

AOUPR EHDEN Database

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Data source

Human

Cancer registry

Disease registry

Hospital inpatient records

Other

Administrative details

Administrative details

Data source ID

1000000024

Data source acronym

AOUPR

Data holder

[University Hospital of Parma](#)

Data source type

Cancer registry

Disease registry

Hospital inpatient records

Other

Data source type, other

Diagnostic tests and procedures, COVID-19, registries, hospital discharge, laboratory data, death data and other

Main financial support

European public funding

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.

No

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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

15/12/2023

Data source time span

First collection: 15/06/2021

The date when data started to be collected or extracted.

Last collection: 15/06/2022

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.

No

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?

Yes

Cause of death

Captured

Cause of death vocabulary

SNOMED

Prescriptions of medicines

Captured

Prescriptions vocabulary

RxNorm

Dispensing of medicines

Captured

Dispensing vocabulary

RxNorm

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?

No

Administration of vaccines

Yes

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.

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.

Not Captured

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

ICD-9-CM

Medicinal product information

Captured

Medicinal product information collected

Formulation

Route of administration

Medicinal product vocabulary

RxNorm

Quality of life measurements

Not Captured

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Gender

Quantitative descriptors

Population Qualitative Data

Population age groups

Paediatric Population (< 18 years)

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 < 65 years)

Adults (18 to < 46 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)

Family linkage

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

Permanently

Family linkage available between the following persons

Mother-child

Population

Population size

573205

Active population size

524208

Population by age group

Age group	Population size	Active population size
Paediatric Population (< 18 years)	77740	77694
Term newborn infants (0 – 27 days)	7282	7279
Infants and toddlers (28 days – 23 months)	6553	6552
Children (2 to < 12 years)	36075	36060
Adolescents (12 to < 18 years)	27830	27803
Adults (18 to < 46 years)	178506	178016

Age group	Population size	Active population size
Adults (46 to < 65 years)	149643	146675
Elderly (\geq 65 years)	167316	121823
Adults (65 to < 75 years)	60101	54646
Adults (75 to < 85 years)	57599	43921
Adults (85 years and over)	49616	23256

Median observation time

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

0.74

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

0.84

Data flows and management

Access and validation

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

Medical records, registries

Event triggering registration

Event triggering registration of a person in the data source

Birth

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

All those who received at least one healthcare provision during the period of interest

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 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?

No

Data source preservation length (years)

10 years

Approval for publication

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

Yes

Data source last refresh

19/09/2023

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

OMOP

CDM website

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

Data source ETL status

Completed