



## Information and Consent Form

### Activating Lived Experience Leadership – Online Survey

**Dear lived experience leader,**

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

We are asking if you would like to engage in an online survey about your knowledge and experience as a person who is a lived experience leader or advocate.

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.

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. Your decision whether to take part in the research will not affect your relationship with the ALEL research project team members.

#### **What is the purpose of this research?**

The broad purpose of the ALEL research project is to examine and describe key aspects of lived experience leadership and how it can be better connected, recognised and used for systems change in South Australia. The key aspects that we will explore include, definitions of leadership, the different roles that leaders take on, the conditions and supports that help with influence and change and the learning resources that help leaders. We would like to learn about your understanding and experience of these areas.

#### **What will I need to do if I participate?**

You will be asked to take part in an anonymous online survey which will take between 30 and 40 minutes. Questions asked will explore your experience as a lived experience leader. There are 16 questions, with many of these being open questions which ask for short text-based responses.

#### **Who is being invited to participate in the research?**

You can participate in this study if

- 1) you are over 18 years of age;
- 2) you have lived experience of mental health related distress or are a carer of a person experiencing mental health related distress; and
- 3) you are active as a leader in contributing to improving services or community awareness. You may be active in advocacy and policy, peer networks and support, community education or advisory roles.

The online survey will be open to people nationally.

#### **How will my confidentiality be maintained?**

Participation in the online survey will be anonymous, with a link to the survey provided below. You will be required to confirm your consent within the survey before proceeding. Any personal information obtained from you will only be used for the purposes of this research project and with your permission. As the

survey will be anonymous there will not be any information which could lead to the identification of any individual. Direct quotes from what you write may be published in a report or a journal article, but you will not be able to be identified.

During the project all data will be stored electronically on a 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) 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 participating in the online survey. You may refuse to answer a question during the online survey if you are not feeling comfortable. Withdrawing from the research will not affect your status in any way.

### **Are there any risks?**

There is a small risk associated with engaging in the online survey, but no more than what you would experience in everyday life. 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 or [www.suicidcallbackservice.org.au](http://www.suicidcallbackservice.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 (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. This will take place in South Australia, however, the project outcomes and reports will offer valuable learning for other states and territories.

### **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](mailto: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:

Ms Heather McIntyre: E: [Heather.McIntyre@unisa.edu.au](mailto:Heather.McIntyre@unisa.edu.au); P: 08 8302 1132;

Dr Mark Loughhead: E: [Mark.Loughhead@unisa.edu.au](mailto:Mark.Loughhead@unisa.edu.au); P: 08 8302 1267;

Ms Ellie Hodges: E: [ehodges@lelan.org.au](mailto:ehodges@lelan.org.au); M: 0422 888 157.

If you have decided to participate, please go ahead and complete the survey by clicking on this link:

**[\(survey link\)](#) The survey is open until Monday 16<sup>th</sup> of November.**

Upon completing the survey, you will be invited to enter a randomly selected draw for a \$200 Visa prepaid gift card. This will involve entering your contact details on a separate online form.

A word or pdf version of the survey is also available if you prefer.

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 (P: +61 8 8302 3118; E: [humanethics@unisa.edu.au](mailto:humanethics@unisa.edu.au)).

Kind regards,  
The research team

Name	Telephone number	Email address
Dr Mark Loughhead <sup>1</sup>	08 8302 1267	<a href="mailto:Mark.Loughhead@unisa.edu.au">Mark.Loughhead@unisa.edu.au</a>
Ms Ellie Hodges <sup>2</sup>	0422 888 157	<a href="mailto:ehodges@lelan.org.au">ehodges@lelan.org.au</a>
Professor Nicholas Procter <sup>1</sup>	08 8302 2148	<a href="mailto:Nicholas.Procter@unisa.edu.au">Nicholas.Procter@unisa.edu.au</a>
Ms Heather McIntyre <sup>1</sup>	08 8302 1132	<a href="mailto:Heather.McIntyre@unisa.edu.au">Heather.McIntyre@unisa.edu.au</a>

### Activating Lived Experience Leadership – Online consent to be completed within survey

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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: <a href="mailto:Mark.Loughhead@unisa.edu.au">Mark.Loughhead@unisa.edu.au</a>
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 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 taking part in the online survey and that this will not affect my status now or in the future.
- I confirm that I am 18 years of age or over.
- I understand that I will be required to participate in an anonymous online survey which will take between 30 and 40 minutes to complete.
- I understand direct quotes from my responses to the online survey could be used in publishing responses in a report or a journal article. The responses are made anonymously to minimise risk of being identified.
- During the project the survey data 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 survey data 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.

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

<sup>2</sup> Lived Experience Leadership & Advocacy Network