

Young Onset Neurodegeneration Register

<https://www.neurodegenerationresearch.eu/survey/young-onset-neurodegeneration-register/>

Title of the register

Young Onset Neurodegeneration 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.tcd.ie

Contact email

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

Alzheimer's disease and other dementias

Motor neurone diseases

Parkinson's disease

Huntington's disease

Neurodegenerative disease in general

2a. Stated aim of the cohort

A incident based study of young onset neurodegeneration in the greater Dublin area

2b. Features distinguishing this register from other disease registers

Population based cohort study in the under 65 age group

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

0

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

Incidence and phenotype of young onset neurodegeneration in a large urban population

4a. Study criteria: age range of participants

Age in years from: 40

To ('until death' is applicable): 64

4b. Study criteria: inclusion criteria

Young onset neurodegeneration

4c. Study criteria: exclusion criteria

Other mimic conditions

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

0 – 500 clinical cases

6a. Measures used to characterise participants

Clinical evaluation, neuropsychological assessment, neuroimaging

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

01-01-2011

7a. iii) Data collection end date

30-12-2016

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

At the planning stage

Data collection ongoing

8. Funding of the register

How the register is funded No dedicated funding to date

9. Data sweeping

Number of data sweeps that have taken place N/A

Date of the most recent data sweep N/A

Date of next data sweep N/A

Number of data sweeps are planned on current funding N/A

Total number of planned data sweeps (with funding and with funding yet to be secured) N/A

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

Yes

Yes

Yes

12b. Data held as individual records

Yes/No % available

Yes

Yes

Yes

13a. Are data available to other groups

2

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

Apply to PI or co-ordinator at resource

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