How to use the non-LCH module in the Core Registry

EuRREB
European Registries for Rare
Endocrine and Bone conditions

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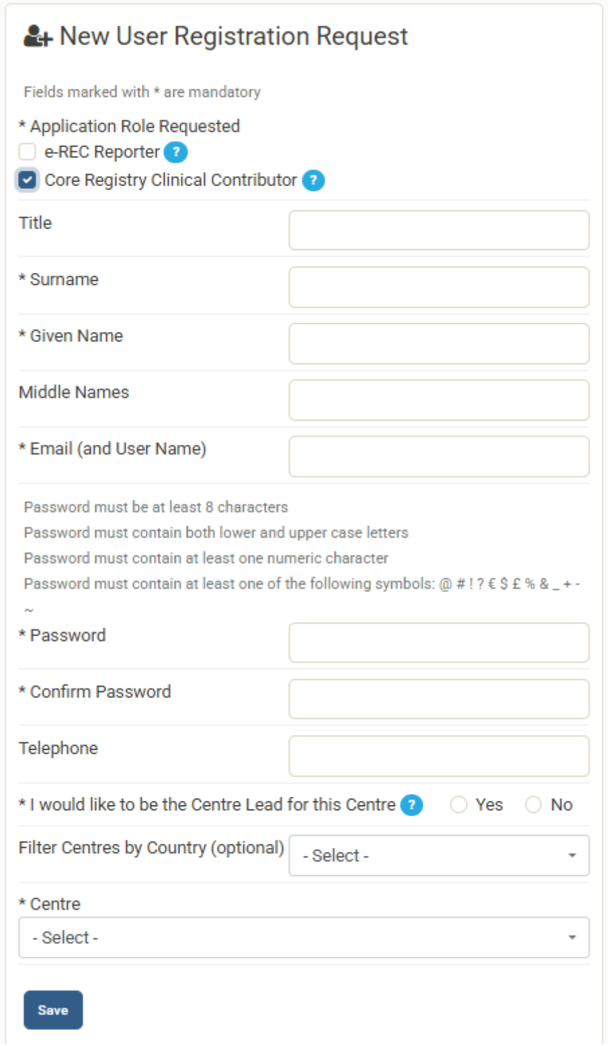
How to create an account in the Core Registry

Use this link for self-registration
https://eurreca.lumc.nl/EuRREBAuth/Registration/Create

Fill in the form, choose the Core Registry Clinical Contributor role to have access to the Core Registry



Fill in the mandatory information.
Your request will be approved shortly.

If your centre is not listed – you can add it to the platform. Any centre could become an active participant – regardless geography and affiliation.

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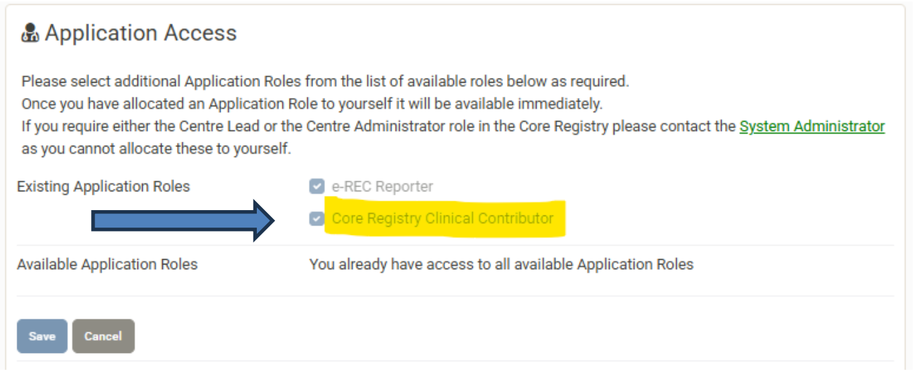
How to change your application role if you already use e-REC

If you are already using e-REC, you can easily allocate the Core Registry Clinical Contributor role to yourself

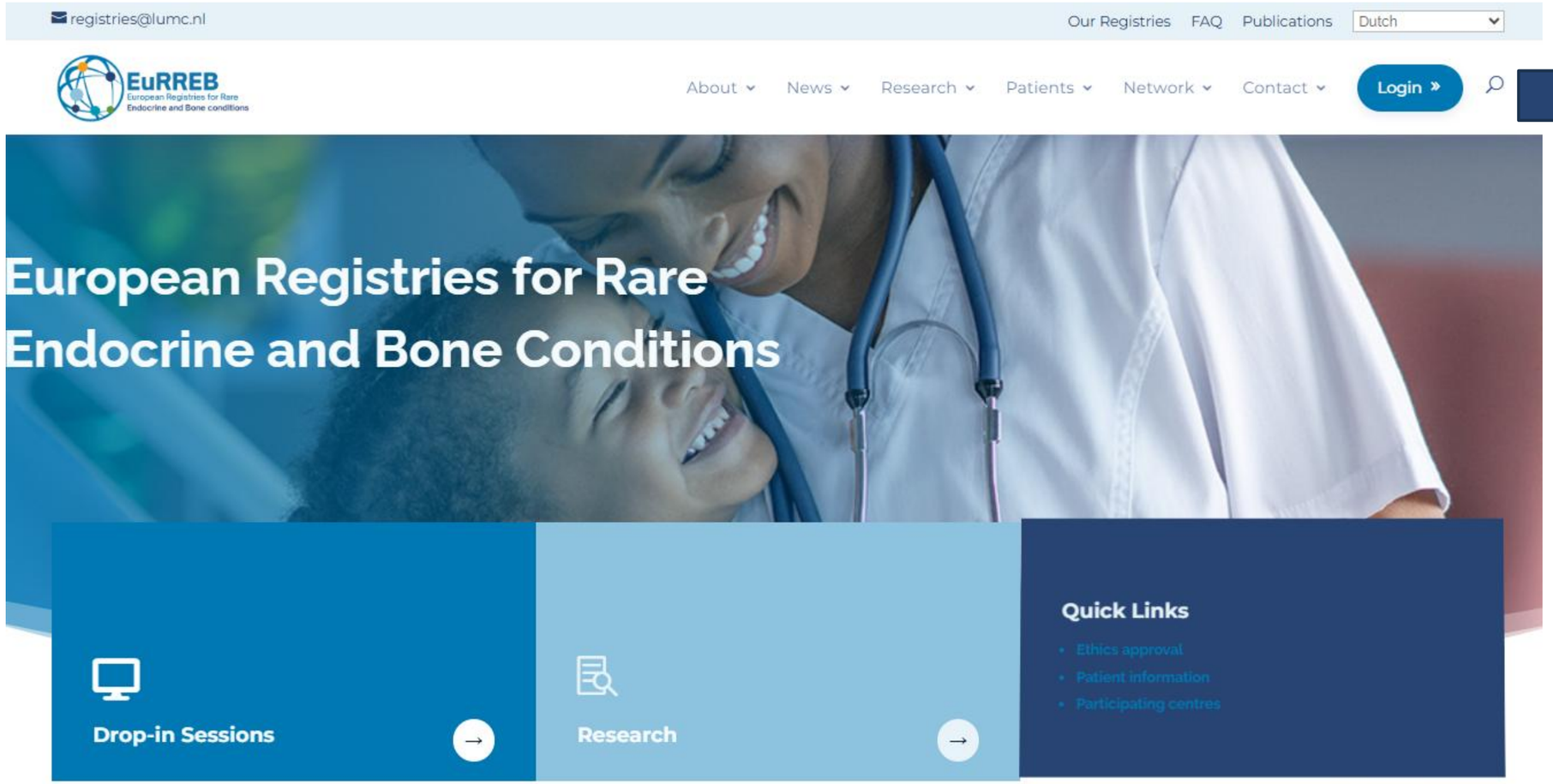
Choose ‘Application access’ from the e-REC menu under your name

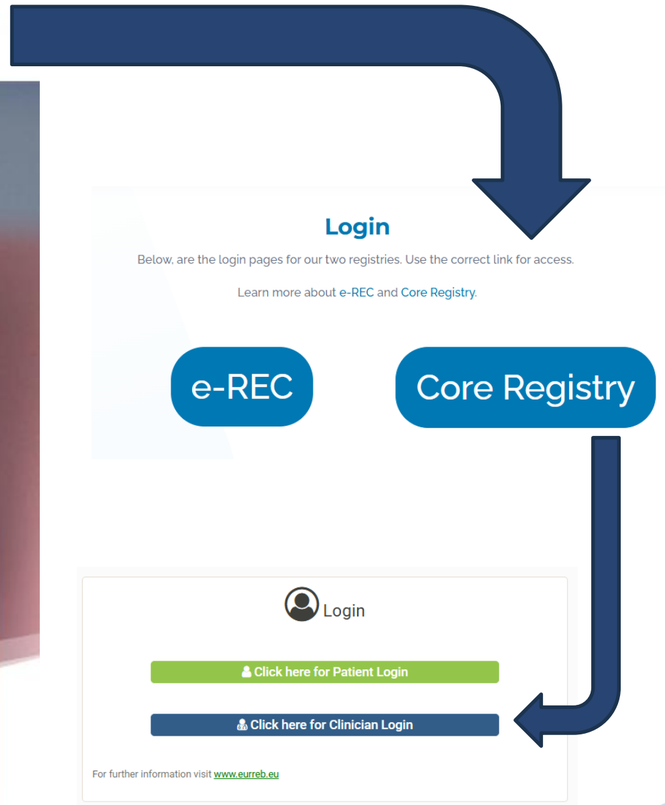
The Core Registry Clinical Contributor role will become available immediately



How to log in into the Core Registry

Go to https://eurreb.eu/ and use Login button and go to the Core Registry and choose Clinician Login page





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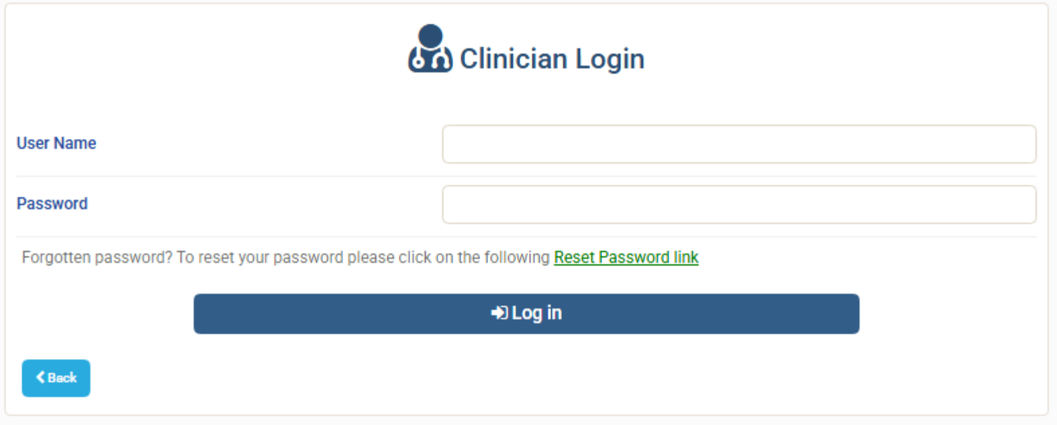
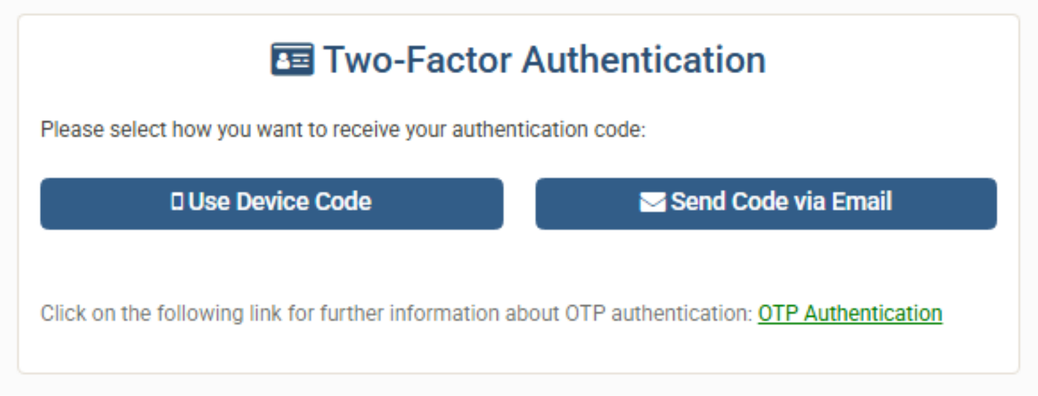
Login to the Core Registry

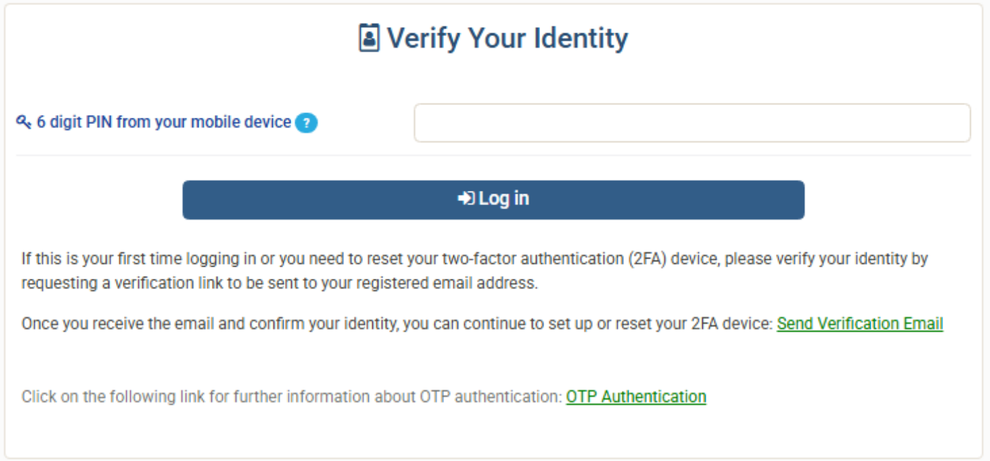
Via this page or by following the previous steps fill in your credentials (username is your e-mail). You can reset password anytime



Choose how you want to receive your authentication code: mobile device or email



Enter the 6-digit PIN you received by either method. If using your mobile device, you will need to request a verification email before logging in for the first time or for resetting your 2FA



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The Core Registry

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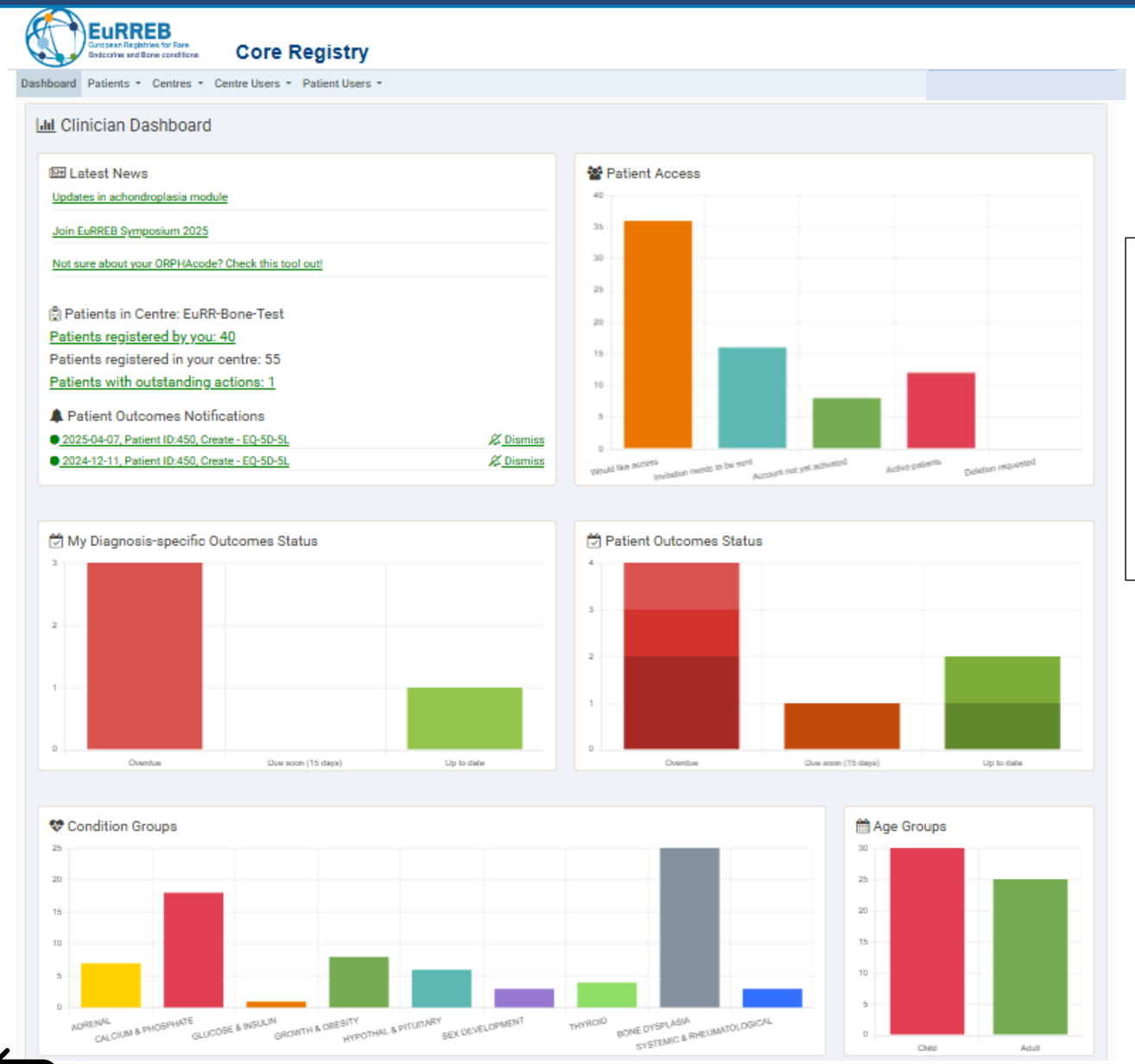
Dashboard



You can explore the different features of the dashboard:

- you have access to all patients registered in your centre
- you can see the latest news
- you can see the distribution of cases by MTG and age groups
- you can check patient access status and patient and clinician outcomes status

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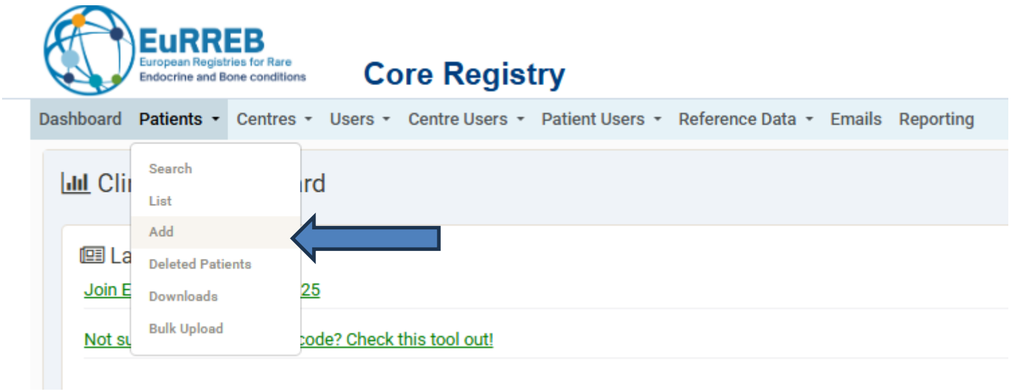
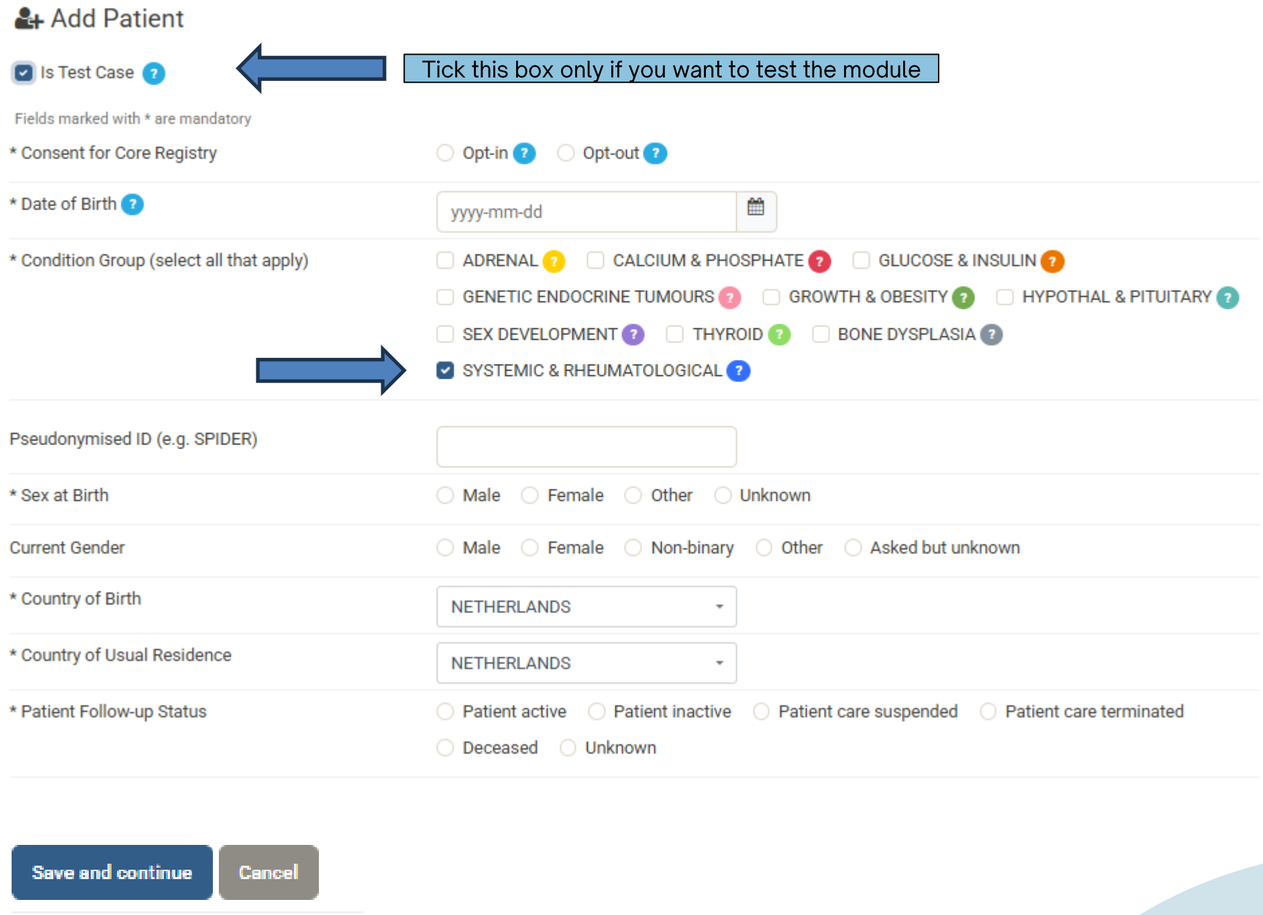
How to add a new patient

Click on “Add” from the menu tab “Patients”



Fill in all mandatory fields in the Common Data Elements,
choose “SYSTEMIC & RHEUMATOLOGICAL” to use the non-LCH module



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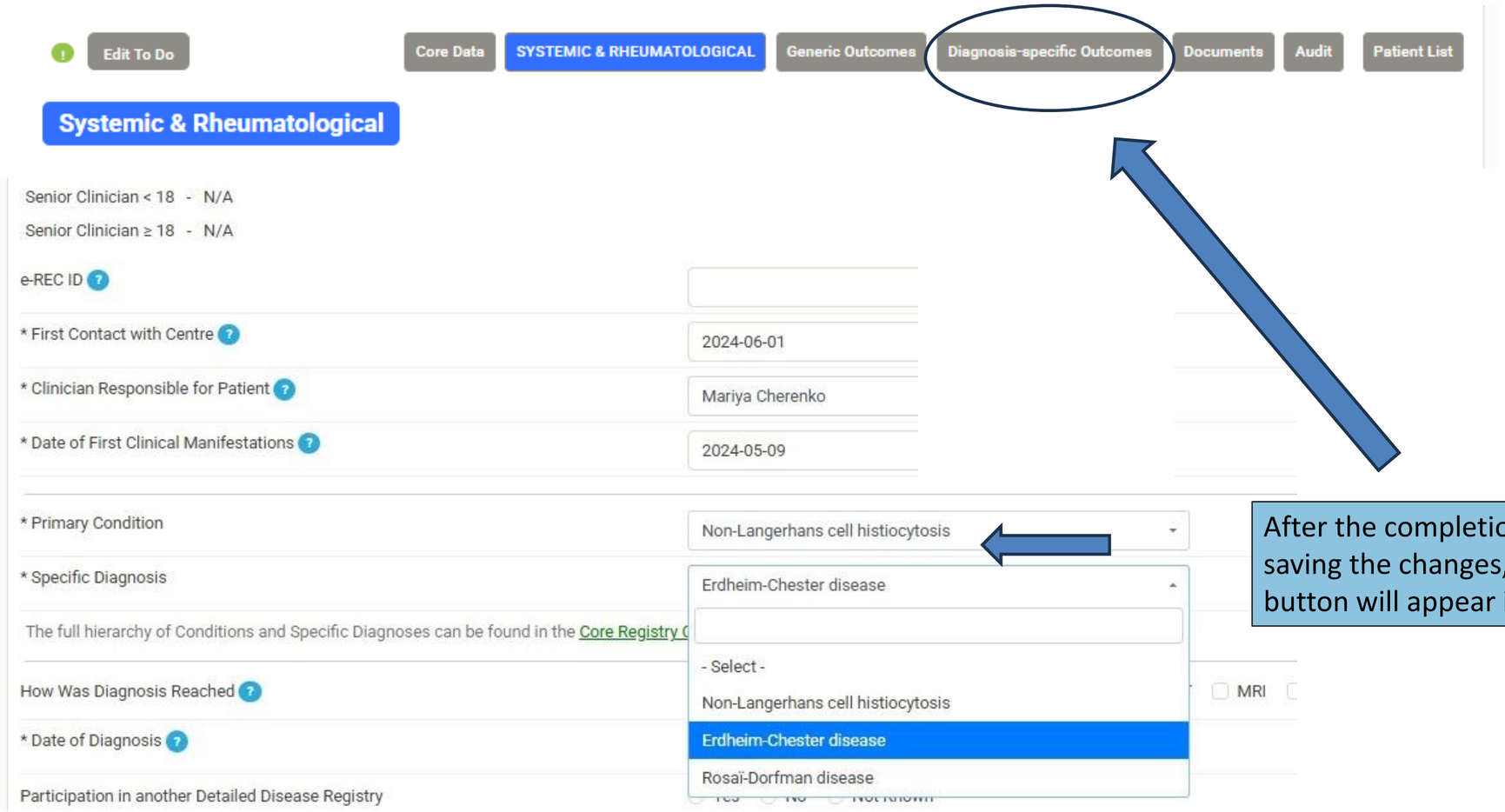
Fill in the mandatory fields in the condition group section



After the completion of the mandatory fields and saving the changes, a “Diagnosis-specific Outcomes” button will appear in the menu

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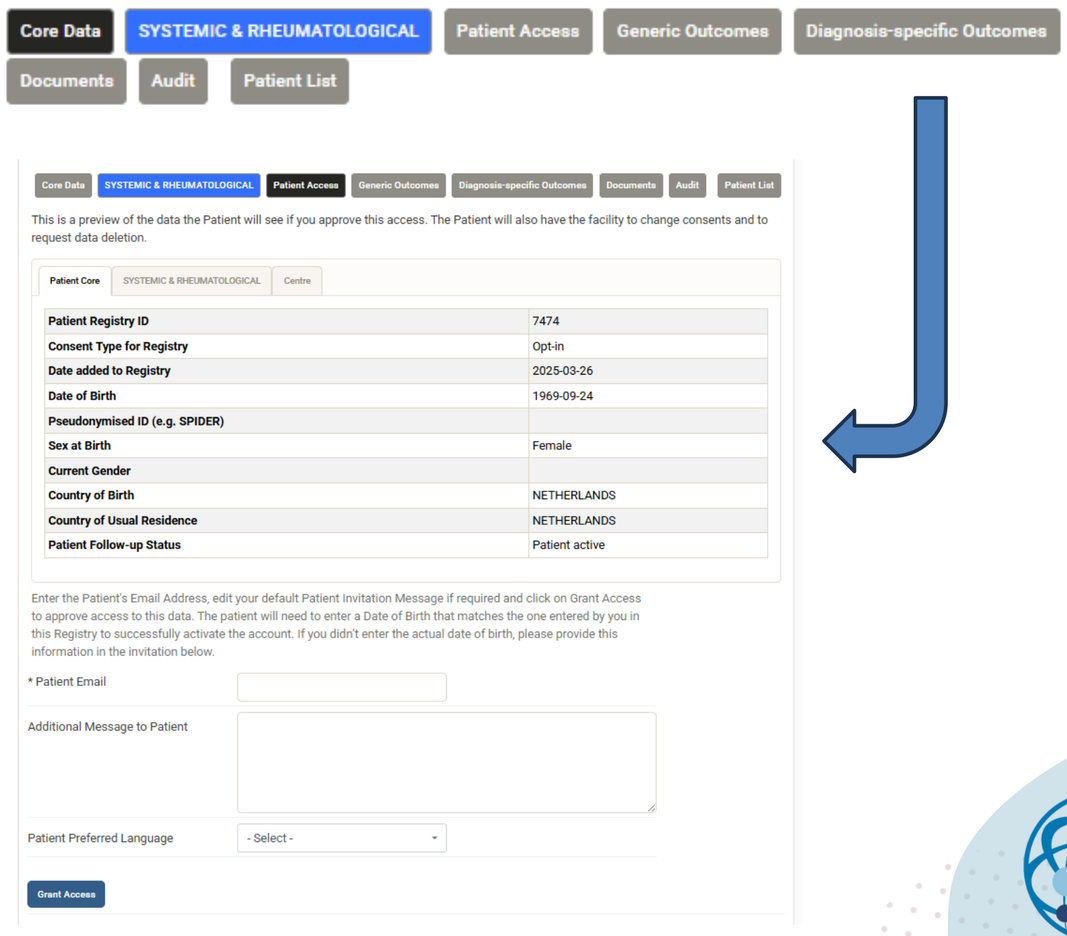
Access for a patient to the Core Registry

If your patient consented for the access to the Core Registry:

After ticking the correspondent answer, ‘Patient Access’ button will appear automatically in the menu



You need to know your patient’s e-mail address. The system will send the invitation link. You can write an additional massage and choose preferred language. On the platform patient can see the information about him and fill in the PROMs.

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The non-LCH Module

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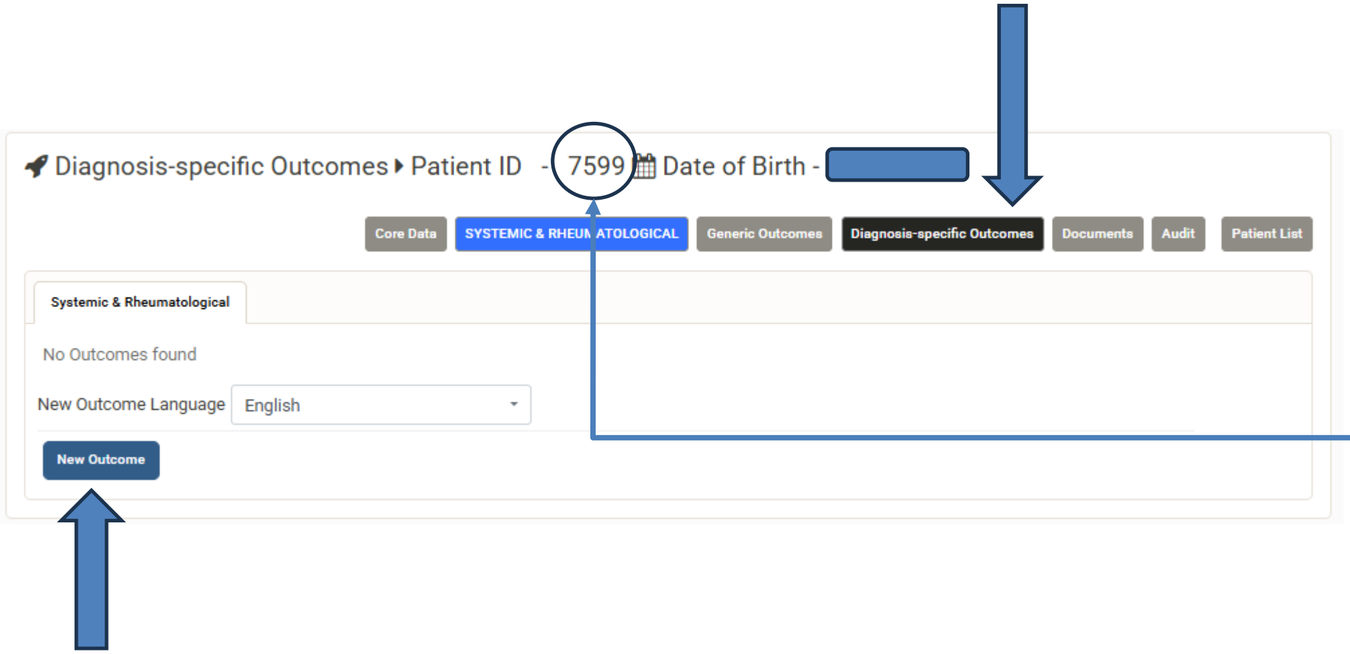
How to fill in the non-LCH module

If you added the patient with LCH to the Core Registry, “Diagnosis-specific Outcomes” button will appear in the menu, click there to create a new outcome



When a patient is registered in the system, a **unique code** is generated and must be stored locally by the healthcare provider, who will be the only one able to retrieve which patient is associated with a specific code.

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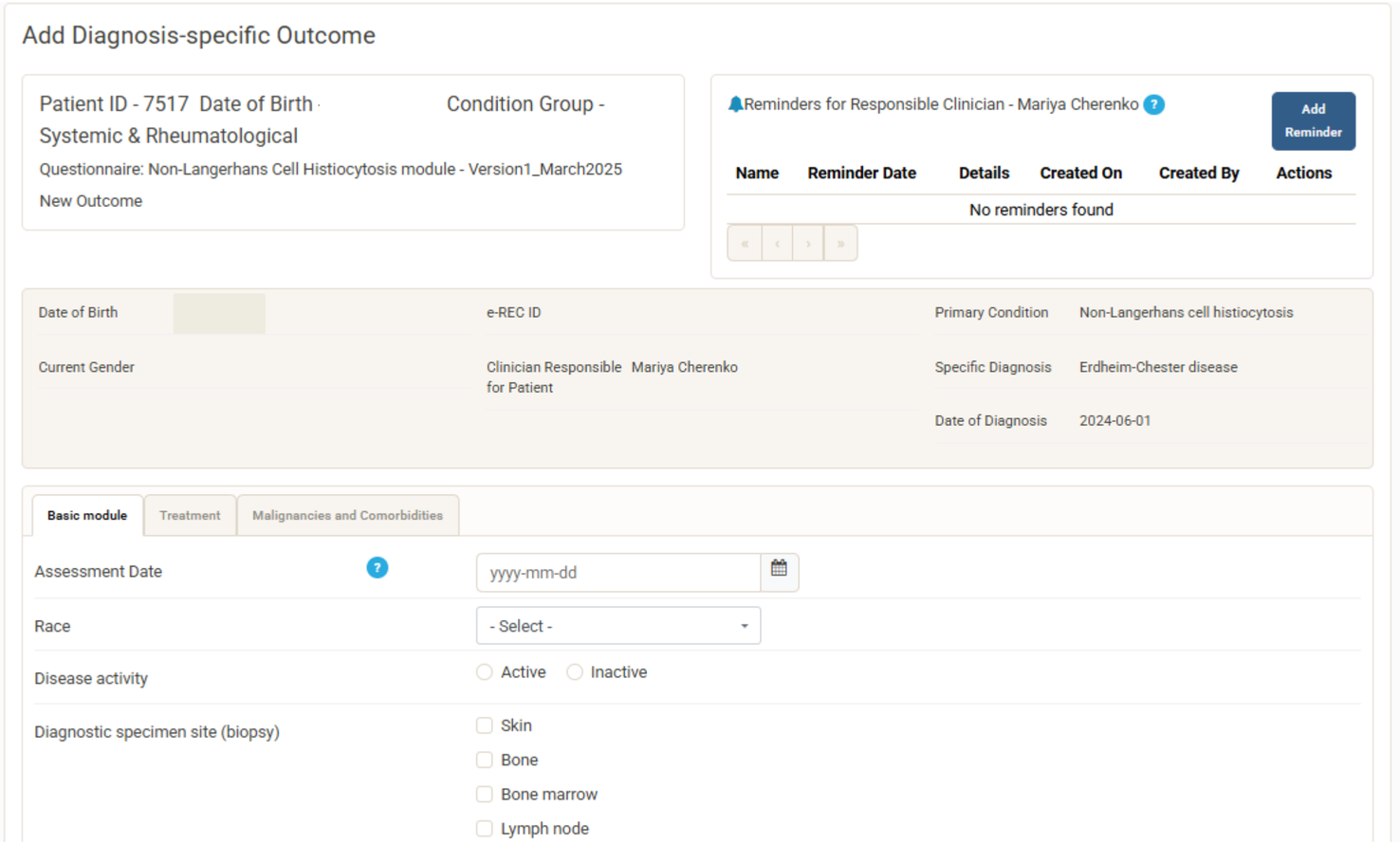
Fill in the data into the module and save

👉 Note: Some questions are hidden and will only appear based on the answers you choose.
Explore all the tabs and the tooltips. Some questions are mandatory.



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PROMs

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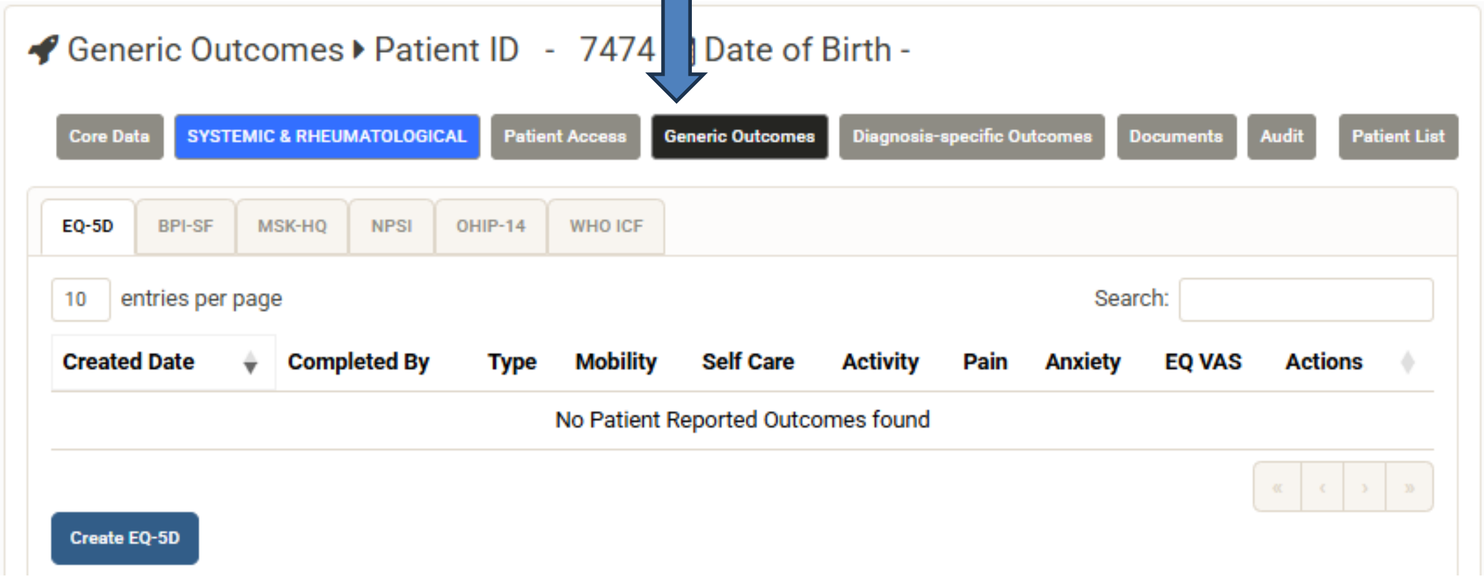
How to fill in PROMs for the non-LCH module

You can fill in PROMs for your patient or the patient can do it himself after activating his access to the Core Registry platform.
Choose ‘Generic Outcomes’ to see which PROMs are available.
For non-LCH we are currently collecting EQ-5D.



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Ways to contact us:

eurreb.eu

registries@lumc.nl

drop-in sessions via Zoom

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