

# AMSLS NEWS



## Australian MS Longitudinal Study (AMSLS)

October 2019

With the prevalence of MS still on the rise in Australia, having an accurate picture of how those with MS are faring is vital to ensure support is provided where it is most needed. Now in its 17<sup>th</sup> year, the AMSLS is well established in providing this picture and we once again wish to share the latest findings and plans for the future.

### Striving for a Healthier Mind and a Healthier Lifestyle

In an AMSLS collaboration, Claudia Gascoyne, Dr Steve Simpson, Jing Chen, Associate Professor Ingrid van der Mei and Dr Claudia Marck, have been exploring the five healthy lifestyle factor recommendations for nutrition, physical activity, body weight, smoking and alcohol consumption and to what extent people with MS follow these recommendations. With twice as many people with MS affected by anxiety and depression than the general population, they also wanted to examine whether lifestyle factors were associated with mental health.

Not being physically active, smoking (more than one cigarette, cigar or pipe per day) and consuming two or more standard drinks per day were linked to increased occurrence of depressive symptoms, with the severity of these depressive symptoms also associated with smoking and insufficient fruit and vegetable intake. Smoking was also associated with severity of anxiety symptoms, but no other lifestyle factors were.

Encouragingly, the benefits of not smoking and limiting alcohol are being heard as 90% of AMSLS participants do not smoke and 83% consume alcohol within recommended levels. When it came to diet and exercise, however, the story wasn't as good. Only 10% of participants met the optimal intake of two serves of fruit and five serves of vegetables a day, 39% had a healthy BMI and 53% engaged in adequate levels of physical activity.

Finally, those who did follow the health recommendations on the whole were found to have lower prevalence and severity of depressive symptoms, and for each extra healthy recommendation followed, the occurrence and severity of depressive symptoms reduced proportionally. These results may indicate that people with depression have more trouble adhering to health recommendations as well as those who don't follow health recommendations have a higher risk for depressive symptoms.

With only 3% of participants meeting all five healthy lifestyle factor requirements, further work is required to help people with MS follow these health recommendations. Further studies are also required to assess whether making changes to these lifestyle factors does translate to a reduction in symptoms of MS, such as depression. However, these findings are a fantastic stepping stone towards developing a strong, evidence-based and holistic approach towards the management of MS, which includes factors people can control themselves.

Do you know someone with MS who is not part of the AMSLS family?

We are always accepting new participants – the more voices we have, the louder we can shout.

To join, download the information sheet and consent forms from:

[www.MSRA.org.au/AMSLS](http://www.MSRA.org.au/AMSLS)

Need to contact us?

[AMSLS.info@utas.edu.au](mailto:AMSLS.info@utas.edu.au)

(03) 6226 4739

We're always happy to hear from you!



## Do you have MS and smoke tobacco or have recently quit?

Researchers from the University of Melbourne, Swinburne University and Cancer Council Victoria invite you to take part in an interview (face-to-face, online or over the phone) to ask you questions about the benefits and disadvantages of smoking tobacco and what may help people with MS to quit smoking if they are interested in doing so.

The interview will take approximately 60 minutes and you will receive a \$30 Coles/Myer gift voucher for your time.

For more information, or to book in an interview time please contact **Dr Assunta Hunter** via email, call or text on:

[assunta.hunter@unimelb.edu.au](mailto:assunta.hunter@unimelb.edu.au)

0421 679 154

## Register now for the Progress in MS Research Live Update

Join MS Research Australia in cyberspace for its Progress in MS Research Live Update 2019.

Hear the latest MS research news direct from the experts on topics including modifiable lifestyle factors, myelin repair, integrating patients with research and more.

**Date:** Saturday 2 November 2019

**Time:** 10am – 11am (AEDT)

**Location:** Live stream on your PC or mobile

**Cost:** FREE – registration required

The internationally renowned expert speakers include:

- **Associate Professor Ellen Mowry** from John Hopkins University, USA
- **Associate Professor Gonçalo Castelo-Branco** from Karolinska Institutet, Stockholm
- **Professor Tanuja Chitnis** from Harvard Medical School & BWH, USA

Register for the live stream now at:

[msra.org.au/events/liveupdate2019](https://msra.org.au/events/liveupdate2019)

## The Challenges Multiple Health Conditions Bring to Employment

Continuing her work in supporting those with MS to be happy and productive in the workforce, PhD student Jing Chen examined how other health conditions in addition to MS (comorbidities) can affect employment outcomes. Considering these comorbidities can also contribute to a lower employment rate overall, effective management would bring substantial personal and societal benefits.

As a quick comparison, for those with no comorbidities, the average productive time lost over a 4-week period due to the impacts of MS symptoms was 1.3 days. For those with at least one other condition, the time lost increased to 2.5 days.

Data from the *Lifestyle and Environment Survey* revealed 90% of working-aged participants reported having one or more comorbidities, with the top four being depression (45%), anxiety (42%), allergies (38%), and migraines (30%). In addition, 38% of respondents said at least one of their comorbidities limited their daily activities, with the most common being osteoarthritis (51%), migraines (40%), anxiety (33%), and depression (29%).

Combining this information, the biggest impacts on people's ability to work effectively were found for depression, allergies, anxiety, migraines and osteoarthritis.

While the number and impact of physical comorbidities increases significantly with age, depression and anxiety are far more likely to occur across the whole working life span. They can also impact quality of life and other MS symptoms, such as fatigue and cognitive function. Considering the impacts and high prevalence, early and routine screening and support for anxiety and depression in people with MS could have huge benefits for their work and everyday lives.

## Understanding Multiple Sclerosis free online course

The *Understanding Multiple Sclerosis* online course has launched with a bang, already ranking 7<sup>th</sup> in the top 100 global ratings for Massive Open Online Courses by Class Central. Enrol now for the next free course starting in March 2020:

[ms.mooc.utas.edu.au](https://ms.mooc.utas.edu.au)

## The Impacts of Multiple Health Conditions

Lara Lo, one of our PhD Students, has continued to look further at the impact of comorbidities on people's overall health-related quality of life (HRQoL).

She found that both mental comorbidities, such as depression and anxiety, and physical comorbidities, particularly diseases of the musculoskeletal system, greatly lower the HRQoL of people with MS. When she looked at the impact of comorbidities on the severity of MS symptoms, initial results revealed the direct association of the total number of comorbidities and symptom severity, with physical comorbidities such as musculoskeletal disorders (osteoporosis, osteoarthritis and rheumatoid arthritis) having the largest impact on the severity of the MS symptoms.

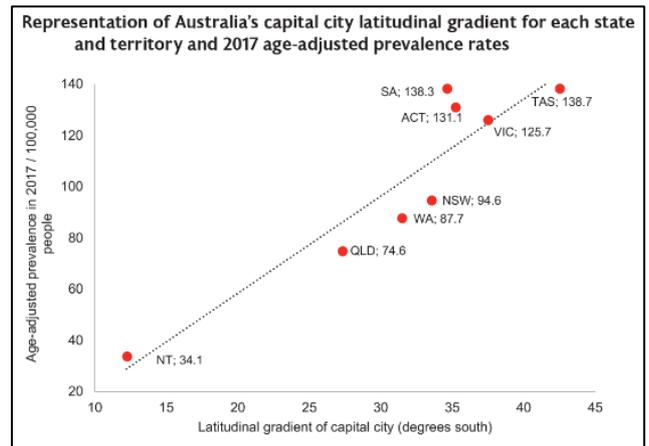
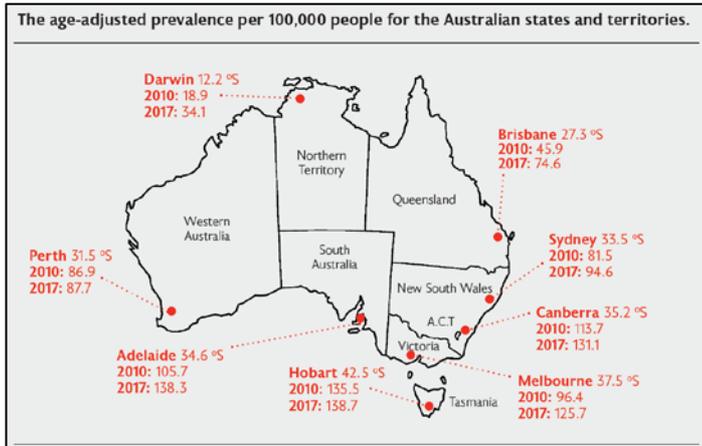
Lara's work will now focus on determining the patterns of comorbidity in MS and how these are associated with different MS outcomes using the data from the *Disease Course Surveys* and the *Lifestyle and Environment Surveys*.

All AMSLS publications can be found on the MS Research Australia website:

<https://msra.org.au/australian-ms-longitudinal-study/publications/>

## How your survey data translates into important information – examples from the Health Economic Impact Report

When completing the AMSLS surveys, the value of each question or group of questions is not always obvious. Below are two examples from the *2016 Economic Impact* study that feed into important planning around MS; one showing the power of one question, and the other showing why we choose to use standard surveys.



**Calculating the prevalence of MS in Australia** - The numbers you frequently hear quoted on the prevalence of MS in Australia are calculated using two sources of information:

- 1) the *percentage* of people with MS in Australia using Disease Modifying Therapies (DMTs) from the AMSLS data, and
- 2) the *total number of scripts* filled for each of the DMTs using PBS data freely available from the Department of Health

website: [http://medicarestatistics.humanservices.gov.au/statistics/pbs\\_item.jsp](http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp).

These calculations showed the total number of people diagnosed with MS in Australia was 25,607 in 2017, with the prevalence increasing from 95.6 people per 100,000 in 2010 to 103.7 people per hundred thousand in 2017. The latitude gradient of prevalence continues to persist, with Tasmania (approximately 42°S) still recording the

highest rate of prevalence at 138.7 people per hundred thousand, compared to 74.6 per hundred thousand in Queensland (approximately 19°S).

For those interested in more details, the full publication "*Change in multiple sclerosis prevalence over time in Australia 2010-2017 utilising disease-modifying therapy prescription data*" can be found on the MS Research Australia website.

**Using the international Assessment of Quality of Life (AQoL)** – We use several standard questionnaires in all our surveys. One such survey that is commonly used with researchers around the world is the *Assessment of Quality of Life*, or AQoL, which contains 35 questions that combine 3 physical dimensions (independent living, senses and pain), with 5 psycho-social dimensions (mental health, happiness, self worth, coping and relationships) to obtain a score between 0 and 1 that represents overall quality of life.

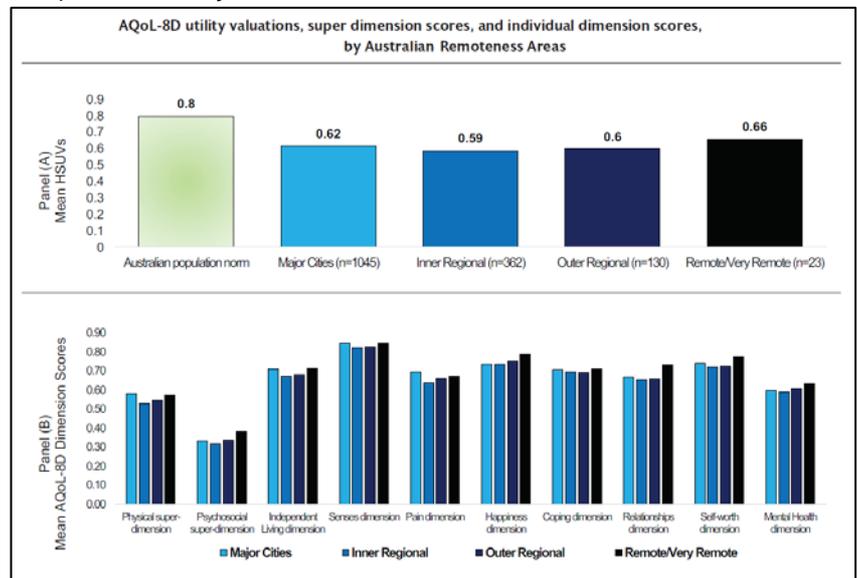
Individually, this score is probably not that remarkable, as we could 'guess' a reasonably accurate score given other answers.

Where it becomes powerful, is where we compare diseases and sub-groups. On the right is an example from the Health Economic Impact Report that examines the impact of residential remoteness on overall health for those with MS – does living a long way from a major city (and it's associated

opportunities and services) have an affect, either positively or negatively, on overall health, or indeed, individual health dimensions?

These analyses provide the basis for where to focus support efforts. In our example, we can see that those in inner regional areas seem to be facing the biggest challenges to quality of life – the next question is why?

The *Health Economic Impact Report* examined many different factors using the AQoL as a base, including age, sex, state, type of MS, DMT usage and disability level. In general, we do similar analyses for all surveys to figure out what is, and conversely, what *isn't* having the most impact on everyday life to ensure support efforts are focused in the right place at the right time.



## AMSLS Focus for 2020

| Topic                                                                                                             | Details                                                                                                                                                                                                                                                            | Supporting Survey(s)                                                            |
|-------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------|
| <b>Sleep</b> – in collaboration with Dr Cynthia Honan (University of Tasmania)                                    | Sleep is essential to our functioning, but MS can adversely impact sleep. We will quantify how many people have issues with sleep, examine factors that might influence sleep, and assess how sleep has an impact on, e.g., quality of life and daily functioning. | <i>2020 MS Nurses and Sleep Survey</i>                                          |
| <b>MS Nurses</b> – in collaboration with MS Australia and MS Nurses Belinda Bardsley and Sue Shapland             | To gain insight into the availability and value of MS Nurses, we will map the accessibility of people to an MS Nurse and examine how an MS Nurse influences the health care of people with MS.                                                                     | <i>2020 MS Nurses and Sleep Survey</i>                                          |
| <b>Feelings of depression</b> – in collaboration with Dr Lisa Grech (Swinburne University)                        | This work will examine whether people with MS are appropriately treated for depression and whether anti-depressants potentially have a positive effect on the progression of disease.                                                                              | <i>Lifestyle and Environment<br/>Disease Course<br/>Prescription data (PBS)</i> |
| <b>Other medical conditions</b>                                                                                   | We continue to examine how other medical conditions are impacting MS outcomes and quality of life.                                                                                                                                                                 | <i>Lifestyle and Environment<br/>Disease Course<br/>Prescription data (PBS)</i> |
| <b>Progressive MS</b>                                                                                             | In all the work we do, we look at whether associations are different for people with progressive MS, in order to improve our understanding of progressive MS.                                                                                                      | <i>All studies</i>                                                              |
| <b>Employment</b> – in collaboration with A/Prof Andrea Kirk-Brown and A/Prof Pieter Van Dijk (Monash University) | Employment remains central to the work we do. With longitudinal data available, we can examine people's long-term work experiences.<br><br>We will also look at the interplay between disclosure of MS at work, support at work, and intention to quit.            | <i>Lifestyle and Environment<br/>Disease Course<br/>Employment</i>              |

## General AMSLS Updates

**AMSLS personnel changes** – Two of our hard-working PhD students, **Jing Chen** and **Yan Zhang**, have completed the analysis part of their candidature and have headed back home to refine their final thesis submissions. Their work focusing on employment and PPMS respectively has been invaluable and they will be sorely missed!

We have been fortunate to welcome **Barnabas Bessing** and **Dr Akhtar Hussain** to the AMSLS research team.



Barnabas joins us as a PhD candidate, and has a wealth of international health experience as a clinical and health tutor nurse in Ghana, field epidemiology training from the Centre for Disease Control in Atlanta (USA), as well as working for two years with the World Health Organisation.

Akhtar has been involved in public health research, education and advocacy for over 13 years. His research has covered a broad range of topics, from immunology in HIV positive individuals, management of infectious diseases, health services research, chronic disease and the presence of multiple health conditions. We are thankful Akhtar has chosen to focus on MS for his postdoctoral research.

Finally, we welcome **Hilary Waugh** to the AMSLS administration team. Many of our participants will have already had the pleasure of chatting to Hilary, as she takes on assisting Carol and Kirsty with looking after our 2500+ participants.

**Survey updates** – Firstly, thank you to those who managed to persevere and complete the *MySymptoMS App* survey earlier this year. With a very different focus and purpose to our 'normal' surveys, all answers and feedback have been put to good use.

The app itself is still under construction, and those who volunteered further time to help test the app might be hearing from us in 2020. Thank you!

If you have been in direct contact with AMSLS staff over the last few months, you may have heard the next survey due was about your experiences with MS Nurses, along with an area well known to provide health benefits, but that can be frustratingly elusive – sleep.

We have had some delays in finalising this survey, and in order not to overload everyone on top of our vital tracking surveys (the yearly *Disease Course Survey* and biennial *National MS Employment Survey*), we have decided to postpone this survey until the new year. Keep an eye out for your survey notifications in early February 2020!

**The AMSLS team thanks you for your ongoing support. Together we can make a difference.**