TURN-PD: A CO-DESIGNED REHABILITATION PROGRAMME TO IMPROVE TURNING AND REDUCE FALLS IN PARKINSON'S DISEASE

PROJECT 1: DEVELOPING A PHYSIOTHERAPY PROGRAMME TO IMPROVE TURNS AND REDUCE FALLS IN PARKINSON'S

PARTICIPANT INFORMATION SHEET

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you.

**One of our team will go through the information sheet with you and answer any questions you have.
Please talk to others about the study if you wish.**

Please ask us if there is anything that is not clear.

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What is the purpose of the study?

Falls are common in people with Parkinson's disease (PwP), resulting in reduced quality of life, increased hospital admittance, and reduced life expectancy. Falls commonly occur during turning in PD, with falls whilst turning eight times more likely to result in hip fracture. As turning accounts for approximately 40% of steps during daily tasks, the risk of falling whilst turning is high. Turning is a complex mobility task, comprising both motor and cognitive skills and the interaction between the two.

Our current understanding of falls because of turning is poor. Improving our understanding of why turns lead to falls in some people with Parkinson's would improve treatment. Currently, evidence for improving turning with physiotherapy is limited. New rehabilitation programmes need to be designed to improve turning and reduce falls in Parkinson's. To ensure such treatments are appropriate, they need to be designed alongside people with lived experience of Parkinson's and experienced healthcare professionals.

The aim of this research is to collect your professional experiences with turning in Parkinson's. To do this, we will conduct interviews to identify; 1) problems you have seen with turning, and 2) strategies you have found most effective in your practice. This information will help to inform the design of a new physiotherapy programme to improve turning and reduce falls in people with Parkinson's.

This study is part of a larger National Institute for Health Research (NIHR) funded study where we are testing a rehabilitation programme to improve turning and falls in Parkinson's. This is the first step of the larger project, later we will test the new treatment we design together.

Why have I been invited?

You are a healthcare professional with expertise in treating Parkinson's. You have indicated that you are interested in taking part in this study

Do I have to take part?

No, it is entirely up to you whether you choose to take part. If you do decide to participate, you will be asked to sign a consent form, but you will still be free to withdraw from the study at any time without giving a reason. Choosing not to take part or withdrawing from the study will not impact on any care you are currently receiving or that you may receive in the future.

If you wish to withdraw from the research at any time, please contact Dr Rosie Morris by email: rosie.e.morris@northumbria.ac.uk or leave a message on 0191 215 6038.

What will happen to me if I decide to take part?

You have been asked to take part in a one-to-one interview to discuss your experience as a healthcare professional of treating Parkinson’s. You will be asked to attend a meeting (this will be either in-person or online, depending on what works best for you) for a maximum of 1.5 hours. In the interview, you will be asked questions around 1) problems you have seen with turning (types of turning, environments where turning is challenging), and 2) the strategies you have found most effective for improving turns in people with Parkinson’s.

You may then be invited to attend a second meeting, ***which is optional***, to help inform the new physiotherapy programme. In this meeting, information will be shared around current research findings, opinions from other healthcare professionals and people affected by Parkinson’s. We will work together to determine the most important elements of the new physiotherapy programme.

The meetings will be audio-recorded and video-recorded and direct quotes from the conversation may be used for future publications.

What are the possible disadvantages or risks of taking part?

There are no significant risks in taking part in this research.

What are the possible benefits of taking part?

We urgently need new treatments to help reduce falls in people with Parkinson’s. By designing and testing new physiotherapy treatments, we hope to improve the care people with Parkinson’s receive.

How will we use information about you?

We will need to use information from you for this research project. This information will include your name and contact details so that we are able to contact you to organise meetings. We may collect additional data which will help describe the characteristics of the group in future publications (such as age, gender, profession, number of years qualified, number of years treating Parkinson’s). People who do not need to know who you are will not be able to see your name or contact details. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that you will remain anonymous.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

Will my personal information be confidential?

The data you provide will be treated in accordance with the Health Research Authority (HRA). Your name and contact details will be kept confidential and will only be available to the research team.

Where will my information be stored?

Your contact details will be securely stored on a password protected document on a password protected computer that can only be accessed by members of the research team. The video and audio recording of the interview and/or focus group will be stored by the researcher only on a password protected laptop. All quotes from the interview and/or focus group will be anonymised.

How will my data be stored and for how long will it be stored?

The research team will use desktop and portable computers such as a laptop, tablet or phones. The use, security, and storage of these devices and their data will be in line with Northumbria University guidance on data storage and protection. Linked anonymised data will then be transferred to university devices for analysis and storage. Our IT Services have set up a SharePoint site which only the research teams involved in the research can access, which is password protected, with hierarchies of access if appropriate. Study data will be kept fully anonymised for a minimum of 10 years according to good research practice.

What will happen to the results following this study?

The results of this study will be written up in reports which we will aim to publish in recognised scientific journals. We may also present the findings at national and international meetings. In any report or publication, we will not use your name or give any information that could identify you. If you would like copies of any publications, then you can contact the researchers involved to request them.

Participants will be provided with feedback on the results of the study. This will include newsletters and dissemination events around the intervention design and results of our future randomised controlled trial.

Who is the Data Controller?

The University of Northumbria will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

What is the legal basis for using my personal data?

According to data protection legislation, we are required to inform you that the legal basis we are applying to process your personal data is that ‘processing is necessary for the performance of a task carried out in the public interest’.

Who is organising and funding the research?

Members of Dr Rosie Morris’s research team will conduct this work. Northumbria University is the lead site for this study and the project is fully funded by National Institute for Health Research: Award Number 303544.

Who has reviewed the study?

The research project has been approved in Northumbria University's Ethics Committee. It has been reviewed to safeguard your interests and has granted approval to conduct the study.

What are my rights as a participant in this study?

Individual's rights under GDPR as follows: a right of access to a copy of the information comprised in their personal data (to do so individuals should submit a Subject Access Request); a right in certain circumstances to have inaccurate personal data rectified; and a right to object to decisions being taken by automated means. If participants are dissatisfied with the University's processing of personal data, they have the right to complain to the Information Commissioner's Office. For more information see the ICO website (www.ico.org.uk).

Contact for further study specific information:

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