

AUSTRALIAN MS LONGITUDINAL STUDY INFORMATION SHEET

Multiple sclerosis (MS) is the most common disease of the central nervous system among Australians aged between 20-40 years. During MS, nerve fibres in the brain and spinal cord lose some of their surrounding insulating myelin casing. This means that the messages that normally travel along nerves are interrupted or changed leading to different amounts of disability. An increasing number of new treatments are becoming available for MS, but there is presently no cure.

The Australian MS Longitudinal Study (AMSLS)

The Australian MS Longitudinal Study (AMSLS) comprises a number of surveys each year about the social and medical consequences of living with MS. The results of these surveys are used for advocacy by MS Societies, and ultimately aim to improve the treatment and services for people with MS.

A few examples of the surveys are:

Prescription Benefit Scheme (PBS) medications and side effects survey. The collective results from this survey provide useful feedback to the doctors and other professionals to help improve the available treatments for MS.

Paid or voluntary employment is seen as an important factor in being part of the community, improving confidence and morale. The Employment survey collects important information about how MS affect a person and their family's income.

MS Research Australia and the Menzies Institute for Medical Research

The Australian MS Longitudinal Study and all its data are owned by MS Research Australia who are a non-profit, national incorporated entity. A Steering Committee at MS Research Australia makes sure that only useful data are collected in the Study. The Committee also ensures that the time for completing surveys by participants is kept to a minimum. Currently, around 4000 Australians have volunteered to complete AMSLS surveys.

Multiple Sclerosis Research Australia has contracted the Menzies Institute for Medical Research at the University of Tasmania to manage the Study. The AMSLS team at the Menzies works together with the MS Societies, as well as other researchers and stakeholders around Australia to get the most out of the data. The AMSLS team also produces newsletters, updates participant details and handles the day-to-day running of the Australian MS Longitudinal Study.

Eligibility

To join the AMSLS, you will need to be:

1. An Australian resident living in any State or Territory
2. Diagnosed with MS by a neurologist
3. 18 years or over.

It does not matter if your MS is mild, or not causing you any problems, you can still have useful input to AMSLS research.

How Surveys Are Conducted

The AMSLS team is shifting to online formats, with a paper-based option only available for those who are not in the position to complete online surveys. For online surveys, an email invitation containing a personalised link to the survey will be sent. Paper-based surveys are posted along with a reply paid envelope and entered manually into the secure database.

For the online system, we will use the University of Tasmania version of Lime Survey. Participants will be sent an email with a “token” or encrypted access code. This code is unique to an individual for a given survey. The code can be used offline to link anonymous surveys with data that is stored offline.

Privacy and Data Security

For people opting for paper based surveys, a letter containing their unique identification number. This number will need to be stored securely and entered on questionnaires you decide to complete.

For people opting for online surveys, best practices in online data security and encryption are used to collect survey responses. This includes SSL encryption, fire walls and survey tokens. The data of the completed surveys will be transferred securely (via an https web-link) and stored on secure university servers.

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.

Ethics Approval

All surveys are approved by the University of Tasmania Tasmanian Health and Medical Human Research Ethics Committee.

Participation in the Australian MS Longitudinal Study is voluntary, and you can elect to withdraw at any time, without giving a reason.

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.

Next Steps

1. Read and complete the Consent Form (provided, or can be downloaded from www.MSRA.org.au/AMSLS)
2. Once the Consent Form is received, you will be asked to complete a Demographic Questionnaire.
3. A Neurologist Questionnaire will be sent to your Neurologist to complete.
4. News of upcoming surveys will be posted on the following website www.MSRA.org.au/AMSLS, sent via email or newsletter depending on how you have opted to complete the surveys.

If you have any questions or enquiries, please email or call. Thank you for joining the Australian MS Longitudinal Study.