Australian and New Zealand Hip Fracture Registry
Data Access Policy

PURPOSE AND SCOPE

Access to data collected and collated by the Australian and New Zealand Hip Fracture Registry (ANZHFR) is guided by protocols and procedures to maintain privacy and confidentiality. Provision of data to the registry is subject to the study protocol, which has been approved by Human Research Ethics Committees in each jurisdiction, and the relevant Research Governance Offices of participating hospitals. This document provides guidance for dealing with requests to access registry data, and outlines the procedures to be followed when requesting data.

BACKGROUND

The ANZHFR holds identified data relating to people 50 years of age and over admitted to a hospital with a fractured proximal neck of femur. The registry contains data submitted by participating hospitals, and it is important that the privacy of this information is maintained. This policy is intended to protect privacy and confidentiality when considering requests from third parties to access the data held in the registry. In considering requests to access and use ANZHFR data, the primary aim of the Steering Group is to protect the individual participant's privacy.

RESPONSIBILITIES

1. People accessing ANZHFR data are responsible for ensuring appropriate security for the storage of any material, confidential or otherwise, held in any format including on computing systems.
2. A date for data disposal must be included in any request for access to data.
3. In accessing de-identified data, no attempt will be made to re-identify individuals in the data provided by the ANZHFR.
4. For research proposals, ethics and governance approvals must be provided prior to the release of data.
5. For research proposals, a schedule for the reporting and dissemination of results must be included in the submitted project outline.

DATA ACCESS

1. Access to data is subject to the protocol statement outlined below.
2. All uses of the data, in whatever context, must receive prior approval from the ANZHFR Steering Group. In some instances, specific ethics approval from the relevant hospital ethics committee will also be required.
3. Any results intended for publication or presentation that use ANZHFR data must be reviewed by the ANZHFR Steering Group before public release. The ANZHFR Steering Group is to be given 14 working days to comment on any material intended for public release.
4. Individually identifiable unit record data (such as name, address, date of birth) will not be provided directly to an applicant. Individually identifiable information would only be made available to third parties (such as data linkage centres) for the purposes of linkage to other data collection(s). No clinical or health information would be provided for the purpose of data linkage. Ethical approval would be required for research involving data linkage and the third party conducting the linkage must have a data governance and data security plan in place.
5. In general, requests from contributing clinicians and hospitals and academic organisations will be fulfilled without charge.
6. Requests for data from other bodies will be considered on a case-by-case basis and may be subject

to a fee.

7. If a fee is charged, agreement in writing from the requesting agency must be received prior to data being extracted.
8. All requests for access to ANZHFR data must take timeframes into account, as data requests will be scheduled alongside routine ANZHFR tasks.
9. Data requests are to be made to the ANZHFR Data Custodian for consideration at ANZHFR Steering Group meetings and clarification of the data access application may be requested after ANZHFR Steering Group review.
10. Steering Group meetings are held four times per year and data will not be extracted until ANZHFR Steering Group approval is given. As a general rule, requests for aggregated data will take 4-6 weeks to complete after approval.
11. All data requests must be lodged in writing on the registry application form (Appendix 1) and sent to the Data Custodian, Australian and New Zealand Hip Fracture Registry, c/- Neuroscience Research Australia, 139 Barker Street, Randwick NSW 2031.

PROTOCOL STATEMENT

1. The request for access to ANZHFR data will be submitted by the ANZHFR Data Custodian at the meeting of the ANZHFR Steering Group after receipt of the request. A decision on whether to grant access to the requested data will be determined on the advice of the ANZHFR Steering Group.
2. Hospitals contributing data to the ANZHFR may have access to their own patient level data but use of the data for quality and safety initiatives must not identify individual participants.
3. If a third party project requires individual data for linkage, the individual data will not be provided directly. A data linkage plan will be developed with each new applicant with the overarching requirement that the privacy of individual hospitals and participants is maintained.
4. If a research proposal requests data for specific hospital(s), then the applicant must provide ethics approval from the specific hospital(s) before ANZHFR data is made available.
5. Data is released for the specific purpose(s) set out in the submitted application. The use of the data for any other purpose without prior approval is not permitted.
6. Prior to any publication or presentation of results that use the ANZHFR data, the applicant will provide the information to the ANZHFR Steering Group at least 14 working days prior to its release.
7. It is a condition of use of the data that the data source is acknowledged, with a statement that the analysis and interpretation of the data are those of the author(s), not the ANZHFR.

APPENDIX 1: ANZHFR DATA APPLICATION FORM

This form must accompany a request for data. Please return with any other requested documentation.

Attention: ANZHFR Data Custodian
c/- Neuroscience Research Australia
139 Barker Street
Randwick NSW 2031

1. *Applicant Information:*

Person Responsible for this Application (for research purposes, specify the Principal Investigator)

Title/Name: _____

Position: _____

Organisation: _____

Affiliation (if applicable): _____

Address: _____

Telephone: Work: _____ Mobile: _____

Email: _____

2. *Requesting Organisation (tick all that apply):*

☐ Research / Academic Institution
☐ Hospital Clinician / Clinical Department
☐ Other Registry
☐ Government Department
☐ Health Organisation
☐ Industry
☐ Other, specify:_____

3. *Purpose of Data Request (tick all that apply):*

☐ Research
☐ Clinical Care Quality and Safety
☐ Health Service Planning
☐ Policy Development
☐ Other, specify: _____

4. Short title of data request:

If this request is for research purposes, please attach a short description of your project (<1000 words). This should be in the form of an extended abstract, and include background, aims, method, and planned analysis.

5. Provide reason for data request:

6. Hypothesis and specific research questions:

7. Provide details of the variables requested by completing appendix 2 ANZHFR Data Variable Checklist. Include justification of the need for the data variable.

8. Cohort description, specifying any inclusion or exclusion criteria (e.g. all ages or 65+ years; only females):

9. Select jurisdiction of interest:

☐ All Australia	☐ All New Zealand	☐ All Australia and New Zealand
Or custom selection (tick all requested jurisdictions)		
☐ Queensland	☐ New South Wales	☐ Victoria
☐ Tasmania	☐ South Australia	☐ Western Australia
☐ Northern Territory	☐ ACT	
☐ Other (specify):		

10. Specify the dates of data required (For example, date of surgery from 1 Jan 2016 to 31 Dec 2016 inclusive OR Date of admission 1 Jan 2016 to 31 Dec 2016 exclusive):

11. Provide intended uses of the data/information (include anticipated publications, reports, presentations and any other projected use):

12. **Security and storage of data** (List all locations where the data will be stored and analysed and specify the measures taken to ensure security of information from misuse, loss or unauthorised access during and after the project):

13. **Data retention and disposal plan** (specify the period of data retention following the completion of the project and how information will be destroyed:

Is this a funded project? ☐ Yes ☐ No

If yes, who has funded the project? _____

Have you received ethics approval to access the ANZHFR? ☐ Yes ☐ No

If yes, please attach a copy of the approval letter and all other project documentation submitted with the ethics application.

Have you read and agree to adhere to the ANZHFR Data Access Policy? ☐ Yes ☐ No

Signature of Applicant:

Date:

Office Use Only

Approved by the ANZHFR Steering Group Chairperson: ☐ Yes ☐ No

Signature of Chairperson:

Date:

Appendix 2: ANZHFR DATA VARIABLE CHECKLIST

The provision of ANZHFR data for the data variables listed below is subject to the approval of the ANZHFR Steering Group via the ANZHFR Data Custodian and a relevant HREC. The list below relates to the current approved version of the ANZHFR Data Dictionary, version 10.2 October 2017. Variables that may identify individual participants have not been included in the checklist.

Check the box for each variable requested and provide a justification in the column beside.

	Variable	Justification
☐	Age - derived	
☐	Sex of person	
☐	Australian Indigenous status**	
☐	NZ ethnic status	
☐	Patient's postcode (Australia)/ domiciliary code (New Zealand)	
☐	Patient type	
☐	Usual place of residence	
☐	Establishment identifier of operating hospital	
☐	Admission via ED of operating hospital	
☐	Transfer hospital	
☐	ED / hospital arrival date (transfer hospital)	
☐	ED arrival time (transfer hospital)	
☐	ED / other ward arrival date (operating hospital)	
☐	ED / other ward arrival time (operating hospital)	
☐	ED departure date (operating hospital)	
☐	ED departure time (operating hospital)	
☐	In-patient fracture date	
☐	In-patient fracture time	
☐	Pain assessment	
☐	Pain management	
☐	Ward type	
☐	Pre-admission walking ability	
☐	Pre-operative cognitive assessment	
☐	Pre-admission cognitive status	
☐	Bone protection medication at admission	
☐	Pre-operative medical assessment	
☐	Side of hip fracture	
☐	Atypical fracture	
☐	Type of fracture	
☐	Surgical repair	
☐	ASA grade	
☐	Date of surgery for hip fracture	
☐	Time of surgery for hip fracture	
☐	Surgery delay	
☐	Surgery delay other text	
☐	Type of anaesthesia	
☐	Analgesia – nerve block	
☐	Consultant surgeon present	
☐	Type of operation performed	
☐	Full weight bear	

	Variable	Justification
☐	First day mobilisation	
☐	New pressure injuries of the skin	
☐	Assessed by geriatric medicine	
☐	Geriatric medicine assessment date	
☐	Specialist falls assessment	
☐	Bone protection medication at discharge from acute hospital	
☐	Delirium assessment	
☐	Discharge date from acute ward	
☐	Discharge destination from acute orthopaedic episode	
☐	Discharge from hospital date	
☐	Length of stay (operating hospital)	
☐	Length of stay (health system)	
☐	Discharge place of residence	
☐	30 day follow-up date	
☐	Survival at 30 days	
☐	Date health system discharge at 30 day follow-up	
☐	Place of residence at 30 day follow-up	
☐	Full weight bear at 30 day follow-up	
☐	Post-admission walking ability at 30 day follow-up	
☐	Bone protection medication at 30 day follow-up	
☐	Re-operation within 30 day follow-up	
☐	120 day follow-up date	
☐	Survival at 120 days	
☐	Date health system discharge at 120 day follow-up	
☐	Place of residence at 120 day follow-up	
☐	Full weight bear at 120 day follow-up	
☐	Post-admission walking ability at 120 day follow-up	
☐	Bone protection medication at 120 day follow-up	
☐	Re-operation within 120 day follow-up	

**Approval of specific Aboriginal Health and Medical Research Ethics Committees may be required to obtain this variable. Please contact the ANZHFR Data Custodian.

Other / Comments