

# 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