

Participant Information Sheet

You are being invited to take part in a research project. Here is some information to help you decide whether or not to take part. Ask us 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 reading this information.

What is the purpose of the study?

The aim of the project is to measure attention and memory in people with PSP or Parkinson's Disease. Previous research, including a pilot study we ran from 2015-2019, suggests that people with PSP have problems with visuospatial attention and short term memory that people PD do not experience. The current study will extend this research by comparing a group people with PSP with a group of people with Parkinson's disease and a group of similarly-aged people who have no neurological disease but on a range of tests that measure these cognitive functions.

Why have I been chosen?

You have been diagnosed with Parkinson's disease

Do I have to take part?

No, it is up to you to decide if you want to take part. If you do, you will be asked to sign a consent form. Even if you sign this form, you will still be free to withdraw at any time. You do not need to give a reason for withdrawing. Withdrawing will not affect your care in any way. If you lose the capacity to give informed consent during the study we will withdraw you from further participation. However, we will retain the data that was collected prior to your withdrawal.

What are the possible disadvantages and risks in taking part?

There is no risk and you can choose where to take part:

- A. You can do the tests in your own home and we will travel to see you
- B. You can do the tests at the Department of Psychology, Durham University

The study has been reviewed and approved by an NHS Research Ethics Committee (reference TBC), the Durham University Dept. of Psychology Ethics Committee and is compliant with British Psychological Society code of Ethics.

What are the possible benefits of taking part?

There are no direct benefits to you for taking part. We hope the research will help us to understand the problems faced by people with illnesses like PSP and Parkinson's Disease. In the long run we hope to make it easier for doctors to make early, reliable diagnoses of PSP.

What will happen to me if I take part?

The first thing we will do is ask for your consent for your contact details and diagnosis to be passed from your NHS care team to the research team at Durham. If you agree you will then be contacted by Dr Cheviet from Durham University. In the study you will be asked to complete some questionnaires and 5 computer based tasks, spread across 2 appointments. In session 1 you will do the questionnaires and 2 of the 5 computer-based tests. In session 2 we will ask you to do the remaining 3 tests.

List of Tests

- **Asking for consent.** We will read you some information about the study and you will be asked to sign a form to say that you have volunteered to take part. This will take about 10 minutes
- **Questionnaires.** We would like you to complete some questionnaires.
 - About You, which tells us about your age, education and how long you have had PSP or Parkinson's Disease. This information helps us make accurate comparisons between the different groups of people in the study
 - The Mini mental state exam, which tests general cognitive function,
 - The PDQ-39 which measures quality of life
 - The NEIVFQ-25 which measures problems with sight and vision
 - The VVIQ which measures visual imagery
 - A questionnaire about whether you have used prism glassesThese questionnaires will take about 20 minutes
- **Testing of eye movements:** This task uses a computer and a mobile eye-tracker.
 - In the first task you will be asked to look a small dot on a computer screen. You will have to follow the dot with your eyes as it jumps around the screen. We will make the jumps bigger and bigger as the test progresses.
 - In the second task you will be asked to read a short paragraph of text. This test will take about 20 minutes
- **The 'Bells' Test:** You will be asked to search a display containing silhouettes of common objects. Your task will be to cross out the bells
- **Attention test 1:** You will be shown some letters on a computer screen. One of the letters will be a "T". Your task will be to find the "T" and decide if it is upside down or right way round. You will press a button to indicate which way round the "T" was. It will take about 20 minutes to do this task
- **Memory test 1:** You will be shown some boxes on a computer screen. The boxes will briefly change colour, one at a time. Your task is to remember the order in which the boxes changed colour then point to the boxes in the order in which they changed colour. The length number of boxes in each sequence

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will increase until you make a mistake on 2 or more tries. This test will take about 20 minutes

- **Emotion Recognition Test:** You will see some faces on a computer screen. You must decide what emotion the face is showing. This test will take about 20 minutes

How long will each session take?

We expect each session to last between 1 and 2 hours

How will we use information about you?

We will need to use information from you for this research project. This information will include your name and contact details. We will use this information to contact you to arrange appointments. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What will happen to the results of the research study?

The results of this research may be published in peer reviewed scientific journals. However, you will not be identified in any report.

What are my choices about how my information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can I find out more about how my information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- via the Durham University Data Protection webpages: <https://www.dur.ac.uk/ig/dp/>
- by asking one of the research team
- by sending an email to alexis.cheviet@durham.ac.uk, or
- by ringing us on 01 91 334 3251.

What if something goes wrong?

We do not anticipate that anything will go wrong. However, please be assured that in case of any accident or mishap full insurance cover is provided by Durham University. If you are not happy with the care or treatment you have received you have the right to complain, have your complaint investigated, and be given a full and prompt reply.

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- If you have concerns about usage of data or compliance with GDPR please contact Ms Jennifer Sewel, who is the Durham University Data Protection Office, at university.secretary@durham.ac.uk

Patient Advice and Liaison Service (PALS)

You can talk to PALS who provide confidential advice and support to patients, families and their carers, and can provide information on the NHS and health related matters.

Telephone: 01642 854807

General information about NHS complaints procedure can be found at:

<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx>

Specific Information for complaints about James Cook University Hospital can be found at: <http://southtees.nhs.uk/patients-visitors/pals/formal-complaints/>

Email: patient.relations@stees.nhs.uk

Telephone: 01642 854500

Who is organizing and funding this research?

The research is organized by Durham University and funded by the Dunhill Medical Trust

Who is conducting this research?

Dr Dr. Alexis Cheviet is part of a team of researchers including Drs Daniel Smith, Alison Lane and Anthony Atkinson from Durham University and Dr Neil Archibald from James Cook University Hospital. If you would like more information, please feel free to contact Dr Alexis Cheviet.

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