# Brains for Dementia Research

https://neurodegenerationresearch.eu/survey/brains-for-dementia-research-3/

**Title of cohort**

Brains for Dementia Research

**Acronym for cohort**

BDR

**Name of Principal Investigator - Title**

Prof

**Name of Principal Investigator - First name**

Paul

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**Funding source**

Alzheimer's Research UK and Alzheimer's Society in association with Medical Research Council

**Q1a. Please indicate below if your cohort includes or expects to include, incidence of the following conditions?**

Alzheimer's disease and other dementias

**Q1b. When are studies on the above condition(s) expected to become possible?**

Already possible

**Q2a. In a single sentence what is the stated aim of the cohort?**

To supply brain tissue and associated cognitive data for research to the neuroscience community, exercising responsible stewardship for the brain tissue and maximizing the potential benefit of this precious resource.

**Q2b. What distinguishes this cohort from other population cohorts?**

This cohort contains a high proportion of registered brain donors without dementia. Participants undergo regular cognitive testing and blood samples are also collected from some of the cohort.

**Q3a. i) Number of publications that involve use of your cohort to date**

161

**Q3a.ii) Please give up to three examples of studies to date (Principal Investigator, Institution, Title of Study)**

A Olmos-Alonso, University of Southampton, Pharmacological targeting of CSF1R inhibits microglial proliferation and prevents the progression of Alzheimer's-like pathology| Rita Guerreiro, UCL, Genome-wide analysis |of genetic correlation in dementia with Lewy bodies, Parkinson’s and Alzheimer’s diseases |Katie Lunnon, University of Exeter, Methylomic profiling implicated cortical deregulation of ANK1 in Alzheimer’s disease.

**Q3b. If data on research outputs are already available please paste the publication list/other data or provide a link to where these data are publicly available**
**Q3c. If no research has been done as yet, please explain in a few sentences what information (i.e. research findings) you expect will be gained from the population**
**Q4a. Study criteria: what is the age range of participants at recruitment? Age in years From:**

65

**Q4a. Study criteria: what is the age range of participants at recruitment? To:**

until death

**Q4b. Study criteria: what are the inclusion criteria?**

Prospective donors must be over the age of 65

**Q4c. Study criteria: what are the exclusion criteria?**

Additional pathology (e.g. Brain tumour, major stroke) affecting suitability of brain tissue.

**Q5. What is the size of the cohort (i.e. how many participants have enrolled)?**

1,000-5,000 participants

**Q6a. Please describe what measures are used to characterise participants**

PAST HISTORY FROM CAMDEX, CLINICAL DEMENTIA RATING WORKSHEET (Study partner), BRISTOL ACTIVITIES OF DAILY LIVING SCALE (BADLS), NEUROPSYCHIATRIC INVENTORY, GLOBAL DEPRESSION SCALE (CORNELL SCALE FOR DEPRESSION IN DEMENTIA, GERIATRIC DEPRESSION SCALE), MINI MENTAL STATE EXAMINATION, TICS-M, MONTREAL COGNITIVE ASSESSMENT, MoCA-Blind, CLINICAL DEMENTIA RATING WORKSHEET (Participant), HEARING AND EYESIGHT IMPAIRMENT, OTHER PHYSICAL PARAMETERS (BLOOD PRESSURE, WAIST/HIP RATIO, GLOBAL DETERIORATION SCALE, HACHINSKI ISCHAEMIC SCORING SYSTEM, LIFESTYLE (DIET & EXERCISE)

**Q6b. Are there additional measures for participants with a clinical disorder?**
**Q6c. Are there defined primary and secondary endpoints (e.g. defined health parameters)?**

No

**If yes please specify**
**Q7. What is the study design (select all that apply)?**

Prospective cohort|Longitudinal

**Q8. Are your cases matched by**
**Q9a. Does your study include a specialised subset of control participants?**

No

**Q9b. If your study includes a specialised subset of control participants please describe**
**Q10a. i) Please enter the data collection start date**

05/01/2008

**Q10a. ii) Please enter the data collection end date**

04/01/2018

**Q10a. iii) Is data collection for this study**

Data collection ongoing| Data analysis ongoing| Closed to new patients

**Q10b. If data collection is ongoing, are there plans to continue the cohort study beyond the current projected end date?**

Yes - intend to apply for funding

**Q11. Is data collected**

Only through the study

**Other please specify here**
**Q12. Is there a system in place to enable re-contact with patients to ask about participation in future studies?**

Yes (participants given permission to be re-contacted via PIs)

**Q13a. Please give information on the format and availability of data stored in a database (1)**

Data summarised in database

**% available**
**Q13a. Please give information on the format and availability of data stored in a database (2)**

No

**% available**
**Q13a. Please give information on the format and availability of data stored in a database (3)**

No

**% available**
**Q13a. Please give information on the format and availability of data stored in a database (4)**

No

**% available**
**Other (please specify)**
**% available**
**Q13b. Please give information on the format and availability of data held as individual records (1)**

Data is held as individual records

**% available**

**Q13b. Please give information on the format and availability of data held as individual records (2)**

No

**% available**
**Q13b. Please give information on the format and availability of data held as individual records (3)**

No

**% available**
**Q13b. Please give information on the format and availability of data held as individual records (4)**

No

**% available**
**Please specify language used**

English

**Q14a. Is data available to other groups?**

Yes

**Q14b. If data is available to other groups what is the access policy/mechanisms for access?**

Apply to PI or co-ordinator at resource| Access independent of collaboration with PI| Access committee mechanism| Local/regional access| National access| International access| Access to industry| Access for pilot studies permitted| Resource has own ethics approval so usually no need for separate external ethics approval

**Q15. What data sharing policy is specified as a condition of use?**

No requirement to make data publicly available

**Q16a. Are tissues/samples/DNA available to other groups?**

Yes

**Q16b i) If yes, please describe below:**

Living donors: blood| Living donors: blood derivatives| Living donors: DNA| Post-mortem donors: brain| Post-mortem donors: spinal cord

**Q16b. ii) In what form are tissues/samples/DNA supplied?**

Primary Samples: Stabilised samples (frozen or fixed)

**Q16b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q14 above)?**

Yes

**Q17. Is information on biological characteristics available to other groups?**

No

**Number of Patients**
**% of total cohort**

**Types:**
Population Cohorts

**Member States:**
United Kingdom

**Diseases:**
Alzheimer's disease & other dementias

**Years:**
2016

**Database Categories:**
N/A

**Database Tags:**
N/A