AMSLS NEWS



Australian MS Longitudinal Study (AMSLS)

November 2026

2026 was an active year of analysing data and planning for the future. In this newsletter, you will read about the NDIS, sleep, long COVID, *InforMS*, MS genetics and ageing.

MS health economic impact report

The *Multiple Sclerosis Prevalence and Health Economic Impact in Australia 2025* report, produced by the Menzies' MS Health Economics team using data from the AMSLS, was released in December 2025. Commissioned by MS Australia, this landmark report has already had a major influence on policy. Earlier this year, the Australian Government proposed removing the highly effective and widely used disease modifying therapies (DMTs) Ocrevus and Kesimpta from the Pharmaceutical Benefits Scheme (PBS). Findings from the report were cited by MS Australia in its campaign opposing the removal, which demonstrated the importance of these DMTs for thousands of Australians with MS. These findings showed the value of effective therapies in reducing disability, preserving workforce participation and reducing long-term costs to government. The campaign was successful, and both these therapies remain available through the PBS. **The full report can be found here:** https://www.utas.edu.au/ms-impact

Report authors (L-R): Professor Bruce Taylor, Dr Julie Campbell (lead report author), Professor Ingrid van der Mei and Dr Glen Henson (Photo credit: UTAS media resources team)



MS AUSTRALIA
AUSTRALIAN MS LONGITUDINAL STUDY

Help our community grow

Know someone else with MS? Invite them to join the Australian MS Longitudinal Study:

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!

UNIVERSITY of TASMANIA
MENZIES Institute for Medical Research

IMPORTANT NEWS: AMSLS survey revamp

As the AMSLS grows and evolves, we've moved to the REDCap survey system to make participation easier for you and data collection more efficient for us. This move offers several key benefits:

1. **One secure portal for all online surveys:** Instead of receiving a separate link for each survey, you'll have a single password-protected portal where you can access all active surveys at any time.
2. **Update your information instead of re-entering it:** REDCap allows us to carry forward many of your previous factual responses, so you can simply review and update them rather than entering the same information year after year. Less repetition for you and better data quality for us.
3. **Enhanced security:** We will not store any identifiable information in REDCap, such as your name, email address, initials, or date of birth. Within the system, you are only your study ID.

Our next step is a complete refresh of the enrolment process and baseline surveys. For existing participants, this will also include reconciling any gaps from previous surveys and renewing consent for our data linkage programs, which expire at the end of 2026.

Have you seen our recruitment campaigns?

Almost 300 new participants joined the AMSLS through our recent social media recruitment campaigns. A warm welcome to all new participants and thanks to those who helped spread the word. Continued recruitment is essential to keeping the study representative of Australians living with MS.

People interested in joining the AMSLS can learn more and register here:
https://www.msaustralia.org.au/amsls/#rego

Is the NDIS an equitable scheme?

A team led by Menzies researchers Dr Rebecca Banham and Professor Bruce Taylor investigated how the National Disability Insurance Scheme (NDIS) is working for Australians with MS. The *2025 NDIS Survey* received responses from 1,289 people, of whom 517 (40%) reported having a current or previous NDIS plan.

The findings suggest that access to the NDIS is largely being driven by need. People with moderate or severe disability, and those with progressive-onset MS, were more likely to have a plan. Reassuringly, factors such as sex, education, income and where a person lived didn't appear to influence whether they received an NDIS plan.

The median value of a participant's first NDIS plan was approximately $35,000 per year. Higher-value plans were generally associated with greater disability, being single and living in more socioeconomically disadvantaged areas.

Participants also shared their experiences of the NDIS through almost 3,000 written comments. Several common themes emerged:

- Many participants reported that the NDIS was life changing as it reduced financial strain, improved independence and helped them remain engaged in work, family life and their communities.
- The application and review processes were often described as complex, inconsistent and stressful.
- Some participants felt that MS was not always well understood and worried they were not viewed as "disabled enough" to qualify for support.
- Support from healthcare professionals, MS organisations, family members and friends was often crucial in giving people the confidence and information to apply for a plan, appeal decisions and advocate within the NDIS.



NDIS study team members (back row, L–R) Chris Gumley, Professor Bruce Taylor, Dr Rebecca Banham and (centre front) Meg Denham

Overall, the study suggests that NDIS plan allocation for people with MS is relatively equitable, with disability severity playing a much larger role than demographic factors. However, receiving a plan is only part of the story. Successfully navigating the NDIS often relies on communication skills, confidence in self-advocacy, and access to formal and informal support networks. These findings highlight the importance of ensuring that people with MS receive guidance and support throughout their NDIS journey.

Does sleep change over time?

Menzies researchers Mr Tadeg Amare and Dr Laura Laslett used information provided by AMSLS participants to investigate how sleep changes over time in people living with MS. Sleep problems are common in MS, but relatively little is known about whether sleep changes as the disease progresses.

The study examined sleep quality and daytime sleepiness over a two-year period among 1,238 AMSLS participants who completed sleep surveys in both 2020 and 2022.

Across the group as a whole, sleep quality remained stable over time, while daytime sleepiness improved slightly. Most participants experienced little meaningful change in either measure. Only 13% showed a substantial change in sleep quality, and only 8% experienced a meaningful change in daytime sleepiness over the two years. The researchers also explored factors that might predict changes in sleep. Higher levels of pain at the start of the study were associated with small improvements in sleep quality over time, while body mass index was linked to minor changes in daytime sleepiness. However, these factors explained only a small proportion of the differences observed between participants.

The findings suggest that sleep outcomes are relatively stable for many people with MS over a two-year period. They also highlight that sleep is likely influenced by a complex combination of biological, behavioural and environmental factors. Future research will examine sleep over longer periods and at different stages of the disease to better understand who is most likely to experience changes and whether there are opportunities to improve sleep and overall wellbeing for people living with MS.

InforMS: One Year On

It has been a year since *InforMS*, our web-based MS management app, was launched to AMSLS participants as part of the ***InforMS* Improvement Project**.



Over the past 12 months, more than 600 participants have explored the platform and provided valuable feedback. Newly recruited AMSLS participants have also been invited to access *InforMS* as one of the benefits of participating in the study.

Many participants have told us that tracking their health information over time has helped them better understand changes in their MS.

One participant shared:

"This is incredibly useful. I have been feeling a progression of disability with walking and can see this reflected in the data I have been filling out for the past two years. Very insightful!" — Yon

The impact of *InforMS* is now being formally evaluated using information collected throughout the project, including data from the 12-month follow-up surveys that are currently underway. These findings will help us understand how the platform is being used and identify opportunities to further improve the app.

We would like to thank all participants in the *InforMS* Improvement Project who have used the app and shared feedback over the past year. Your contributions are helping us better understand how digital tools can support people living with MS to monitor their health, recognise changes over time, and have more informed conversations with their healthcare team.

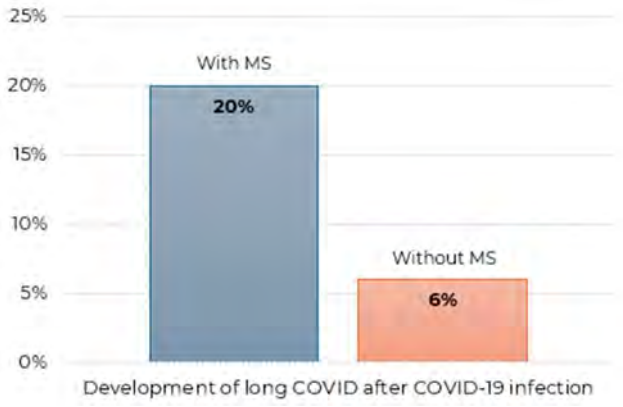
The *InforMS* Improvement Project will continue over the next one to two years, after which we hope to make the app available more broadly to Australians living with MS.

InforMS is jointly funded by the National Health and Medical Research Council (NHMRC) and MS Australia, Grant IDs 1193008 and 25-PFM-06-01. The views expressed here may not reflect those of the funding bodies.

More often long COVID?

Researchers from the Menzies MS Research Flagship, including Dr Julie Campbell and Dr Glen Henson, investigated how Australians living with MS were affected by long COVID. Long COVID refers to symptoms that persist for weeks or months after a COVID-19 infection and can include fatigue, shortness of breath, and difficulties with concentration and memory.

Data from the *2022 Disease Course Survey* showed that almost half (49%) of participants had experienced at least one COVID-19 infection. Among those who had been infected, 20% reported developing long COVID, compared with an estimated 6% in the general population.



Participants experiencing long COVID reported significantly worse MS symptoms and poorer quality of life. In particular, higher levels of fatigue, pain and anxiety were strongly associated with reduced health-related quality of life. These findings suggest that long COVID may place an additional burden on people already managing the challenges of living with MS.

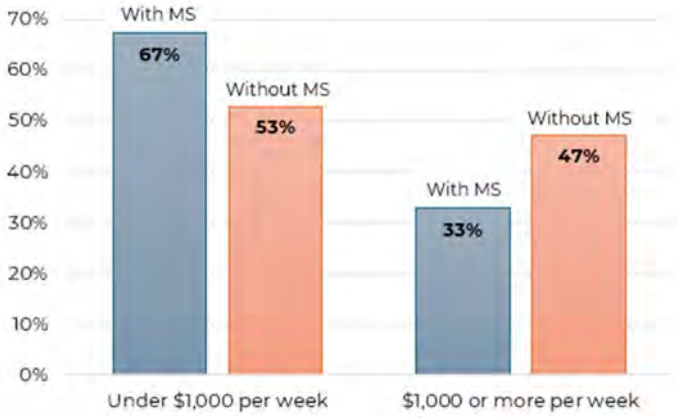
Interestingly, people with greater MS-related disability were less likely to report a COVID-19 infection, possibly because reduced mobility or retirement from the workforce resulted in fewer opportunities for exposure. However, disability was not clearly associated with the likelihood of developing long COVID.

Because many symptoms of long COVID overlap with those of MS, recognising and diagnosing long COVID can be challenging. Our findings highlight the importance of considering long COVID when assessing changes in symptoms and wellbeing, and ensuring that people with MS can access appropriate support and care.

Is there a double whammy for women?

MS is most commonly diagnosed between the ages of 20 and 40, a time when many people are building their careers and financial security. Researchers from the Menzies MS Health Economics team, led by Dr Julie Campbell and Dr Mustafa Kamal, together with collaborators from the University of Tasmania and Griffith University, analysed responses from 716 AMSLS participants who completed the *2023 Economic Impact Survey*. They compared the incomes and employment status of people with MS with those of a similar group of Australians without MS.

The findings showed that people living with MS were more likely to have lower incomes and be out of the workforce than those without MS. Around two-thirds (67%) of people with MS earned less than $1,000 per week, compared with just over half (53%) of those without MS. Similarly, 62% of people with MS were retired or not working, compared with 45% of the comparison group.



The study also found that women faced an additional disadvantage. Women were generally more likely than men to have lower incomes, regardless of whether they had MS. While MS reduced income opportunities for both women and men to a similar degree, women often started from a lower income base. This means that women with MS may have less financial capacity to absorb the impacts of illness, reduced work hours or unexpected expenses.

Importantly, among people with MS who remained employed, lower incomes were not primarily linked to taking sick leave or working while unwell. Instead, the strongest factor was changing jobs or careers because of MS, often into lower-paid roles. These findings highlight the importance of workplace supports, such as flexible hours and modified duties, that help people remain in their chosen careers for longer.

Understanding ageing with MS: what can the AMSLS tell us?

As people with MS are living longer and healthier lives than ever before, it is increasingly important to understand what ageing with MS looks like today.

One of the challenges in research on ageing is working out whether differences seen in older adults are truly due to ageing itself, or whether they reflect the different experiences of people born in different generations. For example, many older people with MS were diagnosed before highly effective disease-modifying therapies became available, and have lived through very different healthcare, disability support, employment and social environments compared with younger generations.

Using more than a decade of AMSLS survey data, Dr Laura Laslett will examine how MS symptoms and quality of life change as people age, and whether these patterns are driven by the biological effects of ageing, broader changes in healthcare and society or differences between generations of people living with MS.

The findings will provide new insights into what ageing with MS may look like for current and future generations of Australians with MS. This knowledge can help guide health service planning, identify groups who may need additional support, and contribute to strategies that help people with MS live well as they grow older. Importantly, this project relies on information already provided by AMSLS participants, demonstrating the ongoing value of your contributions to MS research.



AMSLS Online

MS Australia
msaustralia.org.au

Recent AMSLS-linked content:

🔗 Multiple sclerosis economic burden exceeds $3 billion as prevalence soars in Australia

🔗 People with MS experience pain more frequently than the general population, research reveals

🔗 Helping people with MS stay in the workforce

🔗 Research insights into MS, sleep and work productivity

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
Duration: self-paced; 12 hours total

Deciding about DMTs for MS
Mental Health and MS
Ageing Well with MS
Duration: self-paced, 4–6 hours total

Menzies Institute for Medical Research
MS Research Flagship's
Research with Connections 2026
https://www.youtube.com/playlist?list=PLDGZHVAwEc6m_IuSAzFwf5N5vrt3FhZno

Update on AMSLS genetics research

In the *2025 Disease Course Survey*, we asked whether participants would support AMSLS genetic research involving the donation of a saliva sample. The response was overwhelmingly positive, with 86% indicating they would be willing to take part and a further 7% unsure, most commonly because they wanted more information about privacy, sample storage and how genetic data would be used.

Should this research proceed, all participants would receive detailed information about the study and have the opportunity to make a fully informed decision about whether to participate.

For now, these findings provide valuable evidence of participant support as we seek funding for this important work.

The proposed research aims to improve our understanding of the genetic factors that influence MS progression, explore the genetics of the Epstein-Barr virus and its relationship to MS, and identify genetic markers that may help predict who is more likely to experience side effects from specific disease-modifying therapies. Ultimately, this research could contribute to more personalised approaches to MS treatment and care.

AMSLS focus for 2027

Topic	Details	Supporting survey(s)
InforMS Led by Professor Ingrid van der Mei and Dr Annie Brennan, Menzies Institute for Medical Research	*InforMS* evaluation: This will analyse the first feedback on the *InforMS* app.	***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. A new survey will include questions investigating reproductive health.	**2027 Women's Health Survey (Mar–May)**
Social determinants of health Led by A/Professor Claudia Marck, The University of Melbourne	This survey will explore how life circumstances – such as where you live, your work, finances, healthcare access and support from others – may influence living with MS.	**2027 Social Determinants of Health Survey (Jun–Aug)**
Understanding ageing with MS Led by Dr Laura Laslett, Menzies Institute for Medical Research	We want to understand why health and quality of life change as people age, and whether these changes are driven by ageing itself, improvements in healthcare and support, or generational differences amongst people living with MS.	**All Disease Course Surveys** **2025 NDIS Survey**

AMSLS research recognition

We would like to congratulate the following AMSLS collaborators on their achievements.

PhD completions

Two PhD students, Mr Tadele Girum Adal and Mr Mohammed Obsa, have submitted their PhD theses, both using AMSLS data.

Tadele's thesis was titled *Investigating and mitigating the burden for informal carers and supporters of people living with multiple sclerosis*. His primary supervisor was Dr Julie Campbell.

Mohammed's thesis was titled *Understanding pain in Multiple Sclerosis*. His primary supervisor was Professor Ingrid van der Mei.

Awards

At the annual Menzies Awards in March, the MS Research Flagship's Health Economics Group, led by Dr Julie Campbell, received the prestigious "Research Impact" award for its report *MS Prevalence and Health Economic Impact in Australia 2025*. You can read more about the impact of the report on page 1 of this newsletter.

Staff profile – Dr Kirsty Hawkes



Kirsty is the AMSLS Data Manager and one of the key people working behind the scenes to keep the study on track. From survey programming to managing the flow of incoming data, she helps ensure that participants have a smooth experience and that researchers receive high-quality information to support MS research.

With a PhD in chemistry and a background in computer programming, Kirsty began helping to steer the AMSLS not long after the study moved to the Menzies Institute for Medical Research in 2014. While participants may not see much of her work, the study would not function without it. Her expertise helps ensure that every survey completed by participants contributes to reliable and meaningful research outcomes.

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