Multiple Sclerosis Centre of Catalonia

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Data source | Human | Disease registry

Administrative details

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PURI

https://redirect.ema.europa.eu/resource/1111178

Data source ID

1111178

Data source acronym

Cemcat

Data holder

Multiple Sclerosis Centre of Catalonia (Cemcat)

Data source type

Disease registry

Main financial support

European public funding

Funding by own institution

Funding from industry or contract research

Funding from public-private partnership

Funds from patients organisations, charity and foundations

National, regional, or municipal public funding

Care setting

Hospital inpatient care

Hospital outpatient care

Secondary care – specialist level (ambulatory)

Data source qualification

If the data source has successfully undergone a formal qualification process (e.g., from the EMA, ISO or other certifications), this should be described.

No

Data source website

https://www.cem-cat.org/en

Contact details

Pere Carbonell

Main

pcarbonell@cem-cat.org

Data source regions and languages

Data source countries

Spain

Data source languages

English

Data source regions

Catalunya [Cataluña]

Data source establishment

Data source established

01/01/1995

Data source time span

First collection: 01/01/1995

The date when data started to be collected or extracted.

Publications

Data source publications

https://www.cem-cat.org/en/node/143

Data elements collected

The data source contains the following information

Disease information

Does the data source collect information with a focus on a specific disease? This might be a patient registry or other similar initiatives.

Yes

Disease details

Multiple sclerosis

Rare diseases

Are rare diseases captured? In the European Union a rare disease is one that affects no more than 5 people in 10,000.

Yes

Pregnancy and/or neonates

Does the data source collect information on pregnant women and/or neonatal subpopulation (under 28 days of age)?

Yes

Hospital admission and/or discharge

Yes

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Captured

Cause of death vocabulary

Not coded (Free text)

Other

Cause of death vocabulary, other

Not coded (Free text)

Prescriptions of medicines

Captured

Dispensing of medicines

Captured

Advanced therapy medicinal products (ATMP)

Is information on advanced therapy medicinal products included? A medicinal product for human use that is either a gene therapy medicinal product, a somatic cell therapy product or a tissue engineered products as defined in Regulation (EC) No 1394/2007 [Reg (EC) No 1394/2007 Art 1(1)].

No

Contraception

Is information on the use of any type of contraception (oral, injectable, devices etc.) available?

Yes

Indication for use

Does the data source capture information on the therapeutic indication for the use of medicinal products?

Not Captured

Medical devices

Is information on medicinal devices (e.g., pens, syringes, inhalers) available?

No

Administration of vaccines

Yes

Procedures

Does the data source capture information on procedures (e.g., diagnostic tests, therapeutic, surgical interventions)?

Captured

Procedures vocabulary

Not coded (Free text)

Healthcare provider

Is information on the person providing healthcare (e.g., physician, pharmacist, specialist) available? The healthcare provider refers to individual health professionals or a health facility organisation licensed to provide health care diagnosis and treatment services including medication, surgery and medical devices.

No

Clinical measurements

Is information on clinical measurements (e.g., BMI, blood pressure, height) available?

Yes

Genetic data

Are data related to genotyping, genome sequencing available?

Not Captured

Biomarker data

Does the data source capture biomarker information? The term “biomarker” refers to a broad subcategory of medical signs (objective indications of medical state observed from outside the patient), which can be measured accurately and reproducibly. For example, haematological assays, infectious disease markers or metabolomic biomarkers.

Captured

Biomarker data vocabulary

Other

Biomarker vocabulary, other

LOINC

Patient-reported outcomes

Is information on patient-reported outcomes (e.g., quality of life) available?

No

Patient-generated data

Is patient-generated information (e.g., from wearable devices) available?

Yes

Units of healthcare utilisation

Are units of healthcare utilisation (e.g., number of visits to GP per year, number of hospital days) available or can they be derived? Units of healthcare utilisation refer to the quantification of the use of services for the purpose of preventing or curing health problems.

Yes

Unique identifier for persons

Are patients uniquely identified in the data source?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

Not coded (Free text)

Medicinal product information

Captured

Medicinal product information collected

Brand name

Dose

Medicinal product vocabulary

Not coded (Free text)

Quality of life measurements

Captured

Quality of life measurements vocabulary

other

Quality of life measurements, other

Expanded Disability Status Scale (EDSS), relapses, Neuro QoL

Lifestyle factors

Captured

Lifestyle factors

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Gender

Sex

Quantitative descriptors

Population Qualitative Data

Population age groups

Paediatric Population (< 18 years)

Preterm newborn infants (0 – 27 days)

Term newborn infants (0 – 27 days)

Infants and toddlers (28 days – 23 months)

Children (2 to < 12 years)

Adolescents (12 to < 18 years)

Adults (18 to < 46 years)

Adults (46 to < 65 years)

Elderly (≥ 65 years)

Adults (65 to < 75 years)

Adults (75 to < 85 years)

Adults (85 years and over)

Description of the population covered by the data source in the catchment area whose data are not collected (e.g., people who are registered only for private care)

The primary catchement area is 600,000 people within the Catalonia region. Patients will not be captured if they visit another hospital within or outside of this region

Population

Population size

3458

Active population size

2490

Population by age group

Age group	Population size	Active population size
Children (2 to < 12 years)	2	1
Adolescents (12 to < 18 years)	11	10
Adults (18 to < 46 years)	1269	997
Adults (46 to < 65 years)	1845	1308
Adults (65 to < 75 years)	263	149
Adults (75 to < 85 years)	61	21
Adults (85 years and over)	7	4

Median observation time

Median time (years) between first and last available records for unique individuals captured in the data source

10.00

Median time (years) between first and last available records for unique active individuals (alive and currently registered) capt

11.40

Data flows and management

Access and validation

Biospecimen access

Are biospecimens available in the data source (e.g., tissue samples)?

Yes

Access to subject details

Can individual patients/practitioners/practices included in the data source be contacted?

Yes

Description of data collection

First, patient information is stored in their digital clinical history and then the information is transferred to an App interface (electronic medical record tool) that feeds a relational database

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

Start of treatment

Event triggering de-registration of a person in the data source

Death

Loss to follow up

Event triggering creation of a record in the data source

The fulfillment of the inclusion criteria for some of the study protocols that mades up the Cemcat cohort. New visits or relapses and new MRIs will update an existing record.

Data source linkage

Linkage

Is the data source described created by the linkage of other data sources (prelinked data source) and/or can the data source be linked to other data source on an ad-hoc basis?

No

Data management specifications that apply for the data source

Data source refresh

Monthly

Informed consent for use of data for research

Required for all studies

Possibility of data validation

Can validity of the data in the data source be verified (e.g., access to original medical charts)?

Yes

Data source preservation

Are records preserved in the data source indefinitely?

Yes

Approval for publication

Is an approval needed for publishing the results of a study using the data source?

Yes

Common Data Model (CDM) mapping

CDM mapping

Has the data source been converted (ETL-ed) to a common data model?

No