

## **GUIDELINES FOR ACCESS TO DATA COLLECTED BY THE BURNS REGISTRY OF AUSTRALIA AND NEW ZEALAND (BRANZ)**

Access to burns data collected and collated by BRANZ is guided by strict protocols and procedures to ensure that privacy and other ethical principles are maintained at all times. Provision of data to BRANZ, particularly since patient consent is not obtained from the outset, is subject to strict guidelines and the study protocol as submitted to all participating hospitals and Monash University ethics committees. In particular, specific measures have been put in place to maintain the confidentiality of personal identifying information.

This document outlines BRANZ Data Access Policy, as agreed to by BRANZ Steering Committee. Access to data is subject to the approval of the Steering Committee.

## **FORMAL POLICY FOR DIRECT ACCESS TO, AND EXTRACTION OF, DATA FROM THE BURNS REGISTRY OF AUSTRALIA AND NEW ZEALAND**

The following data access policy has been adopted:

1. Access to the data is subject to the Specific Access Guidelines given on the next page.
2. Only BRANZ staff who report directly to the Chair of the BRANZ Steering Committee have direct access to Burns Registry of Australia and New Zealand database.
3. All uses of BRANZ, in whatever context, must receive prior approval from the Chair of the BRANZ Steering Committee. In some instances, specific hospital ethics committee approval is also required.
4. Any material to be published using BRANZ data must be seen by the BRANZ Steering Committee before it is released for publication.
5. Under no circumstances will individual unit record data be made available to third parties.
6. Only requests that meet Specific Access Guidelines 1 and 4 (see next page) will be provided free of charge, unless a large number of such requests are made. This will be reviewed periodically. The provision of data for all other data requests (specific access guidelines 2-3) will be subject to a fee-for-service. See Data Access Fees document for an explanation of these.
7. All third party requests for access to BRANZ data must take appropriate timelines into account as these requests will need to be scheduled along with routine BRANZ tasks. As a general rule, requests for data under Specific Access Guidelines 1 and 4 will take 2-4 weeks to complete. Data cannot be supplied within 2 weeks of a request. All other requests must be first made to the Chair of the BRANZ Steering Committee who will then table such request at the next Steering Committee meeting. Steering Committee meetings are held quarterly and data cannot be extracted until approval is given. Under exceptional circumstances, when data is required earlier, the Chair of the BRANZ Steering Committee may convene a 'special meeting' to consider specific data requests. Once approval has been received, it will take 2-4 weeks to supply the data.
8. All data requests must be formally lodged via email: [anzba.registry@monash.edu](mailto:anzba.registry@monash.edu).

## BRANZ SPECIFIC ACCESS GUIDELINES

1. Where only summary data is requested and this is available from the quarterly reports (after formal acceptance of the report by the Steering Committee which is usually 4 months after the end of the quarter), this information can be provided by BRANZ staff. Such provision of data would not require Steering Committee advice but BRANZ 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 a quarterly basis. A caveat and conditions of use statement will be provided with the data.
2. All requests for other aggregate data must be made in writing to the Chair of the BRANZ Steering Committee. The Chair 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. At no stage will data summaries that could identify hospitals or patients be provided. 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 BRANZ. A caveat and conditions of use statement will be provided with the data.
3. No requests by third parties for direct access to unit records will be approved under any circumstances as this contravenes confidentiality and data access policies as required under the privacy legislation and ethics agreements. However, researchers may request BRANZ to undertake specific analyses of data. In all cases, the researchers would be provided with aggregate data only. Once again, a formal written request needs to be made to BRANZ for subsequent advice from the Steering Committee. If a researcher requires analysis of data from a particular hospital or hospitals that is not covered by BRANZ ethics, a specific ethics application approval from that hospital(s) will be required before data can be made available. This ethics approval should be made jointly with BRANZ.
4. If a hospital makes a specific request for its own performance data or individual level data, this will be provided by BRANZ. All requests for this level data should be made by the Director of the unit or nominee in writing to the Chair of the BRANZ Steering Committee. Whilst such data requests would not require specific Steering Committee advice, BRANZ will notify the Steering Committee of such requests.