# European Platform on Rare Disease Registration (EU RD Platform)

# European Rare Disease Registry Infrastructure (ERDRI)

Andri PAPADOPOULOU | Joint Research Centre | European Commission

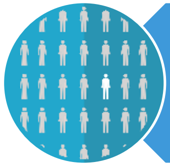
27/02/2025

HemaFAIR

European Commission

# European Commission’s Strategy for Rare Diseases

Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions on “Rare Diseases: Europe’s challenges” (2008)



**To improve recognition and visibility on rare diseases**

**To support policies on rare diseases in the EU Member States**

**To develop European cooperation, coordination and regulation for rare diseases**

# Some Facts about Rare Diseases

https://www.youtube.com/watch?v=qKq4IJP6jKo&t=26s

# Why and EU RD Platform for Rare Disease Registries?

To cope with the extreme fragmentation of data sources across EU Member States

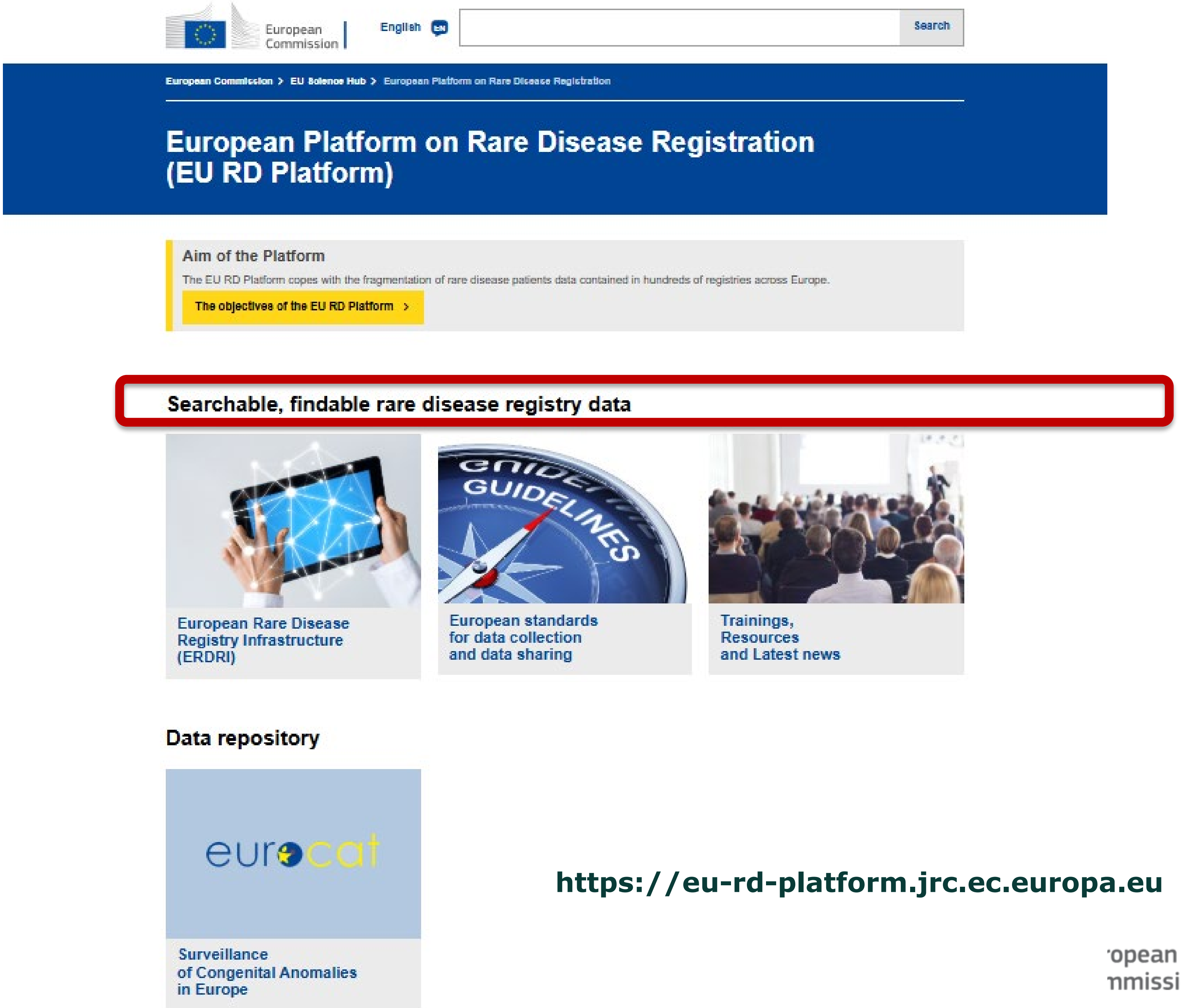
- Lack of interoperability severely limits the registries' potential
- No standardised data collection for most RDs

To reach <u>interoperability between registries</u>

Semantic interoperability
Standardised data collection and exchange
Make data FAIR
Data linkage
Data transfer

Reach the critical number of patients for

- Studies (epidemiological, clinical, translational, pharmacological, quality of care, etc.)
- Research



European Commission > EU Science Hub > European Platform on Rare Disease Registration

# European Platform on Rare Disease Registration (EU RD Platform)

**Aim of the Platform**

The EU RD Platform copes with the fragmentation of rare disease patients data contained in hundreds of registries across Europe.

The objectives of the EU RD Platform >

## Searchable, findable rare disease registry data

European Rare Disease Registry Infrastructure (ERDRI)

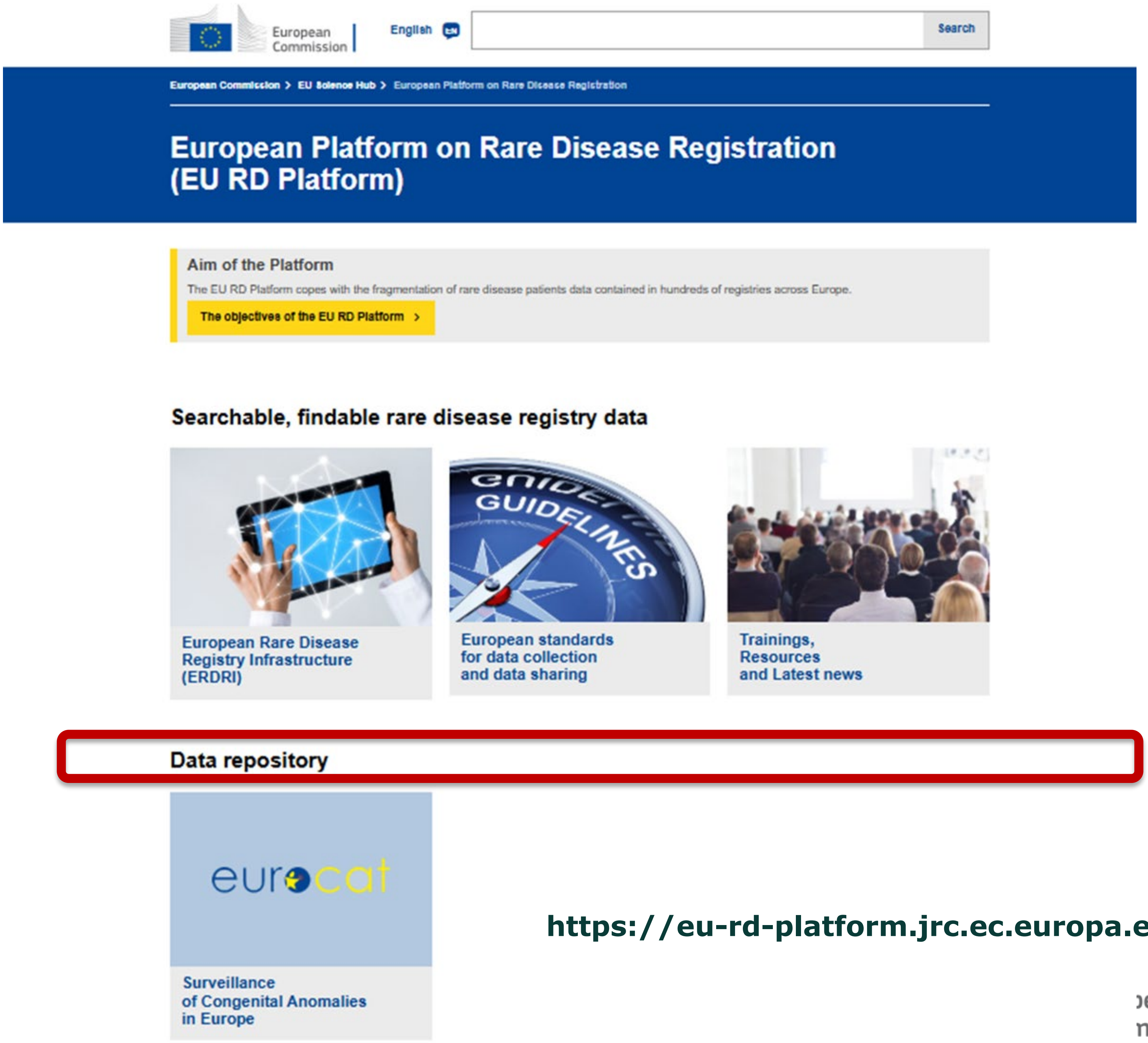
European standards for data collection and data sharing

Trainings, Resources and Latest news

## Data repository

Surveillance of Congenital Anomalies in Europe

**https://eu-rd-platform.jrc.ec.europa.eu**



European Commission

English

Search

European Commission > EU Science Hub > European Platform on Rare Disease Registration

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Read more ›

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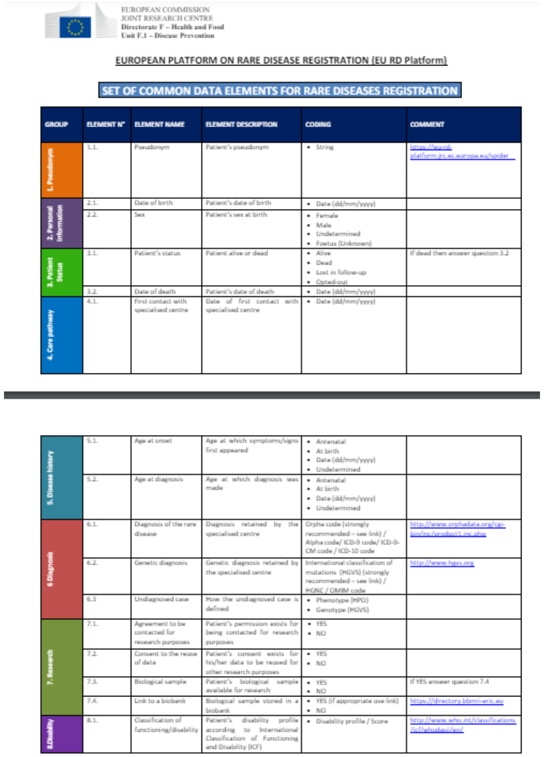
eurocat

Surveillance of Congenital Anomalies in Europe

**Set of Common Data Elements (CDE)**

https://eu-rd-platform.jrc.ec.europa.eu/set-of-common-data-elements_en



EUROPEAN COMMISSION
JOINT RESEARCH CENTRE
Directorate F – Health and Food
Unit F.1 – Disease Prevention

EUROPEAN PLATFORM ON RARE DISEASE REGISTRATION (EU RD Platform)

SET OF COMMON DATA ELEMENTS FOR RARE DISEASES REGISTRATION

| GROUP | ELEMENT N° | ELEMENT NAME | ELEMENT DESCRIPTION | CODING | COMMENT |
|---|---|---|---|---|---|
| 1. Pseudonym | 1.1. | Pseudonym | Patient's pseudonym | • String | https://eu-rd-platform.jrc.ec.europa.eu/spider |
| 2. Personal information | 2.1. | Date of birth | Patient's date of birth | • Date (dd/mm/yyyy) | |
| | 2.2. | Sex | Patient's sex at birth | • Female<br>• Male<br>• Undetermined<br>• Foetus (Unknown) | |
| 3. Patient Status | 3.1. | Patient's status | Patient alive or dead | • Alive<br>• Dead<br>• Lost in follow-up<br>• Opted-out | If dead then answer question 3.2 |
| | 3.2. | Date of death | Patient's date of death | • Date (dd/mm/yyyy) | |
| 4. Care pathway | 4.1. | First contact with specialised centre | Date of first contact with specialised centre | • Date (dd/mm/yyyy) | |
| 5. Disease history | 5.1. | Age at onset | Age at which symptoms/signs first appeared | • Antenatal<br>• At birth<br>• Date (dd/mm/yyyy)<br>• Undetermined | |
| | 5.2. | Age at diagnosis | Age at which diagnosis was made | • Antenatal<br>• At birth<br>• Date (dd/mm/yyyy)<br>• Undetermined | |
| 6 Diagnosis | 6.1. | Diagnosis of the rare disease | Diagnosis retained by the specialised centre | Orpha code (strongly recommended – see link) / Alpha code/ ICD-9 code/ ICD-9-CM code / ICD-10 code | http://www.orphadata.org/cgi-bin/inc/product1.inc.php |
| | 6.2. | Genetic diagnosis | Genetic diagnosis retained by the specialised centre | International classification of mutations (HGVS) (strongly recommended – see link) / HGNC / OMIM code | http://www.hgvs.org |
| | 6.3 | Undiagnosed case | How the undiagnosed case is defined | • Phenotype (HPO)<br>• Genotype (HGVS) | |
| 7. Research | 7.1. | Agreement to be contacted for research purposes | Patient's permission exists for being contacted for research purposes | • YES<br>• NO | |
| | 7.2. | Consent to the reuse of data | Patient's consent exists for his/her data to be reused for other research purposes | • YES<br>• NO | |
| | 7.3. | Biological sample | Patient's biological sample available for research | • YES<br>• NO | If YES answer question 7.4 |
| | 7.4. | Link to a biobank | Biological sample stored in a biobank | • YES (if appropriate use link)<br>• NO | https://directory.bbmri-eric.eu |
| 8.Disability | 8.1. | Classification of functioning/disability | Patient's disability profile according to International Classification of Functioning and Disability (ICF) | • Disability profile / Score | http://www.who.int/classifications/icf/whodasii/en/ |

EUROPEAN COMMISSION
JOINT RESEARCH CENTRE
**Directorate F – Health, Consumers and Reference Materials**
**Unit F.1 – Health in Society**

# EUROPEAN PLATFORM ON RARE DISEASE REGISTRATION (EU RD Platform)

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| | | | | | |
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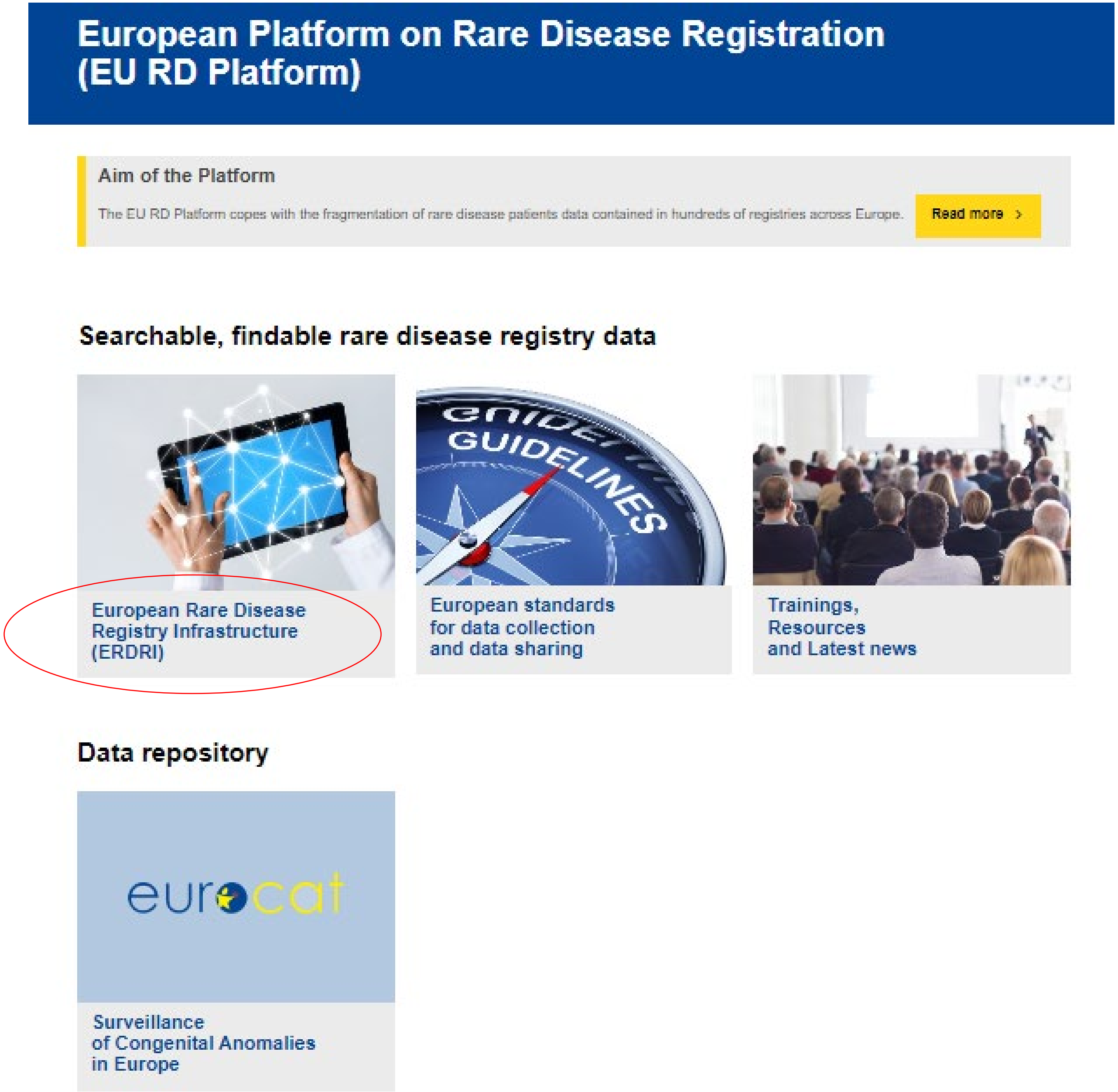


# European Platform on Rare Disease Registration (EU RD Platform)

**Aim of the Platform**

The EU RD Platform copes with the fragmentation of rare disease patients data contained in hundreds of registries across Europe.

## Searchable, findable rare disease registry data

European Rare Disease Registry Infrastructure (ERDRI)

European standards for data collection and data sharing

Trainings, Resources and Latest news

## Data repository

Surveillance of Congenital Anomalies in Europe

# ERDRI characteristics

Ensures DISCOVERABILITY of DATA from participating RD registries via the ERDRI Search tool

Registries remain owners of their data and decide about use of the data

# The main components of ERDRI

European Commission > EU Science Hub > European Platform on Rare Disease Registration > ERDRI

ERDRI

European Rare Disease Registry Infrastructure (ERDRI)

European Directory of Registries (ERDRI.dor)

Overview of rare disease registries in Europe including their characteristics

Central Metadata Repository (ERDRI.mdr)

Database containing the data elements used by rare disease registries

Search Broker (ERDRI.sebro)

ERDRI.sebro allows researchers to retrieve metatata of interest

Pseudonymisation tool (ERDRI.spider)

Service offering registries at local level the solution for patient pseudonymisation

# European Rare Disease Registry Infrastructure (ERDRI)

## The European Directory of Registries (ERDRI.dor)

**European Directory of Registries (ERDRI.dor)**

Overview of rare disease registries in Europe including their characteristics

List of participating RD registries with their main characteristics and description

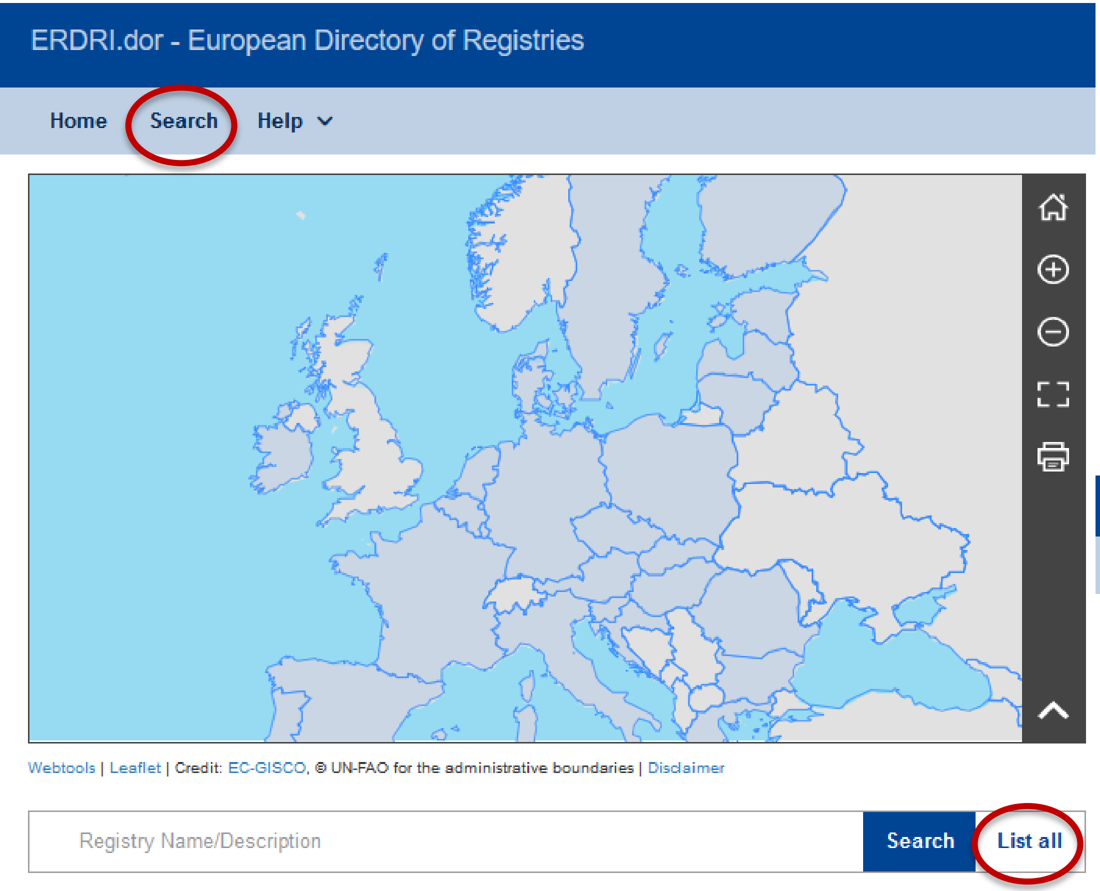
**Descriptive metadata - eight sections with 38 data fields related to a registry of which 23 are obligatory**
- **specific rare disease addressed**
- **scope**
- **operating institution**
- **contact information**

Data input is performed by registry owners

List of the data elements collected by the registries according to the ERDRI.mdr:

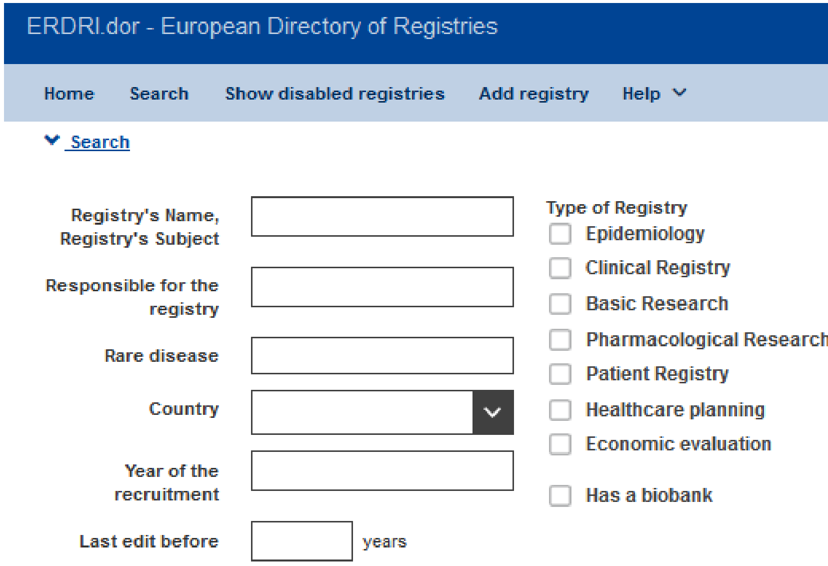
registry-specific data scheme

# The European Directory of RD registries - ERDRI.dor



Webtools | Leaflet | Credit: EC-GISCO, © UN-FAO for the administrative boundaries | Disclaimer

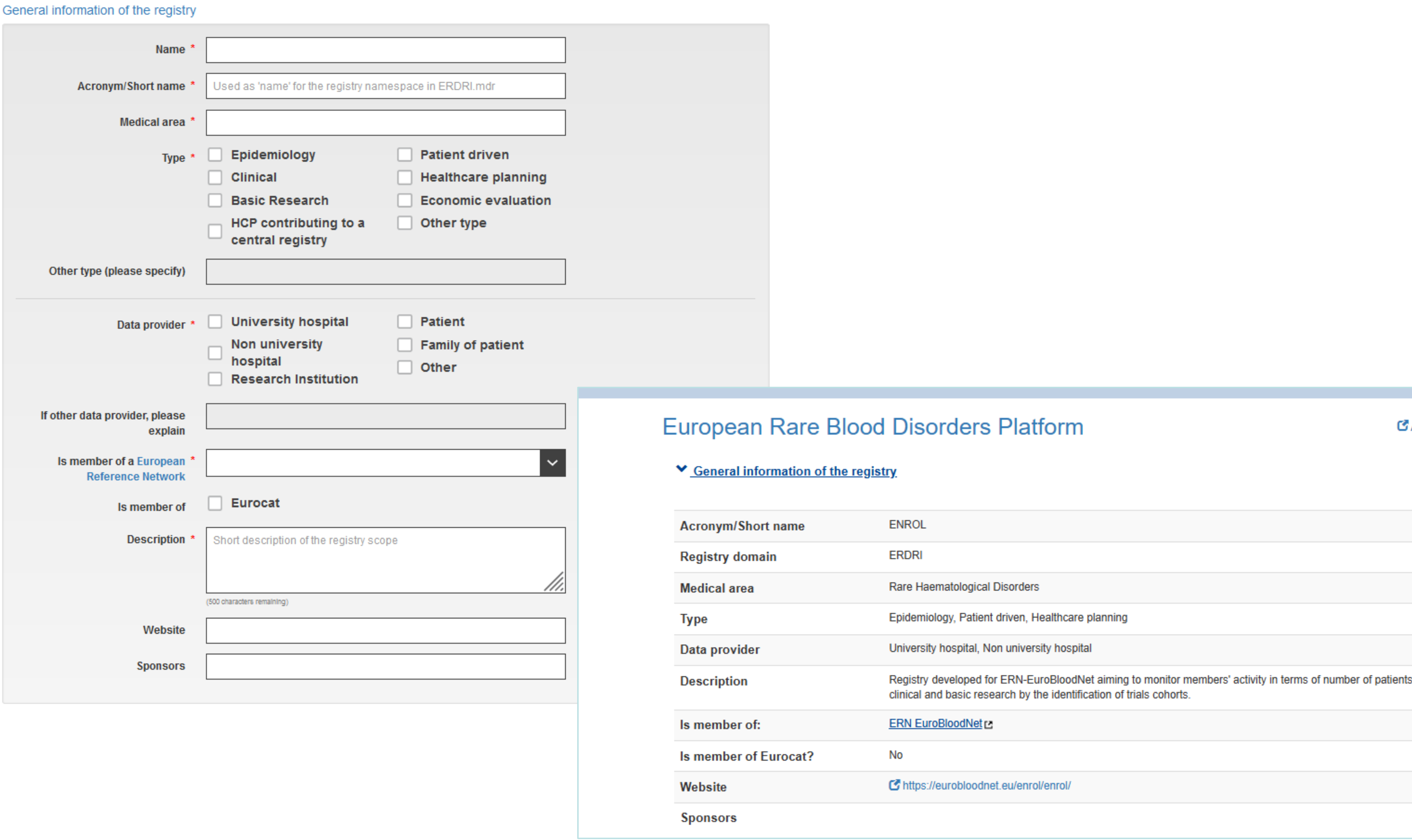
- ➢ Clickable map
- ➢ “List all” function
- ➢ Search function



- Ongoing campaign in recruiting new registries
- ERN network registries

European Commission

# Directory of Registries - ERDRI.dor



General information of the registry

Name *

Acronym/Short name * Used as 'name' for the registry namespace in ERDRI.mdr

Medical area *

Type *
- ☐ Epidemiology
- ☐ Clinical
- ☐ Basic Research
- ☐ HCP contributing to a central registry
- ☐ Patient driven
- ☐ Healthcare planning
- ☐ Economic evaluation
- ☐ Other type

Other type (please specify)

Data provider *
- ☐ University hospital
- ☐ Non university hospital
- ☐ Research Institution
- ☐ Patient
- ☐ Family of patient
- ☐ Other

If other data provider, please explain

Is member of a European Reference Network *

Is member of ☐ Eurocat

Description * Short description of the registry scope

(500 characters remaining)

Website

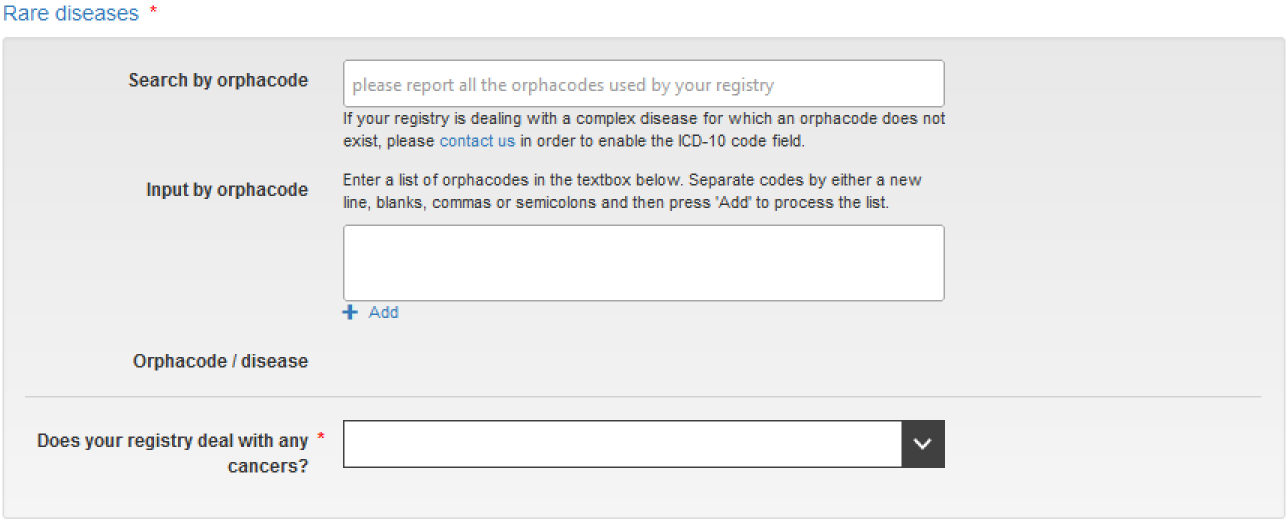
Sponsors

## European Rare Blood Disorders Platform

General information of the registry

| | |
|---|---|
| Acronym/Short name | ENROL |
| Registry domain | ERDRI |
| Medical area | Rare Haematological Disorders |
| Type | Epidemiology, Patient driven, Healthcare planning |
| Data provider | University hospital, Non university hospital |
| Description | Registry developed for ERN-EuroBloodNet aiming to monitor members' activity in terms of number of patients<br>clinical and basic research by the identification of trials cohorts. |
| Is member of: | ERN EuroBloodNet |
| Is member of Eurocat? | No |
| Website | https://eurobloodnet.eu/enrol/enrol/ |
| Sponsors | |

# Directory of Registries - ERDRI.dor



Rare diseases *

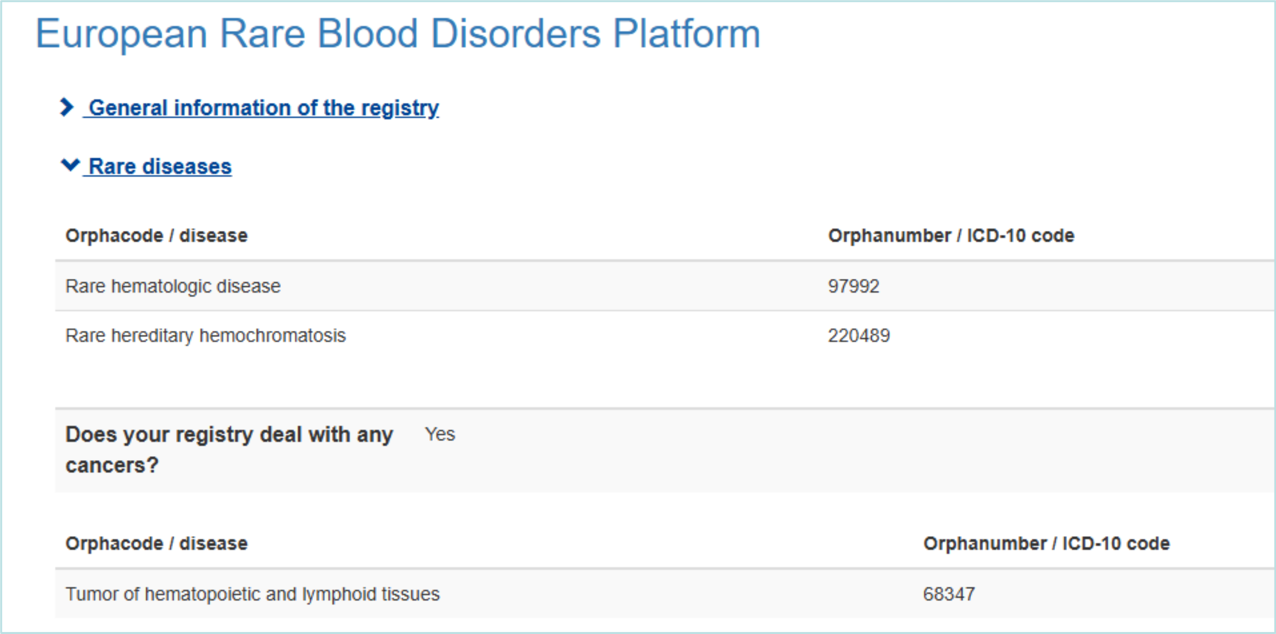
**Search by orphacode** please report all the orphacodes used by your registry

If your registry is dealing with a complex disease for which an orphacode does not exist, please contact us in order to enable the ICD-10 code field.

**Input by orphacode** Enter a list of orphacodes in the textbox below. Separate codes by either a new line, blanks, commas or semicolons and then press 'Add' to process the list.

**Orphacode / disease**

**Does your registry deal with any cancers?** *



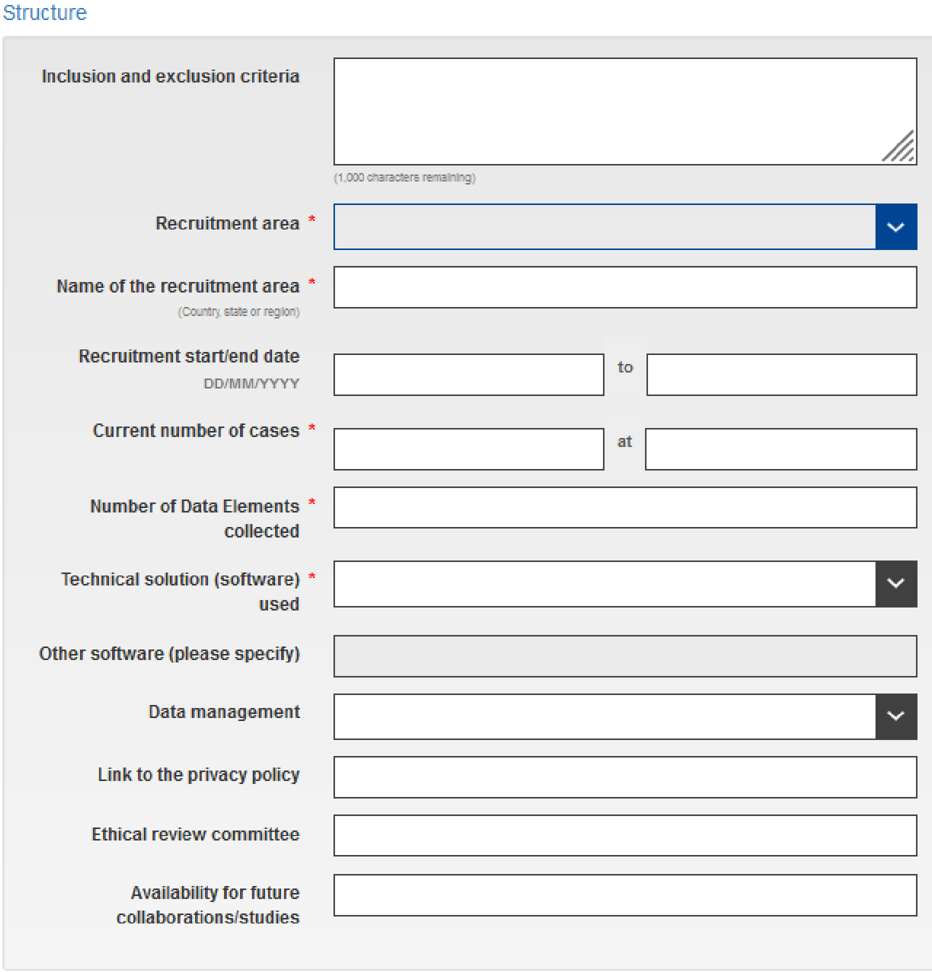
European Rare Blood Disorders Platform

| Orphacode / disease | Orphanumber / ICD-10 code |
|---|---|
| Rare hematologic disease | 97992 |
| Rare hereditary hemochromatosis | 220489 |

**Does your registry deal with any cancers?** Yes

| Orphacode / disease | Orphanumber / ICD-10 code |
|---|---|
| Tumor of hematopoietic and lymphoid tissues | 68347 |

# Directory of Registries - ERDRI.dor



Structure

Inclusion and exclusion criteria

(1,000 characters remaining)

Recruitment area *

Name of the recruitment area *
(Country, state or region)

Recruitment start/end date
DD/MM/YYYY
to

Current number of cases *
at

Number of Data Elements collected *

Technical solution (software) used *

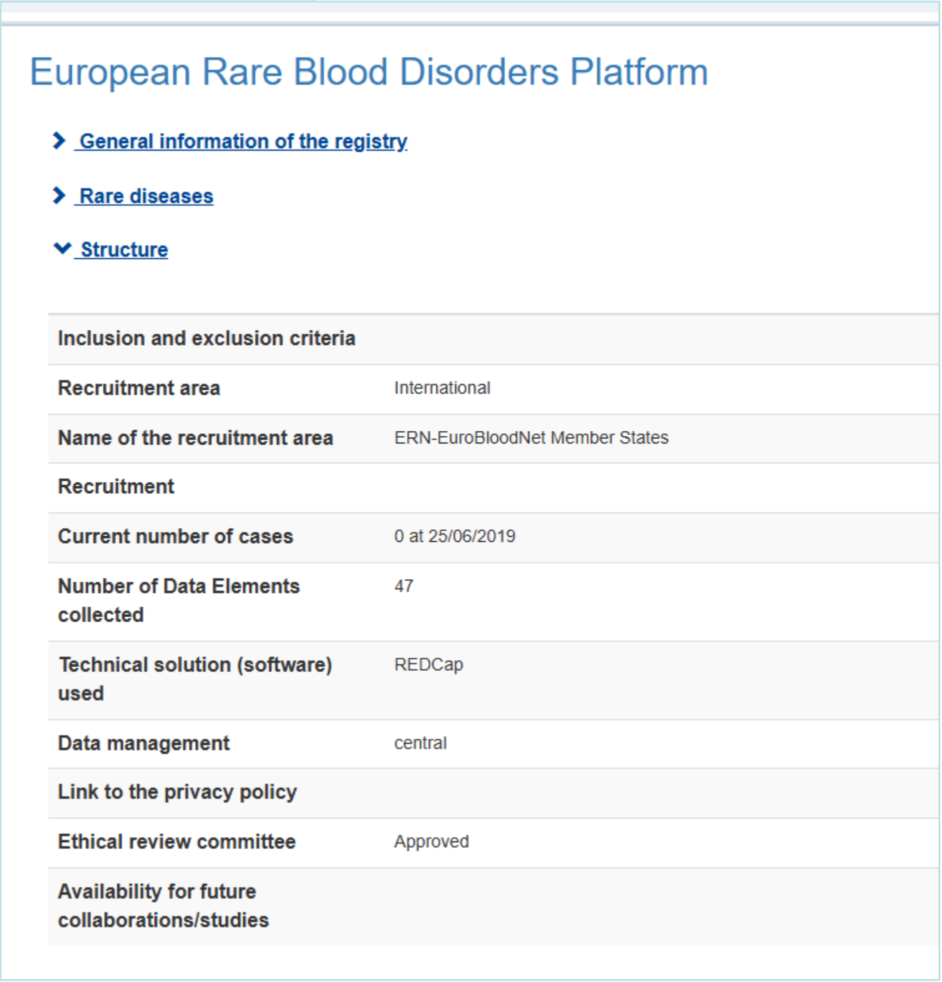
Other software (please specify)

Data management

Link to the privacy policy

Ethical review committee

Availability for future collaborations/studies

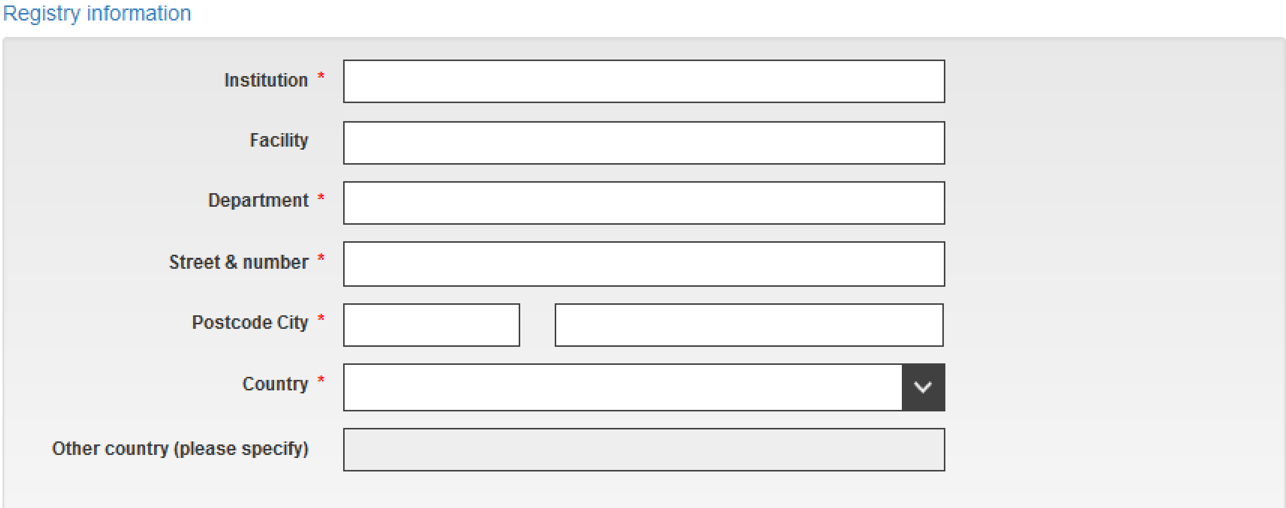


## European Rare Blood Disorders Platform

- General information of the registry
- Rare diseases
- Structure

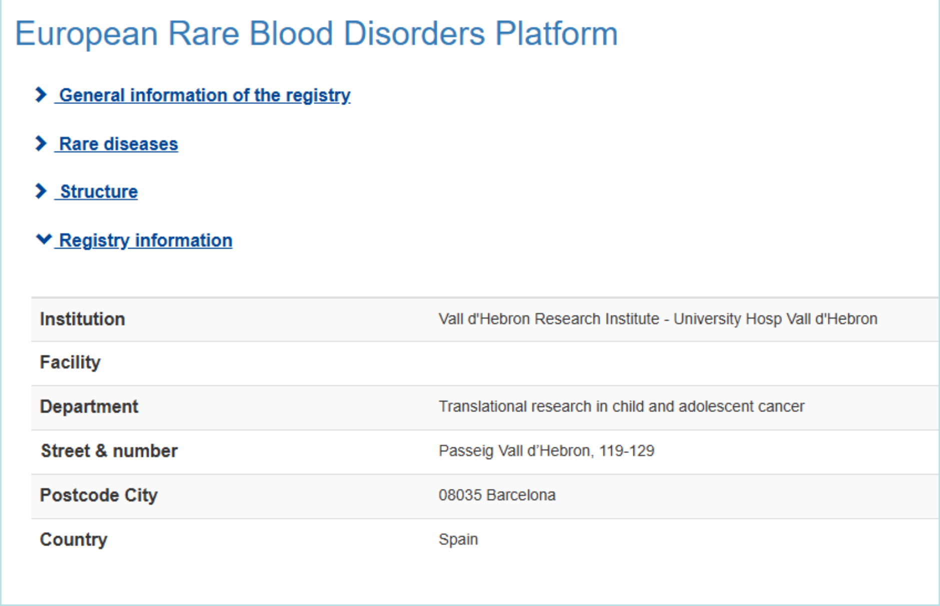
| | |
|---|---|
| **Inclusion and exclusion criteria** | |
| **Recruitment area** | International |
| **Name of the recruitment area** | ERN-EuroBloodNet Member States |
| **Recruitment** | |
| **Current number of cases** | 0 at 25/06/2019 |
| **Number of Data Elements collected** | 47 |
| **Technical solution (software) used** | REDCap |
| **Data management** | central |
| **Link to the privacy policy** | |
| **Ethical review committee** | Approved |
| **Availability for future collaborations/studies** | |

# Directory of Registries - ERDRI.dor



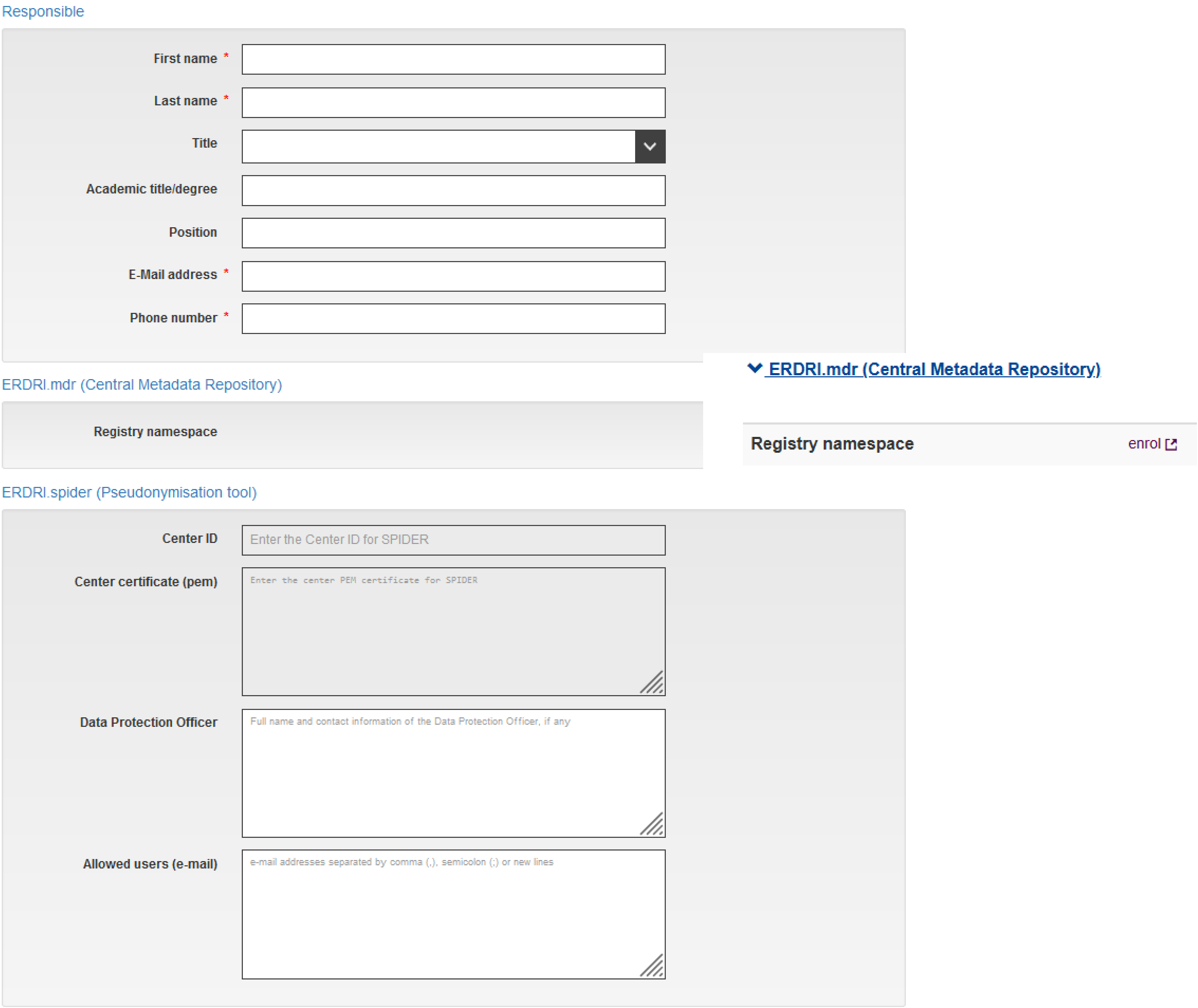
Registry information

| | |
|---|---|
| Institution * | |
| Facility | |
| Department * | |
| Street & number * | |
| Postcode City * | |
| Country * | |
| Other country (please specify) | |



European Rare Blood Disorders Platform

| | |
|---|---|
| **Institution** | Vall d'Hebron Research Institute - University Hosp Vall d'Hebron |
| **Facility** | |
| **Department** | Translational research in child and adolescent cancer |
| **Street & number** | Passeig Vall d'Hebron, 119-129 |
| **Postcode City** | 08035 Barcelona |
| **Country** | Spain |



Responsible

First name *

Last name *

Title

Academic title/degree

Position

E-Mail address *

Phone number *

ERDRI.mdr (Central Metadata Repository)

Registry namespace

ERDRI.spider (Pseudonymisation tool)

Center ID: Enter the Center ID for SPIDER

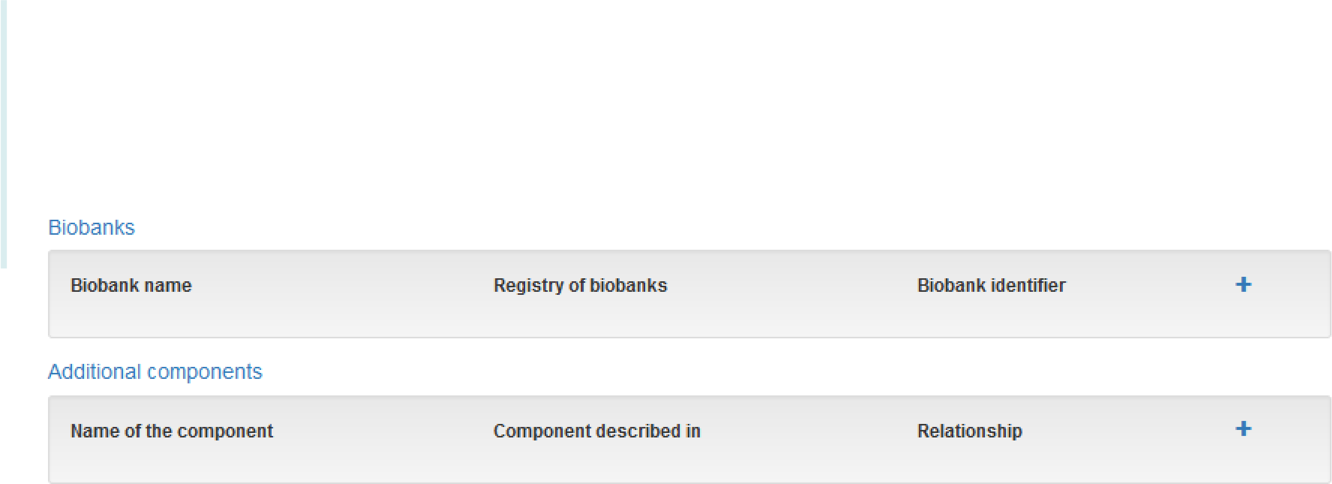
Center certificate (pem): Enter the center PEM certificate for SPIDER

Data Protection Officer: Full name and contact information of the Data Protection Officer, if any

Allowed users (e-mail): e-mail addresses separated by comma (,), semicolon (;) or new lines

ERDRI.mdr (Central Metadata Repository)

Registry namespace: enrol



Biobanks

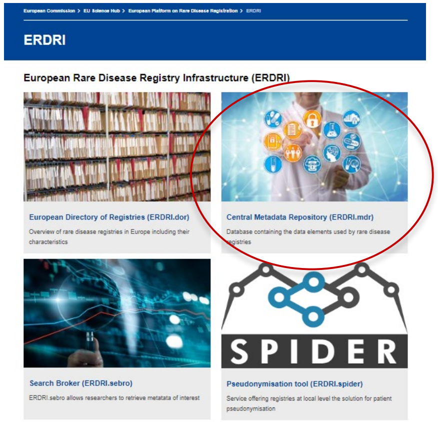
| Biobank name | Registry of biobanks | Biobank identifier | + |
|---|---|---|---|

Additional components

| Name of the component | Component described in | Relationship | + |
|---|---|---|---|

# ERDRI.mdr

## Central Metadata Repository ERDRI.mdr



**ERDRI**

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SPIDER

**Pseudonymisation tool (ERDRI.spider)**
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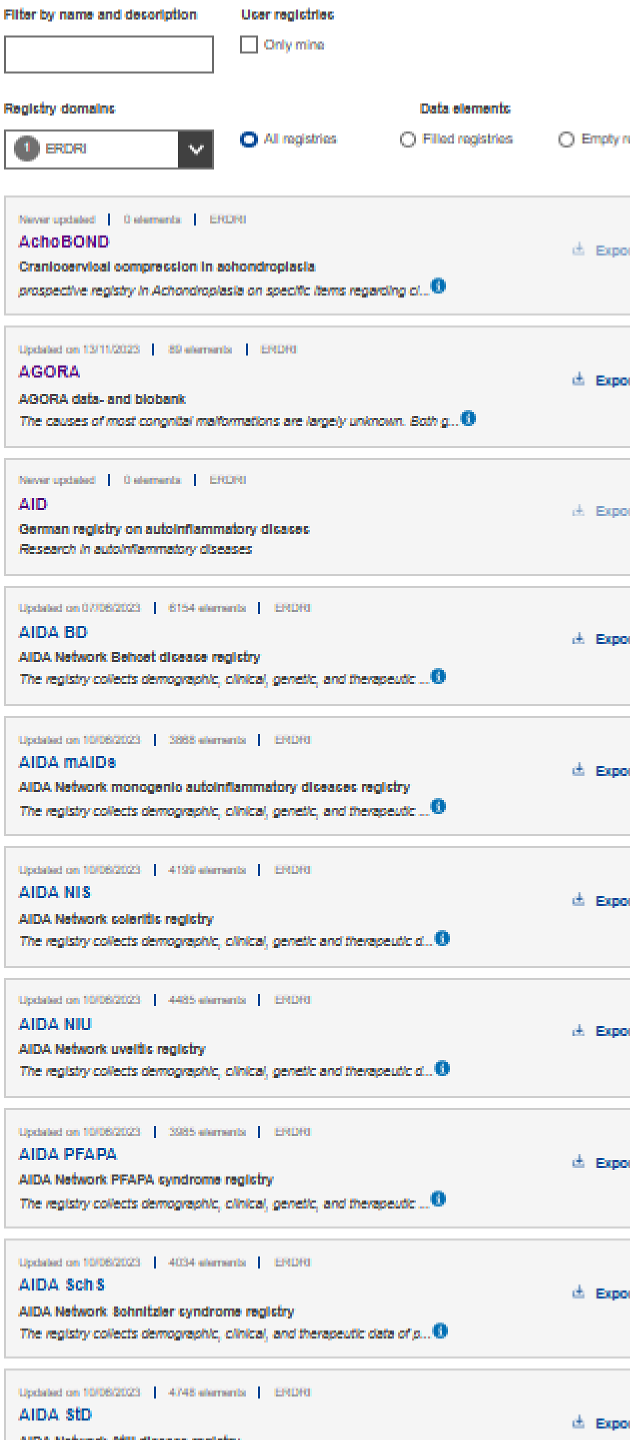


Never updated | 0 elements | ERDRI
**AchoBOND**
Craniocervical compression in achondroplasia
*prospective registry in Achondroplasia on specific items regarding cl...*

Updated on 13/11/2023 | 89 elements | ERDRI
**AGORA**
AGORA data- and biobank
*The causes of most congenital malformations are largely unknown. Both g...*

Never updated | 0 elements | ERDRI
**AID**
German registry on autoinflammatory diseases
*Research in autoinflammatory diseases*

Updated on 07/08/2023 | 6154 elements | ERDRI
**AIDA BD**
AIDA Network Behcet disease registry
*The registry collects demographic, clinical, genetic, and therapeutic ...*

Updated on 10/08/2023 | 3888 elements | ERDRI
**AIDA mAIDs**
AIDA Network monogenic autoinflammatory diseases registry
*The registry collects demographic, clinical, genetic, and therapeutic ...*

Updated on 10/08/2023 | 4199 elements | ERDRI
**AIDA NIS**
AIDA Network scleritis registry
*The registry collects demographic, clinical, genetic and therapeutic d...*

Updated on 10/08/2023 | 4485 elements | ERDRI
**AIDA NIU**
AIDA Network uveitis registry
*The registry collects demographic, clinical, genetic and therapeutic d...*

Updated on 10/08/2023 | 3985 elements | ERDRI
**AIDA PFAPA**
AIDA Network PFAPA syndrome registry
*The registry collects demographic, clinical, genetic, and therapeutic ...*

Updated on 10/08/2023 | 4034 elements | ERDRI
**AIDA Sch S**
AIDA Network Schnitzler syndrome registry
*The registry collects demographic, clinical, and therapeutic data of p...*

Updated on 10/08/2023 | 4748 elements | ERDRI
**AIDA StD**

**Metadata = Data about data**

**Key:value pairs**
**Designation / Definition /Measurement unit + range**

**Collection of metadata on all data elements collected by participating registries**

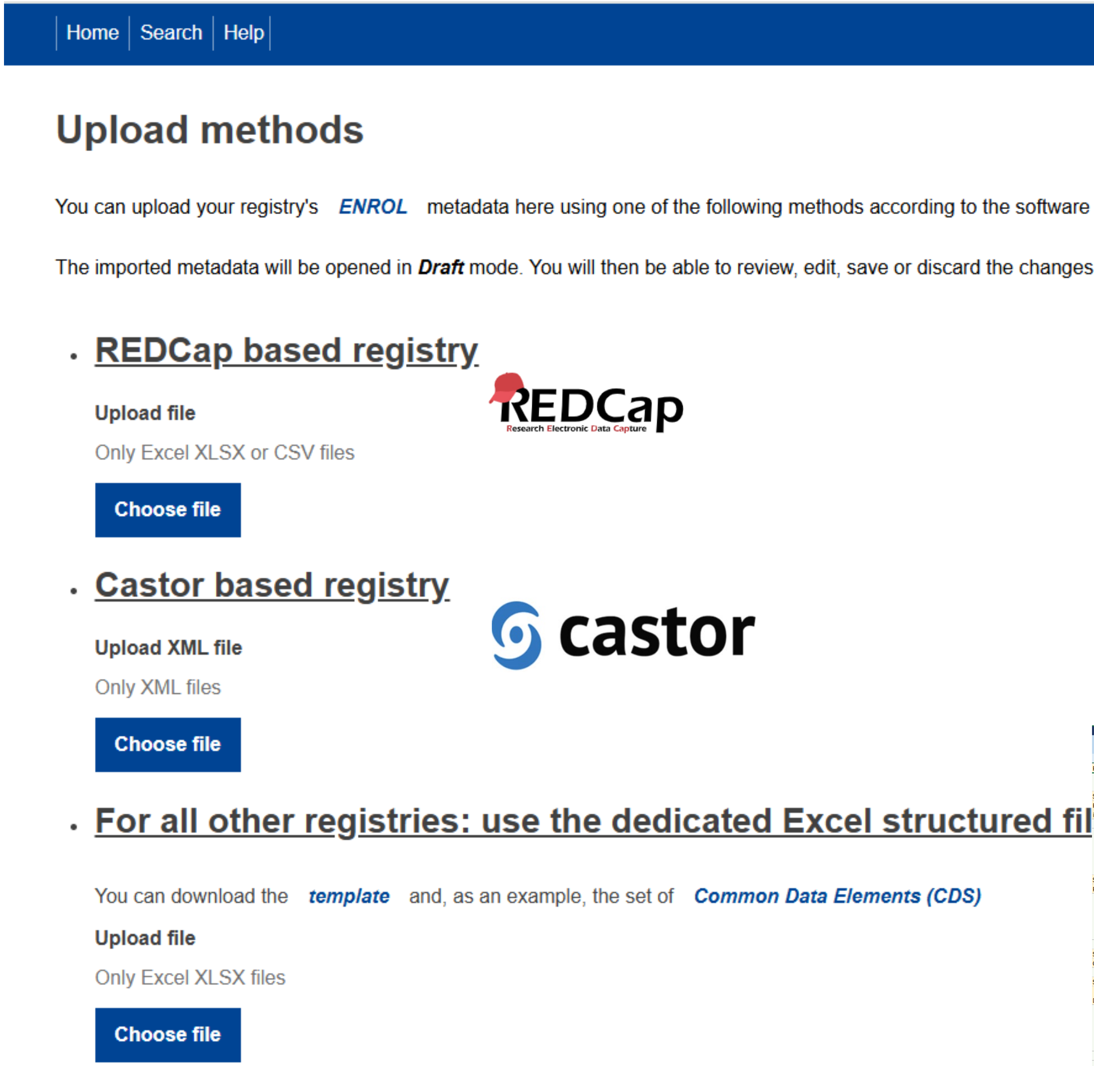
**Semantic Interoperability**

common definitions for data elements

Human readability

Machine readability
Semantic web technologies

# ERDRI.mdr – metadata input



## Upload methods

You can upload your registry's *ENROL* metadata here using one of the following methods according to the software of your registry.

The imported metadata will be opened in ***Draft*** mode. You will then be able to review, edit, save or discard the changes.

- **REDCap based registry**

  **Upload file**

  Only Excel XLSX or CSV files

- **Castor based registry**

  **Upload XML file**

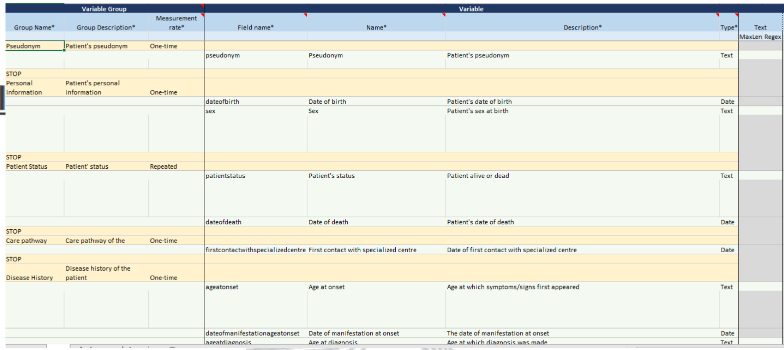
  Only XML files

- **For all other registries: use the dedicated Excel structured fil**

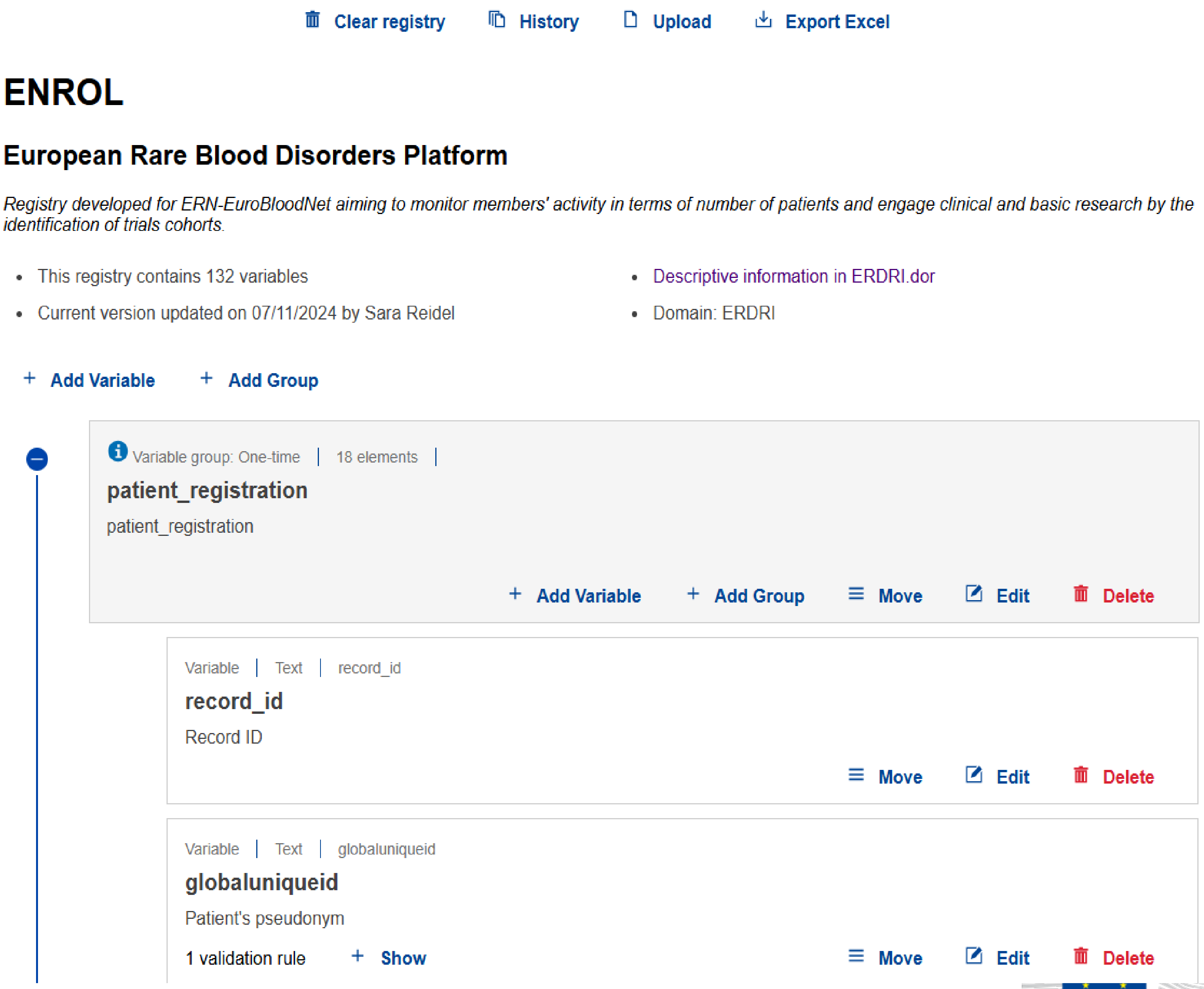
  You can download the *template* and, as an example, the set of *Common Data Elements (CDS)*

  **Upload file**

  Only Excel XLSX files



| Variable Group | | | Variable | | | | | |
|---|---|---|---|---|---|---|---|---|
| Group Name* | Group Description* | Measurement rate* | Field name* | Name* | Description* | Type* | Text MaxLen | Regex |
| Pseudonym | Patient's pseudonym | One-time | | | | | | |
| | | | pseudonym | Pseudonym | Patient's pseudonym | Text | | |
| STOP | | | | | | | | |
| Personal information | Patient's personal information | One-time | | | | | | |
| | | | dateofbirth | Date of birth | Patient's date of birth | Date | | |
| | | | sex | Sex | Patient's sex at birth | Text | | |
| STOP | | | | | | | | |
| Patient Status | Patient' status | Repeated | | | | | | |
| | | | patientstatus | Patient's status | Patient alive or dead | Text | | |
| | | | dateofdeath | Date of death | Patient's date of death | Date | | |
| STOP | | | | | | | | |
| Care pathway | Care pathway of the | One-time | | | | | | |
| | | | firstcontactwithspecializedcentre | First contact with specialized centre | Date of first contact with specialized centre | Date | | |
| STOP | | | | | | | | |
| Disease History | Disease history of the patient | One-time | | | | | | |
| | | | ageatonset | Age at onset | Age at which symptoms/signs first appeared | Text | | |
| | | | dateofmanifestationageatonset | Date of manifestation at onset | The date of manifestation at onset | Date | | |
| | | | ageatdiagnosis | Age at diagnosis | Age at which diagnosis was made | Text | | |



# ENROL

## European Rare Blood Disorders Platform

*Registry developed for ERN-EuroBloodNet aiming to monitor members' activity in terms of number of patients and engage clinical and basic research by the identification of trials cohorts.*

- This registry contains 132 variables
- Current version updated on 07/11/2024 by Sara Reidel
- Descriptive information in ERDRI.dor
- Domain: ERDRI

Variable group: One-time | 18 elements |

**patient_registration**

patient_registration

Variable | Text | record_id

**record_id**

Record ID

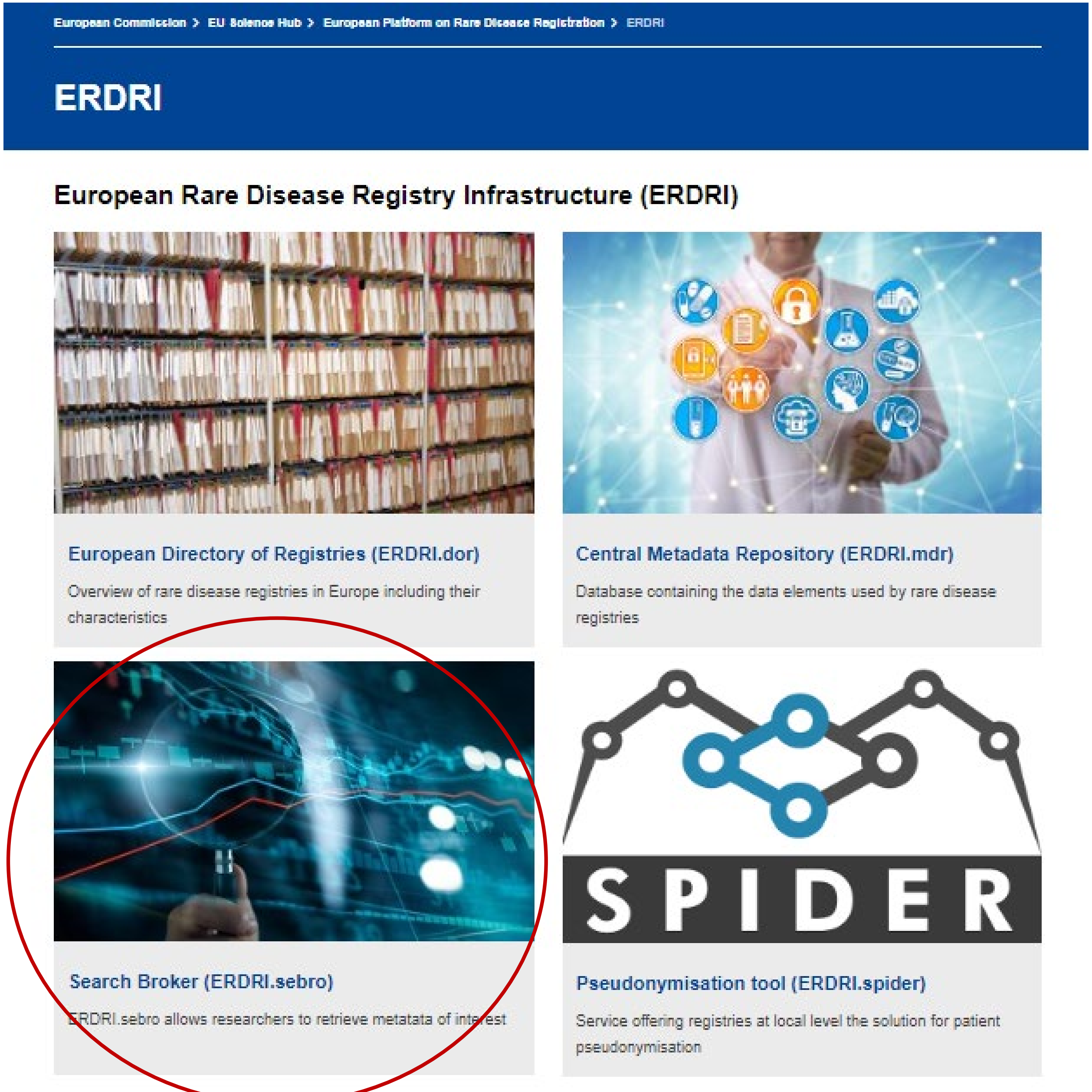
Variable | Text | globaluniqueid

**globaluniqueid**

Patient's pseudonym

1 validation rule

# The main components of ERDRI



European Commission > EU Science Hub > European Platform on Rare Disease Registration > ERDRI

ERDRI

European Rare Disease Registry Infrastructure (ERDRI)

**European Directory of Registries (ERDRI.dor)**

Overview of rare disease registries in Europe including their characteristics

**Central Metadata Repository (ERDRI.mdr)**

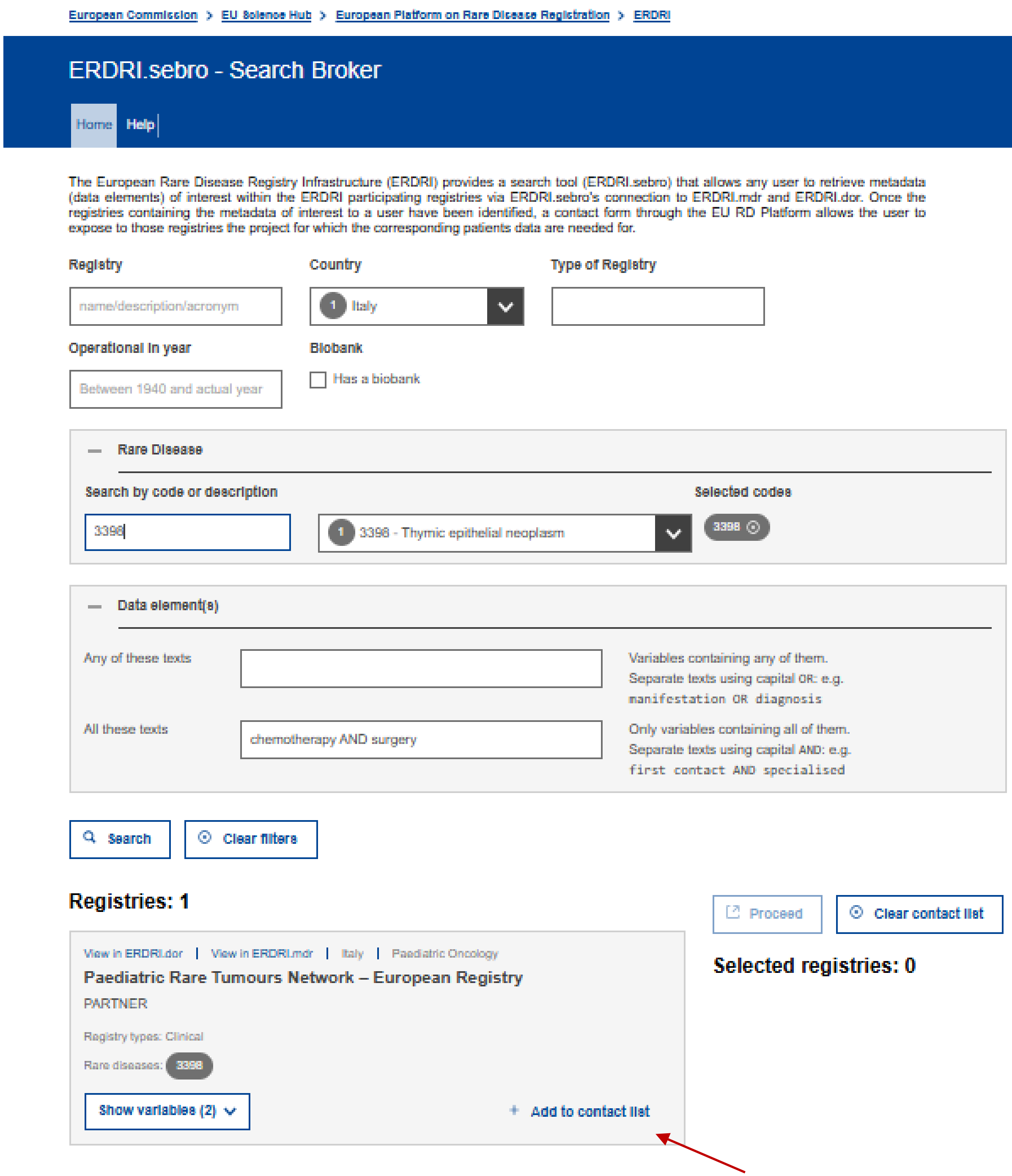
Database containing the data elements used by rare disease registries

**Search Broker (ERDRI.sebro)**

ERDRI.sebro allows researchers to retrieve metatata of interest

**Pseudonymisation tool (ERDRI.spider)**

Service offering registries at local level the solution for patient pseudonymisation



European Commission > EU Science Hub > European Platform on Rare Disease Registration > ERDRI

ERDRI.sebro - Search Broker

The European Rare Disease Registry Infrastructure (ERDRI) provides a search tool (ERDRI.sebro) that allows any user to retrieve metadata (data elements) of interest within the ERDRI participating registries via ERDRI.sebro's connection to ERDRI.mdr and ERDRI.dor. Once the registries containing the metadata of interest to a user have been identified, a contact form through the EU RD Platform allows the user to expose to those registries the project for which the corresponding patients data are needed for.

**FILTERS**

Registry: name/description/acronym

Country: 1 Italy

Type of Registry:

Operational in year: Between 1940 and actual year

Biobank: ☐ Has a biobank

Rare Disease

Search by code or description: 3398

1 3398 - Thymic epithelial neoplasm

Selected codes: 3398

Data element(s)

Any of these texts:

Variables containing any of them.
Separate texts using capital `OR`: e.g. `manifestation OR diagnosis`

All these texts: chemotherapy AND surgery

Only variables containing all of them.
Separate texts using capital `AND`: e.g. `first contact AND specialised`

**RESULTS**

Registries: 1

View in ERDRI.dor | View in ERDRI.mdr | Italy | Paediatric Oncology

Paediatric Rare Tumours Network – European Registry

PARTNER

Registry types: Clinical

Rare diseases: 3398

Selected registries: 0

▶ https://eu-rd-platform.jrc.ec.europa.eu/search_broker

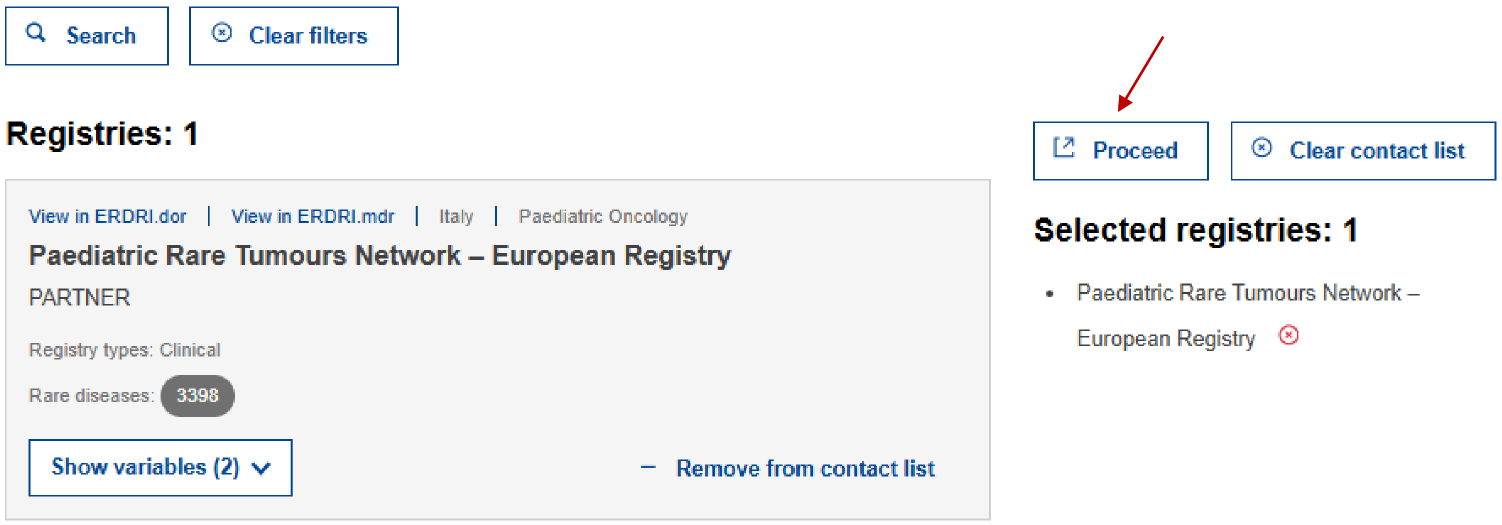
**User inserts keywords**

**DOR and MDR are queried**

**Registries matching the request are identified**

**DOR: >70 var**

**MDR: >20 var**



**Registries: 1**

View in ERDRI.dor | View in ERDRI.mdr | Italy | Paediatric Oncology

**Paediatric Rare Tumours Network – European Registry**

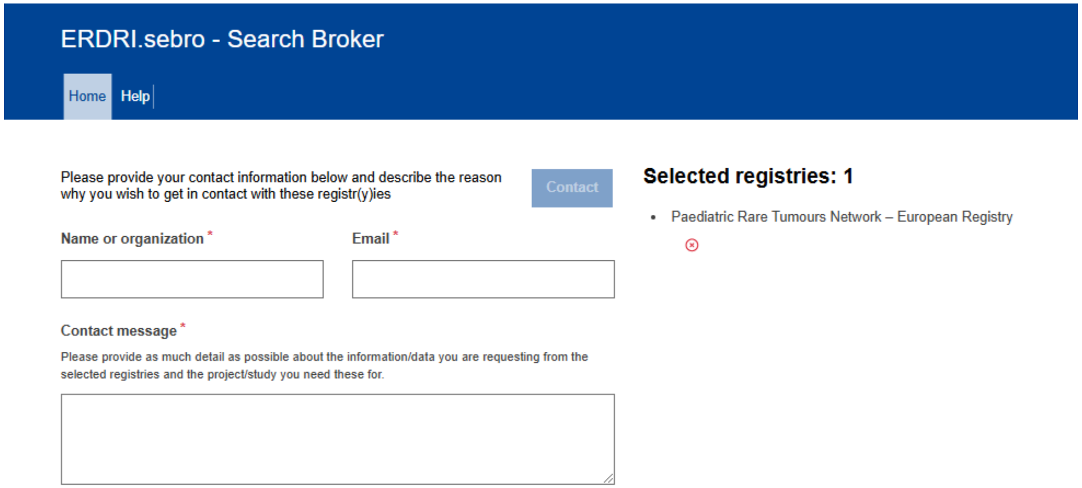
PARTNER

Registry types: Clinical

Rare diseases: 3398

**Selected registries: 1**

- Paediatric Rare Tumours Network – European Registry



Please provide your contact information below and describe the reason why you wish to get in contact with these registr(y)ies

Name or organization *

Email *

Contact message *

Please provide as much detail as possible about the information/data you are requesting from the selected registries and the project/study you need these for.

**Selected registries: 1**

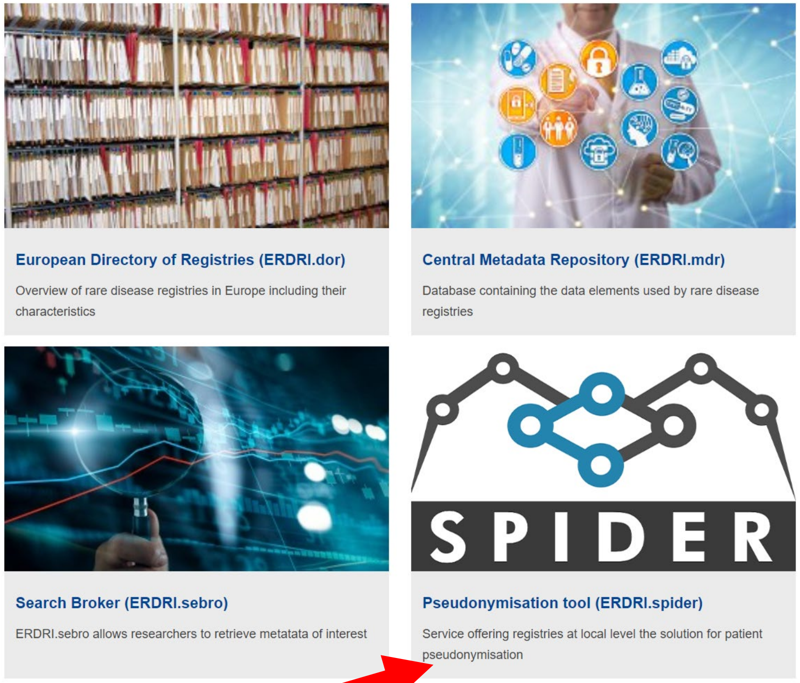
- Paediatric Rare Tumours Network – European Registry

Request/study proposal - contact with the registries

# ERDRI Spider

**Reachable from the ERDRI homepage**

- **https://eu-rd-platform.jrc.ec.europa.eu/erdri**



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# Main Functionalities

Does NOT have access to patient data!

Pseudonym ***GENERATION***

Pseudonym ***LINKAGE***

Encrypted pseudonymised data
***TRANSFER***

SPIDER

Spider

Share

Network

***policy enforcement***

# Prerequisites

- ✓ *Have a EU Login account*
- ✓ *Be "verified" according to the ERDRI User Access Guide*
- ✓ *Fill registry information in ERDRI.dor according to ERDRI.dor User Guide*
- ✓ *Fill metadata information in ERDRI.mdr ERDRI.mdr User Guide*
- ✓ *Be a registry owner or be added by a registry owner in the Allowed users (e-mail)" field in the "SPIDER information" section of the ERDRI.dor*

**Allowed users (e-mail)**

registry.owner@example.com
additional.user.one@example.com
additional.user.two@example.com

European Commission > EU Science Hub > European Platform on Rare Disease Registration > Trainings, Resources and Latest news > Resources

# Resources

## Manuals and instruction videos

- **ERDRI User access guide** | PDF
- **ERDRI.dor User documentation** | PDF
- **ERDRI.mdr User documentation** | PDF
- **ERDRI.mdr Video tutorial**


European Platform on Rare Disease Registration (EU RD Platform)
The European Rare Disease Registry Infrastructure
ERDRI User Access Guide

European Platform on Rare Disease Registration (EU RD Platform)
The European Rare Disease Registry Infrastructure (ERDRI)
The European Directory of Registries (ERDRI.dor)
User Guide Version 3.0

European Platform on Rare Disease Registration (EU RD Platform)
The European Rare Disease Registry Infrastructure (ERDRI)
ERDRI.mdr User Guide

User Documentation 1.0

User Documentation 3.0

User Documentation 4.0


EU RD Platform
Central Metadata Repository
ERDRI.mdr
Tutorial session
JRC.F.1

SPIDER presentation video

**https://eu-rd-platform.jrc.ec.europa.eu/spider/**

Please watch these short video tutorials to get started with SPIDER:

- Tutorial 1 - create a cryptographic archive
- Tutorial 2 - allow a user to access SPIDER
- Tutorial 3 - access SPIDER
- Tutorial 4 - generate a pseudonym for a patient
- Tutorial 5 - generate pseudonyms for a list of patients
- Tutorial 6 - enter medical data of a patient
- Tutorial 7 - enter medical data of a patient list
- Tutorial 8 - create patient groups
- Tutorial 9 - set pseudonym linkage policies
- Tutorial 10 - find additional data sources for a patient
- Tutorial 11 - request data on a mutual patient
- Tutorial 12 - share data on a mutual patient
- Tutorial 13 - share data on a patient, no matter if mutual or not
- Tutorial 14 - manage received pseudonymised data on patients, no matter if mutual or not

The FAQ page provides more information on the topics covered in the video tutorials.

## Frequently asked questions

**Frequently asked questions >**

**https://eu-rd-platform.jrc.ec.europa.eu/erdri-description_en#inline-nav-5**

European Commission

# Thank you