



A joint project between Terrence Higgins Trust and Waverley Care

Positive Ageing: Growing Older with HIV in Scotland

19th April 2011 Royal College of Physicians

Conference Report

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Summary

Positive Scotland organised a one day conference at the Royal College of Physicians, Edinburgh, on 19th April, to raise awareness and explore the issue of growing older with HIV in Scotland. The conference provided a key learning opportunity for Positive Scotland to hear directly from people living with HIV (PLWH), the HIV sector and from the older people's sector regarding this issue. The findings from the conference will inform Positive Scotland's work in this area.

Positive Scotland is a joint project delivered by Waverley Care and Terrence Higgins Trust and is funded by the Big Lottery. Positive Scotland supports people across Scotland living with HIV and/or Hepatitis C. The project focuses on three specific areas of work: direct support for gay and bisexual men; support for people as they grow older with HIV and/or Hepatitis C and support for people around employment and skills.

The conference was marketed well with over 100 delegates attending. Promotional materials were distributed to the voluntary and statutory sector health and social care organisations across Scotland. Delegates represented PLWH, the HIV sector and the older people's sector.

Ageing with HIV is a real concern. Around 28% of all people living with HIV in Scotland are over 50 years of age, and this figure is set to increase significantly over the next 10 years, as all the people currently in their 40s reach their next decade and as new people are diagnosed. It is likely that, by 2020, half the HIV population in Scotland will be over 50 years of age.

As people age with HIV there are new challenges ahead: coping with their HIV alongside other illnesses; long term side effects of medication; stigma and discrimination; uncertainty around their long term care; isolation; and little or no financial provision for their future care.

The conference opened up the debate about these issues. The morning programme focused on presentations from key speakers. The speakers included: four people living with HIV, all long term diagnosed; Garry Brough from Terrence Higgins Trust (THT) who presented the findings from the THT and Age UK 2010 national study of people over the age of 50 living with HIV; Gordon Scott a senior GUM consultant with NHS Lothian who presented on the impact of HIV, retrovirals and old age; Alastair Hudson from the HIV Stigma Index who presented their research findings on HIV stigma and old age; and Callum Chomczuk from Age Scotland who presented on the ageing demographics in Scotland. However, it was the voices of the four people living with HIV, over the age of 50, that gave this conference its credibility and immediacy.

The afternoon programme was given over to workshops which examined the following issues:

- Disclosure, discrimination and integration into older people's services
- Sexual health, sexual identity and sexual lives
- Physical and emotional impact of ageing with HIV
- Money, housing and finances for people as they get older

The conference closed with brief feedback from each of the workshops. The conference was funded by the HIV Stigma Index project, Merck Sharpe & Dohme and Positive Scotland (Big Lottery Fund).

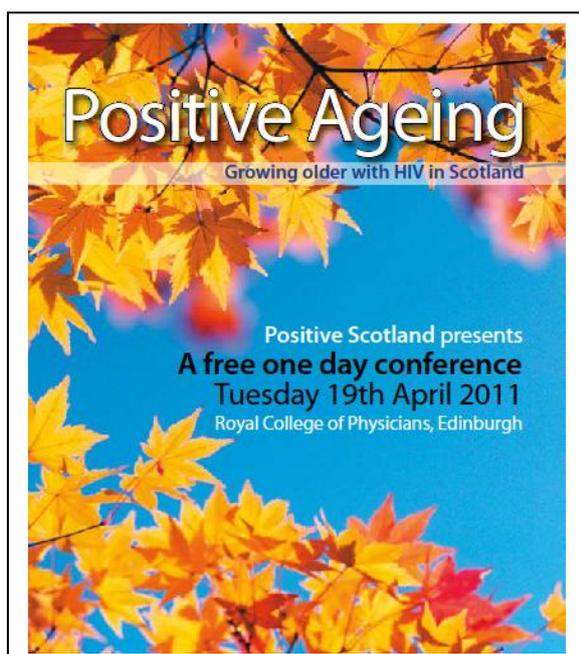
Background: A Service User Led Conference

As previously indicated, HIV and ageing is a real concern, as the HIV population grows older with their diagnosis and faces a multitude of new challenges. It is essential that all social care and health services are responsive to the needs of this ageing community. Positive Scotland has been funded in Scotland by the Big Lottery Fund to deliver a responsive service to people as they grow older with HIV, ensuring that their needs are met. Positive Scotland aims to do this by working in partnership with the voluntary, statutory and private social care and health services. This conference provided a unique learning opportunity for Positive Scotland to hear from the HIV community and these partners.

The HIV and Ageing conference was very much service user led from its concept, organisation and delivery. One of the HIV positive men, involved in the delivery of the Positive Scotland service, who was also a researcher for the 'People Living with HIV Stigma Index' alerted Positive Scotland to the seed grant available from this organisation. An application was made and once we had heard that we had been successful, a conference steering group was set up. The membership of the conference steering group was made up of three people living with HIV and Positive Scotland staff. The steering group felt that it was essential that the voices of people living with HIV were central to the conference and its planning and four PLWH were approached and agreed to speak. Two of the professional speakers also disclosed to the conference that they were living with HIV.

Conference Identity

The conference and accompanying literature were consistently badged and promotional materials were distributed widely to the voluntary, statutory and private sector health and social care organisations throughout Scotland.



Conference Speakers

The four speakers living with HIV spoke of their past, present and future hopes and anxieties, as they age with HIV. Their powerful testimonies helped set the scene for the day.

The four remaining speakers represented collectively three national voluntary sector organisations and one major Scottish NHS Board. Two of the speakers Garry Brough (THT) and Alastair Hudson (The HIV Stigma Index) presented on national research findings, focusing on 'growing older with HIV' and 'stigma'. Gordon Scott, a senior GUM consultant with NHS Lothian, presented on the impact of HIV, retrovirals and old age and Callum Chomczuk from Age Scotland presented on the ageing demographics in Scotland.

Copies of the presentations can be found on the Waverley Care website: www.waverleycare.org

Workshops

The afternoon programme was divided into four workshops and each delegate was able to attend two of these. In total eight workshops were facilitated.

The workshops focused on four distinct themes:

- Disclosure, discrimination and integration into older people's services
- Sexual health, sexual identity and sexual lives
- Physical and emotional impact of ageing with HIV
- Money, housing and finances for people as they get older

Delegates were asked to discuss and share their knowledge of these issues, identifying what resources were available and what the gaps were. Each workshop was asked to consider and to feed back on how we take these issues forward and the role for Positive Scotland.

The following statements were recorded from each of the workshops:

Workshops 1: Disclosure and discrimination and integration into older people's services

How do we take this forward/ what role for Positive Scotland?

Awareness training for:

- support organisations
- health and social care
- general public
- older people organisations

With a specific focus on LGBT and drug awareness training.

Training should be delivered and involve people living with HIV – meaningful involvement of positive community.

Communication – style guide. Standardised communication in the language that we use.

HIV/Blood Borne Viruses (BBV's) should be universally built into all individual assessment tools.

Influencing policy and working practices

Support for front line workers.

Service level agreements need to include dealing with BBV in policy and practice. Support organisations need to look at policy and practice – especially in relation to BBV's.

Scoping exercise to find out level of knowledge

- Positive Scotland should develop a star rating system.

Make sure the right questions are asked.

Develop existing resources.

Pool partner resources; work in partnership with national organisations.

Produce resource pack to identify issues and how to address such issues.

Influence policy makers around issues identified.

Provide localised information to assist with raising awareness.

Integration with older people's services – joint project.

We need to influence guidelines and policy. e.g. work with Age Scotland to assist us in working with the older people's sector.

Workshops 2: Sexual Health, Sexual Identity, Sexual Lives

How do we take this forward/ what role for Positive Scotland?

Media - Work with Media more – correct misinformation – i.e. I'm not dying of AIDS I'm living with HIV. Promote more media work.

Services –Championing sex for older people.

Campaigning – raise awareness at every point of contact.

Policy - Influence policy makers to ensure policy is adequate, up to date, and easy to access. Develop HIV workplace policies and work with older people's organisations.

Research and education - Forums in schools and colleges. The Stigma Index are releasing a book looking at gender dimensions of stigma. Work with age organisations to educate.

Training - for healthcare workers on sexual health.

Talk about sex - Encourage professionals to talk about sex.

Workshop 3: Physical and Emotional Impact of Ageing with HIV

How do we take this forward/ what role for Positive Scotland?

Bringing more normality to HIV and raise awareness.

Discussions of HIV at strategic levels across all services and involving all stakeholders

Make care pathways more proactive and focus on sexual health, prevention, emotional and physical support needs.

Remember we are all a resource in our own communities and workplaces.

Offer training to health care providers to feel more confident talking about sex.

Promote more media representations of People Living with HIV and HIV issues including positive messages.

Build links between agencies – improving HIV awareness.

Workshop 4: Money, Housing and Finance for People as they Age with HIV

How do we take this forward/ what role for Positive Scotland?

The creation of localised HIV advice services for people living with HIV need to be created as people are unlikely to access mainstream services for fear of stigma and discrimination. This could be organised peripatetically and paid for by local HIV organisations or other funding sources.

Training for agencies such as the Department for Work and Pensions (DWP) and Atos Origin (the company employed to carry out DWP medicals).

Lobbying appropriately to give a louder voice to people living with HIV.

Quality assurance mark, which demonstrates that care companies have attained a minimum standard of BBV awareness, including care and support.

Advocacy for people living with HIV to enable them (and organisations) to navigate the confusing social care maze.

Evaluation

At the end of the conference each delegate was asked to provide feedback on the conference. 51/100 evaluations were returned and their responses are detailed below. Overall the conference was well evaluated. See Appendix 1 for further recorded evaluation comments.

Evaluation Summary

100+ delegates

51 Evaluations

1) Overall, how would you rate the conference

Excellent 20	Very Good 25	Good 4	Fair 2	Poor 0
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2) Please rate the following statements

	Strongly Agree	Agree	Neither Agree or disagree	Disagree	Strongly disagree
The organisation of the conference was good	33	14	4	0	0
I like the venue and the food	34	14	3	0	0
I thought the conference a good use of my time	27	18	4	2	0
Overall, the presentations were appropriate and useful	24	21	6	0	0
I enjoyed the workshops and thought they were useful	21	15	10	3	0

Conclusion:

The conference aimed to give a platform to the voices of people living with HIV, to raise their concerns about ageing with HIV, and to provide a learning opportunity for Positive Scotland in taking forward our work in this area. This was successfully achieved and, as the delegate feedback illustrates, this was generally seen as an enjoyable and well organised event.

Positive Scotland would like to extend its thanks to all involved: to the members of the Steering Group, the conference speakers, to our funders and to the conference delegates all of whom made the day possible.

Next Steps:

The findings from the conference will inform the work and direction of Positive Scotland:

In the first instance Positive Scotland will:

- Send out a targeted questionnaire to our service users to gain further information from them on the issues that have been highlighted.
- Develop a toolkit. The information collated from the conference will inform the development of a toolkit. The toolkit will target mainstream organisations that may at some point have contact with people living with HIV and/or Hepatitis C. These organisations will include older people services, benefit agencies and health and social care agencies. The toolkit will inform these agencies of the issues facing people living with HIV and /or Hepatitis C and will assist them to effectively support people with either of these conditions.
- Deliver a range of training to the older people services with regards to these Blood Borne Viruses.
- Train people living with HIV and /or Hepatitis C to be involved in the delivery of the above training.
- Publish the findings of the conference on the Waverley Care and Terrence Higgins Trust websites.
- Continue to work in partnership with the older people's sector in taking this area of work forward at a delivery and strategic level.

Comments from evaluations

Thank you for a great conference and a great venue, city.

I liked that workshops asked "What can Positive Scotland do to improve / build upon these areas" so turning discussion into action.

Ask someone from care services and social work involved with HIV to come to speak about their part of care. We listened to doctors, service users, charity. Where is social services?

Difficult to hear speakers who did not use the lectern but overall an enjoyable and worthwhile day. Name badges bearing organization names where appropriate, would have allowed more targeted networking in the breaks. Was clueless as to the backgrounds of other participants in one of the workshops.

An informative day.

Good balance of participants. Couldn't hear Justine. 1/2 hour too short for workshops - probably just one workshop taking up to 120 minutes would have been fine, especially as there were positive people in my workshop who really wanted/needed to get their stories told.

It may have been useful to have a Q & A session in the morning. It may be useful to link with SSSC (Scottish Social Services Council) and training and education for care workers and ensuring HIV is linked to occupational standards. Link to local change plans which are prepared by all sectors locally to reshape care. Thank you very much for a very good day.

The workshops could have benefited from less "generic" questions and more structure. They were nonetheless interesting and enjoyable.

Well organized and informative - got things to think about my future now.

Well done for organizing.

Thank you.

Not just vegetarian food.

Thanks to those who organized and attended.

Fab

Please continue using this platform – excellent.

A two day conference may give more time to discuss these issues.

Well done to all involved. An excellent, informative and interesting day.

This was a useful, informative and thoroughly enjoyable day and the venue was amazing.

Excellent - well organized, up to date, relevant information.

Well put together.

Thank you for a very informative and interesting day - raised plenty of points for discussion.

Thank you for an enjoyable day.

Need for public awareness campaign.

I think we need to be careful re: how we classify people 50+ as with or without HIV, the majority do not class themselves as old and certainly not elderly! A number of issues discussed (nursing homes etc) only seem relevant at a later stage, i.e. 70+ or 60+ at least.