

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
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Sign or acronym	FRALim
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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)
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General Aspects

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

Name of the director	Marin
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Surname	Benoit
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Unit	UMR Inserm 1094 NET
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Organization	Institute of Neurological Epidemiology and Tropical Neurology
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Unit	UMR Inserm 1094 NET
Organization	Institute of Neurological Epidemiology and Tropical Neurology

Name of the director	Couratier
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Unit	UMR Inserm 1094 NET
Organization	Institute of Neurological Epidemiology and Tropical Neurology

Collaborations

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

Funding status	Public
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Details	National Research Agency; ALS Research Association; Limousin - Poitou - Charentes Centre for Research and Higher Education
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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
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Labelling and database evaluation	Steering Committee at Inserm UMR 1094
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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