

# Irish ALS Register

<https://www.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

[www.mnd.ie](http://www.mnd.ie)

## Contact email

[email protected]; [email protected]

## 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