MS Nurse Care in Australia

Patterns of access and impact on health outcomes

This Report is an MS Australia initiative.

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

Prepared for

Multiple Sclerosis Australia
Level 19, 100 Miller St
North Sydney NSW 2060

Prepared by

Dr Jing Chen[1]
Dr Julie Campbell[1]
Professor Ingrid van der Mei[1]

and
Belinda Bardsley[2]
Sue Shapland[3]
Dr Therese Burke[4]
Professor Bruce Taylor[1]

[1] Menzies Institute for Medical Research, University of Tasmania, TAS, Australia
[2] MS Nurses Australasia Inc.
[3] MSWA
[4] MS Australia

Menzies Institute for Medical Research
University of Tasmania
17 Liverpool Street, Hobart TAS 7000
T +61 3 6226 7710
E Ingrid.vanderMei@utas.edu.au

Published: April 2022

Acknowledgements

Many people assisted in the development of this Report. We thank those with MS and the dedicated AMSLS team at the Menzies Institute for Medical Research: Dr Kirsty Hawkes, Carol Hurst, Carol Ingram, Dot Melross and Wendy Davidson.

We thank Deidre Mackechnie, former CEO and Bea Beswick, Advocacy Project Officer, both of MS Australia, for their energy, initiative, and tireless work in driving the early stages of this project. Also for their advocacy in recognising the value and benefit of MS Nurses in the education and care of people living with MS in Australia.

We thank the MS Nurses who contributed to the study through supporting recruitment, contributing to research and survey development, representation on the AMSLS Steering committee, and for raising concerns about decreasing numbers of MS Nurses and issues of equity of access for people with MS.

Thank you to MS Australia for establishing and supporting the AMSLS since its inception in 2002, and the state and territory MS Member Organisations for their ongoing support with recruitment.

Cover Image: MS Nurses in Australia
Opposite: MS Research Nurse Melanie McMurtrie measuring blood pressure during a clinical trial


COACHED
C
O
A
C
H
E
D

Foreword

MS is the most common chronic neurological disease diagnosed in young Australian adults, affecting more than 25,000 people. With onset most commonly occurring between the ages of 20 and 40 years, a diagnosis of MS can be devastating. This disease most commonly strikes at a highly productive time of life, when study, career-building, relationship development and family-making are the focus, and the unpredictable nature of the disease can sabotage plans and disrupt dreams. At this time of uncertainty, the input of an MS Nurse is arguably of most importance.

The MS Nurse provides education, counselling, and compassion, supporting people with MS to understand and live with this complex disease, assisting people with accessing relevant support services, and empowering people through informed and shared decision-making about treatment, lifestyle, and research choices.

This critical and empowering partnership continues from diagnosis to relapse management and beyond, with the provision of medication information, safety vigilance programs, counselling, education, and symptom management throughout the life trajectory. It is telling how often people with MS reveal their most personal difficulties and intimate concerns to their MS Nurse, who facilitates evidence-based, best-practice intervention for these issues and more.

The MS Nurse commonly intervenes at crucial moments of urgent need and can advise or expedite clinical review, avoiding unnecessary emergency room presentation and hospital admission while optimising the client's wellbeing. Management of MS symptoms, relapses, and treatment side effects enable people with MS to remain on medication and engage in a holistic wellbeing program. This results in staying out of hospital as much as possible and enables people to lead happy and productive lives. As such, MS Nurses are the lynchpin of the multi-disciplinary team of health professionals needed to support, provide holistic care (including physical, mental, social, spiritual, and cultural care domains), educate and advocate for people living with MS during all stages of the disease.

In 2016, MS Australia was alerted to the concerns of our community regarding the declining number of MS Nurses across Australia. The consumer consultation commissioned in response revealed that people with MS wanted greater access to MS Nurse care. Given the urgency, a preliminary Report was prepared as an advocacy tool by representatives from MS Australia's research arm (formerly MS Research Australia), MS Nurses Australasia, MS Health Professionals Network, Australian and New Zealand Association of Neurologists and two consumer representatives and published by MS Australia. The Report described the role of MS Nurses in Australia and noted external factors impacting their declining numbers.

However, more detailed research was required to better understand the current situation in Australia and support advocacy efforts. To do this, we needed to measure the impact and value of MS Nurses in Australia for people living with MS. So began a collaboration with the Menzies Institute for Medical Research at the University of Tasmania to ask these questions of the generous participants of the Australian MS Longitudinal Study. We are exceedingly grateful for their time, careful consideration, and altruism in providing their perspective.

We are delighted to deliver this Report to the MS community and the wider Australian healthcare communities. It is the culmination of many behind-the-scenes discussions and rich collaborative work. For the first time it provides high-quality and robust evidence of the value of MS Nurse care in Australia: convincing in terms of economic benefit, but more importantly, in delivering better health outcomes and improved quality of life for people living with MS.

This Report marks the beginning of a new conversation, and we hope provides a catalyst for change. It highlights important areas of unmet need, including a lack of awareness of the incredibly valuable services provided by MS Nurses, and the breadth of their role, from the time of diagnosis throughout the spectrum of the disease course. It has also quantified, for the first time, the significant problem with equitable access to MS Nurse care in this country. Beyond this, the Report exemplifies the benefits of specialist nurse care in chronic disease and the impact of a disease-specific nurse specialist, with capacity for even greater reach to other specialties.

We look forward to working with all stakeholders to change this landscape. The significance of this Report will be reflected in MS Australia's policies and submissions in the future as it continues to advocate for better care and improved access to care for people living with MS and their carers. Our great hope is that the recommendations from the Report will be important tools in improving the health and quality of life for people living with MS in Australia, in all geographical regions, including those living remotely from specialist care.

> "The MS Nurse commonly intervenes at crucial moments of urgent need and can advise or expedite clinical review, avoiding unnecessary emergency room presentation and hospital admission while optimising the client's wellbeing."

Ivander Mei

Professor Ingrid van der Mei
MSci, PhD
Menzies Institute for Medical Research, University of Tasmania

Belinda Bardsley
BNurs, DipMgt
Austin Health,
MS Nurses Australasia

Associate Professor Desmond Graham
MSc, RN, AICD
President, MS Australia
Director, MS Limited
Adjunct Associate Professor, University of Tasmania
Board Trustee, Multiple Sclerosis International Federation

Table of Contents

Tables

Supplementary Tables

Figures

Executive Summary

Introduction

In Australia, Multiple Sclerosis Specialist Nurses (MSSNs) or MS Nurses for short, are an integral part of the multidisciplinary team of specialist healthcare professionals involved in the provision of support, education, advice, and care for people with MS. However, changes in traditional funding models have led to a reduction in the number of MS Nurses, particularly in rural and regional areas, and concern about inequity of access. Furthermore, there is no Australian data on the patterns of access to MS Nurses and the value of MS Nurses in the care of people with MS.

Aims and Methods

Utilising a large cohort of 1,417 people with MS in Australia, this Report aimed to 1) describe the patterns of access to MS Nurse care and patterns of those receiving MS Nurse care 2) describe access to MS Nurse care and receiving MS Nurse care by differences in personal/clinical characteristics, lifestyle behaviours and use of disease-modifying therapies (DMTs) 3) examine whether people with MS who did not have access to an MS Nurse service had poorer disease outcomes and 4) describe the overall value of MS Nurses and the reported benefits of MS Nurse care by people with MS. Data derived from three surveys between 2018 and 2020 of participants within the Australian MS Longitudinal (AMSLS) Study, an ongoing survey-based cohort study. An exploratory cost savings analysis estimated potential avoided costs if people currently without access to an MS Nurse service gained access. For this analysis we used data from our previous Report, the *Health Economic Impact of Multiple Sclerosis in Australia in 2017.*

Results

We found that 31.5% of people with MS in our study did not have access to an MS Nurse, associated with consistently worse health outcomes. These included higher disability levels, faster self-reported disease progression, greater severity of MS symptoms, higher levels of depression and anxiety and a lower health-related quality of life. The associations remained after adjusting for differences in education level, age, MS duration, onset type (progressive or relapsing onset) and remoteness, suggesting that MS Nurse care significantly benefits people with MS and that people who are not able to access this service are adversely affected in terms of health outcomes.

In addition, we found that MS Nurse care reduced the need for people with MS to see other, more costly health professionals, such as GPs and neurologists, and prevented unplanned emergency department presentations and potentially, hospital admissions. Even with conservative estimates on avoided costs, MS Nurse care seems to be a highly cost-effective model of care. At a cost of $5 million to provide MS Nurse care to around 8,000 people currently without access, this could reduce the cost of their overall MS care by $64.3 million annually, assuming cost savings of 10%. MS Nurses tailored their care well to the needs of the individual, with high levels of satisfaction with the frequency and types of services provided. The most frequent support types identified related to providing information about and management of MS symptoms and treatments and their side effects. The knowledge shared and care provided improved the self-management and self-care skills of people living with MS. DMT use was a prime reason to seek MS Nurse care more frequently and this was consistent irrespective of remoteness.

Discussion and Recommendations

Overall, MS Nurse care directly benefits people with MS and people who are unable to access this care are adversely affected in terms of health outcomes. This aligns with the *Brain Health: Time Matters in MS* initiative which advocates for improved access to specialist care in MS to reduce disability progression. Other international studies have also demonstrated improved health outcomes and significant cost savings with specialist nursing services for chronic diseases, both within and beyond MS care. There is a strong case to be made that every Australian with MS should have access to MS Nurse care as part of their ongoing MS management plan.

The results support the need for policies and practices, and access to funding, that will improve access to MS Nurse care. The following four recommendations arose from this Report:

1. Raise awareness

Work is needed to raise awareness of the existence of MS Nurses, the value of MS Nurse care to the individual and society, and the supports and services that they provide to both people with MS and health practitioners. We recommend a review of existing resources describing MS Nurse care, the potential development of new resources and a review of the distribution channels of those resources, including health professional associations and societies. This MS Nurse Report will be used to heighten awareness of MS Nurses and their value among funding stakeholders, hospitals, neurologists, people with MS, their advocates and the broader community.

2. Assist the existing MS Nurse workforce

The MS Nurse workforce should be supported and expanded. We recommend mentorship and preceptorship (directed practical training by an expert in the field) programs and exploring opportunities within university nursing courses to include education about MS Nursing and MS Research Nursing.

3. Increase the number of MS Nurses

Our effectiveness analyses suggest that the economic benefits of an expanded MS Nurse service would far outweigh the costs, even using conservative assumptions. We recommend advocating for expansion of the MS Nurse workforce to the federal and state/territory governments, hospitals, private neurologists, and other potential funders. We also recommend assessing funding arrangements for MS Nurse-led clinics in Australia, whether led by MS Nurse Practitioners, MS Nurse Consultants or MS Specialist Nurses.

4. Increase access to MS Nurses

- Expand telehealth services to improve access to MS Nurse care - this requires amendment to Medicare which currently covers telehealth appointments with neurologists, but not MS Nurses.
- Advocacy to the Australian Government on this issue is recommended, possibly in collaboration with other organisations.

Introduction

In Australia, Multiple Sclerosis Specialist Nurses (MSSNs), or MS Nurses for short, are an integral part of the multidisciplinary team of specialist healthcare professionals involved in the provision of support, education, advice, and care for people living with Multiple Sclerosis (MS), from the time of their diagnosis.

MS Nurses play an important role in providing tailored patient education which supports diagnosis acceptance, fosters informed, shared decision-making amongst a wide variety of treatment choices, and encourages self-management strategies (i.e. modifiable lifestyle factors).[1-3] They play a vital role in assisting people with MS to navigate complex information and service systems across the community, health, disability and aged care interfaces to ensure they are aware of and can access the supports they need. The MS Nurse plays an important role in both symptom and relapse management and enabling participation in clinical research opportunities.[4] They are particularly relevant in the setting of high efficacy therapies, which have complex logistical requirements and necessitate regular safety monitoring over many years.[1] Their advice and intervention at times of urgent patient need can also expedite clinical review, avoid unnecessary emergency room presentation and hospital admissions,[5,6] assist with treatment adherence, manage symptoms and treatment side effects and enable people with MS to continue to lead productive lives.[7,8]

However, changes in traditional funding models have led to a reduction in the number of MS Nurses available, particularly in rural and regional areas, and widespread concern about access inequity led to a baseline Report: *Multiple Sclerosis Specialist Nurses in Australia 2017*, prepared with input from several stakeholders across Australia and published by MS Australia.[9]

Australian data on the benefits of MS Nurses is currently limited to individual centres who have conducted small research projects or who have been required to write business plans to support ongoing employment of an MS Nurse. Internationally, the *Generating Evidence in MS Services (GEMSS)* project is probably the most substantial body of work.[10] This project was conducted in the UK by the MS Trust and facilitators between 2012 and 2015. They worked with 16 MS specialist teams to evaluate the value of MS specialist nursing provision and used this work to improve services across the country. Through their work, they were able to provide evidence on the benefits and economic value of MS Nurse care. Building on this, they established the next phase of their research, *MS Forward View*,[11] to assess how they can meet the ongoing challenges identified for health organisations focussing on MS. This led to a further project, the Specialist Nurses Programme, where the Trust provides initial training, support, and funding of an MS Nurse in areas of greatest need and evaluates the value of these nurse placements through improved patient and quality outcomes.

The value of specialist nursing roles has been demonstrated in other health areas in Australia such as breast cancer,[12] mental health,[13] and Parkinson's disease.[14] To date, this data has not been available for MS Nurses. This Report will assess whether there is an overall benefit derived from access to MS Nurse care in Australia. Furthermore, it is important to establish whether there are gaps in access to MS Nurse care and if so, to understand whether reduced access has a negative impact on health outcomes and health-related quality of life for people with MS.

Opposite: MS Research Nurse Melanie McMurtrie testing vision

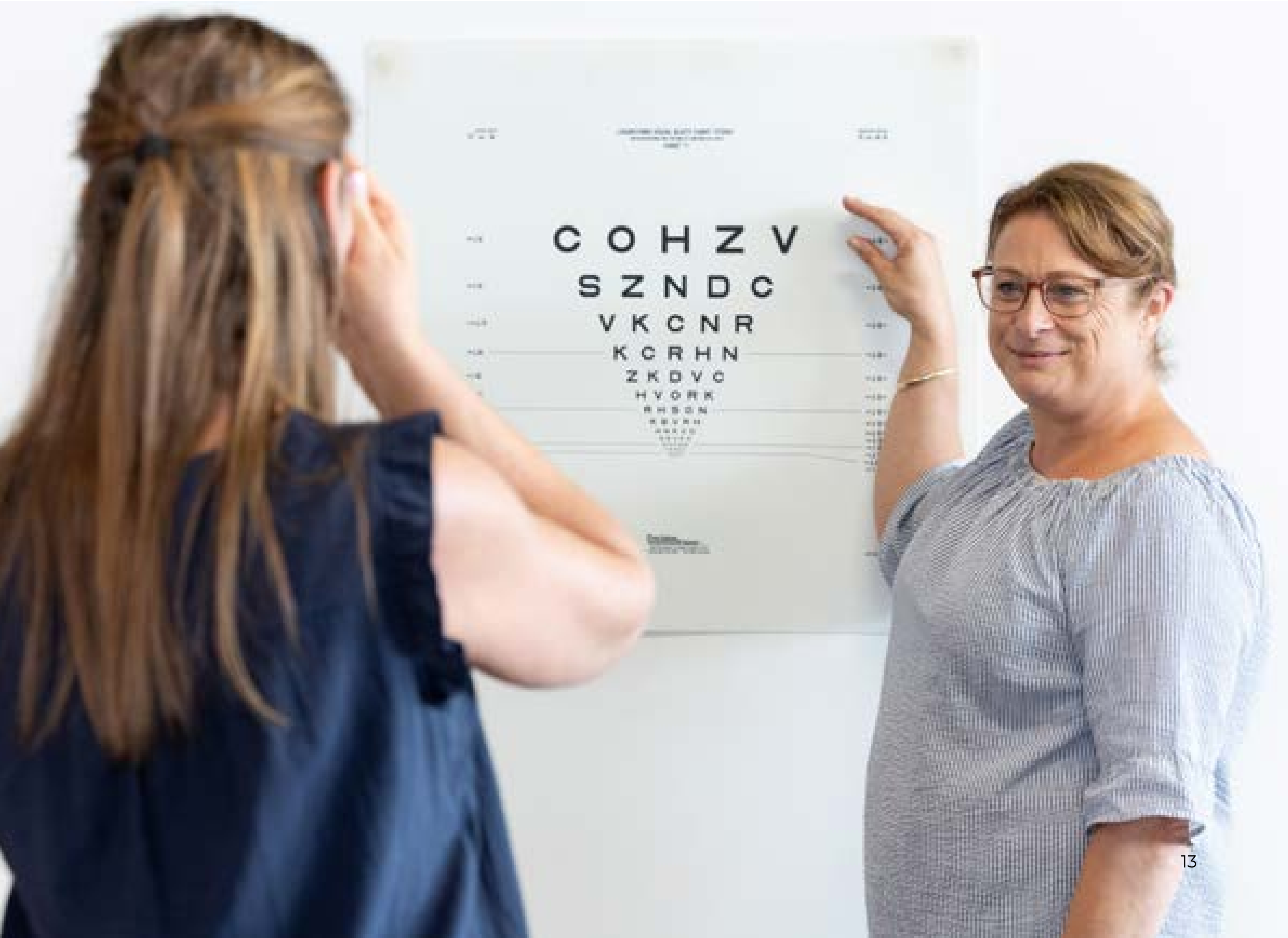
Aims

1. Describe the patterns of access to MS Nurse care for Australians with MS (percentage with access to MS Nurse care and percentage receiving MS Nurse care overall, within the last 12 months, and by subgroups such as state/territory, remoteness, and MS type; reasons for not using; types of MS Nurse care received).

2. Describe access to MS Nurse care and receiving MS Nurse care according to differences in personal/clinical characteristics, lifestyle behaviours and use of DMTs.

3. Examine whether people with MS who did not have access to MS Nurse care had worse health outcomes and health-related quality of life, and whether these differences remained after accounting for different personal and clinical characteristics.

4. Describe the overall value of MS Nurse care as well as the reported effects of MS Nurse care on adherence to MS treatments, management of MS symptoms and side effects, and leading a healthier lifestyle.



Methods

Participants and data collection

The Australian MS Longitudinal Study (AMSLS) is a survey-based cohort study, established in 2002. Recruitment to the AMSLS is ongoing and is carried out with the assistance of MS Australia and state and territory MS Member Organisations to counter attrition. The study cohort currently comprises around 3,000 active participants and has been shown to be representative of the overall Australian MS population. An estimated 96% are diagnosed with definite MS by neurologists according to the McDonald criteria[15], and all participants provided informed consent. The study has been approved by the Tasmanian Health and Medical Human Research Ethics Committee.

Data for this Report derived from three AMSLS surveys. The 2020 MS Nurses and Sleep survey was specifically designed for this Report and was completed between February and April 2020 (2,496 participants invited and 1,722 [69.0%] responded), with 94.4% completing the survey prior to the first official Australian lockdown on 23/3/2020 due to the COVID-19 pandemic. The 2019 Medication and Disease Course Survey (October – December 2019) assessed disease outcomes and DMT usage (2,537 participants invited and 1,767 [69.6%] responded), and the 2018 Lifestyle and Environment survey assessed lifestyle factors and comorbidities (2,678 participants invited and 1,707 [63.7%] responded).

Measurements

MS Nurse care

Appendix 1 shows the questions related to MS Nurses in the 2020 MS Nurses and Sleep survey. Participants were asked to report whether they had access to an MS Nurse as part of their care (yes/no). If they reported 'no', the reasons for not having access to MS Nurse care were queried, including the categories 'there are no MS Nurses in the area I live', 'there are no MS Nurses in the neurologist practice that I go to', 'I did not know about the existence of MS Nurses', or 'other, please describe:' (free text). Those who reported that there was no MS Nurse in the area they lived or that there was no MS Nurse in their neurologist practice were combined as 'MS Nurse service not available'. They were also asked whether they would like to have access to an MS Nurse as part of the care (yes; no; do not know).

For those who reported having access to an MS Nurse as part of their care, information was collected about:

- The MS Nurse care provider, including the categories 'public hospital clinic', 'private neurologist', 'community provider such as the MS Society (MS Member Organisation)', 'Pharma patient support program', 'unsure', and 'other, please describe' (free text).
- The frequency of contact with an MS Nurse, including the categories 'weekly', 'monthly', 'quarterly', 'annually', and 'less than annually'.
- The frequency of consultation with an MS Nurse in different settings in the past 12 months, including the categories 'clinic consultations (outpatient clinic or drop-in clinic)', 'home visits', 'consultations over the phone', 'consultations via telehealth (Skype/Zoom/webcam)', 'email contact', and 'visits from an MS Nurse whilst an inpatient in hospital'.
- The satisfaction with the amount of contact including the categories 'it was too much contact', 'it was about right', 'it wasn't enough – I would have liked more'.
- The length of MS Nurse care, including 'less than one year', '1-5 years', '6-10 years', and 'more than 10 years'.

- The types of supports that were provided using a list of 16 types of supports. The survey asked whether the Nurse provided these and whether they were helpful ('the Nurse provided this and it was helpful', 'the Nurse provided this, but it wasn't helpful', 'I didn't need this' and 'I didn't get this, but I would have liked it').
- The difference it would have made if they had not had access to MS Nurse care in the last 12 months, including the categories 'it would have made no difference', 'I would have struggled on my own', 'I would have seen my GP more', 'I would have asked to see my neurologist more', 'I would have had to go to the hospital emergency department' and 'other, please specify' (free text).
- The overall value of having an MS Nurse including 'very helpful', 'somewhat helpful', 'neither helpful nor unhelpful', 'somewhat unhelpful', 'very unhelpful', and 'I really don't know'.
- The perceived effects on 1) adherence to MS treatment 2) management of MS symptoms or side effects and 3) lifestyle behaviours including the categories 'yes, it definitely improved my ….', 'Yes, it might have improved my….', 'No, it did not result in any real changes to my…', 'Yes, it might have worsened my…', 'Yes, it definitely worsened my …', and 'I really don't know'.

MS symptom severity

Symptom severity in the previous four weeks compared to before MS was measured using the MSSymS using single-item 0–10 numeric rating scores, where 0 signifies no symptoms and 10 signifies the worst possible symptoms[16]. Participants reported the symptom severity for 13 symptoms, including fatigue, cognitive symptoms (including problems with concentration, attention, and memory), walking difficulties, balance difficulties, pain, vision problems, bladder problems, bowel problems, sexual dysfunction, feelings of depression, feelings of anxiety, sensory symptoms, and spasticity. In addition, fatigue was measured using the Fatigue Severity Scale (FSS), which assesses fatigue in the preceding week (mean of 9 items [1-7 scale])[17]. Before answering the FSS, participants were asked if they experienced any symptoms of fatigue; if they reported none, they were assigned a score of 0 and instructed to skip the FSS. Depression and anxiety were also measured using the Hospital Anxiety and Depression Scale (HADS)[18] (total score of 14 items from 0-21)[19]. A mean sub-depression/sub-anxiety score of greater than or equal to 7 was used to define clinical depression or anxiety.

Disability and disease progression

Disability was measured using the Patient Determined Disease Steps scale (PDDS, scored from 0-8), a validated patient-reported instrument to measure disability in MS. The PDDS is strongly correlated with the Expanded Disability Status Scale (EDSS, r=0.78).[20,21] A PDDS score of 3 reflects gait disability without the need for assistance to walk and is approximately equivalent to an EDSS score of 4.0–4.5. PDDS scores of 4 (early cane), 5 (late cane) and 6 (bilateral support) indicate the need for assistance in walking, which are approximately equivalent to EDSS scores of 6–6.5. Like the EDSS, score 7 indicates wheelchair users and 8 indicates bedridden. Self-reported 12-month disease progression was assessed by a numeric rating scale (0-10) where 0 signifies no progression and 10 signifies the worst possible progression.

Health-related Quality of Life

Health-related Quality of Life (HRQoL) was assessed by the European Quality of Life with five dimensions (EQ-5D) (5 items, 1-5 scale, converted to a utility score from 0 [death] to 1 [perfect health]).[22]

Disease modifying therapies (DMTs)

Participants reported whether they used a DMT and which DMT they were currently using, presented as a list. These DMTs include interferon β-1b (Betaferon, sub-cutaneous injection), interferon β-1a (Rebif, sub-cutaneous injection), interferon β-1a (Avonex, intramuscular injection), pegylated interferon β-1a (Plegridy, sub-cutaneous injection), glatiramer acetate (Copaxone, sub-cutaneous injection), natalizumab (Tysabri, intravenous infusion), fingolimod (Gilenya, oral), teriflunomide (Aubagio, oral), dimethyl fumarate (Tecfidera, oral), alemtuzumab (Lemtrada, intravenous infusion), and novantrone (Mitoxantrone, intravenous infusion), azathioprine (Azasan, oral), methotrexate (Trexall, oral), cladribine (Mavenclad, oral) and ocrelizumab (Ocrevus, intravenous infusion).

DMTs were classified into three broad categories based on their recognised clinical efficacy derived from pivotal clinical trials[23-26]. **The category 1 DMTs** (injectable platform DMTs) included interferons-β (Betaferon, Rebif, Avonex and Plegridy) and glatiramer acetate (Copaxone); **the category 2 DMTs** included teriflunomide (Aubagio, oral) and dimethyl fumarate (Tecfidera, oral); and **the category 3 DMTs** (higher efficacy) included natalizumab (Tysabri, infusion), fingolimod (Gilenya, oral), alemtuzumab (Lemtrada, infusion), ocrelizumab (Ocrevus, infusion), and cladribine (Mavenclad, oral). There were no participants who took azathioprine nor mitoxantrone. For the DMT analysis, we excluded two people who were using methotrexate.

DMTs were also classified by administration route, including **injectable DMTs** interferons-β (Betaferon, Rebif, Avonex and Plegridy), and glatiramer acetate (Copaxone); **infusion DMTs** natalizumab (Tysabri), alemtuzumab (Lemtrada), and ocrelizumab (Ocrevus); and **oral DMTs** fingolimod (Gilenya), teriflunomide (Aubagio), dimethyl fumarate (Tecfidera), and cladribine (Mavenclad).

Lifestyle characteristics

The lifestyle survey collected data on physical activity level (measured by International Physical Activity Questionnaire), diet quality (Dietary Habits Questionnaire), vitamin D supplementation (yes/no, amount, frequency), sun exposure (exposure per day, summer/winter), smoking (yes/no, amount), and marijuana use (yes/no, amount/frequency).

Assessment of remoteness

We used the participant's postcode of residence in 2020 to create a class of remoteness based on the Australian Statistical Geography Standard (ASGS) Remoteness Structure of Remoteness Area by postcode from the Australian Bureau of Statistics.[27] Remoteness Areas divide Australia into five classes of remoteness based on a measure of relative access to services: Major Capital Cities, Inner Regional Australia, Outer Regional Australia, Remote Australia, and Very Remote Australia.[27]

Other measures

Other measures included gender, date of birth, year of MS diagnosis, MS type, and education level.

Statistical analysis

The analysis included participants who responded to both the 2019 disease course and medication course survey and the 2020 MS Nurses survey (n=1,417), after excluding participants (n=3) who did not answer any questions relating to MS Nurses and people with missing value of postcode data (n=12). Of those 1,471 respondents, a sub-sample of people who also responded to the 2018 lifestyle survey was used to examine difference in lifestyle behaviours (n=1,118).

According to whether people had access and were receiving MS Nurse care or not, we grouped people to make the following comparisons: 1) compare those without access to MS Nurse care to those who did have access to MS Nurse care (irrespective of whether they received care), and 2) among those who did have access to an MS Nurse, compare those who did and did not receive MS Nurse care. Means (SD) or medians (interquartile range; IQR) of continuous variables, and percentages and frequencies of categorical variables are reported to summarise the characteristics of participants in the total sample and by access to and receiving MS Nurse care. To examine whether health outcomes differed by access to an MS Nurse, we used log-binomial regression for the 13 MS symptoms, Patient Determined Disease Steps and self-reported progression in the past 12 months, and linear regression for the Hospital Anxiety and Depression Scale depression, HADS anxiety and EQ-5D. With these analyses, we adjusted for differences in education level, age, MS duration, onset type and remoteness area. A p-value <0.05 (two-tailed) was considered as statistically significant. All statistical analyses were performed using Stata/ SE V.15.

Cost savings analysis

We estimated the potential cost savings (or avoided costs) from a health payer and societal perspective if people without access to an MS Nurse service had access to an MS Nurse service. To do that, we used the results of our 2017 Report on health economic impact.[28,29] This study estimated that the total number of Australians with MS was 25,607 and that the total cost of MS per person (including direct and indirect costs) by disability level was $30,561 (for those with no disability), $55,815 (with mild disability), $76,916 (moderate disability), and $114,813 for those with severe disability. We combined those with no and mild disability into a single group and used their weighted average cost, $44,254.

> "The total (estimated) number of Australians with MS was 25,607"

First, we estimated the total cost for those without access to an MS Nurse service by estimating the number of Australians with MS without access to an MS Nurse service in each disability category. This was calculated by multiplying the proportions of people without MS Nurse access in each disability category with the total number of Australians with MS without access. Next, we estimated the total costs of those without access to an MS Nurse service by multiplying the number of Australians with MS without MS Nurse service access with the total 2017 costs per person for each disability category and combining the costs for all disability categories. The 2021 costs were estimated from 2017 costs (rounded to the nearest dollar) by correction for inflation, using the Reserve Bank of Australia's inflation calculator. We estimated potential costs avoided if people without access to an MS Nurse service had access; assuming this access resulted in cost reductions of 5%, 10%, 15% or 20%.

Examples of cost reductions include 1) lower frequency of GP and neurologist appointments 2) avoidance of emergency department presentations and hospital admissions and 3) improved health outcomes, including lower severity of symptoms, higher health-related quality of life and higher work productivity. This would be achieved through, for example, better disease management skills, better health behaviours, and improved adherence to disease modifying therapies and other MS-related medications.

Results

Who were the people with MS in this Report?

The study sample included 1,417 participants (Table 1). The mean age was 58 years, and the mean MS duration since diagnosis was 16.7 years. The mean age at MS diagnosis was 41.2 years, 79.6% were female and 39.2% had a university degree. In relation to MS type, 61.5% had relapsing remitting MS (RRMS), 15.3% secondary progressive MS (SPMS), and 11.9% primary progressive MS (PPMS). Overall, 46% had mild or no disability and the majority were living in major cities (66.2%) or inner regional areas (25.0%) of Australia.

In total, 2,496 participants were invited to participate in the MS Nurses survey. When we compared those included in the study (N=1,417) with those not included (N=1,079), we found that those who participated were somewhat older (58.1 vs. 56.1 years, p=0.003), and had a longer MS duration since diagnosis (17.5 years vs. 16.7 years, p=0.046), but there was no significant difference in gender or education level.

Left: MS Nurse administering a 'nine-hole peg test' to test upper limb function

> "In total, 2,496 participants were invited to participate in the MS Nurses survey"

Table 1. Participant characteristics.

	Total sample
	N=1,417
Age (years), mean (SD)	58.0 (11.3)
MS duration since diagnosis (years), mean (SD)	16.7 (9.2)
Age at MS diagnosis	41.2 (10.9)
Gender, n (%)	
Female	1137 (79.6)
Male	292 (20.4)
Education, n (%)	
Primary/secondary school	374 (26.3)
Occupational certificate	490 (34.5)
University degree	559 (39.2)
MS type in 2019, n (%)	
Relapsing remitting MS	863 (60.1)
Secondary progressive MS	217 (15.3)
Primary progressive MS	167 (11.8)
Progressive relapsing MS	31 (2.2)
Unsure	139 (9.8)
Disability level, n (%)	
No disability or Mild	652 (46.0)
Moderate	503 (35.5)
Severe	264 (18.6)
Use of a DMT, n (%)	
Yes	905 (64.1)
No	516 (35.9)
State/Territory	
NSW	428 (30.2)
VIC	387 (27.3)
QLD	191 (13.5)
SA	135 (9.5)
WA	131 (9.2)
TAS	85 (6.0)
ACT	57 (4.0)
NT	3 (0.2)
Remoteness level, n (%)	
Major Cities	938 (66.2)
Inner Regional	354 (25.0)
Outer Regional	108 (7.6)
Remote/Very Remote	17 (2.0)
Total work productivity loss (%), mean (SD)*	13.9 (22.2)

*Work productivity was assessed in those in paid work. SD: standard deviation.

Who didn't receive MS Nurse care in Australia and was there an access problem?

First, we wanted to understand who did and didn't have access to MS Nurse care, and who received and didn't receive MS Nurse care in Australia, and why. Of the 1,417 participants included, 48.9% (n=693) participants reported they received MS Nurse care, while 51.1% (n=724) did not receive MS Nurse care (Figure 1). There were 64.9% of participants with access to MS Nurse care, including the 48.9% who received care, and 15.9% who had access but did not receive care.

In this section we explore:

- The reasons for not receiving MS Nurse care
- Whether not receiving MS Nurse care was primarily due to lack of access
- Whether there were people not receiving MS Nurse care who would have liked to
- Whether remoteness was a major barrier to accessing or receiving MS Nurse care in Australia
- What characterised the group that had no access to MS Nurse care
- What characterised the group that had access but did not receive MS Nurse care

Reasons for *not receiving* MS Nurse care

The reasons given for not receiving MS care included that an MS Nurse was not available in the area the person lived or the neurologist practice they visited (12.9%; n=183 of 1,417 participants), that they did not know of the existence of MS Nurses (17.8%; n=252) (Figure 1) or other reasons (possibly multiple, using an open text field in the survey: 19.2%; n=272). These included that people thought they did not need an MS Nurse (n=190; 13.4%), that they were not contacted by an MS Nurse (n=15; 1.1%), that they thought MS Nurses were not helpful (n=4; <1%), that they were using other types of care (n=4; < 1%), that they thought they were not eligible for an MS Nurse (n=2; < 1%), that they were living in a nursing home (n=5; <1%) or that an MS Nurse was too far away from where they lived (n=4; <1%). In addition, 48 participants (3.4%) did not provide specific reasons for not having an MS Nurse as part of their care; and made up most of the group for whom access to an MS nurse could not be determined (3.6%, n=51).

Top: MS Nurse assessing arm strength during a neurological examination

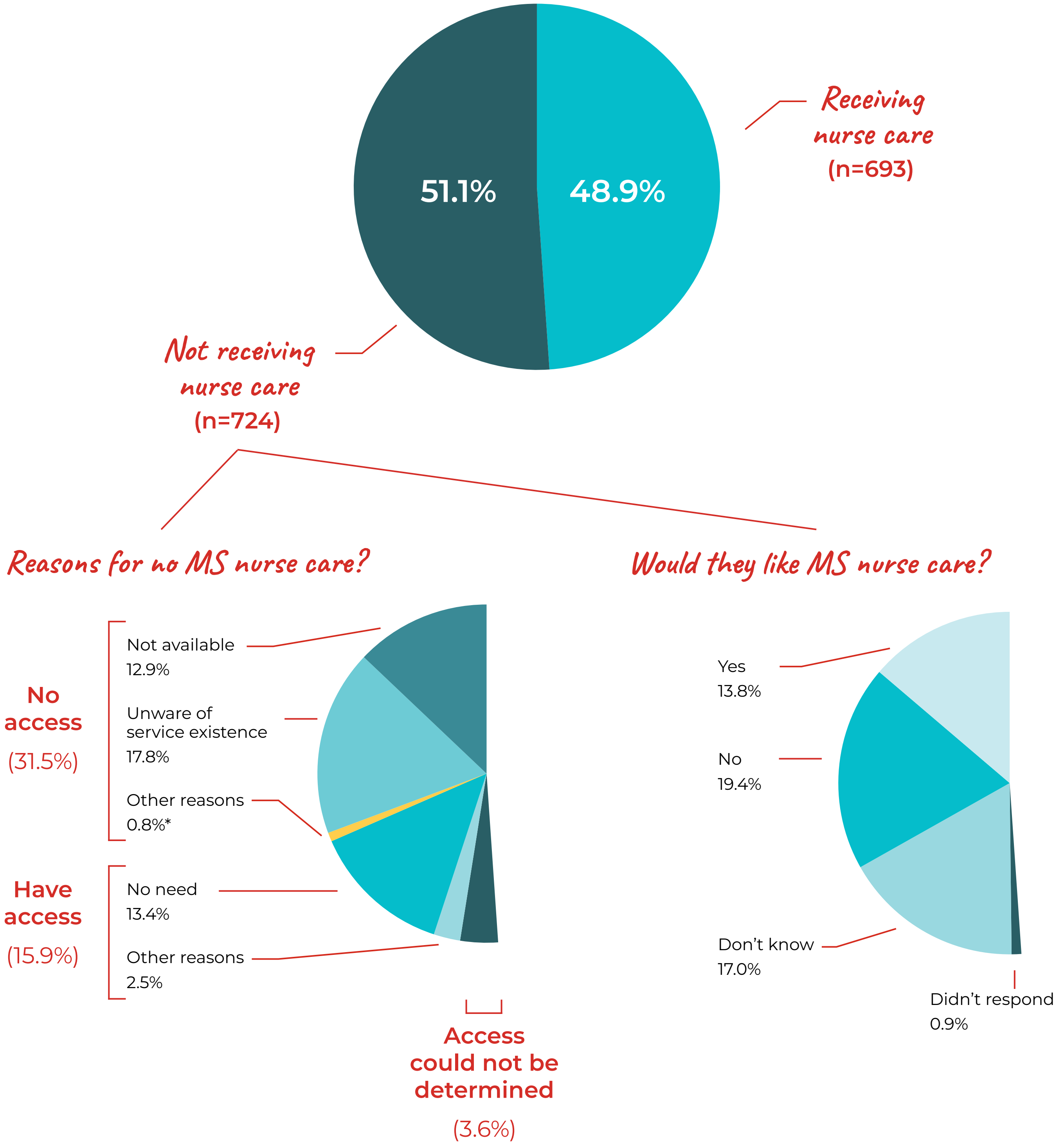


Figure 1. How many people did and did not receive MS Nurse care in Australia, the reasons and whether they would like to receive care. All values expressed as a percentage of the entire cohort (n = 1,417).

*Other reasons for no access included that they did not think they were eligible for an MS Nurse, they were living in a nursing home, or an MS Nurse was too far away.

Was not receiving MS Nurse care due to lack of access?

We also classified people not receiving MS Nurse care based on whether they had access to care (Figure 1):

- 15.9% (of n = 1,417) had access to MS Nurse care, with most of these people indicating that they did not believe they needed an MS Nurse.
- 31.5% had no access to an MS Nurse, including 12.9% who indicated that an MS Nurse was not available, 17.8% who were unaware of the existence of an MS Nurse, and 0.8% for other reasons including that they did not think they were eligible for an MS Nurse, that they did not have access because they were living in a nursing home, or that an MS Nurse was too far away.
- 3.6% of people did not receive MS Nurse care for reasons that were not specified well enough to categorise (i.e. could not define whether they had access).

> *"The majority of people with access to MS Nurses were clustered around major city centres, especially Perth, Adelaide, Hobart, Melbourne, Sydney, and Brisbane."*

Were there people *not receiving* MS Nurse care who would have liked to?

We asked those people not receiving MS Nurse care whether they would like to be. The 51.1% of participants not receiving MS Nurse care included 13.8% who said that they would like to receive care, 19.4% who said they would not like to receive MS Nurse care (i.e. they answered 'no' to this question) and 17.0% who did not know (Figure 1).

Among those not receiving MS Nurse care, those who would have liked to were on average, younger, had a shorter disease duration, were more likely to be female, were more likely to have a progressive disease course when surveyed, had a higher level of disability, were more likely to use a DMT, and were more likely to live in inner regional or outer regional Australia, compared to those who did not feel they needed MS Nurse care (Supplementary Table 1, Appendix 2).

Within this group, the major reasons for not receiving care were that an MS Nurse was not available to them (46%), or that they were unaware of the existence of MS Nurse care (37%; Supplementary Table 1).

Among people with RRMS not receiving MS Nurse care, those who said they would like to receive care were more likely to use DMTs and in particular, infusion or injection DMTs (Supplementary Table 2, Appendix 2).

For participants not receiving MS Nurse care who answered that they would not like to, the most common reason was that they believed they did not need MS Nurse care. For those that answered that they did not know if they would like to receive care, 44% reported they were unaware of the existence of MS Nurses and 28% reported that an MS Nurse was not available to them (Supplementary Table 1).

Was remoteness a major barrier to access or to receiving MS nurse care in Australia?

We next wanted to understand whether living remotely was a major barrier to accessing or receiving MS Nurse care in Australia. The majority of people with access to MS Nurses were clustered around major city centres, especially Perth, Adelaide, Hobart, Melbourne, Sydney, and Brisbane (Figure 2).

To examine this further, we used postcodes to assess how far people lived from major centres, and classified their location as either major cities, inner regional, outer regional, or remote and very remote. Those who reported having access to MS Nurse care were more likely to live in major cities (70.5%) compared to those without access (57.5%) and less likely to live in inner regional areas (22.7% vs 29.5% respectively) and outer regional areas (5.8% vs 11.2% respectively) (Supplementary Table 3, Appendix 2). This demonstrates that living further away from major care centres does reduce access to MS Nurse care in Australia.

However, even among those living in major cities, a substantial percentage (28.4%) indicated that they did not have access. And vice versa, among those living in outer regional areas, remote or very remote areas, more than half reported having access (51.2%), indicating that there were additional factors that determined whether people had access to MS Nurse care in Australia.

Lastly, we found that a high percentage of those who reported having access also received MS Nurse care. For example, 79.0% of those in outer regional areas, remote or very remote areas who reported having access to MS Nurse care also received it, suggesting that distance from major care centres was not prohibitive for most.

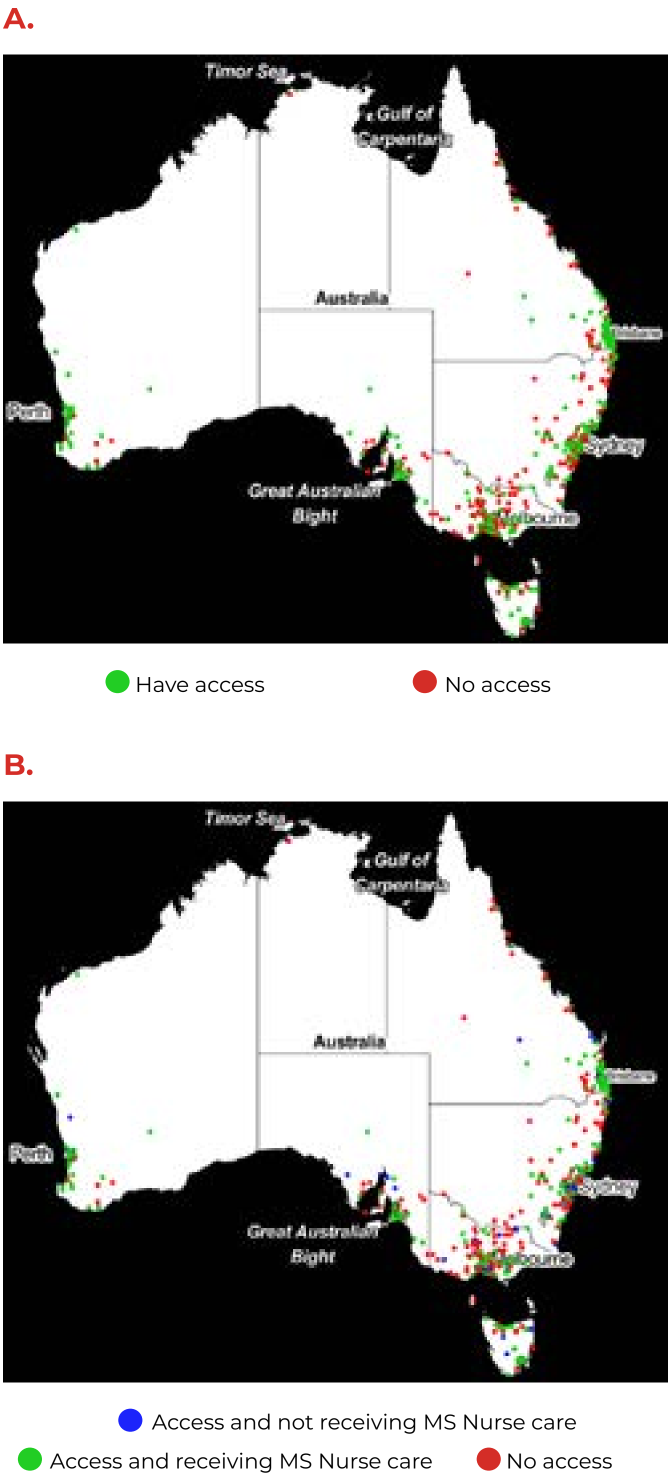


Figure 2. Location of participants by those with access (A) and those receiving MS Nurse care (B). (n = 1,417).

What characterised the group with *no access* to MS Nurse care?

We have identified three main groups of people with MS in Australia with respect to access to MS Nurse care and receiving MS Nurse care: those with no access, those with access who are not receiving MS Nurse care, and those with access who are receiving MS Nurse care. To understand how these groups differed from each other, in the next sections we examined differences in various personal and clinical characteristics (Supplementary Table 3), lifestyle and DMT use (Supplementary Tables 4 and 5, Appendix 2). In this section we compared those people *without access* to those *with access* to MS Nurse care, irrespective of whether they were receiving care.

Personal and clinical characteristics

In terms of personal and clinical characteristics, those *without access* were substantially older (60.3 years vs 56.7 years), had a longer disease duration (18.2 vs 15.9 years), were more likely to be male (23.9% vs 18.9%), were less educated (34.2% vs 42.6% with university degree), were more likely to have progressive MS (42.9% vs 24.4%), with greater disability (e.g. 25.8% vs 14.7% with severe disability), were less likely to use a DMT (54.7% vs 68.1%) and lived in areas that were more remote (e.g. 57.5% vs 70.5% in major cities) (Supplementary Table 3).

Interestingly, New South Wales (NSW) had a higher proportion of people without access to MS Nurse care (40.3%) than other states and territories (0.2-28.9%; Supplementary Table 3 even though NSW did not have higher proportions of people with MS living more remotely. The reasons for this are not clear.

Lifestyle Behaviours

There was little difference in most lifestyle behaviours measured (such as smoking, drinking alcohol, amount of sun exposure, and diet quality) between those with and without access to MS Nurse care. However, those *without access* engaged in less physical activity than those with access (e.g. 39.0% of those without access engaged in low levels of activity compared to 28.5% of those with access (Supplementary Table 4). Even after adjusting for other factors (disability, age, disease duration, education level, and gender) there was an independent effect of not having access to MS Nurse care on physical activity level. (This was shown using ordered logistic regression analysis, with an OR=0.72 (0.52-0.99), p=0.047 for every unit increase in physical activity category).

DMT use

We also assessed DMT use specifically by people with RRMS (the major users). DMT use by people with RRMS was different between those with and without access to MS Nurse care (Supplementary Table 5). Those *without access* were more likely not to use a DMT (26.2% vs 21.2%), more likely to use an oral DMT (43.6% vs 34.7%) and less likely to use an infusion DMT (16.0% vs 27.0%).

What characterised the group that *had access but did not receive* MS Nurse care?

Next, we looked at the group who *had access to MS Nurse care* and within that, compared those *receiving care* to those *not receiving care*. Those not receiving MS Nurse care were older (60.5 vs 55.5 years), had a longer disease duration (18.7 vs 15.0 years), were more likely to be male (22.1% vs 17.9%), were less educated (e.g. 37.1% vs 44.3% with a university degree), and were living in areas that were more remote (67.7% in major cities vs 71.4%). However, the major difference was that this group of people had a substantially lower level of disability (60.2% with no or mild disability compared to 49.1% for those receiving MS Nurse care). Aligned with that, they had very minimal loss of work productivity (Supplementary Table 3, Appendix 2). In terms of DMT use, those not receiving MS Nurse care were less likely to use a DMT (39.3% not using a DMT vs 15.8% of those receiving MS Nurse care) and less likely to use category 3 DMTs (35.7% vs 54.4%) or infusion DMTs (14.3% vs 30.8%) (Supplementary Table 5).

These findings suggest that this group of people chooses not to use an MS Nurse. However, it might also be driven by neurologists choosing not to refer these people to MS Nurses. To see whether there were particular patient characteristics that could underlie referral patterns from neurologists (e.g. not referring people to an MS Nurse if the disability level is very low or high), we compared histograms of age, disease duration and disability (PDDS) among those *without access* to MS Nurse care (and within this group, those who indicated they were unaware of the existence of MS Nurses), with those who *had access (including those receiving and those not receiving* MS nurse care). However, no particular patterns (e.g. bimodal distributions) were observed, and the data distributions of those without access were similar to those who had access to MS Nurse care (data not shown).

Did access to MS Nurse care alter the health outcome?

We next wanted to understand whether MS Nurse care made a difference to the health outcome. To do this, we compared health outcomes based on *access* to MS Nurse care rather than *receiving* MS Nurse care.

We compared health outcomes of those without access to MS Nurse care (31.5%) to those with access (64.8%). We excluded the 3.6% of people who did not receive MS Nurse care for reasons that were not specified well enough to classify them. In this analysis, we adjusted for differences in education level, age, MS duration, onset type and remoteness.

We found that those without access to an MS Nurse had, on average, worse disease outcomes. Table 2 shows that those who did not have access to an MS Nurse had a higher mean disability level (PDDS), self-reported progression over the past 12 months, and symptom severity for all 13 symptoms. Adjusting for differences in education level, age, MS duration, onset type and remoteness area only marginally altered the associations. For example, after accounting for difference in these factors, the mean PDDS score of those who did not have access to an MS Nurse was 1.21 (95% CI: 1.10 to 1.33) times higher than those who had access to an MS Nurse.

> "We found that those without access to an MS Nurse had, on average, worse disease outcomes."

Table 3 shows that those who did not have access to an MS Nurse had, on average, higher depression and anxiety levels, measured by the HADS (Hospital Anxiety and Depression Scale), and a lower health-related quality of life, measured by the EQ-5D. For example, after accounting for difference in education, age, MS duration, onset type and remoteness area, those who did not have access to an MS Nurse had a HADS depression score that was on average 0.87 units higher. They also had a HADS anxiety score that was on average 0.86 units higher, and an EQ-5D index score that was 7% lower compared to those who had access to an MS Nurse.

Table 2. Associations between access to an MS Nurse and health outcomes, using negative binomial regression analysis.

		Univariable	Multivariable¥
	Mean (SD)	Mean Ratio (95% CI)	Mean Ratio (95% CI)
PDDS (0-8)			
Access to an MS Nurse	2.5 (2.3)	1.00 (Ref)	1.00 (Ref)
No access	3.4 (2.4)	**1.37 (1.24 to 1.52)****	**1.21 (1.10 to 1.33)****
Self-reported progression (0-10)			
Access to an MS Nurse	1.9 (2.3)	1.00 (Ref)	1.00 (Ref)
No access	2.6 (2.5)	**1.34 (1.17 to 1.53)****	**1.23 (1.08 to 1.41)***
Vision problems (0-10)			
Access to an MS Nurse	2.1 (2.5)	1.00 (Ref)	1.00 (Ref)
No access	2.8 (2.8)	**1.31 (1.14 to 1.51)****	**1.24 (1.07 to 1.43)***
Pain (0-10)			
Access to an MS Nurse	3.1 (3.1)	1.00 (Ref)	1.00 (Ref)
No access	3.9 (3.1)	**1.26 (1.12 to 1.43)****	**1.22 (1.08 to 1.38)***
Spasticity problems (0-10)			
Access to an MS Nurse	3.4 (3.1)	1.00 (Ref)	1.00 (Ref)
No access	4.4 (3.0)	**1.28 (1.15 to 1.43)****	**1.21 (1.08 to 1.35)***
Depressive feelings (0-10)			
Access to an MS Nurse	2.8 (2.8)	1.00 (Ref)	1.00 (Ref)
No access	3.5 (2.8)	**1.23 (1.09 to 1.39)***	**1.23 (1.09 to 1.39)***
Anxious feelings (0-10)			
Access to an MS Nurse	3.0 (2.8)	1.00 (Ref)	1.00 (Ref)
No access	3.3 (2.7)	**1.13 (1.01 to 1.27**)*	**1.16 (1.03 to 1.30)***
Walking difficulties (0-10)			
Access to an MS Nurse	4.0 (3.3)	1.00 (Ref)	1.00 (Ref)
No access	5.4 (3.2)	**1.33 (1.21to 1.46)****	**1.19 (1.09 to 1.31)****
Balance problems (0-10)			
Access to an MS Nurse	4.3 (3.0)	1.00 (Ref)	1.00 (Ref)
No access	5.5 (3.0)	**1.27 (1.17 to 1.38)****	**1.17 (1.08 to 1.26)****
Bowel problems (0-10)			
Access to an MS Nurse	3.0 (3.1)	1.00 (Ref)	1.00 (Ref)
No access	3.8 (3.2)	**1.28 (1.13 to 1.46)****	**1.18 (1.03 to 1.34)***
Bladder problems (0-10)			
Access to an MS Nurse	4.0 (3.2)	1.00 (Ref)	1.00 (Ref)
No access	4.8 (3.3)	**1.22 (1.09 to 1.35)****	**1.12 (1.01 to 1.24)***

Sensory problems (0-10)			
Access to an MS Nurse	4.0 (2.8)	1.00 (Ref)	1.00 (Ref)
No access	4.6 (3.1)	**1.16 (1.06 to 1.26)***	**1.15 (1.05 to 1.25)***
Fatigue (0-10)			
Access to an MS Nurse	4.9 (2.8)	1.00 (Ref)	1.00 (Ref)
No access	5.4 (2.7)	**1.11 (1.04 to 1.19)****	**1.10 (1.03 to 1.18)**
Cognitive problems (0-10)			
Access to an MS Nurse	3.6 (2.7)	1.00 (Ref)	1.00 (Ref)
No access	4.1 (2.7)	**1.13 (1.04 to 1.23)***	**1.12 (1.02 to 1.23)***
Sexual problems (0-10)			
Access to an MS Nurse	3.4 (3.5)	1.00 (Ref)	1.00 (Ref)
No access	4.3 (3.6)	**1.26 (1.09 to 1.44)***	**1.13 (0.98 to 1.30)**

Data in bold indicates statistical significance. *P<0.05; **P<0.001. SD: standard deviation; CI: confidence interval.

¥ Adjusted for education, age, MS duration, onset type and remoteness area.

Table 3. Associations between access to an MS Nurse and quality of life, depression and anxiety, using linear regression analysis.

		Univariable	Multivariable¥
	Mean (SD)	Co-efficient (95% CI)	Co-efficient (95% CI)
EQ-5D index (0-1)			
Access to an MS Nurse	0.74 (0.22)	0.00 (Ref)	0.00 (Ref)
No access	0.65 (0.25)	**-0.09 (-0.12 to – 0.07)****	**-0.07 (-0.10 to – 0.5)****
HADS-depression score (0-21)			
Access to an MS Nurse	5.0 (3.8)	1.00 (Ref)	1.00 (Ref)
No access	5.9 (3.7)	**0.88 (0.46 to 1.31)****	**0.87 (0.43 to 1.30)****
HADS-anxiety score (0-21)			
Access to an MS Nurse	6.6 (4.1)	1.00 (Ref)	1.00 (Ref)
No access	7.3 (4.4)	**0.71 (0.25 to 1.18)**	**0.86 (0.37 to 1.33)***

Data in bold indicates statistical significance. *P<0.05; **P<0.001. SD: standard deviation; CI: confidence interval.

¥ Adjusted for education, age, MS duration, onset type and remoteness area.

How is MS Nurse care provided in Australia?

We next sought to understand how MS Nurse care is provided in Australia, including:

- Which organisations were providing care
- Length of time people received care
- How often people received care (and determining factors)
- Level of satisfaction with the frequency of MS Nurse contact
- Types of MS Nurse consultations, including for people living remotely

Which organisations provided MS Nurse care?

Among the 693 participants who received MS Nurse care, this occurred most often through community providers (such as a state or territory MS Member Organisation) (45.7%) and public hospital clinics (44.9%) (Figure 3). Fewer people received MS Nurse care via a private neurologist (13.4%) or a pharma patient support program (4.8%).

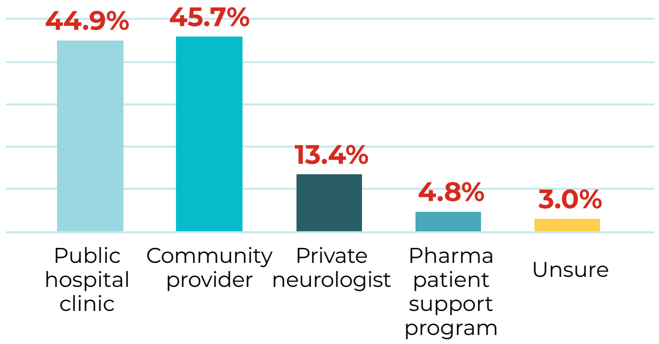


Figure 3. MS Nurse providers used by people with MS (n = 693).

Length of time people received MS Nurse care?

Among those receiving MS Nurse care, 45% had received MS Nurse care for more than 10 years, 24% for 6-10 years, 24% for 1-5 years and 7% for less than 1 year (Figure 4).

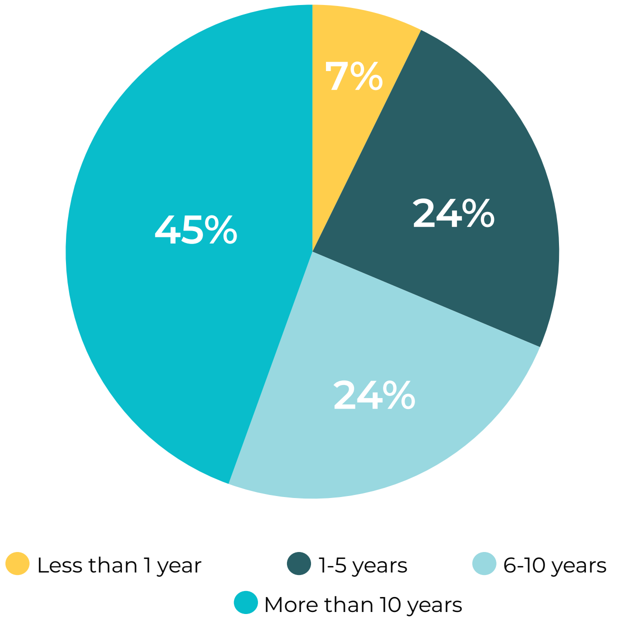


Figure 4. Duration of MS Nurse care (n = 693).

How often did people contact their MS Nurse and what determined the frequency?

Among those receiving MS Nurse care in Australia, almost half (49%) reported that they had contact with an MS Nurse less than once per year, 29% annually, 4% monthly, and 1% weekly (Figure 5).

Compared to those who had quarterly/ monthly/weekly contact with an MS Nurse, those who had less than annual contact were slightly older (56.5 years vs 53.2-55.5 years), had a lower level of disability (54.2% vs 38.5-48.0% with no or mild disability), and were more likely to live in major cities (73.7% vs 67.5-70.9%) (Supplementary Table 6, Appendix 2). In addition, they were less likely to use infusion DMTs (22.1% vs 36.9-47.8%) and more likely to use oral DMTs (38.5% vs 25.0%-31.1%) (Table 4: full data in Supplementary Table 7, Appendix 2), suggesting that use of infusion DMTs might be a major reason for receiving MS Nurse care more frequently.

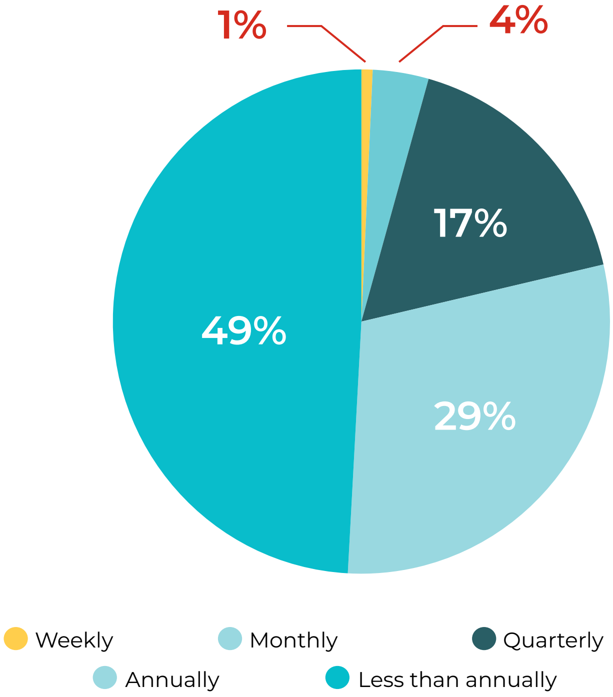


Figure 5. Frequency of contact with an MS Nurse (n = 693).

Table 4. DMT use (by people with relapsing remitting MS) receiving MS Nurse care according to frequency of contact.

	Less than annually	Annually	Quarterly	Monthly/Weekly
	N=231	N=141	N=83	N=16
Route of administration for DMTs used				
Not using a DMT	42 (18.2)	21 (14.9)	8 (9.6)	4 (25.0)
Injectable DMTs	48 (20.8)	24 (17.0)	10 (12.0)	1 (6.3)
Infusion DMTs	51 (22.1)	52 (36.9)	35 (42.2)	7 (47.8)
Oral DMTs	89 (38.5)	44 (31.2)	30 (36.1)	4 (25.0)

Above: MS and Continence Nurse K-J Lazarus reviewing results during a telephone consult

Were people satisfied with the frequency of MS Nurse contact?

When asked what they thought about the level of contact with an MS Nurse over the past 12 months, 79% indicated that the amount was about right (Figure 6). The percentage of people satisfied increased with increased frequency of contact over the last 12 months. Very few people reported that the amount of contact was too much (0.3%).

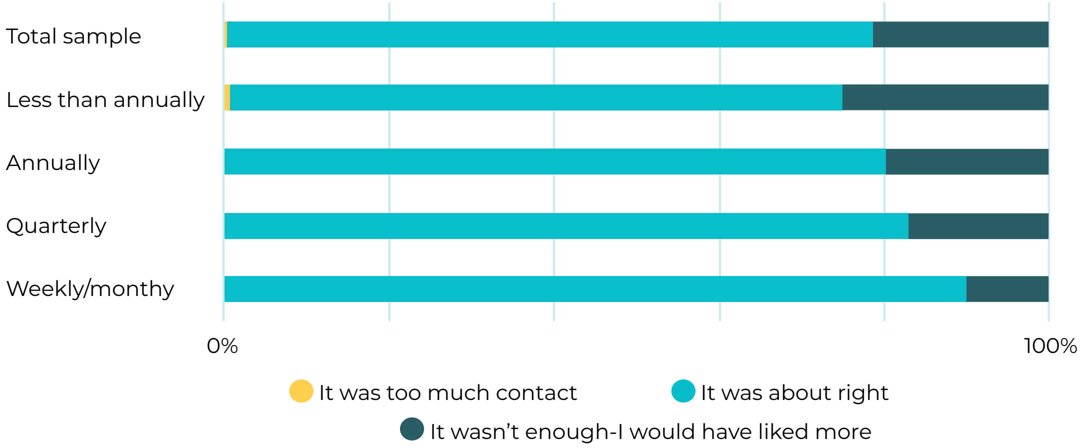


Figure 6. Satisfaction with the amount of MS Nurse contact in the last 12 months (n = 656).

Types of consultations with an MS Nurse in the past 12 months

We asked those receiving MS Nurse care how many times they had had a consultation with an MS Nurse in different settings in the past 12 months, including clinic consultation, home visit, phone or telehealth (Skype/Zoom/webcam) consultation, email contact or visit from an MS Nurse while a hospital inpatient.

People most frequently had phone consultations (40.1%), clinic consultations (39.8%), and email contact (26.7%) (Table 5). Telehealth was not used by many people (2.2%), and 5.5% and 3.0% received a visit from an MS Nurse in the home or hospital, respectively. Remoteness had little impact on the use of clinic consultations, but those living in more remote areas were more likely to have phone consultations or home visits (Table 6).

Table 5. Number of consultations with an MS Nurse over the past 12 months for each type of consultation.

	Phone consultation	Clinic consultation	Email contact	Home visit	Telehealth	While a hospital inpatient
Had any consultations, n (%)	278 (40.1)	276 (39.8)	185 (26.7)	38 (5.5)	15 (2.2)	21 (3.0)
One consultation	147 (21.2)	152 (21.7)	70 (10.1)	27 (3.9)	11 (1.6)	12 (1.7)
Two consultations	65 (9.4)	85 (12.3)	42 (6.1)	8 (1.1)	3 (0.4)	4 (0.6)
3-5 consultations	51 (7.4)	28 (4.0)	56 (8.1)	2 (0.3)	1 (0.1)	5 (0.7)
>5 consultations	15 (2.1)	11 (1.6)	17 (2.4)	1 (0.1)	0 (0.0)	0 (0.0)

Table 6. Consultations with an MS Nurse over the past 12 months according to remoteness.

	Overall	Major Cities	Inner Regional	Outer Regional/ Remote/Very Remote
	N=693	N=495	N=149	N=49
Any consultations over the phone, n (%)	278 (40.1)	183 (37.0)	72 (48.3)	23 (46.9)
Any clinic consultations, n (%)	276 (39.8)	196 (39.6)	61 (40.9)	19 (38.8)
Any home visits, n (%)	38 (5.5)	24 (4.8)	8 (5.4)	6 (12.2)
Any telehealth, n (%)	15 (2.2)	8 (1.6)	5 (3.4)	2 (4.1)
Any visits while a hospital inpatient, n (%)	21 (3.0)	12 (2.4)	5 (3.4)	4 (8.2)

Are MS Nurses valuable to people with MS?

We wanted to understand whether people with MS felt that MS Nurse care was valuable, and what difference it made to their health.

We asked:

- Whether MS Nurse care was helpful overall
- Which specific supports were provided as part of MS Nurse care and whether they were useful
- What difference it would have made if MS Nurse access was removed
- Whether MS Nurse care helped with:
  - adherence to MS treatments
  - management of MS symptoms or side effects
  - leading a healthier lifestyle

> *"A total of 78% reported that receiving MS Nurse care was very helpful (49%) or somewhat helpful (29%)."*

Was MS Nurse care helpful overall?

We asked participants: "Overall, how would you rate the value of having an MS Nurse?" A total of 78% reported that receiving MS Nurse care was very helpful (49%) or somewhat helpful (29%) (Figure 7).

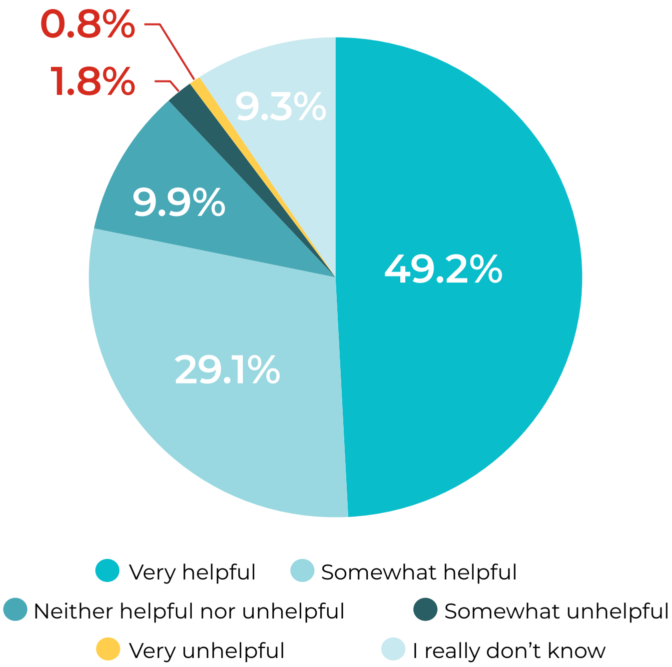


Figure 7. Rated overall value of receiving MS Nurse care (n = 667).

The percentage of people rating MS Nurse care as very helpful was higher among those who received MS Nurse care more frequently or for longer (Figure 8). For example, among those who had monthly or weekly contact with an MS Nurse, 83% rated MS Nurse care as very helpful and 13% somewhat helpful. In contrast, among those who had less than annual contact with an MS Nurse, only 43% rated MS Nurse care as very helpful.

When we examined the value of MS Nurse care by type of service provider, we found similar total proportions (combining very helpful and somewhat helpful) for all service provider types, although the proportion of those rating it as 'very helpful' was a little lower for MS Nurse care provided through a private neurologist (Figure 9).

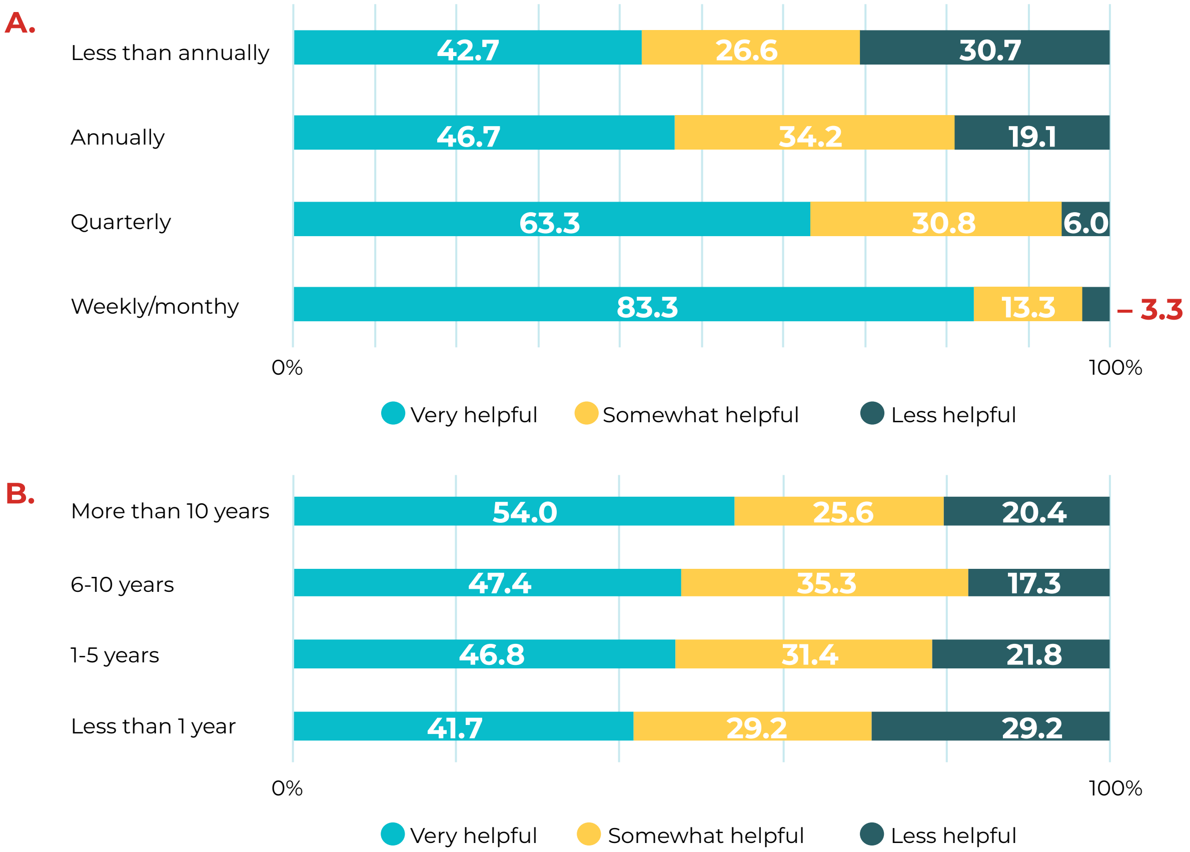


Figure 8. Rated value of MS Nurse care according to the frequency (A) and length (B) of care. (Panel A: less than annually, n = 316; annually, n = 119; quarterly, n = 117; weekly/monthly, n = 30. Panel B: more than 10 years, n = 285; 6-10 years, n = 156; 1-5 years, n = 156; less than 1 year, n = 48. 'Less helpful' includes 'neither helpful nor unhelpful', 'somewhat unhelpful', 'very unhelpful', 'I really don't know').

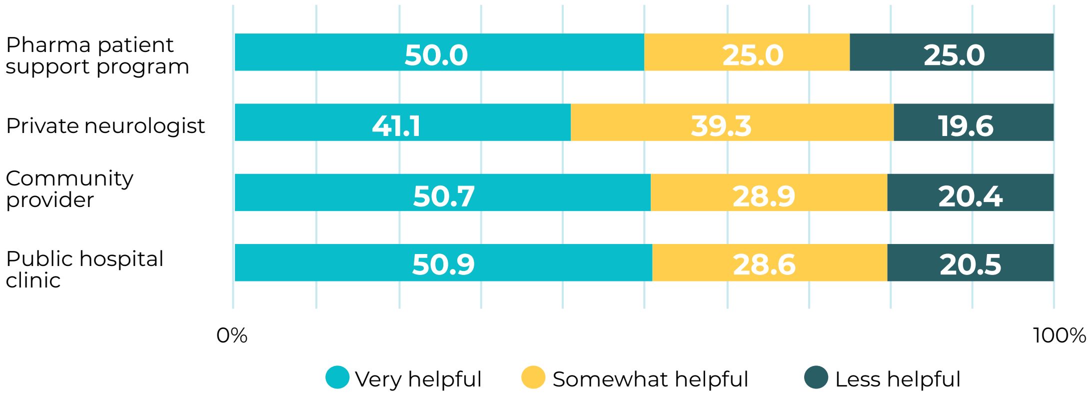


Figure 9. Rated value of MS Nurse care by service provider. (Pharma patient support program, n = 12; private neurologist, n = 56; community provider, n = 211; public hospital clinic, n = 220. 'Less helpful' includes 'neither helpful nor unhelpful', 'somewhat unhelpful', 'very unhelpful', 'I really don't know').

We also examined characteristics of people with MS by the rated overall value of having an MS Nurse. Those who rated MS Nurse care as less helpful were more likely to be male, have a higher education level, have progressive MS (PPMS or SPMS) and to live in inner regional Australia (Table 7).

Opposite: MS Nurse and Research Manager Belinda Bardsley explaining the disease process in MS

Table 7. Personal and clinical characteristics according to rated overall value of MS Nurse care.

	Very helpful	**Somewhat helpful**	**Less helpful***
	N=328	N=194	N=145
Age (years), mean (SD)	54.9 (11.3)	55.0 (10.0)	56.5 (11.3)
MS duration since diagnosis (years), mean (SD)	14.9 (8.3)	14.9 (7.2)	15.3 (7.4)
Age at MS diagnosis	39.9 (10.6)	40.0 (10.2)	41.0 (11.3)
Gender, n (%)			
Female	280 (85.4)	155 (79.9)	112 (77.2)
Male	48 (14.6)	39 (20.1)	33 (22.8)
Education, n (%)			
Primary/secondary school	70 (21.4)	45 (23.3)	39 (26.9)
Occupational certificate	118 (36.1)	65 (33.7)	32 (22.1)
University degree	139 (42.5)	83 (43.0)	74 (51.0)
MS type in 2019, n (%)			
Relapsing remitting MS	239 (72.9)	133 (68.6)	88 (60.7)
Secondary progressive MS	37 (11.3)	33 (17.0)	25 (17.2)
Primary progressive MS	28 (8.5)	16 (8.3)	20 (13.8)
Progressive relapsing MS	4 (1.2)	5 (2.6)	3 (2.1)
Unsure	20 (6.1)	7 (3.6)	9 (6.2)
Disability level, n (%)			
No disability or Mild	167 (51.2)	92 (47.9)	68 (47.2)
Moderate	114 (35.0)	70 (36.5)	55 (38.2)
Severe	45 (13.8)	30 (15.6)	21 (14.6)
Use of a DMT			
Yes	255 (78.2)	149 (76.8)	99 (69.3)
No	71 (21.8)	45 (23.2)	44 (30.7)
Remoteness level			
Major Cities	240 (73.2)	137 (70.6)	98 (67.6)
Inner Regional	68 (20.7)	38 (19.6)	38 (26.2)
Outer Regional	17 (5.2)	17 (8.8)	8 (5.5)
Remote/Very Remote	3 (0.9)	2 (1.0)	1 (0.7)

* Includes ‘neither helpful nor unhelpful’, ‘somewhat unhelpful’, ‘very unhelpful’, ‘I really don’t know’


A look at the nervous system

What specific supports were provided as part of MS Nurse care and were they useful?

We identified a list of specific supports provided as part of MS Nurse care. For each type of support, we asked whether 1) the support was provided and helpful 2) the support was provided but not helpful 3) the support was not needed or 4) they did not receive the support but would have liked it. These are shown as percentages in Figure 10 (with absolute numbers in Supplementary Table 8, Appendix 2). Supplementary Table 9 (Appendix 2) shows these data, but with the people who did not need a particular support excluded. Thus, it provides the percentages among those who needed the services.

The most frequently reported helpful supports provided by an MS Nurse included 'advice on the management of MS symptoms' (54.7%), 'advice on the management of treatment side effects' (48.6%), 'providing education and information to assist with informed treatment decisions' (46.9%) and 'providing education to assist with the use and follow-up monitoring of disease modifying therapies' (41.7%).

Very few people indicated that the support provided was not helpful (<3%). The supports that were most frequently reported as not helpful were 'advice on the management of treatment side effects' (2.8%), 'advice on the management of MS symptoms' (2.2%), and 'providing education to assist with the use and follow-up monitoring of disease modifying therapies' (2.2%).

The more frequently reported supports that people did not receive but would have liked to, were 'providing information and education about clinical trials' (24.4%), 'assisting with assessing other support services (e.g. physiotherapist, occupational therapist, psychologist, disability employment services, speech pathologist, massage therapist, Continence Nurse, peer support programs, counsellor, dietitian and psychiatrist)' (22.1%), 'providing information, resources or weblinks to relevant research' (17.3%) and 'emotional or psychological support' (17.0%).

"The most frequently reported helpful supports provided by an MS Nurse included 'advice on the management of MS symptoms' (54.7%), 'advice on the management of treatment side effects' (48.6%) [and] 'providing education and information to assist with informed treatment decisions' (46.9%)..."

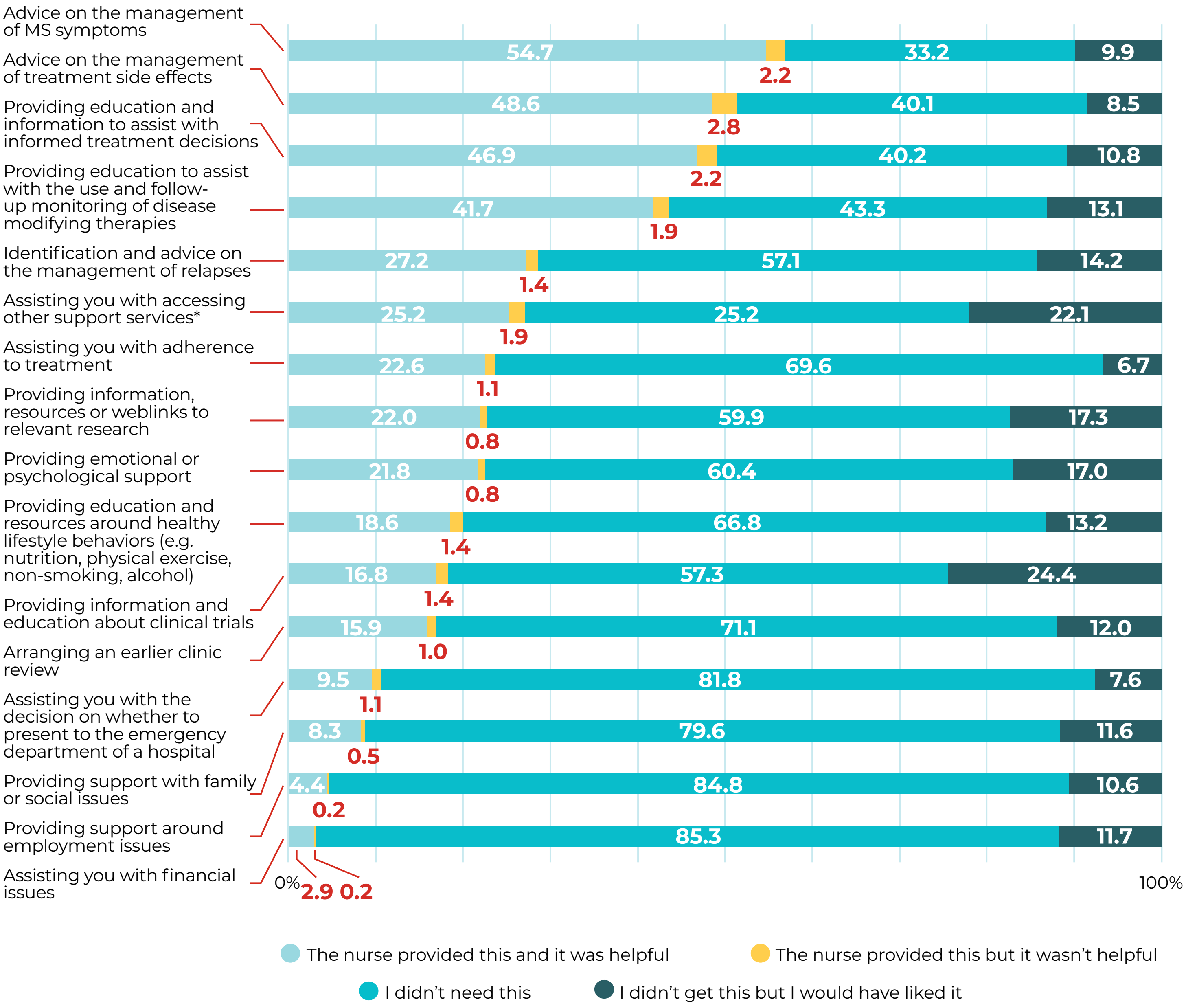


Figure 10. Rated usefulness of specific supports received as part of MS Nurse care. Categories are sorted by whether ‘the Nurse provided this and it was helpful’. (*E.g. physiotherapist, occupational therapist, psychologist, disability employment services, speech pathologist, massage therapist, Continence Nurse, peer support programs, counsellor, dietitian and psychiatrist) (% of n = 693).

What difference would it have made if access to MS Nurse care was removed?

We asked people with MS: “If you hadn’t had access to an MS Nurse service over the past 12 months, what difference do you think it would have made to you?”

Overall, 35% reported that it would have made no difference, 21% would have seen their GP more, 21% would have asked to see their neurologist more, 20% reported that they would have struggled on their own, and 5% would have had to go to the hospital or the emergency department more often (Figure 11A).

There were clear patterns when this was viewed against frequency with which people received MS Nurse care in the last 12 months (Figure 11B). For example, those who received MS Nurse care weekly or monthly were far less likely to report that it would have made no difference (4%), compared to those who received MS Nurse care less than once a year (47%). In contrast, those who received MS Nurse care weekly or monthly were more likely to report that they would have had to see a GP, neurologist, or go to the hospital or emergency department more often or would have struggled on their own if access was removed.

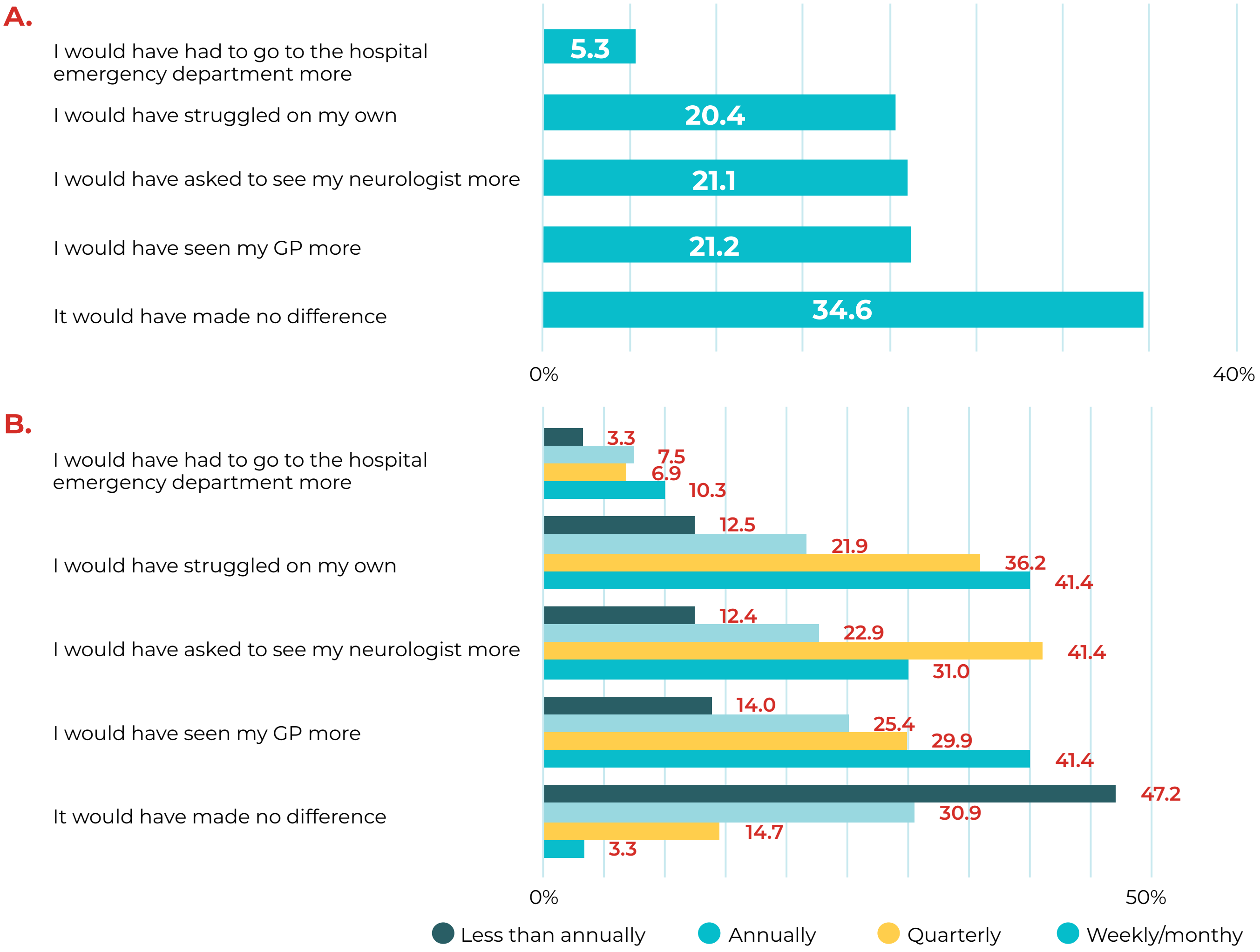


Figure 11. The difference it would have made having no access to MS Nurse care over the past 12 months. Results are presented overall (A) (n = 693) and by the frequency of MS Nurse care (B) (less than annually, n = 338; annually, n = 203; quarterly, n = 117; weekly/monthly, n = 30).

Did MS Nurse care help with adherence to MS treatments?

We asked whether MS Nurse care improved adherence to MS treatments among people with RRMS who were using a DMT. In total, 30.4% reported that MS Nurse care definitely or may have improved adherence to treatment, 50.9% reported it did not result in any changes in adherence and 18.8% did not know whether it made a difference to adherence (Figure 12). The 30.4% who thought it definitely or may have improved adherence to treatment increased to 51.3% when we restricted the analysis to those who felt they needed assistance with adherence.

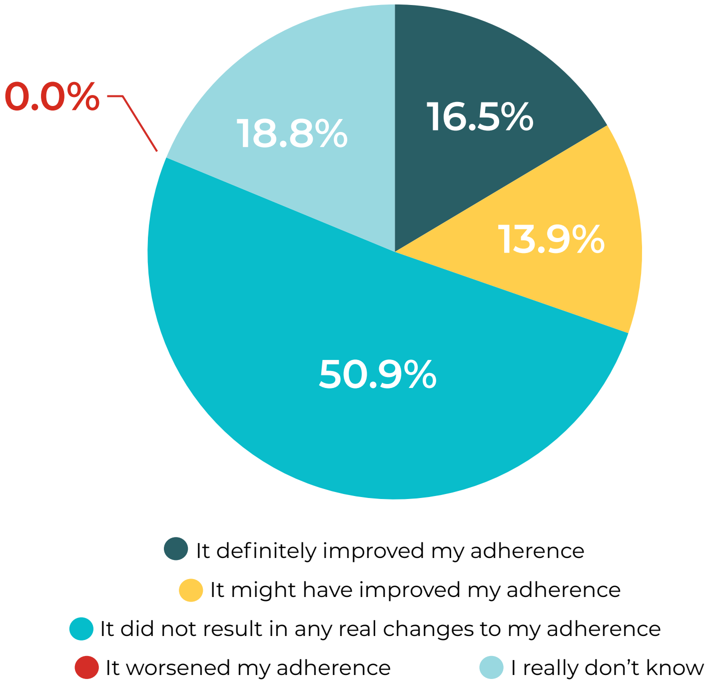


Figure 12. Reported effect of MS Nurse care on the adherence to treatments among people with relapsing remitting MS who were using a DMT (n = 389).

Right: MS Research Nurse Melanie McMurtrie recording observations during a medication infusion

> *"Those using oral DMTs were more likely to report that MS Nurse care improved or might have improved their adherence."*

Those using oral DMTs were more likely to report that MS Nurse care improved or might have improved their adherence (Table 8).

Those using category 2 DMTs were more likely to report that an MS Nurse improved or might have improved their adherence, possibly due to category 2 DMTs including many of the oral DMTs.

Table 8. Reported effect of MS Nurse care on the adherence to treatments among people with relapsing remitting MS who were using a DMT (according to route of administration and DMT category).

	Routes of DMT administration		
	Injectable DMTs	Infusion DMTs	Oral DMTs
It definitely improved my adherence, n (%)	11 (13.4)	23 (16.1)	30 (18.4)
It might have improved my adherence, n (%)	11 (13.4)	15 (10.5)	28 (17.2)
It did not result in any real changes to my adherence, n (%)	41 (50.0)	77 (53.9)	79 (48.5)
It worsened my adherence, n (%)	0 (0.0)	0 (0.0)	0 (0.0)
I really don't know, n (%)	19 (23.2)	28 (19.6)	26 (15.9)
Total, n (%)	82 (100.0)	143 (100.0)	163 (100.0)
	DMT category*		
	Category 1 DMTs	Category 2 DMTs	Category 3 DMTs
It definitely improved my adherence, n (%)	11 (13.1)	12 (23.1)	41 (16.3)
It might have improved my adherence, n (%)	11 (13.1)	14 (26.9)	29 (11.5)
It did not result in any real changes to my adherence, n (%)	41 (48.8)	22 (42.3)	134 (53.2)
It worsened my adherence, n (%)	0 (0.0)	0 (0.0)	0 (0.0)
I really don't know, n (%)	21 (25.0)	4 (7.7)	48 (19.0)
Total, n (%)	84 (100.0)	52 (100.0)	252 (100.0)

*DMT categories: Category 1 DMTs (injectable platform DMTs) include interferons-β and glatiramer acetate; Category 2 DMTs include teriflunomide and dimethyl fumarate; Category 3 DMTs (higher efficacy) include natalizumab, fingolimod, alemtuzumab, ocrelizumab and cladribine.

Did MS Nurse care help with the management of MS symptoms or side effects?

We asked whether MS Nurse care improved the management of MS symptoms or side effects. In total, 43.2% reported that MS Nurse care definitely or may have improved MS symptoms or side effects, 38.3% thought it did not result in any real changes, 17.9% did not know whether it made a difference and 0.6% thought it might have worsened management of symptoms (Figure 13).

The 43.2% who thought it definitely or may have improved MS symptoms or side effects increased to 52.5% when we limited to those people who felt that they actually needed assistance with symptom management or side effects.

The proportion of people who reported ‘it definitely improved my management of MS symptoms and side effects’ was somewhat higher in RRMS (24%) than SPMS (18%) or PPMS (19%) (Figure 14).

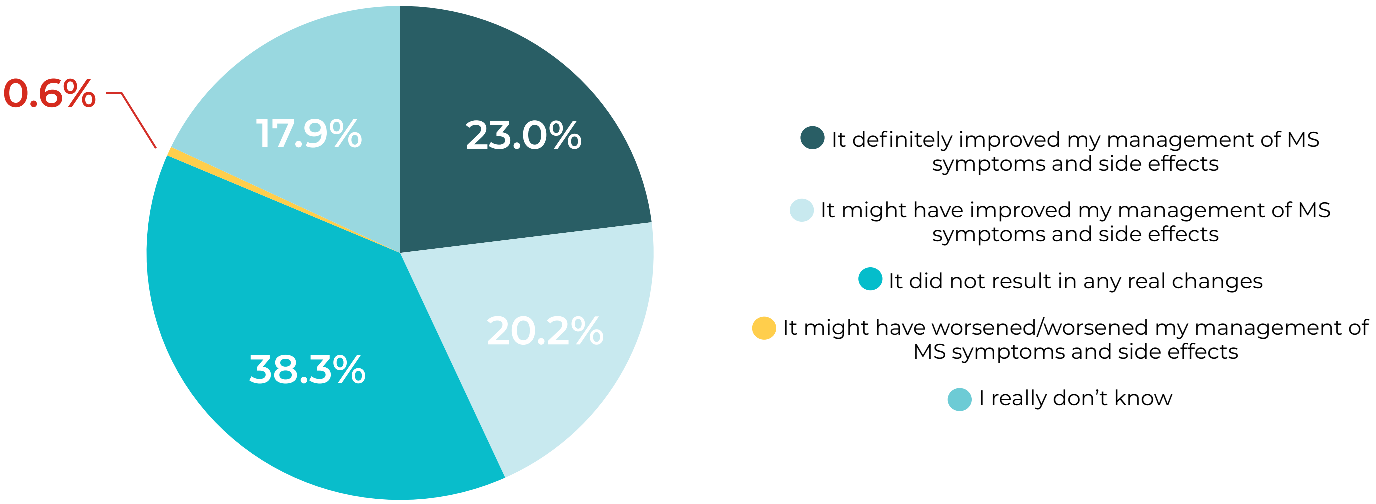


Figure 13. Reported effect of MS Nurse care on the management of MS symptoms and side effects (n = 669).

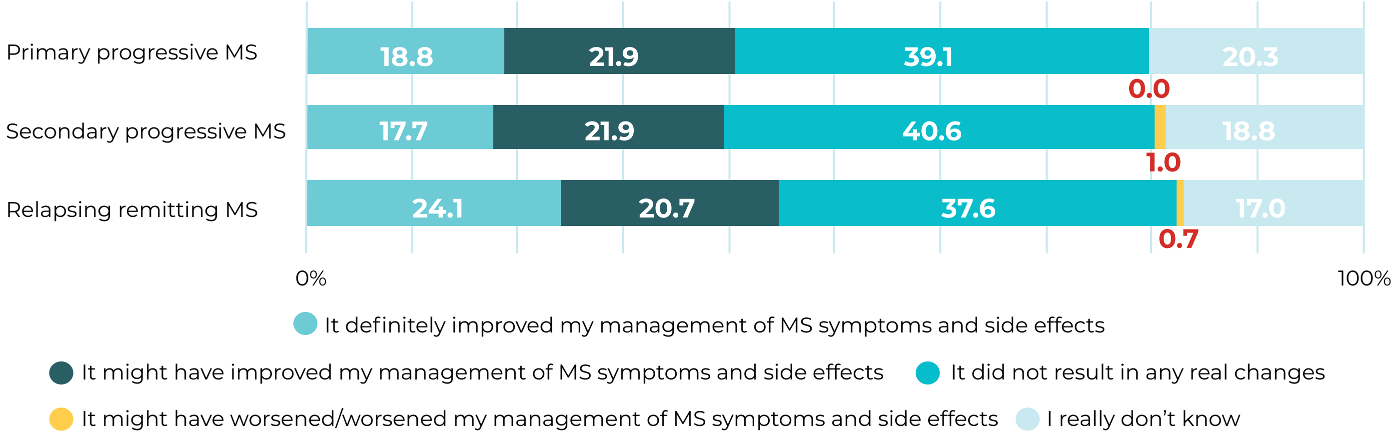


Figure 14. Reported effect of MS Nurse care on management of MS symptoms and side effects by MS type (primary progressive MS, n = 64; secondary progressive MS, n = 96; relapsing remitting MS, n = 460).

Did MS Nurse care help people lead a healthier lifestyle?

We asked whether MS Nurse care contributed to leading a healthier lifestyle. In total, 36.2% thought it definitely or might have assisted them with leading a healthier lifestyle, 41.6% thought it did not assist with a healthier lifestyle, and 22.1% did not know whether it made a difference (Figure 15). The 36.2% who thought an MS Nurse definitely or may have contributed to a healthier lifestyle increased to 54.3% when we limited to those people who felt that they actually needed assistance with leading a healthier lifestyle.

The percentage of people reporting 'it definitely assisted me with leading a healthier lifestyle' was higher in people with PPMS (18%) compared to people with SPMS (10%) or RRMS (13%) (Figure 16).

Not surprisingly, those who rated MS Nurse care as being very helpful overall were more likely to report that MS Nurse care improved their adherence to MS treatments, improved their management of MS symptoms or side effects, assisted them with leading a healthier lifestyle (Supplementary Table 9, Appendix 2).

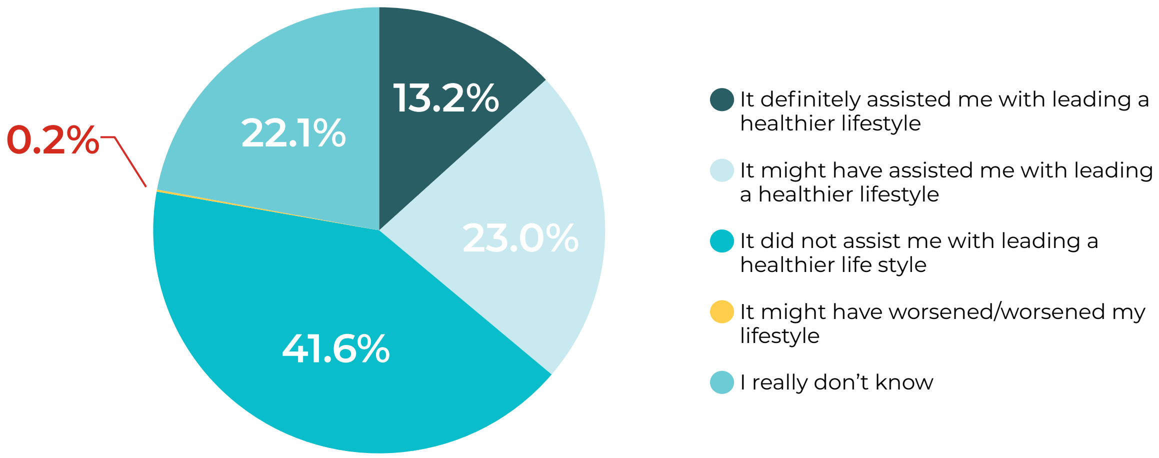


Figure 15. Reported effect of MS Nurse care on leading a healthier lifestyle (n = 666).

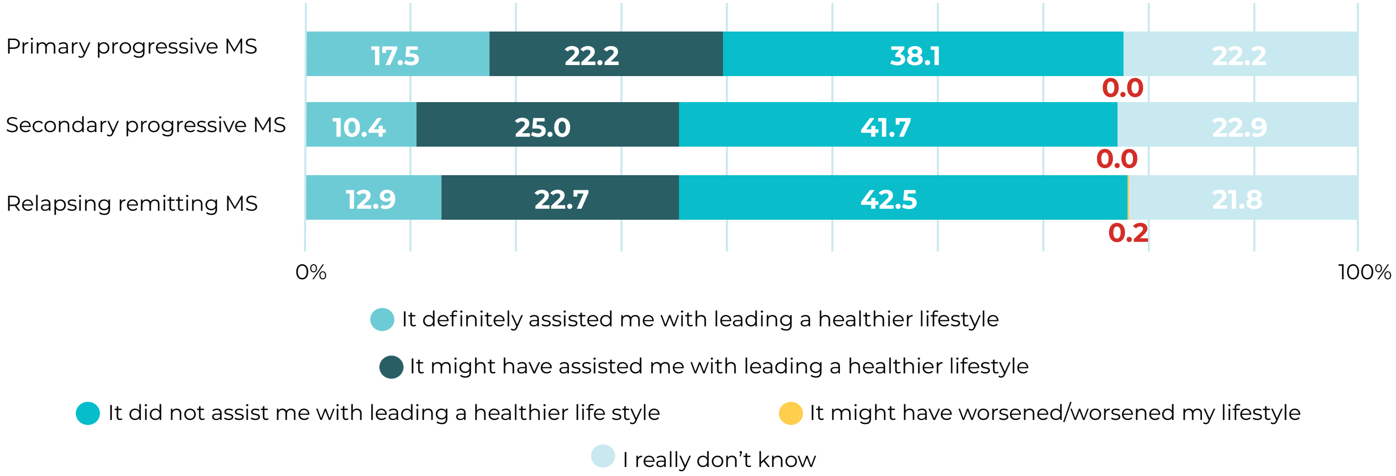


Figure 16. Reported effect of MS Nurse care on leading a healthier lifestyle by MS type (primary progressive MS, n = 63; secondary progressive MS, n = 96; relapsing remitting MS, n = 459).

MS Immunotherapy Nurse Edith Cinc conducting routine blood sampling for safety monitoring of MS medications

Could increased access to MS Nurse care reduce the overall economic cost of MS in Australia?

We wanted to understand whether increased access to MS Nurse care could reduce the economic cost of MS in Australia. We estimated the total economic cost of MS for those who do not currently have access to MS Nurse care in Australia. Estimated cost savings of 5%, 10%, 15% and 20% if this group did have access were calculated and compared with the estimated cost of providing access.

The results in the previous sections provided the following evidence for potential cost savings with increased access to MS Nurse care:

- 21% of participants who used an MS Nurse service reported that they would have seen their neurologist more frequently in the previous 12 months if they had no access to an MS Nurse service. Thus, an MS Nurse service seems to avoid more costly neurologist appointments.
- 20% of participants who used an MS Nurse service reported that they would have seen their GP more frequently in the previous 12 months if they had no access to an MS Nurse service. Thus, an MS Nurse service seems to avoid more costly GP appointments.
- 5% of participants who used an MS Nurse service reported that they would have otherwise needed to go to an emergency department. Thus, an MS Nurse service avoids unnecessary emergency department presentations, and any related costly hospital admissions.
- People without access to MS Nurse care had health outcomes that were, on average, 10-24% worse than those with MS Nurse care access, including disability and 13 common MS symptoms. In addition, the health-related quality of life (assessed with the EQ-5D-5L) was 7% (0.07 utility points) lower. The clinically meaningful difference for the EQ-5D-5L for people with chronic and complex disease is 4% (0.04 utility points). Thus, an MS Nurse service improved health outcomes, which may be expected to translate to reduced health economic impact of MS.
- Improved health and health-related quality of life outcomes may be partly the result of improved DMT adherence, improved symptom management and a healthier lifestyle. People with access to an MS Nurse service were more likely to use DMTs (68.1%) compared to those without access to an MS Nurse (54.7%). For those using an MS Nurse, 30.4% thought it definitely or may have improved the adherence to treatment, 43.2% thought it definitely or may have improved MS symptoms or side effects and 36.2% thought it definitely or might have assisted them with leading a healthier lifestyle.

We estimated that the total annual cost of those without access to an MS Nurse – 7,938 Australians with MS (31% of the total MS population in this country) – was $599 million in 2017 which in 2021 equated to $643 million. We accounted for the proportions of different levels of disability measured within our representative cohort, and the costs of each of these (from 2017 estimates, corrected for inflation to reflect 2021 estimates). If access to an MS Nurse service reduced by 5%, 10%, 15% or 20%, the total costs of those currently without access to an MS Nurse, then this would generate an annual cost saving of $32.2 million, $64.3 million, $96.5 million, or $128.7 million respectively (Table 9).

Table 9. Potential cost savings if people without access to MS Nurse care had access to an MS Nurse, for different percentages of avoided costs.

Disease severity category	Proportions of those without MS Nurse access (%)	Total number of Australians with MS without MS Nurse access*	Total 2017 costs for those without MS Nurse access ($Mil)	Total 2021 costs for those without MS Nurse access** ($Mil)	Cost savings for various percentages of avoided costs 2021 AUD ($Mil)			
					5%	10%	15%	20%
No/mild	34.4	2,731	120.8	129.8	6.5	13.0	19.5	26.0
Moderate	39.8	3,159	243.0	261.0	13.1	26.1	39.2	52.2
Severe	25.8	2,048	235.1	252.6	12.6	25.3	37.9	50.5
Total	**100**	**7,938**	**599.0**	**643.4**	**32.2**	**64.3**	**96.5**	**128.7**

*31% of 25,607 people with MS in Australia[30] = 7,938 people living with MS without access to an MS Nurse service.

**Estimated from 2017 AUD costs per person per annum from 2017 Report on health economic impact[28] (2017 total costs, including direct and indirect costs for each level of disability were: no/mild disability $44,254; moderate disability $76,916; severe disability $114,813). Costs were corrected for inflation (rounded to the nearest dollar) using the Reserve Bank of Australia's calculator for the Consumer Price Index https://www.rba.gov.au/calculator/

If an additional 50 MS Nurses were required to provide care for the nearly 8,000 people currently without MS Nurse access in Australia, at a conservative cost of $100,000 per annum per MS Nurse, the total salary costs would be $5.0 million.

> *"We estimated that the total annual cost of those without access to an MS Nurse – 7,938 Australians with MS (31% of the total MS population) – was $599 million in 2017 which in 2021 equated to $643 million."*

Discussion

In this Report, we have described, for the first time, patterns of access to MS Nurse care in Australia in a large representative cohort of people with MS. We identified significant gaps in access to MS Nurse care for people with MS in Australia. Among those with access, we identified the reasons for receiving MS Nurse care. We demonstrated that access to MS Nurse care improved the health outcomes of people with MS and defined the healthcare services through which MS Nurse care is delivered in Australia.

This Report also describes the specific care provided by MS Nurses and its value to people with MS. We explored the potential to decrease the economic costs of MS by expanding MS Nurse care in Australia. In this section we discuss potential ways to improve access to and uptake of MS Nurse care in Australia and recommend specific steps towards equitable access and optimal provision of MS Nurse care in Australia.

> "Those without access to MS Nurse care had a lower level of physical activity compared to those who had access... suggesting that MS Nurse care may contribute positively to levels of physical activity."

Who didn't receive MS Nurse care in Australia and was there an access problem?

Of the 31.5% who did not have access to MS Nurse care, 12.9% indicated that MS Nurse care was not available, 17.8% were unaware of the existence of an MS Nurse, and the remaining <1% did not have access because they thought they were not eligible for MS Nurse care, were living in a nursing home, or an MS Nurse service was too far away.

Compared to those with access, those without access were substantially older, had a longer disease duration, were more likely to be male, were less educated, were more likely to have progressive MS, had more disability and lived in areas that were more remote. Despite remoteness being a factor, an examination of the postcodes of participants showed that 28% of people in major cities had no access, while 51% of people living in outer regional areas, remote or very remote areas have access. This indicates that there are additional factors underlying lack of access. People without access were less likely to use DMTs, more likely to use oral DMTs and less likely to use infusion DMTs. On the other hand, there was little difference in lifestyle behaviours such as smoking, drinking alcohol, amount of sun exposure, and diet quality between the two groups. However, those without access to MS Nurse care had a lower level of physical activity compared to those who had access, with only part of the effect due to differences in disability, suggesting that MS Nurse care may contribute positively to levels of physical activity.

The percentage of people without access to MS Nurse care was higher in New South Wales compared to other states and territories and this was not due to being more likely to live in remote areas. We also assessed across the entire cohort whether there were particular patterns in disability, age and disease duration that could underlie referral patterns from neurologists that bias access or receiving care (i.e. not referring people to an MS Nurse if the disability level is very low or high), but no such patterns were observed.

Among the 64.9% of participants who could access MS Nurse care, 15.9% did not receive this care. While they shared many characteristics with the group without access to an MS Nurse (older, longer disease duration, more likely male, less educated, and living in areas that were more remote), the major difference was that this group of people had a substantially lower level of disability (60.2% had no or mild disability compared to 49.1% of those receiving MS Nurse care). This suggests that among those with access to MS Nurse care, disability is a major driver to seek MS Nurse care. In terms of DMT use, those not receiving MS Nurse care were less likely to use a DMT (39.3% not using a DMT vs 15.5% who received MS Nurse care not using a DMT) and less likely to use high efficacy DMTs (35.7% vs 54.4%) or infusion DMTs (14.3% vs 30.8%).

Among the 51.1% of participants who did not receive MS Nurse care, 13.8% indicated that they would like to receive MS Nurse care, while 19.4% did not feel the need for MS Nurse care and 17.0% did not know. Compared to those who did not feel the need for MS Nurse care, those who would have liked to receive MS Nurse care were younger, had a shorter disease duration, were more likely to be female, were more likely to have a progressive disease course, had a higher level of disability, were more likely to use a DMT, and were more likely to live in inner regional or outer regional Australia. Among those who answered ‘don’t know’ to the question whether they wanted to receive MS Nurse care, most indicated that they did not know of the existence of an MS Nurse (44%) and/or they indicated that an MS Nurse was not available to them (28%).

There are several potential ways to increase access to and uptake of MS Nurse care in Australia. The provision of clear information on the availability of the supports provided as part of MS Nurse care, and potentially improved distribution channels of this information, might increase the uptake of MS Nurse care where available. In addition, identifying areas where there is a lack of availability of MS Nurse services and providing a well-resourced MS Nurse service to these areas will be important to reduce the number of people who do not have access. An increased use of telehealth services is another avenue to improve access and reduce inequity. Telehealth services are theoretically not dependent on the location where people live. However, rules around Medicare payments for telehealth pose restrictions on what is possible. Telehealth not only assists with reduced clinic visits access due to geographical remoteness, but also with reduced access due to other reasons such as mental health difficulties, social isolation, physical difficulties such as impaired mobility and fatigue, lack of access to transport or the financial burden associated with attending clinic visits. This telehealth model would need to provide adequate remuneration for the MS Nurse service to allow this to be a continuing, long-term option.

Did access to MS Nurse care alter health outcomes?

We found that 31.5% of Australian participants did not have access to MS Nurse care. Notably, compared to those with access to MS Nurse care (including those who did not receive it), those who did not have access had consistently worse health outcomes, namely a higher a) level of disability b) rate of self-reported progression in the past 12 months c) severity of all MS symptoms and d) a lower health-related quality of life. The associations remained after adjusting for differences in education level, age, MS duration, onset type (relapsing or progressive MS onset) and remoteness.

This suggests that MS Nurse care directly benefits people with MS and that people who are unable to access this care are adversely affected in terms of health outcomes. The results support the need for policies, practices, and access to funding to improve access to MS Nurse care. There is a strong case to be made that every Australian with MS should have the opportunity to access ongoing MS Nurse care. The *Brain Health: Time Matters in MS* initiative also supports this argument and advocates for improved access to specialist care in MS, which can minimise irreversible disability progression.[2]

How is MS Nurse care provided in Australia?

The survey found that most MS Nurse care was provided through public hospital clinics (44.9%) and community providers (such as state and territory MS Member Organisations) (45.7%), with far less MS Nurse care provided via private neurology practices (13.4%) or a pharma patient support program (4.8%). It is possible that people with MS who see a private neurologist are unaware that they can access MS Nurse care via public hospital clinics and community providers. As many as 45% had received MS Nurse care for more than ten years, indicating that MS Nurse care plays a long-term role that is viewed as beneficial and provides continuity, confirmed in a number of other studies.[4,31] Regarding the amount of contact with an MS Nurse over the past 12 months, almost half (49%) reported that they had consulted with an MS Nurse less than once per year, 29% annually, 4% monthly, and 1% weekly. Compared to those who had frequent contact (quarterly/monthly/weekly), those who had less than annual contact were somewhat older, had a lower level of disability, were more likely to live in major cities, and were less likely to use infusion DMTs and more likely to use oral DMTs. This suggests that DMT use is a major reason to receive MS Nurse care more frequently and that remoteness was not a primary driver of reduced contact. When we asked about satisfaction with the amount of contact in the past 12 months, as many as 79% of people indicated that the amount was about right. This percentage was even higher for those who had a higher frequency of contact over the last 12 months. This indicates that MS Nurses can deliver a frequency of contact that is well-tailored to the needs of people with MS. This finding aligns with the findings of a recent review, suggesting that MS Nurses are skilled in providing personalised care that is tailored to the individual and adjusts across the various stages of the disease.[31]

People most frequently had phone consultations (40.1%), clinic consultations (39.8%), and email contact (26.7%). Telehealth usage was infrequent (2.2%) just before the COVID-19 outbreak, and 5.5% and 3.0% received a visit from an MS Nurse in the home or hospital, respectively. Notably, the proportion of people attending clinic consultations did not change with remoteness, however those living in more remote areas were more likely to have phone consultations or home visits.

While more costly in terms of time, home visits have the added advantage of seeing people in their own space. This provides the opportunity to identify social issues, the need for modifications that could be beneficial for improving function, safety and independence and the opportunity to identify other areas of need.[32] Unfortunately, home visits have been reduced in the MS specialty in recent years as MS community Nurse numbers have reduced across Australia. Many more MS Nurses acted in this role within the state and territory MS Member Organisations a decade ago, but a lack of funding has forced these numbers to decline.[33]

Telehealth with video on mobile devices can offer some opportunity to 'see people in their own space'. Expanding access to this option could potentially increase access to MS nursing services in a way that suits people living with MS while supporting greater productivity and time management for MS Nurses. Existing evidence suggests that telehealth, for both new and established neurological patients, can be an important and workable form of healthcare.[34] Of course, telehealth appointments do not allow for thorough clinical examination which may be necessary to identify certain neurological signs, evidence of disability progression, and other functional changes in MS. While telehealth appointments will never replace clinical examination, telehealth usage interspersed with face-to-face appointments could remove logistical barriers and enable more regular monitoring and care where this is acceptable and available for those with MS.

It is important to note the current challenges for funding of MS Nurses in Australia. Anecdotally, we are aware that many hospital MS Nurse positions are fixed term and part-time roles, with insecure ("soft") funding sources, including short-term research funding or clinical trial funding. In the less common case that these roles are operationally funded, there are often high administrative loads required to regularly justify the business case for maintenance of the role. In some areas, the MS Nurse role has been diluted to a general Neurology Nurse role. It can be difficult to retain these highly skilled professionals under these conditions, and we are aware of MS Nurses lost to the specialty due to these pressures. With the breadth of expert knowledge required to perform the MS Nurse role well, and the need for the MS Nurse to take an active role in the education, logistics and complex monitoring programs involved in the safe use of the higher efficacy DMTs, loss of MS Nurses incurs significant safety implications and may lead to discontinuation of these more effective therapies. It may also make it difficult, if not impossible, for some neurologists to prescribe these more effective therapies.

Going forward, the path to increasing MS Nurse care in Australia must be carefully considered. MS Nurse care is beneficial throughout the MS disease course, but particularly important at the distressing and confusing time of diagnosis, when education, information, support, and compassion is essential. It is important that access to or funding for MS Nurse care is not tied to severity of symptoms or degree of disability, especially as careful management of MS in the early stages can reap the benefits of preventing, minimising, and delaying progression of disability.

Is MS nurse care valuable to people with MS?

Those using DMTs, particularly infusion DMTs, were more likely to receive MS Nurse care and contacted MS Nurses more frequently. While DMT use is an important reason for accessing an MS Nurse, MS Nurses provide many other beneficial supports. Those supports most frequently reported as helpful included ‘advice on the management of MS symptoms’ (54.7%), ‘advice on the management of treatment side effects’ (48.6%), ‘providing education and information to assist with informed treatment decisions’ (46.9%) and ‘providing education to assist with the use and follow-up monitoring of disease modifying therapies’ (41.7%). Notably, very few people indicated that a provided support was not helpful (<3%). The more frequently reported supports that people did not receive but would have liked to, were ‘providing information and education about clinical trials’ (24.4%), ‘assisting you with assessing other support services (e.g. physiotherapist, occupational therapist, psychologist, disability employment services, speech pathologist, massage therapist, Continence Nurse, peer support programs, counsellor, dietitian and psychiatrist)’ (22.1%), ‘providing information, resources or weblinks to relevant research’ (17.3%) and ‘emotional or psychological support’ (17.0%). With the wide diversity of supports provided by MS Nurses, it is not surprising they are the healthcare professional with whom people with MS most want contact.[31] We found that 25.2% received assistance with accessing other support services and 22.1% would have liked to. This suggests that the coordination of care, which can often be fragmented due to difficult-to-navigate systems, is important for people with MS. This finding aligns with other research indicating that MS Nurses play a vital role in the coordination of care.[4,31]

What difference would it make if MS Nurse care was removed?

We asked people who received MS Nurse care what difference it would have made to them if they hadn’t had MS Nurse care over the past 12 months. Overall, 35% reported that it would have made no difference, 21% would have seen their GP more, 21% would have asked to see their neurologist more, 20% reported that they would have struggled on their own, and 5% would have had to go to the hospital or the emergency department. People who received MS Nurse care more often were more likely to say it made a difference to their health management. They were more likely to say that they would have had to see a GP or neurologist, would have struggled on their own or would have had to go to the hospital or emergency department more without an MS Nurse. These findings suggest that MS Nurse care can reduce the need for more costly GP and specialist consultations and prevent unnecessary and unplanned hospital and emergency department presentations and/or admissions.

A total of 78% reported that MS Nurse care was very helpful (49%) or somewhat helpful (29%), and the rate was higher among those who received MS Nurse care more often or for longer. There were few differences by service provider, apart from a slightly lower proportion rating MS Nurse care as ‘very helpful’ when delivered by a private neurology practice. We found that those who rated having an MS Nurse overall as less helpful were more likely to be male, have a higher education level, have progressive MS (PPMS or SPMS) and live in inner regional Australia.

We assessed whether people believed that MS Nurse care improved:

1. Their adherence to MS treatments
2. Their management of MS symptoms or side effects, and
3. Living a healthier lifestyle.

Around one third of people (30.4%) thought it definitely or may have improved adherence to treatment, and this increased to 51.3% when we restricted the analysis to those who felt they needed help in this area. Those using oral DMTs were even more likely to report that MS Nurse care improved or might have improved their adherence. Regarding MS symptoms or side effects, 43.2% thought MS Nurse care definitely or may have improved the management of symptoms or side effects, and this increased to 52.5% when we limited the analysis to people who felt they needed help in this area. Over a third (36.2%) of people thought MS Nurse care definitely or may have helped them lead a healthier lifestyle, and this increased to 54.3% when we limited the analysis to those who felt they needed help in this area.

This data indicates that MS Nurse care plays an important role in improving adherence to DMTs. This is critical as it has been clearly shown that adherence to DMTs significantly improves their effectiveness.[35] Similarly, knowledge of treatment side effects and their management also improves persistence and adherence and thus supports improved outcomes for people with MS treated with DMTs, resulting in fewer relapses requiring hospitalisation and lower medical costs.[36] Starting or changing a DMT often results in side effects. MS Nurses are well trained in guiding people through this phase without the need for other appointments with treating physicians. Additionally, some DMT side effects can be fatal, and the careful supervision of DMTs, and monitoring for adverse effects, often falls to the MS Nurse.[37]

Top: MS Nurse and Research Manager Belinda Bardsley delivering professional education to the MS Nursing team

Could increased access to MS Nurse care reduce the overall economic cost of MS in Australia?

Our work indicates that MS Nurse care can generate cost savings by avoiding more costly neurologist and GP appointments, unnecessary emergency department presentations, and possibly costly unplanned hospital admissions, and through improved health outcomes with better DMT adherence, symptom management and lifestyle.

If access to MS Nurse care could, conservatively, reduce 10% of the total costs of MS of those currently without access, this would generate annual cost savings to Australian society (includes individuals and health payers) of $64.3 million. If it reduced 20% of the total costs, this would generate an annual cost saving of $128.7 million, while even a 5% cost reduction would represent a saving of $32.2 million. If an additional 50 MS Nurses were required to service the nearly 8,000 people currently without access to MS Nurse care, at an approximate $100,000 per annum per MS Nurse, the total salary costs would be $5 million. Thus, the potential cost savings far outweigh the MS Nurse salary costs by between six and 26 times, depending on whether we assume 5% or 20% of costs would be avoided.

This aligns with work conducted in the United Kingdom.[10] Using conservative assumptions, their study suggests that each full-time equivalent MS Nurse position saved £77,400 (AU$139,000) in ambulatory care costs (GP appointments, neurology appointments and Accident and Emergency visits) per year.[10] Whilst reductions in emergency admissions are difficult to measure, the authors were confident that MS Nurses reduce admissions and that the savings generated by MS Nurses were likely to far exceed the costs of employing them.[10]

Interestingly, another study indicates that 'knowing the patient' appears to be intensely important to people with MS and interlinked with the continuity of care that MS Nurses provide. 'Knowing the patient' may enhance patient engagement in their own health management, bringing multiple benefits, including reduced healthcare services, fewer diagnostic tests, and referrals.[38]

Our findings also align with work conducted outside MS, where streamlined models of disease-specific specialist nurse care (including specialist nurses embedded in specialist clinics such as cardiology or cancer) generate cost savings across many complex and chronic disease areas[39] including diabetes,[40] mental health, cardiovascular disease,[41,42] rheumatology,[43] and epilepsy.[44] A good example is a Rapid Access Chest Pain Clinic where the Specialist Cardiology Nurse is the first point of clinic contact and integral to the clinic team. This model of care reveals both improved health outcomes (including preventative health with quantitative reductions in risk with lifestyle modifications post counselling[42]) and cost savings. Another study found a nurse-led self-management intervention for people with epilepsy to reduce emergency department visits to be cost effective with a mean reduction in costs of just over 20%, mainly because the duration and therefore cost of hospital admissions was reduced.[45] Another study found that there was a 13% mean annual cost saving for a nurse-led rheumatology clinic versus a specialist-led clinic in Sweden.[43]

Key recommendations

The following four recommendations flow from the findings of this Report:

1. Raise awareness of the existence of MS Nurses, the value of MS Nurses and the supports that they provide, among people with MS and other health practitioners. This is critical to reduce the number of people who do not know that MS Nurses exist, or who do not receive MS Nurse care because they have insufficient understanding of available MS Nurse supports. This could include:

- A review of the existing resources describing MS Nurse care and access and, where required, development of new practical resources.
- A review of the existing distribution channels of this information.
- Approaching health professional associations and state and territory MS Member Organisations to share this MS Nurse Report as well as relevant/new MS Nurse resources. Additionally, this MS Nurse Report should be shared through conferences and publications.

2. Develop and support the MS Nurse workforce through the following:

- Developing mentorship and preceptorship (directed, practical training by an expert in the field) programs to assist new MS Nurses and new MS Research Nurses.
- Connecting and educating existing MS Nurses through organisations such as MS Nurses Australasia and MS Health Professionals Network.
- Exploring opportunities within university nursing courses to include education about MS Nursing and MS Research Nursing.

3. Increase the number of MS Nurses in Australia by exploring the following opportunities:

- Using the effectiveness analysis, which demonstrates that the benefits of an MS Nurse service far outweigh the costs, even using conservative assumptions, to advocate for an expansion of the MS Nurse workforce to the federal, state and territory governments, hospitals, private neurologists, and other potential funders.
- Assessing the current funding arrangements for MS Nurse-led clinics in Australia, whether run by MS Nurse Practitioners, MS Nurse Consultants or MS Specialist Nurses.

4. Increase access to MS Nurses

- Expand telehealth services to improve access to MS Nurse care - this requires amendment to Medicare which currently covers telehealth appointments with neurologists, but not MS Nurses.
- Advocacy to the Australian Government on this issue is recommended, possibly in collaboration with other organisations.

Strengths and limitations

One of the major strengths of this study is the large, demographically representative cohort of people with MS in Australia.[46] When we compared those who responded to the surveys to those who did not respond, we found few differences. Those who responded were slightly older and had a longer disease duration, neither of which are likely to affect our outcomes materially. In addition, we adjusted for age and disease duration when determining differences in health outcomes according to access. Despite that, some selection bias may have occurred, as not all invited participants completed the surveys. Most data sets were collected in close proximity to each other, except for the health behaviour data gathered at the end of 2018, which yielded no major findings.

For the associations between access and health outcomes, we excluded 4% of people who did not receive MS Nurse care because it was unclear whether this was due to lack of access. This could have marginally affected the associations. Participants completed the MS Nurses survey between February and April 2020, when the COVID-19 pandemic emerged. Of all participants, 94.4% completed the survey prior to the first official Australian lockdown (23/3/2020). The lockdown is unlikely to have affected many of the survey responses completed during this period.

We were unable to perform a full economic health analysis. Still, the avoided cost analysis was based on robust data, and we were able to demonstrate that the potential cost savings generated by access to an MS Nurse service are likely to far outweigh the costs, even using conservative assumptions.

Top: MS and Continence Nurse K-J Lazarus reviewing magnetic resonance imaging

Conclusions

Overall, our results show that nearly one third of Australians with MS do not have access to MS Nurse care and that these individuals have consistently worse health outcomes. In addition, MS Nurse care reduces the need for people with MS to unnecessarily see other, more costly health professionals, such as GPs and neurologists, and seems to reduce unnecessary emergency department presentations and potentially, hospital admissions. Even with conservative estimates of avoided costs, MS Nurse care seems to be a highly cost-effective model of care. MS Nurses tailor their information provision and services well to the needs of the individual, with high percentages of satisfaction with the frequency and types of supports provided. With the most frequent support types around the management and education of MS symptoms, treatments and side effects, MS Nurse care improves the self-management and self-care skills of people with MS. Previous research has shown that education from MS Nurses leads the way to empowerment and independence, which is a major goal of care[4] and that people with MS benefit from such bespoke MS management and education provision.[31] Use of DMTs was a major reason to seek MS Nurse care more frequently and this group did not seem disadvantaged in terms of remoteness. Based on these findings, we recommend initiatives to raise awareness of the existence and benefits of MS Nurse care, to enable Medicare-subsidised access to telehealth for MS Nurse consults, to expand the MS Nurse workforce in Australia to improve access, and to develop and support the MS Nurse workforce through mentorship and education.

References

1. Haartsen J, Ben-Zacharia A, Butzkueven H, et al. Brain health in multiple sclerosis: A nursing resource. *MS Brain Health*. 2019; https://www.msbrainhealth.org/wp-content/uploads/2021/05/en-brain-health-in-multiple-sclerosis-a-nursing-resource.pdf

2. Giovannoni G, Butzkueven H, Dhib-Jalbut S, et al. Brain health: time matters in multiple sclerosis. *Mult Scler Relat Disord*. 2016;9 Suppl 1:S5-S48.

3. Burke T, Dishon S, McEwan L, Smrtka J. The evolving role of the multiple sclerosis nurse: an international perspective. *Int J MS Care*. 2011;13(3):105-112.

4. Burke T, Patching J. Conductors of care: exploring the role of the multiple sclerosis nurse in Australasia, phase 1. *Br J Neurosci Nurs*. 2021;17:S42-S47.

5. Quinn D, Bowen A, Leary A. The value of the multiple sclerosis specialist nurse with respect to prevention of unnecessary emergency admission. *Mult Scler*. 2014;20(12):1669-1670.

6. Leary A, Quinn D, Bowen A. Impact of Proactive Case Management by Multiple Sclerosis Specialist Nurses on Use of Unscheduled Care and Emergency Presentation in Multiple Sclerosis: A Case Study. *Int J MS Care*. 2015;17(4):159-163.

7. Thotam SM, Buhse M. Patient Satisfaction with Physicians and Nurse Practitioners in Multiple Sclerosis Centers. *Int J MS Care*. 2020;22(3):129-135.

8. Newland PK, Lorenz R, Budhathoki C, Jensen MP. The Presence of Symptoms With Comorbid Conditions in Individuals With Multiple Sclerosis (MS). *Clin Nurs Res*. 2016;25(5):532-548.

9. Beswick, B. Multiple Sclerosis Specialist Nurses in Australia 2017. *Multiple Sclerosis Australia*. 2017, https://msnainc.org.au/wp-content/uploads/2019/08/Multiple-Sclerosis-Specialist-Nurses-in-Australia-Report-2017.pdf

10. Mynors G, Suppiah J, Bowen A. Evidence for MS Specialist Services: Findings from the GEMSS MS specialist nurse evaluation project. *Letchworth: Multiple Sclerosis Trust*;2015.

11. Croft, A, Mynors, G, Roberts, M, Doncaster, D, Bowen, A. MS Forward View: a consensus for the future of MS services. *MS Trust* 2016; https://ukclinicalpharmacy.org/wp-content/uploads/2017/07/MS-Trust-Forward-View-2016.pdf

12. Ahern T, Gardner A, Courtney M. Exploring patient support by breast care nurses and geographical residence as moderators of the unmet needs and self-efficacy of Australian women with breast cancer: Results from a cross-sectional, nationwide survey. *Eur J Oncol Nurs*. 2016;23:72-80.

13. Happell B, Platania-Phung C, Watkins A, et al. Developing an Evidence-Based Specialist Nursing Role to Improve the Physical Health Care of People with Mental Illness. *Issues Ment Health Nurs*. 2019;40(10):832-838.

14. Jones B, Hopkins G, Wherry SA, Lueck CJ, Das CP, Dugdale P. Evaluation of a Regional Australian Nurse-Led Parkinson's Service Using the Context, Input, Process, and Product Evaluation Model. *Clin Nurse Spec*. 2016;30(5):264-270.

15. Taylor BV, Palmer A, Simpson S, Jr., et al. Assessing possible selection bias in a national voluntary MS longitudinal study in Australia. *Mult Scler*. 2013;19(12):1627-1631.

16. Zhang Y, Taylor BV, Simpson S, Jr., Blizzard L, Palmer AJ, van der Mei I. Validation of 0-10 MS symptom scores in the Australian multiple sclerosis longitudinal study. *Mult Scler Relat Disord*. 2019;39:101895.

17. Krupp LB, LaRocca NG, Muir-Nash J, Steinberg AD. The fatigue severity scale. Application to patients with multiple sclerosis and systemic lupus erythematosus. *Arch Neurol*. 1989;46(10):1121-1123.

18. Spinhoven P, Ormel J, Sloekers PP, Kempen GI, Speckens AE, Van Hemert AM. A validation study of the Hospital Anxiety and Depression Scale (HADS) in different groups of Dutch subjects. *Psychol Med*. 1997;27(2):363-370.

19. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta psychiatr scand*. 1983;67(6):361-370.

20. Learmonth YC, Motl RW, Sandroff BM, Pula JH, Cadavid D. Validation of patient determined disease steps (PDDS) scale scores in persons with multiple sclerosis. *BMC Neurol*. 2013;13:37.

21. Hohol M, Orav E, Weiner H. Disease Steps in multiple sclerosis A simple approach to evaluate disease progression. *Neurology*. 1995;45(2):251-255.

22. Herdman M, Gudex C, Lloyd A, et al. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Qual Life Res*. 2011;20(10):1727-1736.

23. Tramacere I, Del Giovane C, Salanti G, D'Amico R, Filippini G. Immunomodulators and immunosuppressants for relapsing-remitting multiple sclerosis: a network meta-analysis. *Cochrane Database Syst Rev*. 2015(9):CD011381.

24. Broadley SA, Barnett MH, Boggild M, et al. Therapeutic approaches to disease modifying therapy for multiple sclerosis in adults: an Australian and New Zealand perspective: part 1 historical and established therapies. MS Neurology Group of the Australian and New Zealand Association of Neurologists. *J Clin Neurosci*. 2014;21(11):1835-1846.

25. Broadley SA, Barnett MH, Boggild M, et al. Therapeutic approaches to disease modifying therapy for multiple sclerosis in adults: an Australian and New Zealand perspective: part 2 new and emerging therapies and their efficacy. MS Neurology Group of the Australian and New Zealand Association of Neurologists. *J Clin Neurosci*. 2014;21(11):1847-1856.

26. Broadley SA, Barnett MH, Boggild M, et al. Therapeutic approaches to disease modifying therapy for multiple sclerosis in adults: an Australian and New Zealand perspective: part 3 treatment practicalities and recommendations. MS Neurology Group of the Australian and New Zealand Association of Neurologists. *J Clin Neurosci*. 2014;21(11):1857-1865.

27. Kite TA, Gaunt H, Banning AS, et al. Clinical outcomes of patients discharged from the Rapid Access Chest Pain Clinic with non-anginal chest pain: A retrospective cohort study. *Int J Cardiol*. 2020;302:1-4.

28. Ahmad H CJ, Taylor BV, van der Mei I, Palmer AJ. The Health Economic Impact of Multiple Sclerosis in Australia in 2017. *Multiple Sclerosis Research Australia*, 2018; https://msra.org.au/news/ms-economic-impact-reportlaunch/

29. Campbell JA, Simpson S, Jr., Ahmad H, Taylor BV, van der Mei I, Palmer AJ. Change in multiple sclerosis prevalence over time in Australia 2010-2017 utilising disease-modifying therapy prescription data. *Mult Scler.* 2019:1352458519861270.

30. Abdollahpour I, Nedjat S, Mansournia MA, Sahraian MA, van der Mei I. Lifestyle factors and multiple sclerosis: A population-based incident case-control study. *Mult Scler Relat Disord.* 2018;22:128-133.

31. Meehan M, Doody O. The role of the clinical nurse specialist multiple sclerosis, the patients' and families' and carers' perspective: An integrative review. *Mult Scler Relat Disord.* 2020;39:101918.

32. Akkus Y, Akdemir N. Improving the quality of life for multiple sclerosis patients using the nurse-based home visiting model. *Scand J Caring Sci.* 2012;26(2):295-303.

33. Burke T, Patching J. Conductors of care: exploring the role of the multiple sclerosis nurse in Australasia, phase 2. *Br J Neurosci Nurs.* 2021;17:S42-S49.

34. McGinley MP, Gales S, Rowles W, et al. Expanded access to multiple sclerosis teleneurology care following the COVID-19 pandemic. *Mult Scler J Exp Transl Clin.* 2021;7(1):2055217321997467.

35. Nicholas JA, Edwards NC, Edwards RA, Dellarole A, Grosso M, Phillips AL. Real-world adherence to, and persistence with, once – and twice-daily oral disease-modifying drugs in patients with multiple sclerosis: a systematic review and meta-analysis. *BMC Neurol*. 2020;20(1):281.

36. Bunz TJ, Xu C, Regine ML, Couto JE. Clinical and Economic Impact of Five-Year Adherence to Disease-Modifying Therapies in a Commercially Insured Multiple Sclerosis Population. *Value in Health.* 2013;16(3):A109-A109.

37. Abel N, Embrey N. Multiple sclerosis: dealing with complex treatment decisions. *Br J Nurs.* 2018;27(3):132-136.

38. Rieckmann P, Boyko A, Centonze D, et al. Achieving patient engagement in multiple sclerosis: A perspective from the multiple sclerosis in the 21st Century Steering Group. *Mult Scler Relat Disord.* 2015;4(3):202-218.

39. Shiu AT, Lee DT, Chau JP. Exploring the scope of expanding advanced nursing practice in nurse-led clinics: a multiple-case study. *J Adv Nurs.* 2012;68(8):1780-1792.

40. Carey N, Courtenay M. A review of the activity and effects of nurse-led care in diabetes. *J Clin Nurs.* 2007;16(11c):296-304.

41. Black JA, Cheng K, Flood JA, et al. Evaluating the benefits of a rapid access chest pain clinic in Australia. *Med J Aust*. 2019;210(7):321-325.

42. Black JA, Campbell JA, Parker S, et al. Absolute risk assessment for guiding cardiovascular risk management in a chest pain clinic. *Med J Aust.* 2021;214(6):266-271.

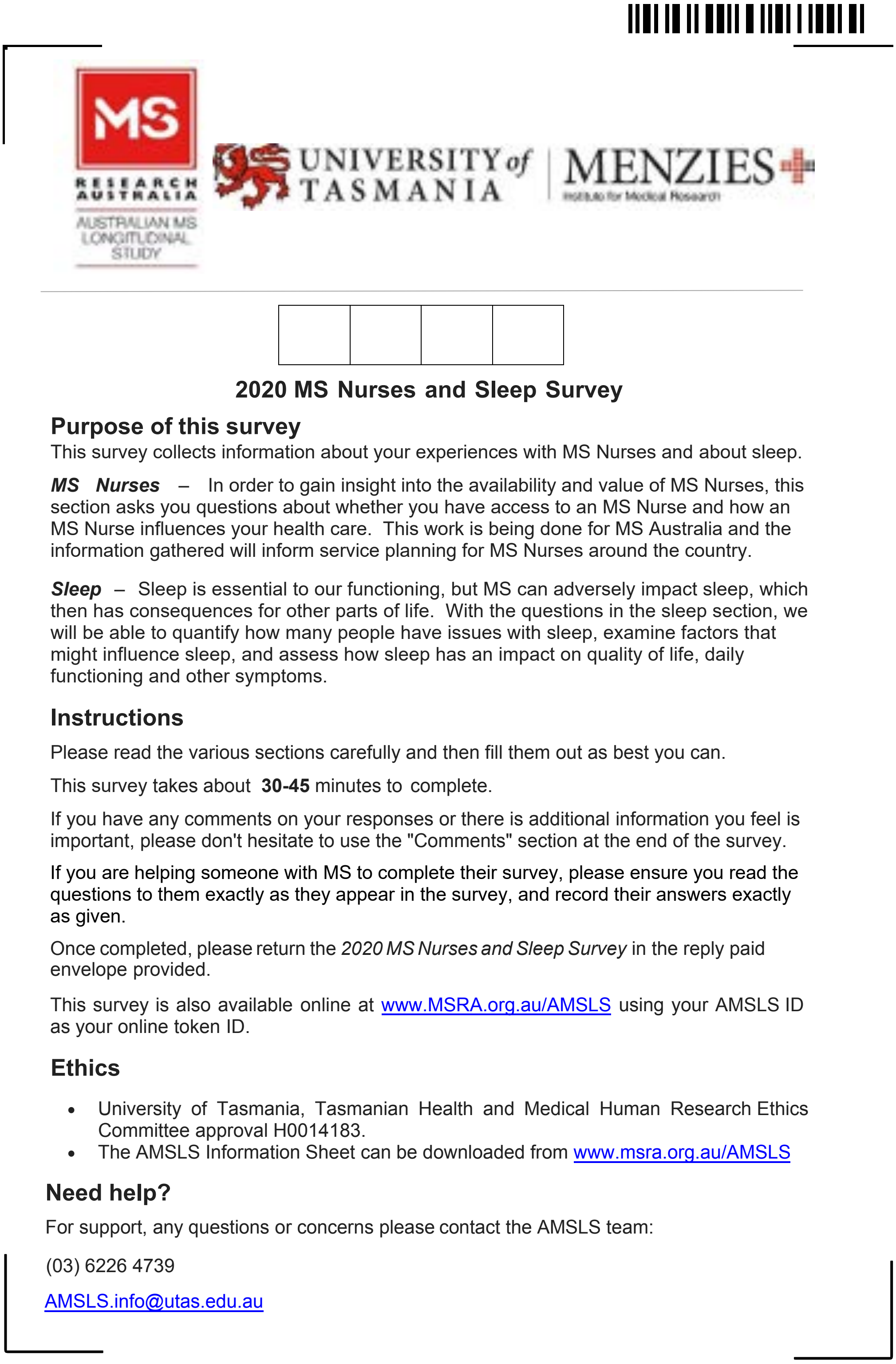
43. Larsson I, Fridlund B, Arvidsson B, Teleman A, Svedberg P, Bergman S. A nurse-led rheumatology clinic versus rheumatologist-led clinic in monitoring of patients with chronic inflammatory arthritis undergoing biological therapy: a cost comparison study in a randomised controlled trial. *BMC musculoskeletal disorders.* 2015;16(1):1-10.

44. Noble AJ, McCrone P, Seed PT, Goldstein LH, Ridsdale L. Clinical – and cost-effectiveness of a nurse led self-management intervention to reduce emergency visits by people with epilepsy. *PLoS One.* 2014;9(6):e90789.

45. Noble AJ, McCrone P, Seed PT, Goldstein LH, Ridsdale L. Clinical-and cost-effectiveness of a nurse led self-management intervention to reduce emergency visits by people with epilepsy. *PloS one.* 2014;9(3):e90789.

46. Taylor BV, Palmer A, Simpson S, Jr., et al. Assessing possible selection bias in a national voluntary MS longitudinal study in Australia. *Mult Scler.* 2013;19(12):1627-1631.

Appendix 1 – MS Nurse questions from the 2020 AMSLS MS Nurses and Sleep Survey



2020 MS Nurses and Sleep Survey

Purpose of this survey

This survey collects information about your experiences with MS Nurses and about sleep.

MS Nurses – In order to gain insight into the availability and value of MS Nurses, this section asks you questions about whether you have access to an MS Nurse and how an MS Nurse influences your health care. This work is being done for MS Australia and the information gathered will inform service planning for MS Nurses around the country.

Sleep – Sleep is essential to our functioning, but MS can adversely impact sleep, which then has consequences for other parts of life. With the questions in the sleep section, we will be able to quantify how many people have issues with sleep, examine factors that might influence sleep, and assess how sleep has an impact on quality of life, daily functioning and other symptoms.

Instructions

Please read the various sections carefully and then fill them out as best you can.

This survey takes about **30-45** minutes to complete.

If you have any comments on your responses or there is additional information you feel is important, please don't hesitate to use the "Comments" section at the end of the survey.

If you are helping someone with MS to complete their survey, please ensure you read the questions to them exactly as they appear in the survey, and record their answers exactly as given.

Once completed, please return the *2020 MS Nurses and Sleep Survey* in the reply paid envelope provided.

This survey is also available online at www.MSRA.org.au/AMSLS using your AMSLS ID as your online token ID.

Ethics

- University of Tasmania, Tasmanian Health and Medical Human Research Ethics Committee approval H0014183.
- The AMSLS Information Sheet can be downloaded from www.msra.org.au/AMSLS

Need help?

For support, any questions or concerns please contact the AMSLS team:

(03) 6226 4739

AMSLS.info@utas.edu.au

Section A: General Information

We will be asking the following question with each of our surveys to ensure that your ID number correctly matches your current details.

A1. Please enter today's date.

Please write your answer using the format DDMMYYYY

☐☐☐☐☐☐☐☐

A2. Please enter your date of birth.

Please write your answer using the format DDMMYYYY

☐☐☐☐☐☐☐☐

Part 1: MS Nurses

The following sections (Section B to Section E) ask questions about your experiences with MS Nurses, to both gain a picture of how you access MS Nurses, and what effect that may have on your overall health.

MS Nurses are provided by the MS Societies to assist people with MS. You can receive MS Nurse care either:

- **Face to face** at hospitals, clinics or through home visit, or
- **Remotely** by phone, Skype or email.

Their services include:

- **Advice, education and management of MS** including symptoms, relapses and treatments.
- **Assistance with life issues**, such as employment, financial management, emotional and psychological support, and lifestyle choices.
- **Assistance with accessing further support services**, such as medical appointments, peer support programs, and employment services.

This section will take about 10-20 minutes to complete.

B1. Do you have access to an MS Nurse as part of your care?

Yes - Go to Section D (Page 4) ☐

No - Go to Section C (Page 3) ☐

Section C: MS Nurses

For those who **do not** have access to an MS Nurse

C1. Why do you not have access to an MS Nurse as part of your care?

There are no MS Nurses in the area I live ☐

There are no MS Nurses in the neurologist practice that I go to ☐

I did not know about the existence of MS Nurses ☐

Other, please describe: ☐

You can receive MS Nurse care either:

- **Face to face** at hospitals, clinics, or through home visits, or
- **Remotely** by phone, Skype or email.

Their services include:

- **Advice**, **education and management of MS** including symptoms, relapses and treatments.
- **Assistance with life issues**, such as employment, financial management, emotional and psychological support, and lifestyle choices.
- **Assistance with accessing further support services**, such as medical appointments, peer support programs, and employment services.

C2. Would you like to have access to an MS Nurse as part of your care?

Yes ☐

No ☐

Don't know ☐

For those who do NOT have access to an MS Nurse,
please proceed to Part 2 - Sleep and Health-related Quality of Life on page 9

Section D: MS Nurses

For those who **do** have access to an MS Nurse

D1. I access an MS Nurse via a:

Please tick all that apply

Public hospital clinic ☐

Private neurologist ☐

Community provider such as the MS Society ☐

Pharma patient support program ☐

Unsure ☐

Other, please describe: ☐

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

D2. On average, how often are you in contact with an MS Nurse?

Weekly ☐

Monthly ☐

Quarterly ☐

Annually ☐

Less than annually ☐

D3. Over the past 12 months, can you give your closest estimate to how many times you had a consultation with an MS Nurse in the following settings?

	Number of times
Clinic consultation with MS Nurse (outpatient clinic or drop in clinic)	☐☐☐
Home visit from MS Nurse	☐☐☐
Consultation over the phone with MS Nurse	☐☐☐
Consultation via telehealth with MS Nurse (Skype/Zoom/webcam)	☐☐☐
Email contact	☐☐☐
Visit from MS Nurse whilst an inpatient in hospital	☐☐☐

D4. **What do you think about the amount of contact you have had with an MS Nurse over the past 12 months?**

It was too much contact ☐

It was about right ☐

It wasn't enough — I would have liked more ☐

D5. **How long have you had an MS Nurse as part of your care?**

Less than 1 year ☐

1–5 years ☐

6–10 years ☐

More than 10 years ☐

D6. An MS Nurse may provide support to you in a variety of ways. Please tell us whether an MS Nurse assisted you with the following types of support and whether it was helpful.

	The nurse provided this and it was helpful	The nurse provided this but it wasn't helpful	I didn't need this	I didn't get this but I would have liked it
Advice on the management of MS symptoms	☐	☐	☐	☐
Advice on the management of treatment side effects	☐	☐	☐	☐
Identification and advice on the management of relapses	☐	☐	☐	☐
Providing education and information to assist with informed treatment decisions	☐	☐	☐	☐
Providing education to assist with the use and follow-up monitoring of disease modifying therapies	☐	☐	☐	☐
Assisting you with adherence to treatment	☐	☐	☐	☐
Assisting you with financial issues	☐	☐	☐	☐
Providing support with family or social issues	☐	☐	☐	☐
Providing emotional or psychological support	☐	☐	☐	☐
Providing support around employment issues	☐	☐	☐	☐
Providing education and resources around healthy lifestyle behaviours (e.g. nutrition, physical exercise, non-smoking, alcohol)	☐	☐	☐	☐
Assisting you with accessing other support services (e.g. physiotherapist, occupational therapist, psychologist, disability employment services, speech pathologist, massage therapist, incontinence nurse, peer support programs, counsellor, dietitian and psychiatrist)	☐	☐	☐	☐
Arranging an earlier clinic review	☐	☐	☐	☐
Assisting you with the decision on whether to present to the emergency department of a hospital	☐	☐	☐	☐
Providing information and education about clinical trials	☐	☐	☐	☐
Providing information, resources or web-links to relevant research	☐	☐	☐	☐

D7. **If you hadn't had access to an MS Nurse service over the past 12 months, what difference do you think it would have made to you?**

Please tick all that apply

It would have made no difference ☐

I would have struggled on my own ☐

I would have seen my GP more ☐

I would have asked to see my neurologist more ☐

I would have had to go to the hospital Emergency Department ☐

Other, please specify: ☐

Section E: Perceived Effects of MS Nurse Care

E1. **Do you believe that the care provided by an MS Nurse may have contributed to changes in your ADHERENCE TO MS TREATMENTS?**

Yes, it *definitely improved* my adherence ☐

Yes, it might have *improved* my adherence ☐

No, it did not result in any real changes to my adherence ☐

Yes, it might have *worsened* my adherence ☐

Yes, it *definitely worsened* my adherence ☐

I really don't know ☐

E2. **Do you believe that the care provided by an MS Nurse may have contributed to changes in your MANAGEMENT OF MS SYMPTOMS OR SIDE EFFECTS?**

Yes, it *definitely improved* my management of MS symptoms and side effects ☐

Yes, it might have *improved* my management of MS symptoms and side effects ☐

No, it did not result in any real changes to my management of MS symptoms and side effects ☐

Yes, it might have *worsened* my management of MS symptoms and side effects ☐

Yes, it *definitely worsened* my management of MS symptoms and side effects ☐

I really don't know ☐

E3. **Do you believe that the care provided by an MS Nurse may have contributed to leading a HEALTHIER LIFESTYLE?**

Yes, it *definitely assisted* me with leading a healthier lifestyle ☐

Yes, it might have *assisted* me with leading a healthier lifestyle ☐

No, it did not assist me with leading a healthier lifestyle ☐

Yes, it might have *worsened* my lifestyle ☐

Yes, it *definitely worsened* my lifestyle ☐

I really don't know ☐

E4. **Overall, how would you rate the value of having an MS Nurse?**

Very helpful ☐

Somewhat helpful ☐

Neither helpful nor unhelpful ☐

Somewhat unhelpful ☐

Very unhelpful ☐

I really don't know ☐

E5. **Please use this box to provide any examples of the positive difference your MS Nurse has made to you.**

Appendix 2 – Supplementary Tables

Supplementary Table 1. Characteristics of those participants not receiving MS Nurse care according to whether they would like to have access to an MS Nurse.

	Yes	No	Did not know
	N=140	N=206	N=184
Age (years), mean (SD)	59.5 (11.6)	62.1 (10.7)	60.1 (11.2)
MS duration since diagnosis (years), mean (SD)	16.0 (9.5)	20.3 (9.9)	19.7 (10.8)
Age at MS diagnosis	43.5 (11.4)	41.7 (11.1)	40.2 (11.1)
Gender, n (%)			
Female	111 (79.3)	145 (70.4)	146 (79.4)
Male	29 (20.7)	61 (29.6)	38 (20.7)
Education, n (%)			
Primary/secondary school	46 (32.9)	58 (28.4)	46 (25.0)
Occupational certificate	47 (33.6)	72 (35.3)	68 (37.0)
University degree	47 (33.6)	74 (36.3)	70 (38.0)
MS type in 2019, n (%)			
Relapsing remitting MS	70 (50.0)	110 (54.2)	95 (61.6)
Secondary progressive MS	30 (21.4)	29 (14.3)	31 (16.9)
Primary progressive MS	23 (16.4)	27 (13.3)	23 (12.5)
Progressive relapsing MS	5 (3.6)	3 (1.5)	6 (3.3)
Unsure	12 (8.6)	34 (16.8)	29 (15.8)
Disability level			
No disability or Mild	36 (25.9)	103 (50.2)	78 (42.6)
Moderate	70 (50.4)	57 (27.8)	64 (35.0)
Severe	33 (23.7)	45 (22.0)	41 (22.4)
Use of a DMT			
Yes	80 (57.1)	79 (38.3)	103 (56.3)
No	60 (42.9)	127 (61.7)	80 (43.7)
State/Territory			
NSW	55 (39.3)	71 (34.5)	75 (40.8)
VIC	43 (30.7)	66 (32.0)	44 (23.9)
QLD	19 (13.6)	29 (14.1)	27 (14.7)
SA	9 (6.4)	12 (5.8)	13 (7.1)
WA	6 (4.3)	14 (6.8)	6 (3.3)
TAS	6 (4.3)	8 (3.9)	13 (7.1)
ACT	2 (1.43)	5 (2.4)	6 (3.3)
NT	0 (0.0)	0 (0.0)	0 (0.0)

Above: Continence Nurse discussing bladder ultrasound technique with MS Immunotherapy Nurse Edith Cinc

Remoteness level			
Major Cities	74 (52.9)	134 (65.1)	113 (61.4)
Inner Regional	44 (31.4)	54 (26.2)	55 (29.9)
Outer Regional	20 (14.3)	15 (7.3)	13 (7.1)
Remote/Very Remote	2 (1.4)	3 (1.5)	3 (1.6)
Reasons for not receiving MS Nurse care			
MS Nurse not available	65 (46.4)	26 (12.6)	53 (28.8)
Unaware of the existence of MS Nurse	52 (37.1)	72 (34.9)	81 (44.0)
Not needing an MS Nurse	7 (5.0)	99 (48.1)	36 (19.6)
Other reasons/reasons not provided	16 (11.4)	9 (4.4)	14 (7.6)

Supplementary Table 2. DMT use by those with relapsing remitting MS who were not receiving MS Nurse care according to whether they would like to have access to an MS Nurse.

	Yes	**No**	**Did not know**
	N=195	N=275	N=241
DMT used at survey time			
Not using a DMT	20 (20.2)	66 (43.1)	37 (28.2)
Interferon β-1b (Betaferon, sub-cutaneous injection)	4 (4.0)	8 (5.2)	2 (1.5)
Interferon β-1a (Rebif, sub-cutaneous injection)	2 (2.0)	2 (1.3)	1 (0.8)
Interferon β-1a (Avonex, intramuscular injection)	2 (2.0)	3 (2.0)	2 (1.5)
Pegylated interferon β-1a (Plegridy, sub-cutaneous injection)	5 (5.1)	1 (0.7)	6 (4.6)
Glatiramer acetate (Copaxone, sub-cutaneous injection)	7 (7.1)	5 (3.3)	7 (5.3)
Teriflunomide (Aubagio, oral)	11 (11.1)	8 (5.3)	6 (4.6)
Dimethyl fumarate (Tecfidera, oral)	9 (9.1)	7 (4.6)	6 (4.6)
Novantrone (Mitoxantrone, intravenous infusion)	0 (0.0)	0 (0.0)	0 (0.0)
Azathioprine (Azasan, oral)	0 (0.0)	0 (0.0)	0 (0.0)
Methotrexate (Trexall, oral)	2 (0.2)	0 (0.0)	2 (0.3)
Cladribine (Mavenclad, oral)	3 (3.0)	6 (3.9)	7 (5.3)
Fingolimod (Gilenya, oral)	17 (17.2)	28 (18.3)	37 (28.2)
Natalizumab (Tysabri, intravenous infusion)	5 (5.1)	10 (6.5)	5 (3.8)
Alemtuzumab (Lemtrada, intravenous infusion)	2 (2.0)	2 (1.3)	3 (2.3)
Ocrelizumab (Ocrevus, intravenous infusion)	12 (12.1)	7 (4.6)	12 (9.2)
DMT categories*			
Not using a DMT	20 (20.2)	66 (43.1)	37 (28.2)
Category 1 DMTs	20 (20.2)	19 (12.4)	18 (13.7)
Category 2 DMTs	20 (20.2)	15 (9.8)	12 (9.2)
Category 3 DMTs	39 (39.4)	53 (34.6)	64 (48.9)
Route of administration for DMTs used			
Not using a DMT	20 (20.2)	66 (43.1)	37 (28.2)
Injectable DMTs	20 (20.2)	19 (12.4)	18 (13.7)
Infusion DMTs	19 (19.2)	19 (12.4)	20 (15.3)
Oral DMTs	40 (40.4)	49 (32.0)	56 (42.8)

*DMT categories: Category 1 DMTs (injectable platform DMTs) include interferons-β and glatiramer acetate; Category 2 DMTs include teriflunomide and dimethyl fumarate; Category 3 DMTs (higher efficacy) include natalizumab, fingolimod, alemtuzumab, ocrelizumab and cladribine.

Supplementary Table 3. Personal characteristics according to access to and receiving MS Nurse care.

	Access to MS Nurse Care		Receiving MS Nurse care	
	No access	**Had access**	**Had access but not receiving**	**Had access and were receiving**
	N=447 (33%)	N=919 (67%)	N=226 (17%)	N=693 (51%)
Age, mean (SD)	60.3 (11.6)	56.7 (10.9)	60.5 (9.7)	55.5 (11.0)
MS duration since diagnosis (years), mean (SD)	18.2 (10.3)	15.9 (8.4)	18.7 (9.3)	15.0 (7.8)
Age at MS diagnosis	41.9 (11.5)	40.7 (10.6)	41.7 (10.4)	40.3 (10.7)
Gender, n (%)				
Female	340 (76.1)	745 (81.1)	176 (77.9)	569 (82.1)
Male	107 (23.9)	174 (18.9)	50 (22.1)	124 (17.9)
Highest level of education, n (%)				
Primary/secondary school	133 (29.9)	220 (24.0)	59 (26.3)	161 (23.3)
Occupational certificate	160 (36.0)	305 (33.3)	82 (36.6)	223 (32.3)
University degree	152 (34.2)	390 (42.6)	83 (37.1)	307 (44.3)
MS type in 2019, n (%)				
Relapsing remitting MS	225 (50.6)	615 (66.9)	140 (62.5)	475 (69.2)
Secondary progressive MS	88 (19.8)	120 (13.1)	23 (10.3)	97 (14.1)
Primary progressive MS	70 (15.7)	89 (9.7)	21 (9.4)	68 (9.9)
Progressive relapsing MS	13 (2.9)	16 (1.7)	2 (0.9)	14 (2.0)
Unsure	49 (11.0)	79 (8.6)	38 (17.0)	32 (4.7)
Disability level				
No disability or Mild	152 (34.4)	474 (51.9)	136 (60.2)	338 (49.1)
Moderate	176 (39.8)	306 (33.5)	58 (25.7)	248 (36.1)
Severe	114 (25.8)	134 (14.7)	32 (14.2)	102 (14.8)
Use of a DMT				
Yes	244 (54.7)	623 (68.1)	108 (47.8)	515 (74.8)
No	202 (45.3)	292 (31.9)	118 (52.2)	174 (25.2)
State/Territory				
NSW	180 (40.3)	231 (25.1)	66 (29.2)	165 (23.8)
VIC	129 (28.9)	244 (26.6)	67 (29.7)	177 (25.5)
QLD	65 (14.5)	118 (12.8)	30 (13.3)	88 (12.7)
SA	27 (6.0)	105 (11.4)	30 (13.3)	83 (12.0)
WA	17 (3.8)	111 (12.1)	22 (9.7)	94 (13.6)
TAS	19 (4.3)	63 (6.9)	17 (7.5)	49 (7.1)
ACT	9 (2.0)	46 (5.0)	9 (4.0)	37 (5.3)
NT	1 (0.2)	1 (0.1)	1 (0.4)	0 (0.0)
Remoteness level				
Major Cities	257 (57.5)	648 (70.5)	153 (67.7)	495 (71.4)
Inner Regional	132 (29.5)	209 (22.7)	60 (26.6)	149 (21.5)
Outer Regional	50 (11.2)	53 (5.8)	10 (4.4)	43 (6.2)
Remote/Very Remote	8 (1.8)	9 (1.0)	3 (1.3)	6 (0.9)
Total work productivity loss (%), mean (SD)*	13.8 (22.7)	13.9 (22.1)	5.2 (16.1)	15.9 (22.8)

*Work productivity was assessed for those who were working for pay. SD: standard deviation.

Supplementary Table 4. Lifestyle behaviours according to access to and receiving MS Nurse care.

	Access to MS Nurse care		Receiving MS Nurse care	
	No access	**Had access**	**Had access but not receiving**	**Had access and were receiving**
	N=367	N=751	N=172	N=579
Current smoking status, n (%)				
Smoking	31 (8.4)	59 (7.9)	163 (94.8)	50 (8.6)
Not smoking	336 (91.6)	692 (92.1)	9 (5.2)	529 (91.4)
Smoking marijuana, n (%)				
Yes	8 (2.2)	35 (4.7)	6 (3.5)	29 (5.0)
No	359 (97.8)	715 (95.3)	166 (96.5)	549 (95.0)
Currently drinking alcohol, n (%)				
Yes	275 (65.1)	573 (66.3)	130 (75.6)	443 (76.5)
No	91 (24.9)	178 (23.7)	42 (24.4)	136 (23.5)
Amount of alcohol consumed per week* (drinks), median (IQR) 1 (1-2)	1 (1-2)	1 (1-3)	2 (1-2)	
Physical activity level, n (%)				
High active	68 (28.8)	206 (33.0)	50 (36.0)	156 (32.1)
Moderate active	87 (34.2)	241 (38.6)	35 (25.2)	143 (29.4)
Low active	99 (39.0)	178 (28.5)	54 (38.9)	187 (38.5)
Taking vitamin D, n (%)				
Yes	269 (73.3)	575 (76.8)	125 (73.1)	450 (77.8)
No	174 (23.2)	98 (26.7)	46 (26.9)	128 (22.2)
Weekly sun exposure (hours), median (IQR)				
In summer	6.8 (2.8-12.5)	6.8 (2.8-12.5)	9.0 (2.8-14.5)	6.8 (2.8-12.5)
In winter	5.3 (1.8-10.8)	5.3 (2.8-10.)	6.8 (2.8-10.5)	5.3 (2.8-10.5)
Diet quality score (#1-100)	72.5 (9.7)	73.8 (10.6)		

* One standard drink is a glass (285ml) normal strength beer or nip (30ml) of spirits; or a small glass (100ml) of wine.

Supplementary Table 5. DMT use (by people with relapsing remitting MS) according to access to and receiving MS Nurse care.

	Access to MS Nurse Care		**Receiving MS Nurse care**	
	No access	Had access	Had access but not receiving	Had access and were receiving
	N=225	N=614	N=140	N=474
DMT used at survey time, n (%)				
Not using a DMT	59 (26.0)	130 (21.2)	55 (39.3)	75 (15.8)
Interferon β-1b (Betaferon, sub-cutaneous injection)	4 (1.8)	24 (3.0)	8 (5.7)	16 (3.4)
Interferon β-1a (Rebif, sub-cutaneous injection)	3 (1.3)	13 (2.2)	1 (0.7)	12 (2.5)
Interferon β-1a (Avonex, intramuscular injection)	3 (1.3)	12 (2.0)	4 (2.9)	8 (1.7)
Pegylated interferon β-1a (Plegridy, sub-cutaneous injection)	7 (3.1)	23 (3.8)	4 (2.9)	19 (4.0)
Glatiramer acetate (Copaxone, sub-cutaneous injection)	15 (6.7)	33 (5.4)	4 (2.9)	29 (6.1)
Teriflunomide (Aubagio, oral)	18 (8.0)	37 (6.0)	6 (4.3)	31 (6.5)
Dimethyl fumarate (Tecfidera, oral)	14 (6.2)	32 (5.2)	8 (5.7)	24 (5.1)
Novantrone (Mitoxantrone, intravenous infusion)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Azathioprine (Azasan, oral)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Methotrexate (Trexall, oral)	0 (0.0)	2 (0.3)	0 (0.0)	0 (0.0)
Cladribine (Mavenclad, oral)	9 (4.0)	30 (4.9)	7 (5.0)	23 (4.9)
Fingolimod (Gilenya, oral)	57 (25.3)	112 (18.2)	23 (16.4)	89 (18.8)
Natalizumab (Tysabri, intravenous infusion)	14 (6.2)	60 (9.8)	6 (4.3)	54 (11.4)
Alemtuzumab (Lemtrada, intravenous infusion)	3 (1.3)	20 (3.3)	4 (2.9)	16 (3.4)
Ocrelizumab (Ocrevus, intravenous infusion)	19 (8.4)	86 (14.0)	10 (7.1)	76 (16.0)
DMT categories*, n (%)				
Not using a DMT	59 (26.2)	130 (21.2)	55 (39.3)	75 (15.8)
Category 1 DMTs	32 (14.2)	107 (17.4)	21 (15.0)	86 (18.1)
Category 2 DMTs	32 (14.2)	69 (11.2)	14 (10.0)	55 (11.6)
Category 3 DMTs	102 (45.3)	308 (50.2)	50 (35.7)	258 (54.4)
Route of administration of the DMTs, n (%)				
Not using a DMT	59 (26.2)	130 (21.2)	55 (39.3)	75 (15.8)
Injectable DMTs	32 (14.2)	105 (17.1)	21 (15.0)	84 (17.7)
Infusion DMTs	36 (16.0)	166 (27.0)	20 (14.3)	146 (30.8)
Oral DMTs	98 (43.6)	213 (34.7)	44 (31.4)	169 (35.7)

*DMT categories: Category 1 DMTs (injectable platform DMTs) include interferons-β and glatiramer acetate; Category 2 DMTs include teriflunomide and dimethyl fumarate; Category 3 DMTs (higher efficacy) include natalizumab, fingolimod, alemtuzumab, ocrelizumab and cladribine.

Supplementary Table 6. Personal characteristics according to frequency of contact with an MS Nurse.

	Less than annually	Annually	Quarterly	Monthly/Weekly
	N=338	N=203	N=117	N=30
Age (years), mean (SD)	56.5 (10.9)	55.0 (11.0)	53.2 (10.8)	55.0 (12.2)
MS duration since diagnosis (years), mean (SD)	15.5 (7.5)	14.7 (8.3)	14.2 (8.1)	15.4 (8.2)
Age at MS diagnosis	40.9 (10.5)	40.1 (10.8)	38.9 (10.5)	39.4 (11.7)
Gender, n (%)				
Female	278 (82.2)	162 (79.8)	97 (82.9)	28 (93.3)
Male	60 (17.5)	41 (20.2)	20 (17.1)	2 (6.7)
Education, n (%)				
Primary/secondary school	81 (24.0)	47 (23.1)	22 (18.8)	8 (26.7)
Occupational certificate	100 (29.7)	62 (30.5)	50 (42.7)	10 (33.3)
University degree	156 (46.3)	94 (46.3)	45 (38.5)	12 (40.0)
MS type in 2019, n (%)				
Relapsing remitting MS	233 (68.9)	141 (69.5)	83 (70.9)	16 (53.3)
Secondary progressive MS	40 (11.8)	34 (16.8)	18 (15.4)	5 (16.7)
Primary progressive MS	32 (9.5)	20 (9.9)	8 (6.8)	6 (20.0)
Progressive relapsing MS	7 (2.1)	3 (1.5)	3 (2.6)	1 (3.3)
Unsure	26 (7.7)	5 (2.5)	5 (4.3)	2 (6.7)
Disability level, n (%)				
No disability or Mild	181 (54.2)	97 (48.0)	45 (38.5)	13 (43.3)
Moderate	110 (32.9)	76 (37.6)	51 (43.6)	8 (26.7)
Severe	43 (12.9)	29 (14.4)	21 (18.0)	9 (30.0)
Use of a DMT, n (%)				
Yes	242 (81.8)	156 (86.9)	97 (84.3)	17 (58.6)
No	95 (28.2)	47 (23.1)	18 (15.7)	12 (41.4)
Remoteness level, n (%)				
Major Cities	249 (73.7)	144 (70.9)	79 (67.5)	21 (70.0)
Inner Regional	72 (21.3)	43 (21.2)	29 (24.8)	4 (13.3)
Outer Regional	15 (4.4)	12 (5.9)	9 (7.7)	5 (16.7)
Remote/Very Remote	2 (0.6)	4 (1.9)	0 (0.0)	0 (0.0)

Supplementary Table 7. DMT use (of people with relapsing remitting MS) receiving MS Nurse care according to frequency of contact*

	Less than annually	**Annually**	**Quarterly**	**Monthly/Weekly**
	N=231	N=141	N=83	N=16
DMT used at survey time				
Not using a DMT	42 (18.0)	21 (14.9)	8 (9.6)	4 (25.0)
Interferon β-1b (Betaferon, sub-cutaneous injection)	9 (3.9)	5 (3.5)	1 (1.2)	1 (6.3)
Interferon β-1a (Rebif, sub-cutaneous injection)	8 (3.5)	4 (2.8)	0 (0.0)	4 (25.0)
Interferon β-1a (Avonex, intramuscular injection)	5 (2.2)	3 (2.1)	0 (0.0)	0 (0.0)
Pegylated interferon β-1a (Plegridy, sub-cutaneous injection)	7 (3.0)	3 (2.1)	8 (9.6)	0 (0.0)
Glatiramer acetate (Copaxone, sub-cutaneous injection)	19 (8.2)	9 (6.4)	1 (1.2)	0 (0.0)
Teriflunomide (Aubagio, oral)	17 (7.3)	8 (5.7)	5 (6.0)	1 (6.3)
Dimethyl fumarate (Tecfidera, oral)	12 (5.2)	7 (5.0)	3 (3.6)	2 (12.5)
Cladribine (Mavenclad, oral)	7 (3.0)	7 (5.0)	8 (9.6)	1 (6.2)
Fingolimod (Gilenya, oral)	53 (22.8)	22 (15.6)	14 (16.9)	0 (0.0)
Natalizumab (Tysabri, intravenous infusion)	19 (8.2)	17 (12.1)	14 (16.9)	4 (25.0)
Alemtuzumab (Lemtrada, intravenous infusion)	3 (1.3)	7 (5.0)	6 (7.2)	0 (0.0)
Ocrelizumab (Ocrevus, intravenous infusion)	29 (12.5)	28 (19.9)	15 (18.1)	3 (18.8)
DMT categories**				
Not using a DMT	42 (18.0)	21 (14.9)	8 (9.6)	4 (25.0)
Category 1 DMTs	48 (21.5)	24 (17.0)	10 (12.0)	1 (6.2)
Category 2 DMTs	29 (12.5)	15 (10.6)	8 (9.6)	3 (18.8)
Category 3 DMTs	111 (47.8)	81 (57.5)	57 (68.8)	8 (50.0)
Route of administration of the DMTs				
Not using a DMT	42 (18.2)	21 (14.9)	8 (9.6)	4 (25.0)
Injectable DMTs	48 (20.8)	24 (17.0)	10 (12.0)	1 (6.3)
Infusion DMTs	51 (22.1)	52 (36.9)	35 (42.2)	7 (47.8)
Oral DMTs	89 (38.5)	44 (31.2)	30 (36.1)	4 (25.0)

*Includes items from Table 4, with additional details.

**DMT categories: Category 1 DMTs (injectable platform DMTs) include interferons-β and glatiramer acetate; Category 2 DMTs include teriflunomide and dimethyl fumarate; Category 3 DMTs (higher efficacy) include natalizumab, fingolimod, alemtuzumab, ocrelizumab and cladribine.

Supplementary Table 8. Rated usefulness of specific supports received as part of MS Nurse care.

	The Nurse provided this and it was helpful	**The Nurse provided this but it wasn't helpful**	**I didn't need this**	**I didn't get this but I would have liked it**
		*n (%)**		
Advice on the management of MS symptoms	352 (54.7)	14 (2.2)	214 (33.2)	64 (9.9)
Advice on the management of treatment side effects	310 (48.6)	18 (2.8)	256 (40.1)	54 (8.5)
Providing education and information to assist with informed treatment decisions	301 (46.9)	14 (2.2)	258 (40.2)	69 (10.8)
Providing education to assist with the use and follow-up monitoring of disease modifying therapies	268 (41.7)	12 (1.9)	278 (43.3)	84 (13.1)
Identification and advice on the management of relapses	172 (27.2)	9 (1.4)	361 (57.1)	90 (14.2)
Assisting you with accessing other support services**	161 (25.2)	12 (1.9)	325 (50.9)	141 (22.1)
Assisting you with adherence to treatment	142 (22.6)	7 (1.1)	438 (69.6)	42 (6.7)
Providing information, resources or weblinks to relevant research	139 (22.0)	5 (0.8)	378 (59.9)	109 (17.3)
Providing emotional or psychological support	139 (21.8)	5 (0.8)	385 (60.4)	108 (17.0)
Providing education and resources around healthy lifestyle behaviors (e.g. nutrition, physical exercise, non-smoking, alcohol)	118 (18.6)	9 (1.4)	425 (66.8)	84 (13.2)
Providing information and education about clinical trials	106 (16.8)	9 (1.4)	361 (57.3)	154 (24.4)
Arranging an earlier clinic review	100 (15.9)	6 (1.0)	446 (71.1)	75 (12.0)
Assisting you with the decision on whether to present to the emergency department of a hospital	60 (9.5)	7 (1.1)	517 (81.8)	48 (7.6)
Providing support with family or social issues	52 (8.3)	3 (0.5)	500 (79.6)	73 (11.6)
Providing support around employment issues	28 (4.4)	1 (0.2)	534 (84.8)	67 (10.6)
Assisting you with financial issues	18 (2.9)	1 (0.2)	538 (85.3)	74 (11.7)

Categories are sorted by whether 'the Nurse provided this and it was helpful'.
*n: number of participants; %: percentage of n = 693 participants receiving MS Nurse care
**e.g. physiotherapist, occupational therapist, psychologist, disability employment services, speech pathologist, massage therapist, Continence Nurse, peer support programs, counsellor, dietitian and psychiatrist

Supplementary Table 9. Rated usefulness of supports received as part of MS Nurse care by those who believed they needed the support (i.e. excluding those who did not need a particular support).

	The Nurse provided this and it was helpful	**The Nurse provided this but it wasn't helpful**	**I didn't get this but I would have liked it**
		n (%)*	
Advice on the management of MS symptoms	352 (81.9)	14 (3.3)	64 (14.9)
Advice on the management of treatment side effects	310 (81.2)	18 (4.7)	54 (5.4)
Providing education and information to assist with informed treatment decisions	301 (78.4)	14 (3.6)	69 (18.0)
Assisting you with adherence to treatment	142 (74.3)	7 (3.7)	42 (22.0)
Providing education to assist with the use and follow-up monitoring of disease modifying therapies	268 (73.6)	12 (3.3)	84 (23.1)
Identification and advice on the management of relapses	172 (63.5)	9 (3.3)	90 (33.2)
Providing education and resources around healthy lifestyle behaviors (e.g. nutrition, physical exercise, non-smoking, alcohol)	118 (55.9)	9 (4.3)	84 (39.8)
Providing emotional or psychological support	139 (55.3)	5 (2.0)	108 (42.9)
Arranging an earlier clinic review	100 (55.3)	6 (3.3)	75 (41.4)
Providing information, resources or weblinks to relevant research	139 (54.9)	5 (2.0)	109 (43.1)
Assisting you with the decision on whether to present to the emergency department of a hospital	60 (52.2)	7 (6.1)	48 (41.7)
Assisting you with accessing other support services**	161 (51.3)	12 (3.8)	141 (44.9)
Providing support with family or social issues	52 (40.6)	3 (2.3)	73 (57.0)
Providing information and education about clinical trials	106 (39.4)	9 (3.4)	154 (57.3)
Providing support around employment issues	28 (29.2)	1 (0.1)	67 (69.7)
Assisting you with financial issues	18 (19.4)	1 (1.1)	74 (79.6)

Categories are sorted by whether 'the Nurse provided this and it was helpful'.
*n: number of participants; %: percentage of those participants who believed they needed the support
**e.g. physiotherapist, occupational therapist, psychologist, disability employment services, speech pathologist, massage therapist, Continence Nurse, peer support programs, counsellor, dietitian and psychiatrist

About MS Australia

MS Australia is the national peak body for people affected by MS. We work with the MS community to fund and coordinate MS research, advocate on behalf of people living with MS and drive awareness and education as part of the worldwide effort to solve MS. We work closely with our four state and territory MS Member Organisations that provide services, programs, and support to the MS community nationwide.

Top: MS and Continence Nurse K-J Lazarus providing tailored MS education

MS Australia
ABN 51 008 515 508

Head Office: Level 19,
Northpoint, 100 Miller Street,
North Sydney NSW 2060

Postal: PO Box 625, North
Sydney NSW 2059

www.msaustralia.org.au

For local support and advisory services contact your state or territory MS Member Organisation.