

Determining Factors and The Progression of The Onset of Alzheimer's Disease and Cognitive Impairment

<https://www.neurodegenerationresearch.eu/survey/determining-factors-and-the-progression-of-the-onset-of-alzheimers-disease-and-cognitive-impairment/>

Title of cohort

Determining Factors and The Progression of The Onset of Alzheimer's Disease and Cognitive Impairment

Acronym for cohort

MEMENTO

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Chêne/Carole

Name of Principal Investigator - Last name

Geneviève/Dufouil

Address of institution -Institution

CHU Bordeaux

Address of institution - Street address

146 rue Léo Saignat

Address of institution - City

Bordeaux

Address of institution - Postcode

33076

Country

France

Website

Contact email

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Funding source

Alzheimer's Foundation Plan (Fondation Plan Alzheimer), PHRC, GE Healthcare, AVID

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

Alzheimer's disease and other dementias

Q1b. When are studies on the above condition(s) expected to become possible?

2016-2020

Q2a. In a single sentence what is the stated aim of the cohort?

Identification and validation of biomarkers or combination of biomarkers that best predict the occurrence of dementia

Q2b. What distinguishes this cohort from other population cohorts?

The largest naturalistic cohort on brain health, with a rigorous prospective design, extensive follow-up (at least 5 years), standardized procedures, multiple biomarkers (imaging, blood CSF) assessed with standardized acquisitions and analyses

Q3a. i) Number of publications that involve use of your cohort to date

0

Q3a.ii) Please give up to three examples of studies to date (Principal Investigator, Institution, Title of Study)

B Dubois, APHP, The Insight Cohort| B Dubois, APHP, The Insight Cohort

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 population****Q4a. Study criteria: what is the age range of participants at recruitment? Age in years From:**

19

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

no limit

Q4b. Study criteria: what are the inclusion criteria?

Adults, either a recently evaluated (< 6 months) cognitive performance worse than one standard deviation to the mean in one or more domains or an isolated cognitive complaint (patient aged ? 60 years), Nondemented, Clinical Dementia Rating Scale (CDR) ?0.5

Q4c. Study criteria: what are the exclusion criteria?

Guardianship, Meeting brain MRI exclusion criteria or refusing MRI, Illiteracy

Q5. What is the size of the cohort (i.e. how many participants have enrolled)?

1,000-5,000 participants

Q6a. Please describe what measures are used to characterise participants

Demographics, neuropsychometric test, neuroimaging, blood and CSF biomarkers, DNA

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

No

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

Yes

If yes please specify

Dementia

Q7. What is the study design (select all that apply)?

Prospective cohort|Longitudinal

Q8. Are your cases matched by

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

Yes

Q9b. If your study includes a specialised subset of control participants please describe

by definition controls are those who do not get the disease at a give,n time of analysis

Q10a. i) Please enter the data collection start date

01/01/2011

Q10a. ii) Please enter the data collection end date

01/01/2019

Q10a. iii) Is data collection for this study

Data collection ongoing| Data analysis ongoing

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

Yes - intend to apply for funding

Q11. Is data collected

Only through the study

Other please specify here

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

Yes (participants given permission to be re-contacted via PIs)

Q13a. Please give information on the format and availability of data stored in a database (1)

Data summarised in database

% available

100

Q13a. Please give information on the format and availability of data stored in a database (2)

Database is web-based

% available

100

Q13a. Please give information on the format and availability of data stored in a database (3)

No

% available

Q13a. Please give information on the format and availability of data stored in a database (4)

No

% available

Other (please specify)

% available

Q13b. Please give information on the format and availability of data held as individual records (1)

Data is held as individual records

% available

Q13b. Please give information on the format and availability of data held as individual records (2)

Data is web-based

% available

Q13b. Please give information on the format and availability of data held as individual records (3)

Data held on computer based records

% available

Q13b. Please give information on the format and availability of data held as individual records (4)

No

% available

Please specify language used

French

Q14a. Is 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 collaboration with PI| Access committee mechanism| Access committee mechanism| International access| Access to industry| Access for pilot studies permitted| Resource has own ethics approval so usually no need for separate external ethics approval| Data are not distributed, access through our secured system

Q15. What data sharing policy is specified as a condition of use?

No requirement to make data publicly available

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| Post-mortem donors: brain

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

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

**Number of Patients
% of total cohort**

Types:

Population Cohorts

Member States:

France

Diseases:

Alzheimer's disease & other dementias

Years:

2016

Database Categories:

N/A

Database Tags:

N/A