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INVOLVING PEOPLE WITH LIVED EXPERIENCE

Frequently Asked Questions

What is the purpose of this FAQ?

This resource offers introductory guidance for professionals and organisations seeking to involve people with lived experience in suicide prevention and suicide bereavement support activities. It aims to address common questions by introducing good practice recommendations. The resource offers points for reflection and suggests further resources throughout.

NSPA has a wealth of expertise in this area through our Lived Experience Network, and are keen to have more detailed conversations with those who want to embed lived experience in suicide prevention work. For more information on how [NSPA's Lived Experience Network](#) can work with or support you, please contact livedexperience@nspa.org.uk.

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References and special thanks

This FAQ was created by National Suicide Prevention Alliance (NSPA) and Support After Suicide Partnership (SASP). It has been developed collaboratively with members of NSPA's Lived Experience Influencer group – with thanks to Fiona Malpass, Maxine Roper, Neil Smith, and Penny Phillips.

Q1: What does Lived Experience mean?

Lived experience refers to first-hand personal and direct experience of something. It is increasingly recognised that a great deal of knowledge, insight and expertise can come from this type of experience, and that policy and practice should be informed by lived experience expertise.

In suicide prevention, lived experience would usually refer to personal experiences related to suicide. For example, NSPA's definition of lived experience includes "people who have experienced or live with suicidal thoughts, people who have attempted suicide, people living with or in relationships with those who have suicidal thoughts, and people who are bereaved by suicide".

Depending on the project we may also include additional relevant experiences, such as having a particular identity or being from a particular community.

Lived experience expertise is different to the expertise that comes from "learnt experience", such as through professional training. However, many people may combine their lived experience with additional experiences and skills when influencing or informing within lived experience roles.



LEX Movement host a report by Barjeet Sandhu that explores Lived Experience Leadership:

[MORE INFO](#)



Q2: Why should we involve people with lived experience in suicide prevention and suicide bereavement work?

People with lived experience are best placed to inform the effectiveness of suicide prevention and suicide bereavement strategies. Involving people with lived experience ensures that approaches are grounded in the realities of those who have been directly impacted by suicide.

As well as having key insights into what may or may not be effective, people with lived experience should have a voice in decisions that impact their lives and be included in the design and implementation of programmes.

It is important to recognise the diversity of experiences and perspectives among people with lived experience. By engaging with a diverse range of people with lived experience, we can gain a more comprehensive understanding and develop more effective strategies that are inclusive of all individuals and communities.

“People with lived experience bring so much veracity to every stage of the process, from supporting with project approaches to directly sharing their reflections on change they want to see. People with lived experience are at the very heart of our sector and it’s vital to include them in what we do as well as how we do it.”

Eva Bell, Participation Officer, Samaritans.

“Being able to influence suicide prevention policy and practice has helped me to find a way forward after bereavement. My perspective is valued and heard, and I have found hope through connection and inclusion with a diverse network of people. Seeing my experiences used to help others has given me a renewed sense of self-worth.”

Penny Phillips, NSPA Lived Experience Influencer.



Q3: I've heard different terms such as "lived experience involvement" "co-production" and "leadership". Are these different or do they mean the same thing?



There are lots of different ways that people with lived experience might influence and inform work, and different ways that organisations can work with people with lived experience. All of these words usually refer to involving people with lived experience in some way, although the differences often link to how much decision-making power is shared with people who have lived experience.


There are some models that refer to different "levels" of involvement, such as:

- Think Local, Act Personal [the ladder of co-production](#) and
- Mind's [ladder of participation](#).

Some projects or areas of work might involve working with different people at different levels – for example, surveys and focus groups informing the direction of the work, whilst also including people with lived experience in a decision-making steering group.

Throughout this FAQ, we are using the term "involvement" as a catch all, which could include the different levels. Whilst we would advocate aiming towards co-production and are keen to see a shift in the suicide prevention and suicide bereavement sectors in which co-production is common, we recognise that there are benefits to good practice involvement at all levels. The important thing is that this involvement is meaningful, and that the roles and influence of the people involved are made clear.

 The **Suicide Prevention Consortium** held a workshop at NSPA's 2023 conference, discussing different ways of working with people with lived experience to influence policy. You can read more here: [MORE INFO](#) 



Q4: How do we ensure meaningful involvement?

It is important to really think through how you are involving people, why, and what difference you intend to make. Having a clear sense of the purpose of any activity and ensuring this is communicated to all involved is vital.



The National Involvement Partnership (NIP), a project hosted by [The National Survivor User Network \(NSUN\)](#), developed the 4Pi National Standards as a framework for involving people with lived experience in service delivery, evaluation, strategy, and governance. This framework encourages us to think about Principles, Purpose, Presence (who), Process and Impact. Whatever the method or level, this can be a very helpful guide to ensure involvement is meaningful, and to avoid tokenism.



For more information about the 4Pis, the more info button will take you to the [National Survivor User Network \(NSUN\)](#) where there are plenty of resources available:

[MORE INFO](#)



“Personally, I get no joy out of simply telling you my story for the sake of it. I need to know what you want to know from me and how you're going to use the information to help suicide prevention as this will also help me to know what to tell you.”

Emma Williams, NSPA Lived Experience Influencer



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Q5: How do we decide who to involve in our work?

This will depend on the nature of involvement or the focus of the work you are planning. Firstly, it is useful to consider if there are particular experiences or voices that you need to hear from. For example, if the activity is about improving support services for LGBTQ+ communities, it would be important that you were including people with lived experience who are LGBTQ+. If it was about suicide bereavement support services, then it would be important to include people who have been bereaved through suicide.

It is also important to proactively plan for diverse representation that is representative of the communities we live in. A diversity of experiences is needed to gain better understanding from different perspectives.

If you are developing formal lived experience roles, it is also important to consider if there are any additional experiences, skills, or qualities needed. For example, a workshop co-facilitator may need to have facilitation skills or previous experience of co-facilitating. Members of a strategic advisory group may need to be able to read and comment on papers. You may consider learning and development opportunities to enable people to participate who may not have these skills at the outset.

EXAMPLE: NSPA Lived Experience Influencer Programme

Along with 1:1 coaching, NSPA Lived Experience Influencers are asked to attend 8 group training sessions. The aims of the training are to equip the Influencers to safely, effectively, and meaningfully use their lived experience to inform and influence suicide prevention policy and practice in a range of settings.

They are also invited to reflective learning spaces and are offered other training and development opportunities where needed and available.

Q6: How do we engage, find, or recruit people?

This will also depend on the nature of the involvement. For lived experience roles, such as Advisors or Experts by Experience, we would advise a more “formal” recruitment process with a role description and a selection process. Other types of involvement, such as focus groups, discussion groups, surveys etc., may not require such a formal process. However, regardless of how formal or informal your recruitment is, it is important to:

- Ensure you are clear about what is expected of people and what they can expect from you.
- Be clear about what experience, and any additional skills, you are looking for.
- Encourage people to think about their wellbeing, the support they have available, and if involvement is right for them at the moment.
- Consider accessibility and reducing barriers where possible.
- Consider how you will advertise opportunities, including whether you want to “target” advertising to particular groups. This may include engaging with communities and grassroots groups.
- Be clear about what any recruitment process entails, including any selection processes. This is especially important in order to manage expectations if people cannot be guaranteed a role or place in a group. If someone isn’t selected to be involved in an activity, consider how you will communicate this sensitively and offer feedback to the person.



Mind’s Influence and Participation toolkit includes guidance and templates which may be helpful when thinking about recruiting people with lived experience, click the button below for the toolkit:

[MORE INFO](#)



Q7: How do we ensure that we are hearing from and working with a diverse range of people with lived experience in our work?

Being proactive and purposeful about diversity and inclusion is essential. In your planning, consider which voices are heard less in relation to the area that your work focuses on. You may find it useful to seek additional expertise about engaging with particular communities.

Connecting with and building relationships with grassroots groups and community leaders can help to connect with and build trust with members of some communities. Consider how you can take a collaborative approach here. This can also help you to learn about grassroots and lived experience-led work that is already taking place, and give you opportunity to uplift that.

Consider potential barriers to taking part in lived experience work, especially for people from marginalised communities, and aim to reduce those barriers where possible. Being proactive shows that you take accessibility and inclusion seriously and will help ensure that equity, diversity and inclusion is woven into your work.

EXAMPLE: Accessibility

Everyone's needs are different, so it is important to ask what each person needs to fully participate in your project.

Here are a few examples:

- Paying travel expenses upfront.
- Wheelchair access for in person events.
- Paying childcare expenses.
- Considering digital literacy and access to technology.
- Avoiding using jargon in written materials.
- Offering alternative ways of applying e.g. submitting a video rather than only accepting written applications.

Q8: How do we ensure it is safe for people with lived experience to be involved in our work around suicide prevention and suicide bereavement?

Safety means different things to different people and is not only about physical or “clinical” safety. The first consideration is to ask the people involved what feels safe for them, and ensure they are in the driving seat, as much as possible, in the way that they are involved.

Whilst drawing on or sharing personal lived experience related to suicide can be painful, for many people involved in lived experience work, what is often most painful is feeling disempowered or not being listened to.

Some general tips include:

- Give people as much information about the activity as possible so that they can make an informed decision about whether it feels safe for them to take part and ensure that people know that they can withdraw their involvement at any time.
- Encourage people to think about whether involvement feels right for them at the moment.
- For group activities, develop shared group agreements between group members.
- Consider what additional resource might be needed.

EXAMPLE: NSPA Lived Experience 'Readiness' document

NSPA have a 'Readiness' document for possible new Influencers to read, it poses the question:

Is your involvement in our Lived Experience Network right for you, right now?

To read this document in its entirety click the button:

[MORE INFO](#)



Q9: What support should we offer people who are using their lived experience to inform our work?

In a similar theme to the above, there is no “one size fits all” and the best thing to do is to ask people what support they might need, and what support they already have.

That said, these are a few things that people in our Lived Experience Network find helpful:

- Training, mentoring and opportunities for peer support and peer learning.
- Opportunities for pre-briefs and de-briefs before and after an event or meeting to prepare for, and then reflect on how the experience was.
- Remember: Consider what you can realistically provide and be transparent if you are unable to provide the support that someone wants or needs. Working with people in a supportive way does not mean being someone’s main source of support. Signpost and/or encourage people to think about where they could go for this support.

On being “trauma informed”

It is important to consider the impact that trauma may have had, which may include traumatic experiences of services or systems, and experiences of oppression and marginalisation in society. This is particularly important when thinking about building trust.

Fulfilling Lives take a more in-depth look at trauma informed practice in co-production here: [MORE INFO](#)

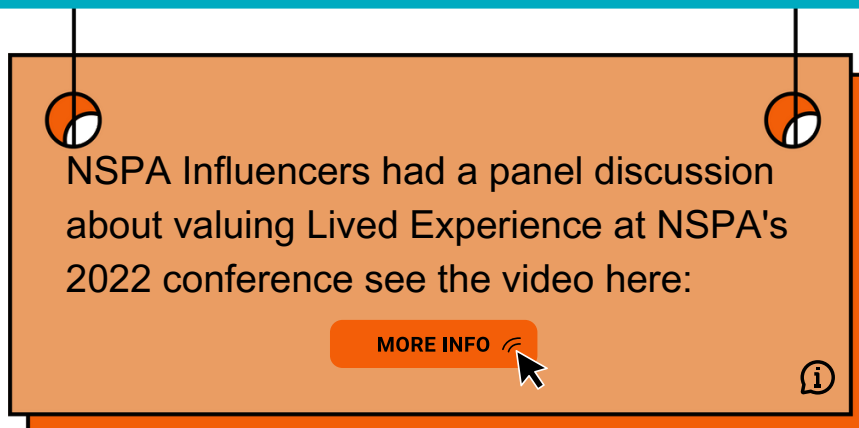


Q10: How do we show that we value people?

There are many things you can do to show that you value those you work with.

Firstly, offering remuneration and paying expenses shows that you value their time, skills, and expertise. We strongly advocate offering payment. Doing this in a flexible way with choice can improve accessibility and reduce barriers to participation. Consider what else you can offer people you are working with, such as learning and development opportunities, as described earlier in this resource.

Communicating well is essential. Be clear about the purpose of your project, what has been achieved and the impact they have made. Unless the person wishes to remain anonymous, credit them for their involvement. Thank people for their time, contributions, and for sharing their expertise!



NSPA Influencers had a panel discussion about valuing Lived Experience at NSPA's 2022 conference see the video here:

[MORE INFO](#)

“Lived Experience Influencing has been a very empowering experience so far. Through training, story sharing and networking I have gained from knowing that I am not alone in my experiences and that there are ways my story and voice can be heard. The process so far has helped to reconnect with my experiences in a positive way to change my own self-perception.”

Ben Perkins, NSPA Lived Experience Influencer

Q11: What wider considerations does my organisation need to make?

It is important to evaluate your organisation's culture and values. Are they consistent with working in a collaborative way with people with lived experience? Do they allow for power sharing? Work towards ensuring that the whole staff team, including those with decision-making power, understand and appreciate the value of working alongside people with lived experience so that everyone is on board.

As well as having "buy in" from everyone at all levels, planning well and ensuring that you have enough time, resource, and capacity for the work that you have planned is vital. This includes having an agreement and clear communication around processes.

Organisations should also decide how you will consider the effectiveness of your lived experience programme and create channels for feedback and improvement.

Consider if there are any organisational policies and processes that you may need to review, update or develop. This includes ensuring appropriate payment and remuneration policies and processes for lived experience involvement and co-production. If this is something that is new to you as an organisation, we strongly recommend seeking advice on this area.

Extra support

You may have concerns about the barriers to involving people with lived experience in your work. We'd like to offer reassurance that, with the right resources, creating opportunities for meaningful involvement is achievable and will bring so much value to your work.

NSPA can offer further support, guidance and consultancy around lived experience involvement. If you would like to find out more, please contact us on livedexperience@nspa.org.uk.

Further Websites and Resources

The following websites provide further resources and information that you may find useful:

Lived Experience Leaders Movement - <https://lexmovement.org/>

Mind's Participation and Influence toolkit - <https://www.mind.org.uk/workplace/influence-and-participation-toolkit/>

NSPA's Lived Experience Network - <https://nspa.org.uk/home/lived-experience-network/>

National Survivor User Network - <https://www.nsun.org.uk/about-us/>

Roses in the Ocean, an Australian suicide prevention organisation who work closely with people with lived experience - <https://rosesintheocean.com.au/lived-experience-of-suicide/>

Social Care Institute for Excellence's co-production resources - <https://www.scie.org.uk/co-production/>

References

'How to involve people with lived experience to shape policies around health inequality', Suicide Prevention Consortium. Available at: nspa.org.uk/wp-content/uploads/2023/03/NSPA-Conference-Workshop-1a.pdf

'Influence and participation toolkit', Mind. Available at: www.mind.org.uk/workplace/influence-and-participation-toolkit/how/methods/

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We would like to acknowledge and thank the Lived Experience Influencers who worked with us to develop this resource – Fiona Malpass, Maxine Roper, Neil Smith, Penny Phillips .