



PARTICIPANT INFORMED CONSENT FORM

1. What is this study about?

This study involves the completion of an anonymous online questionnaire. No identifying personal details will be collected and your responses are kept anonymous. This questionnaire aims to explore the impact of Multiple Sclerosis (MS) on health related quality of life (HRQoL). The questions will cover a range of relevant topics including type of MS, voice quality, swallowing, language, and the state of your social and psychological wellbeing. The information gathered will be used to evaluate and validate this questionnaire. We are also interested whether the questionnaire is stable over time. Therefore, if you leave your e-mail address at the end of the questionnaire, we will contact you after 2 weeks and we will ask you to complete a shorter version of the questionnaire.

2. How much of my time will the study take?

It is estimated that the questionnaire will take around 15 to 25 minutes to complete. The second questionnaire, after 2 weeks, will take around 10 minutes to complete.

3. 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 are not under any obligation to consent to complete the questionnaire. Submitting a completed questionnaire is an indication of your consent to participate in the study. You can withdraw at any time prior to submitting your completed questionnaire. Once you have submitted your questionnaire anonymously, your responses cannot be withdrawn.

4. Are there any risks or costs associated with being in the study?

We anticipate that giving up your time is likely to be the only cost associated with participation. This questionnaire does discuss health issues and diseases, 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
- Lifeline Ph: 13 11 14 www.lifeline.org.au

5. Are there any benefits associated with being in the study?

We will hold a prize draw. You have the option of providing your e-mail address at the end of the questionnaire if you are interested in being included in the prize draw. The prize draw includes a chance to win 1 of 2 \$50 gift vouchers (Australian dollar or equivalent). If you choose to provide your e-mail address, it will be stored separately from the questionnaire data. It will be used to contact you for the second shorter questionnaire and to inform you if you have won a prize. The prize draw will be drawn on 05/12/17 and the prize winners will be notified via e-mail 1 week later. In addition, a donation of \$2 will be made to MS Australia for each completed questionnaire, with a maximum donation of \$500.

6. What will happen to information about me that is collected during the study?

By providing your consent, you are agreeing for us to collect personal information about you for the purposes of this research study outlined in this *Participant Informed Consent Form*. The information you provide will remain anonymous and will not be shared with any third parties.

7. Can I tell other people about the study?

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

8. What if I would like further information about the study?

If you have any questions or would like to know more information please feel free to contact:

Dr. Hans Bogaardt,
Faculty of Health Sciences,
Discipline of Speech pathology,
The University of Sydney.
Phone: +61 9351 9334.
E-mail: hans.bogaardt@sydney.edu.au

9. Will I be told the results of the study?

You can request to receive feedback about the overall results of this study. An option will be available at the end of the questionnaire for you to provide your e-mail address if you would like to receive a summary of the results. The feedback provided will be in the form of a 1 page lay summary. Your details will be stored separately from the questionnaire data. You will receive this feedback after the study has been completed.

10. What if I have a complaint or any concerns about the study?

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 (2017/197).

The Manager,
Ethics Administration,
University of Sydney,
Telephone: +61 2 8627 817