



Participant Information - Interviews

Co-designing a digital educational resource to improve medication adherence for people with Parkinson's Disease

Queen's University of Belfast are seeking people from Northern Ireland who are living with or affected by Parkinson's to talk to our PhD researcher about their experiences of managing Parkinson's medications. The results of these interviews will help to inform the content of a digital educational tool aimed at supporting Parkinson's medication adherence. By medication adherence we mean being able to understand and manage Parkinson's medications.

You have been provided this information so that you can decide whether you would like to take part in this research.

What will be involved?

We would like to invite you to an interview to discuss your experiences of taking Parkinson's medication. The interview will be scheduled in a place where you feel comfortable such as at your home, or online via Zoom or MS Teams. The interview will be very relaxed and unrushed. We expect it to take no longer than an hour. The researcher will audio record in-person interviews, or video record online interviews. The recording will be used to type up a transcript of the interview which will be used as part of the research. The researcher may also take some notes during the interview. The interview can be scheduled at a time that suits you best.

Why am I being asked to participate?

You are invited to express your interest to participate if the following apply to you,

- You are over 18
- You live in the Northern Ireland
- You have a diagnosis of Parkinson's Disease, **or** you are a person who supports a family member or friend with their Parkinson's medication
- You are not a member of the expert advisory group

If both the person with Parkinson's and their support person wish to participate then two separate interviews will be scheduled.

Do I have to take part?

Taking part in this study is entirely optional and you can withdraw at any point without having to provide any reason.

Can I have someone with me during the interview?

Yes. If you feel that you need support, you are welcome to have someone with you during the interview. They may help to jog your memory, or may help with finding the right words, for example. It will be important that they do not answer the questions on your behalf though as we really want to hear about your experiences.

Will my answers be kept confidential?

All findings and any publications resulting from this study will use an alias to protect the confidentiality and privacy of participants. Identifying features will be removed to protect the confidentiality of participants. Direct quotes may be used in publications, but they will be anonymised to protect your privacy. Recordings and notes from the interviews will be safely stored within encrypted Queen's University computer systems and will be password protected. The recordings will be destroyed once the anonymised transcripts are completed.

What are the benefits of taking part?

By taking part in this study, you will be helping important research that will inform the design of a digital educational tool which will support people with Parkinson's Disease with their medication management. Your answers will help us to understand what, if any, challenges people face.

Are there any risks to taking part?

The interview will ask about your experiences with Parkinson's medications. It is unlikely that there will be any direct risk to you in taking part in this interview. However, if you find any of the questions distressing you are free to skip the question or stop the interview.

Who will be interviewing me?

Our PhD researcher, Hazel Haworth, is completing a PhD with Queen's University Belfast's school of Nursing and Midwifery. Hazel is a mature student who has many years of experience working in the care sector. She has experience of conducting interviews and research groups involving people living with dementia and is keen to learn more about Parkinson's.

Contact Information

Hazel Haworth, PhD Researcher
Hhaworth01@qub.ac.uk



What will happen to the results of the interviews?

The data collected from interviews will be used as a basis for workshops where we will work with people affected by Parkinson's to develop the content for a digital educational tool that supports with Parkinson's medication adherence. Results from the interviews will be anonymised and will be published within research journals, presented at conferences, and used within the researcher's PhD thesis. If you wish to obtain a copy of the results you can contact Hazel via email.

Can I withdraw from the study?

You can change your mind about being included in the study before, during, or after the interview. If you request this, any notes or recordings taken from your interview will be destroyed. However, once the analysis of the interviews is complete it will no longer be possible to withdraw. As mentioned previously, all published findings will remain anonymous.

Who has reviewed the study?

The Queen's University Faculty of Medicine, Health and Life Sciences Research Ethics Committee has reviewed and approved this study. If you have any concerns about the study, you can contact the Chief Investigator, Dr Patrick Stark (p.stark@qub.ac.uk). Should you remain unhappy and wish to make a formal complaint, you can contact the Research Governance Team at Queen's University Belfast (028 9097 2529; Email: researchgovernance@qub.ac.uk)

Will I be reimbursed for my time and travel?

As this is a PhD project there is unfortunately no budget to allow for payment to those who attend. We will, however, reimburse reasonable travel costs if you are required to attend an interview away from home.

How do I express my interest in taking part?

Please complete the expression of interest form attached to this message and return to Hazel at the above email address. Alternatively, you can express your interest directly to Parkinson's UK by phone or email, and they will pass your information on to Hazel.

Thank you for your interest in taking part in this study.

Hazel Haworth, PhD Researcher, School of Nursing and Midwifery, Queen's University Belfast, Medical Biology Centre, 97 Lisburn Road, Belfast, BT9 7BL

Email: hhaworth01@qub.ac.uk



Expression of Interest Form

Co-designing a digital educational resource to improve medication adherence for people with Parkinson's Disease

I have read the participant information sheet and would like to express my interest in participating in the Queen's University Belfast research interviews	
Name	
Email address and/or phone number	
Whereabouts do you live? (Name of town, city or village)	
What is your association with Parkinson's?	<input type="checkbox"/> I have a diagnosis of Parkinson's <input type="checkbox"/> I support a person with Parkinson's to manage their medications

Appendix III – Participant Information Sheet – Interviews – Version 3 -
16/07/2024

Would you prefer a face-to-face interview or an online interview?	<input type="checkbox"/> Face-to-face <input type="checkbox"/> Online
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If you would prefer to provide this information via phone, please reply to Parkinson's UK who will request Hazel to contact you