College of Health, Medicine and Life Sciences

Department of Health Sciences

PARTICIPANT INFORMATION SHEET

The Experience of Physical Activity when Living with a Neuromuscular Disease

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. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

Research suggests that physical activity is helpful for people living with a neuromuscular disease. It can help manage symptoms such as muscle weakness and reduces the impact of other health problems. Despite the benefits, people with a neuromuscular disease are less physically active than their counterparts. However, very little is known about peoples experience of physical activity when they have a neuromuscular disease. Understanding this might help us to better support people to particulate in physical activity, in the future. Therefore, this study aims to explore what the meaning of physical activity is for people with neuromuscular disease, what your experience of physical activity has been in the past, and what your beliefs and attitudes towards physical activity are now. The study will take place in July and August 2024 and is being undertaken as part of a Master’s Degree programme.

Why have I been invited to participate?

You have been invited because you are an adult living with a neuromuscular disease. To be included in this study, you must be able to understand and communicate in English and be able to participate in a one-to-one discussion. You must have access to a smartphone or laptop etc. with a camera and be able to attend an online meeting using Microsoft Teams. Up to 8 people will be interviewed as part of this study.

Do I have to take part?

No. It is up to you to decide whether you take part. If you decide to take part, you will be asked to sign a consent form. However, you can still withdraw from the study at any time, without giving a reason. This will not affect any care you receive in the future.
What will happen to me if I take part?

If you decide to volunteer, you will email the address below. We will arrange a telephone call where you will answer some questions to establish if you are eligible to participate. The telephone number you provide for this purpose will be deleted at the conclusion of this study. You will be asked to sign a consent form to confirm that you understand what is involved when taking part in this study. You will be able to electronically access both the information and consent form for future reference. After you have agreed to participate, I will ask you some questions about you, and your condition. I will send an email invite you to join an online meeting, using your smartphone or laptop etc. When you join, I will ask questions about what physical activity means for you, what your experience of physical activity has been in the past, and what your beliefs and attitudes towards physical activity are now. Please remember, you have the right to decline to answer any questions you do not want to, and you can ask to pause or stop the interview at any time. You will be offered breaks as needed. If you are comfortable, I will ask that you keep your camera on for the duration of the meeting, which will be recorded and transcribed. This is so I can listen back, and read back the discussion, to understand your answers and identify themes between your answers and those of the other participants, who I will meet separately. The interview will last approximately 30 minutes.

What are the possible disadvantages and risks of taking part?

You may be asked to talk about your own experience of physical activity which some people can find uncomfortable or frustrating. If you experience this, or other feelings following the interview, please talk to me so that I can signpost you to support services such as your GP, local community services or charitable services. I will also follow up with you by email or telephone call (per your preference) after the interview.

What are the possible benefits of taking part?

There are no direct benefits from taking part in the interview, but the results may help people with neuromuscular disease in the future.

What if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone’s negligence, then you may have grounds for a legal action, but you may have to pay for it.

If you wish to complain about your experience of taking part in this research project, you should contact the Chair of the College Research Ethics Committee, Professor Louise Mansfield (contact details below).
Will my taking part in this study be kept confidential?

After the interview, only I, the researcher conducting this study, and my supervisor, will have access to the discussions you shared. I will keep all personal information about you (e.g. information about you that can identify you) confidential. I will remove any personal information from the written record of your contribution. The video will be deleted. All reasonable steps will be taken to protect the anonymity of all participants.

If you agree to take part in the research study, I will use your anonymised data in the ways needed to conduct and analyse the research study. If necessary, I will also use it to verify and defend the process and outcomes of the research study.

When we do not need to use personal data, it will be deleted, or identifiers will be removed.

The only exception to maintaining confidentiality is where information is disclosed which indicates that there is a serious risk to you or to others.

Will I be recorded, and how will the recording be used?

The video recording of the interview made during this study will be used only for analysis. No other use will be made of them without your written permission. The recordings will be stored securely on the IT system of Brunel University London. Once they have been transcribed, the recordings will be deleted.

What will happen to the results of the research study?

The researcher intends to publish the results in a dissertation, which is being undertaken as part of a Master’s Degree programme. The researcher also intends to share a summary of the results at conferences relating to physiotherapy and neuromuscular disease, and to publish the study in a research journal. If you would like, the researcher will send you a summary of the results for your interest.

Who is organising and funding the research?

The research is being organised by Claire O’Farrell in conjunction with Brunel University London. There is no external funding for this research.
What are the indemnity arrangements?

Brunel University London provides appropriate insurance cover for research which has received ethical approval.

Who has reviewed the study?

The study has been reviewed by the College of Health, Medicine and Life Sciences Research Ethics Committee at Brunel University London.

Research Integrity

Brunel University London is committed to compliance with the Universities UK Research Integrity Concordat. You are entitled to expect the highest level of integrity from the researchers during the course of this research.

For more information or clarity please contact me via the email below.

Researcher name and details: Claire O’Farrell. Email: 2337125@brunel.ac.uk

Supervisor name and details: Dr Alyson Warland. Email: Alyson.warland@brunel.ac.uk

For complaints, Chair of the Research Ethics Committee:
Professor Louise Mansfield, Chair, College of Health, Medicine and Life Sciences Research Ethics Committee: Louise.Mansfield@brunel.ac.uk