At the Dementia Research Centre we have a number of research projects for which you may be eligible but which do not involve a trial of a new medication. These ‘non-drug’ studies are vitally important to allow us to learn more about how dementia diseases cause symptoms and how these can best be measured.

Our non-drug studies involve several different kinds of assessment. These often include questionnaires; detailed psychology tests looking at memory, but also often language and other cognitive functions; MRI scanning of the brain; and sometimes other tests such as measurement of eye movements, pupil reactions and muscle activity, or donation of blood, urine or spinal fluid. In addition to memory we are particularly trying to understand other kinds of complex brain functions that can be affected in dementia; these include aspects of perception, feeling, spatial navigation, emotion and social awareness. The studies have been designed to help us address these aspects.

As a participant in a research study we may ask you to spend up to two consecutive days at the Dementia Research Centre (Queen Square), but it is completely up to you how much time you would like to contribute to your visit. During that time, you might participate in various research activities and may see several different researchers on a prearranged schedule, with plenty of time for breaks. The Dementia Research Centre would pay for, or book your travel (and travel for the person accompanying you) and reimburse you for the cost of meals and refreshments during the visit. If you are attending the Dementia Research Centre for two consecutive days we can also make arrangements for you and the person accompanying you to stay in a nearby hotel if this would be more convenient for you; the costs of the hotel stay would be met by the Dementia Research Centre. Unlike clinic appointments there is flexibility about the timing of research visits, and if we cannot finish a particular assessment on the day we may ask if you would be happy to arrange a later date to visit you at home to complete this.

We also run a number of drug studies, if you are interested in finding more out about these, please email drctrialenquiries@ucl.ac.uk.

If you would like more information about taking part in any of our studies please contact drcresearch@ucl.ac.uk. The DRC also actively supports Join Dementia Research (www.joindementiaresearch.nihr.ac.uk) which matches registrants to appropriate studies throughout the UK.
Ongoing Studies at the Dementia Research Centre

It is important to remember that there is no obligation to participate in any of the studies outlined within this booklet. If you are interested in a study but would like to opt out of certain procedures, please feel free to get in touch with drcresearch@ucl.ac.uk and they will let you know whether it is still possible to take part.

**C-PLACID**

The C-PLACID (‘Computational PLatform for the Assessment of Cognition In Dementia’) project aims to improve cognitive assessments using new technology (e.g. eye-tracking, voice-recording and virtual reality).

Recruiting people with **behavioural variant and linguistic forms of frontotemporal dementia, typical Alzheimer’s disease, posterior cortical atrophy** and **healthy volunteers**.

**What does C-PLACID involve?**
- A day long annual visit for three years to the DRC
- Neuropsychological tasks
- Tracking eye-movements and audio/video recording responses
- Interacting with characters within a simulated scene who will ‘chat’ to you
- Filling out questionnaires

**Longitudinal Study of PCA**

This study aims to improve characterisation and diagnosis of **posterior cortical atrophy (PCA)** and to investigate behavioural interventions/strategies to ameliorate symptoms.

Recruiting people with **posterior cortical atrophy** and **typical Alzheimer’s disease**.

**What does the Longitudinal Study of PCA Involve?**
- A 1 or 2 day annual visit to the DRC (can be a home visit if more appropriate)
- Neuropsychological tasks
- An MRI scan
- A neurological assessment
- A blood test (only at initial visit)
Participants may be approached about one-off studies (e.g. looking at reading or balance abilities).

**LIFTD**

The ‘Longitudinal Investigation of FTD’ project studies people with frontotemporal dementia to understand complex symptoms, how it changes over time and the impact of brain changes (e.g. on perception of humour, music, pain, temperature or speech).

Recruiting people with **behavioural and linguistic variants of frontotemporal dementia, typical Alzheimer’s disease** and **healthy volunteers**.

**What does LIFTD involve?**
- An annual visit to the DRC for three years
- Neuropsychological tasks
- An MRI brain scan
- A blood test to donate a small amount of blood
- To consider having a lumbar puncture to donate a small amount of spinal fluid.
- Neurological assessment
- Having photographs taken of the retina

**Brain Signatures**

Brain Signatures investigates the ways in which the brain’s processing of complex sounds (such as speech, music and environmental noises) goes wrong in different dementia diseases.

Recruiting people with both **behavioural and linguistic variants of frontotemporal dementia** as well as people with **typical Alzheimer’s disease**. All participants must have an available caregiver or partner with them during their visits.

**What does Brain Signatures involve?**
- A 2 day visit to the DRC
A combination of:
- Structural and functional MRI scans
- Neuropsychological tests
- Autonomic and EEG recordings
Biomarker Studies

Cerebrospinal fluid (CSF), obtained through a lumbar puncture, can provide invaluable information about the underlying cause of an individual patient’s dementia, and is frequently carried out in patients with young onset dementia. Through collaborations we have established a new research programme to develop and validate novel CSF measures of neurodegenerative disease for diagnosis and disease tracking.

If you are having a lumbar puncture as part of your diagnostic assessment, you may be asked if you are willing to donate an additional sample for research. Alternatively, if you are taking part in some of the other studies mentioned in this booklet, you may be asked if you are willing to have a lumbar puncture for research purposes.

GENFI

This project studies people who have the genetic forms of frontotemporal dementia, with problems in the genes called progranulin, tau and C9orf72. Recruiting anyone who has genetic frontotemporal dementia, as well as the siblings and children of people with genetic frontotemporal dementia.

What does GENFI involve?
- At least 1 annual assessment for three years
- Giving a medical history
- A physical examination
- Neuropsychological tasks
- A blood test to donate a small amount of blood
- A lumbar puncture to donate a small amount of spinal fluid
- An MRI and PET scan (PET scan for the first year only).

Seeing What They See (SWTS)

This study is investigating the impact of dementia-related visual impairment on every day activities (e.g. locating objects, getting around independently), in order to develop aids/strategies to minimise such impairment. Recruiting people with posterior cortical atrophy or typical Alzheimer’s disease.

What does SWTS involve?
1. A full day visit to the PAMELA lab (Tufnell Park, London)
   - Participants will be asked to walk around or locate objects within a simplified environment
2. A half-day interview at home with researchers about individual coping strategies used. This will be audio recorded.

Participants are not required to take part in both aspects of this study.

TMS in Alzheimer’s disease

Patients with Alzheimer’s disease are usually prescribed Donepezil; a medication that works by boosting the function of certain brain cells. We want to assess how effective Donepezil is by using a technique called transcranial magnetic stimulation (TMS).

TMS involves stimulating a small part of the brain using a magnetic pulse, which results in a brief (about 1 second) and painless twitch of hand muscles.

The study uses two sets of TMS experiments on the same day: one before, and one after, the daily dose of Donepezil is taken (NB: healthy volunteers will not take the Donepezil). This is repeated two weeks later.

Recruiting people with Alzheimer’s disease and healthy volunteers.

Thank you very much for taking the time to read this booklet and for considering participating in our research. It is important to remember that there is no obligation to participate in any of the studies outlined within this booklet. For those considering participating, please either email drcresearch@ucl.ac.uk or speak to a member of staff at the DRC who will be happy to go through what is involved with specific studies in more detail.