

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)

Name of the director Guillemin

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Unit CIC-EC NANCY

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Unit	CIC-EC NANCY
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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Unit	CIC-EC NANCY

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.
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Link to the document	https://www.ncbi.nlm.nih.gov/pubmed/27936086/
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Description	Geographical heterogeneity of multiple sclerosis prevalence in France
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Link to the document	https://www.ncbi.nlm.nih.gov/pubmed/26148099
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Description	Excess Mortality in Patients with Multiple Sclerosis Starts at 20 Years from Clinical Onset: Data from a Large-Scale French Observational Study.
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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
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Access to aggregated data	Access on specific project only
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Access to individual data	Access on specific project only
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