MAKING THE VISION A REALITY:

Services supporting people living with and at risk of HIV in Scotland

JANUARY 2015
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EXECUTIVE SUMMARY

Scotland’s response to HIV has reached a critical stage: one less obvious than the initial epidemic, but just as urgent. Scotland’s current national framework on sexual health and blood borne viruses is coming to an end and while there have been successes and progress in some key areas, there is still so much to be done. People living with HIV still face stigma and prejudice every day, and as a nation we have failed to reduce new infection rates in any significant way across the last ten years.

The first step we must take is to make use of the tools we already have. National policy initiatives and strategies on health and social care can seem remote and theoretical, but they set out a strong vision for support and services in Scotland that are person-centred and holistic. Used in the right way, these initiatives provide an effective set of tools to improve the reality that service users experience.

With this in mind, this report sets out to examine the services available for people living with and at risk of HIV right across Scotland, whether directly related to HIV or otherwise. Part 1 sets out the policy initiatives that outline the vision for what services should be expected to deliver, and how; Part 2.1 considers the reality that individual service users experience, and the gaps these experiences highlight; Part 2.1 goes on to explore this reality from the perspective of the services themselves, examining how they function, who delivers services, the challenges and barriers they face, and examples of what works well; and finally Part 3 gives recommendations for a way forward, working toward making Scotland’s vision for services a reality.

The report is inevitably wide-ranging and detailed. The key points made are:

> Examples of good practice in the provision of services exist in Scotland and many service users (both living with and at risk of HIV) are satisfied with the services they have access to and use.

> Links must be improved between sexual health and mental health services (See Recommendation 6.1).

> There are a range of approaches and actions that could have significant impact across services: from encouraging ‘whole system’ commissioning, to developing systems to map relevant programmes and funding, to mainstreaming HIV issues into local and national frameworks and performance monitoring mechanisms (See Recommendations 5.1, 5.2 and 5.3).

> Services should be more flexible and accessible to ensure greatest reach (See Recommendations 2.1, 2.2 and 2.3).

> Information sharing and management are key and improvements can be made: from confidentiality and privacy, to information about available services, through to training for staff - whether clinical or support staff, local authority or third sector workers (See Recommendations 3.1, 3.2 and 3.3).
Location and physical environment have a significant impact on service users’ experience of and engagement with a service. The needs of people in rural areas, the potential for co-location of services, and the importance of a welcoming, comfortable environment must be considered (See Recommendations 4.1, 4.2 ad 4.3).

1. Involvement

1.1: 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, such as community health partnerships, managed care networks, and the new integrated health and social care partnerships.

2. Flexible/accessible services

2.1: Service providers should work to make services more accessible in order to increase the likelihood of people at risk of HIV engaging with prevention services. This could include increasing the number of mobile services which are available or providing transport for people.

2.2: Services for people living with and at risk of HIV should adopt a wider range of opening times and increase the number of appointments available to people.

2.3: Service providers should consider how they could use telehealth and telecare options to increase the availability and flexibility of services.

3. Information

3.1: Services should provide greater clarity about what the information they collect from people will be used for and in exactly which circumstances information may be shared.

3.2: Service providers should develop clear information about how services can be accessed, in consultation with service users. This information should be available in a variety of formats and be displayed in places where people can easily access it.

3.3: Specialist HIV training should be available for staff and volunteers working within health and social care services. This is of particular importance in generic rather than specialist services that people living with and at risk of HIV use. Opportunities for professionals to share skills, information and learning should be created wherever possible to help services adapt to the distinct needs of service users, and to ensure that services always have a supportive culture and that staff understand the facts about HIV.

People living with or at risk of HIV and the third sector should be included as key partners within networks and bodies which have a key role in planning and delivery of services (See Recommendation 1.1).

Local authorities see self-directed support as having a significant impact on the way services are provided, and this will affect service providers of all types.
4. Physical environment and locations

> **4.1:** Future strategies on sexual health and blood borne viruses should include a particular focus on ensuring that people living in rural areas of Scotland have access to the full range of services that are relevant to their needs, on an equal basis with people living within other parts of the country.

> **4.2:** Sexual health services would benefit from approaches where a variety of services or different professionals are available in the same location. However, co-located services need to ensure that robust measures are in place to protect the confidentiality and anonymity of service users.

> **4.3:** Service providers should work to create physical environments where service users feel welcome and comfortable. Privacy should be prioritised so that people feel safe and feel confident to talk openly about their health with staff.

5. National initiatives

> **5.1:** The Scottish Government should develop a guide to whole system commissioning for sexual wellbeing and blood borne viruses, addressing the wider determinants of health and societal factors that impact on sexual wellbeing and blood borne viruses. This would help clarify not only where responsibilities for commissioning sit but also how commissioners can work together collaboratively to deliver improved outcomes.

> **5.2:** Robust systems should be put in place to capture information about how funds to support work in relation to sexual health and blood borne viruses are distributed at both a national and local level. This should be supported through the development of a funding map.

> **5.3:** Considerations of HIV should be mainstreamed through local and national outcome frameworks, and incorporated into national and local performance monitoring mechanisms e.g. single outcome agreements and drug and alcohol partnership outcomes. This would not only help to ensure that actions are taken forward on a local level but also assist with reviewing progress and ensuring accountability.

6. Links between services

> **6.1:** Service providers must create stronger links between sexual health and mental health services, with greater provision of mental health support within sexual health settings or through clear referral pathways.
ABOUT THIS REPORT

In the last five years there has been significant reform of public services and the introduction of a range of new national policy initiatives in relation to both health and social care. In addition, key strategies specific to sexual health and blood borne viruses have recently ended or are about to end. As such, this is an opportune time to review progress, identify where improvements are needed and bring stakeholders together to ensure that HIV is truly a priority for everyone.

With this in mind, this report sets out to examine the services available for people living with and at risk of HIV right across Scotland, whether directly related to HIV or otherwise. Part 1 sets out the policy initiatives that outline the vision for what services should be expected to deliver, and how; Part 2.1 considers the reality that individual service users experience, and the gaps these experiences highlight; Part 2.2 goes on to explore this reality from the perspective of the services themselves, examining how they function, who delivers services, the challenges and barriers they face, and examples of what works well; and finally Part 3 gives recommendations for a way forward, working toward making Scotland’s vision for services a reality.

It is intended to provide researchers, policy makers and stakeholders with a discussion of the range of services being provided and accessed, key trends in service provision, as well as examples of good practice and recommendations for change. With the current Sexual Health and Blood Borne Virus Framework coming to an end in March 2015, this report should inform future strategies by improving understanding of people’s needs and experiences.


www.hivscotland.com
METHODOLOGY

The research used in this report was carried out using a combination of surveys, interviews, focus groups and desktop research, using data from the 2013/14 financial year.

The table below summarises contributors and how information was obtained from them.

<table>
<thead>
<tr>
<th>CONTRIBUTOR</th>
<th>METHODS USED</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOCAL AUTHORITIES</td>
<td>➤ A survey was sent to all 32 local authorities in Scotland</td>
</tr>
<tr>
<td></td>
<td>➤ Responses were received from 15 local authorities</td>
</tr>
<tr>
<td>HEALTH BOARDS</td>
<td>➤ A survey* was sent to all 14 regional health boards</td>
</tr>
<tr>
<td></td>
<td>➤ Responses were received from 10 health boards</td>
</tr>
<tr>
<td>HIV SPECIFIC THIRD SECTOR ORGANISATIONS</td>
<td>➤ Face-to-face interviews took place with 4 organisations</td>
</tr>
<tr>
<td>GENERAL THIRD SECTOR ORGANISATIONS</td>
<td>➤ A survey* was distributed through national third sector networks</td>
</tr>
<tr>
<td></td>
<td>➤ Responses were received from 13 organisations</td>
</tr>
<tr>
<td>PEOPLE LIVING WITH HIV</td>
<td>➤ A survey** targeted at people living with HIV was distributed via the HIV Scotland website, social media, national third sector networks and organisations working directly with people living with HIV</td>
</tr>
<tr>
<td></td>
<td>➤ 96 responses were received</td>
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<td></td>
<td>➤ Two follow-up focus groups were held in Dundee and Aberdeen</td>
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<tr>
<td>PEOPLE AT RISK OF HIV</td>
<td>➤ A survey** was targeted at people at risk of HIV was distributed via the HIV Scotland website, social media, third sector organisations and relevant events</td>
</tr>
<tr>
<td></td>
<td>➤ 206 responses were received</td>
</tr>
<tr>
<td></td>
<td>➤ Two focus groups were held: one with sex workers and one with an LGBT group</td>
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</tbody>
</table>

*The survey enquired about the type and location of services provided, partnerships, recent changes in services, commissioning, challenges and future opportunities in service delivery.

**The survey enquired about the type of services used, where people accessed them from, positive and negative experiences, types of providers and gaps in service provision.
As shown in the table above, the experiences and opinions of people living with and at risk of HIV were primarily collected through two surveys. This type of survey research relies on people volunteering information and self-selecting their answers.

This means the information given could not be independently verified. It is also possible that some people who are at risk of HIV but do not consider themselves to be are not represented in the data.

**SURVEY PROMOTION**

In order to ensure data collected from people at risk was reflective of the needs of all those in this category, promotion of the survey for this group was targeted at key and vulnerable at-risk populations as defined by the World Health Organization and the Sexual Health and Blood Borne Virus Framework. In Scotland those defined as particularly at risk of HIV are men who have sex with men and people from areas of high prevalence – particularly sub-Saharan Africa. The World Health Organization has also identified groups who, due to specific higher-risk behaviours are at increased risk of HIV irrespective of the local epidemic type or context. These include: men who have sex with men; people who inject drugs; people in prisons and other closed settings; sex workers; and transgender people.

The surveys were proactively promoted to the groups described above using a number of methods, including: face-to-face promotion at Pride events in Scotland, distribution of the survey through the communication channels of organisations working with key and vulnerable populations, and by contacting grassroots community groups of people from areas of high prevalence and prisons.

In addition, the surveys collected equalities data from respondents to enable a comparison of the experiences of different groups. Notable differences are highlighted in this report.

However, despite best efforts to target key at-risk populations, some groups are still poorly represented in the research. This includes black and minority ethnic groups, people who inject drugs and prisoners. As such, we recommend that further research focusing on the specific service needs of these groups be carried out in the future. In addition it should be noted that we did not collect any information from children living with or at risk of HIV about their experiences of accessing services.

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2 World Health Organization, Consolidated Guidelines on HIV prevention, diagnosis, treatment and care for key populations, July 2014, [http://go.u/3nv1vbr](http://go.u/3nv1vbr)


4 See note 2
ABOUT HIV SCOTLAND

This report was produced by HIV Scotland. HIV Scotland is the national HIV policy charity for Scotland: we speak out for people living with or at risk of HIV. We want a society which is well-informed about HIV and devoid of HIV-related stigma and discrimination.

HIV Scotland provides:

> Knowledge and expertise to help inform and deliver strong policies and effective strategies;
> Expert advice and a voice for HIV in Scotland;
> Information, training and resources;
> Signposting to evidence, expertise and community experience; and
> Opportunities to engage with others in shaping policy and practice.

OUR VISION is a society which is well informed about HIV, devoid of HIV-related stigma and discrimination, and where everyone living with or affected by HIV has access to and helps shape excellent services.

OUR MISSION is to ensure that all HIV relevant policy and practice in Scotland is grounded in evidence and in the experience of people living with and affected by HIV.
ABOUT HIV IN SCOTLAND

HIV is a major public health challenge for Scotland. Since 2001 the number of people diagnosed and currently living with HIV in Scotland has doubled, reaching an estimated 4,800 people as at September 2014. It is also estimated that approximately 25% of people living with HIV in Scotland are as yet undiagnosed. The NHS board areas with the highest prevalence of people diagnosed with HIV include NHS Lothian, NHS Greater Glasgow and Clyde, NHS Tayside and NHS Grampian.

The needs of people living with, affected by, or at increased risk of HIV are wide-ranging and can involve a variety of health and social care issues. With access to good quality health and social care services people living with HIV can live healthy and fulfilling lives. Since the start of the epidemic, there has been great progress in treatment and care for people with HIV in Scotland, bringing significant improvements to both clinical outcomes and to the lives of people living with HIV.

However, the needs of people living with or at risk of HIV can involve the statutory and third sectors beyond just health and social care - relating to issues such as housing, education, employment, welfare and criminal justice.

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5 Health Protection Scotland, HIV infection and AIDS in Scotland: Quarterly update to 31 September 2014 (ANSWER), 2014


7 See note 5
PART ONE: THE VISION
The health and social care landscape in Scotland is changing. The Scottish Government is reforming public services to improve care and make better use of resources, introducing a range of policies to help drive up the quality of health and social care, integrate services, and give people more choice and control over the services they receive.

Taken together, these policy developments set out a vision for how the services being accessed by people living with and at risk of HIV in Scotland should be designed and delivered.

This section will consider:

- Commission on the future delivery of public services (Page 16)
- Patient Rights (Scotland) Act 2011 (Page 16)
- Scotland’s National Action Plan for Human Rights 2013-17 (Page 16)
- Self-directed Support (Page 17)
- Integration of health and social care (Page 17)
- Healthcare Quality Strategy for NHS Scotland (Page 18)
- Sexual Health and Blood Borne Virus Framework 2011-2015 (Page 18)
- Standards for HIV Services (Page 19)
- Single outcome agreements (Page 19)
In 2011, a commission was established to make recommendations for the future delivery of public services in Scotland, known as the Christie Commission. The commission considered the whole system of public services provided through the public, third and private sectors. It concluded that public services are facing their most serious challenges since the inception of the welfare state and identified four key objectives for reform:

> Public services are built around people and communities, their needs, aspirations, capacities and skills, and work to build up their autonomy and resilience;

> Public service organisations work together effectively to achieve outcomes.

Specifically, by delivering integrated services which help to secure improvements in the quality of life, and the social and economic wellbeing, of the people and communities of Scotland;

> Public service organisations prioritise prevention, reduce inequalities and promote equality;

> All public services constantly seek to improve performance and reduce costs, and are open, transparent and accountable.

The Scottish Government subsequently committed to creating the conditions for reform of public services, and has put in place a series of policies and pieces of legislation to develop services in the way envisioned by the Commission on the Future Delivery of Public Services.

The Patient Rights (Scotland) Act 2011 was passed by the Scottish Parliament in February 2011 and gained royal assent in March 2011. The Act aims to improve patients’ experiences of using health services and support people to become more involved with their health and healthcare.

The Act includes sections on patient focus; quality care and treatment; patient participation; communication; patient feedback and the waste of resources. The Act also made provision for the introduction of a charter of the rights and responsibilities patients have when using the NHS.

Scotland’s National Action Plan for Human Rights (SNAP) was developed by a coalition of organisations including local authorities, the NHS and the Scottish Government. These bodies and others have made a firm commitment to integrate human rights more closely into their work as a result of the action plan. SNAP provides a roadmap for the realisation of all internationally recognised human rights in Scotland.

The model promoted by SNAP is a ‘human rights-based approach’, emphasising participation, accountability, non-discrimination, empowerment and legality. This has several benefits: upholding the rights of everyone; supporting person-centred services; helping good decision making; improving institutional culture and relationships and, finally, ensuring legal compliance and promoting best practice.
The Social Care (Self-directed support) (Scotland) Act 2013 was passed in November 2012 and received royal assent in January 2013. Self-directed support (SDS) allows individuals and families to exercise an informed choice about how their support is provided to them. It is most commonly used in the delivery of social care and support but it can cover a much wider range of services.

‘Integrated health and social care’ is the term used to describe the goal that services should be planned and delivered seamlessly from the perspective of service users and that systems for managing services should actively support this. Integration is seen as a way of improving both the quality and efficiency of services.

The concept of integration is not new to Scotland and there have been many attempts to achieve greater integration, including through the creation of local healthcare cooperatives and community health partnerships.

The Act, which was implemented in March 2014, requires local authorities to give people a range of options for how their social care is delivered, empowering them to decide how much ongoing control and responsibility they want over their own support arrangements. For example, through self-directed support people can choose to receive a direct payment to individually purchase the types of services and supports they require.

Despite such initiatives, there have been persistent concerns that joint working between partners has not been as effective as it could be, or that it has been inconsistent across the country. To tackle this, the Public Bodies (Joint Working) Scotland Act 2014 was passed. The Act puts a framework in place for the integration of health and social care in Scotland by requiring health boards and local authorities to deliver services jointly. It is designed to ensure that health and social care provision across Scotland is joined-up and seamless, especially for people with long term conditions and disabilities, many of whom are older people.

From April 2015, new integration authorities will have responsibility for the planning and resourcing of a significant proportion of health and social care services across Scotland. Nine new national health and wellbeing outcomes came into force in December 2014, setting out what integration authorities should achieve by working with individuals and local communities.

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13 Scottish Government SPICe Briefing, Public Bodies (Joint Working) (Scotland) Bill, 2013

14 See note 13


HEALTHCARE QUALITY STRATEGY FOR NHS SCOTLAND

The Healthcare Quality Strategy for NHS Scotland\(^\text{16}\) aims to deliver the highest quality healthcare to the people of Scotland and ensure that the NHS, local authorities and the third sector work together – and with patients, carers and the public – towards the shared goal of world-leading healthcare. Three ‘quality ambitions’ to provide focus for all activity are set out within the strategy. These are:

- **Safe**: There will be no avoidable injury or harm to people from healthcare, and an appropriate, clean, safe environment will be provided for the delivery of healthcare services at all times.

- **Person-centred**: Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision making.

- **Effective**: The most appropriate treatments, interventions, support and services will be provided at the right time to everyone who will benefit, and wasteful or harmful variation will be eradicated.

All healthcare policy in Scotland should be aligned to support the delivery of these ambitions.

THE SEXUAL HEALTH AND BLOOD BORNE VIRUS FRAMEWORK 2011-2015

In 2011 the Scottish Government launched the Sexual Health and Blood Borne Virus Framework 2011-2015, which draws together five high level outcomes regarding sexual health, HIV, hepatitis C and hepatitis B\(^\text{17}\):

- Fewer newly acquired blood borne viruses and STIs; fewer unintended pregnancies;

- A reduction in the health inequalities gap in sexual health and blood borne viruses;

- People affected by blood borne virus(es) lead longer, healthier lives;

- Sexual relationships are free from coercion and harm; and

- A society whereby the attitudes of individuals, the public, professionals and the media in Scotland towards sexual health and blood borne viruses are positive, non-stigmatizing and supportive.

The framework is monitored by a series of indicators against each outcome. A national monitoring and assurance group is responsible for measuring and monitoring these indicators.

The current framework runs until 2015. Progress against the outcomes and indicators is being reviewed and the Scottish Government have stated that a refreshed policy will be produced and published to follow it.


\(^{17}\) Scottish Government, The Sexual Health and Blood Borne Virus Framework 2011-2015, [http://goo.gl/8g7Feg](http://goo.gl/8g7Feg)
In 2011 Healthcare Improvement Scotland produced standards for clinical HIV services in Scotland aiming to improve the quality and coordination of HIV care. There are 11 standards which focus on:

- Service organisation;
- Prevention;
- Recognition and diagnosis; and
- Treatment and care.

The HIV national clinical leads review practice in relation to policy, including these standards. Data on testing, monitoring and prevalence are published by Health Protection Scotland.

In November 2007 national and local government signed a concordat which committed both to moving towards single outcome agreements for all 32 of Scotland’s councils and to extending these to community planning partnerships (which bring key public, private, community and voluntary representatives together to deliver services). Single outcome agreements are formal agreements between the Scottish Government and community planning partnerships. They set out how each will work towards improving outcomes for the local people in a way that reflects local circumstances and priorities.

The concordat gave councils more local flexibility in the way they spend the funds received from the Scottish Government, in order to achieve the agreed set of outcomes. This was largely achieved through the removal of a substantial number of ring-fenced funding streams, including removing ring-fenced funding for HIV prevention work. This established single outcome agreements as the main framework for aligning public sector activity towards agreed priorities. As such, the Sexual Health and Blood Borne Virus Framework specifically states that local authorities and local partners should link progress against the framework outcomes to single outcome agreements.

The national policies set out in this section dictate that people in Scotland should experience person-centered care which is supportive, holistic and takes into account their individual needs. Care pathways should be clear and where necessary people should be seamlessly and efficiently referred between the services they need. There should also be a focus on preventing problems before they arise and helping people self-manage their condition.

As Part 2.1 and Part 2.2 of this report demonstrate, Scotland has still some way to go before this vision can be a reality, but it is important to note that we do have many of the policies, laws and tools required to move forward. Part 3 (page 63) outlines specific recommendations for such ways forward.

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PART TWO: THE REALITY
PART 2.1 THE REALITY – THE SERVICE USER PERSPECTIVE

The national policies set out in Part 1 of this report dictate that people in Scotland should experience person-centered care which is supportive, holistic and takes into account their individual needs. Care pathways should be clear and where necessary people should be seamlessly and efficiently referred between the services they need. There should also be a focus on preventing problems before they arise and helping people self-manage their condition.

In order to explore the extent to which this vision is reflected in reality, this section examines the perspective of people living with or at risk of HIV who use services in Scotland: which services they use, the experiences they have had with these services and the issues they identify that may require particular attention. Any issues identified are accompanied by references to relevant recommendations for action in Part 3 of this report.

This section includes:

> Key findings (Page 23)
> Types of services being accessed (Page 24)
  > Services accessed by people at risk (Page 25)
  > Services accessed by people living with HIV (Page 26)
> Gaps in service provision (Page 28)
> Location of services (Page 31)
> Out-of-hours access and convenience (Page 32)
> Confidentiality and information sharing (Page 34)
> Co-location of services (Page 35)
> Staff attitudes and relationships (Page 36)
> Environment and atmosphere (Page 38)
> Information provision (Page 40)
> Person-centered care (Page 41)
People living with and at risk of HIV often access multiple services for a broad range of needs.

Many people are satisfied with available services; but gaps do exist, particularly relating to mental health and peer support (See Recommendation 6.1, page 66).

Geographical differences in the availability of services are causing some service users to seek support outside their local area, and even outside Scotland (See Recommendation 4.1, page 66).

Location is a key factor in determining whether people have a positive experience of a service or use it repeatedly; some people living with HIV feel more support is required locally, rather than centrally as is increasingly the case (See Recommendation 4.1 and 4.2, page 66).

People living with and at risk of HIV value facilities where they can access multiple services in one location and where holistic approaches are taken to meeting their needs (See Recommendation 4.2, page 66).

A significant number of people living with and at risk of HIV are frustrated at the inflexibility of some services, citing inconvenient opening hours, small numbers of appointments, lack of telephone or online services and long waiting times as particular concerns (See Recommendations 2.1, 2.2 and 2.3, page 65).

Confidentiality is a key concern for people at risk of and living with HIV: from concerns about where personal information disclosed might be stored or passed to, through to the layout of services and admission processes (See Recommendations 3.1 and 3.3, page 65).

While there are many examples of good practice, some people still describe encountering negative or stigmatising attitudes from staff (See Recommendation 3.3, page 65).

People at risk of HIV describe a lack of information about available sexual health services and how to access them, and also a lack of accessible information for people with learning difficulties (See Recommendation 3.2, page 65).
TYPES OF SERVICE BEING ACCESSED

People living with HIV and people at risk of HIV were asked to identify the types of services they had used in the last three years, in order to set out a clear picture of the range of services they access.

The responses received are displayed in Figures 1 and 2.

FIG 1: Percentage of people at risk of HIV who have used service type in last three years

Data from survey respondents; see page 9 for methodology.

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>HIV treatment</td>
<td>3%</td>
</tr>
<tr>
<td>STI testing</td>
<td>53%</td>
</tr>
<tr>
<td>Condoms</td>
<td>61%</td>
</tr>
<tr>
<td>Sexual health education</td>
<td>32%</td>
</tr>
<tr>
<td>Surgical procedures</td>
<td>9%</td>
</tr>
<tr>
<td>Mental health (including counselling)</td>
<td>35%</td>
</tr>
<tr>
<td>Peer support and befriending</td>
<td>7%</td>
</tr>
<tr>
<td>Advocacy</td>
<td>4%</td>
</tr>
<tr>
<td>Housing</td>
<td>9%</td>
</tr>
<tr>
<td>Addiction</td>
<td>3%</td>
</tr>
<tr>
<td>Welfare advice</td>
<td>7%</td>
</tr>
<tr>
<td>Food banks</td>
<td>2%</td>
</tr>
<tr>
<td>Services for asylum seekers and refugees</td>
<td>0%</td>
</tr>
<tr>
<td>General sexual health services</td>
<td>35%</td>
</tr>
<tr>
<td>Residential/respite care</td>
<td>1%</td>
</tr>
<tr>
<td>Telephone helpline</td>
<td>11%</td>
</tr>
<tr>
<td>None of the above</td>
<td>13%</td>
</tr>
</tbody>
</table>
As shown in figure 1, the majority of people at risk of HIV surveyed were using multiple services, with access to free condoms (61%) and STI testing (53%) being the two most common. Mental health services (35%) were the third most common service used by people at risk, with sexual health education (32%) and general sexual health services (35%) also commonly being accessed. Services accessed less frequently included telephone helplines (11%), surgical procedures (9%), housing (9%), welfare advice (7%) and peer support or befriending (7%). Additionally, 13% of respondents indicated that they had not used any of the services listed.

When asked to explain the type of service they used in more detail, respondents accessing general sexual health services described having regular sexual health checkups as opposed to having an STI test on one particular occasion. Women using general sexual health services also referred to hormonal contraception and cervical smear tests.

People who indicated they had accessed sexual health education referred to receiving advice from sexual health clinics and through LGBT societies or support groups.

Of respondents at risk of HIV, a particularly high proportion (77%) of transgender people indicated they had used a mental health service in the last three years. It is possible that this high number is a reflection of mental health services being a gateway to gender identity clinical services, however it could also indicate a significantly higher level of need for mental health services among this part of the population.

Effective prevention strategies should not consider sexual health in isolation from other aspects of health and wellbeing. Evidence suggests that stronger links between sexual health and mental health services could be particularly beneficial given that both types of services are being accessed by a high proportion of people at risk of HIV.
People living with HIV also access multiple services. HIV treatment was accessed by 94% of HIV positive respondents, followed by free condoms (53%) and STI testing (53%). Mental health services (39%), welfare advice, (36%) and general sexual health services (36%) were each also accessed by over a third of respondents.

A smaller, but still significant, proportion of respondents living with HIV reported accessing housing support (19%), respite care (16%), and advocacy services (20%). In many instances, people are accessing support for multiple needs from a range of service providers.
I meet with my consultant every 3 months and get general sexual health services at the same time. I get STI testing as and when required. I collect condoms from the clinic. I have used various websites such as THT for sexual health education. I have received peer support through an activity group I used to attend. I have accessed welfare advice when I have needed it. As for mental health services, I have accessed a psychologist once. I used to access a CPN on an ad hoc basis.”

– Person living with HIV

People living with HIV stand to benefit from holistic approaches which are person-centered and take into account the diversity of people’s needs.

GAPS IN SERVICE PROVISION

People should be able to access a range of services relevant to their individual needs, either through interaction with one service or seamless referral between services, as set out in Part 1 of this report. People living with and at risk of HIV were asked if there were any services which they would like to access but could not currently, to help identify any unmet needs.

A large proportion of people living with and at risk of HIV indicated they were satisfied with the range of services currently available. While this finding is certainly encouraging, a number of gaps in service provision were also identified, as set out in the following sections.

When asked how often they accessed services, a large number of people using support services other than HIV treatment alone indicated that they were receiving support on a regular or at least repeated basis. The responses also show that people living with HIV are accessing generic services for support in relation to a range of issues, including welfare advice and mental health.

Given the generic nature of these services, it is unlikely that they will be equipped to provide advice and support specifically tailored to the needs of people living with HIV. However, there is evidence that people living with HIV would prefer to access support from people with an understanding of HIV and related issues. For example, a recent NHS Lothian and Greater Glasgow and Clyde needs assessment of men who have sex with men found that men living with HIV thought that counselling should be available from a professional person who understood what it is like to live with HIV, even if the focus of support is not directly about HIV.

Both people living with HIV and those at risk highlighted difficulties accessing mental health support, describing inflexible and unsuitable service provision, costs and long waiting lists as significant barriers:

“ I wish I could continue using the mental health services, but they are not very flexible. Evening sessions would be useful for people who work during the day.”

– Person living with HIV

“Sexual health counselling is very difficult with extraordinarily long waiting list for appointments.”
– Person living with HIV

Other gaps in service provision specifically identified by respondents living with HIV related to social care services, housing services, respite services, complementary / alternative therapies, support to undertake social activities, and peer support. Peer support was identified as a particular gap in this regard, with several respondents also commenting on inequalities in access for people living in rural areas:

“Living in a rural community is problematic when newly diagnosed as all the nearest support services are located in Edinburgh or Glasgow. This can leave you feeling quite isolated and alone. It would be good on diagnosis to be linked to a peer who you can contact for advice or just an ear to listen to your concerns.”
– Person living with HIV

“Living in the islands there is no meaningful form of peer support and I am not sure whether it would be feasible. Mainland services when they make suggestions about that kind of thing do not seem to appreciate the issues involved.”
– Person living with HIV

While peer support was most commonly mentioned, people living with HIV also highlighted geographical inequalities in access to other types of services and support.

This had caused some people to seek support outwith their local area and even outwith Scotland:

“I live in East Lothian and I am trying to access residential care but my council won’t pay. Also some individual funding opportunities are regional, for instance there is a holiday fund in Edinburgh which I cannot access as I live in East Lothian.”
– Person living with HIV

“Services in the Highlands are quite limited. If the services I need (e.g. welfare advice, alternative therapies, or any information beyond the basic normal stuff) are not available here I bypass the rest of Scotland and go direct to the large London-based charities who can help instantaneously.”
– Person living with HIV

“Everything seems to be mainland based – and around the central belt.”
– Person living with HIV

Several respondents at risk of HIV described gaps in testing services. Some commented that they had not been able to access testing either due to lack of information, inflexible opening hours, or because there was not a nearby testing facility. A number of at-risk respondents also highlighted a lack of peer-led sexual health services:

“[I would like] peer to peer support for MSM. Better access to condoms and lube, without questions or a lecture.”
– Person at risk of HIV
“I would just like to stress the importance of community based LGBT services in regards to sexual health and wider wellbeing. Having access to professional expert advice and support from peers makes a big difference and reduces intimidation and stigma around accessing help.”
– Person at risk of HIV

Several respondents commented on particular gaps in service and information provision for lesbian and bisexual women, as well as for transgender people:

“There is no clear and correct sexual health information for bisexual women, trans people or people with trans lovers, or if there is any it is not easily available... It also makes me really angry that I have been told a couple of times by charities that ‘there is no funding to give women condoms’.”
– Person at risk of HIV

“I can’t access any STI testing for bisexual woman like MSM can... It’s even harder to get trans specific info and trans friendly and INFORMED testing.”
– Person at risk of HIV

LOCATION OF SERVICES

Services should be located in places which are easily accessible for people and there should be equality of access to services22. A large number of respondents, both living with and at risk of HIV, commented on the importance of services being available locally. The location of a service is an important factor for people in determining whether they have a positive experience and also whether they use it repeatedly.

Specific examples were cited of services which are provided in convenient locations, such as those located centrally or close to transport links. However, some respondents living with HIV commented on the increasing centralisation of HIV-specific services and felt that more support needed to be made available locally. A number of at-risk respondents had also experienced difficulties accessing sexual health services, including testing services, because they were only available in distant or difficult to access locations:

“They [services] are a while away for me to get to.”
– Person at risk of HIV

“All services that we could use are in Glasgow... this causes problems for the surrounding areas to get to.”
– Person at risk of HIV

“It takes an hour to get there and an hour back plus the time to see consultant so it can take up to half a day. One of the big draw backs of centralising the service. Would be much better to have an HIV consultant in a local hospital.”
– Person living with HIV


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MAKING THE VISION A REALITY
A number of at risk respondents also highlighted the importance of outreach services, whereby STI testing was provided in locations such as saunas or LGBT community hubs:

“ As I’m at the sauna anyway, I’m more likely to get tested than to make an appointment and go in to the clinic.”
– Person at risk of HIV

It may not always be possible to have services in close proximity to everybody who needs to access them.

However, given the focus of fewer newly acquired infections in the current Sexual Health and Blood Borne Virus Framework, service providers should carefully consider how to increase the likelihood of people at risk of HIV engaging with prevention services; particularly how to make services as accessible as possible. This might include increasing the number of mobile services available, providing transport for people or increasing home sampling and self-testing services (See recommendations in Part 3 on page 65).

OUT-OF-HOURS ACCESS AND CONVENIENCE

The Scottish Government’s emphasis on person-centered planning should result in convenient, accessible services. Service users should also be able to access support flexibly, when they need it, in order to prevent problems before they arise, given the Christie Commission’s focus on prevention.

A number of respondents living with HIV highlight the importance of being able to contact services outside of working hours for additional advice and support. Some commented that access to out-of-hours support had enabled them to self-manage their condition better and had improved their mental health and wellbeing:

“ Just knowing that there is an expert at the end of a phone day or night was invaluable when newly diagnosed, particularly when starting ARVs... it is quite comforting knowing there is a clinician there when I need them.”
– Person living with HIV

However, a significant number of respondents both living with and at risk of HIV were frustrated at the inflexibility of some services, highlighting inconvenient opening hours, small numbers of appointments and long waiting times as particular concerns.

Some people living with HIV found it difficult to balance clinical appointments with their working lives due to inflexible or inconvenient appointment times. A number of people at risk also commented that accessing testing services could be problematic for those working full-time as few services offered testing outside normal working hours. Some suggested increased access to home-testing could provide a potential solution.
Several respondents also felt that accessing sexual health services was made more difficult because services were often oversubscribed and under-resourced:

“Service is only available one day each week, often busy and oversubscribed and very restricted hours.”
– Person at risk of HIV

“[I would like] postal services to allow me to test for HIV and STIs at home, the current appointment system at local clinic does not always suit my work rota.”
– Person at risk of HIV

“Arrangement of appointments could be improved – more flexibility required.”
– Person at risk of HIV

“Longer opening hours at the clinic would help me to better fit my appointments around my work commitments.”
– Person living with HIV

Several respondents at risk of HIV commented that they would like to access STI test results and sexual health services via telephone and online. Those who were already able to access test results via telephone or text message found this highly beneficial, while others felt frustrated by a lack of flexibility in how they could access their results. Other comments related to the waiting time to receive STI test results, highlighting variations in the availability of rapid result testing:

“There is no text message service like other health boards to let us know if results are negative.”
– Person at risk of HIV

“The waiting for test results (mainly HIV) has been a problem, especially as I know rapid result tests have been available in other places and countries for a long time.”
– Person at risk of HIV

While examples of good practice were cited, it is clear that sexual health services need to be more flexible and convenient for people to use. In particular, service providers should consider a wider range of opening times and larger number of appointments to meet demand.

As well as increasing flexibility of face-to-face appointments, there could be opportunities to increase the availability of services through the use of technology, particularly for people who may have difficulties accessing services in person.

Using technology in a health or social care context is increasingly referred to as telehealth and telecare. The Scottish Government’s National Telehealth and Telecare Delivery Plan for Scotland to 2015 emphasises the opportunities that telehealth and telecare services offer in giving service users greater choice, control and personalised care and also helping generate increased efficiencies in service delivery. Some telehealth services are already available to people living with HIV such as the MyHIV website and mobile app designed by the Terrance Higgins Trust and available in Scotland though hosted in England.

Online forums are useful for sharing experiences with other people and has definitely helped me to normalise HIV.”  
– Person living with HIV

While telehealth or telecare services should be used to complement and not replace face-to-face support, further consideration should be given as to how telehealth services could be further developed to complement aspects of sexual health services.

This provides people with information, reminders for medication and appointments, support resources and community forums to support people living with HIV:

“Online forums are useful for sharing experiences with other people and has definitely helped me to normalise HIV.”  
– Person living with HIV

CONFIDENTIALITY AND INFORMATION SHARING

Information about people accessing services must be kept securely and confidentially. People have a right to know how information about them is stored, shared and used by service providers. People should feel confident that information will not be passed to different agencies without their permission or unless there are exceptional circumstances.

Confidentially is a particularly important consideration for both people at risk and people living with HIV when accessing services. This lay at the core of many of the negative and positive experiences described in the following sections of this report, such as those relating to staff attitudes and the location and layout of services. Considerations of confidentiality also had a significant impact on how people used services and interacted with service staff:

“[The HIV Clinic has] excellent links with my GP whilst protecting my confidentiality, despite my long-held concerns that this could become awkward. I had not registered with a GP for 17 years (coinciding with diagnosis) but was able to negotiate a level of confidentiality acceptable to me.”  
– Person living with HIV

While some at-risk respondents wanted improved access to STI testing within general health settings, specialist sexual health services were seen to provide a higher degree of anonymity and confidentiality. Some people at risk of HIV expressed particular concerns about where personal information they disclosed might be stored or who it might be passed on to:

“It would be good if general health services operated in such a way as to make it easy to get tested there (e.g. GP) but anonymity provided by more specialist clinics is also very important. Having said that it’s not clear where information is shared and who can access info between various services and clinics.”  
– Person at risk of HIV

Several sex workers also highlighted that they were not always open with service staff due to fears over how information would be shared and the potential repercussions of this:

“We give this information which is on a file somewhere which says I sell sex…. You feel that you should be as truthful as possible but you find yourself always lying about things.”  
– Person living with HIV

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"They have a database and everything gets entered onto a database which gets shared with the police and social work, and any women that have kids wouldn’t use [name of service] because immediately a report goes to social work saying they are selling sex and they are worried about losing their children."

For prevention strategies to be successful, a culture of trust must be maintained between people accessing services and service providers. The implementation of the Public Bodies (Joint Working) (Scotland) Act and Getting It Right For Every Child approach could bring significant changes to the ways in which information is shared.

The results of the Christie Commission should lead to public service organisations working together effectively to achieve outcomes, with effective arrangements in place for joint and multidisciplinary working. When a person visits a service they should also be able to access or be signposted to a range of services which suit their particular needs.

Respondents living with HIV valued facilities where they could access multiple services responding to a range of needs in one location. People preferred a holistic approach to managing their condition and said multiple services in one place (or ‘co-location’) was also helpful in making them feel less conspicuous when attending a sexual health service or specialist HIV service:

"They were all in the one place, every staff member knew most of the staff in other departments. It is not all about your blood results, it is about how you are coping with everyday life."

– Person living with HIV

"The specialist HIV service is provided in a general health center where there are a range of other services offered e.g. GPs, dental and diabetic services etc. Having a range of general services in the building makes it look less obvious you are attending a sexual health service."

– Person living with HIV

CO-LOCATION OF SERVICES

The Scottish Government is currently developing a framework outlining how integrated health and social care partnerships will share information. Services need to provide greater clarity about what the information they collect from service users will be used for, particularly as new integrated information systems are developed. An example of openness in how and why information is shared is the Scottish Accord on the Sharing of Personal Information (SASPI) framework which was developed in Fife by public sector agencies with input and support from the Scottish Government, NHS Lothian and NHS Tayside.

28 Scottish Government, A guide to getting it right for every child, June 2012 http://goo.gl/5EIB0p

29 Scottish Government, Strategic action plan for effective and responsible collection, management and use of data across Scottish Public Services, June 2014 http://goo.gl/Jl4vml

30 Scottish Government, Scottish Accord on the Sharing of Personal Information (SASPI), 2010


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The benefits of having multiple services in one location were further highlighted by a focus group of people at risk of HIV. When asked what their ideal service would be designed to involve, this group highlighted that access to health, social care and other support services in one place would be highly beneficial:

“As well as health services, and while we are still in a criminalised environment some sort of legal advice and advocacy would be crucial.”
– Person at risk of HIV

This suggests that sexual health services may benefit from approaches where a variety of services or different professionals are available to provide support from the same location – such as Ward 41 at the Western General Hospital in Edinburgh, which is described in the case study below.

Case study: Ward 41

Ward 41 is an out-patient clinic at the Western General hospital in Edinburgh which supports approximately 170 people and takes a multidisciplinary approach, providing a range of different services for people living with HIV in one location. An HIV consultant and nurse specialist are available five days a week and patients are able to choose which day is most convenient for them to attend.

There is also a dietician, a large mental health team (including a psychiatrist, psychologist and several mental health nurses) and a sexual health consultant available. As a result, patients can be referred on the day of their standard appointment if they require additional support from other service types.

However co-location does present some practical challenges which need to be considered. In particular, co-located services need to ensure robust measures are in place to protect the confidentiality and anonymity of service users:

“The down side of attending a general local centre is that you may see friends and colleagues that you work with, who may ask you questions on why you are attending the clinic. Anonymity may not be as possible in a local centre as opposed to one more centralised such as Edinburgh or Glasgow. This is important when living with HIV, particularly if you haven’t disclosed your status to others.”
– Person living with HIV

Staff attitudes and relationships

As set out in the Healthcare Quality Strategy for NHS Scotland32, all staff within services – including those being accessed by people living with or at risk of HIV - should respect the values of service users and demonstrate compassion when providing care.

No person accessing services should experience discrimination, stigmatising attitudes or behaviours as a result of their HIV status, sexuality, race or any other characteristic they may have.


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While this report found many examples of good practice, some people described experiences where they had encountered negative attitudes amongst staff and felt uncomfortable within services.

A significant number of respondents both living with and at risk of HIV commented on the attitudes of staff and the way in which this impacted on their engagement with services. Many described having very positive experiences where they felt welcomed and found staff to be friendly and non-judgmental.

A large number of respondents praised the efforts of staff and found the support they received to be invaluable. A number of at risk respondents explained that experiencing a friendly environment within sexual health services had led to them feeling more able to talk openly and increased their confidence in accessing services:

“Friendly relaxed service with no hang ups about what seems like a difficult subject area sometimes. The staff manage to create an environment where sexual health and wellbeing can be discussed openly.”
– Person at risk of HIV

“It was welcoming and confidential.”
– Person at risk of HIV

Honest discussions make it more likely that potential issues will be identified and prevention interventions more effective, because they will be based on the reality of people’s situations and their individual needs. Several respondents living with HIV also described finding a sense of community within HIV-specific services and had established excellent relationships with those involved in providing their care and support:

“All staff continue to work above and beyond to be as helpful and caring as possible”
– Person living with HIV

“I have a good relationship with my consultant who is non-judgmental, but who demonstrates expertise and is engaging and interested.”
– Person living with HIV

“The staff (at the HIV clinic) deserve the highest praise and commendation for their professionalism, quality of care and decency.”
– Person living with HIV

However, some respondents described negative experiences of staff they encountered. At times, staff within sexual health services had acted in a way which was extremely insensitive to service users’ concerns over confidentiality. Others described situations where staff seemed disinterested or unwilling to help. Some respondents had also felt judged by staff and had felt stigmatised or discriminated against within HIV-specific services:

“As a gay man there is still discrimination from staff working in the HIV services.”
– Person at risk of HIV

“The last time I was at the clinic a guy’s name was being shouted out by a member of staff in the waiting area like it was for a taxi in a pub.”
– Person at risk of HIV

“Some new nurses can be judgmental, this could be avoided with some training!”
– Person living with HIV
Some respondents living with HIV also commented on experiences of discrimination and feeling stigmatised because of their status when receiving support outwith specialist HIV or sexual health services:

“...I think they [carers] are judgmental towards me which can make me feel shite. For instance they put on 2 pairs of gloves to prepare food for me. They need training in HIV.”
— Person living with HIV

This highlights the need for health and social care service providers to invest in staff training and development, in order to create a supportive culture where staff understand the facts about HIV and how to best support people living with the condition. This is particularly important in the context of the implementation of the Social Care (Self-directed Support) (Scotland) Act 2013, given that people may increasingly be receiving social care and support from non-specialist services. It is critical that there is consistency in the standard of care people receive, with recognition that the training needs of staff with regards to HIV span a wide range of sectors and staff roles.

ENVIRONMENT AND ATMOSPHERE

The physical environment and atmosphere of sexual health services is important to services users. Some people described accessing services where there is a distinct lack of privacy, chaotic reception and admission processes and unpleasant physical surroundings. The layout of services and the admission processes in particular impact on the actual or perceived levels of confidentiality within a service:

“...I want] more confidential waiting rooms.”
— Person at risk of HIV

“...It’s a depressing place, with walls covered in images of needles, bruised veins and brick walls.”
— Person at risk of HIV

Service providers should recognise the value of creating spaces where service users feel welcome and comfortable. Privacy should be prioritised so that people feel safe and are confident to talk openly about their health with staff.

“The reception... is not user friendly... we need to check in twice. There is no sense of a queue. I have no idea who is front or behind me. Queue management is confused and therefore confusing for users.”
— Person living with HIV

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INFORMATION PROVISION

People should have easy access to information about the range of services that are available to them. The Patient Rights Charter\(^{33}\) states that people have the right to be given the information they need to make informed choices about their healthcare and treatment options. Furthermore, the Sexual Health and Blood Borne Virus Framework 2011-2015\(^{34}\) states that local authorities should work with partners to ensure that all young people, parents and carers have access to high quality and consistent information on sexual health and wellbeing.

People at risk of HIV surveyed highlighted a lack of information about available sexual health services and how to access them. Some people had only found out about testing services through friends or because they knew other people already in contact with services. While sexual health services were most commonly mentioned, several respondents both living with and at risk of HIV also highlighted the importance of being able to access information about services and support for a range of needs:

- “I’m not sure how or where to get STD tests.”
  - Person at risk of HIV
- “I only heard through a friend of a friend.”
  - Person at risk of HIV
- “Getting access to good information is very important especially for homelessness and benefits.”
  - Person at risk of HIV
- “I would greatly benefit from social work support as I am currently unwell and, not being from the area, am unsure of how to access any service.”
  - Person living with HIV

An LGBT focus group made similar comments, especially about the lack of accessible information for people with learning disabilities. This highlights a continued need for service providers to develop, in consultation with service users, clear information about how to access services. This information should be available in a variety of formats and be displayed in places where people can easily access it.

Some people found it was difficult to find reliable information about particular aspects of sexual health, while others had been given conflicting information:

- “My partner and I tried to find PEP treatment... We called the free NHS number and they... didn’t understand our situation. We then looked online and found... that the ER / NHS would provide treatment... We then went to hospital... to be finally seen by a young doctor who told us “we do not give PEP as we cannot follow up the treatment”... We finally went back home and got up early to go to a sexual health clinic and got PEP without any problem. It was just really frustrating to get either the wrong info online, or that the ER didn’t know about PEP.”
  - Person at risk of HIV
- “I find the information provided by staff can be inconsistent (e.g. about STI risks and accuracy of tests) and this can undermine my confidence in the testing process.”
  - Person at risk of HIV

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PERSON-CENTERED CARE

Health and social care services should take full account of the needs and aspirations of the people who use services35. Services should be planned around people so they receive the right service at the right time, in the right place. A number of people surveyed made comments about person-centered care and the ways in which services responded to their individual needs and concerns. Some people have had positive experiences and felt that the services they used listened to them and were sensitive to the needs of particular groups. In some cases this had led the respondent to access services on a more regular basis.

“'The service is youth friendly, discreet but empowering.’”
- Person at risk of HIV

“'As it is run within the LGBT community there is much less fear of stigma when going to test, meaning I have tested much more regularly or after any risky sexual behaviour.’”
- Person at risk of HIV

“'[The service was] good at finding an LGBTQ-friendly counsellor.’”
- Person at risk of HIV

“I found that the advice and services offered were for those until age 21; the service made a special exception for us, as I was 22. It would be good to see further services for young adults.”
- Person at risk of HIV

Others feel that they have very few choices of which services they can use, or that services are generic rather than tailored to individuals.

“I go there because it's the only place... where they provide services tailored to my needs as a sex worker.”
- Person at risk of HIV

Some people said they were not consulted about what they needed or would like:

“I've been going there (sexual health service) for a few years and not once did they ask me about how I work or what services I need.”
- Person at risk of HIV

I found that the advice and services offered were for those until age 21; the service made a special exception for us, as I was 22. It would be good to see further services for young adults.”
- Person at risk of HIV

The next section of this report will consider the perspective of service providers – examining how services are provided and funded, and the challenges service providers themselves identify.

For detailed recommendations on how the issues raised in both Part 2.1 and Part 2.2 of this report can be addressed, see page 65.

PART 2.2 THE REALITY – THE SERVICE PROVIDER PERSPECTIVE

In order to further explore the extent to which the vision set out in the national policy initiatives outlined in Part 1 is reflected in reality, this section examines the perspective of those providing the services used by and available to people living with or at risk of HIV across Scotland.

The ways in which services are provided and funded are considered, along with current trends and considerations that impact service delivery, and the challenges service providers face. Any issues identified are accompanied by references to relevant recommendations for action in Part 3 of this report.

This section includes:

- Key findings (Page 44)
- How services are provided (Page 44)
  - Who provides which services (Page 44)
  - Statutory services (Page 44)
  - Third sector services (Page 47)
- How services are funded (Page 48)
- Trends in delivery of services (Page 51)
  - Joint working and partnerships (Page 51)
  - Self-directed support and personalisation (Page 55)
  - Involving people and communities (Page 56)
- Current and future challenges (Page 58)
  - Funding and budget constraints (Page 58)
  - Gaps in services (Page 59)
  - Geographical challenges (Page 59)
  - Increased demand (Page 59)
  - Difficulty identifying needs and engaging people and communities (Page 60)
  - Training (Page 61)
  - Changing and complex needs (Page 61)
KEY FINDINGS

> A broad range of services are being provided across all sectors, by the NHS but also by local authorities, third sector organisations and others.

> As services are increasingly being designed and delivered on a generic basis (rather than specifically for those with particular conditions or from particular groups) staff training and development becomes critical (See Recommendation 3.3, page 65).

> It is difficult to track expenditure relevant to the needs of people living with and at risk of HIV at a local level due to the lack of information on services for these groups, the way services are structured and budgets recorded, and the cross-cutting nature of the work.

> Mechanisms such as managed care networks and shared outcomes are used by some health boards and local authorities in providing relevant services. >

Third sector organisations did not appear to have been included within formal partnerships and networks to the same extent as statutory bodies (See Recommendation 1.1, page 65).

> Local authorities identify self-directed support as having a significant impact on the commissioning, planning and delivery of services, which will have impact for all service providers.

> Service providers identified key challenges they face as: funding and budget constraints; increased demand for services; variations in access to and provision of services varies across Scotland; staff development and training; and uncertainty over whether the needs of people living with or at risk of HIV are properly understood (See Recommendations 3.3, 5.1, 5.2 and 5.3, pages 65, 66).

HOW SERVICES ARE PROVIDED

Who provides which services

In order to gain a better understanding of service provision for people living with or at risk of HIV, local authorities, health boards and third sector organisations were asked about the services they provided (or funded) that could be accessed by these groups. The responses received demonstrate that the NHS has a critical role in preventing, diagnosing and treating infections, but also that it operates in a context where many other partners can influence service uptake and the factors that put people at increased risk of infection.

Furthermore, a broad range of services are being provided across all sectors which help to support the health and wellbeing of people living with or at risk of HIV.

Statutory services

Figure 3 compares responses received from NHS boards and local authorities. It shows the broad range of services which are relevant and available to people living with and at risk of HIV.
FIG 3: Percentage of health boards and local authorities providing service type in 2013/14
Data from survey respondents; see page 9 for methodology.

- HIV treatment: 100% (13%)
- HIV and STI testing: 100% (44%)
- HIV and STI prevention: 100% (50%)
- Sexual health education: 90% (38%)
- Home support: 40% (75%)
- Transport: 40% (38%)
- Surgical procedures: 80% (0%)
- Personal care: 0% (75%)
- Mental health: 90% (94%)
- Peer support and befriending: 60% (50%)
- Advocacy: 90% (75%)
- Family/carer support: 90% (75%)
- Housing: 20% (81%)
- Addiction: 90% (81%)
- Welfare advice: 80% (94%)
- Food banks: 30% (38%)
- Services for asylum seekers and refugees: 40% (25%)
- General sexual health services: 100% (31%)
- Residential/respite care: 20% (56%)
- Telephone helpline: 30% (13%)

Percentage of health boards providing service
Percentage of local authorities providing service

Data from survey respondents; see page 9 for methodology.

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All NHS boards indicated that they provided HIV treatment, HIV/STI testing and general sexual health services. The vast majority also indicated that they provided sexual health education (90%), mental health (90%), advocacy (90%), family/carer support (90%) and addictions services (90%). Many stated that although they did not directly provide some of the services identified, funding was transferred from the NHS board to councils to support the development of community services in the local area. Others commented that while some of the services listed were available in the board area these were not provided or commissioned by the NHS.

Local authorities were more likely than health boards to provide support for issues such as welfare (94%) and housing (81%), as well as personal care (75%) and home support (75%). A significant amount of the participating local authorities also indicated that they provided HIV and STI prevention services (50%), HIV and STI testing (44%), and sexual health education (38%). Although 13% of local authorities indicated that they provided HIV treatment, the given comments suggest that HIV treatment was in fact being provided by the NHS within the local authority area, rather than directly by the local authority itself:

“Service users would all prefer more specialist service provision in relation to HIV, but services are often commissioned on a more generic basis, with the assumption that the service providers provide specialist staff training accordingly to meet specific needs.”
— Local authority

“Some of these services will be HIV specific while others are more general services available to NHS patients that may require them.”
— Local authority

“Our services are accessible to the general community with care needs regardless of their underlying health conditions.”
— Local authority

Both health boards and local authorities highlighted that while some services are specifically provided for people living with or at risk of HIV, the majority are generic services which are available to anyone who needs them. This also reinforces the need for staff training and workforce development to ensure that staff feel confident working with particular groups and can respond to people’s needs appropriately (this point is further discussed in the challenges section on page 58):

“Both health boards and local authorities highlighted that while some services are specifically provided for people living with or at risk of HIV, the majority are generic services which are available to anyone who needs them. This also reinforces the need for staff training and workforce development to ensure that staff feel confident working with particular groups and can respond to people’s needs appropriately (this point is further discussed in the challenges section on page 58):

“Service users would all prefer more specialist service provision in relation to HIV, but services are often commissioned on a more generic basis, with the assumption that the service providers provide specialist staff training accordingly to meet specific needs.”
— Local authority

“Some of these services will be HIV specific while others are more general services available to NHS patients that may require them.”
— Local authority

“Our services are accessible to the general community with care needs regardless of their underlying health conditions.”
— Local authority
Third sector services

All third sector organisations with a remit to provide direct services to people living with HIV indicated that they provided peer support and befriending services. A significant majority also indicated that they provided: sexual health education; home support; transport services; mental health support; advocacy; family/carer support; respite care; housing; and welfare advice. Many were providing a broad range of supports specifically tailored to meet the often multiple and complex needs of individuals and families affected by HIV:

“[We provide] All sexual health services i.e. contraception, STI testing, emergency contraception. We are the only dedicated young people’s sexual health service... covering a large geographical area.”
– Third sector service provider

“We do more on the prevention side and have seen an increase in the number of men injecting NPS [New Psychoactive Substances] some of whom are at high risk of HIV, or already diagnosed.”
– Third sector service provider

“We do not have specialised knowledge in HIV but can offer general information and signposting.”
– Third sector service provider

Third sector organisations without a specific remit to provide services to people living with HIV were similarly providing a broad range of services and supports, tailored to individual needs and circumstances. This included support for mental health needs, welfare advice and addictions services. Many commented that they worked with groups and individuals who were at an increased risk of HIV, and that they played an important role in relation to HIV prevention and sexual health education. Some provided HIV and STI testing and had specific HIV prevention services, while others provided support to the friends and families of people who were living with HIV.

It was also highlighted by several respondents that while they did not have specialist knowledge in relation to HIV, they did provide general information and signposted people appropriately.
HOW SERVICES ARE FUNDED

At a national level, funds to support work on sexual health and blood borne viruses are mostly provided through core funding given to NHS boards. However, an additional £29 million of funding specifically to meet the outcomes of the Sexual Health and Blood Borne Viruses Framework 2011-15 is provided annually by the Scottish Government. Of this, £27 million is allocated directly to NHS boards with the remaining £2 million supporting specific projects and third sector organisations.

NHS boards transfer funds to councils to support community services relevant to sexual health and blood borne viruses. These are mainly provided by social work departments and services commissioned from the third and private sectors. NHS boards also commission some services directly from the third sector.

It is more difficult to track expenditure by local authorities on HIV related services due to the lack of information on care for people living with or at risk of HIV, the way services are structured and budgets recorded, and the fact the work cuts across so many areas. A number of local authorities reported that HIV was specifically mentioned within their commissioning strategies but there is little information available about how this has influenced spending priorities. Local authority areas with a higher level of HIV prevalence were more likely to report that HIV was included in their commissioning strategies. Several local authorities also commented that while HIV was not specifically mentioned it was included as a long term condition:

“For example: younger people, men who have sex with men, asylum seekers or people with chaotic lives. They also highlighted their key role in linking people to statutory services and supporting them to remain engaged.”

“There is not, as yet, an overall community care commissioning framework however, it is anticipated that, when this finalised, HIV will be included as a long term condition.”

– Local authority

“The commissioning strategy refers to people who have long term conditions... The services around HIV have been developed in a way that links with universal services and that builds capacity within all services to respond to the individual’s needs.”

– Local authority

“(HIV is specifically mentioned in our commissioning strategy) because of the high prevalence in the area.”

– Local authority

In order to gain a better understanding of commissioning by public bodies in relation to the services which may be accessed by people living with or at risk of HIV, local authorities and NHS boards were asked about the services they commissioned from third sector organisations. The length and type of agreements used were also discussed – see figure 4 and figure 5.
FIG 4: Percentage of health boards and local authorities that commissioned service type from third sector organisations in 2013/14

Data from survey respondents; see page 9 for methodology.

Percentage of health boards commissioning service type from third sector
Percentage of local authorities commissioning service type from third sector

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Health Boards</th>
<th>Local Authorities</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV treatment</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>HIV and STI testing</td>
<td>30%</td>
<td>0%</td>
</tr>
<tr>
<td>HIV and STI prevention</td>
<td>60%</td>
<td>7%</td>
</tr>
<tr>
<td>Sexual health education</td>
<td>20%</td>
<td>7%</td>
</tr>
<tr>
<td>Home support</td>
<td>20%</td>
<td>53%</td>
</tr>
<tr>
<td>Transport</td>
<td>20%</td>
<td>20%</td>
</tr>
<tr>
<td>Surgical procedures</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Personal care</td>
<td>0%</td>
<td>53%</td>
</tr>
<tr>
<td>Mental health</td>
<td>30%</td>
<td>67%</td>
</tr>
<tr>
<td>Peer support and befriending</td>
<td>60%</td>
<td>40%</td>
</tr>
<tr>
<td>Advocacy</td>
<td>80%</td>
<td>60%</td>
</tr>
<tr>
<td>Family/carer support</td>
<td>60%</td>
<td>40%</td>
</tr>
<tr>
<td>Housing</td>
<td>20%</td>
<td>27%</td>
</tr>
<tr>
<td>Addiction</td>
<td>40%</td>
<td>53%</td>
</tr>
<tr>
<td>Welfare advice</td>
<td>80%</td>
<td>47%</td>
</tr>
<tr>
<td>Food banks</td>
<td>30%</td>
<td>47%</td>
</tr>
<tr>
<td>Services for asylum seekers and refugees</td>
<td>40%</td>
<td>13%</td>
</tr>
<tr>
<td>General sexual health services</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Residential/respite care</td>
<td>30%</td>
<td>53%</td>
</tr>
<tr>
<td>Telephone helpline</td>
<td>10%</td>
<td>0%</td>
</tr>
</tbody>
</table>
The responses show that local authorities were most likely to award an annual grant to organisations they commissioned work from, whereas health boards were more likely to award a 1, 2 or 3 year contract. No public body reported using contracts or grants of 5 years or more. A number of concerns were expressed by third sector organisations in relation to funding and commissioning arrangements, and are discussed in the challenges section on page 58.

As well as receiving funding from public bodies to provide specific services, many third sector service providers accessed additional funding to complement the work of statutory services e.g. securing funding to improve people’s quality of life in addition to core services. A large number of third sector organisations relied on funding from multiple charitable grants and trusts – as well as through donations and community fundraising – in order to provide services.
TRENDS IN SERVICE DELIVERY

All of the policy initiatives described in Part 1 of this report should have had an impact on the way in which services are designed and delivered in Scotland. Service providers were asked about any changes in the ways in which they delivered services in order to assess the extent of this impact.

Joint working and partnerships

A number of health boards and local authorities identified formal mechanisms through which they worked together to provide services to people living with or at risk of HIV. While some referred to community health partnerships, the majority commented on the establishment of managed care networks (MCNs). These were described as having a key role in the integration and co-ordination of services relevant to HIV - bringing together staff from across the health and local authority sectors to assess local needs and plan services.

There was some geographical variation in the types of managed care networks which had been established, with some focusing solely on blood borne viruses and others also incorporating sexual health.

Several respondents also commented that some services relevant to HIV were jointly commissioned, although this was certainly not the case in all areas:

“...We work jointly with the NHS to plan/deliver services for those with blood borne viruses, which includes HIV. There is a social work representative on the managed care network for blood borne viruses... who contributes to assessment of local need, service planning and service monitoring across health and social care services.”
– Local authority

“The work around HIV has developed in partnership with NHS and will be enhanced by the re-establishment of the managed care network.”
– Local authority

“At the moment there are no jointly commissioned services for people living with or at risk of contracting HIV. However, there is local authority representation on the blood borne virus MCN and all associated working groups.”
– Local authority

“We have seen more integration with sexual health/ other blood borne virus services. With the integrated MCN approach, we are able to dedicate more time to HIV issues. We have an HIV clinical lead attached to the MCN.”
– NHS board
The development of drug and alcohol partnerships was seen to help promote joint working by establishing shared outcomes which could be applied across the statutory and third sectors:

“Via the Alcohol and Drug Partnership we commission services on an outcomes focussed basis to assist in prevention, treatment, support and peer support... we have refocused funding allocation to reflect outcomes so that all recipients of funding from the independent, voluntary and statutory sector are required to report on how the strategic aims of the partnership are being met.”
– Local authority

There are also examples of less formal joint working arrangements between health boards, local authorities and the third sector e.g. through the establishment of integrated referral pathways, staff training and the co-location of staff and services:

“We have very close working links with health colleagues to deliver services to this client group (people living with or at risk of HIV).”
– Local authority

“We have drugs, alcohol and blood borne virus social work teams in each of our local authorities whom we work closely with to deliver support to people living with HIV.”
– Health board

“Some of our addiction services are jointly provided with local authorities. In the last two years input from local authorities in relation to the provision of HIV-specific services has ended. However our joint work programme of covering HIV education in schools continues.”
– Health board

Third sector organisations do not appear to have been included within formal partnerships and networks to the same extent as statutory bodies. However, a number of health boards and local authorities commented that closer working relationships had been established with the third sector over recent years. This included through the development of ‘step-up/step-down care’ services for people living with HIV, whereby people were able to receive more support than was available to them at home (step-up) and to leave hospital and get ready to return home (step-down).
Service providers highlighted the importance of the third sector in providing people living with or at risk of HIV with additional support and advocacy, and engaging key groups and enabling them to access statutory services. Case study examples provided by respondents are set out here:

**Case study: Men Only Tayside**

The Men Only Tayside (MOT) service is a partnership between NHS Tayside and Terrence Higgins Trust Scotland to provide STI and HIV prevention, testing, risk reduction interventions and community outreach targeting men who have sex with men. Since launching it has significantly improved access to services for high risk men who have sex with men (MSM) who may not have accessed services otherwise. Co-production between the NHS service, Terrence Higgins Trust and their volunteers has achieved a breadth and standard of care that neither organisation could provide alone. The service has received recognition and quality awards from the Scottish Health Council, WiSHH (Wellbeing in Sexual Health and HIV network) and the health board for this work. 49% of attendees were new to sexual health services and 43% had no documented history of past HIV testing. HIV testing uptake was 94%. The number of MSM seen within the sexual health service overall increased by 85% from 2012.

**Case study: Gay Men’s Health and NHS Lothian**

Gay Men’s Health (GMH) have established a community testing initiative in collaboration with NHS Lothian. This was created in recognition of the fact that gay men and other men who have sex with men are one of the community groups most at risk of acquiring HIV, but that too many men continue to be diagnosed too late for effective treatment. The ‘walk-in’ clinic is based in GMH’s office and GMH volunteers welcome attendees and provide them with additional information and access to condoms and lube. In addition an opt-in ‘peer to peer’ initiative is offered to men, whereby they can opt to take part in a one-off training session (facilitated by GMH) which provides sexual wellbeing messages they are then asked to share with peers. Clinical aspects of the service are delivered by NHS Lothian staff, and any men with symptoms or positive results are referred to NHS Lothian’s Chalmers Sexual Health Centre for screening and treatment.
Self-directed support and personalisation

Self-directed support (SDS)\(^{37}\) was highlighted almost exclusively by local authorities as having had an impact on the delivery of services. This impact was seen to be significant with implications for the way in which services were or would be planned and commissioned in the future. Service providers highlighted that there had been a decisive shift towards the creation of outcomes focused and person-centred services, with people having far greater control over the supports which they received.

“We are moving from conventional service based provision to person centred /outcomes focused support plans – now a statutory duty via the self-directed support act.”
– Local authority

“As we have developed our assessments and resource allocation systems in line with self-directed support we are now working with support providers to revise how we commission support provision, as the purchasing power and direction gradually shifts from the local authority to people.”
– Local authority

“All contractual arrangements will be subject to development in light of self-directed support legislation.”
– Local authority

Self-directed support has also meant that services are less likely to be provided specific to particular conditions, with packages of support instead being tailored to meet individual needs regardless of the nature of a person’s condition.

This was seen by local authorities as a positive development with some commenting that it would also better enable gaps in service provision to be identified. It was also highlighted that a move away from more traditional forms of service provision makes it necessary to adopt a ‘whole system’ approach to workforce development and commissioning processes:

“We have developed support and services for people with a range of complex needs via self-directed support. This allows tailored packages of formal support and people’s natural supports to be combined to ensure that their quality of life is maintained regardless of the nature of their condition.”
– Local authority

“Retaining a person focused perspective and supporting people to access support unique to them will improve outcomes for individuals and better inform gaps in available support provision.”
– Local authority

“The introduction of self-directed support has promoted a shift towards outcomes focused assessment and service provision and necessitated a whole system approach to workforce development and commissioning /brokerage.”
– Local authority

Local authorities have a key role in providing and commissioning services which are being accessed by people living with and at risk of HIV. The introduction of self-directed support presents challenges for learning how the new arrangements work in relation to sexual wellbeing and blood borne viruses. However, given the sometimes multiple and complex needs of people living with or at risk HIV, they stand to benefit from more person-centred approaches and greater control over their own support arrangements.

Involving people and communities

In order to deliver efficient services which are relevant to people’s needs, all organisations working with people living with or at risk of HIV need to involve service users in the design and delivery of their services. A number of service providers highlighted the ways they had sought to better involve people and communities to this end.

Several NHS boards said that services are being regularly adapted in order to meet the evolving needs of people living with or at risk of HIV, with some having conducted an HIV needs assessment through consultation with key communities. Where this had occurred, community consultation was held to be of significant value for the planning and delivery of NHS sexual health and HIV services:

“We recently completed an HIV needs assessment which identified a number of areas for improvement which we have actioned.”
– NHS board

“We are constantly evaluating and reviewing services in light of the needs of people living with or at risk of acquiring HIV. This means that services are constantly adapting to the evolving needs.”
– NHS board

“Service changes have been undertaken to ensure we continue to meet Health Improvement Scotland HIV Standards and deliver a quality service to meet the changing needs of our cohort.”
– NHS board

Some NHS boards also expressed a clear desire to increase the extent to which service users were involved in the design of their services:

“It would be good to see a focus on patient experience so that feedback from patients is a core part of service design.”
– NHS board

There were also some examples of good practice in this regard. The establishment of formalised patient involvement groups, like the one described in the next case study, is one such example.

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There were also some examples of good practice in this regard. The establishment of formalised patient involvement groups, like the one described in the next case study, is one such example.
Based within Glasgow’s Gartnavel Hospital, the Brownlee Outpatient service provides people with HIV testing, support and treatment. Through the establishment of an HIV Peer Patient Forum, patients at the Brownlee have been supported to meet regularly to discuss issues and changes and to put forward any ideas they have about the service. This has led to improvements in service delivery and has empowered service users in relation to their own treatment and care. The idea of a patient forum was first raised by participants of a peer support project run by the Brownlee service. Through subsequent consultation with the peer supporters and patients it was identified that they wanted formal and regular meetings.

These meetings to be facilitated by someone who could operate as a link between the patients and the clinic staff – someone who could understand both perspectives and speak both languages. The Forum was established in 2013 and now meets monthly with approximately 20 members, and over 140 on the mailing list. The forum meetings alternate between agenda driven meetings and workshop driven meetings. The group have successfully developed a peer led patient orientation process, which includes meeting with a peer supporter and a staff member when newly diagnosed and accessing the service. The forum also produces a quarterly newsletter. The peer support and patient engagement manager acts as a bridge between patients and staff, and shares agendas and minutes of these meetings with the forum and vice versa.

Third sector organisations described a range of ways in which they involved people and communities, particularly through the development of peer support. Some described how the development of successful third sector peer support initiatives has brought significant benefits for the people receiving this support, for the health system as a whole and also for the peer workers themselves by increasing their levels of self-esteem, confidence and ability to manage their own condition. Other examples of involvement provided by third sector organisations include the creation of service user involver groups, which enable service users to communicate ideas about how services might be improved or provided directly to management.

“...It is our experience that the best way to understand changing needs is to place service user involvement at the heart of our organisation... Recent examples of service user involvement include the full involvement of service users in the review and redevelopment of services.”
– Third sector organisation

Local authorities mainly referred to self-directed support as being the route through which people had been given greater involvement and control over the services they received. Many saw the implementation of self-directed support as marking the start of a new relationship between services and the public, allowing individuals and communities to take the lead where this would achieve better outcomes.
Those issues identified by statutory and third sector service providers as current and potential future challenges in relation to service provision for people living with or at risk of HIV are discussed in this section. These are grouped under the most commonly occurring themes.

**Funding and budget constraints**

Funding emerged as the primary challenge for third sector organisations. Many commented that funding received through statutory bodies was insufficient to meet core operating costs, while others had difficulty accessing any funding from statutory bodies. Some were particularly concerned that funding would become a greater challenge should HIV come to be afforded less priority by statutory bodies and commissioners:

“Funding is the main challenge: we have to raise a lot of our own income. Trusts and contracts won’t cover core costs.”
– Third sector organisation

“Funding - at the moment it’s fine but it would only take the council to decide that HIV isn’t a priority for that to have a domino effect on our services.”
– Third sector organisation

Third sector service providers commented that funding uncertainties and short-term contracts could be a barrier to innovation and undermine continuity in service provision, with an impact on service users. Furthermore, tendering processes were often extremely resource intensive and resulted in less human and financial resources being available for other areas of work.

Local authorities and NHS boards also face funding and budget constraint challenges, with some local authorities expressing concern that this may result in fewer people with support needs being able to receive support. Local authority budget constraints have a knock-on impact on third sector service providers:

“Due to constraints in local authority budgets there has been a driving down of hourly rates. This is in spite of the fact that the needs of the individuals we support hasn’t changed and probably never will.”
– Third sector service provider

As a result, some were unsure as to what the needs of these groups were and whether existing services were properly equipped to meet those needs. This is discussed further in the challenges section below.
“From a social work perspective, all service users with HIV who are referred to the service are required to meet the service eligibility criteria prior to being considered for funding for services. Due to current budget constraints, funding is targeted at those with significant need/risk, and not all people with HIV may meet the critical eligibility criteria we can currently fund, therefore may not be able to access social work funded services.”
— Local authority

Gaps in services

Gaps in service provision were identified by both third sector and statutory service providers. Consistent with the personal experiences discussed in Part 2.1 of this report, this included gaps in mental health services specific to HIV. It was also commented that certain types of service were coming to be afforded less priority by statutory services, resulting in third sector services being required to provide greater levels of support for unmet needs:

“...There seems to be a gap in mental health services specific to HIV. It would be useful if there was more integration between mental health and sexual health.”
— Third sector organisation

“Long term condition management is becoming less of a priority for health boards and local authorities aren’t picking it up. There is a ground swell of need the third sector is having to pick up.”
— Third sector organisation

Geographical challenges

Both local authorities and NHS boards highlighted geographical inequalities in access to services and service provision across Scotland. 67% of participating NHS boards identified geographical challenges as being their key difficulty in delivering services to people living with or at risk of HIV. The delivery of specialist services was seen as unsustainable in some rural areas, while it is also difficult to establish support such as peer support for people living with HIV:

“Peer support in the local area is a challenge. We would like to support/develop this more effectively, but due to the rurality of the area, and small population sites, there remains an unwillingness to become involved.”
— NHS board

“Delivering a full range of prevention, testing, treatment and support services to those in rural areas remains a challenge.”
— NHS board

“...The cohort of people living with HIV in the area is too small to make specialist services sustainable.”
— NHS board

Increased demand

Several NHS boards identified that the increasing numbers of people living with HIV presented a challenge for the future – with services which were already overstretched being required to meet increased demand. It was also highlighted that more successful testing strategies could potentially lead to an increase in the numbers of people being identified as HIV positive and therefore requiring support.
Our biggest challenges are the substantial increases to the numbers of patients living with HIV which has more than doubled in the last 10 years and ensuring our services are able to respond to the increase.”
– NHS board

Future challenges are likely to be that the patient group will continue to increase as we advance our HIV testing strategy.”
– NHS board

A number of third sector providers also highlighted that demand for their services had grown significantly due to the effects of welfare reform. Responding to the effects of welfare reform had forced some organisations to divert time and resources from other areas of their work, and made it more difficult for them to focus on their core activities supporting people in relation to their health and wellbeing:

Welfare reform is significantly affecting people.”
– Third sector service provider

We are supporting 100% more people through our benefits advice service.”
– Third sector service provider

In addition to citing increased demand for services as a challenge, a number of providers referred to how increased demand had impacted on staff and volunteers.

We are overworked. When either of us wants to take leave we have to close the office.”
– Third sector organisation

There was concern from some providers about a lack of staff or volunteers able to carry out particular pieces of work.

Home support demand is almost double what we can provide and this is because we have a lack of volunteers willing to do this work.”
– Third sector organisation

Difficulty identifying needs and engaging people and communities

Some local authorities raised challenges engaging with people and communities, with 69% indicating difficulties identifying local needs as the primary challenge they faced in providing services to people living with or at risk of HIV in the future:

There is still a real lack of being able to identify exactly what individuals require from services and given the vast area, I also think it is difficult to target the community in the right way.”
– Local authority

There are some difficulties in engaging with groups of service users due to the stigma issues for the service user who may want to keep their health issue confidential.”
– Local authority

Our local testing rates are low and we have difficulty in getting at-risk populations to come forward for testing.”
– Local authority
Training

Service providers recognised the importance of staff training and development, with several noting the need for training for non-specialist staff to help them understand the distinct needs of people living with and at risk of HIV. It was felt that this was particularly important where services were being commissioned on a generic rather than specialist basis, and also increasingly within social care services:

“**There is a lack of specialist training for social care staff in relation to HIV and supporting people living with this.**”
– Local authority

Changing and complex needs

The changing needs of people living with HIV can pose issues for service providers. In particular, service providers referred to the needs of a population ageing with HIV and uncertainty over what types of support they may require in future:

“**A future challenge will be the changing and disparate needs of the ageing cohort of HIV positive service users.**”
– Local authority

“**The patient group will become increasingly heterogeneous and complex with diverse cultural and sexual identities, understandings and experiences of the condition in relation to duration of diagnosis, and with an increasing age variance as we see an ageing cohort joined by increases in newly diagnosed younger people.**”
– NHS board

This section has set out the perspective of those who provide services for people living with and at risk of HIV, regarding how services are delivered and the challenges they face as service providers. While many operate good quality services and seek to provide the best possible support, many identify issues and changes that can prove challenging and must be overcome before the reality of service provision can meet the vision set out by the policy initiatives described in Part 1 of this report.

The next section of this report sets out recommendations for steps that can be taken to address the issues highlighted in Parts 2.1 and 2.2.
PART THREE: THE WAY FORWARD
CONCLUSION AND RECOMMENDATIONS FOR CHANGE

The national policy and strategies discussed in this report have the potential to greatly improve the experiences of people living with and at risk of HIV when they access services. This report shows a number of examples of where these policies have already positively impacted on practice and on the experiences of people. However there are also some inconsistencies in the quality of services which need to be addressed.

Furthermore, this report highlights that there continues to be a high level of change and uncertainty in how services will be delivered in the future, with service providers facing many challenges.

The recommendations of this report seek to consider how these challenges will be overcome in order for people living with and at risk of HIV to receive the high quality care and support they need, and for the vision for Scotland’s services to become a reality.
## RECOMMENDATIONS

### 1. Involvement

| 1.1 | 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, such as community health partnerships, managed care networks, and the new integrated health and social care partnerships. |

### 2. Flexible/accessible services

| 2.1 | Service providers should work to make services more accessible in order to increase the likelihood of people at risk of HIV engaging with prevention services. This could include increasing the number of mobile services which are available or providing transport for people. |
| 2.2 | Services for people living with and at risk of HIV should adopt a wider range of opening times and increase the number of appointments available to people. |
| 2.3 | Service providers should consider how they could use telehealth and telecare options to increase the availability and flexibility of services. |

### 3. Information

| 3.1 | Services should provide greater clarity about what the information they collect from people will be used for and in exactly which circumstances information may be shared. |
| 3.2 | Service providers should develop clear information about how services can be accessed, in consultation with service users. This information should be available in a variety of formats and be displayed in places where people can easily access it. |
| 3.3 | Specialist HIV training should be available for staff and volunteers working within health and social care services. This is of particular importance in generic rather than specialist services that people living with and at risk of HIV use. Opportunities for professionals to share skills, information and learning should be created wherever possible to help services adapt to the distinct needs of service users, and to ensure that services always have a supportive culture and that staff understand the facts about HIV. |
4. Physical environment and locations

> **4.1:** Future strategies on sexual health and blood borne viruses should include a particular focus on ensuring that people living in rural areas of Scotland have access to the full range of services that are relevant to their needs, on an equal basis with people living within other parts of the country.

> **4.2:** Sexual health services would benefit from approaches where a variety of services or different professionals are available in the same location. However, co-located services need to ensure that robust measures are in place to protect the confidentiality and anonymity of service users.

> **4.3:** Service providers should work to create physical environments where service users feel welcome and comfortable. Privacy should be prioritised so that people feel safe and feel confident to talk openly about their health with staff.

5. National initiatives

> **5.1:** The Scottish Government should develop a guide to whole system commissioning for sexual wellbeing and blood borne viruses, addressing the wider determinants of health and societal factors that impact on sexual wellbeing and blood borne viruses. This would help clarify not only where responsibilities for commissioning sit but also how commissioners can work together collaboratively to deliver improved outcomes.

> **5.2:** Robust systems should be put in place to capture information about how funds to support work in relation to sexual health and blood borne viruses are distributed at both a national and local level. This should be supported through the development of a funding map.

> **5.3:** Considerations of HIV should be mainstreamed through local and national outcome frameworks, and incorporated into national and local performance monitoring mechanisms e.g. single outcome agreements and drug and alcohol partnership outcomes. This would not only help to ensure that actions are taken forward on a local level but also assist with reviewing progress and ensuring accountability.

6. Links between services

> **6.1:** Service providers must create stronger links between sexual health and mental health services, with greater provision of mental health support within sexual health settings or through clear referral pathways.