

Cohort – Understanding Society

<https://neurodegenerationresearch.eu/survey/cohort-understanding-society/>

Title of the cohort

Cohort – Understanding Society

Acronym for cohort

Name of Principal Investigator

Title Professor

First name Nick

Last name Buck

Address of institution where award is held

Institution University of Essex

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City Essex

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Country

- United Kingdom

Website

<http://www.understandingsociety.org.uk/>

Contact email

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Funding source

Economic and Social Research Council, Government's Large Facilities Capital Fund, Consortium of Government Departments

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

A major research study designed to provide valuable new evidence about the people of the UK, their lives, experiences, behaviours and beliefs.

2b. Features distinguishing this cohort from other population cohorts

Understanding Society will every year track the fortunes, attitudes and circumstances of 100,000 people living in Britain. The focus is on the household, looking at how different members of a family relate to each other.

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)

<http://research.understandingsociety.org.uk/publications>

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: 10

To ('until death' if applicable): until death

4b. Study criteria: inclusion criteria

Randomly selected household

4c. Study criteria: exclusion criteria

Depending on weighting on household samples, new immigrants in the UK

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

- More than 15,000

6a. Measures used to characterise participants

6b. Additional measures for participants with a clinical disorder

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

- No

7. Study design

- Longitudinal
- Longitudinal
- Household panel survey

8. Cases matched by

- Age
- Sex

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

- No

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

10a. i) Data collection start date

01-01-2009

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

- Yes – funding applied for

11. Data collected

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

15. Data sharing policy specified as a condition of use

- Data to be made publicly available immediately

16a. Are tissues/samples/DNA available to other groups

No

16b. i) Description of available tissues/samples/DNA

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

16b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data

17. Is information on biological characteristics available to other groups

- No