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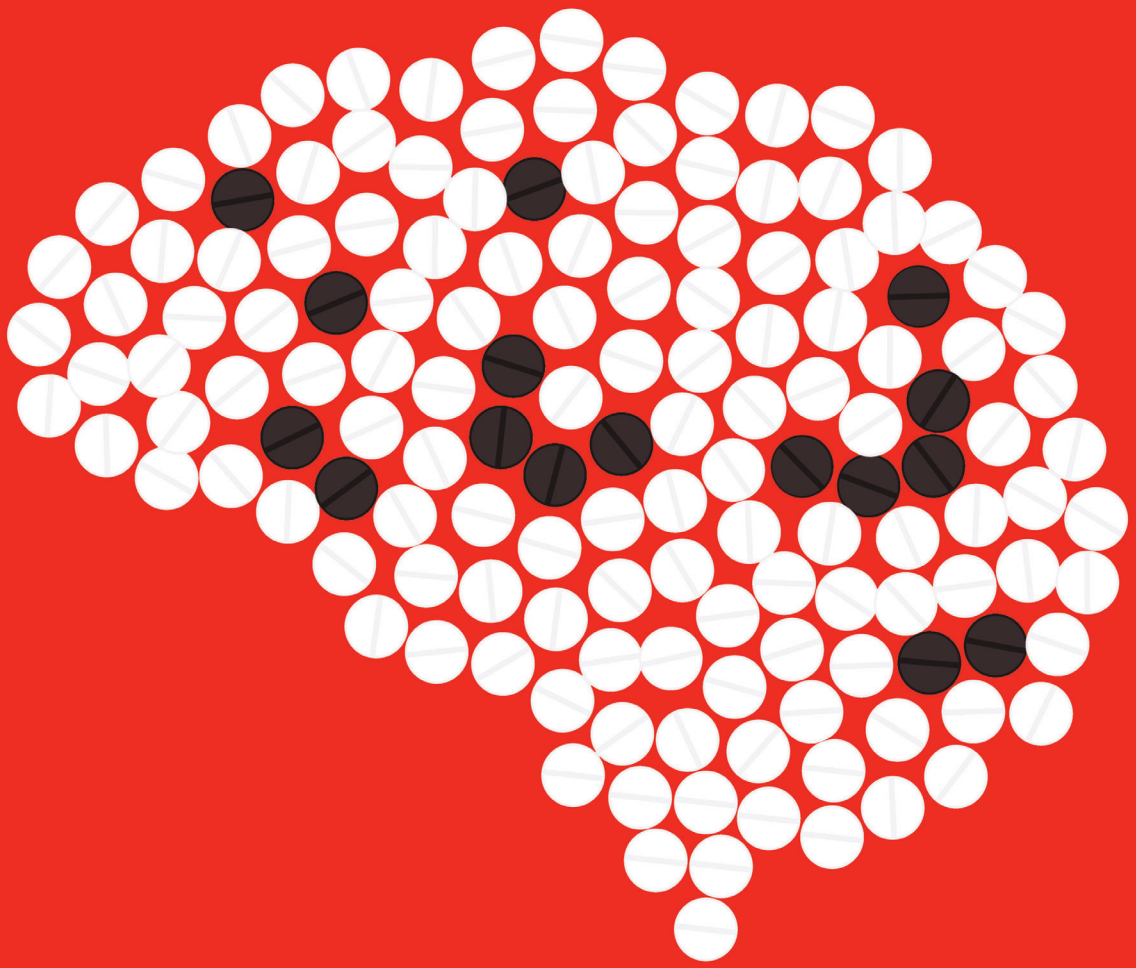

Health Economic Impact of Multiple Sclerosis in Australia in 2017

An analysis of MS Research Australia's platform – the Australian MS Longitudinal Study (AMSLS)

This Report is a MS Research Australia initiative and was generously supported by an unconditional grant provided to MS Research Australia by Merck Australia.

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

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Published August, 2018

Acknowledgements
There are many people to thank who assisted in some way in the preparation of this report. We would like to thank all the people with MS who participated in the AMSLS surveys and cost diaries – this valuable data informed the comprehensiveness of this report. We would also like to thank Associate Professor Ingrid van der Mei's wonderfully dedicated team who managed the AMSLS survey design, management and data entry including Dr Kirsty Hawkes, Carol Hurst, Alice Saul, Bronwyn Weaver-Pirie, Furley Johnston, Heather Chaplin, Mithun Rajshekar, Carol Ingram, Dot Melross and Wendy Davidson.
Thank you to MS Research Australia for establishing and supporting the AMSLS over 16 years, and the MS Societies for providing data for the age-adjustments of the prevalence in Chapter 2.

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Executive Summary

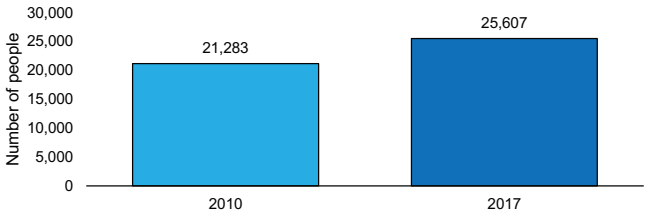
Multiple Sclerosis (MS) is an autoimmune disease in which the myelin sheath covering nerve fibres in the central nervous system (brain, optic nerves and spinal cord) is damaged, leading to impairment of cognitive, motor and/or sensory functions.[1, 2] MS has a substantial effect on health and wellbeing, as well as being a major economic burden to people with MS, their caregivers and family members. Progress in research and therapeutics has transformed the MS treatment landscape over the past few years, which has health economic consequences for MS in Australia.

In this report, we have set out to provide a comprehensive landscape analysis of MS in Australia, and how that landscape has changed since 2010. The report aimed to provide an up to date prevalence of MS in Australia for 2017, estimate the costs of MS in Australia from an individual and societal perspective, and assess the impact of MS on QoL using the latest available data and updated methodologies.

Using a previously published method of estimating Australian prevalence of MS using data from the Pharmaceutical Benefits Scheme on prescriptions of MS disease modifying therapies (DMTs), that takes in to account the proportion of people with MS who use DMTs, we found that the number of people in Australia affected by MS in December 2017 was 25,607 (95% confidence interval [CI]: 24,874–26,478).

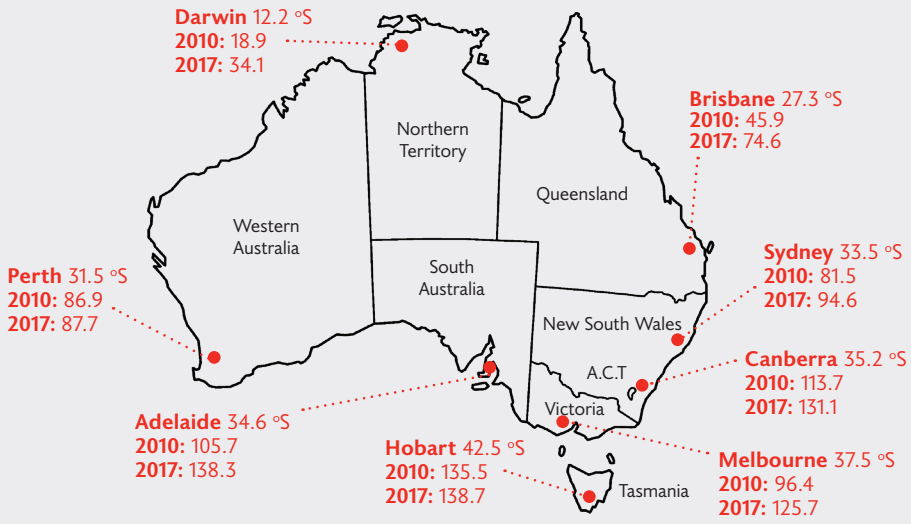
The prevalence of **MS is highest in Tasmania,** and almost double that of Queensland and Western Australia.

Figure I. Number of people living with MS in Australia



This was an increase of 4,324 people with MS from 2010. The overall Australian prevalence of MS in 2017 was 103.7 people with MS per 100,000 people, compared to the 2010 prevalence of 95.5 people with MS per 100,000 people.

Figure II. The age-adjusted prevalence per 100,000 people for the Australian states and territories.



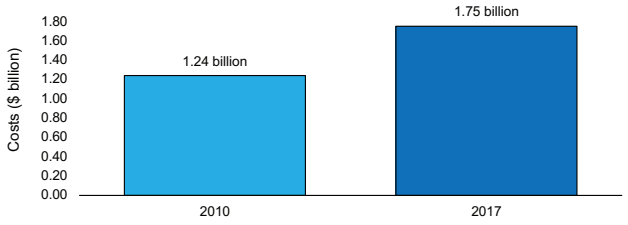
The cost analysis was based mainly on data from the Economic Impact Survey 2016 (EIS 2016, hereafter) of the Australian Multiple Sclerosis Longitudinal Study (AMSLS). The AMSLS is a validated, representative sample of over 3,000 Australian people with MS who complete regular patient-reported outcome surveys. The EIS 2016 consisted of a baseline survey (3,163 active participants invited, 1,577 [49.9%] responded), and a cost diary (3,163 active participants invited, 488 [15.5%] responded). The EIS 2016 captured detailed information on various cost categories (direct and indirect) related to the management of MS and established the health, employment, and financial profiles of people with MS.

Overall, the availability of such a large, comprehensive and representative dataset provided the opportunity to determine the updated estimates of costs of MS in Australia from an individual and societal perspective. It also enabled the rigorous assessment of the impact of MS on QoL through health state utility values (HSUVs). We have segregated the costs and QoL/HSUV estimates in this report by disability severity (classified as no, mild, moderate, and severe), sex, age group, state/territory and geographical remoteness of residence, MS type, and DMT usage.

The economic cost of MS to the community is a staggering **$1.75 billion.**

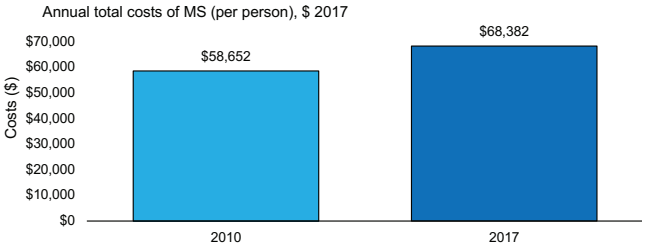
The total costs for all people with MS in Australia in 2017 were $1.75 billion (2017 Australian dollars), which is an increase of $0.51 billion compared to the $1.24 billion (2017 Australian dollars) in 2010.

Figure III. Total costs for all people with MS in Australia ($ billion), $ 2017



The estimated average annual costs per person with MS in 2017 were $68,382 (95%CI: 63,442–73,322).

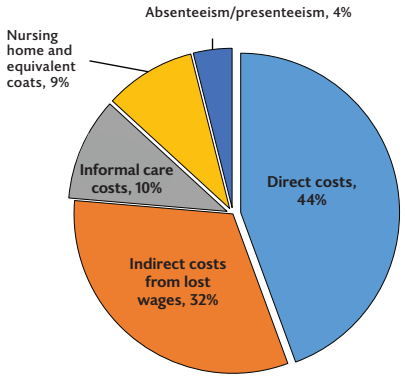
Figure IV. Annual total costs of MS (per person), $ 2017



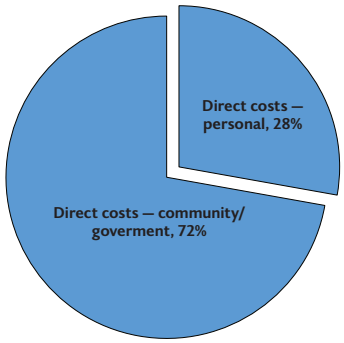
Direct costs now constitute the largest component of the economic impact of MS at 44% of the total costs. Whereas in 2010, lost wages were the largest at 49% of the overall costs, compared to just 32% of the overall costs in 2017. This is consistent with the findings of a recent study that demonstrated that the newer generation of higher efficacy DMTs are associated with better employment outcomes for people with MS.

Indirect costs due to lost wages are 32% of the total costs in 2017 compared to 50% in 2010.

Figure V. Percentage Distribution of Costs of MS



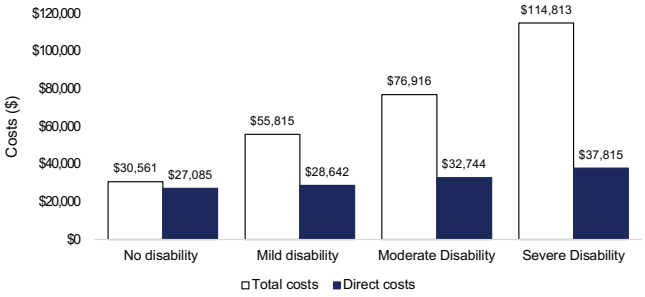
Total costs of MS



Direct costs of MS

The costs of MS increased with increasing disability severity. The costs more than tripled in people with severe disability ($114,813) compared to those with no disability ($30,561).

Figure VI. Annual costs of MS (per person) by disability severity, $ 2017

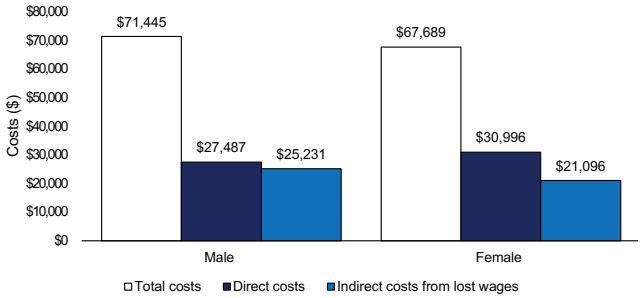


No disability includes EDSS level 0, Mild includes EDSS levels 1 – 3.5, No/mild includes EDSS levels 0-3, Moderate includes 4 – 6, and Severe includes levels 6.5 – 9.5.

Male sex was associated with relatively higher mean costs ($71,445), compared to females ($67,689), driven mainly by higher indirect costs from lost wages for males.

On average males have higher costs than females due to lost wages.

Figure VII. Annual costs of MS (per person) by sex, $ 2017



Costs increased with age up to 54 years, and then substantially decreased in those over 65 years, mainly because of the lower proportion on DMTs, and also because the indirect costs from lost wages were lower for this age group. However other costs were likely to be substantially higher e.g. direct medical costs/informal care costs.

Costs increased with age up to 54 years, and then substantially decreased after 65 years.

Costs per person did not vary substantially between the Australian states and territories, with the Australian Capital Territory (ACT) being an exception. The lower community/government direct costs and the indirect costs from lost wages, and zero informal care costs for the ACT population appear to be driving the significantly lower overall per person costs of MS in the ACT. However, differences between states and territories should be interpreted with caution due to the low sample sizes for TAS and the ACT. Costs did not vary markedly between the Australian Remoteness Areas, although costs for Inner Regional Australia were higher, driven mainly by higher indirect costs from lost wages.

Costs were highest for people with Secondary Progressive MS (SPMS), followed by Primary Progressive MS (PPMS), Progressive Relapsing MS (PRMS) and Relapsing Remitting MS (RRMS).

Eighty-five percent of people with MS are diagnosed with Relapsing Remitting MS which can later become secondary progressive, and 10-15% are diagnosed with a progressive form of MS from the outset.

Figure VIII. Annual costs of MS (per person) by MS type, $ 2017

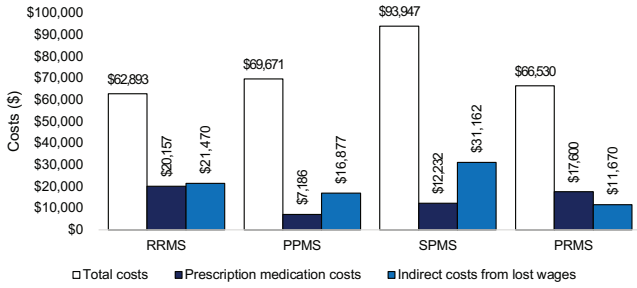
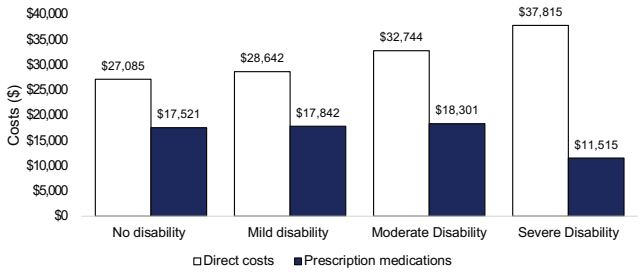


Figure IX. Annual direct costs of MS (per person) by disability severity, $ 2017



No disability includes EDSS level 0, Mild includes EDSS levels 1 – 3.5, No/mild includes EDSS levels 0-3, Moderate includes 4 – 6, and Severe includes levels 6.5 – 9.5.

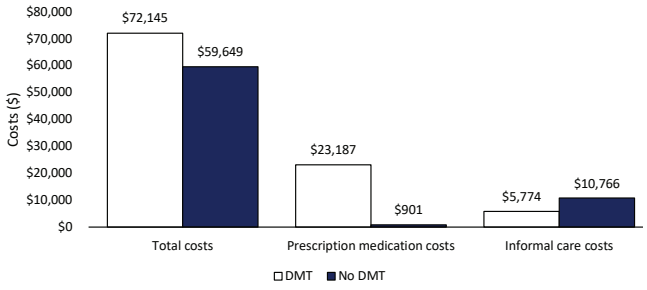
The direct per person costs of MS exhibited a steady increase with increasing disability severity. The prescription medications were the largest direct cost component for all disability classes.

Being on DMTs was associated with higher costs ($72,145), compared to those not on DMTs ($59,649). Costs of people on DMT are driven by high costs of prescription medications.

Around two-thirds of people with MS are treated with DMTs (compared to 47% in 2010)

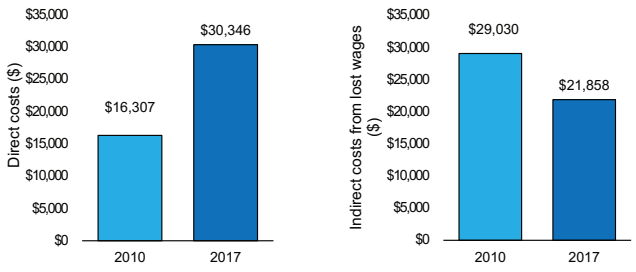
People with MS using DMTs are on average 10 years younger, and while costs of people on DMTs are slightly higher, their quality of life is higher, and direct personal costs and informal care costs are lower.

Figure X. Annual costs of MS (per person) by DMT usage, $ 2017



The annual per person costs of MS are comparable to those of a person with Parkinson's disease, or the first year following a stroke and are three times higher than for Type II Diabetes.

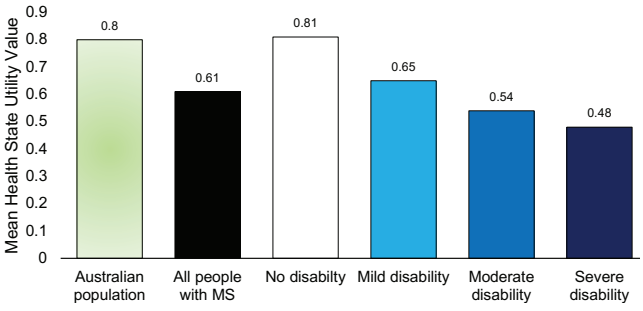
Figure XI. Annual Direct and Indirect costs of MS (per person) in 2010 and 2017, $ 2017



While the direct costs of MS have almost doubled between 2010 and 2017, driven largely by the cost of DMTs, the overall increase in costs per person with MS has been limited to less than $10,000 due to a significant reduction in the indirect costs of MS through lost wages and informal care. Lost wages now account for only 32% of the economic burden of MS compared to almost 50% in 2010.

We used the Assessment of Quality of Life 8 Dimension (AQoL-8D) multi-attribute utility instrument to assess the QoL for people with MS. The average AQoL-8D's HSUV (on a scale of 0-1 where '1' represents perfect health and '0' represents death) for people with MS was 0.61 compared to the HSUV of 0.80 for the Australian general population. The impacts of the AQoL-8D's individual dimensions of Pain, Independent Living, Relationships and Mental Health were the main drivers of the lower HSUV for people with MS.

Figure XII. Mean HSUV/QoI of people with MS in 2017



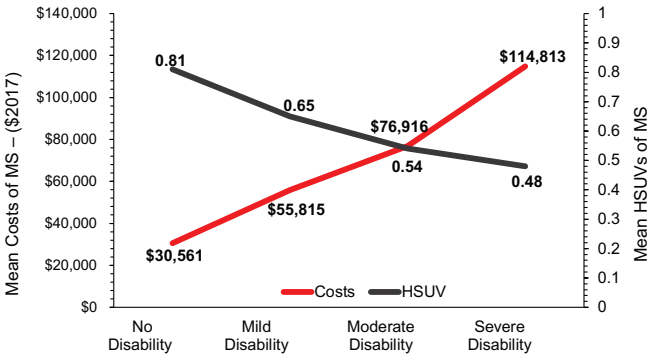
No disability includes EDSS level 0, Mild includes EDSS levels 1 – 3.5, No/mild includes EDSS levels 0-3, Moderate includes 4 – 6, and Severe includes levels 6.5 – 9.5. HSUV = health state utility value (0=dead, 1= perfect health)

HSUVs declined with increasing disability, with an overall decrease of 41% from 0.81 in people with no disability to 0.48 in people with severe disability. Additionally, people with more progressive forms of MS recorded a lower HSUV. Using DMTs was associated with higher QoL/HSUV estimates compared to people not using DMTs. The HSUV estimates were lower for males, and in both sexes, exhibited a general decline with increasing age. This result contrasts with the AQoL-8D's Australian population norms that increase as age increases. The HSUVs did not vary substantially between the Australian states and territories.

Men and people living in non-metropolitan areas are more vulnerable to loss of earnings due to MS than women and people living in metropolitan areas.

People with the more progressive forms of MS recorded much lower Quality of Life, driven by low composite physical and psychosocial scores and low individual dimensional scores for Independent Living, Pain, Relationships and Mental Health.

Figure XIII. Mean costs per person and the AQoL-8D HSUVs of people with MS by disease severity



Note: No disability includes EDSS level 0, Mild includes EDSS levels 1 – 3.5, No/mild includes EDSS levels 0-3, Moderate includes 4 – 6, and Severe includes levels 6.5 – 9.5. HSUV = health state utility values (0=dead, 1= perfect health).

This report provides current estimates of the number of people with MS, prevalence, cost of illness, and impact on QoL for people with MS in Australia, and compares the current results with previous relevant Australian and international studies. While there is a shift towards improved outcomes in terms of employment and a reduced need for informal care, MS continues to represent a serious burden for people with MS and the Australian community in terms of both economic impact and QoL.

While there are positive signs, **MS continues to represent a serious burden for people with MS and the community** in terms of both economic impact and QoL. Interventions that slow or prevent the accumulation of disability in MS are likely to have a substantial impact on the economic costs and QoL of people with MS.

This report demonstrates that MS remains a challenging condition in our community, placing a very significant toll on Australians, particularly for adults of working age who should be in the prime of life when MS is most frequently diagnosed. The introduction and use of a new generation of DMTs with improved efficacy over the past few years in Australia have had profound effects on the management of the disease, and hence, on the costs of MS.

While there are positive signs, further improvements in the management and care of MS, and interventions aimed at preventing the progression of MS, have the potential to substantially reduce the human and economic burden of MS.

Recommendations

- **Interventions to prevent people from developing MS are crucial** to counteract the rising prevalence of MS in Australia.
- **Improving early diagnosis and affordable access to effective treatments** to slow or prevent disability accumulation is likely to have a substantial impact on the economic costs and quality of life of people with MS.
- **To further reduce the economic costs and improve quality of life for people with MS,** research is urgently needed to develop further effective interventions to slow or prevent disease progression.
- **There should be a continued focus on managing symptoms and supporting people with MS and their carers in employment,** particularly for men with MS and people living outside of major metropolitan areas.
- **Quality of life for people with MS could be significantly improved through effective interventions to manage pain and mental health,** and support people with MS to maintain independent living and relationships.
- **Interventions and support to help people with MS to maintain physical health** as they age will also improve quality of life for older people with MS.

This study provides an up-to-date, reliable reference to support the MS community in advocating for increased and targeted support for people with MS and for increased research funding to develop further strategies to improve the lives of people with MS through prevention of disease onset and progression.

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List of Abbreviations

Abbreviation	Definition
AMSLS	Australian Multiple Sclerosis Longitudinal Study
ANZSCO	Australian and New Zealand Standard Classification of Occupations
AQoL-8D	Assessment of Quality of Life 8 Dimension
AUD	Australian Dollars
CI	Confidence Interval
COI	Cost of Illness
DMT	Disease Modifying Therapy
EDSS	Expanded Disability Status Scale
EIS	Economic Impact Survey
EQ-5D	EuroQol's Five Dimensions Questionnaire
QoL	Quality of Life
HSUVs	Health State Utility Values
PBAC	Pharmaceutical Benefits Advisory Committee
PBPA	Pharmaceutical Benefits Pricing Authority
PBS	Pharmaceutical Benefits Scheme
PDDS	Patient Determined Disease Steps
MRI	Magnetic Resonance Imaging
MS	Multiple Sclerosis
PPMS	Primary Progressive Multiple Sclerosis
PRMS	Progressive Relapsing Multiple Sclerosis
RRMS	Relapsing Remitting Multiple Sclerosis
SPMS	Secondary Progressive Multiple Sclerosis
QALY	Quality Adjusted Life Years
WHO	World Health Organization
WHOQOL-100	World Health Organization's 100 Items Quality of Life Instrument

Chapter 1 Introduction

1.1 A Brief Overview of MS

Multiple sclerosis (MS) is an autoimmune disease in which the myelin sheath covering nerve fibres in the central nervous system (brain, optic nerves and spinal cord) is damaged, leading to impairment of cognitive, motor and/or sensory functions.[1, 2] MS has a substantial effect on health and wellbeing, as well as being a major economic burden to people with MS, their caregivers and family members. The majority (85%) of people with MS are diagnosed with a clinical subtype characterised by episodes of acute neurological deterioration (relapses), followed by partial or complete recovery (remission) referred to as relapsing remitting MS (RRMS). This may later develop into secondary progressive MS (SPMS), marked by fewer or no periods of remission and gradual neurological worsening with brain atrophy. The remaining 10–15% of people with MS are diagnosed with progressive relapsing MS (PRMS) or primary progressive MS (PPMS) – characterised by continuous neurological worsening from the first onset of symptoms, either with (PRMS) or without (PPMS) relapses.[3-5]

There is no single cause of MS; however, several genetic, environmental and other factors have been shown to significantly contribute to its development. The symptoms of MS are extremely variable for any given individual and can vary over time within individuals and include: extreme tiredness (fatigue); visual disturbances; difficulties with walking, balance, or coordination; dizziness; tingling and numbness; heat/cold sensitivity; pain; bladder and bowel problems; mood swings; sexual problems; and changes in concentration, memory or speech.

103.7 people per 100,000 have MS in Australia.

Whilst a range of treatment options is available for people with RRMS, limited options are available for people living with progressive forms of MS. For instance, there are currently 12 disease-modifying therapies (DMTs) available in Australia for people with RRMS. The choice of therapy for a person with MS will depend on the phase and clinical activity of the disease, individual patient considerations such as other health conditions, access to health care services, family planning, and the practicalities of drug administration. DMTs act by modifying the activity of the immune system to reduce the frequency and severity of inflammatory/immune attacks targeting the central nervous system. Other available drug treatments include symptom specific medications and steroid medications (such as methylprednisolone) which are used to treat relapses. Twelve DMTs were recorded in the cost diary survey of the EIS 2016 which was used to calculate the cost of illness in this Report. Supplemental Table 1A provides the data on DMTs and other important (prescription and non-prescription) medications that were used by Australian people with MS in 2017.

1.2 Rationale and Background

MS affects more than 2.3 million people worldwide and remains a potentially severely disabling condition with no known cure. The costs associated with MS include: direct medical costs (pharmaceutical, disposable equipment, medical, nursing, community and private services, hospitalisations, special equipment, home and car alternations); direct non-medical costs such as informal care costs; indirect costs from lost wages; indirect costs from lost productivity (due to absenteeism/presenteeism); and intangible costs (pain, anxiety, and reduced quality of life).[2, 6, 7] Cost of illness (COI) analyses are commonly performed to measure the costs associated with any specific health condition. The results from these analyses provide a useful platform for policy makers and researchers by providing a snapshot of the nature and extent of costs related to a disease in a given environment and over time. COI studies provide information on the main cost drivers, which are important for development of health policies and efficient allocation of scarce healthcare resources.

Two reports on the economic impact of MS in Australia have been produced previously, in 2005 and 2011 (also commissioned by MS Research Australia), utilising data from the 2003 and 2007-08 Economic Impact Surveys (EIS) of the Australian Multiple Sclerosis Longitudinal Study (AMSLS), respectively. These reports have been vital for MS Research Australia and other stakeholders in underpinning advocacy and building the case for increased research and social and healthcare supports for people with MS. The AMSLS repeated the Economic Impact Survey in 2016 (EIS 2016, hereafter), which provided a large and comprehensive data set that has been used to determine the updated economic burden of MS in Australia and to review any major changes that may have occurred over time. The updated information on the burden of MS is particularly relevant in this new era of increased access to effective MS medications and patient-centred approaches to the management of MS.

This report provides a comprehensive analysis of the burden of MS in Australia and how that landscape has changed since 2010.[8] It provides a current, reliable reference to support the MS community in advocating for increased financial and in-kind support for people with MS and for increased research funding to develop further strategies to improve the lives of people with MS, and to prevent disease onset and progression.

1.3 Aims and Objectives

The objectives of this study were:

1. To estimate the prevalence of MS in Australia;
2. To estimate the costs of MS in Australia from an individual and societal perspective; and
3. To assess the impact of MS on quality of life (QoL) and health state utility values (HSUVs) using the latest available data and updated methodologies.

The costs and HSUV/QoL estimates were further analysed by disability severity (classified as no, mild, moderate, and severe disability), sex, age group, state/territory of usual residence, Australian Remoteness Areas, MS type, and DMT usage (treatment vs no treatment). The report aims to compare the current results (where possible) with the results reported in the Economic Impact of Multiple Sclerosis in Australia in 2010 Report and other relevant Australian and international studies. A comparison between costs of illness of MS and other diseases in Australia has also been made to provide context.

The number of people living with **MS in Australia increased by just over 20%** from 21,283 in 2010 to 25,607 in 2017.

Chapter 2 Prevalence of Multiple Sclerosis

2.1 Summary

The aim of this chapter was to estimate the 2017 prevalence of MS in Australia.

Using a previously published and validated DMT prescription method[9], the number of people with MS in Australia in December 2017 was 25,607 (95%CI: 24,874–26,478). This is an increase of 4,324 additional people with MS in Australia from 2010, and an increase of 20.3%. The 2017 prevalence was 103.7 per 100,000 compared to the 2010 prevalence of 95.5 per 100,000 people, an increase of 8.2 per 100,000 people over the interval.

There were 188,243 prescriptions for 10 DMTs with 22 modes of therapeutic delivery in 2017. Australia-wide, the percentage of people with MS using DMTs (DMT penetrance) was 64%, an increase of almost 40% for DMT use from 2010[9].

Comparing the Australian states and territories, the age-standardised prevalence estimates were highest in Tasmania (TAS) (138.7 per 100,000 people [95%CI: 137.2–140.1]), almost double that of Queensland (QLD) (74.6 per 100,000 [95%CI: 73.5–75.6]) and Western Australia (WA) (87.7 per 100,000 [95%CI: 86.6–88.9]), in line with the known latitudinal gradient in prevalence of MS.

Our findings of an increased prevalence of people with MS in Australia from 2010 reflect recent global trends. One of the key reasons for this increase likely reflects increased survival of people with MS, as noted in the International Federation of MS Atlas of Multiple Sclerosis[10] Another reason is an increase in incidence of MS as reflected in a recent study regarding the city of Newcastle in the Australian state of New South Wales (NSW).[11]

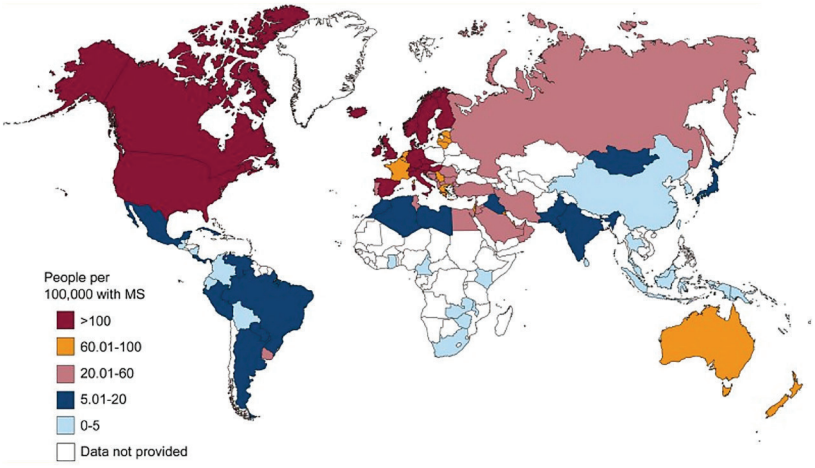
2.2 Introduction

2.2.1 Worldwide Prevalence of MS

The number of people with MS in the world has increased from 2.1 million people in 2008 to 2.3 million people in 2013.[10] This increase can be attributed in part to an increased world population, increased survival (of both people with MS and the wider general population), and in some countries to increasing MS incidence. It may also reflect improvements in the diagnosis and reporting of MS and the establishment of clinical registries and the publication of new epidemiological research.[10]

Figure 2.1 shows an increasing MS prevalence as latitude (distance from the equator) increases. Of the environmental risk factors linked to MS, the robust latitudinal gradients of prevalence and incidence rate have been among the most consistent and striking findings in MS epidemiology.[12] Indeed, a recent systematic review and meta-analysis revealed a positive association between latitude and MS prevalence with a 1.04 change in prevalence/100,000 per degree-latitude ($p<0.001$).[13] Another study demonstrated that MS incidence increased 30% in women and 50% in men per each 10 degree increment of latitude.[14] Importantly, prevalence studies of MS in Australia have provided some of the strongest and most consistent evidence regarding the relationship between latitudinal gradient and prevalence of MS.[9, 13]

Figure 2.1. Global prevalence of MS in 2013



2.2.2 Prevalence of MS in Australia

There have been several prevalence studies regarding MS undertaken with Australian data and these studies have generally used complex and resource-intensive methods to calculate prevalence.[9] In 2010, an estimate of the prevalence of MS in Australia was generated by using 2010 Australian Pharmaceutical Benefits Scheme (PBS) prescription data from 1 January 2010 to 31 December 2010.[9] This novel method for calculating the prevalence of MS in Australia was robustly validated against other estimates including the MS Society Client Database and the Australian Bureau of Statistics Survey of Aging, Disability and Carers (2009).[9] The results of this study were also used for a prevalence-based cost of illness analysis of MS in Australia.[8] Importantly, this current study employed the same validated methodology to calculate the prevalence of MS in Australia for December 2017 using PBS prescription data from 1 January 2017 to 31 December 2017. The prevalence estimates generated from this study inform the cost of illness analyses contained in this report.

The latitude gradient of MS prevalence continues to persist with the prevalence of **MS highest in Tasmania (TAS) at 138.7 per 100,000 people,** almost double that of Queensland (QLD) at 74.6 per 100,000 and Western Australia (WA) 87.7 per 100,000.

2.3 Materials and methods

2.3.1 Data Sources

Australia's PBS is part of the Australian universal healthcare system that provides subsidised medications to all Australian residents. [15-17] Medicare Australia provided the number of PBS and Repatriation PBS scripts for MS-related DMTs prescribed for the period from 1st January 2017 to 31st December 2017. [17] We did not include medications used 'off-label', or medications or treatments that may have been received or sourced overseas.

Table 2.1 describes the PBS code, generic and trade name for the MS-specific DMTs prescribed for people with MS during this study's pre-determined time horizon for all Australian states and territories. The percentage of people with MS who were using DMTs (penetrance) for Australia overall and each Australian state and territory were calculated from the AMSLS data. The most recently available (September 2017) Australian population estimates were sourced from the Australian Bureau of Statistics (ABS).[18]

2.3.2 Statistical Analyses

To estimate the prevalence using the prescription method, the annual number of PBS and Repatriation PBS (RPBS) scripts dispensed for the medications listed in Table 2.1 was divided by 12, as these were monthly prescriptions (except for Alemtuzumab (Lemtrada) which is prescribed and administered annually). This estimate was then adjusted for penetrance of the MS-specific DMTs for Australia overall, and for each Australian state and territory. This prescription methodology reflected the novel method employed in the 2011 economic impact of MS report and subsequent scholarly publications. [6, 8, 9] We also extracted the number of cases by age category: < 25 years, 25-29, 30-34, 35-39, 40-44, 45-49, 50-54, 55-59, 60-64, 65-69, 70-74, 75-79, and 80+ years from de-identified MS Society client databases and the AMSLS for states and territories.

Table 2.1. Australian Pharmaceutical Benefits Scheme (PBS) and Repatriation PBS disease modifying therapies exclusively prescribed for people with MS in Australian states and territories: January 2017 to December 2017

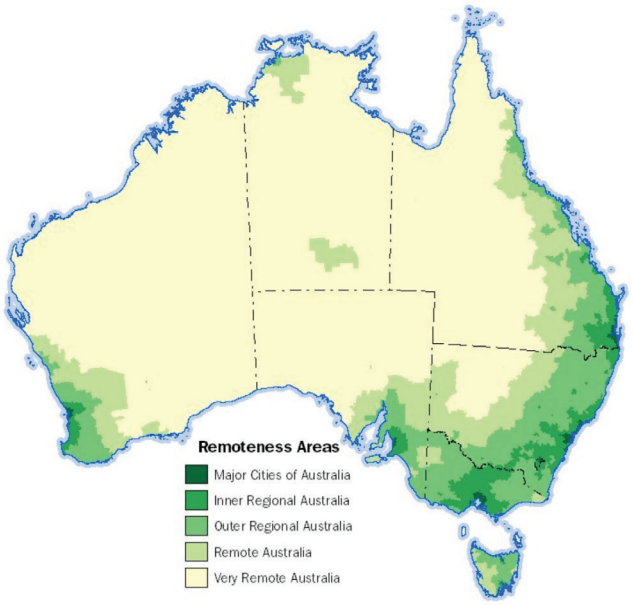
PBS Code	Generic name (trade name)	Australian states and territories							
		NSW	VIC	QLD	SA	WA	TAS	ACT	NT
9505G	Natalizumab (Tysabri)	6,743	10,842	2,287	2,826	2,276	939	170	28
9624M	Natalizumab (Tysabri)	1,028	1,243	1,556	61	2,002	91	0	0
10228H	Alemtuzumab (Lemtrada)	57	54	33	16	25	21	8	0
10232M	Alemtuzumab (Lemtrada)	55	79	51	36	26	25	2	0
10242D	Alemtuzumab (Lemtrada)	37	28	49	23	0	0	0	0
10246G	Alemtuzumab (Lemtrada)	54	35	52	30	0	0	0	0
2966D	Dimethyl Fumarate (Tecfidera)	8,047	6,930	3,525	2,105	2,853	644	665	48
2896K	Dimethyl Fumarate (Tecfidera)	203	142	58	28	54	9	25	3
2943X	Dimethyl Fumarate (Tecfidera)	141	72	50	7	21	3	3	0
11101G	Daclizumab (Zinbryta)	77	237	161	101	37	18	14	0
5262Y	Fingolimod (Gilenya)	19,669	24,135	7,824	6,036	5,031	950	1,411	271
2898M	Teriflunomide (Aubagio)	3,871	6,139	2,240	1,178	1,325	584	168	15
10218T	Peginterferon (Plegridy)	79	42	29	9	20	7	4	0
10212L	Peginterferon (Plegridy)	557	419	362	74	127	87	53	19
10220X	Peginterferon (Plegridy)	2,029	1,497	875	237	816	289	89	22
9332E	Interferon beta-1A (Rebif 44)	857	688	633	270	129	65	81	11
8403G	Interferon beta-1A (Rebif 44)	1,022	852	375	323	284	50	71	7
8968B	Interferon beta-1A (Rebif 44)	88	63	41	21	88	0	7	0
8805K	Interferon beta-1A (Avonex)	2,062	2,306	873	879	424	140	100	9
8101J	Interferon beta-1B (Betaferon)	2,283	2,102	1,655	571	748	443	79	97
8726G	Glatiramer Acetate (Copaxone)	2,147	1,689	963	697	306	253	269	25
10416F	Glatiramer Acetate (Copaxone)	3,812	3,619	2,859	970	957	356	737	29
TOTAL		**54,918**	**63,213**	**26,551**	**16,498**	**17,549**	**4,974**	**3,956**	**584**

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

Age-adjusted prevalences were then calculated for each state and territory using the direct method employed in the 2011 economic impact of MS report.[8] DMT penetrance was calculated using the survey participants' responses to the AMSLS regarding use of DMTs. Ninety-five percent confidence intervals were calculated for Australia overall, and for each state and territory estimate of DMT penetrance. The age and sex profiles of these respondents were also calculated.

We also calculated MS prevalence for Remoteness Areas using de-identified MS Society clients' postcode data. We used the Australian Statistical Geography Standard (ASGS) Remoteness Structure of Remoteness Area by postcode from the Australian Bureau of Statistics.[19] In summary, Remoteness Areas divide Australia into five classes of remoteness based on a measure of relative access to services. A map of the 2016 Remoteness Areas are shown in Figure 2.2 and these are classified as Major Capital Cities, Inner Regional Australia, Outer Regional Australia, Remote Australia and Very Remote Australia.[19]

Figure 2.2. Australian Remoteness Areas by the Australian Statistical Geography Standard



2.4 Results

Table 2.1 provides the number of PBS and RPBS scripts dispensed for the 12-month time period of 1st January 2017 to 31st December 2017 for MS-specific DMTs (prescribed only for people with MS) overall and for each Australian state and territory.

The percentage of people using disease modifying therapies (DMTs) in 2017 **increased by 40%** compared to 2010.

The age and sex profiles of the people with MS who provided the AMSLS survey data employed for the penetrance calculations (n=1,699) are provided in Table 2.2. This table shows that people currently being treated with DMTs are almost a decade younger than people with MS who are not being treated with DMTs. This relative trend is consistent for Australia's state and territories.

Table 2.2 also shows that the mean (standard deviation) age of diagnosis for the sample (not age of onset) was 41 (SD 11) years, and that this age of diagnosis was consistent across the Australian states and territories. Females also represented 78% of the entire sample.

Table 2.3 presents the prevalence of MS expressed as the absolute number of people with MS in Australia and Australia's states and territories, and the unadjusted and age-adjusted prevalence rates of people with MS per 100,000 people based on the PBS/RPBS prescriptions and reported DMT penetrance.

Overall, 188,243 scripts for MS-specific DMTs were dispensed over the time horizon. Penetrance rates of DMTs were 64% (95%CI: 62–66) for Australia overall, ranging from 59% (95%CI: 48–69) in TAS to 69% (95%CI: 64–73) in Victoria (VIC) (Tables 2.3).

Table 2.2. Average sociodemographic characteristics of people with MS on an Australian, and state and territory basis, and penetrance of disease modifying therapies (DMTs).

	Australia (N=1699)*	NSW (n=519)	VIC (n=470)	QLD (n=241)	SA (n=143)	WA (n=159)	TAS (n=88)	ACT (n=74)	NT (n=NA)†
DMT Penetrance % (95%CI)	64 (62–66)	62 (58–66)	69 (64–73)	60 (54–66)	60 (52–68)	68 (61–75)	59 (48–69)	63 (55–68)	63 (55–68)
Age (entire sample) Mean (SD)	55 (11)	55 (11)	54 (11)	55 (12)	56 (11)	57 (11)	56 (11)	55 (12)	NA
% Female	78	77	75	83	76	83	81	77	
Age (yes DMT) Mean (SD)	52 (11)	52 (10)	52 (11)	51 (11)	52 (10)	54 (11)	55 (12)	49 (12)	NA
% Female	81	80	78	88	79	80	81	77	
Age (no DMT) Mean (SD)	61 (10)	61 (11)	60 (10)	61 (11)	61 (11)	62 (10)	59 (9)	16 (7)	NA
% Female	75	73	69	77	72	86	76	77	
Years with MS (entire sample)	15 (9)	15 (9)	15 (9)	14 (8)	14 (10)	14 (8)	17 (10)	13 (7)	NA
Years with MS (yes DMT)	13 (8)	13 (8)	13 (7)	12 (7)	13 (10)	12 (7)	16 (10)	11 (7)	NA
Years with MS (no DMT)	17 (10)	19 (10)	18 (10)	16 (9)	17 (10)	18 (10)	19 (9)	15 (7)	NA
Age at diagnosis (entire sample)	41 (11)	41 (10)	40 (10)	41 (12)	41 (11)	43 (11)	39 (11)	42 (10)	NA
Age at diagnosis (yes DMT)	39 (10)	39 (10)	40 (10)	39 (11)	40 (11)	42 (12)	39 (11)	39 (11)	NA
Age at diagnosis (no DMT)	43 (11)	43 (11)	42 (11)	46 (12)	44 (11)	44 (11)	40 (12)	48 (8)	NA

*N=1699 people with MS who responded to the Medications and Disease Course Survey of AMSLs regarding their current treatment with disease-modifying therapies (DMT). †NT data unavailable.

The total number of people with MS in Australia was 25,607 people (95%CI: 24,874–26,478), and the prevalence was 103.7 per 100,000 (95%CI: 100.7–107.2).

In regard to the individual Australian states and territories, the presence of a latitudinal gradient was observed with TAS recording the highest prevalence for both unadjusted and age-adjusted figures of 148.3 per 100,000 (95%CI: 126.8–182.3), and 138.7 per 100,000 (95%CI: 137.2–140.1) respectively, despite the lower DMT penetrance in TAS (59%), and QLD recording the lowest prevalence of 80.2 (unadjusted) people with MS per 100,000 (95%CI: 72.9–89.1), and 74.6 (age-adjusted) people with MS per 100,000 (95%CI: 73.5–75.6) with a penetrance rate of 60% (Table 2.3).

VIC, with a total population of 6,254,900, had 7,895 people with MS and an unadjusted prevalence of 126.2 people with MS per 100,000 and an age-adjusted prevalence rate of 125.7 people with MS per 100,000. Whereas NSW (total population 7,895,800) had 7,682 people with MS and 97.3 people with MS per 100,000 (unadjusted), and 94.6 people with MS per 100,000 (age-adjusted). The likely explanation for this result is that VIC is at a higher latitude than NSW (i.e. is further from the equator).

Table 2.3 and Figure 2.3 compare the age-adjusted increase in prevalence of people with MS from 2010 to 2017 for the Australian states and territories. The table and figure highlight the general trend of an increase in prevalence of MS from 2010 for Australia's states and territories (also see section 2.5).

Table 2.3. Calculation of prevalence of people with MS based on Australian Pharmaceutical Benefit Scheme prescribed disease modifying therapies, and age-adjusted prevalence using the Australian MS Societies age-structures on a state and territory basis, and the Australian MS Longitudinal Study (AMSLS)

	NSW	VIC	QLD	SA	WA	TAS	ACT	NT	Australia
Population^	7,895,800	6,358,900	4,948,700	1,726,900	2,587,100	522,000	412,600	246,100	24,702,900
Penetrance of DMTs, % (95%CI)	62 (58–66)	69 (64–73)	60 (54–66)	60 (52–68)	68 (61–75)	59 (48–69)	63* (55–68)	63* (55–68)	64 (62–66)
Number of people with MS based on prescribed DMTs agents	7,682	7,895	3,970	2,452	2,219	774	538	77	25,607
Lower 95%CI	7,216	7,462	3,609	2,163	2,474	662	498	72	24,874†
Upper 95%CI	8,211	8,512	4,411	2,829	2,012	951	616	88	26,478†
Unadjusted prevalence of MS per 100,000 by prescription^^	97.3	124.2	80.2	142.0	85.8	148.3	130.4	31.3	103.7
Lower 95%CI	98.5	121.5	77.8	136.48	82.3	138.2	119.8	25.0	100.7
Upper 95%CI	99.5	126.9	82.8	147.7	89.4	159.1	141.9	39.1	107.2
2017 age-adjusted prevalence of MS	94.6	125.7	74.6	138.3	87.7	138.7	131.1	34.1	NA
Lower 95%CI	93.4	124.3	73.5	136.8	86.6	137.2	129.6	33.3	
Upper 95%CI	95.9	127.1	75.6	139.8	88.9	140.1	132.5	34.8	
2010 age-adjusted prevalence of MS	81.5	96.4	45.9	105.7	86.9	135.5	113.7	18.9	NA
Lower 95%CI	80.31	95.1	45.0	104.4	85.7	134.0	112.3	18.4	
Upper 95%CI	82.68	97.7	46.8	107.1	88.2	137.1	115.1	19.5	

^ Australian Bureau of Statistics Population Estimates: September 2017. * ACT and NT penetrance and CI based on averages of all States.

† Calculated from prescription bounds for Australia, not from summing individual state and territory totals.

State and territory capital city latitudinal gradient and prevalence are also shown in Figures 2.3 and 2.4.

Figure 2.3. The age-adjusted prevalence per 100,000 people for the Australian states and territories.

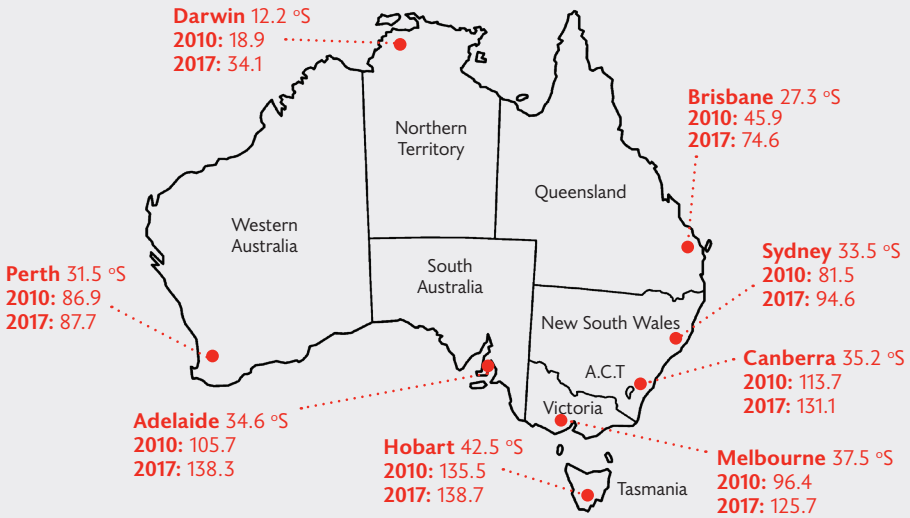
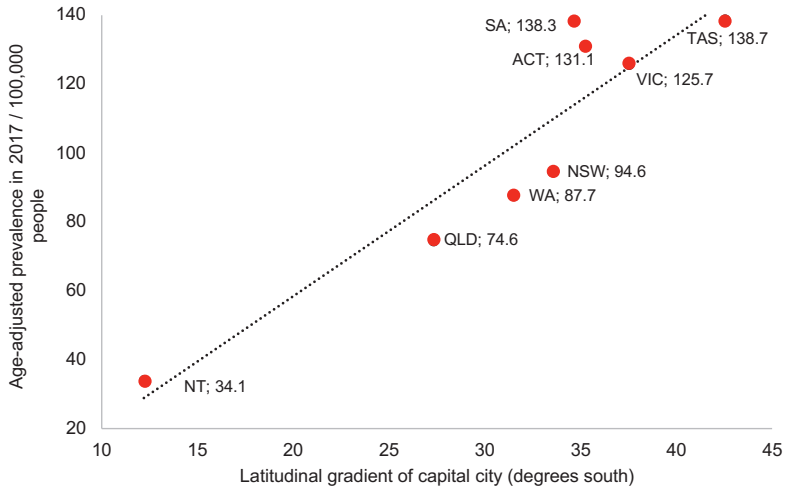


Figure 2.4. Representation of Australia's capital city latitudinal gradient for each state and territory and 2017 age-adjusted prevalence rates



Information on geographical remoteness is also available for the sample of MS patients for whom DMT penetrance rates were calculated. Figure 2.2 highlights the Australian Remoteness Areas and Table 2.4 provides the absolute number and percentage of people with MS in Australia who live in Major Cities of Australia, Inner Regional Australia, Outer Regional Australia, Remote Australia and Very Remote Australia.

Table 2.4. The number and percentage of people with MS who responded to the AMSLS survey regarding treatment with disease-modifying therapies living in the Australian Remoteness Areas

	Major Cities	Inner Regional	Outer Regional	Remote	Very Remote
	n (%)	n (%)	n (%)	n (%)	n (%)
New South Wales (n=516)	339 (66)	136 (26)	39 (8)	1 (0.2)	1 (0.2)
Victoria (n=470)	316 (67)	129 (27)	25 (5)	0	0
Queensland (n=241)	163 (68)	41 (17)	32 (13)	3 (1)	2 (1)
Western Australia (n=159)	110 (69)	25 (16)	16 (10)	5 (5)	3 (2)
South Australia (n=143)	89 (62)	22 (15)	21 (15)	10 (7)	1 (1)
Tasmania (n=88)	NA**	66 (75)	20 (23)	1 (1)	1 (1)
ACT (n=74)	67 (91)	7 (9)	0	0	0
Australia (n=1691)	1084 (64)	426 (25)	153 (9)	20 (1)	8 (0.5)

*Penetrance data not available for the Northern Territory;
** Tasmania's capital city is classified as Inner Regional Australia.

Table 2.4 demonstrates that the majority (just under two-thirds; 64%) of people with MS (based on MS society client figures) reside in Major Cities of Australia (this figure concurs with 2016 Census data for the Australian population[20]), followed by one-quarter residing in Inner Regional Australia (25%). The Remoteness Areas of Outer Regional Australia, Remote Australia and Very Remote Australia account for just over 10% of people with MS. Table 2.4 also provides the state and territory breakdowns of the Remoteness Areas and these revealed a similar pattern, with most people with MS living in Major Cities of Australia.

2.5 Discussion

2.5.1 Comparison to 2010 Prevalence Estimates From the Economic Impact of MS in Australia 2011 Report

This study adopted the same methodology as our prescription-based study published in 2013 to calculate unadjusted and age-adjusted prevalence of MS for the Australian population. There were several advantages of using the same PBS prescription-based method for extracting medications that were used by people with MS, including the ascertainment of all prescription data Australia-wide from the one centralised and continually updated Medicare Australia database. This same methodological approach also supported a direct comparison of the estimates from 2010 to 2017.

Overall, there was an increase in the number of people living with MS in Australia over the 7-year time horizon of 4,324 people, from 21,283 in 2010 (95.5/100,000 people) to 25,607 (103.7/100,000 people) in 2017.

Age-adjusted figures also revealed that the prevalence rates of people with MS per 100,000 people for all the states and territories also increased from 2010 (Figure 2.3), and that the relative latitudinal gradient relationship for higher prevalence rates in higher latitudinal regions (i.e. further from the equator) remained stable from 2010.

Our findings of an increased prevalence of people with MS in Australia from 2010 reflect recent global trends. One of the key reasons for this increase likely reflects increased survival of people with MS, as noted in the MS International Federation's Atlas of Multiple Sclerosis[10]. Another reason is an increase in incidence of MS as reflected in a recent study regarding the city of Newcastle in the Australian state of NSW[11].

2.5.2 Importance of Timely and Accurate Prevalence Estimates for Healthcare Resource Allocation Decisions

The Atlas of Multiple Sclerosis 2013, called for increased surveillance to support the equitable allocation of scarce healthcare resources and access to specialist neurologists, nurses and equipment (such as MRI machines) across worldwide jurisdictions. Our prescription method has demonstrated a timely and resource-efficient methodology for calculating the prevalence of MS due to the easily accessed and accurate data sources in Australia, namely, government DMT prescription data and treatment penetrance rates calculated from the patient-reported data gathered in the AMSLS.

We suggest that this methodology should be explored for other countries where central repositories of prescription data and penetrance rates can potentially be accessed via patient registries and clinical databases.

The prescription data method was a particular strength of this study, however, one potential disadvantage of using this method was that we could have marginally underestimated the prevalence calculations because we have not included people using off-label medications, or those sourcing medications or treatments overseas.

Chapter 3 Costs of Multiple Sclerosis

3.1 Summary

This chapter provides a comprehensive analysis of the economic burden of MS in Australia and how that landscape has changed since 2010.[8] The cost analysis is based on data from the Economic Impact Survey (EIS) 2016 of the Australian MS Longitudinal Study (AMSLS) – a validated, representative sample of over 3,000 Australian people with MS who complete regular patient-reported outcome surveys. The EIS 2016 consisted of a baseline survey (3,163 active participants invited, 1,577 [49.9%] responded), and a cost diary (3,163 active participants invited, 488 [15.5%] responded. The survey captured detailed information on various cost categories (direct [pharmaceutical, disposable equipment, medical, nursing, community and private services, hospitalisations, special equipment, home and car alternations, transport] and indirect [costs from lost wages and lost productivity]) related to the management of MS and established the health, employment, and financial profiles of people with MS.

Annual, average total costs of MS per person increased 17% from $58,652 in 2010 to $68,382 in 2017, driven largely by increased costs of disease modifying therapies, but offset by decreased costs of lost wages. Annual per person costs increased by 276% from $30,561 for people with MS with no disability to $114,813 for people with severe disability. The total costs for all people with MS in Australia in 2017 were $1.75 billion (2017 Australian dollars), which is an increase of $0.51 billion compared to the $1.24 billion (2017 Australian dollars) in 2010. The increased overall cost is driven largely by increased direct costs (mainly DMT costs), while indirect costs have substantially declined. Indirect costs from lost wages was the major cost component (32% of the estimated costs per person with MS in 2017). When compared to the costs in 2010, we found that indirect costs from lost wages and informal care costs now contribute relatively less to the overall costs of MS. For instance, the indirect costs per person from lost wages declined by 25% from $29,030 (49% of the overall costs) in 2010 to $21,858 (32% of the overall costs) in 2017. Consistent with findings of recent studies,[21] we expect that the availability of the newer generation of higher efficacy DMTs and the availability of timely and better healthcare facilities in this era of patient-centred approaches regarding the management of MS are likely to be the key contributing factors behind this change.

The annual total costs of MS per person (direct and indirect costs) increased by **17% from $58,652 in 2010 to $68,382 in 2017,** driven largely by increased costs of DMTs and offset by decreased costs of lost wages and decreased informal care costs.

Total costs for all people with MS in Australia have increased substantially over time from **$1.24 billion in 2010 to $1.75 billion in 2017 (an increase of 41%)** due to both an increase in number of people living with MS and increased per person costs.

When looking at the costs by sub-groups, the costs of MS increased with increasing disability severity. The costs more than tripled from $30,561 in those with no disability to $114,813 in people with severe disability. Male sex was associated with relatively higher mean costs ($71,445), compared to females ($67,689), driven mainly by higher indirect costs from lost wages for males. Costs increased with age up to 54 years, and then substantially decreased in those over 65 years, mainly because of the lower proportion of people on DMTs in this group, and also because the indirect costs from lost wages were lower for this age group. However, other costs were higher e.g. direct medical costs and informal care costs.

Annual per person costs increased by 276% from $30,561 for people with MS with no disability to $114,813 for people with severe disability. The direct costs were the largest total cost component for all disability classes.

Costs per person did not vary substantially between the Australian states and territories, with the Australian Capital Territory (ACT) an exception, but differences between states and territories should be interpreted with caution due to the low sample sizes for Tasmania (TAS) and the ACT. Costs did not vary markedly between the Australian Remoteness Areas. Costs for people with MS living in Inner Regional Australia were relatively higher, driven mainly by higher indirect costs from lost wages in that area. Costs were highest for people with Secondary Progressive MS (SPMS), followed by Primary Progressive MS (PPMS), Progressive Relapsing MS (PRMS) and Relapsing Remitting MS (RRMS). Being on DMTs was associated with higher costs ($72,145), compared to those not on DMTs ($59,649).

We compared our results with the 2011 economic impact of MS report that matches with our analysis both in terms of its methodological framework and in terms of the majority of the cost categories considered.

We also drew a comparison between the costs of MS in Australia and those from other nations. Whilst costs were substantial in all countries, there is a significant range of costs recorded between countries, which may be partly

driven by differing methods as well as healthcare systems. To provide a context for MS, a comparison of costs associated with other diseases in the Australian setting was also performed. Once again, differences in the costs of various diseases in Australia were found that could be due to a multitude of factors including study methods and demographics. Nevertheless, despite these methodological differences the costs of MS are most comparable to the overall costs of Parkinson's disease.

The results reported in this chapter provide a useful platform for policy makers and researchers by providing a snapshot of the nature and extent of costs related to MS in Australia in 2017. It also provides information on the main cost drivers, which are important for development of health policies and efficient allocation of scarce national healthcare resources. The updated COI of MS information provided in this chapter is particularly relevant in this new era of increased access to effective MS medications and patient-centred approaches to the management of MS. Our results provide a current reliable reference to support the MS community in advocating for increased financial and in-kind support for people with MS and for increased research funding to develop further strategies to improve the lives of people with MS, and to prevent disease onset and progression.

3.2 Introduction

Economic costs associated with MS may result in a substantial burden to people with MS and society as a whole. COI analyses provide a snapshot of the nature and extent of the costs related to a disease in a given environment and over time. Two reports on the economic impact of MS in Australia have been produced previously: in 2005 and 2011,[8, 22] utilising data from 2003 and 2007-08 EIS of the AMSLS, respectively. These reports have been vital for MS Research Australia and other stakeholders, in underpinning advocacy and building the case for increased research and social and healthcare supports for people with MS. However, the most recent of these reports was based on now a decade old data. An updated COI analysis of MS in Australia is timely, given the new era of increased access to effective MS medications and patient-centred approaches to the management of MS, as well as the availability of new datasets to provide up-to-date information. For example, most of the newer generation DMTs were not fully established at the time of the publication of the 2011 economic impact of MS report. [8] The current landscape of MS in Australia differs substantially from that in 2007-08. Australians with MS now have access to a range of DMTs for relapsing MS, bringing potential impacts on health outcomes for people with MS. There is also a trend towards earlier diagnosis of MS (due to application of new diagnostic criteria) and earlier treatment (due to therapeutic advances and growing evidence of the long-term benefits of early effective treatment). All of this may contribute to differences in the costs and impact of MS over time.

The aim of this chapter was to provide a comprehensive contemporary analysis of the costs of MS in Australia and to examine how that landscape has changed since 2010.[8]

3.3 Materials and Methods

3.3.1 Study Design

Participants in this study were part of the AMSLS, a longitudinal, survey-based study, which comprises over 3,000 active participants. AMSLS is a large national sample of Australian people with MS, with an estimated 96% with a confirmed diagnosed of definite MS from a neurologist according to McDonald criteria.[23] A recent study validated the AMSLS cohort as being highly representative of Australians with MS.[23] Recruitment to the AMSLS is ongoing (to counter attrition) and is undertaken with the assistance of MS Research Australia and all Australian state and territory MS Societies. To join AMSLS, a participant must be: 1) an Australian resident; 2) diagnosed with MS by a neurologist; and 3) aged 18 years or over. Participation in the AMSLS is voluntary, and participants can choose to withdraw at any time, without giving a reason. AMSLS participants gave their informed consent to participate in the study and periodically complete inter-disciplinary research surveys in socioeconomic, clinical and psychosocial fields.[6, 24, 25] The analysis presented here is based predominantly on data from the EIS 2016 that was conducted as part of the AMSLS. The EIS 2016 consisted of a baseline survey (3,163 active participants invited, 1,577 [49.9%] responded) and, and a cost diary (3,163 active participants invited, 488 [15.5%] responded. The baseline survey established basic health, employment and financial profiles of people with MS, as well as provided an indication of the indirect costs of MS (such as costs from lost wages due to early retirement, occupation change, and employment status change) and direct non-medical costs (such as informal care costs due to carers' reduced employment). The cost diary captured detailed information on various cost categories relating to MS, such as prescription medications, non-prescription medications, disposable equipment, health professionals, nursing services, community and private services, medical tests, hospital stays, special equipment-hire, special equipment-purchase (mobility, visual aids, communications, bathroom, kitchen, bedroom, general), alterations to home, alterations to car, and transport. The cost diary included (where possible) a comprehensive list of the items related to each cost category to assist respondents in reporting information on costs

incurred due to MS. Participants were asked to complete the cost diary everyday over the six-month period to minimise the possibility of any recall bias. Supplemental Tables 1A and 1B provide the list of items included in the 2016 cost diary.

Some supplementation of data was achieved through other AMSLS surveys that were conducted around the same time. The EIS 2016 did not capture information on type of MS and DMT usage. We obtained this information from the 2016 Medications and Disease Course Survey of AMSLS by matching participants' ID numbers. Furthermore, the EIS 2016 did not capture MS-related work productivity losses (due to absenteeism and presenteeism). MS-related absenteeism and presenteeism were therefore measured based on data from the Employment Survey 2015 of the AMSLS, a survey conducted only four to five months prior to the baseline EIS survey.

3.3.2 Data Analysis

The EIS 2016 captured detailed information on various cost categories from 488 people with MS who completed both the baseline survey and the cost diary as part of the survey (a response rate of 15%). Table 3.1 provides an overview of the categories of costs considered in this analysis. These data were used to determine the full societal costs of MS in Australia, using similar methodology to that described in the 2011 economic impact of MS report.[8]

In the baseline survey, respondents provided information on their basic demographic, health, employment and financial profiles. The completion of the cost diary however was relatively time consuming and demanding and as such fewer participants completed this part of the EIS 2016 survey. Respondents were asked to complete the cost diary daily over six months. They were asked to record all costs and resource use related to their MS, regardless of whether they paid for them personally or not. The use of a cost diary that needed to be completed every day obviated the need for recall, which is a frequently cited concern in surveys where participants with MS are required to remember what occurred in weeks or months previously. This approach was used to minimize recall bias in this study. Respondents reported the direct costs in 2017 Australian Dollars (AUD).

Table 3.1. Categories of costs considered in the current analysis

Cost category	Inclusions
Direct costs - overall Direct costs – personal Direct costs – community / government	Prescription medications, non-prescription medications, disposable equipment, health professionals, nursing services, community and private services, medical tests, hospital stays, special equipment-hire, special equipment-purchase (mobility, visual aids, communications, bathroom, kitchen, bedroom, general), alterations to home, alterations to car, and transport
Nursing home and equivalent costs	Residential care
Informal care costs	Costs to carers due to reduced employment
Indirect costs from lost wages	Early retirement, occupation change and employment status change (e.g.: from fulltime to part-time)
Indirect costs from lost productivity	Absenteeism and presenteeism costs*

*MS-related work productivity loss was measured from the Employment Survey 2015

Costs were analysed by disability severity (classified as no disability [Expanded Disability Status Scale - EDSS 0], mild disability [EDSS 1.0-3.5], moderate disability [EDSS 4.0-6.0], and severe disability [EDSS 6.5 to 9.5]), sex, age group, state/territory of usual residence, Australian Remoteness Areas, MS type, and whether or not they were receiving DMTs.

Prescription medication costs were calculated using the Pharmaceutical Benefits Schedule (PBS) cost schedule (1 June 2017).[26] The improved and much more detailed EIS 2016 enabled us to breakdown the 'prescription medication costs into three sub-categories (i.e.: DMTs, symptom-specific, and others). As we did not know the co-payment types (general vs concessional) of our sample for MS-specific prescription medications, the average co-payment amount of AUD 8.9 (= [38.80 x 8%] + [6.30 x 92%]) was applied. This was based on the June 2017 general co-payment of AUD 38.80 and concessional co-payment of AUD 6.30, and the 2016-17 expenditure and prescription data from the PBS Pricing and Policy Branch (Technology Assessment and Access Division),[27] suggesting that a significant majority of Australians (about 92%) made concessional co-payments between July 2016 and June 2017.

Contrary to the previous work,[6, 8, 22] we have provided a breakdown of the 'special equipment' costs into 8 sub-categories (i.e.: Special equipment- Hire, Special equipment Purchase-MOBILITY, Special equipment Purchase-VISUAL AIDS, Special equipment Purchase-COMMUNICATIONS, Special equipment Purchase-BATHROOM, Special equipment Purchase-KITCHEN, Special equipment Purchase-BEDROOM, and Special equipment Purchase-GENERAL). Also, the EIS 2016 provided the breakdown of "alteration to car/home" costs into two separate categories (i.e. alteration to home, and alteration to car). The overall costs of MS and the breakdown of the overall costs by key cost categories (i.e.: direct costs-total, direct costs-personal, direct costs-community/government, nursing home and equivalent care costs, informal care costs, indirect costs from lost wages, and indirect costs from lost productivity) and sub-groups (disability severity, sex, age group, state/territory, Australian Remoteness Areas, MS type, and DMT usage) is provided in the results section. In addition, the results section also provides a breakdown of total direct costs by key categories (prescription medications, non-prescription medication, disposable equipment, health professionals, nursing services, community and private services, medical tests, hospital stay, special equipment, alteration to car/home and transport costs) and sub-groups. As has been noted earlier, some of the key cost categories of this analysis (i.e. prescription medication, special equipment, alterations to car/home, indirect costs from lost wages, and indirect costs from lost productivity) have been further broken down into more than one sub-categories. A more detailed cost breakdown by sub-categories is provided in the supplemental tables included with this report.

It was not possible to estimate nursing home and equivalent high-support care costs from the AMSLS data as only 2 of the 488 respondents indicated that they resided in a nursing home. This is likely to be an underestimation of the actual number of people in nursing homes as respondents in nursing homes are less likely to be able to complete the survey. The nursing home costs were therefore estimated indirectly using information from other sources. The Australian Bureau of Statistics Survey of Disability, Aging and Carers 2009 (4430.0) estimates the proportion of people with MS who reside in nursing homes is 5.66%. We applied the Australian Institute of Health and Welfare estimate of accommodation support of $109,715 per person (for 2015-16)[28] and inflated the costs to 2017 levels to reach to an estimated mean annual nursing home cost of $6,343 (= 109,715 x 0.0566 x 1.0215). We used the average health inflation factor of 2.15% between 2005/06 and 2015/16 to inflate the nursing home costs.[29] In the current analysis, the nursing home costs are only applied to severely disabled people with MS (n=88). This is in contrast with the previous approach used in the 2011 study,[6, 8] where an average nursing home cost was applied to all individuals with MS (irrespective of their disability status).

The informal care costs were assessed directly from the reported changes in average weekly earnings of the carers due to care provision to a person with MS. In cases where the average weekly earnings were missing but the number of work hours lost due to care provision was available, an average hourly wage rate (of $33) was multiplied with the number of work hours lost due to care provision to obtain an estimate of the informal care costs. Because the informal care costs were based on 2016 income estimates, we inflated these costs to 2017 levels using an annual wage inflation factor of 2% for the year 2017.[30] The indirect costs from lost wages were calculated by taking the difference between each participant's pre- and post-MS-onset wage. The respondents reported their Australian and New Zealand Standard Classification of Occupations (ANZSCO) occupation category (i.e.: Manager, Professional, Technician or Trade Worker, Community or Personal Service Worker, Clerical and Administrative Workers, Sales Workers, Machinery Operator or Driver, Labourer). They were asked to indicate if they had left employment due to their MS. The respondents also reported any changes to their pre- and post-MS-onset employment status (e.g. full-time, part-time) and occupation groups. A wage was attributed to each participant pre and post-MS-onset using the average wage by occupation and sex from the ABS Employee Earnings and Hours (Cat No. 6306.0), May 2016. In cases where the occupation category of respondents was missing but the number of work hours pre and post-MS symptoms was available, an average hourly wage rate (of $33) was used.[31] Contrary to the previous (2011) approach, we also broke down the indirect costs from lost wages into 3 sub-categories. These are: (1) indirect costs from lost wages due to early retirement; (2) indirect costs from lost wages due to employment status change; and (3) indirect costs from lost wages due to occupation change. Because the indirect costs from lost wages were based on 2016 income estimates, we inflated these costs to 2017 levels using an annual wage inflation factor of 2% for the year 2017.[30]

We also calculated indirect costs from lost productivity (absenteeism + presenteeism) in the analysis using the work productivity and activity impairment questionnaire (MS version [WPAI: MS]), administered as part of the Employment Survey 2015 of AMSLS. WPAI is a validated and reliable instrument to evaluate health-related impairments in work.[32] Lost productive days due to absenteeism were captured by the number of days respondents missed from work in the past four weeks due to MS. Lost productive days due to presenteeism were calculated by multiplying the number of days worked when suffering from MS-related problems by how much MS affected productivity while working (numeric rating scale 0–10, converted to a percentage of impairment at work by dividing by 10 and multiplying by 100%). We expressed the outcomes in percentages (percent productive time lost due to absenteeism/presenteeism divided by the total number of days the person should have worked in the past 4 weeks). Costs from absenteeism and presenteeism were calculated by multiplying the percent productive time lost by the average weekly income of the respondents (taken from EIS 2016 data). Annual total work productivity loss was obtained by adding the annualised costs from absenteeism and presenteeism together.
As the costs from lost work-productivity were based on 2016 income estimates, we inflated these costs to 2017 levels, using the wage inflation factor of 2%.[30]

3.3.3 Costing Approach

In order to estimate the costs, a 'top–down' or 'bottom up' approach may be adopted. The 'top–down' approach entails measurement of health service utilisation and expenditure using aggregate figures related to diagnoses codes from databases, national statistics and registries. The advantage of this approach is that it can be used for a variety of diseases facilitating comparisons. A drawback is that it may be limited by the availability of the required information on specific components within cost categories.

The 'bottom up' approach requires the data collection from a sample of the population with a health condition and extrapolating to the entire population with the condition. The advantage of this approach is that it is able to provide a greater level of detail of the cost components than is available from the top down approach. As the EIS 2016 provided detailed information on a variety of cost items from a large representative sample of people with MS, our study relied primarily on the 'bottom-up' costing approach (supplemented by a 'top-down' approach where patient level data were unavailable) to estimate the costs of MS.

3.3.4 Disability Measurement

Disability was assessed with the patient determined disease steps (PDDS) and mapped against the gold-standard Expanded Disability Status Scale (EDSS) as outlined in Table 3.2. The PDDS provides an assessment of mobility-based functional disability in MS and correlates highly with the EDSS.[24] Based on approximate EDSS scores, we classified our respondents into four categories, namely: no disability [EDSS level 0], mild disability [EDSS levels: 1–3.5], moderate disability [EDSS levels: 4–6] and severe disability [EDSS levels: 6.5–9.5].

While the direct costs of MS have almost doubled between 2010 and 2017, driven largely by the cost of DMTs, the overall increase in costs per person with MS has been limited to less than $10,000 due to a significant reduction in the indirect costs of MS through lost wages and informal care. **Lost wages now account for only 32% of the economic burden of MS compared to almost 50% in 2010.**

Table 3.2. The approximate EDSS equivalents of the PDDS

Patient Determined Disease Steps (PDDS) Description	Approximate EDSS Equivalent	Broad Disability Category
0 (I may have some mild symptoms, mostly sensory, due to MS but they do not limit my activity or lifestyle)	0	No Disability
1 (I have some noticeable symptoms from my MS, but they are minor and have only a small effect on my lifestyle)	1	Mild Disability
2 (I don't have any limitations in my walking ability. However, I do have problems due to MS that limit daily activities in other ways)	2-3.5	
3 (MS does interfere with my activities, especially walking. I can work a full day, but athletic or physically demanding activities are more difficult than they used to be. I usually don't need to use a walking stick (cane) or other walking aid, but I might during an MS attack)	4-5	Moderate Disability
4 (I can walk about 8 meters (or 25 feet) without using a walking stick (cane) or other walking aid such as a splint, brace, or crutch, but I may use a walking aid for greater distances)	6	
5 (To be able to walk 8 meters (or 25 feet), I have to have a walking stick (cane), a single crutch, or someone to hold onto. I can get around the house by holding onto furniture or touching the walls for support. I may use a scooter or wheelchair for greater distances)	6	
6 (To walk 8 meters (or 25 feet), I must have two walking sticks (canes), two crutches, or a walking frame (walker). I may use a scooter or wheelchair for greater distances)	6.5	Severe Disability
7 (My main form of mobility is a wheelchair. I may be able to stand and/or take one or two steps, but I can't walk 8 meters (or 25 feet), even with crutches or a walking frame)	7	
8 (I am unable to sit in a wheelchair for more than 1 hour, and I spend most of my time in bed)	8-9.5	

3.4 Results

3.4.1 Sample Characteristics

The cost analysis was based on data from 488 cases who completed both the Baseline Questionnaire and the Cost Diary as part of the EIS 2016. We assessed the representativeness of our sample by comparing the demographic and other features of respondents (n=488) with non-respondents (n=2675), comparing participants' age at the diagnosis of MS, age group distribution, sex, disease duration, and geographic distribution.

As shown in Table 3.3, four out of five respondents and non-respondents (81% and 78%, respectively) were female. The mean age 55.8 years (respondents) and 54.8 years (non-respondents) were similar. In addition, the mean duration of MS from diagnosis for respondents was 15.5 years, which closely matched with 15.2 years for non-respondents. We split respondents and non-respondents into five age groups (namely: <35 years, 35–44 years, 45–54 years, 55–64 years, and 65+ years). The age group distribution of respondents and non-respondents was similar, except the response group had a slightly higher proportion of people aged 65+ years (+2 percentage points). More than half of the respondents and non-respondents came from New South Wales (NSW) and Victoria (VIC), as expected from the geographical distribution of people with MS. The data on type of MS, DMT usage, and disability severity was available for the respondents only. Two thirds of our respondents had RRMS, followed by SPMS (14%), PPMS (6%) and PRMS (3%). More than two-thirds (69%) were using DMTs, and over half were either moderately or severely disabled.

To statistically confirm the representativeness of our sample, we compared the demographic and other characteristics of respondents with non-respondents using t-test. Our results suggested no statistically significant differences between respondents and non-respondents in sex (P =0.10), age (P =0.07), state/territory of residence (P-value=0.50), age group (P =0.26), and MS duration from diagnosis (P =0.50). Respondents could therefore be considered highly representative of the AMSLS cohort as a whole. The AMSLS cohort has been previously validated as representative of the Australian MS population.[23]

Table 3.3. Characteristics of the participants in the Cost Analysis (EIS 2016)

	Respondents	non-respondents
Characteristics	(N=488)	(N=2675)
Sex		
Male % (n)	19 (90)	22 (583)
Female % (n)	81 (398)	78 (2092)
Age group		
<35 % (n)	4 (18)	4 (107)
35-44 % (n)	15 (73)	16 (441)
45-54 % (n)	26 (125)	26 (705)
55-64 % (n)	31 (151)	31 (810)
65+ % (n)	24 (119)	22 (590)
Not stated % (n)	<1 (2)	1 (22)
State of usual residence		
NSW % (n)	27 (132)	31 (837)
VIC % (n)	25 (123)	27 (728)
QLD % (n)	15 (72)	14 (386)
SA % (n)	10 (50)	8 (223)
WA % (n)	11 (52)	11 (286)
ACT % (n)	6 (28)	3 (74)
TAS % (n)	5 (25)	5 (128)
NT % (n)	<1 (1)	<1 (6)
Not stated % (n)	1 (6)	<1 (6)
MS type		
PPMS % (n)	6 (32)	N/A
RRMS % (n)	60 (291)	N/A
SPMS % (n)	14 (68)	N/A
PRMS % (n)	3 (13)	N/A
Unsure % (n)	10 (49)	N/A
Not stated % (n)	7 (35)	N/A
DMTs		
Yes % (n)	69 (339)	N/A
No % (n)	30 (142)	N/A
Not stated % (n)	1 (7)	N/A
Disability severity		
No disability % (n)	21 (103)	N/A
Mild disability % (n)	25 (122)	N/A
No/mild disability % (n)	46 (225)	N/A
Moderate disability % (n)	35 (173)	N/A
Severe disability % (n)	18 (88)	N/A
Not stated % (n)	<1 (2)	N/A
MS duration		
Average in years (n)	15.5 (472)	15.2 (2,349)
Age		
Average in years (n)	55.8 (486)	54.8 (2,643)

N/A = Not Applicable

3.4.2 Costs of MS by Cost Category (the Overall Sample)

As shown in Table 3.4, the total annual costs per person with MS were estimated to be $68,382 (95% confidence interval [CI]: 63,442–73,322). The total costs for all people with MS in Australia (n=25,607) were $1.75 billion (95%CI: $1.70–$1.81 billion). The largest component was the direct costs (44%, $30,346 [95%CI: $28,336–$32,354]). The total direct costs for all people with MS were $777 million (95%CI: $755–$804 million). Twenty two percent of the direct per person costs ($8,437 [95%CI: $7,154–$9,721]) was born by the people with MS, while government and community jointly incurred 78% of the direct per person costs ($21,911 [95%CI: [$20,447–$23,375]). The second largest component was the indirect costs from lost wages (32%, $21,858 [95%CI: $18,743–$24,974]), representing per person loss of wages due to early retirement/employment status change/ occupation change.

Table 3.4. Cost of MS by cost category per person and for Australia ($2017)

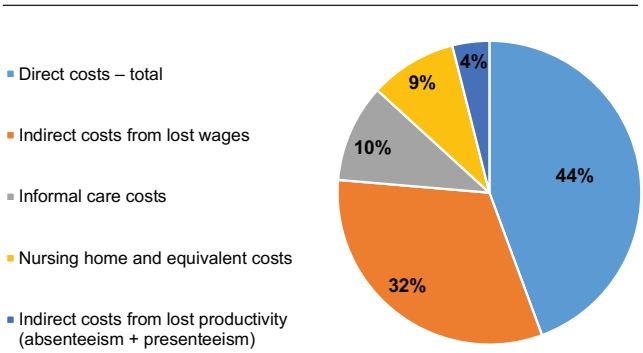
Cost Category	Per Person Costs (n=488)	Total (Million)*
	Mean (95%CIs)	Mean (95%CIs)
Direct costs – personal	$8,437 ($7,154–$9,721)	$216 ($210–$223)
Direct costs – community / government	$21,911 ($20,447–$23,375)	$561 ($545–$580)
Direct costs – total	$30,346 ($28,336–$32,354)	$777 ($755–$804)
Nursing home and equivalent costs	$6,343 ($5,139–$7,547)	$162 ($158–$168)
Informal care costs	$7,144 ($5,283–$9,005)	$183 ($178–$189)
Indirect costs from lost wages – early retirement	$13,468 ($10,931–$16,004)	$345 ($335–$357)
Indirect costs from lost wages – employment status change	$5,408 ($3,982–$6,835)	$138 ($135–$143)
Indirect costs from lost wages – occupation change	$2,982 $(1,848–$4,117)	$76 ($74–$79)
Indirect costs from lost wages – overall	$21,858 ($18,743–$24,974)	$560 ($544–$579)
Indirect costs from lost productivity - absenteeism	$482 ($312–$651)	$12 ($12–$13)
Indirect costs from lost productivity - presenteeism	$2,209 ($1,677–$2,741)	$57 ($55–$58)
Indirect costs from lost productivity – overall	$2,691 ($2,052–$3,329)	$69 ($67–$71)
Total Costs	**$68,382 ($63,442–$73,322)**	**$1,751 ($1,701–$1,811)**

*Based on 2017 prevalence of MS in Australia of 25,607 (95%CI: 24,874–26,478)

Over 60% of the indirect costs from lost wages ($13,468 [95%CI: $10,931–$16,004]) was due to early retirement of people with MS.

Other significant cost components included the informal care costs (10%, $7,144 [95%CI: $5,283–$9,005]), nursing home costs (9%, $6,343 [95%CI: $5,139–$7,547]) and the indirect costs from lost productivity (absenteeism + presenteeism) (4%, $2,691 [$2,052–$3,329]), with presenteeism being the largest component of the lost productivity costs. Figure 3.1 provides the percentage distribution of costs of MS between the key costs categories considered.

Figure 3.1. Cost of MS by cost categories – percent



The largest component was the direct costs (44%, $30,346). Twenty two percent of the direct per person cost ($8,437) were borne 'out of pocket' by the people with MS themselves, while government and community jointly incurred 78% of the direct per person costs ($21,911). The second largest component was the indirect costs from lost wages (32%, $21,858).

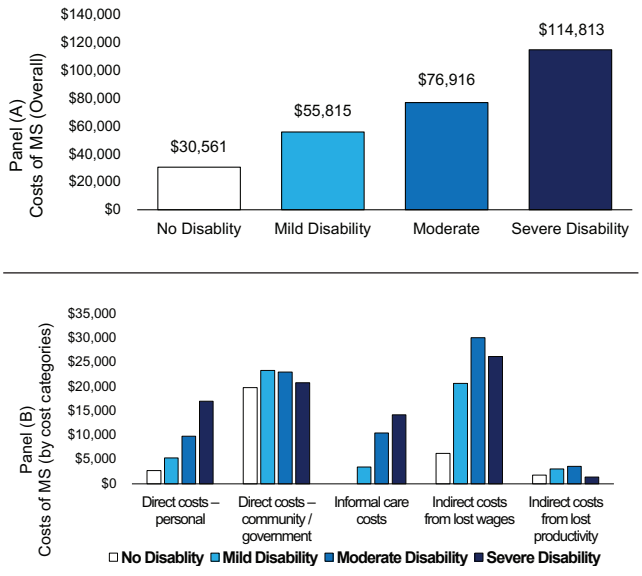
3.4.3 Costs of MS by Cost Category and Sub-group

3.4.3.1 Costs of MS by Cost Category and Disability Severity

The costs broken down by disability severity are shown in Figure 3.2 (Panels A and B). From Panel A, the total per person costs of MS increased with increasing disability severity: $30,561, $55,815, $76,916, and $114,813 for no, mild, moderate and severe disability, respectively. From Panel B, the direct personal costs and informal care costs increased with increasing disability severity. The no disability group did not incur any informal care costs. The direct community government costs, indirect costs from lost wages, and indirect costs from lost productivity generally increased with increasing disability severity.

Compared to the mild and moderate disability groups, the severe disability group incurred lower costs in the categories of direct costs (community/government) (due to lower DMTs costs), indirect costs from lost wages and indirect costs from lost productivity (due to a substantial proportion of severely disabled people aged 65 years and over).

Figure 3.2. Costs of MS by cost category and disability severity - per person ($2017)



No disability includes EDSS level 0, Mild includes EDSS levels 1 – 3.5, Moderate includes EDSS levels 4 – 6, and Severe includes EDSS levels 6.5 – 9.5. *Note:* disability state was not known for 2 people with MS

As shown in Figure 3.2 (Panel B), informal care costs and indirect costs from lost wages increased markedly from mild disability to moderate disability. Supplemental Table 3A provides the itemised breakdown of costs of MS by key cost categories/sub-categories and disability severity. Because the information on the nursing home distribution of people with MS by sub-groups (age group, sex, geographic location, MS type, Immunotherapy usage) was not available, the nursing home costs are not presented in any of the figures comparing costs by sub-groups as the comparison does not appear meaningful.

3.4.3.2 Costs of MS by Cost Category and Sex

The costs broken down by sex are shown in Figure 3.3 (Panels A and B). From Panel A, the total per person costs of MS were slightly higher for males ($71,445) compared to females ($67,689). From Panel B, the direct costs, informal care costs, and indirect costs from lost productivity were similar for both sexes. Indirect costs from lost wages however were higher for males relative to females. The higher indirect costs from lost wages for the male sex appear to be driving the trend observed in the analysis of total costs by sex. This is in accordance with the previous findings,[21] suggesting that the gap in employment (between the Australian general population and the Australian population of people with MS) is larger for males than females and over time the gap has not been bridged for males in the same way as it has for females.[31] Therefore, higher indirect costs from lost wages for the male sex is not surprising. Supplemental Table 3B provides the itemised breakdown of costs of MS by key cost categories/sub-categories and sex.

Figure 3.3. Costs of MS by cost category and sex - per person ($2017)

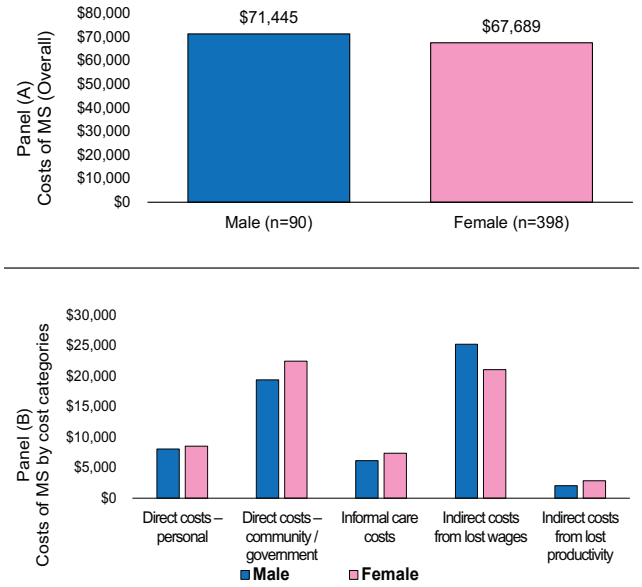
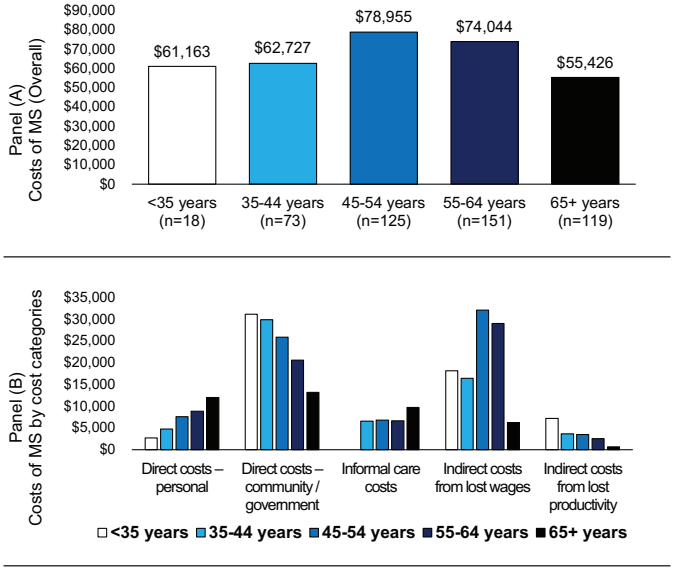


Figure 3.4. Costs of MS by cost category and age group - per person ($2017)



Age group was not known for 2 participants

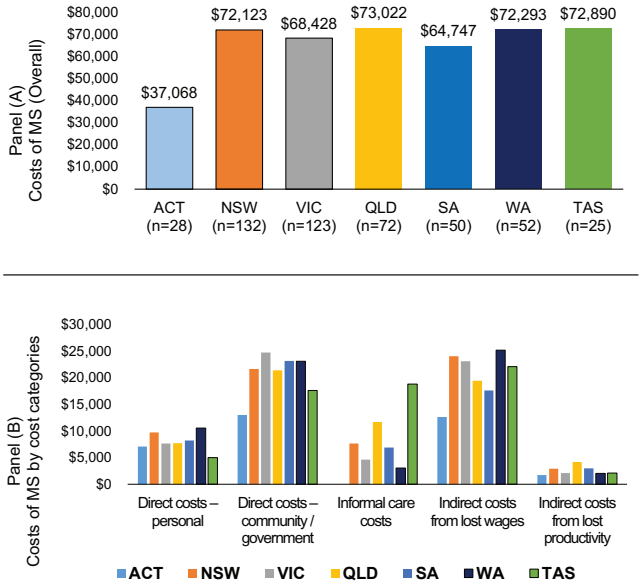
3.4.3.3 Costs of MS by Cost Category and Age Group

The costs broken down by age group are shown in Figure 3.4 (Panels A and B). From Panel A, the total per person costs of MS increased with age up to 54 years, and then decreased. The total per person costs did not vary considerably between the people aged <35 years and those aged 35-44 years. People aged 65 years and over incurred the lowest per person costs. From Figure 3.4 (Panel B), the direct personal costs, and informal care costs increased with age. People aged <35 years did not incur any informal care costs. In addition, the direct personal costs were minimal for this age group. The direct community/government costs (driven mainly by DMT costs), and indirect costs from lost productivity decreased with age. Indirect costs from lost wages generally increased with age up to 54 years, and then decreased. Supplemental Table 3C provides the breakdown of costs of MS by key cost categories/sub-categories and age group.

3.4.3.4 Costs of MS by Cost Category and State/Territory

The costs broken down by state/territory are shown in Figure 3.5 (Panels A and B). From Panel A, the total per person costs of MS did not vary considerably between the Australian states and territories, with the ACT being an outlier (having significantly lower total per person costs of MS). From Figure 3.5 (Panel B), no clear patterns emerge. However, the lower community/government direct costs and the indirect costs from lost wages, and zero informal care costs for ACT appear to be driving the significantly lower overall per person costs of MS in the ACT. Just over 50% of the ACT sample were on DMTs (compared to 70% in NSW and 80% in VIC), which resulted in lower community/ government direct costs in the ACT.

Figure 3.5. Costs of MS by cost category and state/ territory - per person ($2017)



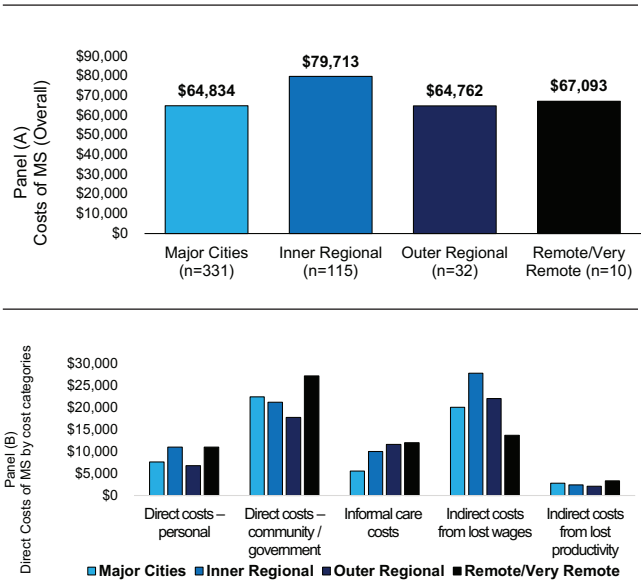
Note: (1) NT provided data on one person with MS only so we have excluded NT from this figure. (2) Five people with MS did not report their usual state/territory of residence.

Furthermore, more than 35% of ACT sample was aged 65 years or above, which resulted in lower indirect costs from lost wages. Finally, less than 1% of the ACT sample had severe disability, which may explain lower informal care costs in the ACT. TAS had the lowest direct personal costs and the highest informal care costs. The higher informal care costs in TAS may be related to the Tasmanian sample's age structure (with more than 75% of the sample aged 55 years or over). Section 3.3.5.4 provides some explanation of the lower direct costs in TAS. Supplemental Table 3D reports itemised breakdown of costs of MS by key cost categories/ sub-categories and location (see also, Figure 3.12 and Supplemental Table 3J).

3.4.3.5 Costs of MS by Cost Category and Australian Remoteness Areas

The costs broken down by Australian Remoteness Areas are shown in Figure 3.6 (Panels A and B).

Figure 3.6. Costs of MS by cost category and Australian Remoteness Areas - per person ($ 2017)



From Panel A, the total per person costs of MS did not vary markedly between the Australian Remoteness Areas, with the Inner Regional having relatively higher costs. From Figure 3.6 (Panel B), no clear patterns emerge. However, the higher indirect costs from lost wages for Inner Regional area appear to be driving the relatively higher overall per person costs of MS in that area. Sixty two percent of Inner Regional people with MS were aged between 45 and 64 years (compared to 53% in major cities). This appears to be driving the higher costs from lost wages for this group, given ages between 45 and 64 years attract higher costs from lost wages (as shown previously in Figure 3.4). People in this age group tend to be in the prime years of their work life (with relatively higher incomes) and mid-to-late stages of their MS (with higher disability levels). Supplemental Table 3E reports itemised breakdown of costs of MS by key cost categories/sub-categories and Australian Remoteness Areas.

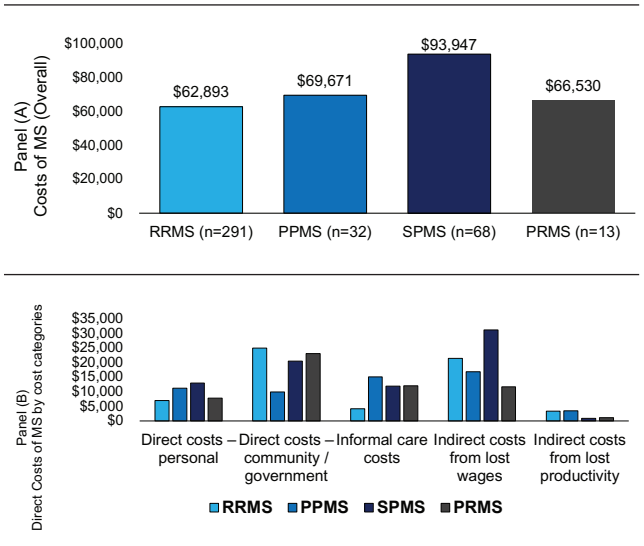
Costs for people living in Inner Regional areas are higher compared to those in metropolitan areas due to higher indirect costs from lost wages.

3.4.3.6 Costs of MS by Cost Category and MS Type

The costs broken down by MS type are shown in Figure 3.7 (Panels A and B). From Panel A, the total per person costs of MS were highest for people with SPMS ($93,947), followed by people with PPMS ($69,671), PRMS ($66,530) and RRMS ($62,893). From Figure 3.7 (Panel B), the direct personal costs were highest for people with SPMS and lowest for people with RRMS. The direct community/government costs were highest for people with RRMS and lowest for people with PPMS. Informal care costs were substantially lower for people with RRMS. Other groups of people with MS (i.e.: PPMS, RRMS, and SPMS) had similar informal care costs. Indirect costs from lost wages increased as the MS type moved from PPMS to RRMS to SPMS. People with PRMS however had much lower costs from lost wages. The lowest indirect costs from lost wages for PPMS group appeared unexpected. However, a closer look at the data revealed that more than half (55%) people with PPMS were aged 65 years and over (compared to 14% from RRMS group and 40% from SPMS group). Such a higher proportion of people aged 65 years and over in the PPMS group, implied that more than half of the PPMS sample did not contribute anything to the costs from lost wages for this group, hence, lower indirect costs from lost wages. Finally, the indirect costs from lost productivity were similar for PPMS and RRMS, and SPMS and PRMS. Supplemental Table 3F provides the itemised breakdown of costs of MS by key cost categories/sub-categories and type of MS.

Costs for people with Primary Progressive MS (PPMS) are also high; however, as they are frequently diagnosed at a later age, the impact of lost earnings contributes less to the overall costs for people with PPMS.

Figure 3.7. Costs of MS by cost category and MS type - per person ($2017)



49 participants were unsure about their MS type and 35 did not state

3.4.3.7 Costs of MS by Cost Category and DMT Usage

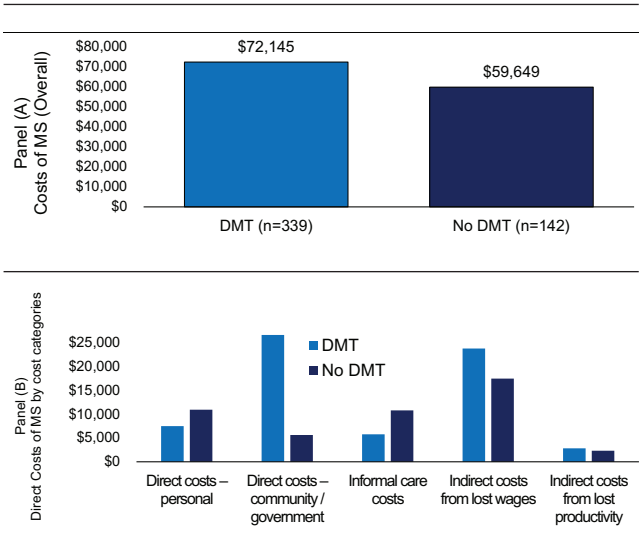
Figure 3.8 (Panels A and B) show per person costs of MS stratified by DMT usage. From Panel A, the total per person costs of MS were higher for people using any kind of DMTs ($72,145), compared to people not on DMTs ($59,649).

From Figure 3.8 (Panel B), the direct personal costs and informal care costs were higher for people not using DMTs. The direct community/government costs (driven mostly by DMTs costs) and indirect costs from lost wages were higher for people using DMTs, mainly because people on DMTs were younger (14% and 51% aged 65 years and over in DMT and no DMT groups, respectively). Our analysis assumed zero wage loss for people aged 65 years and over. After we excluded those aged 65 years and over from both (DMT and No DMT) groups and reanalysed the indirect cost data for people of working ages only, we found that the DMT group had lower costs from lost wages ($26,421), compared with the No DMT group ($30,567). Overall, the indirect costs from lost productivity did not vary substantially between the two groups.

Costs of people on DMT are slightly higher, driven by higher costs of medicines, but informal care costs and costs from lost wages (for people aged <65 years) are lower.

The higher direct community/government costs and indirect costs from lost wages for those using DMTs appeared to be driving the trend observed in the analysis of total costs by DMT usage. Supplemental Table 3G provides the itemised breakdown of costs of MS by key cost categories/sub-categories and DMT usage.

Figure 3.8. Costs of MS by cost category and DMT usage- per person ($2017)



DMT usage history was not available for 17 participants.

3.4.4 Direct Costs of MS by Cost Category (Overall)

As shown in Table 3.5, the direct costs per person with MS were estimated to be $30,346 (95%CI: 28,336–32,354). The total direct costs for all people with MS in Australia (n=25,607) totalled $777 million (95%CI: 756–804). The largest component was the prescription medication costs (55%, $16,723 [95%CI: $15,588–$17,858]), with DMTs being the largest component (95% of the prescription medication costs).

The total prescription medication costs for all people with MS in Australia totalled $428 million (95%CI: $416–$443), which is roughly one quarter of the total costs of all people with MS in Australia ($1,751 million). The second largest direct costs component was alterations to car/home ($2,814 [95%CI: $1,928–$3,700]), followed by hospitalisations ($2,455 [$1,806–$3,103]), health professionals ($2,282 [$2,016–$2,548]) and community and private services costs ($2,045 [$1,488–$2,601].

Table 3.5. Direct costs - by cost category - per person with MS and for Australia ($2017)

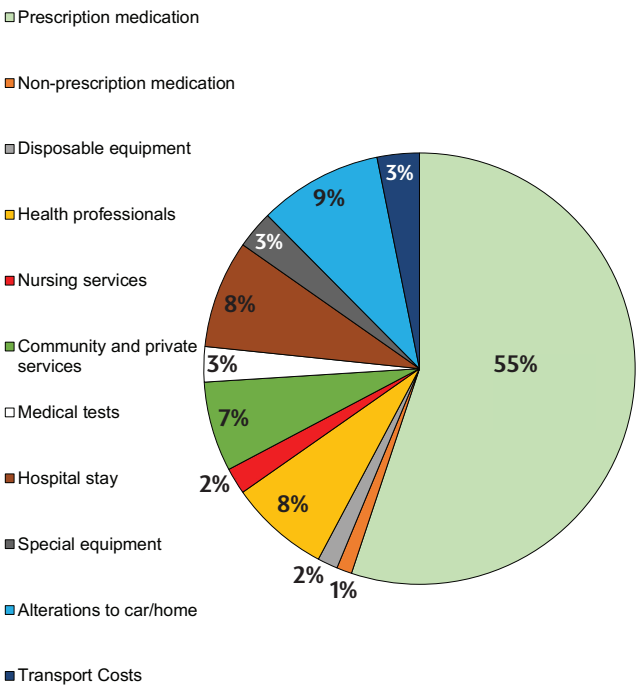
Cost Category	Per Person Costs (n=488)	Total (Million)*
	Mean (95%CIs)	Mean (95%CIs)
Prescription medication: DMTs	$15,882 ($14,771–$16,992)	$406.7 ($395.0–$420.5)
Prescription medication: Symptom Specific	$524 ($386–$663)	$13.4 ($13.0–$13.9)
Prescription medication: Others	$317 ($204–$430)	$8.1 ($7.9–$8.4)
Prescription medication: Overall	$16,723 ($15,588–$17,858)	$428.2 ($416.0–$442.8)
Non-prescription medication	$347 ($299–$395)	$8.9 ($8.6–$9.2)
Disposable equipment	$460 ($265–$656)	$11.8 ($11.5–$12.2)
Health professionals	$2,282 ($2,016–$2,548)	$58.4 ($56.8–$60.4)
Nursing services	$600 ($407–$793)	$15.4 ($14.9–$15.9)
Community and private services	$2,045 ($1,488–$2,601)	$52.4 ($50.9–$54.1)
Medical tests	$801 ($705–$898)	$20.5 ($19.9–$21.2)
Hospital stay	$2,455 ($1,806–$3,103)	$62.9 ($61.1–$65.0)
Special equipment Hiring	$17 ($3–$31)	$0.4 ($0.4–$0.4)
Special equipment Purchase-MOBILITY	$390 ($310–$470)	$10.0 ($9.7–$10.3)
Special equipment Purchase-VISUAL AIDS	$59 ($41–$78)	$1.5 ($1.5–$1.6)
Special equipment Purchase-COMMUNICATIONS	$95 ($64–$126)	$2.4 ($2.4–$2.5)
Special equipment Purchase-BATHROOM	$72 ($45–$99)	$1.8 ($1.8–$1.9)
Special equipment Purchase-KITCHEN	$24 ($12–$37)	$0.6 ($0.6–$0.6)
Special equipment Purchase-BEDROOM	$115 ($77–$153)	$2.9 ($2.9–$3.0)
Special equipment Purchase-GENERAL	$87 ($64–$110)	$2.2 ($2.2–$2.3)
Special equipment Purchase-OVERALL	$860 ($709–$1,010)	$22.0 ($21.4–$22.8)
Alterations to home	$2,228 ($1,374–$3,082)	$57.1 ($55.4–$59.0)
Alterations to car	$586 ($424–$749)	$15.0 ($14.6–$15.5)
Alterations to car/home	$2,814 ($1,928–$3,700)	$72.1 ($70.0–$74.5)
Transport Costs	$959 ($555–$1,363)	$24.6 ($23.9–$25.4)
Total Direct Costs	**$30,346 ($28,336–$32,354)**	**$777.0 ($755.8–$803.5)**

*Based on 2017 prevalence of MS in Australia of 25,607 (95%CI: 24,874–26,478)

Other significant direct cost components were: transport ($959 [95%CI: $555–$1,363]), special equipment ($860 [95%CI: $709–$1,010]), medical tests ($801 [95%CI: $705–$898]), nursing services ($600 [95%CI: $407–$793]), and disposable equipment ($460 [95%CI: $265–$656]). Whereas, the non-prescription medications cost the least ($347 [$299–$395]). Notably, over 45% of the special equipment costs was related mobility needs of people with MS.

Figure 3.9 provides the percentage distribution of direct costs of MS between the key direct costs categories included.

Figure 3.9. Direct Cost of MS by cost categories – percent



3.4.5 Direct Costs of MS by Cost Category and Sub-group

3.4.5.1 Direct Costs of MS by Cost Category and Disability Severity

The direct per person costs broken down by disability severity are shown in Figure 3.10 (Panels A and B). From Panel A, the direct per person costs of MS exhibited a steady increase with increasing disability severity: $27,085, $28,642, $32,744, and $37,815 for no, mild, moderate and severe disability, respectively. From Panel B, the prescription medications were the largest direct cost component for all disability classes. Notably, the prescription medication costs for severe disability group were substantially lower than other disability groups, which is not surprising as DMTs are the biggest component of the prescription medication costs and are only rarely administered to people with severe MS.

As shown in Figure 3.10, costs of non-prescription medication, disposable equipment, health professionals, nursing services, community and private services, special equipment, alterations to car/home and transport generally increased with increasing disability severity. Notably, the costs of community and private services, and alteration to car/home increased markedly as a person with MS transitioned from no disability through to severe disability. People with no disability did not incur any special equipment costs.

Compared to people with mild or moderate disability, those with severe disability incurred lower costs in the category of medical tests (which is expected, as this group may have undergone most of the necessary medical tests at the early-to-mid stages of their MS). The hospitalisation costs were highest for mild disability (which may be because people at early stages of their MS were accessing new DMTs (such as Tysabri and Lemtrada) through hospital-administered infusions to halt disease progression and associated disability acquisition or because they may still be having more relapses as they try to find the most effective DMT for them. Other DMTs such as Gilenya (introduced in 2011) require 6 hours first dose monitoring which may also contribute to hospitalisation costs.

Supplemental Table 3H provides the itemised breakdown of direct costs of MS by key cost categories/sub-categories and disability severity.

Figure 3.10. Direct Costs of MS by cost category and disability severity - per person ($2017)

No disability includes EDSS level 0, Mild includes EDSS levels 1 – 3.5, Moderate includes EDSS levels 4 – 6, and Severe includes EDSS levels 6.5 – 9.5. Disability state was not known for 2 participants.

The direct per person costs of MS exhibited a steady increase with increasing disability severity. The prescription medications were the largest direct cost component for all disability classes.

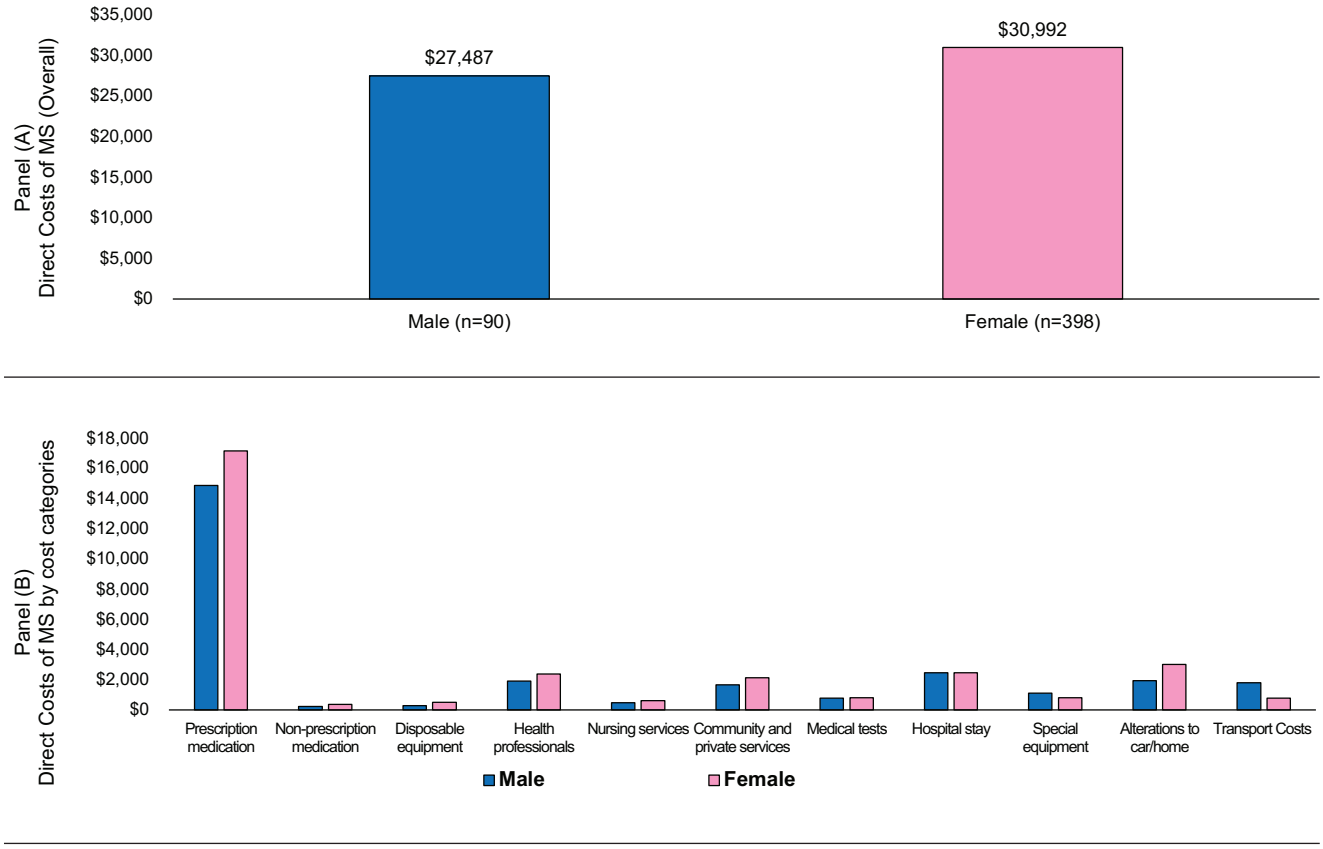
3.4.5.2 Direct Costs of MS by Cost Category and Sex

The direct costs broken down by sex are shown in Figure 3.11 (Panels A and B). From Panel A, the direct per person costs of MS are slightly higher for females ($30,992) compared to males ($27,487). From Panel B, the higher prescription medication and alteration to car/home costs for females appear to be driving the trend observed in the analysis of the overall direct costs by sex.

The total per person costs of MS were slightly higher for males compared to females. Whereas direct costs for women are higher, including costs of medications, alterations to car and home, and health and community services, indirect costs due to lost wages are higher for men.

From Panel B, women appear to be using more health professional services, nursing services, community and private services then men. Whereas, non-prescription medication, disposable equipment, medical tests, and hospitalisations costs are similar for both sexes. Men spend more on special equipment purchases and transport. Upon checking the data, 30% of men and 15% of women had severe disability, which may explain the higher special equipment costs for the male sex. Supplemental Table 31 provides the itemised breakdown of costs of MS by key cost categories/sub-categories and sex.

Figure 3.11. Direct Costs of MS by cost category and sex - per person ($2017)



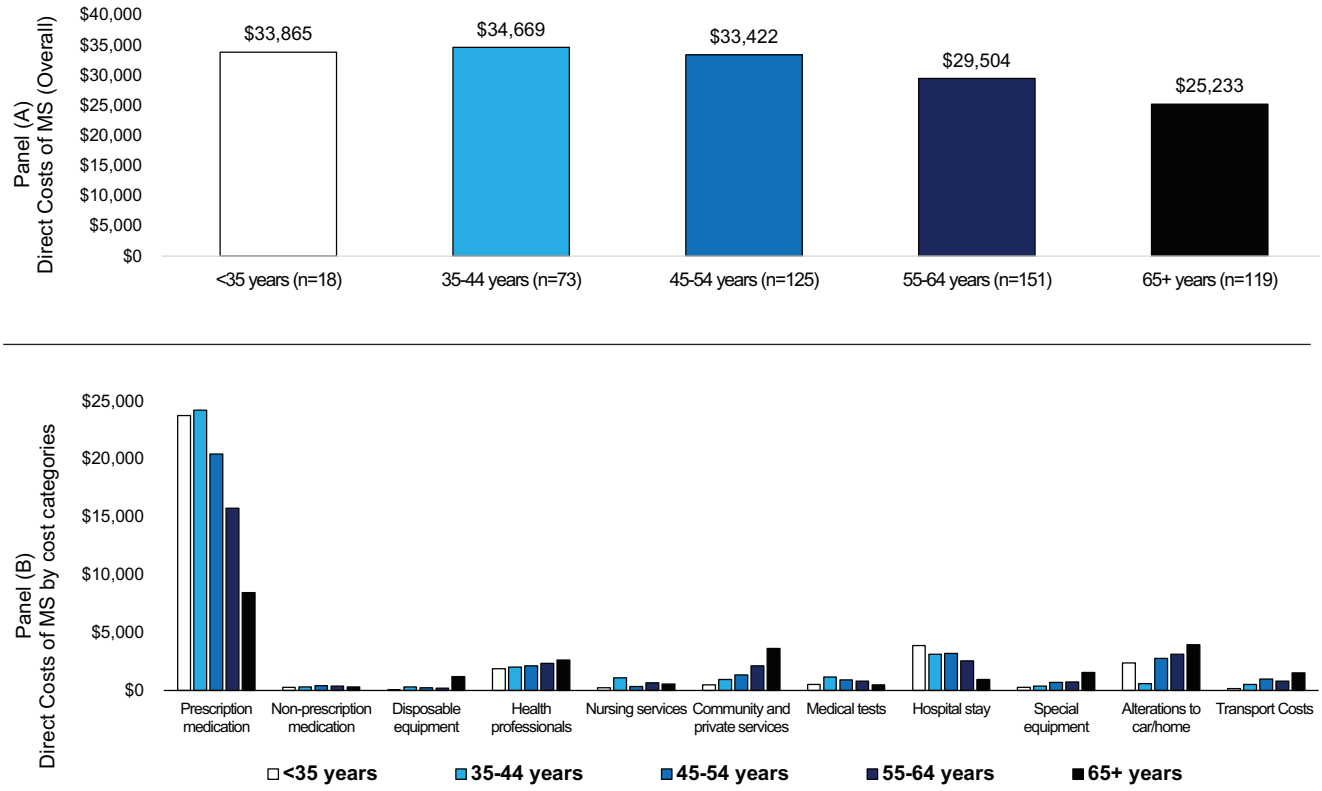
3.4.5.3 Direct Costs of MS by Cost Category and Age Group

The direct costs broken down by age group are shown in Figure 3.12 (Panels A and B). From Panel A, the direct per person costs of MS increased with age up to 44 years, and then decreased. The direct per person costs did not vary considerably between the people aged <35 years and those aged 35-44 years. People aged 65 years and over incurred the lowest direct per person costs (which is mainly because the DMT penetrance was lowest for this age group).

From Figure 3.12 (Panel B), the costs of non-prescription medication, disposable equipment, health professionals, community and private services, special equipment, alterations to car/home and transport costs generally increased with age.

Whereas, costs of medical tests and hospitalisations generally exhibited a decreasing trend with age. A negative correlation between the costs of medical tests and age was expected as people tend to undergo the necessary medical (diagnostic and other) tests at early ages, with relatively less disease severity. Similarly, a negative relationship between the hospitalisation costs and age was expected, especially given the changed DMTs landscape in recent years, as people at younger age groups and earlier stages of MS are more likely to access DMTs which may be administered in hospital (such as Tysabri and Lemtrada infusions) or require hospital-based first dose monitoring (e.g. Gilenya). Supplemental Table 3J provides the breakdown of direct costs of MS by key cost categories/sub-categories and age group.

Figure 3.12. Direct Costs of MS by cost category and age group - per person ($2017)



Age group was not known for 2 participants

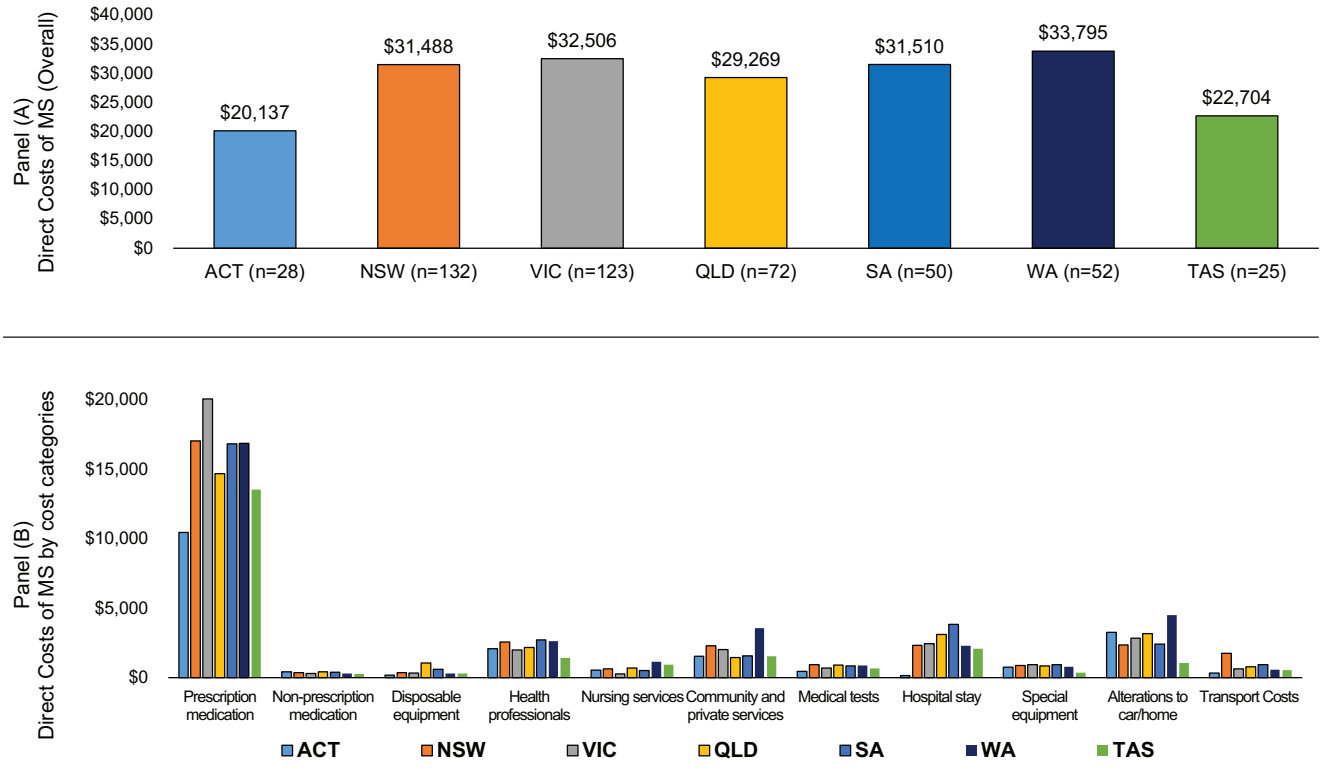
3.4.5.4 Direct Costs of MS by Cost Category and State/Territory

The costs broken down by state/territory are shown in Figure 3.13 (Panels A and B). From Panel A, the direct per person costs of MS did not vary considerably between the Australian states and territories, with the ACT and TAS being the outliers (having significantly lower direct per person costs of MS).

From Figure 3.13 (Panel B), no clear patterns emerged. The ACT had the lowest prescription medication costs, with TAS showing the second least prescription medication costs.

The lower prescription medication costs in ACT and TAS appear to be driving the significantly lower overall direct per person costs of MS in the ACT and TAS. Notably, TAS ranked the lowest in almost all the direct cost categories, hence lower overall direct costs of MS in TAS (Figure 3.13). The differences between states and territories should however be interpreted with caution due to the low sample sizes for TAS and ACT. Supplemental Table 3K reports itemised breakdown of costs of MS by key cost categories/sub-categories and state/territory.

Figure 3.13. Direct Costs of MS by cost category and state/territory - per person ($2017)



Note: (1) NT provided data on one person with MS only so we have excluded NT from this figure.
(2) Five people with MS did not report their usual state/territory of residence.

3.4.5.5 Direct Costs of MS by Cost Category and Australian Remoteness Areas

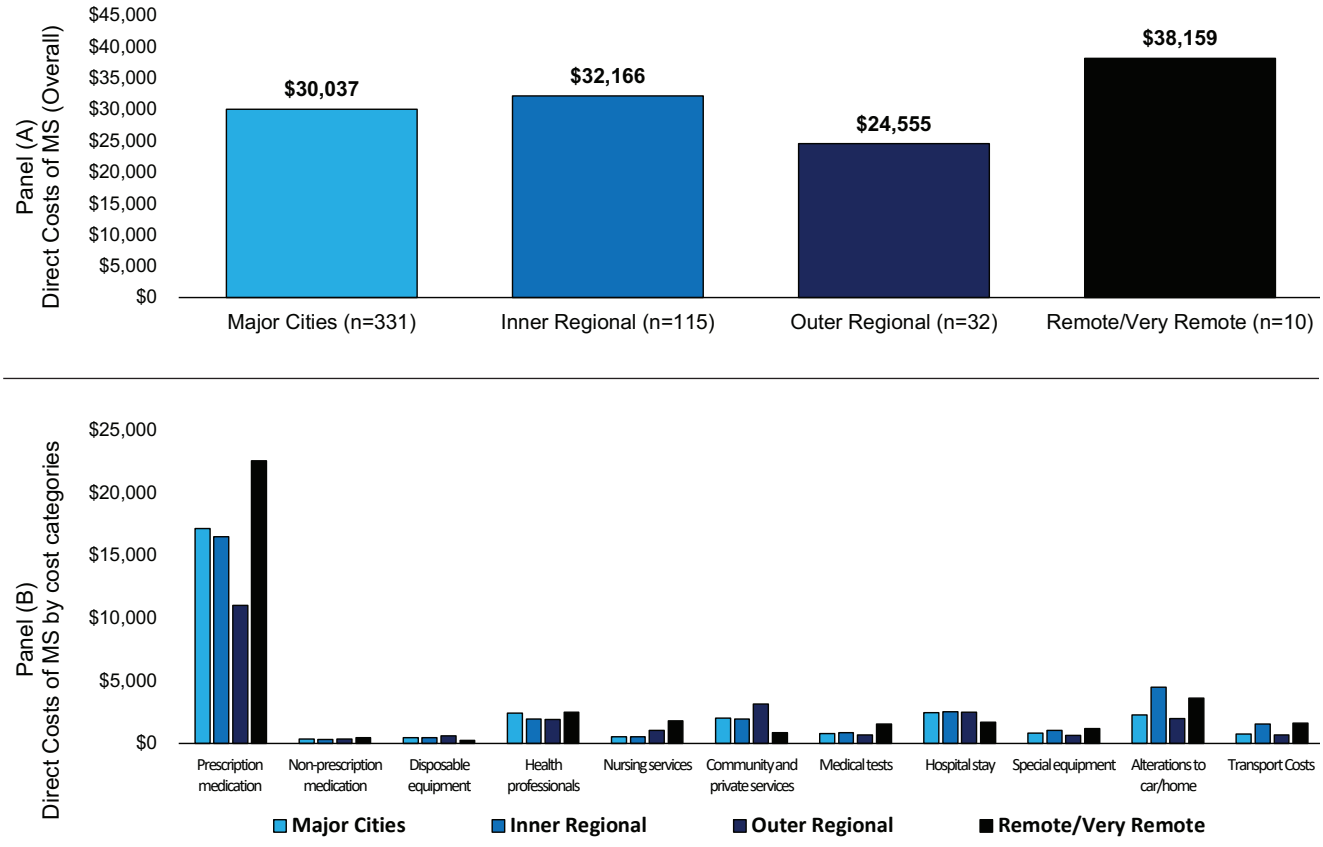
The direct costs broken down by Australian Remoteness Areas are shown in Figure 3.14 (Panels A and B). From Panel A, the direct per person costs of MS did not vary markedly between major cities ($30,037) and inner regional areas ($32,166). The Outer Regional area had the lowest direct per person costs of MS ($24,555) and remote/very remote area the highest (38,159).

From Figure 3.14 (Panel B), no clear patterns emerged, except the prescription medication costs vary noticeably between the Australian Remoteness Areas. The Outer Regional area attracted lowest prescription medication costs and Remote/Very Remote area the highest. The differences in prescription medication costs between Australian regions appear to be driving the trends observed in the Panel A of Figure 3.14.

People in Outer Regional areas may have different treatment choices as newer generation medications that require hospital delivery or more complex monitoring requirements may be less likely to be selected as the most appropriate treatment choice in Outer Regional areas. Because both (Outer Regional and Remote/Very Remote) areas comprised only a small number of people with MS, we cannot say for sure what truly is causing these costs differences. It could merely be because of the uncertainty surrounding low numbers.

Whilst people living in remote/very remote areas have the lowest community and private services costs, transport costs are highest (as expected) for this group. Supplemental Table 3L provides the itemised breakdown of costs of MS by key direct cost categories/sub-categories and Australian Remoteness Areas.

Figure 3.14. Direct Costs of MS by cost category and Australian Remoteness Areas - per person ($ 2017)



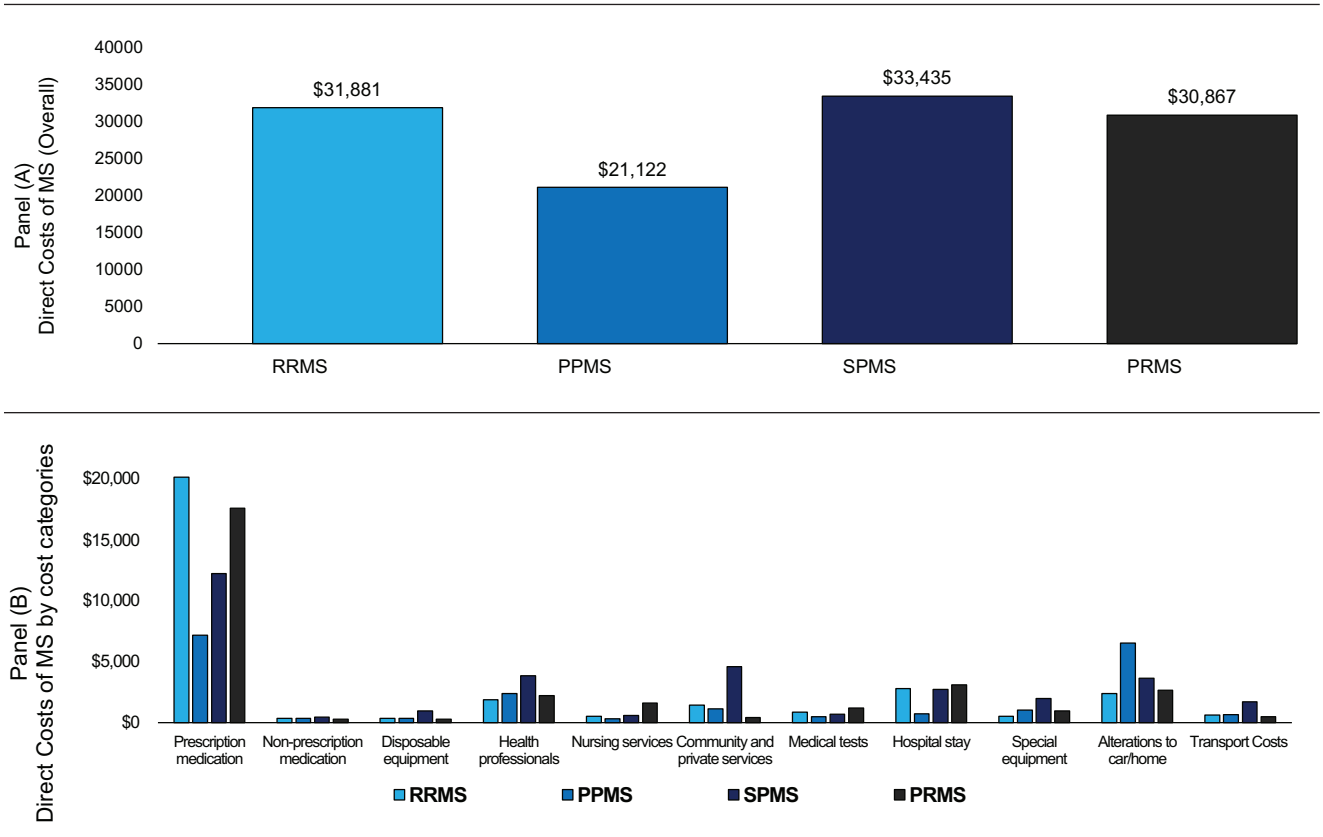
3.4.5.6 Direct Costs of MS by Cost Category and MS Type

The direct costs broken down by MS type are shown in Figure 3.15 (Panels A and B). From Panel A, the direct per person costs of MS were highest for people with SPMS ($33,435), then people with RRMS ($31,881), closely followed by people with PRMS ($30,867). People with PPMS had the lowest per person direct costs of MS ($21,122). From Figure 3.15 (Panel B), as expected, the prescription medication costs were highest for RRMS people and the lowest for people with PPMS.

Whilst people with SPMS ranked the second lowest on prescription medication costs, they ranked highest on direct cost categories of non-prescription medications, disposable equipment, health professionals, community and private services, special equipment, and transport.

The tendency of people with SPMS to have higher direct costs in most categories appears to be driving the highest overall direct costs for this group (Panel A of Figure 3.15). Importantly, because the costs for people with SPMS are higher despite the low DMT costs in this group, this additionally highlights the need for interventions to prevent people from developing SPMS. Supplemental Table 3M provides the itemised breakdown of direct costs of MS by key cost categories/sub-categories and type of MS.

Figure 3.15. Direct Costs of MS by cost category and MS type - per person ($2017)



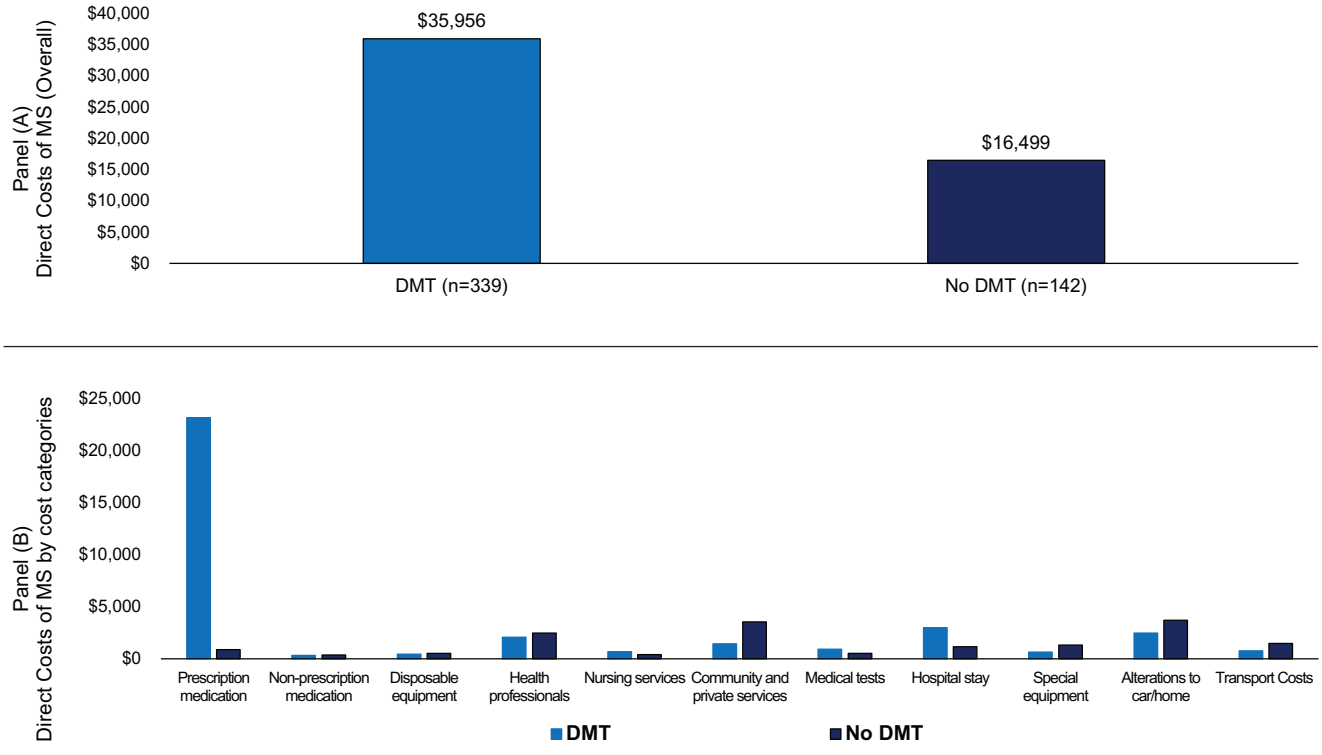
49 participants were unsure about their MS type and 35 did not state.

3.4.5.7 Direct Costs of MS by Cost Category and DMT Usage.

Figure 3.16 (Panels A and B) show direct per person costs of MS (overall and stratified by DMT usage). As expected, the overall direct costs of MS were higher for people using DMTs ($35,956), compared to people not using DMTs ($16,499). From Panel B, the largest direct cost component was the prescription medication costs. As expected, the prescription medication costs were higher for people using DMTs.

Costs of non-prescription medications, nursing services, and medical tests were reasonably similar for both groups. Finally, costs related to health professionals, community and private services, special equipment, alterations to car/home and transport costs were higher for people not using DMTs. Supplemental Table 3N provides the itemised breakdown of direct costs of MS by key cost categories/sub-categories and DMT usage.

Figure 3.16. Direct Costs of MS by cost category and DMT usage- per person ($2017)



DMT usage history was not known for 7 participants.

3.5 Discussion

This chapter has set out the COI estimates for a large representative group of Australian people with MS (n=488). Whilst some past studies have investigated the COI of MS in Australia, these studies suffer from limitations: 1) they were based on what is now decade old data; 2) some methodological limitations; and 3) these studies lacked some of the details that have been incorporated into this report. [8, 20] We have used the updated (2016) data to assess the costs of MS in Australia in 2017. The COI analysis of this report provides per person costs as well as the total costs for all people with MS in Australia (based on updated 2017 Australian MS prevalence estimates).

A strength of this study is that it captured detailed information on a variety of cost items from a large representative sample of people with MS. The availability of such detailed data allowed us to provide a breakdown of costs by various cost categories and sub-categories. A further strength is that the study primarily adopted a 'bottom-up' approach, which led to more reliable cost estimates than the 'top-down' approach. The use of a cost diary that needed to be completed every day minimised the chances for someone to forget about the costs that they incurred during the six-month period, therefore minimising the potential for recall bias. In addition, the provision of a comprehensive list of items provided within each section of the cost diary reminded people of smaller cost items that otherwise may have been forgotten. This is the first time that transport costs and costs from lost productivity (absenteeism + presenteeism) have been accounted for, which provides a more comprehensive estimate of costs compared to the previous COI analyses in Australia. Additionally, in this report and unlike the previous reports, we have been able to provide the cost breakdowns by type of MS, state/territory of usual residence, and DMT usage.

A possible limitation of this study is that we had relatively small number of participants from the ACT (n=28) and TAS (n=25), which may make the estimates for these states/territories relatively less reliable. In addition, we had just one participant complete the cost diary from the NT, which did not allow us to provide the breakdown of overall and/or direct costs of MS for the NT population. A further limitation is that our analysis did not include intangible costs (like the costs of pain, grief and suffering) associated with MS, however these are captured elsewhere in this report by measuring quality of life/health state utility values. Finally, no direct clinical measures of disability levels were included in the AMSLS EIS 2016. However, the survey captured self-reported estimates of disability using PDDS that provides an assessment of mobility-based functional disability in MS. PDDS has previously been validated as correlating highly with the EDSS.[24] We used the self-reported PDDS scores to calculate approximate EDSS scores for our sample.

The following sections compare our results with those from previous Australian studies, as well as those from other nations. We also compared the COI of MS with COI estimates of other diseases in Australia to provide the context for MS.

3.5.1 Comparison with Previous COI Studies in MS for Australia

Two previous COI studies in MS have been published for Australia.[8, 22] In 2005, Access Economics performed an analysis of the economic costs of MS in Australia.[22] The study primarily took a 'top-down' approach supplemented by a 'bottom-up' approach where data were available. The Access Economics study estimated that the total (direct and indirect) financial costs of MS in 2005 were $37,333 per person with MS.[22]

The 2011 study later updated these cost estimates using primarily a 'bottom up' research methodology.[8] Whilst the current analysis is based on a methodology similar to that of 2011 study, our results are much more detailed and include some additional cost categories/sub-categories that are important to the detailed analyses of costs for MS.

Importantly, the cost categories covered in the 2005 Access Economics study as well as the methodology they used to generate these costs were very different from the analysis presented in this report. Additionally, the 2005 Access Economics study did not report socio-demographic characteristics of the sample, which makes it hard to know if the sample was representative of the overall Australian MS population.

Based on the reasons explained above; it was not possible to draw a meaningful comparison between the 2005 results and the current study. We have therefore only compared our results with the 2011 economic impact of MS report that matches with our analysis both in terms of its methodological framework and in terms of the majority of the cost categories considered. Table 3.6 compares (where possible) the demographic and other features of the participants included in 2010 and 2017 COI analyses.

In particular, we compared participants' age (at the diagnosis of MS), age group distribution, sex, disability severity and geographic distributions.

Table 3.6. Characteristics of the participants in the 2017 and 2010 analyses

Characteristics	2017 Analysis (N=488)	2010 Analysis (N=712)
Sex		
Male % (n)	19 (90)	21 (146)
Female % (n)	81 (398)	79 (565)
Age group		
<35 % (n)	4 (18)	6 (43)
35-44 % (n)	15 (73)	17 (124)
45-54 % (n)	26 (125)	30 (215)
55-64 % (n)	31 (151)	31 (223)
65+ % (n)	24 (119)	14 (99)
Not stated % (n)	<1 (2)	N/A*
State of usual residence		
NSW % (n)	27 (132)	34 (245)
VIC % (n)	25 (123)	28 (200)
QLD % (n)	15 (72)	12 (85)
SA % (n)	10 (50)	10 (71)
WA % (n)	11 (52)	7 (49)
ACT % (n)	6 (28)	3 (23)
TAS % (n)	5 (25)	5 (34)
NT % (n)	<1 (1)	<1 (1)
Not stated % (n)	1 (6)	<1 (4)
MS type		
PPMS % (n)	6 (32)	N/A
RRMS % (n)	60 (291)	N/A
SPMS % (n)	14 (68)	N/A
PRMS % (n)	3 (13)	N/A
Unsure % (n)	10 (49)	N/A
Not stated % (n)	7 (35)	N/A
DMT		
Yes % (n)	69 (339)	N/A
No % (n)	30 (142)	N/A
Not stated % (n)	1 (7)	N/A
Disability severity		
No disability % (n)	21 (103)	N/A
Mild disability % (n)	25 (122)	N/A
No/mild disability* % (n)	46 (225)	44 (315)
Moderate disability % (n)	35 (173)	33 (236)
Severe disability % (n)	18 (88)	16 (113)
Not stated % (n)	<1 (2)	7 (48)
MS duration		
Average in years (n)	15.5 (472)	N/A
Age		
Average in years (n)	55.8 (486)	52.6 (712)

N/A = not applicable
*mild disability category of the 2011 economic impact of MS report

As shown in Table 3.6, four out of five respondents in both samples (81% in 2017 and 79% in 2010) were female. The mean age (55.8 years) in 2017 was slightly higher than the 2010 sample's mean age (52.6 years). We had data on age distribution of both samples. The participants were grouped into five age groups (namely: <35 years, 35–44 years, 45–54 years, 55–64 years, and 65+ years). The age group distribution of both samples was reasonably similar, although the 2017 analysis included a considerably higher proportion of people aged 65+ years (+10 percentage points). The geographic distribution of both samples was comparable. Whilst more than half of both samples came from NSW and VIC, the 2017 analysis had a greater representation from WA and ACT.

Contrary to the 2017 analysis, the 2010 analysis grouped people with no disability and mild disability together in one category of disability (namely: mild disability). We have therefore created an additional disability group (No/mild disability) by combining our 'no disability' and 'mild disability' groups together to make the disability severity comparison more meaningful. As shown in table 3.7, the disability severity distribution of the two samples is comparable, with 46% and 44% mild, 35% and 33% moderate, and 18% and 16% severe people with MS in 2017 and 2010 respectively. The data on type of MS, DMT usage, and duration of MS was available only for the sample used in 2017 analysis. Therefore, comparison between the two samples was not possible for these variables.

Total costs: Table 3.7 provides the total per person costs of MS in Australia based on 2017 and 2010 analyses. Please note that we have inflated the estimates of 2010 analysis to 2017 levels to draw a more meaningful comparison. The overall per person costs of MS increased to $68,382 in 2017 from $58,652 in 2010. Despite a doubling of direct costs due to DMTs and other factors between 2010 and 2017, the overall increase in costs between the two periods is less than $10,000. This maybe an indication of the benefits associated with newer higher efficacy DMTs to offset some of the indirect costs associated with MS.

Direct costs: It can also be seen that total direct per person costs in 2017 ($30,346) have nearly doubled from 2010 ($16,306). Whilst the difference appears substantial, this was expected because the current treatment landscape in Australia has changed in the past decade. Australia has introduced a number of new DMTs during this period. The new DMTs are not only relatively high in price but the mode of administration of these drugs is different, with many requiring hospitalisation for infusions (e.g. Tysabri and Lemtrada) and/or additional safety monitoring (e.g. Fingolimod). This will lead to higher inpatient care needs for people with MS, resulting in higher costs related to hospitalisation, health professionals, and others. In addition, a higher percentage of people with MS now use DMTs (~69%) compared to 2010 (~47%). The 2017 direct costs are also higher because the 2017 analysis included an additional

direct cost category of 'Transport Costs', which represents costs associated with the use of private car, patient transport, public transport, taxis, and car parking fees by people with MS in relation to their disease (see Table 3.8). We have provided the breakdown of direct costs for both samples (2017 and 2010) in Table 3.8 (discussed later in this section).

Table 3.7. Comparing the per person cost of MS by cost category ($2017)

Cost Category	2017 Estimates (n=488)	2010 Estimates (n=712)
	Mean	Mean
Direct costs – personal	$8,437	$4,181
Direct costs – community / government	$21,911	$12,125
Direct costs – total	$30,346	$16,307
Nursing home and equivalent costs	$6,343	$4,958
Informal care costs	$7,144	$8,357
Indirect costs from lost wages – early retirement	$13,468	N/A
Indirect costs from lost wages – employment status change	$5,408	N/A
Indirect costs from lost wages – occupation change	$2,982	N/A
Indirect costs from lost wages – overall	$21,858	$29,030
Indirect costs from lost productivity - absenteeism	$482	N/A
Indirect costs from lost productivity - presenteeism	$2,209	N/A
Indirect costs from lost productivity – overall	$2,691	N/A
Total Costs	**$68,382**	**$58,652**

N/A = Not Applicable

Nursing home costs: The nursing home costs reported in Table 3.7 are higher for 2017 ($6,343), compared to 2010 ($4,958). This increase is due to a substantial increase in the Australian Institute of Health and Welfare (AIHW)'s estimate of accommodation support per person between 2008-09 ($75,057) and 2015-16 ($109,715). Section 3.2 (Materials and Methods) explains how we obtained the estimate of per person nursing home costs for our sample using AIHW's accommodation and support estimates of 2015-16. The 2010 estimates were obtained following the same approach but using 2008-09 estimates of accommodation and support from AIHW.

Indirect costs from lost wages: Interestingly, the indirect costs from lost wages declined from $29,030 (49% of the total costs) in 2010 to 21,858 (32% of the total costs) in 2017. This could be because of the recent positive shifts in the employment landscape for people with MS in Australia - A 2017 Australian study has demonstrated that the long-standing difference in employment rates for people with MS compared to the general population has reduced.[21] The study shows that the employment outcomes for people with MS in Australia have improved, with more people with MS now staying in the labour market and returning to the workplace. Consistent with the findings of this previous Australian study,[21] we expect that the availability of more recent higher efficacy DMTs and this new era of patient-centred MS management approaches has resulted in better employment outcomes for Australian people with MS. In addition, the recent evidence shows that requests for work role and work environment adjustments in today's Australia are almost always provided,[21] which may also contribute to the improved employment outcomes for people with MS. Together, these factors largely explain the reduced indirect costs from lost wages (due to early retirement/employment status change/occupation change) in 2017 analysis, compared to 2010. In this 2017 analysis we have broken down the indirect costs from lost wages into three sub-categories, however, no comparison can be made within these sub-categories to the 2011 study as this breakdown was not performed at that time.

Informal care costs: Like indirect costs from lost wages, the informal care costs also recorded a decline between the two periods. Specifically, the informal care costs declined from $8,357 (in 2010) to 7,144 (in 2017). Better health outcomes for people with MS due to the use of more effective DMTs, and better (patient-centred) management of MS may explain this pattern.

Lost productivity: As shown in Table 3.7, the 2017 COI analysis covered an additional cost category: indirect costs from lost productivity (absenteeism + presenteeism). Because the 2010 COI analysis did not cover these costs, we are unable to compare the lost productivity costs between the two samples.

Table 3.8 provides the breakdown of direct costs for both samples. The 2017 analysis is much more detailed as it has broken down the costs of prescription medication, special equipment, and alteration to car/home into more than one sub-category, which was not the case with the 2010 analysis. A substantial increase in the costs of prescription medications (DMTs and others), health professionals, medical tests and hospitalisations occurred between 2010 and 2017. The increased health professional, medical tests and hospitalisations costs could be due to the increased monitoring with some of the higher efficacy, higher risk medications. In addition, some of the new DMTs (such as Tysabri and Lemtrada) are given through hospital administered infusions so may have consequences to further inflate the hospitalisation and health professional costs.

Table 3.8. Comparing the direct costs - by cost category - per person with MS ($2017)

Cost Category	2017 Estimates (n=488)	2010 Estimates (n=712)
Prescription medication_DMTs	$15,882	N/A
Prescription medication _Symptom Specific	$524	N/A
Prescription medication_Others	$317	N/A
Prescription medication_Overall	$16,723	$9,648
Non-prescription medication	$347	$321
Disposable equipment	$460	$163
Health professionals	$2,282	$970
Nursing services	$600	$551
Community and private services	$2,045	$1,051
Medical tests	$801	$265
Hospital stay	$2,455	$379
Special equipment Hiring	$17	N/A
Special equipment Purchase-MOBILITY	$390	N/A
Special equipment Purchase-VISUAL AIDS	$59	N/A
Special equipment Purchase-COMMUNICATIONS	$95	N/A
Special equipment Purchase-BATHROOM	$72	N/A
Special equipment Purchase-KITCHEN	$24	N/A
Special equipment Purchase-BEDROOM	$115	N/A
Special equipment Purchase-GENERAL	$87	N/A
Special equipment -OVERALL	$860	$556
Alterations to home	$2,228	N/A
Alterations to car	$586	N/A
Alterations to car/home	$2,814	$2,403
Transport Costs	$959	N/A
Total Costs	**$30,346**	**$16,307**

N/A = not applicable

A considerable increase in the categories of disposable equipment and special equipment costs was also observed between the two periods, which may be because the provision of a comprehensive list of items provided within each section of the cost diary prompted people to record smaller cost items that otherwise may have been forgotten.

3.5.2 Comparison with International COI estimates of MS

Whilst the costs of MS vary considerably between countries, the economic impact of MS is substantial in all countries. The cost of illness per person with MS in Australia of $68,382 is consistent with the range of reported estimates from most other nations. Table 3.9 shows per person total mean costs, direct (medical and non-medical) costs and indirect costs of MS for Australia and 15 other nations. All costs are presented in AUD 2017.

Table 3.9. Costs per person with MS in Australia and other nations ($ 2017)

Country	Direct Costs*	Indirect Costs	Total Costs
Australia	$43,833	$24,549	$68,382
Austria [a]	$52,505	$20,562	$73,067
Belgium [b]	$43,480	$24,818	$68,298
Czech Republic [c]	$9,798	$8,566	$18,364
Denmark [d]	$42,292	$25,205	$67,497
France [e]	$39,469	$16,150	$55,619
Germany [f]	$44,445	$24,478	$68,923
Hungary [g]	$16,022	$8,595	$24,617
Italy [h]	$44,495	$14,939	$59,434
Poland [i]	$14,584	$8,647	$23,231
Portugal [j]	$28,409	$12,250	$40,659
Russia [k]	$12,124	$5,515	$17,639
Spain [l]	$51,247	$19,139	$70,386
Sweden [m]	$60,577	$22,148	$82,725
Switzerland [n]	$60,107	$31,977	$92,084
United Kingdom [o]	$31,868	$19,216	$51,084
Overall Average	**$37,203**	**$17,922**	**$55,126**

*includes direct medical and direct non-medical costs; a, Berger and Kobelt et al (2017)[33]; b, Dubois and Kobelt et al 2017 [34]; c, Havrdova and Kobelt et al 2017 [35]; d, Rasmussen and Kobelt et al 2017 [36]; e, Lebrun-Frenay andKobelt et al 2017[37], f, Flachenecker and Kobelt et al 2017 [38]; g, Péntek and Kobelt et al 2017 [39]; h, Battaglia and Kobelt et al 2017 [40]; i, Selmaj and Kobelt et al 2017 [41]; j, Sá and Kobelt et al 2017 [42]; k, Boyko and Kobelt et al 2017 [43]; l, Oreja-Guevara and Kobelt [44]; m, Brundin and Kobelt et al [45]; n, Calabrese and Kobelt et al 2017 [46]; o, Thompson and Kobelt et al 2017 [47]

As shown in Table 3.9, the costs per person with MS ranged from $17,639 in Russia to $92,084 in Switzerland, with an overall average of $55,126. The direct (medical and non-medical) costs ranged between $9,798 (Czech Republic) and $60,577 (Sweden), and indirect costs ranged between $5,515 (Russia) and $31,977 (Switzerland).

The figures reported in Table 3.9 show that per person costs of MS in Australia are comparable with most nations. For instance, Belgium ($68,298), Denmark ($67,497), Germany ($68,923) and Spain ($70,386) had overall per person costs of MS that were similar to those in Australia ($68,382). Whereas Austria ($73,067), Sweden ($82,725) and Switzerland ($92,084) ranked higher than Australia in terms of their per person costs of MS. We found that, per person costs of MS in Australia are substantially higher than Russia ($17,639), Poland ($23,231) and the Czech Republic ($18,364). Australian costs are also ahead of France ($55,619), Italy ($59,434), Portugal ($40,659), and the United Kingdom ($51,084), but the difference between these nations are relatively small. Switzerland appears to be the highest-ranking country with a total per person costs of ($92,084), followed by Sweden ($82,725).

Overall, the differences in costs could be due to several reasons, including the underlying differences in the MS treatment and management costs, the cost categories considered in the analysis, cost analysis approaches, and typical care provided to people with MS during the time-period of analysis. Additionally, the demographics of the nation (or the composition of the samples) including age, disease severity, and DMT usage will differ (e.g. the European nations in Table 3.9 recorded a range of DMT usage from 26 to 79%, and a mean age range of 38.5 to 56.7 years). Differences in resource consumption may also be heavily influenced by healthcare system organisation and availability of services in various nations. These differences may lead to a range of estimates; therefore, care must be taken when comparing results from different studies.

3.5.3 Comparison with Other Chronic Diseases in Australia

To provide a context for MS, a comparison of costs associated with other diseases in the Australian setting is provided in Table 3.10. All costs are presented in AUD 2017. It is important to note that many of these comparison studies have not adopted the comprehensive methodological approach of this report regarding both direct and indirect costs. One study that was reasonably broad (and comparable) in the identification of costs was a COI study regarding Parkinson's disease. [48] This study showed that the costs per person for Parkinson's disease was comparable to the costs of MS. Additionally, this study also showed that the costs of Parkinson's disease escalated as disease severity increased, which is also consistent with our findings in MS. It can be seen that mean costs per person with MS in Australia are lower than dementia and comparable to the costs for the first year following a stroke (all severity) and diabetic renal failure, however, both measured direct costs only. The costs of MS per person is three times more than those of a person with type 2 diabetes.

The annual per person costs of MS are comparable to those of a person with Parkinson's disease, or the first year following a stroke and are three times higher than for a person with Type 2 Diabetes.

The differences in costs of various diseases can arise for many reasons. For instance, in direct contrast to the patient-level costing methodology adopted in our study and all other studies in Table 3.10, a study that described the per person costs of Motor Neuron Disease adopted a top-down approach to costing. Furthermore, the studies in Table 3.10 differ in terms of the key cost categories considered (e.g. direct health care costs, direct non-healthcare costs, indirect costs and government subsidies). We therefore recommend that the costs presented in Table 3.10 be interpreted with caution as being derived from different methodologies using varying sample sizes, and cost categories.

Table 3.10. Comparing the costs of MS and other diseases in Australia

Disease	Cost categories	Total costs
Multiple Sclerosis	Direct (healthcare + non-healthcare) and Indirect	$68,382
Motor Neuron Disease[49]	Direct (healthcare + non-healthcare) and Indirect	$151,913
Dementia [50]	Direct (healthcare + non-healthcare)	$89,740
Parkinson's disease [48]	Direct (healthcare + non-healthcare) and Indirect	$79,107
Stroke first year [51]	Direct (healthcare + non-healthcare) and Indirect	$55, 272
Diabetic renal failure subsequent years [52]	Direct healthcare costs	$54,803
Diabetic renal failure first year [52]	Direct healthcare costs	$34,252
Diabetes both micro and macro vascular symptoms [53]	Direct (healthcare + non-healthcare) and government subsidies	$21,888
Diabetes-related chronic leg ulcer first year [52]	Direct healthcare costs	$18,420
Diabetes no symptoms [53]	Direct (healthcare + non-healthcare) and government subsidies	$12,143
Hemochromatosis (severe) [54]	Direct (healthcare + non-healthcare) and Indirect	$10,435
Obesity (BMI 30–34.9 kg/m2) [55]	Direct (healthcare + non-healthcare) and indirect (government subsidies)	$9,181
Overweight [55]	Direct (healthcare + non-healthcare) and indirect (government subsidies)	$6,349
Depression/anxiety [56]	Direct (healthcare + non-healthcare) and Indirect	$4,977

Chapter 4 Quality Of Life/Health State Utility Values For People With Multiple Sclerosis

4.1 Summary

The aim of this chapter was to assess the impact of MS on quality of life (QoL). We achieved our aim by estimating and analysing measures called health state utility values (HSUVs also known as 'utilities'), and unique measures, called dimensional scores, of physical and psychosocial health states using the latest available data and updated methodologies of the Assessment of Quality of Life 8 Dimension (AQoL-8D) multi-attribute utility instrument.

HSUVs are a numerical measure of QoL measured by a multi-attribute utility instrument. Importantly, HSUVs are derived from what is known as a *patient-reported* outcome and are anchored at a HSUV or utility valuation of '0' for death and '1' for perfect health (maximum value). The AQoL-8D's unique super and individual dimensional 'scores' are also scored between 0 and 1.

In summary, we found that the HSUV in 2016 for people with MS sourced from the EIS 2016 was mean (SD) 0.61 (0.22). This HSUV is substantially reduced from that of the Australian general population with a HSUV of 0.80 (0.19).

We also found that as MS-related disability increased, the HSUV decreased substantially. People with MS with no disability reported a HSUV that was similar to the general Australian population. There was a substantial fall in HSUV (almost 0.20 utility points) between no disability and mild disability from mean (SD) 0.81 (0.16) to 0.65 (0.19). HSUVs substantially diminished further for people with moderate (0.54 [0.19]) and severe disability (0.48 [0.19]).

On average, the Quality of Life (QoL) as measured by the health state utility valuation (HSUV) of the Australian MS population is 31% less than the Australian population norm.

When the overall sample was investigated for different groups of people with MS such as males and females, age groups, geographical location (including Australian Remoteness Areas of geographical location), disease severity and people using DMTs or not, we found that the highest recorded HSUV (or utility) was for people with MS with 'no disability'. The lowest recorded HSUV was for people with 'severe disability'. In other words, as MS-related disability worsens, QoL worsens dramatically. People using DMTs had a higher HSUV compared to those not using DMTs.

Importantly, the assessed psychosocial health status for people with MS was low (measured by the AQoL-8D's Psychosocial super dimension) and partially drove the low HSUVs for the overall sample.
The key drivers for low psychosocial health status were the individual dimensions of Mental Health and Relationships. Additionally, the assessed physical health status through the Physical super dimension was also relatively low and the key drivers identified for this reduced physical health were the individual physical dimensions of Pain and Independent Living.

QoL for people with severe MS is comparable to, or even lower than the QoL reported for people with terminal metastatic cancer, chronic kidney disease and severe heart disease.

Additionally, the physical dimensions of Independent Living (increased) and Pain (decreased) drove the higher HSUV for people with MS using DMTs, compared to people not using DMTs. Psychosocial health was similar for both groups using DMTs.

As age increased, HSUV decreased and this trend was the opposite of the Australian population norms for the AQoL for older age groups. We found that the physical health impacts of MS were proportionally higher than the psychosocial impacts of the disease as people with MS aged.

Compared to the 2011 economic impact of MS report, we found that the overall HSUV was slightly lower compared to the HSUV of 0.65 in 2010. The likely explanation for this are the differences in instrument measurement: the 2011 report's HSUVs were *derived* from mapped responses to the EQ-5D-3L (indirect) rather than directly measured using the *direct* reported outcomes from people with MS. In other words, the HSUVs from the mapped (or derived) values cannot be compared to the AQoL-8D, which contains a sophisticated and broad health status classification system to particularly capture complex health needs at a particular time-point and longitudinal changes for people with complex and chronic disease.

When the AQoL-8D has been used for other chronic disease states, [57] we found that the HSUV for people with MS (0.61) was similar to people with chronic cancer and arthritis (HSUV 0.66 and 0.63), and the HSUV for people with MS was also similar to an AQoL-8D composite measure of chronic disease of 0.64 where the chronic diseases included cancer, heart disease, asthma, depression, arthritis, diabetes and hearing loss. As MS disease severity worsened for our study respondents, the AQoL-8D HSUV was similar to people with chronic depression, namely a HSUV of 0.45.

4.2 Introduction

4.2.1 The Quality Of Life For People With MS

The age of onset of MS typically occurs when people are establishing families and careers.[6, 58] MS symptoms are complex, interdependent and affect both the physical and psychosocial QoL for people with MS. [58, 59]

The International Society for Quality of Life Research states that a number of definitions exist, but there is broad agreement that QoL "is a functional effect of a medical condition and/or its consequent therapy upon a patient: it is subjective and multidimensional, encompassing physical and occupational function, psychological state, social interaction and somatic sensation".[60]

For people with chronic disease, capturing and assessing complex physical and psychosocial health needs through *patient-reported outcomes* is crucial. [57, 61-63] In turn, QoL changes for people with MS have been widely documented using a range of client-reported, disease-specific and generic QoL, and multi-attribute utility instruments.[59, 64, 65]

Multi-attribute utility instruments measure QoL by asking the participant to respond to a range of survey questions.[66-68] An algorithm specific to the multi-attribute utility instrument then uses the participants' responses to these questions to calculate a single measure called a HSUV or 'utility' to measure QoL. A HSUV is valued between 0 (death) and 1 (perfect health). Utilities can also be scored at less than 0: a health state considered to be worse than death. Importantly, HSUV's are a health economic input measure for health economic evaluation [69] and can also be used as independent predictors of health.[68]

Until now, the most recent Australian study that assessed HSUVs from the AMSLS (the 2011 economic impact of MS report) used an indirect method to approximate values for the EQ-5D-3L multi-attribute utility instrument and compared HSUVs with the severity of disease using the Expanded Disability Status Scale (EDSS) of mild, moderate and severe.[59]

Importantly, this 2011 economic impact of MS report found that as disease progressed from mild to severe, there was a substantial decrease in the patient-reported QoL - the HSUV decreased by approximately 0.2 utility points or one-fifth of the reportable QoL.

This current report is the first study to employ the AQoL-8D multi-attribute utility instrument to assess quality of life for Australian people with MS.

4.3 Materials And Methods

4.3.1 Assessing Physical And Psychosocial Health Using The AQOL-8D

The AQoL–8D multi-attribute utility instrument was specifically developed to achieve an increased sensitivity for capturing and assessing the complex physical and particularly psychosocial QoL health states that are relatively neglected in other multi-attribute utility instruments, particularly for people with chronic disease states. [67, 70 71, 72 63]

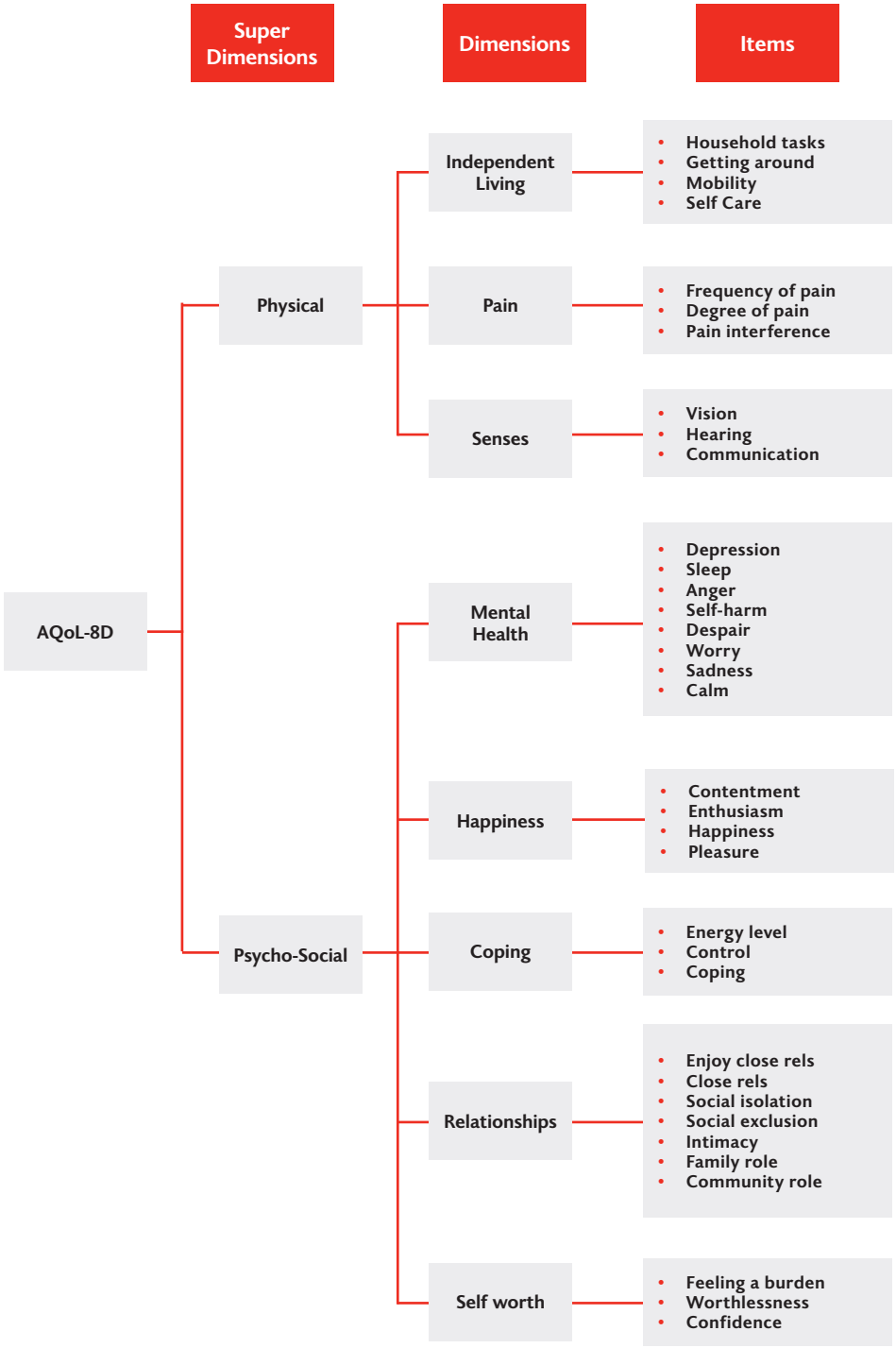
Importantly, the AQoL-8D estimates a HSUV and the unique composite 'super-dimension' and individual dimension scores between '0' and '1'.

Figure 4.1 reveals the depth and breadth of the AQoL-8D's classification system where the AQoL-8D's 35 items (or questions) load to eight individual dimensions of physical and psychosocial health to generate individual dimensional scores. The three physical health dimensions are Independent Living, Senses and Pain. The five psychosocial health dimensions are Mental Health, Self-worth, Relationships, Coping and Happiness. From these individual dimensions the AQoL-8D also generates two 'weighted' super dimension scores: the Physical super dimension and the Psychosocial super dimension.[70]

Because of the AQoL-8D's detailed classification system, it helps to identify the reasons that drive the overall HSUV for the study population, and it can also help to identify the reasons why a HSUV changes in response to an intervention such as a DMT.[57, 61-63, 73]

Psychosocial QoL impacts for people with MS are substantial across all age groups, whereas physical health impacts become substantially higher as people with MS get older.

Figure 4.1. The AQoL-8D structure: Items, individual dimensions and super dimensions



Source: Richardson et al (2014).[70]

The AQoL-8D's comprehensive classification system and algorithm enables it to capture and assess *billions* of separate health states (namely 2.4 times 10 to the power of 23) [74] compared to, for example, the EQ-5D multi-attribute utility instruments that only measure 243 (EQ-5D-3L) and 3,125 (EQ-5D-5L) separate health states.[67]

A HSUV is generated for each participant's responses to the AQoL-8D's 35 questions, and a mean (average) HSUV (utility) for the study population is also calculated. Mean super and individual dimension scores are also generated for values between 0 and 1. These mean valuations are reported in this study.

The Physical and Psychosocial super dimension scores can be lower than all of the individual dimension scores because the AQoL-8D's mathematical algorithm may provide more weight to particular responses to questions and indeed the population norms generated for the Australian population reflect this point. To illustrate, the Psychosocial super dimension score for the general Australian population is 0.50 and the scores for the individual dimensions of psychosocial health (Mental Health, Coping, Relationships, Self-worth and Happiness) are higher than 0.50 ranging from 0.69 to 0.85.

4.3.2 Assessing Physical and Psychosocial Health for People with MS in Australia using the AQoL-8D

The EIS 2016 (Baseline Survey) participants were asked to complete the AQoL-8D's 35 item questionnaire, providing baseline cross-sectional data for detailed QoL analyses. Longitudinal AQoL-8D data will be available for future analyses and reports.

The AQoL-8D's HSUVs and individual and super dimension scores were expressed as mean (standard deviation (SD)). Proportions were expressed as a percentage. AQoL-8D Australian population norms were recently generated by the instrument's developers and these norms were extracted from the published sources and expressed as mean (SD).[72]

We stratified our QoL/HSUV results by age groups (namely, < 35 years, 35 – 44 years, 45 – 54 years, 55 – 64 years, and 65 + years), sex, Australian geographical location and Remoteness Areas, MS type, use of DMTs (yes, no), and MS-disease severity.

In regard to MS-disease severity, the respondents were stratified into severity of disease categories of no disability (EDSS level: 0), mild disability (EDSS levels: 1–3.5), moderate disability (EDSS levels: 4–6) and severe disability (EDSS levels: 6.5–9.5). Please see Table 3.4 for further details.

4.4 Results

4.4.1 Participant Characteristics

We invited all 3,163 active AMSLS participants to complete the AQoL-8D questionnaire from April to June 2016. N = 1,577 (49.9%) participants responded with n = 1,112 online, and n = 465 paper-based questionnaires.

Table 4.1 describes the characteristics of the participants included in the QoL/HSUV analysis. The key characteristics of the 2016 EIS (Baseline Survey) non-respondents, and the EIS 2007-08 respondents are also provided in Table 4.1. We compared respondents with non-respondents of the EIS 2016 (Baseline Survey) to test for selection-bias. Compared to the 2007-08 baseline survey, the 2016 participants were a little older (+1.26 years, $p<0.01$), but there were no differences in sex ($p=0.76$), Australian state of residence ($p=0.37$), and duration of MS from diagnosis ($p=0.72$).

In regard to respondent characteristics, the average age was 55.5 years and MS-duration was 15.3 years, four out of five respondents were female for all of the categories. Similarly, almost three-quarters of the participants were in the 35 to 64-year age group. Most participants resided in VIC and NSW.

For the EIS 2016 (Baseline Survey) respondents, (a different sample to the prevalence calculations) 58% were currently being treated with DMTs and 55% of this 2016 survey respondent group reported their disease course as RRMS, followed by 12% reporting their disease course as SPMS. For the 2016 survey respondent group, the measure of disability severity showed that over half the sample of people with MS were in the moderate and severe disability categories.

Quality of Life for people with MS who are living with severe disability is 41% lower compared to people with MS with no disability.

This substantially reduced QoL is primarily driven by the individual health domains of pain, independent living, mental health and relationships.

Table 4.1. Characteristics of the participants in the QoL/HSUV analyses

	EIS 2016 Respondents	EIS 2016 Non-respondents	EIS 2007-08 Respondents
Characteristics	(N=1,577)	(N=1586)	(N=2146)
Sex			
Male % (n)	21 (339)	21 (334)	20
Female % (n)	79 (1,238)	79 (1,252)	80
Age group			
<35 % (n)	4 (60)	4 (70)	8 (181)
35-44 % (n)	15 (237)	18 (282)	18 (382)
45-54 % (n)	26 (404)	27 (437)	29 (626)
55-64 % (n)	31 (495)	28 (448)	26 (552)
65+ % (n)	23 (368)	21 (328)	10 (223)
Not stated % (n)	1 (13)	1 (21)	8 (182)
State of residence			
NSW % (n)	29 (457)	32 (511)	31 (665)
VIC % (n)	27 (434)	26 (417)	27 (576)
QLD % (n)	14 (218)	15 (245)	13 (269)
SA % (n)	9 (138)	9 (135)	8 (173)
WA % (n)	11 (167)	11 (172)	10 (204)
ACT % (n)	4 (61)	2 (37)	3 (58)
TAS % (n)	6 (90)	4 (60)	5 (109)
NT % (n)	<1 (4)	<1 (3)	<1 (3)
Not stated % (n)	<1 (8)	<1 (6)	N/A
MS type			
PPMS % (n)	8 (125)	N/A	N/A
RRMS % (n)	55 (863)	N/A	N/A
SPMS % (n)	12 (192)	N/A	N/A
PRMS % (n)	2 (35)	N/A	N/A
Unsure % (n)	10 (163)	N/A	N/A
Not stated % (n)	13 (199)	N/A	N/A
DMT			
Yes % (n)	58 (908)	N/A	N/A
No % (n)	34 (540)	N/A	N/A
Not stated % (n)	8 (129)	N/A	N/A
Disability severity			
No disability % (n)	20 (315)	N/A	N/A
Mild disability % (n)	24 (385)	N/A	N/A
No/mild disability % (n)	46 (700)	N/A	41
Moderate disability % (n)	36 (575)	N/A	38
Severe disability % (n)	18 (289)	N/A	16
Not stated % (n)	<1 (13)	N/A	5
MS duration			
Average in years (n)	15.3 (1,436)	15.2 (1,385)	N/A
Age			
Average in years (n)	55.5 (1,564)	54.3 (1,565)	50.99 (2022)

N/A = Not applicable

4.4.2 Quality Of Life/HSUV Estimates (Overall Sample)

Table 4.2 provides the AQoL-8D's mean HSUVs for people with MS in this sample, their Physical and Psychosocial super dimensions, and their individual dimensional scores of Independent Living, Senses, Pain, Happiness, Coping, Relationships, Self-worth and Mental Health, compared to AQoL-8D Australian population norms. HSUVs were calculated for 1,566 participants.

Table 4.2. AQoL-8D utility valuations, super dimension scores, and individual dimension scores

AQoL-8D characteristics	EIS 2016 (N=1,566)	Australian population norms (general population)*	Australian population norms (45-54 years)*
	Mean (SD)	Mean (SD)	Mean (SD)
HSUV	0.61 (0.22)	0.80 (0.19)	0.77 (0.20)
Super dimension scores			
Physical	0.57 (0.22)	0.83 (0.18)	0.79 (0.20)
Psychosocial	0.33 (0.19)	0.50 (0.24)	0.47 (0.24)
Individual dimensions (physical health)			
Independent Living	0.70 (0.20)	0.94 (0.11)	0.93 (0.12)
Senses	0.84 (0.13)	0.91 (0.10)	0.88 (0.10)
Pain	0.68 (0.26)	0.86 (0.19)	0.84 (0.21)
Individual dimensions (psychosocial health)			
Happiness	0.74 (0.16)	0.80 (0.15)	0.77 (0.16)
Coping	0.70 (0.15)	0.83 (0.15)	0.80 (0.16)
Relationships	0.66 (0.17)	0.79 (0.16)	0.78 (0.16)
Self-worth	0.74 (0.18)	0.85 (0.15)	0.84 (0.16)
Mental Health	0.60 (0.15)	0.69 (0.17)	0.67 (0.17)

Notes: *Source: Maxwell et al (2016)[72]; HSUV = health state utility value

The overall mean (SD) HSUV (utility valuation) was 0.61 (0.22), which is much lower than the comparable Australian population norms for the general Australian population of 0.80 (0.19), and the 45–54 year age group of 0.77 (0.20) (Table 4.2).

Importantly, this relatively low HSUV for the respondent population was partially driven by low scores in Mental Health and Relationships that produced a substantially reduced Psychosocial super dimension score of 0.33 (0.19). The individual physical dimension of Pain also drove the low HSUV through the relatively low Physical super dimension of mean (SD) 0.59 (0.22) (Table 4.2).

4.4.3 Quality of Life/HSUV Estimates: Stratified By Socio-demographic Factors

4.4.3.1 Sex

Figure 4.2 and Table 4.3 provide the AQoL-8D's HSUVs and associated dimensional scores for the respondent population that generated a utility valuation (n = 1566) into male and female and compared to Australian population norms. Table 4.3 reveals that the HSUVs for males (mean (SD) 0.59 (0.21)) and females (0.61 (0.22)) with MS were similar, and that the HSUVs for males and females were substantially reduced from their Australian population norm counterparts of 0.78 (0.19) for females and 0.82 (0.17) for males.

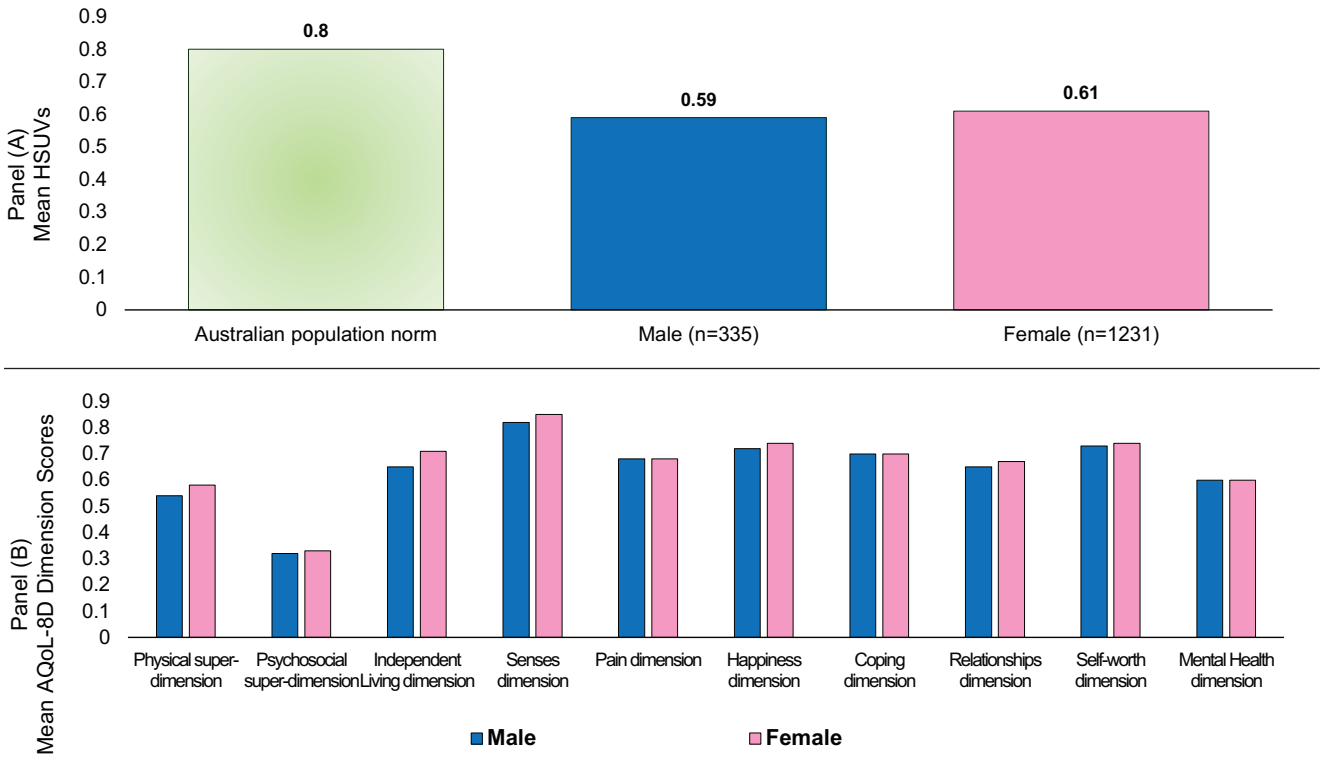
The marginally higher HSUV for females is explained by the small difference in the Physical super dimension between males and females: females recorded a marginally higher score of 0.58 (0.20) compared to 0.54 (0.21) for males. This was driven by a higher Independent Living dimensional score for females of 0.71 (0.20) compared to 0.65 (0.20) for males.

Table 4.3. AQoL-8D utility valuations, super dimension scores, and individual dimension scores, by sex

AQoL-8D characteristics	Male (n=335)	Female (n=1231)	Overall (n=1566)
	Mean (SD)	Mean (SD)	Mean (SD)
HSUV for people with MS	0.59 (0.21)	0.61 (0.22)	0.61 (0.22)
Australian population norms*	0.82 (0.17)	0.78 (0.19)	0.80 (0.19)
Super dimension			
Physical	0.54 (0.21)	0.58 (0.20)	0.57 (0.22)
Psychosocial	0.32 (0.19)	0.33 (0.19)	0.33 (0.19)
Individual dimensions (Physical health)			
Independent Living	0.65 (0.20)	0.71 (0.20)	0.70 (0.20)
Senses	0.82 (0.14)	0.85 (0.12)	0.84 (0.13)
Pain	0.68 (0.26)	0.68 (0.26)	0.68 (0.26)
Individual dimensions (Psychosocial health)			
Happiness	0.72 (0.16)	0.74 (0.16)	0.74 (0.16)
Coping	0.70 (0.16)	0.70 (0.15)	0.70 (0.15)
Relationships	0.65 (0.16)	0.67 (0.17)	0.67 (0.17)
Self-worth	0.73 (0.17)	0.74 (0.18)	0.74 (0.18)
Mental Health	0.60 (0.16)	0.60 (0.15)	0.60 (0.15)

Notes: *Source, Maxwell et al 2016 [72]; HSUV = health state utility value

Figure 4.2. AQoL-8D utility valuations, super dimension scores, and individual dimension scores, by sex



4.4.3.2 Age Group

Figure 4.3 and Table 4.4 provide the AQoL-8D's HSUVs and associated dimensional scores for the respondent population that generated a utility valuation (n = 1566) into age groups, compared to Australian population norms for age groups.

Table 4.4 reveals that as the age of a person with MS increased, their HSUV decreased. This trend was somewhat different to the Australian population norms for age groups – the HSUV increases for those in the 55-64 and 65+ age groups. The order of magnitude of the Physical and Psychosocial super dimensions that drove the decreasing HSUVs for people with MS as age increased, were the same as for the overall sample.

Interestingly, the Physical super dimension score was higher than the overall sample for the < 35 years age group mean (SD) 0.70 (0.23), however, for the same age group the Psychosocial super dimension was comparable to the overall sample at 0.35 (0.23). Another interesting point is that while the Physical super dimension substantially decreased (as disability also increased), as age increased, the Psychosocial super dimension score was almost the same (0.35 at <35 years and 0.32 at 65+ years).

Regarding the individual dimensional changes, the physical dimensional scores of Pain and Independent Living decreased as age increased. The individual dimension of Relationships also decreased the most in psychosocial health.

Figure 4.3. AQoL-8D utility valuations, super dimension scores, and individual dimension scores, by age group, compared to Australian population norms for the age group

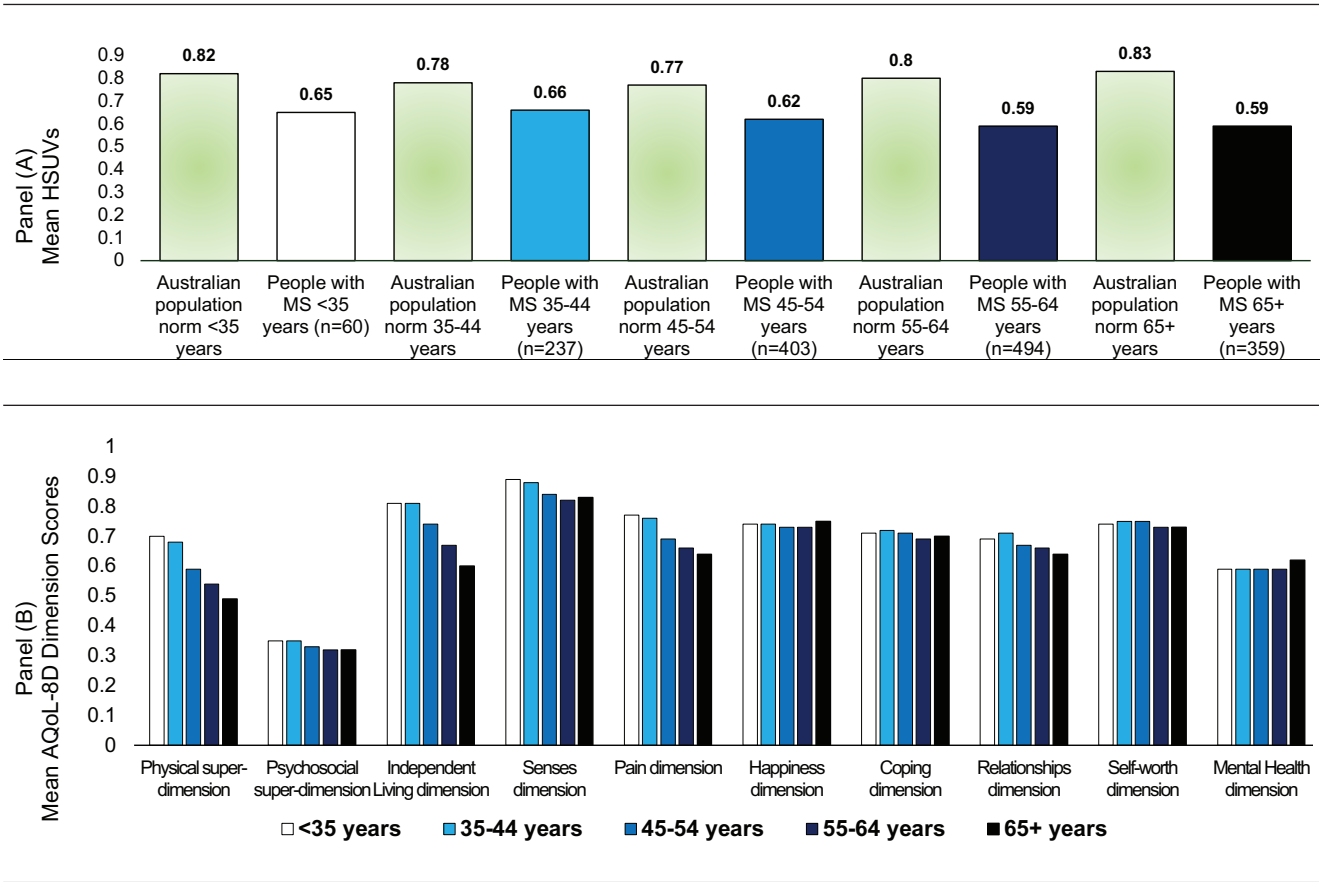


Table 4.4. AQoL-8D utility valuations, super dimension scores, and individual dimension scores, by age group

AQoL-8D characteristics	<35 years (n=60)	35–44 years (n=237)	45-54 years (n=403)	55–64 years (n=494)	65+ years (n=359)	Not Stated (n=13)	Overall (n=1566)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
HSUV for people with MS	0.65 (0.22)	0.66 (0.22)	0.62 (0.21)	0.59 (0.22)	0.59 (0.21)	0.61 (0.27)	0.61 (0.22)
Australian Population norms*	0.82 (0.15)	0.78 (0.17)	0.77 (0.20)	0.80 (0.21)	0.83 (0.22)*		0.80 (0.19)
Super dimensions							
Physical	0.70 (0.23)	0.68 (0.23)	0.59 (0.22)	0.54 (0.21)	0.49 (0.19)	0.61 (0.27)	0.57 (0.22)
Psychosocial	0.35 (0.23)	0.35 (0.21)	0.33 (0.20)	0.32 (0.20)	0.32 (0.17)	0.35 (0.25)	0.33 (0.19)
Individual dimensions (physical health)							
Independent Living	0.81 (0.19)	0.81 (0.19)	0.74 (0.19)	0.67 (0.19)	0.60 (0.18)	0.76 (0.22)	0.70 (0.20)
Senses	0.89 (0.11)	0.88 (0.11)	0.84 (0.12)	0.82 (0.14)	0.83 (0.13)	0.88 (0.08)	0.84 (0.13)
Pain	0.77 (0.27)	0.76 (0.24)	0.69 (0.26)	0.66 (0.26)	0.64 (0.26)	0.66 (0.29)	0.68 (0.26)
Individual dimensions (psychosocial health)							
Happiness	0.74 (0.17)	0.74 (0.16)	0.73 (0.16)	0.73 (0.16)	0.75 (0.15)	0.72 (0.18)	0.74 (0.16)
Coping	0.71 (0.16)	0.72 (0.16)	0.71 (0.15)	0.69 (0.16)	0.70 (0.14)	0.70 (0.21)	0.70 (0.15)
Relationships	0.69 (0.17)	0.71 (0.17)	0.67 (0.17)	0.66 (0.17)	0.64 (0.15)	0.69 (0.19)	0.66 (0.17)
Self-worth	0.74 (0.18)	0.75 (0.17)	0.75 (0.17)	0.73 (0.18)	0.73 (0.17)	0.72 (0.21)	0.74 (0.18)
Mental Health	0.59 (0.17)	0.59 (0.14)	0.59 (0.15)	0.59 (0.15)	0.62 (0.14)	0.58 (0.16)	0.60 (0.15)

*Source, Maxwell et al 2016 [72], HSUV = health state utility value

4.4.3.3 Australian States and Territories

Figure 4.4 and Table 4.5 provides the AQoL-8D's HSUVs (utility valuations) and associated dimensional scores for people with MS in the Australian states and territories. It shows that there were differences in HSUVs according to Australian geographical location with a range of 0.54 to 0.64. Nevertheless, the trend for psychosocial and physical health were the same as the overall results reported in Table 4.2 where psychosocial health was low and driven mainly by the individual dimensions of Mental Health and Relationships, and the individual dimension of Pain was the key driver for relatively low scores of physical health. Interestingly, Tasmania (TAS) recorded one the lowest HSUVs of the Australian states and territories, however, the sample size for this state was relatively small (n=90) and the age profile (older) suggesting increased disease severity as a likely explanation for this low score.

Figure 4.4. AQoL-8D utility valuations, super dimension scores, and individual dimension scores, by state/territory

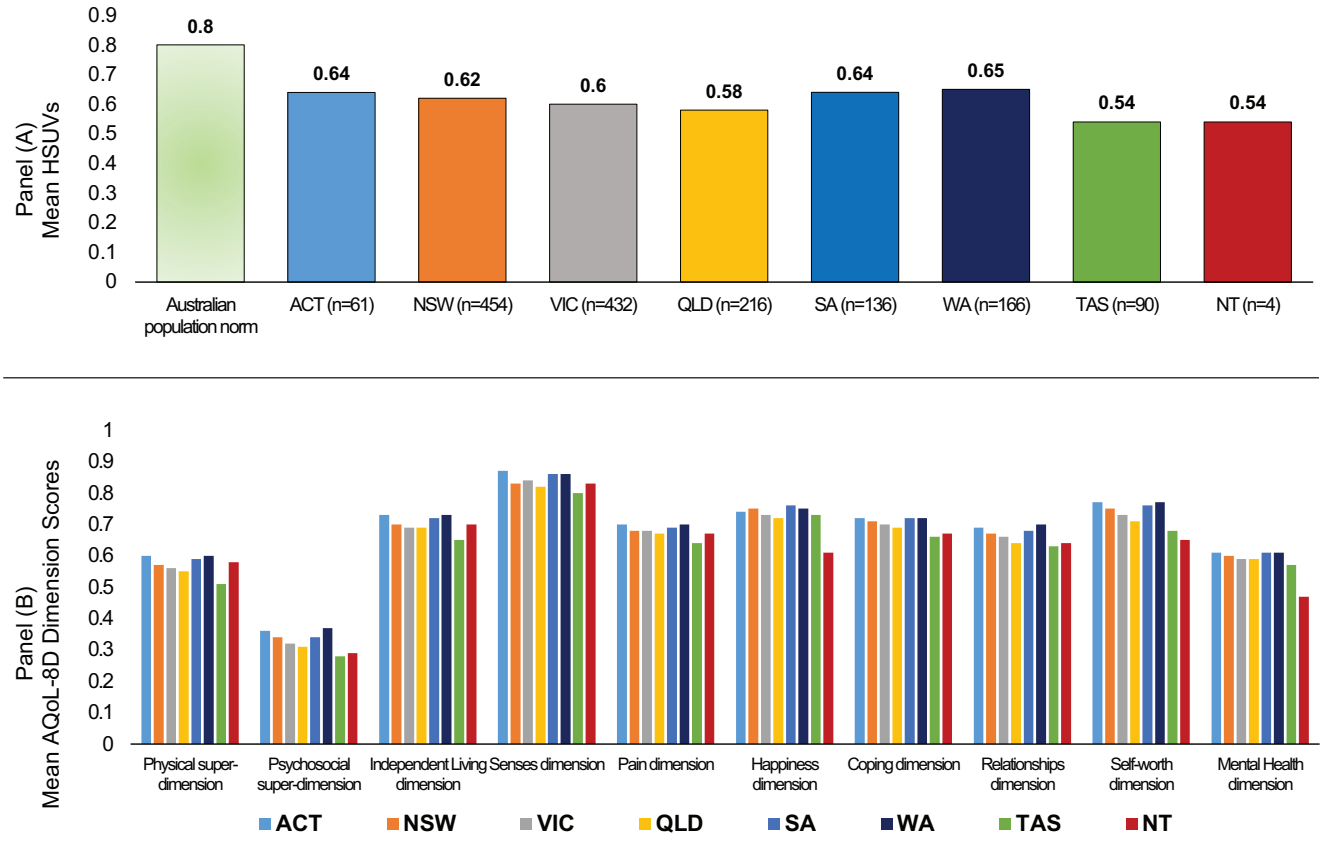


Table 4.5. AQoL-8D utility valuations, super dimension scores, and individual dimension scores, by state and territory

AQoL-8D characteristics	NSW (n=454)	VIC (n=432)	QLD (n=216)	WA (n=166)	SA (n=136)	TAS (n=90)	ACT (n=61)	NT (n=4)	Not Stated (n=7)	Overall (n=1566)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
HSUV	0.62 (0.22)	0.60 (0.21)	0.58 (0.22)	0.65 (0.23)	0.64 (0.20)	0.54 (0.20)	0.64 (0.23)	0.54 (0.38)	0.68 (0.20)	0.61 (0.22)
Super dimensions										
Physical	0.57 (0.23)	0.56 (0.21)	0.55 (0.23)	0.60 (0.22)	0.59 (0.22)	0.51 (0.21)	0.60 (0.23)	0.58 (0.33)	0.58 (0.17)	0.57 (0.22)
Psychosocial	0.34 (0.20)	0.32 (0.18)	0.31 (0.19)	0.37 (0.22)	0.34 (0.18)	0.28 (0.17)	0.36 (0.22)	0.29 (0.28)	0.40 (0.23)	0.33 (0.19)
Individual dimensions (physical health)										
Independent Living	0.70 (0.21)	0.69 (0.19)	0.69 (0.20)	0.73 (0.20)	0.72 (0.21)	0.65 (0.20)	0.73 (0.20)	0.70 (0.25)	0.70 (0.15)	0.70 (0.20)
Senses	0.83 (0.13)	0.84 (0.12)	0.82 (0.14)	0.86 (0.11)	0.86 (0.11)	0.80 (0.15)	0.87 (0.09)	0.83 (0.17)	0.88 (0.16)	0.84 (0.13)
Pain	0.68 (0.26)	0.68 (0.26)	0.67 (0.26)	0.70 (0.26)	0.69 (0.25)	0.64 (0.27)	0.70 (0.27)	0.67 (0.36)	0.69 (0.22)	0.68 (0.26)
Individual dimensions (psychosocial health)										
Happiness	0.75 (0.16)	0.73 (0.15)	0.72 (0.16)	0.75 (0.14)	0.76 (0.15)	0.73 (0.14)	0.74 (0.18)	0.61 (0.28)	0.79 (0.16)	0.74 (0.16)
Coping	0.71 (0.15)	0.70 (0.15)	0.69 (0.16)	0.72 (0.16)	0.72 (0.15)	0.66 (0.15)	0.72 (0.14)	0.67 (0.28)	0.77 (0.13)	0.70 (0.15)
Relationships	0.67 (0.17)	0.66 (0.16)	0.64 (0.16)	0.70 (0.18)	0.68 (0.17)	0.63 (0.15)	0.69 (0.18)	0.64 (0.19)	0.73 (0.17)	0.66 (0.17)
Self-worth	0.75 (0.17)	0.73 (0.17)	0.71 (0.18)	0.77 (0.18)	0.76 (0.16)	0.68 (0.17)	0.77 (0.18)	0.65 (0.29)	0.80 (0.16)	0.74 (0.18)
Mental Health	0.60 (0.15)	0.59 (0.14)	0.59 (0.16)	0.61 (0.16)	0.61 (0.13)	0.57 (0.14)	0.61 (0.16)	0.47 (0.29)	0.63 (0.15)	0.60 (0.15)

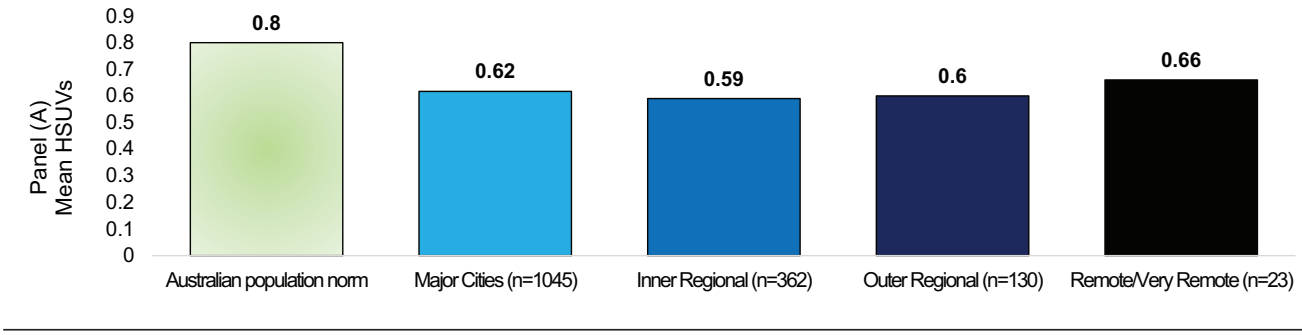
HSUV = health state utility value

4.4.3.4 Australian Remoteness Areas

Figure 4.5 and Table 4.6 provides the AQoL-8D's HSUVs (utility valuations) and associated dimensional scores for people with MS in the Australian Remoteness Areas according to postcode (see Figure 2.2) of Major Capital Cities, Inner Regional, Outer Regional and the combined Remoteness Area of Remote and Very Remote (due to the small sample size for these areas (n=23)).

It shows that the HSUVs, super dimension and individual dimension scores were the same, and the Inner and Outer Regional areas were similar. The Remote and Very Remote HSUVs and scores were slightly higher, however, the sample size was small therefore these results should be interpreted with caution. We found that the Relationships dimensional score for the Remote and Very Remote areas were slightly higher than the Major Capital Cities score.

Figure 4.5. AQoL-8D utility valuations, super dimension scores, and individual dimension scores, by Australian Remoteness Areas



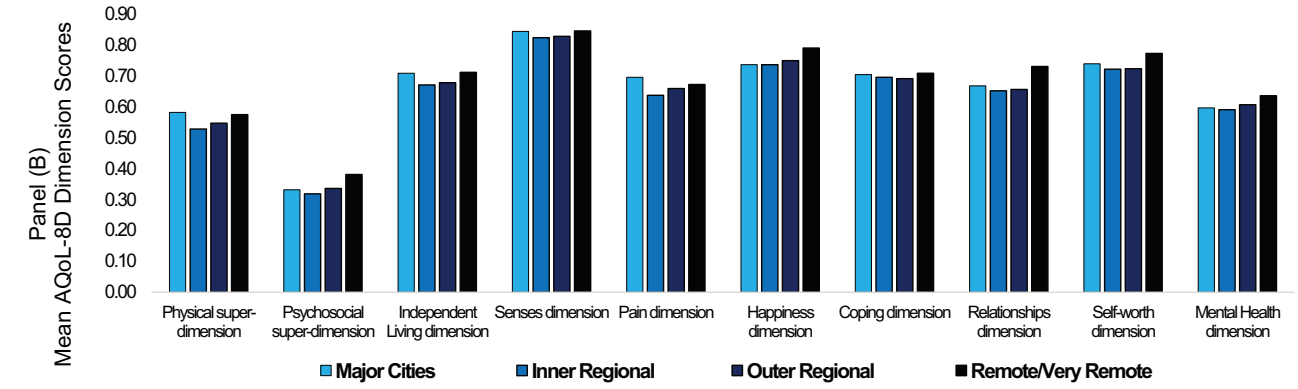


Table 4.6. AQoL-8D utility valuations, super dimension scores, and individual dimension scores, by Australian Remoteness Areas

AQoL-8D characteristics	Major Cities (n=1,045)	Inner Regional (n=362)	Outer Regional (n=130)	Remote and Very Remote (n=23)	Overall (n=1,560)*
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
HSUV	0.62 (0.22)	0.59 (0.22)	0.60 (0.23)	0.66 (0.20)	0.61 (0.22)
Super dimensions					
Physical	0.58 (0.22)	0.53 (0.22)	0.55 (0.22)	0.58 (0.21)	0.57 (0.22)
Psychosocial	0.33 (0.19)	0.32 (0.19)	0.34 (0.21)	0.38 (0.19)	0.33 (0.19)
Individual dimensions (physical health)					
Independent Living	0.71 (0.20)	0.67 (0.20)	0.68 (0.19)	0.71 (0.22)	0.70 (0.20)
Senses	0.84 (0.13)	0.83 (0.13)	0.83 (0.13)	0.85 (0.12)	0.84 (0.13)
Pain	0.70 (0.26)	0.64 (0.26)	0.66 (0.27)	0.67 (0.21)	0.68 (0.26)
Individual dimensions (psychosocial health)					
Happiness	0.74 (0.16)	0.74 (0.15)	0.75 (0.17)	0.79 (0.12)	0.74 (0.16)
Coping	0.71 (0.15)	0.70 (0.15)	0.69 (0.17)	0.71 (0.16)	0.70 (0.15)
Relationships	0.67 (0.17)	0.65 (0.16)	0.66 (0.16)	0.73 (0.17)	0.66 (0.17)
Self-worth	0.74 (0.17)	0.72 (0.18)	0.72 (0.19)	0.77 (0.14)	0.74 (0.18)
Mental Health	0.60 (0.15)	0.59 (0.14)	0.61 (0.17)	0.64 (0.14)	0.60 (0.15)

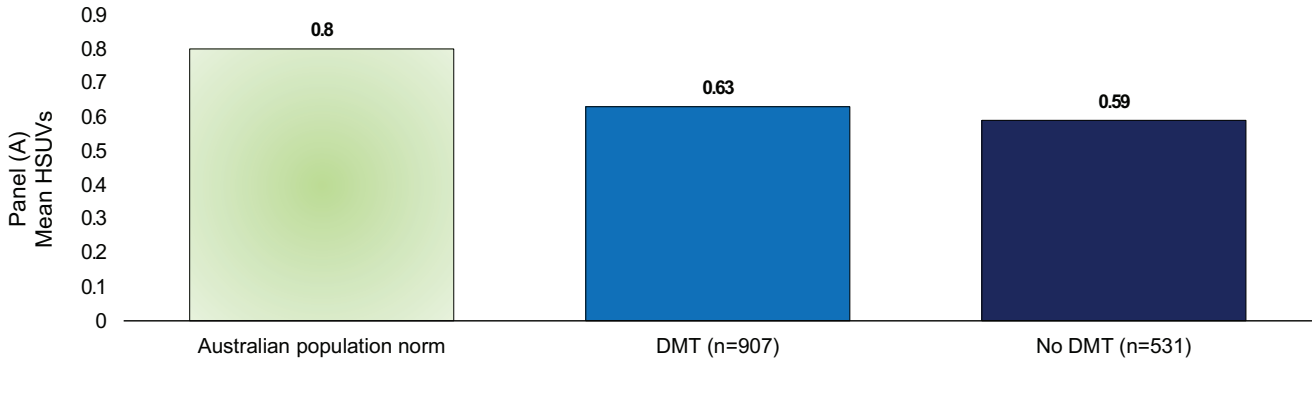
* Six people did not report a postcode; HSUV = health state utility value

4.4.4 Quality of Life/HSUV Estimates: Stratified By Disease-specific Factors

4.4.4.1 DMT Usage

Figure 4.6 and Table 4.7 provide the AQoL-8D's HSUVs (utility valuations) and associated dimensional scores stratified by DMT usage. People using DMTs recorded a mean (SD) HSUV of 0.63 (0.21) that was 0.04 utility points higher than for people not using DMTs, and 0.02 utility points higher than the overall sample utility valuation of 0.61 (0.22). The key driver of the higher score was the higher individual dimensional score for Independent Living that was 0.73 (0.19) for people with MS using DMTs compared to 0.64 (0.21) for people not using DMTs. The individual scores of Pain and Relationships for people not using DMTs were also slightly lower. People using DMTs recorded an individual score for the Pain dimension of 0.03 points lower, indicating that they experienced less pain than people with MS not using DMTs. The Psychosocial super dimension for both groups was similar and comparable to the low score recorded for the overall respondent sample. Chapter 2 revealed that people with MS using DMTs were a decade younger than people with MS not using DMTs (Table 2.2)

Figure 4.6. AQoL-8D utility valuations, super dimension scores, and individual dimension scores, by DMT usage



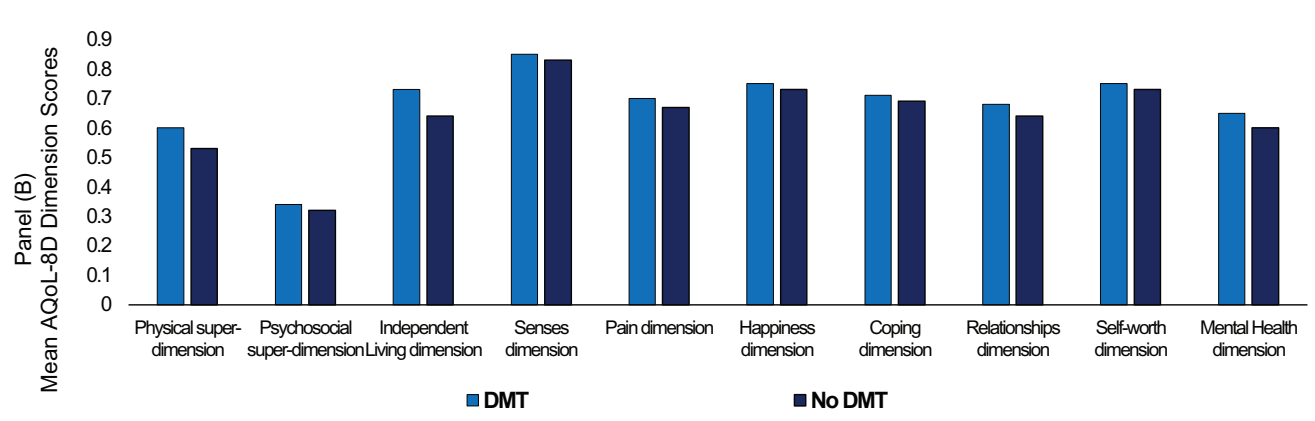


Table 4.7. AQoL-8D utility valuations, super dimension scores, and individual dimension scores, by DMT usage

AQoL-8D characteristics	DMT (n=907)	No DMT (n=531)	Not Stated (n=128)	Overall (n=1,566)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
HSUV	0.63 (0.21)	0.59 (0.22)	0.56 (0.24)	0.61 (0.22)
Super dimensions				
Physical	0.60 (0.22)	0.53 (0.22)	0.52 (0.24)	0.57 (0.22)
Psychosocial	0.34 (0.19)	0.32 (0.19)	0.31 (0.21)	0.33 (0.19)
Individual dimensions (physical health)				
Independent Living	0.73 (0.19)	0.64 (0.21)	0.69 (0.21)	0.70 (0.20)
Senses	0.85 (0.12)	0.83 (0.14)	0.81 (0.14)	0.84 (0.13)
Pain	0.70 (0.25)	0.67 (0.27)	0.61 (0.28)	0.68 (0.26)
Individual dimensions (psychosocial health)				
Happiness	0.75 (0.15)	0.73 (0.16)	0.72 (0.19)	0.74 (0.16)
Coping	0.71 (0.15)	0.69 (0.16)	0.67 (0.18)	0.70 (0.15)
Relationships	0.68 (0.17)	0.64 (0.16)	0.64 (0.17)	0.66 (0.17)
Self-worth	0.75 (0.17)	0.73 (0.18)	0.70 (0.20)	0.74 (0.18)
Mental Health	0.60 (0.14)	0.60 (0.15)	0.57 (0.17)	0.60 (0.15)

HSUV = health state utility value

4.4.4.2 Type of MS

Figure 4.7 and Table 4.8 provide the AQoL-8D's HSUVs (utility valuations) and associated dimensional scores stratified by the type of MS namely RRMS, PPMS, SPMS, and PRMS. RRMS accounted for 55% of the sample.

People with RRMS recorded a HSUV of mean (SD) 0.65 (0.21), compared to the lower HSUVs for SPMS 0.51 (0.18), PPMS 0.54 (0.21) and PRMS 0.51 (0.22). These substantially reduced HSUVs for the more progressive forms of MS were particularly driven by physical health through reduced Independent Living and Pain as disability increased.

Psychosocial health was also reduced for the more progressive types of MS than the overall sample and drove the lower HSUV. To illustrate, the Psychosocial super dimension score for PRMS was tremendously low with a mean (SD) score of 0.28 (0.16).

The individual psychosocial health dimensional scores for Relationships and Mental Health were substantially lower for the more progressive forms of MS, for example, the Relationships score for RRMS was 0.70 (0.17) compared to 0.58 (0.12) for SPMS. On the other hand, the individual scores of Happiness and Self-worth were higher and also accord with the individual scores for these two individual dimensions of health for the overall sample of respondents.

Figure 4.7. AQoL-8D utility valuations, super dimension scores, and individual dimension scores, by MS type

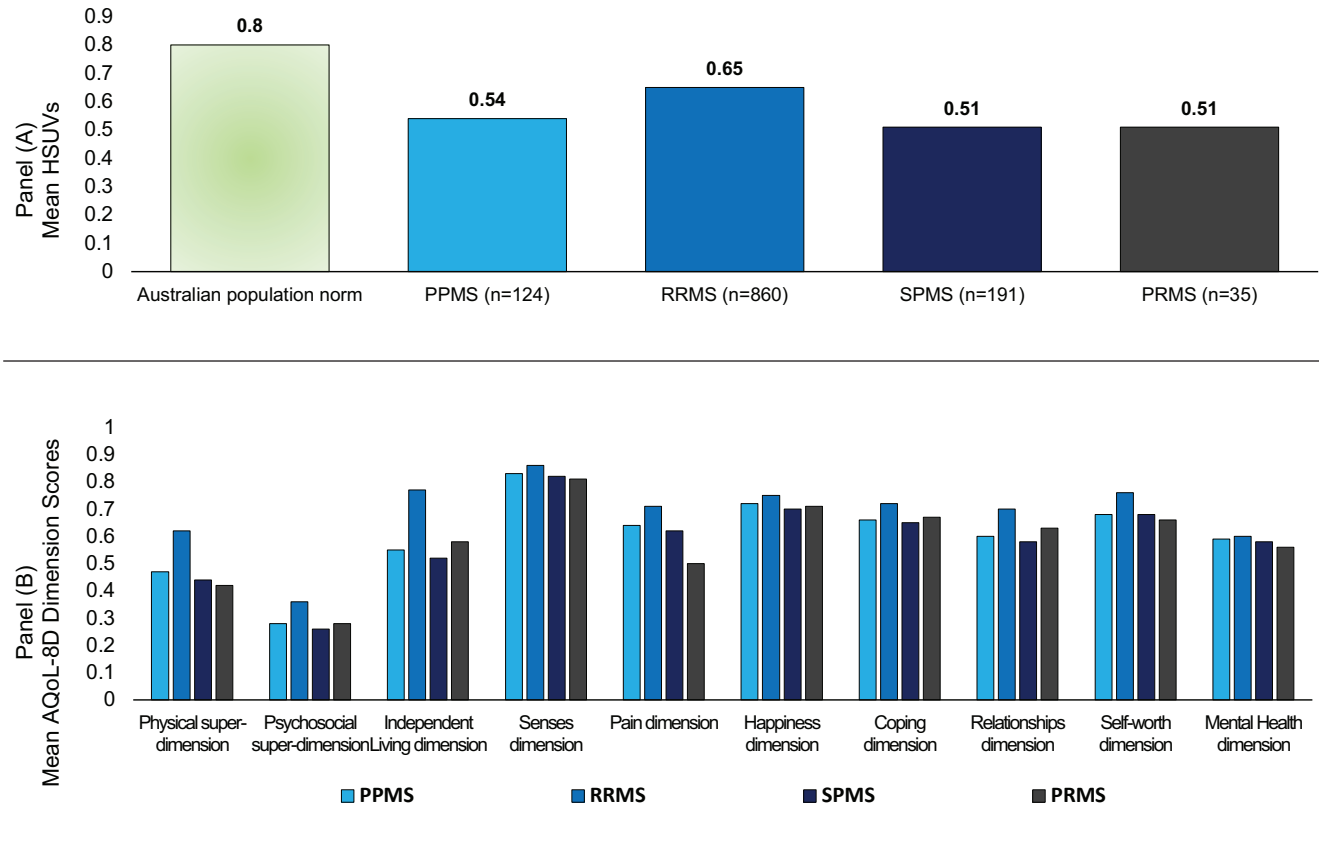


Table 4.8. AQoL-8D utility valuations, super dimension scores, and individual dimension scores, by MS type

AQoL-8D characteristics	RRMS (n = 860)	PPMS (n = 124)	SPMS (n = 191)	PRMS (n = 35)	Unsure (n = 159)	Not Stated (n=197)	Overall (n=1,566)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
HSUV	0.65 (0.21)	0.54 (0.21)	0.51 (0.18)	0.51 (0.22)	0.62 (0.22)	0.58 (0.23)	0.61 (0.22)
Super dimensions							
Physical	0.62 (0.22)	0.47 (0.18)	0.44 (0.15)	0.42 (0.19)	0.56 (0.22)	0.54 (0.24)	0.57 (0.22)
Psychosocial	0.36 (0.16)	0.28 (0.16)	0.26 (0.16)	0.28 (0.16)	0.35 (0.20)	0.31 (0.20)	0.33 (0.19)
Individual dimensions (physical health)							
Independent Living	0.77 (0.18)	0.55 (0.16)	0.52 (0.12)	0.58 (0.18)	0.69 (0.20)	0.70 (0.21)	0.70 (0.20)
Senses	0.86 (0.11)	0.83 (0.13)	0.82 (0.14)	0.81 (0.13)	0.81 (0.15)	0.82 (0.14)	0.84 (0.13)
Pain	0.71 (0.25)	0.64 (0.26)	0.62 (0.26)	0.50 (0.25)	0.70 (0.26)	0.64 (0.28)	0.68 (0.26)
Individual dimensions (psychosocial health)							
Happiness	0.75 (0.15)	0.72 (0.15)	0.70 (0.15)	0.71 (0.18)	0.75 (0.16)	0.72 (0.18)	0.74 (0.16)
Coping	0.72 (0.15)	0.66 (0.16)	0.65 (0.15)	0.67 (0.16)	0.73 (0.15)	0.69 (0.17)	0.70 (0.15)
Relationships	0.70 (0.17)	0.60 (0.15)	0.58 (0.12)	0.63 (0.15)	0.67 (0.17)	0.65 (0.16)	0.66 (0.17)
Self-worth	0.76 (0.16)	0.68 (0.18)	0.68 (0.17)	0.66 (0.22)	0.74 (0.28)	0.71 (0.19)	0.74 (0.18)
Mental Health	0.60 (0.15)	0.59 (0.15)	0.58 (0.15)	0.56 (0.15)	0.62 (0.15)	0.58 (0.16)	0.60 (0.15)

HSUV = health state utility value

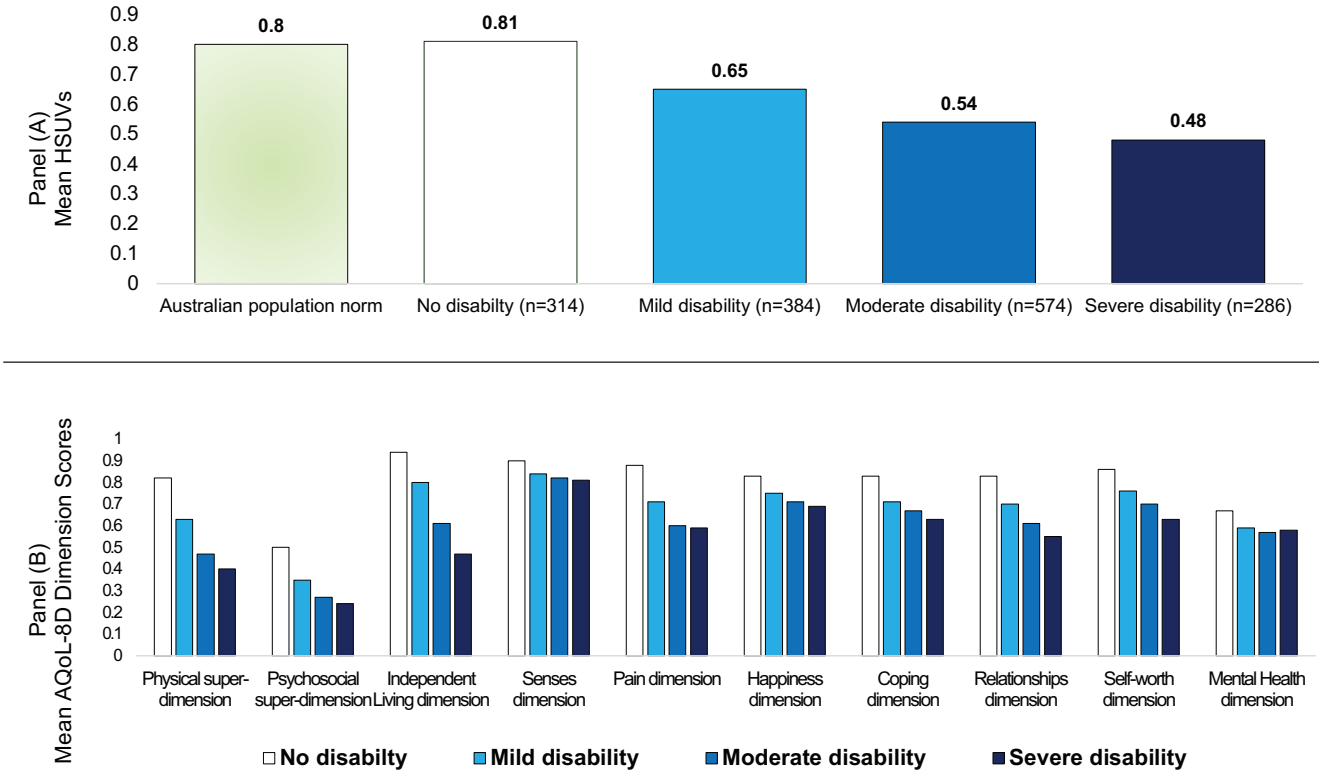
4.4.4.3 Disability Severity of MS

Figure 4.8 and Table 4.9 show the AQoL-8D's (HSUVs) utility valuations and associated dimensional scores, and Australian population norms stratified by disease severity.

It shows that as MS-related disability increased, health utility decreased, and therefore quality of life decreased. Those with no disability reported a HSUV that was similar to the general Australian population and reported similar scores to the general Australian population in physical and psychosocial super dimensions and individual dimensions of Independent Living, Senses, Pain, Happiness, Coping, Relationships, Self-worth and Mental Health.

There was a substantial fall in HSUV (almost 0.20 utility points) between no disability and mild disability, and the HSUVs were also substantially diminished from moderate to severe disability. People with MS in the severe disability category reported the lowest HSUVs for the entire study, namely, severe disability mean (SD) 0.48 (0.19), with similar low scores for both the Physical super dimension (mean (SD) 0.40 (0.15)) and the Psychosocial 0.24 (0.13) super dimensions of health. The low HSUVs and composite super dimension scores were driven by substantially diminished dimensional scores for Independent Living, Pain, Mental Health, Relationships and Coping.

Figure 4.8. AQoL-8D utility valuations, super dimension scores, and individual dimension scores, by disability severity



No disability includes EDSS level 0, Mild includes EDSS levels 1–3.5, Moderate includes EDSS levels 4–6, and Severe includes EDSS levels 6.5–9.5.

Table 4.9. AQoL-8D utility valuations, super dimension and individual dimension scores, by disability severity

AQoL-8D characteristics	No Disability (n=314)	Mild Disability (n=384)	Moderate Disability (n=574)	Severe Disability (n=286)	Not Stated (n=8)	Overall (n=1,566)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
HSUV	0.81 (0.16)	0.65 (0.19)	0.54 (0.19)	0.48 (0.19)	0.45 (0.17)	0.61 (0.22)
Super dimensions						
Physical	0.82 (0.15)	0.63 (0.19)	0.47 (0.16)	0.40 (0.15)	0.45 (0.13)	0.57 (0.22)
Psychosocial	0.50 (0.21)	0.35 (0.18)	0.27 (0.15)	0.24 (0.13)	0.19 (0.11)	0.33 (0.19)
Individual dimensions (physical health)						
Independent Living	0.94 (0.08)	0.80 (0.14)	0.61 (0.13)	0.47 (0.10)	0.56 (0.22)	0.70 (0.20)
Senses	0.90 (0.09)	0.84 (0.12)	0.82 (0.12)	0.81 (0.16)	0.81 (0.12)	0.84 (0.13)
Pain	0.88 (0.16)	0.71 (0.24)	0.60 (0.25)	0.59 (0.27)	0.63 (0.27)	0.68 (0.26)
Individual dimensions (psychosocial health)						
Happiness	0.83 (0.13)	0.75 (0.15)	0.71 (0.15)	0.69 (0.17)	0.60 (0.15)	0.74 (0.16)
Coping	0.83 (0.12)	0.71 (0.14)	0.67 (0.14)	0.63 (0.16)	0.62 (0.15)	0.70 (0.15)
Relationships	0.83 (0.15)	0.70 (0.15)	0.61 (0.13)	0.55 (0.10)	0.56 (0.15)	0.66 (0.17)
Self-worth	0.86 (0.13)	0.76 (0.16)	0.70 (0.17)	0.63 (0.18)	0.62 (0.19)	0.74 (0.18)
Mental Health	0.67 (0.14)	0.59 (0.14)	0.57 (0.14)	0.58 (0.15)	0.55 (0.19)	0.60 (0.15)

HSUV = health state utility value
No disability includes EDSS level 0, Mild includes EDSS levels 1–3.5, Moderate includes EDSS levels 4–6, and Severe includes EDSS levels 6.5–9.5.

4.5 Discussion

We found that the mean (SD) HSUV was 0.61 (0.22) in a large representative sample of the AMSLS (n = 1,566). This utility value was substantially lower than that of the Australian general population (mean (SD) 0.80 (0.19)).

Psychosocial health status for people with MS was relatively low and partially drove the low HSUVs. Moreover, the individual dimensions of Mental Health and Relationships were the lowest individual dimensional scores in the psychosocial range. Physical health status was also relatively low and the key drivers identified for a diminished physical health status were Pain and Independent Living.

When the overall sample was investigated for different groups of people with MS such as males and females, age groups, geographical location, disease severity and people using DMTs or not, we found that the highest recorded HSUV (utility valuation) was for people with MS with 'no disability' namely mean (SD) 0.81 (0.16) and the lowest recorded HSUV (utility valuation) was for people with 'severe disability', namely mean (SD) 0.48 (0.19).

When the sample was stratified for sex we found that the marginally higher HSUV for females was driven by the individual dimension of Independent Living.

As age increased, quality of life decreased. This trend is opposite to the Australian population norm.

When the sample was stratified for age, we found that as the age of a person with MS increased, their HSUV decreased and this trend was opposite to the Australian population norms for older age groups. We found that the physical health impacts of MS were proportionally higher as people with MS aged than the psychosocial impacts of the disease that impacted on people with MS earlier on (when they were younger). Regarding the individual dimensional changes, the physical dimensions of Pain and Independent Living decreased as age increased. The individual dimension of Relationships also decreased the most in psychosocial health.

There were differences in HSUVs according to the Australian states and territories with a range of 0.54 to 0.64. Nevertheless, the recorded trends for psychosocial and physical health were the same as the overall results. TAS recorded one the lowest HSUVs of the Australian states and territories, however, the sample size for TAS was relatively small (n=90) and the age profile was older suggesting increased disease severity may have been the likely explanation for this low score. Regarding Remoteness Areas, people with MS in Major Capital Cities recorded the same HSUV as the overall sample (Major Capital Cities were one-third of the sample). For people with MS living in Remote and Very Remote Australia, the HSUV was higher, however this result should be interpreted with caution due to the very small sample size.

People using DMTs were a decade younger and also recorded a higher quality of life than people not using DMTs.

In regard to DMT usage, people using DMTs were a decade younger and also recorded a higher HSUV than people not using DMTs. The physical dimensions of Independent Living (increased) and Pain (decreased) drove the higher utility score for people with MS using DMTs, compared to people not using DMTs. Psychosocial health was similar for both groups.

When the overall sample was stratified for type of MS, we found that people with the more progressive forms of MS recorded much lower HSUVs, driven by low composite physical and psychosocial scores and low individual dimensional scores for Independent Living, Pain, Relationships and Mental Health.

Additionally, as severity of disability increased, health utility decreased, and therefore QoL decreased. Those with no disability reported a HSUV that was the same as the general Australian population and reported similar scores to the general Australian population in physical and psychosocial super dimensions and individual dimensions of Independent Living, Senses, Pain, Happiness, Coping, Relationships, Self-worth and Mental Health. On the other hand, those with mild to severe disability recorded decreased scores in all of these dimensions.

When the no disability (n = 314; 45%) and mild disability (n = 384; 55%) groups are combined, the reported HSUV was 0.72 (0.20), driven by the higher QoL for a person with MS with no disability.

People with the more progressive forms of MS recorded much lower HSUVs, driven by low composite physical and psychosocial scores and low individual dimensional scores for Independent Living, Pain, Relationships and Mental Health.

4.5.1 Previous Australian Evidence

Compared to those reported in 2011, we found that the overall mean HSUV in 2017 was slightly lower. The likely explanation for this difference are the differences in instrument measurement: the 2011 report's HSUVs were *indirectly derived* from mapped responses from 5 questions of the WHOQOL-100 (World Health Organization Quality of Life instrument) to the EQ-5D-3L multi-attribute utility instrument rather than directly measured using the *direct* reported responses from people with MS to the AQoL-8D's 35 questions.

In line with the 2011 economic impact of MS report, we also found that there was a substantial reduction in the quality of life as disease severity increased. The 2011 economic impact of MS report found that there was an almost 50% reduction in utility when disability was severe. We found similar results.

The study found that the HSUV for severe disease was extremely low with a reported mean utility of 0.40 (95%CI: 0.49–0.56).[59] This utility valuation was comparable to, or even lower than, patient-reported outcomes of people with terminal metastatic cancer, chronic kidney disease and severe heart disease. [57, 75, 76]

The 2005 Access Economics report titled *Acting Positively: Strategic Implications of the Economic Costs of MS in Australia* discussed the rate of depression amongst people with MS and suggested that between 40–60 % of people with MS suffer depression at some point over the course of the illness. Our study found that psychosocial health status was substantially reduced for all people with MS, particularly from the "mild disability" severity of disease category onwards and that the psychosocial health super dimension was substantially reduced in the "severe disability" disease category. This reduction in psychosocial health in the severe disability category was driven by all of the individual dimensions of psychosocial health including Happiness, Coping, Self-worth, Mental Health and Relationships.

4.5.2 Comparison to Other Chronic Diseases using the AQoL-8D

Table 4.9 provides HSUVs for other chronic diseases measured by the AQoL-8D, and Australian population norms. It shows that the overall HSUV for people with MS (0.61) was comparable to people with chronic conditions including chronic cancer or chronic arthritis. The utility valuations for people with severe disability were lower than for people with most chronic diseases, and similar to those of people with chronic depression.

There were two studies that used the AQoL-8D to measure HSUVs on different severity classifications (severe obesity and ulcerative colitis) and they found a similar trend of decreasing HSUV with increasing severity as we showed in our study. More specifically, people with severe ulcerative colitis recorded a reduced HSUV from 0.80 (remission) to 0.66 severe disease, compared to people with MS who recorded a HSUV of 0.81 for no disability and 0.48 for severe disability.

QoL for people with severe MS is comparable to, or even lower than the QoL reported for people with terminal metastatic cancer, chronic kidney disease and severe heart disease.

Table 4.10. Utility weights reported for other chronic diseases using the AQoL-8D, Australian population norms, and inclusive of an Australian population.

Health State measured by AQoL-8D	Location of study population	HSUV
Australian population norm**	Australia	0.80
Chronic cancer [a]	6 countries including Australia*	0.66
Chronic diabetes [a]	6 countries including Australia*	0.69
Chronic asthma [a]	6 countries including Australia*	0.69
Chronic heart disease [a]	6 countries including Australia*	0.68
Chronic arthritis [a]	6 countries including Australia*	0.63
Chronic hearing loss [a]	6 countries including Australia*	0.72
Chronic depression [a]	6 countries including Australia*	0.45
Average measure of chronic disease [a]	6 countries including Australia*	0.64
Public 'healthy' population norm [a] ***	6 countries including Australia*	0.83
Diabetes [b]	6 countries including Australia*	0.66
Obesity [c]	Australia	0.69
Long term publicly waitlisted severely obese bariatric surgery patients [d]		
• Before surgery	Australia	0.51
• Three months after surgery		0.61
• One year after surgery		0.67
Private bariatric surgery patients many years after surgery [e]	Australia	0.76
Ulcerative colitis [f]		
• Remission	Australia	0.80
• Active disease		0.70
• Mild disease		0.76
• Moderate/severe disease		0.66
Multiple Sclerosis (2016 study) [g]		
• **Overall sample**	**Australian MS Longitudinal Survey**	**0.61**
• **No disability**		**0.81**
• **Mild disability**		**0.65**
• **Moderate disability**		**0.54**
• **Severe disability**		**0.48**

Notes: Sources: a, Richardson et al 2015 [77]; b, Chen et al 2015 [78]; c, Khan et al 2012 [74]; d, Campbell et al 2017 [63]; e, Campbell et al 2106 [61]; f, Gibson et al 2015 [79]; g, 2016 MSRA study *Countries included Australia, Canada, Germany, Norway, United Kingdom, and United States ** Australian population norm *** Public 'healthy' composite population norm for the six countries included in the study

Chapter 5 Summary and Conclusions

5.1 Overall Summary

MS remains a challenging condition in our community, placing a very significant toll on Australians, particularly in adults of working age, who should be in the prime of life, when it is most frequently diagnosed. MS has a major impact on health and QoL and poses a substantial economic burden to people with MS and society. The introduction and use of DMTs with improved efficacy over the past few years in Australia have had profound effects on the management of the disease, and hence, on the costs of MS. This report provides an important insight into the health economic burden of MS in Australia. It provides the updated estimates of costs and QoL/HSUV impacts of MS in Australia in 2017, using the latest available data from a large representative sample of Australian people with MS. Whilst some studies have investigated the QoL and costs of MS in Australia,[6, 8, 80] these studies are now out of date and had some methodological limitations. The analyses presented in this report provides per person costs as well as the total costs for all people with MS in Australia, based on the most recent 2017 MS prevalence estimates. Furthermore, the QoL/HSUV of Australian people with MS presented in this report revealed the extent to which MS may impact on the QoL of people with MS. To provide a context for MS, we have compared our results with those from previous Australian studies, as well as those from other nations around the globe.

Our study had several strengths, including the large and representative sample, minimal possibility of recall bias, and the inclusion of additional cost categories compared to previous reports, with some cost categories broken down into additional sub-categories to provide a more detailed picture (e.g. indirect costs from lost wages, lost productivity costs). Regarding the QoL/HSUVs analysis, this is the first time that a direct measurement of HSUVs was used. Additionally, the use of the AQoL-8D provided a substantially more detailed picture of QoL in that it captured the impact that both complex and interdependent physical and psychosocial factors may have on the QoL and HSUVs of people with MS. This is the first time that a breakdown of QoL and HSUV estimates have been provided by age, sex, location, MS type, and DMT use.

Whilst MS results in huge economic costs to individuals and the community and a substantial reduction in the QoL of people with MS, it remains firmly under the radar, with only 4 out of 10 Australians ranking MS a community health priority.[81] The comprehensive landscape analysis of MS provided in this report highlights the need to communicate the burden of MS to the broader community and to ensure it receives the attention it deserves. The report also highlights the changes to the MS landscape that have occurred over time, and should be of immense value for advocacy as well as for researchers to demonstrate the impact of MS on individuals and society.

5.2 Summary of the Key Findings of This Report:

5.2.1 Prevalence of MS

The number of people living with MS in Australia is on the rise, with the new estimates showing that 25,607 (95%CI: 24,874–26,478) Australians now live with the MS (an increase of 4,324 or a 20.3% increase of people with MS from 2010). The overall prevalence was 103.7 per 100,000 people (95%CI: 100.7–107.2). Comparing states and territories, the age-standardised prevalence estimates were highest in TAS (138.7 per 100,000 [95%CI: 137.2–140.1]), almost double that of QLD (74.6 per 100,000 [95%CI: 73.5–75.6]) and WA (87.7 per 100,000 [95%CI: 86.6–88.9]), in line with the known international latitudinal gradient of MS prevalence.

Our findings of an increased prevalence of MS in Australia compared with 2010 reflect recent global trends. One of the key reasons for this increase likely reflects increased survival of people with MS, as noted in the International Federation of MS Atlas of Multiple Sclerosis[10]. Another reason is an increase in incidence of MS as reflected in a recent study regarding the city of Newcastle in the Australian state of NSW[11].

5.2.2 Costs of MS

Total costs for all people of MS in Australia have increased substantially over time (from $1.24 billion in 2010 to $1.75 billion in 2017). This is because of both the increase in costs per person of MS in Australia, as well as the increasing prevalence of MS in Australia. Annual total per person costs of MS increased by 17% from $58,652 in 2010 to $68,382 in 2017, driven largely by increased costs of DMTs and offset by decreased costs of lost wages and decreased informal care costs.

The largest total cost component was the direct costs (44%, $30,346). Twenty two percent of the direct per person costs ($8,437) was born by the people with MS, while government and community jointly accounted for 78% of the direct per person costs ($21,911). Indirect costs due to lost wages comprised a substantial portion of the overall costs of illness of MS (32%, $21,858), representing per person loss of wages due to early retirement/employment status change/occupation change). The early retirement of people with MS comprised more than 60% of the indirect costs from lost wages ($13,468). Other significant cost components included the informal care costs (10%, $7,144), nursing home costs (9%, $6,343) and the indirect costs from lost productivity (4%, $2,691).

Annual total costs increased by 276% from $30,561 for people with MS with no disability to $114,813 for people with severe disability. Male sex was associated with relatively higher mean costs ($71,445), compared to females ($67,689), driven mainly by higher indirect costs form lost wages for males. Costs increased with age up to 54 years, and then substantially

decreased in those over 65 years, mainly because of the lower proportion of this group on DMTs, and also because the indirect costs from lost wages were lower for this age group. However, other costs were substantially higher e.g. direct medical costs/informal care cost.

Annual per person costs did not vary substantially between the Australian states and territories, with the ACT being an exception. However, differences between states and territories should be interpreted with caution due to the low sample sizes for TAS and the ACT. Annual per person costs did not vary markedly between the Australian Remoteness Areas. Costs for the Inner Regional Australia were relatively higher, driven mainly by higher indirect costs from lost wages in the Inner Regional Australia.

Costs were highest for people with Secondary Progressive MS (SPMS), followed by Primary Progressive MS (PPMS), Progressive Relapsing MS (PRMS) and Relapsing Remitting MS (RRMS). Being on DMTs was associated with higher costs ($72,145), compared to those not on DMTs ($59,649).

People with Secondary Progressive MS (SPMS) incurred the highest total costs and this is despite the significant drop in costs relating to DMTs.

About 69% of participants included in the cost analysis were receiving a DMT, with use declining with increasing disability severity. Prescription medications represented a substantial proportion (~25%) of the overall costs of MS. We found that patients on DMTs had higher costs ($12,000+) compared to people not using DMTs. Almost half the expenses on special equipment related to mobility needs of people with MS.

The availability of new treatment options and also adjustments in the diagnostic criteria for MS have led to changes not only in the management of people with MS but also to a focus on earlier diagnosis and treatment. Such treatment landscape changes have resulted in cost shifts. For instance, the indirect costs from lost wages has declined from $29,030 (49% of the total costs) in 2010 to 21,858 (32% of the total costs) in 2017. Despite a doubling of direct costs due to DMTs and other factors between 2010 and 2017, the overall increase in per person costs between the two periods is less than $10,000 as a result of the decrease in indirect costs from lost wages and others. A separate analysis has shown that newer higher efficacy DMTs are linked positively to the employment outcomes of people with MS,[21] and our results are in accordance with these findings, suggesting that the cost of the newer higher efficacy DMTs has been substantially offset by reductions in some of the indirect and other costs associated with MS.

We compared our results with the 2011 Australian COI of MS study[8] that matches with our analysis both in terms of its methodological framework and (most of) the cost categories considered and found considerable cost shifts between the various cost components over time. We also compared our COI estimates with those from other nations and found that costs of MS vary between nations, however, Australian per person costs of MS were comparable to nations such as Belgium, Denmark, Germany, and Spain. To provide a context for MS, a comparison of costs associated with other diseases in the Australian setting was also performed. Once again, considerable differences in the costs of various diseases in Australia were found that could be due to a multitude of factors (e.g.: cost categories considered, the differences in international healthcare systems, and differences in sample demographics including age and sex).

Our cost estimates provide a useful platform for policy makers and researchers by providing a snapshot of the nature and extent of costs related to MS in Australia in 2017. The cost estimates also provide information on the main cost drivers, which are important for the development of health policies and efficient allocation of scarce national healthcare resources. Our results provide an up-to-date, reliable reference to support the MS community in advocating for increased and targeted support for people with MS and for increased research funding to develop further strategies to improve the lives of people with MS through prevention of disease onset and progression.

5.2.3 QoL/HSUVs of MS

We have demonstrated that increasing disability associated with MS considerably impacts health utility. This is the first study to perform a direct measurement of HSUVs for Australian people with MS using the AQoL-8D - a multi attribute utility instrument that accounts for the complex interdependence of physical and psychosocial aspects of QoL. Therefore, the impact of MS on various health dimensions (eight individual dimensions of physical and psychosocial health and two composite 'super-dimensions') of people with MS has also been demonstrated.

We found that the mean (SD) HSUV for people with MS was 0.61 (0.22). This HSUV is substantially lower (31% lower) than that of the Australian general population (mean 0.80; SD 0.19).

Psychosocial health status for people with MS was relatively low and partially drove the low overall HSUVs for people with MS. The individual dimensions of Mental Health and Relationships were the lowest individual dimensional scores in the psychosocial range. Physical health status was also relatively low and the key drivers identified were Pain and Independent Living.

When the overall sample was investigated for different groups of people with MS we found that the highest recorded HSUV (utility valuation) was for people with MS with 'no disability' namely mean (SD) 0.81 (0.16) and the lowest recorded HSUV (utility valuation) was for people with 'severe disability', namely mean (SD) 0.48 (0.19).

We found that as the age of a person with MS increased, their HSUV decreased and this trend was opposite to the Australian population norms for older age groups when measured using the AQoL. We found that the physical health impacts of MS were proportionally higher as people with MS aged than the psychosocial impacts of the disease that impacted on people with MS earlier on (when they were younger at diagnosis).

Concerning DMT usage, people using DMTs were a decade younger and also recorded a higher HSUV than people not using DMTs. The physical dimensions of Independent Living (increased) and Pain (decreased) drove the higher utility score for people with MS using DMTs, compared to people not using DMTs. Psychosocial health was similar for both groups.

People with the more progressive forms of MS recorded much lower HSUVs, driven by low composite physical and psychosocial scores and low scores for Independent Living, Pain, Relationships and Mental Health. Additionally, as disease severity increased health utility decreased, and therefore QoL decreased.

Those with no disability reported a HSUV that was the same as the general Australian population and reported similar scores to the general Australian population in physical and psychosocial super dimensions and individual dimensions of Independent Living, Senses, Pain, Happiness, Coping, Relationships, Self-worth and Mental Health. On the other hand, those with mild to severe disability severity recorded decreased scores in all of these dimensions.

MS represents a serious burden for people with MS and the community in terms of both economic impact and QoL. Interventions that slow or prevent the progression of MS may have a substantial impact on the economic costs and quality of life of people with MS.

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Supplemental Tables

Supplemental Table 1A. Medications included in the 2017 Cost Diary

Prescription Medications (DMTs)
Aubagio (Teriflunomide), Avonex (Interferon Beta-1a), Betaferon (Interferon Beta-2b), Copaxone (Glatiramer acetate; sub-cutaneous injection, every day), Copaxone (Glatiramer acetate; sub-cutaneous injection, every 3 days), Gilenya (Fingolimod), Lemtrada (Alemtuzumab; intravenous infusion, two courses one year apart), Mitoxantrone (Novantrone; intravenous infusion, once every 3 months for up to 3 years), Plegridy (Pegylated Interferon Beta-1a), Rebif (Interferon Beta-1a; subcutaneous injection, 3 times per week), Tecfidera (Dimethyl fumerate [DMF]; oral capsule, twice daily), and Tysabri (Natalizumab; intravenous infusion, every 28 days)
Prescription Medications (Symptom-specific and others)
Amoxycillin, Augmentin, Antenex, Baclofen, Biotin, Botox, Codalgin Forte, Cialis, Cymbalta, Dantrium, Ditropan, Ducene, Endep, Fampyra, Hiprex, Imuran, Keflex, Lioresal, Lyrica, Macrodantin, Methoblastin, Naltrexone, Neurontin, Norspan, Oxybutinin,Oxytrol Patches, Panadeine Forte, Panafcort/Sone, Panafcortelone/Solone, Panamax Co, Paxam, Pro-Banthine, Prodeine Forte, Rivotril, Sativex, Symmetrel, Tegretol, Thyroxine, Tofranil, Tramal, Valium, Valpam, Vesicare, Zoloft, Zydol, and others.
Non-prescription medication and other products
Actilax, Adipex, Adrenotone, Advacal, Aerius, Alendronate, Aspirin, Barberry Tea, Benefibre, Betadine, Bio Magnesium, Calamine Lotion, Calcium, Caltrate, Cardiprin, Cenovis Mens/Womens Multivitamin, Claratyne, Cod Liver Oil, Coenzyme Q10, Coloxyl, Consti-Eze, Curcumin, Disprin Max, Dry Mouth Relief Mouthwash, Ducolax, Duro-Tuss Forte, Ellura Caps, Evening Primrose Oil, Fero Gradumet, Fish 0il, Flax Seed Oil, Folic Acid, Garlic Vitamins, Gastro-Ease, Gelatine Capsules, Ginkgo Biloba, Glucosamine, Glycerin Suppositories, Heron Gold, Ibuprofen, Inner Health Plus, Iron Tablets, Joint Restore, Krill Oil, Liver Tonic, Linseed Meal, Macu-Vision, Magnesium, Mega B Complex, Metamucil, Milk Thistle, Multi & Vision Supplement, Nurofen, Nuromol, Nexium, Omega 3, Panadeine, Panadol, Panamax, Paracetamol, Paracodeine, Poly Visc, Potassium, Probiotics, Remifemin, Sorbolene, Sudafed, Paracetamol, Vitamin D, Systane Balance Eyedrops, Sustagen, Swabs, Tea Tree Spray, Thiamin, Turmeric, Ubiquinol, Ural Sachets, Ventolin, Viclofen, Vitamins (Various), Voltaren, and others

Supplemental Table 1B. Cost Items included in 2016 Cost Diary

Disposable equipment and continence items
Catheters And Accessories, Container(Various), Diapers, Pads, Liners, Pants, Protectors (Mattress/Chair), Urine Bags/Bottles, Drainage Bags, Dressing Packs, Enema Kits, Gloves, Lubricants, Sterilising And Cleaning Products, Suppositories, Wipes, Other
Health professional services (other than nurses)
Acupuncturist, Chiropractor, Clinical Psychologist, Consultant/Rehab Physician, Continence Advisor, Counsellor/Outreach Worker, Dentist, Dietician/ Nutritionist, General Practitioner(GP), Massage Therapist, Meditation Teacher, Myotherapist, Naturopath, Neurologist, Neuropsychologist, Occupational Therapist, Ophthalmologist, Optometrist, Osteopath, Physiotherapist, Pilates Teacher, Podiatrist, Psychiatrist, Reflexologist, Social Worker, Tai Chi Teacher, Urologist, Yoga Teacher, Other
Nursing services
DMT Nurse From Pharmaceutical Company, DMT Or Community Nurse From MS Society, DMT Or Community Nurse From MS Hospital Or Clinic, Mental Health Nurse, Other Community Or Private Nursing.
Community and private services-other than nurses
Community Pool (Including Classes), Hydrotherapy (Including Classes), Household Duties (Including Homecare Assistance For Ironing, Cleaning And Cooking), Gardening (Including Lawn Mowing, Garden Maintenance, Tree Lopping), House Repairs And Maintenance(Including Handy-Men, Painters, Electricians, Plumbers, Builders And Labourers), Gym (Including Membership And Classes), Personal Assistance (Shopping, Paying Bills, Household Duties, Travel Assistance, Hair Dressing, Dressing), Day Centre, Other
Medical tests
Blood Test-Full Blood Count, Blood Test-Vitamin D, Blood Test-Other Tests, CT("CAT") Scan, EEG (Electroencephalogram), Eye/Optical, Liver Function Test, MRI, Nerve Conduction Studies, Thyroid And Free T4 Tests, Ultrasound, Urine Test (Microscopy & Culture), Urodynamic (Bladder Function), X-Rays, Other
Hospital stay/ rehabilitation stay/ nursing home visit/ respite care stay/ hospital in the home
Special equipment hiring
Walker With Seat, Adjustable Chair, Bed, Bed Hoist, Bed Rail, Commode Chair, Electric Road Scooter, Gopher, Hospital Bed, Monitored Alarm System, Shower Chair, Walking Frame, Wheelchair, Zimmer Frame.

Continued onto next page.

Supplemental Table 1B continued.

Special equipment purchase (mobility purchases)	**Special equipment purchase (bedroom)**
Braces, Supports, Splints And Inserts, Crutches, Equipment Accessories (Batteries, Tyres), Exercise Accessories (Bikes, Treadmills, Weight), Orthotics/ Specialist Footwear, Pick Up Or Reaching Aids, Scooter, Scooter-Repairs And Maintenance, Walking Frames, Walking Stick, Wheelchair, Wheelchair-Cushion, Wheelchair-Repairs, Maintenance, Modifications, Others	Bed, Bedding-Blankets, Sheets, Underlays, Hoists, Over-Bed Aid Or Pole, Pressure Or Support Mattress, Pressure Or Support Pillow Or Cushion, Others
Special equipment purchase (visual aids)	**Special equipment purchase (general)**
Glasses, Spectacles, Contact Lenses, Magnifiers, Special Lights, Sunglasses, Others	Clothing-Medical Stockings, Clothing-Temperature Control, Cooling Equipment (Fans, Portable Air Conditioners) Furniture-Other, General Equipment Repairs, Heating Equipment, Rugs/Mats, Symptom Management Equipment (Massage Items, TENS Machines), Trolley, Others
Special equipment purchase (communications)	**Housing related cost (housing costs more than $5,000)**
Computer Or Laptop, Computer-Accessories, Computer-Specialist Software, Device Repairs, Hearing Aids, Intercom, Phone, Phone Accessories, Safety Monitoring, Alarms, Pagers, Others	Purchase Of More Suitable House, Sale Of Previous House, Fees Charged For Purchase/Sale, Major Alterations, Others
Special equipment purchase (bathroom)	**Housing related cost (housing costs under $5,000)**
Bath Board Or Seat, Electric Toothbrush, Grab Rails, Hand-Held Shower Hose, Non-Slip Mats Or Tiles, Shower Chair, Stool Or Commode, Taps/Special Tap Handles, Toilet Surround or Commode, Others	Air Conditioning/ Fans/Heating, Automatic Gates/ Garages, Blinds, Insulation, Minor Structural Changes, Non-Slip Items, Railing, Other
Special equipment purchase (kitchen)	**Alteration to Cars**
Assistance Equipment (Jar/ Can Openers), Chairs, Non-Slip Items, Specialised Appliance, Specialised Cooking Tools, Specialised Crockery, Specialised Cutlery, Others	Alterations To Car Controls, Car Accessories (E.G. Shades, Tinting, Covers), Car Purchase Or Upgrade, Car Sales, Easy Loader/ Hoist, Others
	Transport costs
	Private Car, Patient Transport, Public Transport, Taxis

Supplemental Table 3A. Costs of MS by severity - per person with MS (AUD 2017)

Cost Category	No Disability	Mild Disability	No/Mild Disability	Moderate Disability	Severe Disability	Not Stated	Overall
	(n=103)	(n=122)	(n=225)	(n=173)	(n=88)	(n=2)	(n=488)
Direct costs – personal	$2,729	$5,317	$4,132	$9,765	$16,995	$1,444	$8,437
Direct costs – community / government	$19,783	$23,325	$21,704	$22,987	$20,820	$194	$21,911
Direct costs – total	$22,513	$28,642	$25,836	$32,744	$37,815	$1,638	$30,346
Nursing home and equivalent costs	0	0	$0	0	$35,175	0	$6,343
Informal care costs	$0	$3,441	$1,866	$10,494	$14,214	$0	$7,144
Indirect costs from lost wages-early retirement	$2,068	$9,456	$6,074	$18,646	$22,500	$0	$13,468
Indirect costs from lost wages-employment status change	$2,667	$6,181	$4,572	$8,215	$2,150	$0	$5,408
Indirect costs from lost wages-occupation change	$1,500	$5,002	$3,399	$3,210	$1,539	$0	$2,982
Indirect costs from lost wages-overall	$6,235	$20,638	$14,044	$30,071	$26,188	$0	$21,858
Indirect costs from lost productivity-absenteeism	$497	$334	$409	$599	$447	$0	$482
Indirect costs from lost productivity-presenteeism	$1,317	$2,759	$2,099	$3,007	$973	$0	$2,209
Indirect costs from lost productivity-overall	$1,814	$3,093	$2,508	$3,606	$1,421	$0	$2,691
Total Costs	$30,561	$55,815	$44,254	$76,916	$114,813	$1,638	$68,382

No disability includes EDSS level 0, Mild includes EDSS levels 1 – 3.5, No/mild includes EDSS levels 0-3.5, Moderate includes 4 – 6, and Severe includes levels 6.5 – 9.5.

Supplemental Table 3B. Costs of MS by sex - per person with MS (AUD 2017)

Cost Category	Male	Female	Overall
	(n=90)	(n=398)	(n=488)
Direct costs – personal	$8,066	$8,522	$8,437
Direct costs – community / government	$19,421	$22,474	$21,911
Direct costs – total	$27,487	$30,996	$30,346
Nursing home and equivalent costs	$10,553	$5,391	$6,343
Informal care costs	$6,147	$7,369	$7,144
Indirect costs from lost wages-early retirement	$19,020	$12,212	$13,468
Indirect costs from lost wages-employment status change	$3,645	$5,807	$5,408
Indirect costs from lost wages-occupation change	$2,566	$3,077	$2,982
Indirect costs from lost wages-overall	$25,231	$21,096	$21,858
Indirect costs from lost productivity-absenteeism	$470	$484	$482
Indirect costs from lost productivity-presenteeism	$1,558	$2,356	$2,209
Indirect costs from lost productivity-overall	$2,028	$2,841	$2,691
Total Costs	$71,445	$67,689	$68,382

Supplemental Table 3C. Costs of MS by age group - per person with MS (AUD 2017)

Cost Category	<35 years	35-44 years	45-54 years	55-64 years	65+ years	Not Stated	Overall
	(n=18)	(n=73)	(n=125)	(n=151)	(n=119)	(n=2)	(n=488)
Direct costs – personal	$2,717	$4,796	$7,585	$8,876	$12,008	$603	$8,437
Direct costs – community / government	$31,148	$29,874	$25,848	$20,628	$13,224	$15,811	$21,911
Direct costs – total	$33,865	$34,669	$33,422	$29,504	$25,233	$16,413	$30,346
Nursing home and equivalent costs	$1,954	$1,446	$3,095	$6,290	$13,597	$0	$6,343
Informal care costs	$0	$6,541	$6,823	$6,642	$9,689	$0	$7,144
Indirect costs from lost wages-early retirement	$0	$7,992	$20,555	$20,395	$2,856	$0	$13,468
Indirect costs from lost wages-employment status change	$10,473	$5,610	$7,671	$5,783	$1,756	$0	$5,408
Indirect costs from lost wages-occupation change	$7,692	$2,802	$3,876	$2,889	$1,611	$0	$2,982
Indirect costs from lost wages-overall	$18,165	$16,403	$32,101	$29,068	$6,224	$0	$21,858
Indirect costs from lost productivity-absenteeism	$998	$719	$700	$369	$163	$1,018	$482
Indirect costs from lost productivity-presenteeism	$6,180	$2,949	$2,814	$2,172	$522	$4,922	$2,209
Indirect costs from lost productivity-overall	$7,178	$3,668	$3,513	$2,540	$685	$5,941	$2,691
Total Costs	$61,163	$62,727	$78,955	$74,044	$55,426	$22,354	$68,382

Supplemental Table 3D. Costs of MS by state/territory - per person with MS (AUD 2017)

Cost Category	NSW	VIC	QLD	WA	SA	TAS	ACT	NT	Not Stated	Overall
	(n=132)	(n=123)	(n=72)	(n=52)	(n=50)	(n=25)	(n=28)	(1)	(n=5)	(n=488)
Direct costs – personal	$9,755	$7,681	$7,757	$10,615	$8,260	$4,993	$7,090	$2,753	$7,083	$8,437
Direct costs – community / government	$21,743	$24,824	$21,511	$23,180	$23,250	$17,712	$13,047	$388	$8,788	$21,911
Direct costs – total	$31,488	$32,506	$29,269	$33,795	$31,510	$22,704	$20,137	$3,141	$15,871	$30,346
Nursing home and equivalent costs	$5,863	$6,005	$8,305	$8,117	$5,628	$7,035	$2,513	$0	$7,035	$6,343
Informal care costs	$7,683	$4,641	$11,706	$3,050	$6,918	$18,901	$0	$0	$16,275	$7,144
Indirect costs from lost wages-early retirement	$15,945	$14,006	$14,246	$11,573	$6,029	$17,506	$9,770	$0	$20,951	$13,468
Indirect costs from lost wages-employment status change	$5,946	$5,943	$4,167	$7,496	$6,703	$2,131	$1,057	$0	$3,098	$5,408
Indirect costs from lost wages-occupation change	$2,237	$3,214	$1,103	$6,222	$4,936	$2,519	$1,859	$0	$0	$2,982
Indirect costs from lost wages-overall	$24,128	$23,163	$19,515	$25,291	$17,668	$22,155	$12,686	$0	$24,049	$21,858
Indirect costs from lost productivity-absenteeism	$519	$375	$769	$107	$957	$369	$84	$0	$0	$482
Indirect costs from lost productivity-presenteeism	$2,443	$1,738	$3,457	$1,932	$2,065	$1,725	$1,648	$0	$0	$2,209
Indirect costs from lost productivity-overall	$2,961	$2,113	$4,226	$2,039	$3,022	$2,094	$1,732	$0	$0	$2,691
Total Costs	$72,123	$68,428	$73,022	$72,293	$64,747	$72,890	$37,068	$3,141	$63,229	$68,382

Supplemental Table 3E. Costs of MS by Geographical Remoteness - per person with MS (AUD 2017)

Cost Category	Major Cities	Inner Regional	Outer Regional	Remote/Very Remote	Overall
	(n=331)	(n=115)	(n=32)	(n=10)	(n=488)
Direct costs – personal	$7,641	$10,959	$6,812	$10,992	$8,437
Direct costs – community / government	$22,400	$21,206	$17,743	$27,167	$21,911
Direct costs – total	$30,037	$32,166	$24,555	$38,159	$30,346
Nursing home and equivalent costs	$6,376	$7,341	$4,397	$0	$6,343
Informal care costs	$5,574	$9,995	$11,636	$11,957	$7,144
Indirect costs from lost wages-early retirement	$12,278	$17,846	$9,984	$13,669	$13,468
Indirect costs from lost wages-employment status change	$5,215	$6,063	$6,741	$0	$5,408
Indirect costs from lost wages-occupation change	$2,530	$3,889	$5,334	$0	$2,982
Indirect costs from lost wages-overall	$20,023	$27,798	$22,059	$13,669	$21,858
Indirect costs from lost productivity-absenteeism	$451	$567	$600	$110	$482
Indirect costs from lost productivity-presenteeism	$2,372	$1,846	$1,515	$3,198	$2,209
Indirect costs from lost productivity-overall	$2,824	$2,414	$2,116	$3,308	$2,691
Total Costs	$64,834	$79,713	$64,762	$67,093	$68,382

Supplemental Table 3F. Costs of MS by MS type - per person with MS (AUD 2017)

Cost Category	PPMS	RRMS	SPMS	PRMS	Unsure	Not Stated	Overall
	(n=32)	(n=291)	(n=68)	(n=13)	(n=49)	(n=35)	(n=488)
Direct costs – personal	$11,244	$6,983	$12,925	$7,829	$8,610	$9,228	$8,437
Direct costs – community / government	$9,878	$24,902	$20,510	$23,039	$14,405	$20,856	$21,911
Direct costs – total	$21,122	$31,881	$33,435	$30,867	$23,015	$30,084	$30,346
Nursing home and equivalent costs	$13,191	$2,055	$16,553	$10,823	$10,050	$9,045	$6,343
Informal care costs	$15,067	$4,175	$11,898	$12,088	$11,556	$7,331	$7,144
Indirect costs from lost wages-early retirement	$8,732	$12,260	$25,435	$4,029	$11,472	$10,886	$13,468
Indirect costs from lost wages-employment status change	$4,795	$6,127	$3,781	$3,820	$3,741	$6,077	$5,408
Indirect costs from lost wages-occupation change	$3,350	$3,082	$1,946	$3,820	$2,542	$4,135	$2,982
Indirect costs from lost wages-overall	$16,877	$21,470	$31,162	$11,670	$17,755	$21,098	$21,858
Indirect costs from lost productivity-absenteeism	$822	$462	$235	$266	$636	$677	$482
Indirect costs from lost productivity-presenteeism	$2,593	$2,850	$663	$815	$331	$2,680	$2,209
Indirect costs from lost productivity-overall	$3,415	$3,312	$899	$1,081	$967	$3,357	$2,691
Total Costs	$69,671	$62,893	$93,947	$66,530	$63,343	$70,916	$68,382

Supplemental Table 3G. Costs of MS by DMT usage - per person with MS (AUD 2017)

Cost Category	DMT	No DMT	Not stated	Overall
	(n=339)	(n=142)	(n=7)	(n=488)
Direct costs – personal	$7,465	$10,901	$5,584	$8,437
Direct costs – community / government	$28,495	$5,598	$33,971	$21,911
Direct costs – total	$35,956	$16,499	$39,555	$30,346
Nursing home and equivalent costs	$3,839	$12,633	$0	$6,343
Informal care costs	$5,774	$10,766	$0	$7,144
Indirect costs from lost wages-early retirement	$14,321	$12,094	$0	$13,468
Indirect costs from lost wages-employment status change	$6,399	$2,967	$6,929	$5,408
Indirect costs from lost wages-occupation change	$3,062	$2,376	$11,443	$2,982
Indirect costs from lost wages-overall	$23,782	$17,437	$18,372	$21,858
Indirect costs from lost productivity-absenteeism	$427	$584	$1,021	$482
Indirect costs from lost productivity-presenteeism	$2,366	$1,730	$4,332	$2,209
Indirect costs from lost productivity-overall	$2,793	$2,315	$5,353	$2,691
Total Costs	$72,145	$59,649	$63,281	$68,382

Supplemental Table 3H. Direct costs - by cost category and disability severity - per person with MS (AUD 2017)

Cost Category	No Disability	Mild Disability	No/Mild Disability	Moderate Disability	Severe Disability	Not Stated	Overall
	(n=103)	(n=122)	(n=225)	(n=173)	(n=88)	(n=2)	(n=488)
Prescription medication_DMTs	$17,432	$17,429	$17,430	$17,130	$9,828	$0	$15,882
Prescription medication_ Symptom Specific	$39	$279	$169	$619	$1,260	$0	$524
Prescription medication_Others	$50	$134	$95	$552	$427	$0	$317
Prescription medication_Overall	$17,521	$17,842	$17,695	$18,301	$11,515	$0	$16,723
Non-prescription medication	$202	$255	$231	$464	$418	$230	$347
Disposable equipment	$20	$66	$45	$379	$1,685	$288	$460
Health professionals	$1,414	$1,788	$1,617	$2,632	$3,344	$121	$2,282
Nursing services	$353	$630	$503	$668	$727	$0	$600
Community and private services	$337	$1,036	$716	$1,892	$5,789	$0	$2,045
Medical tests	$739	$971	$865	$814	$633	$0	$801
Hospital stay	$1,084	$3,782	$2,547	$2,068	$3,037	$0	$2,455
Special equipment Hiring	$3	$3	$3	$4	$79	$0	$17
Special equipment Purchase-MOBILITY	$17	$52	$36	$397	$1,272	$839	$390
Special equipment Purchase-VISUAL AIDS	$26	$42	$35	$81	$82	$0	$59
Special equipment Purchase-COMMUNICATIONS	$33	$44	$39	$110	$209	$0	$95
Special equipment Purchase-BATHROOM	$7	$34	$22	$66	$211	$160	$72
Special equipment Purchase-KITCHEN	$5	$2	$4	$39	$48	$0	$24
Special equipment Purchase-BEDROOM	$10	$94	$56	$110	$280	$0	$115
Special equipment Purchase-GENERAL	$19	$47	$34	$112	$174	$0	$87
Special equipment Purchase-OVERALL	$122	$319	$229	$918	$2,356	$999	$860
Alterations to home	$355	$1,252	$841	$2,765	$4,768	$0	$2,228
Alterations to car	$59	$205	$138	$835	$1,258	$0	$586
Alterations to car/home	$414	$1,456	$979	$3,600	$6,026	$0	$2,814
Transport Costs	$307	$497	$410	$1,010	$2,285	$0	$959
Total Costs	$27,085	$28,642	$25,836	$32,744	$37,815	$1,638	$30,346

No disability includes EDSS level 0, Mild includes EDSS levels 1 – 3.5, No/mild includes EDSS levels 0-3.5, Moderate includes 4 – 6, and Severe includes levels 6.5 – 9.5.

Supplemental Table 31. Direct costs - by cost category and sex- per person with MS (AUD 2017)

Cost Category	Male	Female	Overall
	(n=90)	(n=398)	(n=488)
Prescription medication_DMTs	$13,798	$16,353	$15,882
Prescription medication_Symptom Specific	$820	$458	$524
Prescription medication_Others	$230	$336	$317
Prescription medication_Overall	$14,848	$17,147	$16,723
Non-prescription medication	$217	$376	$347
Disposable equipment	$283	$500	$460
Health professionals	$1,909	$2,366	$2,282
Nursing services	$489	$625	$600
Community and private services	$1,663	$2,131	$2,045
Medical tests	$783	$806	$801
Hospital stay	$2,448	$2,456	$2,455
Special equipment Hiring	$30	$14	$17
Special equipment Purchase-MOBILITY	$555	$353	$390
Special equipment Purchase-VISUAL AIDS	$54	$61	$59
Special equipment Purchase-COMMUNICATIONS	$94	$95	$95
Special equipment Purchase-BATHROOM	$119	$62	$72
Special equipment Purchase-KITCHEN	$15	$26	$24
Special equipment Purchase-BEDROOM	$107	$117	$115
Special equipment Purchase-GENERAL	$136	$76	$87
Special equipment Purchase-OVERALL	$1,110	$803	$860
Alterations to home	$879	$2,533	$2,228
Alterations to car	$1,068	$477	$586
Alterations to car/home	$1,947	$3,010	$2,814
Transport Costs	$1,789	$772	$959
Total Costs	$27,487	$30,992	$3,0346

Supplemental Table 3J. Direct costs - by cost category and age group - per person with MS (AUD 2017)

Cost Category	<35 years	35-44 years	45-54 years	55-64 years	65+ years	Not stated	Overall
	(n=18)	(n=73)	(n=125)	(n=151)	(n=119)	(n=2)	(n=488)
Prescription medication_DMTs	$23,385	$23,617	$19,407	$14,954	$7,483	$15,455	$15,882
Prescription medication_Symptom Specific	$110	$390	$545	$502	$685	$0	$524
Prescription medication_Others	$256	$207	$480	$273	$282	$0	$317
Prescription medication_Overall	$23,751	$24,214	$20,431	$15,729	$8,451	$15,455	$16,723
Non-prescription medication	$270	$298	$403	$376	$295	$270	$347
Disposable equipment	$57	$299	$219	$210	$1,198	$0	$460
Health professionals	$1,861	$2,012	$2,115	$2,346	$2,640	$179	$2,282
Nursing services	$225	$1,107	$336	$656	$561	$0	$600
Community and private services	$479	$935	$1,349	$2,127	$3,623	$0	$2,045
Medical tests	$529	$1,170	$910	$822	$483	$510	$801
Hospital stay	$3,891	$3,130	$3,191	$2,556	$962	$0	$2,455
Special equipment Hiring	$1	$10	$5	$13	$41	$0	$17
Special equipment Purchase-MOBILITY	$53	$120	$242	$360	$807	$0	$390
Special equipment Purchase-VISUAL AIDS	$89	$34	$80	$57	$52	$0	$59
Special equipment Purchase-COMMUNICATIONS	$16	$54	$122	$83	$121	$0	$95
Special equipment Purchase-BATHROOM	$28	$20	$39	$77	$140	$0	$72
Special equipment Purchase-KITCHEN	$5	$13	$32	$24	$27	$0	$24
Special equipment Purchase-BEDROOM	$10	$92	$98	$68	$225	$0	$115
Special equipment Purchase-GENERAL	$84	$44	$87	$62	$146	$0	$87
Special equipment Purchase-OVERALL	$287	$386	$705	$745	$1,559	$0	$860
Alterations to home	$1,917	$388	$2,157	$2,397	$3,301	$0	$2,228
Alterations to car	$444	$218	$618	$721	$639	$0	$586
Alterations to car/home	$2,362	$606	$2,776	$3,118	$3,940	$0	$2,814
Transport Costs	$154	$511	$986	$819	$1,521	$0	$959
Total Costs	$33,865	$34,669	$33,422	$29,504	$25,233	$16,413	$3,0346

Supplemental Table 3K. Direct costs - by cost category and state/territory - per person with MS (AUD 2017)

Cost Category	NSW	ACT	VIC	QLD	SA	WA	TAS	NT	Not stated	Overall
	(n=132)	(n=28)	(n=123)	(n=72)	(n=50)	(n=52)	(n=25)	(n=1)	(n=6)	(n=488)
Prescription medication_DMTs	$15,961	$9,928	$19,215	$13,791	$16,135	$16,120	$13,010	$0	$7,739	$15,882
Prescription medication_ Symptom Specific	$648	$320	$493	$551	$427	$559	$316	$0	$568	$524
Prescription medication_Others	$409	$198	$339	$329	$239	$173	$190	$0	$775	$317
Prescription medication_Overall	$17,019	$10,445	$20,047	$14,672	$16,801	$16,852	$13,515	$0	$9,082	$16,723
Non-prescription medication	$363	$426	$302	$408	$398	$301	$264	$324	$116	$347
Disposable equipment	$373	$174	$332	$1,041	$595	$304	$300	$576	$250	$460
Health professionals	$2,574	$2,078	$1,987	$2,161	$2,701	$2,632	$1,432	$242	$1,522	$2,282
Nursing services	$639	$528	$282	$707	$511	$1,131	$946	$0	$0	$600
Community and private services	$2,280	$1,525	$2,009	$1,441	$1,563	$3,558	$1,539	$0	$334	$2,045
Medical tests	$929	$458	$685	$909	$851	$882	$656	$0	$200	$801
Hospital stay	$2,314	$153	$2,452	$3,119	$3,820	$2,289	$2,079	$0	$0	$2,455
Special equipment Hiring	$4	$1	$11	$55	$4	$27	$30	$0	$0	$17
Special equipment Purchase-MOBILITY	$406	$365	$406	$364	$499	$393	$115	$1,679	$126	$390
Special equipment Purchase-VISUAL AIDS	$67	$114	$66	$50	$27	$27	$79	$0	$100	$59
Special equipment Purchase-COMMUNICATIONS	$86	$30	$123	$92	$142	$44	$18	$0	$504	$95
Special equipment Purchase-BATHROOM	$91	$55	$67	$38	$92	$75	$52	$320	$104	$72
Special equipment Purchase-KITCHEN	$27	$0	$34	$2	$28	$44	$8	$0	$0	$24
Special equipment Purchase-BEDROOM	$109	$146	$140	$149	$51	$106	$4	$0	$300	$115
Special equipment Purchase-GENERAL	$89	$56	$101	$80	$91	$66	$67	$0	$246	$87
Special equipment Purchase-OVERALL	$880	$767	$948	$830	$935	$781	$372	$1,999	$1,380	$860
Alterations to home	$1,591	$2,671	$2,406	$2,513	$1,522	$4,310	$752	$0	$1,316	$2,228
Alterations to car	$761	$578	$426	$671	$892	$196	$308	$0	$1,240	$586
Alterations to car/home	$2,353	$3,249	$2,832	$3,183	$2,414	$4,506	$1,059	$0	$2,556	$2,814
Transport Costs	$1,764	$336	$629	$798	$921	$561	$541	$0	$431	$959
Total Costs	$31,488	$20,137	$32,506	$29,269	$31,510	$33,795	$22,704	$3,141	$15,871	$3,0346

Supplemental Table 3L. Direct costs - by cost category and geographical remoteness - per person with MS (AUD 2017)

Cost Category	Major Cities	Inner Regional	Outer Regional	Remote/Very Remote	Overall
	(n=331)	(n=115)	(n=32)	(n=10)	(n=488)
Prescription medication_DMTs	$16,333	$15,541	$10,588	$21,801	$15,882
Prescription medication_Symptom Specific	$558	$476	$333	$593	$524
Prescription medication_Others	$278	$494	$118	$200	$317
Prescription medication_Overall	$17,168	$16,511	$11,039	$22,593	$16,723
Non-prescription medication	$357	$305	$353	$476	$347
Disposable equipment	$452	$467	$589	$234	$460
Health professionals	$2,429	$1,943	$1,914	$2,494	$2,282
Nursing services	$543	$532	$1,044	$1,821	$600
Community and private services	$2,011	$1,935	$3,159	$870	$2,045
Medical tests	$774	$855	$664	$1,539	$801
Hospital stay	$2,448	$2,526	$2,502	$1,713	$2,455
Special equipment Hiring	$20	$11	$5	$11	$17
Special equipment Purchase-MOBILITY	$372	$422	$357	$732	$390
Special equipment Purchase-VISUAL AIDS	$60	$75	$19	$0	$59
Special equipment Purchase-COMMUNICATIONS	$86	$128	$105	$0	$95
Special equipment Purchase-BATHROOM	$58	$124	$30	$66	$72
Special equipment Purchase-KITCHEN	$21	$32	$13	$79	$24
Special equipment Purchase-BEDROOM	$106	$150	$75	$151	$115
Special equipment Purchase-GENERAL	$89	$87	$43	$145	$87
Special equipment Purchase-OVERALL	$812	$1,030	$646	$1,183	$860
Alterations to home	$1,725	$3,890	$1,383	$2,452	$2,228
Alterations to car	$560	$611	$592	$1,160	$586
Alterations to car/home	$2,285	$4,501	$1,975	$3,612	$2,814
Transport Costs	$758	$1,561	$669	$1,624	$959
Total Costs	$30,037	$32,166	$24,555	$38,159	$3,0346

Supplemental Table 3M. Direct costs - by cost category and MS type - per person with MS (AUD 2017)

Cost Category	PPMS	RRMS	SPMS	PRMS	Unsure	Not Stated	Overall
	(n=32)	(n=291)	(n=68)	(n=13)	(n=49)	(n=35)	(n=488)
Prescription medication_DMTs	$6,272	$19,684	$9,912	$15,843	$8,341	$15,223	$15,882
Prescription medication_Symptom Specific	$466	$258	$1,562	$1,331	$385	$676	$524
Prescription medication_Others	$448	$216	$758	$426	$260	$215	$317
Prescription medication_Overall	$7,186	$20,157	$12,232	$17,600	$8,986	$16,114	$16,723
Non-prescription medication	$364	$351	$440	$268	$199	$354	$347
Disposable equipment	$346	$340	$967	$295	$514	$565	$460
Health professionals	$2,396	$1,885	$3,848	$2,236	$1,746	$3,202	$2,282
Nursing services	$306	$535	$594	$1,613	$742	$839	$600
Community and private services	$1,129	$1,426	$4,610	$426	$2,552	$2,936	$2,045
Medical tests	$474	$856	$691	$1,192	$838	$668	$801
Hospital stay	$722	$2,791	$2,714	$3,108	$1,682	$1,579	$2,455
Special equipment Hiring	$28	$10	$58	$2	$4	$7	$17
Special equipment Purchase-MOBILITY	$646	$174	$949	$486	$732	$355	$390
Special equipment Purchase-VISUAL AIDS	$35	$66	$79	$22	$37	$37	$59
Special equipment Purchase-COMMUNICATIONS	$55	$77	$217	$9	$58	$130	$95
Special equipment Purchase-BATHROOM	$91	$41	$160	$86	$129	$57	$72
Special equipment Purchase-KITCHEN	$28	$22	$51	$0	$7	$23	$24
Special equipment Purchase-BEDROOM	$99	$74	$269	$156	$200	$33	$115
Special equipment Purchase-GENERAL	$38	$61	$186	$207	$120	$60	$87
Special equipment Purchase-OVERALL	$1,021	$525	$1,968	$968	$1,289	$702	$860
Alterations to home	$5,576	$2,025	$2,681	$2,477	$1,108	$1,448	$2,228
Alterations to car	$953	$352	$976	$199	$871	$1,189	$586
Alterations to car/home	$6,528	$2,377	$3,657	$2,676	$1,979	$2,637	$2,814
Transport Costs	$650	$637	$1,714	$486	$2,487	$488	$959
Total Costs	$21,122	$31,881	$33,435	$30,867	$23,015	$30,084	$3,0346

Supplemental Table 3N. Direct costs - by cost category and DMT usage - per person with MS by DMT usage (AUD 2017)

Cost Category	DMT	No DMT	Not stated	Overall
	(n=339)	(n=142)	(n=7)	(n=488)
Prescription medication_DMTs	$22,359	$0	$24,384	$15,882
Prescription medication_Symptom Specific	$509	$584	$64	$524
Prescription medication_Others	$320	$317	$172	$317
Prescription medication_Overall	$23,187	$901	$24,619	$16,723
Non-prescription medication	$333	$385	$268	$347
Disposable equipment	$434	$546	$0	$460
Health professionals	$2,093	$2,468	$7,642	$2,282
Nursing services	$691	$412	$0	$600
Community and private services	$1,432	$3,536	$1,445	$2,045
Medical tests	$915	$523	$943	$801
Hospital stay	$2,993	$1,169	$2,447	$2,455
Special equipment Hiring	$8	$38	$0	$17
Special equipment Purchase-MOBILITY	$312	$591	$100	$390
Special equipment Purchase-VISUAL AIDS	$53	$73	$66	$59
Special equipment Purchase-COMMUNICATIONS	$67	$162	$111	$95
Special equipment Purchase-BATHROOM	$51	$122	$60	$72
Special equipment Purchase-KITCHEN	$19	$35	$74	$24
Special equipment Purchase-BEDROOM	$73	$216	$100	$115
Special equipment Purchase-GENERAL	$80	$98	$188	$87
Special equipment Purchase-OVERALL	$664	$1,335	$699	$860
Alterations to home	$1,996	$2,870	$437	$2,228
Alterations to car	$467	$858	$857	$586
Alterations to car/home	$2,463	$3,728	$1,294	$2,814
Transport Costs	$751	$1,494	$198	$959
Total Costs	$35,956	$16,499	$39,555	$3,0346

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Published August, 2018

Acknowledgements
There are many people to thank who assisted in some way in the preparation of this report. We would like to thank all the people with MS who participated in the AMSLS surveys and cost diaries – this valuable data informed the comprehensiveness of this report. We would also like to thank Associate Professor Ingrid van der Mei's wonderfully dedicated team who managed the AMSLS survey design, management and data entry including Dr Kirsty Hawkes, Carol Hurst, Alice Saul, Bronwyn Weaver-Pirie, Furley Johnston, Heather Chaplin, Mithun Rajshekar, Carol Ingram, Dot Melross and Wendy Davidson.

Thank you to MS Research Australia for establishing and supporting the AMSLS over 16 years, and the MS Societies for providing data for the age-adjustments of the prevalence in Chapter 2.

This Report is an MS Research Australia initiative and generously supported by an unconditional grant provided to MS Research Australia by Merck Australia.

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

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