



# HealthHIV STATE OF Aging with HIV™ Fourth Annual National Survey

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# Highlights: Fourth Annual State of Aging with HIV Survey

Now in its fourth year, this national survey captures the experiences of people aging with HIV (PAWH) and the professionals who support them.

- Developed by HealthHIV to inform service delivery, policy, and advocacy across the aging and HIV care continuum.
- The survey was fielded in August, September, and October of 2024.

Brings together perspectives from nearly 750 respondents—including long-term survivors, older adults with HIV, and a diverse HIV care workforce.

- Elevates the voices of PAWH to spotlight unmet needs in care, housing, mental health, and financial stability.

Helps guide education, training, and systems change efforts to improve quality of life and reduce health inequities.

# Participant Breakdown

## Community Participants



- **Respondents:** 390 individuals aged 50+ and/or living with HIV for 15+ years
- **Key Stats:** 54% diagnosed with AIDS, 51% late diagnoses



## Workforce Participants



- **Respondents:** 346 professionals (65% non-clinical, 35% clinical) including providers, case managers, and advocates

# Challenges to Aging with HIV: Finances, Services, Quality of Life



Financial strain  
and insurance  
gaps hinder  
access to care



Disconnected  
aging services  
leave caregivers  
and communities  
unsupported

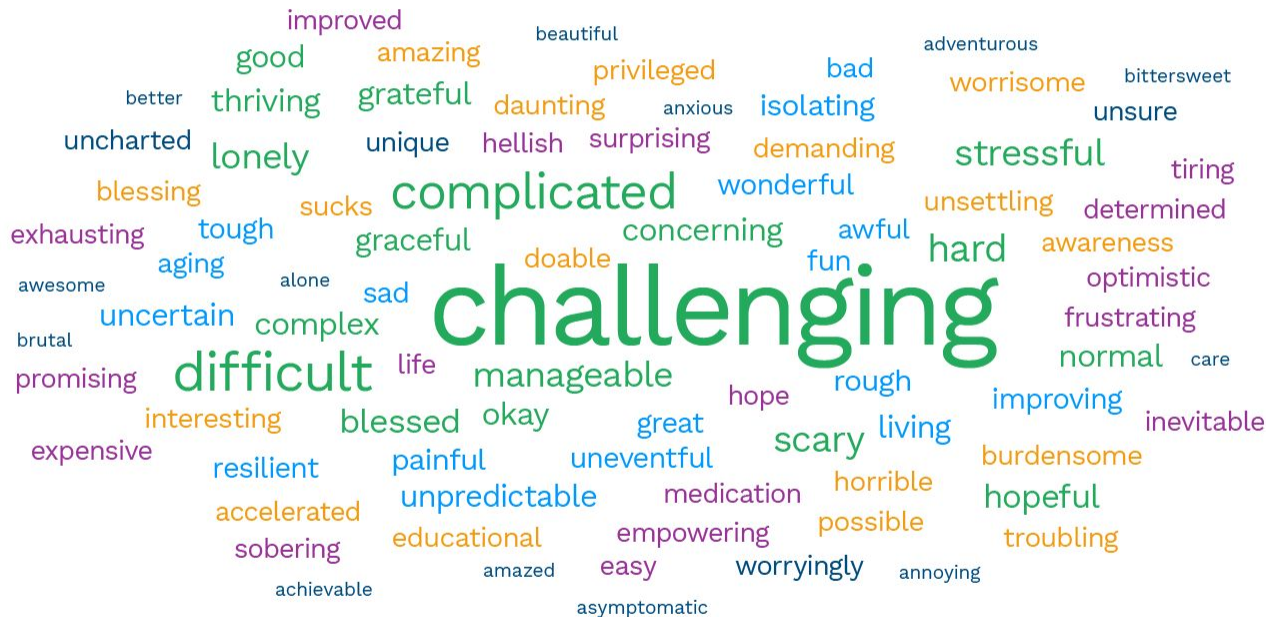


Quality of life  
declines due to  
mental health  
challenges



Increasing discontent  
and anger, and  
growing fatigue and  
frustration with  
healthcare system

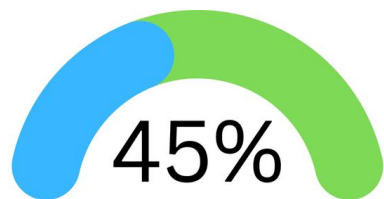
When asked to describe aging with HIV in one word, participants most frequently said, “challenging,” followed by the descriptors “difficult” and “complicated,” — for the second year in a row. Providers and community members were completely aligned, with both groups selecting the same three top words.



# Need for Provider Education and Training

## Challenges Identified:

- Shortage of healthcare providers trained in *both* HIV *and* geriatric care
- Need for stigma-free, compassionate care for LGBTQ+ individuals and older adults with HIV



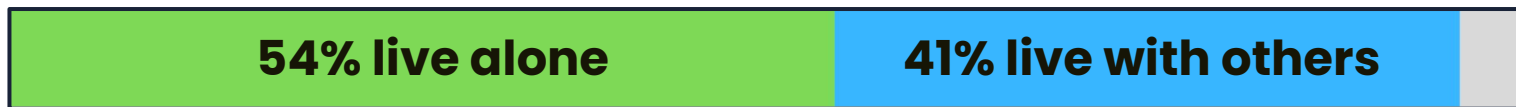
Only 45% of respondents feel healthcare providers are knowledgeable about HIV and aging needs

**"This training needs to start in medical school for providers to fully understand the aging experience of long-term survivors." – Survey participant**

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# PAWH Face Isolation and Housing Challenges

## Current Living Situation of PAWH



**“Isolation and cognitive decline are huge for our patients. Addressing this in supportive environments is critical.” – Provider**

- Limited access to supportive housing and facilities for those requiring assistance remains critical

**“I have outlived most of my support network. If I become incapacitated, who will be there?” – Survey participant**

- Social isolation and loneliness is a key issue – 49% of respondents report frequent feelings of loneliness



# Financial Challenges Impact People Aging with HIV

## Key Data:

- **45% of respondents lack a financial plan** for retirement; **79% delayed medical care** due to cost concerns
- Financial assistance program dependency (e.g., Ryan White, ADAP)

## Impact Areas of Financial Stress:



Housing affordability



Utility payments



Long-term care costs

**“Many don’t have savings or retirement plans, as they didn’t expect to live this long.” – Case Manager**



# Insurance Barriers Delay Care and Strain Finances for PAWH

**“The high out-of-pocket costs for essential medications means I sometimes have to choose between health and housing.” – Survey participant**

## Challenges with Health Insurance

### Prior Authorizations + High Copayments + Formulary Changes

- 47% of respondents feel insurance does not support their HIV and aging needs
- **Over half have delayed care** due to insurance-related costs
- 22% lack confidence that their insurance would cover HIV-related emergency expenses

# Fragmented Care, Transportation Barriers Delay Treatment

## Fragmented Care:

- 27% of PAWH respondents report inadequate communication and coordination among providers

## Healthcare Access Issues:

- 40% experience transportation delays, especially for Medicaid-covered transport

**“For those with complex needs, lack of communication among providers is frustrating and impacts quality of care.” – Survey participant**

## Suggested Strategies:

- ★ Implement patient-centered, cross-sector collaboration and address social determinants of health



# Stigma in Healthcare Hinders Care for PAWH

## Stigma in Healthcare Settings:

- 59% of PAWH report stigma or discrimination from healthcare providers due to age or HIV status

**“Stigma compounds the stress of aging with HIV—many patients fear disclosing their status or feel judged.” – Survey participant**

## Provider Perspectives:

- Need for more advocacy and legal education to help PAWH understand their rights

**“We need a healthcare environment where older adults with HIV feel safe and valued, free from stigma.” – Provider perspective**

# Implications from the State of Survey



**Provider Education:** Enhanced training in geriatric and HIV care, starting in medical school.



**Supportive Housing Programs:** Increased funding and infrastructure for supportive housing options.



**Insurance Reform:** Policies to reduce copay and out-of-pocket costs for essential treatments.



**Advocacy:** Stronger advocacy for PAWH, focusing on inclusive policy changes.