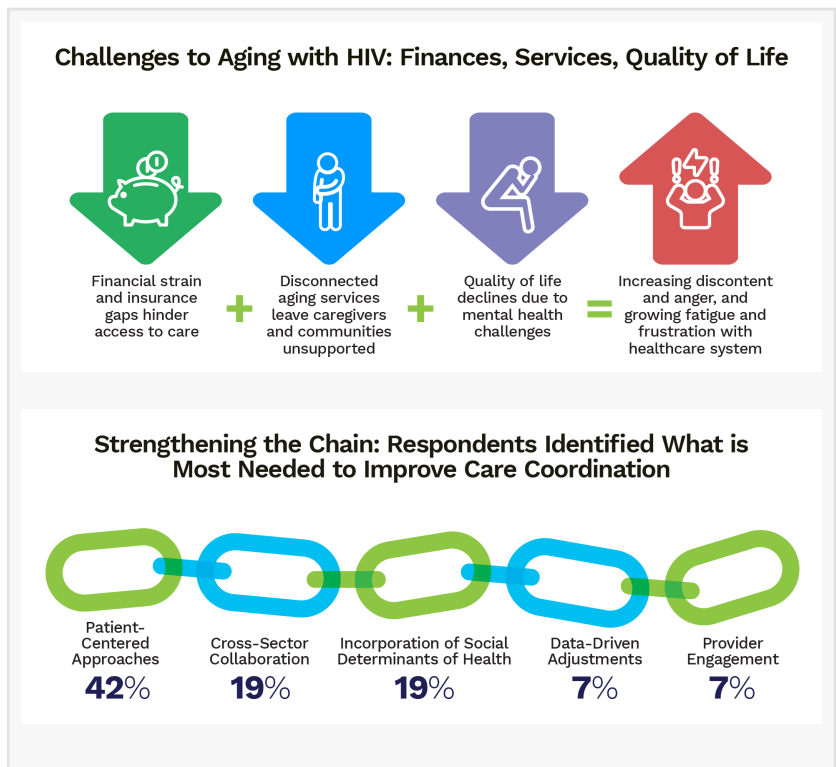


Urgent Need for Systemic Change, Targeted Interventions, and Enhanced Advocacy to Address Needs of People Aging with HIV

HealthHIV's Fourth Annual State of Aging with HIV™ National Survey Identifies Current Issues Affecting People Aging with HIV and the Healthcare Workforce

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HealthHIV's Fourth Annual State of Aging with HIV National Survey examines crucial issues affecting people aging with HIV (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.



Key findings include:

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.

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.

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. Over 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.

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.

"Behind our survey lies a palpable sense of anger and ire—a collective frustration shaped by the weight of managing a lifelong condition amidst mounting healthcare challenges, both systemic and personal," states HealthHIV Director of Advocacy and Pozitively Aging Program Lead Scott Bertani. "It reflects barriers to care, a diminishing quality of life, and a system that, for many, feels bound by outdated frameworks and resistance to change—underscoring the urgent need for action and accountability in today's reality."

One survey respondent shared, "HIV does not exist in isolation. 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."

Improving care coordination for PAWH means focusing on key priorities that address their unique needs. Respondents emphasized the importance of care that puts individuals first, strengthening collaboration across different sectors of healthcare and community services, and addressing how social factors influence access and outcomes. Using data to guide improvements and ensuring providers are engaged and supported were also highlighted as essential steps. Together, these priorities create a clear path to building a healthcare system that better serves PAWH and improves their overall quality of life.

About the Fourth Annual State of Aging with HIV™ National Survey

The 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. Survey data was collected between August and September 2024 and included responses from 907 participants. HealthHIV conducted the survey as part of its Pozitively Aging program, which is supported by Gilead's HIV Age Positively Initiative.

In coordination with HealthHIV's Pozitively Aging program, 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. To access the survey report, please visit healthhiv.org/stateof/agingwithhiv.

About the Pozitively Aging Program

HealthHIV's Pozitively Aging program empowers Persons Aging with HIV (PAWH)—Long-Term Survivors, Individuals >65, Lifetime Survivors ("Dandelions"), and those with unmet needs—by improving access to comprehensive, person-centered services. The program addresses systemic inequities, enhances workforce capacity, and strengthens care coordination through targeted training and a National Resource Center. Guided by research and continuous quality improvement (CQI), it promotes health literacy, supports self-advocacy, drives systemic change, and prioritizes equity and social determinants of health to improve quality of life and outcomes. Learn more at healthhiv.org/positivelyaging.

About HealthHIV's "State Of" Surveys

HealthHIV Research and Evaluation conducts regular national surveys to better inform ongoing advocacy, education, research, and training activities. These "State Of" surveys provide unique insight into patient and provider issues in order to optimize primary and support services for diverse communities. The regular reports offer the ability to study multi-year trend analyses illustrating changes, challenges, and opportunities to address the needs of providers and patients. HealthHIV, HealthHCV, and the National Coalition for LGBTQ Health conduct "State Of" surveys addressing HIV Care, HCV Care, LGBTQ Health, Harm Reduction, and Aging with HIV.

About HealthHIV

HealthHIV is a national non-profit working with healthcare organizations, communities, and providers to improve HIV, HCV, STI, and LGBTQ healthcare and advance harm reduction and health equity through education and training, technical assistance and capacity building, advocacy, communications, and health services research and evaluation. Learn more at healthhiv.org.

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