

EURACAN Head and Neck Registry

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Data source

Human

Cancer registry

Administrative details

Administrative details

Data source ID

1000000411

Data source acronym

EURACAN H&N 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

Cancer care for head and neck cancers is complex in particular for the rare ones.

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Data source regions and languages

Data source countries

Belgium

Czechia

Denmark

Italy

Data source languages

Czech

Danish

Dutch

English

French

Italian

Data source establishment

Data source established

20/04/2022

Data source time span

First collection: 20/04/2022

The date when data started to be collected or extracted.

Publications

Data source publications

The observational clinical registry (cohort design) of the European Reference Network on Rare Adult Solid Cancers: The protocol for the rare head and neck cancers

The Head and Neck Registry of the European Reference Network on Rare Adult Solid Cancers (EURACAN)

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

Head and neck cancer

Head and neck cancer metastatic

Head and neck cancer stage I

Head and neck cancer stage II

Head and neck cancer stage II

Head and neck cancer stage III

Head and neck cancer stage IV

Head and neck procedural complication

Radiotherapy to head and neck

Squamous cell carcinoma of head and neck

Unhealthy lifestyle

Karnofsky scale

Adenocarcinoma of salivary gland

Neck dissection

Surgery

Chemotherapy

Immunotherapy

Disease progression

Neoadjuvant therapy

Disease recurrence

Adverse event

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?

No

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 information collected

Brand name

Medicinal product vocabulary

ATC

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

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

1016

Median observation time

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

0.00

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](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 EURACAN registry on rare head and neck cancers (nasopharynx; nasal cavity and paranasal sinuses; salivary gland; middle ear) was set up with the following objectives:

- to help describe the natural history of rare head and neck cancers
- to evaluate factors that influence prognosis
- to assess treatment effectiveness
- to measure indicators of quality of care

The registry started the data collection in 2021.

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