

## **Exploring the impact of face and body movement on communication in people with Parkinson's**

### **Participant Information Sheet (PIS)**

This PIS should be read in conjunction with The University privacy notice

You are being invited to take part in a research study investigating what people with Parkinson's think about facial masking – diminished facial expressivity. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

#### **Who will conduct the research?**

Heather Lane, Dr Karen Lander and Dr Ellen Poliakoff, Division of Psychology, Communication and Human Neuroscience, The University of Manchester.

#### **What is the purpose of the research?**

To understand and explore the impact of face and body movements on communication and social interaction in people with Parkinson's. As you have identified yourself as a person with Parkinson's your thoughts and ideas on this topic are invaluable to this research.

#### **Will the outcomes of the research be published?**

The outcomes of this research will be set out to be published in journals and will form part of a student thesis. An anonymised data set will also be available on an open science data repository/database at the end of this research project. Results will be shared with Parkinson's UK and they may share it on their website. Any potentially identifiable information will be removed.

If you are interested to hear the findings of the research, do join the Body Eyes and Movement (BEAM) lab mailing list. You will also hear about other opportunities to volunteer and research findings.

#### **What would my involvement be?**

##### **What would I be asked to do if I took part?**

You will be asked to complete an online one-to-one interview with a researcher. This will involve questions regarding the impact of your face and body movement on communication, as well as questions exploring the impact on your ability to recognise and describe your own emotions. You will also be asked about other aspects of your social communication. The interviews will be audio-recorded and transcribed.

As the interview is online you can complete this in the comfort of your own home, and it will take up to 1 hour. You can bring someone else along to the interview (to sit with you) if you would like.

You can withdraw your data up to the point of transcription. After transcription our data will be anonymised. There will be an option at the end of the survey where you can leave contact details should you wish to be placed on our mailing list should you wish to be contacted regarding other research in this area.

By taking part in this research, you will be able to share your views on facial masking and possible advances for future research with the hopes of improving communication within Parkinson's.

#### **☐ Will I be compensated for taking part?**

You will be sent a £10 evoucher (there is a choice of places to spend it at) for taking part in the interview.

#### **☐ What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part.

You are free to withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised as we will not be able to identify your specific data. Your data will be anonymised once it has been transcribed. You will have a period of 2 days after the interview when transcription will not occur and hence you will be able to withdraw your interview within these two days if you so wish. This does not affect your data protection rights. If you decide not to take part you do not need to do anything further.

### **Data Protection and Confidentiality**

#### **What information will you collect about me?**

We will not be asking for any personal identifiable information such as name/address/etc.

There will be an option within the survey for you to give your email address should you wish to be contacted about taking part in an optional follow up interview regarding similar topics that will take place online and/or joining the brain, eye and movement lab (at the University of Manchester) mailing list.

In order to undertake the research project, we will need to collect the following personal information/data about you:

- Age, ethnic background and education background
- Information regarding your diagnosis/motor symptoms of your Parkinson's disease and any current medication taken to manage this
- Whether you currently live in the UK

#### **☐ Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

#### **□ What are my rights in relation to the information you will collect about me?**

You have several rights under data protection law regarding your personal information. If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our Privacy Notice for Research.

#### **□ Will my participation in the study be confidential and my personal identifiable information be protected?**

Only the research team at The University of Manchester will have access to the data you provide. If you choose to submit an email address for information to join the Brain, Eye and Movement Lab mailing list then this information will only be used for these purposes and removed from the data set as soon as possible.

Any identifiable information you may provide in the free text space will be anonymised/removed.

Data will be stored on a secure University of Manchester data storage space.

There may be circumstances where we need to disclose information to individuals outside the research team. For example, in the event that there are concerns about your safety or the safety of others we may need to contact the relevant authorities.

Your participation in this research will be audio-recorded in Zoom and your personal data will be processed by Zoom. This may mean that your personal data is transferred to a country outside of the European Economic Area, some of which have not yet been determined by the United Kingdom to have an adequate level of data protection. Appropriate legal mechanisms to ensure these transfers are compliant with the Data Protection Act 2018 and the UK General Data Protection Regulation are in place.

The audio-recordings will be removed from the above third party platform and stored on University of Manchester managed file storage as soon as possible following the completion of data collection. The audio-recordings will be transcribed by a member of the research team. Your personal identifiable information will be removed in the final transcript and the original audio-recording destroyed after transcription.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

#### **What if I have a complaint?**

If you have a complaint that you wish to direct to members of the research team, please contact:

**Dr Karen Lander (karen.lander@manchester.ac.uk)**

**Number: 0161 275 7997**

**If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact**

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: [research.complaints@manchester.ac.uk](mailto:research.complaints@manchester.ac.uk) or by telephoning 0161 275 2674.

If you wish to contact us about your data protection rights, please email [dataprotection@manchester.ac.uk](mailto:dataprotection@manchester.ac.uk) or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the Information Commissioner's Office about complaints relating to your personal identifiable information (Tel 0303 123 1113)

If you have any queries about the study then please contact the researcher: **Karen Lander (karen.lander@manchester.ac.uk)**

**This project has been approved by the University of Manchester's Research Ethics Committee [ERM Reference Number]**

**If you want to participate in the interview then please contact the researcher via email [heather.lane@postgrad.manchester.ac.uk](mailto:heather.lane@postgrad.manchester.ac.uk) to organise a suitable date and time**