FRALim - Registry on Amyotrophic Lateral Sclerosis (ALS) in Limousin

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General

Identification

Detailed name	Registry on Amyotrophic Lateral Sclerosis (ALS) in Limousin
Sign or acronym	FRALim
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL: 911038 (June 2011); CCTIRS: 10487 bis (January 2011)

General Aspects

Medical area	Disability/handicap Neurology Rare diseases
Pathology (details)	Amyotrophic lateral sclerosis
Health determinants	Genetic
Keywords	amyotrophic lateral sclerosis; ALS; Limousin; treatment; registry

Scientific investigator(s) (Contact)

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Collaborations

Participation in projects, networks and consortia	Yes
Details	EURALS (European ALS Consortium)

Funding

Funding status	Public
Details	National Research Agency; ALS Research Association; Limousin - Poitou - Charentes Centre for Research and Higher Education

Governance of the database

Sponsor(s) or organisation(s) responsible	UMR Inserm 1094 NET, Limoges
Organisation status	Public
Presence of scientific or steering committees	Yes
Labelling and database evaluation	Steering Committee at Inserm UMR 1094

Additional contact

Main features

Type of database

Type of database	Morbidity registers

Database objective

Main objective	To improve the epidemiological and clinical description of ALS in France.
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.

Population type

Age	Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years) Elderly (65 to 79 years) Great age (80 years and more)
Population covered	Sick population
Gender	Male Woman
Geography area	Regional
French regions covered by the database	Aquitaine Limousin Poitou-Charentes
Detail of the geography area	Limousin

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	2000

Size of the database

Size of the database (number of individuals)	< 500 individuals
Details of the number of individuals	322

Data

Database activity	Current data collection
Type of data collected	Clinical data Administrative data
Details of collected clinical data	Start site; familial ALS vs. sporadic ALS
Administrative data (detail)	Personal demographic data (name, age, sex, address), medical data (treatment start date, treating physician, Airlie House diagnostic classification).
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality Health care consumption and services
Care consumption (detail)	Hospitalization Medical/paramedical consultation

Procedures

Data collection method	Retrospective from medical administrative data.
Quality procedure(s) used	The collaborating centre for methodology is CEBIMER (Centre of epidemiology, biostatistics and research methodology), Limoges University Hospital, led by Prof. Preux; Dr. Marin, deputy head of the Capture-R System Management software.
Participant monitoring	Yes
Links to administrative sources	Yes

Promotion and access

Promotion

Link to the document	http://onlinelibrary.wiley.com/doi/10.1111/ene.12474/abstract;jsessionid=4DA9D9A2A656588F1CED30D101B2B8D9.f02t02
Link to the document	http://tinyurl.com/PUBMED-FRAlim
Link to the document	http://tinyurl.com/HAL-FRAlim

Access

Terms of data access (charter for data provision, format of data, availability delay)	Available under certain conditions (contact 1 of 3 scientists in charge).

Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only