Onco-Data-Hub (ODH)

First published: 21/02/2025

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Data source   Human   Cancer registry   Death registry   Disease registry

Drug registry   Hospital inpatient records

Administrative details

Administrative details

Data source ID

1000000453

Data source acronym

ODH

Data holder

Unicancer

Data source type

Cancer registry

Death registry

Disease registry

Drug registry

Hospital inpatient records

Main financial support

Funding from industry or contract research

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.

Yes

Description of the qualification

ISO certification for project management activities

Data source website

https://www.unicancer.fr/en/programs/esme/

Contact details

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(**Main**)

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Data source regions and languages

Data source countries

France

Data source languages

English

French

Data source establishment

Data source established

16/06/2021

Data source time span

First collection: 01/01/2020

The date when data started to be collected or extracted.

Publications

Data source publications

Benhajkassen, N., Bosquet, L., Deniau, M., Bachot, C., Guesmia, T., Robert, V., ... & Martin, A. (2023). CO10. 7-Plateforme de données de vie réelle ODH: élaboration d'un observatoire du médicament en oncologie. Revue d'Épidémiologie et de Santé Publique, 71, 101633.

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

Breast cancer

Non-small cell lung cancer

Small cell lung 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.

No

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

No

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Captured

Prescriptions of medicines

Captured

Prescriptions vocabulary

other

___

Prescriptions vocabulary, other

international nonproprietary name (INN) for anti-cancer drugs only

___

Dispensing of medicines

Captured

___

Dispensing vocabulary

other

___

Dispensing vocabulary, other

international nonproprietary name (INN) for anti-cancer drugs only

___

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

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Contraception

Is information on the use of any type of contraception (oral, injectable, devices etc.) available?

No

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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

Oncology systemic drugs

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

Procedures vocabulary, other

(not coded) Free text

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?

Not 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.

Captured

Biomarker data vocabulary

Other

Biomarker vocabulary, other

oncogenic drivers (EGFR / KRAS / ALK/ etc.) coded with COSMIC catalog

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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

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Brand name

Dosage regime

Dose

Route of administration

Medicinal product vocabulary

Other

If 'other,' what vocabulary is used?

international nonproprietary name (INN)

Quality of life measurements

Not Captured

Lifestyle factors

Captured

Lifestyle factors

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Gender

Sex

Socioeconomic status

Quantitative descriptors

Population Qualitative Data

Population age groups

Adult and elderly population (≥18 years)

Elderly (≥ 65 years)

Estimated percentage of the population covered by the data source in the catchment area

38 000 Breast cancer patients

23 000 lung cancer patients

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)

All stages of patients with breast cancer or lung cancer diagnosis

Population

Population size

61000

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).

ODH_governance_2025_final.pdf

English (68.09 KB - PDF)

View document

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

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

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

SNDS : Système National des données de santé (France) / will be available from second semester 2025.

Linkage description, possible linkage

probabilistic linkage

Data management specifications that apply for the data source

Data source refresh

Yearly

Possibility of data validation

Can validity of the data in the data source be verified (e.g., access to original medical charts)?

No

Data source preservation

Are records preserved in the data source indefinitely?

No

Data source preservation length (years)

20 years years

Approval for publication

Is an approval needed for publishing the results of a study using the data source?

Yes

Data source last refresh

23/10/2024

Common Data Model (CDM) mapping

CDM mapping

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

No