COVANCE

Menzies Research Institute Tasmania

Economic Impact of Multiple Sclerosis in 2010

Australian MS Longitudinal Study

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MS RESEARCH AUSTRALIA

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~ Abbreviations~

ABS	Australian Bureau of Statistics
AMSLS	Australian Multiple Sclerosis Longitudinal Study
AMSLS EIS	Australian Multiple Sclerosis Longitudinal Study Economic Impact Study
ANZSCO	Australian and New Zealand Standard Classification of Occupations
AQoL	Assessment of Quality of Life
ARIA	Accessibility/Remoteness Index of Australia
ASCO	Australian Standard Classification of Occupations
ASGC	Australian Standard Geographical Classification
DALY	Disability adjusted life years
EDSS	Expanded Disability Status Scale
GDS-5	Geriatric Depression Scale – short version
LYG	Life years gained
MAUI	Multi-attribute utility instrument
MS	Multiple sclerosis
MSA	Multiple Sclerosis Australia
MSIF	Multiple Sclerosis International Federation
NA	Not available
NDIS	National Disability Insurance Scheme
PBPA	Pharmaceutical Benefits Pricing Authority
PBS	Pharmaceutical Benefits Scheme
PPMS	Primary Progressive MS
PwMS	Person with multiple sclerosis
QALY	Quality adjusted life year
RPMS	Relapsing-Progressive MS
RRMS	Relapsing Remitting MS
SDAC	Survey of Disability, Ageing and Carers
SPMS	Secondary Progressive MS
TTO	Time trade off
UVR	Ultraviolet radiation
WHO	World Health Organisation
WHOQOL	World Health Organisation Quality of Life

EXECUTIVE SUMMARY

Multiple sclerosis (MS) is a progressive, chronic disease of the central nervous system (brain and spinal cord). It is the most frequent neurological disease in young and middle-aged adults in developed countries and has a lifelong impact. Because MS involves multiple areas of the central nervous system, it is characterised by a variable and complex range of symptoms, including visual disturbance, fatigue, pain, reduced mobility and coordination, cognitive impairment, and mood changes. Average age at onset is between 20 and 40, and 75% of people with MS are women. Thus, MS tends to strike people in their most productive years. It affects ability to fulfil expected life roles at a stage when careers, relationships, and adult life in the community are consolidating, with resulting impact on work, family, and social life. Thus, MS may result in profound biographical disruption.

The typical course of MS is initially relapsing-remitting, with symptoms partially or completely disappearing during remissions. However, after about 10 years, the majority of people enter a secondary progressive phase and disability gradually accumulates. For a smaller group, the disease course is primary progressive, with ongoing worsening of the initial presentation. Many of these people with MS develop other chronic conditions in the course of the disease.

One of the key aims of treatment for MS is to delay the progression of the disease to more permanent disability. Therefore the clinical and economic benefits will be realised at a future time. Clinical trials are frequently too short in duration to capture the economic benefits of treatment and therefore data are required on the costs incurred by people experiencing the condition in order to predict the impact of new interventions.

The objective of this study is to estimate the cost of MS in Australia from an individual and societal perspective and to assess how MS affects the quality of life using data from the Australian MS Longitudinal Study (AMSLS). The AMSLS is an ongoing research project that includes around 3,100 volunteers with MS from all States and Territories of Australia. The survey captured information that could be used to determine direct costs such as pharmaceutical, medical, nursing, community and private services, hospitalisations, home and car alterations, special equipment and informal care, and indirect costs such as sickness leave and early retirement. Thus, availability of this large and comprehensive data set provides a unique opportunity to determine the societal cost of MS in Australia.

ES.1 Prevalence of MS

The prevalence of MS is estimated to be 21,200 (95.2 per 100,000 persons) based on the Australian Bureau of Statistics (ABS) survey of disability, ageing and carers (SDAC). This estimate is in close agreement with that obtained from alternative methods using prescription data (95.6 per 100,000 persons) and MS Society client data (89.3 per 100,000 persons) providing confidence that the estimate is reasonable and valid. These estimates are higher than those obtained in previous studies, and thus are consistent with previous observations that the prevalence is increasing in Australia. Increased longevity and a decreased mortality are considered to have contributed to the increasing prevalence of MS observed in studies conducted in Hobart and this is likely to be the case Australia wide.

ES.2 Cost of MS

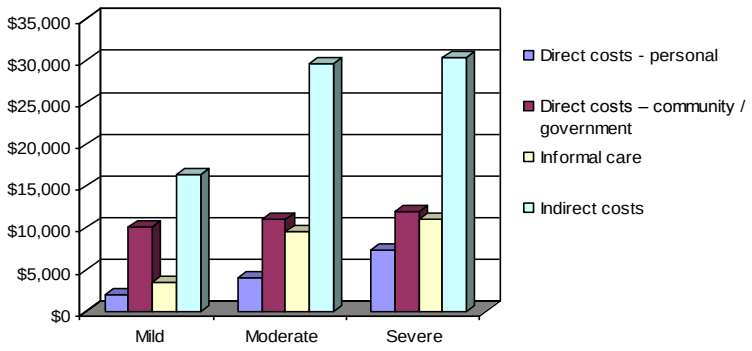
The cost per person with MS in 2010 was $48,945 with the total cost for all patients being $1,038M based on a prevalence of MS of 21,200 estimated from the ABS survey. The largest component is the indirect cost, representing a loss of wages due to the inability to work. Direct costs including those related to prescription medications are also a significant component as is the cost of informal care.

Table ES.1 Cost of MS by cost categories in 2010

Cost category	2010	
	Cost per person with MS	Total $M
Direct costs – personal	$3,697	$78
Direct costs – community / government	$10,721	$227
Nursing home and equivalent costs	$4,384	$93
Informal Care	$6,857	$145
Indirect costs	$23,286	$494
Total costs	**$48,945**	**$1,038**

There was a consistent trend towards increased cost with progressive severity of MS, classified as mild to severe by Expanded Disability Status Scale (EDSS) score or inferred based on age. The increased costs in the severe subgroup are due to higher community and private services, alterations to car, home and special equipment, which more than offset the lower cost of prescription medication in this subgroup. Indirect costs and informal care are also higher in the moderate and severe subgroups as a consequence of foregone income due to increased disability. This increased financial burden is exacerbated by increased direct personal costs incurred by these people.

Figure ES.1 Cost of MS by severity – per person with MS ($)



Notes: Mild severity includes EDSS levels 1 - 3, Moderate includes 4 – 6, Severe includes levels 6.5 – 9. Nursing home costs are excluded as they are unable to be broken down by MS severity.

ES.3 Quality of life with MS

Utility is a measure of quality of life. The utility score for all people with MS was 0.65 out of a maximum value of 1.0. This compares with a mean utility of 0.80 for Australians aged 50-59, the mean age of people with MS. Thus people with MS incur almost a 20% reduction in utility and once the condition becomes severe, the reduction is almost 50%.

ES.4 Summary and conclusions

This study provides an important insight into the burden of MS. Key findings are:

- The prevalence of MS has increased steadily over time to the current estimate of 21,200 Australians living with the condition.
- There are substantial direct costs associated with MS. These costs increase with severity due to the requirements for more community and private care and alteration to cars and houses. This is despite the cost of prescription medicines being lower in patients with more severe MS as they are not eligible for the MS-specific immunotherapies under the PBS.
- The indirect costs also increase with MS severity due to the income foregone with increased disability. This occurs concurrently with an increase in personal costs, thereby imposing an additional financial burden on these patients.
- The reduction in quality of life associated with MS is commensurate with other serious conditions, such as stroke and end stage cancer. There is a 20% reduction in utility in MS patients and this increases to 50% when a person‘s condition becomes severe.

MS imposes a substantial economic and social burden on the people with the condition and the community and society as a whole. The burden increases as the condition becomes more severe,

suggesting that investment in research of innovations that would further delay or ideally prevent the progression of the condition could bring substantial rewards in terms of both reducing the financial burden and increasing the quality of life for persons with MS.

The results of this study confirm the findings of previous studies and can inform the development of policy positions, planning of healthcare services and prioritisation of research funding.

1 INTRODUCTION

1.1 Explanation of Multiple Sclerosis

Multiple sclerosis (MS) is one of the most common diseases of the central nervous system (brain and spinal cord). The underlying cause is the loss of myelin (demyelination), a fatty material that insulates nerves, which disrupts their ability to conduct electrical impulses to and from the brain. The cause of MS is not yet known. The pathology is suggestive of an auto-immune disease where the body attacks its own cells and tissues, which in the case of MS is myelin.

While an individual genetic predisposition to having MS has been scientifically demonstrated, the environment has also been shown to strongly influence the development and risk of MS. For instance, research into the links with the Epstein Barr Virus and with Vitamin D deficiency indicate that they both play a significant role.

The average age of diagnosis of MS in Australia is typically between ages 20 to 40, an age when people are establishing careers and families. The disease process can create social dislocation in these areas as well as the chronic health impacts of a degenerative condition.

Once MS presents, the condition is permanent, and degenerative. It has highly variable effects and is different for every individual. Precise symptoms depend on which areas of the central nervous system have been affected. There is considerable inter-individual heterogeneity and even within the individual, symptoms will vary in severity and duration. Symptoms include; visual disturbances, balance & co-ordination problems, spasticity, altered sensation, pain, abnormal speech and fatigue.

Although MS symptoms vary from person to person, there are distinct patterns relating to the course of the disease. Four different clinical courses of MS are recognised:

- Relapsing Remitting MS (RRMS): In this form of MS there are unpredictable relapses (exacerbations, attacks) during which new symptoms appear or existing symptoms become more severe. In between attacks, the person with MS is in remission;
- Primary Progressive MS (PPMS): Unlike RRMS, PPMS is characterised by a steady worsening of symptoms. There is a lack of distinct attacks and the disease may stabilise or continue to progress;
- Relapsing Progressive MS (RPMS): In this form of MS, there is gradual progression interspersed with relapses; and

- Secondary Progressive MS (SPMS): Most people with RRMS ultimately deteriorate to SPMS which is characterised by gradual deterioration in function interspersed with relapses.

The majority of people with MS are initially diagnosed with RRMS, however with time, there is less recovery and eventually most progress to SPMS. About 10% of people have PPMS from the outset.

The severity of MS is measured using the Kurtzke Expanded Disability Status Scale (EDSS) (Table 1.1). The EDSS quantifies disability in eight functional systems (pyramidal, cerebellar, brainstem, sensory, bowel and bladder, visual, cerebral and other) by assigning each a score. EDSS steps 1.0 to 4.5 refer to people with MS who are fully ambulatory while EDSS steps 5.0 to 9.5 are defined by the impairment to ambulation. EDSS steps of 6 or greater represents the need for ambulatory aids.

Table 1.1 Kurtzke Expanded Disability Status Scale

0.0	Normal neurological examination
1.0	No disability, minimal signs in one FS
1.5	No disability, minimal signs in more than one FS
2.0	Minimal disability in one FS
2.5	Mild disability in one FS or minimal disability in two FS
3.0	Moderate disability in one FS, or mild disability in three or four FS. Fully ambulatory
3.5	Fully ambulatory but with moderate disability in one FS and more than minimal disability in several others
4.0	Fully ambulatory without aid, self-sufficient, up and about some 12 hours a day despite relatively severe disability; able to walk without aid or rest some 500 meters
4.5	Fully ambulatory without aid, up and about much of the day, able to work a full day, may otherwise have some limitation of full activity or require minimal assistance; characterised by relatively severe disability; able to walk without aid or rest some 300 meters
5.0	Ambulatory without aid or rest for about 200 meters; disability severe enough to impair full daily activities (work a full day without special provisions)
5.5	Ambulatory without aid or rest for about 100 meters; disability severe enough to preclude full daily activities
6.0	Intermittent or unilateral constant assistance (cane, crutch, brace) required to walk about 100 meters with or without resting
6.5	Constant bilateral assistance (canes, crutches, braces) required to walk about 20 meters without resting
7.0	Unable to walk beyond approximately five meters even with aid, essentially restricted to wheelchair; wheels self in standard wheelchair and transfers alone; up and about in wheelchair some 12 hours a day
7.5	Unable to take more than a few steps; restricted to wheelchair; may need aid in transfer; wheels self but cannot carry on in standard wheelchair a full day; may require motorised wheelchair
8.0	Essentially restricted to bed or chair or perambulated in wheelchair, but may be out of bed itself much of the day; retains many self-care functions; generally has effective use of arms
8.5	Essentially restricted to bed much of day; has some effective use of arms retains some self care functions
9.0	Confined to bed; can still communicate and eat
9.5	Totally helpless bed patient; unable to communicate effectively or eat/swallow
10.0	Death due to MS

Abbreviations: FS, functional systems.

1.2 Current treatments and management

While there is currently no cure for MS, the disease can be managed with a range of medications, and people can be supported by a range of community services. MS is a disease that is largely managed in the community, and these services, such as information, employment support, aids and

equipment, attendant care and allied health are all important at different stages to enable individuals to maintain their independence and engagement with the community.

Specific MS immunomodulatory medications act to delay the progression of the disease by reducing the number and duration of attacks, with other medications being used to ease specific symptoms. Drug treatments available in Australia include MS-specific immunotherapies, methylprednisolone and in some people, methotrexate or mitozantrone.

The MS-specific immunotherapies work to affect the rate and extent of axonal loss during this phase of the disease. Clinical trials have shown these drugs reduce the frequency and severity of relapses and slow the rate of disability progression. The first wave of MS drugs, interferon beta-1b (Betaferon), interferon beta-1a (Avonex and Rebif) and glatiramer acetate (Copaxone), have been available in Australia and subsidised on the Pharmaceutical Benefits Scheme (PBS) since 1996 for people with relapsing-remitting MS. These are all administered by daily, several times weekly or weekly injections.

Natalizumab (Tysabri), a humanised monoclonal antibody is a relatively new monthly infusion treatment for MS that was introduced in 2008. In 2011, fingolimod (Gilenya), an oral treatment was introduced into Australia. The introduction of the first oral medication is a major step forward in the treatment of MS, as it offers a reduced treatment burden for individuals with MS.

Acute attacks can be treated with intravenous methylprednisolone which shortens the duration of symptoms associated with a relapse, although probably not altering the ultimate recovery following an attack[(1)]. For some people, especially those with progressive MS, immunosuppressants such as methotrexate or mitozantrone are used[(2)].

Other experimental treatments including stem cell therapies are in the early stages of development.

1.3 Burden of disease

The burden of illness can be assessed using a variety of measures such as utilities or disability weights.

Utilities are measured on a scale of 0 to 1 where 0 is assigned to a state comparable to death and 1 is assigned to a state of perfect health. The utility can be measured directly by the use of

questionnaires (multi-attribute utility instruments (MAUIs)) such as the EQ-5D or Assessment of Quality of Life (AQoL) or indirectly by mapping results of other quality of life instruments or creating scenarios to elicit utility weights. The utility is multiplied by the life years gained (LYG) to provide a measure of quality adjusted life years (QALYs).

The disability weight is a similar concept however the focus is on disability. The direction of the scale is opposite to the utility measurement with a score of 0 equating to perfect health (or no disability) and 1 equating death. The disability weight is multiplied by the LYG to provide a measure of disability adjusted life years (DALYs).

A range of values for the utility associated with MS have been reported. In a recent study of MS in nine European countries by Kobelt et al[3] the utility associated with an EDSS of 2.0 was around 0.70, while for people with an EDSS of 6.5 the utility was around 0.45. The disability weights associated with MS have been reported by Mathers et al[4] who assigned a value of 0.33 for the relapsing-remitting phase and 0.67 when progressive.

1.4 Cost of illness studies

One of the key aims of treatment for MS is to delay the progression of the disease to more permanent disability. Thus the clinical and economic benefits will be realised at a future time. Clinical trials are frequently too short in duration to capture the full benefits of treatment and therefore observational data are required in order to project the impact in economic analyses.

Cost of illness analyses are descriptive studies that measure all costs related to a specific illness. The results of these studies provide useful information to policy makers and researchers by providing a snapshot of the distribution of costs related to a disease in a given environment at a given point in time. Cost-of-illness studies also provide information on the main cost drivers which inform priority setting for resource allocation by decision makers[5].

Cost of illness analyses can be either prevalence or incidence based. Prevalence based studies give the cost of all cases in a given time period, usually one year. Incidence based studies give an estimation of life-time costs for a person with MS contracting the illness during a given time period. A prevalence based approach is typically taken for a chronic condition as it allows a comparison with total health expenditure[6].

Economic costs associated with health care can be categorised as direct, indirect and intangible. Direct costs are typically broken down to direct medical and direct non-medical. Direct medical includes the costs of prescription drugs, physician services, hospital separations and nursing home stays. Direct non-medical includes the cost of informal care and many home and community based services. Indirect costs include the lost wages due to the loss of productivity due to short term illness, early retirement and premature mortality. Intangible costs include the pain, grief and social impacts of living with a progressive (degenerative) disease resulting in a reduction in the quality of life[6, 7].

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[6].

The 'bottom up' approach requires the data collection from a sample of the population with the 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. The drawback is the resource required to identify an appropriate sample and collect sufficient data to allow an accurate estimate.

Cost-of-illness estimates for MS have been published in a number of countries including Australia, UK, US, Europe and individual EU countries and Canada. There is a considerable range in the estimates due to the methodology adopted for collection of data, inclusion and valuation of resource use and valuation of the intangible losses. Many of the studies utilise a survey where respondents with MS recall the costs incurred over a previous period, typically one to three months. Most studies include lost productivity due to a reduction in workforce participation or early retirement. Further, some studies place a value on the intangible cost by applying society's willingness to pay for a QALY and avoid the reduction in quality of life as measured by the individual's loss of amenity of life. These differing approaches lead to a range of estimates and care must be taken when comparing results from different studies.

In Australia, two cost of illness studies in MS have been conducted. In 2005, Access Economics published an analysis of the economic costs of MS in Australia[8]. The study primarily took a 'top-down' approach supplemented by a 'bottom-up' approach where data were available. The analysis also included an estimate of the intangible costs resulting from the burden of disease due to suffering and premature death from MS.

The Access Economics study estimated that the total (direct and indirect) financial costs of MS in 2005 were over $600M (0.07% of GDP) corresponding to $37,333 per person with MS. The intangible costs were $1.34 billion, twice the financial costs. Overall the total cost of MS was estimated to be over $2 billion per annum[8].

Taylor et al[9] estimated the cost of MS in Australia in 2007 using a 'bottom up' approach based on the results of a questionnaire completed for 100 people with MS in Tasmania. The questionnaire was completed by the study investigator for persons with MS attending the MS clinic of the Royal Hobart Hospital. Overall, the average annual direct and indirect costs per person with MS were AU$20,396 and AU$15,085, respectively, totalling $35,481.

1.5 Objective and rationale of this study

The objective of this study is to estimate the cost of MS in Australia from an individual and societal perspective and to assess how MS affects the quality of life using data from the Australian MS Longitudinal Study (AMSLS). The AMSLS is an ongoing research project that includes around 3,100 volunteers with MS from all States and Territories of Australia[10].

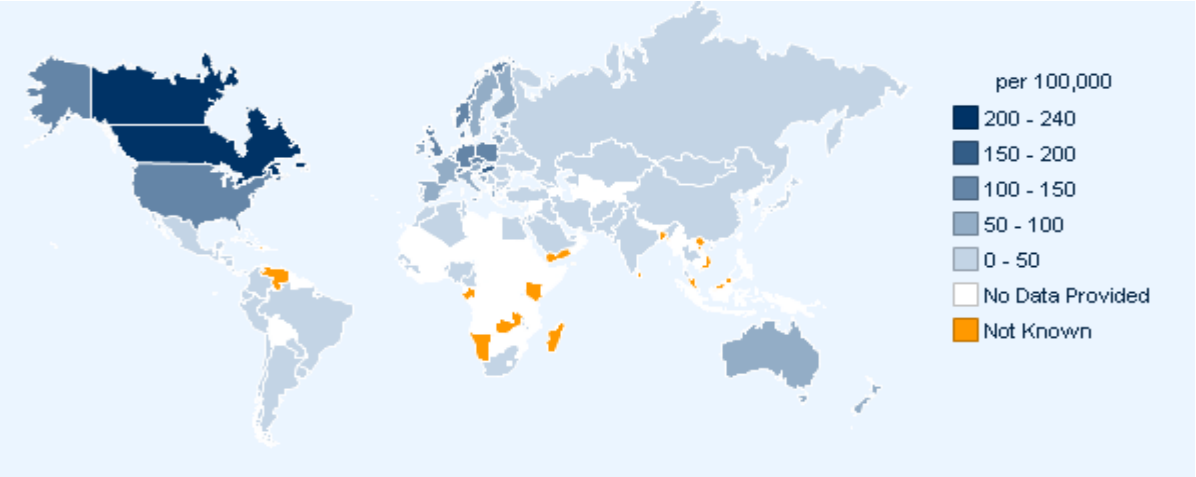
The AMSLS has conducted two large-sample nationwide AMSLS Economic Impact Studies (AMSLS EIS) in Australia. These studies consisted of a baseline questionnaire and cost diary on economic circumstances. The surveys were distributed to participants in the AMSLS in September 2003, and four years later in 2007. The survey captured information that could be used to determine direct costs such as pharmaceutical, medical, nursing, community and private services, hospitalisations, home and car alterations, special equipment and informal care, and indirect costs such as sickness leave and early retirement. Thus, availability of this large and comprehensive data set provides a unique opportunity to determine the full societal cost of MS in Australia.

2 PREVALENCE OF MS

2.1 Prevalence of MS

The prevalence of MS generally increases with increasing distance from the equator. The highest prevalence is seen in northern and central Europe, Canada, Australia, US and New Zealand. Low-risk areas include Asia, many parts of South America, the Caribbean and Mexico (Figure 2.1).

Figure 2.1 Prevalence of MS throughout the world



Source: Multiple Sclerosis International Federation 2008.

It is postulated that decreasing exposure to sunlight is a contributing factor to the latitude gradient in MS prevalence, either through vitamin D or ultraviolet radiation (UVR) levels. A close association between MS prevalence and lower UVR levels has been found in Australia[11].

2.2 Prevalence of MS in Australia

There have been several epidemiological studies of MS undertaken in Australia[12-17]. Some of these studies reported a latitudinal gradient of MS prevalence. In previous studies, it was observed that the MS prevalence and incidence in Hobart was nearly double that of Newcastle and Perth[12, 13], and another study demonstrated that the MS prevalence in Hobart was over six times that of northern Queensland[14].

The prevalence estimated in the 2005 Access Economics report was 79.12 per 100,000 or 16,081 persons with MS. This was generated from imputing age-specific prevalence rates for the Australian population for the year 2001 based on the two 1996 studies which surveyed Australians living in the middle latitude areas.

In order to determine the total cost of MS in Australia in 2010, the prevalence was obtained from the Australian Bureau of Statistics (ABS) survey of disability, ageing and carers (SDAC) conducted in 2009. The estimates from this survey were compared with that obtained by two other sources; prescription data and from each state jurisdiction's MS Society client database.

2.2.1 Survey of Disability, Ageing and Carers

The ABS conducted the SDAC throughout Australia between April and December 2009. The main objectives of the survey were to estimate the prevalence of disability in Australia and their need for support. Three population groups were targeted for the survey:

- people with a disability;
- older people (aged 60 years and older); and
- people who provide assistance to older people and people with disabilities.

Approximately 27,600 private dwellings and 200 non-private dwellings were included in the household sample, and 1,100 establishments in the cared-accommodation sample. The final sample comprised 64,213 persons for the household component and 9,470 persons for the cared-accommodation component.

The SDAC estimated that there were approximately 21,200 people with MS in Australia (95.2 per 100,000 persons) of whom 1,200 (5.7%) were living in establishments. The number of persons with MS broken down by age group, gender, living circumstance and state/territory are presented in Table 2.1 and Table 2.2.

Table 2.1 People with MS by living in household or establishment, by age groups (estimates '000)

	0-19	20-44	45-54	55-64	65 and over	Total
Living in an establishment	-	-	0.1[b]	0.4[a]	0.3[a]	1.2[c]
Living in households	-	2.3[a]	4.6[a]	6.4[a]	5. 1[a]	19.9
Total	-	2.3[a]	4.7[a]	6.8[a]	5.4[a]	21.2

Notes:
[a] estimate has a relative standard error of 25% to 50% and should be used with caution
[b] estimate has a relative standard error greater than 50% and is considered too unreliable for general use
[c] The sum of the components may not equal the total due to rounding.

Table 2.2 People with MS by state or territory, by gender (estimates '000)

	New South Wales	Victoria	Queensland	South Australia	Western Australia	Tasmania	Northern Territory	Australian Capital Territory	Australia
Males	2.3[a]	0.9[b]	0.1[b]	0.9[b]	0.3[b]	np	-	np	4.6[a,c]
Females	5.4[a]	4.2[a]	4.5[a]	0.8[a]	1.0[a]	0.2	np	0.2[b]	16.5
Persons	7.7	5.1[a]	4.7[a]	1.7[a]	1.4[a]	0.3	np	0.3[b]	21.2

Abbreviations: np - not available for publication but included in totals where applicable, unless otherwise indicated.

Notes: [a] estimate has a relative standard error of 25% to 50% and should be used with caution

[b] estimate has a relative standard error greater than 50% and is considered too unreliable for general use

[c] The sum of the components may not equal the total due to rounding.

2.2.2 Estimates of prevalence obtained from prescription data and the MS society client base

2.2.2.1 Data sources

2.2.2.1.1 Pharmaceutical data

Medicare Australia provided the number of PBS scripts prescribed in the 12 month period from March 2010 to March 2011, broken down by state for medications that are used exclusively for the treatment of MS[(18)]. Numbers of scripts dispensed were obtained by state for Betaferon (PBS code 8101J), Avonex (PBS codes 8289G and 8805K), Rebif 44 (PBS codes 8403G and 9332E), Copaxone (PBS code 8726G) and Tysabri (PBS code 9624M). Additionally, unpublished data were obtained from Biogen Idec for the prescription of Tysabri provided under the Special Access Scheme. A study on the penetration of MS-specific immunotherapies reported that the percentage of persons with MS that are taking medication ranges from 42% to 46% for each state[(19)]. To estimate the total number of persons with MS, the annual number of scripts dispensed was divided by 12 and adjusted for penetration of MS-specific immunotherapies by state.

2.2.2.1.2 MS Society client database

Client numbers were provided by each MS Society per state or territory by postcode. The ABS provided data on the 2006 Australian Standard Geographical Classification (ASGC) of remoteness area by postcode. Remoteness areas are calculated using the Accessibility/Remoteness Index of Australia (ARIA), which is an index of remoteness derived from measures of road distance between populated localities and service centres. It is recognised as a nationally consistent measure of geographic remoteness. Postcodes were classified into five areas of remoteness: Major Cities of Australia, Inner Regional Australia, Outer Regional Australia, Remote Australia and Very Remote Australia. An adjustment has been made for the estimated percentage of persons that are clients of an MS Society to provide an estimate of the total number of persons with MS. The number of MS Society clients has been reported to be 90-95% of the total population in Australia with MS[(19)].

2.2.2.2 Results

The prevalence of MS in Australia using prescription data was 95.6 per 100,000 persons, and using MS Society client data was 84.6 per 100,000 persons (Table 2.3 and Table 2.4). If only 92% of the "true" MS population were assumed as clients of the MS Societies, the prevalence was 89.3 per 100,000 population. The prevalence determined by the two different methods agree well with the 21,200 (95.2 per 100,000) estimate from the ABS SDAC.

The presence of a latitudinal gradient is observed with the highest prevalence in Tasmania, followed by Victoria with Queensland having the lowest prevalence.

Table 2.3 Prevalence of MS in Australia, 2010

	NSW	VIC	QLD	SA	WA	TAS	ACT	NT	TOTAL
Penetration of Immuno-modifiers	45.0%	45.0%	44.9%	46.0%	45.0%	42.0%	55.0%	46.0%	
Number of PwMS based on prescriptions	6,268	6,637	3,179	1,760	2,313	718	360	49	21,283
MS Society clients	5,717	5,400	3,020	1,507	1,964	690	496	39	18,833
Number of PwMS based on MS clients, assuming only 92% of true MS population are clients of MS societies	6,214	5,870	3,283	1,638	2,135	750	539	42	20,471
Prevalence of MS (per 100,000) by prescription	86.8	120.0	70.7	107.2	101.2	141.6	100.6	21.2	95.6
Prevalence of MS (per 100,000) by MS society numbers unadjusted	79.2	97.7	67.1	91.9	85.9	136.1	138.7	17.1	84.6
Prevalence of MS (per 100,000) by MS Society number adjusted assuming only 92% membership rates	86.1	106.2	73.0	99.8	93.4	147.9	150.7	18.6	89.3

Abbreviations: ACT, Australian Capital Territory; NSW, New South Wales; NT, Northern Territory; QLD, Queensland; PwMS, people with MS; SA, South Australia; Tas, Tasmania; Vic, Victoria; WA, Western Australia.

Information on the geographical remoteness is also available from the MS Society client database. The majority of clients reside in major cities of Australia, followed by inner regional, outer regional, remote and very remote Australia (Table 2.4).

Table 2.4 MS Society clients in Australia, by State/Territory and remoteness

	NSW	VIC	QLD	SA	WA	TAS	ACT	NT	AUST
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Unknown	757 (13.2)	304 (5.6)	169 (5.6)	11 (0.7)	51 (2.6)	0 (0)	48 (9.7)	2 (5.1)	1,342 (7.1)
Major Cities of Australia	3,804 (66.5)	3,821 (70.8)	1,948 (64.5)	1,112 (73.8)	1,442 (73.4)	0 (0)	448 (90.3)	0 (0)	12,575 (66.8)
Inner Regional Australia	936 (16.4)	1,050 (19.4)	613 (20.3)	184 (12.2)	237 (12.1)	470 (68.1)	0 (0)	0 (0)	3,490 (18.5)
Outer Regional Australia	201 (3.5)	222 (4.1)	257 (8.5)	155 (10.3)	158 (8)	212 (30.7)	0 (0)	24 (61.5)	1,229 (6.5)
Remote Australia	17 (0.3)	3 (0.1)	19 (0.6)	36 (2.4)	60 (3.1)	5 (0.7)	0 (0)	11 (28.2)	152 (0.8)
Very Remote Australia	2 (0)	0 (0)	13 (0.4)	9 (0.6)	16 (0.8)	3 (0.4)	0 (0)	2 (5.1)	45 (0.2)
TOTAL	5,717 (100)	5,400 (100)	3,020 (100)	1,507 (100)	1,964 (100)	690 (100)	496 (100)	39 (100)	18,833 (100)

Abbreviations: ACT, Australian Capital Territory; Aust, Australia; NSW, New South Wales; NT, Northern Territory; QLD, Queensland; SA, South Australia; Tas, Tasmania; Vic, Victoria; WA, Western Australia

2.2.3 Comparison with other studies

The estimates of prevalence of MS obtained from the three different methodologies are close. The strength of using the estimate from the SDAC in the costing analysis is that it was obtained from a large nationwide survey specifically designed to determine the prevalence of conditions that lead to disability. Despite the wide standard error of the ABS data, the close agreement with the estimates derived from the MS client database and prescription data provides confidence that the estimate is reasonable and valid.

The prevalence of 95.2 per 100,000 obtained from the SDAC is higher than the 79.12 generated in the Access Economics report which relied on adjustment of the findings from localised studies[8]. Based on their estimates, there is an apparent increase in prevalence of 4% per year since 2005.

Prevalence and incidence have been shown to increase over time, with increases observed from studies that followed cases of MS in Hobart, Newcastle and Perth from 1961 to 1981[12, 13]. In 1997, Barnett et al[16] undertook a follow-up study in Newcastle which demonstrated a significant increase in prevalence from 19.6 to 59.1 per 100,000 population and a significant increase in incidence from 1.2 to 2.4 per 100,000 population from 1961 to 1996.

Hobart has also been the subject of a follow-up study, with time-trend analysis of MS epidemiology over a 58-year period from 1951 to 2009[17]. This study reported that the age-standardised prevalence increased significantly from 32.5 per 100,000 in 1961 to 99.6 per 100 000 in 2010 ($p<0.001$). For the whole of Tasmania, an even higher prevalence, ranging from an estimate of 122.9

to 147.9 cases per 100,000, was observed. Simpson et al[17] considered that an increased longevity and a decreased mortality have significantly contributed to the increasing prevalence of MS in their Hobart study, and this is likely to be the case Australia wide.

3 COST ANALYSIS

3.1 Cost of MS

The Multiple Sclerosis International Federation (MSIF) has conducted a review of international data on the costs and quality of life of MS[7]. The review found that while the total costs of MS varied by country the costs were substantial in all countries. The total average cost per person with MS varied from US$16,378 in France to US$54,489 in Norway, for an overall prevalence-weighted average of US$41,335.

3.2 Cost of MS in Australia in 2010

The AMSLS has conducted two large-sample nationwide economic impact studies (EIS) in Australia. The first study was performed in 2003 and the second four years later in 2007. The study protocol and methods are reported elsewhere[20]. The costing analysis presented in this report is based on the data from a total of 712 subjects who completed both the baseline questionnaire and the cost diary as part of the 2007 AMSLS EIS.

3.2.1 Baseline Questionnaire

The baseline questionnaire provided information on the cost of informal care and the indirect costs related to lost productivity.

The informal care costs were assessed directly from the average weekly earnings of the carer, pre and post care provision collected in the survey. The difference was inflated using an annual wage inflation factor of 4%. In cases where the average weekly earnings were missing and the average hours work pre and post care provision was present an average hourly wage rate of $34.50 obtained from the ABS employee earnings and hours for May 2010 was used[21].

The indirect costs from lost wages were estimated using question 2b from the baseline questionnaire which asked “Whether or not you are currently employed”. Subjects indicated their Australian Standard Classification of Occupations (ASCO) employment occupation category currently and prior to displaying MS symptoms. A wage was attributed to each subject pre and post MS symptoms using the average wage by occupation and gender from the ABS Employee Earnings and Hours – 6306.0 – May 2010 data. The ABS currently uses Australian and New Zealand Standard Classification of Occupations (ANZSCO) (1220.0) to classify occupation and the 2007 baseline survey used ASCO. The occupation estimates were converted from ANZSCO to ASCO using the ABS

concordance file. Subjects who were 65 years of age or greater were allocated an indirect cost of $0 unless they indicated that they were currently part of the work force.

3.2.2 Cost diary

The 2007 cost diary collected detailed information on the costs and resource use related to MS. Subjects were requested to complete the cost diary daily over six months. Subjects were asked to record all costs and resource use that related to their MS, regardless of whether they paid for them or not. The cost diary included questions on all expenditure related to: prescription medication; non-prescription medication and other products; disposable equipment and continence items; health professional services (other than nurses); nursing services; community and private services; medical tests; hospital stay/rehabilitation stay/nursing home visit/respite care, stay/hospital in the home; special equipment purchased over the last 5 years; and alterations to car or house undertaken over the last 5 years

The items included are listed in Table 3.1. Costs collected for special equipment and alterations to car or house were based on costs incurred over a five year period while all other costs were based on a six month period. For each item, the study participants completed how much they paid and who paid the balance.

Special equipment and alterations to car or house costs were annualised by dividing the costs reported by five. All other costs based on a six monthly period were annualised by multiplying by two. The annualised 2007 direct costs were inflated to 2010 levels using an annual inflation factor of 3.2% based on the health price index[22].

The prescription medications costs were updated using the PBS cost schedule (1 December 2010). For the MS-specific immunotherapies (Avonex, Betaferon, Rebif, Copaxone and Tysabri) subjects indicated the treatment was taken regularly, in nearly all cases, and therefore it was assumed that the treatment was used for the whole six month period of the cost diary. The average co-payment of $9.60 was applied based on an analysis of data from the Pharmaceutical Benefits Pricing Authority (PBPA) 2009/2010 annual report.

Table 3.1 Items included in the 2007 Cost Diary

Prescription medication		
Interferon beta-1a (Avonex)	Azathioprine (Imuran)	Rivotril
Interferon beta-1b (Betaferon)	Methotrexate	Ditropan
Interferon beta-1a (Rebif)	Baclofen	Probanthine
Glatiramer acetate (Copaxone)	Valium	Amantadine
Prednisolone	Dantrium	Other
Non-prescription medication and other products		
Aspirin	Mineral Supplements	Evening Primrose Oil
Paracetamol	Cranberry Tablets	Bandages / Dressings
Ibuprofen (Nurofen)	Cranberry juice	Ointment/Cream
Vitamin Supplements	Fish Oil/ Omega 3	Other
Disposable equipment and continence items		
Catheter	Pads	Enemas
Drainage bag	Pants	Suppositories
Dressing pack	Protectors (mattress/chair)	Other
Health Professional Services (other than nurses)		
Neurologist	Opthalmologist	Acupuncturist
GP, local doctor	Optician	Massage therapist
Consultant/ Rehabilitation Physician (Specialist)	Urologist	Naturopath
Continence Advisor	Occupational Therapist	Yoga
Psychiatrist	Speech Pathologist	Tai Chi
Clinical Psychologist	Recreation Officer	Aromatherapist
Neuropsychologist	Diversional Therapist	Reflexologist
Social Worker	Chiropractor	Meditation
Counsellor/Outreach worker	Podiatrist	Other
Physiotherapist	Dietician/ Nutritionist	
Nursing Services		
Immunotherapy or community nurse	Other community or private nursing	
Community and private services		
Meals on Wheels	Hydrotherapy Pool	Gardener
Community Pool	Day Centre	Other services
Medical Tests		
MRI	X-Ray	Lumbar Puncture
CT Scan (“CAT” Scan)	EEG	Urine Microscopy & Culture
Liver Function Test	Eye/Optical	Urodynamics
Full Blood Count	Nerve Conduction	
Hospital Stay/Rehabilitation Stay/Nursing Home Visit/Respite Care Stay/Hospital in the home		
Rehabilitation	Urology Problems	Tysabri
Relapse	Infusion/ Injection	Other
Respite	Mitozantrone treatment	
Special Equipment purchased over the last 5 years		
Mobility	Bedroom	General
Bathroom	Communication	Other
Modified kitchen equipment	Visual	
Alterations to Car or House purchased over the last 5 years		
New car – upgraded to Automatic	Ramps	Electric doors
New car – upgraded for Hoist	Rails near steps	Relocation of bathroom
Easy loader/car hoist	Air conditioner	Removed bath, shower installed
Alteration to car controls	Blinds to help with Temperature	Other
Non stick flooring	Insulation	

It was not possible to estimate the nursing home and equivalent high support care costs from the AMSLS data as only 4 of the 712 subjects indicated that they resided in a nursing home. This is likely to be an underestimate as subjects who are in nursing homes are unlikely to be able to complete the cost diary. The 2009 ABS SDAC estimated that the proportion of people with MS in nursing

homes is 5.7% (1,200 of 21,200). The AIHW estimate of accommodation support of $75,057 per person (for 2008-2009), where accommodation support includes institutional accommodation, group homes and other accommodation type[23] was applied. This cost was inflated to 2010 and multiplied by the prevalence to give an average cost of nursing home care per person. Unlike the cost categories collected in the cost diary, nursing home costs were unable to be distributed by subgroups such as severity and an average has been applied to all individuals with MS.

3.2.3 Assessment of disease severity

No direct measures of disability were included in the surveys however physicians' estimates of mobility using Disease Steps were available for a majority of respondents within 12 months of the 2003 survey. The Disease Steps scale is mobility based and correlates highly with the EDSS, but has the advantage of low inter-rater variability so that specialist training in use of the scale is not required[20]. The EDSS was mapped from the self reported disease step collected in the AMSLS survey as outlined in Table 3.2.

Table 3.2 Collapsed Expanded Disability Status Scale (EDSS) Used For Analysis

Self-Reported Disease Step	Description	Approximate EDSS Equivalent (Used for analysis)
1	I may have some mild symptoms, mostly sensory, due to MS but they do not limit my activity or lifestyle.	0-1
2	I have some noticeable symptoms from my MS, but they are minor and have only a small effect on my lifestyle	2-3
3	MS does interfere with my activities, especially my 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
4	I can walk about 8 metres [or 25 feet] without using a walking stick [cane] or other walking aid such as a splint, brace or crutch, but I may use walking aid for greater distances.	6
5	To be able to walk 8 metres [or 25 feet], I have to have a walking stick [cane], 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 metres [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 great distances.	6.5
7[a]	My only form of mobility is a wheelchair.	7
8[a]	I am unable to sit in a wheelchair for more than one hour, and I spend most of my time in bed.	8-9
9	None of the above options describe my MS. I do <u>not</u> have any mobility problems, but I do have other MS symptoms that limit my activities and lifestyle.	NC (not classified)

Notes: [a] due to low numbers Self-Reported Disease Step 7-8 were collapsed into one group (equivalent to EDSS 7-9)

3.2.4 Statistical analysis

Summary statistics (mean costs) are presented for all costs by disease severity, collapsed EDSS, age group, gender and geographical remoteness (ARIA).

The mean costs per person with MS are evaluated directly from the 712 records available. The total population estimate is evaluated by multiplying the mean cost per person by the prevalence estimate of 21,200. The population cost estimates by category are evaluated by allocating the 21,200 patients estimate according to the distribution of the 712 sample within the specific category.

All analysis was undertaken in SAS version 9.1.3. The raw data was supplied in an SPSS file. This was converted to a SAS dataset using Stat Transfer.

3.2.5 Cost categories

The definitions of the cost categories used in the AMSLS EIS study are shown below in Table 3.3.

Table 3.3 Categories of costs captured in the AMSLS EIS

Cost category	Inclusions	
Direct costs **– personal** **– community / government**	medications medical services support services medical tests	hospital stays assistive and medical aids medical products home and car alterations
Nursing home and equivalent costs	residential care	
Informal Care	paid care and unpaid care	
Indirect costs	sickness absence and early retirement	

3.3 Results

3.3.1 AIMSLS EIS participant demographics

In order to assess the representativeness of the 712 participants in the AMSLS EIS, the study population demographics were compared with the 17,014 persons registered with Multiple Sclerosis Australia (MSA) from NSW, Victoria, Queensland, Western Australia and the ACT. As are shown in Table 3.4, the persons who participated in the AMSLS EIS compare well in terms of age and gender. While, no information is available on the severity of each individual person, the similarity of the age distribution suggests that the AMSLS EIS population is likely to be reasonably similar to the MS population as a whole.

Table 3.4 Characteristics of the participants in the AMSLS EIS

Characteristics	AIMLS EIS (N=712)	MSA database (N=17,014)
Gender		
N	712	14,881
Male	146 (20.5%)	3,691 (24.8%)
Female	565 (79.4%)	11,190 (75.2%)
Not Stated	1 (0.1%)	-
Age		
N	704	13,642
Mean	52.6	51.5
S.D.	11.3	13.3
Age Group		
<35	43 (6.0%)	1,390 (10.2%)
35-44	124 (17.4%)	2,899 (21.3%)
45-54	215 (30.2%)	3,754 (27.5%)
55-64	223 (31.3%)	3,283 (24.1%)
65+	99 (13.9%)	2,316 (17%)
State		
N	712	17,014
NSW	245 (34.4%)	6,293
VIC	200 (28.1%)	5,367
QLD	85 (11.9%)	2,866
SA	71 (10.0%)	-
WA	49 (6.9%)	1,989
NT	34 (4.8%)	-
ACT	1 (0.1%)	499
Other	23 (3.2%)	-
Not Stated	4 (0.6%)	-

Notes: Derived from Table 2.2 p16 of this document.

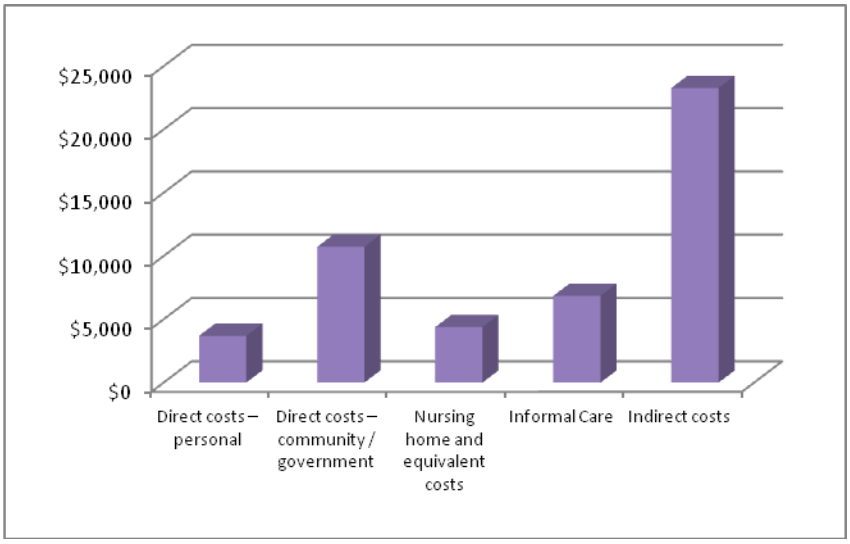
3.4 Cost of MS

The cost per person with MS in 2010 was $48,945 with the total cost for all patients being $1.038M (Table 3.5 and Figure 3.1). The largest component is the indirect cost, representing a loss of wages due to the inability to work. Direct costs also are a significant component as is the cost of informal care.

Table 3.5 Cost of MS by cost categories in 2010

Cost category	2010	
	Cost per person with MS	Total $M
Direct costs – personal	$3,697	$78
Direct costs – community / government	$10,721	$227
Nursing home and equivalent costs	$4,384	$93
Informal Care	$6,857	$145
Indirect costs	$23,286	$494
Total costs	**$48,945**	**$1,038**

Figure 3.1 Cost of MS by cost categories in 2010 – per person with MS ($)



The cost broken down by severity is shown in Table 3.6, Figure 3.2 and Figure 3.3. There is an increase in personal costs as severity increases while informal care and indirect costs increase markedly as the condition becomes of moderate severity. This is expected as persons with MS need greater care and their ability to participate in the workforce diminishes as the symptoms of the condition worsen. Due to the lack of information on the nursing home distribution of persons with MS by disease severity and other categories presented below (EDSS, age group, gender and geographic location), a uniform distribution is assumed. This assumption is made so that nursing home costs can be factored into the total costs within each category and the category totals add to the overall total. The nursing home costs are not presented in any of the figures comparing costs by category as the comparison is not meaningful.

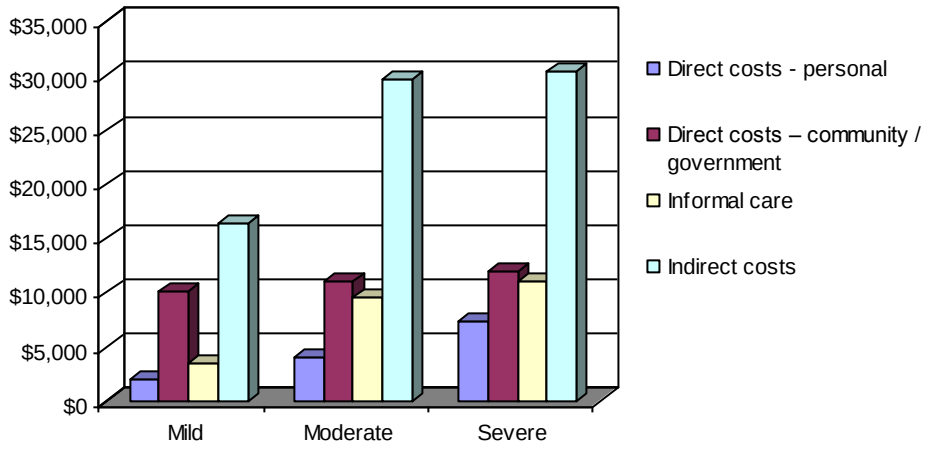
Table 3.6 Costs of MS by severity

	Mild	Moderate	Severe	Not stated	Total
Per person with MS ($'s)					
Direct costs - personal	$2,062	$4,097	$7,380	$3,788	$3,697
Direct costs - community / government	$10,181	$11,098	$12,042	$9,304	$10,721
Nursing home and equivalent costs*	$4,384	$4,384	$4,384	$4,384	$4,384
Informal care	$3,395	$9,569	$11,111	$6,227	$6,857
Indirect costs	$16,347	$29,743	$30,388	$20,354	$23,286
Total costs	**$36,369**	**$58,890**	**$65,305**	**$44,057**	**$48,945**
Total ($000's)					
Direct costs - personal	$19,345	$28,787	$24,831	$5,414	$78,376
Direct costs - community / government	$95,492	$77,984	$40,516	$13,297	$227,288
Nursing home and equivalent costs[a]	$41,118	$30,806	$14,750	$6,266	$92,941
Informal care	$31,843	$67,238	$37,383	$8,900	$145,365
Indirect costs	$153,319	$209,004	$102,245	$29,090	$493,657
Total costs	**$341,117**	**$413,819**	**$219,724**	**$62,967**	**$1,037,627**

Notes: Mild severity includes EDSS levels 1 - 3, Moderate includes 4 – 6, Severe includes levels 6.5 – 9.

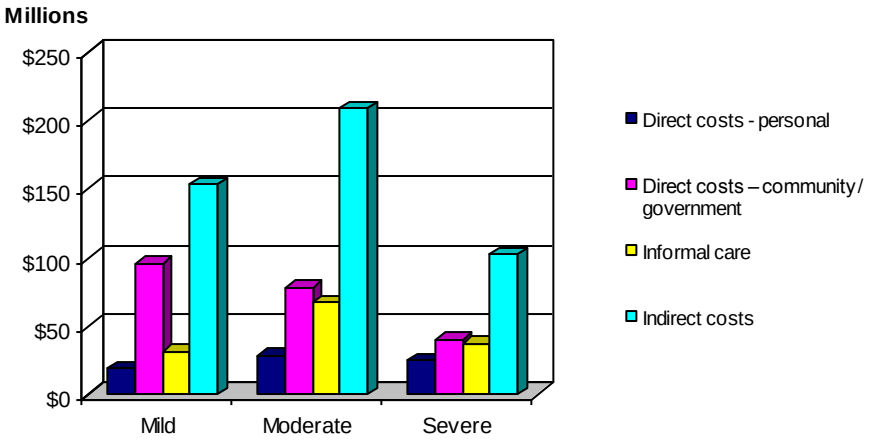
[a] Nursing home costs are not broken down by MS severity. Nursing home costs are available for the total population only. Total cost in each category is calculated from the category population and the overall mean cost. Therefore no inference should be made for the difference in cost between categories

Figure 3.2 Cost of MS by severity – per person with MS ($)



Notes: Mild severity includes EDSS levels 1 - 3, Moderate includes 4 – 6, Severe includes levels 6.5 – 9. Nursing home costs are excluded as they are unable to be broken down by MS severity.

Figure 3.3 Cost of MS by severity – Total ($M)



Notes: Mild severity includes EDSS levels 1 - 3, Moderate includes 4 – 6, Severe includes levels 6.5 – 9.9
Nursing home costs are excluded as they are unable to be broken down by MS severity.

The trends observed in the analysis of the cost by severity are confirmed when the breakdown is by EDSS (Figure 3.4, Figure 3.5). There is a substantial increase in personal costs when a person with MS reaches an EDSS level of 7-9, and this occurs at a time when income as evidenced by indirect costs is decreasing. Direct costs are reasonably constant while informal care and indirect costs increase markedly with severity.

Table 3.7 Cost of MS by EDSS

	0-1	2-3	4-5	6	6.5	7-9	NC	Not stated	Total
Per person with MS ($'s)									
Direct costs - personal	$1,237	$2,754	$3,511	$4,608	$4,859	$10,338	$2,792	$3,788	$3,697
Direct costs - community/ government	$10,517	$9,660	$11,912	$10,387	$9,567	$14,944	$10,385	$9,304	$10,721
Nursing home and equivalent costs*	$4,384	$4,384	$4,384	$4,384	$4,384	$4,384	$4,384	$4,384	$4,384
Informal care	$849	$5,721	$6,070	$12,623	$11,442	$10,722	$5,244	$6,227	$6,857
Indirect costs	$9,801	$19,481	$23,969	$34,784	$29,547	$31,375	$27,050	$20,354	$23,286
Total costs	**$26,788**	**$42,001**	**$49,846**	**$66,786**	**$59,799**	**$71,764**	**$49,855**	**$44,057**	**$48,945**
Total ($000's)									
Direct costs - personal	$5,341	$9,432	$11,500	$17,287	$8,825	$16,006	$4,572	$5,414	$78,376
Direct costs - community/ government	$45,407	$33,079	$39,016	$38,968	$17,377	$23,138	$17,006	$13,297	$227,288
Nursing home and equivalent costs[a]	$18,928	$15,012	$14,359	$16,447	$7,963	$6,788	$7,179	$6,266	$92,941
Informal care	$3,664	$19,591	$19,880	$47,358	$20,782	$16,601	$8,588	$8,900	$145,365
Indirect costs	$42,313	$66,707	$78,505	$130,499	$53,665	$48,579	$44,299	$29,090	$493,657
Total costs	**$115,653**	**$143,820**	**$163,259**	**$250,560**	**$108,612**	**$111,112**	**$81,644**	**$62,967**	**$1,037,627**

Abbreviations: NC, not classified.

Notes: [a]Nursing home costs are available for the total population only. Total cost in each category is calculated from the category population and the overall mean cost. Therefore no inference should be made for the difference in cost between categories.

Figure 3.4 Cost of MS by EDSS – per person with MS ($)

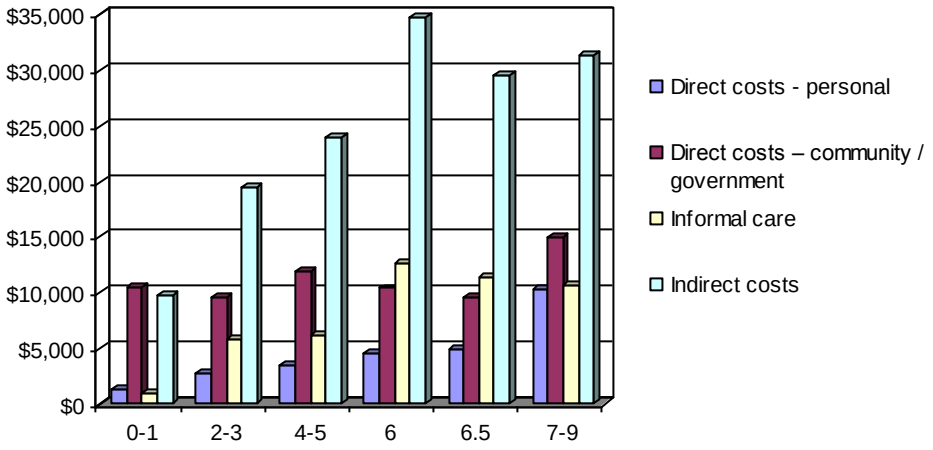
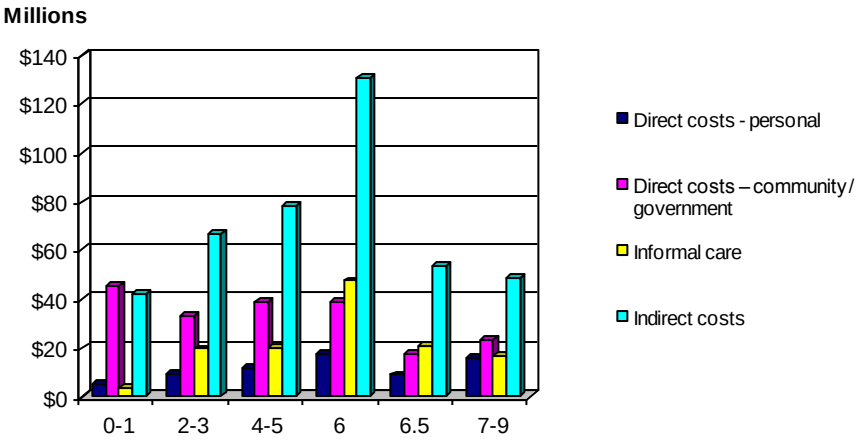


Figure 3.5 Cost of MS by EDSS – Total ($M)



There is a direct association between age and severity (chi-square 68.8; degrees of freedom = 8; $p \leq 0.0001$) and the cost increases with age up to 64. In people with MS aged 65 and over, the cost of informal care and indirect costs are low as no lost income from work foregone is assumed for this age group (Table 3.8, Figure 3.6, Figure 3.7).

Table 3.8 Cost of MS by age group

	<35	35-44	45-54	55-64	65+	Not Stated	Total
Per person with MS ($'s)							
Direct costs - personal	$3,726	$3,207	$3,106	$4,603	$3,490	$4,325	$3,697
Direct costs - community / government	$11,221	$12,528	$11,689	$9,696	$8,594	$8,929	$10,721
Nursing home and equivalent costs[a]	$4,384	$4,384	$4,384	$4,384	$4,384	$4,384	$4,384
Informal care	$8,097	$4,948	$3,640	$11,948	$4,397	$4,753	$6,857
Indirect costs	$11,051	$15,891	$24,056	$38,748	$939	$28,507	$23,286
Total costs	**$38,478**	**$40,958**	**$46,874**	**$69,379**	**$21,804**	**$50,898**	**$48,945**
Total ($000's)							
Direct costs - personal	$4,770	$11,841	$19,882	$30,565	$10,288	$1,030	$78,376
Direct costs - community / government	$14,367	$46,256	$74,828	$64,377	$25,334	$2,127	$227,288
Nursing home and equivalent costs[a]	$5,613	$16,186	$28,065	$29,109	$12,923	$1,044	$92,941
Informal care	$10,367	$18,268	$23,302	$79,335	$12,961	$1,132	$145,365
Indirect costs	$14,149	$58,671	$153,997	$257,282	$2,768	$6,790	$493,657
Total costs	**$49,265**	**$151,223**	**$300,074**	**$460,668**	**$64,274**	**$12,124**	**$1,037,627**

Notes: [a] Nursing home costs are available for the total population only. Total cost in each category is calculated from the category population and the overall mean cost. Therefore no inference should be made for the difference in cost between categories.

Figure 3.6 Cost of MS by age – per person with MS ($)

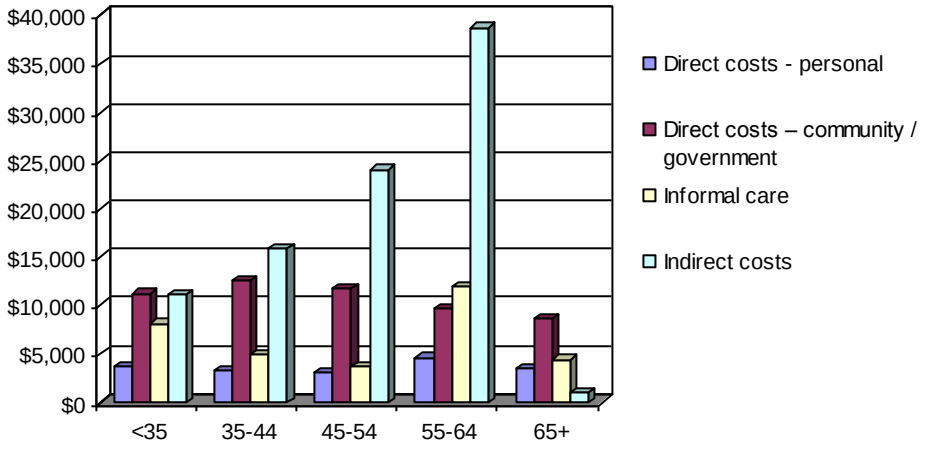
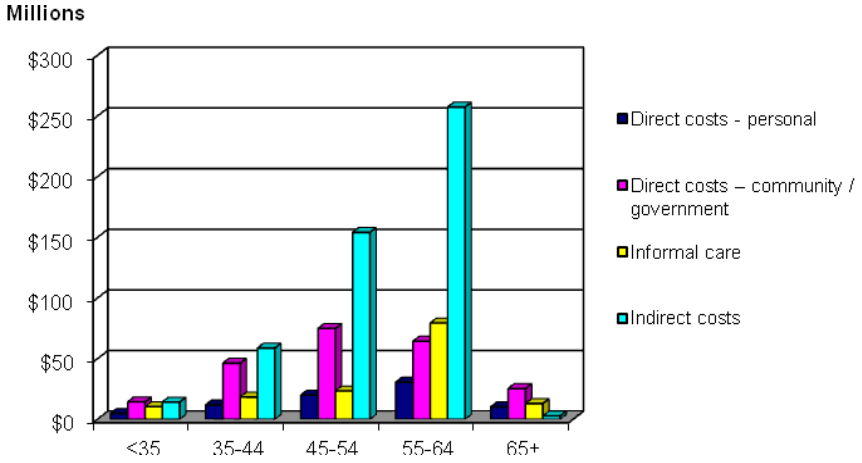


Figure 3.7 Cost of MS by age group – Total ($M)



Females make up 79.4% of the AMSLS EIS sample population (see Section 3.3.1). As expected the total costs are higher for females due to the higher prevalence, however the cost per female with MS is slightly lower than for males due to the difference in productivity costs. More men were in paid employment and on higher salaries prior to the onset of MS; thus there is a greater decline in paid work foregone as assessed by monetary value when a male stops work prematurely.

Table 3.9 Cost of MS by gender

	Male	Female	Total
Per person with MS ($'s)			
Direct costs - personal	$3,504	$3,751	$3,697
Direct costs - community / government	$10,114	$10,896	$10,721
Nursing home and equivalent costs*	$4,384	$4,384	$4,384
Informal care	$7,543	$6,692	$6,857
Indirect costs	$29,529	$21,714	$23,286
Total costs	**$55,073**	**$47,437**	**$48,945**
Total ($000's)			
Direct costs - personal	$15,230	$63,104	$78,376
Direct costs - community / government	$43,968	$183,307	$227,288
Nursing home and equivalent costs[a]	$19,058	$73,752	$92,941
Informal care	$32,789	$112,575	$145,365
Indirect costs	$128,368	$365,290	$493,657
Total costs	**$239,414**	**$798,029**	**$1,037,627**

Notes: [a]Nursing home costs are available for the total population only. Total cost in each category is calculated from the category population and the overall mean cost. Therefore no inference should be made for the difference in cost between categories.

Figure 3.8 Cost of MS by gender – per person with MS ($)

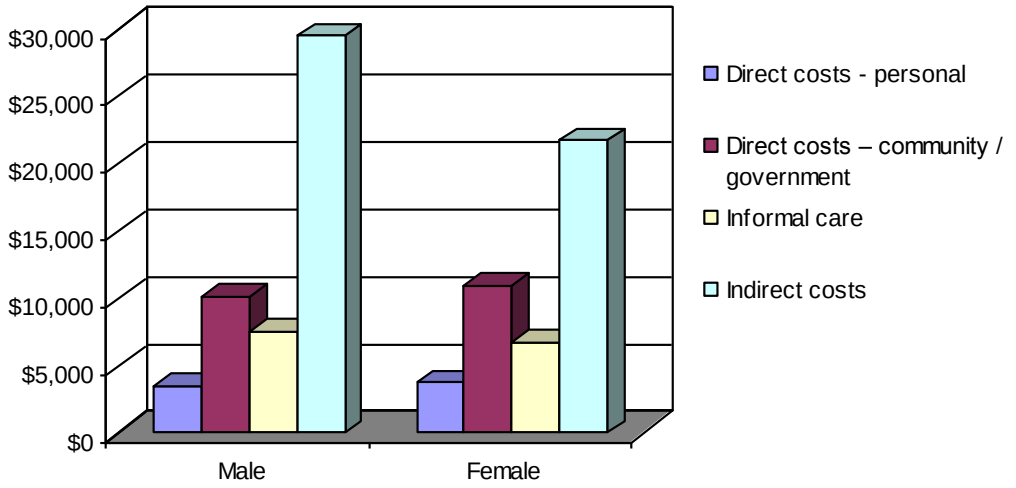
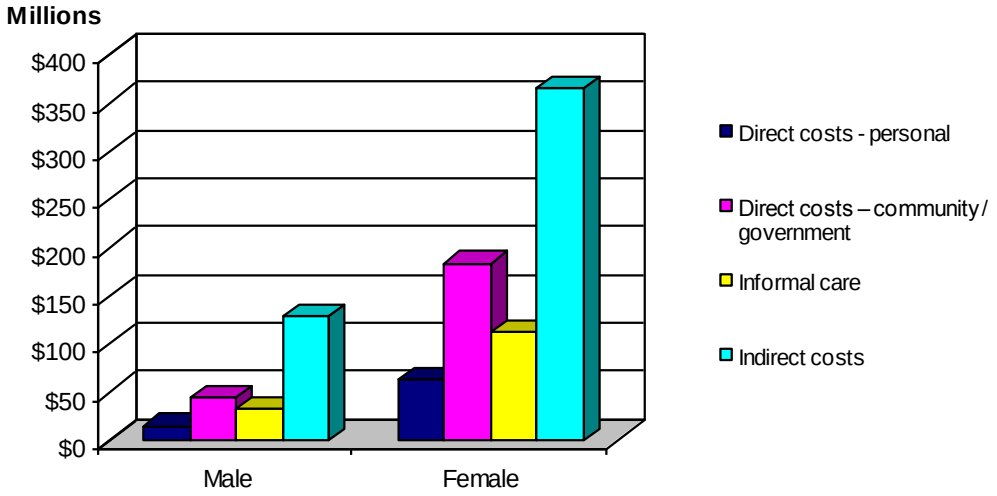


Figure 3.9 Cost of MS by gender – Total ($M)



The cost of MS by geographical remoteness is shown in Table 3.10 and Figure 3.11. In general the cost per individual did not differ markedly except for the indirect cost which is likely to be due to a greater proportion of higher earning people with MS in major cities and inner regional centres. The personal costs are somewhat lower in people with MS in the outer regional areas and this may reflect a lower disposable income.

Table 3.10 Cost of MS by geographical remoteness

	Major City	Inner Regional	Outer Regional	Other	Total
Per person with MS ($'s)					
Direct costs - personal	$3,230	$5,006	$2,763	$2,972	$3,697
Direct costs – community / government	$10,552	$11,562	$9,720	$6,744	$10,721
Nursing home and equivalent costs[a]	$4,384	$4,384	$4,384	$4,384	$4,384
Informal care	$6,530	$7,220	$6,002	$20,377	$6,857
Indirect costs	$24,087	$23,492	$16,688	$26,067	$23,286
Total costs	**$48,782**	**$51,665**	**$39,557**	**$60,545**	**$48,945**
Total ($000's)					
Direct costs - personal	$41,838	$30,558	$5,183	$796	$78,376
Direct costs – community / government	$136,671	$70,577	$18,233	$1,807	$227,288
Nursing home and equivalent costs[a]	$56,783	$26,760	$8,224	$1,175	$92,941
Informal care	$84,576	$44,069	$11,259	$5,461	$145,365
Indirect costs	$311,974	$143,394	$31,303	$6,985	$493,657
Total costs	**$631,843**	**$315,358**	**$74,202**	**$16,225**	**$1,037,627**

Note: [a] Nursing home costs are available for the total population only. Total cost in each category is calculated from the category population and the overall mean cost. Therefore no inference should be made for the difference in cost between categories.

Figure 3.10 Cost of MS by location – per person with MS ($)

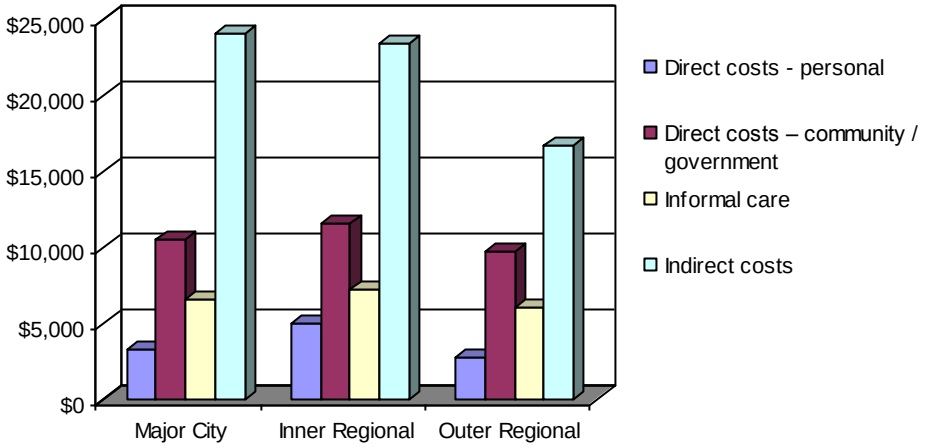
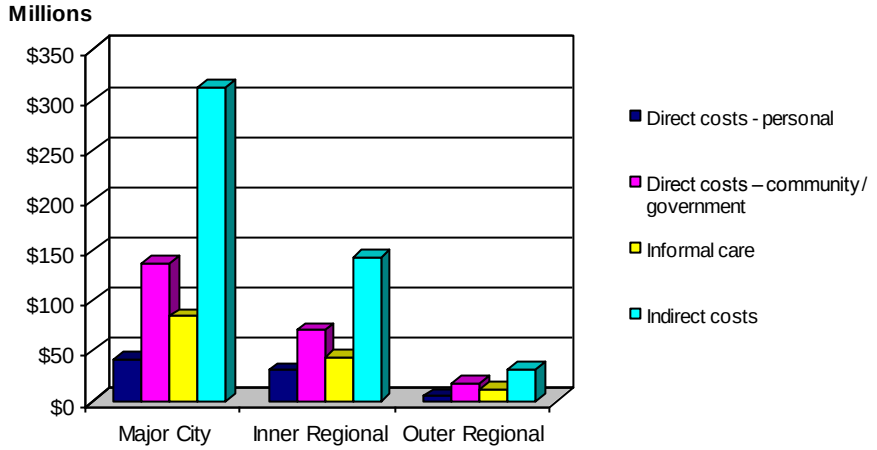


Figure 3.11 Cost of MS by location – Total ($M)



A breakdown of the direct costs (personal and community/government) by MS severity is shown in Table 3.11 and Figure 3.12. The mean cost per person is $14,418 of which $8,530 (59%) was attributable to pharmaceutical use. The cost of pharmaceuticals was similar for mild and moderate categories but decreased when the condition becomes severe. This is likely to be due to the MS-specific immunotherapies being reimbursed for RRMS only, having limited efficacy in progressive forms of MS. Hence those with more severe disease are unlikely to be prescribed these treatments. The other key contributors to cost were the alterations to the car and home, and community and private services which increased with disease severity. Despite the high cost of the MS-specific immunotherapies, the direct costs for people with mild and moderate disease are less than for those with severe disease.

These trends are observed when severity is represented by the EDSS as in Table 3.12 and Figure 3.13.

Table 3.11 Direct costs - by cost category and disease severity - per person with MS

	Mild	Moderate	Severe	Not stated	Total
Prescription medication	$9,387	$8,725	$5,508	$9,057	$8,530
Non-prescription medication	$226	$303	$400	$291	$284
Disposable equipment	$53	$121	$468	$95	$144
Health professional	$617	$1,061	$1,071	$950	$858
Nursing services	$81	$615	$1,501	$127	$487
Community and private services	$273	$911	$3,056	$312	$929
Medical tests	$188	$294	$203	$321	$234
Hospital stay	$125	$326	$921	$375	$335
Alterations to car/home	$1,157	$2,320	$4,839	$1,132	$2,125
Special equipment	$137	$519	$1,455	$432	$492
Total	**$12,244**	**$15,194**	**$19,422**	**$13,092**	**$14,418**

Figure 3.12 Direct costs - by cost category and disease severity - per person with MS

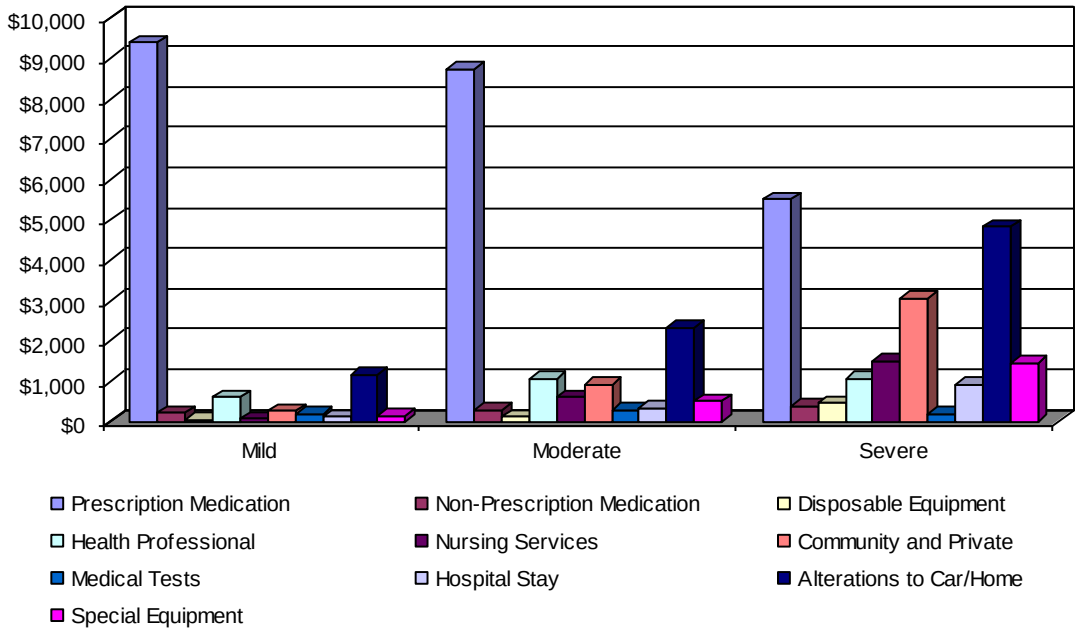
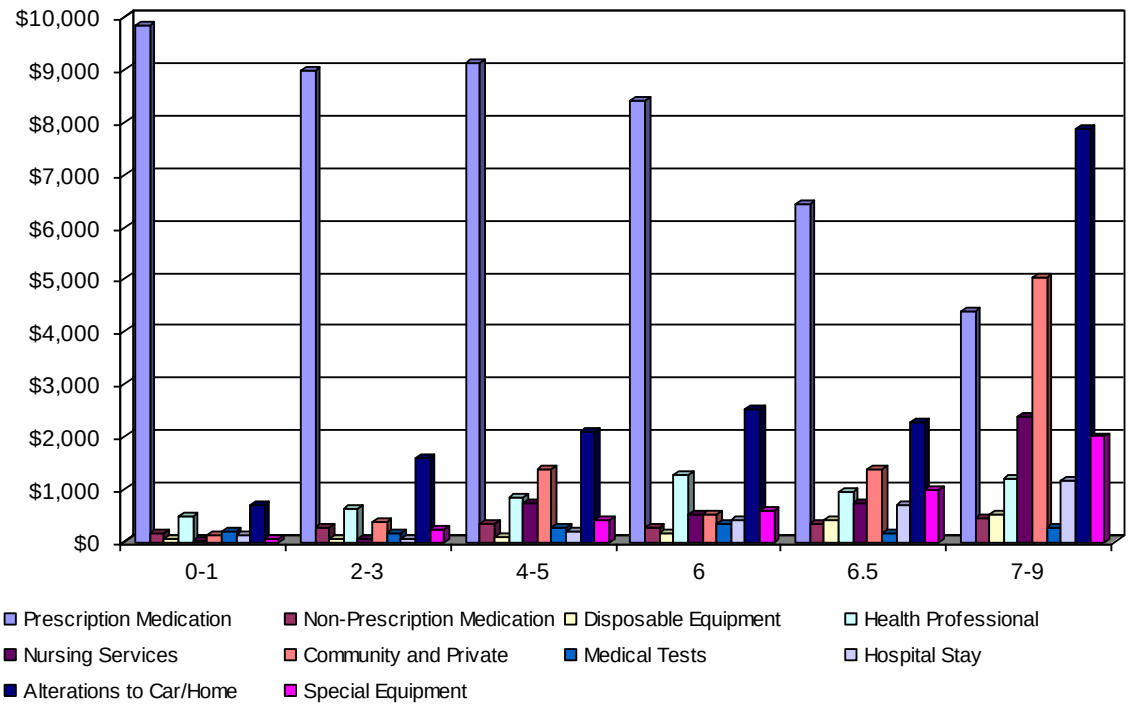


Table 3.12 Direct costs - by cost category and EDSS - per person with MS

	0-1	2-3	4-5	6	6.5	7-9	NC	Not stated	Total
Prescription medication	$9,822	$8,993	$9,109	$8,390	$6,447	$4,406	$9,063	$9,057	$8,530
Non-prescription medication	$171	$273	$329	$280	$356	$451	$273	$291	$284
Disposable equipment	$50	$50	$87	$150	$424	$520	$68	$95	$144
Health professional	$468	$637	$836	$1,258	$951	$1,211	$967	$950	$858
Nursing services	$36	$62	$724	$521	$748	$2,385	$241	$127	$487
Community and private services	$123	$384	$1,366	$514	$1,378	$5,024	$435	$312	$929
Medical tests	$199	$162	$254	$329	$151	$263	$213	$321	$234
Hospital stay	$133	$49	$211	$426	$715	$1,164	$262	$375	$335
Alterations to car/home	$685	$1,580	$2,088	$2,522	$2,271	$7,851	$1,519	$1,132	$2,125
Special equipment	$68	$224	$419	$606	$984	$2,008	$134	$432	$492
Total	**$11,754**	**$12,415**	**$15,423**	**$14,995**	**$14,426**	**$25,282**	**$13,176**	**$13,092**	**$14,418**

Abbreviations: NC, not classified.

Figure 3.13 Direct costs - by cost category and EDSS - per person with MS



4 QUALITY OF LIFE WITH MS

The reduction in the quality of life of people with MS has been widely documented[3, 24]. In a study of quality of life (as assessed by utility) in 13,186 people with MS in Europe, utility was similar across countries at around 0.70 for an individual with an EDSS of 2.0 and around 0.45 when the EDSS increases to 6.5[3].

The AMSLS collected data from 2,139 people with MS in 2008 using the WHOQOL 100, an instrument developed by the World Health Organization (WHO) with the objective of measuring quality of life in a variety of cultural settings and allowing the results from different populations and countries to be compared. The instrument consists of six broad domains of quality of life, and twenty-four facets. Each facet consists of four items. There are four additional general items covering overall quality of life and health, resulting in a total of 100 items. All items are rated on a five point scale (1-5). The domains and facets of the WHOQOL 100 are shown in Table 4.1.

Table 4.1 Domains and facets of the WHOQOL 100

1. Physical Health	Energy and fatigue
	Pain and discomfort
	Sleep and rest
2. Psychological health	Bodily image and appearance
	Negative feelings
	Positive feelings
	Self-esteem
	Thinking, learning, memory and concentration
3. Level of Independence	Mobility
	Activities of daily living
	Dependence on medicinal substances and medical aids
	Work capacity
4. Social Relations	Personal relationships
	Social support
	Sexual activity
5. Environment	Financial resources
	Freedom, physical safety and security
	Health and social care: accessibility and quality
	Home environment
	Opportunities for acquiring new information and skills
	Participation in and opportunities for recreation/leisure
	Physical environment (pollution/noise/traffic/climate)
	Transport
6. Spirituality/Religion/Personal beliefs	Religion/Spirituality/Personal beliefs
Overall Quality of Life and General Health	

Source: WORLD HEALTH ORGANIZATION DIVISION OF MENTAL HEALTH GENEVA Available at http://www.who.int/mental_health/who_qol_field_trial_1995.pdf

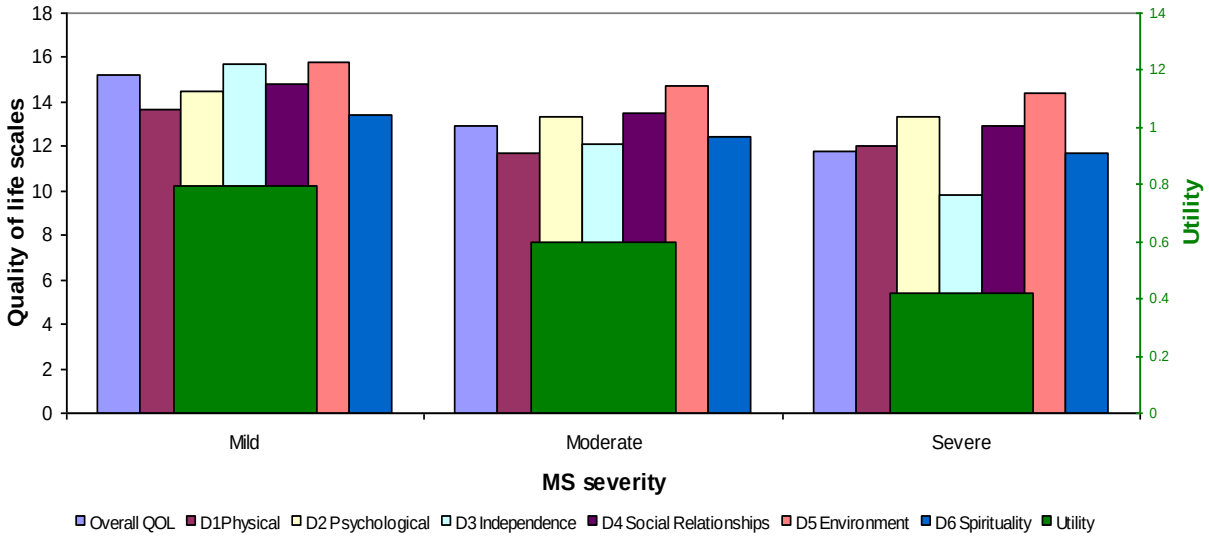
The utility score was calculated by mapping five questions from the WHOQOL-100 to the EQ-5D descriptive system as described by Al-Ruzzeh et al [25] and then applying utility weights to each of the levels in each dimension[26, 27] (refer to Statistical Report (available on request)). The average quality of life and utility score for all persons with MS and broken down by disease severity is presented in Table 4.2. The utility score for all people with MS was 0.65 out of a maximum value of 1.0. As expected the utility decreased with increasing disease severity as did the total WHOQOL-100 and its domains.

Table 4.2 Utility and Quality of Life by MS severity

	Mild (N=869)	Moderate (N=807)	Severe (N=340)	Average (N=2139)
Utility	0.796	0.596	0.422	0.652
Overall QOL	15.2	12.9	11.8	13.7
D1 Physical health[a]	13.7	11.7	12	12.6
D2 Psychological health[a]	14.5	13.3	13.3	13.8
D3 Level of independence[a]	15.7	12.1	9.8	13.3
D4 Social Relationships[a]	14.8	13.5	12.9	14
D5 Environment[a]	15.8	14.7	14.4	15.1
D6 Spirituality/Religion/Personal beliefs[a]	13.4	12.4	11.7	12.7

Notes: [a] maximum score is 20 and higher scores denote better quality of life.

Figure 4.1 Utility and Quality of Life by MS severity



5 DISCUSSION

5.1 Comparison with estimates from other countries

The cost per person with MS of AU$48,945 determined in this analysis is consistent with reported estimates from other countries. The MSIF conducted a review of international data on the costs and quality of life of MS[7]. The review found that while the total costs of MS varied by country the costs were substantial in all countries. The total average cost per person with MS varied from US$16,378 in France to US$54,489 in Norway with an overall prevalence-weighted average of US$41,335 (Table 5.1). This review found that in addition to underlying differences in the costs of MS treatment and management, differences in MS costs across countries were due to differences in the categories of costs included in each study, typical care provided to people with MS during the time period of analysis, and cost analysis approaches. Canada and France stand out for being markedly lower than other countries as the most recent published studies in these countries used data from 1995, prior to the introduction of MS-specific immunotherapy.

Table 5.1 Total Costs per person with MS

Country	Total Direct Medical Cost[a]	Total Direct Non-Medical Cost[a]	Total Indirect Costs[a]	Total Cost[a]
Australia	$18,809	$16,167	$6,890	$41,866
Austria	$20,738	$10,010	$17,569	$48,317
Belgium	$13,746	$10,108	$13,267	$37,121
Canada	$3,162	$2,421	$15,932	$21,514
France	$6,078	$4,718	$5,582	$16,378
Germany	$20,246	$6,986	$19,946	$47,178
Italy	$13,001	$19,225	$13,237	$45,462
Netherlands	$9,845	$8,910	$15,849	$34,605
Norway	$10,995	$12,472	$31,023	$54,489
Poland	$3,495	$2,713	$11,423	$17,631
Spain	$15,973	$16,498	$11,544	$44,015
Sweden	$15,431	$21,607	$17,427	$54,465
Switzerland	$10,211	$13,365	$14,473	$38,048
United Kingdom	$10,969	$19,858	$17,995	$48,822
United States	$23,975	$7,844	$18,888	$50,707
Weighted average[b]	$13,198	$11,383	$16,755	$41,335

Notes: [a] 2007 international dollars, [b] Weighted by prevalence of MS in each country.

5.2 Comparison with previous studies conducted in Australia

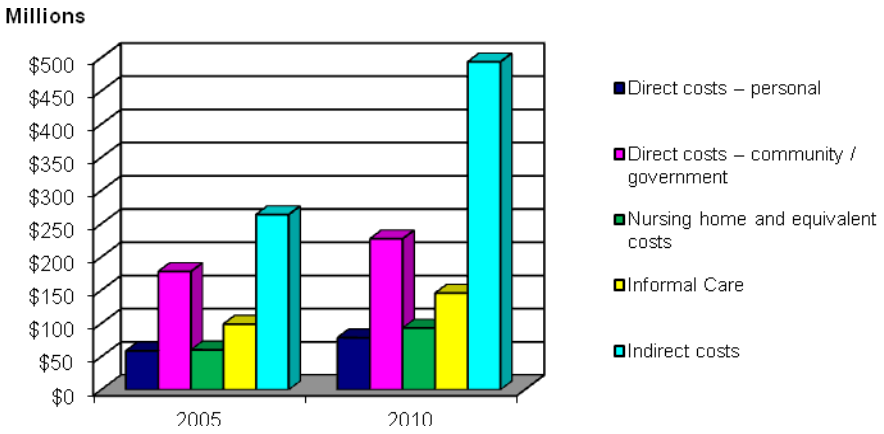
The cost of MS in 2010 is shown alongside the corresponding cost in 2005 calculated from the 2003 AMSLS EIS[8]. The costs per person are largely unchanged in each of the categories with the exception of an increase in the indirect costs. This is likely to be a consequence of the increase in salaries over this time with ABS data showing that the average salary has risen around 23% since 2005[21].

The total cost to society has increased 58% from $659M to $1,038M, driven by the increase in the prevalence and to a less extent an increase in indirect costs. The prevalence in 2010 is estimated to be 21,200 while the 2005 report assumed a prevalence of 16,081.

Table 5.2 Total cost of MS by cost categories in 2005 and 2010

	2010		2005	
Cost category	**Cost per person**	**Total $M**	**Cost per person**	**Total $M**
Direct costs – personal	$3,697	$78	$3,893	$58
Direct costs – community / government	$10,721	$227	$11,873	$178
Nursing home and equivalent costs	$4,384	$93	$4,013	$60
Informal Care	$6,857	$145	$6,593	$99
Indirect costs	$23,286	$494	$17,580	$264
Total costs	**$48,945**	**$1,038**	**$43,953**	**$659**

Figure 5.1 Cost of MS by cost categories in 2005 and 2010 ($M)



The results are also consistent with a cost of MS study conducted in Tasmania using a questionnaire completed by the study investigator for persons attending the MS clinic of the Royal Hobart Hospital between 2001 and 2002. In this study, the average annual direct and indirect costs per person with MS were AU$20,396 and AU$15,085, respectively[9].

The cost estimates were further validated by a comparison with the recently published report by the Productivity Commission 'Disability Care and Support, Draft Inquiry Report'[28]. This report describes the proposed National Disability Insurance Scheme (NDIS), which if introduced would provide long-term high quality care and support (but not income replacement) to people with severe or profound disabilities who request significant care and support. Tier 3 covers people with significant care and support needs and includes people with MS.

The report presents cost estimates for four categories associated with people in tier 3: care and support, aids and appliances, home modifications, and transport. It is estimated that the average annual gross cost of tier 3 of the NDIS in 2018-2019 would be $13.6 billion which would cover around 411,250 people. The largest component is care and support which accounts for 87% of the total annual cost. These include a range of formal services such as attendant care, accommodation support, nursing care, day programs, therapy, domestic assistance and meal preparation. The Productivity Commission report differs from AMSLS EIS analysis in that it did not include costs already paid by other schemes such as primary care and hospital (in-patient and outpatient) based services, medical services, and pharmaceutical products. Nor did the report include indirect costs. The report did include the cost of transport which the AMSLS EIS does not capture.

Of relevance is that the annual gross cost of the NDIS is estimated to be approximately $33,000 per person in need of tier 3 support ($13.6 billion for 410,000 persons in need of tier 3 support) which suggests that the estimate derived from the AMSLS EIS of $48,945 per person may be somewhat conservative given that the Productivity Commission estimates do not include the direct medical costs paid by government and indirect costs.

5.3 Cost of MS in sub-populations

There was a consistent trend towards increased cost with progressive severity of MS. This finding was observed when severity was classified as mild to severe by EDSS score or assumed based on age. This was despite the cost of prescription medication being much higher in the mild subgroup ($9,387) compared with $5,508 in the severe subgroup. The increased costs in the severe subgroup are due to community and private services, alterations to car and home, and special equipment (Table 3.11). Indirect costs and informal care are also higher in the moderate and severe subgroups as a consequence of foregone income due to increased disability. This increased financial burden is exacerbated by increased direct personal costs in this subgroup.

While there was a higher proportion of females with MS, the costs were similar with the exception of the indirect costs which again reflects the lower forgone income in this group. This trend was also observed with persons with MS in more remote locations.

5.4 Quality of Life

It has been well documented that people with MS suffer a reduction in quality of life, particularly as their condition deteriorates[3, 6, 29]. In the study of nine European countries, the utilities associated with MS as assessed by the EQ-5D were found to be similar across countries for each severity level. An average utility score of 0.707 was reported by patients with EDSS 2.0 and 0.456 by patients with EDSS 6.5. This indicated a consistent disease definition across geographies and a strong correlation between disability and quality of life. The utility loss due to MS resulted in a mean loss of quality adjusted life year of 0.27 ranging from 0.21 to 0.32.

While there are no population norms for the Australian population using the EQ-5D, values have been determined using an alternative instrument, the Assessment of Quality of Life (AQoL) [30]. The utility for Australians aged 50-59, the mean age of people with MS, is 0.80. This study showed that people with MS incur almost a 20% reduction in utility and once MS becomes severe, the reduction is almost 50%.

To place the loss of quality of life with MS into context, these findings are compared with utility weights reported in Australia associated with a range of health conditions (Table 5.3)[31]. As noted above, the utilities of persons with MS range from 0.796 (mild) to 0.422 (severe), indicating a similar utility loss to living with end stage malignancy or major disabling stroke.

Table 5.3 Utility weights reported in Australian population

Health State	Weight
Advanced liver failure	0.25
Major disabling stroke	0.36
End stage malignancy	0.40
Hospital haemodialysis	0.43
Neuropathy	0.62
Amputation (two years after event)	0.68
Angina	0.68
Obese	0.78
Hearing loss (requiring hearing aid)	0.86

Source: The CEA registry 2011.

5.5 Comparison with other conditions

A limited number of cost of illness studies have been conducted in Australia that can be used to provide a context for MS. One study estimated the cost per person with schizophrenia was $46,180 (in 2000 dollars)[32], not dissimilar to the cost of MS estimated in this report. The AusDIAB study reported that the cost of type 2 diabetes mellitus to be $10,900 per year ($5,360 per person for direct and indirect costs plus $5,540 in Commonwealth benefits)[33]. These costs need to be interpreted with caution as being derived with different methodologies, nevertheless suggest that the cost of MS is similar to other severe illnesses and higher than diabetes mellitus which is considered to be a substantial burden to the individual and community as a whole.

5.6 Strength and limitations of study

A strength of this study is that detailed information on all costs incurred due to MS is able to be captured by a large sample of people with MS. 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 the past.

A possible limitation is that the 712 participants with MS may not be representative of all Australians with MS. If for example, the sample is under-represented by younger patients with mild MS, then the survey will overestimate the costs while if the sample is under-represented by more people with severe MS then the converse will be true. As with all surveys where participation requires time commitment, the incentive of patients with MS to participate and express their experience may be more pronounced for patients with severe MS. This may be balanced by patients with greater levels of disability finding it harder to respond to such a survey. Less severe patients may also be motivated by the opportunity to share their experiences however this subgroup may also be less accepting of their condition and therefore less inclined to spend the time required completing the survey.

Comparison with the MSA membership database suggests that the sample population is reasonably representative of the broader MS population and therefore does not bias the findings.

The analysis does not include the intangible cost associated with MS which results in a more conservative estimate. The intangible cost could be estimated by quantifying the reduction in either quality of life[3, 6] or disability[8] and valuing this loss using society's willingness to pay for a year of life. While valuation of the intangible cost enables a monetary value to be placed on the pain and

grief associated with MS, the costs are not borne by the person with MS or the community and have not been incorporated into this analysis.

The analysis does however include the indirect costs resulting from the use of informal care and productivity loss. The cost of informal care contributed 14% of the cost per person with MS while productivity losses contribute 48% and was the highest single element of cost. These costs are less visible as they do not represent a direct expenditure outlay; however have a very real and significant impact on the community. The requirement for informal care and the foregone income due to the inability to participate in the workforce represent a substantial burden to persons with MS and their families.

6 SUMMARY AND CONCLUSION

This study provides an important insight into the burden of MS. Key findings are:

- The prevalence of MS has increased steadily over time to the current estimate of 21,200 Australians living with the condition.
- There are substantial direct costs associated with MS. These costs increase with severity due to the requirements for more community and private care and alteration to cars and houses. This is despite the cost of prescription medicines being lower in patients with more severe MS as they are not eligible for the MS-specific immunosuppressants under the PBS.
- The indirect costs also increase with MS severity due to the income forgone with increased disability. This occurs concurrently with an increase in personal costs, thereby imposing an additional financial burden on these patients.
- The reduction in quality of life associated with MS is commensurate with its other serious conditions, such as stroke and end stage cancer. There is a 20% reduction in utility in MS patients and this increases to 50% when a person‘s condition becomes severe.

MS imposes a substantial economic and social burden on the people with the condition and the community and society as a whole. The burden increases as the condition becomes more severe, suggesting that investment in research and innovations that would delay or ideally prevent the progression of the condition could bring substantial rewards in terms of both reducing the financial burden and increasing the quality of life for persons with MS.

While an individual genetic predisposition to having MS has been scientifically demonstrated, the environment has also been shown to strongly influence the development and risk of MS. More research that could protect future generations, including studies into relevant viral influences and the potential for inexpensive Vitamin D intervention strategies, would appear to offer a substantial benefit.

Considering the greatest proportion of the cost of MS to the individual and society lies in lost productivity, investment in resources, services and employment environments that assist people with MS to remain in employment is of paramount importance, both in terms of quality of life and economic impact.

The results of this study confirm the findings of previous studies and can inform the development of policy positions, planning of healthcare services and prioritization of research funding.

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