AMSLS NEWS

Australian MS Longitudinal Study (AMSLS)
November 2016

It's getting towards the end of a big year for the AMSLS and it is time to share a few of the highlights and outcomes from the year, along with what's in store for next year.

Looking towards an easier 2017

It's been a very busy year for everyone involved with the AMSLS and we just wanted to thank you all for your patience, understanding and support. After such a demanding year on you all (especially new recruits who have also completed consent forms and the Demographic Survey along with everything else), we are happy to announce you will get a bit more of a rest in 2017 with a lighter survey load of 3 or 4 smaller surveys, starting with one for our COMPANZ study. The AMSLS team will focus on analysis of the results from the 2015 and 2016 surveys, advancement of the MS Portal and Data Linkage and improvements in the administration of surveys and data collection.

Accepted papers & prizes

We had two papers accepted by scientific journals in the last couple of months. One paper – collaboration with A/Prof Pieter van Dijk and A/Prof Andrea Kirk-Brown (Monash University) – looks at the longitudinal changes in employment, and found that more people are able to remain working compared to 2010. There now seems to be little difference between the percentage of working women with MS compared to the general population. The gap has also substantially reduced in men, but is still present (59.0% employed vs 67.3% in general population). We also found that most people with MS who ask for adjustments to their work role or environment were receiving this.

The other paper – collaboration with Prof Andrew Palmer and Hasnat Ahmad (Menzies) - looked at quality of life. The paper investigated the relationship between MS severity and quality of life where an increase in MS severity was associated with a lower quality of life. For future health economic work and advocacy, it was important to quantify this data. For example, mildly and moderately disabled MS patients had a mean quality of life that was 26% and 36% lower than that of Australian general population respectively, and once MS became severe, the quality of life loss was 47%. Importantly, Hasnat received a Best Podium Presentation award for a conference paper "Life expectancy, quality, adjusted life years and total time cost for Australian people with Multiple Sclerosis" from the International Society for Pharmacoeconomics and Outcome Research. The paper presented the first results generated from the DEVA model.

Do you know someone with MS who is not a part of the AMSLS family but would like to join?

To sign up, 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!

MS RESEARCH AUSTRALIA

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Importance of the Medication and Disease Course Surveys

We previously spoke about the vision of an online Portal where research data is being visualised so that people can track themselves over time, compare themselves to others (for example to those with similar disease duration or MS type) and share their data with health professionals (optional). There seems to be a lot of interest in this idea. The Medication and Disease Course surveys contain a lot of key information for this tracking, so completing this annual survey, as well as helping with research, could result in personal benefits to you once we get the portal up and running.

2015 Medication and Disease Course & Employment Surveys

MS WorkSmart Program - Analysis on work-related outcomes is being use in the development of the MS WorkSmart Program. This is an online program that we are developing to provide people with tools and strategies that they can apply to their own working and daily lives for optimal management of fatigue and other MS symptoms.

Predictors of work productivity loss - Jing Chen, a PhD student, is examining which factors are most strongly associated with loss in work productivity due to MS. Compared to many other diseases, people with MS are able to work rather productively despite their MS. However, there are some symptoms that make it quite challenging. She found that fatigue, pain, and cognition issues were most strongly predictive of work productivity loss, while issues with vision, bladder, and bowel were less predictive.

Effect of disease modifying therapies on patient-reported outcomes – Prudence Tettey has recently joined us from Ghana. He is using the medication data that you have provided over the years to compare different disease modifying therapies in relation to employment outcomes and symptom severity. This is important as randomised controlled trials generally do not measure these types of outcomes.

2016 Economic Impact Study

The AMSLS is well-known for its economic impact data. Working out what MS costs, both individuals and society, is critically important for advocacy, researchers and policymakers. This data also feeds into the DEVA study, which is developing a model to predict the cost-effectiveness of MS medications and other interventions in particular situations and circumstances for people with MS.

Thank you to the 1,563 participants who have braved the 2016 Economic Impact Baseline Survey and have been filling in the Cost Diary, which is the biggest request we make of our participants. To those who have managed to stick it out, we thank you and hope you know your effort will provide data to show how much of a burden MS can be financially.

We would also like to thank those who have given feedback about the process or tried to complete the Cost Diary but were unable to. Trying to make a 'one size fits all' Diary for a group of people with such wide ranging costs, funding and support is incredibly difficult. We are already thinking about the next round and how to ease the burden to allow everyone to participate in a way that is not as intensive or complicated.

MS Research Australia - The Australian community's priorities for MS research

Earlier this year, MS Research Australia surveyed people with MS, their friends and family, health professionals and researchers, to gather feedback on the priorities for MS research. MS Research Australia and the AMSLS Steering Committee will be working to ensure that we align as closely as possible with those priorities. While developing a cure for MS is the top priority, followed by better treating MS, and preventing MS, the results also reveal a Community priority is to improve the management and care of MS. There is a strong interest in research to understand whether lifestyle factors such as stress, diet and physical activity can improve outcomes and quality of life. The top priorities for symptom management relate to walking and mobility, pain, fatigue and cognition. The AMSLS is well placed to help address these issues. Please visit the MS Research Australia website (www.msra.org.au) in December for more detail on the survey results.

The AMSLS team thanks you for your support in 2016 and wishes you all a happy festive season.