

Multiple Sclerosis Data Alliance Catalogue

Manual

Last updated: 24 March 2022





Contents

1	Background	3
2	How can I access the MSDA Catalogue?	5
3	How can I sign in once I created an account?	7
4	What should I do if I forgot my password?	7
5	What can I see and do within the MSDA Catalogue?	9
5.1	View databases	9
5.2	Filter / order databases	11
5.3	Compare different databases	13
5.4	Export databases	14
5.4.1	Custom view (recommended)	14
5.4.2	Export a whole database that you own to PDF	16
5.4.3	Export module (not recommended)	16
6	How can I add a new registry/cohort to the MSDA Catalogue?	18
7	Publishing your database	19
7.1	How can I make a draft database public?	19
8	How can I edit a database in the Catalogue?	20
9	Can I share database ownership with someone else?	21



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 niche 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.

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

If you have questions or if you are facing issues with the Catalogue, do not hesitate to contact lotte.geys@uhasselt.be and/or liesbet.peeters@uhasselt.be.

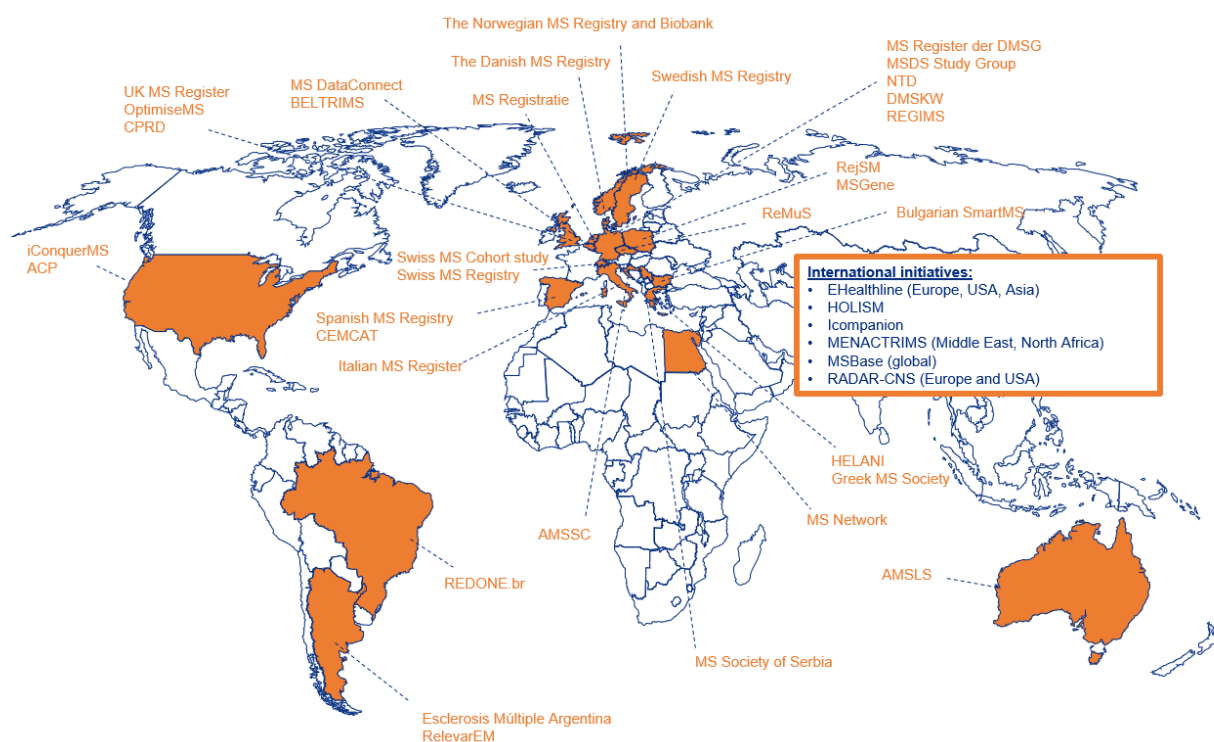
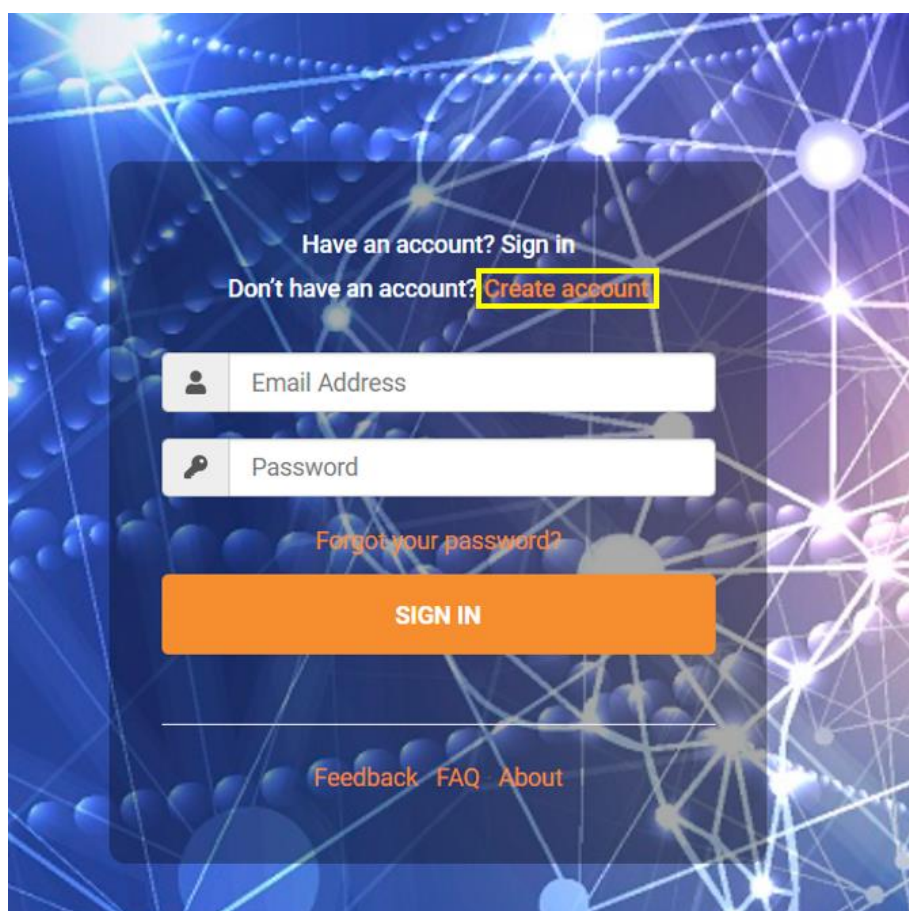


Figure 1: map showing the initiatives / cohorts / registries that are currently part of the MSDA Catalogue and their geographical locations.

2 How can I access the MSDA Catalogue?

The MSDA platform, containing the general as well as the COVID-19 niche 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/>.

A screenshot of the MSDA login page. The background is a blue and purple abstract design with glowing nodes and connecting lines. A dark grey login form is centered. At the top of the form, it says "Have an account? Sign in" and "Don't have an account? Create account". The "Create account" link is highlighted with a yellow box. Below this are two input fields: "Email Address" with a person icon and "Password" with a key icon. A link "Forgot your password?" is positioned between the two fields. A large orange button labeled "SIGN IN" is at the bottom of the form. At the very bottom of the form, there are links for "Feedback", "FAQ", and "About".

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

Email Address
Password

[Forgot your password?](#)

SIGN IN

[Feedback](#) [FAQ](#) [About](#)



You will need to provide the following information:

Create Account (all fields 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 ?

Clear

Create Account

or [sign in](#)

Note: the terms and conditions of the MSDA Catalogue are currently under construction and will be available soon.

Once you 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) 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”.

You will receive an email from 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



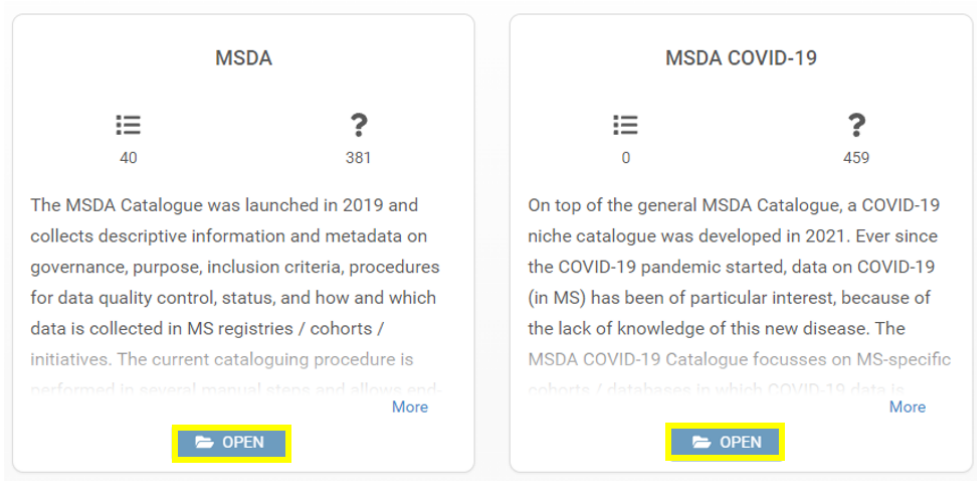
5 What can I see and do within the MSDA Catalogue?

5.1 View databases

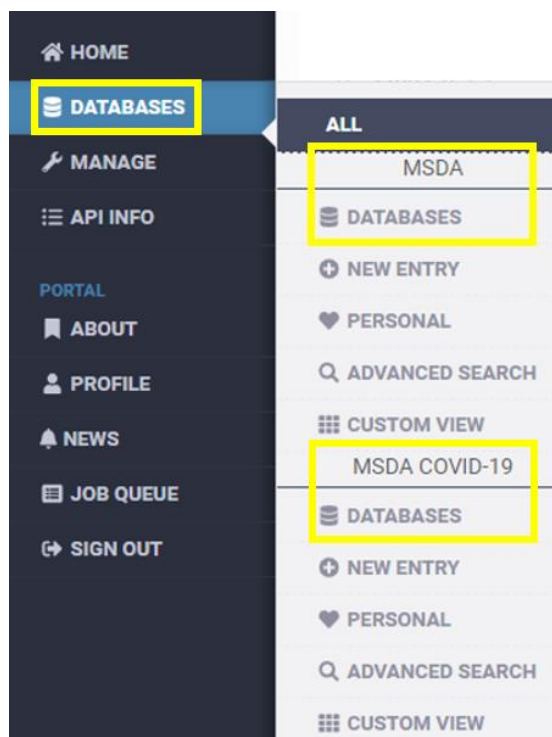
All registered MSDA Catalogue users are able to view the databases within the MSDA Catalogue. When you log in on the MSDA Catalogue (via <https://msda.emif-catalogue.eu/login>) you will see a distinction is made between the general MSDA Catalogue and the MSDA COVID-19 Catalogue:

- “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).

To open one of the two catalogues (MSDA or MSDA COVID-19), you click “open” in the box of the MSDA or MSDA COVID-19 Catalogue on the homepage:



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



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 of the registry
- inclusion criteria of patients and centers
- information regarding documentation processes
- data collected (including high-level questions regarding e-health technologies and COVID-19)
- quality control mechanisms
- governance
- status of the registry

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

- organizational information / background
- documentation process

- data collected
- governance
- current state

You can do this by opening a certain database by clicking on the respective database name (in the “Full Name of Registry/Database” column).

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

Summary View

Hits: 64 Unique Views: 36 Filled: 71.8 %

ORGANIZATIONAL INFORMATION

1.01. Full Name of Registry/Database

Summary View Items:

Item	Completion
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”.

Detailed View

Hits: 145 Unique Views: 57 Filled: 79.8 %

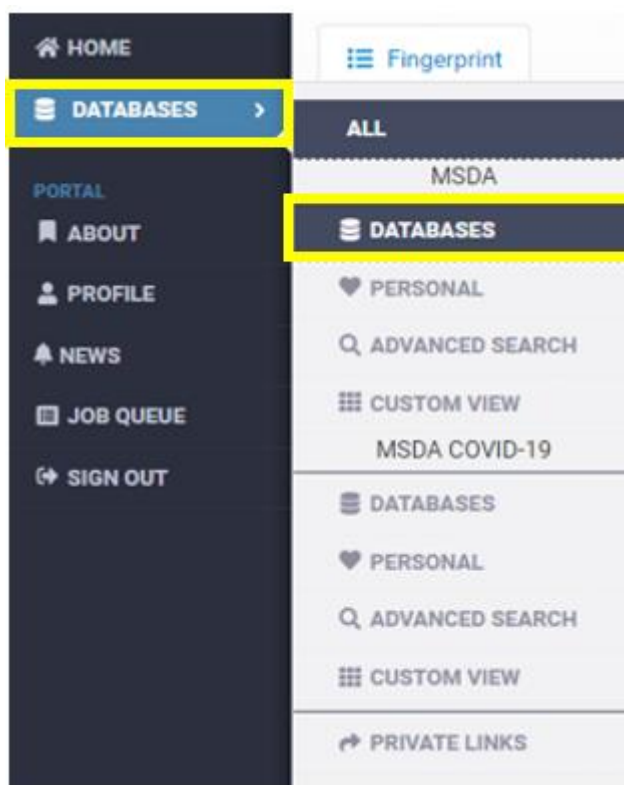
Detailed View Items:

- 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):



⌵ FILTERS / ⬆ ORDER BY

Close

Order By

Database Acronym

☒ Ascending
 ☐ Descending

Filter By

Name

Registry/Database was initiated in the year
 1958 to 2000

Approximate number of registered patients
 to

Language of the registry
 English

Approximate number of registered visits
 to

Database Acronym

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 of the registry, inclusion criteria of patients and centers, ... 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.

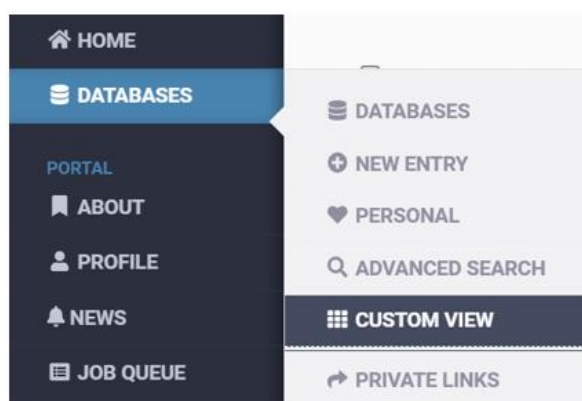
	Data source 1	Data source 2	Data source 3
	Reference	Compared	Compared
Organizational Information	Organizational Information	Organizational Information	Organizational Information
Background/Purpose	Background/Purpose	Background/Purpose	Background/Purpose
Inclusion criteria (patients/centres)	Inclusion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

	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	• Yes	• Yes	• Yes
What is the requirement of this data?	• Mandatory		• Mandatory
Number of registrations		1787	
Gender	• No	• Yes	• Yes

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. 6. 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.

Custom View

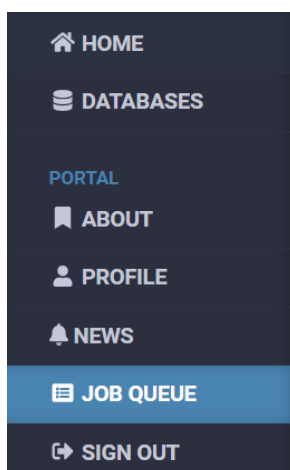
To see a tabular view of selected databases, please choose the questions and the databases and select "Export"

[illegible]

You can expand a category (e.g. 6. Data that are collected) by clicking on the arrow at the very front (circled in yellow in the picture above).

You can get the export by clicking on “Export” (at the right).

In Job Queue you can check the progress of the export and download the csv file with the requested information.



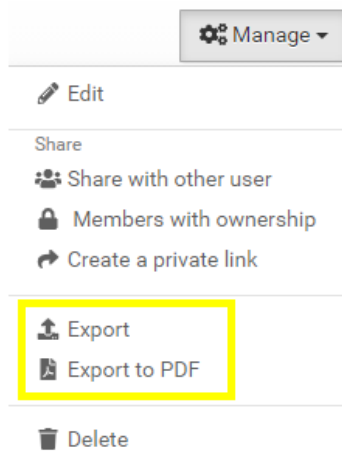
Job Queue

Task	Start Date	End Date	Progress	Status	Output
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 %	✓	Download



5.4.2 Export a whole database **that you own** to PDF

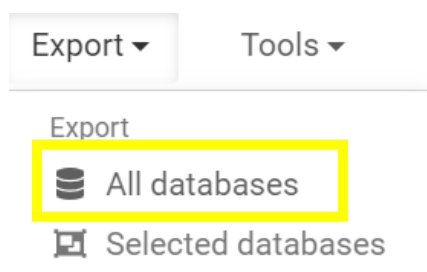
If you want to export a database you are the owner of to a pdf file, you can open the database via the Home page by clicking on the Full name of Registry/Database and click on “Manage”. Choose “Export to PDF” and a pdf file will be provided.



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%.



-  HOME
-  DATABASES
-  PORTAL
-  ABOUT
-  PROFILE
-  NEWS
-  **JOB QUEUE**
-  SIGN OUT

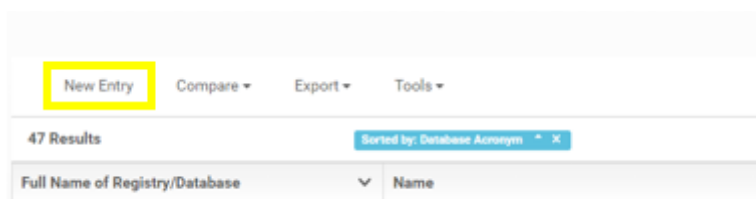
Job Queue

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 %		Download

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 your database to the Catalogue yourself, you should contact Lotte Geys (lotte.geys@uhasselt.be) so she can give you **editing rights**.

When you log in to the MSDA Catalogue, 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” will be created, which you can complete.

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

1.05. Is a MS Society/Patient organisation involved?

1.06. Contact Person for the Registry/Database

< Previous Next >

Cancel Save

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 data, 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!

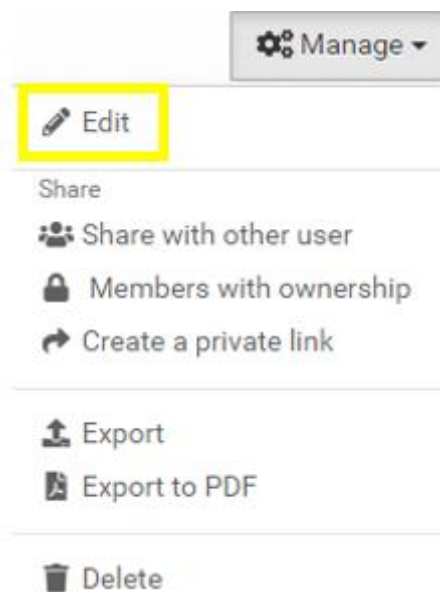
7 Publishing your database

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.

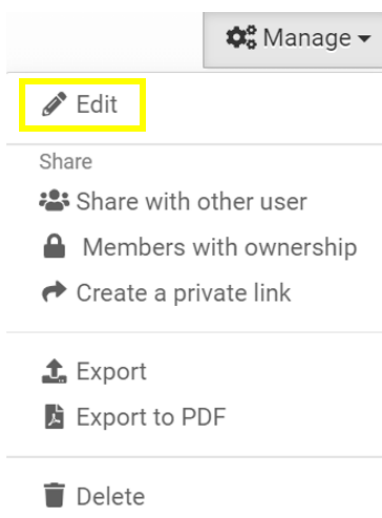
By unchecking, the database will be made public, which means that all registered users of the MSDA Catalogue will be able to see the database.

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 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

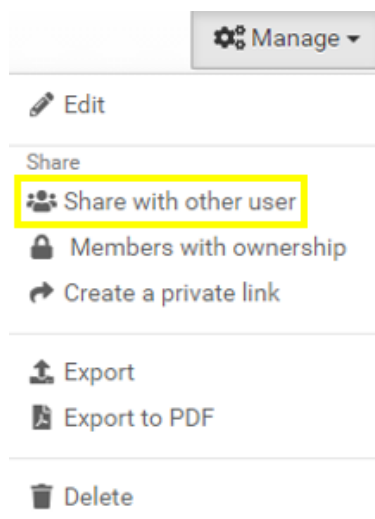
Cancel
Save

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. 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 you 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>.

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/they. By clicking the notification, the database will be activated.

The screenshot shows the MSDA Catalogue interface. On the left is a dark sidebar with a user profile section (Username, profile icon) and a menu with options: HOME, DATABASES, PORTAL, ABOUT, PROFILE, NEWS (highlighted with a yellow box and a notification badge), JOB QUEUE, and SIGN OUT. The main content area is titled 'MSDA CATALOGUE' and features a search bar labeled 'Free text search MSDA'. Below the search bar, there's a 'Notification' section. It includes a list of notifications, with one visible: 'Name database has been shared with you, please click here to activate it.' The notification table has columns for 'Notification', 'Sender', and 'Date'. The notification is dated '2021-06-10 08:44:32'. Below the notification list, it says 'Showing page 1 of 1' and 'Show All per page'.

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

The screenshot shows the navigation menu of the MSDA Catalogue. The menu is divided into two columns. The left column contains: HOME, DATABASES (highlighted), PORTAL, ABOUT, PROFILE, NEWS, JOB QUEUE, and SIGN OUT. The right column contains: DATABASES, NEW ENTRY, PERSONAL (highlighted), ADVANCED SEARCH, CUSTOM VIEW, and PRIVATE LINKS.