

Australian Trauma Registry

Data Access Policy

Access to major trauma data collected and stored by the Australian Trauma Registry (ATR) is guided by strict protocols and procedures to ensure that privacy and other ethical principles are maintained at all times. Provision of data to is subject to strict guidelines, as per the study protocol that has been submitted to all collaborating sites and ethics committees. The Collaboration Agreement also requires certain conditions and legal obligations to be met.

Data submitted to, and stored by, the ATR is not identifiable at a patient level. It is re-identifiable by the submitting site at an institutional level for quality assurance purposes only. Thus identifiable records will never be available. Data that is identified as having originated at a specific institution will not be released without authorised, written permission by that institution, which authorship of any resulting publication will reflect accordingly.

This document outlines the ATR Data Access policy, as agreed to by the ATR Steering Committee. Each data request is subject to the required process and will be individually assessed.

Policy for direct access to, and extraction from, the Registry

- Access to the data is subject to the Specific Access Guidelines below.
- Only ATR staff who report directly to the Co-ordinating Investigator have direct access to the Registry database.
- All uses of the Registry, in whatever context, must receive prior approval from the Co-ordinating Investigator and/or the Steering Committee. In some instances, specific hospital ethics committee approval is also required.
- Any material to be published using ATR data must be seen by the ATR Steering Committee before it is released for publication.
- The interpretation of the data will be reviewed and approved by the ATR Steering Committee prior to publication.
- Researchers will be advised whether the data request is subject to Section 8 of the Collaboration Agreement. See Item 2 of the Specific Access Guidelines.
- De-identified aggregate data will be provided to researchers subject to ethics approval for their project.
- Only requests that meet Specific Access Guidelines 1 and 4 will be provided free of charge. The provision of data for all other data requests will be subject to a fee-for-service. Refer to the Fees for Provision of Data document for an explanation. Fees will be reviewed and updated periodically.

- All third party requests for access to ATR data must take appropriate timelines into account as these requests will need to be scheduled along with routine ATR tasks. The ATR Data Manager will circulate the request to the ATR Steering Committee members for out of session approval. Data cannot be extracted until approval is given. Under exceptional circumstances, when data is required earlier, the Co-ordinating Investigator may convene a 'special meeting' to consider specific data requests. Once approval has been received, an estimate will be given as to when the data will be supplied. The time frame will depend on the complexity of the request and the current workload.
- All data requests must be formally lodged via email to the ATR Data Manager (emily.mckie@monash.edu) or post to: Emily McKie, ATR Manager, Department of Epidemiology and Preventive Medicine, Monash University, Level 3, 553 St Kilda Road, Melbourne, VIC 3004.

Specific Access Guidelines

1. Where only summary data is requested and this is available from the quarterly reports, this information can be provided by the ATR. Such provision of data would not require Steering Committee approval but the ATR 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 ATR Data Manager, on the specified form. The request will be circulated to the Co-ordinating Investigator and the Steering Committee members. 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 the relevant HREC will be required before data can be made available. This ethics approval should be made jointly with authorised, written specific permission as per Section 8 of the Collaboration Agreement. A caveat and conditions of use statement will be provided with the data.
3. Direct access to unit records is not possible and no such requests will be approved. However, researchers may request the ATR to undertake specific analyses. In all cases, the researchers would be provided with aggregate data only. A written request should be made to the ATR in the usual way, and will be submitted to the Steering Committee for advice and approval.
4. If an institution makes a specific request for its own performance data, this should be provided by the ATR. All requests for this level data should be made in writing to the ATR Data Manager, with accompanying authorisation from the site Principal Investigator to establish bonafide. Whilst such data requests will not require specific Steering Committee approval, the Co-ordinating Investigator will sight and authorise the request. The ATR will maintain a log of such requests and table it routinely at Steering Committee meetings.