Egas Moniz Database

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Data source





Administrative details

Administrative details

PURI

https://redirect.ema.europa.eu/resource/1111133

Data source ID

1111133

Data source acronym

EMDB

Data holder

Clinical Academic Center Egas Moniz (CAC-EMHA)

Data source type

Other

Data source type, other

EHRs contain totality of hospital visits, surgical procedures, prescribed medications (inpatient and outpatient), totality of laboratory measurements, selected specimen and device data, death date and hospital diagnosis associated with death, allergies, nursing procedures, totality of clinical notes

Main financial support

European public funding

Funding by own institution

Care setting

Hospital inpatient care

Hospital outpatient care

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 ongoing by EHDEN project

Data source website

https://www.ua.pt/pt/cacemha

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

01/01/2008

Data source time span

First collection: 01/01/2008

The date when data started to be collected or extracted.

Publications

Data source publications

Prediction of Survival after 48 Hours of Intensive Unit Care following Repair of Ruptured Abdominal Aortic Aneurysm—Multicentric Study for External Validation of a New Prediction Score for 30-Day Mortality

Prevalence of paroxysmal atrial fibrillation in a population assessed by continuous 24-hour monitoring

Very long-term survival and late sudden cardiac death in cardiac resynchronization therapy patients

Diagnosis of obstructive coronary artery disease using computed tomography angiography in patients with stable chest pain depending on clinical probability and in clinically important subgroups: Meta-analysis of individual patient data

Effectiveness and safety of bedaquiline containing regimens in the treatment of MDR- and XDR-TB: A multicentre study

Studies

List of studies that have been conducted using the data source

DARWIN EU® – Paracetamol prescribing and paracetamol overdose in Europe: a descriptive analysis of trends and patient characteristics

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.

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

Captured

Cause of death vocabulary

SNOMED

SNOMED CT

Prescriptions of medicines

Captured

Prescriptions vocabulary

RxNorm

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)].

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

No

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

Biomarker data vocabulary

Other

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

ICD-10-CM

ICD-9-CM

SNOMED CT

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

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
Not Captured
Sociodemographic information
Captured
Sociodemographic information collected
Age
Country of origin
Deprivation index
Gender
Health area
Quantitative descriptors

Population Qualitative Data

Dose

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 (≥ 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 in public institutions, part of a 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

Mother-child

Population

Population size

1394490

Active population size

1232296

Population by age group

Age group	Population size	Active population
Paediatric Population (< 18 years)	134942	134370
Term newborn infants (0 - 27 days)	268	266
Infants and toddlers (28 days - 23 months)	8936	8914
Children (2 to < 12 years)	67402	67010
Adolescents (12 to < 18 years)	58336	58180
Adults (18 to < 46 years)	354272	352660

Age group	Population size	Active population
Adults (46 to < 65 years)	353858	342216
Elderly (≥ 65 years)	551418	403050
Adults (65 to < 75 years)	180378	163880
Adults (75 to < 85 years)	151420	121948
Adults (85 years and over)	219620	117222

Median observation time

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

14.00

Median time (years) between first and last available records for unique active individuals (alive and currently registered) capt 13.00

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 / Clinical Academic Center Direction Board

Access to subject details

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

Yes

Description of data collection

Each type of data is collected using a different information system/electronic record. Support staff, nurses, medical doctors, and allied health professionals are involved to input data. Each information system/electronic uses a different database that associates a patient's unique ID number to the collected data. Data from several databases is collected in a unique database (master_database), using the patient's unique ID to interlink the information. Details on the specific information system/electronic are provided as follows:

i) Slinico software » Sclinico_database (medical, nursing, ancillary studies data);

ii) RNU » RNU_database (administrative data); iii) PEM software » PEM_database (prescription data).

Event triggering registration

Event triggering registration of a person in the data source

Start of treatment

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

Each patient has a unique patient ID (ID variable) that corresponds to the number of the citizenship ID card or passport. This a unique number, therefore no duplicates can occur.

The ID variable will be associated to all the events (e.g., procedure, appointment, administrative task, prescriptions) recorded on the databases previouly mentioned (Sclinico_database; RNU_database; PEM_database). This ID variable is used to assemble a unique database that includes all the data recorded, for each patient, in the previouly mentioned databases.

Linked data sources

Pre linked

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

Yes

PEM_database	
Linkage strategy	
Deterministic	
Linkage variable	
Unique patient ID	
Linkage completeness	
10000.00%	
Pre linked	
Is the data source described created by the linkage of other data sources?	
No	
Data source, other	
RNU_database	
Linkage strategy	
Deterministic	
Linkage variable	
Unique patient ID	
Pre linked	
Is the data source described created by the linkage of other data sources?	

Data source, other

Data source pr	eservation length (years)
No	
-	ed in the data source indefinitely?
Data source pr	eservation
Yes	
Can validity of the da	ata in the data source be verified (e.g., access to original medical charts)?
Possibility of d	ata validation
Required for inte	ervention studies
Informed conse	ent for use of data for research
Every 6 months	
Data source re	fresh
circ data 5	
the data s	
Data mana	agement specifications that apply for
Unique patient II	
Linkage variab	le
Deterministic	
Linkage strate	ду

Data source, other

Approval for publication

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

Yes

Data source last refresh

01/03/2023

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

1

Data source ETL frequency

6,00 months

Data source ETL specifications (file)

CAC EMHA ETL design.pdf(1.29 MB)

Data source ETL status

In progress