European Reference Network
for rare or low prevalence complex diseases

Network Neuromuscular Diseases (ERN EURO-NMD)

ERN Euro-NMD - User guide

https://ern-euro-nmd.eu/

Version 16/12 /2024

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TASK LIST URLs

Register / Login: https://ern-euro-nmd.eu/login/

Private space: https://ern-euro-nmd.eu/private/

Edit profile: https://ern-euro-nmd.eu/profile/

Groups Membership: https://ern-euro-nmd.eu/private/groups-membership/

Shared files: https://ern-euro-nmd.eu/private/shared-files/

Data collaborations forms: https://ern-euro-nmd.eu/data-collaboration-forms/

Request a group membership: https://ern-euro-nmd.eu/data-collaboration-forms/create/group-membership-request/

Propose a new healthcare provider: https://ern-euro-nmd.eu/data-collaboration-forms/create/healthcare-provider/

Propose a new organization: https://ern-euro-nmd.eu/data-collaboration-forms/create/organisation/

Create a news post: https://ern-euro-nmd.eu/data-collaboration-forms/create/post/

Create an opportunity post: https://ern-euro-nmd.eu/data-collaboration-forms/create/opportunity/

Add an event to the website: https://ern-euro-nmd.eu/data-collaboration-forms/create/event/

Add a publication to the website: https://ern-euro-nmd.eu/data-collaboration-forms/create/publication/

Add a poster to the website: https://ern-euro-nmd.eu/data-collaboration-forms/create/poster/

Submit an educational activity: https://ern-euro-nmd.eu/data-collaboration-forms/create/educational-activity/

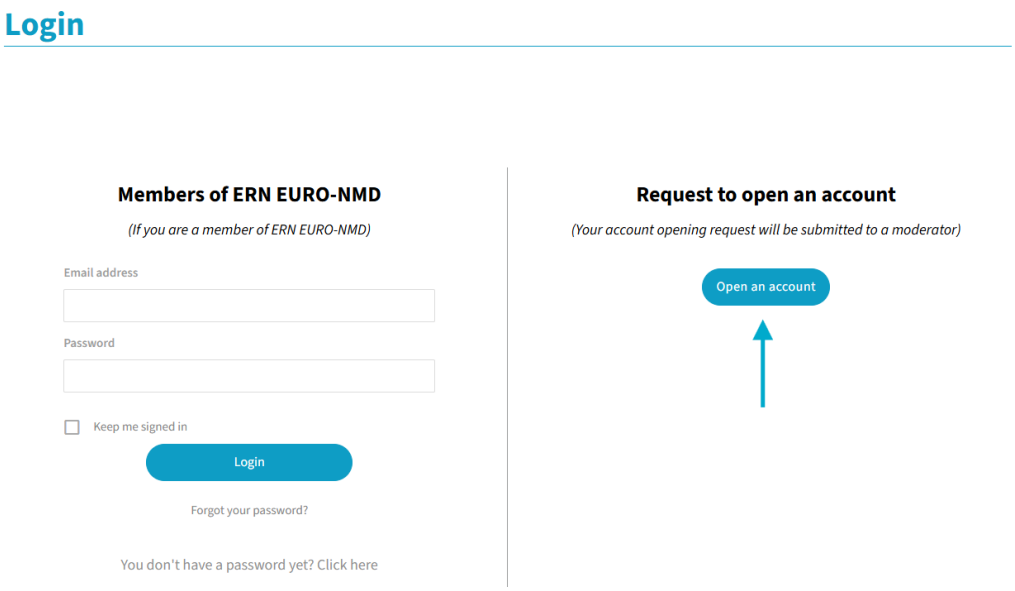
1. REGISTER TO ERN-EURO-NMD

If your name appears on "Who's who in EURO-NMD" you already have a profile in the contacts database. You will need an account to edit your profile.

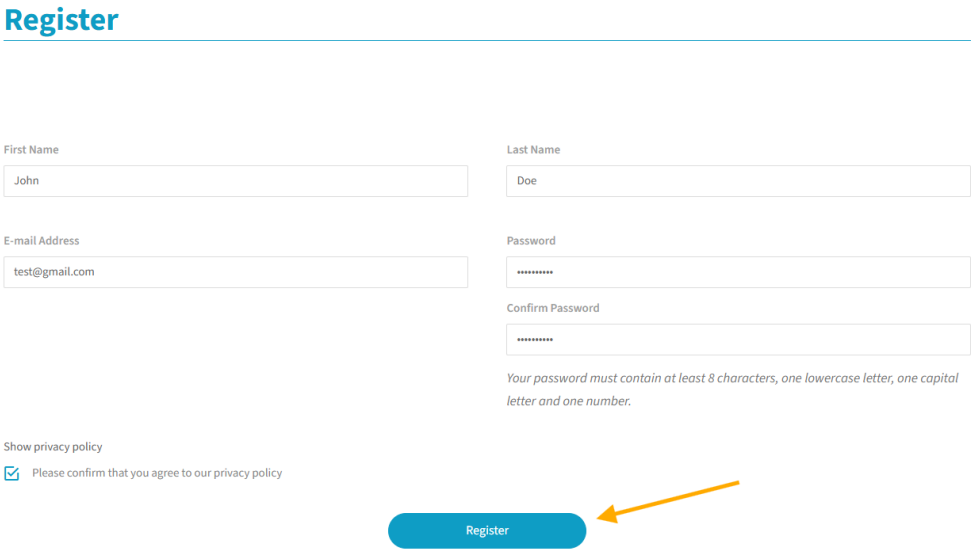
- If you already have the credentials for your account, please log in and edit your profile in the private area.
- If you do not have one, please create a new account.

1.1 - Create your account

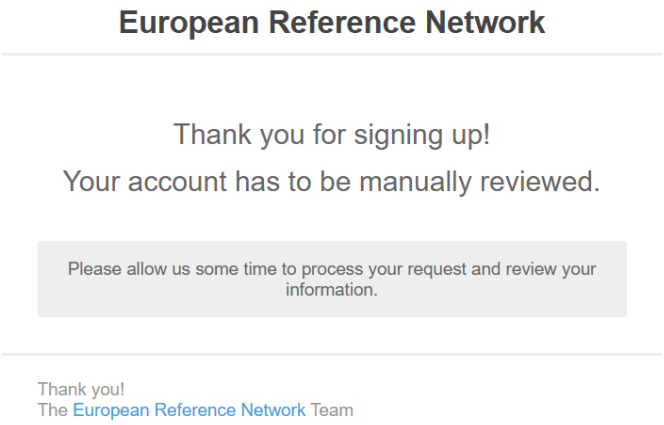
https://ern-euro-nmd.eu/login/



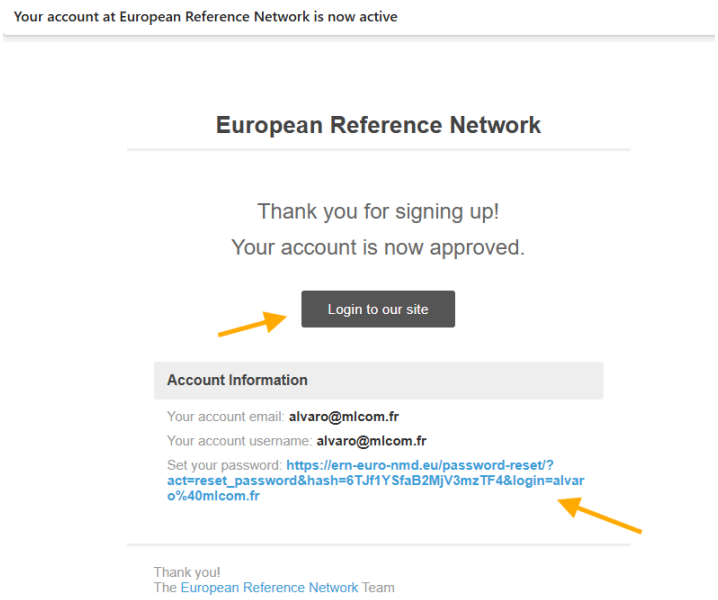
Enter your data, create a password and click on "Register"



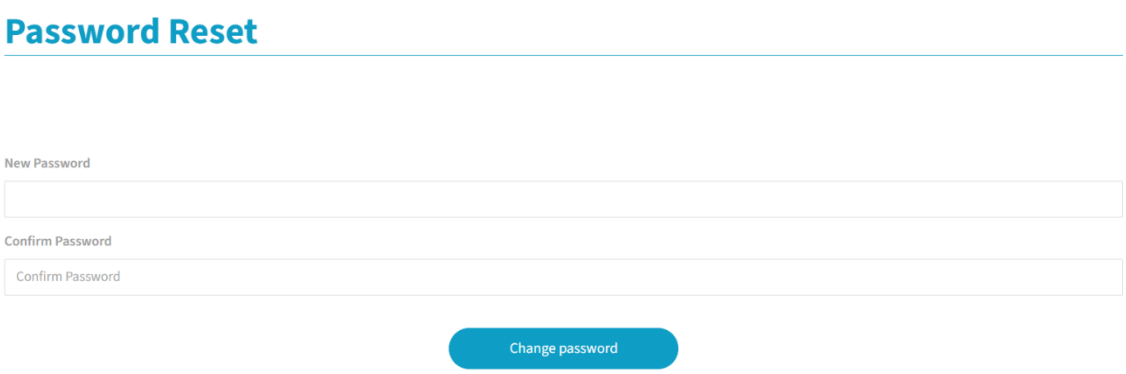
You'll receive a confirmation e-mail letting you know your account will be reviewed



Once your account has been approved, you'll receive an e-mail inviting you to log in.



If you forgot your password, you can set up a new one by requesting to receive a link in your email.

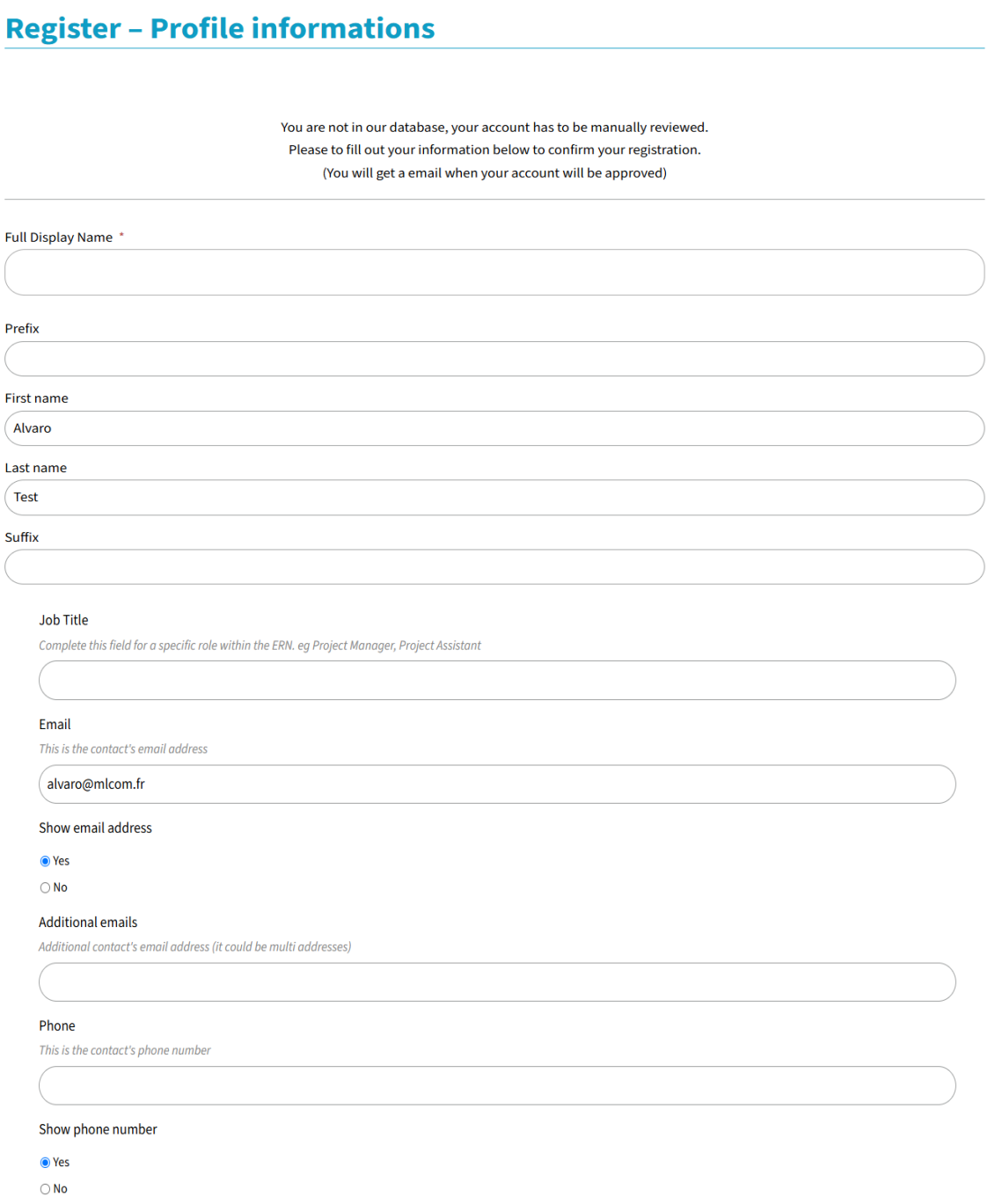


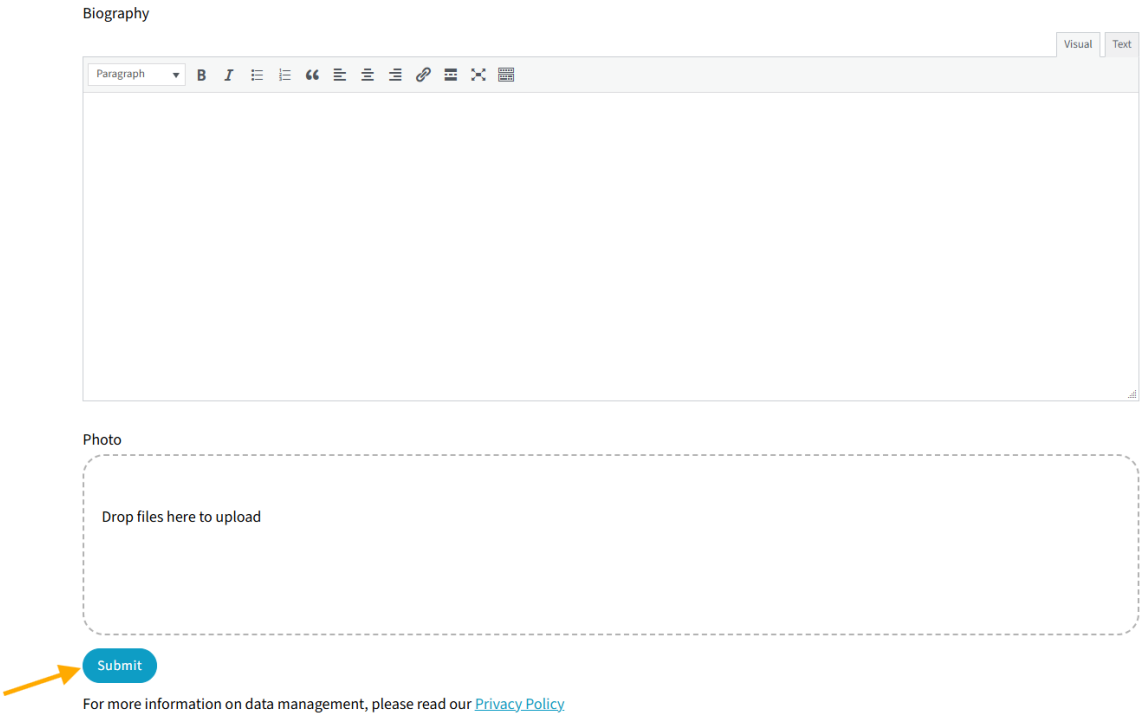
1.2 - Create your contact page

After you receive your credentials (username and password), you can either create a profile **if you do not have one** or edit the existing one (see chapter 2.2)

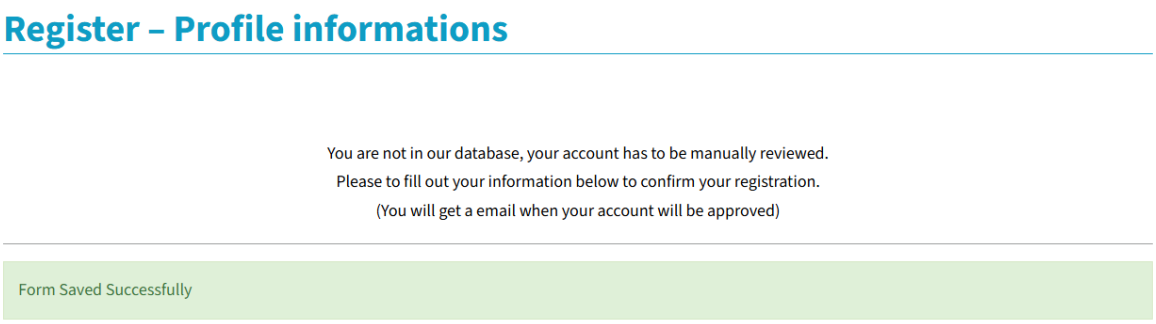
To know if you have a contact profile page, look for your name under “Who’s who in NMD” https://ern-euro-nmd.eu/whos-who-in-euro-nmd/.

If you don’t have a contact page, you will be invited to complete your information through this form.





Once you're done, click submit. You'll receive a confirmation message.

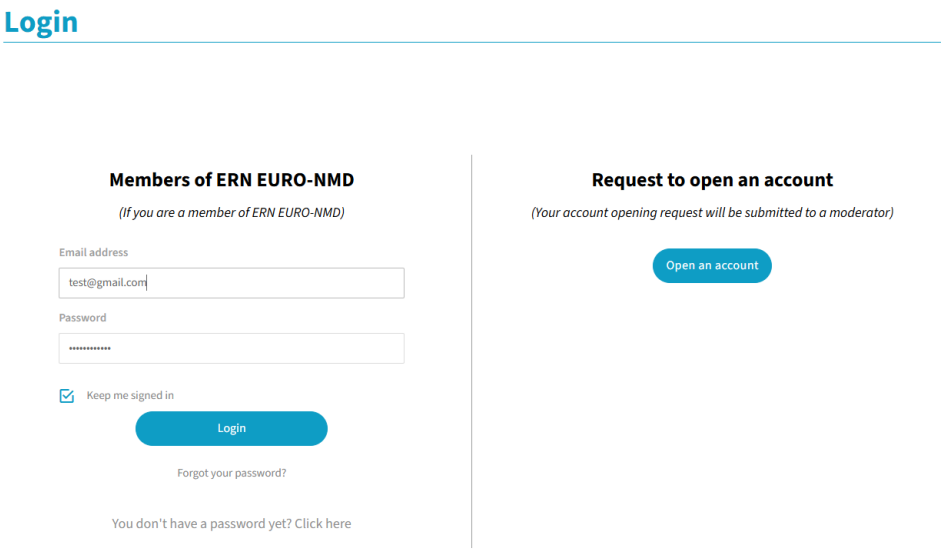


2. PRIVATE SPACE

2.1 - Login to your space

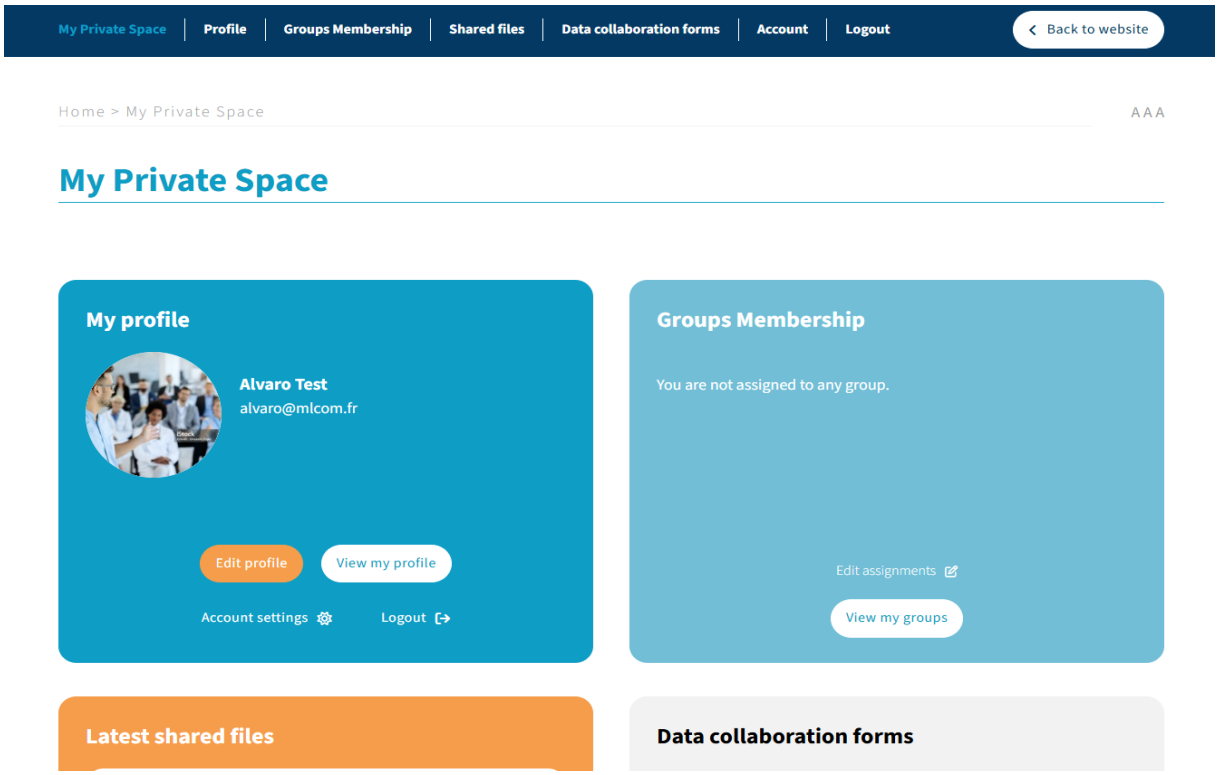
https://ern-euro-nmd.eu/login/

Enter your login credentials and click “Login” to access your private space.

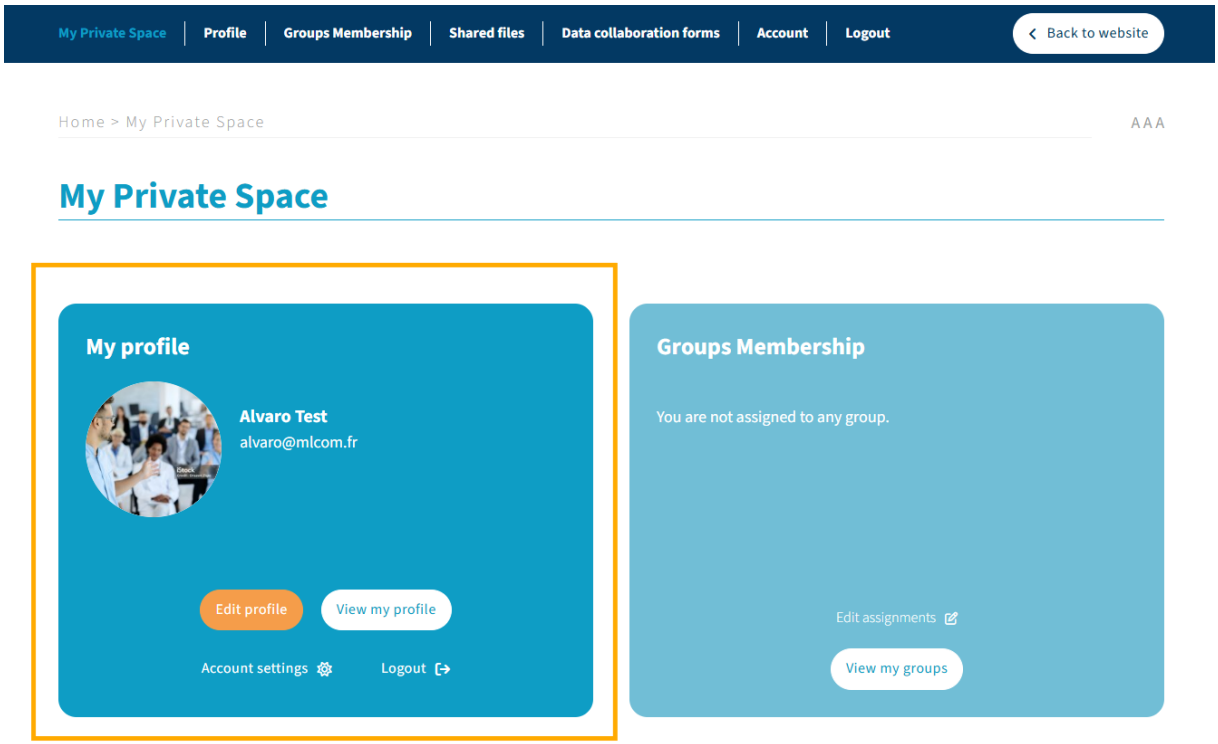


Once you’re logged in, your full name will appear on the menu and clicking on it will let you access your private space.

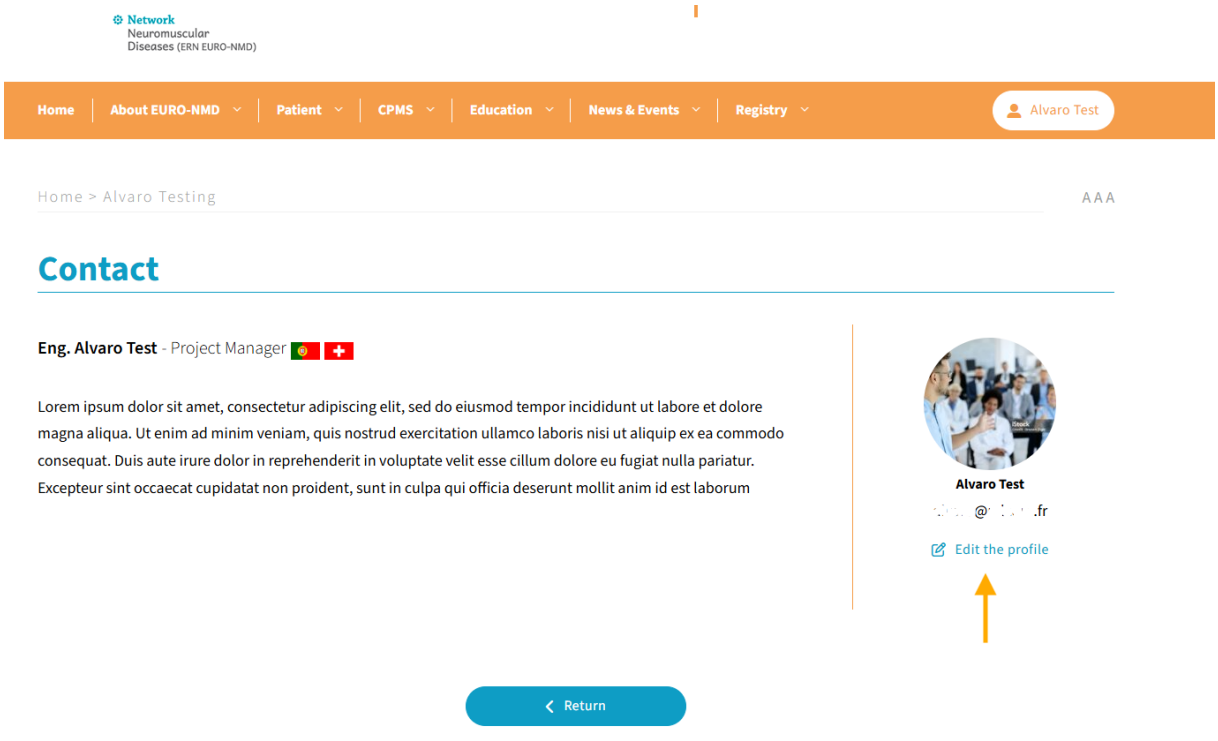
https://ern-euro-nmd.eu/private/



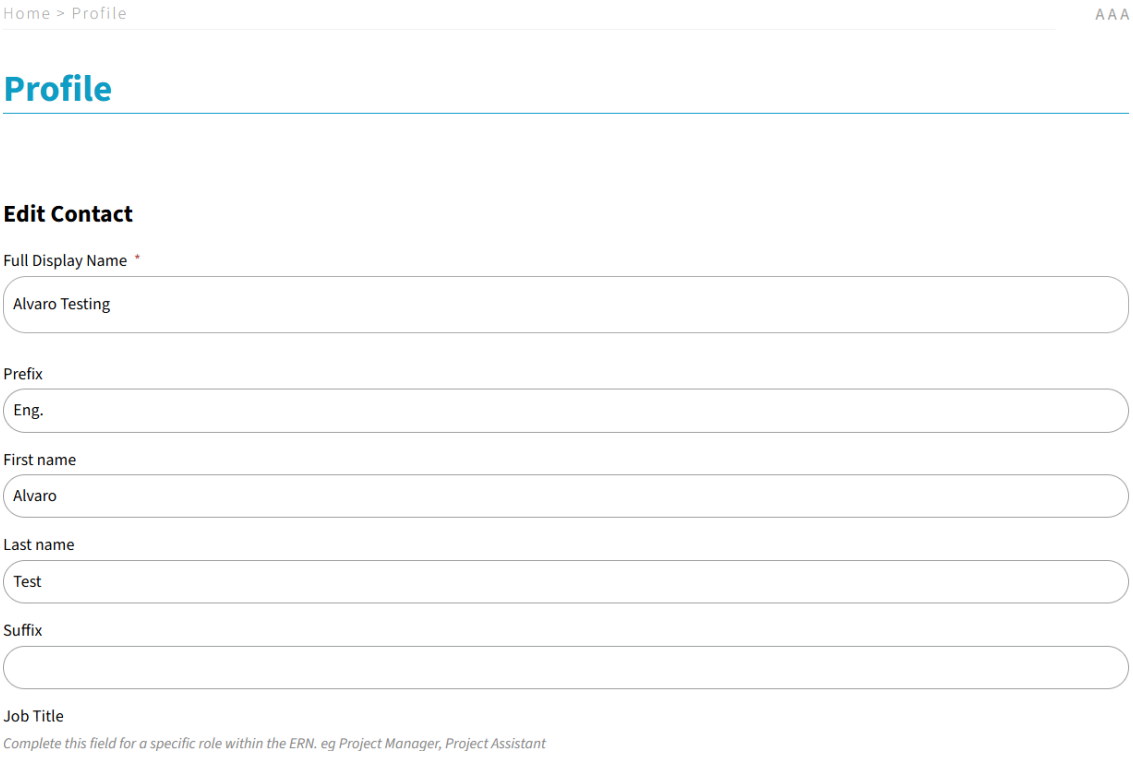
2.2 - Edit your public profile



Clicking on your name, photo or “View my profile” lets you see your public profile

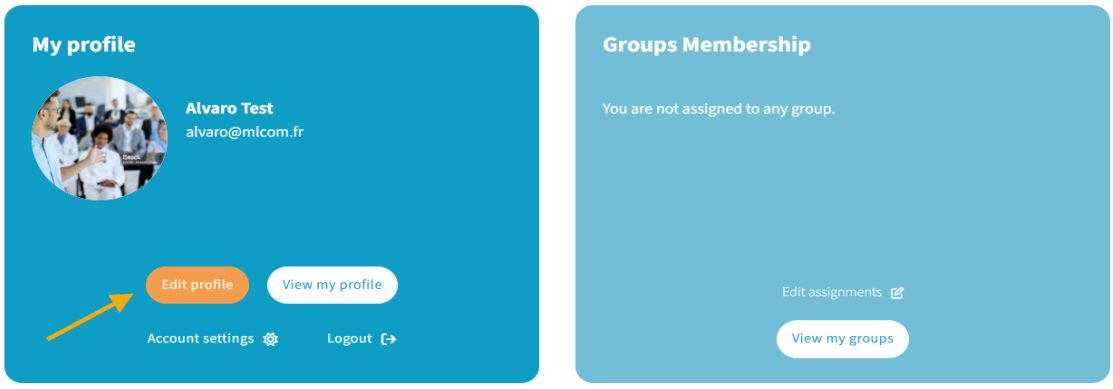


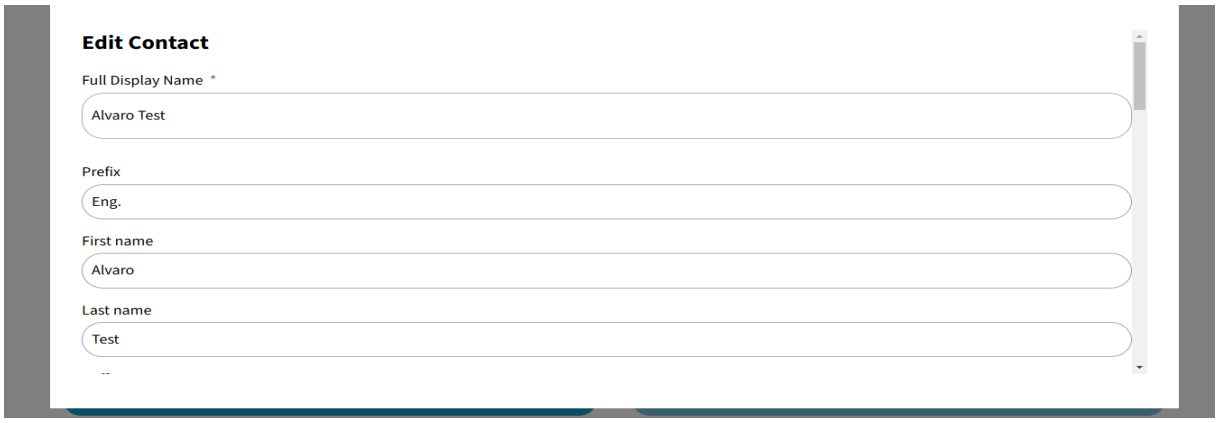
Click on the link indicated by the arrow to edit your profile.



You can also edit your profile in your private space with “Edit profile” button.

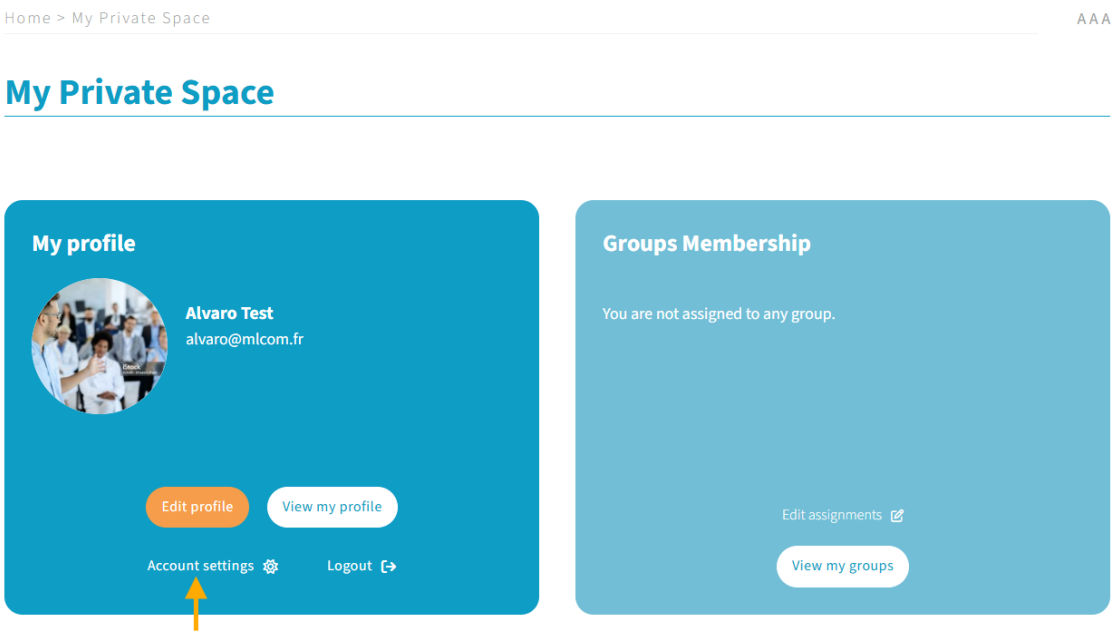
My Private Space





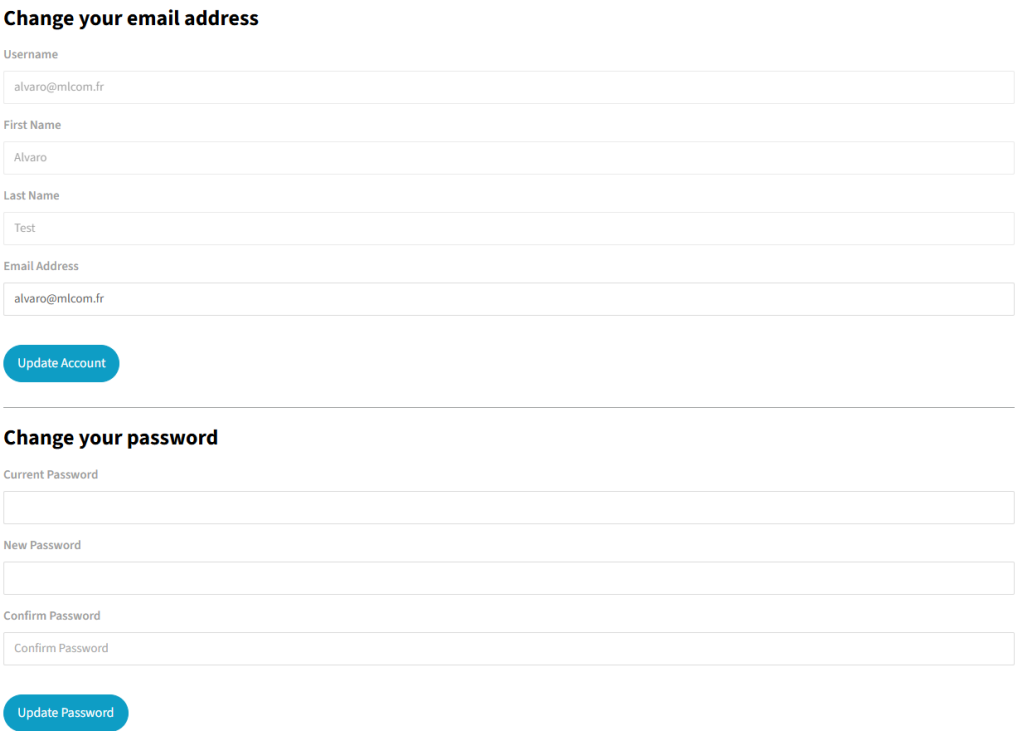
2.3 - Edit your account settings

Click “Account settings” to manage your user account.

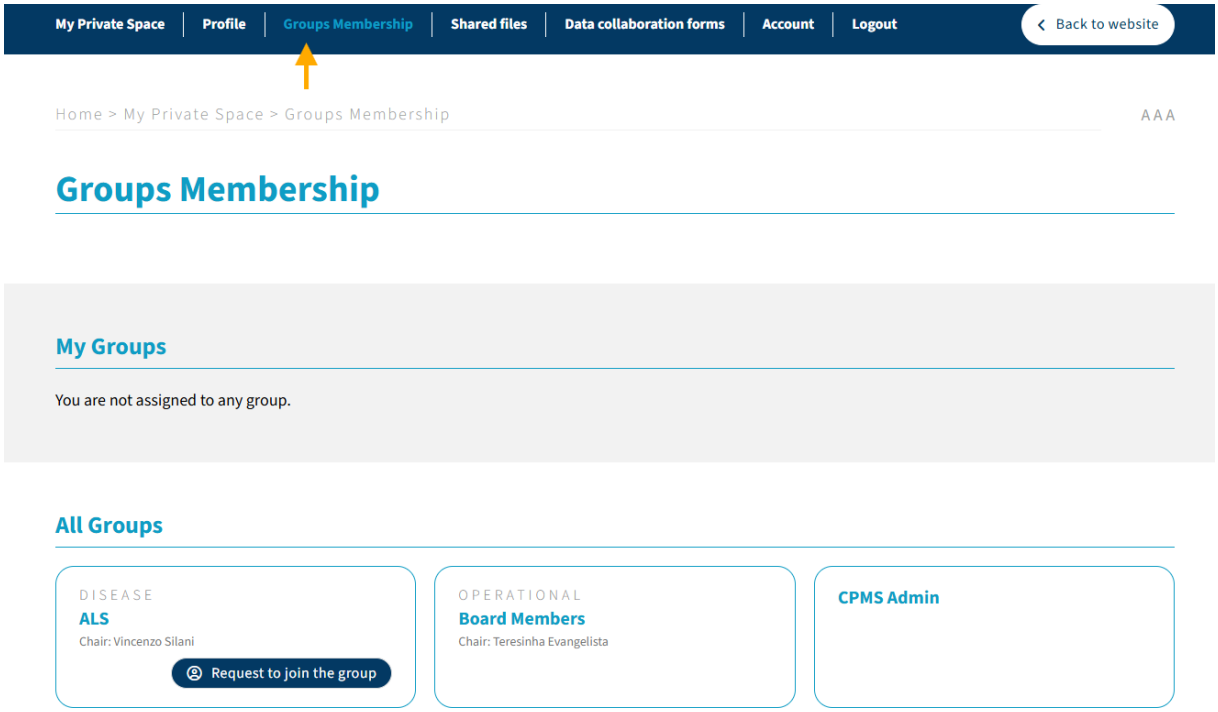


https://ern-euro-nmd.eu/account/

Here you can edit the email address associated with your account or change your password.



3. Group Membership

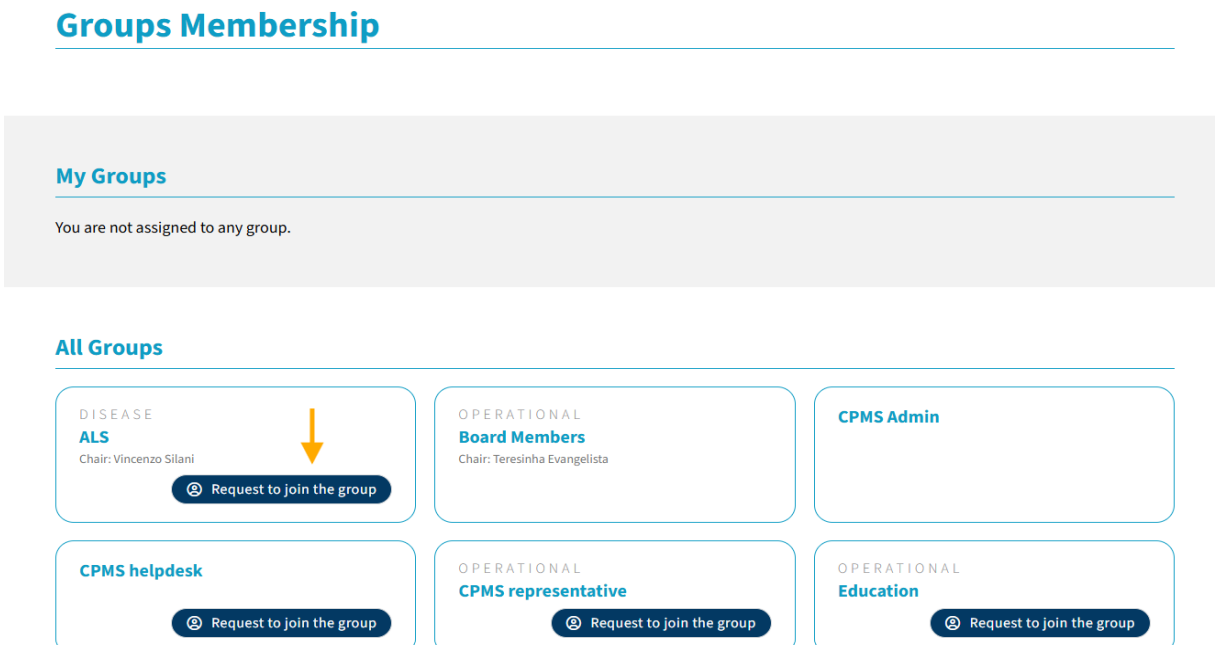


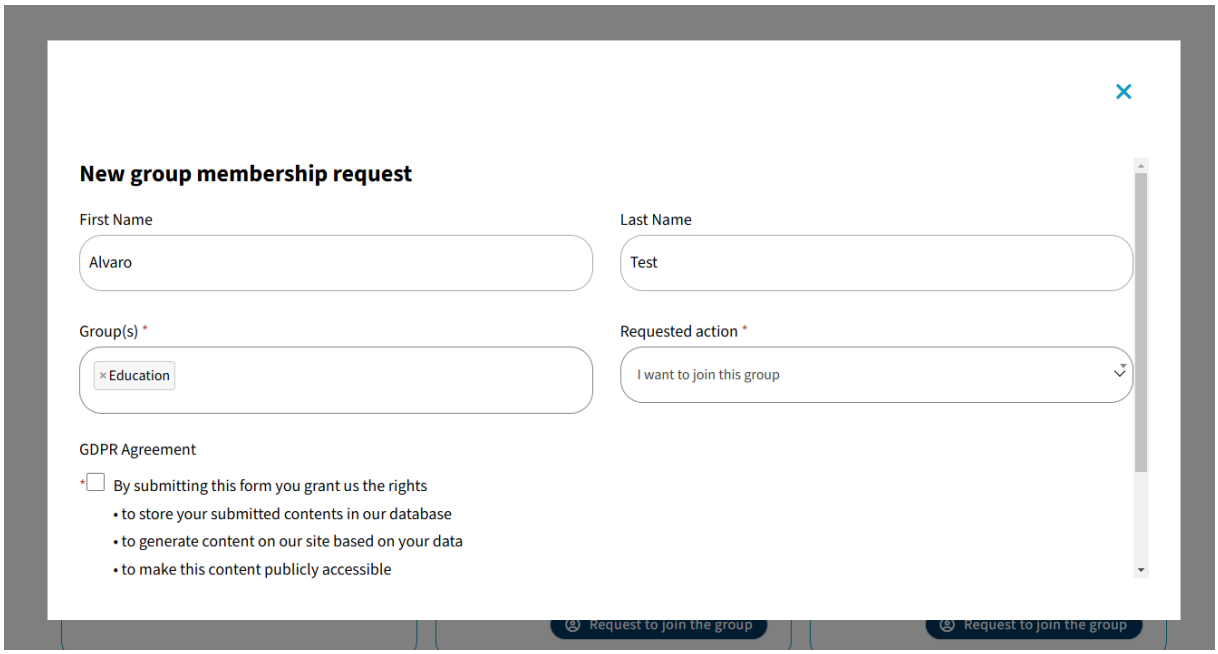
3.1 Join a group

3.1.1 - From the groups-membership page

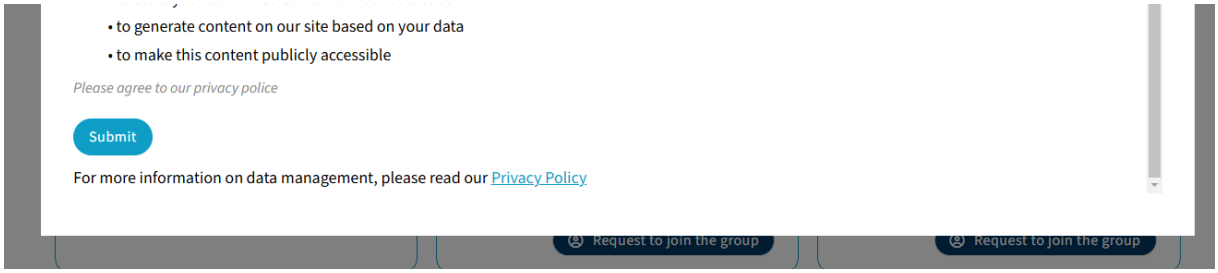
https://ern-euro-nmd.eu/private/groups-membership/

You can request to join a group by clicking the “Request to join the group”





Don’t forget to click the” Submit” button

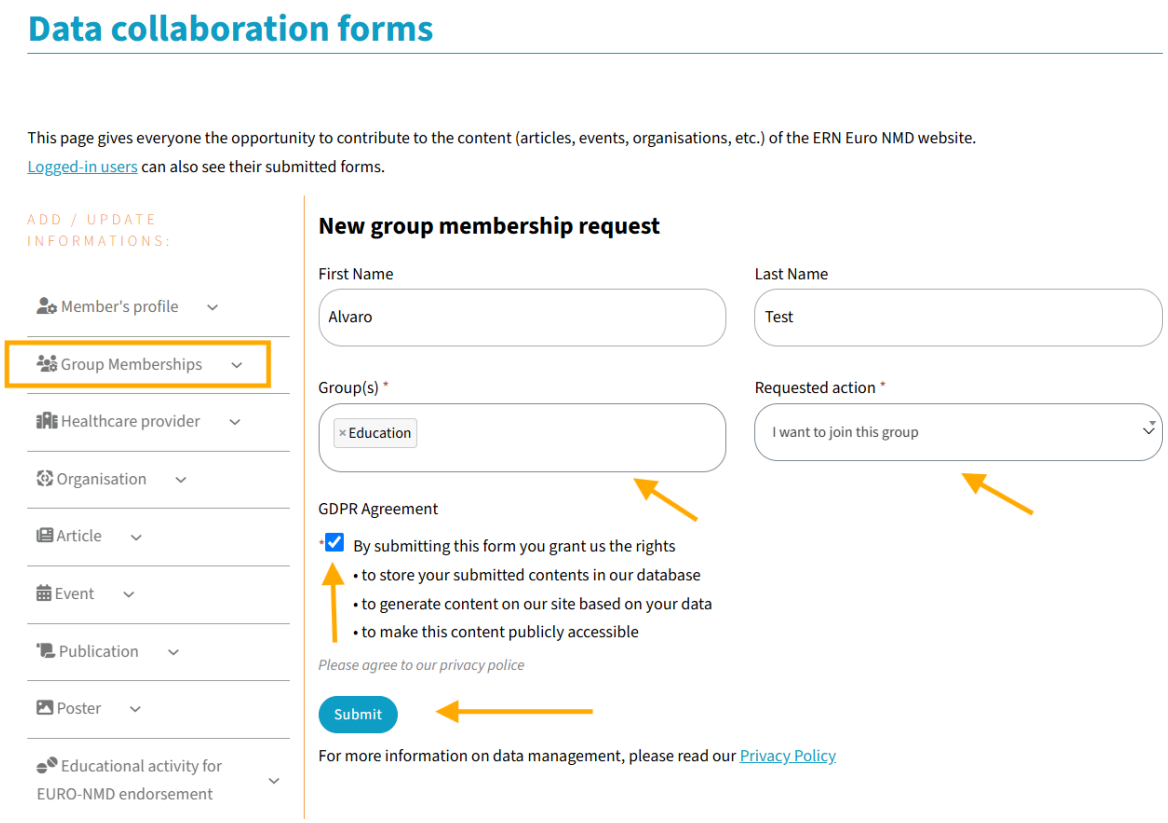


The admin of that group will need to approve your request to join.

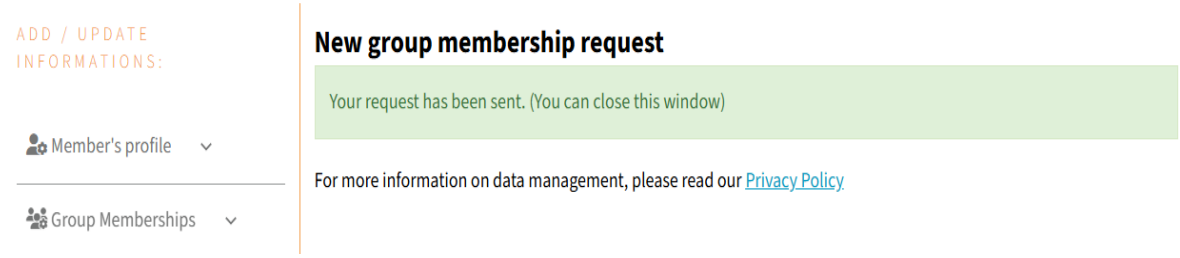
3.1.2 - From Data collaboration forms

https://ern-euro-nmd.eu/data-collaboration-forms/create/group-membership-request/

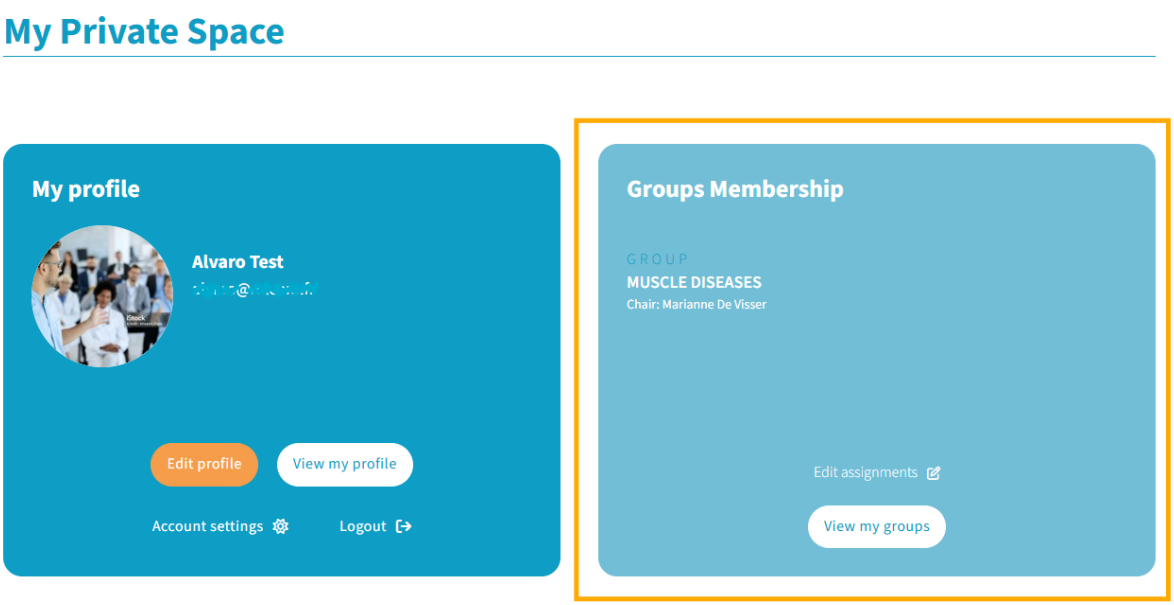
In the Group Memberships tab, you can also request to join or leave a group.



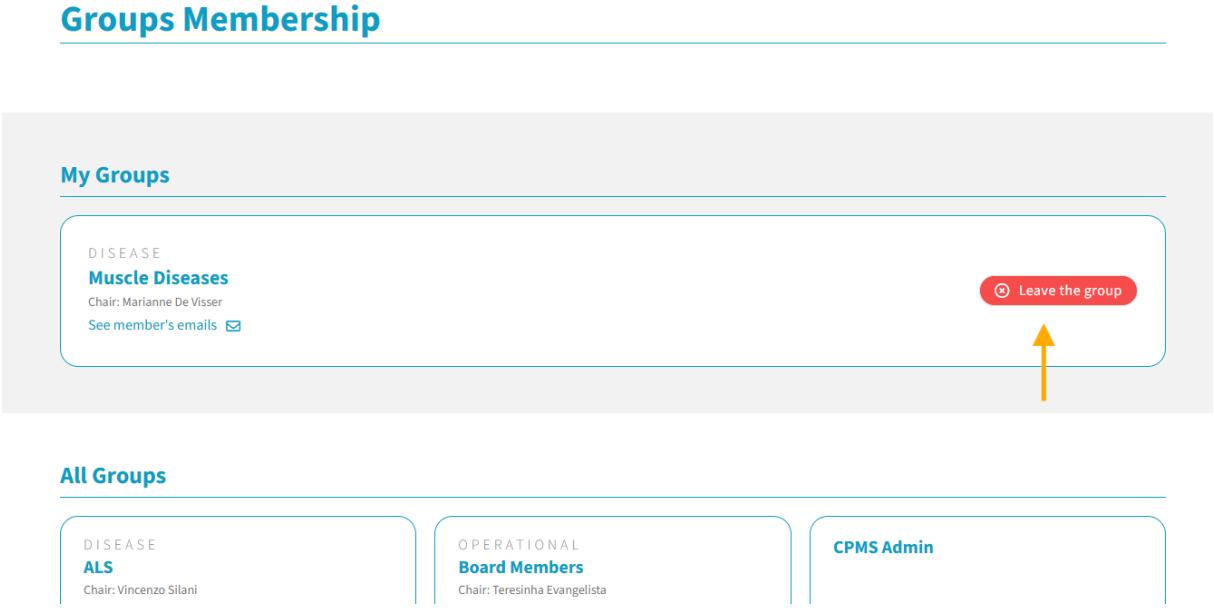
Once you click on" Submit", you'll get a confirmation message



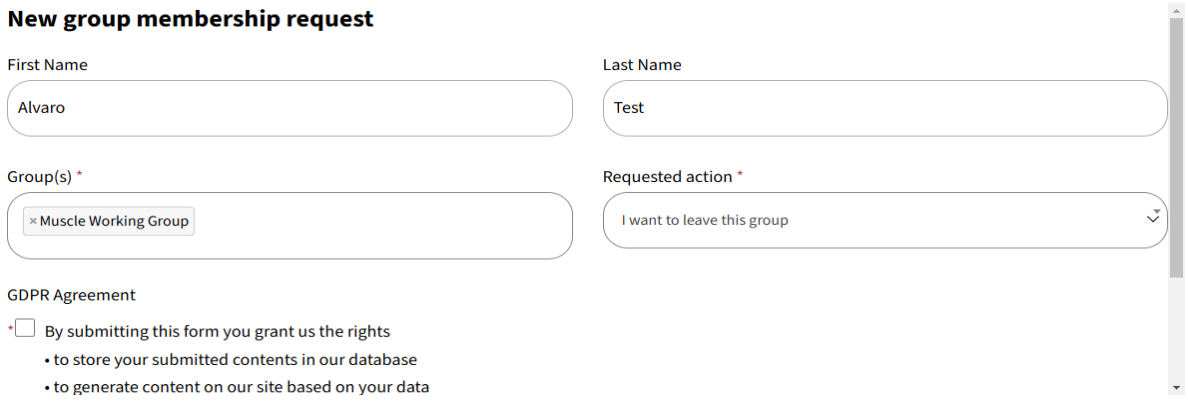
Your private web page will have a blue square with your profile and another showing your group memberships.



or in the Groups Membership page if you are logged in.

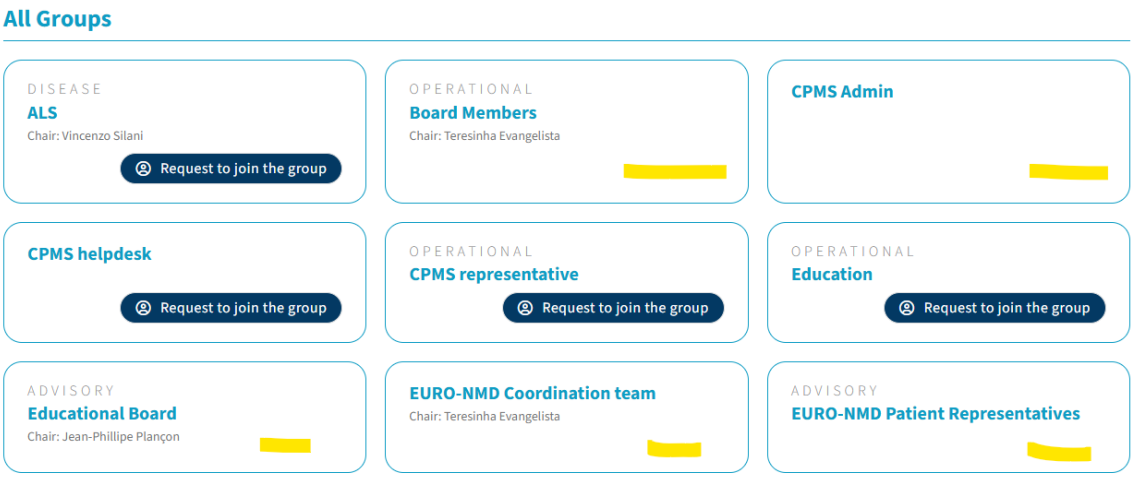


You can also request to leave a Group.



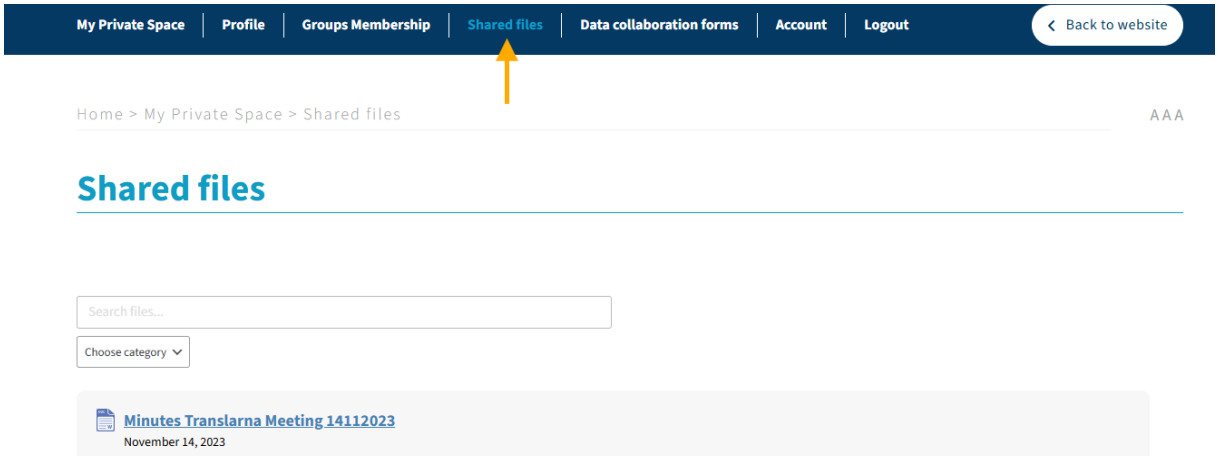
3.1.3 - Groups by nomination

When a group has no “Request to join” button, it means that its members are nominated, so they are not open to anyone wanting to join. They usually have roles defined by the ERN’s governance, and the nomination requires approval from the ERN's Board or Executive. You can send an email to info@ern-euro-nmd.eu for additional details.



4. SHARED FILES

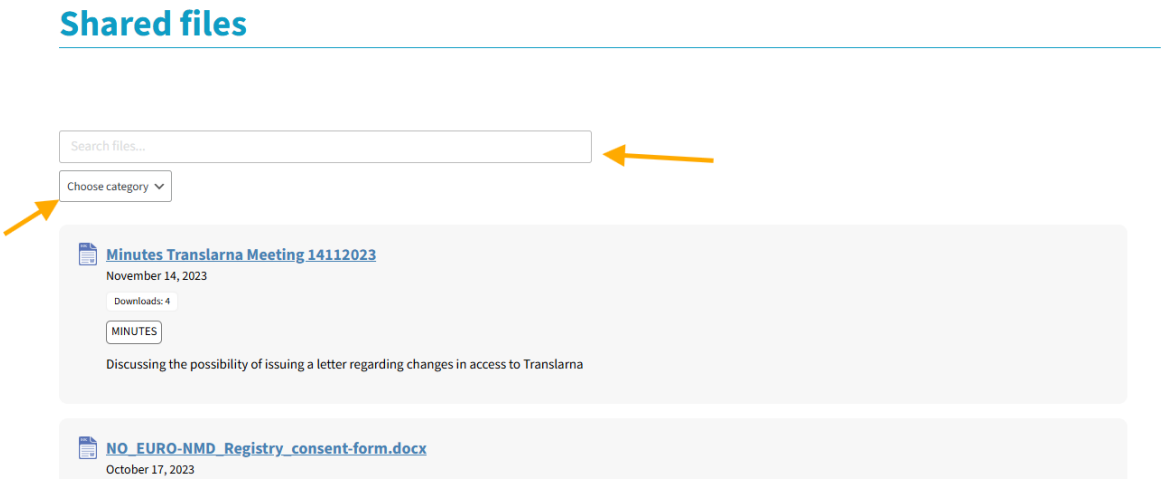
https://ern-euro-nmd.eu/private/shared-files/



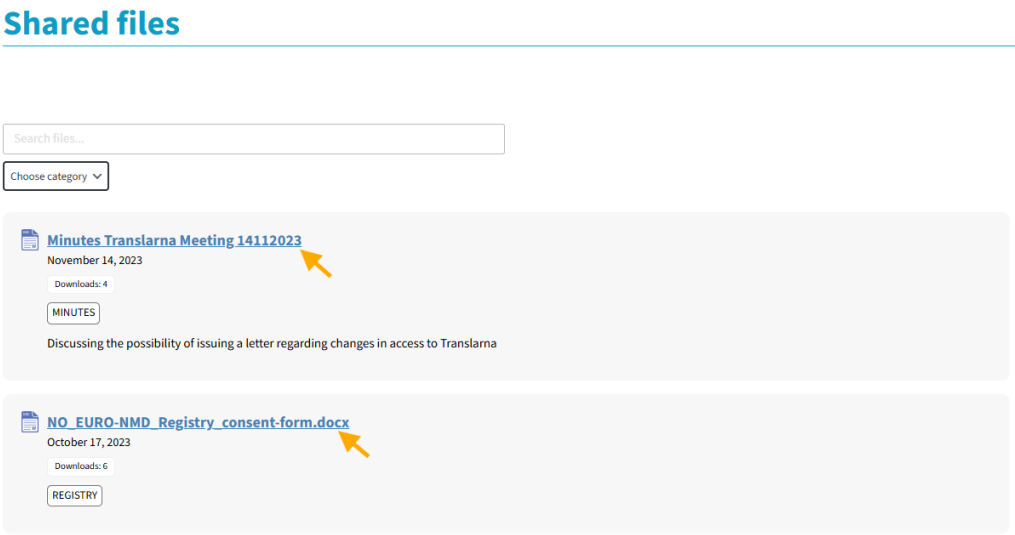
4.1 - View and download shared files

Shared files can be found in the *shared files* page.

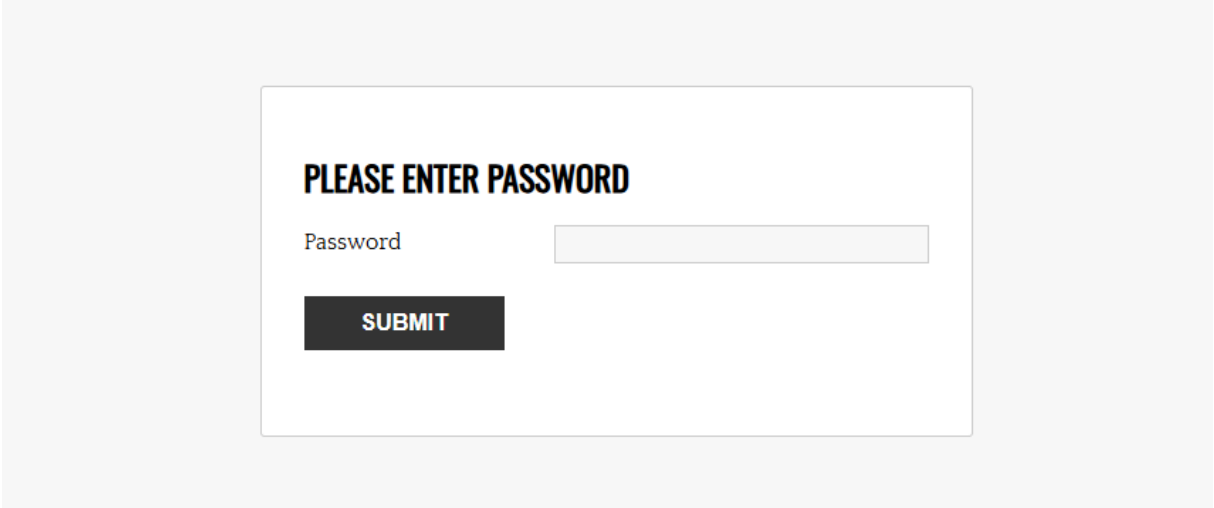
Here you can navigate through the list and use the search bar or “Choose category” to filter them



To download a file, just click on the title



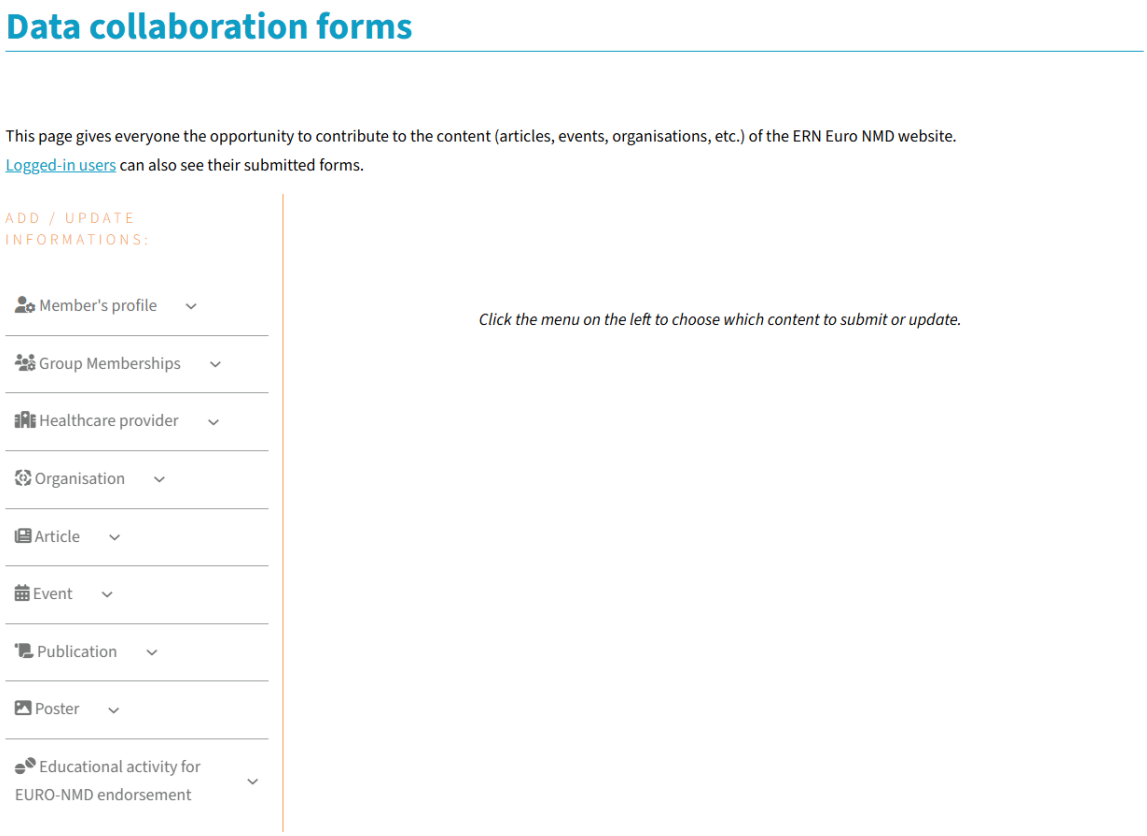
A password protects some files. The rule is that the default password is the date indicated under the file following the format ddmmyyyy, but it may depend. Contact support@euronmd.raiseaticket.com when in doubt.



5. DATA COLLABORATION FORMS

This page gives everyone the opportunity to contribute to the content (articles, events, organisations, etc.) of the ERN Euro NMD website.
Logged-in users can also see their submitted forms.

https://ern-euro-nmd.eu/data-collaboration-forms/



5.0 - The global process of collaboration of the content

All sections (Group, Article, Event, etc.) will offer a similar experience:

1 – It will display a form to fill

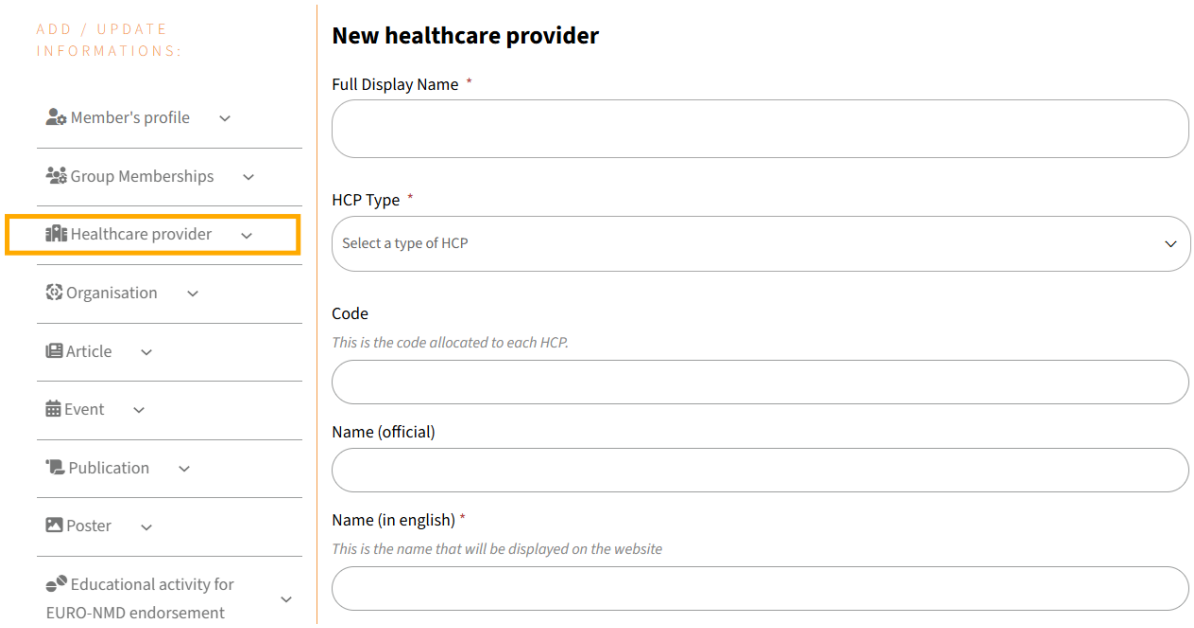
2 – Before sending the form, you can save it as a draft by clicking the “Save” button. (You can edit and send it for submission at a later time)

3 – Your submission will then be sent to the admins

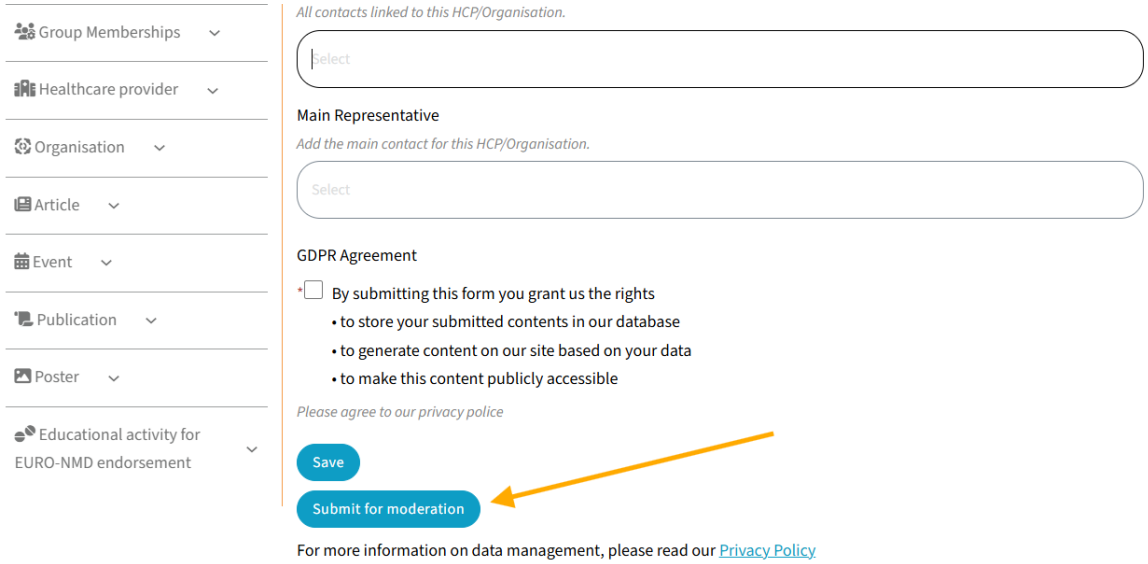
4 – Once approved, your submission will appear on the website in the corresponding section and your private space.

5.1 - HEALTHCARE PROVIDER - Propose a new healthcare provider

https://ern-euro-nmd.eu/data-collaboration-forms/create/healthcare-provider/



Fill in the form with all the information you can provide.



At the bottom of the form, select your representatives in the list (**if you can't find them**, **it means they have not yet created their account on the ERN-EURO-NMD website**)

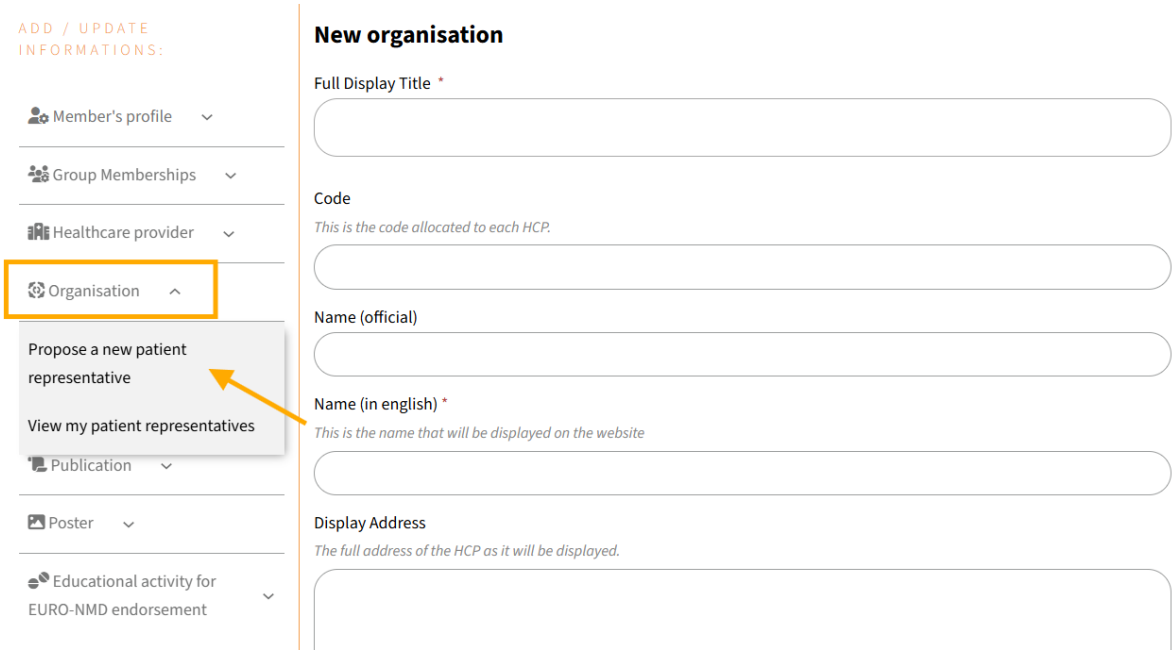
Your submission will then need approval from the administrators.

Once approved, the healthcare provider can be found in the list here:

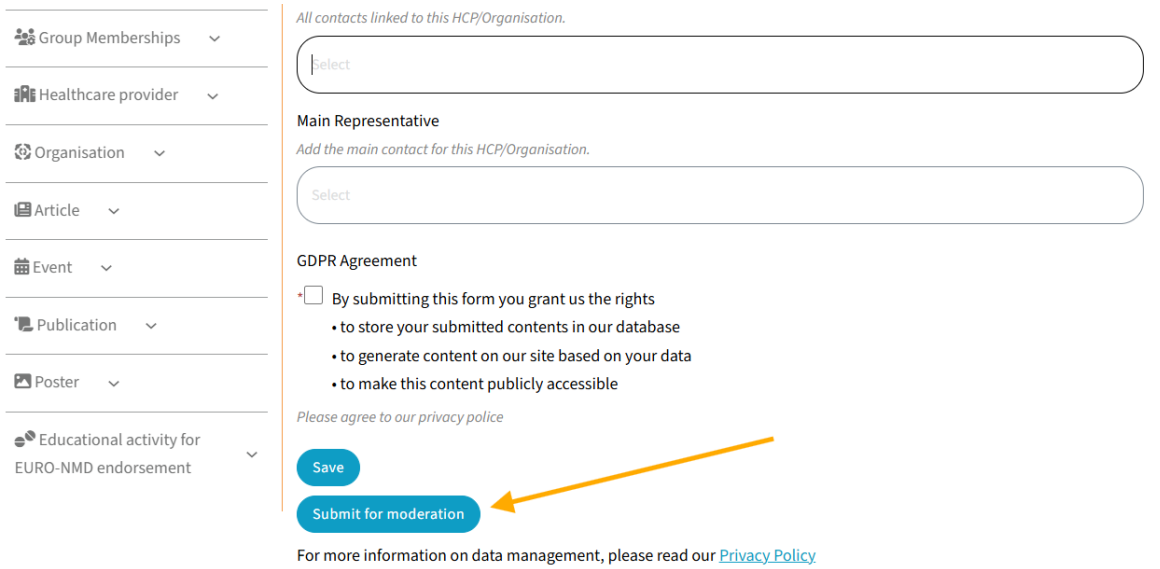
https://ern-euro-nmd.eu/healthcare-providers/

5.2 - ORGANISATION - Propose a new patient representatives organisation

https://ern-euro-nmd.eu/data-collaboration-forms/create/organisation/



Fill in the form with all the information you can provide.



At the bottom of the form, select your representatives in the list (**if you can't find them, it means they did not create their account on the ERN-EURO-NMD website yet**)

Your submission will then need approval from the administrators.

Once approved, the organization can be found in the list here:

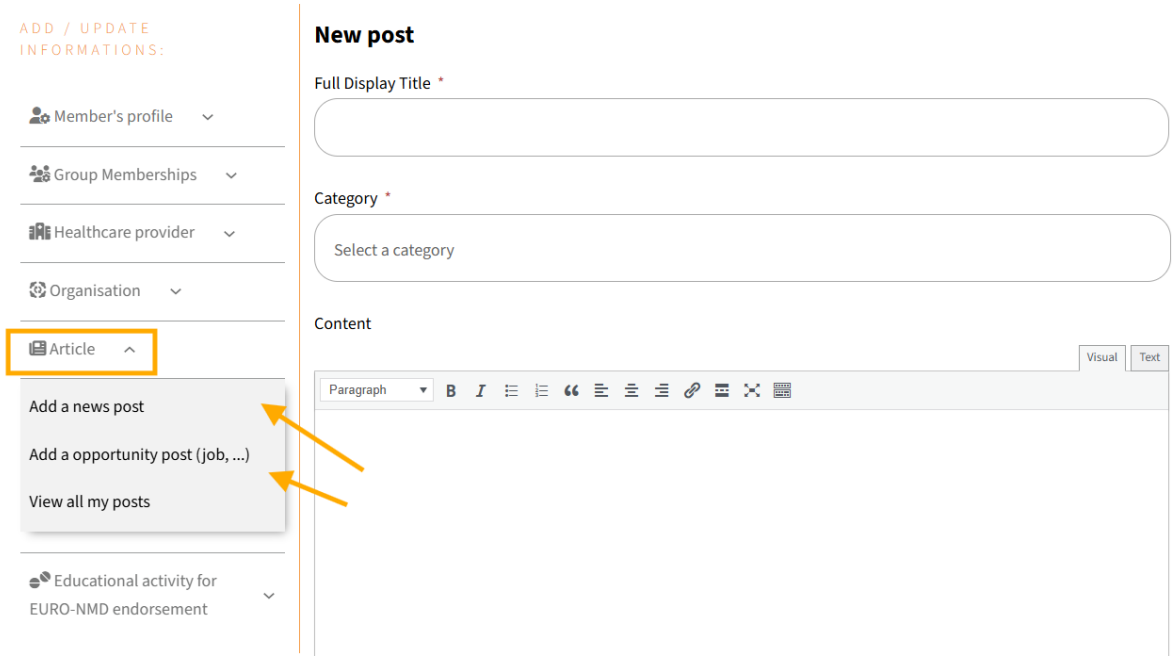
https://ern-euro-nmd.eu/organisations/

5.3 - ARTICLE - propose content for the website

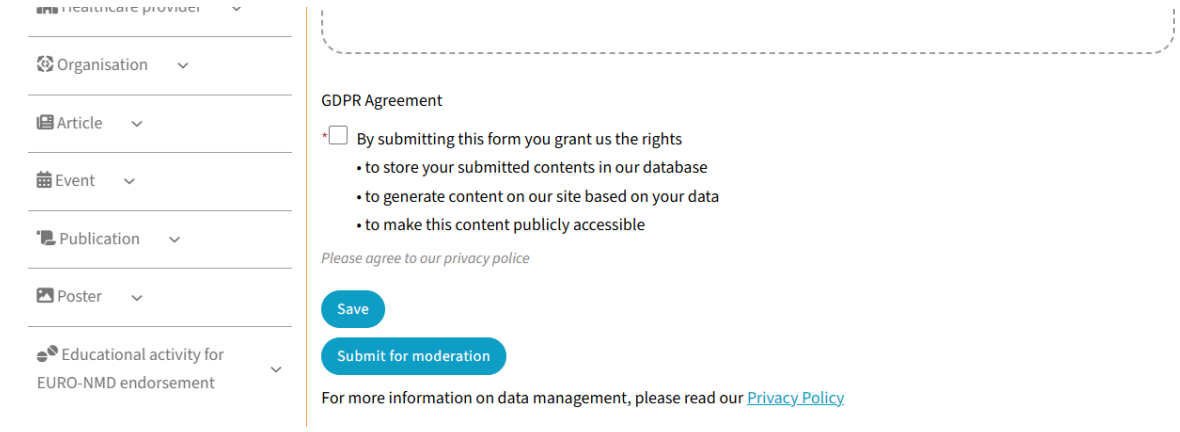
In this section you can create a post

A news post https://ern-euro-nmd.eu/data-collaboration-forms/create/post/

or an opportunity https://ern-euro-nmd.eu/data-collaboration-forms/create/opportunity/



Just fill in the associated form with all the information and click ”submit for moderation“



Your submission will then need approval from the administrators.

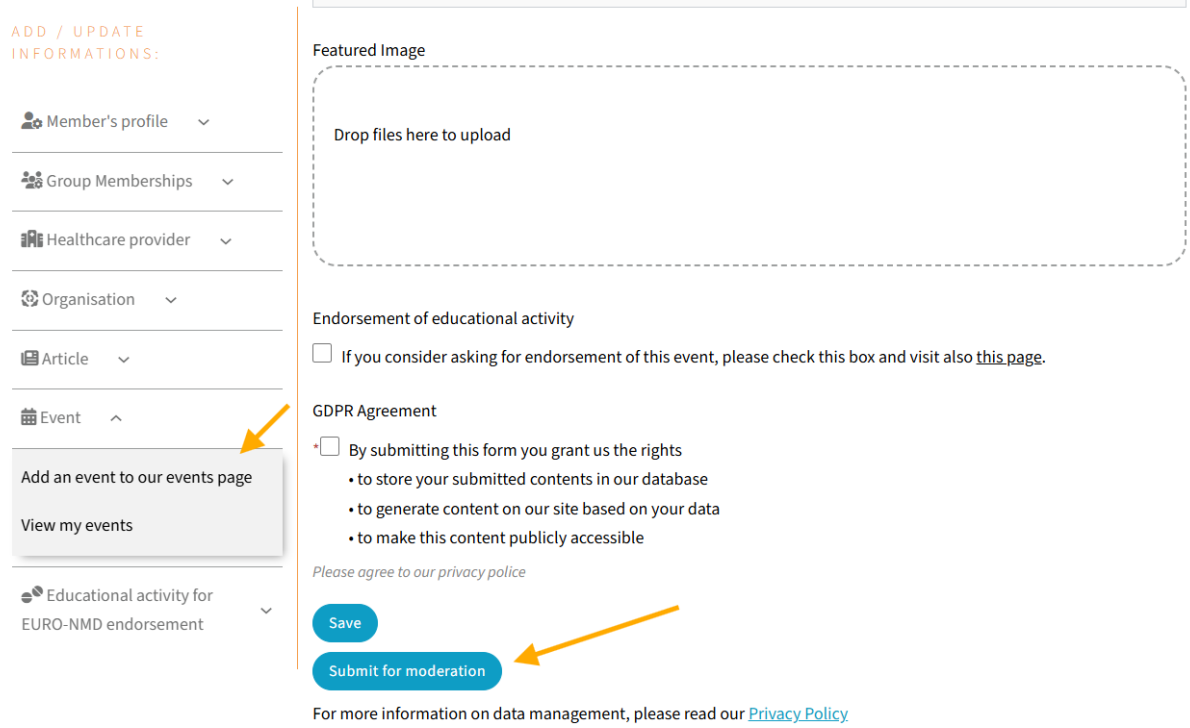
Once approved, the posts can be found in the list here:

https://ern-euro-nmd.eu/all-posts/

5.4 - EVENT - propose an event to be shared on the website

https://ern-euro-nmd.eu/data-collaboration-forms/create/event/

Just fill the associated form with all the information and submit for moderation.



Your submission will then need approval from the administrators.

Once approved, the events can be found in the list here:

https://ern-euro-nmd.eu/events/

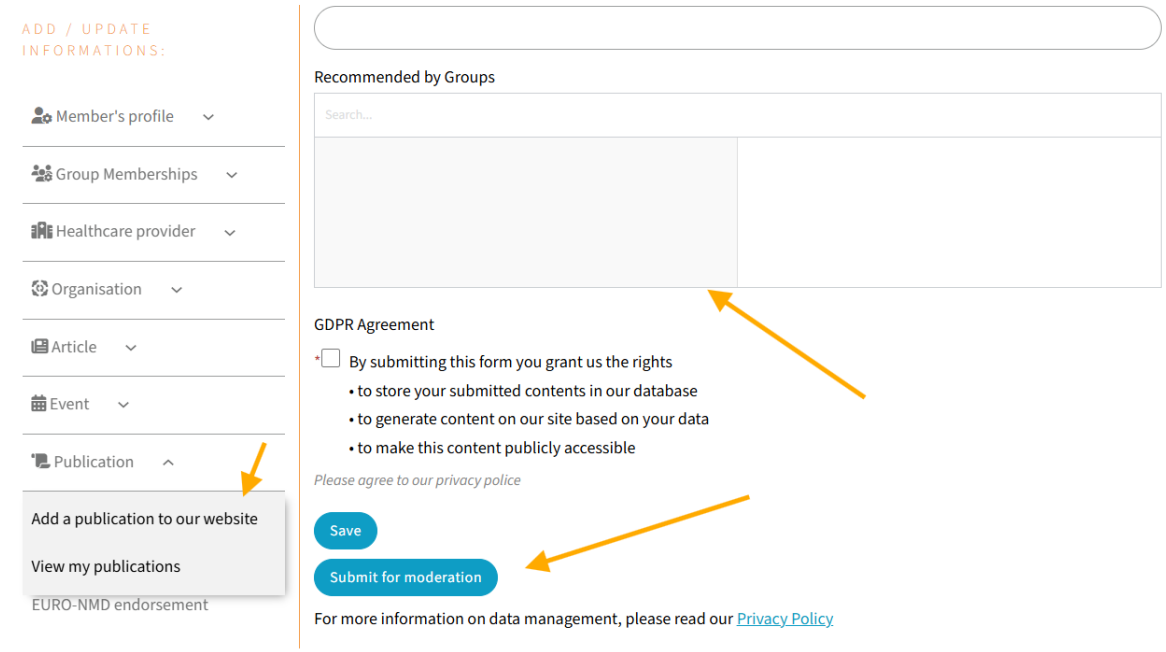
5.5 - PUBLICATION - add a publication quote to the website

This is mainly for network members to make their work acknowledging EURO-NMD visible

https://ern-euro-nmd.eu/data-collaboration-forms/create/publication/

Just fill the associated form with all the information.

If the publication was recommended by a specific group, you can add it at the bottom of the form.



Your submission will then need approval from the administrators.

Once approved, the publication can be found in the list here:

https://ern-euro-nmd.eu/publications/

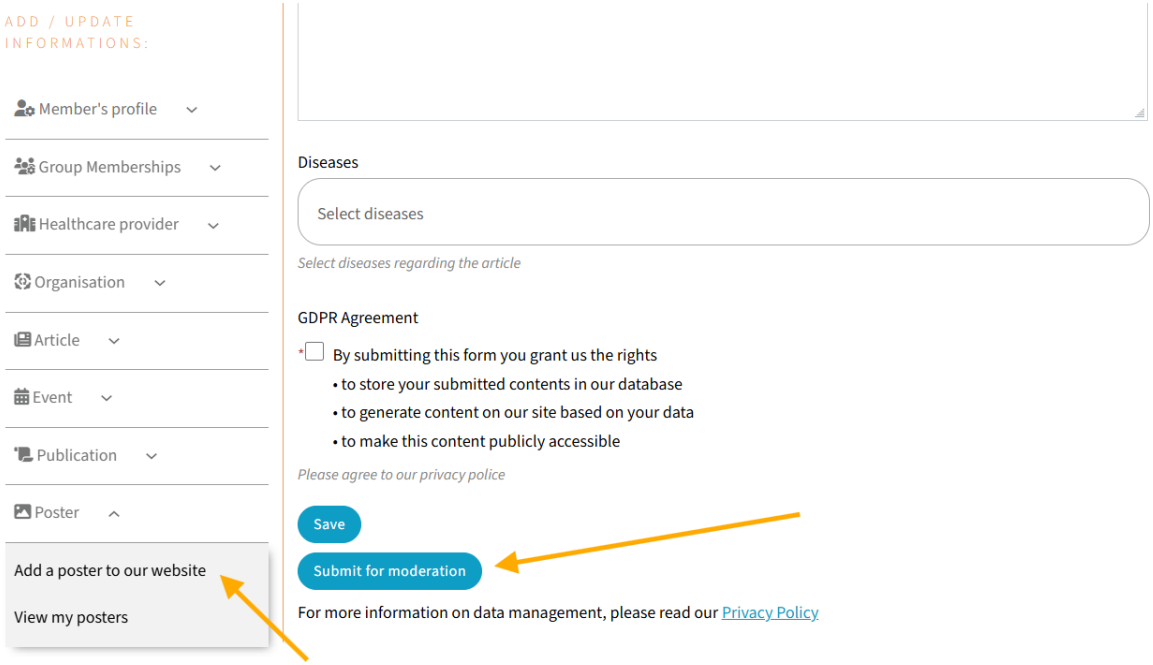
5.6 - POSTER - Propose a poster to be listed on the website

This is mainly for network members to make their work acknowledging EURO-NMD visible.

https://ern-euro-nmd.eu/data-collaboration-forms/create/poster/

Just fill in the associated form with all the information and submit for moderation.

Make sure you provide a high-quality image for your poster



Your submission will then need approval from the administrators.

Once approved, the posters can be found in the list here:

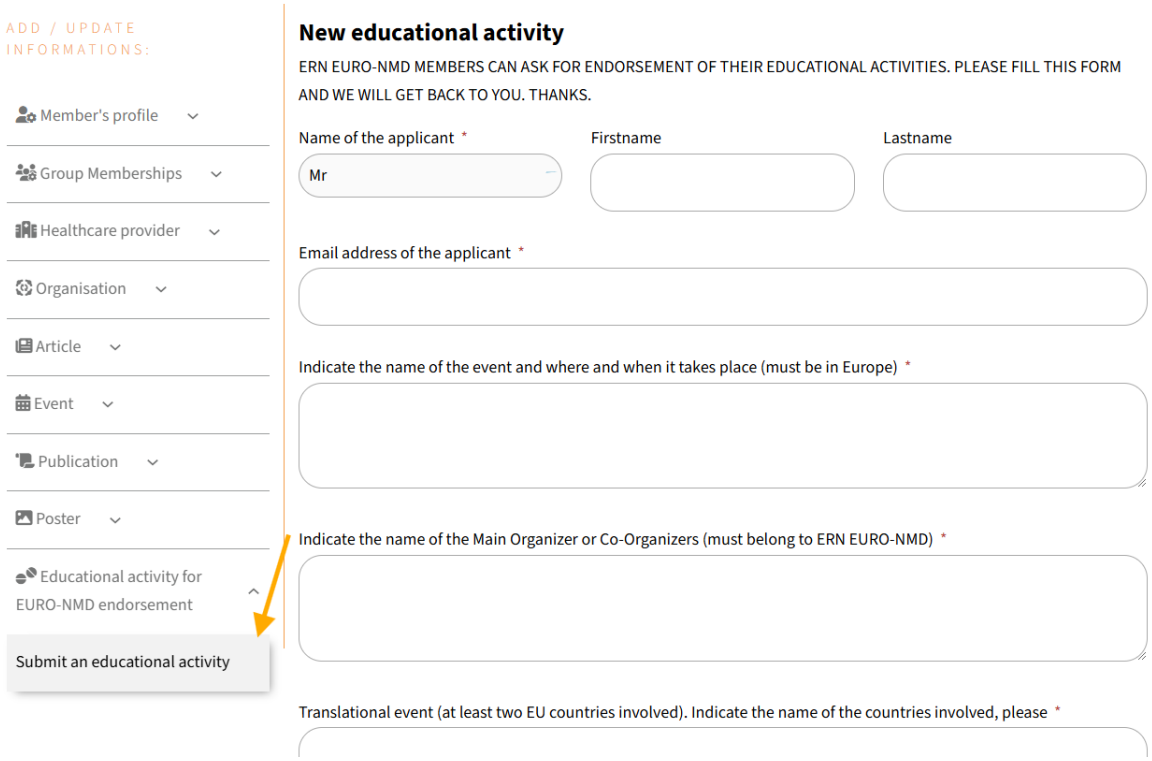
Emmanuel : https://ern-euro-nmd.eu/publication-type/poster/

5.7 - EDUCATIONAL ACTIVITY - submit an educational activity for EURO-NMD endorsement

https://ern-euro-nmd.eu/data-collaboration-forms/create/educational-activity/

Just fill in the associated form with all the information and submit for moderation.

Note that ERN EURO-NMD members can ask for endorsement of their educational activities.



Note: that you will need to upload the programme. This will be sent to the Educational Advisory Board of the EURO-NMD ERN for approval. The final decision of endorsement depends on the approval by the Executive Committee of the EURO-NMD ERN. Despite previous endorsements, new editions of an event require a new submission for approval.

Contact

All email support enquiries should be addressed to support@euronmd.raiseaticket.com