School of Psychological Sciences

Establishing Priorities for the Treatment of Mental Health Difficulties in People with Multiple Sclerosis (MS)

PARTICIPANT INFORMATION SHEET FOR THOSE WITH MS

1. Invitation

You are invited to participate in an online survey (approximately 30-minutes) as part of a study investigating treatment priorities for the management (i.e., treatment and support) of mental health disorders in adults living with Multiple Sclerosis (MS).

This study is being conducted by Dr Holly Emery (Lecturer) and Associate Professor Cynthia Honan (Senior Lecturer and Clinical Neuropsychologist) in the School of Psychological Sciences, University of Tasmania, and Professor Ingrid van der Mei (Epidemiologist) at the Menzies Institute for Medical Research.

2. What is the purpose of this study?

The purpose of this study is to better understand what is important for adults living with MS concerning treatment and management of mental health disorders. Your responses will help inform future research efforts addressing treatment of mental health disorders among adults living with MS.

What are mental health disorders? Mental health disorders are commonly experienced among individuals living with MS and you may have experienced one or more of these yourself. Some of the most common mental health disorders experienced among those with MS include depression, anxiety, substance abuse, and bipolar disorder, among others.

3. Who are we looking to participate?

We are looking for participants who are over the age of 18 years and have been diagnosed with MS.

Participation in this study is entirely voluntary. There will be no consequences should you not wish to participate.

4. What will I be asked to do?

We are wanting to know your thoughts and ideas as a person living with MS to guide the direction of future research and to help inform the development of treatment protocols. We

want to know what areas of treatment are important to you. Your answers will help us understand treatment priorities for mental health difficulties among those living with MS.

We will first ask you some questions regarding you and your MS. We will then ask you questions about: (1) which mental health difficulties are most important/relevant to people living with MS; and (2) what outcomes you believe to be *critical* or *important* following treatment for mental health difficulties. Your participation is expected to take 30 minutes and can be completed online. You can also contact the research team if you require any support.

To help you make an informed decision about your participation in this study, we strongly encourage you to speak to your general practitioner and a support person (i.e., a partner, family member, friend or carer) about your decision before you agree to participate in the study. We also encourage you to have your support person with you while completing the survey. If you would like to complete the survey with a researcher over the phone or online via a Zoom meeting, please contact Dr Holly Emery (03 6226 7739; holly.emery@utas.edu.au).

5. Are there any possible benefits from participation in this study?

While there are no expected direct benefits to you for your participation in this study, your participation will help us improve our understanding of treatment priorities for mental health disorders among individuals living with MS. This improved understanding will guide future research efforts and will be useful in informing the development of treatment protocols and agendas, thus benefiting the MS community as a whole.

6. Are there any possible risks from participation in this study?

There are no anticipated risks associated with participating in this study. However, if thinking about your experience of living with MS has led to some distress, please contact your regular general practitioner, mental health professional (if you have one), Lifeline on 13 11 14, or MS Connect on 1800 042 138. You may also contact a member of the research team: Dr Holly Emery (03 6226 7739; holly.emery@utas.edu.au).

7. Is there any reimbursement for participation?

We understand that participating in research of this nature can take time away from other important tasks. To thank you for your generosity in assisting us and as recompense for your time, we will offer you a $25 Coles/Myer gift card at the conclusion of your participation.

8. What if I change my mind during or after the study?

Your participation in the study is entirely voluntary and you are free to withdraw before or while completing the survey without penalty. To do this, do not submit your final survey answers. It will not be possible to withdraw from this study after you have submitted your final survey. This is because it will not be possible to know which survey is yours as we are not collecting any information that will personally identify you. You may also change your answers to any question up until the time you submit your final survey responses.

9. What will happen to the data when this study is over?

All information collected for this study will be kept confidential and no personally identifiable information will be collected from you. All information will be stored at the University of Tasmania under password protected computer software. The data will be kept secure for a period of twelve years following the date of publication, after which all information will be destroyed. The information and data collected for this study will only be accessible to, and viewed by, the research team.

10. How will the results of the study be published?

The results of this study will be reported and published in a scientific journal and presented at a scientific conference. No identifying information (such as your name) will be used in any publication.

Although data will be anonymised by pseudonym, you may be able to recognise quotes that you have given in the final publication.

Data from this study may also be used to answer future research questions, but in doing so will remain broadly within the general aims and scope of the current study.

11. What if I want further information about the study?

If you would like to know more about this study or have any questions, please feel free to contact the research team:

- Dr Holly Emery (Lecturer) – email: holly.emery@utas.edu.au, phone: 03 6226 7739
- Dr Cynthia Honan (Senior Lecturer and Clinical Neuropsychologist) – email: cynthia.honan@utas.edu.au, phone: 03 6324 3819.

12. How can I agree to be involved?

If you would like to participate in this study, please follow the link at the end of this page. This link will direct you to the full online survey. Prior to participating you will be asked to provide your consent in agreement to participate. Prior to participating you will be asked to provide your consent in agreement to participate and acknowledge that you have discussed your participation with a family member, carer or medical practitioner.

13. Who do I contact if I have any concerns?

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 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 [**INSERT ETHICS APPROVAL NUMBER HERE**].

Thank you for considering participating in this study.

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PARTICIPANT CONSENT FORM FOR THOSE WITH MS

Lead Researchers

Dr. Holly Emery, School of Psychological Sciences, University of Tasmania
holly.emery@utas.edu.au
03 6226 7739

A/Prof. Cynthia Honan, School of Psychological Sciences, University of Tasmania
cynthia.honan@utas.edu.au
03 6324 3266

Professor Ingrid van der Mei, Menzies Institute for Medical Research, University of Tasmania
Ingrid.vanderMei@utas.edu.au
03 6226 7710

By signing below, I confirm that I have read and understood the Participant Information Sheet, and in particular:

- I understand that my involvement in this research will include completing an online survey (taking up to 30 minutes) that will involve responding to a series of questions that aims to establish priorities about the treatment of mental health disorders among individuals living with MS.
- I understand that participation involves the risk of potential discomfort and/or distress due to the personal nature of the study topic. I understand that should I experience any distress I should contact my regular doctor or mental health professional (if you have one), phone Lifeline (13 11 14), or alert a member of the research team.
- Any questions that I have asked have been answered to my satisfaction.
- I understand that all study data will be securely stored on the University of Tasmania premises for 12 years from the publication of the study results and will then be destroyed.
- I agree that my study data can be used for this specific project.
- I understand that the results of the study will be published so that I will not be identified as a participant.
- I understand that my participation in this research is voluntary and that I am free to withdraw at any time, without explanation or penalty.

- I understand that for my participation I may elect to receive a $25 Coles/Myer voucher for recompense of my time.
- I understand that I will not be able to withdraw my data after submitting my survey as the nature of the study means all my data will be combined with other participants' data and thus will be no longer identifiable as my own.
- I agree to participate in the study.

By selecting yes to participating in this online survey, you are providing consent for your participation in this study and for your data to be used for the purpose of this study.

Yes/No

I acknowledge that where possible, I have discussed my participation with a GP, family member or carer, and they are happy for me to participate.

Yes/No

Optional extended consent
I understand that the data from this study may also be used to answer future research questions, but in doing so will remain broadly within the general aims and scope of the current study.

Yes/No

[*note: Both the Participant Information Sheet and Consent Form will be presented online (on the RedCap platform) and participants will be required to provide consent online].