Cohort of Norway

https://neurodegenerationresearch.eu/survey/cohort-of-norway/

Title of the cohort

Cohort of Norway

Acronym for cohort

CONOR

Name of Principal Investigator

Title	Adviser and CONOR Coordinator
First name	Kjersti
Last name	Andersen Nerhus

Address of institution where award is held

Institution	The Norwegian Institute of Public Health
Street Address	P.O.Box 4404 Nydalen
City	Oslo
Postcode	NO-0403

Country

Norway

Website

http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4220:1

Contact email

kjersti.andersen.nerhus@fhi.no

Funding source

The Research Council of Norway and other national and international funding sources.

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

- Neurodegenerative disease in general

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

Already possible

2a. Stated aim of the cohort

CONOR is a collection of health data and blood samples from several Norwegian health surveys. When the data collection is complete, CONOR will be a unique database with health data and

biological samples of about 200 000 individuals. The purpose of CONOR is investigating the causes of disease.

2b. Features distinguishing this cohort from other population cohorts
3a. i) Number of publications that involve use of cohort to date
0
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)
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:
To ('until death' if applicable): 100
4b. Study criteria: inclusion criteria

http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4220:1

4c. Study criteria: exclusion criteria

http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4220:1

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

More than 15,000

6a. Measures used to characterise participants

http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4220:1

6b. Additional measures for participants with a clinical disorder
6c. Are there defined primary and secondary endpoints (e.g. defined health parameters)

http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4220:1

7. Study design

- Cross sectional survey
- Other (please specify)
- A collection of population cohorts

8. Cases matched by

- Age
- Sex
- Co-morbidities
- Cognitive function
- Physical ability
- Other health assessment (specify) / N/A
- http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4

9a. Does the study include a specialised subset of control participants

Yes

9b. If yes, description of specialised subset of control participants

CONOR is a collection of population cohorts.

10a. i) Data collection start date

01-03-2011

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
11. Data collected

- Through links to medical records
- Through links to other records or registers (such as dental records, police records etc). Please specify
- http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4

12. System in place to enable re-contact with patients for future studies
13a. Format and availability of data stored in a database
Language used:
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

- Access independent of collaboration with PI
- Access Committee mechanism
- National access
- International access
- Applicant needs to provide separate external ethics approval

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: DNA

16b. ii) Form available tissues/samples/DNA are supplied in

- Primary Samples: Stabilised samples (frozen or fixed)
- Secondary samples: DNA
- Other, please specify
- http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4

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