

PRINCIPLES OF INDIGENOUS DATA SOVEREIGNTY

Incorporating Indigenous Data Sovereignty in the ANZICS Registry

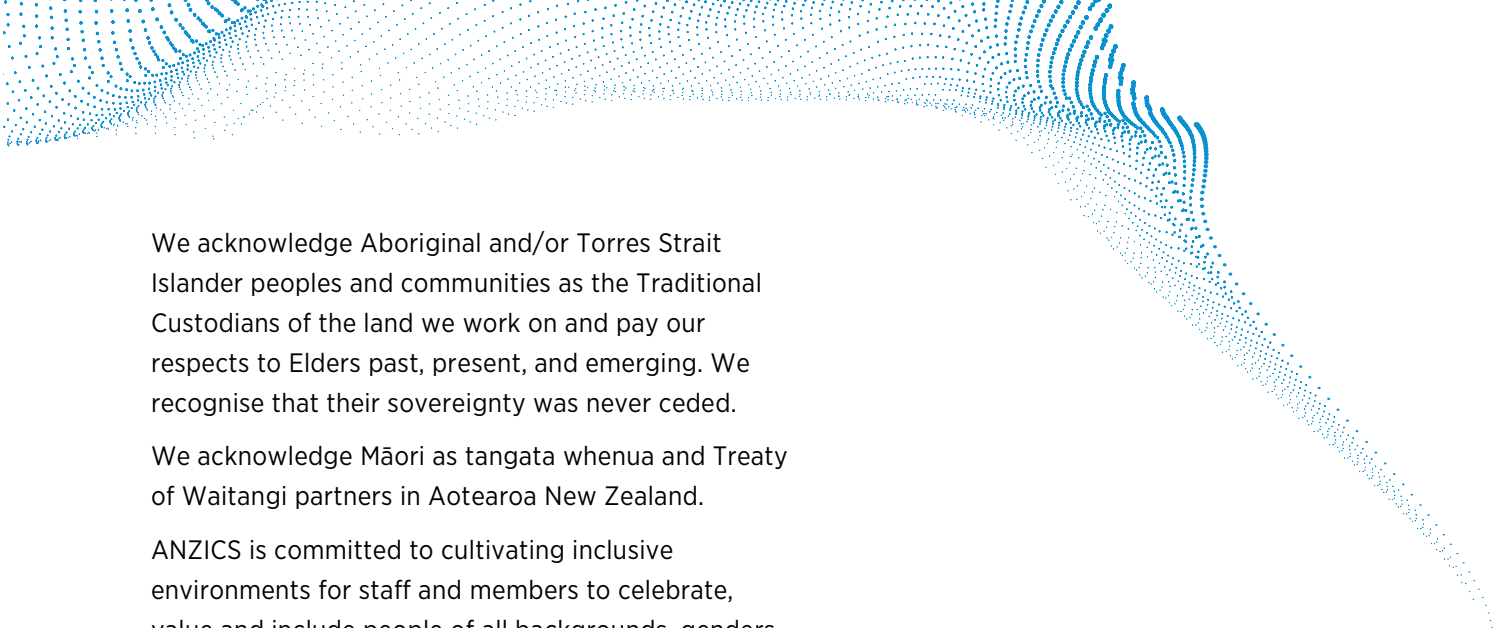
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The Australian and New Zealand Intensive Care Society
Centre for Outcome and Resource Evaluation
ANZICS CORE



**Indigenous
Data Network**

Endorsed by the Indigenous Data Network



We acknowledge Aboriginal and/or Torres Strait Islander peoples and communities as the Traditional Custodians of the land we work on and pay our respects to Elders past, present, and emerging. We recognise that their sovereignty was never ceded.

We acknowledge Māori as tangata whenua and Treaty of Waitangi partners in Aotearoa New Zealand.

ANZICS is committed to cultivating inclusive environments for staff and members to celebrate, value and include people of all backgrounds, genders, sexualities, cultures, bodies and abilities.

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ANZICS REGISTRY Principles of Data Sovereignty

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Background

Indigenous data sovereignty refers to the right of Indigenous peoples to govern the collection, ownership, and application of their own data. It is a concept that recognises the unique relationship that Indigenous communities have with their data and asserts their authority over how that data is collected, used, and shared. This includes information about their cultures, languages, traditional knowledge, and other aspects of their lives.

Key Principles of Indigenous Data Sovereignty

- * **Self-determination:** Indigenous communities should have the authority to make decisions about their data and how it is used. This aligns with the broader principle of self-determination, allowing communities to define their own priorities and development pathways.
- * **Control:** Indigenous peoples should have control over the collection, management, and interpretation of their data. This involves determining who has access to the data and for what purposes, as well as ensuring that data is used in ways that respect and benefit the community.
- * **Benefit:** Indigenous data should be used for the benefit of the Indigenous communities from which it is derived. This can include informing policies and programs that address community needs and contributing to research that aligns with Indigenous goals and aspirations.
- * **Cultural integrity:** Indigenous data sovereignty recognises the importance of protecting the cultural integrity of Indigenous information. This involves respecting the context, values, and significance of the data within the cultural framework of the community.
- * **Consent and Free, Prior, and Informed Consent (FPIC):** Indigenous communities should provide informed consent for the collection and use of their data. This includes understanding the potential impacts of data collection and having the opportunity to make decisions without coercion.
- * **Capacity building:** Indigenous communities should be supported in developing the necessary skills and capacity to manage their own data effectively. This includes training community members in data governance, analysis, and other relevant skills.

Indigenous data sovereignty is crucial in addressing historical and ongoing issues of data exploitation, misrepresentation, and the marginalisation of Indigenous voices. It is a framework that seeks to empower Indigenous communities in the digital age and promote ethical and respectful practices in data management and research involving Indigenous peoples.

ANZICS CORE is committed to respecting the principle of Indigenous Data Sovereignty for the First Nations peoples of Australia and Aotearoa New Zealand. Indigenous status (represented by two variables – Indigenous status and Indigenous origin) forms part of the minimum dataset within the

Australian and New Zealand Paediatric Intensive Care Registry (ANZPICR), and the Adult Patient Database (APD) at the request of the funding jurisdictions, with the option for patients to “opt out” of data collection. Although an opt-out model may appear inconsistent with the principle of FPIC, the collection of clinical quality registry (CQR) data for benchmarking without informed consent can be justified under specific ethical and legal conditions, primarily related to public health interests and the improvement of healthcare for both the Australian and Aotearoa New Zealand communities. Further details and the definition for each variable can be found in their respective data dictionaries.

ANZICS CORE acknowledges that ethnic populations (including First Nations people of Australia and Aotearoa New Zealand) experience health inequities, and that both registry science, and the secondary use of registry data in research may both highlight and mitigate some of these inequities. It is recognized, however, that ethnicity is a complex social construct that influences personal identity and group social relations. Data managers, clinicians and researchers working with ANZICS Registry data commit to engaging meaningfully and respectfully with the relevant concepts, including that of Indigenous Data Sovereignty.

ANZICS CORE further acknowledges the complexity around nomenclature, recognizing that the term “Indigenous” may be considered offensive by some given its historical use in describing First Nation Peoples as part of the flora and fauna of a country by colonisers, and in homogenizing highly diverse linguistic and cultural groups. Further information around appropriate terminology can be found in guidelines produced by Reconciliation Australia, and this policy aligns with their recommendations around terminology and nomenclature.

This policy seeks to ensure that the ANZICS Registry operates in a manner that respects and upholds Indigenous Data Sovereignty, fostering trust, equity, and collaboration with Indigenous communities. It has been endorsed by the Indigenous Data Network, a national network of Aboriginal community-controlled organisations, university research partners, Indigenous businesses and government agencies and departments. The role of the IDN is to empower Aboriginal and Torres Strait Islander communities to decide their own local data priorities, including how their data is used, as well as ensuring those decisions are supported and reinforced by national legal and policy frameworks. ANZICS has entered an enduring Memorandum of Understanding (MOU) with the IDN to support these goals.

CORE Activities

Benchmarking

Benchmarking involves comparing performance metrics to identify best practices and areas for improvement. ANZICS Registry data includes a combination of clinical and patient-derived data entered by individual intensive care unit (ICUs) designed to report timely, actionable and risk-adjusted benchmarked data back to clinicians, health providers and other relevant stakeholders for the purposes of quality improvement. ANZICS CORE provides comparative case-mix reports, risk-adjusted clinical outcomes, process measures, and quality of care indicators to over 200 ICUs.

The ANZICS Registry outlier program for adult and paediatric ICUs provides detailed analyses and reports about ICUs with a standardised mortality ratio outside the 99% confidence intervals to ICU directors, hospital executives, and jurisdictional leads. These offer insights into areas for improvement in quality and equity of clinical care. The ANZICS Outlier Management Policy contains further details.

Through the MOU with the Indigenous Data Network, ANZICS Registry aspires to incorporate concepts of Indigenous Data Sovereignty into its benchmarking activities in a culturally sensitive, collaborative, and rights-based approach. Where Indigenous data is involved, ANZICS Registry commits to ensure that benchmarking activities respect Indigenous ownership, control, and self-determination of their data.

Incorporating Indigenous Data Sovereignty into benchmarking activities, ANZICS Registry seeks to ensure that its work is respectful, equitable, and beneficial to Indigenous communities. This approach not only upholds the rights of Indigenous peoples but also enhances the quality and relevance of the registry's output

Research

ANZICS CORE is strongly supportive of the secondary use of data for research. This policy ensures that concepts of Indigenous Data Sovereignty are embedded in the existing structures of the secondary use of registry data and should be read in conjunction with the ANZICS Registry Data Access and Publication Policy.

Types of Requests

Requests for ANZICS Registry data that include Indigenous status will be submitted according to the ANZICS Registry data request policy. Further to this, requests for data that include Indigenous status

will make clear the rationale for inclusion of Indigenous status in the dataset. These requests will be classified further.

Group 1A: Indigenous status is requested to describe the cohort. It will NOT be included in statistical models for analysis.

Group 1B: Indigenous status is requested for describing the cohort and will be included in statistical models for analysis, but Indigenous status is not the primary focus of the research

Group 2: Indigenous status is requested and the primary focus of the request is related to Indigenous status.

Group 1 requests will be asked to read a short article on Indigenous Data Sovereignty and answer a question related to the article. Once completed, the data set will be released in line with the ANZICS Registry data and publication policy.

Group 2 requests will be asked to complete a series of questions related to Indigenous Data Sovereignty which include:

1. Whether an Indigenous author/researcher is included in the research group, and if not what the reasons are for not including an Indigenous author/researcher.
2. The steps taken to ensure data is analysed and presented using a strengths based (rather than a deficits based) approach
3. Exploration of the core values that describe how the proposed research will be of benefit to, or impact Indigenous peoples.
 - a. Reciprocity
 - b. Respect
 - c. Equity
 - d. Responsibility
 - e. Cultural continuity
 - f. Spirit and Integrity

If requesters communicate a meaningful and appropriate engagement with the concepts raised by these questions as assessed by the CORE management committee, data will be released in line with the ANZICS Registry data and publication policy.

If the responses do not sufficiently communicate a meaningful and appropriate engagement with the concepts raised by these questions as assessed by the CORE management committee, further contact with the requesters will be made by a member of the CORE management committee.

Attachments

1. Example manuscript describing Indigenous Data Sovereignty
https://www.researchgate.net/publication/344961693_Indigenous_Data_Sovereignty_in_the_Era_of_Big_Data_and_Open_Data
2. Flow diagram for data requests involving Indigenous Status
3. Core values for Group 2 requests

Acknowledgements/Bibliography

ANZDATA Policy 2.9 Guidance on data requests relating to patient ethnicity https://www.anzdata.org.au/wp-content/uploads/2023/03/2.9-Guidance_on_data_requests_relating_to_patient_ethnicity_v2023.1.pdf

Ethical conduct in research with Aboriginal and Torres Strait Islander People and Communities. The National Health and Medical Research Council (NHMRC). 2018.

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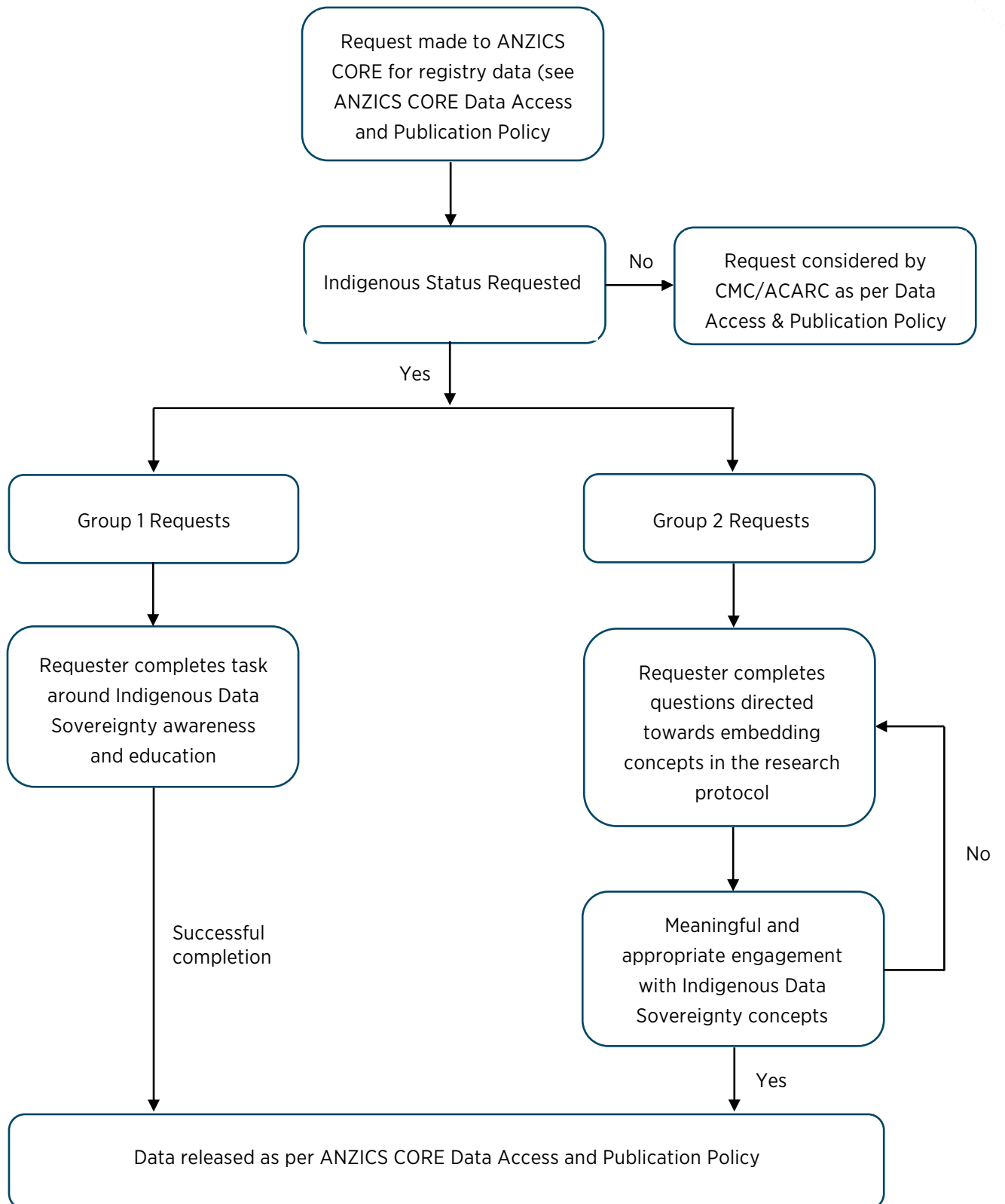
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Guidelines for Researchers on Health Research involving Māori. Health Research Council of New Zealand. 2010. <https://www.hrc.govt.nz/resources/guidelines-researchers-health-research-involving-maori>

Reconciliation Australia Demonstrating inclusive and respectful language.

<https://www.reconciliation.org.au/wp-content/uploads/2021/10/inclusive-and-respectful-language.pdf>

Figure 1: Flow Diagram for Data Requests Involving Indigenous Status



CORE Values for Group 2 Requests

To satisfy issues around Indigenous Data Sovereignty, any data request that seeks to include Indigenous status as a primary focus of the research question (Group 2 requests) will need to be supplemented by additional information from the researcher including a justification for its inclusion. Additional questions below need to be answered by the research team.

Please be advised that ANZICS CORE lacks confidence in the accuracy of coding for Indigenous status for some sites before the introduction of COMET in 2017.

1. Is there an Indigenous author/researcher on the group? If not, why not?

2. What steps has the research group taken to ensure that the data is presented using a strengths-based approach (rather than a deficits-based one)?

3. Please address each of the 6 core values that describe how this research will be of benefit to, or impact Indigenous peoples.

- a. **Reciprocity:**

Mutual obligation. Benefit through the establishment or enhancement of capacities, opportunities or outcomes.

- b. **Respect:**

Acknowledgement of individual and collective contribution, interests and aspirations.
Acknowledgement and affirmation of the rights to have difference values, norms and aspirations.

- c. **Equity:**

Acknowledgement that all partners are equal, regardless that they may be different. The distribution of benefit.
The value of collective memory and shared experience as a resource and inheritance.

- d. **Responsibility:**

To do no harm to individuals or communities, or to those things that they value. Establishment of processes to ensure researcher accountability to individuals and communities, particularly with respect to cultural and social dimensions of community life.

- e. **Cultural Continuity:**

Protection against assimilation, integration and/or subjugation of values. Respect for social cohesion. Involvement that does not diminish the right to assertion or enjoyment of cultural distinctiveness.

f. Spirit and Integrity:

Demonstration of other five values and credibility in intent and process. An approach that does not impede upon the richness and integrity of cultural inheritance.

Reciprocity:

Respect:

Equity:

Responsibility:

Cultural Continuity:

Spirit and Integrity: