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Welsh Government
Consultation – summary of responses

Draft HIV Action Plan for Wales (2022)

March 2023

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Overview

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. A consultation on a draft HIV Action Plan was held between 14 June 2022 and 14 September 2022. This document provides a summary of the responses to the consultation.

Action Required

This document is for information only.

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Additional copies

This summary of response and copies of all the consultation documentation are published in electronic form only and can be accessed on the Welsh Government's website.

Introduction

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.

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 consisted 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 were 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.

Consultation

The draft HIV Action Plan for Wales contained clear priorities and targeted actions that relate to these priorities. The aim of this consultation was to help us establish whether these were the correct priorities and actions to focus on to achieve our aims. There were 5 questions for consideration, however we also welcomed general contributions.

During the consultation period, Welsh Government held two online consultation/information sessions to provide an overview of the draft Action Plan, its aims and proposed approach for organisations and those members of the public with an interest in this area. Fast Track Cities Cardiff and the Vale also hosted a well-attended public meeting to discuss the HIV Action Plan.

Who responded to the consultation

We received 55 responses to the main consultation. The Welsh Government would like to thank all those who responded, in particular those individuals living with HIV.

The respondents represented a range of public, private and third sector bodies, as well as health boards, organisations working with individuals living with HIV and importantly those living with HIV.

Key messages

There were a number of themes that came through in responses to more than one of the consultation questions, and as a result of these, the key changes to the original draft plan are as follows:

- Proposed timescales for completion of the key actions have been added to the plan where relevant.

- A commitment has been added that the Minister for Health and Social Services will make an annual statement to the Senedd on progress in implementing the plan.
- Increased emphasis on the role primary care will have 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 illnesses.
- A new action requiring all health boards to evidence that children and young people living with HIV are supported by multi-disciplinary teams, and that their transition to adult services is seamless.
- A new action highlighting the fact that as people with HIV now live longer, they will, as with all ageing populations, develop comorbidities and it is imperative that their care is joined up with regular multi-disciplinary team meetings.
- A new action stating that the evidence base and current research undertaken in sexual health and HIV will be optimised and overseen by PHW and the Research Network from Welsh universities.
- Actions on stigma have been strengthened, particularly in relation to care home and school settings.

Summary of responses

All the responses have been considered and informed the final version of the HIV Action Plan for Wales. This document summarises responses to the consultation questions. It does not aim to capture every point raised by respondents. It presents the key recurring themes and issues.

Not all respondents replied to every question. Some respondents who replied provided general responses rather than answering the specific questions. Where this is the case, the response has been included under the most appropriate question.

Question 1

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

Most respondents agreed with the overarching actions, though there were some specific comments relating to some actions and additional points to consider.

Common themes included:

Strong support for the Case Management system. Consensus from many respondents that this would be huge asset in delivering on many of the actions within the Plan. Suggestions to link with Welsh clinical portal to reduce error associated

with manual input of test results. Comments that the system should include children, but overall overwhelming agreement that this would be an important step in addressing the current challenges Wales experiences with data.

In relation to health boards and trusts being asked to report on the implementation of the actions within the plan, a number of respondents suggested that shared responsibility and monitoring should also include PHW, NHS Wales and WG. Suggestions made that health boards would benefit from suitable guidance with timescales to ensure the required information was accurately reported and consistent. Several respondents called for outcome measures or key performance indicators to be included to help monitor the implementation and success of the plan.

There was a suggestion that membership of the Oversight Group should be included within the plan with membership drawn from a range of interest groups and organisations including Women's health, maternity and Antenatal Screening Wales and children's groups representatives. This would ensure a strong voice for children, women and maternity services which did not feature prominently in the draft plan. Also strong consensus, as with the Task and Finish Group, that people living with HIV be represented on the Oversight Group.

There were suggestions that research could be added as an action in the plan and that strengthened research and data collection could direct and highlight development areas, changing demographics, attitudes and whether stigma is being reduced.

There were a range of other points and suggestions also noted as responses to this question. These included:

Embedding testing in primary care was a priority.

Provision of multidisciplinary medical care and treatment for children should be included, including transition services for teenagers and young adults linking paediatrics and sexual health.

Provision and prevention of mother to child transmission of HIV for all pregnant women testing positive for HIV.

There should be more information about HIV in the school curriculum.

In relation to HIV stigma, there were several comments that measuring progress would be challenging. There was a suggestion that it would be helpful to develop indicators that capture individual level drivers in and outside of healthcare settings. These could include fear of infection, prejudice, blame and social judgement, and organisation level drivers such as social/cultural norms, policies and practices.

Many respondents were concerned about health board resources, workforce and funding to deliver these overarching actions and wider actions within the plan.

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?

There was overwhelming support for the action list. Many respondents stressed the importance of access to PrEP in primary care as well as sexual health clinics. This was particularly important for patients in rural areas and those in underserved groups. Many also suggested that this action in particular required a timeframe.

Other suggestions included:

That there should be an explicit commitment that no one should leave a sexual health clinic without a HIV test.

That the proposed seroprevalence study for HIV and blood borne viruses should be a specific action.

That reference to partner notification and track and trace system was missing from the testing section.

That there should be more reference and focus in the plan on those ageing with HIV and for those experiencing comorbidities and access to other NHS services and social care. Several respondents commented that there should be a specific action for ageing (over 50) people living with HIV.

A number of respondents commented that Welsh Government should remain vigilant about how outdated rules can impact negatively on those living with HIV, and to work with partners to ensure latest evidence informs policy and service providers.

There was no reference to formal discrimination in the stigma section.

There was strong and consistent support for the online testing which continues to encourage more people to test more regularly.

That there should be better HIV training for GP's, mental health nurses and psychiatrists in general and specifically to address stigma around people who take PrEP.

There was a query on why health boards should hold annual meetings to discuss late diagnoses and that lessons were best learned sooner after the event, followed by prompt action if necessary.

Case Management system. As mentioned in the Question 1 analysis, there was strong and overwhelming support for this system and the impact it would have on achieving the aims of this plan, and the overall WHO 2030 target. Many respondents commented that it was important that such a system could link with other health data sets to enhance the understanding of the epidemiology of HIV infections.

There was a need to ensure young people can access services and are aware of them.

There was a comment on the importance of ensuring that HIV testing strategies include the testing of children and youth, and that Wales should have a funded HIV paediatric care team ensuring children have access to specialist care and support.

Not all respondents agreed with the expansion of the Texting for Testing pilot. There was a suggestion that there could be potential harm to patients who receive this text and might be distressed by it.

The provision of improved peer support was an important action and should not only be for patients, but partners and family members of those living with HIV.

That educational settings (HE & FE) could provide additional opportunities to engage and increase participation in HIV testing.

There was a suggestion that a national clinical network for sexual health and HIV should be established. Without a clinically led network sitting in the new NHS Executive, there was a real risk that this could undermine and derail the HIV action plan as health boards may not prioritise its implementation.

That sexual health services should maximise equality of access to condoms and related advice and information.

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?

Common themes identified in the responses were:

Lack of budget – a high majority of responses referred to budget and reduction to services within sexual health currently happening due to financial pressures. Funding for some of the actions listed are going to be key to the Action Plan's success, in particular the case management system; testing week to include resources to get first time testers engaged; peer support programme and importance of this meeting the need as identified by the Cardiff University research.

Realistic and sustained funding was key to the action plan's success. Funding was required to establish Fast Track Cymru and ensure that it provides an equitable service across Wales.

Key actions require timescales and deadlines to ensure commitment and delivery, in particular on the case management system, PrEP to be provided in communities and the training programme for health and social care staff.

There were several comments that the needs of children, young people and pregnant women needed to be reflected in the Plan.

The plan needed to recognise the challenges of engaging with underserved groups

which might include certain ethnic minorities and those residing in prisons.

There was a comment that NHS Wales was continuing to face intense challenges during recovery from the COVID pandemic. New challenges were emerging such as Mpox which disproportionately impacts MSM and places additional pressures on sexual health and infectious disease services. These combined challenges meant that it might not be possible to prioritise all the actions set out in current policies and frameworks.

One respondent had concerns about the future of the HIV and sexual health workforce in Wales and suggested that there needed to be a costed workforce plan focused on the training, recruitment and retention of specialist HIV staff, including physician associates.

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?

Comments on this question included:

More training in workplaces such as compulsory sessions for staff about people living with HIV.

Leadership was key to the successful implementation of the actions. This has been in abundance at a national level with inclusion in every Party's manifesto, however this must be replicated locally. Health boards need to identify someone who can steer the work and be accountable to local and national oversight. Health boards and trusts needed to be represented on the Oversight Group.

Specialist psychological support was a gap that needed to be addressed in the final plan.

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.

A number of different points were noted in response to this question:

Some questioned whether the goals and targets were achievable and how success would be measured.

The vast majority of the respondents were very supportive of the actions within the Plan and expressed pride that Wales was taking the lead in this area.

There were comments that the Plan should be strengthened from a women's health perspective, drawing out links with the wider health team, including midwifery.

Welsh Government response

Your views were important in contributing to and finalising our HIV Action Plan for Wales. Welsh Government is grateful to everyone who has participated in this consultation, whether through submitting a response or participating in the engagements events both online and the face to face event facilitated by our partner organisation.

As a summary document, not all the points made in the responses may have been reflected fully in the finalised version of the Plan. Each response has been considered and the absence of issues or suggestions does not mean they have been disregarded; indeed, many will be considered by the HIV Action Plan Oversight Group.

As a result of the feedback four new actions were developed, and other sections and actions strengthened. The new actions are:

- 1. 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.**
- 2. 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. Pregnant women who are HIV positive must also be supported by a multi-disciplinary team.**
- 3. 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.**
- 4. 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.**

Next Steps

We have used the feedback in the consultation responses to update the HIV Action Plan for Wales. The revisions mentioned above were considered and agreed by the HIV Action Plan Task and Finish Group, the Minister for Health and Social Services and the Welsh Government's Cabinet. We are currently establishing a new HIV Action Plan Oversight Group that will oversee the delivery of the actions agreed within this finalised plan.