

# Clinical Investigation and research for the Rendu Osler Cohort

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Data source

Human

Disease registry

Drug registry

## Administrative details

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#### PURI

<https://redirect.ema.europa.eu/resource/1000000547>

#### Data source ID

1000000547

#### Data source acronym

CIROCO

#### Data holder

[Hospices Civils de Lyon \(HCL\)](#)

#### Data source type

Disease registry

### **Main financial support**

European public funding

Funding by own institution

Funding from industry or contract research

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### **Care setting**

Hospital inpatient care

Hospital outpatient care

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

Secondary care – specialist level (ambulatory)

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### **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

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### **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.

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### **Data source website**

[http://www.rendu-osler.fr/base\\_donnees.php](http://www.rendu-osler.fr/base_donnees.php)

## **Contact details**

Sophie Dupuis-Girod

## Data source regions and languages

### Data source countries

Denmark

France

Germany

Italy

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### Data source languages

English

French

## Data source establishment

### Data source established

23/11/2007

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### 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

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### Disease details

Hereditary haemorrhagic telangiectasia

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### Disease details (other)

undefined

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### 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

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### Pregnancy and/or neonates

Does the data source collect information on pregnant women and/or neonatal subpopulation (under 28 days of age)?

Yes

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### **Hospital admission and/or discharge**

Yes

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### **ICU admission**

Is information on intensive care unit admission available?

Yes

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### **Cause of death**

Captured

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### **Cause of death vocabulary**

Not coded (Free text)

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### **Prescriptions of medicines**

Captured

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### **Prescriptions vocabulary**

not coded

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### **Dispensing of medicines**

Captured

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### **Dispensing vocabulary**

not coded

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### **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

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## **Contraception**

Is information on the use of any type of contraception (oral, injectable, devices etc.) available?

No

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## **Indication for use**

Does the data source capture information on the therapeutic indication for the use of medicinal products?

Not Captured

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## **Medical devices**

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

No

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## **Administration of vaccines**

No

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## **Procedures**

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

Captured

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## **Procedures vocabulary**

Not coded (Free text)

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## **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

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### **Clinical measurements**

Is information on clinical measurements (e.g., BMI, blood pressure, height) available?

Yes

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### **Genetic data**

Are data related to genotyping, genome sequencing available?

Captured

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### **Genetic data vocabulary**

HGVS

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### **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

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### **Patient-reported outcomes**

Is information on patient-reported outcomes (e.g., quality of life) available?

Yes

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### **Patient-generated data**

Is patient-generated information (e.g., from wearable devices) available?

No

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### **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

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### **Unique identifier for persons**

Are patients uniquely identified in the data source?

Yes

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### **Diagnostic codes**

Captured

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### **Diagnosis / medical event vocabulary**

Orphacode

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### **Medicinal product information**

Captured

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### **Medicinal product information collected**

Active ingredient(s)

Brand name

Dosage regime

Dose

Route of administration

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### **Medicinal product vocabulary**

Not coded (Free text)

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### **Quality of life measurements**

Captured

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## **Quality of life measurements vocabulary**

other

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### **Quality of life measurements, other**

QOL-HHT (24 Items)

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### **Lifestyle factors**

Captured

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### **Lifestyle factors**

Alcohol use

Frequency of exercise

Tobacco use

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### **Sociodemographic information**

Captured

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### **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 ( $\geq 18$  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)

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## **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

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## Family linkage available between the following persons

Father-child

Mother-child

## Population

### Population size

8801

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### 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 ( $\geq 18$ years)	8432

## Data flows and management

## Access and validation

## **Biospecimen access**

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

No

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## **Access to subject details**

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

No

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## **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

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

Other

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

Withdrawal of consent

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## **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

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### Informed consent for use of data for research

Required for general use

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### Possibility of data validation

Can validity of the data in the data source be verified (e.g., access to original medical charts)?

Yes

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### Data source preservation

Are records preserved in the data source indefinitely?

Yes

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### Approval for publication

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

Yes

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## **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