

HIV Action Plan for Wales

Question 1. Do you agree with the five overarching actions identified within this plan? Are there other overarching actions that should be included?

These 'overarching actions' are welcome and will drive change – especially the creation of Fast Track Cymru (Action 1), the involvement of the voluntary sector (Action 2) and improved data with a new 'case management surveillance system' (Action 3).

While it is welcome that 'health boards and trusts will be required to report actions they are taking to implement the HIV Action Plan' (Action 4) so too must Public Health Wales, NHS Wales and the Welsh Government as a whole. In Westminster and Holyrood annual reports to parliament are included in their respective plans, this should be true in Wales too. The Senedd needs to monitor progress of the plan and the 2030 goal, as Senedd debates on 1st December 2021 and 14 June 2022 show that there is an appetite for this from legislators.

This monitoring should take the form of a formal evaluation – with the creation of a monitoring and evaluation framework underpinning the various aims and actions in the plan. This should include accurate and measurable targets so that progress can be clearly tracked by political, healthcare and community stakeholders. This monitoring should be done annually to allow time for proper scrutiny by the Senedd and to ensure any necessary corrective actions by relevant bodies and organisations to meet the Plan's progress are implemented in a timely fashion. Evaluation should also take a note of, and propose any remedial action to, any differences between different localities within Wales. Equity should be a key overriding aim of the plan – that gains are made across all population groups, across men and women living with and at risk of HIV, all ethnic groups and areas of Wales.

The HIV Action Plan Oversight Group (Action 5) must have each health board represented as well as local government, the HIV voluntary sector and people living with HIV. The people living with HIV should come from diverse groups affected by HIV – to ensure that the experiences are diverse and not merely reflective of the most engaged communities on HIV issues (typically white men who have sex with men (MSM)).

Question 2. Do you agree with the proposed list of actions? Are there any that you would add or remove from the 26 currently identified?

The scale and scope of the HIV Action Plan are welcome. There are some particularly strong recommendations.

However, there are a number that need to be strengthened further:

- PrEP in GPs and Pharmacy: What is the deadline for this action? (Action 8)

If there is no deadline to achieve this action, there is a chance that it will not be achieved by the end date of the Action Plan. Currently PrEP is only available in sexual health clinics, which are typically urban services and are less likely to be visited by those groups with the worse HIV outcomes. It is vital for both rural constituents across Wales and women and ethnic minority groups that access to this HIV prevention drug is available in GPs and pharmacies by April 2023.

- No missed opportunity to test for HIV (Action 9)

There should be an explicit commitment in Action 9, that no one should leave a sexual health clinic without being offered a HIV test (for all those not previously diagnosed with HIV). There are common instances of people not being offered an HIV test in sexual health setting or being given an introductory conversation about PrEP and HIV prevention. This must change. Those not offered, and most likely to decline a test, are from communities that experience the greatest health inequalities. This must become a normal process and seen as routine in the eyes of all sexual health patient in Wales.

- The anonymised seroprevalence study (Action 9)

One of the most important parts of the action plan is lost in the prose of the report and not reflected in the actual actions. The 'anonymised seroprevalence study' is vital to evaluating whether an end of day batch-HIV testing system would be effective in diagnosing people, especially those from groups likely to present late. The accountability of this proposal cannot be lost and should be monitored in line with

our above suggestions for monitoring the Action Plan's priorities.

There are some issues not currently addressed in the actions:

- Missing in the 'Testing' section: Anything on 'partner notification'

The focus on partner notification cannot be lost, as this is important to stop HIV transmission. The experience of the COVID-19 'Track and Trace' program shows that sexual health clinics have proved effective at doing this when they are resourced to do so.

- Missing in the 'Clinical Care' section: Coordination with other health and non-health services

As outlined in the England HIV Action Plan, the Welsh Action Plan should include an action for health manager to work with local providers and community organisations to ensure better co-delivery between drug and alcohol services (including a specific focus on chemsex issues), domestic violence, mental health, and sexual health services. This should also consider the specific needs of other groups such as migrants, the homeless or those in insecure housing.

- Missing in the 'Living Well' section: Anything on ageing

People living with HIV are now living into old age, meaning increasingly they face issues with older age, polypharmacy, interaction with other life-long conditions and social care needs. This is a remarkable phenomenon given the historical context of the disease. Whilst it is great that combating HIV-related stigma in social care workers is a priority for this report, this is not the only issue about aging with HIV. There are also issues associated with long periods without treatment; poverty; adherence to drugs; co-morbidities; trauma and experiencing long term stigma. This should be an ongoing programme of work for the oversight group.

- Missing in the 'Stigma' section: Anything on formal discrimination

Stigma isn't just a societal problem - out-dated ideas live in policies of important organisations. For example, in Wales:

- o The DVLA (based in Swansea) still asks people to tell them if they are 'living with AIDS' at risk of £1000 fine, even though nearly all people living with HIV do not go on to develop AIDS today.
- o Welsh Boxing requires a HIV test before every competitive fight, despite no risk of HIV transmission from any activity involved in boxing.
- o In Wales, the partners of people living with HIV on effective treatment still cannot give blood, despite scientists recommend ending the ban in 2020 and the PARTNER2 study confirming there is no risk of HIV transmission in a sexual relationship with someone who is undetectable.

NAT through our helpline, regularly receives cases of people living with HIV denied access to services (whether tattooing/piercing, beauty treatments or care services), facing challenges getting insurance or experiencing discrimination and poor treatment at work.

The Welsh Government should be an active partner in challenging stigma & prejudice against those living with HIV and make a commitment in the Action Plan to review and repeal existing legislation and guidelines that discriminate against people living with HIV in Wales (directly or indirectly). This should include a commitment to raise relevant identified issues with the Westminster Government if the legislation concerned is not a devolved matter.

Question 3. What are the challenges that could mean the commitment to eliminating HIV transmission by 2030 are not met? Are there any clear challenges relating to any specific actions you feel should be highlighted?

The £3.9m to make postal HIV sample testing, with 'including an option for rapid test and "click and collect" services' permanent is vitally important and extremely welcome.

However, funding for some of the other actions and innovations in the report is yet to be committed. These are going to be key to the Action Plan's success. For example:

- An all-Wales HIV testing week (Action 14)– the report says it 'will be funded appropriately by Welsh Government for the duration of this action plan'. This must include the resources to get to first time testers and those in communities who have lower rates of HIV testing.
- The national peer support programme for Wales (Action 19) – the plan says it 'will be commissioned by Welsh Government in the autumn of 2022'. This must be able to meet the need identified by the Cardiff University research and the effectiveness of the programme should be formally evaluated.

In addition, key actions need clearer timescales and deadlines for completion. The case management surveillance system (Action 2, end of 2022), PrEP being provided by GPs and community pharmacies in all health board areas (Action 8, should be by April 2023) and the HIV awareness training programme for healthcare and social care workers (Action 21 & 22, summer 2023) all require clearer timescales for delivery, to allow for clearer evaluation of these actions.

Finally, while we welcome that 'it will be mandatory that all late HIV diagnoses should be investigated and reported by health boards', the default should be that this is dealt with under the Serious Incident process. This call has been longstanding from BHIVA and was included in the HIV Commission's key recommendations.

There are also specific concerns related to the ongoing monkeypox outbreak. If the outbreak is not kept under control, and if the vaccine is not rolled out quickly enough, then there is a danger that sexual health services may be deprioritised. If HIV services are deprioritised to contain the monkeypox outbreak, this could derail goals to eliminate transmission by 2030, in the short term – by failing to make progress against the 2030 goal.

The Welsh Government must therefore ensure that the monkeypox outbreak is appropriately resourced – so the burden of dealing with it does not fall squarely on sexual health services. In this way, the sector need not be distracted from provision of key sexual health services, including those related to eliminating HIV transmission.

Question 4. Are there any resources (this could include funding, staff time, training, access to support or services among other things) that are not referred to in our Plan, but will be necessary in achieving the aims and actions detailed within this Plan?

None of the Plan's aims can be achieved without appropriate leadership by the Welsh Government. This has been in abundance at a national level – such as by inclusion in every party's manifesto, the First Minister making this a priority policy and the scheduling of two Senedd debates on this topic in seven months. However, this must be replicated locally. Health boards need to be accountable to local and national oversight and must be represented on the Oversight Group. Local sexual health service planners must have the appropriate funds to deliver on the priorities in the Action Plan, and funding levels must be reviewed regularly.

Funding is needed for the plan's anti-stigma work. This will not happen without drive and resource. The message that people living with HIV on effective treatment cannot pass it on to a partner should be promoted widely (Action 23) – funding for a prolonged campaign and the commitment of at least several partners is needed. The HIV voluntary sector is best placed to do this work in partnership with the Welsh Government.

Similarly, as outlined in the England HIV Action Plan, there must be clear financial accountability and responsibility for PrEP provision in the community. This will ensure that organisations at a local level are held responsible for ensuring all those that need to access PrEP will be able to do so, including for conducting the necessary community outreach.

From a survey of clinicians conducted by NAT & the Terrence Higgins Trust (results to be published in a forthcoming report), one of the clearest findings was that staff within the sector are not adequately trained in the prescribing & dispensation of PrEP. This was seen as a barrier to clearing waiting lists and ensuring that there were enough appointments to dispense & prescribe PrEP to all those who are at risk of HIV. Specific training could include the use of patient group directions, which were seen as a skills gap for many clinicians.

Question 5. We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to report them:

Success: How will the Senedd know that the HIV Action Plan is a success? Is Wales confident it has met the UNAIDS 2020 goal of 90-90-90 (% of those living with HIV diagnosed, in treatment, undetectable)? Where is the commitment to meet the UNAIDS mid-decade goal of 95-95-95? Will Welsh Government meet the HIV Commission's recommendation to get new diagnosis down by 80% from 2019 levels by 2025? Interim milestones are vital to ensure adequate progress is being made towards 2030, and work is not being backloaded.

Postal testing: Does the £3.9m for the postal testing service includes budget to promote the service to users, particularly those from underserved groups and those who have yet to test or test infrequently but would be advised to test? Will this recognise the balance between volume of tests and the higher costs to get some at-risk communities to test? Will this be linked to funding for HIV Testing Week?

Peer support: Will clinics be encouraged or directed to refer newly diagnosed people into the soon -to-be-commissioned Peer Support programme and the resources be able to support this? Manchester Hospitals have developed an opt-out referral service to George House Trust's peer support with positive outcomes after only a short period.

Capacity & resources for evaluation: There is a question about whether there will be additional resources to drive the plan and its actions, and to formally evaluate the actions with the Plan. If all the Plan's actions are not formally evaluated, it will be impossible to know if Wales is meeting its targets. A new section on intended evaluation of the Plan would add confidence that there will be accountability for delivering the Plan's intended actions, and that lessons will be learned if the actions are not achieved.

Measurement of stigma: There is a question of how can reduction in stigma (Priority 5) be measured? This could potentially be through evaluated programmes – such as by gathering data on how successful these education plans are. A broad-brush survey (Action 26) will not necessarily provide data on the effectiveness of the individual programmes – evaluation will need to be built into the design of all programmes to determine which approach(es) are effective and which are not.

Human rights of people living with HIV: As part of the Action Plan, the Welsh Government should commit to safeguarding & standing up for the rights of people living with HIV in Wales. The Bill of Rights legislation currently passing through the Westminster Parliament may have negative implications for human rights for people living with HIV and other groups vulnerable from the withdrawal of current human rights legislation. The Welsh Government could make an explicit commitment in the Action Plan to stand against the principles of this legislation, and to actively stand up for the human rights of those living with or at risk of contracting HIV.

The Welsh Government should also review new Welsh and UK national legislation to consider if any other national legislative changes will similarly impinge on the work of the Action Plan & the rights and/or dignity of people living with HIV. If such legislative changes are identified, the Welsh Government should reach out to community organisations to discuss the impacts of such legislation, and how to best challenge these.

Submit your response

You are about to submit your response. Please ensure you are satisfied with the answers you have provided before sending.

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If you want to receive a receipt of your response, please provide an email address.

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