COMMUNITY INSIGHTS ON
HIV AND AGING
LIFETIME SURVIVORS
LONG-TERM SURVIVORS

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PREPARED BY

AIDS United

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Ending the HIV Epidemic

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HIV CAUCUS
U.S. PEOPLE LIVING WITH HIV CAUCUS

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INTRODUCTION

In the earliest years of the HIV epidemic, one of the epidemic's most notable features was its disproportionate impact on young adults.

Although young people today continue to acquire HIV, more than half of all people with HIV are now over age 50, as people are living much longer due to the powerful benefits of antiretroviral therapy (ART). Many of those living with HIV were diagnosed 30 or more years ago, including some who acquired the virus at birth and have lived with HIV their entire lives, often referred to as lifetime survivors.

The US has established bold targets toward the goal of ending the national HIV epidemic. But even if our country meets its goal of reducing new HIV cases by 90% by 2030 (2017 baseline), that won't end the need to respond in the coming years and decades to the health needs of the 1.2 million people living with HIV (PLWH). Although holistically addressing the needs of a steadily aging HIV community is one of the most critical challenges facing our national HIV fight, a clear, coordinated national commitment to do so has yet to emerge, *and given the current political climate, we are facing the potential of a massive rollback of our progress.*

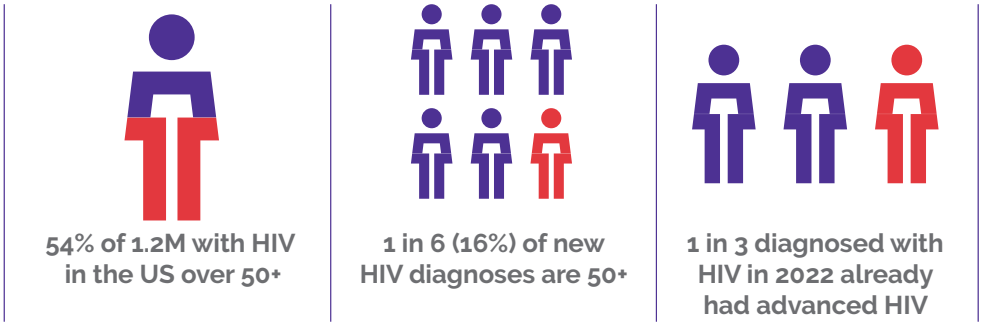
People over age 50 account for 54% of the 1.2 million people with HIV in the United States. Older people are also at considerable vulnerability for HIV, as people who are 50 years or older comprised 1 in 6 (16%) of new HIV diagnoses in 2022.

That must change if we as a country are to keep our promises to people aging with HIV. AIDS United, SAGE, the US People Living with HIV Caucus, The Reunion Project, and the National Minority AIDS Council convened two listening sessions to shed light on what a policy agenda for people aging with HIV would need to include and to hear from people who have lived with HIV for decades, one at the 2023 AIDSWatch, and a second listening session at the 2023 US Conference on HIV/AIDS and altogether, over 130 individuals offered their insights at the two listening sessions.

Towards the goal of catalyzing a powerful national movement to address the needs of an aging HIV population, this brief summarizes the key themes and recommendations that emerged from these listening sessions. After an introductory session summarizing what we know from the scientific literature about HIV and aging, lifetime survivors, and long-term HIV survivors, the brief highlights participants' wisdom and insights.

AGING WITH HIV: WHAT THE DATA TELL US

People over age 50 account for 54% of the 1.2 million people with HIV in the United States. Older people are also at considerable vulnerability for HIV, as people who are 50 years or older comprised 1 in 6 (16%) of new HIV diagnoses in 2022. Among people over age 55 who were diagnosed with HIV in 2022, 1 in 3 already had advanced HIV disease at the time of their diagnosis – a rate that is markedly higher than among younger people newly diagnosed. Late diagnosis of HIV contributes to poorer health outcomes among those with HIV.



Antiretroviral therapy has transformed health prospects for those with HIV, allowing them to live long lives. However, even with ART, they are at significantly greater vulnerability to so-called diseases of aging, such as heart disease, cancers, diabetes, osteoporosis, and frailty. There is some evidence that HIV can accelerate the aging process, although this may vary considerably for each individual.

Although ART improves cardiovascular outcomes among HIV-positive people, especially if initiated early, they are nevertheless at substantially greater vulnerability of poorer cardiovascular outcomes than people without HIV, regardless of treatment status. While more research is needed to understand how and why they are at increased vulnerability of cardiovascular disease, ART does not appear to be primarily responsible, with evidence pointing instead to changes in the body as a result of HIV. In 2023, a clinical trial found that taking a daily statin reduces cardiovascular events among PLWH by more than one-third.

Managing the health of older people with HIV also poses additional challenges. Older adults with HIV are more likely than younger people living with HIV to experience adverse events due to taking ART. This heightened vulnerability to adverse events is further amplified by the likelihood of drug interactions among older individuals living with HIV, who often take multiple medications.

Mental health is a central priority for older adults with HIV. They are more likely to experience a decline in neurocognitive function compared to people without HIV and also at high vulnerability to depression or other mental health disorders, especially if they are socially isolated.

Addressing the multiple, often complex needs of older people with HIV and younger lifetime HIV survivors represents the next frontier in our country's long fight against HIV. Over the coming years and decades, the 1.2 million PLWH will require person-centered health services that meet their needs as they age.

PHYSICAL HEALTH OF OLDER PEOPLE LIVING WITH HIV

The transformative impact of ART has led observers to commonly characterize HIV as a "chronic, manageable" disease. However, the benefits of ART can obscure the broad spectrum of often severe health problems confronting many PLWH.

"My health is deceptive," said one participant. "I appear to be in decent shape. But no one sees the huge pile of pills I consume daily. No one sees the 'old lady' beneath my skin. No one sees the osteoporosis or rheumatoid arthritis that are destroying my joints. No one sees the chronic non-viral hepatitis. No one sees that after 37 years living with HIV, I am only 57 but feel like I'm turning 87."

The individuals who participated in the 2023 listening session have been living with HIV for decades, including several who have been living with the virus for nearly 40 years. Although there is gratitude in knowing that one has survived a disease that has killed more than 700,000 people in the United States, many people who have lived with HIV for decades are confronting difficult, painful, and often life-threatening health challenges.

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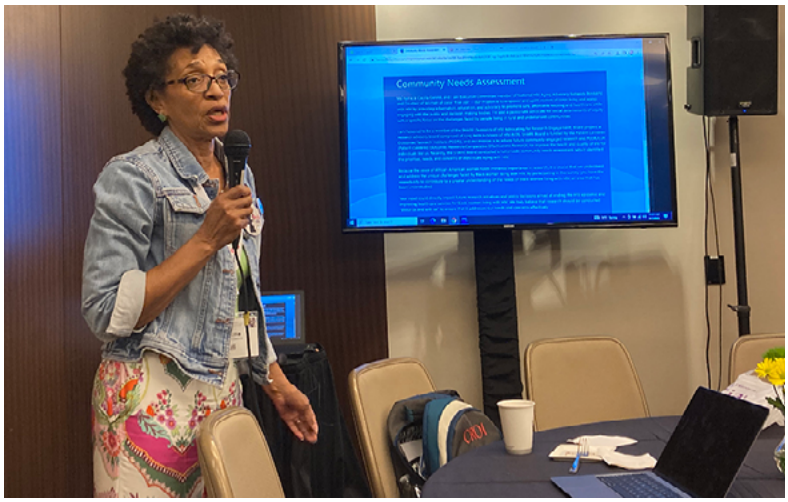
One participant, living with HIV since 1987, reported experiencing high blood pressure, diabetes, and broken bones. Several others described coping with severe and painful neuropathy, while others mentioned liver and kidney damage and bone density issues. Many participants noted living in constant pain, partly due to long-term use of ART. One individual who began treatment with early medications like AZT and 3TC shared that she now experiences ongoing joint pain. Many people living with HIV reported considerable weight gain because of decades on ART. One participant reported living in such pain that "I still have days where I can't get out of bed because the pain is so severe."



"I have so many co-morbidities that it sometimes gets scary," said one participant. Another participant said: "When I was diagnosed with HIV at the age of 47, I already had 13 chronic conditions." According to another, "My bones hurt, I get shots in my knees, My back goes out." "I look like I'm 30 or 40," said another participant, "but I feel like I'm 65." "Most days I actually feel like I got

run over by a Mack truck and they've forgotten to scoop me up," another participant said.

"My quality of life, my physical health overall, has taken its own turn due to years of antiretroviral therapy," one participant said. "I started [taking ART] in 1997. Thank God people aren't dying from the meds as much as they were in the earlier years. But [decades of taking ART] has caused liver damage and kidney damage and bone density issues and surgeries I've had to have on my spine because of spurs from the medication."

"I have been diagnosed for 24 years," said another participant. "We know HIV lives in your gut. So, I have gastritis, colitis, pancreatitis – all these different things – and I do really believe it's because of the medications."

"I have been living with HIV for 36 years and I am feeling every one of those 36 years," reported one participant. "At this point, I am 57 and there are days when I feel like I'm 77 or more."

HIV therapies have been simplified, evolving from multiple pills at different times of the day in earlier years to a single pill for HIV treatment for many people. However, the multiplicity of health issues facing many people with HIV means that they still take large amounts of pills every day. "I take about 20 medications," reported one person living with HIV.

"I used to take many pills for HIV, but right now I take only one pill for HIV," one participant reported. "But I take a lot of pills for co-morbidities. I have osteoporosis, mitosis, atrial fibrillation, bradycardia – too many things!"

"I am 62 years old and have lived with HIV for more than 38 years," said one person. "HIV drugs have left me with neurological nerve damage from the waist down and in my hands. I can't hold things and also have mobility issues, which causes me to fall out at times."

Given the numerous serious co-morbidities affecting older individuals living with HIV, it is crucial for healthcare providers and systems to coordinate care effectively. This involves breaking down care silos and ensuring seamless collaboration among different parts of the healthcare system. Additionally, since these individuals often take multiple medications, vigilance for potential drug interactions is essential.

04 | MENTAL HEALTH CHALLENGES

MENTAL HEALTH CHALLENGES ASSOCIATED WITH LIVING WITH HIV FOR DECADES

The listening sessions underscored the centrality of mental health services to comprehensive HIV care. "My mental health has taken the place of my HIV-related concerns," said one person living with HIV. "My mental health is bad," reported another person who experiences post-traumatic stress disorder, depression, and anxiety. "My mental health is in the basket, and as an aging person, there are some days I don't want to be here," reported another person.

There are many reasons why PLWH experience mental health issues. People with any chronic disease are at increased vulnerability to depression and other mental health problems., and the participants in the listening session have been coping with HIV for decades. Living with illness and, in some cases, constant pain takes a toll on a person's mental health.

Memories of the early years of the HIV epidemic, including the loss of family members, friends, colleagues, and other loved ones, cause lingering sadness, anxiety, and depression. "I have PTSD and AIDS Survivor Syndrome from living with HIV for between 30 and 40 years," reported one person. "Memories from the early days of AIDS are difficult," another person noted. "It is so much to deal with."

Others live with the legacy of trauma in their lives. One participant in the listening session reported having been kidnapped at gunpoint as a fast-food worker and experiencing the murder of her 8-year-old son. "As an older trans woman, I have experienced trauma, assault and other forms of stress," said another person living with HIV over age 60.

Integrating and ensuring adequate coverage of mental health services and trauma-informed care in the context of HIV service delivery is imperative. "We need interventions that reinforce resilience, which declines with age," advises one participant. However, several participants cited the stigma associated with seeking help for mental health services as a deterrent to adequate care and support.

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For many PLWH, COVID-19 compounded their mental health challenges, exacerbating depression and intensifying social isolation. Some are grappling with Long COVID, and many have lost family members, friends, or loved ones to COVID-19. "When COVID hit, I lost my mental health doctor," said one person. "I lost my therapist. I lost my main doctor. They all went to different places. And then there were so many deaths."

05 | HEALTH SERVICE DELIVERY

HEALTH SERVICE DELIVERY FOR OLDER ADULTS LIVING WITH HIV

In the early years of the HIV epidemic, there was a focus on building a sufficient network of healthcare providers capable of providing HIV care. Many healthcare providers and educators began to think of HIV as a medical specialty.

As health appointments for people living with the virus focus more time on co-morbidities and less on HIV itself, some people aging with HIV struggle to obtain care that is holistic, coordinated, and of good quality, even when they have excellent care addressing HIV. One concern expressed by participants is that existing HIV care models are based on research insights from the 1980s and 1990s, even though the reality of effective care management for PLWH has changed as the community has aged. "I have so many co-morbidities that I now have a team of 10 specialists to manage my care," one person reported.

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Many people struggle to find informed medical providers who can address the many co-morbidities experienced by individuals living with HIV. "Routine screenings, such as bone density or kidney and liver levels, need to be done for us," one participant advised. Given the accelerated aging process experienced by some PLWH, participants recommended that routine and geriatric screenings occur earlier.

Women living with HIV require access to providers capable of addressing menopause, obstetrics, gynecology, and other women's health issues. Services also need to be tailored to address the needs of trans elders, Spanish speakers, and other underserved PLWH.

A key to a successful provider-patient relationship is developing open, nonjudgmental communication, which enables better healthcare outcomes. Participants noted the importance of having a healthcare provider who is comfortable discussing sensitive topics, including sexual health.

As is typical for many individuals in the United States, regardless of their HIV status, accessing affordable, essential health care can be a challenge for those living with HIV.

HEALTH SERVICE DELIVERY

While Medicare has been a lifesaver for people with HIV, several listening session participants reported experiencing Medicare-related gaps and challenges. Medicare Advantage plans, for example, may impose limits on service access and choice of providers, resulting in reduced quality of care, according to participants.

When services are not covered by Medicare or private insurance, PLWH are forced to pay for the service out of pocket or to do without. "Co-pays can be very high," one participant reported. "I need physical therapy," another person noted, "but I can't afford it. If I tried to access it and couldn't pay my bill, that would mess up my credit."

One participant reported having had satisfactory coverage from Medicare for several years until the person's children grew up and moved out of the house. "Medicare said my [Social Security disability] benefits were too much for a one-person household. I now have $164.90 a month being taken out of my benefits for Medicare Part D, and I now have to cover my co-pays, healthy food, and utilities. I now struggle to pay my bills and buy my food. I have gotten a part-time job, but there is still a monthly limit I am allowed to make."

"I broke my leg and lived by myself," said one participant. "I have both Medicare and Medicaid, but I could only get custodial care if I turned over all of my material possession to the state upon my death."

Several participants in the listening sessions reported challenges navigating needlessly complicated bureaucratic hurdles associated with health coverage. "I have to run rings to get services like physical therapy, which is disheartening," one person said. "It turns me away from even getting the care that I actually need." Another person who returned to work reported that Medicare failed to cover drug costs not covered by her employer's plan, contrary to assurances she had previously been given. "Why do we have to always fight to get the things we need?" asked one participant. Ryan White covers Medicare premiums, but many older people are unaware of this.

Others report problems in accessing Social Security Disability Insurance (SSDI) benefits. One participant became homeless during the four years she waited to be certified as eligible for SSDI.

SOCIAL SUPPORT FOR LONG-TERM HIV SURVIVORS

More than four decades into our national response to HIV, stigma continues to be a significant barrier for people with HIV, hindering their access to health services and the social support they need. According to one participant, the stigma associated with HIV is compounded by the ageism that many older people with HIV experience. "We need to change the narrative of HIV and the related stigma and train the community to address those living with HIV with respect and dignity as fellow human beings," said one person living with HIV.

Social isolation is a significant problem for many older adults living with HIV. "The isolation, especially with COVID, the lack of intimacy when you're aging with HIV, and the ability to have a community that supports you is important to your well-being," said a 69-year-old living with HIV whose partner died a decade ago.

Finding supportive, non-toxic social networks is one-way participants said they use to improve their mental health. In addition, supporting other fellow community members enables people living with HIV to experience fulfillment and strengthen their resilience. Access to a support group can help build resilience and reduce social isolation, but some PLWHs lack access to social support. "I wish more health insurance companies offered more support programs," said a session participant living with HIV. A person living with HIV from Oregon noted that it was difficult or impossible for people living in rural areas to access support services.

Several participants reported trying to get connected to senior centers in their communities, with mixed results. One community member reported that the senior centers they had tried were depressing. "Even the paint job is depressing," the participant said. Another person living with HIV from New York reported that several senior centers closed during COVID-19 and never came back.

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HOUSING, EMPLOYMENT, AND OTHER SOCIOECONOMIC ISSUES

HIV, of course, is a medical condition that must be medically managed. However, effective treatment and care must extend well beyond the clinic and the pharmacy.

For example, safe and adequate housing is essential to health and well-being. However, many PLWHs struggle to obtain acceptable housing amid a national housing crisis. One participant who lost her apartment this year is now forced to live in an unsafe situation with family members who are unconcerned about her well-being. Another reported that housing in his California community, once cheap by comparison within San Francisco, doubled in price during COVID-19, triggering a housing crisis for people who live on a fixed income. For others, housing that was satisfactory during one's younger years may become unsuitable for older people – for example, stairs can become more difficult or impossible to navigate due to mobility issues.

"I live in senior housing in Maryland," one participant stated. "Repairs take months to happen. I have mold in my bathroom. I am severely allergic to it, and it makes me very ill. I was without air conditioning during the hot months, even though I'm susceptible to heat stroke."

Even with stable housing at the moment, many PLWHs experience worries about how secure their housing is. "I used to be in government housing, but I lost it when I got a job," one participant reported. "They say my pay is higher than what is allowed [for government housing]. But I worry if I ever get so sick that I lose my job, what would happen? Would I be allowed back on the list [for government housing]?"

Food insecurity is a significant challenge. Many people living with HIV reside in so-called "food deserts," where finding healthy foods to buy is hard, if not impossible. Integrating food and nutrition in HIV programs, including special provisions for people who live in rural or other remote areas, is a crucial service priority. One participant recommended supporting educational tools and other resources to help people in food deserts find healthier foods.

Accessing traditional aging services can sometimes be difficult, mainly due to a lack of transportation. "Transportation services suck in Maryland," said one community member. One participant who has accessed local food services found that much of the fresh produce delivered was inedible. "Quality food, things you can actually swallow, makes a difference," they said.

Several participants cited employment-related challenges. Some people living with HIV who are over age 50 would like to return to work, for example, but, in the words of one participant, "experience [is] being overlooked in their contributions."

08 | THE NEED FOR ADVOCACY

THE NEED FOR CONCERTED ADVOCACY ON HIV AND AGING

Participants in the listening session emphasized the need for robust, community-led advocacy to implement a comprehensive policy agenda for older adults living with HIV and long-term survivors. It was agreed that addressing the needs of people who have lived with HIV for decades needs to move higher on the HIV advocacy agenda. A key action step is to ensure the meaningful involvement of older people with HIV in the planning and implementation of advocacy.

Care systems need to evolve or be reconfigured to ensure proper treatment and care for older individuals living with HIV. This suggests the need to update services under the Ryan White HIV/AIDS Program to ensure that these services are fit for managing treatment and care for older adults with HIV. In particular, funding is needed for coordinated services for people living with HIV over 50, long-term and lifetime survivors.

"We've had thousands of listening sessions, and now we need action," said one participant. "We need implementation and not just talk because we need specialized services as part of Ryan White Care [services]. This participant recalled that the Ryan White HIV/AIDS Program was created as an emergency response to keep people alive as long as possible and was never designed to address the health needs of people who are aging.

Participants emphasized the need for more and better research on the health and well-being of people aging with HIV, including the validation of care models that promote health and improve the quality of life for long-term survivors aging with HIV. This requires an advocacy focus on the National Institutes of Health and other sponsors of HIV-related research.

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people living with HIV over 50, long-term and lifetime survivors.

Given the unacceptably large number of older people who are newly diagnosed with HIV each year, prevention services for older people must be strengthened. This includes bolstering harm reduction services and a coordinated HIV prevention/STI/Sexual Health campaign, ensuring their ability to engage and effectively service older people.

Policies and programs need to be in place to ensure that older people living with HIV can obtain the essentials of life, including but not limited to safe and affordable housing and proper food and nutrition. Advocacy should focus on the Social Security program to ensure access to Social Security when needed and remove inappropriate roadblocks and bottlenecks. Resources for early retirement could improve the health, well-being, and quality of life of many people who have lived with HIV for decades.

Advocacy also must drive an agenda to address the social determinants of health for people aging with HIV. This includes strategies to address intersectional stigma, including ageism, HIV stigma, homophobia, sexism, racism, and transphobia. Laws criminalizing HIV exposure, non-disclosure, and transmission must be repealed – not only are these laws scientifically groundless, as people with an undetectable HIV viral load cannot transmit the virus., but these laws are also an essential driver of HIV-related stigma. The reproductive rights of people with HIV also need to be promoted and protected.

CONCLUSION

The HIV/Aging listening sessions highlighted the complex interplay of physical and mental health, social support, socioeconomic factors, and advocacy needs for individuals aging with HIV. As the participants described, aging with HIV is often associated with sub-optimal quality of life and often with chronic pain and discomfort. In some cases, these issues can be life-threatening.

People in the United States have been advocating for improved quality of life for those living with HIV for over 40 years. Now, addressing the multiple, interrelated health and social service needs of people aging with HIV is the next frontier of our national HIV response. An urgent, high-profile, prioritized policy agenda for people living with HIV is needed now.

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