Policy

Data Requests Relating to Patient Ethnicity

1. Purpose

This document provides guidance on the approval process for data requests relating to Aboriginal and/or Torres Strait Islander People of Australia, Māori of New Zealand and ethnic groups living within Australia and New Zealand. It ensures compliance with national standards and promotes culturally safe research practices.

2. Scope

This policy applies to:

- All staff, researchers, and collaborators accessing ethnicity data from the registry.
- All data requests involving ethnicity as a variable, whether primary or secondary.

3. Guiding Principles

- Respect and cultural safety: Data use must respect the cultural values and sensitivities of Indigenous and ethnic communities.
- Transparency: Researchers must clearly state the purpose and method of ethnicity data use.
- Community engagement: Projects involving Indigenous or ethnic communities should demonstrate meaningful consultation and benefit.

4. Policy Details

4.1 Background on Data Collection

ANZDATA is a custodian of health outcomes data on behalf of specialist renal health care services which deposit data on behalf of consenting individual patients. Additionally, ANZDATA collects data on patient and organ/ tissue donor ethnicity. Prior to 2014, the Registry collected information on 'racial origin' according to a bespoke coding system. Since 2014 the Registry has collected information on patient and donor 'ethnicity' according to the Australian Bureau of Statistics, Australian Standard Classification of Cultural and Ethnic Groups (ASCCEG). Since 2019 data collection tools have enabled renal units to document more than one ethnicity for a patient. The method for ascertaining patient ethnicity is determined by the renal unit submitting data and the accuracy of this data in representing a patient's own ethnic identity cannot be verified by the Registry.

4.2 Justification for Policy

- Specific ethnic populations including Australian Aboriginal and Torres Strait Islander people, Māori people of New Zealand, Pacific peoples, and other culturally and linguistically diverse populations may experience specific health inequities due to historical and current systemic racism and other factors.
- Potential genetic variation relevant to disease prevalence and severity, and treatment responsiveness may be associated with ethnic identity.

Therefore, research that includes patient ethnicity data may be valuable in addressing ANZDATA's mission to improve the understanding of kidney disease and outcomes of treatment for patients with end stage kidney disease. However, ethnicity is a complex personal and cultural identity and research that includes information collected by the Registry on ethnicity should engage meaningfully and respectfully with the relevant concepts The National Health and Medical Research Council of Australia (NHMRC) and The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) have produced guidelines for ethical conduct in health research involving Aboriginal and Torres Strait Islander people which outline a number of relevant principles[2,3]. The Health Research Council of New Zealand has produced a guideline for researchers involved in health research involving Māori which outlines a number of relevant principles[4].

4.3 Policy Description

This policy should be read with reference to ANZDATA the Data Request Procedure and the Data Linkage Procedure. All requests for data from the ANZDATA registry for research purposes will be classified according to the following criteria:

- Group 1: no ethnicity data requested
- Group 2A: ethnicity data requested to describe the cohort. It will NOT be included in statistical models for analysis.
- Group 2B: ethnicity data is requested for describing the cohort and for inclusion in statistical models for analysis, but ethnicity is not the primary focus of the research
- Group 3: ethnicity data requested, and the primary focus of the research is related to patient ethnicity

Classification will be determined at the ANZDATA requests meeting. Where ambiguity exists between Group 2A, Group 2B and Group 3, further information should be sought from the requestor for clarification.

Group 1

- Requests processed as per the Data Request Procedure and the Data Linkage Procedure

Group 2

- If not included on the initial request form, researchers will be contacted and asked to provide a response to the following question:

1.Please describe how you plan to categorise ethnicity (For example the ANZDATA standard categories for reporting are Aboriginal/Torres Strait Islander, Māori, Pacific Peoples and Other.)

- If a clear and appropriate description of the planned use of this data is provided, then data will be approved for release according to the procedures outlined in the Data Request Procedure.
- If justification for the release of data cannot be ascertained through correspondence with the requestor, the request will be referred to the ANZDATA Executive for review.

Group 2B

- If not included on the initial request form, researchers will be contacted and asked to provide a response to the following questions:

1.Please describe how you plan to categorise ethnicity (For example the ANZDATA standard categories for reporting are Aboriginal/Torres Strait Islander, Māori, Pacific Peoples and Other.)

2.Please outline how ethnicity is relevant to your research question and why you plan to adjust for this in your model

- If a clear and appropriate description of the planned use of this data is provided, then data will be approved for release according to the procedures outlined in the Data Request Procedure
- If justification for the release of data cannot be ascertained through correspondence with the requestor, the request will be referred to the ANZDATA Executive for review.

Group 3

- If not included on the initial request form, researchers will be contacted and asked to provide a response to the follow questions:

1. Please describe how you plan to categorise ethnicity (For example the ANZDATA standard categories for reporting are Aboriginal/Torres Strait Islander, Māori, Pacific Peoples and Other.)
2. Please outline how ethnicity is relevant to your research question?
3. Do any of your research team identify as a member of the ethnic group(s) who will be included in this research?
4. What previous experience and/or relationships do members of your research team have working with members of the ethnic groups(s) who will be included in this research?
5. What consultation has been undertaken regarding this specific project with members of the ethnic group(s) who will be included in this research?
6. How will this research improve knowledge and add value for members of the ethnic group(s) included in this research?

7. How will this information be translated and shared with members of the ethnic group(s) included in this research?

- If researchers communicate a meaningful and appropriate engagement with the concepts raised by the above questions, data will be approved for release according to the Data Requests and Data Linkage Procedures.
- Note that this list is not a set of criteria that must be fulfilled prior to data release, but rather serves to explore relevant concepts to allow ANZDATA to perform due diligence as the custodian of ethnicity data.
- If the requests team are not satisfied that the relevant concepts have been sufficiently addressed by the requestor, or other issues arise, the request will be referred to the ANZDATA Executive for review.

Notes:

- Requests for data relating to research specifically focusing on patients from New Zealand, including research relating to Māori or other specific populations, will be referred to the ANZDATA New Zealand Working Group for review and approval.
- Requests for data relating to ethnic populations within Australia, including research relating to Aboriginal and/or Torres Strait Islander people of Australia, will be referred to the ANZDATA Executive for review and approval.
- Requests for data relating to Aboriginal and/or Torres Strait Islander Peoples of Australia will be communicated or referred to the ANZDATA Aboriginal and Torres Strait Islander Health Working Group at each of its meetings.

5. Data Security and Privacy

- Ethnicity data must be stored securely and accessed only by authorized personnel.
- Data must be de-identified unless explicit consent is obtained.
- Use must comply with relevant privacy legislation (e.g., Australian Privacy Act 1988, NZ Privacy Act 2020).

6. Reporting and Publication

- Ethnicity data must be reported accurately and respectfully.
- Avoid deficit framing or stereotyping.
- Include community perspectives where applicable.

7.Acknowledgments

- Assoc Prof Jaqui Hughes and Adjunct Assoc Prof Donisha Duff, former Aboriginal and Torres Strait Islander Health Working Group conveners, who worked closely with ANZDATA to develop this document.

- The ANZDATA Aboriginal and Torres Strait Islander Health Working Group led consultations that gives expert witness to the important change in Registry data processes to advance Aboriginal and Torres Strait Islander peoples kidney health.
- "L Mick-Ramsamy, J Kelly, **D Duff**, A Cass, L Ross, D Croker, H Hall, P Mills, **JT Hughes** (2019) Catching Some Air - Asserting Aboriginal and Torres Strait Islander Information Rights in Renal Disease Project- The Final Report. ISBN: 978-1-922104-63-2 (Online): Menzies School of Health Research. Available at: https://www.menzies.edu.au/CatchingSomeAir/FinalReport

8. Exhibits/ Appendices

1. Statistics. 2019. https://www.abs.gov.au/ausstats/abs@.nsf/mf/1249.0

2. Ethical conduct in research with Aboriginal and Torres Strait Islander People and Communities. The National Health and Medical Research Council (NHMRC). 2018. https://www.nhmrc.gov.au/about-us/resources/ethical-conduct-research-aboriginal-and-torres-strait-islander-peoples-and-communities

3. Guideline for Ethical Research in Australian Indigenous Studies. The Australian Institute of Aboriginal and Torres Strait Islander Studies. 2012 https://aiatsis.gov.au/sites/default/files/docs/research-and-guides/ethics/gerais.pdf

4. Guidelines for Researchers on Health Research involving Māori. Health Research Council of New Zealand. 2010. https://www.hrc.govt.nz/sites/default/files/2019-06/Resource%20Library%20PDF%20-%20Guidelines%20for%20Reseasrchers%20on%20Health%20Research%20involving%20Maori%20.pdf

9. Review

This policy will be reviewed annually or following any significant changes in legislation, operational procedures, or governance structures

10. Document History

Version	Date	Description	Author
2020.1	21/07/2020	Creation	M. Sypek
2020.2	20/08/2020	Reviewed and edited post ANZDATA Advisory Committee feedback	K. Hurst
2020.3	01/09/2020	Aotearoa New Zealand reference and review date	K. Hurst
2023.1	14/03/2023	Updated Ethnicity Group 2A and 2B	K. Hurst
2024.1	28/11/2024	Updated Justification of Policy	K. Hurst
2025.1	06/08/2025	Added Scope, Added Guiding Principles, reformatted document, updated Pasifika to Pacific Peoples, Added	L.Greenham

		Data Security and Privacy, Added Reporting and Publication and Review	