Rare Anaemia Disorders European Epidemiological Platform

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Data source | Human | Disease registry

Administrative details

Administrative details

Data source ID

1000000658

Data source acronym

RADeep

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

RADeep Network Webpage

Contact details

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Main

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Data source regions and languages

Data source countries

Austria

Belgium

Bulgaria

Croatia

Cyprus

Czechia

Denmark

France

Germany

Greece

Hungary

Ireland

Italy

Lithuania

Netherlands

Poland

Portugal

Slovenia

Spain

Sweden

United Kingdom

Data source languages

English

Data source establishment

Data source established

01/02/2018

Data source time span

First collection: 30/11/2021

The date when data started to be collected or extracted.

Publications

Data source publications

RARE ANAEMIA DISORDERS EUROPEAN EPIDEMIOLOGICAL PLATFORM: PB2285

Distribution of Patients Affected by RADs in Europe Through RADeep

5610939 RARE ANAEMIA DISORDERS EUROPEAN EPIDEMIOLOGICAL PLATFORM (RADEEP)

COVID-19 Outcomes in Patients with Red Blood Cell Disorders: ERN-EuroBloodNet Registry Experience

Data-Driven Research through the European RADeep Registry and the Use of AI Toward Personalized Medicine in SCD

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

Sickle cell anaemia

Thalassaemia alpha

Thalassaemia beta

Glucose-6-phosphate dehydrogenase deficiency

Pyruvate kinase deficiency anaemia

Hereditary spherocytosis

Elliptocytosis hereditary

Congenital dyserythropoietic anaemia

Iron deficiency anaemia

Disease details (other)

Other enzymopathies, Other membrane disorders, Iron-related Rare Anaemias, Other rare anaemia syndromes

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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

Yes

ICU admission

Is information on intensive care unit admission available?

Yes

Cause of death

Captured

Cause of death vocabulary

Human Phenotype Ontology (HPO)

Orphacode

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)?

Captured

Procedures vocabulary

Human Phenotype Ontology (HPO)

Orphacode

Orphanet Rare Disease Ontology (ORDO)

SNOMED

SNOMED CT

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?

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?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

Human Phenotype Ontology (HPO)

Orphacode

Orphanet Rare Disease Ontology (ORDO)

SNOMED

SNOMED CT

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

RADeep currently covers approximately 30–50% of the diagnosed rare anaemia disorder (RAD) patient population in participating countries.

The platform includes data from 19 European countries and integrates national and regional registries, hospital databases, and expert centres.

While comprehensive in several countries (e.g., France, Italy, Spain), coverage varies depending on national registry maturity and data sharing agreements.

Population estimates are based on national prevalence rates and expert input from ERN-EuroBloodNet.

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)

The population not covered by RADeep includes patients receiving care exclusively in private healthcare settings, those followed in non-participating hospitals or countries, and undiagnosed or misdiagnosed individuals.

Additionally, some migrant or vulnerable populations may be underrepresented due to barriers in diagnosis, registration, or data sharing.

The degree of under coverage varies by country depending on the structure of national healthcare and registry systems.

Population

Population size

4860

Active population size

4860

Population by age group

Age group	Population size
Paediatric Population (< 18 years)	1960
Adult and elderly population (≥18 years)	2900

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 & Steering Committee

Data Access Committee

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

Data in RADeep is collected through standardized electronic case report forms (eCRFs) within a secure REDCap platform. The process includes patient registration and longitudinal follow-up visits, where clinical, demographic, and laboratory information is systematically recorded by healthcare professionals or trained data entry staff. Quality control procedures such as automated validation rules, branching logic, and periodic data audits ensure accuracy and completeness. The data source integrates information from multiple clinical centers, harmonizing inputs to support comprehensive rare anemia disorder research.

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

Signed Informed Consent

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 withdrawal of consent, transplantation

Event triggering creation of a record in the data source

In RADeep, the creation of a new record in the registry is triggered by the initial clinical encounter during which a patient with a suspected or confirmed rare anemia disorder is assessed by a specialist within the network.
The record is created once the patient meets eligibility criteria (alive, not transplanted, and diagnosed with a rare anemia disorder) 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

Yes, RADeep is linked with national registries that provide information about patients included in the RADeep database.
Currently, RADeep integrates data from several national registries related to rare anemia disorders. These pre-linked sources enrich the registry through established national health systems and disease-specific registries.

Linkage description, possible linkage

In addition to existing pre-linked national registries, RADeep can establish ad-hoc linkages with other relevant data sources using Common Data Elements (CDEs) and the SPIDER pseudonymization framework developed by the Joint

Research Centre (JRC).

Furthermore, RADeep patients are included in ENROL, the European Rare Blood Disorders Platform, which acts as an umbrella within the ERN-EuroBloodNet network. ENROL consolidates both new and existing registries on rare hematological disorders (RHDs) to avoid data fragmentation by promoting EU RD platform standards for patient registry interoperability.

Data management specifications that apply for the data source

Data source refresh

Monthly

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

Data source last refresh

01/07/2025

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