



## PARTICIPANT INFORMATION SHEET

Version 2 31052022

<b>PROJECT TITLE:</b>	<b>Murru Minya Baarra 1: Exploration of Aboriginal and Torres Strait Islander communities' experiences of health research (Survey)</b>
<b>HREC REFERENCE NUMBER:</b>	<b>1924/22 (AH&amp;MRC), EO323-20220414 (AIATSIS), H-2022-0211 (UoN)</b>
<b>PRINCIPAL INVESTIGATOR:</b>	<b>Dr Michelle Kennedy</b>
<b>INVESTIGATORS AND RESEARCH TEAM:</b>	<b>Jamie Bryant, Bree Hobden, Alexandra McGhie, Ray Lovett, Alex Brown, Mark Wenitong, Jaqui Hughes, Sandra Eades, Catherine Chamberlain, Maggie Walter, Kelvin Kong, Peter O'Mara, Kalinda Griffiths, Romany McGuffog, Tanika Ridgeway, K Booth, Felicity Collis</b>
<b>INSTITUTION RESPONSIBLE FOR THE RESEARCH:</b>	<b>The University of Newcastle</b>
<b>PROJECT SPONSER/FUNDER:</b>	<b>NHMRC</b>

### Who is conducting this research?

An Aboriginal and Torres Strait Islander led research team at the University of Newcastle is undertaking research to investigate Aboriginal and Torres Strait Islander communities' experiences and involvement in health research. This research is funded by the National Health and Medical Research Council (NMHRC).

### What is this research about?

The aim of this project is to understand the experiences of Aboriginal and Torres Strait Islander communities in health research. This knowledge will contribute to the development of practical recommendations to strengthen ethical practices, the research workforce and research conducted with Aboriginal and Torres Strait Islander people and communities.

### Who can complete this survey?

You are eligible to participate if you are a Chief Executive Officer (CEO) or General Practice Manager of an Aboriginal and Torres Strait Islander organisation currently delivering health services to a community (i.e., Aboriginal Community Controlled Health Service (ACCHS)).

### What does participation involve?

You will be asked to complete an online survey that takes around 5-10 minutes to complete. You will be asked a series of questions around your service's engagement in Aboriginal and Torres Strait Islander health research. You will also be asked to provide some demographic information about your service. At the end of the survey, you will be asked to indicate your interest in hosting yarning circles in your community.

### What are the risks and benefits of participating?

For your participation, you can enter the draw to win one of 5 x \$100 gift vouchers. Your survey responses will also provide valuable information about your community's experiences with health research and ways to improve research into the future. The questions are not expected to cause any



distress or discomfort. If the survey results in any emotional distress, then you may contact Lifeline's free national counselling service at 13 11 14 or Beyond Blue's helpline on 1300 22 4636.

### What choice do you have?

Participation in this research is entirely your choice. **This means you can say NO.** Whether you choose to participate will not impact you in any way. You may stop completing the survey at any time without giving a reason.

### How will your privacy be protected?

The survey is hosted on REDCap, and the data will be stored in password-protected files and only accessed by the researchers on the team. We don't ask any personal information, your responses will be non-identifiable. The contact details asked at the end for the survey for yarning circles will be kept separate from the survey questions.

All hard copies of study documentation will be stored in a locked filing cabinet at the University of Newcastle. All electronic data will be stored in password protected files on the University of Newcastle secure network. Identifying data (i.e., names and contact details) will be stored separately. Only the key research personnel will have access to this data. Data will be stored for a minimum of 7 years in line with University of Newcastle policy.

### What will the information collected be used for?

This information will help the research team to have a better understanding of Aboriginal and Torres Strait Islander communities' knowledge, experiences, and perceptions of research processes. This will inform the development of strategies to improve research and ethical processes in Aboriginal and Torres Strait Islander health. The information may be published in scientific journals and used in presentations at national and international conferences. A Round table will be held at the conclusion of the project to develop key recommendations to improve the conduct of Aboriginal and Torres Strait Islander health research. This information will form a key aspect of this discussion. Only de-identified data will be presented in any reports or publications arising from this research.

### Aboriginal and Torres Strait Islander people are actively involved in this project

This project is Aboriginal and Torres Strait Islander-led, with 13 members of the research team being Aboriginal and/or Torres Strait Islander researchers. For further information on our research team, please visit [www.murruminya.com.au](http://www.murruminya.com.au).

- **Dr Michelle Kennedy** (Wiradjuri, University of Newcastle)
- **Prof. Raymond Lovett** (Wongaibon Ngiyampaa, Australian National University)
- **Prof. Alex Brown** (Yuin, The University of Adelaide)
- **Dr Mark Wenitong** (Kabi Kabi, The Lowitja Institute)
- **A/Prof. Jacqui Hughes** (Wagadagam, Flinders University)
- **Prof. Sandra Eades** (Noongar, The University of Melbourne)
- **Prof. Catherine Chamberlain** (Palawa Trawlwoolway, La Trobe University)
- **Dist. Prof. Maggie Walter - Ermerita** (Palawa, University of Tasmania)
- **Prof. Kelvin Kong** (Worimi, University of NSW, University of Newcastle)
- **Prof. Peter O'Mara** (Wiradjuri, University of Newcastle)
- **Dr Kalinda Griffiths** (Yawuru, University of NSW)
- **Tanika Ridgeway** (Worimi, University of Newcastle)



- **Felicity Collis** (Gamilaroi, University of Newcastle)

The National Health Leadership Forum and Aboriginal and Torres Strait investigators will oversee all aspects of the research and ensure it meets the principles and values for ethical research with Aboriginal and Torres Strait Islander people.

### What will happen next?

Please read this Information Statement and make sure you understand it before you agree to take part. If you would like to participate, please click **here** to complete the consent form and begin the survey.

### Complaints

This project has been approved by the University's Human Research Ethics Committee, (HREC Reference No. H-2022-0211), the Aboriginal Health & Medical Research Council of NSW (AH&MRC) (HREC Reference No. 1924/22), and the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) (HREC Reference No. EO323-20220414). Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred:

- The Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 49216333, email [Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au);
- AH&MRC, Aboriginal Health & Medical Research Council of NSW, Harvey Street Little Bay NSW 2036 Australia, telephone (02) 9212 4777, email [ethics@ahmrc.org.au](mailto:ethics@ahmrc.org.au);
- The Executive Director of Research or the Chair of the AIATSIS Research Ethics Committee, AIATSIS, 51 Lawson Crescent, Acton ACT 2601, email [ethics@aiatsis.gov.au](mailto:ethics@aiatsis.gov.au)

### Further information and who to contact

If you have any questions or comments, or if you require any further information about this research project, then please contact the Chief Investigator, Dr Michelle Kennedy, School of Medicine and Public Health, The University of Newcastle, Callaghan, NSW 2308, Australia.  
Email: [Michelle.Kennedy11@newcastle.edu.au](mailto:Michelle.Kennedy11@newcastle.edu.au), Telephone: (02) 4055 3313