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HIV services at the crossroads: The role of the voluntary sector and needs of communities

May 2025

Contents

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 for people living with HIV in the UK.

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.

Introduction

The contribution of HIV Voluntary, Community, and Social Enterprises (HIV VCSEs) to improving the quality of life for people living with and affected by HIV is profound.

For many people, the access to services and peer support has been life-changing, and in some cases life-saving. The care, passion, and knowledge of staff and volunteers has been and continues to be fundamental in supporting people to live well from the point of diagnosis and through all stages of their lives when support is needed. And it is clear that the role of the HIV voluntary sector goes way beyond 'HIV' but has a lasting and meaningful impact on challenging inequalities, campaigning for rights, and reducing stigma and discrimination.

But the ability for HIV VCSEs to continue to play their vital role is under threat, more so perhaps than has ever been. Across the board, organisations are seeing demand for services rise and change, cuts to statutory services and contracts, and a decline in key areas of funding.

It is hard to see how, if these trends continue, the loss of such support will not severely impact the HIV response and quality of life of people living with HIV. As a consequence, it is very likely that the numbers of people becoming disengaged from HIV care will rise.

This cannot be allowed to happen.

To understand and identify the solutions and interventions that are needed to ensure the sustainability of the HIV voluntary sector, a comprehensive review of the state of HIV VCSEs was needed – looking at the value of these services, the challenges organisations are facing, and co-creating the recommendations that if taken on can shift the dial.

This is why HIV Outcomes UK has undertaken this project – to gain a shared understanding of the value of HIV VCSEs in the UK and to present a set of recommendations that can safeguard the support and services that so many people living with and affected by HIV rely on.

This review takes place at a critical time for the HIV response in the UK. The goal of ending new transmissions and ending AIDS-related deaths in the UK by 2030 is possible – but is unlikely to happen on the current trajectory of new diagnoses, and if the HIV voluntary sector experiences the level of cuts and drops of funding that many anticipate. After the targets are met, sustained and high-quality services will remain essential to support people living with and affected by HIV beyond 2030.

We hope that this report will positively and proactively inform commissioners, policy-makers, and funders, and believe that the recommendations set out are both practical and achievable. We look forward to working with all partners and decision-makers to bring about the changes that are needed so that people living with HIV can thrive with the essential high quality, responsive and culturally competent services that HIV VCSEs provide and everyone deserves access to.

Key headlines across the UK:

Evidence from organisations and communities

Organisations

51

organisations responded across the UK

3

Just 3 organisations felt that they have been completely able to meet demand over the last five years

66%

organisations mentioned the words funding, finance or income when asked what their number one biggest current challenge is that impacts provision of services

33%

of organisations are somewhat or very concerned that they will not be able to deliver services over the next three years

20

Organisations **(39%)** reported that they have less than 6 months worth of cash reserves

34

Organisations **(67%)** reported having to do at least one of the following over the last three years: reduce number of staff, close services, merge with other organisations(s), use cash reserves to cover operating costs

- **19** organisations (37%) reported having to do more than one
- Overall, **41%** had to reduce their staff numbers and **52%** had to dip into cash reserves to cover operating costs
- **70%** of organisations reported anticipating having to take at least one of these measures over the next financial year

People living with HIV

322

people living with HIV responded across the UK

69%

of respondents had accessed HIV orgs to receive support in the last three years

89%

reported that they know what peer support is, and 63% of respondents said they can always access this if they choose

Most accessed and accessible services for people living with HIV include information access, advice on HIV treatment, online communities and peer support

4 in 5

respondents (81%) report that they feel more satisfied with their life and/or have increased general wellbeing after utilising and accessing HIV services

43%

of respondents have been involved in co-production of a project or campaign with an HIV organisation, but another 34% have never heard of an opportunity like this

38%

of respondents regularly or sometimes volunteer for an HIV organisation, and another 26% have done in the past

1

Vision, principles and recommendations:

An HIV VCSE sector fit for the future

Vision

> **Our vision is for all people living with, affected by, or who could acquire HIV to have access to high-quality, whole person [1], and person-centred care.[2] These must be sustainable, community-led, and equitable so that no one is left behind in the HIV response across the UK.**

Key principles

> **To achieve our vision for HIV care across all UK nations, national-level recommendations must be built upon five core principles:**

1. **Recognise the unique contribution of HIV VCSEs and commit to equitable partnerships that include funding parity where appropriate.** The full and unique role that HIV VCSEs play in providing essential services and advancing the systemic and social change to challenge stigma and bring the voices of all communities to the fore must be acknowledged and recognised. The sector must be seen as an equal and respected partner throughout the HIV response - from meaningful involvement in commissioning through to fair funding settlements.
2. **Ensure equitable access to high-quality, person-centred HIV VCSE support across the whole of the UK.** In the face of an ever-evolving epidemic, the role of the VCSE in responding to health inequities is vital. This support is particularly needed at critical moments such as following a new diagnosis, during periods of disengagement from care, or when HIV disrupts daily life due to stigma, discrimination, or other challenges.
3. **Services must be funded over multiple years, including the provision of core running costs.** By providing multi-year funding settlements for services, governments will support high-quality, efficient services that achieve better health outcomes. People living with and affected by HIV need sustainable, high-impact services that can be relied on to deliver consistent support year on year. Multi-year commissioning saves money on procurement and tendering costs, as well as providing stability to the provider and sector.
4. **Invest in appropriate, high-quality data** to drive evidence-informed decisions, support retention in care, and strengthen collaboration between statutory and HIV VCSE providers.
5. **Enable HIV VCSEs to sustain and scale excellence.** HIV VCSEs have led the way in developing effective, person-centred approaches to prevention, testing and support. To meet evolving needs, governments and funders must invest in the long-term capacity and infrastructure of HIV VCSEs - sustaining what works and scaling evidence-informed development.

Recommendations

> The following country-specific recommendations outline tailored steps that should be taken in each UK nation to help ensure that the principles above are taken forward effectively at a national level.

UK Government

- **A renewed meaningful partnership with VCSEs in delivery of the HIV Action Plan for England.** This should include:
  - A strengthened role for the Community Advisory Group in the delivery and oversight of the new plan, ensuring community perspectives are central to decision-making.
  - Place-based approaches and strengthened partnerships between VCSEs, Strategic Authorities and Integrated Care Boards (ICBs).
  - Local HIV Action Plans, co-developed by stakeholders within each Integrated Care System (ICS), that detail how they will consult and engage HIV VCSEs and communities living with HIV.
  - Alignment with the principles of the forthcoming Civil Society Covenant.[3]
- **Dedicated funding should be set aside for HIV VCSE organisations.**
In line with the new National Procurement Policy Statement [4], the Department of Health and Social Care (DHSC) and the Ministry of Housing, Communities & Local Government should work with public sector commissioners to set appropriate spending targets for the HIV VCSE sector. Local authority and NHS commissioners should be able to reserve contracts specifically for VCSEs to ensure delivery of essential services and to recognise the crucial role that the sector plays in the HIV response.
- **Guarantee access to psychosocial support including peer support.**
DHSC, in partnership with ICBs and local authorities, should provide a national guarantee for psychosocial support services including HIV peer support. This should incorporate in-community, in-clinic and online methods to ensure that people living with HIV have access to peer support as part of their care pathway and can access it whenever they need.
- **Commission a national HIV Retention and Re-engagement programme.**
Building on successful pilot work by HIV clinics and voluntary organisations across the country which demonstrated how people can be re-engaged in care, DHSC should work with NHS England to commission a national programme for retention and re-engagement.
- **Invest in VCSE-led training, campaigns and services to tackle HIV stigma.**
DHSC, ICBs and local authorities should invest in a national programme of VCSE-led training for healthcare staff, public awareness campaigns, and peer-led support services to tackle HIV stigma.
- **Ensure the long-term provision of VCSE testing and prevention services.**
These are critical yet they remain vulnerable due to inconsistent funding, meaning that VCSEs are unable to plan for the long-term. Funding must be provided to ensure sustained delivery beyond 2026.
- **Expand community-based PrEP services.**
To tackle inequalities and inequities, and improve access pathways for PrEP beyond specialist sexual health services (SHSs), DHSC should work with partners to scale up successful interventions like PrEP Emerge and PrEP2U. [5] [6]

Scottish Government

- **Develop a new HIV Transmission Elimination Delivery Plan from 2026.** To be developed in collaboration with the wider HIV sector in Scotland, including VCSEs, this updated Plan should have an enhanced remit to include both the ending of new cases of HIV in Scotland by 2030 as well as ensuring people diagnosed with HIV in Scotland have a good quality of life. The Scottish Government should commit long-term, sustainable funding for the delivery of the Plan and should also set out a clear role for HIV VCSEs.
- **Establish a baseline offer for peer support provision.** The Scottish Government should undertake a scoping exercise to identify gaps in HIV peer support services in all NHS Boards across Scotland. This exercise should inform new Scottish Government national guidelines on the baseline provision of peer support that Health Boards must adhere to.
- **Establish a national framework for HIV retention and re-engagement.** There is a growing number of people in Scotland who are diagnosed with HIV but are no longer accessing vital treatment and support. The Scottish Government should prioritise action for re-engaging this group back into care through the improving of data collection and reporting, strengthening partnerships and access to support services, and ensuring there is access to VCSE-provided 'loss to follow-up' services in all NHS Boards. This framework should be underpinned by enhanced data systems, co-produced research and partnership with VCSEs and communities to ensure targeted re-engagement strategies.
- **Fund long-term campaigns to combat HIV stigma.** The Scottish Government should commit long-term funding for campaigns to tackle HIV stigma and improve education in the health and social care sector.
- **Ensure sustainable funding for VCSE HIV testing and prevention programmes.** Current funding is insecure, putting at risk the essential outreach and prevention efforts to find the 500 people estimated to be living with undiagnosed HIV in Scotland.[7] A framework for national Government funding for Scotland, such as HIV Prevention England and Fast Track Cymru, would enable strategic resource allocation, support innovative testing models, and ensure VCSEs can continue reaching underserved communities.

Welsh Government

- **Deliver on the goals of the HIV Action Plan for Wales** and ensure that the priorities and ambitions are continued through renewed action in the next Parliament and a strategic and joined-up approach across the policy and health landscape, including but not limited to the Women's Health Action Plan and the LGBTQ+ Action Plan.
- **Deliver on the commitment to fund a national peer support network.** The Welsh Government should deliver on the Welsh HIV Action Plan commitment to fund a national peer support network in Wales. This will maximise outreach and support, ensuring people living with HIV can access tailored, accessible services wherever they are. Sustainable funding for VCSEs must be a central component of this.
- **Prioritise re-engagement in HIV care.** Building on the HIV Engagement (HIVE) Project in Cardiff which piloted a re-engagement model to reach those not served by existing services [8], the Welsh Government should ensure funding for voluntary-sector based engagement support workers and local multi-agency networks in all Health Boards.
- **Fund a national HIV anti-stigma campaign.** The Welsh Government should fund the development of a national HIV anti-stigma campaign for Wales to raise awareness of HIV and tackle common misconceptions about the virus. This must be delivered in collaboration with VCSEs and informed by the experiences of people living with HIV across Wales.
- **Improve data collection.** The Welsh Government, in partnership with Public Health Wales, should improve HIV data and surveillance methods, with an improved focus on people who are diagnosed with HIV but are not currently engaged with HIV care and treatment. Central to this approach must be the delivery of an all-Wales sexual health case management system, as committed to in the HIV Action Plan.

Northern Ireland Executive

- **Develop a dedicated HIV Action Plan.** The Northern Ireland Executive should commit to developing a dedicated HIV Action Plan from 2026, aligned with the ambition of becoming a Fast Track Region and ending new HIV transmissions by 2030. This must be co-produced in partnership with VCSEs, communities, clinical and public health specialists. An HIV Action Plan for Northern Ireland should include renewed commitments on tackling stigma and, given the life-long physical and mental health impacts of HIV, must include a long term commitment to sustaining VCSE-led support services aimed at improving quality of life for people living with HIV. A standalone HIV plan will enable targeted and evidence-led action and investment, accountability, measurable impacts and a coordinated approach across partners in the system.
- **Restore core grant funding to Positive Life to protect essential HIV services.** The Northern Ireland Department of Health must urgently support the funding of core costs for Positive Life - Northern Ireland's only dedicated HIV charity - to ensure the continuation of vital HIV support, prevention and intervention services and public health work.

All health commissioners across the UK, including DHSC, health boards and local authorities

- **Ensure all contracts allow full cost recovery.** Contracts that only fund direct delivery and do not appropriately cover the true costs of a service to an organisation are manifestly inequitable and put VCSEs at risk of financial instability. Commissioners must ensure that all contracts for HIV VCSE fully cover the operational costs of delivering services, including overheads, staff time, and infrastructure, ensuring sustainability and continuity to service users to improve outcomes for their overall health and wellbeing.
- **Prioritise VCSEs in commissioning.** In line with the direction of the National Procurement Policy Statement [9], local authorities and NHS commissioners should establish clear, measurable targets for spending on VCSE-led services. Commissioners should develop VCSE-friendly procurement processes, incorporate social value into the selection criteria, reduce barriers and always allow for consortium bids (with the resourcing to allow for effective partnership working), enabling smaller VCSEs to collaborate and compete for larger contracts.
- **Meaningful involvement of VCSEs and communities in commissioning.** National Governments should mandate the active involvement of VCSEs and community representatives (including those with lived experience) in all stages of project development, from inception to delivery, concept to outcomes, thereby ensuring that voices are consistently heard and acted upon.
- **Integration of VCSEs into local and regional HIV strategies.** Commissioners should ensure HIV VCSE services are fully integrated into local and regional HIV strategies and clinical care pathways. This must include streamlining the process for VCSE staff - particularly peer support workers - to access honorary NHS contracts, which are key for safe data sharing, multidisciplinary team working, and coordinated care.

Healthcare providers

- **Strengthen partnerships and referral mechanisms between healthcare providers and HIV VCSEs.** There should be stronger partnerships and clear referral pathways between both primary and secondary care services and HIV VCSEs. Funding should be tied to the patient, ensuring it follows them when referrals are made. A key component of this approach should be expanding the use of ‘opt-out’ referrals from HIV services to community-based peer support programmes, such as those successfully implemented in Manchester.[10] Strengthening partnerships will enhance care coordination, improve patient outcomes, and ensure seamless linkage to both local and national support services.

Trusts, foundations, statutory commissioners and the pharmaceutical industry

- **Commit to full cost recovery on funding to HIV VCSEs.** Grant funding for HIV VCSEs should fully cover the operational costs of delivering services, ensuring that organisations are adequately resourced to meet their objectives. This will help ensure the long-term sustainability and effectiveness of HIV VCSEs, enabling them to deliver high-quality services without compromising their financial stability.
- **Increase core and unrestricted funding for HIV VCSEs.** This flexible funding is critical for VCSEs to be more responsive to communities and co-create strategies, to fund the necessary work that VCSEs do beyond service delivery, and drive greater impact in meeting the needs of people living with and affected by HIV.
- **Funders should join efforts to end new HIV cases and ensure everyone can live well with HIV.** To end new HIV transmissions by 2030 and support communities to live well with HIV, funders must invest in HIV VCSEs and remain focused on addressing health inequalities. Deprioritising these organisations risks undermining progress and the essential services they provide to those most in need.
- **Invest in leadership development and innovation.** Funders should support HIV VCSEs to enhance leadership capacity and future-proof skills by embedding quality improvement mechanisms and flexibility to adapt to changing needs within contracts. This includes funding opportunities to harness AI and digital tools, adapt to an evolving landscape, and invest in the next generation of VCSE leaders - particularly those with lived experience and young people.
- **Invest in research to build the evidence base for VCSE services.** Funders should support further research that evaluates the effectiveness and impact of HIV VCSE services. By supporting these studies, funders can help enhance service delivery, demonstrate the value and cost-effectiveness of VCSE interventions, and ensure that services are continuing to meet the evolving needs of people living with HIV.

HIV VCSEs

- **Continue to champion the meaningful involvement of people living with HIV.** This includes creating supportive structures and processes that enable communities living with HIV to play an active role in co-designing and co-creating services, and to respond to evolving needs and priorities of people living with HIV. VCSEs should also continue to implement robust feedback and accountability mechanisms, ensuring that the voices of the communities they serve are heard, valued, and integrated into decision-making.
- **Strengthen diversity and inclusion within leadership and governance.** This should include developing and implementing comprehensive equality, diversity, and inclusion policies, with a focus on improving the representation of people living with HIV and individuals from global majority communities within Senior Management Teams and boards.
- **Develop partnerships and collaboration outside the HIV sector.** Wherever possible, HIV VCSEs should contribute to wider partnership working and upskilling other sectors and organisations - whether with local networks and organisations, or on wider thematic issues. This will enhance the HIV response, as well as have wider benefits with challenging stigma or work on addressing social determinants of health. However, it is acknowledged that VCSEs are limited by what they can do due to funding and capacity.
- **Strengthen organisational sustainability.** To navigate a challenging funding landscape, HIV VCSE organisations will need to continually review and adapt organisational strategies, fundraising activities, ways of working, and income diversification. Many organisations are already taking steps in this direction, and sharing learning, resources, and best practices across the sector can help build collective resilience and sustainability.
- **Continued collaboration to end HIV transmissions and support people to live well.** Collaboration has been at the heart of the HIV response since the start of the epidemic, driving groundbreaking advances in treatment, prevention and support. By continuing to strengthen partnerships, sharing resources, and co-developing projects, the sector can ensure services remain effective, responsive, and accessible - especially for underserved communities.

2 Understanding the full value of HIV support, prevention and testing

Key findings from the evidence: **How services make a difference**

1. **Life-changing impact:** VCSE support services have a profound, often life-changing impact for people living with HIV, supporting them to move from simply surviving to truly thriving.
2. **Improved mental health & treatment outcomes:** By prioritising a whole-person approach to support and wellbeing, VCSE services lead to better treatment adherence, health, and mental health outcomes for people living with HIV.
3. **Filling critical gaps:** HIV VCSEs provide holistic care that complements clinical treatment for issues such as isolation, poverty, managing other disabilities, supporting people in employment and sharing their status with others, all of which are essential to supporting people to live well with HIV.

A snapshot of the wide variety of services provided by the HIV VCSE

Type of service	Organisations offering this service (%)	People living with HIV who needed this service that could access it about half the time of most/all of the time (%)
Information provision: Accessible, accurate information through websites, publications, and outreach on rights, treatment options, stigma, and self-management of HIV.	63%	59%
Advice on HIV treatment: including treatment options, medication adherence, and navigating healthcare systems, delivered online, or in person.	49%	54%
Peer support: Facilitated group sessions, one-on-one mentoring, online and community networks that enable people living with HIV to connect, build resilience, and support one another.	78%	44%
Online communities: Digital platforms and forums offer safe, accessible spaces for people living with HIV to share experiences, reduce isolation, and access information and are particularly valuable for those in rural areas or who may not feel comfortable accessing in-person services.	47%	44%
General sexual and reproductive health services: including STI testing, contraception advice, and broader sexual wellbeing support.	39%	41%
Counselling or other mental health support: HIV-literate and culturally competent mental health services, including counselling and psychological support on stigma, and the emotional impact of living with HIV.	59%	40%
Social activities and community events: Events, workshops, and social groups that foster social connections, combat isolation, and provide safe spaces where people living with HIV can feel supported and included.	78%	38%
HIV testing: Community-led HIV testing initiatives including home-testing and in settings like bars and nightclubs that reach people who are less likely to go to a sexual health service, supporting early diagnosis, linking people to care, and reducing onward transmission.	41%	36% *

***Before respondents were diagnosed with HIV**

Type of service	Organisations offering this service (%)	People living with HIV who needed this service that could access it about half the time of most/all of the time (%)
Telephone helpline: Confidential helplines offering immediate advice, information, and emotional support to people living with HIV, their families, and those seeking guidance.	27%	29%
Sex and relationship support: Support services offering advice and workshops on sex, intimacy, disclosure, and relationships.	45%	25%
Dietary/nutritional advice: Tailored dietary support and advice to help people living with HIV maintain good nutrition, which is vital for immune health and wellbeing.	33%	21%
Welfare benefits advice/support: Assistance navigating the welfare system to access benefits and financial support.	49%	21%
Discrimination advice/legal support: Legal advice and advocacy services supporting people who experience discrimination related to their HIV status.	25%	19%
Hardship funds/support:: Emergency financial assistance provided to people living with HIV experiencing poverty or financial crises.	45%	16%
Housing advice/support: Practical support to help people living with HIV secure safe, stable, and affordable housing.	47%	13%
Immigration advice/support: Specialist support to help people living with HIV navigate complex immigration systems, ensuring they understand their rights, access healthcare, and address legal barriers that impact their health and wellbeing.	35%	8%

89%

of respondents living with HIV strongly or somewhat agreed that accessing HIV support services improved their overall life satisfaction and well-being, with

78%

strongly or somewhat agreeing that they felt more empowered to manage their HIV after engaging with support services.

Life-changing impact of support services

For so many people VCSE services are the single-most important thing throughout their whole life with HIV, supporting them to go beyond 'simply surviving' with their diagnosis to thriving in their lives.

People consistently reported significant improvements in their mental wellbeing, social inclusion, and self-management of HIV having accessed VCSE support services. This complements findings from previous research on HIV support services [11] and national guidelines and service specifications for HIV treatment and support.[12] [13] In a focus group hosted at Body & Soul their members highlighted the value of holistic support which is available across their whole lives that goes beyond medication.

> **"mental, physical and emotional [support], you can get help with all the issues to do with HIV from charities like Body & Soul."**
>
> – Focus group participant

2 in 5

people living with HIV in the UK have been diagnosed with at least one mental health condition, substantially higher than the general population.

Improved mental health and wellbeing

Despite the UK having some of the best HIV treatment outcomes in the world, people living with HIV in the UK have a 63% greater risk of being diagnosed with mental illness compared to people without HIV.[14] Findings from the Pharmacokinetic and clinical Observations in PeoPle over fiftY (POPPY) study highlight unmet mental healthcare needs for people living with HIV.[15] Mental health support, peer support, and counselling were reported in our survey as the most needed services for people living with HIV.

Many people living with HIV face stigma which can lead to worse health outcomes. 1 in 3 people living with HIV report low self-esteem due to their HIV status and 1 in 10 have not shared their HIV status with anyone aside from healthcare staff.[16] A woman at one of our community focus group sessions stated, "there's a huge stigma which makes you not seek support or even know it exists".

One of the strongest themes emerging from focus groups was the role of support services in improving mental health and wellbeing. Many participants at our community focus group sessions described how their initial HIV diagnosis led to fear, isolation, and anxiety. A man living with HIV from the North East of England told us that "the voluntary sector are massively important at the early point after diagnosis", noting the "crucial" mental health support which they provided.

It is important to recognise that for many people living with HIV, the provider and setting of the service is hugely important, not just the availability of a service itself. With 1 in 9 (11.8%) people reporting being afraid to attend healthcare services in the last year due to concern that someone may learn their HIV status, and over a quarter (26.4%) ever feeling afraid [17], the trust and confidence in the VCSE as a safe place to go where you will not be judged, stigmatised, or discriminated against is a huge factor in mental health services leading to successful outcomes.

For example, previous 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.[18]

It is not surprising then that people living with HIV strongly felt that counselling services provided by HIV VCSEs are more accessible for them and lead to better outcomes.

One of the services that was consistently pointed to throughout the research as being pivotal is peer support. Peer support can take various forms but at its heart is the ability for someone living with HIV to talk to, hear from, and discuss their life and needs with someone also living with HIV. The National Standards for Peer Support in HIV highlight that peer support empowers people living with HIV by improving physical and emotional wellbeing, enhancing self-management, reducing social isolation, and delivering measurable benefits for individuals, communities, and the wider health system.[19]

Peer support is a cost-effective approach to improving mental health and responding to psychosocial needs, and people accessing peer support have reported experiencing fewer depressive symptoms.[20] It has been shown to be effective in decreasing the severity of internalised stigma and improves coping mechanisms to better manage stigma and adherence to treatment. British HIV Association (BHIVA) Standards also recognise a variety of benefits of peer support, including addressing problems of isolation and facilitating access to further psychological support.[21] [22]

During our research we heard the benefits of collaboration between peer workers and mental health professionals, such as adding peer support coordinators to HIV multidisciplinary teams. This helps with care coordination and better informs care planning which ensures more holistic, person-centred care.

However, accessibility and knowledge of peer support remains a challenge with more than 1 in 10 stating that they do not know what peer support is, and just 63% saying that they were able to access it when needed.

Daisy Puller

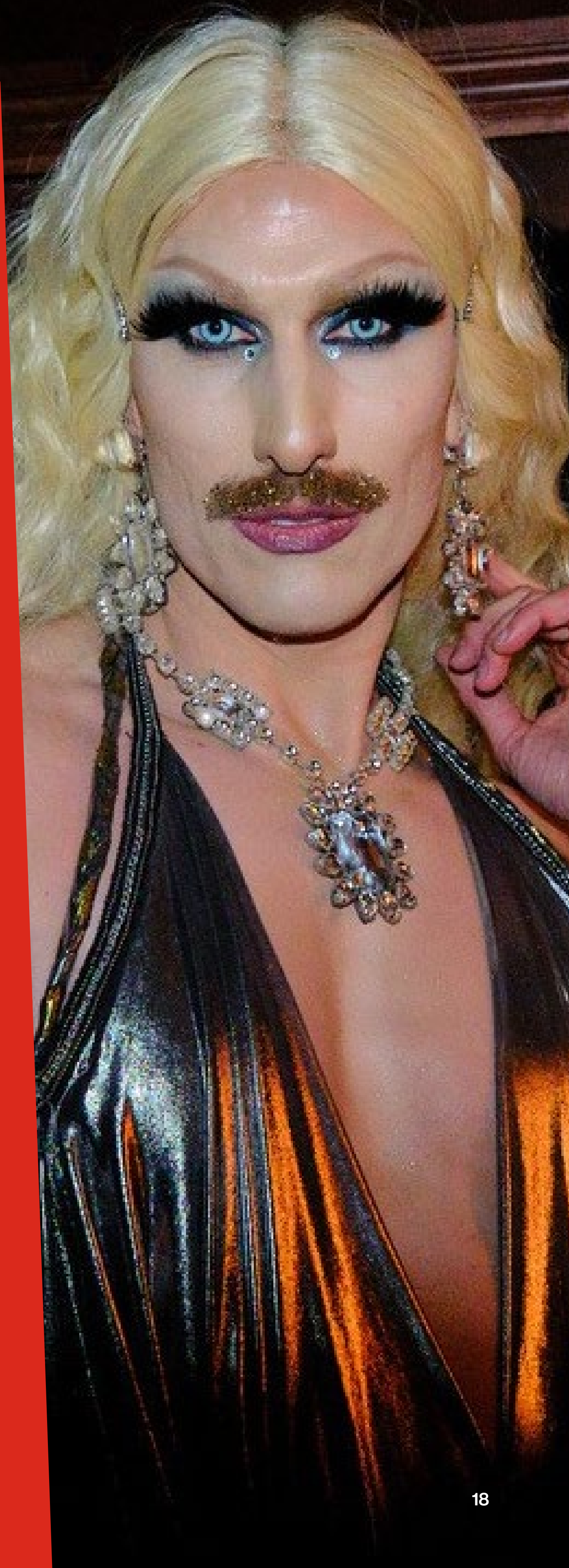
“When I got my diagnosis I was extremely lucky that it was at the Jonathan Mann clinic, which has an incredible integrated peer navigation programme run by Positively UK.

I honestly think it’s a lifesaver, for so many people, something that offers continued support to people – especially women. That’s indicative of the fact that women tend to be forgotten and left out of the HIV conversation, despite the fact that, at Positively UK, 50% of the service users are women.

Peer navigators help patients with so much, it’s very holistic, it’s much more than just HIV. Sometimes an HIV diagnosis can be the straw that breaks the camel’s back – just one more thing that people are dealing with. Having people on the ground or readily-accessible when people are at that point of diagnosis is so valuable, because that’s the tipping point – the sliding doors moment.

I think about how my life might have been if, on the day I was diagnosed, I hadn’t been matched with a peer mentor. Because doctors, nurses, the pharmacists and everybody else that you meet on that day all mean very well, and share information with you but honestly, it’s not until you hear it from the horse’s mouth and you see someone in front of you and you are able to think: well, they are functioning, they are healthy. And they can tell you: I went through this and look – I’m OK, these are the steps you need to follow and you will be OK too. Hearing it from somebody who has been in the same boat as you is life-changing.

The difference that you see between somebody at the beginning of a peer navigation process and at the end is just beautiful. It’s super-important that people know that there is a community here to support them, and to help them, and there will always be somebody who has faced a similar issue to what you are experiencing.”



Supporting retention and re-engagement to care

78% of respondents strongly or somewhat agreed that they feel more able to navigate the healthcare system after using VCSE services and the World Health Organisation (WHO) recommends community support for people living with HIV to improve retention in HIV care.[23] Multiple focus group participants highlighted this, explaining that without these services people would be at risk of disengaging from their HIV healthcare due to the stigma they experience, mental health challenges, or barriers such as poverty, caring obligations, or requirements of their work.

It is estimated that there could be over 13,000 people in the UK with diagnosed HIV that are currently out of care [24], presenting serious risks to health, increasing the likelihood of onward transmission, and impacting efforts to achieve the 2030 target.

Pilot work by HIV clinics and VCSEs across the UK has demonstrated that with intense case finding, care coordination and casework support, people can be successfully re-engaged in care. For example, George House Trust's Intensive Support Service (funded through the Greater Manchester ICB) provides person-centred social and wellbeing support to people who experience significant challenges with their HIV care. In 2023, 57% of people supported through the programme had attained an undetectable viral load, meaning the levels of HIV are so low that the virus cannot be passed on.[25] Furthermore, 95% had improved their engagement with clinical appointments and 78% reported an improvement in their emotional health and 83% an increase in their overall wellbeing.[26]

> **"It's because of you that I come to the hospital."**
>
> – Service user of Waverley Care's Lost to Follow Up service

Whilst there are local projects in some UK cities, most areas do not have dedicated funding for either clinical or VCSE-led work focused on supporting re-engagement to care. To reach the 2030 goals and stop preventable mortality and morbidity, it is essential that UK Governments ensure sufficient funding for VCSE services which focus on supporting long-term retention and re-engagement in care.

> “That was the best day I’ve had in a long time.”

Jane

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

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

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

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

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

Reengagement in care programme in London

In partnership with The Food Chain, 4M Mentor Mothers Network and Africa Advocacy Foundation, THT have established a care coordination service supporting people disengaged from care to identify barriers to care and how to overcome them. One-to-one support with a care coordinator to discuss:

- Concerns about care, treatment and the importance of adherence
- Psychological support to process diagnosis and address self-stigma and/or denial
- Access to food and nutrition support, financial, housing and immigration support and peer support

To date since the programme was established in 2024, 46 referrals have been made from 6 clinics across London. 70% of people supported by the service are now better engaging with their clinic, attending appointments and taking their medication.

"I'm feeling on top of things now, mentally I'm in a good place and physically I'm getting much better and more mobile, more than I thought I was going to be. I'm now taking my medications every day" - Service user of the care coordination service

Support for people affected by HIV including partners and families

An HIV diagnosis can have a significant impact not only on the individual but on the whole family unit. Partners, care-givers, children and the whole family need to be able to access the right support. Since the start of the epidemic, HIV VCSEs have been there to offer whole-family support for people living with HIV.

At our focus group with young people living with HIV and Chiva staff, it was shared that Chiva's Families' Weekend has given valued support for families who have a child growing up living with HIV, and for adults who themselves grew up living with HIV and now have their own family.

In our focus group with Body & Soul members, participants highlighted the value of holistic and lifelong support from VCSEs that takes a whole-family approach that means that children of people living with HIV can access support. One participant highlighted how life-changing this organisation was to her and her family when she was having serious health issues and admitted to hospital. She highlighted that Body & Soul helped her and her child 'so so much'; working to overcome serious health issues, supporting her to look after the baby and to share her HIV status with her child.

With the small risk of vertical transmission of HIV BHIVA recommends that parents formula feed to eliminate all risk of transmission.[27] HIV VCSEs including Chiva, Food Chain, George House Trust, Sussex Beacon and Waverley Care have services which provide formula milk for parents living with HIV. However provision is ad hoc and heavily reliant on the presence and capacity of voluntary sector organisations, who are often reliant on their own charitable fundraising rather than statutory support to operate these services. To ensure equity of access VCSEs are currently campaigning for a prescription model to be introduced which allows any person living with HIV to go to their nearest GP for free infant formula.[28]

HIV VCSEs also play a critical role in supporting partners of people living with HIV, in times of particular difficulty such as diagnosis and bereavement. By involving partners (with consent of the person living with HIV), services can help reduce fear and misinformation within couples. Clinical guidelines recommend supporting serodiscordant couples – for example, providing counselling and education on U=U (Undetectable = Untransmittable) so that couples can maintain intimacy without fear.

+Family Life Project

Positive Life's +Family Life project supports families in Northern Ireland where there are children under the age of twelve and where someone within the family unit is affected by HIV.

The project is holistic and tailored to meet the specific needs of each family, and seeks to build people's resilience and confidence so they can feel less isolated and re-join their local communities with a renewed sense of belonging. 94% of people who accessed the +Family Project felt the support changed their and their family's skill and understanding to overcome adversity, and 92% felt they become more confident in progressing their own issues.

Service users also credit Positive Life in helping them to share their HIV status with children, with one person commenting that "Positive Life did a seminar on talking to children... I thought it was wonderful".

In our interview with Grace (not her real name), a woman living with HIV in Northern Ireland, she credits Positive Life as 'going above and beyond' to support her and her family.

Upon being diagnosed with HIV when pregnant with her first child, Grace said that her 'whole life changed'. Being impacted by HIV stigma, Grace says she 'struggles even saying HIV' and that 'the only person in my life who knows anything about [her diagnosis] is my husband'. She credits the life-changing support that Positive Life gave her when pregnant, when raising her daughter and being supported in the decision to have another child.

Grace highlighted that Positive Life was instrumental in supporting her to make a complaint against a healthcare provider after her HIV status was inappropriately shared. Grace feels the 'only thing which could be improved is to give Positive Life the funding they rightly deserve'. She commented that if there were a reduction in the services which Positive Life provides, it would have 'a major impact on the mental health of people living with HIV'.

Interview with Peter

Peter (not his real name), a man living in the North East of England whose partner living with HIV had passed away, highlighted the need for support systems for partners and caregivers living with HIV. He reflected on the intersecting HIV and homophobic discrimination they both faced throughout their journey with HIV. Peter then supported his partner through palliative care.

Peter commented that "just because I don't have an HIV diagnosis, it doesn't mean that I haven't lived it in a such a horrific way".

After his partner's passing, Peter sought to access support from bereavement services but felt that they are "shockingly poor and geared to heterosexual people" and not informed for HIV-related loss. Whilst Peter initially faced challenges in finding a HIV VCSE which could support him, he credits George House Trust for "going outside the box and above and beyond" with the one to one support they provided him. Peter highlighted unmet needs among people affected by HIV and recommended the establishment of dedicated peer support groups for partners and caregivers of people living with HIV.

Value of HIV VCSE testing initiatives

Key messages

- **VCSE-led HIV testing reaches people who would not access traditional clinical services.** Culturally specific outreach and peer-led approaches have been particularly effective for the LGBTQ+ community, migrants, and people for whom English is a second language.
- **National and regional HIV testing initiatives coordinated by HIV VCSEs have expanded access and been fundamental to the success of the UK's HIV responses.**
- **Community-based HIV testing offers more than just screening.** Outreach connects people to wider support, addressing broader health and social needs.
- **Funding instability and unequal commissioning practices threaten the sustainability of voluntary sector HIV testing.** Many services operate on short-term, project-based funding, limiting their ability to expand and reach more people.
- **Local authorities often prioritise NHS-led services over voluntary sector organisations, despite the voluntary sector's proven ability to engage underserved communities.**

Importance of HIV VCSE testing and outreach

It is essential that the estimated 5,200 people living with undiagnosed HIV in the UK [29] can get tested and be linked into care, and more VCSE community testing is needed to reduce late diagnoses and onward transmission.

Unlike many NHS-led testing services, VCSE-led initiatives actively take testing into communities, reaching those who might not engage with healthcare services due to fear, stigma, or logistical barriers. A VCSE representative at a focus group commented that: "VCSEs proactively reach out to people, unlike clinical care. Clinical care relies on people finding and accessing clinical care; VCSEs go out of their way to test in churches, in social spaces, outside of normal working hours".

One of the key advantages of VCSE testing through outreach is that it can be culturally tailored and responsive to local needs, making it more accessible to groups who may otherwise avoid testing due to social stigma. Research highlights that VCSE outreach provides a key opportunity to address health messaging, myths and concerns within the Black African and Caribbean communities.[30]

Community-driven testing and outreach is particularly important considering the UK has seen recent increases in HIV diagnoses among women and migrants, communities who can face barriers and are less likely to seek testing in sexual health services.[31]

However, while these approaches are effective, they remain underfunded, limiting the scale of outreach and follow-up care.

Role of HIV VCSEs coordinating national testing initiatives

National HIV Testing Week is an annual campaign run by HIV Prevention England, which is coordinated by Terrence Higgins Trust and funded by DHSC. The campaign, and wider work by HIV Prevention England, aims to promote regular testing in England, particularly among groups at increased risk of contracting HIV and has successfully increased HIV testing and increased awareness, particularly through self-testing and community engagement strategies.

The 2025 HIV Testing Week saw over 21,000 tests ordered, with a successful media and social media campaign encouraging people to get a test also tackled associated stigma. This year's Testing Week saw the UK Prime Minister become the first G7 leader to ever take a public HIV test. To successfully coordinate and execute HIV Prevention England as a programme, Terrence Higgins Trust have partnered with VCSEs, other providers across England and content creators to tailor local testing strategies and campaigns, combining creativity and lived experience to craft innovative and culturally relevant campaigns.

Wales HIV Testing Week, led by Fast Track Cymru and Public Health Wales, raises awareness and increased access to HIV testing. The Welsh campaign directed people to order free and confidential postal STI test kits which can be delivered anywhere in Wales all year round. This led to a marked increase in the number of people accessing and ordering home HIV testing kits.

In addition, the partnership approach taken by Fast Track Cymru with other charities and agencies ensured that the campaign was not only widespread, but also embedded within the community which led to high levels of engagement and participation.

In Scotland, Terrence Higgins Trust receive funding from the Scottish Government to provide a national, at home HIV self-testing service. In its first 18 months of delivery, the service has issued nearly 9,000 test kits, with 60% of users reporting their result. 22 people reported a reactive result and were offered appropriate information, support and onward connection to specialist HIV services.

Challenges in sustaining HIV VCSE testing

A major concern identified by our research was the lack of long-term funding for VCSE-led HIV testing programmes. Many services operate on short-term, project-based funding, limiting their ability to plan for the future or expand their reach.

The UK Government public health grant has been cut by 26% on a real-terms per person basis since 2015/16 and the largest cut in public health spending has been on sexual health services [32], directly impacting the provision and sustainability of vitally needed HIV testing and outreach services in England.

HIV VCSEs are also often having to compete on an unfair playing field with the private sector and other providers for contracts, despite HIV VCSEs often being best placed to deliver the work and having established key partnerships within the community. In our focus groups, we heard examples of HIV VCSEs losing out on contracts for HIV testing and outreach to other providers, who it is felt do not have the same ability, trust, and partnerships for successful community engagement. We also heard that sometimes HIV VCSEs are not trusted as being professional enough despite being held to higher standards than other sectors.

There is a clear need for multi-year investment in VCSE provided HIV testing, alongside better integration into NHS pathways and local authority commissioning. Without sustained funding, there is a risk that vital community-based HIV testing services will be lost, undermining UK efforts to reduce HIV transmissions and improve early diagnosis rates.

Value of HIV VCSE work on HIV prevention

Key messages

- **HIV VCSEs play a crucial role in preventing HIV transmissions** through awareness-raising, condom distribution, harm reduction, and improving access to PEP and PrEP.
- **Community-based interventions enhance HIV testing and reach underserved populations,** reducing transmission risks.
- **Innovative VCSE-led PrEP delivery models, such as PrEP Emerge and PrEP2U, demonstrate the effectiveness of targeted approaches.**
- **Despite clear evidence that HIV prevention interventions reduce overall healthcare costs, funding remains inconsistent.**

Knowledge, awareness, and attitudes to HIV

Understanding and awareness about HIV, treatment, and prevention remains low across society. Research from the National AIDS Trust found that the majority of the public believe HIV can be transmitted in ways that are in fact extremely low risk or zero risk.[33] Young people living with HIV in our focus groups reported a lack of comprehensive, up-to-date HIV information in schools.

Without VCSE-led outreach and programmes, many more people would remain unaware of U=U, HIV prevention methods, and the fact that HIV is now a manageable condition.

Our focus group discussions highlighted several impactful VCSE initiatives that have improved HIV education and awareness, particularly among young people and underserved communities. This includes:

- Terrence Higgins Trust's Positive Voices programme.[34] This provides informative talks and education sessions to education, corporate, public sector and other audiences about their personal experiences of living with HIV. Terrence Higgins Trust's trained, paid speakers cover HIV prevention and safer sex messages and share their own experiences of living with HIV. Last year, Positive Voices speakers reached over 15,400 people.
- Fast Track Cymru's Three Letters legacy project.[35] This is an arts-based initiative providing creative HIV education resources for all school learners in Wales.
- The National AIDS Trust's HIV Schools Pack.[36] This supports educators with guidance, lesson plans, and activities to teach key facts about HIV, what it's like to live with HIV, and how to combat stigma.

Condom distribution

VCSE-led outreach and condom distribution programmes have been effective in increasing condom use, particularly among young people and individuals who may not feel comfortable accessing condoms through sexual health services or face financial barriers in buying them.

There are impactful condom distribution programmes, including one run by the Eddystone Trust which also includes training for professionals from other organisations in order to help people make more informed choices when it comes to sex.

The GMI Partnership is a partnership between three HIV VCSEs, Positive East, METRO and Spectra and funded by the London HIV Prevention Programme (Do it London). It works to ensure an all-inclusive pan-London HIV and sexual health service to all communities by conducting HIV testing and free condom distributions in bars, clubs, saunas and events across London.

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

Access and awareness of PrEP

PrEP is a game-changing drug that has been a key factor in the significant reductions of HIV transmissions across the UK - particularly in white gay and bisexual men. But it is not reaching its potential and many people face barriers accessing PrEP, particularly among Black African communities, women, and trans*[37] people. Barriers include lack of awareness, stigma, difficulties navigating the healthcare system and structural barriers of how and where PrEP is available.

The Roadmap for Meeting the PrEP Needs of Those at Significant Risk of HIV published by the DHSC recognises the vital role of HIV VCSEs in ensuring PrEP access is effective and equitable.[38] VCSEs have been instrumental in raising awareness and improving PrEP uptake among communities at higher risk of HIV.

Examples include:

- **Sophia Forum's website and video series** which addresses common questions women have about PrEP.[39] The site also provides a space for women to share experiences and access information on HIV prevention and testing.
- **BHA for Equality developed the PrEP clinic buddy initiative** to facilitate access to PrEP to Black and other minoritised ethnic communities living in Liverpool. By working directly within the community, BHA raises awareness about PrEP and supports individuals to connect with sexual health services, breaking down barriers related to digital literacy and appointment scheduling.
- **Africa Advocacy Foundation's PrEP & Prejudice campaign** which influences how Black African communities engage with PrEP. The programme is delivered in collaboration with other HIV VCSEs and commissioned Sexual & Reproductive Health services in various localities in England.[40]
- **Positive East's Women 4 Women service** produced two videos on PrEP for African women that were co-produced with members of the community.[41]

Community-based PrEP services

VCSEs have been at the forefront of developing innovative approaches for digital and community based PrEP services, addressing inequalities in access and better meeting community demand.

Developed by Brighton-based HIV VCSE, Martin Fisher Foundation, in partnership with Terrence Higgins Trust, PrEP EmERGE is an app launched in Brighton and Hove in 2021 which supports a digital pathway for PrEP. This means that once users have started on PrEP, they can visit the clinic in-person less frequently. Alongside the app, a community clinic (PrEP2U) was established in partnership between the sexual health service and Terrence Higgins Trust which runs Brighton and Hove HIV prevention and promotion services.

Waverley Care has recently established a sexual health clinic for trans* people, in partnership with LGBT Health & Wellbeing, LGBT Youth Scotland, and NHS Lothian. Interventions like this are critical given trans* people are at a higher risk of acquiring HIV, but only 226 trans* people access PrEP in Scotland.[42]

To tackle inequalities and improve access pathways for PrEP beyond specialist sexual health services (SHSs), UK Governments and commissioners should work with VCSEs to scale up successful community based PrEP services. These VCSE-led initiatives have demonstrated effectiveness in increasing uptake among underserved groups by offering streamlined, community-led PrEP delivery through digital tools and drop-in services, reducing pressure on sexual health services while reaching those who may not engage with traditional healthcare settings.

Harm reduction

UNAIDS considers people who inject drugs as among the five main key population groups that are particularly vulnerable to HIV and frequently lack adequate access to services.[43]

In Scotland between 2010 and 2019, there was a 50% increase in the annual number of first ever HIV diagnoses among people who inject drugs and this occurred despite relatively high coverage of harm reduction measures.[44]

The public health response to the increase of HIV transmissions among people who inject drugs in Glasgow has been considerable, including a range of novel approaches to increasing access to harm reduction, scaling up HIV testing and achieving higher adherence to antiretroviral therapy among those living with the virus. HIV VCSEs in Scotland have been central to this response through person-centred support offered to people who inject drugs.

For example Waverley Care's Prison Link service connects people in prisons living with, or at risk of, blood-borne viruses (BBVs) to a support network as they approach, at the time of, and following their release. The service offers education, awareness programmes and harm reduction measures for those involved in the justice system. However, dedicated funding for VCSEs to conduct needed support among prisoners and people who use drugs is very limited, leaving many prisons, cities and communities without the support they need.

3

Advocacy, tackling inequalities and driving change: The voluntary sector's role in tackling inequalities and creating change

Key messages

- **We must respond to the social determinants of health** such as poverty, housing insecurity, immigration barriers, and systemic discrimination. Biomedical interventions alone will not succeed. HIV VCSEs are crucial to bridging this gap.
- **HIV VCSEs deliver vital, cost-effective services which respond to health inequalities that statutory systems often overlook.** These services - ranging from housing support to peer-led stigma reduction - address 80% of the factors determining health outcomes, yet are often delivered on precarious, short-term funding.
- **VCSEs are trusted, community-rooted lifelines for marginalised groups.** Led by or embedded within communities affected by HIV, they provide culturally competent, person-centred care, breaking down barriers that statutory services cannot reach.
- **Sustainable funding and systemic policy change are necessary to dismantle inequalities.** Governments must commit to long-term investment in community-led organisations, alongside policy reforms targeting housing, employment, immigration, and anti-discrimination efforts, to ensure equitable health outcomes for all.

Why tackling inequalities is essential to the UK's HIV response

Health inequalities and the broader social determinants of health are inextricably linked to the UK's HIV epidemic. People living with and affected by HIV are disproportionately impacted by poverty, unstable housing, workplace discrimination, immigration insecurity, stigma, and systemic racism.

These intersecting inequalities not only increase vulnerability to acquiring HIV but also create barriers to accessing treatment and maintaining good mental and physical health. Recent data highlights increased diagnosis rates and worse treatment outcomes for women, Black communities, and other marginalised groups across the UK.[45] [46] [47]

These disparities are worsened by how there can be distrust in the healthcare system, especially among Black communities who have faced racism, dismissal, and poorer outcomes across generations and disease areas. As one VCSE representative noted, "sometimes people are reluctant to enter care due to prior negative experiences" and people can think "why bother – no one listens or believes me."

Led by or rooted in the communities they serve, HIV VCSEs have built long standing trust and relationships, often being the first point of contact for communities facing marginalisation. Their cultural competency and ability to respond flexibly to emerging needs make them best placed to understand and respond to the issues people face.

> **"VCSEs have the ability to understand the nuances of individuals' lives ... and we can have holistic views which direct support based on need."**
>
> - VCSE focus group participant

It is clear through their services, advocacy and campaigns that HIV VCSEs play a fundamental role in tackling inequalities and addressing the social determinants of health. Sustainable funding for these interventions must be ensured but it is critical that as part of the proposed shift in the UK Government's long term health plan to move from sickness to prevention, we address the root causes and make sure that increasing numbers of people living with HIV don't need to access these types of support from VCSEs.

As part of this, UK governments must implement policies and legislation that address the social determinants of health, such as housing, employment, and access to social services, while committing to cross-Government approaches to combat stigma and discrimination. By addressing the root causes of ill-health alongside supporting VCSE services, we can ensure that people living with HIV have the infrastructure to live healthy and fulfilling lives.

Addressing social determinants of health

Stable housing is intrinsically linked to treatment adherence, mental wellbeing, and good long-term health outcomes. Many HIV VCSEs either offer dedicated housing advice services or advocate alongside clients with local authorities and private landlords. Our research found that 47% of HIV VCSEs offered housing support, with this being among the most needed services for people living with HIV. Despite this, just 10% of those who needed housing support reported being able to access it all or most of the time. People living with HIV in our community focus group meetings stressed how precarious housing situations have direct consequences for their health.

Income security and employment are similarly critical for having a better health-related quality of life (HRQoL) and HIV treatment outcomes. The Positive Voices 2022 survey highlights that just under half of people living with HIV in the UK always had enough money to meet their basic needs.[48] This was lowest among people of black African ethnicity with 74.4% stating that they did not always have money to meet their basic needs.[49]

Addressing poverty among people living with HIV, 23 organisations responded to our organisational survey noting that they offer hardship funds for people living with HIV in poverty. This includes Terrence Higgins Trust's Hardship Fund which is open to anyone living with HIV that is experiencing financial difficulties. The fund aims to alleviate poverty by providing small grants where a specific HIV-related need presents itself, for example during a period of ill health, entering older age and helping to cover living experiences.

> “I didn't have a place to stay in 2017, but they saved me. I was homeless but I was still able to eat hot food thanks to Food Chain... I got leave to remain and Food Chain supported me with my application”

> “In 2021, Body & Soul helped apply for my accommodation. Council gave me accommodation but it was freezing and no heating. Body & Soul supported me with a social worker and legal advisor who are in contact with council”

During our focus groups, HIV VCSE representatives also highlighted services which support people living with HIV with employment and financial resilience. Services offered include return-to-work support for people living with HIV, benefits navigation, and advice on managing disclosure and employment rights.

At our focus group in Scotland, a healthcare provider highlighted the value of integrated VCSE support in the Brownlee Clinic in Glasgow that provided support for people struggling with their benefits and housing. However with this service no longer funded, the healthcare provider noted that often people “have nowhere else to go apart from Citizens Advice, but they don’t want to go there because of stigma”. A VCSE representative in Scotland at this focus group voiced a recurring concern: “When you don’t get the same funding, service users lose facilities. It’s not fair to have something and then lose it”.

VCSEs often feel trapped in cycles of financial precarity, limiting their ability to build long-term, sustainable employment, immigration and housing support programmes. The need for these support programmes is growing with an increasing number of people living with HIV being impacted by financial insecurity, cuts to social welfare and ‘hostile environment’ immigration and asylum policies.

While generic support services like Citizens Advice are available, some communities report long waiting times and that services were not HIV literate and responsive to their needs. Participants at our community focus group meetings emphasised how discrimination intersects with race, gender identity, and immigration status, reinforcing the need for specialist, community-based services responsive to these dynamics.

A key strength of the UK’s HIV response is having VCSE that are led by and specifically focused on supporting different communities living with and affected by HIV. These VCSEs ensure that there are community-led services which are tailored, responsive, and accessible to the diverse needs of different communities. For example:

- The Sophia Forum and 4M Mentor Mothers provide crucial support specifically for women living with HIV.
- Chiva supports the health and wellbeing of children and young adults living with HIV in the UK and Ireland.
- CliniQ offers holistic sexual health, mental health and wellbeing service for all trans* people
- The 18 VCSEs that are members of the One Voice Network provide services and advocacy which drives health equality and improves outcomes for Black communities living with and affected by HIV in the UK.

Manoel

“I sought asylum in the UK because my life was in danger back in Brazil after homophobic threats from the Military Police. I was already on PrEP back in Brazil, but struggled to get it here – at the time, the NHS didn’t provide it freely, so I was buying it online. Unfortunately, after fleeing an abusive relationship here in England, I became homeless. It became extremely difficult to access and maintain medication when I was sleeping rough. I became ill at the start of the COVID-19 lockdown, in March 2020, and was taken to hospital, at which time I was also diagnosed with HIV.

I felt like my whole world had ended, I didn’t know what to do. I had no home, no money and now I had HIV. I wondered to myself what the point of even taking the medication was.

But that’s where people stepped in to help me. The hospital (Chelsea and Westminster) and the Dean Street Clinic wouldn’t let me be discharged onto the streets. They connected me with Look Ahead, a charity who found me a hotel room through the “Everyone In” scheme. That saved my life. Positively UK gave me a peer mentor, who showed me that life with HIV wasn’t over. Metro helped with welfare support and wrote letters in support of my asylum case. Without them, I don’t think I would have had any chance of being granted asylum. And Food Chain – I can’t describe how much their meals meant to me. I was weak, I had been on the streets, and suddenly there was this food, and this care. Their meals gave me the nutrition I needed to recover. They treated me with dignity when I felt invisible.

Without these charities I wouldn’t be here today. If they hadn’t reached out, I wouldn’t have survived. They’re doing the work the government should be doing – giving people like me a chance to live, not just survive.”

Support for migrants living with HIV

Upon arriving in the UK, many people do not know how or where to access treatment or, in some cases, that they are entitled to it at all.

In our survey, organisations reported providing services for migrants living with HIV in the form of assistance to navigate healthcare and immigration systems, providing information in accessible English or native languages and supporting with visas, referrals and specialist legal advice. Some organisations offer peer support tailored to migrants to support them in their transition to living in the UK and can provide emergency assistance in the form of access to hardship funds, as many migrants face increasing financial restrictions through having no recourse to public funds or the right to work.

People seeking asylum and refugees, in particular, noted the difference HIV VCSEs made to them: a focus group participant said that as a migrant, she was “scared to go to the police after facing domestic violence”, but after speaking with Body & Soul, she was able to get the support she needed.

Many participants at our community focus group sessions described HIV VCSEs as their “second home”, providing social connection, reducing isolation and building a sense of belonging. This work goes unrecognised in many funding frameworks, yet has profound impacts on mental health, resilience and service access.

June

June is 55 year old woman of black African heritage who presented to Positive East as she was homeless. June had disconnected from care because of a bad experience with a clinician and fear that she would be reported to the Home Office as her immigration status was not settled at that point. She had stopped taking her HIV medication and developed a cytomegalovirus (CMV) infection which has severely affected her sight and also developed painful peripheral neuropathy that was having an impact on her mobility. She was, unsurprisingly, in a low mood, and feeling very isolated.

Positive East reconnected June with an HIV clinic and supported her in building a relationship with the clinic team, supported her with getting her immigration status regularised, provided advice and advocacy to support her getting housed by a local authority, and also to access benefits to which she was entitled. They helped her with a charity grant to buy essential items, and referred her to the Royal National Institute of Blind People for support with her eyesight. June has since attended the Positive East Women’s and Over 50s groups, and the Food Chain’s eating together programme and is attending their counselling service to address her low mood.

Challenging stigma and discrimination

HIV stigma remains one of the biggest challenges for people living with HIV. The Positive Voices 2022 survey found that almost half of those living with HIV in the UK felt ashamed of their HIV status, and 1 in 7 avoided accessing healthcare services because of their HIV status in the last year alone.[50] To reduce stigma, there is a pressing need to tackle societal prejudices and misinformation. For example, YouGov polling conducted in 2023 as part of Terrence Higgins Trust's 'Stigma is more harmful than HIV' campaign, found that only one-third of people in Scotland would be happy to kiss someone living with HIV, despite it being known since the 1980s that HIV can't be passed on through saliva.[51]

At our community focus groups, participants shared how VCSEs intervened in cases of overt discrimination. For example, a woman living with HIV in London shared how she tried to change dentist because she faced discrimination and was able to be referred to Guy's Hospital thanks to the Food Chain.

National AIDS Trust runs a discrimination advice and support service, funded by the National Lottery Community Fund. The service offers free and confidential legal advice to people who have experienced discrimination of their HIV status. Since starting in September 2022, the service has supported over 150 people who have faced HIV discrimination.

In addition to direct advocacy and community support, focus group participants highlighted the critical role that VCSEs play in tackling HIV stigma at a health system and societal level.

For example, National AIDS Trust and Positively UK have developed HIV Confident, a charter mark for organisations that provides training and policy review to help ensure that people living with HIV can work for them, and access any services they provide, with confidence.[52] As part of the delivery of the Scottish Government HIV Transmission Elimination Delivery Plan, Waverley Care has recently been commissioned to deliver a training programme to address educational needs across the health and Social Care sector, with the Government commenting that the 'lack of up-to-date knowledge may exacerbate stigma and lead to inappropriate behaviour in relation to concerns around infection control'.[53]

Person who faced experienced HIV discrimination in the workplace and accessed support from National AIDS Trust's discrimination support service:

> **"The support service was one of the few sources of real help. They provided me with guidance on my rights, helped me understand the discrimination I was facing, and connected me with legal advice. When I felt powerless against my employer's actions, they made me feel that I wasn't alone, and reminded me that there were protections in place, and people willing to fight for them. Their support helped me to keep pushing back, to demand fairness, even when it felt like the system was against me."**

George House Trust has been fundamental in tackling HIV stigma and discrimination in different settings at a regional level, including research and campaigning to end HIV stigma in the hair, beauty and barbering sector.[54] Through its Ageing Well programme, George House Trust also offers HIV awareness training to organisations working with older people, which includes care homes.[55] Offering such training to care homes is particularly important as several older people living with HIV we spoke to for our research shared concerns on the quality of care they think they would receive from social care providers later in life and the need for more education.

Terrence Higgins Trust's London HIV Ambassador Programme similarly brings together key organisations, community leaders and influencers to tackle societal stigma and support London's ambition of reaching zero HIV stigma in London by 2030.

VCSEs have also campaigned to stop stigma and raise awareness of HIV among the general public.

For example, 2023 saw Terrence Higgins Trust partner with the Scottish Government on the 'Stigma is more harmful than HIV' campaign, which involved a national TV advert, billboards and media coverage. Zero HIV Stigma Day, coordinated by NAZ and partners, is a global awareness campaign that aims to redefine narratives and challenge the societal stigma and discrimination surrounding HIV. It is estimated that last year's campaign reached 893,717 people on social media.

Fast Track Cymru's Stop HIV Stigma campaign was highlighted in a focus group with their campaign toolkit used by over 440 groups in Wales to challenge harmful stereotypes and misinformation.

The need for sustainable, long-term resources for the contribution from VCSEs to tackle HIV stigma was also highlighted by participants in our focus groups across the UK. For example, whilst it is welcome that the Scottish Government has made tackling HIV stigma a key political commitment and partnered with VCSEs on this, Scottish VCSE representatives recommended that the Government should fund long-term campaigns addressing stigma.

It is estimated that last year's 'Stigma is more harmful than HIV' campaign reached

893,717

people on social media

Fast Track Cymru's Stop HIV Stigma campaign was highlighted in a focus group with their campaign toolkit used by over

440 groups

Beyond services: the value of VCSEs in systemic change

Key messages

- **Catalysts of systemic change.** HIV VCSEs often shape not just service delivery but the entire HIV policy and health landscape. Their work influences national strategies, sets new care standards, and addresses inequalities at their root.
- **Initiators of impactful approaches.** HIV VCSEs have led the way in developing effective, person-centred approaches to prevention, testing and support - with successful models often adopted system-wide.
- **Drivers for leadership.** HIV VCSEs challenge systemic inequities, amplify the voices of underserved communities, and are unafraid to hold institutions legally or politically accountable when necessary.
- **Delivering strong return on investment.** Their interventions improve health outcomes, reduce long-term costs, and enhance social cohesion - bringing long-term value far beyond the initial investment.

HIV VCSEs are embedded in communities, trusted by service users, and able to respond flexibly to emerging needs. Participants across focus groups and interviews consistently highlighted that VCSEs are often the first to identify where existing services are falling short and where things should change.

This flexibility and culture of innovation enables the sector to trial new approaches ahead of statutory bodies. The introduction of opt-out blood-borne virus (BBV) testing testing was repeatedly cited as a prime example. Early pilots, secured by Elton John AIDS Foundation (EJAF)'s Social Impact Bond, demonstrated the model's effectiveness in Lambeth, Southwark and Lewisham.[56] Sector advocacy then secured government funding for the national roll-out in England's high-prevalence areas and three short pilots in Scotland. As a result of campaigning, the voluntary sector has secured a total of £67 million of government investment in HIV testing. Nearly 7,300 people have been diagnosed with HIV, Hep B and Hep C in A&Es in England through the programme to date.[57]

However, participants at our focus group stressed that the sector's capacity to sustain or scale-up these innovations themselves is increasingly constrained by short-term, project-based funding. While funding may be provided to highlight proof of concept or 'innovation', it can be challenging for HIV VCSEs to get continued funding to scale-up and sustain these innovations. And whilst there is a push by funders for 'innovation', this can sometimes come at the expense of funding core services.

Influencing and challenging the system

The HIV VCSE sector's systemic influence also stems from its campaigning, advocacy, and activist role. The sector's impact in securing systemic change was highlighted repeatedly in focus groups.

A prominent example is National AIDS Trust's legal challenge that ensured NHS England commissioned PrEP freely. When NHS England abandoned its work for the commissioning of PrEP, National AIDS Trust considered it had no option but to challenge this through judicial review. With the legal challenge from National AIDS Trust and campaigning from HIV VCSEs, the court ruled that NHS England's interpretation of the law was incorrect and commissioning of free access to PrEP through the NHS was ensured.

In Scotland, sustained advocacy from Waverley Care, Terrence Higgins Trust and National AIDS Trust secured a commitment from the Scottish Government to fund a national postal STI testing service. These organisations continue to call for the full roll-out of this service so that every one in Scotland has equal access to STI testing, no matter what health board they reside in.

Participants at our focus groups also highlighted the sector's role in challenging HIV stigma and discrimination. Campaigns led by Terrence Higgins Trust and National AIDS Trust have removed discriminatory policies - such as barring people living with HIV from serving in the armed forces, becoming commercial pilots, on blood donation and for equal HIV fertility rights.

Since the start of the epidemic, HIV VCSEs have been instrumental in strengthening the Government, local authority and the NHS' leadership and investment for the HIV response. This can be seen recently with 17 UK cities or regions becoming Fast Track Cities; the UK and all devolved nation Governments have committed to the target of ending new HIV transmissions by 2030 and developing HIV or Sexual Health Action Plans to support delivering on this.

Through their research and campaigning, HIV VCSEs have not only just helped secure these important Government commitments which bring the possibility of reaching the 2030 goals into reality, but are a trusted partner to the Government within these efforts. In our focus groups across the four nations of the UK, participants highlighted how HIV VCSEs have been instrumental in the development, operationalisation and review of HIV Action Plans at a national, regional and local level.

Strong return on investment

In our focus groups and interviews, it was highlighted that HIV VCSE services consistently deliver a strong return on investment - not only in public health outcomes, but in long-term cost savings and social value.

HIV peer support offers a strong return on investment through reducing pressure on other health and social care services and enabling people to go back to work, education and volunteering. According to Realising the Value's economic modelling, it is estimated that peer support provision can save the health system up to £2,100 per person, per year.[58]

At Guy's and St Thomas' NHS Foundation Trust, from 2018 to 2019, the annual cost for admissions for patients living with HIV not engaged in care amounted to £408,135.[59] Provision of adequately funded HIV support, outreach, and social care services can help to prevent disengagement from HIV care and hospital admissions.

Research from NCVO highlights that the voluntary sector contributed about £18bn to the UK's economy in 2022.[60] HIV VCSEs are part of this contribution and provided services, including return-to-work support, to help people living with HIV to build the confidence, skills and resilience needed to have pathways to employment and thrive in the workplace. The Positive Voices 2022 survey found that people living with HIV experience disproportionately high levels of unemployment and financial insecurity, with 1 in 10 unemployed. HIV VCSEs help mitigate these barriers by offering tailored support, peer mentoring, and awareness on employment rights under the Equality Act.

Given the pivotal role that VCSEs play in facilitating optimal treatment outcomes, sustaining engagement in care, and mitigating the risk of costly hospital admissions, it is essential governments and commissioners give greater consideration to the allocation of resources and recognise the demonstrable return on investment that these services deliver. In light of the Northern Ireland Department of Health's recent decision not to fund Positive Life, a Member of the Legislative Assembly (MLA) noted that the cost to the health service of providing medication for a single additional person diagnosed with HIV would be sufficient to core-fund three years of the charity's HIV prevention, awareness, and support initiatives.[61]

Despite delivering clear public health savings, some organisations report challenges in evidencing their full economic and social value due to limited capacity and funding for evaluation. Given this, funders should support further research that evaluates the effectiveness and impact of HIV VCSE services.

Regional inequalities in support available for people living with HIV

Key messages

- **There is a postcode lottery of services across the UK.**
  Big cities often have established HIV VCSEs and services, or offer a choice of services and providers, whereas many rural and remote areas have few or no local services.
- **Online support services can help mitigate regional inequalities, but cannot replicate the value of in-personal services**
  and risk leaving people behind due to digital exclusion.

Regional variation in VCSE support

The quality and availability of HIV support services varies dramatically both between UK nations and within countries themselves. Our research highlighted that people living with HIV in England are, overall, better able to access key HIV VCSE support services than people from other UK nations.

Focus group discussions highlighted that the variation of VCSE support happens at all levels, nationally, regionally, and within counties or cities. For example whilst Brighton has leading provision of a range of services provided by HIV VCSEs, elsewhere in Sussex there is very limited access to critical services including peer support. In high prevalence cities in low prevalence areas, there can be challenges in securing adequate NHS commissioning of needed services and political prioritisation to meet the needs of communities.

Approximately 50% of people living with HIV reside in cities, 36% in conurbations and 12% in rural areas.[62] In cities like London, Brighton and Manchester, which have higher prevalence of HIV, there is a relatively dense network of clinics and VCSEs. People in these cities often benefit from a choice of services – for example, multiple peer support groups catering to different demographics and specialised programs for women, young people, or specific ethnic communities.

Cities also often have additional initiatives such as being part of the Fast Track City initiative, which can sometimes bring additional resources as seen in London. Fast Track Cities often strengthen the local political prioritisation for the HIV response and unlock partnerships for VCSEs to be more involved in co-developing strategies and commissioning.

However, even in cities, demand can outstrip supply. Participants in the London focus group noted that although the city offers many services, resources are often stretched thin - especially in areas with high HIV prevalence and when people living with HIV face barriers such as poverty, homelessness, unstable housing, or insecure immigration status.

People living with HIV in London that we spoke to for our research also highlighted they have faced barriers for accessing needed services due to borough-based restrictions.

A man living with HIV commented that the services that Positive East offers in East London "are one of a kind, but if you live in a different London borough, you won't be able to access their support".

In contrast, many rural and remote areas in the UK have limited services provided by VCSEs. A person living with HIV in a rural county might find that the nearest HIV clinic or in-person support group is hours away, and there may be no local support group at all. A man living with HIV in York shared with us that in rural areas "services are so limited, if they even exist".

We heard from people living with HIV in rural parts of the UK who described having to travel to larger cities to attend any HIV-specific support or relying on phone helplines because no face-to-face support was nearby. One woman living with HIV in the South West of England shared that "it's many miles to travel to get support" and that people in her area often "have no money for transport". A man living with HIV from South Wales shared that when he goes to his HIV clinic, it involves a whole day of travel.

In rural areas with lower prevalence of HIV, people often turn to non-HIV specialist charities for support, for example in seeking mental health support or addiction. People living with HIV that we heard from at focus groups reported that these charities and services can be stigmatising and not offer the level and quality of support they need.

Becky

"At my first hospital appointment after my diagnosis, I was told about a woman's group at the Terrence Higgins Trust offices in Bristol, which was crucial for me in terms of the invaluable and non-judgemental support they provided. It was also nice to be amongst people who understood where I was coming from and to hear their stories and for them to answer any questions that I had, because it was early days for me. Some of these women were really strong – really amazing. It was a safe space to share stories, so I felt quite privileged to be there and part of that. The Bristol offices closed a few years ago, and I feel really sad about it. It had been there for a long time and is definitely missed, particularly because of the Women's Group.

After a low time when my mum passed away, I went on a weekend away with the Sophia Forum, called "Wise Up+ Ageing with HIV". It was just brilliant because that was my age group and it was so useful to hear people's experiences about how menopause and HIV affect women. The weekend also co-developed a guide to menopause for women living with HIV, helping to ensure accurate and accessible menopause information and support in HIV clinics.

I was fortunate to have had support close to where I lived at the time of my diagnosis, in Bristol. I now live in Devon, and if I had been diagnosed there I would definitely have found it more of a struggle, with fewer resources nearby.

When you get your diagnosis community support is key. If you're isolated, it is so much harder."

Online and digital tools

47%

of HIV VCSEs surveyed reported offering a form of online communities, with the impact of the COVID-19 pandemic leading to changes in delivery

“Covid have made us think differently about online services and potential for reaching people across the country”

- A VCSE representative in Wales

Whilst digital services can mitigate geographic barriers for people living with HIV accessing support, commissioners should ensure that people are able to access in-person support services where that is their preference and where it is needed. At one of the community focus group meetings, a woman living with HIV shared that ‘people may need in person support, and digital tools can’t address everything’. Having a person-centred approach is particularly important given digital exclusion among older people, migrants and other people with less ability to access technology.

Terrence Higgins Trust’s My Community

My Community is a private, and secure online peer support space where people living with HIV can connect with others living with HIV, access group and one-to-one support, and participate in social spaces tailored to different communities, hobbies and interests. The service also provides reliable information about HIV including diagnosis, treatments and managing multiple health conditions, and can connect people to in-person support through it sharing events and opportunities across the UK. It was launched on 24 September 2024 and at the time of publication it had 475 members, with high engagement and activity.

“I’ve been diagnosed a few weeks ago. I still don’t understand how this is going to change my life, but after reading your posts I feel that I’m not the only one who feels the same way”
- My Community user

How integration into care pathways strengthens health outcomes

Key messages

- **Strong partnerships between clinical teams and HIV VCSEs ensure people living with HIV can access holistic, person-centred care.** Strong care pathways are essential when supporting someone newly diagnosed with HIV or facing challenges with adhering to treatment.
- **Referral pathways and embedded peer support improve treatment engagement and health outcomes.** Opt-out referral models and honorary contracts streamline collaboration, ensuring no one is left behind.
- **Barriers to integration, including inconsistent signposting, short-term funding, and administrative hurdles, must be addressed to deliver person-centred care.**

Strengthening pathways and referrals between HIV VCSE and the health service

Strong partnerships between clinical teams and HIV VCSEs are essential to ensure people living with HIV can access high quality, timely, tailored support. Our research highlighted several good practice examples where strong referral pathways and collaboration improved outcomes.

However focus group participants highlighted that clinics sometimes fail to signpost people to available VCSEs services, leaving many unaware of the support on offer.

> “Some clinics feel they do a brilliant job in addressing clinical and mental aspects of living with HIV, but when I asked to speak directly with a peer, I was told no and had to try to find support myself.”
> - A woman living with HIV

Similarly, a man living with HIV in the North East of England explained that it took him years to find support, only connecting with a local HIV VCSE after a friend recommended it.

Participants also noted the importance of ensuring that when referrals are made, funding should follow the patient in this pathway.

Embedded peer support

Several good-practice examples emerged from our research where integrating VCSE and clinical care has improved patient outcomes. In London, the Fast Track Cities ‘Getting to Zero’ Collaborative aims to embed peer support in every HIV clinic. Working with 11 HIV VCSEs organisations, the partnership offers a range of support, including welfare and housing advice, psychological support, re-engagement services, courses for newly diagnosed people, and in-clinic peer support.

Focus group participants consistently emphasised the importance of peer support being embedded at the point of diagnosis. A man living with HIV in Scotland shared “If peer support was included at point of diagnosis, it would definitely feel more human.” Participants also highlighted how this model could help overcome barriers in rural areas, where people may struggle to access in-community VCSE services but could be guaranteed peer support through their clinic.

While London is making notable progress, our research found barriers in embedding this model more widely in the UK. Commissioners and VCSEs reported challenges for embedding peer support in clinics, including financial pressures, practical limitations, and low patient numbers in some clinics. Focus group participants recommended that regional and national approaches should be explored, allowing trained peer workers to support services across wider geographies or be available on request. This model could allow people to readily request peer support tailored to specific characteristics, such as gender or ethnicity.

Opt-out approach to VCSE support

Our research also highlighted innovative models where referrals to voluntary sector support are standard practice. In Manchester, George House Trust worked with NHS Manchester Foundation Trust to implement an opt-out referral system as part of the city’s opt-out BBV testing in emergency departments. This system ensures that people are automatically referred to voluntary sector support unless they choose otherwise.

The approach recognises that referrals are often based on clinician discretion, which can result in missed opportunities. Under the opt-out system, people’s details are shared with community support providers, who can follow up to discuss available support. These providers have significant experience supporting people who are newly diagnosed or who need to re-engage with care. This proactive approach ensures that everyone has the chance to access tailored support, rather than relying on ad hoc signposting.

Honorary contracts

Focus groups also highlighted the role of honorary contracts in strengthening partnerships between VCSEs and clinical services. Honorary contracts are used for individuals who are not directly employed by NHS organisations but who need to work within them. This enables VCSE representatives to attend clinical meetings, access and share needed information, and be better equipped to provide more person-centred care.

A clinician in the North West of England described how George House Trust’s intensive support and peer support workers have honorary contracts in Greater Manchester. They reported that this has improved care coordination and outcomes for people living with HIV. Beyond individual care, they noted that this partnership also contributed to wider system improvements. For example, the workers on honorary contracts supported the development of a mandatory HIV stigma training module for healthcare providers, completed over 18,000 times in just a few months.

Despite their value, in focus groups, VCSEs highlighted they continue to face barriers in securing honorary contracts. Participants raised concerns that processes can be slow, inconsistent, and bureaucratic, limiting opportunities for closer joint working. The NHS and commissioners across the UK should enable honorary contracts across hospital trusts, streamlining processes and reducing bureautic barriers for doing this at the needed scale.

4

Financial sustainability and preparing for the future: Strengthening VCSE financial sustainability and approaches to commissioning

Key messages

- **The ambition to end new HIV transmissions by 2030 is at risk.** Funding reductions from multiple sources are leaving people living with HIV without vital support, disrupting services, and increasing unmet needs. This weakens health outcomes and leads to higher long-term health system costs.
- **Sustainable, multi-year funding is urgently needed to ensure stability and prevent further closures.** HIV VCSEs face a severe funding crisis, with many organisations already having to cut services, use reserves, or shut down due to short-term, insecure funding.
- **Commissioning processes often disadvantage HIV VCSEs through short-term contracts, lack of full cost recovery, and complex procurement.** Governments must prioritise multi-year, fair contracts and actively involve VCSEs in commissioning and strategy development.

Impact of funding cuts

When funding is not secure, VCSEs cannot confidently commit to multi-year programmes, leaving people either without services, or worried about their ability to access them in the future. In our focus groups we also heard that the stop-start nature of short-term projects also hinders efforts in building long-term relationships with communities.

At a focus group, one man living with HIV recounted how following the closure of North Yorkshire AIDS Action, in-person support services are very limited in his area and that people in his community are left with significant unmet needs.

Additionally, funding insecurity often forces organisations to limit or close particular services. Currently, there are no pan-London Support Services for gay men living with HIV. Until recently, the only service of this nature was Positively UK's Gay Men's Project, described as 'more than a support group that provided a vital space for members of the community to connect, share experiences and find strength without fear of stigma'. However due to funding cuts, this important service was recently forced to close.

At our focus group in Northern Ireland, Positive Life shared how statutory funding cuts had impacted them. Despite spearheading efforts to tackle HIV-related stigma, increase testing, and provide essential support to a community of over 1300 individuals living with HIV, the charity now faces an uncertain future after the Northern Ireland Department of Health didn't provide core grant funding for their organisation.

Financial instability also hampers the innovation and effectiveness of the voluntary sector. Organisations that are unsure of their future cannot easily invest in new approaches or scale up successful pilots. They are often preoccupied with fundraising and survival, taking capacity from service improvement and innovation.

Economically, making funding multi-year and secure is cost-effective for the health system and society. When HIV support services are sufficiently funded, they help avoid costlier outcomes like preventable HIV transmissions and in-patient hospital admissions.

Financial sustainability of HIV VCSEs

In the last three years, 32% of HIV VCSEs closed services and 52% used cash reserves to cover operational costs. During the next financial year, several organisations reported that they are anticipating having to further reduce numbers of staff, utilise cash reserves and reduce services and 7 organisations specifically mentioned potentially having to close their services or organisation altogether. This comes after several key HIV VCSEs have been forced to close in recent years due to a lack of funding, including NAM aidsmap and The Crescent.

HIV VCSEs find resources for essential services from a mix of sources.

Our research found that overall, trusts and foundations were the most commonly reported source of income for VCSEs, with 70% of organisations answering this question sharing that they receive some funding from them. The proportion of funding from trusts and foundations varied considerably between organisations, from 5% through to 95% of all funding, but overall provided the most income for organisations. Almost double the amount of funding came from trusts and foundations than from local authorities, which provided the second highest amount of money to organisations overall.
This was followed by funding from NHS and health boards, then individual donors and pharmaceutical companies, with community fundraising and corporate funders providing the least amount of funding overall.

It is, however, important to note that variation in funding sources between organisations was vast, so amounts of money contributed from each source overall may not correspond to the most and least important sources of funding for individual organisations.

The challenges facing HIV VCSEs shouldn't be seen in isolation to the pressure that broader VCSEs are facing. For example, the most recent NPC State of the Sector report found that "only one quarter of contracts that charities hold have been uplifted in line with inflation" and that essential public services are at risk due to underfunded contracts held by charities.[63]
And in the last year, owing to funding reductions, health charities such as Macmillan Cancer Support lost a quarter of their staff and closed their hardship scheme.[64]

Veritee

"I'm 72 years old and I live in a remote rural part of Cornwall. Our lovely home is at the end of a dirt track, surrounded by countryside, but in the middle of nowhere. When I was diagnosed with HIV in 2007, after recognising the symptoms in my husband and then myself, I quickly discovered how little support existed for women where I live.

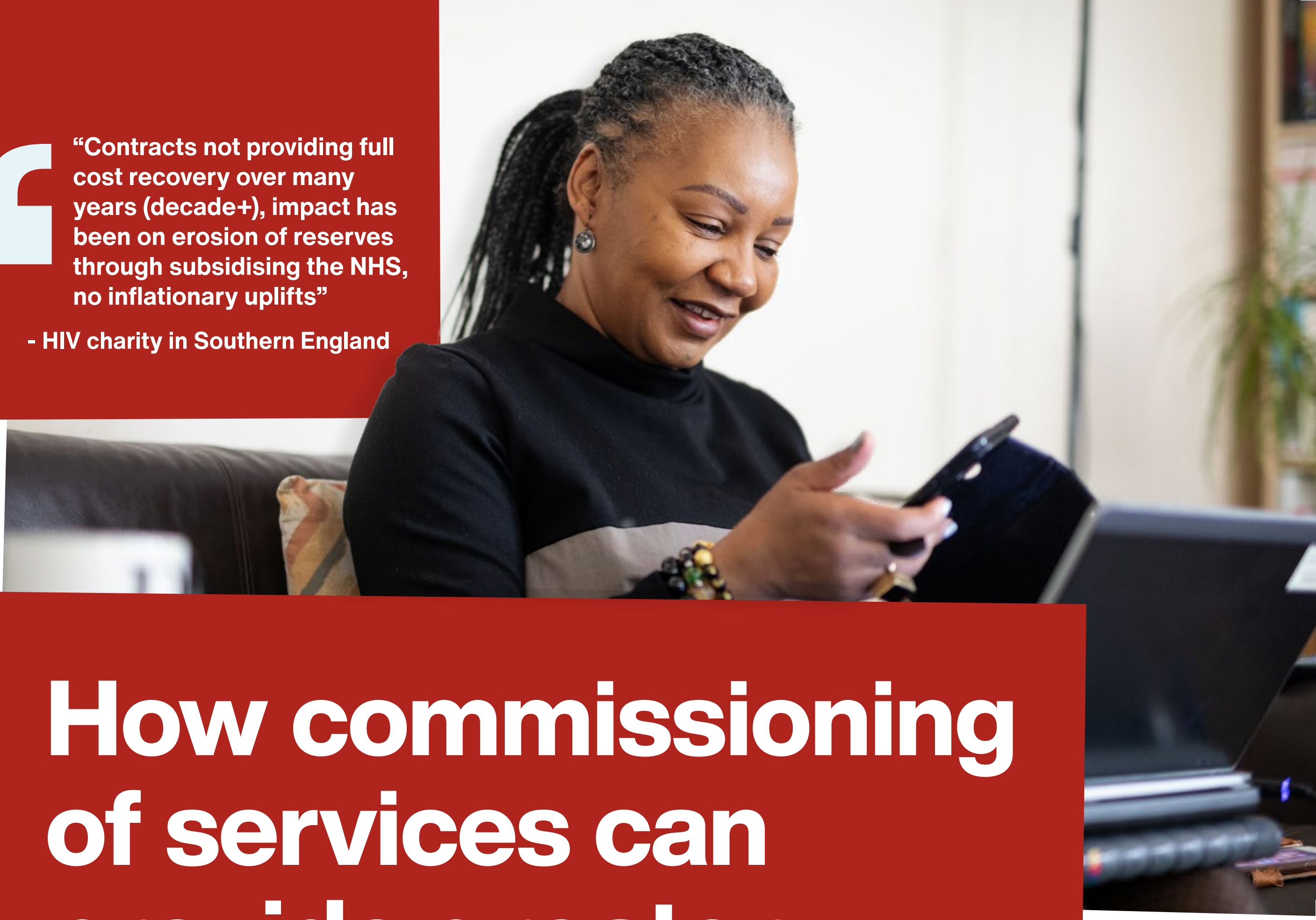
At the time, the only HIV charity in Cornwall was mainly set up for gay men. When I reached out, I was met with suspicion, and they didn't provide me with any emotional or peer support, no one to talk to. They just did not know what to do with a woman my age.

With no local options, I turned to national organisations like Positively Women (now Positively UK). They ran quarterly face-to-face meetings, but these were hours away and mostly at my own expense. I lived for those meetings – they really helped me, but the travel was exhausting. Online support didn't work for me either. I've tried Zoom meetings, but I get overwhelmed and struggle to make myself heard.

Accessing medical care, to keep up with my treatment, is difficult. My nearest clinic is over 20 miles away, and with rural roads, it takes at least 45 minutes to get there. It's a whole day gone just to get to the clinic. There used to be volunteer drivers through local charity Kernow Positive Support, but that service disappeared when the organisation folded. Home delivery for medication was also stopped years ago, so I have no choice but to make the journey.

Not being able to access local support has shaped my entire experience of living with HIV. I've had no emotional support, no peer connections nearby. Now, as my husband and I are getting older, we're facing a sad reality: we have realised we've got to move because we can't cope any more, living in this isolation. If proper support services existed here, I wouldn't have to leave this home that I've loved for the last 40 years."

> “Contracts not providing full cost recovery over many years (decade+), impact has been on erosion of reserves through subsidising the NHS, no inflationary uplifts”
>
> - HIV charity in Southern England



How commissioning of services can provide greater financial resilience

Ensuring all contracts allow full cost recovery

Survey responses repeatedly highlighted that the lack of full cost recovery in contracts places HIV VCSEs under substantial financial pressure.

Similarly, a HIV charity in Northern England noted that while demand had increased, no inflationary uplifts had been applied to their public sector grants or contracts: “We’ve used our reserves as demand was there so we couldn’t reduce our number without having a negative impact. We haven’t had inflationary uplifts on public sector grants or contracts, which mean real terms cuts. It’s like people don’t recognise how challenging it is for charities”.

Several organisations described how this shortfall directly impacts their ability to meet service demand. A London HIV VCSE flagged challenges in “funding our core costs to run the charity”, noting increased demand alongside decreased funding.

Not funding VCSE services fully and fairly forces VCSEs to make difficult decisions to subsidise the cost of delivery, including cutting other services, freezing staff recruitment, or relying heavily on reserves. For example, a charity in England which provides care for people living with HIV reported that there is ‘commissioning chaos in the NHS’. This organisation had to use reserves to cover operating costs due to funding cuts and changes in commissioning, leaving them with only 2.5 months’ reserves left.

It is critical that funding, whether statutory or from other funders, is fair and provides full cost recovery. This will help ensure the long-term sustainability and effectiveness of HIV VCSEs, enabling them to deliver high-quality services without compromising their financial stability.

Prioritise VCSEs in commissioning

The survey responses demonstrate that many HIV VCSEs face systemic disadvantages in commissioning processes. A HIV charity in Northern England raised concerns over being subcontracted, stating that “Private and not-for-profit companies [do not] realise the worth of the VCS” and challenges with being subcontracted.

The UK Government’s new National Procurement Policy Statement aims to give VCSEs in England a fair chance at public contracts, creating high quality jobs and championing innovation.[65] However we heard from several VCSEs that complex, bureaucratic procurement processes currently make it difficult for smaller community organisations to compete. HIV VCSE representatives at focus groups highlighted frustration that commissioning structures often favour larger providers, sidelining HIV VCSEs and community organisations.

To give HIV VCSEs ‘a fair chance at public contracts’ as outlined in the UK Government’s Procurement Policy, commissioners should work to address the barriers for VCSEs and prioritise HIV VCSEs in the commissioning of services. Local authority and NHS commissioners should be able to reserve contracts specifically for VCSEs to ensure delivery of essential services and to recognise the crucial role that the VCSE plays as a partner in the HIV response.

Meaningful involvement in commissioning and integration into HIV strategies - partnerships with ICBs and Strategic Authorities in England

The delegation of specialised services to ICBs have meant they’ve become key stakeholders in the commissioning of HIV services which should include those provided by VCSEs. NHS England has noted that delegating HIV services to ICBs will enable local systems to take joint approaches to delivering recommendations from the HIV Action Plan and strengthen partnerships with Local Authorities. However, to realise these benefits, the right systems, strategies and accountability measures need to be in place.

For ICBs and local service commissioning to be effective, they will need to meaningfully engage with people living with HIV, VCSEs, HIV health care professionals, and social care providers.

NHS England guidance highlights that VCSE partnership should be embedded in how an ICS operates.[66] However focus group participants highlighted significant challenges that VCSEs face in engaging with ICBs - both in consultations on service development and strategies, and in the commissioning of VCSE services. There is very limited mention of HIV in ICB strategic plans and just 15 organisations in England responding to our survey - fewer than half of those who answered the question around funding sources - reported that any proportion of their funding comes from the NHS. This is despite critical services like peer support being included in the national service specification for HIV services.[67]

Whilst further action is needed across all ICBs, good practices were noted at our focus group in the Midlands and Northern England. The Greater Manchester ICB is closely engaged in working with cross-sector partners for Greater Manchester’s HIV strategy and are funding HIV VCSE services including George House Trust’s Intensive Support Service.

Given the planned merging of NHSE and DHSC, DHSC should work with ICBs to strengthen their local leadership for the delivery of the next HIV Action Plan. A key part of this is ensuring that all ICBs meaningfully engage VCSEs across all stages of commissioning. This should go alongside commissioners formally embedding VCSEs in local HIV strategies and care pathways, streamline honorary contract processes, and ensure VCSEs are represented in governance structures.

The UK Government’s devolution plans, set out in Power and Partnership: Foundations for Growth [68], also present opportunities to advance place-based approaches and strengthen partnerships between ICSs and HIV VCSEs. Proposed reforms include the creation of Strategic Authorities and a new bespoke duty in relation to health improvement and health inequalities, alongside strengthened roles for Mayors in leading ICSs and setting health priorities.[69] These reforms present opportunities for the next HIV Action Plan for England to scale place-based approaches and embed HIV VCSEs as strategic partners in local planning, service design and delivery.

How HIV VCSE organisations can prepare for the future

Key messages

- **HIV VCSEs continue to evolve and adapt to meet emerging needs,** take advantage of U=U and PrEP, and utilise online and digital tools.
- **The sector must continue to lead the way in championing diverse leadership,** embedding co-production, and ensuring that people living with HIV are central to designing and delivering services.
- **Funders and commissioners must invest in leadership development, innovation, digital skills, and research** to ensure HIV VCSEs have the resources, capacity, and data to adapt, scale impact, and demonstrate their value in improving health outcomes and tackling inequalities.

Changing epidemic, changing HIV VCSEs

As the UK's HIV epidemic evolves so too have HIV VCSEs and the services they provide.

Biomedical advances mean that HIV is now a long-term manageable condition and the virus can't be passed on through sex when someone has an undetectable viral load. With people living longer and healthier lives with HIV, the services they need have changed, alongside the intensive and critical support for those with greater need such as people newly diagnosed or facing challenges with staying in HIV care.

While recent financial pressures have shaped the HIV VCSE landscape, it is important to recognise the sector's proactive evolution and adaptability in response to the changing epidemic.
Many organisations have actively driven new approaches such as digital services, expanding peer-led models, and developed or prioritised services which respond to the evolving needs of communities.

In future years, VCSEs will need to continue to respond to evolving community needs and challenges and the changing nature of the epidemic. Funders and partners need to enable this continued evolution by investing in leadership development and innovation which should include working with VCSEs to future-proof skills by embedding development and innovation within contracts.

Whilst this report gives an overview of the state of the VCSE sector, more evidence, data, and insight is needed to more fully understand the economic value and quality of HIV VCSE services. Several VCSEs have a strong evidence base for their services and studies have been conducted which demonstrate a high ROI on interventions like peer support. However, some VCSEs do not have the financial capacity or resources to conduct ongoing evaluation studies to the same scale as statutory or non-VCSE providers.

Championing community leadership

HIV VCSEs represent and support some of the most marginalised people in society, with the values of equality and championing of their rights as central to their missions.

Ever since the Denver Principles on the greater involvement of people living with HIV were set in 1983 [70], the community has rightly demanded to be listened to and part of decisions that are made that affect their lives. The progress in treatment, care, and prevention made since then must be recognised as being driven by community leadership and advocacy, which are often channelled through HIV VCSE organisations that are rooted in and led by those communities.

Our survey highlighted that 43% of people living with HIV had been involved in co-production of a project or campaign with an HIV organisation, and we heard that VCSEs offer a range of structured opportunities for this. 38% of respondents regularly or sometimes volunteer with an organisation, and another 26% don't currently volunteer but have done in the past.

Research highlights the social and health benefits from volunteering, with over three-quarters of volunteers reporting that volunteering improved their mental health and wellbeing.[71] People living with HIV told us that they strongly value opportunities for such volunteering and co-production, which includes peer support and mentoring, fundraising, being a Terrence Higgins Trust Positive Voices speaker and supporting campaigning through being a member of networks like the Chiva youth committee, HIV Ambassador or UK-CAB.

HIV VCSEs should continue to champion the meaningful involvement of people living with HIV in all areas of their work. This includes creating supportive structures and processes that enable communities living with HIV to play an active role in co-designing and co-creating services, and to respond to evolving needs and priorities of people living with HIV. The inherent value of involvement of communities in service design and delivery however needs to be recognised in funding settlements and in commissioning of services - it does not come free.

In our focus groups and interviews, it was also recommended by people living with HIV that VCSEs should continue to implement robust feedback and accountability mechanisms, ensuring that the voices of the communities they serve are heard, valued, and integrated into decision-making.

As continued good practice, senior leadership teams and trustee boards should have an ongoing priority to strengthen diversity, inclusion, and representation throughout their organisations, including leadership teams. This should include developing and implementing comprehensive equality, diversity, and inclusion policies, training, and have a focus on improving the representation of people living with HIV and individuals from global majority communities and those that are most marginalised and with higher unmet need.

Collaboration: how HIV VCSEs achieves more together

Collaboration has been at the heart of the HIV response since the start of the epidemic. No single organisation or body can end HIV transmissions and support all communities to live well.

Working together HIV VCSEs can be greater than the sum of their parts. Our research highlighted notable examples of different HIV VCSEs collaborating in service provision, campaigning and co-creating strategies. This includes the UK Providers' Forum which brings together over 30 HIV VCSEs, and specific coalitions representing different types of organisations such as the One Voice Network.

At our focus groups, notable examples were highlighted where VCSEs have worked with others to support skill development and knowledge sharing. This includes George House Trust working with Saving Lives (a HIV VCSE based in the West Midlands) on the training of peer support workers and scaling up their services. The Providers' Forum has discussed opportunities to improve HIV VCSE financial sustainability through further sharing of approaches to costing, funding bids, and full cost recovery.

HIV VCSEs work with a range of local and national providers - including those in addiction, criminal justice, domestic abuse, homelessness, housing, immigration, and legal advice - to ensure people living with HIV can access holistic and person-centred support wherever possible. However our research highlighted the need for VCSEs to continue to develop partnerships outside the HIV sector and upskill other sectors. This will enhance the HIV response, as well as providing wider benefits for challenging stigma and addressing the social determinants of health. However, VCSEs are limited by what they can do due to funding and capacity so it is important that funders and commissioners support the sector within these efforts.

In focus groups, we heard a number of examples of how VCSEs are seeking to establish these partnerships. For example VCSEs like the George House Trust and METRO are now offering HIV awareness training to residential care homes so they can tackle stigma and improve their care for older people living with HIV. It was also noted that establishing partnerships outside the HIV sector was a key priority for Fast Track Cymru and Fast Track Scotland.priority for Fast Track Cymru and Fast Track Scotland.

Methods

The project used several research methods including:

Survey for HIV VCSEs and people living with HIV

The surveys for HIV VCSEs and people living with HIV ran from 15 November 2024 until the 15 February 2025.

1:1 interviews

Online interviews were conducted with key stakeholders, including people living with and affected by HIV, VCSE representatives, a clinician and those involved in policy making and commissioning HIV services.

Focus groups and engagement sessions

12 focus groups were held across the UK, including both online and in-person sessions. This included dedicated meetings for stakeholders working in Southern England, the Midlands and Northern England, London, Scotland, Northern Ireland and Wales. These focus groups discussions were attended by HIV VCSE representatives, healthcare professionals, commissioners, researchers and representatives from ViiV Healthcare and Gilead Sciences.

We held two dedicated online focus group discussions with communities living with HIV and additional sessions with Food Chain service users, Body & Soul members and the Chiva youth committee and Chiva staff. Additional insights were gathered through discussions with partners including a workshop at the Fast Track Cities UK & Ireland Unconference, online consultation with the National AIDS Trust's Community Advisory Group, and an HIV Providers' Forum meeting.

Interpreting findings and limitations

Following data collection, HIV Outcomes UK conducted a thematic analysis across all sources, identifying recurring themes, challenges, and considering policy interventions to meet the needs of communities living with and affected by HIV.

While engagement from the HIV sector and communities was strong across the research, the survey for people living with HIV had a relatively low response rate and is not representative of all people living with HIV in the UK. In particular, responses were limited from individuals in the devolved nations. To address these gaps and ensure a broader range of lived experiences were captured, HIV Outcomes UK prioritised additional qualitative research through targeted focus groups and one-to-one interviews.

Survey demographics

The community survey yielded 322 responses from people living with HIV across the UK. Almost a third (31%) of these were from London, and another 51% of the total were from other parts of England. We saw 34 responses from people in Scotland, 10 from Wales and 6 from Northern Ireland. 66% of respondents were men, 28% were women and 2% were non-binary or gender fluid. 98% of respondents reported that their gender is the same as the one they were assigned at birth. 58% of people identified as gay or lesbian and 33% identified as straight, with another 6% identifying as bisexual or pansexual.

Our community cohort reflected an ageing population living with HIV, with almost three quarters (75%) of respondents being aged 45 and older. This pattern was also reflected in time living with HIV, with 70% of the group reporting that they had been living with diagnosed HIV for over 10 years. The majority of respondents were white (69%); 20% were Black African and 2% were Black Caribbean. 70% of respondents reported that they have a disability or other long term condition aside from HIV, and 32% shared that they are a migrant.

51 separate organisations responded to our survey for HIV third sector organisations. 41 of these (80%) self-reported as charities, another 5 (10%) as community interest companies and one unregistered community group.

Of the organisations that answered the relevant question, 27 (56%) shared that they focus only or predominantly on HIV support, 18 (37%) focus on equal parts HIV and other support, and 4 (8%) reported that HIV is only a small part of the support they provide to service users.

20 organisations (41%) reported that their main centre is in London, with another 21 (43%) spread across other parts of England. We had responses from 1 organisation in Wales, 4 in Scotland and 1 in Northern Ireland, and one other organisation report that they have equally important offices across England and Scotland.

Income level for organisations varied (see table).

Income level (£)	Number of organisations
1-10,000	4
10,001-50,000	7
50,001-100,000	3
100,001-200,000	4
200,001-500,000	7
500,001-700,000	0
700,001-1,000,000	4
1,000,001-1,500,000	4
1,500,001-5,000,000	6
Above 5,000,000	1

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