



## Participant Information Form

**Project title:** Building capacity with and for people with lived experience to inform, co-design and co-produce health research

**Name of Investigators:**

Academic investigators: Craig Cumming, Leah Roberts, Louise Southalan

Lived-experience investigators: Margaret Doherty, Wendy Cream, Virginia Catterall, Ron Deng

Note: All investigators have a role in the leadership and decision-making relating to the research. Research questions, protocols and methods are being co-produced by all investigators.

**Invitation:**

You are invited to participate in this research project entitled “Building capacity with and for lived-experience partners to inform co-design and co-produce health research”. This project is a collaboration between academic researchers from the University of Western Australia (UWA) and Lived Experience researchers.

**Aims of the research**

It is established that there are many benefits of involving people with lived experience in all aspects of research. Evidence of this is provided by the Western Australian Health Translation Network’s Consumer and Community Involvement Program, who are focussed on ensuring that people with lived experience are involved in a range of research projects. Their handbook highlights the following benefits of involving people with lived experience in research projects:

- increases the relevance and responsiveness of research to health needs
- improves the quality of research and its impact on health outcomes
- strengthens the effective translation of research into policy and practice
- builds public confidence in health and medical research

In order to assist academic research organisations in improving their ‘organisational readiness’ to work with people with lived experience of mental health challenges, alcohol and other drug use, criminal justice system involvement, or any combination of these, the research aims to understand the perspectives of this group of people with respect to:

- How researchers and research organisations that conduct research may need to adapt their practices, processes, values and behaviours so that they are more trauma-informed and strengths-based when working with lived experience partners;
- Strengths and skills they may bring as health research partners;
- challenges or obstacles that may prevent them from being meaningfully (i.e. a reciprocal, non-tokenistic relationship) involved as research partners in health research;
- What can be done to help prepare people with lived experience to become effective research partners.

### **Who is eligible to participate?**

Anyone with lived experience of alcohol and other drug use issues, mental health challenges and contact with police, the courts or prison. This lived experience can be directly as an individual, or as a family member or supporter of someone with lived experience. We are looking for people both with and without prior experience of being involved in research.

### **What does participation involve?**

- People who consent to participating in the research project will be invited to join a focus group with seven other people that will meet with members of the research team to hear participants' perspectives on being involved (or potentially being involved) in research as research partners.
- Each focus group will run for 2 hours and may be conducted in-person, or virtually online depending on what is the preferred format among participants.
- Each focus group session will be recorded, with the recording transcribed confidentially by a professional transcription service. All participants will be offered the opportunity to review and correct the transcription of their focus group session.
- All recordings and transcriptions will be stored securely and will not be accessed by anyone outside of the research team and transcription service. The recordings will be securely destroyed after 7 years from the date of the research project finishing, or the final publication of the research, whichever is later.
- Participants will also be invited to attend a one-hour session to review the main findings of the study and provide any feedback prior to the final report being completed.

### **Voluntary Participation and Withdrawal from the Study**

Should you consent to participating, your participation is voluntary, and you are free to withdraw from the research project at any time. If you choose to withdraw from the research project, any information that you have provided to the research team will be destroyed, unless you agree that this information can be retained and used.

### **Your privacy**

Your participation in this study and any information you provide will be treated in a confidential manner. Information gathered from this project will be published, but your name and identifying details will not be used in any publication arising out of the research. Any quotes used from the focus group sessions will be deidentified.

All participant data, including personal identifying information and focus group recordings, will be stored on a password protected computer or a secure server only accessible to the research team. Any paper records will be scanned and stored securely and the hard copies will be securely destroyed. All records and data will be kept in line with the WA University Sector Disposal Authority (WAUSDA). Data will be stored on the University of Western Australia's (UWA) Institutional Research Data Store (IRDS) for a minimum of 7 years after date of publication of the final report, or 7 years after conclusion of the project, whichever is later. Following this, all records and data will be securely destroyed.

### **Possible Benefits**

Potential benefits of the study for lived experience participants include:

- The opportunity to provide your perspective on possible engagement in health research as a research partner.
- The opportunity to communicate to researchers what barriers you may experience, and what would need to happen for you to be meaningfully involved in health research as a research partner.
- The opportunity to inform researchers how things could be changed to create the conditions for meaningful engagement of and more people with lived experience to be partners in health research.
- Potential benefits of the study for academic researchers include: Increased awareness of values, behaviours, practices and processes required to engage in trauma-informed ways with lived experience partners.
- Identification of the skills and approaches which underpin effective Lived Experience partnerships.

## Reimbursement

Each participant will be compensated in accordance with the Mental Health Commission's Consumer, Family, Carer and Community Paid Participation Policy at the Active Participant level of \$37.50 per hour. Participants will be reimbursed for 3 hours of their time (total \$112.50), regardless of whether they attend the session to provide feedback on the main findings of the study.

## Possible Risks and Safeguarding Plan

A Safeguarding Plan will be co-produced to guide engagement and to ensure that focus groups are designed and co-facilitated in ways that are as 'safe-enough' as possible. However, in the event that something discussed during a focus group session does cause you any distress, a member of the research team with extensive peer-support experience will be available to assist you.

You are welcome to contact anyone from the research team at any time during the study if you have any concerns or questions. We encourage you to use your existing supports and resources. However, the following resources are also available should you need additional support.

- **Parent and Family Drug Support line (and associated resources)** 24/7 helpline: 9442 5050 or 1800 653 203 (country callers).
- Additional resources available at <https://www.mhc.wa.gov.au/about-us/our-services/alcohol-and-drug-support-service/parent-and-family-drug-support-line/>

## Lifeline

- 24/7 helpline: 13 11 14
- Crisis support chat: <https://www.lifeline.org.au/get-help/online-services/crisis-chat>
- Website: <https://www.lifeline.org.au>

## Beyond Blue

- 24/7 helpline: 1800 512 348
- Website: <https://www.beyondblue.org.au/Q-Life>
  - <tel:1800184527> (3pm – midnight AEST) – 7 days per week
  - Website: [www.qlife.org.au](http://www.qlife.org.au)

## 13YARN

- 139276
- 24/7 helpline

## Contacts

If you would like to participate in, or discuss any aspect of this study, please contact Margaret Doherty, Lived Experience Investigator via email [margaret4mhm2@gmail.com](mailto:margaret4mhm2@gmail.com) or phone 0413 861 049, or Chief Investigator Craig Cumming via email [craig.cumming@uwa.edu.au](mailto:craig.cumming@uwa.edu.au) or phone 6488 1298. For any queries relating to logistics or payment, please contact Virginia Catterall via email [taylorv4m@yahoo.com.au](mailto:taylorv4m@yahoo.com.au) or phone 0422 411 696.

Sincerely,

Craig Cumming, Chief Investigator

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Approval to conduct this research has been provided by the University of Western Australia, in accordance with its ethics review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time. In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Ethics office at UWA on (08) 6488 3703 or by emailing to [humanethics@uwa.edu.au](mailto:humanethics@uwa.edu.au). All research participants are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form relating to this research project.