

## **Policies and Procedures: Access to MSOD Data for a Data Linkage**

### **Study**

Data linkage studies involve the linkage of other databases with the MSOD Project database. Researchers must demonstrate why the linkage of these databases is beneficial and how participant confidentiality and anonymity will be maintained. Other considerations include feasibility, scientific value, consistency with the overall aims of MSOD and logistical requirements.

Data linkage studies should be undertaken using the approach outlined by Kelman, Bass and Holman<sup>1</sup>, which states:

- Accuracy of linkage is generally increased when all available means of identification are used;
- A linkage key file should be generated, essentially linking the databases using available means of identification;
- Where possible, the individual/s creating the linkage key file should not be involved in analysis, in order to protect confidentiality and anonymity of participants;
- The use of personal identifiers should be limited to the initial linkage stage of research and removed thereafter, unless they are essential to the research question.

The full paper by Kelman et al should be read and integrated into research methodology where appropriate at the time of application.

Please note a fee may be incurred on a cost-recovery basis if significant additional MSOD resources are required to complete the request for data. Contact the MSOD Secretariat for details.

### **Process**

The general process for conducting a data linkage study using MSOD data is as follows:

1. Researchers must read this document, the paper by Kelman et al, and complete an Expression of Interest form.
2. The MSOD Research and Scientific Advisory Committee will assess the application.
3. Once the application is successful, a contract is signed.
4. Ethics approval must then be sought from relevant institutions as appropriate. This can be a lengthy process and applicants are advised to speak with the relevant ethics committees to familiarise themselves with the process before submitting an EOI to MSOD.

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<sup>1</sup> Kelman, C.W; Bass, A. J. & Holman, C. D. J (2002) 'Research use of linked health data – a best practice protocol', *Australia and New Zealand Journal of Public Health*, 26 (3), pp.251-255

5. Progress reports are provided to the MSOD Research and Advisory Committee at pre-defined intervals.
6. The MSOD Research and Scientific Advisory Committee is informed of any changes to the study as they occur.
7. Any resultant papers, reports, publications etc., along with the appropriate acknowledgements, are provided to the MSOD Research and Scientific Advisory Committee for approval prior to submission.

## **Participants**

Data linkage studies can be managed in one of two ways:

1. By MSOD – where the MSOD Data Manager manages the combined, de-identified dataset and provides the researcher with the required dataset with the unique link numbers attached.
2. By the researcher – where data are provided to the researcher as separate, de-identified datasets by the data custodian/s, with the unique link numbers attached, the researcher links the datasets and is the only person to hold the complete linked data.

Where information about participants (such as contact details, withdrawal from MSOD) is found to be different from that provided by MSOD, details must be passed on to the MSOD office for its records.

## **Data**

Data are provided either in spreadsheet form or as tab delimited text files. Data files include all survey items and derived variables approved for release on a project-by-project basis. The MSOD Data Dictionary provides a detailed description of survey questions, their source, how they are used and information regarding the derived and calculated variables. Data should be used according to standards established and defined in the Data Dictionary, unless a variation is approved. All data provided will be cleaned, and protocols for the cleaning process will be made available to researchers. It is the responsibility of the analyst to become familiar with and carefully examine the data prior to analysis.

The first variable in each file is the Study ID, which is a unique participant identifier. Data are compiled in such a way as to ensure confidentiality and anonymity, thus some survey items (such as birth date, country of birth, language spoken at home) may be removed or aggregated. Such data will only be available if relevant to the specific research proposal and with appropriate ethics approval.

Requested data will be released after the MSOD Research and Scientific Advisory Committee approves the study and once all Human Research Ethics requirements are fulfilled. Data may not

be used for any purposes other than those approved by the MSOD Research and Scientific Advisory Committee and cannot be passed on to third parties. Data must be securely stored where it is accessible only to the researcher/s.

Once analysis is complete, data files must be removed from the computer on which they were stored and archived on a CD in accordance with scientific research guidelines. This will be confirmed in writing upon completion of the research and stored at the MSOD office.

### **Questionnaires and Variables**

MSOD questionnaires (Commencing Student Questionnaire, Exit Questionnaire and PGY1/Intern Questionnaire), a full list of MSOD variables, and a collection schedule for future questionnaires are available on the MSOD website: <http://www.medicaldeans.org.au/medical-schools-outcomes-database>. Some questionnaires have undergone minor modifications between collections, thus it is imperative the researcher correctly identifies the corresponding questionnaire for the data requested.

### **Acknowledgement and Publication**

All publications, revisions and resubmissions (including accompanying paperwork such as author approval forms) must be approved by the MSOD Research and Scientific Advisory Committee prior to submission. A hard or soft copy of the published paper must be provided to MSOD for its records.

The following statement acknowledging MSOD must be included in all publications and approved by the MSOD Research and Scientific Advisory Committee with the proposed publication:

*The research on which this paper/book/monograph/report/presentation was based on data provided by the Medical Schools Outcomes Database (MSOD) Project, Medical Deans Australia and New Zealand. We are grateful to the Australian Government Department of Health and Ageing for funding the project and to the medical students/graduates/doctors who participated.*

### **Privacy, Confidentiality and Anonymity**

All research and studies associated with the MSOD Project must comply with the Information Privacy Principles, Section 14 of the Privacy Act 1988 (and future amendments) and the National Privacy Principles (contained in the 2000 Amendment to the Act). Copies of these documents can be found on the Privacy Commission website ([www.privacy.gov.au](http://www.privacy.gov.au)) or provided by MSOD upon request.

Anonymity and confidentiality of subjects must be preserved in all analyses and publications. This applies to individual participants and subgroups. Identification of individual medical

schools can only be made after permission has been given by Medical Deans Australia and New Zealand, as well as the Deans of the affected medical schools.

### **Human Research Ethics**

The MSOD Project has been granted ethics approval from all participating medical schools for data linkage studies between MSOD and the medical register. Other data linkage studies may require additional ethics approval from the researcher's host institution Human Research Ethics Committee as well as the Human Research Ethics Committee of other institutions from which participants are sourced.

Obtaining ethics approval for data linkage studies can be a lengthy process due to the number of bodies from which approval needs to be sought and the additional risk of compromising confidentiality and anonymity of participants. Generally the researcher must obtain ethics approval from the primary ethics committees overseeing all database studies, as well as liaise with the management committee/s for the database studies – that is, the data custodians. In the case of the MSOD Project, the relevant ethics committees will be those from which participants are sourced (anywhere from one to 18 medical schools) and the data custodian is the Medical Deans Australia and New Zealand.

It is the researcher's responsibility to ensure all ethics requirements are fulfilled.

### **Ownership and Intellectual Property**

MSOD data is owned by Medical Deans Australia and New Zealand (Inc.). Appropriate acknowledgement must be made in any research which utilises MSOD data. Research carried out using MSOD data is the intellectual property of the researchers who conduct the study.