



**QUEEN'S  
UNIVERSITY  
BELFAST**

**Participant Information Sheet**

**Semi-structured interviews**

**Exploring the public perceptions and understanding about Parkinson's disease: An all-Ireland study**

**1. Invitation Paragraph**

You are being invited to take part in a research study exploring the public perceptions and understanding about Parkinson's disease (PD) across the island of Ireland. Please take the time to read the following information carefully before deciding whether you wish to take part. If you have any questions or would like any further information about the study, please do not hesitate to contact me. Thank you for taking the time to read this information.

**2. What is the purpose of the study?**

The aim of this study is to explore public perceptions, awareness and understanding about Parkinson's disease within Ireland and how this impact people with PD and their families.

**3. Why have I been chosen?**

You have been chosen as you are a person living with Parkinson's disease in Northern Ireland.

**4. 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 given this information sheet to keep and you will be asked to sign a written consent form. If you choose to take part, you can change your mind at any time and withdraw from the study without giving a reason.

**5. What will happen to me if I take part?**

If you take part, I (Sophie Crooks) will conduct an interview with you or you and a family member/caregiver. This interview can take place online, telephone or face-to-face, depending on your preference. The interview will take place at a date and time at your convenience. Interviews will last approximately 1 hour.

**6. What are the possible risks or disadvantages of taking part?**

During the interview you may feel some emotional distress from speaking about sensitive topics. If emotional distress occurs, all data collection will stop immediately. Interviews taking place online or via telephone will stop

recording. Interviews taking place face-to-face will be stopped and the interviewer will accompany you to a safe space. In this situation, our emergency contact person will be contacted.

### **7. What are the possible benefits of taking part?**

Understanding the experiences of people with PD in their communities is essential for reducing stigma and improving quality of life for people with PD. It can also help with the development of educational resources that will increase public understanding of the disease, as well supporting those with PD to live better within their communities.

### **8. What if something goes wrong?**

If you have any concerns about any aspects of the study, you can contact the Chief Investigator, Dr Gillian Carter. Should you remain unhappy and wish to make a formal complaint, you can contact the Research Governance Team at Queen's University Belfast (Telephone: 028 9097 2529; Email: [researchgovernance@qub.ac.uk](mailto:researchgovernance@qub.ac.uk)).

### **9. Will my taking part in this study be kept confidential?**

All data collected will be used only for the stated and limited purpose of this study. Data collection will commence only after consent is signed. All data will be retained and potentially included in the analysis of findings. De-identified results will be used in presentations and scholarly publications. All personal information that is obtained for the study (e.g. personal contact information and address) will be held as strictly confidential and will only be accessible to the investigators involved in this study. An exception to this would be if you were to reveal any information that indicated illegal activity or information that suggests a risk to yourself or others. In this case, information will be shared with the relevant authorities. In this situation, you will be notified in advance.

This research will be conducted in compliance with data protection legislation. For more information about how your data is handled, how to access your rights and who to contact if you have any queries or concerns about data protection please visit the Queen's University Belfast website.

<https://www.qub.ac.uk/privacynotice/Research/ListofResearchPrivacyNotices/PrivacyNoticeforResearchParticipants.html>

Research documentation will be stored securely in the Active Data Storage Service Queen's University Belfast for 5 years after the end date of the study. After this time, data will be disposed of securely.

### **10. What will happen to the results of the research?**

It is anticipated that the results of this research will be published in research journals and presented at conferences nationally and/or internationally. A summary of the findings will be made available to the participants as a research finding summary via email.

### **11. Who is organising and funding the research?**

This research is funded by the Northern Ireland Department for the Economy (DfE) Postgraduate Studentship Scheme and is organised by Queen's University Belfast.

### **12. Who has reviewed the study?**

This study has been reviewed by the Faculty of Medicine, Health and Life Sciences Research Ethics Committee at Queen's University Belfast.

### **13. Contact for Further Information**

Contact PhD Student: Sophie Crooks

[scrooks08@qub.ac.uk](mailto:scrooks08@qub.ac.uk)

07763573206 (Work Mobile)

Chief Investigator:

Dr Gillian Carter

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02890 975762

*This research will be conducted in compliance with data protection legislation. For more information about how we look after your information, how to access your rights and who to contact if you have any queries or concerns about data protection please visit the Queen's University Belfast website -*

<https://www.qub.ac.uk/privacynotice/Research/ListofResearchPrivacyNotices/PrivacyNoticeforResearchParticipants.html>

**Thank you for your interest in this study and for taking the time to read through this information sheet.**