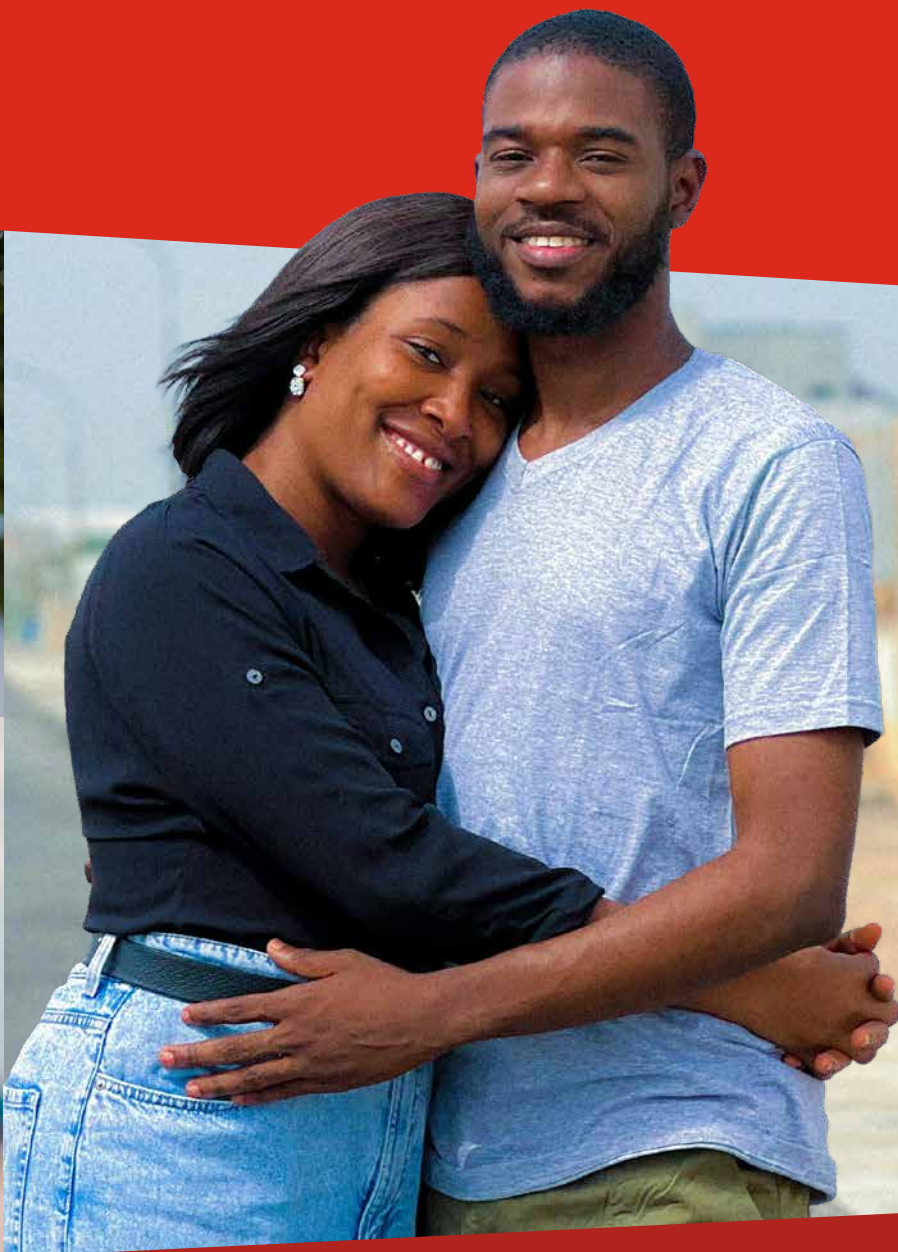




No one left behind:

prioritising retention and re-engagement
in care for people living with HIV in Scotland

April 2026



Background

Scotland has a historic opportunity in its grasp. Advances in HIV treatment and prevention tools mean that ending HIV transmission is possible by 2030. With bold action and funding that matches the scale of our ambition, Scotland could be the first country in the world to achieve this goal and do so without a vaccine or a cure.

To meet this 2030 goal, it is critically important that no one is left behind and that every person living with HIV has access to the treatment, care and support they need.

Despite marked progress towards HIV transmission elimination, data shows that there are up to 1400 people living with diagnosed HIV in Scotland who are not engaged in HIV care or are lost to follow up.¹ This represents around 20% of the population of people living with diagnosed HIV, and compares with the approximately 6% of people living with HIV who are undiagnosed.

People who are diagnosed with HIV but are not engaged in care are not receiving the treatment and support they need to protect their health and support their wellbeing. Some of these people will already be very ill, and others will become so.

Without urgent action, this risks putting the 2030 ambition in jeopardy. It must be prioritised now.

Effective HIV treatment also prevents onward sexual transmission of HIV, so increasing retention in care and treatment supports the goal to end HIV transmission. It also reduces costs to the health service, by reducing missed appointments, avoiding costly in-patient admissions, and preventing the costs associated with onward transmission.

The Scottish Government has demonstrated its commitment to addressing HIV in the 2021-26 Parliament, and the next Government must commit to doing the same.

ⁱ. See section on 'People not in HIV care' for full definition of these terms.

The HIV Transmission Elimination Delivery Plan 2023-26ⁱ recognises the need for further work to re-engage people not in HIV care, and the potential for opt-out testing in emergency departments to help find and re-engage people in HIV care.



Work is required to establish the number of people who are living with HIV in Scotland but are not currently under care, and work to re-engage those who are not attending for care; termed 'Trying to Find' (TtF).

It [Opt-out Emergency Department] testing also offers an opportunity to re-engage people previously diagnosed with BBVs [Blood Borne Viruses] but who are not currently in care. ”

HIV Transmission Elimination Delivery Plan 2023-26

The next Scottish Government must renew the HIV Transmission Elimination Delivery Plan and commit to clear, funded action to prioritise retention and re-engagement in HIV care for everyone not currently attending or lost to follow up. The HIV voluntary and community sector must be partners in this effort, recognising the reach and trust these organisations have with people who face barriers to engaging in HIV treatment and care and the essential insights they bring.²

Investment in retention and re-engagement services will save lives, save money to the healthcare service, and reduce new transmissions of HIV.

The next Scottish Government must develop a national programme to find and re-engage the significant number of people lost to HIV care.

This briefing builds on a report, [No one left behind: Re-engaging the 12,000 people not in HIV care by the National AIDS Trust, on re-engagement in HIV care across the UK.](#)

That report was informed by a parliamentary roundtable that the National AIDS Trust convened with the All-Party Parliamentary Group on HIV & Sexual Health in April 2025. This meeting brought together multi-stakeholder leaders in the UK's HIV response - voluntary sector and community leaders, clinicians, civil servants, researchers, and parliamentarians. It featured presentations from the UK Health Security Agency, clinicians in South East London and Terrence Higgins Trust.

People not in HIV care in Scotland

Numbers of people not in HIV care³ in Scotland:

As of 31 December 2024, there were 6,079 individuals diagnosed and living with HIV in Scotland. 93% (5,640 people) had seen an HIV specialist in the last 18 months.

Clinic attendance was slightly lower among people whose mode of HIV transmission was recorded as 'other' or unknown, and among people of Chinese or Indian background.

- 439 people (7%) had not attended an HIV clinic in the last 18 months. Of this group:
- 359 people had attended within the last two to three years
- 80 people had not been to an HIV clinic for more than three years, but had used other NHS services during this time.

There were also 926 people recorded as 'Lost to Follow Up'. This means they had not attended HIV specialist services and had not used other NHS services in the last three years. They are not included in the main count of people currently living with diagnosed HIV in Scotland.

Scotland's progress on the 95-95-95 UNAIDS targets

Based on data to the end of 2024,

94%

(6,079) of the estimated cohort of 6,467 people living with HIV in Scotland had been diagnosed and, of these diagnosed individuals,

91%

(5,520/6,079) were recorded as receiving treatment between 1 July 2023 and 31 December 2024 and, of those on treatment

95%

(5,260/5,520) had a suppressed viral load

https://publichealthscotland.scot/media/35162/final-hiv-in-scotland-update-to-31-december-2024_checked.pdf

Retention and Re-Engagement in Care

The next Scottish Government must develop a national programme to re-engage the significant number of people lost to HIV care. With 7% of people living with diagnosed HIV not engaged in care, and a further almost 1000 people lost to follow up, there is an urgent need for nationally coordinated action to prioritise retention and re-engagement in care.

There are many factors that drive disengagement in care, including poverty, discrimination, stigma and complex health needs⁴, which also cause ongoing challenges to engagement and retention in care. An intersectional approach which recognises and addresses the interlocking inequalities that drive some people out of care and keep people out of care is essential. In Scotland, the majority of those no longer attending HIV treatment and care are gay and bisexual men and other men who have sex with men. People who inject drugs are also over-represented in the disengaged cohort.

The HIV voluntary and community sector is a vital partner in efforts to re-engage people in HIV care. There is a growing body of evidence of what works to successfully get people back into care, through case-finding, a flexible and personalised approach, focussed follow up and holistic services, and collaboration between clinicians and voluntary sector organisations⁵.

The UK Government has committed to a national retention and re-engagement programme in England as part of the HIV Action Plan 2025-2030, with £9 million of funding and a commitment to partner with the voluntary sector⁶. A similar approach must also be taken by the Scottish Government.

The Scottish Government have recently allocated funding to Terrence Higgins Trust to deliver a programme in NHS Lanarkshire which aims to support people living with HIV to re-engage and stay engaged in their HIV care. The one-year pilot will provide targeted, person centred support to people who have disengaged from HIV care or who have been identified as being at risk of disengagement.

We need a national approach to re-engagement to find and support everyone living with HIV and end new cases by 2030, with the voluntary sector as a key delivery partner from the outset.

Without a targeted, funded and strategic approach to bringing people back into HIV care, the Scottish government risks jeopardising its 2030 ambition, further entrenching inequalities in our HIV response and an increase in preventable HIV-related illness and deaths.

Addressing the root causes of disengagement from care

Multiple, complex factors lead people to disengage from care, reflecting broader health inequalities. Social, economic and systematic challenges create barriers to accessing and remaining in care. Successful retention and re-engagement programmes must address these intersecting challenges to ensure no one is left behind.

Barriers include⁷:

- Persistent HIV stigma within healthcare and other services, and internalised stigma experienced by people living with HIV.
- Poor mental health, and inconsistent and unequal access to mental health treatment and care.
- Challenges caused by insecure immigration status and limited awareness of how to navigate the NHS and rights to healthcare and treatment.
- Economic deprivation, food insecurity, insecure housing and homelessness, and intimate partner violence which create direct barriers preventing people engaging with healthcare.
- Standard clinical systems (limited hours, strict appointment rules, lack of continuity) which can fail to meet people where they are including difficulties surrounding work commitments, childcare and travel to clinics.
- Treatment fatigue and healthcare-related trauma.
- Competing priorities and limited ability to prioritise health and wellbeing.
- Lack of system-level priority and funding for retention and re-engagement.
- Inconsistent access to support and services, due to long travel distances to sexual health clinics, particularly for those living in rural areas of Scotland.

Re-engagement in action: Learning the lessons from successful projects in Scotland

Waverley Care Case Study



It's because of you that I come to the hospital."

"... now I got accommodation after living on the street ... I know I need the help to get out this way of life and plan on settling in to new accommodation and engaging with services better. Thanks for being there and helping me through this. I know once I am settled I can start to take better care of my health and make better choices."

"That was the best day I've had in a long time."

Service users of Waverley Care's Lost to Follow Up service

Stats for Waverley Care Lost to Follow Up Service:

44

people supported through the programme had attained an undetectable viral load,

26

had improved their engagement with clinical appointments and medication adherence

58%

felt better connected to services

55%

felt an improvement in their overall wellbeing

Jane

Jane, who has a history of substance misuse, was referred to Waverley Care because she disengaged from HIV clinical services. Although she continued to collect and adhere to her medication, she had missed multiple clinic appointments, and had not been seen by a specialist for more than two years. She now urgently needed blood investigations.

Waverley Care made contact with Jane, with an initial telephone call after which it was agreed that the next communications were by text, to help her to prepare for a follow-up phone call. After several text messages, the follow-up conversation by telephone was able to establish what the barriers were that were preventing Jane from attending her appointments, such as anxiety about exacerbating her COPD, the logistical difficulties of getting to the HIV clinic, which involved several long bus journeys, the expense of bus tickets, her difficulties remembering appointments and her fear of altercations with a neighbour when leaving the house.

Waverley Care were able to provide interventions to address these barriers, including providing taxis, text and phone reminders leading up to scheduled hospital appointments, accompanying Jane to appointments, and helping Jane to fill out documentation to apply for a concessionary bus pass.

An in-person meeting established a good working relationship with Jane, and allowed her to discuss the difficult life experiences, mental ill health, isolation and self-stigma that resulted from living with HIV. She agreed that she would benefit from wider community support and help with referrals.

Jane is now re-engaged in HIV care, and has a concessionary bus pass which will enable her to travel to hospital appointments. She is able to talk more openly about her HIV status, and she has been encouraged to attend the Waverley Care Living Well support group, and is also being encouraged to consider attending local recovery groups. She has been to see her GP, and after a review of her inhalers, she feels that her COPD is much more under control now.

Action is needed now

With up to one in five people living with HIV in Scotland either not engaged in care or lost to follow up, the situation requires bold and urgent action. This problem can be solved. We have the evidence that shows what programmes and interventions work to re-engage people back into care. What is now needed is political will, funding, and a strategic approach.

A national HIV retention and re-engagement programme, building on the evidence of good practice from HIV clinics and voluntary organisations, can support a coordinated approach that fulfils the commitment to leave no-one behind. The whole HIV response is interconnected, so with retention and re-engagement as a missing piece, the response overall is undermined.

Disengagement from care costs the healthcare system at every stage: HIV clinics lose time on missed appointments, untreated HIV often leads to costly inpatient admissions; and new cases of HIV, resulting from onward transmission, create lifelong care costs.

For example, in 2019 at Guy's and St Thomas' hospital alone, the cost of inpatient care for people out of HIV care was over £408,135 in a single year⁸. Supporting people to live well with HIV and maintain an undetectable viral load also means they cannot pass the virus on. This not only prevents new HIV transmissions - and the potentially life-changing impact this has on people - but also avoids lifetime care costs estimated at £220,000 per person.

Most importantly, for people living with HIV, disengagement with care is driven by entrenched inequalities, stigma and discrimination and compounds challenges including mental ill health, isolation, socioeconomic challenges and poor wellbeing. Each of these people deserves the comprehensive, holistic and person-centred support to re-engage in care, improve their health and live well. We must not leave any one of them behind.

The Scottish Government must commit to urgently renew the HIV Transmission Elimination Delivery Plan. Within this plan, it must set out the following recommendations:

- **Commit to a national retention and re-engagement programme with investment to scale and sustain re-engagement activities and ensure national reach. This programme should build on evidence from effective voluntary sector projects, and involve the voluntary sector as a key delivery partner.**
- **Deliver targeted action to address disengagement from care linked to alcohol and drug misuse and ensure support is available.**
- **Guarantee access to psychosocial support including peer support for everyone living with HIV, with a person-centred approach in line with BHIVA guidelines.**

These commitments must be underpinned by the following actions:

- **Ensure that all HIV services are sufficiently resourced to meet BHIVA standards and provide comprehensive services for everyone living with HIV.**
- **Ensure training and awareness-raising programmes are in place in all healthcare settings so that staff have the right knowledge on HIV and no one living with HIV experiences discrimination.**
- **Continue efforts to tackle HIV stigma and discrimination, at all levels**

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