

# 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](http://www.tcd.ie)

## Contact email

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## 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