GUIDELINES FOR INVOLVING YOUNG PEOPLE WITH LIVED AND LIVING EXPERIENCE OF **SUICIDE IN SUICIDE RESEARCH** 



MIN

LUTION NON IN M NNDREVO

POLITION IN

UTION IN

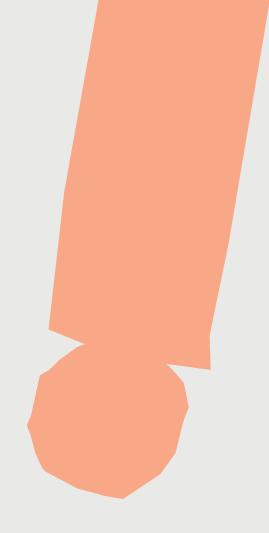
EVOLUTION

VOLUTION

BLUTION

olution

LUTIO



#### ACKNOWLEDGEMENT

This project is funded by the National Health and Medical Research Council (NHMRC) via the YOUTHe Centre of Research Excellence.

We thank the following people for their advice and feedback about the Delphi process: Eleanor Bailey, India Bellairs-Walsh, Sam McKay, Tharindu Jayadeva, and Alexandra Boland. We also extend thanks to Samuel Hockey for reviewing these guidelines and providing invaluable insights and suggestions.

We thank the following panel members for their contribution to the development of these guidelines: Professor Di Bailey, Mikaela Basile, Vanessa Bennett, Tara L. Bruno Associate Professor of Sociology, Dr Sadhbh Byrne, Min Chong, Mr Shannon Dance, Dr Lindsay Dewa, Sharla Eddleston, Bronwen Edwards, Jo Farmer, Dr Sarah-Jane Fenton, Rebecca Fraser, Jacinta Freeman, Laura Grattidge, Kristen Haddad Ph.D., Vicki Harrison MSW, Sarah Hetrick, Stephanie Hillman, Charlie Ho, Maddison Huckel, Sam Huntley, Dr Laura Kennedy, Dr Sarah Knowles, Karolina Krysinska Ph.D., Robin Lindquist-Grantz, Mary Mansilla, Martina McGrath, Lizzie Mitchell, Tomasina Model, Katherine Poulton, Danielle Rifahi, Pluto Rosner, Pooja Saini, Idrees Saleem, Madeline Sampson, Judah Teo, Rachel Thomson, Ms Pinar Thorn, Mx Rosie Webling, Makayla Weido Social Service Worker, Kay Wilhelm. Dr A. Jess Williams, Michael Wilson

We would also like to thank all those interviewed and the panel members who completed one round of the Delphi consensus study or opted not to be acknowledged.

#### © 2023 Orygen

This publication is copyright. Apart from use permitted under the Copyright Act 1968 and subsequent amendments, no part may be reproduced, stored or transmitted by any means without prior written permission of Orygen.

Suggested citation: Marianne Webb, Charlie Cooper, Laura Hemming, Alexander Dalton, Emily Unity, Magenta Simmons, Sarah Bendall, and Jo Robinson. Guidelines for involving young people with lived and living experience of suicide in suicide research. Melbourne: Orygen, 2023.

**Disclaimer:** This information is provided for general educational and information purposes only. It is current as at the date of publication and is intended to be relevant for all Australian states and territories (unless stated otherwise) and may not be applicable in other jurisdictions. Any diagnosis and/or treatment decisions in respect of an individual patient should be made based on your professional investigations and opinions in the context of the clinical circumstances of the patient. To the extent permitted by law, Orygen will not be liable for any loss or damage arising from your use of or relance on this information. You rely on your own professional skill and judgement in conducting your own health care practice. Orygen does not endorse or recommend any products, treatments or services referred to in this information.

Orygen acknowledges the Traditional Owners of the lands we are on and pays respect to their Elders past and present. Orygen recognises and respects their cultural heritage, beliefs and relationships to Country, which continue to be important to First Nations people living today.



# **CONTENTS**

# FOREWORD FROMTHE YOUTH ADVISORS4

## INTRODUCTION

GUIDELINE DEVELOPMENT METHOD	6
GUIDELINE USAGE	6
TERMINOLOGY	7

5

8

#### GUIDELINES FOR INVOLVING YOUNG PEOPLE WITH LIVED AND LIVING EXPERIENCE OF SUICIDE IN SUICIDE RESEARCH

1.	PREPARATION	8
1.1	STAFFING	8
1.2	RECRUITING YOUNG PEOPLE	9
1.3	ONBOARDING YOUNG PEOPLE	10
1.4	TRAINING	10
1.5	CREATING SAFE ENVIRONMENTS	11
1.6	GROUP ACTIVITIES	12
1.7	STUDY PLANNING AND ETHICS APPROVAL	13
1.8	INVOLVING YOUNG PEOPLE IN DATA ANALYSIS	13
1.9	DISSEMINATING FINDINGS	13
2.	SUPPORTING SAFETY AND WELL-BEING	14
2.1	SAFETY AND WELL-BEING PROTOCOLS	14
2.2	INDIVIDUAL WELL-BEING PLANS	14
2.3	PROVIDING GENERAL SUPPORT	15
2.4		
	ROUTINE CHECK-INS	15
2.5	ROUTINE CHECK-INS RESPONDING TO DISTRESS OR SUICIDE RISK	15 16
	RESPONDING TO DISTRESS OR SUICIDE RISK COOL DOWN	16
2.6	RESPONDING TO DISTRESS OR SUICIDE RISK COOL DOWN	16 17









# FOREWORD FROM THE YOUTH ADVISORS

As young people with lived and living experience of suicide, we know how important it is to involve our expertise in suicide prevention research. However, all too often, research tends to leave lived and living experience in the dark.

We're excited to be part of a project that's taking a crucial step in the right direction - creating guidelines that help ensure best practice standards for involving lived and living experience in youth suicide prevention research.

We're incredibly proud of what we've achieved through our diverse and passionate team. We believe these guidelines will shape the future of youth involvement in suicide prevention research and beyond. We hope that researchers will use these guidelines to ensure they amplify our voices as young people with lived and living experience in meaningful, effective, and safe ways.

Our work on this project is just the beginning. We believe it can serve as a model for future research projects, and we're committed to continuing to contribute to this critical field. We're excited to be part of a movement that's working to create meaningful change, where research is done "with" or "by" us, not "to" us.

With hope, Alex Dalton (he/him) and Emily Unity (they/them)



# INTRODUCTION

Suicide is the fourth-leading cause of death of young people aged 15 to 29 years worldwide, after road injury, tuberculosis, and interpersonal violence (1). In addition, young people exposed to suicide or a suicide attempt are at risk of suicide or suicide attempt (2). However, despite the prevalence and risk of suicide for young people, there is limited evidence regarding interventions that work for suicide-related behaviours in young people (3).

Ensuring that interventions meet the population's needs requires the involvement of people with lived and living experience in research, where research is conducted 'with' or 'by' rather than 'to', 'about' or 'for' them (4). Involving young people in mental health research improves data collection and analysis and leads to more relevant findings and dissemination to academic and stakeholder audiences (5).

There is an increasing expectation and requirement for all suicide prevention activities to be informed by the expertise of those with lived experience (6-8). However, very few research studies have involved people with lived and living experience of suicide in the development of interventions for suicide prevention (9), and few suicide researchers are partnering with young people (10). In addition, researchers report key barriers to involving young people in suicide research as a lack of guidelines on which to base involvement, the process of gaining ethics approval and difficulty addressing perceived risk and recruitment (11). A range of evidence-based guidelines have been developed for supporting the involvement of young people in mental health research (5,12-15). However, in suicide research activities, there are currently no evidence-based guidelines on safely and effectively involving young people with lived and living experience of suicide. Given the sensitive and complex nature of this research, concerns about the potential for adverse effects, and the lack of current youth involvement, there is an urgent need for best practice guidelines for actively involving young people with lived and living experience in suicide research.

In order to address this need, Orygen has developed these guidelines with two international expert panels: suicide researchers and young people with lived and living experience of suicide. The first three sections of the guidelines focus on how researchers can prepare to involve young people in suicide research, support safety and well-being, and evaluate involvement. The final section includes **tips for young people** on actions to promote well-being and reduce the potential for distress during involvement, as well as safely communicating about suicide, and ensuring young people have appropriate supports in place.

The hope is that these guidelines will provide researchers worldwide with greater confidence and willingness to involve young people with lived and living experience of suicide in research activities, as well as improved confidence and willingness of young people to participate in suicide research activities. Ultimately it is hoped that these guidelines will lead to improved support and outcomes for young people at risk of suicide.

## **GUIDELINE DEVELOPMENT METHOD**

We used a Delphi expert consensus method to develop these guidelines. The Delphi method surveys experts' opinions via questionnaires to establish group consensus about best practices in a particular domain (6). It comprised four key stages:

- 1. systematic literature search;
- semi-structured interviews with young people with lived and living experience of suicide and researchers who had involved young people in suicide-related research;
- 3. questionnaire development; and
- 4. the Delphi consensus process, where expert panels of young people and researchers rated their agreement with statements in the questionnaire for inclusion into the final guidelines presented in this report.

The eligibility criteria were the same for both the interviews and panels. Young people were required to: be aged 15 to 30 years; currently live in Australia, Ireland, Canada, United States of America, New Zealand, United Kingdom; identify as having lived and living experience of suicide and/or self-harm; have participated in a research study focused on their lived or living experience of suicide or self-harm; and, had not been bothered by suicidal thoughts on more than half the days in the past two weeks. Researchers were required to: have published peer-reviewed papers in the area of youth suicide, youth suicide prevention and/or self-harm in youth, or have involved young people with a lived experience of suicide and/ or self-harm in their research; and, currently live in Australia, Ireland, Canada, United States of America, New Zealand, United Kingdom.

## **GUIDELINE USAGE**

The recommendations in these guidelines reflect the items rated as essential or important to include by greater than 80% of both expert panels; therefore, the guidelines are not an exhaustive list.

Researchers are encouraged to use their professional judgment when applying these guidelines, considering contextual factors such as the study type and setting, the expertise of the research team, and available resources. Researchers are also encouraged to use these guidelines in conjunction with other best practice principles and guidelines for involving young people in mental health research, which provide advice regarding general principles of youth engagement, considerations for budgeting for involvement, and examples of research projects involving young people (e.g., (14,17)).

It is also important that researchers acknowledge that young people are not a homogenous group. Researchers should consider the socio-cultural and historic contextual factors and needs of specific and priority populations, such as young people that identify as First Nations, LGBTQIA+, disabled, neurodiverse, culturally and linguistically diverse, or any intersectional experiences.



## TERMINOLOGY

The following terms are used throughout the guidelines, and their definitions in the context of this work are as follows:

- Activity is any way in which a young person is involved in research. This can include consultation via a meeting, participating in a co-design workshop, reviewing documents, or co-analysing data.
- **Clinician** is a mental healthcare professional that may support a young person, including psychologists, counsellors, therapists, psychiatrists, social workers, occupational therapists, doctors, and nurses.
- **First Nations people** are people descended from the first inhabitants of a country.
- Involvement means contributing to the design, conduct, or dissemination of research, where research is carried out 'with' or 'by' young people (for example, co-production or co-design) rather than 'to', 'about' or 'for' them (for example, being interviewed or completing a survey as a participant of a study).
- LGBTIQA+ stands for Lesbian, Gay, Bisexual, Transgender, Intersex, Queer, and Asexual. The '+' symbol represents all other sexualities, sexes, and genders not defined by these letters.
- Lived and living experience refer to the expertise gained by someone through experiencing any one or more of the following: suicidal thoughts or feelings (this experience may be previous or ongoing); self-harm (with or without intent to die); survival of a suicide attempt; caring for someone who has been suicidal; and loss of someone they know or care about to suicide.
- **Researcher** refers to someone employed professionally with expertise and expert knowledge in suicide and suicide prevention.
- **Suicide** refers to the spectrum of suicidal thoughts, feelings and behaviours that relate to intentionally ending one's own life.
- Suicide attempt is an act where a person harms themselves, intending to die.
- **Self-harm** is a non-fatal act where someone injures or poisons themselves intentionally, with varying motives, including the wish to die.
- Young people, unless otherwise stated, refers to those aged 15 to 25 years who are involved in conducting research studies, not as participants (for example, youth advisory group, data analysis).
- Safety protocols are designated, documented procedures for promoting young people's wellbeing and safety throughout their involvement and preventing, identifying, and managing suicidal distress in the context of youth involvement in suicide research activities.



# GUIDELINES FOR INVOLVING YOUNG PEOPLE WITH LIVED AND LIVING EXPERIENCE OF SUICIDE IN SUICIDE RESEARCH

## **1. PREPARATION**

Meaningful and effective involvement of young people in suicide research requires appropriate preparation across key areas, including staffing, recruitment, training and creating a safe environment.

## 1.1 STAFFING

When involving young people in suicide research, it is essential to consider the staffing resources necessary to facilitate safe, supportive, and meaningful involvement. Staffing needs, particularly whether a mental health clinician (hereafter referred to as clinician) is needed to support involvement, may vary depending on factors such as whether the research is in a clinical setting, funding, the type of study and the experience and skills of the researchers and young people.

### **General staffing**

- Ensure at least one research team member has experience talking to young people about suicide.
- Have a nominated person on the team for young people to communicate with about their safety and well-being.
- Ensure multiple staff members are present at activities (for example, to allow for staff members to leave an activity to attend to young people who need additional support or become distressed).
- If deemed unnecessary, or not possible, to have a clinician on the research team, partner with community organisations that can support young people during their involvement (for example, recruit young people through a local mental health service so that they have an external support network).

### Role of any clinicians on the team

- Develop safety protocols that clearly outline steps to support young people's well-being, including specific measures for preventing and responding to distress.
- Clearly communicate the role and availability of the clinician to young people and the whole research team.
- The clinician's role should include support and scaffolding for researchers on the team as well as youth participants. This might include helping to manage complex scenarios and young people's well-being.

## **1.2 RECRUITING YOUNG PEOPLE**

The following section contains items relevant for researchers when recruiting young people for involvement in suicide research. It does not refer to the recruitment of young people as research subjects or study participants.

#### **Recruitment process**

The process of setting up safe and meaningful opportunities for youth involvement in suicide research should begin before young people come into contact with your team. It's important to give careful thought to how you will equitably recruit diverse young people whilst also ensuring there are mechanisms in place to enable a safe and supportive environment for participation.

- The research team should hold primary responsibility for recruiting young people.
- Recruit young people through a multi-step process (for example, consisting of more than one interaction with the research team, such as via an expression of interest form, as well as an informal or formal telephone or video conferencing conversation/interview).
- Specify what types of lived and living experience (if any) you are looking for on the project or study (for example, being bereaved by suicide, personal experience of suicidal thoughts or feelings, experience as a carer).
- Be open and honest with young people about potential risks and safety measures that will be put in place to support their involvement.
- Inform young people of the potential benefits of being involved in suicide research.
- Follow up with young people if they flag in the recruitment process that they have current suicidal thoughts or behaviours (for example, provide contact details for telephone/online support services).
- Where appropriate, recruit young people through community organisations (including youth organisations) to ensure that those involved have existing support networks.

#### Helping young people to consider their 'readiness' for involvement in suicide research

'Readiness' refers to a young person's subjective feeling of being emotionally and practically prepared to engage in research activities. Every young person's lived and living experience is unique and multi-dimensional, and their 'readiness' depends on a range of factors. Therefore, the decision-making process around readiness will differ for each young person and may change over time.

- In collaboration with the young person and any clinician on the team, the researcher should be responsible for determining if a young person is well enough to be involved.
- Consult with the young person to collaboratively consider whether they are well enough and feel ready to be involved.
- Follow up with the young person directly if you are concerned that the young person may not be well enough and/or is not ready to be involved.
- Inform young people that involvement in research is not a replacement for professional support.
- If including young people with current (for example, within the last two days) suicidal thoughts or feelings, or self-harm, you should require young people to have both informal supports (for example, friends or family) and a safety and well-being plan in place.

#### Recruiting diverse young people

One key facilitator of impactful youth involvement in suicide research is the participation of young people with diverse lived and living experiences (in relation to age, gender, cultural background, education, ability and community). It is especially important to proactively seek the involvement of young people who identify within communities that are disproportionately affected by suicide, and to consider the associated socio-cultural and historic attitudes and contexts.

- Recruit young people with diverse lived and living experience of suicide (for example, being bereaved by suicide, caring for someone who is experiencing thoughts or feelings of suicide, supporting someone online).
- When involving young people from diverse backgrounds and communities (for example, LGBTIQA+, culturally and linguistically diverse), partner with relevant local community organisations to ensure accommodation of cultural nuances/differences.

## **1.3 ONBOARDING YOUNG PEOPLE**

Young people and researchers may wish to do the following after recruitment but before they have commenced involvement:

- Dedicate sufficient project time to build rapport with young people to create a safe environment (see more about creating a safe environment in Section 1.5).
- Before starting their involvement, send young people information about available support services (for example, crisis support services).
- Tell young people what to expect from each activity in advance (for example, sensitive topics, the structure of involvement and any preparation needed).
- Discuss with young people potential stressors of being involved.



## **1.4 TRAINING**

Training young people and researchers may be necessary before they commence their involvement in suicide research. The following items refer to training needs for young people and researchers.

#### Training for young people

- Provide young people with an induction program that covers the following:
  - Definitions of terminology commonly used in suicide research.
  - How to safely communicate about suicide.
  - Basic suicide prevention literacy (for example, protective factors, risk factors, suicide prevention strategies).
  - The diverse lived and living experiences of suicidal people.
  - Processes for conducting ethical suicide research.
  - Content tailored to the needs/knowledge gaps identified by young people.
  - How to support themselves and take care of their well-being.

#### **Training for researchers**

- Research institutions should provide the research team with training on the following:
  - Evidence-based youth suicide prevention/intervention skills.
  - How to assess and manage general distress.
  - How to manage and contain difficult conversations that may arise (for example, about traumatic lived and living experience, suicide attempts, etc.).
  - How to support young people to safely share their lived and living experience (for example, identifying and asserting personal boundaries, safe communication).
  - How researchers can take care of their own well-being.

## 1.5 CREATING SAFE ENVIRONMENTS

Many young people involved in suicide research don't experience distress from their involvement. However, as with all youth mental health research, it is essential to consider how to ensure young people feel supported and safe when working together. The following items refer to how to create a safe and supportive environment, regardless of the type of activity.

- Consult individuals' safety and well-being plans to become familiar with their support needs before engagement.
- Adjust activities to accommodate young people's needs and preferences (for example, having a support person attend, camera off during online meetings, frequency of breaks).
- If it is not felt that appropriate mechanisms are in place to ensure the safety of young people, activities or involvement should be delayed until those mechanisms are in place.
- Conduct activities in a private, quiet space.
- Ensure breakout rooms are available for young people if they need a break.
- Explore with young people what a 'safe environment' means and how to make and keep it safe together.
- If specifically discussing lived and living experience of suicide, methods or details, or other aspects of suicide, it's essential to discuss the topic of suicide directly, safely, and confidently. This can be achieved by:
  - Providing a content warning.
  - Telling young people how long a particular topic will be discussed.
  - Allowing young people to step away while the topic is being discussed.
  - Notifying young people when to come back if they have stepped away (particularly important in a virtual environment).
- If communicating with young people via phone call or text message, only use work devices, not personal devices.
- When involving young people online, ask young people to identify a quiet place.

#### Sharing lived and living experience of suicide

Researchers should consider the implications of young people sharing their lived and living experience as part of their involvement and support young people to consider these implications. The following items refer to actions that researchers and young people might consider to ensure the safe sharing of stories about suicide and to protect the young person's privacy and personal boundaries.

- Be clear with young people about whether they will be expected to share their lived and living experience at any stage.
- Ask young people what they do and don't want to share about their lived and living experience.
- Remind young people at each research project stage that they should contribute as much or as little of their story as they want to on any given day.
- Inform young people of what will happen with the information if they share their lived and living experience (for example, confidentiality, privacy policies).
- Provide support to young people who are sharing their lived and living experience by:
  - Respecting their boundaries.
  - Assisting them to understand how to safely communicate lived and living experience of suicide (for example, safe language use).
  - Allowing sufficient time for them to share their lived and living experience.
- Research institutions should have a policy about whether and how researchers share their lived and living experience with young people involved in their research.



### **1.6 GROUP ACTIVITIES**

When involving more than one young person in an activity, researchers should consider group-specific recommendations. Creating a safe group environment may include developing a shared agreement on how to work together safely and respectfully. The following items refer to how researchers can do this when conducting group activities.

- At the beginning of the group activity, researchers should spend time with young people:
  - Discussing and agreeing on group practices (or 'rules') (for example, respecting confidentiality, being mindful of what they choose to and not to share about their lived and living experience).
  - Getting to know each other and researchers.
- Review the group practices (or 'rules') with young people to check they are still in agreement with them:
  - At subsequent activities, to clarify that they are still in agreement about them.
  - If additional young people join a group or ongoing activities.
- Remind young people that:
  - The research is about suicide, which may be sensitive, uncomfortable, or distressing for some people.
  - They can disclose their lived and living experience of suicide if they want to, but it's not expected or required that they do so.
  - They should be respectful and sensitive if other people disclose their lived and living experience.
  - They should respect others' privacy and not repeat discussions outside of the group.
  - It is a safe and supportive environment.
  - Understandably, specific topics may be upsetting.
  - They should respect that everyone's lived and living experience is different.
  - It can be normal to feel uncomfortable when discussing suicide.
- Inform young people that:
  - They can withdraw, pause, or change the nature or extent of their involvement without any negative consequences.
  - If they are worried or upset, stepping away or taking a break is okay.
  - They should let the researcher (or person leading the activity) know if they step away or take a break.
  - Let the young person know you will notify them when to return.

- Seek consent from young people to record any activities and inform young people what these recordings will be used for.
- If the activities are being recorded, pause the recording during introductions, wellness plan discussions and other parts of the activity where confidential discussions take place.
- Provide various options to support young people's different sensory needs when engaging in activities (for example, sensory toys, dimming lights, and choice of music).
- Inform young people that researchers cannot provide clinical support but can direct people to available support if needed.
- Reschedule activities if young people are not feeling well enough to engage.



#### 1.7 STUDY PLANNING AND ETHICS APPROVAL

Planning and obtaining ethics approval for a research study is an essential component of most research studies. Involving young people in this early stage can significantly increase the study's success.

- Involve young people in designing research studies (for example, contributing to decisions on research questions and study methodology).
- Work with young people to educate ethics committees on safe and meaningful involvement.
- When developing the ethics application:
  - Refer to previous studies with ethics approval to demonstrate competence and expertise in involving young people in suicide research.
  - Describe any previous experience the research team has had with involving young people with lived and living experience in suicide research.
  - Include detailed safety and well-being protocols for the young people and the researchers about how they will be supported.

#### 1.8 INVOLVING YOUNG PEOPLE IN DATA ANALYSIS

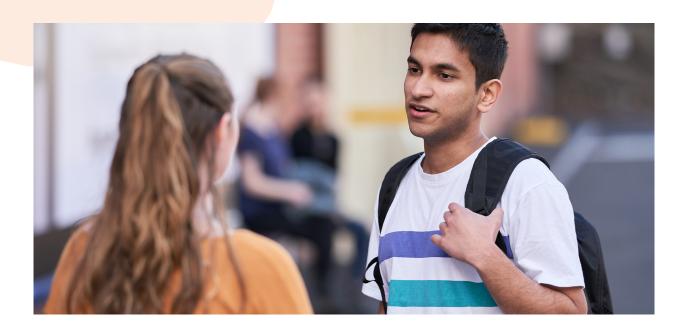
Gaining young people's interpretations of data can be helpful in research projects. Young people's involvement in data analysis might involve reading and coding interview transcripts or analysing numerical data sets using specific analysis software.

- If involving young people in data analysis in suicide research:
  - Inform young people of the nature or focus of data before introducing young people to the data.
  - Encourage them to consider and discuss potential distress or discomfort, given the topic (for example, this may include sharing the **Tips for Young People section** of these guidelines).
  - Provide relevant training (for example, how to conduct thematic analysis in suicide research).
  - Provide support in how to conduct data analysis in suicide research.

### **1.9 DISSEMINATING FINDINGS**

When supporting young people's involvement in the dissemination of research, consider support structures and processes around these activities.

- Review any public-facing communication created by young people to ensure safe communication about suicide and that it aligns with ethics-approved materials.
- If a young person is attending an event or participating in a media opportunity ensure that a research team member or other staff member or person with lived and living experience is available to help them prepare and check-in with them after the event



## 2. SUPPORTING SAFETY AND WELL-BEING

When involving young people in suicide research, safety and well-being must remain a priority. This requires a clear, multi-dimensional strategy with in-built flexibility to be responsive to the individual needs of young people, from providing general support to responding to distress.

#### 2.1 SAFETY AND WELL-BEING PROTOCOLS

Safety and well-being protocols are guidelines for researchers and staff members to recognise and respond appropriately to any young person at serious risk of harm at any stage of involvement. The following items refer to how safety and well-being protocols should be developed and implemented.

- Develop protocols in consultation with clinicians and young people.
- Develop comprehensive protocols to support the ongoing safety of young people.
- Protocols should address the needs of young people, researchers, and any other staff on the research team (for example, administrative staff/project managers).
- Protocols should be regularly reviewed, for example, annually.
- Provide young people with a copy of the protocols.
- Safety and well-being protocols should give guidance on:
  - How to respond if a young person becomes distressed during involvement.
  - How to react if a young person discloses current suicidal thoughts, feelings, intent or plans.
  - How to respond to a suicide attempt while a young person is involved.
  - How to adapt the support to the individual needs of young people and researchers.
  - How to minimise risk specific to the type or nature of involvement activities (for example, for in-person vs remote involvement activities, one-off vs ongoing).
  - Information about the role of all team members in supporting young people (for example, researchers, clinicians).
  - If/when confidentiality will be broken in the interest of the young person's safety.
  - Researchers' responsibilities in managing and preventing distress.

## 2.2 INDIVIDUAL WELL-BEING PLANS

Proactively developing individual plans with young people to support their well-being and involvement can provide the research team with information about how best to support the needs of the young person. The following items refer to how such a plan should be developed and implemented.

- A template for any safety and well-being plan should be co-developed with young people (for example, designed, developed, and written collaboratively).
- An individual safety and well-being plan should be developed at the start of involvement (immediately after recruitment/before commencement).
- Any safety and well-being plan should be updated whenever a young person re-engages with the research project after taking a break.
- Invite young people to provide the following information on a safety and well-being plan:
  - Emergency contact details.
  - Details of anything the young person might find distressing or especially difficult.
  - Personalised coping strategies (for example, self-care, self-management strategies).
  - The young person's preferred contact method (for example, text message, phone call).
  - Details on what they find helpful/ supportive should they become distressed.
  - An overview of specific steps you will take if they think the young person is at immediate risk of harm to themselves or others.
- An individual safety and well-being plan should include a reminder to young people about available support resources (for example, contact details of telephone/ online support services).

## 2.3 PROVIDING GENERAL SUPPORT

Providing young people and the research team with general support is an effective way to nurture a safe and productive environment and experience.

- Offer all young people the same support options, with additional personalised support options if required/available.
- Offer support that meets the needs of diverse young people (for example, those with a disability, neurodiverse).
- Take time to identify the support needs of young people, yourself, and other researchers and staff members involved in the project.
- Set expectations with young people around what kinds of support will be provided.
- Encourage young people to monitor their mood and well-being throughout their involvement and seek support if needed.
- Provide young people, both verbally and in writing, with the following:
  - Information on how to get support, for example, national crisis lines.
  - Tools that young people can use to maintain their well-being and safety (for example, self-care activities, safety planning tools).
  - Contact details of a nominated person on the team for young people to communicate to about their safety and well-being.
  - Contact details for any clinical staff member available to offer clinical support.
- Encourage young people to consider who to contact if their nominated member of the research team is not available.
- Have access to professional supervision to help the research team navigate the relevant challenges of involving young people (for example, this may involve having a discussion with the research lead).

## 2.4 ROUTINE CHECK-INS

'Checking-in' with young people can be an effective way to support their safety and well-being throughout their involvement. This may differ in timing (for example, during or after involvement) and setting (for example, in a group or individually). The following items refer to considerations when checking-in with a young person about their well-being.

- Regularly check-in with young people about their well-being.
- Inform young people about any check-in process at the start of their involvement.
- When conducting a check-in with a young person:
  - Use the preferred mode of communication indicated by the young person in their safety and well-being plan (see section 2.2).
  - Conduct the check-in within approximately one week following involvement.
  - Give the young person the opportunity to share experiences, ask questions, and provide feedback.
  - As well as looking for distress or worsening of suicidality, check-in broadly around the young person's well-being.
- If you are still concerned about the young person after conducting a 'check-in':
  - Consult the safety and well-being plan on supporting the young person best (if they have one).
  - Check-in again with the young person later that day.
- If a young person doesn't respond to a check-in request, attempt to contact them via a different form of communication.
- Communicate concerns about a young person to any clinician or lead/principal investigator on the project to keep them informed.



#### 2.5 RESPONDING TO DISTRESS OR SUICIDE RISK

Some young people may experience distress during involvement, and researchers should feel confident and prepared to respond safely and compassionately if this occurs. The following items refer to ways researchers, and young people may wish to identify and manage potential distress. **Please keep in mind this is not an exhaustive list of actions and only includes items that reached consensus in the Delphi survey; that is, both researchers and young people deemed these to be essential actions.** 

- Ask young people to let you or someone in the research team know if they are feeling distressed and would like support.
- Monitor young people's mood throughout any activity (for example, through observing body language, facial expressions, or any sudden changes in engagement).
- Trust young people to inform you if they are finding things too distressing.

#### If distress is identified in young people

- If a young person becomes distressed:
  - Let the young person know that you've noticed they are distressed.
  - Check whether they want to stop, break, or continue.
  - Respect a young person's choice not to continue with their involvement.
  - Enact the safety and well-being plan if the young person has one.
  - Provide the young person with contact information for helplines and support services.
  - Plan to check-in with the young person later, for example, on the next day.
- If distress occurs in a group activity, check-in with other young people.
- If a young person is thought to be at immediate risk of suicide, you or any clinician involved should:
  - If possible, obtain the young person's consent to contact their emergency contacts.
  - If possible, inform the young person that their emergency contacts are being contacted.
  - Inform the young person's emergency contact.
  - If possible, stay with the young person until help arrives, or maintain continuous contact with the person if online.

- If a young person indicates that they would like to speak with a clinician and the appropriate clinician is not present:
  - Obtain consent from the young person to provide a clinician with their first name and mobile number.
  - Provide the clinician with the relevant details.
- If the clinician needs to call later:
  - Inform the young person and (where possible) provide the specific time the clinician will contact them.
  - If possible, remain in contact with the young person until the clinician has contacted them.

#### Taking a break or opting out

- Support young people to take a pause from, or opt out of, involvement if they feel distressed.
- Offer young people a range of cues to communicate their need to step away, pause or opt out of an activity (for example, emojis (if online), safety words, hand signals when leaving the room etc.) in both online and in-person settings.
- Support young people to be autonomous in making decisions about opting out or pausing their involvement in particular activities and projects.
- Support young people's return to involvement after taking a break (for example, updating them on progress while they have been away).



## 2.6 COOL DOWN

"Cool down" sessions are generally held at the end of activities. These aim to foster psychological safety through reflection, validation and providing support to let go of or 'shake off' the content covered before finishing. The following items refer to ways you might conduct a "cool down" activity.

- Following activities:
  - Facilitate a discussion where young people can reflect and share challenges and learnings from involvement.
  - Give young people the option to choose between one-on-one and group reflection or cool down activity.
  - Encourage young people to schedule some self-care or a pleasant activity after their involvement (for example, watching a favourite movie, talking on the phone with a friend, playing with a pet).
- When conducting a group cool down, remind young people they are welcome to speak with you one-on-one afterwards.



## **3. EVALUATING INVOLVEMENT**

It is important to evaluate the process and impact of involving young people in suicide research. Evaluations can support the improvement of future involvement activities. The following items refer to actions that you can take to successfully monitor and assess the impact of young people's involvement on their well-being and the research output.

- Tell young people they can give feedback about their involvement if they want to.
- Ask for feedback from young people formally (for example, via surveys, interviews) and/or informally (for example, casual individual or group discussion).
- Provide mechanisms for young people to provide feedback anonymously (for example, online surveys).
- Fully document the processes used to engage young people with lived and living experience to ensure transparency and to aid future research efforts.
- Evaluate the impact of young people's involvement on their well-being, including any impact on their suicidal thoughts and feelings:
  - In the short term, for example, after each activity.
  - At the conclusion of their involvement.
  - In the longer term (for example, three months after involvement).
- Evaluate the impact of young people's involvement on the research process and/or output.
- Evaluate any impact on yourself as a researcher (for example, learning, development, specific challenges).
- In any evaluation, ask young people:
  - If they found their involvement distressing.
  - If any positive outcomes resulted from their involvement (for example, increased skills, confidence, financial, sense of worth).
  - If they would like to speak further about their experience with a member of the research team or clinician.
  - How researchers could improve involvement in suicide research.
  - How comfortable they felt talking about suicide.

## 4. TIPS FOR YOUNG PEOPLE

Being involved in suicide prevention research can be very exciting, but it is important to remember to take care of yourself first.

This page includes 10 tips to make sure your experience is as meaningful and safe as possible. These tips were agreed on by both young people and researchers. You can use these tips as a starting point and add more if you want to! For more information about how to talk about suicide safely visit #chatsafe at https://www.orygen.org.au/chatsafe

#### TIPS ASK YOURSELF ... Are you ready? Only begin your involvement when Why do I want to share my experience? you feel ready to. You are under no • Is now the best time to share my experience? obligation to disclose your lived or • Is there something that would help living experience and should only me feel more ready? do so if you feel comfortable. **Think ahead** Consider the potential positive • How might my involvement be good for me? and negatives of involvement • How might my involvement be bad for me? on your well-being. How might I feel during and after my involvement? **Identify your triggers** It can be helpful to consider what • Am I comfortable talking about means or methods of suicide? topics are likely to be distressing for you and let the researcher/s • How about the content of suicide notes? know prior to your involvement. • Is there anything else that might trigger me? **Set boundaries** Think about your boundaries before • What am I comfortable sharing? your involvement. Only be involved • What am I not comfortable sharing? in activities you are comfortable • Who am I comfortable sharing with? with. This could help prevent • When might I be most comfortable sharing? you from becoming distressed/ (for example, am I happy to do this in upset during your involvement or the evening?) regretting things later. **Be honest** If you decide to share your story, do • What are my lived (previous) experiences? your best to be honest about your • What are my living (current) experiences? symptoms/lived or living experience • What am I comfortable talking about in the recruitment process. with researchers?

CONTINUE TO NEXT PAGE

# TIPS

## ASK YOURSELF ...

#### **Share safely**

Your experiences are important, but it's important to learn how to share them safely. Use safe language when talking about suicide, including avoiding stigmatising or glorifying suicide, or discussing suicide methods.

- How can I make the way I share my experiences more safe?
- How can I avoid unsafe language?
- Where can I learn more about talking about suicide safely?

#### **Consider others**

Suicide is a sensitive topic. Consider the consequences for other people when sharing your lived and living experience with other people.

- How could my story affect others?
- How can I consider others when telling my story?
- How will I talk about my involvement with my friends, family, or community?

#### Ask for help

You're allowed to ask for support any time during your involvement. This can be support from researchers, professional / psychological support, or support from family and friends.

- Do I need more support from the researchers?
- Do I need more professional / psychological support?
- Do I need more support from my family and friends?

#### **Take breaks**

- You can pause or change the nature or extent of your involvement when you feel it is in your best interest.
- This includes asking to reschedule your involvement if you're not
- feeling up to engaging at that moment in time.
- Is there a better time for me to be involved?
- Would it help me to take a break?
- Would I prefer to be involved less or in a different way?
- Would stopping my involvement help me?

#### It's okay to stop

what's best for you!

You can tell the researcher/s if you are feeling upset or distressed and want to opt out of being involved. They won't get upset, they just want

- Is the research making me distressed or upset?
- Would I feel better if I wasn't involved?

## REFERENCES

- 1. World Health Organization. Suicide worldwide in 2019: global health estimates. WHO. Geneva; 2021.
- Hill NTM, Robinson J, Pirkis J, Andriessen K, Krysinska K, Payne A, et al. Association of suicidal behavior with exposure to suicide and suicide attempt: A systematic review and multilevel metaanalysis. PLoS Med. 2020;17(3):1–28.
- Robinson J, Bailey E, Witt K, Stefanac N, Milner A, Currier D, et al. What Works in Youth Suicide Prevention? A Systematic Review and Meta-Analysis. EClinicalMedicine. 2018;4–5:52–91. Available from: https://doi.org/10.1016/j.eclinm.2018.10.004.
- Thomson A, Peasgood E, Robertson S. The Youth Patient and Public Involvement Café—A youth-led model for meaningful involvement with children and young people. Health Expectations. 2022;25:2893-2901. Available from: https:// onlinelibrary.wiley.com/doi/10.1111/hex.13597.
- 5. McCabe E, Amarbayan M, Rabi S, Mendoza J, Naqvi SF, Thapa Bajgain K, et al. Youth engagement in mental health research: A systematic review. Health Expectations. 2022; 26:30-50.
- National Action Alliance for Suicide Prevention. The Surgeon General's Call to Action to implement the national strategy for suicide prevention. U.S. Department of Health & Human Services. Washington, D.C; 2021.
- National Suicide Prevention Office. National Suicide Prevention Advisor Final Advice. National Mental Health Commission, Australian Government. Canberra; 2021. Available from: https://www.mentalhealthcommission. gov.au/national-suicide-prevention-office/nationalsuicide-prevention-adviser-final-advice.
- World Health Organization. Live life: an implementation guide for suicide prevention in countries. WHO. Geneva; 2021. Available from: https://www.who.int/publications/i/item/9789240026629.
- Watling D, Preece M, Hawgood J, Bloomfield S, Kölves K. Developing an Intervention for Suicide Prevention: A Rapid Review of Lived Experience Involvement. Archives of Suicide Research. 2022; 16-24. Available from: https://doi.org/10.1080/13811118.2020.1833799.
- Bailey E, Teh Z, Bleeker C, Simmons M, Robinson J. Youth partnerships in suicide prevention research: A failed investigator survey. Early Interv Psychiatry. 2020; (November):1-4.

- Wadman R, Williams AJ, Brown K, Nielsen E. Supported and valued? A survey of early career researchers' experiences and perceptions of youth and adult involvement in mental health, selfharm and suicide research. Res Involv Engagem. 2019;5(1):1-12.
- 12. Aceves-Martins M, Aleman-Diaz AY, Giralt M, Solà R. Involving young people in health promotion, research and policy-making: Practical recommendations. International Journal for Quality in Health Care. 2019;31(2):147-53.
- Heffernan OS, Herzog TM, Schiralli JE, Hawke LD, Chaim G, Henderson JL. Implementation of a youth-adult partnership model in youth mental health systems research: Challenges and successes. Health Expectations. 2017; 20(6):1183–8.
- Shaw C, Brady L, Davey C. Guidelines for research with children and young people. National Children's Bureau Research. London; 2011. Available from: http://www.nfer.ac.uk/nfer/schools/ developing-young-researchers/NCBguidelines.pdf
- Simmons MB, Fava N, Faliszewski J, Browne V, Chinnery G, van der El K, et al. Inside the black box of youth participation and engagement: Development and implementation of an organization-wide strategy for Orygen, a national youth mental health organization in Australia. Early Interv Psychiatry. 2020; (June 2019):1–8.
- Jorm AF. Using the Delphi expert consensus method in mental health research. Australian and New Zealand Journal of Psychiatry. 2015;49(10):887–97.
- 17. Darnay K, Hawke LD, Chaim G, Henderson J, Hawke LD and the INNOVATE Research team. INNOVATE Research Youth Engagement Guidebook for Researchers. Toronto, ON. 2019.







## REVOLUTION IN MIND • r y 9 e h

#### GET IN TOUCH

IF YOU'D LIKE MORE INFORMATION ABOUT ORYGEN, PLEASE CALL +61 3 9966 9100 OR SEND AN EMAIL TO INFO@ORYGEN.ORG.AU

ORYGEN.ORG.AU

## ORYGEN LTD

35 POPLAR ROAD PARKVILLE VIC 3052 AUSTRALIA

FOLLOW US ON

