The Community Empowerment and Renewal Bill

About HIV Scotland

HIV Scotland is the national HIV policy charity for Scotland: we speak out for people living with and at risk of HIV. We want a society which is well informed about HIV and devoid of HIV related stigma and discrimination. Our mission is to ensure that all HIV relevant policy and practice in Scotland is grounded in evidence and the experience of people living with and affected by HIV.

Introduction

The most effective way to ensure the best outcomes for people living with and at risk of HIV is to involve them in all aspects and decisions about their health and care. The 2014 Positive Persons’ Forum which brought together people living with HIV from across Scotland, named patient involvement as one of five priority issues for change. This Bill is of particular relevance to people living with and at risk of HIV, given its implications for increased involvement of communities in the work of public bodies. The Bill has the potential to ensure that communities are meaningfully involved in the planning, design and delivery of public services. However, HIV Scotland believes that the provisions in the Bill require to be strengthened if this potential is to be realised and to ensure a genuine focus on the needs and rights of individual patients and service users.

To what extent do you consider the Bill will empower communities, please give reasons for your answer?

Involvement in decisions that affect you as referenced by the UN convention on the rights of persons with disabilities and Scotland’s National Action Plan is a principle which underpins a human rights based approach to health and social care. Involving people in decision making processes also helps ensure that services are responsive, flexible and able to meet the needs of all communities. It is therefore essential that people living with and at risk of HIV are empowered to participate in the decision making processes of public bodies. Despite some significant improvements in understanding of HIV, people living with and at risk of HIV are sometimes still an ostracised and disempowered community and for this reason, HIV Scotland welcomes the Scottish Government’s plans to pass a Community Empowerment Bill.

However the Bill, as it stands, could have unintended negative consequences for some less well established community groups, including those working with people living with HIV, which are currently marginalised from mainstream engagement.

The current Bill provides additional routes to engagement for established community bodies who are already well placed to make use of them. Our concern is that there are no provisions to ensure

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that public bodies support less empowered, less formalised bodies such as peer groups of people living with HIV, sex workers, and LGBT communities to take advantage of these routes.

If communities of interest are to be affectively empowered and barriers to engagement in decision making processes removed, public bodies also need to proactively inform communities of their rights as proposed in this Bill. Public sector staff will need support to understand and fulfil their roles and responsibilities. Successful implementation of these proposals will require guidance for public bodies in supporting peer community projects to meaningfully engage with them.

**What will be the benefits and disadvantages for public sector organisations as a consequence of the provisions in the Bill?**

In order for public services to be truly successful in their aims, it is vital that the people using those services are involved in their development and delivery from the offset. For this reason we consider the provisions in this Bill to be of benefit to public sector organisations by advancing their ability to deliver quality, flexible services which are able to meet the needs of all communities.

However, public sector organisations will also need to acknowledge that the voluntary sector has a key role to play, both in engaging people and communities and giving them a voice in decisions which affect them.

**Do you consider communities across Scotland have the capabilities to take advantage of the provisions in the Bill? If not, what requires to be done to the Bill, or to assist communities, to ensure this happens?**

The Bill makes some positive proposals to help communities have more control in local decision making and builds on examples of good practice in patient and service user involvement. However, it will be critical that there is a consistency across Scotland in the extent to which people living with and at risk of HIV are able to take advantage of provisions in the Bill.

We support proposals by Oxfam, Barnardo's and the Poverty Alliance to renew existing national standards for community engagement. We agree that the Bill should enable Ministers to create statutory regulations for the engagement and empowerment of communities, which all public bodies must follow and regularly report upon. We also believe that a key part of the standards should focus on empowering communities of interest rather than just those of place and are supportive of proposals to require Community Planning Partnerships to adhere to the Standards when they are creating a local outcomes improvement plans.

However, if community engagement standards are to be relevant to patients and service users, consideration needs to be given as to how such standards would interact with existing policy. This includes: the Patient Rights (Scotland) Act 2011⁴, General Medical Council’s guidance for shared decision-making⁵ and British HIV Association ‘Standards of Care for People Living with HIV⁶. The new standards should be easy to understand and patients and service users should be informed about how to effectively use them.

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⁶ Standards of Care for People Living with HIV, British HIV Association, 2013, [http://goo.gl/mJMzHm](http://goo.gl/mJMzHm)
Are you content with the specific provisions in the Bill, if not what changes would you like to see, to which part of the Bill and why?

Involvement in decision making is central to a human rights based approach to health and social care and it is paramount that people living with and at risk of HIV are active participants in the design and delivery of services. It is therefore welcome that the Bill proposes protecting the existence of Community Planning Partnerships (CPPs) and creates a community’s right to request to participate in decision making and improvement processes.

We believe that these proposals have the potential to increase the participation of people living with and at risk of HIV in service delivery. However, in the spirit of the Christie Commission, it is important that the Bill also challenges the existing hierarchy and focus of community planning in order that people living with and at risk of HIV can meaningfully influence the planning of the services they use.

Taking into account comments in the 2013 Audit Scotland report on Community Planning which said that “there is a long way to go before services are truly designed around communities and the potential of local people to participate in, shape and improve local services is realised”, the Bill needs to clearly articulate how local outcomes improvement plans will be produced through a meaningfully participative process.

Regarding the proposed ‘right to request to participate; current proposals give public bodies the power to decide whether to accept or decline requests, as well as how to facilitate them. A more robust challenge mechanism is required in order to ensure that the proposals are fairly implemented for the benefit of people living with and at risk of HIV. We agree with the proposal that it would be preferable to have an independent third party act as a facilitator and mediator through a challenge mechanism or appeals procedure.

5. What are your views on the assessment of equal rights, impacts on island communities and sustainable development as set out in the Policy memorandum?

HIV Scotland supports the principles of the Bill and doesn’t consider that it would have a negative impact on the rights of people living with and at risk of HIV. The Bill has the potential to help communities better exercise their right to be involved in decisions that affect them and to particularly help marginalised groups identified by the World Health Organisation as the key groups at risk of HIV. These include gay men and other men who have sex with men, transgender people, prisoners, people who inject drugs and sex workers.

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7 Improving Community Planning in Scotland, Audit Scotland, March 2013, [http://goo.gl/mEaaHF](http://goo.gl/mEaaHF)
8 Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations, World Health Organisation, July 2014, [http://goo.gl/UCB1Yq](http://goo.gl/UCB1Yq)