Luxembourg Cohort

https://neurodegenerationresearch.eu/survey/luxembourg-cohort/

Title of the cohort

Luxembourg Cohort

Acronym for cohort

Lux.Cohort

Name of Principal Investigator

Title Doctor

First name Sophie

Last name COUFFIGNAL

Address of institution where award is held

Institution

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Luxembourg

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Funding source

Ministry of Research Ministry of Health Biobank

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

- Parkinson's disease
- Neurodegenerative disease in general

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

2011 - 2015

2a. Stated aim of the cohort

To study particularly mechanism of development of parkinson disease, diabetes and lung cancer, for propose method of pre-diagnosis, and personalised medicine

2b. Features distinguishing this cohort from other population cohorts

this cohort will be built from EHES cross sectional survey, and with volonteers.

research in proteomics and metalobomics are priorities

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

0

- 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: 18 years
To ('until death' if applicable): 75 years
4b. Study criteria: inclusion criteria

people with parkinson diseases
people with diabetes
people with cancer
people who participate in EHES cross sectional study

4c. Study criteria: exclusion criteria

institutionalised people

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

More than 15,000

6a. Measures used to characterise participants

age, gender, ethnical informations, socio economic conditions, educational conditions, diseases and medications, family diseases, lifestyle (tobacco, alcoohol, physical activity, nutrition), work situation, environmental conditions, health status, health care using, cognitiv assessement, anthropometric measures, blood pressure, biological analysis, genetic informations

6b. Additional measures for participants with a clinical disorder

if diabetes, more blood analysis and family disease if parkinson, more blood analysis, some neurological tests, family disease

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

Nο

7. Study design

Prospective cohort

8. Cases matched by

- Age
- Sex
- Co-morbidities
- Cognitive function
- Physical ability

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

01-01-2012

10a. ii) Data collection end date

31-12-2017

10a iii) Data collection for this study is

At the planning stage

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

Yes – intend to apply for funding

11. Data collected

- Only through the study
- Through links to medical records

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 Yes

Database on spreadsheet

Database is on paper

Other (specify)

Language used:

french, german, english, portugues

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

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
- Access independent of collaboration with PI
- Access Committee mechanism
- National access International access
- Access to industry
- · Access for pilot studies permitted
- Access restricted to peer-reviewed work
- Applicant needs to provide separate external ethics approval

15. Data sharing policy specified as a condition of use

Data made publicly available after a specified time point

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

Yes

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

- Living donors:blood
- Living donors: blood derivatives
- Living donors: DNA

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

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

Yes, for all the cohort