Sydney Memory and Ageing Study

https://neurodegenerationresearch.eu/survey/sydney-memory-and-ageing-study/

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Sydney Memory and Ageing Study

Acronym for cohort

MAS

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Henry

Name of Principal Investigator - Last name

Brodaty

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University of New South Wales

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2031

Country

Australia

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Funding source

NHMRC Australia

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

Alzheimer's disease and other dementias|Parkinson's disease|Neurodegenerative disease in general

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?

The Sydney Memory and Ageing Study investigates the rates and predictors of cognitive decline (MCI, dementia) in an ageing population.

Q2b. What distinguishes this cohort from other population cohorts?

Method of recruitment is unique as the cohort were recruited from the electoral roll (registration on the electoral roll is compulsory in Australia and this is a public document). Wide breadth of risk factors examined, e.g., neuroimaging, genetics, proteomics.

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

112

Q3a.ii) Please give up to three examples of studies to date (Principal Investigator, Institution, Title of Study)

Megan Heffernan, UNSW, Alcohol Consumption and Incident Dementia: Evidence from the Sydney Memory and Ageing Study (2016)|Zixuan Yang, UNSW, Age-associated structural brain differences on MRI from eighth to eleventh decades of life (2016)|Perminder Sachdev, UNSW, The Sydney Memory and Ageing Study (MAS): methodology and baseline medical and neuropsychiatric characteristics of an elderly epidemiological non-demented cohort of Australians aged 70-90 years - 2010

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

https://cheba.unsw.edu.au/project/sydney-memory-and-ageing-study

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:

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

90

Q4b. Study criteria: what are the inclusion criteria?

Community dwelling, proficiency in English sufficient to complete a psychometric assessment.

Q4c. Study criteria: what are the exclusion criteria?

Previous diagnosis of dementia, psychotic symptoms, diagnosis of schizophrenia, bipolar disorder, multiple sclerosis, motor neuron disease, developmental disability, progressive malignancy, MMSE score <24 adjusted for age, education and non-English speaking background, or a diagnosis of dementia after comprehensive assessment.

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 mulitiple

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

No

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|Longitudinal

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

Q10a. ii) Please enter the data collection end date

08/01/2020

Q10a. iii) Is data collection for this study

Data collection ongoing|Data analysis ongoing|Closed to new patients

Q10b. If data collection is ongoing, are there plans to continue the cohort study beyond the current projected end date?

Yes - funding applied for/funding awarded

Q11. Is data collected Other please specify here

through the study, medical records and other records or registers (e.g dental records, police records etc)

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

No

Q13a. Please give information on the format and availability of data stored in a database (1)

Data summarised in database

% available

100

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)

Database on spreadsheet (e.g. excel)

% available

100

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

100

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

100

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

No

% available

Please specify language used

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 committee mechanism|Local/ regional access|National access|International access|Access to industry|Access for pilot studies permitted|Applicant needs to provide separate external ethics approval|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 requirement to make data publicly available

Q16a. Are tissues/samples/DNA available to other groups? Q16b i) If yes, please describe below:

Living donors: blood|Living donors: blood derivatives|Living donors: DNA|Post-mortem donors: brain

Q16b. ii) In what form are tissues/samples/DNA supplied?

Primary samples: Supplied fresh| Primary Samples: Stabilised samples (frozen or fixed)|Secondary samples: plasma|Secondary samples: DNA|Secondary samples: RNA

Q16b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q14 above)?

Yes

Q17. Is information on biological characteristics available to other groups?

If available for a subset please specify number of patients and % of total cohort

Number of Patients

943

% of total cohort

91

Types:

Population Cohorts

Member States:

Australia

Diseases:

Alzheimer's disease & other dementias, Neurodegenerative disease in general, Parkinson's disease & PD-related disorders

Years:

2016

Database Categories:

N/A

Database Tags:

N/A