

**Waverley
care**



ENDING HIV TRANSMISSION BEGINS WITH YOU

Join the #GetToZero movement at waverleycare.org and help end HIV transmission in Scotland by 2030.

Evidence Brief



An HIV diagnosis can feel overwhelming.

Despite medical advances, access to testing and treatment in Scotland continues to be unequal, and action is not being taken fast enough to reach everyone who might need it.

You can change this, and make Scotland one of the first countries in the world to reach zero new HIV transmission.



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Waverley Care is Scotland's leading HIV and hepatitis C charity. We provide advice and support for people living with, or at risk of, HIV and hepatitis, as well as services such as testing, community-based work and HIV prevention. To find out more about our work, visit waverleycare.org.

For more information about the campaign, please visit waverleycare.org/GetToZero, or get in touch with Anna Cowan (anna.cowan@waverleycare.org).

Executive Summary

In 2020 the Scottish Government committed to get to zero new HIV transmission by 2030. Thanks to advances in treatment for HIV, we have the opportunity to make history. However, Scotland is now falling behind England and Wales in achieving this goal. We need action to ensure that everyone in Scotland has equitable access to testing, treatment and support, regardless of their postcode or life circumstances.

Key campaign asks:

In order for Scotland to #GetToZero new HIV transmission by 2030, we are calling on the Government to:

1. Introduce a pilot of opt-out blood borne virus (BBV) testing in emergency departments in areas with high HIV prevalence

2. Launch a Scottish national HIV testing week

3. Ensure people in Scotland have universal and barrier free access to Pre-Exposure Prophylaxis (PrEP)

The following report outlines why these asks are important, and the evidence of success that can be achieved through piloting and developing these commitments.

To help us get there, we are asking you to:

Meet with us to talk about our three campaign asks.

Share our campaign content on social media, using the hashtag #GetToZero.

Keep HIV on the agenda, by asking parliamentary questions or raising key issues in committee.

Back initiatives that will help us, such as the upcoming Sexual Health and Blood Borne Virus Strategy (SHBBVS).

Speak to constituents about HIV. Showing that you support the campaign may even encourage constituents living with HIV to speak with you about their lived experience.

Get informed about HIV, by ensuring you know the key terms provided on page 10. The language you use matters.

Introduction

We are approaching a monumental point in our HIV story: Scotland could become one of the first countries in the world to reach zero new HIV transmission by 2030.

Significant advances in treatment mean that if you are diagnosed with HIV today, you can take medication that prevents you from passing it on. Once the HIV in your blood becomes undetectable, it is untransmittable. Scotland has a track record of forward-thinking and innovative approaches to reducing HIV transmission.

Scotland has long led the way in ending the HIV epidemic. Edinburgh opened some of the first needle exchange services during the height of the epidemic¹. We were also the first country in the United Kingdom to introduce PrEP, a

drug which can significantly reduce the risk of getting HIV, on the NHS in 2017.

However, Scotland is beginning to fall behind other nations and must act now to keep up.

There is currently not enough tangible action at a national level to suggest that we will reach this goal.

The HIV transmission elimination proposal Ending HIV transmission in Scotland by 2030², presented to the Scottish Government on World AIDS Day 2022, provides 22 recommendations on how to get to zero by 2030. Our #GetToZero campaign focuses upon three key recommendations from this work, which evidence suggests are needed to ensure that Scotland can reach its target.

Why do we need to #GetToZero?

The 2030 goal is an international benchmark first introduced by the World Health Organisation. It is being used by many countries around the world as each work to end new HIV diagnoses.

While you can live a healthy and happy life with HIV, a new diagnosis can be immensely challenging and life-changing. Often, it is not the virus itself that affects a person's life, but rather HIV stigma.

Outdated and damaging ideas about HIV are still widespread among the public, with a recent study showing that **most people would feel uncomfortable having a sexual relationship with a person living with HIV**³. Stigma continues to force many people living with HIV to feel shame about their status. It can make someone more likely to

face discrimination⁵, can make someone less likely to adhere to their medication⁶, and can significantly worsen mental health⁷. HIV stigma is harmful and damaging.

“Stigma kills, HIV doesn’t”

- person living with HIV, anti-stigma campaign focus group, May 2023

Across the following sections, we outline the actions and commitments which we are calling on the Scottish Government to take to ensure Scotland becomes a country where no person faces discrimination because of their HIV status.

What's the picture of HIV in Scotland today?

HIV remains a life-altering condition. While medical advancements mean people living with HIV today can live long and healthy lives, it's often the stigma that remains around HIV that makes it such a life-altering condition.

There are a number of communities disproportionately affected by HIV in Scotland, namely:

- gay, bisexual and other men who have sex with men;
- people from African communities living in Scotland;
- people who inject drugs.

These communities face a heightened risk of contracting HIV due to issues such as:

- sharing injecting equipment with someone with undiagnosed/untreated HIV;
- difficulty accessing services such as sexual health services, harm reduction and PrEP due to factors including geographical location (services are often located inner city) and stigma;
- late diagnosis leading to poorer health outcomes;
- other inequalities such as insecure housing and discrimination.

Approx. 6415 people living with HIV in Scotland³

317 new cases recorded in 2022

Est. 500 people living with undiagnosed HIV

In 2022 for the first time since 2007, heterosexually acquired first-ever diagnoses exceeded diagnoses amongst gay and bisexual men and men who have sex with men

What needs to happen to #GetToZero?

Recommendation 1: Opt-out BBV testing in A&E departments

We want to see opt-out blood borne virus (BBV) testing introduced in Scotland's emergency departments where the diagnosed population HIV prevalence is more than 1 in 500 people (prevalence testing recommended via NICE Guidelines).

Opt-out BBV testing involves screening and testing for blood borne viruses (HIV, hepatitis B and hepatitis C) in those already taking a blood test in emergency departments. This takes place unless a person specifically opts out. This process already occurs in the NHS in Scotland in departments such as maternity services, where this testing has successfully eliminated vertical (mother to baby) transmission of HIV.

As part of their 'Towards Zero' HIV Action Plan⁸, the UK government committed to piloting opt-out BBV testing in emergency departments in areas of highest diagnosed HIV prevalence. The success of the programme in England has been significant and far-reaching: *in the first 12 months, more than 1,998 people were found to have HIV, hepatitis B and hepatitis C because of opt-out testing*⁹.

It is also cost-effective. In England, the first 100 days of opt-out testing in areas with high prevalence of HIV cost £2 million. However, the programme has estimated that a *minimum of £6-8 million will be saved in care costs*¹⁰, through reducing length of hospital stays, lessening late-stage diagnosis, and lowering the cost of treatment.

Opt-out testing is also an opportunity to tackle unmet needs and inequalities. Testing in emergency departments presents opportunities to reach those whom we know are being missed in other sectors of the health service, as well as those who are 'lost to care' (see key terms).

"A high proportion of the people we are diagnosing didn't suspect they had HIV and would never visit a sexual health clinic."

- Dr Orla McQuillan, project lead for opt-out testing in Manchester, at the British HIV Association Conference 2023¹¹

In Scotland, following NICE (2017) guidelines would mean that opt-out testing should be introduced as a pilot in emergency departments in Edinburgh and Glasgow. The expert group formed to provide recommendations to the Scottish Government on how to eliminate HIV transmission noted the importance of opt-out testing as a tool to get us to zero¹².

A nationally led pilot, with sufficient funding for evaluation and after care, is vital to finding people living with undiagnosed HIV in Scotland and ending new transmission. It would also help to ensure that the Scottish Government reaches their 2024/2025 elimination target for hepatitis C.

Recommendation 3: Universal and barrier free access to PrEP

We want equitable and barrier-free access to PrEP, regardless of postcode or life circumstances, to be guaranteed across Scotland. This requires expanding the ways and places in which PrEP can be prescribed (expanding beyond sexual health clinics to local and community settings) and increasing awareness of the medication.

Pre-exposure prophylaxis (PrEP) is a medication which reduces transmission of HIV. When taken as prescribed, PrEP is highly effective for preventing HIV (99% effective).

In July 2017, Scotland became the first country in the UK to make PrEP available by the NHS free at the point of delivery. At present, it is available through sexual health clinics for individuals meeting eligibility criteria. The most recent statistics show that over 6,500 people have been prescribed PrEP at least once¹⁶. There has been a significant reduction in new diagnoses of HIV for bisexual and gay men since the launch of PrEP.

However, PrEP is not currently reaching all populations who may benefit - notably women, intravenous drug users, heterosexual men and minority ethnic populations.

Since PrEP was made available in Scotland, the majority of people accessing it have been white (92%), and 2020 data shows that fewer than 10 heterosexual men and fewer than five heterosexual women were prescribed PrEP.

The prescribing of PrEP through sexual health clinics introduces inequalities for those living in rural areas, furthest away from clinics.

Knowledge about PrEP is also very low among members of the public. A 2021 study of knowledge and attitudes of HIV found only a quarter of people believed there is medicine available that will stop someone acquiring HIV¹⁷.

In December 2022, the Scottish Government announced that they were developing an online e-PrEP clinic to make it possible for participants to order medication without needing to attend a specialist clinic. This is vital to enabling wider access to healthcare and reducing wait times at sexual health clinics. However, progress has been slow, and community provision is needed to ensure that inequalities are not exacerbated for those with limited digital access.

Not everyone in Scotland needs to be on PrEP; but those who are more at risk of acquiring HIV need to have PrEP easily accessible, and available for them.



Your role to help us #GetToZero

We want to see our three asks committed to by the Scottish Government. To help us get there, here's how you can help.

Get behind the campaign by:

▶ Meeting with us to talk about our three campaign asks.

▶ Sharing our campaign content on social media, using the hashtag #GetToZero.

▶ Keeping HIV on the agenda, by asking parliamentary questions or raising key issues in committee.

▶ Backing initiatives that will help us, such as the upcoming Sexual Health and Blood Borne Virus Strategy (SHBBVS).

▶ Speaking to constituents about HIV. Showing that you support the campaign may even encourage constituents living with HIV to speak with you about their lived experience.

▶ Getting informed about HIV, by ensuring you know the key terms provided on page 10. The language you use matters.



Key Terms

The language we use matters. When talking about HIV, certain words and language may have a negative meaning. Using a phrase like AIDS when meaning HIV, for instance, can promote stigma and misinformation around HIV. The definitions below outline what words to use in different contexts as we use them through the report, and what they mean.

HIV - HIV (Human Immunodeficiency Virus) is a virus that attacks the body's immune system. If HIV is left untreated, it can lead to AIDS (acquired immunodeficiency syndrome). There is currently no cure, however with effective treatment HIV can be controlled and a person living with HIV can lead a long and healthy life.

Person with HIV/living with HIV – Person-first language, rather than using terms like 'sufferer' is preferred by many people as they place the focus on the individual. Other terms can negatively define people or increase stigma and discrimination.

AIDS - AIDS (acquired immune deficiency syndrome) is the name used to describe a number of potentially life-threatening infections and illnesses that happen when your immune system has been severely damaged by HIV. While AIDS cannot be transmitted from one person to another, the HIV virus can.

BBV – BBV (bloodborne virus) are transmitted through contact with infected blood. Hepatitis B, hepatitis C and HIV are BBVs. (Note that hepatitis B and HIV may also be transmitted through other body fluids).

ART - ART (anti-retroviral therapy) refers to a variety of HIV treatment which can suppress the HIV viral load in someone's blood and therefore mean they cannot pass HIV onto others. Examples of ART include abacavir, emtricitabine, and nevirapine.

PrEP - PrEP (pre-exposure prophylaxis) is a highly effective preventative medication people can take regularly to reduce chances of getting HIV

PEP – PEP (Post Exposure Prophylaxis) is a combination of HIV drugs that can stop the virus taking hold. It can be used after you believe you have been exposed to HIV.

U=U - Undetectable = Untransmittable (U=U) When a person is living with HIV and is on effective treatment, it lowers the level of HIV (the viral load) in the blood to a level low enough to be classed as 'undetectable'. When you this stage is reached, HIV cannot be passed on, so it is 'untransmittable'.

Viral load - Viral load is a measure of how much HIV is in someone's body. The higher the viral load the more infectious someone is.

Lost to care – A term used to classify people no longer being seen in a clinical care program, including HIV treatment programmes. It is often unclear if the individual has transferred their care services elsewhere, died, or if there are other reasons. This can also reflect significant health inequality, as those who are lost to care are often from minoritised populations. If a person living with HIV is lost to care, they are no longer in official HIV population data. This means that data on the population of people living with HIV can be inaccurate.

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