Mayi Kuwayu Study Partners

Aboriginal Health Council of South Australia Inc.

AIATSIS
AUSTRALIAN INSTITUTE OF ABORIGINAL AND TORRES STRAIT ISLANDER STUDIES

ABORIGINAL MEDICAL SERVICES ALLIANCE NORTHERN TERRITORY
AMSANT

VACCHO

WINNUNGA NIMMITYJAH
ABORIGINAL HEALTH SERVICE

TASMANIAN ABORIGINAL CENTRE INC.

NACCHO
National Aboriginal Community Controlled Health Organisation

AHCWA

Australian National University

For your records

If you agree to participate in the Study you are also asked to consider agreeing to have other information about you included. Other records you can agree to be released to the Mayi Kuwayu Study team are:

- Hospital records
- Cancer records
- Medicare Services provided
- Pharmaceutical Benefits scheme
- Death records

You do not have to agree to provide access to these records, however they provide us with the ability to understand how your survey answers affect hospital access, Medicare access and services.

This information will help us to have a more detailed view of your health and wellbeing.

You can agree to data being included until the end of the Study, or for the duration of your involvement in the Study. Your agreement (consent) can change at any time.

You are also being asked to agree to being contacted in the future to fill out the same survey again. This will happen for the first time within three years of filling out the survey.

Funded by: the Lowitja Institute — Australian Government National Health and Medical Research Council NHMRC

Information for participants

What is Mayi Kuwayu?

Mayi Kuwayu
The National Study of Aboriginal and Torres Strait Islander Wellbeing

Mayi Kuwayu - the National Study of Aboriginal and Torres Strait Islander Wellbeing is a longitudinal cohort Study being led by Aboriginal researchers and staff at the Australian National University (ANU). Mayi Kuwayu means to follow Aboriginal people over time in Ngiyampaa language.

The Study aims to understand how Aboriginal and/or Torres Strait Islander culture relates to health and wellbeing.

The team has worked with many Aboriginal and Torres Strait Islander communities over the last three years to develop questions that best represent Aboriginal and/or Torres Strait Islander culture and wellbeing. These questions have been made into a survey.

The Study will provide information for the community, for services and for policy makers about the things that improve Aboriginal and Torres Strait Islander health and wellbeing.

Who can participate?

Any Aboriginal or Torres Strait Islander person over 16 years of age can complete the survey.

What do I need to do?

To take part you need to complete the survey. This will take about 30 minutes. Then please sign and date the consent form. Your signature on the consent form is important, so please make sure that the consent form is signed before returning it.

Do I have to participate?

No. It is your choice if you take part in the Study. If you agree to participate and then change your mind you are free to withdraw from the Study at any time. To withdraw, free-call us on 1800 531 600 or email mkstudy@anu.edu.au

How do I know my information will be treated confidentially?

This Study is bound by strict privacy laws. All information collected will be treated completely confidentially and used for this research only. No information will be reported in a way that will allow you, your household or your community to be identified.

Further protecting your information, the Study has a Data Governance committee, a community and technical panel and is accountable to Human Research Ethics Committees in each State and Territory.

How will information from the Study be used to help me and others?

Information from Mayi Kuwayu will give us a better understanding of how Aboriginal and Torres Strait Islander culture relates to health and wellbeing. The data from the Study is intended to be used to better inform services, programs and policy.

The importance of change over time?

An important part of this Study is seeing how things in the survey change for you over time. That is why we are asking you to agree to provide your contact details so we can send you the survey every three years to look at changes.

Where can I find out more about the Study?

You can call the Study helpline on 1800 531 600 or email mkstudy@anu.edu.au to find out more and to receive regular updates on the Study's progress. People taking part can also agree to receive newsletters about the Study.

Mayi Kuwayu
The National Study of Aboriginal and Torres Strait Islander Wellbeing

Any questions or comments?

If you have any questions, comments or concerns about the Study, you can call our helpline on 1800 531 600.

You can also contact the Mayi Kuwayu Study Director:

Dr Ray Lovett
mkstudy@anu.edu.au
1800 531 600

For any complaints, you may also contact:

Ethics Manager
The ANU Human Research Ethics Committee
The Australian National University
Human.ethics.officer@anu.edu.au,

You can also contact the relevant State/Territory Human Research Ethics Committee:
http://www.healthinfonet.ecu.edu.au/health-infrastructure/ethics/organisations/hrec