

National Survey of Health and Development

<https://neurodegenerationresearch.eu/survey/national-survey-of-health-and-development/>

Title of the cohort

National Survey of Health and Development

Acronym for cohort

NSHD

Name of Principal Investigator

Title Professor

First name Diana

Last name Kuh

Address of institution where award is held

Institution MRC Unit of Lifelong Health and Ageing

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Funding source

Core funding from Medical Research Council

1. The cohort includes, or expects to include, incidence of the following conditions

- Alzheimer's disease and other dementias
- Neurodegenerative disease in general

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

Already possible

2a. Stated aim of the cohort

Now, as participants reach retirement, the research team is developing the NSHD into a life course

study of ageing.

2b. Features distinguishing this cohort from other population cohorts

3a. i) Number of publications that involve use of cohort to date

650

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://www.nshd.mrc.ac.uk/findings/publications.aspx> <http://www.nshd.mrc.ac.uk/research.aspx>

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: birth

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

4b. Study criteria: inclusion criteria

A sample of 5362 babies of all those born in one week of March 1946

4c. Study criteria: exclusion criteria

illegitimate babies

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

5,001 – 10,000 participants

6a. Measures used to characterise participants

Participants have been followed up at two and four years between 6 and 31 years there were 15 follow ups research nurses visited study members at 36,43,53 at 43 and 53 cognitive capability tests were included at 53 tests of physical capability were included between 47 and 54 and again at 57 women were sent questionnaires to obtain information about timing of the menopause 60-64 physical and cognitive capability and ageing of cardiovascular and musculoskeletal body systems

6b. Additional measures for participants with a clinical disorder

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

death

7. Study design

- Longitudinal

8. Cases matched by

- Age

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

03-03-1946

10a. ii) Data collection end date

03-03-2046

10a iii) Data collection for this study is

- Data analysis ongoing
- Closed to new patients

10b. Plans to continue the cohort study beyond the current projected end date

- Yes – intend to apply for funding

11. Data collected

- Only through the study
- Through links to medical records
- Through links to other records or registers (such as dental records, police records etc). Please specify
- ONS deaths and cancers, Census 1951,1971,2001

12. System in place to enable re-contact with patients for future studies

13a. Format and availability of data stored in a database

Yes/No % available

Data summarised in database yes 100

Database is web-based

Database on spreadsheet

Database is on paper

Other (specify)

Language used:

13b. Format and availability of data held as individual records

Yes/No % available

Data held as individual records

Data is web-based

Data held on computer based records yes 100

Data held on cards

Other (specify)

Language used:

14a. Are data available to other groups

Yes

14b. Access policy/mechanisms for access if data are available to other groups

- Access Committee mechanism

15. Data sharing policy specified as a condition of use

Data made publicly available after a specified time point

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

Yes

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

- Living donors: blood
- Living donors: DNA

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

- Primary Samples: Stabilised samples (frozen or fixed)
- Secondary samples: plasma
- Secondary samples: cell lines derived from primary samples
- Composite samples: chip for a particular ND condition

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

Yes

17. Is information on biological characteristics available to other groups

Yes, for all the cohort