

Cognitive Complaints Cohort – Longitudinal Neuropsychological Assessment

<https://neurodegenerationresearch.eu/survey/cognitive-complaints-cohort-longitudinal-neuropsychological-assessment/>

Title of the cohort

Cognitive Complaints Cohort – Longitudinal Neuropsychological Assessment

Acronym for cohort

CCC

Name of Principal Investigator

Title Professor

First name Alexandre

Last name

Address of institution where award is held

Institution Institute of Molecular Medicine

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City Lisbon

Postcode 1649-028 Lisbon

Country

- Portugal

Website

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Funding source

1. The cohort includes, or expects to include, incidence of the following conditions

- Alzheimer's disease and other dementias

When studies on the above condition(s) are expected to become possible

- Already possible

2a. Stated aim of the cohort

predict the stability or evolution to dementia of subjects with cognitive complaints based on a comprehensive neuropsychological evaluation

2b. Features distinguishing this cohort from other population cohorts

detailed neuropsychological and functional evaluation

3a. i) Number of publications that involve use of cohort to date

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3a. ii) Up to three examples of studies to date (PI, Institution, Title of Study)

3b. Publication list/link to where data or publications are accessible (if available)

3c. Information (i.e. research findings) expected to be gained from the population cohort

4a. Study criteria: age range of participants at recruitment

Age in years from: older than 50

To ('until death' if applicable):

4b. Study criteria: inclusion criteria

cognitive complaints

detailed neuropsychological testing

non-demented

4c. Study criteria: exclusion criteria

dementia

neurological, psychiatric, medical disorders that cause cognitive impairment

drugs interfering with cognitive function

5. Size of the cohort (i.e. number of participants enrolled)

- 1,000 – 5,000 participants

6a. Measures used to characterise participants

demographic data, medical history, neurological examination, laboratory analyses, brain imaging, neuropsychological and functional evaluation, depressive symptoms assessment

6b. Additional measures for participants with a clinical disorder

6c. Are there defined primary and secondary endpoints (e.g. defined health parameters)

conversion to dementia

7. Study design

- Prospective cohort

8. Cases matched by

- Cognitive function

9a. Does the study include a specialised subset of control participants

- No

9b. If yes, description of specialised subset of control participants

10a. i) Data collection start date

01-01-1999

10a. ii) Data collection end date

10a. iii) Data collection for this study is

- Data collection ongoing
- Data analysis ongoing

10b. Plans to continue the cohort study beyond the current projected end date

- Yes – funding applied for

11. Data collected

- Only through the study

12. System in place to enable re-contact with patients for future studies

- Yes (participants have given permission to be re-contacted via the PIs to ask if they would participate in further studies)

13a. Format and availability of data stored in a database

Yes/No % available

Data summarised in database Yes

Database is web-based

Database on spreadsheet Yes

Database is on paper

Other (specify)

Language used:

english

13b. Format and availability of data held as individual records

Yes/No % available

Data held as individual records Yes

Data is web-based

Data held on computer based records Yes

Data held on cards

Other (specify)

Language used:

english – portuguese

14a. Are data available to other groups

Yes

14b. Access policy/mechanisms for access if data are available to other groups

- Access through collaboration with PI only

15. Data sharing policy specified as a condition of use

- No requirement to make data publicly available

16a. Are tissues/samples/DNA available to other groups

Yes

16b. i) Description of available tissues/samples/DNA

- Living donors: DNA

16b. ii) Form available tissues/samples/DNA are supplied in

- Primary Samples: Stabilised samples (frozen or fixed)

16b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data

Yes

17. Is information on biological characteristics available to other groups

- No