

**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/>