

ALS quality register

<https://neurodegenerationresearch.eu/survey/als-quality-register/>

Title of the register

ALS quality register

Name of Principal Investigator - Title

Dr

Name of Principal Investigator - First name

Caroline

Name of Principal Investigator - Last name

Ingre

Address of institution -Institution

Dept of clinical neuroscience

Address of institution - Street address

Karolinska Institute

Address of institution - City

Stockholm

Address of institution - Postcode

171 77

Country

Sweden

Website

<http://www.neuroreg.se/sv.html/motoneuronsjukdom>

Contact email

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

Motor neurone diseases

Q2. In a single sentence, what is the stated aim of your register?

Q2b. What distinguishes this register from other disease registers?

national data, high coverage, longitudinal follow up

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

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

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 register

We aim to understand the demographic differences when examining a whole nations ALS-population. Establish a Swedish phenotype. Identify specific traits and use of non medical drugs.

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

18

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

until death

Q4b. Study criteria: what are the inclusion criteria?

All newly diagnosed ALS patients in Sweden

Q4c. Study criteria: what are the exclusion criteria?

none

Q5. What is the size of the register (i.e. how many patients have been enrolled)?

501-1000 clinical cases

Q6a. Please describe what measures are used to characterise participants

Questionnaire data, clinical findings, neurophysiological findings, imaging, laboratory tests, funtional scales

Q6b. Are there defined primary and secondary endpoints (e.g. defined health parameters)?

Yes

If YES, please describe

death

Q7a. i) Is the register of fixed duration?

No

Q7a. ii) Please enter the data collection start date

Q7a. iii) Please enter the data collection end date

Q7b. Could you provide some information about the data collection for this register?

Data collection ongoing|Data analysis ongoing

Q8. Funding of the register - How is the register funded?

Swedish Association of Local Authorities and Regions (SKL)

Q8. Funding of the register - Is this funding expected to continue

Yes

Q8. Funding of the register - If so, for how long (months)?

one-two years at a time

Q9. Could you provide information about data sweeping? - How many data sweeps have taken place?

none

Q9. Could you provide information about data sweeping? - When was the most recent data sweep?

Q9. Could you provide information about data sweeping? - When is the next data sweep?

Q9. Could you provide information about data sweeping? - How many more data sweeps are planned on current funding? e.g 0,1,2.....

Q9. Could you provide information about data sweeping? -How many more data sweeps are planned in total (with funding and with funding yet to be secured) e.g. 0,1,2...

Q10. Is the clinical (phenotypic) information that is held in the register from patients and other participants such as family members:

Routinely collected as medical records

Q11. Is there a limit on the number of studies that can be based on this set of patients?

No

If YES, please give details

Q12a. Please give information on the format and availability of data stored in a database (1)

Data summarised in database

% Available

100

Q12a. Please give information on the format and availability of data stored in a database (2)

Database is web-based

% Available

100

Q12a. Please give information on the format and availability of data stored in a database (3)

Database is web-based

% Available

Q12a. Please give information on the format and availability of data stored in a database (4)

No

% Available

Q12a. Please give information on the format and availability of data stored in a database (5)

% Available

Please specify language used

Swedish

Q12b. Please give information on how data is held as individual records (1)

Data is held as individual records

% Available

Q12b. Please give information on how data is held as individual records (2)

Data is web-based

% Available

100

Q12b. Please give information on how data is held as individual records (3)

Data held on computer based records

% Available

100

Q12b. Please give information on how data is held as individual records (4)

No

% Available

Please specify language used

Swedish

Q13a. Is data available to other groups?

Yes

Q13b. If data is available to other groups what is the access policy/mechanisms for access?

Apply to PI or co-ordinator at resource|National access|Resource has own ethics approval so usually no need for separate external ethics approval

Q14. What data sharing policy is specified as a condition of use?

Q15a. Are tissues/samples/DNA available to other groups?

No requirement to make data publicly available

Q15b. i) If yes, please describe below:

Q15b. ii) In what form are tissues/samples/DNA supplied?

Q15b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q13b above)?

Q16a. Is information on biological characteristics available to other groups?

Number of patients

% of total cohort

Q16b. If yes, is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q13b above)?

Types:

Disease Registers

Member States:

Sweden

Diseases:

Motor neurone diseases

Years:

2016

Database Categories:

N/A

Database Tags:

N/A