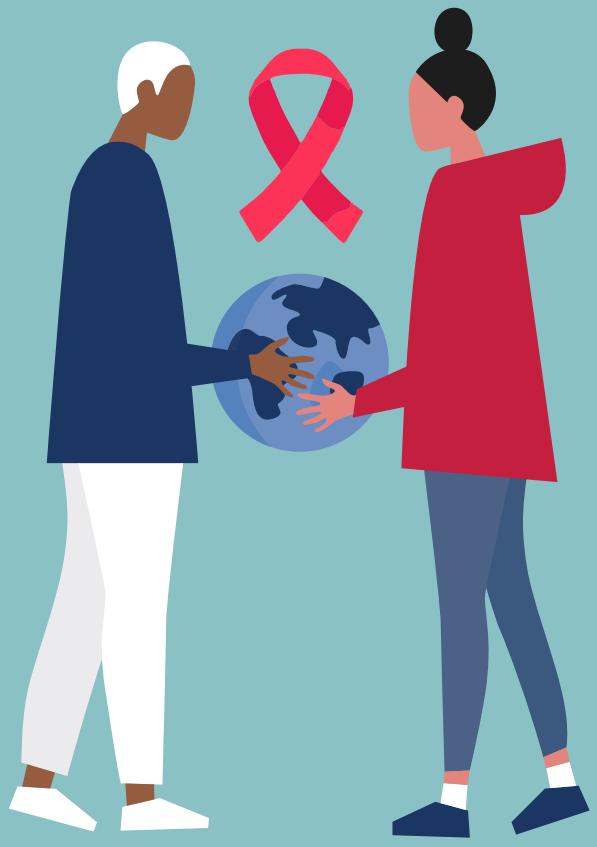
LONG-TERM SUCCESS IN HIV:

# Policy Actions to Support High-Quality Health Outcomes for People Living with HIV



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# Table of Contents

# 1 Introduction

When highly active antiretroviral therapy (HAART) was first introduced in 1996[1], a recently diagnosed 20-year-old was expected to only live another 10 years, at most.[2] With modern HIV treatments, a person living with HIV who starts treatment soon after their diagnosis can expect to have a similar lifespan as their HIV-negative peers.[3] This is due, in large part, to modern HIV treatments, which have enormous benefits over earlier treatments, including being simple to take and more tolerable with minimal side effects, higher barriers to resistance, and fewer drug-drug interactions.[4]

Modern treatments also help people living with HIV suppress the virus to undetectable levels, both protecting their own health and preventing sexual transmission to others. This concept, undetectable equals untransmittable (U=U), is vital to ending the HIV epidemic.

The global community has set ambitious targets in pursuit of ending the epidemic. By 2030, countries and other jurisdictions that have committed to this goal aim to diagnose 95 percent of all people living with HIV, with 95 percent on effective treatment, and 95 percent reaching undetectable levels of the virus. The COVID-19 pandemic, along with numerous humanitarian and economic crises, have threatened progress toward these goals. In 2021, 650,000 people died from AIDS-related illnesses, with 1.5 million new HIV infections, resulting in more than 38 million people now living with HIV worldwide.[5] It is critical that governments act now to change the trajectory of the epidemic.

To reach the 2030 targets, all people living with HIV should have access to modern treatments, particularly single-table regimens (STRs) and evolving long acting treatments (LATs). Modern innovative treatments are a highly cost-effective way to address HIV, providing significant savings through prevented infections, reduced comorbidities and increased productivity.[6] These treatments also support high levels of adherence, decreasing the risk of virological failure. People receiving STRs also had the risk of hospitalization (and thus, costs on the health system) cut by 25%.[4] Despite these benefits, significant barriers and challenges still exist to access, uptake of and adherence to HIV treatment.

Many people living with HIV face economic and food insecurity, housing instability, systemic racism, stigma, discrimination, and legal barriers to care. These issues inhibit their ability to prioritize their health, engage in care and take their medications. Additionally, increasing numbers of people are growing old with HIV, experiencing comorbidities and other challenges that add to the burden and complexity of their care. Many health systems, from the local to national level, struggle to provide integrated, person-centered care, making it difficult for people living with HIV to navigate their care pathways.

An effective HIV response must address these barriers and challenges to help people living with HIV reach and sustain **long-term success in HIV**. Long-term success in HIV necessitates a holistic approach to care that makes people living with HIV equal partners in decisions affecting their long-term health and wellbeing. Though access to modern HIV treatments is at the core of long-term success, it must be reinforced by ensuring the chosen treatment regimen is the best one for each person, and that their care is responsive to — and respectful of — their preferences. It must support them in addressing the non-medical challenges they face.


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This paper explores policy actions that will better support people living with HIV achieve long-term success, while simultaneously working to end the HIV epidemic. Grounded in the principles of person-centered care, and the meaningful inclusion of people living with HIV, this paper proposes action across three domains:

- Addressing health inequity;
- Designing health systems to provide integrated care; and
- Responding to the challenges of HIV, aging, and comorbidities.

By addressing these priorities and incorporating global WHO guidelines in HIV and public health strategies, governments and policymakers can help improve outcomes for people living with HIV and move closer to ending the HIV epidemic.

## Prioritizing Person-Centered Care

Evidence repeatedly has shown that when people living with and impacted by HIV are proactively involved in managing their own care, the likelihood of success increases. Meaningful involvement helps improve long-term health outcomes, as it improves engagement in care, improves adherence to treatment, and lowers overall healthcare costs.[7]

The early actions of the HIV response were based on the adage “nothing about us without us,” the principle that policy and programs affecting people living with HIV requires their meaningful involvement.[8] This principle ensures that people living with HIV receive high-quality, culturally relevant, and responsive care that helps them live and age well.

Achieving long-term success in HIV cannot be achieved without prioritizing these principles of person-centered care.

# 2 Design Policy that Addresses Health Inequities

To help people living with HIV access care and modern treatments that promote long-term success in HIV, policymakers need to address a range of health inequities: economic and food insecurity; housing instability; access to affordable and high-quality healthcare; systemic racism; and stigma; and discrimination. Given the entrenched structural nature of these issues, they can be addressed only through sustained public policy action.[9]

One of the key barriers undermining equitable access is the prevalence of social and cultural stigmas faced by marginalized communities.[10] Gender identity, immigration status, systemic discrimination, institutionalized racism, and histories of oppression impact how people living with HIV navigate the health care system and can result in disparate health outcomes.

In 2019, gay and bisexual Black men accounted for 26% of all new HIV diagnoses in the United States,[11] due in part to intersectional stigma and discrimination on the basis of race and sexual orientation.[12] Transgender people are 49 times more likely to be living with HIV than the general population.[13] For some women, gender-based violence can drive disparities in HIV infection rates and prevent women living with HIV from accessing care.[14]

Refugees, asylum seekers, and people with uncertain immigration status are more likely to have poor adherence to treatment due to a lack of support, financial security, and health information to help manage their HIV.[15,16] In Europe, the number of migrants living with HIV is disproportionately higher than other key populations, making it a persistent sub-epidemic.[17] In 2019, an estimated 44 percent of new HIV infections in Europe were among migrants.[18] While new HIV diagnoses among heterosexual migrants have almost halved over the last decade, diagnoses among migrant men who have sex with men increased between 2008–2015.[19]

## Discriminatory Laws and Criminalization of HIV

Many people living with HIV face additional challenges achieving long-term success due to human rights-related barriers, such as discriminatory laws that criminalize HIV status, gender identity, sexual orientation and conduct.[20] These laws prevent people from seeking care and intensify stigma, which contributes to "a cycle of stigma, homonegativity and discrimination" undermining awareness of and access to HIV testing, prevention, and care[21] This pattern is repeated in other communities who are at increased risk of HIV, particularly sex workers and people who use drugs.[22]

Many jurisdictions around the world criminalize people for transmitting HIV (regardless of intent or knowledge), not disclosing HIV status to sexual partners, and/or potentially exposing partners to HIV (sometimes regardless of status).[23] These laws may refer to HIV specifically or may target communicable diseases. Sometimes, general laws may be used to prosecute people living with HIV. All are out of step with modern science — particularly U=U — yet continue to be applied. These laws have a negative effect on HIV testing and treatment, and they perpetuate HIV stigma.[24]

Discriminatory policies inhibit the ability of governments and civil society organizations to mount an effective HIV response by hindering open discussion and preventing inclusive and non-stigmatizing HIV efforts.[24] Countries need to undertake policy action that decriminalizes behaviors and communities, while simultaneously addressing inequities in order to achieve long-term success in HIV.

## Bias and Stigma Among Health Providers

Many healthcare providers carry biases and prejudices that deter people living with HIV from accessing necessary care.[25] Personal opinions among healthcare professionals about a patient's "lifestyle choices" can lead some providers to be less likely to listen to individual patient's needs.[26] In 2016, 60% of countries in the European Economic Area reported discrimination by healthcare professionals towards men who have sex with men and people who inject drugs, which impeded access to HIV prevention services.[27] More training and continuing education for providers to reduce their stigmas, biases and prejudices improves interaction with healthcare systems for people living with HIV.

## Rural Access to Care

People living with HIV in remote areas often face the added challenge of being unable to access care at the same rates as those living in cities and urban areas. As a result, they have fewer engagements with the healthcare system, which can definitely affect their health outcomes.[28] To promote stronger links to care, governments must support telehealth and virtual care coverage. However, these efforts need to acknowledge the "digital divide," or the existence of barriers to modern communication technology, including limited or no internet connectivity, and lack of video chat/webcam.[29] Lower-income individuals (often racial and ethnic minorities), people in non-urban areas with less access to technology (e.g., broadband internet), older populations, and those with low tech literacy are disproportionately affected.[30]

## Access to Modern Treatments

Everyone living with HIV deserves access to modern HIV treatments, including the most recently approved STRs, that protect their health, improve their quality of life and promote long-term success in HIV. However, inequitable access to high-quality HIV treatment and care hinders global efforts to end the epidemic, affects local responses and increases the vulnerability of communities most at risk. Ultimately long-term success in HIV requires a truly equitable healthcare system that is culturally sensitive, relevant and responsive for all people living with HIV.

# 3 Design Health Systems that Facilitate Integrated Care Delivery

Care for people living with HIV is often administered in silos, focusing on one aspect of an individual's health, rather than holistically. Many factors, including total cost of medical and social care, frequency of healthcare visits, number of medications, and quality of care have an impact on adherence to HIV treatment regimens and can influence a person's ability to achieve long-term success in HIV.[31]

People living with HIV need integrated, person-centered care that addresses comprehensive healthcare needs, including case management, HIV care and treatment, behavioral healthcare (mental and substance abuse screening and treatment) and social support services (transportation, emergency food assistance, emergency financial support, housing, and legal assistance).[32] Decisions about how a person living with HIV engages with the healthcare system should be made in collaboration between the individual and their doctor, prioritizing the effectiveness of modern treatments over cost or convenience for the healthcare system.[9]

For those newly diagnosed with HIV, linking them to modern and appropriate HIV treatment soon after diagnosis is critical; starting HIV treatment as soon as possible is shown to reduce risk of serious health effects by more than 50% compared to delaying the start of treatment and can also get them to be undetectable sooner.[33] Among people who have stopped their HIV treatment, better coordination between their primary care providers and specialists has been shown to improve re-engagement with care and subsequent achievement of viral suppression and long-term success in HIV.[34]

Clinical care is a key component of long-term success in HIV and when integrated, linkage between HIV prevention, testing, and treatment services can help promote long-term success among people who test positive and prevent future transmissions through increased awareness of HIV status and U=U.[35] Funding for coordinated care allows facilities to dedicate resources that help reduce onward HIV transmission and support long-term success through one point-of-care location.[36]

The UNAIDS Global AIDS Strategy 2021–2026 states that 90% of people living with HIV should "have access to integrated or linked services for HIV treatment and cardiovascular diseases, cervical cancer, mental health, diabetes diagnosis and treatment, education on healthy lifestyles, counselling, smoking cessation advice and physical exercise."[37]

An integrated approach to care is critical in supporting positive health outcomes for people living with HIV, as it can help in the prevention and early detection of other conditions. It also facilitates the collection and monitoring of comprehensive health data, which helps track unmet need and effectiveness of interventions.[38] Some comorbidities, such as mental health conditions, can inhibit adherence to HIV treatment regimens by increasing the overall healthcare burden for people with HIV.[39] Developing care models that treat HIV and its comorbidities simultaneously can increase adherence and support long-term success in HIV. Embedding primary care services within HIV clinical settings may serve to decrease the impact of comorbidities on long-term success and decrease overall healthcare spending, especially as the population of people living with HIV grows older.[40]

# 4 Design Policy that Responds to Challenges of Aging, Comorbidities and Quality of Life

There are an estimated 6 million people 50 years and older living with HIV globally, with this number expected to steadily grow.[41] This is a positive consequence of improvements in HIV treatments and increasing rates of treatment uptake. Recognizing that the number of people over 50 living with HIV will continue to grow provides significant opportunities to begin building the systems necessary to achieve long-term success in HIV. As people living with HIV are at risk of accelerated aging, increasing the likelihood of multiple comorbidities, it is critical to act now.[42] Although HIV treatment limits this risk, it does not eliminate it, meaning services that can address comorbidities will be important regardless of treatment access.[43]

Aging with HIV gives rise to new challenges and considerations in health, wellbeing and health-related quality of life. Frailty is a geriatric condition that may develop earlier for older people living with HIV than their peers who do not have HIV. Frailty may make people living with HIV more vulnerable to adverse health outcomes and poorer health-related quality of life. Ultimately, frailty is associated with an increased risk of mortality and longer hospital admissions and requirements for nursing home care for older people living with HIV, which could mean higher public health costs.[44]

People living with HIV are more likely to experience certain comorbidities (including acute renal disease, bone fractures, mental health challenges, cardiovascular disease and hepatitis)[45] and tend to develop them earlier than people who are HIV-negative.[46] Among long-term survivors of HIV, many live with the lingering effects of early, toxic treatments, and may lack effective treatment options, further complicating their care.[47]

Over time, HIV can also have negative impacts on the central nervous system, which can become more severe over time and lead to symptoms including anxiety and depression.[48] Older people are more likely to experience mental health stresses like social isolation, loneliness, and cognitive impairment. When combined with the stresses of managing HIV, older adults are more likely to need support for these comorbid mental health conditions.[49] The increased incidence of major depression in older adults living with HIV is linked to higher rates of systemic inflammation, a contributor to poor health.[50]

Unfortunately, most healthcare systems are not equipped to cope with the complex care requirements of people aging with HIV, leading to significant burdens on both the individual and health systems.[51, 52] Addressing these challenges requires a comprehensive, person-centered approach that promotes long-term success in HIV and integrated care.

When it comes to measuring long-term success in HIV, there are currently no standardized processes or metrics. However, patient-reported outcomes measures (PROMs), which are tools used to report a patient's health condition status and come directly from the patient without interpretation from a healthcare professional are becoming increasingly valuable in care management and may help measure long term-success in HIV.[53] Care models developed for people living with HIV should factor in PROMs, health-related quality of life measurements and contain input from appropriate medical experts on factors that will sustain individuals' ability to manage their condition for the long-term.

Policies must also endorse the importance of community-based resources as trusted partners in delivering care that is relevant to the everyday lives of people living with HIV. Investments should include funding for community-based care that may be able to deliver treatment more effectively based on community circumstances.[54]

# 5 Global Policy Recommendations to Support Long-Term Success in HIV

While success in addressing HIV varies across the world, certain policy recommendations apply to countries no matter their national progress in addressing HIV/AIDS. All countries should have in place national HIV strategies which include the recommendations set out in this paper. Global recommendations include:

## I. Address Health Inequities:

### » Remove discriminatory laws and regulations:

Eliminate laws that criminalize or discriminate against people living with HIV and key populations, particularly people who use drugs, sex workers and LGBTQ+ people. Implement laws that promote non-discrimination and protect human rights. Address inequities that inhibit advancement in areas like innovative treatment, quality of life, treatment adherence, and access to prevention, including pre-exposure prophylaxis (PrEP).

### » Support peer-designed approaches to engage people living with HIV:

Support and fund the rollout of comprehensive measures and interventions, health literacy programs and U=U public awareness campaigns, with the meaningful leadership and involvement of people living with HIV and key populations.

### » Reduce the burden of stigma on engagement with care:

Mandate training and certification for all medical professionals to raise awareness of stigma and its negative impact on diagnosis, treatment and health outcomes. Addressing stigma is critical to delivering patient-centered HIV care and will have a positive impact on treatment uptake, adherence, and engagement in care..[8, 55]

### » Improve access to modern HIV medicines:

Ensure all people with HIV are connected to modern STR and treatment regimens that are highly effective, durable, simple to take, and tolerable (i.e. they minimize toxicity, side effects and drug-to-drug interactions). Improved access can lead to more efficient use of healthcare resources, increase adherence and improve long-term health outcomes—supporting long-term success in HIV.

### » Develop both short-term measures and long-term frameworks:

Develop national and sub-national implementation plans to increase adoption of HIV prevention, treatment, and care services, with specific attention to disadvantaged communities and vulnerable populations. Clinical guidelines for delivering patient-centered HIV care and improving reimbursement models should integrate patient-reported outcomes measures (PROMs).

### » Improve data collection:

Provide adequate funding to track the epidemic and identify key populations at risk of HIV and allocate healthcare resources accordingly to address the health inequities in HIV.[56,57]

### » Update clinical guidelines for first-line treatments:

Clinical guidelines should continue to be updated to recommend modern STRs/LATs as first-line treatment.

## II. Develop health systems that facilitate integrated care delivery

### » Ensure there is a process and infrastructure in place to allow people newly diagnosed with HIV to access treatment soon after diagnosis:

Publish guidelines and mandate national and sub-national HIV care delivery strategies that incorporate pathways for people with HIV to access modern HIV treatment on the same day as or soon after their diagnosis. Doing so will improve engagement in care, reduce the time to reaching undetectable viral load and enhance long-term success in HIV. HIV testing and linkage to care programs should be coordinated with HIV treatment services to ensure integrated healthcare delivery.

### » Maintain sustainable financing for innovative HIV treatment options:

Dedicate funding for innovative HIV treatment options to ensure reimbursement decisions incorporate the value of long-term health benefits of newer HIV medicines.

### » Establish person-centered, integrated, and coordinated HIV care models:

Integrate HIV care delivery and coordinate across multidisciplinary teams, focusing on individual need. Care design should ensure flexible visits and monitoring that accommodate the patient preference[58,59] and consider the impact of comorbid conditions on overall health burden.

- **Support person-centered flexible care delivery:** Governments and payers should expand coverage and payment for various types of care delivery, including long-term support for telehealth.
- **Mandate integrated and patient-centered care into continuing education/professional development for HCPs:** Require that all primary care physicians, nurses and geriatric and mental health professionals to train in providing integrated, person-centered care as part of their continuing education and professional development curricula. Provide up-to-date information on HIV clinical guidelines, scientific advancements and care modalities as part of training. Support professional development mandate with adequate funding.
- **Implement case management strategies for people living with HIV:** Treatment for people living with HIV should be holistic and involve a plan for ensuring individuals can access the care and medications necessary to sustain long-term success, using peer navigation or community-based case managers.

## III. Address aging, comorbidities and quality of life

### » Ensure integrated health systems are equipped to address accelerated aging and multiple comorbidities:

Integrated health systems must be designed around providing complex care for people aging with HIV, including people presenting with signs of accelerated aging. Services must be adequately funded, with monitoring and evaluation included to ensure services are effective and responsive to patient need.

### » Incorporate commitments and targets set out in UNAIDS Global Strategy within national and sub-national HIV plans:

Governments should publish and commit to a strategy that delivers on their commitments under the UNAIDS Global Strategy 2021–26, which states that 90% of people living with HIV should "have access to integrated or linked services for HIV treatment and cardiovascular diseases, cervical cancer, mental health, diabetes diagnosis and treatment, education on healthy lifestyles, counselling, smoking cessation advice and physical exercise."[37]

### » Develop and implement Patient Reported Outcome Measures (PROMs):

Care models for people living with HIV should factor in health-related quality of life (HRQoL) measurements through the use of PROMs and, developed with input from people living with HIV that support shared decision making.

### » Provide community and social support:

Prioritize national and local commitments to support community-based programs that address social isolation and stigma among older people living with HIV. Creating social networks for racial, sexual, and gender minorities who are more likely to be socially and financially isolated will support better mental health and yield better health outcomes.

### » Incorporate mental health care into overall health related quality of life (HRQoL) measures:

Develop policies that require payers to cover mental health care services that are needed by people living with HIV and hold providers accountable for delivering these services by assessing mental health care status in patient reported outcome measures.

### » Support awareness of the impact of frailty on long-term success in HIV:

Fund campaigns that educate healthcare practitioners on the importance of addressing frailty as part of holistic HIV care plans to increase rates of long-term success for older people living with HIV.

# 6 Summary

The issues and priorities presented in this paper show there is still much work and attention needed to advance an effective and holistic HIV response that supports long-term success. Modern treatment and prevention therapies are a core part of the answer, but a broad view that encompasses and addresses non-medical issues is needed to achieve long-term success for people living with HIV. It cannot be ignored that the decline in new HIV infections achieved since the height of the epidemic is stalling and, in some parts of the world, even reversing. Ending the epidemic is a complex endeavor, but is it is possible and necessary. We must continue to re-define and update our treatment and prevention strategies to meet the needs for everyone, everywhere living with HIV today.

Achieving and sustaining viral suppression is a great achievement, but we must respect that some people are not able to achieve undetectable viral loads. Other priorities such as mental health, physiological conditions, family, finances, and housing and use of older HIV regimens can be barriers to viral suppression. People should not be stigmatized, or in some cases arrested/criminalized, for not being virally suppressed. Governments should look to address the factors that limit long-term success in HIV.

Gilead remains committed to supporting the UNAIDS goal to get every community and country on track to end AIDS as a public health challenge by 2030. We are strengthened by partnerships and collaborations. Working in conjunction with stakeholders, Gilead has extended research, improved HIV education, expanded access and addressed barriers to care. Until new cases of HIV are eliminated, our workforce will remain steadfast in championing innovations, programs, philanthropy and partnerships that support the wellness and long-term success of all people impacted by HIV.

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