

## **Participant information sheet**

### **Study title:**

Exploring experiences of mouth care in people with Parkinson's

### **Information about the study**

We would like to hear from people living with Parkinson's, or care partners (e.g. family member, spouse, partner) involved in the care of someone with Parkinson's. The purpose of this research is to understand the experiences of people living with Parkinson's of keeping their mouth and teeth healthy.

We would like to know about what people with Parkinson's do on a regular basis to keep their mouth and teeth healthy (e.g. toothbrushing, keeping dentures clean) and what they think about mouth and dental health. We are interested in knowing whether having Parkinson's has affected this, and whether there has been any change over time.

### **Why have I been asked?**

You have been asked because you belong to one of the groups of people that we want to hear from; someone with lived experience of Parkinson's, or caring for somebody diagnosed with Parkinson's.

### **What do I have to do?**

You will be asked to take part in an interview with a researcher which may last between 30 and 90 minutes, and can include any breaks you may wish to take. People with Parkinson's who have a care partner who also wishes to be interviewed, can choose to be interviewed together or separately. The interview will finish when you choose to finish. Different dates and times will be offered to you to participate in the interview.

There are a number of options available to you to take part in this interview. These options include:

- virtually using Google Meet or WhatsApp video
- by telephone
- face to face (limited to the Sheffield region)

If you experience difficulty with your speech, you can instead:

- nominate someone known to you (a proxy) to support you at the interview, or to speak with the researcher on your behalf
- participate by email

The interview will be recorded and stored securely. The recording will be sent to a professional transcription service who will turn what is said in the recording into written text. You will be provided with a copy of this to check whether you feel that the text puts your views across in the way you would like.

At this point, you will have two weeks to request any changes to the text, or withdraw from the study. After this, your responses will be carefully anonymised so your answers will not be able to be identified as yours. If you think you may need longer than two weeks, please let the researcher know at the interview.

### **What will happen to the results?**

All of the anonymised written texts will be analysed by the research team. The analysed data may be written up and published or presented in public to raise awareness about the experiences of people with Parkinson's, and their mouth and dental health. As the data will be anonymised, no one will be able to identify you.

### **What are your commitments if you take part in this project?**

Your main commitment is that your participation in the interview will take up some of your personal time.

If you feel uncomfortable or distressed discussing specific topics during the interview, you don't have to discuss them, and you can ask to stop the recording at any time.

The researcher can provide you with contact or support information from Parkinson's UK, if there is something you feel you need extra advice or support about, following the interview.

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

You should not expect any immediate direct personal benefit. However, the findings from this research will help to design future projects aimed at supporting people with Parkinson's, to achieve good mouth and dental health.

You will also contribute towards increasing the knowledge and understanding of the experiences of people living with Parkinson's. It will help to make sure that any future projects are relevant, acceptable and produce meaningful change.

### **Do I have to take part or what about if I don't want to carry on?**

You can decide for yourself whether to take part. You will be asked for your permission to take part in the project if you decide to do so. This information sheet is yours to keep.

Participation is voluntary and you can withdraw at any point up until your answers become anonymised. After this point, because your answers cannot be identified as yours, so you will not be able to withdraw them from the study.

### **How will I know what the results are?**

When the study has finished, we will send you a summary of the findings, together with details of how you can obtain a full copy of the report. We can also provide you with copies of any publications based on the results of the study.

### **Who is funding the project?**

This project has been awarded funding from the University of Sheffield and from the British Society for Special Care Dentistry.

### **What will happen to the results after the study?**

Other researchers may find the data collected to be useful in answering future research questions. We will ask for your explicit consent for your data to be shared in this way.

The anonymised data and the analysis will be uploaded and stored on ORDA (the secure University of Sheffield's data repository hub for managing and sharing research data) for 10 years after which it will be deleted. The anonymised data will be made available to other researchers on request.

### **Data protection and confidentiality**

All information you provide as part of this project will be securely kept on a password protected computer. Data from the interviews will be kept securely and fully anonymised. Only the research team will retain access to this. Names and other identifying features will not be used in any reports.

Any personal and sensitive data (for example, names, ethnicity, age, gender) will be kept separately from the anonymised information collected from the interviews. Only the research team will retain access to personal or sensitive data.

According to data protection legislation (GDPR), we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)).

Further information can be found in the University's Privacy Notice (<https://www.sheffield.ac.uk/govern/data-protection/privacy/general>).

### **Who has reviewed the study?**

The University of Sheffield Research Ethics Committee reviewed and approved the project's plan.

### **Who can I contact for further information?**

Further information about the project is available from Jessie Tebbutt, School of Clinical Dentistry, University of Sheffield, Sheffield, S10 2TA by email [jessie.tebbutt@sheffield.ac.uk](mailto:jessie.tebbutt@sheffield.ac.uk).

If you have any concerns you wish to discuss, you can contact the project's Designated Safeguarding Contact, Professor Zoe Marshman, School of Clinical Dentistry, University of Sheffield, Sheffield, S10 2TA by email [z.marshman@sheffield.ac.uk](mailto:z.marshman@sheffield.ac.uk).

If you have a concern relating to the Designated Safeguarding Contact, or if you feel a report you have made to has not been handled adequately, you can contact the Head of the Department of Clinical Dentistry, Professor Daniel Lambert by email: [d.w.lambert@sheffield.ac.uk](mailto:d.w.lambert@sheffield.ac.uk) or the University's Research Ethics & Integrity Manager, Lindsay Unwin by email: [l.v.unwin@sheffield.ac.uk](mailto:l.v.unwin@sheffield.ac.uk).

**I already think that I would like to take part. What should I do next?**

If you have read the information sheet and would like to take part in this project, you can complete the [online consent form here](#). Alternatively, you can call 07703179151 to request a paper copy.

