



## AMSLS CONSENT FORM for Data Linkage

Please read the AMSLS Data Linkage Information Sheet as this explains the process of data linkage and how confidentiality is ensured. This can also be downloaded from [www.msra.org.au/AMSLS](http://www.msra.org.au/AMSLS).

### By agreeing to AMSLS Data Linkage, I agree to:

- AMSLS researchers accessing my health-related data from the following external databases or organisations:
  - Medicare and Pharmaceutical Benefits Scheme datasets (PBS and MBS), hospital databases, clinical MS databases including MSBase, other research datasets, Australian Cancer Registry, National Death Index, and other health databases/datasets.
- The information will be collected, stored and analysed only for the purposes of the Australian MS Longitudinal Study.

### By agreeing to AMSLS Data Linkage, I acknowledge that:

- I have received, read and understood the AMSLS Data Linkage Information Sheet provided, which explains the process of data linkage, the possible databases/datasets to link with and how confidentiality is ensured.
- I have been given an opportunity to ask questions and understand that some personal identifiers will be sent to a designated Data Linkage Unit or supplier of information but this is not accompanied by content information.
- All identifying information will be removed before the data are analysed, and only grouped results from this research will be made public, both on the website of MS Australia and in appropriate publications.
- If I decide to withdraw my consent for my external data to be used in this study, release of the data and its use in the AMSLS study will cease from the date of withdrawal.
- Data linkage for the Australia Multiple Sclerosis Longitudinal Study has been approved by the University of Tasmania Medical Human Research Ethics Committee.
- Should I have any problems or queries about the way in which the Australian MS Longitudinal Study was conducted, and do not feel comfortable contacting either the research staff, I may contact the Tasmanian Health and Medical Human Research Ethics Officer on phone number 03 6226 7479 or email [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au)

### Agreement to AMSLS Data Linkage

I, \_\_\_\_\_ (Name of participant with MS)

(Please tick one).....

Agree to have external data linked to the AMSLS study

Do not agree to have external data linked to the AMSLS study

Signed: \_\_\_\_\_ (participant's signature)      Dated: \_\_\_\_\_ (DD/MM/YYYY)

## Participant details

AMSLS ID number (if known):     Date of birth:   /   /

Title: Mr  Mrs  Miss  Ms  Other

Address

Street address

Suburb

City

State

Postcode

For data linkage with MSBase, we require the following details:

Are you part of MSBase?  No  Yes  Don't know

MSBase ID number (if known):

## Neurologist details

Neurologist name

First Name

Last Name

Neurologist practice

Name of Practice/ Hospital

Address

Street address

Suburb

City

State

Postcode

## Proxy Details and signature

Please complete this section ONLY if you are filling in the form on behalf of the above participant with MS

Full Name

Street Address

Suburb

City

State

Postcode

Relative, carer, nurse etc... (if a relative please state relationship, e.g. wife, son etc...)

(Name of participant above/ person with MS)

Signed: \_\_\_\_\_

Dated: \_\_\_\_\_ (DD/MM/YYYY)

**PARTICIPANT CONSENT FORM**

Consent to release of Medicare and/or Pharmaceutical Benefits Scheme (PBS) claims information for the purposes of Australian Multiple Sclerosis Longitudinal Study (AMSLS).

**Important Information**

Complete this form to request the release of personal Medicare claims information and/or PBS claims information to AMSLS.

Any changes to this form must be initialled by the signatory. Incomplete forms may result in the study not being provided with your information.

By signing this form, I acknowledge that I have been fully informed and have been provided with information about this study. I have been given an opportunity to ask questions and understand the possibilities of disclosures of my personal information.

**PARTICIPANT DETAILS**

1. Mr  Mrs  Miss  Ms  Other

Family name: \_\_\_\_\_ First given name: \_\_\_\_\_

Other given name (s): \_\_\_\_\_

Date of birth: DD/MM/YYYY

2. Medicare card number: \_\_\_\_\_

3. Permanent address: \_\_\_\_\_

Postal address (if different to above): \_\_\_\_\_

**AUTHORISATION**

4. I authorise the Department of Human Services to provide my:

- Medicare claims history OR
- PBS claims history OR
- Medicare & PBS claims history

for the period\* 31/12/2016 to: 31/12/2026 to the AMSLS.

\*Note: The Department of Human Services can only extract 4.5 years of data (prior to the date of extraction), The consent period above may result in multiple extractions.

**DECLARATION**

I declare that the information on this form is true and correct.

5. Signed: \_\_\_\_\_ (participant's signature) Dated: DD/MM/YYYY **OR**

6. Signed by \_\_\_\_\_ (full name) \_\_\_\_\_ (signature) on behalf of participant

Dated: DD/MM/YYYY

- Parent (where the participant is under the age of 14 years old\*)
- Legal guardian\*\* (where the participant is under the age of 14 years old\*)
- Power of attorney\*\*  Guardianship order\*\*

\* Once a young person has turned 14 years old they must consent to their own information being released.

\*\* Please attach supporting evidence

## APP 5 – PRIVACY NOTICE

Your personal information is protected by law, including the Privacy Act 1988, and is collected by the Australian Government Department of Human Services. The collection of your personal information by the department is necessary for administering requests for statistical and other data.

Your information may be used by the department or given to other parties for the purposes of research, investigation or where you have agreed or it is required or authorised by law.

You can get more information about the way in which the Department of Human Services will manage your personal information, including our privacy policy at [humanservices.gov.au/privacy](http://humanservices.gov.au/privacy) or by requesting a copy from the department.

**Power of attorney** – A power of attorney is a document that appoints a person to act on behalf of another person who grants that power. In particular, an enduring power of attorney allows the appointed person to act on behalf of another person even when that person has become mentally incapacitated. The powers under a power of attorney may be unlimited or limited to specific acts.

**Guardianship order** – A Guardianship order is an order made by a Guardianship Board/Tribunal that appoints a guardian to make decisions for another person. A Guardianship order may be expressed broadly or limited to particular aspects of the care of another person.

A sample of the information that may be included in your Medicare claims history:

Date of service	Item number	Item description	Provider charge	Schedule Fee	Benefit paid	Patient out of pocket	Bill type
20/04/09	00023	Level B consultation	\$38.30	\$34.30	\$34.30	\$4.00	Cash
22/06/09	11700	ECG	\$29.50	\$29.50	\$29.50		Bulk Bill

Scrambled ordering Provider number*	Scrambled rendering Provider number*	Date of referral	Rendering Provider postcode	Ordering Provider postcode	Hospital indicator	Item category
	999999A		2300		N	1
999999A	999999A	20/04/09	2300	2302	N	2

\* Scrambled Provider number refers to a unique scrambled provider number identifying the doctor who provided/referred the service. Generally, each individual provider number will be scrambled and the identity of that provider will not be disclosed.

A sample of the information that may be included in your PBS claims history:

Date of supply	Date of prescribing	PBS item code	Item description	Patient category	Patient contribution (this includes under copayment amounts**)	Net Benefit (this includes under copayment amounts**)	Scrambled Prescriber number*	Pharmacy postcode
06/03/09	01/03/09	03133X	Oxazepam Tablet 30 mg	Concessional Ordinary	\$5.30	\$25.55	9999999	2560
04/07/09	28/05/09	03161J	Diazepam Tablet 2 mg	General Ordinary	\$30.85		9999999	2530

Form Category	ATC Code	ATC Name
Original	N05 B A 04	Oxazepam
Repeat	N05 B A 01	Diazepam

\* Scrambled Prescriber number refers to a unique scrambled prescriber number identifying the doctor who prescribed the prescription. Generally, each individual prescriber number will be scrambled and the identity of that prescriber will not be disclosed.

\*\* Under co-payments can now be provided for data after 1 June 2012