



Document Number:	2.5
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1.0 Purpose

This document outlines the procedures relating to data linkage requests made to the registry and should be read in conjunction with policy 2.2 (Data custodianship and release) policy and procedure 2.3 (Data requests standard procedure) that outlines the process for reviewing and approving general requests.

2.0 Procedure Details

2.2. Data requests are received and considered by the ANZDATA Executive following principles agreed by the Steering Committee (see Policy 2.2)

The implementation of this is performed by ANZDATA staff under the direction of ANZDATA Executive in line with the Registry's principles of data governance.

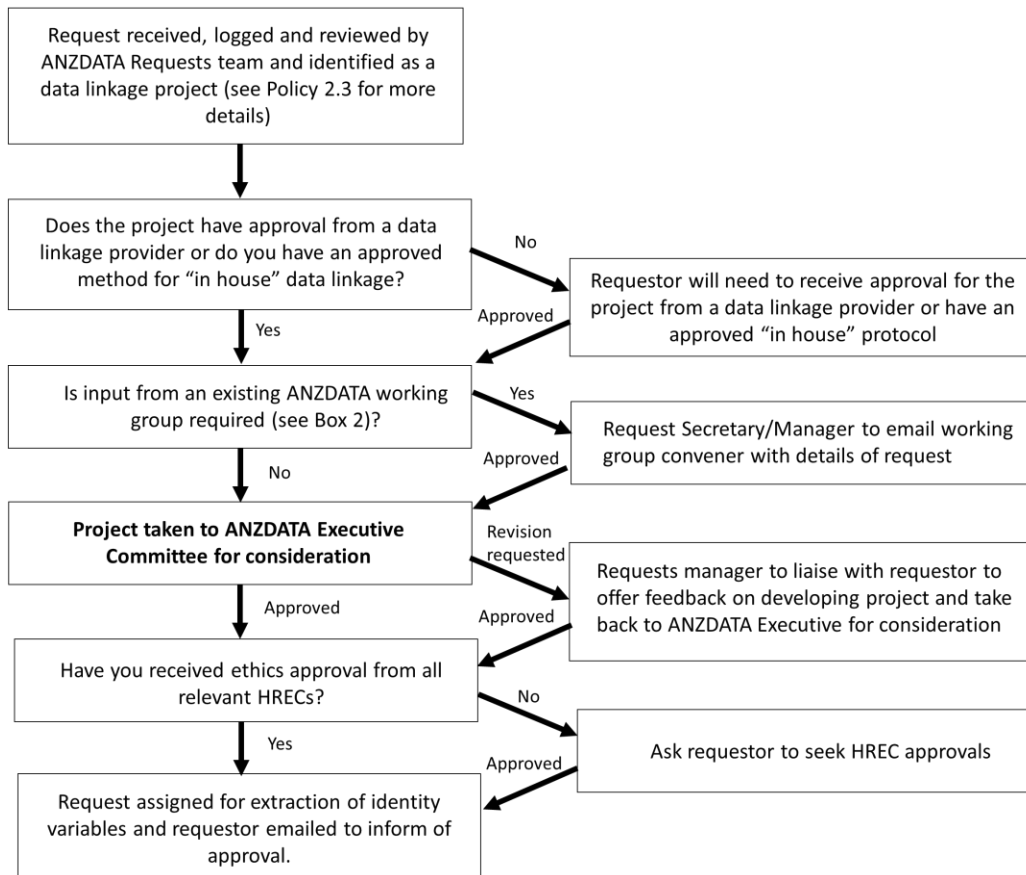
2.3. Principles of data linkage

- Identifiable variables required for linkage must be kept separate from clinical variables at all times
- Extraction of identifiable and clinical data sets must be performed by separate individuals
- Linkage should be performed by an appropriate third party with expertise in data linkage and appropriate data security processes in place
- The analysis data set must contain only variables approved by the Health Research Ethics Committees (HREC) overseeing the project
- All requests for data linkage must be reviewed at the ANZDATA executive meeting prior to approval

2.4. Typical procedure for data requests (See figure 1 from Policy 2.2)

2.4.1. When a request is related to data linkage is identified, figure 1 outlines the additional step required prior to approval for data extraction.

Figure 1:



2.4.2. Extraction Process

Once a request has been approved by the ANZDATA Executive committee and all relevant ethics approvals have been granted extraction can commence. All data linkage extractions are a two-stage process. The first stage is extraction of identity variables and the second is extraction of clinical variables. Extraction of identity variables must be performed by appropriately trained staff who are not involved in the specific project and will not be accessing clinical data related to the project.

Identity variables (see Box 1):

- The extraction process commences once ANZDATA receives an email from the project's data linkage provider requesting the extraction of identity variables
- Extraction assigned to an ANZDATA statistician/staff member
- Request log updated with status changed to 'identity variables extract'. Approval date, assignment details, request category, and urgency category entered.
- Email sent to requestor by request administrator informing them of tracking number, approval and assignment. A data use agreement form should be attached to this email
- Project title and requestor details uploaded to the ANZDATA website by requests administrator
- The timeline for data extraction will be negotiated with requestor
- When extraction of the identity variables is complete, the code will be checked by a second statistician/staff member for quality assurance
- Data transfer:
 - All extractions for data linkage projects must be transferred via the ANZDATA secure report depot, or another secure report depot provided by a data linkage provider
 - Data is transferred to the data linkage provider not the requestor
- Data linkage requests will not be released until all relevant ethics approvals are received by ANZDATA
- The identity variables extraction does not contain patient's ANZDATA IDs but it does contain a project specific record ID which can be used to link the data to clinical variables in the second stage of the process

Clinical variables

- Once the identity variables have been sent and the project specific linkage keys have been allocated by the linkage provider, a spreadsheet containing the de-identified record ID (allocated by ANZDATA) and the project specific linkage keys (allocated by the data linkage provider) are sent to ANZDATA via a secure report depot.
- The extraction of the clinical variables is performed by a separate ANZDATA statistician/staff member (from the individual who performed the extraction of the identity variables for the project)
- Request log updated with status changed to 'clinical variables extract'
- Email sent to requestor by request administrator informing them that the second half of extraction has commenced
- The timeline for data extraction will be negotiated with requestor
- When extraction of the clinical variables is complete, the code will be checked by a second statistician/staff member for quality assurance (different to any statistician/staff member involved in the extract or code checking of the identity variables for the project)
- Data transfer:



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- All extractions for data linkage projects must be transferred via the ANZDATA secure report depot, or another secure report depot provided by a data linkage provider
- Data is transferred to the requestor not the data linkage provider

Administration

For the general administration of a data request please see policy 2.3.

- Due to the involvement of identifiable information in a data linkage request, all ANZDATA statisticians/staff members are required to sign a confidentiality form which states that they will only access identifiable data for the purposes directly related to their work and only when accessing this data is necessary for a specific task
- For all data linkage requests the ANZDATA statistician/staff member who extracted or reviews the code for the identity variables will be different from the ANZDATA statistician/staff member who extracts or reviews the code for the clinical variables
- As outlined in the 'Identity Variable' section above, the extraction process only commences once ANZDATA receives an email from the project's data linkage provider requesting the extraction of identity variables, in no instance will any identifiable information be provided directly to the data requestor.
- Identifiable data related to data linkage projects will be stored in a separate password protected folder on the ANZDATA S:/ drive

3.0 Definitions

Box 1: Identifiable variables

Variables considered identifiable data

- Hospital name/code
- Surname
- Given name
- Date of birth
- ANZDATA ID number
- Hospital Medical Record Number

Variables consider potentially identifiable data (avoid release unless essential for project, does not require head of unit approval)

- Postcode

Box 2: List of current ANZDATA working groups

- Indigenous Working Group
- Paediatric Working Group
- Peritoneal Dialysis Working Group
- Haemodialysis Working Group
- Transplantation Working Group
- Patient Reported Outcomes Measures (PROMs) Working Group
- New Zealand Working Group

4.0 Exhibits / Appendices / Forms

5.0 Document History

Revision	Date	Description
2017.1	21/09/2017	Creation