

**Participant Information Sheet**

**“The predictive value of capacity, capability and performance measures of walking ability to predict participation in community dwelling adults with Multiple Sclerosis.”**

A study to explore the relationship between different measures of walking ability in adults with Multiple Sclerosis (MS).

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If you have any questions or would like any more information please do not hesitate to contact the researchers. Their contact details are at the end of this information sheet. **Take time to decide whether or not you wish to take part. Thank you for reading this.**

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

The aim of the study is to establish the relationship between outcome measures used to assess different aspects of a person’s walking ability. We want to see if measures used commonly by Physiotherapists can predict how well a person with MS walks and participate within their home environment.

**Why have I been invited to participate?**

You have been invited to participate because you have MS and are a member of one of the MS therapy centres from which recruitment will take place. Approximately 150 adults will participate in this study. To be eligible to participate you need to be able to walk independently (without the assistance of another person); you can use the assistance of a walking aid.

**Do I have to take part?**

As participation is entirely voluntary, it is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason and this will have no detrimental effect on your involvement with the MS therapy centre or MS society.

**What will happen to me if I take part?**

If you decide to participate in the study it will involve attending 2 data collection sessions held at your local MS therapy centre with a one week interval between. The researcher will endeavour to schedule these sessions on the most convenient days for both participants and the centre. During the week interval you will be required to wear a pedometer during waking hours and keep a very simple diary. You are not required to change any of your normal daily activities in that time.

At the initial session prior you will need to sign a consent form and you will complete a short questionnaire to gather some basic information. You will also complete a 6-minute walk test (for which you can walk at your own pace, use your walking aid if you use one, and rest if necessary) and 1 questionnaire that asks about the activities you do in everyday life. You will then be given a pedometer to be worn for the next 7 days, instructions on how to use it and the simple diary. It is anticipated this session will last approximately 30 minutes.

After one week the second session will take place at the therapy centre. At this session you will return your pedometer and completed diary and complete two questionnaires that ask about your walking and your physical activity. It is anticipated this session will last approximately 30 minutes.

When you provide consent to participate in this study you will be asked if you want to be informed about other studies related to people with MS that are being conducted at Brunel University London. If you would like to be informed about other studies you will be asked to provide your name and contact details (phone number, email address or postal address).

Providing your contact details does not automatically mean you consent to participate in future studies. We will simply provide you with information about other studies and you will have the opportunity to consent to or decline to participate in these. Your details will be stored for 10 years and you may be contacted about studies once a year at most. If you want to remove your contact details from our database you can contact us any time at the details below.

**Are there any benefits of taking part?**

There are no direct benefits in taking part in this study although you may find reflecting on your activities useful. You will also find out how many steps you take each day. We hope that this study will inform how therapists use measures of walking more effectively in the future.

**What are the possible disadvantages and risks of taking part?**

There is a risk of discomfort and exertion with the 6 minute walk test; however you are allowed to complete this at entirely your own pace and can rest whenever necessary throughout the duration of the test to minimise this risk.

Due to the nature of the measures being investigated there is a low risk of potential distress while reflecting on physical challenges you may face due to MS. If any of the activities cause you any distress you may stop at any time and if necessary discuss this further with a designated member of the therapy centre staff or the researcher.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential and anonymised so you cannot be identified from it. All of the information collected will be kept by the researcher in accordance with the Data Protection Act. If you provide your contact details so that we can inform you of other studies these details will be stored securely and separately from the data that is collected as part of this study.

**What will happen to the results of the research study?**

If requested you can obtain a copy of your own personal results from the measures taken after data collection is completed from the researcher. A summary of the final results of the study will be available either through a short presentation from the researcher at the therapy centre or as information leaflets. The findings will also be written up in the dissertation as part of an MSc Physiotherapy and may be published in a scientific journal.

**What if something goes wrong?**

Should you have any complaints during the study you should direct these to Dr John Barker the Chair of the Clinical Sciences Research Ethics Committee at Brunel University.

Email: [john.barker@brunel.ac.uk](mailto:john.barker@brunel.ac.uk)

**The study has been reviewed and approved by Brunel University Clinical Sciences Research Ethics Committee.**

**Thank you so much for your time.**

**If you want to take part in this study or you have any questions you can contact the researcher assistant/ researchers at:**

Sarah Peacock (Research Assistant) Jennifer Ryan

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