ANZDATA Registry
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Document Number:	2.2
Document Name:	Data custodianship and release policy
Version Number:	2017.1
Effective Date:	21/09/2017

1.0 Purpose

The purpose of this document is to describe the data custodianship of ANZDATA and the principles that underlie data governance and data release to third parties.

2.0 Policy Details

2.1 Background

The custodianship of data in the Registry rests with the ANZDATA Steering Committee on behalf of the Heads of Renal Units, the membership of the ANZSN, and those health care professionals and patients contributing data to the Registry. The ANZDATA Steering Committee determines the principles and policies of ANZDATA data release, which are carried out by the Registry Executive and staff.

Data in collated and analysed by registry staff on behalf of the Steering Committee and is published in a series of publicly available reports including a comprehensive annual report summarizing the data set, quarterly key performance index (KPI reports), and monthly incidence reports. Individual hospital performance reports are also produced and distributed to contributing units and regular summary reports are provided to funding bodies.

Ad hoc reports are also prepared for government and health services to address specific auditing and quality assurance priorities. De-identified data may also be released to individual contributors on request of facilitate epidemiological and clinical research related to renal replacement therapy.

The following principles and policies apply to the release of individual line data extracts by ANZDATA.

2.2 Data Governance Principles

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- Recognition of contributors
    - Acknowledge the contributions made by renal units and ANZDATA funders (AOTA, NZ Ministry of Health, KHA, ANZSN)
- Data and Report Quality
    - Maintain the highest standards of quality and accuracy at all levels of data collection, storage, analysis, reporting and provision to external parties
- Protection of privacy
    - Maintain security measures and data management and release practices that ensure the privacy of individuals and contributing units is protected and are in line with Australian and New Zealand national privacy principles
    - Enable individuals to view, access and correct their own personal data held within the registry
- Data usage
    - Encourage utilisation of data collected for the benefit of patients and the renal community in Australia and New Zealand, to improve care quality and health outcomes
    - Encourage and develop the breadth and depth of the use of data by members of the renal community
    - Encourage analysis of data by multiple different groups (beyond the core ANZDATA biostatistical resource) to increase the breadth and diversity of projects performed
- Continuous improvement
    - Data collection and use remain relevant and reflect the needs of stakeholders.
- Risk Management
    - Maintain processes for internal auditing and appropriate management of incidents and complaints.

2.3 Data Release Principles and Policies

- Encourage data use
    - Data extracts will be made available to contributors of ANZDATA on request, provided evidence of appropriate expertise for analysis/interpretation is shown by the requestor.
- Protect privacy
    - In general, only de-identified data is released. Exceptions to this are data linkage projects, where there is ethics committee approval specifically for release of identified data for data linkage. Contributing units also have access to view, receive and review their own identifiable data.
- Encourage efficiency

    - Where adequate for a project, release of aggregate data (group level), is preferred to the release of individual line data.
    - Only data fields required for analysis of the issues / questions identified in any given request will be released.
- Protect data integrity
    - Data sets released are only approved for use in the specified project, subsequent use for other projects will require further approval in consultation with the registry.
    - Where individual line datasets are provided, responsibility for design, conduct and interpretation of analyses lies with the requestor. A disclaimer should be included in any publications arising from these data sets.
    - Details of the database structure are available in the data set specification documents and ANZDATA are available to explain the structure of the data set.
    - Although much effort is put into collecting and recording data accurately, as in any large database, there may be occasional errors, for which ANZDATA does not take responsibility.
- Transparency
    - ANZDATA will keep and show on its website a list of the data requests (the name of the requestor and the title).
    - Where a subsequent request is received for a similar or overlapping area we will endeavour to identify requestors with similar or overlapping proposals, but cannot guarantee to do so.
    - Where there are overlapping requests, data will not be released for the subsequent request within 6 months of provision of data for the original request.
- Prioritize contributors and funders
    - Priority for data access is given to ANZDATA contributors and funders. Where requests are received from external parties, collaboration with a contributor is strongly encouraged.
    - Identification of a local contributor is essential for release of identified individual line datasets – this person then acts as the “guarantor” of appropriate use and interpretation of the data and analyses.
    - For release of New Zealand individual line datasets, involvement of a New Zealand ANZDATA contributor is highly desirable and consultation with Māori may be appropriate.
    - Individual line data will not be released to corporations. Where requests are received, these analyses are performed “in-house”. These are generally performed on a cost recovery basis, taking into account other contributions to the Registry.
- Ensure ethical research practices
    - The requirement for ethics committee approval depends on the nature of the project. For many clinical audits or similar projects this will not be required, but is often appropriate for research studies.
    - Formal ethics approval and oversight is mandatory for data linkage studies.

    - Where the need for ethics oversight is unclear, the requestor will be asked to seek advice from their local health research ethics committees, external to ANZDATA.
- Recognise custodianship of linked data from external sources
    - Australian transplant waiting list and some other transplant data are supplied by National Organ Matching Service (NOMS). Approval for use of this data outside the terms stipulated in the joint memorandum of understanding is required from NOMS, in addition to ANZDATA.
    - New Zealand transplant waiting list and some other transplant data are supplied by the New Zealand Blood Service (NZBS). Approval for use of this data outside the terms stipulated in the joint memorandum of understanding is required from the New Zealand Transplant Leadership Team, in addition to ANZDATA.

3.0 Exhibits / Appendices / Forms

Nil

4.0 Document History

Revision	Date	Description
2017.1	21/09/2017	Creation