Closing the Loop

Active involvement of people with lived experience of suicide in suicide research: a Delphi consensus study

---

This series is designed to 'close the loop' between research and policy by translating research evidence into policy directions and advice. These papers review key findings from National Suicide Prevention Research Fund projects and identifies evidence-based policy recommendations. This edition focuses on the inclusion of lived experience in research on suicide prevention.

Research summary

This article identifies recommendations to involve people with lived experience of suicide in suicide research (Krysinska et al 2023). The research sought to address the lack of guidance on lived experience research collaboration and co-production in suicide research. The outcome is a set of guidelines on active involvement of people with lived experience of suicide in research.

The study involved two processes. The authors undertook a systematic literature review, to identify statements about active involvement of people with lived experience of suicide in suicide research. Two expert groups (lived experience and researchers) where then tasked with assessing 114 statements which had been identified in the literature review across 17 categories to pertaining to research processes and procedures. Statements were rated "essential", "important", "don't know/depends", "unimportant" or "should not be included". Those that did not reach consensus ratings of "important" or "essential" were eliminated throughout three rounds. At the conclusion of these rounds, statements retaining 80 per cent endorsement across both groups formed the basis of the guidelines.

This study examined areas where both researchers and participants with lived experience reached consensus on statements to actively involve people with lived experience of suicide in suicide research.

Similarities and differences between lived experience participants and researchers

- The study panellists endorsed statements in the 17 proposed domains (sections), which span across the full research cycle.
- In Round One, both panels agreed on specific "how to" recommendations regarding co-production and the broader co-production values reflected in the statements.
- Two statements endorsed unequivocally by the two panels stipulated that lived experience researchers receive information and support on research ethics, privacy, and confidentiality, and a recommendation for academic researchers to present research data in understandable terms.
- Eight of 126 statements were rejected by both panels., including practical ways Research Institutions can support engagement of lived experience researchers, Representativeness and Diversity of Lived Experience, Collaboration and Co-production, Development of Collaborative Networks, Conduct of Research, Communication and Shared Decision, and Sharing of Power.

- Consistent discrepancies between the lived experience and researcher panels rejected 15 statements , with the lived experience panel consistently endorsing and the researcher panel consistently rejecting statements for researchers to contact their research organization or university to see if they have any funding for lived experience researcher(s) involvement, prior to the grant application being successful, involving more than one lived experience researcher in a research project, and ensuring that findings are available to public contributors, e.g., via open access journals.

- Lived experience panellists endorsed two statements on training around language, which were rejected by research panellists, recommending training in the language and terminology used in research for lived experience researchers and training in lay-friendly research language for academic researchers.

Evidence review

While it has been recognised that lived experience input can enhance suicide research, to-date there have been no formal processes developed to guide lived experience involvement. A lived experience of suicide is defined as "having experienced suicidal thoughts, survived a suicide attempt, cared for someone through suicidal crisis, or been bereaved by suicide" (Roses in the Ocean, 2021). Generally, in suicide research people with lived experience are referred to as consumers.

The active involvement of people who have a personal experience, through their exposure to their own or others' suicidality in service and policy development has been relatively well established (Cluley, 2022; O'Shea, 2019; NMHC, 2016). This has evolved into an emphasis on making these people more central to the process of research, rather than being to, about or for them (NHMRC 2016), while shifting from the assumption that the subject and type of research should be the domain of professional researchers.

Value of lived experience involvement

The active involvement of consumers in health research can have a positive impact on both the research process (Brett, 2014a) and consumers, researchers and communities (Brett, 2014b), including enhanced quality and appropriateness of research questions, more consumer-focused interpretation of research data, and better dissemination and implementation (Brett, 2014a; Gradinger, 2015; Sangill, 2019).

From the perspective of the consumers, involvement can boost confidence and provide additional life skills, empowerment and feelings of value. Researchers can achieve new insights and a greater understanding of their research area and value the views of those who 'live' the topic being investigated (Brett, 2014b; Gradinger, 2015; Malterud, 2020).

On the community level, consumer involvement contributes to a deeper understanding of mental health conditions for researchers and improved knowledge of research for consumers (Brett, 2014b).

On the more challenging side, issues include tokenistic involvement, power struggles, and compromised scientific quality (Sangill, 2019; Malterud, 2020). These can be countered by appropriate training to consumers and researchers, careful planning, and adequate funding (Brett, 2014a).

Policy Implications

Formalising the inclusion of people with lived experience of suicide into research will achieve both greater clarity of expectations of research as well as utilisation of a valuable resource through lived experience.

The guidelines should enable and encourage studies to include lived experience perspectives, enabling a unique qualitative sense to be added.

In terms of policy implications, the findings emphasise the need to embed lived experience within all aspects of suicide research and policy making.

As suicide prevention becomes more entrenched and sophisticated in Australia's Governments, the guidelines should help support better leadership in the utilisation of suicide-specific lived experience.

Policy recommendations

1. That Commonwealth, State and Territory Governments adopt guidelines to incorporate lived experience in codesigning Australian suicide prevention policies.
2. That academic institutions and research agencies adopt the guidelines and embed the voice of lived experience in research on suicide, including evaluation to ascertain meaningful outcomes are met.
3. There should be an increase in investment for research with a lived experience focus and adequate funding and continuity of funding for the National Suicide Prevention Research Fund.
4. That provisions are made for training lived experience representatives to enable meaningful and timely participation in co-design processes.
5. Results and achievements from lived experience co-designed research should be shared widely to improve suicide prevention policy and practice, allowing translation to other research-based policy making throughout Governments and agencies.

Note: recommendations are proposed by Suicide Prevention Australia based on the above research, they are not recommendations of the researchers referenced.

References

Brett JO, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. Health Expect. 2014a;17(5):637–50.

Brett JO, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. A systematic review of the impact of patient and public involvement on service users, researchers and communities. PCORI. 2014b;7(4):387–95.

Cluley V, Ziemann A, Feeley C, Olander EK, Shamah S, Stavropoulou C. Mapping the role of patient and public involvement during the different stages of healthcare innovation: a scoping review. Health Expect. 2022;25(3):840–55.

Gradinger F, Britten N, Wyatt K, Froggatt K, Gibson A, Jacoby A, et al. Values associated with public involvement in health and social care research: a narrative review. Health Expect. 2015;18(5):661–75.

Jorm A. Using the Delphi expert consensus method in mental health research. Aust NZJ Psychiatry. 2015;49(10):887–97.

Krysinska, K; Ozols, I; Ross, A: Andriessen, K; Banfield, M; McGrath, M; Edwards, B; Hawgood, J; Kõlves, K; Ross, V, and Pirkis,J Active involvement of people with lived experience of suicide in suicide research: a Delphi consensus study. BMC Psychiatry (2023) 23:496. https://doi.org/10.1186/s12888-023-04973-9

Malterud K, Elvbakken KT. Patients participating as co-researchers in health research: a systematic review of outcomes and experiences. Scand J Public Health. 2020;48(6):617–28.

National Mental Health Commission. Sit beside me, not above me: supporting safe and effective engagement and participation of people with lived experience. Sydney: NMHC; 2019.

National Health and Medical Research Council and the Consumers Health Forum of Australia. The Statement on Consumer and Community involvement in Health and Medical Research. Canberra: NHMRC; 2016.

O'Shea A, Boaz AL, Chambers M. A hierarchy of power: the place of patient and public involvement in healthcare service development. Front Sociol. 2019;4:38.

Roses in the Ocean. Lived experience of suicide [Internet]. Brisbane Qld: Roses in the Ocean; 2021 [cited 15 November 2021]. Available from: https://rosesintheocean.com.au/lived-experience-suicide.

Sangill C, Buus N, Hybholt L, Berring LL. Service user's actual involvement in mental health research practices: a scoping review. Int J Ment Health Nurs. 2019;28(4):798–815.

Research authors

Krysinska, K; Ozols, I; Ross, A: Andriessen, K; Banfield, M; McGrath, M; Edwards, B; Hawgood, J; Kõlves, K; Ross, V, and Pirkis,J Active involvement of people with lived experience of suicide in suicide research: a Delphi consensus study. BMC Psychiatry (2023) 23:496. https://doi.org/10.1186/s12888-023-04973-9

Suggested citation

Suicide Prevention Australia and University of Melbourne, Sydney, 2024, Closing the loop: Active involvement of people with lived experience of suicide in suicide research: a Delphi consensus study, Suicide Prevention Australia, Sydney. https://www.suicidepreventionaust.org/closing-the-loop-series.

@SuicidePrevAU
@unimelb.edu.au

There are crisis services available 24/7 if you or someone you know is in distress

Lifeline: 13 11 14
www.lifeline.org.au

Suicide Call Back Service: 1300 659 467
www.suicidecallbackservice.org.au

For general enquiries

02 9262 1130 | policy@suicidepreventionaust.org | suicidepreventionaust.org