%
Often	18%
Never	11%
All the time	4%

Which insurance-related issues most commonly impact patients/clients?

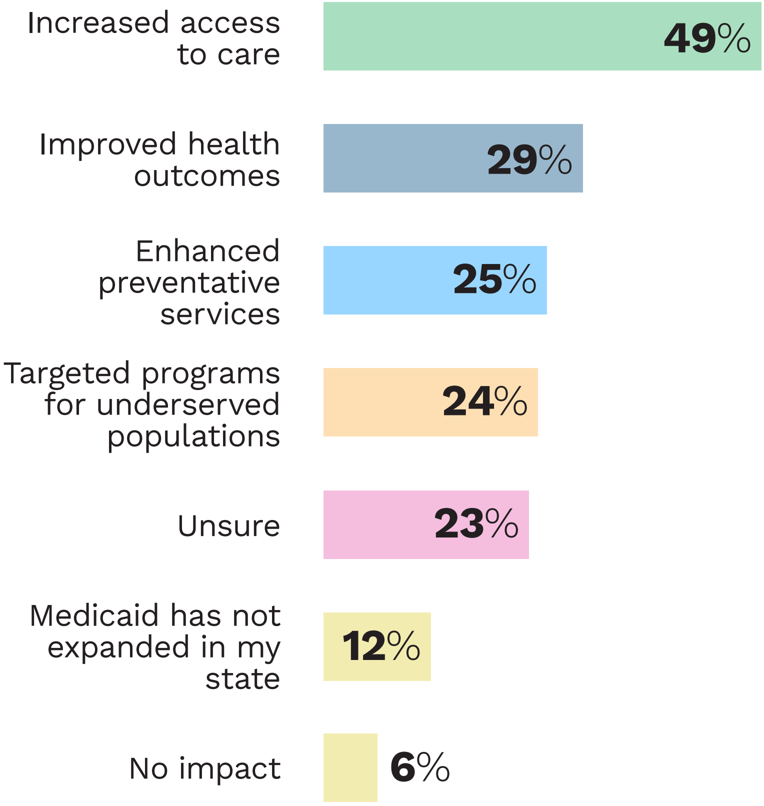


More than half (59%) say their patients have delayed or avoided seeking care due to concerns about their insurance coverage or out-of-pocket costs.

- Most PAWH who took this survey (79%) say they have delayed or avoided care due to insurance concerns, indicating a gap in provider knowledge—insurance barriers may be higher than the workforce realizes.

How significant is the administrative burden of insurance requirements for providers?

Providers working in Medicaid expansion states say expansion has impacted HIV care and prevention services for prioritized patients by...



Almost half of responding Medicare providers (44%) are concerned about the proposed 2.8% reduction in the Physician Fee Schedule (PFS) conversion factor for 2025, particularly in terms of its potential impact on your ability to sustain HIV care practices.

- This reduction means physicians are likely to be reimbursed less for any services covered under the PFS, and could disincentivize providers from offering services key to PWH, including antiretroviral therapies (ARTs), HIV care coordination, and high-impact and innovative telehealth services.

Current Health Issues

This section covers emerging trends in healthcare approaches, including diagnostic, treatment, and telehealth practices. While few providers currently use non-invasive diagnostic tools like frailty assessments, there is strong interest in adopting these in the future to enhance preventive care for aging patients. Injectable treatments for HIV are gaining attention, particularly for patients with adherence challenges, though there are concerns about out-of-pocket costs. Telehealth is widely available, with most providers facing minimal regulatory issues; however, many anticipate disruptions if Medicare's temporary telehealth flexibilities expire, highlighting the need for sustained telehealth support in HIV care.

Very few providers frequently engage in non-invasive diagnostic tests like **frailty assessments** with their current patients, but **a large portion would be interested in using them in the future (68%).**

- This echoes findings from PAWH who took this survey, a staggering **75%** say they have NOT been screened for frailty or fall risk in the past year.

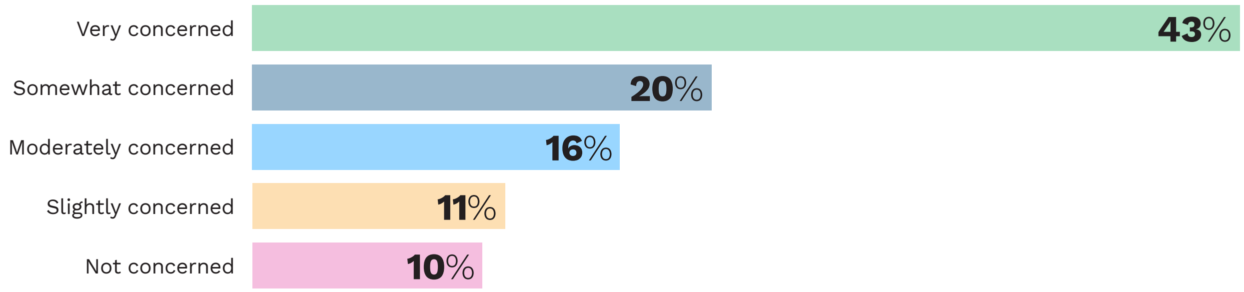
INJECTABLE TREATMENTS

55% are interested in prescribing injectable treatments for their patients.

Populations that would benefit most from injectable treatments

47%	26%	22%
patients with adherence challegences	patients who prefer not to take daily oral medications	patients with stable conditions seeking less frequent dosing

How concerned are providers about the out-of-pocket costs for injectable treatments?



TELEHEALTH

A significant number of providers offer telehealth services (69%), improving access to care for people aging with HIV.

- Many have not faced any regulatory or legal difficulties in maintaining telehealth services (**64%**).
- Among Medicare providers who use telehealth, **only 26%** are currently utilizing the permanent Medicare changes that allow Federally Qualified Health Centers (FQHCs) and Rural Health Clinics (RHCs) to serve as distant site providers for behavioral/mental telehealth services.
  - **36% anticipate challenges** in their practice if the temporary Medicare telehealth flexibilities for non-behavioral/mental health services, set to expire on December 31, 2024, are not extended or made permanent.

Advocacy

Respondents make a strong demand for increased advocacy and legal education to support people aging with HIV, especially regarding their rights and protections under the Americans with Disabilities Act (ADA). Many providers acknowledge that HIV-related discrimination remains a significant barrier to accessing public services and employment for their patients. However, providers often feel only somewhat equipped to advocate on legal or discrimination issues, and few regularly discuss ADA protections with patients to help them understand their rights.

97%

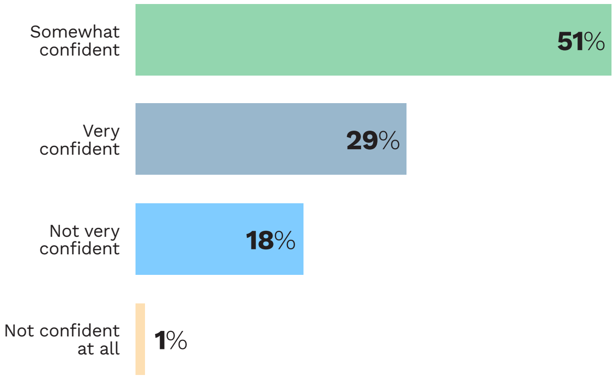
of respondents feel that more advocacy efforts are needed to address the needs of people aging with HIV.

About a third of providers say they have patients living with HIV who face difficulties in accessing public services due to discrimination based on their HIV status.

Have any of your patients living with HIV faced difficulties in accessing public services (e.g., transportation, education, social services due to discrimination based on their HIV status?

No	36%
Unsure	32%
Yes	32%

Most providers are only somewhat confident in their ability to advocate for their patients living with HIV who face legal or discrimination issues related to their healthcare.



- ▶ More than half support the decriminalization of HIV (**58%**) and even more (**64%**) support decriminalization of HIV exposure without intent.

MOLECULAR HEALTH SURVEILLANCE

With respect to whether respondents think that Molecular Health Surveillance (MHS) is an effective tool to help stop the spread of HIV, the vast majority (70%) say they need more information to answer.

- ▶ Crucially, the use of MHS data raises ethical concerns, including issues of consent and potential misuse in legal contexts. The need for a person-centered approach in MHS practices, respecting individual rights and privacy, is ongoing, as is the need for greater education on what MHS actually is.

DISABILITY AND DISCRIMINATION

38%

More than a third say their patients living with HIV are experiencing discrimination in employment or public accommodations

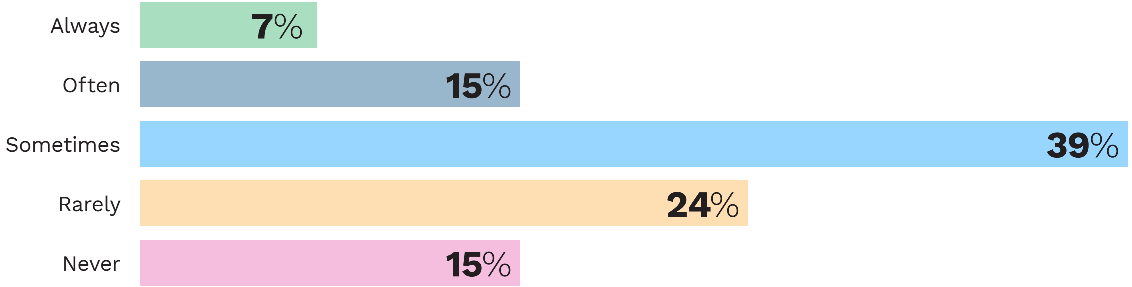
39%

The majority are aware of the specific federal protections under the Americans with Disabilities Act that apply to PLWH

11%

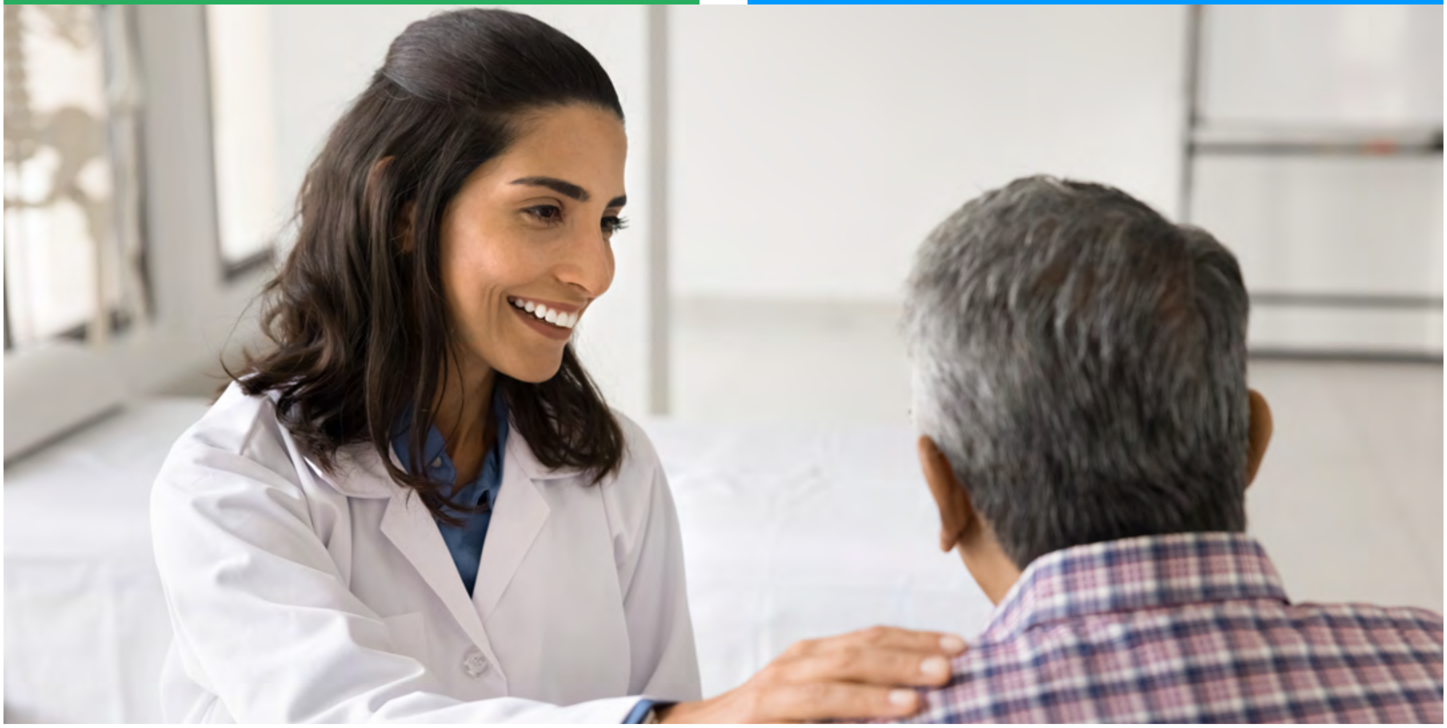
Most are very or somewhat familiar with the ADA's requirements for reasonable accommodations for people living with HIV in the workplace

Only 15% of providers often discuss legal protections under the ADA and other Federal laws with their patients living with HIV to help them understand their rights.



The majority of providers say healthcare facilities sometimes adequately accommodate the needs of older patients living with HIV as required under the ADA—only 13% believe they do so all the time.

Almost all (89%) strongly agree or agree that more education is needed for healthcare providers regarding the legal rights of people living with HIV under federal laws like the ADA.

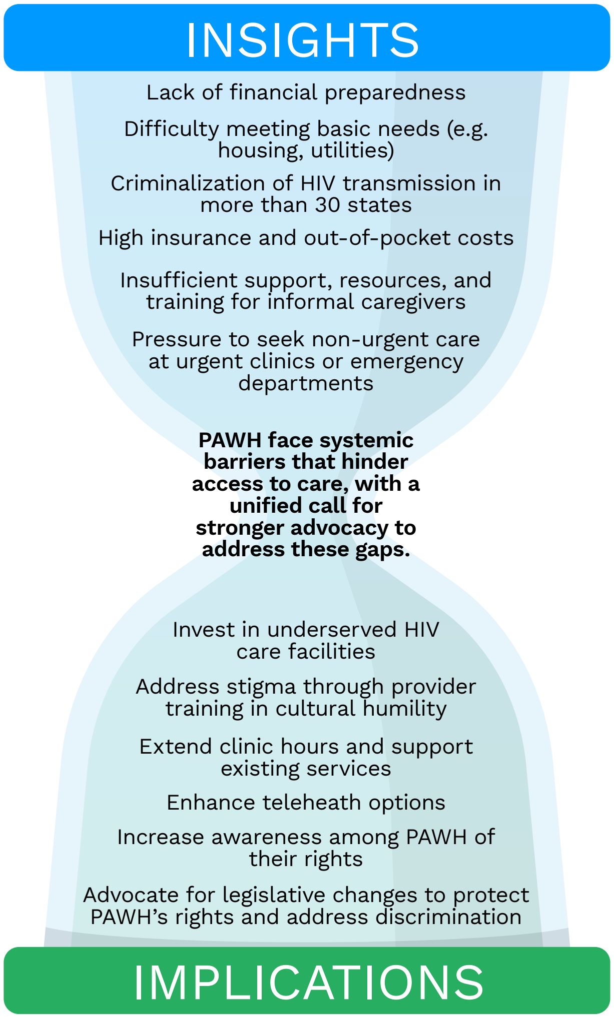


Implications

Serious work needs to be done to secure the future material well-being of this diverse population. In the absence of resources that meet the bedrock needs of PAWH, the medical system is significantly limited in its capacity to effectively engage with and provide care to them. As newer medications become available and cost challenges continue, it is crucial to advocate for policies that support long-term funding for assistance programs, and promote collaborative efforts to enhance affordability and reduce out-of-pocket burdens for all people living with HIV. These measures can help build a more equitable, accessible healthcare landscape for PAWH and beyond.

THE SHIFTING SANDS OF TIME: MOVING FROM INSIGHTS TO IMPLICATIONS

The hourglass illustration captures both the enduring challenges and critical opportunities for People Aging With HIV (PAWH). The sands of the hourglass symbolize the passage of time for this population, each grain representing a pivotal moment in their journey—from the early days of the HIV epidemic to the advent of antiretroviral therapies and the evolving realities of aging with a chronic condition. As the grains fall, they reflect lives marked by resilience, progress, and ongoing struggles. The narrowing space within the hourglass represents the convergence of these challenges with the urgent need for advocacy. At this pinchpoint, almost all respondents (97%) agree that advocacy efforts are essential to address the needs of PAWH. This visual metaphor emphasizes how key findings, such as financial instability, limited access to care, and the pressure to seek care in emergency settings, fuel the call for policy changes, greater resource allocation, and stigma reduction. The hourglass serves not only as a reminder of the urgency in addressing these needs but also as a reflection of the strength and lived experiences of the PAWH community. It underscores the importance of personalized care, support systems, and long-term solutions, including better access to healthcare, caregiver support, and legislative action to protect the rights of PAWH. As the sands continue to fall, they remind us of both the challenges faced and the collective hope and determination to ensure every PAWH can age with dignity, health, and purpose.



INSIGHTS

Lack of financial preparedness

Difficulty meeting basic needs (e.g. housing, utilities)

Criminalization of HIV transmission in more than 30 states

High insurance and out-of-pocket costs

Insufficient support, resources, and training for informal caregivers

Pressure to seek non-urgent care at urgent clinics or emergency departments

PAWH face systemic barriers that hinder access to care, with a unified call for stronger advocacy to address these gaps.

Invest in underserved HIV care facilities

Address stigma through provider training in cultural humility

Extend clinic hours and support existing services

Enhance teleheath options

Increase awareness among PAWH of their rights

Advocate for legislative changes to protect PAWH's rights and address discrimination

IMPLICATIONS

A message for future generations:

> *"Advocacy is key-whether advocating for yourself in healthcare settings or standing up for others in the community, your voice is powerful. The fight for equity and access to care continues, and your contributions can help shape a future where HIV is no longer a burden but simply a part of life ... Every step you take to educate yourself and others, push for progress, and live authentically is a testament to your strength. Remember, you are not alone, and together we can build a world that is more inclusive, compassionate, and hopeful."*
>
> — SURVEY RESPONDENT, PERSON WITH HIV

Implications of Key Findings on Aging with HIV and Healthcare System

SYSTEMIC BARRIERS AND FRAGMENTED CARE

PAWH face significant systemic barriers that undermine their access to comprehensive and effective care. Financial insecurity remains a pervasive challenge, with 79% of respondents delaying or avoiding care due to insurance coverage or out-of-pocket costs. Many also struggle with basic expenses, with 27% reporting difficulty paying for housing and 32% struggling to afford food. Additionally, 40% of respondents face transportation challenges that delay access to personalized, community-based HIV care, while the numerous hurdles and advanced booking requirements of Medicaid transportation services further contribute to these delays.

The fragmentation of care further complicates health management for PAWH. 36% reported using emergency departments for non-urgent primary care needs, reflecting inadequate access to local, tailored services. Over 30% of PAWH surveyed indicated that they rely on emergency departments for non-urgent care due to transportation barriers, stigma in traditional settings, or a lack of nearby dedicated services. Lack of care coordination between providers is also an issue, with 27% of respondents stating their providers do not communicate with one another about their care. This disjointed and fragmented approach is particularly detrimental to those managing multimorbidities, complex medication regimens, and mental health challenges.

Survey findings also highlight several recent systemic barriers, including vertical integration in healthcare, formularies that often change from calendar or benefit year to year (particularly in Medicaid and employer-sponsored plans), treatment delays, and limited access to essential diagnostic and preventive services. Specifically, over 50% of providers noted gaps in diagnostic tools for frailty and cardiovascular disease, key areas for aging PAWH, while 34% of community respondents reported challenges in accessing dental care. These missed opportunities heighten preventable health risks. Specific data from the survey shows that 63% of PAWH lack access to case management services, a critical resource for care coordination and preventing fragmented care. These issues disproportionately affect lower-income PAWH, whose care often involves eligibility hoops and navigating multiple providers and medications.

The strain on care coordination and reliance on emergency departments for non-urgent needs reflect a healthcare system ill-equipped to manage the complexities of aging with HIV. For example, the reliance on emergency departments for non-urgent care highlights gaps in routine, outpatient care access, as reflected in the survey findings where over 30% of PAWH reported using emergency departments for primary care needs in the past year. These gaps are often driven by transportation barriers, stigma in traditional settings, or a lack of nearby accessible services. This underscores the healthcare system's failure to provide consistent, comprehensive care for PAWH, forcing them into less appropriate, higher-cost care environments. Addressing these gaps requires stronger advocacy for patient-centered approaches, improved integration of services, and the removal of financial and logistical barriers to care.

So, too, social determinants of health, like stigma, social isolation, and inadequate support networks, compound these barriers and echo the call for better efforts towards quality-of-life. Crucially, 76% of PAWH reported moderate to high mental health stress, with many citing discrimination and loneliness as persistent challenges. The survey further revealed that 51% of providers believe informal caregivers lack the resources and training needed to support PAWH adequately. Furthermore, 46% of providers stated that unreliable transportation disproportionately impacts their patients' access to specialized HIV services. Addressing these systemic issues requires a coordinated effort to integrate services, improve transportation and financial access, and create more inclusive and equitable care environments for PAWH.

INSUFFICIENT GERIATRIC-INFORMED HIV CARE

Survey findings reveal that 59% of providers identified a shortage of clinicians trained in both HIV and geriatric care as the primary barrier to fully meeting the needs of PAWH. This lack of specialized expertise contributes to fragmented care for a population managing accelerated aging and higher rates of chronic conditions than their peers. For instance, 75% of PAWH take at least two medications daily to address multimorbidities, but 27% report that their providers do not coordinate or communicate with one another about their care needs. Furthermore, 63% of PAWH do not have access to case management services, which are critical for ensuring seamless care coordination, particularly for those with complex health challenges.

Moreover, fewer than half of PAWH have been screened for frailty or fall risk in the past year, despite the elevated risk of frailty in this population due to the long-term impacts of HIV and aging. This lack of preventive assessments underscores the need for providers trained to anticipate and address age-related conditions in conjunction with HIV care. Additionally, gaps in care coordination are evident, with 63% of PAWH lacking access to case management services—an essential resource for integrating medical, mental health, and social care.

The growing PAWH population—projected to comprise the majority of those living with HIV by 2030—faces unique challenges that demand investment in interdisciplinary training and retention strategies. Expanding geriatric-informed HIV care is crucial to ensuring this population can access seamless, comprehensive services that address their unique health trajectories. Addressing frailty and multimorbidity requires not only regular clinical assessments but also interdisciplinary care models that bring together specialists in geriatrics, infectious diseases, and primary care to manage the complexities of aging with HIV.

Additionally, the elevated risk of drug-drug interactions among PAWH due to polypharmacy underscores the critical need for coordinated communication between providers to ensure safe and effective care. The anticipated decline in the HIV clinical workforce, with 10.5% of current clinicians planning to leave the field within the next five years and an additional 7.3% reducing their caseload, adds urgency to these challenges.[11] This reduction coincides with a growing demand for HIV care as the population ages, necessitating a significant increase in primary care clinicians capable of managing both HIV and age-related conditions. Without substantial investment in workforce readiness and geriatric-informed practices, disparities in care coordination and health outcomes for PAWH will persist and likely worsen as the population ages.

ADVANCING EQUITY AND SUSTAINABILITY

The findings underscore the critical need for sustained advocacy and inclusive policies to address the intersecting challenges of HIV and aging. PAWH disproportionately face stigma, mental health challenges, and social isolation, compounded by a lack of aging-focused support services and caregiver resources. 76% of PAWH reported moderate to high mental health stress in the past six months, and 49% feel lonely or isolated all the time or often. Additionally, 51% of providers believe informal caregivers lack adequate resources and training to meet the complex needs of their loved ones, leaving many PAWH without the support they need to age with dignity.

To address these challenges, policymakers must prioritize funding for aging-focused programs, such as caregiver assistance and mental health services, while investing in research through OAR (the NIH Office of AIDS Research) to mitigate the comorbidities and accelerated aging experienced by PAWH. Despite facing higher rates of frailty (often undiagnosed), neurocognitive disorders, and metabolic complications, 63% of PAWH lack access to case management services, which can disrupt care coordination and lead to increased health disparities. The report emphasizes the need for a syndemic approach that integrates HIV care with mental health, aging, and social determinants of health to improve quality of life and health equity for this population.

Within this syndemic framework, individuals aging with HIV face unique challenges, including accelerated biological aging and increased susceptibility to age-related conditions. Research indicates that HIV infection can expedite the body's aging processes, leading to earlier onset of comorbidities such as cardiovascular disease, neurocognitive disorders, and metabolic complications. For PAWH aged 65 and older, these challenges are compounded by systemic barriers, including Medicare's limitations for HIV-specific care, increased risks of conditions like osteoporosis and cardiovascular disease, and a lack of HIV-informed geriatric services in senior living facilities, where stigma often persists. Tailoring programs to meet these needs is critical to bridging gaps in care coordination and ensuring that PAWH over 65 can age with dignity, security, and comprehensive support.

Equally critical is the alignment of national HIV strategies with the unique needs of aging populations. Programs like the Ryan White Program and Bureau of Primary Health Care (BPHC) must expand their focus to include aging-related services, as many PAWH rely on these programs to manage chronic conditions and address barriers such as transportation, housing, and financial insecurity.

27% of PAWH reported difficulty paying for housing, while 33% struggled with debt, underscoring the financial precarity many face. In fact, employment challenges remain significant, with 34% of respondents earning less than $32,000 annually, leaving many living below the poverty line. These financial struggles are compounded by barriers to stable employment and limited access to workplace accommodations—further emphasizing the need for tailored support programs and policies that address both economic security and health equity.

And, for those in unstable housing or considering senior living facilities, fear of stigma and discrimination remains a significant concern, compounded by the lack of culturally sensitive care and the absence of a comprehensive Long-Term Care Services Bill of Rights tailored to the needs of PAWH. These factors not only discourage PAWH from seeking support but also compel some to consider "going back into the closet" to avoid bias or mistreatment—amplifying feelings of isolation and insecurity.

Without expanded aging-focused services, PAWH may experience increased isolation and fragmented care, as evidenced by the 36% of those surveyed who rely on emergency departments for non-urgent primary care needs. Addressing these barriers requires sustained funding and the adaptation of HIV programs to incorporate aging-related services, ensuring that financial insecurity, stigma, and gaps in support do not undermine the health and dignity of PAWH.

The future of aging with HIV depends on protecting these essential programs and fostering a healthcare system that values the dignity, resilience, and health of long-term survivors, including those with advanced HIV disease and individuals experiencing accelerated biological aging due to HIV, regardless of their chronological age. Advocacy efforts must continue to push for equitable care models that integrate medical, mental health, and social services, ensuring that PAWH can age securely and with dignity—while honoring the resilience that has defined their journey and continues to inspire innovation and progress.

POLICY AND FUNDING UNCERTAINTY

Moving forward, the Trump Administration's public health agenda represents a potential shift away from further effectuating the substantive work needed to secure the future material well-being of PAWH.

Thus, unfortunately, the state of—and thus the future of—aging and HIV are broadly uncertain in the United States. Funding and policy continuity in particular, for many of the programs that serve PAWH—such as the Ending the HIV Epidemic Initiative (EHE), the Ryan White Program, the BPHC, the Office of AIDS Research (OAR), and Infectious Disease initiatives as a whole—remains uncertain.

With the incoming Administration's selection of individuals for key public health positions—including Health and Human Services (HHS), the Centers for Medicare & Medicaid Services (CMS), the Centers for Disease Control and Prevention (CDC), and the Food and Drug Administration (FDA)—there is significant concern about the future of care for aging populations with HIV. Some of these nominees have denied well-established medical evidence, called for drastic reductions in infectious disease research, and promoted unproven treatments, threatening decades of progress in HIV prevention and treatment.

For PAWH, who already face unique challenges such as stigma, comorbidities, and limited access to geriatric-informed care, these appointments could add to existing barriers to treatment and further deprioritize their needs. This concerning direction highlights the critical need to protect evidence-based policies that support aging individuals living with HIV and to ensure leadership that prioritizes equitable, science-driven public health initiatives.

So, too, the potential elimination of infectious disease funding would devastate the OAR, which has been instrumental in coordinating NIH's HIV/AIDS research initiatives and ensuring a national strategy focused on aging with HIV, comorbidities, and disparities. Without the OAR, critical research into the effects of accelerated aging among PAWH, as well as the development of novel interventions, would grind to a halt, undermining years of scientific progress.

Moreover, eliminating EHE funding would severely impact the BPHC, which is pivotal in supporting PAWH by addressing comorbidities, care coordination, and access to essential services. BPHC-supported health centers are instrumental in delivering integrated, aging-informed care to individuals already diagnosed with HIV. These centers provide vital support for managing multimorbidities, such as cardiovascular disease and neurocognitive disorders, while addressing social determinants of health that disproportionately affect PAWH, such as housing instability and transportation challenges.

Without EHE funding, these health centers would face significant resource gaps, limiting their ability to offer aging-focused services, including case management and comprehensive care coordination. This would disproportionately harm low-income and underserved individuals who depend on BPHC-supported centers for consistent access to culturally competent, geriatric-informed HIV care.

At the same time, the Ryan White Program remains a critical lifeline for PAWH, providing comprehensive services that include medical care, mental health support, housing assistance, and nutrition programs. As the aging population grows, the RWP must evolve to address the unique complexities of multimorbidities and polypharmacy. Cuts or reauthorization delays would fracture the coordinated care RWP facilitates, leaving PAWH without the integrated services necessary to maintain their health and quality of life. Many RWP beneficiaries are low-income and face barriers such as housing instability and food insecurity, further emphasizing the program's importance in addressing social determinants of health alongside medical care.

The 2024 survey underscores the importance of sustained funding for programs like RWP and BPHC, which are pivotal in supporting PAWH through integrated services that address comorbidities, mental health, and social determinants of health. For example, despite facing higher rates of physical health challenges such as frailty and metabolic complications, three-quarters of PAWH have not been screened for frailty or fall risk in the past year, revealing critical gaps in preventive care. Similarly, 34% of respondents indicated difficulty accessing dental services, which are often overlooked but essential for maintaining overall health as individuals age. These gaps illustrate the extent to which PAWH rely on health centers and programs supported by BPHC and RWP for comprehensive care coordination.

Without continued investment in these programs, PAWH—already managing complex multi-morbidities—would face increased barriers to culturally competent and age- and person-first-informed care. The BPHC's role in addressing transportation challenges and providing aging-focused resources, such as accessible case management, is vital for ensuring PAWH remain engaged in care. Meanwhile, delays or reductions in RWP funding would compromise access to integrated medical and supportive services, leaving aging individuals with fragmented care and diminishing quality of life. The findings highlight the urgent need for policymakers to secure the future of these programs to protect the health and dignity of Persons Aging and Living with HIV.

The challenges faced by PAWH are worsened by systemic trends like vertical integration within healthcare systems. Consolidation of insurers, Pharmacy Benefit Managers (PBMs), and pharmacies can limit competition, increase costs for diagnostics and specialty medications, and disrupt continuity of care. This is particularly challenging for PAWH, who often depend on personalized, community-based care for effective medication management. Vertical integration also contributes to pharmacy deserts, where reduced access to retail pharmacies forces patients to rely on mail-order services that introduce logistical barriers, such as delivery delays and limited pharmacist interaction, making it harder to maintain complex treatment regimens.

Medication access is further complicated by restrictive formularies and utilization management practices, like those seen under Medicare Part D. Research shows that from 2011 to 2020, coverage exclusions and requirements for prior authorization or step therapy increased, creating delays in accessing necessary medications for PAWH. These policies often create additional challenges for those managing polypharmacy and comorbidities, leading to interruptions in care that can impact overall health outcomes.

Additionally, ongoing issues such as food insecurity, financial instability, and compounded stigma—alongside persistent shortages of qualified providers—make care access even more precarious for PAWH. And, by 2030, the anticipated “Silver Tsunami” will deepen these challenges as more PAWH face the compounded effects of multimorbidities and the long-term impact of earlier antiretroviral therapies. Unlike conventional aging populations, PAWH often experience accelerated aging and unique healthcare needs, underscoring the urgency for programs to adapt. Federal and state initiatives must prioritize the integration of HIV and aging care by expanding capacity, addressing systemic barriers, and tailoring services like case management, caregiver support, and transportation to ensure PAWH can age with both dignity and security.

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