

## INFORMATION SHEET FOR PARTICIPANTS

*Ethical Clearance Reference Number: HR/DP-24/25-45663*

### YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

#### **Title of study**

Psychometric Properties of Sexual Difficulties Scales in People Living with Multiple Sclerosis

#### **Invitation to participate**

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact the researchers if there is anything that is not clear or if you would like more information.

#### **What is the purpose of the study?**

Sexual difficulties are a common symptom reported among people with MS, that has been shown to negatively impact quality of life, relationship satisfaction, body image, and exacerbate mental health symptoms. This study is to help us test the validity and reliability of sexual difficulties scales in people with multiple Sclerosis (MS). Which will help us to gain a better understanding of which scales are reliable in capturing sexual difficulties in people with MS. This can be used in both clinical practice and research to help better support people living with MS.

#### **Why have I been invited to take part?**

To participate, you must:

- Be at least 18 years old
- Have been diagnosed with MS
- Be able to read and write in English

#### **What will happen if I take part?**

If you agree to take part, you will complete a pseudo anonymous survey that will take approximately 30 minutes to complete. This will involve:

- 1) **Eligibility screen:** After you have read the information sheet, we will need to ask you some questions to confirm that you are eligible to take part in this study. These questions are to check that you have a physical long-term health condition, and that you are over 18 years of age. The research team's contact information is below so you can contact us to ask any questions about the study before deciding to take part.
- 2) **Online consent form:** This will confirm that you have read and understood the information sheet, and that you are happy to take part in the study.

- 3) **Questionnaire:** After you have consented you will go through to an online questionnaire. This will ask about your demographics (age, gender, ethnicity, education level), questions regarding your diagnosis of MS and questions regarding sexual difficulties, as well as about your mood and emotional distress. Some example questions include “In the last month, did you feel no excitement or arousal during sex?” and “How often in the last 30 days did you feel frustrated by your sexual problems?”.
- 4) **Prize draw:** Upon completion of the survey, you can opt in to taking part in a prize draw where you can enter your email address in a separate survey independent of your survey response for a chance to win one of 5 x £20 Love2Shop vouchers.

### **Do I have to take part?**

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway. If you choose to take part, you will be asked to provide your consent. To do this you will be asked to indicate that you have read and understand the information provided and that you consent to your data being used for the purposes explained.

You have up to 7 days to decide whether to take part after reading the information sheet. You can download and view this information sheet online at any point in time. You are free to withdraw at any point during completion of the survey, without having to give a reason. However, given the nature of the data being collected, we cannot delete survey data that has already been completed. You will be given the option at the end of the survey to request withdrawal. If you do not request withdrawal your data, it will be used in the study.

### **What are the possible benefits of taking part?**

There are no direct benefits to participating in this study. We expect this research to inform future intervention trials aiming to treat sexual difficulties in people with MS.

### **What are the possible risks of taking part?**

Some people may find it distressing to answer questions about their sexual difficulties and their physical and/or mental health. If you feel you need more support, you can contact a member of the research team [study email address]. If you are experiencing a lot of distress, there are people who want to help. You can contact:

**MS Society** - Call 0808 800 8000, (9am-7pm, Monday to Friday) or [Or email email\\_help@msociety.org.uk](mailto:email_help@msociety.org.uk)

**Mind** – Call 0300 123 3393 (9am to 6pm, Monday to Friday)

**Samaritans** – Call 116 123 (24/7) or email [jo@samartians.org](mailto:jo@samartians.org)

You can also contact your GP for additional support.

### **Important information**

It is up to you whether or not you want to take part. If you do decide to take part, you will be asked to sign an online consent form.

You can stop taking part in all aspects of this study, or any part of it, at any time and without giving a reason.

The research is organised by King's College London. The study has been approved King's College London Psychiatry, Health Faculties Research Ethics Subcommittee (rec@kcl.ac.uk).

Our aim is to publish the study results in scientific journals. The results may also be used in a thesis for a Bachelor's or Masters's degree. All results will be fully anonymised. This means that you cannot be identified by the information in any way. If you are interested in the results, you can consent to receiving a report from the research team, after the study has been analysed.

### **How will the data collected during the study be used?**

All identifiable personal data will be deleted and the data from the questionnaires will be stored confidentially, using a unique ID number. Your contact details will be stored separately. All information will be stored securely on KCL servers and only members of the research team will be able to access this information. All members of the research team have all undergone General Data Protection Act (2018) (GDPR) training and have the necessary clearances in place.

The anonymised data will be kept according to KCL's data management policy. According to this policy the data will be stored securely at KCL for 7 years after the study is complete. All data will be destroyed securely (by deleting this) after this time period. Anonymised study data may be archived for further analysis. All data will be managed in line with General Data Protection Act (2018) (GDPR) and the Caldicott Principles. The study Lead Investigator remains responsible for overseeing data collection, quality and recording.

If you consent to take part in the research study, your records may be looked at by regulatory authorities or ethics committees. These inspections are to check that the study is being carried out correctly and is following all the correct confidentiality and security procedures. Some data collected in the study will be stored online in a data sharing repository in order to support other research. This data will **not** include any personal information or data that could identify you in any way (e.g., name, email address, health data). We will **never** share information that could identify you personally or provide others with personal contact details without your explicit consent. If you are interested in taking part in future research, you can indicate this on the consent form. Qualtrics will be viewing IP addresses in order to stop multiple submission, but this information will not be collected or viewable to the research team (For more information on this, please view <https://www.qualtrics.com/privacy-statement/>).

### **What if I have further questions?**

#### **Research team contact details:**

Emily White (Lead researcher): [Emily.white@kcl.ac.uk](mailto:Emily.white@kcl.ac.uk)

Dr Ashley Brown (Principal investigator): [Ashley.brown@kcl.ac.uk](mailto:Ashley.brown@kcl.ac.uk)

#### **Department address:**

Health Psychology Section (IoPPN)  
King's College London  
5th Floor Bermondsey Wing  
Guy's Hospital, SE1 9RT

If you are experiencing a lot of distress, there are people who want to help. You can contact the Samaritans on 116 123 (open 24 hours a day, 7 days a week) or Mind on 03001233393 (Mon-Fri, 9am-6pm).

**Thank you for considering taking part in this research.**