

Community engagement:

Good engagement
practices for Aboriginal
and Torres Strait
Islander research



Our cultures count.

Introduction

The Mayi Kuwayu Study is the national longitudinal study of Aboriginal and Torres Strait Islander wellbeing. When baseline data collection is complete in 2019, it will have a minimum of 16,000 participants.

The Mayi Kuwayu Study aims to provide evidence on drivers of health and wellbeing, with a focus on culture.

This is a summary of how the Mayi Kuwayu Study works with communities.

The Mayi Kuwayu Study has implemented partnerships with several communities and community organisations to drive recruitment in communities and to strengthen research findings. The partnerships have improved local community awareness of the study, strengthened data collection, and provide an opportunity to translate research findings to outcomes or outputs with communities.

The study is targeting people in three ways: via a postal mail-out, community-based recruitment and the survey online.

The community-based recruitment targets hard-to-reach groups, particularly remote communities where postal surveys might not have been received, where literacy levels make it hard to complete the survey, or where English is not a first language.

Current status overview

- Ambassadors' program to promote the study
- National recruitment ongoing until the end of 2019
- ≈ 8000 responses to date (as of May 2019)
- Program of in-community recruitment
- Current expansion of community-based recruitment activity
- Individual communities approaching the study to participate
- Research and statistical training for community/Aboriginal researchers

Ref: Study protocol: Jones, R., Thurber, K., Chapman J., Lovett, R. on behalf of the Mayi Kuwayu Study team et al. (2018). Our Cultures Count, the Mayi Kuwayu Study, a national longitudinal study of Aboriginal and Torres Strait Islander wellbeing, *BMJ Open* 2018;8:e023861. doi.10.1136/bmjopen-2018-023861

Jones R, Thurber K, Wright A, Chapman J, Donohoe P, Davis V, et al. Associations between participation in a ranger program and health and wellbeing outcomes among Aboriginal and Torres Strait Islander People in Central Australia: A proof of concept study. *International Journal of Environmental Research and Public Health*. 2018;15(7):1478.

We acknowledge the contribution and wisdom of Aboriginal and Torres Strait Islander peoples to the content of this publication and pay our respects to them.



Community-based research good practice

Currently, there are two regions supporting recruitment in communities – Central Australia and Far North Queensland. Both regions support community members' participation in the MK Study in their major towns (Alice Springs and Cairns) and in several remote communities of Central Australia, the Cape and Torres Strait Islands.

Engagement

Case study 1: Strong partnering Aboriginal organisations in Central Australia

Three regional Aboriginal organisations are partners in the Mayi Kuwayu Study in Central Australia and each engages with the study in very different ways.

Tangentyere Research Hub at Tangentyere Council is funded by Mayi Kuwayu to support community-based recruitment in Central Australia. This partnership was initiated during the Mayi Kuwayu survey development, when Tangentyere Council hosted a focus group and helped pilot the initial survey. They were re-funded in August 2018 to assist with baseline data collection and to work alongside an ANU researcher, who is based in their hub. Over the period, five researchers were trained in survey collection at the research hub. Local Aboriginal researchers have supported the face-to-face interpretation of the survey into Warlpiri and Arrernte. In-kind contribution from Tangentyere included vehicle use and fuel for travel to remote communities. We have worked in Alice Springs and remote communities including: Nyewente, Little Sisters, Athepe, Laramba, Ali Curung, Engawala, Atitjere, Ntaria, Laramba and Nyrripi. We have worked closely with the research team on research skills, including holding a data analysis workshop with Aboriginal researchers in October 2018. The Tangentyere Council hopes to use the Mayi Kuwayu data to support their Community Development Program and the town camp residents of Alice Springs.

Central Land Council: This partnership was initiated during the proof-of-concept study and has continued. The CLC Rangers have now participated in two waves of data collection at their annual Ranger Camp meeting (2017 – pilot, 2019 – baseline). The proof-of-concept research findings demonstrated that rangers had higher levels of family wellbeing, self-reported health and life satisfaction compared to non-rangers. We have also worked alongside the rangers to present the findings back to rangers, communities and policymakers. We are hoping to expand this partnership beyond rangers and start to work with the Council membership.



Finally, **Waltja Tjutangku Palyapayi Aboriginal Corporation** are a more recent partner. We delivered a workshop in February 2019 to Waltja staff on data collection. We have visited two communities with Waltja staff – Nyrripi and Laramba – as part of their “culture, language and bush tucker” project. In May 2019, we held a workshop at the Waltja AGM to assist 30-40 members in completing the survey. We will continue to work with Waltja to support an evaluation of their “culture, language and bush tucker” project and to translate key Mayi Kuwayu Study terms into different Aboriginal languages of Central Australia. Waltja have provided in-kind support in use of Waltja vehicles and fuel to support fieldwork trips.

Case study 2 Far north Queensland

Gurriny Yealamucka Health Service is an Aboriginal Community Controlled Health Service located in Yarrabah. Gurriny has become a partner and plans to use the survey as a method to gather baseline data for the Yarrabah community at a population level. The data will assist in monitoring change in the community. Local employees at Gurriny will be involved in statistics training as part of the partnership. ANU staff will work with Gurriny to provide meaningful data for the community to use for its needs.

The partnership is in the early stages and requires a longer-term relationship to see through Yarrabah and Gurriny’s vision of community ownership, control and governance.

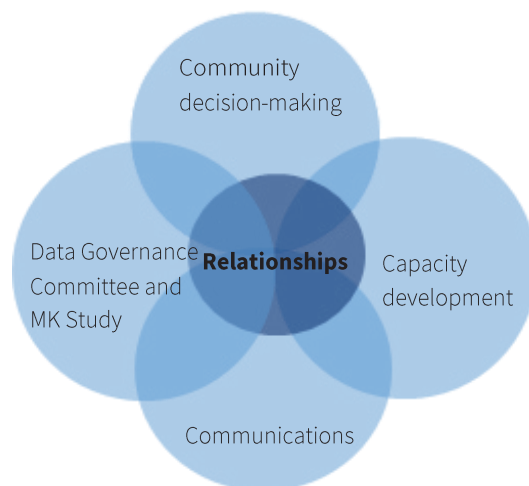
Apunipima Cape York Health Council is also a partner of the MK Study. In this partnership the Apunipima community engagement officer works with the ANU community researcher based in Cape York across 11 communities to facilitate involvement in the study locally. Apunipima provides a working space for ANU research staff when travelling to communities.

Thursday Island

Thursday Island in the Torres Strait has become a partner through its local community-controlled running group, Deadly Runners. The partnership was developed to increase awareness and participation of study. The Mayi Kuwayu funding provides sponsorship to the Thursday Island Deadly Runners and members of the ANU research team attended their annual event on Thursday Island in 2018, which brought over 200 people in from the Torres Strait. The event provided an opportunity to raise the awareness and facilitated recruitment. Study ambassador Jack Wilson was a key contributor to the event and contributed to raising awareness through his different social media streams. This partnerships uses local volunteers to promote the survey and get the messaging more broadly to the community through its local community initiative.



Research model



Relationships

Mayi Kuwayu partners with Aboriginal and Torres Strait Islander groups as part of its governance. The study also works with local community organisations to implement the study in communities and also aims to contribute to some organisational needs as part of reciprocity (receiving and giving back).

In building partnerships at the local level, we are able to contribute to capacity building, facilitate reciprocity and ensure that ethical research practice is being undertaken. This can happen through several different platforms.

a) Community decision-making

A key principle of the study is to seek community endorsement and decision-making from Aboriginal and Torres Strait Islander governed groups on their community's participation in the study. This community consent process sits over individual consent. Before we start survey work, we meet with the Aboriginal/Torres Strait Islander governance groups to seek their support for the project prior to working with their community. This process enables us to be responsive to community protocols, listen to community research priorities and ways of working. For example, some communities have requested that researchers don't approach families in their homes but remain in public areas, whereas other communities have asked that we go door-to-door to enable participation. Other communities have requested that we work closely with agencies and services (e.g. aged care, cultural centres and employment agencies/CDP providers) in the community to collect data.

Some communities have also requested that the data be returned to them in a way that the results can be applied to the whole population. This requires the study to work differently in some areas. For example, where recruitment based on age and gender quotas is required.

i. Indigenous-led organisations: Engagement and agreement making

Our community engagement approach is adaptive and flexible because it is important to respect and adhere to community protocols. Organisations were approached to participate in the study recruitment with the emphasis on allowing the organisation to decide how they wanted to work with the Mayi Kuwayu Study team. Discussion around what would work for the organisation and what works for Mayi Kuwayu was a reciprocal collaboration designed to meet each other's needs.

ii. Resourcing community organisations

We were able to develop a somewhat flexible research agreement contract that organisations could amend in limited ways to fit around the ways organisations could conduct community-based recruitment processes while also committing to our obligations in terms of capacity building for organisations.

Community research partners are able to negotiate contract price and other resources within the available resources of the study and according to contract policies of both organisations. This process was aimed at respecting the structures of community governance and valuing what it costs locally.

b) Study governance

The study has a number of partners involved in decision-making for the study. This includes peak Indigenous health and well-being organisations (NACCHO, VACCHO, AHCWA, AHCSA, AMSANT and The Healing Foundation). Partners were involved early in the study design and continue to be involved in decisions about study implementation and planning for research priorities. A Data Governance Committee has been formed to develop the process for applying and using MK data. The committee is made up of 11 Aboriginal and Torres Strait Islander people who have experience across research and research ethics, community services and policy.

c) Capacity development

Communities benefit from the research, and capacity of Aboriginal and Torres Strait Islander community researchers and scholars is supported. Some examples of capacity development include:

i. Aboriginal researchers and organisations

Aboriginal and Torres Strait Islander organisations and researchers are driving the local recruitment in their communities. The study supports partners by enhancing the skills of these researchers to collect survey data. In addition, we developed a training package to support organisational capacity and upskill staff in data literacy and analysis. We have delivered two workshops in October 2018 at Alice Springs and in December 2018 at Cairns. We will expand on the workshop materials, including the development of a qualitative data analysis workshop.

ii. Aboriginal and Torres Strait Islander scholars

The Masters of Philosophy in Applied Epidemiology (MAE) at the Australian National University (ANU) provides opportunities for Aboriginal and Torres Strait Islander scholars to build research skills. The proof-of-concept work with the Central Land Council formed an MAE research project where the scholar administered surveys, undertook data analysis and presented the findings back to rangers and in other forums including conferences. The same scholar has revisited the ranger camp to assist in administering surveys ensuring continuity in community members engaging with the same researchers.


iii. Research outputs

There have been a number of opportunities to involve partners in authorship on papers, co-presenting at conferences and with membership on the Data Governance Committee. Additionally, MAE scholars have contributed to papers and presentations on the Study and we are delivering workshops in research to community organisations. We are working with Gurriny Yealamucka Health Service to develop a population level data strategy, for example.

d) Communications

The study is being promoted to Aboriginal and Torres Strait Islander communities through several platforms, including:

- Study ambassadors: Promotional resources have been developed featuring the ambassadors as a strategy to increase the study's profile at the community, regional and national levels. The ambassadors attend events, administer surveys and leverage off their own projects, events and social media to promote the study.
- Events: We work with our ambassadors, study partners and ANU staff to promote the study, administer surveys and engage with Aboriginal and Torres Strait Islander community members at key conferences and events (see text box,



following page). Presentations at other forums have occurred, including The Public Health Conference, a luncheon and the Queensland ranger forum. The study has also provided sponsorship for local events, gatherings and supporting community groups. For example, the study helped sponsor the Bush to Beach project, organised by a study ambassador, and surveys were completed at this event. On Thursday Island, the study sponsored an afternoon tea to support social connectedness and enable surveys to be completed.

- Media: The study has a strong presence on social media, with regular posts providing updates, community participation and other supportive events and partnerships. Radio interviews, newspaper and other forms of media all help promote the study and are broadening the promotional reach to different regions across the country.
- Newsletter: A study newsletter is produced on a monthly basis and provides updates on the study progress. The newsletter is distributed to almost 1500 individuals and organisations.

Key events where the study has been promoted

- NACCHO conference
- NATSIWA Health Workers Professional Development Symposium
- Healing Our Spirit
- Public Health Association Australia conference
- Yabun festival
- Koori Knockout
- Canberra Multicultural Festival
- Indigenous Marathon Foundation events
- Running festivals – Thursday Island, Port Macquarie

Long-term engagement and multi-engagement approaches

Our most productive work is done when we are working with communities where there are long-standing, ongoing and committed relationships. Our partnerships are an opportunity to nurture the study's value and to build community capacity to use the Mayi Kuwayu dataset for the communities' needs and priorities. This approach is an opportunity to build up value of the data and to support Aboriginal and Torres Strait Islander communities engaged in the research.

Multiple ways to engage communities in research allows research to be responsive to groups that are left out or passive. This can overcome situations where communities prefer personal approaches, where English is not the primary language spoken, where literacy and numeracy skills prevent participation and in places where research does not have a good reputation.

Reflections

Community-based participatory research is often described as “best practice” in Aboriginal and Torres Strait research. The approach can be resource and time intensive, and needs to be adaptable and flexible to communities. Theoretical frameworks are important and useful guides, however they don't always take into account many of the complexities of communities and their contexts – culturally and geographical. This summary provides some approaches we have found useful in engaging communities in the Mayi Kuwayu Study.

