



Information and Consent Form

Activating Lived Experience Leadership – Leader Interviews

Dear Participant,

You are invited to participate in a research project: **Activating Lived Experience Leadership**

We are asking if you would like to engage in an audio-recorded one-to-one interview about your knowledge and experience with lived experience (LE) leadership and advocacy.

The Activating Lived Experience Leadership (ALEL) research project is a partnership between the Lived Experience Leadership & Advocacy Network (LELAN) and University of South Australia's Mental Health and Suicide Prevention Research Group (MHSPRG). The research project is the most significant investment to date in the area of inquiry in South Australia and has been funded by the Fay Fuller Foundation for two years.

Participation in this research is completely voluntary. If you do not wish to take part, you do not have to. If you decide to take part, you will be given this Participant Information and Consent Form to sign and a copy to keep.

Your decision whether to take part or not in this research will not affect your relationship with the ALEL research project team members. However, before you decide whether or not to be involved, it is important that you are clear on what you are being asked to do and the benefits of being involved.

What is the purpose of this research?

The broad purpose of the ALEL research project is to examine and describe how lived experience advocacy and leadership embedded within the mental health ecosystem can be defined, recognised and utilised in South Australia. We would like to understand your perceptions about LE leadership and advocacy and what would support service leaders to include more people with lived experience in mental health related organisations (not just as peer workers or advocates/representatives). We would also like to discuss what opportunities you see for advancing lived experienced leadership?

What will I need to do if I participate?

You will be asked to take part in an audio-recorded one-to-one interview with a member of the research team. This will occur via telephone or an online video meeting. Topics covered will include What would increase your skill, knowledge and comfort for involving people with lived experience more in the workplace; opportunities for lived experience leadership you see within services; what you believe other staff need to know to better support and involve people with lived experience in the workforce or as representatives included in decision-making. The interview may take up to 45 minutes and will be transcribed.

Who is being invited to participate in the research?

Workers who are consumer engagement or managerial leaders across a range of SA health services (LHNs, NGOs, PHNs, private hospitals, general practice and health promotion), to gain their views on effective leadership and advocacy for those with LE. We are planning to conduct interviews in rural and metropolitan settings.

How will my confidentiality be maintained?

Before the interviews commence you will be asked to choose a pseudonym to be used during the audio-recorded interview. Any personal information obtained from you will only be used for the purposes of this research project and with your permission, and no information which could lead to the identification of any individual will be released, unless in the unlikely event that disclosure is required by law. Direct quotes from what you have said may be published in a report or a journal article, but you will not be able to be identified.

During the project all data (including the transcript and audio recording of the interview) will be stored electronically on the password protected UniSA computer server and in paper copy in a locked office at the Mental Health and Suicide Prevention Research Group offices at the University of South Australia. At the end of the research project, data will be securely stored for a period of five years (University of South Australia guidelines: Ownership and Retention Policy) on the secure UniSA server and in a locked compactus in a locked room (University of South Australia, City East Campus, School of Nursing and Midwifery) and will only be accessed by the research team. After the five year period, all digital files will be erased and the USB and paper copy documents destroyed and deposited in a confidential bin.

What if I want to withdraw from the research?

You are free to withdraw from the research at any time before or during the interview. After this time, we will begin to review the information. Withdrawing from the research will not affect your status in any way.

Please note that, following the completion of the interview, the researchers will be unable to remove your results as data will be rendered non-identifiable and it will be difficult to distinguish and remove your individual responses.

Are there any risks?

There is a small risk associated with engaging in the interview, but no more than what you would experience in everyday life. If you have any discomfort as a result of the interview, you can stop the interview at any time. However, if you experience any distress at any later time, please contact one of the following:

- Your local GP
- Lifeline Australia – 13 11 14 or <https://www.lifeline.org.au/> (available 24/7)
- Suicide Call Back Service – [1300 659 467](tel:1300659467) or www.suicidecallbackservice.org.au (available 24/7)
- Beyondblue – 1300 22 4636 <http://www.beyondblue.org.au/> (available 24/7)
- MensLine Australia – 1300 78 99 78 or <https://www.mensline.org.au/> (available 24/7)
- Mental Health Triage – [13 14 65](tel:131465) (available 24/7)

What are the merits of being involved?

This research will provide important information about the nature of lived experience leadership and contribute to improved understanding about leadership roles, change and supportive environments. This understanding will also be used to generate learning resources and training opportunities. It will also be used to strengthen networks where lived experience leaders contribute to progressive change in community mental health.

When will I find out the results?

If you would like a summary of the anonymous research findings please contact Dr Mark Loughhead at the end of the research project: E: Mark.Loughhead@unisa.edu.au; P: 08 8302 1267.

What next?

If you would like to find out more information or to participate, please contact Dr Mark Loughhead:
E: Mark.Loughhead@unisa.edu.au; P: 08 8302 1267.

If you agree to participate please sign the consent form below and return it the research team prior to the interview.

This project has been approved by the University of South Australia's Human Research Ethics Committee (202513). If you have any ethical concerns about the project or questions about your rights as a participant, or should you or any third parties wish to lodge a complaint about either the study or the way it is being conducted, please contact the Executive Officer of this Committee – Ms Vicki Allen: (tel: +61 8 8302 3118; email: humanethics@unisa.edu.au).

Kind regards,
The research team

Additional details of the research team

Name	Telephone number	Email address
Dr Mark Loughhead ¹	08 8302 1267	Mark.Loughhead@unisa.edu.au
Ms Ellie Hodges ²	0422 888 157	ehodges@lelan.org.au
Professor Nicholas Procter ¹	08 8302 2148	Nicholas.Procter@unisa.edu.au
Ms Heather McIntyre ¹	08 8302 1132	Heather.Eaton@unisa.edu.au

¹ Mental Health and Suicide Prevention Research Group, School of Nursing and Midwifery, University of South Australia.

² Lived Experience Leadership & Advocacy Network

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Consent Form**

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SECTION 1: Contact and research project details

Researcher’s Full Name:	Dr Mark Loughhead
Contact Details:	P: 08 8302 1267; E: Mark.Loughhead@unisa.edu.au
Protocol Number:	202513
Research Project Title:	Activating Lived Experience Leadership

SECTION 2: Certification

Participant Certification

In signing this form, I confirm that:

- I have read the Participant Information Sheet and the purpose of the research project has been explained to me. I understand and agree to take part.
- I understand the purpose of the research project and my involvement in it.
- I understand that I may not directly benefit from taking part in this research.
- I understand that I can withdraw from the research at any stage prior to the interview taking place and that this will not affect my status now or in the future.
- I confirm that I am over 18 years of age.
- I understand that I will be required to participate in an audio-recorded telephone or online interview of up to 45 minutes.
- I understand direct quotes from the interview of statements I make could be used in publishing responses in a report or a journal article. The responses are made under a pseudonym to minimise risk to being identified.
- I understand that although every care will be taken to guard my anonymity there may be a small risk that my responses will be identifiable, and I am aware of that risk.
- I understand that during the project your audio-recorded interview will be stored electronically on a password protected computer in a locked office at the Mental Health and Suicide Prevention Research Group offices at the University of South Australia. At the end of the research project, the transcript and recording of the interview will be stored on an encrypted USB for a period of five years (University of South Australia guidelines: Ownership and Retention Policy) in a locked compactus in a locked room (University of South Australia, City East Campus, School of Nursing and Midwifery) and will only be accessed by the research team. After the five-year period, all digital files will be erased from the USB and the USB destroyed and deposited in a confidential bin.

Participant Certification

<i>Participant Signature</i>	<i>Printed Name</i>	<i>Date</i>

Researcher Certification

I have explained the research to the subject and consider that they understand what is involved.

	Dr Mark Loughhead	
<i>Researcher Signature</i>	<i>Printed Name</i>	<i>Date</i>