Waverley care

The Future of HIV in Scotland

The priorities of people living with HIV for Scotland's next HIV plan

Contents

Acknowledgements	03
Executive Summary	04
Introduction	07
HIV in Scotland – the statistics	08
Tackling HIV-related stigma and discrimination	09
High-quality, person-centred HIV care pathways	13
Joined-up care across the healthcare system	19
Living well with HIV	23
Ageing with HIV	29
Policy and living experience involvement	32
Conclusion	35
Appendix one: Our approach	36

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Executive Summary

This report presents findings from Waverley Care's engagement and consultation with people living with HIV in Scotland to inform the development of the Scottish Government's new plans on HIV. Between March and June 2026, we gathered evidence through an online survey, semi-structured interviews and a community event, exploring participants' experiences of HIV diagnosis, treatment, care and support, and their priorities for future policy.

The findings demonstrate that Scotland has made significant progress in its response to HIV. Participants consistently recognised the advances in HIV treatment and the high quality of specialist HIV services, with many describing positive relationships with HIV clinicians and specialist nurses. However, they also highlighted that improving the quality of life for people living with HIV depends on much more than access to effective treatment.

Across every stage of the project, participants described the continuing impact of HIV-related stigma. Stigma was experienced across healthcare settings, workplaces and wider society, affecting mental wellbeing, confidence, relationships and engagement with services. Participants highlighted the need for sustained public awareness, education and workforce development to improve understanding of HIV and ensure people are treated with dignity and respect.

Participants also emphasised the importance of person-centred care that recognises individual circumstances, preferences and changing needs throughout life. While experiences of specialist HIV care were overwhelmingly positive, participants described variation in access to holistic support, including peer support, mental health support and information at key points such as diagnosis. They consistently highlighted the importance of informed choice, flexibility, and ensuring that support is available when it is needed.

A recurring theme throughout the project was the need for better integration across health and social care. Participants described fragmented communication between services, uncertainty about who was responsible for different aspects of care and the burden of repeatedly sharing their HIV status and medical history. While recognising the wider pressures facing the NHS, they highlighted opportunities to improve communication between services and ensure that healthcare professionals have access to the knowledge and specialist support needed to provide coordinated, person-centred care.

As the population of people living with HIV continues to age, participants also highlighted growing concerns about managing multiple long-term conditions, accessing informed health and social care and planning for later life. They emphasised

the need for services, workforce development and research to keep pace with the changing needs of an ageing population.

Underlying all these themes was the importance of meaningful involvement of people living with HIV in decisions that affect them. Participants emphasised that direct lived and living experience involvement should be embedded throughout policy development, service design and delivery, and highlighted the need for sustained political commitment and investment beyond 2030.

Together, these findings demonstrate that Scotland's next phase of HIV policy must extend beyond preventing new transmissions.

Alongside sustaining progress towards HIV transmission elimination, there is a need to improve person-centred and joined-up care, tackle HIV-related stigma, improve equitable access to holistic support and ensure that people living with HIV remain at the centre of policy and service development. Together, these findings reinforce the existing evidence base on living well with HIV, while providing current lived and living experience evidence to inform Scotland's next phase of HIV policy.

Summary of recommendations

Tackle HIV-related stigma and discrimination

1. Deliver a national, coordinated anti-stigma strategy
2. End the criminalisation of reckless HIV transmission and exposure

High-quality, person-centred HIV care pathways

1. Provide structured, early support following diagnosis
2. Review and benchmark HIV care pathways
3. Ensure equitable access to a choice of HIV treatments
4. Scale innovative best practice
5. Develop a national re-engagement and retention in care programme
6. Measure individuals' experiences of clinical care and use findings to improve services
7. Involve people with lived and living experience at all stages of projects and initiatives

Joined-up care across the healthcare system

1. Improve communication and coordination across the health system
2. Improve coordination with primary care
3. Improve the quality, coordination and experience of hospital care for people living with HIV

Living well with HIV

1. Improve access to peer support
2. Improve access to mental health and psychological support
3. Ensure the third-sector is sufficiently resourced to deliver high-quality services across Scotland

Ageing with HIV

1. Ensure all health and social care teams have up-to-date information about HIV
2. Ensure fair care, quality of life and empowerment of people ageing with HIV
3. Increase investment in research on ageing with HIV

Policy and living experience involvement

1. Involve people with lived and living experience in decision-making
2. Commit to sustained prioritisation of HIV beyond 2030, taking a whole government approach

Introduction

2026 represents a pivotal moment for the future of HIV in Scotland. As Scotland approaches its 2030 target to end new HIV transmission, the current HIV Transmission Elimination Delivery Plan[1] is coming to an end, and the Scottish Government is developing new plans for HIV.

The purpose of this project was to gather lived and living experience evidence to inform those plans. It aimed to ensure that the priorities and experiences of people living with HIV in Scotland are reflected in future policy and that their voices play a meaningful role in shaping its development.

Through a survey, interviews and a community event, we gathered evidence on the key challenges facing people living with HIV in Scotland today and identified opportunities to improve HIV treatment and care and reduce HIV-related stigma. Further information on the project methodology is provided in Appendix 1.

This project builds on an existing evidence base on the experiences and needs of people living with HIV, including previous research and policy recommendations on living well with HIV in Scotland. Rather than seeking to duplicate this work, our findings provide further lived and living experience evidence of where previously identified challenges remain and reinforce the case for implementing existing recommendations. They also identify additional priorities and opportunities for action raised by people living with HIV through this project. In particular, our findings strongly reinforce HIV Outcomes UK's 2024 report, Beyond the Virus: Prioritising mental health for people living with HIV in Scotland, which set out recommendations to improve mental health, psychological and peer support.[2]

This report presents the key findings from the project alongside recommendations for the Scottish Government and NHS, to improve the quality of life of people living with HIV in Scotland. While this report focuses on informing future HIV policy, some recommendations extend beyond the remit of HIV or health policy. This reflects the reality that HIV affects many different aspects of people's lives.

HIV in Scotland – the statistics

As of 31 December 2024, there were 6,079 individuals diagnosed and living with HIV in Scotland. Thanks to advances in treatment, people living with HIV can live fulfilling and healthy lives. However, ensuring that everyone can access the treatment, care and support they need remains a significant challenge.

Based on data to the end of 2024:[3]

- 94% (6,079) of the estimated cohort of 6,467 people living with HIV in Scotland had been diagnosed.
- Of those diagnosed, 91% (5,520/6,079) were recorded as receiving treatment between 1 July 2023 and 31 December 2024.
- Of those on treatment, 95% (5,260/5,520) had a suppressed viral load.

Despite this progress, important challenges remain:

- 439 people (7% of Scotland's diagnosed and living HIV cohort) had not attended an HIV clinic in the last 18 months.
- Just under 1,000 people are recorded as 'Lost to Follow Up'. This means they had neither attended HIV specialist services in the last three years nor was there evidence of them using other NHS services during this time. They are not included in the main count of people currently living with diagnosed HIV in Scotland.
- Public Health Scotland estimates that around 400 people are living with undiagnosed HIV in Scotland.

While Scotland is on track to achieve the Joint United Nations Programme on HIV/AIDS 95-95-95 targets,[4] further action is needed to engage and support the estimated 1,400 people who are not currently in HIV care and find the estimated 400 people living with undiagnosed HIV.

Beyond these statistics, this project found that further action is needed to improve the everyday experiences of people living with HIV. The findings and recommendations in this report therefore focus not only on diagnosis and treatment, but also on the wider changes needed to improve quality of life for people living with HIV.

Tackling HIV-related stigma and discrimination

Introduction

HIV-related stigma refers to negative beliefs, feelings and attitudes towards people living with HIV, people associated with HIV, and key populations at higher risk of HIV.[5] While HIV is now a manageable long-term health condition and effective treatment enables people to live long, healthy lives, stigma remains a significant challenge. It continues to affect people's health, wellbeing and quality of life, creating barriers to accessing treatment, care and support and preventing many people from living well.[6,7]

A 2024 Scottish Parliament inquiry into HIV found that people living with HIV in Scotland experience stigma in healthcare, workplaces, education, relationships, families and communities. This includes discrimination, breaches of confidentiality, fear of sharing one's status, social exclusion, judgement and internalised stigma, with significant impacts on wellbeing and access to care.[8] These findings align with polling undertaken by Terrence Higgins Trust and YouGov that found almost half (46%) would be ashamed to tell other people they had HIV and a quarter (25%) would feel worried about receiving medical treatment from a doctor or nurse living with HIV.[9]

Project findings

Across all engagement activities, HIV-related stigma emerged as one of the most significant challenges facing people living with HIV in Scotland. Participants described stigma as a pervasive issue that affects many aspects of life, including healthcare, relationships, employment and confidence in sharing HIV status. While advances in treatment have transformed HIV into a manageable long-term condition, participants felt public understanding has not kept pace. As a result, stigma continues to create barriers to accessing care, engaging with treatment and living well with HIV. Community event participants ranked tackling HIV-related stigma as the highest priority for improving HIV outcomes in Scotland.

Survey participants were also asked where they felt HIV-related stigma remains most pervasive in Scotland today. While a wide range of settings were identified, three settings most commonly selected were:

- Amongst the general public (18%)
- Healthcare settings outside of HIV clinics (13%)
- With employers or colleagues (11%)

As one participant reflected:
"We're still lagging in the 80s and 90s on the stigma side of things, but we're streets ahead on the medication."

Stigma in non-specialist HIV services

While specialist HIV services were generally viewed positively, stigma in wider healthcare services remained a concern for participants. Participants reported negative experiences in emergency departments, dental services and hospitals, including inappropriate questions and judgemental attitudes. Concerns were also raised about misinformation within healthcare training, which risks perpetuating stigma among professionals.

Trust and confidentiality

Many participants expressed concerns about their HIV status being shared without their consent, particularly in healthcare settings, including hospitals and GP practices, and in employment contexts. Some participants described experiences where their HIV status had been shared by healthcare professionals in shared environments, such as hospital wards. These experiences raised concerns about confidentiality, stigma and trust in services.

Wider society

Stigma was reported to be high among the general public, including on dating platforms and within specific communities, including some minoritised and rural communities. In smaller or close-knit communities, fear of being recognised when accessing services can act as a significant barrier.

Impact of stigma

Participants described the impact that HIV-related stigma had on their own lives, as well as on people they knew within their communities. Reported impacts included:

- Travelling outside their local area to access HIV care to avoid being seen entering sexual health clinics.
- Fear of disposing of HIV medication packaging at home in case it reveals their status.
- Reluctance to access sexual health services locally, particularly in rural areas or through GP practices.
- Avoidance of non-HIV healthcare services due to perceived or anticipated stigma.

Self-stigma and perceived stigma were also identified as important barriers, influencing individuals' confidence in seeking healthcare services and sharing their status.

Many participants described a "cycle" of sharing their status, educating others and managing reactions. While some viewed this as empowering and an opportunity to challenge stigma, others noted the significant emotional burden this placed on them.

Rights and the law

Legal and structural issues also contribute to anxiety about stigma. Participants raised concerns about the implications

of Scotland's common law offence of culpable and reckless conduct. Under this offence, 'reckless' HIV transmission and, in exceptional circumstances, HIV exposure can be prosecuted in Scotland.[10]

Scotland's prosecution guidance states that prosecution is unlikely where a person is receiving effective HIV treatment and has been advised that there is a low or negligible risk of transmission.[11] However, unlike the guidance in England and Wales, it does not explicitly reflect the current evidence that people with a sustained undetectable viral load cannot sexually transmit HIV – a term called Undetectable=Untransmittable (U=U). This lack of clarity can contribute to anxiety for people living with HIV.

Participants also raised concerns about navigating travel and healthcare abroad, including sharing their status with healthcare professionals abroad, accessing medication, and potentially facing discrimination. These findings highlight the need for systems to ensure robust confidentiality, individual control over sharing status and accessible information for people living with HIV about their rights. This must be complemented by sustained, society-wide action to address the underlying stigma that continues to shape experiences across healthcare and everyday life.

As one survey participant shared:
"Stigma exists in all these avenues. Ultimately, a national [effort] as effective as the first needs to happen. The stigma will never get better unless you make a literal song and dance about it."

Opportunities for improvement

Survey participants were asked where they saw the greatest opportunities to tackle HIV-related stigma. The three most commonly identified opportunities were:

- Public awareness campaigns which show people living with HIV live long and fulfilled lives (32%)
- Education in schools and universities (28%)
- Education for healthcare professionals (21%)

Evidence supports approaches to tackle HIV-related stigma including public and media campaigns to raise awareness and challenge harmful attitudes; community-led interventions and meaningful involvement of people living with HIV; education and workplace initiatives; training for health and social care professionals; and changes to discriminatory laws, policies and practices.[12]

The Scottish Government has taken important steps to tackle HIV-related stigma, including partnering with Terrence Higgins Trust to deliver a national anti-stigma campaign in 2023 and working with NHS Scotland and Waverley Care to develop and roll-out HIV Informed, an online learning hub for health and social care staff.[13] While this action is welcomed, the findings from this project demonstrate that much more needs to be done to eliminate HIV-related stigma in Scotland.

Recommendations to tackle HIV-related stigma and discrimination

1. Deliver a national, coordinated anti-stigma strategy

Recommendation: The Scottish Government should lead and fund a sustained, cross-sector anti-stigma response, bringing together public awareness, education, and workforce development, with the third-sector funded to deliver key components.

Key components should include:

- Ongoing **public awareness campaigns** that reflect modern realities of HIV, including that people on effective treatment can live long, healthy lives and cannot pass on the virus. Campaigns should be co-produced with people living with HIV.
- Funding for the development of a **National HIV Testing Week** for Scotland which includes roll-out of programmes in key settings, including incentivised testing in **universities and colleges**, using approaches such as small giveaways to encourage engagement and normalise HIV testing.
- Ensure schools have the resources needed to implement Scotland's national resource for relationships, sexual health and parenthood (RSHP) education for children and young people which includes activity plans on BBVs and HIV.
- Support the roll-out and sustainability of learning resources for health and social care workers, including exploring mandatory training options, through the HIV Informed programme.
- Take action to tackle HIV-related stigma and discrimination in the workplace, including improving employer and employee awareness of legal protections for people living with HIV.
- Join the Global Partnership for Action to Eliminate All Forms of HIV-Related Stigma and Discrimination and draw on its expertise and guidance to drive its anti-stigma work. Given the diversity of people living with HIV in Scotland, including people who have moved to Scotland from other countries, engagement with international approaches and learning should inform action that meets the needs of all communities.

2. End the criminalisation of reckless HIV transmission and exposure

Recommendation: The Scottish Government should review Scots law on Culpable and Reckless Conduct relating to HIV transmission and exposure, with a view to ending criminalisation of reckless HIV transmission and exposure. The Crown Office and Procurator Fiscal Service should also review its relevant guidance on how this law is implemented. This would help reduce HIV-related stigma and remove barriers to HIV testing, prevention and care, supporting Scotland's ambition to end HIV transmission.[14]

High-quality, person-centred HIV care pathways

Introduction

In Scotland, people living with HIV receive treatment and ongoing monitoring through specialist HIV clinics based within sexual health or infectious disease services. Modern HIV treatment is highly effective, enabling people to live long, healthy lives. It reduces the amount of virus in the body to undetectable levels, meaning people cannot pass HIV on through sex (U=U).[15]

While Scotland has a strong record of providing effective HIV treatment and care,[16,17] not everyone benefits equally. It is estimated that up to 1,400 people in Scotland are either not currently engaged in HIV care or have been lost to follow-up, and 400 people are living with undiagnosed HIV.[18] Ensuring that everyone can access high-quality, person-centred and accessible HIV care pathways is therefore essential, both to enable people living with HIV to live well and to achieve Scotland's wider public health ambitions.

Project findings

Across all engagement activities, many participants described HIV services in Scotland as providing high-quality, compassionate care. They valued the strong relationships they had built with their HIV clinic and recognised the significant advances that have transformed HIV into a manageable long-term condition. However, participants also identified opportunities to improve person-centred care by ensuring flexibility, choice and communication throughout HIV care pathways. Across all aspects of care, people wanted services that better reflected individual circumstances, preferences and changing needs.

Strengths of current HIV care

Many participants described overwhelmingly positive experiences of HIV services – when event participants were asked to rate their experience of their HIV clinic, the average ranking was 4.4 out of 5 (range = 3 to 5). HIV clinics were often described as safe, welcoming and supportive environments. Many participants valued the professionalism, compassion and continuity of care provided by staff, as well as the time taken to listen, build relationships and understand what mattered to them. Participants consistently described HIV specialist nurses as central to person-centred HIV care and a vital source of support, particularly at the point of diagnosis. They were seen as responsive, knowledgeable and trusted, often acting as the main point of contact within services. Participants also expressed concern about increasing workloads, highlighting the importance of protecting and strengthening these roles within HIV care pathways.

> [My HIV clinic] is the best. The staff members there are like family, loving and caring. Excellent treatment, no stigma, only prevention and support.
>
> **Survey participant**

For many, advances in HIV treatment represented a turning point. Participants described a renewed sense of choice, freedom, hope, resilience and possibility. The speed at which modern treatments can achieve an undetectable viral load was seen as motivating and empowering, enabling people to move forward with their lives. Some reflected that this clinical progress has not been matched by wider public understanding, contributing to ongoing stigma and reduced public conversation about HIV.

Opportunities to improve HIV care pathways

While participants generally reported positive experiences of HIV care, they also identified opportunities to make care pathways more person-centred and responsive to individual needs. Participants recognised the increasing demands placed on specialist HIV teams and were keen to ensure that future improvements build on the strengths of existing services.

Person-centred care and shared decision-making

Participants consistently highlighted the importance of person-centred care throughout the HIV care pathway. Many valued care that recognised their individual circumstances, preferences and goals and wanted to be active partners in decisions about their treatment and care.

These findings are supported by the BHIVA Standards of Care, which state that people living with HIV should be at the centre of decisions about their care, with services responding to their individual needs, preferences and circumstances and supporting them to make informed decisions about treatment and care.[19]

This was particularly important at the point of diagnosis. Participants described diagnosis as a critical moment when many felt less confident and most in need of clear information, reassurance and holistic support. Many felt overwhelmed and less able to ask questions, absorb clinical information or advocate for themselves.

One survey participant reflected:
"I was never educated about HIV. I didn't know anything about it when I was diagnosed. I was tested for HIV without my knowledge, so it was a shock when I found out."

Survey participants also identified several opportunities to improve experiences at the point of diagnosis. The three most commonly selected were:

- More information about living well with HIV (24%)
- More information about HIV, including treatment options and Undetectable = Untransmittable (23%)
- Access to peer support (18%)

Participants noted that language barriers could make it more difficult for some people to advocate for themselves. They highlighted the importance of providing information in ways that reflect people's individual needs, preferences and readiness to take in information.

Participants emphasised that the language used matters. In some cases, messages about treatment adherence were felt to be focused primarily on preventing onward transmission, which could feel blaming or coercive. Participants felt communication should instead place greater emphasis on supporting people to live well with HIV.

Experiences of involvement in treatment decisions varied. Many participants felt well informed and supported, particularly in relation to decisions about their HIV treatment. However, some felt they had limited involvement in decisions about their care, including feeling expected to accept a particular medication or undergo tests without clear explanations. Some participants also felt discussions about newer treatment options, including injectable treatment, did not always happen routinely and instead relied on information from social media or peer networks. Participants emphasised that people should be supported to understand their options and feel able to participate fully in decisions about their care. With rapid advances in HIV treatment, including long-acting injectables and weekly oral treatment options, it is essential that people are actively involved in decisions about their treatment.

While daily oral medication works well for many, participants described challenges including managing medication around others who may not know their HIV status, travelling with medication, the pressure of taking a daily pill and high pill burdens. Long-acting, six-monthly injectable treatment was viewed positively by many participants to increase flexibility and reduce some of these pressures. However, participants emphasised that choice is essential, as different treatment options will suit different people.

Treatment and care delivery models

Participants felt there should be greater flexibility in how care is delivered, including more opportunities to access aspects of HIV care closer to home. Some felt that getting some of their tests at the GP would be a positive move and allow more flexibility however, others valued the regular touchpoints with their HIV clinic.

There was mixed feedback on moves towards less frequent clinic appointments, such as annual reviews for people whose HIV is stable and undetectable. While some participants welcomed this as a convenient and appropriate approach, others valued regular contact with their HIV clinic as an important source of support. Participants highlighted the importance of ensuring appointment frequency reflects individual preferences and circumstances.

A number of participants reported difficulties with home delivery of HIV medication. These included: short notice of deliveries, delays or missed deliveries, incomplete prescriptions and a lack of flexible delivery options. These issues could create stress and, in some cases, risk interruptions to treatment.

Across Scotland, innovative and best practice models of care are already demonstrating how services can be delivered more flexibly and closer to people's homes, particularly in rural areas. Creating opportunities for health boards and healthcare professionals to share learning and build on these examples will be essential to supporting wider adoption of approaches that improve access, experience and outcomes. Ensuring each health board has the resources and capacity to deliver care in a way that meets individual needs is also essential to enabling flexible care pathways.

Engagement in care

Participants described a range of barriers to remaining engaged in care, including challenges around shared accommodation, difficulties taking medication privately, lack of family support, unstable housing and poor mental health.

Among survey participants, of those who reported experiencing challenges in getting and staying on HIV treatment*, the most commonly selected were:

- Worries their community will find out that they are on treatment for HIV (29%)
- Difficulty getting appointments or long waits for sexual health services (25%)
- Side effects or problems when medicines are mixed with HIV treatment (25%)

*11% of survey participants experienced no challenges in getting and staying on their HIV treatment.

Some participants felt that responses to missed appointments or difficulties remaining on treatment did not always take account of the wider challenges they were experiencing. There was strong support for a compassionate, holistic approach to re-engagement - one that meets people where they are at and supports them to reconnect with care.

This is supported by wider research showing that engagement in HIV care is shaped by interacting individual, social and structural factors, many of which sit beyond an individual's control. This reinforces the importance of re-engagement approaches that recognise and respond to people's wider circumstances.[20]

The role of peer support

Participants viewed peer support as an essential part of HIV care pathways but highlighted significant variation in access across Scotland. The role of peer support is explored in detail in the 'Living well with HIV' section of this report.

Recommendations to improve HIV care pathways

1. Provide structured, early support following diagnosis

Recommendation: The Scottish Government should commission the third-sector to develop a national support offer for people newly diagnosed with HIV.

Further detail:

- This should provide timely, accessible information and support at the point of diagnosis. It should help individuals understand their condition, explore treatment options, be aware of their lawful rights and protections, and build confidence to engage with care and make informed decisions.
- It should include structured pathways to peer support.
- It should also be available to people newly diagnosed in and outside of Scotland, and those previously diagnosed who would benefit from additional information or support, recognising that many may not have received comprehensive information at the time of diagnosis or may wish to refresh their knowledge as HIV care and treatment have evolved.
- This course should build upon the findings of pilots delivered by Waverley Care and Terrence Higgins Trust.

2. Review and benchmark HIV care pathways

Recommendation: NHS territorial health boards should review and audit their HIV care pathways against the BHIVA Standards of Care for people living with HIV to identify and address any gaps.[21]

3. Ensure equitable access to a choice of HIV treatments

Recommendation: The Scottish Government should ensure NHS territorial Boards have sufficient funding and capacity to offer people living with HIV a choice of clinically appropriate treatment options, including long-acting treatments. Treatment decisions should be made jointly between people living with HIV and their clinical team, taking account of individual needs, circumstances and preferences.

4. Scale innovative best practice

Recommendation: Health boards should be given opportunities to share learning from innovative and effective pathways, particularly those which provide care closer to home, to support the adoption and replication of best practice where appropriate.

5. Develop a national re-engagement and retention in care programme

Recommendation: The Scottish Government should develop a national programme to support people living with HIV who are not currently accessing treatment and care to re-engage in a way that meets their needs.

Further detail:

- The programme should be based on the principle of meeting people 'where they are at', recognising that disengagement from care is often shaped by wider barriers, including stigma, mental health, social and economic barriers and challenges accessing services.
- The programme should provide a range of support options, including intensive and consistent support where needed and links to relevant services addressing wider social and economic needs. It should be co-designed with people living with HIV.
- The voluntary sector should be a key planning, delivery and evaluation partner in the programme.
- Funding should be informed by health board level data on the number of people not currently engaged in HIV care, ensuring resources are targeted proportionately to local need.
- The programme should establish clear and appropriate data-sharing arrangements between NHS services and voluntary sector partners, where needed, to help identify and support people who are no longer accessing HIV care, while protecting confidentiality and ensuring appropriate information governance.

6. Measure individuals' experiences of clinical care and use findings to improve services

Recommendation: Ensure that patient-centred outcome measures (PROMs) and patient-reported experience measures (PREMs) are integrated into clinical practice. This could include exploring the use of the Positive Outcomes: HIV PROM tool.[22]

7. Involve people with lived and living experience at all stages of projects and initiatives

Recommendation: Each NHS territorial Board should act with urgency to embed meaningful and ongoing involvement of people living with HIV at every level of decision-making, ensuring representation from the diverse communities affected by HIV.

Further detail:

- NHS Boards should use **BHIVA Standard 2c** to review existing mechanisms for involving people living with HIV and ensure these meet BHIVA standards.[23]
- Where standards are not met, Boards should report this transparently, including the reasons and action being taken to address gaps.
- Clear accountability structures should be established to embed co-production as standard practice.
- NHS Board commissioners should also involve people living with HIV in the development and review of relevant service specifications and tenders.[24]

Joined-up care across the healthcare system

Introduction

People living with HIV are not defined by their diagnosis. Like anyone else, they may live with multiple health conditions and, as they age, are increasingly likely to need support from a range of services across the health and social care system. Joined-up, coordinated care is therefore essential. While fragmented care is a challenge across the NHS, it can be particularly pronounced for people living with HIV. Concerns about privacy and confidentiality, uncertainty around information sharing and the emotional burden of repeatedly sharing HIV status add to the complexity. For many, every interaction with a new service carries a risk of stigma or judgement.

As part of its Health and Social Care Service Renewal Framework, the Scottish Government has committed to redesigning services around people's needs through people-led care, greater integration across health and care, multidisciplinary working and improved digital integration.[25] These reforms provide an important opportunity to improve care for people living with HIV.

Project findings

Across all engagement activities, participants highlighted the importance of joined-up care across the healthcare system. While specialist HIV services were widely regarded as providing high-quality care, experiences of other health and care services varied considerably. Inconsistent communication and coordination often meant people had to navigate the healthcare system themselves, repeatedly sharing their HIV status and medical history and advocating for their own care.

Participants recognised that many of these challenges reflect wider pressures across the health and social care system, including workforce capacity and system challenges. Participants felt staff should be better supported through improved awareness of the basics of HIV, alongside stronger coordination with and access to specialist HIV expertise when needed.

Fragmented care

Participants often described a lack of coordination between services, which had practical, emotional and clinical consequences. Many spoke about having to repeat their medical history and share their HIV status multiple times with different healthcare teams. While this reflects a wider issue across the NHS, for people living with HIV it carries an additional layer of stress. Each time they share their status, there is a risk of stigma, and this repetition can feel exhausting and at times, retraumatising.

Participants often found themselves coordinating their own care, following up

test results, navigating communication between services and determining which team was responsible for different aspects of their care. This was particularly challenging for those living with multiple long-term conditions. Some also described unnecessary duplication of tests across different specialties, which they viewed as an inefficient use of NHS resources and an unnecessary burden on individuals.

Scotland's digital transformation agenda, including implementation of the Health and Social Care Data Strategy, MyCare.Scot and improvements to primary care data infrastructure, presents an opportunity to strengthen joined-up care while maintaining trust and confidentiality. [26,27] Given the ongoing stigma experienced by many people living with HIV when accessing healthcare, it is essential that these developments consider and respond to their specific needs.

Alongside these concerns, some participants valued the closer monitoring they received for other conditions, such as cardiovascular health, and felt this should be retained within future models of care.

GP services

Participants had varied experiences of their GP services. Some reported having knowledgeable and supportive GPs; however, many participants felt their GP did not have sufficient knowledge of HIV. They described occasions where symptoms were attributed to HIV without thorough assessment, or where they felt they had to educate their GP about HIV. In some cases, this contributed to people disengaging from primary care and relying instead on their HIV clinic. Participants recognised that GPs should not be expected to have specialist expertise in every condition. They felt easier access to advice from specialist HIV teams would increase confidence in managing HIV-related care.

Concerns about confidentiality were also common, particularly in smaller or rural communities where participants worried their HIV status could be inadvertently shared in reception areas.

Improving communication between HIV clinics and GPs was identified by survey participants as one of the strongest opportunities to improve HIV care. Participants felt that strengthening communication between primary care and specialist HIV services would benefit both individuals and healthcare professionals, enabling GPs to feel more confident managing aspects of HIV care while ensuring specialist advice remains readily available when needed.

Hospital care

Participants recognised the pressures facing hospital staff but identified opportunities to improve care through clearer guidance, stronger links with specialist HIV teams and protocols to ensure confidentiality. Several participants either reported disruptions to their HIV medication during hospital admissions, including medication being lost, or expressed worries that this could happen. These experiences and concerns caused significant stress and anxiety as well as additional work for hospital staff to arrange replacement prescriptions.

As noted in the 'Tackling HIV-related stigma' section of this report, confidentiality was also a major concern. Some participants

worried that their HIV status might be accidentally shared with family members or visitors during hospital stays. Others described instances where their HIV status had been shared inappropriately on hospital wards.

HIV and maternity care

Participants with experience of maternity services described occasions where care did not appear to reflect the latest evidence. They emphasised the importance of trust in healthcare professionals and highlighted that negative experiences during pregnancy could have lasting emotional impacts. Improving links between maternity services and specialist HIV teams was seen as important to support evidence-based, coordinated care.

Overall, participants were clear that the challenges described throughout this chapter reflect opportunities to improve education, communication and coordination across services which would better support staff to deliver consistently high-quality, person-centred care for people living with HIV.

These findings are supported by wider research - a systematic review of integrated care approaches for people living with HIV and/or multimorbidity identified a range of different models and approaches, commonly involving multidisciplinary working, continuity and coordination of care, and greater involvement of people using services.[28] The review highlights the importance of adapting integrated care to local contexts and taking account of HIV-specific considerations, including stigma and confidentiality. This supports further exploration of how integrated models of care could be developed in Scotland to meet the changing needs of people living with HIV.

Recommendations for improving joined-up care across the healthcare system

1. Improve communication and coordination across the health system

Recommendation: The Scottish Government should work with people living with HIV to identify how communication and coordination across services can be improved, so that people living with HIV have the information they need about their health and rights and receive joined-up, person-centred care.

2. Improve coordination with primary care

Recommendation: The Scottish Government should appoint a national, HIV GP Champion to facilitate coordination and engagement between primary care and HIV specialist services.

This Champion would:

- Support engagement between primary care and national HIV plan delivery groups, helping to coordinate the delivery of HIV-related actions within primary care.
- Support the establishment of a primary care network to promote more consistent HIV care across Scotland and explore opportunities to expand the role of primary care in HIV prevention, testing and re-engagement in care.

This approach would help address the current variation in GP knowledge and reduce reliance on individuals having to educate their own healthcare providers.[29]

3. Improve the quality, coordination and experience of hospital care for people living with HIV

Recommendation: NHS territorial health boards should ensure that hospital care for people living with HIV is person-centred and integrated. This should include:

- Implementing protocols to protect confidentiality and privacy, particularly in shared wards and visitor-facing environments.
- A review of protocols for the safe and secure handling of patients' own medicines to identify and address any gaps in the protocols or challenges with their implementation.
- Improving coordination between specialist HIV services and other hospital services including maternity care, to ensure care is informed by current evidence and delivered through joined-up, multidisciplinary pathways.

Living well with HIV

Introduction

HIV is now a manageable long-term condition, and with effective treatment people can live long and healthy lives. However, many people continue to face barriers that affect their mental wellbeing, relationships, confidence and quality of life.

People living with HIV in the UK have a 63% greater risk of being diagnosed with a mental health condition compared to people without HIV.[30] Individuals with unsupported mental health conditions are less likely to stay engaged in HIV care.[31]
This highlights the importance of access to timely information, emotional and practical support, strong social connections and person-centred services that respond to people's changing circumstances throughout their lives.

However, there are significant inequalities in access to this kind of support. UK evidence shows that certain groups of people living with HIV experience particularly high levels of unmet need, including women, migrants, trans and gender-diverse people and older people.[32,33]

There is no single definition of 'living well' – it can mean different things to different people. The aim is to ensure everyone can live in a way that reflects their own needs, priorities and circumstances.

Project findings

Across all engagement activities, participants consistently described the importance of having choice, control and confidence in everyday life, supported by access to accurate information, peer and mental health support and trusted relationships. Participants emphasised that support should be holistic, person-centred and enable people to make informed decisions, build confidence and access the right support at the right time.

Information and awareness (including U=U)

Participants consistently described the importance of having access to clear, accurate and timely information to enable them to understand their diagnosis, make informed decisions about treatment and feel more confident managing their health.

Awareness of U=U – the fact that people on effective treatment cannot pass HIV on through sex – was identified as particularly important. Survey participants identified greater awareness of U=U as the single biggest opportunity to improve HIV treatment pathways, accounting for 21% of responses. Despite this, some participants reported limited awareness of U=U, with some only learning about it later through third-sector organisations or peer networks. Others remained unclear about what might

happen if they stopped treatment. Participants also highlighted gaps in information about treatment options, often feeling responsible for researching these independently. Without reliable information, some turned to online sources, where they risked encountering misinformation and HIV-related stigma.

The timing and delivery of information was equally important. At the point of diagnosis, many participants described feeling overwhelmed and unable to absorb complex clinical information. Participants emphasised that information and signposting should be person-centred and delivered in ways that reflect individual readiness, preferences and needs.

Peer support

Peer support emerged as one of the most important opportunities for improving quality of life for people living with HIV and an essential part of HIV care. Survey participants identified it as one of the biggest opportunities to improve HIV care, accounting for 19% of responses.

Peer support means people with similar life experiences come together to help and learn from each other.[34] It can take many forms, from informal social connections to structured mentoring programmes. Evidence shows that it can reduce internalised stigma, strengthen coping mechanisms and improve adherence to HIV treatment.[35]

> I feel privileged to access the high-quality mental health and peer support available in Glasgow. However, this 'gold standard' should not be a privilege; it must be the baseline for HIV care across the whole of Scotland.
>
> **Survey participant**

Participants consistently described peer support as vital at many different stages. It was seen as particularly valuable at key moments, including after diagnosis and when making treatment decisions. Support groups were described as safe, non-judgemental spaces where people could speak openly without needing to explain themselves. Hearing others share their experiences helped many participants realise that it is possible to live well with HIV, while ongoing peer support helped people stay motivated and engaged in their care.

Participants also highlighted the wider benefits of peer support. It helped build confidence, including around sharing HIV status in ways that supported wellbeing, navigating relationships and managing everyday life. Those who had become peer supporters spoke positively about the impact that supporting others had on their own confidence, purpose and quality of life.

Participants emphasised that meaningful peer support relies on representation, connection and choice. While some highlighted the value of connecting with someone from a similar background or with shared experiences, they stressed that individuals should have choice over who they receive support from. Participants also highlighted the value of locally based peer support, with peer supporters who understand the local context and can provide relevant signposting to services and support.

Despite its vital role in HIV care, access to peer support is inconsistent across Scotland. Some participants reported that peer support services were unavailable in their local area and others described services being reduced or withdrawn.

Holistic support

Participants consistently highlighted the importance of early access to emotional and practical support. Early awareness of third-sector services providing emotional support, practical advice and opportunities to connect with others was seen as particularly important, even if people did not wish to access support immediately. Knowing that support was available, and how to access it, helped build confidence and reduce feelings of isolation.

Survey participants also highlighted access to mental health support and counselling as one of the priorities for improving care and

support accounting for 21% of the votes. Many participants felt support was too often offered only when problems became acute. There was a strong call for a more preventative approach, with support offered earlier to help prevent deterioration in mental health and wellbeing. Delays in accessing support were seen as having long-lasting consequences, particularly given the ongoing effects of stigma and impact on mental health.

Participants also recognised that different forms of support may be needed at different life stages and services should be flexible to respond to these changing needs. A key principle identified throughout the project was the importance of 'meeting people where they are at'. Not everyone will be ready for the same type of support at the same time and care pathways should reflect this.

Relationships

Participants also highlighted the importance of support around relationships and sharing their status with others. While some described the positive impact of sharing their HIV status with trusted family and friends, helping them build strong support networks, others wanted more guidance and support around when and how to share their status.

Participants felt that greater awareness of U=U, alongside access to peer support, could help build confidence in navigating relationships, reduce anxiety around sharing their status and enable people to feel less isolated.

Recommendations to support living well with HIV

Our findings reinforce the recommendations of HIV Outcomes UK's 2024 report, Beyond the Virus: Prioritising mental health for people living with HIV in Scotland, which identified significant gaps and inequalities in mental health and wellbeing support and set out actions for the Scottish Government and NHS territorial Health Boards.[36] Our engagement with people living with HIV provides further evidence that these challenges remain and further strengthens the case for change. In particular, our findings reinforce the need to:

1. Improve access to peer support

Recommendation: The Scottish Government must ensure equitable access to peer support for everyone living with HIV by establishing a national baseline for peer support provision in NHS territorial health boards. This should be underpinned by sustainable funding for HIV voluntary sector organisations and additional paid peer workers, recognising their central role in delivering peer support and improving outcomes for people living with HIV.

National minimum standard for HIV peer support should include:

- Delivery in line with BHIVA guidelines and the opt-out guideline update.[37]
- Integration of peer support within NHS HIV services, drawing on the Fast-Track Cities London model.[38]
- Peer supporters trained to nationally recognised standards.
- Flexible models of peer support that enable people to choose the type of support, and where possible the peer supporter, that best reflects their preferences, circumstances and living experience.
- Consideration should also be given to how peer support can be delivered effectively in health boards with lower prevalence of HIV.

2. Improve access to mental health and psychological support

Recommendation: The Scottish Government and NHS territorial Boards should ensure people living with HIV have equitable access to appropriate mental health and psychological support, in line with the BHIVA Standards of Psychological Support for Adults Living with HIV.[39]
This should include:

- Ensuring HIV services have the resources, staffing and pathways needed to implement the BHIVA Standards.
- Embedding access to specialist mental health provision within HIV services and strengthening referral pathways between HIV and mental health services.
- Funding HIV literacy and training for mental health and social care practitioners.
- Meaningfully involving people living with HIV and HIV voluntary sector organisations in the design and development of mental health services.

3. Ensure the third-sector is sufficiently resourced to deliver high-quality services across Scotland

Recommendation: The Scottish Government should ensure equitable access to high-quality, person-centred third-sector support for people living with HIV across Scotland. This should include resource for HIV-specific support and services that address wider social and economic barriers to living well.

Third-sector organisations should receive sustainable, multi-year funding that covers core running costs and enables them to maintain and scale effective, person-centred services and maintain trust with individuals accessing services.

Ageing with HIV

Introduction

Almost 70% of people diagnosed and living with HIV in Scotland are aged 45 or over.[40] This reflects significant advances in HIV treatment, which have enabled people to live long, healthy lives. As a result, supporting people to age well with HIV is an increasingly important priority. Future national policy, research and service development must consider the specific needs and experiences of people ageing with HIV, ensuring that Scotland's response continues to support people to live well throughout the life course.

Project findings

Across all engagement activities, participants highlighted ageing with HIV as an increasingly important issue. While many of the challenges discussed in the 'Improving joined-up care across the healthcare system' section of this report already affect people living with HIV, participants felt they become more significant with age as people navigate multiple long-term conditions and increasing contact with health and social care services. They emphasised the need for policy, research and services to keep pace with the changing needs of an ageing HIV population.

This was reinforced by the survey findings. Survey participants were asked to identify their top three challenges they face in getting care and support to live well with HIV. The two most commonly selected were managing ageing with HIV (22%) and managing other long-term conditions (20%).

Managing multiple conditions and medications

As people age, they are more likely to develop additional health conditions and require multiple medications.[41]

Participants expressed concerns about drug interactions, particularly between HIV treatment and medicines prescribed for other conditions. While tools such as the Liverpool HIV drug interaction checker exist and are widely used, participants felt that awareness and use of these tools was low across the wider healthcare settings. They highlighted the importance of ensuring that healthcare professionals involved in the care of older people with HIV have access to the knowledge and resources needed to support informed prescribing.

Social care and care homes

Many participants expressed deep anxiety about the prospect of needing residential or social care in the future. Some had heard of individuals being refused care home places, or being charged higher fees because of their HIV status. Whether or not these experiences are widespread, the perception alone contributes to fear, mistrust and concerns about future care.

These concerns are reflected in wider UK evidence. Previous research and engagement with people ageing with HIV has identified concerns about stigma and discrimination in later life, including anxiety about whether residential and social care services have the knowledge and confidence to provide appropriate care.[43,44]

Participants also raised concerns about HIV knowledge, awareness and stigma among the social care workforce and the potential impact on the quality and dignity of care. Some were particularly worried about this in the context of becoming less able to advocate for themselves as they age.

Participants felt many social care staff have limited opportunities to develop their knowledge and confidence in supporting people living with HIV. They highlighted the need for more education and training to ensure people receive informed, compassionate and person-centred care. This could be achieved through the HIV Informed programme.

Building the evidence base

Participants also highlighted the need for greater research into ageing with HIV, including the interaction between HIV, long-term treatment and age-related conditions as well as research exploring the everyday experiences and health and wellbeing of older people living with HIV.

As the number of older people living with HIV continues to grow, participants felt it is essential that policy, research and service planning keep pace. This includes ensuring that health and social care services are equipped to meet changing needs and that people living with HIV can access safe, informed and respectful care throughout later life.

Recommendations for improving experiences of ageing with HIV

1. Ensure all health and social care teams have up-to-date information about HIV

Recommendation: NHS territorial health boards and local authorities should ensure that all health and social care professionals involved in the care and support of people living with HIV have access to up-to-date HIV information and appropriate training. This should include:

- Ensuring relevant healthcare professionals are aware of and, where clinically appropriate, consistently use the Liverpool HIV Drug Interactions Checker.
- Ensuring health and social care staff have access to appropriate HIV training and learning resources, including through the HIV Informed programme, and explore options for mandatory training.

2. Ensure fair care, quality of life and empowerment of people ageing with HIV

Recommendation: The Scottish Government should implement the actions set out in The Glasgow Manifesto. Developed by the International Coalition of Older People with HIV (iCOPeHIV), the manifesto sets out key actions around improving care, quality of life and empowerment.[45]

3. Increase investment in research on ageing with HIV

Recommendation: The Scottish Government should support research to address evidence gaps on ageing with HIV and inform future policy and service development. This should include research into the changing health and social care needs and experiences of people ageing with HIV in Scotland, alongside the development, piloting and evaluation of integrated models of care that respond to these needs.

Policy and living experience involvement

Introduction

Scotland has made significant progress on ending HIV transmission, underpinned by clear policy direction and a dedicated HIV Transmission Elimination Delivery Plan.[46] This has driven important improvements in HIV treatment, care, prevention and testing, bringing Scotland closer to its goal of ending HIV transmission by 2030.

However, participants raised concerns about the future policy and funding landscape, and whether it will reflect the needs and experiences of people living with HIV. As Scotland approaches its transmission elimination target, there is a risk that HIV will increasingly be viewed as a condition that has been "solved", despite the fact that over 6,000 people in Scotland continue to live with HIV and require lifelong treatment, care and support.

Maintaining progress will require continued political leadership, sustained investment and meaningful involvement of people living with HIV in the development of future policy.

Project findings

Participation and representation in decision-making

Participants consistently highlighted the importance of meaningful involvement in policy and decision-making. Many felt that the voices of people living with HIV are not consistently heard or reflected in policy, particularly those from diverse communities, women, people from ethnic minority communities, those more recently diagnosed and those living outside Scotland's major urban areas.

Participants emphasised that involving people with lived and living experience leads to more responsive and effective policy and should be embedded as standard practice.

Sustaining investment and commitment

Some participants expressed concern about the long-term sustainability of investment in HIV and described anxiety about recent changes to global HIV funding and the potential implications of these changes.[47] While the direct impact on the UK may be uncertain, the visibility of funding being reduced or withdrawn internationally created concern about how secure HIV investment is more broadly. This reflects a wider sense of vulnerability - that progress on HIV, both globally and nationally, can be fragile if not sustained by long-term commitment.

This concern extended to Scotland's 2030 HIV transmission elimination target. Participants worried that once this ambition

is achieved, HIV could fall down the list of government priorities, resulting in reduced funding and support for services.

Participants emphasised that ending HIV transmission will not mark the end of HIV. Over 6,000 people in Scotland are living with HIV and will continue to require treatment, care and support throughout their lives. Sustained investment will therefore be essential not only to maintain transmission elimination, but also to ensure that people living with HIV can live well, free from stigma and discrimination.

Recommendations for improving HIV policy and living experience involvement

1. Involve people with lived and living experience in decision-making

Recommendation: The Scottish Government should establish sustainable approaches to meaningfully involve people living with HIV in national HIV governance and decision-making. This should ensure representation reflects the diversity of people living with HIV in Scotland, including groups who experience additional barriers, inequalities or challenges in accessing care and support.

2. Commit to sustained prioritisation of HIV beyond 2030, taking a whole government approach

Recommendation: The Scottish Government should maintain HIV as a clear national priority beyond the achievement of transmission elimination targets. Sustained action will be needed to protect progress towards elimination and ensure everyone living with HIV can live and age well, free from stigma and discrimination.
This should include:

- Sustained investment in treatment, support, prevention and testing, and tackling HIV-related stigma, with targeted investment to address the needs of communities experiencing additional social, economic and health inequalities.
- Establishing a national 'fourth 95' ambition to measure quality of life, ensuring Scotland's HIV response measures not only diagnosis, treatment and viral suppression, but whether people living with HIV are able to live well.
- Taking a whole-government approach to HIV, recognising that health outcomes and quality of life for people living with HIV are shaped by factors beyond the health system. The Scottish Government should establish mechanisms for coordinated action across relevant portfolios, including health, housing, social security, mental health, drugs and alcohol, equalities and justice, to address the wider social and structural factors affecting people living with HIV.[48]

Conclusion

Scotland has made significant progress in responding to HIV. Advances in treatment mean that people living with HIV can now expect to live long and healthy lives, and Scotland is on track to achieve its ambition of ending HIV transmission by 2030. However, this project highlights that success in the HIV response must also be measured by the experiences of people living with HIV, including whether they can access the support, care and services they need to live well.

Across every stage of this project, participants consistently highlighted the need for action that goes beyond diagnosis and treatment. They described the continuing impact of HIV-related stigma, the importance of person-centred and joined-up care, the need for equitable access to peer and mental health support and a focus on ageing well with HIV. Underpinning all these themes was a shared desire for services that provide greater choice, flexibility, dignity and support throughout people's lives. The findings also demonstrate the importance of directly involving people living with HIV at every stage – from shaping national policy to delivering local services.

As the Scottish Government develops new plans on HIV, it has a unique opportunity to build on the significant progress made and address the challenges that remain for people living with HIV. Embedding the priorities identified through this project will be essential to achieving Scotland's ambition of ending HIV transmission while ensuring that everyone living with HIV can live and age well, free from stigma and discrimination.

Appendix one: Our approach

Consultation and engagement

Between March and June 2026, Waverley Care undertook a mixed-methods consultation with people aged 18 and over living with HIV in Scotland. The project included an online survey, semi-structured interviews and a community engagement event.

The aim was to gather both quantitative and qualitative evidence on the experiences of people living with HIV in Scotland, identify the key challenges they face and understand their priorities for improving HIV policy, treatment, care and support.
In addition to the survey, we conducted two semi-structured interviews with people living with HIV and held a community event attended by 17 people from across Scotland.

Survey participants

The survey was promoted through Waverley Care's social media channels, website and newsletter. It was also shared through the British HIV Association (BHIVA) members' newsletter and UK-CAB, the UK HIV treatment advocates' network.
A total of 38 people living with HIV completed the survey.

Geography: Participants represented all NHS territorial health boards except NHS Shetland, NHS Orkney and NHS Fife.

Age: Participants ranged in age from 25–34 years to 75–84 years.
Gender: 54% identified as male, 46% identified as female. 5% identified as transgender.*
Sexual orientation: 46% identified as heterosexual, 43% identified as gay, 3% identified as bisexual, 5% identified as lesbian and 3% identified as 'Something else'.
Ethnicity: Participants represented a range of ethnic backgrounds. The largest ethnic groups were White Scottish (41%), White Other British (19%) and White Irish (14%). Participants also identified as African, Scottish African or British African, Mixed or Multiple Ethnic Groups, and other ethnic backgrounds.
Country of birth: 84% were born in the UK, and 16% were born outside the UK.
Place of HIV diagnosis: Nearly three-quarters (73%) were diagnosed in Scotland, 16% were diagnosed elsewhere in the UK, and 11% were diagnosed outside the UK.
*Participants were able to identify as transgender in addition to their gender identity, so percentages may therefore total more than 100%.

Community event

On 2 June 2026, Waverley Care held a community event in Edinburgh for people living with HIV. Through facilitated discussions and interactive activities, participants explored their experiences of

living with HIV in Scotland and identified priorities for improvement. 17 people from a range of backgrounds, genders and geographical areas took part.

Developing the recommendations

The recommendations in this report were developed using findings from the survey, interviews and the community event, alongside a review of existing evidence and consideration of potential policy levers for change.

Draft recommendations were reviewed by two members of Waverley Care's Community Panel and a small group of professionals with expertise in HIV policy, healthcare and service delivery.

Strengths and limitations

Participants were self-selecting and therefore may not be representative of everyone living with HIV in Scotland. In addition, we did not receive survey responses from people living in NHS Shetland, NHS Orkney or NHS Fife.

Given the small sample size, it was not possible to identify statistically significant differences in reported experiences of participant subgroups.

While the sample size was small, many participants were well connected to the wider HIV community in Scotland, including through their involvement in peer support. Participants therefore drew on their own experiences while also reflecting on issues and challenges they had encountered through supporting or connecting with other people living with HIV. These wider perspectives provided valuable context to the findings, although they should not be considered a substitute for direct participation from those individuals.

The project explored a broad range of topics affecting people living with HIV. As a result, it was not possible to examine every issue in depth. Instead, the findings provide an overview of the priorities identified by participants and highlight areas where further research and evidence generation are needed.

Despite these limitations, the project provides valuable insights into the experiences and priorities of people living with HIV who participated, adding to the wider evidence base and identifying priorities for future policy and further investigation.

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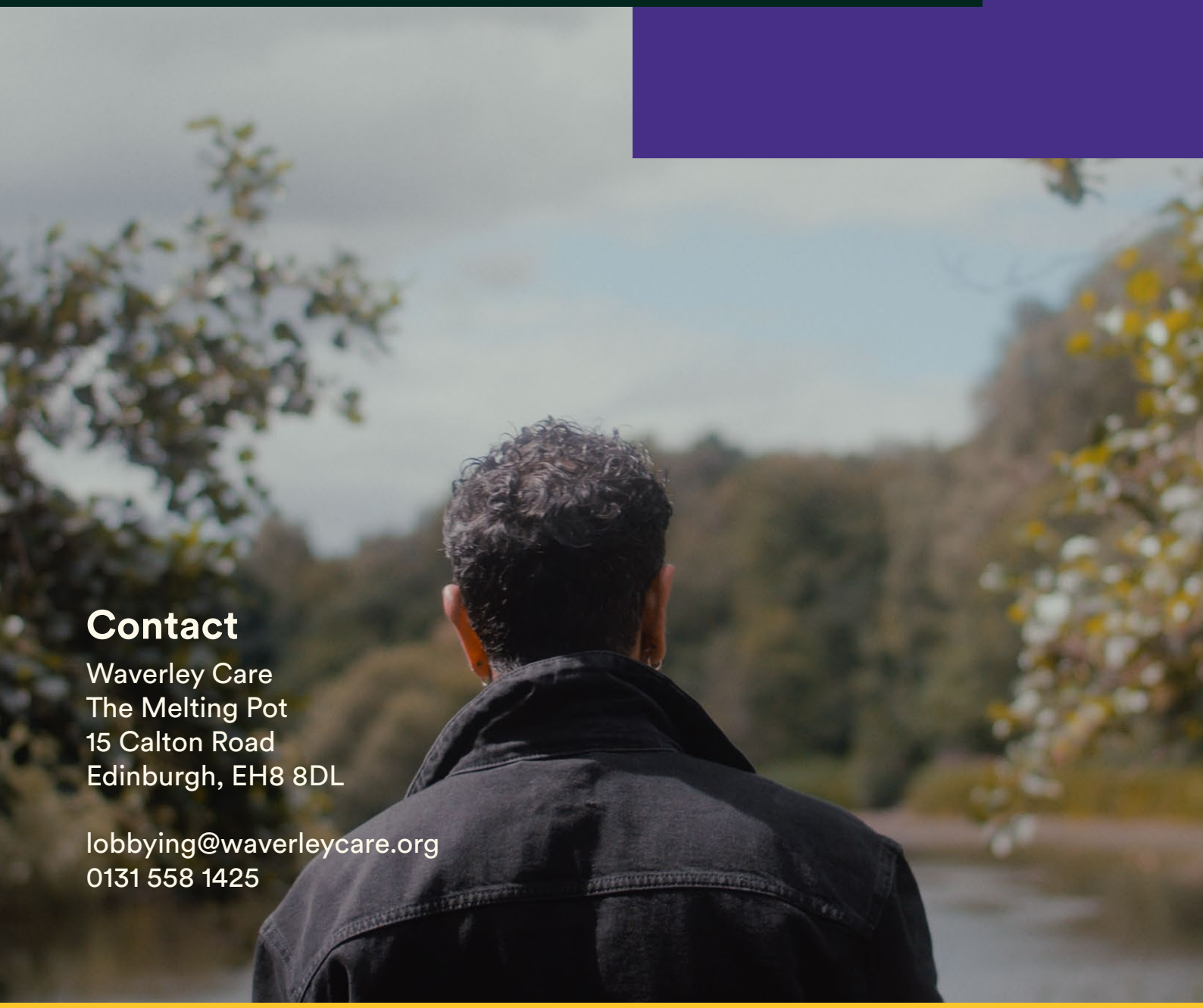

Contact

Waverley Care
The Melting Pot
15 Calton Road
Edinburgh, EH8 8DL

lobbying@waverleycare.org
0131 558 1425

www.waverleycare.org.uk

Waverley care