

Hertfordshire Birth Cohort

<https://www.neurodegenerationresearch.eu/survey/hertfordshire-birth-cohort/>

Title of the cohort

Hertfordshire Birth Cohort

Acronym for cohort

Name of Principal Investigator

Title Professor

First name Cyrus

Last name Cooper

Address of institution where award is held

Institution MRC Lifecourse Epidemiology Unit

Street Address Southampton General Hospital

City Southampton

Postcode SO16 6YD

Country

United Kingdom

Website

www.mrc.soton.ac.uk

Contact email

Funding source

Medical Research Council

University of Southampton

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

To investigate the role of early growth in the development of adult disease

2b. Features distinguishing this cohort from other population cohorts

The availability of data on birthweight and weight at one year in people born from 1911-39

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://www.mrc.soton.ac.uk/index.asp?page=3>

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: recruited at birth

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

4b. Study criteria: inclusion criteria

Born in Hertfordshire 1911-39
birthweight and weight at one stated
singleton birth
traced on NHS central register

4c. Study criteria: exclusion criteria

Not the above

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

More than 15,000

6a. Measures used to characterise participants

Birthweight
Weight at one year
Cause of death
Detailed clinical characterisation of subset (C4000)

6b. Additional measures for participants with a clinical disorder

No

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

Death

7. Study design

- Longitudinal

8. Cases matched by

- Other health assessment (specify) / N/A

- n/a

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

01-01-1911

10a. ii) Data collection end date

31-12-2039

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

- No

11. Data collected

- Through links to medical records

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

Yes (participants have given permission to be re-contacted via the PIs to ask if they would participate in further studies)

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

	Yes/No	% available
Data summarised in database	Yes	100
Database is web-based	No	
Database on spreadsheet	No	
Database is on paper	No	
Other (specify)	Yes	

Language used:

Stored in Access Database

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

	Yes/No	% available
Data held as individual records	Yes	100
Data is web-based	No	
Data held on computer based records	Yes	
Data held on cards	No	

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

- Apply to PI or co-ordinator at resource
- Access Committee mechanism

15. Data sharing policy specified as a condition of use

No requirement to make data publicly available

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

Yes

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

- Living donors: blood
- Living donors: blood derivatives
- Living donors: DNA
- Living donors: skeletal muscle biopsy
- Other, please specify
- Above samples stored from a subset (C4000), some of whom have since died

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

- Other, please specify
- By negotiation

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

- If available for a subset please specify number of patients and % of total cohort
- 4000/35,000 = 11%