

Research into the Economic and Social Cost of Parkinson's

Information sheet for participants

You are being invited to take part in a research project. Before you decide whether 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, and discuss it with others if you wish so you can decide whether or not you wish to take part. Thank you for reading this.

Research project title:

Assessing the economic and social cost of Parkinson's on people with the condition, their carers and families.

What is the purpose of this research?

Parkinson's is a progressive, degenerative condition that primarily affects the nervous system. Individuals experience it in different ways throughout its course. The provision of both health and social care services to address the management of Parkinson's comes at great economic and financial cost to the government and to society. The purpose of this project is to assess what that cost might be.

Why is this research needed?

There is a lack of research in estimating total economic cost and burden of Parkinson's in the UK, and a study such as this can assess in detail the expenses of the condition for the individuals and carers, health and social care providers, and to the wider society.

Am I eligible to take part/ why have I been chosen?

Any person with Parkinson's, their carer and family members are eligible to take part. We hope for approximately 1200 people to participate in this study from across the four home countries.

How will this research be carried out?

If you agree to take part, you will be either sent a questionnaire to fill-in or invited to be interviewed by a member of the research team. The interview will last about 1 hour and take place at a time and venue that is convenient to you. Information will be asked on income, living conditions, use of the health and social care system, wellbeing of the households, and indirect costs to the individual and their families over the year as well as likely to occur over the individual's lifespan as a result of the progression of Parkinson's.

Do I have to take part?

It is up to you to decide whether or not to take part. A decision not to take part will not affect you in any way. If you agree to take part you will be offered a signed consent form to keep.

Will my taking part in this project be kept confidential?

All information which is collected from and about you during the course of the research will be kept strictly confidential. The information you give will not be used in any way that could identify you.

What will happen to the results of the research project?

The results of this study will be a report with case studies to Parkinson's UK and published in academic journals. Nobody will be able to identify you in any reports or publications. If you would like a copy of these results please contact the research team.

Who is organising and funding the research?

The Centre for Health and Social Care Research at Sheffield Hallam University are undertaking the research, and it is funded by **Parkinson's UK**.

Who has ethically reviewed the project?

This research project has been reviewed by the Sheffield Hallam University Research Ethics Committee for ethical aspects.

If you have any questions about the about the research, please contact:

Centre for Health and Social Care Research, Sheffield Hallam University

For more information about the research

Email: Parkinsons@shu.ac.uk

Please Contact

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Thank you very much for reading this sheet.