

Multiple Sclerosis DataConnect

First published: 01/02/2024

Last updated: 17/10/2024

Data source

Human

Hospital inpatient records

Other

Administrative details

Administrative details

Data source ID

1111203

Data source acronym

MSDC

Data holder

[University MS Center \(UMSC\) - Hasselt University](#)

Data source type

Hospital inpatient records

Other

Data source type, other

Electronic health records, In the Rehabilitation and MS Center in Pelt (Belgium) clinical data is collected by neurologists. EPTS are measured and MRI scans are taken once a year (in general). The clinical data is entered in iMed and the EPD (NexuzHealth) and linked to the EPTS and MRI features, which results in the so called RADIOMCS-EPOMICS dataset. We are working on integrating the data collected by the physiotherapists, psychologists, speech therapists and occupational therapists too, as well as patient-reported outcomes, but currently, the MSDC dataset only consists of the RADIOMICS-EPOMICS dataset.

Main financial support

Funding from industry or contract research

Care setting

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

Contact details

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Main

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Data source regions and languages

Data source countries

Belgium

Data source languages

Dutch

English

Data source regions

Antwerpen

Limburg

Oost-Vlaanderen

Vlaams-Brabant

West-Vlaanderen

Data source establishment

Data source established

01/01/2017

Data source time span

First collection: 01/01/2017

The date when data started to be collected or extracted.

Publications

Data source publications

[Safety and effectiveness of cladribine tablets for multiple sclerosis: Results from a single-center real-world cohort](#)

[Machine learning analysis of motor evoked potential time series to predict disability progression in multiple sclerosis.](#)

[Motor evoked potentials for multiple sclerosis: A multiyear follow-up dataset](#)

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

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

Not Captured

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?

Not Captured

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)?

Not 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.

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.

Not 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.

No

Unique identifier for persons

Are patients uniquely identified in the data source?

No

Diagnostic codes

Captured

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Brand name

Dose

Route of administration

Quality of life measurements

Captured

Quality of life measurements vocabulary

EQ5D

other

Quality of life measurements, other

FSMC, HADS

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Ethnicity

Gender

Quantitative descriptors

Population Qualitative Data

Population age groups

Adults (18 to < 46 years)

Adults (46 to < 65 years)

Elderly (\geq 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)

Region-wide

Family linkage

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

Ad hoc

Population

Population size

800

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).

<https://www.uhasselt.be/UH/CME/Procedure-voor-het-indienen-van-een-studie/Documenten-nodig-ter-indiening.html>

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

In the Rehabilitation and MS Center in Pelt (Belgium) clinical data is collected by neurologists. EPTS are measured and MRI scans are taken once a year (in general). The clinical data is entered in iMed and the EPD (NexuzHealth) and linked to the EPTS and MRI features, which results in the so called RADIOMCS-EPOMICS dataset. We are working on integrating the data collected by the physiotherapists, psychologists, speech therapists and occupational therapists too, as well as patient-reported outcomes, but currently, the MSDC dataset only consists of the RADIOMICS-EPOMICS dataset.

Event triggering registration

Event triggering registration of a person in the data source

Other

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

The subject is admitted to a specialist outpatient clinic

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

Other

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

The subject is discharged from an specialist outpatient clinic

Event triggering creation of a record in the data source

Patient visit (yearly)

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

Yearly

Informed consent for use of data for research

Other

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

Informed consent, other

We collect data in the Noorderhart Rehabilitation and MS Center in Pelt as part of the standard follow-up of patients. These data can be reused for research (secondary reuse)

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

OMOP

CDM website

<https://www.ohdsi.org/Data-standardization/>

Data source ETL CDM version

5.3

Data source ETL frequency

12,00 months

Data source ETL status

Completed