



Dating with a diagnosis: The lived experience of people with Multiple Sclerosis

Information Sheet for Participants

Why should you take part in this study?

Thank you for taking the time to read this. You are invited to take part in a study focusing on the experiences of dating and romantic relationships for Irish adults living with M.S. This study may provide useful information for health professionals when working with adults living with M.S. Before you decide to take part, it is important that you understand why the research is taking place and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please do not hesitate to ask any questions you may have.

Why are we doing this research?

We are interested in exploring the experience of people with a diagnosis of Multiple Sclerosis as they navigate the dating world. We want to better understand how living with MS influences developing romantic relationships. We are particularly interested in this study in the experiences of those who are single or in the early stages of relationships.

Why have I been invited?

You have been invited to participate as you have a diagnosis of M.S. and are over the age of 18. You may have experience in dating or in using online dating or dating apps.

Do I have to take part?

It is entirely up to you to take part in this study. If you do want to participate, please e-mail sinead.hynes@nuigalway.ie. We can then discuss the study and you will have a chance to have any queries or concerns addressed. If you decide to take part in the study, you will be asked to sign a consent form.

What would I have to do?

This study will explore your dating experiences through participating in an online focus group. If you decide to take part in the study, you will be asked to take part in one online focus group with a few other people. We anticipate that the group will last no longer than 90 minutes and you can participate from home or wherever you are comfortable. You will be able to join using a smart phone or computer/laptop/tablet. You do not have to turn on your camera for the discussion. You can also ask the researchers for help at any stage.

You do not have to discuss anything that you are not comfortable with. We will not ask for any intimate information. We will provide you with a sheet that covers some of the areas that we will discuss in the focus group. We will use the software Zoom to host the focus group.

When you and other participants in the study have completed the focus group we will analyse the data and come up with results based on what is submitted. We will get back in touch with you at this point to tell you about the results we have found and make sure that they fit with your experiences.

Please note that we need a minimum number of participants to complete this research study. If we do not meet that minimum number then we will not be able to complete the project at this time. We will let you know if this is the case and we will not keep any of your details stored in this situation.

Are there any risks involved?

Participating in the research is not anticipated to cause you any disadvantages or discomfort. If you find the topics too hard or personal to talk about, you are not obliged to discuss them. Please take time to reflect on if you are willing to discuss details of your personal romantic relationships in an online focus group for the purpose of this study. Please note that even if you initially agree to participate in the study, you can change your mind at any point and your data will not be used. You are free to withdraw from the study with no consequence at any time.

What are the benefits of participating?

There are no immediate benefits to participating in this research project. However, this project may help guide health professionals working with adults with MS. in the future. It will also help us to understand what the dating experience is like for adults with MS.

Will my taking part in this study be kept confidential?

Yes. Only the researchers will have access to your information. The focus group will be recorded and the audio from it will be transcribed and any information identifying you or anyone you mention will be omitted. Once the recordings have been transcribed, the focus group files will be permanently deleted. All participant information will be stored securely in Áras Moyola, NUI Galway and only the researchers will have access to the files. You will not be named in the study or any publication relating to the study.

What will happen to the results of the research project?

Results of the research will be published. You will not be identified in any report or publication. If you wish to be given a copy of any reports resulting from the research, please ask us to put you on our circulation list. 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.

What do I need to know about data protection?

- ***Why do you need my personal information?*** We need your personal information for when we need to contact you throughout the research study.
 - o We are using your information under two legal bases as defined by the General Data Protection Regulations 2016: Because we feel this study is important for scientific research (Article 9(2)(i)) and because we feel the information you provide could be important for the public interest (Article 6(1)(f))
- ***Who will have access to my information?*** Only the researchers who need to have your information (to email/post something to you or to ring you) will have access to your personal information.

- **How long will you keep my information?** Your personal details e.g. name, email address will be deleted when the research has finished. We will still keep the transcripts from the audio-recordings for a period of 5 years. This will be stored in a locked filing cabinet in Dr Sinéad Hynes office. You will not be identifiable from these.
- **What are my rights?**
 - You have the right to lodge a complaint with the Data Protection Commissioner if you are dissatisfied.
 - You have the right to request access to your information. However, once these have been made anonymous i.e. once they have all been collected, it may not be possible for us to know which data is yours.
 - 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.
 - You have the right to have any inaccurate information about you corrected or deleted.
 - You have the right to have your personal information deleted when it is no longer required for the study.
 - You have the right to ask for any of your information in a readable format.

Who can I contact if you have questions about the study?

If you have any questions or concerns about what we are asking of you, please contact the researchers listed below.

Ms. Jackie Fox or Dr Sinéad Hynes
School of Health Sciences, National University of Ireland, Galway

Email: Jackie.fox@nuigalway.ie OR sinead.hynes@nuigalway.ie

Principal investigators and Data Controllers: Dr. Sinéad Hynes and Ms Jackie Fox

Email: jackie.fox@nuigalway.ie or sinead.hynes@nuigalway.ie

Data Protection Officer: Data Protection, Room A129, The Quadrangle, NUI Galway

Data Protection Officer's Contact Details: dataprotection@nuigalway.ie

This study obtained full ethical approval from the NUI Galway Research Ethics Committee on 16th December 2019.