

Participant Information Sheet for AMSLS Support Team Survey and MS-CaPPS Pilot Study

Research team

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1. Invitation

You have been randomly selected to receive this invitation to participate in the AMSLS Support Team Survey and to become part of the MS-CaPPS Pilot Study. MS-CaPPS stands for *MS Caregivers and People Providing Support*.

2. What is the purpose of MS-CaPPS?

Most people with MS have people around them who support them. This support can come from partners, parents, siblings, children, other relatives, or friends, which is unpaid, and may be supplemented with paid services. Generally, people with MS rely on more than one person to support them, and the roles may differ from person to person. As the disease progresses, the level of support that a person with MS requires might increase, with some people receiving a carers allowance from the government.

There is currently no deep understanding of the support roles of these 'significant others', how their roles change over time, and the impact that MS has on them. To address this, we are conducting an AMSLS survey on the support network (or support team) that people with MS have.

In addition, to assess impact on the unpaid supporters and carers, we are interested in setting up a new cohort, linked to the AMSLS cohort, of people who care for and/or support AMSLS participants. The advantage of a linked cohort is that already collected AMSLS data can be combined with MS-CaPPS data, which reduces the questionnaire burden for the MS-CaPPS participants. To ensure that this idea of a linked cohort is feasible, we are first conducting a pilot study.

3. What will I be asked to do now?

- a. Firstly, we would like to ask you to complete a *Support Team Survey* which will take about 30 minutes to complete. This survey asks about the people that you have in your Support Team: the medical professionals, any paid support at home, and the support you receive from family and friends, including both practical support as well as emotional support that helps you lighten the load as a person living with MS.
- b. Secondly, within this Support Team Survey (*Section J and Section K for our administrative purposes*) we would like to ask you to complete a *MS-CaPPS Nomination Form and Linking Consent Form*.

With the Nomination Form, you can nominate up to three members in your Support Team who may be interested in participating in MS-CaPPS. These Support Team members need to be 18 years or over. The MS-CaPPS study will collect data from carers and supporters over time in a similar way as the AMSLS does. **We will email or post you MS-CaPPS Information Packs** that you can pass on to the nominated members in your nominated Support Team and you will be able to either email these or hand on a paper-based version. Also, each MS CaPPS Information Pack will have an encrypted number on it and this is an administrative number that we need to use for data linking.

With the Consent Form we require your consent to link your AMSLS data to the MS-CaPPS data of your nominees who decide to participate. You can read more about this in section 5. Your consent is an essential part of their participation.

If you do not wish to nominate anybody (including consent), **please still complete the Support Team Survey**, as it is important for us to understand why you do not wish to nominate a member.

Please note that not participating in the *Support Team Survey* or not completing the *MS-CaPPS Linking Consent Form* will not affect the data already collected for AMSLS.

4. Are any of the nominated members obligated to participate in MS-CaPPS?

Not at all. They will be provided with a separate MS-CaPPS Information Pack, including information needed to make an informed decision about their participation in MS-CaPPS. We will send these in the MS-CaPPS Information Pack that we will later ask you to hand on to them according to the preferences for contact that you provide in the Nomination Form attached to the Support Team Survey.

5. Why is my consent required to link my AMSLS data to the MS-CaPPS data of my nominees?

Combining your AMSLS data with MS-CaPPS data of your carers/supporters reduces the questionnaire burden of your supporters. With your consent, we will store your AMSLS ID number with the MS-CaPPS record of your supporters.

The actual data will always be stored in separate databases, but the AMSLS ID number will allow us to combine your AMSLS data with MS-CaPPS data for analysis purposes. For example, if we wish to examine whether the amount of support provided by your carer/supporter differs by the fatigue level of AMSLS participants, then we will combine your AMSLS fatigue measures with your carers/supporter's MS-CaPPS survey that assessed the amount of support provided.

If any of your nominees decide not to participate in MS-CaPPS, your linking Consent Form will not be valid for that person. If one of your nominees decides to withdraw from the study, your linking Consent will be automatically terminated.

6. What will happen to the data of the *MS Support Team Survey*?

As with all AMSLS surveys, the data is entered using LimeSurvey, and stored in a Microsoft Access database with unique identification numbers, but without identifiable information. All data is stored on secure University servers.

The survey data will be analysed and published in scholarly journals, with plain language summaries published on the MS Australia website. As with all AMSLS publications, the results will be reported in aggregated and/or de-identified ways, so that no individual will be able to be identified.

This pilot data will also form part of grant applications for funding for MS-CaPPS, with the findings also included in the yearly AMSLS newsletter.

7. Who is conducting the MS-CaPPS Pilot Study?

The Menzies Institute for Medical Research at the University of Tasmania is responsible for conducting both the AMSLS and MS-CaPPS. Professor van der Mei, who is the Project Manager of the AMSLS, is also leading MS-CaPPS. Dr Julie Campbell is responsible for the development of the materials and overseeing the day to day running of the study, including the supervision of Mr Henson who will be building and managing the MS CaPPS database for the pilot study.

8. How is the study being funded?

The Menzies Institute for Medical Research has provided seed funding to conduct the pilot study.

9. What if I have questions about this study?

If you have any queries, concerns or issues with this study, please feel free to contact us on mscapps.info@utas.edu.au. To contact us by phone, please phone Julie Campbell on 03 6220 9498. For any specific questions related to the AMSLS Support Team Survey, please contact AMSLS.info@utas.edu.au or 03 62264739.

This study has been approved by the University of Tasmania Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, you can contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 6254 or email human.ethics@utas.edu.au The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote H0014183.

10. I am happy to participate. What is next?

To be involved, we would like you to complete the Support Team Survey as described above and this includes the Nomination Form and the Linking Consent Form.

Please follow the instructions in the cover letter regarding the return of the Support Team Survey, including the Nomination Form (Section J) and Linking Consent Form (Section K).

We will then be in touch with you regarding the MS CaPPS Information Pack according to your preferences outlined in the Nomination Form.

If you do not wish to nominate anyone in the Nomination Form nor consent for data linkage, please still complete the Support Team Survey and you can provide reasons for not wishing to nominate anyone in that survey at Section J.

Thank you for your time