Involving Young People With Lived and Living Experience of Suicide in Suicide Research

A Delphi Study

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Abstract: *Background:* Research into youth suicide prevention rarely involves young people with lived and living experiences as collaborators. Key barriers include a lack of guidelines or frameworks to inform collaboration, appropriate ethical approval processes, perceived risk, and recruitment. *Aim:* To develop guidelines for involving young people with lived and living experiences in suicide research as collaborators. *Method:* A Delphi expert consensus study was conducted with two expert panels: a youth lived and living experiences panel and a traditionally qualified researcher panel. Items rated as *essential* or *important* using a five-point Likert scale by more than 80% of both panels were included in the guidelines. *Results:* Forty-nine experts completed two consensus rounds. The guidelines are organized as follows: (1) preparation, (2) supporting safety and well-being, (3) evaluating involvement, and (4) tips for young people. *Limitations:* Participants were from English-speaking, Western countries only. *Conclusion:* These world-first guidelines address the unique challenges and opportunities for involving young people with lived and living experiences in suicide research.

Keywords: young people, suicide, lived and living experience, research involvement, guidelines

Suicide is the fourth leading cause of death of young people aged 15–29 years worldwide (World Health Organization, 2021b) and the leading cause of death in young Australians (Australian Bureau of Statistics, 2022). In addition, young people who are exposed to suicide or a suicide attempt are at greater risk of suicide themselves (Hill et al., 2020). The high incidence of youth suicide globally highlights a need for research to develop targeted and effective interventions with and for this cohort.

There is a growing awareness of the benefits of including young people as active partners in mental health research, leading to improved processes, interventions, and outcomes (McCabe et al., 2022). Although the involvement of young people with lived and living experience in suicide prevention research is evolving year by year, there is still a lack of a participation of young people with lived and living experience across the suicide prevention literature due to (Watling et al., 2020) a lack of guidelines or framework on which to base involvement (Bailey et al., 2020), the process of gaining ethics approval, and perceived risk of involving young people with lived and living experiences (Wadman et al., 2019). While two meta-analyses have found no harms among young people as participants in suicide research (Blades et al., 2018; Polihronis et al., 2022), evidence on the impact on young people of being involved more actively in research is limited. One study where young people were involved in the co-design of a suicide prevention social media campaign found that although most young people reported no harm, a small proportion (8/134, 6%) reported feeling suicidal as a result of participation (Thorn et al., 2020).

Guidelines for involving young people in mental health research exist and include practical tips for researchers on how to partner with young people throughout the research process (Aceves-Martins et al., 2019; Heffernan et al., 2017; McCabe et al., 2022; Simmons et al., 2020). However, no equivalent guidelines exist to guide involvement specifically for young people with lived and living experience in suicide research. Guidelines specifically for suicide research with young people are needed given the additional ethical and risk management considerations (Dempster et al., 2022) to guide involvement specifically for young people with lived and living experience in suicide research. Thus, the aim of this study was to develop

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guidelines to help support the involvement of young people with lived and living experience in suicide research.

Methods

Study Design

This was a Delphi expert consensus study (Jorm, 2015), involving three phases: questionnaire development, expert panel formation, and the Delphi consensus process. The study was approved by the University of Melbourne Human Research Ethics Committee (2022-20356-32312-6).

Questionnaire Development

A systematic search of the peer-reviewed and grey literature was conducted to identify specific action items for involving young people in suicide research. Search strategies were informed by the guidelines on Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Page et al., 2021), to ensure the searches were conducted using evidence-based and transparent steps, and were developed in consultation with two specialist academic librarians at the University of Melbourne. The literature searches were supplemented by stakeholder interviews.

Peer-Reviewed Literature Search

Three authors (MW, JR, and MS) developed search terms for the peer-reviewed literature search. Medline, PsycInfo, EMBASE, and CINAHL databases were searched using the multipurpose search (including title, keyword, and abstract fields). The following search string was used: (Adolescen* or teen* or youth or young person or young adult or adolescent) AND (Action or research or Participative or Participatory or Cooperative or Co-operative or Patient and public involvement or Co-research or Codesign or co-design or Youth-led or User-led or Liv* experience or Advoca* or partnership or Consumer involvement or Advisor* or Consumer* or involvement or peer involvement or participation or Engagement or Community-based participatory research or patient advocacy or consumer advocacy or community participation) AND (Suicide or suicide attempt or self-harm or parasuicide or nonsuicidal self-injury or self-injurious behavior).

One author (MW) conducted the peer literature search, which produced 8,528 results. Duplicates were removed, and titles and abstracts of all remaining papers were screened (n = 6,176). Articles that did not meet inclusion criteria were excluded (n = 3,923). The full texts of the remaining 94 articles were assessed for eligibility, resulting in 27 peer-reviewed articles included.

Grey Literature Search

Two researchers (MW and CC) developed the grey literature search strategy. Search terms spanned four concepts: *suicide*, *research involvement*, *youth*, and *guidelines*. The search was conducted across five separate country-specific Google search engines: Australia, the United States, the United Kingdom, New Zealand, and Canada. The grey literature search was conducted across multiple country-specific search engines as grey literature was often region-specific and the search results varied slightly across these engines. For example, government reports from one country may not have been indexed through search engines in another country. Countries chosen were large English-speaking countries, with substantial suicide prevention activities, and in line with previous Delphi studies (Cox et al., 2016; Robinson et al., 2023). The search captured websites, blogs, government reports, unpublished theses, conference papers, posters, and internal research documents. The initial search produced only four records, so two additional broader searches were conducted. One identified guidelines with a broader mental health focus, replacing terms relating to "suicide" with "mental health." The second focused on suicide but did not include youth-related terms. One author (CC) completed the grey search and initial eligibility screening. Individual web results from the first 40 google results were screened for relevance from the heading and first page only, resulting in 10 documents included.

Stakeholder Interviews

Semistructured stakeholder interviews were conducted (MW, LH) with young people with lived and living experience (n = 13) and researchers (n = 14). Researchers were identified from the grey and peer-reviewed literature and from the researchers' existing networks. Young people were eligible if they (1) were aged 15–30, an extended upper range to enable participants to reflect on involvement when they were a young person aged 15–25; (2) lived in Australia, Ireland, Canada, the United States, New Zealand, or the United Kingdom; (3) reported a lived or living experience of suicide and/or self-harm; (4) had participated in a study focused on suicide and/or self-harm; and (5) had not experienced suicidal thoughts on more than half the days in the previous two weeks (assessed by an adapted Question 9 of the PHQ-9; Kroenke et al., 2001). In this study, lived and living experience of suicide is defined as a previous or current experience of suicidal thoughts, attempted suicide, caring for a suicidal loved one, or having been bereaved by suicide (World

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Health Organization, 2021a). Researchers were eligible if they (1) had published peer-reviewed papers in the area of youth suicide and/or self-harm in youth or (2) had involved young people with lived or living experience of suicide and/or self-harm in research activities.

Interview schedules were developed in collaboration with the two youth advisors (EU, AD), and focused on eliciting views and experiences of being involved in suicide research, processes and strategies for facilitating successful partnerships, and ethical considerations. Young people completed a wellness plan containing information about coping and support strategies. Participants under 18 years were required to have parental or guardian consent. Interviews were conducted via Zoom, audio-recorded, and transcribed by a transcription service. Interviews with young people ranged from 30 to 60 min (M = 43.15 min, SD = 10.59), and interviews with researchers ranged from 24 to 97 min (M = 50.14 min, SD = 19.00).

Data Extraction and Synthesis

Peer-reviewed and grey literature items and interview transcripts were manually screened by three researchers (MW, LH, and CC). Data were extracted by two authors (MW and LH) from the peer-reviewed and grey literature and the interview transcripts. Action items were collated into an Excel spreadsheet. A working group comprising four researchers (MW, JR, LH, and CC) reviewed and revised all extracted items. Two youth advisors (EU, AD) participated in selected working group meetings and helped review and revise all youth-specific action items. The working group met regularly to review extracted items, omit irrelevant or repetitive information, and paraphrase items where needed for clarity. This ensured that each item appeared only once, that each item contained only one actionable and unambiguous statement, and that the underlying meaning of all original items was preserved.

Three researchers (MW, LH, and CC) grouped action items according to specific stages in the research cycle (e.g., study design, recruitment, or data collection) or general principles (e.g., access and equity; safety and well-being) to create the survey. The two youth advisors helped identify and group youth-specific action items under a separate theme.

Expert Panel Formation

Two expert panels were formed for the Delphi consensus rounds: a youth lived and living experience panel, hereafter referred to as the youth panel, and a traditionally qualified researcher panel, hereafter referred to as the researcher panel. Eligibility for the youth and researcher panels was the same as for the interviews, described above. Panels were recruited in multiple ways. Three groups were invited to participate in the researcher panel: interview participants, senior authors of included publications, and researchers known to the research team. In addition, for the recruitment of young people, a study advertisement video co-developed with the two youth advisors (EU, AD) was promoted on social media. The researchers aimed to recruit at least 20 individuals per panel, as recommended by Jorm (2015).

Delphi Consensus Process

The Delphi process comprised two survey rounds in which panel members were invited to rate items according to their perceived importance for inclusion in the guidelines using a five-point Likert scale. In Round 1, participants were given the option to suggest additional items, which were included in the Round 2 survey. Items that did not reach consensus in Round 1 were presented again in Round 2. Items rated as "essential" or "important" by >80% of participants across the two panels were included in the final guidelines, and items were excluded if rated <70% across both panels after the second round.

Youth interview participants and panel members were reimbursed AU$ 30 per hour; researchers were given an AU$ 50 gift voucher on completion of both questionnaires.

Results

Participant Characteristics and Participation Rates

Researcher panel members (n = 28) were located across Australia (53.57%), Canada (3.57%), Ireland (3.57%), New Zealand (3.57%), the United States (10.71%), and the United Kingdom (25.00%). Years working in suicide research ranged from two to 40 (M = 8.90, SD = 9.16). Over half held a doctoral qualification (55.55%), with the remaining holding Masters (18.51%), Honors (3.70%), Bachelor (7.41%), Diploma (7.41%), or Graduate Certificate (7.41%). In total, 10 of the 28 (35.71%) members of the research panel had been interviewed as part of the stakeholder interviews.

The youth panel (n = 27) comprised 17 who identified as female (61%), three as male (11%) and seven as nonbinary or gender diverse (25%). M_{age} was 22.89 years (SD = 3.66, range = 17–30). Over half reported a sexuality other than heterosexual (n = 16, 59.26%). They were predominantly located in Australia (n = 20, 74.07%), with two in Canada

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(7.41%) and five in the United Kingdom (18.52%). Six (23%) reported experiencing suicidal ideation on several days in the previous fortnight, eight (31%) reported suicidal ideation on one or two days, and 12 (46%) reported no recent suicidal ideation. In total, 10 of the 27 (37.04%) members of the youth panel had been interviewed as part of the stakeholder interviews. The participation rate of panel members completing the two consensus rounds was high (49/55, 89.09%; see Electronic Supplementary Material 1 [ESM 1] for completion rates of individual panels).

Rating of Action Items

ESM 2 shows a flowchart of the number of items included, excluded, and re-rated during the two questionnaire rounds. The panels rated 467 items in total (369 in Round 1 and 98 new items in Round 2 based on participant feedback in Round 1). A total of 231 (49.46%) individual items were included in the guidelines. ESM 3 shows the percent rated as essential or important for every item rated by the panels in both rounds. The correlation between the two panels was strong in Round 1 ($r = .83$, $p < .01$) and moderate in Round 2 ($r = .65$, $p < .01$).

At the completion of the Round 2 questionnaire, all included items were collated into a final set of guidelines (see ESM 4). While all items endorsed were included, many were collapsed into a single item or edited to improve readability. The final guidelines are divided into four main sections: (1) preparation, which includes staffing, recruitment and onboarding, training, and creating safe environments; (2) supporting safety and well-being, including safety protocols, individual well-being plans, providing general support, and responding to distress or suicide risk; (3) evaluating involvement, including asking young people for feedback regularly on the impact of their involvement on their well-being and on the research output; and (4) tips for young people, which are recommendations for actions young people can take to have a safe and positive experience.

Discussion

This study aimed to develop evidence-informed guidelines to support the involvement of young people with lived and living experience in suicide research. These are world-first guidelines and provide clear and practical recommendations for the safe and effective involvement of young people with lived and living experiences in suicide research. These guidelines are not intended to be a rule book, and their usage will depend on a range of factors including the study type and setting, the expertise of the research team, community partners, and the needs of the young people themselves.

Given the sensitive nature of the topic and concerns identified previously by researchers (Wadman et al., 2019), it is unsurprising that a large proportion of the guidelines cover safety and well-being. Sections 1 and 2 of the guidelines include guidance on safety protocols, distress identification and management, and strategies for providing general support throughout involvement. They encourage a personalized and collaborative approach, where safety strategies are iteratively negotiated, so they meet the needs of each individual. This acknowledges that well-being is not static and may shift over the period of involvement. Prebeg et al. (2023) recently proposed that authentic engagement of young people in mental health research should be reconceptualized around relational empowerment, fluidity, and flexibility. Furthermore, while ensuring inclusive and adaptable involvement is relevant for all young people, it is particularly important for young people who may have additional support needs (Bradbury-Jones et al., 2018). This emphasis in the guidelines also reflects the need for a trauma-informed approach in suicide research with young people, integrating key principles such as safety, transparency, collaboration and mutuality, and empowerment, voice, and choice (Bendall et al., 2021; Epp et al., 2022; Quijada et al., 2021).

Section 3, evaluating involvement, recommends short-term and long-term evaluation on the impact of involvement on young people's well-being, including suicidal thoughts. This should occur in partnership with young people. Additionally, the guidelines recommend evaluating the impact of involvement on the research itself. A recent review on involving young people in mental health research found no formal or longer-term assessment of the impacts of youth involvement on research and identified a need for more robust evaluation (McCabe et al., 2022). Rigorous evaluation of the impact of young people's involvement in suicide research is particularly lacking.

The final section of the guidelines provides tips for young people to help them advocate for a positive and safe experience. These items encourage young people to have agency over their experience, consider and mitigate potential stressors, and proactively advocate for appropriate support. Youth participatory research is conceptualized around recognizing young people as experts and reducing inherent power imbalances common in traditional research. However, guidelines and research for young people's involvement in research to date have focused on the actions that researchers can take (McCabe et al., 2022). The guidelines developed in the current study address this gap by suggesting actions that young people themselves

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can take. They reflect those in recently published guidelines for involving adults in suicide research, which included actions that people with lived experience can take to enable self-care and autonomy in their involvement (Krysinska et al., 2023).

Items that were endorsed for inclusion by only one panel provide an insight into a fundamental difference in the preferences of young people and researchers. The majority of young people wanted clinicians to be involved and have an active role in supporting them. Researchers' lack of endorsement for this may be due to a general lack of resources or access to include clinicians as part of the research team. Indeed, previous research has highlighted lack of resources as a major barrier for involving young people in mental health research (Faithfull et al., 2019), suggesting that adequate and appropriate resourcing is an urgent need for supporting researchers with these activities. Alternatively, it may be that researchers do not consider a clinician relevant to their research, for example, if their research is not conducted in clinical settings. From a young person's perspective, they may believe that providing support is a specialized skill and should not necessarily be expected of researchers. Future qualitative research is needed with young people and researchers to explore these findings further. Despite these conflicting views, the final guidelines include strategies researchers can implement to create a safe environment and provide appropriate support to young people even if a clinician is not part of the team.

Items that did not reach consensus raise interesting considerations for researchers. Items regarding whether young people with current or recent suicidal thoughts should be involved in suicide research did not reach consensus. Typically, young people with current or recent suicidal thoughts are excluded from research, with the potential exception being those receiving clinical care, the assumption being that participation may increase risk. However, suicidal thoughts are often dynamic (Gee et al., 2020), and young people may still have capacity to participate safely. Therefore, the possibility of active involvement in research, even for those experiencing suicidal thoughts, warrants exploration.

Strengths and Limitations

A key strength of this study is the youth involvement. Young people with lived and living experience who had previously been involved in suicide research directly informed the guidelines via interviews and panel participation. This was particularly important given that the voices of young people who have been involved in suicide research have generally been absent from the academic literature. Additionally, two youth advisors were employed throughout the project, providing an essential lived and living experience lens to the entire study. Another strength was the gender and sexual diversity of the youth panel. Gender and sexuality diverse young people are disproportionately affected by suicide (Miranda-Mendizábal et al., 2017; Perez-Brumer et al., 2017), so their involvement in research is particularly important. The high retention rates of both panels increase the potential validity and generalizability of the findings and guidelines.

In terms of limitations, participants were from only English-speaking individuals and in Western countries, so there is likely a lack of cultural diversity and as a result the guidelines may not reflect the needs of all young people. To our knowledge, there were also no participants from First Nations communities. Given there is evidence to suggest culturally diverse and First Nations young people have higher rates of self-harm, suicide attempts, and suicide (Basu et al., 2022), there is a need for further research into how to better involve young people from these communities in research. Another limitation of this study is the Delphi method used to develop the guidelines. The requirement for items to have reached consensus from both panels means that important perspectives, nuances, and needs may not be fully represented in the final guidelines. For instance, the guidelines are inclusive of all types of lived and living experience in suicide and thus have the potential to be relevant and useful to a wide range of suicide research studies. However, implementing these guidelines may require tailored approaches and applications of the guidelines for specific types of lived and living experience or populations. Finally, while it was a requirement for young people interviewed and on the youth panel to have lived or living experience of suicide, we did not collect data on the type of lived experience. Thus, the final guidelines are not exhaustive, and researchers are encouraged to consider how they may be adapted to suit the study and the specific needs of the young people they are involving.

Conclusions

These guidelines address the unique challenges and opportunities for involving young people with lived and living experience in suicide research and provide a much-needed framework for researchers to prepare, support, and evaluate involvement. They also provide youth-friendly, practical advice to encourage young people to help them ensure a safe and positive experience. The hope is that these guidelines will provide researchers with greater confidence and willingness to involve young people with lived and living experience in research activities, as well as

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improved confidence and willingness of young people to participate in suicide research activities.

Electronic Supplementary Material

The electronic supplementary material is available with the online version of the article at https://doi.org/10.1027/0227-5910/a000938

ESM 1. Round 1 and Round 2 questionnaire participation rates by panel.

ESM 2. Flowchart of items included, excluded, and re-rated across the two questionnaire rounds.

ESM 3. Delphi items included, excluded, and re-rated by youth and researcher panels.

ESM 4. Guidelines for involving young people with lived and living experience of suicide in suicide research.

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