

The Swedish National study on Aging and Care in Kungsholmen

<https://www.neurodegenerationresearch.eu/survey/the-swedish-national-study-on-aging-and-care-in-kungsholmen/>

Title of the cohort

The Swedish National study on Aging and Care in Kungsholmen

Acronym for cohort

SNAC-K

Name of Principal Investigator

Title Professor

First name Laura

Last name Fratiglioni

Address of institution where award is held

Institution Aging Reseach Center

Street Address

City Stockholm

Postcode 113 30

Country

- Sweden

Website

www.ki-su-arc.se

Contact email

Funding source

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

- Alzheimer's disease and other dementias
- Parkinson's disease

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

- Already possible

2a. Stated aim of the cohort

To trace the changes in health status and detect factors leading to negative health and functional outcomes in the elderly

2b. Features distinguishing this cohort from other population cohorts

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

4

3a. ii) Up to three examples of studies to date (PI, Institution, Title of Study)

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: 60 +

To ('until death' if applicable): until death

4b. Study criteria: inclusion criteria

60 + living in Kungsholmen area at 2001

4c. Study criteria: exclusion criteria

No

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

- 1,000 – 5,000 participants

6a. Measures used to characterise participants

As well as biological and genetic data

6b. Additional measures for participants with a clinical disorder

Yes

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

Dementia, Alzheimer, Parkinson and other chronic disorders

7. Study design

- Longitudinal

8. Cases matched by

- Other health assessment (specify) / N/A
- Not relevant

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

01-01-2001

10a. ii) Data collection end date

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

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

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

Data is web-based

Data held on computer based records yes 100

Data held on cards

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

- Resource has own ethics approval so usually no need for separate external ethics approval

15. Data sharing policy specified as a condition of use

- No policy exists

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

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

17. Is information on biological characteristics available to other groups

- No
- Yes, for all the cohort