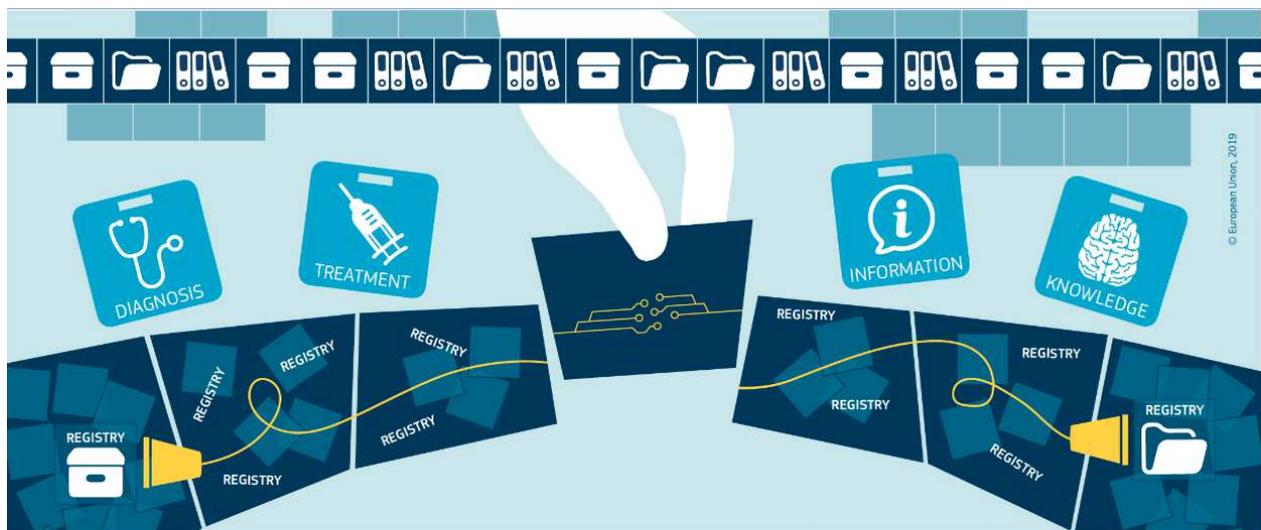




# European Platform on Rare Disease Registration (EU RD Platform)

## The European Rare Disease Registry Infrastructure

### ERDRI.mdr – The ERDRI Metadata Repository



EUROPEAN PLATFORM ON RARE DISEASES REGISTRATION



## User Documentation 1.0



## Table of Contents

1	Preface.....	3
2	Access to ERDRI.mdr .....	3
3	Namespace.....	3
4	Processing of Namespaces.....	3
4.1.	Creating a new data element .....	4
	Definitions .....	5
	Validation .....	5
	Slots .....	11
	Verification .....	12
4.2.	Modification of Data Elements.....	14
4.3.	Aggregation of Data elements.....	15



## 1 Preface

This documentation describes how to work with the ERDRI Metadata Repository (ERDRI.mdr). Graphical examples are used to explain creating a namespace and adding data elements in ERDRI.mdr.

## 2 Access to ERDRI.mdr

The user reaches ERDRI.mdr via a web browser at <https://eu-rd-platform.jrc.ec.europa.eu/mdr/>. By clicking on "Login" you will be redirected to the EU login page. You have to register on the ERDRI platform to upload or amend data.

## 3 Namespace

A namespace in the ERDRI.mdr corresponds to a personal workspace. Within ERDRI, the namespace represents the respective location. Individual namespaces have already been created for all registered users, in which the local data elements and their metadata can be entered and maintained.

## 4 Processing of Namespaces

Depending on the authorisation, a namespace can be edited. For this purpose select the respective namespace and click on "Edit".

Afterwards you can edit the designation(s) as well as the definition(s) of the namespace as required.

Home New Select a namespace My drafts View Search About

### ERDRI – Permissions

Edit Namespace

1 Definitions 2 Permissions 3 Constraints 4 Verification

Michael Folz <folz@med.uni-frankfurt.de> read, write, admin Remove

#### Add new permission

read Add

Cancel Previous Next



Clicking on the „Next“ button, the user will be redirected to access the Permissions view, which lists all users who have read and/or write access to the namespace. New users can also be added here by entering parts of the name or email into the marked field and choosing the authorisation "read", "read, write" or "read, write, admin". Only users with "admin" permission can edit the namespace's permissions, and edit, delete or release data elements of this namespace.

Next, one can define constraints for a namespace. The defined specifications, like required languages and required slots will be mandatory then, when you create a new data element. The shown example depicts that a description of the element in German as well as the slots UCT\_STUDREG\_VARNAME and CENTRAXX\_EXPORT always have to be defined. If this information is missing when entering or editing a data element, a corresponding error message will be displayed.

Finally, all defined settings are summarised in the verification view and can be checked. With "Finish" all changes are finally accepted and saved.

#### 4.1. Creating a new data element

To specify a dataset, its data elements have to be created via the tab "New" → "New Dataelement".



## Definitions

The name of the data element is entered in the designation field. The field "Definition" briefly describes the data element. The aim should be to provide concrete and detailed information. The language of the data element is determined in the bottom field (English, German, Spanish, French). Last, Click „Next“-Button.

## Validation

In the next window the properties of the data element can be specified. A distinction is made between the validation types List of permitted values, Integer, Float, Boolean, String, Date, Time, Date time and catalogs, which are described in detail below:

- **List of permitted values** (self-defined values)

This datatype allows defining a list of possible values of the data element. The values can then be specified, e.g.:



## A simple Test Element – Validation

New Dataelement

1 Definitions 2 Validation 3 Slots 4 Verification

Validationtype

List of permitted values

Permitted value

1 Remove

Designation

Test Value 1

Definition

Thorough description of test value 1

Language

English Remove

Add another definition

Add another permitted value

Cancel Previous Next

With "Add another definition", you can optionally create further definitions for the value (usually in other languages, e.g. German). Use "Add another permitted value" to add the remaining values. Click on "Next" to continue with the creation of the data element.

- **Float** (floating point values)
- **Integer** (whole numbers)

A range can be defined for float and integer values. The unit of the value can also be specified.



## A simple Test Element – Validation

New Dataelement

1 Definitions 2 Validation 3 Slots 4 Verification

Validationtype

Integer ▼

Within range

Lower bound  0

Upper bound  100

Unit of measure

Cancel Previous Next

- **Boolean** (datatype with two possible values: true or false)  
No further settings need to be made for boolean values.



## A simple Test Element – Validation

New Dataelement

1 Definitions 2 Validation 3 Slots 4 Verification

Validationtype

Boolean

Cancel

Previous

Next

- **Date (Date)**

Date formats, like ISO 8601 or DIN 5008, can be selected for date values. You also have to define whether the date should be precise to the day or the month.

## A simple Test Element – Validation

New Dataelement

1 Definitions 2 Validation 3 Slots 4 Verification

Validationtype

Date

Date representation

The local date format

The local date format

YYYY-MM-DD, YYYY-MM (ISO 8601)

DD.MM.YYYY, MM.YYYY (DIN 5008, ...)

Cancel

Previous

Next

- **Time (Time)**

If the value of a data element is representing a time, the format and the accuracy (only minutes or seconds) have to be specified.



## A simple Test Element – Validation

New Dataelement

1 Definitions 2 Validation 3 Slots 4 Verification

Validationtype

Time

Time representation

The local time format

The local time format

The 24 hours time format (22:34:54, 22:34)

The 12 hours time format (11:34:54 PM, 11:34 PM)

Cancel Previous Next

- **Datetime** (date and time)

This validation type is for data elements to representing an exact point in time (combination of date and time).



## A simple Test Element – Validation

New Dataelement

1 Definitions 2 Validation 3 Slots 4 Verification

Validationtype

Datetime

Date representation

YYYY-MM-DD, YYYY-MM (ISO 8601)

Time representation

The 24 hours time format (22:34:54, 22:34)

With seconds

Cancel Previous Next

- **String** (free text)

For string values, one can specify a maximum length of characters. In addition, a regular expression (Regex) can be defined to check subsequent input using syntactic rules.



## A simple Test Element – Validation

New Dataelement

1 Definitions 2 Validation 3 Slots 4 Verification

Validationtype

String

Max length

0

Use Regex

Regex

`^[A-Z]\d{2}(\.\d){0,1}$`

Cancel Previous Next

### Slots

In the next step slots so-called key-value pairs can be defined. This means one can define attributes that were not provided on the previous screens, but are still necessary in certain application scenarios. Slots set as constraints in a namespace are already displayed and have to be specified. However, additional slots can also be defined.

**Important:** „Slots" are not interpreted further by ERDRI.mdr, but merely stored as additional information about a data element.



## A simple Test Element – Slots

New Dataelement

1 Definitions 2 Validation 3 Slots 4 Verification

Name	Value	
<input type="text" value="some_external_id"/>	<input type="text" value="&lt;id&gt;"/>	<a href="#">Remove</a>
<input type="text" value="data_source"/>	<input type="text" value="external registry"/>	<a href="#">Remove</a>
<input type="button" value="Add another slot"/>		

[Cancel](#) [Previous](#) [Next](#)

With a click on "Next", you get to a summary page.

### Verification

Here all entered data are summarised again. An identifier is allocated to the data element and the revision (1 if newly created) is displayed. Finally, the data element can be assigned to an existing namespace.



## A simple Test Element – Verification

New Dataelement

1 Definitions 2 Validation 3 Slots 4 Verification

Language	Designation	Definition
EN	A simple Test Element	test

### Validation

Validationtype

String

Max length

0

Use Regex

Regex

^[A-Z]\d{2}(\.\d){0,1}\$

### Slots

Name	Value
some_external_id	<id>
data_source	external registry

### Identification

Identifier \*

1

Revision \*

1

Namespace \*

erdri : ERDRI, The default ERDRI namespace

Cancel Previous Finish as draft Finish and release

There are now two alternatives for saving the element. (1) „Finish as draft“ or (2) „Finish and



release“:

1. If further changes are necessary or if another person has to check the data element, these should be saved as "Finish as draft" first. This draft - and all other data elements in this state - can be displayed at any time on the "My drafts" tab.
2. Via "Finish and release" the data element is saved and released afterwards. All data elements that have been released can be displayed via the "View" tab and clicking on the corresponding namespace. Also note, that some properties can no longer be changed ("Validation" step). **In the event of an incorrect entry, the data element has to be deleted and recreated.**

Due to the conditions mentioned in the two points above, we strongly recommend saving ALL data elements / data element groups as drafts first!

## 4.2. Modification of Data Elements

After a data element has been released, editing of the data element is only possible to a limited extent. With "Edit this element" you can edit the descriptions of the data element and the slots.

Home New Select a namespace My drafts View Search About

# A simple Test Element Released

test

urn:erdr:data

Revisions Edit

- Edit this element
- Use this element as template
- Delete element
- Import into my namespace
- test : Test Namespace
- Misc.
- Find other representations
- Duplicate this element
- Export this element

Validation

Validationtype

String

Max length

0

Use Regex

Regex

Slots

Name	Value
data_source	external registry
some_external_id	<id>



To change the validation type, a new data element has to be created. The function "Use this element as template" can be used for this purpose. A new data element will be created, in which case the individual fields are prefilled with the specifications of the original data element and only the necessary adjustments have to be made.

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

The ERDRI Metadata Repository (MDR)

Home New Select a namespace My drafts View Search About

## A simple Test Element Released

test

urn:erdri:data

Validation

Validationtype

String

Max length

0

Use Regex

Regex

`^[A-Z]d{2}(\.d){0,1}$`

Slots

Name	Value
data_source	external registry
some_external_id	<id>

Revisions Edit

- Edit this element
- Use this element as template**
- Delete element

Import into my namespace

test : Test Namespace

Misc.

- Find other representations
- Duplicate this element
- Export this element

### 4.3. Aggregation of Data elements

The more data elements are created in a namespace, the more difficult it can be to keep an overview of them. To simplify, data elements can be structured hierarchically by creating data element groups. This is done in the same way as for data elements, where a designation and definition can be defined and finally the desired data elements can be stored in it. The hierarchy can be of any depth, i.e. data element groups can also be nested into each other. However, it is important that all data elements, which should be combined into a data element group, have to exist before the data element group is created or edited. Thus, the elements can be dragged and dropped into the group. This also applies to groups to be nested, whereby subgroups can still be filled with data elements later.

**Please note:** To complete the creation of a group, the specified slots (see Constraints) have to



be filled in. The slots can be removed using the remove button, but in this case, an error message appears when trying to save the group. Even if the slots are not relevant for the groups, they need to be filled. Instead of values, a placeholder, e.g. "-", can be entered.

Home New Select a namespace My drafts View Search About

## Definitions

New Dataelementgroup

1 Definitions 2 Members 3 Slots 4 Verification

**Designation**  
A Test Group

**Definition**  
This will only contain one element

**Language**  
English Remove

Add another definition

Cancel Previous Next

Home New Select a namespace My drafts View Search About

## A Test Group – Assign members and subgroups

1 Definitions 2 Members 3 Slots 4 Verification

View Search Search results Starred

Show / Hide Namespaces

**Filter**  
Registry

My namespaces

**erdri : ERDRI**

**test : Test Namespace**

Other namespaces

**example : Example**

**Browse**

A simple Test Element  
test um:erdri:dataelement:1:1

Cancel Previous Next