

FRAlim : Registry on Amyotrophic Lateral Sclerosis (ALS) in Limousin

<https://neurodegenerationresearch.eu/survey/fralim-registry-on-amyotrophic-lateral-sclerosis-als-in-limousin/>

Title of the register

FRAlim : Registry on Amyotrophic Lateral Sclerosis (ALS) in Limousin

Name of Principal Investigator - Title

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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?

To improve the epidemiological and clinical description of ALS in France using a reliable tool (exhaustive case ascertainment)

Q2b. What distinguishes this register from other disease registers?

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

4

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

B Marin, UMR Inserm 1094, Population-based epidemiology of amyotrophic lateral sclerosis (ALS) in an ageing Europe--the French register of ALS in Limousin (FRALim register).|B Marin, UMR Inserm 1094, Stratification of ALS patients' survival: a population-based study.|B Marin, UMR Inserm 1094, Population-Based Evidence that Survival in Amyotrophic Lateral Sclerosis is Related to Weight Loss at Diagnosis.

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

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

0

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

until death

Q4b. Study criteria: what are the inclusion criteria?

Patients with ALS identified by one of the following 3 sources: The French national body coordinating ALS referral centres; public and private hospitals in the Limousin region; health insurance data.

Q4c. Study criteria: what are the exclusion criteria?

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

0-500 clinical cases

Q6a. Please describe what measures are used to characterise participants

Demographic characteristics, neurological evaluations, nutritional evaluations

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

Yes

If YES, please describe

Survival

Q7a. i) Is the register of fixed duration?

No

Q7a. ii) Please enter the data collection start date

01/01/2001

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|Closed to new patients

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

National Research Agency; ALS Research Association; Limousin - Poitou - Charentes Centre for Research and Higher Education

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

We will search for other funds

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

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

2

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

2013

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

2016

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

Not defined

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...

Not defined

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

Only collected through the study

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)

No

% Available

Please specify language used

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

Data is held as individual records

% Available

10

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

90

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

No

% Available

Please specify language used

Q13a. Is data available to other groups?

Yes

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

Access through collaboration with PI only| Local/ regional access|National access|International access|Access for pilot studies permitted|Access restricted to peer-reviewed work|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?

No policy exists

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

No

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:

France

Diseases:

Motor neurone diseases

Years:

2016

Database Categories:

N/A

Database Tags:

N/A