**A longitudinal qualitative study of the effects of COVID-19 on informal carers of individuals with Parkinson’s**

We would like to invite you to take part in a research project. Before you decide whether to take part, we would like you to understand why the research is being done and what it would involve for you. We are happy to go through this information sheet with you and answer any questions you have. We suggest this should take about 10 minutes. Please talk to others about the study if you wish, including the person you provide care for.

**What is the study about?**

The purpose of this study is to gain an in-depth understanding of your experiences of providing care for someone living with Parkinson’s during the COVID-19 pandemic. We would also like to know how your experience and understanding of providing care, treatment path, and the type of support available to you during the COVID-19 pandemic changes over time.

**Why have I been asked to participate?**

We would like to speak to people who currently provide informal (unpaid) care for someone living with Parkinson’s and have done so for several years before the pandemic.

**What does taking part involve?**

We would like you to complete a total of three interviews between August 2021 and October 2022 (approximately six months between each interview). While the UK is coming out of lockdowns and easing social restrictions, there is the possibility future lockdown may occur. Furthermore, other countries will not be easing lockdown restrictions until a later date. Therefore, by understanding how things progress for you as lockdown eases, we can better guide others who will face similar challenges in the future.

During each interview we would like to discuss topics that you feel are important based on your experiences during the COVID-19 pandemic in relation to your providing care and the impact it has had on you. However, the specific areas of discussion within these topics will largely be dependent on what you feel is important.

We will also ask a few personal details from you – such as your age, gender, how long you have provided care for, and if you have any underlying health conditions. We would also like some background on the individual you provide informal care for such as severity of symptoms, how long they have lived with Parkinson’s, treatment path, and the type of support they need from you etc.

If you are unable to take part in all of the interviews then we will use the information we have collected from the interview(s) you have completed so far, providing you are happy for us to do so. We are aware it might be difficult to know for sure that you can do all three interviews so please do not let this put you off taking part, even if you only complete one interview it will be a great help to the research. We are also aware that you may have a busy schedule so we will try to be as flexible as possible depending on your availability.

The interviews will be conducted on a date and at a time that is convenient for you and will be completed either via telephone call or online video call such as Zoom/Teams. The interviews will also be recorded to allow us to transcribe (change the call from verbal to written format) and analyse the interviews at a later point.

**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. Even if you decide to take part, you do not have to answer any questions you do not wish to during the interview and you can stop the interview at any time. You are free to withdraw from the project at any time and without giving a reason. If following the completion of an interview you wish to withdraw from the study you are free to do so, however, if more than a 2-week period since your interview was completed has elapsed it may not be possible to withdraw your data from the study, although all reasonable efforts will be made to do so. We will check that you consent to continue taking part at the start of each interview, even though you have given consent during a previous phone call.

**Will my data be Identifiable?**

The data collected for this study will be stored securely using University-approved secure cloud storage. Your interview data will be encrypted and will be accessed by the research team.

Your data will be transcribed by either a member of the research team by hand or using transcription software providing it offers sufficient accuracy (which will be determined by a member of the research team), or by a university-approved transcriber (who will sign a confidentiality agreement prior to receiving the interview).

Your data will be anonymised and all identifiable data of individuals and organisations external to the research team will be anonymised. Following data analysis, the findings of the study will be presented in written reports, written papers and conference presentations. Quotes from the interviews will be used. You will also be allocated a participant ID number which will be used to collate your data across interviews.

All your personal data will be kept confidential and will be kept separately from your interview responses. There are some limits to confidentiality: if the researcher thinks that you, or someone else, is 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.

Audio recordings will be deleted at the end of the study in 2022. All other data related to the project will be deleted ten years after the study is completed (2032).

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

Following the completion of the study, we would like to upload your interview transcript and all non-identifiable data (information we collect from the interview process that cannot be used to identify you) to the data repository ReShare.

ReShare is an online database that researchers upload their anonymised data for use by other researchers who may find 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.

**Do I have to allow my data to be made publicly available?**

This is entirely optional. You do not have to consent to your data being made publicly available.

**Can I take part in the study if I do not consent to my data to be publicly available?**

You are still welcome to take part in the current study and your participation is still greatly appreciated irrespective of whether you consent to your data being made publicly available or not. If you prefer for your data not to be publicly available, your full transcript will be accessible only to the research team. We will still publish quotes from you, as stated above, but the full transcript will not be publicly shared.

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

The research team does not think that there are disadvantages to taking part, although we accept that sometimes it can be upsetting recounting any difficult experiences. If you take part each telephone call will take 30-45 minutes of your time, although this may vary depending on responses in your interview.

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

The research team cannot promise that the study will help you but the information we gain from your interview will be used to help improve knowledge and understanding of the impact of the COVID-19 outbreak and the ongoing pandemic on the lives and wellbeing of carers of people living with Parkinson’s. We are working with Parkinson’s UK to make sure the information we gain is used to improve support for carers and to consider the implications of any long-term changes arising from the consequences of the COVID-19 pandemic. This study will be used to help inform responses from Parkinson’s UK to provide appropriate support for members, to inform other third sector organisations and health and social care policy-makers and to provide theoretical insights.

**Who is organising the study?**

The study is being carried out by Lancaster University.

**Who is funding the research?**

The research is funded by the UK Research and Innovation (UKRI) body.

**Who has reviewed the project?**

The study is part of a wider ongoing project looking at the experiences and impact of COVID-19 for individuals associated with and individuals living with Parkinson’s disease. It 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 [**FHMREC20168**].

**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:

**Dr Ian Garner** **Email:** [i.garner2@lancaster.ac.uk](mailto:i.garner2@lancaster.ac.uk) **Phone:** 07875 072 675

**Professor Jane Simpson Email:** j.simpson2@lancaster.ac.uk

**Complaints**

If you have a concern about any aspect of this study, or if you wish to gain further information, please contact:

**Dr Ian Garner Email:** [i.garner2@lancaster.ac.uk](mailto:i.garner2@lancaster.ac.uk) **Phone:** 07875 072 675

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

If you would prefer to speak to someone outside of the research team then 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

**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:

* **Your GP**
  + **Or you can find GP practices to register with here:** https://www.nhs.uk/Service-Search/GP/LocationSearch/4
* **Samaritans Telephone:** 116 123; or **Email:** jo@samaritans.org
* **The Parkinson’s UK telephone helpline:** 0808 800 0303
* **The Silver Line Telephone:** 0800 470 80 90; or **visit:** https://www.thesilverline.org.uk/
* **Information and support for people living with Parkinson’s during the COVID-19 outbreak** available at: <https://www.parkinsons.org.uk/news/understanding-coronavirus-and-parkinsons>

**Carers UK** available at: <https://www.carersuk.org/>