



Invitation to participate in research

I am a Master's Student studying Clinical Health Research at the University of Birmingham and also a Physiotherapist working at the Queen Elizabeth Hospital Birmingham. For my thesis I will be conducting a research study exploring physical activity and exercise for people living with Pompe disease..... and I would appreciate your help!

Study Title: Barriers and facilitators to Physical Activity and exercise in Late Onset Pompe Disease (LOPD): A qualitative study exploring patient perspectives and experiences

About the study: The purpose of this research study is to explore the perspectives and experiences of people with Pompe Disease when engaging in physical activity and exercise. To do this I am interviewing people with Pompe disease who are happy to talk about their experiences with exercise before and after their diagnosis and any challenges encountered when incorporating physical activity and/or exercise into your lives.

What does the study involve?: The study will involve an interview, which will likely take no longer than an hour. It can be completed over the phone or on-line Zoom video call, whichever is easiest for you.

Who can take part?: You have been invited to take in this research study because you are aged 18years or over, a UK resident and have been diagnosed with Pompe Disease. I am interested in hearing your views and experiences, and keen to hear from all perspectives:

- Whatever your age or physical limitations
- Whether you see yourself as generally physically active or not
- Your experiences with exercise – good or bad / past and present
- If you wish to be more active what are the major barriers or possible solutions
- How important physical activity is to you as part of managing your condition
- How the national pandemic has impacted on physical activity

Consent to participate and Participant Information Leaflet: If you are interested in taking part in this study further information can be found on this URL link <https://bham.onlinesurveys.ac.uk/exercise-and-pompe-disease-1>. Participants will provide electronic consent after reading the Participant Information Leaflet embedded in the survey.

Study Timeline: Recruitment period - February 2022- March 2022.

Ethical Approval: The study has been approved by the University of Birmingham's Science, Technology, Engineering and Mathematics Ethical Review Committee

Plans for publication of results/findings: We plan to present the findings of the study in national and international conferences and to publish them in a reputable peer-reviewed journal.

Contact and Further information:

If you want any further information about this study, please contact Nicola Condon via e-mail NJC645@student.bham.ac.uk

Thank you for your time and interest in this study.