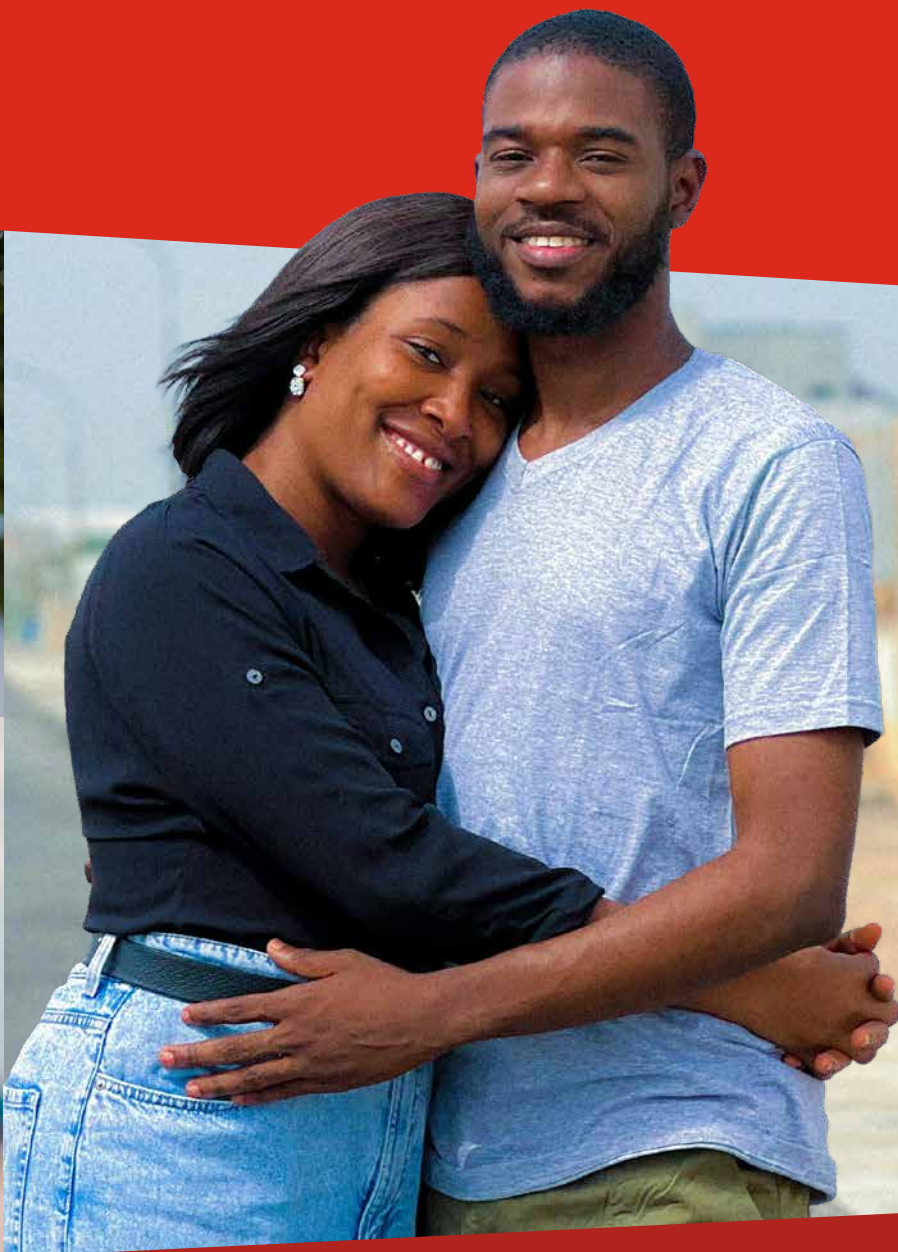




No one left behind:

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

April 2026



Background

Wales has made significant progress towards ending HIV transmission by 2030, with increases in HIV testing and access to the prevention drug PrEP helping to prevent new transmissions of the virus. In 2024, rates of new diagnosis fell by nearly 20%, while HIV testing increased by 8% and the number of people prescribed PrEP increased by 4%¹.

The Welsh Government has demonstrated its commitment to addressing new HIV transmissions in the 2021-26 Parliament, and the next Government must commit to doing the same. The HIV Action Plan for Wales 2023-26 commits to “Eliminating HIV, improving quality of life and tackling stigma associated with the virus”². Laying out a roadmap to achieve the 2030 goal of ending new HIV transmission, the Action Plan identifies five priority action areas:

1. Prevention
2. Testing
3. Clinical Care
4. Living well with HIV
5. Tackling HIV-related stigma.

In order to achieve these aims, it is essential to recognise the rights and support the wellbeing of everyone living with HIV, and ensure that no one is left behind. This must include people who are not engaged in HIV treatment and care.

The Action Plan acknowledges the benefits of treatment and care for everyone living with HIV, both for the individual, and for preventing onward transmission of the virus. It also acknowledges the challenges of engaging in care for some people.

To meet the 2030 goal, every person living with HIV must have access to the treatment, care and support they need.



However, there remains a very small number of people living with HIV for whom engagement with clinical care and adherence to ART is extremely challenging and these individuals are at risk of increased morbidity and mortality, and of transmitting the virus to other people.

HIV Action Plan for Wales

The next Welsh Government must renew the HIV Action Plan and commit to clear, funded action to prioritise re-engagement in HIV care for everyone not currently attending or lost to follow up. This should include improved data collection and reporting mechanisms so that everyone living with HIV is counted, including those who are not currently engaged in HIV care and treatment.

Investment in re-engagement and retention services will save lives, save money to the healthcare service, and reduce new transmissions of HIV. 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. Renewed commitment and funding are needed for collaboration between services, strengthened access to peer support both at the point of diagnosis and beyond, and prioritising prevention of disengagement as well as re-engagement and retention in care.

The next Welsh Government must prioritise re-engagement in 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 Wales

Numbers of people not in HIV care³ in Wales:

As of 31 December 2024, there were 2670 individuals receiving HIV care in Wales. Of these, 2616 (98%) reported receiving treatment.

Public Health Wales does not report data on non-attendance in HIV care or numbers of patients lost to follow up. This is a critical data gap that must be addressed in order to meet the 2030 goals. The absence of this data undermines the progress on the 95-95-95 targets currently reported by Public Health Wales.

Interventions to address re-engagement in care in Wales have indicated the scale of the challenge. The HIV Engagement (HIVE) project in Cardiff found that, in 2023, over 20% of their patient cohort was not optimally engaged in HIV care, this included people who had not been seen for care in 12 months, those who had missed three or more appointments in 12 months and those who reported only unscheduled sporadic attendance.⁴ Of those not engaged in HIV care, 59% had untreated HIV at their last attendance, i.e. they were at risk of becoming unwell and requiring hospital admission, as well as being able to transmit HIV to others. Some people had been disengaged from care for several years at the time of reporting.

Progress in Wales on the 95-95-95 UNAIDS targets

Based on data to the end of 2024,

98%

of people living with HIV reported receiving treatment, and

99%

were virally suppressed.

<https://phw.nhs.wales/publications/publications1/trends-in-the-prevention-diagnosis-and-treatment-of-hiv-in-wales/>

Retention and Re-Engagement in Care

Addressing the barriers some people face in accessing and remaining in HIV care must be made a priority for the next Welsh Government and for a refreshed HIV Action Plan.

There are many factors that drive disengagement in care, include poverty, discrimination, stigma and complex health needs⁵, 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.

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 organisations⁶.

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 sector⁷. A national-level strategic approach should also be taken by the Welsh Government.

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, Wales risks failing to meet its 2030 targets, and inequalities in our HIV response will persist.

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 re-engagement programmes must address these intersecting challenges to ensure no one is left behind.

Barriers include⁸:

- 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 re-engagement.

The HIV Engagement (HIVE) project piloted in Cardiff explored risk factors for disengagement. 54.6% of people reported risk factors, of these 54% had 3 or more risk factors.⁹

Mental health problems	82%	Stigma/Fear	16%
Substance misuse	53%	Medication fatigue	11%
Poverty	46%	Prison experience	11%
Housing instability	30%	Discouraging partner	6%
Caring responsibilities	26%	Seeking asylum	6%
Comorbidities	21%	Other	6%

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

The HIV Engagement Project (HIVE) Case Study

The HIVE project supported people to re-engage with care and was a partnership project between Cardiff and Vale University Health Board, Cardiff University and Fast Track Cardiff and Vale. It was funded by a Gilead Need to Find grant. An initial 12-month pilot was launched in January 2024.

The project piloted a re-engagement model to address barriers to accessing care, recognising the critical need to improve retention and re-engagement in care in Wales. The objectives of the project were:

- To accurately and systematically identify people living with HIV who are not in care.
- To collect data on patient demographics, barriers to engagement and patient experience.
- To pilot the role of HIV Engagement Support Worker, providing individually tailored support and acting as a single point of contact.
- To pilot the role of HIV Clinic Coordinator, with responsibility for maintaining an engagement database and supporting adaptations to clinic processes and a stakeholder engagement programme.
- To develop a multiagency local network of NHS and community partners to support engagement.

Flexible approaches to appointments and capacity for walk-in appointments made accessing care easier for people balancing competing priorities.

59% of people not in care and 15% of those with intermittent engagement had a detectable HIV viral load at their last attendance before disengaging from care. The interventions delivered under the pilot supported people back into HIV care and treatment.

A survey of people who were engaged in care demonstrated:

- 38% of people reported regular conflicts between clinic appointments and work commitments.
- 28% of people reported travel time and costs as barriers to attendance.
- 31% of people reported travel expenses.
 - Of these, 30% paid more than £10 to come to their appointment.

Outcomes of the HIVE project:

- Overall, disengagement rates reduced by 58% as a result of the HIVE project.
- For those not seen in care for 12 months, there was a reduction of 65%.
- For those with multiple missed appointments, rates fell by 61%.
- 1.1% had unpredictable engagement (walk-in care only), compared to 0.9% by the end of the pilot period.

Learning from the HIVE project

- Clinical services need access to routinely available engagement data in order to focus their efforts on re-engaging people who are not in care.
- Clinical services must increase access and flexibility of care, with dedicated re-engagement support, to remove the barriers to care which exist for a significant number of people living with HIV.
- Clinical services must work collaboratively with other partners in health, social care, third sector and community to reduce stigma, improve HIV awareness and develop effective pathways back into care.
- Re-engagement is more effective where local peer support services exist; these were not fully operational in Wales during the project period.

Action is needed now

The next Welsh Government must ensure that re-engagement in HIV care is properly understood and addressed in a refreshed HIV Action Plan to ensure that the HIV response is not missing this essential component. Improved data collection is essential to understand the numbers of people living with HIV who are not currently in care, and the inequalities underpinning disengagement. A strategic, national-level approach is vital to ensure a coordinated response that leaves no one behind.

The 2030 goals will not be achieved unless everyone living with HIV is reached, brought into care and supported to live well and manage their HIV. This problem can be solved, with effective data collection and reporting, targeted and sustainably funded services, and a commitment to prioritising the health and wellbeing of every individual living with HIV in Wales. 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.

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 year¹⁰. 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 individuals - but also avoids lifetime care costs estimated at £220,000 per person.

Most importantly, for individuals living with HIV, disengagement from 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 Welsh Government must:

- Deliver on the goals of the HIV Action Plan for Wales and ensure that the priorities and ambitions are continued through renewed action in the next Parliament and a strategic and joined-up approach across the policy and health landscape, including but not limited to the Women's Health Action Plan and the LGBTQ+ Action Plan.
- Improve data collection. The Welsh Government, in partnership with Public Health Wales, should improve HIV data and surveillance methods, with an improved focus on people who are diagnosed with HIV but are not currently engaged with HIV care and treatment. Central to this approach must be the delivery of an all-Wales sexual health case management system, as committed to in the HIV Action Plan.
- The Welsh Government must ensure the sustainability of funding for a national peer support network in Wales. This will maximise outreach and support, ensuring people living with HIV can access tailored, accessible services wherever they are. Sustainable funding for VCSEs must be a central component of this.
- Prioritise re-engagement in HIV care. Building on existing voluntary sector projects, the Welsh Government should ensure funding for voluntary-sector based engagement support workers and local multi-agency networks in all Health Boards.
- Ensure that all HIV services are sufficiently resourced to develop re-engagement programmes with dedicated staffing and flexibility of approach, as well as increasing access to care more generally. This may require modernisation of services and streamlined care pathways for stable engaged patients, releasing resource for those who require more intensive engagement support.
- Continue efforts to tackle HIV stigma and discrimination, at all levels.
- 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.

The development of this policy briefing was supported by funding from Gilead Science's Fellowship Programme.

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