

Project Cygnus

<https://www.neurodegenerationresearch.eu/cohort/project-cygnus/>

Cohort Acronym

CYGNUS

Cohort type

Neurodegenerative disease-specific cohort

Disease

Alzheimer's disease, Dementia (unclassified), Frontotemporal dementia, Lewy body disease, Mild cognitive impairment (MCI), Other NDs not listed, Parkinson's disease, Subjective memory complaints (SMC) or subjective cognitive decline (SCD), Vascular dementia

Participant type

At-risk diagnosis

Profile

Recruitment Period 1st April 2016 - 30th September 2017

Sample size at start or planned sample size if still recruiting 389

Estimated Current Sample Size 0 to 4,999

Age at Recruitment >18

Gender Male and Female

Abstract

This is a feasibility study which has a Longitudinal Cohort design, following up participants at selected time points over a 1 year duration. The study will recruit 2 distinct groups: (1) patients with symptoms of cognitive impairment, and (2) study partners who are cognitively normal. The patients recruited to group 1 will have been recently referred to a Memory Assessment Service by their GP with suspected Mild Cognitive Impairment (MCI) & mild dementia. All patients referred to a Memory Assessment Service for this reason will be potentially eligible for inclusion in the study. Close friends or family members involved in looking after the cognitively impaired participants will also be asked to participate as study partners to attempt to measure the impact that looking after a partner, friend or family member with memory problems can have on a carer's Quality of Life and other variables such as financial burden. Both cognitively impaired participants and their study partners will be given the option of additionally participating in two sub-studies:

– Mobile data collection: Using a web/mobile app to collect self-reported data on a more regular basis from home

– Wearable device: Using a wearable device that looks like a watch to collect information on activity and sleep

Country United Kingdom

Contact details

Institution name IXICO PLC., University of Manchester, Northern Health Science Alliance Network (NHSA)

Website <http://www.ecygnus.com/>

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Funders (Core support) Innovate UK

Variables Collected

Brain related measures:

N/A

Functional rating:

Caregiver, Individual physiological, Individual psychological

Anthropometric:

Height, Weight

Physical:

Cardiovascular, Hearing and Vision, Respiratory

Biological samples:

N/A

Genotyping:

N/A

Brain imaging:

N/A

Brain banking:

N/A

Lifestyle:

Alcohol, Physical activity, Smoking

Socio-economic:

Education, Ethnic group, Family circumstances, Housing and accommodation, Income and finances, Informal support, Marital status, Occupation and employment, Unpaid care

Health service utilisation:

Formal health and social care service utilisation including private care