



## **People's experiences of the use of technology in healthcare for Parkinson's**

My name is Hannah Gotheridge, and I am a PhD student conducting research on Parkinson's and the impact of the pandemic. I would like to invite you to take part in a research project. Before you decide whether to take part, I would like you to understand why the research is being done and what it would involve for you. This document will provide you with this information and should take around 10 minutes to read. Feel free to ask any questions you may have by using the contact information on page 4.

### **What is the study about?**

The purpose of this study is to understand your experience and views on the use of technology and telemedicine in Parkinson's-related healthcare which has been impacted by the COVID-19 pandemic. Examples of this include video consultations and online therapeutic interventions. We know from research that the use of telemedicine is rising in healthcare, but opinions and experiences vary. Thus, we would like to gain a broad perspective from both the people who deliver these services as well as those who access them. We expect the findings to inform the improvement of Parkinson's-related healthcare and direct the policy stances of the Parkinson's UK charity.

### **Why have I been approached?**

You have been approached because the study is interested in the views and experiences of people that have provided healthcare services for people with Parkinson's in the UK using telemedicine or technology. To take part in the study, we ask that you have been providing Parkinson's-related healthcare for at least five years.

### **What does taking part involve?**

You will be asked to take part in a single interview between September 2023 and August 2024. The interview is expected to take around 1 hour but may be between 45-90 minutes depending on your answers.

At the beginning of the interview, we will ask you your age, what gender you identify as, your ethnicity, how long you have provided Parkinson's-related healthcare, and your job title. The interview itself will include questions about your experience of and opinions about the

use of technology and telemedicine in Parkinson's healthcare. You will be asked questions about, for example, positive and negative experiences with the use of technology in healthcare, the development of rapport with service users, and your opinions on the quality of care. However, the specific areas of discussion within these topics will be dependent on what you feel is important. After the interview it may be possible that the researcher has follow-up questions for you about something that was said during the interview. Thus, the researcher may try to contact you at a later date.

If you agree to take part, the interview will be conducted on a date and at a time that is convenient for you. This will be completed either via telephone call or online video call using a platform such as Teams. In-person interviews may take place under certain circumstances. If you do not have access to the required technology, we will attempt to make other arrangements to enable the interview to be carried out. The interviews will be recorded to allow us to type what is said and extracts from this would be used in written reports.

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

Your participation is completely voluntary. If you agree to take part, we will go through a consent form together on the day of the interview. When the interview begins, you do not have to answer any questions you do not wish to and you have the right to stop the interview and withdraw from the study at any time, without giving a reason. You also have the right to withdraw your data from the study once the interview is completed. We ask that you request to withdraw from the study within 2 weeks of participation. If you request to withdraw from the study after more than 2 weeks has passed since your interview was completed, we will make all reasonable attempts to fulfil your request, although it may not be possible. This is due to the data being anonymised after this 2-week period before then being grouped into themes alongside the data of other participants.

### **Will my data be identifiable?**

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be deleted once the interview has been typed into a document, which will be done by a member of the research team.

- The files on the computer containing your contact details, consent and interview transcript will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself will be password protected.
- The typed document of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from your interview responses.
- At the end of the study, we would like to upload your interview transcript and verbal consent to the university storage system Pure, where it will be kept for 10 years with Professor Jane Simpson as data custodian and subsequently deleted.

There are limits to confidentiality: if the researcher thinks that you or someone else is at a significant risk of harm, they may have to break confidentiality and speak to a member of staff about this. If possible, the researcher will tell you if they have to do this.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage:

[www.lancaster.ac.uk/research/data-protection](http://www.lancaster.ac.uk/research/data-protection)

### **What will happen to the data I provide?**

As previously mentioned, we will collect background data such as your age and gender. These data will be included in the publication to provide context to the data that was collected and analysed. Real names will not be included alongside this information although pseudonyms may be included to facilitate understanding of the analysis. Additionally, the interviews will be analysed and grouped into key themes which will be supported by quotations from the interviews. These quotations will be anonymised by removing uniquely identifying information such as names and places. Because of this, we do not believe that the data you provide will be identifiable when the study is published.

### **Will my data be made publicly available?**

Following the completion of the study, we would like to upload your typed interview to the data repository ReShare, an online database that researchers upload their anonymised data for use by other researchers who may find the data collected valuable to their research. It is only accessible by affiliates of universities and therefore anyone who is not affiliated with a university cannot access the data. Furthermore, your data will only be used for non-commercial purposes such as use in other research projects and/or teaching purposes. You will be given the opportunity to opt out of sharing your data on ReShare as part of the consent form. Doing so will not impact your ability to take part in the study.

### **What are the disadvantages to taking part?**

We acknowledge that you may feel some discomfort when talking about, for example, potentially negative experiences in the work environment. We would therefore like you to consider if you are comfortable talking about these topics during the interview before agreeing to take part. If you feel any discomfort during the study, you have the right to withdraw at any time, and we encourage you to inform the researcher and contact the resources provided on page 5. If you take part, we predict the interview will take between 60 and 90 minutes of your time, although this may vary depending on responses in your interview.

### **Are there any benefits to taking part?**

The study was developed in collaboration with Parkinson's UK's and will enable them to better understand experiences of and beliefs about the use of technology in healthcare and subsequently contribute to how they advocate for people with Parkinson's. The research may be used by the organisation to inform and support policy stances, as well as to provide theoretical insights in academic literature.

### **Who is organising the study?**

The study is being carried out by Lancaster University in partnership with Parkinson's UK.

### **Who is funding the research?**

The research is funded by the UK Research and Innovation (UKRI) Economic and Social Research Council (ESRC) as part of the North West Social Science Doctoral Training Partnership (NWSSDTP).

**Who has reviewed the project?**

The study has been approved by Lancaster University's Faculty of Health and Medicine Research Ethics Committee which is responsible for ensuring that ethical considerations and issues are addressed in the conduct of research.

## **Where can I obtain further information about the study if I need it?**

If you have any questions about the study and would like further information, please contact:

**Hannah Gotheridge**      **Email:** [h.gotheridge@lancaster.ac.uk](mailto:h.gotheridge@lancaster.ac.uk)

**Professor Jane Simpson**      **Email:** [j.simpson2@lancaster](mailto:j.simpson2@lancaster)

## **Complaints**

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

### **Professor Mark Limmer**

Head of the Division of Health Research

Faculty of Health and Medicine

Lancaster University

Lancaster, LA1 4YG

**Email:** [m.limmer@lancaster.ac.uk](mailto:m.limmer@lancaster.ac.uk)

If you would prefer to speak to someone outside of the Department of Health Research, please contact:

### **Dr Laura Machin**

Chair of the Faculty of Health and Medicine Research Ethics Committee

Faculty of Health and Medicine (Lancaster Medical School)

Lancaster University

Lancaster, LA1 4YG

**Telephone:** 01524 594 973

**Email:** [l.machin@lancaster.ac.uk](mailto:l.machin@lancaster.ac.uk)

## **Resources in the event of distress**

Should you feel distressed, either as a result of taking part in the study or in the future, the following resources may be of assistance:

**Frontline:** Text 'FRONTLINE' to 85258

**Samaritans helpline:** 116 123

**SANEline:** 0300 304 7000

**AWARE (Belfast) helpline:** 028 9035 7820

**AWARE (Derry/Londonderry) helpline:** 028 9035 7830

**AWARE email:** [info@aware-ni.org](mailto:info@aware-ni.org)

We also encourage you to discuss your experiences with family or friends, or a trusted colleague.

**Thank you for reading this participant information sheet!**