Clinical Investigation and research for the Rendu Osler Cohort

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Data source | Human | Disease registry | Drug registry

Administrative details

Administrative details

Data source ID

1000000547

Data source acronym

CIROCO

Data holder

Hospices Civils de Lyon (HCL)

Data source type

Disease registry

Drug registry

Main financial support

European public funding

Funding by own institution

Funding from industry or contract research

Care setting

Hospital inpatient care

Hospital outpatient care

Primary care – specialist level (e.g. paediatricians)

Secondary care – specialist level (ambulatory)

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

The CIROCO database received authorisation from the CNIL on June 3rd, 2001. It is hosted by a HDS certified data provider in compliance with the ISO 27001 standard.

Data source website

http://www.rendu-osler.fr/base_donnees.php

Contact details

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Data source regions and languages

Data source countries

Denmark

France

Germany

Italy

Data source languages

English

French

Data source establishment

Data source established

23/11/2007

Data source time span

First collection: 03/06/2001

The date when data started to be collected or extracted.

Publications

Data source publications

How to improve specific databases for clinical data in rare diseases? The example of hereditary haemorrhagic telangiectasia

Studies

List of studies that have been conducted using the data source

Real-life data study of the French cohort of patients with Rendu Osler disease treatment with bevacizumab:the CoBevaRO study.

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

Hereditary haemorrhagic telangiectasia

Disease details (other)

undefined

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

Not coded (Free text)

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?

Not Captured

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?

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.

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?

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

Orphacode

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Brand name

Dosage regime

Dose

Route of administration

Medicinal product vocabulary

Not coded (Free text)

Quality of life measurements

Captured

Quality of life measurements vocabulary

other

Quality of life measurements, other

QOL-HHT (24 Items)

Lifestyle factors

Captured

Lifestyle factors

Alcohol use

Frequency of exercise

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Gender

Sex

Quantitative descriptors

Population Qualitative Data

Population age groups

Paediatric Population (< 18 years)

Neonate

Preterm newborn infants (0 – 27 days)

Term newborn infants (0 – 27 days)

Infants and toddlers (28 days – 23 months)

Children (2 to < 12 years)

Adolescents (12 to < 18 years)

Adult and elderly population (≥18 years)

Adults (18 to < 65 years)

Adults (18 to < 46 years)

Adults (46 to < 65 years)

Elderly (≥ 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

Based on an estimated 68,290,000 people in France and a prevalence of 1 in 6,000 individuals, the theoretical number of people affected by hereditary Haemorrhagic Telangiectasia is approximately 11,382.
The CIROCO database currently includes 5,973 unique individuals, representing an estimated 52.48% coverage of the affected population

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

Father-child

Mother-child

Population

Population size

8801

Active population size

5973

Population by age group

Age group	Population size
Children (2 to < 12 years)	127
Adolescents (12 to < 18 years)	242
Adult and elderly population (≥18 years)	8432

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

The hospitals are organized as a network and work in close collaboration with the Fava-Multi healthcare network.
A team of clinical research associates, employed by the network, is responsible for filling out patients' data into the database.
Thus, when a patient is seen in consultation or undergoes a medical examination, the report is forwarded to the CRA in charge of data entry.

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

Other

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

Withdrawal of consent

Event triggering creation of a record in the data source

Whenever a patient is seen for a consultation at an expert center or undergoes a medical examination related to Hereditary Haemorrhagic Telangiectasia (such as a cardiac ultrasound, chest CT scan, abdominal ultrasound, video capsule endoscopy, etc.), the report is forwarded to the CRA responsible for data entry.

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 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

09/04/2025

Common Data Model (CDM) mapping

CDM mapping

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

No