

Getting on track

Becoming the first country to
end new HIV cases by 2030



Introduction

The Government has the chance to achieve something incredible: make England the first country to stop the onward transmission of HIV, by 2030, without a vaccine or a cure.

Medically, we have everything we need: quick and easy HIV testing technologies, pills and new injectables that prevent anyone acquiring HIV, and treatment that means a person living with HIV can live a healthy life and can't pass the virus on. But scientific advances can only take us so far. The Government must now take action to ensure everyone can access these game-changing medicines.

Significant progress has been made in the four years since the HIV Commission established by our three organisations published its roadmap to ending new HIV cases in England by 2030.¹ The introduction and subsequent expansion of opt-out HIV testing in emergency departments has been even more successful than expected. Year on year, more people access PrEP to prevent them getting HIV. And progress continues to be made to overturn outdated and stigmatising laws and policies, such as bans on military service, blood donation, driving, and access to fertility treatment, that stand in the way of the rights of people living with HIV.

However, these strides forward have left some people and communities behind. And unless that is addressed – urgently, equitably, and fully – the opportunity we have will be lost. What has been done so far is not enough to get us to where we need to go next. We are not on track to reach the 2030 goal to end new cases of HIV in England.

An estimated 4,500 people in England are living with undiagnosed HIV.² Even more – up to 14,000 – are diagnosed but no longer in HIV care.³ These people have been diagnosed with HIV but haven't been seen by their clinic for more than a year, either because of negative experiences in healthcare or because they are dealing with complex needs across their lives.

The full potential of PrEP has not been realised, and last year there was a 15% rise in new HIV diagnoses first made in England.⁴ Year on year, the government data is clear: inequalities run deeply through the epidemic, from prevention, to diagnosis, to treatment and support. Failing to take action now will result in more HIV transmissions, more people needing treatment and care, and increased costs to the health and social care sector.

With only 1 in 8 people living with HIV having shared their status with most people in their lives, and people living with HIV reporting poorer quality of life in every measured area compared to the general population, it is clear that much more must be done to support everyone to feel safe, confident, well, and in control of their lives.⁵

¹The HIV Commission, How England will end new cases of HIV, December 2021.

²UKHSA, HIV Action Plan Monitoring and Evaluation Framework, December 2023.

³Ibid.

⁴UKHSA, HIV testing, PrEP, new HIV diagnoses and care outcomes for people accessing HIV services, October 2024.

⁵UKHSA, Positive Voices 2022; Survey Report, January 2024.

The Government's new HIV Action Plan for England

It will take ambition, investment, clear direction and accountability to do so. Interventions must be culturally competent and be responsive to how the epidemic changes – not least because as we get closer to zero transmissions, it will only become harder to find the last people who need a test, care, and treatment. As we get closer to the finish line, we will have to speed up – not slow down.

We have identified six key goals for getting there:

1	HIV prevention should be the responsibility of the whole health service.
2	Everyone in England should be able to get an HIV and STI test at home.
3	We must find everyone living with undiagnosed HIV.
4	Everyone who can benefit from PrEP should be able to access it, including online.
5	Everyone living with HIV should have the support they need to access care.
6	Everyone living with HIV must feel safe and confident in every healthcare setting that they go to.

Over the last few months we have held conversations with a wide range of people living with HIV, as well as clinicians, commissioners and charities about what they think is needed from the new HIV Action Plan. We'd like to thank all those who took the time to share their views and experience during those workshops.

This report makes six policy recommendations which we believe must be central to the new HIV Action Plan:

1	NHS England should co-own the new HIV Action Plan with the Department for Health and Social Care and appoint a new designated HIV lead in NHS England to drive the changes needed.
2	The Department for Health and Social Care should invest in a year-round online HIV and STI postal testing service.
3	Opt-out HIV testing in emergency departments must continue and be expanded to other health settings, including to GPs and termination of pregnancy services, in line with clinical guidelines.
4	The Government should introduce a national PrEP Expansion Plan.
5	NHS England should commission a national HIV retention and re-engagement programme.
6	Training and awareness-raising programmes should be in place in all healthcare settings so that staff have the right knowledge on HIV and no one living with HIV experiences discrimination.

This is not intended as a full draft of the new HIV Action Plan, nor a full report of everything that was shared with us in the engagement discussions we held, but a clear set of core principles and recommendations for what's needed from the next HIV Action Plan for England, to end new HIV cases in the next 5 years. Getting there won't be easy, but we all owe it to everyone lost to AIDS-related illness and to everyone living with HIV today to do everything we can to make it happen.

As we strive to end new transmissions, we must never forget that HIV will be a continuing reality for the 100,000+ people living with HIV. Working for a world where everyone living with HIV can live well, safely, and healthily beyond 2030 must be an overriding priority – both now, and for the years ahead.



Anne Aslett
Chief Executive
Elton John AIDS Foundation



Richard Angell
Chief Executive
Terrence Higgins Trust



Robbie Currie
Chief Executive
National Aids Trust

Key principles

While each conversation during our engagement process was different, there were common themes and shared priorities. What was strikingly clear was that any set of recommendations has to be underpinned by four core principles if it is to be truly equitable and successful.

In the new HIV Action Plan, the Government must continue to deliver what has been proven to work and:

- Ensure person-centred care throughout the health system that supports people living with HIV at all stages of their lives to take an active role in their own health management.
- Prioritise interventions that proactively address the health inequalities across the HIV response. Services must involve communities and be codesigned and informed by people with lived experience.
- Recognise and respond to the role that the social determinants of health play in HIV transmissions and how they prevent people living with HIV from having a good quality of life.
- Acknowledge the impact of racism (including institutional racism), sexism, homophobia, and transphobia in driving the stigma, discrimination and health inequalities that affect the lives of people living with HIV.

Priorities for the new HIV Action Plan

1 Leadership

HIV prevention should be the responsibility of the whole health service. **NHS England should co-own the new HIV Action Plan with the Department for Health and Social Care and appoint a new designated HIV lead in NHS England to drive the changes needed.**

NHS England's opt-out HIV testing programme in A&Es was the flagship success of the last HIV Action Plan. The programme's success has demonstrated the value of the wider health system (beyond specialist services) in HIV prevention and tackling stigma. As HIV care is delegated to Integrated Care Boards (ICBs), we believe maintaining national leadership and oversight on HIV will be crucial for our 2030 goal.

That's why the new HIV Action Plan should be a shared plan between the Department for Health and Social Care and NHS England, with NHS England nominating a new designated lead for driving change on HIV across the system and ensuring that national clinical standards on care and testing are met everywhere.

Delivery of the plan must bring in key partners – particularly local government and Integrated Care Boards, who are fundamental to success – and be aligned to other health strategies, including on women's health inequalities, ageing and complex needs. The voluntary sector must also be a full and meaningful partner in this joint leadership, bringing diverse representation, community insight, relationships of trust, and the efficient use of resources to the table.

The plan must be driven by an outcomes not outputs approach. The government should agree on a clear outcomes and evidence framework, to guide decisions around focus, interventions, funding flows, and accountability, to ensure that the strategy evolves in line with the changing nature of the epidemic as we close in on zero new cases.

Outcomes must include achieving meaningful improvements in quality of life for people living with HIV, as well reducing new HIV transmissions. Unlike the targets for treatment and prevention, there are no equivalent targets set for improving the quality of life for people living with HIV. The new Action Plan should set targets to be achieved so that the quality of life for people living with HIV can reach parity with the general population.

It must provide a framework to support and enable the local leadership, partnerships, and accountability that are so key to successful implementation on the ground.

2

Testing at home

Everyone in England should be able to get an HIV and STI test at home. **The Department for Health and Social Care should invest in a year-round online HIV and STI postal testing service.**

30% of sexual health services in rural England don't offer postal STI and HIV testing.⁶ Sexual health services are under intense strain, having faced severe real-terms funding cuts and rising demand, which has undermined the universality of services like postal testing. An increasing proportion of people are accessing postal HIV testing over in-person testing (where it is accessible).

However, only in National HIV Testing Week is postal HIV testing available universally in England, crucially with both self-sampling and self-testing options. Latest UK Health Security Agency (UKHSA) data suggests that postal testing is the preferred option for Black African heterosexuals, who bear a disproportionate burden of HIV and of late HIV diagnoses.⁷

There is no need for the current variation of access – a single national portal in Wales for HIV and STI testing and the portal for Hepatitis C testing in England has shown what's possible. This service, if funded from a national budget, would be cheaper than the current patchwork of services and free up the public health grant for other crucial sexual health services that can and should be locally tailored.

As the government seeks to move the health service from 'analogue to digital', a single postal testing portal online / on the NHS app should be included in this transformation, which could be integrated with an online PrEP initiation service. This service would complement the wider expansion of testing that is needed if we are to get to zero, and work alongside community-based HIV testing initiatives and targeted HIV testing campaigns like National HIV Testing Week, that we know reach communities who are less likely to test.⁸

⁶ Terrence Higgins Trust, Overstretched and under strain: A mystery shopper approach to access to sexual health services in England, Scotland and Wales, July 2022.

⁷ UKHSA, HIV annual data tables, October 2024.

⁸ Public Health England, Community-based testing in Europe: a systematic review, 2019.

3 Testing in the health service

We must find everyone living with undiagnosed HIV. Opt-out HIV testing in emergency departments must continue and be expanded to other health settings, including to GPs and termination of pregnancy services, in line with clinical guidelines.

The simple 'opt-out' testing principle has been game-changing for our HIV (and hepatitis) response. In just a year, in London, Brighton, Blackpool and Manchester, more than 900 people were found with HIV (more than 1 in 3 of them previously diagnosed but disengaged from care).⁹ A further 3,600 with hepatitis B or C were found. The programme is saving the NHS money, relieving pressure and addressing health inequalities – with people diagnosed in emergency departments more likely to be women, of Black African ethnicity and older (all groups disproportionately likely to be diagnosed late).

Now as the programme expands across England, we expect hundreds more diagnoses in the 47 hospitals going live with testing this year. We can't stop here. Funding for all emergency departments in the programme must be extended beyond the current March 2025 cliff edge, including the crucial ring-fencing of funding for voluntary sector support, for those newly diagnosed and returned to care.

National clinical guidelines for opt-out HIV testing must be implemented across the health system, including opt-out HIV testing for everyone attending sexual health, termination of pregnancy and substance misuse services anywhere in England, and for everyone having blood taken or registering with a GP service in areas with a high HIV prevalence.¹⁰

⁹DHSC, Press release: New research into expansion of life-saving testing programme, December 20223.

¹⁰BHIVA, BASHH and BIA, Adult HIV Testing Guidelines, 2020; NICE, HIV testing guidelines: increasing uptake among people who may have undiagnosed HIV, 2016.

4 PrEP

Everyone who can benefit from PrEP should be able to access it, including online. **The Government should introduce a national PrEP Expansion Plan, that includes the development of an online PrEP access portal.**

HIV pre-exposure prophylaxis (PrEP) plays a key role in reducing HIV transmissions. Based on absolute numbers of HIV diagnoses from UKHSA statistics, the populations most at risk of acquiring HIV are white gay, bisexual, and other men who have sex with men (GBMSM) and heterosexual women of Black African heritage, making them essential targets for initial PrEP expansion efforts.

A national PrEP Expansion Plan is required to dramatically increase the availability of and adherence to PrEP if the goal of becoming the first country to eliminate new transmissions by 2030 is to be reached.

There are significant barriers to scaling PrEP that include lack of knowledge; stigma associated with using sexual health services; missed opportunities for prescribing; and long waiting times for appointments. PrEP initiation and continuation must fit in with people's daily lives if it is to reach its game-changing potential.

Analysis by the Elton John AIDS Foundation indicates that, to succeed, the PrEP Expansion Programme should include a fully integrated online portal that delivers PrEP direct-to-the-door dropbox, or local pharmacy.¹¹ The plan should diversify the places where people can have a conversation about their HIV risk and be given PrEP, for example antenatal care, women's health hubs, contraception services, and prisons, among others. Pharmacies must be able to dispense the PrEP that is prescribed by these services. These avenues provide a rare opportunity to address PrEP awareness and initiation, with ongoing care and support delivered in adapted sexual health services.

The PrEP Expansion Programme can build on existing structures where possible, including voluntary sector services that reach underserved communities, and be fully integrated into sexual health services and responsive to local needs to be effective. The Government will need to carefully consider how funding flows support all aspects of this system from testing, to delivery, to engagement with sexual health services and integration with electronic patient record systems.

¹¹Elton John AIDS Foundation, Improving PrEP in England: Landscape analysis and pilot recommendations, April 2024.

5

Retention and Re-engagement in care

Everyone living with HIV should have the support they need to access care. **NHS England should commission a national HIV Retention and Re-engagement programme.**

UKHSA estimates there could be more than 14,000 people not in HIV care in England, who have been diagnosed with HIV but not attended their clinic in more than 15 months.¹² These people are at risk of getting seriously ill or dying. Many already are, with some hospitals in London reporting that disengagement from HIV care has overtaken undiagnosed HIV as the leading cause of HIV-related hospital admissions.

People disengage from their HIV care for a range of different, interacting factors including internalised, anticipated and actual HIV stigma, their socio-economic circumstances and drugs and alcohol misuse.¹³ The majority of people diagnosed but not in HIV care are from groups most disproportionately affected by HIV: gay, bisexual and other men who have sex with men and women of Black African ethnicity, followed by heterosexual men of Black African ethnicity. Young people (aged between 16-25) are disproportionately likely to not be in HIV care, and ensuring enhanced support during the transition between paediatric and adult HIV care is crucial.¹⁴

Pilot work by HIV clinics and voluntary organisations across the country has demonstrated that with intense case finding, care coordination and casework support, people can be re-engaged in care. It's time to scale this up and introduce a national programme to retain and re-engage people in HIV care. This must include a national guarantee of peer support through every HIV clinic in England.

Ensuring voluntary sector staff can be given honorary contracts in the NHS so they can access patient data is crucial for this work. Voluntary sector staff are well placed to build trust with clients and help address wider determinants of health.

With more responsibility for HIV commissioning being moved to ICBs, a national programme will need to respond to local needs and be delivered by local providers.

¹²UKHSA, HIV Action Plan Monitoring and Evaluation Framework, December 2023.

¹³Haworth et al, 'REACH: A mixed methods study to investigate the measurement, prediction and improvement of retention and engagement in outpatient HIV care', Health Services and Delivery Research, No.5.13, March 2017; Dr Veronique Martin, 'Monitoring people not engaged in care and subsequent re-engagement', presentation at BHIVA conference, May 2024.

¹⁴Dr Veronique Martin, 'Monitoring people not engaged in care and subsequent re-engagement', presentation at BHIVA conference, May 2024.

6 HIV stigma in healthcare settings

Everyone living with HIV must feel safe and confident in every healthcare setting that they go to. **Training and awareness-raising programmes should be in place in all healthcare settings so that staff have the right knowledge on HIV and no one living with HIV experiences discrimination.**

One in seven people report they avoided accessing healthcare services because of their HIV status – stigma and discrimination are unacceptably prevalent in healthcare settings, leading to worse health outcomes and poor mental health, and in many cases, people disengaging from care.¹⁵ Great work has been happening in some NHS trusts such as Manchester Foundation Trust, as well as through HIV Confident.¹⁶ The next HIV Action Plan should fund and champion training programmes that we know improve awareness and confidence in healthcare settings.

Promoting a good quality of life for people living with HIV has to be much more than aiming for an absence of stigma or provision of basic healthcare. Good levels of life satisfaction and wellbeing must become the benchmark, and can be achieved by ensuring equitable access across England to high quality, person-centred HIV care and psychological support – the BHIVA Standards of Care for Living with HIV must be met everywhere, and be complemented by availability of peer support through every HIV clinic.

¹⁵UKHSA, Positive Voices 2022; Survey Report, January 2024.

¹⁶<https://www.hivconfident.org.uk>.

