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## ***Questionnaire for persons with multiple sclerosis: Language, communication, and quality of life***

### **PARTICIPANT INFORMATION STATEMENT**

#### **(1) What is this study about?**

You are invited to take part in a research study about the communication experiences of persons living with multiple sclerosis (MS). We are looking both for people with MS who do and who do not experience communication problems in their daily life.

We are interested in understanding how often persons with MS experience communication difficulties, what these communication difficulties may be, and how they impact on quality of life and everyday activities. Information collected from this study will help raise awareness of communication difficulties in MS. It will also provide health professionals with important information to help manage and treat these difficulties in MS. Findings from this study will guide future research investigating communication in MS with the aim to help persons with MS maintain quality of life, including participation in the community and workforce.

You have been invited to participate in this study because you have a diagnosis of MS. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully and contact the research team with questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary.

By giving your consent to take part in this study you are telling us that you:

- Understand what you have read.
- Agree to take part in the research study as outlined below.
- Agree to the use of your personal information as described.

#### **(2) Who is running the study?**

The study is being carried out by the following researchers:

- Professor Kirrie Ballard, Professor in Speech Pathology at The University of Sydney
- Dr. Hans Bogaardt, Senior Lecturer in Speech Pathology at The University of Sydney  
Dr. Fiona Kumfor, Clinical Neuropsychologist and Senior Research Fellow at The University of Sydney
- Ms Sarah El-Wahsh, PhD student in Speech Pathology at The University of Sydney

Ms Sarah El-Wahsh is conducting this study as the basis for the degree of Doctor of Philosophy (PhD) at The University of Sydney. This will take place under the supervision of Professor Kirrie Ballard.

**(3) What will the study involve for me?**

This study involves you completing an anonymous online questionnaire. You will be asked to answer questions about your communication, memory and thinking, quality of life, social support and networks, and demographic information. No identifying personal details will be collected, and your responses are kept anonymous. All that is needed to complete the questionnaire is a computer, mobile device, or tablet that is connected to the Internet.

We are also interested whether the questionnaire is stable over time. Therefore, if you leave your e-mail address, we will e-mail you after 2 weeks and ask you to complete a shorter 10-minute version of the questionnaire.

**(4) How much of my time will the study take?**

It is estimated that the questionnaire will take around 30 to 45 minutes to complete. You can complete the questionnaire in one session or in multiple sessions (there is no limit to the number of times you can enter and leave the questionnaire). If you use the save and return later function, please complete the full questionnaire within 7 days of starting.

**(5) Who can take part in the study?**

You can participate in this study if you:

- Have a diagnosis of MS
- Are an adult aged 18 years or over

We are looking both for people with MS who do and who do not experience communication problems in their daily life.

**(6) Do I have to be in the study? Can I withdraw from the study once I've started?**

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at The University of Sydney.

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time. You can do this by leaving the questionnaire. The questionnaire contains 6 modules. At the end of each module there is a "Submit" button. Submitting a completed module is an indication of your consent to participate in the study. You can withdraw your responses any time before you have submitted a module. Once you have submitted a module, your responses cannot be withdrawn because they are anonymous and therefore, we cannot tell which one is yours.

**(7) Are there any risks or costs associated with being in the study?**

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study. This survey does discuss health issues and disease, which can be distressing. If you experience any distress, please seek appropriate psychological/emotional support. Examples of appropriate services in Australia include:

- Beyond Blue Ph: 1300 22 4636 (24 Hours/7 days per week) [www.beyondblue.org.au](http://www.beyondblue.org.au)
- Lifeline Ph: 13 11 14 [www.lifeline.org.au](http://www.lifeline.org.au)

**(8) Are there any benefits associated with being in the study?**

We cannot guarantee that you will receive any direct benefits from being in the study. Findings of this study will increase our knowledge of the communication difficulties experienced by persons with MS. We hope that this information will guide future research and treatment to help persons with MS get the support they need to maintain their quality of life.

In order to thank you for your time and participation we will hold a prize draw after the study is finished. You have the option of providing your e-mail address if you are interested in being included in the prize draw. The prize draw includes a chance to win 1 of 4 \$25 gift vouchers (Australian dollar or equivalent). If you choose to provide your e-mail address, it will be stored separately from the survey data. It will be used to contact you for the second shorter questionnaire and to inform you if you have won a prize.

**(9) What will happen to information about me that is collected during the study?**

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement.

Your information will be stored securely, and your identity/information will be kept strictly confidential, except as required by law. Study findings may be published, but you will not be individually identifiable in these publications.

**(10) Can I tell other people about the study?**

Yes, you are welcome to tell other people about the study.

**(11) What if I would like further information about the study?**

If you would like to know more at any stage during the study, please feel free to contact Ms Sarah El-Wahsh, PhD student at The University of Sydney on [selw5849@uni.sydney.edu.au](mailto:selw5849@uni.sydney.edu.au).

**(12) Will I be told the results of the study?**

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by leaving your e-mail address in the relevant box in the questionnaire. This feedback will be in the form of one-page summary in easy English. You will receive this feedback after the study is finished.

**(13) What if I have a complaint or any concerns about the study?**

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney [Protocol number: 2019/619]. As part of this process, we have agreed to carry out the study according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** [human.ethics@sydney.edu.au](mailto:human.ethics@sydney.edu.au)
- **Fax:** +61 2 8627 8177

*This information sheet is for you to keep*