

Information for Study participants

Kulay Kalingka explores cancer outcomes for Aboriginal and Torres Strait Islander peoples. The Study is controlled by Aboriginal and Torres Strait Islander researchers. In Ngiyampaa language, 'Kulay Kalingka' means 'net bag in the water'.

What is the Study about?

The Kulay Kalingka Study will monitor and inform improvements in cancer outcomes for Aboriginal and Torres Strait Islander peoples against Cancer Australia's National Cancer Control Indicators. The study will provide data about our experiences of cancer where no data currently exists.

Who runs the Study?

The Study is designed, led, and controlled by Aboriginal and Torres Strait Islander peoples. The Study is funded by Cancer Australia.

Who can participate?

Any Aboriginal and/or Torres Strait Islander person 18 years or older with or without a cancer diagnosis can complete the survey. You do not have to participate. It is your choice to take part.



What do I need to do?

- The survey will take you roughly 15-20 minutes to complete.
- Complete the survey on paper, online (www.kulaykalingkastudy.com.au), or over the phone 1800 531 600.
- Write your full name and address on the front page of the survey.
- By returning the survey to us you are providing consent to be involved in the study.

How will this Study help me and my community?

Sharing your cancer story, and adding it to other people's stories, means we can show how to make services, preventative programs, and policy better for Aboriginal and Torres Strait Islander peoples experiencing or caring for someone with cancer.

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?

We will only use your information for research about Aboriginal and Torres Strait Islander cancer outcomes. Linking your survey data to your health records will help us understand how your survey answers relate to using health services and how your health and wellbeing can change over time. If you agree to have your data linked, select 'Yes' on the Consent Form.

Follow up in the future.

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

What are the potential risks?

The survey covers topics such as cancer experiences, awareness, attitudes, treatment, and carer journeys. Some questions may make you feel uncomfortable or upset. Contact Lifeline at 131 114. Resources are at: beyondblue.org.au/who-does-it-affect/aboriginal-and-torres-strait-islander-people/helpful-contacts-and-websites

Has the Study been approved?

The ethical aspects of this research have been approved by the following Human Research Ethics Committees: AIATSIS (EO324-20220414 & REC-0121) and ANU (2022/465 & 2023/278).

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

You can withdraw from the Kulay Kalingka Study any time by free calling us on 1800 531 600 or emailing kulay.kalingka@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.



WURRIRRI-L – extracting (Bernard Lee-Singleton)

This artwork looks at how rainforest Bama poses highly toxic foods by placing them in woven baskets and running it through a slow-moving stream to leach out their toxins, making them safe over time. The artwork illustrates how people and families fighting cancer can include – alongside clinical treatments – Indigenous health and wellbeing concepts for cultural, medical, and spiritual healing.

Any questions, comments, or concerns?

If you have any questions about Kulay Kalingka, or if you know someone else who would like to do the survey, contact us at:

- free call 1800 531 600
- email kulay.kalingka@anu.edu.au
- visit kulaykalingkastudy.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 (02) 6246 1111 or ethics@aiatsis.gov.au.

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 the Kulay Kalingka Study, then securely destroyed. Data 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 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.

Mayi Kuwayu Study.

Kulay Kalingka is a sub-study of the Mayi Kuwayu Study. For more information about the Mayi Kuwayu Study, please visit mkstudy.com.au