Cohort – TwinsUK

https://neurodegenerationresearch.eu/survey/cohort-twinsuk/

Title of the cohort

Cohort – TwinsUK

Acronym for cohort

TUK

Name of Principal Investigator

Title	Prof
First name	Tim
Last name	Spector

Address of institution where award is held

Institution	Dep. of Twin Research & Genetic Epidemiology
Street Address	Westminster Bridge Road
City	London
Postcode	SE1 7EH

Country

United Kingdom

Website

http://www.twin-research.ac.uk/

Contact email

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Funding source

The main funding bodies currently supporting TwinsUK are the Wellcome Trust, European Union (EU), and National Institute for Health Research (NIHR)

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

- Alzheimer’s disease and other dementias
- Parkinson’s disease

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

Already possible

2a. Stated aim of the cohort

The TwinsUK is an adult twin British registry shown to be representative of the United Kingdom population

2b. Features distinguishing this cohort from other population cohorts

Healthy Twins cohort

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

600

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.twin-research.ac.uk/publications.html

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: 18

To ('until death' if applicable): until death (or retirement from the study)

4b. Study criteria: inclusion criteria

No inclusion criteria

4c. Study criteria: exclusion criteria

No exclusion criteria

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

10,001 – 15,000 participants

6a. Measures used to characterise participants

Clinical visit and questionnaire

6b. Additional measures for participants with a clinical disorder

No

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

No

7. Study design

- Prospective cohort

8. Cases matched by

- Other health assessment (specify) / N/A

- no match

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

01-01-1992

10a. ii) Data collection end date
10a iii) Data collection for this study is

Data collection ongoing

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

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
Database is web-based	no
Database on spreadsheet	no
Database is on paper	no
Other (specify)	

Language used:

English

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

	Yes/No % available
Data held as individual records	yes
Data is web-based	no
Data held on computer based records	yes
Data held on cards	no
Other (specify)	

Language used:

English

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
- Resource has own ethics approval so usually no need for separate external ethics approval

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

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

Yes

17. Is information on biological characteristics available to other groups