

Indigenous Health and Wellbeing Grand Challenge (IHWGC)



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Message from the Co-Directors

In 2020, we embarked on a journey to propel the advancement of Aboriginal and Torres Strait Islander health and wellbeing through the establishment of the Indigenous Health and Wellbeing Grand Challenge (IHWGC), a cross-disciplinary strategic research initiative. Today, in 2023, as we reflect on the past three years, we are filled with pride of what we have achieved and hold a hopeful outlook for the promising future of this essential research endeavour.

Our commitment to understanding and addressing the health and wellbeing disparities faced by Indigenous communities has been unwavering. This initiative, comprising five distinct research programs, has made remarkable strides in the pursuit of knowledge and solutions. The five programs span a wide range of topics, from medical research and mental wellbeing, to the preservation of cultural heritage and progression of First Nations music.

The achievements of the Indigenous Health and Wellbeing Grand Challenge would not have been possible without the dedication of our exceptional research teams. Their work has not only expanded our understanding of the unique challenges faced by Aboriginal and Torres Strait Islander populations but has also contributed to the development of innovative interventions and policy recommendations.

One of the most significant achievements of the Grand Challenge was the creation of strong partnerships with Indigenous communities and organisations. These partnerships are built on trust, respect, and a shared commitment to improving the health and wellbeing of Indigenous peoples. Our engagement with local communities has been instrumental in ensuring that our research is not only rigorous but also culturally sensitive and relevant.

Throughout our journey, we have encountered challenges and obstacles, but we have met them with determination and resilience. The path to positive change is seldom easy, but the strength of our collective purpose has propelled us forward. We acknowledge that there is much work still to be done, but we remain steadfast in our resolve to make a lasting impact.

Looking ahead, we are filled with optimism. The knowledge and insights we have gained over the past three years have laid the foundation for even more meaningful contributions in the future. Our commitment to Indigenous health and wellbeing is not just a short-term endeavour; it is a long-term, ongoing commitment that will continue to evolve and adapt as we learn more and new challenges arise.

Azure Hermes and Ute Roessner

Co-Directors of the Indigenous Health and Wellbeing Grand Challenge

The Tiwi Kidney Health Project

This collaborative project, involving researchers at the ANU John Curtin School of Medical Research (JCSMR) clinical geneticists and the ANU National Centre for Indigenous Genomics (NCIG) is seeking to address the gap in integrating genomic information into Indigenous Australian healthcare.

Focusing on the Tiwi Islanders, who have a high prevalence of chronic kidney disease (CKD), our initiative involves developing a pipeline for genome and clinical data annotation, and gene discovery and clinical translation to uncover the genetic basis of CKD in this population and explore potential therapeutic strategies. Additionally, we are working to establish a secure repository for Tiwi health, genetic, and genealogical data, along with a governance framework, which can be extended to address other Indigenous health issues that benefit from clinical genomics.

- Significant successes of the project include: The establishment of a highly collaborative multi-disciplinary ANU team that has attracted new funding from the MRFF and NHMRC, produced several publications in leading journals, recruited Indigenous students into ANU Honours and PhD programs, and developed resources for undergraduate teaching.
- Contributions to the assembly and annotation of the largest genome sequence data resource for Indigenous Australians.
- Identification of genetic variants that may influence CKD in the Tiwi and translated these into cellular and animal models for further validation.

Genetics plays an increasingly vital role in healthcare, but precision medicine is primarily focused on individuals from European and Asian populations. Indigenous Australians are underrepresented. Our work has and continues to bridge this gap through facilitating community engagement and governance in genomics, creating bioinformatic systems for genomic data from Indigenous groups, and use basic research to connect genetic variation to health outcomes and potential treatments to enhance their well-being.



Azure Hermes and participants of the Tiwi Kidney Health project.

Lasting impacts of the Tiwi Kidney Health Project

Genomics will be widely used in clinical decision making and ANU is leading national initiatives and programs that will enable inclusion of Indigenous Australians. Two major programs of work at the ANU to conduct research on the use of genomics for Indigenous peoples and processes for costeffective implementations and identifying healthcare implementation strategies that addresses priorities and aspirations of Indigenous Australians. These programs of work will generate policies and procedures for the use of genomics in Indigenous healthcare in the future.

Going forward

Established new collaborative research initiatives between ANU and communities in Australia, such as Purple House in the Northern Territory and Queensland, as well as relationships with additional Indigenous communities across Australia to enable greater participation in genomicbased healthcare. We predict our novel insights into the basis of kidney disease in the Tiwi and the capacity we have developed from this work will translate to these other communities in the next few years.

Beyond Reconciliation: Truth-Telling for Indigenous Wellbeing and the Health of the Nation

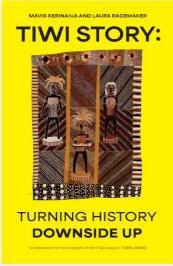
This project was a response to the demand for a thorough-going process of truth-telling about – and not merely reconciliation with – Australia's past. Truth-telling is everyone's responsibility, but to bring about lasting political, cultural and social change it must, we contend, be led by local Indigenous communities according to their own priorities and perspectives.

Formed under the umbrella of Beyond Reconciliation, a series of unique individual projects were initiated in collaboration with the following communities: Tiwi (NT), Yawuru (WA), Pilbara (WA), Wiradyuri (Wagga Wagga, NSW), Wiradyuri, (Erambie, NSW), La Perouse, (Sydney NSW).

These projects supported capacity building to pursue history-making and truth-telling in local Indigenous communities; and facilitated connections to material records and cultural heritage collections in Australia and internationally. The challenge was to work collaboratively with diverse communities to tell the true stories they want to tell in the ways they want to tell them.

Case study: 'Strong people, strong story'

The project focusing on intergenerational sharing of Tiwi history involved a partnership between ANU researcher Laura Rademaker and Tiwi Islands communities. Tiwi researchers received training in navigating archival collections and libraries and presenting Tiwi history in public forums for non-Tiwi. Likewise, Tiwi people taught the ANU historian about research on Country, and respect for Tiwi cultural protocols and Tiwi methods for conducting research.



Cover of Tiwi Story: Turning History Downside Up, New South Press, 2023. Image: Courtesy New South Press

The outputs of the research have included the publication of Tiwi Story: Turning History Downside Up (New South Press, 2023) a history of the Tiwi Islands based on Tiwi oral history and memory, and a forthcoming children's picture book published by the Indigenous Literacy Foundation.

The COVID pandemic, while limiting opportunities for faceto-face engagement between Canberra- and Tiwi-based researchers, provided an opportunity for the research to become more Tiwi-driven. Community-based researcher Mavis Kerinaiua led the community consultation process and engaged with Elders. While COVID slowed the pace of the project, this turned out to be for its benefit as it allowed time for consultation and reflection as suits Tiwi priorities and cultural values.

Many Tiwi people have testified that the process of sharing their histories and learning stories has been healing for the tellers and builds confidence for the rising

generation. ANU now has a productive research partnership with Tiwi Islanders and a strong reputation with Tiwi people. Tiwi people have asked for this partnership to continue. Having seen the success of the Indigenous Health and Wellbeing Grand Challenge, more Tiwi have come forward asking for stories to be recorded and published. We are anticipating that the work will continue.

Lasting impacts of Beyond Reconciliation

ANU is well positioned to lead this initiative and to build on the Beyond Reconciliation foundation. Our projects supported capacity-building in Indigenous communities; they also built capacity within the University for this work to continue. This national truth-telling project will round off and build on the Grand Challenges Scheme (IHWB). It will be part of the University's commitment to the longer-term goals of the Makarrata. It will facilitate the inclusion of Aboriginal and Torres Strait Islander voices in national policy development, and by dealing with the past, contribute to the health and wellbeing of the nation.

Going forward

Going forward, we are planning a major event – 'Beyond Reconciliation: Stories from the Riverbanks' – that will bring Aboriginal and Torres Strait Islander storytellers to ANU to perform at the amphitheatre on the bank of Sullivan's Creek in the Kambri Precinct. The idea is to draw on wisdom from storytelling traditions across the continent to encourage people to think about the principles of truth, voice and treaty, and what comes after reconciliation. We envision an event that is prominent on campus and finds the best possible media placement and presence to reach the wider public. It will feed discussions, recently initiated between the First Nations Portfolio and the School of History, to establish a National Oral History project. After the Referendum the need for truth-telling is even more urgent. It is a priority for the unacknowledged, and often uncomfortable, truths of Australian history to be voiced and heard. We must move beyond a single shallow story. We need a medley of voices, a mosaic of histories, and truth-telling that generates respect.

Murrudha: Sovereign Walks – tracking cultural actions through art, Country, language and music

Murrudha: Sovereign Walks – tracking cultural actions through art, Country, language and music addresses three Research Priorities: Addressing Racism, Social and Emotional Wellbeing, and Relationship between Culture and Wellbeing. The primary research priority is Relationship between Culture and Wellbeing. Led by Professors Brenda L Croft and Jamie Pittock, working closely with First Nations and non-Indigenous academics and staff across ANU and other tertiary, government and community organisations conducting ongoing two-way culturally truthful consultation with associated First Nations communities from the ACT and High Country regions during the life of the project (2020 – 2026) and beyond. Since the earliest days of colonial contact there are documented examples of First Nations Peoples undertaking sovereign actions by walking on, in and through their country.



Murrudha research team and Traditional Custodians meeting in Tumut

A key Murrudha outcome is tied to the centenary of the journey undertaken by Wiradjuri Elders/Knowledge Holders Nangar/Yangar/Jimmy Clements and George/John Noble journey Brungle from Aboriginal community, located between the towns of Gundagai and Tumut across the Brindabella Range to be present at the official opening of Parliament House in Canberra in May 1927. Two other sovereign events/actions/walks included in Murrudha are: a) the 1834 journey undertaken Polish by

explorer/naturalist Johan Lhotsky from Sydney through the Limestone Plains/Kamberry into the High Country, following early colonial pathways built upon ancient First Nations routes. On this journey Lhotsky documented the 'Song of the Women of the Meneroo', the second First Nations song in language which was published in 1836; b) a walk undertaken in 1873 by Molonglo/Ngarigo/Ngunawal Elder, Nellie Hamilton from Queanbeyan to Cooma to meet with Ngarigo community following her husband's death.

The Murrudha team is working with associated communities to document and site these respective journeys, while reclaiming and reimagining ceremony, language and song through Creative-led Critical Indigenous Performative Collaborative Autoethnography & Storywork methodologies. Successes have included establishing a deepening relationship with respective First Nations community representatives from the Canberra region, Brungle and Tumut, the High Country, and further afield, as well as colleagues from across ANU and other universities. The team has participated in key events including: a) *Murrudha: Track #1* - presented 2 panels at the AAANZ (Art Association of Australia and New Zealand) Annual Conference, Impact (December 2021); b) *Murrudha: Track #2* presenting 2 panels at the 2022 AIATSIS Summit (June 2022); c) *Murrudha: Track #3* – 3-day symposium and events held at ANU Drill Hall Gallery, School of Music, and Kambri Cultural Centre (12-14 December 2022); d) *Murrudha: Track #4* – 4-day Workshop Gathering to be held at ANU (20-24 November 2023), which will include a photographic shoot and filmed oral/community histories.

Past events also include 5-day test walk of the Brungle – Canberra route was conducted in November 2020; site visits to Brungle, Gundagai, Tumut, Kosciuszko National Park, and Djinama

Yilaga performers workshop at ANU Kioloa Campus as part of an ANU Engaged Pilot Project. Funding and in-kind support partnerships have been established with Brungle Tumut Local Aboriginal Land Council, AIATSIS, National Film and Sound Archive of Australia, National Archives of Australia, Ronin Films and Strathnairn Arts. Challenges included COVID caused delays in 2020 and 2021 which limited further site visits, a National Arboretum Sculpture Commission submitted 2023 that was unsuccessful, and HDR students having been overcommitted due to involvement with other IHWGC projects and having to withdraw from Murrudha.

Lasting impacts of Murrudha

Murrudha has built long term, deep relationships with local and regional First Nations communities, a key tenet of Critical Indigenous Studies methodologies, and engaged with local First Nations communities. The project has established a long-term commitment across ANU with First Nations communities involved in Murrudha: a) ANU proposes to take responsibility for legacy management/support for cultural events/outcomes associated with Murrudha.

Going forward

The Clements/Noble Brungle/Canberra walk is being nominated to the 2024 National Heritage List of the Department of Climate Change, Energy, the Environment and Water, with local councils and community organisations consulted thus far offering unequivocal support in principle. The Nellie Hamilton Queanbeyan – Cooma 1873 journey, and the Lhotsky/Meneroo/Ngarigo High Country 1834-1836 journey and song reclamation will be nominated in 2026.

A 4-day cultural event is being proposed for the centenary anniversary of the Brungle – Canberra Walk in 2027 comprising talks, presentations, celebrations, walk for those who register, in consultation with relevant councils. Funding would be split across Create NSW, Arts ACT, ANU, philanthropic avenues. This would culminate at the Museum of Australian Democracy (Old Parliament House) and the Aboriginal Tent Embassy site for official acknowledgement of Clements/Noble Brungle to Canberra Trek.

Professor Croft is in preliminary discussions with ANU and outside academic colleagues towards establishing a Centre of Excellence for Creative-led Critical Indigenous Research Knowledges, with nodes at other tertiary institutions around Australia and overseas.

Making Music: Yil Lull Studio

Making Music is an initiative that affirms identity, health, and wellbeing through music performance and recording. This is largely centred in the Yil Lull Studio in the ANU School of Music, where First Nations music producer and engineer Will Kepa is based, a position enabled through the Indigenous Health and Wellbeing Grand Challenge.

In any week at Yil Lull Studio one may see visiting established First Nations acts such as The Green Hand Band (Redfern) or Warren H Williams (Tennant Creek), as well as community groups such as Djinama Yilaga Choir (South Coast) or local Canberra rock group The Djaarmby Band. Or it may be Uncle Ozzie Cruze and the Gumleaf Band (Eden), Lillian Fromhyr (Yuin and current SoM music student), or visiting 'traditional' singers (Arnhem Land).

Groups that utilise the space are engaged with a wide range of Indigenous matters articulated through music, such as: relationship to land, land rights, language revival, mental health, incarceration, creation stories, other stories, and even music for its own sake. The breadth of expression is wide, and the depth of culture endless.



Will Kepa in the Yil Lull Studio. Image: Tracey Nearmy, ANU.

For the past two years, we have partnered with the Australia Council for the Arts in delivering the Space to Create program – a residency for 8 to 10 First Nations artists from around the country, musicians whom are either established or emerging with a sure career ahead of them. This partnership has also lifted our profile nationally, and our first national release Truth Matters will stem from work in that program.

Whilst First Nations music enjoys a good level of support in an industry context, to access the industry, one needs a pathway, which is often blocked, and we are finding that the Making Music program with the Yil Lull Studio at the centre is such a mechanism to enable such access. In addition, many community musicians never have the opportunity to access a professional studio, nor have professional musicians to perform on their songs, and we are providing that service for them.

Whilst we have enjoyed significant sponsorship from Yamaha Music in the form of equipment at ca. \$100,000, we have not been able to realise the full potential of that sponsorship due to building delays at ANU that have held up the construction of our purpose built facility, a build for which we have budget.

Lasting impacts of Making Music

The Making Music program and the Yil Lull studio have established a national profile within the First Nations music industry, and both professional First Nations acts and local community are accessing our service, and participating in the affirmation of identity and articulation of culture through making music. This always points to here, to the Yil Lull Studio at the ANU School of Music, enabled through the grand Challenge.

Going forward

Whilst the Yil Lull studio is not yet a national label of renown, such as Motown became in the USA under producer and engineer Berry Gordy, the potential exists that it could become such – a renowned centre and label within the broader music industry, not just within our own First Nations circles. In the ANU School of Music we are building educational pathways with and for First Nations musicians, and the Making Music project is building the industry and career connections. It takes the two.

Mapping a New Path: Strengthening social and emotional wellbeing through community-led research and knowledge sharing

The Mapping a New Path (MaNP) project brings together Indigenous knowledge systems and western scientific worldviews, co-producing research that is holistic, cross-cultural, cross-disciplinary and intergenerational.

The starting point for the project has been to collaborate with Indigenous organisations to build cultural values base-maps. These maps have served to develop ideas and priority areas for ongoing community led research. In broad terms, Geographic Information Systems (GIS) are built through integrating spatial layers and cultural values maps provide a 'missing layer' that is frequently excluded from academic, industry or government collaborations with Traditional Owners. Initiatives emerging from initial mapping involve different areas of academia and demonstrate how to improve research and teaching partnerships with Indigenous Australia.

Selected case studies

Cultural-environmental accounting on Yawuru country

The focus of this collaboration has been on developing a method for culturalenvironmental accounting through adapting the UN System of Environmental-Economic Accounting (SEEA). Anna Normyle has led much of this work through her PhD research. Successes include using the draft accounts being used to inform the management of Roebuck Plain Station (a key asset for the Yawuru people), co-presentation of the method at the 2023 Native Title conference, and international recognition through the publication of key findings in international journals and invited plenaries.

Building the Arakwal in-house and Story Mapping

Initial cultural values mapping has led to a longer-term partnership to assist the Arakwal Native Title body to build an 'in-house' GIS with full control of cultural data (e.g. this information does not need to be stored at a university or external organisation). This collaboration has also explored community-based Story Mapping of significant sites. This represents an innovative and very promising means of collecting community cultural data.

Lasting impacts of Mapping a New Path

The main impact of the MaNP project has been to assist a number of Indigenous organisations with developing in-house GIS systems and the emergence of some long-term relationships with the university. A number of key lessons have been learned since the start of the project include:

- Successful mapping leads to further collaborations: A number of new organisations have approached the MaNP team after seeing examples from the earlier collaborations.
- The importance of spending time on country: The progress made post-COVID has reemphasized the importance of ANU staff to visit Traditional Owners and invest in the building of relationships and to collaboratively explore research avenues in-situ.
- ANU-AIATSIS ethics processes: The AIATSIS ethics process is more established than that of the ANU HREC and is a viable alternative for ANU-led research initiatives.

- Enabling access to mapping software: A major breakthrough for the MaNP team was to identify how Indigenous organisations could access non-profit licencing for commercial mapping software through the Australian Charities and Not-for-profits Commission.
- Collaborate first publish later: As one of our Yawuru colleagues pointed out during a discussion about sharing research: *...we need to make sure this works in our own back yard before telling the rest of the world.*'



Arakwal GIS Training at ANU, August 2022. L-R: Leon Kelly, Norm Graham, Michael Kay-Watson.

Going forward

- CRCNA Grant (2023-2026, \$1.7 million) Integrating Indigenous priorities in spatially enabled planning of the Indigenous Estate: This major grant is led by Anindilyakwa Land Council (ALC) and involves ANU, Geoscience Australia, and Aerometrex Ltd.
- Yawuru-Arakwal knowledge exchange workshop (December 2023) bringing together two Native Title organisations for direct sharing of GIS innovation.
- Widjabul Wia-bal GIS capacity building: The Bundjalung Nation's Widjabul Wia-bal people have approached ANU to assist in establishing a GIS, with a key priority being a cultural assessment of housing needs resulting from the 2022 Lismore floods.