



Ending new HIV transmissions in Wales

Seeking solutions that work for people living with HIV
to build a national HIV action plan for all

A briefing paper in support of the Welsh national HIV action plan

01 Introduction

The nature of the HIV epidemic in Wales and across the UK has fundamentally changed over the past few decades. Diagnoses are falling and people living with the virus can enjoy a near-normal life expectancy. However, despite this significant shift, there are still 2,358 people living in Wales receiving treatment for HIV.ⁱ Moreover, late diagnosis remains a problem, with 59% of all HIV diagnoses in Wales made at a late stage, in comparison to a UK average of 42%.ⁱⁱ People diagnosed at a late stage have a seven-fold increased risk of death, within a year of diagnosis.ⁱⁱⁱ These statistics show that complacency is not an option. Progress has been made but further improvements are urgently required.

Although HIV now represents a long-term, manageable condition, people living with HIV in Wales still face health and wellbeing challenges. These include a poorer quality of life than the general population; increased rates of co-morbidities; persistent stigma; mental health challenges; and inequalities in the experience of care. In addition, like all areas of healthcare, the impact of COVID-19 across HIV services is still being felt. As these services recover, the needs of people living with HIV must not be forgotten. Steps must be taken to address these ongoing challenges and ensure the voices of this population are at the forefront of these reforms.

The Welsh Government was the first UK nation to commit to ending new HIV transmissions by 2030 and during the last Welsh election pledged to create an HIV Action Plan for Wales.^{iv} Gilead welcomes and fully supports this pledge. We believe a comprehensive, fully funded, and measurable HIV Action Plan that places people living with HIV at its core is vital to ensuring all people with HIV are supported to live and age well and can easily access the treatments and services they need. This plan should also be used to help Wales reach the 2030 target. For any plan to succeed, it's vital that measured targets and a reporting structure for Health Boards to follow are implemented to ensure accountability across the health system and collective responsibility for turning these aims into a reality.

The introduction of a national plan could mirror the creation of similar plans across the UK. The end of 2021 saw the publication of a National HIV Action Plan in England and the publication of a recovery plan for sexual health and blood-borne virus services (SHBBV) in Scotland with a particular focus on reaching the 2030 target. In 2022, Scotland will go further and publish a more fundamental review of the SHBBV Framework.^v The publication of an action plan in Wales will ensure consistency across the UK, strengthening the collective effort to drive improvements for all those living with and a risk of HIV.

The voices of those living with HIV must be the keystone for any plan, driving its content and direction. This paper aims to support those voices. Based on HIV data from Wales, content from pre-existing strategies, and discussions with the HIV

community across Wales to understand the country's bespoke needs, this paper sets out suggestions that could be considered as part of an HIV Action Plan for Wales. It makes recommendations covering the following areas:

- Meeting the 2030 zero new HIV transmissions target
- Living and ageing well with HIV
- Successfully preventing the spread of HIV
- Tackling discrimination, stigma, and mental health issues
- Improving surveillance and evaluation
- Ensuring access to the latest and most innovative treatments

02 HIV in Wales

As of 2019, 2,358 people in Wales were receiving HIV care, equating to 2.4% of the population.^{vi} Mirroring progress made in other parts of the UK, Wales has seen improvements in the prevention, diagnosis, treatment and care for people living with HIV. Infections have fallen by 15% since 2018.^{vii} In 2019, 126 people in Wales were diagnosed with HIV, by 2020 this had dropped to 75 – a 60% drop.^{viii} The country has also seen a drop in AIDS at HIV diagnosis with 9% of all diagnoses falling into this category in 2019 dropping to less than 4% in 2020.^{ix} These significant declines are likely to reflect the difficulty of obtaining testing and access to health services during the pandemic rather than any real shift in the HIV landscape. The most common exposure category remains sex between men with 37 diagnoses in this category in 2019 decreasing to 30 in 2020.^x

These statistics demonstrate a decreasing trend in new HIV transmissions and improvements in diagnosis. However, they do not paint a full picture with further data suggesting they mask some serious challenges. HIV-related deaths saw a small increase from 2019 to 2020, with deaths amongst women seeing a more significant increase in the same timeframe from 0 to <5.^{xi} The probable exposure category amongst injecting drug users increased from 0 in 2019 to <5 in 2020 suggesting that Wales' progress in HIV prevention has not been universal.^{xii}

Moreover, and as previously mentioned, late HIV diagnosis remains a key challenge in Wales with 59% of all diagnoses made at a late stage in comparison to a UK average of 42%.^{xiii} This percentage rises to 62% in Cardiff.^{xiv} With late diagnosis associated with a 7-fold increase in the chance of death one year after diagnosis, this statistic is concerning.^{xv} Furthermore, a late diagnosis increases dependency on hospital-care, reduces response to HIV treatment and makes onward transmission more likely.^{xvi} Direct medical costs in the first year after HIV diagnosis are twice as much for late diagnosed individuals, largely due to higher inpatient costs, highlighting the financial implications of this challenge.^{xvii}

Individuals already living with HIV in Wales continue to face challenges. These populations are disproportionately vulnerable to a wide range of other conditions which can make daily life and care more challenging. People living with HIV are:

- 77% more likely to develop cardiovascular disease and 84% more likely to have a heart attack than the general population^{xviii}
- Four times more likely than the general population to develop chronic kidney disease^{xix}
- At greater risk of developing cancer at a younger age than the general population, particularly lung cancer, liver cancer, and Hodgkin Lymphoma^{xx}

Alongside an increased risk of physical co-morbidities, people living with HIV are also more likely to face stigma and discrimination resulting in mental health challenges that can have wide-ranging implications. In their 2020 report surveying 4,400 people living with HIV in England and Wales, Positive Voices found that, of those surveyed:^{xxi}

- 49% experienced mental health concerns, compared to 30% of the general population
- 16% worried that they would be treated differently because they were HIV positive and 10% had avoided seeking healthcare when they needed it in the past year
- 33% said access to HIV services had become more difficult over the past two years
- 14% were unemployed, more than triple that of the general population (4%)

This research suggests that HIV-related stigma may be worse in Wales than the rest of the UK.^{xxii} Key findings from the two clinics in Wales that responded to the survey showed that:^{xxiii}

- Around 1 in 7 Welsh participants had never told anyone about their HIV status outside a healthcare setting, contrasting with 1 in 8 in the UK. This suggests that HIV positive people in Wales may be more likely to feel isolated and stigmatised as a result of their status
- 21% of Welsh respondents had avoided seeking healthcare when they had needed it in the preceding year, which is more than double the UK average of 10%. This suggests that HIV positive people in Wales are less likely to proactively manage their own health and co-morbidities than the general UK HIV population
- 1 in 5 Welsh respondents had avoided seeking medical care in the previous year for fear of reception they would get upon disclosure^{xxiv}

Perhaps contributing to the stigma and discrimination experienced by people with HIV living in Wales are the low levels of engagement and awareness of HIV amongst the general population.^{xxv} There has been no national awareness campaign for almost 15 years and very little local activity on promoting prevention. Further compounding this issue is the sparse support for those living with the

disease. There is virtually no funded NGO sector left in Wales and no funding for formal HIV support outside clinics.^{xxvi} According to Public Health Wales data, there are 11 sexual health clinics across Wales and only eight of those provide access to PrEP.^{xxvii} In comparison, London has 20 sexual health clinics where residents can access PrEP.^{xxviii}

Despite these gaps, Wales currently has highly supportive and informed politicians, both in power and in opposition, who support action on HIV as highlighted by the latest government commitments.^{xxix} The creation of an HIV Action Plan would not only set up a roadmap for ending HIV transmission by 2030 but would also set in place care and prevention policies to address the challenges outlined above and create a bold approach to improving the quality of life of individuals already living with HIV.

03 Recommendations

Meeting the 2030 zero new HIV transmissions target

There is strong support from the Welsh Government and across opposition parties to meet the UNAIDS target of eradicating all new HIV transmissions by 2030. As this paper sets out, this goal is an important first step in preventing the harm caused by the virus and protecting those at risk. However, it is only part of the puzzle; in parallel, any HIV Action Plan must focus on supporting all those with HIV to live and age well. Whilst this multi-faceted approach will be vital in improving overall HIV outcomes, an HIV Action Plan does provide an important opportunity to implement strategies which will make the 2030 target reachable.

Recommendation: An Action Plan for Wales must set out steps to reach the 2030 target of zero new HIV transmissions. The plan must be fully funded with clear targets to increase testing, target resources, and tackle stigma. The plan must also go beyond this goal and put people with HIV at the heart of it to ensure that those living with HIV in Wales today have their voices heard and are supported to live and age well.

Recommendation: Support for Fast Track Cardiff and Vale in aiming to reach this goal must continue with additional support given for the establishment of a Fast Track City collaborative network, enabling cities across Wales to support each other in reaching the transmission goal.

Improving surveillance and evaluation

There are gaps in HIV-related data across Wales.^{xxx} These gaps include a lack of understanding of the total number of people living with HIV in Wales and a lack of real time knowledge about late diagnoses which makes planning targeted interventions difficult.^{xxxi} Limited surveillance data also makes it difficult to

understand the 'at-risk' profiles of those diagnosed^{xxxii} and there are reportedly challenges with connectivity between Health Boards which result in a lack of transparency and knowledge sharing.^{xxxiii}

These gaps must be remedied to enable the Government, health services and communities to work together to improve the lives of those living with HIV, protect those at risk and eliminate new HIV transmissions by 2030.^{xxxiv} There is clear ambition to reform data with Public Health Wales already seeking to increase access to quality data including on who has HIV, where it was acquired, and where they are in Wales.^{xxxv} It would be helpful to ensure the learnings from other Fast Track Cities on data needs and strategies are fed into any new data collation programmes in Wales.^{xxxvi} The introduction of an HIV Action Plan provides the opportunity to realise this ambition and to ensure that Wales' data sets on HIV are robust and can accurately inform prevention and care strategies across the HIV pathway.

Recommendation: A pathway should be established to produce and report robust and regular data on new and established HIV infections, on Wales' progress towards the UNAIDS 90:90:90 targets and the frequency and characteristics of those diagnosed late with HIV.^{xxxvii}

Ensuring access to the latest and most innovative treatments

The last few decades have seen continual advances in HIV care and treatment, which have resulted in an exponential increase of life expectancy and quality of life for people living with HIV. Anti-retroviral therapies (ARTs) have been transformative with triple therapy and single-tablet regimens significantly reducing the numbers of pills required to be taken each day. ARTs offer a range of long-term benefits, including lessening the viral load – thereby requiring less clinical monitoring – and are better tolerated by people with HIV. These benefits support regimen adherence, decrease footfall in clinical settings and thus reduce the burden on healthcare professionals.

Advances in technology, across testing and prevention, have also been seen with these technologies becoming increasingly easy to access and more cost-effective. With scientific research into HIV continuing, further innovations will arise which Wales must be able to adopt with designated funds so that people living with HIV who choose to access these innovations can do so in a timely manner.

The pandemic also saw accelerated innovation with healthcare services and technologies adapting so they were able to continue to reach people despite requirements to shield and to lessen footfall in traditional healthcare settings. Digital services, such as tele-medicine, for both HIV prevention and management, can remove barriers to care, including by reducing travel times, offering convenient alternatives to attending clinics and avoiding any stigma associated with seeking HIV care.^{xxxviii} In a post-pandemic world, provision of these digital appointments and use of tele-health services should continue for those who wish to use them

whilst ensuring that a more traditional approach to obtain care and treatment is still there for those without access to technology or who prefer this option.

Recommendation: A person-centred approach should be implemented across the entire care pathway. This should be developed in partnership with community-based organisations to ensure individuals can access the best available innovation for prevention, treatment and care based on their medical needs and choices.

Recommendation: Ensure prescribing guidelines are relevant, up-to-date, and include enough flexibility to appropriately support individualised care. As innovative medicines come through the pipeline, it's important that the system is flexible enough to adopt new innovations and ensure people living with HIV receive the most appropriate treatment to support individual needs, in a timely way.

Recommendation: Encourage the appropriate adoption of digital care technologies, which include providing training for clinicians and people living with HIV to ensure technology is used and standards maintained.

Living and ageing well with HIV

As set out above, it is evident that people living with HIV in Wales are more likely to experience poor health-related quality of life and self-rated health and life satisfaction compared to the general population.^{xxxix} The Positive Voices survey covered 29 different types of health and social services which people living with HIV accessed in the previous year. It found that 49% needed information about living with HIV and 43% needed support in managing other long-term health conditions^{xl} As the HIV population ages, new and complex demands will be placed on the broader healthcare system, across primary and secondary care, which will require changes in the provision of services.

An HIV Action Plan for Wales provides the opportunity to make these changes and to set in motion frameworks to ensure services and providers, across HIV specialists and wider NHS and social care settings, are equipped to respond to these shifting needs, particularly in the context of HIV associated co-morbidities. A failure or delay in making these changes will not only mean that the needs of people living with HIV are neglected, but it will also place a significant strain on other parts of the healthcare system.

Recommendation: Ensure that Health Boards organise the delivery and evaluation of HIV services based on national guidelines including the BHIVA standards of care for people living with HIV. Concrete commitments and associated funding would make sure the newest and most innovative treatments and interventions are delivered promptly, enabling quality of life improvements by the most appropriate care provider.

Recommendation: Quality of Life targets and indicators should be adopted in Wales alongside the existing UNAIDS 90:90:90 targets.

Recommendation: Provide enhanced clinical support through guidelines, standards, and training to ensure primary care professionals can monitor and deliver regular comorbidity checks for people living with HIV.

Recommendation: All HIV diagnoses should be accompanied by the provision of peer support programmes, which should include a particular focus on living and ageing well, as well as retention in care.

Tackling discrimination, stigma, and mental health issues

As highlighted above, evidence shows that there are continuing issues relating to stigma, discrimination, and associated implications around mental health for people living with HIV in Wales. The Positive Voices data showed that across every age group and gender, people living with HIV reported worse mental health than the general public, and only 1 in 6 (17%) respondents felt able or willing to disclose their HIV status beyond immediate family, partners, and friends.^{xli} The survey also found that people living with HIV in Wales were more likely to have never told anyone outside a healthcare setting about their HIV status, than people living with HIV in England, suggesting they feel a stronger sense of stigma.^{xlii}

As well as detrimentally impacting the lives of those living with HIV, stigma contributes to the high rates of late HIV diagnoses in Wales. Stigma makes clinicians reluctant to recommend HIV as a differential diagnosis for fear of offending or a simple lack of awareness that it might be likely, and it also makes individuals less likely to choose to test.^{xliii}

There has been some work in recent years to address HIV stigma in Wales. The Terrence Higgins Trust Cymru offers a range of services, including counselling, peer support, outreach at LGBT community events, and long-term condition management services to improve both the physical and mental health of those living with HIV.^{xliv} Cardiff and Vale local authorities have both committed to including HIV and sexual health within the new 'Relationship and Sex Education' curriculum in the hope that education in schools will dispel myths around HIV amongst the younger population.^{xlv}

The most high-profile recent programme is the Tackle HIV campaign, launched by ex-Wales rugby player Gareth Thomas in 2020. The campaign sought to challenge stigma and misconceptions about HIV. The campaign found that 61% of respondents would, or might, end a relationship if their potential partner had HIV, and only 19% of respondents knew that if a person living with HIV is taking effective treatment, they can't pass it on to a partner. Despite the success of the campaign, and the efforts of the organisations mentioned above, these results suggest that further awareness campaigns are needed.^{xlvi}

If the general population was to become more aware of the realities of HIV, particularly the U=U principle, it would likely greatly reduce the psychological toll

on those who live with the virus. For many people with HIV, the first time they hear about U=U is during discussions with their HIV clinicians. However, these discussions can be limited and some people with HIV report never having discussed U=U with their healthcare practitioner. Evidence shows that those who do have these discussions have favourable health outcomes suggesting that such conversations should be embedded into clinical guidelines.^{xlvii}

Mental-health related addiction issues are also frequently seen in HIV clinics, including dependency on drugs. The Positive Voices campaign found that 20% of gay and bisexual men with HIV had engaged in chemsex in the past three months.^{xlviii} With no specific services in Wales for those who engage in chemsex, there is likely to be a significant need for drug and alcohol services for people with HIV and provision for mental health and addiction issues.

Regardless of the specific population, there is an evident need to have a wider spectrum of support services such as buddying, peer support, counselling, psychology and health and wellbeing-related services available to provide a preventative approach to mental health services and support for those in crisis. There are commitments from politicians in Wales to provide funding for peer support and to continue running the annual national survey around stigma and quality of life. These pledges should be built into the Wales HIV Action Plan which must also ringfence funding for public awareness campaigns to reduce stigma and improve mental health services to support people living with HIV.

Recommendation: Renew and reinvest in a HIV public awareness campaign. U=U should be embedded into both public awareness campaigns and clinical guidelines. A national campaign should be made relevant for diverse groups such as BAME, Trans, and migrant communities to address nuanced barriers faced by different communities. This national effort should include the introduction of HIV and sexual health programmes in schools should address stigma and misconceptions.

Recommendation: All health and social care staff must be trained to understand the complex and diverse needs of people living with HIV. This would reduce unintentional stigma and discrimination and enhance the likelihood of positive communication.

Recommendation: Stigma reduction messages should be built into existing training programmes and events across clinical settings, youth services, social services, housing, and employment schemes with messages included about HIV support, referral routes, ageing well, quality of life and the benefits of early treatment and prevention.^{xlix}

Recommendation: Greater provision of HIV support for individuals suffering from substance abuse should be provided.

Improving surveillance and evaluation

It will be impossible to end new HIV transmissions and reach the 2030 UNAIDS target without addressing the needs of people living with HIV today. This group must be at the forefront of prevention efforts across Wales with an enhanced focus on Treatment as Prevention (TasP), retaining individuals in care, and education around undetectable = untransmissible (U=U).

To compliment these efforts, a focus on testing is also important. Wales has made good progress in the accessibility of testing. There is a free national postal testing service, which has proved very successful in engaging people who are reluctant to attend clinics or are unable to do so, and a texting for testing programme which provides an alternative channel through which to access HIV tests.ⁱ

Despite these improvements, pressure on existing HIV testing services has been reported and community feedback frequently mentions challenges in getting timely appointments. There is also reportedly some reluctance to take on new initiatives, which would increase pressure on staff.ⁱⁱ These pressures are likely contributing to the challenges of late diagnoses in Wales with research showing that most missed opportunities for diagnosis were due to clinicians failing to offer an HIV test, rather than individuals declining one.ⁱⁱⁱ Analysis shows that to reach the 2030 target, more must be done to increase testing, particularly targeted testing for those most at riskⁱⁱⁱⁱ

Mirroring this mixed picture on the accessibility of testing, is mixed success across the provision of Pre-exposure prophylaxis (PrEP). PrEP is now available, free of charge, to all Welsh residents.^{lv} Data from 2018 showed that no one in Wales in the previous year who had been prescribed PrEP had been diagnosed with HIV, highlighting its efficacy and the importance of timely access to this treatment^{lv}

Despite the evident value of this treatment, not all individuals who meet the eligibility criteria for PrEP in Wales accept it, and there is little understanding of the reasons behind this.^{lvi} There also exists a substantial postcode lottery between Health Boards, with some individuals having to travel outside their area to access PrEP and reports of long waiting times for the treatment.^{lvii}

The creation of an HIV Action Plan provides Wales with the opportunity to build on successes across these areas and overcome the aforementioned challenges with the creation and implementation of strategies that ensure equitable, timely and consistent access to both testing and preventative treatments.

Recommendation: Work with people living with HIV to improve education around the prevention of HIV and enhance pathways to drive retention in care, increase the understanding of U=U, and the use of TaSP.

Recommendation: Universal opt-out testing in A&Es should be introduced to help reduce late diagnoses. Improved access to testing must also be made in primary

care settings and across a more diverse range of hospital areas, including medical admissions, dermatology, haematology, and gastroenterology.^{lviii} Widening access and awareness of self-testing kits at varied locations such as pharmacies, vending machines at sites of sexual activity, and through community outreach projects should be prioritised to improve access and ease pressure on existing sexual health services.^{lix}

Recommendation: Focus resources on ensuring access and uptake of PrEP and TasP to prevent onward transmission of HIV, including through community setting such as pharmacies, and undertake work to understand hesitancy to use these treatments amongst those who refuse them.

04 Conclusion

With health services looking to rebuild in a post-pandemic environment, and strong cross-party support for improving HIV outcomes as well as the Government's pledge to create an Action Plan, now is the time to bring the community together to understand the needs of those living with HIV in Wales and ensure they are enshrined in a future Action Plan. The plan also provides a vital opportunity to build a roadmap towards the 2030 target of ending all new HIV transmissions

People living with HIV should be at the heart of this plan and included in all aspects of the drafting, consultation, and final publication process. The Welsh Government's commitment to driving change and delivering improvements across the HIV care continuum is truly welcomed. Gilead stands ready to work collaboratively with stakeholders across government, charities, professional organisations, and interested groups throughout the consultation period to support the delivery of a plan and ensure tangible changes for all those living with and at risk of HIV in Wales.

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05 Case Study: HIV in England and Scotland

As mentioned previously, Wales' determination to improve the lives of people living with HIV and achieve the 2030 goal of zero new HIV transmissions is an ambition shared with the other UK nations. In August 2021, Scotland published [*Reset and Rebuild: A Recovery Plan for Sexual Health and Blood Borne Virus Services*](#) (SHBBV). This plan takes stock of the impact of COVID-19 on service provision for the prevention, treatment and care of HIV, hepatitis B and C, and other sexually transmitted infections ahead of a more fundamental review of the

SHBBV framework in 2022. This framework which is due to be published towards the end of the year will set out service planning over the next five years.^{lx}

England too is focused on improving the lives of people living with HIV and reaching the 2030 goal. A notable step towards realising these ambitions in England was the recent publication, in December 2020, of a new national HIV Action Plan for England: [*Towards Zero - An action plan towards ending HIV transmission, AIDS and HIV-related deaths in England - 2022 to 2025.*](#)

England's HIV Action Plan is backed by over £23 million of government funding.^{lxi} £3.5 million of this has been ring-fenced to deliver a National HIV Prevention Programme from 2021 to 2024.^{lxii} £20 million will be invested over the next three years to introduce opt-out testing in NHS emergency departments within all local authority areas with 5 or more cases of HIV per 1,000 residents.^{lxiii}

The plan aims to support the Government in meeting the 2030 target whilst achieving three interim targets by 2025:^{lxiv}

- To reduce the number of people first diagnosed in England from 2,860 in 2019 to under 600
- To reduce the number of people diagnosed with AIDS within three months of HIV diagnosis from 219 to under 110
- To reduce deaths from HIV/AIDS in England from 230 in 2019 to under 115

The plan is underpinned by four key objectives:^{lxv}

- Objective 1: Ensure equitable access and uptake of HIV prevention programmes
- Objective 2: Scale up HIV testing in line with national guidelines
- Objective 3: Optimise rapid access to treatment and retention in care
- Objective 4: Improve quality of life for people living with HIV and addressing stigma

The Secretary of State for Health and Social care will annually update Parliament on progress towards the objectives and the UK Health and Security Agency is due to shortly publish a monitoring and evaluation framework and details of funding^{lxvi}

The creation and implementation of an HIV Action Plan for England provides a valuable example of how an HIV Action Plan for Wales might look and how it could be managed. Whilst an Action Plan for Wales will differ, mirroring the needs of the Welsh HIV population and considering, first and foremost, their voices, the existence of two National Action Plans would complement one another. They would equip the UK to move forwards together, bringing us closer to reaching the 2030 target and in ensuring people living with HIV have all the support they need to live long and healthy lives.

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