

Our cultures count.



Information for Study participants

Mayi Kuwayu, the National Study of Aboriginal and Torres Strait Islander Wellbeing is controlled by Aboriginal and Torres Strait Islander researchers. In Ngiyampaa language, 'Mayi Kuwayu' means to follow Aboriginal people over time.

What is the Study about?

This Study is about how Aboriginal and Torres Strait Islander culture links to health and wellbeing. It's about how culture makes us strong.

Who runs the Study?

The Study is designed, led and controlled by Aboriginal and Torres Strait Islander people. The Study is **not** run by government.

Who can participate?

Any Aboriginal and/or Torres Strait Islander person 16 years or older can complete the survey. You do not have to participate. It is your choice to take part.



What do I need to do?

- Complete the survey on paper, online, or over the phone. By starting the survey and returning it to us you are providing consent to be involved in the study.
- Write your full name and address and sign the front page of the survey.
- If you agree to be contacted by our team in the future fill in your details.
- If you agree to have your data linked to your health records, such as Hospital records, Cancer records and Death records fill in the circle next to **Yes**.
- The survey will take you roughly 30-45 minutes to complete.

How will this Study help me and my community?

Sharing your story, and adding it to other people's stories, means we can show how to make services, programs and policy better for the health and wellbeing of Aboriginal and Torres Strait Islander people.

We will share our findings with Aboriginal and Torres Strait Islander communities around Australia so they can use the results in ways that help them.

How will my information be used?

Your information will only be used for research about Aboriginal and Torres Strait Islander health and wellbeing. If you agree to have your survey data linked to your health records, this will help us understand how your survey answers relate to using health services and how your health and wellbeing can change over time.

Follow up in the future

We would like to contact you in the future. If you agree, we will send you follow-up surveys so we can track your health and wellbeing over time. We will also send you updates on the Study and its findings.

What are the potential risks?

The survey covers topics such as the Stolen Generations, cultural practices, racism and worries in the community. Some questions may make you feel uncomfortable or upset. If so you can contact Lifeline on **131 114** or visit lifeline.org.au.

Visit sewbmh.org.au/location/list for a list of services in your local community.

For more information visit our website: mkstudy.com.au, call 1800 531 600 (free) or find us on social media



Has the Study been approved?

The ethical aspects of this research have been approved by the following Human Research Ethics Committees:

ACT Health (2018/ETH/00205);
AH&MRC (1268/17);
AHREC (04-17-723);
AIATSIS (E030/22052015);
ANU (2016/767); CAHREC (CA-17-2810);
Department of Health (Cth) (10-2017);
Metro South Health (HREC/19/QMS/56115);
Northern Territory Department of Health and Menzies School of Health Research (2017- 2804);
St Vincent's Hospital Melbourne (HREC 132/17);
University of Tasmania (H0016473);
WAAHEC (787).

Don't want to be part of the Study anymore?

You can withdraw from the Study at any time by calling us on 1800 531 600 (free) or emailing mkstudy@anu.edu.au. If you request to leave the Study, we will securely destroy your data.

Your consent will still apply following your death or disablement. If you wish for your data to be withdrawn from the Study in that event, let your next of kin (or other person responsible for your affairs) know so that they can contact us to withdraw you from the Study.

How do I know my information will be safe?

This Study is bound by strict privacy laws (Privacy Act 1988*). All information collected will be used for this research only and treated confidentially (as far as allowed by law). No information will be reported in a way that will allow you, your household or your community to be identified.

All data will be stored securely at the ANU. Data will be kept for the duration of Mayi Kuwayu Study research. The use of data from the Mayi Kuwayu Study will be strictly controlled by an Aboriginal and Torres Strait Islander governance committee.

**In collecting your personal information within this research, the ANU must comply with the Privacy Act 1988. The ANU Privacy Policy is available at https://policies.anu.edu.au/ppl/document/ANUP_010007 and it contains information about how a person can: access or seek correction to their personal information; or complain about a breach of an Australian Privacy Principle by ANU, and how ANU will handle the complaint.*

Any questions, comments, or concerns?

If you have any questions about the Study, or if you know someone else who would like to do the survey, call us on 1800 531 600 (free), email us at mkstudy@anu.edu.au or visit mkstudy.com.au.

If you have any concerns about how this research has been conducted, please contact: The Chair of the AIATSIS Research Ethics Committee, AIATSIS, 51 Lawson Crescent, Acton ACT 2601 on (02) 6246 1111 or ethics@aiatsis.gov.au.

Mayi Kuwayu Study Partners:



Mayi Kuwayu is funded by:

