Cancer Registry of Instituto Português de Oncologia do Porto Francisco Gentil, E.P.E

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Data source   Human   Disease registry

Administrative details

Administrative details

Data source ID

1111146

Data source acronym

IPO-Porto Cancer Registry

Data holder

Instituto Português de Oncologia do Porto (IPO-PORTO)

Data source type

Disease registry

Main financial support

Funding by own institution

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

Aveiro

Braga

Bragança

Porto

Viana do Castelo

Vila Real

Viseu

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

Morais S, Antunes L, Rodrigues J, Fontes F, Bento MJ, Lunet N. The impact of the COVID-19 pandemic on the short-term survival of patients with cancer in Northern Portugal. Int J Cancer. 2021 Jul 15;149(2):287-296. Epub 2021 Mar 13. PMID: 33634852; PMCID: PMC8014057.

Nikšić M, Matz M, Valkov M, Marcos-Gragera R, Stiller C, Rosso S, Coleman MP, Allemani C; CONCORD Working Group. Worldwide trends in net survival from pancreatic cancer by morphological sub-type: An analysis of 1,258,329 adults diagnosed in 58 countries during 2000-2014 (CONCORD-3). Cancer Epidemiol. 2022 Oct;80:102196. Epub 2022 Jul 13. PMID: 35841761.

Brandão M, Morais S, Lopes-Conceição L, Fontes F, Araújo N, Dias T, Pereira D, Borges M, Pereira S, Lunet N. Healthcare use and costs in early breast cancer: a

patient-level data analysis according to stage and breast cancer subtype. ESMO Open. 2020 Nov;5(6):e000984. PMID: 33234552; PMCID: PMC7689066.

Ghione P, Palomba ML, Patel AR, Bobillo S, Deighton K, Jacobson CA, Nahas M, Hatswell AJ, Jung AS, Kanters S, Snider JT, Neelapu SS, Ribeiro MT, Brookhart MA, Ghesquieres H, Radford J, Gribben JG. Comparative effectiveness of ZUMA-5 (axi-cel) vs SCHOLAR-5 external control in relapsed/refractory follicular lymphoma. Blood. 2022 Aug 25;140(8):851-860. PMID: 35679476.

Soares M, Antunes L, Redondo P, Borges M, Hermans R, Patel D, Grimson F, Munro R, Chaib C, Lacoin L, Daumont M, Penrod JR, O'Donnell JC, Bento MJ, Gonçalves FR. Treatment and outcomes for early non-small-cell lung cancer: a retrospective analysis of a Portuguese hospital database. Lung Cancer Manag. 2021 Feb 19;10(2):LMT46. PMID: 34084212; PMCID: PMC8162184.

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 patient demographics, tumor (cancer) characteristics, diagnosisis, treatment, and outcomes.

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

No

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Captured

Cause of death vocabulary

Other

Prescriptions of medicines

Not Captured

Dispensing of medicines

Captured

Dispensing vocabulary

other

Dispensing vocabulary, other

Portuguese hospital drug code transposable to the ATC code

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?

Captured

Indication vocabulary

Other

Indication vocabulary, other

ICD-O-3

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

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

No

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-3

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Dose

Route of administration

Strength

Medicinal product vocabulary

Other

If 'other,' what vocabulary is used?

Portuguese hospital drug code transposable to the ATC code

Quality of life measurements

Not Captured

Lifestyle factors

Captured

Lifestyle factors

Alcohol use

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Education level

Gender

Marital status

Other

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

15%

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)

Being part of the National Health System, IPO-Porto covers the general population (public). The database is composed of all types of socioeconomic status patients.

Population

Population size

400000

Active population size

45000

Population by age group

Age group	Population size
Paediatric Population (< 18 years)	4000
Adults (18 to < 46 years)	40000
Adults (46 to < 65 years)	172000
Adults (65 to < 75 years)	112000
Adults (75 to < 85 years)	60000
Adults (85 years and over)	12000

Median observation time

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

10.00

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

10.00

Data flows and management

Access and validation

Biospecimen access

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

Yes

Biospecimen access conditions

Biospecimens can be accessed under the signture of a protocol approved by IPO-Porto internal review board.

Access to subject details

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

No

Description of data collection

The database is updated in real-time via FHIR messages, integrating information from several IPO-Porto databases. However, this data needs to be manually curated by data managers. So, we only have validated information up

to 2020, which is the information we make available.

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

Other

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

Patients may request to be de-registered from the IPO-Porto cancer registry

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Event triggering creation of a record in the data source

A record is created in real-time via FHIR message at the first contact of a patient with administrative service.

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

The database is updated in real-time integrating information from several IPO-Porto databases.

Linkage description, possible linkage

A process of linking databases real-time will be established soon.

Linked data sources

Pre linked

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

Yes

Data source, other

Outpatient electronic health records; Inpatient hospital electronic health records; Inpatient hospital billing systems; Biobank

Linkage variable

All data sources are linked by an internal IPO-Porto patient number.

Pre linked

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

No

Data source, other

Portuguese National Cancer Registry

Linkage variable

Data sources are linked by a unique cancer identification number

Data management specifications that apply for the data source

Data source refresh

Monthly

Informed consent for use of data for research

Other

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

Informed consent, other

Waiver to informed consent can be requested to conduct non-intervention studies

Common Data Model (CDM) mapping

CDM mapping

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

No