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

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.

![Search for registry details through the "Search" field.](image-url)
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.

![Figure 5 Registry search criteria in ERDRI.dor.](image)

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](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.

![ERDRI.dor - European Directory of Registries](image)

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.

![Figure 9 General information of the registry](image-url)
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.

![Figure 10 HCP contributing to a central registry.](image-url)
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).

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:

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).

![Image of registry form]

**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.

**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).

![Figure 15 Input require in the Registry's location](image)

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.

![Figure 16 Responsible of the registry section.](image)

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 it in. This is automatically filled by the ERDRI.dor system and the registry owner does not deal with filling in this field.

![Figure 17 ERDRI.mdr information.](image)
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)](image)

**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](image)

**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.

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)
Figure 21 Technical support assistance form.