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An Interim Update of Prevalence, Costs and Cost of Illness from 2017 to 2021

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Health Economic Impact of Multiple Sclerosis in Australia in 2021:

RESEARCH

ADVOCACY

CURE

An Interim Update of Prevalence, Costs and Cost of Illness from 2017 to 2021

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We thank those people with MS who participated in the Australian MS Longitudinal Study (AMSLS) surveys that informed this Interim Report and the dedicated AMSLS team at the Menzies Institute for Medical Research. The AMSLS is one of MS Australia's collaborative research platforms.

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Abbreviations

Abbreviation	Meaning
ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
CPI	Consumer Price Index
DMT	Disease Modifying Therapy
GFCE	Government Financial Consumption Expenditure
PBS	Pharmaceutical Benefits Scheme
RPBS	Repatriation Pharmaceutical Benefits Scheme

1.0 Executive Summary

Rationale for this Interim Report

Following our comprehensive report titled *Health Economic Impact of Multiple Sclerosis in Australia in 2017* commissioned by MS Research Australia and published in 2018 (1), this Interim Report was requested by MS Australia to provide an update on the prevalence of MS in Australia, the per person costs and the total cost of illness for people living with MS in Australia in 2021.

It is envisaged that this brief Interim Report will precede a comprehensive report in future years, particularly given the escalation of prevalence noted in this report, and the current inflationary economic climate in 2022.

Prevalence of people living with MS in Australia in 2021

There were 33,335 people living with MS in Australia in 2021.

This is an increase of 7,728 people (from 25,607 people) in four years from 2017. Notably, this increase is accelerating (more than doubled) from our previous estimate from 2010 to 2017 where there was an increase of 4,324 people.

Taking the 2021 Australian Census population estimates into account (and noting slowed population growth from the previous reporting period due to COVID-19 and the halt in overseas migration to Australia), there were 131.12 people living with MS per 100,000 people in Australia in 2021. This is an increase from 103.7 per 100,000 people in 2017 and aligns with the increase in prevalence in local areas of Australia and globally.

Costs for people living with MS in Australia in 2021

Annual per person costs in Australia in 2021 were \$73,457 an increase of \$5,075 from 2017.

Annual per person costs increased with increasing disability levels from \$32,829 for people with MS with no disability to \$123,333 for people with severe disability.

Cost of illness of MS in Australia in 2021

Total costs for all people with MS in Australia have increased from \$1.751 billion in 2017 to \$2.449 billion in 2021. This increase reflects both the increasing number of people with MS in Australia and the change in consumer price index (CPI) from 2017 to 2021.

2.1 Introduction

Multiple sclerosis (MS) is an inflammatory and neurodegenerative disease of the central nervous system (brain, optic nerves, and spinal cord) leading to increasing disability over time and reduced health-related quality of life (2). The *Atlas of MS* estimated that from 2013 to 2020, the global prevalence of MS increased by 500,000 to 2.8 million people (3). From a local perspective, a study of Greater Hobart in Tasmania (Australia's southernmost state with the highest MS prevalence) estimated a crude prevalence of 197.1 per 100,000 people (4).

MS generally presents in younger people between the ages of 20 and 40, an age at which many people are starting families and building careers (1). The inflammatory demyelination of the brain and spinal cord causes lesions that manifest in a diverse array of symptoms including visual problems, sensory disturbances, cognitive problems, sexual dysfunction, motor dysfunction and weakness, bowel or bladder continence issues, fatigue, anxiety, sleep disturbance and depression (2). Symptoms can appear individually or in concert and can result in marked declines in both physical and psychosocial health-related quality of life (2, 5).

2.2 Methods

The medications prevalence methodology adopted for this Interim Report reflects the validated medications method employed in our 2010 and 2017 prevalence estimates (6, 7). This enables direct comparisons between these previous estimates.

2.2.1 Information Sources

In line with our 2017 findings, the disease modifying therapy (DMT) revolution continues in Australia. Both the mode of delivery (oral medications replacing infused medications; decreased prescribing yet with the same or improved efficacy) and the number of available medications is changing.

Australia's Pharmaceutical Benefits Scheme (PBS) and Repatriation PBS (RPBS) for eligible veterans and their families remain important components of Australia's universal healthcare system for access by Australian citizens and residents.

Since 2017, the number of DMTs listed on the PBS for MS has increased to 14 types of DMTs. However, modes of delivery have changed and one DMT was removed from the PBS. More specifically, daclizumab (Zinbryta) was removed from the PBS, and cladribine (oral), ofatumumab (subcutaneous injection), ocrelizumab (IV), ozanimod (oral), and siponimod (oral) (all generic names) have joined the PBS list of approved medications.

Therefore, the 14 types of DMTs that could be prescribed and were subsidised in Australia from 1 January 2021 to 31 December 2021 included alemtuzumab (Lemtrada), cladribine (Mavenclad), dimethyl fumarate (Tecfidera), fingolimod (Gilenya), glatiramer acetate (Copaxone), interferon β -1A (Rebif 44 and Avonex), interferon β -1B (Betaferon), natalizumab (Tysabri), ocrelizumab (Ocrevus), ofatumumab (Kesimpta), ozanimod (Zeposia), pegylated β -1A (Plegridy), teriflunomide (Aubagio), and siponimod (Mayzent). Unique identifiers for each DMT and each medication's therapeutic mode of delivery were extracted from the Australian Government's PBS website (8). Using these medication identifiers, the number of PBS prescriptions from 1 January 2021 to 31 December 2021 were then extracted from the Australian Government's Medicare Australia website (9).

To follow the same methodology as our 2017 study, we assumed that if a person with MS filled a prescription in 2021, they were counted as a case for that year. The division of prescriptions (to ascertain a prevalent case) is described in section 2.2.3.

Population estimates for the overall Australian population and for each Australian state and territory were sourced from the Australian Bureau of Statistics' (ABS) most recent and accurate estimates for 2021, namely the 2021 ABS Census data (10).

DMT penetrance data for 2021 was sourced from the Australian MS Longitudinal Study (AMSLS) that was established in 2001. The AMSLS includes a sample of over 2,600 Australians living with MS that has been shown to be representative of Australian people with MS (11). The DMT usage question (yes/no) was included in the AMSLS Medications and Disease Course Survey where participants were surveyed in October-December 2021.

2.2.2 Sociodemographic characteristics and DMT penetrance

The age, sex and DMT penetrance of people with MS were calculated for Australia overall and for each Australian state and territory (where sufficient data were available) from the DMT usage question (yes/no) on the AMSLS Medications and Disease Course Survey. For consistency, we followed the method of 2017, where we calculated penetrance as a proportion of people who responded yes/no to the question regarding DMTs.

2.2.3 Calculation of crude prevalence using the PBS DMT prescription data

To estimate the crude prevalence, the annual number of PBS and RPBS prescriptions dispensed for most DMTs was divided by 12 to reflect the monthly script for one person living with MS. For cladribine and ocrelizumab, the annual number of PBS and RPBS prescriptions dispensed were divided by two to reflect the two scripts per year per person living with MS (note that cladribine is two scripts per year for two years only). To avoid double counting people in 2021 who were treated with cladribine or ocrelizumab but did not receive a prescription (technically still on treatment) we expected that the DMT penetrance would capture this. Finally, in line with our methods of the 2017 study, we did not divide alemtuzumab by two. The number of prescriptions was small (less than 100 prescriptions) and we maintained the methodological consistency with our previous study.

2.3 Results

2.3.1 DMTs

Table 1 shows the PBS and RPBS prescriptions dispensed for each Australian state and territory in 2021. We found that 174,464 prescriptions for DMTs were dispensed with 33 modes of therapeutic delivery (as noted with the individual PBS identifiers) in 2021. Notably this is a reduction in 13,779 prescriptions due to the reduction in the requirement for monthly prescriptions for some therapies. However, the modes of therapeutic delivery increased from 22 to 33 as noted by separate PBS identifiers.

The overall penetrance of DMTs in Australia has reduced slightly from 64% in 2017 to 62% in 2021. **Figure 1** shows the state breakdowns of DMT penetrance. Compared to 2017, DMT penetrance increased in South Australia, decreased in Tasmania, Western Australia, and Queensland, while Victoria and New South Wales remained about the same. There was insufficient data for Australia's two territories in 2021 to accurately estimate DMT penetrance. This is in line with our 2017 study where we used an average of the state DMT penetrance estimates to calculate DMT penetrance for the Northern Territory and Australian Capital Territory.

The age and sex profiles of people living with MS who used a DMT for each state are: New South Wales and Victoria 82% female, mean age 57 years; Queensland 85% female, mean age 57 years; South Australia 83% female, mean age 56 years; Western Australia 72% female, mean age 57 years; Tasmania 80% female, mean age 60 years.

2.3.2 Crude Prevalence

Our prescription method estimated that the number of people living with MS in Australia was 33,335 (plausible range: 30,394 – 39,746) based on an Australian population in 2021 of 25,422,788 people estimated from the Census 2021 data and a DMT penetrance of 62%. This is an increase of 30% from our 2017 estimates and is in line with the increase in prevalence estimates both locally and globally (3, 4).

The crude prevalence of MS in Australia was 131.12 per 100,000 people in 2021, compared to 103.7 per 100,000 people in 2017. This reflects the increase in unadjusted prevalence, which is also accelerating, locally and globally (3, 4). A detailed discussion in section 4.2 supported by **Figure 4** reveals the acceleration in prevalence from 2010 to 2017 and 2017 to 2021.

Based on the Australian state DMT penetrance range of 52-68%, the crude prevalence (33,335 people living with MS in Australia 2021) plausible range was also calculated. The plausible range was 30,394 to 39,746 people living with MS in Australia.

Table 1: The number of Australian PBS and RPBS DMT prescriptions exclusively prescribed to people with MS in Australian states and territories: January 2021 to December 2021 inclusive.

		Australian states and territories							
PBS Code	Generic name (trade name)	New South Wales	Victoria	Queensland	South Australia	Western Australia	Tasmania	Australian Capital Territory	Northern Territory
9505G	Natalizumab (Tysabri)	7289	10187	3348	2618	1808	963	411	46
9624M	Natalizumab (Tysabri)	1824	1059	1441	138	2436	77		
10228H	Alemtuzumab (Lemtrada)	4		24	2		5	3	
10232M	Alemtuzumab (Lemtrada)	10	2	25	1		3	2	
10243D	Alemtuzumab (Lemtrada)	3		11					
10246G	Alemtuzumab (Lemtrada)	3		17	2				
2966D	Dimethyl Fumarate (Tecfidera)	9205	5859	3276	1541	1669	572	563	32
2896K	Dimethyl Fumarate (Tecfidera)	183	125	47	7	11	5	7	
2943X	Dimethyl Fumarate (Tecfidera)	139	64	30	3	19	1	6	
5262Y	Fingolimod (Gilenya)	12744	18661	7345	5279	3171	678	1152	181
111818B	Fingolimod (Gilenya)	78	56	35	8	8	9		
2898M	Teriflunomide (Aubagio)	4712	6589	3101	1087	1244	631	275	16
10218T	Peginterferon (Plegridy)	22	8	4	5	4		5	
10212L	Peginterferon (Plegridy)	254	288	147	25	69	41	27	9
10220X	Peginterferon (Plegridy)	1534	1257	827	274	472	248	134	28
9332E	Interferon beta-1A (Rebif 44)	388	226	261	116	64	25	35	
8403G	Interferon beta-1A (Rebif 44)	496	512	194	139	161	20	23	
8968B	Interferon beta-1A (Rebif 44)	84	109	43	1	64	8		
8805K	Interferon beta-1A (Avonex)	992	1178	363	673	246	78	74	14
8101J	Interferon beta-1B (Betaferon)	1040	1069	719	348	413	222	33	16
10416F	Glatiramer Acetate (Copaxone)	4100	3780	2701	998	905	357	568	10
12641H	Ofatumumab (Kesimpta)	857	43	19	1	25	3	7	
12642J	Ofatumumab (Kesimpta)	74	31	19	1	8	1	2	
11611D	Cladribine (Mavenclad)	503	537	106	126	137	59	23	12
11604R	Cladribine (Mavenclad)	458	377	163	120	105	59	22	6
11603Q	Cladribine (Mavenclad)	346	356	70	96	40	49	14	6
11237K	Ocrelizumab (Ocrevus)	830	578	554	153	755	8	4	
11242Q	Ocrelizumab (Ocrevus)	1822	2847	832	880	687	371	305	27
12172P	Siponimod (Mayzent)	122	198	70	37	13	13	12	1
12160B	Siponimod (Mayzent)	275	220	88	67	11	3	28	
12158X	Siponimod (Mayzent)	1088	1464	486	271	183	74	99	1
12271W	Ozanimod (Zeposia)	101	148	25	14			29	
12278F	Ozanimod (Zeposia)	19	24	4	3			5	
	STOTAL	51599	57852	26395	15034	14728	4583	3868	405
	TOTAL								174,464

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



Figure 1: DMT penetrance (%) for Australian states in 2017 and 2021*.

Notes: *insufficient data available for Northern Territory and Australian Capital Territory.

3.0 Costs and Cost of Illness of Multiple Sclerosis in Australia in 2021

3.1 Introduction

Our Health Economic Impact of Multiple Sclerosis in Australia in 2017 showed that the total costs for all people with MS in Australia increased substantially from \$1.24 billion in 2010 to \$1.75 billion in 2017 (1). This 2017 report also established that the annual total costs of MS per person (direct and indirect costs) increased by 17% from \$58,652 in 2010 to \$68,382 in 2017, driven largely by increased costs of DMTs and offset by decreased costs of lost wages and decreased informal care costs (1).

In 2017, the largest component was the direct costs (44%, \$30,346). Twenty two percent of the direct per person costs (\$8,437) was born 'out of pocket' by people with MS themselves, while the government and community jointly incurred 78% of the direct per person costs (\$21,911). The second largest component was the indirect costs from lost wages (32%, \$21,858). Annual per person costs in 2017 for people living with MS with no disability to severe disability increased by 276% from \$30,561 (no disability) to \$114,813 (severe disability). The direct costs were the largest total cost component for all disability classes.

The Australian Institute of Health and Welfare's (AIHW) Health Expenditure for Australia (2019–2020) (12) provides estimates for total health spending capturing the national aggregate of all spending on health goods and services for recurrent and capital purposes. Considering population size and growth, the AIHW report found that the average spending on health in the general population in 2019–20 was \$7,926 per person.

3.2 Methods

3.2.1 Choice of Inflator: Reserve Bank of Australia's Cost Inflator

Based on cost estimates from the *Health Economic Impact of Multiple Sclerosis in Australia in 2017* report that were mainly determined by the bottom-up costing methodology, as an interim measure for this report, we adopted a cost inflator to estimate the increase in MS-related costs from 2017 to 2021. The choice of inflator for this task was important (see sensitivity analysis in section 3.2.2). For the purpose of this Interim Report we used the Reserve Bank of Australia's Cost Inflator (13). This cost inflator calculates the change in cost of purchasing a representative 'basket of goods and services' over a period of time. For example, it may show that items costing \$10 in 1970 cost \$26.93 in 1980 and \$58.71 in 1990.

From the September quarter 1948 onwards, the 'Quarterly' calculator uses the CPI published by the ABS. From 1949 onwards, the 'Calendar Year' calculator adopted for this report uses an annual index, where the level of the annual index is the arithmetic average of the CPI in the four quarters of the calendar year. Similarly, the 'Financial Year' calculator uses an annual index, where the level of the annual index is the arithmetic average of the CPI in the four quarters of the annual index is the arithmetic average of the CPI in the level of the annual index are an annual index of the calendar year.

Notably, for the years 2017 to 2021 the Reserve Bank of Australia's Inflation Calculator inflates total change in cost by 7.4% over the four years at an average of 1.8%.

3.2.2 Sensitivity analysis

There is a wide variety of price indexes (inflators/deflators) for the Australian health sector, and these may be distinguished by the scope of the index or the technical manner in which the indexes are constructed. Our study's costs were adjusted for inflation using the Reserve Bank of Australia's Cost Inflator and these are conservative cost estimates because they reflect Australia's CPI (13). We used this inflator because we were considering a wide range of goods and services, as well as indirect costs due to lost productivity. If an alternative inflator/deflator was adopted such as the Total Health Price Index or the Government Final Consumption Expenditure (GFCE) for hospitals and nursing homes (12) that better reflect the increases of direct medical costs (but may overinflate indirect costs) we expect that our cost estimates would be higher.

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Therefore, we conducted a sensitivity analysis for the total cost component of this Interim Report using the GFCE for hospitals and nursing homes (14) - this deflator is a chain price index calculated at a detailed level, providing a close approximation to measures of pure price change. The AIHW's Health Expenditure Report 2019-20 reproduces the index (see Supplementary Table 1a (index) and 1b (changes in the index with the base year 2019-20). For the purposes of this study, we used the average change for this index of 2.7% over the four year period.

Notably, inflation has also accelerated in 2022 (see **Figure 2** sourced from the Reserve Bank of Australia <u>Australian Inflation | Chart Pack | RBA</u>) and we also expect a spike in these per person and societal costs moving forward from 2022.

3.3 Results

3.3.1 Total costs and costs of illness

Table 2 shows the costs of MS by cost category per person and for Australia inflated to 2021 Australian dollars. The total costs of MS for Australian society were \$2,448,689,000 (\$2.449 billion) in 2021. This increase from \$1,751,058,000 (\$1.751 billion) reflects the increased number of people with MS in Australia, as well as CPI increases for the four years. It is likely that this estimate from 2022 onwards will escalate due to the current climate of inflationary pressures.

Using the GFCE for hospitals and nursing homes index, our sensitivity analysis revealed that these costs increased by almost \$100 million in 2021 (\$98,838,000) to \$2,547,527,000 (\$2.548 billion).

3.3.2 Costs per person living with MS

Table 2 also shows that the total average costs per person living with MS are now approaching \$74,000 per year (\$73,457) up from \$68,382 in 2017. **Figure 3** shows the increase in costs for each disability severity category. People living with MS with severe disability have MS-related costs of \$123,333 per year, and this is substantially higher than people living with MS with no disability who also incurred large MS-related costs of \$32,829 in 2021.

3.3.3 Comparisons with other nations

Table 3 shows the inflated per person total mean costs, direct (medical and non-medical) costs and indirect costs of MS for Australia and 15 other nations in 2021 Australian dollars. The cost of illness per person with MS in Australia of \$73,457 is consistent with the range of reported estimates from other nations, and less than some European countries including Sweden, Switzerland, Germany and Austria.

3.3.4 Comparisons with other diseases in Australia

Other examples of complex and chronic diseases in Australia where comparisons can be made with our study population include Parkinson's disease with an average societal cost in 2012 Australian dollars of \$45,104 inflated to 2021 Australian dollars to \$53,318 and Type 2 diabetes with an average direct medical cost per person of \$5,209. Long-term cancer survivors in Australia also recorded mean annual costs of \$15,889 in 2016 dollars inflated to 2021 Australian dollars to \$17,401. Within this group of long-term cancer survivors, the highest costs were for myeloma (\$45,951 inflated to 2021 dollars of \$50,323), brain (\$30,264 inflated to 2021 dollars of \$33,143) or liver cancer (\$29,619 inflated to 2021 dollars to \$30,437) **(see section 4.5)**.

Table 2: Cost of MS by cost category per person and for Australia inflated to 2021 from 2017 dollars using the Reserve Bank of Australia's Inflation Calculator**.

Cost Category	Per Person Costs 2017*	Total (Million)*	al (Million)* Per Person Costs 2021**	
	Mean*	Mean*	Mean**	Mean***
Direct costs – personal	\$8,437	\$216	\$9,063	\$274,445,766
Direct costs – community / government	\$21,911	\$561	\$25,537	\$773,311,434
Direct costs – total	\$30,346	\$777 \$32,597		\$987,102,354
Nursing home and equivalent costs	\$6,343	\$6,343 \$162 \$6,8		\$206,311,266
Informal care costs	\$7,144	\$183	\$7,674	\$232,384,068
Indirect costs from lost wages – early retirement	\$13,468	\$345	\$14,467	\$438,089,694
Indirect costs from lost wages – employment status change	\$5,408	\$138	\$5,809	\$175,908,138
Indirect costs from lost wages – occupation change	\$2,982	\$76	\$3,203	\$96,993,246
Indirect costs from lost wages – overall	\$21,858	\$560	\$23,480	\$711,021,360
Indirect costs from lost pro- ductivity - absenteeism	\$482	\$12	\$518	\$15,686,076
Indirect costs from lost pro- ductivity - presenteeism	\$2,209	\$57	\$2,372	\$71,828,904
Indirect costs from lost pro- ductivity – overall	\$2,691	\$69	\$2,891	\$159,374,166
Total Costs	\$68,382	\$1,751	\$73,457*	\$2,448,689,000**

*2017 estimates for mean costs sourced from the Health Economic Impact of MS in Australia in 2017 report

**Using the Reserve Bank of Australia's Inflation Calculator

***Based on 2021 prevalence of MS in Australia of 33,335

Table 3: Costs per person with MS in Australia and other nations (2017 and inflated to 2021 Australian dollars).

		2017 Costs (AUD)		2021 Costs (AUD)					
Country	Direct Costs*	Indirect Costs	Total Costs	Direct Costs*	Indirect Costs	Total Costs			
Australia	\$43,833	\$24,549	\$68,382	\$47,086	\$26,371	\$73,457			
Austria ^a	\$52 <i>,</i> 505	\$20,562	\$73,067	\$56,401	\$22,088	\$78,489			
Belgium ^b	\$43,480	\$24,818	\$68,298	\$46,706	\$26,660	\$73,366			
Czech Republic ^c	\$9 <i>,</i> 798	\$8,566	\$18,364	\$10,525	\$9,202	\$19,726			
Denmark ^d	\$42,292	\$25,205	\$67,497	\$45,430	\$27,075	\$72,505			
France ^e	\$39,469	\$16,150	\$55,619	\$42,398	\$17,348	\$59,746			
Germany ^f	\$44,445	\$24,478	\$68,923	\$47,743	\$26,294	\$74,037			
Hungary ^g	\$16,022	\$8,595	\$24,617	\$17,210	\$9,233	\$26,443			
Italy ^h	\$44,495	\$14,939	\$59,434	\$47,796	\$16,048	\$63,844			
Poland ⁱ	\$14,584	\$8,647	\$23,231	\$15,666	\$9,289	\$24,955			
Portugal ^j	\$28,409	\$12,250	\$40,659	\$30,517	\$13,159	\$43,676			
Russia ^k	\$12,124	\$5,515	\$17,639	\$13,023	\$5,924	\$18,947			
Spain ¹	\$51,247	\$19,139	\$70,386	\$55,049	\$20,559	\$75,608			
Sweden ^m	\$60,577	\$22,148	\$82,725	\$65,072	\$23,792	\$88,864			
Switzerland ⁿ	\$60,107	\$31,977	\$92,084	\$64,567	\$34,349	\$98,916			
United Kingdom °	\$31,868	\$19,216	\$51,084	\$34,232	\$20,642	\$54,874			
Overall Average	\$37,203	\$17,922	\$55,125	\$39,964	\$19,252	\$59,216			

Notes: *includes direct medical and direct non-medical costs; a, Berger and Kobelt et al (2017)(15); b, Dubois and Kobelt et al 2017 (16); c, Havrdova and Kobelt et al 2017 (17); d, Rasmussen and Kobelt et al 2017 (18); e, Lebrun-Frenay andKobelt et al 2017(19), f, Flachenecker and Kobelt et al 2017 (20); g, Péntek and Kobelt et al 2017 (21); h, Battaglia and Kobelt et al 2017 (22); i, Selmaj and Kobelt et al 2017 (23); j, Sá and Kobelt et al 2017 (24); k, Boyko and Kobelt et al 2017 (25); l, Oreja-Guevara and Kobelt (26); m, Brundin and Kobelt et al (27); n, Calabrese and Kobelt et al 2017 (28); o, Thompson and Kobelt et al 2017 (29). AUD, Australian dollars

Figure 2: Current inflationary pressures for Australia.

CONSUMER PRICE INFLATION*



Source: https://www.rba.gov.au/chart-pack/aus-inflation.html

Figure 3: Increases in costs per person living with MS from 2017 to 2021 stratified by disability severity, with costs inflated to 2021 from 2017 dollars using the Reserve Bank of Australia's Inflation Calculator.



COST PER PERSON LIVING WITH MULTIPLE SCLEROSIS CLASSIFIED BY DISABILITY SEVERITY FROM 2017 TO 2021

Notes: disability severity stratified by the Expanded Disability Status Scale (EDSS) where no disability includes EDSS level 0, mild includes EDSS levels 1 – 3.5, moderate includes 4 – 6, and severe includes levels 6.5 – 9.5.



Figure 4: The total number of Australians with MS (left axis) and the crude prevalence of MS in Australia (right axis) in 2010, 2017 and 2021, demonstrating an acceleration in the increase.

4.1 Summary

We found that there were 33,335 people living with MS in Australia in 2021 at a total cost to Australian society of \$2.449 billion.

4.2 Increasing prevalence of people living with MS in Australia

We found that the prevalence of people living with MS in Australia has increased by 7,728 people (from 25,607 to 33,335; an increase of 30%) in the four years from 2017. Notably, this increase is accelerating (where the rate of increase has more than doubled over the four-year period) compared to our previous estimate from 2010 to 2017 where there was an increase of 4,324 people.

Our updated crude prevalence estimates align with global and local prevalence estimates that are increasing at an accelerated rate (3, 4). **Figure 4** demonstrates the acceleration of prevalence with the gradient substantially increasing from 2017 to 2021, compared to 2010 to 2017. From a local perspective, a recent prevalence study in Greater Hobart in Tasmania found a significant increase in MS prevalence and incidence in this well-studied MS population. More specifically, the 2019 estimate of crude prevalence in the Greater Hobart region was 197.1 per 100,000 people. In 2017, the crude prevalence for the Tasmanian study population was 148.3 per 100,000 people (6). In context, Tasmania has consistently recorded the highest prevalence in Australia (Tasmania is Australia's southernmost state). This Interim Report estimated a national prevalence of 131.1 per 100,000 people. The Greater Hobart study also noted a significant continuing fall in mortality and an overall ageing of the MS population (4).

From a global perspective, a recent study that analysed the findings of the *Atlas of Multiple Sclerosis* (81 countries and six regions namely African, Americas, E. Mediterranean, European, South East Asia and Western Pacific) estimated that someone in the world is diagnosed with MS every five minutes (3). The study also found that MS prevalence increased in every world region from 2013 to 2020 and that the global absolute increase per 100,000 people was just over 50% higher (29.26 per 100,000 people in 2013 and 43.95 per 100,000 in 2020) with some regions such as the Americas recording a 54.6% absolute increase (62.89 per 100,000 people in 2013 and 117.49 per 100,000 in 2020) and the European region recording a 34.56% absolute increase in prevalence (108.25 per 100,000 people in 2013 and 142.81 per 100,000 in 2020). This study also found that across countries the consensus is that earlier diagnosis, improved ascertainment and longer survival have all contributed to these trends (3).

As per the Hobart study it is also likely that changes in exposure to known MS risk factors such as increased adolescent obesity, decreased parity and decreased sun exposure may also play a role in the significantly increasing prevalence and incidence of MS.

Increased prevalence has important implications for healthcare resource allocation.

4.3 DMTs: the continuing revolution

Our investigation of the Australian Government's PBS/RPBS data revealed that the number of subsidised DMTs has increased from 10 to 14 types with the mode of delivery increasing from 22 to 33 and continuing to shift to oral therapies from 2017. We observed a reduction in the number of prescriptions, however, the number of people using oral therapies that are prescribed twice-yearly has increased. We also observed a slight decrease in the penetrance of DMTs. One reason for this may be the increase in the use of intermittent treatments, which require less prescriptions, rather than treatments with monthly prescriptions. DMTs such as cladribine have short defined treatment courses that are followed by no active treatment. It is likely that people who had previously received these treatments and are no longer actively treated answered no to the DMT usage question in the AMSLS Medications and Disease Course Survey. Additionally, the COVID-19 pandemic may have impacted DMT penetrance in several ways. It may have caused people to stop or reduce DMT usage

due to concerns regarding the effect of DMTs on COVID-19 severity, and it may have also resulted in people having less contact with their clinicians, leading to a reduction in prescriptions for their DMTs.

4.4 Total costs and our assumptions: an underestimate

The total costs for MS in Australia in 2021 were almost \$2.5 billion. This is likely an underestimate because we used the Reserve Bank of Australia's Cost Inflator. Our sensitivity analysis with the GFCE for hospitals and nursing homes index supports this assumption where the total cost for 2021 is almost \$100 million greater. In addition, increasing inflationary pressure in the current economic landscape for 2022 also suggests that our total cost estimate of \$2.449 billion is conservative.

4.5 Per person costs for people living with MS compared to average costs for the general population and other chronic diseases

The AIHW estimated the average spending on health per person in the general Australian population was \$7,926 in 2019-20. Using the Reserve Bank of Australia's Cost Inflator this is approximately \$8,222 in 2021 dollars. People living with MS even with no disability are bearing a much higher cost (approximately four times more) for their health than the general population. Importantly, for people living with MS with severe disability, this cost substantially increases to approximately 15 times more than the costs for the Australian general population.

The average cost for a person living with MS exceeds the cost of living with many other chronic diseases in Australia including Parkinson's Disease (30), Type 2 Diabetes (31) and long-term cancer survivorship (32). For people living with moderate and severe MS, these costs well-exceed the average costs for these other comparable chronic diseases.

4.6 Strengths and Limitations

Strengths of our study include the use of our validated prescription method to calculate crude prevalence for the purposes of this Interim Report. This is the third time we have used this prescription method to calculate the prevalence of MS in Australia where the Medicare data of all prescriptions Australia-wide are held in one centralised and frequently updated database. A limitation that also applies to our previous two studies is that we assumed that filled prescriptions were used but it is likely that there were some unused prescriptions, or a person switched or stopped the medication. However, the literature suggests that the persistence and adherence to DMTs over a 12-month timeframe is relatively stable (33, 34). A further limitation of our prescription method is that people with clinically isolated syndrome may receive a MS-specific DMT, however, it is likely that this is a small number of people. In addition, it has been suggested that this small number would likely offset the people who fill a prescription but do not use it (33). A final limitation of our prescription method is the use of the AMSLS penetrance estimates. The use of the AMSLS to calculate penetrance is a strength, however, we note that the average age of participants in the AMSLS has increased by 3.5 years since 2017. This could contribute to a decrease in penetrance of DMTs and therefore an increase in our prevalence and total costs estimates.

In this Interim Report, we used the cost estimates from our comprehensive *Health Economic Impact of Multiple Sclerosis in Australia in 2017* report which were then inflated to 2021 values – these 2017 costs are a detailed and accurate reflection of the costs for that year. We used the Reserve Bank of Australia's Cost Inflator to inflate the 2017 costs, but this is likely an underestimate of the costs given the inflator's use of CPI. However, we have also conducted a sensitivity analysis using an alternative inflator to demonstrate that our estimated costs are likely between the two estimates. A final limitation is that the estimates of 2021 costs for this Interim Report are based on inflators alone. Previous MS cost studies have used detailed cost questionnaires combined with "bottom-up" costing methodologies. In this interim study, we have inflated the costs from the 2017 values to 2021 values. However, to calculate national total costs, we have used detailed assessments of prevalence in 2021 and multiplied these with the inflated per person costs. The current economic climate of increasing inflation in 2022 indicates that the 2021 costs are going to accelerate moving forward. A detailed update of MS costs using a comprehensive cost questionnaire and prevalence is planned for 2024.

5.0 Conclusions

This report provides prevalence and interim cost estimates for people living with MS in 2021. These results can be used for resourcing allocation decisions and advocacy. A comprehensive analysis of costs will be conducted in 2024.

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Supplementary Table 1a and 1b: Alternative Indices and their growth rates per annum for healthcare expenditure including the GFCE for hospitals and nursing homes*.

Index	2009–10	2010–11	2011–12	2012–13	2013–14	2014–15	2015–16	2016–17	2017–18	2018–19
Total health price index ^(a)	83.5	84.3	85.8	87.6	89.3	90.7	92.6	94.7	96.2	98.2
Government final consumption ex- penditure on hospitals and nursing homes	79.1	80.2	82.1	84.5	86.9	89.0	90.6	92.3	94.7	97.5
Medicare medical services fees charged ^(b)	87.6	88.9	90.4	92.6	94.2	95.3	95.8	96.5	97.4	98.5
Dental services ^(a)	94.9	95.8	95.8	97.2	98.5	99.9	100.1	98.3	100.3	99.8
Other health practitioners ^(a)	71.4	73.7	77.7	80.3	83.6	86.7	89.2	91.5	95.0	96.9
Professional health workers wage rates	75.2	77.9	80.1	82.8	85.2	87.5	89.7	91.9	94.3	97.1
PBS pharmaceuticals ^(a)	95.2	96.8	96.5	90.4	87.7	84.2	93.6	107.0	102.0	99.2
HFCE on chemist goods	94.6	92.8	91.9	93.4	95.2	94.5	95.8	96.0	96.9	97.8
Aids and appliances ^(a)	101.1	95.4	93.6	93.5	91.1	94.2	93.2	97.6	100.2	100.4
Australian Government gross fixed capital formation	99.4	97.9	97.2	97.2	96.9	98.2	99.2	98.3	98.3	99.6
State and territory and local govern- ment gross fixed capital formation	86.9	87.6	88.5	89.6	90.2	92.0	93.5	93.7	95.7	99.1
Private gross fixed capital formation	85.7	86.8	86.4	87.4	89.7	92.4	94.6	95.3	96.8	98.8
GDP IPD	82.7	87.9	89.5	89.4	90.8	90.3	89.8	93.1	94.9	98.1
GNE IPD	83.9	85.7	87.3	89.0	91.1	92.7	94.2	95.0	96.4	98.3

Supplementary Table 1a: Total health price index and industry-wide indexes, 2009–10 to 2019–20 (reference year 2019–20 = 100)

(a) IPD, constructed by the AIHW.

(b) Chain price index, constructed by the AIHW.

Note: For more information about concepts, definitions and data sources, see Overview of data sources and methodology of Health Expenditure Australia 2019–20 report.

Source: AIHW Health Expenditure Database.

Supplementary Table 1b: /	Growth rates for the total heal	h price index and industr	y-wide indexes	, 2009–10 to 2019–20 (%)
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	2009–10	2010-11	2011-12	2012–13	2013–14	2014–15	2015–16	2016–17	2017–18	2018–19
	to									
Index	2010–11	2011–12	2012–13	2013–14	2014–15	2015–16	2016–17	2017–18	2018–19	2019–20
Total health price index ^(a)	1.0	1.7	2.1	1.9	1.7	2.1	2.2	1.6	2.0	1.9
Government final consumption ex- penditure on hospitals and nursing homes	1.4	2.4	3.0	2.8	2.4	1.9	1.8	2.6	3.0	2.6
Medicare medical services fees charged ^(b)	1.4	1.7	2.3	1.8	1.1	0.6	0.7	0.9	1.1	1.6
Dental services ^(a)	0.9	_	1.5	1.3	1.5	0.2	-1.8	2.0	-0.5	0.2
Other health practitioners ^(a)	3.2	5.5	3.3	4.1	3.8	2.8	2.6	3.8	2.1	3.2
Professional health workers wage rates	3.6	2.9	3.4	2.8	2.8	2.5	2.4	2.7	3.0	2.9
PBS pharmaceuticals ^(a)	1.8	-0.3	-6.3	-3.0	-4.0	11.1	14.3	-4.6	-2.7	0.8
HFCE on chemist goods	-1.9	-1.0	1.6	1.9	-0.7	1.3	0.2	0.9	1.0	2.2
Aids and appliances ^(a)	-5.6	-1.9	-0.1	-2.6	3.4	-1.0	4.7	2.6	0.2	-0.4
Australian Government gross fixed capital formation	-1.5	-0.7	-0.1	-0.2	1.3	1.0	-0.9	_	1.3	0.4
State and territory and local govern- ment gross fixed capital formation	0.8	1.1	1.2	0.7	2.0	1.5	0.2	2.2	3.5	0.9
Private gross fixed capital formation	1.3	-0.4	1.1	2.7	3.0	2.4	0.7	1.6	2.0	1.3
GDP IPD	6.3	1.9	-0.1	1.5	-0.5	-0.5	3.7	1.9	3.4	1.9
GNE IPD	2.2	1.8	1.9	2.3	1.8	1.6	0.8	1.4	2.0	1.7

rounded to zero

Note: For more information about concepts, definitions and data sources, see Overview of data sources and methodology of Health Expenditure Australia 2019–20 report.

Source: AIHW Health Expenditure Database.