

## Aspirations for community controlled research

Have your say about the priorities, experiences and aspirations for future health and wellbeing research led by Aboriginal and Torres Strait Islander community controlled organisations.

# Participant Information Sheet – Survey

## Project Title:

Looking back to look forward: Aspirations for Community Controlled Research

## Researchers:

Paul Stewart, Michael Newman, Rosemary Smith, Jaki Adams, Sonia Waters, Jo Cackett, Leanne Coombe, Deb Knoche, Aaliyah Davey, and Kathleen Stacey.

## Organisation:

Lowitja Institute

## What is the project about?

An Aboriginal-led research team at Lowitja Institute is conducting this research. We are Australia's only Aboriginal and Torres Strait Islander community controlled health research institute, named in honour of our namesake and co-patron, the late Dr Lowitja O'Donoghue AC CBE DSG. We deliver high-impact quality research, knowledge exchange, and by supporting a new generation of Aboriginal and Torres Strait Islander health researchers. We were established to centre our peoples within research, to ensure that research is no longer done on and about us; and instead advocate for and facilitate research **done by us and for us**.

Lowitja Institute's *2024-2027 Strategic Plan* highlights our commitment to pursuing a new generation of solutions, which make a real difference to the health and wellbeing of Aboriginal and Torres Strait Islander peoples, that are sustainable into the future. This project will support the development of Aboriginal and Torres Strait Islander research priorities and ways of working to progress this agenda. However, we also need to look at, and learn from, the past.

The aim of the project is to understand the aspirations of the Aboriginal and Torres Strait Islander community controlled sector in relation to research. We understand that Lowitja Institute grant rounds are currently oversubscribed and there is a need to increase the availability of funding for health research that reflects the priority needs of Aboriginal and Torres Strait Islander peoples.

The project objectives therefore include:

1. To assess how Lowitja Institute's activities produce benefits for external stakeholders and how this can be further strengthened.
2. To develop an Aboriginal and Torres Strait Islander led research agenda for health and wellbeing that reflects community needs.
3. To explore Aboriginal community controlled organisations' aspirations, scope the sector's level of readiness for research, and explore what the enablers and barriers are to achieving those aspirations.

Overall, this project will include a survey, descriptive case studies and workshops.

## Who is involved in the project?

This research project is being conducted by an Aboriginal and Torres Strait Islander led team at Lowitja Institute. The researchers involved in the project are Paul Stewart, Michael Newman, Rosemary Smith, Jaki Adams, Sonia Waters, Jo Cackett, Leanne Coombe, Deb Knoche, Aaliyah Davey, and Kathleen Stacey, who work for Lowitja Institute. This project is funded by Lowitja Institute.

## Why have I been invited to participate?

You are being invited to complete the **survey** because you have interacted with Lowitja Institute.

This survey offers a way to have your say about the priorities, experiences and aspirations for future health and wellbeing research led by Aboriginal community controlled organisations. This project will privilege Aboriginal and Torres Strait Islander people and communities' experiences from across the country.

We are inviting all those who have interacted with Lowitja Institute, via the members community or as external stakeholders who have accessed or utilised tools and resources, conferences or policy and advocacy activities, to complete the survey. By continuing with this survey, you are providing your agreement to participate.

Participation in this project is entirely your choice, it is voluntary, and you can pull out at any time. All responses are anonymous and will be kept private and confidential. Withdrawing won't change your relationship with the researchers, Lowitja Institute, or anyone else. Participants will not be paid for completing the survey.

## What will the researchers do and when?

The researchers are asking you to complete this online survey, which takes around 10 minutes to complete, but may be less depending on your relationship with Lowitja Institute and how many questions you will consequently be directed to answer. In the survey, you will be asked questions about research, research priorities, and how Lowitja Institute can improve its support and advocacy.

This project will inform the research commissioning, workforce development, and policy and advocacy work of Lowitja Institute for the next three years.

## What will happen to my information?

This project is delivered by Lowitja Institute, a community controlled Aboriginal and Torres Strait Islander health research peak body. The project has been developed in line with principles of Indigenous data sovereignty, acknowledging the rights of Indigenous people to control the development and dissemination of data for and about them.

Any information that is obtained in connection with this research project and that can be used to identify you will remain confidential unless otherwise permitted by you, or as required by law. The procedures for ensuring the confidentiality of your information during the collection phase and the later publication of results are by collecting de-identified information in the survey and storing your contact details in a separate, secure database. Only the research team will have access to this information.

Your information will contribute to the development of a rigorous, community-led Aboriginal and Torres Strait Islander research agenda for health and wellbeing that will inform governments, research funding bodies and Lowitja Institute's own research commissioning processes, as well as our policy and advocacy agenda into the future.

Updates on this research project will be published in *The Doris* newsletter and reports outlining results will be made available on Lowitja Institute's website. Copyright will be owned by Lowitja Institute.

## What are the potential risks?

Participation in this project 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. You may exit the survey at any time – your data will not be used if you do not submit the survey. As the survey is anonymous, if you complete and submit the survey, we cannot remove your responses as we will not know which responses you submitted.

We don't anticipate any risks being involved in this project. The questions are not expected to cause discomfort or distress. However, should you experience distress or need to seek support, please reach out to one of the following services:

- [13YARN | 13 92 76 - 24/7 yarning support for Aboriginal and Torres Strait Islander peoples](#)
- [Brother to Brother | 1800 435 799 - support line for Aboriginal and Torres Strait Islander men and youth](#)
- [WellMob - resources for social, emotional and cultural wellbeing](#)
- [Gayaa Dhuwi \(Proud Spirit\) Australia - peak body for Aboriginal and Torres Strait Islander mental health and wellbeing](#)
- [Lifeline Australia | 13 11 14 – crisis support and suicide prevention services](#)
- [Beyond Blue | 1300 224 636 – support for anxiety, depression and suicide prevention](#)

## Data storage

During the project, data will be stored on password protected computers as electronic files on Lowitja Institute's secure network. All survey results will be de-identified. Only the key research personnel will have access to this data. The information will be kept for a minimum of five years.

## Culturally restricted information

This project is focused on health and wellbeing research priorities and does not intend to be collecting any culturally restricted information. If culturally sensitive/restricted data is unexpectedly collected during the research activities, we will seek expertise and advice from the communities to whom it belongs.

## Inclusion and exclusion criteria

You are eligible to participate if you are an Aboriginal and Torres Strait Islander researcher, currently working for an Aboriginal and Torres Strait Islander community controlled organisation, or have interacted with Lowitja Institute via the members community or as an external stakeholder who has accessed or utilised tools and resources, conferences, or policy and advocacy activities of Lowitja Institute and are over 18 years of age.

## Contact

If you have queries about the research, you can contact project manager A/Prof Leanne Coombe at [leanne.coombe@lowitja.org.au](mailto:leanne.coombe@lowitja.org.au)

## Complaints

If you have a complaint about this research, you can contact:

- Deputy CEO, Lowitja Institute, 71 Oxford Street, Collingwood Victoria 3066 (e) [Michael.Newman@lowitja.org.au](mailto:Michael.Newman@lowitja.org.au)
- The Executive Director of Research, AIATSIS, 51 Lawson Crescent, Acton ACT 2601, (e) [ethics@aiatsis.gov.au](mailto:ethics@aiatsis.gov.au)
- The Chair of the AIATSIS Research Ethics Committee, AIATSIS, 51 Lawson Crescent, Acton ACT 2601, (e) [ethics@aiatsis.gov.au](mailto:ethics@aiatsis.gov.au)
- If I think there has been a breach of my privacy I can write to the Office of the Australian Information Commissioner, GPO Box 5218 Sydney NSW 2001 or call 1300 363 992.

## Ethics Committee Clearance

The ethical aspects of this research project have been approved by the AIATSIS Research Ethics Committee #REC-0579.