EURACAN Epithelioid Hemangioendothelioma Registry

First published: 15/07/2025

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Data source | Human | Cancer registry

Administrative details

Administrative details

Data source ID

1000000416

Data source acronym

EHE Registry

Data holder

Fondazione IRCCS Istituto Nazionale dei Tumori

Data source type

Cancer registry

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

Data source website

Given its incidence of 0.038/100 000/year, Epithelioid Hemangiohendotelioma (EHE) is an ultra-rare sarcoma, with distinctive, well-defined pathological, molecular and clinical features.

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Data source regions and languages

Data source countries

Austria

Denmark

France

Germany

Italy

Poland

Spain

Sweden

United Kingdom

Data source languages

Danish

English

French

German

Italian

Polish

Spanish

Swedish

Data source establishment

Data source established

01/12/2023

Data source time span

First collection: 01/12/2023

The date when data started to be collected or extracted.

Publications

Data source publications

The Epithelioid Hemangioendothelioma Registry of the European Reference Network on Rare Adult Solid Cancers (EURACAN) (EHE)

Studies

No information provided.

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

Sarcoma

Disease details (other)

Epithelioid hemangioendothelioma

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

No

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Captured

Prescriptions of medicines

Captured

Prescriptions vocabulary

not coded

Dispensing of medicines

Captured

Dispensing vocabulary

not coded

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?

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

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.

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?

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?

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?

No

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

Other

Diagnosis / medical event vocabulary, other

ICD-O-3

Medicinal product information

Captured

Medicinal product vocabulary

ATC

Quality of life measurements

Not Captured

Lifestyle factors

Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Education level

Ethnicity

Marital status

Sex

Quantitative descriptors

Population Qualitative Data

Population age groups

Adult and elderly population (≥18 years)

Adults (18 to < 65 years)

Elderly (≥ 65 years)

Population

Population size

13

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).

REGISTRY-GOVERNANCE.pdf

English (260.41 KB - PDF) View document

https://cdn.prod.website-files.com/678e61688455d6c62fc215f8/67b58e3ea021586081deb936_(18)%20REGISTRY-GOVERNANCE.pdf

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

The EHE tumors collected must meet the following inclusion criteria:

- New patients managed by the contributing centers with a pathological EHE diagnosis performed or
verified by an expert sarcoma pathologist starting from 1 December 2023 onwards and to be
performed within 6 months from the registration
- Molecular confirmation of the diagnosis (WWTR1::CAMTA1 or YAP1::TFE3)
- Adult patients (aged ≥ 18 years)

The registry started the data collection in 2023.

Data will be prospectively collected on patient characteristics (e.g., information on patient demographics, medical history, health status, etc.), exposure data (e.g., the disease, devices, procedures, treatments or services of interest and outcome data (e.g. survival, progression, progression-free survival, death, etc.). In addition, data on potential confounders will also be collected.

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

Start of treatment

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

Death

Event triggering creation of a record in the data source

Specialist encounter

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

Every 6 months

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

Data source last refresh

15/07/2025

Common Data Model (CDM) mapping

CDM mapping

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

No