Biohealth Norway

https://www.neurodegenerationresearch.eu/survey/biohealth-norway/

Title of the cohort

Biohealth Norway

Acronym for cohort

Name of Principal Investigator

Title	Director, MD PhD
First name	Camilla
Last name	Stoltenberg

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=5906:0:15,4627:1

Contact email

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

Biohealth Norway is a large population based cohort established for genetic epidemiologic research.

2b. Features distinguishing this cohort from other population cohorts

When completed, the cohort will comprise biological samples and standardised health and exposure

data from 500 000 Norwegian individuals of all ages, corresponding to approximately 1/10 of the Norwegian population.

The main research purpose is to improve prevention and treatment of disease by increased knowledge of the molecular nature of disease, based on discoveries of new genes associated to complex diseases and new information on the interaction between genes and environmental factors.

The Norwegian Institute of Public Health (NIPH), Division of Epidemiology, is responsible for the technology platform. The network is organised in collaboration with the regional health studies at the four universities in Norway, represented in the steering group.

The Norwegian health registries may provide valuable data by linking to the data obtained in the cohort studies. By utilising high-throughput genotyping, microarray analyses of RNA and proteins as well as measures of environmental exposure in biological samples, many very specific research questions can be resolved. Biohealth intend to provide technology support for other biobanks and will interact with other platforms such as the platforms on bioinformatics, SNP genotyping and microarrays.

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

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

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3b. Publication list/link to where data or publications are accessible (if available)

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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

This is a population cohort. When completed, the cohort will comprise biological samples and standardised health and exposure data from 500 000 Norwegian individuals of all ages, corresponding to approximately 1/10 of the Norwegian population.

4c. Study criteria: exclusion criteria

See Q4b

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

- More than 15,000

6a. Measures used to characterise participants

DNA, blood parameters, coupling to registries.

6b. Additional measures for participants with a clinical disorder

Yes.

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

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7. Study design

- Cross sectional survey
- Other (please specify)
- Population cohort

8. Cases matched by

Age

Sex

Co-morbidities

Cognitive function

Physical ability

Other health assessment (specify) / N/A

Individuals used in research studies may be matched at all these and more parameters.

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

- Yes

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

This is a population cohort. Thus, cases and control individuals are both present and may be picked out for each individual research study.

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

- No

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=5906:0:15,4

12. System in place to enable re-contact with patients for future studies

- No

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

- National access
- Access independent of collaboration with PI
- Access Committee mechanism
- 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=5906:0:15,4

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