

NSPA Conference Workshop 1a: How to involve people with lived experience to shape policies around health inequality

As part of this workshop we completed a discussion group activity where each table was assigned a different way of involved lived experience into policy development work around health inequalities.

Each table reflected on the benefits, opportunities and good practice examples of involving lived experience in both of suicide for both developing policy around health inequalities and for people with lived experience.

This document provides an overview of the discussion groups key reflections.

Interviews

Usually one-on-one, this is an in-depth engagement method to really understand a person's experience and views.

- This can be a great way to discuss topics in a structured way.
- It is a way to have in depth conversations and gather lots of information on a topic.
- You can send the questions in advance so that people can think about the issues.
- Setting up clear processes and procedures on safeguarding and risks involved is important to ensuring safe and ethical interview practices.

Focus groups

Usually one-off, focus groups bring together people with similar experiences. They can be used in a range of ways, including engagement to share views, consultation on something you've already produced, or part of a co-design process.

- Focus groups can generate quite detailed discussion/conversations.
- Can be an interesting experience for everyone to be involved in learning from others experienced.
- It's a space where you can learn things that you hadn't considered before.
- There is an opportunity to move beyond text book/theory and brings in a more emotive and personal understanding of issues.
- This works well where facilitation allows to hear from all participants and quieter people are supported and encouraged to contribute too.

Surveys

This is an engagement method to gather insights from many people. You can ask questions to a local mailing list, publish them widely on websites and social media or use a nationally representative panel (e.g. YouGov).

- You can have a wide participation through this way of involving people.
- This can allow people to share their insights anonymously, which can be very valued in a space where the topic is sensitive.
- It gives you the ability focus on a particular issue and/or group.
- It is important for accessibility to allow surveys to be responded to in a mixture of methods and approaches i.e. online survey, paper survey, phone survey.
- It is also important to include people with lived experience into the design of the survey.
- Good practice example: Suicide Bereavement UK Survey to understand the impact of suicide in the UK by Dr Sharon McDonnell.

Lived Experience Advisory Groups

This is a co-design technique, where a group of people with similar lived experience meet regularly throughout the course of a project, usually advising on key decisions and co-creating project materials.

- This can ensure the lived experience is embedded in a project from start to finish
- This can help to amplify experiences and voices of lived experience within a projects development by giving over key elements to the group.
- There is a place for sharing stories within this space but it is primarily about drawing on lived experience to create and shape change within the sphere of influence the project has.
- It is important to consider the specific lived experience you are looking for within a project, this may not be external but people who have experience of the service you are providing.
- It is important to set out clear roles, responsibilities for a lived experience advisory group and for the wider organisation or team that the group will be working with.

Mixed Advisory Groups

This is a co-design technique, where a group of people with lived experience alongside people with professional experience meet regularly throughout the course of a project, usually advising on key decisions and co-creating project materials.

- Mixing views and experiences in this way can give rich and balanced insights.
- Mixed nature allows for a better understanding through common language of complex issues.
- Important to clarify roles and responsibilities within the group, including identifying any hierarchy.

Project Advisors

This is a co-design technique, where one person with lived experience works jointly with the project team, usually advising on key decisions and co-creating project materials. People may be offered training and support to be advisors.

- This can be a great way to involve someone in a project when the commitment level is high or the topic is particularly niche.
- It can provide insights into language and terms used by people themselves in particular service settings.
- This offers many opportunities including co-producing a service or programme.
- Can provide personal understanding of a particular topic which people have become experts in due to the nature of their lived experience.
- It is important as with other ways of involving people to clearly set expectations, roles and responsibilities for what an advisor will bring to a given opportunity.
- This allows for involvement from the start of a project and should also be used as an opportunity for feedback to improve future opportunities.
- Helps to bridge the gap between policy maker and real life.
- Allows for the inclusion of intersectionality within a project and amplifies intersectional voices and experiences.
- Can help to provide contextual information to data and statistics.

Project co-leads

This is a co-production method where people with lived experience lead, or co-lead, a project. Examples include people with lived experience facilitating a training session or leading on project development. This can be alongside other professionals. People may be provided with training and support to develop or build on relevant skills and experience (e.g. leadership skills).

- Having an equal partnership means that there is genuine, not tokenistic, equal voice in decisions, project direction, scope, methods and purpose. Including opportunities to challenge decisions.
- This way of involving lived experience improves leadership, fulfilment and skills development within an organisation.
- This increases the level of empowerment given to lived experience. In a sector where timing is everything it's important not waiting until the late stage to get feedback and ideas from lived experience perspective.
- Monitoring and evaluation approach can better reflect people's experiences and desired outcomes.
- Transparency and accountability increase the quality of the role.
- Project co-leads with lived experience can increase the credibility of a project.
- It's important that a proper support network is provided to co-lead roles that is inclusive and aware of intersectionality.
- Payment for involvement is also key here as it highlights the value of contributions and acknowledgment of the expertise brought to a co-lead role.