Carers / Partners Participant Information Sheet

Dear participants, I am a PhD Researcher at Ulster University Belfast and I am doing a study that is:

"Exploring the use of voice assisted technology as a facilitator of speech maintenance for people with Parkinson's"

Thank you for your interest in taking part. Before you decide, it is important you know why we are carrying out this research, what it involves and how it might help in the future.

Why are we carrying out this study?

People with Parkinson's may experience speech and voice difficulties like quiet speech. This can mean other people don't understand them. People with Parkinson's may also feel like they are shouting when talking at normal volume, which can make these difficulties more noticeable.

Research shows that not all people with Parkinson's can access speech and language therapy and the waiting lists in Northern Ireland are long. The improvements people make during their speech therapy don't always last a long time afterwards. Therefore, we want to make a new speech and language therapy tool to help people with Parkinson's improve their speech and voice, and that might help the changes last better.

Smart speakers like Alexa and Google Home, are starting to be used in healthcare, and speech and language therapy. Smart speakers can give feedback on how loud you are speaking and how clearly you are speaking. Some people with parkinson's have said that smart speakers make them speak 'slowly, loudly and clearly'. There are things that help people with speech difficulties to use smart speakers, but there are also problems. We want to make something to help with speech and voice difficulties using a smart speaker, and we want to solve these problems with you, people with Parkinson's, speech and language therapists, technology experts and people from charities.

<u>Who do we need to participate in the study?</u>

- Adults over 18 years of age

- Who live with /care for someone with Parkinson’s Disease with a speech / voice difficulty
- Have a laptop with a camera that can facilitate videoconferencing software

What role do participants have?

People who want to take part, have to sign a consent form giving their permission to take part. This is called giving your consent.

There are two different workshops, on two different days. Each different workshop will take between 1 hour 30 minutes and 2 hours and will be held online via MS Teams.

You will work with researchers, people with Parkinson’s, other carers, speech and language therapists, people from Parkinson’s charities and technology experts to think about solutions to the problems people with Parkinson’s have when using a smart speaker.

- In workshop A, you will be asked to think, in groups, to solve problems about smart speakers.
- In workshop B, you will select the solutions you like the best. You will tell us which ones are the most important and least important to you.

Risks and Benefits

All information produced in the workshops will be treated confidentially in accordance with GDPR guidelines. This means that researchers will make sure no one will know who you are from reading the information or from any of the direct quotes we use.

There may be people who know you at the workshops. Although we ask people not to, people may tell others who didn’t come to the workshops that you were there, or about what you said. This means that other people might mean you do not stay anonymous.

You are helping with a study that will allow researchers to understand how people with Parkinson’s are using smart speakers and create a new tool smart speaker together. This may help other people with Parkinson’s to speak clearer, louder or to maintain their speech and voice for longer. Although you might feel self-conscious about your speech, or find it hard to understand other people, the workshops will be a supportive place. Other people with Parkinson’s will have similar difficulties to you, with speech and voice problems. It is ok for participants not to have solutions to all of the problems we give to you to solve.

To make sure everyone is kept safe, researchers have a duty of care. This means if anyone shares details about something which puts themselves of others at risk, researchers have to share this information. This may be with other health and social care professionals. If this happens participants may be asked to leave the workshops to chat to the researchers about what they said, and the researchers will make notes.

We don't expect there to be any out-of-pocket cost for you if you participate in this research.

Confidentiality

Data collected during workshops will be written notes, drawings and feedback to the wider group and this will be confidential. Participations will not be identified in the research documents, although the meeting will be recorded. All information that is collected, including personal data will remain confidential, and no one will know who you are by reading the data. Only the researcher and supervisors will have access to personal and gathered data. Electronic data will be stored in an encrypted computer file or in locked storage for hard copies of data. This will be held for 10 years after the completion of research.

Data will be subject to GDPR guidelines and Ulster University's privacy notice. It is held for up to 10 years. This can be found at:

https://www.ulster.ac.uk/__data/assets/pdf_file/0006/286008/Data-Protection-Policy-2023.pdf

Your participation

Taking part in this research is voluntary. This means you do not have to take part. You do not have to have solutions to all the problems.

You can stop taking part in the workshops by asking the researchers, and do not have to explain why. You can do this up until the workshops have finished. Any withdrawal from a workshop is obvious to other participants and may be difficult to do. Once the workshops have finished you cannot ask for your data to be removed, because the workshops have conversations and group work. People who take part are asked not to identify other people who take part or their affiliations outside the group. People who take part should note anonymity to other participants is limited.

Each workshop will last between 1 hour 30 minutes and 2 hours, with around 20 participants. Smaller group work will have around 4 participants per group. Once enough carers have been recruited, anyone else who wants to take part will be added to a waiting list.

What are the next steps?

This research has been approved by Research Ethics Committee at Ulster University and is being conducted as a part of the PhD project.

If you would like to take part, **please complete the consent form and return this via email to the contact details listed below.** If you have any questions about this research, please do not hesitate to contact me. If you wish to make a complaint, please contact Ulster University Research Governance at j.mccarroll@ulster.ac.uk. Although I am a Speech and Language Therapist, I cannot assess or treat anyone during this research. If you need to see and speech therapist, please visit your GP for a referral.

Kind Regards,

Miss Jodie Mills

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If you feel upset distressed, and need to talk to someone use the number below or contact your local GP:

Parkinson’s UK Support Line

0808 800 0303