
Participant Information Sheet

Initial requirements for TORUS

[Understanding patient needs and acceptability of technologies to develop digital tools measuring Parkinson's symptoms and activities.]

Invitation paragraph

The TORUS project is developing a platform of sensors that will monitor the health and wellbeing of people living at home. Specifically, TORUS aims to measure symptoms (captured through mobility-related activities of daily living) many times every day autonomously, continuously, and objectively, for people with Parkinson's Disease. This technology will be co-designed with those with direct lived experience of Parkinson's (i.e., patients and carers). The first study includes a 60' interview (online) to identify initial requirements for TORUS system.

What is the purpose of this study?

This study is a 60' interview (online) to define the initial requirements for deploying TORUS, an in-home monitoring system to track the progression of Parkinson's. In this study, you will be presented with the list of movements we are interested to measure, and the sensors we will use to measure them. You will be asked to discuss how you think of these movements as part of your daily activities, and how monitoring these movements might impact your daily life at home. You will be asked to rank which movements and sensor combinations you find most acceptable, and which movements do you find more meaningful to measure. Finally, you will be asked to consider other movements or activities that you would find meaningful to measure; and which of the outcome measures do you find more relevant to assessing quality of life.

Why have I been invited to participate?

You are a person with lived experience of Parkinson's.

Do I have to take part?

Taking part is entirely voluntary. We will describe the study and go through this information sheet with you before you participate and answer any questions you might have. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. If you wish to withdraw at a later date, after taking part in research activities, please note that once the data has been anonymised that data cannot be withdrawn.

What will happen to me if I take part and what will I have to do?

If you choose to take part, you will be asked to participate in a 60' interview via Zoom. Participating in the interview will require you to take and sharing images of your home. The interview will be video/ audio recorded, and any notes or images will be digitally recorded. Photographs may also be taken of workshop activities. Audio files will be transcribed by members of the research team using the Microsoft Teams transcription service.

What will happen if I don't want to carry on with the study?

If you prefer not to continue you can withdraw at any time. However please note that data linked to published papers will be available for research and all other anonymised data will be kept securely within the Newcastle University Information Technology Services and University of Bristol Information Technology services until the completion of the TORUS project.

What are the possible disadvantages and risks involved in taking part in the project?

The main potential risk of taking part in this study is the potential distress caused from discussing upsetting, frustrating, or negative experiences.

What are the possible benefits of taking part?

Participants will be compensated for their time (£25 Love-2-Shop or Amazon voucher per hour of participation). The information collected from this study will help develop a monitoring technology to assess progression of Parkinsons and identify therapies, which could help many people in the future; bringing a potential positive altruistic psychological benefit through research participation.

Will my participation in this project be kept confidential?

What will happen to my data?

Your involvement in the study will remain confidential. Directly-identified personal information (e.g., contact details) will be held securely and separately, and deleted at the completion of the TORUS project (**30.09.2028**). This information will only be available to research staff and national bodies which monitor whether research studies are conducted properly. Your study data will be anonymised every three months (dates provided on the consent form). This means that it will be given an identification number and any identifying information about you will be removed. Therefore, it will not be possible to identify you by name from any aspect of documentation or reporting for this research study. At the end of the study your anonymized data will be stored in a secure University of Bristol online database for 10 years or more and made "Open Data". Specifically, this means that it will be released online so that it is publicly available.

What is open Data?

Open data means that data are made available, free of charge, to anyone interested in the research, or who wishes to conduct their own analysis of the data. We will therefore have no control over how these data are used. However, all data will be anonymised before it is made available and therefore there will be no way to identify you from the research data.

Why open data?

Open access to research findings and access to data is considered best research practice and is a requirement of many funding bodies and journals. As a large proportion of research is publicly funded, the outcomes of the research should be made publicly available. Sharing data helps to maximise the impact of investment through wider use, and encourages new avenues of research.

What will happen to the results of the research project?

The results of the research will be shared with members of the TORUS project (those working on other aspects, i.e., technical aspects) and may be shared on the TORUS project website, at research seminars and conferences, and in journal articles or conference proceedings. Any information that could identify you will be removed, and you will be pseudonymised (given a fake name) in any publications. This will also mean any photos or video clips used in publications will blur your face so that you are effectively unidentifiable.

Who is organising and funding the research?

The research is funded by the Engineering & Physical Sciences Research Council (EPSRC), Grant Ref: EP/X036146/1. The research is being organised and run on their behalf by the TORUS team at the University of Bristol and Newcastle University.

Who has reviewed the study?

The study has been reviewed by the University of Bristol Faculty of Engineering Research Ethics Committee (FREC) and Newcastle University Research Ethics Committee.

Further information and contact details

More information about the project is on our website www.torus.ac.uk. If you require further information please email TORUS-project@bristol.ac.uk