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The HIV Outcomes UK programme is funded by Gilead Sciences, ViiV Healthcare and MSD as co-sponsors. Editorial control sits with National AIDS Trust

# Prioritising quality of life in HIV policy:

HIV Outcomes UK briefing on England's 10 Year Health Plan and HIV Action Plan

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## Background

The next five years will be critical for the HIV response, in England and across the UK, as well as globally. It is imperative that quality of life for people living with HIV is prioritised alongside prevention and testing. Ensuring that people living with HIV have access to quality care, effective treatment, holistic support, and comprehensive services that meet their needs, is the foundation of an appropriate HIV response, and must be prioritised across the health service and beyond.

As we enter the final straight in the race to achieve the 2030 goal to end new transmissions of HIV, it is critical to ensure that the focus of HIV policy does not shift wholesale to prevention. Ensuring quality of life for people living with HIV is essential now, and will continue to be long beyond 2030.

The HIV response in England to 2030 will be guided by the HIV Action Plan for England, 2025 to 2030<sup>1</sup>, published by the government in December 2025, and further shaped by wider policy changes in the NHS, defined by the 10 Year Health Plan for England<sup>2</sup>. This briefing, published by HIV Outcomes UK, explores how quality of life for people living with HIV can be enhanced through the implementation of these Plans, and potential challenges and pitfalls that must be addressed.

## Introduction

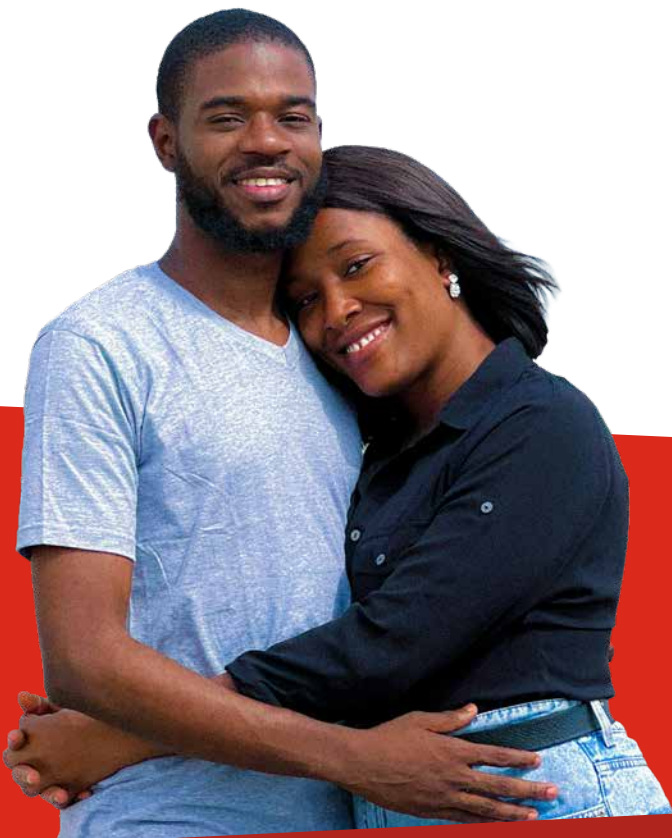
We welcome the Government's 10 Year Health Plan and the commitment it reinforces, to end new HIV transmissions in England by 2030 through delivering the next HIV Action Plan.



**We will end new HIV transmissions in England by 2030. Later this year, we will publish a new HIV action plan to continue our progress towards this ambition. This will include efforts to improve testing, tackle inequalities in access to HIV prevention interventions, and better identify the need for and initiation of HIV pre-exposure prophylaxis particularly among people from ethnic minority groups such as Black African and Black Caribbean communities.**<sup>3</sup>

The HIV Action Plan, published in 2025, reaffirms this commitment, in addition to broader commitments across the HIV care pathway. Framed as a collective plan, it acknowledges the need for cross-sector engagement to effectively deliver the HIV response, underpinned by a £170 million investment. We welcome the Action Plan's inclusion of quality of life for people living with HIV as a priority area, and the clear recognition it states of the requirement for HIV policy to look beyond 2030 and address the continuing needs of people living with HIV.

- <https://www.gov.uk/government/publications/hiv-action-plan-for-england-2025-to-2030/hiv-action-plan-for-england-2025-to-2030>
- <https://www.gov.uk/government/publications/10-year-health-plan-for-england-fit-for-the-future>
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# HIV Action Plan

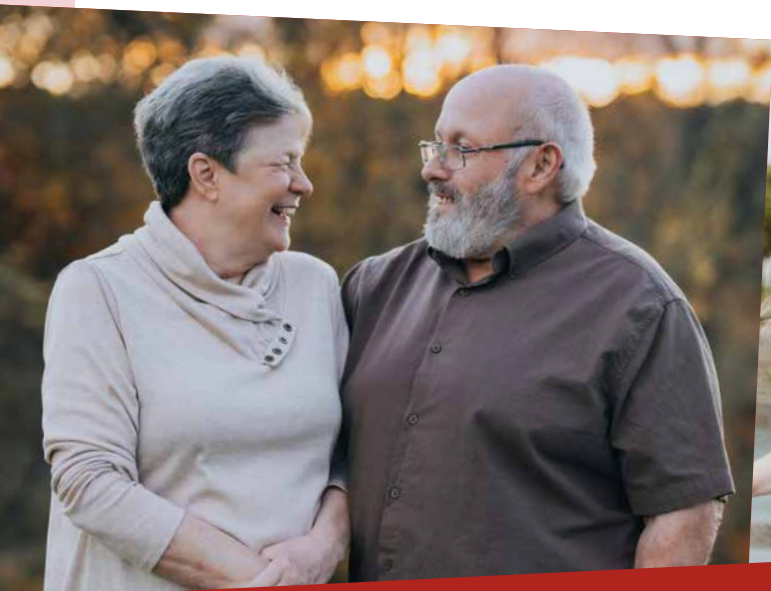
## Priorities in the HIV Action Plan

The Action Plan identifies five strategic priorities to drive action on HIV in England:

1. **Prevent – equitable access to prevention**
2. **Test – scale up HIV testing**
3. **Treat – rapid linkage and retention in care**
4. **Thrive – address stigma and improve quality of life**
5. **Collaborate – strengthen, and partner across, sexual and reproductive health and wider systems**

Quality of life for people living with HIV is a thread running throughout these priority areas. It will not be possible to deliver against these priorities without addressing inequalities in access. That means ensuring that resources and interventions are accessible to everyone who needs them, addressing bias and discrimination in services and tackling societal stigma. We have hugely effective prevention tools, but they only work when the people who need them have access to them. Each new HIV transmission is a failure of prevention, and we must be committed to addressing this for everyone.

The Action Plan takes important steps forward from previous iterations of HIV policy in England, in recognising the specific needs of women, identifying priority populations currently underserved, and acknowledging the impact of gender, sexism, racism and other systems of power and oppression that both fuel the HIV pandemic and inhibit quality of life for people living with HIV. But more must be done to recognise the rights and needs of people living with HIV in all their diversity, including trans and gender diverse persons and people in prisons.



## Treat: Rapid linkage and retention in care

**The previous HIV Action Plan had limited attention to re-engaging people who have been diagnosed with HIV but have either not been linked into or have disengaged from HIV treatment and care. This has emerged as a much stronger priority in HIV policy in recent years. The new Action Plan describes the “quiet crisis” of people who are disengaged from care – describing stigma, discrimination, and inequality as the drivers of this problem.**

To address this crisis, the Action Plan commits to a first of its kind national programme of re-engagement, which HIV Outcomes UK had previously advocated for in our report *No one left behind: Re-engaging the 12,000 people not in HIV care*.<sup>4</sup> The programme, with an investment of £9 million, will work with local services and the voluntary and community sector and industry to support re-engagement into care, supporting the health and wellbeing of individuals as well as supporting prevention of onward transmission.

This commitment is welcome, and could be transformational, especially with the funding in place to support it. While the Action Plan includes an estimate that there are around 5000 people disengaged from care, national HIV data shows there could be up to 12,000 people – our call is for everyone that may be disengaged from care to be identified and reached. This must include attention to inequalities in who is engaged and disengaged from care and targeted action to address barriers for different communities.

As our research and stakeholder engagement made clear in the No One Left Behind report: we can solve this problem of disengagement from HIV care, people can be found and supported back into care and what we need is political will and funding. The Action Plan importantly signals both of these – we now need implementation that is holistic, targeted, and shaped by the voices of people living with HIV.

The national programme must prioritise harnessing multidisciplinary partnerships and the leadership of the HIV voluntary sector and communities living with HIV. There are examples of good practice already in the voluntary sector and this should be supported, sustained, and advanced. We do not need a national programme to reinvent the wheel, but to take what is

already working to scale and ensure that we do not have a patchwork of services and support across the country.

Stigma, discrimination, and isolation are often greater in places with fewest services available and least access to support – a national programme is essential to mitigate these increased risks of disengagement.

Everyone living with HIV should have access to treatment and care that works for them, that respects them as an individual and meets their needs. Systemic inequalities drive people out of care and keep them out of care. It is critical that re-engagement efforts both reach individuals with the support they need, and address systemic challenges to ensure our HIV services are accessible to everyone. The HIV voluntary, community and social enterprise sector has a critical role to play in achieving this.

## Thrive: Address stigma and improve quality of life

**The HIV Action Plan identifies stigma, along with racism, homophobia, discrimination, and other challenges, as negatively impacting on wellbeing and access to care for people living with HIV. It commits to a range of efforts to address stigma and enhance HIV awareness, as well as ensuring the needs of women living with HIV are addressed – an important first in HIV policy, which has previously neglected the needs of women as a group.**

However, it is important to address wellbeing and quality of life beyond the impact of stigma, and ensure that the social determinants of health and wider inequalities are also addressed through the HIV response. This is particularly important for structurally marginalised communities, older people living with HIV, people diagnosed before effective treatment or with no access to effective treatment, and people with more biopsychosocial complexity. The HIV Outcomes UK framework includes the impact of mental health, data and confidentiality, and care engagement and coordination, in addition to stigma, and we will continue to advocate across all these areas, which collectively are essential to enhanced quality of life for people living with HIV.

4. <https://nat.org.uk/publications/no-one-left-behind-reengaging-people-hiv-care/>

# 10 Year Health Plan

**The framework for wider health policy set out in the 10 Year Health Plan provides further routes towards achieving improved quality of life for people living with HIV through the health service. The three shifts outlined in the 10 Year Health Plan - hospital to community, analogue to digital, and sickness to prevention – can contribute towards meeting the goals of ending new HIV transmissions, supporting people to live well with HIV, and tackling growing health inequalities.**

## Hospital to community

This shift envisages a transfer of care from hospital into local communities, improving access to general practice and allowing hospitals to focus on specialist care through the creation of the Neighbourhood Health Service. This has a number of potential benefits for HIV care.

Locating HIV testing, PrEP access, and support services within Neighbourhood Health Centres could improve access, particularly for underserved communities and those who face barriers to access specialist services. Co-location with other services (mental health, sexual health, substance use, frailty services, dementia services, brain health services) could enable services to address co-morbidities and social determinants of health in one place. Extended opening hours and community-based urgent care could help those who struggle to attend hospital-based clinics during standard hours.

The Plan's emphasis on bringing care into communities and creating multidisciplinary teams aligns with re-engaging people who are out of HIV care. It has the potential to particularly support those facing multiple barriers such as stigma, housing instability, or mental health challenges.

The national re-engagement programme committed to in the HIV Action Plan can exemplify the move toward community-based care, proactively identifying people who have disengaged and supporting them through community and nurse-led outreach, voluntary sector partnerships, and trusted local clinics. Re-engagement interventions and holistic support for people living with HIV could also be integrated into plans for the Neighbourhood Health Service. Stigma can be a barrier for people living with HIV, particularly older people, to engage with new systems, so it will be important to ensure that HIV representation is included in multi-disciplinary teams and neighbourhood health services to ensure people with HIV are not excluded.

Further policy commitments in the 10 Year Plan can also support quality of life for people living with HIV. The Plan commits to ensuring people with complex needs have an agreed care plan by 2027, co-created with patients who will be able to access their care plan through the NHS app, and discuss it with their clinician. This can benefit people living with HIV by supporting better coordination between HIV clinics, GPs, mental health services, and social care. Including voluntary sector input in care planning could better reflect the person's holistic needs, including housing, benefits advice, and peer support. Formally recognising HIV as a long-term condition in primary care can ensure this commitment is extended to all people living with HIV.

The Plan's goal of at least doubling the uptake of personal health budgets by 2028 offers opportunities to address non-clinical needs affecting HIV outcomes, such as transport to appointments, access to exercise programmes or tailored nutrition support. Ensuring linkages between personal health budgets and local voluntary sector services could maximise their impact on wellbeing and treatment adherence. There is a need to review and address barriers to personal health budgets for people living with HIV, to ensure maximum impact.

The 10 Year Health Plan recognises that more integrated working between the NHS and the voluntary sector can deliver large efficiencies, and that voluntary sector organisations 'all have the ideas, networks, and drive to transform outcomes for patients'. This opportunity is clear for the HIV response given that the HIV voluntary sector offers unique reach, trusted relationships with communities, and high-quality person-centred care.

The Plan describes an intention to use patient reported outcome measures (PROMS) and patient reported experience measures to help patients when choosing their provider on the NHS App. PROMs in HIV care could capture outcomes beyond viral suppression, including mental health, experiences of stigma, and treatment side effects - to ensure services are assessed on what matters to people living with HIV. Careful analysis of PROMs data by demographics could help to identify inequalities in HIV care, if biases and nuances are accounted for.

## Analogue to digital

Moving from an analogue health service to comprehensive, integrated digital systems has the potential to substantially benefit people living with HIV, who currently face fragmented data systems and siloed services that negatively impact health outcomes and experiences. Digital systems which are not integrated hinder collaboration and joined up care. With two-thirds of people living with HIV in the UK having at least one additional long-term condition, coordinated care is essential. Incompatibility between systems can prevent HIV clinicians and nurses, GPs, mental health providers, and peer support workers from easily sharing information and coordinating. It can also mean that people living with HIV cannot readily access comprehensive information about their own health, hindering potential for greater self-management and shared decision-making.

The 10 Year Health Plan proposes the development of a Single Patient Record, bringing together all of an individual's records across primary and secondary care and different specialties into one place. This can support ensuring that care is seamless across all parts of the NHS. However, many people living with HIV are reluctant to share their HIV status with their GP or other secondary care providers outside their HIV clinic, a concern compounded by ongoing stigma and discrimination within the health system.

Any shift towards greater sharing of HIV status must be accompanied by an investment into addressing stigma and discrimination, through expansion of initiatives such as HIV Confident<sup>5</sup> across the health system. It must also be supported by engagement with people living with HIV and patient organisations, to ensure that the concerns of people living with HIV are understood and addressed, and consent is central to the process.

In addition, while the Government's ambition to roll out Single Patient Records is welcome, this will be a long-term project and there is a pressing need to improve the current use of electronic patient record (EPR) systems. Although 90% of NHS trusts now have an EPR in place, only 10–30% are using more advanced functionalities such as integrated prescriptions or record sharing with other hospitals.<sup>6</sup> Strengthening how existing systems are used will be essential to realising the full benefits of digital transformation. It will also be vital to ensure that people living with HIV are not excluded from digital systems, and that confidentiality and security issues are addressed to ensure inclusion of HIV rather

than current practices which see HIV diagnostic codes removed when patient data is transferred into anonymised research datasets.<sup>7</sup>

The Plan also sets out longer-term ambitions for the Single Patient Record to include a personalised account of health – drawing on lifestyle, demographic, and genomic data – to tailor NHS services and support individual behaviour change. In HIV care, this could offer real value, particularly in supporting people who face barriers in engaging with their HIV care or whose wider needs, such as housing instability or substance use, impact their health.

However, these tools carry risks if implemented without transparency, ethical safeguards, and meaningful community involvement. Similarly, plans to expand the NHS App to act as the 'front door' to the NHS as a whole, with a range of services as well as access to patient records, can enhance HIV care if delivered with consent, transparency and with HIV care and services fully integrated.

## From sickness to prevention

Commitments to HIV PrEP and testing in the 10 Year Health Plan are welcome, alongside the commitments outlined in the HIV Action Plan. Increasing access to testing and prevention, in more settings and through digital tools, can help to address inequalities and improve outcomes for people living with HIV.

The Plan's emphasis on reducing long-term ill health aligns with the need to address higher rates of cardiovascular disease, certain cancers, and mental health conditions among people living with HIV. Neighbourhood Health Centres and prevention programmes could include targeted screening and support for comorbidities in this population. Smoking cessation, weight management, and vaccination programmes should be inclusive of and accessible to people living with HIV.

The Plan's cross-sector prevention approach offers opportunities to address poverty, housing, and employment barriers that undermine HIV health outcomes. Linking HIV care to Health and Growth Accelerators and community wellbeing programmes could reduce isolation and improve economic participation. Including voluntary sector organisations in prevention initiatives will help ensure culturally competent, targeted outreach to communities most affected by HIV.

5. <https://www.hivconfident.org.uk/>

6. <https://www.health.org.uk/reports-and-analysis/analysis/electronic-patient-records-nhs-strategy>

7. <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0316848>

## Recommendations

In order to ensure that health-related quality of life for people living with HIV is supported through the implementation of the HIV Action Plan and the 10 Year Health Plan, we recommend that the Government, NHS and service providers:

- Ensure that the commissioning of the national re-engagement programme happens as quickly as possible, building on local knowledge and partnerships and in full collaboration with the voluntary sector.
- Meaningfully engage with people living with HIV when taking forward the three shifts outlined in the 10 Year Health Plan, ensuring that their experiences, priorities and preferences are reflected and shape implementation.
- Develop the single patient record with confidentiality and agency at the centre, ensuring that people living with HIV have confidence and trust in who has access to their data, choice in how and where it is shared, and agency over their own data.
- Prioritise addressing the role and impact of social determinants of health.
- Recognise that supporting a good quality of life and improving wellbeing takes more than reducing stigma, which is essential but must be part of wider measures to support quality of life for everyone living with HIV.

## About HIV Outcomes UK

An effective HIV response must be comprehensive, encompassing prevention, treatment, care, and support for people living with and vulnerable to acquiring HIV. In the UK, there is excellent access to HIV treatment and care. Yet many people living with HIV continue to face stigma, discrimination, and barriers to accessing and maintaining a good quality of life. This is exacerbated by persistent inequalities in access to and quality of HIV prevention and care, especially for structurally marginalised groups.

To address these challenges, HIV Outcomes UK was formed in 2023 as a cross-sector collaboration working through partnership to eliminate stigma in HIV care, enhance care engagement and coordination, support mental health needs, and improve data and confidentiality practices in the NHS. The HIV Outcomes UK programme is funded by Gilead Sciences, ViiV Healthcare and MSD as cosponsors. Editorial control sits with the HIV Outcomes Secretariat at the National AIDS Trust. The group is affiliated with HIV Outcomes at a European level.

## Further information and partnership

For more information on HIV Outcomes UK, please visit: [www.nat.org.uk/hiv-outcomes](http://www.nat.org.uk/hiv-outcomes). If you have any questions or would like to arrange a meeting, please get in touch with us at [HIV.Outcomes@nat.org.uk](mailto:HIV.Outcomes@nat.org.uk).

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