Incidence of Cognitive Impairments in Cohorts with Longitudinal Evaluation in Parkinson’s disease

https://neurodegenerationresearch.eu/survey/incidence-of-cognitive-impairments-in-cohorts-with-longitudinal-evaluation-in-parkinson%c2%92s-disease/

Title of study

Incidence of Cognitive Impairments in Cohorts with Longitudinal Evaluation in Parkinson’s disease

Acronym for cohort

ICICLE-PD

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

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Funding source

Parkinson's UK

Q1a. Please indicate below if your cohort includes or expects to include, incidence of the following conditions?

Parkinson's disease

Q2a. In a single sentence what is the stated aim of the study? (Maximum 30 words)
Q2b. What distinguishes this case-control study from other studies?

To understand the anatomical, biochemical and genotypic mechanisms determining the transition from Parkinson's to Parkinson's dementia, and to determine high risk clinical features and putative biomarkers predictive of dementia.

Q3a. i) Number of publications that involve use of your cohort to date
Q3a. ii) Please give up to three examples of studies to date (PI, Institution, Title of Study)
Q3b. If data on research outputs are already available please paste the publication list/other data or provide a link to where these data are publicly available
Q3c. If no research has been done as yet, please explain in a few sentences what information (i.e. research findings) you expect will be gained from the case-control study
Q4a. Study criteria: what is the age range of participants at recruitment? Age in years From:

35

Q4a. Study criteria: what is the age range of participants at recruitment? To:

until death

Q4b. Study criteria: what are the inclusion criteria?

Newly diagnosed idiopathic PD was diagnosed by a movement disorder specialist and fulfilled Queen's Square Brain Bank criteria

Q4c. Study criteria: what are the exclusion criteria?

1. People suspected of parkinsonism prior to the onset of the study on the basis that they are prevalent rather than incident. 2. People who do not possess a working knowledge of English (defined as insufficient to perform the neuropsychological assessments and questionnaires in the opinion of the assessor). 3. Patients with significant memory impairment at presentation (defined as MMSE score < 24), or meeting DSM IV criteria for dementia at presentation. By published standards these patients will not, by definition, have idiopathic PD. Patients with significant memory impairment at presentation (defined as MMSE score < 24), or meeting DSM IV criteria for dementia at presentation. By published standards these patients will not, by

definition, have idiopathic PD. 4. Patients who do not have the capacity to consent to be involved in the study (as assessed by criteria laid out in the MHA code of practice, section 4-3). 5. The following parkinsonian disorders:

Q5a. What is the size of the cohort (i.e. how many participants have enrolled)?

1-1,000

Q5b. What is the expected number of control participants?
Q6a. Please describe what measures are used to characterise participants

Queen's Square Brain Bank Criteria, medical history, social history, Movement Disorders Society Unified Parkinson's Disease Rating Scale (MDS-UPDRS) Part II and III, Hoehn and Hahr stage.

Q6b. Are there additional measures for participants with the clinical disorder?

Yes, including Non-Motor System Questinniare, Geriatric Depression Scale, Epworth Daytime Sleepiness Scale, Pitsburg Sleep Quality Index, Parkinson's Disease Questionnaire (PDQ-39) and neuropsychological test.

Q6c. Are there defined primary and secondary endpoints (e.g. defined health parameters)?

Yes

If YES please specify

Diagnosis of dementia

Q7. What is the study design?

Prospective cohort

Q8. Are your cases matched by

Age| Sex

Q9a. Does your study includes a specialised subset of control participants?

No

Q9b. If your study includes a specialised subset of control participants please describe
Q10a. Is data collection for this study

Data collection ongoing| Data analysis ongoing| Closed to new patients

Q10b. If data collection is ongoing, are there plans to continue the cohort study beyond the current projected end date?

No

Q11. Are data collected

Only through study| Through links to medical records

Q12. Is there a system in place to enable re-contact with patients for future studies?

No

Q13a. Please give information on data stored in a database (1)

Data summarised in database

% Available
Q13a. Please give information on data stored in a database (2)

Database is web-based

% Available
Q13a. Please give information on data stored in a database (3)

Database on spreadsheet (e.g. excel)

% Available
Q13a. Please give information on data stored in a database (4)

No

% Available
Q13a. Please give information on data stored in a database (5)

No

% Available
Please specify language used
% Available
Q13b. Please give information on how data is held as individual records

No

% Available
Q14a. Are data available to other groups?

Yes

Q14b. If data is available to other groups what is the access policy/mechanisms for access?

Apply to PI or co-ordinator at resource| Access independent of PI| National access| International

access| Access for pilot studies permitted

Q15. What data sharing policy is specified as a condition of use?
Q16a. Are tissues/samples/DNA available to other groups?

Yes

Q16b i) If yes, please describe below

Living donors: blood| Living donors: blood derivatives| Living donors: DNA| Living donors: cerebro-spinal fluid

Q16b. ii) In what form are tissues/samples/DNA supplied?

Primary Samples: Stabilised samples (frozen or fixed)| Secondary samples: plasma| Secondary samples: DNA| Secondary samples: RNA

Q16b iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q14 above)?

Yes

Q17. Is information on biological characteristics available to other groups?

Yes, for all the cohort

Types:
Case Control Studies

Member States:
United Kingdom

Diseases:
Parkinson's disease & PD-related disorders

Years:
2016

Database Categories:
N/A

Database Tags:
N/A