



## AMSLS DATA LINKAGE INFORMATION SHEET

Thank you for being part (or considering to be part) of the Australian MS Longitudinal Study (AMSLS). We would like your permission to link data from external sources with your AMSLS data. This information sheet provides the details needed to make an informed decision about that request.

For general information about the AMSLS, please see the AMSLS Information Sheet on [www.msra.org.au/AMSLS](http://www.msra.org.au/AMSLS).

### What is data linkage?

Throughout our lives, information is collected about our health and health care. This information is collected by hospitals, health departments and other groups or organisations that provide health services. The collection of this information is usually required by law and is securely stored by the service or agency that collects it.

Data linkage is a way of connecting information held by different groups or services in a way that protects a person's privacy. Being able to link data can be very useful in health research including MS. It is cost-effective because we are re-using data that is already collected, and it is non-intrusive because we don't have to obtain already collected information again. Thus, it will create new research opportunities without the need for additional surveys.

Through data linkage we would bring information from other sources into the AMSLS study.

### What are the benefits of linked data?

The data sources that will be linked with the AMSLS data will be used to answer new research questions. For example, by linking prescribed medication data from the Pharmaceutical Benefits Scheme (PBS), we can examine trends in MS drug utilisation, and associations between drug use and disease outcomes. Linking with clinical MS information from neurologists via e.g. MSBase will allow us to examine relapse and disability data or carefully examine factors that might influence the relapse rate. In addition, you may have participated in genomic studies where a large amount of genetic data (gene markers or gene expression markers) are generated. It would be highly beneficial to join those data in order to examine patterns with disease outcomes. Some linkages will only become useful after many years as the events do not occur frequently, such as cancers (Australian Cancer Registry) or deaths (National Death Index). However, in order to create these linkages in the future, it is beneficial to obtain consent at this point in time.

### What external data sources could be linked?

There are potentially a large number of external data sources that we could link with and it is hard to envisage all possible options. Below are a number of datasets where data linkage will be useful, either in the short-term or the long-term.

#### Commonwealth data sources

The Australian Institute for Health and Welfare, in its capacity as an Integrating Authority, is authorised to link several Commonwealth datasets but doesn't actually hold the data:

- **Pharmaceutical Benefits Scheme (PBS)** – The PBS consists of data of current and historical prescriptions that are subsidised by the Government under the scheme.
- **Medicare Benefits Schedule (MBS)** – The MBS contains data on medical and hospital services that are subsidised by the Government under the scheme.

## Contact

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- **Australian Cancer Database (ACD)** – The registration of cancers by doctors is compulsory. Cancer data is collected by State Cancer Registries who supply the data to the Australian Institute for Health and Welfare. Data includes type of cancer, age/date of diagnosis, and country of birth.
- **National Death Index (NDI)** – Mortality data is collected by Registries of Births, Deaths and Marriages, the Australian Bureau of Statistics and the National Coroners Information System. The Australian Institute for Health and Welfare maintains the National Mortality Database and the National Death Index. Data includes date/age of death and cause of death code.

## State data sources

Some databases need to be linked at the state level:

- **Morbidity and emergency department data** – Each hospital collects a number of sets of data (emergency department data, hospital admission data). This database contains data on episodes of care in public and private hospitals in Australia (e.g dates of stay, principle diagnosis, co-existing diagnoses, complications).

## Clinical MS data (MSBase)

Your neurologist may collect clinical information about you in a database that is linked with an international database called MSBase. This information could include data on the treatments being used, relapses experienced, severity of MS symptoms, disease onset and diagnosis and type of MS.

## Data sources from other research studies

You might have participated in other studies where detailed data was collected such as genetic, gene expression, or metabolomics data. Often these studies do not have detailed data on the disease course. Linking the datasets will provide important new research opportunities.

## How does the linkage process work?

The process of linkage will be somewhat different for each dataset.

## Commonwealth data sources

For many Commonwealth datasets, a designated Data Linkage Unit will conduct the linkage. Both sources (AMSLS and other source) will separate identifying data from other content and send the identifiers to the Data Linkage Unit. The identifiers from both sources (e.g. person identifier, surname, given name, date of birth, sex, address) will be used to create a link. The goal is to link records belonging to the same individual together, with minimal miss-links (as few as possible linkages being made for records that actually belong to different individuals). Once a link is established, the record will receive a unique Project Person Linkage ID (PPID) number. Because data changes over time (e.g. surname and postcode) and errors in spelling may have occurred, a perfect match may not always occur. The likelihood of a perfect match can be estimated and checks will be carried out if there is uncertainty about the link.

Once the link is established, both sources will be provided with their source person identifiers as well as the PPID. Anonymised content data is then provided to the AMSLS study including the PPID number, which the AMSLS can link to their data using the PPID number. In order to improve the matching process with the Department of Human Services (MBS/PBS) databases, we are requesting your Medicare number.

### State data sources

Some databases will need to be linked at a state level. A state Data Linkage Unit will conduct the data linkage in a similar way as described above.

### Clinical MS data (MSBase)

For clinical MS data, the process will be different. The treating neurologist is the custodian of the patient's data. The AMSLS participant data linkage consent (+AMSLS ID number) will be sent to their treating neurologist. With their approval, they allow the patient to become part of the AMSLS sub-study within MSBase. Once that is achieved, MSBase data from these AMSLS participants can be obtained and linked to the AMSLS study.

### Data sources from other research studies

Depending on the data set-up of each individual study, a similar system that maintains confidentiality and is secure will be designed. The Tasmanian Data Linkage Unit will assist where required.

### What are the benefits for me?

At this stage, it is not likely that there will be any direct benefits to you.

### Confidentiality, Data Security and Destruction of Data

*Confidentiality* – In some instances Independent Data Linkage Units from the government or university will be used to create the Linkage ID numbers. These Data Linkage Units will receive personal identifiers but never have access to any content data. Content data from other data sources will always be received without personal identifiers. In other instances, data requests will be made to an organisation, for example the Department of Human Services for PBS/MBS data who will approve the project. We will send the minimum number of personal identifiers and they will deliver the requested data after creating the match with the identifiers.

*Data security* – All received data will be stored in close proximity to the AMSLS data on secure university servers. This data will only be accessible by AMSLS staff. Many suppliers of data will not allow the data (even without personal identifiers) to be passed on to a third party such as our research collaborators. In the event that it is allowed, strict data release agreements will limit the use of this data and ensure that the data is used in an ethical manner. As with all AMSLS results, study results are published in scientific journals, as reports and/or summarised in AMSLS newsletters. Results may also be presented at conferences, meetings and workshops. In all cases, only group results are reported and individuals will not be identified.

*Destruction of data* – In principle, the AMSLS study does not destroy its data as it is a longitudinal study where the value of the data increases over time. However, some suppliers will have different rules and we will conform to those rules. Currently, the Department of Human Services (PBS/MBS data) requires that all confidential information supplied by them be destroyed 10 years from the date of supply or 7 years from the publication of the final project report. However, further approval for retention of data may be sought after this time.

### Ethics and withdrawal of data linkage consent

AMSLS data linkage has been approved by the University of Tasmania Tasmanian Health and Medical Human Research Ethics Committee. Consent for data linkage is voluntary and will not influence your participation in the Australian MS Longitudinal Study surveys. If you decide to withdraw the data linkage consent at a later time, release of the external data and its use in the AMSLS study will cease.

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from the date of withdrawal. If you have concerns or complaints about the conduct of the studies, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au).

## Next Step

Please complete two forms:

1. The [AMSLS Data Linkage Consent Form](#) to indicate whether you approve or do not approve to linking external data with AMSLS data.
2. A separate [PBS/BMS Consent Form](#) authorising the study access to your complete Medicare and Pharmaceutical Benefits Scheme (PBS) data as outlined on the back of the consent form. Medicare collects information on your medical visits and procedures, and the associated costs, while the PBS collects information on the prescription medications you have filled at pharmacies. The consent form is sent securely to the Department of Human Services who holds this information confidentially. We will request data annually or less frequently, covering PBS/MBS use over the next 10 years (31/12/2016-31/12/2026). The first extraction will include data from the 4.5 years prior to date of extraction.

If the forms are not provided, they can be downloaded from [www.MSRA.org.au/AMSLS](http://www.MSRA.org.au/AMSLS).

If you have any questions or enquiries, please email or call.

*Email: [AMSLS.info@utas.edu.au](mailto:AMSLS.info@utas.edu.au)*

*Phone: 03 6226 4739*

*Thank you for being part of the Australian MS Longitudinal Study.*

## Definitions for Medicare and Pharmaceutical Benefits Scheme

Medicare (MBS)	Pharmaceutical Benefits Scheme (PBS)
<ul style="list-style-type: none"><li>• Date of service (Date that the service was rendered by the provider, to the patient)</li><li>• MBS Item number (Items Numbers as per the Medicare Benefits Schedule)</li><li>• MBS Item description (describes the service as per the Medicare Benefits Schedule)</li><li>• Provider charge (the dollar amount the provider charged for the service)</li><li>• Schedule fee (fee as listed in the Medicare Benefits Schedule i.e.: the Governments recommended fee for that service)</li><li>• Benefit paid (this is the benefit paid to the patient)</li><li>• Patient Out of Pocket (the dollar amount the patient is out of pocket)</li><li>• Hospital Indicator (Indication of whether or not the service was provided in hospital)</li><li>• Item category (where the service sits in the hierarchical structure according to the Medicare Benefits Schedule)</li></ul>	<ul style="list-style-type: none"><li>• Date of supply (Date the prescription was supplied by the pharmacy)</li><li>• PBS Item Number (Items Numbers reflected in the Pharmaceutical Benefits Scheme)</li><li>• PBS Item Description (the item description as noted in the Pharmaceutical Benefits Scheme)</li><li>• Patient category e.g. general, concession, safety net, doctor's bag (Patient's eligibility status at the time of supply)</li><li>• Patient contribution (the contribution paid by the patient)</li><li>• PBS Net Benefit (Amount paid by the Government)</li><li>• Scrambled Prescriber Number (<i>a unique scrambled number identifying the particular prescriber of the PBS item</i>)</li><li>• ATC Code (<i>the code allocated by the World Health Organisation Collaborating Centre for Drug Statistics Methodology</i>)</li><li>• ATC Name (<i>the group the drug falls under in the Anatomical Therapeutic Chemical (ATC) classification system</i>)</li></ul>