Biomarkers, environmental and lifestyle risk factors for amyotrophic lateral sclerosis

https://neurodegenerationresearch.eu/survey/biomarkers-environmental-and-lifestyle-risk-factors-for-amyotrophic-lateral-sclerosis/

Title of study

Biomarkers, environmental and lifestyle risk factors for amyotrophic lateral sclerosis

Acronym for cohort

ALSrisc

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Funding source

Swedish Research Council, Karolinska Institutet, Ulla-Carin Lindqvist Foundation

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

Motor neurone diseases

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

To identify potential biomarkers as well as genetic and non-genetic risk factors for ALS

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

Population-based design, multiple control groups, rich biosamples

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)
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

We aim to understand the impact of environmental and lifestyle risk factors on ALS risk, the interactions between these risk factors and ALS genes, as well as the impact of these risk fators on ALS prognosis.

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

20

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

until death

Q4b. Study criteria: what are the inclusion criteria?

Newly diagnosed ALS patients in the Stockholm area, during 2016-2018

Q4c. Study criteria: what are the exclusion criteria?

Non-Swedish speaking

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

1-1,000

Q5b. What is the expected number of control participants?

200-500

Q6a. Please describe what measures are used to characterise participants

Questionnaire data, clinical medical records, and biosamples

Q6b. Are there additional measures for participants with the clinical disorder?
Q6c. Are there defined primary and secondary endpoints (e.g. defined health parameters)?

Yes

If YES please specify

Death

Q7. What is the study design?

Prospective cohort| population-based case-control study

Q8. Are your cases matched by

Age| Sex|

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

Yes

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

We include sibling and spouse controls

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?

Yes - intend to apply for funding

Q11. Are data collected

Only through the study| Through links to medical records| Through links to other records or registers(Swedish National Health Registers)

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)

Data summarised in database

% Available

100

Q13a. Please give information on data stored in a database (2)
% Available
Q13a. Please give information on data stored in a database (3)
% Available
Q13a. Please give information on data stored in a database (4)
% Available
Q13a. Please give information on data stored in a database (5)

Yes

% Available

100

Please specify language used

SAS/ACCESS

% Available

100

Q13b. Please give information on how data is held as individual records
% Available
Q14a. Are 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 Committee mechanism| Local/ regional access| Local/ regional access| Local/ regional access| Access for pilot studies permitted| Access restricted to peer-reviewed work| Applicant needs to provide separate external ethics approval

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?

Yes

Q16b i) If yes, please describe below

Living donors: blood| Living donors: blood derivatives| Living donors: DNA| Living donors: cerebro-spinal fluid| Living donors: other (saliva, fecal, hair, and nail samples)

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

Years:
2016

Database Categories:
N/A

Database Tags:
N/A