## **Egas Moniz Database**

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### Administrative details

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#### **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

#### Data source website

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

### Contact details

### Firmino Machado



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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

### 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

Cause of death Captured  Cause of death vocabulary SNOMED SNOMED CT  Prescriptions of medicines Captured  Prescriptions vocabulary RxNorm  Dispensing of medicines Not Captured  Advance therapy medicinal products (ATMP) Is information on advanced therapy medicinal products included? A medicinal product for human use that is either
SNOMED CT  Prescriptions of medicines Captured  Prescriptions vocabulary RxNorm  Dispensing of medicines Not Captured  Advance therapy medicinal products (ATMP)
Prescriptions vocabulary RxNorm  Dispensing of medicines Not Captured  Advance therapy medicinal products (ATMP)
Dispensing of medicines Not Captured  Advance therapy medicinal products (ATMP)
Not Captured  Advance therapy medicinal products (ATMP)
. , ,
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) 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

Not Captured

### Sociodemographic information

Captured

### Sociodemographic information collected

Age

Country of origin Deprivation index Gender Health area

## 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 (? 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 between the following persons Mother-child

## **Population**

## Active population

Active population size 1232296

### 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

## 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 previously mentioned databases.

### Linked data sources

### **Pre linked**

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

Yes

Data source, other

PEM database

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? No
Data source, other Sclinico_database
Linkage strategy Deterministic
Linkage variable Unique patient ID

Linkage strategy

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 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

01/03/2023

## 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