Cohort – The Kungsholmen projekt

https://neurodegenerationresearch.eu/survey/cohort-the-kungsholmen-projekt/

Title of the cohort

Cohort – The Kungsholmen projekt

Acronym for cohort

Name of Principal Investigator

Title	Professor
First name	Laura
Last name	Fratiglioni

Address of institution where award is held

Institution	Aging Research Center
Street Address	
City	Stockholm
Postcode	113 30

Country

- Sweden

Website

www.kungsholmenproject.se

Contact email

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Funding source

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

The aim is to detect occurrene and determinants of dementia and Alzheimer.

2b. Features distinguishing this cohort from other population cohorts

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

400

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.kungsholmen.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: 75+

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

4b. Study criteria: inclusion criteria

75+ years living in Kungsholmen area, Stockholm at 1987

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

Social, medical and functional characterise

6b. Additional measures for participants with a clinical disorder

Yes

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

All cronic disorders, functional impairoment mortality

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

31-01-1987

10a. ii) Data collection end date

31-12-2000

10a iii) Data collection for this study is

- Data analysis ongoing
- Closed to new patients

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

- No

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

	Yes/No	% available
Data summarised in database		
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

- Apply to PI or co-ordinator at resource
- 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

- Secondary samples: plasma

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