The Health Survey in Nord-Trøndelag

https://www.neurodegenerationresearch.eu/survey/the-health-survey-in-nord-trondelag/

Title of cohort

The Health Survey in Nord-Trøndelag

Acronym for cohort

HUNT

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Steinar

Name of Principal Investigator - Last name

Krokstad

Address of institution -Institution

HUNT Research Center NTNU (Norwegian University of Science and Technology)

Address of institution - Street address

Forskningsvegen 2

Address of institution - City

Levanger

Address of institution - Postcode

7600

Country

Norway

Website

http://www.ntnu.no/hunt

Contact email

Funding source

Public funding source for NTNU, but also for the wider research community nationally and internationally.

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

Parkinson's disease and PD-related disorders|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 study health and diseases in the general population and the effects of environmental and genetic interactions to identify potential causes of diseases as well as preventive strategies

Q2b. What distinguishes this cohort from other population cohorts?

It is longitudinal and prospective with repeated measures and covers the entire population above the age of 13 within one county of Norway. It has been conducted since 1984 and a wide variaty of disease outcomes have been identified based on linkage to registry data.

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

Approx 1600

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

Kristian Hveem, NTNU, Studying genes affecting cardiovsacular traits|Kristian Hveem, NTNU, Studying genes affecting cardiovsacular traits|Geir Selbæk, University of Oslo, Cognitive impairment and the risk of Alzheimers disease (HUNT4)

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

1) Holmen OL et al. Systematic evaluation of coding variation identifies a candidate causal variant in TM6SF2 influencing total cholesterol and myocardial infarction risk. Nat genet, 2014, April, 46(4) 3) Bergh S et al, Cohort profile: the Health and Memory Study (HMS): a dementia cohort linked to the HUNT study in Norway, Int J of Epidem, 2014 Dec 43(6)

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:

13

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

until death

Q4b. Study criteria: what are the inclusion criteria?

Resident in the county

Q4c. Study criteria: what are the exclusion criteria?

Not a resident in the county

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

More than 15,000 participants

Q6a. Please describe what measures are used to characterise participants

Questionairre data, clinical measurements, biological samples, linkage to local, regional and national health registries

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

Yes, for several

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

Yes

If yes please specify

Type 2 Diabetes, Myocardial Infarction, Dementia and several others

Q7. What is the study design (select all that apply)?

Prospective cohort|Longitudinal|Cross sectional survey

Q8. Are your cases matched by

Age

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

01/08/1984

Q10a. ii) Please enter the data collection end date

01/02/2019

Q10a. iii) Is data collection for this study

At the planning stage|Data analysis ongoing

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

Yes - funding applied for/funding awarded

Q11. Is data collected

Through links to medical records

Other please specify here

Also to other registries, such a prescription, familiy, birth, CVD, cause of death, fractures, income, disabilty pensions and many orthers

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

Yes (participants given permission to be re-contacted via PIs)

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)

Database is web-based

% available

100

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

% available
Q13a. Please give information on the format and availability of data stored in a database (4)
% available
Other (please specify)
% available
Q13b. Please give information on the format and availability of data held as individual records (1)

No

% available
Q13b. Please give information on the format and availability of data held as individual records (2)
% available
Q13b. Please give information on the format and availability of data held as individual records (3)
% available
Q13b. Please give information on the format and availability of data held as individual records (4)
% 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|Access committee mechanism|Local/ regional access|National access|International access|Access to industry|Access for pilot studies permitted|Access restricted to peer-reviewed work|Applicant needs to provide 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| Living donors: other, please specify below|Post-mortem donors: other - FFPE-samples may be retrieved and accessed through the Dept of Pathology, St Olav's Hospital, Trondheim

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

Primary samples: Supplied fresh| Primary Samples: Stabilised samples (frozen or fixed)|Secondary samples: plasma|Secondary samples: DNA|Secondary samples: RNA|Immortalized cells

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:
Norway

Diseases:
Alzheimer's disease & other dementias, Neurodegenerative disease in general, Parkinson's disease & PD-related disorders

Years:
2016

Database Categories:
N/A

Database Tags:
N/A