



PALM PARTICIPANT INFORMATION SHEET

Research title: Parkinson's speech to text training using artificial learning methods

We'd like to invite you to take part in our research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you. Please take time to read this information and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please ask us.

What is the purpose of the study?

The primary aim of the project is to investigate and analyse the common effect that Parkinson's Disease (PD) 'freezing' has on speech and:

- 1) whether a computer can be trained to accurately convert volunteer speech to text through machine learning,
- 2) to what extent a computer could predict further speech to text conversion after deterioration of speech, without the need for additional voice recordings

The research will require recording speech from volunteers, then periodic re-training to determine the extent of changes to the voice. The recordings will take the form of spoken passages, phrases and words.

Why have I been invited?

You have been invited to take part in the research because you have been diagnosed with a PD condition.

We are currently only looking to invite 40-50 people living with PD to take part in the research, since we will also be integrated existing data from people without PD from Open Access pre-trained neural network data sets.

Do I have to take part?

No, you do not have to take part. Involvement in the research is entirely voluntary. You can withdraw at a later stage if you change your mind, without giving a reason.

What will happen to me if I decide to take part?

There are 2 options available for recording your speech –

- a) We will meet with you at a convenient location suitable for voice recording, if you live within a 1.5 hours driving radius of Loughborough.
- b) We will use proprietary Zoom meeting software for voice recording using your existing computer microphone.

Before recording, we will:

- 1) Ask you to warm up your voice with simple vocal exercises.
- 2) Ask you to read through printed paragraphs of text, individual short phrases, such as carrots are orange vegetables, and ask you to tell a story or memory for a few minutes.

This process should take no more than 50-60 minutes.

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The interval for subsequent recording sessions will be discussed at the end of the first session and will be based on your current speech (potentially every 2-4 months depending on changes in your condition). The following sessions will use the same procedure as detailed above, using the same text material.

We are looking to collect recordings from each volunteer from 3-4 sessions over the course of a 12-month period.

What should I consider?

It may be you consider that you are not well enough on the day which has been set for a recording. If you are physically not able to attend because of reduced mobility, but still want to take part, we may be able to change the location of the recording, or re-schedule for another day.

The voice recordings should not be affected by any medication that you are taking, and you should continue to take your medication as prescribed by your GP.

It will not affect the research if you are involved in any other research studies.

Are there any possible disadvantages or risks from taking part?

We do not consider there will be any risks from taking part in the research studies, apart from possible tiredness from speaking for the duration of the recording sessions. If you feel tired during the recording process, then we are happy to pause and resume at a later stage.

What are the possible benefits of taking part?

We hope the findings of the research will lead to further development of the trained neural network which could form an online speech-to-text conversion service for those living with PD. You would benefit from having already trained the neural network with different samples of your voice, which would result in higher accuracy of the speech-to-text conversion process.

Will my General Practitioner/family doctor (GP) need to be informed of my participation?

Your GP does not need to be informed of your participation in the research study.

Will my taking part in the study be kept confidential?

Your involvement in the study will be kept confidential. Any links between recordings will be encrypted and personal information will be stored within a secure database. This will be stored onsite at the Advanced Technology and Innovation Centre at Loughborough University.

This personal information will include your name, address, email, brief information about your current condition and unique ID that will be associated with your individual sound recordings and associated labels detailing the phrases or words.

This information will be stored for the duration of the research study period. Once the study has been completed, the information will be fully anonymised, however the recordings and associated label of the words will be kept within the neural network for training purposes. If you wish to have your data removed, it must be before the end of the research period before the data is anonymised.

Responsible members of Protocol IT staff may be given access to data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

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Will I be reimbursed for taking part?

There is no financial compensation for your time, however we hope that the research will provide further advancement of the understanding of speech changes caused by PD, that will benefit others living with PD and potentially other neurological diseases.

What will happen to the speech samples I give?

Your voice recordings along with associated labels for each phrase / word, will be stored in a secure computer at the Advanced Technology and Innovation Centre at Loughborough University during the research phase. It will also be incorporated into a neural network along with other voice recordings obtained from Open Access datasets.

Personal information stored separately will include your name, address, email address, brief information about your current condition and unique ID that will be associated with individual sound recordings and the label detailing the words or phrases that have been recorded. You may provide feedback on how you feel the research may assist people living with PD and how better understanding of your speech would impact you. This may be anonymised and used within research reports or publications.

What will happen to my data?

We will be using your voice recordings to undertake this study. Protocol IT Ltd, as sponsor, is the data controller. This means that we, Protocol IT Ltd staff, are responsible for looking after your information and using it properly. We will use the minimum personally identifiable information possible.

We will keep identifiable information about you for the duration of the study. We will store the research data and any research documents, such as consent forms, securely at the offices at the Advanced Technology and Innovation Centre at Loughborough for up to 5 years after the end of the research period.

Protocol IT Ltd staff will hold your name, home address, and email address in a separate password encrypted file to contact you about the research study, and make sure that relevant information about the study is available to you if required. This identifiable information about you associated with this study will be stored for 5 years after the research has finished.

Your rights to access, change, or move your personal information may be limited, as we need to manage your information in specific ways for the research to be reliable and accurate.

The voice recordings may continue to be held after the end of the research period, at which point your recordings will be anonymised.

What will happen if I don't want to carry on with the study?

Participation with the research is voluntary, and if you change your mind at a later stage before the end of the research phase, then your voice recordings can be removed from our secure computer and neural network.

To withdraw from the research, simply write a signed letter along with your name and address to our office, stating that you would like to withdraw and for the removal of your speech from the neural network. We will however use the data collected from the accuracy of the speech up to the point of your withdrawal.

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What happens at the end of the study?

Following the end of the research, your voice recording may be anonymised and incorporated within neural network with the potential opportunity for others to learn from the speech recognition.

It will not be identified from any report or publication placed in the public domain. If it will be used in the public domain we will seek to obtain specific consent for this.

We intend to publish our findings from the study in research papers and/or conferences. We will provide a summary of the research, which will be available on our website.

The research is part of a project to understand whether a speech-to-text system can be trained to predict further changes in speech as deterioration occurs, with the possibility of developing an online tool that would be available for those living with PD, to assist with understanding of speech to text conversion.

What if we find something unexpected?

We do not consider that we will reveal any unexpected findings from analysis of the speech as a diagnosis.

What if there is a problem?

if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, you should contact the chief investigator, Paul Gadd at:

A : Advanced Technology and Innovations Centre, 5 Oakwood Drive, Loughborough, LE11 3QF

E : info@protocolit.co.uk

T : 01509 278645

There are no special compensation arrangements.

How have patients and the public been involved in this study?

Volunteers who are living with PD have helped to develop the research topic, along with advice from speech therapists who assist PD patients adapt to the changes in speech as a result of the effects on their voices.

The study has been discussed with the research department at Parkinson's UK, detailing the methods and processes that will be employed. They are happy for individual Parkinson's UK groups to participate. Once the research has obtained full ethical approval or letter of support, then the research project can be promoted throughout the Parkinson's UK network of support groups.

In designing the research, we have taken into account volunteer opinions on the frequency of voice recordings that we will carry out.

Who is organising and funding the study?

Protocol IT Ltd is sponsoring the research, with additional funding provided via the iNet from the European Regional Development Fund (ERDF) towards the procurement of the specialist computer to be used to develop the neural network that will be used for voice training.

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Who has reviewed the study?

We are currently in the early stages of seeking full ethical approval for the research through Loughborough University.

Participation in future research:

If you would like to be involved in future research, then your personal details will be held separately from this study. Your details will be held in a password encrypted file at the company office.

Agreeing to be contacted does not oblige you to take part in future research.

Further information and contact details:

Please contact Paul Gadd at :

A : Advanced Technology and Innovations Centre, 5 Oakwood Drive, Loughborough, LE11 3QF

E : info@protocolit.co.uk

T : 01509 278645

Thank you for considering taking part in this research.