



Inquiry into COVID-19 and its impact on matters relating to the Equality, Local Government and Communities Committee's remit

1. We're 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.
2. We welcome the opportunity to provide evidence to this inquiry by the Welsh Parliament into the impact of COVID-19 on the remit of the Equality, Local Government and Communities Committee.
3. 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.¹ HIV is defined as a disability from the point of diagnosis under the Equality Act 2010, which means it is a legal requirement to treat people living with HIV fairly and with respect. For this reason people living with HIV, and HIV services in Wales, fall into the remit of this Committee.
4. This consultation response has been written with the input of two HIV clinicians based in Wales: Dr Olwen Williams OBE, Consultant Physician in Genitourinary/HIV Medicine at Glan Clwyd Hospital, Betsi Cadwaladr University Health Board in Wales and Vice President of the Royal College Physicians for Wales, and Dr Darren Cousins, Consultant in Sexual Health & HIV at the Royal Infirmary in Cardiff.
5. Overall, Wales has seized opportunity during the COVID-19 response to improve the accessibility and provision of HIV testing, treatment and care, and the advances and improvements made must continue beyond the pandemic. The changes were long awaited and much needed. In March, when the national lockdown came into force, Sexual Health services closed down overnight and clinics had to transition from being able to operate as a walk in service to telephone consultations.
6. 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.²
7. The pilot was expanded early into the first lockdown by Public Health Wales to cover the whole of Wales. 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

¹ 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).

² Hywel Dda University Health Board, *Sexual health pilot scheme extended*, <https://hduhb.nhs.wales/news/press-releases/sexual-health-pilot-scheme-extended/>.

services to everyone who was able to access to platform digitally. Telemedicine is delivered by a blend of telephone calls and video conference (Attend Anywhere). Before the pandemic, there had been no national scheme that facilitated telemedicine and at home testing, although many clinicians and people in the community had been calling for it for years. There had been enormous pressure on face to face services which was exacerbated by some staff being redeployed due to COVID-19.

8. Before the pandemic, due to the pressures on face to face sexual health services, Cardiff-based patients with STIs with symptoms, such a Gonorrhoea, were prioritised over people only accessing HIV testing as HIV does not have any symptoms. This meant that you often had to have symptoms of another STI in order to access an HIV test, resulting in a missed opportunity for HIV testing.
9. Increased access to HIV testing is essential if we are to end new HIV transmissions by 2030 and despite the improved access to testing during the pandemic, there are still people being left behind. In North Wales, three patients were admitted to hospital 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 concerted effort to target prevention and testing campaigns at people not necessarily considered a key population to reduce onward transmission of HIV.
10. There are of course drawbacks to telemedicine. In Cardiff, it was noted that patients who did not speak English as their first language struggled to communicate only over the phone, whilst in North Wales, older patients found it harder to use the software required for online-only consultations. Fortunately, 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.
11. Public Health Wales also authorised the platform to prescribe and monitor people on PrEP. 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, and the waiting list has been reduced from 120 in March to 12 in November. Being able to prescribe and monitor people on PrEP has helped with clinic efficiency.
12. Restrictions due to COVID-19 have presented new opportunities for HIV testing and treatment. In a study published in September 2020, it was shown that PrEP users in Wales were having less condomless sex after the introduction of restrictions at the start of the pandemic, therefore reducing the need to take PrEP.³ However, patients in North Wales, and possibly patients in other places, continued to be monitored and clinicians had the opportunity to do more wellbeing work with their patients to help treat depression and isolation. Loneliness and social isolation is a recognised public

³ Gillespie D, Knapper C, Hughes D, et al, Early impact of COVID-19 social distancing measures on reported sexual behaviour of HIV pre-exposure prophylaxis users in Wales, *Sexually Transmitted Infections*. Published Online First: 23 September 2020

health issue that can have serious consequences on our health and quality of life. Loneliness and isolation disproportionately affect people living with HIV; in 2017, one in 5 people living with HIV said that they needed help dealing with isolation and loneliness in the last year, of which 75% reported that this need was unmet.⁴

13. HIV support services are essential in meeting the physical, emotional and mental needs of people living with HIV. Terrence Higgins Trust has centres in Cardiff and Swansea, however all but one staff member was furloughed reducing the capacity of the organisation to provide much needed support. Third-sector partnerships have had to expand to meet the need. A Freedom of Information Act request in 2017 showed that the total reported expenditure known to be exclusively on HIV support services in Wales for 2016/17 was £0. Total reported expenditure on HIV support services (including joint contracts) in Wales for 2016/17 was £135,352, which is a 34% reduction from 2015/16. HIV support services should be properly funded, and not be simple add-ons to wider sexual health services, and providers must have the appropriate expertise to meet local population needs.⁵
14. As well as experiencing HIV related stigma and discrimination, people living with HIV are often affected by other forms of inequality. HIV disproportionately affects men who have sex with men, the Black African population, migrants and people who inject drugs. These communities are already marginalised, and there needs to be targeted efforts to ensure these populations receive the HIV testing, treatment and care they need. People who do not have access to a smartphone or laptop will struggle to make the most of the telemedicine pilot in Wales, as will people who do not speak English as their first language. Those living in shared housing who have not shared their HIV status with the people they live with may be reluctant to have STI testing kits sent to them in the post or lack the privacy to have a telephone consultation. Maintaining some face to face services has been essential in not further restricting access to care for these marginalised populations, however post-COVID-19 planning must continue to take these populations into account.
15. In September 2020, Cardiff became the first city in Wales to join the Fast Track Cities Initiative (FTCI). This is a commitment to end new transmissions of HIV, AIDS-related deaths and HIV stigma in Cardiff by 2030. This is a positive step for Wales and one that many campaigners had been calling for. 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.⁶ Furthermore, 62% of all people diagnosed with HIV in Wales are diagnosed late, which is considerably higher than the UK average of 42%.⁷ 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.

⁴ Changing Perceptions, *Talking about HIV and our needs*, https://www.nat.org.uk/sites/default/files/publications/web_PV_Changing%20Perceptions-needs-report.pdf

⁵ National AIDS Trust, *HIV Support Services: The State of the Nations*, https://www.nat.org.uk/sites/default/files/publications/NAT_HIV_Support_Services_The_state_of_the%20nations%20_2017_FULL.pdf

⁶ 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.

⁷ *Ibid.*

16. There is a concern that other cities and towns in Wales will not be able to benefit from the FTCl because they are too small to sign up but would still benefit from the additional support in ending HIV transmissions. One idea would be to create Fast Track Wales so that there would be a national commitment to end HIV transmissions.
17. There is evidence to suggest that HIV stigma is worse in Wales than in other areas of the UK. Positive Voices 2017 was a survey of people living with HIV receiving care in England and Wales funded and administered by Public Health England. It was implemented in 73 HIV clinics and recruited 4422 participants. Two clinics in Wales participated, DOSH in Cardiff and the Royal Gwent Hospital in Newport. Findings from Welsh participants showed that around 1 in 7 had never told anyone about their HIV status outside a healthcare setting, contrasting with 1 in 8 in the UK as a whole. Less than half had told their friends about their diagnosis, and less than two thirds had shared their diagnosis with their family which has implications on rates of loneliness and isolation. 21% of respondents said they had avoided seeking healthcare when they had needed it in the preceding year, which is more than double the UK average of 10%. This means that people living with HIV in Wales are less likely to proactively manage their HIV and comorbidities.⁸ There must be a concerted effort to reduce HIV stigma across Wales, and not just in Cardiff.
18. Despite a general improvement in the quality of HIV services across Wales, there are concerns about poorly developed services for Trans people. Clinicians in Cardiff especially have been informally creating networks to develop the services currently offered and have recognised the need to continue working with Welsh Gender Services.
19. Wales has seized opportunity to improve the provision and quality of HIV care during the COVID-19 pandemic despite very challenging circumstances. However, there is still a need to improve, especially in the following areas:
 - a. Commitment not to roll back on progress made since March. Some of the changes were much needed and long awaited, and there are concerns among clinicians across Wales that the improved ways of working will not be supported as restrictions are eased, despite the fact they have been embraced by clinicians and patients alike.
 - b. Continued support for innovation and different ways of working, especially provision of technology to improve the delivery of services (such as the roll out of Office 365 across the NHS in Wales).
 - c. Commitment to support *everyone* in Wales living with or at risk of HIV, including Trans people, migrants, people in insecure housing and people with disabilities other than HIV which make accessing testing, treatment and care remotely difficult or impossible.

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⁸ 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>, 11-12.