



## **Participant Information Sheet: Photo interviews**

### **2024 ALIVE National Lived Experience priorities study: mental health research priorities of young people**

#### **Research Team**

This research is being conducted by researchers from The ALIVE National Centre for Mental Health Research Translation at The Australian National University and the University of Melbourne. The members of our research team are:

#### **Principal Investigators**

Prof Michelle Banfield, Professor, Lived Experience Research, ANU and Co-Director ALIVE National Centre

Prof Victoria Palmer, Professor, Co-Design and Primary Mental Health Care, University of Melbourne and Co-Director ALIVE National Centre

#### **Co-investigators**

Dr Amelia Gulliver, Senior Research Fellow, ANU

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Dr Alexandra Johnston, Lived Experience Research Fellow, ALIVE National Centre

Dr Wendy Hermeston, Aboriginal & Torres Strait Islander Senior Research Fellow, ALIVE National Centre

Phillip Orcher, Research Associate, ALIVE National Centre

Dr Dana Jazayeri, Senior Research Support Officer, ALIVE National Centre

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Dr Caroline Tjung, Translation & Communications Specialist, ALIVE National Centre

#### **Overview**

**Description:** This project is the third annual ALIVE Lived Experience priority-setting study. The aim of these studies is to develop a living roadmap for mental health research, driven by the perspectives of people with lived experience of mental ill-health and their carers, families and kinship group members. Our intention is for the roadmap to underpin research within the ALIVE National Centre, and also contribute to mental health research more broadly in Australia.

The purpose of the current study is to elevate the voices of young people aged 16-25, who are underrepresented in our work to-date. This part of the study involves photo interviews, where we will ask you to suggest your own ideas for research as described in this information sheet. Other parts of the study include crowdsourcing, an online survey and emotion mapping, which you can learn about on our study page <https://alivenetwork.com.au/2024-anu-alive-national-lived-experience-priorities-survey/>

**Participants:** Australian residents between the ages of 16 and 25 years, who identify as someone with personal lived experience of mental ill-health, or as a carer, family or kinship group member supporting someone who experiences mental ill-health are invited to take part. We are looking for around 100 young people.

**Use of Data and Feedback:** Priorities shared in the interviews will be combined with those gathered through the other parts of the study to add to our growing roadmap for mental health research. Findings will be used to create a pocket map of research priorities, our annual consensus statement and implementation actions, which you can see here <https://alivenetwork.com.au/our->

[research/mental-health-care-at-scale/](#). Study findings will also be published in peer-reviewed journal papers and academic presentations and a summary made available on the project page.

**Project Funding:** This project is supported by funding from the National Health and Medical Research Council for the ALIVE National Centre.

### **What's involved?**

**Voluntary Participation & Withdrawal:** Participation in this research is voluntary. You don't have to take part, you don't have to answer all the questions and you can stop the interview at any time. Any information you have given us up until that point will not be included unless you ask us to keep it. You can also withdraw your responses by emailing us, up until the time we start our analysis.

**What does taking part involve?** In this project you will be asked to take part in an interview online via Zoom videoconferencing. We will ask for your gender, age and location, and whether you identify as someone with personal experience of mental ill-health, or as a carer, family or kinship group member as a part of the consent process. We are collecting this personal information to allow us to describe the range of people who have completed the study.

You will be asked to bring some photos to the interview, to help start the discussion on the issues you think mental health research needs to address. Photos should not include people or graphic content (e.g., no photos of bodily harm), but can otherwise be of anything that represents what you would like to talk about regarding mental health research priorities. During the interview, you will be asked to share three priorities for mental health research, using your photos as discussion points. We will not keep copies of the photos. If you are a carer, family or kinship group member, we ask that you do not share information in your responses such as name, diagnosis or other personal details of the person you support.

With your permission, we will record the interviews to help with analysis. For Zoom interviews, this will involve both video- and audio-recording to the ANU or University of Melbourne cloud. We will only keep the audio-recording and delete the video-recording when it is available. Interviews will be digitally transcribed using Zoom or Word. We will send you the transcript to check including telling us about any sections you would like to remove. You will have 2 weeks to review transcripts. No response will be taken as permission to keep the transcript in the research project without change.

If you want to take part but don't agree to be recorded, we will keep notes during the interview instead. As for transcripts, we will send these to you to check.

**Location and Duration:** Interviews will be done online and will take around 30-45 minutes.

**Inclusion criteria:** Participants must be Australian residents aged 16-25 years and identify as someone with lived experience or mental ill-health, either personally or as a carer, family or kinship group member supporting someone with mental ill-health.

**Risks:** There is a risk that answering questions about mental health may trigger unpleasant feelings or memories. A list of support services is attached to this information sheet. We also have a protocol for managing distress during the interview. The interviewer will go through how this works before you start.

There is also a risk of you being identified by your answers. We strongly believe in sharing research priorities as they are spoken or written by people with lived experience, including in our online public priorities database. This may be enough for someone to recognise you. The combination of your gender, age, lived experience (personal and/or carer/family/kinship) state and whether you are from a city, regional or remote area might also be enough for someone to guess which priorities are yours. You can choose not to answer the personal information questions if you would like to reduce this risk but still take part.

**Benefits:** We do not expect that you will personally benefit from the research. However, conducting lived experience priority-setting may benefit the mental health sector broadly by ensuring that research conducted in Australia is relevant to current priority issues identified by the people most affected. Research into current issues has the potential to influence policy and practice, improving

our mental health system.

### Confidentiality & Privacy

**Confidentiality:** Your information will be kept confidential as far as the law allows. Please try not include identifying information about yourself or others in your discussions, and do not make statements that defame others. Any potentially identifying or personal information will be removed during data analysis. Only named research staff will have access to interview recordings and transcripts. As described under data storage, your de-identified responses will be added to our database for use in future research by researchers who may be outside the current named team.

**Privacy Notice:** In collecting your personal information within this research, the ANU must comply with the Privacy Act 1988. The ANU Privacy Policy is available at [https://policies.anu.edu.au/ppl/document/ANUP\\_010007](https://policies.anu.edu.au/ppl/document/ANUP_010007) and it contains information about how a person can:

- Access or seek correction to their personal information;
- Complain about a breach of an Australian Privacy Principle by ANU, and how ANU will handle the complaint.

Participants should be aware that the World Wide Web is an insecure public network that gives rise to a potential risk that a user's transactions are being viewed, intercepted or modified by third parties or that data which the user downloads may contain computer viruses or other defects.

### Data Storage

**Where:** Interview recordings, transcripts and identifiable notes will be stored on ANU and University of Melbourne OneDrive servers and will be accessible only to the named research team. De-identified data will be uploaded to the ALIVE National Centre searchable lived experience priorities database <https://alivenetwork.com.au/mental-health-priorities-database/> and the ANU Data Commons <https://datacommons.anu.edu.au/DataCommons/>

**How long:** Data associated with this project will be kept for a minimum of 5 years from publication, after which it will be archived for use in future projects.

**What about long-term?** The final combined research agenda dataset will be made available in data archives including the ALIVE National Centre website <https://alivenetwork.com.au/mental-health-priorities-database/> and the ANU Data Commons <https://datacommons.anu.edu.au/DataCommons/>. Archived priorities will identify participants by gender, age, state, remoteness category and their lived experience perspective (personal or carer, family or kinship group member). Use by other researchers and organisations is encouraged. By consenting to take part, you are agreeing to this future use.

### Queries and Concerns

**Contact Details for More Information:** If you have any queries or concerns regarding this research, please contact Michelle Banfield ([acacia@anu.edu.au](mailto:acacia@anu.edu.au) or 0434 766 291) or Victoria Palmer ([alive-hub@unimelb.edu.au](mailto:alive-hub@unimelb.edu.au) or 03 8344 4987.)

### Ethics Committee Clearance

The ethical aspects of this research have been approved by the ANU Human Research Ethics Committee (protocol number H/2024/0495). If you have any concerns or complaints about how this research has been conducted, please contact:

Ethics Manager  
The ANU Human Research Ethics Committee  
The Australian National University  
Telephone: +61 2 6125 3427  
Email: [Human.Ethics.Officer@anu.edu.au](mailto:Human.Ethics.Officer@anu.edu.au)

## USEFUL SUPPORT SERVICES

If you are feeling distressed or would like some additional support, please contact your GP. If you need urgent medical help, please call 000 (or on a mobile you can call 112). Other numbers that you can call at any time, if you want help and support:

### 24/7 Crisis Support Services

<p><b>LIFELINE</b>  <b>24 hours a day, 7 days a week</b>  <b>Crisis support over the phone, for all ages</b> Lifeline also has an online crisis support chat from 7pm to 4am, 7 days a week. To find out more, you can do an internet search for "Lifeline" or go to <a href="http://www.lifeline.org.au">www.lifeline.org.au</a> and click on the "online services" tab.</p>	<p>13 11 14  (free call from mobiles)</p>
<p><b>Kids Helpline – Teens and Young Adults</b>  <b>24 hours a day, 7 days a week</b>  <b>Phone support and counselling, for ages 13-25</b>          Kids Helpline also have WebChat Counselling available between 8am and midnight, 7 days a week and Email Counseling. For more information, search for "Kids Helpline" or go to <a href="http://www.kidshelp.com.au/teens">www.kidshelp.com.au/teens</a></p>	<p>1800 55 1800  (free to call)</p>
<p><b>Suicide Call Back Service</b>  <b>24 hours a day, 7 days a week</b>  <b>Phone crisis counselling and support, ages 15 plus</b>          Crisis support for people who are suicidal, carers of someone who is suicidal and people bereaved by suicide. The Suicide Call Back Service provides immediate telephone support in a crisis and can provide up to 6 further telephone counselling sessions with the same counsellor. For more information go to <a href="https://www.suicidecallbackservice.org.au">https://www.suicidecallbackservice.org.au</a></p>	<p>1300 659 467</p>
<p><b>13YARN</b>  <b>24 hours a day, 7 days a week</b>  <b>Phone crisis counselling and support, with a Lifeline-trained Aboriginal &amp; Torres Strait Islander Crisis Supporter</b>          [Thirteen YARN] is the first national crisis support line for mob who are feeling overwhelmed or having difficulty coping. They offer a confidential one-on-one yarning opportunity with a Lifeline-trained Aboriginal &amp; Torres Strait Islander Crisis Supporter who can provide crisis support 24 hours a day, 7 days a week. 13YARN empowers our community with the opportunity to yarn without judgement and provide a culturally safe space to speak about their needs, worries or concerns. If you, or someone you know, are feeling worried or no good, we encourage you to connect with 13YARN on 13 92 76 (24 hours/7 days) and talk with an Aboriginal or Torres Strait Islander Crisis Supporter.          For more information go to:  <a href="https://www.13yarn.org.au/factsheets">https://www.13yarn.org.au/factsheets</a></p>	<p>13 92 76  (free to call)</p>

If you are not experiencing a crisis but would like to access some general help and support, you can try contacting some of the services listed below, or visit their websites for more information.

### Support and counselling services

<p><b>beyondblue Support Service</b>  <b>24 hours a day, 7 days a week</b>  <b>Phone support, for all ages</b>          Support, information and advice over the phone, for concerns big and small. beyondblue also have an online chat service available between 3pm and midnight, 7 days a week and an email service. For more information search “beyondblue” or go to <a href="https://www.beyondblue.org.au/">https://www.beyondblue.org.au/</a></p>	<p>1300 224 636</p>
<p><b>Carer Advisory Service</b>  <b>Available during business hours</b>  <b>Short term counselling services, for carers</b>          This service provides information and advice about carer supports and services. It is also the number for the National Carer Counselling Program, which provides short-term counselling specifically for carers; you can make an appointment by calling this number. For more information search “Carers Australia”</p>	<p>1800 242 636          (free call from landline)</p>
<p><b>SANE Helpline</b>  <b>9am-5pm, weekdays</b>  <b>Information and referrals</b>          The SANE Help Centre provides information, guidance and referrals for people living with a mental illness and their families and carers. They also have an online chat service available 9am-5pm weekdays and an email service. For more information visit: <a href="https://www.sane.org/">https://www.sane.org/</a></p>	<p>1800 187 263</p>
<p><b>MensLine Australia</b>  <b>24 hours a day, 7 days a week</b>  <b>Phone support and information, for men</b>          Support, information and referral service for men with family and relationship concerns. MensLine also offer a call back service, online counselling and video counselling. For more information search “MensLine” or go to <a href="http://www.mensline.org.au/">http://www.mensline.org.au/</a></p>	<p>1300 789 978</p>
<p><b>Indigenous Wellbeing Course</b>  <b>By MindSpot</b>  <b>24 hours a day, 7 days a week</b>  <b>Phone support and information, for Aboriginal and Torres Strait Islanders aged 18+ years</b>          Helps Aboriginal and Torres Strait Islanders aged 18+ years learn to manage mild, moderate, and severe symptoms of depression and anxiety with core skills that will improve confidence and quality of life.          Go to: <a href="https://www.mindspot.org.au/course/indigenous-wellbeing/">https://www.mindspot.org.au/course/indigenous-wellbeing/</a></p>	<p>1800 61 44 34</p>
<p><b>Mental health resources for First Nations People</b>  <b>By Beyond Blue</b>  <b>24 hours a day, 7 days a week</b>          Reducing the impact of depression and anxiety among Aboriginal and Torres Strait Islander communities is a priority for Beyond Blue. A range of research, information, education</p>	<p>1300 22 4636</p>

<p>and support strategies have been developed. Also featured are publications, personal stories and community forums. Go to: <a href="https://www.beyondblue.org.au/who-does-it-affect/aboriginal-and-torres-strait-islander-people">https://www.beyondblue.org.au/who-does-it-affect/aboriginal-and-torres-strait-islander-people</a></p>	
<p><b>Suicide Prevention Information for First Nations communities</b> <b>By Lifeline</b> <b>24 hours a day, 7 days a week</b> This information may help Aboriginal and Torres Strait Islander people work out what they can do and who can help when they are worried about self-harm or suicide. Go to: <a href="https://www.lifeline.org.au/media/2uzp3v41/rev1_sept_11-4pp-tool-kit_suicide-prevention-info-aboriginal-tsi-people.pdf">https://www.lifeline.org.au/media/2uzp3v41/rev1_sept_11-4pp-tool-kit_suicide-prevention-info-aboriginal-tsi-people.pdf</a></p>	13 11 14