

## Research Roundup for Summer

December 2021

There is a bumper crop of recent Australian research this quarter to help you answer the never-ending challenging questions in clinic and keep you up to date with all the recent happenings in allied health research to improve quality of life for patients living with MS. No doubt, many of you have participated in some of this research, whether by collecting or entering crucial MSBase data or by more active participation in specific projects - none of it can happen without you. Enjoy!

### Australian research:

1. Improving smoking cessation support for people with multiple sclerosis: A qualitative analysis of clinicians' views and current practice

Australian researchers have continued to explore one of the key modifiable lifestyle factors in MS, investigating smoking cessation support. As MS healthcare providers have a major role to play in educating people with MS about the negative effects of smoking on MS progression, little is known about how they deliver smoking cessation information and support. This study aimed to uncover current practices, barriers, and facilitators to smoking cessation. A total of 19 MS Nurses and neurologists were interviewed by telephone to uncover their views on smoking cessation and current practice using the qualitative method of framework analysis. Participants reported that they assessed the smoking status of their patients, regularly in the first appointment but less so in follow-up. However, the content of how they provide information about smoking and MS varies. Some clinicians offered smoking cessation support options, but others did not see it as their responsibility or were unsure of pathways to support. These findings indicate there are unmet needs for MS clinicians to provide support to their patients, to tailor resources, to train clinicians and a need to collaborate with smoking cessation service providers. This provides an opportunity for the development of bespoke smoking cessation advice resources for MS Nurses and neurologists, with the aim of improving quality of life and delaying MS progression.

Read more: doi: [10.1016/j.msard.2021.103289](https://doi.org/10.1016/j.msard.2021.103289)

## 2. Cognitive function and oral health in relapsing remitting Multiple Sclerosis

MS is often associated with reduced cognitive function, and recently it has been suggested that people living with MS may be vulnerable to oral health problems. Researchers in this study explored if there were links between cognition and oral health in people with relapsing remitting MS (RRMS). A total of 111 people were included in the study, half with RRMS and half healthy controls, with all participants undergoing an oral health assessment as well as neuropsychological tests. Findings showed that people with RRMS presented with higher rates of tooth decay and gingivitis and performed worse than the healthy controls in several neuropsychological domains (specifically language, complex attention and executive function). However, overall, the study failed to show strong associations between specific cognitive function domains and oral health. The researchers suggest that there is a need for early assessment of both oral health and cognitive function in people with RRMS.

Read more: doi: [10.1007/s00784-021-04272-1](https://doi.org/10.1007/s00784-021-04272-1)

## 3. Self-reported behaviour change among Multiple Sclerosis community members and interested laypeople following participation in a free online course about Multiple Sclerosis

The Understanding Multiple Sclerosis massive online course (MOOC) was created to increase awareness and understanding of MS for all people in the MS community and has been a tool often recommended by MS Nurses for their MS patients and families. The impact of this course has now been evaluated to assess the effects of the MOOC on self-reported health behavioural change. Study participants completed pre- and post-course surveys to both explore and measure changes to health behavior. A total of 560 course completers were included in this study, including people living with MS, MS healthcare professionals and non-MS community members. Just under half of participants (44.1%) reported health behavior change after the course, with 68.1% of these participants showing improvement. The researchers determined that these improvers had significantly lower pre-course health behaviours, with most of the changes encompassing knowledge, exercise, diet and care practice. This confirms that the provision of information, discussions about MS and

goal setting encourages positive changes to health behaviours, especially for those people with little knowledge about MS. This is increasingly important for all MS clinicians in the current climate of improving brain health.

Read more: doi: [10.1002/hpja.559](https://doi.org/10.1002/hpja.559)

4. Greater mastery is associated with lower depression risk in a large international cohort of people with Multiple Sclerosis over 2.5 years

The concept of “mastery” is the extent to which an individual perceives their life circumstances as being under their control and not predominately influenced by external factors. Working with people living with MS, we often see a perception of loss of control following an MS diagnosis or when changes occur throughout the life trajectory with MS. However, there has been little research into relationships between mastery and clinical outcomes. Researchers from Melbourne assessed mastery with fatigue, disability, number of relapses and depression risk in n=839 people with MS over 2.5 years of follow-up. Findings from this cross-sectional study showed that people with the highest mastery scale scores had 90% lower frequency of depression risk and 60% lower frequency of clinically significant fatigue. As expected, there were less associations with disability and no robust associations with number of relapses. This study suggests that prospectively there may be a protective relationship of mastery with subsequent risk of depression, representing a point of intervention to improve well-being in MS and an area where MS Nurses could target discussion and education.

Read more: doi: [10.1007/s11136-021-03033-7](https://doi.org/10.1007/s11136-021-03033-7)

5. Do people with Multiple Sclerosis receive appropriate support from the National Disability Insurance Scheme matching their level of disability? A description of disease ‘burden and societal cost in people with Multiple Sclerosis in Australia’ (BAC-MS)

This study from the team at John Hunter has been the first to explore if people with MS receive appropriate support from the National Disability Insurance Scheme (NDIS) matching their level of disability. Researchers enrolled 10 people with MS at each step of the expanded disability status scale (EDSS) and investigated their NDIS application. The value of n=186 packages were compared against individual mobility, cognition and psychological impact scores. A total of 49% of participants had an NDIS package approved. Findings suggested that there was a striking variability in the packages approved, with restricted mobility being the driving factor. The package values tended to be correlated with EDSS steps (greater disability, higher packages) and with cognitive impacts, but not with psychological effects of MS. The researchers suggest that the time spent assessing cognition in clinic can be beneficial for people with MS in supporting their applications. However, there is still work to be done to ensure that the psychological impacts of MS are well recognised in NDIS packages to help promote the best quality of life for people living with MS.

Read more: doi: [10.1071/AH21056](https://doi.org/10.1071/AH21056)

#### 6. Exercise and Sports Science Australia (ESSA) position statement on exercise for people with mild to moderate Multiple Sclerosis

Exercise and Sport Science Australia (ESSA) have released a position statement on exercise for people with mild to moderate MS, which has now been published. As recent research has demonstrated, exercise provides many benefits for people living with MS. There is strong evidence that resistance *and* aerobic training performed 2 -3 times a week at a moderate intensity, are safe for people with MS and can improve muscle strength, cardiorespiratory fitness, balance, fatigue, functional capacity, mobility, and quality of life in people with mild to moderate disability, which is defined as EDSS <6.5 (needing bilateral assistance). The evidence for EDSS steps higher than 6.5 is less clear. The position statement recommends resistance and aerobic training to alleviate symptoms of MS and balance exercises to prevent falls, with exercise programs prescribed and delivered by qualified

exercise professionals who can accommodate exercise-related complications to MS, such as fatigue and heat sensitivity.

Read more: doi [10.1016/j.jsams.2021.08.015](https://doi.org/10.1016/j.jsams.2021.08.015)

## 7. Role of environmental factors in MS

Environmental factors play a significant role in both the pathogenesis and progression of MS, often interacting with other environmental or genetic factors. This article reviews the current evidence of the role of environmental risk factors including gene-environment interactions and timing of exposure. The authors suggest there is *good evidence* supporting tobacco smoking, low vitamin D levels and/or low sun exposure, Epstein Barr virus (EBV) seropositivity and a history of infective mononucleosis as increasing the risk of developing MS. Additionally there is *some evidence* that gene-smoking, gene-EBV and smoking-EBV interactions additively affect the risk of MS onset. Overall, the picture is complex with many risk factors and multiple interactions at play. By pinpointing the sources of risk for MS onset and progression, this research identifies avenues for possible risk-reducing interventions, an important part of educating and informing people with MS and their families in the clinical setting.

Read more: doi:[10.1080/14737175.2021.1978843](https://doi.org/10.1080/14737175.2021.1978843)

## 8. Experiences of healthcare for people living with Multiple Sclerosis and their healthcare professionals

This research from Canberra explores the healthcare experiences of people with MS and their healthcare professionals (HCPs), identifying areas that appear to work well and other areas which could be improved. The study sample comprised seven neurologists, four MS Nurses and 15 people living with various types of MS, who were interviewed individually. The study data was explored using thematic analysis. Findings revealed similarities for both groups (HCPs and people living with MS), including valuing clear communication, recognising the uncertainty surrounding MS diagnosis, treatment and progression and the importance

of developing rapport in the HCP/patient relationship. Communication was the salient theme across all interviews, with a lack of open and empathic communication with their HCP identified by people with MS as being a cause of disappointment in their care. However, there are multiple factors considered by HCPs that are not readily transparent to people living with MS. The study authors provide recommendations to help HCPs to improve the therapeutic alliance and provide reassurance to patients. To give people with MS realistic expectations of what their HCP can provide, HCPs should clearly outline the role they will play in MS management, as well as the roles that can be played by MS support organisations, and other HCPs. This may improve healthcare experiences for both patients and HCPs, leading to better engagement with treatment and better overall health outcomes.

Read more: doi: [10.1111/hex.13348](https://doi.org/10.1111/hex.13348)

#### 9. Improving the detection and treatment of depression in Australians with MS: A qualitative analysis

Despite being common in people living with MS, depression is not always formally or regularly assessed through MS healthcare services and often goes undetected, untreated, or undertreated. This study aimed to explore current practices, barriers, and facilitators for detecting and treating depression in Australians with MS. Participants included 26 people living with MS recruited by social media, completing a series of scales, and telephone or video interviews which were explored using framework analysis. Findings revealed that 73% of participants were experiencing severe depression symptoms, also reporting that depression was not regularly assessed in their MS healthcare setting and that information on depression was often limited in clinic. Barriers identified to mental health support included recognising depression itself, resistance to treatment and limitations to collaborative support between GPs and MS healthcare services. Participants expressed a need for more open conversations about depression and information during their MS healthcare consultations. The researchers suggest that to improve the detection and treatment of depression in the MS population, there needs to be better provision of

information to patients, more regular and consistent screening and assessment, and improved collaboration between the GP and the MS healthcare team.

Read more: doi: [10.1016/j.msard.2021.103290](https://doi.org/10.1016/j.msard.2021.103290)

#### 10. Sociodemographic and clinical characteristics of diet adherence and relationship with diet quality in an international cohort of people with Multiple Sclerosis

Diet has previously been implicated in both the onset and progression of MS, with multiple and conflicting recommendations for people with MS. A recent AMSLS study revealed that just over 20% of participants reported following a particular diet, with 7.7% following an MS-specific diet. This new study used data from the Melbourne based HOLISM study (n=2466), recruiting participants online to explore the characteristics of those who followed specific diet programs and the relationships of these programs to diet quality. Participants were queried on several factors, including the degree of adherence to their chosen diet, socioeconomic and clinical characteristics. A total of 48.8 % of participants reported following a diet for their MS, the majority following the “Overcoming MS” (OMS) diet, followed by the Swank and Wahls diets. Diet adherence was more common amongst those with a higher socioeconomic status and higher quality of life. Diet adherence was less common amongst people with higher disability and fatigue, and in females. Overall, diet quality was higher amongst participants following any diet program, particularly OMS and Swank diets, but not the Wahls diet. These characteristics can help clinicians to understand demographic and clinical associations with diet adherence and what sorts of diets the MS community more commonly embark on.

Read more: doi: [10.1016/j.msard.2021.103307](https://doi.org/10.1016/j.msard.2021.103307)

#### 11. Association Between Cognitive Trajectories and Disability Progression in Patients with Relapsing-Remitting Multiple Sclerosis

Longitudinal cognitive trajectories in MS are diverse and difficult to measure. This study aimed to identify longitudinal reaction time trajectories in RRMS using a computerised cognitive battery, and to assess the association between trajectories of reaction time and disability progression. Participants (n=460) serially completed computerised reaction time tasks measuring psychomotor speed, visual attention, and working memory. Participants completed at least 3 testing sessions over 6 months. Modelling of the data collected by the computerised battery (MSReactor) showed that the visual attention and working memory tasks could identify a group of participants who were more likely to experience a 6-month confirmed disability progression. Participants could be classified into predicted cognitive trajectories after just 5 tests with high accuracy. This work provides an exciting base for further studies in cognition, hopefully leading to a clinically useful tool in the future.

Read more: doi: [10.1212/WNL.00000000000012850](https://doi.org/10.1212/WNL.00000000000012850)

## 12. Long-term outcomes in patients presenting with optic neuritis: Analyses of the MSBase registry

This study utilised the MSBase registry to evaluate long-term vision and other neurological outcomes in patients presenting with optic neuritis (ON). Many MS Nurses regularly contribute to the registry by collecting and/or entering data to this large international database. For this study, a total of 41 centres across the world submitted data from just over 1,300 patients towards understanding the long-term effects after optic neuritis as a first Clinically Isolated Syndrome (CIS) event with a median follow-up of 5 years. Most patients had good visual acuity several years after ON. However, treatment of ON with disease modifying therapies (DMTs) was associated with reduced risk and delayed conversion to clinically definite MS, sustained EDSS progression and sustained visual function scores. This suggests that early treatment with DMTs for patients presenting with ON is associated with lower conversion to MS and better neurological and visual outcomes.

Read more: [10.1016/j.jns.2021.118067](https://doi.org/10.1016/j.jns.2021.118067)

### **International research:**

13. Sociodemographic and clinical factors associated with depression, anxiety, and general mental health in people with Multiple Sclerosis during the COVID-19 pandemic

As more COVID-19 related research is presented, we can start to become more confident in both our responses to patient questions and in the more general health advice we provide. COVID-19 brought with it great potential to cause increased psychological distress for people living with MS. This study explored the self-reported mental health of people in the United States living with MS through COVID-19, prior to the vaccine rollout. A cross-sectional online survey assessing depression and anxiety symptom burdens and general mental health status were measured using validated scales for n=610 people with MS. Findings revealed the prevalence of moderate to severe depression in this cohort to be 27.4%, with 14.7% for anxiety, with 55.1% of participants experiencing fair to poor general mental health. A small proportion of the study sample went on to test positive for COVID-19 (7.7%) and they reported higher depression and anxiety symptom burdens. People living with higher disability burdens also reported greater depressive symptoms and worse general mental health, as did people of a younger age. Females reported higher levels of anxiety symptom burden. These findings help clinicians to be aware of those most at risk of psychological distress during the pandemic and to maintain vigilance.

Read more: doi: [10.1016/j.msard.2021.103327](https://doi.org/10.1016/j.msard.2021.103327)

14. Effects of pregnancy and breastfeeding on clinical outcomes and MRI measurements of women with Multiple Sclerosis: An exploratory real-world cohort study

Pregnancy represents an important event for women with MS and is often accompanied by post-partum disease reactivation. The objective of this study was to characterise a large real-world cohort of women with MS to evaluate the effects of pregnancy and breastfeeding

on short- and long-term clinical and magnetic resonance imaging (MRI) outcomes. A total of n=210 MS patients with and without pregnancy were recruited, with 61.4% experiencing at least one pregnancy. The study then examined 90 pregnancies that occurred after the onset of MS. Clinical relapses and MRI activity of the year before conception versus the year after delivery were evaluated. Regression models investigated the relationships between long-term MS outcomes (EDSS score and MRI brain measurement) and pregnancy and breastfeeding duration.

Results showed that clinical activity after delivery was associated with clinical activity of the year before conception. Similarly, post-partum MRI activity was associated with pre-conception MRI activity. Regarding long-term outcomes, having had at least one pregnancy during MS was associated with a lower EDSS score while no relationships were reported with MRI measurements. Conversely, a breastfeeding duration > 6 months was associated with lower white matter volume. This study highlights the importance of pregnancy planning and treatment optimisation in the post-partum period, particularly for women who choose to breastfeed.

Read more: [doi: 10.1007/s40120-021-00297-6](https://doi.org/10.1007/s40120-021-00297-6)

#### 15. Effects of melatonin on sleep disturbances in Multiple Sclerosis: A randomized, controlled pilot study

Sleep disturbances are commonly reported by people with MS, yet optimal management of sleep disturbances is lacking. This study explored the use of exogenous melatonin on sleep quality and sleep disturbances in n=30 people with MS in a double-blind cross-over study. Participants took either melatonin or placebo for 2 weeks, then the opposite for the following 2 weeks, whilst total sleep time and sleep efficiency were also measured, along with patient reported outcomes pre, during and at the end of the trial. Results showed that melatonin significantly improved total sleep time with a trend towards higher sleep efficiency. The researchers suggest that melatonin, as a low-cost supplement, could help improve sleep in people living with MS.

Read more: [10.1177/20552173211048756](https://doi.org/10.1177/20552173211048756)

## 16. Pregnancy in women with MS: Impact on long-term disability accrual in a nationwide Danish Cohort

Pregnancy is considered to influence the disease course in women with MS. The aim of this study was to investigate the effect of pregnancy on long-term disability accrual in women with CIS and MS using the Danish Multiple Sclerosis Registry (DMSR). Models with pregnancy as a time-dependent exposure were used to evaluate time to reach a confirmed EDSS score of both 4 and 6. A total of 425 women who became pregnant were included in the study. When including pregnancy as a time-dependent exposure, a non-significant association with time to reach EDSS 4 and 6 was found. The study researchers suggest that this study confirms the current view that pregnancy does not affect long-term disability accumulation in women with MS, an important message for clinicians providing pregnancy planning advice to discuss with patients.

Read more: doi: [10.1177/13524585211057767](https://doi.org/10.1177/13524585211057767)