Early Intervention in Psychosis

Learning from the Lived Experience Reference Group

Case study

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1. Context

There is an increasing focus on the need for lived experience to be meaningfully involved in strategy development and service design. This is reflected in statements and commitments in Scottish Government, Health and Social Care Partnerships and NHS strategies. There is a growing interest in exploring new approaches to engagement. However, it is generally recognised that there is a considerable gap between the commitment to lived experience engagement and the experience of this in practice.

The Lived Experience Reference Group was developed to support the planning and delivery of lived experience engagement as part of phase one of the Early Intervention in Psychosis work programme. This case study draws on the reflections from those involved in the Lived Experience Reference Group and shares the learning from their experiences.

Scottish Recovery Network facilitated a reflection session with members of this group. The aim of the session was to capture learning to share with agencies and organisations interested in developing meaningful engagement opportunities for people with lived experience.

This case study pulls together key themes discussed in the reflection session. It explores:

- The experience of being involved in the group
- The impact the work of the group has had to date
- Learning and recommendations

2. Background

The work of the Early Intervention in Psychosis programme has been identified as a priority from Action 26 of the Scottish Government's Mental Health Strategy (2012 – 2027).

It is led by Healthcare Improvement Scotland and supported by a structure that includes:

- A project team
- The Lived Experience Reference Group
- An advisory group
- Early Intervention in Psychosis project report writing subgroup

From the onset the Early Intervention in Psychosis project team had a commitment to engagement. Support in Mind Scotland agreed to facilitate this and reached out to a number of national organisations to help develop the Lived Experience Reference Group. A key aspect of this was the recruitment of an Engagement Project Worker to support the work of the group. This role was a lived experience role which further emphasised that lived experience sat at the heart of the reference group's development and work.

Support in Mind Scotland recognised the centrality that lived experience played in the development of this work. As well as capturing people's views and experiences they wanted the planning, delivery and evaluation of engagement activities to be led by people with lived experience. The Lived Experience Reference Group had a central role in shaping the engagement approach in the Early Intervention in Psychosis project.

Development of the engagement work was paused with the first Covid-19 lockdown but was re-started in November 2020. This shortened the available time to complete the project which had a direct impact on the ability to influence the progress of phase one.

Voices of Experience (VOX) were commissioned by Healthcare Improvement Scotland to recruit and support a lived experience Co-Chair for the Advisory Group. The need for this role was initiated by the Lived Experience Reference Group and Health Care Improvement Scotland listened and agreed to fund it.

Both Support in Mind and VOX were operating on behalf of the Lived Experience Reference Group. The reference group, being un-constituted required these two third sector organisations to support the work of the group including the receipt of funding.

Some members of the Lived Experience Reference Group also sat on the Advisory Group and the Early Intervention in Psychosis project report writing subgroup.

3. Being involved

At the reflection session run by the Scottish Recovery Network, members of the group discussed the experience of being involved in the Lived Experience Reference Group. What did this look and feel like for them?

Three themes became apparent:

- The way in which the group worked together
- The impact of timescales
- The approach to developing engagement activities

3.1 Working together

The way in which members of the group worked together had a significant impact on the overall experience of being involved. All of the group members had personal and / or family / carer lived experience.

The group came together in online meetings via ZOOM facilitated by a nominated Chair. This enabled members to connect regularly and feel involved. The working environment that the group created was mutual and respectful, drawing on and valuing different group members experiences. It was reflected on as an open and connected space. The benefits of this were evident in how members of the group worked together productively driven by a sense of shared purpose.

"We worked together, shared lots of our own personal experiences and its always felt like it was in a very safe environment."

"I just have a sense that it was a caring group. It was a group that had a passion to make a difference to people but it was done in a very caring way."

This environment enabled the group to work towards their shared vision – meaningful engagement with people who have lived experience of psychosis. A key factor in this was that group members were driven by their own lived experience and passion for the development of Early Intervention in Psychosis services across Scotland. They wanted to influence change and make other people's experiences central. This created a different kind of dynamic. One that was bound by shared goals and diverse views of understanding psychosis. Different people brought different skills and this was valued and celebrated. This generated 'energy and commitment' to the project.

"What really impressed me and was a lesson to me was how we were able to come to agreements given we all have diverse backgrounds but what brought us together was what we were here for, what we wanted to achieve and the differences go to one side."

3.2 Timescales

The issue of time was raised throughout the reflection session. The limited period of time allocated to the group to plan and deliver the engagement work felt challenging. In one sense it was a lot to ask of the group. However, group members also felt that the time pressure presented an opportunity in that everyone pulled together and this built a momentum to deliver.

"Sometimes in large organisations there is too much time and planning when in fact, just get down to the nitty gritty. It was definitely challenging but in fact this was an opportunity and we delivered."

Members of the group had committed to the project because they wanted to make a meaningful contribution to the Early Intervention in Psychosis work programme. They wanted to improve people's experiences and outcomes of support across Scotland. They recognised the importance of the project progressing at pace in order to make an impact of people's lives in the near future.

3.3 The approach to engagement

The group planned and facilitated a programme of engagement activities across Scotland. This enabled the group to gather insight, views and experiences from those with lived experience of psychosis, their carers, family and friends. The approach to engagement was flexible and used a number of different online methods. This included:

- Group workshops
- Surveys
- 1:1 interviews

The mix of approaches supported more people to participate in a way that worked for them. This was further enhanced by the diversity of the members in Lived Experience Reference Group and the reach that they had across Scotland.

People within the group contributed what they could. They drew on their different skills and supported one another. This process had power and influence. It evidenced a different way of engaging lived experience. One that moves away from more traditional engagement approaches.

"Someone in Healthcare Improvement Scotland made a comment on the way the engagement process had worked. And the power and influence that the group had and I felt such a buzz at that point that this was being recognised."

The positive response to the engagement activities in feedback reflected the work that the group had contributed to the planning and delivery of the activities.

4. Impact

As part of the reflection session the group explored its impact and the difference it had made to the Early Intervention in Psychosis work programme. What came out of this discussion were views around:

- Influencing change
- Collaboration and sharing the learning
- The impact of engagement activities on people participating

4.1 Influencing change

The group felt that they had a real opportunity to influence Healthcare Improvement Scotland and others on how they think about meaningful involvement of people with lived experience. It was a chance to demonstrate the benefits of engaging with people in a different way. They achieved this by evidencing the value of investing in a variety of approaches to engagement where the voice of lived experience is central.

"We were able to combine these skills into a situation where we were both lobbying to the work whilst doing the work at the same time."

Healthcare Improvement Scotland were open to listening to ideas from the group. One of the group members referred to this process as being able to push a 'semi-open door' with Healthcare Improvement Scotland.

"There was a responsibility on us to make it work and I think that between us we have done that really well and I think Healthcare Improvement Scotland have noticed that."

As a result the group was able to shape and inform phase one of the Early Intervention in Psychosis project, in particular, how people with lived experience would be involved. The combination of people, their commitment to creating change for people experiencing psychosis and their interest in exploring different engagement approaches reflected a real can-do attitude. Not only to the work being undertaken but to the future of lived experience engagement across Scotland.

"Having let that cat out the bag (referring to resourcing lived experience engagement) they will need to realise that we will have expectation on them in the future."

4.2 Collaboration and sharing the learning

The Lived Experience Reference Group developed a report that shared the findings from the engagement activities with Healthcare Improvement Scotland and others. This was used to inform and influence the Early Intervention in Psychosis project report.

It was felt that being invited to be part of the sub-group for the wider project report helped increase the impact of not only the engagement findings but the promotion of the over-arching project report – again tapping into the diversity and reach of the Lived Experience Reference Group.

The drafting of the Early Intervention in Psychosis project report was described as a collaborative process which enabled the group to contribute meaningfully by commenting, directing and supporting the report development. There was an 'appreciation and understanding from all sides' which helped to establish an honest way of working.

"I found that an exceptional experience. I really felt that we were included, encouraged to comment, suggested changes and these were responded to."

The project report and its messages around psychosis and lived experience engagement reached wider audiences both nationally and internationally.

A Scotsman article was published and two blogs were written for the Health and Social Care Alliance Scotland (the ALLIANCE) and Healthcare Improvement Scotland. The group were also invited to submit a blog to IEPA Early Intervention in Mental Health an international early intervention network. The group welcomed this and saw the publicity as an opportunity to build on a conversation around psychosis. Despite increased discussions around mental health it was agreed by members of the group and through conversations in the engagement activities that psychosis 'is not talked about that often'. This gave a platform to the voice of lived experience.

"We are beginning to be out there much more and once people start a conversation it opens opportunities for others, and I really think that happened."

4.3 Impact of engagement activities

It was felt that the engagement spaces the group created and the activities developed offered the opportunity for different types of conversations. Strengths based discussions with hope and vision for the future.

There was a strong sense that the various engagement options provided an opportunity for people from across Scotland with lived experience of psychosis, their carers, family and friends to share and be heard. The workshops took an informal, peer led and participative approach to engagement.

Those participating were able to come together around shared experiences and be part of a process to create change for others. This is not something that is often experienced and the approach to engagement and facilitation really supported this.

"I think people felt empowered to share their experience. It highlighted the lack of opportunities that exist to express your views in this way."

Throughout the engagement activity it was recognised that the voice of lived experience brings something different by contributing and informing the work though experiential evidence.

The work felt like part of a 'culture shift' where people participating were meaningfully part of redesigning things for the better.

5. What enabled this to happen?

The final area of reflection explored what supported the group to work well. Three key themes were identified:

- The resource allocated to the group
- The positioning of the project within the third sector
- The diversity in skills and experience

5.1 Resources

The early work of the group identified that to make lived experience input a meaningful part of the overall project then resources would be needed. A case was developed. Healthcare Improvement Scotland then allocated funding to Support in Mind Scotland to employ an Engagement Project Worker. In addition, Voices of Experience (VOX) were commissioned to recruit a lived experience Co-Chair to support the Early Intervention in Psychosis Advisory Group.

"I think being able to get some dedicated resource out of Healthcare Improvement Scotland for this is probably the biggest enabler out of all of it."

The Co-Chair did not sit within the Lived Experience Reference Group. However having this role meant that that lived experience was in a position to set and shape the agenda, rather than a sense previously experienced of just 'responding to someone else's' agenda. This was supported by having members of the Lived Experience Reference Group sit on the Advisory Group too.

From the groups reflections it was very clear that the voice of lived experience needs to be represented in projects in different ways to avoid becoming pigeon-holed. It was felt this was particularly relevant when different structures and hierarchies are in place across a project.

"This felt closer to an equal partnership than we've ever had before. A lot of this happened because we pushed for it."

The group members felt strongly that resources to support lived experience engagement need to be an integral and routine part of all projects and allocated at the outset.

It was commented that in the future no-one should be put in the position of having to lobby for resources whilst being expected to deliver programmes of engagement.

"The trick is how we make sure we don't go backwards and how we make sure that the gains we have made become the starting point for the next project."

5.2 Role of the third sector

This work has demonstrated the significant benefit in working with the third sector and the value of having lived experience input at all levels of a project.

The Lived Experience Reference Group, the Engagement Project Worker and the Co-Chair for the Advisory Group were located within the third sector. This was a conscious repositioning suggested by group members and agreed to by Healthcare Improvement Scotland. This was reflected on as appropriate and influential. It allowed the Lived Experience Reference Group to develop independently and gave them greater scope and creativity in the planning and delivery of the activities.

"I think there was something important about having this group sit within a partner organisation and having the support independent from Healthcare Improvement Scotland. I think that added a bit of value."

The third sector as a whole played a key role in ensuring people were able to participate in the project. It was felt that as a sector they have significant knowledge and experience to share; both in terms of the design and delivery of services and listening to and acting on lived experience.

Another reflection was that when different organisations collaborate it is beneficial to have a hosting organisation. This can provide benefits especially in relation to employing someone as they already have the structures in place to support this. However, central to the collaborative relationship (and an area to be developed in the future) is the communication channels between all partners. When there are different structures as part of an individual project, the importance of understanding how they relate to one another was highlighted. This is something that is easier to do if everything required is in place from the outset.

5.3 Diversity

The group members emphasised that the depth of lived experience and the range of professional expertise within the group positively contributed to their overall impact.

"My mindset coming into this was a bit more hierarchical than what it actually was, which was more lateral."

The group was comprised of a range of different people, with different experiences and the dynamic was of mutual respect. With this diversity, between them, group members could draw on a wealth of connections and networks across Scotland. The combination of people and the spaces that were created for the development work supported the project to deliver as well as it did.

"The outcomes that we have achieved are probably beyond what we ever thought we could."

Something that enabled the group to work well was that members could contribute their own experiences and perspectives within this work and it was valued and encouraged. This supported the project to flow. There is a valuable skill in sharing your own experiences within engagement to support others to have a voice. This has been clearly evidenced in the way the group has operated as a whole.

"I'm always conscious thinking am I speaking from my own opinion or am I speaking as a worker. I've always heard from everyone in this group that you can say what you really think."

6. Conclusion

The Early Intervention in Psychosis project and the establishment of the Lived Experience Reference Group provided a welcome opportunity to demonstrate the power and benefits of meaningful engagement of lived experience in service design.

This work has set an expectation as to how engagement work should be planned, developed and facilitated. This includes an openness to collaboration, dedicated resource and a commitment to change. The work of the Lived Experience Reference Group has been holistic in its approach throughout and this is essential as we develop engagement going forward.

It is vital that lived experience engagement work is invested in. We must ensure that people are enabled and supported to shape the change required to make our mental health system one that works for people in our communities. This requires approaches that value and celebrate diverse knowledge and experiences, developing and delivering engagement in a mutual environment.

- For key recommendations see page 15 below
- For a summarised version take a look at the Top Tips

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Organisations involved in the Lived Experience Reference Group:
Bipolar Scotland, Carers Trust, Healthcare Improvement Scotland, Health and Social Care Alliance Scotland, Mental Health Network (Greater Glasgow), Mental Welfare Commission for Scotland, Scottish Recovery Network, SeeMe, Soroptimist International Great Britain & Ireland, Support In Mind Scotland, University of Glasgow, VOX Scotland.

Key recommendations

Involvement

People with lived experience should be represented and supported at all stages and levels of your project and clear communication channels put in place.

Resources

Allocation of resources is essential to ensure that lived experience is invested in from the start.

Lay foundations

Sufficient planning time is fundamental at the beginning of any engagement project. This allows for relationship building, ideas sharing and activity planning to happen collaboratively.

Common purpose

A dedicated group for planning and delivery of engagement activities enables a co-ordinated approached drawing on different people's skills and experiences.

Participant trust

Activities planned and delivered by people with lived experience can lead to greater trust and understanding from the people you are engaging with. The result? Honest insights and new ideas.

Variety matters

A mix of engagement approaches is important. It means people can take part in a way that works for them.

Third sector magic

Positioning your project and activity in the third sector allows for greater flexibility, creativity and responsiveness to opportunities that arise.

For un-constituted projects / groups the third sector can play a valuable hosting role.