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PARTICIPANT INFORMATION SHEET

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

PCA Sub-study 4: Evaluation of current standard vision and other non-invasive clinical assessments in participants with PCA

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. 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 current standard vision testing and other non-invasive clinical assessments 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?

The purpose of this sub-study is to better understand the best methods for testing visual impairment in posterior cortical atrophy. We aim to produce guidance to help healthcare professionals better assess both eyesight and brainsight in individuals with and without dementia, and to produce training packages designed for specific professional audiences (such as members of the College of Optometrists).

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

We will ask individuals with a diagnosis of posterior cortical atrophy to be assessed by different clinical professionals, eg. an optometrist, an ophthalmologist and a neurologist. Each assessment will last approximately 20 minutes and be followed by a 10 minute debrief to gather feedback. You will be asked about your experience of the tests (e.g. were the tests clearly explained?) and also about previous experiences of consultations eg. with eye health and vision professionals. The testing sessions and debrief interviews will be video recorded. The total additional testing session will last approximately two hours.

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.