

Multiple sclerosis

Assessing the social and economic burden

NZIER report to MSNZ

30 November 2020

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NZIER is a specialist consulting firm that uses applied economic research and analysis to provide a wide range of strategic advice.

We undertake and make freely available economic research aimed at promoting a better understanding of New Zealand's important economic challenges.

Our long-established Quarterly Survey of Business Opinion (QSBO) and Quarterly Predictions are available to members of NZIER.

We pride ourselves on our reputation for independence and delivering quality analysis in the right form and at the right time. We ensure quality through teamwork on individual projects, critical review at internal seminars, and by peer review.

NZIER was established in 1958.

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Key points

Understanding the total costs and benefits of a health challenge is good health economics which matters for society because a person's health has implications for families, society and the economy.

In 2021, the combination of the loss of earnings, health system costs and intangible losses in health quality associated with the prevalence amounted to \$266.3 million, excluding the cost of MS-related mortality.

- In 2021, around 4,130 people had MS
- MS affects people in their prime earning and caring years, and these factors are not always fully considered in funding decisions
- MS is a disease of the middle-aged, with the onset of symptoms occurring predominantly in people aged 25 to 50 years old. These tend to be the peak earning years for New Zealanders. This is a time in people's lives when they have made consequential financial decisions such as home loans, children and retirement saving plans. These decisions are invariably informed by assumed continued employment and the financial pay-offs associated with career progression. MS can significantly disrupt these plans and oppose unanticipated costs on households and society.

Access to medicines in New Zealand is falling behind comparator OECD countries due to a combination of reasons, including:

- Medicines funding is not keeping pace with health spending
- Social costs and benefits being systematically under-counted in funding decisions
- The emergence of effective new medicines is not accommodated by current funding appraisal processes.
- The speed of access to new medicines can be slower in New Zealand than elsewhere.

What needs to be considered to make progress

Making progress in the assessment of the social cost and benefits of health intervention for MS and other conditions would require the following changes:

- Greater use of social-benefit analysis in pharmacoeconomic analyses would provide greater insight into the benefits of emerging treatments for MS.
- Adding cost-benefit analysis to the suite of tools would support more fulsome decisions about how to set budgets to deliver better health and wellbeing outcomes for New Zealanders.
- Commissioning research into the social benefits and costs would support greater transparency.



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1 What we were asked to do

1.1 Research objectives

- MSNZ commissioned NZIER to investigate the economic burden of multiple sclerosis (MS) in New Zealand.

The research objectives were to:

- **Assess** the economic burden of MS, including the impacts on health quality, productivity and economic wellbeing.
- **Compare** the approaches taken by PHARMAC, which uses cost-utility analysis and social cost-benefit analysis, recommended by Treasury.
- **Recommend** an approach that focuses most on supporting improvement in everyday life and enhances the general wellbeing of people with MS.

1.2 Research scope

The scope of the research includes the following considerations:

- The health effects of MS.
- The economic productivity effects including but are not limited to employment status and labour force participation.
- Household consequences such as loss of potential earnings, diminished savings, and effects on partners.

1.3 Report structure

The report has three parts. Firstly, the approach to the research is introduced. Secondly, economic and health impacts are investigated in the context of the prevalence of MS in New Zealand. Finally, the analytical approaches applied by Pharmac and Treasury are compared and contrasted with reviewing the implications for improving the wellbeing of people with MS.

1.4 Funding statement

The funding for this report was generously provided by Roche in support of MSNZ. NZIER was honoured to be commissioned to conduct this research to improve the wellbeing of those with MS in New Zealand.



2 The approach to the research

This research is interested in the answers to the following research questions:

1. What is the social and economic impact of MS in New Zealand?
2. How does the approach to assessing that impact shape the estimates of the impact of MS in New Zealand?

The first question starts by considering the burden of the disease on the quality of health experienced by people with MS. This required us to assess the prevalence of MS in New Zealand and the distribution of the negative effects MS has on the quality of people's health. Standard practice, supported by peer-reviewed literature and world-class data sources, were used to assess the burden of disease associated with MS.

The second question was motivated by the need for high-quality economic analysis to support epidemiological and medical research to transcend the gap between academia, policy and practice. Economic analysis has a critical role to play in translating scientific medical research into a policy or business case for change. Budget, investment and policy decisions in New Zealand require an assessment of the benefits and costs of the proposed change. Medical and epidemiological research is not enough to change the way things are done in New Zealand. When corporate or government spending is involved, economic analysis is the tool to reach for because economics is about the allocation of scarce resources.

2.1 Cost-effectiveness analysis versus cost-benefit analysis

The assessment of the social and economic impact of health issues varies based on the interest of the assessor. For example, PHARMAC uses cost-utility analysis, a form of cost-effectiveness analysis, to enable comparison between the cost-effectiveness of interventions treating different conditions taking into account benefits resulting from both decreases in mortality and decreases in morbidity (PHARMAC 2015). In comparison, the Treasury recommends cost-benefit analysis (CBA).

Cost-effectiveness analysis (CEA) is a widely used alternative to cost-benefit analysis, especially in health policy analysis. CEA investigates the merits of mutually exclusive alternatives based on the ratio of quantitative non-monetised measures of effectiveness, such as improvements in health outcomes, to the cost of the alternative inventions. The cost-effectiveness of a suite of options can be ranked by comparing the ratios of the alternatives, and the most cost-effective option rises to the top of the ranking.

CBA goes a step further than CEA. The outcomes or benefits of the alternatives are monetised and compared to the costs of the intervention. This allows analysis to show the value of the net benefits to society.

CEA and CBA can include markets effects (e.g. capital investment) and non-market effects (e.g. the monetised value of improvement in the quality of health). CEA has advantages over CBA in the following situations:

- Unwillingness or inability to monetise the benefits, as is sometimes the case in health.
- When the benefits can only be partially monetised.



- When the link to preferences is unclear, and the uncertainty means that the ranking of alternatives is more credible than the estimated value (Broadman et al., 2011).

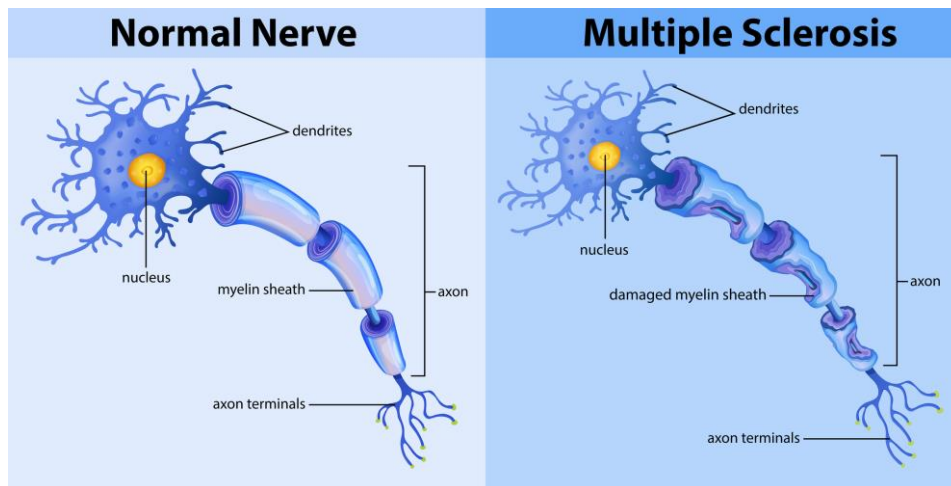
The disadvantage of CEA, compared with CBA, is that the absence of any monetisation of the benefits results in more focus on the costs. When in fact, the outcomes are what really should matter. Therefore, CBA is a more balanced and persuasive tool in a world of competing objectives and constrained budgets. In comparison, CEA is more useful as an internal decision-making tool for organisations, which is consistent with its less intensive demand for information inputs in the analysis.



3 What is multiple sclerosis?

MS is a disease of the central nervous system. MS involves the immune system attacking the protective layer of nerve fibres. Figure 1 shows the MS nerve damage compared to a normal nerve.

Figure 1 MS nerve damage



Source: Dreamstime.com

This causes communication problems within the central nervous system, which can lead to problems in many systems, including:

- **Movement:**
 - Numbness or weakness in one or more limbs that typically occurs on one side of your body at a time, or your legs and trunk
 - Electric-shock sensations that occur with certain neck movements, especially bending the neck forward (Lhermitte sign)
 - Tremor, lack of coordination or unsteady gait.
- **Vision:**
 - Partial or complete loss of vision, usually in one eye at a time, often with pain during eye movement
 - Prolonged double vision
 - Blurry vision.
- **Other MS symptoms may include:**
 - Slurred speech
 - Fatigue
 - Dizziness
 - Tingling or pain in parts of your body
 - Problems with sexual, bowel and bladder function.



4 How prevalent is MS in New Zealand?

Estimating the prevalence of MS in New Zealand

The societal and economic burden of MS is fundamentally shaped by the prevalence and distribution of the disease. The demographic patterns are presented to provide the vital context for the subsequent analysis of the social and economic burden of MS in New Zealand. An updated estimate of the prevalence of MS is the first step in the research process.

NZIER estimated that there were around 4,130 people with MS in New Zealand in 2021. The prevalence of MS was estimated by combining the prevalence rate estimates of Frampton with population estimates and population projections published by Statistics New Zealand. The prevalence rate was estimated for males and females in five-year age bands.

Table 1 Prevalence of MS in New Zealand in 2021

Net of mortality estimates

Age (years)	Male	Female	Total
<20	5	31	36
20-24	22	73	95
25-29	43	145	188
30-34	92	287	379
35-39	69	354	423
40-44	102	365	467
45-49	168	408	576
50-54	141	396	537
55-59	151	396	547
60-64	112	312	424
65-69	69	178	247
70-74	20	94	114
75-79	12	59	71
80-84	3	19	22
85+	0	4	4
Total	1,009	3,121	4,130

Source: NZIER

NZIER's estimate was in line with the prevalence estimates for New Zealand published by the Global Burden of Disease Study (GBDS), which source its inputs from micro-data from the Ministry of Health and peer-reviewed studies. In a Lancet article, the GBDS 2016 prevalence estimate for MS in NZ was 3,803 with a 95% confidence interval of 3,440-4,237.

MS is disproportionately higher among females

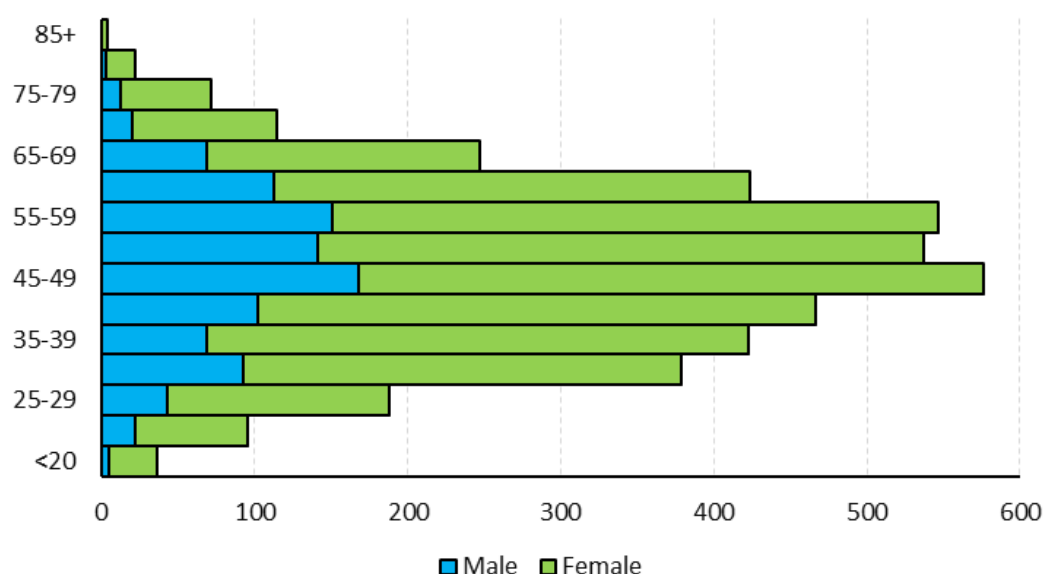
The prevalence of MS is disproportionately higher among females. Among the New Zealand population, 76% of people with MS were female (3,121), and the remainder were male (1,009). This pattern of higher prevalence among females is a global feature of MS (Wallin et al. 2019; Stenager 2019).

MS disproportionately presents in people in middle age

MS could also be described as a disease of middle-age. The prevalence and onset of MS can begin in the late twenties. In New Zealand, MS is most commonly diagnosed in people between the ages of 30 and 60 years old (Taylor et al., 2010). Figure 2 shows the number and distribution of MS cases by age and gender.

Figure 2 Overall prevalence of MS in New Zealand in 2021

Number of cases



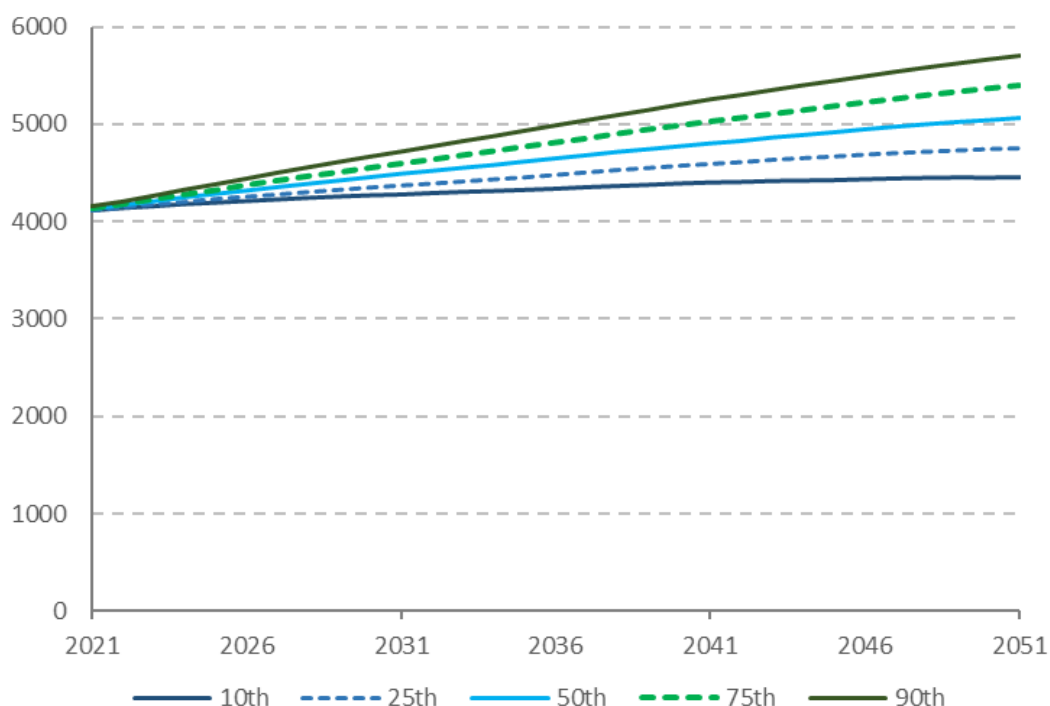
Source: NZIER based on Statistics NZ Population Estimates and Frampton (2017)

The population of New Zealand is projected to increase and age in the future, which could contribute to an increase in the number of cases and a greater burden from MS. Policy and research decisions made now will shape the implication of that burden for people, communities and demand on governmental budgets for years to come. In the context of an ageing population and MS being a disease of middle-age, it may become more visible in health rankings in New Zealand over the next 30 years.

Figure 3 shows the projected prevalence of MS based on assumptions of constant prevalence rate by age and gender applied to the official population projections from Statistics NZ. The projections indicate that without a change in the prevalence rates, the total number of people with MS will be between 4,450 and 5,700 by 2051. The burden of MS will be greater in all scenarios, which mean it will have a greater impact on health system costs if nothing changes.

Figure 3 The projected prevalence of MS in New Zealand in 2021-2051

Cases of MS



Source: NZIER

Ethnicity matters

Results from the NZMSPS found the prevalence of MS in Māori to be a third of the national rate (24.2 versus 73.1 per 100,000) (Alla and Mason 2014). The under-reporting of disease among the indigenous population should not be ignored. However, there is genetic evidence to support substantial differences in the prevalence of MS in co-located populations of different ethnic heritages. Miller et al. (1986) found that the frequency of MS-risk genes was lower in Māori than non-Māori people in the sample. In Norway, Harbo et al. (2007) found that the low frequency of the disease-associated genes in the Norwegian Sami population may contribute to the low prevalence of MS compared to other Norwegians.

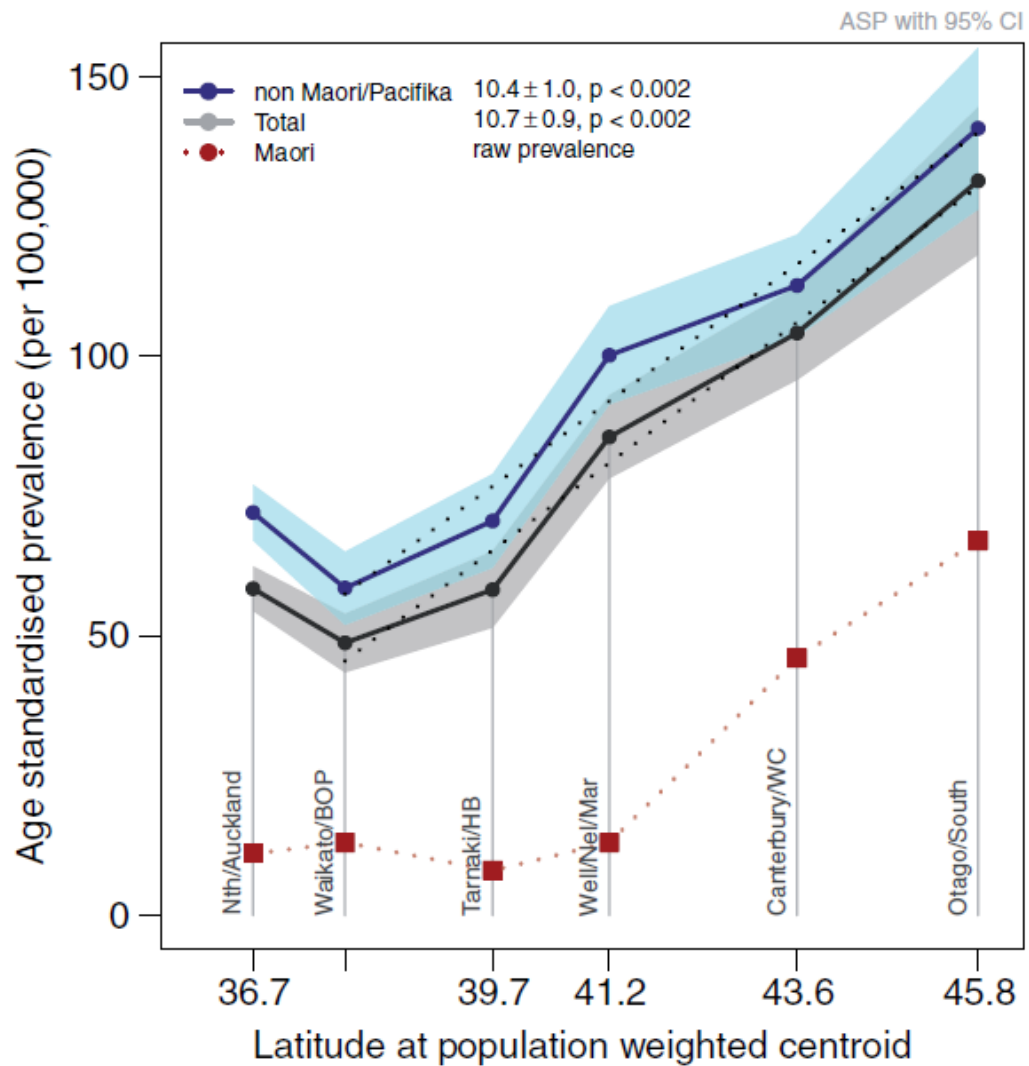
The MS latitude gradient in New Zealand

There is a highly significant latitudinal gradient of MS prevalence in New Zealand, with prevalence increasing threefold between the North and South of the country (Taylor et al. 2010). Figure 4 shows the prevalence rate of MS throughout New Zealand by ethnicity, latitude and region. From the figure, it can be seen that there is an association between latitude and the prevalence rate. Higher latitude, which is further south in New Zealand, is associated with an increased prevalence rate. The latitude gradient is also seen among Māori.

Taylor et al. (2010) conclude there are currently two biologically plausible explanations for the latitudinal gradient: decreased ambient winter UVR and subsequent decreased vitamin D levels, and the role of vitamin D in reducing the risk of Epstein-Barr virus (EBV). EBV is an

environmental risk factor that is strongly related to MS since EBV seropositivity¹ is linked to a significant risk of developing MS (Fernández-Menéndez et al., 2016).

Figure 4 MS prevalence by latitude and major ethnic groups in New Zealand



Source: Taylor et al. (2010)

¹ Seropositivity is the presence of antibodies or other immune markers in serum, that indicate prior exposure to a particular organism or antigen.

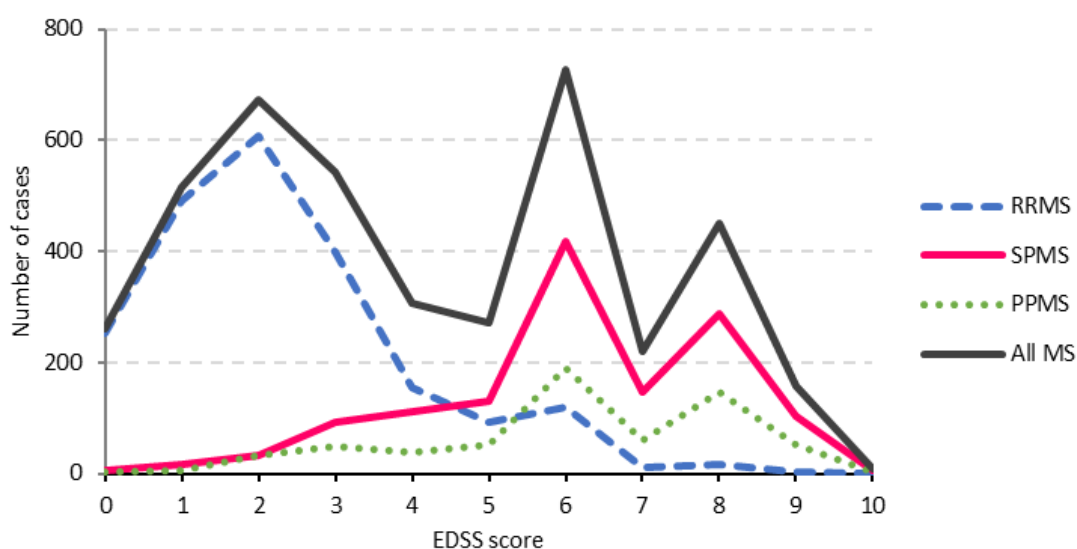
5 The health quality burden of MS

Health impacts of MS

The change in the quality of health associated with the severity of MS was modelled using the Expanded Disability Status Scale (EDSS). The EDSS is a method of quantifying impairment in multiple sclerosis and monitoring changes in the level of impairment over time. It is widely used in clinical trials and in the assessment of people with MS. EDSS steps 1.0 to 4.5 refer to people with MS who can walk without any aid and is based on measures of impairment in functional systems. EDSS steps 5.0 to 9.5 are defined by walking impairment. The scale is sometimes criticised for its reliance on walking as the main measure of disability (Multiple Sclerosis Trust UK (2020)). The EDSS is widely used in peer-reviewed journals, and thus it assists with comparing findings in different studies and populations.

NZIER estimated the number of people with MS by EDSS score by updating the estimates of Frampton and relevant population statistics, including age group and gender. Figure 5 shows the prevalence and distribution of MS cases in New Zealand by EDSS score.

Figure 5 Prevalence of MS by EDSS score

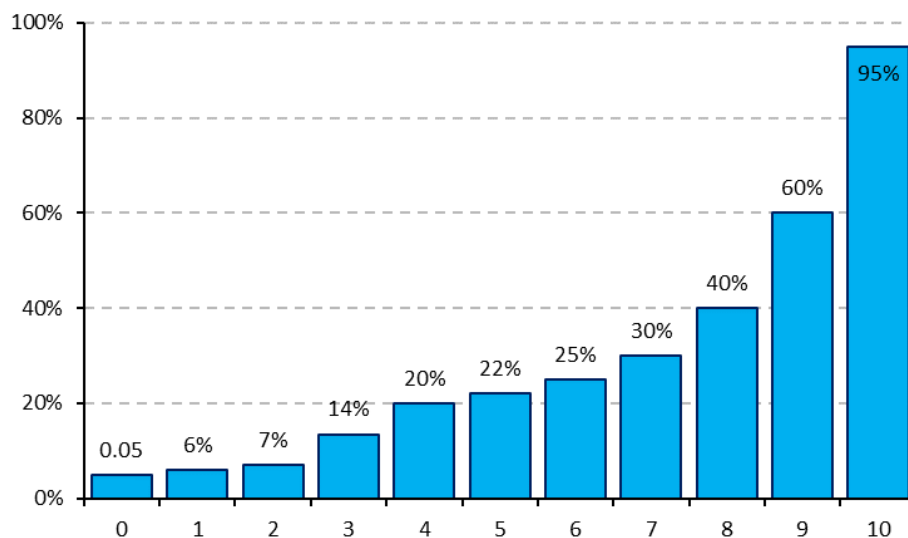


Source: NZIER

The quality of health lost at each EDSS was based on estimates from Casado et al. (2007) and Kobelt (2006). Figure 6 shows the percentage of health quality lost for each EDSS level. The health quality loss at each EDSS was then applied to NZIER's estimates of the number of cases in each EDSS score level. Lost health quality was measured using Quality-adjusted life years (QALYs), which is consistent with international best practices (PHARMAC 2015; Broadman et al. 2011; Casado et al. 2007). The core concept of a QALY is that individuals move through health states over time and that each health state has a value attached to it. Health states are valued on a scale between 0 and 1. Being dead has a value of 0 because the absence of life is considered to be worth 0 QALYs perfect health has the value of 1 (Weinstein, Torrance, and McGuire 2009).



Figure 6 Quality of life loss by EDSS score with MS



Source: NZIER based on Casado et al. (2007) and Kobelt (2006)

A perfect QALY was valued at \$32,260 based on the recommended value in the CBAX impacts database publish by Treasury NZ. The purpose of the impacts database is to provide guidance, consistency and comparability in policy analysis and business case development. Using the recommended provides comparability with other assessments. The estimated total cost of lost QALYs associated with the prevalence of MS is \$26.3 million in 2021. Table 2 shows the estimated value of QALY lost by EDSS with MS in terms of the individual and population cost.

Table 2 Health quality loss with MS

EDSS	QALY-loss	Value of QALY loss per person	Cases	Total value of QALY lost in NZ
0	5%	\$1,613	260	\$419,380
1	6%	\$1,936	514	\$995,548
2	7%	\$2,258	673	\$1,518,965
3	14%	\$4,355	543	\$2,364,042
4	20%	\$6,452	307	\$1,980,331
5	22%	\$7,097	272	\$1,933,162
6	25%	\$8,065	727	\$5,863,194
7	30%	\$9,678	219	\$2,116,920
8	40%	\$12,904	449	\$5,798,898
9	60%	\$19,356	157	\$3,046,468
10	95%	\$30,647	8	\$248,689
Total value of QALY loss				\$26,285,597

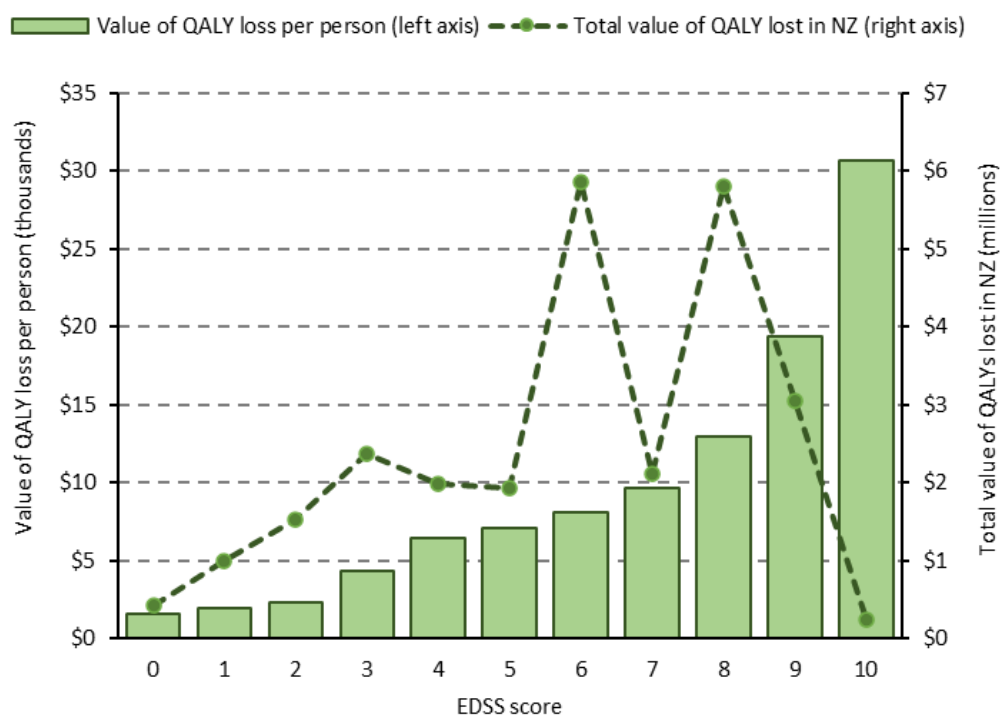
Source: NZIER



The values are estimated based on the prevalence and QALYs lost at each of the eleven EDSS scores. The individual-level cost of QALYs lost increases as the disease state becomes more severe and the associated EDSS score increases. At the population level, the distribution of MS cases in each EDSS score is not uniform.

The five-fold increase in the collective cost of the QALYs lost at EDSS score level six is the combination of a larger number of cases and a much higher health quality loss compared to lower scoring EDSS levels.

Figure 7 The cost of individual and collective health quality loss



Source: NZIER

Mortality with MS

In 2019, 27 females and 9 males died with MS. The number of deaths related to MS is increasing. Figure 8 shows the number and trend of lives lost with MS from 1990 to 2019 by sex. In 2019, 36 people died with MS compared to 16 people in 1990. This is an increase of 71.6% in 29 years. The value of 36 deaths with MS is \$164.1 million based on the value of a statistical life in the CBAX database (\$4.56 million per life lost).

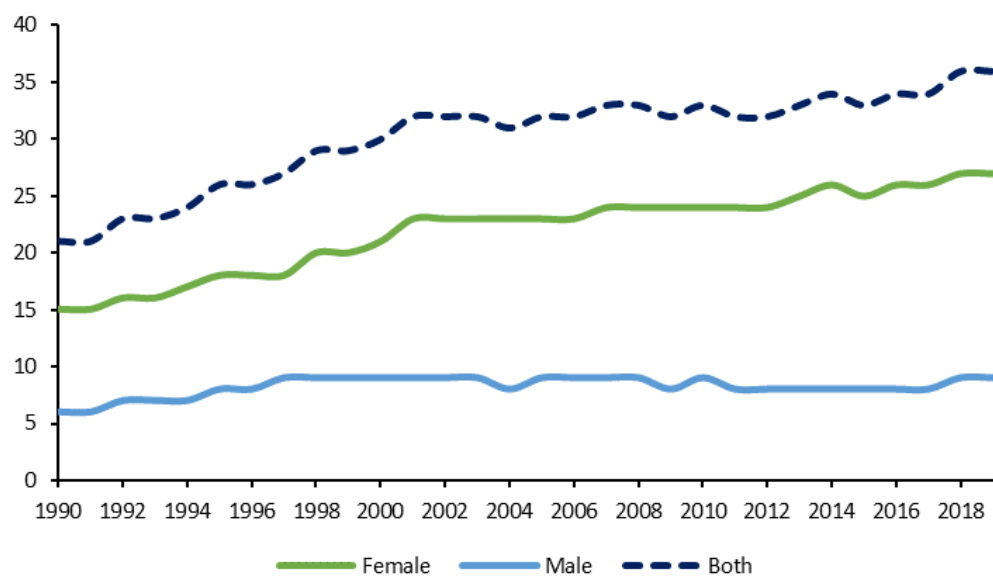
Overall health impact associated with MS

In 2021, the combined cost of the health impact of MS was \$190.4 million.



Figure 8 MS deaths in New Zealand

Deaths with MS



Source: Global Burden of Disease Collaborative Network (2020b)



6 Health care system costs

The literature on health system costs associated with MS varies from country to country. The variation is due to different levels of service in the health systems in different countries. The cost and availability of disease-modifying therapies is also a source of uncertainty, as pharmaceutical prices are rarely published.

In Ireland, the average health system cost per case of MS was estimated to be \$27,611 in 2015 (MS Ireland 2016). Access Economics (2005) estimated an average cost per case of AU \$7,279 in Australia, which is NZD \$10,121, in 2021 dollars. A study of 16 EU countries estimated the average health system cost of MS cases was \$28,816 (NZD 2021).

Table 3 shows the estimated health system costs per case of MS by EDSS score in 2020 dollars. The health system costs increase exponentially with an increase in EDSS scores. The healthcare system costs for MS were published by Pharmac in their Technology Assessment Report No. 229 on the economic analysis on natalizumab for relapse remitting MS (Pharmac 2014). These costs were adjusted for inflation based on the Consumers Price Index to reflect the 2021 costs. They were also aggregated to match the severity groups used in this analysis.

Table 3 The estimated health system costs per case by severity

2021 \$

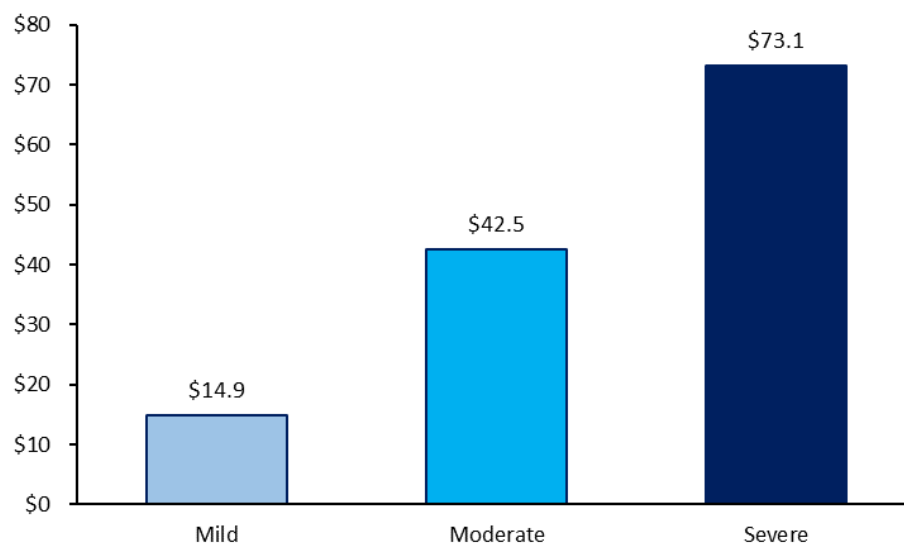
Severity of MS	Health system cost per person
Mild	\$7,485
Moderate	\$32,580
Severe	\$87,640

Source: NZIER

Figure 9 shows the estimated total annual health system costs of MS by EDSS score. The health system cost for mild, moderate and severe cases of MS was estimated to be \$14.9 million, \$42.5 million and \$73.1 million, respectively. In 2021, the total health system cost of MS was \$130.5 million. This represents an average cost of \$31,607 per case of MS per year, which puts the estimated cost per case just above the estimates in Ireland and Kobelt et al.



Figure 9 Estimated total annual health system costs of MS by severity



Source: NZIER



7 Economic burden of MS

The effect of MS on employment and economic outcomes

MS has a profound negative effect on the likelihood of employment which can have economic and social consequences for households and the economy.

MS is a disease of middle age with the onset of symptoms occurring in people aged 25 to 50 years old. These are peak earning years for New Zealanders. It is a time in people's lives when they have made consequential financial decisions such as home loans, children and retirement saving plans. These decisions are invariably informed by the continuation of employment and the financial pay-offs associated with career progression.

The financial consequences of lost employment and lost potential to earn due to the onset of MS are likely to be significant. For example, lost potential earnings could force decisions about re-financing household debt, downsizing the home and substantial reductions in consumption. All these could cause decreased wellbeing on top of losses in health quality and self-esteem.

The presence of severe depression or anxiety disorders was associated with a significant reduction in earnings in the previous 12 months among South African adults (Lund et al., 2013). A Norwegian study found that the prevalence of symptoms of depression and anxiety is two to three times higher for those with MS than in the general population (Beiske et al., 2008).

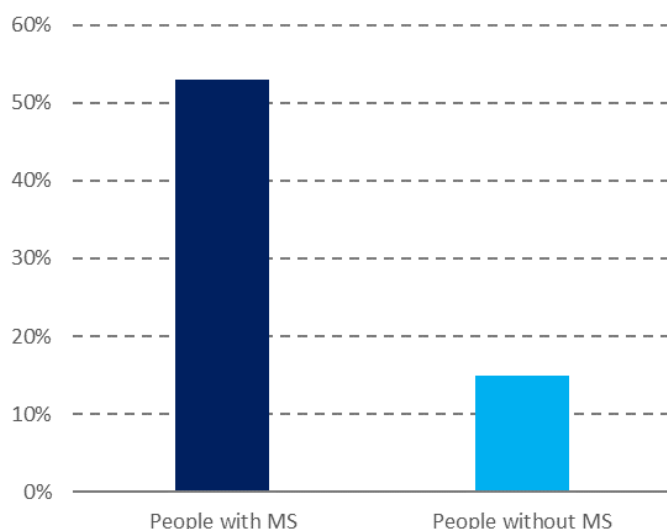
People with MS are less likely to be employed compared to the average New Zealander, despite 95% of people with MS having employment histories. MS is a common cause of a change in employment status for people with the disease. In the NZMSPS, 69% of those in the working-age group reported they had become unemployed as a consequence of the effects of MS on functional ability (Pearson et al., 2017).

The disease has considerable consequences on the likelihood of being employed when education qualification is controlled for. Figure 10 compares the employment status of people with and without MS who had achieved a post-secondary school qualification. Fifty-three percent of people with MS were not working compared with 15% of people without MS (Pearson et al., 2017).



Figure 10 Unemployment among those with a post-secondary school qualification

Percentage not working

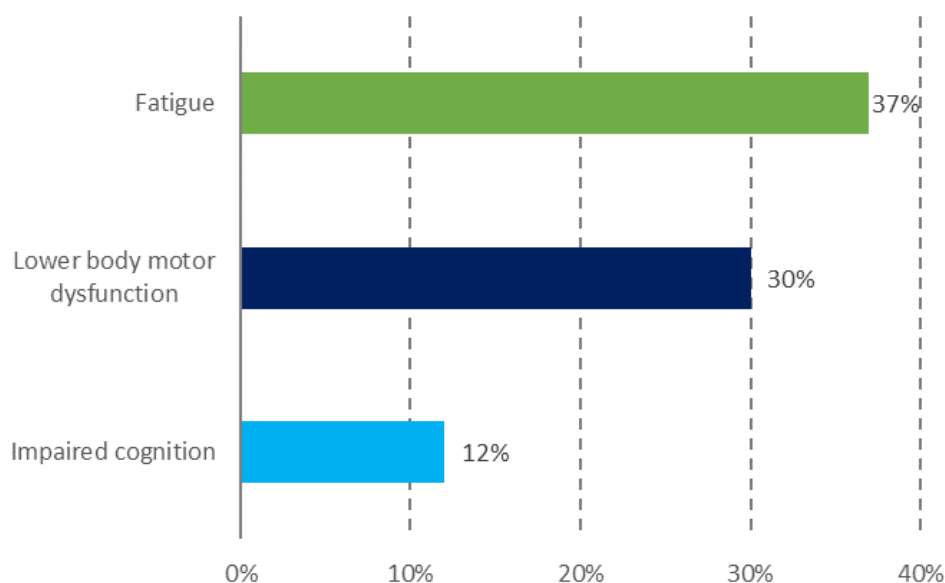


Source: Pearson et al. (2017)

Figure 11 shows the self-reported reasons for a change in employment status due to MS as reported in the NZMSPS. Fatigue was the most common reason people with MS reported a disease-related change in their employment status, followed by lower body motor dysfunction. Fewer respondents reported impaired cognition than fatigue or motor function. This suggests the people in knowledge-driven employment may be more able to manage employment with MS than those in labour driven employment if they are supported to stay employed by their employer and the government.

Figure 11 Self-reported reasons for a change in employment status due to MS

Self-reported reason for a change in employment status



Source: Pearson et al. (2017)

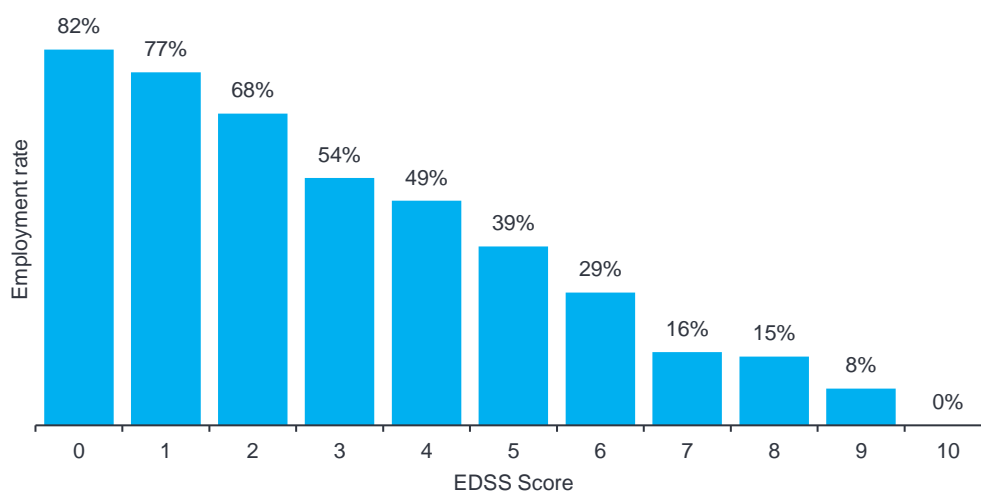


Estimating the cost of decreased employment among people with MS

The approach for estimating the cost of decreased employment among people with MS was based on the methodology and findings of Kobelt (2006), Kobelt et al. (2017) and Castelo-Branco et al. (2019). The approach is consistent with investigating employment effects in many other burden of illness studies such as Access Economics (2005) and MS Ireland (2016).

The first step in assessing the employment cost is estimating the level of employment with MS compared to the counterfactual of the level of employment that would have been for the cases without MS. Figure 12 shows the employment rate among people with MS by EDSS score based on (Kobelt 2006). The loss of employment increases as the EDSS score increases. The severity of MS is negatively associated with employment. Delaying the progression of MS is likely to have material effects on employment, earnings and the associated standard of living.

Figure 12 Employment rate among people with MS

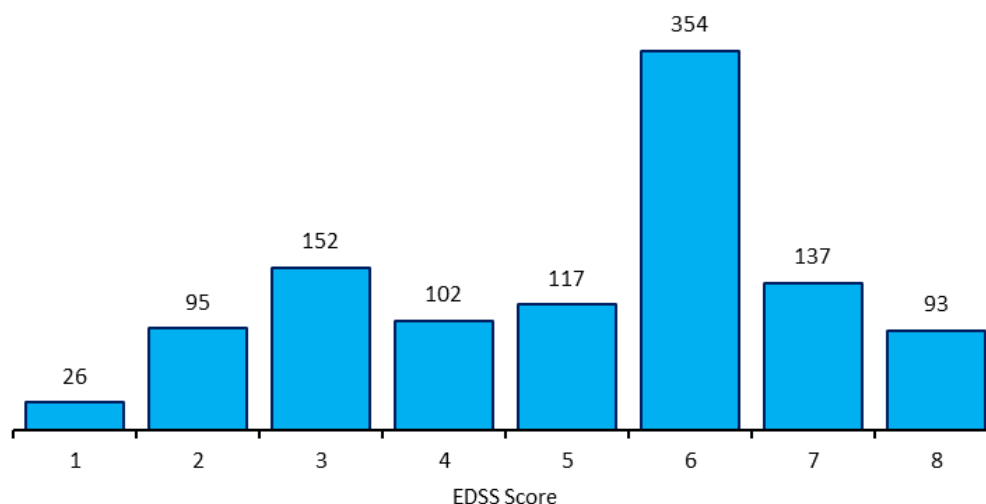


Source: Kobelt (2006)

The loss of employment lifted the employment rate in EDSS score levels 1-10 to the employment at the earliest stage of the disease represented by EDSS score level 0, which has an employment rate of 82%. Figure 13 shows the number of people who were estimated to have lost their employment with MS. Estimating the number of people who lost their employment by EDSS score required splitting the total cases by the working-age population and the rest. There was limited information on EDSS score by age, but it indicated that the EDSS score is positively correlated with age. The number of cases aged 65 years and over was estimated, then those cases were filtered from the cohort to approximate a working-age MS population. The working-age population was estimated to include 3,582 cases representing 87% of the MS population.



Figure 13 Loss of employment among people with MS



Source: NZIER

MS is more prevalent in the higher-skilled workforce. The educational achievement of people with MS is higher than the general population. The MS population had higher rates of post-secondary school qualification (54%) compared to the general population (42%) at the time of the NZMSPS (Pearson et al., 2017).

Estimating the average earnings for people with MS

The average earnings of a person with MS were estimated by weighting the New Zealand earnings by the proportion of people with MS by the higher than average qualification level and the associated earnings difference by gender. The average person with MS was estimated to earn \$76,170 after adjusting for the higher rate of tertiary qualification among people with MS. The level of labour force participation among people before MS was diagnosed was assumed to be 82%, which is consistent with the labour force participation rate among those with tertiary education in New Zealand.

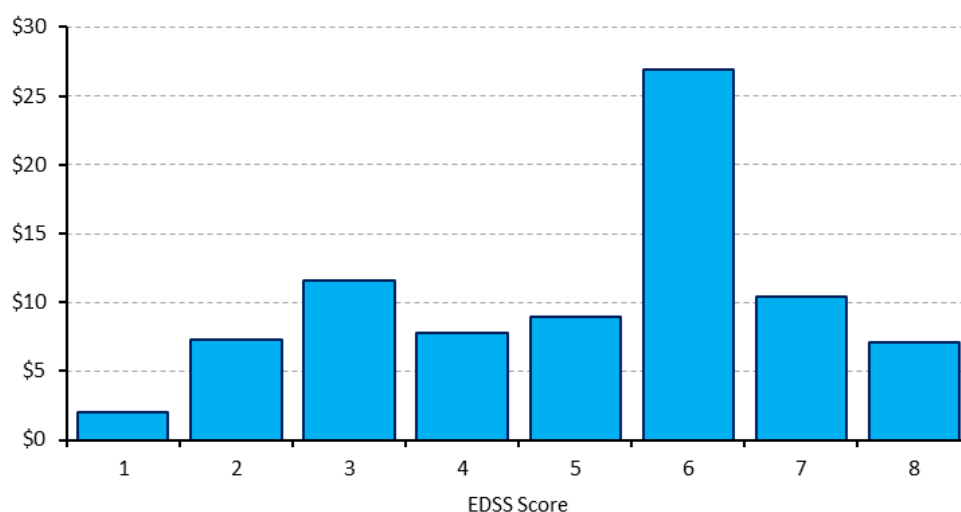
The total loss in earnings in New Zealand due to MS

For 2021, the aggregated loss in total earnings for New Zealanders due to MS was calculated by multiplying the cases per EDSS score by the average loss in earnings for each EDSS score cluster. Figure 14 shows the estimated loss in annual earnings by EDSS score in the population with MS due to an impairment-induced change in employment. The distribution reflects the number of MS cases by EDSS scores. In 2021 the total estimated loss in earnings due to MS-related employment loss was \$82 million.



Figure 14 Lost earnings by EDSS score per person with MS

Millions



Source: NZIER

Informal care costs

People with MS often require some form of informal care or support. This may require informal carers such as spouses to reduce their working hours and leisure time (Kobelt 2006; Kobelt et al. 2017). Informal care increases as the disease become more severe when people with MS lose more functionality and independence.

The estimation of the monthly cost in hours contributed to informal care was based on the estimates of Kobelt et al. (2017) for the UK. The number of hours contributed by informal carer per month increased from 20 for a mild case to 150 hours for a severe case. On an annual basis, that is equivalent to between 240 hours and 1,800 hours of informal care, which is a substantial contribution from informal carers. In New Zealand, the total contribution of informal care was estimated to be about three million hours per year.

Table 4 Informal care costs by MS severity

2021 \$

MS Severity	Monthly informal care hours	Annual informal care hours	Annual cost per case	Annual cost (m)
Mild	20	240	\$6,662	\$13.26
Moderate	70	840	\$23,318	\$8.70
Severe	150	1800	\$49,968	\$5.56
				\$27.52

Source: NZIER based on Gisela Kobelt et al. (2017)



Table 4 shows the number of informal carer hours per case, the number of cases in New Zealand and the estimated cost of informal care on a case and MS severity level. The total cost of informal care contribution was estimated to be \$27.5 million for 2021.

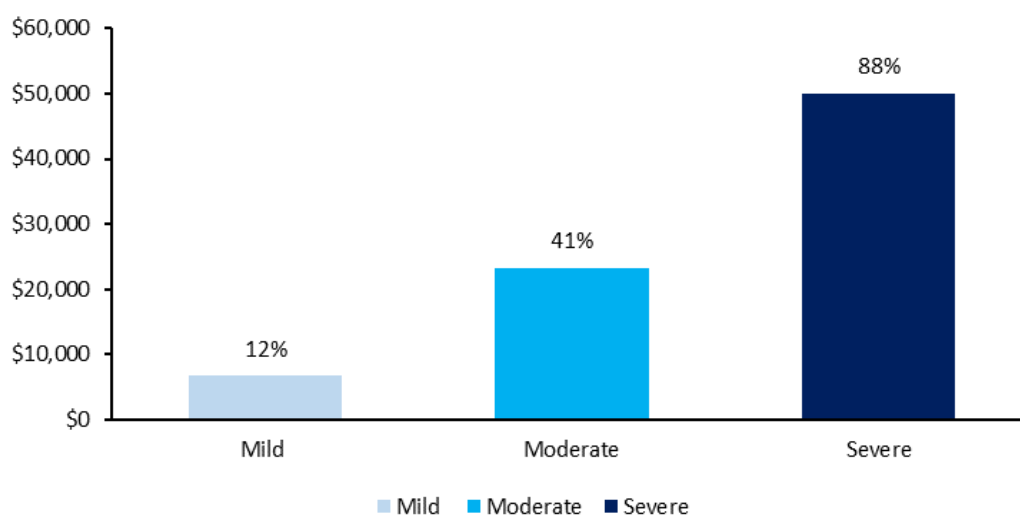
Following Kobelt et al., the value of an hour was assumed to be the median hourly earnings from wages and salaries, which was \$27.76 in New Zealand (Statistics NZ 2021). The annual cost of informal care per case of MS was estimated to be:

- \$6,662 for a mild case of impairment,
- \$23,318 for a moderate case of impairment
- \$49,968 for a severe case of impairment.

Figure 15 shows those costs of informal care by the severity of MS compared to median annual earnings. The informal care cost increased from 12% of median earnings to 88% of annual earnings. The informal care for a person with severe MS contributes a large proportion of the median earnings. Informal care contributions are likely to affect the ability of carers to work full-time at some stage during the disease progression. The impact of informal care on employment, hours worked, and income was not examined due to data limitations.

Figure 15 Cost of informal care per MS case by EDSS score

Costs of informal care contribution per MS case. The percentage is the proportion of the median income in 2021.



Source: NZIER



8 Bringing it all together

Table 5 shows the total social cost associated with the prevalence of MS. The total cost of MS was estimated to be \$266.3 million in 2021. The average social cost of a MS case was estimated to be \$64,484 annually. This estimate is consistent with the average annual cost of a case in the EU, estimated to be \$63,635 (Kobelt et al. 2017) in 2021 dollars.

Table 5 the total social cost associated with the prevalence of MS
2021 \$

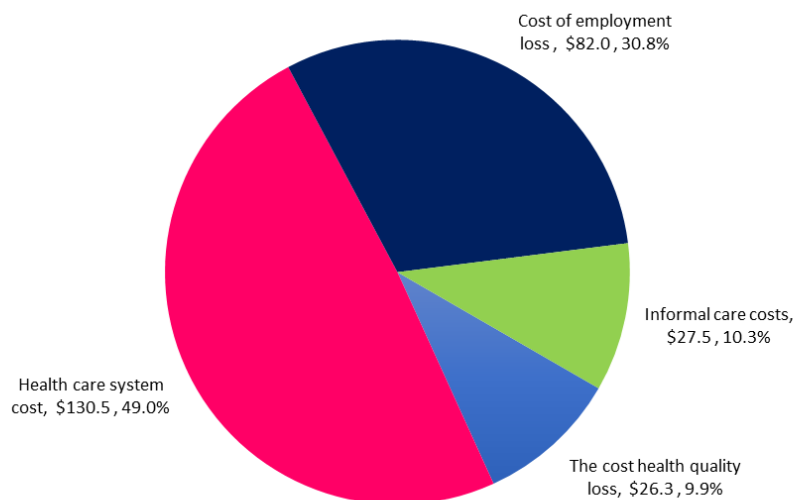
Cost component	Total annual cost in NZ (2021 \$m)
The cost health quality loss	\$26.3
Health care system cost	\$130.5
Cost of employment loss	\$82.0
Informal care costs	\$27.5
Total social cost of MS	\$266.3

Source: NZIER

The health system cost was the largest source of social costs associated with MS (49.0%). Then the cost of employment loss contributes 30.8% of the social cost of MS. The informal care costs contribute 10.3 % of the overall cost of MS. The smallest contributing cost was the cost of health quality loss (9.9%).

Figure 16 The components of the cost of MS

Millions



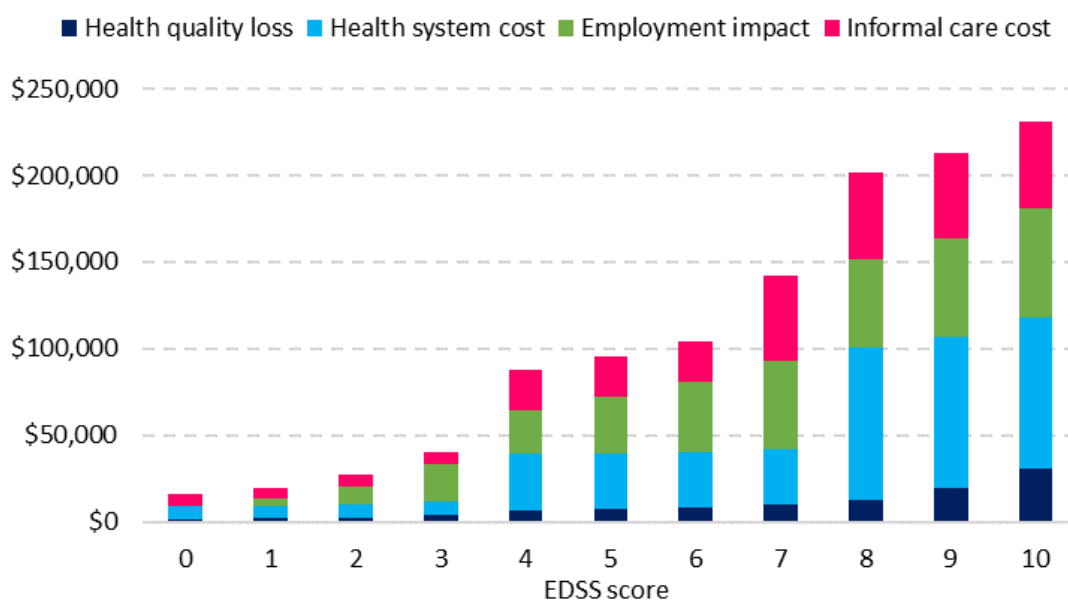
Source: NZIER



The combination of informal care and the cost of employment loss contributes 41.1% of the total cost, four times the cost of health quality loss. It is also the equivalent of 69.8% of the combined cost of health quality loss and health care system costs, which are the main costs considered in a pharma-economical assessment for funding new treatments. Ignoring the employment loss and informal costs could exclude benefits that would offset the cost of emerging treatments.

Figure 17 shows the annual average social cost of MS by EDSS score. It shows that the social costs increase as the disease progresses. Slowing the progression of the MS will generate private and social costs savings beyond avoided pain and suffering. Delaying the disease will support people to be more independent, lessen the need for informal care and improve the probability of staying at work.

Figure 17 Per person economic burden of MS by EDSS score



Source: NZIER estimates

How much of this burden can be mitigated?

The understanding of MS is evolving. There is evidence that earlier intervention has a positive effect on outcomes. Studies show that the progression of the disease to the severe disability level can be delayed by between 6 to 10 years (He et al. 2020). The present value of such a delay in moving from EDSS level 6 to 8 could be between \$500,000 and \$1 million per case over the delay period.

8.1 Why do other costs matter?

Pharmac's current cost-effectiveness approach is good for ranking interventions in the context of budget constraints. But the approach does not consider some material social and economic benefit that might be realised when treatments cure or delay the progression of a disease.



Pharmac's approach to assessing the impact of a disease or treatment considers health system costs and the cost of lost health quality. In contrast, cost-benefit analysis would include the material economic costs of employment effects and lost earnings. If Pharmac included employment effects, its assessment would be a more fulsome assessment of the economic benefits that would be offset against the cost of treatments for MS.

NZIER (2020) found that access to medicines in New Zealand is falling behind OECD countries due to a combination of reasons, including:

- Medicines funding not keeping pace with health spending
- Social costs and benefits being systematically undercounted in funding decisions
- The emergence of effective new medicines that are not accommodated by current funding appraisal processes.
- The speed of access to new medicines can be slower in New Zealand.

So while cost-effectiveness analysis helps rank interventions, it is blind to the full extent of the benefits. Social cost-benefit analysis is insightful for understanding total costs and total benefits for better decision making. Ranking interventions is only part of the story. Using social cost-benefit analysis could be helpful for decision-makers to understand the extent of the benefits and costs that could be realised if the budget was available. Therefore, a more fulsome analysis of the benefits and costs of health interventions would assist in providing insights into how budgets could affect outcomes for people and society.

What needs to be considered to make progress

Making progress in the assessment of the social cost and benefits of health interventions for MS and other conditions would require the following changes:

- Greater use of social-benefit analysis in pharmacoeconomic analyses would provide greater insight into the benefits of emerging treatments for MS.
- Adding cost-benefit analysis to the suite of tools would support more fulsome decisions about setting budgets to deliver better health and wellbeing outcomes for New Zealanders.
- Commissioning research into the social benefits and costs would support greater transparency.



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