

ONTology-based Web Database for Understanding Amyotrophic Lateral Sclerosis (Sweden)

<https://neurodegenerationresearch.eu/survey/ontology-based-web-database-for-understanding-amyotrophic-lateral-sclerosis-sweden/>

Title of study

ONTology-based Web Database for Understanding Amyotrophic Lateral Sclerosis (Sweden)

Acronym for cohort

ONWEBDUALS

Name of Principal Investigator - Title

Prof

Name of Principal Investigator - First name

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Funding source

VR

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

Motor neurone diseases| Prion disease

Q2a. In a single sentence what is the stated aim of the study? (Maximum 30 words)

ALS genetic epidemiology and environmental exposure in 4 EU countries Portugal, Germany, Poland, Sweden

Q2b. What distinguishes this case-control study from other studies?

systematic collecting of data in 4 countries combined with genetic studies

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

0

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

n/a

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

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 case-control study

Association between exposure and specific defined genetic variants of ALS

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

18

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

until death

Q4b. Study criteria: what are the inclusion criteria?

standard EFNS clinical diagnostic criteria for ALS

Q4c. Study criteria: what are the exclusion criteria?

lack of informant consent from the patient to participate. Patients with very advanced disease

Q5a. What is the size of the cohort (i.e. how many participants have enrolled)?

1,001-5,000

Q5b. What is the expected number of control participants?

200-500

Q6a. Please describe what measures are used to characterise participants

Standard neurological measures

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

Genetic analysis for specified ALS genes

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

No

If YES please specify

Q7. What is the study design?

Prospective cohort| dna analysis for SOD1 and C9orf72 mutations

Q8. Are your cases matched by

Age| Sex| Cognitive function| Genetic results

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

No

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

Q10a. Is data collection for this study

Data collection ongoing

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

No

Q11. Are data collected

Only through the study

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

No

Q13a. Please give information on data stored in a database (1)

No

% Available

Q13a. Please give information on data stored in a database (2)

Database is web-based

% Available

unknown

Q13a. Please give information on data stored in a database (3)

Database on spreadsheet (e.g. excel)

% Available

Unknown

Q13a. Please give information on data stored in a database (4)

No

% Available

Q13a. Please give information on data stored in a database (5)

No

% Available

Please specify language used

% Available

Q13b. Please give information on how data is held as individual records

Data is web-based

% Available

Q14a. Are data available to other groups?

No

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

Not applicable

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

No requirement to make data publicly available

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

No

Q16b i) If yes, please describe below

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

Primary samples: Supplied fresh| Secondary samples: plasma| Secondary samples: DNA

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

Yes

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

No

Types:

Case Control Studies

Member States:

Sweden

Diseases:

Motor neurone diseases, Prion disease

Years:

2016

Database Categories:

N/A

Database Tags:

N/A