



Requesting Data from the ANZ Fragility Fracture Registry

Requesting data from the ANZFFR is guided by the ANZFFR Data Access Policy.

We encourage you to contact the Registry Manager to discuss your proposed research question prior to commencing your application. Please ensure that you have reviewed the lists of approved projects and those under consideration.

Applications for data are reviewed by the ANZFFR Data Management Committee Chair in the first instance.

Applications must be received 21 days prior to the next Data Management Committee meeting to be included for review.

Meeting dates for 2025:

June

September

Data Access Policy

Purpose and Scope

Access to data collected and collated by the Australia and New Zealand Fragility Fracture Registry (ANZFFR) is guided by protocols and procedures to maintain privacy and confidentiality. Provision of data is subject to the study protocol which has been approved by a Human Research Ethics Committee in each jurisdiction and the relevant Research Governance Office of participating hospitals. This document provides guidance to the ANZFFR's approach to dealing with requests to access registry data and outlines the procedures for applicants to follow when making a request to access registry data.

Background

The registry holds identified data relating to people over the age of 50 years that have suffered a fragility fracture. The registry contains data submitted by participating Fracture Liaison Services (FLS), and it is important that the privacy of this information is maintained. This policy is intended to maintain privacy and confidentiality when considering requests from third parties to access the data held in the registry. In considering requests to access and use ANZFFR data, the primary aim of the Steering Committee is to protect the individual participants' privacy.

Applicant Responsibilities

1. People accessing ANZFFR data are responsible for ensuring appropriate security of any material, confidential or otherwise, held in any format on computing systems.
2. A date for data disposal must be included in any request to access data

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3. In accessing de-identified data no attempt will be made to re-identify individuals in the data provided by the ANZFFR.
4. For research proposals, ethics and governance approvals must be provided prior to the release of data.
5. For research proposals, a schedule for reporting and dissemination of results must be included in the submitted project outline.
6. For research proposals, an annual progress report must be submitted to the ANZFFR.

Approved Projects

ANZFFR prefers collaboration of research using ANZFFR data, where possible, rather than duplication of research.

Requests under consideration

ANZFFR prefers collaboration of research using ANZFFR data, where possible, rather than duplication of research.

Requesting Data Access: A Step-by-Step Guide

Please review ANZFFR publications and approved / in progress projects listed above prior to submitting a data request.

Below is a step-by-step guide on how to apply for access to ANZFFR data.

Step 1: Review approved projects and requests under consideration

You are encouraged to contact the registry manager to discuss your proposal.

Step 2: Submit an abstract outlining your proposal.

Step 3A: Complete data access application

If you receive support to complete a full application for data access, the registry manager will send you the most recent data access application form to complete.

Step 3B: Amendments

Complete any requested amendments to the ANZFFR data access request form and resubmit. Based on feedback from the ANZFFR Data Custodian, make any changes and re-submit.

Step 4: ANZFFR Data Management Committee Recommendation

ANZFFR Data Management Committee reviews data application and HREC approval and makes recommendation to the ANZFFR Steering Committee.

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Once the application has been accepted by the Data Custodian, it will be submitted to the ANZFFR Data Management Committee for its review at its next scheduled meeting. Data Management Committee recommendations will be tabled at the next Steering Committee Meeting.

Step 5: Ethics Approval.

Submit and receive ethics approval from relevant HREC and governance body.

All research projects must undertake appropriate applications for ethics and governance approval and provide copies of approved documents and approval letter(s) prior to ANZFFR data being released.

Step 6: ANZFFR Steering Committee Recommendation.

ANZFFR Steering Committee makes recommendation to Data Custodians (Australia / New Zealand) and applicant advised of outcome.

The ANZFFR Steering Committee will make recommendations to the Data Custodian (Australia / New Zealand) and contact the applicant with the outcome of the review. At that time the ANZFFR will be able to provide a more definitive timeline for the provision of the ANZFFR data.

Step 7: Data Extraction

The data extract will be provided to the applicant after returning signed confidentiality undertaking.

Data variables will be extracted into a csv or excel file. The file will be encrypted and the file protected with a password. The file will be sent to the applicant using a secure data transfer mechanism. The password to access the file will be delivered separately by telephone, person to person. The applicant will then use the password to open the file and then unencrypt the data in the file.

Step 8: Prior to Publication

The applicant will provide the ANZFFR Steering Committee a copy of any manuscripts submitted to peer-reviewed journals, and the reference once published.

Abstracts submitted to conferences should also be provided.

Link to Data Dictionary [Fragility Fracture Registry NZ – Making the first break the last](#)

Link to Variable Concordance Table [Fragility Fracture Registry NZ – Making the first break the last](#)