

Cross-Party Group on Sexual Health and Blood Borne Viruses

Theme of meeting: Patient involvement and access to peer support

Draft minutes from second meeting (Parliamentary session 2016-2021)

Wednesday 21st June 2017

Committee Room 4, The Scottish Parliament

1. Welcome and apologies

Present: Patrick Harvie MSP, Tom Arthur MSP, Nicoletta Policek (HIV Scotland), Rik Hodgson (HIV Scotland), Rebecca Sibbett (HIV Scotland), Rev. Pius Danso Burns, Deacon Haruna Kwada, Swang Shallangwa (Waverley Care), Bibiana Zirra (Waverley Care), Minister Ayi Iboh, Matthew Gilbert-Straw (Positive Help), Leon Wylie (Hepatitis Scotland), Jim Clark (Hep C Trust), Dr Nicola Boydell (University of Edinburgh), Alastair Rose (S-X), Dr Lisa McDaid (University of Glasgow), Yvonne Kerr (NHS Lothian), Dr Jamie Frankis (Glasgow Caledonian University), Liam Beattie (HIV Scotland), Pamela Nash (HIV Scotland), Will Dalgleish (Lothian Patient Forum), Prof Claudia Estcourt (Glasgow Caledonian University), Hannes Neugebauer (Scottish Government).

Apologies: Alex Cole-Hamilton MSP, Kezia Dugdale MSP, Monica Lennon MSP, Dr Ingrid Young (University of Edinburgh), Aileen Ferguson, (NHS National Services Scotland), Dr Lesley Wallace (Health Protection Scotland), Kathleen Grieve (MSD), Michael Verlander, (Lothian Patient Forum), Cathy Crawford (Lothian Patient Forum), Cara Spence (LGBT Youth Scotland), Dr Indranil Banerjee (NHS Fife), Grant Sugden (Waverley Care), Maruska Greenwood (LGBT Health & Wellbeing), Catherine Somerville (Stonewall Scotland), Gail Grant (Abbvie), Kay Eadie (Gilead), Hosanna Bankhead (Hwupenyu Project).

The meeting was convened by Patrick Harvie MSP.

2. Introductions and new members

The CPG agreed to approve the membership of LGBT Youth Scotland.

3. Minute of the last meeting 14th March 2017

Minutes were agreed and have since been published on the Scottish Parliament website.

4. Matters arising

Liam Beattie (HIV Scotland) noted that all actions agreed to at the March meeting had been complete: circulation of CHIVA schools guidance, NHS Lothian Tasc report on RSHP, letter from General Teaching Council for Scotland on RSHP guidance for teachers, letter from Education Scotland on RSHP resources and evaluation, parliamentary questions tabled by Kezia Dugdale MSP on headship qualification and LGBT+ education training. All documents have been circulated among CPG members.

5. Presentations, followed by open discussion

- a. **Oonagh O'Brien, Lecturer, Institute for Global Health and Development, Queen Margaret University:** *What experiences and challenges can be learned from peer research? The research focused on monitoring attitudes towards female genital mutilation among the African community in Scotland, through using a network of peer researchers.*
- b. **Will Dalgleish, Chair, Lothian HIV Patient Forum:** *Forum has been going for two years, originally supported by HIV Scotland but now its own independent group managed by people living with HIV. Whilst challenges remain to recruit more members, the Forum has strong links with HIV organisations including Waverley Care and Positively UK.*
- c. **Jim Clark, Peer Educator, Hep C Trust and NHS Forth Valley:** *A network of peer supporters has been created across NHS FV where there are approximately 1,500 people living with Hepatitis C and treatment drop outs continue to be a problem. Peer support allows people to open up about their experience and encourage others to adhere to treatment.*
- d. **Swang Shallangwa, Waverley Care Health and Faith Worker:** *Waverley Care's African Health Project works with a range of community representatives, including faith groups where HIV testing is offered. Promoting involvement within the African community is vital to addressing stigma and finding solutions to problems.*

6. Discussion on provision of sexual health education in schools and follow-up action points

Establishment of other HIV patient forums

Rik Hodgson noted that HIV Scotland has been working to set up patient forums in all mainland parts of Scotland. Ensuring that patients remain engaged can be challenging. Will Dalgleish highlighted challenges in sourcing funding for patient forums and ensuring that groups can access banking services. Comments were raised that despite the Scottish Government's Sexual Health and BBV Framework Update noting that patient involvement should not be considered optional, there was no formal monitoring mechanism for this. Pamela Nash noted that HIV Scotland had produced a set of National Involvement Standards which were co-produced with people living with HIV and should be used across Scotland to measure involvement. Yvonne Kerr stated that funding cuts to NHS services had resulted in additional pressures and that there was a challenge to ensure the involvement of people not attending forums.

Impact of peer research

Leon Wylie stated that peer research results in quality research being carried out and proposed there should be a legislative requirement for services to conduct regular peer research on accessibility of services.

Academic evidence

Claudia Estcourt remarked that research findings from engaged groups of patients are often different to those not engaged and their views on services are also likely to differ. We must ensure that opinions of those not currently engaging are captured. Lisa McDaid stated that patient involvement is a key aspect of funding applications being successful and there are various sources of funding available.

Challenges for third sector service providers

Alastair Rose stated that involvement was a key part of the work of S-X but acknowledged the third sector still needed to improve on this. Matt Gilbert Straw suggested there may be a fatigue factor resulting in lower levels of involvement.

Action points

- Ask parliamentary questions on resources and measurements for patient involvement, with reference to specific patient groups. (PH).
- Letter to Sexual Health and BBV Executive Leads on funding for patient forums and what actions are being taken to ensure involvement of people at risk of HIV in services.

7. Any other business

Funding for speakers: agreed that the group would make a longer term decision on this when presented with funding models (subscriptions, donations etc.)

8. Future meetings

The next meeting is due to take place on Thursday 14th September at 5:30pm in the James Clerk Maxwell Room (CR4). Alex Cole-Hamilton will convene the meeting which will be focusing on sexual health and blood borne virus stigma. A working group with Alastair Rose (SX-Scotland), Hosanna Bankhead (Hwupenyu Project), Nicola Boydell (University of Edinburgh), will shape the agenda.