

**Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Flaenoriaethau'r Chweched Senedd](#)**

**This response was submitted to the [Health and Social Care Committee](#) consultation on [Sixth Senedd Priorities](#)**

**HSC PSS 103**

**Ymateb gan: | Response from: Yr Ymddiriedolaeth AIDS Genedlaethol |  
National AIDS Trust**

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## Question 1: Initial priorities identified by the Committee

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

### Q1. Which of the issues listed above do you think should be a priority, and why?

You can comment on as many or few of the issues as you want.

In your answers, you might want to think about:

- What impact or outcomes could be achieved through any work by the Committee?
- How the Committee might address the issue?
- When any Committee work should take place?
- Whether there are any specific groups, communities or stakeholders that the Committee should involve or hear from in any work?

National AIDS Trust is the UK's HIV rights charity. We work to stop HIV from standing in the way of health, dignity and equality, and to end new HIV transmissions. Our expertise, research and advocacy secure lasting change to the lives of people living with and at risk of HIV.

We welcome the opportunity to respond to the Health and Social Care's Committee. We feel there are multiple priorities for work during the Sixth Senedd; some have already been identified by the Committee but there are other areas of focus we think warrant consideration. We have included more information on these in our response to question 2. We have also explored how HIV can form a part of the priorities identified by the Committee.

HIV (Human Immunodeficiency Virus) is a virus that, when untreated, damages the immune system. There are more than 105,000 people living with HIV in the UK and 94% of these people are diagnosed. This means that around 1 in 17 people living with HIV in the UK do not know that they have the virus. In 2019, 2,358 people received HIV care in Wales.<sup>1</sup>

This consultation response has been written with the input of two clinicians: Dr Olwen Williams OBE, Consultant Physician in Genitourinary/HIV Medicine at Glan Clwyd Hospital, Betsi Cadwaladr University Health Board in Wales, Vice President of the Royal College Physicians for Wales and Trustee of National AIDS Trust; and Dr Darren Cousins, Consultant in Sexual Health & HIV at the Royal Infirmary in Cardiff and Fellow to the Board of the British Association of Sexual Health and HIV (BASHH).

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<sup>1</sup> National AIDS Trust, HIV in the UK Statistics, [https://www.nat.org.uk/about-hiv/hiv-statistics#:~:text=In%20Wales%20%2C358%20\(2.4%25\),1.1%25\)%20in%20Northern%20Ireland](https://www.nat.org.uk/about-hiv/hiv-statistics#:~:text=In%20Wales%20%2C358%20(2.4%25),1.1%25)%20in%20Northern%20Ireland).

## **Public health and prevention**

We are pleased that the Health and Social Care Committee consider public health and prevention to be a priority for the Sixth Senedd. We agree and have set out why HIV should form a key part of the public health and prevention policy framework.

The Welsh Government was the first UK government to commit to ending new HIV transmissions by 2030. Long-term access to HIV testing and prevention is essential if we are to meet this ambitious goal.

Wales has made significant progress in recent years in increasing the accessibility and provision of HIV testing to improve HIV prevention efforts. The Test and Post (TAP) project run by Hywel Dda University Health Board, Public Health Wales and Signum Health, and funded by Welsh Government, began in November 2018 in mid Wales. It allowed people to carry out a home STI test and post their samples to a laboratory for analysis without having to attend a sexual health clinic. The pilot was expanded early into the first lockdown by Public Health Wales to cover the whole of Wales under a pilot called Frisky Wales. We understand that the name is currently under consultation. Any adult in Wales aged 16 and over can order a test. Users can test for HIV, Chlamydia, Gonorrhoea, Syphilis, Hepatitis B and Hepatitis C. Clinicians welcomed the decision to expand the pilot as it widened access to sexual health to everyone who was able to access the platform digitally. Dr Olwen Williams reported that over 80,000 people had accessed tests through TAP since it started. It has played a crucial role in recent weeks as it is not affected by the national blood bottle shortage.

**Recommendation: Commission the Frisky Wales Test/Post (TAP) project after a successful pilot to allow people in Wales to access at home STI testing.**

Access to PrEP (pre-exposure prophylaxis) is also key to ending new HIV transmissions by 2030. PrEP is medicine taken to prevent HIV acquisition.

Recent polling by National AIDS Trust shows that awareness of PrEP in Wales is low. In response to the statement 'There is medicine people can take that will stop them acquiring HIV', only 9% were certain the statement was true. 21% felt that the statement was true, but 24% felt it was false and 18% responded that they were certain it was false. Additionally, 26% said they did not know.<sup>2</sup>

Public Health Wales authorised the platform Attend Anywhere to prescribe and monitor people on PrEP during the pandemic. Since a negative HIV test is required before PrEP can be prescribed, clinicians were able to post HIV antibody/antigen tests to people's homes and prescribe up to six months' worth of PrEP. Patients could then be monitored online, removing the need to attend clinic at all. In Cardiff, no one has been added to the waiting list for PrEP since the start of lockdown in March 2020, and the waiting list has been reduced from 120 in March 2020 to 12 in November 2020. Being able to prescribe and monitor people on PrEP has helped with clinic efficiency.

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<sup>2</sup> National AIDS Trust, Fast Track Cities Initiative, 'HIV: Public Knowledge & Attitudes Survey', Dataset available on request,

[https://www.nat.org.uk/sites/default/files/publications/HIV%20Public%20Knowledge%20and%20Attitudes\\_0.pdf](https://www.nat.org.uk/sites/default/files/publications/HIV%20Public%20Knowledge%20and%20Attitudes_0.pdf)

Before the pandemic, due to the pressures on face-to-face sexual health services, Cardiff-based patients with STIs with symptoms, such as Gonorrhoea, were prioritised over people only accessing HIV testing as HIV does not have any symptoms. This meant that patients often had to have symptoms of another STI in order to access an HIV test, resulting in a missed opportunity for HIV testing. The progress made in the last 18 months must be sustained for effective HIV prevention.

**Recommendation: Continue to prescribe and monitor people on PrEP online removing the need to come into clinic. Maintain face-to-face services for people who prefer or need in-person appointments to ensure equitable access.**

HIV prevention in Wales is also supported by Fast Track Cities Initiative (FTCI), a global partnership between cities and municipalities around the world to commit to achieve shared objectives of ending new HIV transmissions, AIDS-related deaths and HIV stigma by 2030. In September 2020, Cardiff became the first city in Wales to join the Fast Track Cities Initiative. Cardiff has the highest HIV prevalence in Wales and at around 1000 cases is comparable to similar size UK cities that have active HIV prevention programmes.<sup>3</sup> Furthermore, 62% of all people diagnosed with HIV in Wales are diagnosed late, which is considerably higher than the UK average of 42%.<sup>4</sup> Late diagnosis increases the risk of mortality in the first year of diagnosis tenfold. It increases the likelihood of ill health and means that those people will have been more likely to have passed on the virus. Reducing the rate of late diagnoses will be crucial in ending the HIV epidemic in Wales by 2030.

There is a concern that other cities and towns in Wales will not be able to benefit from FTCI because they are too small to sign up but still require additional support in ending HIV transmissions. In North Wales, three patients were admitted to hospital at the beginning of the pandemic with symptoms of COVID-19 which transpired to be an AIDS defining illness demonstrating a lack of awareness around HIV and potentially missed opportunities for testing in healthcare settings. There must be a concerted effort to target prevention and testing campaigns at people not necessarily considered a key population to reduce onward transmission of HIV.

Both Labour and Plaid Cymru have committed to end HIV transmissions by 2030 (2026 for Plaid Cymru) in their 2021 manifestos. There is great political will across all political parties to end HIV transmissions in Wales and this needs to be translated into actionable public policy and funding. Broadening the scope of Fast Track Cardiff would help achieve this aim.

**Recommendation: Expand Fast Track Cardiff and Vale to Fast Track Wales so that the whole nation can benefit from the initiative to end new HIV transmissions by 2030.**

**Recommendation: HIV prevention efforts in Wales must also take into account people not necessarily considered to be a part of a key population affected associated with high HIV prevalence.**

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<sup>3</sup> Fast Track Cardiff & Vale Steering Group, The Data Report: Bringing Fast Track Cities to Cardiff & Vale and to Wales, <https://fasttrackcardiff.files.wordpress.com/2020/07/ftc-report.pdf>, 3.

<sup>4</sup> Ibid.

## **Access to mental health services**

Access to mental health services is essential for people living with HIV (PLWH). Findings from the Positive Voices survey of 4,400 people living with HIV in England and Wales in 2017 showed that PLWH are twice as likely to experience mental health issues compared to the general population. It also found that 29% of PLWH had been screened positive for a mental health condition compared to 19% of the general population, and 50% of PLWH also reported feelings of depression or anxiety on any given day (compared to 24% of the general population). The survey found that the most common mental health conditions reported by PLWH were depression (diagnosed in a third) and anxiety (diagnosed in a quarter). However, it also found significant experience of rarer mental health conditions such as sleep disorders (15%), post-traumatic stress disorder (5%), psychosis/schizophrenia (2.4%) and bipolar disorder (1.7%).<sup>5</sup>

People living with HIV also have complex and acute mental health needs. A Lancet paper published in 2017 found a suicide rate for HIV positive men in the first year after diagnosis over five times higher than that for men in the general population.<sup>6</sup>

Many people living with HIV in North Wales experiencing psychological problems related to their HIV are referred to Relate by their HIV clinic. The decision to refer by the clinician will be informed by conversations in appointments yet after the referral clinicians do not have access to any information from Relate which has an impact on the holistic care an HIV clinic can provide. It also limits the ability on clinics to measure the outcomes of psychological referrals and adjust their services appropriately. Given the given the high prevalence of mental health issues among people living with HIV, it is essential to facilitate greater collaboration between all bodies which would improve care coordination with regards to HIV and mental health.

In Cardiff, it was noted that whilst the provision of mental health services used to be through a third sector provider, the mental health services provided by the health board have been transformed. All GPs have mental health liaisons, as well as a mental health liaison at the HIV clinic. This increases scope for the provision of comprehensive pathways for mental health support for people living with HIV.

**Recommendation: Welsh Health Boards should ensure collaboration between all bodies commissioning mental health services within their footprint, so that comprehensive pathways for the full range of mental health support are available for people living with HIV, whatever their particular needs.**

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<sup>5</sup> Positive Voices Survey, 'Changing Perceptions: Talking about HIV and our needs', November 2018. Available at: [https://www.nat.org.uk/sites/default/files/publications/web\\_PV\\_Changing%20Perceptions-needs-report.pdf](https://www.nat.org.uk/sites/default/files/publications/web_PV_Changing%20Perceptions-needs-report.pdf)

<sup>6</sup> Croxford S et al 'Mortality and causes of death in people diagnosed with HIV in the era of highly active antiretroviral therapy compared with the general population: an analysis of a national observational cohort' Lancet Public Health Vol 2 Jan 2017.

**Recommendation: All HIV clinics should include a psychologist/mental health professional on their multi-disciplinary team (MDT).**

There is limited HIV support service provision in Wales. HIV support services play a vital role in addressing the mental health needs of people living with HIV and to fill the gaps left by generic services. This will be particularly important given longer waiting lists for psychological services after the COVID-19 pandemic.

**Recommendation: Voluntary sector HIV support services should be commissioned in line with need, both to meet needs which generic services are unable to provide appropriately (including peer support), and also to complement, train and work alongside generic provision.**

**Access to services for long-term chronic conditions**

Access to HIV services has been improved for many people in Wales during the pandemic. The expansion of Frisky Wales/TAP and Access Anywhere software allowing people to test for HIV and have virtual clinic appointments has increased ease of access and shortened waiting lists.

However, it's important to consider the limits of telemedicine and providing HIV services virtually and/or digitally. The reliance on telemedicine was appropriate during an unprecedented crisis and facilitated access to sexual health services for many people in Wales when face-to-face appointments were no longer a safe option. We're now at a crossroads where we must consider what we want access to services to look like in the future.

In a report by Public Health Wales published in July 2021 'Emerging Drivers of Vulnerability to Health Inequity in the Context of COVID-19,' the impacts of digital exclusion were acknowledged.<sup>7</sup> Based on responses and perspectives from the voluntary sector, the report found that digital exclusion operates as a 'compounding factor of vulnerability.' Specifically focusing on health, it was reported that 'the sudden reliance on digital connectivity for health care appointments and participation in social activities' excluded some service users. This was seen in families on low incomes with insufficient access to Wi-Fi or IT equipment, and in older people, people with disabilities and people with learning needs.<sup>8</sup>

Evaluation of the NHS Wales Video Consultation Service by tec Cymru published in June 2021 provides further insight. In their Phase 2a Evaluation, the findings suggest that across a range of health conditions, specialties and appointment times, video consultation has been working well. They found that 20.7% of patients who used video consultation were over the age of 65 years, comparable to the proportion of over 65-year-olds in the national population. Socioeconomic measures such as ethnicity and income showed that only 3.8% of patients were within Black, Asian, Mixed/Multiple

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<sup>7</sup> Willatt A., Jones D.P., Kyle, R.G., Davies, A.R. (2021). Emerging Drivers of Vulnerability to Health Inequity in the Context of COVID-19: Perspectives and response from the Voluntary and Community Sector in Wales. Cardiff: Public Health Wales.

<sup>8</sup> Ibid., 22-23.

group, or other Ethnic groups). This was noted to be lower than the national population for BAME groups of 5.2%. These data only tell us who is using video consultation services, and don't necessarily help us identify where there is unmet need. Although they show that some people over the age of 65 are using it, given the more complex health needs of the over 65 population it would be reasonable to expect that a greater proportion of patients using video consultation were in that category.<sup>9</sup>

The data also show that 29% of video consultation users have a disability, and suggests that where some disabilities hinder accessing care, video consultation presents a useful alternative.<sup>10</sup> This is important to consider for people in Wales with multimorbidity and complex health needs for whom travelling to many appointments can be taxing. It certainly demonstrates that people in Wales of various age, ethnicity, household income and disability *can* access and are accessing health services digitally. However, there is little data available on those who cannot and are not accessing health services in this way.

In Cardiff, it was felt by clinicians that patients who did not speak English or Welsh as their first language struggled to communicate only over the phone, however this narrative needs to be more nuanced and consider the challenges people face attending appointments in person, and the fact that many within the migrant community are used to interacting with family and friends outside the UK over video call. A focus on developing interpretation services could support this population access services digitally.

In North Wales, clinicians reported older patients finding it harder to use the software required for online-only consultations. Throughout both lockdowns, sexual health clinics were able to run a very limited service for patients who were unable to access all services online. For example, some patients can have their consultation over the phone before coming into the clinic to have bloods or vaccinations. This reduced the amount of time patients spent in the clinic. Since people have started returning to work, it has been noted that there is a preference among some patients to come into the clinic for appointments rather than have them over the phone. It's also important to note that some people living with HIV or at risk of HIV do not want to be seen entering a sexual health clinic and for that reason prefer to access services digitally where possible. It's unfortunate that HIV stigma is still so prevalent that this continues to be a factor.

A model where digital services are offered where appropriate but where appointments can still take place in-person would be ideal. The wishes of the patient should be respected, and the preferences of the clinicians taken into consideration.

**Recommendation: Face to face HIV services should continue where required to ensure retention in care with patients able to decide what is best for them.**

It is also crucial to consider access to services for *multiple* long-term health conditions. Data from the Positive Voices survey in 2017 showed that 72% of people diagnosed with HIV have at least one other long-term health condition. The most prevalent is high cholesterol, hypertension and diabetes (all precursors of cardiovascular disease, for

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<sup>9</sup> Tec Cymru, 'NHS Wales Video Consultation Service: Phase 2a Evaluation Discussion and Conclusion of Quantitative Data, June 2021.

<sup>10</sup> Ibid.

which people with HIV have double the risk<sup>11</sup>), arthritis, peripheral neuropathy, and kidney disease.

HIV clinics are likely to be first recognised by HIV services, however legislative reform in 2012 subsequent developments have reconfigured commissioning models and HIV clinics are not funded to provide or coordinate non-HIV care. This results in fragmentation of care for people living with HIV with comorbidities.

There needs to be a focus on designing services that encompass whole patient pathways and allow clinicians to view comprehensive clinical records to allow them to deliver whole patient care. There is desire among clinicians to pull together all clinical records into one place, the Welsh Clinical Portal, which all seven Health Boards would have access to. Where patients have consented, HIV clinicians would be able to see GP records and vice versa. The aim in sexual health is to have patient sexual health records which will follow people around as they move around Wales. Without this, there is duplication of work with the same tests being done in different places, and safeguarding issues with people lost to follow up or lost to mental health services.

**Recommendation: NHS commissioners should allow for and encourage direct referrals between secondary care providers, with mechanisms to inform GPs built in.**

**Recommendations: Health Boards should continue to develop the Welsh Clinical Portal to facilitate greater collaboration between specialities where consent is given.**

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<sup>11</sup> Shah ASV, Stelzle D, Lee KK, Alam S, Clifford S, Longnecker TC et al. 'Global Burden of Atherosclerotic Cardiovascular Disease in People Living with the Human Immunodeficiency Virus: A Systematic Review and Meta-Analysis'. *Circulation*. 2018 Jul 2

## Question 2: Key priorities for the Sixth Senedd

**Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:**

- a) health services;**
- b) social care and carers;**
- c) COVID recovery?**

You can comment on as many or few of the issues as you want.

In your answers, you might want to think about:

- What impact or outcomes could be achieved through any work by the Committee?
- How the Committee might address the issue?
- When any Committee work should take place?
- Whether there are any specific groups, communities or stakeholders that the Committee should involve or hear from in any work?

### **a) Health services**

A key priority for the Committee to consider during the Sixth Senedd is addressing health inequalities affecting people living with or at risk of HIV and providing a more equitable health service.

Although this consultation is focused on healthcare, delivering effective and equitable HIV prevention, testing, treatment and care relies on addressing social determinants of health which extend beyond healthcare alone to include housing and welfare, unemployment and job insecurity and intersecting inequalities faced by many people living with HIV such as homophobia, transphobia and racism.

This consultation is running alongside the LGBTQ+ strategy consultation which itself suggests it should be read alongside the Strategic Equality Plan, Race Equality Action Plan, Framework for Action on Disability and Gender Equality Plan. The draft LGBTQ+ Action Plan for Wales includes an action to publish and act on a new HIV and Sexual Health Action Plan which includes a focus on prevention, education and equitable service provision.<sup>12</sup> Priorities for the Sixth Senedd must take these action plans into consideration when deciding on priorities and consider how they work together to achieve their aims. There is a need for a cross-government strategy in Wales to address healthcare inequalities taking into account equality considerations and their impact on people living with HIV and other long-term conditions. This work must involve people with lived experience and be supported by VCSE organisations.

**Recommendation: Call for and implement a cross-government strategy to address health inequalities in Wales**

<sup>12</sup> Welsh Government, 'LGBTQ+ Action Plan for Wales', July 2021, <https://gov.wales/sites/default/files/consultations/2021-07/lgbtq%2B-action-plan.pdf>