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## PARTICIPANT INFORMATION SHEET

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### ***“Neuropsychological investigation of visuoperceptual, visuospatial and literacy skills in posterior cortical atrophy”***

#### ***PCA Sub-study 5: Home-based observations of everyday activities***

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You are being invited to take part in a research study. This is a subsidiary study to the “Neuropsychological investigation of visuoperceptual, visuospatial and literacy skills in posterior cortical atrophy” study in which you have already participated. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. 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.

#### **1. Why have I been asked to participate in this study?**

You are being asked to consider taking part in this subsidiary study about carrying out everyday tasks because you took part in the principal *posterior cortical atrophy* study.

#### **2. Do I have to take part?**

It is up to you to decide whether or not to take part. You are under no obligation, and deciding not to take part or withdrawing will not affect your participation in the main study nor your current or future medical care.

#### **3. What is the purpose of this subsidiary study?**

This sub-study aims to complement our lab-based assessments (psychology tests, questionnaires and brain scan) with more real-world (so-called ‘ecologically valid’) tests of everyday abilities and to understand any factors (e.g. reasonable changes in lighting levels, decors, signs, etc.) which predict the ease, comfort and accuracy with which you carry out these activities.

#### **4. What will be involved if I decide to take part?**

**(i) Sensor data collection:** We would like to measure aspects of your physical activity at home through a combination of wearable and non-wearable sensors. Wearable sensors (for example, the Fitbit® or EmpaticaE4) calculate users’ motion temperature, heart rate and electrodermal activity. We would like you to wear these devices as you go about your daily activities. If they become uncomfortable or

if you feel they seem intrusive or unnecessary (e.g. when bathing) please feel free to remove them. Non-wearable sensors (for example, MobileRF) estimate users' location using radio signal. We would provide you with all sensors and would ask you to keep sensors for up to eight weeks. We may collect information on physical characteristics of the home environment, for example, measuring the dimensions of a room or the levels of lighting. The data collected will not retain any identifiable information and will only be interpretable once transferred to the UCL network for subsequent analysis.

**(ii) Video data collection:** We would like to use video recording to observe you interacting physically with your home environment, including any outdoor spaces belonging to your home if applicable (e.g. garden). Specifically we would like to observe you completing everyday tasks. Examples of such everyday tasks may include using cutlery to eat a meal, navigating through your home, using the stairs, house cleaning, using the TV remote. This data will be collected through a hand-held camcorder and/ or a wearable clip-on camera. We will not collect video data of activities which you feel are intrusive (e.g. dressing/ undressing, toileting). Before any video data is collected, we will ask you to indicate the areas of your home where you would like us to avoid capturing video footage. We will stop recording at any point should you feel uncomfortable.

We will visit you for up to three sessions over the course of one month, during which we will capture your activities across the morning, afternoon and evening. The timings of these slots will be agreed upon to suit you. Our aim will be to capture a total of approximately 16 hours of observational data during our visits. When scheduling the home visit with you, the researcher will ask you to make any planned visitors aware that filming and data recording will be taking place within your home on the particular day(s); visitors should attend your home on the understanding that there is a possibility that they will be included in the recordings. If any children are present at the time of the observation, the researcher will not direct any video or audio recording towards them. However, it is possible that video footage of children present in the home may be captured via wearable body cameras. The researcher will use their discretion to ensure that any sensitive, intrusive and/ or inappropriate video footage is deleted. Observational notes may be taken on interactions you have with anyone else present in the home during the research visit; all information that might reveal their identity will be excluded from these notes.

You will be able to request the deletion of some or all data at any point during the visit, or up to one week after the visit. Our researcher will contact you after one week as a final check that you are happy for the remaining data to be used in our research.

All video data will be uploaded onto an encrypted computer system which will be password protected. Video data will only be watched by research staff for the purposes of coding participants' responses to the environment. Names and personal information will be anonymised when coding this data. You will be given the opportunity in the Consent Form to opt out of this should you not wish to provide video data.

We would also ask for your consent to use select video footage captured during the visit(s) for select future teaching purposes, for example educational presentations. You will be given the opportunity in the Consent Form to opt out of this should you not wish to consent to video footage being used for this purpose.

**(iii) Interview participation:** During our visits we may ask you some interview-style questions relating to your daily activities and home environment. These conversations may be captured in the video footage as outlined above, or via audio recordings. We may also ask you to respond to items from standardised questionnaires, measures or scales. Information gathered will be reviewed by research staff to create anonymised transcripts, which will assist them to analyse data after the research visit. You will be given the opportunity in the Consent Form to opt out of this should you not wish to provide interview data.

**(iv) Photographic information collection:** We would like to take selective photographs of parts of your home which you may have adapted or modified to aid you in your daily activities. We would like to use the photographs to identify stresses and coping mechanisms within home surroundings. Examples of such mechanisms include particular furniture arrangements, and wayfinding lighting attached to stair banisters.

Every effort will be made to anonymise photos as much as possible. You will be able to view and request the deletion of any photographs taken at any point during the visit, or up to one week after the visit. Our researcher will contact you after one week as a final check that you are happy for the photographs to be used in our research.

The photographs would be used for research as well as for select teaching purposes, for example educational presentations. You will be given the opportunity in the Consent Form to opt out of this should you not wish to consent to photograph data.

5. **Are there any risks, disadvantages or benefits of taking part in this sub-study which are different to the main study in which I have already participated?** No.
6. **Does the same information about confidentiality, and the outcomes, funders and reviewers of the research apply to this sub-study as to the principal study?** Yes.
7. **Who should I contact for further information?** Professor Sebastian Crutch during office hours on 020 3448 3113.

Thank you for considering taking part in this study. You will be given a copy of the information sheet and a signed consent form to keep.