HIV Scotland submission on Preventative Agenda

HIV Scotland welcomes the opportunity to contribute to this inquiry by the Health and Sport Committee. HIV prevention strategies and the associated spending form an integral part of meeting Outcome 1 of the Sexual Health and Blood Borne Virus Framework Update.

HIV in Scotland

- In Scotland **5,200 people** are **currently diagnosed** as living with HIV
- **One in six people** living with HIV in Scotland **unaware of their status**.
- On average **359 people are infected** with HIV every year in Scotland, a rate that has **remained the same** over the past **decade**.
- The average **lifetime cost** of treatment and care for a person living with HIV is **£360,800**

1. **Which areas of preventative spending/ the preventative agenda would it be most useful for the Health and Sport Committee to investigate?**

- **Pre-Exposure Prophylaxis (PrEP)**

Pre-Exposure Prophylaxis (PrEP) is anti-HIV medication taken by people who are HIV negative to lower their risk of acquiring HIV infection. It usually involves an HIV negative person taking drugs daily. It most commonly entails the ARV drug Truvada, which is already licensed for use in Scotland for treatment. Recent research suggests that PrEP is as effective as condoms at preventing HIV. Analysis of the PROUD study – the first UK trial that measured the effectiveness of a daily oral regime of PrEP for men who have sex with men (MSM) – found that PrEP could be cost effective and cost saving if it was provided to gay men who recently had a STI or condomless sex with at least five casual partners in the previous three months. HIV Scotland, with partner organisations, surveyed those who may be interested in using PrEP and found 63% of people who would like to take PrEP do not feel existing prevention tools are sufficient to protect them from HIV. In addition, 87% of people currently taking PrEP stated it has increased their quality of life.

At present, PrEP is not being made available via the NHS in Scotland as it is pending a decision by the Scottish Medicines Consortium, expected in April 2017. A report by the Short Life Working Group on PrEP, estimates that the number of people likely to access PrEP would be approximately 1,000 in the first year.

Whilst recognising the Committee does not have a role in influencing the current SMC decision making process, HIV Scotland believes the scope of this inquiry merits PrEP being raised as an important tool in HIV prevention and wider preventative spend. The Committee should consider investment needed for services to be ready for PrEP. This preparation is needed now. Irrespective of the SMC decision, people are already accessing PrEP through being issued a private prescription or purchasing generic medication online. Service providers need to be upskilled and knowledgeable to support those currently accessing PrEP or considering doing so. Should the decision be made for the NHS to provide PrEP, processes will also have to be put in place to determine whether a person meets the criteria to access PrEP, and answer questions that service users may have.

- **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. 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 MSM, remains problematic with some locations only providing generic services. The physical environment and atmosphere of sexual health services is important to service users. Layout of services and the admission processes impact on the actual or perceived levels of confidentiality within a service. Services must also be mindful of the needs of diverse communities who are disproportionately affected by HIV. In Scotland gay, bisexual and other MSM account for 47% of all new HIV diagnoses since 2011, with 38% of diagnoses attributable to heterosexually acquired infection[1]. Within these two cohorts are specific populations at increased risk of HIV, including people from Sub-Saharan Africa and sex workers. There are a range of best practice examples of how services engage with these communities, e.g. outreach projects – consideration should be given on how to scale-up these services across Scotland.

- **Barriers to HIV testing**

It is estimated that there are currently 1,000 people in Scotland who are living with HIV but remain undiagnosed. Furthermore, the proportion of late diagnoses of HIV in Scotland during 2015 was 45% 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 note that people diagnosed late continue to have a ten-fold increased risk of death in the first year of diagnosis compared with those diagnosed early.[2] 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.

There have been significant advances in HIV testing; rapid testing, home sampling and the availability of instant self-testing kits now offer people choice in how they test. To improve the uptake of testing, people need ready access to a range of testing options and services which are relevant to their needs, especially groups at increased risk of HIV. The Committee should consider ways in which access to testing could be improved. In 2013, the British HIV Association issued UK-wide guidance that said in high prevalence areas (where there are two or more people in every 1,000 diagnosed with the virus) all men and women should be offered a test on registration with their GP or admission to a medical unit in hospital. However, an investigation in 2016 found that neither NHS Greater Glasgow and Clyde, nor NHS Lothian were routinely offering HIV testing, despite being classed as areas of high HIV prevalence[3].

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[1] HIV infection and AIDS: Quarterly report to 31 March 2016 (ANSWER). Health Protection Scotland, 2016
[2] HIV in the UK 2016 Report, Public Health England, 2016
[3] Hospitals and GP practices fail to check for HIV, BBC News, 2016

2. **How can health boards and integrative authorities overcome the (financial and political) pressures that lead to reactive spending/ a focus on fulfilling only statutory duties and targets, to initiate and maintain preventative spend?**

The number of people being diagnosed with HIV in Scotland has not decreased in the last decade, despite HIV being considered as a public health priority by the Scottish Government. Despite major improvements in mortality with antiretroviral therapy, HIV remains a life changing condition with significant physical and psycho-social impact. Based on a median life expectancy of 71.5 years, the average lifetime cost of HIV care in the UK is £360,800. Contrast this, for example, with the estimated £2,561 (ex VAT) that the PrEP Short Life Working Group identified as being the annual cost per eligible person to access PrEP. Moreover, this cost is likely to go down should generic medication become available in healthcare settings (generics are available online for private purchase for £39 per month) and it should be noted that this is not medication for life.

There is evidence to suggest that many people who are eventually diagnosed with HIV have previously been in contact with health services regarding HIV related symptoms and that opportunities for earlier HIV testing have been missed. Although HIV infection may be difficult to recognise, particularly in its early stage, this highlights the importance that healthcare staff are trained to identify early signs of HIV infection and feel confident talking about HIV and providing testing. A 2010 study by NHS Brighton and Hove Clinical Commissioning Group on the cost effectiveness of universal HIV testing with newly registering patients (aged 16-59) in primary care found that universal HIV testing is both acceptable and feasible [4]. HIV Scotland would like to see more routine HIV testing taking place outside of specialist settings, particularly for people who may be at an increased risk of HIV. This could be within community settings and specialist third sector organisations, where some people may feel more comfortable testing than within a clinical setting.

The case for prioritising HIV preventative spend is clear both in terms of improving the lives of people living with HIV but unaware of their status and those at increased risk of HIV, but also to ensure that public resources prioritise early intervention over reactive spending.

3. **How could spend that is deemed to be preventative be identified and tracked more effectively? What is required in terms of data, evidence and evaluation to test interventions for producing 'best value for money'?**

Currently there is no 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. Improved data collection would provide services with information that would allow messaging to be tailored towards specific populations who are at present not accessing testing services. Previously, a system was in place that allowed NHS Scotland to monitor the number of HIV tests taking place, however this was ended due to pressures on resources.

HIV Scotland conducted research into the experiences of primary care providers with HIV and sexual health, receiving responses from 10% of the total GP workforce. Findings revealed high numbers of GPs from all areas of Scotland have training needs around HIV. Respondent GPs' confidence levels in

[4] Bryce G, Jeffrey A, Hankins M, Nicholson S, Jackson D, Wilkinson P, "A study to assess the acceptability, feasibility and cost-effectiveness of universal HIV testing with newly registering patients (aged 16 – 59) in Primary Care" NHS Brighton and Hove, Brighton and Sussex Medical School, University of Surrey

their knowledge around possible HIV primary infection symptoms have been shown to be low. This demonstrates a potential reason for missed diagnostic opportunities in primary care. We therefore recommend that data is collected from late HIV diagnoses to better understand how and why previous testing opportunities were not pursued. Having this information collected across Scotland and published would be extremely useful in monitoring missed diagnoses and identifying ways to reduce the number.

The recent HIV outbreak in Glasgow among injecting drug users 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.

We would draw attention to recent HIV data collection in London which measured the impact of PrEP as being an example of how data can greatly enhance the HIV response.[5] Four sexual health clinics saw a decline in new HIV infections among gay men of nearly 40%, which has in part been attributed to the use of PrEP purchased from online retailers. Whilst the decision to make PrEP available on the NHS in Scotland is a matter for the SMC, this data further demonstrates the impact the drug is presently having within populations at increased risk of HIV.

4. **How can the shift of spending from reactive/acute services to primary/preventative services be speeded up and/or incentivised?**

Despite HIV testing being free to access, approximately one in six people living with HIV in Scotland remain unaware of their status. Moreover, most new HIV infections in the UK are passed on from persons unaware of their infection[6]. The cost of late diagnosis is estimated to be 200% higher than for those who present at an earlier stage.[7] This highlights a need to urgently scale up testing services and ensure they are available in a range of settings. Whilst barriers to testing can remain physical – as outlined in response to Question 1 – HIV-related stigma remains a significant barrier for people to present for testing. A commitment to reducing stigma is included within the Sexual Health and Blood Borne Virus Framework and is noted as "*the most ambitious of the Framework outcomes"*. In terms of shifting spending towards preventative services, addressing stigma through informative public messaging and awareness campaigns is a crucial means of ensuring people better understand HIV and feel confident when accessing sexual health services. Moreover, at present Scotland is not meeting the UNAIDS 90-90-90 target which states by 2020: 90% of people living with HIV will be diagnosed, 90% of those will receive antiretroviral therapy, and 90% of those will have viral suppression. Scotland has achieved the treatment and suppression targets but has yet to achieve 90% rate of diagnosis[8].

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[5] Four London clinics report dramatic drops in HIV incidence in gay men: PrEP, early testing and early ART likely to be key, i-base, 2017

[6] HIV in the UK 2016 Report, Public Health England, 2016

[7] Krentz HB. The high cost of medical care for patients who present late (CD4<200 cells/ /µl) with HIV infection. HIV Med 2004; 5:53-98.

[8] UNAIDS: 90-90-90 – Is Scotland on target? Health Protection Scotland, 2016