

## AUSTRALIAN AND NEW ZEALAND COLLABORATIVE PERFUSION REGISTRY

### Data Access and Publication Policy

Access to information collected and collated by the Australian and New Zealand Collaborative Perfusion Registry (ANZCPR) is guided by strict protocols and procedures to ensure that privacy and other ethical principles are maintained at all times. Provision of data to the ANZCPR is subject the study protocol which has been submitted to all hospital ethics committees. In particular, specific measures have been put in place to maintain the confidentiality of personal identifying information.

This document outlines the Australian and New Zealand Collaborative Perfusion Registry Data Access and Publication Policy, as agreed to by the ANZCPR Steering Committee.

1. Access to the data is subject to the Specific Access Guidelines given on the next page;
2. Only staff who report directly to the Principal Investigator of the ANZCPR have direct access to the data base;
3. All uses of the ANZCPR, in whatever context, must receive prior approval from the ANZCPR Steering Committee to access data unless a project falls within the scope of an institutional quality assurance activity. Specific hospital ethics committee approval is required for all research activity.
4. Any material to be published using the ANZCPR data must be seen by the ANZCPR Steering Committee before it is released for publication;
5. Under no circumstances will individually identifiable unit record data be made available to third parties;
6. In general, requests from contributing clinicians and academic organisations will be fulfilled without charge. Request from other bodies are considered on a case-by-case basis by the ANZCPR Steering Committee, and may be subject to a processing fee;
7. All third party requests for access to ANZCPR data must take appropriate timelines into account as these requests will need to be scheduled along with routine ANZCPR tasks. As a general rule, requests for tabulated data will take 6-8 weeks to complete. All other requests must be first made to the Project Manager, ANZCPR who will then table such request at the next Steering Committee meeting. Steering Committee meetings are held annually and on an ad-hoc basis as requested. Data cannot be extracted until approval is given. However when data is required outside these timelines, the Project Manager may request out of session approval by the Steering Committee;
8. All data requests must be formally lodged via email to [richard.newland@sa.gov.au](mailto:richard.newland@sa.gov.au) or post to: Project Manager, Mr Richard Newland, ANZCPR, c/- Cardiac Surgery Research and Perfusion, Flinders Medical Centre, Flinders Drive, Bedford Park SA 5042 or fax to: 08 8404 2019.

## SPECIFIC ACCESS GUIDELINES

### Data Access Process

1. All requests for data must be in writing to the ANZCPR Project Manager using the Release of Data Application Form.
2. The ANZCPR Project Manager will take the data request to the next Steering Committee meeting. A decision on whether to grant access to the data will be considered following advice from the Steering Committee.
3. Contributing hospitals have access to their own case-level data. The release of these data must be authorised by the local investigator according to institutional policy.
4. If a researcher requires data from a particular hospital or hospitals, a specific ethics application approval from that hospital(s) will be required before data is able to be made available. This ethics approval should be made jointly with the ANZCPR.
5. Where tabulated summary data is requested, this information can be provided by ANZCPR staff. Such provision of data would not require Steering Committee advice but ANZCPR will require a formal request in writing and will keep a record of such requests. The Steering Committee will be given a summary record of such requests on an annual basis.

### Privacy Restrictions

6. The Commonwealth Privacy Act impacts on release of some forms of data. In particular, individually identifiable data will not be released.
7. If a third party research or student project requires individual data for linkage, this will not be provided directly. However, it may be possible for the third party to provide their data to the ANZCPR for linkage purposes and for the ANZCPR to provide aggregate data summaries based on the linked data. All such projects will require separate ethics committee approval from each hospital involved.
8. Data is released for the specific purpose set out in the Release of Data Application Form; use for any other purpose is not permitted without prior approval by the ANZCPR Steering Committee.

### Publication

9. If data from the ANZCPR is the primary source for a report or publication, a copy of this must be submitted to the ANZCPR Steering Committee prior to its publication. It is a condition of use of ANZCPR data that the source of the data is acknowledged, along with a statement that the analysis and interpretation are those of the author, not the ANZCPR (see Attribution of publications section below).

## Attribution of publications

10. Where a member of a participating hospital has analysed data provided by the ANZCPR and subsequently prepared a manuscript, then "Australian and New Zealand Collaborative Perfusion Registry" should be acknowledged as a secondary institution in addition to the author's Hospital or University. This applies whether the primary data analysis is performed by the author or by ANZCPR staff.
11. Where ANZCPR data is only a minor portion of the work, then it may be more appropriate to acknowledge the source explicitly in the "Acknowledgements" section.

In both cases the disclaimer below should be included.

*The data reported here have been supplied by the Australian and New Zealand Collaborative Perfusion Registry. The interpretation and reporting of these data are the responsibility of the Editors and in no way should be seen as an official policy or interpretation of the Australian and New Zealand Collaborative Perfusion Registry.*

12. In all cases the source and treatment of the data should be made clear in the "Methods" section. Preferably the abstract (and keywords if applicable) should also include "Australian and New Zealand Collaborative Perfusion Registry" which would allow for searching Registry publications.
13. Authorship Policy: The ANZCPR contributing site principal investigators and data managers should be acknowledged on all publications. Where the publication primarily is of a Registry nature the contributing site principal investigators and data managers should be offered authorship. Where the number of authors exceeds the Journals maximum number the group may be included as *for the Australian and New Zealand Collaborative Perfusion Registry contributors*.

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This Policy has been ratified by the Australian and New Zealand Collaborative Perfusion Registry Steering Committee on:        \_\_/\_\_/\_\_\_\_.

Signed: \_\_\_\_\_

Associate Professor Robert A Baker  
Chief Investigator, Australian and New Zealand Collaborative Perfusion Registry