

## **Participant Information Sheet**

**Title:** The impact of COVID-19 on lifestyle and dietary habits during and after lockdown in people with neurological conditions, and their perceptions of how these changes have impacted their physical and mental health.

### **Invitation Paragraph**

You are being invited to take part in a survey-based research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

### **What is the purpose of this study?**

The purpose of this study is to understand the impact the COVID-19 lockdowns have had on the lifestyles of people with Parkinson's. People with long term conditions such as those with Parkinson's are likely to be affected both physically and mentally from COVID-19. People with Parkinson's are considered a vulnerable group by Public Health England, however many may not consider themselves at most need of attention. Little to no research has assessed the lifestyle changes and wellbeing of this sub group during and after the pandemic.

The aim of this research is to explore changes in lifestyle and dietary habits during and in the aftermath of COVID-19 in people with Parkinson's. Also, concerns and barriers to living healthy on the transition into a new 'normal' during the recovery from the pandemic will be assessed. We will assess impacts from these lifestyle changes on both physical and mental health, and on symptoms that are specific to people with Parkinson's.

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

You have been invited to participate because you have Parkinson's and are above the age of 18 years old. We will be recruiting 100 people with Parkinson's to participate in this study.

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

It is up to you to decide whether or not to take part in this research study. If you do decide to take part, you will be asked to consent by clicking the consent box below, so that we are able to collect your answers and use your data. If you do not wish to take part, simply do not complete the rest of the questionnaire. You are free to stop the questionnaire at any time. Whether you take part or not, it will have no impact on your treatment or access to the services through which you may have obtained the link for this questionnaire.

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

If you decide to take part you will be asked to consent by confirming below. You will then be asked to complete the questionnaire. It should take approximately 20-30 minutes to complete. All answers are anonymous, and we ask that you do not write your name anywhere. Your answers will then be recorded by our system, and analysed. If you would like to print the questionnaire out and complete it that way, please do so and then email your responses to the research team: [scoe@brookes.ac.uk](mailto:scoe@brookes.ac.uk). If you would like to print the questionnaire and then return it through the post, please contact the research team, and we will make the appropriate arrangements, including postage.

### **What are the possible disadvantages or risks of participation?**

There are very little disadvantages to taking part in this research, and the risk for participants remains very low. We are aware that completing a questionnaire like this might be a bit distressing to some participants. In that case, we do ask that you contact the research team, so that we can offer you the appropriate support, and monitor the wellbeing of our participants. If you would like further support you may contact: <https://www.parkinsons.org.uk/information-and-support/parkinsons-support>. During

the completion of the questionnaire you may decide to stop completely or take required breaks at any time.

**What are the potential benefits of taking part?**

There will be no direct benefits to you for taking part in this study, however the results will help with future research for those with Parkinson's in light of COVID-19.

**Will what I say in the study be kept confidential?**

All of the information you provide will remain completely confidential within the legal limitations of the law. Data will be both encrypted and password protected, it will be stored on the Oxford Brookes University system in electronic form. Data will be shared with the named researchers only. The only people who will have access to your information is the research team, and this will be securely stored at Oxford Brookes University.

**What should I do if I want to take part?**

Complete the consent form on the following page and continue with the survey from there. Alternatively you can ask the research team for a hard copy of the survey.

**What will happen to the results of the research study?**

The results of this study will help us to develop further research to help people with Parkinson's to live better during the aftermath of the pandemic. The results will be presented at conferences and published in peer reviewed journals. Individual results will not be possible due to the anonymous nature of data collection however if you would like to know the group results of this research we can send you a summary.

**Who has reviewed the study?**

The research has been approved by the University research ethics committee, Oxford Brookes University. If you have any concerns about the conduct of the study please contact [ethics@brookes.ac.uk](mailto:ethics@brookes.ac.uk).

**Contact for Further Information**

If you have any questions about this research please contact: Oumaima Akrane at [19129167@brookes.ac.uk](mailto:19129167@brookes.ac.uk)

**Thank you for taking time to read this information and thank you in advance for your participation in our research.**

**Version no. 2\_Parkinson's**