

PAQUID

<https://neurodegenerationresearch.eu/survey/paquid/>

Title of cohort

PAQUID

Acronym for cohort

PAQUID

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Jean-François

Name of Principal Investigator - Last name

DARTIGUES

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Funding source

IPSEN France, Novartis Pharma France, CNSA (Caisse Nationale de Solidarité et d'Autonomie), Roche

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

Alzheimer's disease and other dementias| Parkinson's disease

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

Already possible

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

To study cerebral and functional ageing

Q2b. What distinguishes this cohort from other population cohorts?

Population-based cohort

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

150

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

<https://www.ncbi.nlm.nih.gov/pubmed/?term=PAQUID>

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:

65

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

until death

Q4b. Study criteria: what are the inclusion criteria?

65 or more years old subjects, living at home and randomly selected from the electoral rolls in 75 different sites of two French administrative districts

Q4c. Study criteria: what are the exclusion criteria?

Living in an institution

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

Sociodemographic characteristics, lifestyle, medical antecedents, medications, depressive symptomatology and activity limitations were assessed at baseline and each follow-up time. A complete cognitive evaluation with systematic screening for dementia was performed at baseline and each follow-up time.

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

Examination by a neurologist or a geriatrician

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

Yes

If yes please specify

Primary endpoint: dementia; secondary endpoint: functional evaluation

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

Participants free of the disease can be used as controls

Q10a. i) Please enter the data collection start date

01/01/1988

Q10a. ii) Please enter the data collection end date

Last follow-up: 2016; however a next follow-up is planned

Q10a. iii) 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?

Yes - intend to apply for funding

Q11. Is data collected

Only through the study

Other please specify here

Mainly through the study + link with cancer registry

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)

No

% available

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

100

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

No

% available

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

Data held on computer based records

% available

100

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

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

No policy exists

Q16a. Are tissues/samples/DNA available to other groups?

No

Q16b i) If yes, please describe below:

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

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

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

No

Number of Patients

% of total cohort

Types:

Population Cohorts

Member States:

France

Diseases:

Alzheimer's disease & other dementias, Parkinson's disease & PD-related disorders

Years:

2016

Database Categories:

N/A

Database Tags:

N/A