PAN Cancer Research Platform

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Last updated: 17/10/2024

Data source

Human

Cancer registry

Administrative details

Administrative details

Data source ID

1111224

Data source acronym

PAN Registry

Data holder

iOMEDICO

Data source type

Cancer registry

Main financial support

Funding from industry or contract research

Care setting

Hospital inpatient care

Hospital outpatient care

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.iomedico.com/en/research/health-care-research/

Contact details

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Main

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Data source regions and languages

Data source countries

Germany

Data source languages

German

Data source establishment

Data source established

01/01/2006

Data source time span

First collection: 01/01/2006

The date when data started to be collected or extracted.

Publications

Data source publications

Association of Disease Progression With Health-Related Quality of Life Among Adults With Breast, Lung, Pancreatic, and Colorectal Cancer

Rare lymphomas in routine practice—Treatment and outcome in Waldenström's macroglobulinaemia in the prospective German Tumour Registry Lymphatic Neoplasms

FOLFIRINOX or gemcitabine/nab-paclitaxel in advanced pancreatic adenocarcinoma: A novel validated prognostic score to facilitate treatment decision-making in real-world

Persistent impairments 3 years after (neo)adjuvant chemotherapy for breast cancer: results from the MaTox project

Survival of Patients With Advanced or Metastatic Renal Cell Carcinoma in Routine Practice Differs From That in Clinical Trials—Analyses From the German Clinical RCC Registry

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)

various types of cancer (colorecal, breast, kidney, urothelial, pancreatic, ovarial, endometrial, gastric, esophageal, liver, cholangiolar) and hematologic maglinancies (NHL, CLL, MM)

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)?

No

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

Other

Cause of death vocabulary, other

cancer, comorbidity, toxicity, other

Prescriptions of medicines

Captured

Prescriptions vocabulary

other

Dispensing of medicines

Captured

Dispensing vocabulary

other

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?

Captured

Indication vocabulary

ICD-10

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

Other

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?

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.

No

Unique identifier for persons

Are patients uniquely identified in the data source?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

Other

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Dosage regime

Dose

Route of administration

Medicinal product vocabulary

Other

Quality of life measurements

Captured

Quality of life measurements vocabulary

HRQOL

Lifestyle factors

Captured

Lifestyle factors

Alcohol use

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Education level

Gender

Other

Quantitative descriptors

Population Qualitative Data

Population age groups

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

5% of newly diagnosed patients in Germany

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 treated at sites not participating in the registry, patients who do not receive any type of systemic treatment for their cancer and patients who do not provide informed consent are not covered

Population

Population size

50000

Active population size

25000

Population by age group

Age group	Population size	Active population size
Adults (18 to < 46 years)	5000	2500
Adults (46 to < 65 years)	10000	5000
Elderly (≥ 65 years)	35000	17500
Adults (65 to < 75 years)	25000	12500
Adults (75 to < 85 years)	7500	3750
Adults (85 years and over)	2500	1250

Median observation time

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

5.00

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

5.00

Data flows and management

Access and validation

Biospecimen access

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

Yes

Biospecimen access conditions

ethics vote and collaboaration agreement

Access to subject details

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

Yes

Description of data collection

Data are transferred from patient files into an electronic data captures system by trained staff

Event triggering registration

Event triggering registration of a person in the data source

Other

Start of treatment

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

informed consent

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

Death

Loss to follow up

Event triggering creation of a record in the data source

informed consent of the patient at start of treatment

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

Data source refresh

Monthly

Informed consent for use of data for research

Required for intervention 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?

No

Data source last refresh

27/10/2023

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

CDISC SDTM

CDM website

https://www.cdisc.org/standards/foundational/sdtm

Data source ETL status

Completed