Unidade Local de Saúde de Matosinhos

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Data source	Human	Other	Primary care medical records

Administrative details

Administrative details

Data source ID

1111171

Data source acronym

ULSM

Data holder

Unidade Local de Saúde de Matosinhos (ULSM)

Data source type Other Primary care medical records

Data source type, other

Electronic health records,EHRs contain totality of primary care and hospital production from 1988 until present for a well defined region of Portugal (Matosinhos) corresponding to a living unselected patient population of 170.000 with complete healthcare coverage from the public sector and spanning over 20 years, and additional 600.000 patients from other regions that visited the Hospital Pedro Hispanho at some point in time. Data contains every visit, imaging and other exams reports (primary care and hospital), procedures (surgical, inpatient, outpatient in both hospital and secondary care) prescribed medications (primary care and hospital inpatient and outpatient), totality of laboratory measurements (inpatient and outpatient), selected specimen and device data, death date and hospital diagnosis associated with death, allergies and the totality of clinical notes (primary care and hospital)

Main financial support

European public funding 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.

Yes

Description of the qualification

Qualification by EHDEN project

Data source website

https://www.ulsm.min-saude.pt/

Contact details

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Data source regions and languages

Data source countries

Portugal

Data source languages

Portuguese

Data source establishment

Data source established

01/01/1998

Data source time span

First collection: 01/01/1998

The date when data started to be collected or extracted.

Publications

Data source publications

Prevalence, outcomes, and cost of chronic kidney disease in a contemporary population of 2.4 million patients from 11 countries: The CaReMe CKD study

Twenty years of real-world data to estimate chronic kidney disease prevalence and staging in an unselected population

Cost of healthcare utilization associated with incident cardiovascular and renal disease in individuals with type 2 diabetes: A multinational, observational study across 12 countries

Prevalence, outcomes and costs of a contemporary, multinational population with heart failure

Cardiovascular Risk Profile and Lipid Management in the Population-Based Cohort Study LATINO: 20 Years of Real-World Data

Studies

List of studies that have been conducted using the data source

DARWIN EU® Monitoring prescription of essential medicines administered in ICU

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 (other)

Source data is recorded using ICD-9 and ICD-10 and mapped into OMOP-CDM standard SNOMED concepts

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?

Yes

Cause of death

Captured

Cause of death vocabulary

SNOMED CT

Prescriptions of medicines

Captured

Prescriptions vocabulary

ATC

RxNorm

Dispensing of medicines

Captured

Dispensing vocabulary

ATC other

RxNorm

Dispensing vocabulary, other

Only for inpatient prescriptions

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?

Yes

Indication for use

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

Captured

Indication vocabulary

Not coded (Free text)

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

SNOMED CT

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?

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-CM ICD-9-CM SNOMED CT

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s) Dose Formulation Route of administration

Medicinal product vocabulary

ATC

RxNorm

Quality of life measurements

Captured

Quality of life measurements vocabulary

Not coded (Free text)

Lifestyle factors

Captured

Lifestyle factors

Alcohol use

Diet

Frequency of exercise

Other

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age Country of origin Education level Gender Health area Socioeconomic status Type of residency

Quantitative descriptors

Population Qualitative Data

Population age groups

Paediatric Population (< 18 years) 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) 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)

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

100%

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 information available is collected from Pedro Hispano Hospital and 17 primary healthcare centers that together form Unidade Local de Saúde de Matosinhos and are responsible for public healthcare coverage for the region of Matosinhos. These institutions are part of the National Health System. These institutions grant access to all the population in the catchment area. Nevertheless, private-sector health records are not included in our database.

Family linkage

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

Permanently

Family linkage available between the following persons Father-child Mother-child

Sibling

Population

Population size

631219

Active population size

300479

Population by age group

Age group	Population size	Active population size
Paediatric Population (< 18 years)	114688	48326
Preterm newborn infants (0 – 27 days)	3781	816
Term newborn infants (0 – 27 days)	34030	7344
Infants and toddlers (28 days – 23 months)	45558	11033
Children (2 to < 12 years)	76440	29066
Adolescents (12 to < 18 years)	62176	18062
Adults (18 to < 46 years)	291822	111308
Adults (46 to < 65 years)	191177	86934
Elderly (≥ 65 years)	140393	70708
Adults (65 to < 75 years)	99644	43756

Age group	Population size	Active population size
Adults (75 to < 85 years)	68974	28627
Adults (85 years and over)	29436	11336

Median observation time

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

8.00

Median time (years) between first and last available records for unique active individuals (alive and currently registered) capt 12.00

Data flows and management

Access and validation

Biospecimen access

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

Yes

Biospecimen access conditions

Upon request and approval by the local Ethics Committee

Access to subject details

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

Yes

Description of data collection

This is EHR data that is created by all healthcare professionals at ULSM during regular care and for healthcare purpose. Data is created by doctors, nurses and other professionals. Most EHR systems are oficial public national software (SONHO, SINUS) with additional EHR systems coming from thrid party vendors. The totality of data recorded within ULSM EHR systems is available for research purposes.

Event triggering registration

Event triggering registration of a person in the data source

Birth Disease diagnosis Practice registration

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

Death

Event triggering creation of a record in the data source

Provision of care, for the first time, inside the hospital. The record is created by the administrative support staff when the patient does the check-in.

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

Patient code is unique and created on birth or immigration. Codes are non overlapping and there guaranteed to be unique

Linkage description, possible linkage

Patient code is unique and created on birth or immigration. Codes are non overlapping and there guaranteed to be unique

Linked data sources

Pre linked

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

No

Data source, other

National Death Registry

Linkage variable

cod_utente

Linkage completeness

100%

Pre linked

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

No

Data source, other

National Drug Prescription and Dispensation Registry

Linkage variable

cod_utente

Linkage completeness

100%

Pre linked

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

No

Data source, other

National Vaccination Registry

Linkage variable

cod_utente

Linkage completeness

100%

Pre linked

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

No

Data source, other

Other quality registers

Linkage variable

cod_utente

Linkage completeness

100%

Pre linked

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

Yes

Data source, other

The totality of data is automatically linked by default because all EHR systems use the same national patient code to register patient data.

Linkage variable

cod_utente

Linkage completeness

100% in ULSM, and can be used to cross agains the totality of national healthcare information available

Data management specifications that apply for the data source

Data source refresh

Monthly

Informed consent for use of data for research

Required for intervention studies

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?

No

Data source preservation length (years)

50 years

Approval for publication

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

Yes

Data source last refresh

01/04/2023

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

5.4

Data source ETL frequency

1,00 month

Data source ETL status

In progress