

[NIHR Three Research Schools - Seminar Series](#)

How we are involving parent carers of children with special educational needs and disabilities in our research, and what impact that has had on the SPaCE Project

26 April 2023

Speakers

Sharon Foxwell and Annabel McDonald, parent carer co-investigators, and Gretchen Bjornstad, University of Exeter

Summary

It can be challenging to meaningfully involve people with lived experience in epidemiological studies from inception, so this would provide an opportunity to highlight some examples of how these parent carers have shaped the project, including involvement in defining the populations that we include, selecting predictors of mental health outcomes to include in the analyses, selecting the mental health outcomes to focus on, and thinking through the implications of our findings. We are also planning to involve parent carers in innovative dissemination strategies, including leading one of our papers and including specific subsections within the discussion sections of all of our papers for our parent carer co-investigators to describe their reflections on the findings.

Speaker biographies

[Gretchen Bjornstad](#) is Senior Research Fellow at the University of Exeter and leads the 3-schools funded project “An investigation of the prevalence of mental health problems in parent carers in England and pathways to support and treatment”.

Sharon Foxwell and Annabel McDonald are parent carer co-investigators for the study.

Seminar series editor commentary and highlights

In this presentation, Sharon and Bel took the lead in describing their role in the Space project. Of particular significance was the way in which they drew on their personal stories to contextualise their contribution to this specific project, and indeed many previous projects. This was made all the more poignant when Sharon reflected on how she acted as a voice for the community, not to share her specific story. In doing so, Sharon highlights the delicate balance required in the transformation of personal experience into professional expertise.

Unusually, Sharon and Bel are co-investigators on the project and their presentation brings into focus how this provides a platform for influence and how public participants have a wealth of transferable skills and knowledge that they can bring to the research arena. Their presentation raises important questions for all of us around our positionality, how we draw on personal experiences and the implications for our research.

References and resources

[About the SPaCE Project > The SPaCE Project \(exeter.ac.uk\)](#)

Links:

- [Link to YouTube Recording](#)