

Our Positive Voice (Grampian)

Present: Dani (NHS, Lead Clinician) Denise, (NHS Health Promotion), Rik (HIV Scotland)
9 people living with HIV

Everyone was welcomed.

Ground rules were agreed:

- Respect each other even if disagree
- One speaker at a time
- Protect each other's confidentiality

People were asked about what they wanted this group to be:

- A place of learning and information sharing
- A place to provide feedback to services in Grampian (not restricted to NHS) - this needs to be a two way feedback process
- A place where informal peer support can happen
- A place where people feel safe and can access support if necessary

Who is the forum for?

There was some discussion about whether this was a BBV forum, but it was felt that just now this is for people living with HIV, but that we would review this in 6 months time.

There was some discussion about if carers and family members could come along. Again people thought that although carers and family member views are important, just now there are other ways that these opinions can be fed in to the group, including the members themselves. Rik can also act as an advocate, and so can the NHS staff present. However, people also wanted to be clear that this forum is for people living with and affected by HIV.

Newsletter: It was suggested that the forum could develop a newsletter in the future.

Website or web presence on NHS Grampian: The group felt the best way to communicate with other people affected with HIV in Grampian was to have a web presence either on NHS Grampian or a standalone website. Denise will explore the possibilities for a page to be added to NHS Grampian Sexual Health website.

Mission Statement

Rik bought a sample mission statement from Lothian which he had amended to reflect Grampian. This was read through and discussed. Basically people felt that if this one worked for Lothian then it should work for Grampian.

However, on closer reading a few people thought that it should be less concerned with 'healthcare' and be more holistic. In addition Rik reminded people of the Denver Principles which state that the term patient is loaded with passivity and is therefore not always the best term of self identification. Consequently people wanted the mission statement amended to refer to people living with HIV and not to patients.

Rik to amend.

There was some discussion about the name of the group.

Rik described how other groups had called themselves:
Lothian HIV Patient Forum
Highland HIV Consultation Group
Our Voice (Tayside)

After some discussion people chose '**Our Positive Voice (Grampian)**'.

The NHS have a designer who Denise will ask to draft up some potential logos for the group. Once we have logos we can try and get promotional material drafted.

Meetings would be held in the 3rd Thursday of the month.

Venues to be figured out. Perhaps something closer to city centre? Rik explained that he was away for most of May and would therefore not be able to support the group that month. Dani can come to that meeting but may be a little late (6:15pm).

HIV Scotland support to the group.

Rik explained that HIV Scotland were willing to offer support over the next 12-18 months to enable the group to grow in confidence and stature. Lothian had been receiving HIV Scotland support for about 18 months and were going independent of this support in April 2017.

Work Plan

3 key items were identified:

- 1) Information given to the newly diagnosed (and the not so newly diagnosed). This could be linked to the work that the National Involvement Network are undertaking on information provided to the newly diagnosed. This information will contain lots of direct quotes from people living with HIV.
- 2) Peer Support: there was a genuine appetite in the room for people to get engaged in a peer support service and Dani said that she had heard from patients wanting to meet other people living with HIV. Project 100 was discussed and there is the possibility of a joint training with Tayside. Rik to explore further.
- 3) It was also suggested that there was expertise in the room which may elicit more items for the work plan. Rik to facilitate a work shop at the next meeting which allows the exploration of this experience, from diagnosis, to starting treatment, to disclosing, etc. This to be done by mixing up people accessing treatment at the two sites.

Rik explained that there was training available including 'Voices' which was developed by Chest Heart Stroke but is applicable across the board and is designed to give people the skills and confidence to provide appropriate feedback to service providers.

It was also suggested that if people had learning needs that this forum could be a place where these can be met through talks and presentations by professionals. However, it was felt that in the first instance getting the forum up and running with a clear identity was more important.

Date of next meeting:

20th April at 6:00PM. Hopefully the same venue. Rik to inform people of venue.

Finally, Rik asked people to say if the meeting met their expectations and everyone present indicated that they were felt it was a good meeting and met and even surpassed expectations.

