

Northern Ireland Cohort for Longitudanal Study of Ageing

<https://www.neurodegenerationresearch.eu/survey/northern-ireland-cohort-for-longitudanal-study-of-ageing/>

Title of cohort

Northern Ireland Cohort for Longitudanal Study of Ageing

Acronym for cohort

NICOLA

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

Frank

Name of Principal Investigator - Last name

Kee

Address of institution -Institution

Queen's University of Belfast

Address of institution - Street address

QUB Centre for Public Health, Institute of Pathology, Royal Hospital Site, Grosvenor Road

Address of institution - City

Belfast

Address of institution - Postcode

BT12 6BA

Country

United Kingdom

Website

<https://www.qub.ac.uk/sites/NICOLA/>

Contact email

Funding source

ESRC (wave 1) , Atlantic Philanthropies (wave 2)

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

Neurodegenerative disease in general

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

2016-2020

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

The study will look at health, lifestyles and financial situations of 8,500 people as they grow older monitoring how their circumstances change over a 10 year period.

Q2b. What distinguishes this cohort from other population cohorts?

Focused on ageing and comparable with other aging studies in UK and Ireland

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

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

50

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

Until death

Q4b. Study criteria: what are the inclusion criteria?

Age 50 and over

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)?

5,001-10,000 participants

Q6a. Please describe what measures are used to characterise participants

Anthropometric and physical: Weight Height Waist & Hip circumference (used to calculate BMI and WHR) Blood pressure (clinic measured) Heart rate Spirometry Step test Timed up and go Visual Acuity & Contrast sensitivity (Matrix Perimetry) Lens Photography (Pentacam HR) Multi-modal retinal imaging (Optical Coherence tomography (OCT), Colour, multi-spectral, infra-red, fundus auto fluorescence (FAF)) Ultra wide field retinal imaging (Colour and auto fluorescence Intra-ocular pressure Auto-refraction Grip strength (dynamometry)

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

No

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)?

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

01/10/2013

Q10a. ii) Please enter the data collection end date

Q10a. iii) Is data collection for this study

Data collection ongoing| 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

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)

Data summarised in database

% available

Q13a. Please give information on the format and availability of data stored in a database (2)

No

% available

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

TBC

% available

Q13a. Please give information on the format and availability of data stored in a database (4)

TBC

% available

Other (please specify)

% available

Q13b. Please give information on the format and availability of data held as individual records (1)

TBC

% available

Q13b. Please give information on the format and availability of data held as individual records (2)

TBC

% available

Q13b. Please give information on the format and availability of data held as individual records (3)

TBC

% available

Q13b. Please give information on the format and availability of data held as individual records (4)

TBC

% 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

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?

Secondary samples: DNA

Q16b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q14 above)?

No

Q17. Is information on biological characteristics available to other groups?

No

Number of Patients

TBC

% of total cohort

Types:

Population Cohorts

Member States:

United Kingdom

Diseases:

Neurodegenerative disease in general

Years:

2016

Database Categories:

N/A

Database Tags:

N/A