EUROPEAN COMMISSION
JOINT RESEARCH CENTRE

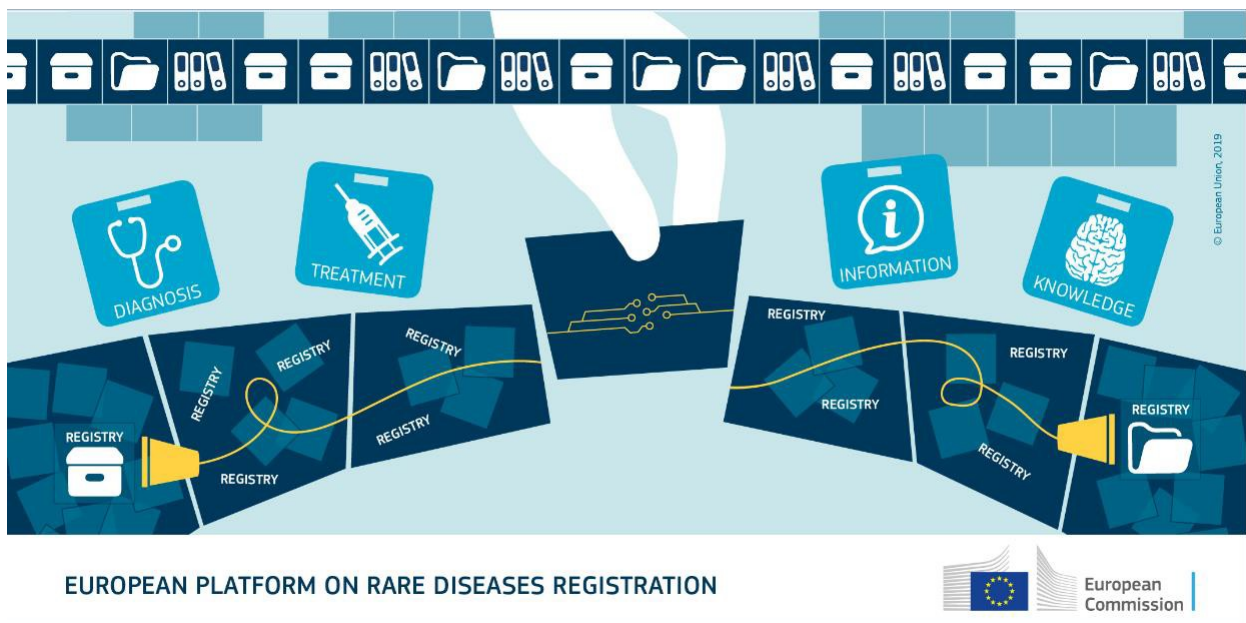Directorate F - Health, Consumers and Reference Materials
F.1 Health in Society

European Platform on Rare Disease Registration (EU RD Platform)

The European Rare Disease Registry Infrastructure

ERDRI User Access Guide

EUROPEAN PLATFORM ON RARE DISEASES REGISTRATION

© European Union, 2019

User Documentation 2.0

Table of Contents

1   About this document

This documentation provides a guide for the different user cases on how each type of user can access the European Rare Disease Registry Infrastructure (ERDRI) and in particular its tools.

https://eu-rd-platform.jrc.ec.europa.eu/erdri-description

2   Aim of the system

The European Rare Disease Registry Infrastructure (ERDRI) is part of the EU RD the Platform. Through ERDRI RD patient data will become searchable and findable largely thanks to the informatics tools it provides. ERDRI's three main components are:

- **European Directory of Registries (ERDRI.dor):** ERDRI.dor provides an overview of the ERDRI participating registries with their main characteristics and description.
- **Central Metadata Repository (ERDRI.mdr):** ERDRI.mdr ensures semantic interoperability between RD registries. It has the task to store all definitions of used data elements (metadata) of the participating registries. Metadata describe the meaning of structured data elements.
- **Pseudonymisation Tool: The Pseudonymisation tool** is provided to all ERDRI participating registries

In this document access instructions to these components for each user case are provided.

3   User access and functions

Users can access different parts of ERDRI within the EU RD Platform according to the workflow outlined in figure 1.
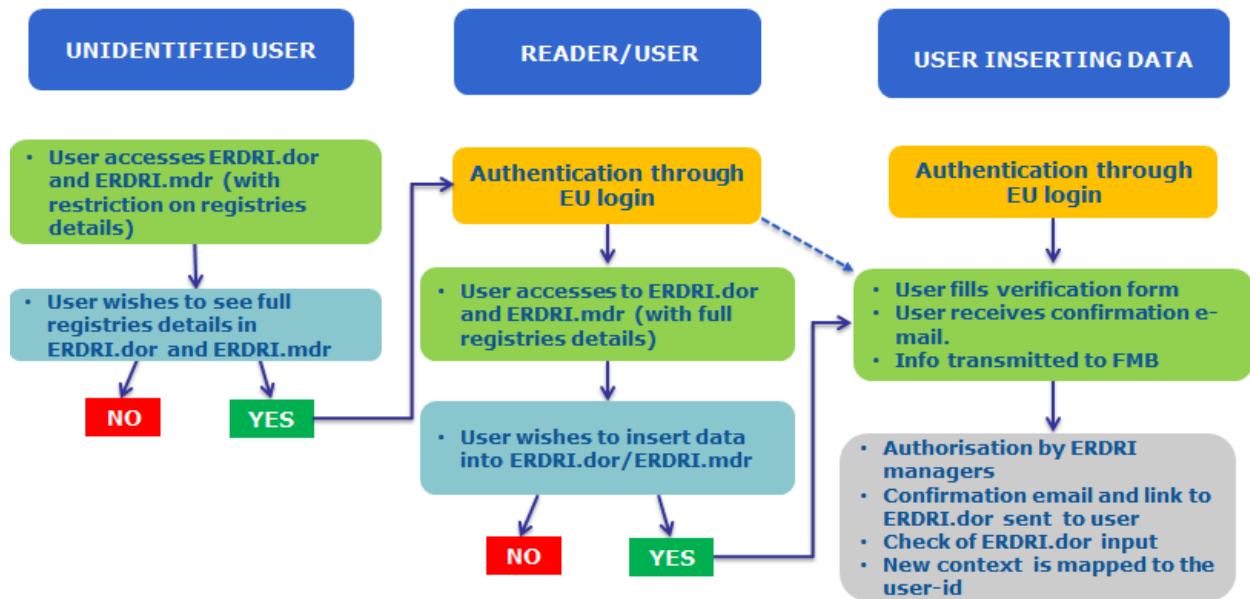
Figure 1. ERDRI user case workflow

Figure 2 shows the main access page is shown through which ERDRI can be accessed.

Figure 2. Accessing ERDRI through the main EU RD Platform page

The Terms of Use should be accepted by each user according to the screen below (figure 3).

Figure 3. ERDRI Terms and Conditions screen

3.1. Unidentified Users

According to this workflow ***unidentified users*** are able to consult those parts of the EU RD Platform that do not require authentication or verification. This means that they have access to the ERDRI.dor registry list of all registries or search results in ERDRI.dor but with limited information about each registry. This information is accessible by clicking on the "Browse anonymously" button as indicated in figure 3. Users wishing to consult full details of these registries can do so by becoming "authenticated users" (Section 3.2. of this document).

3.2. Authenticated Users

A user wishing to consult ERDRI.dor for the list of registries and full description of these registries or a single registry and ERDRI.mdr for browsing the existing registry metadata (***reader/user***) and ERDRI.mdr collection of meta data from the participating registries.
To become an authenticated user you need to have an EU login account. You will be asked to enter your EU login credentials as indicated in figure 4.

Figure 4. Entering credentials (EU-login)

In case you do not possess already an EU-login you can create one by accessing the "About EU-login" page on the bottom of the same page (figure 5).
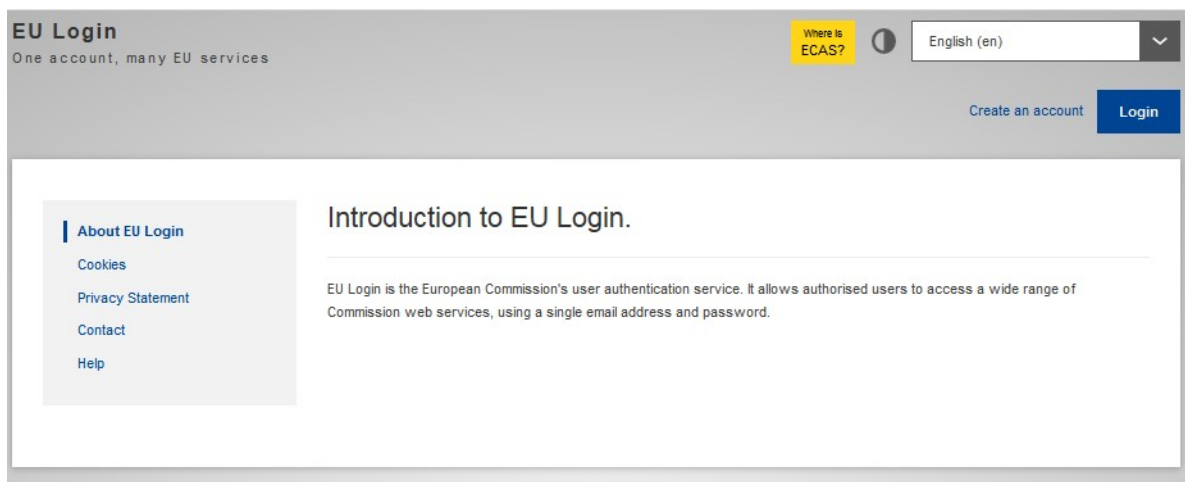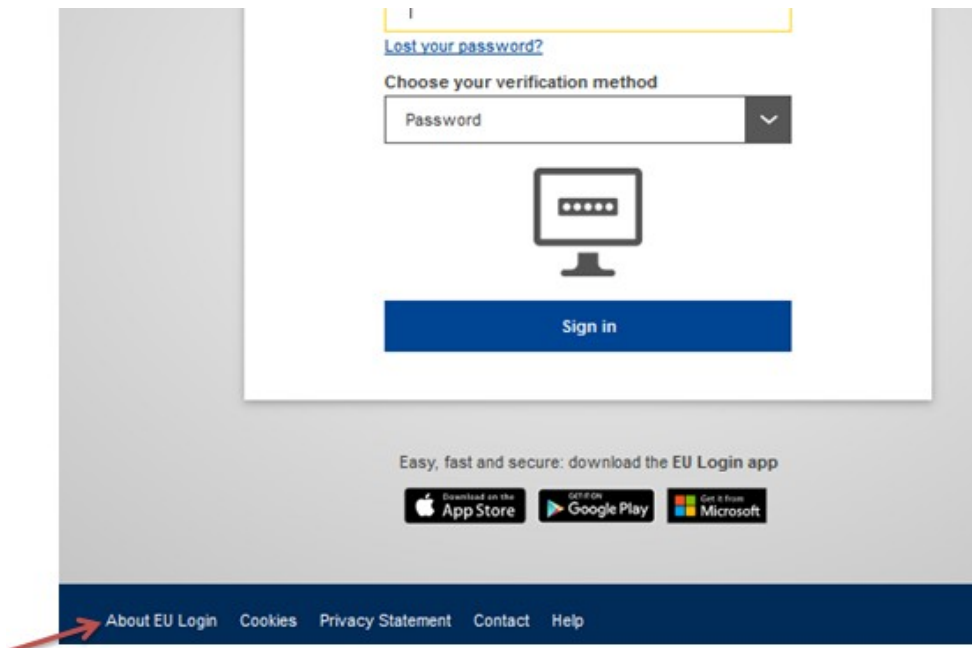
Figure 5. EU login information and creation page

3.3.   Verified Users

Verified Users are those contributing with information about their registries. They will be able to insert registry information in ERDRI.dor and the meta data information of their registry into ERDRI.mdr (please consult ERDRI.dor and ERDRI.mdr User Documentation for instructions on how to use these tools).

Furthermore, access to the pseudonymisation tool is granted only to authorised and verified users whose registries have already completed their entries in ERDRI.dor (descriptive data) and ERDRI.mdr (metadata). More than one verified user request access to the pseudonymisation tool per registry.

To become a verified user and use the pseudonymisation tool https://eu-rd-platform.jrc.ec.europa.eu/verification-form (figure 6).

Figure 6. Contact form for becoming a verified user

4   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 in each of the tools https://eu-rd-platform.jrc.ec.europa.eu/erdri/support/ (figure 7).

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*

What code is in the image?

Enter the characters shown in the image.

Preview   Submit

European Platform on Rare Disease Registration   Contact
          Privacy statement

Figure 7. Technical support assistance form