

Working together



The HIV Outcomes UK programme is funded by Gilead Sciences and Viiv Healthcare as co-sponsors

HIV services at the crossroads: Scotland

Key evidence headlines:

Unmet need and service pressure.

No HIV Voluntary, Community, and Social Enterprises (HIV VCSEs) in Scotland felt completely able to meet demand for their services over the last five years, and none are very confident that they will be able to deliver services over the next three years.

Impact of HIV support services.

Nine in ten people living with HIV in Scotland reported that they feel more empowered and confident in managing their HIV after accessing services.

The continuation of life-changing HIV VCSE services in Scotland and across the UK is under threat, with increasing demand for services coupled with severe funding challenges. This comes at a time when, as highlighted in our 'Beyond the Virus' report¹, people living with HIV continue to face significant barriers to having a good quality of life - and when Scotland is falling short of meeting the Standards of psychological support recommended by the British HIV Association for adults living with HIV.

The two largest charities that provide HIV prevention and support for people living with HIV in Scotland - Waverley Care and Terrence Higgins Trust - have to varying degrees had to reduce the number of their staff, adapt services because of funding cuts, and use cash reserves to cover operating costs.

If this trajectory continues, and without substantive action, the goals of the Scottish Transmission Elimination Delivery Plan will not be met, and people living with HIV will have higher unmet need and decreased quality of life.

Recommendations for the Scottish Government

- **Develop a new HIV Transmission Elimination Delivery Plan from 2026.** To be developed in collaboration with communities directly affected by HIV the wider HIV sector in Scotland, including VCSEs, this updated Plan should have an enhanced remit to include both the ending of new cases of HIV in Scotland by 2030 as well as ensuring people living with HIV in Scotland have a good quality of life. The Scottish Government should commit long-term, sustainable funding for the delivery of the Plan and should also set out a clear role for HIV VCSEs.
- **Establish a baseline offer for peer support provision.** The Scottish Government should undertake a scoping exercise to identify gaps in HIV peer support services in all NHS Boards across Scotland. This exercise should inform new Scottish Government national guidelines on the baseline provision of peer support that Health Boards must adhere to.
- **Establish a national framework for HIV retention and re-engagement.** There is a growing number of people in Scotland who are living with HIV but are no longer accessing vital treatment and support. The Scottish Government should prioritise action for re-engaging this group back into care through the improving of data collection and reporting, strengthening partnerships and access to support services, and ensuring there is access to VCSE-provided 'loss to follow-up' services in all NHS Boards. This framework should be underpinned by enhanced data systems, co-produced research and partnership with VCSEs and communities to ensure targeted re-engagement strategies.
- **Fund long-term campaigns to combat HIV stigma.** The Scottish Government should commit long-term funding for campaigns to tackle HIV stigma and improve education in the health and social care sector.
- **Ensure sustainable funding for VCSE HIV testing and prevention programmes.** Current funding is insecure, putting at risk the essential outreach and prevention efforts to find the 500 people estimated to be living with undiagnosed HIV in Scotland.² A framework for national Government funding for Scotland, such as HIV Prevention England and Fast Track Cymru, would enable strategic resource allocation, support innovative testing models, and ensure VCSEs can continue reaching underserved communities.



¹ HIV Outcomes UK (2024) Beyond the virus: Prioritising mental health for people living with HIV.

Available at: <https://nat.org.uk/wp-content/uploads/2024/11/Beyond-the-virus-Prioritising-mental-health-for-people-living-with-HIV-in-Scotland.pdf>

² Public Health Scotland (2024) HIV in Scotland: update to 31 December 2023. Available at: <https://publichealthscotland.scot/media/31064/revised-final-hiv-in-scotland-update-to-31-december-2023.pdf>

How HIV VCSE services are key to ending HIV transmissions and supporting people to live well with HIV in Scotland

Life-changing impact of support services

People living with HIV in Scotland highlight the value of HIV VCSE services, such as peer support, in meeting their needs to manage their treatment, deal with stigma, reduce isolation and improve their mental health and wellbeing.

Whilst there are multiple successful local models (including Waverley Care's embedded peer support at Chalmers Centre, Our Positive Voice's weekly drop-in online service in Grampian, and Terrence Higgins Trust's online peer support platform My Community), there is currently no consistent and universal approach to peer support provision in Scotland, meaning that some people - particularly those in rural communities - have no access to peer support.

“

If peer support was included at the point of my diagnosis, it would definitely feel more human.”

– Man living with HIV in Scotland

“

When you don't get the same funding, service users lose facilities. It's not fair to have something and then lose it”

– VCSE representative



One in six people

living with diagnosed HIV in Scotland are no longer engaged with HIV clinical services.

Tackling health inequalities and the social determinants of health

HIV VCSEs undertake a range of work to meet the wider needs of people living with HIV, including psychosocial support services, practical support as well as information, advice and signposting on issues including finance, benefits, living well and immigration.

However funding and access for these services is inconsistent across Scotland. In our focus group, participants highlighted the vital role of Positive Help's 'supportive transport' service - offering medical appointment transport and food deliveries - has been made possible by consistent funding. However, this essential service is now at risk due to planned funding cuts. In addition, a healthcare provider also highlighted the value of integrated VCSE support in the Brownlee Clinic in Glasgow that provided support for people struggling with their benefits and housing.



Underserved communities – including women, migrants, older people, and those in rural areas – are being left behind”

– VCSE representative and woman living with HIV in Scotland

However, with this service no longer funded, the healthcare provider noted that often people “have nowhere else to go apart from Citizens Advice, but they don't want to go there because of stigma”.

Our research also found the urgent need for more investment in voluntary sector support services to support retention and re-engagement in care. One in six people living with diagnosed HIV in Scotland (1,109 people) are no longer engaged with HIV clinical services.³ This presents serious risks to their health, increases the likelihood of onward transmission, and impacts Scotland's efforts to achieve the 2030 target. People disengage from their HIV care for a range of different, interacting factors including HIV stigma, their socio-economic circumstances, drug and alcohol misuse and poor mental health. HIV VCSEs in Scotland have shown that through case finding, care coordination and case work support, people can be successfully re-engaged in care. However VCSE re-engagement services are not available in every NHS Board.

Underserved communities, including migrants, often face heightened health inequalities and barriers for their engagement in care. Upon arriving in Scotland, migrants living with HIV may not know how or where to access treatment or, in some cases, that they are entitled to it at all. Our research highlighted the positive impact of HIV VCSE services in Scotland for migrants, including African Scottish Development Organisation's work with asylum seekers and Waverley Care's community based services for people from African communities.

Jane

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

Waverley Care were able to address the barriers that were preventing Jane from attending her appointments. This included providing taxis, reminders leading up to hospital appointments, accompanying Jane to appointments, and helping her apply for a concessionary bus pass. Wider support from Waverley Care allowed Jane to discuss the difficult life experiences, mental ill health, isolation and self-stigma that resulted from living with HIV. With this support, Jane is now re-engaged in HIV care and is able to talk more openly about her HIV status.



Value of HIV VCSE testing and prevention initiatives in Scotland

It is essential that the estimated 500 people living with undiagnosed HIV in Scotland⁴ can get tested and be linked into care. VCSE outreach and community testing is critical in reaching communities that may not access traditional services. In Scotland, VCSE's culturally specific outreach and peer-led approaches have been particularly effective for reaching underserved communities including LGBTQ+ community and migrants. Waverley Care has recently established a sexual health clinic for trans* people and an outreach clinic for BAME communities.

VCSEs in Scotland also do critical work in preventing HIV transmissions through awareness-raising, condom distribution, harm reduction, and improving access to PEP and PrEP.

For example, Terrence Higgins Trust is currently funded by three NHS boards in Scotland to distribute free subscription based postal condoms and lube for gay, bisexual and other men who have sex with men.

The Scottish Government commissions Terrence Higgins Trust to provide a national HIV postal testing service.⁵ However, unlike in England and Wales, there is no dedicated national funding from the Scottish Government to promote HIV testing and prevention, such as through a National HIV Testing Week. As a result, essential outreach services lack long-term sustainability and are inconsistently available across NHS Boards - leaving significant gaps in access, particularly in areas and communities where outreach is most needed.

Waverley Care

Challenging stigma and discrimination

HIV stigma remains one of the biggest challenges for people living with HIV in Scotland. The Positive Voices 2022 survey found that almost half of those living with HIV in the UK felt ashamed of their HIV status.⁶ To reduce stigma, there is a pressing need to tackle societal prejudices and misinformation. For example, YouGov polling conducted in 2023 found that only one-third of people in Scotland would be happy to kiss someone living with HIV, despite it being known since the 1980s that HIV can't be passed on through saliva.⁷

Scottish HIV VCSEs have led the way in addressing stigma at a health system and societal level. In 2023, Terrence Higgins Trust was funded by the Scottish Government to deliver the 'Stigma is more harmful than HIV' national campaign and Waverley Care is currently funded to provide HIV education to the NHS workforce in Scotland. Whilst it is welcome that the Scottish Government has made tackling HIV stigma a key political commitment, there is a need for long-term Government funding for campaigns and training to address stigma.

Further information and partnership

For more information on HIV Outcomes UK, and to download the full 'HIV Services at the Crossroads' report, please visit: 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.

3 *ibid*

4 *ibid*

5 **Terrence Higgins Trust (2025) Testing service.**
Available at: <https://test.tht.org.uk/scotland/>

6 **UK Health Security Agency (2024) Positive Voices 2022: survey report.**
Available at: <https://www.gov.uk/government/publications/hivpositive-voices-survey/positive-voices-2022-survey-report>

7 **Terrence Higgins Trust (2024) Scottish Government commit to further action to tackle HIV stigma.**
Available at: <https://www.tht.org.uk/news/scottish-government-commit-further-action-tackle-hiv-stigma>

Over the last year we have had to make some really difficult decisions at Waverley Care to reduce costs. Waverley Care, like most charities, was hit by the inflationary pressures that affected the UK and global economy from 2022 onwards and this has led to significant increases in all our running costs.

We have also been heavily reliant on statutory funding and contracts which regrettably have been reducing significantly in real terms. This means we have had to continue delivering funding commitments with funding that doesn't go as far as it used to. It also doesn't adequately contribute to core running costs.

While we have invested in our fundraising team in order to diversify our income, this income growth will take time and hasn't yet been able to fill the gap.

While we reduced non-staffing related expenditure as much as we could, this wasn't enough. We undertook a strategic review last year, looking at every role and function across the whole organisation in order to make savings that protected front line services and roles, while reducing the numbers of managers in the organisation.

With 10 redundancies last year and 8 resignations which we haven't backfilled, we have seen our headcount reduce from 60 to 42 in a year. This has obviously had a tremendous impact on the charity and the people we support. We're having to look very carefully at what we do, how we do it and what we should stop doing.

We've been a lifeline to so many people living with HIV – many of whom face real barriers accessing services from other organisations – but we are having to think carefully about who needs us most and who can have their needs met elsewhere. This is not easy at a time when all organisations face real capacity challenges.