



**TEN to
MEN**

The Australian Longitudinal
Study on Male Health
tentomen.org.au



Ten to Men: The Australian Longitudinal Study on Male Health

Data Access Policy (June 2019)

1. Terms and Definitions

Australian Data Archive: national service provider responsible for the providing access to datasets through a platform called Dataverse.

Data: Research data captured by the *Ten to Men* study instruments. All data has been confidentialised to ensure anonymity of respondents.

Restricted Release Dataset: While all datasets have been confidentialised, there are fewer restrictions on the data available in the Restricted Release dataset. Access to this dataset may be granted where the researcher can demonstrate a genuine need for the additional data and that they meet the necessary additional requirements. **Overseas users are not eligible to apply for this dataset.**

General Release Dataset: The data available in this dataset has been more heavily confidentialised. Some information available in the restricted release dataset is not available in this dataset. All researchers are eligible to apply for access to this dataset.

Data Access Team: *Ten to Men* personnel responsible for administering data access requests and the provision of data.

Data Access Committee: The body responsible for reviewing and approving data requests.

Lead Investigator: Researcher responsible for overseeing a research project.

External administrative dataset: A dataset containing information from an external data source – Medicare Benefits Scheme, Pharmaceutical Benefits Scheme and National Death Index.

Metadata: Contextual information about the *Ten to Men* datasets primarily documenting the research datasets, including data dictionaries.

Personal information: Data that may identify a study participant.

Research Project: Individuals conducting approved research projects using *Ten to Men* research data.

Researchers: Individuals using *Ten to Men* data for research purposes

2. Background

- 2.1. *Ten to Men* is a publicly-funded resource to be used for the purpose of furthering the public good with a particular emphasis on expanding the knowledge base on male health and supporting policy and program development in male health.
- 2.2. *Ten to Men* data are available for use in projects that are scientifically and ethically sound as defined by the NHMRC Code for the Responsible Conduct of Research.
- 2.3. *Ten to Men* data will not be made available for commercial purposes/benefits.
- 2.4. The Australian Institute of Family Studies manages access to *Ten to Men* data.
- 2.5. This policy applies to researchers seeking access to the following datasets:
 - Research data from the *Ten to Men* questionnaires (General Release or Restricted Release);
 - External administrative datasets containing data from external sources, such as Medicare Benefits Scheme (MBS), Pharmaceutical Benefit Scheme (PBS) and National Death Index (NDI).
- 2.6. This policy should be read in conjunction with the Terms and Conditions of Data Use which details the conditions for use of *Ten to Men* data.
- 2.7. Approval of requests for *Ten to Men* data will be via a process that is transparent, accountable and equitable.

3. Data Access – General Conditions

- 3.1. The privacy of study participants is to be protected at all times.
- 3.2. Personal or identifiable information of *Ten to Men* participants is not available.
- 3.3. Researchers affiliated with a University or recognised research institution or research organisations, government department or enrolled Research students are eligible to access *Ten to Men* data. Overseas users are not eligible to apply for the Restricted Release dataset.

- 3.4. Requests can be made for data for research projects, and in-principle approval to include *Ten to Men* data in research funding applications.
- 3.5. Research projects must meet the public good criteria, be scientifically and ethically sound and contribute to the knowledge base on male health as described in the study aims and objectives.
- 3.6. Access is limited to those researchers named in an approved request.
- 3.7. Researchers must provide the Study with a written update on the progress of the Project **each year**. Progress updates will include the stage of the Project, relevant data outputs and dissemination. Researchers who continue to disseminate findings through presentations or publications are deemed to be current data users and therefore annual progress reports are required.
- 3.8. Researchers must notify the Study in writing to confirm that they are no longer using the data. This includes:
 - No longer conducting analyses if the data or producing outputs;
 - No longer producing publications or reports using the data; and
 - No longer presenting findings using the data.

Researchers will need to complete a short End-of-Project form to verify this.

4. Data Access Procedure – Research Project

- 4.1. The data request process is managed by the Australian Institute of Family Studies.
- 4.2. A Request for Data Access Form must be submitted.
- 4.3. The Request Form includes the following:
 1. Project title;
 2. 100 word lay summary of the proposed project;
 3. Project outline describing the background and significance of the project, main research questions and relation to the aims of *Ten to Men*;
 4. Intentions to combine external data sources to *Ten to Men* data (excluding the administrative datasets offered for access by the Study);
 5. Brief analysis plan;
 6. Time frame and funding;

7. Expected research outputs;
 8. Details of data storage and access management arrangements;
 9. Proposed outputs;
 10. Name, contact details and signature of lead investigator, and supervisor for student projects;
 11. Details of all other researchers requiring access to the data;
 12. External administrative datasets requested.
- 4.4. The Request for Data Access Form should be submitted to the *Ten to Men* AIFS Data Manager at ttmdatamanager@aifs.gov.au.
- 4.5. The review process comprises two stages: a Technical and Administrative Review and a Data Access Committee review.
- 4.6. Requests will be approved by the AIFS Data Access Review Committee. The Committee will convene every two months to process requests. The review process will take up to 8 weeks from the date of receipt of the request.

Technical and Administrative Review

- 4.7. Requests undergo initial review by the AIFS *Ten to Men* Data Access Team for completeness, eligibility and general feasibility based on the information provided in the Request for Data Access Form.
- 4.8. Requests that are incomplete, or where further information is required to assess eligibility or feasibility, will be returned with a request for additional information.
- 4.9. Researchers are responsible for ensuring that *Ten to Men* data are suitable for the proposed Project. The *Ten to Men* data dictionaries, data books and questionnaires are available at <http://www.tentomen.org.au/index.php/researchers.html> to aid in evaluating the suitability of Ten to Men data for proposed Projects.
- 4.10. Researchers may request additional information to assist in evaluating suitability. If substantial data manipulation or analyses are required to provide that information Researchers may be asked to cover costs.
- 4.11. Projects will not be formally assessed with respect to overlap or duplication. However, in order to avoid duplication of effort information on previous and currently approved Projects is provided at <http://www.tentomen.org.au/index.php/researchers.html>. It is the researchers'

responsibility to assess potential overlap and to revise their research questions accordingly to avoid duplication with already approved projects.

4.12. Following successful Technical and Administrative review, requests will progress to the Data Access Committee review.

Data Access Committee Review

4.13. The Data Access Committee comprises members of the *Ten to Men* project team with expertise in a wide variety of population and health fields, survey methodology, research and analysis, and statistical sciences.

4.14. Each request will be independently reviewed by all members of the Committee.

4.15. Requests will be reviewed against the following criteria:

- Serves the public good/relates to Ten to Men objectives;
- Data is fit for purpose;
- Strength/feasibility of the hypothesis/research questions;
- Research plan is achievable;
- Appropriateness of proposed methodology;
- Appropriateness of principles and practices to handle research datasets while maintaining the anonymity of information.

4.16. The Committee may approve, deny, or request further information.

4.17. The Data Access Review Committee will provide their feedback and final decision to the Data Access Team to communicate the outcome to the Lead Investigator.

4.18. All approved data users are required complete and sign a Data User Agreement and Deed of Confidentiality. This will be provided to the Lead Investigator via email. The Lead Investigator is responsible for ensuring that each researcher named on the application completes their own Data User Agreement and that this is returned via email to the Data Manager.

4.19. The Data Manager will facilitate delivery of the data for approved requests through the Australia Data Archive.

5. Research Funding Applications

- 5.1. Researchers seeking to include the future use of *Ten to Men* data as part of a research funding application are required to complete the Request for Data Access Form.
- 5.2. The Request for Data Access Form and any related documentation should be submitted via email to the Data Manager at ttmdatamanager@aifs.gov.au.
- 5.3. Requests to use *Ten to Men* data in future research projects are subject to the same criteria as described above in Section 3.2.3.
- 5.4. Following the technical and administrative review the *Ten to Men* Data Access Review Committee will review requests.
- 5.5. If the review is favourable, in-principle approval to use *Ten to Men* data will be granted.
- 5.6. In-principle approval does not result in release of *Ten to Men* data. It merely approves the inclusion of *Ten to Men* as a data source in a funding application.
- 5.7. Should the funding application subsequently be successful, the researchers must follow the standard data access procedures as described in Section 3 and 4 to obtain access to *Ten to Men* data.

6. External Administrative Datasets

- 6.1. *Ten to Men* provides Researchers with the opportunity to apply for external administrative datasets containing Medicare Benefits Scheme (MBS), Pharmaceutical Benefits Scheme (PBS) and National Death Index (NDI) data.
- 6.2. The process to access to external administrative datasets is currently under review. For further information, contact the Data Manager at ttmdatamanager@aifs.gov.au.

7. Ethics Approvals

- 7.1. Existing Australian Institute of Family Studies Human Research Ethics Committee approval is considered sufficient to use *Ten to Men* data to contribute to the knowledge base on male health as described in the study aims and objectives and no additional ethics documentation is required.



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8. Fees and charges

- 8.1. Approval of data requests are subject to researchers having the requisite funding to conduct the project and to meet any applicable fees and charges for use of the study resource as outlined above.

