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PARTICIPANT INFORMATION SHEET

“Neuropsychological investigation of visuo-perceptual, visuo-spatial and literacy skills in posterior cortical atrophy”

PCA Sub-study 6: “Am I the right way up?” Balance problems in PCA

You are being invited to take part in a research study. This is a subsidiary study to the “Neuropsychological investigation of visuo-perceptual, visuo-spatial 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. Do 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 balance, navigation and motion control because you took part in the main 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?

The aim of this sub-study is to characterize the nature and extent of balance control in PCA and typical AD. We wish to understand what types of balance difficulties people experience, how often, and what causes the balance problems.

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

You will be asked to complete two types of tasks:

- In the first type you will be seated in front of a screen and asked to keep an image of a straight line oriented directly upwards using a hand-operated dial whilst we show you various other visual cues and distractions on the screen.

- In the second type you will be asked to stay standing upright. For all the standing tasks we will measure any movements your body makes to keep you upright. In some of the standing tasks we will manipulate what you are seeing by standing you in front of a screen with moving dots, or by asking you to wear special glasses that temporarily obscure your vision.

As part of this study we might ask you to consider participating in some additional tasks. These would include:

- The standing test outlined above during which we will deliver subtle electrical stimulation (Galvanic Vestibular Stimulation) to the area behind the ear to make your inner ear's sense organs think that your head is moving. The procedure involves placing a carbon rubber electrode (approximately 2x4cm) behind each ear. The electrodes will have a small amount of electrode gel on their surface and they will be attached to the skin using surgical tape. A small (<1mA) electric current will be passed between the electrodes, resulting in the perception you are rotating.
- A brief set of standardised sensory tests that would complement the background psychometry, clinical assessments and MRI scan acquired in the principal PCA study. One of these is an assessment of vibration sensitivity which involves applying a probe to the surface of the front and back of your lower leg. As we vary the speed at which the probe vibrates we will ask you to indicate when you can sense the vibrations. The other is an assessment of sensitivity to light pressure where we would gently press a filament against the bottom surface of your foot and ask you to respond to the sensations of the pressure.

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?

Whilst there are risks involved with every procedure we do put in place measures to minimise these as much as possible. In the tasks of this sub-study you may be at risk of:

- *Falling:* To prevent this you will be supervised at all times by one of our researcher staff. You will also wear a harness to keep you upright in the event that you may lose your balance and to exclude any risk of falling over.
- *Fatigue:* A chair will always be readily available, you may sit down (with refreshments) at any time.
- *Nausea:* Some participants who are susceptible to motion sickness may experience a sense of nausea when looking at the moving dots on the screen. Should you experience this we would stop the task immediately and you will be under no obligation to continue the task.
- *Minor discomfort:* Galvanic vestibular stimulation can produce a mild prickling sensation at the site of the electrodes as well as a weak sensation of vertigo, temporary feelings of instability or sensations of dizziness. There is a minor risk of skin burns at the electrode site or an allergic reaction to the conductive gel or electrodes. These effects are rare and if you experience any of these you can stop the test at any time. You will be given the opportunity in the Consent Form to opt out of this test should you not wish to receive the vestibular stimulation.

6. Are there any reasons that might prevent me from participating in this study?

You will not be able to participate in tasks involving GVS if you:

- Have a fitted cardiac pacemaker
 - Are (or think you might be) pregnant. Whilst there is no evidence to suggest that GVS would pose a risk to the health or well-being of either mother or baby, hormone levels associated with pregnancy could alter the balance response and confound results.
 - Have previously had (or are currently receiving) deep brain stimulation
 - Have a diagnosis or past history of epilepsy. Whilst GVS is not known to cause or exacerbate seizures, we will not include individuals with a past or current diagnosis of epilepsy.
- 7. 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.**
- 8. 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.