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1.0 Purpose

This document provides guidance on the principles relating to international requests for data from the ANZDATA registry.

2.0 Background

Details of the principles and policies that govern data usage are outlined in document 2.2 *Data custodianship and release policy*. These include but are not limited to: encouraging data use, protective privacy, protecting data integrity and prioritizing contributors and funders. Occasionally, ANZDATA receives data requests from international parties, this raises unique issues about how to protect privacy and recognize the work of ANZDATA's contributors whilst at the same time fostering appropriate international partnerships to help improve the care of people with end stage kidney disease

3.0 Principles

- 3.1 International data requests must involve a contributor each for Australia and New Zealand (if applicable), not just as a named investigator but as a substantial collaborator who provides local responsibility
- 3.2 International data requests must demonstrate how the project will benefit locals in Australia and New Zealand and what consultation has occurred in each country, including with Indigenous people (if relevant)
- 3.3 Publications arising from use of ANZDATA data must include at least one ANZDATA contributor in the authorship and acknowledge the contributions of ANZDATA within the manuscript
- 3.4 Identifiable data will not be sent outside Australia/New Zealand



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- 3.5 Where possible, aggregate data will be provided to international requestors, however, in some circumstances limited data sets of de-identified line data may be provided in order to perform multijurisdictional analysis. In those circumstances, a named ANZDATA contributor must be a collaborator, and takes responsibility for appropriate utilization and security of the data. For multijurisdictional projects, there would usually be an ANZDATA contributor as chief investigator or steering committee member or similar.
- 3.6 All international requests for data from the ANZDATA registry must be approved by the ANZDATA Executive and relevant working groups prior to data extraction and release.
- 3.7 International data requests relating to New Zealand data must be approved by the New Zealand working group prior to data extraction and release.
- 3.8 International recipients of ANZDATA data must sign a data use agreement outlining the conditions of data usage