ReLSEP - Lorraine Registry of Multiple Sclerosis (Qualified Register 2017-2022)

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General

Identification

Detailed name	Lorraine Registry of Multiple Sclerosis (Qualified Register 2017-2022)
Sign or acronym	ReLSEP
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL : 909089 CCTIRS : 10.258 Clinical trials : NCT02883335

General Aspects

Medical area	Immunology Neurology
Pathology (details)	Multiple sclerosis
Health determinants	Geography
Keywords	Diagnosis, progression, therapeutic care

Scientific investigator(s) (Contact)

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Collaborations

Participation in projects, networks and consortia	Yes
Details	Involvement in a Cohort Network: EDMUS

Funding

Funding status	Public
Details	Health network

Governance of the database

Sponsor(s) or organisation(s) responsible	CIC-EC
Organisation status	Public

Additional contact

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Organization	CIC-EC

Main features

Type of database

Type of database	Morbidity registers
Additional information regarding sample selection.	Prospective

Database objective

Main objective	General objective: to study MS treatment modalities and determinants. To move towards a greater representation of patient population with multiple sclerosis as defined by geographical criteria.
Inclusion criteria	Patients with multiple sclerosis in the Lorraine region

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
Pathology	VI - Diseases of the nervous system
Gender	Male Woman
Geography area	Regional
French regions covered by the database	Alsace Champagne-Ardenne Lorraine
Detail of the geography area	Multicentric cohort (40 centres), 5 départements: 52, 54, 55, 57, 88

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	01/2003

Size of the database

Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	6331

Data

Database activity	Data collection completed
Type of data collected	Clinical data Paraclinical data
Clinical data (detail)	Direct physical measures Medical registration
Paraclinical data (detail)	Imaging
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality

Procedures

Data collection method	Clinical exams: manual input
Participant monitoring	Yes
Details on monitoring of participants	Indefinite duration
Links to administrative sources	No

Promotion and access

Promotion

Link to the document	http://tinyurl.com/PUBMED-ReLSEP
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/22354740
Description	Estimating the prevalence and incidence of multiple sclerosis in the Lorraine region, France, by the capture-recapture method.
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/18637953
Description	Natural history of multiple sclerosis in a population-based cohort.
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/17623734

Description	Increasing incidence of multiple sclerosis among women in Lorraine, Eastern France.
Link to the document	https://www.ncbi.nlm.nih.gov/pubmed/27936086/
Description	Geographical heterogeneity of muliple sclerosis prevelence in France
Link to the document	https://www.ncbi.nlm.nih.gov/pubmed/26148099
Description	Excess Mortality in Patients with Multiple Sclerosis Starts at 20 Years from Clinical Onset: Data from a Large-Scale French Observational Study.

Access

Terms of data access (charter for data provision, format of data, availability delay)	Data may be used by academic teams Data may be used by industrial teams
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only