

Terrence Higgins Trust Cymru

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The HIV and sexual health charity for life

Russell George MS

Chair, Health and Social Care Committee

Senedd Cymru

28th March 2024

Dear Russell,

RE: Terrence Higgins Trust response to the Senedd Health and Social Care Committee request for evidence

Thank you for your letter requesting a submission of evidence to the committee. As you'll be aware, Wales has an ambitious HIV Action Plan that seeks to eliminate HIV transmission by 2030. This work has started slowly, but we hope that with focus and constructive scrutiny this plan can be successful if strong partnerships can be achieved.

For those living in Wales with HIV currently, the holistic care they receive is a postcode lottery, with greater access to support and wider non-clinical services in the larger urban areas. In fact, while developing the HIV Action Plan with the Welsh Government, we were anecdotally told by a person living with HIV that 'the best thing you can do if you are living with HIV in Wales is to move' – which is a stark reminder of the work we have to do.

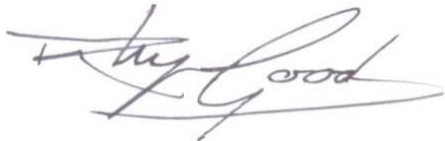
However, some positive work has begun to happen through the HIV Action Plan working group – including a commitment to a new patient management system which will allow a national picture to be created of those lost to care and living with the virus. Much of this work however focuses on prevention rather than developing the care for PLWHIV. It is our belief more focus must be given to this, particularly within the social care sector where for the first time, people living with HIV will be reaching retirement age – a miraculous change from the many people's expectations even just a decade ago.

Below, we have provided some positive examples of holistic care in England that we hope will prove useful and that could be encouraged in Wales. Overarchingly, stronger partnership working between central government, health boards, Public Health Wales and the HIV charitable sector is needed to ensure people aren't lost

to care and enables them to live the full healthy lives that are achievable with the right support.

We would welcome a further discussion with the committee around HIV in Wales and the work that is needed to achieve the end of HIV transmission by 2030. We would also be happy to provide further evidence as required.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Rhys Goode', with a stylized flourish at the end.

Rhys Goode

Head of the Terrence Higgins Trust Cymru

Pennaeth Terrence Higgins Trust Cymru

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Evidence to the Senedd Health and Social Care Committee on holistic care for chronic conditions

At Terrence Higgins Trust our mission is to end new cases of HIV across the UK by 2030 and be here until the last people living with HIV needs us.

Medical advances mean that HIV is now a manageable chronic condition. People living with HIV on effective treatment can expect to have a normal life expectancy and can't pass on the virus. This means that HIV treatment also acts as prevention.

The population of people living with HIV is ageing - nearly half of people living with HIV in the UK are now over 50 years old and many live with comorbidities. In 2022, 64% of people living with HIV reported having been diagnosed with one or more long-term condition in addition to HIV.¹

Holistic, specialist care for people living with HIV is crucial, particularly as people living with HIV often face stigma or fear facing stigma in non-specialist services.

Work to engage and re-engage people in HIV care in England provides a good model for what good holistic care for chronic conditions can look like.

Stigma and specialist services

Stigma associated with HIV and self-stigma affects people's access to care. The most recent national survey of people living with HIV found that:

- 1 in 10 had not told their GP about their HIV status
- 1 in 14 had avoided accessing healthcare services because of their HIV status
- 1 in 10 had not told anybody apart from health care staff about their HIV status

This means that it is crucial that people living with HIV can get holistic support from their HIV clinic, which for some is their only interaction with the health care system. The best services in England have peer support services and caseworkers embedded in the clinic.

People lost to HIV care

The UK government reports that England has exceeded the UN's 95:95:95 targets, with 95% people living with HIV having been diagnosed, 98% of those people on treatment and 98% of those virally suppressed (Comparative data is not publicly available in Wales currently).

However, there is a significant group not captured in this cascade. A growing number of people living with HIV in England are 'lost to care': they have been previously diagnosed with HIV but have not attended an HIV clinic for more than 15 months and so are not getting the care they need. UKHSA estimates that up to 14,773 people with diagnosed HIV in England are either not accessing care. This is a result of complex factors, including experiences of HIV stigma and poverty.

¹ UKHSA, Positive Voices 2022: Survey report, January 2024.

Terrence Higgins Trust is calling for a national programme in England to re-engage those lost to HIV care, building on effective pilot work that has taken place. We believe this to also been needed in Wales, but due to deficiencies in data available and a lack of a patient management system it is currently difficult to scope. That is why we have pushed the Welsh Government to prioritise the development of a new patient management system as part of the HIV Action Plan for Wales, developed in conjunction with us.

Re-engaging people in HIV care in South London

Pilot work funded by the Elton John AIDS Foundation and National Lottery in South London provide a framework for re-engaging patients currently not access the HIV care they need. The project found that engagement work was most effective and cost efficient when it was based directly in the HIV clinic (although work in GPs and from community organisation was also effective).

The project identified that 824 people living with HIV in Lambeth, Southwark and Lewisham were not accessing care. The three hospitals were able to successfully re-engage 153 people in the course of a year, at an average cost of £3,000 per patient. Of this group, 71% were from Black African, Black Caribbean and Black 'other' communities. More than half were women and 44% of those re-engaged lived in the most deprived 20% areas (based on the Index of Multiple Deprivation).

Dedicated engagement and re-engagement work is resource intensive, but it is cheaper when compared to the cost of care for people with untreated HIV and onward transmissions of HIV (with average care costs for HIV £200,000). In 2018/19, at Guys and St Thomas' Hospital Trust alone, the cost of in patient admissions for people living with HIV not accessing care was £408,135.²

Following the project, this work has become systematic at hospitals in South London. For example, Kings College Hospital's clinic employs a dedicated administrator whose sole role is to identify people lost to follow up and encourage them to attend the clinic. They make contact with them on a dedicated mobile phone, with WhatsApp the most effective way to reach patients. The clinic also has a patient representative and peer mentor based in clinic and embedded in this work. All attend a fortnightly vulnerable patients meeting with the clinical team.

Engaging and re-engaging people in HIV care in Bristol

Pilot work funded by Fast Track Cities Bristol, with charity Brigstowe and Southmead Hospital, has demonstrated the value of embedding community support in HIV care.

The project involved the secondment of a support worker from voluntary organisation Brigstowe to the HIV clinic, who worked intensely with patients from January to October. This formal secondment was crucial as it enables the support worker to access patient contact details.

The project calculated that a single missed appointment can cost the HIV clinic three hours in staff time. The most complex patients missed up to six appointments a year, with 19.5 hours of staff time wasted – and so this work can save significant amounts of staff time.

² Dr Kate Childs, Presentation at the British HIV Association Conference, March 2023.

The project identified that it was often secondary issues that were the obstacles to patient engagement: mental health, addiction, financial and housing issues were all preventing people from attending the clinic, as well as HIV stigma.

The community support worker developed relationships with clients, facilitated attendance at the clinics (including through appointment reminders, escorting patients to them) and address secondary issues including referral on to other services.

The length of engagement with a patient varied significantly from case to case, with some people needing active support for two weeks, but in more complex cases intense support was required for as much as sixteen weeks, with the ultimate aim of creating a long-term package of support that meant the patient could stay independently engaged.

As a result of the support, of 24 patients, nine had an improved attendance, seven had their first clinic appointment in 12 months and seven had a viral load that became undetectable (meaning they can't pass on the virus).

Care for people diagnosed through opt-out HIV testing in A&ES

Nearly one in three of the people who have been diagnosed with HIV through opt-out HIV testing in emergency departments in England were people previously diagnosed but lost to care.

As the programme expands to 47 more hospitals, 10% of the allocated £20 million funding will go to community and peer support for retention and re-engagement in care, in recognition of the important role that community and peer support plays in holistic HIV care.

Terrence Higgins Trust's re-engagement project in London

Terrence Higgins Trust has just launched a project funded by Fast Track Cities London, which will work across six HIV clinics to engage and re-engage people living with HIV in care. This work is in partnership with other charities: partnership with The Food Chain, African Advocacy Foundation and 4MNetwork.

This will include a holistic care package of tailored support for patients to improve the quality of life of people with a detectable viral load – both who have recently been out of care and those who are not entirely out of care but engage sporadically and are more likely to stop attending altogether.

The project will include a dedicated care coordinator who will work within HIV clinics and also be able to refer patients to other services and support them to access them. This will include peer support services, food and nutrition services, chemsex support, and tailored support for mothers and carers.

We would be pleased to share the results of this work with the committee when they are available.

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