



SCHOOL OF PHARMACY, INSTITUTE OF CLINICAL SCIENCES

School of Pharmacy, Institute of Clinical Sciences, Robert Aitken Institute for Clinical Research, College of Medical and Dental Sciences, Edgbaston, Birmingham, B15 2TT

Participant Information Sheet for the study: Accessibility and Effectiveness of Physical Therapy Interventions in patients with Parkinson's disease (AEPTIP)

Title: *Accessibility and Effectiveness of Physical Therapy Interventions in patients with Parkinson's disease (AEPTIP)*

Principal investigator: Dr Anisa Choudhary

University of Birmingham of Research Committee Ref: ERN_0804-Dec2023

We would like to invite you to be part of this research project. If you choose not to take part, there won't be any disadvantages for you and you will hear no more about it.

Please read the following information carefully before you decide to take part; this will tell you why the research is being done and what you will be asked to do if you take part. Please ask if there is anything that is not clear or if you would like more information. The study is an online questionnaire-based study and will take approximately 30-60 minutes.

You can contact our research team if you require further clarification or further information, using the contact details provided in section 1.10 of this document.

1.1 What is the purpose of the study?

Parkinson's disease is a common condition that affects a person's movement, balance and other functions. People with Parkinson's take medicine to help with their symptoms, but as the disease progresses, they may need higher doses and add-on treatments. Non-medicine treatments such as physical therapy and exercise have been shown to help with motor symptoms, balance and mental health in people with Parkinson's. However, in some areas, it can be hard for people with Parkinson's to access physical therapy and exercise services as they may not be available or may be too expensive. This can create health inequalities, where some people with Parkinson's can get the benefits of physical therapy and exercise, whilst others cannot. The purpose of this study is to explore how the frequency of exercise correlates with symptom progression and thereafter determine the health inequalities that may prevent people with Parkinson's disease from participating in physical therapy and exercise.



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1.2 Do I have to take part?

No. Participating in this research study is entirely voluntary. The decision whether or not to take part is entirely yours. If you are considering participating, you should first read this information sheet. You can contact us if you require any clarification or further explanation. You should take as long as you wish to consider the information in this document and if you wish you should also discuss this with any family, friends.

1.3 What will happen if I take part?

If you are interested in taking part in the study, you will complete a series of questionnaires. The link to the questionnaires will be sent to you via the Parkinson's UK society. You will need access to a computer/I-Pad/phone to fill in the questionnaires. The questionnaires will ask you general questions such as your age, gender, duration of Parkinson's disease, the medications you take AND any other medical conditions you may have. We will also ask which local authority you live in and your postcode as this will enable us to correlate your responses to the socio-economic status of your specific postcode. Thereafter you will be given a set of questionnaires which will look at how much exercise and what kind of exercise you participate in, severity of your Parkinson's motor and non-motor symptoms, presence of gastrointestinal symptoms and psychological symptoms such as anxiety and depression. Lastly, we will enquire about your quality of life through the final questionnaires.

1.4 What are the possible benefits of taking part?

Identifying the potential socio-economic inequalities existing in the management of Parkinson's disease could serve as a basis for advocating for the allocation of public resources, such as physical therapy, to certain regions. Consequently, this could eventually lead to better management of Parkinson's symptoms in areas facing socio-economic challenges.



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1.5 What are the possible disadvantages?

The disadvantages include the time commitment to complete the questionnaires (30-60 minutes).

1.6 What happens if I don't want to continue with the study?

You may withdraw from the study up until the researchers begin data analysis which will occur in September 2024. You will be free to stop completing the questionnaire at any stage and we will retain the answers you have provided us with. However, if you complete the questionnaire or certain stages of the questionnaire but later inform us that you are no longer happy with us storing personal data (as long as analysis has not begun), we will ensure this is disposed of appropriately and not included in our results analysis. Once we have used your address to extract the information we require with regards to the socio-economic status of your local area, we will adequately dispose of your address from our dataset.

1.7 How will my data be protected?

All your data will be stored on an encrypted, password secure safe stick to which only the principal investigator (Dr Anisa Choudhary) will have access. You can also find out more about how we use your information by contacting Dr Anisa Choudhary (a.choudhary.1@bham.ac.uk).

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

The results of this study may be published in a medical journal or be presented at a scientific conference. The data will be anonymous and none of the participants involved in the study will be identified in any report or publication. Should you wish to see the results, or the publication, please ask a member of the research team. A lay summary of the overall results of the study will be available. If you would like a copy, please inform one of the study team.



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1.9 Expenses and payments

The first 900 participants in the study will be reimbursed for their time with a £25 Amazon voucher.

1.10 Further information and contact details

You are encouraged to ask any questions you wish before, during or after you have participated in the study. If you have any questions about the study, please speak to a member of the research team, who will be able to provide you with up to date information about the study procedures involved. If you would like further information about this research, please contact Anisa Choudhary (a.choudhary.1@bham.ac.uk)

1.11 Sources of Support

Please refer to the Parkinson's UK website where you will be able to find information on how Parkinson's UK can support those living with Parkinson's.