

# Challenges and benefits of co-creating suicide prevention research with a learned and lived experience team

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## Background

The aim of this project was to co-create a study exploring people's experiences of talking to their GP about suicide with people who have lived experience of suicidal ideation as part of a programme of research for a PhD.

Volunteers from Expert Citizens with lived experience of suicidal ideation worked with the researcher in developing the study, designing the accompanying participant literature and ethics application.

Expert Citizens are an independent group of people who have all experienced multiple needs – combinations of mental ill health, homelessness, addiction and offending behaviour. They use their experience to give ideas to services of Stoke-on-Trent and nationally to help guide and shape them to improve the care of multiple needs citizens<sup>1</sup>

The process was guided by information provided by INVOLVE.<sup>2</sup>

## What we did

Meetings with the volunteers and the university researcher were held every two weeks, a meeting room was provided by Expert Citizens. Initially these meetings were about giving the team the space to get to know each other and to talk about how we could co-create.

The complexity of suicidal thoughts and feelings were discussed at length and the volunteers used their lived experience to steer the project development, and ensure that the approach was trauma informed. Avoiding the re-traumatisation of participants was the top priority.

The design of two projects was decided upon, one online open-ended qualitative survey, and one that would interview people about their experiences. The ethics applications, participant information and questions were co-created. The online survey is currently in the analysis process and a lived experience volunteer is working with the researcher to add depth to the interpretation of the findings.

The Corona-virus outbreak meant that we had to move our co-creating online in March. We set up a WhatsApp group for staying in touch and support, a private Facebook group for document sharing and we continued to have meetings every two weeks using Skype.

We have written blogs about working together and presented at online conferences.

## The challenges of working this way

- Building trust. Academics were perceived as difficult to work with because of their attitude towards people with lived experience, using unnecessarily complicated language. The volunteers with lived experience thought they would be pre-judged.
- Digital exclusion: the move to online methods to continue the co-creation was challenging. Internet connections and digital literacy were barriers.
- Online meetings are missing 'the human touch' of face-to-face meetings with a cup of tea.
- Time consuming for both the volunteers and the project generally.
- Lack of funding to support activities and to pay public involvement contributors.
- COVID-19 related stress was a barrier for volunteers and for the university researchers.

## The benefits of working this way

- Lived experience involvement meant we approached the study in a trauma informed way
- This methodology had a huge impact on the question and participant information development.
- Different perspectives building richer understanding throughout the analysis process.
- The team provided mutual support for each other.
- Expanding networks. As a result of this partnership both volunteers and the university researcher have been introduced to a range of different organisations and individuals that has benefited both sides.

## Moving forward

- Lived experience volunteers would feel more comfortable and confident working with university researchers in the future.
- University researcher recognises that one size does not fit all for public involvement. Flexibility, creativity and patience are key.

### References

1. About the Expert Citizens - Expert Citizens. <http://www.expertcitizens.org.uk/about-us/>. Accessed August 20, 2020.
2. INVOLVE | INVOLVE Supporting public involvement in NHS, public health and social care research. <https://www.invo.org.uk/>. Accessed August 20, 2020.