Transforming Parkinson's Care in Africa (TraPCAf)

Participant Information Sheet and Consent Form:

Healthcare professional/policy maker interview

Part 1: Participant Information Sheet

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others, but it is up to you to decide whether to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This research is about a condition called Parkinson's disease. Parkinson's disease affects the brain. It involves symptoms such as shaking, slow movement and stiffness that get worse over time. Parkinson's disease can have a big impact on someone's life. It can also affect the person's family and the people close to them.

This aspect of the study is part of a bigger research study taking place across Africa to understand more about Parkinson's disease. The research, called Transforming Parkinson's Care in Africa (TraPCAf), is funded by the National Institute for Health and Care Research (NIHR) in the UK. We are carrying out interviews so we can speak with healthcare professionals and policymakers who are involved in care for people Parkinson's disease, or in making decisions about care, to better understand your experiences.

Why have I been asked to participate?

You have been approached as you have been identified as being someone who is involved with Parkinson's care, or in decision making around healthcare, and can offer unique insights into the experiences of Parkinson's disease in your area.

What will happen to me if I take part?

You will be invited to take part in an interview with a researcher. The interview can be at a place that is convenient for you, either your home, the local neurology clinic, or even a café. We can also do the interview over the phone or using videoconferencing technology like Zoom. If you choose to do an interview over the phone or via video call, you will need to make sure your confidentiality is ensured, and the researcher will do the same. There will be specific questions asked which will enable to you to best describe your experiences related to Parkinson's disease, for example, how you perceive access to care and treatment. If you don't feel comfortable answering a question, that's fine, we can skip it. The interview will be audio recorded with your consent, so that we can listen to this again and make sure we capture everything you say. There also might be an interpreter present to help translate the interview.

What are the benefits in my taking part?

By participating in this study, you will play an important role in helping us understand the impact of Parkinson's disease on someone's life and family. This study is being conducted in a number of countries in Africa, so it gives us a bigger picture of the impact of this condition worldwide. The information you provide will give us valuable insights that can help people with Parkinson’s disease around the world.

Are there any risks involved?

There are no risks involved with this study. If you don’t feel comfortable answering a question, we can skip it or stop the interview at any time.

What data will be collected?

We will collect data about your experience with Parkinson’s disease, this will be in the form of an audio recorded interview. The researcher may also take notes during the interview to use as reminders or prompts to ask you some questions.

Will my participation be confidential?

Your participation will be confidential, and all data collected about you will be confidential. Your data will be anonymised (this means that we will allocate a code to your information so that no one can identify you). All data will be stored on password protected computers and only members of the clinical and research team will have access to it. The consent form you sign will be locked away in a safe. The recording of the interview will be used to transcribe the interview, and then will be deleted. Data about you will be stored securely for 10 years after the end of the study and then deleted.

Do I have to take part?

Participation in this part of the study is voluntary and you are free to decline to be in this study or change your mind at any point. You do not have to decide now if you want to participate, you can think about it and discuss it with your family. If you have any questions, you can contact the researcher.

If you change your mind about taking part, just let us know. You can withdraw your data and information even after the data has been collected.

What will happen to the results of the research?

The goal of this research is to understand more about Parkinson’s disease in Africa, and to help advocate for better care and rights for people with Parkinson’s disease. All the data we collect will be anonymised, stored and analysed by the researchers. This data, along with the data we collect as part of the wider research study, will be published in academic journals and be fed back to policy makers to advocate for better care and support for people with Parkinson’s disease.

Where can I get more information?

If you want to discuss this study further, please get in touch with the research team:

Contact name:

Phone number:

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains 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.

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Part 2: Consent form

Participant consent

I have been invited to take part in this research study about Parkinson's disease. I have been given and read the information sheet, or the information sheet has been read to me. I have had the opportunity to ask questions about it and any questions have been answered to my satisfaction. I understand my participation is voluntary and I may withdraw (at any time) for any reason without my participation rights being affected. I have consented voluntarily to be a participant in this study and agree for my data to be used for the purpose of this study outlined in the information sheet.

Name of participant:

Signature/Initials:

Thumbprint: ☐

Date:

Please put your initials in the box below if you agree with the following statements:

☐ I consent to the interview being audio recorded for the purposes of transcribing and analysing the data.

For researcher

To the best of my ability, I have provided the information sheet, and accurately read out the information sheet to the potential participant, if necessary. I have ensured that the participant understands the details of the study. I confirm that the participant was given an opportunity to ask questions about the study, and these were answered correctly to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily. A copy of this Participant Information Sheet has been provided to the participant.

Name of researcher:

Signature:

Date:

For interpreter (if present)

I can confirm that the information I have translated today will not be shared with anyone and the participant will not be made identifiable. I have read the information sheet and confirm that the confidentiality of the participant will be ensured at all times.

Name of interpreter:

Signature:

Date: