

# With Us, For Us

A case study on integrating the role of lived experience as a key driver for projects.

Healthcare Improvement Scotland commissioned Scottish Recovery Network and VOX to support the work of the Personality Disorder Improvement Programme. The With Us, For Us project provided an opportunity for people living with trauma and/or who have been given a diagnosis of personality disorder to share their experiences and what supports their recovery and wellbeing.

We established and hosted a Lived Experience Project Group to ensure people's experiences were at the heart of this project. We were keen to provide opportunities for lived experience involvement that was not limited to the engagement aspect of the project, but embedded from the beginning to end.

Although we had objectives to meet as part of our commission, we wanted the voice of lived experience to play a key role in the planning and delivery of the project, ensuring people's ideas could be implemented, where possible, as it progressed.



“Putting the human element to it, it’s part of a bigger project but this group has brought the human element to it.”

# Structure

The five members of the Lived Experience Project Group were initially identified during the reach out phase of the project. Then a programme of group workshops and meetings were devised together. We were mindful to ensure that the group was mutually beneficial to the facilitators and the group members and we were keen to avoid it feeling like an extractive process. As such, we offered learning and development opportunities to the group including PhotoVoice training and support to co-facilitate recovery conversation cafés.

The group meets fortnightly on Zoom, if anyone cannot attend the session, they can catch up on a 1-1 basis to ensure they are included in the decision-making. Sessions have a flexible structure, beginning and ending with a wellbeing activity that was decided by the group members. The sessions are informal, and space is held for open discussion around project topics.

Group members have been involved in planning and delivering engagement and co-design sessions, collating feedback and identifying key themes and interpreting the findings for the report. They have also played a central role in the development of the creative outputs, such as a Practice Learning Workbook, an animation and a storytelling with photography and artwork booklet.

**Small group**

**Fortnightly online meetings**

**1-1 meetings**

**Designed informality**

**“There was an informality, of sorts, to the sessions which made it feel easy to contribute. Although there were particular questions to answer/tasks to complete in each session, the conversations felt natural and not forced or overly directed.”**

## What worked well

### Coproduction

The group felt truly listened to and valued throughout the project. Their experience of being part of the group has been validating, as what they have shared has been acted on. The group has been a true collaboration and co-production.

**"It's very clearly our voice, its not us having spoken then the organisation squeezing it into what they put across, it's what we truly said."**

### Flexibility

The informality and flexibility within meetings, and the opportunity to contribute in a variety of ways meant members felt valued and able to participate fully.

**"We are still being involved, considered, and it's not been judged or looked down upon because you can't make it. There's still the option to speak to someone about my ideas which is appreciated."**

### Investing in the group

We invested in opportunities for the groups own personal development, but also allocated budget to support members participation, including covering refreshments, travel and accommodation expenses.

**"The willingness to make it accessible, helping with transport those type of things. It's made it a very non-judgmental space and you don't feel self-conscious."**

**"Think about what your participants are getting out of the experience. Yes, they might be contributing to a meaningful project, but what else are they gaining through their participation? What can you offer them?"**

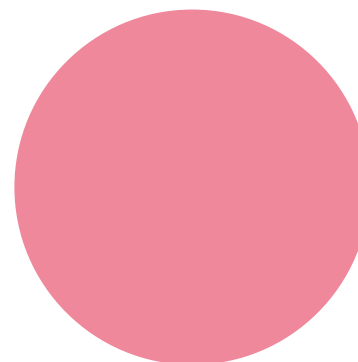
### Peer approach & group size

Initial sessions focused on connecting, using wellbeing as a neutral topic to open discussions. We also developed a group agreement. This helped gel the group together and naturally peer support began to develop within the group. The group was kept small to ensure everyone felt able to contribute during the sessions.

**“Everyone’s been very accepting of each other, it’s been a safe place.”**

**“The group felt like a manageable size where relationships were able to develop and everyone was given space to contribute and be heard.**

**[Team member’s] facilitation skills really fostered this atmosphere in the early days while we all got to know and feel comfortable with each other.”**



## Session length

Sessions could have been a longer in order to facilitate further discussion. In future, we will be mindful of topics which may require a longer discussion and plan sessions accordingly.

**"Be mindful for meetings where there will be a lot of discussion to plan adequately.**

**Sometimes it can work only having an hour as it makes us accountable and responsible to be productive."**



# Top tips for organisations

The group members share their top tips for organisations who are interested in setting up their own lived experience project group. The below matrix highlights four key areas to consider.

## Invest

Investment in your staff time, especially outside of meetings to provide 1-1 and necessary adjustments. You need time and money. Make realistic budgets and invest in the people. Because it's those relationships that make it work and helps the group.

## Build relationships

Take the time to get to know people and make sure you offer any adaptations that will empower them to fully participate. There needs to be an acknowledgement that this may require an investment of both time and money, so ensure you have planned for this.

## Collaborate

Take a collaborative approach from the get-go. Participants should be able to shape and direct the whole experience/project, not just contribute their thoughts to a set of pre-directed questions/goals.

## Compromise

Compromise - on where you meet, when you meet, having a break - so everyone feels comfortable to share. Everyone's got a voice to be heard, it's not just one person sharing their vision. What everyone has to say matters.



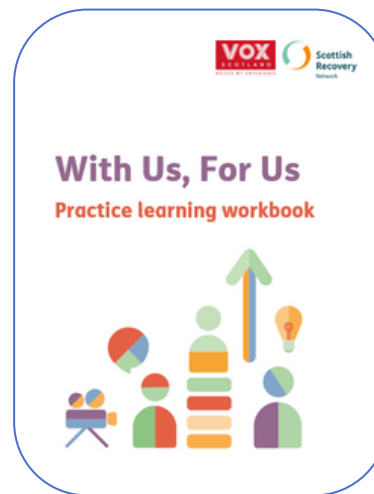
**"If you are going to do it, DO IT. Invest in it 100%, don't just do it for the sake of ticking a box to say we are getting lived experience. Make it count. Understand WHY you are doing it and understand the benefits."**

We want to see a commitment to ensuring the mental health system is powered by lived experience. We have developed the following resources with our Lived Experience Project Group:

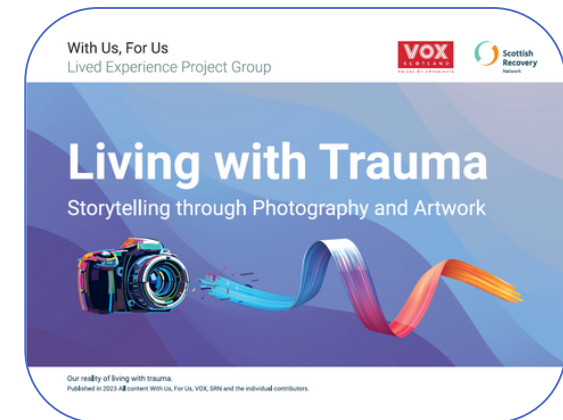
## Animation



## Practice learning workbook



## Photography booklet



You might also be interested in the [With Us, For Us report](#)

Sign up to the Scottish Recovery Network [newsletter](#) to hear about upcoming opportunities and new resources.

Keep up to date with VOX Scotland on [Twitter](#), and if you have lived experience of mental health issues you can [join as a member](#)

If you have any questions or need this report in a different format please contact us:

Call us on **0300 323 9956** | British Sign Language (BSL) users can contact us directly using [ContactScotlandBSL](#)