



# Lived Experience Involvement

**Our guidance for best practice**

Created by Leeds Mind Suicide Prevention Volunteers

## Leeds Mind Suicide Prevention Coproduction Project

Leeds Mind has been commissioned by the West Yorkshire Health and Care Partnership to deliver a coproduction project focussed on suicide prevention. The project was funded for two years from March 2022, and covers Leeds, Bradford, Kirklees, Wakefield, and Calderdale.

We have been working with a team of volunteers from across West Yorkshire who all have lived experience of being impacted by suicide. Drawing on lived experience, volunteers have been working on projects and campaigns that aim to;

- Reduce stigma around mental health and suicide.
- Raise awareness.
- Champion the voices of people with lived experience.
- Challenge and influence decision makers to improve mental health support for clients and families.

## Lived Experience Involvement – Our guidance for best practice

**These guidelines have been written by our team of lived experience volunteers and are informed by their own experiences. They also draw on materials from the Mind ‘Influence and Participation toolkit’.**

*“Involving people with lived experience in the work of your organisation offers many benefits. Lived experience input is a valuable resource, and involvement should be given careful consideration to ensure people feel valued and supported.*

*The guidelines we have put together come from our own experiences of what good practice feels like. Whilst examples we may give come from a suicide prevention perspective; we feel they are relevant to all lived experience involvement work. We hope that the guidance we give can start a conversation in West Yorkshire and encourage this method of working”.*

## Principles of good involvement

Mind has signed up to the 4PI model, a framework for meaningful involvement developed by a partnership of organisations, hosted and led by National Survivor User Network (NSUN).

4PI stands for 'Principles; Purpose; Presence; Process; Impact'. You can find out more about the framework by visiting NSUN's website.

Principles of good involvement as defined by 4PI National Standards

– [Involvement for Influence:](#)

- Inclusivity, equality of opportunity and fairness
- Clarity and transparency
- Listening to each other with respect and openness
- Sensitivity about language and actions, an understanding that there are different ways of expressing and doing things
- Support for race equality and a commitment to challenge discriminatory practices
- An open-minded approach towards cultural differences and diversity in ways of working
- Acknowledgement of the power differentials that exist between people, and a commitment to minimise them wherever possible
- A commitment to change in response to the views of service users and carers

These principles are the basis of all good quality involvement work. Before involving people in your work, it's worth considering if your organisation can commit to the principles outlined.

Mind has developed a detailed 'Influence and Participation Toolkit', which is a valuable resource for anyone whose organisation or workplace wants to engage with people facing mental health challenges in a meaningful way. It is available publicly and anyone can use it. The toolkit can be found here: [Influence and Participation Toolkit - Mind](#)

Drawing on our own experiences, and condensing some of the toolkit, our guidelines share what we feel are the most important things to consider, to help you get started.

## Top tips for Planning

- It's essential to recognise that people with lived experience have skills, knowledge, and experience to contribute equally with the staff at all levels.
- It's critical to take an asset-based approach – focus on what people can do instead of what they cannot do.
- Be clear about the nature of the work that people can get involved in.
- Be specific about what people can and cannot influence.
- Focus on the outcomes you want to achieve and minimise all activities unrelated to these outcomes.
- Provide an itinerary before the involvement opportunity, so that people know what to expect and when to expect it. Trigger warnings could be included as part of this.
  - What is a trigger warning? A trigger warning can take the form of a sentence or a few words to caution people about the content which will follow. This content might include a topic or images someone could find unsettling. Trigger warnings exist so people can choose if they wish to engage any further.

## In the moment:

- Consider creating a group agreement, co-designed by all participants. This will ensure that:
  - Everyone clearly understands the aim of the work and why they are there.
  - Any misunderstandings can be ironed out.
  - An atmosphere of inclusion is created from the offset.

The Mind guide to creating a group agreement can be found here:

[creatingagroupagreement\\_aw1.docx \(live.com\)](#)

- Encourage the use of inclusive language when working in larger groups, conversation guidelines could be provided. For example, events relating to suicide could provide language support: [Creating hope through language \(210 x 345 mm\) \(suicidepreventionwestyorkshire.co.uk\)](#)
- Use plain English, avoid jargon and avoid acronyms.
- Involving people with lived experience in your work can sometimes present challenging situations, but this shouldn't put you off reaching out to people. Think about support systems you may need in place. Do you have a trained member of staff you can call upon if needed? For example, is there

a Mental Health First Aider in your team who can support in conversations about mental health?

- Depending on the nature of the opportunity, it can be good practice to provide a separate breakout space, so people with lived experience can safely step out of the discussion if they find it too challenging.
- Facilitators may want to consider planning time for a debrief at the end of the work, to create a space for people to reflect and talk through difficult feelings that may have come up. At Leeds Mind, we often run a ‘wellbeing round’ at the end of a session, asking people ‘What is something that you will do for your wellbeing after the session?’. This enables the work to end on a positive note.

### **What comes after:**

- One of the concerns people with lived experience sometimes have about influence and participation is that their views are not taken into account and no action is taken as a result of their involvement. Providing feedback demonstrates that you have listened to people's ideas and assures them that their participation was not simply tokenistic. It also demonstrates the process and outcome is credible.
  - Mind has created a ‘You said, we did’ tool, to support you to structure this kind of feedback. It can be found here: [yousaidwedid\\_aw1.docx \(live.com\)](#)
- When you've conducted your activity, it's important to ask for feedback from the people who participated. Asking for feedback shows people that their input is valued and that they are listened to. As a result, they will be more likely to get involved again. The Mind feedback tool can be found here: [feedbackform\\_aw1.docx \(live.com\)](#)

### **Making people feel comfortable:**

- Ask about access needs before the event or session and strive to meet them. For example:
  - Select a venue which is accessible to wheelchair users, making sure doorways are wide enough, a ramp is provided, a disabled toilet is available, and the space is arranged in a way that considers physical access.

- Neurodiverse individuals may request reasonable adjustments, such as having a seat close to the door on the edge of the room, reducing background noise, having written communication as well as oral or 'easy read' manuals and printed documents on coloured paper.
- Adhere to the principle of reciprocity – people should get something back for putting something in.
  - This may take the form of payment, a gift voucher or a donation to a chosen charity of the lived experience participant. Remember, when you pay people, their benefits or income tax payments may be affected. Remind them to contact the DWP or Citizens Advice to ask for specific personal information about accepting payment. Everyone's circumstances will be different, so they need to find out precisely what they need to do if anything.
- Besides payment, there are endless ways you could offer incentives or rewards for people's participation, such as a reference, training, or further opportunities to work with you or your organisation. Think about what would make you feel valued.

#### **If online:**

- Working with people online is a different experience to working together in person, so extra consideration should be given to planning. Some important things for us:
  - Share joining information and passwords in plenty of time.
  - Having an additional person on hand for IT support. This shouldn't be the main facilitator as it can derail the session.
- For a more detailed guide on running online participation work, you may find this Mind guide useful: [Running an activity - Mind](#)

#### **If in-person:**

- Consider picking a venue with good transport links and send out information of how to get there/where to park in good time.
- Make sure the room is clearly signposted.
- Providing some light bites and refreshments can make participants feel more comfortable and appreciated for their involvement.



**Have you found this guidance helpful? What work has it supported you with? What hasn't worked?**

**Please get in touch with your feedback and to engage with our group.**

Contact us directly through our project coordinator, Arlie:  
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**To find out more about our project, visit our page at:**

<https://www.leedsmind.org.uk/services/suicide-prevention-co-production/>

**For more information on Suicide Prevention and support in West Yorkshire, visit:**

<https://suicidepreventionwestyorkshire.co.uk/>

Leeds Mind is your local mental health charity, working towards a vision of better mental health for all. Leeds Mind is part of the Mind network, which includes Mind, Mind Retail (charity shops) and around 100 other local Minds.



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