



The Menzies Institute for Medical Research

AUSTRALIAN MS LONGITUDINAL STUDY (AMSLS) December 2014

Behind the scenes: Achievements of 2014

Behind the scenes, a number of things have been done:

- All study documents have been transferred from Canberra to Hobart, both electronic and hard-copy information (many boxes of information).
- A contract between MS RESEARCH AUSTRALIA and the University of Tasmania has been set up.
- Ethics approval has been transferred to Tasmania.
- An AMSLS Steering Committee has been set up. This committee has at least one representative from the following stakeholder

groups: People with MS, Carers of people with MS, MS Research Australia Governance Executive Group, MS Australia (representing state MS Societies), and MS Nurses. The Committee will provide guidance and advice to the AMSLS Project Management Team (Ingrid/Bruce) with respect to the core focus of the AMSLS, being the 'here and now' of living with MS, and the aim of providing data of practical use for improving the lives of Australians living with MS.

- A new vision has been developed for the AMSLS through discussions with the different stakeholders as

well as the Scientific Advisory Group.

- A Study Liaison Officer / Data manager, Helen Hornsby, has been appointed to assist with the running of the study. She will be the main point of contact for AMSLS participants, together with Dr Ingrid van der Mei.

Welcome to the first newsletter to be produced by the Menzies Institute for Medical Research, University of Tasmania. In 2014, Dr Ingrid van der Mei & Professor Bruce Taylor have taken over the AMSLS from Rex Simmons for MS Research Australia.



AMSLS Communications Survey now online
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The AMSLS Team

Dr Ingrid van der Mei

Ingrid is the AMSLS Project Manager and has over 15 years of experience in MS research. She has obtained more than \$5.6M in research funding and has about 80 publications. She is an epidemiologist, which means that she loves obtaining high quality data from large population groups and analysing this statistically in order to work out how to prevent or improve the management of disease. Her research so far has contributed substantially to the discovery of the link between sun exposure / vitamin D and MS. In 2003, she published that people with MS generally had less sun exposure, particularly early in life, compared to healthy controls. More recently, she published a high impact paper showing that higher levels of vitamin D were associated with having fewer relapses.

Helen Hornsby

Helen joined the AMSLS team in September 2014. Her background includes a Master of Psychology degree and working as a consultant.

Helen is your point of contact for day-to-day enquiries about **the study**.

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The new AMSLS vision

Expand the number of participants – The study hopes to expand the number of participants. It has removed the eligibility criteria of needing to be diagnosed after 2002, which was added in 2002 after the baseline sample was established. Thus, the study is open to any adult diagnosed with MS living in Australia.

Online expansions – More opportunities for participating in the study will be provided via online mechanisms, as this is more flexible and far cheaper. Particularly when expanding the sample, it becomes more cost effective and less labour intensive to use online mechanisms. However, we value every participant's contribution and will still provide a paper-based option for those who are not able to complete questionnaires online.

Increased tracking over time – Examining changes over time is important in relation to predicting what factors influence MS progression and understanding the impact that MS has on the individual over time. Once we understand what predicts change over time, and which factors are most important in driving that change, we can guide health professionals, or develop new interventions. To do that, we will add some core questions to surveys annually or biennially, depending how quickly that factor might change. These will include e.g. disability level, quality of life, hours of employment, or change in specific symptoms. This will also mean that we can link data from one survey to another, and will substantially expand the number of research questions we can address. This will mean an increased number of questions you will need to answer. We will test all our surveys on participants before sending them out. Balancing the use of additional questions with the extra burden it provides to you is important to us. Please provide us with feedback by giving us a ring if you feel the burden is too high, or have any other comments on the surveys.

Develop an MS Portal – We are hoping to expand the value of the AMSLS in different ways by creating an MS Portal. In the MS Portal, data can be transferred between the AMSLS and other health professionals. For example, we have heard that particular information collected by the AMSLS is of use to neurologists, e.g. quality of life or cognitive function measures. In return, many of you may already be signed up to MSBase, a registry with clinical data that is collected by your neurologist. This MSBase information is of great value to the AMSLS, and in the future you will be given the option to link your MSBase data to the AMSLS study. A secure system will need to be set up, and you will always be in charge of providing approval for these linkages. It will be similar to MyGov website which allows you to create links between the Australian Taxation Office, Medicare, and Centrelink. An MS Portal should theoretically provide benefits to your personal healthcare and also expand research options.

Continue the surveys – We will continue the surveys in a similar way to as Dr Rex Simmons did when the study was run by him from Canberra Hospital. A research plan will be developed prior to each survey, so it is

The AMSLS Team

Prof Bruce Taylor

Bruce is a neurologist and MS researcher. He has an impressive track record with papers ranging from descriptive epidemiology, to genetics and laboratory science. Bruce will provide practical advice on many aspects of the study. He has worked closely with Ingrid for more than 10 years. With their different expertise, they make a good team. Each week, they have MS meetings with their research staff, including a postdoc, 5 PhD students and 2 honours students.

The people behind the scenes –

There are a number of people at the Menzies who provide assistance to the project. Tim Albion is the Menzies data manager and he will provide advice on database related issues. A/Prof Leigh Blizzard is a senior biostatistician. He has been involved in each MS study conducted at the Menzies. Dr Steve Simpson is a postdoctoral fellow and has been working with the MS team for the last 5 years. Prof Andrew Palmer is a health economist and will lead the AMSLS health economic work. Dr Michelle Callisaya is a physiotherapist researcher and has worked with people with MS. She will provide advice in relation to allied health aspects of MS care. Two Melbourne based neurologists and MS researchers, Professor Trevor Kilpatrick and A/Prof Helmut Butzkueven, also play an advisory role.

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clear what the purpose is of the survey, and how the questions will be analysed. Thought will go into how to get the best use out of the data. This is so that no information is wasted.

- **Employment survey** – We will repeat the 2013 employment survey two more times, in order to capture change over time. Collaborators at Monash University, A/Prof Andrea Kirk-Brown and Pieter van Dijk, will lead this work.
- **Comorbidities survey** – Another survey we wish to conduct in 2014 is on co-morbidities. Co-morbidities are other health issues that an individual may experience in addition to the main condition that they have been diagnosed with. It seems that people with MS have a higher chance of getting some co-morbidities, but it is unclear whether these co-morbidities occurred prior to MS or as a result of having MS. We would like to tease that out. A current PhD student from Ghana, Prudence Tettey, is hoping to expand his work on lipids and MS with the help of the AMSLS study.
- **Economic Health Survey** – The last economic health surveys were done 5 and 10 years ago. This data has been of immense value for advocacy for the MS Societies, but also for researchers to demonstrate in dollar figures the impact that MS has on individuals and society. We will repeat this survey in 2015. We hope that a substantial number who participated in the survey 5 years ago, will do so again, because we can then make direct comparisons to understand the changes that have occurred over time. Prof Andrew Palmer, from the Menzies, will lead this work. He has just been funded by MSRA to develop a computer simulation model that can test the relative costs and benefits of potential interventions (drug treatment, psychology intervention, etc.).

For the latest study news visit

www.msra.org.au/amsls

