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

- As of 31st March 2017, there are 5,287 people diagnosed as living with HIV in Scotland, with the highest number of new diagnoses within Greater Glasgow and Clyde, and Lothian.¹
- It is estimated that one in six people living with HIV in Scotland are unaware of their status.²
- There were 285 new cases of HIV were reported in 2016.³ This represents the first significant drop (approximately 20%) in new cases for over a decade.
- It is estimated that 30% of those individuals diagnosed with HIV currently living in Scotland are aged 50 and over.

Are patient and service users’ perspectives taken into account in the planning and delivery of services?

The involvement of people affected by HIV in the planning and delivery of services in Scotland remains inconsistent. Within the Sexual Health and Blood Borne Virus Framework Update 2015 – 2020, the Scottish Government has identified patient involvement as “core to good practice and should not be considered optional”.⁴ There is also a commitment from the Government to work with third sector organisations and NHS Boards to formalise national patient involvement groups. However, the Framework does not detail what mechanisms are used to monitor and quality check patient involvement in Scotland. This presents a challenge in understanding how patient and user perspectives are taken into account.

¹ HIV infection and AIDS: Quarterly report to 31 March 2017 (ANSWER), Health Protection Scotland, June 2017
² Why Get Tested, HIV Testing Week Scotland
³ HIV infection and AIDS in Scotland: HIV infection and AIDS: Quarterly report to 31 December 2016 (ANSWER), Health Protection Scotland, March 2017
People living with HIV have experience of living and managing their HIV-related, illnesses, and – prior to infection – they have experience of some of the factors that put individuals and communities at risk of HIV. As a result, people living with HIV are uniquely placed to provide insight on prevention messages, as well as the development of services and policy. Involving people therefore increases how effective, appropriate and relevant these programmes are, and can contribute to better health outcomes for individuals.

Involvement is a key priority for people living with HIV, in particular being involved in decisions about care and treatment options. The annually updated Positive Persons’ Manifesto outlines the policy priorities for people living with HIV, with greater involvement being consistently identified as a core ask. Through being involved in decisions about treatment, people living with HIV can develop trusting relationships with GPs and consultants and care can be shaped around the need of the individual.

“We need to get involved and have a voice to make and change policy” 2016 Positive Persons’ Manifesto.

HIV Scotland has previously conducted research examining the services supporting people living with and at risk of HIV in Scotland. One of the biggest concerns among local authorities was difficulties in understanding the needs of populations affected by HIV in the design and operation of services. It was therefore recommended that people living with or at risk of HIV and the third sector should be included as partners within networks and bodies which have a key role in planning and delivery of services, for example health and social care partnerships. Evidence of how meaningful patient and service users’ involvement will be achieved should be a prerequisite for funding grants being made available for relevant HIV and sexual health services.

HIV Scotland is working alongside all mainland NHS Health Boards and people living with HIV to create involvement initiatives. These groups aim to provide meaningful opportunities for patients to share their views and experiences with NHS practitioners. The success of these groups relies upon resources and staff time being available. There are now seven involvement groups operating across Health Boards. HIV Scotland and people living with HIV have co-designed a set of National Involvement Standards that provide an effective means of evaluating and recognising where involvement is being done well and of highlighting where improvements need to be made. We would recommend that these standards are adopted as the national assessment toolkit by the NHS to assess what level and quality of patient and service user involvement is taking place across Scotland. Crucially, people affected by HIV must be included in any auditing process.

6 Making the Vision a Reality: Services Supporting People Living With or at Risk of HIV in Scotland, HIV Scotland, 2015
Do services treat people with dignity and respect?
Stigmatising attitudes towards people living with HIV continue to exist within health services in Scotland. The Stigma Index 2015, revealed that nearly one-third of respondents living in Scotland worried about being treated differently to other patients at their GP and dentist, with 18% and 12% having avoided care in either setting all together. The report also noted that a number of people living with HIV had been pressured by a healthcare worker to disclose their status to others in the last 12 months.

Awareness of the modern day realities of HIV also continues to be a major challenge within health services. Practices such as ‘double gloving’ and being only offered the last appointment of the day continue to be reported to HIV Scotland by people living with HIV. This can result in unnecessary stress and anxiety when accessing services.

Are the correct systems in place to detect unacceptable quality of care and act appropriately when things go wrong?
People living with HIV can experience unique challenges when accessing services, for example stigmatising attitudes and unwanted disclosure. HIV Scotland strongly advocates that patients must have the ability and confidence to exercise their human rights when things go wrong. People living with HIV have told us that information on where to seek advice when their rights are violated is essential.

7 The People Living With HIV Stigma Survey UK 2015: Scotland, Stigma Index UK, 2016