Biobanco-iMM

First published: 01/02/2024

Last updated: 17/10/2024

Data source | Human | Biobank

Administrative details

Administrative details

Data source ID

1111122

Data source acronym

BB-iMM

Data holder

Instituto de Medicina Molecular (iMM)

Data source type

Biobank

Main financial support

Funding by own institution

Care setting

Hospital inpatient care

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

General Email biobanco-imm@medicina.ulisboa.pt

Main

biobanco-imm@medicina.ulisboa.pt

Data source regions and languages

Data source countries

Portugal

Data source languages

English

Portuguese

Data source establishment

Data source established

15/06/2012

Data source time span

First collection: 15/06/2012

The date when data started to be collected or extracted.

Publications

Data source publications

Biobanco-IMM, Lisbon Academic Medical Centre

Biobanco-IMM, Lisbon Academic Medical Centre: a case study

EpiReumaPt- the study of rheumatic and musculoskeletal diseases in Portugal: a detailed view of the methodology

EpiReumaPt: how to perform a national population based study - a practical guide

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)

Diagnosis (uses local codes),Diagnosis date (uses local codes), Co-morbidities (uses MedDRA codes), Vaccination status (uses local codes), Appropriate disease activity & Functional status (uses local codes), EVA score - doctor (uses local codes), EVA score - patient (uses local codes),

---

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?

No

Cause of death

Captured

Cause of death vocabulary

MedDRA

Prescriptions of medicines

Captured

Dispensing of medicines

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)].

No

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

MedDRA

Medical devices

Is information on medicinal devices (e.g., pens, syringes, inhalers) available?

No

Administration of vaccines

Yes

Procedures

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

Captured

Procedures vocabulary

MedDRA

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.

No

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.

Not Captured

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?

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

MedDRA

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Medicinal product vocabulary

Other

If 'other,' what vocabulary is used?

INN

Quality of life measurements

Captured

Quality of life measurements vocabulary

Not coded (Free text)

Lifestyle factors

Captured

Lifestyle factors

Tobacco use

Alcohol use

Frequency of exercise

Sociodemographic information

Captured

Sociodemographic information collected

Ethnicity

Age

Education level

Gender

Health area

Country of origin

Marital status

Quantitative descriptors

Population Qualitative Data

Population age groups

Paediatric Population (< 18 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

20%

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)

Patients who are admitted to the Hospital de Santa Maria, Lisbon, Portugal

Family linkage

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

Ad hoc

Population

Population size

27000

Active population size

2300

Population by age group

Age group	Population size	Active population size
Paediatric Population (< 18 years)	7290	10
Adolescents (12 to < 18 years)	27	10
Adults (18 to < 46 years)	4050	125
Adults (46 to < 65 years)	6750	437
Elderly (≥ 65 years)	15930	1728
Adults (65 to < 75 years)	8100	851
Adults (75 to < 85 years)	4050	638
Adults (85 years and over)	3780	239

Median observation time

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

62.00

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

67.00

Data flows and management

Access and validation

Biospecimen access

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

Yes

Biospecimen access conditions

Samples collected directly by the Biobanco-IMM are available to be shared. The Scientific
Commission validates the request of the samples after the evaluation of a project submitted by the requesting researchers. The project should be previously approved by the local Ethics Committee. The meeting of the Scientific Committee for validation of the request should take place within one month after the application.

Access to subject details

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

No

Description of data collection

The Biobanco-IMM is authorized by the ethics committee of the Centro Hospitalar Lisboa Norte -
Hospital de Santa Maria (approved on September 17, 2008) to collect and store samples for scientific research. The storage and management of clinical data, associated with the samples collected, is authorized by the National Data Protection Commission (authorization number 7435/2011 of 11 July 2011).When a sample is collected, a minimum core data set about the donor is gathered, which includes pseudonymized socio-demographic data such as birth date, gender, race, weight, hight, birth place, diagnostic and if the written informed consent was signed. When the sample is stored, the LIMS software keeps information about where the sample is stored.

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

Other

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

Sample Regustry into the Biobank

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

Other

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

Asked by the donor

Event triggering creation of a record in the data source

Sample Registry into the Biobank and medical appointment

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

Linked data sources

Pre linked

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

Yes

Data source, other

Reuma.PT

Linkage variable

Patient Number

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

30/03/2023

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

5.4

Data source ETL status

In progress