



# Multiple Sclerosis Data Alliance Catalogue

Manual

*Last updated: 21 June 2022*





## Contents

<b>1</b>	<b>Background.....</b>	<b>3</b>
<b>2</b>	<b>How can I access the MSDA Catalogue?.....</b>	<b>5</b>
<b>3</b>	<b>How can I sign in once I created an account?.....</b>	<b>8</b>
<b>4</b>	<b>What should I do if I forgot my password?.....</b>	<b>9</b>
<b>5</b>	<b>What can I see and do within the MSDA Catalogue?.....</b>	<b>11</b>
	5.1 View databases .....	11
	5.2 Filter / order databases.....	14
	5.3 Compare different databases .....	16
	5.4 Export databases.....	17
	5.4.1 Custom view <b>(recommended)</b> .....	17
	5.4.2 Export a whole database <b>that you own</b> to PDF.....	18
	5.4.3 Export module <b>(not recommended)</b> .....	19
<b>6</b>	<b>How can I add a new registry/cohort to the MSDA Catalogue?.....</b>	<b>21</b>
<b>7</b>	<b>Publishing your database.....</b>	<b>22</b>
	7.1 How can I make a draft database public?.....	22
<b>8</b>	<b>How can I edit a database in the Catalogue?.....</b>	<b>23</b>
<b>9</b>	<b>Can I share database ownership with someone else?.....</b>	<b>24</b>



## 1 Background

The Multiple Sclerosis Data Alliance ([MSDA](#)) is a global multi-stakeholder non-profit collaboration acting under the umbrella of the European Charcot Foundation ([ECF](#)) that strives to overcome the sociological and technical challenges that arise when scaling-up real- world MS data.

There are many existing and arising real-world data (RWD) sources in MS. They differ in purpose, maturity and collect different variables. The MSDA launched the MSDA Catalogue in 2019. It allows end-users with particular study requirements or research questions to browse metadata profiles of MS real-world data cohorts (called “databases” in the Catalogue). Detailed cataloguing of MS RWD is a first and useful step towards reducing the time needed to discover real-world MS datasets and therefore to facilitate collaborative research.

The **MSDA Catalogue** is available worldwide and collects **descriptive information** on governance, purpose, inclusion criteria, procedures for data quality control, how and which data is collected. The current cataloguing procedure is performed in several manual steps and only consists of metadata / descriptive data and therefore has **very limited to no privacy concerns**. The MSDA Catalogue used to be hosted by the European Medical Information Framework ([EMIF](#)), which was organised around disease communities (MSDA was one of the communities in the EMIF platform). Currently, the MSDA Catalogue has its own personal platform, under the umbrella of the EMIF platform, and today, there are more than 40 globally spread registries / initiatives that share descriptive data with the MSDA Catalogue (see Figure 1).

On top of the general (main) MSDA Catalogue that was launched in 2019, a **COVID-19 in MS catalogue** was developed recently. Ever since the COVID-19 pandemic started, data on COVID-19 (in MS) has been of particular and pressing interest, because of the lack of knowledge of this new disease. This MSDA COVID-19 Catalogue focusses on cohorts in which MS-specific COVID-19 data is collected.

In 2022, a 3<sup>rd</sup> Catalogue was added to our MSDA platform: the **eHealth Catalogue** of the Global Patient Reported Outcomes for Multiple Sclerosis ([PROMS](#)) Initiative. The multi-stakeholder PROMS Initiative is jointly led and coordinated by the European Charcot Foundation (ECF) and the Multiple Sclerosis International Federation (MSIF) with the Italian MS Society (AISM) as lead agency on behalf and for the MSIF Movement. A dedicated working group within the PROMS initiatives focuses on “eHealth”. This working group concluded rapidly that there are many existing and emerging (i.e. “in development”) eHealth Tools available that collect relevant PROMS for people with MS. Improved awareness of these tools is needed. Therefore, they aim to execute a landscaping exercise and developed a survey that was implemented in our MSDA platform, to provide an overview of the available digital self-monitoring or assessment tools. It allows end-users to browse metadata based on the information collated on the measures and tools available and in development. For more information regarding this specific catalogue, please contact [proms\\_ehealthcatalogue@aism.it](mailto:proms_ehealthcatalogue@aism.it).

**This document serves as the manual for the MSDA Catalogue** and will be updated when necessary. Additional documents that could be helpful and/or of interest:

- [Scientific publication](#) on the MSDA Catalogue that was published in December 2021 in the International Journal of MS Care
- [Demo](#) on the MSDA Catalogue (2021)

*Please note that the questionnaire has been updated since the demo was recorded*

If you have questions or if you are facing issues with the Catalogue, do not hesitate to contact [lotte.geys@msdataalliance.com](mailto:lotte.geys@msdataalliance.com) and/or [info@msdataalliance.com](mailto:info@msdataalliance.com).

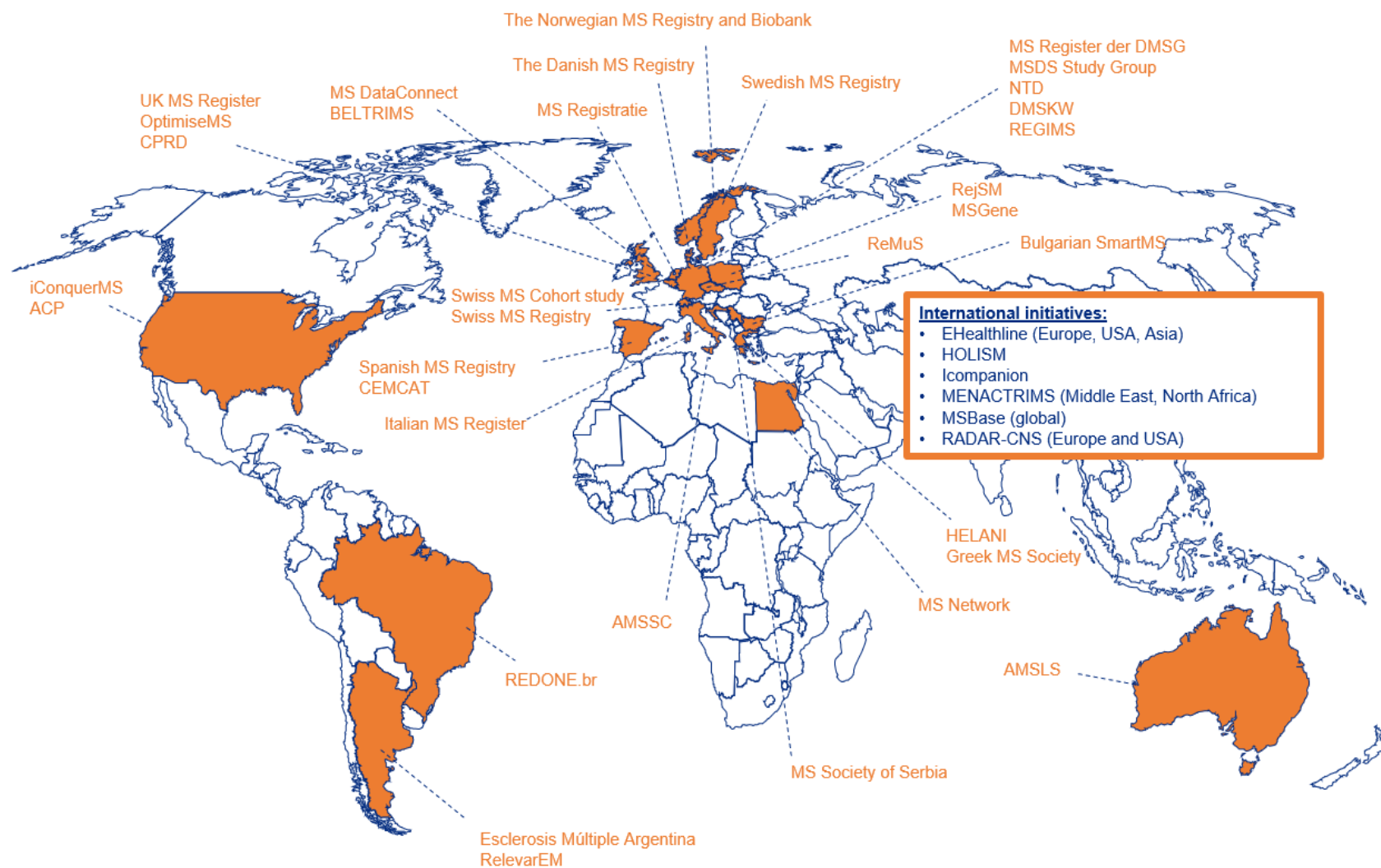


Figure 1: map showing the initiatives / cohorts / registries that are currently part of the MSDA Catalogue and their geographical locations



## 2 How can I access the MSDA Catalogue?

The MSDA platform, containing the general MSDA as well as the COVID-19 in MS catalogue and the PROMS eHealth catalogue, can be accessed via <https://msda.emif-catalogue.eu/login>. However, to view the MSDA Catalogues you will need to create an account first (*this only has to be done once*).

To create an account, you can either click on “Create account” on the login page (<https://msda.emif-catalogue.eu/login>) or go directly to <https://msda.emif-catalogue.eu/accounts/signup/>.

Have an account? Sign in  
Don't have an account? **Create account**

Email Address  
Password

Forgot your password?

**SIGN IN**

Feedback FAQ About Manual

You will need to provide the following information:

- Email address
- First Name
- Last Name
- Country
- Organization



**Create Account** (fields with \* are mandatory)

Email\*

Create password\*

Repeat password\*

First name\*

Last name\*

Country\*

Organization\*

☐ Receive weekly newsletter e-mail with database updates ?

☐ Receive all notifications over e-mail ?

In order to be able to create an account and to get access to the MSDA Catalogue, you will have to agree with our [Terms of Use](#) and give your specific and informed consent to the processing of your personal data as stated in our [Privacy Notice](#).





## Terms of Use

## Terms of Use of the MSDA Catalogue

## Last update 03 May 2022

The Multiple Sclerosis Data Alliance ("MSDA") is a global multi-stakeholder non-profit collaboration that strives to overcome the sociological and technical challenges that arise when scaling-up real-world MS data. The MSDA is acting and operating via the European Charcot Foundation ("ECF"), an independent non-profit organization, organized and existing under the laws of Belgium, having its registered office located at Vaartdijk 3, bus 2, 3018 Leuven, Belgium and with company number (RLE Leuven) 0547.995.164.

Finding real-world MS data sources that have the potential to address urgent needs within the ecosystem is challenging and time-consuming. To overcome this challenge, the MSDA strives towards developing and implementing tools to reduce the time needed to find and assess real-world MS data sources and data acquisition systems. Since 2019, the MSDA has developed and maintained a metadata catalogue ("MSDA Catalogue"). The MSDA Catalogue allows metadata providers ("Metadata Providers") to make available metadata profiles ("Metadata") that can be browsed, filtered, ordered and exported by end-users, including but not limited to Metadata Providers ("Users").

The present Terms of Use govern the use of the MSDA Catalogue and MSDA Services (as defined hereinafter) ("Terms").

**BY REGISTERING AND USING THE MSDA CATALOGUE, THE USER ACKNOWLEDGES THAT HE/SHE HAS READ THESE TERMS CAREFULLY AND THAT HE/SHE IS LEGALLY COMPETENT TO AGREE WITH THESE TERMS WITHOUT RESERVATION.**

## 1. Description of the MSDA Catalogue

The MSDA Catalogue is made available through a platform accessible via the following url: <https://msda.emif-catalogue.eu/>.

The MSDA shall use its best endeavours to provide the User access to and use of the MSDA Catalogue ("Access and Use") in accordance with the standards that may be expected from a similar service provider delivering similar services. Access and Use shall include, but is not limited to, the right to browse, compare, filter, ordered and/or export the Metadata, and/or, for Metadata Providers only, certain editing rights on their own Metadata.

The MSDA Catalogue is provided to the Users "AS IS".

The Users accept and acknowledge that the MSDA Catalogue is dependent on software, which means that flawless operation and permanent availability cannot be assured. Access and Use is granted after registration and are free of charge. Access and Use is granted and allowed for the purpose to acquire and browse the Metadata on multiple sclerosis real-world data sources and acquisition tools ("Scope").

Any responsibility and/or liability of the MSDA outside the Scope shall be excluded. During the registration process, Users will be asked to accept these Terms, which is a

By checking the check boxes below, you give your specific and informed consent to the processing of your personal data as stated in [this Privacy Notice](#). You have the right at all times to revoke this consent to use your personal data. In order to do so, please send an e-mail to [info@msdataalliance.com](mailto:info@msdataalliance.com).

Please check boxes below:

- ☒ I consent to BMD Software processing my personal data for the purposes of the Multiple Sclerosis Data Alliance (MSDA) described in [this Privacy Notice](#), more specifically, I give my consent for the processing of my personal data collected in the context of creating an account on the MSDA Catalogue platform.
- ☒ To the extent I am a Metadata Provider, I also consent to the processing of my personal data for the purpose of populating the MSDA Catalogue as described herein.
- ☒ I also understand that I can withdraw my consent at any time.
- ☒ I agree to the [terms and conditions](#).

[Clear](#)[Create Account](#)[or sign in](#)

Once you accepted the Terms of Use, gave your informed consent and clicked "Create Account", an email with an activation link will be sent to the email address you entered. You should click on the activation link in the email. The email you will receive (from [IEETA-bioinformatics@ua.pt](mailto:IEETA-bioinformatics@ua.pt)) will look like this:



## MSDA CATALOGUE

Thank you for signing up at MSDA Catalogue.

To activate your account you should click on the link below:

<http://msda.emif-catalogue.eu/accounts/activate>

Thanks for using our site!

Sincerely,  
MSDA Catalogue

You will be able to access the MSDA platform immediately after creating your account.

### 3 How can I sign in once I created an account?

Go to <https://msda.emif-catalogue.eu/> and click on sign in:



You will be referred to the login page (alternatively, you can directly go to this login page):

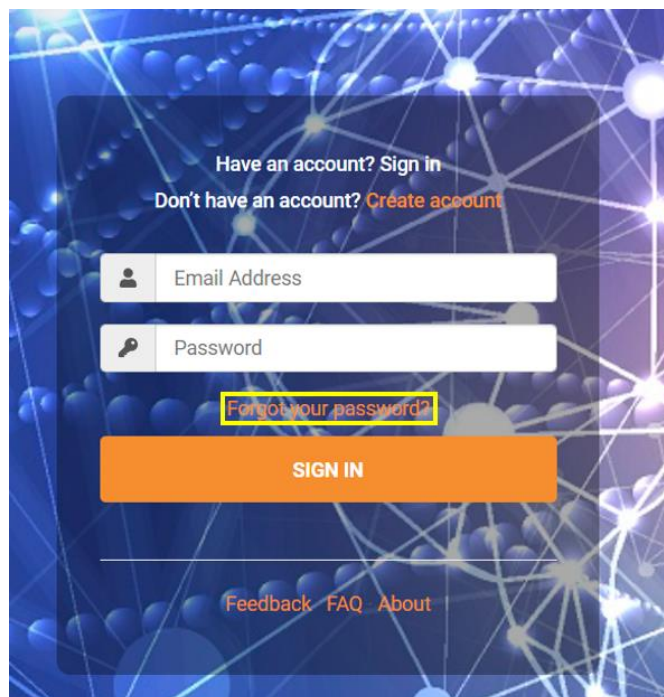
<https://msda.emif-catalogue.eu/login>

Enter your email address, which you used to request access and password, and click on SIGN IN.



## 4 What should I do if I forgot my password?

If you don't remember your password anymore, you can press "Forgot your password?" on the login page of the MSDA catalogue (<https://msda.emif-catalogue.eu/login>).



Then you should enter the email address you created your account with and press "Send password".

Reset Password [Return to Login](#)

Email\*

Send password

You will receive an email from [IEETA-bioinformatics@ua.pt](mailto:IEETA-bioinformatics@ua.pt) with a link you should click on to choose a new password.



You're receiving this e-mail because you requested a password reset for your user account at MSDA Catalogue.

Please go to the following page and choose a new password:

<http://msda.emif-catalogue.eu/accounts/password/reset/>

*Link you should click on*

Your username, in case you've forgotten:

*Email address*

Thanks for using our site!

Sincerely,  
MSDA Catalogue












## 5 What can I see and do within the MSDA Catalogue?

### 5.1 View databases

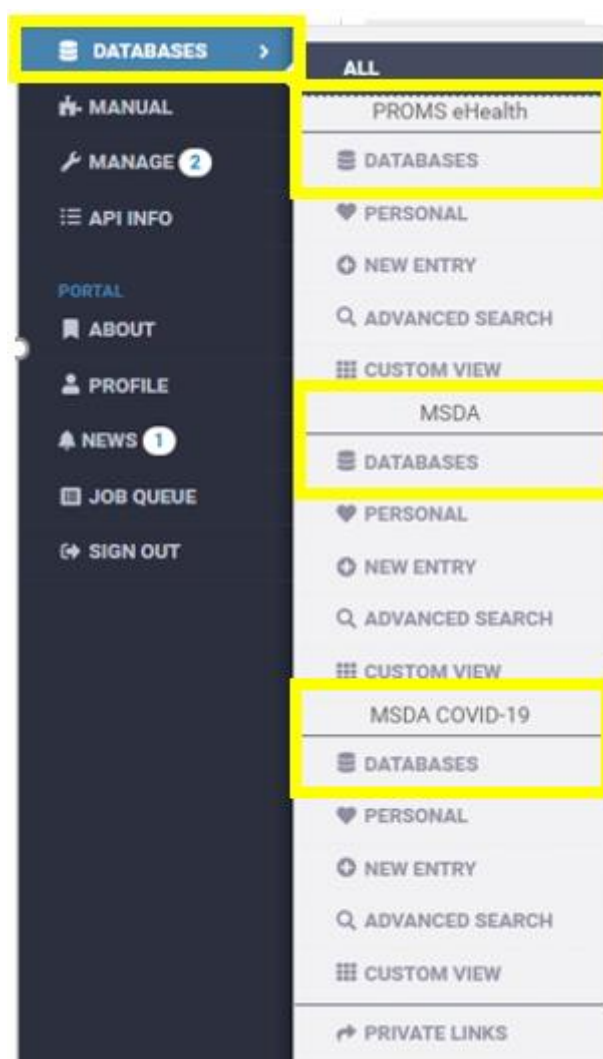
All registered MSDA Catalogue users are able to view the databases within the MSDA Catalogue (containing the general MSDA catalogue, the COVID-19 in MS catalogue and the PROMS catalogue). When you log in on the MSDA Catalogue (via <https://msda.emif-catalogue.eu/login>) you will see a distinction is made between the general MSDA Catalogue, the MSDA COVID-19 Catalogue and the PROMS eHealth Catalogue:

- “MSDA” Catalogue is the general, main MSDA Catalogue that was launched in 2019.
- “MSDA COVID-19” Catalogue is a niche catalogue specifically designed for the COVID-19 pandemic and focusses on cohorts / databases in which COVID-19 data is collected (MS-specific).
- “PROMS eHealth” Catalogue is the eHealth Catalogue of the Global Patient Reported Outcomes for Multiple Sclerosis (PROMS) Initiative. There are many existing and emerging (i.e. “in development”) eHealth Tools available that collect relevant PROMs for people with MS. Improved awareness of these tools is needed. Therefore, a survey was developed by PROMS and implemented in our MSDA platform, to provide an overview of the available digital self-monitoring or assessment tools. It allows end-users to browse metadata based on the information collated on the measures and tools available and in development. For more information regarding this specific catalogue, please contact [proms\\_ehealthcatalogue@aism.it](mailto:proms_ehealthcatalogue@aism.it).

To open one of the three catalogues (PROMS eHealth, MSDA, MSDA COVID-19), you click on the title in blue on the homepage:

Questionnaires				
	<a href="#">PROMS eHealth</a>	eHealth applications and measures are thought to form the future foundation of patient reported and provided outcomes. This eHealth catalogue of the Global Patient Reported Outcomes for Multiple Sclerosis (PROMS) Initiative ( <a href="https://www.aism.it/proms">https://www.aism.it/proms</a> ) is being created to provide a living reference source of available tools that collect relevant PROMS for people with MS.	 0	 315
	<a href="#">MSDA</a>	The MSDA Catalogue was launched in 2019 and collects descriptive information and metadata on governance, purpose, inclusion criteria, procedures for data quality control, status, and how and which data is collected in MS registries / cohorts / initiatives. The current cataloguing procedure is performed in several manual steps and allows end-users with particular study requirements or research questions to browse metadata profiles of MS real-world data cohorts.	 40	 492
	<a href="#">MSDA COVID-19</a>	On top of the general MSDA Catalogue, a COVID-19 niche catalogue was developed in 2021. Ever since the COVID-19 pandemic started, data on COVID-19 (in MS) has been of particular interest, because of the lack of knowledge of this new disease. The MSDA COVID-19 Catalogue focusses on MS-specific cohorts / databases in which COVID-19 data is collected.	 0	 372

Alternatively, in the left menu you can click on “Databases” and subsequently open “Databases” specifically for the general MSDA Catalogue (“MSDA”), for the MSDA COVID-19 (“MSDA COVID-19”) Catalogue, or for the eHealth Catalogue (“PROMS eHealth”):



There are three distinct views to show the descriptive data in the MSDA: Table, List and Card view. Switching between these different views can be done by these icons, respectively:



Table view



List view



Card view

For each data source in the general MSDA catalogue, you can check its:

- Organizational information
- Background / Purpose / Description
- Documentation process
- Data that are collected
- Quality control



- Governance and Data protection

For each data source in the MSDA COVID-19 catalogue, you can check its:

- Organizational information / Background / Description
- Documentation process
- Data collected
- Governance and Data protection

For each data source in the PROMS eHealth catalogue, you can check its:

- Organizational information
- Background / Purpose of the eHealth Tool
- Data that is collected
- Technology and platform for the eHealth Tool
- Governance
- Data Privacy, Data Flow, Storage and Models for Data sharing
- Analytics and Visualization
- Publications, Certification and Validation
- Current state of the eHealth Tool

You can do this by opening a certain database by clicking on the respective database name (in the first column: “Full Name of Registry/Cohort” / “Name of eHealth Tool” / “Name of the host registry/organization of the COVID-19 cohort/questionnaire/survey” depending on which Catalogue you are in).

By default, the detailed overview will be shown. However, at the right, you can click on “Summary” to switch to the summary view.

Hits: 64 Unique Views: 36 Filled: 71.8 %

### ORGANIZATIONAL INFORMATION

1.01. Full Name of Registry/Database

Summary Collapse Show

1. Organizational Infor...	100%
2. Contact Details (2/3)	66%
3. Background/Purpos...	92%
4. Inclusion criteria (pa...	100%
5. Documentation proc...	100%

You can switch back to the detailed view by clicking on “Detailed”.





Hits: 145 Unique Views: 57 Filled: 79.8 %

Detailed Expand Hide Empty

Organizational Information

Background/Purpose

Inclusion criteria (patients/centres)

Documentation process

Data that are collected

Quality Control

Governance

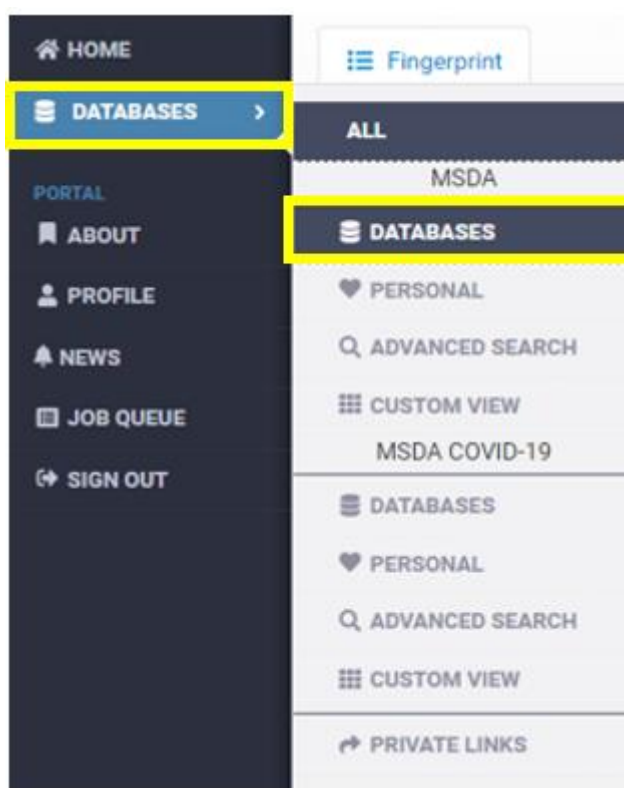
State of the registry

Thank you for your collaboration!

By clicking on Collapse or Expand you can collapse or expand, respectively, the information in the database.

## 5.2 Filter / order databases

In the overview of all registries/cohorts in the Catalogue ("Databases" → "Databases" (see *print screen below*)), there is the possibility to filter and order the databases as you prefer by clicking on "Filters / Order by" (right side):





Close

## Order By

Database Acronym

☒ Ascending ☐ Descending

## Filter By

Database Acronym

Registry/Database was initiated in the year

dd-mm-yyyy



to

dd-mm-yyyy

In which language(s) is data originally entered by the  
people who are collecting the data?Approximate number of actively followed registered  
patients on the current date to Average number of visits per year per registered  
patient to 

Geographical origin of the population in the registry

Last Update

dd-mm-yyyy



to

dd-mm-yyyy



Apply



### 5.3 Compare different databases

You can compare up to four different databases at the same time. In the list of databases, you select (in the rightmost “Select” column) which databases you would like to compare.

Then at the top click on “Compare” and subsequently on “Databases”:



One of the selected databases will be labelled as “Reference”, the other(s) as “Compared”, but you can switch this yourself by clicking on “Reference” and selecting which of the selected databases should be set as reference.

For the selected databases all categories of the Catalogue (i.e. organizational information, Background/Purpose/Description, Documentation process, ... for the general MSDA Catalogue) and the descriptive data entered for these categories are listed. The metadata entered for the “Reference” database are always green and the metadata entered for the “Compared” databases are compared to the reference.

	Registry 1	Registry 2	Registry 3
	Reference	Compared	Compared
Organizational Information	Organizational Information	Organizational Information	Organizational Information
Background/Purpose	Background/Purpose	Background/Purpose	Background/Purpose
Inclusion criteria (patients/centres)	Inclusion criteria (patients/centres)	Inclusion criteria (patients/centres)	Inclusion criteria (patients/centres)
Documentation process	Documentation process	Documentation process	Documentation process
Data that are collected	Data that are collected	Data that are collected	Data that are collected
Quality Control	Quality Control	Quality Control	Quality Control
Governance	Governance	Governance	Governance
State of the registry	State of the registry	State of the registry	State of the registry

If the information for the “Compared” database is exactly the same as for the Reference database, it will be coloured green, but if it’s different from the Reference database, it will be coloured yellow or red. Yellow means that it’s slightly different as compared to the reference data source, red indicates that it’s completely different.

**The colours do not indicate whether something is right or wrong, but refers to if certain information is identical (green) or almost the same (yellow) or completely different (red) from the reference database.**

	Data source 1 Reference	Data source 2 Compared	Data source 3 Compared
Organizational Information	Organizational Information	Organizational Information	Organizational Information
Background/Purpose	Background/Purpose	Background/Purpose	Background/Purpose
Inclusion criteria (patients/centres)	Inclusion criteria (patients/centres)	Inclusion criteria (patients/centres)	Inclusion criteria (patients/centres)
Patient inclusion criteria	<ul style="list-style-type: none"> <li>Patients with MS according to McDonald criteria</li> <li>Patients with possible MS/CIS, not fulfilling McDonald/Poser criteria</li> <li>Patients with self-reported MS (without clinical validation)</li> </ul>	<ul style="list-style-type: none"> <li>Patients with MS according to Poser criteria</li> <li>Patients with MS according to McDonald criteria</li> <li>Patients with possible MS/CIS, not fulfilling McDonald/Poser criteria</li> <li>Other</li> </ul>	<ul style="list-style-type: none"> <li>Patients with MS according to McDonald criteria</li> </ul>

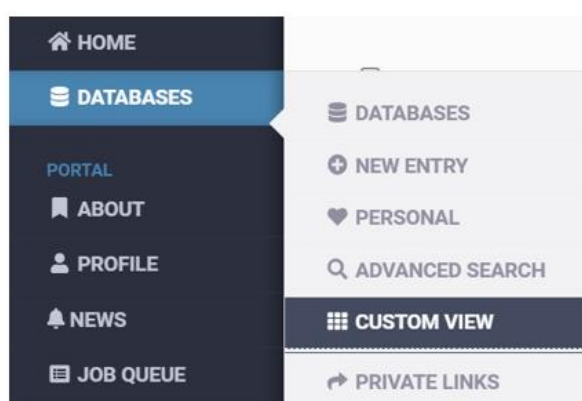
  

	Data source 1 Reference	Data source 2 Compared	Data source 3 Compared
Organizational Information	Organizational Information	Organizational Information	Organizational Information
Background/Purpose	Background/Purpose	Background/Purpose	Background/Purpose
Inclusion criteria (patients/centres)	Inclusion criteria (patients/centres)	Inclusion criteria (patients/centres)	Inclusion criteria (patients/centres)
Documentation process	Documentation process	Documentation process	Documentation process
Data that are collected	Data that are collected	Data that are collected	Data that are collected
Personal Data			
Date of birth	<ul style="list-style-type: none"> <li>Yes</li> </ul>	<ul style="list-style-type: none"> <li>Yes</li> </ul>	<ul style="list-style-type: none"> <li>Yes</li> </ul>
What is the requirement of this data?	<ul style="list-style-type: none"> <li>Mandatory</li> </ul>		<ul style="list-style-type: none"> <li>Mandatory</li> </ul>
Number of registrations		1787	
Gender	<ul style="list-style-type: none"> <li>No</li> </ul>	<ul style="list-style-type: none"> <li>Yes</li> </ul>	<ul style="list-style-type: none"> <li>Yes</li> </ul>

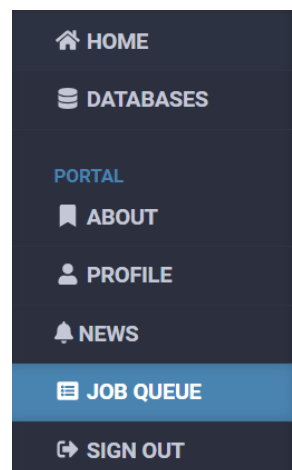
## 5.4 Export databases

### 5.4.1 Custom view (recommended)

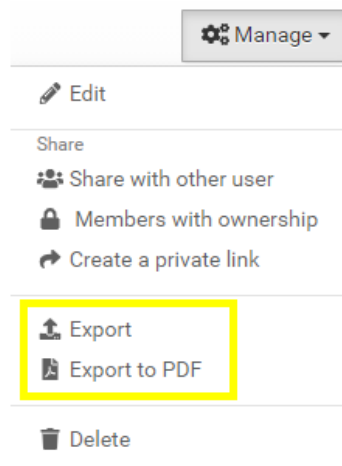
You can export databases or specific parts of certain or all databases via the “custom view” function:



In the custom view function, you can select at the left which metadata (e.g. 5. Data that are collected) you want to export, and at the right side you can select of which databases you would like to get the export.



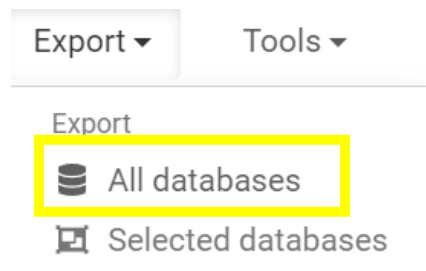




If you choose “Export”, a csv file will be created, which can be downloaded in the Job Queue once the progress is 100%. However, the csv file is not really user-friendly (it will be the internal representation of the database). Therefore, we do not recommend this.

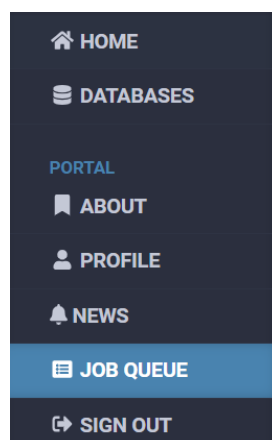
#### 5.4.3 Export module (not recommended)

At the overview page of the databases (“Home”) you can export all databases at once via the “Export” module:



This will take a while and the resulting csv file is not very user-friendly (internal representation of the database). Therefore, we do not recommend this option to export the databases.

In Job Queue you can check the progress of the export and download the csv once the progress is 100%.





## Job Queue

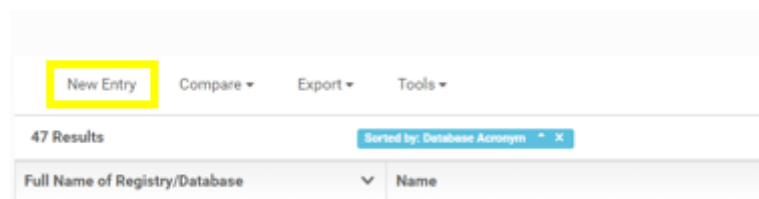
Task	Start Date	End Date	Progress	Status	Output
Export of all database answers in MSDA - June 15, 2021, 08:55 AM	June 15, 2021, 9:55 a.m.	None	2.00 %	🕒	
Export of datatable view - June 14, 2021, 10:43 AM	June 14, 2021, 11:43 a.m.	June 14, 2021, 11:43 a.m.	100.00 %	✓	<a href="#">Download</a>



## 6 How can I add a new registry/cohort to the MSDA Catalogue?

By default, every user of the MSDA Catalogue can view the Catalogue. However, if you want to add metadata of your database to the Catalogue yourself, you should contact Lotte Geys ([lotte.geys@msdataalliance.com](mailto:lotte.geys@msdataalliance.com)) so she can give you **editing rights**.

When you log in to the MSDA Catalogue and you open one out of the 3 catalogues (MSDA, MSDA COVID-19 or PROMS eHealth), you get the overview of all registries / cohorts (“databases”) that are already part of the Catalogue. Once you have editing rights, you can click on “New Entry” in the taskbar above the overview table.



Next, you can add the logo of your registry via “Select Image”.

When you click “Next”, an empty “fingerprint” (questionnaire) will be created, which you can complete.

**Organizational Information**

1.01. Full Name of Registry/Database

1.02. Abbreviation/acronym of Registry/Database

1.03. Name of Organisation/Institution keeping the registry/database

1.04. Type of Organisation/Institution keeping the registry/database

☐ Healthcare organisation  
☐ Patient organisation  
☐ Academic/Research institution  
☐ Other

1.05. Is a MS Society/Patient organisation involved?

☐ Yes  
☐ No

1.06. Contact Person for the Registry/Database

MSDA Questionnaire Database

1. Organizational Information (0/11)	0%
2. Background/Purpose (0/16)	0%
3. Inclusion criteria (patients/centres) (0/4)	0%
4. Documentation process (0/4)	0%
5. Data that are collected (0/95)	0%
6. Quality Control (0/7)	0%
7. Governance (0/3)	0%
8. State of the registry (0/5)	0%
9. Thank you for your collaboration! (0/0)	0%

Don't forget to press “Save” at the end. Please note that you don't need to wait until you entered all the metadata, but you can save in between as well.

Via the “Documents” tab of your database, you can add files (e.g. a data dictionary) to your database in the MSDA Catalogue:



Fingerprint

Documents

Via “+ Add Files”, you can add gif, jpeg, jpg, png, pdf, xls, doc, docx, tsv and txt files.

### No documents associated with this database yet.

This database fingerprint does not have documents yet. Please contact the database owner to get more information.

[+ Add files...](#)

Once the file is added, press “Upload”.

**IMPORTANT: Don't add files that contain patient-level data!**

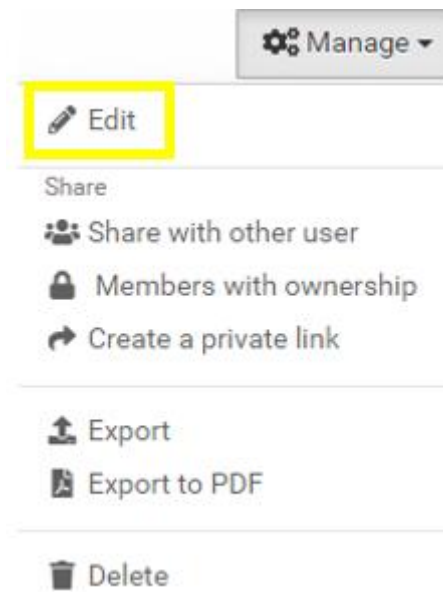
## 7 Publishing your database

Every database you add will remain “Draft” until you specify that it can be made publicly available. Only database owners can make their draft database public.

A draft database is only visible to the database owners and the community managers of the MSDA Catalogue, but not to the other registered users of the Catalogue. Once a database is made public, it is visible to all registered users of the MSDA Catalogue.

### 7.1 How can I make a draft database public?

A newly created database is “draft” by default and remains draft until the database owner makes it public. To make a database public, the database owner (the registered user who created the database) should open the database, click “Manage” (top right) and choose “Edit”:



Then there will be the possibility to uncheck a checkbox on the top of the page:

☐ This database is a draft, not visible to other users. By unchecking this box you, you request to turn it public. The Community Manager will be notified about your request.

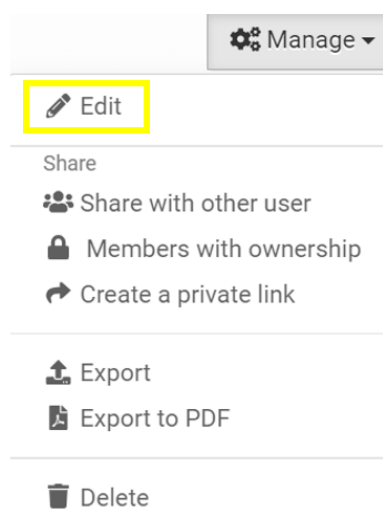
By unchecking, the database will be made public, which means that all registered users of the MSDA Catalogue will be able to see the database.

## 8 How can I edit a database in the Catalogue?

You can only edit a database if you're the database owner.

Go to the database you want to edit (via "Home" or via "Databases" → "Personal") and open the database.

Click "Manage" at the right upper corner and then "Edit":



Now you can edit the database. Don't forget to save the updates by pressing "Save".





To change the image (e.g. a logo) of your database in the MSDA Catalogue or COVID-19 Catalogue, please click “Manage”, followed by “Edit” and click “Previous” on the fingerprint screen:

Organizational Information Show ▾ Collapse all Permissions ▾

1.01. Full Name of Registry/Database

1.02. Abbreviation/acronym of Registry/Database

1.03. Name of Organisation/Institution keeping the registry/database

1.04. Type of Organisation/Institution keeping the registry/database  
☐ Healthcare organisation  
☐ Patient organisation  
☐ Academic/Research institution  
☐ Other

1.05. Is a MS Society/Patient organisation involved?  
☐ Yes ☐ No Clear Selection

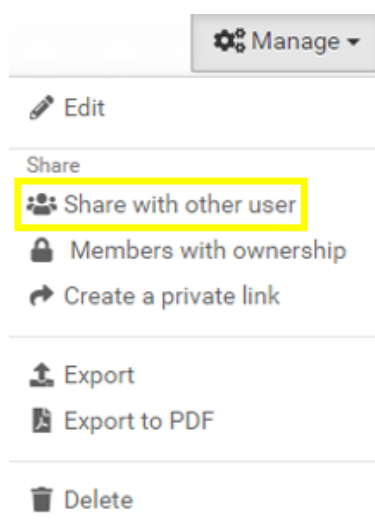
1.06. Contact Person for the Registry/Database  
< Previous Next > ✕ Cancel Save

Then you will be able to add a new image via “Select Image”.

## 9 Can I share database ownership with someone else?

Yes, you can. If you create a new “database”, you are the owner of that specific database, meaning that you can edit and update the answers to the questionnaire whenever necessary. However, you can share your ownership with other registered users of the MSDA Catalogue (everyone who created an account on the MSDA Catalogue) as well. To do so, open your database in the Catalogue, click on “Manage” and choose “Share with other user”.

*Note: you will also be informed about shared ownership via a pop-up window when you create your database.*



After you have selected “Share with other user”, you can enter the email address of the person who you want to share your membership with. The system recognizes whether or not the email address belongs to a valid user (i.e. whether or not the email address belongs to a registered MSDA Catalogue user). If the email address is valid, an email will be sent. Otherwise an invitation to create an account on the MSDA Catalogue will be sent.

Before sending the email, you also have the option to personalize the message that will be sent to your desired person.

×

Share with other user

This page allows current owners of this database, to share the database ownership with other registered users.

What is the email address of your team member? (must be a registered user)

Email:

Message to be sent to user

Dear colleague,

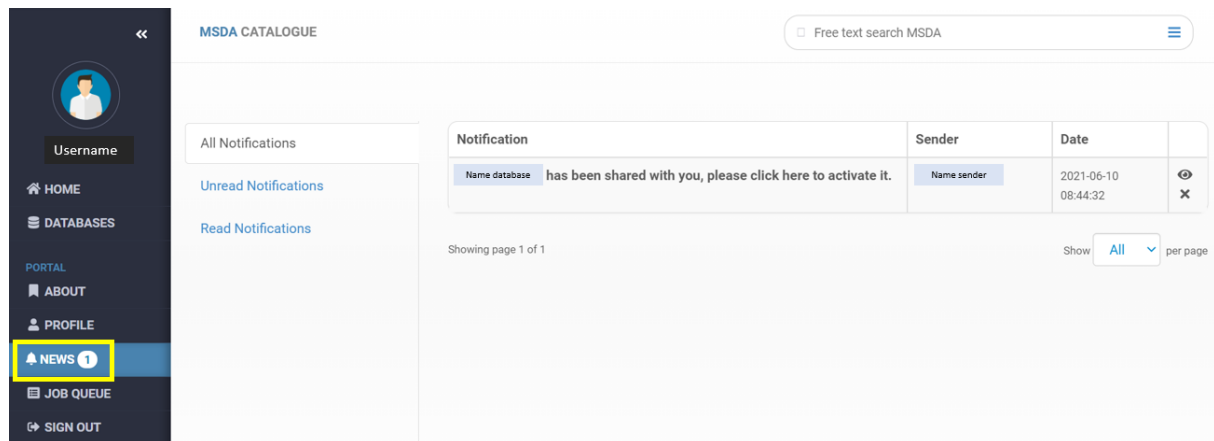
This is an invitation sent by **user name** to share with you the fingerprint of the database **Name database** which is currently described in the MSDA Catalogue: <http://bioinformatics.ua.pt/MSDA>.

Share

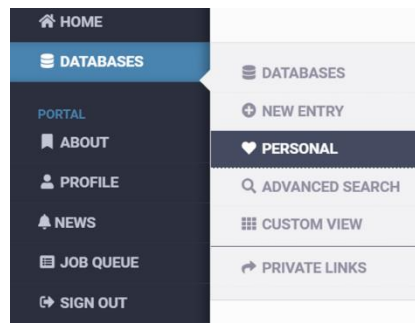
Cancel

The registered user will be informed by email that a database has been shared with him/her/them.

Once the person logs in on the MSDA Catalogue, he/she/they will have a notification (“News” in the menu) that a database has been shared with him/her/them. By clicking the notification, the database will be activated.



He/She/They will receive a confirmation email and will be able to access and edit the database via “Databases” → “Personal”:



***If you have any comments, feedback or questions related to the MSDA Catalogue, do not hesitate to contact Lotte Geys ([lotte.geys@msdataalliance.com](mailto:lotte.geys@msdataalliance.com)).***