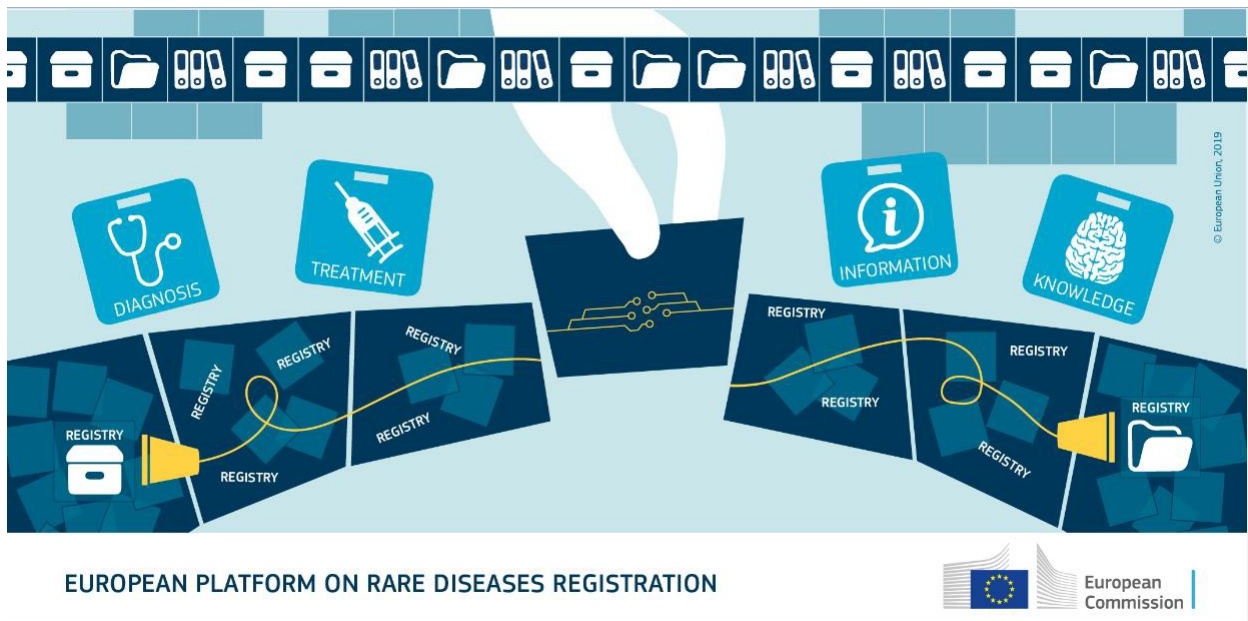# European Platform on Rare Disease Registration (EU RD Platform)

The European Rare Disease Registry Infrastructure (ERDRI)

ERDRI.mdr User Guide

EUROPEAN PLATFORM ON RARE DISEASES REGISTRATION

© European Union, 2019

User Documentation 2.0

Table of Contents

Table of figures

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 ERDRI.dor according to the ERDRI.dor User Guide. Upon completion of the ERDRI.dor entry, ERDRI managers 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

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:

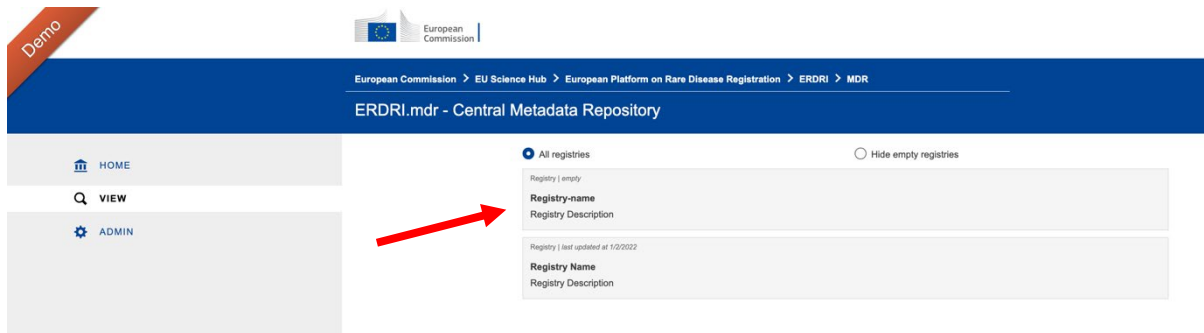1. Go to View menu and click the registry where you want to add the metadata

Figure 2. View section of ERDRI.mdr

There are three options to upload the metadata:
- 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 .

For this example, we choose the option of using the dedicated **excel file**:
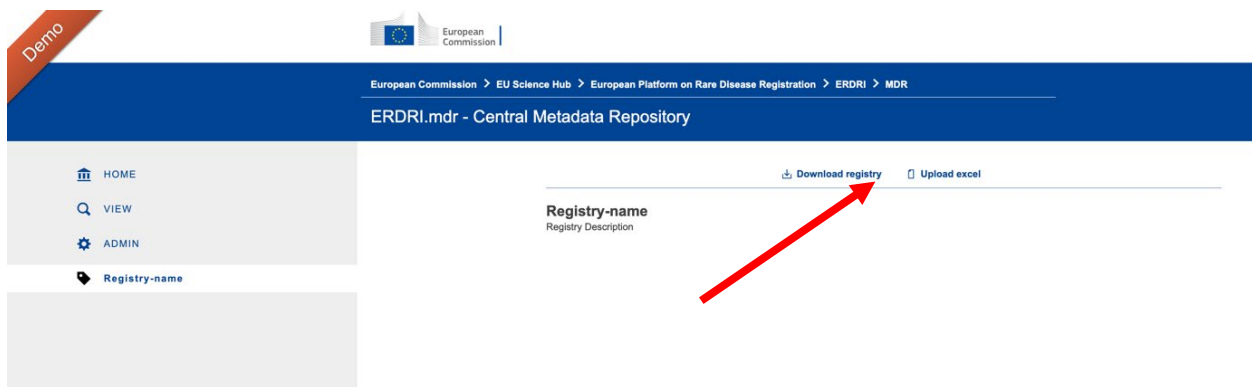
2. Press the link with the text **"upload excel"**

Figure 3. Upload excel

2. Click on **"Choose file"** and select the prefilled file from your computer with your metadata according to the dedicated template.
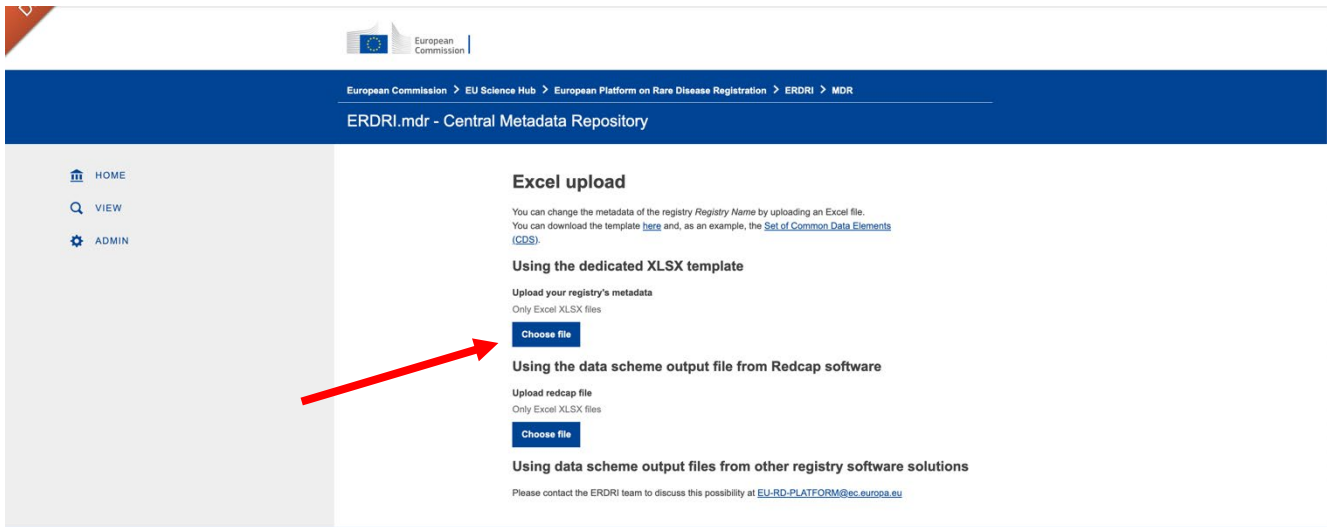
Figure 4. Choose file

3. After uploading the file, you will see the message **"Excel upload result"**. At this stage you can preview your registry's uploaded data elements (Figure 5) and you have the opportunity to check them. If any errors can be detected by the system you will be informed through a message.
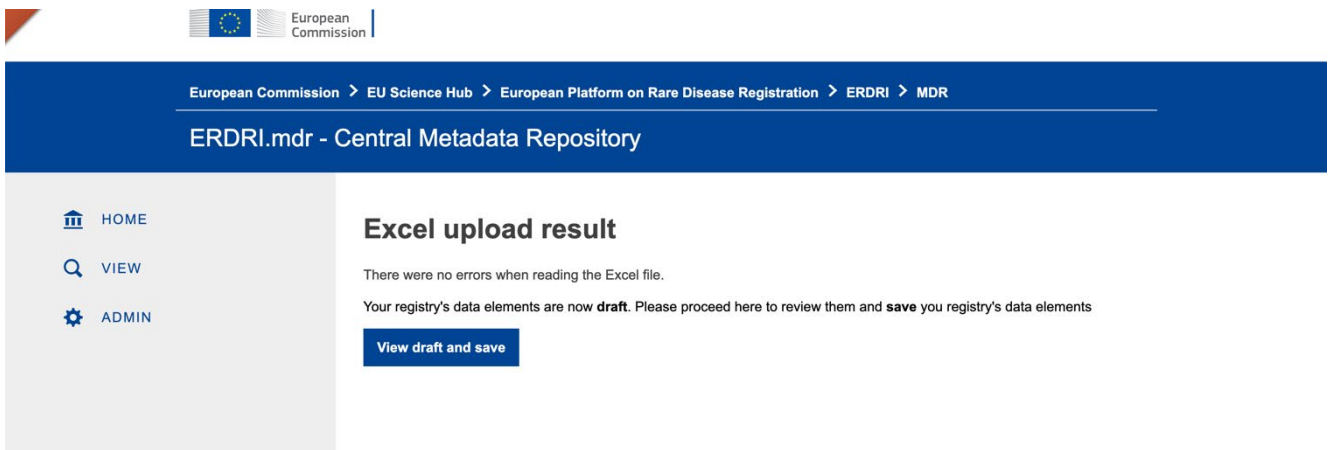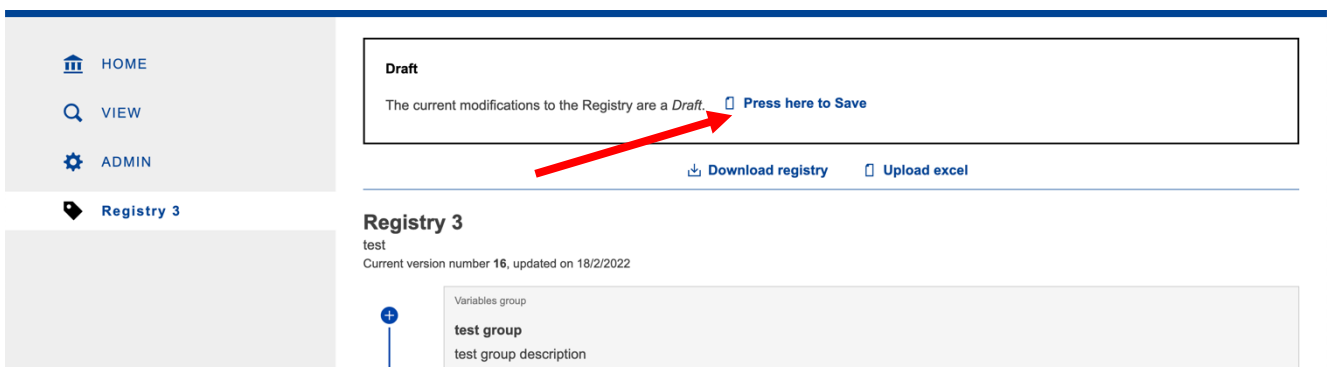

Figure 5. Upload excel result message

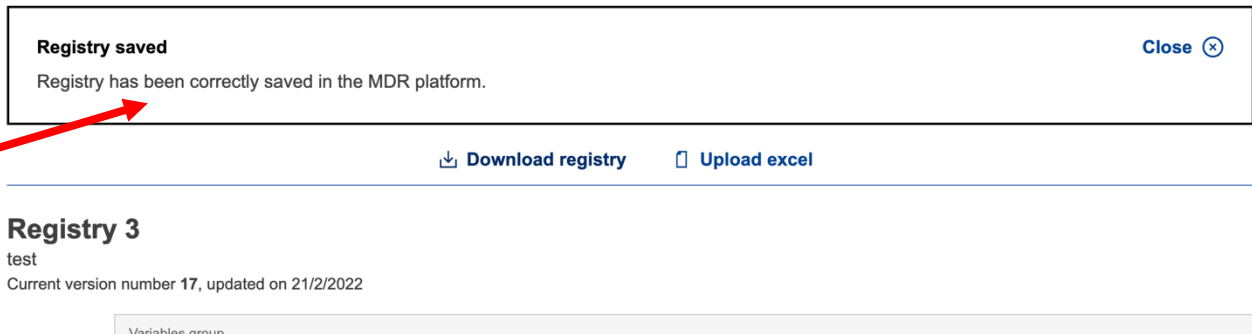4. You will then be prompted to click on **"Press here to Save"** and a confirmation message will appear (Figure 6**).**

Figure 6. *Saving the registry in ERDRI.mdr and confirmation message.*

4.2 View, edit or modify your registry's metadata

In order to vision your registry's entry of the metadata please go to **"View"** in the main ERDRI.mdr page menu, click your registry's space and the new registry data will be displayed as in Figure 2. View section of ERDRI.mdr. In case you wish to modify any element from your registry or add new elements or remove any, please do this offline on your computer and upload your new excel sheet explained in 4.1. Every time a new sheet is uploaded a new version is created and only the latest version is published.

4.3 Demo / training area

ERDRI.mdr offers the possibility to access a **demo/training** section (ERDRI.mdr demo) from the main ERDRI.mdr page, by clicking on "ERDRI.mdr demo instance" as indicated in Figure 7**.** In this section, the already "verified" users can access the system in a dedicated test registry area before uploading the registry's metadata in the production ERDRI.mdr.

EUROPEAN COMMISSION
JOINT RESEARCH CENTRE

Directorate F - Health, Consumers and Reference Materials
F.1 Health in Society

🎧 Log in

European Commission

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

ERDRI.mdr - Central Metadata Repository

ERDRI.mdr serves to ease the integration of heterogeneous data from different rare disease registries. For this purpose, it contains a collection of metadata which specifies the used data elements of a registry including the designation of the used data elements, their definition and units of measurement. The more registries define their data elements in a comprehensible way and use identical data definitions, the easier it is to use these data for overarching studies and research questions.

In the long term the harmonisation of used data elements and data structures in existing and upcoming registries is aimed at. The use of the "Set of common data elements for rare diseases registration" by each registry is a first step towards this objective and the interoperability of rare disease registries.

Before entering data you are strongly advised to make yourself familiar with the ERDRI.mdr environment. You can do so at the ERDRI.mdr demo instance, which can be accessed with the same credentials as the production ERDRI.mdr.

European Platform on Rare Disease Registration

Terms of use

Privacy statement
Contact

Figure 7. Demo/training area.

5 Contact and technical assistance

For any further questions you may have regarding ERDRI.mdr, please contact us at: EU-RD-PLATFORM@ec.europa.eu or through the ERDRI support form as shown in Figure 8. You can also consult the frequently asked questions section.

Figure 8. Technical support assistance form.