

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



Table of contents

1	How to create an account in the Core Registry?
2	How to login if you have an account?
3	How to add a new patient in the Core Registry?
4	How to use non-LCH module?
5	How to fill in PROMs?
6	How to contact us?



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

[Join EuRREB Symposium 2025](#)

[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](#)


registries@lumc.nl


Our Registries FAQ Publications Dutch

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

About News Research Patients Network Contact Login

European Registries for Rare Endocrine and Bone Conditions

 **Drop-in Sessions** →

 **Research** →

Quick Links

- [Ethics approval](#)
- [Patient information](#)
- [Participating centres](#)

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](#)

[Join EuREB 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](#)

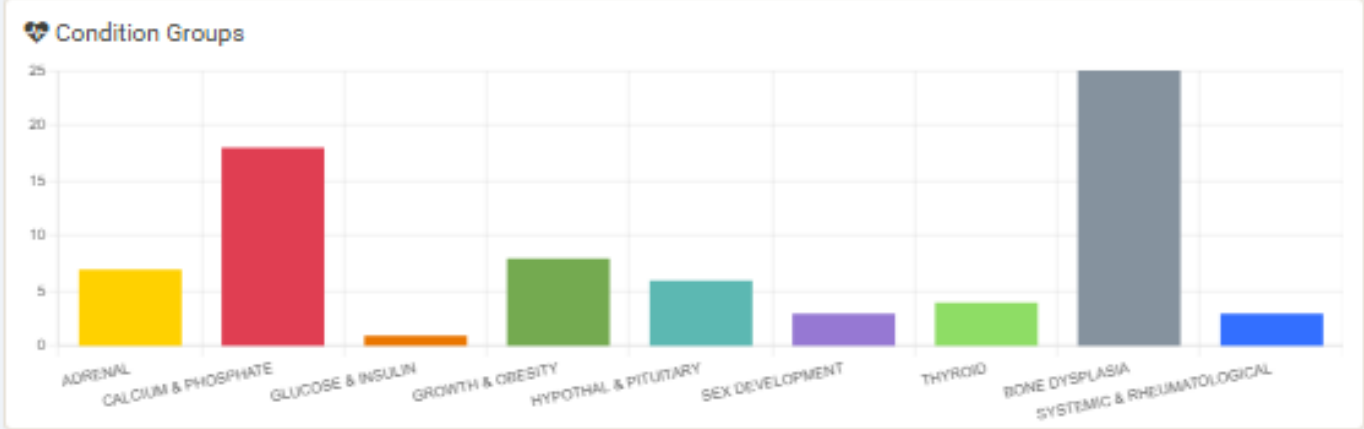
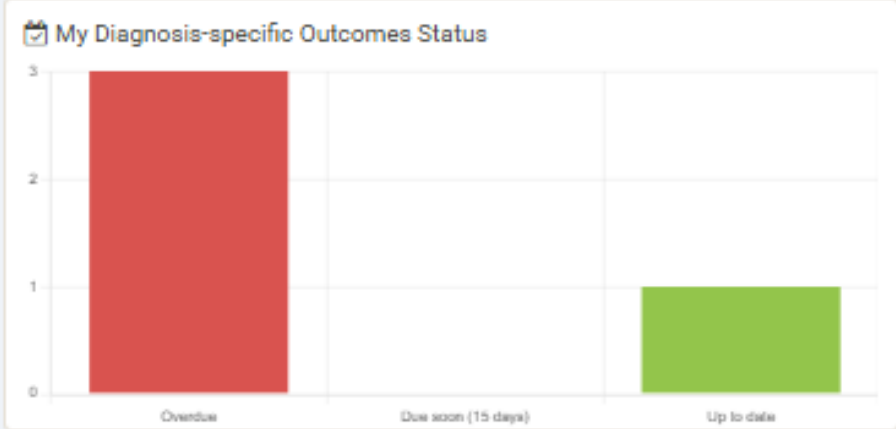
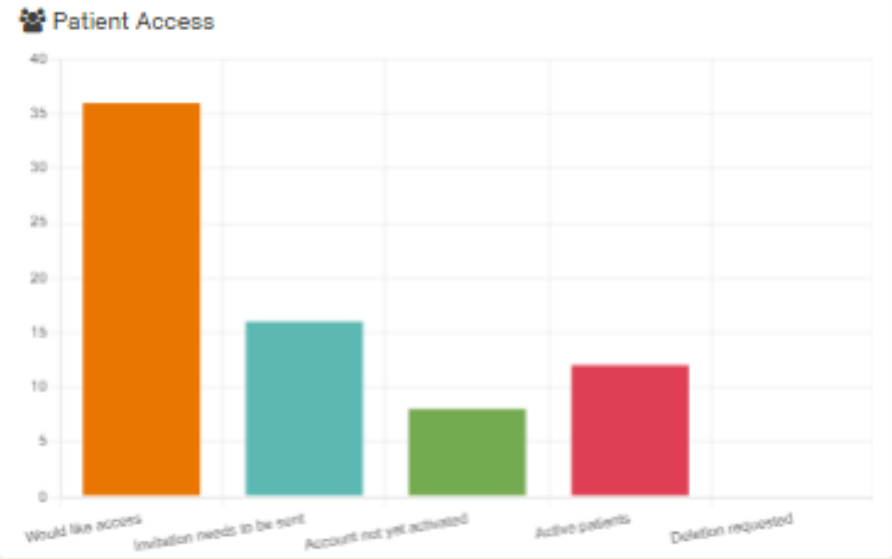
Patient Outcomes Notifications

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

Dismiss

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

Dismiss

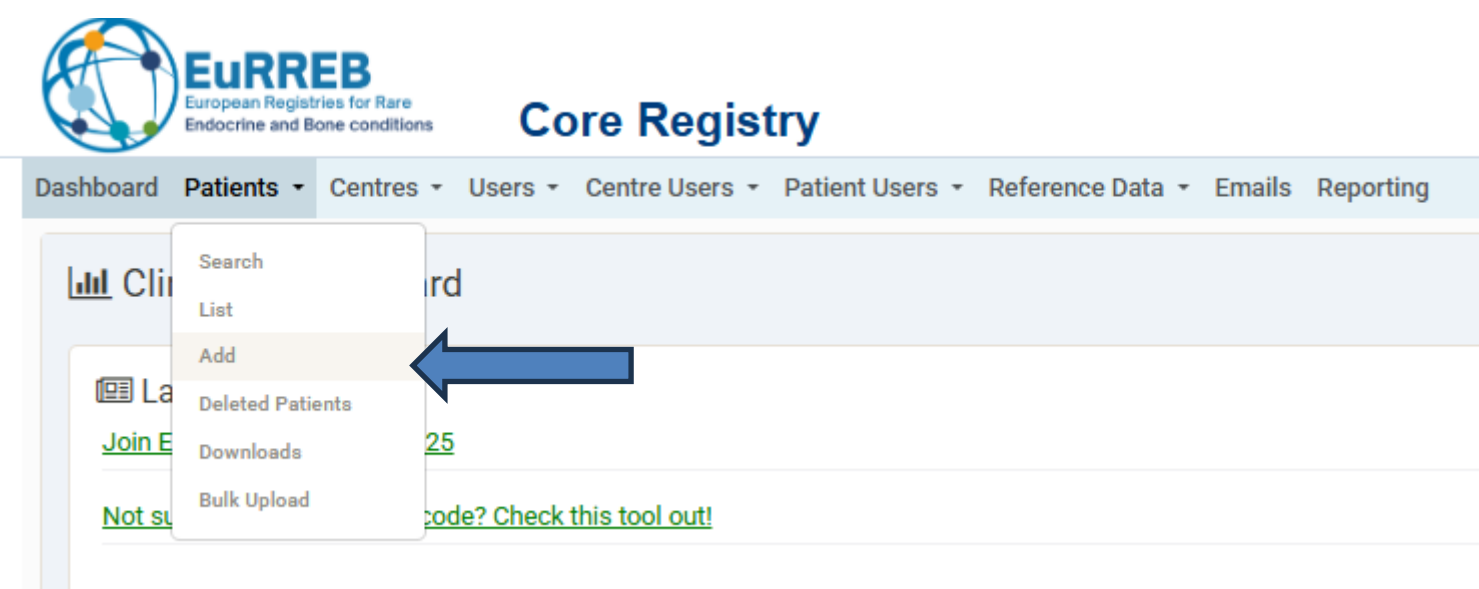


- You can explore the different features of the dashboard:
- you have access to all patients registered in your centre
 - you can see the latest news
 - you can see the distribution of cases by MTG and age groups
 - you can check patient access status and patient and clinician outcomes status



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 non-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

!

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 C](#)

How Was Diagnosis Reached ?

* Date of Diagnosis ?

Participation in another Detailed Disease Registry

2024-06-01

Mariya Cherenko

2024-05-09

Non-Langerhans cell histiocytosis

Erdheim-Chester disease

- Select -

Non-Langerhans cell histiocytosis

Erdheim-Chester disease

Rosai-Dorfman disease

☐ MRI

☐

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

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 non-LCH Module



How to fill in the non-LCH module

If you added the patient with non-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.

Patient ID - 7517

Date of Birth ·

Condition Group -

Systemic & Rheumatological

Questionnaire: Non-Langerhans Cell Histiocytosis module - Version1_March2025

New Outcome

🔔 Reminders for Responsible Clinician - Mariya Cherenko ?

Add Reminder

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

Date of Birth		e-REC ID	Primary Condition	Non-Langerhans cell histiocytosis
Current Gender		Clinician Responsible Mariya Cherenko for Patient	Specific Diagnosis	Erdheim-Chester disease
			Date of Diagnosis	2024-06-01

Basic moduleTreatmentMalignancies and Comorbidities

Assessment Date ?

yyyy-mm-dd

Race

- Select -

Disease activity

Active

Inactive

Diagnostic specimen site (biopsy)

Skin

Bone

Bone marrow

Lymph node



PROMs

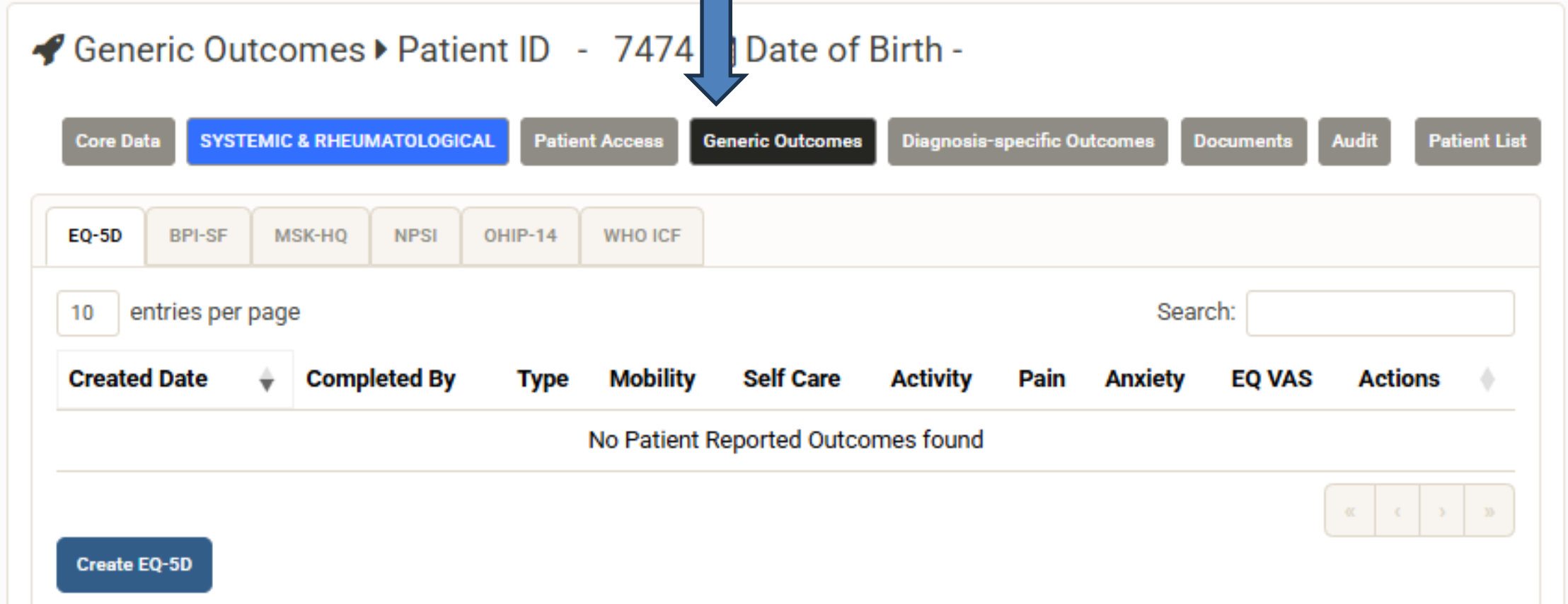


EuRREB

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 non-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' (highlighted in black), 'Diagnosis-specific Outcomes', 'Documents', 'Audit', and 'Patient List'. Under the 'Generic Outcomes' tab, there is a sub-menu with 'EQ-5D', 'BPI-SF', 'MSK-HQ', 'NPSI', 'OHIP-14', and 'WHO ICF'. The 'EQ-5D' option is selected. Below the sub-menu, there is a '10 entries per page' selector and a 'Search:' input 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 contains the text '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
Endocrine and Bone Conditions



EuRREB

European Registries for Rare
Endocrine and Bone conditions

