

# How to use the LCH module in the Core Registry



# Table of contents

1	<a href="#">How to create an account in the Core Registry?</a>
2	<a href="#">How to login if you have an account?</a>
3	<a href="#">How to add a new patient in the Core Registry?</a>
4	<a href="#">How to give patients access to the Core Registry?</a>
5	<a href="#">How to use the LCH module?</a>
6	<a href="#">How to fill in PROMs?</a>
7	<a href="#">How to contact us?</a>



# 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

**New User Registration Request**

Fields marked with \* are mandatory

\* Application Role Requested

e-REC Reporter ?

Core Registry Clinical Contributor ?

Title

\* Surname

\* Given Name

Middle Names

\* Email (and User Name)

Password must be at least 8 characters  
Password must contain both lower and upper case letters  
Password must contain at least one numeric character  
Password must contain at least one of the following symbols: @ # ! ? € \$ £ % & \_ + - ~

\* Password

\* Confirm Password

Telephone

\* I would like to be the Centre Lead for this Centre ?  Yes  No

Filter Centres by Country (optional)

\* Centre

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.



Back to the index

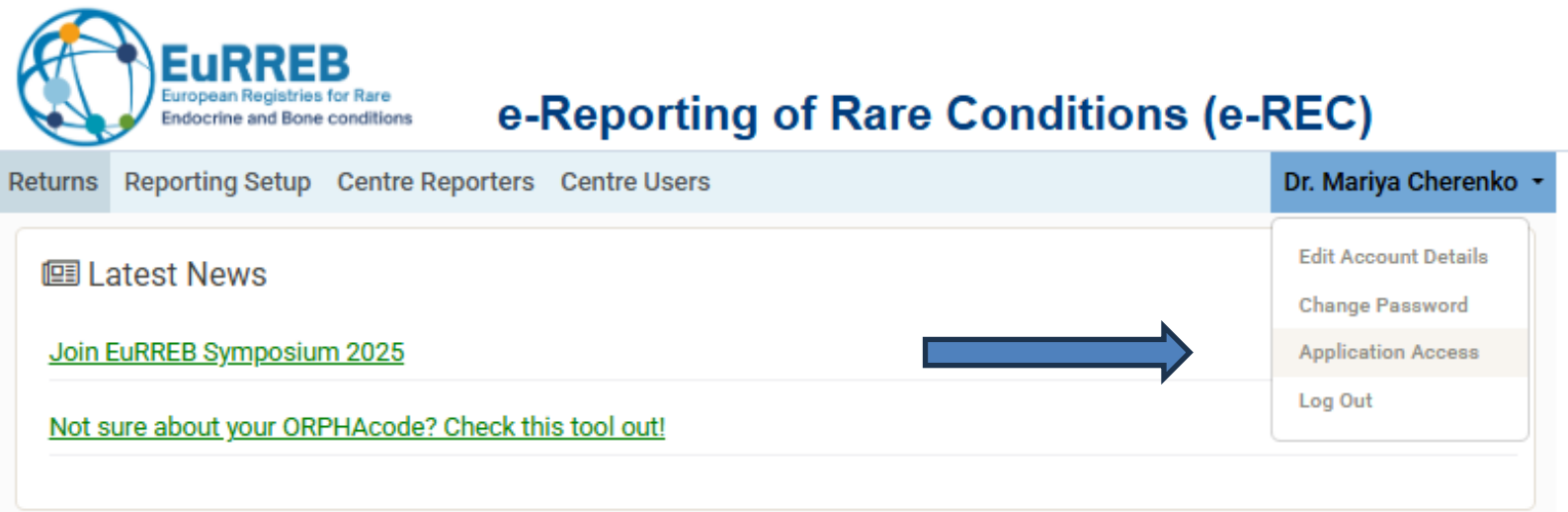


# How to change your application role if you already use e-REC

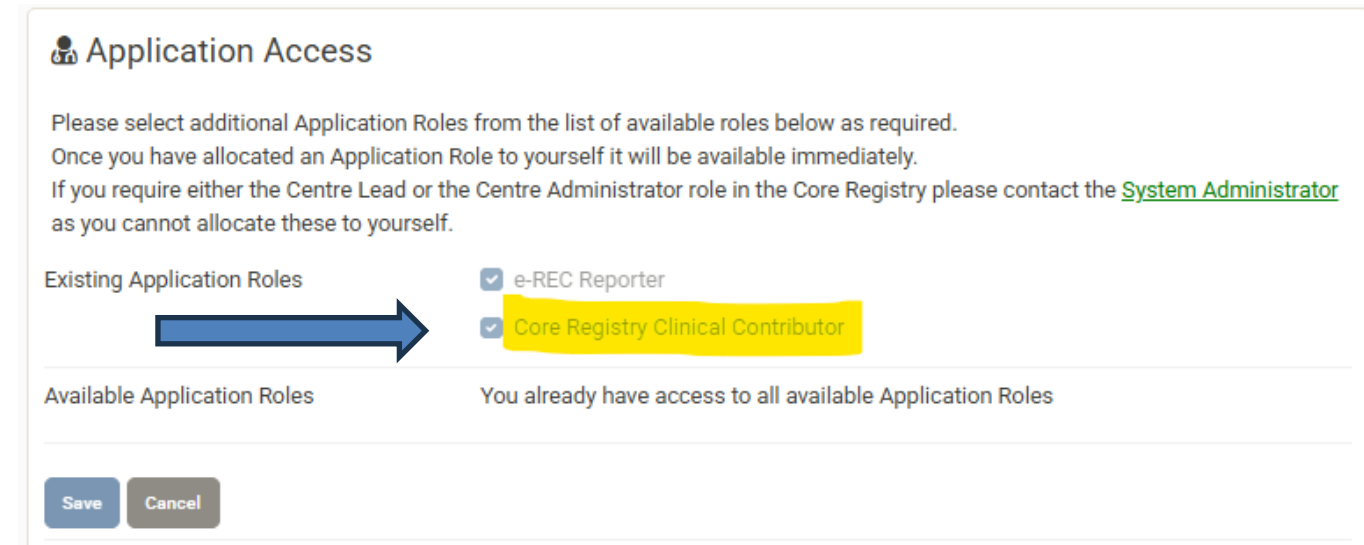
If you are already using e-REC, you can easily allocate the Core Registry Clinical Contributor role to yourself

The Core Registry Clinical Contributor role will become available immediately

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



The screenshot shows the top navigation bar of the e-REC system. On the left is the EuRREB logo (European Registries for Rare Endocrine and Bone conditions). The main title is "e-Reporting of Rare Conditions (e-REC)". Below the title are navigation tabs: "Returns", "Reporting Setup", "Centre Reporters", and "Centre Users". On the right, the user's name "Dr. Mariya Cherenko" is displayed with a dropdown arrow. A menu is open under the user name, listing "Edit Account Details", "Change Password", "Application Access", and "Log Out". A blue arrow points from the "Application Access" menu item to the right.

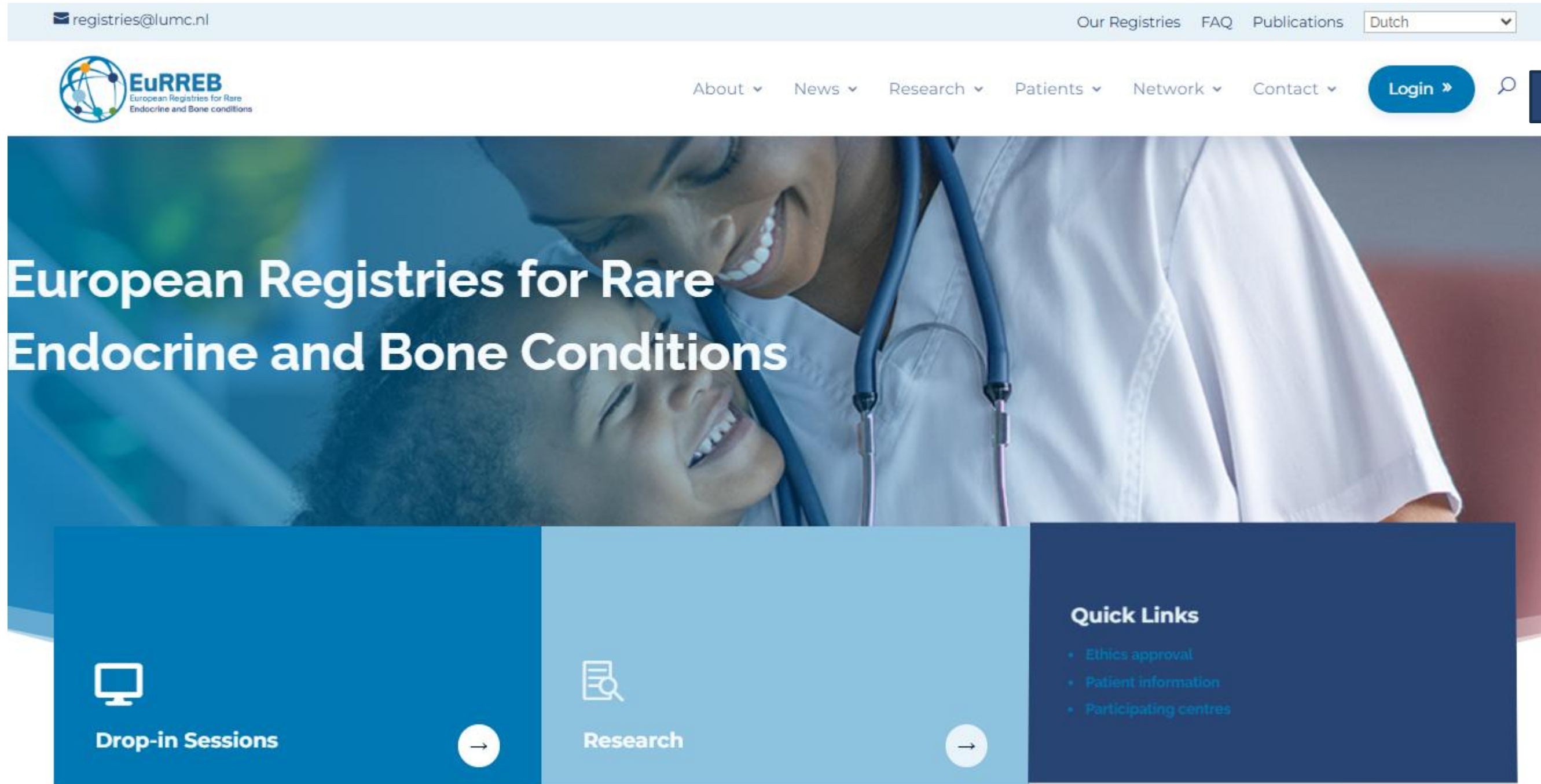


The screenshot shows the "Application Access" configuration page. It includes a title "Application Access" and a user icon. Below the title is a paragraph: "Please select additional Application Roles from the list of available roles below as required. Once you have allocated an Application Role to yourself it will be available immediately. If you require either the Centre Lead or the Centre Administrator role in the Core Registry please contact the [System Administrator](#) as you cannot allocate these to yourself." Below this is a section "Existing Application Roles" with two checked items: "e-REC Reporter" and "Core Registry Clinical Contributor". A blue arrow points from the "Application Access" menu in the previous screenshot to this section. Below "Existing Application Roles" is a section "Available Application Roles" with the text "You already have access to all available Application Roles". At the bottom are "Save" and "Cancel" buttons.

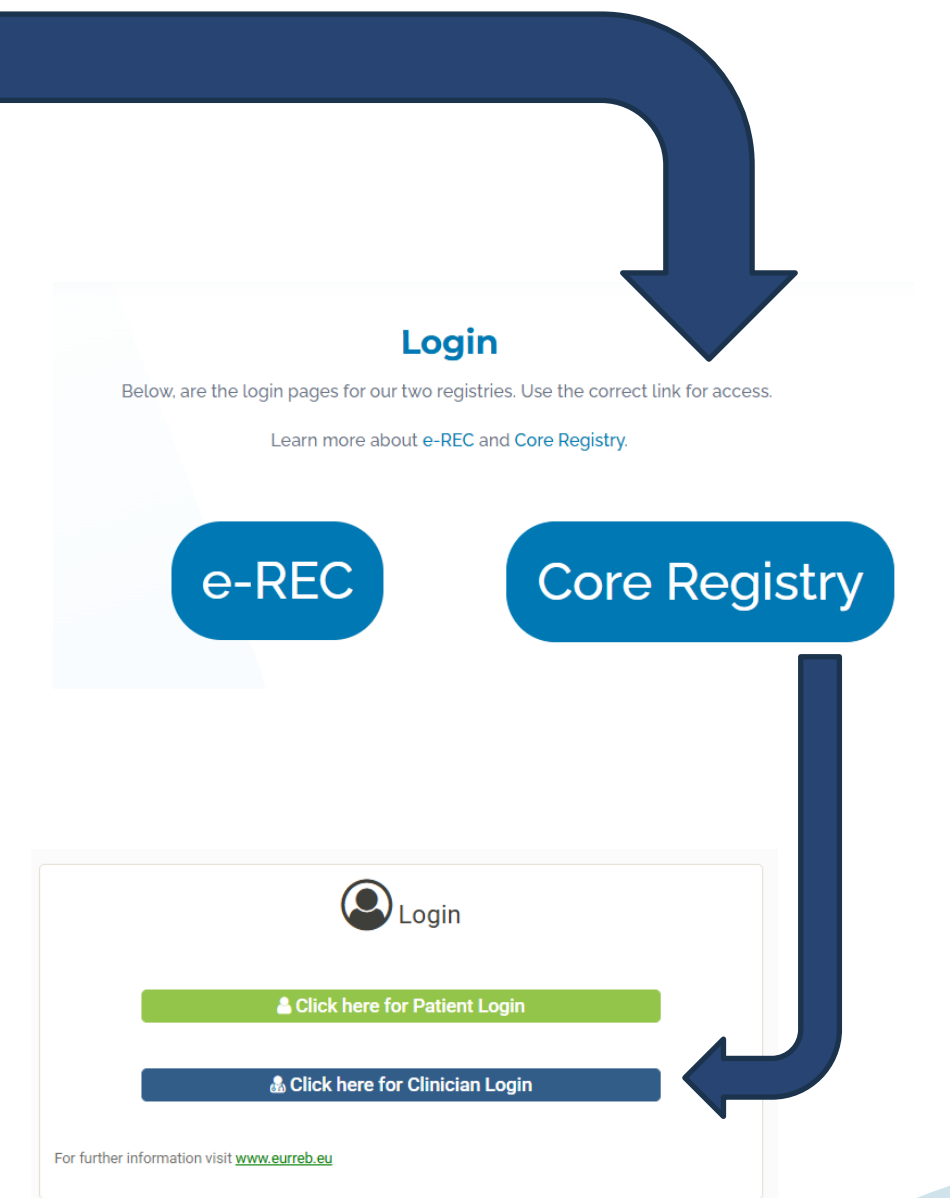


# How to log in into the Core Registry

Go to <https://eurreb.eu/> and use [Login button](#) and go to the Core Registry and choose [Clinician Login page](#)



The screenshot shows the EURREB website homepage. At the top left is the email address [registries@lumc.nl](mailto:registries@lumc.nl). The top right navigation bar includes links for "Our Registries", "FAQ", "Publications", and a language dropdown menu set to "Dutch". Below this is the EURREB logo and a main navigation menu with "About", "News", "Research", "Patients", "Network", and "Contact". A prominent blue "Login" button is located to the right of the main menu. The main banner features a photograph of a doctor smiling at a young girl, with the text "European Registries for Rare Endocrine and Bone Conditions". At the bottom, there are three sections: "Drop-in Sessions" with a monitor icon, "Research" with a magnifying glass icon, and "Quick Links" with a list of links: "Ethics approval", "Patient information", and "Participating centres".



The screenshot shows the EURREB login page. At the top, it says "Login" and "Below, are the login pages for our two registries. Use the correct link for access." Below this is a link to "Learn more about e-REC and Core Registry." There are two large blue buttons: "e-REC" and "Core Registry". A blue arrow points from the "Login" button on the homepage to the "Login" section. Below the buttons is a "Login" section with a user icon and the text "Login". There are two buttons: a green one that says "Click here for Patient Login" and a blue one that says "Click here for Clinician Login". A blue arrow points from the "Core Registry" button to the "Click here for Clinician Login" button. At the bottom, it says "For further information visit [www.eurreb.eu](http://www.eurreb.eu)".



# 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

### Clinician Login

User Name

Password

Forgotten password? To reset your password please click on the following [Reset Password link](#)

[→ Log in](#)

[← Back](#)

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

### Two-Factor Authentication



Please select how you want to receive your authentication code:

[Use Device Code](#) [Send Code via Email](#)

Click on the following link for further information about OTP authentication: [OTP Authentication](#)

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

### Verify Your Identity

 6 digit PIN from your mobile device 

[→ Log in](#)

If this is your first time logging in or you need to reset your two-factor authentication (2FA) device, please verify your identity by requesting a verification link to be sent to your registered email address.

Once you receive the email and confirm your identity, you can continue to set up or reset your 2FA device: [Send Verification Email](#)

Click on the following link for further information about OTP authentication: [OTP Authentication](#)



# The Core Registry



# Dashboard

## Clinician Dashboard

### Latest News

[Updates in achondroplasia module](#)

[Join EuRREB Symposium 2025](#)

[Not sure about your ORPHAcode? Check this tool out!](#)

### Patients in Centre: EuRR-Bone-Test

[Patients registered by you: 40](#)

Patients registered in your centre: 55

[Patients with outstanding actions: 1](#)

### Patient Outcomes Notifications

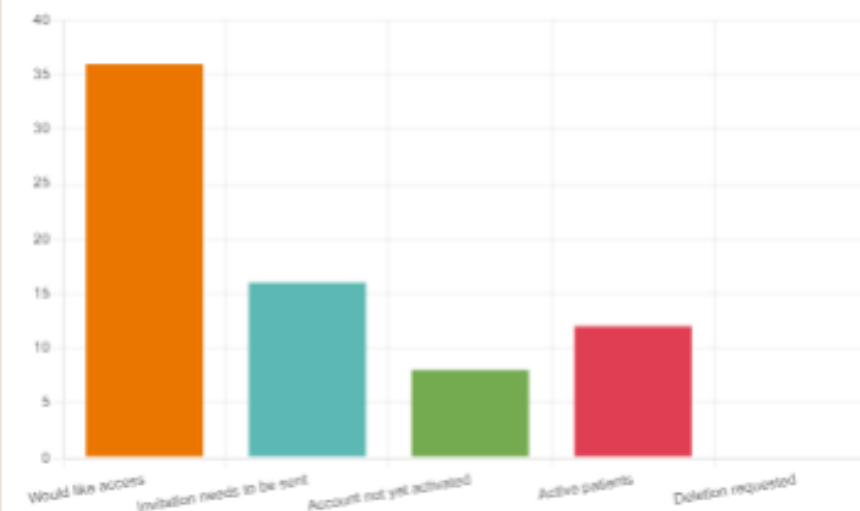
[2025-04-07, Patient ID:450, Create - EQ-5D-5L](#)

[Dismiss](#)

[2024-12-11, Patient ID:450, Create - EQ-5D-5L](#)

[Dismiss](#)

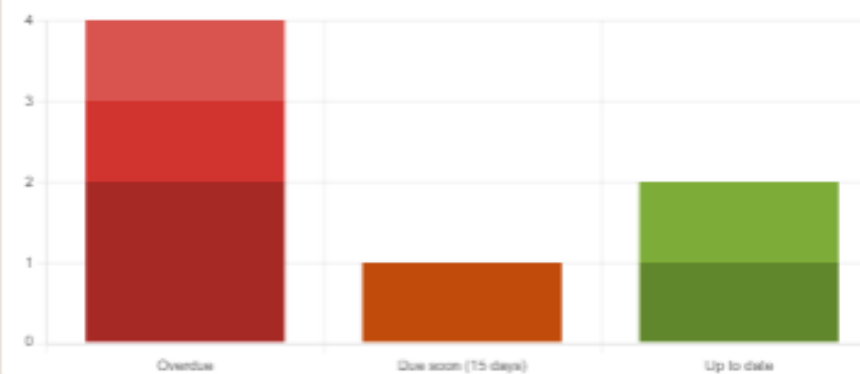
### Patient Access



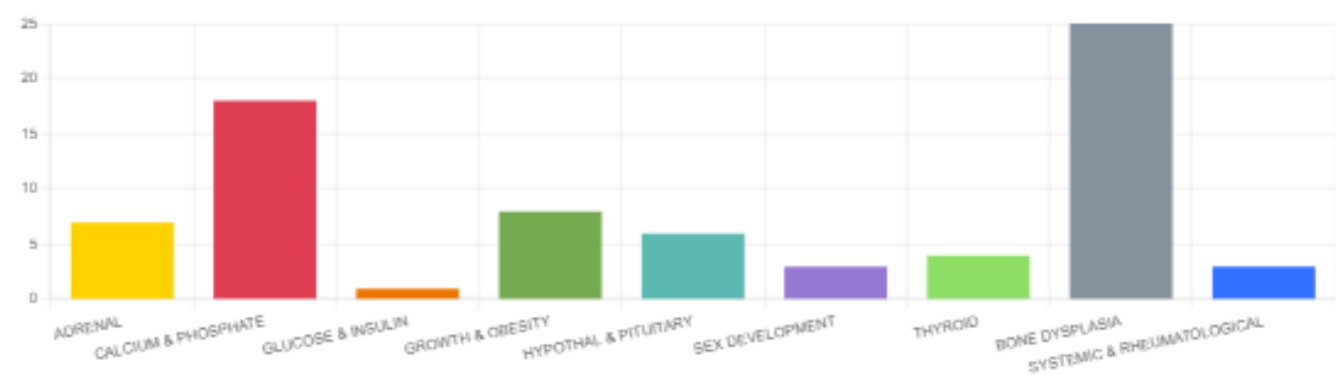
### My Diagnosis-specific Outcomes Status



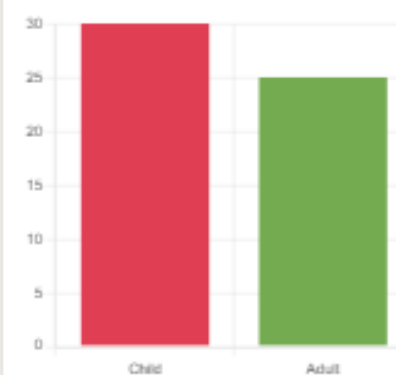
### Patient Outcomes Status



### Condition Groups



### Age Groups



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

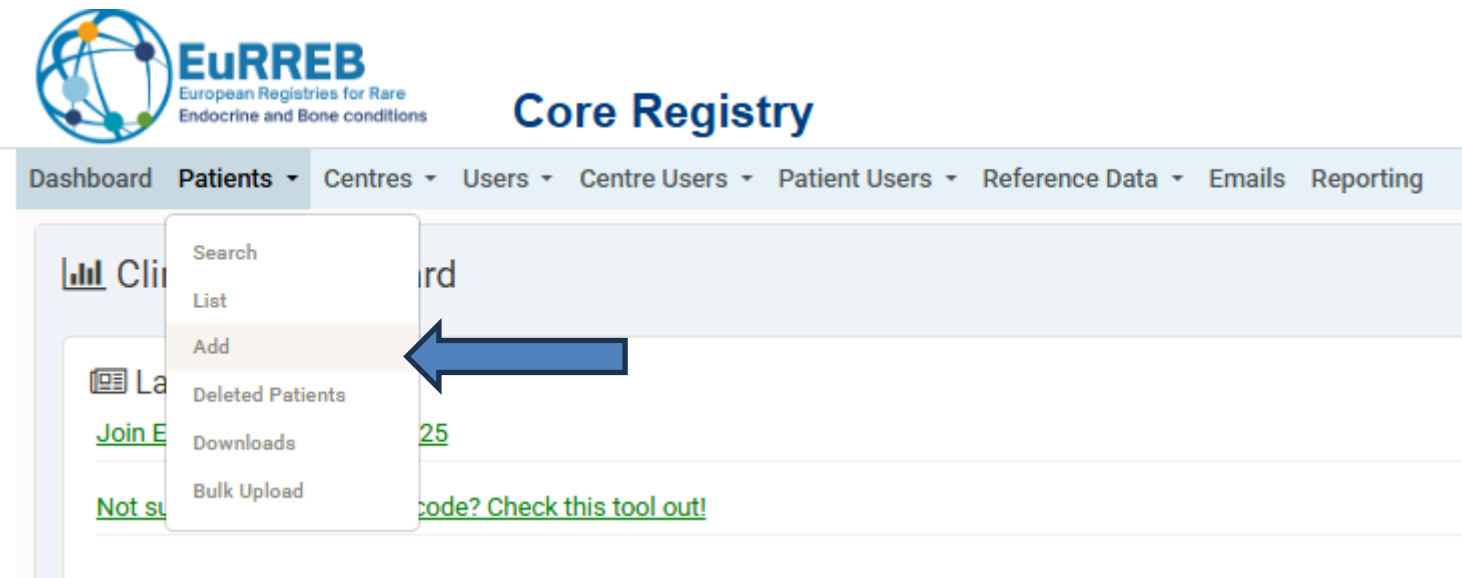


Back to the index



# 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 LCH module

The 'Add Patient' form includes the following fields and options:

- Is Test Case ? (Annotated with a blue arrow and a callout box: "Tick this box only if you want to test the module")
- Fields marked with \* are mandatory
- \* Consent for Core Registry:  Opt-in ?  Opt-out ?
- \* Date of Birth ?: Input field with placeholder 'yyyy-mm-dd' and a calendar icon
- \* Condition Group (select all that apply):
  - ADRENAL ?  CALCIUM & PHOSPHATE ?  GLUCOSE & INSULIN ?
  - GENETIC ENDOCRINE TUMOURS ?  GROWTH & OBESITY ?  HYPOTHAL & PITUITARY ?
  - SEX DEVELOPMENT ?  THYROID ?  BONE DYSPLASIA ?
  - SYSTEMIC & RHEUMATOLOGICAL ? (Annotated with a blue arrow)
- Pseudonymised ID (e.g. SPIDER): Input field
- \* Sex at Birth:  Male  Female  Other  Unknown
- Current Gender:  Male  Female  Non-binary  Other  Asked but unknown
- \* Country of Birth: Dropdown menu with 'NETHERLANDS' selected
- \* Country of Usual Residence: Dropdown menu with 'NETHERLANDS' selected
- \* Patient Follow-up Status:  Patient active  Patient inactive  Patient care suspended  Patient care terminated  Deceased  Unknown

At the bottom, there are two buttons: 'Save and continue' and 'Cancel'. A blue arrow points to the 'Save and continue' button.



# Fill in the mandatory fields in the condition group section

You can use this field for your notes

1 Edit To Do

Core Data **SYSTEMIC & RHEUMATOLOGICAL** Generic Outcomes **Diagnosis-specific Outcomes** Documents Audit Patient List

## Systemic & Rheumatological

Senior Clinician < 18 - N/A  
Senior Clinician ≥ 18 - N/A

e-REC ID ?

\* First Contact with Centre ?

\* Clinician Responsible for Patient ?

\* Date of First Clinical Manifestations ?

\* Primary Condition

\* Specific Diagnosis

The full hierarchy of Conditions and Specific Diagnoses can be found in the [Core Registry Conditions Dictionary](#)

How Was Diagnosis Reached ?  Clinical  Biochemistry  Genetic  Histology  CT  MRI  PET  USS  X-Ray  Other  Not Known

\* Date of Diagnosis ?

Participation in another Detailed Disease Registry  Yes  No  Not Known

Name of Detailed Disease Registry

**Save**

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



# Access for a patient to the Core Registry

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

\* Can be contacted for research purposes by clinician responsible for patient  Yes  No  Not Known

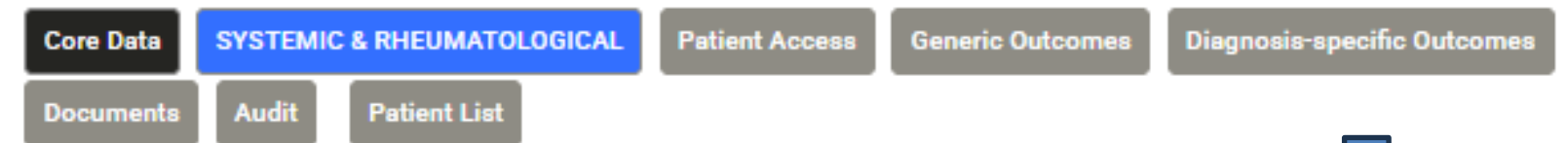
\* Data can be shared for research purposes  Yes  No  Not Known

Can be contacted for collecting Patient Reported Outcomes  Yes  No  Not Known

\* Patient would like access to Core Registry  Yes  No  Not Known

Consent for Newsletters  Yes  No  Not Known

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



This is a preview of the data the Patient will see if you approve this access. The Patient will also have the facility to change consents and to request data deletion.

Patient Core	SYSTEMIC & RHEUMATOLOGICAL	Centre
Patient Registry ID	7474	
Consent Type for Registry	Opt-in	
Date added to Registry	2025-03-26	
Date of Birth	1969-09-24	
Pseudonymised ID (e.g. SPIDER)		
Sex at Birth	Female	
Current Gender		
Country of Birth	NETHERLANDS	
Country of Usual Residence	NETHERLANDS	
Patient Follow-up Status	Patient active	

Enter the Patient's Email Address, edit your default Patient Invitation Message if required and click on Grant Access to approve access to this data. The patient will need to enter a Date of Birth that matches the one entered by you in this Registry to successfully activate the account. If you didn't enter the actual date of birth, please provide this information in the invitation below.

\* Patient Email

Additional Message to Patient

Patient Preferred Language

[Grant Access](#)

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



# The LCH Module



# How to fill in the 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

Diagnosis-specific Outcomes ▶ Patient ID - 7599 Date of Birth - [ ]

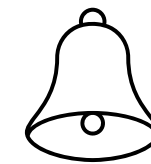
Core Data SYSTEMIC & RHEUMATOLOGICAL Generic Outcomes Diagnosis-specific Outcomes Documents Audit Patient List

Systemic & Rheumatological

No Outcomes found

New Outcome Language English

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.



# 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.

## Add Diagnosis-specific Outcome

Patient ID - 7276 Date of Birth Condition Group - Systemic & Rheumatological  
Questionnaire: Langerhans Cell Histiocytosis module - beta version  
New Outcome

Reminders for Responsible Clinician - Dr. Mariya Cherenko ? [Add Reminder](#)

Name	Reminder Date	Details	Created On	Created By	Actions
No reminders found					

Date of Birth	<input type="text"/>	e-REC ID	Primary Condition	Langerhans cell histiocytosis
Current Gender		Clinician Responsible for Patient	Specific Diagnosis	Langerhans cell histiocytosis
		Mariya Cherenko	Date of Diagnosis	2025-01-06

Basic module Treatment Malignancies/Comorbidities

Assessment Date ?

Race

Disease activity  Active  Inactive

Specimen Type ?  
 Skin  
 Bone  
 Lymph node  
 Lung (BAL)  
 Lung  
 CNS  
 Liver



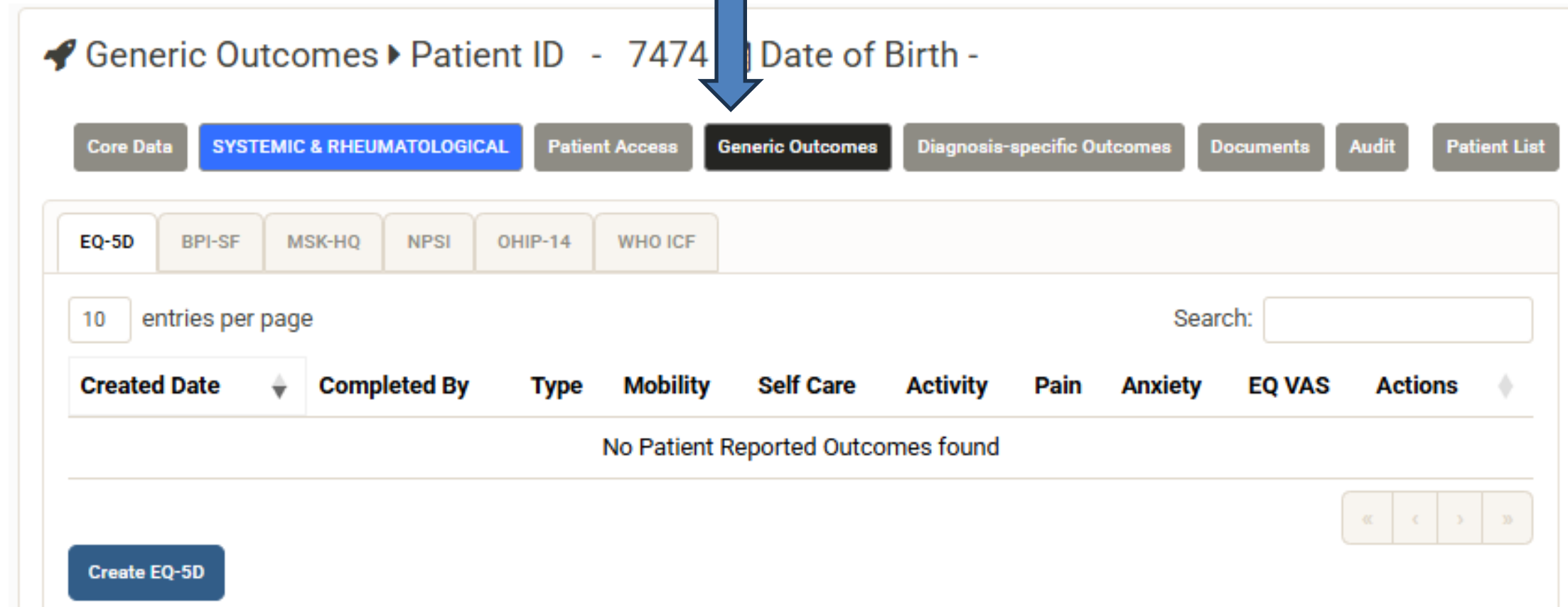
# PROMs



**EuRREB**  
European Registries for Rare  
Endocrine and Bone conditions

# How to fill in PROMs for the 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 LCH we are currently collecting EQ-5D.



The screenshot shows a web interface for 'Generic Outcomes'. At the top, it displays 'Patient ID - 7474' and 'Date of Birth -'. Below this is a navigation bar with buttons for 'Core Data', 'SYSTEMIC & RHEUMATOLOGICAL', 'Patient Access', 'Generic Outcomes', 'Diagnosis-specific Outcomes', 'Documents', 'Audit', and 'Patient List'. The 'Generic Outcomes' button is highlighted. Underneath, there are tabs for 'EQ-5D', 'BPI-SF', 'MSK-HQ', 'NPSI', 'OHIP-14', and 'WHO ICF'. The 'EQ-5D' tab is selected. Below the tabs, there is a search bar and a dropdown menu for '10 entries per page'. A table header is visible with columns: 'Created Date', 'Completed By', 'Type', 'Mobility', 'Self Care', 'Activity', 'Pain', 'Anxiety', 'EQ VAS', and 'Actions'. The table content is empty, displaying the message 'No Patient Reported Outcomes found'. At the bottom left, there is a 'Create EQ-5D' button. At the bottom right, there are navigation arrows.





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## Ways to contact us:



[eurreb.eu](http://eurreb.eu)



[registries@lumc.nl](mailto:registries@lumc.nl)



[drop-in sessions via Zoom](#)



[European Registries for Rare  
Endocrine and Bone Conditions](#)



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Back to the index