Clinical, imaging and biological investigations of frontotemporal dementia and related conditions

https://neurodegenerationresearch.eu/survey/clinical-imaging-and-biological-investigations-of-frontotemporal-dementia-and-related-conditions/

Title of study

Clinical, imaging and biological investigations of frontotemporal dementia and related conditions

Acronym for cohort

FRONTIER

Name of Principal Investigator - Title

Prof

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Funding source

NHMRC and ARC

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

Alzheimer's disease and other dementias|Motor neurone diseases

Q2a. In a single sentence what is the stated aim of the study? (Maximum 30 words)

Improving diagnosis, prognosis and clinico-pathological correlations of frontotemporal dementia and related neurodegenerative brain conditions

Q2b. What distinguishes this case-control study from other studies?

Comprehensive investigations of these disorders that include clinical, cognitive, neuroimaging, biological and genetic investigations with brain banking for pathological confirmation

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

>100

Q3a. ii) Please give up to three examples of studies to date (PI, 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 case-control study
Q4a. Study criteria: what is the age range of participants at recruitment? Age in years From:

>18

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

until death

Q4b. Study criteria: what are the inclusion criteria?

clinical diagnosis of frontotemporal dementia or presence of causative mutation for the disease

Q4c. Study criteria: what are the exclusion criteria?

Other CNS related conditions; mental disorders; TBI; history of subtance abuse

Q5a. What is the size of the cohort (i.e. how many participants have enrolled)?

1-1,000

Q5b. What is the expected number of control participants?

200-500

Q6a. Please describe what measures are used to characterise participants

Clinical, cognitive, neuroimaging, biological investigations

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

genetic screening

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

No

If YES please specify
Q7. What is the study design?

Prospective cohort|Retrospective cohort|Age|Sex

Q8. Are your cases matched by

Cognitive function

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

No

Q9b. If your study includes a specialised subset of control participants please describe
Q10a. 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 - funding applied for

Q11. Are data collected

Only through the study|Through links to medical records

Q12. Is there a system in place to enable re-contact with patients for future studies?

Yes (participants have given permission to be re-contacted via the PIs)

Q13a. Please give information on data stored in a database (1)

Data summarised in database

% Available

100

Q13a. Please give information on data stored in a database (2)

No

% Available
Q13a. Please give information on data stored in a database (3)

No

% Available
Q13a. Please give information on data stored in a database (4)

No

% Available
Q13a. Please give information on data stored in a database (5)

No

% Available
Please specify language used
% Available

100

Q13b. Please give information on how data is held as individual records

No

% Available
Q14a. Are 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|Local/ regional access|National access|International access|Resource has own ethics approval so usually no need for separate external ethics

approval

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

No policy exists

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

Types:
Case Control Studies

Member States:
Australia

Diseases:
Alzheimer's disease & other dementias, Motor neurone diseases

Years:
2016

Database Categories:
N/A

Database Tags:
N/A