

Irish ALS Register

<https://neurodegenerationresearch.eu/survey/irish-als-register/>

Title of the register

Irish ALS Register

Name of Principal Investigator

Title Professor

First name Orla

Last name Hardiman

Address of institution where award is held

Institution Trinity College

Street Address College Green

City Dublin

Postcode 2

Country

Ireland

Website

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Contact email

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

Motor neurone diseases

2a. Stated aim of the cohort

Characterisation of demographics, phenotype, natural history; survival of ALS in Ireland

2b. Features distinguishing this register from other disease registers

Population based, includes nested case controlled studies

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

70

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

1. Incidence ; prevalence of ALS

1. Name of PI 2. Case control study of cognitive function in ALS

3. WGAS in ALS

3b. Publication list/link to where data or publications are accessible (if available)

4a. Study criteria: age range of participants

Age in years from: 18

To ('until death' is applicable): Death

4b. Study criteria: inclusion criteria

Possible, probable, definite ALS

4c. Study criteria: exclusion criteria

Conditions other than ALS

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

1,001 – 5,000 clinical cases

6a. Measures used to characterise participants

Clinical examination

Chart review

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

01-01-1995

7a. iii) Data collection end date

01-01-2024

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 Health Research Board, Framework 7, Research Motor Neuron

Is funding ongoing Health Research Board grant expires in 2012

9. Data sweeping

Number of data sweeps that have taken place 10

Date of the most recent data sweep Jan 2011

Date of next data sweep July 2011

Number of data sweeps are planned on current funding 3

Total number of planned data sweeps (with funding and with funding yet to be secured) 6

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

Routinely collected as medical records

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 80

no

yes 30

yes 100

12b. Data held as individual records

Yes/No % available

yes

no

yes

no

13a. Are data available to other groups

2

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

Access through collaboration with PI only

14. Data sharing policy specified as a condition of use

No requirement to make data publicly available

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

2

15b. i) Description of available tissues/samples/DNA

Living donors: DNA

15b. ii) Form available tissues/samples/DNA are supplied in

Secondary samples: DNA

15b iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data

2

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

Yes, for all the cohort

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

2