

Data Request for a Research Project

What is ANZDATA?

ANZDATA is a clinical quality registry which has data collection dating back to 1963. People are included in the registry when they commence kidney replacement therapy (dialysis or transplantation). Inclusion is an opt out process meaning that there is almost complete data on patients who have kidney replacement therapy. Key events are reported by units in real-time, but most data are collected as an annual survey at the end of the calendar year. There have been updates to how variables have been collected over time to align with changes in clinical practice, which means certain data fields may be available at different time points. A detailed list of contributors to ANZDATA can be found at the below link and consist of a variety of clinicians including Australia or New Zealand nephrologists, surgeons, nurses, dieticians, and other health providers.

<https://www.anzdata.org.au/anzdata/about/our-contributors/>

How does ANZDATA review your request?

Your data request will be reviewed by ANZDATA's requests committee made up of biostatisticians, epidemiologists, clinicians and administrators. Incomplete data requests or those lacking sufficient detail (as outlined below) will be returned to the requestor for further clarification, this can cause delays in overall completion of your data request. Your data request will then be forwarded to the appropriate working group (a collection of clinicians with an interest in the field),

See <https://www.anzdata.org.au/anzdata/about/working-groups/>.

If deemed necessary, your data request will also be reviewed by the ANZDATA executive committee <https://www.anzdata.org.au/anzdata/about/our-committees/>.

Complete this form as accurately as possible so these groups can help you with your request.

Complete details in ALL boxes with as much information as possible. The bullet points in each box identify the minimum information required. Please reference ANZDATA's guidance documents to assist in completing your request

<https://www.anzdata.org.au/anzdata/services/data-policies/>

- > [2.3 Data request procedure](#)
- > [2.5 Data linkage request procedure](#)
- > [2.7 Guidance for international requests](#)
- > [2.9 Guidance on data requests related to patient ethnicity](#)

ANZDATA staff can assist with the preparation of your data request – please do not hesitate to ask if you are unsure how to proceed.

Title

- > *Full title*

Investigators

- > *At least one of the investigators should generally be an ANZDATA contributor Renal advanced trainee projects require a nephrologist supervisor*

Background

- > *This section is optional, but is usually helpful*
- > *At a minimum should outline any previous ANZDATA publications on the same topic*

Aims

Hypotheses

Inclusion and exclusion criteria

- > *Think “who, what, where, when”. Be as precise as possible.*
- > *Common exclusions (not always justified) – children, patients treated outside Aust/NZ, multiple organ transplant recipients, patients surviving <30 days after commencing RRT*
- > *Example: “Adult (aged 18+) recipients of primary kidney-only transplants performed in Australia during 2001-2010”*

Clear definitions, where relevant

- > *Exposure(s) – Example: Donor type (living or deceased)*
- > *Confounders – Example: Age at transplant*
- > *Primary outcome – Example: Graft survival*
- > *Secondary outcome(s) – Example: Patient survival*
- > *Please note if any of the above are to be obtained from data sources other than the ANZDATA, ANZOD or ANZLKD registries.*

Ethnicity Consideration

- > *Refer to [2.9 Guidance on data requests relating to patient ethnicity](#)*
- > *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*
- > *ANZDATA strongly discourages researchers from treating ethnicity as a confounder and adjusting for this within analyses without careful consideration. Instead, we would encourage adjusting for the determinants of health or risk factors that may be differentially and inequitably distributed. Further information on ANZDATA’S position can be found [here](#).*

- > *Ensure you outline the group your data request fits and provide a clear and appropriate description of the planned use of this data. If you plan to report on or analyse ethnicity data, document how you plan to categorise this.*

Data fields required

- > *The ANZDATA data collection forms and data dictionaries are available on the ANZDATA website – reading these helps to understand what is and isn't collected. It's best to start by perusing the main [data collection form](#) – the vast bulk of information collected can be gleaned from this form*
- > *Be aware that not all data elements have been collected since ANZDATA's inception, and some data elements are no longer collected. Details of collection dates are in the data dictionary*
- > *Some variables collected by ANZDATA are considered potentially identifying and are not provided for deidentified data requests (for example date of birth, however age at certain time points can be provided instead).*
- > *ANZDATA can derive variables from those collected to assist with simplification of the data requested (For example: any transplant rejection episodes reported: Yes/No).*
- > *Limit request for variables to those that are required to answer your research question i.e. are an exposure, cofounder or outcome variable*
- > *For variables that ANZDATA collects at multiple time points (e.g., comorbidities), please indicate at what time point you are requesting the variables (e.g., at the start of kidney replacement therapy or at transplant).*

Planned statistical analyses

- > *Who will perform analyses (investigators or ANZDATA)?*
 - > *Expertise if investigators will perform analyses*
- > *Planned statistical methods*
- > *Statistical software to be used*
- > *Due to limitations in statistician time and the priority to complete core business, the ability of ANZDATA to aid with statistical analysis to external parties is limited. Please refer to [2.8 Guidance on statistical support for external researchers](#) which outlines how ANZDATA will assess requests for statistical assistance from external researchers.*

Data format requested

- > *e.g., Stata, SPSS, CSV file, Excel spreadsheet – including version*
- > *Statistical software format is preferable since more information is preserved such as variable and value labels*

Ethical considerations

- > *Whether ethical clearance is required depends on several factors. In many cases analyses of de-identified data extracts may only require “expedited” or limited ethical overview – the data are collected expressly for this purpose and patients' consent (generally on an opt-out basis) for such data use*
- > *Data requests that require release of identified information (i.e., data linkage projects), require formal ethical approval from the investigator's institution. In all cases, this would require prior discussion with the ANZDATA executive*

Timeline

- > *Note that ANZDATA requires a progress report within 12 months of data provision, and suggests a maximum of 24 months from data provision to publication*

> *Release and use of a de-identified dataset is contingent on acceptance of standard data use conditions*

Summary

> *Provide a brief (1-2 sentence) summary suitable for publication on the ANZDATA website. This summary will enable other researchers to know (at a broad level) what work is already underway, to prevent duplication of effort*

Requestor's Signature _____ Date _____
Requestor's Name _____ Organisation _____

OFFICE USE ONLY

Received _____ Status _____
Allocated _____ ANZDATA Request ID _____