Information Sheet (Version No. 1, date 14/11/17)

THE NEUROLOGICAL VISION LOSS PANEL

You are being invited to join a database of potential research participants held by a team of vision researchers at Cardiff University. Before you decide, it is important that you take time to understand what being a participant will involve and why our research is taking place.

Purpose of the database

The database allows us to identify potential research participants for studies of neurological vision loss. Although vision loss is our main research area, our studies may also include measures of memory, perception and attention. The database will also support the investigation of brain structure and function resulting from vision loss. The database also seeks to recruit healthy, normally-sighted individuals to act as scientific comparisons (controls) with those who have vision loss.

What will happen to me if I join the database?

The decision to join the database is explicitly yours. If you decide you wish to be included in the database you will be asked to fill in a short personal information sheet either through a web-based form, via telephone, or in person, using a paper form. Agreeing to join the database does not mean that you agree to participate in any particular research study – it simply means that you agree to being approached about forthcoming studies. Importantly, you are free to withdraw from the database at any time by emailing the database administrator (NVLpanel@cardiff.ac.uk).

What types of studies will I be approached about if I join the database?

The personal information sheet allows you to indicate what types of experiments you would like to be approached about. These include behavioural experiments and neuroimaging investigations (see below for more information).

Once you have joined the database, researchers may approach you about experiments for which you might be suitable (e.g., a glaucoma study if you have glaucoma). If you join the database as a normally-sighted control participant, you may be approached to take part in a range of studies (if you are eligible). You will be given detailed information about the experiment, including what you would be required to do if you choose to take part. You are free to withdraw from any individual experiments or to change your details on the database at any time.

What is a behavioural experiment?

Behavioural experiments typically involve pressing buttons in response to images or patterns shown on a screen. These may be simple memory tests, such as remembering faces or scenes, or you may be asked to discriminate between different objects. We may also use remote (camera-based) eye tracking systems to measure how your eyes respond to certain situations. As for all studies, you would be provided with more detailed information about a particular experiment in order to allow you to decide whether to take part or not.

What is neuroimaging?

Some studies may use neuroimaging to understand how the brain supports different types of cognitive processes (e.g., memory, language and attention). The techniques we will use to address these questions are structural imaging and fMRI (functional magnetic resonance imaging).

In structural imaging, we use a brain scanner to obtain detailed images of the brain (similar to a black and white photograph). Different types of structural imaging can be carried out which differ in the time required to obtain the images (e.g., 15 minutes to an hour). These allow us to investigate how parts of the brain are linked anatomically. In another type of imaging, fMRI, we use a magnetic field to measure blood flow to different parts of the brain whilst you are performing simple tasks. By acquiring a series of images we can build up a picture of how the brain supports behaviour. These scan do not involve any medications, injections or x-rays, and fMRI is generally considered a safe, non-invasive technique for understanding the workings of the human brain.

Certain people cannot have a structural or fMRI scan, including people who have implants containing metal such as cardiac pacemakers, metal pins, screws or plates. The MRI machine can also induce claustrophobia in a small number of participants as the central ‘tunnel’ of the scanner is small. If you were interested in participating in neuroimaging, the researchers will ask you some questions to ensure you have no metal in your body.

How often will I be seen?

How often you will be asked to participate in studies will depend both on the type of studies we run and your suitability for them. In the any circumstance that you feel the level of contact from the database is too high, please email the database administer and the level of contact can be tailored to your request. Of course, you can ask to be permanently removed from the database at any time.

What are the possible benefits of taking part?

Taking part in these studies will make an important contribution to our understanding of the relationship between vision, the brain and subsequent behaviour, and how these relationships can be affected by brain damage. Many discoveries about how the brain works have been derived from studying individuals with neurological vision loss. Likewise, it is difficult to generalise findings from our research to the wider population without the use of matched control participants.

Will my information be kept confidential?

Yes. All information collected about you for inclusion in the database will be kept confidential. It will only be accessible by those you have been approved to have access to your data. Researchers may only obtain this data if they have ethical approval from the School of Psychology Ethics Committee. All data is encrypted and stored securely at Cardiff University.

Further information

If you would like further information about the Neurological Vision Loss panel or the techniques we use, please contact us at; NVLpanel@cardiff.ac.uk.