RIOJA SALUD

First published: 01/02/2024

Last updated: 17/10/2024

Data source

Human

Other

Population registry

Registration with healthcare system

Administrative details

Administrative details

Data source ID

1111160

Data source acronym

RIOJA SALUD

Data holder

Fundacion Rioja Salud

Data source type

Other

Population registry

Registration with healthcare system

Data source type, other

Electronic health records

Main financial support

European public funding

National, regional, or municipal public funding

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.

No

Data source website

https://www.fundacionriojasalud.org/

Contact details

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Data source regions and languages

Data source countries

Spain

Data source languages

Spanish

Data source regions

La Rioja

Data source establishment

Data source established

01/01/2016

Data source time span

First collection: 01/01/2016

The date when data started to be collected or extracted.

Publications

Data source publications

La Rioja Government Act for Health Data Lake Platform (PASCAL) Create and Governance

European Health Data and Evidence Network (EHDEN) Data Partner. European Union Horizon 2020 initiative

Federated Artificial Intelligence Network to accelerate Health Research Project. European Union Next Generation

Data Science Team (Unidad Ciencia del Dato). Member of OHDSI Spanish node

National project: Extrahospitalaria/Out of Hospital Spanish Cardiac Arrest Registry (OHSCAR). Declared National Health System Registry by Ministry of Health

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.

No

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 vocabulary
ICD-10
SNOMED CT
Prescriptions of medicines
Captured
Prescriptions vocabulary
ATC
RxNorm
Dispensing of medicines
Captured
Dispensing vocabulary
RxNorm
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

Cause of death

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

Captured

Indication vocabulary

ICD-10

SNOMED CT

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

ICD-10

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?

Captured

Genetic data vocabulary

Other

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

Yes	
Unique identifier for perso	ons
Are patients uniquely identified in the	e data source?
Yes	
Diagnostic codes	
Captured	
Diagnosis / medical event	vocabulary
ICD-10	
SNOMED CT	
Medicinal product informa	ntion
Captured	
Medicinal product informa	ition collected
Brand name	
Dose	
Formulation	
Package size	
Route of administration	
Medicinal product vocabul	lary
RxNorm	
SNOMED	
Quality of life measuremen	nts
Captured	

of services for the purpose of preventing or curing health problems.

Quality of life measurements vocabulary

Not coded (Free text)

Lifestyle factors

Captured

Lifestyle factors

Alcohol use

Diet

Frequency of exercise

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Gender

Health area

Living in rural area

Socioeconomic status

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%

Family linkage

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

Ad hoc

Population

Population size

Active population size

320000

Population by age group

Age group	Population size	Active population size
Paediatric Population (< 18 years)	99697	53910
Preterm newborn infants (0 - 27 days)	6	6
Term newborn infants (0 – 27 days)	123	123
Infants and toddlers (28 days - 23 months)	5423	4483
Children (2 to < 12 years)	50975	29169
Adolescents (12 to < 18 years)	50015	20258
Adults (18 to < 46 years)	227907	102544
Adults (46 to < 65 years)	180442	90957
Elderly (≥ 65 years)	217761	69397
Adults (65 to < 75 years)	65234	29871
Adults (75 to < 85 years)	54271	22529
Adults (85 years and over)	91277	12959

Median observation time

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

20.00

Median time (years) between first and last available records for unique active individuals (alive and currently registered) capt 20.00

Data flows and management

Access and validation

Governance details

Documents or webpages that describe the overall governance of the data source and processes and procedures for data capture and management, data quality check and validation results (governing data access or utilisation for research purposes).

https://www.fundacionriojasalud.org/innovacion/unidad-ciencia-dato/pascal

Biospecimen access

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

No

Access to subject details

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

Yes

Description of data collection

Global initial load plus daily, standardized and pseudo-anonymized load from EHR (primary and hospital patient attention) to a global data set used for secondary purposes (research, development and innovation) using open source tools (Phyton and Apache)

Event triggering registration

Event triggering registration of a person in the data source

Birth

Insurance coverage start

Start of treatment

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

Death

Insurance coverage end

Event triggering creation of a record in the data source

All contact of the patient with public care system of La Rioja (hospital procedures, medical attention, medical product dispensing...)

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

Healthcare databases and electronic medical record are linked in a deterministic way

Linked data sources

Pre	Hi	n	ke	d

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

No

Data source, other

Enviroment and other open data source databases

Linkage strategy

Deterministic

Linkage variable

Date, address, others...

Linkage completeness

Daily monitoring to identify and correct unreferenced records

Pre linked

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

Yes

Data source, other

HIS

Linkage strategy

Deterministic

Linkage variable

Pseudo anonymous code in compliance with the Spanish Regulation (Organic Law 3/2018, of December 5, Protection of Personal Data and guarantee of digital rights)

https://www.boe.es/boe/dias/2018/12/06/pdfs/BOE-A-2018-16673.pdf

Linkage completeness

Daily monitoring to identify and correct unreferenced records

Pre linked

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

Yes

Data source, other

LIS

Linkage strategy

Deterministic

Linkage variable

Pseudo anonymous code in compliance with the Spanish Regulation (Organic Law 3/2018, of December 5, Protection of Personal Data and guarantee of digital rights)

https://www.boe.es/boe/dias/2018/12/06/pdfs/BOE-A-2018-16673.pdf

Linkage completeness

Daily monitoring to identify and correct unreferenced records

Pre linked

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

Yes

Data source, other

Pharmacy, Primary Health Care and specialized databases for professionals healthcare support

Linkage strategy

Deterministic

Linkage variable

Pseudo anonymous code in compliance with the Spanish Regulation (Organic Law 3/2018, of December 5, Protection of Personal Data and guarantee of digital rights)

https://www.boe.es/boe/dias/2018/12/06/pdfs/BOE-A-2018-16673.pdf

Linkage completeness

Daily monitoring to identify and correct unreferenced records

Data management specifications that apply for the data source

Data source refresh

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

19/04/2023

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

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