 **

**Seeing What They See:**

#### Compensating for Cortical Visual Dysfunction in Dementia

**Participant Information Sheet**

***What is the purpose of the study?***

It is important to explore the perspectives and opinions of professionals that provide care and intervention to people with dementia-related visual loss, and to ascertain what training and or support may be required by differing professional groups to facilitate assessment and management of people with this problem. This study is one of three studies that all form part of a research project exploring visual impairment in dementia. The research project has been funded by the Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR) and was announced (along with other research studies exploring different aspects of dementia) at the G8 summit on Dementia in the UK in November 2013. The project is being carried out by an interdisciplinary and international research team led by Professor Sebastian Crutch, Dementia Research Centre, University College London.

The overall study not only aims to deliver interventions that can compensate for dementia-related visual impairment, but also to investigate health related quality of life of people with this impairment and their carers.

***Why have I been invited to participate?***

You have been invited to participate in this study because you have a t least one year’s experience working within your profession or role and ideally come into contact with people with dementia as part of your daily practice. We value your experience and insights about how to support people with dementia and related visual impairment.

***Do I have to take part?***

Participation in this study is voluntary. You may decide to participate and then withdraw your agreement at any time during the course of the study. Your manager will not be informed if you decide not to participate, or decide to withdraw from the study. The research team will still use your contributions made in the focus groups up to the point that you decide to withdraw from the research project.

***What will happen to me if I take part?***

If you agree to participate, you will be asked to take part in a one – one and half hour focus group with your colleagues to discuss dementia care and related visual impairments at your place of work. The discussion will focus on your daily practice and therefore no preparation is required. The purpose of the focus group discussion is to discuss the ‘collective’ response to dementia care rather than an assessment or inspection of individual practice.

The focus group will be held on-site at your place of employment at an agreed date and time. Refreshments will be served in thanks for your interest and participation.

***What do I have to do?***

If you are interested in participating please contact the researchers (contact information below). We are happy to answer any questions in advance of you agreeing to take part. Once we have confirmed interest we will contact your manager to confirm the date and time of the focus group. At the time the focus group is held we will obtain written consent from you and also ask you to complete a short form where you can provide us with some anonymous information about yourself.

***What are the possible disadvantages and risks of taking part?***

The disadvantages or risks associated with taking part are minimal. You may feel that this is a disruption to your daily work routine, but we aim to minimise this by holding the focus group at a convenient day and time. We also aim to keep the focus group to no more than 90 minutes in length.

Your participation is also confidential, but you will need to feel comfortable sharing your practice and/or opinions with your colleagues. The focus group discussion will also be audio-recorded for purposes of data analysis. Any personal information will be deleted from the final transcript of the focus group and all names, if any, will appear as pseudonyms.

You are free to withdraw your participation at any time without consequence.

***What if something goes wrong?***

We do not anticipate that something will go wrong. We will agree conduct at the outset of the group with all participants (e.g. confidential nature of discussion, minimising interruptions). If you need to leave the focus group at any time that is up to you. If you disclose practice that may be deemed unprofessional or unethical we may need to report this to your line manager. In this event we would first speak with you privately, and then inform your line manager. We will keep you informed at all times.

***Will my taking part in this study be kept confidential?***

We aim to keep your participation confidential. Personal information, such as your name and contact details, will remain confidential to the research team and removed from any information so that you cannot be recognised. We will destroy all notes and recordings at the end of the project. It is likely that the results of this study will be disseminated at professional conferences and/or journals and direct quotes from participants may be used. Pseudonyms will be used so that no participant is identifiable.

***What will happen to the results of the research study?***

The results of the study will primarily be used to inform the development of dementia care interventions for people with dementia and their carers. We also intend on developing training materials for family/friend carers and health and social care staff working with people with dementia.

***Who is organising and funding the research?***

This study is funded by the ESRC and NIHR. The study is being organised and carried out by University College London with Brunel University, London School of Hygiene and Tropical Medicine, University of Toronto and Moorefield’s Eye Hospital.

***What are the indemnity arrangements?***

This portion of the study is being sponsored by Brunel University. Brunel University is providing indemnity for compensation in the event of personal injury or death arising out of participation in the research.

***Who has reviewed the study?***

This study has received ethical approval from NHS Health Research Authority and from the Research Ethics Committee of the Department of Clinical Sciences, Brunel University, London.

***Contact for further information:***

If you want to know more about this study please contact: Dr. Anne McIntyre ([anne.mcintyre@brunel.ac.uk](mailto:anne.mcintyre@brunel.ac.uk)) or Dr. Mary Pat Sullivan ([mary.sullivan@brunel.ac.uk](mailto:mary.sullivan@brunel.ac.uk)).

For ethical issues or if you wish to complain about any aspect of this study please contact Dr. John Barker ([john.barker@brunel.ac.uk](mailto:john.barker@brunel.ac.uk)), Chair of the Department of Clinical Sciences Research Ethics Committee.

For questions pertaining to the full study on dementia-related visual impairment, please contact Professor Sebastian Crutch ([s.crutch@ucl.ac.uk](mailto:s.crutch@ucl.ac.uk)).