

Participant Information Sheet

Project title: Impaired facial emotion communication in Parkinson's Disease: A qualitative study

Research Lead: Dr Abigail Webb (a.webb6@uos.ac.uk)

Ethical approval code (date approved): RETH24_007

Ethical approval authorised by: University of Suffolk Research Ethics Committee. Should you have any concerns about the ethics of this research, please feel free to contact the Research Ethics Committee (research.ethics@uos.ac.uk).

Hello,

We'd like to invite you to take part in our research project by taking part in ***an online interview about facial expressivity in Parkinson's.***

Before you decide, it is important that you fully understand why the evaluation is being done, and what it will involve for you. Please take the time to fully read this information and discuss it with others if you wish. If there is anything that is not clear, or you have any questions, please contact us (see below, 'Who do I contact for more information?')

Who is conducting the research?

Name	Location	Role (responsibilities)
Abigail Webb	University of Suffolk	Principal Investigator, data controller (project management, correspondence, interviews, analysis)
Hannah Stansfield	East Suffolk and North Essex NHS Foundation Trust (Research and Development)	Co-Investigator, data processor (interviews, analysis)
Aristotelis Mazarot	"	Co-Investigator, data processor (interviews, analysis)
Katherine Fowler	"	Co-Investigator (project consultation)
Sheeba Suresh	"	Project consultation
Edward Holmes	University of Suffolk	Co-Investigator, data processor (analysis)

What is the purpose of the study?

To capture a rich understanding, through the use of qualitative methods, of how changes in facial expressivity (e.g., 'masking', or 'hypomimia') impact those living with Parkinson's **and**

their loved ones. We will use qualitative research methods to (1) interview participants, (2) confirm with participants that researchers' interpretations of interviews are correct, and (3) analysis of the process by which researchers on the project interpret anonymised text transcripts of interviews using 'thematic analysis' methods. We will use this information to create an information support resource for people living with Parkinson's, their loved ones, and clinicians

Why have I been invited?

Because you are a person living with Parkinson's, or a loved one e.g., a friend, neighbour, family member, spouse.

Do I have to take part and how will I benefit from participating?

No, there is no obligation to participate. Your participation is an opportunity to share your experiences and have your voice heard.

What will my participation involve?

We would like to interview everyone separately. This means that if you are taking part with another person, we would prefer this to happen on separate occasions, though this is not essential

Interviews will last for around 60-minutes, which can be spread over several sessions and at any time of day if this is more comfortable for you. Interviews will be audio recorded for transcription purposes.

To thank you for your time, you will be sent a £50 voucher following your interview.

What kind of information will I be asked in the interview?

We will ask you semi-structured questions, so that you have an opportunity to guide the topics of conversation towards those that you feel are most important and/or relevant to you. We may ask questions such as: how does it impact daily life with familiar and unfamiliar people, have you discovered strategies to mitigate it, how could healthcare professionals support you, and has it altered your personal relationships with others?

What happens after the interview?

Once we have completed all interviews, we will compile a summary of our findings and share these with all participants for verification. This is called member-checking; a process that allows us to validate whether our interpretation of your experiences is accurate and true. It also gives you an opportunity to add any additional information or tell us where we may have over- or under-emphasised something important to you.

If you choose to participate in this part of the study, you will be sent a £25 voucher as a thank you.

Where and how will my information be stored, and for how long?

There are three types of information that we will collect:

1. 'About you' data. You will be asked for this information when you complete your online consent form. This includes your first name and email address for contact purposes, which will be permanently deleted within 6-months of your participation. We will also ask for your age (in years), gender and ethnicity, for equality, diversity and inclusion (EDI) reasons. It is a requirement for most journals when findings are published; but it will not be traceable to you as an individual. Storage of this information will be managed by Abigail Webb (University of Suffolk)
2. Raw audio recordings of your interview. Recordings will be text-transcribed and fully anonymised (e.g., names replaced with randomly generated codes) within 5 working days of the interview, at which point raw recordings will be permanently deleted to maximise anonymity. Storage of this information will be managed by Abigail Webb (University of Suffolk)
3. Anonymous text transcripts. Will be stored indefinitely. We aim to publish our findings from interviews in the form of an information support resource and peer-reviewed journal publication. Any information, including direct quotes, included in these reports will **always** be anonymous and untraceable to you. Storage of this information will be managed by Abigail Webb (University of Suffolk) and shared with Co-Investigators from University of Suffolk and ESNEFT (see 'Who is conducting the research?' on Page 1).

All information will be stored via university-owned password-protected cloud-based storage systems, in folders only accessible to project members (see, 'Who is conducting the research?')

Can I withdraw my data?

You can withdraw your data at any time, without explanation (see, 'Who do I contact?'). **Please note** that once transcribed and anonymised, audio recordings will no longer be traceable to you, and we will not be able to withdraw this information. If you'd like to withdraw from the interview, you may close the window at any time without explanation.

What if I do not want to answer a question?

Please only answer questions and/or share information that you feel comfortable and happy sharing.

Who do I contact for more information?

If you have any questions, please do contact Dr Abigail Webb (a.webb6@uos.ac.uk) or Hannah Stansfield (hannah.stansfield@esneft.nhs.uk) in the first instance.