Caerphilly Prospective Cohort study

https://www.neurodegenerationresearch.eu/survey/caerphilly-prospective-cohort-study/

Title of the cohort

Caerphilly Prospective Cohort study

Acronym for cohort

CaPS

Name of Principal Investigator

Title	Dr.
First name	John
Last name	Gallacher

Address of institution where award is held

Institution	Department of Primary Care and Public Health
Street Address	Heath Park
City	Cardiff
Postcode	CF14 4XY

Country

United Kingdom

Website

http://www.epi.bris.ac.uk/caerphilly/caerphilly.htm

Contact email

Funding source

None at the moment

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

Was initially set up to examine cardiovascular risk factors but then included cognitive function and

other age-related phenotypes

2b. Features distinguishing this cohort from other population cohorts

Long term follow-up and wide range of phenotypes

3a. i) Number of publications that involve use of cohort to date
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)
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: 45

To ('until death' if applicable): 59

4b. Study criteria: inclusion criteria

Middle men registered in specific general practices in Caerphilly and surrounding villages

4c. Study criteria: exclusion criteria

None

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

1,000 – 5,000 participants

6a. Measures used to characterise participants

Mulitple phenotypes

6b. Additional measures for participants with a clinical disorder

No

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

Mortality, CVD, stroke, Heart failure, dementia, PD, diabetes, renal failure

7. Study design

- Prospective cohort

8. Cases matched by

- Other health assessment (specify) / N/A
- No matching

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

10-07-1979

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

- 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)		

Language used:

English

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	100
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
- National access
- International access
- Access to industry
- Access restricted to peer-reviewed work

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

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

- Primary Samples: Stabilised samples (frozen or fixed)
- Secondary samples: derivatives of primary samples
- Secondary samples: plasma
- Secondary samples: DNA

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