

Information Sheet

The Activity Matters Project.

What is the background to this study and what does it hope to achieve?

The Activity Matters project is a collaboration between MS Ireland and the MS Research team at UL led by Prof Susan Coote. It aims to provide a web based programme for people with MS to access information and strategies to enable them to become more physically active. This project aims to investigate if the website is feasible and if people have changes in physical activity as a result of completing the 12 week programme.

What is the procedure involved?

First read this information leaflet and if you would like to take part we will send you a consent form for you to send back to us by e-mail or by post. We will then send you a link to the website, and your study code which you will use for the remainder of the study.

Having read the first two pages on the website and before you begin exercising, you will first complete a questionnaire about your health and your MS through a website called “survey monkey” that is linked to the Activity matters website. If you meet the safety and eligibility criteria you will be sent a link and invited to create a username and to log onto the Activity Matters website. You will be asked to complete some questionnaires about your MS symptoms and your physical activity and you will also complete questionnaires that measures

the factors associated with activity that we are aiming to change, for example your beliefs about exercise and your ability to set goals and how long you have had MS.

You will then log onto the website once or twice each week for the next 12 weeks to take the activity matters exercise and education programme. The program is designed to provide you with the information and tools required to set and achieve your own exercise goals. For example, rather than being prescribed exercise, you will choose your own exercise activity as part of the programme and complete exercise action plans and goals that you set yourself each week. You can choose to join a closed and private Facebook group (moderated by the researchers) to chat to other participants during the programme if you would like to, and over the course of the program you will receive three phone calls from the researchers to check in on your progress and answer any questions that you may have. If you choose to provide us with your e-mail address and mobile phone number on the consent form, we will contact you intermittently to prompt you to keep going or to provide coaching at certain times in the programme. Once you have completed the programme we will ask you if you would like to give us feedback on the website by completing a short, phone based interview which will be recorded and analysed with those of other participants.

Who is being asked to take part?

People with a definite diagnosis of MS who can walk with or without an aid will be invited to take part in the study. We are hoping to recruit twenty people for this first study.

What are the benefits of taking part in this study?

You will be taking part in an evidence informed and theory based programme and may find benefits of exercising such as reductions in fatigue or improvements in mood or walking.

Are there any risks to me by taking part in this study?

There are no risks greater than taking part in usual exercise or physiotherapy. You may experience muscle soreness and some exercises might challenge your balance. The website will guide you through the safety aspects of exercise and choosing the right exercise and is in line with the recent MS exercise guideline.

What happens to the information?

We will store your name and contact details in a password protected file so that we can contact you during the study to see how you are getting on, only the investigators will have access to these details. You can choose to join a private Activity Matters Facebook group to chat to other people doing the programme, we will need your Facebook name to add you to this group and it will be stored in the same way as your contact details and not shared with anyone.

For the research, you will complete questionnaires on survey monkey and these are automatically anonymous; we will give you a code to put in so we can link your questionnaires before to your responses after the programme. Only the research team will have access to your data for this study. We will never publish individual results and will use averages and other statistics in any papers or conference presentations we do. We may combine your questionnaire results with data from other studies to answer other questions about physical activity and MS in the future.

What happens if I change my mind during the study?

Your participation in the study is voluntary and you can withdraw from the project at any stage without giving any reason. You can chose to take part in the programme but not have your questionnaire data used for research purposes.

What do I do now?

If you would like to take part in this study please contact the research team below. We are happy to answer any other questions you have about the study too.

What if I have more questions or do not understand something?

If you would like more information before you decide, please do not hesitate to contact Prof. Susan Coote using the details below. At **ANY** point in the study, any queries that you may have can be answered by contacting Prof Susan Coote, 061-234278, susan.coote@ul.ie or Cillian McDowell cillian.mcdowell@ul.ie

This research study has received Ethics approval from the Education and Health Sciences Research Ethics Committee (2018_03_28 EHS). If you have any concerns about this study and wish to contact someone independent you may contact:
Chairman Education and Health Sciences Research Ethics Committee
EHS Faculty Office
University of Limerick
Tel (061) 234101

Study Code;

Participant Consent Form

Activity Matters in MS

Please read the following questions and tick the appropriate Yes or No box. Please sign the bottom of the page if you consent to participate in this study

I have read and understand the information sheet	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I agree to complete the questionnaires online and for my data to be analyzed	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I agree to complete the online course but do not want my data to be analysed for the research study	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I understand what the project is about, and what the results will be used for.	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I agree that my GP can be contacted if there are concerns about my suitability to take part in exercise;	YES <input type="checkbox"/>	NO <input type="checkbox"/>
GP Name;		
I agree to notify the Investigator of any side effects arising during the study.	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I understand that I can withdraw from this project at any stage without giving any reason.	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I consent for my data from this study to be used by the team in combination with data from other studies to learn further about physical activity and MS	YES <input type="checkbox"/>	NO <input type="checkbox"/>

Participant email address:
Participant mobile phone number:

.....
Name of Participant (in block letters) Date Signature

.....
Researcher Date Signature