

Prospective Population Study of Women in Gothenburg

<https://neurodegenerationresearch.eu/survey/prospective-population-study-of-women-in-gothenburg/>

Title of the cohort

Prospective Population Study of Women in Gothenburg

Acronym for cohort

PPSW

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) 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 women followed from 1968-2011

2b. Features distinguishing this cohort from other population cohorts

The long follow-up

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: 38

To ('until death' if applicable): 60

4b. Study criteria: inclusion criteria

Women born 1908, 1914, 1918, 1922 and 1930 on certain dates and living in Gothenburg, Sweden 1968

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, personality inventories, physical examinations, DNA-analyses, comprehensive laboratory tests, CT-scan of the head, cerebrospinal fluid analyses, psychosocial factors, functional ability, and case record studies. See also www.epinep.gu.se

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
- Longitudinal
- Cross sectional survey

8. Cases matched by

- Other health assessment (specify) / N/A
 - representative sample

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

01-01-1968

10a. ii) Data collection end date

31-12-2025

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

- 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
- Living donors: cerebro-spinal fluid

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