

AMSLS NEWS



Australian MS Longitudinal Study (AMSLS) June 2016

Welcome to the June 2016 edition of the Australian MS Longitudinal Study (AMSLS) newsletter. With many participants busily filling in surveys, it's a good time to share some of the news and visions for the data that is being collected.

A Snippet of Great News

In collaboration with A/Prof Pieter van Dijk and A/Prof Andrea Kirk-Brown (Monash University), we are analysing the AMSLS National Employment Surveys. The data is not ready for publication yet, but we can tell you that the percentage of people with MS who are in the workforce has been steadily increasing since 2007. This is a fantastic finding and we will be looking at the data to analyse what factors might have influenced this, such as the use of disease modifying treatments, better access to employment support services or other changes in disease management.

New Recruits

Together with significant help from MS Research Australia, MS Nurses and the MS Societies we have been extending the awareness of the AMSLS to increase the number of participants in the study. To the end of February, the outstanding support of the MS Societies of Queensland and Western Australia resulted in 99 new recruits (welcome all!), including an astounding 68 from Queensland and 21 from Western Australia.

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!



The AMSLS Team:

Associate Professor Ingrid van der Mei

Ingrid is the AMSLS Project Director and she has almost 20 years of experience in MS research, including over 115 publications. She is an epidemiologist, which means she loves obtaining high quality data from large population groups and analyzing this statistically in order to work out how to prevent or improve the management of disease.

Professor Bruce Taylor

Bruce is a neurologist and MS researcher, who provides practical advice on many aspects of the AMSLS. He has worked closely with Ingrid for over 10 years and has recently been awarded funding for the COMPANZ study to investigate the effectiveness of immunotherapies on quality of life for those with MS.

The Team

Kirsty Hawkes, Carol Hurst, Claire Knowles and Alice Saul are the team responsible for the day to day running of the AMSLS. Their aim is to ensure the data collection is as easy as possible for you, while still being truly representative and accurate from a research perspective. While you may hear from all of us at various points, **Kirsty** is your first point of contact for enquiries or feedback related to the study.

Jing Chen, Yan Zhang and Alice are our AMSLS PhD students who will be analysing the data under the guidance of Ingrid and Bruce.



The AMSLS Team (L to R): Yan Zhang, Jing Chen, Ingrid van der Mei, Alice Saul, Bruce Taylor, Kirsty Hawkes, Claire Knowles, Carol Hurst

The AMSLS Surveys

2015 National Employment and Medications & Disease Course Surveys - Thank you to the 1,976 participants who found the time to complete the *2015 National Employment Survey* and *Medications and Disease Course Survey*. We apologise for the timing of the surveys, especially for those who received the paper copy over the busy and often stressful Christmas period.

We are currently finalising the surveys in preparation for analysis.

2016 Economic Impact Study - Many of you will have just completed the *2016 Economic Impact Baseline Survey* and have just received the associated 6-month *Cost Diary*. Combined, these have been developed to get an up to date picture of all the expenses associated with living with MS, whether that be direct costs to you, the health service or the Government.

This is an exceptionally large and time consuming survey (sorry!), but the extended questions and level of details required in both the *Baseline Survey* and *Cost Diary* are to try and get internationally comparable data and build on the results of the 2008/2009 survey. Please remember, accurate results in this study can be used for advocacy for financial

subsidies and other assistance, as was the case in the successful lobbying for subsidies after the 2008 *Keeping it Cool* survey, which revealed that those with MS spent ten times more on air conditioning than the average Australian household to assist in reducing symptoms of MS. Accurate results in the current *Economic Impact* study will be used in a similar ways to support advocacy activities of MS Australia and the state MS societies.

The Next Surveys

As with the current survey, we are planning to have future surveys open for around 2 months. There will be a friendly reminder with a few weeks to go for those who have yet to respond. Here's a quick overview of the remaining surveys for 2016.

2016 Lifestyle and Environment Survey and 2016 Oral Health Survey - These will be running through July and August. They focus on exercise, sun exposure, smoking, alcohol and supplement use, social connection, comorbidities (diseases or conditions that you may have in addition to MS) and oral health. The surveys aim to identify lifestyle factors that may be associated with better outcomes and will help health professionals develop interventions that may improve quality of life for people living with MS.

2016 Medications and Disease Course Survey – This survey will be similar to the 2015 surveys to help track progression in symptom severity, ability to perform normal activities and work productivity.

Feedback and Comments – Keep it Coming!

Throughout the course of all our surveys we receive a considerable amount of important feedback. This ranges from technical issues, the content of the surveys themselves, or overall observations about having MS and the support provided.

We strongly encourage everyone to continue writing these thoughts. Everyone's experience with MS is different and the level of adjustment to people's lives varies so greatly it is impossible to create a survey that fits everyone. By providing comments, it gives us the opportunity to make sure the questions are appropriate, and more importantly this provides 'richness' from the data that isn't necessarily captured in statistics. So whether your feedback is to a specific question or you feel your answers need explaining, every piece of information is important – feel free to vent, be wordy, or scribble a quick note, and if you don't feel you can adequately write something down we are just a phone call or email away.

AMSLS – The BIGGER Picture

Combining data and longitudinal tracking – Rather than having each survey analysed separately, we will start combining the data from different surveys. This will make the dataset richer and we can address far more research questions. To this end, one of the most important subsections is the measurement of Disease Course. How well are you going with your MS? Have some aspects become better or worse?

We use the same methods that are used in other registries so that we can pool and compare data. We will also repeat the Disease Course survey yearly to track how you go over time. We understand that this survey may be confronting in places, so please feel free to provide feedback if this is the case. However, the strength of this method is that we can put data together over multiple years and examine factors that influence those changes.

Data linkage – Rather than asking you questions all the time, we would also like to use data that is already collected about you by hospitals or other government organisations and link this data with the AMSLS dataset. Before we can do that, we require your consent and we are hoping that the majority of AMSLS participants will be willing to have their data linked. This will create new research opportunities without the need for additional surveys!

MS Portal – We have secured a grant to develop the possibility of creating an online portal where participants can view their personal research data and choose how to share that data and who with, e.g. their neurologist.

PPMS study – We have been funded to conduct a study on Primary Progressive MS (PPMS), which focuses on the risk factors of PPMS and the factors that may influence its progression. Any new PPMS participants will also be enrolled in the AMSLS, so we can track them over time in the same way as other AMSLS participants.

Help us stretch our funding further!

Are you receiving paper surveys or postal notifications where electronic communication would be just as easy?

If so, please let us know your current email address. We appreciate the electronic world is not for everyone and we will always support your choice, however, paper based surveys cost over \$5 per participant per survey, postal notifications for web surveys are around \$1.25 per participant, while email notifications for completing web based surveys cost only 2 cents per participant.

With over 3000 participants, electronic communication is a very easy way for us to stretch our funding much further so let us know if you can help.

Priorities of MS Research from MS Research Australia

MS Research Australia who fund and support the AMSLS are currently surveying the Australian MS community on their thoughts about the priorities for MS research. This is not an AMSLS research survey, however, MS Research Australia have asked us to let you know about the survey and encourage you to take part. For more information, go to:

<https://www.surveymonkey.com/r/MSResearchAustralia>

Examples of the AMSLS projects

The data collected by the AMSLS study is a very powerful resource and can assist in many research projects that rely on data from long term follow-up of individuals with MS. Some projects that are connected to the AMSLS study are:

COMPANZ

Members of the AMSLS have received funding from MS Research Australia to compare MS patients from Australia and New Zealand. Australian MS patients with Relapsing-Remitting MS have been largely treated over the last few years while the treatment rules in New Zealand have been far more restrictive. This study will answer the question whether the use of very costly disease-modifying therapies in MS have had a significant positive impact on the long-term clinical course.

DEVA Study

Members of the AMSLS research team have also been funded from MS Research Australia to develop a validated Relapsing-Remitting MS disease model that simulates the progression of MS. The aim is to build a gold standard, validated, transparent decision analysis tool to identify cost-effective interventions amongst a plethora of existing and future medications.

Other Research

- How do different disease modifying therapies compare in relation to long-term disability outcomes, symptom severity and quality of life?
- What are the differences between Relapsing-Remitting MS and Primary Progressive MS in relation to employment, income and socio-economic status?

Some feedback from us

Completing a survey that does not seem relevant

– Many people have commented they didn't respond to a particular survey because they didn't think their situation was relevant to the survey. For example, those who were retired or unemployed believed they had nothing to contribute to the *Employment* survey. We cannot stress enough how valuable *everyone's* responses are!

Without the 'non-employed' portion of our respondents, we miss not only a true reflection of the percentage of people employed, but more importantly, factors that may have contributed to people being out of the workplace, whether that's due to MS or not. Please look past the names of the surveys and always remember. all information can be

used by MS Societies in relation to support services and underpinning advocacy.

Completing a survey where 'nothing has changed'

– Always remember - if you don't respond, we can't tell if that's because "nothing has changed" or "a lot has changed, but I am too busy to respond". The L in AMSLS stands for Longitudinal – we need to understand whether things change, or don't change, for people with MS over time, so that we can understand the factors that influence quality of life and circumstances for people with MS in the long-term. We are looking at ways to decrease the burden of completing data that will not change (such as year of diagnosis or retirement), but in the meantime, please just bear with us, and remember you are still helping and there are always new participants, or people who have had a change in response that are participating alongside you.

Why is there some repetition?

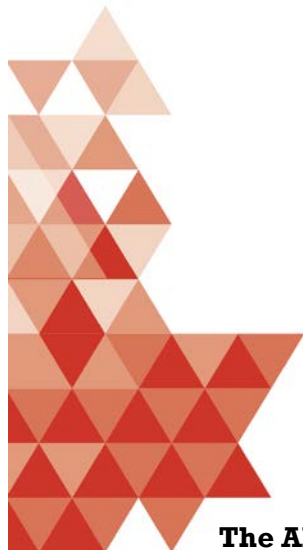
It might sometimes feel that questions are similar. This is because we try to use standardised questions and scales that have been used by other international studies or registries. Occasionally we use multiple ways of assessing a particular situation and assess which one work best in our group.



The more you participate, the more valuable your data becomes

– Where we can, we are combining data from different surveys to identify patterns and expand on our research questions. For example, the *Economic Impact Survey* provides data on quality of life, while later this year we will ask you questions about other conditions that you may have in addition to MS (comorbidities) that may affect your health. We will then combine these datasets to assess to what extent specific comorbidities influence quality of life. We then can look at whether efforts can be made to prevent the onset of those comorbidities that affect quality of life most. Further in the year we will ask you about the types of exercise you do (walking, yoga, stretching) and see if these have any beneficial effects on your MS symptoms.

Each survey is another piece of the puzzle in finding some answers.



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