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## Study Protocol: Kulay Kalingka, a national cohort study of Aboriginal and Torres Strait Islander peoples' cancer experiences

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**Study Protocol: Kulay Kalingka, a national cohort study of Aboriginal and Torres Strait Islander peoples’ cancer experiences**

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## Abstract

### Introduction

Aboriginal and Torres Strait Islander peoples are the First Peoples of Australia. Since settler-colonisation, Aboriginal and Torres Strait Islander peoples have experienced disparities in health outcomes, including cancer, when compared to non-Indigenous Australians. Aboriginal and Torres Strait Islander peoples have higher cancer incidence rates, higher cancer mortality rates, and lower participation rates in cancer screening programs.

The Kulay Kalingka Study will be a national cohort study designed to understand Aboriginal and Torres Strait Islander people's beliefs about cancer, experiences with cancer care and treatment, and to improve experiences and outcomes.

### Method and analysis

Kulay Kalingka participants will be sampled from the Mayi Kuwayu Study and in-community recruitment. Mayi Kuwayu Study participants aged 18 years or over who consented to being recontacted will be invited to participate, with the goal of recruiting four participants who have never had a cancer diagnosis for every one participant who has had a cancer diagnosis.

From 2023, Kulay Kalingka participants will be invited to complete a questionnaire relevant to their cancer-status. Collecting this community-driven data will enable the monitoring and reporting of national trends over time. This will guide national cancer control in research, policy and clinical care and improve outcomes for Aboriginal and Torres Strait Islander peoples.

### Ethics and dissemination

The Kulay Kalingka Study has ethics approval from Australian Institute of Aboriginal and Torres Strait Islander Studies (#EO324-20220414) and the Australian National University (#2022/465). The Kulay Kalingka Study is being developed with Aboriginal and Torres Strait Islander communities, and follows the Ma'am nayri Wingara Indigenous Data Sovereignty Collective principles [1].

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**Article Summary**  
**Strengths and Limitations**

- The Kulay Kalingka Study will answer Aboriginal and Torres Strait Islander community calls to better understand cancer attitudes, beliefs and experiences, and for greater inclusion of and leadership by Aboriginal and Torres Strait Islander patients, families and communities in cancer research.
- The Kulay Kalingka Study will provide Aboriginal and Torres Strait Islander led, designed, and governed national-level data to monitor and guide improved cancer awareness, understandings of care, treatment, and service delivery for Aboriginal and Torres Strait Islander peoples.
- Contribute to monitoring and reporting on 37 of Cancer Australia’s National Aboriginal and Torres Strait Islander Cancer Control Indicators, where no data currently exist.
- The study is designed to be inclusive of the diversity of the Aboriginal and Torres Strait Islander population and is not designed to be representative of this population.

## Introduction

We begin by acknowledging the sovereign Indigenous peoples around the world who are the Custodians of their lands, waterways and skies, who have cared for and maintained Country, culture and community since time immemorial. We acknowledge the ancestral lands of the Ngannawal and Ngambri peoples on which this study protocol was written, and thank the Elders past and present for our safe passage through their Country.

By qualification, we the authorship team, are researchers, but our positioning from the onset of this Study is that of sovereign Aboriginal and Torres Strait Islander peoples with our own cultures, histories and communities and allies supporting such sovereignty. We have a shared commitment of service to mob that seeks to understand how mob can live healthy lives. We follow the Indigenist and Indigenous research methodologies set before us by trailblazers including Nurungga Professor Lester-Irabinna Rigney[2], Palawa Distinguished Professor Maggie Walter[3], Opaskwayak Cree Researcher Shawn Wilson[4], and Ngāti Awa, Ngāti Porou, Tūhourangi Professor Linda Tuhiwai Smith[5]. By doing so we privilege our cultural knowledges, ways of knowing, being and doing, and conduct our research with respect, responsibility, generosity, obligation and reciprocity to our peoples[6].

Aboriginal and Torres Strait Islander peoples maintain the oldest living cultures in the world, with an estimated 250 Aboriginal and Torres Strait Islander languages and 600-700 dialects across the continent prior to colonisation[7]. Along with diverse languages, Aboriginal and Torres Strait Islander groups also have diverse histories, cultures, lore/law and other practices and have lived, for generations, healthy and culturally enriched lives[8, 9]. Colonial processes and policies dispossessed and dislocated Aboriginal and Torres Strait Islander peoples from our families, Country, cultures and languages, but culture remains strong and languages continue and many are being reclaimed. Currently, there are an estimated 798,400 Aboriginal and Torres Strait Islander peoples living in Australia. Over 30% of the population lives in major cities of Australia, while 24% live in inner regional Australia, 20% in outer regional Australia, and 7% in remote or very remote Australia [10]. Today, the Aboriginal and Torres Strait Islander population bears a disproportionate burden of disease, including cancer.

Prior to colonisation, cancer impacted Aboriginal and Torres Strait Islander populations but the attribution of illness to cancer was limited[11]. Only in the last two decades has cancer received attention specific to our population[12]. This is largely due to the high number of conditions other than cancer that greatly impact Aboriginal and Torres Strait Islander peoples, including poor mental health, injury, and cardiovascular disease[13]. The quality of data also limits what we know about diagnosis and treatment outcomes via cancer registry data[14]. In more recent times cancer has become one of the leading contributors to the burden of disease for Aboriginal and Torres Strait Islander peoples[15].

Between 2015-2019, cancer and other neoplasms were the leading cause of death for Aboriginal and Torres Strait Islander peoples in states where adequate data on deaths exists, contributing to almost a quarter of total deaths[15]. The most commonly diagnosed cancers are lung, breast, colorectal, prostate and head and neck cancers. These cancer types are amenable to prevention and have high fatality rates[15].

In 2012-2016, for all cancers combined, incidence was 14% higher among Aboriginal and Torres Strait Islander peoples compared to non-Indigenous peoples[16]. When diagnosed, Aboriginal and Torres Strait Islander peoples are also more likely to be at a more advanced stage of disease impacting prognosis and treatment options, less hospitalisations and wait longer for surgery. From 2015-2019, the age-standardised mortality rate for all cancers for Aboriginal and Torres Strait Islander peoples

was 45% higher than in the non-Indigenous population[16]. Cancer doesn't just effect our older community members. Concomitantly, the median age of an Aboriginal and Torres Strait Islander person in 2016 was 20 years compared with 38 for non-Indigenous peoples, with some types of cancers showing up earlier in the Aboriginal and Torres Strait Islander population compared to the non-Indigenous population[16].

There are a range of risk factors that are associated with an increased likelihood of a person developing cancer. All cancers are caused by changes in genes that control the way cells grow and multiply. However, there are certain exposures that contribute to changes within genes. These exposures are classified as modifiable and environmental. Key modifiable risk factors include tobacco smoking (lung cancer) and alcohol (breast and stomach cancers), and environmental risk factors include exposure too much sun (melanoma)[16]. There is a growing body of evidence internationally that links discrimination and racism to increased prevalence in modifiable risk factors including tobacco smoking, higher levels of alcohol use and obesity. The increased prevalence and mortality from cancer among Aboriginal and Torres Strait Islander peoples are largely due to socially-driven increased prevalence of cancer risk factors[17]. Additional upstream factors that affect Aboriginal and Torres Strait Islander peoples' cancer experiences include barriers to accessing cancer services such as screening and treatment.

Aboriginal and Torres Strait Islander community beliefs about cancer are varied. Many Aboriginal and Torres Strait Islander peoples understand that tobacco, poor diet and other risk factors cause cancer[18]. However, the general population often look to external factors to explain things that are happening to them, rather than looking to factors within their own control[19]. For example, some Aboriginal and Torres Strait Islander communities are unwilling to talk about cancer, believe it is black magic, or believe it to be contagious. Further, some believe cancer invaded the bodies of Aboriginal and Torres Strait Islander peoples when colonisers arrived in 1788[11, 20, 21]. In some Aboriginal and Torres Strait Islander languages, including Aboriginal languages across the Northern Territory, there is no word for cancer[22]. Regardless of the timing of cancer's arrival, it places a heavy burden on those diagnosed with the disease, as well as their families, friends, carers, Elders and the community.

It is in this context that the National Aboriginal and Torres Strait Islander Cancer Framework 2015 was developed by Cancer Australia to provide high level guidance for stakeholders working to improve cancer outcomes and reduce disparities[23]. It aligns with the Optimal Care Pathway (OCP) for Aboriginal and Torres Strait Islander peoples with cancer, which identifies critical seven steps in the patient journey [see figure 1; 23].

Figure 1: Patient-centred care for Aboriginal and Torres Strait Islander people

Cancer Australia developed a set of National Aboriginal and Torres Strait Islander Cancer Control Indicators (NCCI) to monitor performance across the OCP areas[23]. There are 22 indicators in total, and progress in these areas is assessed using 57 measures comprising of:

- 20 measures which are currently reported on the website, available at: <https://ncci.canceraustralia.gov.au/aboriginal-and-torres-strait-islander-cancer-control-indicators>
- 37 measures where no data exist and/or require further progress for data development

No data exist for over half of the Aboriginal and Torres Strait Islander NCCI identified measures, and as a result we cannot monitor progress in a range of areas. It is essential that data about our attitudes,

beliefs and experiences of cancer be developed and governed for and by Aboriginal and Torres Strait Islander peoples. This will help ensure community and relational accountability, which is particularly important given the ongoing colonial context outlined above, including the programs and policies that have aimed to actively erode power, social structures and community resources. In response to the impacts of cancer and the lack of data to inform the Aboriginal and Torres Strait Islander NCCI, a proposed national study is being developed.

The Kulay Kalingka Study will be a prospective national cohort study that is designed to understand Aboriginal and Torres Strait Islander people's beliefs about cancer, experiences with cancer care and treatment, and to improve experiences and outcomes for Aboriginal and Torres Strait Islander peoples with cancer and their families. The Study is designed to inform the Cancer Australia priority areas. The study name, 'Kulay Kalingka' translates to 'net bag in the water' in Ngayampaa (Wongaibon) language. Woven net bags have been used by rainforest Bama (peoples) to process highly toxic foods, whereby foods are placed in net bags and run through a slow-moving stream to leach out their toxins and make them safe over time. This concept is woven into the Kulay Kalingka Study: the net bag is symbolic of how people and families fighting cancer can include Aboriginal and Torres Strait Islander health and wellbeing concepts for cultural, medicinal and spiritual healing, alongside clinical treatments (Figure 2).

Figure 2 Photo of net bag created by Yirrganydji and Nughi artist Nicole Enoch-Chatfield (Goompi's Girl)

## Methods and analysis

### Patient and public involvement statement

The Kulay Kalingka Study arose from Aboriginal and Torres Strait Islander community needs, to better understand cancer attitudes, beliefs and experiences and from calls for the inclusion of Aboriginal and Torres Strait Islander patients, families and communities in cancer research[24]. Additionally, the Study arose from a call from Cancer Australia to improve cancer outcomes for Aboriginal and Torres Strait Islander peoples, including across cancer prevention, screening and early detection, diagnosis and treatment, palliative care and survivorship, and their corresponding service areas[25]. Aboriginal and Torres Strait Islander peoples will be involved in all stages of the project, from development and survey testing through to analysis and dissemination.

There are three stages to Kulay Kalingka Study: the development of the questionnaires, incorporating a literature search, questionnaire item refinement and pilot testing (Figure 3); the recruitment, and analysis to inform the Aboriginal and Torres Strait Islander NCCI (Figure 4). Here, we are detailing stages one and two.

It is essential that Aboriginal and Torres Strait Islander communities are involved in questionnaire development and testing. This participatory-based research approach is necessary in order to help ensure the Study meets the dual criteria of Aboriginal and Torres Strait Islander community relevance and scientific excellence. Aboriginal and Torres Strait Islander peoples are involved in and lead all stages of the Kulay Kalingka Study.

### Stage 1: Development of Questionnaires

#### *Literature search*

We conducted a comprehensive literature search using the Google Scholar database to identify existing questionnaire items and measures that map onto the each of the 22 Aboriginal and Torres



Strait Islander NCCI Indicators. Search terms were developed by the Kulay Kalingka Study team. Final search terms were:

*Aboriginal, Torres Strait Islander, AND cancer, AND awareness, AND beliefs, AND prevention, AND risk reduction, AND smoking cessation programs, AND quit smoking programs, AND screening, AND screening test follow up, AND incidence, AND stage at diagnosis, AND culturally competent health services, AND treatment, AND patient experience*

A second search was conducted to find supplementary questionnaire items and measures that relate to specific cancer types. Final search terms were:

*Aboriginal, AND Torres Strait Islander, AND cancer, AND bladder, AND breast, AND cervical, AND bowel, AND head and neck, AND kidney, AND lung, AND liver, AND melanoma, AND throat, AND ovarian, AND pancreatic, AND prostate, AND stomach, AND thyroid, AND uterine, AND cancer of unknown primary site, AND non-Hodgkin lymphoma*

If research papers did not publish questionnaire items or measures, we contacted corresponding authors and requested these questionnaire items or measures. We also worked with experts in the field and checked reference lists of included material for other relevant questionnaire items and measures.

Finally, items and measures that met the following three criteria were moved into the item development stage for inclusion or modification:

1. had been developed for or used with Aboriginal and Torres Strait Islander peoples
2. captured information about cancer knowledge, attitudes, beliefs, screening, diagnosis, treatment, services and/or systems
3. map onto the Aboriginal and Torres Strait Islander NCCI.

*Item development and refinement*

We also developed new items and measures where no appropriate items existed. These novel quantitative and qualitative were created in collaboration between the Kulay Kalingka Study team, the Thiitu Tharrmay Aboriginal and Torres Strait Islander reference group, Aboriginal and Torres Strait Islander individuals and communities, and Cancer Australia.

The outcome is two questionnaires. Questionnaire 1 is designed for people who have ever had a cancer diagnosis, and focuses on indicators related to cancer screening, diagnosis, care, and experiences of cancer treatment. Questionnaire 2 is designed for people who have never had a cancer diagnosis, which focuses on indicators related to knowledge (including cancer screening), attitudes and beliefs about cancer.

*Pilot testing*

Questionnaire items will be pilot tested prior to rolling out data collection via questionnaire, to ensure that the wording of items supports understanding and reduces cognitive burden and that meaningful data are yielded[26]. This process will assist to assess questionnaire items for appropriateness, accuracy and interpretation. This assessment will directly inform development of the questionnaires, including item inclusion, exclusion and/or modification.

Aboriginal and Torres Strait Islander communities will self-nominate to be part of the pilot testing processes, based on existing community relationships. Each community will self-determine the constitution of the focus groups, in line with Principle 1 of the Australian Institute of Aboriginal and Torres Strait Islander Studies Code of Ethics for Aboriginal and Torres Strait Islander Research[27].

There will be three focus groups at each community, with 6-8 participants in each focus group. Participants will be selected by the communities through word-of-mouth building on relational accountability. Focus groups will be independently conducted with people who have had a cancer diagnosis, and people who have not had a cancer diagnosis. A minimum of 30 pilot-testing participants with a cancer diagnosis will pilot-test Questionnaire 1. A minimum of 30 pilot-testing participants without a cancer diagnosis will pilot-test Questionnaire 2. Focus group participants will be conducted with Aboriginal and/or Torres Strait Islander peoples, aged  $\geq 18$  years. Pilot-testing focus groups are voluntary and participants can leave at any time.

Figure 3: flow-chart of stage 1 (questionnaire development)

## Stage 2: Recruitment

The Kulay Kalingka Study is nested within 'Mayi Kuwayu: the National Study of Aboriginal and Torres Strait Islander Wellbeing' (the Mayi Kuwayu Study). The Mayi Kuwayu Study is a large-scale, longitudinal study of Aboriginal and Torres Strait Islander adults aged  $\geq 16$  years with approximately 11,000 participants to date. The Study aims to improve the understanding of the role cultural factors play in Aboriginal and Torres Strait Islander peoples' wellbeing and their interaction with standard health risk and protective factors. The Mayi Kuwayu Study is developed and governed by Aboriginal and Torres Strait Islander peoples [28, 29].

The Kulay Kalingka Study sampling frame is from baseline Mayi Kuwayu Study participants aged  $\geq 18$  years who have consented to being recontacted by the Mayi Kuwayu Study. Participants will be recruited in 2023 from saltwater, freshwater, desert and Island groups, and living across urban, regional and remote Australia to ensure diversity of experiences are captured in the Kulay Kalingka Study.

All existing Mayi Kuwayu Study participants who self-reported a doctor diagnosed cancer ( $n \approx 700$  participants) will be invited to participate in Questionnaire 1 of the Kulay Kalingka Study. Existing participants who have never had a cancer diagnosis ( $n \approx 2800$ ) will be invited to participate in Questionnaire 2, with the goal of recruiting four participants without cancer for every one participant with cancer. Selection of participants who have never had a cancer diagnosis into the Kulay Kalingka Study sample will be stratified by age, gender and remoteness (see table 1).

Table 1. Selection of Kulay Kalingka study participants (restricted to those who have consented to follow up).

Demographic group	Number in MK Study with cancer (all to be recruited)	Number in MK Study without cancer	Number without cancer to be recruited
Total (incl. missings)	619	7614	2476
<b>Men</b>			
Aged 18-50, major cities	13	416	52
Aged 51+, major cities	91	741	364
Aged 18-50, regional/remote	9	541	36
Aged 51+, regional/remote	135	1032	540
<b>Women</b>			
Aged 18-50, major cities	44	1134	176
Aged 51+, major cities	120	740	480
Aged 18-50, regional/remote	42	1349	168
Aged 51+, regional/remote	137	1145	548
Total (excl. missings)	591	7098	2364

In addition to recruiting existing Mayi Kuwayu Study participants, the Kulay Kalingka Study will conduct supplementary recruitment across self-nominated urban, regional and remote Australian communities. This will enable Aboriginal and Torres Strait Islander peoples with or without a cancer diagnosis, and from diverse settings, contexts, and environments, to participate in the Kulay Kalingka Study if they want to share their story. All Kulay Kalingka Study potential participants will be posted a survey pack in the mail (containing an information sheet, a questionnaire, a national support service brochure, and a pre-paid reply envelope).

Participation in the Kulay Kalingka Study is voluntary and participants can withdraw consent at any time. Potential participants will receive a plain-language information sheet about the study, along with the consent form, support services directory and questionnaire.

Figure 4: Flow-chart of stage 2 (study recruitment)

## Statistical Methods

Analysis of data from Kulay Kalingka Study can be used to monitor and inform improvement in cancer outcomes for Aboriginal and Torres Strait Islander peoples, including generating evidence to inform service delivery, cancer screening, participation in prevention activities, and cancer awareness. Statistical analyses will involve cross-sectional and potentially longitudinal methods if multiple waves of data are collected. We will examine cancer attitudes, beliefs and experiences for Aboriginal and Torres Strait Islander peoples who have been diagnosed with cancer and those who have never been diagnosed with cancer. This will include estimates of the prevalence of participation in health promotion programs, risk factor exposure, cancer screening participation and behaviours, and importantly cancer treatment experiences and participation in trials. Analyses will also include an examination of cancer impacts on broader health and wellbeing outcomes. Data from these two questionnaires will also enable robust monitoring and reporting of the Aboriginal and Torres Strait Islander NCCI over time.

## Ethics and dissemination

The Kulay Kalingka Study has ethics approval from AIATSIS (reference #EO324-20220414) and the Australian National University (reference #2022/465). Where required, data custodian approvals and additional ethics approvals will be obtained.

### Indigenous data sovereignty principles

To better understand Aboriginal and Torres Strait Islander experiences of cancer, the Kulay Kalingka Study will privilege Aboriginal and Torres Strait Islander voices and build on inherent roles and responsibility of sovereignty and self-determination. To do so, the Kulay Kalingka Study follows the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research from the onset and throughout the life of the Study[27]. In doing so and consistent with United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), we recognise and respect Aboriginal and Torres Strait Islander peoples' right to self-determination which is fundamental to all research.

Aboriginal and Torres Strait Islander peoples have identified that our involvement and Indigenous data sovereignty in cancer research is "critical to ensuring that Indigenous values and priorities underpin research"[24]. We will ensure that our needs are central in improving cancer outcomes for mob. The Kulay Kalingka Study follow the Maiam nayri Wingara Indigenous Data Sovereignty Collective principles for Indigenous data sovereignty[1]. These principles assert that Aboriginal and Torres Strait Islander peoples have the right to:

1. Exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure.
2. Data that is contextual and disaggregated (available and accessible at individual, community and First Nations levels).
3. Data that is relevant and empowers sustainable self-determination and effective self-governance.
4. Data structures that are accountable to Indigenous peoples and First Nations.
5. Data that is protective and respects our individual and collective interests.

The Kulay Kalingka team is Aboriginal and Torres Strait Islander designed and led, and has Aboriginal and Torres Strait Islander governance over the project. This includes all output being bound by these principles through the application to the Mayi Kuwayu Data Governance Committee (MKDGC)[30]. See Supplementary File 1 for an outline of how we will address these principles.

### Knowledge Translation

The Kulay Kalingka Study will produce knowledge translation outputs using iterative and participatory approaches which will summarise findings for Aboriginal and Torres Strait Islander communities and our stakeholders, including policy makers and service providers. The data presented in the form of presentations will be tailored to their wants and needs, consistent with the Study principles of Aboriginal and Torres Strait Islander sovereignty and self-determination[27]. All results will be reviewed by Thiitu Tharrmay, MKDGC, and Cancer Australia before dissemination.

We will continue to work with Aboriginal and Torres Strait Islander peoples and communities, across a range of saltwater/freshwater/desert/Island groups, and in urban, regional and remote areas where possible, to develop these knowledge translation tools. We will disseminate study findings which are meaningful, accessible, and culturally adapted to each Aboriginal and Torres Strait Islander community through activities including community workshops, reports and feedback sheets, and in other ways as determined by the community. We will also return data to participating communities.

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We will also engage with policymakers to co-produce knowledge translation tools. For example, this is expected to include policy briefs, factsheets, and snapshots of data for presentation on the Cancer Australia website. Finally, we will produce peer reviewed publications to help disseminate results to a broader audience.

**Implications**

The Kulay Kalingka Study is a national, Aboriginal and Torres Strait Islander designed, governed and led study for Aboriginal and Torres Strait Islander experiences, attitudes and beliefs of cancer. The Kulay Kalingka Study will fill knowledge gaps by providing national level data on and monitor changes of cancer knowledge, understanding and experiences of diagnosis and treatment over time. The Study will address the gaps in data and knowledges, including exploring attitudes, beliefs and experiences of cancer to support the health and wellbeing of our peoples, and for future generations. The work will have many important and lasting benefits to Aboriginal and Torres Strait Islander peoples. This includes strengthening healthcare and cancer care services, increasing understanding and awareness of cancer risk factors and how to mitigate these risks, and supporting Aboriginal and Torres Strait Islander peoples with a diagnosis of cancer to receive optimal and culturally secure care throughout their cancer journey.

**Strengths and limitations**

The Kulay Kalingka Study aims to improve cancer outcomes for Aboriginal and Torres Strait Islander peoples. There are a range of benefits to participants of this research, which includes self-determination by centring Aboriginal and Torres Strait Islander voices in national level data about cancer (risks, screening and treatment), and empowering Aboriginal and Torres Strait Islander people to tell their stories in a safe and culturally appropriate way.

A major strength of the Study is our relational ties and community accountability to Aboriginal and Torres Strait Islander peoples through our strong relationships with communities, our knowledge translation practices (including returning data to communities), our adherence to Indigenous data sovereignty and governance principles[1, 30], and our engagement with Thiitu Tharrmay and the Cancer Australia Leadership Group on Aboriginal and Torres Strait Islander Cancer Control.

Another strength is that the Kulay Kalingaka Study uses an Indigenist methodology as outlined by Nurungga Professor Lester-Irabinna Rigney[2] by:

- Resistance as the emancipatory imperative in Indigenist research
- Political integrity in Indigenist research
- Privileging Indigenous voices in research

While we cannot ensure that participants involved in development of the questionnaires are representative of all Aboriginal and Torres Strait Islander peoples, we are committed to engaging Aboriginal and Torres Strait Islander peoples from diverse settings, contexts, and environments. This program of work will therefore focus on representing and encompassing Aboriginal and Torres Strait Islander experiences, attitudes and beliefs regarding cancer, from our Indigenist perspectives and worldviews.

We do not anticipate that participants in the Kulay Kalingka Study will be representative of all Aboriginal and Torres Strait Islander peoples with and without a cancer diagnosis. The lack of representativeness of the Kulay Kalingaka sample does not interfere with internal comparisons (i.e., identifying relationships between exposures and outcomes in the sample) or with quantifying within-

person changes over time. Findings from other populations show that exposure-outcome associations are robust and generalizable even when the sample is not representative of the total population[31].

## Conclusion

The Kulay Kalingka Study will provide Aboriginal and Torres Strait Islander led, governed and designed national data on the National Aboriginal and Torres Strait Islander NCCI. Through collecting this essential information, we aim to improve cancer understandings, cancer care, cancer treatment, and service delivery for Aboriginal and Torres Strait Islander peoples.

## Acknowledgements

The authors acknowledge all Aboriginal and Torres Strait Islander peoples and their continuing connection to culture, land, and seas. We acknowledge the assistance and guidance of the Mayi Kuwayu Study Data Governance Committee, the Thiitu Tharrmay Aboriginal and Torres Strait Islander Reference Group, and the Cancer Australia Leadership Group on Aboriginal and Torres Strait Islander Cancer Control. SW (Taungurung), MB (Wiradjuri), LJW (Wagadagam, Gumulgal), RM (Modewa Clan) and RL (Ngiyampaa/Wongaibon) also acknowledge their cultures, histories, and communities.

## Author contributions

SW and MB drafted the manuscript. KAT, EB, LJW and RL contributed to developing the study design and content. All authors provided comments and critical revisions on the manuscript and approved the final version.

## Funding statement

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## Competing interests

A/Prof Lisa J. Whop is a member of Cancer Australia's Leadership Group on Aboriginal and Torres Strait Islander Cancer Control.

## Data statement

Kulay Kalingka Study data will be available through application to the Mayi Kuwayu Data Governance Committee. The corresponding author can be contacted for assistance with data requests.



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#### Figure legend:

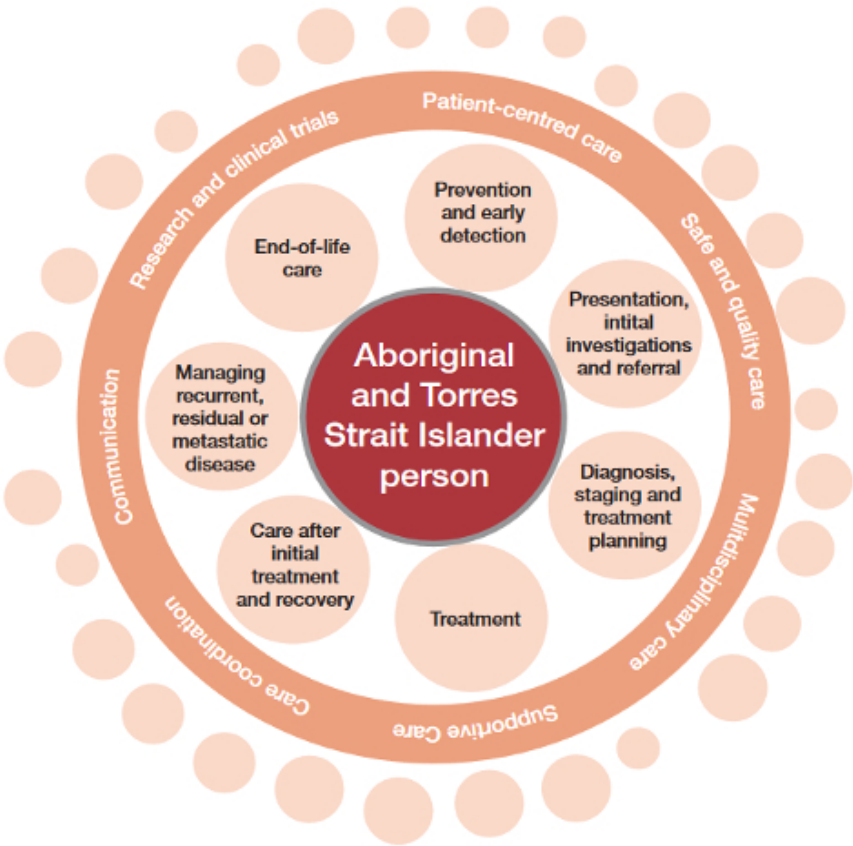
Figure 5: Patient-centred care for Aboriginal and Torres Strait Islander people

Figure 6 Photo of net bag created by Yirrganydji and Nughi artist Nicole Enoch-Chatfield (Goompi's Girl)

Figure 7: flow-chart of stage 1 (questionnaire development)

Figure 8: Flow-chart of stage 2 (study recruitment)





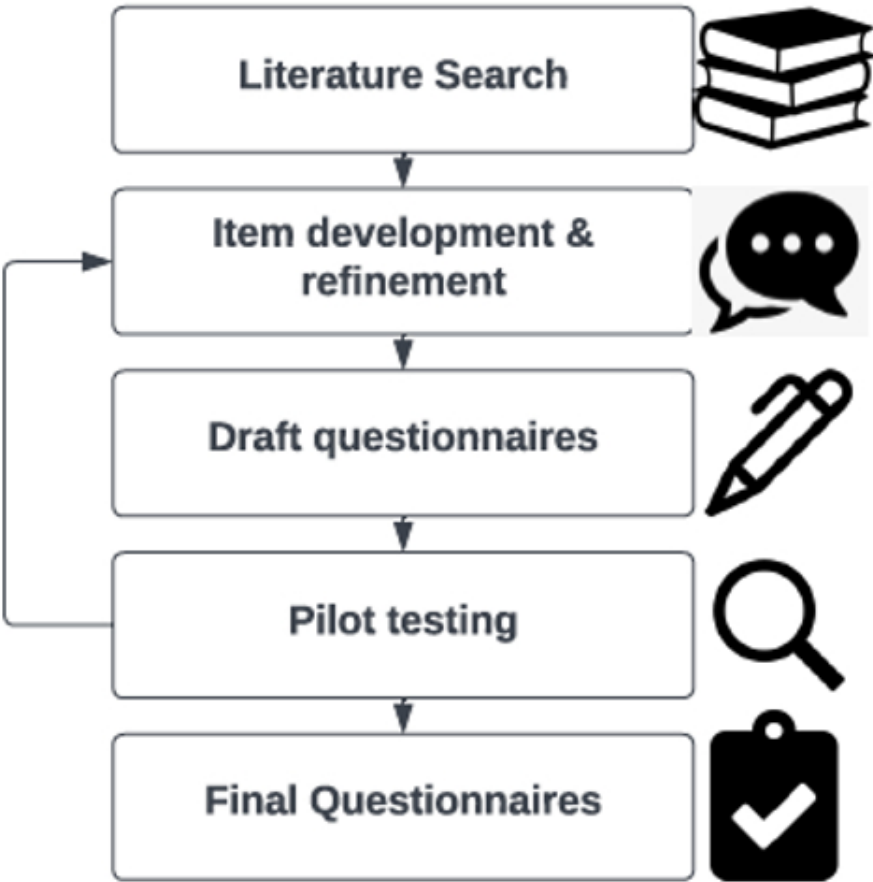
Patient-centred care for Aboriginal and Torres Strait Islander People

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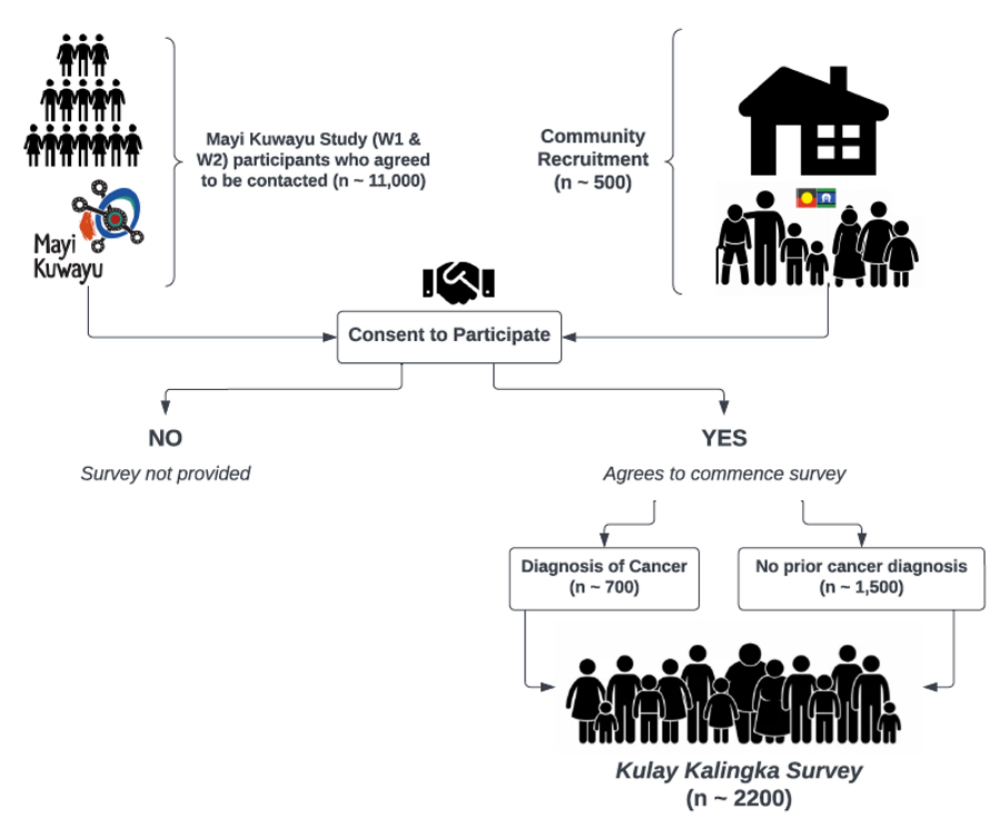
Photo of net bag created by Yirrganydji and Nughi artist Nicole Enoch-Chatfield (Goompi's Girl)

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Flow-chart of stage 1 (questionnaire development)

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Flow-chart of stage 2 (study recruitment)

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**Supplementary File 1:** Details on how the Maiam nayri Wingara Indigenous Data Sovereignty Principles will be enacted within the Kulay Kalingka Study<sup>1</sup>

**Principle 1:** Demonstrate how your proposed project ensures Aboriginal and Torres Strait Islander people will exercise control (all or individual elements) of the data ecosystem.

**Control:** An Aboriginal and Torres Strait Islander led research team control all aspects of the Kulay Kalingka Study. The Study is under the leadership of an Aboriginal Project Manager (SW, Taungurung), with majority Aboriginal and Torres Strait Islander project team members (MB Wiradjuri; LW Wagadagam; JC Taungurung; RL Ngiyampaa/Wongaibon) who are supported by non-Indigenous (KT, EB) team members. This collaboration ensures that Aboriginal and Torres Strait Islander peoples exercise control over the project while bringing a variety of skill sets into the team. The Kulay Kalingka Study is also supported by Aboriginal and Torres Strait Islander partner communities who are involved in questionnaire testing, data collection, community engagement and Study dissemination.

**Data stewardship:** All stages of the data ecosystem will be controlled by the research team under the guidance of an Aboriginal and Torres Strait Islander governance committee *Thiitu Tharrmay*, who will:

1. Be a source of expertise and advice on Aboriginal and Torres Strait Islander cultures;
2. Provide advice on the appropriate conduct of research including ensuring that the research, dissemination and policy agenda reflect Aboriginal and Torres Strait Islander community priorities and values;
3. Contribute to the Study methodology and methods;
4. Review and assist in interpreting results before publication and dissemination;
5. Contribute to publications where appropriate;
6. Provide links to other relevant research, policy and practice initiatives that may benefit from Study results;
7. Facilitate the dissemination and translation of research findings with Aboriginal and Torres Strait Islander communities and organisations

**Data analysis:** While non-Indigenous team members have input into the development of the data analysis plans; the project retains Aboriginal and Torres Strait Islander control over the data ecosystem as all data will be collected and analysed by Aboriginal and Torres Strait Islander team members. Only Aboriginal and Torres Strait Islander team members will have access to sensitive and personal information, which are protected under MKDGC and ethics requirements. Interpretation and analysis of results will be conducted by Aboriginal and Torres Strait Islander team members with input from *Thiitu Tharrmay* to ensure the data stories are strengths-based and protect Aboriginal and Torres Strait Islander peoples without causing further harm.

**Data dissemination:** Aboriginal and Torres Strait Islander people will receive information from the Kulay Kalingka Study through community focus groups, seminars and workshops; community reports; and social media posts. Information will also be available to Aboriginal and Torres Strait Islander peoples and non-Indigenous people in peer reviewed journals, conferences, and policy briefs. Finally, results will also be available to broad audiences online on the Cancer Australia website. This data dissemination strategy will be developed by the Kulay Kalingka Study team members in collaboration with Aboriginal and Torres Strait Islander partner communities and *Thiitu Tharrmay*.

**Principle 2:** Demonstrate how your proposed project will include contextual aspects and be disaggregated (available and accessible at individual, community and Indigenous national levels).

**Contextual:** All Kulay Kalingka Study project work (i.e. community workshops and presentations, reporting on the NCCI's, reporting on the Cancer Australia website, and peer-review papers) will include contextual aspects to support a strengths-based analysis. Contextual information will include the diversity of Aboriginal and Torres Strait Islander peoples and cultures, the impacts of colonial processes in the dispossession and dislocation of individuals and communities, and the ongoing structural racism including in healthcare systems. This contextual information is important as it helps

in explaining cancer attitudes, outcomes and screening and treatment opportunities that Aboriginal and Torres Strait Islander peoples experience. When working with Aboriginal and Torres Strait Islander partner communities, they will have opportunities throughout to comment, influence and work with the data outputs, including the way the data is presented back to community members. This gives scope for community-specific contextual information.

**Accessible and available:** Outputs will be made available to Aboriginal and Torres Strait Islander communities through focus groups, interviews, workshops and presentations to give the requested data back to communities in ways relevant and meaningful to them. Pending COVID travel restrictions, these will be held on site in communities to allow for as many participants attending as possible. Resources on the data and outputs will also be provided to communities in plain-language and accessible formats for wider community distribution. These details are to be confirmed with the Kulay Kalingka Study partner communities.

**Principle 3:** Demonstrate how your proposed project will empower sustainable Indigenous self-determination and effective self-governance.

**Relevant:** The Study is both relevant to key policy-maker calls, such as those by Cancer Australia, for improving cancer understandings, screening and treatment. It is also relevant to Aboriginal and Torres Strait Islander communities as it will answer calls to better understand cancer attitudes, beliefs and experiences, and for greater inclusion of and leadership by Aboriginal and Torres Strait Islander patients, families and communities in cancer research.

**Self-determination and self-governance:** The Study will contribute to Indigenous self-determination and governance through Aboriginal and Torres Strait Islander control and governance of the project. It will contribute to community knowledge cancer risk factors, cancer screening opportunities, and cancer prevention techniques. It will also contribute to understanding Aboriginal and Torres Strait Islander peoples' attitudes and beliefs about cancer which will be used to inform and improve cancer prevention, screening and treatment services and programs. Aboriginal and Torres Strait Islander communities will be empowered with local-level data to assist in local decision making.

**Principle 4:** Demonstrate how your proposed project has data structures that are accountable to Indigenous peoples.

The research team will be guided by any specific data storage procedures developed and required by the Mayi Kuwayu Data Governance Committee (MKDGC)<sup>2</sup>. Data will be stored on the ANU secure server which is only accessible by approved members of the research team. Data stored on the ANU secure server is backed up daily at midnight. The data is stored at three geographically separate off-site Data Centres: Crisp, Huxley, and NCI. At the completion of the research project, the data will be stored on the secure, password-protected shared drive for 7 years after data collection, or 5 years after any publication, whichever is longer. The protection of participant's identities is very important. Identifiable data will not be published.

**Principle 5:** Demonstrate how your proposed project results are protective and respects Indigenous individual and collective interests.

The Kulay Kalingka Study is conducted under a strengths-based methodology: the study is designed to be inclusive of the diversity of the Aboriginal and Torres Strait Islander population, and national-level data can be used to monitor and guide improved cancer experiences for Aboriginal and Torres Strait Islander peoples. Our findings will be protected after dissemination through clear and consistent messaging in peer reviewed publications, reports, social media, public presentations and on the Cancer Australia NCCI website.

<sup>1</sup> Indigenous Data Sovereignty Principles available at: <https://www.maiamnayriwingara.org/key-principles>

<sup>2</sup> MKDGC information available at: <https://mkstudy.com.au/overview/>

# BMJ Open

## Study Protocol: Kulay Kalingka, a national cohort study of Aboriginal and Torres Strait Islander peoples' cancer experiences

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Date Submitted by the Author:	20-Apr-2023
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<b>Primary Subject Heading</b>:	Oncology
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Keywords:	EPIDEMIOLOGY, ONCOLOGY, Health Equity

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**Study Protocol: Kulay Kalingka, a national cohort study of Aboriginal and Torres Strait Islander peoples’ cancer experiences**

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MMB – Makayla-May Brinckley  
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## Abstract

### Introduction

Aboriginal and Torres Strait Islander peoples are the First Peoples of Australia. Since settler-colonisation, Aboriginal and Torres Strait Islander peoples have experienced disparities in health outcomes, including cancer, when compared to non-Indigenous Australians, including higher cancer incidence and mortality rates, and lower participation in cancer screening programs. Data to monitor and improve outcomes are limited.

### Aims, method and analysis

The Kulay Kalingka Study will be a national cohort study aiming to understand Aboriginal and Torres Strait Islander people's beliefs about cancer and experiences with cancer care and treatment, and to improve experiences and outcomes. It will be nested within the Mayi Kuwayu Study, a national community-controlled cohort study of Aboriginal and Torres Strait Islander people (n>11,000), with supplementary in-community recruitment.

Mayi Kuwayu Study participants aged  $\geq 18$  years who consented to being recontacted, and a diversity of local community members will be invited to participate through completing a questionnaire relevant to their cancer status, aiming to recruit 2800 participants without prior doctor-diagnosed cancer and 700 with a cancer diagnosis.

This community-driven data will enable monitoring and reporting of national trends over time and will guide national cancer control research, policy and clinical care, to improve outcomes for Aboriginal and Torres Strait Islander peoples.

### Ethics and dissemination

The Kulay Kalingka Study has ethics approval from Australian Institute of Aboriginal and Torres Strait Islander Studies (#EO324-20220414) and the Australian National University (#2022/465). The Kulay Kalingka Study is being developed with Aboriginal and Torres Strait Islander communities, following the Maïam nayri Wingara Indigenous Data Sovereignty Collective principles. Meaningful, accessible, and culturally adapted Study findings will be disseminated to Aboriginal and Torres Strait Islander communities through activities including community workshops, reports and feedback sheets, and in other ways as determined by the community. We will also return data to participating communities.

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**Article Summary**  
**Strengths and Limitations**

- The Kulay Kalingka Study questionnaires were developed through consultations with Aboriginal and Torres Strait Islander peoples and communities Australia-wide, and includes items on cancer care, cancer beliefs, accessibility of cancer screening programs, and cancer survivability.
- The Kulay Kalingka Study will provide Aboriginal and Torres Strait Islander led, designed, and governed national-level data to monitor and guide improved cancer awareness, understandings of care, treatment, and service delivery for Aboriginal and Torres Strait Islander peoples.
- It will contribute to monitoring and reporting on 37 of Cancer Australia’s National Aboriginal and Torres Strait Islander Cancer Control Indicators, where no data currently exist.
- The Study is designed to be inclusive of the diversity of the Aboriginal and Torres Strait Islander population and is not designed to be representative of this population.

## Introduction

We begin by acknowledging the sovereign Indigenous peoples around the world who are the Custodians of their lands, waterways and skies, who have cared for and maintained Country, culture and community since time immemorial. We acknowledge the ancestral lands of the Ngunnawal and Ngambri peoples on which this study protocol was written, and thank the Elders past and present for our safe passage through their Country.

By qualification, we the authorship team, are researchers, but our positioning from the onset of this Study is that of sovereign Aboriginal and Torres Strait Islander peoples with our own cultures, histories and communities and people supporting such sovereignty. We have a shared commitment of service to mob that seeks to understand how mob can live healthy lives. We follow the Indigenist and Indigenous research methodologies set before us by trailblazers including Nurungga Professor Lester-Irabinna Rigney[1], Palawa Distinguished Professor Maggie Walter[2], Opaskwayak Cree Researcher Shawn Wilson[3], and Ngāti Awa, Ngāti Porou, Tūhourangi Professor Linda Tuhiwai Smith[4]. By doing so we privilege our cultural knowledges, ways of knowing, being and doing, and conduct our research with respect, responsibility, generosity, obligation and reciprocity to our peoples[5].

Aboriginal and Torres Strait Islander peoples maintain the oldest living cultures in the world, with an estimated 250 Aboriginal and Torres Strait Islander languages and 600-700 dialects across the continent prior to colonisation[6]. Along with diverse languages, Aboriginal and Torres Strait Islander groups also have diverse histories, cultures, lore/law and other practices and have lived, for generations, healthy and culturally enriched lives[7-8]. Colonial processes and policies dispossessed and dislocated Aboriginal and Torres Strait Islander peoples from our families, Country, cultures and languages, but culture remains strong and languages continue and many are being reclaimed. Currently, there are an estimated 798,400 Aboriginal and Torres Strait Islander peoples living in Australia. Over 30% of the population lives in major cities of Australia, while 24% live in inner regional Australia, 20% in outer regional Australia, and 7% in remote or very remote Australia[9]. Today, the Aboriginal and Torres Strait Islander population bears a disproportionate burden of disease, including cancer.

Prior to colonisation, cancer impacted Aboriginal and Torres Strait Islander populations but the attribution of illness to cancer was limited[10]. Only in the last two decades has cancer received attention specific to our population[11]. The quality of data also limits what we know about diagnosis and treatment outcomes via cancer registry data. Problems with data quality include issues with misidentification and under-identification of Aboriginal and Torres Strait Islander peoples in general administrative datasets and cancer-specific datasets[12-13], and a lack of national data on screening programs[14]. In more recent times cancer has become recognised as one of the leading contributors to the burden of disease for Aboriginal and Torres Strait Islander peoples[15].

Between 2015-2019, cancer and other neoplasms were the leading cause of death for Aboriginal and Torres Strait Islander peoples in states where adequate data on deaths exist, contributing to almost a quarter of total deaths[15]. The most commonly diagnosed cancers are lung, breast, colorectal, prostate and head and neck cancers. These cancer types are amenable to prevention and have high fatality rates[15].

In 2012-2016, for all cancers combined, incidence was 14% higher among Aboriginal and Torres Strait Islander peoples compared to non-Indigenous peoples[16]. When diagnosed, Aboriginal and Torres Strait Islander peoples are also more likely to be at a more advanced stage of disease impacting prognosis and treatment options, less hospitalisations and wait longer for surgery[15]. From 2015-2019, the age-standardised mortality rate for all cancers for the Aboriginal and Torres Strait Islander

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1 population was 45% higher than in the non-Indigenous population[16]. Cancer does not only affect  
2 our older community members. Concomitantly, the median age of an Aboriginal and Torres Strait  
3 Islander person in 2016 was 20 years compared with 38 for non-Indigenous people, with some types  
4 of cancers showing up earlier in the Aboriginal and Torres Strait Islander population compared to the  
5 non-Indigenous population[16].

7 There are a range of risk factors that are associated with an increased likelihood of people in the  
8 general population developing cancer. Key modifiable risk factors include tobacco smoking, alcohol,  
9 obesity and exposure to too much sun (melanoma)[16]. There is a growing body of evidence  
10 internationally that links discrimination and racism to increased prevalence of modifiable risk factors  
11 including tobacco smoking, higher levels of alcohol use and obesity. The increased prevalence of, and  
12 mortality from cancer among Aboriginal and Torres Strait Islander peoples is largely due to socially-  
13 driven increased prevalence of cancer risk factors[17]. Additional upstream factors that affect  
14 Aboriginal and Torres Strait Islander peoples' cancer experiences include barriers to accessing cancer  
15 services such as screening and treatment[18-19].

17 Aboriginal and Torres Strait Islander community beliefs about cancer are varied. Many Aboriginal and  
18 Torres Strait Islander peoples understand that tobacco, poor diet and other risk factors cause  
19 cancer[20]. However, the general population often look to external factors to explain things that are  
20 happening to them, rather than looking to factors within their own control[21]. For example, some  
21 Aboriginal and Torres Strait Islander communities are unwilling to talk about cancer, believe it is black  
22 magic, or believe it to be contagious. Further, some believe cancer invaded the bodies of Aboriginal  
23 and Torres Strait Islander peoples when colonisers arrived in 1788[10, 22-23]. In some Aboriginal and  
24 Torres Strait Islander languages, including Aboriginal languages across the Northern Territory, there is  
25 no word for cancer[24]. Regardless of these beliefs, it places a heavy burden on those diagnosed with  
26 the disease, as well as their families, friends, carers, Elders and the community.

28 It is in this context that the National Aboriginal and Torres Strait Islander Cancer Framework 2015 was  
29 developed by Cancer Australia to provide high level guidance for stakeholders working to improve  
30 cancer outcomes and reduce disparities[25]. It aligns with the Optimal Care Pathway (OCP) for  
31 Aboriginal and Torres Strait Islander peoples with cancer, which identifies seven critical steps in the  
32 patient journey (see figure 1)[25].

Figure 1: Patient-centred care for Aboriginal and Torres Strait Islander people

Cancer Australia developed a set of National Aboriginal and Torres Strait Islander Cancer Control Indicators (NCCI) to monitor performance across the OCP areas[25]. There are 22 indicators in total, and progress in these areas is assessed using 57 measures comprising of:

- 20 measures which are currently reported on the website, available at: <https://ncci.canceraustralia.gov.au/aboriginal-and-torres-strait-islander-cancer-control-indicators>
- 37 measures where no data exist and/or require further progress for data development, including participation in national cancer screening programs (i.e., cervical, breast, bowel); participation in clinical trials; experiences of racism/discrimination in health care; beliefs about whether cancer can be prevented.

No data exist for over half of the Aboriginal and Torres Strait Islander NCCI identified measures, and as a result we cannot monitor progress in a range of areas. It is essential that data about our attitudes, beliefs and experiences of cancer be developed and governed for and by Aboriginal and Torres Strait Islander peoples. This will help ensure community and relational accountability, which is particularly important given the ongoing colonial context outlined above, including the programs and policies that have aimed to actively erode power, social structures and community resources. In response to the impacts of cancer and the lack of data to inform the Aboriginal and Torres Strait Islander NCCI, a proposed national study is being developed.

The Kulay Kalingka Study will be a prospective national cohort study that is designed to understand Aboriginal and Torres Strait Islander people's beliefs about cancer; experiences with cancer care and treatment; and to improve experiences and outcomes for Aboriginal and Torres Strait Islander peoples with cancer and their families. The Study is designed to inform the Cancer Australia priority areas. The study name, 'Kulay Kalingka' translates to 'net bag in the water' in Ngayampaa (Wongaibon) language. Woven net bags have been used by rainforest Bama (peoples) to process highly toxic foods, whereby foods are placed in net bags and run through a slow-moving stream to leach out their toxins and make them safe over time. This concept is woven into the Kulay Kalingka Study: the net bag is symbolic of how people and families fighting cancer can include Aboriginal and Torres Strait Islander health and wellbeing concepts for cultural, medicinal and spiritual healing, alongside clinical treatments (Figure 2).

Figure 2 Photo of net bag created by Yirrganydji and Nughi artist Nicole Enoch-Chatfield (Goompi's Girl)

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**Methods and analysis**

**Patient and public involvement statement**

The Kulay Kalingka Study arose from Aboriginal and Torres Strait Islander community needs, to better understand cancer attitudes, beliefs and experiences and from calls for the inclusion of Aboriginal and Torres Strait Islander patients, families and communities in cancer research[26]. Additionally, the Study arose from a call from Cancer Australia to improve cancer outcomes for Aboriginal and Torres Strait Islander peoples, including across cancer prevention, screening and early detection, diagnosis and treatment, palliative care and survivorship, and their corresponding service areas[27]. Aboriginal and Torres Strait Islander peoples are involved in all stages of the project, from conception, development and survey testing through to analysis and dissemination.

**Mayi Kuwayu Study**

The Kulay Kalingka Study is nested within ‘Mayi Kuwayu: the National Study of Aboriginal and Torres Strait Islander Wellbeing’ (the Mayi Kuwayu Study). The Mayi Kuwayu Study is a large-scale, longitudinal study of Aboriginal and Torres Strait Islander adults aged ≥16 years with approximately 11,000 participants to date. The Study aims to improve the understanding of the role cultural factors play in Aboriginal and Torres Strait Islander peoples’ wellbeing and their interaction with standard health risk and protective factors. The Mayi Kuwayu Study is developed and governed by Aboriginal and Torres Strait Islander peoples[28-29]. The Mayi Kuwayu Study has developed and maintained Aboriginal and Torres Strait Islander community partnerships around Australia[30], and the Kulay Kalingka Study utilises these strong relationships throughout its development.

It is essential that Aboriginal and Torres Strait Islander communities are involved in questionnaire development and testing. This participatory-based research approach is necessary in order to help ensure the Study meets the dual criteria of Aboriginal and Torres Strait Islander community relevance and scientific excellence. Aboriginal and Torres Strait Islander peoples are involved in and lead all stages of the Kulay Kalingka Study.

There are three stages to Kulay Kalingka Study: Stage 1 – the development of the questionnaires, incorporating a literature search, questionnaire item refinement and pilot testing (Figure 3); Stage 2 – the recruitment, and Stage 3 – follow up recruitment (Figure 4).

**Stage 1: Development of questionnaires**

*1.1 Existing item search*

Between October 2021 and April 2022, we explored existing questionnaire items for potential use in the Kulay Kalingka Study questionnaires. This was to identify existing questionnaire items and measures that map to the 22 Aboriginal and Torres Strait Islander NCCI, using Google Scholar. Search terms were developed by the Kulay Kalingka Study team. Final search terms were:

*(Aborigin\* OR "Torres Strait\*") AND (cancer) AND (awareness OR beliefs OR prevention OR "risk reduction" OR "smoking cessation programs" OR "quit smoking programs" OR screening OR "screening test follow up" OR incidence OR "stage at diagnosis" OR "culturally competent health service" OR treatment OR "patient experience")*

The second search was conducted in Google Scholar to find supplementary questionnaire items and measures that relate to specific cancer types. Final search terms were:

*(Aborigin\* OR "Torres Strait\*") AND (cancer) AND bladder OR breast OR cervical OR bowel OR "head and neck" OR kidney OR lung OR liver OR melanoma OR throat OR ovarian OR pancreatic OR prostate OR stomach OR thyroid OR uterine OR "cancer of unknown primary site" OR "non-Hodgkin lymphoma"*



## 1.2 Hand search

If research papers did not publish questionnaire items or measures, we contacted corresponding authors and requested these questionnaire items or measures. We also worked with experts in the field and checked reference lists of included material for other relevant questionnaire items and measures.

Finally, items and measures that met the following three criteria were moved into the item development stage for inclusion or modification:

1. had been developed for or used with Aboriginal and Torres Strait Islander peoples
2. captured information about cancer knowledge, attitudes, beliefs, screening, diagnosis, treatment, services and/or systems
3. map onto the Aboriginal and Torres Strait Islander NCCI.

## 1.3 Novel item development

We also developed new items and measures where no appropriate items existed. These novel quantitative and qualitative items were created in collaboration between the Kulay Kalingka Study team, the Thiitu Tharmmay Aboriginal and Torres Strait Islander reference group, Aboriginal and Torres Strait Islander individuals and communities, and Cancer Australia.

## 1.4 Draft questionnaires

After collating and developing the draft items, two draft questionnaires are formed. Questionnaire 1 is designed for people who have ever had a cancer diagnosis, and focuses on indicators related to cancer screening, diagnosis, care, and experiences of cancer treatment. Questionnaire 2 is designed for people who have never had a cancer diagnosis, which focuses on indicators related to knowledge (including cancer screening), attitudes and beliefs about cancer.

## 1.5 Pilot testing – recruitment

Aboriginal and Torres Strait Islander communities will self-nominate to be part of the pilot testing processes, based on existing community relationships[30]. Pilot testing will be conducted with self-nominated communities until good representation across the ASGS Remoteness Areas 2011 (Remote, Inner Regional and Major City) is achieved. If multiple communities self-nominate from the same ASGS Remoteness Areas (2011), the community will not be turned away from participating; all communities who want to participate can participate. Each community will self-determine the constitution of the focus groups, in line with Principle 1 of the Australian Institute of Aboriginal and Torres Strait Islander Studies Code of Ethics for Aboriginal and Torres Strait Islander Research[31].

There will be three focus groups at each community, with 6-8 participants in each focus group. Participants will be selected by the communities through word-of-mouth building on relational accountability. Focus groups will be independently conducted with people who have had a cancer diagnosis, and people who have not had a cancer diagnosis. A minimum of 30 pilot-testing participants with a cancer diagnosis will pilot-test draft Questionnaire 1. A minimum of 30 pilot-testing participants without a cancer diagnosis will pilot-test draft Questionnaire 2. Focus group participants will be conducted with Aboriginal and/or Torres Strait Islander peoples, aged  $\geq 18$  years. Pilot-testing focus groups are voluntary and participants can leave at any time.

## 1.6 Pilot testing – questionnaire refinement

Each focus group will be conducted by two Aboriginal or Torres Strait Islander facilitators with experience in conducting focus groups. Focus groups are held in culturally safe spaces as self-

determined by the community. Focus groups will follow the probing approach method, where the facilitator's role is proactive and direct questions are asked to extract specific information from participants[32]. Participants are provided with a draft questionnaire and asked about questionnaire length, cultural appropriateness of items, interpretation and misunderstandings of items, and the overall tone of questions being asked. Participants can provide this feedback either on the page or to the focus group facilitators.

Focus group feedback will be collated and iteratively incorporated to the questionnaire by Aboriginal and Torres Strait Islander members of the research team. The purpose of this process will be to ensure the wording of items supports understanding, reduces cognitive burden, and to refine questionnaire items, including item inclusion, exclusion and/or modification. The goal is to support appropriateness, accuracy and interpretation of items so meaningful data are yielded[33].

1.7 Final questionnaires

The result of the literature search, hand search, novel item development, and pilot testing are the final questionnaires.

Figure 3: Stage 1 (Development of Questionnaires)

Stage 2: Recruitment

2.1 Mail out recruitment

The Kulay Kalingka Study primary sampling frame is from baseline Mayi Kuwayu Study participants aged ≥18 years who have consented to being recontacted by the Mayi Kuwayu Study. Mail out recruitment will begin in mid to late 2023.

All existing Mayi Kuwayu Study participants who self-reported a doctor diagnosed cancer (n≈600 participants) will be invited to participate in Questionnaire 1 of the Kulay Kalingka Study. Existing participants who have never had a cancer diagnosis (n≈2400) will be invited to participate in Questionnaire 2, with the goal of recruiting four participants without cancer for every one participant with cancer. Selection of participants who have never had a cancer diagnosis into the Kulay Kalingka Study sample will be stratified by age, gender and remoteness (see table 1).

Table 1. Selection of Kulay Kalingka Study participants (restricted to those who have consented to follow up).

Demographic group	Number of potential participants with cancer	Number of potential participants without cancer	Number without cancer to be recruited
Total (incl. missings)	619	7614	2476
Men			
Aged 18-50, major cities	13	416	52
Aged 51+, major cities	91	741	364
Aged 18-50, regional/remote	9	541	36
Aged 51+, regional/remote	135	1032	540
Women			
Aged 18-50, major cities	44	1134	176
Aged 51+, major cities	120	740	480
Aged 18-50, regional/remote	42	1349	168



Aged 51+, regional/remote	137	1145	548
Total (excl. missings)	591	7098	2364

All potential Kulay Kalingka Study participants will be posted a survey pack in the mail (containing an information sheet, a questionnaire, a national support service brochure, and a pre-paid reply envelope).

## 2.2 Supplementary community recruitment

In addition to recruiting existing Mayi Kuwayu Study participants, the Kulay Kalingka Study will conduct supplementary recruitment across ASGS Remoteness Areas 2011, following the same method as pilot testing recruitment. Supplementary community recruitment will begin in mid to late 2023 from saltwater, freshwater, desert and Island groups, and living across urban, regional and remote Australia to ensure diversity of experiences are captured in the Kulay Kalingka Study. This will enable Aboriginal and Torres Strait Islander peoples with or without a cancer diagnosis, and from diverse settings, contexts, and environments, to participate in the Kulay Kalingka Study.

Participation in all stages of the Kulay Kalingka Study is voluntary. Participants provide informed consent and can withdraw consent at any time. Potential participants will receive a plain-language information sheet about the study, along with the consent form, support services directory and questionnaire.

Figure 4: Kulay Kalingka study recruitment

## Stage 3: Follow up recruitment

The first wave of recruitment will commence mid to late 2023. The second wave of follow-up questionnaires will commence approximately one year after baseline data collection completion. This follow-up wave will recruit the same Kulay Kalingka Study participants and additional participants through supplementary community recruitment to help with participant drop-off. Participants can cross over from the without cancer diagnosis group to the with cancer diagnosis group at any stage. This initial follow up will allow us to report on changes in cancer attitudes, beliefs and experiences over time.

There is also potential for ongoing follow up waves if funding allows, to enable further longitudinal examination of cancer attitudes, beliefs and experiences over time.

## Statistical analysis

Analysis of data from Kulay Kalingka Study can be used to monitor and inform improvement in cancer outcomes for Aboriginal and Torres Strait Islander peoples, including generating evidence to inform service delivery, cancer screening, participation in prevention activities, and cancer awareness. Statistical analyses will involve cross-sectional and potentially longitudinal methods if multiple waves of data are collected. We will examine cancer attitudes, beliefs and experiences for Aboriginal and Torres Strait Islander peoples who have been diagnosed with cancer and those who have never been diagnosed with cancer. This will include estimates of the prevalence of participation in health promotion programs, risk factor exposure, cancer screening participation and behaviours, and importantly cancer treatment experiences and participation in trials. Analyses will also include an examination of cancer impacts on broader health and wellbeing outcomes. Data from these two

questionnaires will also enable robust monitoring and reporting of the Aboriginal and Torres Strait Islander NCCI over time.

**Ethics and dissemination**

The Kulay Kalingka Study has ethics approval from AIATSIS (reference #EO324-20220414) and the Australian National University (reference #2022/465). Where required, data custodian approvals and additional ethics approvals will be obtained.

**Indigenous data sovereignty principles**

To better understand Aboriginal and Torres Strait Islander experiences of cancer, the Kulay Kalingka Study privileges Aboriginal and Torres Strait Islander voices and build on inherent roles and responsibility of sovereignty and self-determination. To do so, the Kulay Kalingka Study follows the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research from the onset and throughout the life of the Study[31]. In doing so and consistent with United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), we recognise and respect Aboriginal and Torres Strait Islander peoples’ right to self-determination which is fundamental to all research.

Aboriginal and Torres Strait Islander peoples have identified that our involvement and Indigenous data sovereignty in cancer research is “critical to ensuring that Indigenous values and priorities underpin research”[26]. We will ensure that our needs are central in improving cancer outcomes for mob. The Kulay Kalingka Study follow the Maiam nayri Wingara Indigenous Data Sovereignty Collective principles for Indigenous data sovereignty[34]. These principles assert that Aboriginal and Torres Strait Islander peoples have the right to:

- 1. Exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure.
- 2. Data that is contextual and disaggregated (available and accessible at individual, community and First Nations levels).
- 3. Data that is relevant and empowers sustainable self-determination and effective self-governance.
- 4. Data structures that are accountable to Indigenous peoples and First Nations.
- 5. Data that is protective and respects our individual and collective interests.

The Kulay Kalingka team is Aboriginal and Torres Strait Islander designed and led, and has Aboriginal and Torres Strait Islander governance. This includes all output being bound by these principles through the application to the Mayi Kuwayu Data Governance Committee (MKDGC)[35]. See Supplementary File 1 for an outline of how we will address these principles.

**Knowledge Translation**

The Kulay Kalingka Study will produce knowledge translation outputs using iterative and participatory approaches which will summarise findings for Aboriginal and Torres Strait Islander communities and our stakeholders, including policy makers and service providers. The data presented in the form of presentations will be tailored to their wants and needs, consistent with the Kulay Kalingka Study principles of Aboriginal and Torres Strait Islander sovereignty and self-determination[31]. All results will be reviewed by Thiitu Tharrmay, MKDGC, and Cancer Australia before dissemination.

We will continue to work with Aboriginal and Torres Strait Islander peoples and communities, across a range of saltwater/freshwater/desert/Island groups, and in urban, regional and remote areas where possible, to develop these knowledge translation tools. We will disseminate study findings which are meaningful, accessible, and culturally adapted to each Aboriginal and Torres Strait Islander community through activities including community workshops, reports and feedback sheets, and in other ways as determined by the community. We will also return data to participating communities.

We will also engage with policymakers to co-produce knowledge translation tools. For example, this is expected to include policy briefs, factsheets, and snapshots of data for presentation on the Cancer Australia website. Finally, we will produce peer reviewed publications to help disseminate results to a broader audience.

## Implications

The Kulay Kalingka Study is a national, Aboriginal and Torres Strait Islander designed, governed and led study for Aboriginal and Torres Strait Islander experiences, attitudes and beliefs of cancer. The Kulay Kalingka Study will fill knowledge gaps by providing national level data on and monitor changes of cancer knowledge, understanding and experiences of diagnosis and treatment over time. The Study will address the gaps in data and knowledges, including exploring attitudes, beliefs and experiences of cancer to support the health and wellbeing of our peoples, and for future generations. The work will have many important and lasting benefits to Aboriginal and Torres Strait Islander peoples. This includes strengthening healthcare and cancer care services, increasing understanding and awareness of cancer risk factors and how to mitigate these risks, and supporting Aboriginal and Torres Strait Islander peoples with a diagnosis of cancer to receive optimal and culturally secure care throughout their cancer journey.

## Strengths and limitations

The Kulay Kalingka Study aims to improve cancer outcomes for Aboriginal and Torres Strait Islander peoples. There are a range of benefits to participants of this research, which includes self-determination by centring Aboriginal and Torres Strait Islander voices in national level data about cancer (risks, screening and treatment), and empowering Aboriginal and Torres Strait Islander people to tell their stories in a safe and culturally appropriate way.

A major strength of the Study is our relational ties and Aboriginal and Torres Strait Islander community accountability. This includes Aboriginal and Torres Strait Islander research leadership, and strong relationships with communities. Further, we use knowledge translation practices (including returning data to communities), our adherence to Indigenous data sovereignty and governance principles [34-35], and our engagement with Thiiitu Tharrmay and the Cancer Australia Leadership Group on Aboriginal and Torres Strait Islander Cancer Control.

Another strength is that the Kulay Kalingaka Study uses an Indigenist methodology as outlined by Nurungga Professor Lester-Irabinna Rigney[1] by:

- Resistance as the emancipatory imperative in Indigenist research
- Political integrity in Indigenist research
- Privileging Indigenous voices in research

While we cannot ensure that participants involved in development of the questionnaires are representative of all Aboriginal and Torres Strait Islander peoples, we are committed to engaging Aboriginal and Torres Strait Islander peoples from diverse settings, contexts, and environments. This program of work will focus on representing and encompassing Aboriginal and Torres Strait Islander experiences, attitudes and beliefs regarding cancer, from our Indigenist perspectives and worldviews.

We do not anticipate that participants in the Kulay Kalingka Study will be representative of all Aboriginal and Torres Strait Islander peoples with and without a cancer diagnosis. The lack of representativeness of the Kulay Kalingaka sample does not interfere with internal comparisons (i.e., identifying relationships between exposures and outcomes in the sample) or with quantifying within-

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person changes over time. Findings from other populations show that exposure-outcome associations are robust and generalizable even when the sample is not representative of the total population[36].

**Acknowledgements**

The authors acknowledge all Aboriginal and Torres Strait Islander peoples and their continuing connection to culture, land, and seas. We acknowledge the assistance and guidance of the Mayi Kuwayu Study Data Governance Committee, the Thiitu Tharrmay Aboriginal and Torres Strait Islander Reference Group, and the Cancer Australia Leadership Group on Aboriginal and Torres Strait Islander Cancer Control. We also acknowledge and thank Claire Zammit for designing the infographics included in this paper. SW (Taungurung), MMB (Wiradjuri), LJW (Wagadagam, Gumulgal), RM (Bagumani (Modewa) Clan) and RL (Ngiyampaa/Wongaibon) also acknowledge their cultures, histories, and communities.

**Author contributions**

SW and MMB drafted the manuscript. KAT, EB, and RL contributed to developing the study design and content. RM and LJW reviewed and edited the manuscript. All authors provided comments and critical revisions on the manuscript and approved the final version.

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**Competing interests**

A/Prof Lisa J. Whop is a member of Cancer Australia's Leadership Group on Aboriginal and Torres Strait Islander Cancer Control and member of the Quality Committee of the National Cancer Screening Register, Telstra Health.

**Data statement**

Kulay Kalingka Study data will be available through application to the Mayi Kuwayu Data Governance Committee. The corresponding author can be contacted for assistance with data requests.

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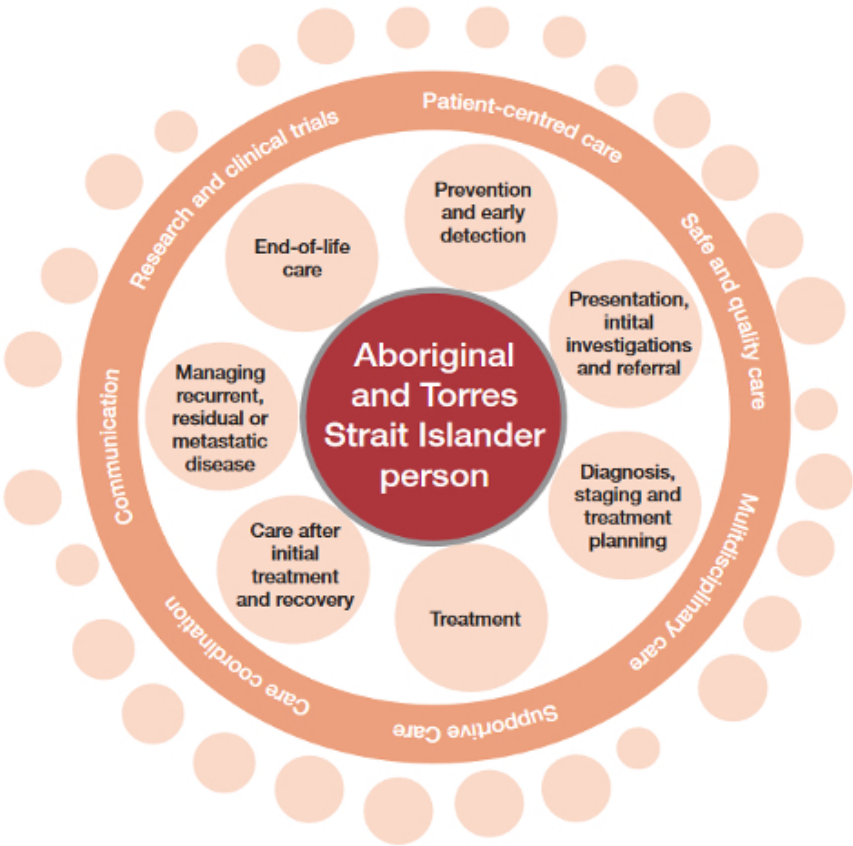
Figure legends

Figure 1: Patient-centred care for Aboriginal and Torres Strait Islander people

Figure 2: Photo of net bag created by Yirrganydji and Nughi artist Nicole Enoch-Chatfield (Goompi’s Girl)

Figure 3: Stage 1 (Development of Questionnaires)

Figure 4: (Kulay Kalingka study recruitment)



Patient-centred care for Aboriginal and Torres Strait Islander People

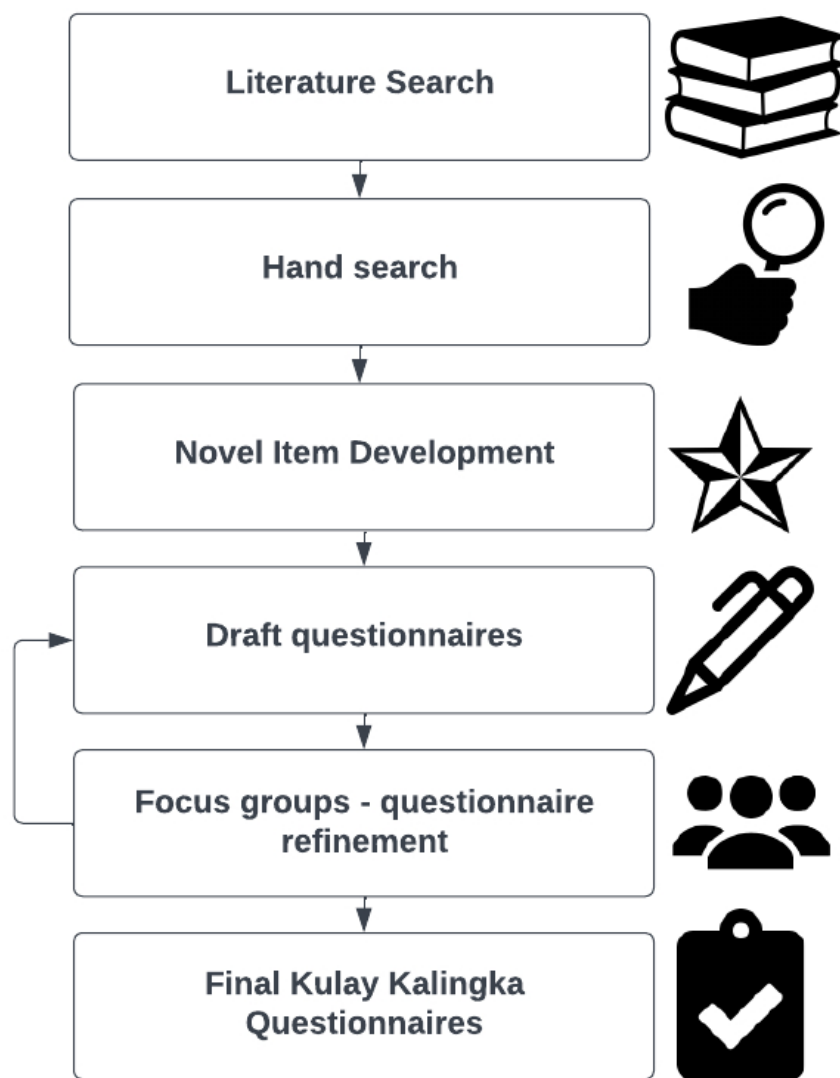
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Photo of net bag created by Yirrganydji and Nughi artist Nicole Enoch-Chatfield (Goompi's Girl)

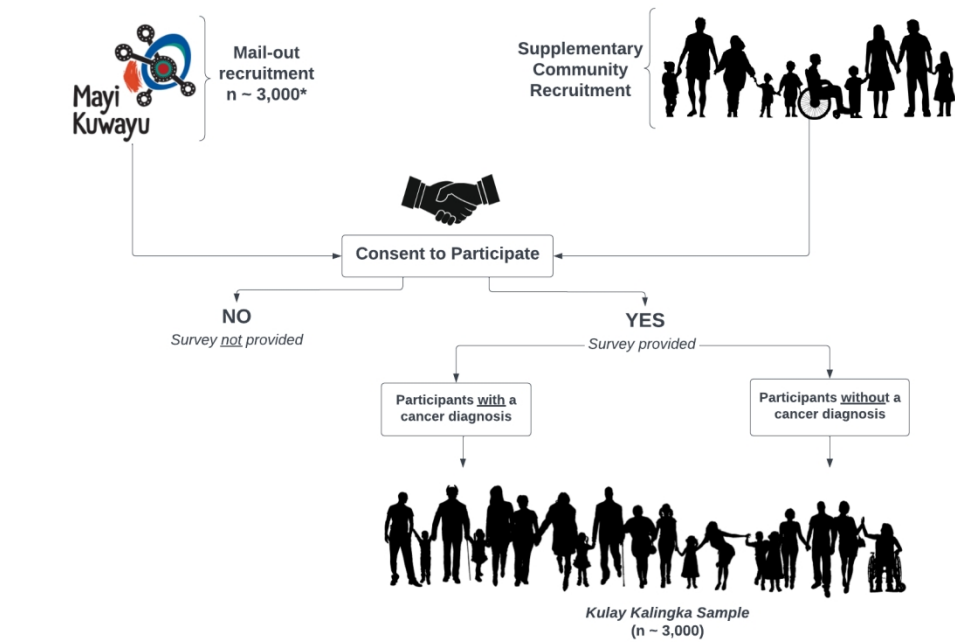
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Stage 1 (Development of Questionnaires)

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\*Mayi Kuwayu participants, including n ~600 with a cancer diagnosis and n ~ 2,400 without a cancer diagnosis

Kulay Kalingka study recruitment

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**Supplementary File 1:** Details on how the Maiam nayri Wingara Indigenous Data Sovereignty Principles will be enacted within the Kulay Kalingka Study<sup>1</sup>

**Principle 1:** Demonstrate how your proposed project ensures Aboriginal and Torres Strait Islander people will exercise control (all or individual elements) of the data ecosystem.

**Control:** An Aboriginal and Torres Strait Islander led research team control all aspects of the Kulay Kalingka Study. The Study is under the leadership of an Aboriginal Project Manager (SW, Taungurung), with majority Aboriginal and Torres Strait Islander project team members (MB Wiradjuri; LW Wagadagam; JC Taungurung; RL Ngiyampaa/Wongaibon) who are supported by non-Indigenous (KT, EB) team members. This collaboration ensures that Aboriginal and Torres Strait Islander peoples exercise control over the project while bringing a variety of skill sets into the team. The Kulay Kalingka Study is also supported by Aboriginal and Torres Strait Islander partner communities who are involved in questionnaire testing, data collection, community engagement and Study dissemination.

**Data stewardship:** All stages of the data ecosystem will be controlled by the research team under the guidance of an Aboriginal and Torres Strait Islander governance committee *Thiitu Tharrmay*, who will:

1. Be a source of expertise and advice on Aboriginal and Torres Strait Islander cultures;
2. Provide advice on the appropriate conduct of research including ensuring that the research, dissemination and policy agenda reflect Aboriginal and Torres Strait Islander community priorities and values;
3. Contribute to the Study methodology and methods;
4. Review and assist in interpreting results before publication and dissemination;
5. Contribute to publications where appropriate;
6. Provide links to other relevant research, policy and practice initiatives that may benefit from Study results;
7. Facilitate the dissemination and translation of research findings with Aboriginal and Torres Strait Islander communities and organisations

**Data analysis:** While non-Indigenous team members have input into the development of the data analysis plans; the project retains Aboriginal and Torres Strait Islander control over the data ecosystem as all data will be collected and analysed by Aboriginal and Torres Strait Islander team members. Only Aboriginal and Torres Strait Islander team members will have access to sensitive and personal information, which are protected under MKDGC and ethics requirements. Interpretation and analysis of results will be conducted by Aboriginal and Torres Strait Islander team members with input from *Thiitu Tharrmay* to ensure the data stories are strengths-based and protect Aboriginal and Torres Strait Islander peoples without causing further harm.

**Data dissemination:** Aboriginal and Torres Strait Islander people will receive information from the Kulay Kalingka Study through community focus groups, seminars and workshops; community reports; and social media posts. Information will also be available to Aboriginal and Torres Strait Islander peoples and non-Indigenous people in peer reviewed journals, conferences, and policy briefs. Finally, results will also be available to broad audiences online on the Cancer Australia website. This data dissemination strategy will be developed by the Kulay Kalingka Study team members in collaboration with Aboriginal and Torres Strait Islander partner communities and *Thiitu Tharrmay*.

**Principle 2:** Demonstrate how your proposed project will include contextual aspects and be disaggregated (available and accessible at individual, community and Indigenous national levels).

**Contextual:** All Kulay Kalingka Study project work (i.e. community workshops and presentations, reporting on the NCCI's, reporting on the Cancer Australia website, and peer-review papers) will include contextual aspects to support a strengths-based analysis. Contextual information will include the diversity of Aboriginal and Torres Strait Islander peoples and cultures, the impacts of colonial processes in the dispossession and dislocation of individuals and communities, and the ongoing structural racism including in healthcare systems. This contextual information is important as it helps

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in explaining cancer attitudes, outcomes and screening and treatment opportunities that Aboriginal and Torres Strait Islander peoples experience. When working with Aboriginal and Torres Strait Islander partner communities, they will have opportunities throughout to comment, influence and work with the data outputs, including the way the data is presented back to community members. This gives scope for community-specific contextual information.

**Accessible and available:** Outputs will be made available to Aboriginal and Torres Strait Islander communities through focus groups, interviews, workshops and presentations to give the requested data back to communities in ways relevant and meaningful to them. Pending COVID travel restrictions, these will be held on site in communities to allow for as many participants attending as possible. Resources on the data and outputs will also be provided to communities in plain-language and accessible formats for wider community distribution. These details are to be confirmed with the Kulay Kalingka Study partner communities.

**Principle 3:** Demonstrate how your proposed project will empower sustainable Indigenous self-determination and effective self-governance.

**Relevant:** The Study is both relevant to key policy-maker calls, such as those by Cancer Australia, for improving cancer understandings, screening and treatment. It is also relevant to Aboriginal and Torres Strait Islander communities as it will answer calls to better understand cancer attitudes, beliefs and experiences, and for greater inclusion of and leadership by Aboriginal and Torres Strait Islander patients, families and communities in cancer research.

**Self-determination and self-governance:** The Study will contribute to Indigenous self-determination and governance through Aboriginal and Torres Strait Islander control and governance of the project. It will contribute to community knowledge cancer risk factors, cancer screening opportunities, and cancer prevention techniques. It will also contribute to understanding Aboriginal and Torres Strait Islander peoples' attitudes and beliefs about cancer which will be used to inform and improve cancer prevention, screening and treatment services and programs. Aboriginal and Torres Strait Islander communities will be empowered with local-level data to assist in local decision making.

**Principle 4:** Demonstrate how your proposed project has data structures that are accountable to Indigenous peoples.

The research team will be guided by any specific data storage procedures developed and required by the Mayi Kuwayu Data Governance Committee (MKDGC)<sup>2</sup>. Data will be stored on the ANU secure server which is only accessible by approved members of the research team. Data stored on the ANU secure server is backed up daily at midnight. The data is stored at three geographically separate off-site Data Centres: Crisp, Huxley, and NCI. At the completion of the research project, the data will be stored on the secure, password-protected shared drive for 7 years after data collection, or 5 years after any publication, whichever is longer. The protection of participant's identities is very important. Identifiable data will not be published.

**Principle 5:** Demonstrate how your proposed project results are protective and respects Indigenous individual and collective interests.

The Kulay Kalingka Study is conducted under a strengths-based methodology: the study is designed to be inclusive of the diversity of the Aboriginal and Torres Strait Islander population, and national-level data can be used to monitor and guide improved cancer experiences for Aboriginal and Torres Strait Islander peoples. Our findings will be protected after dissemination through clear and consistent messaging in peer reviewed publications, reports, social media, public presentations and on the Cancer Australia NCCI website.

<sup>1</sup> Indigenous Data Sovereignty Principles available at: <https://www.maiamnayriwingara.org/key-principles>

<sup>2</sup> MKDGC information available at: <https://mkstudy.com.au/overview/>

# BMJ Open

## Study Protocol: Kulay Kalingka, a national cohort study of Aboriginal and Torres Strait Islander peoples' cancer experiences

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**Study Protocol: Kulay Kalingka, a national cohort study of Aboriginal and Torres Strait Islander peoples’ cancer experiences**

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## Abstract

### Introduction

Aboriginal and Torres Strait Islander peoples are the First Peoples of Australia. Since settler-colonisation, Aboriginal and Torres Strait Islander peoples have experienced disparities in health outcomes, including cancer, when compared to non-Indigenous Australians, including higher cancer incidence and mortality rates, and lower participation in cancer screening programs. Data to monitor and improve outcomes are limited.

### Aims, method and analysis

The Kulay Kalingka Study will be a national cohort study aiming to understand Aboriginal and Torres Strait Islander people's beliefs about cancer and experiences with cancer care and treatment, and to improve experiences and outcomes. It will be nested within the Mayi Kuwayu Study, a national community-controlled cohort study of Aboriginal and Torres Strait Islander people (n>11,000), with supplementary in-community recruitment.

Mayi Kuwayu Study participants aged  $\geq 18$  years who consented to being recontacted, and a diversity of local community members will be invited to participate through completing a questionnaire relevant to their cancer status, aiming to recruit 2800 participants without prior doctor-diagnosed cancer and 700 with a cancer diagnosis.

This community-driven data will enable monitoring and reporting of national trends over time and will guide national cancer control research, policy and clinical care, to improve outcomes for Aboriginal and Torres Strait Islander peoples.

### Ethics and dissemination

The Kulay Kalingka Study has ethics approval from Australian Institute of Aboriginal and Torres Strait Islander Studies (#EO324-20220414 and REC-0121) and the Australian National University (#2022/465). The Kulay Kalingka Study is being developed with Aboriginal and Torres Strait Islander communities, following the Maïam nayri Wingara Indigenous Data Sovereignty Collective principles. Meaningful, accessible, and culturally adapted Study findings will be disseminated to Aboriginal and Torres Strait Islander communities through activities including community workshops, reports and feedback sheets, and in other ways as determined by the community. We will also return data to participating communities.



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**Article Summary**  
**Strengths and Limitations**

- The Kulay Kalingka Study questionnaires were developed through consultations with Aboriginal and Torres Strait Islander peoples and communities Australia-wide, and includes items on cancer care, cancer beliefs, accessibility of cancer screening programs, and cancer survivability.
- The Kulay Kalingka Study will provide Aboriginal and Torres Strait Islander led, designed, and governed national-level data to monitor and guide improved cancer awareness, understandings of care, treatment, and service delivery for Aboriginal and Torres Strait Islander peoples.
- It will contribute to monitoring and reporting on 37 of Cancer Australia’s National Aboriginal and Torres Strait Islander Cancer Control Indicators, where no data currently exist.
- The Study is designed to be inclusive of the diversity of the Aboriginal and Torres Strait Islander population and is not designed to be representative of this population.

## Introduction

We begin by acknowledging the sovereign Indigenous peoples around the world who are the Custodians of their lands, waterways and skies, who have cared for and maintained Country, culture and community since time immemorial. We acknowledge the ancestral lands of the Ngannawal and Ngambri peoples on which this study protocol was written, and thank the Elders past and present for our safe passage through their Country.

By qualification, we the authorship team, are researchers, but our positioning from the onset of this Study is that of sovereign Aboriginal and Torres Strait Islander peoples with our own cultures, histories and communities and people supporting such sovereignty. We have a shared commitment of service to mob that seeks to understand how mob can live healthy lives. We follow the Indigenist and Indigenous research methodologies set before us by trailblazers including Nurungga Professor Lester-Irabinna Rigney[1], Palawa Distinguished Professor Maggie Walter[2], Opaskwayak Cree Researcher Shawn Wilson[3], and Ngāti Awa, Ngāti Porou, Tūhourangi Professor Linda Tuhiwai Smith[4]. By doing so we privilege our cultural knowledges, ways of knowing, being and doing, and conduct our research with respect, responsibility, generosity, obligation and reciprocity to our peoples[5].

Aboriginal and Torres Strait Islander peoples maintain the oldest living cultures in the world, with an estimated 250 Aboriginal and Torres Strait Islander languages and 600-700 dialects across the continent prior to colonisation[6]. Along with diverse languages, Aboriginal and Torres Strait Islander groups also have diverse histories, cultures, lore/law and other practices and have lived, for generations, healthy and culturally enriched lives[7-8]. Colonial processes and policies dispossessed and dislocated Aboriginal and Torres Strait Islander peoples from our families, Country, cultures and languages, but culture remains strong and languages continue and many are being reclaimed. Currently, there are an estimated 798,400 Aboriginal and Torres Strait Islander peoples living in Australia. Over 30% of the population lives in major cities of Australia, while 24% live in inner regional Australia, 20% in outer regional Australia, and 7% in remote or very remote Australia[9]. Today, the Aboriginal and Torres Strait Islander population bears a disproportionate burden of disease, including cancer.

Prior to colonisation, cancer impacted Aboriginal and Torres Strait Islander populations but the attribution of illness to cancer was limited[10]. Only in the last two decades has cancer received attention specific to our population[11]. The quality of data also limits what we know about diagnosis and treatment outcomes via cancer registry data. Problems with data quality include issues with misidentification and under-identification of Aboriginal and Torres Strait Islander peoples in general administrative datasets and cancer-specific datasets[12-13], and a lack of national data on screening programs[14]. In more recent times cancer has become recognised as one of the leading contributors to the burden of disease for Aboriginal and Torres Strait Islander peoples[15].

Between 2015-2019, cancer and other neoplasms were the leading cause of death for Aboriginal and Torres Strait Islander peoples in states where adequate data on deaths exist, contributing to almost a quarter of total deaths[15]. The most commonly diagnosed cancers are lung, breast, colorectal, prostate and head and neck cancers. These cancer types are amenable to prevention and have high fatality rates[15].

In 2012-2016, for all cancers combined, incidence was 14% higher among Aboriginal and Torres Strait Islander peoples compared to non-Indigenous peoples[16]. When diagnosed, Aboriginal and Torres Strait Islander peoples are more likely to be at a more advanced stage of disease impacting prognosis and treatment options, have lower rates of hospitalisations (due to the later stage at diagnosis and barriers to treatment such as distance from transport services) than non-Indigenous people, and wait

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1 longer for surgery[15]. From 2015-2019, the age-standardised mortality rate for all cancers for the  
2 Aboriginal and Torres Strait Islander population was 45% higher than in the non-Indigenous  
3 population[16]. Cancer does not only affect our older community members. Concomitantly, the  
4 median age of an Aboriginal and Torres Strait Islander person in 2016 was 20 years compared with 38  
5 for non-Indigenous people, with some types of cancers showing up earlier in the Aboriginal and Torres  
6 Strait Islander population compared to the non-Indigenous population[16].

8 There are a range of risk factors that are associated with an increased likelihood of people in the  
9 general population developing cancer. Key modifiable risk factors include tobacco smoking, alcohol,  
10 obesity and exposure to too much sun (melanoma)[16]. There is a growing body of evidence  
11 internationally that links discrimination and racism to increased prevalence of modifiable risk factors  
12 including tobacco smoking, higher levels of alcohol use and obesity[17-19]. The increased prevalence  
13 of, and mortality from cancer among Aboriginal and Torres Strait Islander peoples is largely due to  
14 socially-driven increased prevalence of cancer risk factors[20]. Additional upstream factors that affect  
15 Aboriginal and Torres Strait Islander peoples' cancer experiences include barriers to accessing cancer  
16 services such as screening and treatment[21-22].

18 Aboriginal and Torres Strait Islander community beliefs about cancer are varied. Many Aboriginal and  
19 Torres Strait Islander peoples understand that tobacco, poor diet and other risk factors cause  
20 cancer[23]. However, the general population often look to external factors to explain things that are  
21 happening to them, rather than looking to factors within their own control[24]. For example, some  
22 Aboriginal and Torres Strait Islander communities are unwilling to talk about cancer, believe it is black  
23 magic, or believe it to be contagious. Further, some believe cancer invaded the bodies of Aboriginal  
24 and Torres Strait Islander peoples when colonisers arrived in 1788[10, 25-26]. In some Aboriginal and  
25 Torres Strait Islander languages, including Aboriginal languages across the Northern Territory, there is  
26 no word for cancer[27]. Regardless of these beliefs, it places a heavy burden on those diagnosed with  
27 the disease, as well as their families, friends, carers, Elders and the community.

29 It is in this context that the National Aboriginal and Torres Strait Islander Cancer Framework 2015 was  
30 developed by Cancer Australia to provide high level guidance for stakeholders working to improve  
31 cancer outcomes and reduce disparities[28]. It aligns with the Optimal Care Pathway (OCP) for  
32 Aboriginal and Torres Strait Islander peoples with cancer, which identifies seven critical steps in the  
33 patient journey (see figure 1)[28].

Figure 1: Patient-centred care for Aboriginal and Torres Strait Islander people

Cancer Australia developed a set of National Aboriginal and Torres Strait Islander Cancer Control Indicators (NCCI) to monitor performance across the OCP areas[28]. There are 22 indicators in total, and progress in these areas is assessed using 57 measures comprising of:

- 20 measures which are currently reported on the website, available at: <https://ncci.canceraustralia.gov.au/aboriginal-and-torres-strait-islander-cancer-control-indicators>
- 37 measures where no data exist and/or require further progress for data development, including participation in national cancer screening programs (i.e., cervical, breast, bowel); participation in clinical trials; experiences of racism/discrimination in health care; beliefs about whether cancer can be prevented.

No data exist for over half of the Aboriginal and Torres Strait Islander NCCI identified measures, and as a result we cannot monitor progress in a range of areas. It is essential that data about our attitudes, beliefs and experiences of cancer be developed and governed for and by Aboriginal and Torres Strait Islander peoples. This will help ensure community and relational accountability, which is particularly important given the ongoing colonial context outlined above, including the programs and policies that have aimed to actively erode power, social structures and community resources. In response to the impacts of cancer and the lack of data to inform the Aboriginal and Torres Strait Islander NCCI, a proposed national study is being developed.

The Kulay Kalingka Study will be a prospective national cohort study that is designed to understand Aboriginal and Torres Strait Islander people's beliefs about cancer; experiences with cancer care and treatment; and to improve experiences and outcomes for Aboriginal and Torres Strait Islander peoples with cancer and their families. The Study is designed to inform the Cancer Australia priority areas. The study name, 'Kulay Kalingka' translates to 'net bag in the water' in Ngayampaa (Wongaibon) language. Woven net bags have been used by rainforest Bama (peoples) to process highly toxic foods, whereby foods are placed in net bags and run through a slow-moving stream to leach out their toxins and make them safe over time. This concept is woven into the Kulay Kalingka Study: the net bag is symbolic of how people and families fighting cancer can include Aboriginal and Torres Strait Islander health and wellbeing concepts for cultural, medicinal and spiritual healing, alongside clinical treatments (Figure 2).

Figure 2 Photo of net bag created by Yirrganydji and Nughi artist Nicole Enoch-Chatfield (Goompi's Girl)

## Methods and analysis

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**Patient and public involvement statement**

The Kulay Kalingka Study arose from Aboriginal and Torres Strait Islander community needs, to better understand cancer attitudes, beliefs and experiences and from calls for the inclusion of Aboriginal and Torres Strait Islander patients, families and communities in cancer research[29]. Additionally, the Study arose from a call from Cancer Australia to improve cancer outcomes for Aboriginal and Torres Strait Islander peoples, including across cancer prevention, screening and early detection, diagnosis and treatment, palliative care and survivorship, and their corresponding service areas[30]. Aboriginal and Torres Strait Islander peoples are involved in all stages of the project, from conception, development and survey testing through to analysis and dissemination.

**Mayi Kuwayu Study**

The Kulay Kalingka Study is nested within ‘Mayi Kuwayu: the National Study of Aboriginal and Torres Strait Islander Wellbeing’ (the Mayi Kuwayu Study). The Mayi Kuwayu Study is a large-scale, longitudinal study of Aboriginal and Torres Strait Islander adults aged ≥16 years with approximately 11,000 participants to date. The Study aims to improve the understanding of the role cultural factors play in Aboriginal and Torres Strait Islander peoples’ wellbeing and their interaction with standard health risk and protective factors. The Mayi Kuwayu Study is developed and governed by Aboriginal and Torres Strait Islander peoples[31–32]. The Mayi Kuwayu Study has developed and maintained Aboriginal and Torres Strait Islander community partnerships around Australia[33], and the Kulay Kalingka Study utilises these strong relationships throughout its development.

It is essential that Aboriginal and Torres Strait Islander communities are involved in questionnaire development and testing. This participatory-based research approach is necessary in order to help ensure the Study meets the dual criteria of Aboriginal and Torres Strait Islander community relevance and scientific excellence. Aboriginal and Torres Strait Islander peoples are involved in and lead all stages of the Kulay Kalingka Study.

There are three stages to Kulay Kalingka Study: Stage 1 – the development of the questionnaires, incorporating a literature search, questionnaire item refinement and pilot testing (Figure 3); Stage 2 – the recruitment, and Stage 3 – follow up recruitment (Figure 4).

**Stage 1: Development of questionnaires**

*1.1 Existing item search*

Between October 2021 and April 2022, we explored existing questionnaire items for potential use in the Kulay Kalingka Study questionnaires. This was to identify existing questionnaire items and measures that map to the 22 Aboriginal and Torres Strait Islander NCCI, using Google Scholar. Search terms were developed by the Kulay Kalingka Study team. Final search terms were:

*(Aborigin\* OR “Torres Strait”) AND (cancer) AND (awareness OR beliefs OR prevention OR “risk reduction” OR “smoking cessation programs” OR “quit smoking programs” OR screening OR “screening test follow up” OR incidence OR “stage at diagnosis” OR “culturally competent health service” OR treatment OR “patient experience”)*

The second search was conducted in Google Scholar to find supplementary questionnaire items and measures that relate to specific cancer types. Final search terms were:

*(Aborigin\* OR “Torres Strait”) AND (cancer) AND bladder OR breast OR cervical OR bowel OR “head and neck” OR kidney OR lung OR liver OR melanoma OR throat OR ovarian OR pancreatic OR prostate OR stomach OR thyroid OR uterine OR “cancer of unknown primary site” OR “non-Hodgkin lymphoma”*

*1.2 Hand search*

If research papers did not publish questionnaire items or measures, we contacted corresponding authors and requested these questionnaire items or measures. We also worked with experts in the field and checked reference lists of included material for other relevant questionnaire items and measures.

Finally, items and measures that met the following three criteria were moved into the item development stage for inclusion or modification:

1. had been developed for or used with Aboriginal and Torres Strait Islander peoples
2. captured information about cancer knowledge, attitudes, beliefs, screening, diagnosis, treatment, services and/or systems
3. map onto the Aboriginal and Torres Strait Islander NCCI.

### *1.3 Novel item development*

We also developed new items and measures where no appropriate items existed. These novel quantitative and qualitative items were created in collaboration between the Kulay Kalingka Study team, the Thlithu Tharmmay Aboriginal and Torres Strait Islander reference group, Aboriginal and Torres Strait Islander individuals and communities, and Cancer Australia.

### *1.4 Draft questionnaires*

After collating and developing the draft items, two draft questionnaires are formed. Questionnaire 1 is designed for people who have ever had a cancer diagnosis, and focuses on indicators related to cancer diagnosis, care, and treatment. Questionnaire 2 is designed for people who have never had a cancer diagnosis, which focuses on indicators related to knowledge about cancer and cancer prevention. Across both questionnaires are items relating to national cancer screening programs, cancer awareness, and cancer beliefs.

### *1.5 Pilot testing – recruitment*

Aboriginal and Torres Strait Islander communities will self-nominate to be part of the pilot testing processes, based on existing community relationships[33]. Pilot testing will be conducted with self-nominated communities until good representation across the ASGS Remoteness Areas 2011 (Remote, Inner Regional and Major City) is achieved. If multiple communities self-nominate from the same ASGS Remoteness Areas (2011), the community will not be turned away from participating; all communities who want to participate can participate. Each community will self-determine the constitution of the focus groups, in line with Principle 1 of the Australian Institute of Aboriginal and Torres Strait Islander Studies Code of Ethics for Aboriginal and Torres Strait Islander Research[34].

There will be three focus groups at each community, with 6-8 participants in each focus group. Participants will be selected by the communities through word-of-mouth building on relational accountability. Focus groups will be independently conducted with people who have had a cancer diagnosis, and people who have not had a cancer diagnosis. A minimum of 30 pilot-testing participants with a cancer diagnosis will pilot-test draft Questionnaire 1. A minimum of 30 pilot-testing participants without a cancer diagnosis will pilot-test draft Questionnaire 2. Focus group participants will be conducted with Aboriginal and/or Torres Strait Islander peoples, aged  $\geq 18$  years. Pilot-testing focus groups are voluntary and participants can leave at any time.

### *1.6 Pilot testing – questionnaire refinement*

Each focus group will be conducted by two Aboriginal or Torres Strait Islander facilitators with experience in conducting focus groups. Focus groups are held in culturally safe spaces as self-determined by the community. Focus groups will follow the probing approach method, where the



facilitator’s role is proactive and direct questions are asked to extract specific information from participants[35]. Participants are provided with a draft questionnaire and asked about questionnaire length, cultural appropriateness of items, interpretation and misunderstandings of items, and the overall tone of questions being asked. Participants can provide this feedback either on the page or to the focus group facilitators.

Focus group feedback will be collated and iteratively incorporated to the questionnaire by Aboriginal and Torres Strait Islander members of the research team. The purpose of this process will be to ensure the wording of items supports understanding, reduces cognitive burden, and to refine questionnaire items, including item inclusion, exclusion and/or modification. The goal is to support appropriateness, accuracy and interpretation of items so meaningful data are yielded[36].

1.7 Final questionnaires

The result of the literature search, hand search, novel item development, and pilot testing are the final questionnaires.

Figure 3: Stage 1 (Development of Questionnaires)

Stage 2: Recruitment

2.1 Mail out recruitment

The Kulay Kalingka Study primary sampling frame is from baseline Mayi Kuwayu Study participants aged ≥18 years who have consented to being recontacted by the Mayi Kuwayu Study. Mail out recruitment will begin in mid to late 2023.

All existing Mayi Kuwayu Study participants who self-reported a doctor diagnosed cancer (n≈600 participants) will be invited to participate in Questionnaire 1 of the Kulay Kalingka Study. Existing participants who have never had a cancer diagnosis (n≈2400) will be invited to participate in Questionnaire 2, with the goal of recruiting four participants without cancer for every one participant with cancer. Selection of participants who have never had a cancer diagnosis into the Kulay Kalingka Study sample will be stratified by age, gender and remoteness (see table 1).

Table 1. Selection of Kulay Kalingka Study participants (restricted to those who have consented to follow up).

Demographic group	Number of potential participants with cancer	Number of potential participants without cancer	Number without cancer to be recruited
Total (incl. missings)	619	7614	2476
<b>Men</b>			
Aged 18-50, major cities	13	416	52
Aged 51+, major cities	91	741	364
Aged 18-50, regional/remote	9	541	36
Aged 51+, regional/remote	135	1032	540
<b>Women</b>			
Aged 18-50, major cities	44	1134	176
Aged 51+, major cities	120	740	480
Aged 18-50, regional/remote	42	1349	168
Aged 51+, regional/remote	137	1145	548

Total (excl. missings)	591	7098	2364
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All potential Kulay Kalingka Study participants will be posted a survey pack in the mail (containing an information sheet, a questionnaire, a national support service brochure, and a pre-paid reply envelope).

## 2.2 Supplementary community recruitment

In addition to recruiting existing Mayi Kuwayu Study participants, the Kulay Kalingka Study will conduct supplementary recruitment across ASGS Remoteness Areas 2011, following the same method as pilot testing recruitment. Supplementary community recruitment will begin in mid to late 2023 from saltwater, freshwater, desert and Island groups, and living across urban, regional and remote Australia to ensure diversity of experiences are captured in the Kulay Kalingka Study. This will enable Aboriginal and Torres Strait Islander peoples with or without a cancer diagnosis, and from diverse settings, contexts, and environments, to participate in the Kulay Kalingka Study.

Participation in all stages of the Kulay Kalingka Study is voluntary. Participants provide informed consent and can withdraw consent at any time. Potential participants will receive a plain-language information sheet about the study, along with the consent form, support services directory and questionnaire.

Figure 4: Kulay Kalingka study recruitment

## Stage 3: Follow up recruitment

The first wave of recruitment will commence mid to late 2023. The second wave of follow-up questionnaires will commence approximately one year after baseline data collection completion. This follow-up wave will recruit the same Kulay Kalingka Study participants and additional participants through supplementary community recruitment to help with participant drop-off. This initial follow up will allow us to report on changes in cancer attitudes, beliefs and experiences over time.

There is also potential for ongoing follow up waves if funding allows, to enable further longitudinal examination of cancer attitudes, beliefs and experiences over time.

For all waves, the intention is that participants will complete the same questionnaire they completed in the first wave of data collection (acknowledging we make any changes in response to participant feedback, issues with original questionnaire, or new priorities). However, if a participant's cancer diagnosis status changes between waves, they will cross from the without cancer diagnosis group to the with cancer diagnosis group.

## Analysis

Descriptive analysis of data from Kulay Kalingka Study can be used to monitor and inform improvement in cancer outcomes for Aboriginal and Torres Strait Islander peoples, including generating evidence to inform service delivery, cancer screening, participation in prevention activities, and cancer awareness. Statistical analyses will involve cross-sectional and potentially longitudinal methods if multiple waves of data are collected. We will examine cancer attitudes, beliefs and experiences for Aboriginal and Torres Strait Islander peoples who have been diagnosed with cancer and those who have never been diagnosed with cancer. This descriptive analysis will include the

prevalence (% , N) of participation in health promotion programs, risk factor exposure, cancer screening participation and behaviours, and importantly cancer treatment experiences and participation in trials.

Statistical analysis is dependent on future funding. This analysis may include an examination of cancer impacts on broader health and wellbeing outcomes. Data from these two questionnaires will also enable robust monitoring and reporting of the Aboriginal and Torres Strait Islander NCCI over time.

**Ethics and dissemination**

The Kulay Kalingka Study has ethics approval from AIATSIS (reference #EO324-20220414 and REC-0121) and the Australian National University (reference #2022/465). Where required, data custodian approvals and additional ethics approvals will be obtained.

**Indigenous data sovereignty principles**

To better understand Aboriginal and Torres Strait Islander experiences of cancer, the Kulay Kalingka Study privileges Aboriginal and Torres Strait Islander voices and build on inherent roles and responsibility of sovereignty and self-determination. To do so, the Kulay Kalingka Study follows the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research from the onset and throughout the life of the Study[34]. In doing so and consistent with United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), we recognise and respect Aboriginal and Torres Strait Islander peoples’ right to self-determination which is fundamental to all research.

Aboriginal and Torres Strait Islander peoples have identified that our involvement and Indigenous data sovereignty in cancer research is “critical to ensuring that Indigenous values and priorities underpin research”[29]. We will ensure that our needs are central in improving cancer outcomes for mob. The Kulay Kalingka Study follow the Maiam nayri Wingara Indigenous Data Sovereignty Collective principles for Indigenous data sovereignty[37]. These principles assert that Aboriginal and Torres Strait Islander peoples have the right to:

- 1. Exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure.
- 2. Data that is contextual and disaggregated (available and accessible at individual, community and First Nations levels).
- 3. Data that is relevant and empowers sustainable self-determination and effective self-governance.
- 4. Data structures that are accountable to Indigenous peoples and First Nations.
- 5. Data that is protective and respects our individual and collective interests.

The Kulay Kalingka team is Aboriginal and Torres Strait Islander designed and led, and has Aboriginal and Torres Strait Islander governance. This includes all output being bound by these principles through the application to the Mayi Kuwayu Data Governance Committee (MKDGC)[38]. See Supplementary File 1 for an outline of how we will address these principles.

**Knowledge Translation**

The Kulay Kalingka Study will produce knowledge translation outputs using iterative and participatory approaches which will summarise findings for Aboriginal and Torres Strait Islander communities and our stakeholders, including policy makers and service providers. The data presented in the form of presentations will be tailored to their wants and needs, consistent with the Kulay Kalingka Study principles of Aboriginal and Torres Strait Islander sovereignty and self-determination[34]. All results will be reviewed by Thiitu Tharmmay, MKDGC, and Cancer Australia before dissemination.

We will continue to work with Aboriginal and Torres Strait Islander peoples and communities, across a range of saltwater/freshwater/desert/Island groups, and in urban, regional and remote areas where possible, to develop these knowledge translation tools. We will disseminate study findings which are meaningful, accessible, and culturally adapted to each Aboriginal and Torres Strait Islander community through activities including community workshops, reports and feedback sheets, and in other ways as determined by the community. We will also return data to participating communities.

We will also engage with policymakers to co-produce knowledge translation tools. For example, this is expected to include policy briefs, factsheets, and snapshots of data for presentation on the Cancer Australia website. Finally, we will produce peer reviewed publications to help disseminate results to a broader audience.

## Implications

The Kulay Kalingka Study is a national, Aboriginal and Torres Strait Islander designed, governed and led study for Aboriginal and Torres Strait Islander experiences, attitudes and beliefs of cancer. The Kulay Kalingka Study will fill knowledge gaps by providing national level data on and monitor changes of cancer knowledge, understanding and experiences of diagnosis and treatment over time. The Study will address the gaps in data and knowledges, including exploring attitudes, beliefs and experiences of cancer to support the health and wellbeing of our peoples, and for future generations. The work will have many important and lasting benefits to Aboriginal and Torres Strait Islander peoples. This includes strengthening healthcare and cancer care services, increasing understanding and awareness of cancer risk factors and how to mitigate these risks, and supporting Aboriginal and Torres Strait Islander peoples with a diagnosis of cancer to receive optimal and culturally secure care throughout their cancer journey.

## Strengths and limitations

The Kulay Kalingka Study aims to improve cancer outcomes for Aboriginal and Torres Strait Islander peoples. There are a range of benefits to participants of this research, which includes self-determination by centring Aboriginal and Torres Strait Islander voices in national level data about cancer (risks, screening and treatment), and empowering Aboriginal and Torres Strait Islander people to tell their stories in a safe and culturally appropriate way.

A major strength of the Study is our relational ties and Aboriginal and Torres Strait Islander community accountability. This includes Aboriginal and Torres Strait Islander research leadership, and strong relationships with communities. Further, we use knowledge translation practices (including returning data to communities), our adherence to Indigenous data sovereignty and governance principles[37-38], and our engagement with Thiiitu Tharrmay and the Cancer Australia Leadership Group on Aboriginal and Torres Strait Islander Cancer Control.

Another strength is that the Kulay Kalingaka Study uses an Indigenist methodology as outlined by Nurungga Professor Lester-Irabinna Rigney[1] by:

- Resistance as the emancipatory imperative in Indigenist research
- Political integrity in Indigenist research
- Privileging Indigenous voices in research

While we cannot ensure that participants involved in development of the questionnaires are representative of all Aboriginal and Torres Strait Islander peoples, we are committed to engaging Aboriginal and Torres Strait Islander peoples from diverse settings, contexts, and environments. This program of work will focus on representing and encompassing Aboriginal and Torres Strait Islander experiences, attitudes and beliefs regarding cancer, from our Indigenist perspectives and worldviews.

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We do not anticipate that participants in the Kulay Kalingka Study will be representative of all Aboriginal and Torres Strait Islander peoples with and without a cancer diagnosis. The lack of representativeness of the Kulay Kalingka sample does not interfere with internal comparisons (i.e., identifying relationships between exposures and outcomes in the sample) or with quantifying within-person changes over time. Findings from other populations show that exposure-outcome associations are robust and generalizable even when the sample is not representative of the total population[39].

**Acknowledgements**

The authors acknowledge all Aboriginal and Torres Strait Islander peoples and their continuing connection to culture, land, and seas. We acknowledge the assistance and guidance of the Mayi Kuwayu Study Data Governance Committee, the Thiitu Tharrmay Aboriginal and Torres Strait Islander Reference Group, and the Cancer Australia Leadership Group on Aboriginal and Torres Strait Islander Cancer Control. We also acknowledge and thank Claire Zammit for designing the infographics included in this paper. SW (Taungurung), MMB (Wiradjuri), LJW (Wagadagam, Gumulgal), RM (Bagumani (Modewa) Clan) and RL (Ngiyampaa/Wongaibon) also acknowledge their cultures, histories, and communities.

**Author contributions**

SW and MMB drafted the manuscript. KAT, EB, and RL contributed to developing the study design and content. RM and LJW reviewed and edited the manuscript. All authors provided comments and critical revisions on the manuscript and approved the final version.

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**Competing interests**

A/Prof Lisa J. Whop is a member of Cancer Australia's Leadership Group on Aboriginal and Torres Strait Islander Cancer Control and member of the Quality Committee of the National Cancer Screening Register, Telstra Health.

**Data statement**

Kulay Kalingka Study data will be available through application to the Mayi Kuwayu Data Governance Committee. The corresponding author can be contacted for assistance with data requests.



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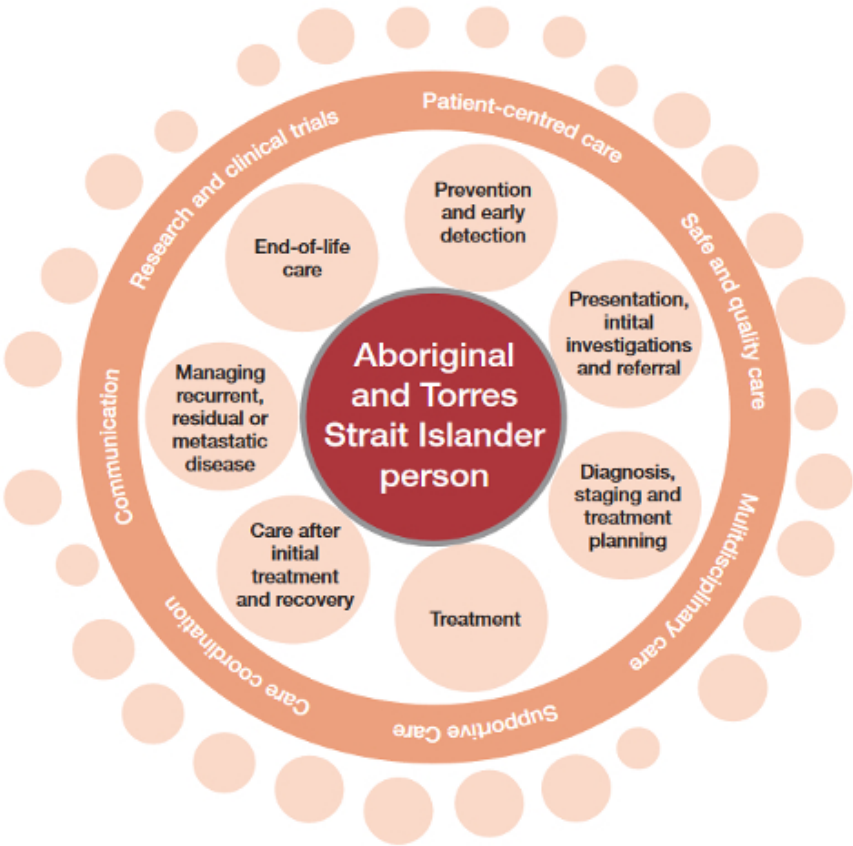
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**Figure legends**

- 1 Figure 1: Patient-centred care for Aboriginal and Torres Strait Islander people
- 2 Figure 2: Photo of net bag created by Yirrganydji and Nughi artist Nicole Enoch-Chatfield (Goompi's
- 3 Girl)
- 4 Figure 3: Stage 1 (Development of Questionnaires)
- 5 Figure 4: (Kulay Kalingka study recruitment)

For peer review only



Patient-centred care for Aboriginal and Torres Strait Islander People

93x81mm (150 x 150 DPI)



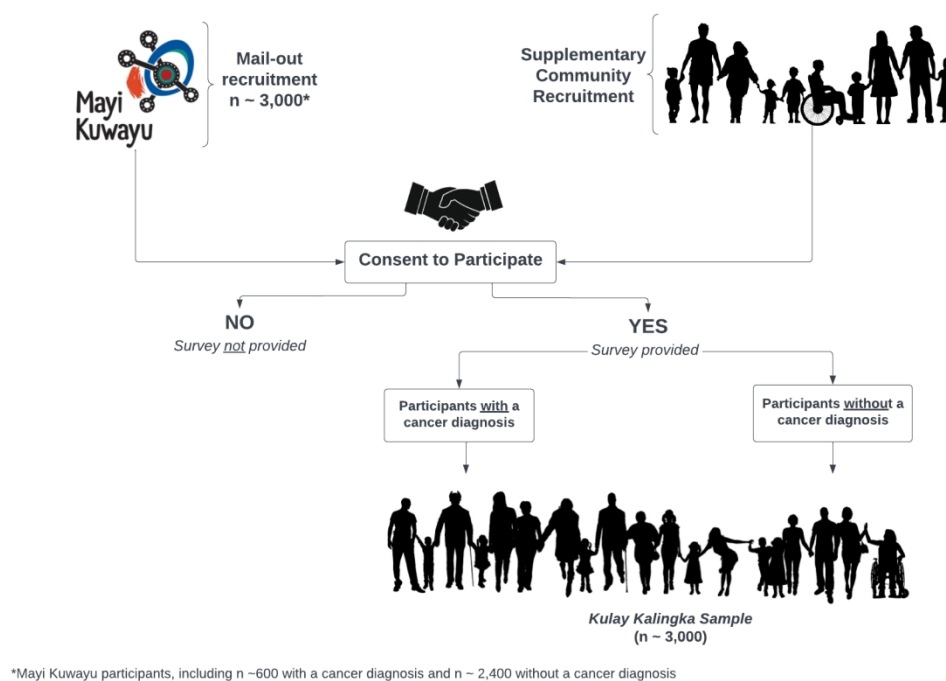
Photo of net bag created by Yirrganydji and Nughi artist Nicole Enoch-Chatfield (Goompi's Girl)

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Stage 1 (Development of Questionnaires)

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Kulay Kalingka study recruitment

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**Supplementary File 1:** Details on how the Maiam nayri Wingara Indigenous Data Sovereignty Principles will be enacted within the Kulay Kalingka Study<sup>1</sup>

**Principle 1:** Demonstrate how your proposed project ensures Aboriginal and Torres Strait Islander people will exercise control (all or individual elements) of the data ecosystem.

**Control:** An Aboriginal and Torres Strait Islander led research team control all aspects of the Kulay Kalingka Study. The Study is under the leadership of an Aboriginal Project Manager (SW, Taungurung), with majority Aboriginal and Torres Strait Islander project team members (MB Wiradjuri; LW Wagadagam; JC Taungurung; RL Ngiyampaa/Wongaibon) who are supported by non-Indigenous (KT, EB) team members. This collaboration ensures that Aboriginal and Torres Strait Islander peoples exercise control over the project while bringing a variety of skill sets into the team. The Kulay Kalingka Study is also supported by Aboriginal and Torres Strait Islander partner communities who are involved in questionnaire testing, data collection, community engagement and Study dissemination.

**Data stewardship:** All stages of the data ecosystem will be controlled by the research team under the guidance of an Aboriginal and Torres Strait Islander governance committee *Thiitu Tharrmay*, who will:

1. Be a source of expertise and advice on Aboriginal and Torres Strait Islander cultures;
2. Provide advice on the appropriate conduct of research including ensuring that the research, dissemination and policy agenda reflect Aboriginal and Torres Strait Islander community priorities and values;
3. Contribute to the Study methodology and methods;
4. Review and assist in interpreting results before publication and dissemination;
5. Contribute to publications where appropriate;
6. Provide links to other relevant research, policy and practice initiatives that may benefit from Study results;
7. Facilitate the dissemination and translation of research findings with Aboriginal and Torres Strait Islander communities and organisations

**Data analysis:** While non-Indigenous team members have input into the development of the data analysis plans; the project retains Aboriginal and Torres Strait Islander control over the data ecosystem as all data will be collected and analysed by Aboriginal and Torres Strait Islander team members. Only Aboriginal and Torres Strait Islander team members will have access to sensitive and personal information, which are protected under MKDGC and ethics requirements. Interpretation and analysis of results will be conducted by Aboriginal and Torres Strait Islander team members with input from *Thiitu Tharrmay* to ensure the data stories are strengths-based and protect Aboriginal and Torres Strait Islander peoples without causing further harm.

**Data dissemination:** Aboriginal and Torres Strait Islander people will receive information from the Kulay Kalingka Study through community focus groups, seminars and workshops; community reports; and social media posts. Information will also be available to Aboriginal and Torres Strait Islander peoples and non-Indigenous people in peer reviewed journals, conferences, and policy briefs. Finally, results will also be available to broad audiences online on the Cancer Australia website. This data dissemination strategy will be developed by the Kulay Kalingka Study team members in collaboration with Aboriginal and Torres Strait Islander partner communities and *Thiitu Tharrmay*.

**Principle 2:** Demonstrate how your proposed project will include contextual aspects and be disaggregated (available and accessible at individual, community and Indigenous national levels).

**Contextual:** All Kulay Kalingka Study project work (i.e. community workshops and presentations, reporting on the NCCI's, reporting on the Cancer Australia website, and peer-review papers) will include contextual aspects to support a strengths-based analysis. Contextual information will include the diversity of Aboriginal and Torres Strait Islander peoples and cultures, the impacts of colonial processes in the dispossession and dislocation of individuals and communities, and the ongoing structural racism including in healthcare systems. This contextual information is important as it helps

in explaining cancer attitudes, outcomes and screening and treatment opportunities that Aboriginal and Torres Strait Islander peoples experience. When working with Aboriginal and Torres Strait Islander partner communities, they will have opportunities throughout to comment, influence and work with the data outputs, including the way the data is presented back to community members. This gives scope for community-specific contextual information.

**Accessible and available:** Outputs will be made available to Aboriginal and Torres Strait Islander communities through focus groups, interviews, workshops and presentations to give the requested data back to communities in ways relevant and meaningful to them. Pending COVID travel restrictions, these will be held on site in communities to allow for as many participants attending as possible. Resources on the data and outputs will also be provided to communities in plain-language and accessible formats for wider community distribution. These details are to be confirmed with the Kulay Kalingka Study partner communities.

**Principle 3:** Demonstrate how your proposed project will empower sustainable Indigenous self-determination and effective self-governance.

**Relevant:** The Study is both relevant to key policy-maker calls, such as those by Cancer Australia, for improving cancer understandings, screening and treatment. It is also relevant to Aboriginal and Torres Strait Islander communities as it will answer calls to better understand cancer attitudes, beliefs and experiences, and for greater inclusion of and leadership by Aboriginal and Torres Strait Islander patients, families and communities in cancer research.

**Self-determination and self-governance:** The Study will contribute to Indigenous self-determination and governance through Aboriginal and Torres Strait Islander control and governance of the project. It will contribute to community knowledge cancer risk factors, cancer screening opportunities, and cancer prevention techniques. It will also contribute to understanding Aboriginal and Torres Strait Islander peoples' attitudes and beliefs about cancer which will be used to inform and improve cancer prevention, screening and treatment services and programs. Aboriginal and Torres Strait Islander communities will be empowered with local-level data to assist in local decision making.

**Principle 4:** Demonstrate how your proposed project has data structures that are accountable to Indigenous peoples.

The research team will be guided by any specific data storage procedures developed and required by the Mayi Kuwayu Data Governance Committee (MKDGC)<sup>2</sup>. Data will be stored on the ANU secure server which is only accessible by approved members of the research team. Data stored on the ANU secure server is backed up daily at midnight. The data is stored at three geographically separate off-site Data Centres: Crisp, Huxley, and NCI. At the completion of the research project, the data will be stored on the secure, password-protected shared drive for 7 years after data collection, or 5 years after any publication, whichever is longer. The protection of participant's identities is very important. Identifiable data will not be published.

**Principle 5:** Demonstrate how your proposed project results are protective and respects Indigenous individual and collective interests.

The Kulay Kalingka Study is conducted under a strengths-based methodology: the study is designed to be inclusive of the diversity of the Aboriginal and Torres Strait Islander population, and national-level data can be used to monitor and guide improved cancer experiences for Aboriginal and Torres Strait Islander peoples. Our findings will be protected after dissemination through clear and consistent messaging in peer reviewed publications, reports, social media, public presentations and on the Cancer Australia NCCI website.

<sup>1</sup> Indigenous Data Sovereignty Principles available at: <https://www.maiamnayriwingara.org/key-principles>

<sup>2</sup> MKDGC information available at: <https://mkstudy.com.au/overview/>