The Kungsholmen Project

https://neurodegenerationresearch.eu/survey/the-kungsholmen-project/

Title of cohort

The Kungsholmen Project

Acronym for cohort

KP

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Laura

Name of Principal Investigator - Last name

Fratiglioni

Address of institution -Institution

Karolinska Institutet

Address of institution - Street address

Gävlegatan 16, plan 9

Address of institution - City

Stockholm

Address of institution - Postcode

113 30

Country

Sweden

Website

www.kungsholmenproject.se/

Contact email

laura.fratglioni@ki.se

Funding source

Q1a. Please indicate below if your cohort includes or expects to include, incidence of the following conditions?

Alzheimer's disease and other dementias||Neurodegenerative disease in general

Q1b. When are studies on the above condition(s) expected to become possible?

Already possible

Q2a. In a single sentence what is the stated aim of the cohort?

To increase our understanding of the aging process and to identify preventive strategies that can lead to improved health and care of the elderly.

Q2b. What distinguishes this cohort from other population cohorts?

Q3a. i) Number of publications that involve use of your cohort to date

300+

Q3a.ii) Please give up to three examples of studies to date (Principal Investigator, Institution, Title of Study)

Fratiglioni, et al. An active and socially integrated lifestyle in late life might protect against dementia. The Lancet Neurology. 2004| Rizzuto, et al. Lifestyle, social factors, and survival after age 75: population based study. BMJ. 2012.| Qiu C Twenty-year changes in dementia occurrence suggest decreasing incidence in central Stockholm, Sweden.

Q3b. If data on research outputs are already available please paste the publication list/other data or provide a link to where these data are publicly available

Data are avalible on request

Q3c. If no research has been done as yet, please explain in a few sentences what information (i.e. research findings) you expect will be gained from the population

Q4a. Study criteria: what is the age range of participants at recruitment? Age in years From:

75

Q4a. Study criteria: what is the age range of participants at recruitment? To:

100

Q4b. Study criteria: what are the inclusion criteria?

75 years or older and living in Kungsholmen area, Stockholm

Q4c. Study criteria: what are the exclusion criteria?

None

Q5. What is the size of the cohort (i.e. how many participants have enrolled)?

1,000-5,000 participants

Q6a. Please describe what measures are used to characterise participants

social interview, physical functioning, clinical examination, including geriatric, neurological and psychiatric assessment, cognitive assessment.

Q6b. Are there additional measures for participants with a clinical disorder?

Proxy interview in case of cognitive impairment

Q6c. Are there defined primary and secondary endpoints (e.g. defined health parameters)?

No

If yes please specify
Q7. What is the study design (select all that apply)?

Longitudinal

Q8. Are your cases matched by
Q9a. Does your study include a specialised subset of control participants?

No

Q9b. If your study includes a specialised subset of control participants please describe
Q10a. i) Please enter the data collection start date

01/10/1987

Q10a. ii) Please enter the data collection end date

01/12/2000

Q10a. iii) Is data collection for this study

Data analysis ongoing| Closed to new patients

Q10b. If data collection is ongoing, are there plans to continue the cohort study beyond the current projected end date?

No

Q11. Is data collected

Through links to medical records

Other please specify here

death registry

Q12. Is there a system in place to enable re-contact with patients to ask about participation in future studies?

No

Q13a. Please give information on the format and availability of data stored in a database (1)

Data summarised in database

% available

100

Q13a. Please give information on the format and availability of data stored in a database (2)

No

% available
Q13a. Please give information on the format and availability of data stored in a database (3)

Database on spreadsheet (e.g. excel)

% available

100

Q13a. Please give information on the format and availability of data stored in a database (4)

Database on paper

% available

100

Other (please specify)
% available
Q13b. Please give information on the format and availability of data held as individual records (1)

Data is held as individual records

% available

100

Q13b. Please give information on the format and availability of data held as individual records (2)

No

% available
Q13b. Please give information on the format and availability of data held as individual records (3)

Data held on computer based records

% available

100

Q13b. Please give information on the format and availability of data held as individual records (4)

No

% available
Please specify language used
Q14a. Is data available to other groups?

Yes

Q14b. If data is available to other groups what is the access policy/mechanisms for access?

Apply to PI or co-ordinator at resource| Access independent of collaboration with PI| Local/ regional access| National access| International access| Access for pilot studies permitted| RAccess restricted to peer-reviewed work| Resource has own ethics approval so usually no need for separate external ethics approval

Q15. What data sharing policy is specified as a condition of use?

Data made publicly available after a specified time point

Q16a. Are tissues/samples/DNA available to other groups?

Yes

Q16b i) If yes, please describe below:

Living donors: blood| Living donors: blood derivatives| Living donors: DNA

Q16b. ii) In what form are tissues/samples/DNA supplied?

Primary Samples: Stabilised samples (frozen or fixed)| Secondary samples:(derivatives of primary samples)| Secondary samples: plasma| Secondary samples: DNA

Q16b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q14 above)?

Yes

Q17. Is information on biological characteristics available to other groups?

Yes, for all the cohort

Number of Patients
% of total cohort

Types:
Population Cohorts

Member States:
Sweden

Diseases:
Alzheimer's disease & other dementias, Neurodegenerative disease in general

Years:
2016

Database Categories:
N/A

Database Tags:
N/A