



MULTIPLE SCLEROSIS PREVALENCE AND HEALTH ECONOMIC IMPACT IN AUSTRALIA 2025

An analysis of MS Australia's National Collaborative Research Platform – The Australian MS Longitudinal Study

EXECUTIVE SUMMARY

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The Australian Multiple Sclerosis Longitudinal Study (AMSLS) is one of MS Australia's national collaborative research platforms.

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Acknowledgements

Australian Multiple Sclerosis Longitudinal Study (AMSLS) participants and team

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Thank you to MS Australia for establishing and supporting the AMSLS since its inception in 2002, and the state and territory MS Member Organisations for their ongoing support with recruitment.

We also thank both Associate Professor Steve Simpson-Yap (Chapter 2) and Professor Paul Scuffham (Chapter 5) who assisted with the development of the prevalence and cost chapters of this report.

Foreword

This report, *Multiple Sclerosis Prevalence and Health Economic Impact in Australia 2025*, is the third major publication produced by the MS Health Economics team led by Dr Julie Campbell at the Menzies Institute for Medical Research. It builds on the two outstanding prior reports that have set the gold standard for advocacy, providing critical data to support people with MS across multiple levels of policy and practice in Australia.

MS is a chronic, incurable neurological disease with increasing prevalence and incidence both in Australia and globally. It is typically diagnosed during the most productive years of a person's life, when individuals are building careers and families. As a lifelong disease, MS often has profound and lasting impacts on quality of life, presenting significant challenges for many people living with it.

Importantly, changes in exposure to known MS risk factors, such as increased rates of adolescent obesity, reduced rates of pregnancy, and decreased sun exposure, are likely significant contributors to the rise in MS prevalence. These trends underscore the need for preventive strategies alongside treatment and support initiatives.

Fortunately, today there are effective treatments and interventions for MS that can slow progression of disability and enhance quality of life. However, there is no cure.

From my perspective as a neurologist and MS researcher, this report is an invaluable and much-needed resource. It provides robust evidence to support advocacy efforts aimed at improving service delivery and interventions for people living with MS. Importantly, the report highlights that MS prevalence continues to rise, and associated costs remain high, driven by the growing number of people living with MS. It also provides critical insights into the impacts of MS on quality of life, employment, and the importance of the NDIS.

The primary data source for this report is the Australian MS Longitudinal Study (AMSLS), a longstanding MS Australia-funded study housed at the Menzies Institute for Medical Research and led by Professor Ingrid van der Mei. As with any report and research publication, the quality of the input data is paramount; without it, the report is not worth the paper it is printed on. Fortunately, the AMSLS is recognised globally as a meticulously conducted study that delivers robust and reliable data, making it a cornerstone for evidence-based insights into MS.

I commend this report to the MS community, clinicians, researchers, and policy and decision-makers as a vital contribution to our collective efforts to prevent MS and improve the lives of people living with the disease, along with their families and supporters.

Professor Bruce Taylor

Neurologist and Academic Lead MS Research Flagship, Menzies Institute for Medical Research

Executive summary and recommendations

Introduction and Aims

Multiple sclerosis (MS) is an immune-mediated disease of the central nervous system (CNS), which comprises the brain and spinal cord. It is the most common acquired chronic neurological disease affecting young adults, with an estimated global prevalence of 2.9 million people. Coupled with the increasing prevalence, MS is also a costly disease with a high health economic burden for the person living with MS, their families and supporters, and society more generally. Additionally, as MS-related disability severity worsens, the economic burden of MS increases.

Our previous reports on the Health Economic Impact of MS in Australia, from 2017 and 2021, found that the number of people living with MS and associated costs have continued to rise. The number of people living with MS in Australia increased by 7,728 people from 25,607 to 33,335 people in the four years from 2017 to 2021. The cost of MS has also continued to rise, with the total societal cost in Australia reaching \$2.45 billion in 2021¹, an increase from \$1.75 billion in 2017 ² and \$1.04 billion in 2010 ³. In 2021, we also found that the mean annual cost per person living with MS was \$73,457. The cost differed by disability level, rising from \$32,829 for people with MS living with no disability to \$123,333 for people with MS living with severe disability ¹.

In line with previous editions, the *Multiple Sclerosis Prevalence and Health Economic Impact in Australia 2025* report provides a comprehensive analysis of the economic and quality of life impacts of MS in Australia. It constitutes a current credible reference to support the MS community in advocating for increased resources to prevent, treat, manage and investigate MS. The aims for this report were to:

- 1. Estimate the number of people living with MS in Australia in 2024 and the prevalence (per 100,000 population), with a breakdown by state and territory (Chapter 2).
- 2. Evaluate the impacts of MS-related disability on health-related quality of life and determine which elements of wellbeing are most affected by MS (Chapter 3).
- 3. Review employment patterns and outcomes for people living with MS, including their experiences on disclosure of diagnoses and workplace discrimination (Chapter 4).
- 4. Assess the overall societal cost of MS in Australia in 2024 (Chapter 5).
- 5. Determine direct and indirect costs for the sociodemographic and clinical characteristics of people living with MS, covering treatment, specialist services, home and vehicle modifications, productivity loss, employment changes, and informal care (Chapter 5).
- 6. Examine access to and utilisation of the National Disability Insurance Scheme (NDIS) among Australians living with MS (Chapter 6).
- 7. Compare findings with previous health economic impact reports and provide recommendations for future action (Executive Summary and Chapter 7).

Methods

This report has mainly been informed by data from the <u>Australian MS Longitudinal Study</u> (<u>AMSLS</u>), which is funded by MS Australia and managed at the MS Research Flagship at the Menzies Institute for Medical Research, Tasmania.

Each chapter adopted specialised methodologies, summarised as follows:

• Chapters 2-6

» Utilised descriptive statistical analysis for each topic. Means, standard deviations, counts and proportions were used to describe the data.

• Chapter 2: Prevalence Estimation

» Applied the novel medications method, as used in previous reports, to estimate the number of people living with MS and its prevalence in Australia for 2024. This enabled the direct comparison with previous years and informed the cost of illness estimates in Chapter 5.

Chapter 3: Health-Related Quality of Life

Assessed health-related quality of life for people living with MS and used the EQ-5D-5L-Psychosocial instrument to derive quality of life as health state utility values
This tool is validated for use in Australia with MS populations and is sensitive to changes in both physical and psychosocial health

Chapter 4: Employment Outcomes

» A new addition to the 2025 report, this chapter investigated employment patterns and outcomes among people living with MS using data from the AMSLS Employment Survey.

Chapter 5: Cost of Illness

» Provided detailed cost and societal cost of illness estimates for MS in Australia, expressed in 2024 Australian dollars (AUD). Detailed AMSLS data sources were used to calculate total costs and direct and indirect costs, including a cost diary, administrative data and survey data.

Chapter 6: NDIS Participation

» Another new chapter, which provided a preliminary investigation into MS-related experiences with the NDIS, based on information provided by participants in the AMSLS NDIS Survey.

Headline Figures

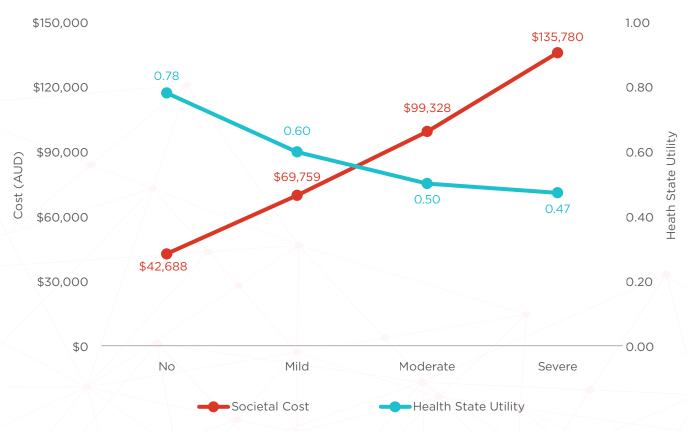
In 2024, there were 37,756 people living with MS in Australia. Analysis of this and previous reports demonstrates that the number of people living with MS and its prevalence has increased substantially over time.

The estimated cost of MS to Australian society was just over \$3.004 billion in 2024, reflecting a substantial increase over previous years.

The mean cost per person living with MS was \$79,581. For people living with MS with no disability, the mean cost was \$42,688. In contrast, those living with severe MS-related disability incurred a significantly higher mean cost of \$135,780 (Figure i).

In 2024, the quality of life for people living with MS, as measured by the mean health state utility (HSU) score, was 0.60 on a scale where 1.0 represents perfect health and 0.0 represents death. This is notably lower than the Australian population norm of 0.80, highlighting the substantial impact of MS on quality of life. For people with no MS-related disability, HSU scores were similar with the Australian population norm at 0.78. In contrast, those with severe MS-related disability had substantially lower HSU scores at 0.47 (Figure i).

Figure i: Mean societal costs per person living with MS and HSU measured for disability severity categories of no, mild, moderate and severe MS-related disability for 2024



Notes: Disability severity based on Expanded Disability Status Scale (EDSS) of no disability (EDSS: 0.0), mild disability (EDSS = 1.0-3.5), moderate disability (EDSS = 4.0-6.0), and severe disability (EDSS = 6.5-9.5).

Prevalence of MS

There were 37,756 people living with MS in Australia in 2024. This represents an increase of 4,421 people (+13.3%) since 2021 and 16,473 people (+77.4%) since 2010 (Figure ii). Overall, these results reflect the substantial increase in the number of people living with MS globally.

Age-adjusted prevalence estimates did not differ materially from crude prevalence estimates across individual states and territories. TAS continues to report the highest age-adjusted prevalence of MS in Australia, at 190.1 per 100,000 people [95% CI: 188.5-191.8). As in previous years, this figure is nearly double the prevalence observed in WA (100.1 per 100,000 [95% CI: 98.9-101.3]) and QLD (99.8 per 100,000 [95% CI: 98.6-100.9]). These findings align with the established latitudinal gradient, which indicates higher MS prevalence in regions further from the equator (Figure iii).

Of the 37,756 Australians living with MS in 2024, 23,217 people (62%) were using disease modifying therapies (DMTs). In 2024, 187,293 prescriptions were dispensed, which was 12,829 more than in 2021.

Figure ii: Number of people living with MS in Australia and the crude prevalence

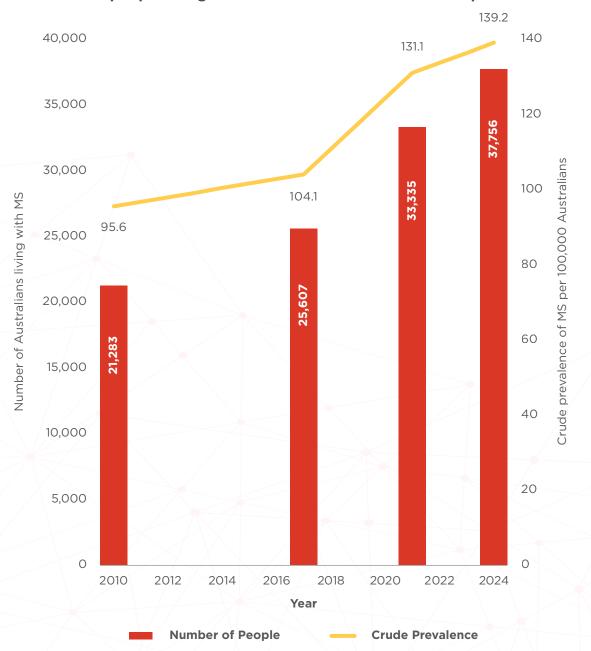
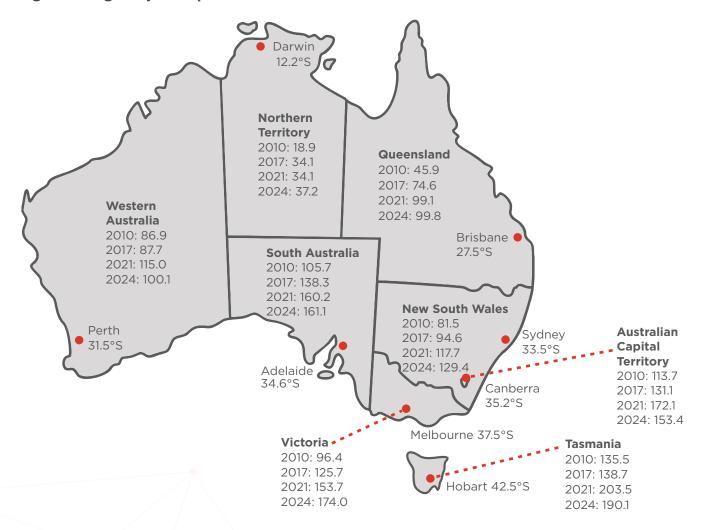


Figure iii: Age-adjusted prevalence in Australia's states and territories



Cost of Multiple Sclerosis

The total societal cost of MS in Australia in 2024 was \$3.004 billion (95% CI: \$2.670-\$3.289 billion). While inflation-adjusted costs have remained relatively stable, the overall economic burden continues to grow due to the rising prevalence.

Compared to 2017, the 2024 cost was \$1.253 billion higher (+71.5%). After adjusting for inflation, the difference remains substantial at \$819 million (+37.5%). This sharp rise is largely attributable to increasing MS prevalence, with the number of cases growing by 47.7% (12,149) between 2017 and 2024.

At the individual level, the mean cost per person living with MS in 2024 was \$79,581 (95% CI: \$70,752-\$87,136). Compared to 2017, the inflation-adjusted cost per person living has decreased slightly, from \$85,297 in 2017 to \$79,581 in 2024 (-6.7%).

When compared to the general population, the disparity in health-related costs is striking. According to the Australian Institute of Health and Welfare (AIHW), the average health spending per person in Australia was \$9,597 in 2022-23, equivalent to approximately \$10,400 in 2024 dollars. This means that people living with MS face health-related costs that are approximately seven times higher than the national average. Even those with no MS-related disability incur costs around four times higher, while those with severe MS-related disability face costs approximately 14 times greater than the average Australian.

Direct costs accounted for 55.1% of the mean cost per person living with MS in 2024 (Figure iv). The two greatest sources of MS-related costs were DMTs (\$592 million; \$15,671 per person living with MS) and lost employment or productivity losses (\$846 million; \$22,411 per person living with MS) (Figure v). Costs varied substantially with AMSLS participant characteristics, particularly disability severity, defined using the Expanded Disability Status Scale (EDSS): no disability (EDSS 0.0), mild (EDSS 1.0-3.5), moderate (EDSS 4.0-6.0), and severe (EDSS 6.5-9.5). As disability severity worsened from no to severe disability, the mean per-person cost increased from \$42,688 to \$135,780, a difference of \$93,092 or approximately 220% (Figure vi).

Figure iv: Percentage contributions of cost categories to mean cost per person living

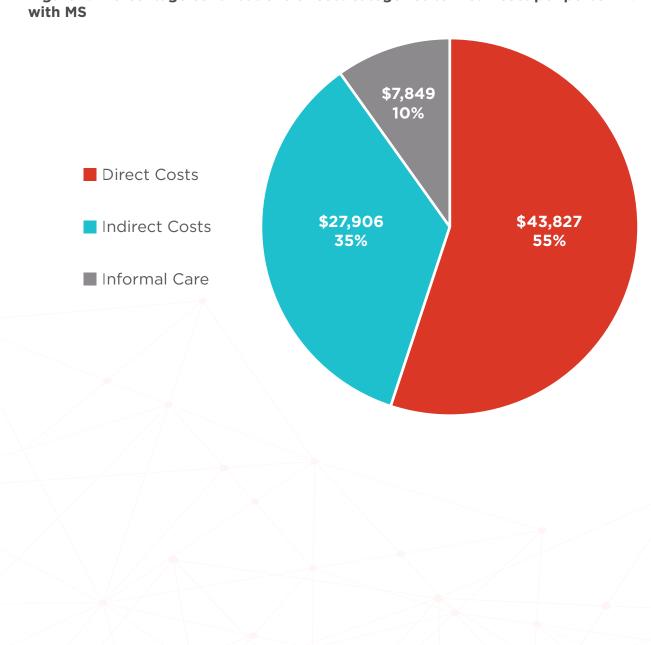
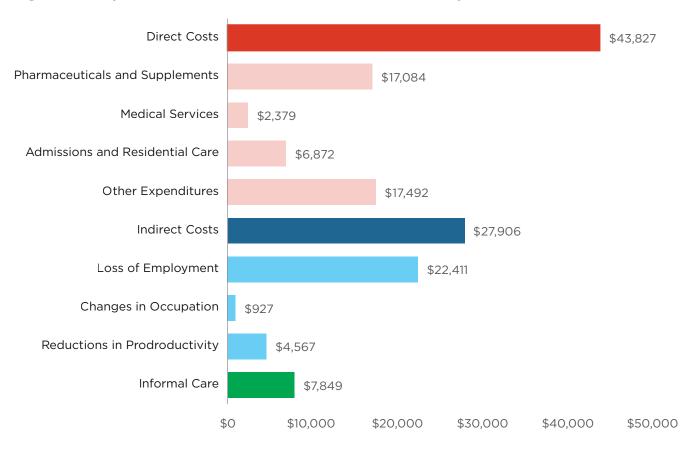
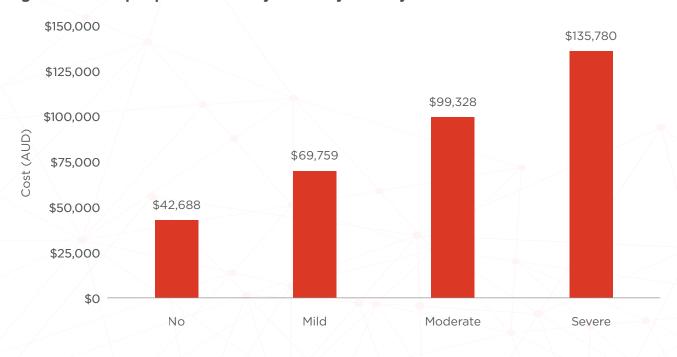


Figure v: Per person direct and indirect costs with cost components



Notes: Darker colours indicate summed costs, whereas light colours indicate component costs. Expenses are colour-coded with red/pink indicating direct costs, dark/light blue indicating indirect costs, and green indicating costs associated with informal care.

Figure vi: Mean per person costs by disability severity



People with progressive MS incurred higher costs than those with relapsing-remitting MS (RRMS), even though RRMS is associated with a wider range of approved and reimbursed DMTs. The mean cost for people with secondary progressive MS (SPMS) was 74.9% higher than those with RRMS. Similarly, the mean cost for people with primary progressive MS (PPMS) was 27% higher than those with RRMS (Figure vii).

In 2024, early retirement was the leading contributor to lost employment, accounting for \$369 million (95% CI: \$350 million-\$388 million), or \$9,767 per person. This figure includes \$79.7 million in forgone superannuation. The second highest contributor was transitions to unemployment (\$295 million, 95% CI: \$280 million-\$310 million), followed by transitions to part-time employment (\$183 million, 95% CI: \$174 million-\$192 million) (Figure viii). Among those employed, productivity losses due to presenteeism were greater than those due to absenteeism, with average costs of \$3,074 and \$1,493 per person, respectively.

Figure vii: Mean per-person costs by type of MS

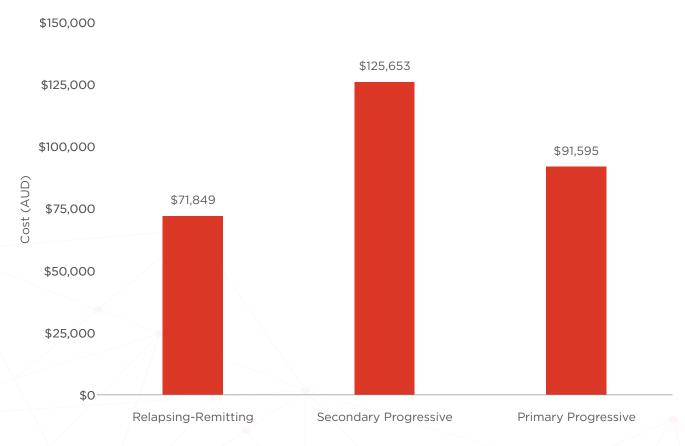
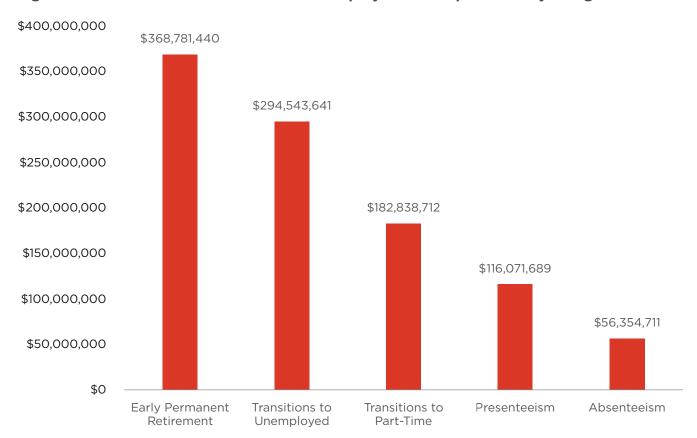


Figure viii: Total societal costs for loss of employment and productivity categories

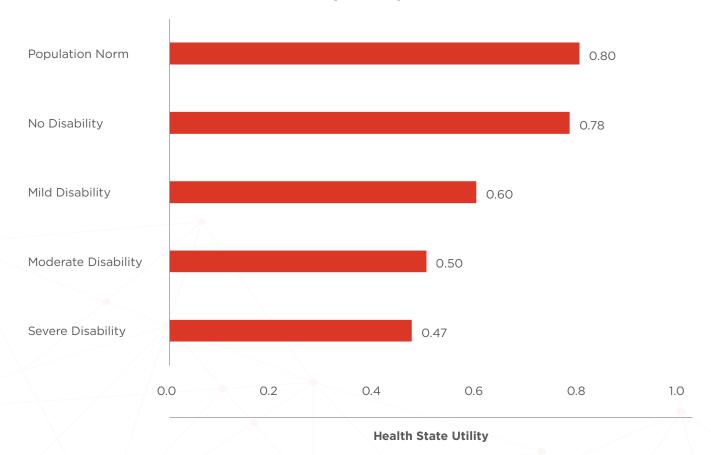


Quality of Life

Quality of life was measured with a multi-attribute utility instrument (EQ-5D-5L-Psychosocial) that estimates health state utility (HSU) on a scale of 0.0 (death) to 1.0 (perfect health). The mean HSU score for Australians living with MS in 2024 was 0.60, which is 0.20 points lower than the Australian population norm at 0.80. This difference exceeded the clinical significance threshold of 0.06 by more than threefold (Figure ix).

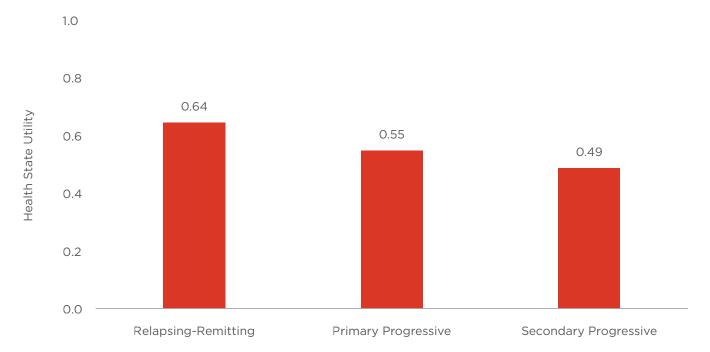
Quality of life declined with increasing disability severity, with HSU scores dropping from 0.78 for those with no disability to 0.47 for those with severe disability (Figure ix). Additionally, people living with progressive MS experienced lower quality of life compared to those with RRMS. (Figure x).

Figure ix: Quality of life reflected in HSU for people living with MS with no, mild, moderate and severe MS-related disability severity



Notes: HSU measured with the EQ-5D-5L-Psychosocial multi-attribute utility instrument ⁵.

Figure x: Quality of life reflected in HSU scores for people living RRMS, PPMS and SPMS





Employment Impacts

MS-related employment impacts had a societal cost of \$846 million in 2024. This estimate represents a cost \$22,411 per person living with MS.

Among AMSLS participants, 44.0% were in the labour force – either in paid employment or actively seeking work – while 43.9% were retired. The remaining 12.1% were not retired and not actively seeking work. Of those retired, 58.2% reported retiring due to the impacts of MS. Among working Australians with MS, 91.0% indicated that their symptoms compromised their ability to work, with 9.2% reporting that their employment was actively at-risk due to the effects of MS.

Disability severity was strongly associated with ceasing employment (Figure xi). The proportion of AMSLS participants who were not in the labour force rose from 23.0% among those with no disability to 75.0% among those with severe disability. This shift had a significant impact on personal income.

The symptoms most frequently reported as contributing to people living with MS leaving their jobs included fatigue, cognitive dysfunction, motor dysfunction of the legs and feet, and heat sensitivity (Figure xii). In addition to physical symptoms, many participants also reported psychosocial reasons for ending their employment, including feeling that their work no longer met their personal standards.

Whilst a relatively high proportion of AMSLS participants indicated that disclosing their MS improved their experiences in employment, some reported a negative impact. The majority of participants reported that they rarely or never felt discriminated against in their workplace in the last 12 months, and about one-third indicated that they experienced excessive levels of workplace stress or were under pressure.

Figure xi: Employment status for people living with MS with no, mild, moderate and severe MS-related disability

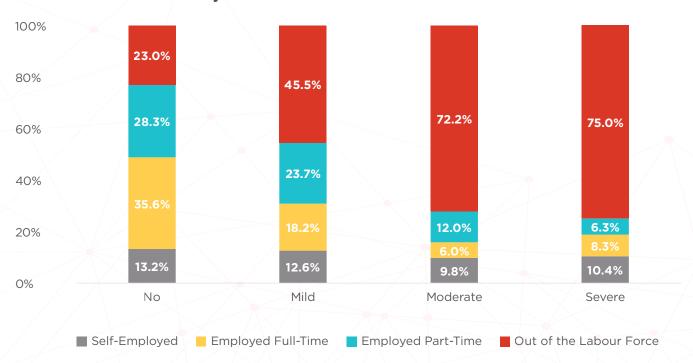
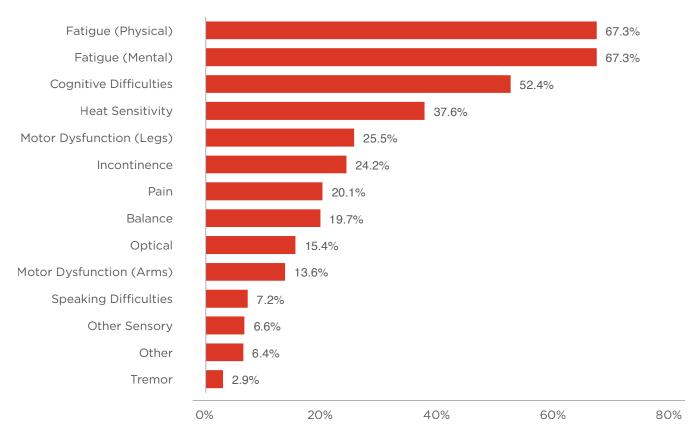


Figure xii: Symptoms that most frequently affected the ability of AMSLS participants to remain in employment

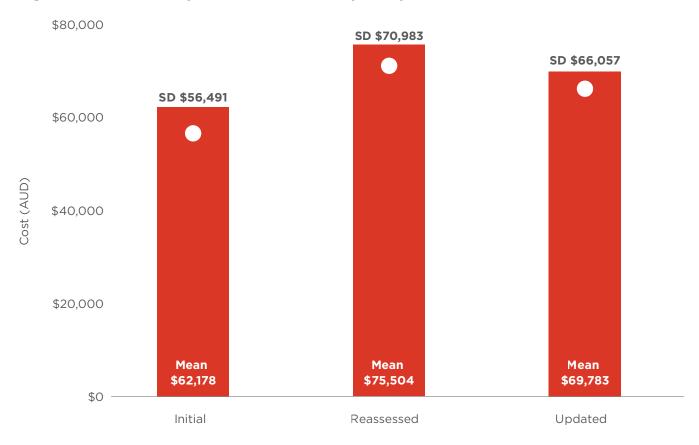


National Disability Insurance Scheme (NDIS)

The mean initial NDIS plan value among AMSLS participants was \$62,178, increasing to \$75,504 following reassessment (Figure xiii). On average, participants spent 23.4 hours applying for access, with a wide variation in effort (SD: 38.0 hours). Encouragingly, a high percentage of the NDIS applicants indicated that they currently have a plan, with 89.0% of potentially eligible participants (meeting the age requirements) living with moderate to severe disability having applied.

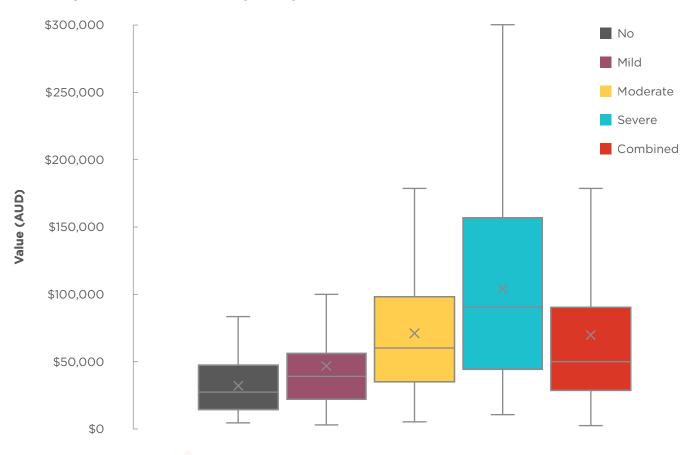
Among those who had a plan, 56.8% were living with moderate to severe MS-related disability, compared to just 20.0% among those without a plan. NDIS plan values, spanning one to five years, rose sharply with disability severity - from an average of \$47,000 for individuals with mild MS-related disability to \$104,000 for those with severe disability (Figure xiv). NDIS plans were also more commonly held by people living with progressive MS, particularly PPMS, compared to individuals with RRMS.

Figure xiii: Mean NDIS plan values of AMSLS participants in 2024 AUD



Notes: Standard deviations (SDs) are represented by the dots, whereas mean values are indicated by the columns. The mean updated plan value excludes initial values where reassessed values were available.

Figure xiv: Box and whisker plot describing variation in updated NDIS plan values across disability severities for AMSLS participants



Notes: The solid line represents the median NDIS plan cost, the opaque box the interquartile range (25th to 75th percentiles), and the lines the remaining range (terminating and minimum and maximum plan values). Xs mark the mean, which is above the median in every plot. Updated NDIS plan values exclude initial values where reassessed values were available.

Key Recommendations

Chapter 7 of this report contains the full recommendations and detailed explanations. Below is a concise summary of those recommendations.

1. Support research and activities focusing on the prevention of MS

» We recommend funding research that focuses on the prevention of MS, including risk factors, biomarkers, immune modulation, antivirals and lifestyle interventions.

2. Support efforts towards earlier diagnosis and intervention

» We recommend that resources be allocated to support earlier diagnosis of MS and earlier intervention to prevent or delay the accumulation of disability. This includes development of biomarkers of early disease; raising awareness of MS among the general public and referring healthcare professionals to reduce diagnostic delays; equitable access to MS specialist care for diagnosis; education for MS specialist and other healthcare professionals on the new 2024 diagnostic criteria supporting earlier diagnosis; and providing access to effective DMTs for people with PPMS, for whom none are currently PBS-approved in Australia.

3. Develop and approve interventions promoting neuroprotection and myelin repair

» We recommend that resources be allocated to new and promising interventions promoting neuroprotection and myelin repair in MS. These treatments should be expeditiously approved by Australia's Therapeutic Goods Administration (TGA) and recommended for subsidy by the Pharmaceutical Benefits Advisory Committee (PBAC).

4. Improve access to MS Nurse care

» We recommend allocating resources to employ at least 65 additional MS Nurses in Australia to ensure all people living with MS have access to this vital service, based on the MS Nurse Care in Australia report. Improved health outcomes resulting from MS Nurse care will translate to immediate cost savings for people living with MS, health payers and society.

5. Empower people with MS to manage their disease and lead a brain-healthy lifestyle

» We recommend continued investment in promoting brain health and raising awareness about the role of modifiable lifestyle factors in the disease course of MS.

6. Implement early support programs that assist people living with MS to remain in the workforce

» We recommend the development and implementation of early support programs that assist people living with MS to remain in the workforce.

7. Access to the National Disability Insurance Scheme (NDIS)

» We recommend the Australian Government improve the NDIS to better meet the needs of people living with MS, including the introduction of a flexible, participant-focused and sustainable pricing model; improved assessment, planning and budgeting processes; an improved early intervention pathway and a better understanding of progressive neurodegenerative diseases such as MS.