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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


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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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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.

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Table of abbreviations

ABBREVIATION	MEANING
ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
AMSLS	Australian Multiple Sclerosis Longitudinal Study
AUD	Australian Dollar
CAD	Canadian Dollar
CI	Confidence Interval
DMT	Disease Modifying Therapy
EDSS	Expanded Disability Status Scale
EQ-5D-5L-Psychosocial	EuroQoL-5 Dimensions-5 Levels-Psychosocial
HSU	Health State Utility
IHACPA	Independent Hospital and Aged Care Pricing Authority
MBS	Medical Benefits Schedule
MS	Multiple Sclerosis
NDIS	National Disability Insurance Scheme
PBAC	Pharmaceutical Benefits Advisory Committee
PBS	Pharmaceutical Benefits Scheme
PPMS	Primary Progressive Multiple Sclerosis
RBA	Reserve Bank of Australia
RPBS	Repatriation Pharmaceutical Benefits Scheme
RRMS	Relapsing-Remitting Multiple Sclerosis
SD	Standard Deviation
SPMS	Secondary Progressive Multiple Sclerosis

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
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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 2021[1], 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 Australian MS Longitudinal Study (AMSLS), 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 [4]. This tool is validated for use in Australia with MS populations and is sensitive to changes in both physical and psychosocial health [5].
- **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

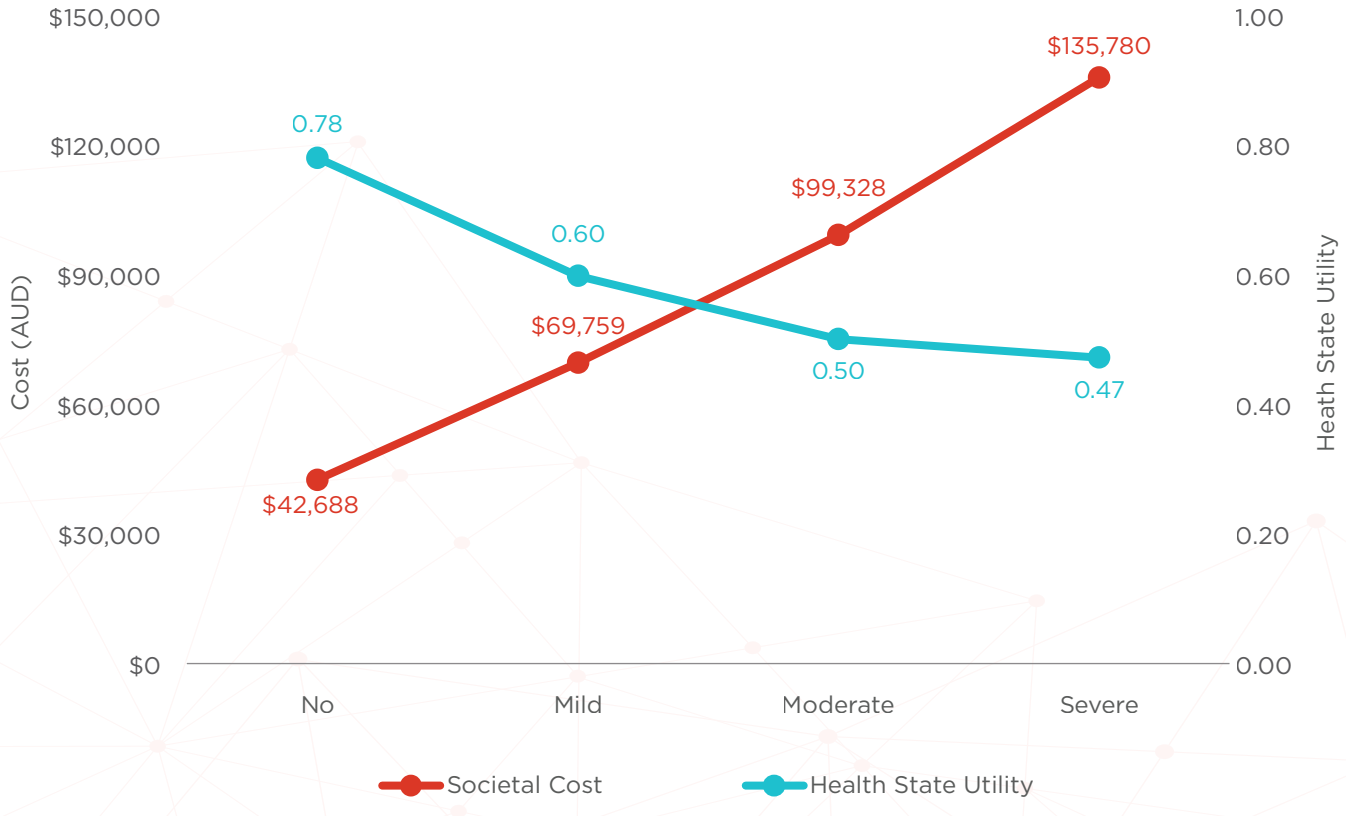
In 2024, there were 37,756 people living with MS in Australia. Analysis of this and previous reports demonstrates that the number of people living with MS and its prevalence has increased substantially over time.

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

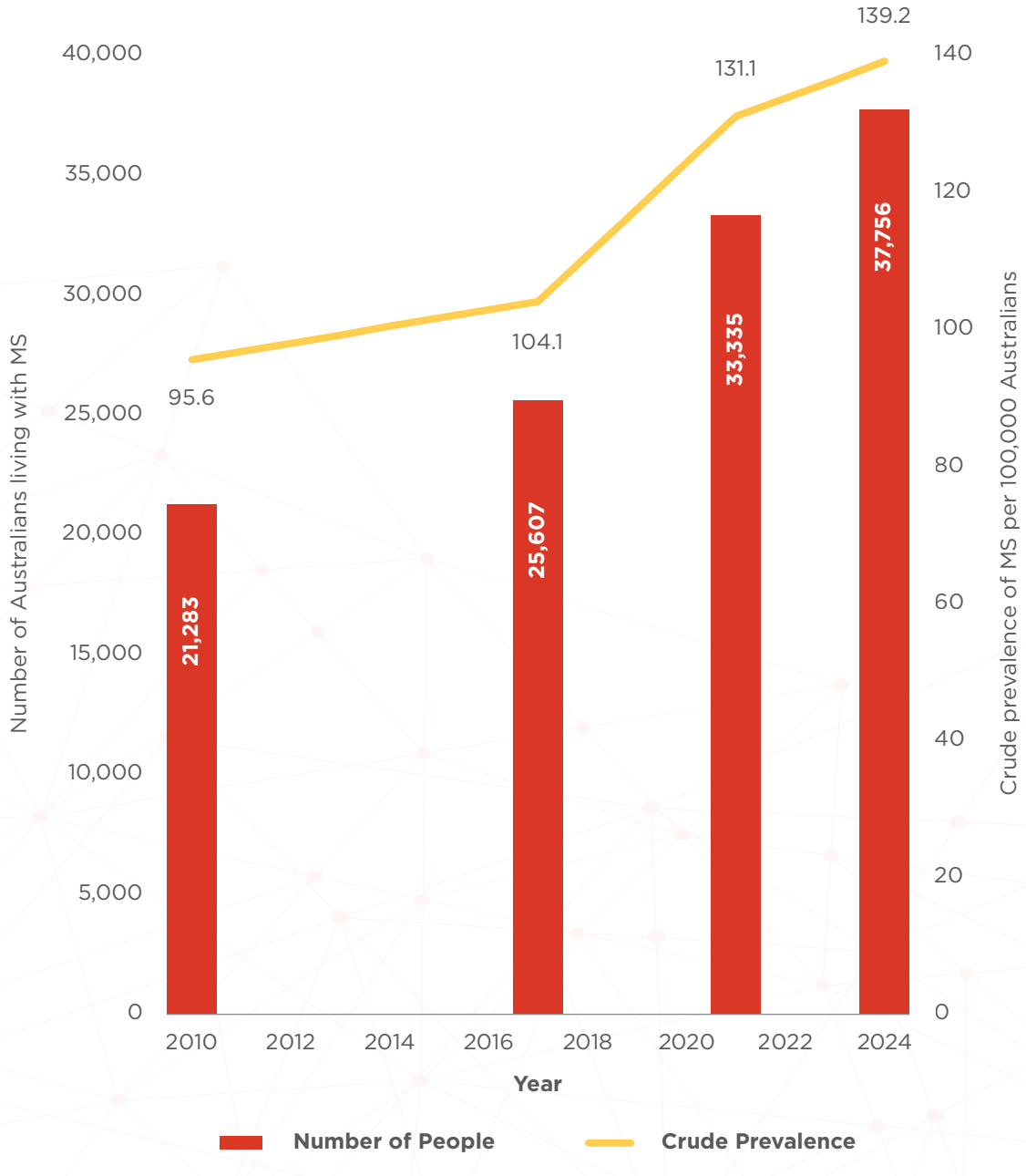
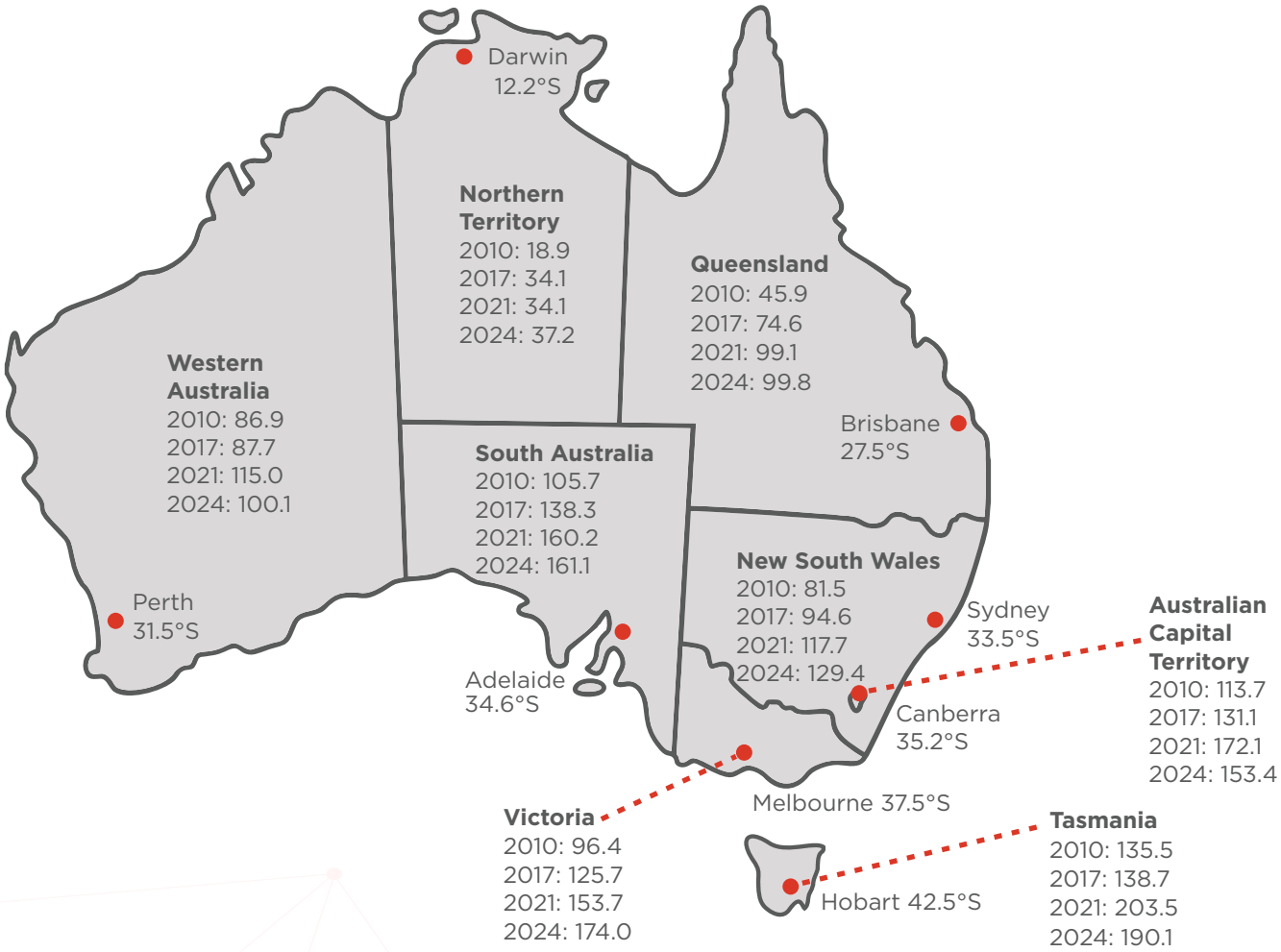


Figure iii: Age-adjusted prevalence in Australia's states and territories



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 with MS

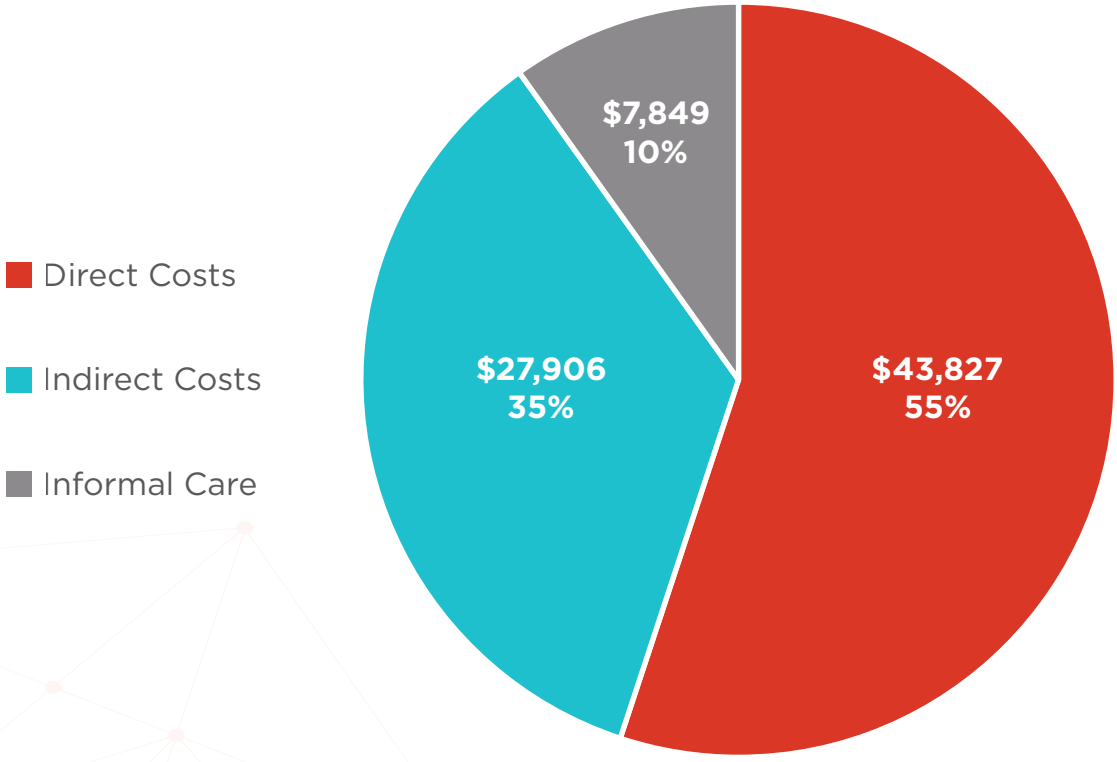
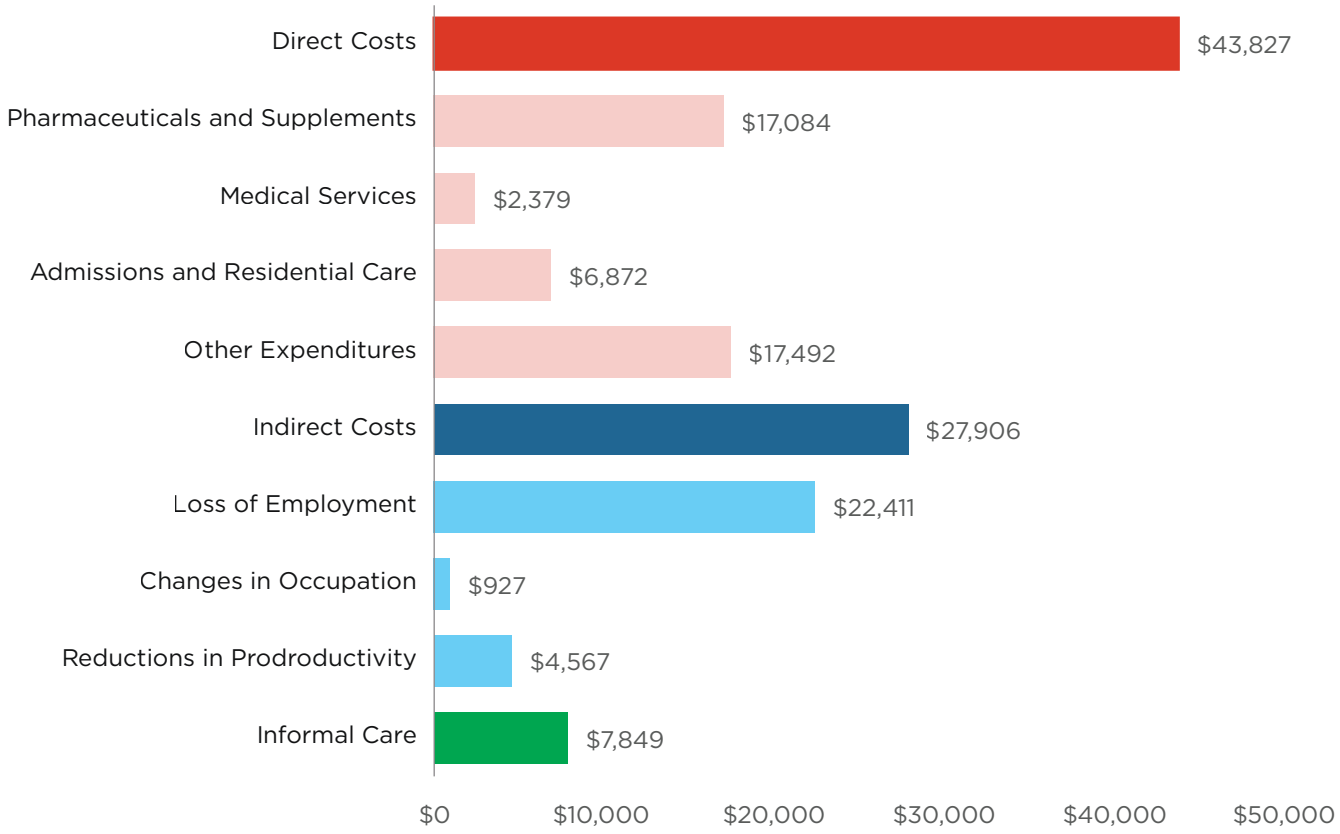
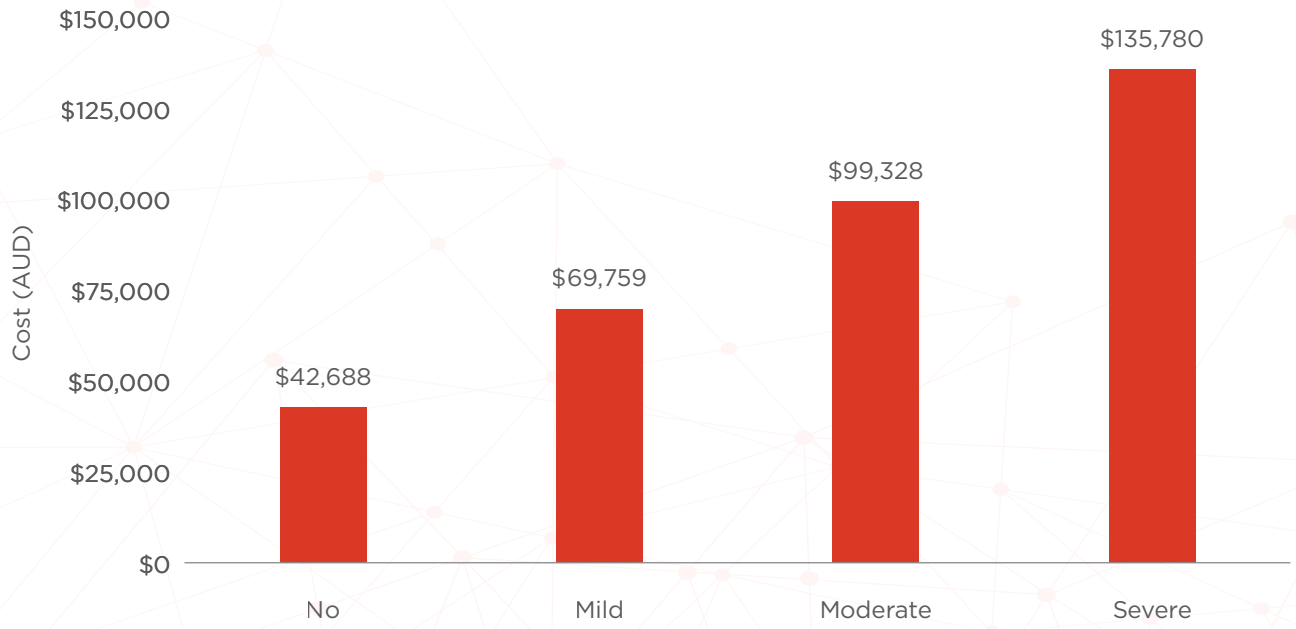


Figure v: Per person direct and indirect costs with cost components



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

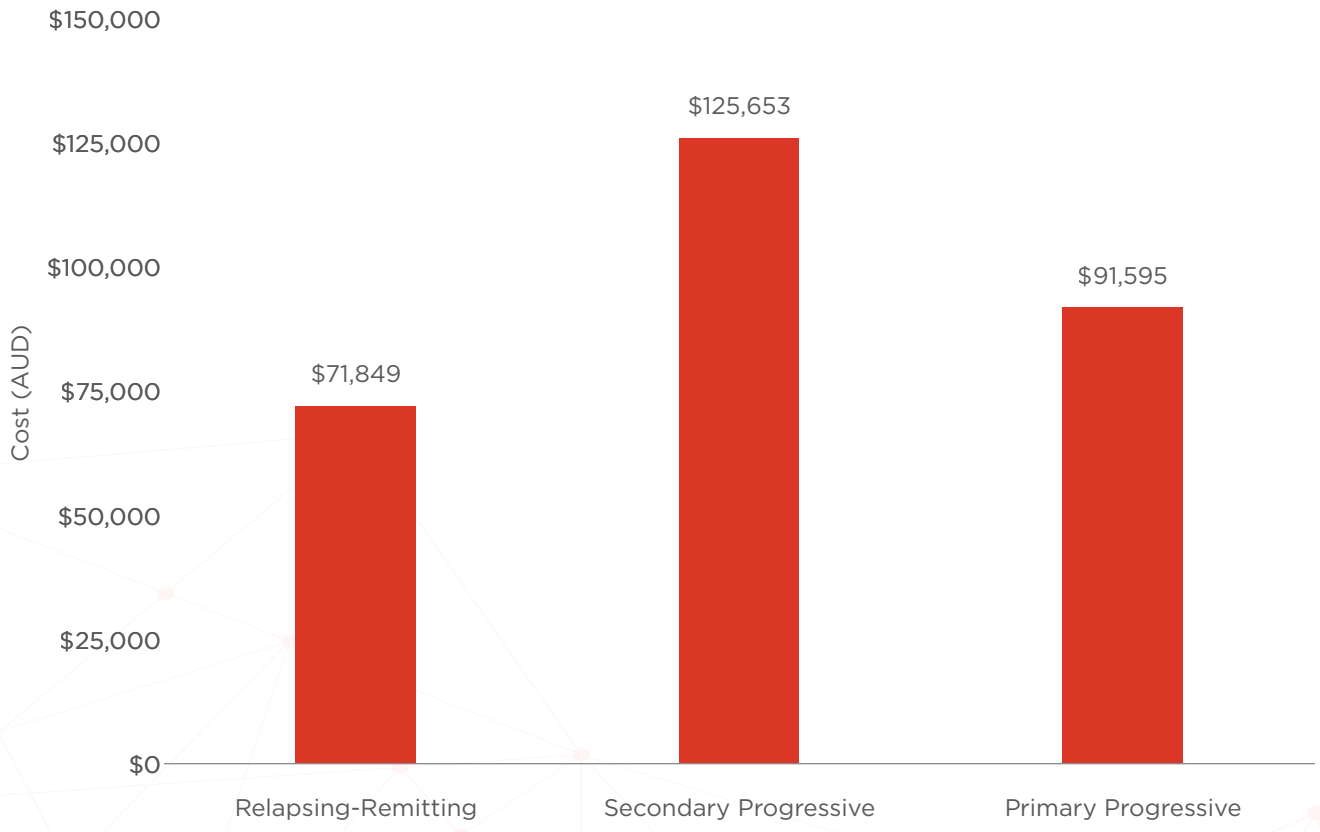
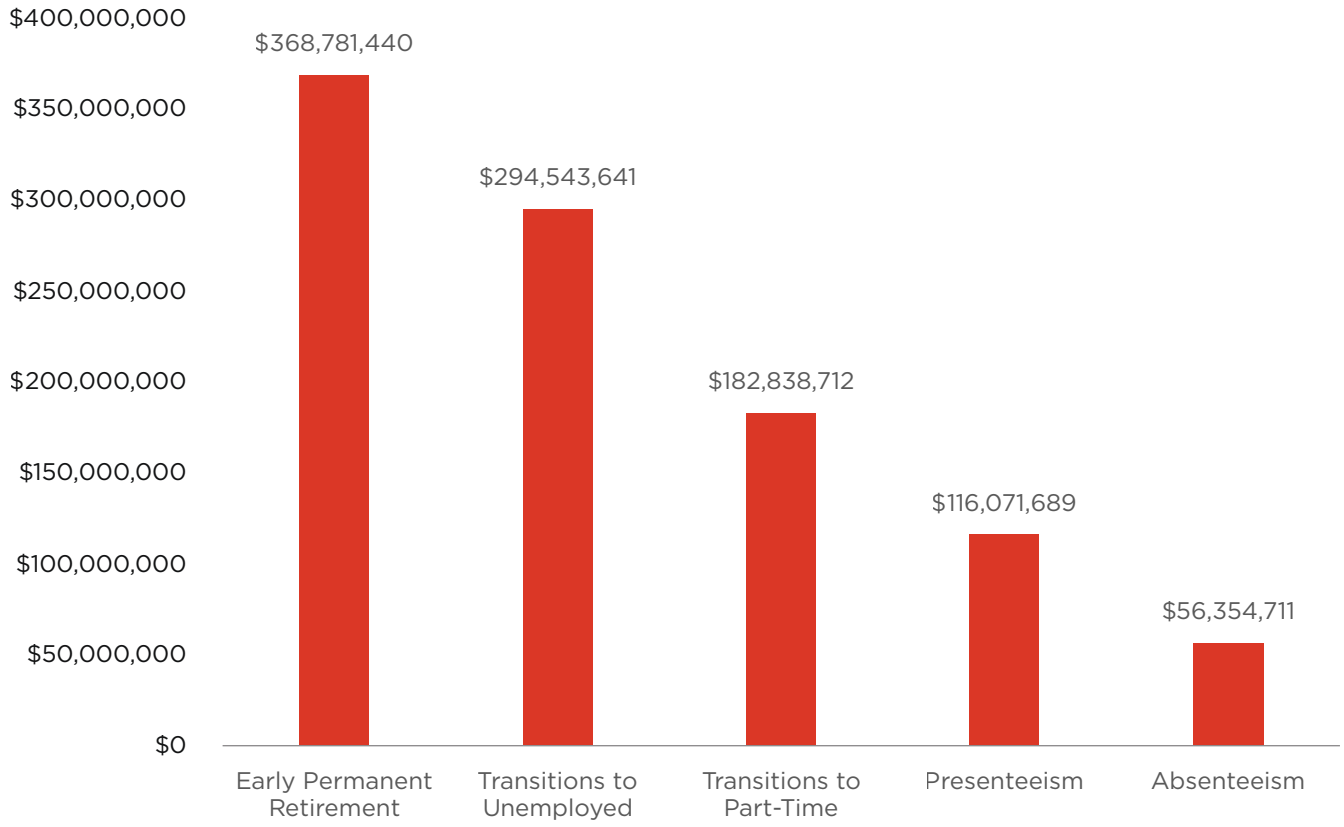


Figure viii: Total societal costs for loss of employment and productivity categories

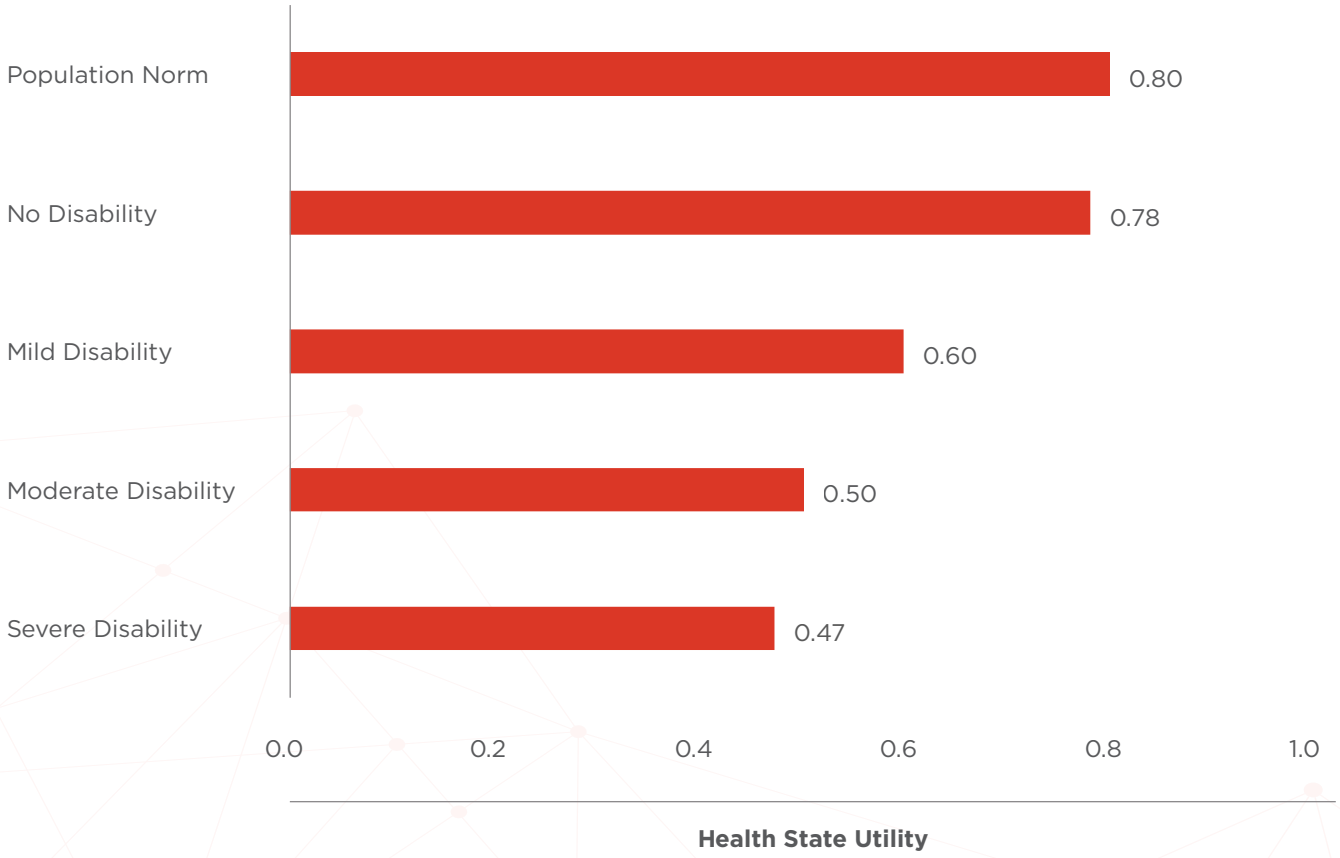


Quality of Life

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).

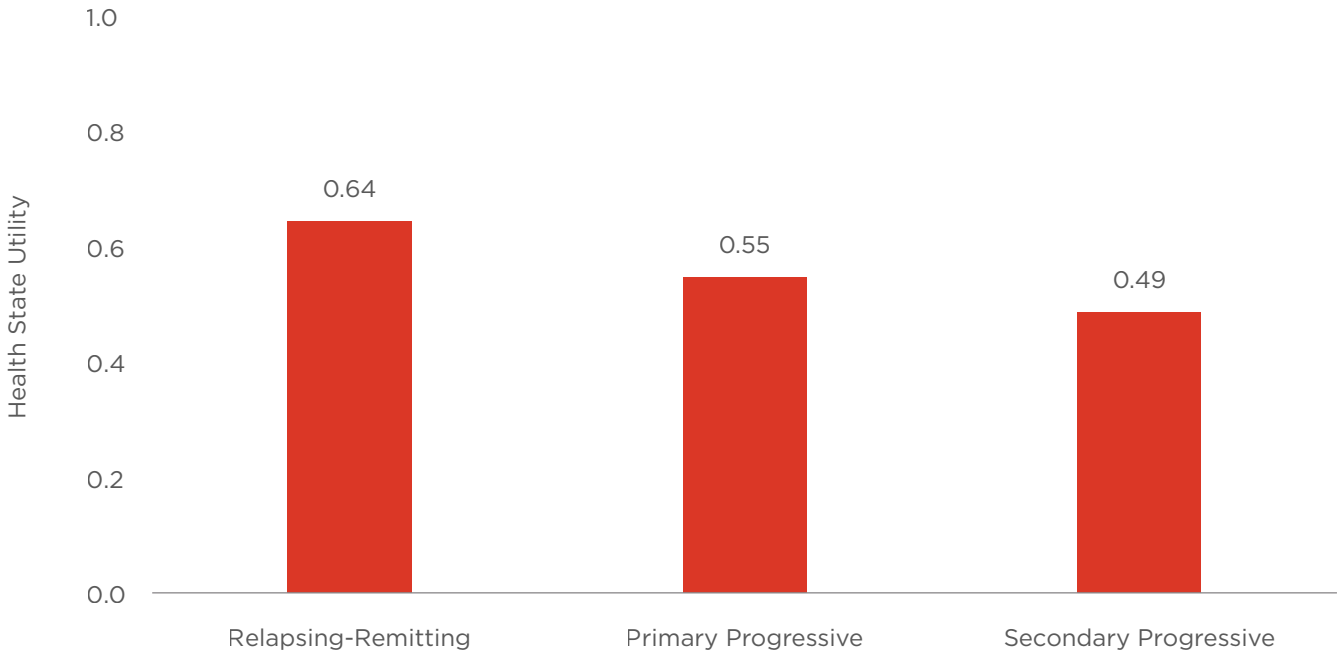
Quality of life declined with increasing disability severity, with HSU scores dropping from 0.78 for those with no disability to 0.47 for those with severe disability (Figure ix). Additionally, people living with progressive MS experienced lower quality of life compared to those with RRMS. (Figure x).

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

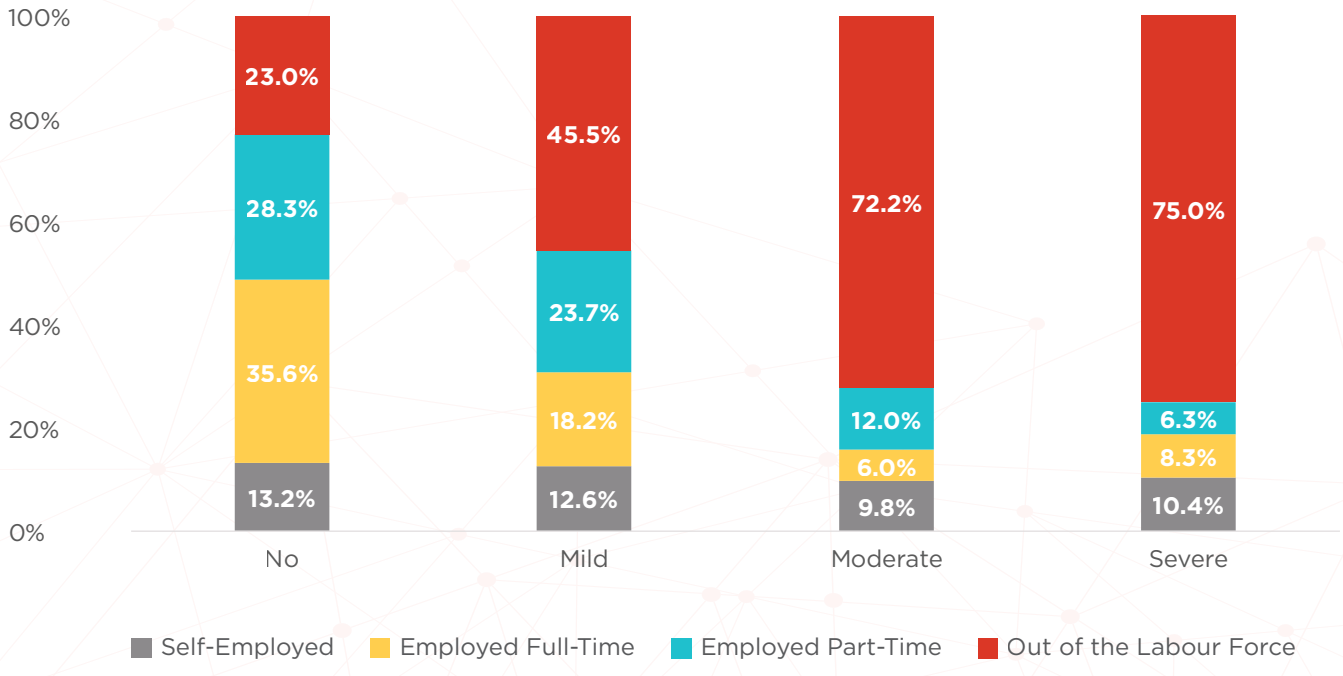
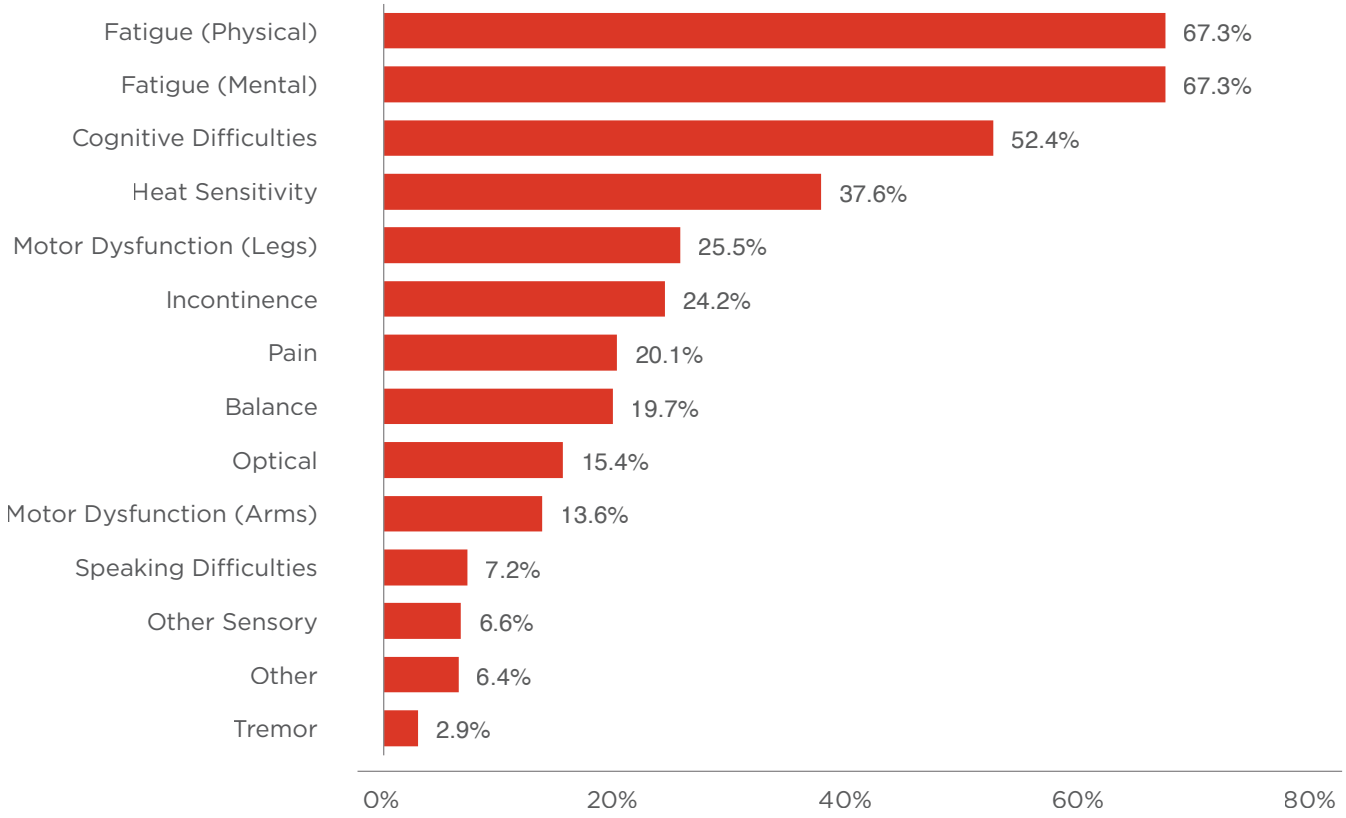


Figure xii: Symptoms that most frequently affected the ability of AMSLS participants to remain in employment

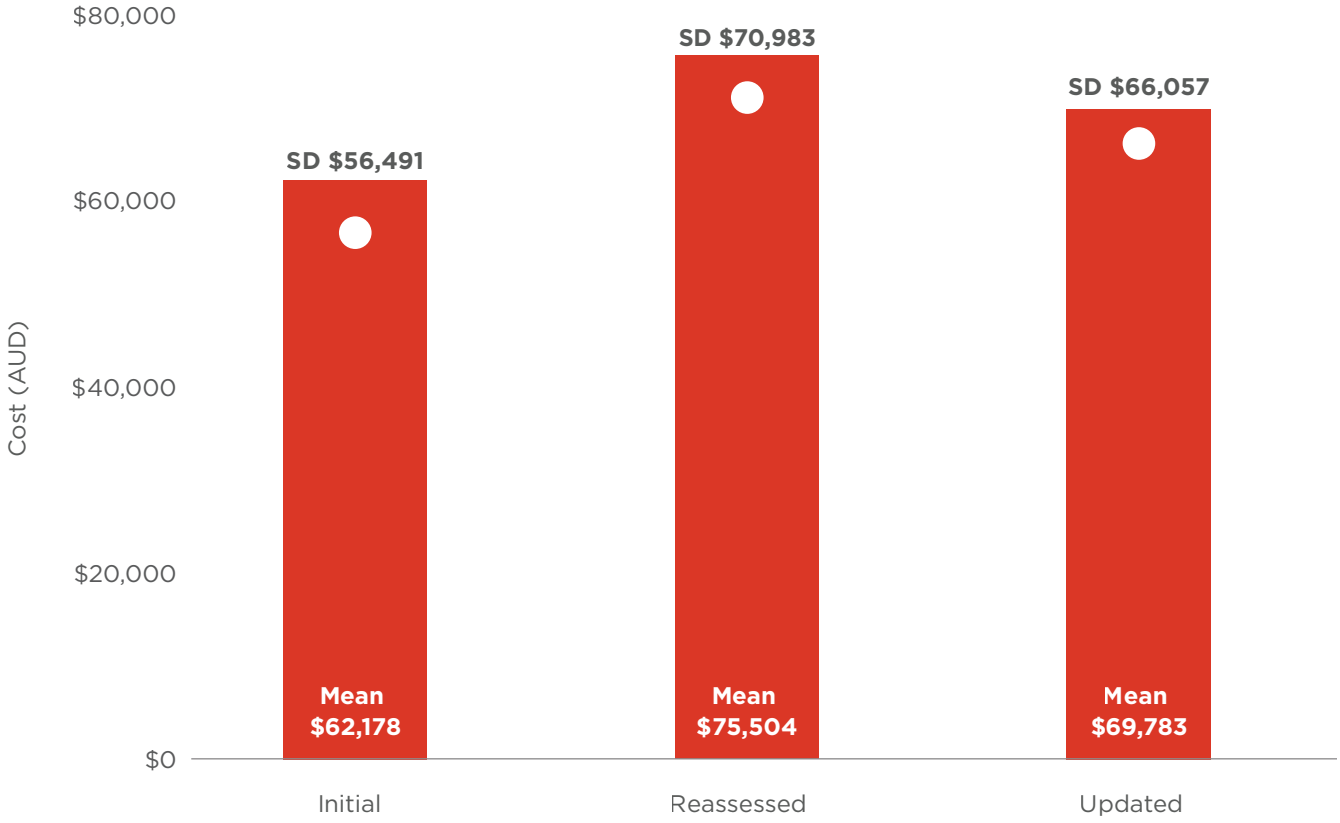


National Disability Insurance Scheme (NDIS)

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.

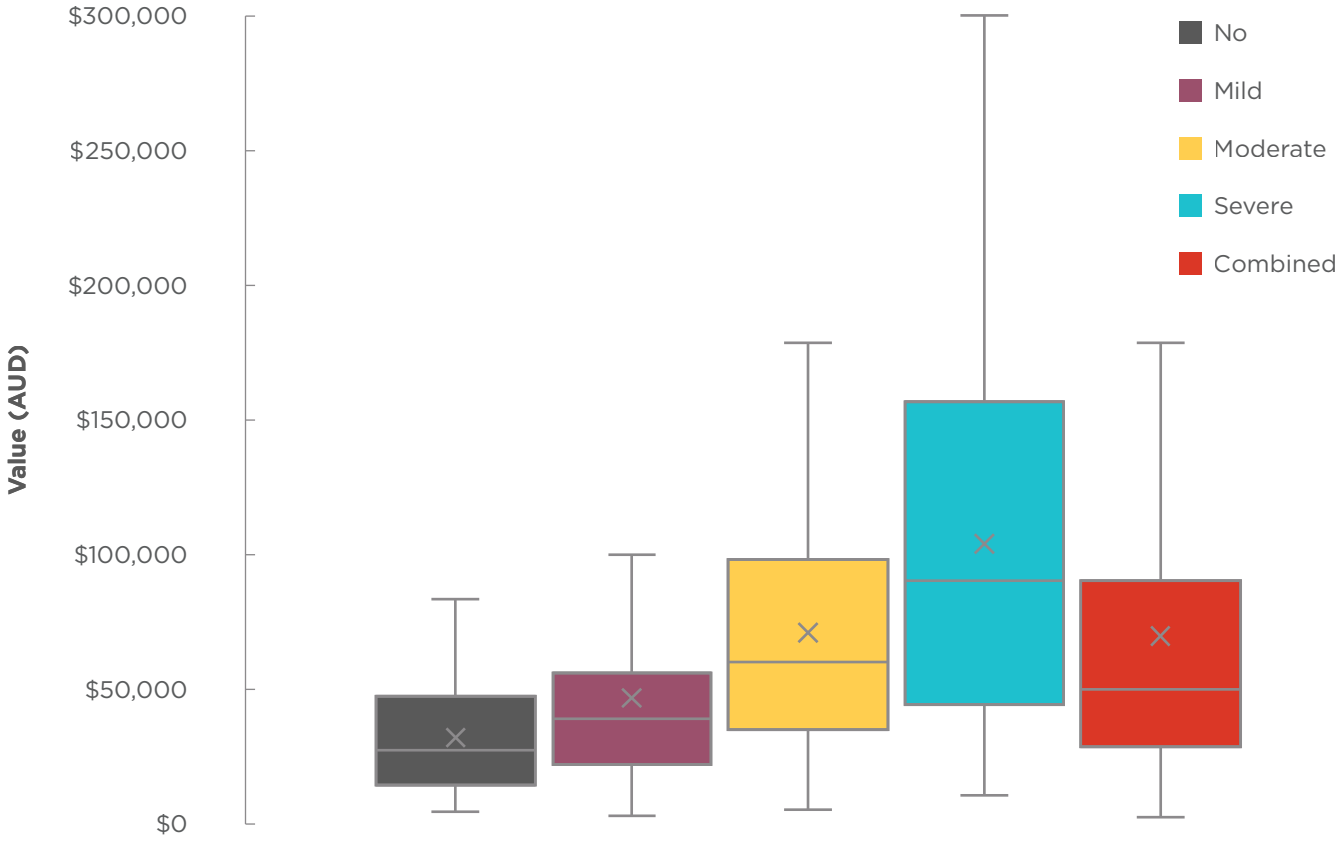
Among those who had a plan, 56.8% were living with moderate to severe MS-related disability, compared to just 20.0% among those without a plan. NDIS plan values, spanning one to five years, rose sharply with disability severity - from an average of $47,000 for individuals with mild MS-related disability 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.

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Introduction

1.1 An overview of MS

1.1.1 Symptoms

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 approximately 2.9 million people [6,7]. Symptom onset typically occurs between the ages of 20 and 40 [8]. MS can have a substantial effect on the health and wellbeing of people and places a considerable burden on their carers and families. As MS can affect many parts of the CNS, its symptoms can vary greatly in type and intensity. Common symptoms include extreme fatigue; impaired vision; difficulties with walking, balance, or coordination; dizziness; tingling and numbness; temperature sensitivity; pain; bladder and bowel problems; mood swings; and issues with concentration, memory or speech [9].

1.1.2 Causes

Disability in MS arises when the protective fatty coating around nerve fibres, called myelin, is damaged [10]. Myelin is essential for efficient communication between neurons (brain cells), and its loss can lead to neuronal death and neurological dysfunction [11]. Current evidence suggests that this process is driven by immune cells, such as lymphocytes (white blood cells), infiltrating the CNS and initiating autoimmune responses [12]. These responses include the production of autoantibodies that target myelin, resulting in damage to the myelin (demyelination) and eventual neuronal loss.

There is no known single cause of MS, but many genetic, environmental, and lifestyle factors have been shown to contribute to its development, including Epstein-Barr virus (EBV) infection, tobacco use, low vitamin D levels, adolescent obesity, and low exposure to sunlight [13,14]. Sunlight exposure, particularly during childhood, is considered one of the most important risk factors for developing MS [15]. However, the most critical environmental risk factor identified to date is infection with EBV; evidence suggests that EBV infection is necessary for a person to develop MS [16,17]. EBV is often contracted during infancy and does not present with symptoms. When contracted later in life, EBV can cause glandular fever [18]. Genetics plays a key role in the development of MS, with certain genes increasing susceptibility to environmental risk factors, such as EBV infection, smoking and adolescent obesity [19].

1.1.3 Types of MS

There are three main types of MS; relapsing-remitting MS (RRMS), secondary progressive MS (SPMS) and primary progressive MS (PPMS) (Figure 1.1). The most common form is RRMS, which is diagnosed in the majority of people living with MS (>80%). RRMS is characterised by episodes of neurological disability followed by complete or partial remission [20]. Over time, people living with RRMS may develop SPMS, which is characterised by the gradual accumulation of neurological disability, with or without relapses. Currently, conversion to SPMS is expected to take up to 30 years [21,22]. Like SPMS, PPMS is defined by the gradual accumulation of disability. However, this type is not preceded by RRMS, and does not involve relapses or recoveries, although people living with PPMS may experience periods of increased disease activity [23,24].

1.1.4 Treatment

A range of disease modifying therapies (DMTs) are available for the treatment of RRMS, with 14 listed on the Pharmaceutical Benefits Scheme (PBS) [25]. However, treatment options for progressive MS in Australia remain limited [6]. Notably, ocrelizumab was recently approved for subsidisation for the treatment of PPMS in New Zealand, but is not subsidised in Australia [26]. DMTs work by modifying the activity of the immune system and can greatly reduce the incidence of relapses and delay disability accumulation [6], as well as reduce mortality [27,28].

The therapies prescribed for people living with MS will often depend on the stage and severity of their disease. Other considerations may include other health conditions a person may have, their access to healthcare services, family planning, and the practicalities of therapeutic administration. Recent evidence strongly suggests that the early commencement of high-efficacy therapies improves long-term disease outcomes among people living with MS [29].

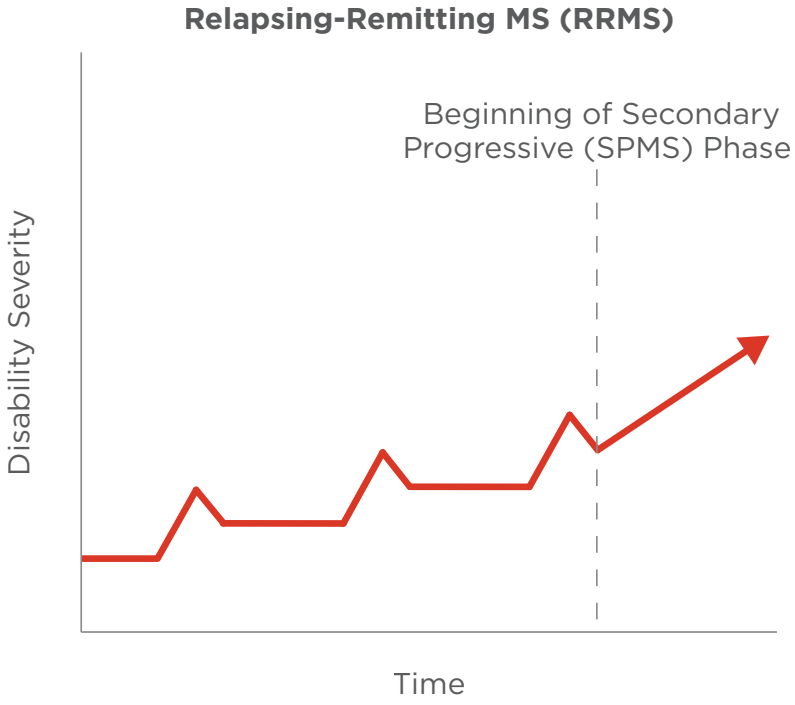
Additionally, corticosteroid methylprednisolone is commonly prescribed to people living with RRMS to reduce inflammation, accelerate recovery and minimise symptoms during a relapse [30]. There also exists a variety of symptomatic medications available for the management of MS, including those to treat muscle spasticity [31], as well as allied health therapies [32].

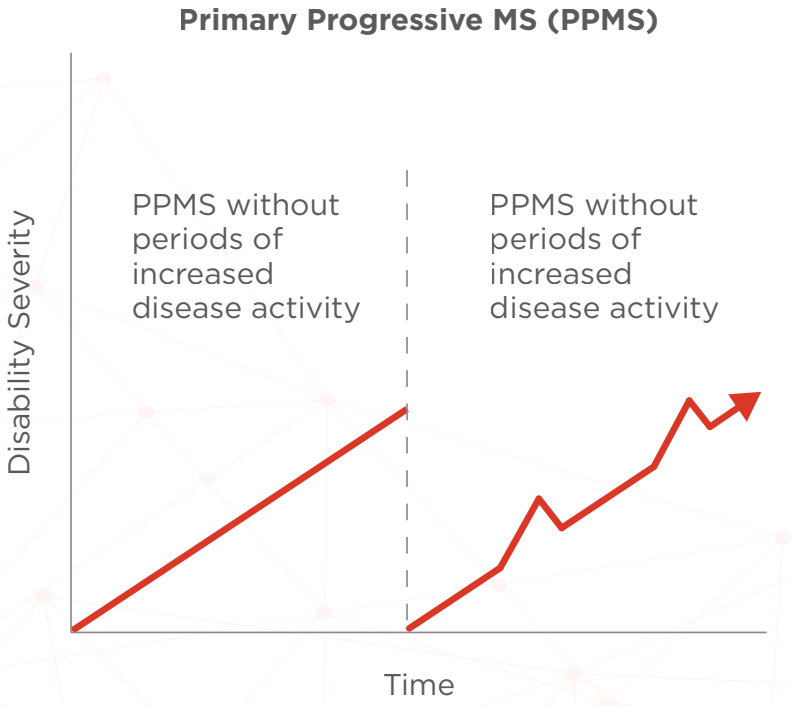
1.2 Rationale for this report: Multiple Sclerosis Prevalence and Health Economic Impact in Australia 2025

MS is a complex chronic neurological disease that carries a high health economic burden, including societal costs and quality of life impacts. Importantly, as disability severity increases, the economic burden of MS also increases. MS Australia has commissioned four previous reports to support its advocacy and awareness efforts. These reports, including both major and interim publications, were publicly released in 2005, 2011, 2018, and 2023. Each of these reports has been informed by data from the Australian MS Longitudinal Study (AMSLS), which is funded by MS Australia and managed at the MS Research Flagship at the Menzies Institute for Medical Research, Tasmania. Each report has provided relevant, comprehensive and up-to-date information regarding the prevalence of MS in Australia, impacts of MS on quality of life, and the financial and economic burdens associated with the disease.

Like previous editions, the 2025 report provides a comprehensive analysis of the economic and quality of life impacts of MS in Australia. It constitutes a contemporary and reliable source of health economic analyses that can support the MS community in its quest for improved health and economic outcomes for people living with MS, their carers and supporters, and broader Australian society. Assessing the health economic impacts of MS is an ongoing project, with each report contributing to a valuable evidence base.

Figure 1.1: Accumulation of disability severity over time for different types of MS





1.3 Aims and data sources

1.3.1 Aims

Our key aims for this health economic impact report were as follows:

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 with diagnosis disclosure 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).

Aims 3 and 6 are new to the 2025 report, introduced in response to the evolving health economic landscape surrounding MS. With respect to Aim 3, employment outcomes have recently been identified as a high priority by members of the MS community, including members of MS Australia's Lived Experience Expert Panel (LEEP), and the Menzies Consumer and Community Reference Committee. In response, we prioritised a comprehensive, Australia-wide study examining employment patterns and outcomes among people living with MS. This included an assessment of the economic impact of lost employment and reduced productivity. Aim 6 will address the NDIS as an important source of financial support for people living with disability in Australia.

1.3.2 Data sources

The AMSLS cohort completed standard economic impact and disease course surveys, and cost diary analyses were supplemented with Medical Benefits Schedule (MBS) and PBS data. Given the expanded scope of the 2025 report, we incorporated data from additional sources, including NDIS data and a dedicated employment survey in the AMSLS. As a result, cost estimates presented in this report are the most comprehensive to date.

The prevalence of MS in Australia

2.1 Summary

This chapter estimates the prevalence of MS in Australia for 2024. This was achieved using the medications-based method, combining national prescription dispensation data for MS DMTs with DMT usage/penetrance data from the AMSLS. The same method was employed in previous reports (2010, 2017, and 2021), enabling direct comparisons of prevalence over time.

In 2024, 37,756 people were living with MS in Australia – an increase of 16,473 cases (77.4%) since 2010. This corresponds to a prevalence of 139.2 per 100,000 Australians, up 45.5% over the same period. Across the major reports (2010, 2017, and 2025), prevalence rose by approximately 8.9% between 2010 and 2017 and by a further 33.7% between 2017 and 2024, indicating a sharp upward trend in recent years. These findings mirror the substantial rise in global MS prevalence. The estimates presented here underpin the cost of illness analyses in Chapter 5.

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 well-established latitudinal gradient, which shows higher MS prevalence in regions further from the equator. This gradient is largely attributed to differences in passive sunlight exposure.

The majority of people living with MS resided in VIC (12,083) or NSW (11,262), chiefly due to the large populations of these states. Additionally, age-adjusted prevalence estimates did not differ materially from crude prevalence estimates for individual states and territories.

Finally, of the 37,756 Australians living with MS in 2024, we identified that 23,217 (62%) were using DMTs. In 2024, 187,293 prescriptions were dispensed, which was 12,829 more than in 2021.

2.2 Introduction

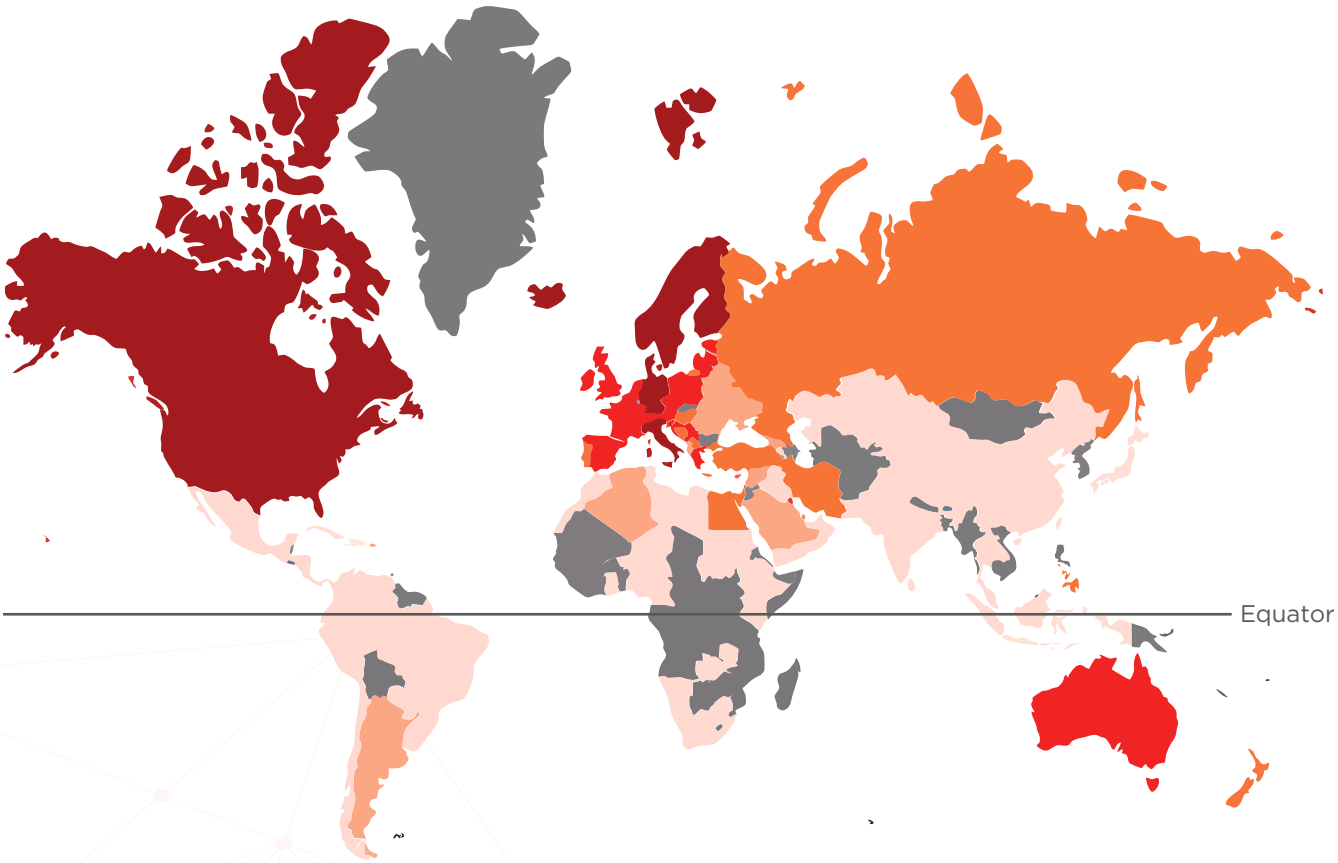
2.2.1 Escalation of worldwide prevalence

The global number of people living with MS continues to rise, with an estimated 2.9 million cases as of 2023 [7]. The estimated number increased from 2.1 million to 2.3 million between 2008 and 2013 [33]. From 2013 to 2020, it grew by a further half a million to 2.8 million [34]. These figures collectively demonstrate an accelerating global trend in MS burden.

Country-specific, relative prevalences are shown in Figure 2.1. The surge in cases over recent decades is explained in part by increasing MS incidence [35] and earlier, more accurate diagnosis [34]. If these circumstances persist, we should expect and be prepared for many more people to be diagnosed with MS in the coming years. Increasing prevalence is also explained by longer lifespans among people living with MS. This is attributed to advances in MS treatments, especially MS DMTs [36] and improved care for people living with MS through specialised services, among other factors.

Although the prevalence of MS is increasing globally, it remains higher at greater latitudes (i.e. further from the equator; see Figure 2.1). This pattern is largely attributed to reduced sunlight exposure among individuals living further from the equator [15]. Sunlight plays a crucial role in regulating vitamin D levels and metabolism, which are important for immune system function [37]. Other major risk factors for MS include tobacco smoking, adolescent obesity, exposure to EBV (a prerequisite for MS development) and genetic predispositions [14]. Importantly, women are more than twice as likely to be diagnosed with MS than men [6].

Figure 2.1: Relative prevalence of MS by country in 2024



Source: Atlas of MS[1]

2.2.2 Escalation in the number of people living with MS in Australia (2010-2021)

Changes in the number of people living with MS globally have been mirrored in Australia. As detailed in our previous reports, an estimated 21,283 Australians were living with MS in 2010 [38]. This increased substantially to 25,607 by 2017 and reached 33,335 in 2021 [39]. Over this 11-year period, the estimated number of people living with MS in Australia rose by 30.2%, with much of the increase occurring in recent years, reflecting an accelerated rise in case numbers. Consistent with global patterns, the number of people living with MS is greater in Australia's southern states, which are further from the equator.

2.2.3 Aims of the chapter

In this chapter, we estimated both the number of people living with MS and its prevalence in Australia in 2024, and compared these estimates with those from the 2010, 2017, and 2021 reports. To ensure consistency, we have applied the same medications-based prevalence calculation method used in our previous reports. This approach is detailed in Section 2.3.

2.3 Methods

2.3.1 Estimating the number of people living with MS who are treated with DMTs

The PBS and the Repatriation PBS (RPBS) are core components of our Australia's universal healthcare system. These schemes provide subsidised medications to Australian citizens and residents. To estimate the number of people living with MS in Australia in 2024, we extracted PBS and RPBS prescription data related to the frequencies with which MS-specific DMTs were prescribed. This data was sourced from Medicare Australia's central repository [40]. We excluded medications used off-label, as well as therapeutics not subsidised under the PBS/RPBS or obtained outside Australia. All prescription data were categorised by state and territory of issue.

Consistent with our previous reports using the medications-based methodology, people who filled MS DMT prescriptions during the 2024 calendar year were classified as people living with MS [38,39,41]. To estimate the number of people living with MS receiving a DMT, the total number of prescriptions for each therapy was divided by the standard annual number dispensed per person (Table 2.1). For example, people receiving ocrelizumab require two prescriptions per year, therefore, the total number of ocrelizumab prescriptions were divided by two to identify the number of individuals treated with this therapy.

2.3.2 Estimating DMT penetrance

To determine what percentage of Australians living with MS were captured in the medications-based prevalence estimate, we first calculated the proportion of individuals using DMTs in 2024, referred to as DMT penetrance, since not every person with MS receives a DMT. This estimate was based on data from the AMSLS 2024 Disease Course Survey, drawn from a large and representative MS population. Active participants of the AMSLS were asked to indicate whether they were using a DMT in 2024, enabling the estimation of DMT penetrance nationally and for each state and territory.

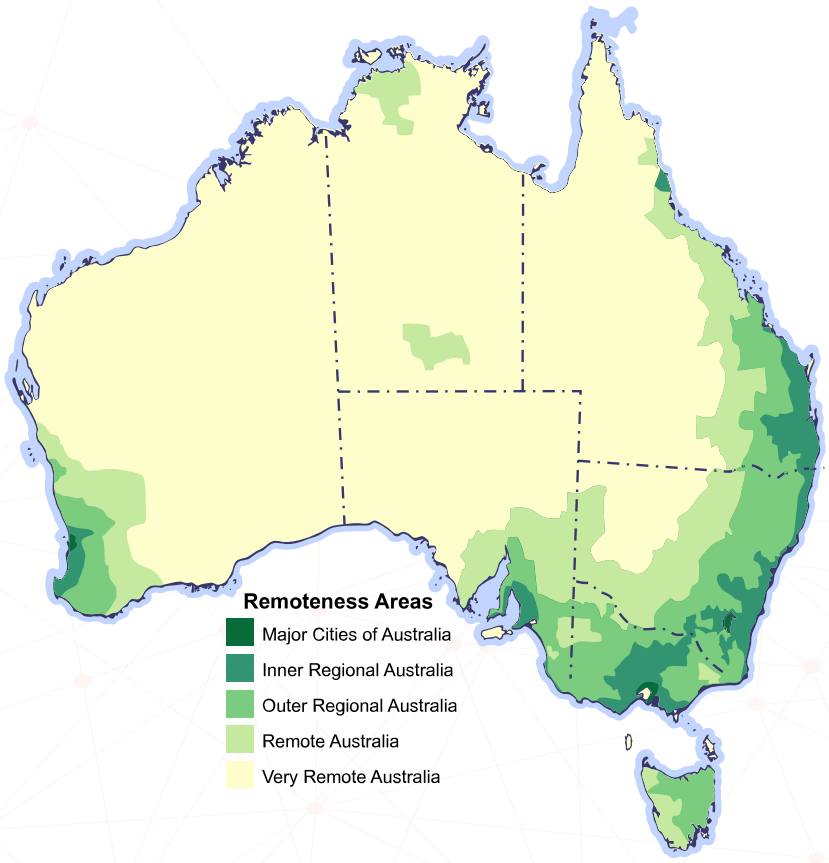
We have also reported summary statistics of key demographics, including age, sex and geographical remoteness for the AMSLS participants whose data was used to calculate DMT penetrance. Remoteness is a measure of a person's distance from major population centres and the services in these centres, and is categorised as *major cities, inner regional, outer regional, remote, or very remote* under the Australian Bureau of Statistics' (ABS) Australian Statistical Geography Standard remoteness areas (Figure 2.2) [42].

Table 2.1: DMTs approved for use and subsidised under the PBS in 2024, along with their modes of administration and the standard annual number of prescriptions per person.

GENERIC NAMES	MODE OF ADMINISTRATION	ANNUAL SCRIPTS
Alemtuzumab	Intravenous Infusion	1
Cladribine	Oral Tablet	2
Dimethyl Fumarate	Oral Tablet	12
Diroximel Fumarate	Oral Tablet	12
Fingolimod	Oral Tablet	12
Glatiramer Acetate	Subcutaneous Injection	12
Interferon Beta-1b	Subcutaneous Injection	12
Natalizumab	Intravenous Infusion / Subcutaneous Injection	12
Ocrelizumab	Intravenous Infusion	2
Ofatumumab	Subcutaneous Injection	12
Ozanimod	Oral Tablet	12
Peginterferon Beta-1a	Subcutaneous Injection	12
Siponimod	Oral Tablet	12
Teriflunomide	Oral Tablet	12

Notes: Between our 2021 and 2024 studies, Interferon Beta-1a (subcutaneous injection) was removed from the PBS and Diroximel Fumarate (oral) was added.[14]

Figure 2.2: Australian remoteness in 2023



Source: Australian Bureau of Statistics

2.3.3 Estimation of crude MS prevalence in Australia in 2024

As described above, we used prescription data to estimate the number of people living with MS who used a DMT in 2024. This figure represents a fraction of people living with MS, as such, AMSLS data was used to determine what proportion were not using DMTs. By combining these data sources, we were able to estimate the total number of Australians living with MS. Plausible ranges for case number estimates were derived from the minimum and maximum state/territory-specific DMT penetrance values. Using ABS census data (September 2024) [43], we also calculated national and state/territory crude MS prevalence, expressed as the number of people living with MS per 100,000 Australians.

2.3.4 Estimation of age-standardised MS prevalence in Australia in 2024

MS prevalence is reported using both crude estimates and estimates that are adjusted for age [39]. The age-adjusted estimates were based on the direct method used in the 2010 and 2017 Health Economic Impact of MS in Australia reports. This age adjustment accounts for the confounding effects of an ageing population and is essential for valid comparisons of prevalence estimates across states and territories. For the purposes of the age-adjustment, demographic data were sourced for the general population and people living with MS from the ABS and client databases of MS organisations, respectively.

2.4 Results

2.4.1 DMT prescriptions and penetrance

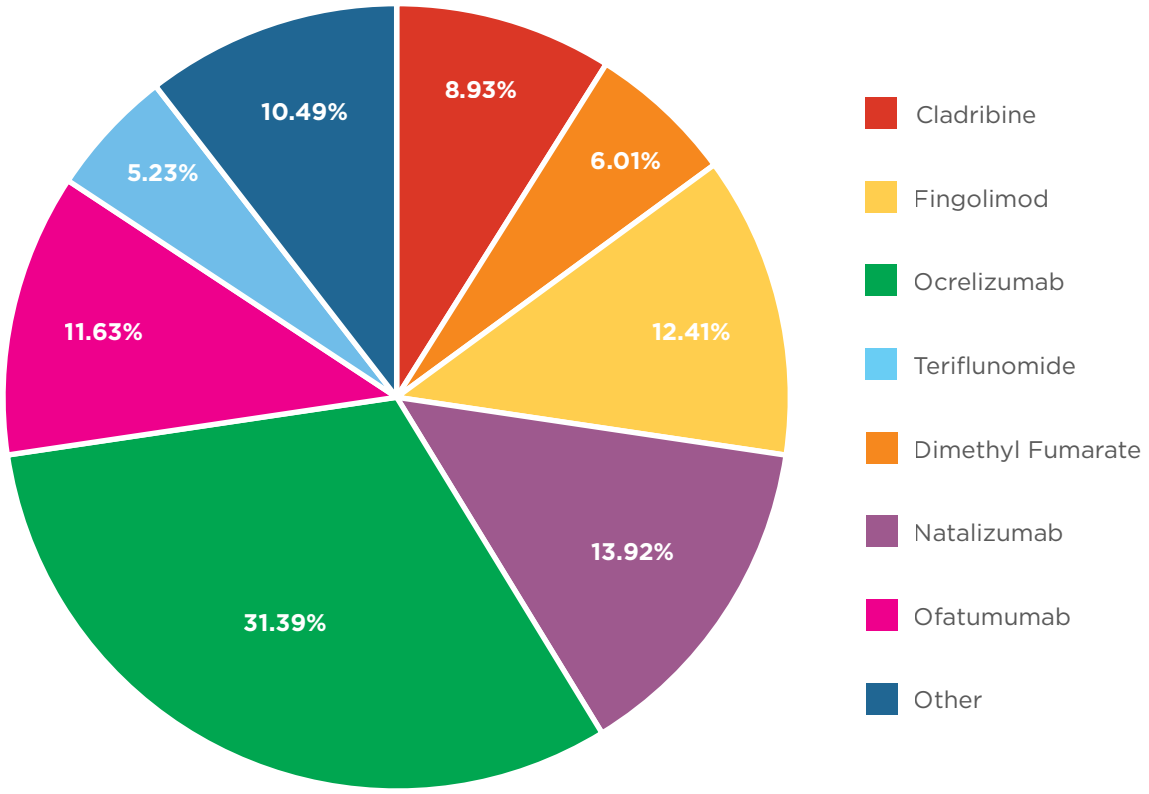
Compared to the 2021 report, an additional 12,829 MS-specific PBS and RPBS DMT prescriptions were dispensed in 2024, increasing from 174,464 to 187,293 (Table 2.2; Supplementary Table 2.1).

The most frequently prescribed DMTs were ocrelizumab (14,790 scripts across 7,395 people), natalizumab (39,347 scripts across 3,279 people), and fingolimod (35,080 scripts across 2,923 people). As with previous years, more prescriptions were dispensed in VIC and NSW (63,234 and 57,782, respectively) than in all other states and territories combined. Overall, we found that 23,540 Australians living with MS were treated with DMTs in 2024 and that 187,293 prescriptions were dispensed (see Figure 2.3 for a full medication-specific breakdown of DMT usage per person).

DMT penetrance has remained largely stable over the seven years ending in 2024 (Table 2.3). Using data from the AMSLS, we estimated that 62% of Australians living with MS were using a DMT in 2024. The highest rate of penetrance was observed in WA, at 66%.

Nationally, AMSLS participants used in the penetrance calculations (n = 1,455) had a median age of 61 years and were 79.4% female (Table 2.3). These numbers were reasonably consistent across all states and territories. While remoteness varied somewhat, particularly in TAS, which lacks an ABS-defined *major city*, it was generally the case that most participants resided in major cities (70.5%).

Figure 2.3: Proportion of people living with MS using commonly prescribed DMTs



Notes: Other DMTs include alemtuzumab (0.17%), diroximel fumarate (1.28%), glatiramer acetate (3.18%), interferon beta-1b (0.83%), ozanimod (0.72%), peginterferon beta-1a (2.01%), and siponimod (2.30%).

Table 2.2: Number of PBS and RPBS DMT prescriptions issued to Australians living with MS, from 1 January 2024 through 31 December 2024.

GENERIC NAME	AUSTRALIAN STATES AND TERRITORIES								
	NSW	VIC	QLD	SA	WA	TAS	ACT	NT	TOTAL
Alemtuzumab	10	4	20	1	0	0	4	0	39
Cladribine	1415	1319	667	376	207	152	62	11	4209
Dimethyl Fumarate	6,794	4,476	2,482	1,322	1,258	353	288	10	16,983
Diroximel Fumarate	1,475	937	523	176	144	190	161	6	3,612
Fingolimod	8,905	12,852	5,472	4,334	2,198	397	781	141	35,080
Glatiramer Acetate	2,847	2,341	1,686	810	773	239	294	12	9,002
Interferon Beta-1b	603	674	498	203	280	74	9	19	2360
Natalizumab	10,265	14,253	6,447	3,018	3,717	1,151	363	133	39,347
Ocrelizumab	3,554	5,720	1,974	1,256	1,490	439	324	33	14,790
Ofatumumab	18,132	5,662	3,617	1,086	2,910	803	581	79	32,870
Ozanimod	935	694	177	96	57	18	47	3	2027
Peginterferon Beta-1a	1,874	1,349	1,075	458	544	170	199	4	5,673
Siponimod	2,427	2,272	768	542	257	55	176	6	6,503
Teriflunomide	3,998	5,229	2,919	836	1,092	548	166	10	14,798
State, Territory, and National Totals	63,234	57,782	28,325	14,514	14,927	4,589	3,455	467	187,293

Source - Medicare Australia Statistics. http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp

Table 2.3: DMT penetrance (AMSLS), sociodemographics (AMSLS), Australian populations (ABS), and estimated number of people living with MS based on the number of dispensed DMT prescriptions

	AUSTRALIAN STATES AND TERRITORIES								
	NSW	VIC	QLD	SA	WA	TAS	ACT *	NT *	NATIONAL
Total Population (ABS)*	8,469,597	6,959,234	5,560,452	1,873,819	2,951,602	575,660	472,803	254,263	27,122,411
AMSLS Participants †	414 (28.5%)	397 (27.3%)	203 (14.0%)	161 (11.1%)	128 (8.8%)	92 (6.3%)	58 (4.0%)	2 (0.1%)	1,455 (100%)
AMSLS Age †	61 (52-68)	60 (51-68)	61 (51-70)	60 (50-66)	60 (51-69)	63 (52-69)	NA	NA	61 (51-68)
AMSLS Female †	78.8%	80.1%	87.2%	77.6%	72.7%	80.4%	NA	NA	79.4%
AMSLS Remoteness †									
Outer regional and remote	4.1%	3.0%	14.8%	14.9%	8.6%	28.3%	NA	NA	3.0%
Inner regional	27.5%	26.5%	21.2%	14.9%	13.3%	71.7%	NA	NA	26.5%
Major cities	68.4%	70.5%	64.0%	70.2%	78.1%	0.0%	NA	NA	70.5%
2017 Penetrance of DMTs [2] †	62%	69%	60%	60%	68%	59%	64%	64%	64%
2021 Penetrance of DMTs [1] †	61%	68%	54%	63%	64%	52%	62%	62%	62%
2024 Penetrance of DMTs †	65%	64%	57%	61%	66%	54%	62%	62%	62%
2024 Estimated number of people living with MS with Plausible Ranges ‡	11,270 (13,499-11,111)	12,086 (14,239-11,720)	6,058 (6,391-5,260)	3,086 (3,472-2,858)	2,950 (3,584-2,950)	1,155 (1,155-951)	725 (831-684)	92 (105-87)	37,756 (43,277-35,621)

Notes: † The AMSLS sample comprised 1,455 people living with MS. Age and disease duration were presented as median (interquartile range).

‡ Plausible ranges were based on the highest and lowest state-specific DMT penetrance values. For ACT and NT, penetrance was assumed to equal the national mean due to data limitations.

*Summary statistics for age, sex, disease duration, remoteness, and DMT penetrance were not estimated for ACT and NT because of data limitations.

2.4.2 Total number of people with MS and crude prevalence of MS in Australia

The total number of people living with MS in Australia in 2024 was 37,756 with a plausible range from 35,621 to 43,277 (inclusive). This represents an increase of 4,321 individuals (13.3%) from 2021, 12,149 (47.4%) from 2017, and 16,473 (77.4%) from 2010 (see Supplementary Table 2 for a complete list of national and state-specific changes in case numbers and crude prevalence per 100,000).

The crude prevalence of MS in Australia has increased by 43.6 cases per 100,000 people (a 45.4% rise) over the past 14 years – from 95.6 cases per 100,000 people in 2010 to 139.2 per 100,000 in 2024 (Figure 2.4). Across the major reports (2010, 2017, and 2024), prevalence grew by approximately 8.9% between 2010 and 2017, and by a further 33.7% between 2017 and 2024, underscoring a sharp upward trend in recent years. Since our interim report in 2021, the crude prevalence of MS in Australia has increased by 8.1 cases, reaching to 139.2 per 100,000 (95% CI: 137.8-140.6; see Figure 2.4).

2.4.3 Age-adjusted prevalence of MS in Australia and its states and territories

Crude and age-adjusted prevalence estimates of MS for 2024, 2021, 2017, and 2010 are provided (Table 2.4 and Figure 2.5). Age-adjusted prevalence estimates enable meaningful comparisons across states by accounting for differences in population age structures. The greatest increase in age-adjusted prevalence was observed in VIC, rising by 20.3 per 100,000 people. A substantial increase was also observed in NSW. Elsewhere, age-adjusted prevalence remained reasonably stable, with a minor decrease observed in some states. Nevertheless, age-adjusted prevalence was still highest in TAS at 190.1 per 100,000 people, showing a continuation of the trend from previous studies. Over the 14 years of prevalence studies, the largest proportional increase in age-adjusted prevalence occurred in QLD, rising by 117.4%, from 45.9 to 99.8 per 100,000 people.

Age-adjusted MS prevalence estimates plotted against to the latitude of state and territory capital cities illustrate the persistent latitudinal gradient in MS prevalence (Figures 2.6a-d and 2.7). For example, Brisbane, the capital of QLD, is located at 27.3˚S and has an age-adjusted prevalence of 99.8 per 100,000 people [95% CI: 98.6-100.9]. In contrast, Hobart, the capital of TAS, is situated at a higher latitude of 42.5˚S and reports the highest age-adjusted prevalence of 190.1 per 100,000 people [95% CI: 188.5-191.8]. Notably, the latitudinal gradient was more pronounced in 2024 and 2021 compared to 2017.

Figure 2.4: Number of Australians living with MS and crude prevalence classified by year of estimation

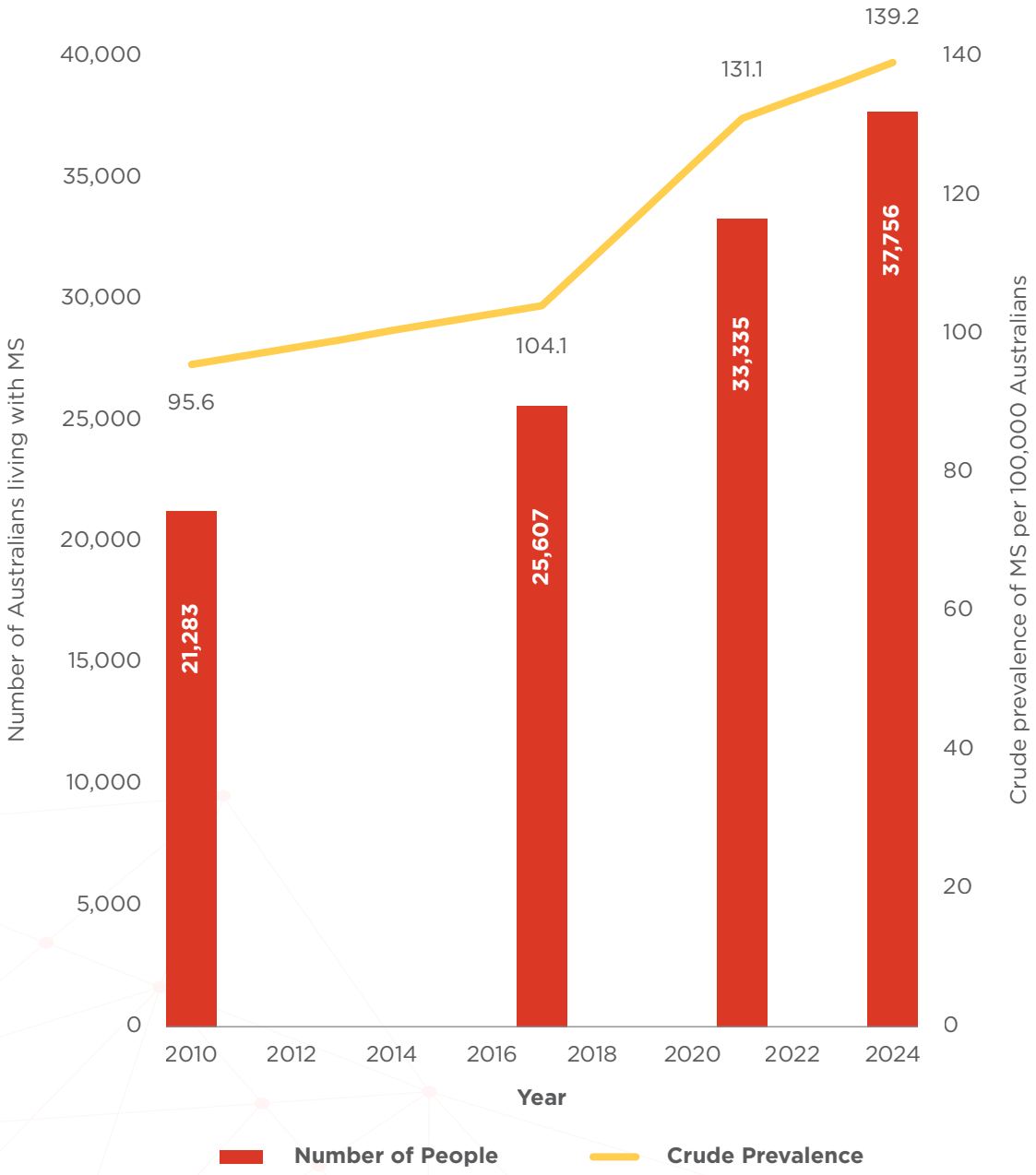


Figure 2.5: Age-adjusted prevalence of MS in Australian states and territories for 2010, 2017, 2021, and 2024

Figure 2.6: Age-adjusted prevalence of MS by latitude across Australian states and territories in 2024, 2021, 2017 and 2010

Figure 2.6a: Latitudinal gradient in 2024

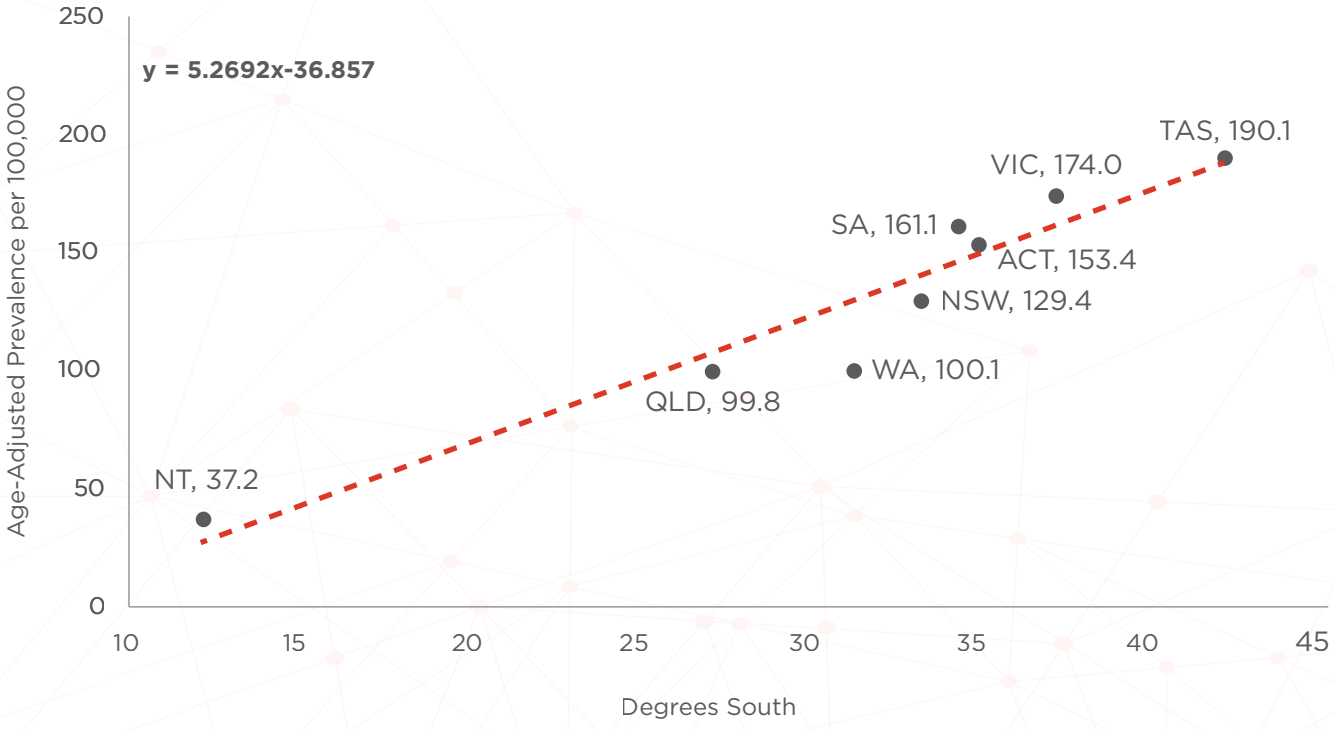


Figure 2.6b: Latitudinal gradient in 2021

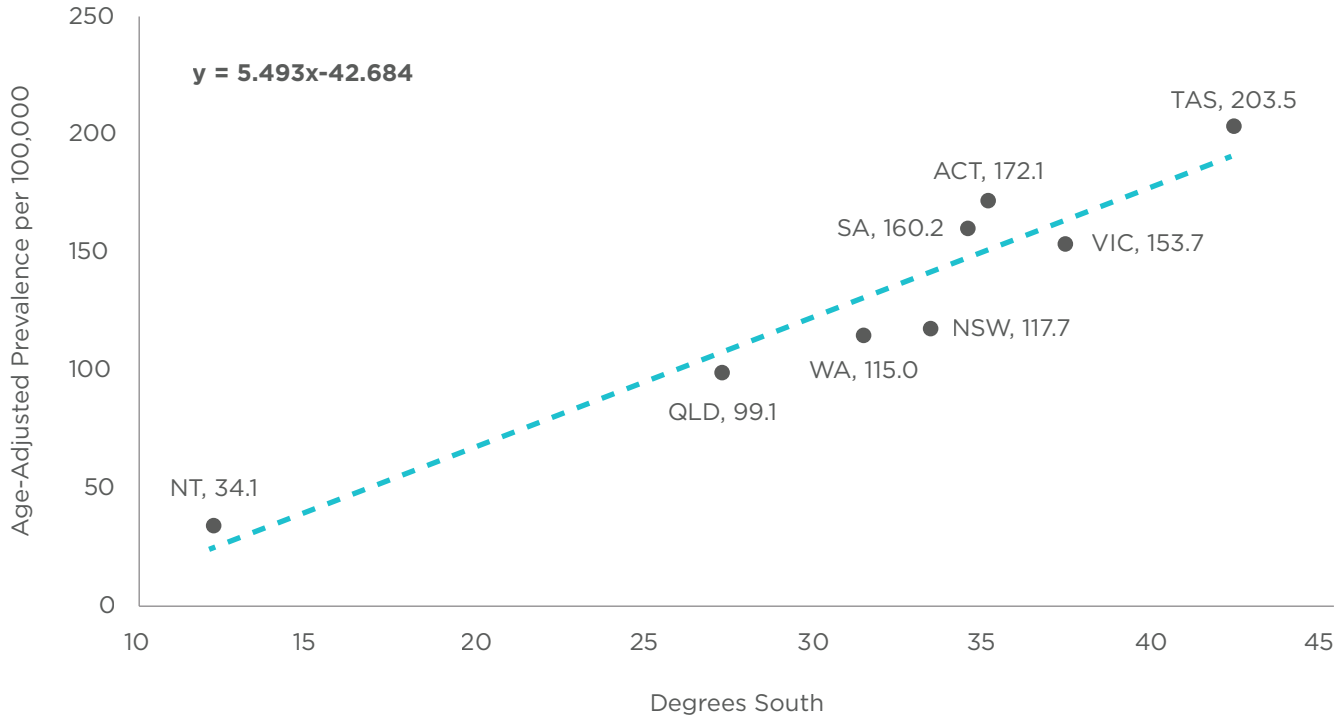


Figure 2.6c: Latitudinal gradient in 2017

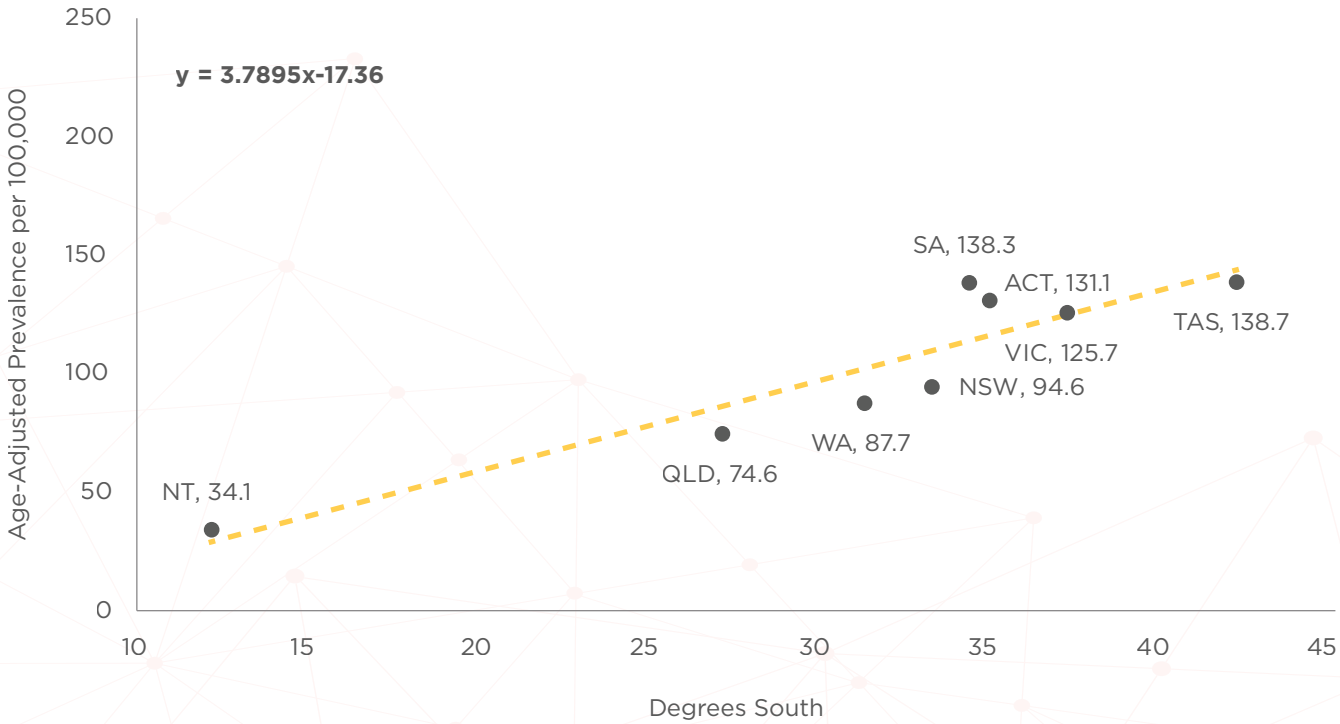


Figure 2.6d: Latitudinal gradient in 2010

Figure 2.7: Age-adjusted MS prevalence estimates (per 100,000 people) for 2010, 2017, 2021 and 2024 in Australia's states and territories

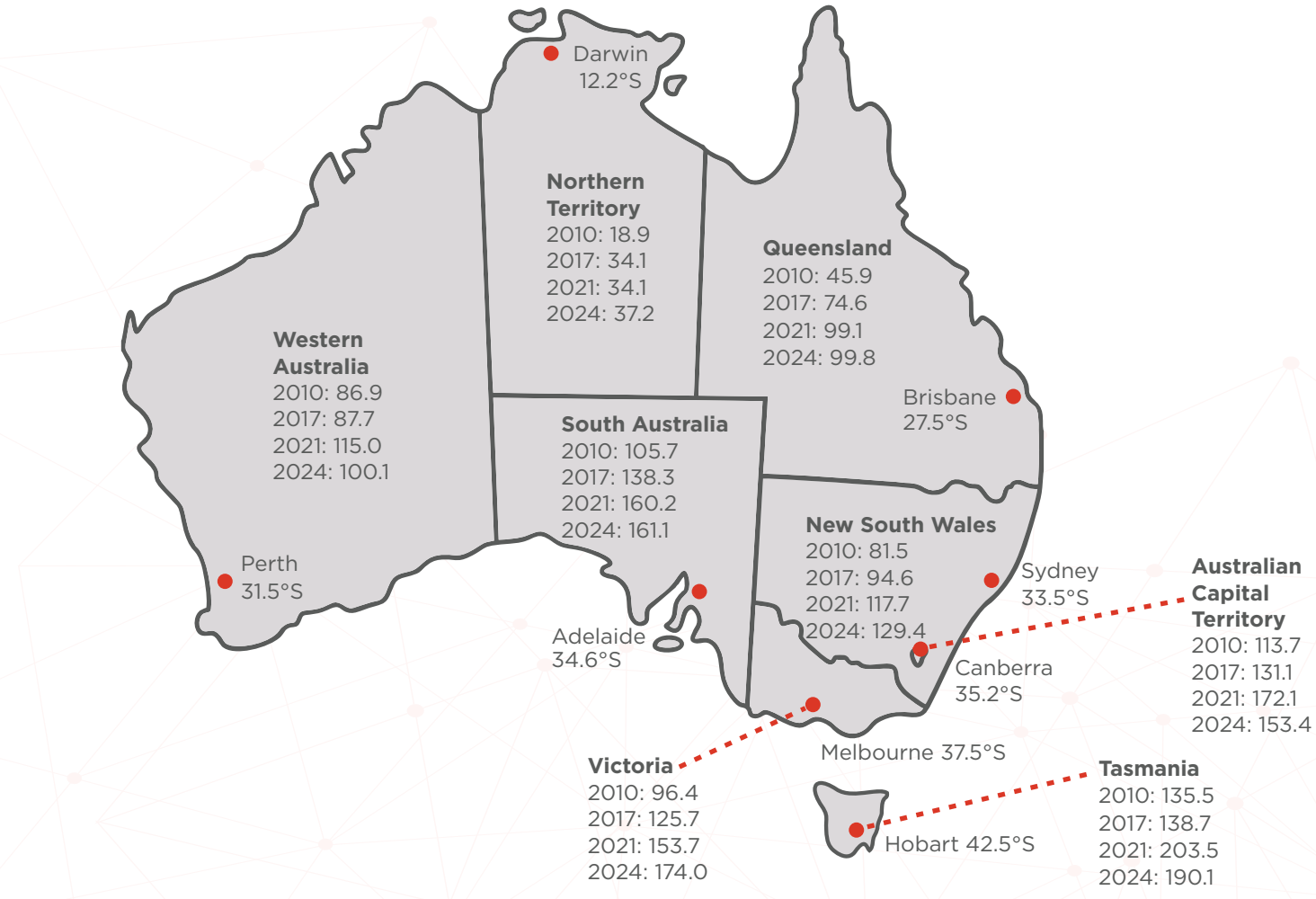


Table 2.4: Crude and age-adjusted prevalence of MS by state and territory

	PEOPLE LIVING WITH MS	TOTAL POPULATION	CRUDE PREVALENCE PER 100,000 (95% CI)	AGE-ADJUSTED PREVALENCE PER 100,000 (95% CI) †
National				
2010	21,283	22,271,900	95.6 (94.3-96.9)	-
2017	25,607	24,598,933	104.1 (102.8-105.4)	-
2021	33,335	25,417,999	131.1 (129.7-132.6)	-
2024	37,756	27,122,411	139.2 (137.8-140.6)	-
New South Wales				
2010	6,268	7,221,000	86.8 (84.7-89.0)	81.5 (80.4-82.6)
2017	7,682	7,895,800	97.3 (95.1-99.5)	94.6 (94.9-97.2)
2021	9,783	8,072,146	121.2 (118.8-123.6)	117.7 (116.4-119.0)
2024	11,270	8,469,597	133.1 (130.6-135.5)	129.4 (128.1-130.8)
Victoria				
2010	6,637	5,529,400	120.0 (117.1-122.9)	96.4 (95.3-97.6)
2017	7,895	6,358,900	124.2 (121.4-126.9)	125.7 (125.9-128.6)
2021	9,969	6,503,498	153.3 (150.3-156.3)	153.7 (152.2-155.2)
2024	12,086	6,959,234	173.7 (170.6-176.8)	174.0 (172.4-175.6)
Queensland				
2010	3,179	4,498,900	70.7 (68.3-73.2)	45.9 (45.1-46.7)
2017	3,970	4,948,700	80.2 (77.7-82.8)	74.6 (74.5-76.5)
2021	5,535	5,156,125	107.4 (104.6-110.2)	99.1 (97.8-100.4)
2024	6,058	5,560,452	108.9 (106.2-111.7)	99.8 (98.6-100.9)
South Australia				
2010	1,760	1,640,700	107.3 (102.4-112.4)	105.7 (104.5-106.9)
2017	2,452	1,726,900	142.0 (136.5-147.7)	138.3 (136.9-139.7)
2021	3,041	1,781,513	170.7 (164.7-176.9)	160.2 (158.7-161.7)
2024	3,086	1,873,819	164.7 (159.0-170.6)	161.1 (159.6-162.6)
Western Australia				
2010	2,313	2,286,100	101.2 (97.2-105.4)	86.9 (85.8-88.0)
2017	2,219	2,587,100	85.8 (82.3-89.4)	87.7 (88.8-91.1)
2021	2,905	2,660,025	109.2 (105.3-113.3)	115.0 (113.7-116.3)
2024	2,950	2,951,602	99.9 (96.4-103.6)	100.1 (98.9-101.3)
Tasmania				
2010	718	507,100	141.6 (131.6-152.3)	135.5 (134.1-136.9)
2017	774	522,000	148.3 (138.2-159.1)	138.7 (138.5-141.3)
2021	1,186	557,568	212.7 (200.9-225.2)	203.5 (201.8-205.2)
2024	1,155	575,660	200.6 (189.4-212.6)	190.1 (188.5-191.8)
Aust. Capital Territory				
2010	360	357,700	100.6 (90.7-111.5)	113.7 (112.4-115.0)
2017	538	412,600	130.4 (119.8-141.9)	131.1 (131.0-133.7)
2021	774	454,500	170.3 (158.7-182.7)	172.1 (170.6-173.6)
2024	725	472,803	153.3 (142.6-164.9)	153.4 (151.9-154.9)
Northern Territory				
2010	49	230,460	21.3 (16.1-28.2)	18.9 (18.4-19.4)
2017	77	247,514	31.1 (25.0-39.1)	34.1 (33.7-35.1)
2021	89	248,387	35.8 (31.1-47.1)	34.1 (33.5-34.7)
2024	92	254,263	36.2 (29.5-44.4)	37.2 (36.5-37.9)

Notes: † Prevalence estimates were standardised based on the distributions of ages observed in the Australian population as of June 2024. Population data was sourced ABS estimates for March 2010, September 2017, and September 2021, and March 2024.

2.5 Discussion

2.5.1 Overview

The number of Australians living with MS continues to rise substantially, reaching 37,756 in 2024. This equates to 139.2 cases per 100,000 people and reflects an increase of 4,390 cases (13.3%) since 2021, 12,118 cases (47.4%) since 2017, and 16,442 cases (77.4%) since 2010. In 2024, approximately 62% of Australians living with MS received treatment with DMTs, consistent with findings from previous reports. Overall, these findings highlight the need for increased and targeted resourcing to support the wellbeing of an ever-growing number of people living with MS.

2.5.2 Comparisons with global trends

Over the past decade, we have observed a strong and sustained increase in MS prevalence in Australia, mirroring global trends. According to the *Atlas of MS* report, global MS prevalence rose by 50% between 2013 (29.3 per 100,000) and 2020 (44.0 per 100,000), with increases reported across all continents [34]. As in Australia, the magnitudes of these increases varied between regions. For example, between 2013 and 2020, MS prevalence in the Americas increased by 54.9 cases per 100,000 (62.89 to 117.49), while Europe saw an increase of 34.8 cases per 100,000 (108.0 to 142.8).

The *Atlas of MS* report attributed this rise in global prevalence to a variety of factors, including improved diagnosis of MS and increased longevity among people living with MS [34]. Improvements in longevity have been documented in Australian and European research, reflected in ageing global MS populations [35,44].

Additional drivers of increased prevalence include higher rates of adolescent obesity [28], a known risk factor for MS onset, along with reduced sun exposure [11], and declining pregnancy rates [45].

2.5.3 Prevalence in Australian states and territories

Among the Australian states and territories, TAS continues to have the highest prevalence of MS. As in previous reports, the age-adjusted prevalence in WA and QLD were approximately half that of Australia's southernmost state, TAS (Figure 2.7). This latitudinal gradient, where there is greater MS prevalence in locations that are further from the equator [15], was also recently observed in a Brazilian study [46].

A Dutch study estimated a crude prevalence of 212.5 per 100,000 people (95% CI: 205.0-220.2), which is similar to our estimates for TAS (crude prevalence of 200.6 per 100,000 [95% CI: 189.4-212.6]) [47]. Notably, our TAS prevalence estimates closely align with those reported in a formal MS prevalence study conducted in Hobart, where cases were directly ascertained using medical records and administrative databases. [28]. This study supports the validity of our medications-based method.

While TAS recorded the highest age-adjusted prevalence of MS, the majority of Australians living with MS resided in the country's most populous states of VIC and NSW. The latitudinal gradient was also evident between these states. Despite NSW having 1.5 million more residents, VIC, which is located further south, reported a higher number of MS cases (NSW: 11,270 cases; age-adjusted prevalence of 129.4 per 100,000 vs. VIC: 12,086 cases; age-adjusted prevalence of 174.0 per 100,000).

The lowest prevalence was observed in the NT, whose capital is situated closer to the equator than any other Australian capital city (12.2˚S).

Additionally, in some states (including TAS, WA, and SA), crude prevalence per 100,000 has declined despite the number of people living with MS increasing or remaining relatively stable. This likely reflects rapid population growth, which can lower prevalence rates despite rising case numbers. Between 2021 and 2024, Australia's population grew by almost two million, an increase of approximately 7% (Table 2.4).

2.5.4 DMT penetrance

DMT penetrance in Australia has remained stable since 2017 at approximately 62% (Table 2.3). However, usage has declined marginally in some states. This may reflect ageing populations, as DMTs are less commonly prescribed for older people living with MS [48]. It may also indicate local prescribing practices that favour non-continuing treatments such as alemtuzumab or cladribine [49].

2.5.5 Strengths and limitations

Our medications-based method for estimating MS prevalence is efficient and effective. This method has relatively simple data requirements and is capable of rapidly generating consistent estimates for prevalence. In contrast, the main alternative approach, which uses health insurance claims data from public and private sources, is time and resource intensive, particularly in large countries like Australia. Importantly, a recent Polish study demonstrated that the claims-based approach is highly sensitive to the specifications of algorithms used to extract prevalence estimates [50]. As such, its performance can vary significantly, with different algorithms producing divergent prevalence estimates. More concerningly, there is currently no validated method to assess whether a particular algorithm is functioning effectively.

The main limitation of this study is the inability to account for people living with MS who (1) ceased DMT use, (2) switched DMTs during the 2024 calendar year, or (3) previously recieved short-course treatments such as alemtuzumab or cladribine [49]. Regarding the first two points, while some individuals may have changed or discontinued DMTs during 2024, existing literature indicates that adherence to MS treatments tends to remain stable over 12-month periods [51,52]. Additionally, under the PBS, concurrent use of multiple DMTs is not permitted.

With respect to the third concern, people who were treated with short-course DMTs in prior years may not have been identified in the 2024 PBS prescription data, potentially leading to a slight underestimation of the number of people living with MS. Moreover, these individuals may have been misclassified as untreated in the AMSLS, which could lower DMT penetrance and result in a slight overestimation of the number of people living with MS. The net impact of these opposing effects would depend on which influence was stronger, with the potential for a non-differential bias.

2.5.6 Conclusions

Consistent with global trends, MS prevalence continues to rise in Australia, with the largest increase observed in VIC. This national growth may be partly attributed to improved longevity among people living with MS and more accurate diagnosis. However, changes in exposure to known MS risk factors, such as increased rates of adolescent obesity, declining rates of pregnancy, and decreased sun exposure, are likely significant contributors to the rise in prevalence.

Up-to-date information on MS prevalence in Australia is crucial to guide and support both advocacy efforts and healthcare planning. The data presented in this chapter will be critical to developing an effective treatment and management response to the increasing burden of MS in Australia.

CHAPTER 3

Health-related quality of life for people living with MS

3.1 Summary

In this chapter, we explored health-related quality of life among people living with MS in 2024. Health-related quality of life refers to the effects of health on an individual's capacity to live a rewarding and satisfying life and can be measured using a self-reported (or 'patient-reported') outcome metric called a health state utility (HSU). As a general measure of health-related quality of life, HSU is represented on a zero (equivalent to death) to one (equivalent to full health) scale. These values are derived using multi-attribute utility instruments, which consist of structured survey questions and an associated scoring algorithm. For this report, we used the EQ-5D-5L-Psychosocial multi-attribute utility instrument, which we have previously identified as sensitive to changes in both the physical and psychosocial health among Australians living with MS [5]. It is also low burden for participants, comprising nine survey questions.

To evaluate the HSU estimates, we compared them against Australian population norms and the minimum important change threshold, defined as a clinically meaningful difference of 0.06 utility points. Additionally, to assess domain-specific aspects of health-related quality of life (i.e. relating to particular elements of health), we examined responses to each of the nine survey questions in the EQ-5D-5L-Psychosocial instrument. These questions cover key health domains including mobility, self-care, the ability to conduct usual activities, pain and discomfort, anxiety and depression, vitality and fatigue, sleep quality, relationships, and social isolation.

We found a mean HSU of 0.60 among Australians living with MS in 2024. This value has remained unchanged since 2017, despite AMSLS participants being older on average and having lived with MS for a longer duration [39]. This mean HSU is substantially lower than the Australian population norm of 0.80, indicating a reduced health-related quality of life and reflecting the high burden of MS-related disability. Moreover, the observed difference exceeds the minimum important change threshold of 0.06 utility points, underscoring its clinical significance.

Using MS-related disability severity categories, we calculated mean HSU scores. The mean utilities were:

- 0.78 for individuals with no disability
- 0.60 for mild disability
- 0.50 for moderate disability
- 0.47 for severe disability

Importantly, we found that the mean HSU for people living with MS who had no disability were similar to Australian population norms.

Compared to 2017, a smaller proportion of AMSLS participants were classified as having moderate disability in 2024, while a greater proportion were classified as having mild disability. As expected, transitioning from moderate to mild disability status was associated with a 0.10-point improvement in HSU (from 0.50 to 0.60), exceeding the threshold for minimum important change.

Differences in health-related quality of life were also influenced by factors beyond disability severity. For instance, we found that people living with MS who were employed had substantially higher HSU scores, and therefore better health-related quality of life, compared to those who were not employed. We also found that people living with progressive MS had worse health-related quality of life than people with RRMS.

An in-depth analysis of the EQ-5D-5L-Psychosocial survey responses revealed that deteriorations in physical health were the primary drivers of increased disability severity among most people living with MS. In particular, reduced mobility and limitations in performing usual activities were key contributors. However, this pattern did not hold for people transitioning between no and mild MS-related disability categories. These individuals experienced declines in all domains of health, including physical, mental, and social. This broader deterioration may explain the substantial drop in mean HSU between people classified as having no disability (0.78) and mild disability (0.60).

Lastly, we compared the HSU estimates for people living with MS to those for people living with other complex and chronic diseases such as Parkinson's disease and diabetes. On average, the HSU among people living with moderate to severe MS was found to be substantially worse than Australians living with other chronic diseases (0.50-0.47 vs. 0.64), underscoring the high burden of MS.

3.2 Introduction

3.2.1 Defining health-related quality of life using HSU

While there is no universally accepted definition of health-related quality of life, one of Australia's Chief Health Officers has defined it as "encompass(ing) the impact of health on the ability to live a fulfilling life by combining positive and negative aspects of physical (and) psychological health with social functioning and wellbeing [53]." Importantly, this definition aligns with the description provided by the International Society for Quality of Life Research [54].

Health-related quality of life can be measured using multi-attribute utility instruments, which consist of a range of self-reported multiple-choice survey questions and an instrument-specific algorithm[55]. Responses to survey questions are entered into the appropriate algorithm, which generates a value known as an HSU. HSU scores represent profiles of health-related quality of life on a zero (death) to one (full health) scale [56].

Multi-attribute utility instruments and their associated HSU scores are essential tools in health economic evaluations. They are particularly useful for estimating and predicting health outcomes in target populations and serve as critical inputs for health economic models [57]. These models inform reimbursement and resource allocation decisions for medical procedures and therapeutics (including DMTs) and guide broader funding strategies [55].

3.2.2 MS and health-related quality of life

MS is a complex and chronic disease associated with a wide range and frequently interdependent symptoms that can significantly affect a person's physical and psychosocial health-related quality of life [5]. Common symptoms include motor and cognitive dysfunction, heat sensitivity, pain, tremors, sensory impairment, and fatigue [58]. Given the variable and individualistic nature of MS, experiences of MS can vary greatly between individuals [58]. The onset of MS typically occurs between 20 and 40 years of age, a time when many people living with MS are seeking to establish families and build their careers [29].

3.2.3 Aims of the chapter

Recognising that MS can profoundly impact health-related quality of life, this chapter aimed to examine HSU scores among a diverse group of people living with MS. We focused on how health-related quality of life differs according to sociodemographic factors (e.g. age and sex) and clinical characteristics (e.g. MS-related disability severity and MS type).

3.3 Methods

3.3.1 Data sources

Data were sourced from the AMSLS 2023 Disease Course Survey, with employment status obtained from the AMSLS 2023 Employment Survey.

3.3.2 Assessing health-related quality of life

In this report, we used the EQ-5D-5L-Psychosocial instrument to assess health-related quality of life as HSU scores [4]. This instrument has been validated for use in Australian MS populations and is sensitive to changes in both physical and psychosocial health [5]. It shares the same conceptual framework as the Assessment of Quality of Life – Eight Dimensions (AQoL-8D) instrument, which was used in previous Health Economic Impact Reports [4,59]. We have demonstrated that the AQoL-8D and EQ-5D-5L-Psychosocial are interchangeable, with both instruments providing comparable HSU estimates [5]. This allows for meaningful comparison between the data presented in this chapter and equivalent data from previous years.

A key advantage of the EQ-5D-5L-Psychosocial over the AQoL-8D is its brevity; it contains only nine items, compared to the 35 items in the AQoL-8D [60]. This significantly reduces the burden on participants.

Figure 3.1: Items included in the EQ-5D-5L-Psychosocial Instrument

Items measuring physical health

- 1. Mobility (EQ -5D-5L Item 1)
- (1) I have no problems in walking about
- (2) I have slight problems in walking about
- (3) I have moderate problems in walking about
- (4) I have severe problems in walking about
- (5) I am unable to walk
- 2. Self -Care (EQ-5D-5L Item 2)
- (1) I have no problems washing or dressing myself
- (2) I have slight problems washing or dressing myself
- (3) I have moderate problems washing or dressing myself
- (4) I have severe problems washing or dressing myself
- (5) I am unable to wash or dress myself
- 3. Usual Activities (EQ -5D-5L Item 3)
- (1) I have no problems doing my usual activities
- (2) I have slight problems doing my usual activities
- (3) I have moderate problems doing my usual activities
- (4) I have severe problems doing my usual activities
- (5) I am unable to do my usual activities
- 4. Pain and Discomfort (EQ -5D-5L Item 4)
- (1) I have no pain or discomfort
- (2) I have slight pain or discomfort
- (3) I have moderate pain or discomfort
- (4) I have severe pain or discomfort
- (5) I have extreme pain or discomfort

Items measuring psychosocial health

- 5. Anxiety and Depression (EQ -5D-5L Item 5)
- (1) I am not anxious or depressed
- (2) I am slightly anxious or depressed
- (3) I am moderately anxious or depressed
- (4) I am severely anxious or depressed
- (5) I am extremely anxious or depressed
- 6. Vitality and Fatigure (AQoL -8D Item 1)
- (1) I am always full of energy
- (2) I am usually full of energy
- (3) I am occasionally full of energy
- (4) I am usually tired and lacking energy
- (5) I am always tired and lacking energy
- 7. Sleep Quality (AQoL-8D Item 12)
- (1) I have no trouble sleeping
- (2) I have trouble sleeping rarely
- (3) I have trouble sleeping occasionally
- (4) I have trouble sleeping frequently
- (5) I have trouble sleeping always
- 8. Personal Relationships (AQoL -8D Item 10)
- (1) I am very satisfied with my close relationships
- (2) I am somewhat satisfied with my close relationships
- (3) I am neither satisfied nor dissatisfied with my close relationships
- (4) I am somewhat dissatisfied with my close relationships
- (5) I am very dissatisfied with my close relationships
- 9. Social Isolation (AQoL -8D Item 31)
- (1) I never feel isolated from my community
- (2) I rarely feel isolated from my community
- (3) I sometimes feel isolated from my community
- (4) I often feel isolated from my community
- (5) I always feel isolated from my community

The EQ-5D-5L-Psychosocial multi-attribute utility instrument comprises nine items (Figure 3.1). Items one through five were derived from the widely used EQ-5D-5L instrument, while the remaining four psychosocial items are adapted from the AQoL-8D survey [59]. The EQ-5D-5L-Psychosocial assesses mobility, self-care, usual activities, pain and discomfort, anxiety and depression, vitality and fatigue, sleep quality, personal relationships, and social isolation. The first four items related to physical health, and the remaining five pertain to psychosocial wellbeing.

A key strength of the EQ-5D-5L-Psychosocial is its unique algorithm, which can value over 1.95 million discrete health profiles [4,59], far exceeding the 3,125 profiles described by the EQ-5D-5L [61]. This expanded sensitivity enhances its utility in capturing the nuanced health experiences of people living with MS.

When analysing HSU data, population norms and minimum important changes serve as essential benchmarks for establishing clinical significance. Population norms reflect the expected HSU values for the general population, while minimum important change represents the smallest HSU difference considered clinically meaningful [62]. For the EQ-5D-5L-Psychosocial instrument, the population norm is approximately 0.80 (based on the AQoL-8D norms) [63] and the minimum important change has been set at 0.06 [9].

3.3.3 Analyses

We calculated the mean HSU for AMSLS participants to estimate the value that was representative of people living with MS in Australia in 2024. We also assessed the distribution of AMSLS participants across different categories of health-related quality of life, defined as follows:

- Critical: HSU = 0.0 - 0.2
- Very low: HSU = >0.2 – 0.4
- Low: HSU = >0.4 – 0.6
- Medium: HSU = >0.6 – 0.8
- High: HSU = >0.8 – 1.0

We then constructed tables of mean HSU scores across a range of sociodemographic and clinical variables. Sociodemographic variables included age (<45, 45-54, 55-64, 65-74, >74 years), sex, employment status (self-employed, employed full-time, employed part-time, out of the labour force), remoteness of residence (major city, inner regional, outer regional and remote), and state/territory of residence.

Clinical variables included disability severity (no disability, mild disability, moderate disability, severe disability), disease duration (0-5, 6-10, 11-20, 21-30, >30 years), type of MS (RRMS, PPMS, SPMS), and DMT use (using, not using). Disability severity was measured using the Patient Determined Disease Steps (PDDS) and mapped to Expanded Disability Status Scale (EDSS) categories [64]. See Table 3.1 for full details. Specifically,

- PDDS of 1 = no disability (EDSS = 0.0),
- PDDS of 2 or 3 = mild disability (EDSS = 1.0-3.5)
- PDDS of 4 or 5 = moderate disability (EDSS = 4.0-6.0)
- PDDS of 6-8 = severe disability (EDSS = 6.5-9.5) [65]

To examine individual-level HSU scores of AMSLS participants, we constructed histograms for the full cohort and subgroups defined by disability severity. To examine subgroup differences in greater detail, we employed a kernel density plot, a specialised line chart that visualises data distribution. In this context, density can be interpreted similarly to frequency, offering a clearer picture of how HSU scores are distributed across varying levels of disability severity.

We then tabulated survey question scores across employment status, disability severity, and MS type. This allowed us to understand differences in domain-specific health, including mobility, self-care, ability to conduct usual activities, pain and discomfort, anxiety and depression, vitality and fatigue, sleep quality, relationships, and social isolation. These variables were selected due to their relevance and impact observed during the HSU analyses.

Finally, we compared our HSU estimates for people living with MS with values reported for other chronic diseases, such as Parkinson's disease and diabetes, as well as our findings from our previous 2017 report. Across all analyses, data were represented using means and standard deviations (SDs), frequencies, or percentages, as appropriate.

3.4 Results

3.4.1 Participant characteristics

Table 3.1 provides an overview of the characteristics of AMSLS participants whose data were included in the analyses reported in this section. Among the 1,456 participants, 79.4% were female, with a mean age of 59 years. Approximately half of the AMSLS participants were university educated, and two-thirds lived in major Australian cities. The mean disease duration was 20.6 years, with mild disability severity (37.4%) and a RRMS disease course (62.7%) being most prevalent. Additionally, 64.2% of participants reported using a DMT.

3.4.2 HSU for people living with MS in Australia

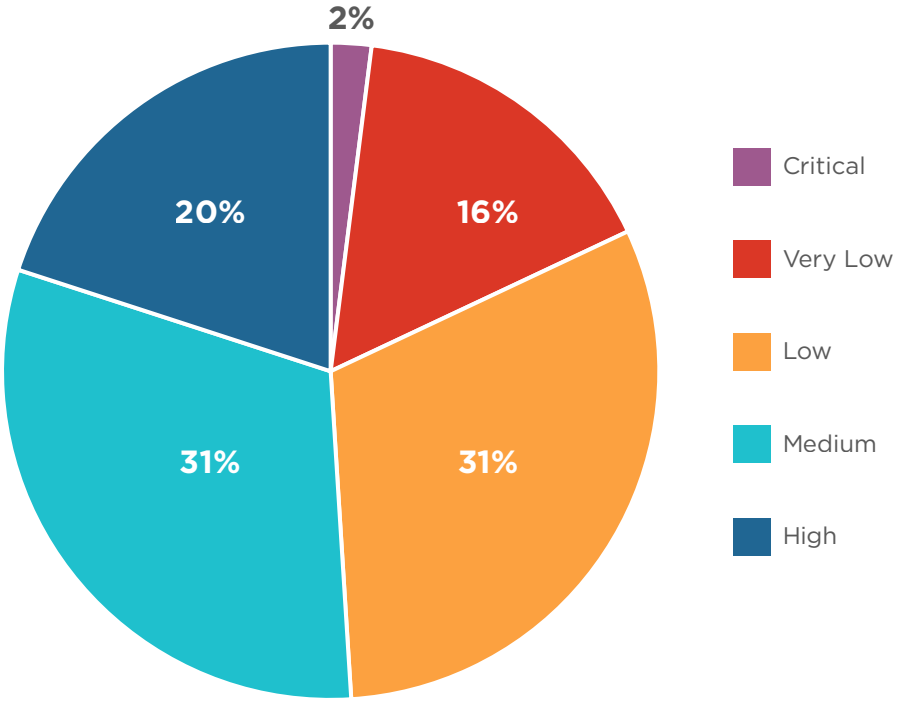
Using AMSLS participant responses to the EQ-5D-5L-Psychosocial survey, we determined that the mean HSU of Australians living with MS was 0.60 (SD = 0.20). This is 0.20 points lower than the Australian population norm of 0.80 and exceeds the threshold for clinical significance by more than threefold. Just over half of the AMSLS participants reported medium to high health-related quality of life (Figure 3.2). Nevertheless, 80.1% had HSU scores below the Australian population norm, indicating lower health-related quality of life among the majority of participants.

Table 3.1: AMSLS participant characteristics

N = 1,456 PARTICIPANTS	
SOCIODEMOGRAPHIC CHARACTERISTICS	**VALUE**
Age: Mean (SD)	59.4 years (11.8)
Sex (Female)	79.4%
Education Level	
Secondary or Lower	20.8%
Certificate or Diploma	33.2%
Bachelor's Degree	22.4%
Postgraduate Degree	23.7%
Remoteness †	
Outer Regional or Remote	8.4%
Inner Regional	25.4%
Major City	66.2%
CLINICAL CHARACTERISTICS	**VALUE**
Duration of MS: Mean (SD)	20.6 years (11.5)
Disability Severity ‡	
No Disability	26.0%
Mild Disability	37.4%
Moderate Disability	18.2%
Severe Disability	18.5%
CLINICAL CHARACTERISTICS	**VALUE**
Type of MS	
Relapsing-Remitting	62.7%
Primary Progressive	13.4%
Secondary Progressive	16.2%
Unsure	7.7%
DMT Usage	
Using	64.2%
Not Using	37.6%

Notes: † Remoteness was determined using the Australian Bureau of Statistics' Remoteness Areas, originally classified as: major cities, inner regional, outer regional, remote, and very remote. ‡ Levels of disability severity refer to the following EDSS categories: no disability (EDSS = 0), mild disability (EDSS = 1.0-3.5), moderate disability (EDSS = 4.0-6.0), and severe disability (EDSS = 6.5-9.5).

Figure 3.2: Proportions of AMSLS participants classified by health-related quality of life, as measured by HSU



Notes: Categories were defined using HSU as follows: Critical (0.0 - 0.2), Very Low (>0.2 – 0.4), Low (>0.4 – 0.6), Medium (>0.6 – 0.8), and High (>0.8 – 1.0).

3.4.3 HSU across sociodemographic and clinical variables

We assessed mean HSU scores for AMSLS participants classified according to sociodemographic and clinical variables (Figures 3.3-3.13 and summarised in Table 3.2). We observed that AMSLS participants under the age of 45 had slightly better health-related quality of life than older age groups (Figure 3.3), as did those residing in major cities compared to regional or remote areas (Figure 3.7). However, these differences did not exceed the 0.06 threshold for minimum important change.

Health-related quality of life showed minimal variation by sex (Figure 3.4), state/territory of residence (Figure 3.6), disease duration (Figure 3.9), or DMT use (Figure 3.11). While no major differences were found in HSU scores based on DMT use, a greater proportion of participants not using DMTs had severe physical disability (25.8% vs. 14.1%).

Importantly, our analyses revealed that health-related quality of life among people living with MS was more than twice the minimum important change below Australian population norms (>0.12). This pattern was consistent across sex and age groups.

In contrast, minimum important changes that were clinically meaningful in health-related quality of life were observed across employment status (Figure 3.5), disability severity (Figure 3.8), and MS type (Figure 3.10). Supporting the findings presented in Section 4.4.2, Figure 3.8 shows that individuals with no MS-related disability had, on average, a health-related quality of life similar to Australian population norms. However, a sharp decline was evident when moving from no to mild MS-related disability, with an average HSU score decrease of 0.18 points – three times greater than the minimum important change. A further decline of 0.10 points was observed between mild and moderate MS-related disability, while health-related quality of life was similar for AMSLS participants living with either moderate or severe MS-related disability.

For those classified as having mild, moderate, or severe disability, mean HSU scores were markedly lower than the Australian general population norm. For instance, AMSLS participants with severe MS-related disability had HSU scores that were, on average, 0.33 points lower, representing a difference more than five times the minimum important change.

Additionally, sizeable differences in health-related quality of life were observed across MS types (Figure 3.10). Specifically, participants with progressive MS reported substantially lower HSU scores compared to those living with RRMS.

Lastly, we found that AMSLS participants who were out of the labour force, had markedly lower health-related quality of life than those who were self-employed or employed full- or part-time (Figure 3.6). On average, the HSU scores among working individuals were 0.10 points higher.

Table 3.2: Mean AMSLS HSU scores classified according to sociodemographic and clinical characteristics

SOCIODEMOGRAPHIC FACTORS	MEAN	SD	N
Age			
<45	0.64	0.21	175
45-54	0.61	0.20	312
55-64	0.59	0.21	452
65-64	0.61	0.20	374
>74	0.60	0.18	137
Sex			
Male	0.61	0.20	299
Female	0.60	0.21	1,151
Employment Status			
Self-Employed	0.66	0.20	113
Employed Full-Time	0.69	0.19	224
Employed Part-Time	0.65	0.19	220
Out of the Labour Force	0.57	0.20	672
State			
New South Wales	0.61	0.21	415
Victoria	0.60	0.21	397
Queensland	0.58	0.20	201
South Australia	0.62	0.20	158
Western Australia	0.63	0.20	127
Tasmania	0.60	0.19	91
Aust. Capital Territory	0.64	0.21	58
Remoteness ‡			
Major Cities	0.61	0.21	960
Inner Regional	0.59	0.20	366
Outer Regional or Remote	0.58	0.20	122

CLINICAL FACTORS	MEAN	SD	N
Disability Severity			
No Disability	0.78	0.15	376
Mild Disability	0.60	0.18	537
Moderate Disability	0.50	0.18	263
Severe Disability	0.47	0.17	267
Disease Duration			
0-5 Years	0.63	0.22	95
6-10 Years	0.63	0.21	145
11-20 Years	0.61	0.21	543
21-30 Years	0.59	0.20	392
>30 Years	0.58	0.19	258
MS Phenotype			
Relapsing-Remitting	0.64	0.20	903
Primary Progressive	0.55	0.19	192
Secondary Progressive	0.49	0.17	233
DMT Usage *			
Not Using	0.60	0.20	541
Using	0.60	0.20	900
Category One	0.65	0.19	82
Category Two	0.60	0.22	125
Category Three	0.59	0.21	462
Overall	**0.60**	**0.20**	**1,450**

Notes: SD = Standard deviation and N = Number of participants who responded to the EQ-5D-5L-Psychosocial and for whom a HSU could be generated. † No estimate was provided for the Northern Territory, as only two participants were available from this territory. ‡ Geographical remoteness is a measure of a person's distance from major population centres and the services in these centres. It is categorised as either major cities, inner regional, outer regional, remote, or very remote under the Australian Bureau of Statistics' Australian Statistical Geography Standard remoteness areas [42]. * The number of AMSLS participants using DMTs differs between the overall and category-specific rows, as not all participants reported the name of their DMT.

Figure 3.3: Mean AMSLS HSU scores sorted by age category and compared with the Australian population norm

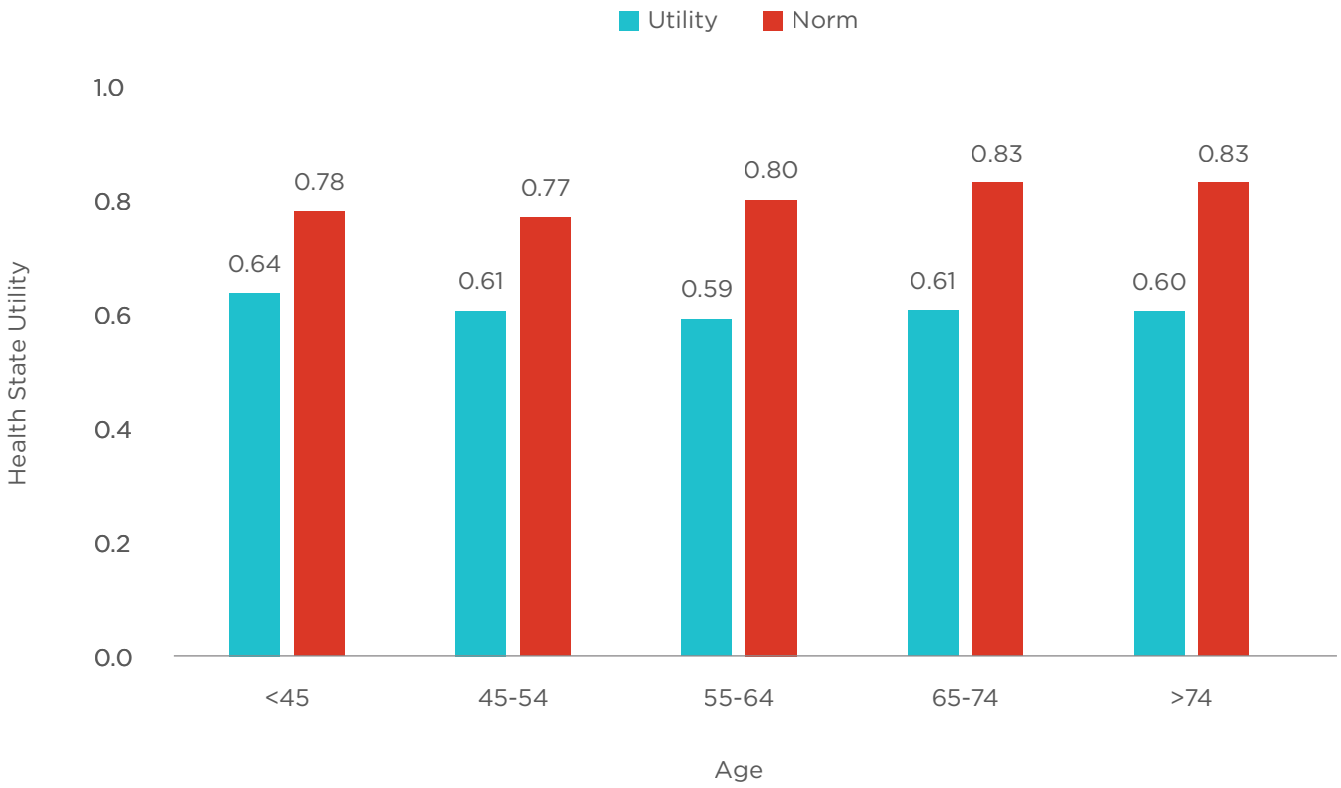


Figure 3.4: Mean AMSLS HSU scores sorted by sex and compared with the Australian population norm

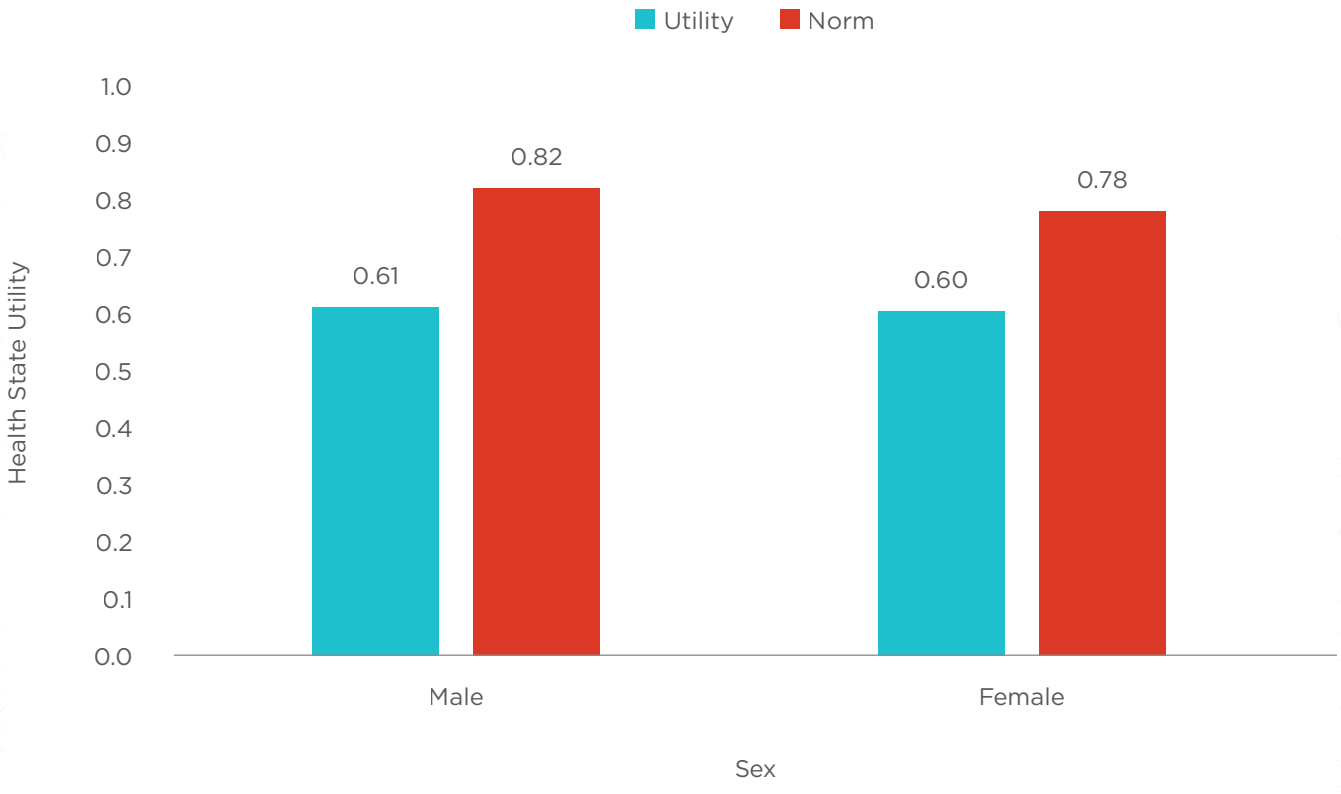


Figure 3.5: Mean AMSLS HSU scores sorted by employment status

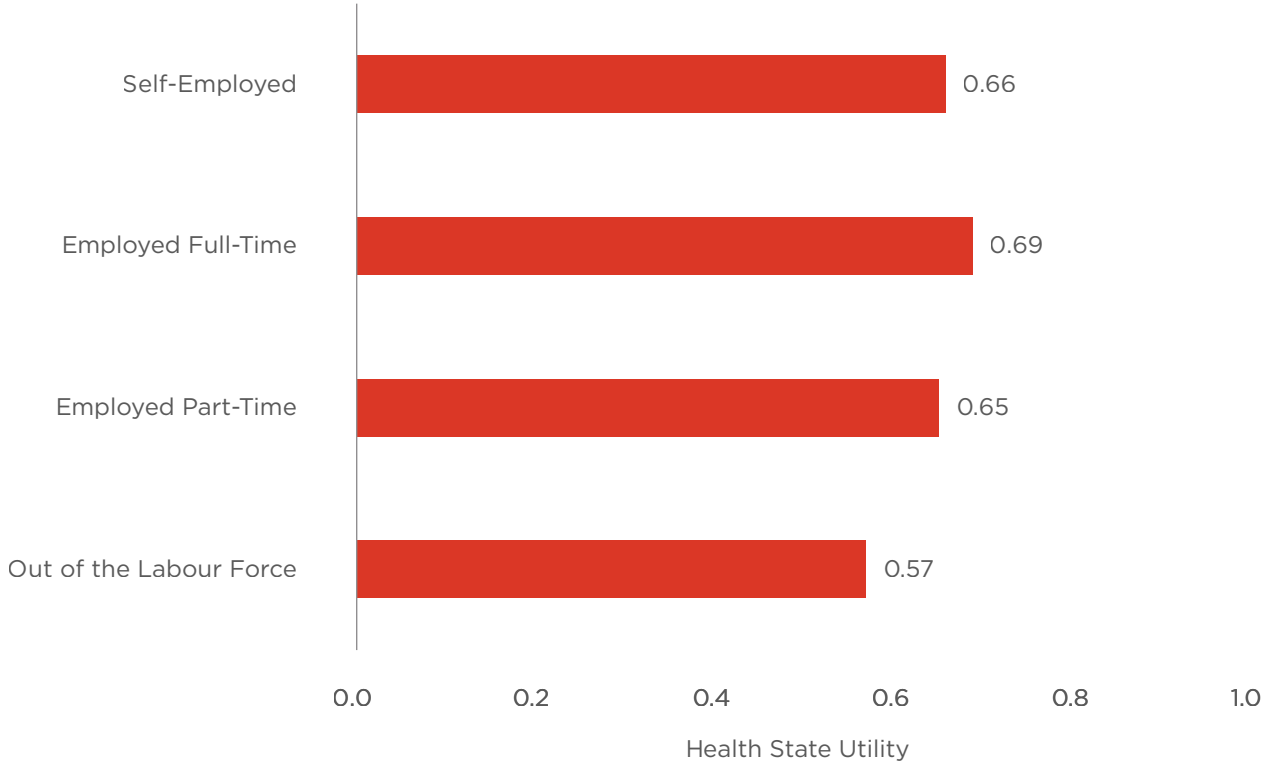
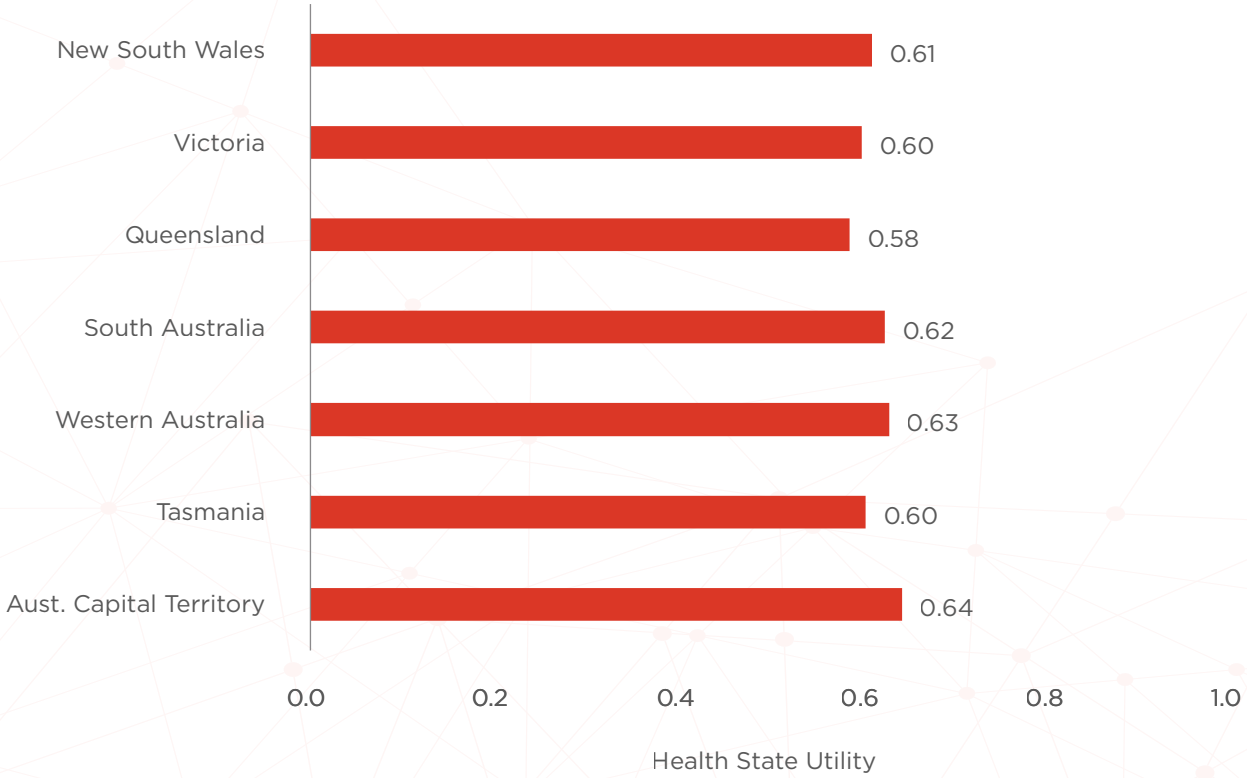


Figure 3.6: Mean AMSLS HSU scores sorted by state/territory of residence



Notes: No estimate was provided for the Northern Territory as only two participants were available from this territory. See Table 4.2 for a full list of participant numbers as they relate to each state.

Figure 3.7: Mean AMSLS HSU scores sorted by geographical remoteness

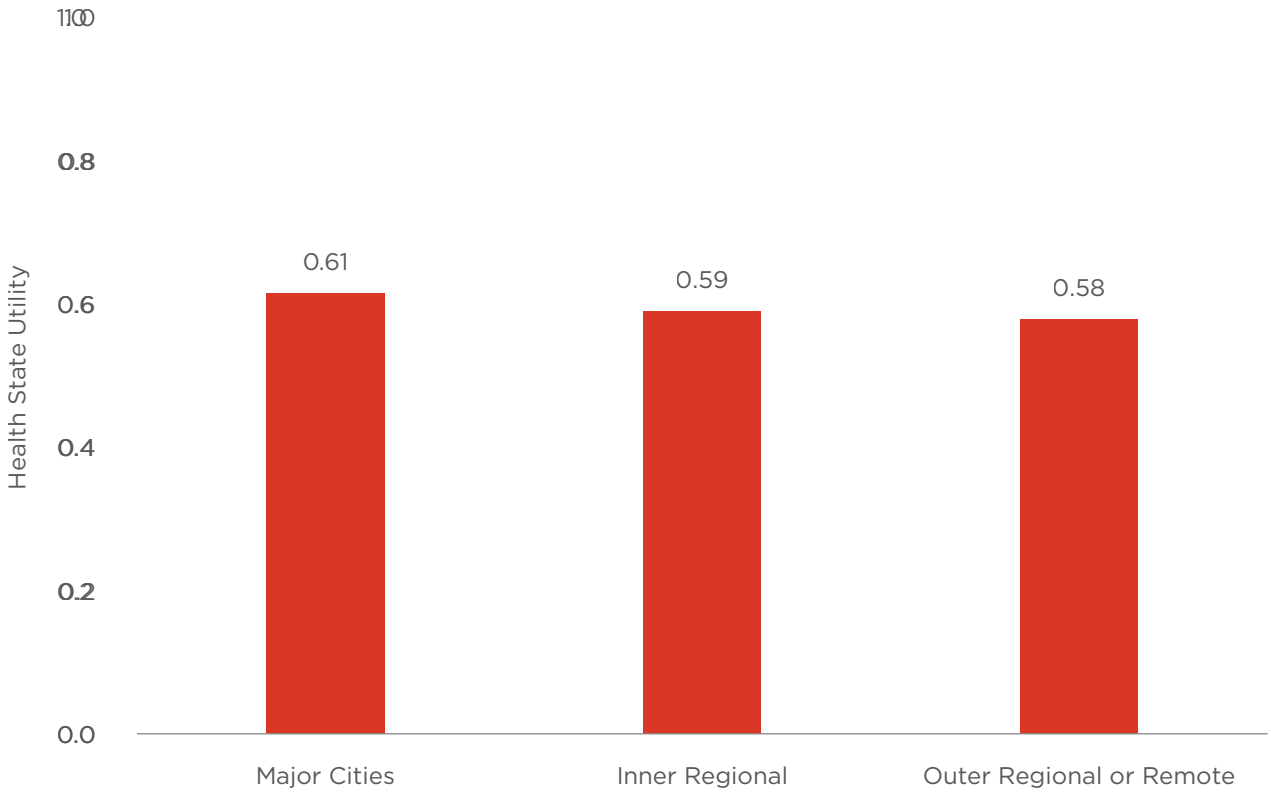


Figure 3.8: Mean AMSLS HSU scores sorted by MS-related disability severity and compared with the Australian population norm

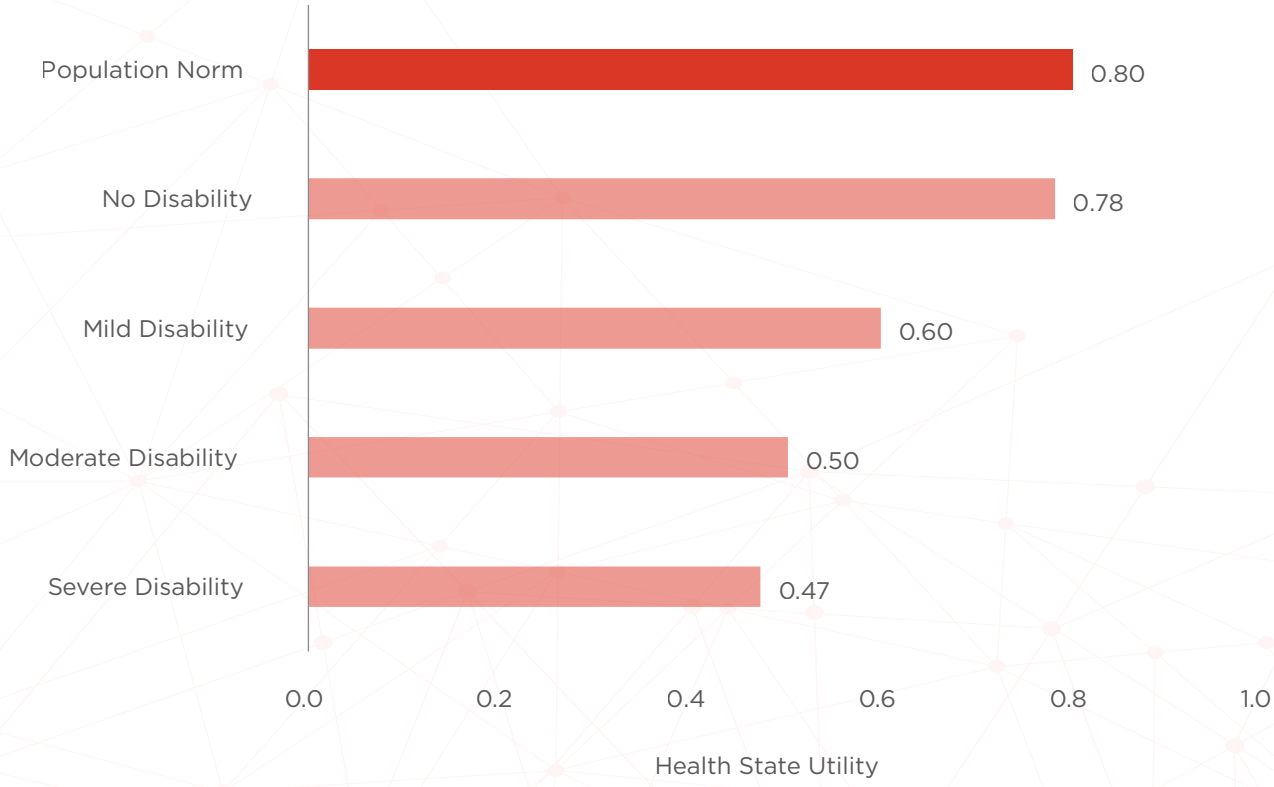


Figure 3.9: Mean AMSLS HSU scores sorted by MS disease duration from diagnosis

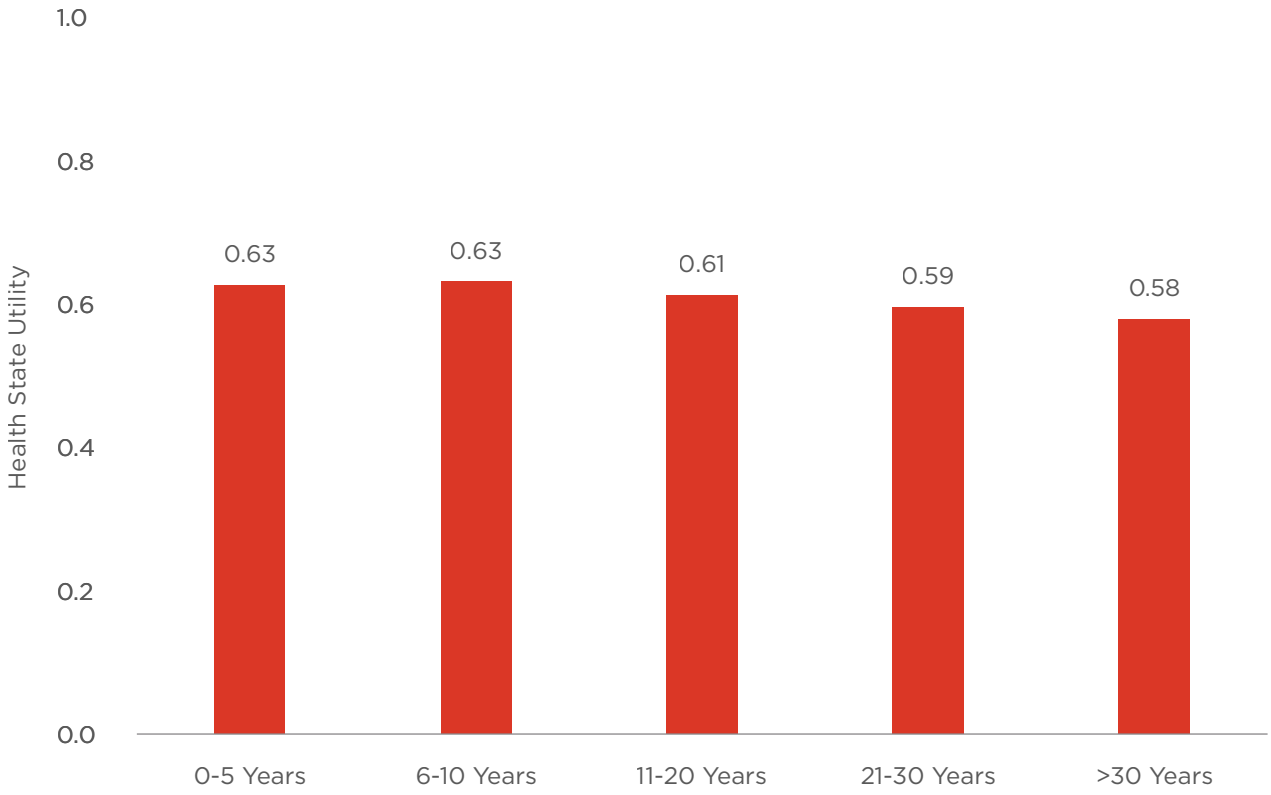


Figure 3.10: Mean AMSLS HSU scores sorted by type of MS

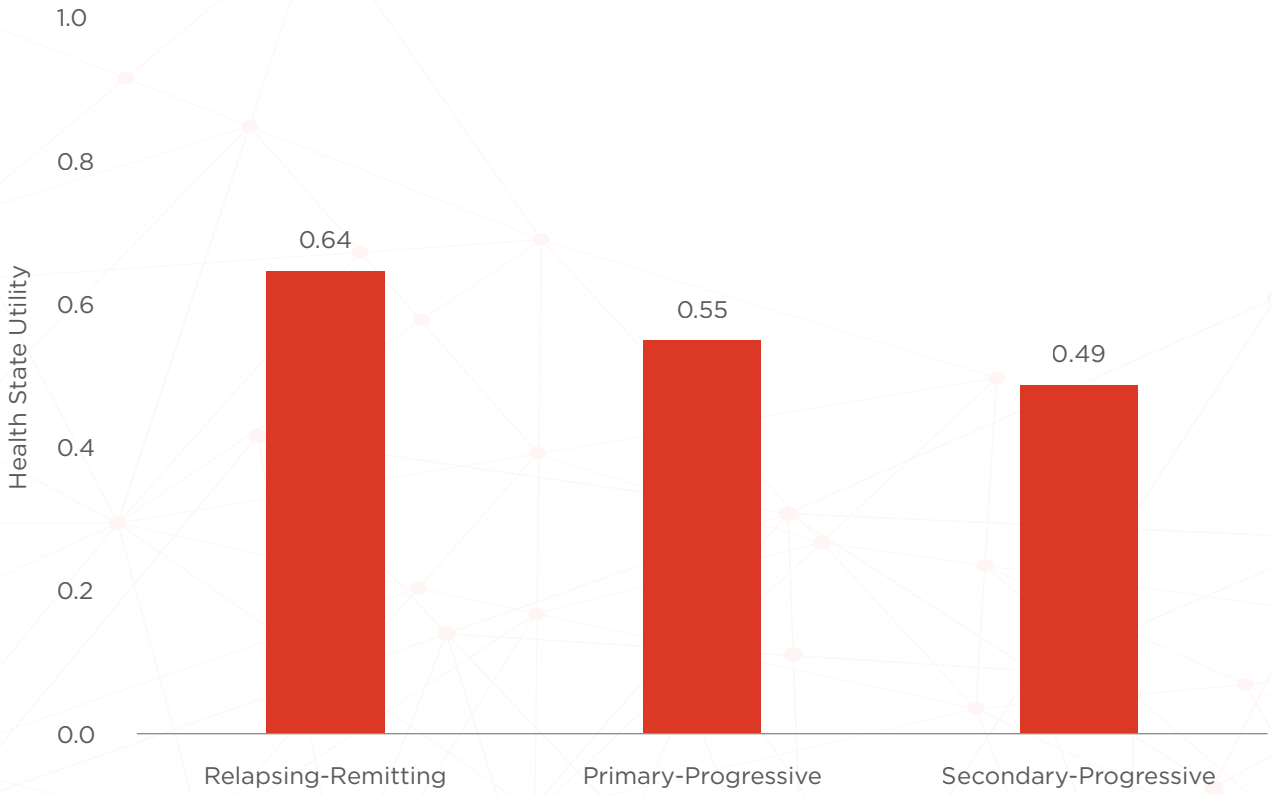
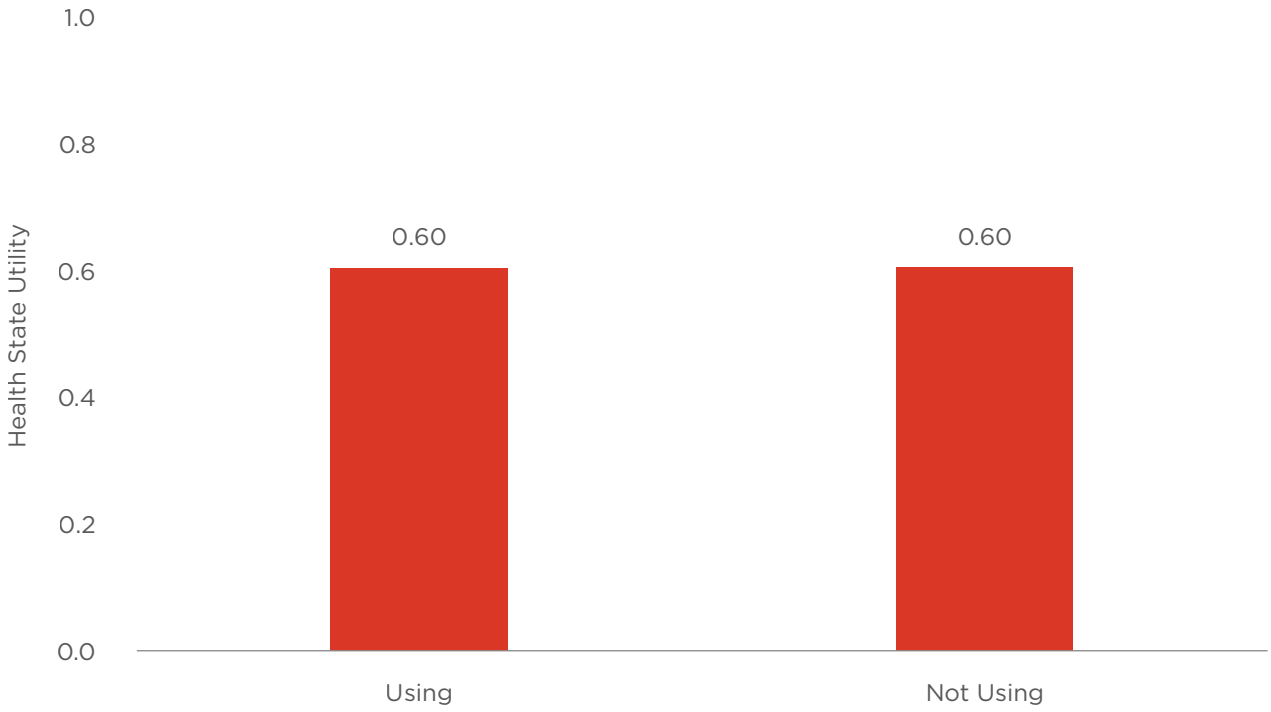


Figure 3.11: Mean AMSLS HSU scores sorted by DMT usage



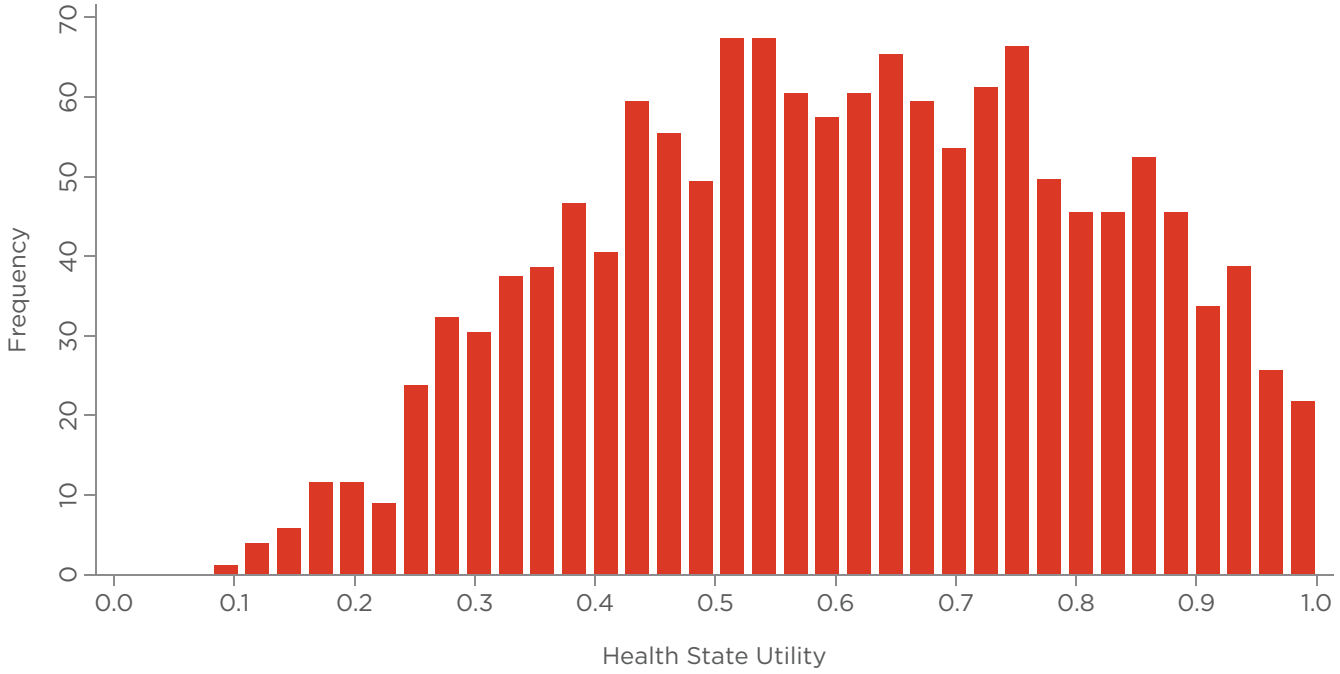
3.4.4 Distributions of HSU and health-related quality of life

The complete distribution of HSU scores that represent health-related quality of life among AMSLS participants is shown in Figure 3.12. Most participants had HSU scores between 0.40 and 0.80.

The kernel density chart in Figure 3.13 displays distributions of HSU scores according to disability severity. Supplementary Figures 3.1-3.4 provide supporting histograms for each subgroup. Participants with no MS-related disability (red) exhibited a prominent peak around 0.9, indicating high health-related quality of life among this group (Figure 3.13). Compared to individuals reporting moderate or severe MS-related disability, those with mild disability were less likely to have HSU scores below 0.5. This suggests that they were less likely to experience substantially reduced health-related quality of life.

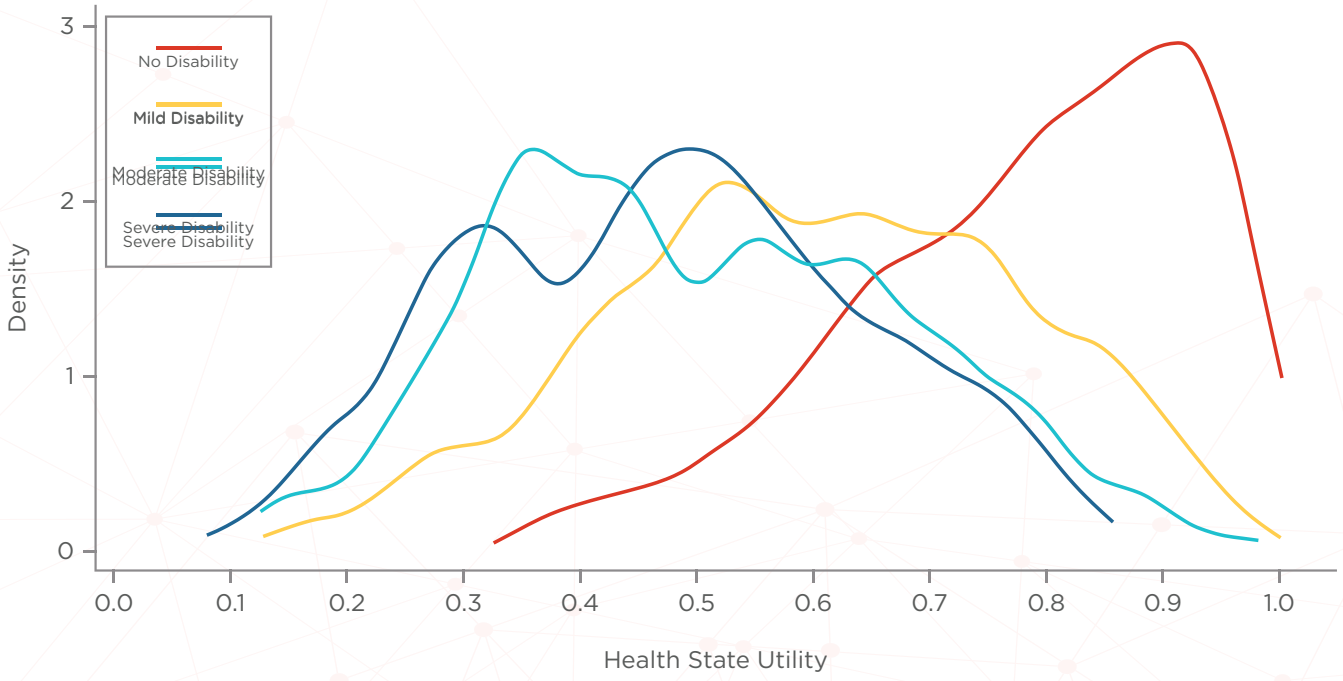
Notably, there was substantial overlap in HSU scores between participants with moderate and severe MS-related disability, suggesting that health-related quality of life is similarly affected in these groups.

Figure 3.12: Histogram showing the frequency distribution of HSUs among AMSLS participants



Notes: Frequency indicates the number of people living with MS assigned each HSU represented on horizontal axis.

Figure 3.13: Kernel density chart comparing HSU scores across disability severity categories in the AMSLS



Notes: Density may be interpreted similarly to frequency, indicating the number of people living with MS corresponding to each HSU value on horizontal axis.

3.4.5 Domain-specific health scores by employment status, disability severity, and MS type

Individual item scores of the EQ-5D-5L-Psychosocial instrument, reflecting specific health domains, were also impacted by key sociodemographic and clinical factors identified in Sections 4.4.3 and 4.4.4 (see Figures 3.14a-c and summarised by Table 3.3). Overall, AMSLS participants reported lower scores in sleep quality (mean: 3.13) and in vitality and fatigue (mean: 3.06).

In the case of employment status (Figure 3.14a), physical health domains (mobility, self-care, usual activities, and pain and discomfort) appeared to be key drivers of reduced health-related quality of life among participants who were out of the labour force.

As individuals progress from no to mild MS-related disability, declines occur across all dimensions of wellbeing (Figure 3.14b). However, further progression in disability is primarily associated with deterioration in physical health domains.

Finally, reduced health-related quality of life among AMSLS participants with progressive MS appears to be largely attributed to declines in physical domains, in contrast to those living with RRMS (Figure 3.14c).

Figure 3.14: Mean scores for AMSLS participants across the nine health domains of the EQ-5D-5L-Psychosocial instrument

Figure 3.14a: Mean scores by employment status across health domains

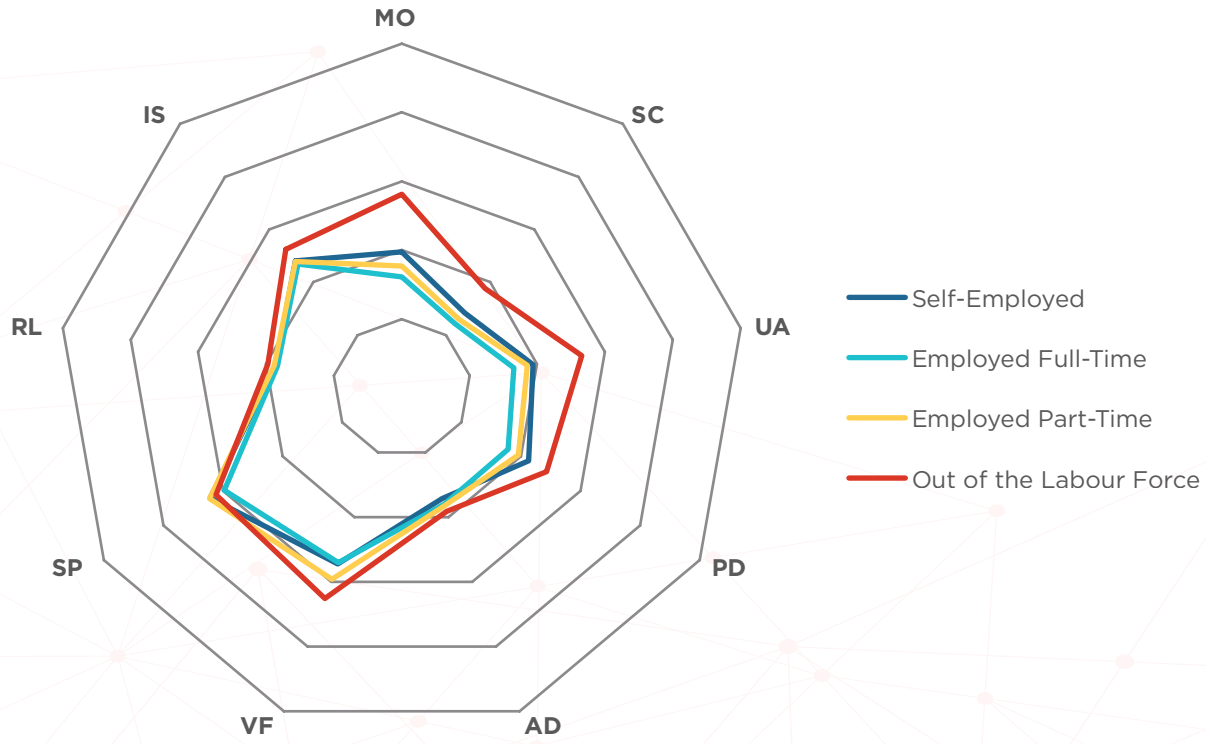


Figure 3.14b: Mean scores by disability severity across health domains

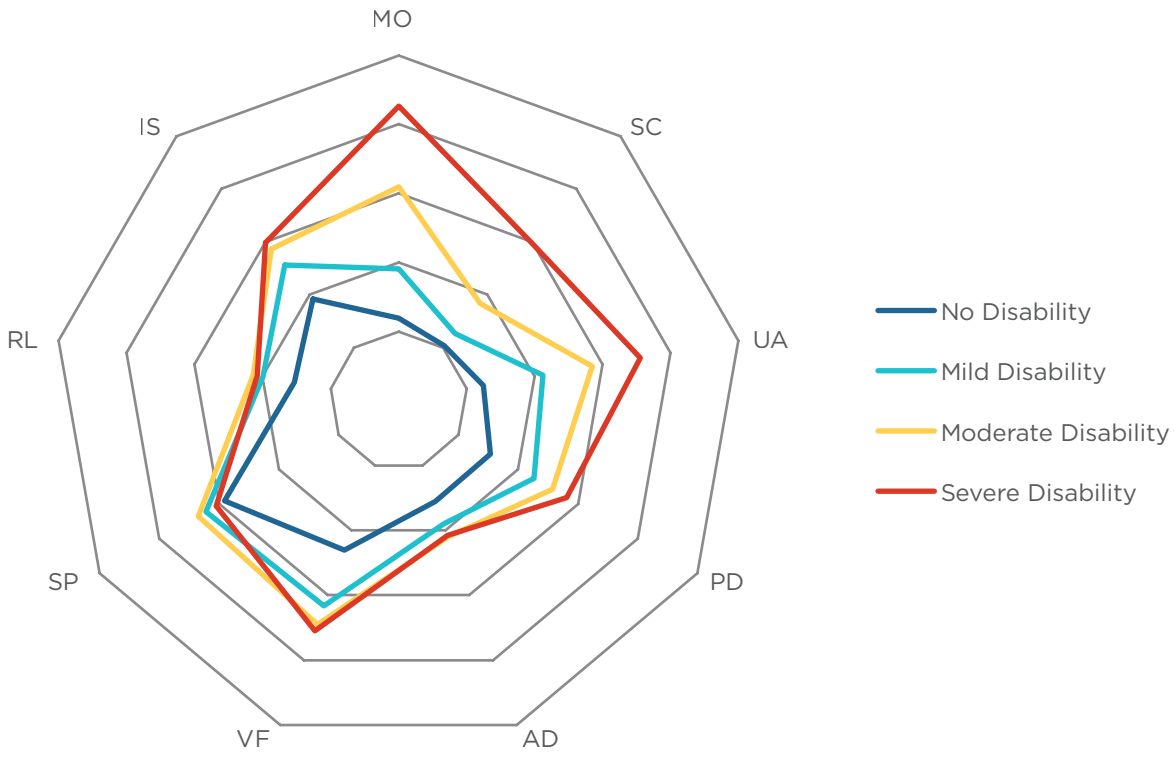
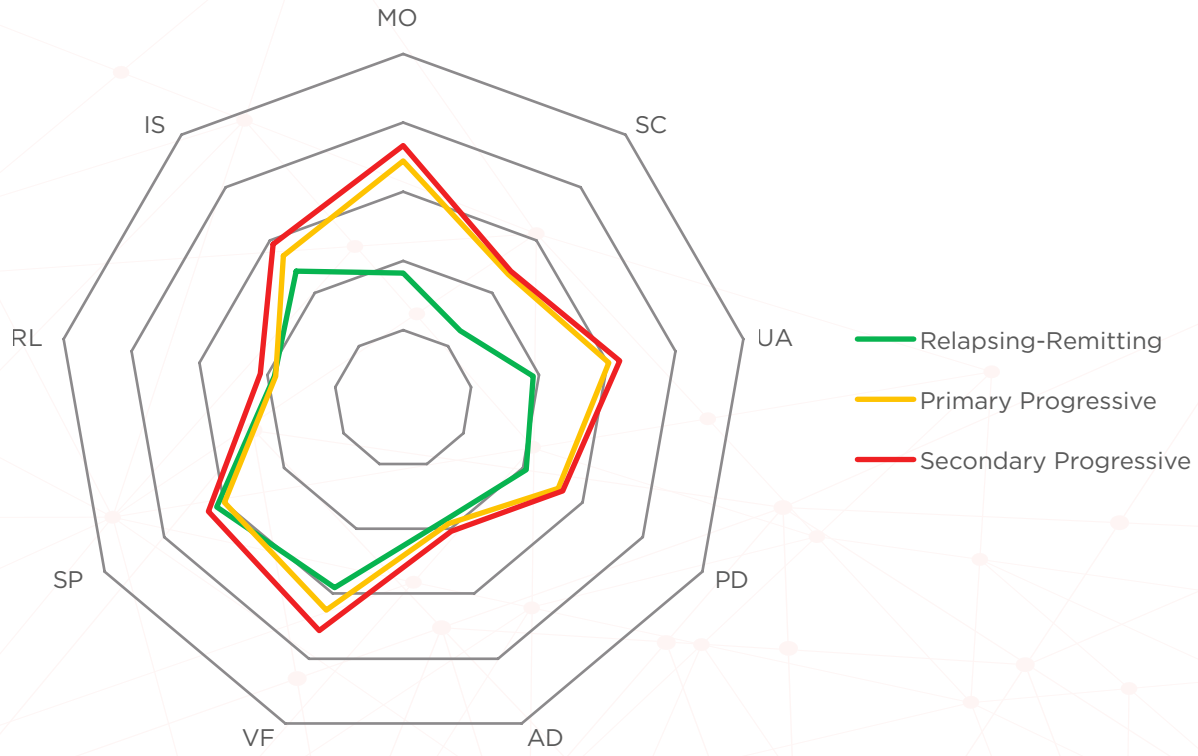


Figure 3.14c: Mean scores by MS type across health domains



Notes: Radar lines represent item/question scores, with a score of five (extreme problems) represented by the outermost line and a score of one (no problems) represented by the innermost line. Item titles have been abbreviated as: Mobility (MO), Self-Care (SC), Usual Activities (UA), Pain and Discomfort (PD), Anxiety and Depression (AD), Vitality and Fatigue (VF), Sleep Quality (SP), Personal Relationships (RL), and Social Isolation (IS).

Table 3.3: Mean scores across the nine health domains of the EQ-5D-5L-Psychosocial for AMSLS participants

DATA PRESENTED AS: MEAN (SD)										
		PHYSICAL DOMAINS				PSYCHOSOCIAL DOMAINS				
	Number of Participants	Mobility	Self-Care	Usual Activities	Pain and Discomfort	Anxiety and Depression	Vitality and Fatigue	Sleep Quality	Relationships	Social Isolation
Employment Status										
Self-Employed	113	1.97 (1.22)	1.42 (0.83)	1.94 (0.93)	2.13 (1.12)	1.72 (0.84)	2.73 (1.02)	3.21 (1.11)	1.86 (0.90)	2.40 (1.09)
Employed Full-Time	224	1.61 (0.92)	1.21 (0.53)	1.66 (0.80)	1.79 (0.83)	1.80 (0.86)	2.70 (1.01)	2.97 (1.04)	1.83 (0.85)	2.34 (1.09)
Employed Part-Time	220	1.76 (0.92)	1.30 (0.64)	1.85 (0.87)	1.95 (0.85)	1.83 (0.86)	2.96 (0.94)	3.22 (1.05)	1.88 (0.86)	2.40 (1.07)
Out of the Labour Force	672	2.81 (1.30)	1.88 (1.15)	2.65 (1.11)	2.43 (0.98)	1.91 (0.92)	3.26 (0.93)	3.11 (1.11)	1.97 (0.95)	2.62 (1.10)
Disability Severity										
No Disability	376	1.19 (0.43)	1.03 (0.27)	1.24 (0.48)	1.54 (0.68)	1.55 (0.72)	2.31 (0.79)	2.91 (1.02)	1.53 (0.66)	1.93 (0.93)
Mild Disability	537	1.91 (0.74)	1.27 (0.52)	2.12 (0.77)	2.26 (0.92)	1.90 (0.89)	3.16 (0.88)	3.22 (1.06)	2.00 (0.89)	2.57 (1.06)
Moderate Disability	263	3.10 (0.68)	1.84 (0.76)	2.85 (0.76)	2.58 (0.95)	2.10 (0.94)	3.45 (0.84)	3.35 (1.12)	2.14 (0.98)	2.86 (1.01)
Severe Disability	267	4.27 (0.80)	2.99 (1.27)	3.55 (0.99)	2.81 (0.93)	2.08 (0.97)	3.54 (0.88)	3.06 (1.13)	2.08 (1.00)	2.99 (1.09)
MS Phenotype										
Relapsing-Remitting	903	1.83 (0.93)	1.29 (0.59)	1.91 (0.90)	2.05 (0.95)	1.85 (0.90)	2.91 (0.96)	3.12 (1.08)	1.89 (0.90)	2.41 (1.09)
Primary Progressive	192	3.45 (1.26)	2.36 (1.34)	3.02 (1.15)	2.59 (0.99)	1.92 (0.95)	3.26 (0.92)	2.99 (1.13)	1.88 (0.91)	2.71 (1.11)
Secondary Progressive	223	3.67 (1.01)	2.42 (1.23)	3.18 (0.95)	2.67 (0.95)	2.04 (0.89)	3.57 (0.87)	3.26 (1.09)	2.11 (0.97)	2.93 (1.01)
Overall	**1,450**	**2.38 (1.29)**	**1.63 (1.01)**	**2.29 (1.10)**	**2.23 (0.98)**	**1.88 (0.90)**	**3.06 (0.97)**	**3.13 (1.09)**	**1.92 (0.91)**	**2.54 (1.10)**

3.5 Discussion

3.5.1 Major findings

We found that the overall health-related quality of life was substantially lower in people living with MS who participated in the AMSLS compared to the Australian general population. The mean HSU score was 0.60 (SD = 0.20), which is 0.20 points below the population norm of 0.80. This difference exceeds the minimum important change threshold of 0.06 by more than threefold, indicating clinical significance.

Our findings also show a clear gradient in health-related quality of life across levels of disability severity. AMSLS participants with no disability had health-related quality of life comparable to those of the general Australian population, indicating minimal impact on perceived wellbeing. However, as disability severity increased, health-related quality of life declined. This trend was particularly pronounced among individuals with progressive MS, who reported lower HSU scores than those with RRMS. These results highlight the compounded impact of both disability severity and disease course on quality of life for people living with MS.

At lower levels of disability, both psychosocial (i.e. mental and social) and physical health domains were the drivers of reduced health-related quality of life in people living with MS. However, as disability severity increased, declines in quality of life were primarily driven by deterioration in physical health. Specifically, mobility, self-care, and the ability to engage in usual activities were the most impacted dimensions at higher levels of MS disability.

Unexpectedly, mean HSU scores were equal between people using DMTs and those not using them, despite the known clinical benefits of DMTs and prior research showing that DMT users typically have lower disability levels [27,66]. Several factors may have contributed to this finding. One possibility is that individuals who previously received cladribine and alemtuzumab, both administered over a limited duration, may have reported not currently using a DMT. This may also reflect bias by indication, where individuals with greater MS-related disability are more likely to use DMTs to mitigate the effects of their illness [66]. Another possibility is that the benefits of DMTs may not be fully captured in self-reported health-related quality of life measures, or that factors such as treatment burden, side effects, or psychological impacts, may offset perceived gains in wellbeing.

We observed no substantial differences between current AMSLS HSU scores and those presented in the *Health Economic Impact of Multiple Sclerosis in Australia in 2017* report [2]. This is despite an increase in average disease duration among AMSLS participants, which is up 5.3 years from 2017. Moreover, the proportion of AMSLS participants classified as having moderate disability has declined substantially, from 36.4% to 18.1%, while reports of mild disability have risen from 24.4% to 37.0%. The percentages of people with no or severe disability has remained largely unchanged.

These findings indicate both stability and improvement in disability severity among AMSLS participants. This trend may reflect increased availability of high-efficacy DMTs in Australia.

3.5.2 Comparisons with other chronic diseases

MS is a relatively high-burden disease when mean HSU scores are compared between MS and other chronic diseases, as reported in published studies using either the EQ-5D-5L-Psychosocial or the AQoL-8D instruments (Table 3.4).

For example, AMSLS participants with moderate to severe MS-related disability reported mean HSU scores ranging from 0.47-0.50, which were lower than those reported for Australians living with:

- Metastatic prostate cancer (0.69)
- Moderate/severe ulcerative colitis (0.66)
- Arthritis (0.63)
- Spinal cord injuries (0.57)
- Other chronic diseases generally (0.64).

Furthermore, individuals with severe MS had HSU scores were comparable to those with:

- Chronic depression (0.45)
- Chronic fatigue syndrome (0.44)
- Untreated post-traumatic stress disorder (0.43).

These comparisons underscore the significant impact of MS-related disability and reinforce the need to prioritise resource allocation toward improving outcomes for people living with MS.

3.5.3 Strengths and limitations

As in other chapters, our research benefitted from the large and comprehensive AMSLS dataset. A key strength of this chapter was the use of the EQ-5D-5L-Psychosocial instrument, with its unique survey design enabling the identification of novel relationships between health-related quality of life and domain-specific wellbeing.

While the AQoL-8D and EQ-5D-5L-Psychosocial are broadly comparable, they differ in how HSU scores are elicited. However, previous research has demonstrated that these differences are minor and unlikely to materially impact study conclusions [5].

It is also important to note that the disability categories used in our analyses were based largely on physical infirmity. This limitation may have contributed to some of the overlap in HSU distributions across disability categories.

3.5.4 Conclusions

Through our analysis of HSU scores among people living with MS, we found that increasing MS-related disability is associated with substantial and clinically meaningful reductions in health-related quality of life. At lower levels of disability, both psychosocial and physical health impact health-related quality of life. However, at higher levels of disability, declines in health-related quality of life are primarily driven by deteriorations in physical health.

Encouragingly, mean HSU scores for MS have remained largely stable since the 2017 report, indicating consistent disability severity among AMSLS participants despite longer disease durations. The continued stabilisation is critical, given the relatively high burden of MS-related disability compared to other chronic diseases.

Table 3.4: Australian mean HSU scores for the general population and other chronic

diseases, contrasted with mean HSU scores for AMSLS participants

NORM	MEAN HSU
General Population Norm [63]	0.80
Healthy Population Norm [67]	0.83
Chronic Diseases Population Norm [68]	0.64
Condition	
Post-Traumatic Stress Disorder [69] Pre-Treatment Post-Treatment	 0.43 0.66
Chronic Fatigue Syndrome [70]	0.44
Clinical Depression [68]	0.45
Fibromyalgia [71]	0.47
Spinal Cord Injury [72]	0.57
Inherited Retinal Diseases [73]	0.58
Respiratory Disorders Requiring Ventilation [74]	0.58
Arthritis [68]	0.63
Cancer [68]	0.66
Ulcerative Colitis [75] Mild Moderate/Severe	 0.76 0.66
Chronic Heart Disease [67]	0.68
Asthma [76]	0.69
Diabetes [77]	0.69
Obesity [78]	0.69
Idiopathic Pulmonary Fibrosis [79]	0.69
Metastatic Prostate Cancer [80]	0.69
Hearing Loss [68]	0.72
Alopecia Areata (Chronic Hair Low) [81]	0.75
MS in 2024	
2024 Mean	0.60
No Disability	0.78
Mild Disability	0.60
Moderate Disability	0.50
Severe Disability	0.47

Notes: Conditions highlighted in grey scored better, on average, than AMSLS participants. Only new 2024 estimates were generated using EQ-5D-5L-Psychosocial HSU scores.

CHAPTER 4

Patterns of employment among people living with multiple sclerosis: Evidence from the AMSLS

4.1 Summary

As a new addition to the report, this chapter provides a comprehensive analysis and discussion of employment outcomes for people living with MS in Australia. Prior research shows that MS-related disability can profoundly impact employment outcomes and that job loss has major psychological and socioeconomic implications. We identified that 44.0% of AMSLS participants were in the labour force, meaning they were either employed or actively seeking employment. An additional 43.9% reported being retired. Of those who were retired, 58.2% indicated that their retirement was due to the impacts of MS.

A concerning finding was that 91.0% of working Australians living with MS reported that their symptoms compromised their ability to work, with 9.2% stating that their employment was actively at risk due to the effects of their MS.

Disability severity was found to be strongly associated with ceasing employment. Our analysis showed that the proportion of AMSLS participants who were out of the labour force increased from 23.0% to 75.0% as disability worsened from none to severe. This trend highlights the significant vocational impact of MS, with job loss considerably limiting personal income.

The symptom most frequently cited as affecting capacity to work was mental and physical fatigue. Among those who had left employment, a substantial 86.2% reported that this was due to their MS on one or more occasions. When asked about the specific MS-related reason for leaving work, 67.3% identified fatigue as a major contributing factor. Other commonly reported symptoms included motor dysfunction of the lower body and cognitive difficulties.

Beyond physical symptoms, psychosocial factors also played a substantial role in employment cessation. For instance, 35.0% of individuals who had left work believed their work quality was insufficient, citing this as a major reason for leaving their job.

Among AMSLS participants who were working, approximately 60.0% had chosen to disclose their diagnosis to their employer. While many participants considered disclosure beneficial, 27.2% reported that it was harmful, and 32.4% felt it made little difference to their working lives.

The most frequently cited factors negatively affecting workplace quality of life were pressure and stress at work. Encouragingly, 91% of employed participants reported rarely or neverexperiencing discrimination in the workplace.

The literature consistently shows that effective treatments that reduce disease progression are critical to maintaining workforce participation among people living with MS. Supportive workplace environments, particularly colleague understanding and flexible working arrangements, such as remote work, are also crucial. Additionally, Australian research has shown that disclosing an MS diagnosis in the workplace can positively influence job tenure [22].

4.2 Introduction

4.2.1 Unemployment among people living with MS

A survey commissioned by the MS International Federation (MSIF) indicated that approximately 40% of people living with MS worldwide were not participating in the labour force [82]. Among those no longer seeking employment, 43% had ceased working within three years of diagnosis, increasing to 70% within ten years. The most frequently cited barriers to continued employment were fatigue (62%) and motor dysfunction (51%). These findings are strongly supported by a large-scale study conducted in the United States involving over 8,000 participants, reinforcing the global consistency of MS-related vocational challenges[83].

More broadly, a systematic review of the global literature found that an EDSS score greater than 6.5, indicative of severe MS-related disability, is associated with a 12-fold increase in the risk of being unable to work [84]. Furthermore, the risk of being unemployed among people with progressive MS was 4.2 times higher than people with RRMS. While this review supported the impact of motor dysfunction and fatigue on cessation of work, it also identified cognitive dysfunction as an important factor.

4.2.2 Impact of unemployment on people living with MS

A systematic review found that unemployed individuals living with MS were approximately seven times more likely to feel stigmatised due to their disability compared to those who were employed. This heightened sense of stigma can have a substantial impact on both social and mental health[85].

Another study found a clear relationship between loss of employment and decreased life satisfaction among people living with MS, particularly in terms of diminished satisfaction with personal achievements [86]. Notably, life satisfaction is associated with subjective wellbeing, which reflects an individual's personal appraisal of their quality of life [87]. Reduced subjective wellbeing has been linked to increased rates of mortality and morbidity through mediators such as suboptimal lifestyle factors (e.g. poor diet, inadequate sleep, and reduced physical activity) and reduced ability to cope with mental stress [88].

More broadly, loss of employment deprives people of its essential psychological benefits, including time structure, social contact, a sense of belonging, status, and personal agency, among others [89]. These factors are particularly pertinent to people with chronic diseases, who are more likely to experience protracted or permanent unemployment [90]. As a result, impairments related to both mental [91] and physical health [92] may be exacerbated over time.

4.2.3 Aims of the chapter

Given the international evidence linking MS to job loss and the profound associated impacts, the primary aim of this chapter was to use data from the AMSLS to summarise the patterns of employment and employment outcomes of Australians living with MS. Specifically, we examined employment status, reasons for leaving work, symptoms most affecting work capacity, and broader workplace experiences.

Unlike previous studies, we sought to quantify the financial impacts of changing employment status. By achieving these aims, this chapter facilitates a deeper discussion of unemployment among people living with MS and how it might be addressed within the Australian context.

4.3 Methods

4.3.1 Sources of data

Data were primarily sourced from the 2023 AMSLS Employment Survey, which was approved by the University of Tasmania's Health and Medical Human Research Ethics Committee (ethics approval number H0014183). Additional data on quality of life, clinical characteristics, sociodemographic factors and economic variables were extracted from the 2023 AMSLS Disease Course Survey and the 2023 AMSLS Economic Impact Survey.

4.3.2 Analyses and measures

To provide an overview of employment outcomes among people living with MS, we calculated a variety of summary statistics. These covered employment levels (e.g. full-time, part-time, unemployed), workplace challenges, perspectives on disclosing MS diagnoses to employers, and reasons for leaving employment.

Across our analyses, means and SDs were reported for continuous measures (e.g. age), while counts and proportions were reported for categorical measures (e.g. MS type classifications).

To understand the financial impact of employment outcomes, we analysed income by labour force status (e.g., employed or unemployed). Labour force status was subsequently examined in relation to several variables, including disease duration, MS type/disease course, disability severity (measured using the PDDS: 1-2, negligible mobility issues; 3-4, mild mobility issues; 5-6, moderate mobility issues; 7-8, severe mobility issues), clinical anxiety or depression, and use of DMTs. These analyses provided insights into patterns of employment across diverse subgroups of people living with MS. To avoid confounding from regular, non-MS-related retirement, analyses were restricted to participants of working age (under 67).

In addition, two questionnaires embedded in the Economic Impact and Disease Course Surveys evaluated other facets of employment. The first focused on workplace supportiveness, including whether people living with MS felt valued or discriminated against. The second assessed workplace stress, and whether participants thought their working hours were sufficient and flexible.

Table 4.1: Summary of AMSLS participant characteristics

TOTAL PARTICIPANTS, N = 1,325	
SOCIODEMOGRAPHIC CHARACTERISTICS	**VALUE**
Age: Mean (SD)	59.0 years (11.9)
Sex (Female)	79.6%
Education Level	
Secondary or Lower	20.2%
Certificate or Diploma	32.3%
Bachelor's Degree	22.9%
Postgraduate Degree	24.7%
Remoteness	
Outer Regional or Remote	7.8%
Inner Regional	25.5%
Major City	66.4%
CLINICAL CHARACTERISTICS	**VALUE**
Duration of MS (Mean [SD])	20.4 years (11.5)
MS Subtype	
Relapsing-Remitting	63.5%
Primary Progressive	13.2%
Secondary Progressive	15.8%
Unsure	7.6%
Motor Dysfunction	
No Mobility Issues	49.9%
Minor Mobility Issues	24.0%
Major Mobility Issues	18.1%
Severe Mobility Issues	8.0%
DMT Usage	
Using	63.1%
Not Using	36.9%

Notes: * Remoteness was determined using the ABS Remoteness Areas, originally classified as: major cities, inner regional, outer regional, remote, and very remote.

4.4 Results

4.4.1 General AMSLS participant characteristics

A total of 1,325 people living with MS responded to the 2023 AMSLS Employment Survey (Table 4.1). Study participants were 79.8% female, reflecting the higher prevalence of MS among women [93], and had a mean age of 59 years. The average participant was diagnosed with MS just over 20 years ago, with 63.5% reporting a diagnosis of RRMS.

Just over half of participants (50.2%) reported some level of mobility impairment, as indicated by a PDDS score greater than 2. The most commonly reported highest level of education was an occupational certificate or diploma (32.3%). Additionally, about two-thirds of participants resided in major Australian cities, aligning with broader national population trends.

4.4.2 Employment among AMSLS participants

Overall, 44.0% of AMSLS participants were currently in the labour force, meaning they were either actively employed in paid work or were actively seeking employment (Table 4.2). Among those in the labour force, 91.0% reported that symptoms of MS impacted their ability to work, and 9.2% indicated they were at risk of leaving work due to these symptoms. Notably, only 1.6% expressed a desire to work additional hours, suggesting a low rate of underemployment and highlighting the far-reaching impact of MS on workforce participation.

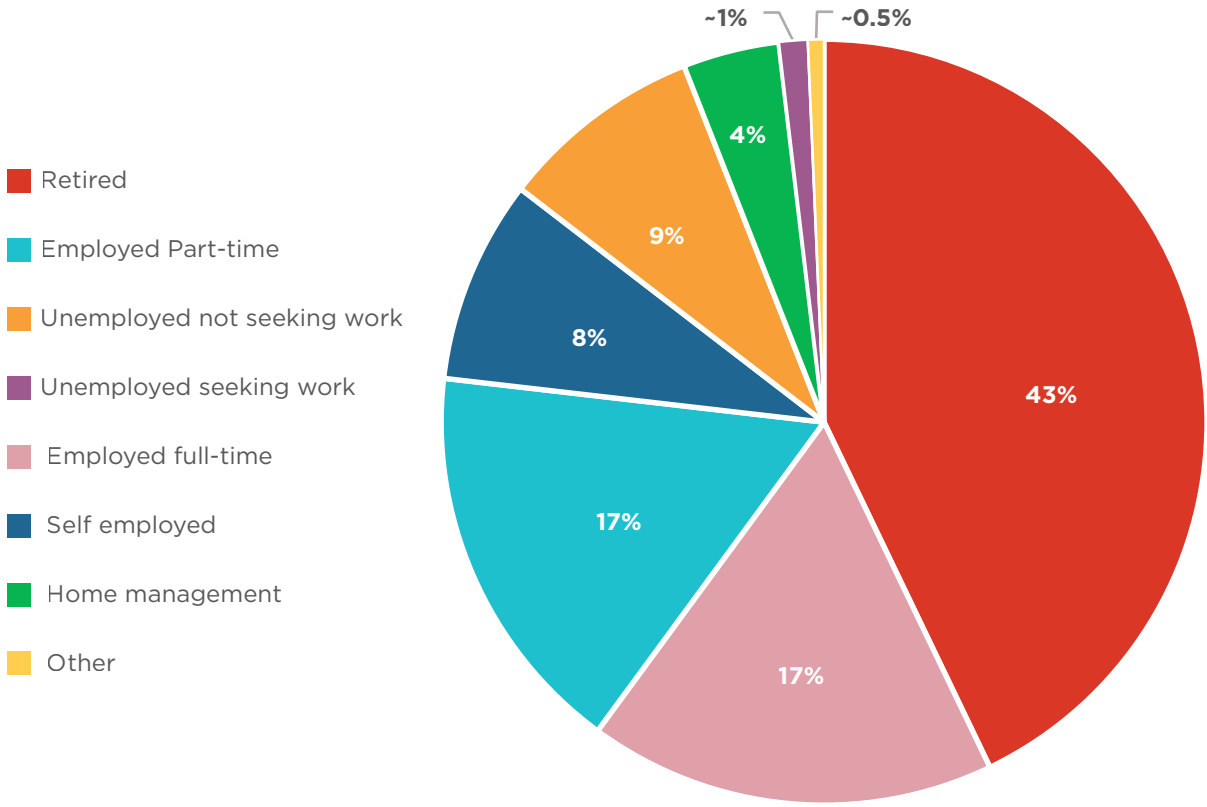
A total of 42.9% of participants were permanently retired, with 58.2% of these individuals retiring due to MS. Additionally, 86.2% of participants who had previously left work (but were not necessarily retired) reported that MS was a major contributing factor.

The most common employment status among AMSLS participants was retired, followed by being in full-time employment (17.2%) and part-time employment (16.8%) (see Figure 4.1).

Table 4.2: AMSLS participant employment characteristics

CHARACTERISTIC	PERCENTAGE
All Participants	
Participating in the Labour Force	44.0%
Retired	42.9%
Proportion Retired due to MS	58.2%
Participants Who Left Work at Least Once	
Left Work due to MS	86.2%
Employed Participants	
Symptoms Impacting Ability to Work	91.0%
Employment at Risk due to MS	9.2%
Seeking Additional Employment	1.6%

Figure 4.1: Employment status of AMSLS participants



4.4.3 Symptoms impacting ability to work

The symptoms most frequently reported as impacting the ability of AMSLS participants to remain in employment were mental and physical fatigue (67.3%) (Figure 4.2). Other frequently reported symptoms included cognitive difficulties (52.4%), heat sensitivity (37.6%), and lower body motor dysfunction (25.5%).

4.4.4 Reasons people living with MS leave employment

The most commonly cited reasons for leaving employment were physical symptoms, particularly physical and mental fatigue (68.3%), motor dysfunction of the legs and feet (41.8%), motor dysfunction of the arms and hands (33.1%), and balance problems (31.5%) (Table 4.3).

Non-physical symptoms, such as cognitive difficulties (42.0%) and heat sensitivity (30.3%), were also frequently reported. In addition, several reasons were psychosocial in nature; 35.0% of participants reported leaving employment because they felt their work quality was insufficient, and 33.5% cited excessive stress from the effort to remain employed.

Workplace-related factors were cited less frequently overall, but notable reasons included lack of opportunity to transfer to more suitable roles (22.4%) and an inability to remain standing for extended periods (20.8%).

4.4.5 Disclosure of MS diagnoses in the workplace

Approximately 60% of AMSLS participants had disclosed their illness to their current employer, regardless of whether they were employed before or after diagnosis (Table 4.4). While many participants described disclosure as a positive experience (40.6%), about one-third reported that it made no difference to their working life (32.4%), and 27.2% indicated that disclosure had a negative impact.

Figure 4.2: Symptoms that most frequently affected the ability of AMSLS participants to remain in employment

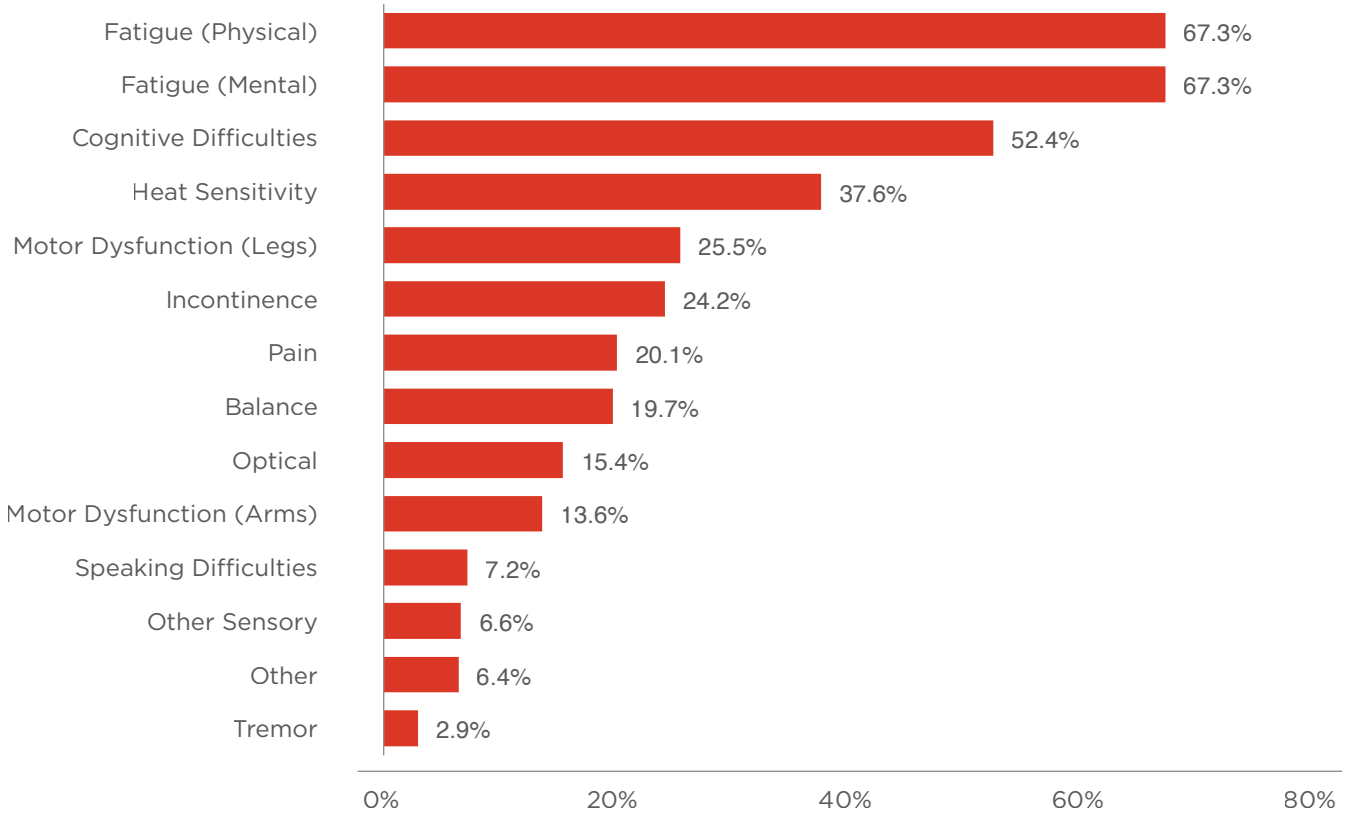


Table 4.3: Reasons AMSLS participants left employment (multiple reasons allowed)

REASON REPORTED FOR ENDING EMPLOYMENT	PERCENTAGE
Organisational factors:	
Not allowed flexible work hours/work conditions	12.5%
Not considered for promotion	5.1%
Ran out of paid sick leave	12.5%
More suitable work not available	22.4%
Asked to leave/sacked	12.5%
Getting to/from work:	
Unable to get to/from work	10.7%
Unable to obtain appropriate parking	6.7%
Unable to get dressed in time for work	3.4%
Getting around at work:	
Architectural barriers	17.4%
Inaccessible (or badly designed) bathroom	4.2%
Inaccessible tearoom or beverage/food area	1.6%
General area accessibility	10.1%
Use of equipment at work:	
Unable to use necessary equipment	11.5%
Unable to stand for long periods to use equipment	20.8%
Chair/desk inappropriate for comfort and support	6.1%
Impacts of physical symptoms:	
Fatigue	68.3%
Physical problems with arms or hands	33.1%
Physical problems with legs or feet	41.8%
Tremors	7.7%
Unable to work fast enough	24.0%
Problems with balance or dizziness	31.5%
Bladder or bowel problems	29.5%
Poor vision	12.9%
Unable to work due to other symptoms:	
Heat sensitivity	30.3%
Difficulty with memory, concentration or thinking	42.0%
Difficulties with speech	7.7%
Pain	25.3%
Other sensory symptoms	12.9%
Other reasons:	
Felt the people at work were critical or unsympathetic	12.3%
Felt as if I was not doing a good enough job	35.0%
Felt as if I was a burden to my colleagues or employers	16.2%
Felt too stressed by the effort involved in continuing work	33.5%
Doctor or health professional advised	21.2%
Reasons not listed	23.2%

Table 4.4: Disclosures of MS diagnoses among AMSLS participants

	PERCENTAGE
Diagnosed Prior to Employment	68.0%
Diagnosed During Employment	32.0%
	PERCENTAGE
If Diagnosed Prior	
Informed Employer when Starting	60.8%
Have not Informed Employer	20.6%
If Diagnosed During	
Informed Employer at Diagnosis	65.0%
Have not Informed Employer	12.7%
Views on Disclosure	
Negative Experience	27.2%
Positive Experience	40.5%
Irrelevant	32.4%

4.4.6 Workplace supportiveness and discrimination among people living with MS

In most cases, workplaces were supportive of people living with MS (Figure 4.3A). Encouragingly, discrimination related to MS was uncommon, with 90.7% of AMSLS participants reporting that they rarely or never felt discriminated against in the 12 months prior to the survey. Only 1.8% indicated frequent experiences of discrimination during this period.

The majority of employed participants reported positive workplace conditions, as shown in Figure 4.3B:

- 71.6% indicated that their employer facilitated an acceptable balance between family and work
- 80.6% said their employer promoted flexible working hours
- 80.6% felt that their current workload was appropriate

Despite these encouraging findings, workplace stress remains a concern, with 45.8% reporting excessive stress and 29.6% experiencing high levels of pressure.

Figure 4.3: Workplace quality of life scores

Figure 4.3A: Workplace supportiveness

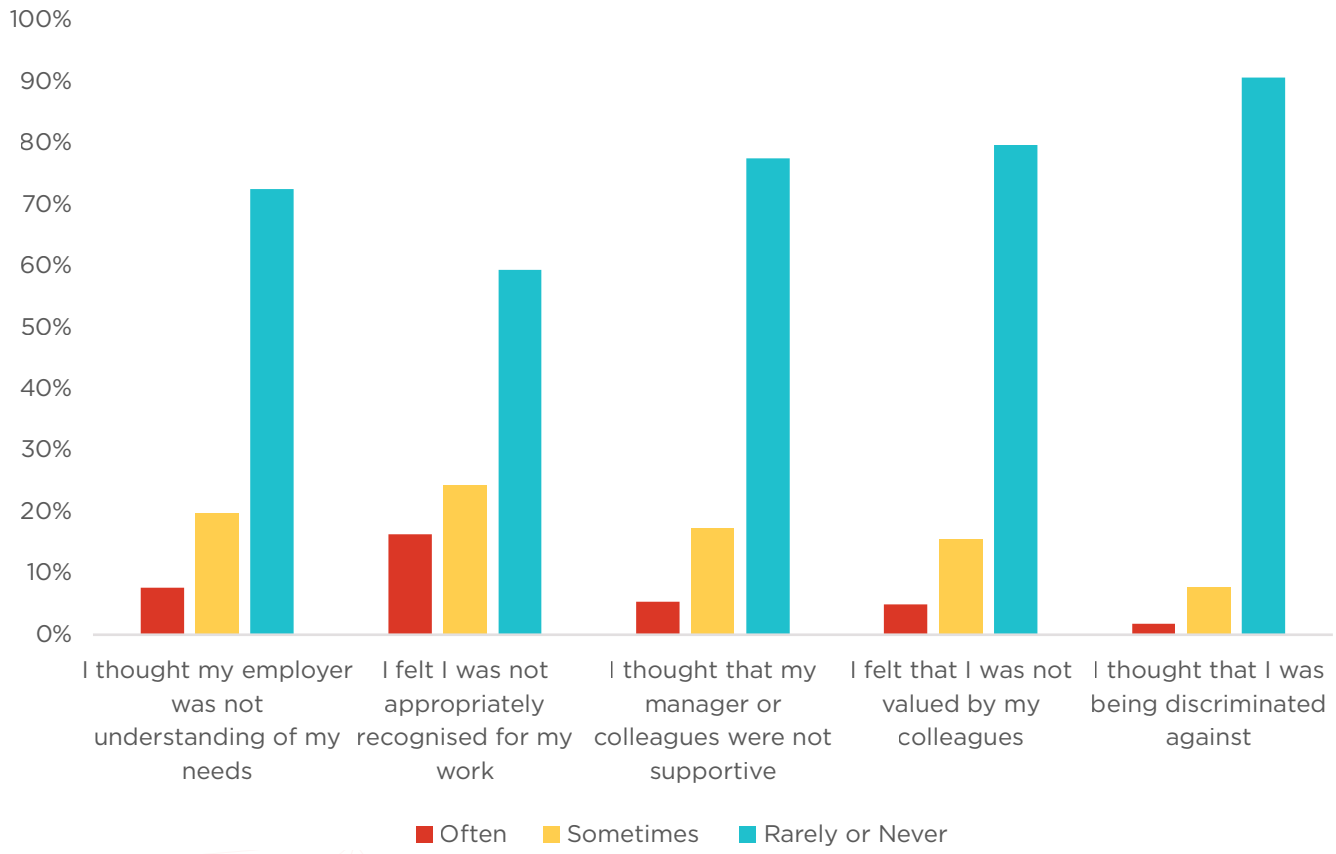
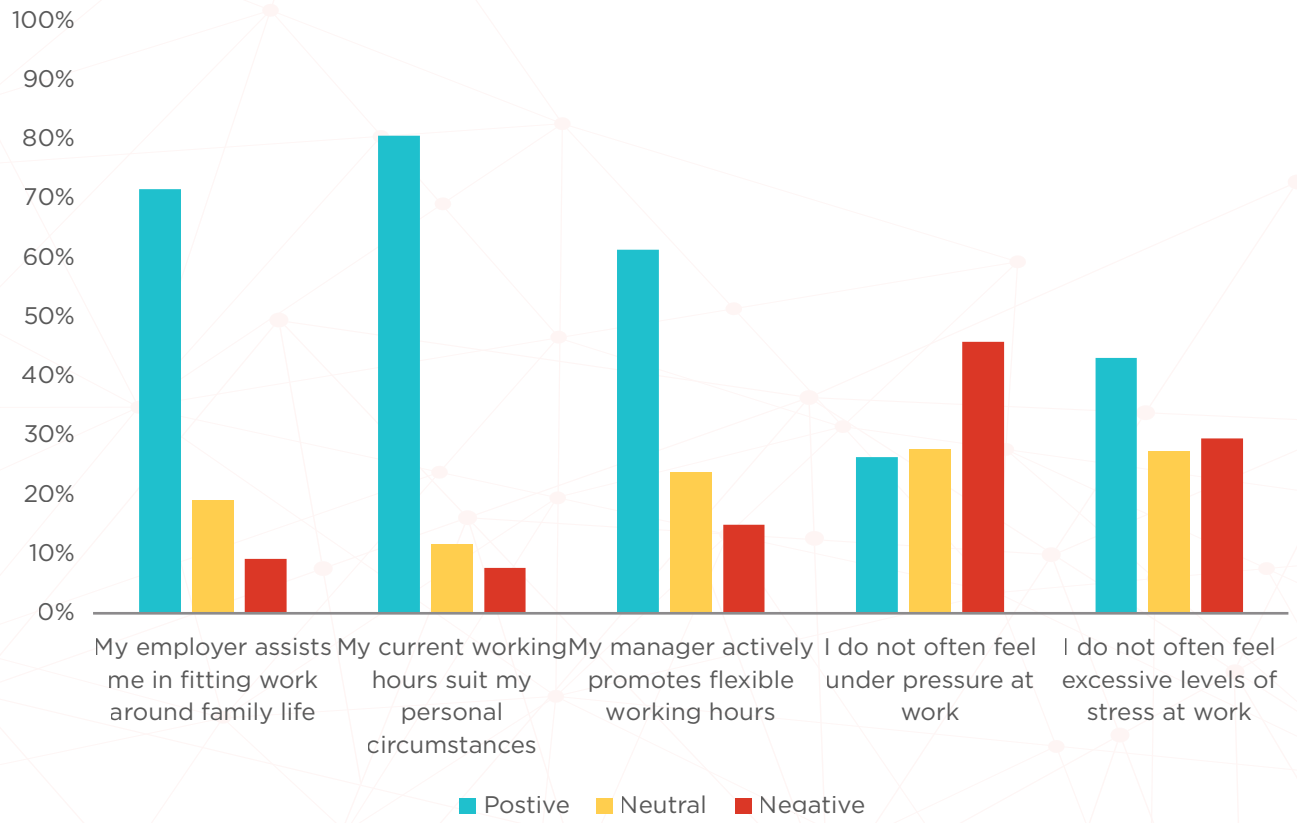


Figure 4.3B: Workplace stress



4.4.7 Income levels and employment status

Analysis of income stratified by employment status showed that the proportion of participants earning $1,500 a week or more decreased sharply as employment status deteriorated (Table 4.5) For example, the proportion of people earning between $1,500-1,999 per week dropped from 27.1% among those employed full-time to just 3.1% among those out of the labour force.

Conversely, the proportion of participants earning $1-499 per week increased from 0.6% among those employed full-time to 39.1% among those out of the labour force. For context, the average weekly gross income for Australians was $1,923.40 as of May 2024, underscoring the financial disadvantage faced by those with reduced workforce participation due to MS.

4.4.8 Differences in employment status

We undertook an analysis of employment status in relation to key factors such as disability severity and DMT use (Tables 4.6 and 4.7).

There was a strong relationship between disability severity and employment status, with the proportion of participants out of the labour force rising by 52.0% (from 23.0% to 75.0%) as mobility issues progressed from negligible to severe. A similar pattern was observed when analysing income by disease duration. Only 16.0% of newly diagnosed participants were out of the labour force, compared to 37.7%% of those with 11-20 years of disease duration and 65.8% of those with more than 30 years.

Regarding MS type, participants with RRMS were more likely to be employed, as were those using DMTs.

Finally, clinical depression was significantly more prevalent among participants out of the labour force (43.5%) compared to those who were either employed full- or part-time (19.0%). In contrast, no substantial relationship was found between employment status and clinical anxiety.

Table 4.5: Gross income tabulated over employment status

	EMPLOYMENT STATUS			
INCOME LEVEL ($/WEEK)	SELF-EMPLOYED	EMPLOYED FULL-TIME	EMPLOYED PART-TIME	OUT OF THE LABOUR FORCE
Nil	0.0%	0.0%	0.0%	16.8%
$1-499	20.5%	0.6%	18.9%	**39.1%**
$500-999	**35.6%**	4.2%	**29.6%**	26.2%
$1,000-1,499	11.0%	14.5%	26.4%	9.4%
$1,500-1,999	9.6%	27.1%	15.1%	3.1%
$2,000-2,999	11.0%	**34.3%**	6.3%	3.9%
>$2,999	12.3%	19.3%	3.8%	1.6%
Totals	**100%**	**100%**	**100%**	**100%**

Notes: The highest percentages in each column are bolded.

Table 4.6: Employment status tabulated over disability severity, disease duration, and MS type

	EMPLOYMENT STATUS			
	SELF-EMPLOYED	EMPLOYED FULL-TIME	EMPLOYED PART-TIME	OUT OF THE LABOUR FORCE
Disability Severity				
No	13.2%	**35.6%**	28.3%	23.0%
Mild	12.6%	18.2%	23.7%	**45.5%**
Moderate	9.8%	6.0%	12.0%	**72.2%**
Severe	10.4%	8.3%	6.3%	**75.0%**
Disease Duration				
0-5 Years	12.3%	**50.6%**	21.0%	16.0%
6-10 Years	11.5%	**36.3%**	28.3%	23.9%
11-20 Years	12.4%	25.1%	24.8%	**37.7%**
21-30 Years	10.6%	14.7%	24.9%	**49.8%**
>30 Years	16.4%	9.6%	8.2%	**65.8%**
Type of MS				
Relapsing-Remitting	12.2%	28.9%	28.7%	**30.2%**
Primary Progressive	10.6%	24.7%	9.4%	**55.3%**
Secondary Progressive	10.0%	7.5%	10.0%	**72.5%**

Notes: Percentages should be read across rows. The highest percentage in each row is bolded.

Table 4.7: Employment status tabulated over DMT use, clinical depression, and clinical anxiety

DMT USE		
Employment Status	**No**	**Yes**
Self-Employed	40.4%	59.6%
Employed Full-Time	20.1%	79.9%
Employed Part-Time	25.0%	75.0%
Out of the Labour Force	46.3%	53.7%
DEPRESSION		
Employment Status	**No**	**Yes**
Self-Employed	81.6%	18.4%
Employed Full-Time	81.9%	18.1%
Employed Part-Time	80.4%	19.6%
Out of the Labour Force	56.5%	43.5%
ANXIETY		
Employment Status	**No**	**Yes**
Self-Employed	59.2%	40.8%
Employed Full-Time	59.1%	40.9%
Employed Part-Time	58.3%	41.7%
Out of the Labour Force	53.2%	46.8%

Notes: Percentages should be read across rows.

4.5 Discussion

4.5.1 Overview

In this chapter, we demonstrated that the majority of retired AMSLS participants exited the labour force due to their MS. The most frequently reported symptoms contributing to job cessation were fatigue, cognitive dysfunction, motor dysfunction of the legs and feet, and heat sensitivity.

In addition to physical symptoms, many participants reported psychosocial factors as reasons for ending their employment, such as feeling that their work no longer met their personal standards.

While a relatively high proportion indicated that disclosing their MS improved their workplace experiences, some reported negative consequences. Nevertheless, an overwhelming majority stated that they rarely or never felt discriminated against in the workplace over the past 12 months. However, approximately one-third reported experiencing excessive workplace stress or feeling under pressure.

We conducted several analyses to more thoroughly investigate employment patterns. These analyses revealed associations between employment status and several clinical factors related to MS, including a higher prevalence of clinical depression among participants who were out of the labour force.

Crucially, our analyses of employment status and income showed that income declines sharply as employment deteriorates. These findings provide valuable data for economic simulation models aimed at quantifying the indirect costs of MS. Such models help health economists better understand the broader societal impact of disability on people living with MS, which in turn supports the advocacy efforts of the MS community.

4.5.2 Comparisons with the literature

Several of this chapter's major conclusions align with the international literature. Most notably, the MSIF identified fatigue and motor dysfunction as key symptoms contributing to workforce exit among people living with MS [82]. A 2020 systematic review drew similar conclusions and also supported our finding that cognitive impairments significantly influence employment outcomes in MS [84].

Several studies corroborate the associations we observed between labour force exit and factors such as MS-related disability severity [83,84,91,94,95], progressive MS[83,84,94,96], and longer disease duration [84,91,94].

Additionally, a study analysing AMSLS data found that "95% of respondents who required changes to their work role … and 82% of those who required changes to their work environment reported that the changes were made." [97] This aligns with our finding that relatively few participants left their jobs due to a lack of accommodation by employers.

Conversely, research has shown that people living with MS who are at risk of leaving employment were more likely to be experiencing mental health issues [95,96]. This suggests that the observed association between clinical depression and unemployment may reflect reverse causality; that is, individuals may leave the workforce because of mental health challenges, rather than developing mental illness as a consequence of unemployment.

4.5.3 Improving employment outcomes among people living with MS

Given that disability severity is a major contributor to unemployment among people living with MS [91], preventing disability progression is paramount to improving employment outcomes.

A study that used AMSLS data from 2016 showed that people using high-efficacy DMTs had 2-3 times higher rates of work attendance and productivity compared to individuals treated with interferons [98]. In related research, differences in employment outcomes between people with RRMS and progressive MS were attributed to the array of treatments available for RRMS, in contrast to the limited subsidised DMT options for progressive MS in Australia [99].

Importantly, research by MSIF has shown that people living with MS regard stable disability status and access to effective treatments as fundamental to maintaining their employment [82].

Beyond therapeutic interventions, studies have identified several strategies to support people living with MS in maintaining employment. In particular, flexible working arrangements, such as working from home, can be beneficial, allowing individuals to better manage their working environment and energy levels [82,100]. People living with MS have also highlighted the importance of employer and colleague support [82], as well as feeling confident that using support aids will not lead to stigma [101].

Workplace assistance has demonstrated significant protective effects on employment [102,103]. However, the services are often accessed too late to prevent people living with MS from leaving the workforce [104].

Our research group recently co-designed an integrative digital health platform, MS WorkSmart, specifically for employed individuals living with MS. This nine-module program promotes empowerment and symptom management, teaches communication strategies for discussing MS in the workplace, assists with navigating workplace adjustments and accommodations, and offers guidance on self-care, stress management and future planning. Ultimately, it aims to reduce job loss.

4.5.4 Disclosures of MS in the workplace

Our results (Table 4.4) showed that most Australians living with MS did not believe that disclosing their illness to an employer would be beneficial. Challenging this belief, a study conducted by Kirk-Brown and colleagues using AMSLS data from 2010-2012 found that disclosure did not lead to statistically significant increases in dismissal rates [103]. On the contrary, the study predicted longer job tenures following disclosure.

A 2020 systematic review focusing on workplace disclosure of MS diagnoses found that fear of discrimination was the primary reason for non-disclosure [85]. This contrasts with our findings (Figure 4.3A), which suggest that despite fear of discrimination, more than 90% of employed individuals reported actually experiencing workplace discrimination only rarely or not at all, in the 12 months prior to our survey.

4.5.5 Strengths and limitations

This chapter benefitted greatly from the large, representative and diverse AMSLS cohort, which enabled the collection and linkage of highly detailed data. A key advantage of the AMSLS is the comprehensive suite of survey questions, which allowed us to deeply investigate a broad range of employment-related issues pertinent to MS.

Regarding limitations, reverse causality may have influenced our analysis of employment status, clinical anxiety and depression (see Section 3.5.2). It is also notable that AMSLS participants have a relatively high mean age (59 years), which may limit the generalisability of our findings to younger people living with MS. However, this age distribution is typical of Western MS populations, as demonstrated in the literature [35,44].

4.5.6 Conclusions

AMSLS data indicate that both symptomatic and psychosocial factors influence employment patterns and job loss among Australians living with MS. In addition to DMTs aimed at reducing disability severity, flexible working arrangements and support from colleagues and employers are essential for helping people living with MS remain in the labour force. This social support is vital, as job loss can have profound psychological and socioeconomic consequences. These broader implications will be examined in detail in the cost of illness section of this report (Chapter 5).

CHAPTER 5

Societal costs and costs of illness associated with MS

5.1 Summary

In this chapter, we present a comprehensive analysis of the costs associated with MS, including a prevalence-based estimate of the overall cost of illness, drawing on the prevalence data outlined in Chapter 2 [105].

Our study draws on data from the AMSLS (including cost diaries), the Medical Benefits Schedule (MBS) and PBS registries, and aggregate data collated by the ABS. Cost diaries and MBS/PBS claims data were used to identify the direct costs of MS, which included expenses related to prescription and non-prescription medications, hospital admissions, consultations with healthcare professionals, mobility equipment, and home modifications.

To estimate indirect costs, such as reduced work productivity due to disability and income loss due to early retirement, we combined AMSLS survey data with ABS statistics.

All our analyses were conducted from a societal perspective, capturing the full spectrum of costs, regardless of whether they were borne directly by people living with MS, their families and carers, healthcare payers, or society.

The total societal cost of MS in Australia for 2024 was $3.004 billion (95% CI: $2.670-$3.289 billion), equating to a mean of $79,581 (95% CI: $70,752-$87,136) per person living with MS. The two greatest sources of MS costs were:

- DMTs: $592 million; $15,671 per person living with MS
- Lost employment and productivity: $846 million; $22,411 per person living with MS

Costs varied substantially based on AMSLS participant characteristics. For example, as MS-related disability severity increased from no disability to severe disability, the mean per person cost rose from $42,688 to $135,780 - a difference of $93,092, representing a 220% increase.

Overall, costs appear relatively stable when accounting for inflation and increasing prevalence. Compared with our 2017 estimates, the inflation-adjusted cost per person living with MS decreased slightly from $85,297 in 2017 to $79,581 in 2024 (-6.7%). In contrast, the total societal cost of MS increased substantially, rising from 1.751 billion in 2017 to $3.004 billion in 2024 - a 71.5% increase. After adjusting for inflation, the difference was $819 million, representing a 37.5% increase. This substantial increase in total costs is primarily driven by rising MS prevalence, with the number of cases growing by 47.7% (an additional 12,149 cases) between 2017 and 2024.

When compared to the general population, the AIHW estimated average health spending per person in Australia was $9,597 in 2022-23, equivalent to approximately $10,400 in 2024 dollars. People living with MS with no disability incurred health costs roughly four times higher than the general population, while those with severe disability faced costs approximately 14 times higher.

5.2 Introduction

5.2.1 Background

MS imposes a substantial health economic burden on people living with the disease, their families and caregivers, and society as a whole. In our 2021 report, we estimated that the total societal cost of MS in Australia was $2.45 billion per year [1], up from $1.75 billion in 2017 [2] and $1.04 billion in 2010 [3]. This figure captures costs borne by people living with MS and their families, as well as those incurred by healthcare payers and society more broadly [55].

At the individual level in 2021, the mean annual cost per person living with MS was $73,457, with costs varying by disability level. For instance, the costs rose from $32,829 for people with MS living with no disability to $123,333 for those living with severe disability [1].

The substantial cost of MS in Australia and elsewhere has been attributed to several key factors:

- The high cost of MS DMTs [106].
- Increased diagnosis rates among younger adults aged 20-40 years [8], a life stage often associated with career development and starting families.
- The chronic nature of MS, which often affects people throughout their lives [6].

MS is widely recognised as a leading cause of neurological disability among working-age adults [107].

In line with health economic conventions, MS-related costs are typically classified into two major categories:

- Direct costs: [55,106] These arise from disease management and include medications, visits to physicians or allied health professionals, hospitalisations, housing modifications, and professional cleaning services [106].
- Indirect costs: These result from the broader impact of MS and include reduced work productivity [106], loss of employment [108], and informal (unpaid) care provided by family or friends [109].

5.2.2 Previous analyses and translational impact

The previous cost of illness analyses conducted in 2010, 2017, and 2021 have been instrumental in supporting MS Australia's advocacy effort. These reports have underpinned efforts towards the subsidisation of new therapeutics under the PBS, expansion of the MS specialist nurse workforce, and increased funding for MS research.

The most recent original cost estimates of MS were produced in 2017, with the 2021 figures derived by adjusting for inflation and incorporating updated prevalence data. Given the evolving landscape of MS DMT availability [110,111], rising living costs, and increasing MS prevalence (see Chapter 2) [39], updated MS cost estimates are clearly warranted.

Unlike many other studies, our cost of illness analyses adopted a largely individual-level approach, sourcing data directly from people living with MS. This has been made possible through the AMSLS, which incorporates cost diaries, surveys, and linked administrative data. The detailed and granular nature of these data enables the investigation of both broad cost trends and group-specific patterns [112]. This approach uniquely facilitates understanding of complex issues such as inequalities in economic outcomes and differences in healthcare needs [113], thereby strengthening the evidence base for advocacy.

5.2.3 Aims

In this chapter, we aimed to provide a comprehensive and updated overview of the societal cost of MS in Australia, using a prevalence-based approach for the overall cost of illness. These new estimates incorporate costs not previously captured, offering a more accurate representation of the economic burden of MS in Australia. Where applicable, we also compared current costs with those of our previous reports to identify how the costs of MS have evolved over time.

Importantly, these updated cost estimates will inform future health economic models, supporting more robust analyses and advocacy efforts.

5.3 Methods

5.3.1 Data sources

Information on the direct costs of MS was collected through two AMSLS sources. The first were the cost diaries voluntarily completed by members of the AMSLS over a six-month period, and MBS/PBS data linked to AMSLS participant records. The inclusion of linked PBS/MBS data, a novel addition to this analysis, has substantially enhanced the robustness and completeness of our direct cost estimates.

Data relating to the indirect costs of MS and sample characteristics were drawn from three AMSLS surveys conducted in 2023: the Economic Impact, Employment, and Disease Course surveys.

We also used the Australian MS population estimate of 37,756, as presented in *Chapter 2*, to generate prevalence-based cost estimates.

5.3.2 Sociodemographic and clinical variables

To understand the characteristics of AMSLS participants and analyse costs across specific subgroups of people living with MS, we collected a range of sociodemographic and clinical data. These included measures of age, sex, education level, current employment status, state/territory of residence, disability severity, MS disease course/MS type, time since diagnosis, and DMT usage.

As in other chapters, MS-related disability severity was captured using the PDDS and mapped to EDSS categories [64]. These categories were defined as *no disability* (PDDS of 1; EDSS = 0.0), *mild disability* (PDDS of 2-3; EDSS = 1.0-3.5), *moderate disability* (PDDS of 4-5; EDSS = 4.0-6.0), and *severe disability* (PDDS of 6-8; EDSS = 6.5-9.5) [65].

5.3.3 Approaches to costing and analysis

Our cost analysis was informed by validated guidelines [114] [105]. When estimating costs of illness, two primary approaches may be used; a population-level (top down) method or individual-level (bottom up) method [55,56].

Population-level methods involve using aggregate measures of health service utilisation and expenditures that are typically stored in national registries or databases [55]. The advantage of such an approach is that it is relatively simple and does not require extensive data collection. However, these methods often preclude detailed comparisons of subgroups of people living with disabilities and limit analyses of individual cost components.

Conversely, individual-level approaches are relatively costly and time-consuming as they often require collecting data from a sample of people living with a disability, from which total costs are then extrapolated [55]. However, such techniques can yield highly detailed data that are unavailable through population-level approach. This chapter primarily employs an individual-level methodology, drawing on data from AMSLS participants through surveys and cost diaries. Aggregate data were used only when participant-level data were unavailable or inapplicable - for example, when estimating costs related to work productivity losses and informal care.

As with previous reports, we adopted a societal perspective in our cost of illness analyses[2]. Accordingly, we accounted for all MS-related costs, regardless of whether they were borne directly by people living with MS, healthcare payers, or the broader community [55]. For example, this study treated the purchase of any MS-related medications as an expense, despite most pharmaceuticals being partially or wholly subsidised by the Australian Government.

Our analyses leveraged the highly detailed data obtained through an individual-level approach to cost estimation. Specifically, we examined mean costs both overall and across subgroups defined by sex, state/territory of residence, disability severity, MS disease course/MS type, and disease duration.

We also conducted detailed cost breakdowns, reviewing levels of costs across various categories and subcategories, which are detailed in the following section.

5.3.4 Direct costs

For direct costs, the primary data sources were the AMSLS cost diaries. A list of included costs is provided in Table 5.1. These diaries collected detailed information regarding various expenses incurred in the management of MS, regardless of whether the participant paid themselves. To assist participants in reporting their expenses, each cost diary was pre-populated with item lists corresponding to each category of costs. To reduce recall bias, participants were asked to record expenses as they occurred over a six-month study period.

Costs recorded by AMSLS participants related to the purchase or hire of items classified into the following categories: prescription medications, non-prescription medications (such as supplements and over-the-counter drugs), durable and disposable equipment, consultations with healthcare professionals, medical diagnostics and procedures, hospital admissions, nursing services, household and personal services, home and car alterations, memberships/subscriptions, allied health utilisation and transportation. Participants were instructed to record costs only if they were directly or indirectly related to their MS.

Because the distribution of disability severity among cost diary participants did not match that of the broader AMSLS cohort (see Table 5.2, *Results*), overall and state-specific cost estimates were weighted by disability severity to improve representativeness. Additionally, to improve the representativeness of hospital admission data for disease duration subcategories, costs were apportioned to these groups according MS-related disability severity.

All cost diary entries were reported in 2024 Australian dollars (AUD). Item prices were either provided by AMSLS participants or, when only unit usage was reported, sourced from representative references such as the 2024 NDIS Pricing Schedule[115], the Australian Taxation Office (85 cents per kilometre for private car travel)[116], and the Independent Health and Aged Care Pricing Authority (IHACPA). A complete list of prices identified using market-based and validated sources external to AMSLS data is presented in Supplementary Figure 5.1.

Table 5.1: Categories considered in our cost analysis

COST CATEGORY	INCLUSIONS
Direct Costs	
Primary Pharmaceuticals	Prescription medications, including disease-modifying therapies.
Other Pharmaceuticals and Supplements	Non-prescription medications, dietary supplements, and other related non-pharmaceutical products.
Medical Services	Imaging, diagnostic procedures, pathology, attendance by health professionals, therapeutic and oral procedures, hospital admissions, nursing, and other related services.
Major Assets	MS-related vehicle or real estate purchases or alterations.
Minor Assets	Other asset purchases or alterations, relating to items such as specialised furniture, exercise equipment, disposable goods (including sanitary products) and mobility aids.
Non-Medical Services	Other services, such as those relating to some allied health services, household maintenance, case management (including NDIS), and community engagement activities.
Transport	MS-related travel private or hired vehicle, plus public or community transportation.
High-Support Care	Residential care, respite, and equivalents.
Indirect Costs	
Lost earnings	Effects of early retirement, reduced employment, cessation of employment, and occupation changes.
Reduced productivity	Workplace absenteeism (hours not worked) and presenteeism (hours worked with limited productivity).
Informal Care	Impacts on carer wellbeing and reductions in carer earnings.

IHACPA data indicated a cost of $6,465 per short hospital admission (three days or less: equal to the 2024 National Efficient Price) and $12,930 per long admission (four days or more: twice the same National Efficient Price) [117]. This categorisation was based on a mean length of stay of 2.7 days reported by the AIHW [118]. Where representative cost estimates were not available, indicative prices were obtained from online sources (Supplementary Table 5.1). Notably, the items associated with these prices were not major contributors to overall expenses. Where cost diary data were missing, values were imputed using mean prices. For instance, if a price was unavailable for a specific product, such as a medication or mobility aids, the mean price for that category was substituted.

Furthermore, participants were asked to report any asset purchases in the five years prior to completing the costdiary, corresponding to June 2019-July 2024 for those starting in July 2024. This aimed to capture large and irregular expenses that fell outside the cost diary period but are necessary for estimating representative annual costs. To incorporate these costs while avoiding adding expenditures accrued over multiple years, asset prices were adjusted for inflation, summed, and divided by 5.5, representing five years plus the six-month cost diary period.

As noted above, additional information on direct costs was obtained from linked PBS and MBS administrative datasets. These data reflect the utilisation of PBS-approved medications and MBS-approved medical services by people living with MS, including item codes (identifying specific services or pharmaceuticals), benefits paid, patient contributions, and dates of dispensation. To conservatively adjust for non-MS related PBS and MBS expenses, we subtracted the 2023-24 per capita expenses (PBS: $708.17 [119], MBS: $1,431.07, both including out-of-pocket contributions [120]) from our estimates. These adjustments reduced PBS and MBS cost estimates by 4.1% and 37.6%, respectively.

Using this information, we were able to produce a more accurate estimate of the direct costs of MS than previous analyses. PBS expenses were divided according to whether they related to DMTs. MBS expenses were categorised into imaging, diagnostic procedures, pathology, healthcare professional attendances, therapeutic procedures (including surgeries, physical therapy, and psychological treatments, among other items), oral procedures (including services such as dental surgery), and other services.

Lastly, cost diary data indicated that relatively few AMSLS participants were residents of nursing homes or equivalent high-support residential care facilities. This is likely to be an underestimation of the broader MS population in such settings, given the challenges this group may have in participating in the AMSLS. To account for this, costs associated with high-supportcare, including nursing homes, were estimated using external data sources. Specifically, the mean annual per capita cost of long-term residential care was set at $132,633.23 annually ($363.13 per day), based on the most recent IHAPCA report [121]. Similarly, the mean daily cost of short-term respite care was set at $388.92, with a median stay of 24 days [122]. Based on ABS estimates from 2018 and 2022, we assumed that 3.8% of Australians living with MS were permanently in residential care in 2024 [123], and that 1.0% accessed respite care, derived from cost diary data. All people living in residential care were conservatively assumed to have severe MS-related disability, while 30% and 70% of those entering respite care were assumed to have moderate or severe disability, respectively. Note that this latter assumption affected disability-specific estimates, but did not impact overall cost estimates.

5.3.5 Indirect costs

Indirect costs in this analysis included early retirement, transitions to part-time work or unemployment, transitions to lower-paying occupations, lost earnings between jobs, workplace presenteeism (reduced productivity at work) and absenteeism (absences from work). The proportions of individuals affected by each of these costs, and the magnitudes of their impacts, were estimated based on responses to the 2023 AMSLS Employment, Economic Impact, and Disease Course surveys. For changes in employment status and workplace productivity, we assumed mean full-time salary cash earnings (including salary sacrifice) of $1,935 per week and a mean hourly wage of $39.47, which were both adjusted for sex. These estimates were based on ABS calculations and represented in 2024 AUD [124].

Early retirement due to MS-related disability was self-reported by participants in the 2023 AMSLS Employment Survey. To estimate its cost, forgone salary was annualised with superannuation contributions assumed at 11.5%, the standard Australian rate in 2024. Reductions in returns to superannuation, a new item in this report, were compounded at a rate of 7.2%, based on the ten-year annualised mean rate of return for Australian superannuation accounts with a 61-80% allocation to growth assets [125]. Other changes in employment status (i.e. transitioning from full-time to part-time or becoming unemployed) were reported in the 2023 AMSLS Economic Impact Survey. The mean change in weekly working hours between employment categories was calculated using these data, multiplied by the assumed mean wage, and annualised to estimate the cost impact.

To assess the impact of MS-related occupational changes, participants in the 2023 AMSLS Economic Impact Survey were asked to report both their current and pre-MS occupations. Occupations were categorised using the Australian and New Zealand Standard Classification of Occupations inventory [126], which includes the following categories: Manager, Professional, Technician or Trade Worker, Community or Personal Service Worker, Clerical or Administrative Worker, Sales Worker, Machinery Operator or Driver, and Labourer. Using category-specific salary estimates published by the ABS, we estimated changes in annual earnings due to MS-related shifts in occupational category. To account for the cost of job transitions, we assumed a four-week period of income loss, consistent with the Reserve Bank of Australia's upper definition of frictional unemployment [127].

Reductions in work productivity (absenteeism and presenteeism among people currently working) were determined using the Work Productivity and Activity Impairment (WPAI) questionnaire, included in the 2023 AMSLS Disease Course Survey. The WPAI is a validated instrument that evaluates health-related impairments to productivity [128]. This questionnaire required participants to report both the number of workdays lost due to disability (absenteeism) and reductions in productivity while at work (presenteeism) during the four weeks prior to completing the survey. Full productivity equates to a full salary. The cost of absenteeism was represented as hours not worked multiplied by the mean wage per hour. The cost of presenteeism was calculated by multiplying the mean salary of a person living with MS by the mean percentage of productivity lost due to MS-related disability. Both estimates were adjusted to reflect the proportions of people working full and part-time.

5.3.6 Informal care

The cost of informal care was sourced from a recent systematic review conducted by our group, which stratified costs over disability levels [129]. Using data provided by 28 studies – originating in various though predominantly high-income and comparable countries – the review estimated annual costs of US$1,123 for people with no or mild disability, US$6,643 for moderate disability, and US$15,855 for severe disability. For this report, these estimates were adjusted for US inflation and then converted to AUD. As informal care is neither wholly a direct nor an indirect cost of MS, it was classified separately.

5.3.7 Confidence intervals

Confidence intervals were estimated under the assumption of normality, with bootstrapping producing similar estimates, though often slightly less conservative. SDs were only estimable for direct costs (excluding residential care) as these data were collected at the individual level. This enabled analysis of between-person variation. Other costs were estimated using population-level data and external sources, including government datasets and academic literature, which did not allow for the calculation of SDs. To mitigate this limitation, we conservatively assumed that the SDs for indirect costs were proportionally equal to twice those of the non-cost diary direct costs, which were also derived from samples exceeding 1,000 participants. This approach was based on the assumption that variation in costs would be similar between cost categories and yielded an estimated SD equal to 2.54% of the related cost estimates.

5.3.8 Sensitivity analyses

The impact of several key study assumptions was assessed through sensitivity analyses. The first analysis examined how cost estimates derived from MBS and PBS data were affected by the assumption that mean per capita MBS/PBS expenditures could not be attributed to MS.

The second analysis explored how costs might change if the proportion of people living with MS in residential care was higher than assumed, given that the related data was not specific to MS. To achieve this, we increased the number of people in care by 1% and 2% of the total MS population (378 and 756 people, respectively).

The third analysis assessed how cost estimates would increase if the intangible cost of reduced quality of life was incorporated. This cost was enumerated using a range of conservatively assumed values that were not in excess of Australian willingness to pay [130]. Specifically, we assumed values of $25,000, $35,000, and $45,000 per quality-adjusted life year (one year lived at full health) lost annually by representative AMSLS participants. Annual reductions in quality of life were calculated by subtracting mean HSU scores for people living with varying levels of MS-related disability (see Chapter 3: 0.78 for no disability, 0.60 for mild, 0.50 for moderate, and 0.47 for severe) from the population norm of 0.80. The total cost of these reductions equalled the quality of life differences multiplied by the assumed costs per QALY and summed over the Australian MS population.

The final analysis explored how varying levels of uncertainty in cost estimates would affect the width of the study's confidence intervals.

5.4 Results

5.4.1 Participant characteristics

The sociodemographic and clinical characteristics of AMSLS participants for whom PBS/MBS (n = 1700/n = 1750) and cost diary (n = 242) data were available are shown in Table 5.2. Cost diary participants were included within the larger PBS/MBS cohort, which was representative of the broader AMSLS population. The mean age in the PBS/MBS cohort was 61 years, with 79.2% identifying as female, consistent with the known epidemiology of MS [93]. The majority of participants reported having RRMS (67.1%), which is consistent with the literature [6]. Furthermore, 38.1% of participants had moderate or severe MS-related disability, and 46.4% had been living with MS for more than 20 years.

The cost diary cohort differed from the broader AMSLS population with respect to disability severity and MS type. Participants who completed the cost diary were less likely to have moderate to severe disability (24.8% vs. 38.1%) and more frequently reported a diagnosis of RRMS (76.6% vs. 67.1%). To account for this difference, estimates based on cost diary data were weighted higher to better reflect the experience of participants living with more severe MS-related disability (further details in Section 5.3.4). In addition, participant numbers for the three surveys used in this chapter – which included the 2023 Economic Impact, Employment and Disease Course surveys – were 1,439, 1,329 and 1,320, respectively. The characteristics of participants in each survey (reported in preceding chapters) reflected those of the PBS/MBS cohort.

5.4.2 Main findings

Based on the estimated number of people living with MS in Australia (see Chapter 2), the total annual cost in 2024 was $3.004 billion (95% CI: $2.670-$3.289 billion) (Table 5.3). This equates to a per-person cost of $79,581 (95% CI: $70,752-$87,136) for individuals living with MS. The largest contributor to these costs were direct costs, accounting for $1.654 billion (55%; see Figure 5.1). Indirect costs and informal care contributed a further $1.054 billion (35%) and $296 million (10%), respectively. Per person costs increased significantly across disability severity categories ($p < 0.001$, paired t-tests). Specifically, the estimated annual cost of MS for individuals with no disability was $42,688 compared to $135,780 for people living with severe disability.

Table 5.2: Participant characteristics

CHARACTERISTICS	PBS/MBS COHORT*	COST DIARY COHORT
Number of Participants	1700/1750	242
Mean Age (Years, SD)	61.1 (11.8)	55.9 (10.5)
Sex: N (%)		
Male	364 (20.8)	44 (18.2)
Female	1386 (79.2)	198 (81.8)
Disability Severity: N (%) †		
No Disability	293 (26.1)	87 (35.9)
Mild Disability	402 (35.8)	95 (39.3)
Moderate Disability	207 (18.4)	30 (12.4)
Severe Disability	221 (19.7)	30 (12.4)
Type of MS: N (%)		
Relapsing Remitting	162 (67.1)	170 (76.6)
Secondary Progressive	694 (17.2)	27 (12.2)
Primary Progressive	178 (15.7)	25 (11.3)
Disease Duration: N (%)		
0-10 Years	173 (15.4)	38 (15.7)
10-20 Years	430 (38.2)	95 (39.3)
>20 Years	524 (46.4)	109 (45.0)
State/Territory: N (%)		
New South Wales	473 (28.4)	82 (33.9)
Victoria	459 (27.6)	54 (22.3)
Queensland	238 (14.3)	22 (9.1)
South Australia	164 (9.8)	39 (16.1)
Western Australia	159 (9.5)	20 (8.3)
Tasmania	104 (6.2)	12 (5.0)
Aust. Capital Territory	67 (4.1)	13 (5.4)
Northern Territory	2 (0.1)	0 (0.0)

Notes: Aside from age and sex data, current sociodemographic and clinical variables for the MBS/PBS linked data were obtained from the 2023 Disease Course survey. Missing data is therefore a result of differences in AMSLS member participation between the data linkage and survey. Additionally, the 50-person discrepancy in participant numbers between the PBS and MBS data-linked cohorts did not materially impact cohort composition. We have therefore provided a summary of participant characteristics for the slightly larger MBS cohort only. Cost diary participants were included in the PBS/MBS cohorts. † Due to gaps in data, category-specific participant subtotals do not necessarily sum to the total numbers of participants.

Table 5.3: Cost of MS in Australia for 2024, including estimates of direct and indirect costs and mean costs by MS-related disability severity

	ESTIMATED VALUE	LOWER 95% CI	UPPER 95% CI
Total Cost			
Overall	$3,003,652,781	$2,670,335,705	$3,288,832,094
Per Person	$79,581	$70,752	$87,136
Direct Cost			
Overall	$1,653,704,128	$1,388,964,444	$1,870,306,050
Per Person	$43,827	$36,814	$49,565
Indirect Cost			
Overall	$1,053,607,911	$1,000,084,629	$1,107,131,193
Per Person	$27,906	$26,488	$29,323
Informal Care Cost			
Overall	$296,340,742	$281,286,633	$311,394,852
Per Person	$7,849	$7,450	$8,248
COSTS BY DISABILITY SEVERITY			
No			
Overall	$592,404,437	$531,503,436	$640,245,829
Per Person	$42,688	$38,299	$46,135
Mild			
Overall	$964,417,894	$815,487,262	$1,096,175,737
Per Person	$69,759	$58,987	$79,289
Moderate			
Overall	$696,819,134	$540,905,813	$823,679,154
Per Person	$99,328	$77,103	$117,411
Severe			
Overall	$946,914,693	$802,999,806	$1,090,585,693
Per Person	$135,780	$115,143	$156,381

Notes: Subtotals may not add exactly to grand totals due to elements of estimation being based on subgroup-specific means.

Figure 5.1: Percentage contributions of major cost categories to mean per person costs

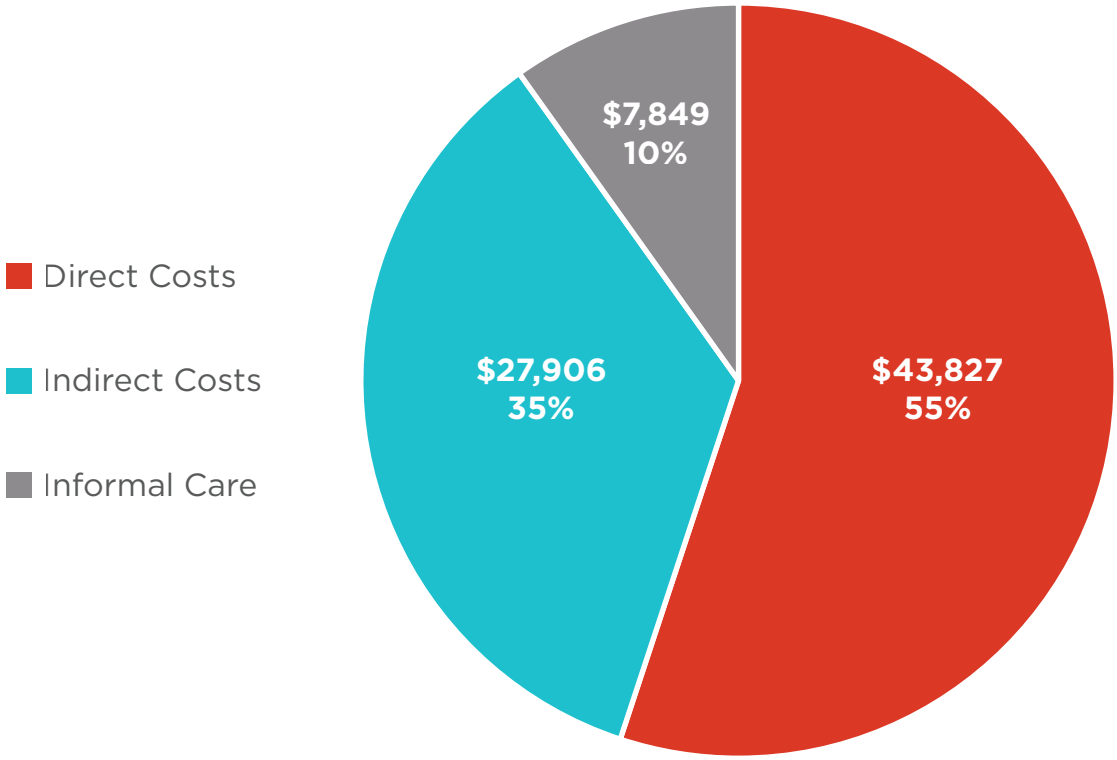
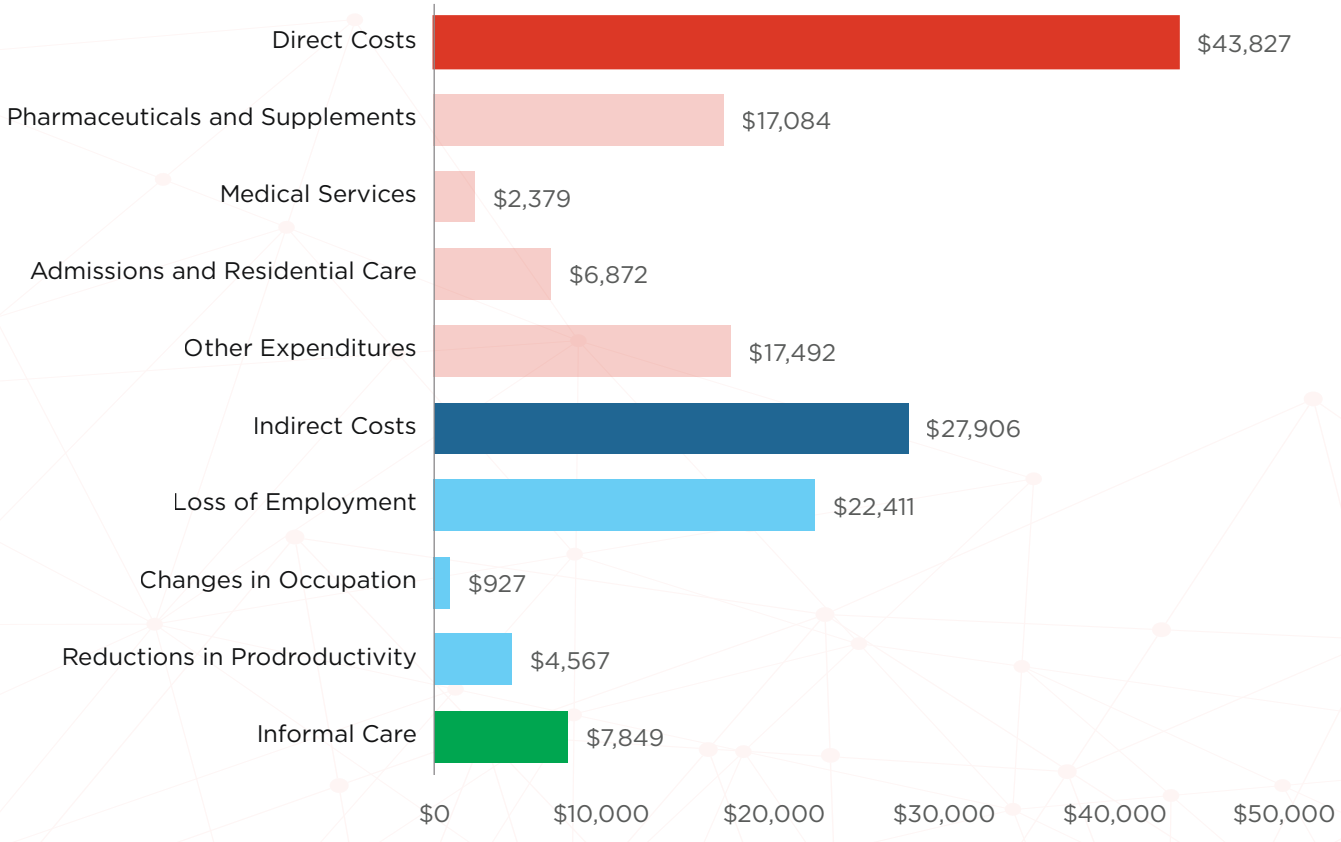


Figure 5.2: Per person direct and indirect costs with expense components



Notes: Darker colours indicate summed costs, while lighter colours represent component costs. Expenses are colour coded red/pink for direct costs, dark/light blue for indirect costs, and green for informal care.

5.4.3 Direct and indirect costs by category

Pharmaceuticals and supplements were the largest single source of direct costs, averaging $17,084 per person living with MS (95% CI: $16,586-$17,586), for a total of $645 million (95% CI: $626 million-$664 million) (Table 5.4). Other expenditures, including transport and the purchase of MS-related assets and services, also contributed substantially, totalling $660 million (95% CI: $482 million-$839 million).

Among indirect costs, loss of employment was the largest component, with estimated annual costs of $22,411 per person living with MS (95% CI: $21,273-$23,550) and $846 million in total (95% CI: $803 million-$889 million) (Table 5.4).

While indirect costs were primarily driven by employment loss, direct costs were distributed across a more diverse range of sources (Figure 5.2).

Table 5.4: Breakdown of direct and indirect costs by category

	ESTIMATED VALUE	LOWER 95% CI	UPPER 95% CI
Direct Costs			
Pharmaceuticals and Supplements			
Overall	$645,024,200	$626,207,390	$663,841,023
Per Person	$17,084	$16,586	$17,582
Medical Services			
Overall	$89,826,031	$88,281,619	$91,370,442
Per Person	$2,379	$2,338	$2,420
Admissions and Residential Care			
Overall	$258,428,986	$216,307,530	$300,550,442
Per Person	$6,872	$5,755	$7,989
Other Expenditures			
Overall	$660,424,910	$481,646,068	$839,203,753
Per Person	$17,492	$12,757	$22,227
Indirect Costs			
Loss of Employment			
Overall	$846,163,793	$803,178,673	$889,148,914
Per Person	$22,411	$21,273	$23,550
Changes in Occupation			
Overall	$35,017,718	$33,238,818	$36,796,618
Per Person	$927	$880	$975
Reductions in Productivity			
Overall	$172,426,400	$163,667,139	$181,185,661
Per Person	$4,567	$4,335	$4,799

Notes: Subtotals may not add exactly to grand totals due to elements of estimation being based on subgroup-specific means. This table is supported by Tables 5.5 and 5.6, which provide a breakdown of costs at the subcategorical level.

5.4.4 Costs by subcategory

Subcategories of direct costs are presented in Table 5.5. Within the pharmaceuticals and supplements category, DMTs accounted for an estimated $592 million in 2024 (95% CI: $577 million-$606 million), while other medications and supplements contributed just 9.0% of this total ($53.4 million). Among the medical service categories, healthcare professional attendance, including specialists and general practitioners, represented the largest cost, totalling $36.1 million (95% CI: $35.9 million-$36.3 million). Imaging costs followed at $20.3 million (95% CI: $20.0 million-$20.6 million).

Among the remaining subcategories of direct costs, residential care ($190 million), major assets ($188 million), and non-medical services ($324 million, including general assistive and some allied health services) were also substantial contributors to the overall direct cost of MS. The major asset costs were driven by housing relocations, averaging $3,056 per person (95% CI: $1,496-$4,617) (Figures 5.3 and 5.4). Additionally, 54% of expenditure on other services was not related to healthcare.

Indirect cost subcategories are summarised in Table 5.6. The largest contributor to lost employment was early retirement, which accounted for a total cost of $369 million in 2024 (95% CI: $350 million-$388 million), or $9,767 per person. This figure includes forgone superannuation totalling $79.7 million. Following early retirement in relative importance were transitions to unemployment ($295 million, 95% CI: $280 million-$310 million) and transitions to part-time employment ($183 million, 95% CI: $174 million-$192 million). Among individuals with MS who remained employed, presenteeism resulted in greater productivity loss than absenteeism ($3,074 vs. $1,493 per person, $p < 0.001$).

5.4.5 Sources of costs for the minor asset subcategory

The minor assets subcategory of direct costs refers to expenditures on various goods required by people living with MS to support their wellbeing. In 2024, the total cost of minor assets was $1,033 per person (95% CI: $628-$1,369), with mobility aids being the largest contributor at $451 per person (95% CI: $317-$584). Other significant contributors included disposable items, such as sanitary products at $174 per person (95% CI: $107-$242), and bedroom-related products, such as hoists and specialist bedding, at $139 (95% CI: $90-$188) per person.

Table 5.5: Breakdown of direct costs by subcategory

	ESTIMATED VALUE	LOWER 95% CI	UPPER 95% CI
Pharmaceuticals and Supplements			
Disease Modifying Therapies			
Overall	$591,670,275	$577,013,670	$606,326,881
Per Person	$15,671	$15,283	$16,059
Other Prescription Medications			
Overall	$37,711,617	$35,600,196	$39,823,050
Per Person	$999	$943	$1,055
Non-Prescription Medications and Supplements			
Overall	$15,642,308	$13,593,524	$17,691,093
Per Person	$414	$360	$469

	ESTIMATED VALUE	LOWER 95% CI	UPPER 95% CI
Medical Services			
Imaging			
Overall	$20,303,693	$20,035,779	$20,571,607
Per Person	$538	$531	$545
Diagnostic Procedures			
Overall	$1,671,560	$1,590,457	$1,752,663
Per Person	$44	$42	$46
Pathology			
Overall	$10,151,120	$10,045,147	$10,257,093
Per Person	$269	$266	$272
Health Professional Attendances			
Overall	$36,088,576	$35,859,906	$36,317,246
Per Person	$956	$950	$962
Therapeutic Procedures			
Overall	$17,298,378	$16,533,294	$18,063,462
Per Person	$458	$438	$478
Miscellaneous			
Overall	$4,312,703	$4,217,036	$4,408,371
Per Person	$114	$112	$117
Admissions and Residential Care			
Hospital Admissions			
Overall	$64,612,202	$32,336,639	$96,887,766
Per Person	$1,711	$856	$2,566
Residential Care			
Overall	$190,292,609	$180,625,744	$199,959,473
Per Person	$5,067	$4,809	$5,324
Respite Care			
Overall	$3,524,175	$3,345,147	$3,703,203
Per Person	$94	$89	$98
Other Expenditures			
Major Assets			
Overall	$188,085,190	$83,599,100	$292,571,279
Per Person	$4,982	$2,214	$7,749
Minor Assets			
Overall	$39,005,040	$31,225,695	$46,784,386
Per Person	$1,033	$628	$1,369

	ESTIMATED VALUE	LOWER 95% CI	UPPER 95% CI
Healthcare and Other Services			
Overall	$323,652,586	$289,620,297	$357,684,874
Per Person	$8,572	$7,671	$9,474
Subscriptions/Memberships			
Overall	$23,163,424	$16,046,743	$30,280,105
Per Person	$614	$425	$802
Transport			
Overall	$86,518,671	$61,154,233	$111,883,109
Per Person	$2,292	$1,620	$2,963

Notes: Subtotals may not add exactly to grand totals due to elements of estimation being based on subgroup-specific means.

Table 5.6: Breakdown of indirect costs by subcategory

	ESTIMATED VALUE	LOWER 95% CI	UPPER 95% CI
Loss of Employment			
Transitions to Part-Time			
Overall	$182,838,712	$173,550,506	$192,126,919
Per Person	$4,843	$4,597	$5,089
Transitions to Unemployed			
Overall	$294,543,641	$279,580,824	$309,506,458
Per Person	$7,801	$7,405	$8,198
Early Permanent Retirement			
Overall	$368,781,440	$350,047,343	$387,515,537
Per Person	$9,767	$9,271	$10,264
Changes in Occupation			
Cost of Job Searching			
Overall	$1,550,203	$1,471,452	$1,628,953
Per Person	$41	$39	$43
Reductions in Earnings			
Overall	$33,467,515	$31,767,365	$35,167,665
Per Person	$886	$841	$931
Reductions in Productivity			
Presenteeism			
Overall	$116,071,689	$110,175,247	$121,968,130
Per Person	$3,074	$2,918	$3,230
Absenteeism			
Overall	$56,354,711	$53,491,892	$59,217,530
Per Person	$1,493	$1,417	$1,568

Notes: Subtotals may not add exactly to grand totals due to elements of estimation being based on subgroup-specific means.

Figure 5.3: Per person costs for subcategories of major asset purchases and alterations

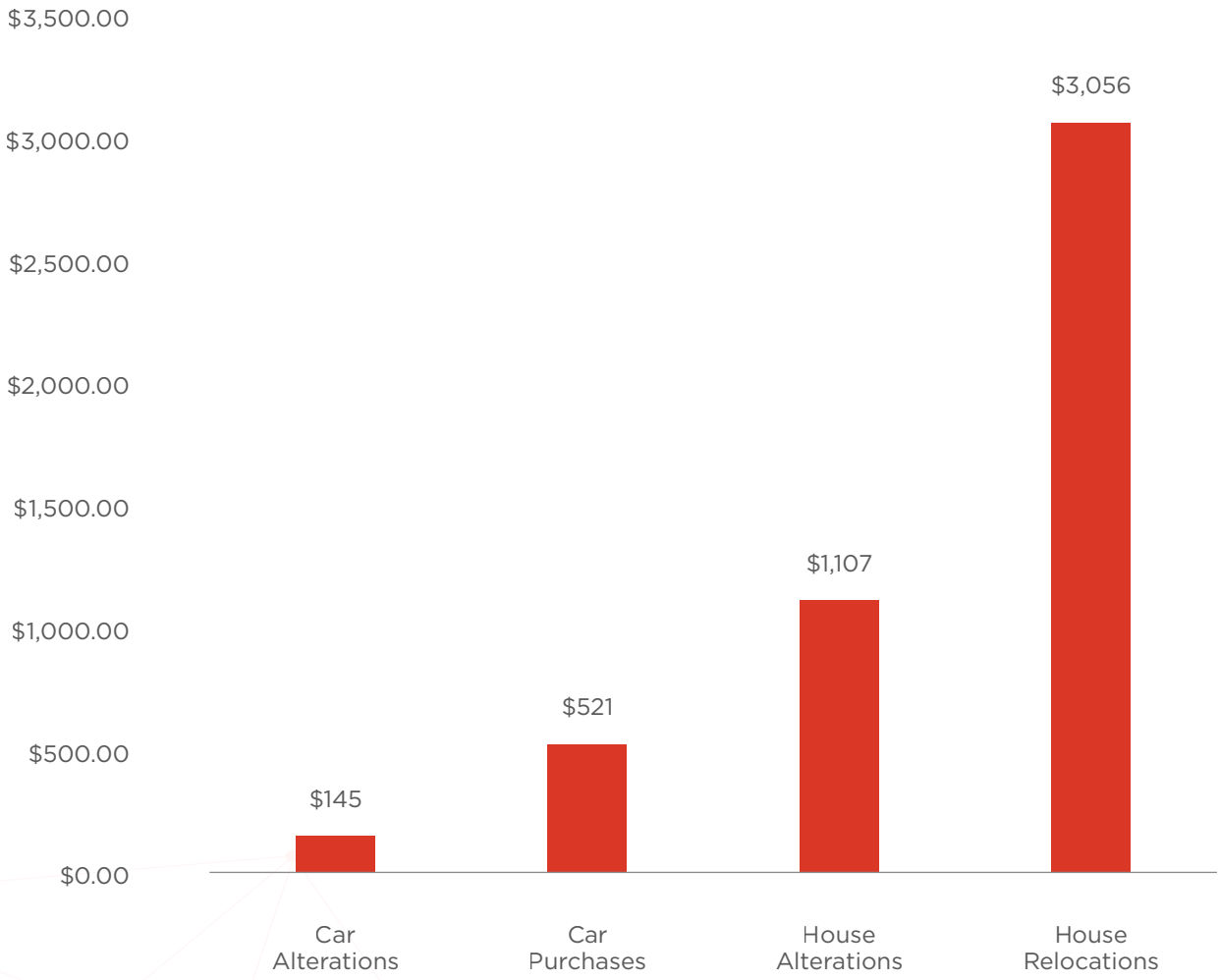
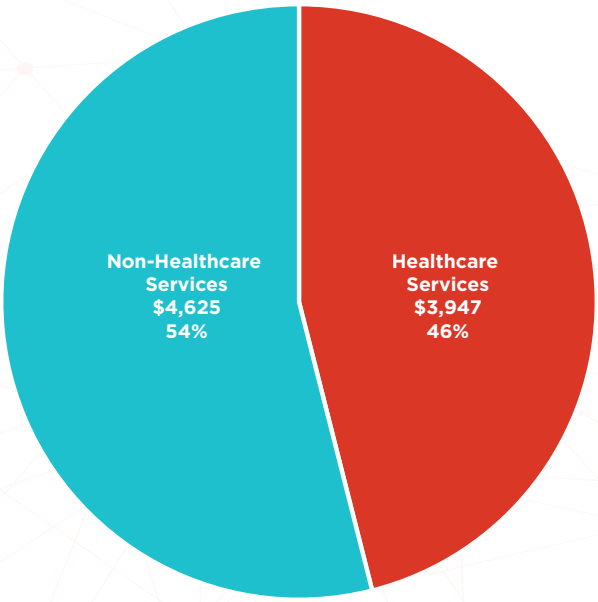
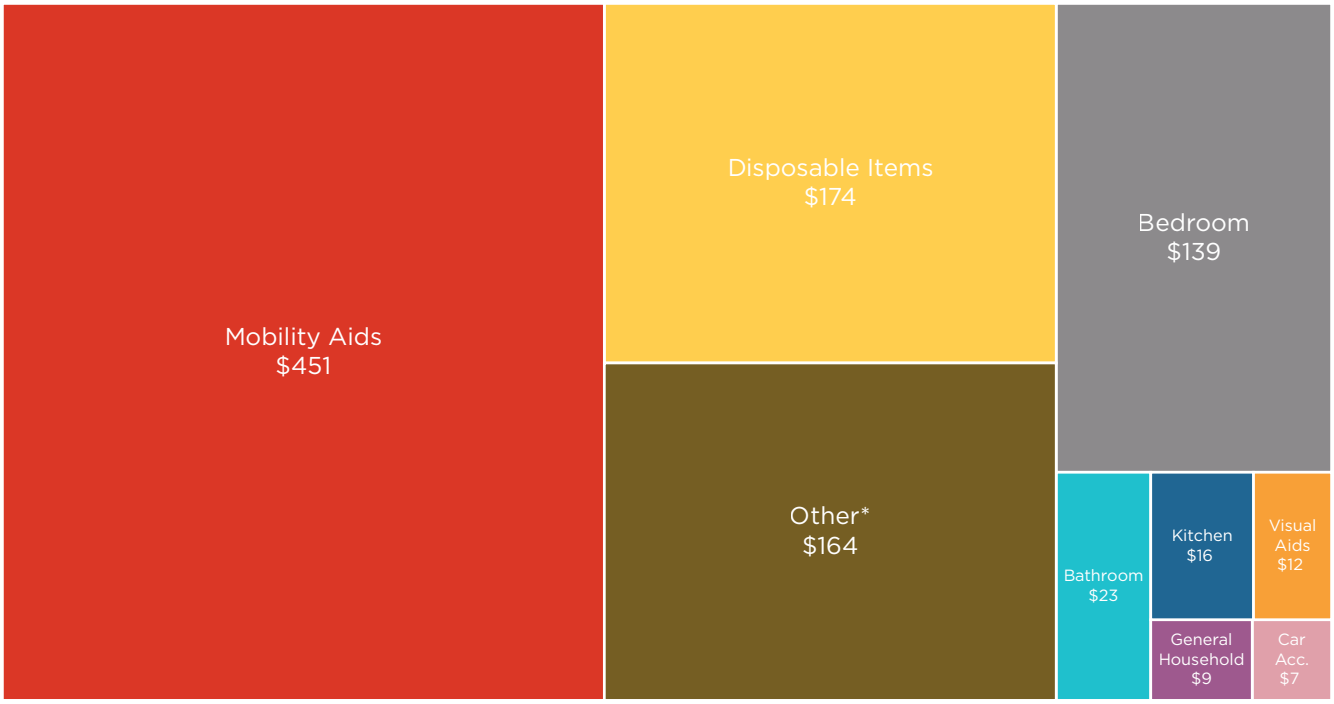


Figure 5.4: Proportion of service expenditure attributable to healthcare



Notes: Healthcare services are inclusive of items such as some allied health (i.e. hydrotherapy and counselling) and nursing services, whereas non-healthcare services are more general in nature, relating to services like household cleaning and maintenance or exercise classes

Figure 5.5: Relative contributions of subcategories to per person minor asset costs



Notes: * The category marked other relates to various products that were not placeable into another category: such products include hand-held massagers, reclining chairs, cooling equipment and specialised clothing. Acc. is an abbreviation of accessories.

5.4.6 Costs by AMSLS cohort clinical and sociodemographic characteristics

Detailed and complete lists of costs by AMSLS cohort clinical and sociodemographic characteristics are provided in Supplementary Tables 5.2-5.7b.

Overall, per person costs did not differ substantially between male and female participants (Figures 5.6 and 5.7). However, healthcare admissions and residential care costs were nearly twice as high among males compared to females ($11,655 vs. $5,663), primarily due to higher rates of hospital admissions and a greater proportion of males in residential care. In contrast, other health-related expenditures were higher among females ($19,581 vs. $15,962) – particularly in services and subscriptions ($10,109 vs. $5,496), as shown in Supplementary Table 5.3. Additionally, the cost of lost employment was greater for females ($23,244 vs. $19,096).

As outlined in Section 5.4.2, costs varied substantially across levels of disability severity, increasing from $42,688 in those with no disability to $135,780 in those with severe disability, or approximately 220% (Figure 5.8). This upward trend was evident across most cost categories (Figure 5.9), with exceptions including expenditure on DMTs, occupational change costs, and work productivity losses (absenteeism and presenteeism). Costs associated with these categories were lower among people living with severe MS-related disability compared to those with no disability.

Figure 5.6: Mean per person cost by sex

Figure 5.7: Mean per person costs by category and sex

Figure 5.8: Mean per person costs by disability severity

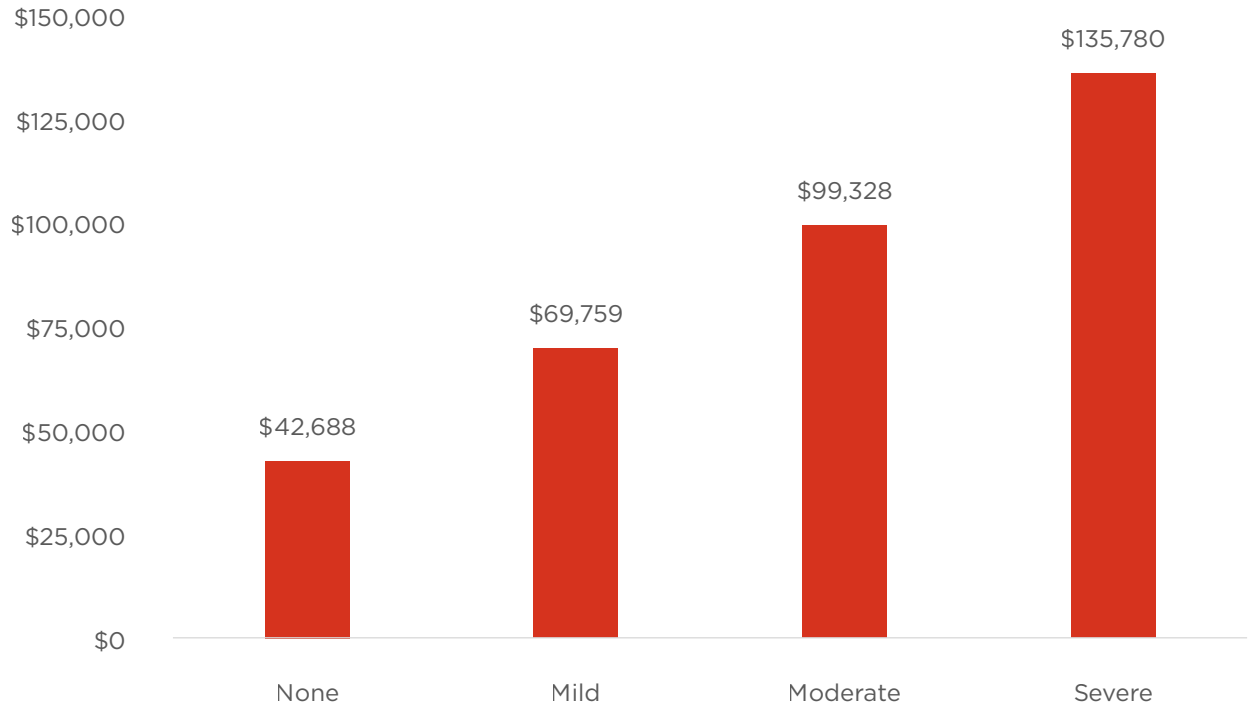


Figure 5.9: Mean per person costs by category and disability severity

Figure 5.10: Mean per person cost by disease duration

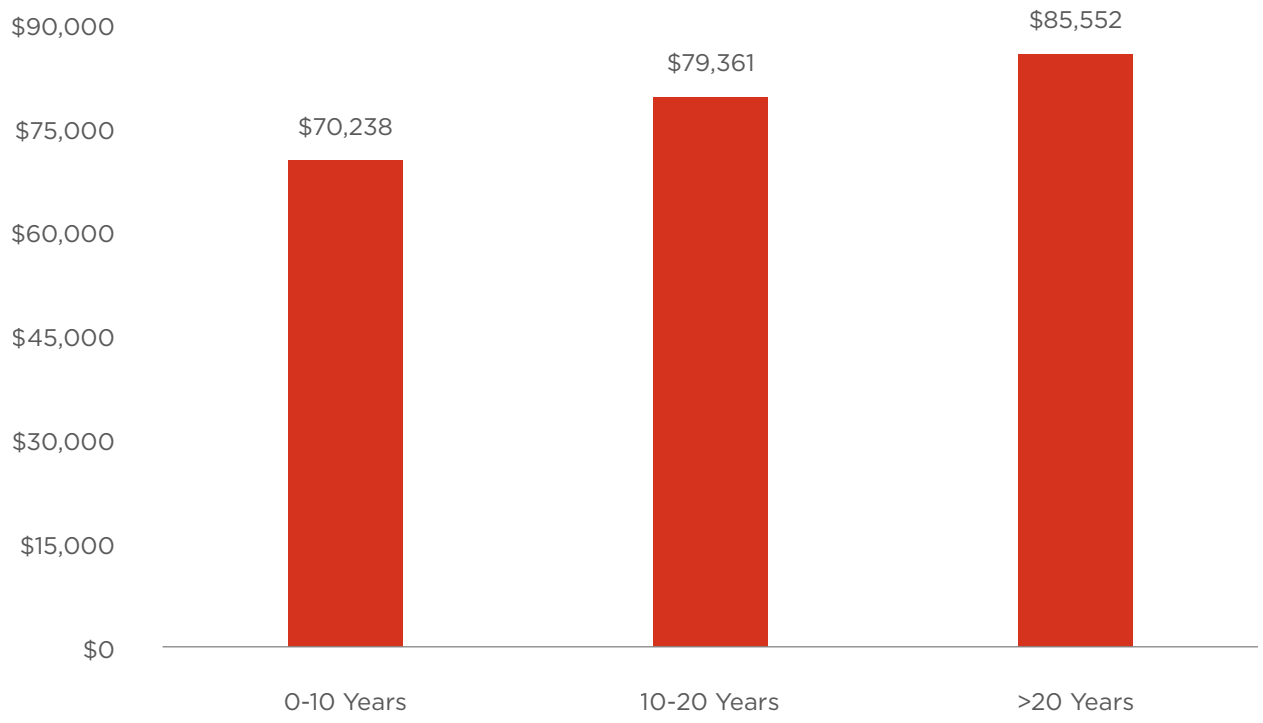


Figure 5.11: Mean per person costs by category and disease duration

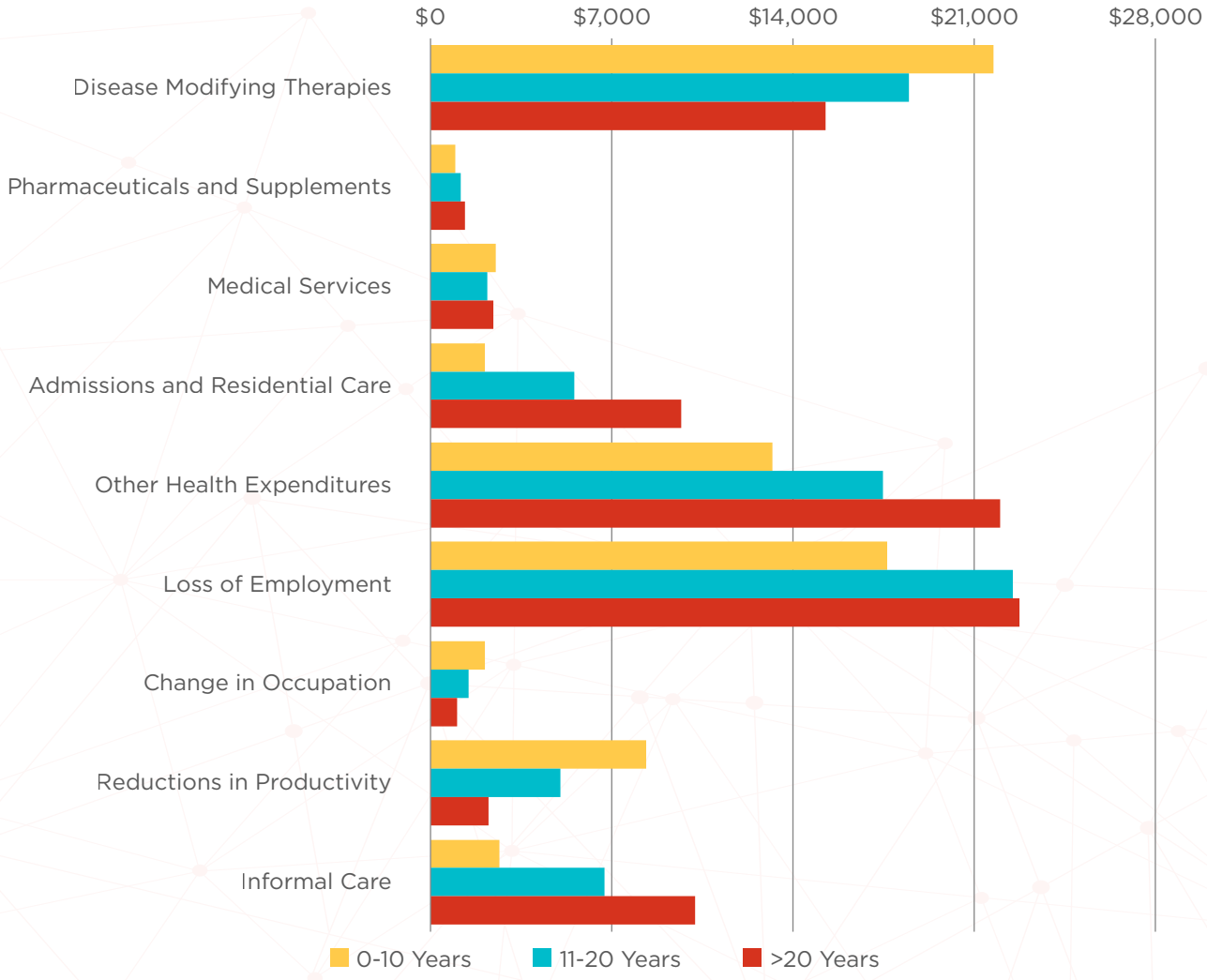


Figure 5.12: Mean per person costs by type of MS

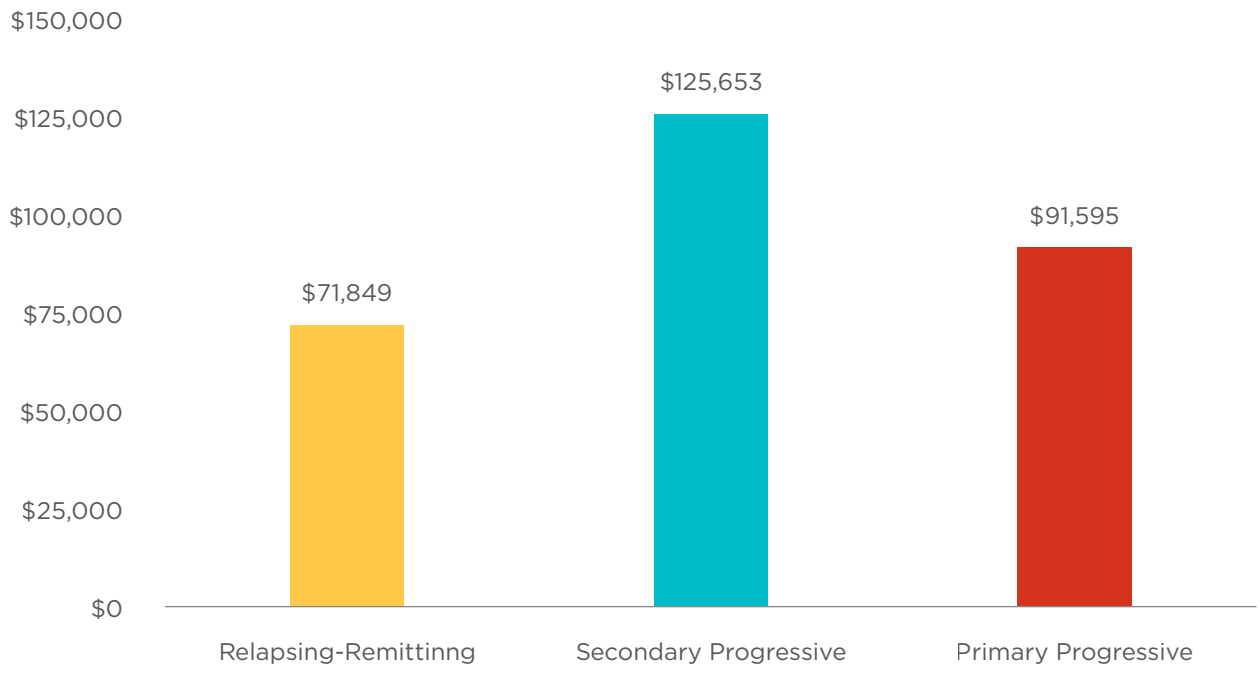
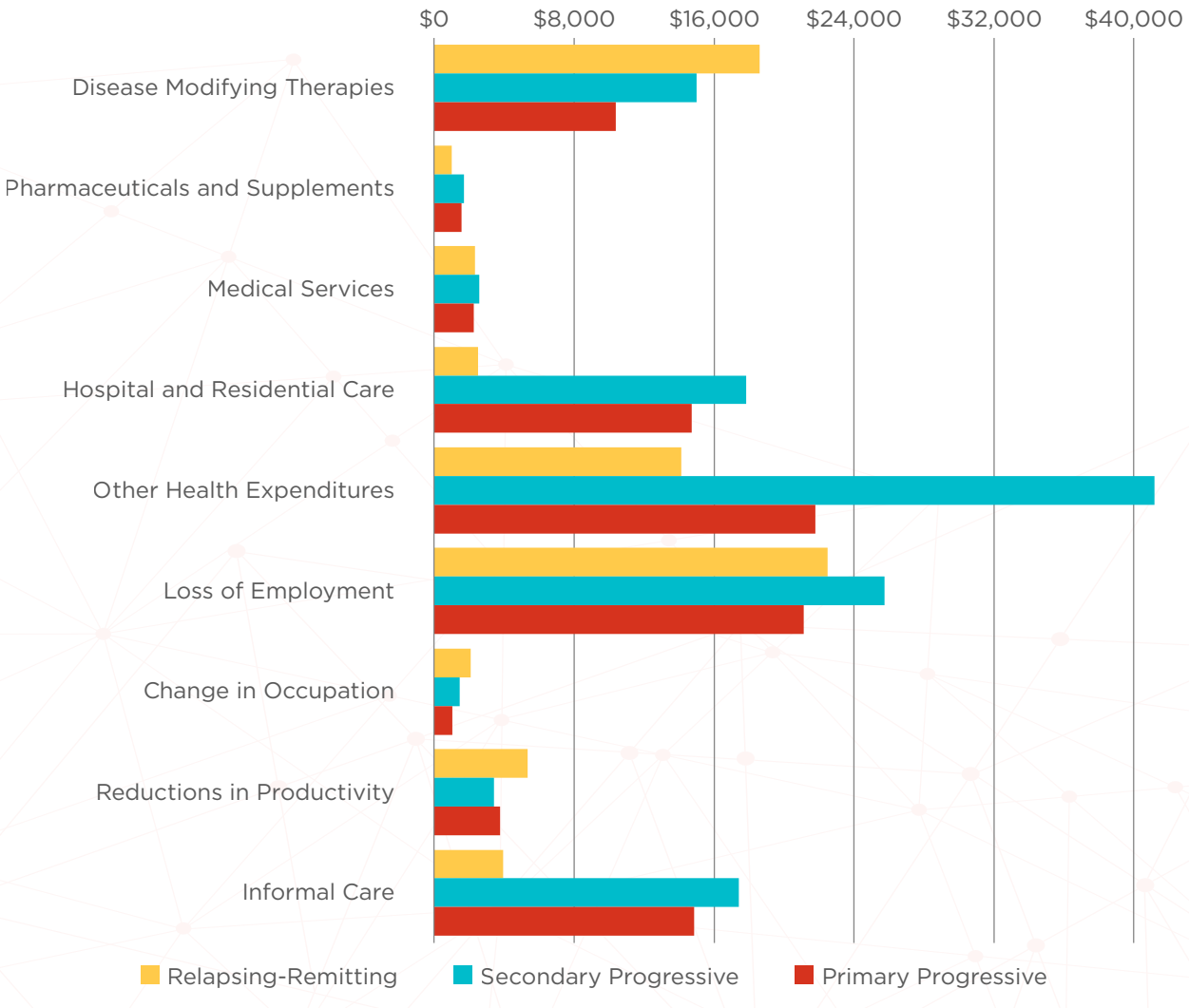


Figure 5.13: Mean per person cost by category and MS type

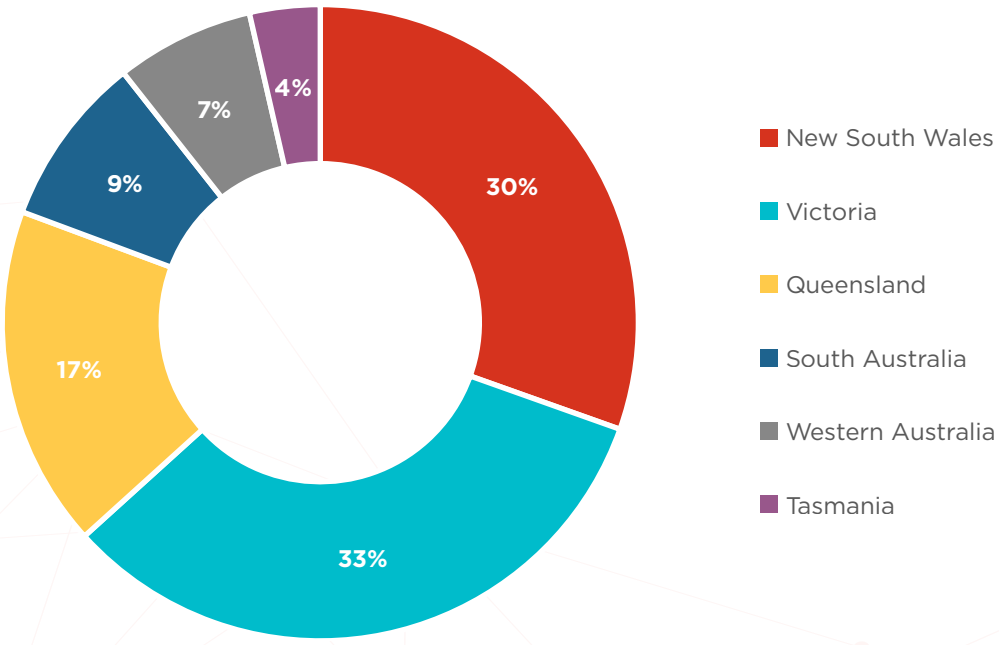


Costs increased with disease duration (Figure 5.10). For example, the mean MS-related cost for people living with MS for 0-10 years was 82.1% of the mean cost of those with a disease duration of 20 years or more. Notably, expenditure on DMTs and productivity losses due to absenteeism and presenteeism decreased at longer disease durations (Figure 5.11). In contrast, costs for other medications and supplements and medical services were comparatively stable over time.

Costs varied markedly by MS type (Figure 5.12). Individuals with RRMS had a mean per person cost of $71,849, compared to $125,653 for SPMS and $91,595 for PPMS. This pattern was consistent across many cost categories, although medical service expenditures did not differ substantially between groups (Figure 5.13). Furthermore, work productivity losses due to absenteeism and presenteeism were more pronounced among the RRMS group ($5,343 for RRMS vs. $3,406 for SPMS and $3,770 for PPMS), while employment loss costs were relatively similar across all groups ($22,495 for RRMS, $25,747 for SPMS, $21,112 for PPMS).

Figure 5.14 shows the state-level contributions to national MS costs. Consistent with population distribution, NSW and VIC together accounted for 63% of total costs, amounting to $1.857 billion.

Figure 5.14: State contributions to national MS costs based on prevalence and disability severity estimates



5.4.7 Comparisons with previous health economic impact reports

Table 5.7 presents both nominal and inflation-adjusted costs, with 2017 values inflated to 2024 values. Nominally, the total costs increased by $1.253 billion, representing a 71.5% increase since 2017. When adjusting 2017 values for inflation, the total MS cost increases were $819 million, which is a 37.5% increase since 2017.

Per person costs for MS have nominally increased by $11,199, representing a 16.4% rise since 2017. After adjusting 2017 values for inflation, the estimated per person cost of MS *decreased* by $5,716, equating to a 6.7% reduction. This decline occurred despite the inclusion of additional cost items, such as superannuation.

When examining disability groups, the largest nominal increase in costs was observed among those living without MS-related disability. For this group, mean per person costs rose by $12,127, representing a 39.7% increase since 2017, likely driven by higher DMT-related expenses.

In contrast, inflation-adjusted estimates showed more nuanced changes across disability severity levels. Costs increased by $4,567 for those with no disability and by $3,386 for those with moderate disability, but decreased by $7,433 among those with severe disability. This suggests that the overall reduction in per person MS costs may be attributed to lower expenses among those with more severe MS-related disability, including lower DMT costs.

Table 5.7: Unadjusted and inflation-adjusted comparisons with previous reports

NOMINAL COSTS *			
Per Person	**2017**	**2021**	**2024**
Overall	$68,382	$73,457	$79,581
Disability Severity			
No	$30,561	$32,829	$42,688
Mild	$55,815	$59,957	$69,759
Moderate	$76,916	$82,624	$99,328
Severe	$114,813	$123,333	$135,780
Total Cost	**$1,751,057,874**	**$2,448,670,617**	**$3,003,652,781**
COSTS ADJUSTED FOR INFLATION ‡			
Per Person		**2017**	**2024**
Overall		$85,297	$79,581
Disability Severity			
No		$38,121	$42,688
Mild		$69,621	$69,759
Moderate		$95,942	$99,328
Severe		$143,213	$135,780
Total Cost		**$2,184,195,644**	**$3,003,652,781**

Notes: * Nominal costs are unadjusted for inflation. ‡ 2021 estimates are not included in the inflation-adjusted analysis as they are based on the 2017 estimates adjusted for inflation as of the 2021 calendar year. ‡2017 values are inflated to 2021 values.

5.4.8 Sensitivity analyses

The results of the sensitivity analyses are presented in Table 5.8. In the first analysis, subtracting mean per capita PBS/MBS costs, intended to eliminate expenditure potentially unrelated to MS, led to a 10.1% reduction in combined MBS/PBS costs ($81.0 million), equivalent to 4.1% of PBS costs and 37.6% of MBS costs. Had these expenses been retained, the estimated total cost of MS would have been 2.7% higher.

The second sensitivity analysis investigated the impact of adjusting the assumed proportions of Australians with MS in residential care and respite care (originally set at 3.4% and 1.0%, respectively). Increasing the residential care proportion by 1% of the total MS population (approximately 378 individuals) would have raised residential care costs by $50.1 million. In contrast, an equivalent increase in respite care would have resulted in a more modest cost rise of $3.5 million.

The third sensitivity analysis assessed the effect of integrating intangible costs related to lost quality of life. Depending on the assumed values of quality-adjusted life years (see Table 5.8), this could increase total cost estimates by $186 million to $334 million.

Finally, Table 5.8 includes CIs and SDs for total cost estimates, reflecting varying levels of uncertainty. The original SD calculated was equivalent to 5.2% of the estimated total cost of MS. Applying SDs of 10% and 15% yielded confidence intervals approximately double and triple the original uncertainty level.

Table 5.8: Sensitivity analyses

PBS/MBS COST ESTIMATES WITHOUT SUBTRACTIONS FOR EXPECTED EXPENDITURE		
	Scheme Cost	**Increase (%)**
PBS Cost Without Subtraction	$656,309,471	$26,927,579 (4.1)
MBS Cost Without Subtraction	$143,857,555	$54,031,524 (37.6)
Total Cost	**$800,167,026**	**$80,959,103 (10.1)**

ADJUSTED PROPORTIONS OF THE MS POPULATION IN RESPITE OR RESIDENTIAL CARE			
	Original Proportions *	**Plus 1%**	**Plus 2%**
Residential Care	$190,292,609	$240,369,611	$290,446,613
Respite Admissions	$3,524,175	$7,048,350	$10,572,526

INCLUSION OF THE INTANGIBLE COST OF REDUCED QUALITY-ADJUSTED LIFE YEARS (QALYS)			
Disability Severity	**$25,000 per QALY**	**$35,000 per QALY**	**$45,000 per QALY**
No	$4,902,617	$6,863,663	$8,824,710
Mild	$70,528,208	$98,739,491	$126,950,774
Moderate	$52,697,937	$73,777,112	$94,856,287
Severe	$57,656,244	$80,718,741	$103,781,239
Total	**$185,785,005**	**$260,099,007**	**$334,413,010**

IMPACTS OF PROPORTIONAL STANDARD DEVIATIONS (SD) ON CONFIDENCE INTERVALS (CIS)				
	Original	**5% of Costs**	**10% of Costs**	**15% of Costs**
Upper 95% CI	$3,313,491,705	$3,304,018,059	$3,604,383,337	$3,904,748,615
Lower 95% CI	$2,693,813,868	$2,703,287,503	$2,402,922,224	$2,102,556,946
SD	$154,919,459	$150,182,639	$300,365,278	$450,547,917

Notes: The original estimates assumed that 3.4% of Australians with MS were in residential care and 1.0% had entered respite care.

5.5 Discussion

5.5.1 Summary of main findings

In this chapter, we present a comprehensive analysis of the costs associated with MS. The study draws on data from the AMSLS, including cost diaries, AMSLS-led surveys, and MBS/PBS claims data. Cost diary entries and MBS/PBS claims data were used to estimate the direct costs of MS, encompassing expenses relating to prescription and non-prescription medications, hospital admissions, appointments with healthcare professionals, mobility equipment, and home modifications.

To assess indirect costs, such as productivity loss due to disability and income forgone due to early retirement, we combined AMSLS survey data with ABS statistics. Analyses were conducted from a societal perspective, expressed in 2024 AUD, and included the full cost of illness, regardless of whether they were borne by people living with MS, health payers, or society.

The total annual cost of MS in Australia for 2024 was estimated at $3.004 billion (95% CI: $2.670-$3.289 billion), equating to a mean per person cost of $79,581 (95% CI: $70,752-$87,136). Costs varied substantially with MS characteristics. For example, as disability severity increased from no disability to severe disability, the mean per person cost rose from $42,688 to $135,780, equating to a 220% increase.

Similarly, individuals living with progressive MS incurred substantially higher costs than those with RRMS. This disparity likely reflects the greater disability burden among those living with progressive MS.

5.5.2 Key cost drivers for direct and indirect costs: DMTs and employment impacts

DMTs were the largest contributor to direct costs, accounting for $592 million, representing 19.7% of total costs and 35.5% of direct costs, or $15,671 per person living with MS. In contrast, the impact on employment was the largest contributor to the indirect costs. This included loss of employment, early permanent retirement, and transitions to part-time employment, totalling $846 million (28.2% of total costs), or $22,411 per person.

These findings align with the cost of illness findings from other countries; however, cross-country comparisons should be interpreted with caution due to differences in healthcare systems and DMT subsidy policies [131]. For example, a 2024 Italian study using detailed clinical and administrative data found that the DMTs and productivity losses together accounted for 84.5% of total costs (DMTs: 62.5% and employment impacts: 22%) [132]. Similarly, a recent US study based on administrative claims data also found that direct medical costs, particularly prescription drugs such as DMTs, were the main cost driver, comprising 54% of the total medical costs per person living with MS [106].

Further analysis of DMT costs revealed that they were mainly attributed to people living with milder forms of MS-related disability. This pattern reflects the indications for DMTs in Australia, where most therapies are available for RRMS. A recent German study using a large administrative dataset found that 70.5% of the total costs of DMTs was attributable to people with mild MS-related disability [133].

5.5.3 Costs over time: increasing prevalence and stability in costs per person living with MS

From 2017 to 2024, the inflation-adjusted cost of MS in Australia increased by $819 million, representing a 37.5% rise. Interestingly, despite the inclusion of additional cost items, such as forgone superannuation, the per person inflation-adjusted cost slightly decreased, from $85,297 in 2017 to $79,581 in 2024 (a 6.7% decrease). This suggests that the overall increase in total cost is largely attributable to the rising prevalence of MS, with the number of Australians living with MS increasing by 47.7% (an additional 12,149 cases) over the same time period.

The relative stability in per person costs may be partly explained by the positive impacts of high efficacy DMTs on disability progression and health-related quality of life [29] (see Section 5.5.5 for further detail). Evidence supports that early initiation of DMTs is beneficial for slowing disease progression [29]. Recent changes to diagnostic criteria have enabled earlier diagnosis, facilitating timely treatment initiation [29]. Additionally, the growing emphasis on brain health and lifestyle optimisation for people with MS could be another contributing factor [134]. The recently updated Living Well with MS Guide, an enhancement of the original 2020 edition, addresses several known modifiable lifestyle factors. Continued efforts to raise awareness of these factors, alongside early DMT initiation, are essential to minimising both per person and total societal cost.

5.5.4 Increasing costs with worsening MS disability severity

We found that the mean per person cost of MS more than tripled as disability severity increased from $42,688 for individuals with no disability to $135,780 for those with severe disability. This trend aligns with previous reports, particularly from high-income countries with comparable health systems [135]. A recent systematic review of cost-of-illness studies (17 reviews, 111 primary studies) highlighted that MS-related costs rise substantially with disability level, relapse episodes, and disease progression [135]. The review confirmed that the costs for higher-income countries are consistent with our findings, and even in low- and middle-income countries, costs increased with disability severity [135]. Importantly, the review found that disability was the key cost driver, with total costs for moderate disability being 1.4 – 2.3-fold higher, and for severe disability 1.8 – 2.9-fold higher [135].

We also established that costs for milder disability levels are primarily driven by DMT costs, whereas costs for more severe disability levels are dominated by acute medical services (e.g. hospital admissions, residential care), loss of employment, pharmaceutical medications and supplements, and informal care costs. This finding also aligns with international findings [132,136]. For example, an Italian study using clinical data reported that DMTs accounted for approximately 62.5% of all direct healthcare costs [132].

5.5.5 Disease modifying therapies: Driving the ongoing revolution in Australia

Our study found that DMTs were the largest component of direct costs, and one of the single largest contributors to overall MS-related costs, alongside employment-related impacts in the indirect cost category. Importantly, DMTs are a cost-effective treatment option for people living with MS, particularly from the societal perspective.

Since their introduction in the 1990s, DMTs have revolutionised MS treatment, leading to significant reductions in disability progression and associated cost savings for people with RRMS. The range of DMTs available continues to expand, with many subsidised by several country-specific government reimbursement agencies including Australia's Pharmaceutical Benefits Scheme (PBS) [49] .

Currently, 14 DMTs are reimbursed in Australia for those with RRMS. There are no reimbursed DMTs for PPMS in Australia, and only one is available for SPMS.

Since the launch of interferons more than 20 years ago, there has been a robust debate regarding the optimal use of MS-specific DMTs. Nevertheless, growing evidence supports early initiation of high efficacy DMTs as a strategy that can significantly improve long-term outcomes for people living with MS. This underscores the importance of offering early access to high-efficacy treatments upon diagnosis[29]. Such an approach may represent the best current opportunity to delay irreversible CNS damage and slow MS-related disability progression by modulating the underlying heterogeneous pathophysiological processes contributing to disease progression. [29].

Another critical aspect of the DMT debate in Australia is the absence of reimbursement of DMTs for progressive MS, with only one treatment currently covered. This cost analysis established that the per person costs for progressive MS far exceed the costs for RRMS. A recent New Zealand study has found that the use of ocrelizumab for the treatment of PPMS is more cost effective from a societal than a healthcare payer perspective[26]. Ocrelizumab is the only DMT currently available to treat PPMS in New Zealand, and it was publicly funded for this indication in 2023 [26]. Given the substantial cost burden associated with progressive MS in Australia, we recommend that further research be undertaken to assess the cost-effectiveness of listing ocrelizumab on the PBS.

5.5.6 Impacts of employment

Employment provides vital socioeconomic benefits, including financial stability, social connections, skills development, and enhanced self-esteem [137]. Furthermore, employment is strongly associated with better health outcomes and overall wellbeing [138,139]. Given MS is commonly diagnosed during the career-building years of 20-40 [140], disruptions to employment can diminish or reverse these positive effects [141,142].

We found that employment impacts associated with MS resulted in a societal cost of $846 million in 2024, or $22,411 per person living with MS. Early retirement was the largest contributor, costing a total of $369 million in 2024, or $9,767 per person, including a newly estimated $79.7 million in forgone superannuation due to early retirement. This was followed by transitions to unemployment ($295 million, 95% CI: $280 million-$310 million) and transitions to part-time employment ($183 million, 95% CI: $174 million-$192 million).

Among those employed, presenteeism was a greater source of productivity loss than absenteeism ($3,074 vs. $1,493 per person, $p < 0.001$), meaning presenteeism contributed twice as much to productivity losses.

We also found that employment-related costs rise sharply with increasing disability severity, reinforcing a key theme of this report - that higher MS-related disability is associated with higher economic burden. Notably, the cost of lost employment was higher among females than males ($23,244 vs. $19,096). This aligns with the concept of a double burden, where women may experience discrimination both due to their MS and their gender [143]. A Swedish registry-based study confirmed the existence of this double-burden for women living with MS [143].

Our employment analysis in Chapter 4 reinforces the importance of meaningful and productive employment for people living with MS. Combined with findings from this chapter, the overall narrative is that such employment positively influences health, economic outcomes and quality of life across the life course of people with MS.

We recommend that employment be addressed holistically, both from a health outcomes perspective aimed at halting or slowing disability progression, and from an early intervention perspective, to support newly diagnosed individuals in achieving better long-term employment and earnings outcomes.

In Australia, Disability Employment Services offer support to people with MS. While workplace assistance has demonstrated positive impacts on employment [102,103], these services are often accessed too late [104]. To address this, early support programs, delivered either face-to-face or digitally, should be made available early, before significant employment disruptions occur. These programs may enhance self-efficacy around work and MS, and could provide guidance on optimal symptom management, effective communication of their MS at work, coping strategies and stress management, suitable workplace adjustments and accommodations, and navigating an uncertain future. Such programs may reduce work instability and support people in maintaining their current employment level, rather than transitioning to a lower-paid role.

5.5.7 Unaccounted intangible costs

We have delivered the most comprehensive report to date on the cost of MS in Australia, building on our 2017 and 2021 analyses and incorporating comparisons with international studies. This iteration includes new cost items, such as forgone superannuation, and draws on broader data sources, including both self-reported data and administrative claims, to strengthen the robustness of our cost estimates.

Nevertheless, there remain additional cost items that could be considered in future analyses. One such category is intangible costs, which include the burden of pain and suffering. These costs are difficult to value and are often omitted from cost of illness studies [144]. While intangible costs were not included in this report, we conducted a conservative sensitivity analysis to estimate their potential impact. This analysis revealed that integrating intangible costs could increase total cost estimates by $186 million to $334 million. Assuming $45,000 per QALY, which is at the lower end of willingness to pay implied by PBAC recommendations [130], intangible costs could increase total estimates by 11%.

A recent systematic review reported that only one study included estimated intangible costs for MS, ranging from USD $7,000 and $14,000 per QALY lost, based on the willingness-to-pay thresholds of $50,000 and $100,000 per QALY [145]. Similarly, an Irish study calculated intangible costs between €5,562–€12,515 per person per year, with a mid-point of €9,038, representing 19% of total costs [144].

5.5.8 Cost comparisons with the general population and other chronic diseases

According to the AIHW, the average health spending per person in the general Australian population was $9,597 in 2022-23, which is approximately $10,400 in 2024 dollars [146]. In contrast, this report found that people living with MS bear costs approximately seven times higher than the general population. Importantly, for people living with severe MS-related disability, this figure rises to approximately 14 times higher, while those with no MS-related disability incur costs that are four times greater.

This disparity is consistent with international findings. A study in British Columbia reported that direct medical costs for people living with MS were four times higher than for the general population ($8,964 vs. $2,083 2020 CAD) [147]. Similarly, a Swedish registry-based study found that societal costs for people with MS were 4.3 times higher than for the general population (€26,516 vs. €5,962) [61].

Furthermore, the average cost for a person living with MS in Australia exceeds that of many other chronic diseases, including Parkinson's disease [148], Type 2 diabetes [149], and long-term cancer survivorship [150]. For people with moderate and severe MS, these costs far surpass the average costs associated with these other chronic diseases.

5.5.9 Global comparisons

Our 2017 and 2021 reports explored global comparisons of cost of illness research for MS, focusing on studies conducted prior to 2017. In current cost of illness study, we have incorporated new evidence and broader data sources. Across all studies reviewed, the health economic burden of MS was found to be substantial in both high-income and low- to middle-income countries [132,133,135,147,151-154]. A consistent finding was that costs increase with disability severity, and that progressive MS is associated with higher per person costs than RRMS, despite the significant DMT-related expenses of RRMS.

A recent US study adopted a prevalence-based approach for the cost of illness, using administrative data for direct costs and survey data for indirect costs [106]. It estimated the total burden for MS at $85.4 billion (2019 USD), with direct medical costs contributing $63.3 billion. The average excess cost per person was almost $66,000 (2019 USD), equivalent to approximately $122,000 AUD in 2024, which is substantially higher than our estimate of $78,581 per person. The differences potentially reflect the structure of the US healthcare system [155].

A recent systematic review pooled international data across disability severity groups (mild, moderate and severe) and estimated the mean costs per person of €18,949, €33,489 and €54,090 (2021 Euros), respectively [135]. For high-income countries such as those in Northern Europe, the corresponding costs were €31,292, €47,303 and €75,225. In contrast, Eastern European countries reported lower costs of €11,557, €16,813 and €20,702 across the same severity levels [135]. When translated to 2024 AUD, this report shows that Australia's MS-related costs exceed those of Eastern Europe, but are lower than the US and Northern Europe.

Several studies also examined the excess cost of MS – the difference in direct medical costs between people with MS and the general population. A study in British Columbia found that inpatient, outpatient and medication costs accounted for 25%, 10% and 65% of excess costs, respectively. Notably, excess costs were significantly higher for people on a DMT, by almost $10,000 CAD (2020), which equates to approximately $13,000 AUD in 2024 [147].

A Swedish registry-based study reported similar findings, showing excess societal costs for people living with MS were significantly higher than for the general population [154].

5.5.10 Strengths and limitations

The key strength of this cost of illness study is the comprehensive scope of cost data used to generate our estimates. We employed both bottom-up and top-down approaches, incorporating a detailed six-month prospective cost diary, MBS/PBS claims data, and relevant AMSLS survey data. These sources were coupled with the large and representative AMSLS cohort, providing a robust foundation for our analysis. Notably, we were able to capture 'lumpy' one-off costs, such as major home renovations, by applying a five-year time frame to the cost diaries.

One potential limitation is the overlap between some cost diary entries and MBS claims data. To mitigate this, we applied a subtraction method to MBS expenses and conducted a sensitivity analysis to test the impact of this assumption. Another limitation is that some costs that are covered under the NDIS plan values (as discussed in Chapter 6) may not have been adequately captured in our estimates. However, it would be inappropriate to simply add these plan values to the cost estimates, as doing so risks double counting.

5.5.11 Conclusions

This comprehensive cost of illness chapter confirms that MS imposes a substantial economic burden in Australia. Compared to 2017, the total cost of MS in 2024 has increased, primarily due to the rising prevalence of MS, while per person costs have slightly decreased when adjusted for inflation.

The analysis shows that costs escalate significantly with increasing levels of disability. Additionally, the per person cost of MS far exceeds that of the general population, particularly those with severe MS-related disability, underscoring the disproportionate financial impact of MS.

CHAPTER 6

The National Disability Insurance Scheme and the Australian MS Longitudinal Survey

6.1 Summary

This chapter provides a preliminary and descriptive summary of selected insights provided by participants in the 2025 AMSLS NDIS Survey. MS Australia continues to advocate on behalf of people living with MS for improvements to the NDIS, and the findings presented here will inform elements of a broader and more detailed NDIS project currently underway using AMSLS data.

Overall, we found that the mean initial value of an NDIS plan – typically spanning 12 months but ranging from one to five years - was approximately $62,000 (2024 AUD). Following reassessment, the mean plan value increased by approximately $13,000, resulting in an estimated post-assessment mean of $75,504.

Among participant subgroups, we identified that people living with severe MS-related disability had a mean plan value of $104,000, which is $57,000 greater than those with mild disability. Plan values were also higher for people living with progressive MS and those residing in regional and remote areas. Conversely, low plan values were observed in NSW and the ACT.

Additionally, we found that NDIS plan values following reassessment have increased in recent years.

Encouragingly, application and approval rates were high among AMSLS participants. Approximately 89.0% of individuals under 65 years with moderate-severe MS-related disability had applied for an NDIS plan, with 88.1% reporting approval of their plan application. Moreover, individual plan values were found to scale with disability severity.

However, only 51.7% of potentially eligible participants (meeting the age requirement) with mild disability had applied. This may reflect underutilisation of the NDIS by this group, potentially due to perceptions of ineligibility, reluctance to engage with the system's complexity, or lack of need for NDIS-level supports at this stage. Further research is required to explore and validate this hypothesis.

6.2 Introduction

6.2.1 Background

The NDIS is a government-funded national insurance scheme that provides individualised financial support for Australians under the age of 65 who are living with permanent and significant disability [156]. Trialled from 2013 and rolled out from 2016 [157], the NDIS currently supports around 500,000 Australians. Eligible participants can receive ongoing access, and individual NDIS plans are typically renewed every 12 months, though durations can range from one to five years [158].

The stated goals of the NDIS are to assist people with disability to achieve "more time with family and friends, greater independence, access to new skills, jobs, or volunteering in their community, and an improved quality of life [159]." In essence, the NDIS aims to substantially reduce the economic burden of disability, including for people living with MS.

NDIS plans tailored to the needs of people living with MS may cover a wide range of MS-related costs, including allied health services (e.g. occupational therapy, physiotherapy, psychotherapy), assistive technology, home and vehicle modifications, transport, nursing care and assistance with personal care, household tasks, equipment, or social activities [160]. The NDIS also provides accommodation and tenancy assistance, including access to specialist disability accommodation, and employment supports to help people maintain employment, transition careers or re-enter the workforce [161,162].

Importantly, the value of an NDIS plan can be adjusted through a process of reassessment to better reflect changing needs. Funding is not rescinded upon reaching 65 years of age, provided funding was approved prior to the participant turning 65 [158,163].

6.2.2 NDIS advocacy by MS Australia

Despite the benefits of the NDIS, several issues remain in its design, operations and sustainability. Over the past decade, MS Australia has actively advocated for improvements to the NDIS on behalf of people living with MS [164]. While the NDIS continues to evolve in response to recommendations from the NDIS Review, MS Australia believes that key issues still need to be addressed to ensure the NDIS adequately meets the needs of people living with MS and other neurological conditions. These include:

- A flexible, participant-focused and sustainable pricing model for the NDIS that reflects real costs and encourages innovation and quality service delivery.
- A sufficiently trained and skilled National Disability Insurance Agency (NDIA) workforce with improved disability awareness and understanding of NDIS legislation and policies, including new assessment, planning and budgeting processes, and more staff with lived experience of disability.
- Increased support to attract, train, upskill and maintain a high-quality disability workforce to meet the diverse needs of people living with disability.
- Improved housing and living supports, enabling people with disability to maintain their independence and choose living arrangements that best align with their goals.

6.2.3 Aims

In this chapter, we aimed to provide a preliminary and descriptive summary of NDIS use by AMSLS participants. Specifically, we estimated their mean NDIS plan values, both in recent years and over the past decade. We also examined NDIS application and approval rates, and determined how plan values varied according to participant characteristics, such as MS-related disability severity.

6.3 Methods

6.3.1 Data sources

For this chapter, data were primarily sourced from the 2025 AMSLS NDIS Survey, with additional sociodemographic and clinical data obtained from the 2024 AMSLS Disease Course Survey. The NDIS Survey enquired about applications for NDIS access, receipt of plans, plan reassessment and plan values.

6.3.2 Specifications of variables

Key study variables included:

- Initial and first reassessed NDIS plan values, represented in 2024 AUD
- Plan approval or reassessment year
- Application status (applied/never applied)
- NDIS plan history (yes/no)
- Current plan status (has/does not have a plan)
- NDIS management type: plan managed by paid case-managers, self-managed, or a combination of the two
- Application rejection reports (yes/no)
- Hours spent applying

Sociodemographic and clinical variables were acquired from the 2025 AMSLS NDIS Survey. These included:

- Age categories: <45, 45-54, 55-64, 65-74, and >74 years
- Sex
- Educational attainment: secondary education or less, vocational training, undergraduate degree, postgraduate qualification
- Current employment status: self-employed, full-time employed, part-time employed, unemployed, retired (including medically), or other (including students and homemakers)
- Language spoken at home: English or other
- State or territory of residence
- Geographical remoteness: major cities, inner regional, outer regional and remote

Using information collected by the 2024 AMSLS Disease Course Survey, we assessed the type of MS (RRMS, SPMS, PPMS, or unsure) and disability severity. Disability severity data was identified using participant responses to the PDDS questionnaire and converted to EDSS categories [64]. Specifically, a PDDS of 1 = no disability (EDSS = 0.0), a PDDS of 2 or 3 = mild disability (EDSS = 1.0-3.5), a PDDS of 4 or 5 = moderate disability (EDSS = 4.0-6.0, and PDDS of 6 through 8 = severe disability (EDSS = 6.5-9.5) [65].

6.3.3 Analyses

All analyses conducted in this chapter were preliminary and descriptive. AMSLS participants were grouped into two categories; those who had ever held an NDIS plan and those who had never held a plan. These groups were compared to identify major differences in their collective sociodemographic and clinical characteristics.

Following this, reported plan values were analysed both overall and by year of approval. For the overall analysis, we presented mean plan values along with their SDs, stratified by disability severity, MS type, state or territory of residence, and geographical remoteness. To ensure comparability across time, all monetary values were adjusted for inflation using the Reserve Bank of Australia inflation calculator based on the Consumer Price Index. Differences between initial and reassessed plan values were also evaluated.

Subsequently, summary statistics were generated to describe the proportion of AMSLS participants who had applied for NDIS access (including mean time spent applying), currently held a plan, self-managed their plan, or had experienced application rejection.

Our final analysis investigated the percentage of AMSLS participants who had applied for NDIS access and how non-applicants differed by level of disability. To account for age-based ineligibility, this analysis excluded AMSLS participants who were 65 years or older in the first year of the full NDIS rollout (2016). Where appropriate, study results were presented graphically.

Categorical data were represented using frequencies and proportions, and comprised distinct categories. For example, MS type is a categorical variable with three categories (RRMS, SPMS, and PPMS). Continuous data were represented with means and SDs, with SDs indicating variability. Unlike categorical data, continuous data do not fall into distinct categories and instead reflect measurable quantities, such as NDIS plan value, which is expressed in dollars.

6.4 Results

6.4.1 Comparison of participants who have and have not held NDIS plans

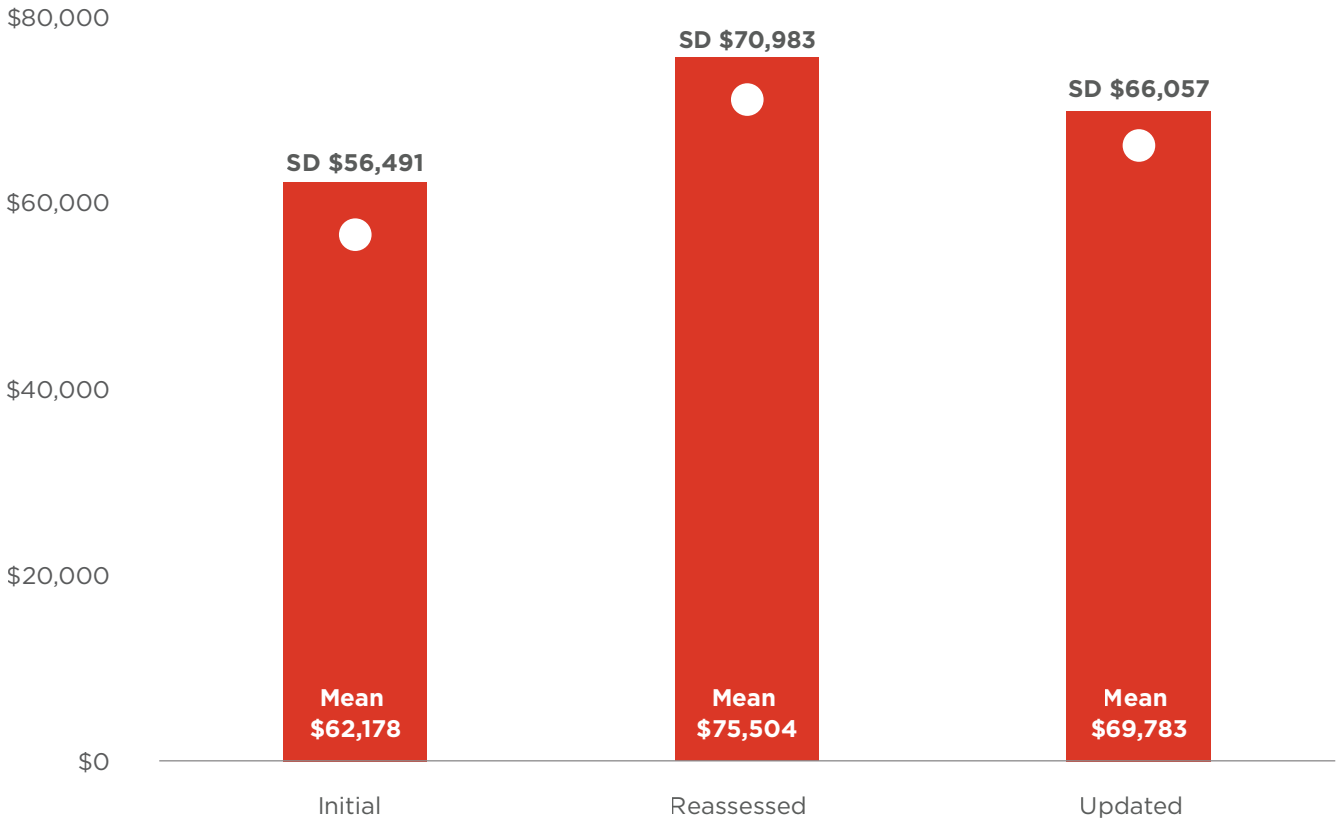
39.7% of AMSLS participants have had an NDIS plan. AMSLS participants were more likely to have held an NDIS plan if they had greater MS-related disability (Table 6.1). Specifically, those with moderate to severe MS-related disability made up 56.8% of those with a plan, compared to only 20.0% of those without a plan.

NDIS plans were also more common among people living with progressive MS, particularly PPMS, compared to those with RRMS. This pattern is likely driven by disability severity, as progressive MS is associated with more rapid disability accrual.

Individuals who never had a plan were more frequently aged over 74, with 18.8% falling into this age group compared to just 1.2% among those who had a plan (Table 6.1). This is likely attributed to the NDIS eligibility criteria, which exclude people aged 65 years or older from applying. Those in this age group who had an NDIS plan must have applied prior to reaching the age threshold.

Among potentially eligible participants (who met the age requirements), plans were more frequently held by people aged 55-64 years. This is likely due to MS-related disability increasing over time and accumulating with age.

Figure 6.1: Mean NDIS plan values of AMSLS participants in 2024 AUD



Notes: 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.

Table 6.1: Characteristics of participants who completed the 2025 AMSLS NDIS Survey and 2024 Disease Course Survey

EVER HAD A PLAN (N=519 [40.4%])			NEVER HAD A PLAN (N=767 [59.6%])		
Characteristic	**N**	**Percentage**	**Characteristic**	**N**	**Percentage**
Age			Age		
<45 Years	53	10.2%	<45 Years	81	10.6%
45-54 Years	98	18.9%	45-54 Years	144	18.8%
55-64 Years	213	41.0%	55-64 Years	183	23.9%
65-74 Years	149	28.7%	65-74 Years	215	28.0%
>74 Years	6	1.2%	>74 Years	144	18.8%
Sex			Sex		
Male	110	21.2%	Male	153	19.9%
Female	409	78.8%	Female	614	80.1%
Type of MS			Type of MS		
Relapsing-Remitting	189	49.5%	Relapsing-Remitting	426	72.8%
Secondary Progressive	108	28.3%	Secondary Progressive	49	8.4%
Primary Progressive	66	17.3%	Primary Progressive	48	8.2%
Unsure	19	5.0%	Unsure	62	10.6%

EVER HAD A PLAN (N=519 [40.4%])			NEVER HAD A PLAN (N=767 [59.6%])		
Characteristic	**N**	**Percentage**	**Characteristic**	**N**	**Percentage**
Disability Severity			Disability Severity		
No	20	5.2%	No	237	40.5%
Mild	144	37.7%	Mild	226	38.6%
Moderate	116	30.4%	Moderate	57	9.7%
Severe	101	26.4%	Severe	66	11.3%
Employment Status			Employment Status		
Self-Employed	39	7.5%	Self-Employed	52	6.9%
Full-Time Employed	51	9.9%	Full-Time Employed	152	20.0%
Part-Time Employed	86	16.6%	Part-Time Employed	121	15.9%
Unemployed	10	1.9%	Unemployed	10	1.3%
Not in Labour Force	315	60.9%	Not in Labour Force	405	53.4%
Other (Non-Paid) *	16	3.1%	Other (Non-Paid) *	19	2.5%
Education Level			Education Level		
Secondary or Less	78	20.5%	Secondary or Less	133	22.7%
Vocational Training	137	36.0%	Vocational Training	197	33.6%
Undergraduate Degree	92	24.1%	Undergraduate Degree	138	23.5%
Postgraduate Qual.	74	19.4%	Postgraduate Qual.	119	20.3%
Language at Home			Language at Home		
English	469	91.6%	English	711	94.0%
Other	43	8.4%	Other	45	6.0%
State or Territory			State or Territory		
New South Wales	144	27.8%	New South Wales	212	27.7%
Victoria	139	26.8%	Victoria	209	27.3%
Queensland	72	13.9%	Queensland	108	14.1%
South Australia	59	11.4%	South Australia	92	12.0%
Western Australia	51	9.8%	Western Australia	68	8.9%
Tasmania	36	6.9%	Tasmania	46	6.0%
ACT	17	3.3%	ACT	31	4.0%
Remoteness			Remoteness		
Major Cities	335	64.7%	Major Cities	492	64.4%
Inner Regional	133	25.7%	Inner Regional	201	26.3%
Outer Regional/Remote	50	9.7%	Outer Regional/Remote	71	9.3%

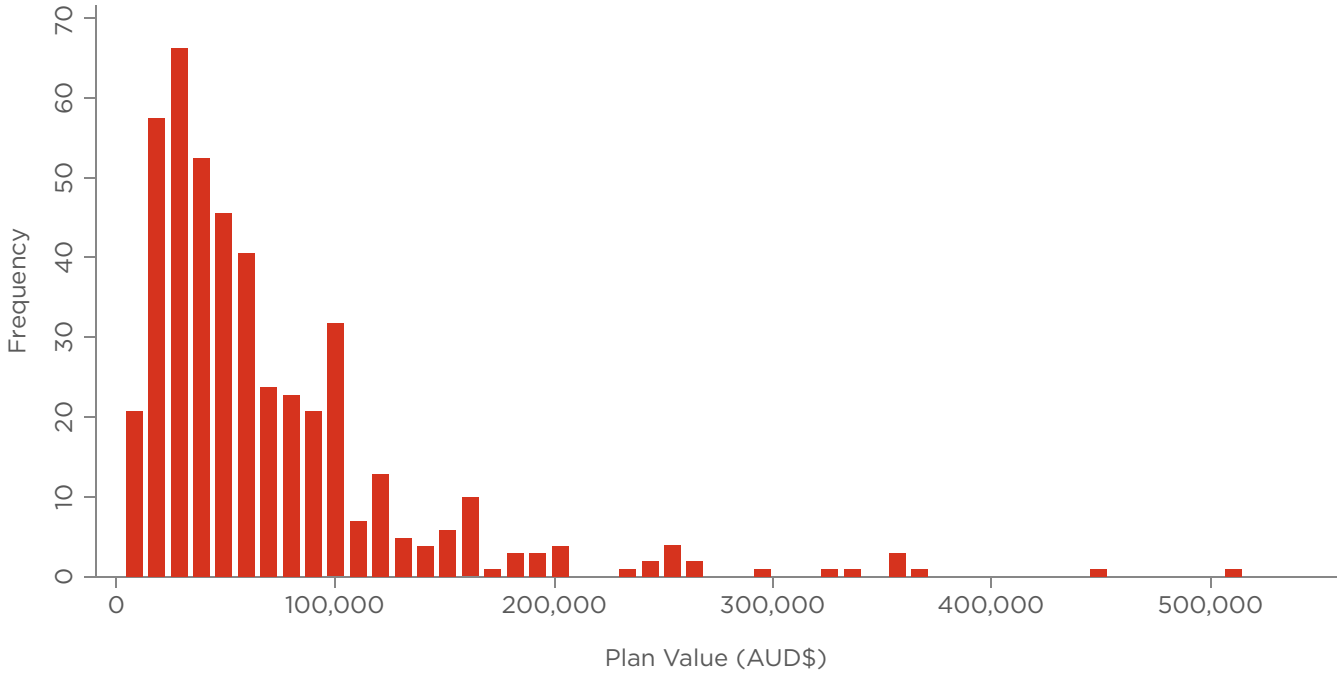
Notes: * *Other occupations* included students and homemakers. Total numbers in each category differ due to missing data.

6.4.2 Mean NDIS plan values

The mean initial value of an NDIS plan for a person living with MS was $62,178 (adjusted to 2024 dollars), with the mean reassessment value being approximately $13,000 higher (Figure 6.1). For 69.2% of participants who had a reassessment, this occurred either within the same year as their initial plan approval (for example, someone with a plan approval in January may have a reassessment in December of the same year) or in the following year after their initial plan was provided. By excluding initial plan values where reassessed values were available, the updated mean plan size was estimated at $69,783. The majority of NDIS plans provided to AMSLS participants were valued at less than $100,000, with reported values ranging from $2,600 to $516,000 (Figure 6.2).

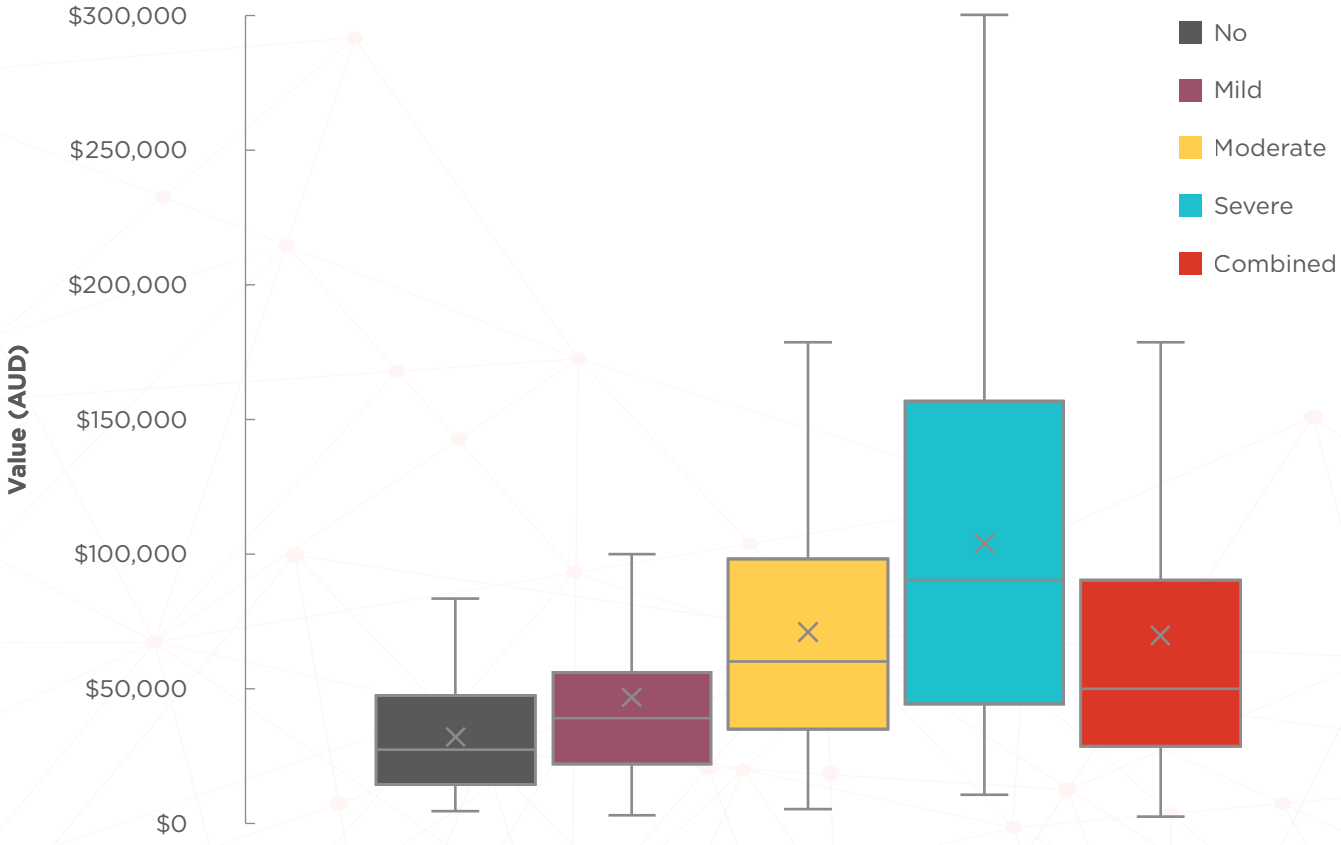
Adjusted NDIS plan values and their variability were analysed for all AMSLS participants, as well as across levels of disability severity (Figure 6.3). Plan values were found to increase with disability severity, as did the variation in those values. Supporting this, updated mean plan value by disability severity are presented in Table 6.2. In the AMSLS, people living with severe MS-related disability had a mean plan value of $104,000, compared to $46,000 for those with mild disability. Plan values were also higher among people living with progressive MS, lower in NSW, and higher in regional and remote areas compared to those in major cities.

Figure 6.2: Histogram of updated NDIS plan values of AMSLS participants



Notes: Updated NDIS plan values exclude initial values where reassessed values were available.

Figure 6.3: Box and whisker plot describing variation in updated NDIS plan values across disability severities among 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.

Table 6.2: Updated NDIS plan values by selected AMSLS participant characteristics

CHARACTERISTICS	MEAN	SD	N (%)
Disability Severity			
No	$32,164.63	$23,389.18	19 (5.5)
Mild	$46,818.25	$45,410.95	134 (39.0)
Moderate	$71,034.35	$47,466.87	106 (30.8)
Severe	$104,088.80	$74,587.97	85 (24.7)
Type of MS			
Relapsing-Remitting	$56,504.03	$51,739.26	170 (52.1)
Secondary Progressive	$77,759.09	$60,214.36	95 (29.1)
Primary Progressive	$85,811.69	$72,134.83	61 (18.7)
State or Territory			
New South Wales	$57,458.70	$48,780.09	130 (28.3)
Victoria	$72,180.83	$73,797.19	125 (27.2)
Queensland	$76,826.24	$66,486.57	62 (13.5)
South Australia	$75,684.55	$79,618.28	50 (10.9)
Western Australia	$78,105.98	$77,811.12	48 (10.4)
Tasmania	$81,334.86	$55,911.88	31 (6.7)
ACT	$56,443.51	$45,341.35	14 (3.0)
Remoteness			
Major Cities	$66,123.28	$60,304.00	301 (65.4)
Inner Regional	$77,837.33	$80,579.89	116 (25.2)
Outer Regional/Remote	$73,677.37	$60,345.28	43 (9.3)

Notes: SD is an abbreviation of standard deviation and N indicates the number of participants. Updated plan values exclude initial values where reassessed values were available.

6.4.3 NDIS plan values from 2016 to 2024

There was no clear trend in initial NDIS plan values (adjusted for inflation) among AMSLS participants since the full rollout of the scheme began (Figure 6.4A). Similarly, no major trend was observed in the size of NDIS plans following the first reassessment (Figure 6.4B). Year-on-year disparities are potentially explained by variation in the disability severity of applicants. Reassessment values were, on average, higher than initial values between 2016 and 2023, inclusive (Figure 6.4C). However, this was not the case in 2024, when reassessed plan values were slightly lower than initial plan values.

Figure 6.4: Mean plan values by year

Figure 6.4A: Initial plan values

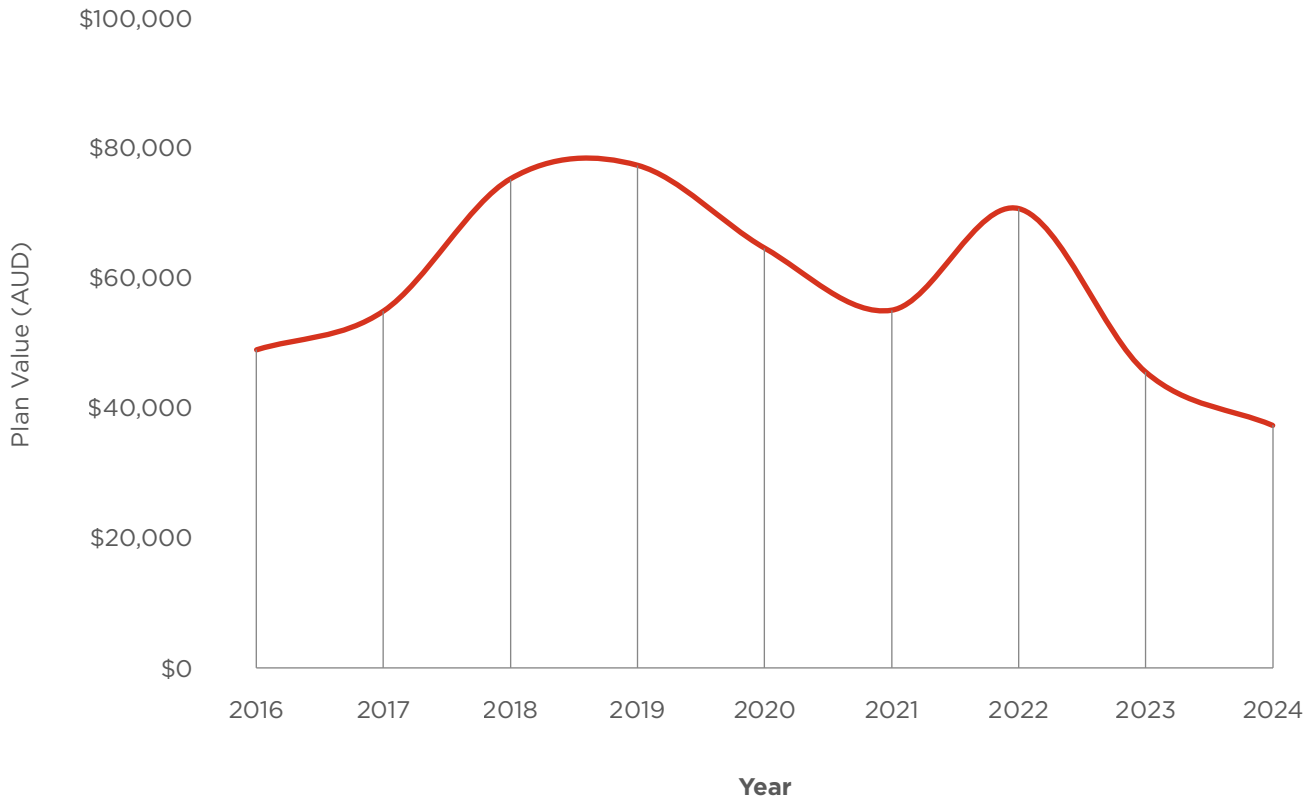


Figure 6.4B: Reassessed plan values

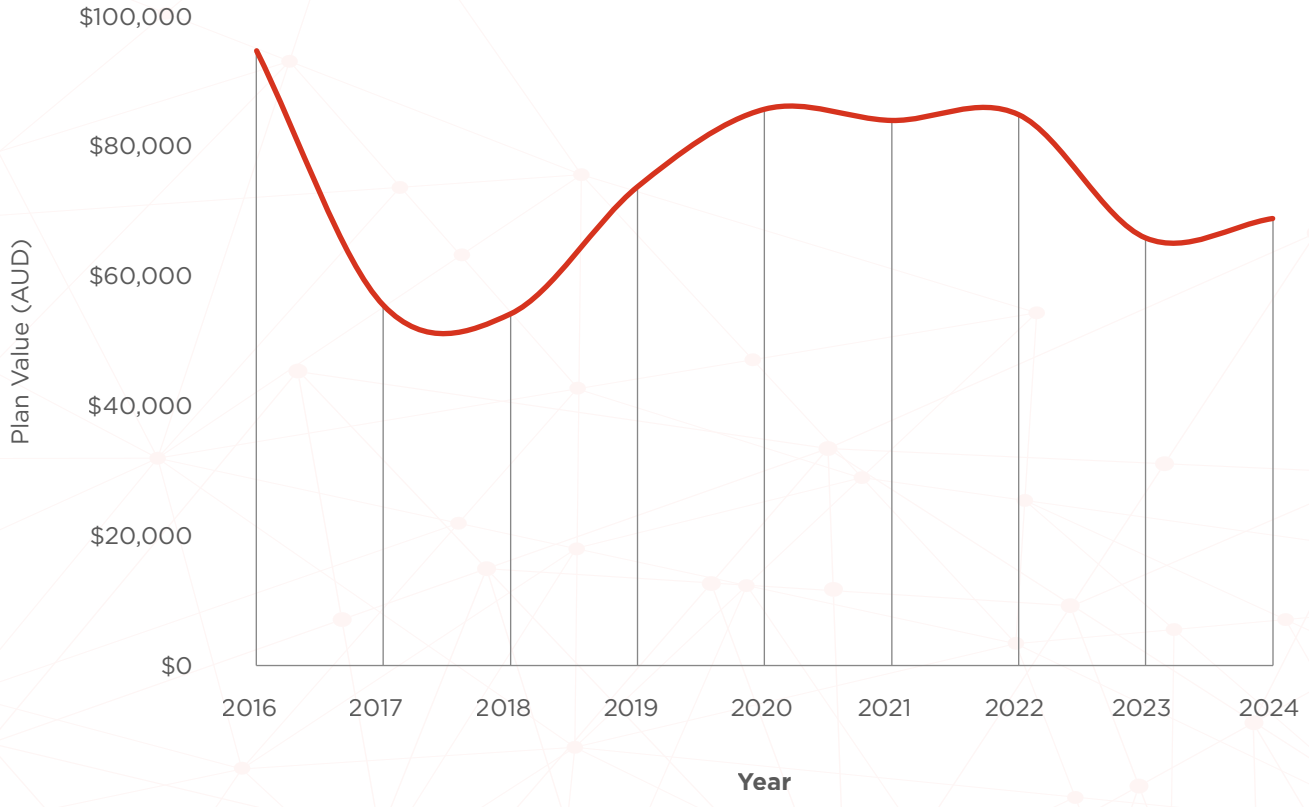


Figure 6.4C: Differences between initial and reassessed plan values

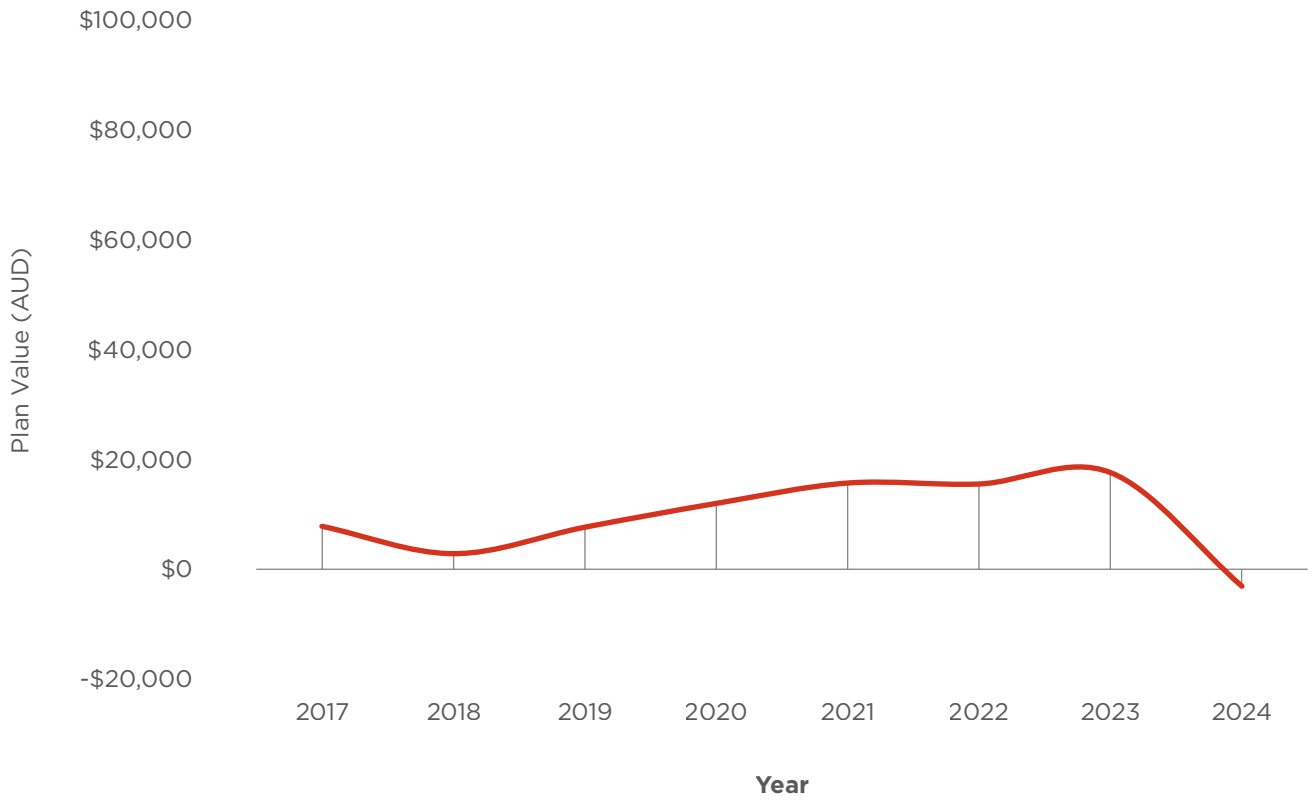


Table 6.3: NDIS plan summary data

	FREQUENCY	PERCENTAGE
Currently has a plan		
Has a plan	510*	39.7%
No Disability	20	7.8%
Mild Disability	140	38.3%
Moderate Disability	114	66.7%
Severe Disability	102	60.7%
Does not have a plan	776	60.3%
No Disability	237	92.2%
Mild Disability	226	61.7%
Moderate Disability	57	33.3%
Severe Disability	66	39.3%
Management type (among those with plans)		
Self-Managed	161	40.1%
Plan-Managed	175	43.6%
Combination	65	16.2%
Applied for access		
Not Applied	690	53.7%
Has Applied	591	46.3%
Had a plan (among those who applied)		
Never acquired a plan	70	11.9%
Has acquired a plan	519	88.1%
Application rejected (among those who applied)		
Rejected	122	23.2%
Never Rejected	404	76.8%

Notes: *Compared to Table 6.1 ever had a plan, n = 9 people in this table ceased to have an NDIS plan.

Figure 6.5: NDIS access application proportions by disability severity

Figure 6.5A: Application proportions for all AMSLS participants

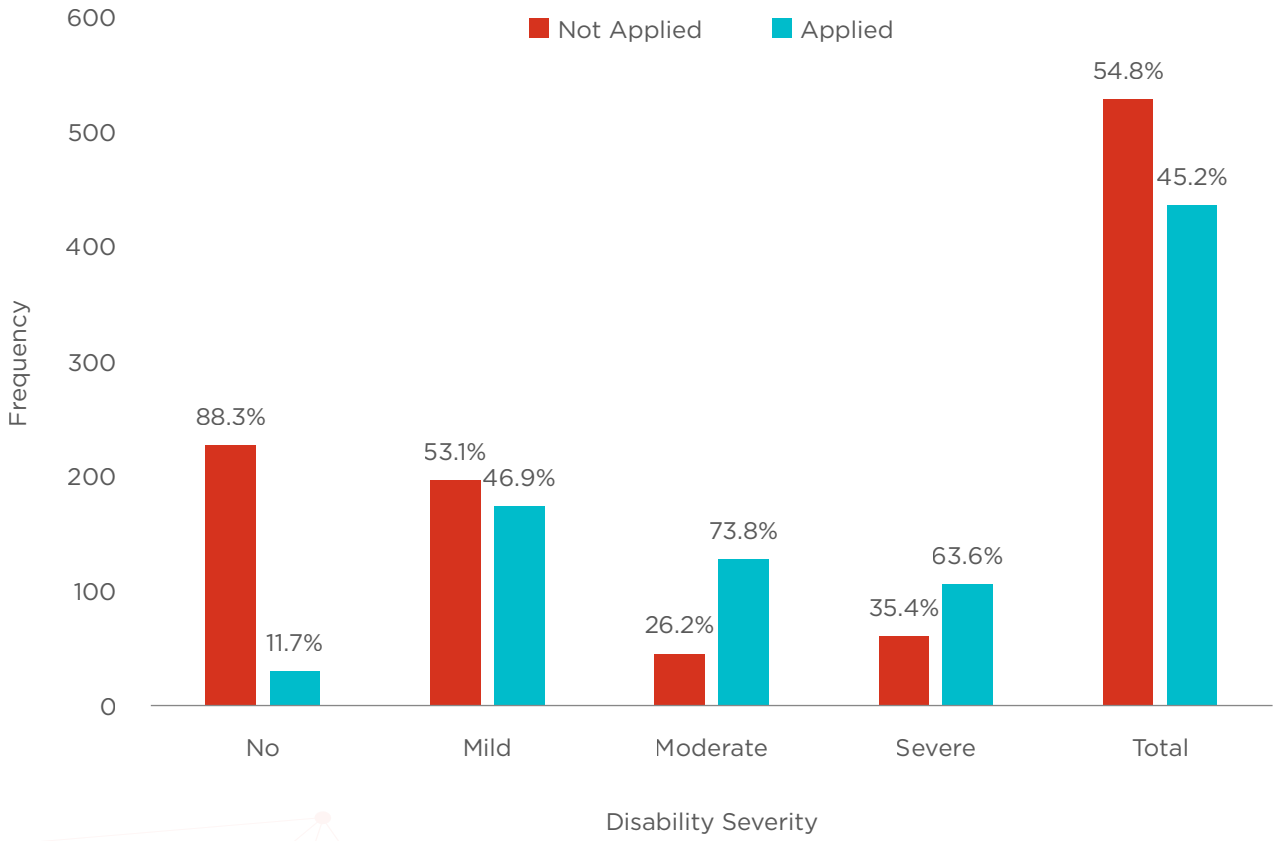
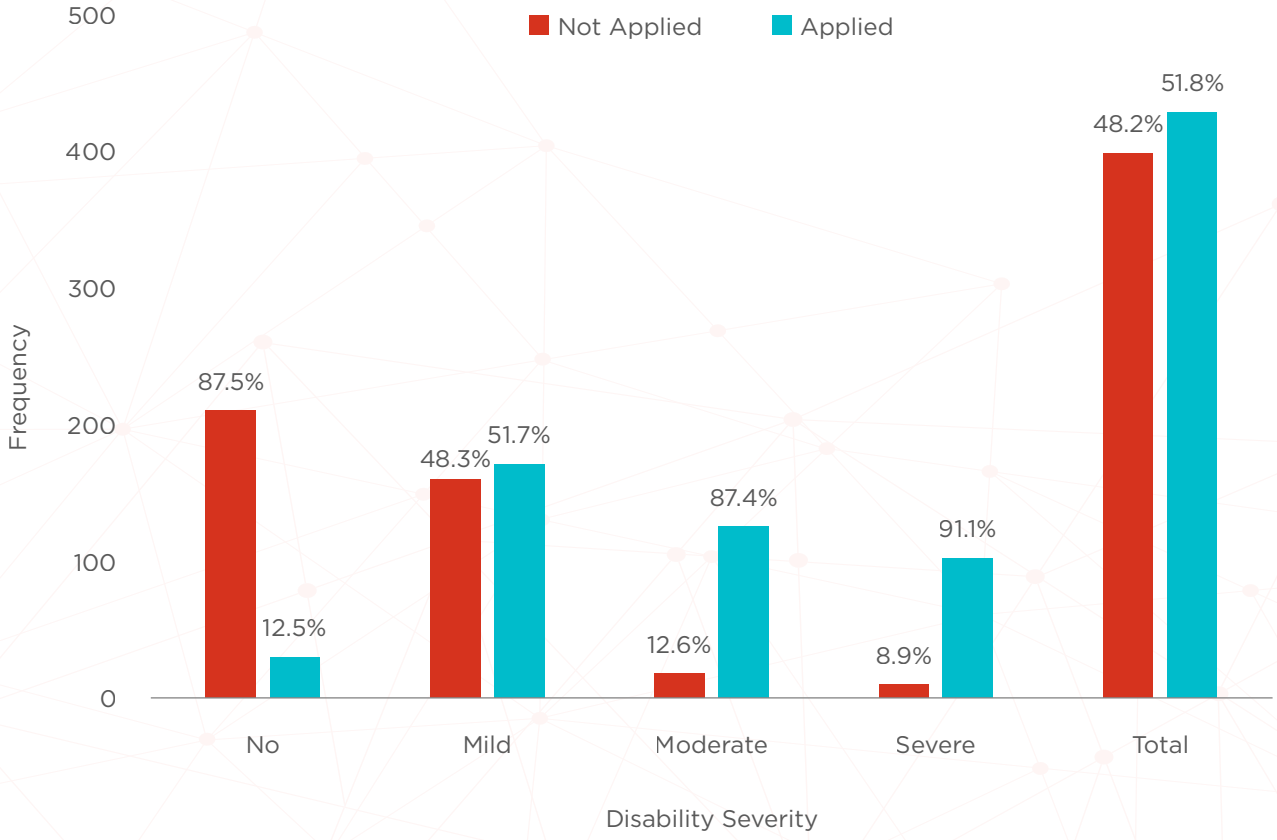


Figure 6.5B: Application proportions for potentially eligible AMSLS participants



6.4.4 Application rates among AMSLS participants

A total of 39.7% of AMSLS participants had an NDIS plan, with 56.3% of these individuals fully or partially self-managing their funding (Table 6.3). Notably, 23.2% of participants who had applied for NDIS access reported that their application was rejected at least once. This is despite 88.1% of participants indicating that they received an NDIS plan. These figures suggest that 11.9% of AMSLS applicants were unsuccessful, with a further 11.3% requiring additional attempts to secure NDIS access.

Of the 591 participants who applied for NDIS access, 72 did not indicate whether their application was ever rejected. Because of this missing information, the reported rejection rate (23.2%) may underestimate the true rate. AMSLS participants reported spending a mean of 23.4 hours (SD 38.6) applying to the NDIS.

People living with MS were more likely to apply to the NDIS if they had greater levels of disability (Figure 6.5A). When adjusting for potential ineligibility by restricting the analysis to those who were under 65 years of age during the initial year of the full rollout (2016), a clear dose-response relationship was observed between disability severity and the percentage of participants who applied (Figure 6.5B). Specifically, the proportion of participants who applied increased from 12.5% among those with no disability to 91.1% among those with severe disability. Overall, 51.8% of potentially eligible AMSLS participants (who where under 65 years of age in 2016) reported applying for an NDIS plan.

6.5 Discussion

6.5.1 Summary of key findings

The mean initial NDIS plan value among AMSLS participants was $62,178, while reassessed plans had a mean value of $75,504. Based on reassessment timing and information from NDIS media releases, these plans frequently spanned a period of around one year [165]. AMSLS participants who applied for NDIS access spent, on average, 23.4 hours (SD 38.6) on the application process, indicating wide variability in effort required.

Encouragingly, a high proportion (88.1%) of NDIS applicants within the AMSLS indicated that they currently hold a plan. Additionally, we found that 89.0% of potentially eligible AMSLS participants (who met the age requirements) living with moderate to severe MS-related disability had applied for access. However, at the time of the survey, only half of AMSLS participants reported applying. Notably, just 12.3% of individuals with no disability and 54.3% of those with mild disability had applied. This may be due to several factors, including perceptions of ineligibility, reluctance to navigate the complexity of the NDIS, or a lack of need for NDIS supports at this stage. Further research will be required to confirm these possibilities.

Another key finding was that NDIS plan values, covering between one and five years, scaled with disability severity, rising on average from $47,000 for people with mild disability to $104,000 for those with severe disability. This suggests that plan values are tailored to individual needs. Plan values were also higher among people living with PPMS, who typically experience greater disability [6]. Additionally, individuals residing in regional and remote areas received higher plan values, likely reflecting the increased cost of service provision outside of major population centres.

Plan values were higher following reassessment across all years except 2024. Lastly, lower mean plan values were observed in NSW and the ACT, which may be due to inconsistencies in NDIS planning and assessment criteria across jurisdictions.

6.5.2 Implications of NDIS plan value estimates

The observed stability of initial inflation-adjusted NDIS plans over time suggests some commitment to the Scheme's sustainability and to maintaining real (inflation-adjusted) plan values. Reassessed plan values have generally exceeded initial values, indicating additional support is being provided to those who require it.

Individuals who have ever had an NDIS plan (40.4%) and those who have never had a plan (59.6%) did not differ substantially in their sociodemographic characteristics. This suggests that no specific population groups are being disproportionately disadvantaged in accessing the NDIS.

While the size of NDIS plans may have kept pace with inflation, this stability raises concerns regarding plan sufficiency, given that their value has changed only nominally in the past decade. Data from the AIHW show that price increases in the healthcare sector have frequently outpaced the CPI, which reflects broader economy-wide inflation [1,146]. The cost of NDIS-funded goods and services may have increased at a rate higher than that represented in the CPI, which reflects general economy-wide inflation. However, NDIS pricing has not kept pace with these rising costs. Pricing limits for many supports have been frozen, reduced, or only minimally increased over several years, creating a gap between actual service cost and the funding provided.

Another factor impacting the overall value of an NDIS plan is the number of support hours for which a person living with MS is approved. Even if the NDIS price matches the cost of the NDIS service, there may be insufficient hours to meet their needs.

The pricing levels set by the NDIS continue to raise serious concerns for people living with MS. The 2024-25 NDIS Pricing Review introduced a range of changes to pricing for therapy supports, support coordination and plan management, which will significantly impact the value and effectiveness of NDIS plans for people living with MS. Key changes include:

- Reducing price limits for physiotherapy, dietetics and podiatry
- Freezing the prices for occupational therapy, speech pathology and exercise physiology
- Reducing travel cost allowances for therapy supports
- Changes to support coordination and plan management, including freezing prices and removing set-up costs and remote and very remote loadings.

We suggest that the increasing gap between the cost of delivering NDIS therapy supports and NDIS pricing will have serious consequences on people living with MS and other neurological conditions, including increased disability and hospitalisation, greater reliance on the health system and the increased financial burden of paying out of pocket to fill the gap in services.

6.5.3 Strengths and limitations

Our preliminary analysis of NDIS utilisation in the AMSLS was strengthened by its large and representative study population. The preliminary results reported in this chapter will support and inform elements of a broader and more detailed NDIS project currently underway using AMSLS data and supported by MS Australia.

6.5.4 Conclusion

Our preliminary research shows high rates of NDIS application and approval among people living with moderate to severe MS-related disability. Plan values tend to increase with the severity of MS-related disability, suggesting that NDIS funding is responsive to need.

While the relative stability of inflation-adjusted plan sizes supports the argument for NDIS sustainability, it also raises questions about plan sufficiency, particularly if healthcare service prices are rising faster than CPI.

NDIS utilisation was relatively low among people living with mild disability, which may reflect perceptions of ineligibility, reluctance to navigate the complexity of the NDIS, or a lack of need for NDIS supports.

Drawing on the data presented in this chapter, further research will investigate these issues in greater depth, alongside other pressing topics affecting people living with MS.

CHAPTER 7

Highlights, conclusions and recommendations

7.1 Introduction

The *Multiple Sclerosis Prevalence and Health Economic Impact in Australia 2025* report provides a comprehensive overview of the current landscape for people living with MS, their families and supporters, and the broader Australian community. While the outlook is positive, there is still much work to be done.

As with previous editions, the 2025 report provides a detailed analysis of the economic and quality of life impacts of MS in Australia. It constitutes a contemporary and reliable source of health economic evidence to support the MS community's efforts towards MS prevention and improved health and economic outcomes for people living with MS, their carers, and supporters.

Assessing the health economic impact of MS is an ongoing endeavour, with each report contributing to a growing evidence base that informs advocacy, policy and service delivery.

The key aims for this report were to:

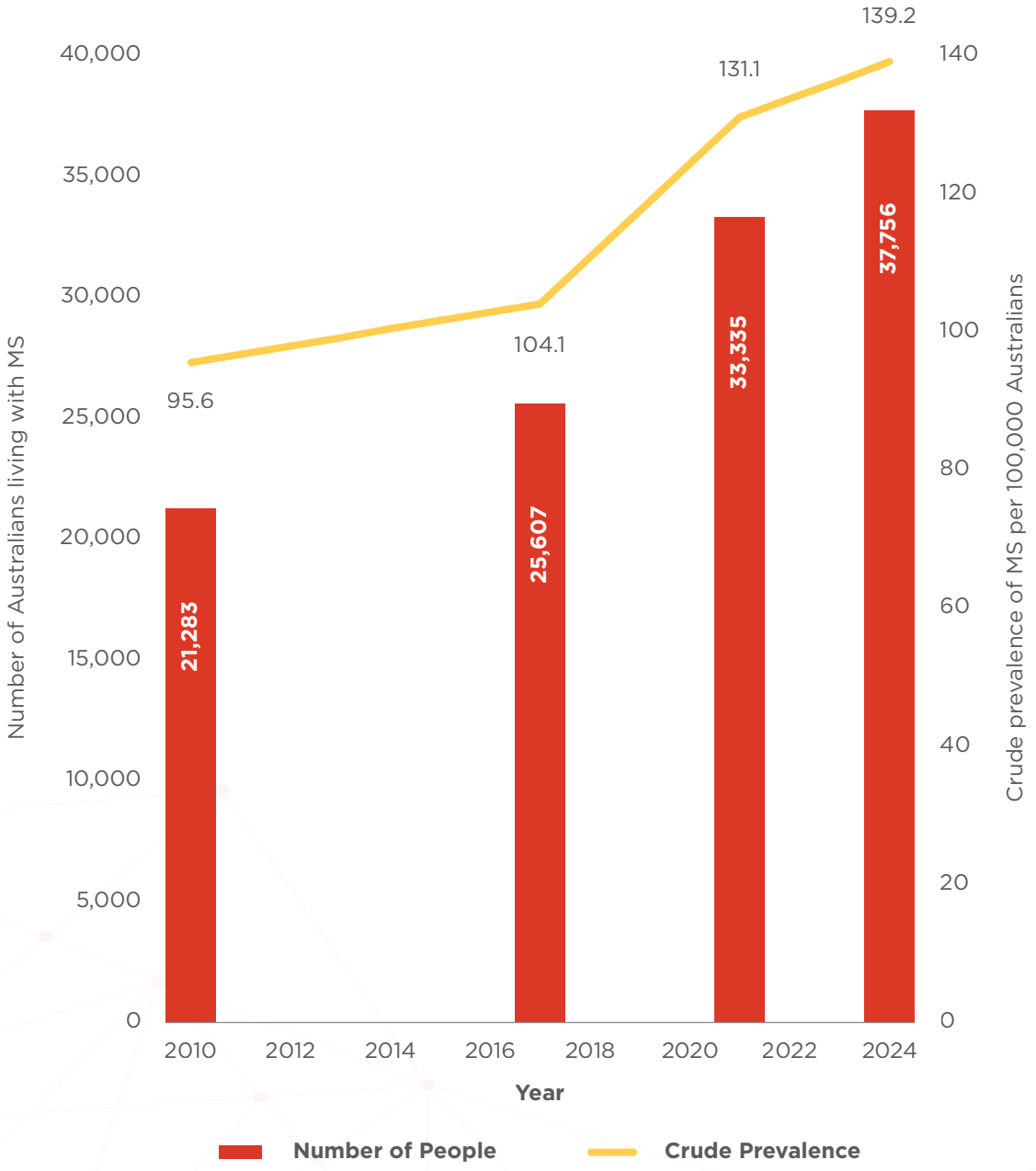
1. Estimate the prevalence of MS in Australia in 2024, including breakdowns by state and territory (Chapter 2).
2. Evaluate the impacts of MS-related disability on health-related quality of life and determine what elements of wellbeing are most affected by MS (Chapter 3).
3. Review employment patterns and outcomes for people living with MS, including their experiences with diagnosis disclosure 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 people living with MS with different sociodemographic and clinical characteristics, 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 offer recommendations for future action (Executive Summary and Chapter 7).

7.2 Main findings

Prevalence

The number of Australians with MS continues to grow, with 37,756 people living with MS in Australia in 2024. This figure has increased from 33,335 in 2021 and 25,607 in 2017 (Figure 7.1; Table 7.1). In 2024, there were 139.2 cases per 100,000 Australians. The number of people with MS has increased by 77.3% since 2010, with cases per 100,000 increasing by 45.6%. Based on major reports (2010, 2017, and 2024), prevalence rose by approximately 8.9% between 2010 and 2017 and by a further 33.7% between 2017 and 2024, highlighting a sharp upward trend in recent years.

Figure 7.1: Number of people living with MS in Australia and the crude prevalence per 100,000 people.

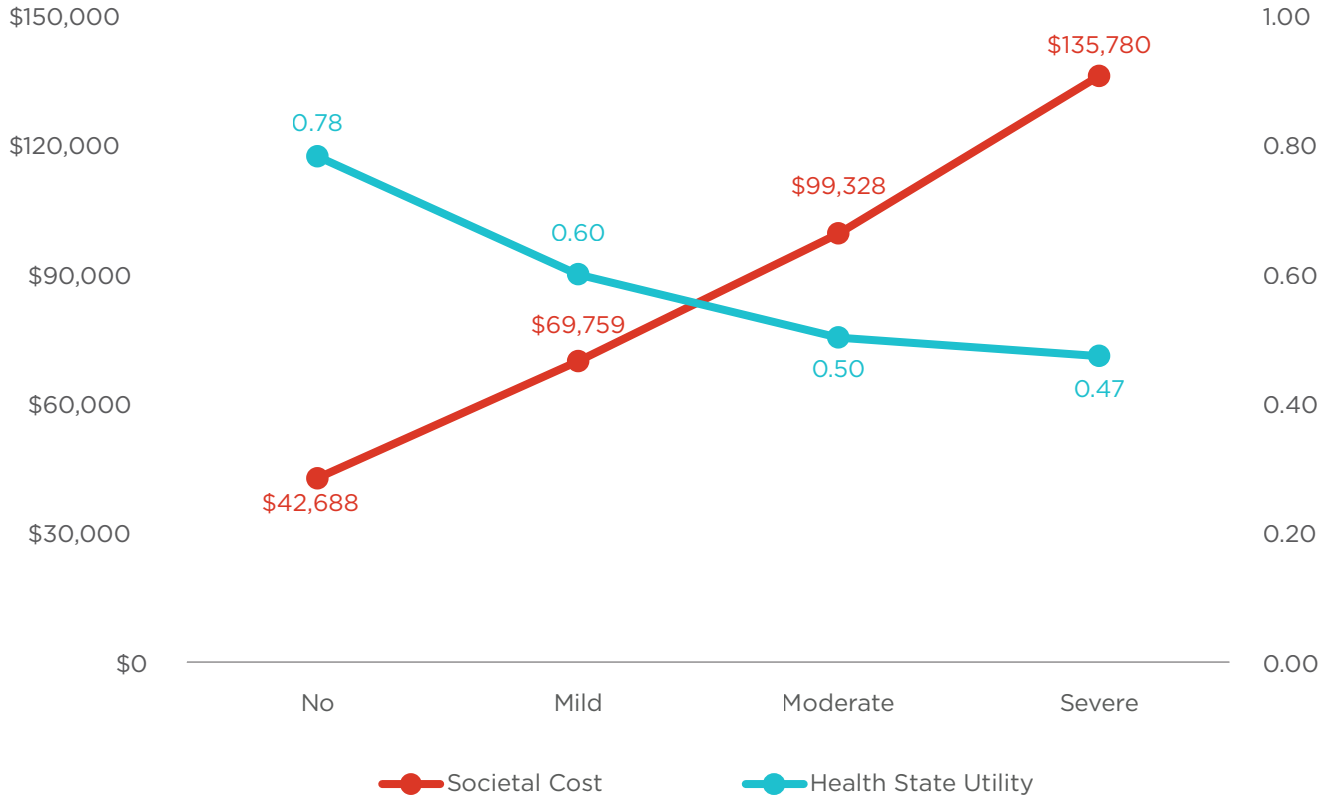


Quality of life

This report underscores the negative impacts of MS-related disability accumulation across the life course. As disability increases, quality of life declines, individuals' costs rise, and workforce participation drops (Figure 7.2, Table 7.1). These effects are particularly pronounced for people living with progressive MS.

Mean quality of life for people living with MS in 2024, measured using health state utility (HSU) scores (1.0=perfect health; 0.0=death), was 0.60, well below the Australian population norm of 0.80. Disability levels also impacted these measures; those living with no MS-related disability had an average HSU score of 0.78 close to the Australian population norm, while those with severe MS-related disability average 0.47.

Figure 7.2: Summary figure showing the 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).

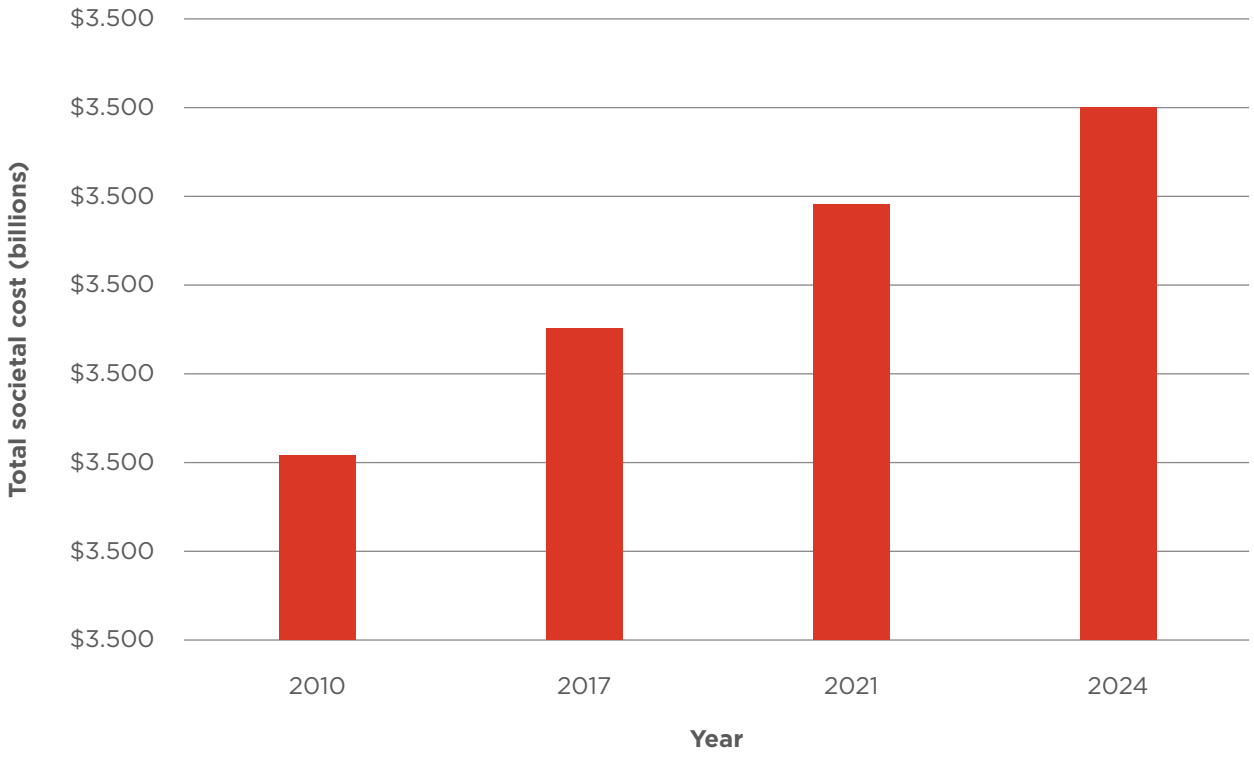
Cost of MS

The total societal cost of MS in Australia has increased substantially over time, rising from $1.04 billion in 2010 to $1.75 billion in 2017, $2.45 billion in 2021, and reaching $3.00 billion in 2024 (Figure 7.3). Importantly, for the first time, the average costs per person have slightly decreased to $79,581 per year. The increase in total societal costs is driven by the growing number of Australians living with MS (Table 7.1).

While individual costs have remained relatively stable, as in previous years, they vary significantly by disability level. For people living with no MS-related disability, the mean costs were $42,688 compared to $135,780 for those with severe MS-related disability.

The largest cost drivers were disease modifying therapies (DMTs) and employment loss, contributing 19.7% and 28.2% to the total societal costs, respectively. The slight reduction in per person costs may reflect the impact of high-efficacy DMTs, particularly for people with relapsing-remitting MS (RRMS).

Figure 7.3: Total societal cost of MS in Australia from 2010 to 2024, as reported in previous reports.



Employment

Loss of employment accounted for 28% of the total cost of MS to Australian society. The majority of retired people living with MS, at 58%, stated that they left the labour force due to their MS. Among those who were still working, 91% indicated that their disability negatively impacted their ability to work.

As with previous reports, employment outcomes worsened with increasing disability severity: 75% of people with severe MS-related disability and 72% with moderate disability were out of the labour force, compared to 46% of those with mild disability and 23% of those with no disability.

National Disability Insurance Scheme

Regarding the NDIS, overall average plan values were $62,000 (2024 AUD) with reassessed plans averaging $13,000 higher. As expected, plan values were the highest for people living with severe MS-related disability.

Table 7.1: Chapter highlights

CHAPTER	HIGHLIGHTS
Chapter 2 Prevalence	• The number of people living with MS in Australia in 2024 is 37,756 people. • There were 139.2 cases of MS per 100,000 Australians. • The total number living with MS had increased by 77.3% since 2010, withprevalence (cases per 100,000) increasing by 45.6%. • Prevalence rose by approximately 8.9% between 2010 and 2017 and by a further 33.7% between 2017 and 2024, highlighting a sharp upward trend in recent years. • 23,217 (62%) of Australians living with MS were using DMTs in 2024.
Chapter 3 Quality of Life	• Mean health-related quality of life (measured using HSU) among people living with MS was estimated at 0.60, 0.20 utility points lower than the Australian population norm. • People living with MS who had no MS-related disability recorded an average HSU of 0.78. This value decreased to 0.60, 0.50, and 0.47 for people living with mild, moderate and severe MS-related disability, respectively.
Chapter 4 Employment	• Loss of employment accounted for 28% of the total cost of MS to Australian society. • 58% of retired AMSLS participants left the labour force due to their MS. • Among those who were still working, 91% indicated that their MS negatively impacted their ability to work. • Fatigue, motor dysfunction, and cognitive impairment were the symptoms most frequently cited as reasons for leaving employment. • About 60% of working participants had disclosed their diagnosis to their employer, with 27% of these people stating that this had a negative effect. • Employment outcomes worsened with increasing disability severity: 75% of people with severe MS-related disability and 72% with moderate disability were out of the labour force, compared to 46% of those with mild disability and 23% of those with no disability.
Chapter 5 Cost of Illness	• The total societal cost of MS in Australia for 2024 was estimated at $3.004 billion. • Nominal total costs for 2024 were 71.5% higher than in 2017 ($1.751 billion), or 37.5% adjusted for inflation. • The mean cost per person living with MS in 2024 was $79,581, slightly lower than the average in 2017 when adjusted for inflation. Costs were highest for people living with severe disability; while estimates remained relatively stable across other disability levels compared with previous reports. • Mean MS-related costs per person ranged from $46,288 for people living with no disability to $135,780 for those with severe disability. • The largest sources of costs were DMTs (20% of total costs) and loss of employment (28%).
Chapter 6 National Disability Insurance Scheme	• Among AMSLS participants, the mean value of initial NDIS plans was $62,000, with reassessed plans averaging $13,000 higher. • Mean NDIS plan values varied by disability severity: individuals with severe disability had an average plan value of $104,000, $57,000 higher than those with mild disability. • Among AMSLS participants with moderate to severe disability, 89% had applied for access to the NDIS, and 88% of those applicants were approved.

7.3 Recommendations

Total societal costs of MS continue to rise due to increasing prevalence. Preventing new cases of MS is an increasing focus of national and global research initiatives with the potential to significantly reduce the health and economic impact of MS in Australia.

For the first time since these reports have been undertaken, the average costs per person living with MS did not increase in Australia for the period 2017 to 2024. With sustained and coordinated efforts in the coming years, further substantial cost savings can potentially be made.These efforts should focus on delaying disability accumulation and maintaining or improving the quality of life.

Building on the findings in this report, the following recommendations outline priority actions to reduce the health and economic burden of MS in Australia.

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.

The rising prevalence of MS in Australia highlights the urgent need for prevention-focused research and public health initiatives. Importantly, changes in exposure to known MS risk factors, such as increased rates of adolescent obesity[28], reduced rates of pregnancy[45], and decreased sun exposure[11], are likely significant contributors to the increase in MS cases. Addressing these factors through targeted research and community interventions may help curb future growth in MS prevalence.

Emerging data is providing "evidence that MS might become a preventable disease"[166] and prevention has been identified as a key aim across global MS research[167] that has been critically underfunded to date[168].

MS Australia and MS Canada recently launched the Global Multiple Sclerosis Prevention Initiative[169]; an international effort aimed at preventing MS and detecting it at ultra-early stages. It focuses on: 1) deepening the understanding of genetic, environmental, and viral risk factors, especially the Epstein-Barr virus; 2) development of biomarkers and tools to detect MS in its preclinical phase, before neurological damage occurs, and; 3) exploring strategies to halt disease onset through immune modulation, antivirals, or lifestyle interventions. These efforts will require significant investment, but the potential cost savings identified in this report strongly support Australian investment in MS prevention.

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 primary progressive MS, for whom none are currently PBS-approved in Australia.

Early and effective management of MS can help individuals remain in the lower disability categories, where quality of life is higher and the societal cost of illness is much lower. MS Australia's 2024 World MS Day "My Diagnosis" Report found that the average time from symptom onset to diagnosis in Australia in 2017-2021 was almost four years (median one year).

Funding is urgently needed to develop and validate clinical, imaging and fluid biomarkers enabling earlier diagnosis and intervention. New biomarkers have already been incorporated into the new diagnostic criteria[170] and more are in development[171,172].

As noted in the 2017 report, Brain Health: Time Matters in Multiple Sclerosis[173], significant delays can still occur between noticing the first symptoms of MS and receiving a diagnosis. These delays could be reduced by improving awareness of MS among the general public and referring healthcare professionals. Access to specialist MS healthcare professionals is important for differential diagnosis and may not be available in a timely manner for all Australians[174], especially those with reduced capacity to pay for private healthcare[175].

The new diagnostic criteria[170] and companion educational resources currently in development will be disseminated by MS Australia in partnership with international MS organisations. Several updates to the criteria support earlier diagnosis, including removal of the requirement for "dissemination in time" in certain circumstances[176].

Many PBS-listed treatments are available in Australia to address inflammatory components of the disease, which are effective at reducing relapse activity[25]. A key component of preserving brain health in MS[177] is the early intervention with these DMTs.

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).

Currently, TGA-approved and PBS-listed therapies for MS in Australia target inflammation in MS via immunomodulatory mechanisms. There is a critical unmet need for therapies that target neurodegeneration in MS, and therapies for people with non-relapsing secondary progressive MS and primary progressive MS, for whom there are no treatment options subsidised in Australia. Treatments exploiting neuroprotective and myelin repair mechanisms are in clinical trials and are active areas of ongoing therapeutic development. Repurposing of therapies already TGA-approved for other indications and adaptive clinical trial design are among the strategies in place to fast-track development of these therapies for progressive MS in Australia. Recently completed trials have provided promising proof-of-concept for successful remyelination in MS[178].

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.

The MS Nurse Care in Australia report, commissioned by MS Australia, found that 31.5% of people living with MS in Australia do not currently have access to MS Nurse care[179]. Importantly, those without access consistently reported worse health outcomes, including:

- Higher levels of disability
- Increased rate of self-reported disease progression in the previous 12 months
- Greater severity across 13 MS-related symptoms
- Lower health-related quality of life

MS Nurse care is a highly cost-effective model of specialist care, reducing the need for more expensive services such as general practitioner and neurologist visits, emergency department presentations and hospital admissions.

With MS prevalence increasing, nearly 12,000 Australians living with MS currently lack access to MS Nurse care. Ensuring universal access would lead to better health outcomes and significant cost savings for MS healthcare in Australia.

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.

In recent years, there has been a growing focus on empowering individuals with MS to take an active role in managing their disease and maintaining brain health. Sustained efforts to raise awareness and encourage a proactive engagement in MS management are essential to improving quality of life, reducing cost and enhancing long-term outcomes. The Brain Health: Time Matters report[177] recommends a proactive approach to MS management, including regular monitoring and shared decision-making to optimise treatment outcomes for people living with MS.

The Brain Health: Time Matters Report 2024 also details lifestyle choices that support brain health, including avoiding smoking, staying physically active, and improving sleep quality.

MS Australia has developed the Living Well with MS Guides, which outline the evidence base for lifestyle factors in managing MS. These guides provide practical recommendations for people living with MS and their healthcare professionals, highlighting strategies that can positively influence health outcomes. Modifiable lifestyle factors covered include regular physical activity, healthy weight management, smoking cessation, eating a healthy diet, stress and sleep management, and managing other health conditions alongside MS [134].

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.

Loss of employment was the largest cost driver identified in this report, so addressing this would have a substantial impact on the societal cost of MS. Additionally, meaningful employment for people with MS has positive health and financial benefits, improving quality of life. While people with MS can be assisted via Disability Employment Services, and these types of services have been shown to have positive impacts on employment [102,103], they are often accessed too late [104]. Therefore, programs aimed at helping people earlier may mitigate negative employment impacts.

People with MS often experience invisible symptoms, which creates a mismatch between how a person with MS feels and how others in the workplace perceive their MS. As every person's MS is unique, there is a potential role for the person with MS to communicate their symptoms directly. Implementing resources and programs for workplaces that increase the knowledge base of MS and how it might impact work is also recommended to reduce stigma and increase understanding.

7. Access to the National Disability Insurance Scheme

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.

The high number of AMSLS participants with NDIS plans indicates a strong reliance on NDIS supports. The goal of NDIS funding is improved quality of life, through greater independence, access to new skills, jobs, or volunteering; more time with family and friends; and access to services in the community[159].

7.4 Conclusions

This report is intended for use by advocacy organisations, governments, researchers and policy makers to inform resource allocation to appropriately support people with MS. Additional investment is needed to prevent MS, halt or slow disability progression for people who have MS, and improve the lives of people living with MS, their families and carers. Ultimately, this will lead to improved health outcomes, reduced MS prevalence, and curbing the cost of MS for Australian society.

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Supplementary material

Supplementary Table 2.1: Counts of Australian Pharmaceutical Benefits Scheme (PBS) and Repatriation PBS (RPBS) DMT prescriptions issued to people living with MS in Australian states and territories, from November 2023 through October 2024 inclusive, stratified by PBS code.

PBS CODE	GENERIC NAME	AUSTRALIAN STATES AND TERRITORIES								
		NSW	VIC	QLD	SA	WA	TAS	ACT	NT	SUM
10228H	Alemtuzumab	3	1	4	0	0	0	1	0	9
10232M	Alemtuzumab	5	2	11	1	0	0	3	0	22
10243D	Alemtuzumab	1	0	1	0	0	0	0	0	2
10246G	Alemtuzumab	1	1	4	0	0	0	0	0	6
11603Q	Cladribine	388	337	173	101	45	44	12	1	1,101
11604R	Cladribine	465	460	244	123	75	44	29	4	1,444
11611D	Cladribine	562	522	250	152	87	64	21	6	1,664
2896K	Dimethyl Fumarate	26	24	9	4	3	1	0	0	67
2943X	Dimethyl Fumarate	75	19	19	0	28	6	0	0	147
2966D	Dimethyl Fumarate	6,693	4,433	2,454	1,318	1,227	346	288	10	16,769
13059H	Diroximel Fumarate	1,475	937	523	176	144	190	161	6	3,612
11818B	Fingolimod	117	53	39	13	36	0	0	0	258
5262Y	Fingolimod	8,788	12,799	5,433	4,321	2,162	397	781	141	34,822
10416F	Glatiramer Acetate	2,455	1,993	1,448	694	671	238	262	12	7,773
13110B	Glatiramer Acetate	392	348	238	116	102	1	32	0	1,229
8101J	Interferon Beta-1b	603	674	498	203	280	74	9	19	2,360

13820J	Natalizumab	437	335	346	61	224	1	1	0	1,405
13825P	Natalizumab	1,516	1,152	985	971	394	351	44	30	5,443
9505G	Natalizumab	5,609	11,068	3,442	1,799	1,394	750	292	103	24,457
9624M	Natalizumab	2,703	1,698	1,674	187	1,705	49	26	0	8,042
11237K	Ocrelizumab	1,127	831	752	175	840	14	54	0	3,793
11242Q	Ocrelizumab	2,427	4,889	1,222	1,081	650	425	270	33	10,997
12641H	Ofatumumab	17,532	5,323	3,451	1,030	2,776	763	554	79	31,508
12642J	Ofatumumab	600	339	166	56	134	40	27	0	1,362
12271W	Ozanimod	674	414	120	28	23	17	47	3	1,326
12278F	Ozanimod	8	3	2	0	1	1	0	0	15
13251K	Ozanimod	12	10	1	9	0	0	0	0	32
13269J	Ozanimod	175	190	41	30	24	0	0	0	460
13271L	Ozanimod	66	77	13	29	9	0	0	0	194
10212L	Peginterferon Beta-1a	223	214	114	55	53	33	27	0	719
10218T	Peginterferon Beta-1a	14	4	6	2	0	0	5	0	31
10220X	Peginterferon Beta-1a	1,637	1,131	955	401	491	137	167	4	4,923
12158X	Siponimod	1,903	1,884	632	458	244	39	141	6	5,307
12160B	Siponimod	483	363	123	72	12	15	32	0	1,100
12172P	Siponimod	34	18	11	11	1	1	3	0	79
14607T	Siponimod	7	7	2	1	0	0	0	0	17
2898M	Teriflunomide	3,998	5,229	2,919	836	1,092	548	166	10	14,798
State, Territory, and National Totals		**63,234**	**57,782**	**28,325**	**14,514**	**14,927**	**4,589**	**3,455**	**467**	**187,293**

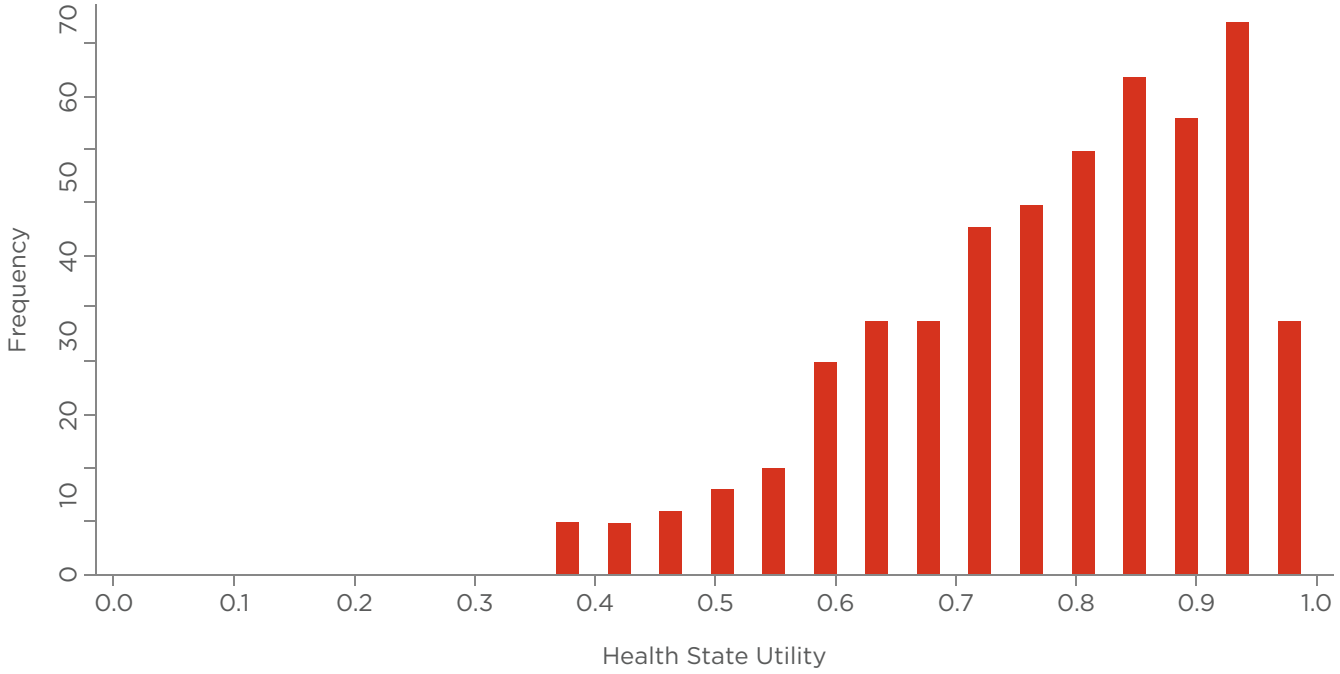
Notes: States/Territories are abbreviated as: New South Wales (NSW), Victoria (VIC), Queensland (QLD), Western Australia (WA), Tasmania (TAS), Australian Capital Territory (ACT), Northern Territory (NT).

Supplementary Table 2.2: Percentage changes in population compared to the percentage changes in crude prevalence from 2010 to 2024

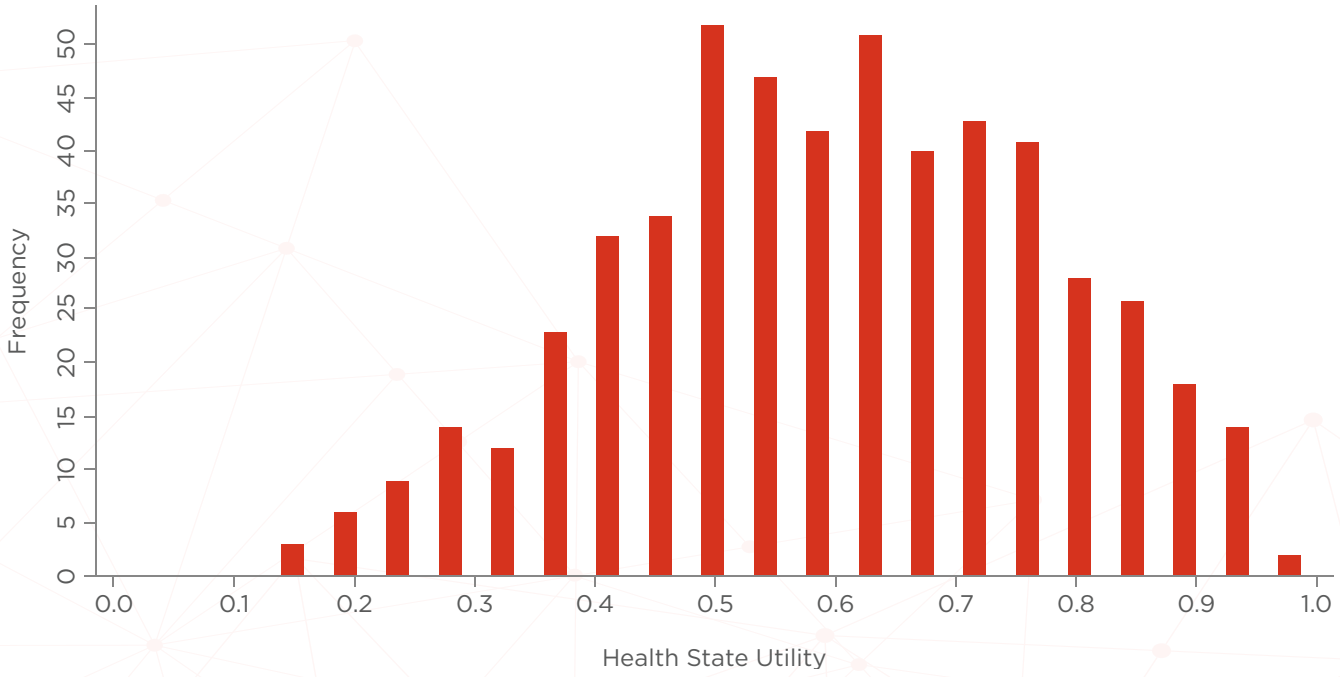
STATE AND YEAR	NUMBER OF CASES				CRUDE PREVALENCE PER 100,000			
	ESTIMATE	VS 2010	VS 2017	VS 2021	ESTIMATE	VS 2010	VS 2017	VS 2021
National								
2010	21,283				95.6			
2017	25,607	4324			104.1	8.5		
2021	33,335	12052	7728		131.1	35.5	27.0	
2024	37,756	16473	12149	4421	139.2	43.6	35.1	8.1
New South Wales								
2010	6,268				86.8			
2017	7,682	1414			97.3	10.5		
2021	9,783	3515	2101		121.2	34.4	23.9	
2024	11,270	5002	3588	1487	133.1	46.3	35.8	11.9
Victoria								
2010	6,637				120			
2017	7,895	1258			124.2	4.2		
2021	9,969	3332	2074		153.3	33.3	29.1	
2024	12,086	5449	4191	2117	173.7	53.7	49.5	20.4
Queensland								
2010	3,179				70.7			
2017	3,970	791			80.2	9.5		
2021	5,535	2356	1565		107.4	36.7	27.2	
2024	6,058	2879	2088	523	108.9	38.2	28.7	1.5
South Australia								
2010	1,760				107.3			
2017	2,452	692			142	34.7		
2021	3,041	1281	589		170.7	63.4	28.7	
2024	3,086	1326	634	45	164.7	57.4	22.7	-6.0
Western Australia								
2010	2,313				101.2			
2017	2,219	-94			85.8	-15.4		
2021	2,905	592	686		109.2	8.0	23.4	
2024	2,950	637	731	45	99.9	-1.3	14.1	-9.3

Tasmania								
2010	718				141.6			
2017	774	56			148.3	6.7		
2021	1,186	468	412		212.7	71.1	64.4	
2024	1,155	437	381	-31	200.6	59.0	52.3	-12.1
Aust. Capital Territory								
2010	360				100.6			
2017	538	178			130.4	29.8		
2021	774	414	236		170.3	69.7	39.9	
2024	725	365	187	-49	153.3	52.7	22.9	-17.0
Northern Territory								
2010	49				21.3			
2017	77	28			31.1	9.8		
2021	89	40	12		35.8	14.5	4.7	
2024	92	43	15	3	36.1	14.8	5.0	0.3

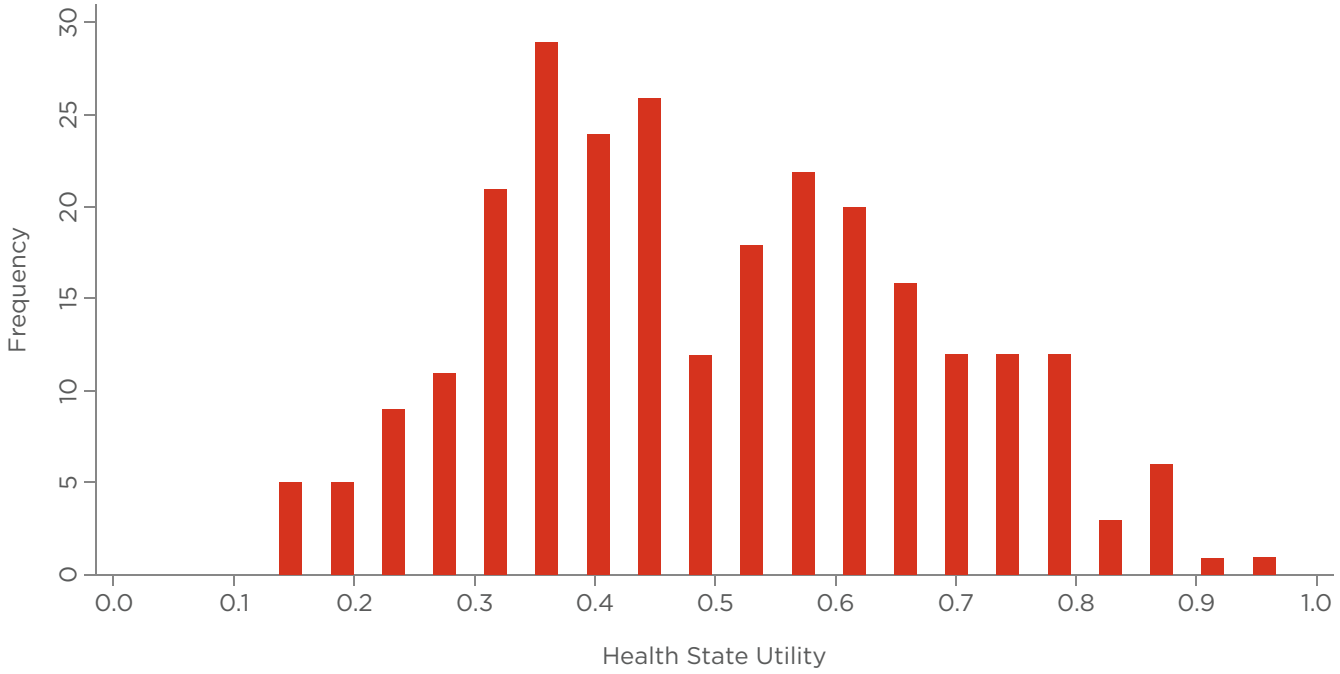
Supplementary Figure 3.1: Histogram/frequencies of HSU scores among people with no disability



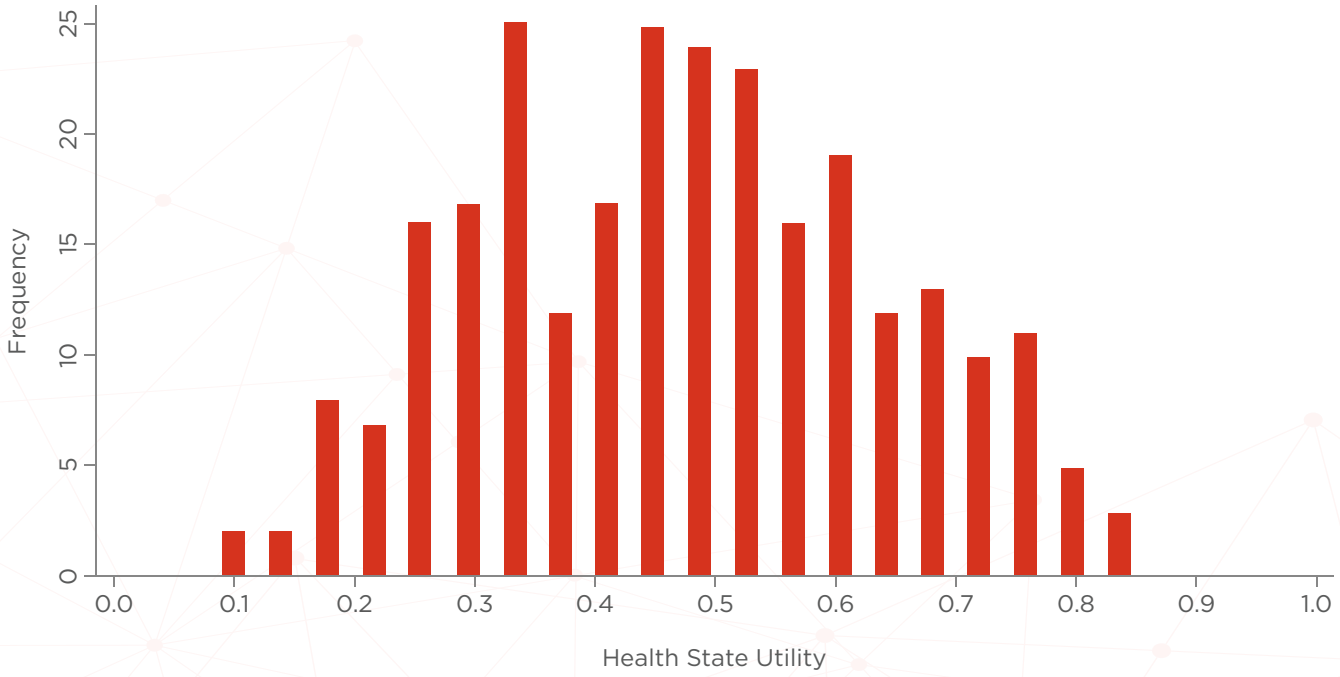
Supplementary Figure 3.2: Histogram/frequencies of HSU scores among people with mild disability



Supplementary Figure 3.3: Histogram/frequencies of HSU scores among people with moderate disability



Supplementary Figure 3.4: Histogram/frequencies of HSU scores among people with severe disability



Supplementary Table 5.1: Sources for extra-AMSLS prices

ITEM	COST UNIT	COST	SOURCE
Assistive Services			
Child Care	Per Day	$123.64	(ACCC) Pricing practices and operating costs of childcare services to be examined - URL: accc.gov.au
Cleaning/Maintenance	Per Hour	$56.23	NDIS Pricing Arrangements and Price Limits 2024-25
Dog Walking	Per Hour	$35.00	(Airtasker AU) Dog walking costs: How much to hire a dog walker in Australia? - URL: airtasker.com/au
Gardening	Per Hour	$55.21	NDIS Pricing Arrangements and Price Limits 2024-25
Meal Service	Per Event	$10.25	(Meals on Wheels Victoria) FAQs - URL: mealsonwheelsvictoria.org.au
Personal Assistance	Per Hour	$67.56	NDIS Pricing Arrangements and Price Limits 2024-25
Exercise			
Dance	Per Hour	$15.00	(Fiesta Loca) How Much Does a Dance Instructor Cost? - URL: fiestaloca.com.au
Gym Session/Exercise Class	Per App.	$27.50	(Yellow Pages) How much does a personal trainer cost? - URL: yellowpages.com.au
Personal Trainer/Health Coach	Per Hour	$64.92	NDIS Pricing Arrangements and Price Limits 2024-25
Pilates Teacher	Per Lesson	$47.00	(Airtasker AU) How much do Pilates classes cost: Pricing, factors, and options - URL: airtasker.com/au
Pool Admission	Per Event	$28.00	(Hobart Aquatic Centre) Fees and Charges- URL: hobartaquaticcentre.com.au
Tai Chi Teacher	Per Lesson	$18.00	(Tai Chi Australia) FAQs - URL: www.taichiaustralia.com.au
Yoga Teacher	Per Lesson	$25.00	(Natural Therapy Pages) Yoga class costs in Australia: What to expect and how to save - URL: naturaltherapypages.com.au
Healthcare			
Acupuncturist	Per App.	$118.91	(Comcare) Rates for medical and allied health treatment - URL: comcare.gov.au
Alexander Technique	Per Hour	$99.00	(Blue Mountains Alexander Technique) How much does Alexander Technique cost? - URL: alexandertechnique.net.au
Bowen Therapy	Per Hour	$75.00	(Natural Therapy Pages) How much do massage therapies cost in Australia? - URL: naturaltherapypages.com.au
Chiropractor	Per App.	$96.50	(Comcare) Rates for medical and allied health treatment - URL: comcare.gov.au

Healthcare			
Continence Clinic	Per Hour	$193.99	NDIS Pricing Arrangements and Price Limits 2024-25
Counsellor	Per Hour	$156.16	NDIS Pricing Arrangements and Price Limits 2024-25
Dentist	Per App.	$219.00	(Canstar) How much does the dentist cost - URL: canstar.com.au
Dietitian	Per Hour	$193.99	NDIS Pricing Arrangements and Price Limits 2024-25
Dry Needling	Per App.	$120.00	(RMADN) How Much Does Dry Needling Cost? A Comprehensive Guide - URL: rmadn.com
Exercise Physiologist	Per Hour	$166.99	NDIS Pricing Arrangements and Price Limits 2024-25
Fall Prevention Class	Per Lesson	$24.00	(Healthcare Australia) Falls Prevention and Management - URL: healthcareaustralia.com.au
Hydrotherapy	Per Hour	$170.00	(Kuremara) Is Hydrotherapy Covered by the NDIS? A Complete Guide - URL: kuremara.com.au
Massage Therapist/ Myotherapist	Per App.	$91.53	(Comcare) Rates for medical and allied health treatment - URL: comcare.gov.au
MS Clinic Services	Per Hour	$119.82	NDIS Pricing Arrangements and Price Limits 2024-25
Naturopath	Per App.	$120.00	(Natural Therapy Pages) How Much Do Natural Medicine Therapies Cost? - URL: naturaltherapypages.com.au
Nursing	Per Hour	$119.82	NDIS Pricing Arrangements and Price Limits 2024-25
Occupational Therapist	Per Hour	$193.99	NDIS Pricing Arrangements and Price Limits 2024-25
Osteopathy	Per App.	$135.74	(Comcare) Rates for medical and allied health treatment - URL: comcare.gov.au
Pain Management Services	Per App.	$132.00	(Department of Health) Medical Costs Finder - URL: medicalcostsfinder.health.gov.au
Physiotherapist	Per Hour	$193.99	NDIS Pricing Arrangements and Price Limits 2024-25
Podiatrist	Per Hour	$193.99	NDIS Pricing Arrangements and Price Limits 2024-25
Psychologist	Per Hour	$222.99	NDIS Pricing Arrangements and Price Limits 2024-25
Reflexologist	Per Hour	$60.00	(Natural Therapy Pages) How much do massage therapies cost in Australia? - URL: naturaltherapypages.com.au
Social Worker	Per Hour	$193.99	NDIS Pricing Arrangements and Price Limits 2024-25
Speech Pathologist	Per Hour	$193.99	NDIS Pricing Arrangements and Price Limits 2024-25

Admission and Residential Care			
Short Admission (< 6 days)	Per Event	$6,465.00	(IHACPA) National Efficient Price Determination 2024–25 - URL: ihacpa.gov.au
Long Admission (> 5 days)	Per Event	$12,930.00	(IHACPA) National Efficient Price Determination 2024–25 - URL: ihacpa.gov.au
Residential Care	Per Day	$363.13	(IHACPA) 2023 Residential Aged Care Costing Study Final Report - URL: ihacpa.gov.au
Respite Care	Per Day	$388.92	(AIHW) People leaving aged care - URL: gen-agedcaredata.gov.au
Other			
Community and Social Activity	Per Hour	$67.56	NDIS Pricing Arrangements and Price Limits 2024-25
Employment Services	Per Hour	$67.56	NDIS Pricing Arrangements and Price Limits 2024-25
Financial Services	Per Hour	$375.00	(Acro) What is the Normal Fee for a Financial Advisor? - URL: acroaccounting.au
Group Based Activities	Per Hour	$67.56	NDIS Pricing Arrangements and Price Limits 2024-25
Plan Management *	Per Hour	$104.45	NDIS Pricing Arrangements and Price Limits 2024-25
Private Travel	Per km	$0.85	(Australian Taxation Office) Cents per kilometre method - URL: ato.gov.au

Supplementary Table 5.2: Costs for the Australian MS population

	COST PER PERSON	LOWER 95% CI	UPPER 95% CI	TOTAL COST	LOWER 95% CI	UPPER 95% CI
Direct Costs						
Pharmaceuticals and Supplements						
Disease Modifying Therapies	$15,670.89	$15,282.70	$16,059.09	$591,670,275.41	$577,013,669.75	$606,326,881.08
Other Prescription Medications	$998.82	$942.90	$1,054.75	$37,711,616.67	$35,600,196.33	$39,823,049.52
Non-Prescription Medications	$414.30	$360.04	$468.56	$15,642,308.18	$13,593,523.73	$17,691,092.62
Category Subtotal	**$17,084.02**	**$16,585.64**	**$17,582.40**	**$645,024,200.26**	**$626,207,389.80**	**$663,841,023.22**
Medical Services						
Imaging	$537.76	$530.66	$544.86	$20,303,693.10	$20,035,779.45	$20,571,606.75
Diagnostic Procedures	$44.27	$42.12	$46.42	$1,671,559.72	$1,590,456.98	$1,752,663.21
Pathology	$268.86	$266.05	$271.67	$10,151,120.41	$10,045,146.94	$10,257,093.12
Health Prof. Attendances	$955.84	$949.78	$961.89	$36,088,576.10	$35,859,905.93	$36,317,246.27
Therapeutic Procedures	$458.16	$437.90	$478.43	$17,298,378.06	$16,533,293.93	$18,063,462.20
Miscellaneous	$114.23	$111.69	$116.76	$4,312,703.38	$4,217,036.12	$4,408,370.64
Category Subtotal	**$2,379.12**	**$2,338.21**	**$2,420.02**	**$89,826,030.76**	**$88,281,619.35**	**$91,370,442.18**
Admissions and Residential Care						
Admissions	$1,711.31	$856.46	$2,566.16	$64,612,202.22	$32,336,638.85	$96,887,765.60
Residential Care	$5,066.75	$4,809.35	$5,324.14	$190,292,608.81	$180,625,744.28	$199,959,473.34
Respite Care	$93.69	$88.93	$98.45	$3,524,175.24	$3,345,147.14	$3,703,203.35
Category Subtotal	**$6,871.74**	**$5,754.75**	**$7,988.74**	**$258,428,986.28**	**$216,307,530.28**	**$300,550,442.28**

Other Expenditures						
Major Assets	$4,981.60	$2,214.19	$7,749.00	$188,085,189.64	$83,599,100.38	$292,571,278.91
Minor Assets	$1,033.08	$827.04	$1,239.12	$39,005,040.21	$31,225,694.62	$46,784,385.81
Healthcare and Other Services	$8,572.22	$7,670.84	$9,473.59	$323,652,585.73	$289,620,297.21	$357,684,874.26
Subscriptions/Memberships	$613.50	$425.01	$801.99	$23,163,423.73	$16,046,742.59	$30,280,104.87
Transport	$2,291.52	$1,619.72	$2,963.32	$86,518,671.05	$61,154,232.72	$111,883,109.37
Category Subtotal	**$17,491.92**	**$12,756.81**	**$22,227.03**	**$660,424,910.37**	**$481,646,067.52**	**$839,203,753.21**
Direct Costs Total	**$43,826.80**	**$37,435.41**	**$50,218.19**	**$1,653,704,127.67**	**$1,412,442,606.95**	**$1,894,965,660.89**
Indirect Costs						
Loss of Employment						
Transitions to Part-Time	$4,842.64	$4,596.63	$5,088.65	$182,838,712.38	$173,550,505.79	$192,126,918.97
Transitions to Unemployed	$7,801.24	$7,404.94	$8,197.54	$294,543,641.25	$279,580,824.27	$309,506,458.22
Early Permanent Retirement	$9,767.49	$9,271.30	$10,263.68	$368,781,439.70	$350,047,342.57	$387,515,536.84
Category Subtotal	**$22,411.37**	**$21,272.88**	**$23,549.87**	**$846,163,793.33**	**$803,178,672.63**	**$889,148,914.03**
Changes in Occupation						
Costs of Job Searching	$41.06	$38.97	$43.14	$1,550,202.63	$1,471,452.34	$1,628,952.93
Reductions in Earnings	$886.42	$841.39	$931.45	$33,467,515.05	$31,767,365.29	$35,167,664.81
Category Subtotal	**$927.47**	**$880.36**	**$974.59**	**$35,017,717.69**	**$33,238,817.63**	**$36,796,617.74**
Reductions in Productivity						
Presenteeism	$3,074.26	$2,918.09	$3,230.43	$116,071,688.62	$110,175,246.84	$121,968,130.41
Absenteeism	$1,492.60	$1,416.78	$1,568.43	$56,354,711.06	$53,491,891.74	$59,217,530.38
Category Subtotal	**$4,566.86**	**$4,334.86**	**$4,798.86**	**$172,426,399.69**	**$163,667,138.58**	**$181,185,660.79**
Indirect Costs Total	**$27,905.71**	**$26,488.10**	**$29,323.32**	**$1,053,607,910.70**	**$1,000,084,628.84**	**$1,107,131,192.56**
Informal Care	**$7,848.84**	**$7,450.12**	**$8,247.56**	**$296,340,742.21**	**$281,286,632.50**	**$311,394,851.91**
Grand Total	**$79,581.34**	**$71,373.62**	**$87,789.07**	**$3,003,652,780.58**	**$2,693,813,868.29**	**$3,313,491,705.37**

Supplementary Table 5.3: Costs by sex

	MALE		FEMALE	
	PER PERSON	OVERALL	PER PERSON	OVERALL
Direct Costs				
Pharmaceuticals and Supplements				
Disease Modifying Therapies	$14,069.73	$108,308,804.60	$16,089.00	$483,603,203.37
Other Prescription Medications	$1,066.71	$8,211,543.64	$981.10	$29,489,823.94
Non-Prescription Medications	$194.80	$1,499,608.82	$469.64	$14,116,478.89
Category Subtotal	**$15,331.25**	**$118,019,957.06**	**$17,539.74**	**$527,209,506.20**
Medical Services				
Imaging	$481.86	$3,709,368.90	$552.44	$16,605,281.60
Diagnostic Procedures	$45.14	$347,488.64	$44.04	$1,323,901.80
Pathology	$258.86	$1,992,716.84	$271.49	$8,160,363.67
Health Prof. Attendances	$921.72	$7,095,410.52	$964.80	$28,999,852.91
Therapeutic Procedures	$439.94	$3,386,692.49	$462.95	$13,915,256.65
Miscellaneous	$104.24	$802,461.54	$116.85	$3,512,198.66
Category Subtotal	**$2,251.77**	**$17,334,138.93**	**$2,412.56**	**$72,516,855.30**
Admissions and Residential Care				
Admissions	$4,101.91	$31,576,464.81	$1,093.84	$32,878,682.93
Residential Care	$7,415.92	$57,087,782.64	$4,431.59	$133,204,826.17
Respite Care	$137.34	$1,057,252.57	$137.11	$2,349,215.22
Category Subtotal	**$11,655.17**	**$89,721,500.03**	**$5,662.54**	**$168,432,724.31**
Other Expenditures				
Major Assets	$7,631.42	$58,746,707.86	$6,030.69	$181,270,626.91
Minor Assets	$1,297.12	$9,985,258.56	$961.04	$28,887,073.49
Healthcare and Other Services	$5,273.92	$40,598,640.00	$9,395.33	$282,404,737.76
Subscriptions/ Memberships	$221.78	$1,707,257.24	$713.29	$21,439,928.51
Transport	$1,537.59	$11,836,357.28	$2,480.69	$74,564,462.61
Category Subtotal	**$15,961.84**	**$122,874,220.94**	**$19,581.04**	**$588,566,829.29**
Direct Costs Total	**$45,200.03**	**$347,949,816.96**	**$45,195.88**	**$1,356,725,915.10**

Indirect Costs				
Loss of Employment				
Transitions to Part-Time	$1,991.70	$15,333,009.16	$5,588.14	$167,965,770.34
Transitions to Unemployed	$4,978.72	$38,328,384.28	$8,452.07	$254,048,509.17
Early Permanent Retirement	$12,125.62	$93,348,490.71	$9,204.15	$276,654,309.69
Category Subtotal	**$19,096.04**	**$147,009,884.14**	**$23,244.36**	**$698,668,589.19**
Changes in Occupation				
Costs of Job Searching	$51.04	$392,946.41	$38.68	$1,162,494.98
Reductions in Earnings	$1,023.82	$6,062,955.63	$1,185.26	$27,404,559.43
Category Subtotal	**$1,074.86**	**$6,455,902.03**	**$1,223.93**	**$28,567,054.41**
Reductions in Productivity				
Presenteeism	$2,695.32	$20,749,773.03	$2,871.30	$86,304,121.53
Absenteeism	$1,379.68	$10,621,410.94	$1,299.05	$39,046,214.81
Category Subtotal	**$4,075.00**	**$31,371,183.97**	**$4,170.34**	**$125,350,336.34**
Indirect Costs Total	**$24,245.91**	**$184,836,970.14**	**$28,638.64**	**$852,585,979.93**
Informal Care	**$8,647.03**	**$66,568,684.33**	**$7,640.73**	**$229,661,786.16**
Grand Total	**$78,092.96**	**$599,355,471.44**	**$81,475.26**	**$2,438,973,681.19**

Supplementary Table 5.4: Costs by disability severity

	NO DISABILITY		MILD DISABILITY		MODERATE DISABILITY		SEVERE DISABILITY	
	PER PERSON	OVERALL	PER PERSON	OVERALL	PER PERSON	OVERALL	PER PERSON	OVERALL
Direct Costs								
Pharmaceuticals and Supplements								
Disease Modifying Therapies	$17,029.65	$166,975,741.14	$17,527.01	$247,236,031.93	$17,878.57	$125,614,838.90	$11,541.08	$80,660,626.56
Other Prescription Medications	$120.51	$175,150,309.43	$644.24	$9,087,680.14	$1,059.12	$7,441,398.12	$1,436.20	$10,037,567.17
Non-Prescription Medications	$81.76	$798,036.52	$490.19	$6,883,618.57	$426.28	$2,981,599.61	$711.85	$4,952,833.02
Category Subtotal	$17,231.92	$342,924,087.09	$18,661.44	$263,207,330.64	$19,363.97	$136,037,836.62	$13,689.13	$95,651,026.76
Medical Services								
Imaging	$481.83	$4,724,385.53	$593.40	$8,370,516.71	$916.59	$6,439,966.84	$760.78	$5,317,102.32
Diagnostic Procedures	$31.42	$308,043.82	$44.42	$626,566.14	$74.68	$524,724.71	$66.96	$467,986.53
Pathology	$229.61	$2,251,361.74	$271.48	$3,829,432.34	$396.21	$2,783,791.99	$450.19	$3,146,408.14
Health Prof. Attendances	$716.65	$7,026,716.38	$889.39	$12,545,746.40	$1,573.80	$11,057,532.99	$1,827.99	$12,775,820.25
Therapeutic Procedures	$460.76	$4,517,712.18	$414.83	$5,851,559.43	$667.15	$4,687,427.82	$782.44	$5,468,472.10
Miscellaneous	$91.07	$892,980.98	$138.93	$1,959,771.83	$197.33	$1,386,460.50	$147.79	$1,032,888.53
Category Subtotal	**$2,011.34**	**$19,721,200.65**	**$2,352.45**	**$33,183,592.86**	**$3,825.78**	**$26,879,904.85**	**$4,036.15**	**$28,208,677.85**

Admissions and Residential Care								
Admissions	$326.73	$3,189,228.97	$598.43	$8,403,643.58	$3,316.31	$23,195,956.73	$4,263.83	$29,666,318.46
Residential Care	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$27,350.04	$190,292,608.81
Respite Care	$0.00	$0.00	$0.00	$0.00	$151.15	$1,057,252.57	$354.56	$2,466,922.67
Category Subtotal	**$326.73**	**$3,189,228.97**	**$598.43**	**$8,403,643.58**	**$3,467.47**	**$24,253,209.30**	**$31,968.43**	**$222,425,849.94**
Other Expenditures								
Major Assets	$112.92	$1,102,172.47	$6,145.06	$86,293,701.76	$7,167.29	$50,131,665.44	$7,228.19	$50,291,405.58
Minor Assets	$3.60	$35,171.91	$280.93	$3,944,967.82	$1,404.63	$9,824,695.88	$3,602.86	$25,067,496.44
Healthcare and Other Services	$1,164.81	$11,369,815.48	$5,651.11	$79,357,266.25	$15,676.04	$109,646,174.03	$17,625.16	$122,630,122.01
Subscriptions/ Memberships	$261.98	$2,557,238.01	$630.89	$8,859,507.41	$1,238.57	$8,663,218.64	$440.84	$3,067,221.70
Transport	$825.86	$8,061,240.51	$1,649.39	$23,161,948.54	$4,706.05	$32,916,502.29	$3,199.51	$22,261,128.55
Category Subtotal	**$2,369.18**	**$23,125,638.38**	**$14,357.38**	**$201,617,391.79**	**$30,192.59**	**$211,182,256.26**	**$32,096.56**	**$223,317,374.28**
Direct Costs Total	**$21,939.17**	**$388,960,155.08**	**$35,969.70**	**$506,411,958.88**	**$56,849.80**	**$398,353,207.05**	**$81,790.27**	**$569,602,928.83**
Indirect Costs								
Loss of Employment								
Transitions to Part-Time	$5,659.99	$44,631,932.62	$6,504.29	$91,747,120.41	$2,832.31	$19,900,953.79	$1,302.78	$9,104,678.78
Transitions to Unemployed	$4,551.85	$55,497,561.63	$5,871.52	$64,206,738.65	$10,929.46	$76,794,657.65	$12,525.57	$87,536,632.27
Early Permanent Retirement	$5,957.91	$58,418,726.59	$10,256.11	$144,669,020.71	$10,740.78	$75,468,911.56	$12,223.16	$85,423,220.08
Category Subtotal	**$16,169.76**	**$158,548,220.84**	**$22,631.92**	**$300,622,879.77**	**$24,502.55**	**$172,164,523.00**	**$26,051.51**	**$182,064,531.13**

Changes in Occupation								
Costs of Job Searching	$18.43	$180,685.72	$64.42	$908,697.10	$52.78	$370,868.57	$17.82	$124,558.15
Reductions in Earnings	$599.62	$5,879,428.32	$1,722.83	$24,301,637.05	$1,059.90	$7,447,275.87	$841.28	$5,879,428.32
Category Subtotal	$618.05	$6,060,114.04	$1,787.25	$25,210,334.16	$1,112.68	$7,818,144.45	$859.11	$6,003,986.47
Reductions in Productivity								
Presenteeism	$1,249.43	$12,250,912.45	$5,229.61	$73,766,967.02	$4,253.24	$29,884,946.56	$1,141.90	$7,980,341.34
Absenteeism	$895.09	$8,776,531.88	$2,324.37	$32,786,744.65	$1,865.66	$13,108,851.37	$294.84	$2,060,517.84
Category Subtotal	**$2,144.51**	**$21,027,444.33**	**$7,553.98**	**$106,553,711.68**	**$6,118.90**	**$42,993,797.94**	**$1,436.74**	**$10,040,859.18**
Indirect Costs Total	**$18,932.32**	**$185,635,779.21**	**$31,973.15**	**$432,386,925.60**	**$31,734.14**	**$222,976,465.38**	**$28,347.36**	**$198,109,376.77**
Informal Care	**$1,816.22**	**$17,808,502.82**	**$1,816.22**	**$25,619,009.07**	**$10,743.70**	**$75,489,461.81**	**$25,642.24**	**$179,204,276.22**
Grand Total	**$42,687.71**	**$592,404,437.12**	**$69,759.08**	**$964,417,893.54**	**$99,328**	**$696,819,134**	**$135,780**	**$946,916,582**

Supplementary Table 5.5: Costs by type of MS

	RELAPSING-REMITTING MS		SECONDARY PROGRESSIVE MS		PRIMARY PROGRESSIVE MS	
	PER PERSON	OVERALL	PER PERSON	OVERALL	PER PERSON	OVERALL
Direct Costs						
Pharmaceuticals and Supplements						
Disease Modifying Therapies	$18,602.09	$440,516,176.62	$14,987.86	$91,785,681.23	$10,391.08	$52,454,187.63
Other Prescription Medications	$655.22	$15,516,290.04	$1,110.58	$6,801,176.76	$887.04	$4,477,756.85
Non-Prescription Medications	$360.49	$8,536,685.29	$589.59	$3,610,647.38	$687.15	$3,468,755.04
Category Subtotal	$19,617.80	$464,569,151.96	$16,688.03	$102,197,505.37	$11,965.27	$60,400,699.52
Medical Services						
Imaging	$584.18	$13,833,856.05	$496.38	$3,039,844.47	$472.84	$2,386,900.02
Diagnostic Procedures	$39.18	$927,710.59	$54.78	$335,499.94	$40.80	$205,961.67
Pathology	$268.48	$6,357,968.56	$290.33	$1,777,983.58	$224.74	$1,134,478.94
Health Prof. Attendances	$893.57	$21,160,647.00	$1,116.32	$6,836,317.64	$935.02	$4,719,981.38
Therapeutic Procedures	$418.92	$9,920,463.64	$498.47	$3,052,608.48	$499.95	$2,523,745.09
Miscellaneous	$123.49	$2,924,276.64	$116.10	$710,994.96	$101.83	$514,046.45
Category Subtotal	$2,327.81	$55,124,922.48	$2,572.38	$15,753,249.06	$2,275.18	$11,485,113.55
Admissions and Residential Care						
Admissions	$938.14	$22,216,156.57	$2,953.41	$18,086,695.76	$4,784.53	$24,152,295.41
Residential Care	$1,557.74	$39,961,447.85	$14,628.88	$97,049,230.49	$9,743.50	$53,281,930.47
Respite Care	$28.85	$740,076.80	$270.92	$1,797,329.37	$180.45	$986,769.07
Category Subtotal	**$2,524.73**	**$62,917,681.22**	**$17,853.22**	**$116,933,255.63**	**$14,708.47**	**$78,420,994.95**

Other Expenditures						
Major Assets	$5,779.31	$136,859,948.33	$11,014.55	$67,453,076.36	$4,163.61	$21,017,904.20
Minor Assets	$401.80	$9,515,007.35	$3,678.86	$22,529,353.29	$1,352.61	$6,827,971.40
Healthcare and Other Services	$5,568.46	$131,866,808.36	$22,132.15	$135,537,277.89	$11,014.12	$55,599,291.51
Subscriptions/ Memberships	$607.84	$14,394,197.92	$1,020.81	$6,251,461.04	$495.55	$2,501,526.79
Transport	$1,766.80	$41,839,676.89	$3,343.70	$20,476,833.81	$4,771.06	$24,084,309.19
Category Subtotal	**$14,124.22**	**$334,475,638.86**	**$41,190.07**	**$252,248,002.40**	**$21,796.95**	**$110,031,003.09**
Direct Costs Total	**$38,594.57**	**$917,087,394.51**	**$78,303.70**	**$487,132,012.46**	**$50,745.87**	**$260,337,811.11**
Indirect Costs						
Loss of Employment						
Transitions to Part-Time	$6,286.07	$148,857,688.23	$3,254.44	$19,930,243.70	$3,008.67	$15,187,687.38
Transitions to Unemployed	$6,965.77	$164,953,243.28	$11,552.36	$70,746,923.08	$8,144.89	$41,115,196.52
Early Permanent Retirement	$9,242.94	$218,877,938.24	$10,940.03	$66,996,973.19	$9,957.97	$50,267,594.80
Category Subtotal	**$22,494.77**	**$532,688,869.75**	**$25,746.82**	**$157,674,139.97**	**$21,111.52**	**$106,570,478.70**
Changes in Occupation						
Costs of Job Searching	$48.84	$1,156,482.25	$20.84	$127,628.32	$41.55	$209,739.91
Reductions in Earnings	$1,417.33	$33,563,136.52	$744.27	$4,557,956.81	$1,067.10	$5,386,676.23
Category Subtotal	**$1,466.17**	**$34,719,618.78**	**$765.12**	**$4,685,585.13**	**$1,108.65**	**$5,596,416.14**

Reductions in Productivity						
Presenteeism	$3,634.71	$86,071,923.88	$1,997.83	$12,234,776.27	$3,298.02	$16,648,348.41
Absenteeism	$1,708.00	$40,446,442.17	$1,408.12	$8,623,341.73	$471.75	$2,381,390.46
Category Subtotal	**$5,342.71**	**$126,518,366.05**	**$3,405.95**	**$20,858,118.01**	**$3,769.78**	**$19,029,738.87**
Indirect Costs Total	**$29,303.65**	**$693,926,854.57**	**$29,917.89**	**$183,217,843.11**	**$25,989.94**	**$131,196,633.71**
Informal Care	**$3,950.98**	**$93,561,547.90**	**$17,431.91**	**$106,753,405.13**	**$14,859.04**	**$75,008,071.34**
Grand Total	**$71,849.20**	**$1,704,575,796.99**	**$125,653.50**	**$777,103,260.71**	**$91,594.85**	**$466,542,516.16**

Supplementary Table 5.6: Costs by disease duration

	0-10 YEARS (MEAN AGE OF 49)		11-20 YEARS (MEAN AGE OF 58)		>20 YEARS (MEAN AGE OF 65)	
	PER PERSON	OVERALL	PER PERSON	OVERALL	PER PERSON	OVERALL
Direct Costs						
Pharmaceuticals and Supplements						
Disease Modifying Therapies	$20,785.99	$131,450,573.49	$17,323.48	$247,691,123.00	$13,916.87	$238,451,665.23
Other Prescription Medications	$653.16	$4,130,606.09	$721.36	$10,313,936.85	$888.67	$15,226,454.31
Non-Prescription Medications	$289.23	$1,829,076.43	$431.35	$6,167,372.09	$444.71	$7,619,639.19
Category Subtotal	**$21,728.38**	**$137,410,256.01**	**$18,476.18**	**$264,172,431.94**	**$15,250.25**	**$261,297,758.73**
Medical Services						
Imaging	$635.80	$4,020,812.34	$529.16	$7,565,906.56	$526.70	$9,024,414.08
Diagnostic Procedures	$26.24	$165,949.76	$40.00	$571,945.09	$49.16	$842,336.53
Pathology	$320.61	$2,027,560.70	$252.53	$3,610,635.42	$250.22	$4,287,252.58
Health Prof. Attendances	$858.25	$5,427,601.89	$871.43	$12,459,669.12	$996.52	$17,074,326.11
Therapeutic Procedures	$517.09	$3,270,084.16	$375.17	$5,364,189.33	$499.56	$8,559,388.42
Miscellaneous	$160.94	$1,017,762.20	$120.25	$1,719,393.59	$97.18	$1,665,039.33
Category Subtotal	**$2,518.94**	**$15,929,771.05**	**$2,188.54**	**$31,291,739.11**	**$2,419.33**	**$41,452,757.05**
Admissions and Residential Care						
Admissions	$1,076.74	$6,809,290.96	$1,478.07	$21,133,503.13	$2,135.94	$36,597,193.06
Residential Care	$1,002.02	$6,336,743.87	$3,992.71	$57,087,782.64	$7,403.35	$126,849,053.03
Respite Care	$18.56	$117,355.04	$73.94	$1,057,252.57	$137.11	$2,349,215.22
Category Subtotal	**$2,097.31**	**$13,263,389.87**	**$5,544.73**	**$79,278,538.35**	**$9,676.40**	**$165,795,461.31**

Other Expenditures						
Major Assets	$4,306.55	$27,234,606.23	$4,380.17	$62,627,698.48	$8,763.57	$150,155,030.08
Minor Assets	$737.03	$4,660,947.25	$770.08	$11,010,569.56	$1,354.08	$23,200,815.24
Healthcare and Other Services	$6,020.64	$38,074,512.32	$9,023.27	$129,014,752.24	$9,023.27	$129,014,752.24
Subscriptions/Memberships	$474.63	$3,001,558.68	$753.93	$10,779,638.37	$546.63	$9,365,988.70
Transport	$1,661.64	$10,508,184.75	$2,548.63	$36,440,242.52	$2,302.58	$39,452,392.62
Category Subtotal	**$13,200.48**	**$83,479,809.23**	**$17,476.07**	**$249,872,901.17**	**$21,990.14**	**$351,188,978.87**
Direct Costs Total	**$39,545.10**	**$250,083,226.15**	**$43,685.52**	**$624,615,610.57**	**$49,336.11**	**$819,734,955.97**
Indirect Costs						
Loss of Employment						
Transitions to Part-Time	$6,568.45	$41,539,715.87	$4,765.27	$68,134,790.36	$3,421.55	$58,623,679.85
Transitions to Unemployed	$3,473.42	$21,966,371.55	$8,200.69	$117,255,106.50	$7,364.73	$126,184,880.61
Early Permanent Retirement	$7,578.63	$47,928,243.99	$9,508.28	$135,951,271.51	$11,951.15	$204,767,087.58
Category Subtotal	**$17,620.50**	**$111,434,331.41**	**$22,474.24**	**$321,341,168.37**	**$22,737.43**	**$389,575,648.04**
Changes in Occupation						
Costs of Job Searching	$104.44	$660,491.04	$33.74	$482,481.84	$19.89	$340,845.30
Reductions in Earnings	$1,984.51	$12,550,318.14	$1,430.42	$20,452,370.31	$1,003.79	$17,198,584.12
Category Subtotal	**$2,088.95**	**$13,210,809.18**	**$1,464.16**	**$20,934,852.15**	**$1,023.68**	**$17,539,429.42**
Reductions in Productivity						
Presenteeism	$5,923.23	$37,459,245.85	$3,469.93	$49,613,751.49	$1,631.91	$27,960,545.29
Absenteeism	$2,405.05	$15,209,879.99	$1,543.82	$22,073,827.35	$601.29	$10,302,364.94
Category Subtotal	**$8,328.28**	**$52,669,125.84**	**$5,013.75**	**$71,687,578.84**	**$2,233.20**	**$38,262,910.23**
Indirect Costs Total	**$28,037.73**	**$177,314,266.44**	**$28,952.15**	**$413,963,599.36**	**$25,994.31**	**$445,377,987.69**
Informal Care	**$2,655.63**	**$27,161,815.86**	**$6,722.95**	**$96,126,020.16**	**$10,221.93**	**$175,139,131.96**
Grand Total	**$70,238.47**	**$454,559,308.45**	**$79,360.62**	**$1,134,705,230.10**	**$85,552.35**	**$1,440,252,075.62**

Supplementary Table 5.7a: Costs by state of residence – Part 1

	NEW SOUTH WALES		VICTORIA		QUEENSLAND	
	PER PERSON	OVERALL	PER PERSON	OVERALL	PER PERSON	OVERALL
Direct Costs						
Pharmaceuticals and Supplements						
Disease Modifying Therapies	$16,299.26	$183,692,694.44	$16,420.33	$198,456,076.63	$16,233.98	$98,345,454.13
Other Prescription Medications	$722.82	$8,146,218.69	$738.22	$8,922,074.72	$771.16	$4,671,685.16
Non-Prescription Medications	$408.46	$4,603,302.31	$420.48	$5,081,907.03	$433.03	$2,623,309.06
Category Subtotal	**$17,430.54**	**$196,442,215.45**	**$17,579.02**	**$212,460,058.39**	**$17,438.17**	**$105,640,448.35**
Medical Services						
Imaging	$518.31	$5,445,448.88	$548.53	$5,839,956.02	$546.72	$5,725,796.75
Diagnostic Procedures	$39.66	$410,677.87	$41.84	$439,507.75	$41.98	$433,037.18
Pathology	$249.30	$2,582,137.74	$261.92	$2,754,445.42	$263.14	$2,716,144.83
Health Prof. Attendances	$883.16	$8,901,983.98	$923.44	$9,458,141.08	$935.38	$9,389,641.79
Therapeutic Procedures	$424.53	$4,320,906.49	$444.53	$4,592,085.39	$446.97	$4,533,696.79
Miscellaneous	$110.77	$1,186,951.75	$117.77	$1,278,225.07	$116.98	$1,249,766.59
Category Subtotal	**$2,225.73**	**$22,848,106.71**	**$2,338.02**	**$24,362,360.71**	**$2,351.18**	**$24,048,083.92**
Admissions and Residential Care						
Admissions	$1,696.93	$19,124,385.93	$1,693.71	$20,470,174.09	$1,817.68	$11,011,483.70
Residential Care	$5,256.68	$59,242,754.42	$4,821.81	$58,276,417.39	$5,716.16	$34,628,485.52
Respite Care	$94.25	$1,062,210.29	$91.06	$1,100,579.12	$102.69	$622,076.06
Category Subtotal	**$7,047.86**	**$79,429,350.64**	**$6,606.58**	**$79,847,170.60**	**$7,636.52**	**$46,262,045.28**

Other Expenditures						
Major Assets	$4,856.46	$54,732,321.53	$5,100.71	$61,647,120.81	$5,214.76	$31,590,998.32
Minor Assets	$1,036.54	$11,681,751.59	$1,013.18	$12,245,290.71	$1,125.64	$6,819,110.26
Healthcare and Other Services	$8,439.33	$95,111,262.91	$8,593.49	$103,860,935.76	$9,045.49	$54,797,555.12
Subscriptions/Memberships	$596.98	$6,727,926.73	$624.82	$7,551,582.89	$623.55	$3,777,462.80
Transport	$2,246.76	$25,320,970.69	$2,305.06	$27,859,015.29	$2,367.15	$14,340,217.42
Category Subtotal	**$17,176.06**	**$193,574,233.45**	**$17,637.26**	**$213,163,945.47**	**$18,376.58**	**$111,325,343.93**
Direct Costs Total	**$43,880.19**	**$492,293,906.26**	**$44,160.89**	**$529,833,535.17**	**$45,802.45**	**$287,275,921.47**
Indirect Costs						
Loss of Employment						
Transitions to Part-Time	$4,636.20	$52,249,985.81	$4,693.70	$56,728,024.85	$4,534.42	$27,469,489.20
Transitions to Unemployed	$7,657.86	$86,304,068.53	$7,687.58	$92,912,054.31	$7,923.79	$48,002,299.74
Early Permanent Retirement	$9,525.56	$107,353,058.77	$9,676.64	$116,951,896.56	$9,797.53	$59,353,460.74
Category Subtotal	$21,819.62	$245,907,113.11	$22,057.92	$266,591,975.72	$22,255.74	$134,825,249.68
Changes in Occupation						
Costs of Job Searching	$40.70	$458,645.89	$43.12	$521,098.35	$42.19	$255,584.26
Reductions in Earnings	$1,127.33	$12,705,023.54	$1,176.21	$14,215,682.64	$1,161.91	$7,038,870.33
Category Subtotal	**$1,168.03**	**$13,163,669.43**	**$1,219.33**	**$14,736,780.99**	**$1,204.10**	**$7,294,454.59**
Reductions in Productivity						
Presenteeism	$3,171.23	$35,739,761.46	$3,382.00	$40,874,884.66	$3,300.01	$19,991,441.11
Absenteeism	$1,458.59	$16,438,329.24	$1,541.46	$18,630,075.37	$1,493.67	$9,048,664.39
Category Subtotal	**$4,629.82**	**$52,178,090.70**	**$4,923.46**	**$59,504,960.03**	**$4,793.68**	**$29,040,105.50**
Indirect Costs Total	**$27,617.47**	**$311,248,873.24**	**$28,200.70**	**$340,833,716.74**	**$28,253.52**	**$171,159,809.76**
Informal Care	**$7,937.36**	**$89,454,048.99**	**$7,703.15**	**$93,100,290.80**	**$8,484.23**	**$51,397,462.32**
Grand Total	**$79,435.02**	**$892,996,828.48**	**$80,064.74**	**$963,767,542.70**	**$82,540.20**	**$509,833,193.55**

Supplementary Table 5.7b: Costs by state of residence – Part 2

	SOUTH AUSTRALIA		WESTERN AUSTRALIA		TASMANIA	
	PER PERSON	OVERALL	PER PERSON	OVERALL	PER PERSON	OVERALL
Direct Costs						
Pharmaceuticals and Supplements						
Disease Modifying Therapies	$16,385.18	$50,564,665.40	$16,196.15	$47,778,644.87	$16,541.86	$19,105,850.57
Other Prescription Medications	$690.52	$2,130,944.52	$715.44	$2,110,556.48	$774.56	$894,613.50
Non-Prescription Medications	$396.47	$1,223,499.23	$402.54	$464,937.65	$430.41	$312,048.88
Category Subtotal	**$17,472.17**	**$53,919,109.15**	**$17,314.14**	**$50,354,138.99**	**$17,746.83**	**$20,312,512.94**
Medical Services						
Imaging	$541.68	$5,753,782.59	$538.23	$5,581,957.78	$554.36	$5,797,956.46
Diagnostic Procedures	$40.89	$429,216.79	$40.84	$417,764.18	$42.62	$439,319.44
Pathology	$259.77	$2,723,538.21	$260.23	$2,659,229.20	$262.42	$2,719,002.27
Health Prof. Attendances	$908.02	$9,291,876.86	$917.05	$9,133,595.95	$934.38	$9,411,573.88
Therapeutic Procedures	$446.80	$4,603,253.26	$449.69	$4,520,750.79	$442.40	$4,505,067.56
Miscellaneous	$115.18	$1,247,285.01	$113.70	$1,202,261.37	$119.61	$1,274,237.42
Category Subtotal	**$2,312.34**	**$24,048,952.72**	**$2,319.73**	**$23,515,559.28**	**$2,355.79**	**$24,147,157.03**
Admissions and Residential Care						
Admissions	$1,582.90	$4,884,824.41	$1,703.93	$1,968,033.85	$1,822.19	$1,321,087.14
Residential Care	$4,786.26	$14,770,388.32	$5,642.31	$6,516,871.46	$4,458.06	$3,232,090.81
Respite Care	$85.66	$264,342.52	$97.13	$112,190.10	$95.58	$69,297.09
Category Subtotal	**$6,454.81**	**$19,919,555.25**	**$7,443.37**	**$8,597,095.41**	**$6,375.83**	**$4,622,475.04**

Other Expenditures						
Major Assets	$4,684.64	$14,456,794.02	$4,710.83	$5,441,008.68	$5,396.68	$3,912,592.12
Minor Assets	$954.59	$2,945,862.76	$1,060.90	$1,225,343.28	$1,049.05	$760,564.44
Healthcare and Other Services	$7,966.58	$24,584,853.12	$8,358.68	$9,654,278.71	$9,231.15	$6,692,581.13
Subscriptions/Memberships	$581.88	$1,795,686.22	$576.80	$666,202.41	$679.64	$492,738.93
Transport	$2,151.05	$6,638,140.03	$2,205.73	$2,547,615.62	$2,505.06	$1,816,166.74
Category Subtotal	**$16,338.73**	**$50,421,336.15**	**$16,912.94**	**$19,534,448.70**	**$18,861.58**	**$13,674,643.36**
Direct Costs Total	**$42,578.05**	**$148,308,953.27**	**$43,990.18**	**$102,001,242.38**	**$45,340.02**	**$62,756,788.36**
Indirect Costs						
Loss of Employment						
Transitions to Part-Time	$4,767.17	$14,711,497.15	$4,593.19	$13,549,896.27	$4,573.22	$5,282,069.32
Transitions to Unemployed	$7,430.13	$22,929,376.96	$7,648.35	$22,562,621.88	$7,962.36	$9,196,521.87
Early Permanent Retirement	$9,386.59	$28,967,017.47	$9,441.47	$27,852,330.20	$9,856.75	$11,384,545.59
Category Subtotal	**$21,583.89**	**$66,607,891.58**	**$21,683.00**	**$63,964,848.35**	**$22,392.33**	**$25,863,136.78**
Changes in Occupation						
Costs of Job Searching	$40.65	$125,446.66	$39.08	$115,293.68	$44.91	$51,876.62
Reductions in Earnings	$1,128.05	$3,481,155.22	$1,096.83	$3,235,644.20	$1,193.59	$1,378,601.23
Category Subtotal	**$1,168.70**	**$3,606,601.88**	**$1,135.91**	**$3,350,937.88**	**$1,238.51**	**$1,430,477.86**
Reductions in Productivity						
Presenteeism	$3,167.70	$9,775,511.05	$3,030.42	$8,939,736.24	$3,540.30	$4,089,045.04
Absenteeism	$1,468.77	$4,532,613.88	$1,401.58	$4,134,649.80	$1,599.17	$1,847,039.31
Category Subtotal	**$4,636.46**	**$14,308,124.92**	**$4,432.00**	**$13,074,386.04**	**$5,139.47**	**$5,936,084.35**
Indirect Costs Total	**$27,389.05**	**$84,522,618.38**	**$27,250.91**	**$80,390,172.27**	**$28,770.30**	**$33,229,698.98**
Informal Care	**$7,380.25**	**$22,775,449.29**	**$8,148.14**	**$24,037,014.98**	**$7,931.73**	**$9,161,153.41**
Grand Total	**$77,347.36**	**$255,607,020.95**	**$79,389.23**	**$206,428,429.63**	**$82,042.06**	**$105,147,640.76**

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