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Document Name:	Guidance on data requests relating to patient ethnicity
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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 other ethnic groups living within Australia and New Zealand.

2. Policy Details

2.1. Background on Collection of Data

- 2.1.1. 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
- 2.1.2. ANZDATA collects data on patient ethnicity
- 2.1.3. Prior to 2014, the Registry collected information on 'racial origin' according to a bespoke coding system
- 2.1.4. Since 2014 the Registry has collected information on 'ethnicity' according to the Australian Bureau of Statistics, Australian Standard Classification of Cultural and Ethnic Groups (ASCCEG)¹
- 2.1.5. Since 2019 data collection tools have enabled renal units to document more than one ethnicity for a patient
- 2.1.6. 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

2.2. Justification for policy

- 2.2.1. Specific populations including Australian Aboriginal and Torres Strait Islander people, Māori and other culturally and linguistically diverse populations may experience specific health inequities due to historical and current systemic racism and other factors
- 2.2.2. Potential genetic variation relevant to disease prevalence and severity, and treatment responsiveness may be associated with ethnic identity
- 2.2.3. Research that includes patient ethnicity data may be valuable to improve the understanding of kidney disease and outcomes of treatment for patients with end stage kidney disease

2.2.4. Ethnicity is a complex personal and cultural concept and research that includes information collected by the Registry on ethnicity should engage meaningfully and respectfully with the relevant concepts

2.2.5. 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}

2.2.6. 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 principles⁴

2.3. Policy Description

2.3.1. This policy should be read with reference to ANZDATA policy 2.3 Data Request Procedure and policy 2.5 Data Linkage Request Procedure

2.3.2. 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 2:** ethnicity data requested but the primary focus of the research is not related to patient ethnicity
- **Group 3:** ethnicity data requested and the primary focus of the research is related to patient ethnicity

2.3.3. Classification will be determined at the ANZDATA requests meeting

2.3.4. Where ambiguity exists between Group 2 and Group 3, further information should be sought from the requestor for clarification

2.4. **Group 1** requests:

2.4.1. processed as per policies 2.3 and 2.5

2.5. **Group 2** requests:

2.5.1. Unless provided on the initial request form, researchers will be contacted and asked to provide a response to the following two questions:

- Which ethnic group(s) will be included in your analysis?
- Please outline how ethnicity is relevant to your research question?

2.5.2. 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 policy 2.3

2.5.3. 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

2.6. **Group 3** requests:

2.6.1. Unless provided on the initial request form, researchers will be contacted and asked to provide a response to the follow questions:

- Which ethnic group(s) will be included in your analysis?
- Please outline how ethnicity is relevant to your research question?

- Do any of your research team identify as a member of the ethnic group(s) who will be included in this research?
 - 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?
 - What consultation has been undertaken regarding this specific project with members of the ethnic group(s) who will be included in this research?
 - How will this research improve knowledge and add value for members of the ethnic group(s) included in this research?
 - How will this information be translated and shared with members of the ethnic group(s) included in this research?
- 2.6.2. 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 procedures outlined in policies 2.3 and 2.5
- 2.6.3. 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.
- 2.6.4. 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.

2.7. Notes

- 2.7.1. 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.
- 2.7.2. 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.
- 2.7.3. 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 Indigenous Health Working Group at each of its meetings.

3. Acknowledgments

- Assoc Prof Jaqui Hughes and Adjunct Assoc Prof Donisha Duff, 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 give expert witness to changes 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>

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4. Exhibits / Appendices / Forms

1. Australian Standard Classification of Cultural and Ethnic Groups. Australian Bureau of 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%20Researchers%20on%20Health%20Research%20involving%20Maori%20.pdf>

5. Document History

Revision	Date	Description
2020.1	21/07/2020 Draft	Creation
2020.2	20/08/2020 Draft	Reviewed and edited post ANZDATA Advisory Committee feedback
2020.3		Aotearoa New Zealand reference and review date