Human prion diseases: molecular characteristics

https://www.neurodegenerationresearch.eu/survey/human-prion-diseases-molecular-characteristics/

Title of cohort

Human prion diseases: molecular characteristics

Acronym for cohort

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Inga

Name of Principal Investigator - Last name

Zerr

Address of institution -Institution

Department of Neurology, University of Göttingen

Address of institution - Street address

Robert-Koch-Str. 40

Address of institution - City

Göttingen

Address of institution - Postcode

37075

Country

Germany

Website

www.cjd-goettingen.de

Contact email

Funding source

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

Prion 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 analyse molecular determinants of the disease

Q2b. What distinguishes this cohort from other population cohorts?
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)
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:

30

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

Until death

Q4b. Study criteria: what are the inclusion criteria?

Dementia, MRI, neuropsychological test profile

Q4c. Study criteria: what are the exclusion criteria?

Other dementia

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

Biomarkers, neuropsychological tests, genetic analyses, MRI, brain lesion profiles

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

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

No

If yes please specify
Q7. What is the study design (select all that apply)?

Prospective cohort

Q8. Are your cases matched by

Age

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

01/06/1993

Q10a. ii) Please enter the data collection end date
Q10a. iii) Is data collection for this study

Data collection 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
Other please specify here
Q12. Is there a system in place to enable re-contact with patients to ask about participation in future studies?
Q13a. Please give information on the format and availability of data stored in a database (1)
% available
Q13a. Please give information on the format and availability of data stored in a database (2)
% available
Q13a. Please give information on the format and availability of data stored in a database (3)
% available
Q13a. Please give information on the format and availability of data stored in a database (4)
% available
Other (please specify)

% available
Q13b. Please give information on the format and availability of data held as individual records (1)
% available
Q13b. Please give information on the format and availability of data held as individual records (2)
% available
Q13b. Please give information on the format and availability of data held as individual records (3)
% available
Q13b. Please give information on the format and availability of data held as individual records (4)
% available
Please specify language used
Q14a. Is data available to other groups?

Yes

Q14b. If data is available to other groups what is the access policy/mechanisms for access?
Q15. What data sharing policy is specified as a condition of use?

Data to be made publicly available immediately

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

Yes

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:
Germany

Diseases:
Prion disease

Years:
2016

Database Categories:

N/A

Database Tags:
N/A