Scottish Dementia Reserch Interest Register

https://neurodegenerationresearch.eu/survey/scottish-dementia-reserch-interest-register/

Title of the register

Scottish Dementia Reserch Interest Register

Name of Principal Investigator

Title	Professor
First name	John
Last name	Starr

Address of institution where award is held

Institution	Royal Victoria hospital
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Country

United Kingdom

Website

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1. Conditions included, or expected to be included, in the disease register

Alzheimer’s disease and other dementias

2a. Stated aim of the cohort

To enable people with dementia and related cognitive disorders, and their carers to have the opportunity to participate in research.

2b. Features distinguishing this register from other disease registers

There is no other disease register like this in the United Kingdom, for people with dementia. It gives people the opportunity to participate in research and gives researchers access to people who have already consented to participate in research with a set of baseline assessments completed. It allows detailed feasibility studies to be commenced and offers the opportunity for researchers to do detailed epidemiology studies in the field of dementia.

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

13

3a. ii) Up to three examples of studies to date (PI, Institution, Title of Study)

1. Name of PI	Michaela Dewar, University of Aberdeen, Long term beneficial effects of Minimal interference in MCI. Derek Brown NHS Greater Glasgow and Clyde – Observational cost of Alzheimer's disease in Europe (GERAS). Alasdair MacLullich University of Edinburgh Development of a new neuropsychological instrument for assessment and monitoring of delirium.

3c. Information (i.e. research findings) expected to be gained from the register

The main purpose of the register is to allow easier access to patients and carers for research and therefore make the process much quicker. The type of findings expected will cross a whole spectrum of the disease trajectory including the outcomes of drug studies, psychological interventions, improved knowledge of non-pharmacological interventions, the use of anti-psychotic drugs within a population, predictors of vascular disease and improved treatment options for vascular dementia, language and social cognition in frontal temporal dementia as compared to motor neurone disease. There is no limit to the use of the register for people with dementia and their carers.

4a. Study criteria: age range of participants

Age in years from: 55

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

4b. Study criteria: inclusion criteria

People with dementia and related cognitive disorders.

4c. Study criteria: exclusion criteria

People who have had no contact with a healthcare provider – diagnosis or cognitive disorder must be confirmed by a healthcare provider prior to inclusion on the register.

5. Size of the register (i.e. number of patients enrolled)

501 – 1,000 clinical cases

6a. Measures used to characterise participants

Family name, given name, maiden name, Community Health Index number, address, diagnosis, date of consent, GP, capacity to consent, details of person consenting on their behalf, carer details, cognitive status, functional ability, behavioural or psychological symptoms present, family history, concomitant disease, medication, sensory impairment, communication difficulties.

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

No

7a. i) Is the register of fixed duration

1

7a. ii) Data collection start date

09-02-2009

7b. Stage of data collection/analysis for the register

Data collection ongoing

Data analysis ongoing

8. Funding of the register

How the register is funded	Through the Chief Scientist Office of the Scottish Government
Is funding ongoing	yes
If so, for how long	until July 2011 – Awaiting outcome of further funding decision

9. Data sweeping

Number of data sweeps that have taken place none

10.The clinical (phenotypic) information held in the register from patients and other participants such as family members is

Only collected through the study

11. Limit on the number of studies that can be based on this set of patients

No

12a. Data stored in a database

Yes/No	% available
yes	100

12b. Data held as individual records

Yes/No	% available
yes	100

13a. Are data available to other groups

2

13b. Access policy/mechanisms for access if data are available to other groups

Access Committee mechanism
National access
Access restricted to peer-reviewed work
Applicant needs to provide separate external ethics approval

14. Data sharing policy specified as a condition of use

Data to be made publicly available immediately

15a. Are tissues/samples/DNA available to other groups

1

16a. Is information on biological characteristics available to other group

No

16b. Is the access policy/mechanism for obtaining details of the characteristics the same as that for obtaining other data

2