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 explicit 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 Head of the BRANZ have direct access to the BRANZ database.
3. It is essential that all data items listed on your Data Request Form have the same data item listed in your approved ethics application. If it is not clear that the requested data item(s) has been approved by an ethics committee, the item(s) cannot be provided.
4. Any material to be published using BRANZ data must be submitted for review by the BRANZ Steering Committee before it is released for publication. Any and all feedback provided by the Steering Committee in regards to appropriate acknowledgements and language used to describe BRANZ processes, data, and analyses must be incorporated (see Policy Guideline – BRANZ Acknowledgements for further details).
5. No requests by third parties for direct access to unit records that could identify hospitals or patients will be approved under any circumstances as this contravenes confidentiality and data access polices as required under the privacy legislation and ethics agreements. 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 a minimum of two to four weeks to complete. Data cannot be supplied within two weeks of a request. All data requests will be discussed by the BRANZ Steering

Committee at quarterly meetings or via email between meetings. Data will not be extracted until approval from the Steering Committee has been granted. Once approval has been received, it will take two to four weeks to supply the data.

6. For aggregate data requests, the BRANZ will employ both primary and secondary suppression for cells with small values (i.e., less than five [5]) to prevent the potential reidentification of individual patients in such requests. Primary suppression involves identifying and hiding cells with values less than five (5), while secondary suppression involves hiding the values of other cells to prevent recalculation of primary suppressed cells through subtraction.
7. All data requests must be formally lodged via email: anzba.registry@monash.edu.
8. Failure to adhere to the data access policy, acknowledgement guideline, and fee guideline may result in the requestor(s) being denied access to BRANZ data.

BRANZ SPECIFIC ACCESS GUIDELINES

1. Where only summary data is requested and this is available from the Annual Report (after formal acceptance of the report by the Steering Committee), 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 in writing to the Chair of the BRANZ Steering Committee. The Chair of the BRANZ Steering Committee 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 polices as required under the privacy legislation and ethics agreements. However, researchers may request BRANZ staff 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 the 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 Head 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.
5. As per the BRANZ Data Sovereignty Policy, any data requests seeking access to First Nations data collected and stored by the BRANZ will be required to have the approval of both appropriate Indigenous representatives as a part of the BRANZ Steering Committee review and a local Indigenous Human Research Ethic Committee (HREC) as well as approval of community elders. Confirmation/evidence that approval by a HREC which confirms that the design, methods, and analysis of the research are appropriate for First Nations people as individuals and communities must be included with any data access requests.