

## **Pain management for people with Parkinson's**

### **Participant Information Sheet**

You are being invited to take part in this research study. Before you decide if you would like to take part, it is important that you read this document so you understand why the study is being carried out and what it will involve.

Reading this document, discussing it with others, or asking any questions you might have will help you decide whether you would like to take part.

#### **What is the Purpose of the Study?**

This research aims to talk to healthcare professionals with experience of working with people with pain and Parkinson's to understand their experiences of pain management. This study aims to explore healthcare professionals understanding of pain, barriers and facilitators to pain management for people with Parkinson's, understand support healthcare professionals need for pain management, and their preferences on learning about pain management.

#### **Why have I been invited?**

You have been invited to take part if you are a healthcare professional who works with people with Parkinson's.

#### **Do I have to take part?**

No. It is up to you whether you would like to take part in the study. I am giving you this information sheet to help you make that decision. If you do decide to take part, remember that you can stop being involved in the study whenever you choose, without telling me why. You are completely free to decide whether to take part, or to take part and then leave the study before completion. You can withdraw your data up to two weeks after the focus groups. After this time has passed, data will be anonymised and integrated with data from other participants. You can withdraw by emailing or telephoning Jenni Naisby.

#### **What will happen if I take part?**

You will be asked to complete pain knowledge and beliefs questionnaires electronically prior to taking part in an online focus group. These questionnaires will help inform questioning for online focus groups but will not be linked back to you.

You will be invited to an online focus group with other healthcare professionals. This focus group will take up to 1.5 hours.

The focus group will be audio recorded and then transcribed by an independent transcriber.

We will collect details including age, gender, healthcare profession, number of years registered as a healthcare professional, number of years experience of working with people with Parkinson's, regional location in the UK and other relevant experience including clinical special interests or relevant qualifications. This will allow us to describe our sample for the research.

### **What are the possible disadvantages of taking part?**

The focus group will take your own time, we expect this to last no longer than 1.5 hours.

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

There is no direct benefit to you taking part in the study. By participating in this study, we hope to understand healthcare professional experiences of supporting management of pain in Parkinson's and barriers and facilitators to this. This work will inform future co-design workshops, to design a pain toolkit for people with Parkinson's and a matched clinician training package.

### **Will my taking part in this study be kept confidential and anonymous?**

Yes. Your name will not be written on any of the data we collect; the written information you provide will have an ID number, not your name. Your name will not be written on the recorded interviews, or on the typed up versions of your discussions from the interview, and your name will not appear in any reports or documents resulting from this study. The consent form you have signed will be stored separately from your other data. The data collected from you in this study will be confidential. The only exception to this confidentiality is if the researcher feels that you or others may be harmed if information is not shared.

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

All electronic data, including the recordings from your interview, typed transcripts and questionnaires will be stored on the University OneDrive, which is password protected. All data will be stored in accordance with **Northumbria University** guidelines and the Data Protection Act (2018).

If you consent, we will store your contact details for one year in order to invite you to co-design activities.

**What categories of personal data will be collected and processed in this study?**

We will collect name, email address, age and gender.

**What is the legal basis for processing personal data?**

Processing is necessary for the performance of a task carried out in the public interest.

**Who are the recipients or categories of recipients of personal data, if any?**

The research team at Northumbria University will have access to personal data.

**What will happen to the results of the study, and could personal data collected be used in future research?**

The general findings will be reported in a scientific journal and presented at a research conference, however the data will be anonymised and you or the data you have provided will not be personally identifiable, unless we have asked for your specific consent for this beforehand. The findings may also be shared with other organisations/institutions that have been involved with the study.

This project will inform a wider programme of research. We would like to use the anonymised results from this study to inform co-design workshops and development of a pain management toolkit. Direct quotes from the interviews may be used alongside the published results or for the toolkit, these will be anonymised and not linked back to you. Anonymised data collected as part of the study may be used to support other research in the future, and may be shared anonymously with other researchers.

We can provide you with a summary of the findings from the study if you email the researcher at the address listed below.

**How do I take part in the study?**

Please email Dr Jenni Naisby using the contact details below and they will email the questionnaires to you. If you would like to participate, we will arrange a time for the focus group.

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

Northumbria University is organising the study. The Medical Research Foundation is funding the development of a pain toolkit and matched clinician training package for people with Parkinson's.

### **Who has reviewed this study?**

The research project, submission reference 9346 has been approved in Northumbria University's Ethics Online system. It has been reviewed to safeguard your interests and have granted approval to conduct the study.

### **What are my rights as a participant in this study?**

A right of access to a copy of the information comprised in your 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 you are dissatisfied with the University's processing of personal data, you have the right to complain to the Information Commissioner's Office. For more information see [the ICO website](#).

### **Contacts for further information**

Researcher email: Jenni Naisby [jenni.naisby@northumbria.ac.uk](mailto:jenni.naisby@northumbria.ac.uk)

For further information about the project: Katherine Baker  
[Katherine.baker@northumbria.ac.uk](mailto:Katherine.baker@northumbria.ac.uk)

Records and Information Officer at Northumbria University: Duncan James  
([dp.officer@northumbria.ac.uk](mailto:dp.officer@northumbria.ac.uk)).

You can find out more about how we use your information at our [GDPR webpage](#), or by contacting a member of the research team.