



EUROPEAN COMMISSION
JOINT RESEARCH CENTRE

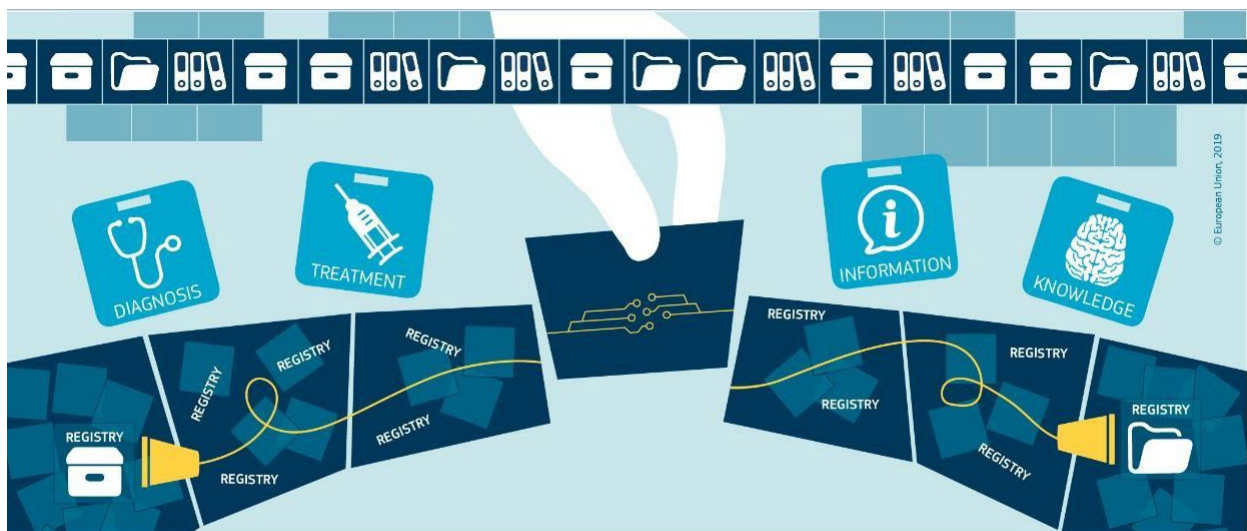
Directorate F – Health and Food
F.1 Disease Prevention

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 DISEASES REGISTRATION



User Documentation 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 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 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.

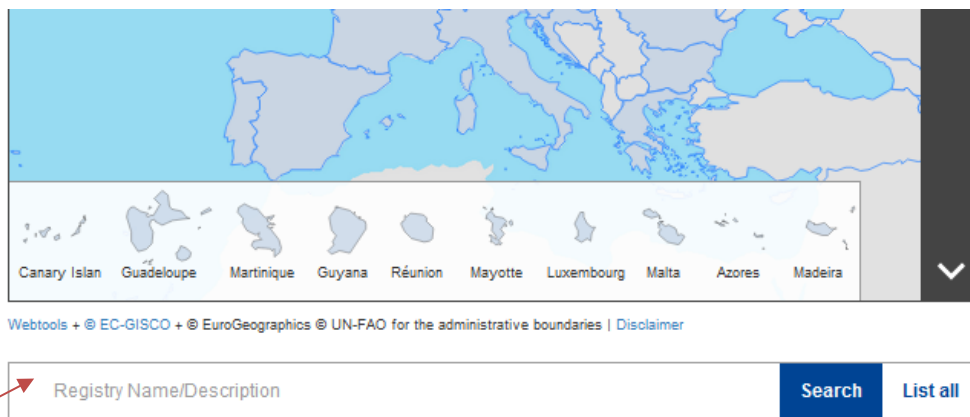
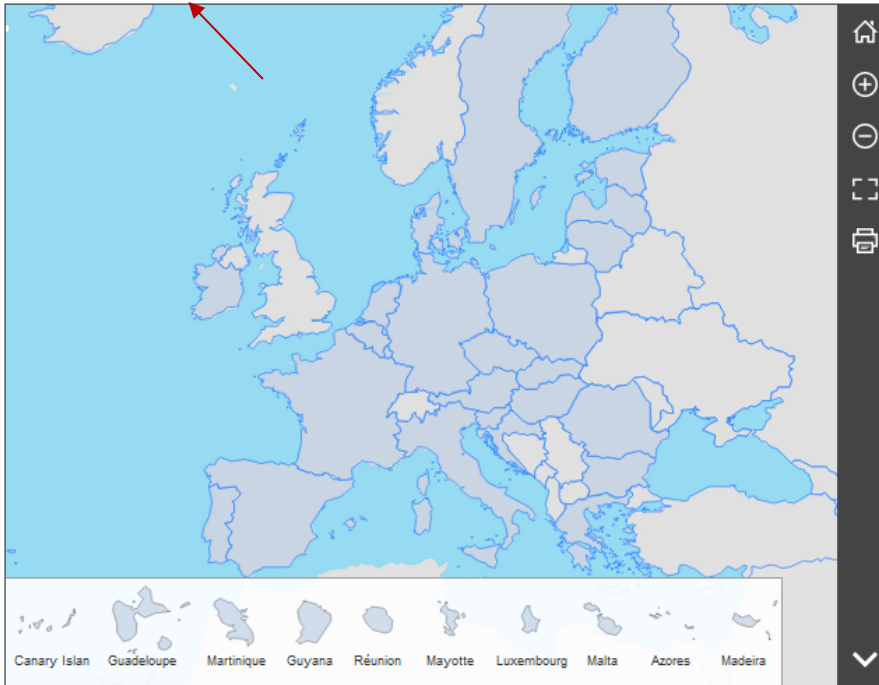


Figure 3 Search for registry details through the "Search" field.



ERDRI.dor - European Directory of Registries

Home Search 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 46 data fields related to a registry of which 25 are obligatory.

Webtools + © EC-GISCO + © EuroGeographics © UN-FAO for the administrative boundaries | Disclaimer

<input type="text" value="Registry Name/Description"/>	<input type="button" value="Search"/>	<input type="button" value="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 the 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" value="Country"/>		<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 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 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 46 data fields related to a registry of which 25 are obligatory.

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.

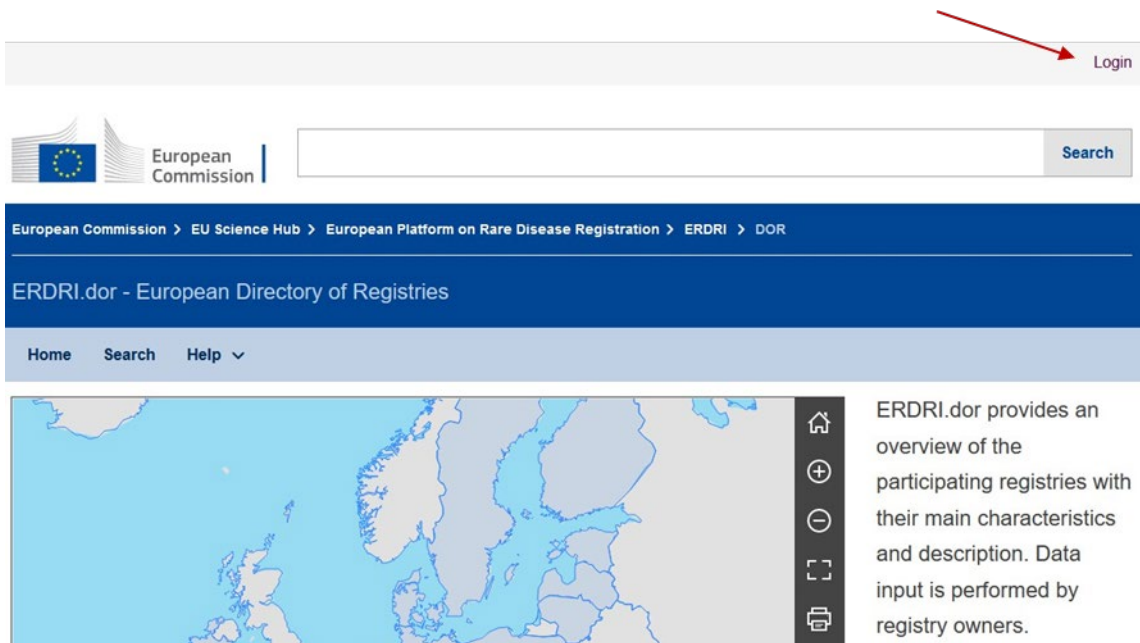


Figure 7 Login to input registry characteristics.

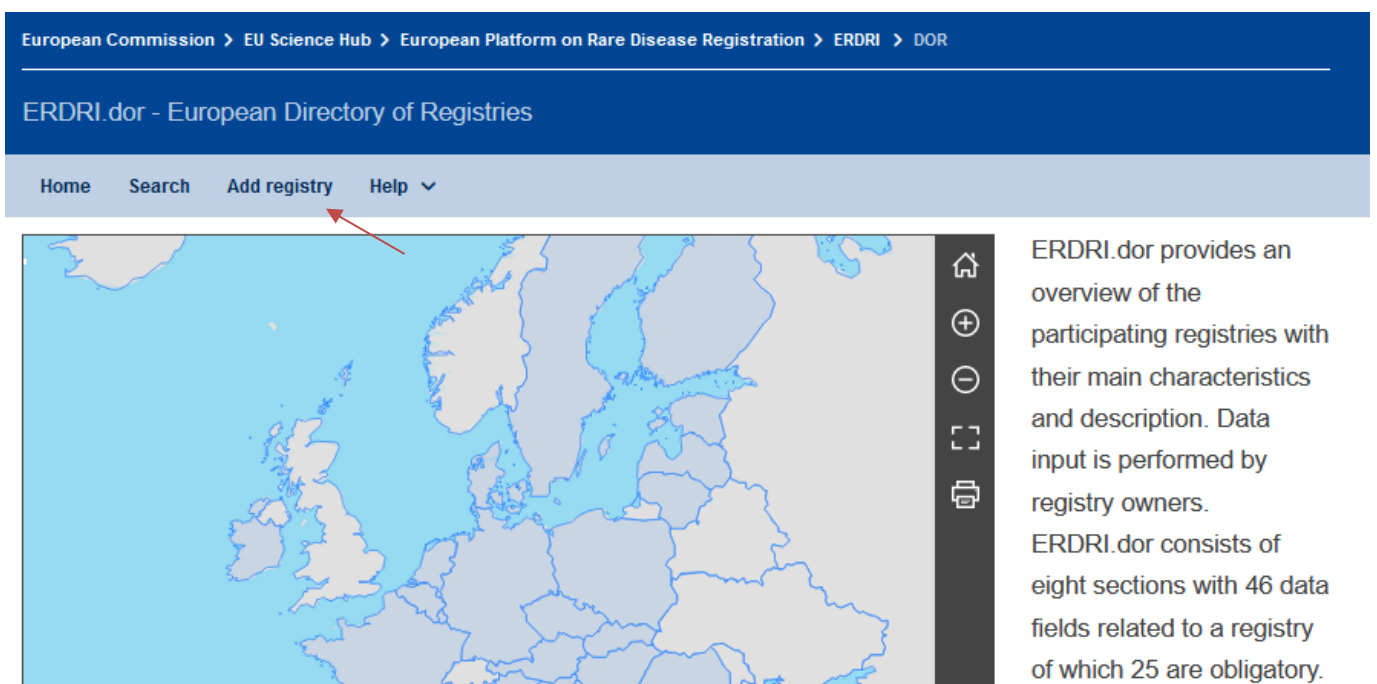


Figure 8 Adding a new registry in ERDRI.dor



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

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

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 *

Acronym/Short name *

Medical area *

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)

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

Is member of a European Reference Network

Is member of Eurocat

Description *
(500 characters remaining)

Website

Sponsors

Figure 9 General information of the registry



All data provides 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
If “Type” is “HCP contributing to a central registry”, the “**Contribution to a Central Registry**” (Figure 10), a list of the central registries to choose from appears.

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

Contribution to a Central Registry *

Figure 10 HCP contributing to a central registry.



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 imported at once through a copy/paste function (Figure 11).

Rare diseases *

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

Does your registry deal with any cancers? *
cancers?

Figure 11 Reporting orphacode(s) for the rare disease(s) dealt by the registry.

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](mailto: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

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

Does your registry deal with any cancers? *
cancers?

Figure 12 Rare diseases reporting by ICD-10 codes in some specific cases.

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?

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.

[+ Add](#)

Orphacode / disease

Figure 13 Registries that deal with any cancers – specific orphacode reporting.



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"/>
	<small>(1,000 characters remaining)</small>
Recruitment area *	<input type="text"/>
Name of the recruitment area *	<input type="text"/>
	<small>(Country, state or region)</small>
Recruitment start/end date	<input type="text"/> to <input type="text"/>
	<small>DD/MM/YYYY</small>
Current number of cases *	<input type="text"/> at <input type="text"/>
Number of Data Elements *	<input type="text"/>
	<small>collected</small>
Technical solution (software) *	<input type="text"/>
	<small>used</small>
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"/> ▼
Other country (please specify)	<input type="text"/>

Figure 15 Input require in 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"/> ▼
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 to when visioning the registry information not when filling in it. This is automatically filled 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
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Figure 17 ERDRI.mdr information.



Figure 18 requires 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 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"/>

Figure 18 ERDRI.spider information.

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”. (Figure 19)

Biobanks

Biobank name	Registry of biobanks	Biobank identifier	+
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Additional components

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

Figure 19 Biobanks and Additional Components.



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.

The screenshot shows the ERDRI.dor website interface. At the top, there is a breadcrumb trail: European Commission > EU Science Hub > European Platform on Rare Disease Registration > ERDRI > DOR. Below this is the title 'ERDRI.dor - European Directory of Registries' and a navigation menu with 'Home', 'Search', 'Show disabled registries', 'Add registry', and 'Help'. A 'Search' button is visible, followed by 'Search results'. The search results show 'Page 1 of 1. (1 entries found)'. A table lists the search results with columns: Name, Description, ERDRI.mdr, Medical area, Country, and Website. The first entry is 'JRC Central Authority' with a description 'JRC Rare Disease team, not belonging to any actual Rare Disease network.', ERDRI.mdr 'cds', Medical area 'None (administrative registry)', Country 'Italy', and Website 'https://eu-rd-platform.jrc.ec.europa.eu'. To the right of the table, there are icons for a list, a pencil (circled in red with an arrow pointing to it), and a trash can. Below the table, there is another pagination control showing 'Page 1 of 1. (1 entries found)'.

Name	Description	ERDRI.mdr	Medical area	Country	Website
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

Figure 20 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 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.

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

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 21 Technical support assistance form.