## Understanding Society: UK Household Longitudinal Study

https://neurodegenerationresearch.eu/survey/understanding-society-uk-household-longitudinal-study/ **Title of cohort** 

Understanding Society: UK Household Longitudinal Study

**Acronym for cohort** 

**UKHLS** 

Name of Principal Investigator - Title

Prof

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## **Funding source**

Core funding from ESRC, co-funding from UK government funders.

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?

Already possible

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

UKHLS is the largest household panel study in the world and tracks individuals within families over time and hence is a vital resource for science and policy.

Q2b. What distinguishes 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.

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

500

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

E. Whitley (Glasgow) (2016) Variations in cognitive abilities across the life course: cross-sectional evidence from Understanding Society: the UK Household| For more publications please see UKDS or our websiteLongitudinal Study, Intelligence http://dx.doi.org/10.1016/j.intell.2016.07.001|

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

www.understandingsociety.ac.uk

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:

10

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

Until death

Q4b. Study criteria: what are the inclusion criteria?

general population in sampled households representative of UK population, with ethnic minority boosts

Q4c. Study criteria: what are the exclusion criteria?
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

Anthropometric and physical biomedical measures: Blood pressure, Weight, Height, Waist, Body fat, Grip strength, Lung function, Blood samples, Biomarker data. Cognitive function. General measures on lifestyle, socio-economics and geography. Self-reported health and prescribed medications.

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)?

If yes please specify

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

Household Panel Study

Q8. Are your cases matched by

Age| Sex

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

01/01/2009

Q10a. ii) Please enter the data collection end date

Ongoing

Q10a. iii) Is data collection for this study

At the planning stage | Data collection ongoing | Data analysis ongoin

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

Also through links to medical records and other records

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

Yes

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)

No

% available

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

No

% available

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

No

% available

Other (please specify)

% available

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

Data is held as individual records % available 100 Q13b. Please give information on the format and availability of data held as individual records (2) No % available Q13b. Please give information on the format and availability of data held as individual records (3) Data held on computer based records % available 100 Q13b. Please give information on the format and availability of data held as individual records (4) No % available Please specify language used English Q14a. Is data available to other groups? Yes Q14b. If data is available to other groups what is the access policy/mechanisms for access? Other criteria (UKDS) Q15. What data sharing policy is specified as a condition of use? Data to be made publically available immediately Q16a. Are tissues/samples/DNA available to other groups? Yes Q16b i) If yes, please describe below:

Living donors: DNA

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

Secondary samples:(derivatives of primary samples)| Secondary samples:(derivatives of primary samples)

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?

Yes, for all the cohort

Number of Patients % 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