

German National Cohort

<https://www.neurodegenerationresearch.eu/survey/german-national-cohort/>

Title of cohort

German National Cohort

Acronym for cohort

GNC

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Karl-Heinz

Name of Principal Investigator - Last name

Joeckel

Address of institution -Institution

University Clinic Essen, Institute of Medical Informatics, Biometry, and Epidemiology

Address of institution - Street address

Hufelandstraße 55

Address of institution - City

Essen

Address of institution - Postcode

45122

Country

Germany

Website

<http://www.imibe.de/index.php>

Contact email

Funding source

Combined national and regional funding

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

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

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

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

Its aim is to investigate the causes for the development of major chronic diseases, i.e. cardiovascular diseases, cancer, diabetes, neurodegenerative/-psychiatric diseases, musculoskeletal diseases, respiratory and infectious diseases, and their pre-clinical stages or functional health impairments.

Q2b. What distinguishes this cohort from other population cohorts?

This is a national initiative of enormous size. More than 200.000 people will be recruited for this study.

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

0

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

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

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

urine, saliva, feces, nasal swabs

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

20

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

70

Q4b. Study criteria: what are the inclusion criteria?

n/a

Q4c. Study criteria: what are the exclusion criteria?

n/a

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

n/a

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

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)?

Prospective cohort| Longitudinal

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

01/01/2013

Q10a. ii) Please enter the data collection end date

31/12/2023

Q10a. iii) Is data collection for this study

At the planning stage

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

Only through the study

Other please specify here

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)

% available

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

(2)

% available

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)

% 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?

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: DNA

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

Primary Samples: Stabilised samples (frozen or fixed)| Secondary samples: plasma| Secondary samples: DNA| Secondary samples: RNA| Secondary samples: protein extracts

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:

Germany

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