

MS Network - A retrospective study on the epidemiology and treatments of patients with multiple sclerosis (MS) in Metropolitan France

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Last update : 10/19/2017 | Version : 1 | ID : 73330

General

Identification

Detailed name	A retrospective study on the epidemiology and treatments of patients with multiple sclerosis (MS) in Metropolitan France
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Sign or acronym	MS Network
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CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CCTIRS : 14.296 bis; CNIL: 914245
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General Aspects

Medical area	Neurology
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Pathology (details)	Multiple Sclerosis
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Health determinants	Medicine
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Keywords	Multiple Sclerosis
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Scientific investigator(s) (Contact)

Name of the director	Pr CLANET
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Surname	Michel
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Address	Toulouse
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Name of the director	Pr DE SEZE
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Surname	Jérôme
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Address	Strasbourg
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Name of the director	Pr DEFER
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Surname	Gilles
Address	Caen
Collaborations	
Participation in projects, networks and consortia	Yes
Details	MS networks
Funding	
Funding status	Private
Details	Merck
Governance of the database	
Sponsor(s) or organisation(s) responsible	Merck
Organisation status	Private
Presence of scientific or steering committees	Yes
Labelling and database evaluation	Scientific Committee
Additional contact	
Main features	
Type of database	
Type of database	Study databases
Study databases (details)	Repeated cross-sectional studies (except case control studies)
Database recruitment is carried out by an intermediary	A selection of health institutions and services
Database recruitment is is made on the basis of:	Another treatment or procedure
Database recruitment is carried out as part of an interventional study	No
Additional information regarding	Observational, descriptive, and retrospective study

sample selection.

based on the data available in health-care centres specialised in MS.

Database objective

Main objective

Describe the demographic characteristics of patients with Multiple Sclerosis (MS) in Metropolitan France and describe their therapeutic management

Secondary objectives:

- describe the conditions of use of long-term MS treatments;
- evaluate the therapeutic effect in real observational situations of the long-term MS treatments;
- describe the reasons for change and discontinuation of long-term MS treatments;
- evaluate compliance to treatment with Rebif

Inclusion criteria

Patients monitored in health-care centres specialised in MS and whose data was recorded in the database of each centre.

Population type

Age

Early childhood (2 to 5 years)
Childhood (6 to 13 years)
Adolescence (13 to 18 years)
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

National

Detail of the geography area

France

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)

01/2015

Date of last collection (YYYY or MM/YYYY)

01/2015

Size of the database

Size of the database (number of individuals)	[10 000-20 000[individuals
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Details of the number of individuals	15039 (11 centres)
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Data

Database activity	Data collection completed
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Type of data collected	Clinical data
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Clinical data (detail)	Direct physical measures Medical registration
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Details of collected clinical data	Sociodemographic characteristics of patients; Diagnosis of the disease; Clinical evaluation of the disease; History of MS treatments and ongoing treatments; Effectiveness of treatments / Compliance data (Rebif)
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Presence of a biobank	No
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Health parameters studied	Health event/morbidity Health event/mortality Health care consumption and services Quality of life/health perception
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Care consumption (detail)	Medicines consumption
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Quality of life/perceived health (detail)	Level/Progression of disability (EDSS score, MSSS score)
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Procedures

Data collection method	Extraction, processing and analysis of databases of French health-care centres managing MS / Extraction of the injection log of the RebiSmart system
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Participant monitoring	No
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Followed pathology	
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Links to administrative sources	No
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Promotion and access

Promotion

Access

Presence of document that lists variables and coding procedures No

Terms of data access (charter for data provision, format of data, availability delay) Access terms and conditions are being defined
Contact: juliette.longin@merckgroup.com

Access to aggregated data Access on specific project only

Access to individual data No access