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## **A scoping review of the international evidence-base for developing guidelines for participants and researchers, in conducting research on suicide and self-harm prevention. The evidence for guidelines for suicide research participants and researchers**

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# A scoping review of the international evidence-base for developing guidelines for participants and researchers, in conducting research on suicide and self-harm prevention.

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## Abstract

**Objective:** To examine the international evidence-base for developing guidelines for participants and researchers, for conducting research on suicide and self-harm prevention.

**Introduction:** The development of guidance materials regarding suicide research can be beneficial for researchers and help both ethics committees and researchers review and conduct suicide-related research. Improved understanding of the ethical considerations, including dialogue between researchers and ethics committees, should sustain and improve the quality of suicide prevention research, a prerequisite to tackle increasing suicide mortality and presentation of self-harm. However, no guidelines specific to suicide and self-harm research exist to inform this process.

**Inclusion criteria:** Empirical studies published in the last ten years and in the English language that assess and report guidance and ethical considerations for the research process in relation to self-harm and suicide, attempted suicide and death by suicide with a specific focus on the welfare and/or support for researchers and/or families participating in this research will be included.

**Methods:** APA PsychArticles, MEDLINE, CINAHL and Web of Science databases will be searched. Following this, all identified citations will be collated and uploaded into Rayyan (Ouzzani et al., 2016) and the full text of selected citations will be assessed in detail against the inclusion criteria. Data will be extracted from papers included in the scoping review by two or more independent reviewers using a data extraction tool developed by the reviewers. Extracted data will be synthesised and presented in diagrammatic or tabular form in a manner that aligns with the objective of the scoping review.

## Introduction

The aim of this review is to gather and examine existing empirical evidence that captures the experiences, risks, and benefits of taking part in suicide prevention research, for both researchers and participants. The findings of the review will inform the development of guidelines for conducting suicide prevention research, considering wellbeing, alongside scientific analytical standards. Considerations of both participants and researchers are included given that they would be expected to overlap and interact, in the spirit of collaborative co-production.

The involvement of people with lived experience of suicide in research is important (O'Connor et al., 2018; Suomi et al., 2019) and provides a rich source of information about the lives and deaths of those who have

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died by suicide. This can contribute to our understanding of the suicidal process and to strategies aimed at preventing such deaths in the future (Simkin et al. 2012). Andriessen et al. (2018) found that most people bereaved through suicide evaluated research participation as a positive experience but providing care for participants is essential, including ensuring the availability of information and support resources during and after a study. In addition, only a small proportion of individuals reported an increase in their urge to self-injure or level of suicide intent (Ward-Ciesielski and Wilks, 2020) however, Biddle et al. (2013) highlight distress would be transient and outweighed by a desire to contribute to research.

For researchers, studying suicide involves collecting, examining, and processing a variety of difficult and potentially distressing data and often involves directly interacting with people affected by suicide. This process can be challenging as well as rewarding and inspiring (Andriessen, 2019). Researchers can experience 'pain by proxy' often characterised by 'overidentification' with participants or records of people who have died (Finchman et al., 2008). This can have a profound impact on the researcher, which would be mitigated by level of experience and employment support. Guidelines could therefore support employers to uphold their legal 'duty of care' toward research employees. Secondary to this concern, long-lasting impacts on researchers will potentially have an influence on the quality of the research outputs, raising further circular ethical considerations.

Additionally, the development of guidance for conducting suicide research would be a beneficial source of guidance for ethics committees who may not have experience of this specialist field, and as a result may be overly cautious about granting permissions (Barnard et al., 2021). Guidelines could support an improved dialogue between researchers and ethics committees, to sustain and improve the quality of suicide prevention research, which is a prerequisite for tackling increasing suicide mortality (Andriessen et al., 2019). However, no such guidelines exist to inform this process (NHMRC, 2016; NMHC, 2019).

This review will examine the international evidence base for developing guidelines for participants and researchers, in conducting research on suicide and self-harm prevention. The objective of this scoping review is therefore to seek empirical evidence to support the development of guidelines to enhance the safety of researchers and participants in the field of suicide prevention.

## Review question

What is the international evidence-base for developing guidelines for participants and researchers, when conducting research on self-harm and suicide prevention?

## Keywords

Suicide; Self-harm; Guidelines; Participants; Researchers; Scoping review.

## Eligibility criteria

### Inclusion Criteria

- Empirical studies that assess and report the research process in relation to self-harm and suicide, attempted suicide, and death by suicide, with a specific focus on the welfare and/or support for researchers and/or families participating in this research.

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- Empirical studies that focus on the ethical considerations for researchers and/or families participating in research that relates to self-harm and suicide, attempted suicide, and death by suicide.
  - Published in the last 10 years to capture the most contemporary cultural experiences of participants and researchers.
  - Published in the English language, due to lack of resources for translation.
  - No restrictions on country of origin.

## Exclusion Criteria

- Empirical studies not pertaining to self-harm and suicide, attempted suicide, and death by suicide.
- Empirical studies not reporting on the impact of research on the researcher, or the participant.
- Opinion pieces, commentaries, editorials.
- Grey literature that offers non-empirical evidence will be excluded, in favour of reviewing only the most robust scientific content and to subsequently indicate any gaps in knowledge.

## Concept

This scoping review will include empirical studies that report on research in relation to suicide and self-harm with a focus on the welfare of, or support for researchers and families and friends who may be participating in those studies.

## Context

This review will consider peer-reviewed empirical studies in any area of healthcare science, including public health, psychiatry, social sciences, and psychology. As this is an international review, work carried out in all geographical locations will be considered. However, as only articles written in English and published in the last ten years will be included, this may create cultural limitations and publication bias.

## Types of Sources

This scoping review considers observational as well as experimental study designs including randomised controlled trials, non-randomised controlled trials, cross-sectional surveys, and interrupted time-series studies. Qualitative studies will also be considered including realist evaluations and action research. In addition, systematic reviews and meta-analysis that meet the inclusion criteria will also be considered.

## Methods

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews (Peters et al., 2015).

## Search strategy

The search strategy will aim to locate both peer-reviewed and published empirical studies. An initial limited search of APA Psych, MEDLINE, and CINAHL was undertaken to identify articles on the topic. Keywords contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles were used to develop a full search strategy for APAPsychArticles, MEDLINE, CINAHL and Web of Science (see *Appendix I*). The search strategy, including all identified keywords and index terms, will be adapted for

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each included database and/or information source. The reference list of all included sources of evidence will be screened for additional studies.

Studies published in the English language and studies published since 2011 will be included. The search period will be limited to the English language and studies published in the last 10 years to capture the most up to date evidence on this topic.

### Study/Source of Evidence selection

Following the search, all identified citations will be collated and uploaded into Rayyan (Ouzzani et al., 2016) and duplicates will be removed. Titles and abstracts will then be screened by two or more independent reviewers utilising the Rayyan platform (Ouzzani et al., 2016) for assessment against the inclusion criteria for the review. The remaining full text of selected citations will be assessed in detail against the inclusion criteria by two or more independent reviewers. Reasons for exclusion of sources of evidence at full text will be recorded and reported. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion, or by arbitration by an additional reviewer(s). The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) flow diagram (Moher et al., 2009).

### Data Extraction

Data will be extracted from papers included in the scoping review by two or more independent reviewers using a data extraction tool developed by the reviewers. The data extracted will include specific details about the author(s), year of publication, country of origin, aims, study design, participants and their characteristics, methods used, outcomes, recommendations, and limitations relevant to the review question.. A draft extraction form is provided (*see Appendix II*). The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included evidence source. Modifications will be detailed in the scoping review. Any disagreements that arise between the reviewers will be resolved through discussion, or with an additional reviewer. If appropriate, authors of papers will be contacted to request missing or additional data, where required.

### Data Analysis and Presentation

Extracted data will be presented in diagrammatic or tabular form in a manner that aligns with the objective of the scoping review. Results will be organised under the categories that relate to the scoping review question, including year of publication, countries of origin, aims, design, population, methodology, outcomes, specific recommendations/suggestions, and any reported limitations. A narrative summary will accompany the tabulated results and will describe how the results relate to the review's objective. This will provide insight into the international evidence-base for developing guidelines for participants and researchers, in conducting research on self-harm and suicide prevention.

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## Conflicts of interest

There is no conflict of interest in this project.

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## Appendices

### Appendix I: Search strategy

1. Participants or interview\* or research\* or methodology or experience\* or involvement or study
2. Research\* or interview\* or study ior qualitative or quantitative or survey or "lived experience"
3. Suicide\* or "self-harm" or "self-injury"
4. 1 and 2 and 3
5. Ethic\* or methodology or supervision or "secondary trauma" or safety or facilitate\*
6. 1 and 2 and 3 and 5
7. Suicide or "self-harm" or "self-injury"
8. 1 and 2 and 7
9. 1 and 7
10. "Suicide\* research\* or "self-harm research" or "self-injury research" or "suicide ideation research" or "research into suicide" or "research into self-harm or "research into self-injury" or "research into suicide ideation"
11. 1 and 10
12. Limit 11 to journal article and English and last 10 years
13. Suicide\* or "self-harm" or "self-injury"
14. Research
15. 1 and 13 and 14
16. Exp Methodology/
17. Exp Suicide/
18. 1 or 16
19. 10 or 17
20. 18 and 19

Appendix II: Data extraction instrument

<b>Authors Name and year</b>	Country of origin	Aim(s)	Design (e.g., RCT, qualitative, cross sectional, case control)	Sample (incl. number of males/females & nature of disabilities)	Methods (e.g., names of questionnaires, topics/questions included at interview)	Outcome(s) that support the welfare of participants and researchers (e.g., focus of paper, how classified...)	Specific Recommendations/ suggestions	Limitations
<b>Pearson et al., 2001</b>								