PARTICIPANT INFORMATION SHEET

COGNITIVE ASSESSMENT AND TREATMENT IN PEOPLE WITH MULTIPLE SCLEROSIS IN IRELAND: A NATIONAL SURVEY

You are being invited to take part in a research study investigating the assessment and treatment of cognitive impairment of people with Multiple Sclerosis in Ireland. Before you make a decision about participating, it is important for you to understand why the research is being done and what it will involve. This *Participant Information Sheet* will tell you about the purpose, risks and benefits of this research study. If there is anything that you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read it. You should only consent to participate in this research study when you feel that you understand what is being asked of you, and you have had enough time to think about your decision.

Why is this study being done?

Approximately 40-65% of people living with multiple sclerosis (MS) have difficulties with cognition. It is unclear how cognitive impairment is currently assessed and managed in the Republic of Ireland and what, if any, rehabilitation programmes are being run and by whom. Such knowledge is important for maximising current treatment available to people living with MS, as well its impact on current and future research in the field. In addition, it is an important step in trying to standardise care at a European level for people with MS who have cognitive difficulties. The aim of this research is to assess what is the 'treatment-as-usual' being provided to people with Multiple Sclerosis in Ireland that have cognitive difficulties.

Why am I being asked to take part?

You are being asked to take part as a Healthcare Professional working in the Republic of Ireland, who has experience working with people with MS.

What can I expect if I agree to take part?

You will be asked to fill out a questionnaire (either online or paper version). This should take about 15-20 minutes. The questions relate to your role and experience, how people with MS in your organisation are assessed for cognitive impairment, and what treatment you offer for cognitive impairment. You will be asked about how important you feel assessment and treatment of cognitive impairment are, and how confident you feel in assessing and treating cognitive impairment. There is also additional space for you to add anything else you feel is important that was not covered in the questionnaire. You may then submit your completed survey online or post it back to the postal address included. If you complete the questionnaire online your responses will be automatically returned to the research team.

What if I do not want to take part?

You are under no obligation to take part in this survey. You are free to decline to take part in this study, by not sending back a completed questionnaire. Declining to take part in this study will not affect your rights in any way.

What are the benefits for me in taking part?

You will be adding to the evidence base in an area relevant to your clinical practice. This study looks to explore what is ‘treatment-as-usual’ for people with MS with cognitive impairment in the Republic of Ireland, in an effort to standardise care across the country, in line with best practice.

What are the risks?

There are no foreseen risks to taking part.

Where can I get further information?

If you are interested in taking part or would like further information on this research, please contact us via email at cobms@nuigalway.ie

What do I need to know about confidentiality?

It is important that you know that:

- You will not be asked to provide any identifying information on the questionnaire – the questionnaire you complete will be assigned a random identification code, which will be the only identifier. You will not be asked to provide your name, place of employment or any other identifying data.
- All physical files will be locked in a secure filing cabinet or stored securely electronically for a period of 5 years, in accordance with NUIG guidelines on data storage, after which they will be destroyed.
- We hope to publish the results of our research. We will disseminate findings through academic journal articles, MS Ireland newsletters and presentations at conferences and relevant meetings. No person or group will be identifiable in the reports.

What do I need to know about data protection?

It is important that you understand how your personal information will be gathered and used for this study. We are required by law to give you all this information before you decide to take part in this research or not.

1. ***Can I withdraw?*** All questionnaires that are returned will be associated with an anonymised number. Therefore, once you return the questionnaire, you will no longer be able to withdraw their data from the study because anonymous responses cannot be identified. You can contact the researcher team if you have questions about this.

2. ***What are my rights?***

a. You have the right to lodge a complaint with the Data Protection Commissioner if you are dissatisfied.

b. You have the right to request access to your information e.g. a copy of your questionnaires. However, once these have been made anonymous i.e. once they have all been collected, it will not be possible for us to know which questionnaire is yours.

c. You have the right to restrict or object to processing of your information. But this would make it difficult for us to complete this research.

d. You have the right to have your personal information deleted when it is no longer required for the study.

How will you use my information?

a. We will not use your personal data to make any predictions about you.

b. Your information will not be processed for any other reason than for this study. And it will not be transferred to any other country or organisation.

Thank you for taking part in our study, if you have any questions, please email cobms@nuigalway or contact the study's primary investigator:

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