

Participant Information Sheet

Planning Ahead: Understanding what is important to people with Parkinson's.

You are being invited to take part in a 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 the study?

The option to make plans for the future has been identified as something which may be of value for people with Parkinson's. Guidelines for clinicians recommend that people with Parkinson's are offered the opportunity to discuss planning for the future with healthcare professionals who are involved in their care. However, research in other countries has identified varied uptake of the option of future planning for people with Parkinson's. It is not clear that approaches to future planning, which have been developed in other medical specialties, are relevant or appropriate to people with Parkinson's.

There is no current understanding of how people with Parkinson's have engaged with the option of planning for the future in the United Kingdom, or whether this is something that is important to them. This study aims to provide a picture of future planning in people with Parkinson's in the United Kingdom through a national survey. The outcomes of this survey will be used to support a second phase of this study which, through interviews with people, will look more deeply at how we can ensure that future planning is relevant and accessible for people with Parkinson's, if this is something that is important to them.

The survey phase of the study is expected to run for four months, after which data collected will be analysed and used to inform the second study phase.

Who is being invited to participate?

This study is open to adult participants (aged 18 or over) with a diagnosis of Parkinson's Disease who are resident in the United Kingdom. Participation is voluntary, and the study will be promoted by Parkinson's UK research network and the Parkinson's Excellence Network. Results from the study will also be published via these groups.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to provide your consent, and you can download a copy of this form if you wish. You are free to withdraw at any time prior to submitting the final page and without giving a reason.

What will happen to me if I take part?

If you choose to take part in the study, you will be presented with an online questionnaire, which should take no longer than 20 minutes to complete. The questionnaire will contain some questions to gain some basic background information about you, questions to understand what you may know about future planning and how you might have approached or would wish to approach this. There will also be a few questions which explore how you generally like to make decisions about your health. Your responses to the survey will be anonymous which means you will not be able to be identified from the information you provide.

in the survey.

There is an option to express interest in the second phase of this study (if you wish) at the end of the survey, any personal information provided here will be securely stored separately from the other survey data.

What are the possible disadvantages and risks of taking part?

The questions do broadly explore potentially difficult topics (such as making a will, planning for when you might need more support with physical tasks) but also aims to think more broadly about what is important to you and how you would like to be cared for if you were unwell or in hospital. If you are affected by the questions and do not wish to continue you can withdraw at any time up to the point of submission. Advice and support is available from the Parkinson's UK Support Line. Contact details can be found at the end of this information sheet, and within the survey.

What are the possible benefits of taking part?

There are no direct benefits of taking part in this study. However, we hope that you will find the questions address an important topic and that outcomes of this study will help to further develop research on this area and alongside the second stage of the study provide advice to people with Parkinson's and healthcare professionals around approaching planning for the future.

Will what I say in this study be kept confidential?

Yes. All questionnaire data will be anonymised which means you cannot be identified from any answers that you choose to provide. Confidentiality, and privacy will be ensured in the collection, storage, and publication of research material (subject to legal limitations). Research data will be stored in Qualtrics and Google Drive, for which the University has security agreements, or uploaded to a repository in anonymised form so that it can be shared for teaching and research purposes.

Data generated by the study must be retained in accordance with the University's policy on Academic Integrity. Data generated in the course of the research will be kept securely in electronic form for a period of ten years after the completion of this research project.

What if I change my mind?

You can withdraw from the study at any time until the point of submission if you choose not to continue and can do so simply by closing your internet browser. Your data however cannot be withdrawn once it is entered into the Qualtrics platform as it is stored once it is entered. All data is anonymous unless you opt to leave contact details (at the end of the survey) expressing an interest in being included in a second phase of this study.

If you choose to withdraw and have already completed some of the survey the responses, you have entered may be included in the final analysis. Any surveys that are more than 50% complete may be reviewed and considered in the final analysis of the data collected.

What should I do if I want to take part?

If you would like to take part, please use the link to access the survey questions online. If you are reading this within the survey platform already, please ensure you have read all the information before proceeding. Once you are happy to proceed, please read and agree to the consent statement. Your agreement is needed for all statements.

If you would prefer to complete the survey in paper format, please contact the researcher using the details below expressing your interest and a survey will be sent to you via post with a paid envelope for return. A consent form will be included which will need to be returned with your questionnaire.

What will happen to the results of the research study?

Both phases of the study will be written up and submitted as a piece of work to fulfil the requirements of a research degree (MPhil/PhD) at Oxford Brookes University. The findings of this study will be used to create materials for professionals to support and improve future planning conversations for people with Parkinson's.

The results may also be published in an academic journal, presented at a conference, or used for future research or teaching on the topic.

Please note: Publications such as journal articles, books, theses or dissertations are increasingly made available in digital repositories and will typically be freely available online. All findings presented will be completely anonymised which means that you will not be identified.

GDPR and your data

Any personal data collected during this study will be processed in accordance with the 2018 UK General Data Protection Regulations (GDPR). A privacy statement is available should you like to review this, please contact the research team using contact details below to receive a copy.

Who is organising and funding the research?

I am conducting this research as a student at Oxford Brookes University, Oxford Institute of Applied Health Research. As a student, my research is supervised by an academic team. There is no external funding for this project.

Who has reviewed the study?

The research has been reviewed by the University Research Ethics Committee, Oxford Brookes University (UREC registration number: 231752).

Contact for Further Information about the research project:

Rachel Lee (Researcher) 17028653@brookes.ac.uk

Professor Eila Watson (Director of studies) ewatson@brookes.ac.uk

"If you have any concerns about the way in which the study has been conducted, you should contact the Chair of the University Research Ethics Committee on ethics@brookes.ac.uk."

What if the survey has raised questions about my Parkinson's?

Free support and advice is available from the Parkinson's UK support line if the survey has raised any questions or concerns.

Contact via

Telephone: 0808 800 0303 to reach the Parkinson's UK helpline for advice and support.

Open Monday to Friday 9am - 6pm and Saturday 10am - 2pm.

Text relay: 18001 0808 800 0303 Email

hello@parkinsons.org.uk

Thank you.

Thank you for taking time to read the information sheet and consider being part of this study, your voice and experiences are incredibly valuable.

If you wish to obtain a summary of the findings when they have been written up, please email Rachel Lee (17028653@brookes.ac.uk).