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 to the ANZHFR's approach to dealing with requests to access registry data, and outlines the procedures for applicants to follow when making a request for access to data.

BACKGROUND

The ANZHFR holds identified data relating to people 50 years of age and over admitted to hospital with a fractured proximal 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.

APPLICANT 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 most 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 15 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 purpose 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 for consideration at ANZHFR Steering Group meetings. 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 6-8 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 to the Data Management Committee and then to the ANZHFR Steering Group at the next meeting after receipt of the request.
2. A decision on whether to grant access to the requested Australian data will be determined by the Data Custodian Australia after considering the advice of the Data Management Committee and the ANZHFR Steering Group.
3. A decision on whether to grant access to the requested New Zealand data will be determined by the Data Custodian New Zealand after considering the advice of the Data Management Committee and the ANZHFR Steering Group.
4. Hospitals contributing data to the ANZHFR may have access to their own patient level data but use of the data must not identify individual participants.
5. 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.
6. 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.
7. 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.
8. Applicants will be required to complete a confidentiality undertaking prior to the release of data.
9. The ANZHFR will not provide data to external jurisdictions but will consider contribution of aggregated results using agreed methods.
10. 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 15 working days prior to its release.
11. 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

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. Must include start and end date. For example, date of surgery from 1 Jan 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

Have you read and agree to the ANZHFR Confidentiality Undertaking?   ☐ Yes   ☐ No

Signature of Applicant:

Date:

Office Use Only

I confirm that the request as stated in this proposal is feasible. When determining whether, and in what form, Custodians will release data to the investigator due regard will be given to any ethical conditions imposed by the approving Human Research Ethics Committee.

Recommendation by the ANZHFR Steering Group Chairperson: ☐ Approve   ☐ Not approve

Additional information required: ☐ Yes   ☐ No

Signature of Chairperson:

Date:

Australian & New Zealand Hip Fracture Registry

Appendix 2: ANZHFR DATA VARIABLE CHECKLIST

The provision of ANZHFR data for the data variables listed below is subject to the approval of the Data Custodian Australia and Data Custodian New Zealand, via the ANZHFR Steering Group, and a relevant Human Research Ethics Committee. The list below includes all variables since inception (ANZHFR Data Dictionary v8.1 to current) including variables that have been retired (and their date of retirement) as well as new variables and their date of inclusion. Variables that may identify individual participants or hospitals have not been included in the checklist.

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

	Variable	Date of inclusion	Date of retirement/inclusion	Comments	Justification
☐	Age - derived	01/01/2015 DD v8.1			
☐	Sex of person	01/01/2015 DD v8.1			
☐	Australian Indigenous status**	01/01/2015 DD v8.1			
☐	NZ ethnic status	01/01/2015 DD v8.1			
	Patient's postcode (Aus)/ domiciliary code (NZ)	01/01/2015 DD v8.1			
☐	Patient type	01/01/2015 DD v8.1			
☐	Usual place of residence	01/01/2015 DD v8.1			
☐	Facility ID (random allocation)	01/01/2015 DD v8.1			
☐	Admission via ED of operating hospital	01/01/2015 DD v8.1			
☐	ED / hospital arrival date (transfer hospital)	01/01/2015 DD v8.1			
☐	ED arrival time (transfer hospital)	01/01/2015 DD v8.1			
☐	ED / other ward arrival date (operating hospital)	01/01/2015 DD v8.1			
☐	ED / other ward arrival time (operating hospital)	01/01/2015 DD v8.1			
☐	ED departure date (operating hospital)	01/01/2015 DD v8.1			
☐	ED departure time (operating hospital)	01/01/2015 DD v8.1			
☐	In-patient fracture date	01/01/2015 DD v8.1			
☐	In-patient fracture time	01/01/2015 DD v8.1			
☐	Pain assessment	01/01/2017 DD v9.1	01/01/2017 (new)		
☐	Pain management	01/01/2017 DD v9.1	01/01/2017 (new)		
☐	Ward type	01/01/2015 DD v8.1			
☐	Pre-admission walking ability	01/01/2015 DD v8.1			

Australian & New Zealand Hip Fracture Registry

	Variable	Date of inclusion	Date of retirement/inclusion	Comments	Justification
☐	**Pre-operative cognitive assessment**	01/01/2017 DD v9.1	01/01/2017 (new)	Coding frame options changed 01/01/2018 and 01/01/2021. Refer to DD v10.2 and DD v13	
	Preoperative AMTS	01/01/2015 DD v8.1	31/12/2016 (retired)		
☐	**Pre-admission cognitive status**	01/01/2015 DD v8.1		Variable name changed on 01/01/2018. Previously Pre-operative cognitive status Coding frame options changed 01/01/2017 and 01/01/2018. Refer to DD v9.1 and DD v10.2	
☐	**Bone protection medication at admission**	01/01/2015 DD v8.1			
☐	**Pre-operative medical assessment**	01/01/2015 DD v8.1			
☐	**Side of hip fracture**	01/01/2015 DD v8.1			
☐	**Atypical fracture**	01/01/2015 DD v8.1			
☐	**Type of fracture**	01/01/2015 DD v8.1			
☐	**Surgical repair**	01/01/2015 DD v8.1		Coding frame options changed 01/01/2021. Refer to DD v13	
☐	**ASA grade**	01/01/2015 DD v8.1			
☐	**Clinical frailty scale**	01/01/2021 DD v13	01/01/2021 (new)		
☐	**Date of surgery for hip fracture**	01/01/2015 DD v8.1			
☐	**Time of surgery for hip fracture**	01/01/2015 DD v8.1			
☐	**Surgery delay**	01/01/2015 DD v8.1		Coding frame options changed 01/01/2017. Refer to DD v9.1	
☐	**Type of anaesthesia**	01/01/2015 DD v8.1		Coding frame options changed 01/01/2017. Refer to DD v9.1	

	Variable	Date of inclusion	Date of retirement/inclusion	Comments	Justification
☐	**Analgesia – nerve block**	01/01/2015 DD v8.1			
☐	**Consultant surgeon present**	01/01/2015 DD v8.1			
	Type of operation performed	01/01/2015 DD v8.1			
☐	**Intraoperative fracture**	01/01/2015 DD v8.1	31/12/2017 (retired)		
☐	**Full weight bear**	01/01/2015 DD v8.1			
☐	**First day mobilisation**	01/01/2015 DD v8.1		Coding frame options changed 01/01/2019 Refer to DD v11	
☐	**New pressure injuries of the skin**	01/01/2015 DD v8.1			
☐	**Assessed by geriatric medicine**	01/01/2015 DD v8.1			
☐	**Geriatric medicine assessment date**	01/01/2015 DD v8.1			
☐	**Specialist falls assessment**	01/01/2015 DD v8.1			
☐	**Bone protection medication at discharge from acute hospital**	01/01/2015 DD v8.1			
☐	**Delirium assessment**	01/01/2018 DD v10.2	01/01/2018 (new)		
☐	**Clinical malnutrition assessment**	01/01/2019 DD v11			
☐	**First day walking**	01/01/2020 DD v12	01/01/2020 (new)		
☐	**Discharge date from acute ward**	01/01/2015 DD v8.1			
☐	**Discharge destination from acute orthopaedic episode**	01/01/2015 DD v8.1			
☐	**Discharge from hospital date**	01/01/2015 DD v8.1			
☐	**Length of stay (operating hospital)**	01/01/2015 DD v8.1			
☐	**Length of stay (health system)**	01/01/2015 DD v8.1			
☐	**Discharge place of residence**	01/01/2015 DD v8.1			
☐	**Survival at 30 days^^**	01/01/2015 DD v8.1	31/12/2018 (retired)		
☐	**Date health system discharge at 30 day follow-up^^**	01/01/2015 DD v8.1	31/12/2018 (retired)		
☐	**Place of residence at 30 day follow-up^^**	01/01/2015 DD v8.1	31/12/2018 (retired)		
☐	**Full weight bear at 120 day follow-up^^**	01/01/2015 DD v8.1	31/12/2018 (retired)		
☐	**Post-admission walking ability at 30 day follow-up^^**	01/01/2015 DD v8.1	31/12/2018 (retired)		

Australian & New Zealand Hip Fracture Registry

	Variable	Date of inclusion	Date of retirement/inclusion	Comments	Justification
	Bone protection medication at 30 day follow-up^^	01/01/2015 DD v8.1	31/12/2018 (retired)		
☐	**Re-operation within 30 day follow-up^^**	01/01/2015 DD v8.1	31/12/2018 (retired)	Coding frame options changed 01/01/2017. Refer to DD v9.1	
☐	**120 day follow-up date^^**	01/01/2015 DD v8.1			
☐	**Survival at 120 days^^**	01/01/2015 DD v8.1			
	Date health system discharge at 120 day follow-up^^	01/01/2015 DD v8.1			
	Place of residence at 120 day follow-up^^	01/01/2015 DD v8.1			
☐	**Full weight bear at 120 day follow-up^^**	01/01/2015 DD v8.1	31/12/2019 (retired)		
	Post-admission walking ability at 120 day follow-up^^	01/01/2015 DD v8.1			
	Bone protection medication at 120 day follow-up^^	01/01/2015 DD v8.1		Coding frame options changed 01/01/2020. Refer to DD v12	
☐	**Re-operation within 120 day follow-up^^**	01/01/2015 DD v8.1		Coding frame options changed 01/01/2017. Refer to DD v9.1	
☐	**Preliminary date of death**	01/01/2020 DD v12	01/01/2020 (new)		
☐	**Final date of death**	01/01/2020, collected via linked data	01/01/2020 (new)		
☐	**Underlying cause of death**	01/01/2020, collected via linked data	01/01/2020 (new)		
☐	**Other cause of death**	01/01/2020, collected via linked data	01/01/2020 (new)		
☐	**EQ5D5L (optional collection)**	01/01/2020 DD v12	01/01/2020 (new)		

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

^^Access to 30-day data and 120-day data will be assessed on a case by case basis due to data quality issues

Other / Comments