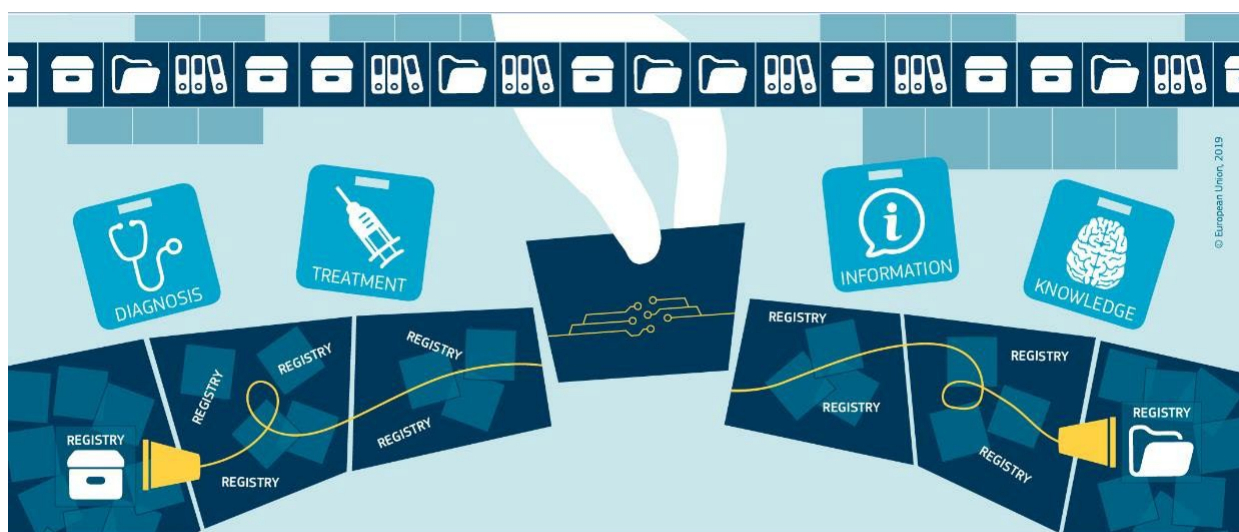




European Platform on Rare Disease Registration (EU RD Platform)

The European Rare Disease Registry Infrastructure (ERDRI)

The European Directory of Registries (ERDRI.dor)



EUROPEAN PLATFORM ON RARE DISEASES REGISTRATION



User Documentation 2.0



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1 About this document

This documentation provides an overview of the functions of the European Directory of Registries, [ERDRI.dor](https://erdri.dor).

2 Aim of the system

The European Directory Registries on rare diseases in Europe (ERDRI.dor) is a meta-registry which provides an overview of existing rare disease registries in Europe. ERDRI.dor provides an overview of the participating registries with their main characteristics and description. Data input is performed by registry owners. Each registry is described by nine sections with forty two data fields, out of which twenty are compulsory.

3 User access and functions

Please refer to document "[ERDRI User Access Guide](#)". In this guide, instructions on ERDRI access for three types of users of ERDRI.dor are provided;

- **non-identified users** who can view limited information of the participating registries,
- **authenticated users** who are able to view details of the ERDRI participating registries
- **verified users** who are users submitting registry characteristics and description are provided.

To access the page containing the ERDRI.dor please enter the page through the main EU RD Platform page and the ERDRI as indicated in Figure 1 and Figure 2.



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.

[Read more >](#)

Searchable, findable rare disease registry data



Data repository



Figure 1 Accessing ERDRI through the main EU RD Platform page

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

Figure 2 Accessing ERDRI.dor through the ERDRI main page.



3.1. Search and display of registry records

Search for a specific registry can be performed through the "Search" field on the start page (Figure 3) or via the menu item "Search" indicated by the red arrows (Figure 4). After EU login authentication users are able to view detailed information of a registry.



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

ERDRI.dor provides an overview of the participating registries with their main characteristics and description. Data input is performed by registry owners. ERDRI.dor consists of eight sections with 42 data fields related to a registry of which 20 are obligatory.

Figure 3 Search for registry details through the "Search" field.

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

ERDRI.dor - European Directory of Registries

Home Search Show disabled registries Add registry Help ▾



ERDRI.dor provides an overview of the participating registries with their main characteristics and description. Data input is performed by registry owners. ERDRI.dor consists of eight sections with 42 data fields related to a registry of which 20 are obligatory.

Figure 4 Search for registry details via the "Search" menu.



Searching through the "Search" tab allows the use of a number of search criteria as indicated in the Figure 5.

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

ERDRI.dor - European Directory of Registries

Home Search Show disabled registries Add registry Help ▾

▾ Search

Name or Subject

Responsible

Rare disease

ICD-10 code

Country ▾

Year of the recruitment

Last edit before years

Type

- ☐ Epidemiology
- ☐ Clinical
- ☐ Basic Research
- ☐ Pharmacological Research
- ☐ Patient
- ☐ Healthcare planning
- ☐ Economic evaluation
- ☐ Has a biobank

Search Reset

Figure 5. Registry search criteria in ERDRI.dor

In the field "Rare disease" of the search box, you get suggestions after typing three characters. The suggestions are terms of the Orphanet classification of rare diseases (<http://www.orpha.net>). It is also possible to search for an ICD-10 code for the cases that has been used by some registries for complex diseases that do not possess an orphacode.


3.2. List all registries

The link "List all registries" (Figure 6), which is located directly under the search field allows you to generate a list with all registries contained in ERDRI.dor. You can display the detail information for each registry as needed.

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

ERDRI.dor - European Directory of Registries

Home Search Show disabled registries Add registry Help ▾



ERDRI.dor provides an overview of the participating registries with their main characteristics and description. Data input is performed by registry owners. ERDRI.dor consists of eight sections with 42 data fields related to a registry of which 20 are obligatory.

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

Registry Name/Description Search List all

Figure 6 List of all registries function.

3.3 List registries of a country

By clicking on a given country on the map displayed all registries of that regarding are listed in the search result. For this function a login is not necessary.



4 Submitting registry's characteristics and description

Users who wish to input their registries characteristics to the ERDRI.dor must be authenticated and verified users according to [ERDRI User Access Guide](#). Login is available in the upper right corner of the screen as indicated in Figure 7 below with a red arrow.

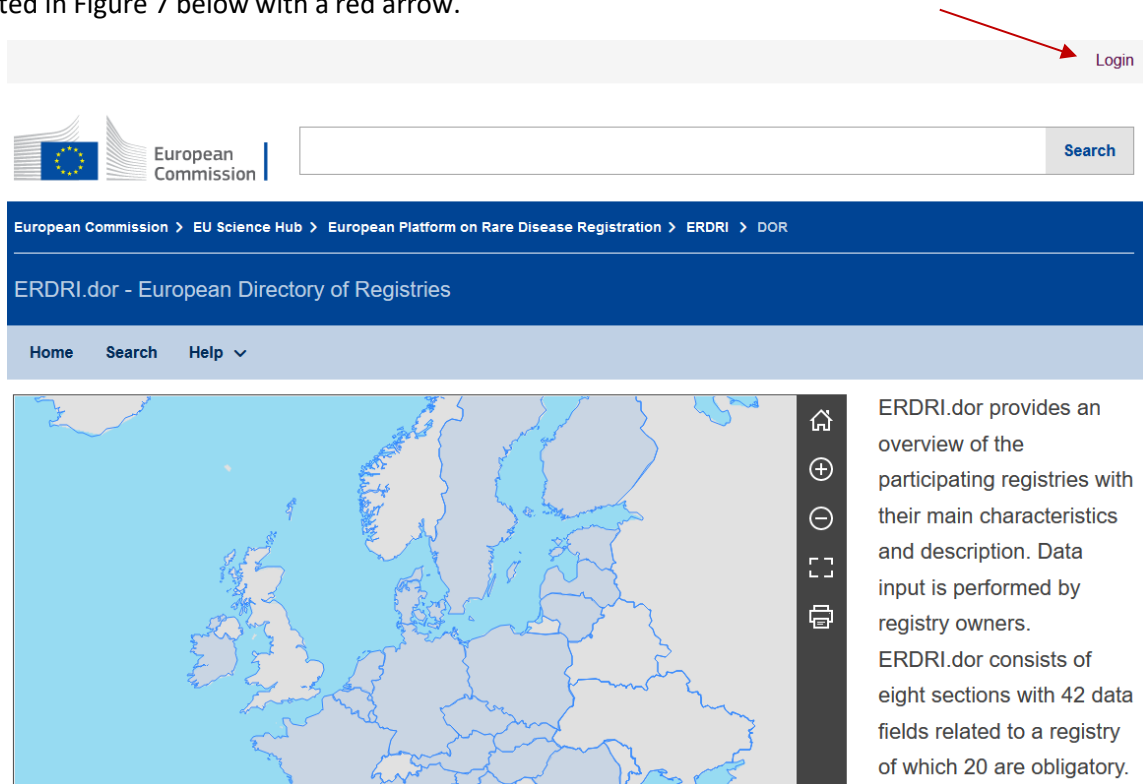


Figure 7 Login to input registry characteristics.

Click the “Add registry” tab to access the ERDRI.dor registry description form as in Figure 8.

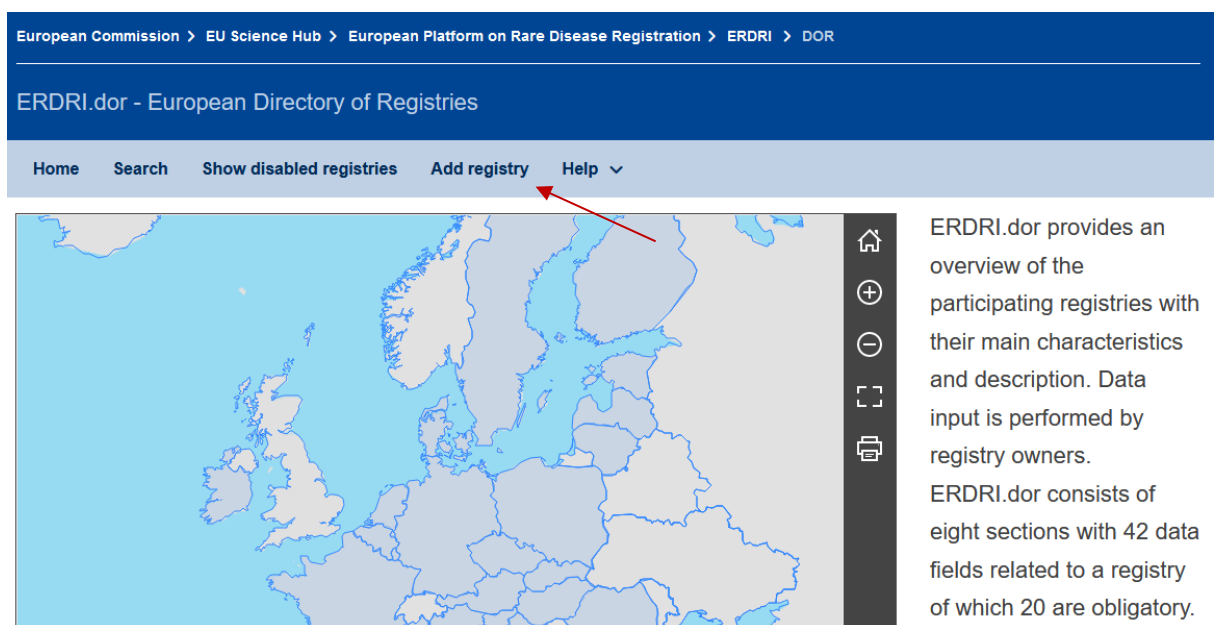


Figure 8 Adding a new registry in ERDRI.dor



ERDRI.dor consists of nine sections containing 42 data fields related to a registry of which 20 are obligatory.

The descriptive metadata fields are divided into nine sections:

- General information
- Rare Disease
- Structure
- Registry information
- Link to the metadata repository (ERDRI.mdr) – this is filled by the ERDRI administrators
- Responsible
- Pseudonymisation Tool
- Biobanks
- Additional components

are displayed and explained here below:

General information of the registry

Name *	<input type="text"/>								
Acronym	<input type="text"/>								
Medical area *	<input type="text"/>								
Type *	<table><tr><td><input type="checkbox"/> Epidemiology</td><td><input type="checkbox"/> Patient</td></tr><tr><td><input type="checkbox"/> Clinical</td><td><input type="checkbox"/> Healthcare planning</td></tr><tr><td><input type="checkbox"/> Basic Research</td><td><input type="checkbox"/> Economic evaluation</td></tr><tr><td><input type="checkbox"/> Pharmacological Research</td><td><input type="checkbox"/> Other type</td></tr></table>	<input type="checkbox"/> Epidemiology	<input type="checkbox"/> Patient	<input type="checkbox"/> Clinical	<input type="checkbox"/> Healthcare planning	<input type="checkbox"/> Basic Research	<input type="checkbox"/> Economic evaluation	<input type="checkbox"/> Pharmacological Research	<input type="checkbox"/> Other type
<input type="checkbox"/> Epidemiology	<input type="checkbox"/> Patient								
<input type="checkbox"/> Clinical	<input type="checkbox"/> Healthcare planning								
<input type="checkbox"/> Basic Research	<input type="checkbox"/> Economic evaluation								
<input type="checkbox"/> Pharmacological Research	<input type="checkbox"/> Other type								
If other type, please explain	<input type="text"/>								
Is member of a European Reference Network	<input type="text" value="Please input your ERN here"/> <input type="button" value="v"/>								
Is member of	<input type="checkbox"/> Eurocat								
Description *	<div>Short description of the registry scope</div> <div>(500 characters remaining)</div>								
Website	<input type="text"/>								
Sponsors	<input type="text"/>								



Rare disease *

Search by orphacode

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.

+ Add

Orphacode / disease

The user can enter an orphacode, or type the name of the disease. Suggestions will start to appear by typing at least two letters of the disease's name. A list of orphacodes can be imported at once through a copy/paste function.

If a registry is dealing with a complex diseases for which an orphacode is not available, the registry can be enabled to use ICD-10 codes. The request can be made by contacting the ERDRI helpdesk at: EU-RD-PLATFORM@ec.europa.eu

When the registry is enabled for the use of ICD-10 codes, this section is as follows:

Rare disease *

Search by orphacode

Search by ICD-10

Input by orphacode/ICD-10

Enter a list of orphacodes/ICD-10 codes in the textbox below. Separate codes by either a new line, blanks, commas or semicolons and then press 'Add' to process the list.

+ Add

Orphacode / disease

As in the case of orphacodes a list of ICD-10 can be copied directly from an excel, word, csv etc. format or through searching the disease directly by typing the at least two letters of the disease name.



Information on the **structure** includes information on the recruitment area and dates, current number of cases, data sources, number of data elements, technical solution etc.

Structure

Inclusion and exclusion criteria	<input type="text"/>
	(1,000 characters remaining)
Recruitment area *	<input type="text"/>
Name of the recruitment area *	<input type="text"/>
	(Country, state or region)
Recruitment start/end date	<input type="text"/> to <input type="text"/>
	DD/MM/YYYY
Current number of cases *	<input type="text"/> at <input type="text"/>
Data source *	<input type="checkbox"/> University hospital <input type="checkbox"/> Non university hospital <input type="checkbox"/> Physician <input type="checkbox"/> Other
	<input type="checkbox"/> Patient/test person <input type="checkbox"/> Family of patient <input type="checkbox"/> Research Institution
If other data source, please explain	<input type="text"/>
Number of Data Elements collected *	<input type="text"/>
Technical solution (software) used *	<input type="text"/>
	eg. Excel, OSSE, Redcap, Oracle, Access etc.
Data management	<input type="text"/>
Link to the privacy policy	<input type="text"/>
Ethical review committee	<input type="text"/>
Availability for future collaborations/studies	<input type="text"/>

Information about the **registry's location** is also requested.

Registry information

Institution *	<input type="text"/>
Facility	<input type="text"/>
Department *	<input type="text"/>
Street & number *	<input type="text"/>
Postcode City *	<input type="text"/>
Country *	<input type="text"/>
Country (please specify)	<input type="text"/>



In the following section please enter the contact information of the **Registry Responsible**.

The registry responsible may be different from the person filling in the ERDRI.dor (Registry Owner). This should be the person who could be responsible to discuss a collaboration project or provide further data in case requested by anyone finding the registry's information in ERDRI.

Responsible

First name *	<input type="text"/>
Last name *	<input type="text"/>
Title	<input type="text"/> ▼
Academic title/degree	<input type="text"/>
Position	<input type="text"/>
E-Mail address *	<input type="text"/>
Phone number *	<input type="text"/>

▼ [ERDRI.mdr \(Central Metadata Repository\)](#)

Registry namespace

[jrocentralauthority](#)

In the next section, information for the use of the **pseudonymisation tool ERDRI.spider** is provided. The registry owner can fill in only the last two fields (information on the Data Protection Officer of the registry and the additional allowed “verified users” e-mails) according to the [ERDRI User Access Guide](#). Further information on the use of ERDRI spider can be found on the dedicated [ERDRI.spider webpage](#).



ERDRI.spider (Pseudonymisation tool)

Center ID	<input type="text" value="Enter the Center ID for SPIDER"/>
Center certificate (pem)	<input type="text" value="Enter the center PEM certificate for SPIDER"/>
Data Protection Officer	<input type="text" value="Full name and contact information of the Data Protection Officer, if any"/>
Allowed users (e-mail)	<input type="text" value="e-mail addresses separated by comma (,), semicolon (;) or new lines"/>

Information on the association of the registries to biobanks can be reported in the section **Biobanks**.

Any other **Additional components** related to the registry that may have not be covered in the previous field can be inserted in "Additional components".

Biobanks

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

Additional components

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



5 Editing the content of your registry in ERDRI.dor

Once the ERDRI.dor has been filled in, the “registry owners” can modify their registries’ descriptive metadata by clicking on the pencil symbol as indicated in Figure 9 below. According to the [ERDRI Terms of Use](#) update of the registries’ information in ERDRI.dor is done at least once per year.

European Commission |

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

ERDRI.dor - European Directory of Registries

Home Search Show disabled registries Add registry Help ▾

> [Search](#)

▼ [Search results](#)

Page 1 of 1. (1 entries found)

Name	Description	Medical area	Country	Website	
JRC Central Authority	JRC Rare Disease team, not belonging to any actual Rare Disease network.	None (administrative registry)	Italy	https://eu-rd-platform.jrc.ec.europa.eu	

Page 1 of 1. (1 entries found)

Figure 9 Editing a registry's characteristics in ERDRI.dor.

6 Contact and technical assistance

For any questions you may have regarding ERDRI.dor, please contact us at: EU-RD-PLATFORM@ec.europa.eu or through the [support form](#). (Figure 10)



ERDRI.dor - European Directory of Registries

Home Search Show disabled registries Add registry **Help**

Instructions

FAQ

Support



and description. Data input is performed by registry owners. ERDRI.dor consists of eight sections with 38 data fields related to a registry of which 23 are obligatory.

ERDRI Support form

Please describe the problem you are experiencing naming the specific tool and adding all relevant information.

Your name*

Your email address*

Subject*

Message*



Captcha

Enter the characters shown in the image (case sensitive).

[Get new captcha](#)

Submit

Figure 10 Technical support assistance form.