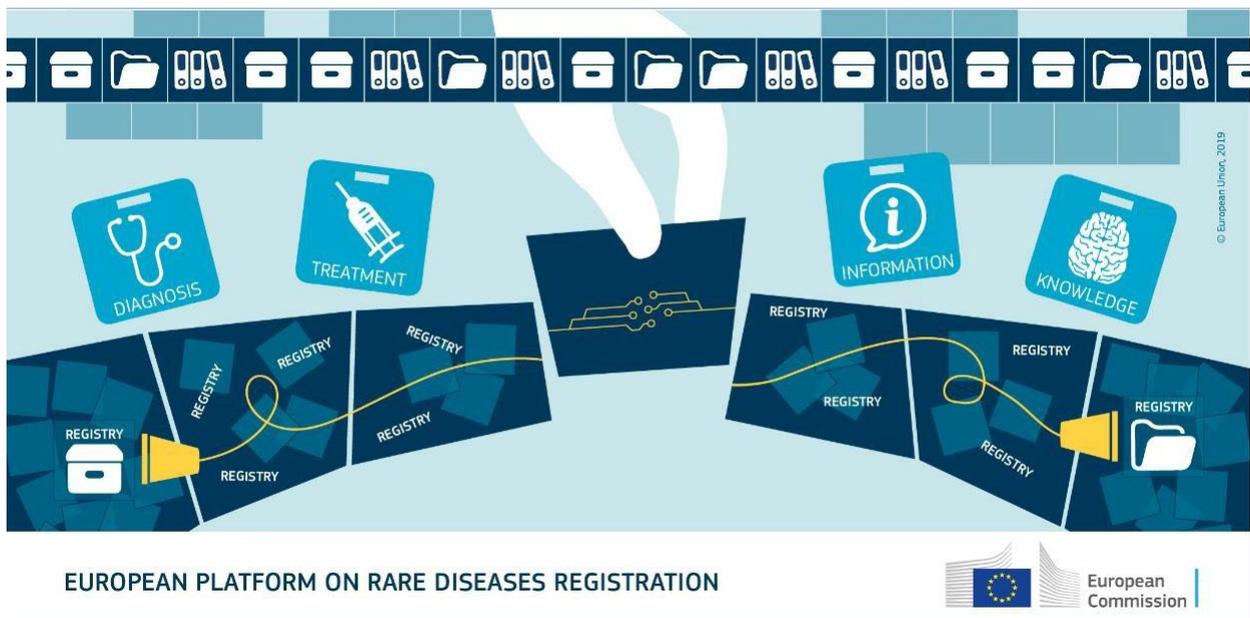




European Platform on Rare Disease Registration (EU RD Platform)

The European Rare Disease Registry Infrastructure (ERDRI)

ERDRI.mdr User Guide



User Documentation 4.0



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1 About this document

This document provides a guide to the users/contributors of the **Central Metadata Repository (ERDRI.mdr)** which is one of the main components of the [European Rare Disease Registry Infrastructure \(ERDRI\)](#), under the umbrella of the European Platform on Rare Disease Registration ([EU RD Platform](#)).

2 Aim of the system

The **Central Metadata Repository (ERDRI.mdr)** stores all data elements (metadata) of the participating registries including their denomination, definition, units of measurement and range. It provides the basis for ensuring semantic interoperability between Rare Disease (RD) registries.

3 User access to ERDRI.mdr

To become contributor to ERDRI.mdr a user needs to be “verified” according to the [ERDRI User Access Guide](#) and have introduced his/her registry’s information in the European Directory of Registries (ERDRI.dor) according to the [ERDRI.dor User Guide](#). Upon the completion of the ERDRI.dor entry, the ERDRI team will create a specific registry space in ERDRI.mdr. Verified users other than the registry owner can also be defined. Once these conditions are fulfilled, the user can access ERDRI.mdr at https://eu-rd-platform.jrc.ec.europa.eu/erdri_en by clicking in the appropriate box as in Figure 1.

4 Upload registry metadata

The screenshot shows the ERDRI access page with a blue header and a navigation menu. A status message indicates the user is logged in. Below the navigation menu, there are four main sections:

- 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. A red arrow points to this section.
- Search Broker (ERDRI.sebro)**: ERDRI.sebro allows researchers to retrieve metadata of interest.
- Pseudonymisation tool (ERDRI.spider)**: Service offering registries at local level the solution for patient pseudonymisation.

Figure 1. Access page of ERDRI.mdr



4.1 Upload registry metadata

In order to upload a registry's metadata in ERDRI.mdr please follow the following steps:

1. Go to "Search" menu, type the namespace of the registry for which you wish to add the metadata for and click on it.

The screenshot shows the ERDRI.mdr search results page. At the top, there is a navigation bar with 'Home', 'Search', and 'Help' links. Below the navigation bar, the text 'Showing 1 registry' is displayed. A search input field contains the text 'JRC d', with a red arrow pointing to it. To the right of the search field are three radio buttons: 'All registries' (selected), 'Filled registries', and 'Empty registries'. Below the search results, there is a card for the 'JRC' registry. The card includes the text 'Updated on 24/11/2023 | 22 elements | ERDRI', the 'JRC' logo, and the text 'JRC Central Authority' and 'JRC Rare Disease team, not belonging to any actual Rare Disease network.' To the right of the card are two buttons: 'Export' and 'History'.

Figure 2. Search section of ERDRI.mdr

There are three options to upload the metadata based on the type of software your registry is using:

- Upload an excel file based on the dedicated template provided in ERDRI.
- Upload a file exported from registries using Redcap as their registry software directly through the web interface.
- Send the data scheme output file from registry software (other than Redcap) to the ERDRI administrators at EU-RD-PLATFORM@ec.europa.eu (this is the case of a software that provides a structured type of output file for the registry's metadata elements).

2. Press the link with the text "Upload".

[European Commission](#) > [EU Science Hub](#) > [European Platform on Rare Disease Registration](#) > [ERDRI](#)

The screenshot shows the ERDRI.mdr 'Upload' button. At the top, there is a navigation bar with 'Home', 'Search', and 'Help' links. Below the navigation bar, the text 'ERDRI.mdr - Central Metadata Repository' is displayed. Below the text, there are two buttons: 'Upload' and 'Export Excel'. A red arrow points to the 'Upload' button.

JRC

Figure 3. Upload the Excel sheet



3. Click on "**Choose file**" and select the prefilled file from your computer with your metadata according to the dedicated template.
 - A) If your registry's software is "REDCap", you can upload your registry's metadata output csv file (converted to excel).
 - B) If your registry's software is a "non-REDCap", you have to fill in a dedicated excel template that you will be able to download from your namespace. You can also download the Set of Common Data Elements (CDS) as an example.

ERDRI.mdr - Central Metadata Repository

Home | Search | Help

Upload methods

You can upload your registry's **JRC** 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 XLSX file

Only Excel XLSX files

Choose file

• For all other registries: use the dedicated Excel structured file

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

Upload XLSX file

Only Excel XLSX files

Choose file

Figure 4. Choosing the file to upload according to whether your registry's software is REDCap or not

4. If the file you uploaded is "correct", according to the validation rules of the ERDRI.mdr, you will be able to save it and publish it by clicking on "**Publish changes**", or to discard the changes by clicking on "**Undo changes**".



ERDRI.mdr - Central Metadata Repository

[Home](#) | [Search](#) | [Help](#)



Draft

Changes to this registry are in Draft.

Undo changes

Publish



JRC

Figure 5. Publishing the registry's metadata in ERDRI.mdr namespace

If the “Excel file error” box appears (Figure 6), the uploaded data are visible only to you as a draft. The errors can be solved either through making changes on the source file. If it is not the first time you upload metadata on your namespace, you can download the excel file from your namespace, as explained in point 3 above.



ERDRI.mdr - Central Metadata Repository

[Home](#) | [Search](#) | [Help](#)



Excel file error

Close

ERR - en : row 8 - Variable 'dateOfBirth': invalid date format 'dd.MM.yyyy' at column 'Q'
ERR - en : row 8 - Variable 'dateOfBirth': invalid time format '(23.05.2019)' at column 'R'
ERR - en : row 22 - Variable 'dateOfdeath': invalid date format 'yyyy-MM-dd' at column 'Q'
ERR - en : row 25 - Variable 'firstContactWithSpecializedCentre': invalid date format 'dd.MM.yyyy' at column 'Q'
ERR - en : row 25 - Variable 'firstContactWithSpecializedCentre': invalid time format '(23.05.2019)' at column 'R'
ERR - en : row 33 - Variable 'dateOfManifestationAgeAtOnset': invalid date format 'yyyy-MM-dd' at column 'Q'
ERR - en : row 39 - Variable 'dateOfManifestationAgeAtDiagnosis': invalid date format 'yyyy-MM-dd' at column 'Q'

Figure 6. Excel file error box

4.2 View and edit your registry's metadata

4.2.1 View your registry's metadata

In order to vision your registry's entry of the metadata please go to "Search" in the main ERDRI.mdr page menu, click your registry's space and the new registry data will be displayed, as in Figure 2.



[European Commission](#) > [EU Science Hub](#) > [European Platform on Rare Disease Registration](#) > [ERDRI](#)

ERDRI.mdr - Central Metadata Repository

[Home](#) | [Search](#) | [Help](#)

[Upload](#) [Export Excel](#)

JRC

Figure 7. Export registry from ERDRI.mdr

4.2.2 Edit your registry's metadata

In order to edit your latest version of your registry's metadata, you can export and upload it again (Figure_8), or use ERDRI.mdr web interface.

If you choose to edit the metadata through the web interface, please scroll down and click on **"Edit"**. In case of doubts on how to fill the different fields, hovering over with the mouse on the symbol  will provide you with indications of what is expected in each field.

[European Commission](#) > [EU Science Hub](#) > [European Platform on Rare Disease Registration](#) > [ERDRI](#)

ERDRI.mdr - Central Metadata Repository

[Home](#) | [Search](#) | [Help](#)

[Upload](#) [Export Excel](#)

JRC

JRC Central Authority

JRC Rare Disease team, not belonging to any actual Rare Disease network.

- This registry contains 23 elements
- Current version updated on 29/11/2023 by Arianna Galli
- [Descriptive information in ERDRI.dor](#)

[+ Add Variable](#) [+ Add Group](#)

  Variable group: One-time | 1 element

Pseudonym

Patient's pseudonym

1 validation rule [+ Show](#)

[+ Add Variable](#) [+ Add Group](#) [≡ Move](#) [✎ Edit](#) [🗑 Delete](#)

Figure 8. Edit metadata using ERDRI.mdr web-interface



5 Getting Support F.A.Qs and videos

Under the “Help” menu as indicated in Figure 9 you will find Instructions that include this guide and a [video](#) explaining how to fill in the excel template, a link to the [F.A.Qs section](#) and a support form link (Figure 10).

[European Commission](#) > [EU Science Hub](#) > [European Platform on Rare Disease Registration](#) > [ERDRI](#)



Figure 9. Help menu in ERDRI.mdr

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

For any further questions you may have regarding ERDRI.mdr, please contact us at: EU-RD-PLATFORM@ec.europa.eu