European Rare Blood Disorders Platform

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Data source | Human | Disease registry

Administrative details

Administrative details

Data source ID

1000000660

Data source acronym

ENROL

Data holder

Vall d’Hebron University Hospital - Vall d’Hebron Research Institute (HUVH/VHIR)

Data source type

Disease registry

Main financial support

European public funding

Care setting

Hospital inpatient care

Hospital outpatient care

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

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

ENROL Website

Contact details

ENROL Coordination Team coordination@eurobloodnet.eu

Main

coordination@eurobloodnet.eu

Data source regions and languages

Data source countries

Austria

Belgium

Cyprus

Denmark

Finland

France

Germany

Greece

Hungary

Ireland

Italy

Luxembourg

Netherlands

Poland

Portugal

Spain

Sweden

United Kingdom

Data source languages

English

Data source establishment

Data source established

01/01/2017

Publications

Data source publications

COVID- 19 in patients affected by red blood cell disorders, results from the European registry ERN-EuroBloodNet

Sickle cell disease landscape and challenges in the EU: the ERN-EuroBloodNet perspective

Specialist training in thrombosis and haemostasis across Europe: From aspirations to actions

Toward responsible clinical n-of-1 strategies for rare diseases

Sickle cell disease: embedding patient participation into an international conference can transform the role of lived experience

The risk of COVID-19 death is much greater and age dependent with type I IFN autoantibodies

Hemochromatosis classification: update and recommendations by the BIOIRON Society

Reply to: Hultström et al., Genetic determinants of mannose-binding lectin activity predispose to thromboembolic complications in critical COVID-19. Mannose-binding lectin genetics in COVID-19

Abnormal B-Cell Maturation and Increased Transitional B Cells in CBL Syndrome

Clonal hematopoiesis is not significantly associated with COVID-19 disease severity

Detailed stratified GWAS analysis for severe COVID-19 in four European populations

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

Bone marrow failure

Congenital dyserythropoietic anaemia

Sideroblastic anaemia

Sickle cell disease

Thalassaemia alpha

Thalassaemia beta

Aplastic anaemia

Myeloid leukaemia

Disease details (other)

Rare Anemias, Diamond-Blackfan Anemia (DBA), Other Hemoglobin Variants and Disorders

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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

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

No

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Captured

Cause of death vocabulary

Human Phenotype Ontology (HPO)

Orphanet Rare Disease Ontology (ORDO)

SNOMED

SNOMED CT

Prescriptions of medicines

Not Captured

Dispensing of medicines

Not Captured

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)?

Not Captured

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?

No

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?

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

Human Phenotype Ontology (HPO)

Orphacode

Orphanet Rare Disease Ontology (ORDO)

Medicinal product information

Not Captured

Quality of life measurements

Not Captured

Lifestyle factors

Not Captured

Sociodemographic information

Not Captured

Quantitative descriptors

Population Qualitative Data

Population age groups

All

In utero

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

ENROL integrates data from multiple national registries and expert centers across Europe within the ERN-EuroBloodNet network.
It is estimated to cover approximately 70–90% of diagnosed patients with rare hematological disorders in the participating countries.
Coverage may vary depending on country-specific factors such as healthcare system organization, registry participation, and diagnosis rates.
The catchment area includes the full population of participating European countries, currently encompassing over 30 nations.
ENROL aims to minimize data fragmentation and improve patient identification and follow-up across the region.

Description of the population covered by the data source in the catchment area whose data are not collected (e.g., people who are registered only for private care)

While ENROL aims to capture data on all patients with rare hematological disorders within its catchment area, certain populations may not be fully represented.
This includes patients exclusively managed in private healthcare settings or outside of the ERN-EuroBloodNet network, those who have not provided informed consent, and individuals not yet diagnosed or referred to specialized centers.

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).

Coordination team

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?

Yes

Description of data collection

ENROL gathers patient data from various rare hematological disorder registries across Europe, functioning as an umbrella platform under ERN-EuroBloodNet.
Participating clinical centers collect data using standardized electronic case report forms built within REDCap, a secure, web-based application designed for data capture in research studies.
Data from these centers and registries are then harmonized and integrated into a centralized database.
This system ensures data quality, interoperability, and supports linkage with national registries and other relevant data sources.

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

Other

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

Registration in the ENROL data source is triggered upon the patient providing informed consent for inclusion. This occurs after the patient with a rare hematological disorder is identified within the network, and eligibility criteria are confirmed.

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

Death

Loss to follow up

Other

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

Patient withdraws their informed consent

Event triggering creation of a record in the data source

A new record is created when a patient with a rare hematological disorder is registered in a contributing registry and their data are integrated into ENROL. This typically occurs following the initial clinical assessment by a specialist within the ERN-EuroBloodNet network, once eligibility criteria are confirmed and informed consent is obtained.

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?

Yes

Linkage description, pre-linked

ENROL integrates data from national and regional registries on rare hematological disorders that are part of the ERN-EuroBloodNet network. This pre-linked data provides a broad view of patients across multiple sources, avoiding data fragmentation and promoting interoperability.

Linkage description, possible linkage

ENROL can be linked on an ad-hoc basis with other data sources using the Common Data Elements (CDE) framework and SPIDER pseudonymization system developed by the Joint Research Centre (JRC).

Data management specifications that apply for the data source

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?

Yes

Approval for publication

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

Yes

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 CDM version

OMOP Common Data Model (CDM) version 5.4

Data source ETL status

In progress