Swedish Adoption/Twin Study of Aging

https://neurodegenerationresearch.eu/survey/swedish-adoptiontwin-study-of-aging/

Title of cohort

Swedish Adoption/Twin Study of Aging

Acronym for cohort

SATSA

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Nancy

Name of Principal Investigator - Last name

Pedersen

Address of institution -Institution

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Country

Sweden

Website

ki.se/en/meb/satsa-the-swedish-adoptiontwin-study-of-aging

Contact email

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Funding source

VR, FORTE, NIA, JPND

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?

A longitudinal program in gerontological genetics (aging)

Q2b. What distinguishes this cohort from other population cohorts?

it is comprised of a sample of elderly twins who were separated at an early age and reared apart, giving unique opportunities to study early environmental effects

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

300

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

Nancy Pedersen, Karolinska Institutet, The Study of Dementia in Swedish Twins

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://dornsife.usc.edu/labs/scrap/publications/

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:

50

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

Until death

Q4b. Study criteria: what are the inclusion criteria?

Swedish twins, separated early or matched to that sample

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

health and cognitive examinations, questionnaires

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)?

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

01/10/1984

Q10a. ii) Please enter the data collection end date

01/06/2014

Q10a. iii) Is data collection for this study

Data analysis ongoing

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

Q11. Is data collected

Only through the study

Other please specify here

and through links to medical records

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
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)

Database on paper

% available
Other (please specify)

Other

% available
Q13b. Please give information on the format and availability of data held as individual records (1)

Data is held as individual records

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

No

% 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?

Apply to PI or co-ordinator at resource| Access independent of collaboration with PI| Access committee mechanism| Local/ regional access| National access| International access| Applicant needs to provide 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?

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:

Sweden

Diseases:
Alzheimer's disease & other dementias

Years:
2016

Database Categories:
N/A

Database Tags:
N/A