Amsterdam Dementia Cohort

https://www.neurodegenerationresearch.eu/survey/amsterdam-dementia-cohort/

Title of cohort

Amsterdam Dementia Cohort

Acronym for cohort

ADC

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Phillip

Name of Principal Investigator - Last name

Scheltens

Address of institution -Institution

Vumc

Address of institution - Street address

de Boelelaan 1118

Address of institution - City

Amsterdam

Address of institution - Postcode

1081 HZ

Country

Netherlands

Website

www.alzheimercentrum.nl

Contact email

Funding source

ZonMW

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?

Already possible

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

Study biomarkers, progression markers, etiology, protective factors

Q2b. What distinguishes this cohort from other population cohorts?

Clinical patient cohort, naturalistic data

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

One paper under review on prediction of time to dementia onset based on baseline grey matter connectivity.

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

n/a

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

n/a

Q4b. Study criteria: what are the inclusion criteria?

not applicable, all patients who visit our center enroll in amsterdam dementia cohort

Q4c. Study criteria: what are the exclusion criteria?

none

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

Clinical data, biomarker data, mri, eeg, meg ,neuropsychology

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

Possibly

Q6c. Are there defined primary and secondary endpoints (e.g. defined health parameters)?
If yes please specify
Q7. What is the study design (select all that apply)?

Other

Q8. Are your cases matched by

Other health assessment

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

No

Q9b. If your study includes a specialised subset of control participants please describe
Q10a. i) Please enter the data collection start date

01/01/2000

Q10a. ii) Please enter the data collection end date

unknown

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

Through links to medical records

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

90

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

90

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

90

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

No

% available
Please specify language used

Dutch and English

Q14a. Is data available to other groups?

Yes

Q14b. If data is available to other groups what is the access policy/mechanisms for access?

Access through collaboration with PI only

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?

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?

Yes, for all the cohort

Number of Patients
% of total cohort

Types:

Population Cohorts

Member States:
Netherlands

Diseases:
Alzheimer's disease & other dementias

Years:
2016

Database Categories:
N/A

Database Tags:
N/A