

# Hertfordshire Birth Cohort

<https://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](http://www.mrc.soton.ac.uk)

## Contact email

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## 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%