Health Services Research Unit
Nuffield Department of Population Health

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The 39-Item Parkinson's Disease Questionnaire (PDQ-39):
A study to explore whether this questionnaire captures and reflects quality of life for people with Parkinson's in 2017 and beyond.

PARTICIPANT INFORMATION SHEET

Ethics Approval Reference: R51535/RE001

Background and aims of the study

Almost 20 years ago, researchers in the Health Services Research Unit (HSRU) at the University of Oxford developed the 39-item Parkinson's Disease Questionnaire (PDQ-39) in order to assess the impact of Parkinson's disease on daily life. We are conducting a small survey to explore and assess the current relevance of the questions in the original PDQ-39. This will help us to determine which questions, if any, may benefit from adjustment.

The study is funded by the Health Services Research Unit (HSRU), Nuffield Department of Population Health, University of Oxford. The members of the research team are Dr David Morley, Mrs Sarah Dummett, Dr Laura Kelly and Professor Crispin Jenkinson.

Why have I been invited to take part?

You have been invited to take part because you are a member of Parkinson's UK. Their Research Support Network and your local branch are helping to promote the project. We are looking for 20 adults with Parkinson's disease who have the cognitive ability to participate without assistance and who live in the UK to complete the PDQ-39 while a researcher is present. After this, participants will discuss whether any changes might be needed.

Do I have to take part?

Participation is voluntary and you do not have to take part. You can ask questions about the study before deciding whether or not to participate. If you do agree to participate, you may withdraw yourself (and your data) from the study at any time, without giving a reason and without penalty, by advising the researchers of this decision.

What will happen in the study?

If you are happy to take part in the study, we will arrange a mutually convenient time and place for a researcher to visit you while you complete the questionnaire. You will be asked to complete the PDQ-39 in the presence of the researcher/interviewer and asked question by question to highlight any issues you have with the wording or terminology used. You will also be asked if there are any areas of your life that are currently affected by Parkinson's which you feel are not currently included in the PDQ-39.

You will be asked to sign a consent form and agree to the discussion being audio recorded. If you wish, a relative or witness may be present. The whole process is likely to take less than an hour. If you wish to stop the interview at any time, you can ask to do so without giving a reason. There will not be any follow-up visits and there will be no reimbursement to participants.

Are there any potential risks in taking part?

No, there are no risks involved. However, if you feel that issues have been brought up that need to be addressed you should contact your GP or healthcare provider at the earliest possible moment, and in the first instance telephone NHS Direct on 111.

Are there any benefits in taking part?

There will be no direct benefit to you from taking part in this research, but the process will help test the continuing acceptability and usability of the PDQ-39. It will also enable us to make an assessment on the relevance of items in the original PDQ-39, and to determine which items, if any, may benefit from adjustment.

What happens to the data provided?

The recording of the interview will provide an accurate record of your discussion about the questionnaire. It will be listened to and transcribed by one of the research team. The audio recording and transcript will be stored in a secure place at the Health Services Research Unit at the University of Oxford. Your responses will be anonymised and personal data will be identified using a number code. Data will be accessed only by members of the research team and will be destroyed after a period of 10 years.

Will the research be published?

The research will be presented at international conferences and published in peer reviewed academic journals. A lay summary will also be made available to all participants and Parkinson’s UK.

Who has reviewed this study?

This study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee (reference number: R51535/RE001).

Who do I contact if I have a concern about the study or I wish to complain?

If you have a concern about any aspect of this study, please speak to the relevant researcher, Dr David Morley (telephone number 01865 289432) who will do his best to answer your query. The researcher should acknowledge your concern within 10 working days and give you an indication of how they intend to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the relevant chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter in a reasonably expeditious manner:

Chair, Medical Sciences Inter-Divisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk;
Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

Contact Details

If you would like to participate or discuss the research with a researcher beforehand (or if you have questions afterwards), please email:

Mrs Sarah Dummett sarah.dummett@dph.ox.ac.uk or Dr David Morley david.morley@dph.ox.ac.uk

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