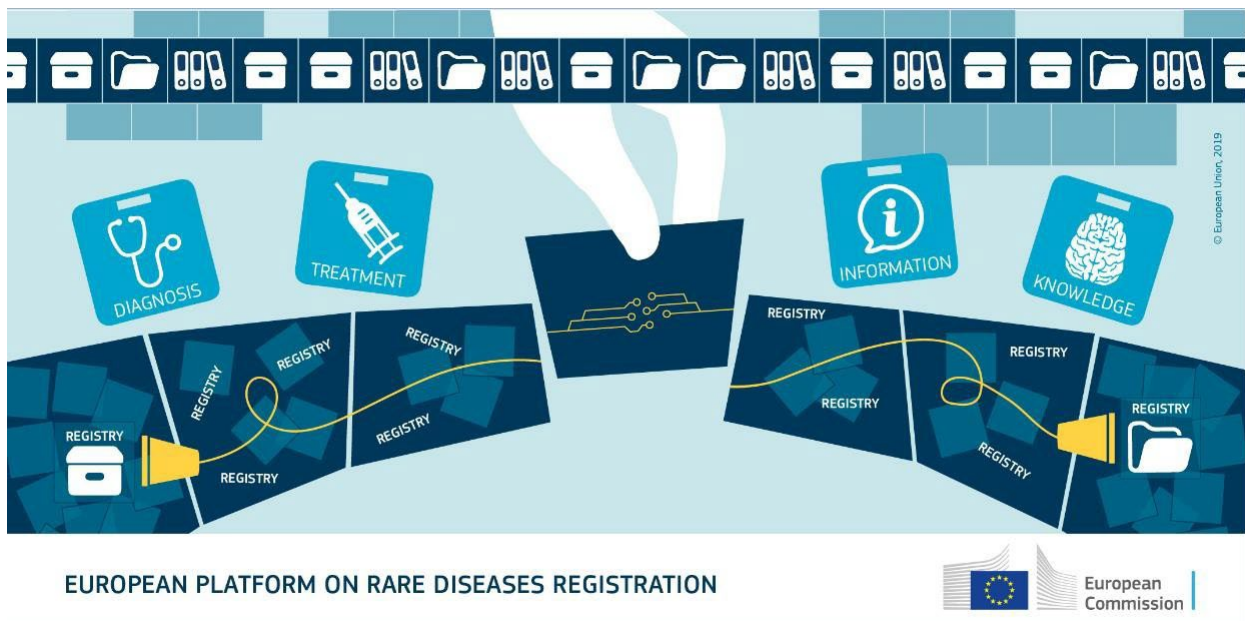




European Platform on Rare Disease Registration (EU RD Platform)

The European Rare Disease Registry Infrastructure (ERDRI)

ERDRI.mdr User Guide



User Documentation 3.0



Table of Contents

1	About this document.....	3
2	Aim of the system.....	3
3	User access to ERDRI.mdr	3
4	Upload registry metadata	3
4.1	Upload registry metadata	4
4.2	View and edit your registry's metadata	7
4.2.1	View your registry's metadata	7
4.2.2	Edit your registry's metadata	8
5	Getting Support F.A.Qs and videos	8

Table of Figures

<i>Figure 1.</i>	<i>Access page of ERDRI.mdr.....</i>	<i>3</i>
<i>Figure 2.</i>	<i>Search section of ERDRI.mdr</i>	<i>4</i>
<i>Figure 3.</i>	<i>Upload the Excel sheet</i>	<i>5</i>
<i>Figure 4.</i>	<i>Choosing the file to upload according to whether your registry's software is Redcap or not</i>	<i>6</i>
<i>Figure 5.</i>	<i>Publishing the registry's metadata in ERDRI.mdr namespace</i>	<i>6</i>
<i>Figure 6.</i>	<i>Excel file error box</i>	<i>7</i>
<i>Figure 7.</i>	<i>Download registry from ERDRI.mdr</i>	<i>7</i>
<i>Figure 8.</i>	<i>Edit metadata using ERDRI.mdr web-interface</i>	<i>8</i>
<i>Figure 9.</i>	<i>Help menu in ERDRI.mdr</i>	<i>8</i>
<i>Figure 10.</i>	<i>Technical support assistance form</i>	<i>9</i>



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 (European Rare Disease Registry Infrastructure) access page. At the top, there is a navigation bar with the ERDRI logo and a breadcrumb trail: European Commission > EU Science Hub > European Platform on Rare Disease Registration > ERDRI. Below the navigation bar, there are tabs for 'View', 'Edit', 'Delete', 'Revisions', and 'Translate'. The main content area is titled 'European Rare Disease Registry Infrastructure (ERDRI)' and contains four main components:

- European Directory of Registries (ERDRI.dor)**: Overview of rare disease registries in Europe including their characteristics. The image shows a bookshelf.
- Central Metadata Repository (ERDRI.mdr)**: Data containing the data elements used by rare disease registries. The image shows a person holding a tablet with various icons. A red arrow points from this component to the SPIDER component.
- SPIDER**: Pseudonymisation tool (ERDRI.spider). Service offering registries at local level the solution for patient pseudonymisation. The image shows a stylized spider logo.
- Search Broker (ERDRI.sebro)**: ERDRI.sebro allows researchers to retrieve metadata of interest. The image shows a hand holding a tablet with a glowing globe.

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 website interface. At the top, there is a navigation bar with the following links: European Commission > EU Science Hub > European Platform on Rare Disease Registration > ERDRI > MDR. Below this is a blue header with the text "ERDRI.mdr - Central Metadata Repository" and three menu items: Home, Search, and Help. The main content area displays "Showing 1 registry" and a search result for "Registry 1". A red arrow points to the search result. Below the search result, there is a summary box containing the text "Registry | Updated on 19/04/2023 | 3 elements" and a link to "Registry 1". At the bottom of the page, there is a pagination bar with the text "< Previous page", a circled "1", "Next page >", and a dropdown menu showing "10".

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 excel**".



ERDRI.mdr - Central Metadata Repository

Home Search Help

[Download registry](#) [Upload excel](#)

Registry 1

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 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.
 - B) If your registry's software is "REDCap", you can upload your registry's metadata output csv file (converted to excel).



ERDRI.mdr - Central Metadata Repository

Home Search Help

Excel upload

You can change the metadata of the registry [Registry 1](#) by uploading an Excel file.

You can download the template [here](#) and, as an example, the set of [Common Data Elements \(CDS\)](#).

Using the dedicated XLSX template

Upload your registry's metadata

Only Excel XLSX files

Choose file



Using the data scheme output file from Redcap software

Upload redcap file

Only Excel XLSX files

Choose file



Using data scheme output files from other registry software solutions

Please contact the ERDRI team to discuss this possibility at EU-RD-PLATFORM@ec.europa.eu

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

- 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 changes



Registry 1

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.



ERDRI.mdr - Central Metadata Repository

Home Search Help

 Download registry  Upload excel


Registry 1

Figure 7. Download 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 download 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.

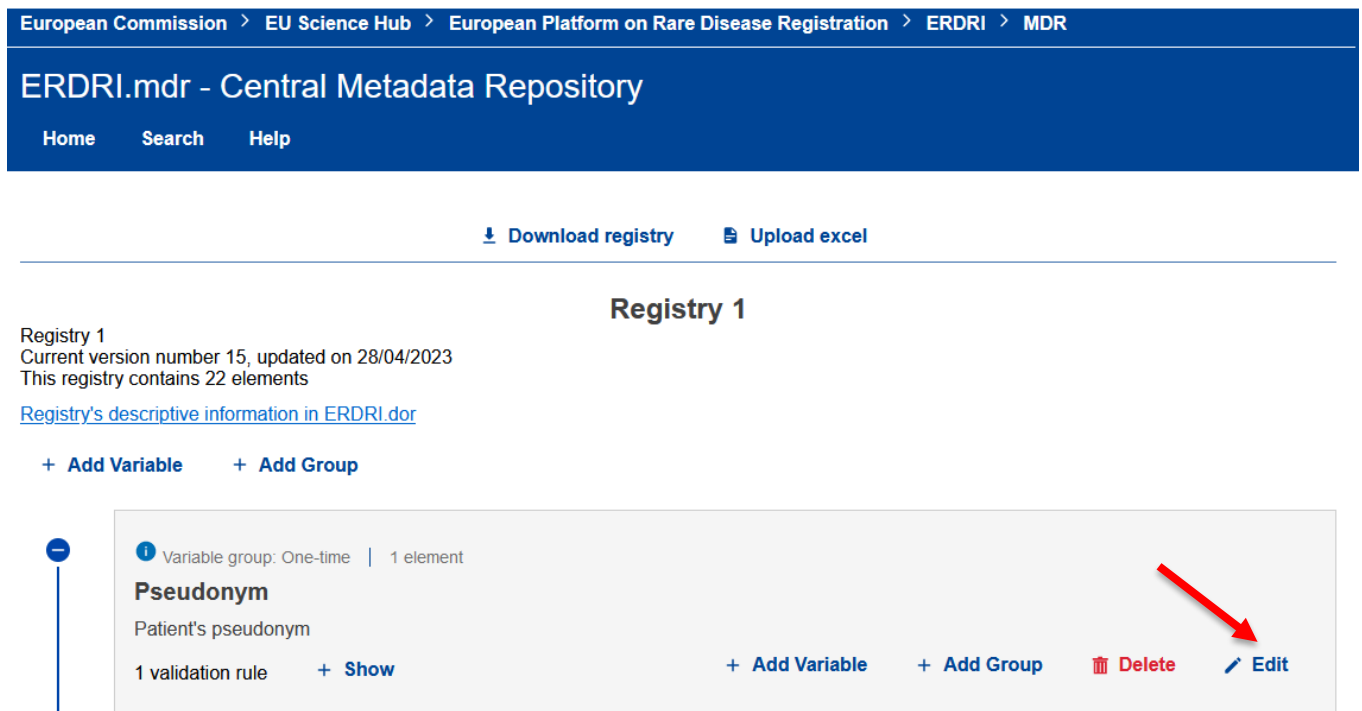


Figure 8. Edit metadata using ERDRI.mdr web-interface

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).



Figure 9. Help menu in ERDRI.mdr



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

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