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# Beyond the virus: Prioritising mental health for people living with HIV in Scotland

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# HIV Outcomes UK

HIV Outcomes UK is a coalition of HIV experts working to secure policy, practice and evidence changes to improve the health-related quality of life (HRQoL) for people living with HIV in the UK. Waverley Care, Scotland's HIV and Hepatitis C charity, are represented on the Steering Group.

Working in partnerships, we are delivering policy projects focused on:

- **Tackling stigma as a barrier to care**
- **Driving better HIV care engagement, integration and coordination**
- **Better meeting the mental health needs of people living with HIV**
- **Improving approaches to information, data and confidentiality in the NHS**

The National AIDS Trust is proud to act as the secretariat for HIV Outcomes UK. We are affiliated with HIV Outcomes at a European level.





# Executive summary

Supporting the mental health of people living with HIV in Scotland must be at the heart of HIV policy. This report, informed by a workshop which brought together key stakeholders in Scotland's HIV response, explores key interventions to improve the mental health and wellbeing of people living with HIV. The report highlights good practice case studies and puts forward evidence-based, cost-effective recommendations which the Scottish Government and NHS Health Boards should implement.

Despite Scotland having some of the best HIV treatment outcomes in the world<sup>1,2</sup>, significant challenges remain in supporting the mental health and wellbeing of people living with HIV. This disparity is a critical barrier to achieving the Scottish Government's goal of ending new HIV transmissions by 2030.<sup>3</sup>

The relationship between HIV and mental health is complex and bi-directional, with psychosocial vulnerabilities increasing the risk of acquiring HIV, and living with HIV exacerbating mental health issues. Stigma related to HIV and mental illness further compounds these challenges.

Effective psychological support can improve both mental and physical health outcomes for people living with HIV, enhancing engagement with HIV care and health-related quality of life (HRQoL). The voluntary sector also plays a fundamental role in supporting the mental health needs of people living with HIV. However, mental health and HIV support services for people living with HIV are inconsistent across Scotland, creating a postcode lottery in care availability and quality.

The Scottish Government's HIV Transmission Elimination Delivery Plan 2023-26<sup>4</sup> outlines actions to prevent HIV transmission and supports equitable care but lacks specific measures for mental health support. The Scottish Government's mental health and well-being strategy<sup>5</sup> outlines their ambition to be a world leader in using innovative and evidence-based approaches to promote good mental health, prevent mental health difficulties, and provide psychological support when people need them.

**For Scotland to become a world leader, future policy supporting the mental health of people living with HIV should be guided by the following principles:**

- Founded on equity and human rights, ensuring accessible and sustainable services for all communities to live well with HIV.
- Developed and delivered in line with the Scottish Government's strategy to end HIV transmissions.
- Based on a 'whole person' and person-centred approach, across the life stage of someone living with HIV.
- Informed by communities living with HIV and practitioners, championing the importance of lived-experience and the meaningful involvement of communities living with HIV at all levels.
- Evidence based and responsive to patient-centred outcomes measures (PROMS) and patient-reported experience measures (PREMS).

To deliver this vision, the Scottish Government must ensure adequate funding, resources, and care pathways for mental health services within HIV care. This includes funding peer support initiatives, improving HIV literacy among mental health and social care practitioners, and tackling stigma through education and training. The commissioning of services should be designed to meet the holistic needs of people living with HIV and champion community leadership.



# We recommend:

**By integrating mental health and HIV interventions, Scotland can improve the quality of life for people living with HIV and move closer to eliminating new HIV transmissions by 2030. To support the mental health of people living with HIV, and deliver the Government's HIV and mental health strategies, we recommend that the Scottish Government and NHS Boards:**

- Ensure all HIV services have the necessary resources, staffing and pathways to implement the BHIVA Standards on psychological support for adults living with HIV. This should include ensuring that more specialist mental health provision is embedded in HIV clinics, and optimising pathways for referral between HIV clinics and mental health services.
- Provide peer support for everyone, wherever they live in Scotland, in line with the National Standards for Peer Support in HIV.
- Fund projects supporting HIV literacy and training for mental health and social care practitioners.
- Meaningfully involve communities and HIV voluntary sector organisations in all areas of mental health service development for the community.
- Ensure that patient-centred outcomes measures (PROMS) and patient-reported experience measures (PREMS) are integrated into clinical practice.
- Develop enabling laws, policies, public education campaigns and services that address HIV discrimination. This should include prioritising action to reduce HIV stigma and supporting the decriminalisation of HIV transmission, sex work and drug use. The Scottish Government should also join the Global Partnership to Eliminate Stigma and Discrimination.
- Prioritise interventions which tackle poverty and inequality among people living with HIV. This should include ensuring that there is sufficient funding for social and welfare services for people living with HIV.



# Mental health, wellbeing and HIV

Despite Scotland having some of the best HIV treatment outcomes in the world<sup>6,7</sup>, there are still many barriers to people living with HIV having a good HRQoL. Progress in biomedical HIV care is not being matched by effective treatment for the mental health and wellbeing of people living with HIV. If Scotland is to achieve its target of ending new HIV transmissions by 2030, it must take seriously the mental health and wellbeing of people living with HIV.

People living with HIV in the UK have a 63% greater risk of being diagnosed with mental illness compared to people without HIV.<sup>8</sup> Two in five people living with HIV in the UK have been diagnosed with at least one mental health condition, substantially higher than the general population.<sup>9</sup>

The relationship between HIV and mental illness is bi-directional. Pre-existing mental health conditions can increase the likelihood of a person acquiring HIV, and the circumstance of acquisition in itself can be traumatic. Living with HIV is also a key risk factor for a decline in someone's mental health and wellbeing. For example, it can lead to isolation and loneliness. Perceived, internalised, as well as enacted stigma negatively affect mental health, and this relationship is further compounded by stigma of mental illness in society. Depression, anxiety and post-traumatic stress disorder are the most common diagnosed mental health conditions among people living with HIV in the UK.<sup>10</sup>

Individuals with unsupported mental health conditions are less likely to seek testing for HIV, and to stay engaged in HIV care.<sup>11</sup> Psychological support improves both mental and physical health, including HIV treatment adherence which leads to having an undetectable viral load. Despite this, the availability and quality of psychological support (including peer support) for people living with HIV is variable across Scotland.

It is estimated that mental health problems cost Scotland at least £8.8 billion a year.<sup>12</sup> The World Health Organisation highlights that investing in treatment for depression and anxiety leads to a fourfold return.<sup>13</sup> Supporting the mental health of people living with, and affected by, HIV offers a strong return on investment as it can improve people's engagement in HIV care, reduce hospital admissions and prevent HIV transmissions.

To support communities to live well with HIV, the Scottish Government must ensure that services meet the British HIV Association (BHIVA) Standards for Psychological Support for Adults Living with HIV.<sup>14</sup> The Standards encompass eight key areas of mental health care expected for every adult living with HIV in the UK.<sup>15</sup> This includes highlighting the importance of referrals, seamless integration with non-specialist services, and the training to ensure psychologically informed care delivery.

## The Scottish Government's HIV and mental health strategies

The Scottish Government's HIV Transmission Elimination Delivery Plan 2023-26 (HIV Delivery Plan)<sup>16</sup> outlines prioritised actions for the elimination of HIV transmission in Scotland by 2030. It seeks to prevent people from acquiring HIV; find people living with HIV and support them to have equitable accessible HIV care and treatment; and to reduce HIV stigma.

Whilst the Plan has welcome commitments on supporting person-centred approaches and reducing HIV stigma (a key driver of mental ill-health), it is a missed opportunity because there are no actions related to supporting the mental health and wellbeing needs of people living with HIV. With mental ill health being a key driver of both HIV acquisition and worse treatment outcomes, to reach its elimination target, the Scottish Government must better align their mental health strategy with HIV care.

The Scottish Government's plan to improve the mental health and wellbeing of people in Scotland is guided by their mental health and wellbeing strategy, and their Core Mental Health Quality Standards.<sup>17,18</sup> The Government plans to be a world leader in using innovative and evidence-based approaches to help **promote** good mental health for the whole population, **prevent** mental health difficulties from getting worse, and **provide** psychological treatments when people need them.

Considering the structural barriers facing people living with HIV in Scotland, it is welcome that the Mental Health and Wellbeing strategy seeks to address mental health inequalities and support the voluntary sector.<sup>19</sup> It is welcome that the strategy recognises that people in poverty, and those with a long-term physical health condition, have lower mental wellbeing. This is particularly pertinent for the HIV response given that in the UK, more than half of people living with HIV do not routinely have enough money to easily cover their basic needs.<sup>20</sup>

Whilst the Scottish Government's Mental Health and Wellbeing Strategy and Quality Standards will hopefully address inequalities and improve access to high-quality services, there are considerable regional variations in what services are available for people living with HIV in Scotland.<sup>21</sup> With people living with HIV in Scotland being disproportionately affected by mental ill-health, to reach their ambition of being a 'world leader' in mental health services delivery, the Government must end these inequalities.





# NHS Lothian

The HIV clinical psychology service in NHS Lothian provides evidence-based psychological therapy for patients living with HIV, those who may be at risk of acquiring HIV and wider multi-disciplinary team input.

The current referral criteria enables them to work with HIV patients for HIV-specific challenges (e.g. HIV stigma) or mild to moderate anxiety and depression, which may be unconnected to their diagnosis. They also have a cognitive concerns pathway, for any patients with concerns around their memory or cognition issues. Their HIV prevention work enables them to provide therapy to individuals who may be engaged in risky behaviours leading to an increased risk of acquiring HIV.

Their current waiting times as of June 2024 are from four to eight weeks, with the majority of patients being seen within 12 weeks. Patient feedback on their experience is collected at the end of therapy, to reflect on and improve the service.

The HIV clinical psychology service attends a regular multi-disciplinary team meeting with fellow HIV clinicians including specialist nurses, doctors, consultants and pharmacists. The psychology team provides regular input, such as psychological education and team formulation sessions. Team formulation involves in-depth discussion, reflection and problem-solving around one patient, with an aim to remove barriers to care and general service improvement.

## Individual case study:

The clinical psychologist worked with a man living with HIV who had varied adherence to their ARV medication and high levels of anxiety. With time and in-depth psychological formulation she was able to identify this man had high levels of internalised HIV shame and stigma with limited knowledge of the condition or U=U. People living with HIV with an undetectable viral load cannot transmit the virus sexually. Despite being diagnosed for many years and informed about U=U on several occasions, high anxiety levels prevented this person from understanding this important concept.

The psychologist facilitated a joint session with an HIV consultant so this man could ask more questions about HIV to deeply understand the condition. Other techniques used in sessions were exploring emotions around HIV diagnosis using writing and imagery, and challenging negative beliefs about the condition.

As a result, this man now has greatly reduced his internalised HIV stigma, and is much more accepting of the condition, which he now sees as 'neutral'. He has also greatly improved his adherence to ARV medication. His management of general anxiety is significantly better and he described feeling less worried about the future.



# Access to mental health and wellbeing services for people living with HIV

With the Scottish Government seeking to be a world leader in their action on mental health, they must provide appropriate services for people living with HIV.

The HIV response has a history of innovation and community leadership. So services for people living with HIV would lend themselves well to being used to pilot or scale up the types of evidence-based interventions proposed in the Government's mental health and wellbeing strategy.

The Scottish Government, guided by the ambition of their HIV and mental health strategies, must ensure that all people living with HIV have access to mental health care that is stigma free and that meets their needs. The Scottish Government and commissioners should work to ensure all HIV services have the necessary resources, staffing and pathways to implement the BHIVA Standards on psychological support for adults living with HIV.

## Person-centred care

Person-centred approaches should underpin the design of HIV, mental health and wellbeing services in Scotland. It is welcome that the Scottish Government's Mental Health and Wellbeing Strategy recognises the need to further develop person-centred approaches to support a whole-person perspective.<sup>22</sup>

The Scottish Government's HIV Delivery Plan also notes that a person-centred approach is required at all stages of the response. Commissioning and service design should better recognise the social, economic, employment, and physical needs that are associated with the mental health of people living with HIV. To turn these welcome commitments into practice, mental health services for people living with HIV should involve collaborative care and support planning, experience-based co-design and shared decision making.



# Comprehensive psychological support services

People living with HIV in Scotland have traditionally accessed mental health support either through HIV clinics or voluntary sector HIV support services. These are often excellent sources of support. UK-wide data from the Positive Voices 2022 report highlights the very high average HIV clinic satisfaction rating among people living with HIV: 9.4 out of 10.<sup>23</sup> HIV clinics often understand the needs of people living with HIV and can offer HIV care and psychological support in the same location.

However a lack of a consistent approach to mental healthcare across Scotland means the availability of comprehensive mental health support and treatment for people living with HIV is a postcode lottery, with little access to mental health and wellbeing services often available to people in low prevalence or remote areas of Scotland.

For the vast majority of HIV services in Scotland, the care recommended in the BHIVA Standards on psychological support for adults living with HIV is simply not available. Despite BHIVA recommendations, a 2017 audit across the UK found that nearly 40% of HIV clinics do not have access to a psychological or mental health professional within their multidisciplinary team.<sup>24</sup> Clinicians have noted challenges in providing other key elements of the care package, such as having partnership with social workers and third sector providers.

Research from BHIVA found that where there was no NHS in-house provision of specialist psychological support, services were often inappropriately reliant on the voluntary sector for all mental health care, with no clear pathways to access NHS mental health services.<sup>25</sup> As highlighted by the case study on NHS Lothian, when in-house provision of specialist psychologist support is offered, it can lead to improved mental and physical health outcomes for people living with HIV.

Patient-centred outcomes measures (PROMS) and patient-reported experience measures (PREMS) should also be better integrated into HIV and mental health clinical practice. This will support better shared decision-making and tailor interventions to individual needs; monitor health outcomes; and improve the experience of care.

Pathways should also be developed between services providing HIV care and those offering psychological support. It is recommended by BHIVA that pathways should also be in place to ensure the availability of psychological support at all levels, and to enable people living with HIV to self-refer into psychological support.<sup>26</sup> Social support services should also establish pathways for mental health support services.

Despite this evidence-based approach, mental health and HIV care in Scotland is often fragmented for people living with HIV. Of the four Scottish HIV services which shared data for BHIVA's 2017 audit, 75% had documented care pathways for mental health, 25% had pathways for drug support, and none had a pathway for alcohol support.<sup>27</sup> Whilst the audit notes that over 70% of assessments in participating Scottish HIV services did consider psychological well-being/mental health, if services do not have clear pathways, people may struggle to get support following screening.<sup>28</sup>

Whilst further work is needed to ensure optimal referral pathways, we welcome the expansion of some generic mental health services in Scotland, including NHS 24's Mental Health Hub which has provided urgent out of hours support since 2020 and computerised Cognitive Behavioural Therapies.<sup>29</sup> But those working in generic mental health services are not routinely trained in HIV or the impact that HIV stigma can have on mental health, or on the intersecting issues faced by the key populations affected by HIV. These factors can both deter people living with HIV from seeking mental health care, and lead to worse treatment outcomes.

Alongside the Scottish Government commissioning more generic online mental health services, HIV support organisations have increased their provision of online and digital support services. This includes Terrence Higgins Trust's (THT) 'My Community Forum' which is a free, safe online space for people living with HIV to meet other peers.<sup>30</sup> Whilst digital services can address barriers for people living with HIV receiving support, particularly for those living in rural areas of Scotland, commissioners should ensure that people still have access to in-person mental and wellbeing support if they wish. Having a person-centred approach is particularly important given high levels of digital poverty among people living with HIV.

# Fundamental role of HIV voluntary and community sector

The HIV voluntary and community sector play a key role in supporting the mental health and wellbeing needs of people living with HIV. HIV support services meet the HIV-relevant physical, mental and emotional health needs that are distinct from, but complementary to, clinical care. Voluntary sector HIV support services provide a wide range of interventions including counselling, psychotherapy, and psychosocial interventions such as peer support. The voluntary sector provides wider invaluable services which can address the social determinants of mental ill-health and support wellbeing. This includes HIV and health information, advice and advocacy, self-management and sex and relationship support.

The Scottish Government and commissioners need to ensure that the HIV voluntary sector is sufficiently funded and available to all who need them. This is particularly pertinent because the underfunding of HIV and mental health services has often left the voluntary sector to fill the gaps, often without the necessary resources.

## Engagement of people living with HIV and ending inequalities

HIV and mental health services should ensure that people living with HIV are engaged in the planning, delivery and evaluation of psychological support services. This should include supporting communities in all aspects of service design and appointing community representatives.

It is welcome that the Scottish Government's mental health and wellbeing strategy takes an intersectional approach and recognises that societal conditions put some groups at greater risk of poor mental health than others. HIV-related stigma can interact with other intersectional inequalities that can impact on the mental health and wellbeing of communities living with HIV.

For example, there is significantly poorer mental health and wellbeing among trans and gender diverse people living with HIV.<sup>31</sup> In addition, women's sexual and reproductive health are often not well linked, meaning that menopausal symptoms can go unmanaged, impacting on the mental health of women living with HIV.<sup>32</sup> Older people living with HIV may also face more challenges because of HIV-related stigma, loss of friends and social networks, and the detrimental effects that HIV and antiretroviral treatment have on normal ageing processes.

Concerns around immigration status, racism, stigma and financial insecurity add additional pressures that negatively impact the mental health of migrants living with HIV. Research from Waverley Care has found that Africans living with HIV in Scotland are often affected by poor mental health and isolation.<sup>33</sup> Migrants living with HIV in the UK have reported barriers in accessing generic NHS mental health services because of waiting lists, and not finding services suitable for them.<sup>34</sup>

Barriers to mental health care among the black community include mental health-related stigma, distrust of services, poor cultural competency, racial discrimination and inadequate referrals.<sup>35</sup> Waverley Care's Health Improvement teams have worked with African migrants for 20 years, and provide support services that can be beneficial to the community's mental health and wellbeing. This includes an offer of 1:1 support, a health and wellbeing group, and a group for new mothers from migrant communities.





# NHS Tayside

## We recommend:

### To improve access to mental health and wellbeing services for people living with HIV, we recommend that the Scottish Government and NHS Boards:

- Ensure all HIV services have the necessary resources, staffing and pathways to implement the BHIVA Standards on psychological support for adults living with HIV. This should include ensuring that more specialist mental health provision is embedded in HIV clinics, and optimising pathways for referral between HIV clinics and mental health services.
- Provide peer support for everyone, wherever they live in Scotland, in line with the National Standards for Peer Support in HIV.
- Meaningfully involve communities and HIV voluntary sector organisations in all areas of mental health service development for the community.
- Prioritise interventions which tackle poverty and inequality among people living with HIV. This should include ensuring sufficient funding for social and welfare services for people living with HIV.
- Ensure that patient-centred outcomes measures (PROMS) and patient-reported experience measures (PREMS) are integrated into clinical practice.

The HIV team at NHS Tayside aims to support the mental health and wellbeing of people living with HIV through a system of in-house support and outward referrals and signposting.

As part of HIV care at clinic appointments, people are asked about their psychological wellbeing, as well as their physical health. Where issues are raised, the HIV team considers if someone's antiretroviral therapy may be part of the cause. With their multidisciplinary team, including their Consultants and Specialist Pharmacist, they would then consider alternatives that patients could try. This could be a little extra support, such as phone calls or home visits from the HIV Nurse Specialists.

For people that may need more structured psychological support to help them live well with HIV, the HIV team offers a referral to the NHS Clinical Health Psychologists. The HIV team can also signpost people to local social activities, or offer referrals to third sector organisations, or NHS Social Prescribers.

Given that people's mental health might be affected by practical considerations (including poor housing conditions, difficulties paying for utility bills or food, or problems with debt), the HIV team offers referrals to impartial, free support from organisations such as the Citizens' Advice Bureau, or other specialists. For people who need support with substance use, the HIV team can also help people access specialist services.

The HIV team at NHS Tayside provides collaborative care for people living with HIV, in partnership with other stakeholders including primary care. GPs can offer prescriptions for medications for depression and anxiety, help people access talking therapies and provide referrals to a local Community Mental Health Team. For people in distress, the Hope Centre (run by Penumbra) offers 24 hour support.



# Stigma and discrimination



# Impact of HIV stigma on the mental health and wellbeing of people living with HIV

Perceived, internalised, and enacted stigma all negatively affect the mental health of people living with HIV. This is further compounded by the stigma of mental illness in society.

A recent report from the Scottish Parliament's Equalities, Human Rights and Civil Justice Committee highlights that HIV stigma impacts directly on someone's mental health and wellbeing and contributes to higher rates of depression, anxiety and post-traumatic stress disorder.<sup>36</sup> The report notes that people living with HIV encounter stigma consistently within healthcare settings including in GP surgeries, vaccination clinics, maternity services and dentists, as well as encountering prejudice across public sector organisations.<sup>37</sup>

Recent research found that a third of UK healthcare professionals respondents did not agree with the well-established zero risk of sexual transmission of HIV for people on suppressive treatment.<sup>38</sup> HIV-related and intersecting stigmas within healthcare, both experienced and anticipated, can lead to avoidance or delays in accessing treatment, and can make the experience of accessing care more stressful when attended.

## Addressing educational needs across the Health and Social Care sector

A strength in both the Scottish Government's HIV and mental health strategies is their efforts to reduce stigma. The Scottish Government's HIV Delivery Plan seeks to address educational needs across the Health and Social Care sector.<sup>39</sup> Action in this area is supported by BHIVA guidance which recommends training of all health professionals involved in an individual's care to avoid negative and stigmatising experiences which impact mental health outside of the HIV clinic environment.<sup>40</sup>

Research has highlighted that a third of people living with HIV who accessed NHS Talking Therapies in England did not think their therapist understood the ways in which HIV affects mental health; and a quarter reported that their HIV status negatively affected the way they were treated.<sup>41</sup> Whilst further Scottish specific research is needed, with Scotland not commissioning mandated HIV awareness education for mental health practitioners, it is likely that there will be similar negative experiences in Scotland.

In partnership with the Scottish Government, THT Scotland delivered a successful public facing, multi-platform campaign – 'Stigma is more harmful than HIV' – which aimed to raise awareness of HIV in the general public and reduce stigma.<sup>42</sup> The anti-stigma campaign provides a foundation for more targeted information provision and training in key groups.

As part of the Scottish Government's action in the HIV Delivery Plan to develop a proposal to address educational needs across the Health and Social Care sector, it should prioritise funding HIV literacy and training for mental health practitioners and ensure the provision of culturally competent services. As explored in the case study below, the Scottish Government should consider work which NHS England has done in collaboration with the HIV sector to improve HIV literacy among NHS Talking Therapies practitioners.

The Scottish Government and NHS boards should also consider partnership with the HIV Confident charter mark. The HIV Confident charter mark aims to enable healthcare organisations to evaluate knowledge and attitudes around HIV, to put policies and procedures in place to guard against stigma and discrimination, to provide anti-stigma training for staff, and to provide clear routes for reporting stigma where it occurs. The Fast Track Cities network in Scotland, Waverley Care and the National AIDS Trust have shown interest in taking forward the HIV Confident programme in Scotland if funding is available.



## Responding to the social determinants of poor mental health for people living with HIV

To support the delivery of the Scottish Government's mental health and wellbeing strategy, the Government should address the social determinants of poor mental health for people living with HIV. With poverty being a key driver of mental ill-health, the Scottish Government should ensure that there is sufficient funding for social and welfare services for people living with HIV. It should also advocate for the UK Government to reform reserved legislation which can push communities living with HIV into poverty (including the 'no recourse to public funds' designation, which can push migrants living with HIV into destitution).

HIV stigma and discrimination are also key determinants of mental ill-health for people living with HIV. Discriminatory laws which criminalise people living with HIV can lead to further marginalisation and ill-health. Unlike in England and Wales, the common law offence of Culpable and Reckless Conduct means that people living with HIV in Scotland can technically be prosecuted for both passing on the virus and for putting someone at risk through unprotected sex. Especially now that the vast majority of people living with HIV in Scotland have an undetectable viral load,<sup>43</sup> HIV criminalisation undermines effective HIV responses and disproportionately targets people who are economically or socially vulnerable.

Groups which are disproportionately affected by HIV are also affected by laws which criminalise sex work and drug use. These punitive laws mean that people living with HIV can be less likely to talk openly to their medical providers, share their HIV status or use available treatment services. Punitive laws can also lead to increased isolation and marginalisation which can contribute to mental ill-health.

Whilst it is welcome that the Scottish Government's Drug Law Reform proposals seek to decriminalise the possession of drugs for personal use to "help and support people rather than criminalise and stigmatise them", the Government should ensure it has wider enabling laws, policies, public education campaigns and services that dispel all HIV and mental health stigma and discrimination. To support these efforts and facilitate peer learning with other Governments and communities on implementing evidence based interventions, the Scottish Government should join the Global Partnership for Action to Eliminate all Forms of HIV-related Stigma and Discrimination.<sup>44</sup>

## We recommend:

### To tackle the impact that HIV stigma has on the mental health and wellbeing of people living with HIV, we recommend that the Scottish Government and NHS Boards:

- Fund projects supporting HIV literacy and training for mental health and social care practitioners.
- Develop enabling laws, policies, public education campaigns and services that address HIV discrimination. This should include prioritising action to reduce HIV stigma and supporting the decriminalisation of HIV transmission, sex work and drug use. The Scottish Government should also join the Global Partnership to Eliminate Stigma and Discrimination.



## Waverley Care Lost to Follow Up Service

Glasgow city has some of the highest rates of local area deprivation in Scotland with 44% of zones within the 20% most deprived across the country. This brings a number of intersecting inequalities and homelessness, drug use, and socio-economic disadvantage. For people facing these things, the standard model of accessing (and staying on) treatment can be difficult, and risk becoming lost within systems.

Waverley Care's Lost to Follow Up (LTFU) service supports people who have not attended appointments related to their blood borne viruses (BBV) care on multiple occasions, or have struggled to engage. This includes transient service users who face additional practical challenges, like residing in homeless accommodation where communication links can be difficult.

To improve health outcomes, reduce transmission and re-infection of BBVs for these populations, clinical models need adjustments. LTFU centres on targeted, person-centred interventions. The model sits alongside NHS services, with referrals from the HIV Brownlee Centre, outreach hubs, and Gartnavel hospital. One-to-one support is given to individuals, building relationships with the goal of (re) engaging them in treatment.

The LTFU service began with a focus on Hepatitis C, but the model is applicable across BBVs. Building trust and offering person-centred interventions has enabled more successful attendance in clinical care. Between April and September 2023, 19 individuals were engaged through the LTFU service, 63% of whom were supported to attend for an end-of-treatment blood sample collection. The service continues to be valued by NHS partners, and other harm-reduction and community services.

“

**It's because of you that I come to the hospital, otherwise I wouldn't bother.”**

– Service user.





## Breaking barriers in HIV care programme

In 2021, National AIDS Trust published its 'HIV and mental health' report, exploring the experiences of people living with HIV when they accessed NHS Talking Therapies.<sup>45</sup> The research found over a third of survey respondents felt their therapist did not understand the ways in which HIV impacted their mental health and only 48% reported their therapist had an above average understanding of HIV.

Acting upon the recommendations from the report, NHS England developed the e-learning module: 'Breaking barriers in HIV care: Optimising interventions in NHS Talking Therapies for anxiety and depression'.<sup>46</sup> The training aims to increase understanding about HIV for staff working in NHS Talking Therapies services in order to improve patient experience. The training includes sections which consider the impact of HIV-related stigma, including its role as a barrier to accessing NHS Talking Therapies services. The training has received a 4.7 out of 5 satisfaction rating amongst healthcare professionals undertaking the course.

With the support of ViiV Healthcare, a creative campaign was developed to help ensure high uptake and completion of the training. HIV Outcomes UK Steering Group members helped to shape the content of the e-learning module including on the use of person-centred language, stigma, key populations and how HIV can impact people's mental health.



# Peer Support

Voluntary sector HIV support services are a lifeline to many people with HIV, providing specialist support and advice and connecting people living with HIV to share experiences and build resilience. One of the key services which the voluntary sector provides is peer support.

Peer support is a cost-effective approach to improving mental health and reducing stigma for people living with HIV. People living with HIV can be linked to peer support, both within services and also via voluntary sector organisations if funded to do so.

Peer support is delivered by trained people living with HIV who may act in an employed or voluntary capacity. Participants see each other as equal partners and there is a focus on mutual learning and growth. This can improve people's knowledge, skills and confidence to manage their wellbeing and overall quality of life.

Peer support can take various forms and address a variety of needs, including psychosocial needs. It has been shown to be effective in decreasing the severity of internalised stigma<sup>47</sup> and improves coping mechanisms to better manage stigma and adherence to treatment.<sup>48</sup> People accessing peer support have reported experiencing fewer depressive symptoms. The BHIVA Standards also recognise a variety of benefits of peer support, including addressing problems of isolation and facilitating access to further psychological support.

HIV Outcomes UK has heard, from communities, the benefits of peer support provision alongside wider psychological support and collaboration between peer workers and mental health professionals. An example of good practice is adding peer support coordinators to HIV multi-disciplinary teams. This could be replicated by inviting peer support coordinators to support local mental health teams or by including both peer support coordinators and mental health practitioners in HIV multidisciplinary teams.

As highlighted by the case studies below, Scotland has several successful peer-support services which have helped to meet the mental health and wellbeing needs of people living with HIV. Despite the importance of peer support, services have been decommissioned across the UK, and the Scottish HIV voluntary sector has faced significant resource constraints. Peer support in Scotland isn't funded by the NHS or the Scottish Government, with both THT and Waverley Care being reliant on raising charitable funds to deliver it.

It is welcome that the Scottish Government's mental health and wellbeing strategy recognises the importance of peer support in helping people with mental health and wellbeing challenges. The Scottish Government should give similar recognition to the importance of HIV peer support as a vehicle to meet the targets of their HIV Delivery Plan.

The Scottish Government and NHS Boards should ensure that peer-support provision and training meets the National Standards for Peer Support in HIV.<sup>49</sup> It should ensure peer support services are commissioned in line with need, and should support the voluntary sector with adequate training, resources, and pathways to ensure consistent and high-quality provision across the whole of Scotland.

## We recommend:

**To fully unlock the benefits that HIV peer support can have on the mental health and wellbeing of people living with HIV, we recommend that the Scottish Government and NHS Boards:**

- Provide peer support for everyone, wherever they live in Scotland, in line with the National Standards for Peer Support in HIV.

# Peer Support Scotland

Peer Support Scotland (PSS) is a funded project led by THT. Established in 2017, it was initially fully funded for three years by The National Lottery Community Fund (NLCF). The project was a success and continued funding was partially funded by NLCF and Health and Social Care Alliance Scotland. The aim of this project was to create an inclusive environment for people living with HIV to interact, empower and support each other as peers, as well as engaging with a range of services including skills development, one-to-one support and volunteering experience, social activities and group work.

One-to-one support encompasses a wide range of needs, typically focused on exploring service users' experience of living with HIV (including, but not limited to, adherence to medication, disclosure and living well). Sessions act as a springboard into either referrals for in-house or NHS counselling services, or engagement with peer-led activities within the programme.

## Individual case study

'A' came to THT at a low point. Their partner was suffering from severe illness. 'A' re-lived past trauma having cared for a partner in the 80s/90s who later died from a HIV-related illness. Combined with a history of childhood/early adulthood abuse, 'A' felt they had no future and were "broken". Their HIV status was concealed from family and friends, something that weighed heavily on them. With support from Peer Support Scotland, 'A':

- Attended a series of one-to-one support sessions
- Completed Skillsshops (Skills development sessions)
- Attended support groups and events
- Completed Volunteer Training
- Shared their story at a World AIDS Day event

They have since discussed their status with family which has strengthened these relationships. Speaking publicly for the first time about living with HIV has also cemented their confidence. At this event, a member of 'A's family spoke to two members of staff and thanked them for "putting them back together" and said that "they feel like they have gotten them back."

'A' hopes to complete THT's 'Positive Voices' programme to provide informative talks and education sessions about their personal experiences of living with HIV, and continue to volunteer for THT in other areas. 'A' feels that their life has vastly improved, being more able to deal with complex emotions and look to a future. 'A' credits their success to the combined support they received from Peer Support Scotland.





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# Waverley Care Peer Support

Waverley Care recognises that peer support is the cornerstone of living well with HIV and produces significant improvements in clinical and psychosocial outcomes. Support from someone who has “walked the walk” goes a long way to helping address many of the barriers to living well. This year has seen a significant increase in peer support provided by Waverley Care, with a continued projected increase leading up to 2030. Peer support is provided on a one-to-one basis both informally from peer supporters and formally through Peer Navigators, trained to address more complex issues arising from living with HIV. These address a range of issues associated with individual HIV journeys from initial diagnosis through to ageing with HIV. Waverley Care’s peer support seeks to offer an individually tailored support plan covering:

- **HIV Knowledge**
- **Adherence**
- **Mental Health**
- **Migration**
- **Housing**
- **Financial Support**
- **Employment**

In addition to the one-to-one informal and Peer Navigator support, Waverley Care offers group support through a range of activity groups which meet on a regular basis. Waverley Care also works more with family and friends of people living with HIV to provide information and support. Waverley Care is looking at the potential of a Family and Friends Support Group to enable people to share common experiences with the input of trained peers.

Befriending arrangements are also available utilising volunteers not necessarily living with HIV, to provide a befriending service mainly to assist with issues surrounding isolation, loneliness and problems accessing social situations.

Following on from the development of peer support in larger areas such as London, Waverley Care are developing in-clinic support, with the eventual objective of fully embedded peer support in HIV clinics. Waverley Care currently provides in-clinic support at a limited number of clinics in Edinburgh and are recruiting additional peer supporters to enable the expansion of this service. Waverley Care continues to liaise with the NHS to facilitate embedded peer support.

Waverley Care acknowledges the benefit of people being able to share their stories and experiences of living with HIV and their “HIV ALOUD” project enables people to do this in a range of ways according to their levels of confidence. The aim of the programme is to develop a cohort of people living with HIV to be able to speak confidently about their experience to a variety of audiences. Part of the project involves a 12 month collaboration with The Playhouse Theatre, Edinburgh, who will be assisting the development of a “Showcase” of shared stories and experiences which they hope to share at the Edinburgh Festival in 2025.

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