## Participant Information Statement and Consent Surveys



From Professor Deborah Loxton
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Regarding Research Project: Trauma informed health care: a co-produced multidisciplinary investigation into service provision and access

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Dear potential research participant,

You are invited to participate in the research project noted above which is being conducted by researchers from the University of Newcastle.

This project has been funded by the Women's Health Research, Translation and Impact Network.

The information below provides more detail about the study and how you can participate if you choose to do so.

#### 1. What is the research study about?

The purpose of the research is to improve best practice when providing health care to women who have lived with violence. 'Trauma-informed care' is considered a high standard of health care for victims-survivors of violence, but research shows the concept is rolled out differently across different health settings and women with lived experience of violence report unmet health care needs. This project collects information from both service providers and victim-survivors to provide the foundation for a high-level consultancy process, which will lead to the development of best practice guidelines in trauma-informed care for women who have lived with violence.

#### 2. Who is conducting the research?

This research project is being conducted by researchers from multiple institutions in collaboration with lived-experience consumer investigators, and is being led by Professor Deborah Loxton, Director of the Centre for Women's Health Research at the University of Newcastle. The research team and their affiliations are listed in a table under the heading 'Research Team' at the end of this document.

#### 3. Who can participate in the research?

This research study is recruiting women aged 18 and over who have previously experienced any form of violence or abuse, are living in regional Australia, and have accessed mental health care (including both face-to-face and telehealth).

# Participant Information Statement and Consent Surveys



You have been identified to receive this invitation through your involvement in various organisations and groups e.g. volunteer databases, alumni newsletters, participation in the Australian Longitudinal Study on Women's Health, or you have requested this invitation by responding to recruitment materials.

#### 4. What does participation involve?

If you agree to participate, you will be asked to complete a confidential survey about your experiences with the use of mental health care and trauma-informed care. The survey will ask questions about your demographics, your experiences of violence, your experiences with the use of mental health care (including mental health care delivered by telehealth), and your experiences and satisfaction with trauma-informed care.

The survey should take approximately 10-minutes to complete.

At the end of the survey you will be asked if you want to receive a summary of the research findings, if you want to hear about future research opportunities and if you want to be contacted further about your responses with a follow-up interview. If you indicate yes to any of the three questions, you will be asked for your personal information (e.g. name, email).

#### 5. Do you have to take part in this research study?

No. Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you choose to cease participation part way through the survey, your answers up until that point will be retained. The provision of identifying information (e.g. name, email) at the end of the survey is for the purposes of expressing an interest in future studies and receiving a summary of findings. If you decide to complete the survey, provide your personal details (e.g. name, email) and then decide to withdraw, the research team are able to withdraw your responses. If you do not provide your personal information, the research team are unable to withdraw your responses.

#### 6. What is the benefit of participating in this research study?

We cannot promise you any direct benefit from participating in this research, but we expect that the data from this study will inform trauma-informed care consensus guidelines that will benefit women victim-survivors living in regional Australia.

#### 7. Are there any risks involved in participating in this research?

Some of the questions deal with potentially sensitive issues such as experiences of violence, abuse and mental health. Should you find any of the survey questions upsetting, you can skip them or stop your participation at any time prior to submission of the survey.

You can contact the following support services should you wish to seek support regarding any of the issues raised within the survey:

 Your nearest Women's Health Centre https://whnsw.asn.au/womens-health-centres-nsw/ or Community Health Centre

# Participant Information Statement and Consent Surveys



- Your General Practitioner for support and advice about who would be the best person in your community to talk to
- Lifeline provides 24-hour crisis support by calling 13 11 14. Lifeline online chat is available from 7pm to midnight AEST through the following website: <a href="https://www.lifeline.org.au/crisis-chat/">https://www.lifeline.org.au/crisis-chat/</a>
- Beyond Blue provides mental health support through calling 1300 224 636. They also offer an online chat on the following website: https://online.beyondblue.org.au/#/chat/start
- 1800RESPECT provides 24-hour confidential information, counselling and support services for people impacted by sexual assault, domestic or family violence and abuse, by calling 1800 737 732. An online chat can be accessed at any time through the following website: https://www.1800respect.org.au

13YARN is run by Aboriginal and Torres Strait Islander people and provides free, one-on-one over the phone yarning opportunity and support service, available 24/7 by calling 13 92 76

If information is disclosed that is considered a serious indictable offence in accordance with Children and Young Persons (Care and Protection) Act 1998 and Crimes Act 1900 (NSW), the research team may have a legal obligation to report this information to the appropriate authorities.

#### 8. How will your privacy be protected?

All personal and survey information collected remains confidential in accordance with the National Health and Medical Research Council ethical guidelines and the Australian 1988 Privacy Act. Your personal information will be securely stored separately from your survey answers. The research database and participant contact information will be securely stored on servers, or hosted through cloud computing providers, physically located within Australian borders. These locations are protected by firewalls.

Access to any identifiable data (such as names and contact details) will be restricted to members of the research team and those outlined in this information statement, unless you have consented otherwise; or disclosure is required by law in order for us to comply with our regulatory obligations.

The survey will be completed online through REDCap (Research Electronic Data Capture), a secure web-based database system. REDCap is a purpose-built software application for the conduct and management of medical research surveys and case report forms for clinical trials. The REDCap application is hosted within Australian borders on Hunter Medical Research Institute secure servers, which are both physically and virtually secured. User authentication is required for logging into REDCap. All database edits and data entries completed by each user (including REDCap Administrators) are logged in the project's audit trail.

# Participant Information Statement and Consent Surveys



The de-identified survey data captured from the online survey will be stored in the research database, separate from participant contact information. For extra privacy protection, different ID numbers will be assigned to these two databases, with the key between the two sets of IDs limited to a small number of staff. Copies of de-identified survey datasets are also archived electronically at the Australian Data Archive (a national repository for the curation of research data assets).

The data will be securely retained for at least five years after the study finishes, and stored in accordance with the University of Newcastle's Research Data and Materials Management Guideline (<a href="https://policies.newcastle.edu.au/document/view-current.php?id=72">https://policies.newcastle.edu.au/document/view-current.php?id=72</a>) or any successor Guideline and applicable University of Newcastle policy provisions (as amended from time to time). After the closure of the study and the mandatory retention period, all personally identifying information (such as names, dates of birth and contact details) will be securely destroyed. De-identified survey data will continue to be maintained in the Australian Data Archive.

#### 9. How will information collected by the research team be used?

If you choose to participate, you will be joining a study that may inform trauma-informed care recommendations and policies.

Individual participants will not be identifiable in any of the outputs generated from the research project, but individual anonymous responses may be quoted. It is expected that the de-identified study results may be used in consensus guidelines, journal articles, reports, conference presentations, seminars, policy submission and recommendations.

Non-identifiable data may be shared with other parties as part of a peer-review process to verify the robustness and integrity of the study, or to contribute to further research and public knowledge.

You will have the opportunity to indicate that you would like a copy of the summary of the results at the end of your survey. Alternatively, please contact the Chief Investigator on (02) 40420690 or <a href="mailto:deborah.loxton@newcastle.edu.au">deborah.loxton@newcastle.edu.au</a>. A summary will be available after June 2025.

#### 10. What you need to do in order to participate

Please read this Information Statement in its entirety and be sure you understand all of the information provided before you agree to participate.

If there is anything you do not understand, or if you have questions, contact the Project Manager Emma Byrnes on (02) 40420706 or <a href="mailto:emma.byrnes@newcastle.edu.au">emma.byrnes@newcastle.edu.au</a>, or the Chief Investigator Professor Deb Loxton on (02) 40420690 or <a href="mailto:deborah.loxton@newcastle.edu.au">deborah.loxton@newcastle.edu.au</a>

If you would like to participate, please click on the following link <a href="https://redcap.link/Victim-survivors">https://redcap.link/Victim-survivors</a> and complete the online survey. If you would then like to complete a follow up interview, please indicate this at the end of your survey. You are encouraged to retain a copy of this document for your reference.

## Participant Information Statement and Consent Surveys



#### 11. Do you need more information?

If you would like more information about this research project, please contact the Project Manager Emma Byrnes on (02) 40420706 or <a href="mailto:emma.byrnes@newcastle.edu.au">emma.byrnes@newcastle.edu.au</a> or click the website link for more information <a href="mailto:https://cwhr.com.au/unpacking-trauma-informed-care/">https://cwhr.com.au/unpacking-trauma-informed-care/</a>

Thank you for considering this invitation,

Professor Deb Loxton

Director of the Centre for Women's Health Research and the Australian Longitudinal Study on Women's Health

University of Newcastle

#### **Research Team**

Name	Affiliation
Prof Deborah Loxton	University of Newcastle
Dr Melissa Harris	University of Newcastle
Ms Emma Byrnes	University of Newcastle
Ms Zoe Crittenden	University of Newcastle
Ms Jemma Henderson	University of Newcastle
Professor Kelsey Hegarty	University of Melbourne
Associate Professor Laura Tarzia	University of Melbourne
Associate Professor Emma Barrett	University of Sydney
Dr Rebecca Waters	Curtin University
Ms Lisa Shippley	Lived-experience consumer investigator
Ms Kristine Vicca	Lived-experience consumer investigator
Dr Susanne Armstrong	Lived-experience consumer investigator
Dr Nafiseh Ghafournia	Lived-experience consumer investigator
Ms Joanne Bell	Lived-experience consumer investigator

#### Concerns or complaints about this research

This project has been approved by University of Newcastle's Human Research Ethics Committee, Approval No. H-2024-0136

# Participant Information Statement and Consent Surveys



If you have concerns about your rights as a participant in this research, or if you have a complaint about the manner in which the research is conducted, you can contact the Chief Investigator Deb Loxton on (02) 40420690 or <a href="mailto:deborah.loxton@newcastle.edu.au">deborah.loxton@newcastle.edu.au</a>.

If you would prefer to contact someone independent of the research project, you can forward your concerns to:

Human Research Ethics Officer Research and Innovation Services University of Newcastle University Drive Callaghan NSW 2308, Australia

Phone: (02) 4921 6333

Email: <u>Human-Ethics@newcastle.edu.au</u>