

How to use the LCH module in the Core Registry



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How to create an account in the Core Registry

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



Fill in the form, choose 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)

- Select -

* Centre

- Select -

Save

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



Fill in the mandatory information.
Your request will be approved as soon as possible.



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



e-Reporting of Rare Conditions (e-REC)

ReturnsReporting SetupCentre ReportersCentre Users

Dr. Mariya Cherenko

Latest News

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

Edit Account Details

Change Password

Application Access

Log Out

Application Access

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.

Existing Application Roles

☒ e-REC Reporter

☒ Core Registry Clinical Contributor

Available Application Roles

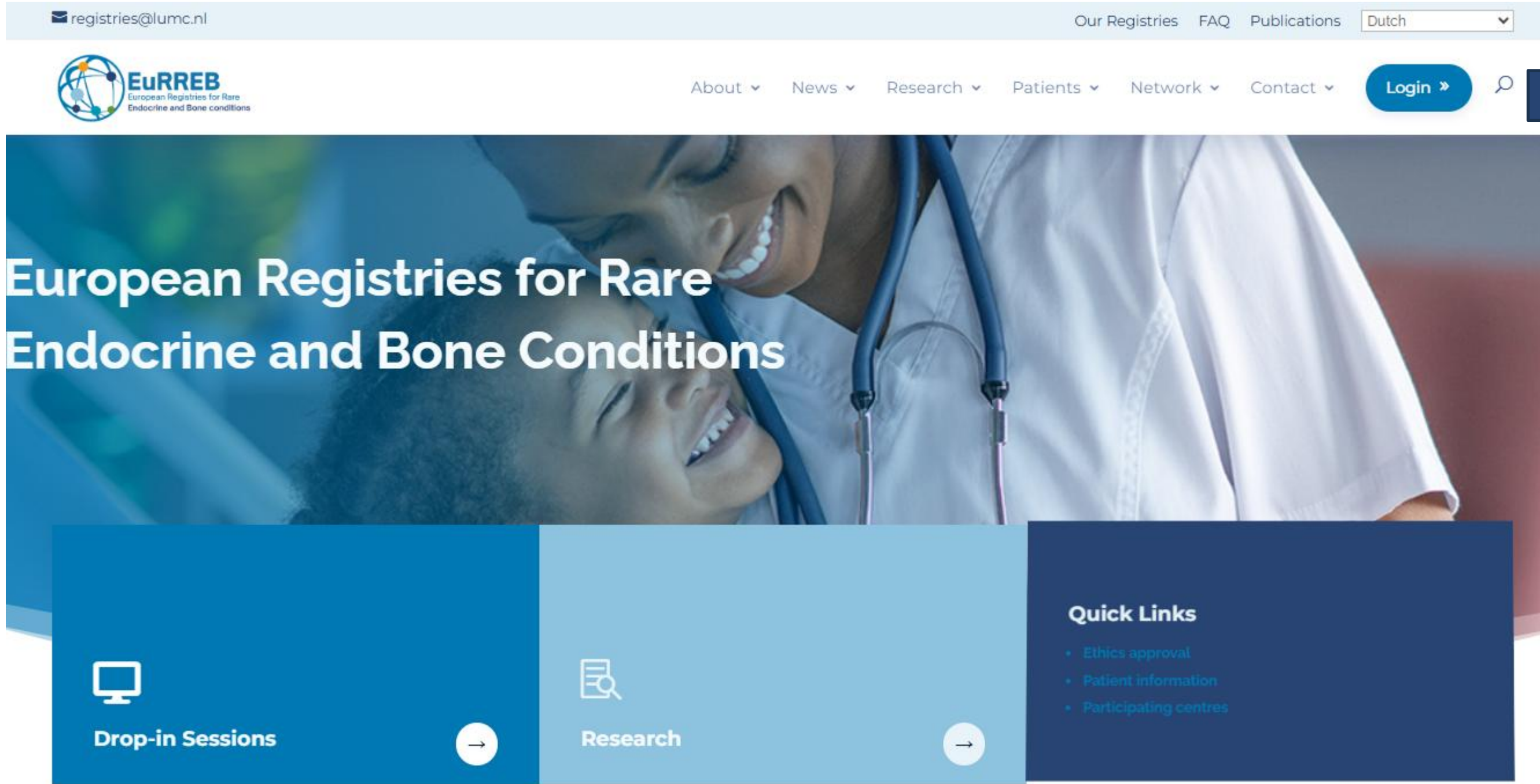
You already have access to all available Application Roles

Save

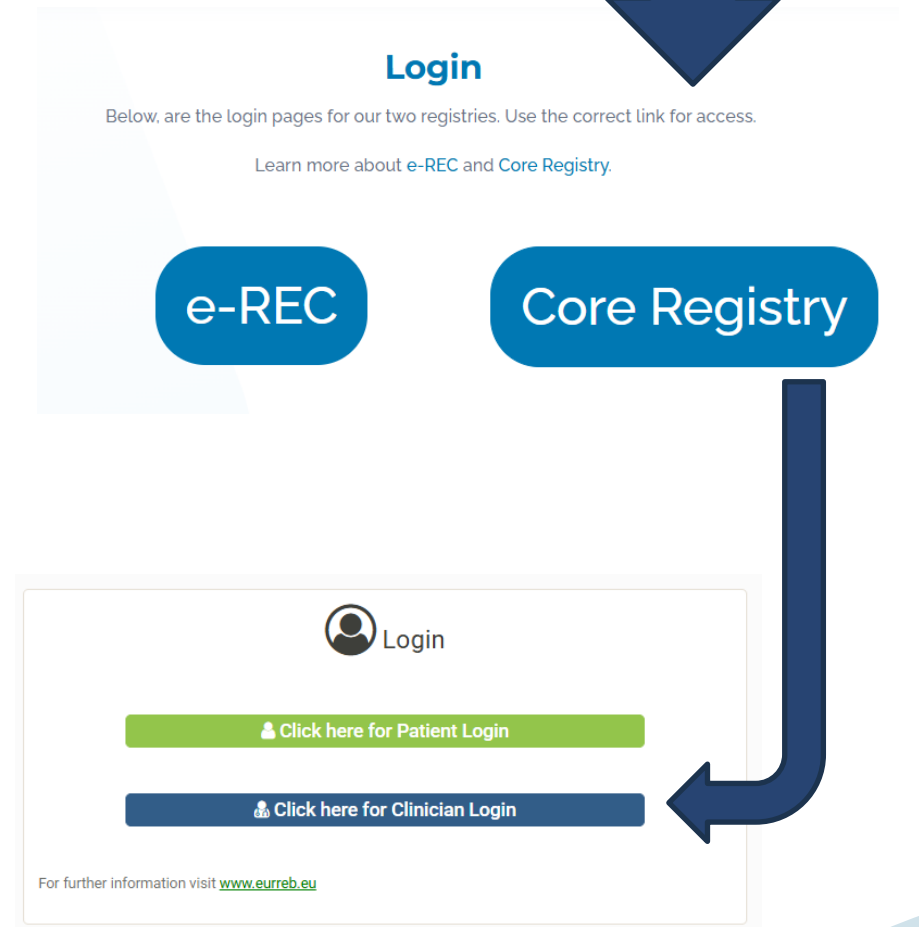
Cancel

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, there is a header with the email registries@lumc.nl, navigation links for "Our Registries", "FAQ", and "Publications", and a language dropdown menu set to "Dutch". The EURREB logo is on the left, and a "Login" button is on the right. Below the header is a large banner image of a doctor smiling at a child, with the text "European Registries for Rare Endocrine and Bone Conditions". At the bottom, there are three main 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 flowchart illustrates the login process. It starts with a "Login" section that says "Below, are the login pages for our two registries. Use the correct link for access." and "Learn more about e-REC and Core Registry." There are two buttons: "e-REC" and "Core Registry". An arrow points from the "Core Registry" button to a "Login" section. This section has a "Login" heading and two buttons: "Click here for Patient Login" (green) and "Click here for Clinician Login" (blue). An arrow points from the "Click here for Clinician Login" button to the next step.

Login

Below, are the login pages for our two registries. Use the correct link for access.

Learn more about e-REC and Core Registry.

e-REC **Core Registry**

Login

Click here for Patient Login

Click here for Clinician Login

For further information visit 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



Connect any OTP device via “send verification email” link or enter PIN from previously connected device.

 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



Core Registry

Dashboard Patients Centres Centre Users Patient Users

Clinician Dashboard

Latest News

[Updates in achondroplasia module](#)

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[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](#)

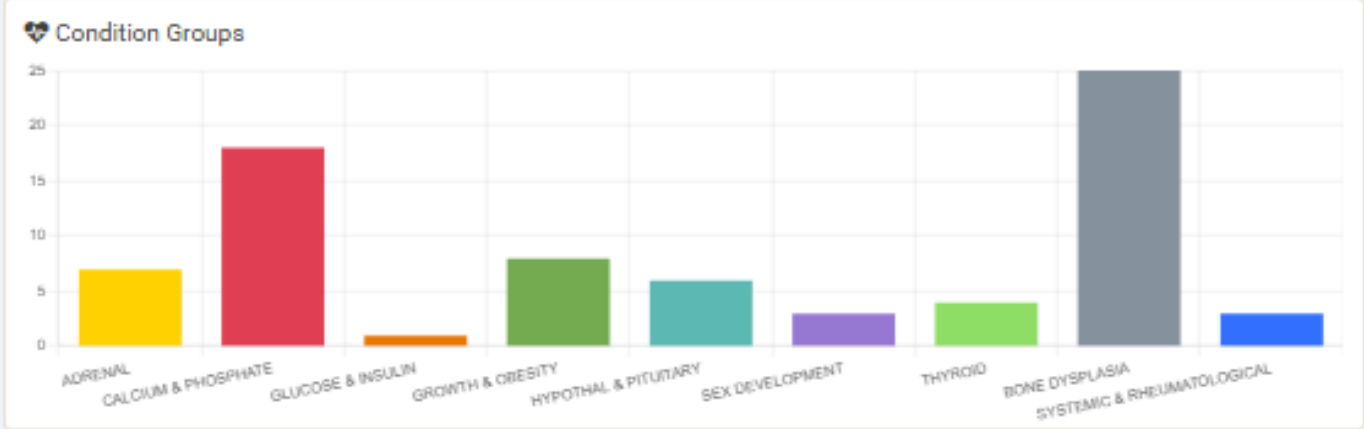
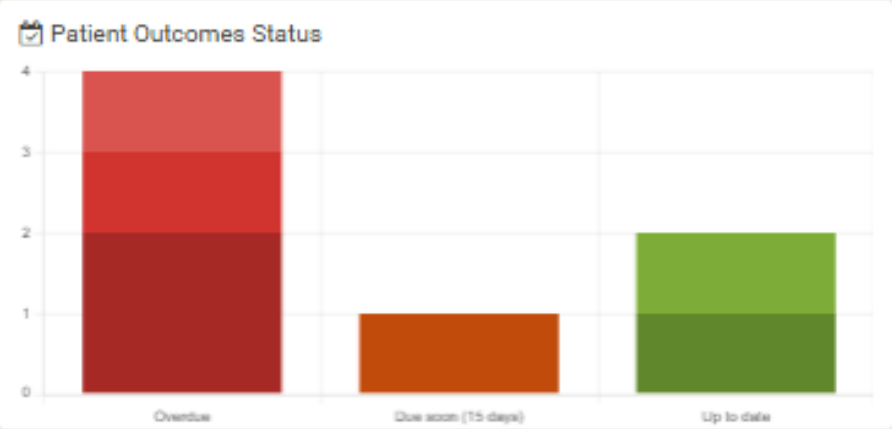
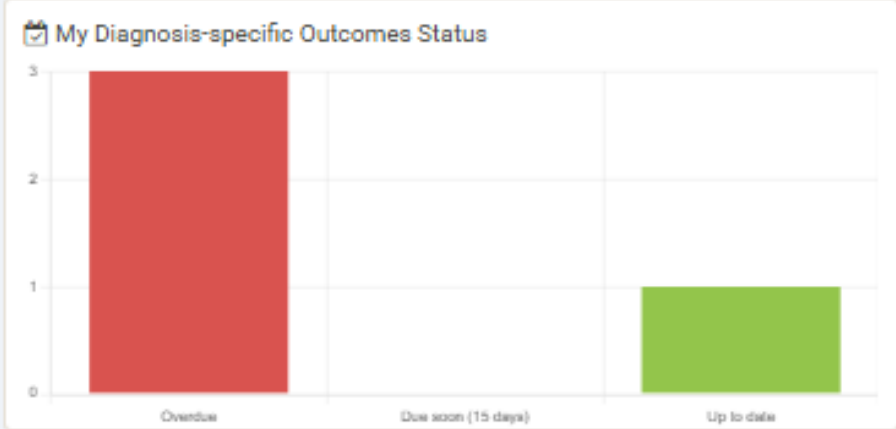
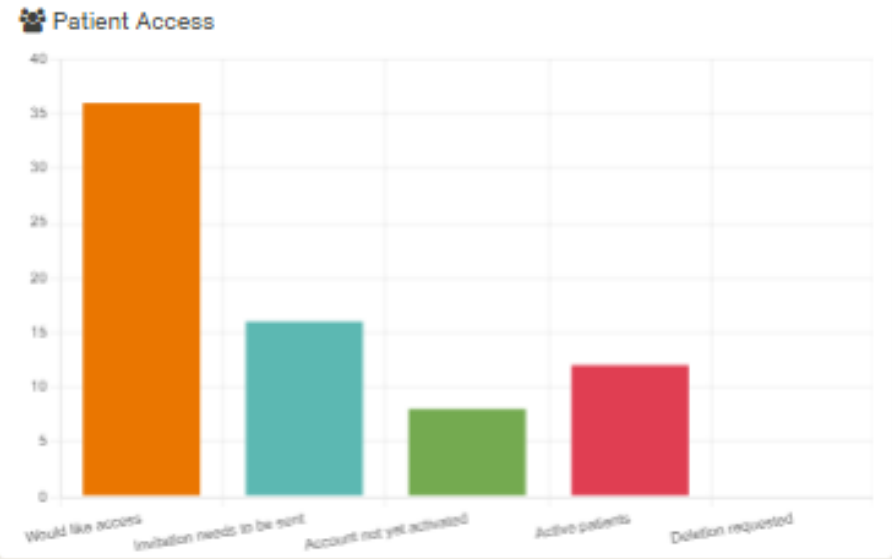
Patient Outcomes Notifications

2025-04-07, Patient ID:450, Create - EQ-5D-5L

Dismiss

2024-12-11, Patient ID:450, Create - EQ-5D-5L

Dismiss

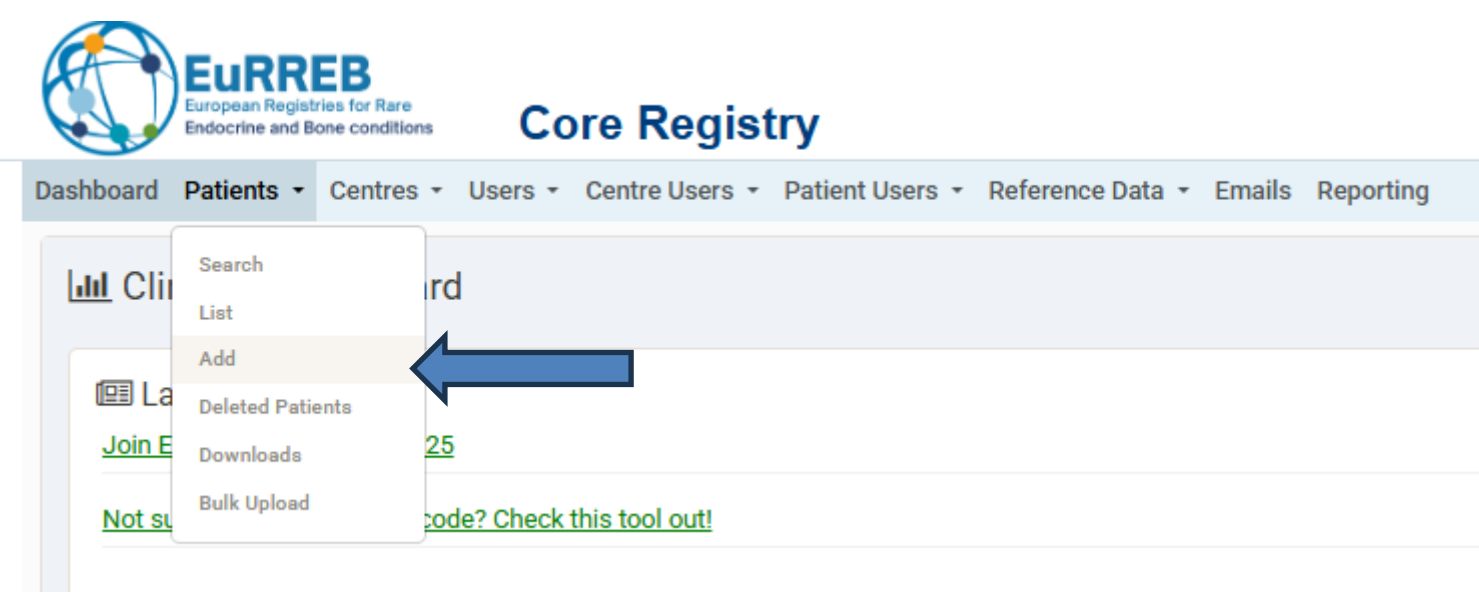


- You can explore the different features of the dashboard:
- you have access to all patients registered in your centre
 - you can see the latest news
 - you can see the distribution of cases by MTG and age groups
 - you can check patient access status and patient and clinician outcomes status



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

Add Patient

☒ Is Test Case ? ← 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 ?

* 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 ? →

Pseudonymised ID (e.g. SPIDER)

* Sex at Birth ☐ Male ☐ Female ☐ Other ☐ Unknown

Current Gender ☐ Male ☐ Female ☐ Non-binary ☐ Other ☐ Asked but unknown

* Country of Birth

* Country of Usual Residence

* Patient Follow-up Status ☐ Patient active ☐ Patient inactive ☐ Patient care suspended ☐ Patient care terminated ☐ Deceased ☐ Unknown

→



Fill in the mandatory fields in the condition group section

You can use this field
for your notes

in notes

! 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 form and saving the changes, a "Diagnosis-specific Outcomes" button will appear in the top navigation bar.

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

Core Data

SYSTEMIC & RHEUMATOLOGICAL

Patient Access

Generic Outcomes

Diagnosis-specific Outcomes

Documents

Audit

Patient List

Core Data

SYSTEMIC & RHEUMATOLOGICAL

Patient Access

Generic Outcomes

Diagnosis-specific Outcomes

Documents

Audit

Patient List

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

- Select -

Grant Access

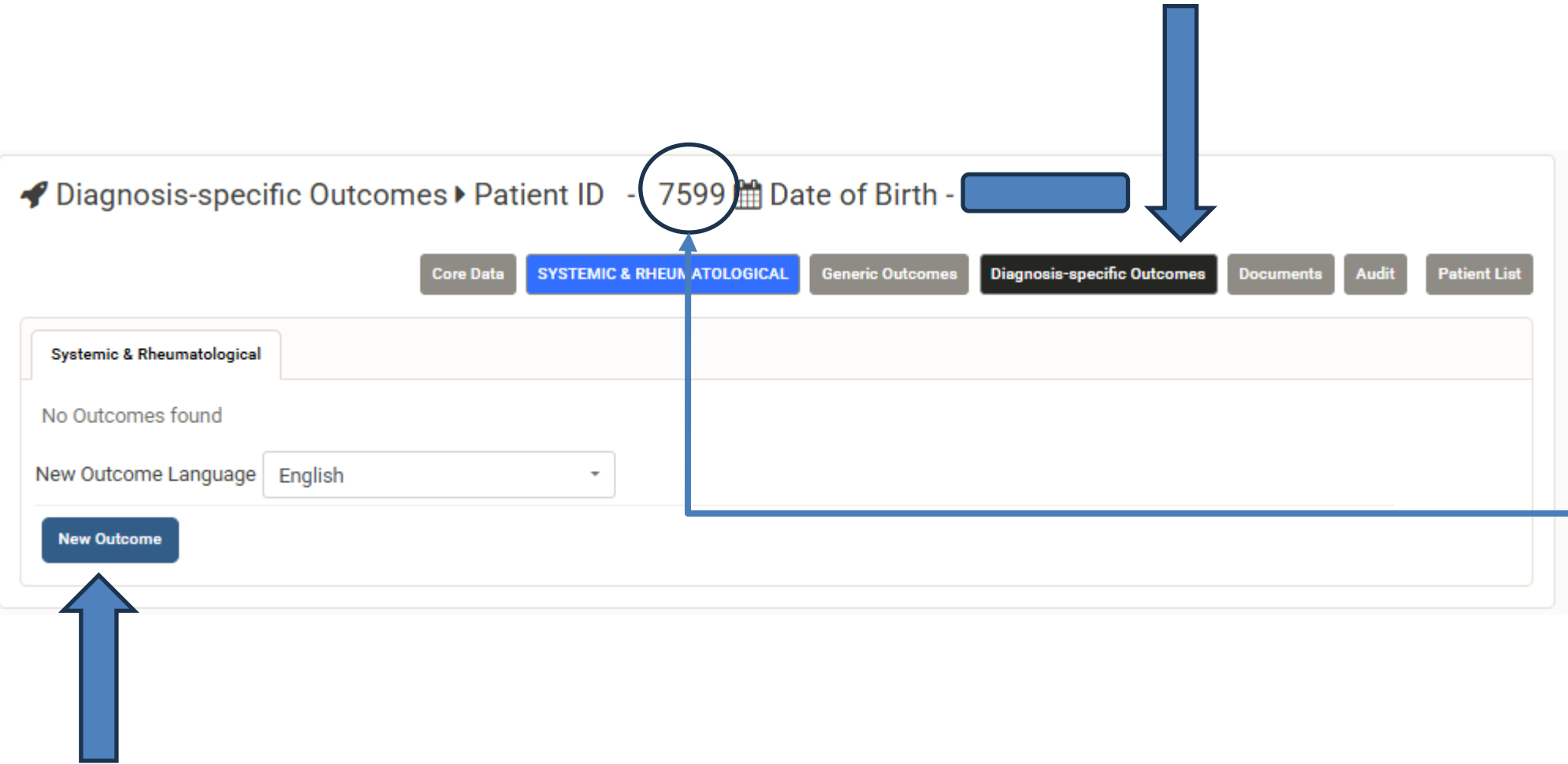
You need to know your patient's e-mail address. The system will send the invitation link. You can write an additional message and choose preferred language. On the platform patient can see the information about him and fill in the PROMs.

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



The screenshot shows the 'Diagnosis-specific Outcomes' page for Patient ID 7599. The interface includes a top navigation bar with tabs: Core Data, SYSTEMIC & RHEUMATOLOGICAL, Generic Outcomes, Diagnosis-specific Outcomes, Documents, Audit, and Patient List. The 'Diagnosis-specific Outcomes' tab is selected. Below the tabs, there is a section for 'Systemic & Rheumatological' outcomes, which currently shows 'No Outcomes found'. A 'New Outcome Language' dropdown menu is set to 'English'. A blue arrow points from the text box above to the 'Diagnosis-specific Outcomes' tab. Another blue arrow points from the 'New Outcome' button to the text box on the right. A third blue arrow points from the 'Diagnosis-specific Outcomes' tab to the 'New Outcome' button.



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

e-REC ID

Primary Condition

Langerhans cell histiocytosis

Current Gender

Clinician Responsible for Patient

Mariya Cherenko

Specific Diagnosis

Langerhans cell histiocytosis

Date of Diagnosis

2025-01-06

Basic module

Treatment

Malignancies/Comorbidities

Assessment Date ?

yyyy-mm-dd

Race

- Select -

Disease activity

☒ Active ☐ Inactive

Specimen Type ?

☒ Skin

☒ Bone

☐ Lymph node

☐ Lung (BAL)

☐ Lung

☐ CNS

☐ Liver

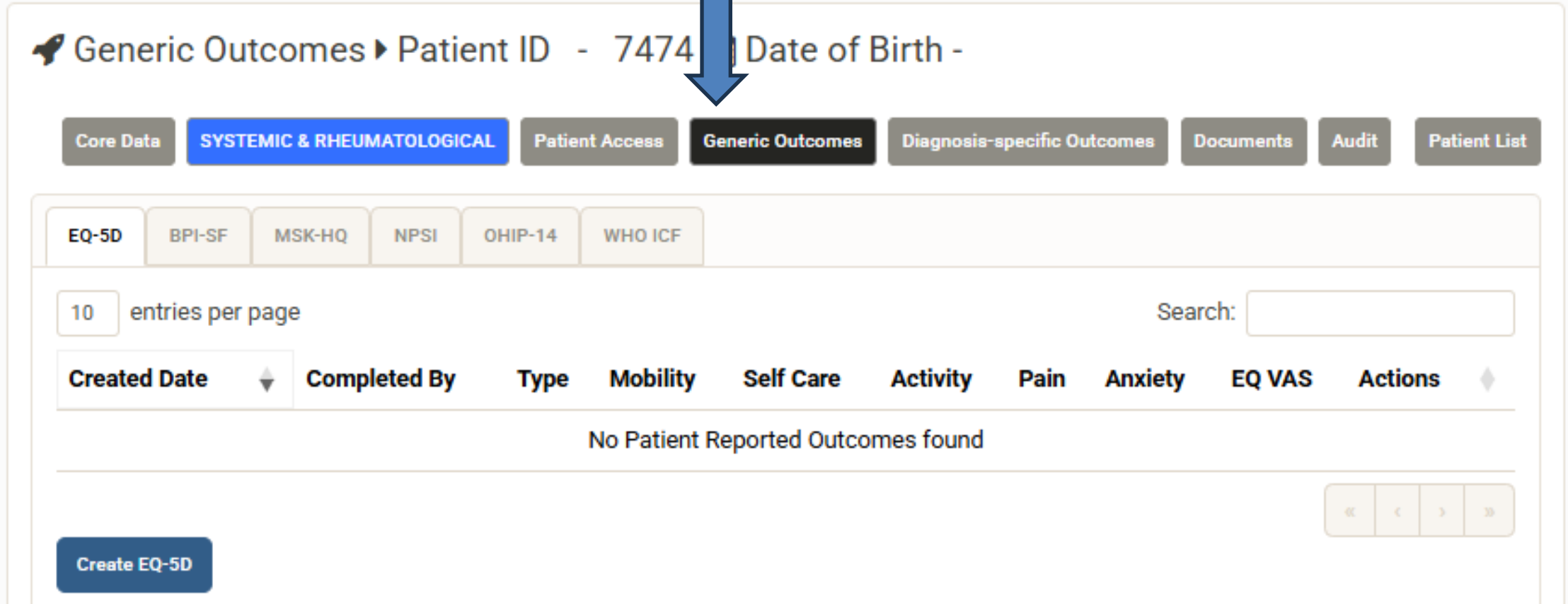


PROMs



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 horizontal menu with tabs: 'Core Data', 'SYSTEMIC & RHEUMATOLOGICAL' (highlighted in blue), 'Patient Access', 'Generic Outcomes' (indicated by a blue arrow from the text box above), 'Diagnosis-specific Outcomes', 'Documents', 'Audit', and 'Patient List'. Under the 'Generic Outcomes' tab, there is a sub-menu with 'EQ-5D' (selected), 'BPI-SF', 'MSK-HQ', 'NPSI', 'OHIP-14', and 'WHO ICF'. Below the sub-menu, there is a '10 entries per page' selector and a 'Search:' field. A table header is visible with columns: 'Created Date', 'Completed By', 'Type', 'Mobility', 'Self Care', 'Activity', 'Pain', 'Anxiety', 'EQ VAS', and 'Actions'. The table body is empty, displaying the message 'No Patient Reported Outcomes found'. At the bottom left is a 'Create EQ-5D' button, and at the bottom right are pagination controls.



Ways to contact us:



eurreb.eu



registries@lumc.nl



drop-in sessions via Zoom



European Registries for Rare
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