

AMSLS NEWS



Australian MS Longitudinal Study (AMSLS)

October 2018

After another big year for the AMSLS, some important messages and outcomes are really starting to shine through. Hopefully you would have seen some of the media coverage surrounding some of these results, but if not, here are some of the highlights of the AMSLS for 2018, and what is planned for 2019 and beyond.

The Health Economic Impact of MS in Australia in 2017

After a considerable amount of hard work by many people, the first comprehensive review of MS in Australia in nearly eight years was launched by MS Research Australia in late August 2018.

The report, prepared by the Health Economics team at the Menzies Institute for Medical Research in collaboration with the AMSLS team, indicates there have been some real positives for those living and working with MS. In 2010, the biggest cost burden of MS was due to lost wages, contributing to 50% of the overall cost of MS. The latest report indicates this has dropped to 32%, showing there has been real progress in treatments and support, allowing people to remain much more active contributors in the workforce.

Despite this, it is clear there is still a long way to go. The overall cost of MS on an individual basis, and to the country as a whole, has increased, and the total number of people diagnosed with MS is still on the rise. Those with more advanced MS face very high costs of living, at the same time as trying to deal with a lower quality of life, often underlined, in particular, by pain and a loss of independent living.

Again, we wish to thank all our participants involved in the *Health Economic Impact of MS* study. Having such a comprehensive report not only allows focus for care providers and the MS societies, but is such a valuable tool to show the facts of living with MS in a way that is rigorous and indisputable. Your input will directly guide the focus for ongoing support and what still needs to be achieved.

If you'd like more information, the media release from MS Research Australia, along with a link to the full *Health Economic Impact of MS* report can be found at:

<https://msra.org.au/news/ms-economic-impact-report-launch>

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

Need to contact us?

AMSLS.info@utas.edu.au

(03) 6226 4739

We're always happy to hear from you!



Physical activity and MS – can you help?

Murdoch University researchers are interviewing people involved in the MS community with regard to exercise provision in Australia.

They are interested in the opinion of:

- those diagnosed with MS
- carers
- healthcare professionals
- managers and organisational professionals.

If you'd like more information, please contact Dr Yvonne Learmonth and the research team:

MShealthstudy@murdoch.edu.au

(08) 9360 6373

Participating in surveys – why every survey is important

While it is tempting to participate only in surveys that seem directly relevant to you, in order for your participation in the AMSLS to have maximum impact, it is really important to try and find the time to complete as many as you possibly can for two very crucial reasons.

Firstly, you are part of the big picture. If only the employed people answer the *Employment Surveys*, then our 'story' suddenly implies that everyone with MS is employed!

Secondly, our surveys are not 'stand-alone'. As you'll see throughout this newsletter, we use sections from many different surveys to answer our research questions. If you haven't answered the relevant questions, there's a possibility your story can't be included.

We know life is busy and doesn't always allow you to complete every survey, and there may be times you're just not up to it. We don't want you to worry about those times – that's quite OK! However, we do want you to know that if you *do* have the time, every section in every survey is important to your personal story and contributes to the overall picture we have of you and the AMSLS family as a whole. Never underestimate your contribution!

Employment and MS

As we have mentioned previously, our *Employment Surveys* have indicated a steady increase in the percentage of people with MS in the workforce since 2007. One of our PhD students, Jing Chen, has been looking further into work-place attendance and productivity for those living with MS, and has recently published two papers on the topic.

In the previous newsletter, we relayed the findings from her first paper, where people using the more recent disease modifying therapies (DMTs), in particular Tysabri and Gilenya, reported not only higher attendance, but a higher level of productivity when at work.

Her second paper looked more closely into work productivity and factors that may affect people's ability to effectively do their job. She found that when focusing on the overall impact of MS on work outcomes, there are actually three times as many days of productive work lost due to experiencing symptoms of MS while at work, compared to days where people are unable to attend work at all.

In addition, the symptoms most likely to be causing productivity issues at work are fatigue and cognitive symptoms, and pain and sensory symptoms. These results are significant in indicating the need for good symptom management strategies to enable those with MS to have a happy and productive work life.

To extend this work, Jing is now looking at the *2016 Lifestyle Survey* and *2017 Disease Course Survey* to further examine the impacts of other medical conditions (comorbidities) on those in the workforce. Initial results indicate that comorbidities are very common in the working-age MS population and significantly impact their daily work, and non-work lives. The relationship between a greater number of comorbidities and higher rating of symptom severity was clear, and the data

suggests that a systematic assessment of comorbidities at an early stage in MS, and then repeated over time is necessary. Importantly, effective simultaneous management of MS and these other conditions would help lessen the impact of symptoms and ultimately improve all aspects of life.

MS and Your Oral Health

Despite being more conscientious dental patients, who actually visit their dentist regularly and remember to brush and floss, the *2016 Dental Health Survey* revealed those with MS still struggle more with poorer oral health than the general Australian population.

Of those with MS, 75% reported experiencing at least two or more issues with toothache, mouth dryness, teeth sensitivity, change of taste, and pain in the face, jaw or mouth over the previous 12 months. In contrast, only 8.4% reported having none of these issues at all over the same period.

Whether the cause of these issues is side effects from medication, MS symptoms or another reason, these results show there is a need for additional advice and support beyond brushing and flossing to ensure those with MS can maintain a good level of oral health.

Progressive-Onset MS versus Relapsing-Onset MS

In our last newsletter we reported details of the study by one of our PhD students, Yan Zhang, where she highlighted the importance for early intervention for those diagnosed with progressive-onset MS, due to the significantly higher reported severity of symptoms compared to those with relapsing-onset MS.

Yan's paper has now been published and can be accessed via the MS Research Australia website (www.MSRA.org.au/AMSLS).

The Presence of Other Medical Conditions Alongside MS

Lara Lo, a PhD student, is determining the presence of other medical conditions (comorbidities) alongside MS, and what changes occur before and after MS symptom onset.

She found from the *2016 Lifestyle and Environment Survey* that prior to any MS symptoms, regardless of the onset type of MS, many conditions were already more common in people who went on to develop MS than the general population. These conditions include cancer, anaemia, psoriasis, migraines, anxiety and depression. Furthermore, the presence of most of these conditions continue to increase after MS symptom onset.

In addition, she found that epilepsy, stomach disorders, osteoporosis, thyroid disorders and osteoarthritis were not more prevalent before MS symptom onset, but became more common afterwards compared to people of similar age in the general population.

Her findings suggest the important need for preventing and treating these comorbidities that have the potential to make an impact on the disease course, severity, health-related quality of life, and treatment of people with MS.

Lara's work will now focus on determining the impacts of comorbidities on health-related quality of life, MS symptom severity and health care costs using the data from the *Disease Course Surveys*, the *Lifestyle and Environment Surveys* and the *2016 Economic Impact Baseline Survey*.



The AMSLS team on MS Red Lab Coat Day 2018.

Back row (L-R): A/Prof. Ingrid van der Mei, Alice Saul, Carol Hurst,

Dr. Kirsty Hawkes, Mara O'Dea, Yan Zhang. **Front row (L-R):** Jing Chen, Lara Lo

InforMS

We are beginning to get some real traction with the development of the InforMS system (previously known as the MS Portal).

InforMS is our way of giving you back control of your AMSLS data, and providing tools that will help you manage not just your MS, but your health in general.

We have just completed an initial prototype, which we will be using in focus groups to further refine what information is useful, what you feel is important to support your ongoing health management, and what else you would like to see included.

At this point, we feel it is important to reiterate that all AMSLS data is, and will continue to be, de-identified data. By this, we mean that regardless of whether it is being used as research data, or in the InforMS system, there are no names or contact details transferred or stored with any of the data.

If you ever have any concerns about your privacy, please don't hesitate

to give us a call, or send us an email as we're more than happy to go into detail so you can make decisions around your AMSLS data with which you are comfortable.

MS Translation – the MS MOOC

The Menzies MS team is developing a Massive Open Online Course (MOOC) for MS.

The MOOC is an online learning resource which is designed for people living with MS, their carers and support networks, and health care providers.

Information on risks, symptom management, interventions and life experiences will be given through a series of video interviews, including interviews with people living with MS, academics, nurses and allied health professionals.

It is a course that will be freely available to anybody and will incorporate data collected by the AMSLS.

We'll let you know as soon as it becomes available!

Are you interested in more detail of the AMSLS results?

For those of you who may be interested in reading the full academic papers resulting from the AMSLS, all publications can be accessed via the "publications" section of our AMSLS page on the MS Research Australia website:

www.MSRA.org.au/AMSLS

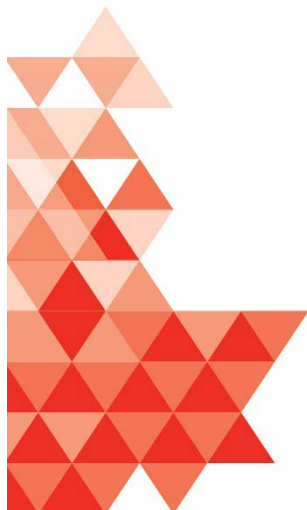
AMSLS Focus for 2019

Topic	Details	Supporting Survey(s)
The benefits of disease modifying therapies (DMTs)	Randomised controlled trials rarely test whether DMTs affect employment outcomes or the severity of symptoms. We are trying to answer those questions.	<i>Disease Course</i>
Economic impact of MS	We are digging deeper into the data collected as part of the <i>Health Economic Impact of MS</i> report, to focus on the key drivers of cost and quality of life.	<i>2016 Economic Impact Disease Course</i>
COMPANZ – comparing Australia and New Zealand in terms of treatment and outcomes	We are studying the long-term effects of treatment with disease modifying therapies on things such as disability level and fatigue, and we are measuring the costs related to MS in New Zealand.	<i>2017 COMPANZ Disease Course</i>
Exercise – in collaboration with Dr Claudia Marck (University of Melbourne)	Exercise is important for many reasons. We are looking at factors that influence how much exercise people do and the types of exercise they do.	<i>Lifestyle and Environment Disease Course</i>
Progressive MS	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>
Lifestyle	We are looking at the effects of many different lifestyle factors on symptom severity and quality of life.	<i>Lifestyle and Environment Disease Course</i>
Employment – in collaboration with A/Prof Andrea Kirk-Brown and A/Prof Pieter Van Dijk (Monash University)	We will look at the interplay between disclosure of MS at work, support at work, and intention to quit.	<i>Employment Disease Course</i>

The AMSLS and You

As many of you would know, the AMSLS was setup by Dr Rex Simmons and MS Australia in 2002 to assist with long-term studies for those with MS. MS Research Australia took over the funding and oversight of the study with Rex in 2004. In 2014, Rex decided to retire, and the management of the AMSLS was passed to Associate Professor Ingrid van der Mei.

We still have 809 participants who joined in the first 2 years of the AMSLS, and I'm sure every one of them could



tell you how important the AMSLS was to Rex, and how much he genuinely cared about each individual.

Nothing has changed in that respect since Ingrid took over, but in reading your comments and feedback, we feel there is an important message we thought we needed to reiterate.

In a time where it's very difficult to trust what happens to your personal information, we need to let you know our one and only aim is to help people living with MS. We have no hidden agendas, no preconceived bias of what's 'important' to you, and we need every one of you, regardless of whether MS is having a big impact on your life or not.

Everything we do is guided by the AMSLS steering committee, which includes representative from people with MS, the MS societies, MS nurses, neurologists and MS Research Australia. Ingrid has an impressive resume as an international researcher, and her demand for excellence is obvious, but what you won't read about her in the professional write-ups is that she is grounded in the real

world and is constantly questioning and checking the practical worth of everything we do. Not a meeting goes by where she doesn't tell us of someone else she's recently met, and their journey (and the 50 million ideas the meeting has generated in her head).

Due to the diverse group of people we have in the AMSLS, the part of my job to capture your story in a 'one size fits all' simple way is not an easy one. There will be times where you honestly don't see the point, or can't understand why we're doing things a certain way. All I ask of you is to remember that you are an important part of the bigger picture, that we DO care about your story, and that we are always open to have a chat. In return, I promise I will endeavour to keep you informed.

Never forget, this is about trying to provide a solid, indisputable foundation of evidence to find some answers, and get you the support you need most. We're in this together!

Yours always,
Kirsty (AMSLS Project Officer)

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