The Scottish Parliament
Pàrlamaid na h-Alba

Ms Jenni Minto, MSP
Minister for Public Health and Women's Health
Scottish Government

Via email only

Equalities, Human Rights and Civil Justice Committee
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8 May 2024

Dear Minister

Scotland's HIV anti-stigma campaign/Achieving zero transmissions by 2030

Thank you for your attendance at our recent Committee meeting in relation to our work on HIV in Scotland focussing on the anti-stigma campaign and the Scottish Government's aim to eliminate transmissions of new cases by 2030.

The Committee welcomes the publication on 26 March 2024 of the Scottish Government's Ending HIV Transmission in Scotland by 2030: HIV Transmission Elimination Delivery Plan 2023-26, and we are pleased to set out our findings from our evidence sessions.

We look forward to receiving your response once you have had the opportunity to consider the Committee's conclusions.

Should you have any questions, please contact the Clerk to the Committee at EHRCJ.committee@parliament.scot.

With best wishes

Yours sincerely

Karen Adam MSP
Convener
Equalities, Human Rights and Civil Justice Committee

HIV in Scotland: Anti-stigma campaign/Achieving zero transmissions by 2030

EHRCJ Committee: Findings and Recommendations

Background

1. The Clerks and the Committee's former convener, Kaukab Stewart met with representatives of the Terrence Higgins Trust and Waverley Care on 26 October 2023 to discuss issues they wished to highlight to the Committee. The meeting primarily focused on:

    - Scotland's HIV anti-stigma campaign; and
    - Achieving zero new transmissions of HIV in Scotland by 2030.

Scotland's HIV anti-stigma campaign

2. In 2022, the Scottish Government committed to funding a national HIV anti-stigma and education campaign in the form of a short film. This was produced by Terrence Higgins Trust and informed by Scottish Government funded research from YouGov into attitudes and beliefs about HIV in Scotland.

3. The short film is the first to highlight HIV since the Government's "Don't Die of Ignorance" campaign featuring falling tombstones 40 years ago and provides an update on the significant medical progress that has made in the treatment of HIV in Scotland.

4. The film attempts to tackle the issue of stigma surrounding the virus by featuring four depictions of HIV stigma based on real experiences of people living with HIV in Scotland.

5. It concludes with the message that stigma is now more harmful than HIV and that the stigma is having a significantly detrimental impact on the lives of people living with HIV.

Achieving zero new transmissions of HIV in Scotland by 2030

6. In 2020, the Scottish Government committed to eliminating new transmissions of HIV by 2030. In December 2022, Scotland's HIV Transmission Elimination Oversight Group published 22 recommendations as part of the Ending HIV Transmission in Scotland by 2030 proposal setting out a route map to achieving Scotland's 2030 goal.

7. At the end of October 2023, the Scottish Government announced that it would be publishing Scotland's HIV Transmission Elimination Delivery Plan "in the coming months" (26 October 2023). An update on HIV Transmission Elimination – Sexual health and blood borne virus action plan: 2023-2026 was published on 28 November 2023.

8. In December 2023, the Scottish Government announced the piloting of opt out blood borne virus testing in three Scottish health boards – NHS Lothian, NHS Highland and NHS Grampian. This is discussed in more detail at paragraphs 67- 76.

9. PrEP (Pre-Exposure Prophylaxis) which is almost 100% effective as a preventative measure can be taken by those at risk of HIV. It is currently administered by sexual health clinics. In December 2022 the Scottish Government announced that it was developing an online e-PrEP clinic. This is discussed in more detail at paragraphs 79-91.

Consideration by the EHRCJ Committee

10. As part of its work programme discussion at its meeting on Tuesday 19 December 2023, the Equalities, Human Rights and Civil Justice Committee agreed to undertake a short inquiry on the progress made with the treatment of HIV in Scotland focussing on the importance of reducing stigma surrounding HIV and the Scottish Government's forthcoming HIV Transmission Elimination Delivery Plan.

11. The Committee also agreed to undertake engagement work with participants who have experience of living with HIV before hearing from the Minister for Public Health and Women's Health.

Oral evidence

12. At its meeting on 12 March 2024[1], the Committee heard from a range of witnesses representing organisations and specialist health services that support people living with HIV:

- Alan Eagleson, Head of Services, Terrence Higgins Trust Scotland
- Gabrielle King, Policy and Research Manager, Waverley Care
- Prof. Claudia Estcourt, Professor of Sexual Health and HIV, Glasgow Caledonian University
- Dr Bridie Howe, BASHH Scotland Chair and HIV lead, NHS Highland.

and then from:

- Dr Kirsty Roy, Consultant in Health Protection, Public Health Scotland
- Nicky Coia, Health Improvement Manager (Sexual Health), NHS Greater Glasgow
- Dr Daniela Brawley, Consultant in Sexual Health and HIV, NHS Grampian
- Dr Dan Clutterbuck, Consultant in Genitourinary and HIV medicine, NHS Lothian.

[1] Official Report of the 8th Meeting of 2024 of the Equalities, Human Rights and Civil Justice Committee, 12 March 2024

13. The Committee also held an engagement session with people living with HIV. We are grateful to the Terrence Higgins Trust and Waverley Care who, in partnership with the Scottish Parliament's PACT team, were able to facilitate this session.

14. We would like to thank everyone who gave evidence to this inquiry but are particularly grateful to the individuals for the time they took to share their experiences of living with HIV. The Committee recognises that this took enormous courage and many of their stories were difficult to hear. This evidence was invaluable to our work.

15. Finally, at its meeting on 26 March[2], the Committee heard from:

- Jenni Minto, MSP, Minister for Public Health and Women's Health, and
- Rebekah Carton, Sexual Health, BBV and Respiratory Surveillance Team Leader, Scottish Government.

Key themes

The nature and impact of stigma

16. The Committee heard from people living with HIV that stigma continues to affect lives daily. Participants spoke of its far-reaching emotional impact describing receiving their diagnoses as being "life changing" and "devastating", resulting for some in suicidal thoughts, feelings of self-hate, shame and withdrawal from their normal lives.

17. Furthermore, the impact led many to withholding information about their status from the people from whom they most need support. They felt unable in many situations to look to their loved ones for support because of the self-stigma that their status creates.

18. We heard that, not only did participants have to come to terms with their HIV status, they were also faced with learning to educate others and advocate for themselves which was an additional pressure. For many we heard from, knowing who they could trust was an issue. Others felt they were forced to take on the role as educator not only for friends and family but in wider settings too.

19. The trauma caused by continuing stigma was described as having a more long-lasting and profound effect than the diagnosis itself.

20. It was clear that stigma is, in part, linked to outdated and unchanging misconceptions about HIV, which can be traced back to the awareness campaigns from decades ago and, specifically, the hugely impactful tombstones advert from the 1980s, and that this had formed the basis of many people's knowledge.

[2] Official Report of the 9th Meeting of 2024 of the Equalities, Human Rights and Civil Justice Committee, 26 March 2024

21. These long predate the very significant developments in antiretroviral treatment and prophylactic medicines, which have not had the same public exposure. These treatments mean that people cannot pass on the virus, because their viral load is so reduced, or, if potentially exposed or at risk of exposure, will prevent infection with HIV. We heard that negative attitudes about HIV were embedded with commonly held misconceptions that those diagnosed with HIV were promiscuous, drug users or sex workers.

22. Participants spoke of stigma they encountered consistently within healthcare settings including in GP surgeries, vaccination clinics, maternity services and dentists but it was evident that those living with HIV encountered prejudice across public sector organisations including the police and within educational settings. Participants spoke of nurses, doctors and dentists “double gloving” or seeking additional advice when a person’s status was revealed.

23. One participant had been denied the opportunity to breastfeed her child due to a lack of knowledge from her midwife. She felt she had been judged throughout her pregnancy and that this came from a lack of training and education. Many felt that training and CPD for healthcare workers and those working with the public should be mandatory and not a “tick box” exercise to ensure those living with HIV were treated the same as anyone else living with a long-term health condition.

24. Others suggested that normalising sexual health check-ups would be helpful to reduce stigma around sexually transmitted disease and sexual health more broadly, in a similar way, for example, to a yearly dental check-up.

25. While the Committee was made aware of the powerful film and a public campaign co-ordinated by the Terence Higgins Trust, it was not clear what reach or impact this has had on the general population.

26. The film was very much welcomed by stakeholders and participants alike. However, some participants felt the coverage had been limited and that it would be helpful if the advert could be complemented with billboards and on the sides of buses. Others suggested schools could play a large part and more innovative approaches could be taken involving organisations or individuals living with HIV speaking in schools to raise awareness.

27. Nicky Coia of NHS Greater Glasgow, stressed that stigma acts as a barrier to the general population becoming better educated about HIV, testing, and about PrEP and PEP for example. We heard that stigma has a double aspect and is still being linked to sexuality and misconceptions about vulnerability to infection. Stigma has also followed the cohort of people diagnosed many years ago, as they move into social care settings.

28. We heard that stigma also impacts directly on someone’s mental health and wellbeing and higher rates of depression, anxiety and post-traumatic stress disorder. People living with HIV are also subject to physical, sexual and emotional abuse and violence.

29. The Committee learned that additional factors such as where people live, or their ethnicity can also combine to compound stigma.

Rurality

30. In rural settings, we heard that there are a lack of bespoke sexual health services and lack of knowledge within GP practices. Close-knit communities can also make people living with HIV feel vulnerable because it is harder to maintain anonymity. Availability of specialist staff in rural areas and training opportunities are also limited. Dr Howe told us:

> "In remote and rural communities, people do not have secrets. Everybody knows everybody else's business, so it is a big deal to go to your GP practice or pharmacy and ask for PrEP or an HIV test or to pick up your medication. It outs you—it outs your sexuality, your lifestyle and your behaviours. It is a big barrier to people accessing care".
>
> "Moreover, in some places, such as the Western Isles, there is no access to specialist sexual health services, so the GP is the first port of call for sexual health issues. That can leave people feeling really exposed, because, although we all know that health professionals are bound by confidentiality rules, I have heard countless stories of receptionists talking to neighbours. Indeed, the receptionist might be your auntie, your next-door neighbour or whoever—such things are particularly common in remote and rural settings."

Ethnicity

31. The Committee heard that people from minority ethnic communities are not served well, and services are not tailored or community-focused to take account of different needs and different cultural perceptions. Professor Estcourt of Glasgow Caledonian University discussed a research study carried out a few years ago. She said:

> "One of the key findings of the study was that, for women of colour, we needed to wrap PrEP in with holistic reproductive care. In other words, PrEP had to be just one part of the approach to reproduction and contraception, not singled out as some great intervention to be focused on that group, for fear of the adverse implications that might arise from targeting it."

32. Furthermore, existing experiences of racism, homophobia and other prejudices within health and care systems, and the justice system are amplified if someone shares their HIV status. Intersecting inequalities further compound how stigma is experienced for someone living with HIV.

Training

33. Training and stigma was also discussed in connection with the piloting of opt-out testing. Gabrielle King from Waverley Care told us:

> "there is a massive amount of stigma among health and social care professionals and misconceptions that need to be addressed, which requires additional training. The importance of that cannot be overstated. In

the prison service and the criminal justice system, for example, opt-out testing for blood-borne viruses should take place but, actually, for a number of reasons, including training resource, that does not happen"

34. Witnesses were keen to see core and CPD training for health professionals, care staff and police about stigma associated with HIV status. A community-focused approach to service planning and organisation was also suggested and consideration of a more ambitious public campaign so there is widespread understanding of the advances in treatment, prevention of spread, benefits of testing for HIV and other blood borne viruses, and potential continuing risks.

Public information and awareness raising

35. Members and witnesses referred to the success of TV programmes like "It's a Sin" or storylines about HIV in increasing testing rates, suggesting that media campaigns could have a positive effect in raising awareness and increasing testing.

36. Members were keen to explore misconceptions among heterosexuals who believe they are 'not the type' to contract HIV.

37. In supplementary evidence, Nicky Coia provided the Committee with details of ongoing work that is "available for the whole population and delivered by public health and health improvement teams in territorial health boards". He highlighted:

- the development of a new sexual health website for Scotland to replace the Sexual Health Scotland website
- universal provision of free condoms and lubricant and
- the provision of Relationships, Sexual Health and Parenthood (RSHP) education in schools which is supported by the teaching resource www.rshp.scot which can be accessed by all teaching staff in schools.

38. As part of RSHP education work, Mr Coia emphasised how vital it is that "parents and carers have the support available to be able to talk openly with their children about relationships and sexual health." He told us that the SSHPS group have commissioned an engagement process with parents and carers across Scotland to ascertain how best this can be done and this will report in the summer.

39. He highlighted the success of the public awareness campaign led by Public Health Scotland in respond to the increased of gonorrhoea cases with an approach to young adults aged 18-24 on social media on primary prevention and promoting safer sex.

40. Terrence Higgins Trust and Waverley Care also provided supplementary evidence on this issue, highlighting work on education and awareness for the general public in universities, hospitals and public settings like train stations, additional awareness raising through community settings, and through creative approaches, such as information and advertisements on dating apps, and use of social media to communicate key messages like U=U.

41. Each year, on World AIDS Day, resource is provided for public information stands, testing and working with existing partners across councils and the NHS.

42. Terrence Higgins Trust added that they "continue to work to support RSHP delivery in schools where we have relationships and capacity to do so" and said "ensuring that misinformation and stigma around HIV is tackled across Scotland will continue to be a key focus of our work, but it is one which requires proper resourcing. It is vital that this includes training for staff working across statutory services where there are opportunities to communicate up-to-date and accurate measuring, and to avoid perpetuating stigma which can stunt the uptake of tests."

43. Dr Clutterbuck of NHS Lothian made reference to extending education across and beyond the health and care sector:

> "Our hope is for the entire health and social care sector to have a basic level of knowledge. It might even be possible to go beyond that to other potential key influencers. We might think about nail bars and tattooists, or about other people with a social care background, for example."

44. He also said that 'really good materials" for the health and social care workforce had been developed and were being worked on further. He suggested that training could be mandated. However, he said that this 'tiered approach to education' is not currently signed off or funded.

45. Professor Estcourt was of the view that to destigmatise HIV, sex needed to be destigmatised. She suggested there is a place for discussing HIV and addressing misconceptions in schools through health and wellbeing education.

46. Gabrielle King referred to the Scottish Government consultation on the delivery of relationships, sexual health and parenthood education late in 2023, based on updated guidance. In that guidance however, HIV is only referred to in relation to LGBT young people, and gay and bisexual men.

47. The Minister for Public Health and Women's Health, Jenni Minto recognised that stigma remained a barrier to accessing treatment and put people at risk and that the Scottish Government aim was to "build a Scotland in which everyone is treated with kindness, dignity and respect". She told the Committee "I am not proud that HIV stigma remains. We are committed to working to tackle that. We must continue to remember that the "H" in HIV stands for "human" and put people at the centre of everything that we do."

48. In response to differing approaches for rural communities, the Minister told us "It is important to recognise that, alongside the delivery plan, we have done some work to look at rural inequalities and how we can ensure that the service that people get in those areas is the same as we would expect in the larger centres and is person centred. I think that that work will be published later this week. The Committee also heard from Professor Estcourt about the amazing work that is being doing with regard to ePrEP. Again, that could work well to support people in rural communities".

49. Rebekah Carton from the Scottish Government said "The other thing to think about is that we focused on Highland for one of the opt outs. Some of this work is about making sure that we take local approaches where they are more appropriate. Some things are better done on a national basis, and some things are better done on a local basis with clinicians who know their population and can tailor what is needed to communities. That is what we have tried to do through the plan."

50. **The Committee heard that misconceptions around HIV remain pervasive and affect the quality of life for those living with HIV. Stigma is a barrier to people accessing testing and staying in treatment and care. Additional factors such as where people live, or their ethnicity can combine to compound stigma.**

51. **Of most concern was the stigma encountered consistently by those living with HIV within healthcare settings, maternity services, dentists and other public sector organisations including Police Scotland and educational settings. While many healthcare workers currently undertake training, we heard that this can be a 'tick-box' exercise.**

52. **The Committee asks the Scottish Government to take urgent steps to address this by developing a comprehensive training programme for healthcare and public sector workers to include up to date information on HIV, dispelling common misconceptions and emphasising the importance of individual care and empathy. The Scottish Government must ensure people's testimonies about how they would like to be treated is taken into account to increase the level of knowledge for what patient care should look like for those living with HIV.**

53. **The Committee heard that health professionals and those living in rural areas face unique challenges and that specialised services may be limited. Online training provision would be helpful and could also assist in addressing difficulties in staff being released to attend face to face training across the broader sector. The Committee notes that tailored approaches must be used for rural communities to ensure equitable access to HIV related services, and this will include initiatives like ePrEP to support individuals. The Committee welcomes the work ongoing in this area. The Committee urges the Scottish Government to look at and fund innovative ways for rural communities to access care while maintaining privacy and anonymity.**

54. **The Committee commends the Scottish Government and the Terrence Higgins Trust for the anti-stigma film and campaign. It asks the Scottish Government to consider building on this work with a broader, community focused public awareness campaign. Various methods such as billboards, public transport, social media or community events could be used to reach a more diverse audience. The Scottish Government could tailor messaging to address specific stigmas prevalent within minority ethnic communities and rural populations to ensure the broadest reach**

possible. The Committee heard, for example, that targeted work is required within communities who have recently arrived in Scotland from countries with a high prevalence of HIV.

55. **The Committee recommends that developments on HIV treatment should be incorporated into the school curriculum as part of broader sex education provision. It is important to ensure educational initiatives are culturally sensitive to diverse communities. The Committee recognises the importance of engaging parents, so they are able to support these conversations.**

Achieving Zero New Transmission of HIV by 2030

56. As detailed in paragraphs 6-8, the Scottish Government has committed to eliminating new transmissions of HIV by 2030. England and Wales have published their delivery plans: Towards Zero: The HIV Action Plan for England 2022 to 2025 and HIV Action Plan for Wales 2023-2026.

57. Alan Eagleson of Terrence Higgins Trust told us that the lack of a published plan means that Scotland is falling behind other UK nations in its action to stop transmissions. Furthermore, he said:

> "if we are to end new cases of HIV by 2030, we need to tackle the inequalities that persist and ensure that progress is felt equally among all communities… We have the opportunity to lead the way not only in the UK but across the world, but we are letting this moment pass us at a rapid pace. The reality is that, in Scotland, we have fallen behind other UK nations in our HIV response."

58. This view was supported by Dr Clutterbuck, who added that while transmission elimination is possible, and that numbers are low, it is not a given, and the country could be at a point where infections could increase, potentially because of a change in the population and immigration trends.

59. Dr Clutterbuck stressed that while the small HIV community/sector has driven forward the advances in HIV, including the PrEP programme, the work needs to be broadened out if zero transmission is to be achieved, with a much broader commitment to action.

60. Professor Estcourt emphasised that approaches and interventions need to be 'very country and region specific'. She told us that England had received £20 million to support its transmission elimination strategy, but did not believe comparable investment has been made for work in Scotland. She believes that 'the ideas and the interventions put forward in the plan are the right ones with the correct weighting', but that budgets were too small to expand any of the current work, and highlighted that:

> "We are seeing rises in STIs like syphilis and gonorrhoea such as have not been seen for decades. That adds additional pressure for services so that

their prevention functions have to take second place to treating people with STIs"

61. On 26 March, the Minister gave evidence to the Committee and announced in her opening statement that the Scottish Government's HIV Transmission Elimination Delivery Plan was published. She told us

> "It focuses the actions that we will take to deliver on the 22 recommendations that were presented to us on 1 December 2022 as part of the HIV transmission elimination proposal. We worked with a wide range of stakeholders to develop the plan, and many of the actions in it are already well under way. We have taken the time to ensure that the plan that we have published today has the support of the sector, is deliverable and achievable and will take us closer to our transmission elimination goal."

62. She advised that £1.7 million had been set aside and that "The Committee heard very clear evidence that resources are tight for this. I am reflecting on that. That is why it is so important that we get the spending on this right. There will be more information coming out on how we decide to spend the money, but we appreciate that we have a tight budget".

63. The Minister advised that the plan would take Scotland up to 2026, at which point the Scottish Government would "take stock" and "adjust its focus" looking towards 2030. She told us that the delivery plan focuses on preventing new cases of HIV and reducing stigma is an important part of that. However, she acknowledged that "it is also important that we continue to support those who are living with HIV. Although we aim to eliminate HIV transmission by 2030, we will continue to care for those who are living with the virus long after that."

64. Ms Minto stressed the importance of monitoring the plan and that the Scottish Government had formed a group to do so - HIV-TEDI. (the HIV transmission elimination delivery plan implementation short-life working group). The group will oversee the introduction of the primary, secondary and tertiary elements of the plan. She told us "Our relationship with Public Health Scotland is also important because of the additional information that it can provide us with and the additional work that it will do to support the plan. That is such a collaborative way forward; PHS is always checking what we are doing. Also, because our relationship with communities is so close, they will be quick to say that perhaps we need to re-emphasise certain aspects"

65. **The Committee welcomes the publication of the Scottish Government's HIV Transmission Delivery Plan and the Minister's clear commitment to improving the lives of those living with HIV. Regrettably, the Delivery Plan was not published ahead of the Committee taking evidence for this inquiry, so it is unable to comment meaningfully on it at this stage. However, it looks forward to monitoring its progress during implementation.**

66. **The Committee agrees that it would be helpful to receive an update from the Minister in due course and will schedule a follow up session in 12**

months' time. In the meantime, it would appreciate any updates the Minister is able to share with the Committee as the plan is implemented and monitored. The Committee is particularly interested in the methods the Scottish Government will adopt to ensure education and training can be rolled out to the health service and within schools to address stigma.

The introduction of an opt out testing pilot in Scotland

67. In 2000, opt-out testing became embedded in maternity services, eliminating vertical (mother to baby) transmission of HIV. Following from these successes, in 2016, NICE guidance stated that on admission to hospital, or presentation in emergency departments, HIV testing is recommended in "areas of high (two to five per 1,000 adults) and extremely high prevalence (more than five per 1000)"[3].

68. In 2021, as part of its HIV Action Plan, the UK Government committed to piloting opt-out HIV testing, and hepatitis B and C testing, in emergency departments in areas of highest HIV prevalence.

69. This took place initially in London, Brighton, Manchester and Blackpool and was hugely successful, identifying almost 2000 new cases of HIV, HBV and HCV within the first 12 months. In addition, 470 people were identified who had been previously diagnosed but who were not receiving treatment.

70. The UK Government are currently considering the extension of opt-out testing to a further 43 emergency departments. The estimated costs of the first 100 days were £2 million. However, it is estimated that the savings in long-term costs were £6-8 million. Hospital stays for newly diagnosed patients were also substantially reduced.

71. Professor Estcourt cautioned against following England's example, stating that the circumstances of the two countries are very different, with nowhere near the prevalence in Scotland that is seen in England, and that such an approach might not be the best use of resource. She said:

> "We could do a huge amount of testing in absolutely the wrong place at cost and with very little gain… I would urge a bit of caution and say that we should proceed in high-prevalence areas, rather than implementing blanket opt-out testing."

72. Other witnesses broadly agreed, but Gabrielle King said that the rapidity of the bidding process for pilots was a concern, giving health boards little time to express interest, and that not enough resource was made available to allow many boards to take part. NHS Greater Glasgow and Clyde might have been a candidate but did not bid. Additionally, no resource was available to support A

[3] National Institute for Health and Care Excellence (NICE) (2016) HIV testing: increasing uptake among people who may have undiagnosed HIV

& E staff to undertake the testing, and the pilots are very short at only three months.

73. The Committee raised concerns around training of those staffing the pilot, against a background where stigma and misconceptions persist, and whether time and resource for training had been factored in. Gabrielle King told us that the impact on, and support for, those diagnosed through the scheme had not been considered.

74. Dr Clutterbuck welcomed the pilots but said that it was not really clear what the best route for monitoring is for Scotland – the pilots, sentinel monitoring[4] or seroprevalence testing[5].

75. In her evidence, the Minister explained that the Scottish Government felt it was important to choose a variety of health boards to participate in the pilot. She told us "They include Lothian, which covers an urban area; Grampian, which includes a mixture of areas; and Highland, which covers a more rural area. We have therefore covered a cross-section of Scotland. It is important to say that the group that had been involved in considering whether optout testing was the right way forward had asked for such an approach."

76. She stressed that pilots were happening in busy A & E departments and it was important not to introduce for long periods of time, additional stressors in areas that are already very stressed. She told us "We felt that we could get the answers from the time periods that we set. It is important that we recognise that pilots are also happening in England. The data that comes out of those, as well as the data that comes out of that about stigma. We need to find the best way to ensure that people who have HIV or might have HIV have the best way of accessing the services that we provide. I hope that the delivery plan will help with that."

77. **The Terrence Higgins Trust has called for urgent piloting of opt-out HIV and BBV testing to take place in emergency departments of highest prevalence with pilots lasting more than a year. While the majority of stakeholders welcomed the opt out testing pilots, the Committee heard it is unclear whether these are the best routes for monitoring or the best use of limited resource. The Committee notes that diagnosing people early has a cost saving aspect which has to be balanced and taken into consideration when looking at the cost and benefit of opt-out testing.**

78. **The Committee acknowledges that it is too early to evaluate the impact or merit of the opt-out testing pilots and asks the Scottish Government to provide it with an update of its findings once these are known.**

[4] Sentinel monitoring is the monitoring of rate of occurrence of specific diseases and conditions with a view to assess the stability or change in health levels of a population

[5] Seroprevalence is the number of persons in a population who test positive for a specific disease based on serology (blood serum) specimens; often presented as a percent of the total specimens tested or as a proportion per 100,000 persons tested.

PrEP (Pre-Exposure Prophylaxis) and e-PrEP pilot

79. PrEP (Pre-Exposure Prophylaxis) is a medicine that can be taken by those at risk of HIV and is almost 100% effective as a preventative measure, In 2017, Scotland became the first country in the UK, and one of the first countries worldwide, to systematically distribute PrEP by the NHS free at the point of delivery for those eligible.

80. While currently administered by sexual health clinics, the Scottish Government announced in December 2022 that it was developing an online e-PrEP clinic to make it possible for participants to order medication without needing to attend a specialist clinic.

81. However, according to the Terrence Higgins Trust, despite its proven success, access to PrEP continues to be hindered by issues of inequality. Populations who may benefit most from the drug, notably women, the transgender community, intravenous drug users, heterosexual men and black and minority ethnic populations are also less likely to access it.

82. Witnesses confirmed this view, agreeing that certain groups continue to be poorly served by testing, support and access to PrEP. Gabrielle King told us:

> "Since it was made available in Scotland, 92 per cent of those accessing it have been white, and data from 2020 shows that fewer than 10 heterosexual men and fewer than five women were prescribed PrEP. The needs of women, people from minority ethnic communities, trans folk, those in the refugee and asylum systems, those facing a range of intersecting inequalities and those living in rural areas are not being met by the existing provision."

83. The Minister told us that the Scottish Government is taking forward work on how to widen the prescribing of PrEP so that GPs have that capacity. As part of that exercise, scoping work is being carried out in NHS Grampian with GPs to find out how open they are and how it can work in the best way possible.

e-PrEP pilot

84. Positive developments with e-PrEP were broadly welcomed by witnesses though it was considered access could be increased generally and particularly in rural areas. Dr Clutterbuck said that most of the high-risk individuals were already covered in getting access, but it could achieve benefits in efficiency and releasing capacity elsewhere.

85. Nicky Coia also cautioned that while PrEP is key it needs to be considered alongside other means:

> "PrEP is at the centre of our primary prevention strategy, [but] other tools are absolutely needed in the toolbox. For other population groups, it is about education and, for example, making sure that anyone who wants to use condoms can access them… I am from Glasgow, where we had an outbreak

among people who inject drugs, so we must also make sure that we still have the more traditional methods, including clean and safe injecting equipment... We need to work in co-production with the population groups that can most benefit from expanded provision of PrEP, but we also need to be mindful that primary prevention is not just about PrEP. We need to make sure that a range of other primary prevention approaches are still in the mix."

86. Innovation was discussed around increasing access for those who encountered barriers in using sexual health services, whether for cultural, geographic or other reasons. However, Dr Howe of NHS Highland urged caution saying that 'swathes of the country do not have the kind of expertise with the health area to back up a self-management approach, nor the clinical governance structures in place." However, she said that there is a subset of heterosexual-identifying men who have sex with men who typically stay away from all sexual health services, who could benefit because of the online and depersonalised nature of the service.

87. Professor Estcourt raised the issue of differential costs, depending on how PrEP was delivered and that:

> "when delivering PrEP in community pharmacies, there are massive structural barriers relating to drug costs, so the Government needs to make changes in that regard. The costs of a pharmacist conducting PrEP care probably exceed the costs of a nurse on a lower band conducting the care in a sexual health clinic…That is legitimate if the pharmacy reaches people who do not go to a sexual health clinic, but if the pharmacy is just providing a more convenient option for people who would go to a sexual health clinic, we are not running an efficient system. The issue is really complex, so we need to think carefully across the whole economy about how we provide services to the right people in the right places while maintaining choice"

88. Dr Brawley was enthusiastic about the ePrEP work but suggested that:

> "Large groups of individuals would benefit from PrEP but do not access sexual health services and do not know about PrEP. The only way we will get the messages out there is by widening access, as we did years ago with regard to different types of contraception that were accessible only in sexual health services at the time, but are now accessible in pharmacies and primary care services. However, that will require resource,"

89. While the drug has been transformational, it is not without side-effects and Professor Estcourt said that in older people (middle aged onwards) it can affect kidney function, and that 40% of people on PrEP in the Greater Glasgow and Clyde service require more than the annual blood test for kidney function.

90. One concern raised by the Committee was that any resource freed up from the ePrEP pilot might be diverted away from specialist sexual health services.

91. In response, the Minister said "Everyone here recognises the pressure that the Scottish Government's budget is under. However, as I said earlier, we have set

aside £1.7 million to support the plan in the next financial year. It is my job, with my critical friends, to ensure that our funding allocation is directed in the right way."

92. **The Committee learned that PrEP awareness and access need to improve for underserved populations including women, transgender individuals, drug users and ethnic minorities. This could involve community outreach and partnership with third sector organisations. The Terrence Higgins Trust urges prompt roll out of Scotland's e-PreP pilot and commitment to PrEP access in community settings including GPs, pharmacies and prisons. The Committee heard, however, that the expense of pharmacist-delivered PrEP care might outweigh benefits compared to specialised care from a nurse in a sexual health clinic. The Scottish Government may need to conduct a cost-benefit analysis to optimise PrEP provision.**

93. **The Committee welcomes the development and work being undertaken with e-PrEP to increase accessibility and reach individuals who face barriers to traditional healthcare services. It asks the Scottish Government to provide an update to it as this work develops**.

HIV testing week

94. The Terrence Higgins Trust have identified further measures to address stigma and to reach zero HIV transmissions. One of their priorities include a National HIV Testing Week for Scotland which would, they say, "normalise HIV testing" among the general population.

95. However, Professor Estcourt was more hesitant and considered a testing week would not necessarily represent good value for money in Scotland because it would pick up such a small number of new cases. She recognised that it could be an important part of an awareness-raising campaign but the aims and costs of it would need to be clear, as well as who would be delivering it.

96. **The Terrence Higgins Trust has called for a national HIV testing week for Scotland building on existing anti-stigma commitments. The Committee heard differing opinions. While witnesses agreed it would normalise HIV testing and raise awareness, Professor Escourt cautioned it might not diagnose many new cases and may divert resources from healthcare services.**

97. **The Committee suggests the Scottish Government conduct a cost-benefit analysis and define clear goals as to what could be achieved. If implemented, it should target high-risk populations with outcomes monitored for future reference.**

Data

98. Another priority for the Terrence Higgins Trust is for regular and comprehensive data publication, inclusive of testing rates and demographic breakdown, with annual progress updates to Parliament.

99. Public Health Scotland publishes data on HIV in Scotland. The latest statistical release published in September 2023 provides data up to 31 December 2022.The data covers those who access PrEP for the first time, the number of HIV diagnoses, the number of recently acquired infections, the number living with HIV and those engaged with services/receiving antiretroviral therapy.

100. The Committee explored the issue of data in relation to what we know about the experience of stigma in Scotland. Alan Eagleson said that:

> "Without consistent and comprehensive data, it is difficult to tell where we are in relation to stigma. We have already heard that we do not have robust data on stigma in rural areas versus urban areas."

101. Gabrielle King spoke of the "HIV confident charter[6], which supports organisations to have an accreditation that shows they have an up to date understanding of HIV and can work to support people"

102. Dr Roy of Public Health Scotland provided a perspective on data more generally. She said that it can help to guide the targeting of interventions, but there is a balance to be struck when considering further stratification of published data into marginalised groups, for example, because you run the risk of creating more stigma for those populations.

103. However, she told us, PHS recognises there are data gaps and that they are strengthening surveillance systems and expanding the number of indicators they share with partners to assist with planning. She said that PHS is working towards an annual interactive public dashboard, as they do in other areas of their work. This should assist in tracking progress towards elimination of transmission. She cautioned that this work is behind as a result of the Covid response work.

104. The Minister told us that the plan supports the need to find ways to increase data gathering and because the numbers in Scotland are so small, we need to ensure we gather and report that data in the best way so that people cannot be identified and we do not create a knock-on effect on stigma.

105. She told us "Dr Kirsty Roy talked about the work that Public Health Scotland is doing to create a dashboard to ensure that we get the best information, and I am fully behind that. Paul O'Kane is right about how different health boards have different pockets of information and we need to pool that, so part of the plan is a national Scotland-wide audit of HIV contact tracing, which I hope will

[6] HIV Confident is a partnership between **National AIDS Trust**, **aidsmap** and **Positively UK** supported by **Fast Track Cities London**.

help to feed into that. The plan specifically includes work to support data gathering, as well as working closely with Public Health Scotland to ensure that we get the right information and that it is produced in the right way."

106. She added that anecdotal evidence is also important. "I appreciate that it is not data, but it adds to the data and makes it more accessible. That is why I am pleased that Public Health Scotland has appointed the coordinator. I am also pleased about the collaboration that is happening across the sector. As Dr Clutterbuck said in his evidence, that is not new. In fact, this area of medicine has been a trailblazer in recognising the importance of various elements working together. The health boards, and indeed the whole of the health sector, can look at that. I understand people's frustration. Am I working hard to move things on? Yes, I am."

107. **While current HIV data is broken down by age and gender, further disaggregation could reveal whether certain marginalised sub-groups of the population are not accessing treatment. The Committee agrees this data is crucial to target interventions effectively. It welcomes the Scottish Government's commitment to improving data collection and asks it to ensure steps are taken as soon as possible to address existing data gaps, improve accuracy of HIV data and expand the number of indicators shared with partners. It asks the Scottish Government to provide an update to Parliament as progress is made.**

108. **The Committee welcomes the development of a public dashboard by Public Health Scotland that will provide transparency in data reporting and show progress towards reaching HIV transmission elimination. It agrees this will allow for greater transparency and accountability.**