CUF Database

First published: 01/02/2024

Last updated: 17/10/2024

Data source | Human | Other

Administrative details

Administrative details

Data source ID

1111129

Data source acronym

CUF DB

Data holder

CUF

Data source type

Other

Data source type, other

Electronic health records

Main financial support

European public funding

Funding by own institution

Care setting

Hospital inpatient care

Hospital outpatient care

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

Contact details

João Paulo Leal joao.p.leal@cuf.pt

Main

joao.p.leal@cuf.pt

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

Ferreira AR, Ribeiro J, Miranda A, Mayer A, Passos-Coelho JL, Brito M, Fernandes J, Gouveia J, Costa L, Vaz-Luis I. Effectiveness of Adjuvant Ovarian Function Suppression in Premenopausal Women With Early Breast Cancer: A Multicenter Cohort Study. Clin Breast Cancer

Chiricozzi A, Balato A, Conrad C, Conti A, Dapavo P, Ferreira P, Gaiani FM, Leite L, Malagoli P, Mendes-Bastos P, Megna M, Messina F, Nidegger A, Odorici G, Panduri S, Piaserico S, Piscitelli L, Prignano F, Ribero S, Valerio J, Torres T. Secukinumab demonstrates improvements in absolute and relative psoriasis area severity indices in moderate-to-severe plaque psoriasis: results from a European, multicentric, retrospective, real-world study

Ferreira P, Mendes-Bastos P. Secukinumab: A complete approach to psoriatic patients-Real-world evidence study. Dermatol Ther. 2021 Mar;34(2):e14815

Lima J, Martins C, Leandro MJ, Nunes G, Sousa MJ, Branco JC, Borrego LM. Characterization of B cells in healthy pregnant women from late pregnancy to post-partum: a prospective observational 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

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

ICD

Prescriptions of medicines

Captured

Prescriptions vocabulary

ATC

Dispensing of medicines

Captured

Dispensing vocabulary

ATC

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

ICD

Other

Procedures vocabulary, other

PT CPT (OM)

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?

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?

Yes

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

Not coded (Free text)

Medicinal product information

Not Captured

Quality of life measurements

Captured

Quality of life measurements vocabulary

EQ5D

other

Quality of life measurements, other

ICHOM

Lifestyle factors

Captured

Lifestyle factors

Alcohol use

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Education level

Gender

Living in rural 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

50%

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)

Data is not collected in the population resorting solely to public health services in the catchment area.

Family linkage

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

Ad hoc

Population

Population size

3900000

Active population size

1000000

Median observation time

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

2.00

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

1.00

Data flows and management

Access and validation

Biospecimen access

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

Yes

Biospecimen access conditions

Any contact with patients, genetic or bio samples or other must be evaluated by the Ethics

Committee and CUF's DPO Office.

Access to subject details

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

Yes

Description of data collection

The patient data is collected through our main healthcare information system. Afterwards this data is extracted, anonymized, cleanned and structured in CUF Datalake, for management and analytical purposes.

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

Practice registration

Start of treatment

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

Loss to follow up

Other

Practice deregistration

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

A person remains in the database unless there is an explicit intent to delete personal data, according to GDPR rules and current legislation.

Event triggering creation of a record in the data source

The trigger for creating a record is any type of encounter or touchpoint with any CUF health-related service, including outpatient and inpatient services.

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

Unique patient and record IDs are collected. These are encrypted and passed to the OMOP-CDM version to allow patient linking within sources.

Linked data sources

Pre linked

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

Yes

Data source, other

OMOP-CDM version of the colorectal cancer data

Linkage strategy

Deterministic

Linkage variable

In the OMOP-CDM version, each patient contains a person_source_value variable that connects to the main source UID.

Linkage completeness

100% of the mapped OMOP-CDM version can be linked back

Pre linked

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

Yes

Data source, other

PRO/CRO data

Linkage strategy

Deterministic

Linkage variable

Unique patient and record IDs

Linkage completeness

100% of the mapped OMOP-CDM version can be linked back

Data management specifications that apply for the data source

Data source refresh

Monthly

Informed consent for use of data for research

Required for all 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?

Yes

Approval for publication

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

Yes

Data source last refresh

20/04/2023

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

Completed