

## **Assessing Usability, Acceptance, and Barriers to Passive Movement Exercise in Individuals with GSD 2, 3 and 5.**

We would like to invite you to participate in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

We would like to invite you to take part in the study entitled “Usability, Acceptance, and Barriers to Passive Movement Exercise in Individuals with GSD 2, 3 and 5”

We hope that you will take part in this study to help us to investigate the facilitators (i. e. what makes it easier) and barriers (i.e what makes it more difficult) to exercise with Glycogen Storage Disease. The study will consist of a 30-minute interactive workshop supervised by a trained physiotherapist and medic at one of two convenient locations: Nottingham Trent University or the AGSD-UK Main Event. We will also ask you to complete pre and post workshop questionnaires and an interview about your experience (approx. 30 mins).

### **Brief Introduction:**

Glycogen Storage Diseases (GSD) are rare inherited metabolic disorders that cause muscle weakness, fatigue, and limitations in physical activity. Motor-assisted passive movement devices represent a promising therapeutic exercise alternative, potentially helping maintain physical activity and improve muscle function safely. This part of the study focuses on understanding how usable and acceptable these devices are to individuals living with GSD types 2, 3, and 5. Your input will provide vital information on how these devices might benefit daily life, what challenges might arise in their use, and how best to integrate them into routine care and home environments. Insights gathered from your participation will directly influence future research designs.

### **Purpose of the Study:**

This study aims to evaluate the usability, acceptance, and barriers related to motor-assisted passive movement devices, guided by insights from earlier patient engagement events.

### **Study Requirements:**

**Inclusion criteria:** Adults (18+) diagnosed with Glycogen Storage Disease 2,3, or 5

**Exclusion Criteria:** Individuals who do not have the capacity to consent.

### **What would taking part involve?**

You will participate in a 30-minute interactive workshop supervised by a trained physiotherapist and a medic at one of two locations: the Nottingham Trent University or the AGSD-UK Main Event. The session will include:

- Up to 15 minutes experience using the device and controls.
- Providing feedback through a short interview and questionnaires evaluating your satisfaction, ease of use, and perceived barriers or facilitators.
- A brief follow-up the next day to check for any muscle discomfort or other feedback.

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

The major benefit of participating in this study is the opportunity contribute to shaping meaningful and relevant research for the GSD community that will hopefully lead to a greater understanding of the potential role of passive movement devices. This knowledge may provide an opportunity to increase the quality and delivery of exercise programmes and an opportunity to personalise exercise prescription to increase exercise levels in those with GSD.

To acknowledge and thank participants for their valuable input and engagement in the passive movement device workshop each will receive £75 compensation, and up to £150 toward travel costs.

**Further supporting information:****Do I have to take part and what will happen if I don't want to carry on with the study?**

Participation is entirely voluntary. You may withdraw at any time without explanation. Discussions will remain confidential, and your feedback will be anonymised for analysis and reporting.

**What if I have any concerns?**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (details below).

If you remain unhappy and wish to complain formally, you can do this via the Principal Investigator, Dr. Philip Hennis, who will aid you in this process (details below). In the event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against Nottingham Trent University.

**Who is organising and funding this study?**

The study is sponsored by Nottingham Trent University (NTU).

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

Group results will be reported in the scientific press and at national and international meetings, such that the gains of the research can be built upon. They may be used for additional and /or future research. The research team recognise and respect your entitlement to privacy. Publication or presentation of data arising from this study will not allow identification of you. We will not directly or indirectly compromise your rights to confidentiality and anonymity.

**How will my information be kept confidential?**

At the start of the study you will be provided with a unique identification code/number. The file linking your personal details with the unique code will be stored securely in a separate computer folder, restricted to only necessary members of the research team. People who do not need to know who you are will not be able to see your name or contact details. Your data will have the unique code number instead. This ensures that personal data can no longer be attributed to a specific participant and is in line with the GDPR and the Data Protected Act 2018. Data will be stored in a folder on NTU secure servers, in which only members of the research team will have access.

**Where can you find out more about how your information is used?**

You can find out more about how we use your information

- by asking one of the research team
- by sending an email to NTU Data Protection Officer: [dpo@ntu.ac.uk](mailto:dpo@ntu.ac.uk)

Thank you very much indeed for your help!

**Further information and contact details**

If you have any queries about the study, please contact one of the research team by telephone, email or post: The details are summarised below

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