Preventative Agenda – Health & Sport Committee Inquiry

About HIV Scotland

HIV Scotland is the national HIV policy organisation for Scotland. We exist on behalf of all those living with and at risk of HIV to ensure that Scotland has responsive policies, quality services and a supportive environment that enable people living with or at risk of HIV in Scotland to live healthy and fulfilling lives.

Statistics about HIV in Scotland

- There are 5134 people diagnosed as living with HIV in Scotland\(^1\)
- Health Protection Scotland estimate that an additional 790 people may be infected but are not diagnosed.
- There were 317 new cases of HIV were reported in 2016\(^2\). This represents the first significant (approximately 20%) drop in new cases for over a decade, although it is unknown if this downward trend will be maintained.
- Over the last 15 years (2002 – 2016), a total of 527 reports of HIV infection among 15-24 year olds in Scotland have been recorded.\(^3\)

1. To what extent do you believe the Scottish Government’s Sexual Health and Blood Borne Virus Updated Framework and the approach by Integration Authorities and NHS Boards is preventative?

HIV Scotland believe that measures to prevent new HIV infections are recognised as a fundamental outcome of Scotland’s HIV response. HIV prevention strategies and the associated spending form an integral part of meeting Outcome 1 of the Sexual Health and Blood Borne Virus Updated Framework (the Framework) - Fewer newly acquired blood borne virus and sexually transmitted infections; fewer unintended pregnancies.

HIV Scotland welcomed the update of the Framework and the commitment from Scottish Ministers that the Framework as a whole will continue to be a priority. We contributed to the development of the update, by providing recommendations based on all of our accumulated learning and consultation with communities and stakeholders.

We were particularly pleased that the update recognised that involving patients in decisions about services should not be considered optional, as well as the commitment from Government to work with HIV Scotland and other stakeholders to consider policy implication of emerging medicines such as PrEP, that present valuable opportunities to both improve the health and wellbeing of the people of Scotland, and contribute to the development of new world-wide strategies on HIV and sexual health.

In 2017 Scotland became the first nation in the UK to make PrEP available on the NHS. Pre-Exposure

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\(^2\) Ibid

\(^3\) Ibid
Prophylaxis (PrEP) is an HIV prevention tool using antiretroviral drugs to protect individuals from acquiring HIV. Being on PrEP involves taking a pill, usually daily, and regularly getting tested for HIV and other sexual infections. Since the updated Framework was published, other emerging issues have arisen such as the importance of Treatment as Prevention which policy has been able to adapt to.

Although Outcome 5 seeks to address stigma, we believe more action is needed which is why HIV Scotland formed the HIV Anti-Stigma Consortium, who, in November 2017, published Scotland’s HIV Anti-Stigma Strategy, Road Map to Zero which stated that increased efforts are needed to scale up access and adherence to treatment coupled with HIV prevention strategies including condom programming, treatment as prevention, pre-exposure prophylaxis (PrEP), post-exposure prophylaxis (PEP), harm reduction services for people who inject drugs, and focused prevention programming for other people living with and affected by HIV.4

2. Is the approach adequate or is more action needed?

Below are four areas where HIV Scotland believe further action is needed to create a more preventative approach.

**Treatment as Prevention** is one of the most powerful tools to curb new transmissions, providing people living with effective treatments not only improves their health, but prevents them from being able to pass HIV on to others. It is therefore important that the best possible treatments are made available to all people living with HIV in Scotland from the earliest possible opportunity.

Advances in HIV treatment now mean people living with HIV who have an undetectable viral load are unable to pass the virus onto another person – this is known as treatment as prevention (TaSP). The Partner study showed that there were zero transmissions from over 58,000 individual times people had sex without condoms5. This provides the strongest estimate of actual risk of HIV transmission when an HIV positive person has undetectable viral load.

Therefore there is an immediate need to increase testing opportunities to ensure more people are diagnosed and referred in to treatment. Promotion of key messages around Treatment as Prevention, including the Undetectable = Untransmittable (U=U) campaign can also be an important action to ensure that people are well informed and mobilised to take action.

**Increasing Testing** - Access to HIV testing services is fundamental in reducing HIV transmissions and to ensure that those living with HIV can take control of their health by receiving treatment and necessary support. Health Protection Scotland estimate that 13% of people who are living with HIV in Scotland are currently undiagnosed6. The proportion of HIV diagnoses occurring late in Scotland during 2015 was 45%7 and there has been little change in recent years. Late diagnosis can result in additional health complications and a lower quality of life, as well as people unwittingly transmitting HIV to others. Public Health England state that people diagnosed late continue to have a ten-fold increased risk of death in the first year of diagnosis compared with those diagnosed early8.

HIV Scotland’s National Survey of GPs in Scotland found that testing opportunities in General Practice are being missed when new patients register at practices. Only 15% of new patients registering at GPs in high prevalence areas are routinely offered an HIV test. With only 3% (13 from

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4 HIV Anti -Stigma Consortium, Road Map to Zero, Scotland’s HIV Anti Stigma Strategy www.zerohivstigma.scot
5 http://i-base.info/htb/30108
419 GPs) of survey respondents correctly identifying each indicator condition opportunities are being missed. Our report recommended that primary care settings should seek to normalise HIV testing as part of routine health checks and GP registrations, especially in high prevalence areas.

A 21st Century approach to testing needs to reflect the modern variety of options available to people for testing, including rapid HIV self-test kits and home sampling services.

HIV Scotland chair the Short Life Working Group on testing which was established in response to the Sexual Health and Blood Borne Viruses (SHBBV) Executive Leads Network noting that HIV Testing was an Area of Priority. The SLWG will report by the end of March 2018 and has already identified key issues surrounding accountability for HIV Testing/Late Diagnoses, national procurement of Point of Care & Self-Test kits, the potential for national self-sampling/self-testing services, and the need for a range of testing options to be available for everyone, everywhere with the capacity to deal with demand. It is important that the Scottish Government carefully consider the SLWG’s recommendations on testing as part of the preventative health agenda to ensure we are able to diagnose everyone in Scotland that is living with HIV.

**Access to sexual health services** - People at increased risk of HIV will access multiple services for a range of needs, this can include HIV testing, advice and support. Our research found 61% of this population access free condom services and 53% access STI testing. Having a positive experience and repeatedly using services is associated with ease of access. Concerns have been raised that sexual health services are often situated in difficult to access locations. The Scottish Government’s emphasis on person-centred planning should result in convenient services, however sexual health services can often be unavailable outside working hours which is problematic for people working full-time.

People living with HIV or at increased risk of HIV have told us there is often a high demand on services which can result in inflexible appointment times, ‘Service is only available one day each week, often busy and oversubscribed and very restricted hours’ – Person at increased risk of HIV.

For people living in rural areas, accessing specialist sexual health services for gay, bisexual and other men-who-have-sex-with-men, remains problematic with some locations only providing generic services. Layout of services and the admission processes can also impact on the actual or perceived levels of confidentiality within a service. Services should be mindful of the needs of diverse communities who are disproportionately affected by HIV, including people from Sub-Saharan Africa and sex workers.

The views of people at increased risk of HIV should be directly heard within networks and bodies which have a key role in planning and delivery of services. This includes community health partnerships and integrated health and social care partnerships.

Service providers should work to make services more accessible in order to increase the likelihood of people at increased risk of HIV engaging with prevention services. This could be increasing the number of mobile services which are available or providing transport for people. Service providers should develop clear information about how services can be accessed and be located in a range of community settings.

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Education - Measures to prevent new HIV infections are recognised as a fundamental principle of Scotland’s HIV response\(^\text{11}\) and reflects the need for prevention work to be done for young people. On average in Scotland two young people between the ages of 15 and 24 are diagnosed with HIV each month.\(^\text{12}\)

HIV Scotland are calling for a 21st century understanding of HIV, with resources providing information on the latest HIV prevention and treatment strategies. This includes legislation to ensure that RSHP lessons become a compulsory component of the curriculum to guarantee equality of access for every young person in Scotland. There is already precedence for this with the UK Parliament passing the Children and Social Work Act (2017) which requires all schools in England to teach Relationships and Sex Education from 2019.

The ongoing national review of Personal and Social Education should identify a best practice model for schools and local authorities to share Relationship Sexual Health and Parenthood (RSHP) resources and training opportunities. Updated RSHP guidance should be produced in collaboration with key stakeholders in education and ensure a stronger focus on HIV and RSHP lessons must be inclusive for all young people and include information on LGBT relationships. Sexual health professionals and third sector providers should have a visible presence within schools.

As part of the Framework, the Scottish Government lists access to sexual health education as a key mechanism to ensure that young people have the information and skills to make healthy choices regarding their sexual health. Despite the importance placed on health and wellbeing elements of the curriculum (the Scottish Government identify Relationship, Sexual Health and Parenthood education as part of this\(^\text{13}\)), it is not borne out in some schools or with consistency across schools.

Stigma - HIV-related stigma causes negative health and social outcomes. It is one of the biggest barriers to testing, treatment and support.\(^\text{14}\) Scotland’s HIV Anti-Stigma Strategy, The Road Map to Zero states that HIV-related stigma undermines prevention efforts, leads to increased risk, nondisclosure, and poorer adherence to treatment. This can lead to increases in late diagnosis which negatively impact on a person’s quality of life and life expectancy\(^\text{15}\). The UNAIDS 2016 -21 strategy, On the Fast-Track to end AIDS says ‘Late diagnosis of HIV remains the most substantial barrier to scaling up HIV treatment and contributes to HIV transmission. Many people delay testing because they fear the discrimination that may follow’.\(^\text{16}\)

The Road Map to Zero demonstrates that while there have been advances in supporting the rights of people living with and affected by HIV in Scotland, there is still a significant amount of work to be done to address social, educational, economic and health disparities that prevent people from accessing and engaging in services. People living with HIV should be supported and empowered from

\(^{11}\) Outcome 1 of the SHBVV framework is Fewer newly acquired blood borne virus and sexually transmitted infections. Page 22 states ‘While treatment is highly effective, public and individual health in Scotland is best improved by preventing infections, and this must also continue to be a priority.’ Sexual Health and Blood Borne Virus Framework, 2015 – 2020, Scottish Government


\(^{15}\) HIV Anti -Stigma Consortium, Road Map to Zero, Scotland’s HIV Anti Stigma Strategy www.zerohivstigma.scot

the point of diagnosis. This requires a non-punitive, non-criminal HIV prevention approach centred within communities, where expertise about and understanding of, HIV issues is best found.\(^\text{17}\)

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3. **Are the services and Sexual Health and Blood Borne Virus Updated Framework being measured and evaluated in terms of cost and benefit?**

HIV Scotland is pleased to be a member of the National Monitoring and Research Group (NMARG) and Executive Leads, both of which form part of the monitoring and evaluating process for the Framework. As the only HIV third sector organisation to sit on both these groups, we provide the crucial link to the community and are able to advocate and promote the needs of the people whom this work is about.

Currently there is no national data collected on the number of people presenting for HIV tests, only tests that result in a new HIV diagnosis are recorded. This presents a significant challenge in better understanding both the number of people accessing HIV testing services and the specific demographics of those who do. HIV Scotland’s recent National GP’s Survey found that opportunities for testing in General Practice are being missed. The report recommended national and local data on testing and diagnoses in primary care settings should be collated and fed into a central resource, such as Health Protection Scotland, and published annually. This would provide services with information that would allow messaging to be tailored towards specific populations who are at present not accessing testing services.

Research has demonstrated that increased HIV\(^\text{18}\) testing in primary care settings is predicted to be cost-effective in the medium term. In high prevalence areas, HIV testing in primary care can even be cost-saving in settings where long-term health-care costs of late-diagnosed patients are much higher (≥60%) than those of patients diagnosed earlier.

The recent HIV outbreak in Glasgow among people who inject drugs demonstrates the need to significantly improve the data collection and monitoring early interventions among this population that remains at increased risk of HIV. One of the factors attributed to this outbreak which affected over 50 people, was that the profile of HIV had decreased as an issue for both injectors and services. Improved data collection of those accessing testing would allow services to become more reactive by identifying possible gaps in delivery.

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4. **Given the high cost of new medicines, what cost–benefit analysis has been done of primary prevention in general, and the role of the new medicines as a means of primary prevention?**

**Treatment as Prevention** - HIV Scotland provided the community voice in the development of the Cost Sensitive Prescribing Guidance for HIV in Scotland.\(^\text{19}\) These guidelines were produced to support optimal HIV therapy prescribing and dispensing by Scottish HIV clinicians in a cost sensitive way. These guidelines also ensure that the patient voice plays an important role in the consideration of prescribing.

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\(^{17}\) Road Map to Zero, Scotland’s HIV Anti Stigma Strategy [www.zerohivstigma.scot](http://www.zerohivstigma.scot)


\(^{19}\) Guidance for cost-sensitive HIV therapy prescribing in NHS Scotland 2017, HIV Clinical Leads.
As part of the development of these guidelines, cost effectiveness was considered when prescribing HIV medicines. For example, where bioequivalence is present in generic medicines, the guidance suggests that clinicians discuss such options with patients as there is likely to be minimal impact on clinical outcomes but provides scope for financial savings.

HIV Scotland is the only third sector organisation, and patient voice, represented on the HIV Clinical Leads group. This group regularly reviews the cost prescribing guidance, especially in light of new procurement contracts for generic treatments which offer significant cost savings.

**Pre-Exposure Prophylaxis (PrEP)** – In 2016 HIV Scotland administered the Short Life Working Group on PrEP, with membership from a range of specialists including public health leads, HIV and sexual health doctors, a community member, pharmacy, third sector, social researchers, drug procurement, and observers from the Scottish Government and the Scottish Medicines Consortium (SMC). It generated a report which included an estimation of the number of individuals who might be eligible for PrEP in Scotland, consideration of cost implications, guidance for accessing and monitoring PrEP, and information for health professionals, patients and the public about PrEP and the available supports.

The report was subsequently used by the SMC as part of their wider cost effectiveness research. The report showed that based on a median life expectancy of 71.5 years, the average lifetime cost of HIV care in the UK is £360,800\(^{20}\). It also estimated that the annual cost per eligible person to access PrEP would be £2,561 (ex VAT). This cost is likely to go down now that generic medication has become available in healthcare settings (generic PrEP is available for private purchase for around £39 per month) and it should be noted that this is not medication for life\(^{21}\).

On 10th April 2017, the SMC published their conclusion of their cost effectiveness investigations that PrEP was a cost-effective treatment to prevent the transmission of HIV and made it available on the NHS in Scotland\(^{22}\).

HIV Scotland is now a member of the PrEP Co-ordination Group, the role of which is to consider the real life settings and track PrEP’s effectiveness in Scotland. We think this is a good model for considering cost effectiveness in relation to new medicines, especially as it benefitted from the meaningful involvement of community voices and experiences.

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