The Danish Multiple Sclerosis Registry

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Data source | Human | Disease registry

Administrative details

Administrative details

Data source ID

1000000796

Data source acronym

DMSR

Data holder

The Danish Multiple Sclerosis Registry (DMSR), Rigshospitalet - Copenhagen University Hospital

Data source type

Disease registry

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

DMSR

Contact details

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Data source regions and languages

Data source countries

Denmark

Data source languages

Danish

English

Data source regions

Hovedstaden

Midtjylland

Nordjylland

Sjælland

Syddanmark

Data source establishment

Data source established

01/01/1956

Data source time span

First collection: 01/01/1948

The date when data started to be collected or extracted.

Publications

Data source publications

The Danish Multiple Sclerosis Registry

Registers of multiple sclerosis in Denmark

A Report from the Danish M.S.-register

Epidemiology of multiple sclerosis: incidence and prevalence rates in Denmark 1948-64 based on the Danish Multiple Sclerosis Registry

Incidence of multiple sclerosis in Denmark 1948-1982: a descriptive nationwide study

Multiple sclerosis in Denmark (1950-2023): mean age, sex distribution, incidence and preva-lence

Studies based on the Danish Multiple Sclerosis Registry

The use of epidemiological multiple sclerosis registers in research: the Danish MS Registry

Excess mortality among patients with multiple sclerosis in Denmark has dropped significantly over the past six decades: a population-based study

Studies

List of studies that have been conducted using the data source

Long-Term Surveillance of Ocrelizumab-Treated Patients With Multiple Sclerosis (MANUSCRIPT Study)

MS700568_0004: Pregnancy outcomes in women exposed to oral cladribine: a multi-country cohort database study (CLEAR)

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

Neuromyelitis optica spectrum disorder

Myelin oligodendrocyte glycoprotein antibody-associated disease

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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.

No

Pregnancy and/or neonates

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

No

Hospital admission and/or discharge

No

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Not Captured

Prescriptions of medicines

Captured

Prescriptions vocabulary

ATC

Dispensing of medicines

Not 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?

No

Indication for use

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

Captured

Indication vocabulary

ICD-10

Medical devices

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

No

Administration of vaccines

No

Procedures

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

Captured

Procedures vocabulary

Other

Procedures vocabulary, other

CSF tests: OCB, IgG etc.

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?

No

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.

Not Captured

Patient-reported outcomes

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

Yes

Patient-generated data

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

No

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.

No

Unique identifier for persons

Are patients uniquely identified in the data source?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

ICD-10

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Brand name

Route of administration

Medicinal product vocabulary

ATC

Quality of life measurements

Not Captured

Quality of life measurements vocabulary

other

Lifestyle factors

Not Captured

Sociodemographic information

Not Captured

Quantitative descriptors

Population Qualitative Data

Estimated percentage of the population covered by the data source in the catchment area

DMSR is a nationwide population-based disease registry encompassing comprehensive demographic and clinical information on persons with MS and related disorders (including CIS, RIS, NMOSD, and MOGAD).

Because notification on all patients with MS treated with disease-modifying drugs is mandatory, data on patients receiving disease-modifying drugs are virtually complete.

All treating clinics record data online on all patients with any of the above-mentioned demyelinating diseases. Notification starts when the disease is diagnosed; however, much attention is paid to anamnestic clarification of the time of clinical disease onset. During treatment, patients are monitored in connection with scheduled clinical visits at regular intervals with recording of demographic, clinical and paraclinical data, as well as Kurtzkes Expanded Disability Status Score (EDSS) and functional systems (FS) (Kurtzke, 1983), and side effects. Relapses are recorded with their dates and whether or not

treatment with corticosteroid was applied. Notification of the DMSR is mandatory for all patients receiving DMT, and data collection is a part of the routine medical follow-up of patients. Failure of reporting mandatory data to the DMSR for a department will be observed by the health authorities who are the owners of the Danish public hospitals.

Population

Population size

35.000

Active population size

19.500

Data flows and management

Access and validation

Biospecimen access

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

No

Access to subject details

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

No

Description of data collection

Data is recorded on a daily basis into the online platform COMPOS by health care professionals as part of clinical care and transferred automatically to the

DMSR data base every morning when an updated DMSR database is created which is then downloaded by DMSR data managers routinely once a month.

The core data set covers:
· Patient characteristics
· Clinical characteristics: onset and diagnosis date and symptom, phenotype, EDSS development
· Tests: MRI, CSF
· Relapses
· Disease modifying treatments
· Adverse Events
· Visits at MS clinic

Event triggering registration

Event triggering registration of a person in the data source
Disease diagnosis

Event triggering creation of a record in the data source
Following the initial creation of a patient at diagnosis, any subsequent event included in the core data set triggers a new record:
· Clinical characteristics: change in phenotype, EDSS development
· Tests: MRI, CSF
· Relapses
· Disease modifying treatments
· Adverse Events
· Visits at MS clinic

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

Linkage description, possible linkage

The Danish Civil Registration System provides all Danish citizens, alive in 1968 and thereafter, with a unique 10-digit person ID (CPR-nr), the first 6 digits being the date of birth.

The CPR-nr enables linkage with other Danish registries including registries on Birth, Causes of Death, Prescriptions, Socio-economics, National Patient Registry, and many more.

Linked data sources

Pre linked

Is the data source described created by the linkage of other data sources?

No

Data management specifications that apply for the data source

Data source refresh

Monthly

Informed consent for use of data for research

Not Required

Possibility of data validation

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

No

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