Portugal North Region Cancer Registry

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Data source Human Cancer registry Population registry

Administrative details

Administrative details

Data source ID

26460

Data source acronym

RORENO - Oncology

Data holder

Registo Oncológico Regional do Norte (RORENO)

Data source type

Cancer registry

Population registry

Main financial support

National, regional, or municipal public funding

Care setting

Hospital inpatient care

Hospital outpatient 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

Data source website

https://ipoporto.pt/eu-cidadao/registo-oncologico-regional-do-norte/

Contact details

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Data source regions and languages

Data source countries

Portugal

Data source languages

Portuguese

Data source regions

Braga

Bragança

Porto

Viana do Castelo

Vila Real

Data source establishment

Data source established

01/01/1988

Data source time span

First collection: 01/01/1988

The date when data started to be collected or extracted.

Publications

Data source publications

Cancer incidence projections RORENO - 2013, 2015 and 2020

RORENO Report 2015

Global survival of patients diagnosed in 2011-2012 RORENO

National Cancer Registry of All Tumors Diagnosed in Portugal - 2019

List of publications by RORENO

Studies

List of studies that have been conducted using the data source

Survey on the collection of data on adverse events related to medicinal products through registries

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)

Cancer

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?

No

Cause of death

Captured

Cause of death vocabulary

ICD-10

Prescriptions of medicines

Not Captured

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?

Yes

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?

No

Administration of vaccines

No

Procedures

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

Captured

Procedures vocabulary

ICD-10-CM

ICD-9-CM

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?

No

Genetic data

Are data related to genotyping, genome sequencing available?
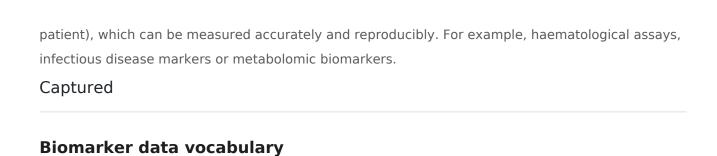
Captured

Genetic data vocabulary

Other

Genetic data vocabulary, other

free text

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

Biomarker vocabulary, other

free text

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

Other

Diagnosis / medical event vocabulary, other

ICD-O

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Dosage regime

Dose

Route of administration

Medicinal product vocabulary

Other

If 'other,' what vocabulary is used?

Código Hospitalar Nacional do Medicamento (CHNM)

Quality of life measurements

Not Captured

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

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

RORENO covers 33% of the total portuguese population, but covers 100% of the population of its designated area (North Region).

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)

Regional sub-set - Specific North regions from the north of Portugal

Population

Population size

276630

Population by age group

Age group	Population size
Paediatric Population (< 18 years)	6789
Infants and toddlers (28 days – 23 months)	1506
Children (2 to < 12 years)	3199
Adolescents (12 to < 18 years)	2816
Adults (18 to < 46 years)	48169
Adults (46 to < 65 years)	93065
Elderly (≥ 65 years)	129777
Adults (65 to < 75 years)	69200

Age group	Population size
Adults (75 to < 85 years)	48078
Adults (85 years and over)	13701

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://dre.pt/dre/detalhe/lei/53-2017-107692693

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?

No

Description of data collection

Every hospital registers new cases of cancer in a national common plataform. The access to the information for registration is enabled by EMR and automatic integration of health systems.

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

Start of treatment

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

Other

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

Formal request by the patient to be excluded from the database.

Event triggering creation of a record in the data source

The data source provides a trigger for follow-up update of the cancer registry but only inside the database. Other data sources can be triggers (e.g. SICO-Death Certificate Information System, SIGLIC- Integrated Surgical Enrollment Management System, SIMH - Information System for Hospital Morbidity). No data is released or triggers other systems.

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?

No

Data management specifications that apply for the data source

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

20/06/2023

Common Data Model (CDM) mapping

CDM mapping

Has the data source been converted (ETL-ed) to a common data model?

No