AMSLS NEWS

Australian MS Longitudinal Study (AMSLS)

November 2025

2025 was the year of the launch of *InforMS*, a new Health Economic Impact report, including some findings from the NDIS survey, and the development of pain resources. Read on for the highlights, and more!

Frontiers in MS Research Symposium

MS Australia's inaugural research symposium was held in Sydney on 29 November 2024, with the key themes of PREVENT | DETECT | MANAGE. The symposium highlighted groundbreaking research on MS prevention, early detection and highly effective treatments, with innovation being driven by global collaborations. Professors Bruce Taylor and Ingrid van der Mei of the Menzies Institute for Medical Research were invited speakers at the symposium.

In his keynote speech, Bruce gave insights into how the overall burden of MS could be significantly reduced through prevention efforts, emphasising the critical role of epidemiology in understanding the disease.

In a session on 'Improving Quality of Life in MS', Ingrid presented on pain in MS, with a focus on specific pain types. The findings are the result of ongoing analysis of data from the AMSLS 2021 Pain Survey, which showed that almost 53% of respondents experience regular pain, with 20% experiencing 5–10 different pain types. Ingrid highlighted how invaluable the AMSLS data is for leveraging policy-making decisions and informing research that directly benefits the MS community.

MS AUSTRALIA

AUSTRALIAN MS LONGITUDINAL STUDY

Our AMSLS community has decreased in recent years.

Can we call on you to recruit someone else?

For anyone to join, go to:

www.msaustralia.org.au/AMSLS

Need to contact us?

✉ **AMSLS.info@utas.edu.au**

☎ **(03) 6226 4739**

We are always happy to hear from you!

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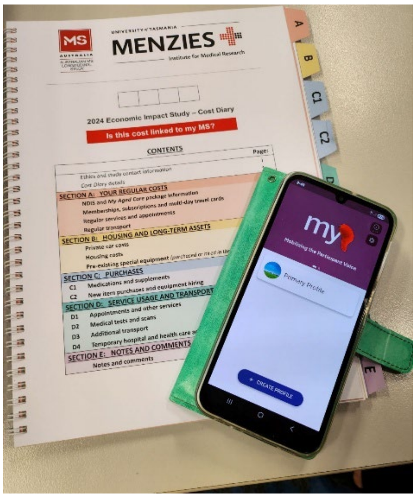
Health Economic Impact of MS in Australia in 2024 for MS Australia



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2024 Economic Impact Study – Cost Diary

Is this cost linked to my MS?

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NDIS and My Aged Care package information

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Regular transport

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Housing costs

Pre-existing special equipment (purchased or hired in th

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Notes and comments

We are excited to announce that the new health economic impact of MS report, prepared by our team at Menzies, will be launched by MS Australia at its **Progress in MS National Conference in December 2025.**

Importantly, we would like to extend a big thank you to AMSLS participants who have made this report possible by completing their cost diaries over a six-month timeframe, consenting to data linkage, and/or completing other important surveys about employment and the National Disability Insurance Scheme (NDIS) that have informed the report.

AMSLS participants may recall that this is the fourth iteration of the health economic impact report (2010, 2017, 2021).

This current report examines in detail the health economic impact of MS in Australia in 2024 and includes important findings about prevalence, quality of life and the cost of MS. It also includes new information about employment impacts for people living with MS and the NDIS.

We found that the total costs to society are still increasing because more people in Australia have MS but, for the first time, the costs per person have not further risen. This might be due to the increased use of effective disease-modifying therapies.

This evidence has informed a wide range of recommendations, including the need for treatments that halt neurodegeneration, which will specifically benefit people with progressive MS. The recommendations will be used for advocacy work with policy and decision makers to raise awareness and increase resourcing for MS.

To find out more about the findings, see the MS Australia website (www.msaustralia.org.au) or social media feed for the formal launch between 3 and 5 December 2025.

InforMS – your new MS health app – has launched!

In mid-September *InforMS* – our new web-based MS-management app – was launched to AMSLS participants, inviting them to have exclusive access as part of the ***InforMS* Improvement Project**.

InforMS will:

- allow you to have all your health information in one place, to avoid having to retell your personal story to health professionals
- enable you to visualise your responses from AMSLS surveys that you have completed
- give you the opportunity to add new health data, upload health documents and synchronise data from other apps and wearables
- put you in the driver's seat to decide what health information you wish to share with health professionals
- provide you with access to evidence-based health information
- be able to assist you with setting health goals and reaching them.

Participants in the *InforMS* Improvement Project are given the opportunity to access the app via their web browser and provide feedback on its usefulness and any ways in which it could be improved. The research project will run for two to three years, after which we hope to roll out the app to all Australians with MS.

This work is jointly funded by the National Health and Medical Research Council (NHMRC) and MS Australia, Grant ID 1193008. The views expressed may not reflect those of the NHMRC or MS Australia.

> *"The biggest benefit for me is to have at the click of a button all my MS information to see how I'm tracking."* – Melissa Quirk, *InforMS Steering Committee member and person with MS*

We would like to hear your thoughts on a new AMSLS research idea!

We are considering expanding the AMSLS to include genetic research. This would involve sending a saliva test kit in the post, where you would spit into a sterile tube and return it to us using a reply-paid envelope.

Complete the upcoming *2025 Disease Course Survey* to provide your thoughts on this idea!

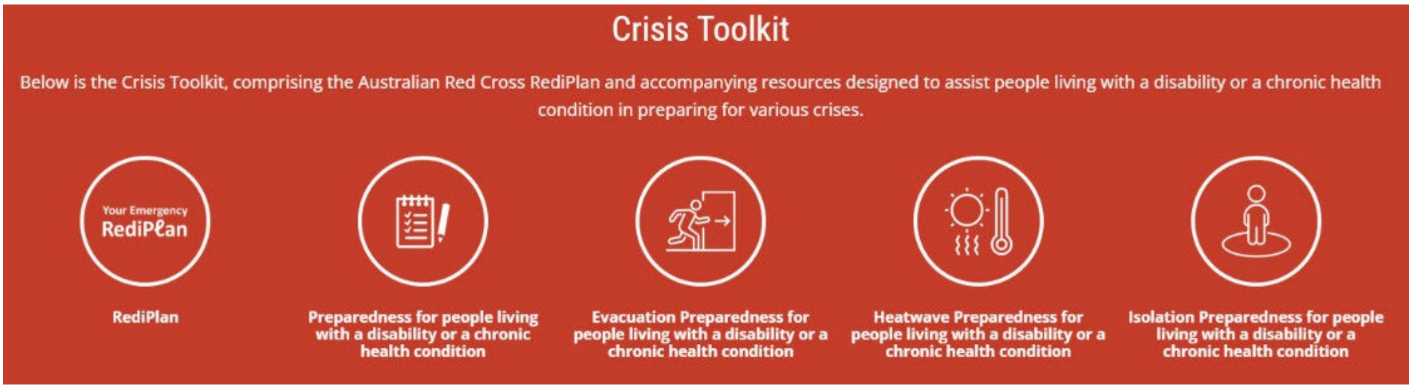
Dr Nicholas Blackburn, geneticist

MS Australia Crisis Toolkit

Data from the AMSLS has contributed to the development of an important new Crisis Toolkit, which is hosted on the MS Australia website (https://www.msaustralia.org.au/crisistoolkit/).

In collaboration with Dr Yvonne Learmonth from Murdoch University and Dr Claudia Marck from the University of Melbourne, AMSLS participants were asked questions in the *2020 Lifestyle and Environment Survey* about ways that the impact of crises, such as pandemics, bushfires and floods, can potentially be reduced. Data from this survey showed that over a third of people living with MS would like to develop or update their crisis plans, and that a third of those need help with this. Yvonne and Claudia developed a toolkit for people with MS, based on the Australian Red Cross RediPlan, by collaborating with the Red Cross, MS community stakeholders and researchers.

Initial evaluations of the toolkit have been positive and have identified that crisis preparation actions were more successful when completed with support from an MS Nurse. Users of the toolkit can complete a feedback survey to share their thoughts and experiences.



Crisis Toolkit

Below is the Crisis Toolkit, comprising the Australian Red Cross RediPlan and accompanying resources designed to assist people living with a disability or a chronic health condition in preparing for various crises.

MS Trial Screen

Dr Laura Laslett and Professor Ingrid van der Mei of the AMSLS have led the development of **MS Trial Screen**, an online tool that helps match people with MS to selected Australian MS clinical trials. By registering and completing the screening survey, you'll find out if you're eligible to take part.

MS Trial Screen is a key part of the Australian MS Clinical Trials Platform (AMSCTP) hosted by MS Australia (www.msaustralia.org.au/amsctp/). The AMSCTP is a national initiative that brings together people with MS, researchers and clinicians, to fast-track MS clinical trial activity in Australia.

The platform currently supports three clinical trials – PLATYPUS, STOP-MS and FIRMS-EBV – with plans to expand.

Launched in May 2025, MS Trial Screen securely stores your information. If you are not eligible for any current trials, you will be notified when new trials open or eligibility criteria change.

To find out more and to access the online survey, go to MS Trial Screen: https://redcap.utas.edu.au/surveys/?s=NEPYCDDNRKKHTRTL.

Update on the *2025 NDIS Survey*

A research project led by Menzies researcher Professor Bruce Taylor is evaluating the impact of the National Disability Insurance Scheme (NDIS) on Australians living with MS.

The first phase of this study involved the *2025 NDIS Survey* that was distributed to AMSLS participants in March. We received 1,289 responses, representing an overall response rate of 56%. Just under half of respondents (46.2%) had experience applying for an NDIS plan. This likely reflects the median age of respondents (62 years), as the NDIS is only available to Australians under the age of 65 at the time of application.

The statistical analysis of this survey data is currently underway, and results will be first presented at MS Australia's Progress in MS Research Conference being held in Brisbane in December 2025.

In addition to the AMSLS survey, 30 in-depth interviews were conducted with people living with MS, carers and healthcare professionals about the ups and downs of applying for, and managing, an NDIS plan. The data from these interviews is currently being analysed and highlights will also be presented at the conference in December.

> *"When [the NDIS are] good, they're brilliant but it requires patience and you have to work for it and have a good support team behind you." – Bree-Arne*

MS and sleep

Information from AMSLS participants has contributed to three recent papers on MS and sleep published by Menzies researchers Dr Laura Laslett, Mr Tadeg Amare and Dr Baye Mekonnon. The research was based on the *2020 MS Nurses and Sleep Survey* and the *2022 Sleep Survey*.

Tadeg's paper explored treatment strategies used by people living with MS to get to sleep or stay asleep, and if they worked. Half (56%) of respondents reported using 'sleep hygiene' behaviours (such as limiting caffeine use or screen time), and 40% reported using medications to get to sleep or stay asleep. However, most medications had no significant impact on sleep quality or daytime sleepiness. The research suggested that there is more work to do in linking individuals with therapies that might improve their sleep.

Baye's paper explored the impact of poor sleep on productivity at work. Poor sleep worsened symptoms such as fatigue, cognitive function, pain and sensory symptoms, which in turn impacted productivity at work. These findings suggest that improving sleep may improve productivity at work.

Laura's paper looked at how we might be able to capture people's experience of MS symptoms holistically, by looking at multiple MS symptoms together rather than focusing on each symptom on its own. She found that there were four distinct symptom subgroups. The first three subgroups had: generally a low severity of symptoms; generally a moderate severity of symptoms; and generally a high severity of MS symptoms. The fourth subgroup was quite different, with only mild anxiety and depression symptoms, yet moderate severity of most other symptoms. This group had a better quality of life than would be expected from the symptom burden of their other MS symptoms. The research suggested that managing anxiety and depression well has beneficial effects on quality of life, even in people with significant MS symptoms, and that sleep is a key invisible symptom of MS.

Polypharmacy in people with MS

Menzies Research Fellow Dr Ting Zhao has conducted a review examining how often people with MS are prescribed multiple medications and what factors contribute to this. Using data from the Pharmaceutical Benefits Scheme (PBS) linked to consenting AMSLS participants, the study focused on polypharmacy; that is, the use of five or more medications prescribed at least four times a year.

Ting's work showed that in 2022, 24% of participants met this definition. Not surprisingly, polypharmacy was more common among older individuals, those with greater disability, and those with other health conditions.

Over time, we can see that polypharmacy rates increased by 4.5% per year on average. The review concluded that people using five or more medications may benefit from a formal review of their medications.

A paper on the study has been submitted to the *Journal of Multiple Sclerosis and Related Disorders.*

MS Caregivers and People Providing Support (MS-CaPPS) pilot study

Some of you were invited to participate in the MS-CaPPS pilot study, where we investigated the feasibility of adding a linked group of supporters and carers to the AMSLS. We invited a random sample of 160 AMSLS participants to complete a Support Team survey, where participants were asked about the family members and friends who were part of their support team. Additionally, we asked them to nominate supporters and carers who might be interested in participating in the study. AMSLS participants who nominated people were sent packs to pass on their loved ones. The aim of approaching supporters and carers was to understand their support roles, how their roles changed over time, and the impact that MS has had on them. The pilot study allowed us to evaluate whether supporters and carers were interested in participating, whether the questions and scales that we were using were suitable and whether our research aims aligned with the views of supporters and carers. This was important to know prior to rolling this out to all AMSLS participants.

We found that insufficient supporters and carers were interested in participating. Firstly, among those completing the survey, 71% of AMSLS participants did not nominate supporters or carers, for reasons such as not feeling comfortable nominating them, feeling it might too much of a burden or because they would probably not be interested. Among the supporters and carers who were invited, only 18% took up the opportunity.

While this was not the outcome we were hoping for, this information was important. Dr Julie Campbell is currently developing a Massive Open Online Course (MOOC) for supporters and carers. We have decided to add an optional research layer to this MOOC. This will hopefully still allow us to understand more about the impacts of MS on people's loved ones.

Coming soon

The AMSLS is changing!

Upcoming changes being phased in over the next year for the AMSLS will include:

- **a move to REDCap for online surveys**
- **introducing an option to update infrequently changing information as needed**, rather than completing answers each time
- **a complete overhaul of AMSLS enrolment.**

We always need the voice of those in the study when we undertake major updates. To be part of our consumer working group, please reach out (AMSLS.info@utas.edu.au or (03) 6226 4739).

MS pain resources

Menzies Research Fellow Dr Alice Saul is leading the development of pain resources for people with MS, with data from the *2021 Pain Survey* making a significant contribution to the project. The information will be hosted on the MS Australia website, with separate webpages for people with MS (PwMS) and health professionals.

A downloadable pain communication flyer can be used by PwMS to assist them with talking about their pain with their healthcare team. It's designed to help people describe the type, intensity and impact of their pain, which will hopefully assist with finding the right support and management. Health professionals will be encouraged to display these flyers in clinic waiting rooms to help facilitate more effective pain-related conversations.

AMSLS Online

MS Australia
msaustralia.org.au

Recent AMSLS-linked content:

🔗 New crisis planning resources now available for people living with MS

🔗 The rising prevalence of MS across Australia's states and territories

🔗 Frontiers in MS Research: Driving Innovation and Collaboration for a Better Future for People with MS

AMSLS scientific publications:
🔗 msaustralia.org.au/AMSLS/key-findings

MS MASSIVE OPEN ONLINE COURSES (MOOCs)
ms.mooc.utas.edu.au

Participation is free, enrol any time

Understanding Multiple Sclerosis
Enrol now for the next course opening on 1 July 2026
Duration: Self-paced; 12 hours total

Deciding about DMTs for MS
Mental Health and MS
Ageing well with MS
Always open
Duration: Self-paced, 4-6 hours total

Participants needed

Telehealth study focusing on weight management in people with MS

Researchers at the University of Wollongong are seeking participants for HALT-MS, a lifestyle clinical trial combining diet, exercise and psychological support management of MS. The free program includes telehealth consultations over six months, with an additional six-month follow-up period, focusing on weight and MS symptoms. Participants will also contribute to new research on taste and the oral microbiome in MS.

To check if you meet the eligibility criteria please click on the following link: https://uow.au1.qualtrics.com/jfe/form/SV_22VJ8orz1gdArrg

For more information about the study, please contact halt-MS@uow.edu.au.

MS Sleep study

Menzies researchers are looking for adults living with MS in Tasmania to participate in a sleep study. Participation involves wearing an activity monitor (a research-grade FitBit) and recording your sleep and MS symptoms for three weeks. To learn more about the study, please click on the following link: https://redcap.utas.edu.au/surveys/?s=ATHJP8CLFY3PKCK8.

HeARTS study

Researchers at Murdoch University and James Cook University invite you to take part in the **pHysical Activity factoRs among people living with mulTiple sclerosis** (HeARTS) global study to understand physical activity participation in people with MS. The anonymous online survey takes around 30 minutes to complete and doesn't need to be finished in one go. Please follow the link to learn more, and complete the survey to fly the flag for Australia:

https://murdochuni.syd1.qualtrics.com/jfe/form/SV_0pLAeGeZ1Jpzsuq.

AMSLS focus for 2026

Topic	Details	Supporting survey(s)
InforMS Led by Professor Ingrid van der Mei and Dr Annie Brennan, Menzies Institute for Medical Research	*InforMS* has launched! We hope you will all try the web-app and give us your feedback via the *InforMS* surveys.	***InforMS* surveys**
Women's health Led by Dr Alice Saul, Menzies Institute for Medical Research	Women are more likely than men to get MS, and the disease can affect them differently. We want to understand why. To help with this, we'll run a survey that includes questions about reproductive health, including periods, menopause and conditions such as endometriosis.	**2026 Women's Health Survey (Jul–Aug)**
MS and the NDIS Led by Professor Bruce Taylor, Menzies Institute for Medical Research	The National Disability Insurance Scheme (NDIS) survey is being analysed to understand the good and the bad of the NDIS.	**2025 NDIS Survey (Mar–May)**
MS WorkSmart scales and health literacy	We will analyse the data of two bespoke scales, developed to measure the effectiveness of MS WorkSmart, to confirm they are fit for purpose.	**2025 Experiences of Work Survey (Jul–Aug)**

AMSLS research recognition and project funding

We would like to congratulate Glen Henson and Baye Mekonnon on being awarded their PhDs in May 2025. They obtained their doctorates largely using AMSLS data, which is a great outcome.

Three of our AMSLS collaborators were recognised for their outstanding work at the Menzies Institute for Medical Research annual excellence awards in April. Dr Julie Campbell and Dr Glen Henson received the 'Ten of the Best' award for their publication in *PharmacoEconomics*, which was judged to be one of the ten best papers from Menzies published in the last year. Dr Annie Brennan won a Professional Staff Award for her outstanding contribution to Menzies through her leadership and management of the *InforMS* project: https://www.msaustralia.org.au/news/informs-launches/.

We are also very pleased to announce that three AMSLS collaborators received MS Australia funding for their pioneering research.

Dr Glen Henson is using health economics to understand the global impact of MS and improve treatment policies. Find out more here: https://bit.ly/3WtjUGl. Dr Valery Fuh-Ngwa's research aims to understand disability progression in relapsing–remitting MS. Find out more here: https://bit.ly/4hyau5X. Dr Julie Campbell's team is investigating whether women and marginalised groups with MS in Australia earn less than men and exploring the reasons behind this wage difference. Find out more here: https://bit.ly/3LyUPYb.

Dr Laura Laslett received an MS Australia Incubator Grant to help answer the question 'Is using smart watches and symptom tracker apps feasible and acceptable?' for sleep research. Laura talks about her research project on MS Australia's The Raw Nerve podcast episode '2025 Incubator Grants: Novel research helping solve the MS puzzle' (https://bit.ly/452eWWd).

The AMSLS team thanks you for your ongoing support.
Together we can make a difference.