

# Cohort – 95+

<https://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

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## Country

- Sweden

## Website

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## 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](http://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