



## Exploring dietary behaviours in MS

### **PARTICIPANT INFORMATION STATEMENT**

<b>HREC Project Number:</b>	HRE2023-0445
<b>Project Title:</b>	Exploring attitudes and behaviours regarding diet among people with multiple sclerosis and their carers and multiple sclerosis nurses
<b>Chief Investigator:</b>	Dr Rebecca Russell
<b>Version Number:</b>	V2
<b>Version Date:</b>	24/07/2023

#### **What is the project about?**

- There is very little research exploring the nutrition education needs of people with multiple sclerosis (MS) who have a carer who assists with their food preparation.
- With this project, we aim to find out what dietary changes are made by people with MS who have a carer who assists with their food preparation, and their views on the role of diet in MS. We also aim to find out what dietary resources are needed.
- This research is important and will be used to develop resources that fill in the gaps in this field.
- We will run at least 12 interviews, with each interview involving a person with MS, their carer who is responsible for food preparation, and one person from the research team (the interviewer).

#### **Who is doing the research?**

- The project is being conducted by Dr Rebecca Russell and Dr Matty Phillips. The research is part of the MS Nutrition Research Program, which is led by Professor Lucinda Black.
- There will be no costs to you, and you will not be paid for participating in this project. You will receive a supermarket gift voucher as a thank you for your time.

#### **Why am I being asked to take part and what will I have to do?**

- You have been asked to take part because you have MS and have a carer who assists with your food preparation.
- Your participation will involve taking part in a one-off interview that will last for around 60 minutes (1 hour). You will be asked to fill out a short questionnaire before the interview starts, with some standard questions about your age, sex, the year you were diagnosed with MS, etc.
- The interviews will take place online, using videoconferencing (Microsoft Teams or WebEx), or in-person (at MSWA Wilson), at a date and time that suits you and your carer.
- The questions will cover topics such as “Has being diagnosed with MS influenced or changed your food intake and what you eat? Why/why not?” and “What dietary resources would you like to have access to?”.



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- We will audio-record the discussion so that we can concentrate on what you have to say and not distract ourselves with taking notes. After the interview we will make a full written copy (transcript) of the recording.
  - Optional Consent Future Research: We would like you to consider allowing us to send you information about future research projects. Once you receive the information it is your choice if you decide to take part or not.
  - Optional Consent: We would like you to consider letting us share the information we collect during this research with other researchers working in this area. The information will be de-identified then re-identifiable, meaning your name will be changed.

### **Are there any benefits to being in the research project?**

- There may be no direct benefit to you from participating in this research, but sometimes, people appreciate the opportunity to discuss their opinions.
- We hope the results of this research will allow us to:
  - Develop nutrition education resources for people with MS and their carers
  - Pinpoint nutrition issues of importance for future research

### **Are there any risks, side-effects, discomforts, or inconveniences from being in the research project?**

- We have been careful to make sure that the questions in the interview do not cause you any distress. But if you do feel anxious about any of the questions, you do not need to answer them. If the questions cause any concerns or upset you, we can refer you to a counsellor or you can contact Beyond Blue on 1300 22 4636 or Lifeline on 13 11 14.
- Apart from giving up your time, we do not expect that there will be any risks or inconveniences associated with taking part in this study.
- To minimise any risks in relation to COVID-19, we will adhere to the current Government health advice and/or the interviews will be conducted online if you prefer.

### **Who will have access to my information?**

- The information collected in this research will be re-identifiable (coded). This means that we will collect data that can identify you but will then remove identifying information on any data and replace it with a code/pseudonym when we analyse the data. Only the research team have access to the code to match your name if it is necessary to do so. Any information we collect will be treated as confidential and used only in this project unless otherwise specified. The following people will have access to the information we collect in this research: the research team and, in the event of an audit or investigation, staff from the Curtin University Office of Research and Development.
- Electronic data will be password-protected and hard copy data will be in locked storage.
- The information we collect in this study will be kept under secure conditions at Curtin University for seven (7) years after the research is published and then it will be destroyed.
- The results of this research may be presented at conferences or published in professional journals. You will not be identified in any results that are published or presented.

### **Will you tell me the results of the research?**

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- If you are interested in obtaining a summary of the results, please contact the researchers three-months after you have completed your interview. Results will not be individual, but based on all the information we collect and review as part of the research.

### **Do I have to take part in the research project?**

- Taking part in a research project is voluntary. It is your choice to take part or not. You do not have to agree if you do not want to. If you decide to take part and then change your mind, that is okay, and you can withdraw from the project. If you choose not to take part, or start and then stop the study, it will not affect your relationship with the University or MSWA staff or colleagues.
- You are free to withdraw from the study prior to approving your transcript.
- With your permission, if you chose to leave the study we will use any information collected unless you tell us not to.

### **What happens next and who can I contact about the research?**

- You can contact Dr Rebecca Russell on 9266 3160 or [MSDietProject@curtin.edu.au](mailto:MSDietProject@curtin.edu.au) to obtain further information or ask any questions.
- If you decide to take part in this research, we will ask you to sign the consent form. By signing it is telling us that you understand what you have read and what has been discussed. Signing the consent indicates that you agree to be in the research project and have your information used as described. Please take your time and ask any questions you have before you decide what to do. You will be given a copy of this information and the consent form to keep.

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HRE2023-0445). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email [hrec@curtin.edu.au](mailto:hrec@curtin.edu.au)