

Document Number:	2.1
Document Name:	Data collection policy
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1.0 Purpose

This document describes the nature and method of data collection and includes a description of data fields collected.

2.0 Policy Details

Scope of data collection

- Data are collected from all adult and paediatric Renal Units in Australia and New Zealand on all persons receiving renal replacement therapy (RRT), either dialysis or kidney transplantation, for the treatment of end stage kidney disease (ESKD)
- Data are collected on all deceased organ donors in Australian and New Zealand from the Australian Organ and Tissue Authority and Organ Donation New Zealand
- Data are collected on all living kidney donors in Australia and New Zealand from all renal transplanting units
- Data are collected on all eye and tissue donors from eye and tissue banks
- Data are collected on kidney transplant waiting lists and organ matches from the Australian National Organ Matching Service (NOMS)
- Data are collected on characteristics and outcomes of peritoneal dialysis patients utilising the HomeChoice Claria with ShareSource APD machine technology from Baxter Healthcare.

2.1. Nature of data collection

ANZDATA

- Real time data is collected on all new incident patients commencing RRT, changes of RRT modality, changes in treating centre, death and other major events such as new cancer diagnoses.
- An annual survey is collected from all dialysis and transplant units in Australia and New Zealand at 31st December.
- The annual survey encompasses all patient events that have occurred in the previous twelve months as well as a "snapshot" of all dialysis and transplants patients on those dates.

- Annual data collection commenced from 31 December 2004. Prior to April 2004, data was collected twice a year at 31st March and 30th September.
- There is voluntary participation by all physicians/surgeons involved in dialysis/transplant treatment in both countries.
- A list of the participating units is available from the most recent ANZDATA Report Contents file on the ANZDATA website and is published with a wide national and international circulation.

ANZOD

- Data is collected on organ donors from donation coordinators as soon as practical following each donation event
- A monthly summary of transplant activities is received from NOMS and cross-checked against organ donor records

ANZLKD

- Data is submitted on all living donation events on a monthly basis by all transplanting units either through an electronic or paper based data entry form
- Units are contacted directly if data has not been submitted each month

Eye & Tissue Donation

- Data is transferred securely to the registry by all Eye and Tissue banks on a monthly basis

Wait listing and Organ Match Data

- Data is transferred securely on a monthly and annual basis from NOMS under the terms of a memorandum of understanding
- A similar arrangement with New Zealand Blood Service is being pursued

Peritoneal Dialysis Data

- Data is transferred securely on a monthly and annual basis from Baxter Healthcare under the terms of a memorandum of understanding

2.2. Methods of data collection

Electronic data transfer

- Data entry using an online system <https://services.anzdata.org.au/>.
- Data transfer using an application programming interface (API) via Web Services
- Data upload submitted via a secure report depot service

Pre-printed survey forms

- A pre-printed survey form of previously recorded information for each patient is distributed for updating purposes annual
- Separate data forms for recording specific details of paediatric, acute rejection, cancer, ABO incompatible transplant and peritonitis are also distributed.

Data entry in the registry

- Data returned via the pre-printed survey form is entered into the online system by ANZDATA administrative staff

Comments

- All data must be prepared to the Registry's data set specifications dependent on method of collection
- The same variables are collected through each method of data collection (see below).
- Increased use of online and automated data collection is part of ANZDATA's strategic direction with a plan to gradually phase out paper based data collection.
- Mechanisms to ensure data completeness and accuracy are outlined in procedure 2.4

2.3. Data set specifications

The data set specification documents describe the structure of the database. These are updated whenever a revised data collection form is produced and also whenever coding or database modifications are made. The data set specifications are available from the ANZDATA website.

3.0 Exhibits / Appendices / Forms

- 8.1 Data Set Specification: ANZDATA
- 8.2 Data Set Specification: ANZDATA Postsurvey
- 8.3 Data Set Specification: ANZOD
- 8.4 Data Set Specification: ANZLKD
- 8.5 Data Set Specification: Eye & Tissue



ANZDATA Registry
C/O SAHMRI, PO Box 11060
SAHMRI Building, Level 4 South, North Terrace
Adelaide, South Australia 5001
Ph: +61 8 8128 4758 | Fax: +61 8 8128 4769

4.0 Document History

Revision	Date	Description
2017.1	21/09/2017	Creation
2019.1	14/02/2019	Updated the 'scope of data collection' and 'nature of data collection' sections to capture the linkage of peritoneal dialysis data from Baxter Healthcare.