The Betula Prospective Study on Aging, Memory, and Dementia

https://neurodegenerationresearch.eu/survey/the-betula-prospective-study-on-aging-memory-and-dementia/

Title of the cohort

The Betula Prospective Study on Aging, Memory, and Dementia

Acronym for cohort

Name of Principal Investigator

Title	Professor
First name	L-G
Last name	Nilsson

Address of institution where award is held

Institution	
Street Address	BVH
City	Umea
Postcode	S-901 87

Country

- Sweden

Website

http://www.betula.su.se/en/index.html

Contact email

lgn@psychology.su.se

Funding source

Swedish Research Council

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

Prospective study of dementia with focus on cognitive and genetic risk factors

2b. Features distinguishing this cohort from other population cohorts

Randomly sampled from pupulation registry — hence representative; low drop-out rates.

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

200

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)

http://www.betula.su.se/en/publikationer_2/

4a. Study criteria: age range of participants at recruitment

Age in years from: 25

To (‘until death’ if applicable): ‘until death’

4b. Study criteria: inclusion criteria

Native Swedish speakers.
Able to read and write.

4c. Study criteria: exclusion criteria

Neurological disease at basline (including dementia)

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

- 1,000 – 5,000 participants

6a. Measures used to characterise participants

Demographics, personality inventories, large cognitive battery, life events inventory, stress and depression scales

6b. Additional measures for participants with a clinical disorder

No

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

- No

7. Study design

- Prospective cohort

8. Cases matched by

- Other health assessment (specify) / N/A
- none

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

05-11-1988

10a iii) Data collection for this study is

- Data collection 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 other records or registers (such as dental records, police records etc). Please specify
- Statistics Sweden

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	Y	99
Database is web-based		
Database on spreadsheet		
Database is on paper		
Other (specify)		

Language used:

Swedish

13b. Format and availability of data held as individual records
Language used:
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 Committee mechanism

- Local/ regional access
- National access
- International access

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: Stabilised samples (frozen or fixed)
- 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

- If available for a subset please specify number of patients and % of total cohort
- 25%