Cohort – 95+

https://www.neurodegenerationresearch.eu/survey/cohort-95/

Title of the cohort

Cohort – 95+

Acronym for cohort

95+

Name of Principal Investigator

Title	Professor
First name	Ingmar
Last name	Skoog

Address of institution where award is held

Institution	Neuroscience and Physiology, Neuropsychiatric epidemiology, Gothenburg University
Street Address	Wallinsgatan 6
City	
Postcode	431 41

Country

- Sweden

Website

www.epinep.gu.se

Contact email

Funding source

1) The Swedish Research Council (VR)
2) Swedish Council for Working Life and Social Research (FAS)
3) US Alzheimer Association

1. The cohort includes, or expects to include, incidence of the following conditions

- Alzheimer’s disease and other dementias
- Neurodegenerative disease in general

When studies on the above condition(s) are expected to become possible

- Already possible

2a. Stated aim of the cohort

To study dementia, other mental disorders (depression, psychotic disorders, anxiety disorders), suicidal behaviour and cognitive function in the very old in longitudinally followed 95 year-olds

2b. Features distinguishing this cohort from other population cohorts
3a. i) Number of publications that involve use of cohort to date

6

3a. ii) Up to three examples of studies to date (PI, Institution, Title of Study)
3b. Publication list/link to where data or publications are accessible (if available)

www.epinep.gu.se

3c. Information (i.e. research findings) expected to be gained from the population cohort
4a. Study criteria: age range of participants at recruitment

Age in years from: 95

To ('until death' if applicable): 107

4b. Study criteria: inclusion criteria

Aged 95 born 1901-11 and living in Gothenburg, Sweden

4c. Study criteria: exclusion criteria

none

5. Size of the cohort (i.e. number of participants enrolled)

- 1,000 – 5,000 participants

6a. Measures used to characterise participants

These studies include psychiatric examinations, close informant interviews, psychometric testings, physical examinations, blood sampling, DNA-analyses, comprehensive laboratory tests, social factors, ADL and case record studies.

6b. Additional measures for participants with a clinical disorder
6c. Are there defined primary and secondary endpoints (e.g. defined health parameters)

Dementia and other mental disorders

7. Study design

- Prospective cohort
- Retrospective cohort
- Longitudinal
- Cross sectional survey

8. Cases matched by

- Age

9a. Does the study include a specialised subset of control participants

- No

9b. If yes, description of specialised subset of control participants
10a. i) Data collection start date

01-07-1996

10a. ii) Data collection end date

31-12-2017

10a iii) Data collection for this study is

- Data collection ongoing
- Data analysis ongoing

10b. Plans to continue the cohort study beyond the current projected end date

- Yes – funding applied for
- Yes – intend to apply for funding

11. Data collected

- Through links to medical records

12. System in place to enable re-contact with patients for future studies

- Yes (participants have given permission to be re-contacted via the PIs to ask if they would participate in further studies)

13a. Format and availability of data stored in a database

	Yes/No	% available
Data summarised in database	Yes	100
Database is web-based	No	
Database on spreadsheet	Yes	100
Database is on paper	Yes	100
Other (specify)		

Language used:

Swedish

13b. Format and availability of data held as individual records

	Yes/No	% available
Data held as individual records	Yes	100
Data is web-based	No	
Data held on computer based records	Yes	100
Data held on cards	No	
Other (specify)		

Language used:

swedish

14a. Are data available to other groups

Yes

14b. Access policy/mechanisms for access if data are available to other groups

- Apply to PI or co-ordinator at resource
- Access through collaboration with PI only

15. Data sharing policy specified as a condition of use

- No requirement to make data publicly available

16a. Are tissues/samples/DNA available to other groups

Yes

16b. i) Description of available tissues/samples/DNA

- Living donors:blood
- Living donors: blood derivatives
- Living donors: DNA

16b. ii) Form available tissues/samples/DNA are supplied in

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

16b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data

Yes

17. Is information on biological characteristics available to other groups

- Yes, for all the cohort