



Llywodraeth Cymru  
Welsh Government

# HIV Action Plan for Wales 2023-2026

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## HIV Action Plan for Wales

### *Eliminating HIV, improving quality of life and tackling stigma associated with the virus – an action plan for 2023-26*

#### Ministerial foreword

HIV and AIDS continue to be a major global public health issue. The World Health Organisation estimates that, globally in 2020, 680,000 people died from AIDS-related causes and 1.5 million people acquired HIV. Although there remains no cure for HIV, effective prevention, diagnosis, treatment, and care are now available, enabling people living with HIV to lead long and healthy lives.

Over the past five years, the Welsh Government, working with other partners, has made huge progress in improving access to testing and treatment in Wales. Wales can be proud of the significant reduction seen in new diagnoses of HIV. Between 2015 and 2021 new diagnosis of HIV decreased by 75%. A significant factor in this achievement can be attributed to the commitment by Welsh Government to provide Pre-Exposure Prophylaxis (PrEP) for all for whom it is clinically indicated since the summer of 2017.

Despite the challenges that faced sexual health services throughout the Covid pandemic, access to HIV testing was maintained through face-to-face consultations and the rapid deployment of on-line testing. As we emerge from the pandemic, this blended model of access to HIV tests has resulted in more people being tested for HIV between January and March 2022 than in any previous quarter.

Our *Programme for Government* sets out ambitious commitments to both develop an *HIV Action Plan for Wales* and tackle the stigma experienced by those living with HIV. The latter is especially significant. We have come a long way since the dark days of the 1980s – so memorably depicted last year in Channel 4's *It's a Sin* – when ignorance and cruelty towards people with HIV was rife. There have been several recent positive developments; in December 2021 the Welsh Government welcomed the Ministry of Defence's lifting of restrictions on people living with HIV and PrEP users in the armed services, but ignorance still exists within certain sectors and within individuals, and there is much more to be done to stamp it out.

In the autumn of 2021, we established an HIV Action Plan Working Group chaired by Dr Marion Lyons, a Senior Medical Officer in Welsh Government, which consists of a diverse range of stakeholders with community based, professional, academic and, importantly, personally lived experiences. The guiding principles underpinning the work of this Group are that no-one should be left behind, that inclusivity and diversity should be encouraged and celebrated and that **all** the communities we serve should be an integral part of the dialogue, debate and decision making on HIV going forward.

The group has worked collaboratively across a number of themes in sub-groups and has co-created a plan which contains 30 actions aimed at eliminating all HIV in Wales and achieving zero tolerance of HIV-related stigma by 2030. The actions are focussed on five key areas: prevention; testing; clinical care; living well with HIV and tackling HIV-related stigma. I am especially pleased to see the group advocating a zero tolerance towards HIV-related stigma. People living with HIV are protected under the Equality Act 2010 and should not face discrimination, either in the workplace or in the delivery of goods, services and facilities. There is no place for ignorance or intolerance in modern Wales and this plan sets out actions aimed at tackling this. I am very grateful to those partners and stakeholders who have worked together to make this plan a reality.

I am also grateful to those that took time to respond to the consultation. The overwhelming majority of the responses were positive about the actions put forward in the Plan. We received many responses that suggested potential new actions and improvements to some of our existing actions. We have listened to those suggestions where possible, strengthened the Plan in several areas and included four new actions which make our commitment and ability to achieve zero transmissions by 2030 even stronger. Once again, I thank our partner organisations for their contributions and support. They will now stand alongside us in implementing these actions. We are at the beginning of an exciting journey which can achieve real change. I look forward to updating on progress towards implementation on an annual basis.

I firmly believe that by accepting and implementing these actions, we will make a massive difference to the lives of people living with HIV and in protecting current and future generations from the virus.



**Eluned Morgan MS**

**Minister for Health and Social Services**

## **Introduction**

The Welsh Government's Programme for Government, published in June 2021, and refreshed in December 2021, outlines a number of commitments aimed at providing effective, high quality and sustainable healthcare. One of the key commitments under this heading is to develop an HIV action plan and to tackle the stigma experienced by those living with HIV.

We recognise the importance of partnership working to achieve our commitments. This Action Plan was developed by an HIV Action Plan Working Group established by Welsh Government and supported by three task-and-finish groups who focused on: stigma; peer support and living well with HIV; and PrEP and prevention. Membership of these groups (attached at Appendix 1), came from a broad range of organisations including people living with HIV (PLWHIV), all with considerable expertise. We have also worked closely with colleagues across Welsh Government, in particular LGBTQ+ policy leads who are developing an LGBTQ+ Action Plan for Wales. Members considered current evidence and good practice and its relevance to Wales and have put forward 30 actions to help meet our 2030 elimination commitment and to tackle HIV-related stigma.

The plan contains five priority areas for action:

1. Prevention
2. Testing
3. Clinical Care
4. Living well with HIV
5. Tackling HIV-related stigma

The actions will be underpinned by three core principles:

1. There should be zero tolerance of HIV-related stigma
2. That plans for implementation of new initiatives and services will be informed by, or developed with, people living with HIV. Alongside this there will be a recognition of contextual differences by sexuality, ethnicity, age, gender and location, to ensure that no one is left behind. Services will take into account the needs of Welsh speakers.

"More Than Just Words" is the Welsh Government's plan to strengthen Welsh language services in health and social care. At its core is the 'Active Offer' principle which places a responsibility on health and social care providers to offer services in Welsh, rather than on the patient or service user to have to request them. Health and care bodies will also need to ensure that they comply with the Welsh language standards to ensure that the Welsh language is not treated less favourably than the English language.

Services will also take into account the needs of those where English or Welsh is not their preferred language.

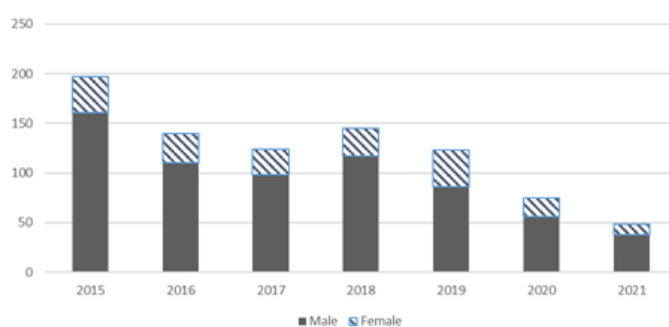
3. All new initiatives and services will be subject to ongoing monitoring and evaluation to make sure they meet the actions and principles laid out in the plan. Actions taken in Wales will be guided by the evidence base, and research in sexual health and HIV will be optimised and overseen by PHW and the research network from Welsh universities.

### **Current position.**

Wales has seen a 75% reduction in new diagnosis of HIV between 2015 and 2021. There was a 77% reduction in new diagnosis in men who have sex with men and a 61% reduction in new diagnosis in heterosexual individuals. Data for the latter years should be interpreted with caution as there was a reduction in testing in the early phase of the pandemic.

While the Covid-19 pandemic disrupted both society and service provision, adaptations to the way that testing and clinic services were provided in Wales meant that access to HIV testing continued, and in 2021 there were 48 people newly diagnosed with HIV infection in Wales. Approximately 2,800 people accessed care in Wales for HIV.

### **New diagnoses of HIV in Wales 2015 -2021**



### **Overarching actions:**

#### **1. Establishing Wales as a Fast Track Nation**

Fast Track Cardiff & Vale – the first Fast Track Health Board in Wales – has been a highly successful collaboration over the past two years in involving local public bodies, increasing collaborative work, and producing new initiatives including GP support for HIV testing and an advocacy network, both of which have attracted non-statutory funding. Even though it is currently unfunded, Fast Track Cardiff & Vale has also successfully embedded Wales HIV Testing Week.

We now have an ideal opportunity to grow other fast track health boards and build on this initiative to co-create with all partners an all-Wales coalition, Fast Track Cymru (FTC). The aspiration is to make Wales a Fast Track Nation. It will be a collaboration of Welsh Government, Public Health Wales (PHW), each LHB, a representative of Welsh local authorities, clinicians, voluntary sector groups and people living with HIV.

Among the things we envisage the FTC network would:

- collaborate to help achieve Wales' ambition to end new cases by 2030;
- support local fast track health boards to establish and sustain themselves;
- promote changes that will improve the quality of life for people living with HIV;
- promote projects that encourage innovation and new ways of working.

## **2. Involvement of voluntary and community groups**

None of the actions in this plan will be achieved without the existing voluntary and community groups working with people living with HIV. This action plan has been developed with partners such as Pride Cymru and Terrence Higgins Trust (THT) Cymru, whose work builds on the legacy of Cardiff AIDS Helpline and Cardiff Body Positive. The Welsh Government were pleased to welcome the THT's new strategy, which looks to make a substantial investment in Welsh provision over the next three years. In addition to their work, the work of third sector HIV groups like PrEPster, National AIDS Trust, Positively UK and CHIVA – the Children's HIV Association – has all been taken into consideration. In the implementation of this plan, Welsh Government, health boards, local authorities and other partners will wish to work closely with the HIV voluntary and community sector.

## **3. Funding and development of an all-Wales sexual health case management system**

An all-Wales sexual health case management, surveillance and reporting system will be funded and developed to support networked all-Wales patient care and data collection. The case management system should have the capability to interface with the other relevant software systems, to enable the support of HIV management and surveillance widely and provide automatic data to a central portal. The system should also support reporting outputs based on World Health Organisation (WHO) targets, British HIV Association (BHIVA) standards for HIV care and other stakeholder requirements.

The case management system will provide robust data and intelligence to monitor trends, assess the success of interventions and for planning service provision. In developing the case management system, we would expect data fields on ethnicity and gender (including transgender) to be included in routine collection. It is important that there is clarity on ownership of the data, and it is recommended that the ownership and oversight of this system rests with Public Health Wales.

#### 4. Health boards and trusts to report on the implementation of the actions in this plan

Health boards and trusts will provide assurance to the Welsh Government on an annual basis that the actions from HIV Action Plan are being taken forward and are making a difference. This will include evidence that care pathways are in place to ensure all those living with HIV from infancy to old age are living well and receiving optimum care.

#### 5. Establishment of an Action Plan Oversight Group

An HIV Action Plan Oversight Group will be established to demonstrate our commitment to maintaining oversight and monitoring the impact that delivery of the HIV Action Plan has made.

1.	Building on the success of the Fast Track Cities initiative in Cardiff and the Vale, a new national umbrella body, Fast Track Cymru (FTC) will be established and funded by Welsh Government. This body will provide capacity and strategic focus for stakeholders, community groups and decision makers, in local fast track collaborations to support the implementation of this Action Plan and ensure that all key partners work together to achieve our objectives. Timescale: Full establishment by March 2024
2.	Involvement of voluntary and community groups. In the implementation of this plan, Welsh Government, health boards, local authorities and other partners will work closely with the HIV voluntary and community sector.
3.	A case management surveillance system, overseen by Public Health Wales, will be funded and established to support clinical management and improve shared care. It will facilitate real-time data collection and timely publication and will ensure decision makers can measure their achievements against ambitions. Timescale: Funding to be made available in early 2023/2024 with implementation in 2024/2025
4.	Health boards and trusts will be required to detail actions they are taking to implement the actions of the HIV Action Plan in their delivery plans. This will include evidence that care pathways are in place to ensure all those living with HIV from infancy to old age are living well and receiving optimum care. Progress can be reported at quarterly Quality and Delivery meetings between Welsh Government and health boards. Timescale: Reporting on progress will commence in summer 2023 with the first annual Ministerial statement to the Senedd
5.	To strengthen the evidence base, a network of researchers in academia in Wales, in collaboration with PHW, will be established and will coordinate current and future research in HIV and sexual health.
6.	An HIV Action Plan Oversight Group, which will involve all key stakeholders including health boards, local government, clinicians, voluntary and community

	<p>organisations and people living with HIV, will be established to monitor progress against our ambitions and to advise Ministers on progress and any further actions required. The Group will provide an annual progress update on the implementation of this plan, following which the Minister will make an annual statement to the Senedd.</p> <p>Timescale: The Oversight Group to be established in the first quarter of 2023.</p>
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## **Priority 1: Prevention**

HIV prevention initiatives are effective in preventing HIV transmission including antenatal screening of all pregnant women, condom use and Pre-Exposure Prophylaxis (PrEP).

The antenatal screening programme was established in 2003 to reduce the risk of the HIV virus being passed to the baby through the placenta, during the birth or through breast milk. The multidisciplinary care provided to mother and child has been extremely successful in reducing this risk.

Condoms prevent HIV, other sexually transmitted infections and unwanted pregnancies. Free condoms are available in a wide range of venues in Wales and can now be ordered on-line through Sexual Health Wales On-line Testing Service. Ease of access to free condoms is further supported by the All-Wales Condom Card scheme. Young people aged 13-25 years can access free, confidential sexual health advice and free condoms from the Condom-Card (C-Card) Schemes across Wales. The schemes operate from youth centres, voluntary organisations, schools and colleges.

PrEP has been available to all those for whom it is indicated in Wales since July 2017 and is provided in Wales through sexual health clinics or infectious disease units.

Analysis has shown that PrEP is largely accessed by those who are aware and confident enough to access it, with under representation of young gay men, and people at risk of HIV through heterosexual sex. In addition, the current model for delivery of PrEP in Wales (through sexual health clinics only) disadvantages many rural communities and groups who traditionally avoid such clinics (women and ethnic minorities). Going forward, health boards must have care pathways in place for PrEP that meet need and demand.

While the significant social restrictions imposed at times during the Covid-19 pandemic did have a negative impact on use of PrEP, usage recovery has been swift and 1,302 individuals were prescribed PrEP in 2021. This is significantly more than the previous two years. 1,280 individuals were prescribed PrEP between July 2017 and September 2019. To address the inequity in awareness of and access to PrEP in underserved communities, pilot initiatives have commenced:



- Ask Me About PrEP programme in Wales – a peer-based approach to PrEP education
- PrEP Campaign – a social marketing campaign delivered by Terrence Higgins Trust.

Following evaluation of their effectiveness, the HIV Action Plan Oversight Group will make further recommendations to the Minister on effective targeted PrEP promotion initiatives that address low levels of knowledge, take up in relevant groups and continuity of care.

A number of service improvement initiatives have also been developed, these include a PrEP self-referral pathway using the Sexual Health Wales online home testing service, and Pretrack – an app that is designed to be used by the individual to keep track of their PrEP use.

## PREVENTION ACTIONS

7.	Continue to deliver, develop and evaluate the “Ask me about PrEP” programme in Wales.
8.	PHW, working with Fast Track Cymru collaborative networks and the voluntary and community sectors, will continue to support the wider use of, and diverse access to, PrEP (including the different regimens and formulations in development), through ongoing awareness raising for both the public and healthcare staff.
9.	Primary care and specialist sexual health services should develop and implement a shared care model to improve access and delivery of PrEP. This will enable PrEP to be provided in all health board areas, with particular emphasis on delivery in rural areas and in underserved communities. In addition, health boards and primary care clusters should explore how community organisations can support PrEP to develop a service that meets local needs. Timescale: Task and Finish Group to be established to develop the shared care model and support its implementation – by March 2023.

### **Priority 2: Testing**

HIV is a virus that causes a chronic lifelong infection that can be managed very successfully by antiretroviral therapy (ART). People diagnosed with HIV who are on ART live long and healthy lives. People who have the HIV virus for some years without a diagnosis and treatment will most likely develop advanced HIV disease or acquired immune deficiency syndrome (AIDS). For this reason, an early diagnosis is important. While it is recommended that all new diagnoses are seen within two

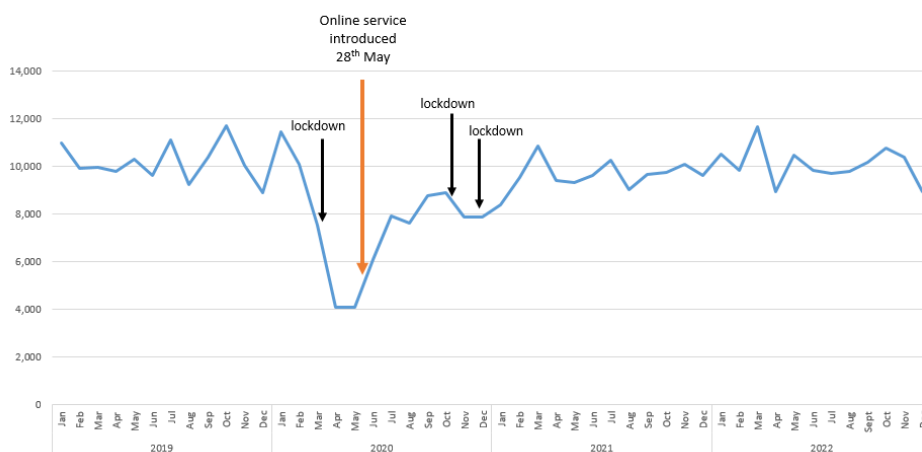
weeks it is also important that all close contacts are identified and screened to ensure they too receive the best care.

The successful HIV screening of pregnant women has been very effective at reducing transmission from mother to child, and the support those who are positive currently receive by the multi disciplinary teams must continue.

In addition, individuals who adhere to ART will have a sustained, undetectable level of HIV viral load in their blood and will not transmit HIV to their sexual partners. This is commonly known as **Undetectable = Untransmissible (U = U)**, where a person living with HIV who is on treatment and has an undetectable viral load cannot sexually transmit HIV.

While there is still more progress to be made, HIV testing episodes in Wales have recovered from the significant decline seen at the start of the pandemic. This is shown in the graph below.

HIV testing by month in Wales 2019 -2022



Covid-19 Lockdown Timeline - 2020

- 24<sup>th</sup> of March – 29<sup>th</sup> of May: First lockdown
- 23<sup>rd</sup> of October – 9<sup>th</sup> of November: Second “firebreak” lockdown
- 20<sup>th</sup> of December: Beginning of Third lockdown

Although the number of new HIV diagnoses is low, there is concern that a significant number of people are presenting with late-stage HIV. While life expectancy of people living with HIV on effective treatment is now similar to that of the general population, the most important predictor of morbidity and premature mortality is late diagnosis. Late diagnosis also increases the risk of onward HIV transmission.

In 2021, 42% of new cases in Wales were late diagnoses, an improvement on previous years. This is still unacceptable and there is an urgent need to understand the missed opportunities that have resulted in people presenting late and to take appropriate measures to address the barriers to testing. We also need to ensure that opportunities to offer a HIV test are not missed in health care settings, and that clinicians focus testing on those presenting with clinical signs or symptoms which may suggest infection with HIV.

Primary care will have a key role to play in the life course of HIV, this will include support for prevention initiatives, normalising testing for HIV, supporting provision for PrEP and being part of the multi-disciplinary response for those who are ageing and have other co-morbidities.

There will be many opportunities for healthcare providers to work together to provide seamless care and make every contact count. There is significant read across to the Hepatitis C elimination agenda and some of the communities we need to reach to achieve elimination will be the same ones we need to encourage to have an HIV test, including those with substance misuse issues and sex workers. Those who test negative should be advised and supported to consider PrEP. An Inclusion Health Programme is being developed by PHW to support this joined-up approach.

The Sexual Health Wales online home testing service has improved access to HIV testing for many, but more can be done to:

- improve the user journey for those requiring a test;
- reach out to and improve access to testing for underserved communities, including ethnic minorities;
- explore a “click and collect” service, known to improve access to people living with a partner or family members, those in houses of multiple occupancy and ethnic minorities.

HIV prevalence in Wales is low and we need to ensure that our HIV testing strategy reflects this, as it will be challenging to identify those with undiagnosed infection. The United Nations originally set a goal of 90-90-90 (that by 2030, 90% of people living with HIV will be diagnosed, 90% of those diagnosed will be on antiretroviral treatment and 90% of those receiving antiretrovirals will be virally suppressed). Work undertaken by Fast Track Cardiff and Vale, supported by data from Public Health England, shows that we had achieved this goal in Cardiff by 2018, but we can go further.

Evidence shows that, for low positivity areas, testing is focussed on primary care targeted home/community testing and testing for other clinical indicator conditions. Fast Track Cardiff and Vale has piloted a successful HIV testing initiative in GP practices in a Cardiff GP Cluster - *Texting for Testing* which is now being expanded to the other GP practices in Cardiff and the Vale. Through the proposed new collaborative Fast Track Cymru, this should be rolled out more widely by health boards and GPs across Wales. A link to the report on the pilot can be found here: [gp-facilitated-hiv-home-testing-pilot-evaluation-report-v1.0-15112021.pdf \(wordpress.com\)](https://www.gp-facilitated-hiv-home-testing-pilot-evaluation-report-v1.0-15112021.pdf)

An anonymised seroprevalence study undertaken by PHW for HIV and Blood Borne Viruses will guide any further refinements to our testing framework in Wales.

The emergence of mpox since May 2022 in multiple countries that are not endemic for mpox virus has reinforced the need to ensure that individuals who have developed symptoms have ready access to advice and appropriate testing and clinical care.

## TESTING ACTIONS:

10.	<p>We need to make every contact count. Testing should be in line with current BHIVA/BASHH/BIA Adult HIV Testing guidelines 2020 (HIV-testing-guidelines-2020.pdf (bhiva.org)).</p> <p>Testing provided as opt out for patients attending certain healthcare settings will be monitored through regular audit.</p> <p>PHW will provide a report on HIV prevalence in existing screening and testing programmes and make recommendations on specific population groups that would benefit from a seroprevalence study. The testing strategy may change depending on the outcome of this work.</p> <p>Timescale: End of March 2023 for receipt of the initial report from PHW on HIV prevalence in existing screening programmes.</p>
11.	<p>PHW will ensure that the online testing will continue to be made more accessible through the provision of sustainable funding for the existing online testing service including an option for rapid test and “click and collect” services. The online testing will be promoted more widely by PHW to tackle inequalities and the user journey improved.</p> <p>NB: Sustainable funding has now been secured and efforts will now focus on wider accessibility. Future monitoring arrangements will be agreed by the Oversight Group.</p>
12.	<p>A testing plan will be developed with Fast Track Cymru, health boards and voluntary and community partners to ensure no individual or community will be left behind when it comes to testing. This will include consideration of community HIV testing kits through community assets and groups, faith communities and support services to reach the needs of underserved populations.</p> <p>Timescale: Summer 2024 for completion of plan</p>
13.	<p>In collaboration with health boards and GP clusters, the GP “Texting for testing” pilot, which has operated successfully in certain areas of Cardiff, will be extended more widely throughout Wales.</p> <p>All general practitioners should support HIV prevention initiatives, normalise HIV testing and ensure as a minimum they can signpost to the online testing service.</p>
14.	<p>The all-Wales HIV testing week will be funded appropriately by Welsh Government for the duration of this action plan. Health boards, local authorities and partners will be expected to support this initiative.</p> <p>Timescale: Annual funding provided to begin in 2023/2024</p>

15.	Tackling late diagnosis will be made a priority. It will be mandatory that all late HIV diagnoses will be investigated and outcomes and lessons learnt reported to their health board and the HIV Oversight Group. The HIV Oversight Group will consider the outcomes of the investigations and agree actions to be taken to mitigate against further incidents.
16.	HIV awareness training will be mandatory for all front line healthcare staff. Training modules for clinicians will include raising awareness of the specific indicator conditions when HIV testing must be undertaken.  Timescale: training package to be developed by Autumn 2023

### **Priority 3: Clinical Care**

The primary aim of antiretroviral therapy (ART) is the prevention of HIV associated morbidity and mortality. The majority of people attending specialist HIV services are on effective ART with virological suppression and good treatment outcomes, including a life expectancy as good as the general population when treatment is started promptly. In the UK in 2020 around 99% of those diagnosed with HIV had initiated ART, with 97% of those on ART having a suppressed viral load. Specifically for Wales, in 2020 of the 2,448 residents of Wales receiving care for HIV 96% had achieved viral load suppression.

A further benefit of ART is the reduction in sexual transmission – **a person living with HIV who is on treatment and has an undetectable viral load cannot sexually transmit HIV.**

However, there remains a very small number of people living with HIV for whom engagement with clinical care and adherence to ART is extremely challenging and these individuals are at risk of increased morbidity and mortality, and of transmitting the virus to other people.

With the implementation of the Sexual Health Wales On-Line Testing Service, many asymptomatic individuals who previously would have attended sexual health clinics no longer require specialist sexual health service support. As a result, specialist sexual health services can focus resources on complex cases including those at high risk of HIV, particularly in underserved communities, with the aim of increasing testing, maximising provision of HIV prevention interventions (as above) and reducing the incidence of late HIV diagnosis.

HIV services (whether they are located in sexual health or other services, e.g. infectious diseases) require adequate staffing and other resources in order to provide high quality care to all people living with HIV, but in particular, newly diagnosed individuals, underserved communities and those individuals who struggle to engage with care and adhere to effective ART. This complex work requires a multidisciplinary approach with the aim of supporting people to take effective ART,

maintain an undetectable viral load and therefore to minimise onward transmission, thereby working towards the revised 95:95:95 goals and HIV elimination.

All pregnant women, either previously diagnosed with HIV or testing positive during pregnancy, should be provided with support from multidisciplinary services in order to prevent mother to child transmission of HIV.

While the number of children living with HIV in Wales is small, they do require provision of multidisciplinary medical care and continue to be supported by the well-established relationship between the Children’s HIV Association (CHIVA) and children in Wales with HIV.

All services must ensure that they can provide treatment and care for children of all ages and a smooth transition of care for teenagers and young adults. Care pathways must be in place to support this.

HIV services should participate in the BHIVA national audit programme and evaluate their services against the BHIVA Standards of Care for People Living with HIV.

The mental health requirements of those living with HIV also need to be better addressed. All HIV clinics should have access to psychological support and prioritise patient referral into peer support and mental health services elsewhere in the NHS or in the voluntary and community sector if needed.

**CLINICAL CARE ACTIONS:**

17.	<p>All services providing HIV care in Wales should review their staffing structure, supporting and protecting the HIV workforce. They need a skilled workforce to provide care to more complex cases, re-engage with positive individuals lost to care and can reach out to underserved populations.</p> <p>A focus must be maintained on those actually or potentially lost to care over the life of the plan. Care will be delivered in accordance with BHIVA Standards of Care for Living with HIV and BHIVA national guidance. This will involve innovative ways of working, and the co-production with PLWHIV, of care pathways with a focus on underserved populations.</p>
18.	<p>All health boards are expected to evidence that all children and young people living with HIV are supported by multi-disciplinary teams and that their transition to adult services is seamless.</p> <p>Pregnant women who are HIV positive must also be supported by a multi-disciplinary team.</p>
19.	<p>As people with HIV now live longer, they will, as with all ageing populations, develop comorbidities. It is imperative that their care is joined up with regular multi-disciplinary team meetings. Social care will need to be part of the dialogue where appropriate. See also action 22.</p>

20.	<p>All newly diagnosed individuals with HIV should be seen within a specialist HIV service within two weeks of diagnosis. All should be offered peer support and fully supported to remain in clinical care, as well as having access to psychological support.</p> <p>All efforts should be made to identify close contacts of HIV positive individuals so that they can be offered testing within two weeks, and on-going support.</p>
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#### **Priority 4: Living Well with HIV**

HIV is a long-term condition and being diagnosed with HIV can be distressing, with feelings of anxiety and depression being common. In addition to the support provided by specialist health clinic staff with referral to specialist counsellor or psychologist, many individuals access voluntary sector support provision. Most find it helpful to talk to others with HIV.

The number of older people living with HIV is growing for two main reasons: anti-retroviral therapies available now, allow many people to lead longer, healthier lives with HIV; and more people over 50 are also acquiring HIV.

Many of the medical problems now faced by people living with HIV have more to do with ageing than with HIV-related illnesses. People who have lived with HIV since the early days of the epidemic may face their own individual issues, both physically and psychologically. However, those over 50 who recently tested positive for HIV often experience the same problems that older people in general face. It is important that this is recognised and that the health and social care needs of both groups mentioned above are co-ordinated. Regular multi-disciplinary team meetings should be held to ensure that their needs are recognised, and actions taken to enable them to live well with HIV.

Benefits of support, including peer support, include maintaining health and well-being through better adherence and understanding of health conditions. Peer support has also been found to create economic benefits by reducing pressure on other health and social care services. It can also have an impact in strengthening communities, creating social connections and contributing to public health and prevention.

Wales does not currently have commissioned HIV support services across the country nor a dedicated HIV peer support network. Cardiff University has undertaken a review of peer support for people living with HIV in Wales and proposed potential principles and structures of an HIV peer support network for Wales, which will be further developed in dialogue with service users and providers. [Planning a new peer support service for people living with HIV in Wales: The first steps - News - Cardiff University](#)

It is important that people living with HIV understand and are empowered to have a role in the management of their health and well-being. There are a number of self-management courses and workshops for people living with any long-term health condition or a caring role. There is an opportunity in Wales to deliver a programme for those living with HIV through Education Programmes for Patients (EPP Cymru) run by Public Health Wales.

Inequality in HIV care is a matter of serious concern. We need to ensure that we reach out to underserved populations, including older people and ethnic minority groups living with HIV. There is no one-size-fits-all solution, but we need the meaningful involvement of their diverse communities using the most appropriate means of communication if the quality of life of those with HIV is to improve.

## **Living Well with HIV**

### **ACTIONS:**

<b>21.</b>	Those living with HIV will be empowered to better self-manage their health through participation in the Positive Self-Management Programme (PSMP) provided by EPP Cymru, PHW. Timescale: Summer 2023 for integration within this programme.
<b>22.</b>	As those living with HIV age over time it is important that they receive holistic, compassionate and non- discriminatory care, and that all who provide care and assistance are supported in delivering this.
<b>23.</b>	A national peer support programme for Wales will be commissioned by Welsh Government, following the now concluded research work carried out by Cardiff University into the potential principles and structures of such a programme. This peer support network will provide support to all those living with HIV that require it. A working group will be established to design the programme. Timescale: End of March 2023 for establishment of the group.
<b>24.</b>	Fast Track Cymru and its local networks working with voluntary and community groups should support health boards and local authorities to engage meaningfully with all diverse communities including ethnic minorities and faith groups so that testing for HIV is accepted, stigma is reduced and those living with HIV are supported to live better lives.

## **Priority 5: Tackling Stigma**

Fear and misunderstanding often lead to prejudice against people with HIV, even among service providers. This prejudice and discrimination can lead to feelings of



hopelessness and shame in those struggling to cope with their situation, creating a serious barrier to diagnosis and treatment.

Zero tolerance of stigma and discrimination is one of the five core principles in this action plan. Stigma impacts on the uptake of HIV testing, sharing of HIV status, engagement and retention in care with healthcare personnel, and uptake of and adherence to HIV treatment. This prevents people from using health care and fuels the ongoing transmission of HIV.

The health system collects a vast amount of insight from patients, and we want to ensure that we are acting on this feedback. The Positive Voices National Survey in 2017 provided insight into the experience of a large and representative sample at a UK level of the HIV population when accessing healthcare. Two centres in Wales promoted the survey and the results for Wales showed that:

- around one in seven patients have never told anyone about their HIV status outside a health care setting;
- 18% of patients reported that they were worried about being discriminated against in a health care setting in the last year;
- 21% of patients said they had avoided seeking healthcare when they had needed it in the last year and
- 5% said they had actually been refused healthcare or delayed a treatment or medical procedure in the last year.

HIV prevention is also dramatically hindered by stigma. Studies have linked stigma to increased risk, non-disclosure and avoidance of health services, including those which may prevent mother to child transmission of HIV.<sup>2</sup> Stigma is also linked to fear and avoidance of HIV testing.<sup>3</sup> Given the preventative benefits of HIV treatment, the part that stigma plays as a barrier to accessing testing and care has an important role in driving the epidemic. Tackling stigma is vital to improving the lives of people living with HIV and is integral to tackling HIV  
([Jun 16 Tackling HIV Stigma.pdf \(nat.org.uk\)](#))

The [Changing Perceptions report](#) identifies what needs to be done within the NHS, including zero tolerance of HIV stigma and discrimination, and staff training. An awareness of the low risk of transmission is important, as is raising awareness of actions and language that could be perceived as stigmatising.

The HIV Action Plan Working Group believe the most effective way to address stigma is through education:

- Know the facts. Educate individuals about HIV.
- Educate others. Pass on facts and positive attitudes; challenge myths and stereotypes.

**To achieve our goal of zero tolerance towards HIV stigma we propose the following actions:**

25.	<p>An HIV awareness training programme will be developed collaboratively, to address misunderstanding and stigma in the healthcare sector, and which will be mandatory for all healthcare providers.</p> <p>Timescale: Autumn 2023</p>
26.	<p>Social Care Wales will adapt this training programme for use in the social care sector and develop a plan for its delivery to all social care workers. Through this awareness raising, all care home providers should be confident that they can provide for the needs of those who are living with HIV and that no stigma will be attached to their diagnosis or care.</p> <p>Timescale: Autumn 2023</p>
27.	<p>The message that people living with HIV on effective treatment can't pass it on to a sexual partner will be promoted widely and all HIV training modules will be consistent with this message.</p>
28.	<p>Mandatory Relationships and Sexuality Education (RSE) will support learners to develop the knowledge and understanding of the causes, symptoms and impact of conditions such as HIV. (<a href="#">Cross-cutting themes for designing your curriculum - Hwb (gov.wales)</a>)</p> <p>High quality curriculum resources for schools will support learners with an aim to effectively address HIV, PrEP and stigma. We want all children living with HIV to have the support that meet their needs with no stigma attached to their diagnosis.</p> <p>Timescale: This work to be commissioned by March 2024.</p>
29.	<p>FTC will work with collaborating organisations and the advocacy network to ensure that awareness of stigma and the promotion of positive messages such as U=U and zero tolerance is a common and ongoing thread in their day-to-day work.</p>
30.	<p>PHW, working with partner organisations and people living with HIV, will introduce and promote an annual Wellbeing Survey of People Living with HIV to monitor whether change has been affected and is effective.</p> <p>Timescale: 2023 baseline year / 2024 for pilot of survey and collection of baseline data.</p>

**Summary of all Actions set within the HIV Action Plan:**

1.	Building on the success of the Fast Track Cities initiative in Cardiff and the Vale, a new national umbrella body, Fast Track Cymru (FTC) will be established and funded by Welsh Government. This body will provide capacity and strategic focus for stakeholders, community groups and decision makers, in local fast track collaborations to support the implementation of this Action Plan and ensure that all key partners work together to achieve our objectives. Timescale: Full establishment by March 2024
2.	Involvement of voluntary and community groups. In the implementation of this plan, Welsh Government, health boards, local authorities and other partners will work closely with the HIV voluntary and community sector.
3.	A case management surveillance system, overseen by Public Health Wales, will be funded and established to support clinical management and improve shared care. It will facilitate real-time data collection and timely publication and will ensure decision makers can measure their achievements against ambitions. Timescale: Funding to be made available in early 2023/2024 with implementation in 2024/2025
4.	Health boards and trusts will be required to detail actions they are taking to implement the actions of the HIV Action Plan in their delivery plans. This will include evidence that care pathways are in place to ensure all those living with HIV from infancy to old age are living well and receiving optimum care. Progress can be reported at quarterly Quality and Delivery meetings between Welsh Government and health boards. Timescale: Reporting on progress will commence in summer 2023 with the first annual Ministerial statement to the Senedd
5.	To strengthen the evidence base, a network of researchers in academia in Wales, in collaboration with PHW, will be established and will coordinate current and future research in HIV and sexual health.
6.	An HIV Action Plan Oversight Group, which will involve all key stakeholders including health boards, local government, clinicians, voluntary and community organisations and people living with HIV, will be established to monitor progress against our ambitions and to advise Ministers on progress and any further actions required. The Group will provide an

	<p>annual progress update on the implementation of this plan, following which the Minister will make an annual statement to the Senedd.</p> <p>Timescale: The Oversight Group to be established in the first quarter of 2023.</p>
7.	Continue to deliver, develop and evaluate the “Ask me about PrEP” programme in Wales.
8.	PHW, working with Fast Track Cymru collaborative networks and the voluntary and community sectors, will continue to support the wider use of, and diverse access to, PrEP (including the different regimens and formulations in development), through ongoing awareness raising for both the public and healthcare staff.
9.	<p>Primary care and specialist sexual health services should develop and implement a shared care model to improve access and delivery of PrEP. This will enable PrEP to be provided in all health board areas, with particular emphasis on delivery in rural areas and in underserved communities. In addition, health boards and primary care clusters should explore how community organisations can support PrEP to develop a service that meets local needs.</p> <p>Timescale: Task and Finish Group to be established to develop the shared care model and support its implementation – by March 2023.</p>
10.	<p>We need to make every contact count. Testing should be in line with current BHIVA/BASHH/BIA Adult HIV Testing guidelines 2020 (HIV-testing-guidelines-2020.pdf (bhiva.org)).</p> <p>Testing provided as opt out for patients attending certain healthcare settings will be monitored through regular audit.</p> <p>PHW will provide a report on HIV prevalence in existing screening and testing programmes and make recommendations on specific population groups that would benefit from a seroprevalence study. The testing strategy may change depending on the outcome of this work.</p> <p>Timescale: End of March 2023 for receipt of the initial report from PHW on HIV prevalence in existing screening programmes.</p>
11.	PHW will ensure that the online testing will continue to be made more accessible through the provision of sustainable funding for the existing online testing service including an option for rapid test and “click and collect” services. The online testing will be promoted more widely by PHW to tackle inequalities and the user journey improved.

	NB: Sustainable funding has now been secured and efforts will now focus on wider accessibility. Future monitoring arrangements will be agreed by the Oversight Group.
12.	A testing plan will be developed with Fast Track Cymru, health boards and voluntary and community partners to ensure no individual or community will be left behind when it comes to testing. This will include consideration of community HIV testing kits through community assets and groups, faith communities and support services to reach the needs of underserved populations. Timescale: Summer 2024 for completion of plan
13.	In collaboration with health boards and GP clusters, the GP “Texting for testing” pilot, which has operated successfully in certain areas of Cardiff, will be extended more widely throughout Wales.  All general practitioners should support HIV prevention initiatives, normalise HIV testing and ensure as a minimum they can signpost to the online testing service.
14.	The all-Wales HIV testing week will be funded appropriately by Welsh Government for the duration of this action plan. Health boards, local authorities and partners will be expected to support this initiative. Timescale: Annual funding provided to begin in 2023/2024
15.	Tackling late diagnosis will be made a priority. It will be mandatory that all late HIV diagnoses will be investigated and outcomes and lessons learnt reported to their health board and the HIV Oversight Group. The HIV Oversight Group will consider the outcomes of the investigations and agree actions to be taken to mitigate against further incidents.
16.	HIV awareness training will be mandatory for all front line healthcare staff. Training modules for clinicians will include raising awareness of the specific indicator conditions when HIV testing must be undertaken.  Timescale: training package to be developed by Autumn 2023
17.	All services providing HIV care in Wales should review their staffing structure, supporting and protecting the HIV workforce. They need a skilled workforce to provide care to more complex cases, re-engage with positive individuals lost to care and can reach out to underserved populations. A focus must be maintained on those actually or potentially lost to care over the life of the plan. Care will be delivered in accordance with BHIVA Standards of Care for Living with HIV and BHIVA national guidance. This will involve

	innovative ways of working, and the co-production with PLWHIV, of care pathways with a focus on underserved populations.
18.	<p>All health boards are expected to evidence that all children and young people living with HIV are supported by multi-disciplinary teams and that their transition to adult services is seamless.</p> <p>Pregnant women who are HIV positive must also be supported by a multi-disciplinary team.</p>
19.	As people with HIV now live longer, they will, as with all ageing populations, develop comorbidities. It is imperative that their care is joined up with regular multi-disciplinary team meetings. Social care will need to be part of the dialogue where appropriate. See also action 22.
20.	<p>All newly diagnosed individuals with HIV should be seen within a specialist HIV service within two weeks of diagnosis. All should be offered peer support and fully supported to remain in clinical care, as well as having access to psychological support.</p> <p>All efforts should be made to identify close contacts of HIV positive individuals so that they can be offered testing within two weeks, and on-going support.</p>
21.	<p>Those living with HIV will be empowered to better self-manage their health through participation in the Positive Self-Management Programme (PSMP) provided by EPP Cymru, PHW.</p> <p>Timescale: Summer 2023 for integration within this programme.</p>
22.	As those living with HIV age over time it is important that they receive holistic, compassionate and non- discriminatory care, and that all who provide care and assistance are supported in delivering this.
23.	<p>A national peer support programme for Wales will be commissioned by Welsh Government, following the now concluded research work carried out by Cardiff University into the potential principles and structures of such a programme. This peer support network will provide support to all those living with HIV that require it. A working group will be established to design the programme.</p> <p>Timescale: End of March 2023 for establishment of the group.</p>

24.	Fast Track Cymru and its local networks working with voluntary and community groups should support health boards and local authorities to engage meaningfully with all diverse communities including ethnic minorities and faith groups so that testing for HIV is accepted, stigma is reduced and those living with HIV are supported to live better lives.
25.	An HIV awareness training programme will be developed collaboratively, to address misunderstanding and stigma in the healthcare sector, and which will be mandatory for all healthcare providers.  Timescale: Autumn 2023
26.	Social Care Wales will adapt this training programme for use in the social care sector and develop a plan for its delivery to all social care workers. Through this awareness raising, all care home providers should be confident that they can provide for the needs of those who are living with HIV and that no stigma will be attached to their diagnosis or care.  Timescale: Autumn 2023
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28.	Mandatory Relationships and Sexuality Education (RSE) will support learners to develop the knowledge and understanding of the causes, symptoms and impact of conditions such as HIV. ( <a href="#">Cross-cutting themes for designing your curriculum - Hwb (gov.wales)</a> )  High quality curriculum resources for schools will support learners with an aim to effectively address HIV, PrEP and stigma. We want all children living with HIV to have the support that meet their needs with no stigma attached to their diagnosis.  Timescale: This work to be commissioned by March 2024.
29.	FTC will work with collaborating organisations and the advocacy network to ensure that awareness of stigma and the promotion of positive messages such as U=U and zero tolerance is a common and ongoing thread in their day-to-day work.
30.	PHW, working with partner organisations and people living with HIV, will introduce and promote an annual Wellbeing Survey of People Living with HIV to monitor whether change has been affected and is effective.  Timescale: 2023 baseline year / 2024 for pilot of survey and collection of baseline data.