

Cohort – H85

<https://neurodegenerationresearch.eu/survey/cohort-h85/>

Title of the cohort

Cohort – H85

Acronym for cohort

H85

Name of Principal Investigator

Title Professor

First name Ingmar

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Address of institution where award is held

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Funding source

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

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

- Alzheimer's disease and other dementias
- Parkinson's disease
- Neurodegenerative disease in general

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

- 2011 – 2015

2a. Stated aim of the cohort

To study dementia and other mental disorders (depression, psychotic disorders, anxiety disorders) in longitudinally followed elderly populations from different birth cohorts.

2b. Features distinguishing this cohort from other population cohorts

The possibility to compare 85-year-olds examined 22 years apart, and the comprehensive examinations.

3a. i) Number of publications that involve use of cohort to date

100

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: 85

To ('until death' if applicable): 107

4b. Study criteria: inclusion criteria

Aged 85 and born 1901-02 or 1923-24 on certain dates, 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

psychiatric examinations, close informant interviews, psychometric testings, ADL, social factors, personality inventories, physical examinations, DNA-analyses, comprehensive laboratory tests, CT-scan of the head, cerebrospinal fluid analyses and case record studies. (see also www.epinep.gu.se)

6b. Additional measures for participants with a clinical disorder

No

6c. Are there defined primary and secondary endpoints (e.g. defined health parameters)

Dementia and other psychiatric 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

01-07-1986

10a. ii) Data collection end date

01-07-2025

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

- Only through the study
- 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

Database is on paper Yes

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: cerebro-spinal fluid
- 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