



European Platform on Rare Disease Registration (EU RD Platform)

The European Rare Disease Registry Infrastructure (ERDRI)

ERDRI.spider User Guide

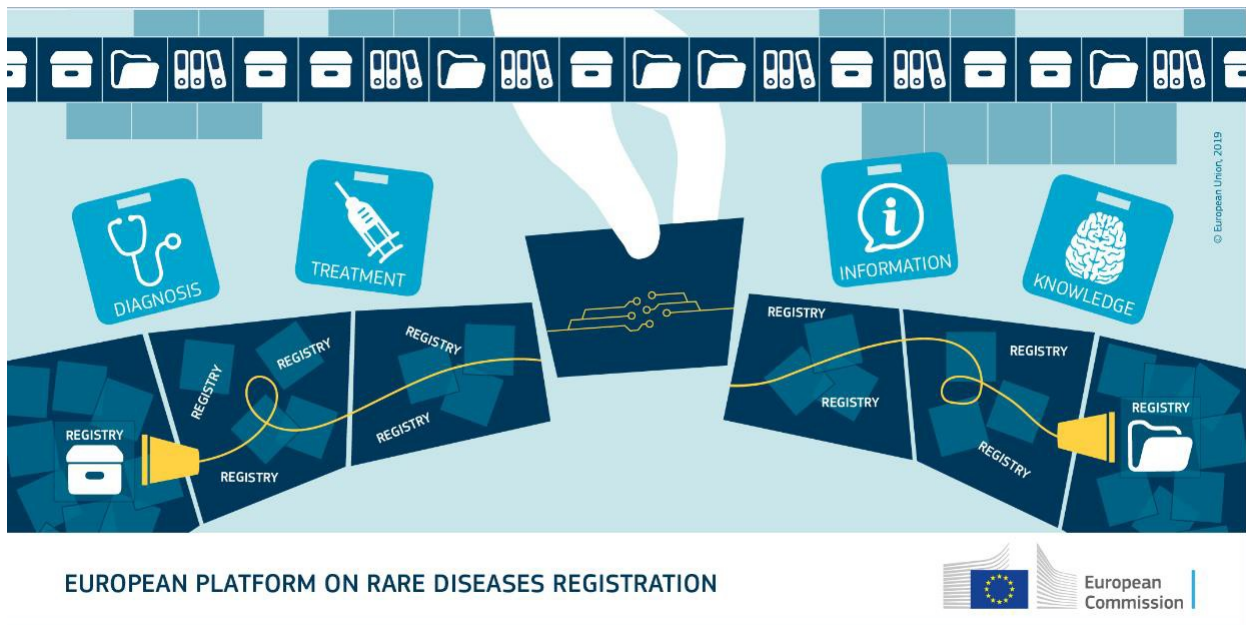




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1 About this document

This document provides a guide to the users of the **SPIDER pseudonymisation tool (ERDRI.spider)** 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 SPIDER pseudonymisation tool (ERDRI.spider) provides three main functionalities:

- pseudonym generation, allowing a registry to compute a series of unique pseudonyms for the same patient without allowing any other party to re-identify the patient;
- pseudonym linkage, allowing a registry to find a list of other registries processing the personal data related to a specific patient provided his/her pseudonym;
- encrypted pseudonymised data transfer, allowing registries to transfer pseudonymised data through end-to-end encrypted channels and build patient cohorts.

When used together with the pseudonym linkage, the encrypted pseudonymised data transfer functionality allows a registry to exploit and combine information about the same patient across different data sources, while the patient's identity remains unknown.

3 User access to ERDRI.spider

To access ERDRI.spider services, a user must be “verified” according to the [ERDRI User Access Guide](#), have introduced his/her registry's information in the European directory of registries (ERDRI.dor) according to the [ERDRI.dor User Guide](#) and have introduced the registry's metadata in the Central metadata repository (ERDRI.mdr) according to the [ERDRI.mdr User Guide](#). Once these two conditions are fulfilled, ERDRI managers will enable the registry owner to access ERDRI.spider. The registry owner can insert at any time the email address of other “verified” users in the “allowed users (e-mail)” field in the “SPIDER information” section of the ERDRI.dor (see [Figure 1](#)) to allow them to use ERDRI.spider as well. The information in this field can only be accessed by the ERDRI management team.

Subsequently, the authorised users can access ERDRI.spider at <https://eu-rd-platform.jrc.ec.europa.eu/spider> by clicking in the appropriate box as in [Figure 2](#).

The ERDRI.spider webpage is also accessible from the ERDRI homepage available at <https://eu-rd-platform.jrc.ec.europa.eu/erdri> (see [Figure 3](#)).

Allowed users (e-mail)

```
registry.owner@example.com
additional.user.one@example.com
additional.user.two@example.com
```

Figure 1: Allowed users (e-mail) field in ERDRI.dor



4 Login

 Log in



SPIDER pseudonymisation tool

ERDRI.spider pseudonymisation tool generates pseudonyms for RD patients. In addition, it allows linking and transferring RD patients' data across registries without revealing patients' identities.

Using ERDRI.spider pseudonymisation tool researchers can combine structured data and create patient cohorts for studies and research without exposing RD patients' privacy to risk. While accessing ERDRI.spider services, sensitive patient data is never communicated to the service provider (EU RD Platform).

Please read the "[Pseudonym generation, pseudonym linkage and encrypted pseudonymised data transfer via the European Platform on Rare Disease Registration pseudonymisation tool](#)" document for further information on the ERDRI.spider processing operations.


If you need further help for using ERDRI.spider services, the EU RD Platform team provides on-line training. Please check the [ERDRI trainings web page](#) to register to the next available training session.

Figure 2: Accessing SPIDER via the ERDRI.spider homepage


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

ERDRI

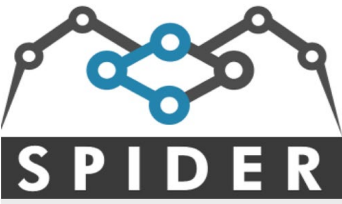
European Rare Disease Registry Infrastructure (ERDRI)




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



Pseudonymisation tool (ERDRI.spider)
Service offering registries at local level the solution for patient pseudonymisation



Search Broker (ERDRI.sebro)
ERDRI sebro allows researchers to retrieve metadata of interest

Figure 3. Accessing SPIDER via the ERDRI homepage



4.1. First login

The first login in ERDRI.spider must be done by the registry owner. When the registry owner accesses ERDRI.spider for the first time, s/he needs to sign the “SPIDER SERVICE Secure Privacy-preserving Identity management in Distributed Environments for Research TERMS OF USE” contract, on behalf of the registry and generate a password-protected file with .p12 extension, called **cryptographic archive**. The cryptographic archive contains a private key, a public key and a public key certificate signed by the SPIDER Certification Authority.

4.1.1. Generating the cryptographic archive file for the registry

To generate a cryptographic archive file, once logged in, the registry owner should take the following steps:

- Click on the link shown on the bottom of the **cryptographic archive page** (see [Figure 4](#)).
- Read carefully the terms of use shown in the **private key generation page** (see [Figure 5](#)).
- Accept the terms (see [Figure 5](#)).
- Generate a private key by clicking on the “generate private key” button (see [Figure 5](#)).
- Download the private key and a pdf copy of the signed terms of use on the local hard drive (see [Figure 6](#)). In this phase, one may be asked to allow multiple file downloads from the web browser.
- Wait for the notification email from the functional mailbox EU-RD-PLATFORM@ec.europa.eu.
- Reach again the ERDRI.spider cryptographic archive page and click on the link shown on the bottom (see [Figure 4](#)).
- Upload the private key file in the cryptographic archive generation page, insert the protecting password and click on the “generate cryptographic archive” button (see [Figure 7](#)).

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

SPIDER pseudonymisation tool

Select the cryptographic archive file for the center you wish to operate in.

Cryptographic Archive file
Only password protected p12 files are allowed.

[Choose file](#)

Cryptographic Archive password

I have received the signed SPIDER SERVICE Terms of Use from the registry owner, I have read them and accept them

[Access SPIDER](#)

If no cryptographic archive has been generated for your centre, click [here](#) to create one.

SPIDER

[Privacy statement](#)
[Contact](#)

Figure 4: Cryptographic archive page



SPIDER pseudonymisation tool

Welcome to the SPIDER pseudonymisation tool

You are operating on behalf of JRC Ispra Unit F.1 - Health and consumer protection Center4

To access the SPIDER services, you first have to read carefully the SPIDER User Manual, sign the "SPIDER SERVICE TERMS OF USE", and generate a cryptographic archive file for your centre.

SPIDER SERVICE TERMS OF USE ▾

1

2 I have read and accept the SPIDER SERVICE Terms of Use

A cryptographic archive contains a private cryptographic key, the corresponding public key, and a public key certificate signed by the SPIDER certification authority.

As a first step, you have to generate a password protected private cryptographic key for your centre. Please note that this key is generated locally and is not communicated to any other party.

Choose a safe password and generate the private key by filling the form below.

Password

Minimum 8 characters, at least one of each: uppercase letter; lowercase letter; number. The only allowed symbols are dot, hyphen and underscore [._-].

3

Generate private key

4

Figure 5: Private key generation page

SPIDER pseudonymisation tool

Request completed

You are operating on behalf of JRC Ispra Unit F.1 - Health and consumer protection Center4

We received your request. The download of your private key file will start shortly, if it does not start automatically click [here](#).

Please remember to store the private key file in a safe place until your request has been approved and you generate a cryptographic archive file for your centre.

Do not share the private key with anyone. SPIDER members and administrators will never ask you to provide them with the key or the protecting password.

Figure 6: Private key download page



SPIDER pseudonymisation tool

You have been granted access to the SPIDER services.

You are operating on behalf of Rare Disease Center 4 Rare Disease Department Center4

Great news, you are just a small step away from using the SPIDER pseudonymisation tool.

Upload the private key file and provide the protecting password to create the cryptographic archive.

Private key file

Only pem files allowed.

Choose file

1

Password

Insert the password protecting the private key file. The cryptographic archive will be protected by the same password.

2 Your strong password here

Please remember to store the cryptographic archive file in a safe place.

If other verified users have to operate on behalf of the same centre, please perform the following operations:

1. insert their email address in the "Allowed users (e-mail)" field in the "SPIDER information" section of ERDRI.dor;
2. provide them with the cryptographic archive file and the protecting password.

Generate cryptographic archive file

3

Figure 7: Cryptographic archive generation page

The password-protected cryptographic archive file is then generated and downloaded automatically to the local hard drive of the user's computer. The registry owner should share this file and communicate the corresponding password only to the verified users authorised to access ERDRI.spider. Those users should have been already inserted in the "Allowed users (e-mail)" field in the "SPIDER information" section of the ERDRI.dor (see [Figure 1](#)).

Please note that the cryptographic private key and the cryptographic archive files are generated by the local browser running on the user's local PC. It's the registry owner responsibility to store and keep the cryptographic archive file and its password in a safe place, according to the security policy of the registry. The JRC can neither restore passwords nor transmit cryptographic archive files, as it never gets in touch with them. The JRC will never ask for those files or password.

Please consult the [SPIDER Certification Practice Statement for the Resource Public Key Infrastructure \(RPKI\)](#) for further details.

4.2. Subsequent logins

A verified user appearing in the "Allowed users (e-mail)" field in the "SPIDER information" section of the ERDRI.dor (see [Figure 1](#)) can access ERDRI.spider by taking the following steps:

- Reach the ERDRI.spider homepage and click on the login button on the top-right (see [Figure 2](#)).
- in the cryptographic archive page, upload the cryptographic archive file, insert the corresponding password, accept the terms of use and then click on the "Access SPIDER" button (see [Figure 8](#)).
- Reach the ERDRI.spider dashboard (see [Figure 9](#)).



SPIDER pseudonymisation tool

Select the cryptographic archive file for the center you wish to operate in.

Cryptographic Archive file

Only password protected p12 files are allowed.

Choose file

1

Cryptographic Archive password

2 Your strong password here

I have received the signed SPIDER SERVICE Terms of Use from the registry owner, I have read them and accept them

Access SPIDER

3

If no cryptographic archive has been generated for your centre, click [here](#) to create one.

Figure 8: Access to SPIDER with a cryptographic archive

5 Pseudonym generation functionality

The pseudonym generation functionality allows a registry user to compute pseudonyms for one or more patients.

5.1. Generate a pseudonym for a single patient

To generate a pseudonym for a single patient, one must take the following steps:

- Reach the ERDRI.spider dashboard (see [Figure 9](#)).
- Click on the “Patients” link at the top of the webpage;
- In the **patients page**, click on the “Add patient” button (see [Figure 10](#)).
- In the **patient insertion page**, fill the form with the first name, the second name and the date of birth of the patient, then click on the “Generate pseudonym” button (see [Figure 11](#)).
- A local pseudonym is automatically computed, as well as the first placeholder pseudonym, whose index is now shown in the patients page (see [Figure 12](#)).

The registry user can use the placeholder pseudonym index as the patient’s pseudonym for his/her daily work. We recall that the local pseudonym as well as the placeholder pseudonyms are 86 characters long, and are not intended to be used by the user.



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SPIDER pseudonymisation tool

Dashboard Patients Groups Notifications Cohort builder Center4

There are no notifications

Pseudonym	Identity	Additional data sources
No patients yet in this group		

[+ Add patient](#)

SPIDER [Privacy statement](#)
[Contact](#)

Figure 9: SPIDER dashboard



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SPIDER pseudonymisation tool

Dashboard **Patients** Groups Notifications Cohort builder Center4

Your patients

Pseudonym	Identity	Additional data sources
No patients yet in this group		

[+ Add patient](#)

Patients shared with you

Pseudonym	Sent by	Additional data sources
No patients shared with you		

SPIDER [Privacy statement](#)
[Contact](#)

Figure 10: Patients section



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SPIDER pseudonymisation tool

Dashboard Patients Groups Notifications Cohort builder Center4

If you want to upload multiple patients at once [Click here](#)

Mandatory information

First name	Last name	Date of birth (dd-mm-yyyy)
<input type="text" value="Alice"/>	<input type="text" value="Red"/>	<input type="text" value="01-01-2000"/>

Patient groups

Figure 11: Patient insertion page

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SPIDER pseudonymisation tool

Dashboard Patients Groups Notifications Cohort builder Center4

Your patients

	Pseudonym	Identity	Additional data sources	
<input type="checkbox"/>	MTAw	Alice Red (01-01-2000)	Center3	View

Patients shared with you

Pseudonym	Sent by	Additional data sources
No patients shared with you		

Figure 12: result of a single patient's pseudonym generation

5.2. Generate a pseudonym for several patients (bulk pseudonymisation)

To generate pseudonyms for a list of patients, one must take the following steps:

- reach the ERDRI.spider dashboard (see [Figure 9](#));
- click on the “Patients” link at the top of the webpage;
- in the **patients page**, click on the “Add patient” button (see [Figure 10](#));



- in the **patient insertion page**, click on the “click here” blue link on the top of the page (see [Figure 11](#));
- click on the “choose file” button (see [Figure 13](#));
- select a CSV file from the local storage (see [Figure 14](#));
- in the **fields mapping page**, indicate which column in the CSV file matches the requested variables, then click on the “Set CSV fields” button (see [Figure 15](#));
- in the bulk sharing policies page, select the sharing policy, if any, and click on the “generate pseudonyms” button (see [Figure 16](#));
- all pseudonyms are computed and shown in the patients page (see [Figure 17](#)).

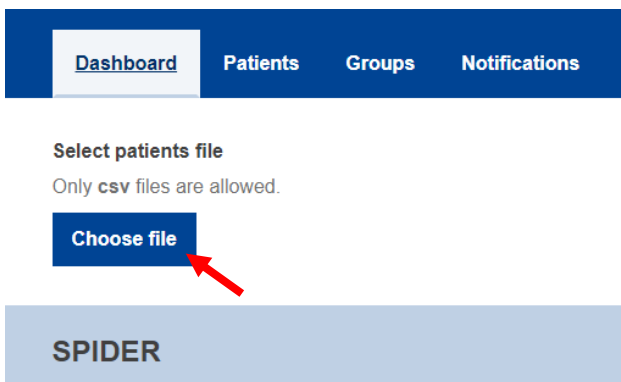


Figure 13: bulk pseudonymisation

```
1 name,surname,date_of_birth
2 Bob,Blue,02-01-2000
3 Charlotte,White,03-01-2000
4 Dylan,Black,04-01-2000
```

Figure 14: CSV file example

Match patient information with CSV fields

Name

Surname

Date of birth



Figure 15: bulk pseudonymisation - CSV fields mapping



Ready to import 3 patients

Sharing policies

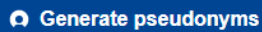
 Generate pseudonyms







Figure 16: bulk pseudonymisation – sharing policies

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SPIDER pseudonymisation tool

Dashboard **Patients** Groups Notifications Cohort builder Center4

Your patients

	Pseudonym	Identity	Additional data sources	
<input type="checkbox"/>	MTAw	Alice Red (01-01-2000)	Center3	 View
<input type="checkbox"/>	MTg1	Bob Blue (02-01-2000)	No other centers treating this patient	 View
<input type="checkbox"/>	OTk=	Charlotte White (03-01-2000)	No other centers treating this patient	 View
<input type="checkbox"/>	Mjl=	Dylan Black (04-01-2000)	No other centers treating this patient	 View

[+ Add patient](#)

Figure 17: Patients page showing pseudonyms computed via bulk pseudonymisation

5.3. View a patient's details

To view a patient's details, one must go to the Patients page and click on the lens icon next to the patient, as shown in [Figure 18](#).

The **patient details page** (see [Figure 19](#)) shows information including:

- The patient's identity, in case it has been collected by the registry.
- The placeholder pseudonym index.
- The 512 bit local pseudonym in base64 form.
- The sharing policies currently applied to the patient's pseudonym.
-



- The creation and modification date.

SPIDER pseudonymisation tool

Dashboard **Patients** Groups Notifications Cohort builder Center4

Your patients






	Pseudonym	Identity	Additional data sources	
<input type="checkbox"/>	MTAw	Alice Red (01-01-2000)	Center3	 View 
<input type="checkbox"/>	MTg1	Bob Blue (02-01-2000)	No other centers treating this patient	 View
<input type="checkbox"/>	OTk=	Charlotte White (03-01-2000)	No other centers treating this patient	 View
<input type="checkbox"/>	Mjl=	Dylan Black (04-01-2000)	No other centers treating this patient	 View
				+ Add patient

Figure 18: access a patient's details



SPIDER pseudonymisation tool

Dashboard Patients Groups Notifications Cohort builder Center4

First name	Alice
Second name	Red
Date of birth	01-01-2000
Pseudonym (PPI)	MTAw
Local pseudonym	L/VkaZSLqL9zsl2O3tVE2j8UKijw5zmSeq29BquGO8N4z7SwSBypkhdVebuFkswt9+OZa299XuoZlgASadhJ3g==

You have not defined any sharing policy for this patient

Current policies ▾

Patient groups

This patient does not belong to any group.

Insert in this group

Remove from this group

Patient

Center3 Request data Send data

Find additional data sources for this patient

Delete patient

Figure 19: view a patient's details

5.4. Delete a patient

To delete a patient one must reach the patient's details page and click on the "delete patient" button, as shown in Figure 20.

You have not defined any sharing policy for this patient

Current policies ▾

Patient groups

This patient does not belong to any group.

Insert in this group

Remove from this group

Patient

Center3 Request data Send data

Find additional data sources for this patient

Delete patient

Figure 20: How to delete a patient



6 Pseudonym linkage functionality

The pseudonym linkage functionality allows a registry to find other data sources for a specific patient. This functionality allows in particular to retrieve the list of other registries processing the personal data related to a patient given his/her pseudonym.

6.1. Find other data sources/registries for a specific patient

In case a data source for a given patient in ERDRI.spider allows for it, a user can immediately see the data source name in the ERDRI.spider dashboard page (see [Figure 21](#)) as well as in the patients page (see [Figure 22](#)). The process of retrieving the additional data source names for a specific patient can also be triggered manually from the patient details page by clicking on the “Find additional data sources for this patient” link (see [Figure 23](#)).

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SPIDER pseudonymisation tool

Dashboard Patients Groups Notifications Cohort builder Center4

There are no notifications

Pseudonym	Identity	Additional data sources	
MTaw	Alice Red (01-01-2000)	Center3	View

Figure 21: finding other data sources in the SPIDER dashboard

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SPIDER pseudonymisation tool

Dashboard Patients Groups Notifications Cohort builder Center4

Your patients

	Pseudonym	Identity	Additional data sources	
<input type="checkbox"/>	MTaw	Alice Red (01-01-2000)	Center3	View
<input type="checkbox"/>	MTg1	Bob Blue (02-01-2000)	No other centers treating this patient	View
<input type="checkbox"/>	OTk=	Charlotte White (03-01-2000)	No other centers treating this patient	View
<input type="checkbox"/>	Mjl=	Dylan Black (04-01-2000)	No other centers treating this patient	View

[+ Add patient](#)

Figure 22: finding other data sources in the patients page



You have not defined any sharing policy for this patient

Current policies ▾

Patient groups

This patient does not belong to any group.

Insert in this group

Remove from this group

Patient

Center3 Request data

Send data

Find additional data sources for this patient

Delete patient

Figure 23: finding other data sources from the patient details page

6.2. Let other centres find one's own centre as additional data source

By default, when a pseudonym is generated in SPIDER, no other registry can link its pseudonyms to this one, and consequently see the name of the registry that has just created the pseudonym among the data sources for the same patient.

To allow other registries for performing pseudonym linkage operations, a registry user must define fine-grained policies and associate them to a patient **group**.

6.2.1. Policies and rights

In ERDRi.spider, a **policy** is a set of **rights** that the user of a registry, called issuer, grants to users of another registry, called target. One or more policies can be associated to a patient group. When a user inserts one or more patients in a group, those patients' information are processed according to the corresponding policies associated to the group.

6.2.1.1. canFind right

The **canFind** right allows a target registry to retrieve the issuer's registry name in the list of additional data sources for a given patient.

Example;

- Centre 1 computes a pseudonym *PX* for the patient Alice Red.
- The pseudonym *PY* is computed by centre 2 for the same patient.

If centre 2 has granted the **canFind** right on *PY* to centre 1, this centre will then be able to retrieve center2 as an additional data source for its patient *PX*.

6.2.1.2. canSeek right

The **canSeek** right allows a target registry to retrieve the list of additional data sources related to a patient whose pseudonymised data has been previously sent by the issuer, provided that the centres in the retrieved list granted the **canFind** right to the requester.

Example:

- Centre 1 computes a pseudonym *PX* for the patient John Doe. Let us assume that centre 1 sends pseudonymised data $\langle PX, sex=male \rangle$ to centre 2.
- If centre 1 provides the **canSeek** right to center2 for patient *PX*, then centre 2 can trigger a pseudonym linkage operation for *PX* and retrieve centre 3 as an additional data source for patient



PX, if centre 3 has previously granted the **canFind** right to centre 2 on the same patient. In this scenario, centre 2 can know that centre 3 is an additional data source for patient *PX*, even if *PX*'s identity is unknown.

6.2.2. Create a group

To create a group, a user must take the following steps:

- Click on the “Groups” link at the top of the webpage.
- Click on the “Add group” in the **groups page** (see [Figure 24](#)).
- Write the group name in the **group page** (see [Figure 25](#)).
- Select a target centre from the list and tick the rights to grant, then click on the “Add policy” button (see [Figure 25](#)).
- If needed, select another target centre from the list and tick the rights to grant, then click on the “Add policy” button (see [Figure 26](#)).
- In the same page, click the “Save group” button (see [Figure 27](#)).
- See the group that has just been created in the groups page (see [Figure 28](#)).

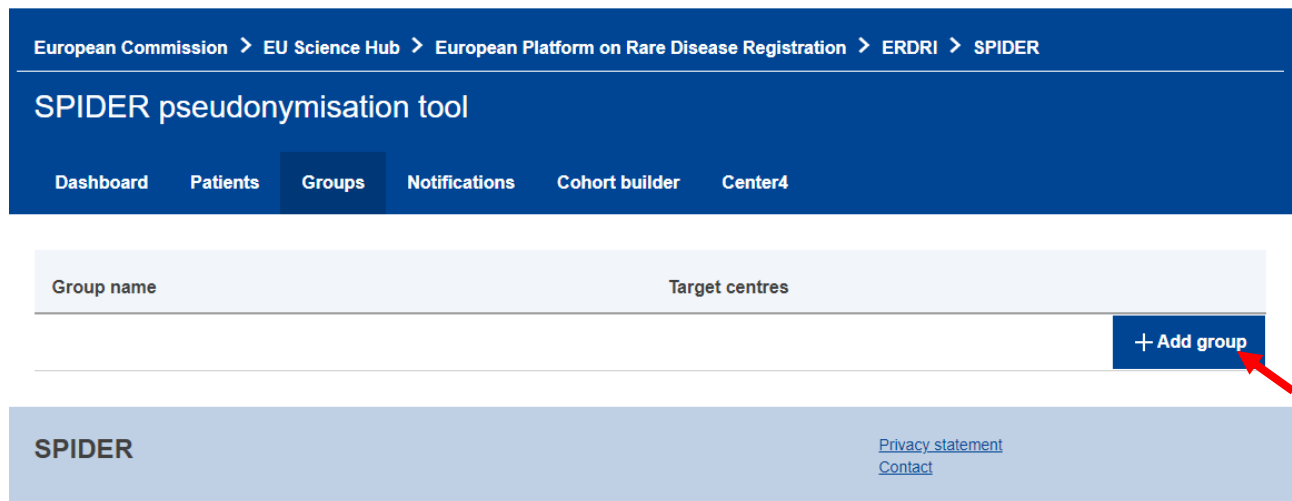


Figure 24: add group



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SPIDER pseudonymisation tool

Dashboard Patients **Groups** Notifications Cohort builder Center4

Group name
My Registry Network Group

Target center	canFind	canSeek
This list is empty		
Center 3	<input checked="" type="checkbox"/>	<input type="checkbox"/>

+ Add policy

Save group

Show patients

SPIDER [Privacy statement](#) [Contact](#)

Figure 25: add a policy in a group

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SPIDER pseudonymisation tool

Dashboard Patients **Groups** Notifications Cohort builder Center4

Group name
My Registry Network Group

Target center	canFind	canSeek
Center3	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Center 6	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

+ Add policy

Save group

Show patients

SPIDER [Privacy statement](#) [Contact](#)

Figure 26: add more policies in a group



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SPIDER pseudonymisation tool

Dashboard Patients **Groups** Notifications Cohort builder Center4

Group name

Target center	canFind	canSeek	
Center3	✓	✘	Delete policy
Center6	✓	✓	Delete policy

canFind canSeek [+ Add policy](#)

[Save group](#)

[Show patients](#) ▾

Figure 27: save a group

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SPIDER pseudonymisation tool

Dashboard Patients **Groups** Notifications Cohort builder Center4

Group name	Target centres	
My Registry Network Group	Center3 Center6	Edit Delete Send

[+ Add group](#)

SPIDER [Privacy statement](#)
[Contact](#)

Figure 28: see all groups

6.2.3. Edit or delete a group

A group can be edited or deleted by clicking on the corresponding buttons in the groups page (see [Figure 29](#)).



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SPIDER pseudonymisation tool

Dashboard Patients **Groups** Notifications Cohort builder Center4

Group name	Target centres	
My Registry Network Group	Center3 Center6	Edit Delete Send

[+ Add group](#)

SPIDER [Privacy statement](#) [Contact](#)

Figure 29: editing or deleting groups

6.2.4. Insert patients in groups

To insert a patient in a group, a user must take the following steps:

- Access the patient details page from the patient page (see [Figure 18](#)).
- Select the group from the dropdown menu under “Select a patient group” (see [Figure 30](#)).
- Click on the “insert in this group” button (see [Figure 31](#)).

The newly added group is shown in the patient details page (see [Figure 32](#)). The abovementioned procedure must be adopted for all groups a patient must belong to. Groups can be associated to patients even during the pseudonym generation phase described in section [5 Pseudonym generation functionality](#), as shown in [Figure 33](#) (single patient pseudonymisation) and [Figure 34](#) (bulk pseudonymisation).



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SPIDER pseudonymisation tool

Dashboard Patients Groups Notifications Cohort builder Center4

First name	Bob
Second name	Blue
Date of birth	02-01-2000

Pseudonym (PPI)	MTg1
Local pseudonym	0Cr4B2dbhagXf9xdiBQI2pK03Yix3P4hwMp59629bpwxHRncDHm+9XZZID59kxef8lFk0ye99d6t2MYlgGoDKQ==

You have not defined any sharing policy for this patient

Current policies ▾

Patient groups

This patient does not belong to any group.

Select a patient group

No group ▾

Insert in this group Remove from this group

Patient

Find additional data sources for this patient

Delete patient

Figure 30: selecting a group for a patient

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SPIDER pseudonymisation tool

Dashboard Patients Groups Notifications Cohort builder Center4

First name	Bob
Second name	Blue
Date of birth	02-01-2000

Pseudonym (PPI)	MTg1
Local pseudonym	0Cr4B2dbhagXf9xdiBQI2pK03Yix3P4hwMp59629bpwxHRncDHm+9XZZID59kxef8lFk0ye99d6t2MYlgGoDKQ==

You have not defined any sharing policy for this patient

Current policies ▾

Patient groups

This patient does not belong to any group.

Select a patient group

My Registry Network Group ▾

Insert in this group Remove from this group

Patient

Find additional data sources for this patient

Delete patient

Figure 31: Updating policies for a patient



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SPIDER pseudonymisation tool

Dashboard Patients Groups Notifications Cohort builder Center4

First name	Bob
Second name	Blue
Date of birth	02-01-2000

Pseudonym (PPI)	MTg1
Local pseudonym	0Cr4B2dbhagXf9xdIBQi2pK03Yix3P4hwMp59629bpwxHRncDHm+9XZZID59kxef8lFk0ye99d6t2MYlgGoDKQ==

Assigned sharing policies affect Center3, Center6

Current policies ▾

Patient groups

Patient in My Registry Network Group

Select a patient group

My Registry Network Group ▾

Insert in this group Remove from this group

Patient [Find additional data sources for this patient](#)

modified_on Mon Apr 18 2022 17:57:50 GMT+0200 (Central European Summer Time)

Delete patient

Figure 32: viewing a patient's groups

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SPIDER pseudonymisation tool

Dashboard Patients Groups Notifications Cohort builder Center4

If you want to upload multiple patients at once [Click here](#)

Mandatory information

First name	Last name	Date of birth (dd-mm-yyyy)
<input type="text"/>	<input type="text"/>	<input type="text"/>

Extra information ▾

Patient groups

Select a patient group

No group ▾

Generate pseudonym

Figure 33: Choosing groups during single pseudonym generation



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SPIDER pseudonymisation tool

Dashboard Patients Groups Notifications Cohort builder Center4

Ready to import 10 patients

Patient groups

Select a patient group

No group 



Figure 34: Choosing groups during bulk pseudonym generation

6.2.5. View the policies associated to a patient

To view all the policies that have been associated to a patient, a user must take the following steps:

- Access the patient details page from the patient page (see [Figure 18](#)).
- Click on the “current policies” button (see [Figure 35](#)).

The policies will appear under the button as shown in [Figure 36](#).


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SPIDER pseudonymisation tool

Dashboard Patients Groups Notifications Cohort builder Center4

First name	Bob
Second name	Blue
Date of birth	02-01-2000
Pseudonym (PPI)	MTg1
Local pseudonym	0Cr4B2dbhagXf9xdIBQi2pK03Yix3P4hwMp59629bpwxHRncDHm+9XZZID59kxet8IFk0ye99d6t2MYlgGoDKQ==


Assigned sharing policies affect Center3, Center6





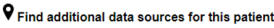
Patient groups

Patient in My Registry Network Group

Select a patient group

My Registry Network Group 

Patient 

modified_on Mon Apr 18 2022 17:57:50 GMT+0200 (Central European Summer Time)




Figure 35: Accessing the policies associated to a patient



SPIDER pseudonymisation tool

Dashboard Patients Groups Notifications Cohort builder Center4

First name Bob
Second name Blue
Date of birth 02-01-2000
Pseudonym (PPI) MTg1
Local pseudonym 0Cr4B2dbhagXf9xdIBQi2pK03Yix3P4hwMp59629bpwxHRncDHm+9XZZID59kxef8IFk0ye99d6t2MYlgGoDKQ==

Assigned sharing policies affect Center3, Center6

Current policies ^

Target center	canFind	canSeek
Center3	✓	✗
Center6	✓	✓

Patient groups

Patient in My Registry Network Group

Select a patient group

No group

Insert in this group

Remove from this group

Patient

Find additional data sources for this patient

modified_on

Mon Apr 18 2022 17:57:50 GMT+0200 (Central European Summer Time)

Delete patient

Figure 36: Viewing the policies associated to a patient

6.2.6. View all the patients in a group

To view all the patients that have been inserted in a group, a user must take the following steps:

- Click on the “Groups” link at the top of the webpage.
- Identify the group of interest and click on the edit button (see [Figure 37](#)).
- Click on the “show patients” button (see [Figure 38](#)).
- View the list of patients on the bottom of the button (see [Figure 39](#)).



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SPIDER pseudonymisation tool

Dashboard Patients **Groups** Notifications Cohort builder Center4

Group name	Target centres	
My Registry Network Group	Center3 Center6	Edit Delete Send

[+ Add group](#)

SPIDER [Privacy statement](#) [Contact](#)

Figure 37: Editing a group

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SPIDER pseudonymisation tool

Dashboard Patients **Groups** Notifications Cohort builder Center4

Group name
My Registry Network Group

Target center	canFind	canSeek	
Center3	✓	✗	Delete policy
Center6	✓	✓	Delete policy

canFind canSeek [+ Add policy](#)

[Save group](#)

[Show patients](#)

Figure 38: Showing patients in a group



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SPIDER pseudonymisation tool

Dashboard Patients **Groups** Notifications Cohort builder Center4

Group name
My Registry Network Group

Target center	canFind	canSeek	
Center3	✓	●	ⓘ Delete policy
Center6	✓	✓	ⓘ Delete policy

canFind canSeek **+ Add policy**

Save group

Show patients ^

Pseudonym	Identity	Additional data sources	
MTIz	Bob Blue (02-01-2000)	No additional data source for this patient	🔍 View

+ Add patient

Figure 39: Viewing the list of patients in a group

6.2.7. Remove a patient from a group

To remove a patient from a group a user must go to the patient details page, select the group the patient should be removed from, and click on the “remove group” button, as shown in [Figure 40](#).

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SPIDER pseudonymisation tool

Dashboard Patients **Groups** Notifications Cohort builder Center4

First name: Bob
Second name: Blue
Date of birth: 02-01-2000

Pseudonym (PPI): MTg1
Local pseudonym: 0Cr4B2dbhagXf9xdiBQ2pK03Yx3P4hwMp59629bpwxHRncDHm+9XZZID59kxef8IFk0ye99d6t2MYlgGoDKQ==

Assigned sharing policies affect Center3, Center6

Current policies v

Patient groups

Patient in My Registry Network Group

Select a patient group

My Registry Network Group v

Insert in this group **Remove from this group**

Patient **Find additional data sources for this patient**

Delete patient

Figure 40: Removing a patient from a group



7 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 41](#).

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*

H b 4 t d

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 41. Technical support assistance form.