

The Irish Longitudinal Study on Ageing

<https://www.neurodegenerationresearch.eu/survey/the-irish-longitudinal-study-on-ageing/>

Title of cohort

The Irish Longitudinal Study on Ageing

Acronym for cohort

TILDA

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

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Kenny

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Ireland

Website

www.tilda.ie

Contact email

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Funding source

Department of Health, Ireland & Atlantic Philanthropies

Q1a. Please indicate below if your cohort includes or expects to include, incidence of the following conditions?

Neurodegenerative disease in general

Q1b. When are studies on the above condition(s) expected to become possible?

Already possible

Q2a. In a single sentence what is the stated aim of the cohort?

To collect high quality, longitudinal, multidisciplinary data to determine the health, social and economic status and needs of older people, and the biological and environmental components of successful ageing.

Q2b. What distinguishes this cohort from other population cohorts?

To collect high quality, longitudinal, multidisciplinary data to determine the health, social and economic status and needs of older people, and the biological and environmental components of successful ageing.

Q3a. i) Number of publications that involve use of your cohort to date

Q3a.ii) Please give up to three examples of studies to date (Principal Investigator, Institution, Title of Study)

Q3b. If data on research outputs are already available please paste the publication list/other data or provide a link to where these data are publicly available

<http://tilda.tcd.ie/research/accessing-data/>

Q3c. If no research has been done as yet, please explain in a few sentences what information (i.e. research findings) you expect will be gained from the population

Q4a. Study criteria: what is the age range of participants at recruitment? Age in years From:

50

Q4a. Study criteria: what is the age range of participants at recruitment? To:

until death

Q4b. Study criteria: what are the inclusion criteria?

Age 50 and over (partner/spouse any age), community dwelling, cognitively intact

Q4c. Study criteria: what are the exclusion criteria?

Must be cognitively intact to complete interview

Q5. What is the size of the cohort (i.e. how many participants have enrolled)?

5,001-10,000 participants

Q6a. Please describe what measures are used to characterise participants

Interviews, self-completion questionnaires, health assessment

Q6b. Are there additional measures for participants with a clinical disorder?

No

Q6c. Are there defined primary and secondary endpoints (e.g. defined health parameters)?

No

If yes please specify

Q7. What is the study design (select all that apply)?

Longitudinal

Q8. Are your cases matched by

Other health assessment

Q9a. Does your study include a specialised subset of control participants?

No

Q9b. If your study includes a specialised subset of control participants please describe

Q10a. i) Please enter the data collection start date

01/01/2009

Q10a. ii) Please enter the data collection end date

01/01/2021

Q10a. iii) Is data collection for this study

Data collection ongoing|Data analysis ongoing

Q10b. If data collection is ongoing, are there plans to continue the cohort study beyond the current projected end date?

Yes - funding applied for/funding awarded

Q11. Is data collected

Only through the study

Other please specify here

Collected data is linked to other records such as mortality, medication use

Q12. Is there a system in place to enable re-contact with patients to ask about participation in future studies?

No

Q13a. Please give information on the format and availability of data stored in a database (1)

Data summarised in database

% available

100

Q13a. Please give information on the format and availability of data stored in a database (2)

No

% available

Q13a. Please give information on the format and availability of data stored in a database (3)

% available

Q13a. Please give information on the format and availability of data stored in a database (4)

% available

Other (please specify)

% available

Q13b. Please give information on the format and availability of data held as individual records (1)

% available

Q13b. Please give information on the format and availability of data held as individual records (2)

% available

Q13b. Please give information on the format and availability of data held as individual records (3)

Data held on computer based records

% available

Q13b. Please give information on the format and availability of data held as individual records (4)

% available

Please specify language used

English

Q14a. Is data available to other groups?

Yes

Q14b. If data is available to other groups what is the access policy/mechanisms for access?

Apply to PI or co-ordinator at resource|Access through collaboration with PI only| Access independent of collaboration with PI|Access committee mechanism|Other access mechanism|Local/ regional access|National access|International access|Access to industry|Public dataset available

Q15. What data sharing policy is specified as a condition of use?

Data made publicly available after a specified time point

Q16a. Are tissues/samples/DNA available to other groups?

Yes

Q16b i) If yes, please describe below:

Living donors: blood|Living donors: blood derivatives|Living donors: DNA

Q16b. ii) In what form are tissues/samples/DNA supplied?

Primary samples: Supplied fresh

Q16b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q14 above)?

No

Q17. Is information on biological characteristics available to other groups?

Yes, for all the cohort

Number of Patients

% of total cohort

Types:

Population Cohorts

Member States:

Ireland

Diseases:

Neurodegenerative disease in general

Years:

2016

Database Categories:

N/A

Database Tags:

N/A