Participant Information Sheet: Emotion mapping

2024 ALIVE National Lived Experience priorities study: mental health research priorities of carer, family or kinship group members

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
Anna Foxcroft, Research Officer, ANU
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
Roxanne Kritharidis, Research Support Officer, ALIVE National Centre
Dr Caroline Tjung, Translation & Communications Specialist, ALIVE National Centre
Dr Caroline Robertson, Research Associate, ALIVE National Centre
Alexandra Lee, Research Associate, ALIVE National Centre
Dianna Smith, Research Officer, ANU

Overview

Description: This project is the fourth 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 carer, family or kinship group members supporting someone with mental ill-health, who are underrepresented in our work to-date. This part of the study comprises online emotion mapping, you will have the chance to work with the ideas generated in our earlier work in a private online workspace called a Mural board. Other completed parts of the study, which you can learn about on our study page https://alivenetwork.com.au/2025-anu-alive-national-lived-experience-priorities-study-for-carers-group/ included an online survey. You can also register for our upcoming public co-design.

Participants: Australian residents aged over 16 years, who identify as someone with personal lived experience as a carer, family or kinship group member supporting someone who experiences mental ill-health. We are looking for around 100 people.

Use of Data and Feedback: Priorities developed in the emotion mapping 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 will be uploaded to 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 and you can stop completing the emotion mapping at any time by just closing your browser. If you decide to stop before finishing, your data will not be included in our analysis. We will take completion of your emotion mapping as consent, but you can still withdraw your data after completing, by emailing the research team. Data can only be withdrawn up until analysis commences.

What does taking part involve? In this project you will be asked to interact with a private online workspace called a Mural board. During registration, you will be asked about your gender, age and location, and whether you identify how you describe your carer, family or kinship roles and whether you also identify as someone with personal experience of mental ill-health. We are collecting this personal information to allow us to describe the range of people who have completed the study. Demographic questions are all optional, but you must provide consent to participate. After consent, you will be provided with a link to a personal Mural board where you can work with the topics suggested by others in our previous and current studies, using tools like virtual post-it notes to indicate their importance and how they should be organised. As 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. To create a complete response that will be included in our research, you will need to respond to all the priorities on the Mural board. Full instructions will be provided when you register.

Location and Duration: You can access the Mural board from any web-enabled device. We estimate that completion of the activity will take around 30-45 minutes. We recognise that this is a large amount of time, but we are keen to ensure that lived experience research priorities are well-covered. As the boards are cloud-based, your progress is saved and you can return to your in-progress submission using the same link on any device, at any time up until we start analysis, when all boards will be closed.

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

Risks: There is a risk that thinking about mental health may trigger unpleasant feelings or memories. A list of support services is attached to this information sheet. If you feel distressed when completing the research, please contact your preferred support person or one of the services listed. Experiencing stigma associated with mental ill-health is also possible. Our de-identification process described under confidentiality reduces the risk of your responses being recognised and prompting stigmatising attitudes from others.

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.

Remuneration: In recognition of your contribution, you will be offered a $20 gift voucher on completion.

Confidentiality & Privacy

Confidentiality: Your information will be kept confidential as far as the law allows. The Mural board does not require any identifying information. Please do not include identifying information in open responses. Any potentially identifying or personal information will be removed from responses during data analysis. Only named research staff will have access to the original data. 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 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. Mural is an online collaboration platform based in the USA. Their privacy policy can be accessed at https://mural.co/terms/privacy-statement and security information at https://mural.co/trust.

Data Storage

Where: Original responses will be stored on ANU and University of Melbourne Mural accounts and 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/. Where provided, 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 of archived data 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 or 0434 766 291) or Victoria Palmer (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

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

LIFELINE **24 hours a day, 7 days a week** **Crisis support over the phone, for all ages** 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 www.lifeline.org.au and click on the "online services" tab.	13 11 14 (free call from mobiles)
Kids Helpline – Teens and Young Adults **24 hours a day, 7 days a week** **Phone support and counselling, for ages 13-25** 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 www.kidshelp.com.au/teens	1800 55 1800 (free to call)
Suicide Call Back Service **24 hours a day, 7 days a week** **Phone crisis counselling and support, ages 15 plus** 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 https://www.suicidecallbackservice.org.au	1300 659 467
13YARN **24 hours a day, 7 days a week** **Phone crisis counselling and support, with a Lifeline-trained Aboriginal & Torres Strait Islander Crisis Supporter** [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 & 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: https://www.13yarn.org.au/factsheets	13 92 76 (free to call)

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

beyondblue Support Service **24 hours a day, 7 days a week** **Phone support, for all ages** 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 https://www.beyondblue.org.au/	1300 224 636
Carer Advisory Service **Available during business hours** **Short term counselling services, for carers** 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"	1800 242 636 (free call from landline)
SANE Helpline **9am-5pm, weekdays** **Information and referrals** 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: https://www.sane.org/	1800 187 263
MensLine Australia **24 hours a day, 7 days a week** **Phone support and information, for men** 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 http://www.mensline.org.au/	1300 789 978
Indigenous Wellbeing Course **By MindSpot** **24 hours a day, 7 days a week** **Phone support and information, for Aboriginal and Torres Strait Islanders aged 18+ years** 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: https://www.mindspot.org.au/course/indigenous-wellbeing/	1800 61 44 34
Mental health resources for First Nations People **By Beyond Blue** **24 hours a day, 7 days a week** 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	1300 22 4636

and support strategies have been developed. Also featured are publications, personal stories and community forums. Go to: https://www.beyondblue.org.au/who-does-it-affect/aboriginal-and-torres-strait-islander-people	
Suicide Prevention Information for First Nations communities **By Lifeline** **24 hours a day, 7 days a week** 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: https://www.lifeline.org.au/media/2uzp3v41/rev1_sept_ll-4pp-tool-kit_suicide-prevention-info-aboriginal-tsi-people.pdf	13 11 14