

Data Curation Policy



Policy for curation of and access to data collected on Registry members

We are asking researchers to deposit data collected on Registry members with TRA for curation so as to generate and facilitate future collaborations and research. The lodgement of data generated by research groups with TRA is outlined in the Working with TRA Guidelines and included in the Access and Services Agreement signed by TRA and researchers.

Depositing cleaned data

- Researchers will deposit data, along with coding and other relevant information, with TRA once it has been cleaned or at a later date agreed between researchers and the TRA.
- Researchers maintain ownership of the data unless otherwise agreed.
- Data will become available for re-use or held back for an exclusivity period of two years if researchers have requested this in the original Agreement.

Exclusivity period– *2 years from when data was deposited with TRA*

- Data will be embargoed for two years from when deposited with the TRA.
- If another researcher requests access to study data, TRA will inform the original researchers.
- At the end of the exclusivity period, the researcher can request an extension detailing why the request has been made.

Data access through collaborative agreement

- Researchers will be provided with details of all applications to TRA to access the data they collected on Registry members for collaborative purposes. The TRA will ask researchers to approve or deny the request.
 - TRA will facilitate discussion between researchers where required.
 - TRA will ask researchers to justify any denials of data access

- Researchers will have the right to earn authorship on publications resulting from the analysis of their data
 - TRA will discuss authorship agreements with both parties under the conditions outlined in the Vancouver Protocol (see below).
- Any research using deposited data must obtain ethics approval from an approved Australian Human Research Ethics Committee.
- The original researchers and TRA must be acknowledged in any publications or presentations, as outlined in the *Working with TRA Guidelines*.
- Publications and presentations resulting from new analysis of the deposited data must be given to TRA to report to funding bodies and for distribution to Registry members (website, E-Bulletin etc.), as in the *Working with TRA Guidelines*.

Extract from the Vancouver Protocol:

'All persons designated as authors should qualify for authorship. Each Author should have participated sufficiently in the work to take public responsibility for the content.'

'Authorship credit should be based on substantial contributions to:

- 1. Conception and design or analysis and interpretation of data*
- 2. Drafting the article or revising it critically for important intellectual content*
- 3. Final approval of the version to be published*

Participation solely in the acquisition of funding or the collection of data does not justify authorship.'

If the TRA is unable to re-contact researchers

- Following a request to access data, TRA will take all available steps to contact researchers.
- If researchers cannot be contacted, TRA will seek advice on data access from the original Human Research Ethics Committee.

Curation of and access to data

- All data, including coding and other relevant information, will be stored on a secure sever within the University of Melbourne. Access to this secure sever will be limited to the Informatics Manager, TRA Manager, Study Coordinator and Project Support Officer.

- All researchers (including those from within TRA) wanting to access deposited data must submit an application through TRA's standard application process outlined in the Working with TRA Guidelines.
- All researchers with approval to access deposited data must enter into an Access and Services Agreement with the University of Melbourne prior to release of the data.
- If a member of the TRA Advisory Board, management team or staff is involved in a request for access they are excluded from the review process. Please see the TRA Conflict of Interest statement on website <http://www.twins.org.au/about-us/governance/structure>