



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

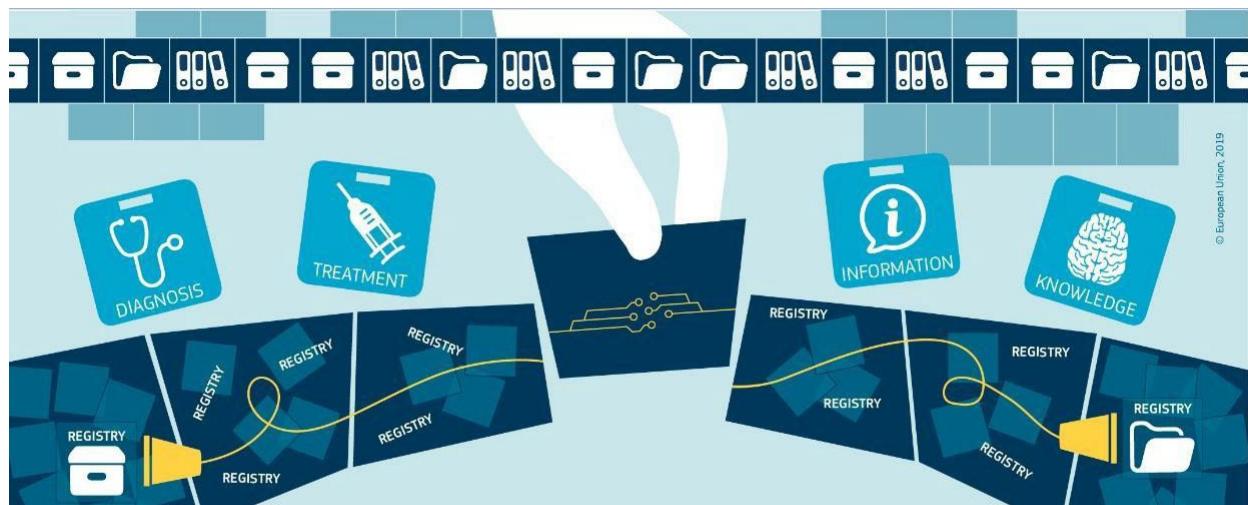




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1 About this document

This documentation provides an overview of the functions of the European Directory of Registries, [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 46 data fields, out of which 25 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.

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. Accessing ERDRI through the main EU RD Platform pageFigure 1 and Figure 2.



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.

[Read more >](#)

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

Figure 1. Accessing ERDRI through the main EU RD Platform page

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

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.

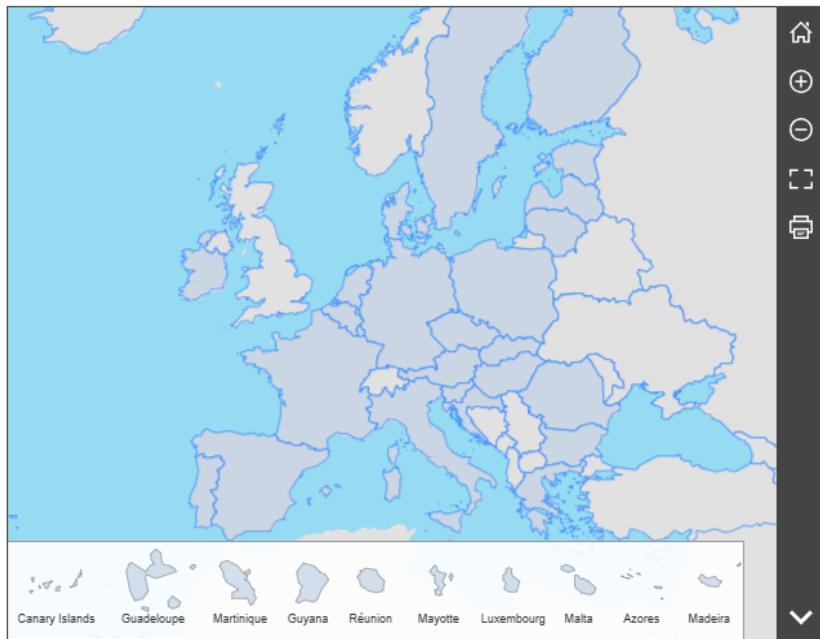


Figure 3. Search for registry details through the "Search" field



ERDRI.dor - European Directory of Registries

Home Search Help ▾



Registry Name/Description

Search

List all

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 Figure 5.

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

ERDRI.dor - European Directory of Registries

Home Search Help ▾

▼ [Search](#)

Name or Subject	<input type="text"/>	Type	<input type="checkbox"/> Epidemiology
Responsible	<input type="text"/>	<input type="checkbox"/> Clinical	
Rare diseases	<input type="text"/>	<input type="checkbox"/> Basic Research	
ICD-10 code	<input type="text"/>	<input type="checkbox"/> Patient driven	
Country	<input type="text"/> ▾	<input type="checkbox"/> Healthcare planning	
Year of the recruitment	<input type="text"/>	<input type="checkbox"/> Economic evaluation	
		<input type="checkbox"/> HCP contributing to a central registry	
		<input type="checkbox"/> 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 complexes 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.

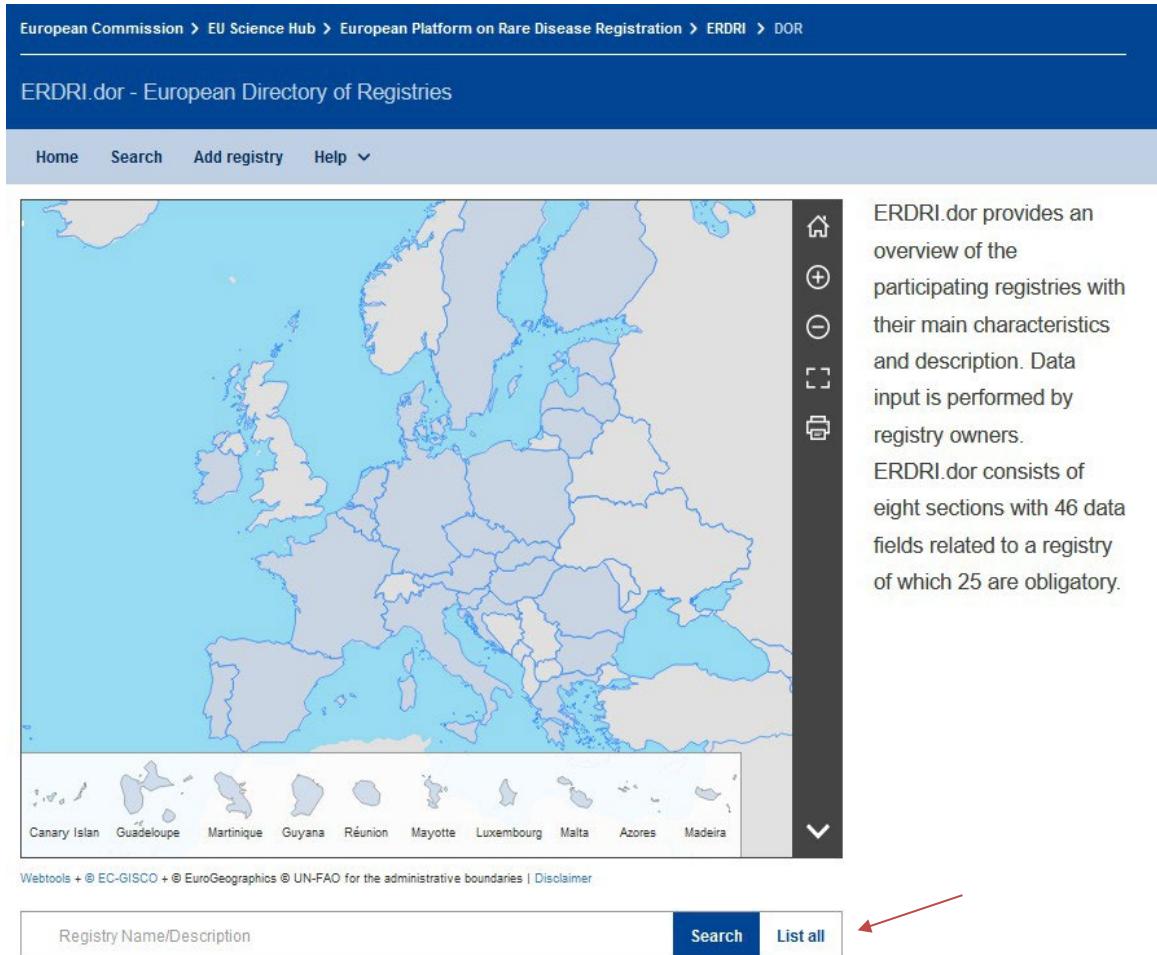


Figure 6. List of all registries function.

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.

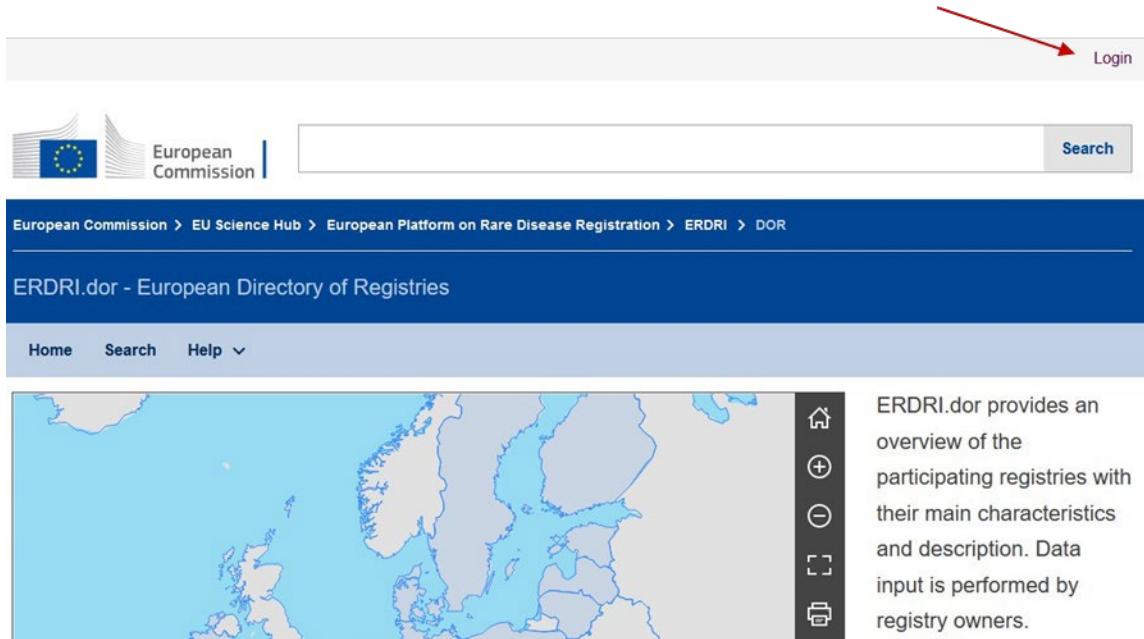


Figure 7. Login to input registry characteristics

To add the descriptive information of a registry the registry “owner” needs to click on the “Add Registry” tab as indicated in Figure 8.

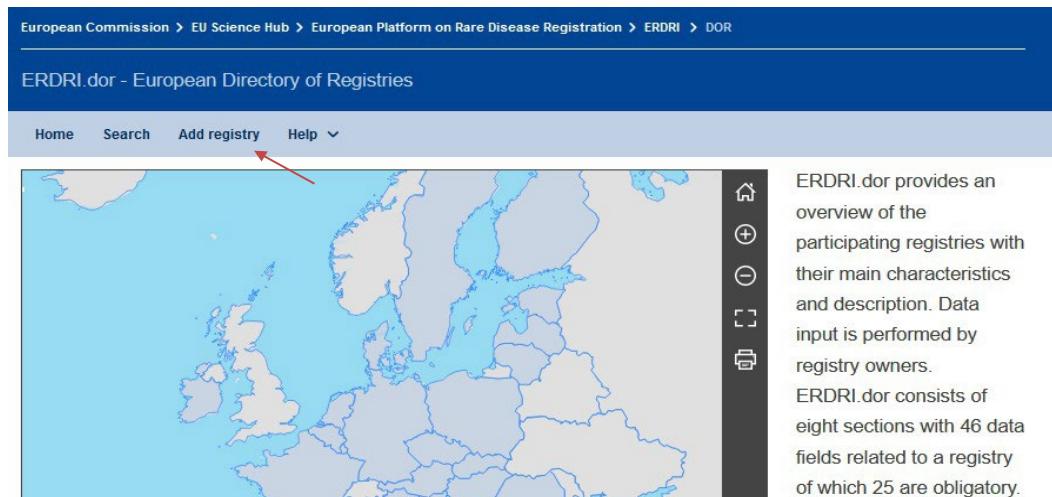


Figure 8. Adding a new registry in ERDRI.dor

ERDRI.dor consists of nine sections containing 46 data fields related to a registry of which 25 are obligatory.

- Structure
- Registry information



The descriptive metadata fields are divided into nine sections:

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

In the first section, General Information is requested as shown in Figure 9. This information includes the name, acronym or in the case an acronym does not exist a short name, the type of registry, the type of data provider.

General information of the registry

Name *	<input type="text"/>
Acronym/Short name *	<input type="text"/> Used as 'name' for the registry namespace in ERDRI.mdr
Medical area *	<input type="text"/>
Type *	<input type="checkbox"/> Epidemiology <input type="checkbox"/> Patient driven <input type="checkbox"/> Clinical <input type="checkbox"/> Healthcare planning <input type="checkbox"/> Basic Research <input type="checkbox"/> Economic evaluation <input type="checkbox"/> HCP contributing to a central registry <input type="checkbox"/> Other type
Other type (please specify)	<input type="text"/>
Data provider *	<input type="checkbox"/> University hospital <input type="checkbox"/> Patient <input type="checkbox"/> Non university hospital <input type="checkbox"/> Family of patient <input type="checkbox"/> Research Institution <input type="checkbox"/> Other
If other data provider, please explain	<input type="text"/>
Is member of a European Reference Network	<input type="text"/> Please input your ERN here
Is member of	<input type="checkbox"/> Eurocat
Description *	<input type="text"/> Short description of the registry scope <small>(500 characters remaining)</small>
Website	<input type="text"/>
Sponsors	<input type="text"/>

Figure 9. General information of the registry



All Health Care Providers (HCPs) contributing to a central registry, such as central registries form the European Reference Networks or other networks are required to choose as “**Type**” of registry “HCP contributing to a central registry” and for the field “**Contribution to a Central Registry**” (Figure 10) to choose a central registry from the drop down menu.

The form shows a list of checkboxes for 'Type' and a dropdown for 'Contribution to a Central Registry'.

Type *	<input type="checkbox"/> Epidemiology	<input type="checkbox"/> Patient driven
	<input type="checkbox"/> Clinical	<input type="checkbox"/> Healthcare planning
	<input type="checkbox"/> Basic Research	<input type="checkbox"/> Economic evaluation
	<input checked="" type="checkbox"/> HCP contributing to a central registry	<input type="checkbox"/> Other type

Contribution to a Central Registry * ▼

Figure 10. HCP contributing to a central registry.

Rare diseases *

The form includes sections for 'Search by orphacode' (text input: 'please report all the orphacodes used by your registry') and 'Input by orphacode' (text input: '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.'), both with explanatory text. It also includes a 'Orphacode / disease' section and a dropdown for 'Does your registry deal with any * cancers?'.

Figure 11 Rare disease /orphacode introduction in ERDRI.dor.

In the section “Rare disease”, the user can enter an orphacode, or type the name of the disease the registry deals with. Suggestions will start to appear by typing at least two letters of the disease’s name. A list of orphacodes can be inserted at once through a copy/paste function (Figure 11).

If a registry is dealing with a complex diseases or a cancer 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 the one in Figure 12:



Rare diseases *

Search by orphacode	<input type="text" value="please report all the orphacodes used by your registry"/>
Search by ICD-10	<input type="text"/>
Input by orphacode/ICD-10	<p>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.</p> <input type="text"/> + Add
Orphacode / disease	
Does your registry deal with any * cancers?	<input type="text" value=""/>

Figure 12 Introduction of ICD 10 codes when this is authorized.

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.



If the registry deals with cancers, you are asked to provide the specific orphacodes or ICD-10 codes that are associated with these cancers. (Figure 13).

Does your registry deal with any * cancers? Yes No

Please report here the orphacodes associated with the cancers dealt with by your registry

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.

Orphacode / disease

Figure 13 Specification of orphacodes (or ICD-10 codes) for registries dealing with cancer.



Information on the **Structure** includes information on the recruitment area and recruitment dates, current number of cases, data sources, number of data elements, technical solution etc. is also required as in Figure 14.

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 DD/MM/YYYY	<input type="text"/> to <input type="text"/>
Current number of cases *	<input type="text"/> at <input type="text"/>
Number of Data Elements collected	<input type="text"/>
Technical solution (software) used	<input type="text"/>
Other software (please specify)	<input type="text"/>
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"/>

Figure 14. Input required on the structure of the registry.

Information about the registry's location is also requested under the section **Registry Information** (Figure 15).

[Registry information](#)

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

Figure 15. Input required about the Registry's location

In Figure 16, the contact information of the **Registry Responsible** should be entered. The registry responsible may be different from the person filling in the ERDRI.dor ("Registry Owner" in ERDRI terms). The registry responsible is the person who is 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"/> <input type="button" value="▼"/>
Academic title/degree	<input type="text"/>
Position	<input type="text"/>
E-Mail address *	<input type="text"/>
Phone number *	<input type="text"/>

Figure 16. Responsible of the registry section.

In Figure 17, the link to the **Registry's namespace ERDRI.mdr** is provided. This is a field visible only when viewing the registry information, not when filling it in. This is filled-in automatically by the ERDRI.dor system and the registry "owner" does not deal with filling in this field.

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

Registry namespace	jrccentralauthority <input type="button" value=""/>
--------------------	---

Figure 17. ERDRI.mdr information.

In Figure 18 is displayed some required information for the use of the **pseudonymisation tool ERDRI.spider**. 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](#). Please note that all users’ emails will need to be inserted in this field, including the registry “owner’s email address. Further information on the use of ERDRI spider can be found in the dedicated [ERDRI.spider webpage](#).

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

Figure 18. ERDRI.spider information.

Information on the association of the registries with 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**”. (Figure 19)



Biobank name	Registry of biobanks	Biobank identifier	+
Additional components			
Name of the component	Component described in	Relationship	+

Figure 19 Links to Biobanks and additional information to be reported by the registries.



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 20 below. According to the [ERDRI Terms of Use](#) update of the registries’ information in ERDRI.dor is done at least once per year. ERDRI will send an automatic reminder each year.

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

Page 1 of 1. (1 entries found)

Figure 20. Searching for registries 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 21)

ERDRI.dor - European Directory of Registries

Home Search Show disabled registries Add registry Help ▾

Instructions

F.A.Q.

Support

and description. Data input is performed by registry owners. ERDRI.dor consists of eight sections with 46 data fields related to a registry of which 25 are obligatory.



Contact

EU RD Platform

Organisation

Phone

Subject*

Message*

CAPTCHA

Antispam Refresh

Move the slider to **seven** or **4**

You've selected: 0

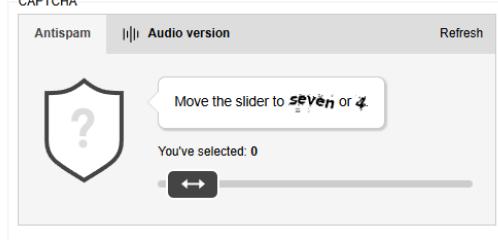


Figure 21. Technical support assistance form.