The Swedish Multiple Sclerosis Registry

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Data source **Human** **Disease registry**

Administrative details

Administrative details

Data source ID

1000001023

Data source acronym

SMSreg

Data holder

Karolinska University Hospital

Data source type

Disease registry

Main financial support

National, regional, or municipal public funding

Care setting

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.

Yes

Description of the qualification

SMSreg was part of the BigMSData Network (BMSD) receiving a Scientific Advice for performing PASS in 2021. We, SMSreg as part of BMSD, are presently (June 2026) at a late review stage to receive a Qualification Opinion for PASS.

Data source website

neuroreg.se/multipel-skleros/

Contact details

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Data source regions and languages

Data source countries

Sweden

Data source languages

Swedish

Data source regions

Blekinge län [SE-10]

Dalarnas län [SE-20]

Gävleborgs län [SE-21]

Gotlands län [SE-09]

Hallands län [SE-13]

Jämtlands län [SE-23]

Jönköpings län [SE-06]

Kalmar län [SE-08]

Kronobergs län [SE-07]

Norrbottens län [SE-25]

Örebro län [SE-18]

Östergötlands län [SE-05]

Skåne län [SE-12]

Södermanlands län [SE-04]

Stockholms län [SE-01]

Uppsala län [SE-03]

Värmlands län [SE-17]

Västerbottens län [SE-24]

Västernorrlands län [SE-22]

Västmanlands län [SE-19]

Västra Götalands län [SE-14]

Data source establishment

Data source established

01/01/2001

Data source time span

First collection: 01/01/2001

The date when data started to be collected or extracted.

Publications

Data source publications

The Swedish MS registry – clinical support tool and scientific resource

Big Multiple Sclerosis Data network: an international registry research network

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

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

No

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Captured

Cause of death vocabulary

ICD-10

Prescriptions of medicines

Captured

Prescriptions vocabulary

ATC

Dispensing of medicines

Captured

Dispensing vocabulary

ATC

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

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

Other

Procedures vocabulary, other

Not certain

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

Unclear

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

Not Captured

Quality of life measurements

Captured

Quality of life measurements vocabulary

EQ5D

Lifestyle factors

Captured

Lifestyle factors

Tobacco use

Sociodemographic information

Not Captured

Quantitative descriptors

Population Qualitative Data

Population age groups

Children (2 to < 12 years)

Adolescents (12 to < 18 years)

Adult and elderly population (≥18 years)

Adults (18 to < 65 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)

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

Estimated coverage of 85 % of Swedish prevalent multiple sclerosis population

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)

All neurology units report, but patient may opt out and clinicians are not obliged to contribute by registering their patients.

Family linkage

Family linkage available in the data source permanently or can be created on an ad hoc basis

Ad hoc

Population

Population size

25372

Active population size

20500

Median observation time

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

12.00

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

10.00

Data flows and management

Access and validation

Governance details

Documents or webpages that describe the overall governance of the data source and processes and procedures for data capture and management, data quality check and validation results (governing data access or utilisation for research purposes).

Neuroreg.se/omoss.se/

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

Clinician reported data are entered by clinicians, most commonly directly in the context of a clinical visit or digital contact, through a clinical decision support tool, named COMPOS-DS, which is part of the clinical documentation systems used in all neurology units in Sweden. From each department's server domain, an export is made every morning to the SQL server which is the proper Swedish MS registry. In addition, patients can log into a patient portail and respond to a set of questionnaires at will. These records are then reviewed and imported into the COMPOS-DS system by the responsible clinician and become part of the daily export roun tine into the SMSreg SQL server domain.

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

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

Death

Emigration

Event triggering creation of a record in the data source

Patients are typically entered into the registry at diagnosis or close thereafter. Records are then created at every direct contact (visit or digital contact) or when investigations have been performed (body fluid analyses, imaging) and when patient reported data are being reviewed and entered into COMPOS-DS by the responsible clinician.

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?

Yes

Linkage description, pre-linked

SMSreg is linked twice a year to the population registry at Statistics Sweden. Patients who are reported dead or emigrated are identified are classified as having terminated the registration but their data are retained.

Linkage description, possible linkage

SMSreg data can be linked to other health data sources in Sweden by using the unique person identifier. Important such data bases are fiscal and socioeconomic data from Statistics Sweden and health data bases from the Board of Health and Welfare: The National patient registry (ICD-10 codes from in-patient and specialised care, the National prescription data base, the

Registry on pregnancy and pregnancy outcomes, and the Swedish Cancer registry. In principle, as being a national quality registry, the SMSreg can be linked to any other of the approximately 150 national quality registries (diseases, procedures, care settings etc)

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

Data source preservation length (years)

Not limited, only taken out at the will of the patient years

Approval for publication

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

No

Data source last refresh

08/06/2026

Common Data Model (CDM) mapping

CDM mapping

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

Yes