H70

https://neurodegenerationresearch.eu/survey/h70/

Title of cohort

H70

Acronym for cohort

H70

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Ingmar

Name of Principal Investigator - Last name

Skoog

Address of institution -Institution

Neuroscience and Physiology

Address of institution - Street address

Wallinsgatan 6

Address of institution - City

Molndal

Address of institution - Postcode

431 41

Country

Sweden

Website

www.epinep.gu.se

Contact email

ingmar.skoog@neuro.gu.se

Funding source

VR, FORTE

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 study aging, health and health related conditions in older populations

Q2b. What distinguishes this cohort from other population cohorts?

The comprehensive examinations, long-follow-up and large time interval between first and last exam

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

700+

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

www.epinep.gu.se

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:

38

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

108

Q4b. Study criteria: what are the inclusion criteria?

Birth dates certain years

Q4c. Study criteria: what are the exclusion criteria?

None

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

5,001-10,000 participants

Q6a. Please describe what measures are used to characterise participants

More than 1000 characteristics

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| Cross sectional survey| Prospective cohort| Retrospective cohort

Q8. Are your cases matched by

Other health assessment

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

Yes

Q9b. If your study includes a specialised subset of control participants please describe

Population cohort

Q10a. i) Please enter the data collection start date

09/01/1971

Q10a. ii) Please enter the data collection end date

09/01/2031

Q10a. iii) Is data collection for this study

At the planning stage| 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 - intend to apply for funding

Q11. Is data collected

Through links to medical records

Other please specify here

Through study

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

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)

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)
% 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 through collaboration with PI only| 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 requirement to make data publicly available

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

No

Q16b i) If yes, please describe below:

Living donors: blood| Living donors: blood derivatives| Living donors: DNA| Living donors: cerebro-spinal fluid

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)?

Yes

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

Yes, for all the cohort

Number of Patients

4000

% of total cohort

Types:
Population Cohorts

Member States:
Sweden

Diseases:
Neurodegenerative disease in general

Years:
2016

Database Categories:
N/A

Database Tags:
N/A