Acronym for cohort: LeARN (WP4)

https://neurodegenerationresearch.eu/survey/acronym-for-cohort-learn-wp4/

Title of the cohort Acronym for cohort

LeARN (WP4)

Name of Principal Investigator

Title prof. dr. First name Frans Last name Verhev

Address of institution where award is held

Institution Alzheimer Center Limburg

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Country

Netherlands

Website

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Contact email

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Funding source

Government, industry and universities

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

2011 - 2015

- 2a. Stated aim of the cohort
- 2b. Features distinguishing this cohort from other population cohorts
- 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: 55

To ('until death' if applicable):

4b. Study criteria: inclusion criteria 4c. Study criteria: exclusion criteria

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

1,000 - 5,000 participants

6a. Measures used to characterise participants

Demographic data, clinical data, Mini Mental State Examination, Clinical Dementia Rating Scale, Neuropsychiatric Inventory, Disability Assessment for Dementia Scale, Geriatric Depression Scale, EuroQol-5D

6b. Additional measures for participants with a clinical disorder

MRI (including DTI and resting state fMRI), PET (FDG and PiB-PET), CSF

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

No

7. Study design

Prospective cohort

8. Cases matched by

Cognitive function

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

Yes

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

Patients with only subjective memory complaints will be controls for patients with objective memory complaints

10a. i) Data collection start date

01-11-2009

10a. ii) Data collection end date

01-05-2011

10a iii) Data collection for this study is

Data analysis ongoing

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

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 100
Database is web-based yes 100
Database on spreadsheet yes 100
Database is on paper yes 100

Other (specify)

Language used:

Dutch

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

Yes/No % available

Data held as individual records yes 100
Data is web-based yes 100
Data held on computer based records yes 100

Data held on cards no

Other (specify)

Language used:

14a. Are data available to other groups

Yes

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

Apply to PI or co-ordinator at resource

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

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

• Living donors: cerebro-spinal fluid

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

• Yes, for all the cohort