Multiple Sclerosis Documentation System (MSDS) - AOK PLUS Linked Database

First published: 24/10/2024

Last updated: 24/10/2024

Data source
Human
Administrative healthcare records (e.g., claims)
Disease registry

Administrative details

Administrative details

Data source ID

1000000346

Data source acronym

MSDS-AOK PLUS

Data holder

GIPAM GmbH

Data source type

Administrative healthcare records (e.g., claims)

Disease registry

Main financial support

Funding by own institution

Care setting

Hospital inpatient care

Hospital outpatient care

Primary care – GP, community pharmacist level

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

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

Data Resource Profile: The Multiple Sclerosis Documentation System 3D and AOK PLUS Linked Database (MSDS-AOK PLUS)

Contact details

Sabrina Mueller sabrina.mueller@gipam-health.com

Main

sabrina.mueller@gipam-health.com

Nils Picker nils.picker@gipam-health.com

Alternate

nils.picker@gipam-health.com

Data source regions and languages

Data source countries

Germany

Data source languages

German

Data source regions

Sachsen

Thüringen

Data source establishment

Publications

Data source publications

Data Resource Profile: The Multiple Sclerosis Documentation System 3D and AOK PLUS Linked Database (MSDS-AOK PLUS)

Introducing the German MSDS-AOK PLUS Database: Linkage of Administrative Claims Data and a Patient Registry for Advanced RWE Capabilities in Multiple Sclerosis

Coding of Multiple Sclerosis Subtypes in German Administrative Claims Data: A Validation Study Using the MSDS-AOK PLUS Linked Database

Claims-based algorithm to estimate the Expanded Disability Status Scale for multiple sclerosis in a German health insurance fund: a validation study using patient medical records

Assessing the Performance of Propensity Score Methods in Balancing Unobservable Confounders: Evidence From Linked Data in Multiple Sclerosis

Data elements collected

The data source contains the following

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.

No

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?

Yes

Cause of death

Not Captured

Prescriptions of medicines

Not Captured

Dispensing of medicines

Captured

Dispensing vocabulary

ATC

other

Dispensing vocabulary, other

OPS: for medications administered in inpatient setting

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?

Yes

Administration of vaccines

Yes

Procedures

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

Captured

Procedures vocabulary

OPS

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.

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.

Yes

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

Dosage regime

Dose

Formulation

Package size

Route of administration

Strength

Medicinal product vocabulary

ATC

Quality of life measurements

Captured

Quality of life measurements vocabulary

other

Quality of life measurements, other

Neuro-QoL, Expanded Disability Status Scale (EDSS), MS Performance Test, Early Mobility Impairment Questionnaire, Multiple Sclerosis Walking Scale (MSWS-12) (EMIQ)

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Health area

Other

Sex

Sociodemographic information other

Insurance status

Quantitative descriptors

Population Qualitative Data

Population age groups

All

Paediatric Population (< 18 years)

Preterm newborn infants (0 – 27 days)

Term newborn infants (0 – 27 days)

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

The database links administrative claims from approximately 3.4 million people with statutory health insurance in the German regions of Saxony and Thuringia with clinical data captured on approximately 2,000 patients with MS who received care at the Center of Clinical Neuroscience Dresden (ZKN). Due to the different catchment areas of the component data sources and the linked nature of the resulting database, an accurate percentage of MS patients covered cannot be calculated. Inclusion into the database is ongoing.

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)

People who reside in German regions outside of Saxony or Thuringia, as well as those who receive statutory health insurance in those regions from providers other than AOK Plus, are not captured in the administrative claims data. Patients with MS who are treated at locations other than the Center of Clinical Neuroscience Dresden are not captured in the clinical data.

Population

Population size

750

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).

Protocol approval is required for use of the data for research purposes, contact GIPAM for more information.

Data Resource Profile: The Multiple Sclerosis Documentation System 3D and AOK PLUS Linked Database (MSDS-AOK PLUS)

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

Using the AOK PLUS sickness fund and the Multiple Sclerosis Documentation System MSDS3D from the Center of Clinical Neuroscience (ZKN) in Dresden, Germany, a linked MS-specific database was developed (MSDS-AOK PLUS). Patients treated at ZKN and insured by AOK PLUS were recruited and asked for informed consent. For linkage, insurance IDs were mapped to registry IDs. After the deletion of insurance IDs, an anonymized dataset was provided to a university-affiliated institute, IPAM e.V., for further research applications. The dataset combines a complete record of patient diagnoses, treatment, healthcare resource use, and costs (AOK PLUS) with detailed clinical parameters, including functional performance and patient-reported outcomes (MSDS3D).

Event triggering registration

Event triggering registration of a person in the data source

Insurance coverage start

Practice registration

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

Insurance coverage end

Loss to follow up

Other

Practice deregistration

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

Withdrawal of informed consent

Event triggering creation of a record in the data source

Any encounter with the medical system that results in a claim during while the patient receives health insurance from AOK Plus triggers the creation of a record in the administrative claims data. Assuming the patient provides informed consent, a visit at the Center of Clinical Neuroscience (ZKN) in Dresden, Germany triggers the creation of a record in the clinical data.

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

Administrative claims from the AOK PLUS sickness fund are linked to clinical data from the Center of Clinical Neuroscience, Dresden (ZKN) Multiple Sclerosis Documentation System (MSDS-3D). Access requires protocol approval from the data owner.

Linkage description, possible linkage

If required, the data could be linked to information extracted from patient charts at other medical offices.

Data management specifications that apply for the data source

Data source refresh

Quarterly

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

Patients treated at ZKN and insured by AOK Plus already provided informed consent for their data to be used for research purposes.

Common Data Model (CDM) mapping

CDM mapping

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

No