

## **Examining control of behaviours in Parkinson's**

### **Participant Information Sheet (PIS) for participants with Parkinson's**

This PIS should be read in conjunction with [The University privacy notice](http://documents.manchester.ac.uk/display.aspx?DocID=37095)  
(<http://documents.manchester.ac.uk/display.aspx?DocID=37095>)

#### **Introduction**

You are being invited to take part in a PhD research study. 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 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. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

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

- Daisy Coggin, School of Health Sciences, University of Manchester
- Dr Jade Pickering, School of Health Sciences, University of Manchester
- Dr Ellen Poliakoff, School of Health Sciences, University of Manchester
- Dr Jennifer McBride, School of Health Sciences, University of Manchester

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

We are interested in how people with Parkinson's behave when faced with different decisions, and how quickly they can respond to different pictures and objects. A small number of people with Parkinson's report that they have problems stopping themselves from engaging in problematic behaviours (e.g. overeating, gambling) or have a tendency to make poor, or risky, choices. We will examine the ways in which people with Parkinson's may be affected by these behaviours.

#### **Why have I been chosen?**

We invite you to take part as a participant with Parkinson's. We will compare people with Parkinson's that report these kind of problems with people with Parkinson's that don't have these problems, as well as healthy people of a similar age.

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

If you agree to take part, we will invite you to participate in up to 2 different testing sessions. Your participation will still be very useful, even if you are only able to attend one session. The sessions will take place at the University of Manchester. During the session, we will ask you to complete some questionnaires (for example, about different aspects of your mood and behaviour) and some short memory and thinking tests. We will also ask you to make judgements about different pictures, shapes, and objects on a computer screen, while we measure your response times, hand movements, or eye movements. At each session, we will measure your Parkinson's symptoms by asking you some questions and assessing your movements (for example opening and closing your

hand as quickly as you can). We will also ask you how long you have had Parkinson's, what medication you are currently taking, and for some basic demographic details.

Each session will last under 3 hours and you will have frequent rest-breaks throughout the session. Any expenses which you or a companion (for example, a friend or carer) incur in attending the testing session will be repaid to you in full on the day.

### **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. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. Simply inform the researcher before, during, or after the session. If you decide to withdraw, your expenses (and those of anyone who accompanies you) will still be reimbursed.

However, it will not be possible to remove your data from the project once it has been anonymised and forms part of the dataset as we will not be able to identify your specific data. This does not affect your data protection rights. Should you lose the capacity to consent at the second visit your data from the first visit will still be retained.

### **Will my data be used for future research?**

When you agree to take part in a research study, information about you may be provided to researchers running other research studies in the BEAM lab at the University of Manchester. The future research should not be incompatible with this research project and will concern Parkinson's. Where your information relates to your health and care it will only be used by organisations and researchers to conduct research in accordance with the [UK Policy Framework for Health and Social Care Research](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/) (<https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/>).

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you regarding any other matter or to affect your care. It will not be used to make decisions about future services available to you.

### **Will I be paid for participating in the research?**

You will not be paid for your participation, but any expenses which you or a companion (for example, a friend or carer) incur in attending the testing session will be repaid to you in full on the day.

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

The study will involve a total of 2 sessions lasting a maximum of 3 hours each. You may choose to attend both sessions on the same day (one in the morning, one in the afternoon), or on different days at a maximum of 2 weeks apart. If you can only attend one session, this will still be very useful to us.

**Where will the research be conducted?**

The research will be conducted in the Zochonis Building, Brunswick Street, University of Manchester, M13 9GB.

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

The results of the study will be presented at academic conferences and published in peer-reviewed academic journals. If you wish, we will tell you the results of the study when it ends.

**What if there is a problem?**

So far as we know, there is negligible risk associated with taking part in the study. You will not be required to change your routine medication in any way, nor will we require you to continue your current course of medication if you wish to discuss changes with your GP, although this may make you ineligible to take part in the second session. However, some of the tests that we use can sometimes indicate the possible presence of undiagnosed dementia, depression, or impulse control disorder(s). Whilst we are not health professionals, and cannot provide you with a diagnosis, we will send a letter to both you and your GP if we believe you may benefit from discussing this further with your GP.

**What will happen to my personal information?**

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

- Name
- Contact details (to be used to arrange visits with you and speak to you about your participation in the study, such as if we would like further information from you). You can also opt in to be contacted about future studies; if you do not consent to this, we will not use your contact details after study completion.
- A brief medical history including details of medication and treatments for your Parkinson's, the duration of your Parkinson's, and any co-occurring health problems you may have
- Demographic details such as gender, date of birth, education level
- GP details

Only the research team will have access to this information. An anonymised dataset may be uploaded to a data repository in the interests of open science and transparency.

We are collecting and storing this personal information in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018 which legislate to protect your personal information. The legal basis upon which we are using your personal information is "public interest task" and "for research purposes" if sensitive information is collected. For more information about the way we process your personal information and comply with data protection law please see our

[Privacy Notice for Research Participants](#)

<http://documents.manchester.ac.uk/display.aspx?DocID=37095>.

The University of Manchester, as Data Controller for this project, takes responsibility for the protection of the personal information that this study is collecting about you. In order to comply

with the legal obligations to protect your personal data the University has safeguards in place such as policies and procedures. All researchers are appropriately trained and your data will be looked after in the following way:

The researchers listed at the end of this information sheet at the University of Manchester will have access to your personal identifiable information, that is data which could identify you, but they will anonymise it within 4 weeks of your visit. However your consent form will be retained for 5 years separately to the study data. All electronic data will be held on secure servers at the University of Manchester, and all paper based data (questionnaires etc) will be held in a locked filing cabinet at the university, accessible only to the researchers.

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you. This is known as a Subject Access Request. If you would like to know more about your different rights, please consult our [privacy notice for research](http://documents.manchester.ac.uk/display.aspx?DocID=37095) (<http://documents.manchester.ac.uk/display.aspx?DocID=37095>) and 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, 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](https://ico.org.uk/concerns) (<https://ico.org.uk/concerns>), Tel 0303 123 1113

### **Will my participation in the study be confidential?**

Your participation in the study will be kept confidential to the study team and those with access to your personal information as listed above. After your visit, your data will be de-identified and only linked back to you via a participant ID known only to the research team and stored separately to your data on a secure server.

There may be circumstances where we need to disclose information to individuals outside the research team:

- In the event that there are concerns about your safety or the safety of others we may need to contact your GP
- In the event of incidental or unexpected findings that could have implications for your health or may need further investigation we may need to inform your GP. We will send a copy of this information to you.
- Individuals from the University, the site where the research is taking place, and regulatory authorities may need to review the study information for auditing and monitoring purposes or in the event of an incident.

If your results are included in a paper published in a medical or scientific journal, or in a presentation given at a conference, you will not be identifiable to anyone else by name or other information.

Confidential data will be destroyed 5 years after the data are published in a scientific journal.

### **Who has reviewed the research project?**

The project has been reviewed by the NHS Research Ethics Committee and received approval from the Health Research Authority.

### **What if I want to make a complaint?**

#### **Minor complaints**

If you have a minor complaint then you need to contact the main research supervisor in the first instance.

**ELLEN POLIAKOFF, [ELLEN.POLIAKOFF@MANCHESTER.AC.UK](mailto:ELLEN.POLIAKOFF@MANCHESTER.AC.UK)**

#### **Formal Complaints**

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

The Research Governance and Integrity Manager, Research Office, Christie Building, 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.

### **What Do I Do Now?**

Please discuss this information with your friends, family, and GP if you wish. If you have any queries about the study or if you are interested in taking part then please contact the researcher(s):

**DAISY COGGIN, [DAISY.COGGIN-2@POSTGRAD.MANCHESTER.AC.UK](mailto:DAISY.COGGIN-2@POSTGRAD.MANCHESTER.AC.UK), 07933 064365**

**ELLEN POLIAKOFF, [ELLEN.POLIAKOFF@MANCHESTER.AC.UK](mailto:ELLEN.POLIAKOFF@MANCHESTER.AC.UK)**

**The project has been reviewed by the NHS Research Ethics Committee and received approval from the Health Research Authority.**

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