Waverley Care and Terrence Higgins Trust Scottish Parliament roundtable: discussion summary

The road to 2030 – Progress towards ending HIV transmission in Scotland

A Parliamentary roundtable chaired by Waverley Care, sponsored by Gilead Sciences

Event outline:

This event brought together MSPs and key third sector and public health representatives to hear from leaders on innovative projects and to discuss the key actions needed to end HIV transmission in Scotland by 2030. The roundtable sought to explore:

- Are we on track towards our 2030 goal?
- What are our key successes so far, and what should we build on?
- What are the learnings from other areas of the UK and beyond?
- With the current HIV Transmission Elimination Delivery Plan ending in 2026, what are the gaps and opportunities to include in the new plan?

Date: Thursday 12 June 2025

Venue: The Scottish Parliament

Organisations in attendance:

- Grant Sugden, Waverley Care
- Laura Brodie, Waverley Care
- Stuart Smith, Terrence Higgins Trust
- Alan Eagleson, Terrence Higgins Trust
- Daniel Fluskey, National AIDS Trust
- Dr Daniel Clutterbuck, NHS Lothian
- Dr Daniella Brawley, NHS Grampian
- Dr Rachel Hill-Tout, NHSE BBV
- Jeff Featherstone, NHS England
- Ian Jackson, NHS England
- Lorraine Fleming, Public Health Scotland
- Claudia Estcourt, Glasgow Caledonian University
- David Weir, Gilead Sciences (Industry sponsor)

MSP attendees:

- Paul Sweeney MSP (Chair) (Scottish Labour)
- Clare Haughey MSP (SNP)
- Richard Leonard MSP (Scottish Labour)

Opening remarks

Grant Sugden welcomed attendees on behalf of Waverley Care (WC) and Terrence Higgins Trust (THT). He referenced the progress made since the 2030 target was announced, specifically on awareness, testing, stigma and piloting ePrEP.

Grant referenced WC & THT's long term campaigning for the recently announced opt-out testing in emergency departments. He called for this to be implemented and funded to ensure wrap around support and linkage into care for those newly diagnosed with HIV or who are re-engaged in care.

Grant made reference to the policy scorecard from WC & THT which evaluates progress and highlights where they believe further action is required. Grant drew attention to the challenges for the HIV target, including funding, stigma and international context, before concluding by encouraging attendees to share their thoughts and ideas throughout the session.

Lorraine Fleming (HIV Coordinator, Public Health Scotland): HIV Transmission Elimination Progress and Next Steps

Lorraine provided an overview of the current epidemiology and progress made against the UNAIDS 95:95:95 targets using data from 2023. She noted areas to be mindful of, such as the changes in HIV epidemiology and the risk of stigma increasing as transmissions decrease. Variations in access to PrEP were noted and the need to widen and ensure access for different populations.

Lorraine ran through progress on key actions in the HIV Transmission Elimination Delivery Implementation Plan (2024), highlighting specifics in each category for example as ePrEP, opt-out testing and workforce education. Lorraine concluded with a focus on next steps, set out in the mid-plan report expected to be published in autumn 2025. The importance of ensuring holistic person-centred care alongside prevention and testing was noted.

Discussion 1

Paul Sweeney MSP began taking the group through a series of questions covering the group's assessment of progress made towards the 2030 target, and how we can learn from this as we look ahead to the coming years. The following themes were raised:

- **Stigma**: It was claimed there has been much progress in tackling stigma in health and social care settings, including a hub for the tier 2 health and social care workforce which is currently being developed by Waverley Care and partners. The group agreed there is still much to do, both within and outside of the healthcare workforce.
    - It was noted that stigma work will remain long term due to the complex nature of it, due to its connections to sexuality and race and other intersecting inequalities.
    - The group heard that stigma has the potential to be a barrier to testing, a big concern given testing is central to the 2030 target.
- **HIV champions and sector support**: The work on HIV champions was described as "invaluable".
- **ePrEP clinic pilot**: The Scottish Government funded pilot was raised as an example of a seamless way for established PrEP users to to access further treatment. The ability to undertake online self-sampling was praised as a huge step forward enabling people to quickly access a clinical prescription.
    - An evaluation is in progress,
    - Early findings indicate a high completion rate and a high adequacy of samples.
- **STI & BBV Postal self-sampling**: As part of the ePrEP discussion it was raised that online postal self-sampling is available in only a few limited areas in Scotland, whereas it is much more common in England. The group agreed that the absence of a viable national online postal self-sampling service is a clear weakness and challenge and one that must be addressed both

for the development of ePrEP longer term but to ensure access to testing for all who need it across Scotland.

- **Digital health literacy**: The group discussed whether digital health literacy had a generational impact.

Dr Rachel Hill-Tout (Clinical Lead HIV/BBV opt-out testing in Emergency Departments, NHS England): Opt-out testing – The experience in England

Rachel provided an overview of the experience of opt-out testing in emergency departments (EDs) in England launched in 2022 following £20m funding for HIV, HBV and HCV testing. The programme covered 34 EDs in very high prevalence areas. It was noted that inequalities and stigma are often a factor in late diagnosis of HIV and that the level of late diagnosis was unacceptable. Rachel ran the team through the rapid mobilisation required and pathway, before explaining the three-year results:

- 89 EDs funded for opt out BBV testing in areas >2/1000 HIV prevalence
- 61 EDs active with BBV testing and reporting data to NHSE
- 9.7 million ED attendances
- 3.5 million HIV, 2.7 million HBV and 3 million HCV tests
- 66% (up to 97%) of people having blood tests in ED had a BBV screen
- 8,800 new BBV diagnoses (1,230 HIV, 5,500 HBV, 2,100 HCV)
- 93% linkage to care for people newly diagnosed with HIV

Rachel highlighted key impacts of the programme:

- Its ability to educate and anti-stigma train all NHS staff in the funded EDs.
- Its ability to educate and tackle stigma amongst the public via messaging which normalises testing.
- Effective case finding and linkage to care for people living with a BBV but unaware of their status or unlinked to care people.
- Rich data on micro-epidemiology of BBVs in England to support further roll-outs and prevention initiatives.

Rachel concluded that the programme has been highly effective at finding people unlinked to care with 75% of new diagnoses never having tested before, and also proved testing can be rapidly scaled up with success. She stressed the importance of collecting and reviewing monthly data which has been so useful. She added that efficiencies in testing and linkage to care will be important going forward. The importance of integrated testing, including viral hepatitis was also noted, as well as the effectiveness of having live data to enable troubleshooting and improve performance of health boards.

Dr Daniella Brawley (Consultant in Sexual Health and HIV, NHS Grampian): Opt-out testing – The experience from NHS Grampian

Daniela provided an overview of the experience of opt-out testing in emergency departments (EDs) in NHS Grampian, a low prevalence area, over 4 months. She detailed the rationale for implementing a pilot in a low prevalence area – the lack of data and guidance for low prevalence areas and the need to test more to find undiagnosed cases. Coupled with this, Grampian had seen a recent increase in new diagnoses with ongoing late diagnoses and missed opportunities.

The results for the 4-month Grampian pilot were overall 40% uptake, new diagnoses/linked to care were * for HIV, * for HBV and 14 for HCV. On staff evaluation, Daniela said that acceptability was high among patients and uptake may have reflected the time of year the pilot was started. A small proportion of patients were concerned about privacy. Workforce acceptability was high with minimal additional workload reported for ED staff. She noted the highly engaged multi-disciplinary team involved, and the importance of ensuring the programme is ED led to allow effective implementation.

Laboratory work however was underestimated. There were clear benefits to staff attitudes and ability when testing for BBVs and discussing the tests with patients. Daniela also noted the effective collaboration with the NHS England pilot where required, for example the original NHS England resources were adapted for use by NHS Grampian.

The challenges included short-term funding which had to be used quickly, the additional resource required and questions over the cost-effectiveness the programme in a low prevalence area. The timing of the programme (starting in January) was also noted to present challenges and if the programme was continued there was a belief they would be able to increase uptake and become more automated.

Discussion 2

Paul Sweeney MSP began taking the group through a series of questions covering the potential of these approaches in Scotland, and the actions we would need to prioritise in support of these and other priority workstreams. The following themes were raised:

- **Support for labs**: After the mention of additional work for NHS Grampian labs, attendees agreed that going forward support for labs is essential if we're to meet the 2030 target given the potential of ED testing as a tool.
- **General support for opt-out testing**: Around the room there was general support for opt-out testing in EDs. Attendees described this intervention as a pathfinder for other things such as peoples' entry into care. It was claimed that the intervention has the potential to address stigma among healthcare professionals due to the training requirements for all staff. In addition, attendees noted its ability to capture people living with HIV who may have left care.
    - NHS Greater Glasgow and Clyde and NHS Lothian were mentioned in the context of high prevalence areas which would benefit from programmes.
- **Mental health concerns**: Attendees expressed concern that we need to continue focusing on the mental health needs of people living with HIV, particularly given the disproportionate impact of poor mental health on people living with HIV. It was noted that the third sector is essential in supporting the mental health and wellbeing of people living with HIV through a range of services, including peer support. However, it was noted that the capacity and resilience of the UK and Scotland's HIV Voluntary and Community Sector has been affected by significant financial and funding pressures. HIV Outcomes, led by National AIDS Trust (NAT) have just released an HIV Services at the Crossroads report detailing these challenges and a Scottish briefing was shared with participants.
- **Diagnostics**: Attendees noted there is more we can do with diagnostics and called for a greater focus on this.
- **The impact in low prevalence areas**: The impact of opt-out testing in low prevalence areas was questioned, with islands noted as an area requiring alternative approaches. There are concerns that while ED tackles diagnoses, it does not impact transmissions.
    - Attendees disagreed on whether this is the case, but acknowledged a myriad of options should be considered to reach 2030.

- **Cost effectiveness:** This came up a number of times during the discussion, it was suggested that a business case is prepared setting out the impact of implementing opt-out testing on the public purse in the long term.
- **Where next:** Lastly, attendees discussed when the time would come for a change in approach from opt-out testing in England. It was noted that there are cheaper testing options, and that we may reach a point in the future where a more targeted approach is required.

Key takeaways for decision-makers to consider

- **Opt-out testing**
  - Further detail on the roll-out of opt-out testing in NHS Greater Glasgow and Clyde (GGC) and Lothian is needed, including on delivery timelines and what funding package is on offer from government. It is essential there is engagement with the third sector to ensure wrap around support is in place for patients who are newly diagnosed or are re-engaged in care, and that this is appropriately funded by government/NHS boards.
  - Areas of low HIV prevalence may require different approaches in their work to end the onward transmission of HIV, however data from areas of high HIV prevalence elsewhere in the UK reinforce the potential benefits of opt-out testing in urban emergency departments, such as Glasgow and Edinburgh.
  - Looking beyond this recent announcement, we need a longer-term commitment of multi-year funding to see the impact of opt-out testing.
- **Prevention (PrEP)**
  - We need to secure the sustainability and expansion of Scotland's e-PrEP pilot.
  - We need investment in other PrEP delivery models to ensure access for all communities who need it. Evidence from pilots in the North East of Scotland, and elsewhere in the UK, should be used to inform the suitability of PrEP provision in primary care and in community pharmacy.
- **Broader testing**
  - There is an urgent need for delivery of Scotland's national online STI & BBV self-sampling service. The roll-out of this service is integral not only to increasing testing rates and improving the nation's sexual health, but also to the future of Scotland's e-PrEP service and the potential to develop national testing campaigns, such as a National HIV Testing Week as seen elsewhere in the UK.
  - An integrated approach testing for HIV and viral hepatitis is crucial to meet both national targets for HIV and HCV.
- **Stigma**
  - While medical advancements now mean that people living with HIV can life a long, healthy life, stigma surrounding a HIV diagnosis is still commonplace. Stigma negatively impacts the mental health of people living with HIV and can prevent people from accessing testing, treatment and support. More work is needed to combat stigma on a national level and targeted in health and social care settings. This requires multi-year funding so progress is not lost.