HIV SELF-TESTING SEMINAR:
Summary of proceedings

On 26 November 2013 HIV Scotland hosted a seminar in Glasgow on HIV instant result self-testing. The event was held in order to develop a detailed report and identify best practice recommendations relating to HIV instant result self-testing in Scotland. This document is an interim summary of the day. HIV Scotland is an independent charity and funded this seminar using its core funding from the Scottish Government.

Purpose of the event

It will be legal to sell and distribute instant result HIV self-testing kits in the UK from April 2014. This seminar brought people together to discuss what the change means for Scotland, the challenges and opportunities it may bring, and what needs to happen next.

Key documents relating to the day include:


Attendance

Sixty six people registered for the event with 57 attending on the day. A broad range of perspectives and sectors were represented: including Scottish Government, health board lead clinicians and public health leads, product manufacturers, the third sector, NHS 24, researchers and other interested individuals.

Event content

Shirley Windsor, Sexual Health, HIV and Hepatitis B Programme Manager for NHS Health Scotland chaired the event after welcoming remarks from George Valiotis, Chief Executive Officer of HIV Scotland.
**Personal experiences** were the foundations of the seminar. A presentation by Aidan Collins (HIV Scotland) highlighted testimonies gathered by HIV Scotland in the run up to the seminar which showed that experiences can vastly differ. Some people described extreme anxiety about not trusting the result given by instant result self-test kits; others liked the simplicity and felt empowered with all the information they need to take a self-test without any other intervention; others were glad to have been able to self-diagnose and deal with information in their own way and connect to support when they were ready. A video containing the personal testimonies can be accessed here: [https://vimeo.com/80534820](https://vimeo.com/80534820).

**Home sampling is already legal.** This is a type of self-testing which does not give an instant result: users place a few drops of blood on a test strip, post them back to a laboratory, and a health professional rings all clients with their results. Robert McKay (Terrence Higgins Trust Scotland) gave details of the Terrence Higgins Trust home-sampling pilot that was funded for and promoted in England, but received 439 orders in Scotland - from across most health boards. It was explained how home-sampling kits could fill an important gap in the portfolio of testing opportunities across statutory, private and third sectors. It was noted that this pilot had a large uptake from men who have sex with men but a small uptake from African populations. Mr McKay concluded that there is a need for a range of testing options relevant to people’s needs.

Gareth Brown (Scottish Government) gave an overview of the change to the law. In August 2013 the UK Department of Health publicly announced intention to change the legal position on instant result HIV self-testing kits. Although health is a devolved matter, the regulations of medical products remain reserved. *HIV Testing Kits and Services Regulations 1992* made the promotion and selling of HIV instant result self-testing kits illegal, though it has never been unlawful for an individual to buy or use them. Instant result self-testing kits have been available since 1992 despite the ban and it is likely that people are already buying poor quality kits online.

In July 2011 a report by the House of Lords Select Committee’s *No Vaccine, No Cure: HIV and AIDS in the UK* stated: “The ban on HIV home testing kits, as laid out in the HIV Testing Kits and Services Regulations 1992, is unsustainable and should be repealed. A plan should be drawn up, in consultation with clinicians, patients, voluntary organisations and professional associations, to license kits for sale with appropriate quality control procedures in place. The licensing regime must make sure that the tests are accurate, and that the process gives comprehensive advice on how to access clinical and support services in order that those who test positive get the care that they need.” This announcement also followed the Food and Drug Administration (FDA) in the US approving the OraQuick In-Home HIV Test for sale directly to Americans in July 2012. It was explained that the change also fits well with Scottish Government’s aim for an NHS that is focused on the needs of patients and service users.

An **NHS Clinician’s perspective** was provided by Dr Dan Clutterbuck (NHS). The challenges faced by current services were presented, such as: high rates of undiagnosed HIV, high rates of late diagnoses, continued high incidence of HIV in men who have sex with men, failure of testing for indicator conditions, and the limited feasibility of universal testing in low prevalence areas. Barriers to testing were also presented: stigma, lack of awareness, fear of
a positive result, limited access to tests, privacy, convenience, and the speed of getting a result.

Dr Clutterbuck then compared and contrasted instant result test kits with home sampling and presented evaluation outcomes from the Terrence Higgins Trust pilot and the Dean Street pilot. Both pilots showed very high levels (96.7 per cent and 95.6 per cent respectively) of participants would recommend the service to a friend expected to test negative, and 68.7 per cent compared with 23.2 per cent (respectively) said they would prefer a home test with immediate results.

Dr Clutterbuck summarised responses he had received informally from clinical colleagues, showing most perceived there to be public health benefit to instant result tests, but that there was a level of uncertainty about a place for the tests in NHS services. Some concerns listed were: the sensitivity and specificity of the tests; false reassurance and increased transmission risk; errors in performing the tests; how a person will cope with a positive result and be linked to care; frequent testing and testing under duress; and lack of comprehensive health care and prevention activity.

Brian Reid of kit manufacturer OraSure is responsible for sales of OraQuick instant result self-test kits and he offered insight into how the kits work and how they are supplied in the USA where they are already legal. In the USA, instant result self-test kits are believed to be providing substantial public health benefit in terms of number of positives identified. The take up of self-test kits there is continuing to build, as awareness builds among high risk populations. Mr Reid stated that although the legal change will take effect in April 2014 it may take several more months for product regulation to be completed.

**Key themes**

The day’s discussions were dynamic and wide ranging. In general, there was a consensus that self-testing may provide real opportunities to improve rates of early diagnosis and link people into support and treatment. However, people also raised a number of concerns and issues that must be addressed if instant result HIV self-testing is to deliver the best possible outcomes for people in Scotland.

Some emerging themes from the day’s discussions include:

- Questions around pricing and equality of access. Units in the USA currently retail for US $39.99.
- The need for clear, accurate information in the testing kit that is relevant to Scotland.
- The need to signpost people to Scottish local and national support and care services, including a helpline.
- It is not well understood why someone would choose a HIV test kit (instant result or sample kit) in place of a full sexual health check-up. The kits may pose challenges to general sexual health screening.
There may be additional options to consider, such as supervised instant result HIV test clinics, where service users can undertake their own instant result test, with support on hand.

There remain uncertainties around which groups would most benefit from the kits, what level of uptake there will be, and that how they are costed and made available may limit people from lower socio-economic backgrounds or with low levels of literacy.

The need for more evidence and research about the impact of instant result self-test kits, especially in a Scottish context. This includes capturing information about people's perceptions of self-testing, the take-up and impact of the kits, evaluating pilot studies and establishing how many people self-test but don't access care on receiving a positive result.

The need a consistent media message/campaign across Scotland in time for the change in the law – both in relation to HIV generally and to the self-test kits. It is important that messages around HIV prevention are also promoted and not diluted or lost.

Attention needs to be paid to privacy and confidentiality of customers buying these kits, how their information is stored and used if bought online, and how they can discreetly dispose of the kits.

Next steps

HIV Scotland will now review all of the information gathered and use this to produce a full report with clear recommendations for action. This shall be available in the near future on our website, www.hivscotland.com.

In the meantime, please contact us if you have anything you would like to raise about instant result HIV self-testing at: info@hivscotland.com.