Swedish Twin Registry

https://neurodegenerationresearch.eu/survey/swedish-twin-registry/

Title of cohort

Swedish Twin Registry

Acronym for cohort

STR

Name of Principal Investigator - Title

Dr

Name of Principal Investigator - First name

Patrik

Name of Principal Investigator - Last name

Magnusson

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Karolinska Institutet, Department of Medical Epidemiology and Biostatistics

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Stockholm

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17177

Country

Sweden

Website

ki.se/en/research/the-wedish-twin-registry

Contact email

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Funding source

Multiple funders

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

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?

To provide a national, population based resource for the study of genetic and environmental influences on behavior and disease.

Q2b. What distinguishes this cohort from other population cohorts?

It is large, covers the entire country of Sweden, and is genetically informative (twins).

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

1000+

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

Nancy Pedersen & Margaret Gatz, Karolinska Institutet and University of Southern California, The Study of Dementia in Swedish Twins (HARMONY)| Nancy Pedersen, Karolinska Institutet, Parkinson's Disease 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

ki.se/sites/default/files/publikationer2_str.pdf

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:

9

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

Until death

Q4b. Study criteria: what are the inclusion criteria?

twins born in Sweden

Q4c. Study criteria: what are the exclusion criteria?

None

Q5. What is the size of the cohort (i.e. how many participants have enrolled)?

More than 15,000 participants

Q6a. Please describe what measures are used to characterise participants

questionnaires, health and cognitive assessments, biological measures

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

disorder relevant assessments

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| Nested case-control within 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

01/01/1961

Q10a. ii) Please enter the data collection end date
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 - funding applied for/funding awarded

Q11. Is data collected

Through links to other records or registers (e.g dental records, police records etc)

Other please specify here

data also collected through the study and 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)

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
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

Swedish

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| Access to industry| Access for pilot studies permitted| Applicant needs to provide separate external ethics approval| Other criteria (Must be in collaboration with a Swedish co-investigator

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?

Yes

Q16b i) If yes, please describe below:

Living donors: blood| Living donors: blood| Living donors: DNA

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

Primary Samples: Stabilised samples (frozen or fixed)| Secondary samples:(derivatives of primary samples)| Secondary samples: DNA

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?

No

Number of Patients
% of total cohort

Types:
Population Cohorts

Member States:
Sweden

Diseases:
Neurodegenerative disease in general

Years:
2016

Database Categories:
N/A

Database Tags:
N/A