

Development of digital intervention for carers of people with Parkinson's disease and cognitive impairment (iSupport-PD)

Participant Information Sheet

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ERGO 79799

You are invited to take part in a research study. To help you decide if you would like to take part, it is important that you understand why the study is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information. You may like to discuss it with others, but it is up to you to decide whether or not to take part.

How do I sign up?

If after reading the information below, you want to sign up/find out more:

Complete an online form to tell us that you are interested in taking part

<https://tinyurl.com/3w9hf3e3>



Dr Joanna Slodkowska-Barabasz

Research Fellow

What is the research about?

This research aims to inform the development of a website to support carers of people with Parkinson's and memory and thinking problems. Carers may provide care or support for a partner, friend, or family member with Parkinson's. This care or support may include emotional or practical support (e.g. driving to appointments, helping with daily activities). Memory and thinking problems experienced by people with Parkinson's may include forgetting things, problems concentrating, or finding it difficult to make decisions. We would like to chat to such carers to learn about their experiences and find out what they would find most helpful from a website to support them.

This study is funded by the NIHR Research for Social Care, which is part of the NHS, and is being run by the University of Southampton.

Who can take part in the research?

We would like to chat to **carers aged 18 years and over who provide support for someone who:**

1. Has a diagnosis of Parkinson's; and
2. You think may have problems with memory or thinking.

You don't need to be living with the person with Parkinson's to take part. The person you provide care or support for does not need to have had an assessment with a health professional for memory or thinking problems.

Do I have to take part?

No, it is up to you whether you take part or not. If you decide to take part, we will ask you to complete a short form that shows you have agreed to take part.

What will I need to do?

If you are interested in taking part, we ask you to let us know by completing an online form. The form will ask you some questions about you and the person you provide care or support for to check that the study is right for you. There is also an option to provide us with some background information about you. It is important that we speak to a wide range of people. To do this, we will try and select people who are different from each other. If you are not eligible to take part, we will contact you within a month to let you know.

If you are selected, a researcher will contact you to arrange a time that suits to have a chat about the website we are developing. We will ask you about your experiences of caring for someone with Parkinson's and memory and thinking problems. You will also be asked to

look at some pages of the website we have created and then let us know what you think about them.

The chat will likely be by video call like Microsoft Teams or Zoom so we can share the website with you as we talk. However, we could arrange to chat by phone if a video call is not possible or face-to-face if you are local to Southampton. The chat will take about an hour. With your permission, this conversation will be recorded and transcribed (written up word-for-word). All details that could identify you will be removed.

We will also ask you if you are happy to be contacted again to be invited to take part in a second interview. If you are selected for the second interview, a researcher will contact you to arrange this. In this interview, you will be asked to look at some more pages of the website we have created and then let us know what you think about them. You may also be asked to provide additional information about your experiences of caring for someone with Parkinson's and memory and thinking problems.

On the online form, we will also ask if you would be happy to be contacted in a year's time to be invited to take part in another study. This study will test the website to see if it helps people like you. We will only contact you if you were not selected for this study.

Are there any benefits in my taking part?

The findings of this study will help researchers understand how to better support carers of people with Parkinson's and memory and thinking problems. You will be given a £10 gift voucher for taking part in the study.

Are there any risks involved?

There are minimal risks to taking part in this study. You may find it upsetting to talk about your experiences. If this happens, you can pause or stop the interview and we can give you details of the Parkinson's UK and Mind charities where you can get advice and support if needed.

What data will be collected?

The researcher will ask about your experiences of caring for a person with Parkinson's and memory and thinking problems. They will also show you some pages from the website we are developing and then ask you to share your thoughts and views about it.

Data about yourself and the person with Parkinson's will also be collected to help us make sure we include a wide range of people in this study. This may include age, gender, and ethnicity. You do not have to give this information if you do not want to.

What happens to the data being collected?

After the chat, recordings made using a recording device will be put on a university password-protected computer and then deleted from the recording device. It will be typed up by a professional transcriber or a member of the research team. They will keep everything they hear private and will type code numbers instead of your name, so no-one can find out who you are. We will delete all recordings as soon as the study team have checked and are happy with the quality of the written transcript.

We will review what you have told us and put it together with what other people tell us. Your personal details that could identify you and code number will be stored separately from the written transcript and recordings. All this information will be stored securely on computers at the University of Southampton and will only be accessible by the research team. We will delete the personal details that match your code number at the end of the study (November 2025) when we have finished our analysis.

You will be asked if you are happy for the transcript of your interview, with all personal details that could identify you removed, to be shared with people outside of the research team for research and education purposes. This part of the research is optional.

Will my participation be confidential?

Your participation and the information we collect about you will be kept strictly confidential and will only be shared with the research team. We follow strict regulations about how health research is carried out. At times, individuals from regulatory authorities may require access to the information we collect about you to check that we are carrying out the study correctly. These people have a duty to keep your information strictly confidential. The only time we would not be able to keep something confidential is if we had serious concerns about your safety or the safety of the person you care for. We would share this information with the most appropriate sources of further support and advice. We would try to get your permission before doing this but would still proceed without it if necessary.

What happens if I change my mind?

You have the right to change your mind and withdraw from the study at any time without giving a reason. If you decide to withdraw, any data you have provided will be deleted if you request this, unless it has already been used anonymously in the analysis or results of the study.

What will happen to the results of the study?

The results of the study will be written up as a report for the National Institute for Health and Care Research and will be published in scientific journals and presented at research

conferences. We may use direct quotes from the chat but **none** of your personal details that could identify you will be used (like your name).

Where can I get more information?

If you have any questions about this study, please contact:

Dr Joanna Slodkowska-Barabasz, Primary Care Research Centre, Faculty of Medicine, University of Southampton, Aldermoor Close, Southampton, SO16 5ST. Email: isupportpd@soton.ac.uk

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researcher (isupportpd@soton.ac.uk) who will do their best to answer your questions. If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk)

Thank you

Thank you for taking the time to read the information sheet and considering taking part in this study

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at

<http://www.southampton.ac.uk/assets/sharepoint/intranet/Is/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 15 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).