

Appendix A: Information Sheet - Research into experiences of Parkinson's disease in adults of working age

Receiving a diagnosis for any long-term health condition is not easy. It can be even more challenging depending on the nature and severity of the individual's condition and also their personal circumstances. There are a number of other factors that are thought to be important, such as age, involvement in medical decisions, quality of information provided about the condition, and contact with other patients.

In this study we are interested in hearing about your experiences of being a patient with Parkinson's. We would like to know what you would advise other people who have recently been diagnosed with Parkinson's and what you would advise healthcare professionals about how to help other patients. We are also interested in knowing whether you think it is important to be knowledgeable about the illness and/or to be actively involved in any healthcare decisions.

This study involves a survey of eleven open-ended questions which you can complete online. You can save your answers and return to them later, should you wish to. You would need to submit your answers by 30 May 2020 in order for them to be included in the study. You will be able to write as much or as little as you want to for each question, but we encourage you to write as much detail as you can.

The information gathered will be shared between Madeleine Carter, Dr Alison Lee and internal/external marking moderators. Data collected in this study will be stored securely and disposed of by 30th September 2020. The findings of the study will be made available on request at the end of the research project, which will be 30th September 2020. If you are interested in this, please contact Madeleine Carter.

The study is independent, and it is not affiliated with Parkinson's UK or any other charity.

To be eligible to take part in this study, you should:

- Have a medical diagnosis for Parkinson's disease, received after you were 21 years old
- Be between 21 and 65 years old
- Not suffer from any cognitive or physical difficulties that would prevent you from being able to answer questions through an online form; for instance, difficulties using your fingers for typing, or understanding long sentences.

If you wish to take part in the study, have further questions about it, or you are in any doubt about your eligibility to take part in this study, please contact Madeleine Carter (madeleine.carter11@bathspa.ac.uk) or Dr Alison Lee (a.c.lee@bathspa.ac.uk).

If you require any support, please contact Parkinson's UK on 0800 800 0303 or hello@parkinsons.org.uk, or visit their website: <https://www.parkinsons.org.uk/>.

Thank you.