ReMuS Registry / ReMuS, The Czech Republic Multiple Sclerosis Patient Registry / ReMuS, Registr pacientů s roztroušenou sklerózou

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Data source | Human | Disease registry

Administrative details

Administrative details

Data source ID

1000000877

Data source acronym

ReMuS

Data holder

ReMuS, nadacni fond (ReMuS)

Data source type

Disease registry

Main financial support

European public funding

Funding by own institution

Funding from industry or contract research

Funds from patients organisations, charity and foundations

Care setting

Hospital inpatient care

Hospital outpatient care

Primary care – specialist level (e.g. paediatricians)

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

About ReMuS Registry

Contact details

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Main

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Data source regions and languages

Data source countries

Czechia

Data source languages

Czech

English

Data source regions

Jihočeský kraj

Jihomoravský kraj

Karlovarský kraj

Kraj Vysočina

Královéhradecký kraj

Liberecký kraj

Moravskoslezský kraj

Olomoucký kraj

Pardubický kraj

Plzeňský kraj

Praha, Hlavní město

Středočeský kraj

Ústecký kraj

Zlínský kraj

Data source establishment

Data source established

20/05/2013

Data source time span

First collection: 30/06/2013

The date when data started to be collected or extracted.

Publications

Data source publications

The Czech National MS Registry (ReMuS): Data trends in multiple sclerosis patients whose first disease-modifying therapies were initiated from 2013 to 2021

Big Multiple Sclerosis Data network: an international registry research network

Does initial high efficacy therapy in multiple sclerosis surpass escalation treatment strategy? A comparison of patients with relapsing-remitting multiple sclerosis in the Czech and Swedish national multiple sclerosis registries

Is pregnancy in MS patients safe and what is its impact on MS course? Real World evidence of 1533 pregnancies in Czech Republic

Multiple sclerosis, neuromyelitis optica spectrum disorder and COVID-19: A pandemic year in Czechia

Analysis of the Group of Pediatric Patients With Relapsing-Remitting Multiple Sclerosis: Data From the Czech National Registry

Proportion and characteristics of secondary progressive MS in five European registries using objective classifiers

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

Myelin oligodendrocyte glycoprotein antibody-associated disease

Neuromyelitis optica spectrum disorder

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

ICD-10

Prescriptions of medicines

Captured

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)].

Yes

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?

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

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.

Yes

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

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?

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.

Yes

Unique identifier for persons

Are patients uniquely identified in the data source?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

MedDRA

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Brand name

Dosage regime

Route of administration

Medicinal product vocabulary

AIC

Quality of life measurements

Not Captured

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Education level

Gender

Sex

Socioeconomic status

Quantitative descriptors

Population Qualitative Data

Population age groups

All

In utero

Paediatric Population (< 18 years)

Neonate

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)

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

ReMuS covers an estimated ~90% of disease-modifying therapy (DMT)-treated multiple sclerosis (MS) patients in the Czech Republic. All 15 specialised MS centres authorised to prescribe DMTs are contractually anchored within the ReMuS registry network, and DMT initiation in the Czech Republic is restricted to these centres. A cross-validation study comparing ReMuS records against national administrative healthcare data from the Institute of Health Information and Statistics of the Czech Republic (IHIS) for cladribine (Mavenclad®) confirmed a 91.9% overlap of unique patient counts between ReMuS and IHIS reimbursement records for 2023–2024, supporting high population coverage for DMT-treated patients. As of the latest data cut (30 June 2025), ReMuS contains records for approximately 24,000 MS patients, of whom approximately 20,000 is actively followed and ~17,400 are on active DMT. The registry does not systematically capture MS patients who are not treated with DMTs at the specialised centres; however, untreated patients who attend these centres for clinical follow-up are also included (approximately 13% of the registry 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)

The following MS patient subgroups in the Czech Republic may not be fully captured in ReMuS:

(1) Patients diagnosed with MS who have never been referred to any of the 15 specialised MS centres — given that DMT prescribing in the Czech Republic is restricted to these centres, such patients would by definition be untreated and managed solely in general neurological care. While this scenario is unlikely given the standard clinical pathway for MS in the Czech Republic, the registry has no mechanism to identify these individuals;

(2) Patients who declined informed consent for registry participation (estimated <5% of eligible patients at participating centres);

(3) Patients with longstanding progressive MS (e.g. disease onset in the 1990s or earlier) who are no longer within DMT reimbursement criteria and have transitioned from specialised centre follow-up to local neurological care — this group represents a meaningful coverage gap, particularly for studies requiring long-term disability progression data. An ongoing cooperation with the Institute of Health Information and Statistics of the Czech Republic (IHIS), established in mid-2025, is being used to assess and quantify these coverage gaps by comparing ReMuS enrolment against the national population of MS patients identified through administrative health insurance claims data.

Population

Population size

24000

Active population size

20000

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).

ReMuS Registry - Key Governance Documents

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

ReMuS data are collected prospectively at all 15 highly specialised MS centres in the Czech Republic during routine clinical practice. These are the only facilities authorised to prescribe disease-modifying therapies (DMTs), and all are contractually part of the ReMuS network. Data are entered by treating

neurologists and nurses into iMed software, built on structured drop-down menus and multiple-choice selections with limited free text.

The core data set covers: MS diagnosis and disease course, neurological episodes and disability (EDSS), relapses, DMT episodes (drug, start/stop dates, dosage, reason for discontinuation), adverse events (condition, severity, outcome, seriousness, suspected drug relationship), CSF and laboratory tests, and socio-demographics. MedDRA coding is used for serious adverse events since July 2023; retrospective conversion of historical free-text SAE records is ongoing. The BMSD Common Data Model (CDM) serves as the core harmonised output format.

Twice a year (30 June and 31 December), centres export data to a centrally secured ReMuS repository. iMed includes built-in validation checks; additionally, ReMuS runs a systematic quality process twice a year with over 100 rules, sending query reports to centres for verification against medical documentation. A continuous benchmarking framework drives data quality improvement across centres (Drahota et al., Mult Scler J 2025;31(3):880–882).

Established in 2013 under the IMPULS Endowment Fund with the Neuroimmunology and Liquorology Section (NLS) of the Czech Neurological Society, registry operations were spun off in 2024 into the ReMuS Endowment Fund.

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

Other

Event triggering registration of a person in the data source, other

Granting informed consent

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

Death

Emigration

Loss to follow up

Other

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

Withdrawal of informed consent

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, possible linkage

Ad-hoc linkage with the Institute of Health Information and Statistics of the Czech Republic (IHIS) is possible through direct patient-level matching for patients who have provided updated informed consent. Available IHIS data sources include: national mortality records (Register of the Deceased), administrative healthcare diagnoses (ICD-10 coded from all healthcare encounters), and pharmacy dispensation/reimbursement data.

Linked data sources

Pre linked

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

No

Data source, other

Institute of Health Information and Statistics of the Czech Republic

Linkage strategy

Deterministic

Data management specifications that apply for the data source

Data source refresh

Every 6 months

Informed consent for use of data for research

Required for general use

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

Data source last refresh

31/12/2025

Common Data Model (CDM) mapping

CDM mapping

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

Yes

CDM Mappings

CDM name (other)

The Big MSData Network CDM

Data source ETL CDM version

0.12

Data source ETL frequency

6,00 months

Data source ETL status

Completed