Centro Oncologico Modenese (COMNET) EHDEN database

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Data source Human Cancer registry Drug registry
Hospital discharge records Hospital inpatient records
Hospital outpatient visit records Other

Administrative details

Administrative details

Data source ID

100000287

Data source acronym

COMNET

Data holder

Oncology Unit, Department of Oncology Hemathology, University Hospital Modena and Reggio Emilia

Data source type

Cancer registry Drug registry Hospital discharge records Hospital inpatient records Hospital outpatient visit records Other

Data source type, other

Diagnostic tests and procedures, hospital discharge, laboratory data, death data

Main financial support

European 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

Contact details

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Data source regions and languages

Data source countries

Italy

Data source languages English Italian

Data source regions Emilia-Romagna

Data source establishment

Data source established

15/07/2022

Data source time span

First collection: 01/01/2003

The date when data started to be collected or extracted.

Last collection: 31/12/2023

If data collection in the data source has ceased, the date new records last entered the data source.

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)

Information for all cancers are available

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?

Yes

Cause of death

Captured

Cause of death vocabulary

ICD

Prescriptions of medicines

Captured

Prescriptions vocabulary

DrugBank

Dispensing of medicines

Captured

Dispensing vocabulary

DrugBank

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)].

No

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?

Not Captured

Medical devices

Is information on medicinal devices (e.g., pens, syringes, inhalers) available?

Yes

Administration of vaccines

No

Procedures

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

Captured

Procedures vocabulary

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?

Yes

Genetic data

Are data related to genotyping, genome sequencing available?

Captured

Genetic data vocabulary

HGVS

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

HGMS

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

ICD

Medicinal product information

Captured

Medicinal product information collected

Brand name Dosage regime Dose Formulation Route of administration Strength

Medicinal product vocabulary

AIC

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 Gender Sex

Quantitative descriptors

Population Qualitative Data

Population age groups

All Paediatric Population (< 18 years) Preterm newborn infants (0 – 27 days) Term newborn infants (0 – 27 days) Children (2 to < 12 years) Adolescents (12 to < 18 years) Adult and elderly population (\geq 18 years) Adults (18 to < 65 years) Adults (18 to < 65 years) Adults (46 to < 65 years) Elderly (\geq 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

The COMNet patients records cover nearly the 100% of the tumor cases in Modena Province and the 15% in the Emilia Romagna 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)

The National Health Service covers almost the entire population affected by cancer. COMNet serves patients from the region of Emilia-Romagna and in particular the province of Modena

Family linkage

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

Ad hoc

Population

Population size

39230

Active population size

3330

Population by age group

Age group	Population size	Active population size
All	39230	3330
Paediatric Population (< 18 years)	32	32
Adolescents (12 to < 18 years)	14	14
Adults (18 to < 46 years)	316	316
Adults (46 to < 65 years)	1151	1151
Elderly (≥ 65 years)	1831	1831
Adults (65 to < 75 years)	900	900
Adults (75 to < 85 years)	745	745
Adults (85 years and over)	186	186

Data flows and management

Access and validation

Biospecimen access

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

Yes

Biospecimen access conditions

Biospecimen available in the context of an approved study protocol upon

dedicated agreements

Access to subject details

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

Yes

Description of data collection

To collect or process data, a clinical protocol needs to be submitted and approved to an Institutional Review Board (IRB) and subsequently also approved by Azienda Ospedaliero Universitaria of Modena (about 4 weeks for approval). The request for approval goes in parallel for IRB and Azienda Ospedaliero Universitaria. Link: https://www.aou.mo.it/ComitatoEticoAVEN Any events related to diagnosis, start or modification of therapy, events related to the patient's medical history (toxicity, disease progression) are recorded in the platform

The Modena Cancer Center (Centro Oncologico Modenese - COM) of the AOU Policlinico (Modena, Italy) annually takes care of several thousand patients affected by solid tumors. All patients are followed within specific diagnostictherapeutic paths for the pathology. All histopathological data, radiological staging documents (US, CT scan, MRI, PET/SPECT), all therapies (chemo, immunotherapies, radiotherapy, target therapies, hormonal therapies) and survival outcomes are stored in an electronic medical platform (COMnet). This platform is also integrated with laboratory assessments (heamatological. biochemical, microbiological, serological).

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

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

Practice deregistration

Event triggering creation of a record in the data source

Diagnosis of cancer or taking charge of an already diagnosed patient

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 general use

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

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

OMOP

CDM website

https://www.ohdsi.org/Data-standardization/

Data source ETL CDM version

5.4

Data source ETL frequency

12,00 months

Data source ETL status

Completed

Data source ETL specifications (link)

https://www.ohdsi.org/Data-standardization/