

AMSLS NEWS



Australian MS Longitudinal Study (AMSLS) November 2017

For our long term participants, 2017 may seem like it was a particularly quiet year for the AMSLS. Behind the scenes, it has been far from it. Here's the latest update on what has been happening and the achievements of the AMSLS in 2017.

Achievements of 2017

There has been a lot going on this year for the AMSLS team. So far we have:

- Published 2 papers, prepared 3 publications, 6 oral and 5 poster presentations (MSRA conference; international conferences).
- Obtained 5 grants to fund specific projects (>\$700k).
- Conducted 3 focus groups for the MS WorkSmart program.
- Conducted 1 workshop for MS Nurses about putting research into practice.
- Produced 2 reports.
- Processed 5244 responses over 4 separate surveys (including manually scanning and verifying 1818 paper surveys ranging from 5 minutes, to an hour and a half per survey).
- Followed up over 500 missing Medicare card numbers, neurologists details, signatures and supporting documentation for data linkage.
- Welcomed 238 new recruits (thanks as always to the MS Societies for their amazing help!)
- Welcomed a further 46 participants as part of Stage 2 of the PPMS study (with more yet to come).

We will expand on some of these highlights in this newsletter. For those with internet access, keep an eye on our pages on the revamped MS Research Australia website for more details and the full publication list (<https://msra.org.au/AMSLS>).

Do you know someone with MS who is not a 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!



Primary Progressive MS – the PPMS study

1 in 10 people with MS are diagnosed with Primary Progressive MS (PPMS), which is still a relatively poorly understood class of MS.

We aim to contribute to the unravelling of the mechanisms of PPMS and ultimately, the developments of treatments and interventions.

If you, or someone you know, has PPMS and has not already signed up, please contact us for a study pack:

ppms.study@utas.edu.au

(03) 6226 4269

Menzies Institute for Medical Research Public Talk

On Wednesday 16th August, the MS researchers from Menzies were invited to do a public talk, to reveal the 10 year plans for the new flagship research group at the Institute. The talk included exciting developments from the AMSLS's own Associate Professor Ingrid van der Mei and Professor Bruce Taylor, as well as neurological researcher Dr Kaylene Young, and MS Australia's National Advocacy Coordinator, Andrew Potter.

For those who are interested and have access to the internet, the full presentation can be found on **YouTube** by searching for:

“Menzies Public Talk: Multiple Sclerosis - The Way Ahead”



Kiss Goodbye to MS Red Lab Coat Day: The Menzies Institute of Medical Research MS Research Team, including staff, students and volunteers. April 29th 2017

Current Surveys and Onward to 2018

There has only been one survey to date this year, the *2017 COMPANZ Survey* (Comparing Australia and New Zealand MS Populations). This survey was only distributed online to a specially targeted group of the AMSLS cohort. Thank you to those who participated (it wasn't an easy survey, especially with the recall period over 10 years for some questions). The New Zealand troops in this study are still completing their surveys, and we expect initial results to come out in 2018.

The two remaining surveys this year are the ones currently open – the *2017 Disease Course Survey* (the third instalment of the yearly tracking survey), and the *2017 National MS Employment Survey* (the unchanged and final instalment of the Employment series... for the time being, at least). We have only made minor adjustments to the questions in the surveys themselves. However, we are trialling some administration changes and have also provided an information sheet for the *Disease Course Survey*, to address some of the most common feedback we have had for this survey. While it certainly isn't a compulsory read

before completing the survey, it hopefully provides a bit more insight into some of the questions, how they're used and interpreted, and how to answer if you're having trouble with some sections.

The promised NDIS survey is under development with the state MS Societies, and we hope it will reach you next year. It is important that this survey should give useful results over time as the NDIS is rolled out. It will be a recurring survey.

Putting Research into Practice – MS Translation

The Menzies has nominated MS as the institute's Flagship Program. This is a big achievement and will result in additional research into MS. A new focus is ensuring that important outcomes from national and international research will actually result in practical and beneficial help to those with MS. This requires researchers to work together with health professionals and people with MS. Ingrid ran a workshop with MS Nurses to kick-start this process. Two other projects currently underway in this area are the MS WorkSmart program and the MS Portal called inforMS.

Data Linkage

The collection and follow-up of the Data Linkage consent forms is almost complete. We are happy to announce, close to 1500 participants have agreed to allow us access to Department of Health records, and/or to linking their AMSLS data to other data systems, such as MS Base. We know that in this day and age, it is not a decision anyone takes lightly, so we thank you for your trust.

We are very excited about the potential of Data Linkage project, not only to give us useful data for research purposes, but also for the long term goal of providing you and your trusted health professionals, with up to date and accurate information that will be directly relevant for your care.

In the coming months, Lara Lo (one of our PhD students), will begin the task of linking your PBS data to the AMSLS dataset. By combing this data with the comorbidities data (other medical conditions) from the *2016 Lifestyle and Environment Survey*, Lara has two research aims in mind. Firstly, to examine the frequency of other medical conditions and their associations with MS symptoms' severity; and secondly, to study how these medical conditions affect medical costs and disease modifying therapy utilisation. By studying these medical conditions that commonly occur in people with MS, it is hoped we can find ways to develop interventions, as well as improve the quality of life for those with MS.

Progressive-Onset MS versus Relapsing-Onset MS

Yan Zhang, a PhD student, is examining the differences between people with relapsing-onset MS (including relapsing remitting MS and secondary progressive MS) and

those with progressive-onset MS (including primary progressive MS and progressive relapsing MS). The severity of each comparative outcome was determined by the patients' own feelings as recorded in the *2015 Medications and Disease Course Survey*. She found that people with progressive-onset MS rated their symptoms as more severe than those with relapsing-onset MS in 11 of the 13 MS symptoms. They also rated a faster progression in their disease, over the last 12 months, and an overall lower quality of life, even after taking into account factors such as age, gender, and age at diagnosis. Only the severity of cognition or vision problems, did not differ very much between the groups.

In addition, the closer it is to the diagnosis of MS, the larger is the difference between relapsing-onset MS and progressive-onset MS symptoms' severity. This highlights the need to identify treatments that are effective early on in the disease.

Yan recently won the people's choice award for a University of Tasmania's "3 Minute Thesis" competition, where PhD students are asked to explain their research in 3 minutes, to a non-specialist (that is, non-academic!) audience. For those wishing to view her presentation on research for Progressive MS, here is the link:

<http://www.utas.edu.au/research-admin/graduate-research/research-training-opportunities/three-minute-thesis-3mt>

To help Yan's work progress, we are still looking for more people to join the Primary Progressive MS study. If you have PPMS, or know someone who does that has not already joined, please consider signing up. We need your help, to help you in return! Details on how to join are in the red "Primary Progressive MS – the PPMS Study" box on the left side of the previous page.

The Survey Cycle

Sometimes it may seem that it takes a long time from when you've filled in a survey, to actually hearing about any results of that survey. Why does it take so long? Even straight forward surveys (such as the *2016 Dental Health Survey*), can take more than a year from initial design to preliminary results, and the more complicated surveys, such as the *2016 Lifestyle and Environment Survey*, can take well over 2 years.

Indicative times for the survey cycle, depending on complexity, are:

- Initial planning and survey design: 4 - 6 months
- Physical and online survey creation, testing, refinement and distribution: 1 - 2 months
- Survey data collection: 2 - 3 months
- Paper survey input and verification: 1 - 4 months
- Final data checks for all survey responses: 2 weeks – 1 month
- Analysis: 3 - 6 months
- Publication: 6 - 12 months

We will certainly let you know as soon as results are available, but we thought it was important to let you know, that even initial results can take up to a year from when you completed a survey.

Congratulation to MS Research Australia!

For those of you who may have missed it, MS Research Australia, who fund and support the AMSLS, took out the *2017 NSW Telstra Business Awards Charity Award*, and then swept the field to become the overall *2017 NSW Telstra Business of the Year*. Following this, they won the national *2017 Telstra Australian Charity Award*.

These awards reflect the dedication and professionalism of MS Research Australia in doing everything they can to put an end to MS.

Contratulations to you all from the AMSLS!

AMSLS Focus for 2018

Topic	Who	Supporting Survey(s)
A better understanding of progressive MS	PhD student Yan Zhang	<i>2016 Lifestyle Survey;</i> <i>Disease Course surveys</i>
How does MS impact employment outcomes?	PhD student Jing Chen; A/Prof Andrea Kirk-Brown & A/Prof Pieter Van Dijk (Monash University)	<i>Employment surveys;</i> <i>2016 Lifestyle Survey</i>
Understanding the role of comorbidities (other conditions) in MS – how do they affect MS and does MS increase the risk of comorbidities?	PhD student Lara Lo	<i>2016 Lifestyle Survey;</i> <i>Disease Course surveys</i>
Do disease modifying therapies influence work outcomes and symptoms such as fatigue?	Dr Prudence Tettey	<i>Disease Course surveys</i>
Economic impact of MS	Prof Andrew Palmer & PhD student Hasnat Ahmed	<i>2016 Economic Impact Study (Baseline Survey and Cost Diaries)</i>
Dental health in people with MS	Prof Pauline Ford (University of Queensland)	<i>2016 Dental Health Survey</i>
The role of physical activity and diet in MS	Dr Claudia Marck (University of Melbourne)	<i>2016 Lifestyle Survey</i>
COMPANZ – comparing Australia and New Zealand in terms of treatment and outcomes	Prof Bruce Taylor & Dr Suzi Clafin	<i>Disease Course surveys;</i> <i>2017 COMPANZ Survey</i>

Disease Modifying Therapies and Work Related Outcomes

One of our PhD students, Jing Chen, has analysed the medication data from the *2015 Medication and Disease Course Survey*, to examine the effect of disease modifying therapies (DMTs) on work-related outcomes. She found that many people in Australia, have transitioned from the classical injectable DMTs, like beta-interferons, to a more effective DMT, since 2010. Compared to beta-interferons, people who used these more effective DMTs,



(in particular Tysabri and Gilenya) were 2 to 3 times more likely to report that the DMT increased their work productivity, work attendance and working hours. However, there may also be higher risks associated with the use of these DMTs and all treatment decisions need to be made, in the full knowledge of a risk/benefit analysis, by the neurologist or treating doctor for each individual.

Jing's focus will now build on the work she completed last year, looking at the most troublesome of MS symptoms for work productivity loss, as she starts to use the data from the *2016 Medication and Disease Course Survey* and *2016 Lifestyle and Environment Survey*, to evaluate the impacts of comorbidities (other medical conditions on top of MS) on work productivity.

DEVA Model and the Economic Impact of MS

A large grant has been secured to analyse the *2016 Economic Impact Study* (both the *Baseline Survey* and *Cost Diary*). Your support and dedication to this study will directly contribute to an updated understanding of the ongoing, direct and indirect costs of MS. Thank you!

The results from the DEVA MS Model ("Development and validation of a cost effectiveness simulation model for Multiple Sclerosis and implications for health policy") have been generated, and as you would expect, the impact of MS, both financially and on the quality of life, can be significant.

The results from the DEVA study have been presented both nationally and internationally, to a wide variety of audiences. For those interested in more details, the current publications are listed on the MSRA website.

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