

PARTICIPANT INFORMATION SHEET

Measuring what matters – in whom it matters – ensuring diversity and equity in Parkinson’s disease research and care

Principal Investigator: Katie Brittain, a professor of Applied Health Research & Ageing at Newcastle University

You are being invited to take part in an interview research study. Before you agree to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this research?

We want to better understand people’s experience of Parkinson’s symptoms and the impact they have on mobility. It is also important that we ensure diversity and equity in the development of digital mobility assessment. So, we would like to hear about your experience of Parkinson’s symptoms and the impact they have on your daily life, and also seek out your views on digital mobility assessment as a way of measuring your mobility and to ask you what you feel is important in the development of these measures.

Why have I been invited?

You have been invited to take part in this study because you have lived experience of Parkinson’s disease and have expressed an interest in this research.

Do I have to take part, or what if I change my mind?

No, you do not have to take part in this study.

If you decide to take part and then change your mind, you can leave the study at any time. You do not need to tell us why you want to leave and if you ask, we will also withdraw all the information you had provided so far.

What will happen to me if I take part?

If you agree to take part, interviews will take place either in your own home or in another private place that suits you, or remotely, using Zoom or Microsoft Teams, or over the telephone. **If you are not sure about using Zoom or Microsoft Teams, the interview can be held over the phone, or a member of the research team can provide you with guidance on how to use this technology.**

In this interview a researcher will ask you questions about your experience of Parkinson’s symptoms and the impact they have on your mobility. We will also ask you about what you want to be measured in digital mobility assessments. You do not

have to tell us about anything that makes you feel uncomfortable if you do not want to. If you prefer, a family member or carer can help you in the interview or answer questions on your behalf.

You will be asked to take part in a single interview. If you are happy to take part, the researcher will then arrange a time, date and format for the interview (in person, by telephone or online) that is convenient for you.

Before undertaking the interview, you will be given an opportunity to ask any questions you may have about the study. You will be asked to declare your consent to participate. If the interview is remote, then we will ask you to complete a consent form which shows that you agree to take part and sign this with a simple e-signature in the form of a typed name. We will also go through the consent form with you and audio-record your verbal consent.

Interviews will be relaxed and last for between 30 – 60 minutes depending on your wishes. You will be given regular opportunities for rest and should inform the researcher if you require any additional breaks or would like to stop at any point.

What are the possible disadvantages or risks of taking part?

We do not see there being any risks to taking part in this interview, many participants enjoy this type of research and are able to talk about what is important to them. However, it is possible that you may will feel tired during the interview, but we will give you as much time to rest as you require.

What are the possible benefits of taking part?

There will be no direct benefit to you for participating in this study. However, you will be making a valuable contribution to the development of a digital assessment of mobility.

What will happen to the results of the research study?

Once we have results, we will aim to publish them in peer reviewed scientific journals.

We will also present the findings at national and international meetings. No participant-identifiable information will be included in any written or oral output from the study.

If you would like us to, at the end of the study we will send you a summary of the findings.

How is the research funded?

The study is funded by The Michael J. Fox Foundation for Parkinson's Research.

Has the study been approved?

The study has been approved by Newcastle University Research Ethics Committee [ref: XXX]. This Committee includes members who are internal to the Faculty. This study was reviewed by members of the Committee, who must provide impartial advice and avoid significant conflicts of interests.

Information and support

If you require more information about Parkinson's disease you can visit the following resources:

<https://www.nhs.uk/conditions/parkinsons-disease/>

<https://www.parkinsons.org.uk/information-and-support/what-parkinsons>

Who should I contact for further information relating to the research?

If you have any questions, please contact the researcher, Katie Brittain, at:

katie.brittain@newcastle.ac.uk