

MSBase Foundation

Registry Quick Start Guide

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1. About the MSBase Registry

The MSBase Foundation is an independent not-for-profit organisation that owns and operates the MSBase Registry - a unique international collaborative registry designed for clinicians working in the field of multiple sclerosis (MS) and other neuroimmunological diseases (NIDs), to collect, track, share and evaluate patient outcomes data.

The MSBase Registry platform enables the collection of data for studies of MS/NIDs regionally, nationally, or globally, with customizable sub-study functionality that filters data according to research themes.

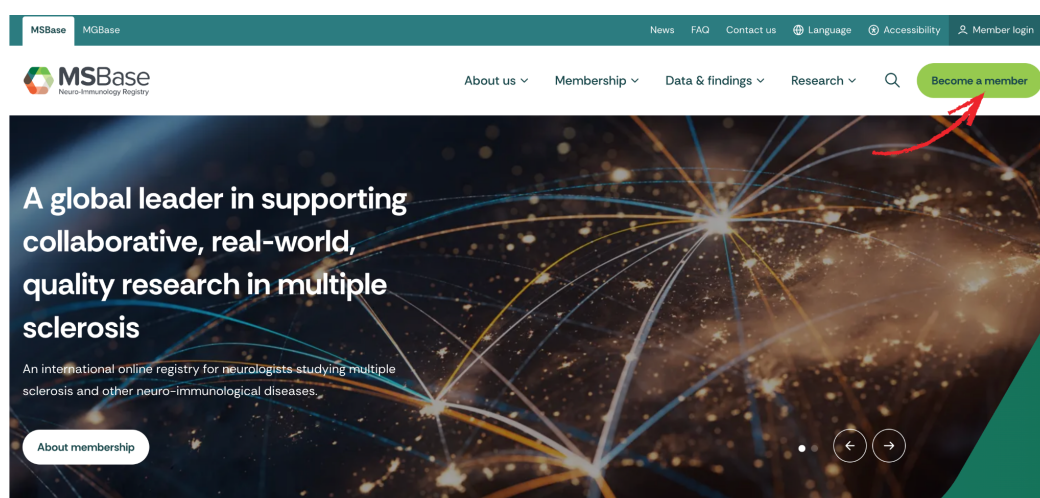
The purpose of this guide is to provide a quick introduction to the website features.

2. Joining the Registry

If your centre is not a member the MSBase Registry, then you will need to apply for membership. [Membership benefits](#) are detailed on our website.

Centre membership must be initiated by the lead Neurologist in charge of the MS or other NID Unit at your hospital/clinic, who will assume the role of centre Principal Investigator (PI). Other MS and NID staff can then become Investigators (I) or Members of the centre, under the PI's lead.

To apply, please visit the [Sign Up](#) link on our website.



You will be required to fill some basic personal and professional details to complete your membership application. Once you have submitted the online registration form, the MSBase Membership Manager will review your application and will advise if your centre has been approved or if additional information is required. All Principal Investigators must read and sign the MSBase Registry Participation Agreement and associated schedules, prior to their centre being approved.

Once your application has been approved and you have agreed to the terms and conditions, your centre will be initialized and be ready for contributing data to the MSBase Registry.

Data can be imported into the MSBase Registry through two methods. Users can contribute data using the iMed Web platform, which provides full functionality for submitting information directly to MSBase. Alternatively, users who prefer the traditional interface can use iMed Classic to enter and submit their data. The MSBase IT team will be able to advise you on which platform is right for you.

Should you have any questions regarding the joining process or data entry software, please email us at info@msbase.org.

3. Existing Members

In June 2017, the MSBase Registry website was updated. MSBase members that were members prior to this date will need to use their email to reset their password. Password reset details are below.

4. Password Management

4.1 Password Reset

Have you forgotten your password and need to reset it? Simply navigate to the [Forgot Password link](#) at the Login screen. Once you have entered your email address then an email will be sent with a reset password link.

If your centre is configured to use Microsoft Entra ID then you will use your Entra ID credentials and MFA. You cannot reset your password via MSBase systems.

Still having problems? Contact info@msbase.org for support.

4.2 Password Change

Would you like to change your current password? Navigate to the My Profile screen. Once there, you will need to enter your old password under “Current Password” and a new password under the “Password” field. All MSBase user passwords must conform to the guidelines described below.

A combination of at least one character from each of the following four listed character types:

- English uppercase letters (A-Z),
- English lowercase letters (a-z),
- Include one or more numerals (0-9);
- Non-alphanumeric characters (such as `~!@#\$%^&*()_+ -= { } | \ : " ; ' < > ? , . / and space)

Guidelines

- Be a minimum length of twelve (12) characters on all systems.
- Not be displayed when entered.
- Not based on any personal information.

5. Member roles and viewing your data

5.1 Roles

Once you have logged into the MSBase Registry, your ability to perform specific functions will depend on your role. The roles are detailed below:

Principal Investigator (PI): This role is assigned to the lead Neurologist of the centre. The PI is responsible for understanding and signing the MSBase Foundation governance documentation and ensuring their centre adheres to all rules and conditions of participation. This role can perform tasks such as: Creating a Sub-study, Joining a Sub-study, Managing a Sub-Study as well as managing their centre, including inviting new users, removing users and modifying user roles. Each centre has one PI.

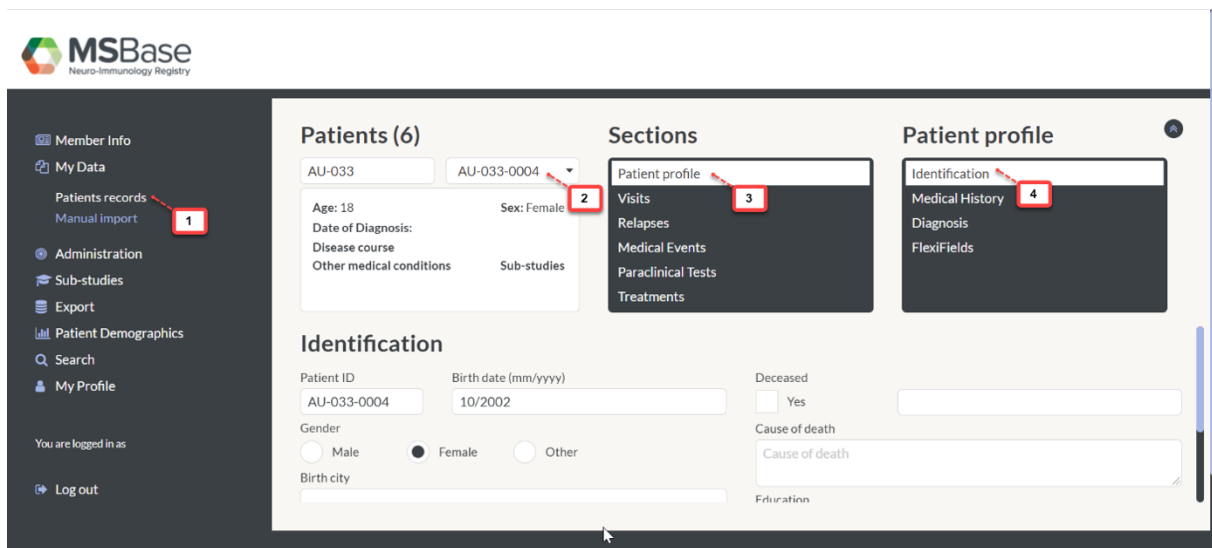
Co-Principal Investigator (Co-PI): A PI may assign other senior members at their centre as a Co-PI should they wish to delegate administrative responsibilities. A Co-PI can perform the same functions as a PI, with the exception of creating a new sub-study. A centre can have multiple Co-PIs.

Investigator: This role is usually assigned to medical or research staff who assist to upload patient data and enrol patients into sub-studies.

Member: This role is usually assigned to staff who provide administrative assistance within the centre. Members do not hold the authority to upload patient data or enrol patients into sub-studies.

5.2 My Data

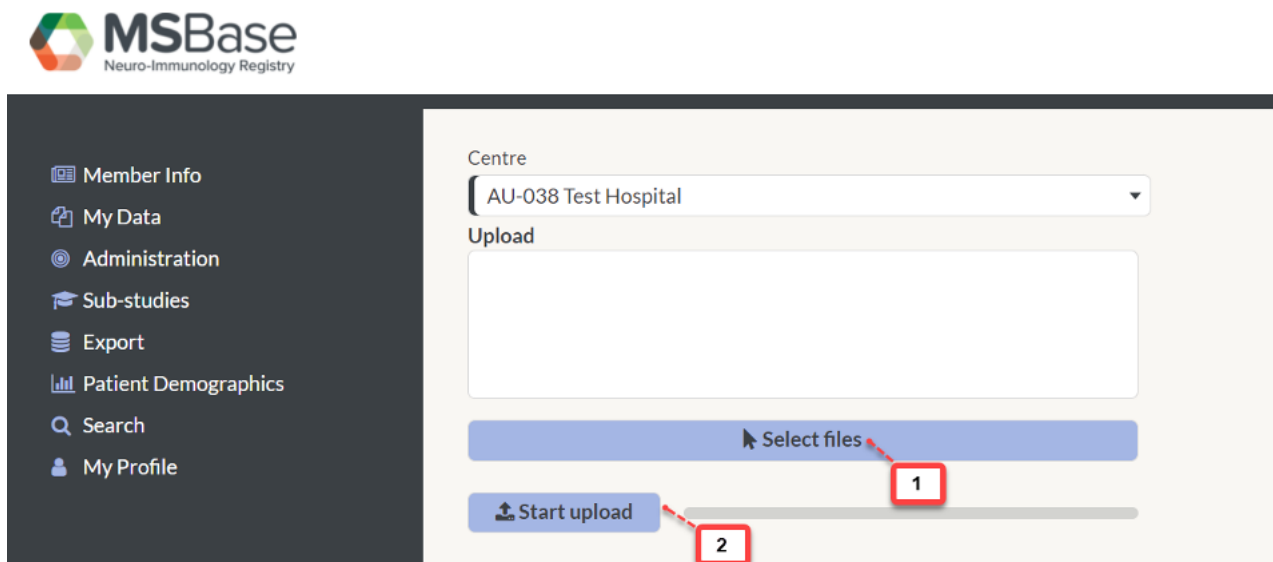
The My Data section contains all your patients. To view patients you have uploaded to the Registry, select Patient Records (1) and use the list to find your patient (2). Once you have located your patient, you can use the category or section (3) and relevant screen (4) to navigate and view the submitted data.



5.3 Manual Import

This feature should only be used when your iMed is unable to synchronize directly with the Registry. This may be due to a firewall or security restriction in your centre. To use this feature locate the MSBaseExtract.xml.zip, typically located in *C:\iMed\MSBase_Dataset* folder using the Select File (1) button. Once the file is located, Start Upload (2).

NB: Please note that any iMed centres participating in sub-studies, must use the direction integration (Send now functionality) that is available within iMed. Using the portal below to manually import patients, will send patient data to the MSBase Registry, but will not pull down the relevant sub-study information or data for participating iMed centres.



6. Sub Studies

What is a sub-study? A sub-study is a mechanism that allows centres to share data for research purposes. Creating a sub-study is a way that you can request data from other centres, while joining an existing sub-study will allow you to contribute your centre's data for research.

How does a sub-study work?

Consider the following scenario: You want to analyse the data for "All females from Australia and New Zealand". Once you have entered the basic details about the sub-study, you then need to identify the Member Selection, Patient Selection and Flexifields. The Member Selection would be *countries that are equal to Australia or New Zealand* and the Patient Selection would be restricted to "Gender = Female".

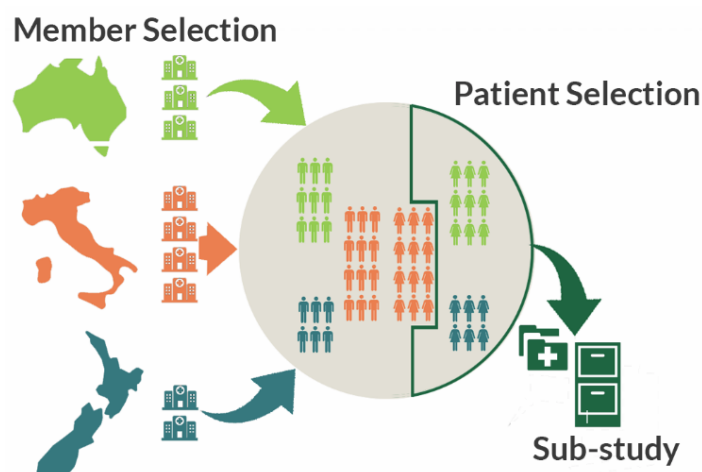


Figure 1: Visualisation of the selection process of All females from Australian and New Zealand centres. Note Italian females were not included as they did not meet the Member Selection criteria.

Once the sub-study is active, as soon as a member joins your sub-study, then the data of all "eligible" patients meeting the selection criteria will be available to download. This is called *Automatic enrolment* and is the default. Some sub-studies may require *Manual enrolment*. These studies require members to manually enrol patients to the sub-study. Reasons for this method might include:

- Selection criteria that is complex or may require a value judgement from the member
- Sub-study that requires special ethics or patient approval

Sub-studies can be created by the centre PI only. The below provides details on how to create a sub-study, manage that sub-study and view and join sub-studies.

All sub-studies will be approved by the MSBase Operations team after submission. If you have any questions, please contact the team at info@msbase.org.

6.1 Creating a sub-study

As a PI, to create a sub-study, select Create Sub-study (1) and fill in the required details (2), (3) and (4). These details will be used by other members to decide whether they wish to contribute data to your research, therefore it is important to be descriptive. Your sub-study details will also be visible on the MSBase website, so please take this into consideration should your research topic contain any confidential or sensitive content. Finally, please ensure that the title and description is in English.

Once you have finished entering details about your sub-study, click Next (5).

The screenshot shows the MSBase Neuro-Immunology Registry interface for creating a sub-study. The form is titled 'Create a Sub-Study' and is divided into five steps: 1. Project description, 2. Member selection, 3. Patient selection, 4. FlexiFields, and 5. Review. The 'Project description' step is active. The form fields include: Study Title (My first Sub-Study - Aus & NZ Female MS Progression), Objectives (To analyse treatment outcomes in all Australian and New Zealand patients. All patients are Female.), Primary and secondary endpoints (1. First endpoint details, 2. Secondary endpoint details.), and Lead Centre. The 'Next' button is highlighted with a red box and labeled 5.

When selecting Members, there are three options.

- Open to all Investigators: This option will allow any member from any country or centre to join
- Restrict to Investigators from the following countries: This option will restrict member selection to country
- Restrict to Investigators from the following centre's: This option will restrict member selection to centre

In our example we are restricting members by country (1), and only allowing Australia and New Zealand members to join (2). Once we have selected our members, click Next (3)

After selecting our members, we must then restrict the patient selection. Patients can be restricted in 3 ways:

- All patients: “All patients” removes all restrictions.
- Restrict by inclusion criteria: All patients that meet a specific search criteria.
Restrict by manual enrolment: Used in combination with the above, if this option is checked, the member must manually enrol each patient individually.

In this example we have made the selection to restrict the patient inclusion by search criteria (1). We then enter the desired search criteria (2) and click Next (3). If you are unsure about which fields you need, or have complex search criteria, simply continue with the sub-study creation process and when finished send an email to the MSBase Operations team at info@msbase.org. Additionally for more complex searches, it may be preferable to be more inclusive and remove additional patients during data cleaning.

6.2 Custom Data Capture

Create a Sub-Study

1 Project description 2 Member selection 3 Patient selection 4 FlexiFields 5 Review

All patients
 Restrict by inclusion criteria **1**
 Restrict by manual enrolment

0 patients in Test Hospital fall within the criteria of this sub-study **Update**

[Profile] [Identification] [Gender] [=] [Female] **2** +

Cancel **Prev** **Next** **3** **Save**

Do you have specific data you require about each patient for your research? For each sub-study it is possible to capture custom data fields – these are referred to as “Flexifields”. Data types include:

- Text: Alphanumeric text restricted to 200 characters
- Numeric: Number only text with a maximum of 3 decimal places
- Date: Date field for past and future dates
- Text-Area: Alphanumeric text for comments and longer text
- Dropdown: Allow the user to select 1 value from a list of many values
- Checkbox: For True (checked) and False (unchecked) values
- Section Break: From complex data entry forms use the section break to sort the fields into logical sections

Data can be captured at the Patient Identification level **(1)** and at a Visit **(2)** level. Patient Identification should be used for data that will be captured only once and won’t change over time (for example patient permission acknowledgement, eye-colour or phone-number). Visit data is captured at each visit and utilises time-series/longitudinal fields (for example height, weight or current mood). Simply select the section you wish to add a field to and click Add **(3)**. When finished, click Next **(4)**.

For our example, we are capturing Internal Ref (Numeric) and Permission from Patient (Checkbox).

Create a Sub-Study

1 Project description 2 Member selection 3 Patient selection 4 FlexiFields 5 Review

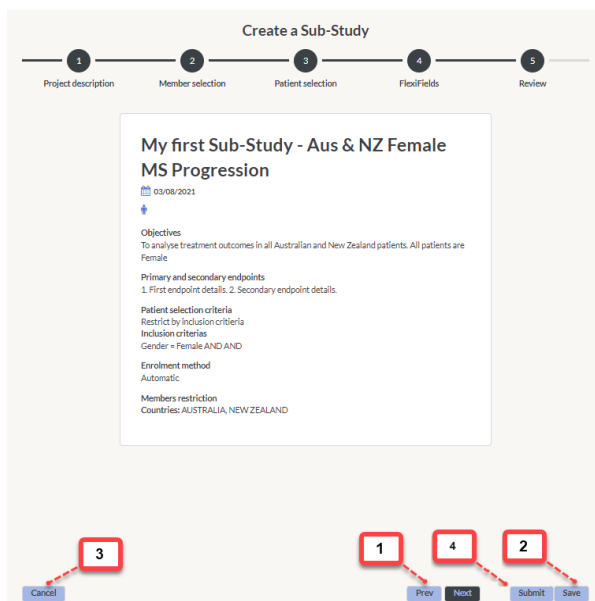
Flexifields **Add** **3**

Patient Identification Visits **2**

Sort	Name	Type 1	Unit	Minimum	Maximum
	Internal Ref	Numeric			
	Permission from Patient?	Checkbox			

Cancel **Prev** **Next** **4** **Save**

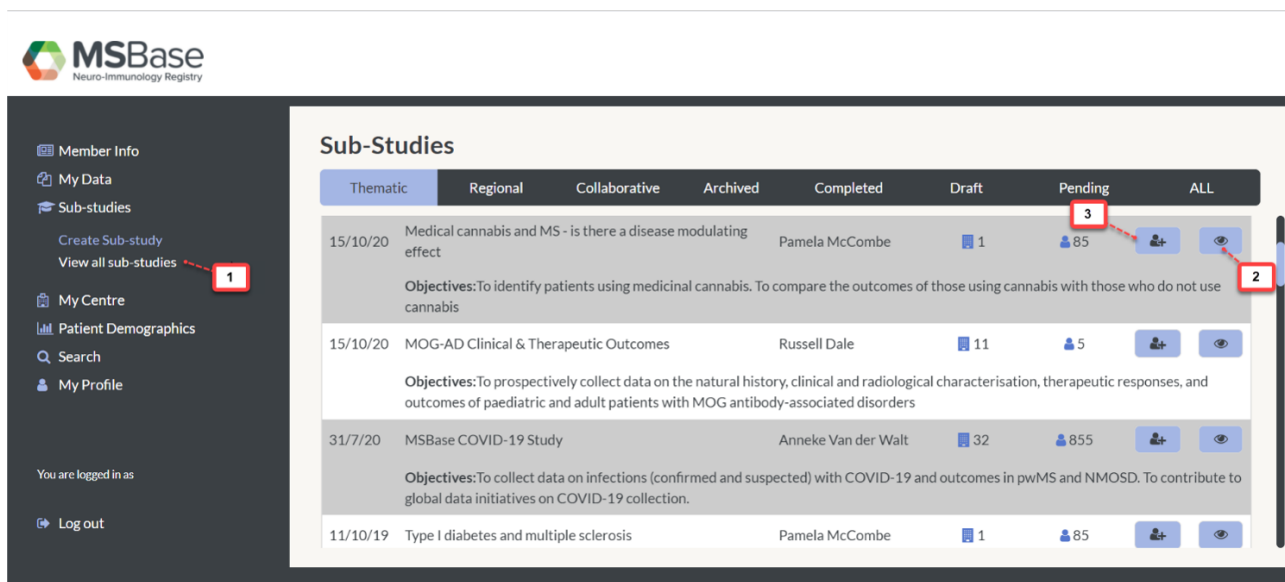
Prior to submitting your sub-study, review the details and make any required changes by going to the 'Previous' pages (1). You can 'Save' (2) to keep the sub-study as a draft for review later or 'Cancel' (3) at any point. When ready to submit your study, click Submit (4)



Congratulations! Your sub-study is now awaiting approval from the MSBase Operations team. You can enquire about progress at any time with the Operation Team at info@msbase.org. You will be notified by email if your sub-study is successful. All eligible members will also be sent an email advising them that a new sub-study has been created.

6.3 Viewing and joining sub-studies

All members can View (1) sub-studies when logged into the Registry, however only a PI or Co-PI will be able to join sub-studies. Sub-studies that your centre is eligible to join will be presented first in the *Available Studies* section, while sub-studies that are not available for your centre (due to centre or country restrictions), are in the *Other Studies* section. You can view the details of the sub-study by selecting View (2) or you can join the sub-study by selecting Join (3).



All users will be able to see basic information about the sub-study prior to joining. This information includes sub-study descriptions and endpoint (1), Enrolment History (2) and Enrolment Country distributions (3). You can also join the sub-study from this section (4).

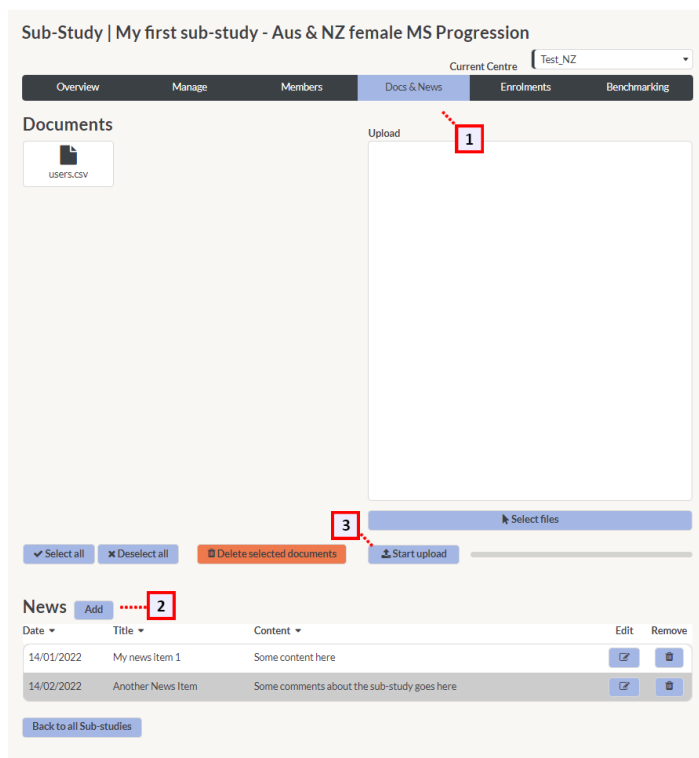
After joining a sub-study, the owner of the sub-study must accept your join request. Once the request has been approved then you will also be able to view other member information, news and documents and patient demographic data.

6.4 Managing your sub-study

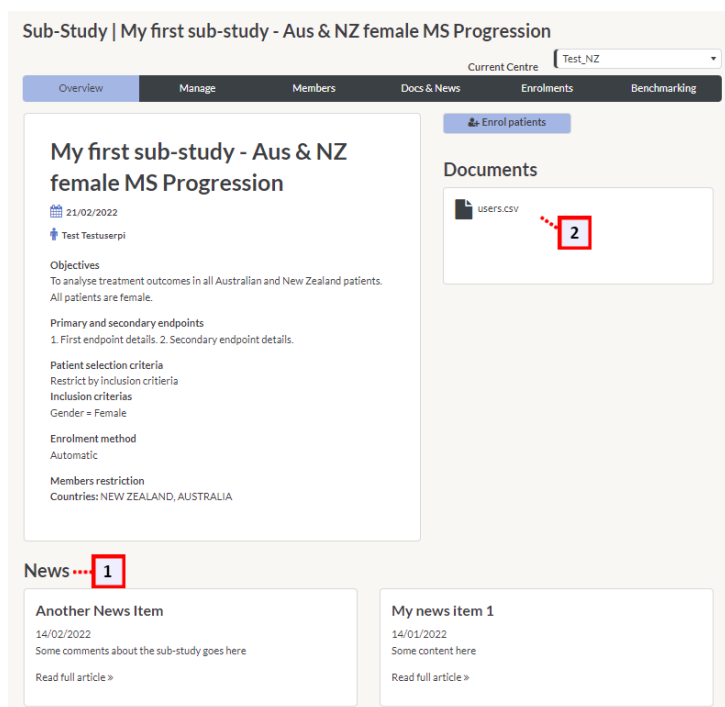
A PI or Co-PI can manage a sub-study. To do this, find your sub-study and click Manage (1). The Manage dashboard allows you to re-invite (2) members (an automatic email will be sent to all eligible centres) and download all the data of the participating patients (3). New centres that wish to join your sub-study will need to be Accepted or Declined (4) before their data becomes accessible.

When a new centre is accepted, the patients will be automatically enrolled into your study (except where manual enrolment is set – see Section 6.6.). As new patients from participating centres become eligible for your study, they will be automatically added to your sub-study. Once a patient is added to your study then they cannot be removed. For example, if your selection criterion is: “Has an ongoing treatment of Drug X” and a patient stops treatment, then that patient will stay in your sub-study.

As the leader of a sub-study, you can communicate with you members by posting Docs & News (1) to keep members up to date. Selecting Add (2) will open a text editor, allowing you to add sub-study news. You are also able to upload documents relevant to the sub-study. Select Files (3) that you want to upload and select Start Upload.

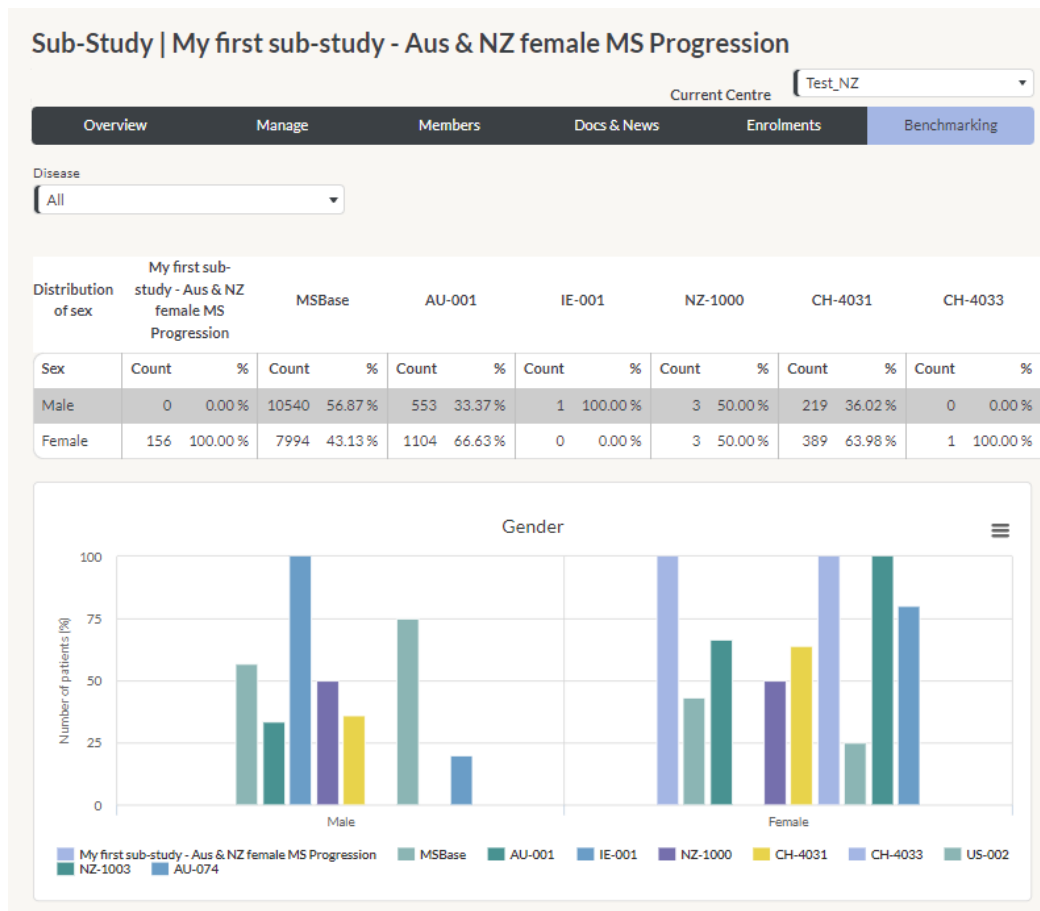


News (1) and Documents (2) will appear to members of the sub-study. Members will also receive an email notification of the News item and Document addition.



6.5 Sub-studies – Benchmarking

The MSBase Registry allows members of a sub-study to benchmark their centre data against the overall data in the sub-study cohort as well as the entire MSBase Registry. In the below example we can see that the sub-study has 156 females (100%), while the MSBase Registry consists of 7994 (43.13%) females.



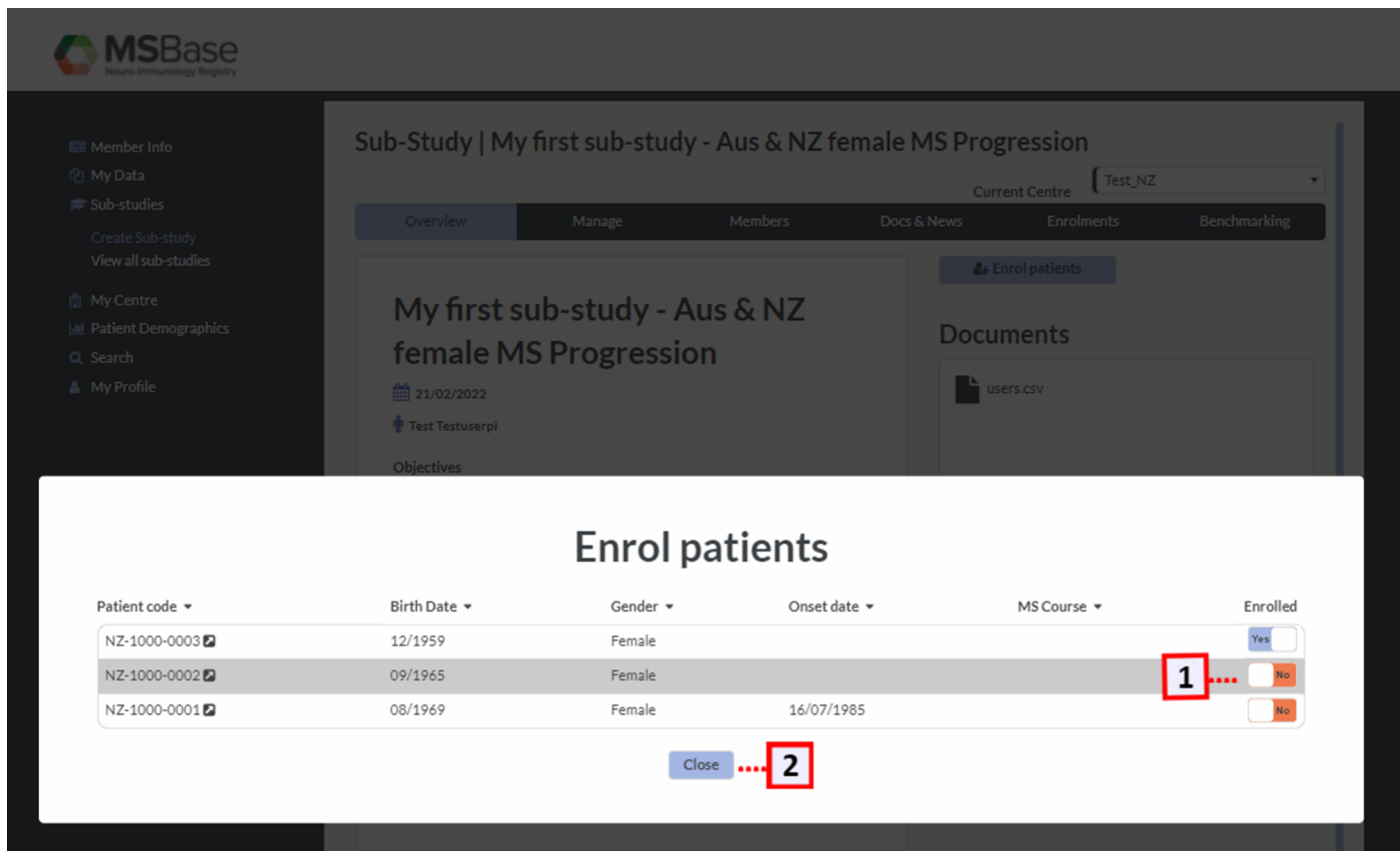
6.6 Sub-studies – Manual Enrolment

Some sub-studies are specified as Manual Enrolment and operate on an opt-in basis. This is different to the automatic enrolment as it requires the member to manually select the patients they want to enrol. This may be useful if the patient inclusion criteria are subjective or complex.

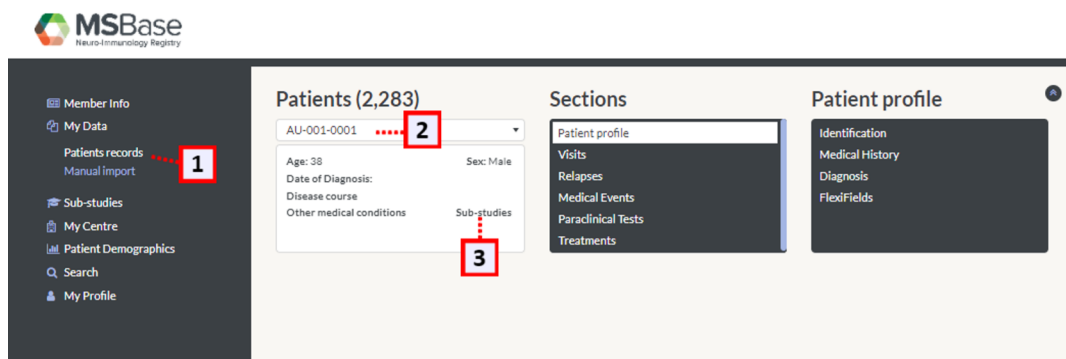
If you have joined a sub-study that has manual enrolment, there are two ways you can add patients. One way to add them is at the sub-study level. Go to the sub-study and on the Overview tab **(1)** select Enrol Patients **(2)**.



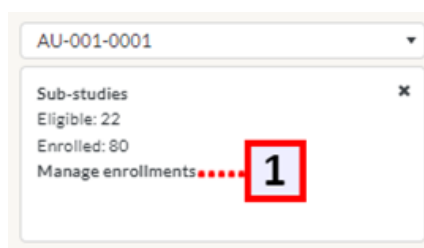
A new window will open to allow you to enrol patients by selecting the Yes/No toggle under Enrolled (1). When finished enrolling patients, select Close (2). In some cases your patient will not be able to be enrolled to a manual sub-study. This is due to the patient criteria restricting access. For example, we can restrict a sub-study to females only and still require manual enrolment.



An alternative way to enrol patients is in the Patient View (1). Navigate to the desired patient (2) and select the Sub-study option from the Patient Summary view (3).



The Patient Summary view identifies the count of sub-studies that the patient belongs to or is eligible to join. This view also enables you to manually enrol the patient to one or more sub-studies. By selecting Manage enrolments (1) the user is presented with a list of all eligible and enrolled studies.



A window will display the sub-studies that the patient is eligible for, or enrolled in (1). Where the patient is automatically enrolled, the 'Yes' button will be displayed (2) and there will be no option to unenroll the patient. To manually enrol a patient in any other eligible studies, select the 'No' to 'Yes' toggle (3) and Close (4) the window.

Eligible sub-studies

Substudy	Start date	Enrolled
New Test Substudy #2	27/09/2016	Yes
New Test Substudy #2	27/09/2016	Yes
New Test Substudy #2	27/09/2016	Yes
Steve's substudy	28/09/2016	Yes
Steve's substudy	28/09/2016	Yes
Manual Enrollment Test #1	30/09/2016	No
Manual Enrollment Test #1	30/09/2016	No
Manual Enrollment Test #1	30/09/2016	Yes

Close

This should provide sufficient context of the enrolment procedure. In both the sub-study specific view and the patient specific view, eligible patients/studies are listed with their current enrolment status displayed. Where 'Yes' indicates the patient has already been enrolled into the sub-study and 'No' is shown for those eligible but not enrolled yet.

In what circumstances should I use either view? The sub-study specific view should be used when you first join a sub-study and want to enrol patients in bulk to the single sub-study. The patient specific view should be used when a patient is new to the registry and you want to enrol him/her to one or more sub-studies.

6.7 Sub-studies – Completing a Sub-study

Only MSBase administration has the ability to mark a sub-study as complete. Should a sub-study leader wish to complete their sub-study, they should contact info@msbase.org to confirm this request in writing.

Once a sub-study is closed, it cannot be re-activated.

The sub-study leader has the ongoing ability to download the study data.

7. My Centre

7.1 Centre users

The PI and Co-PI can manage their centre Users (1). This includes removing (2) users, editing (3) the details of users and inviting new users (4).



The screenshot shows the 'My Centre' page for 'MSBase Test Centre'. The left sidebar contains navigation options: Member News, Member Documentation, My Data, Sub-studies, My Centre (with sub-items: Centre users (1), Centre details, MDS), Patient Demographics, Search, and My Profile. The main content area is titled 'Centre' and shows a dropdown menu for 'MSBase Test Centre'. Below this is the 'Staff for MSBase Dusko Test Centre' section, which includes an 'Invite user' button (4) and a table of staff members. The table has columns for First name, Last name, E-mail, Role, Last login date, Edit, Remove, and Enabled. The table contains two rows: one for a PI (Principal Investigator) with a last login date of 09/02/2023, and one for a Co-PI with a last login date of 17/01/2023. The Co-PI row has a red circle with the number 3 next to the Edit button and a red circle with the number 2 next to the Remove button.

When inviting a new user to your centre, you will need to supply an email address (1) and the role (2). The Permissions role is for centres that are using iMed Web (the MSBase Data-entry System). If you are currently using iMed, or if you are in doubt, leave as Admin and the MSBase Operations team can further advise or can edit this role later as required. When complete, click Send (3).



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The screenshot shows the 'Invite user to MSBase Test Centre' form. The left sidebar is the same as in the previous screenshot. The main content area is titled 'Invite user to MSBase Test Centre' and contains a form with two fields: 'E-mail' (with a red circle 1 next to the input field) and 'Role' (with a dropdown menu showing 'Investigator' and a red circle 2 next to it). Below the form are 'Send' and 'Cancel' buttons, with a red circle 3 next to the 'Send' button. To the right of the form is a section with definitions for the roles: 'Principal Investigator (PI)', 'Co-Principal Investigator (Co-PI)', 'Investigator', and 'Member'. The 'Send' button is highlighted with a red circle 3.

The invited user will receive an email invitation. Once they have completed the sign-up process, they will be active users of your centre.

7.2 Centre Details

A PI or Co-PI can change the contact details of the centre at any time by selecting centre details and updating the form.



Member News
Member Documentation
My Data
Sub-studies
My Centre
Centre users
Centre details
Patient Demographics
Search
My Profile

You are logged in as
Log out

My Centres

MSBase Centre of Testing

Hospital: MSBase Centre of Testing
Department: IT Support
Street Address: 123 Fake St
City: Fakesville
Country: AUSTRALIA
Postal Code: 3000

Mailing address different

Centre Contact Phone: 0412503212
Do you currently use iMed? Yes No Don't know
iMed version: 7.0.0
Comments:


Mailing address 1
Mailing address 2
Mailing street
Mailing City
Mailing Country: Select an option
Mailing Postal Code

Centre Contact Email
Are you interested in MDS? Yes No Don't know

Save Cancel

8. My Profile

All users can update their details by selecting My Profile **(1)**. Mandatory fields are required and denoted by the blue cell padding on the left. Once fields have been completed select 'Save' **(2)**.

About us | Become a member | Data and findings | Sub-studies | FAQ | News | Contact us | [Log out](#)

- Member News
- Member Documentation
- My Data
- Administration
- Sub-studies
- Export
- Patient Demographics
- Search
- My Profile 1**

You are logged in as

[Log out](#)

Basic Info

Title	Birth Year	E-mail
<input type="text" value="Mr"/>	<input type="text" value="1994"/>	<input type="text" value="testuser@gmail.com"/>
First Name	Last Name	
<input type="text" value="Test"/>	<input type="text" value="User"/>	
Sex	Country of practice	
<input checked="" type="radio"/> Male <input type="radio"/> Female	<input type="text" value="AUSTRALIA"/>	
Preferred Phone	Profession Role	
<input type="text" value="0412345678"/>	<input type="text" value="Lead Neurologist"/>	
Comments		
<input type="text"/>		
Internal MS Base Foundation comments		
<input type="text"/>		

Password

Current Password	<input type="text"/>	
Password	Password Confirm	
<input type="text"/>	<input type="text"/>	

Professional Details

University/Medical school	Year of Highest medical degree
<input type="text"/>	<input type="text"/>

2