

From 'they' to 'we' Reflections on working as lived experience advisors

These reflections have been produced by lived experience advisors (referred to as 'advisors') and researchers at Samaritans, who have worked together on a research project on how peer support can benefit people who self-harm¹.

The advisors all have direct experience of self-harm and were recruited and paid to work with the research team for the duration of the project. Everyone involved was keen to share their reflections about the benefits of having advisors, including both how the advisors have found the process meaningful and valuable, and the benefits to the work itself from the perspective of the researchers. Our reflections on the benefits, but also the challenges and learnings, have informed the development of a shared set of principles for ensuring meaningful and appropriate engagement for people with lived experience in advisory roles.

We hope it will be useful for professionals and researchers who are working with people with lived experience, as well as anyone with lived experience who is considering engaging in research.

¹ Within the context of this project, self-harm is defined as any deliberate act of self-poisoning or self-injury without suicidal intent. This excludes accidents, substance misuse and eating disorders.



Meaningful engagement benefits people with lived experience

Written by the advisors

Taking on the role of a lived experience advisor with Samaritans has brought a number of professional and personal benefits to us.

Overcoming stigma

Working with people who have similar lived experience has helped us to feel less alone and isolated. It has also created the opportunity for conversations around self-harm with friends and family and for self-reflection, as we have felt more equipped to talk about self-harm.

This has helped some of us in processing trauma and overcoming internalised self-stigma. We have been able to deconstruct and shift some of the negative feelings such as shame and anxiety around self-harm through these conversations with our relatives, friends and ourselves. The team at Samaritans have been supportive throughout, and genuinely considered our welfare, making themselves available for debrief sessions if needed.

Empowerment

We have felt a collective sense of empowerment working with Samaritans. We have been listened to and treated with respect. Our "expertise by experience" has been acknowledged and valued. This project has set a standard of good practice for working with people with lived experience and our learnings could benefit anyone looking to work with people with lived experience for their own projects. It can also be used to challenge any practices that people may face when working as an advisor on other research projects, that fail to involve people with lived experience in a safe and meaningful way. Every advisor has been able to contribute regardless of where we are on our self-harm journey. There has been a sense of purpose and meaning to all our contributions and we have been able to be part of something that will help others who self-harm. The role of being an advisor feels valuable because we have been given a voice in influencing the care and support we receive. Including us in the research helps to ensure that the views of people with lived experience of self-harm are represented, shifting the narrative from "they" to "we".

“ There’s a huge difference in being asked what we want or what could help in terms of support rather than someone saying externally what we are going to get without consultation.

People with lived experience can myth bust, help fine tune language choices and speak with conviction from a first person perspective. ”

Lived Experience Advisor

Professional development

There have been opportunities to develop our skills throughout the course of the project. We have had regular meetings to keep us informed and enable us to offer feedback. We have had the chance to shape research questions, fine-tune language and facilitate workshops. For many of us, these have been new experiences which have helped boost our confidence. We have also had access to a package of Samaritans' training resources online, which include courses on a range of topics such as coaching skills, display screen equipment and stress at work.

Being part of the project as a whole has been interesting and given us an understanding of the research process. We have been able to work with a team who have made us feel respected, listened to and empowered and we have been able to use our experiences to help individuals who may be struggling with self-harm. It has been a positive experience which would both encourage us to contribute to other research projects and recommend to others with lived experience to work with Samaritans.

“ I have felt confident to recommend to other people that working with you would be a good experience for them. ”

Lived Experience Advisor

Meaningful engagement improves our research

Written by the lead researcher

“ From sharing their knowledge to ensuring the language and terminology used within surveys is appropriate, the advisors have shaped this project. They have provided valuable feedback which has helped to shape and inform our thinking about how we can engage people with lived experience across different projects at Samaritans. ”

Samaritans staff member

Shaping how we carried out the research

As the flow chart illustrates, the advisors have shaped the development of all our research materials. This included the questions we asked participants in both the survey and workshops, as well as all the information that participants received as part of the research.

This helped ensure we were using language that was accessible and sensitive, as well as providing an external view on whether questions felt leading. In addition, developing the survey and workshop questions with the advisors ensured that the questions we asked considered the complexity of self-harm based on their own experiences. The group's knowledge of self-harm, mental health and support services helped develop research materials that were fully informed, by both research evidence and real-life experiences.

“ The advisors' shared understanding helped foster open and honest participation, so our conclusions accurately reflected the needs and experience of those who may use peer support for self-harm. Utilising the experiences of the advisors in our research also highlighted key areas of consideration for the Samaritans Research team right from the start of the project. ”

Samaritans staff member

Humanising the subject and supporting a person-centred approach

Working with the advisors has really helped to humanise the topic of self-harm and has been a constant reminder that people are at the heart of this work.

We have had in-depth discussions about some of the difficulties around supporting someone to manage their self-harm. These conversations have really helped widen our view and take into account the nuances around self-harm. For example, we had conversations around the fact that some people might not feel ready to stop self-harming, especially if they don't have alternative coping mechanisms in place. These discussions helped ensure our research wasn't perpetuating assumptions that could act as a barrier to people getting the right support. This was valuable when thinking about the questions we asked and how we asked them, and it will inform the way the final output is written. I believe that this will make the research more relevant to the experience of people who self-harm, and hopefully set a good example around the importance of holding space to consider these complexities.

Improving the research experience for participants

Having the advisors working as part of the team has created a better research experience for the participants. This is not only through advising us on how to improve the research process but helping to carry out the research itself by co-facilitating research workshops. I feel that this helped to create a safe and trusting space, where participants felt able to speak openly about their experience without fear of stigma or judgement.

“ By having the lived experience advisor working on the research, for me made it not only better as it has come from first-hand experience but in the way it is both communicated and delivered, especially the feelings or emotions behind it. ”

Research participant

How to work with people with lived experience of self-harm in a meaningful way

When implemented effectively, lived experience involvement can lead to a wide range of benefits. It improves the quality of research projects and has personal and professional benefits for advisors. However, researchers need to make sure they engage people with lived experience in a safe and meaningful way. Otherwise, lived experience engagement risks being harmful, tokenistic or lacking any benefit to the research.

The principles below have been developed by the advisors and the research team based on the shared experience within this project, for researchers and professionals to consider when working with people with lived experience of self-harm and suicide. These principles are informed by what went well in the project and what could be improved in future projects.

1. Ensure there is a proper application process

Like any other job opportunity, lived experience roles should have a formalised and structured application process. This means that people with lived experience who are considering applying know there is a level of professionalism, that the work is 'real' work and that they are not going to be considered as a box-ticking initiative. Having a professional application process shows people that they will be valued for their skills as well as their life experiences. In addition, all advisors should be paid to acknowledge their time and contributions.

“ Meaningful engagement takes the experience beyond a tick box exercise. At all times, I have felt respected and listened to. ”

Lived Experience Advisor

2. Recruit a diverse range of advisors to represent different perspectives

The experiences of people of different ethnicities, genders, sexualities, socio-economic status and ages varies significantly. Including a range

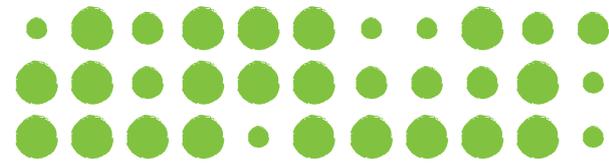
of perspectives can help lived experience engagement be more meaningful. To support this, researchers should consider where and how opportunities are advertised – are they reaching and appealing to a diverse range of people with lived experience? Are there groups of people who may be missing these opportunities and how could they be included? Mitigating against any potential barriers to participation (for example, childcare, IT equipment or accessibility issues) can help to attract a more diverse group of applicants. Where possible, this should include offering flexibility and choice around how and in what ways people would like to engage.

3. Empower advisors to be actively involved at all stages of the project

Advisors should be actively involved throughout the project and be regarded as part of the team, rather than a separate group. Researchers should ensure that everyone has the opportunity to contribute and they should take on board different perspectives. Researchers should account for the resource and time needed to do this well, which should be built into both the timeline of the project and the time of the researchers. By ensuring that advisors feel listened to and respected, lived experience involvement does not feel tokenistic. Advisors also need to be updated regularly during the process to support their involvement. Researchers should provide regular opportunities to give feedback and make changes if needed.

4. Provide additional training opportunities and welfare support

Meaningful lived experience involvement should benefit the advisors as well as the research. This means that researchers should provide appropriate training (eg, for workshop facilitation skills) so that advisors can make meaningful contributions to the project. This also supports the advisors with any personal or career development goals that they may have. As meetings with researchers and advisors often deal with difficult subjects, wellbeing protocols and support packages should be in place.



5. Tailor activities and tasks to the skills of the advisors

All sessions and activities should be well planned and tailored to advisors' skills. Advisors have a wealth of expertise alongside their lived experience, which can be utilised effectively by researchers. This joining of expertise, both of the researchers and the advisors, is meaningful engagement. If activities and tasks are designed with the consideration of the advisor as a whole person and not just as their primary lived experience, cooperative work between researchers and advisors will be meaningful.

“ Although we all have lived experience of self-harm and all come under the heading of 'lived experience advisor', we each have unique experiences within this and we have been treated as individuals. We have been listened to as individuals whose experiences are not all the same. This is meaningful engagement. ”

Lived Experience Advisor



If you have any questions about lived experience engagement at Samaritans, or would like to enquire about any opportunities, please email MyExperience@samaritans.org