

# How to use the Melorheostosis 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 Melorheostosis 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.

Choose your centre from the list or add your centre's details if not listed yet. We will approve the centre addition along with your registration.



Back to the index

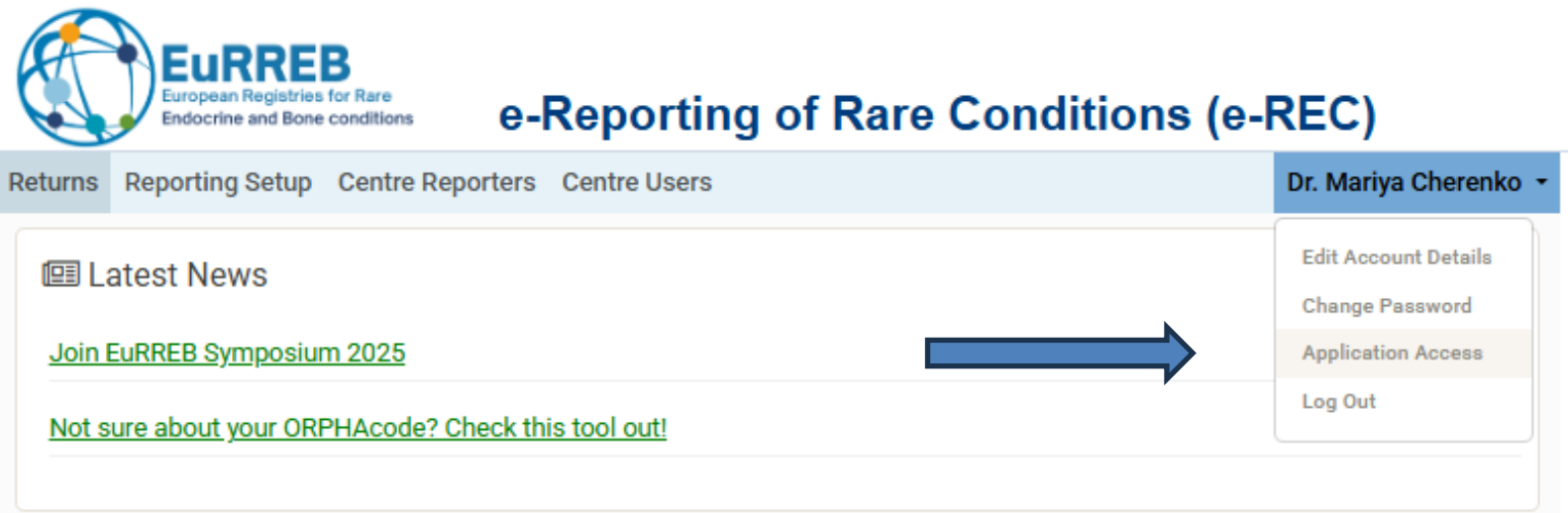


# How to change your application role if you already use e-REC

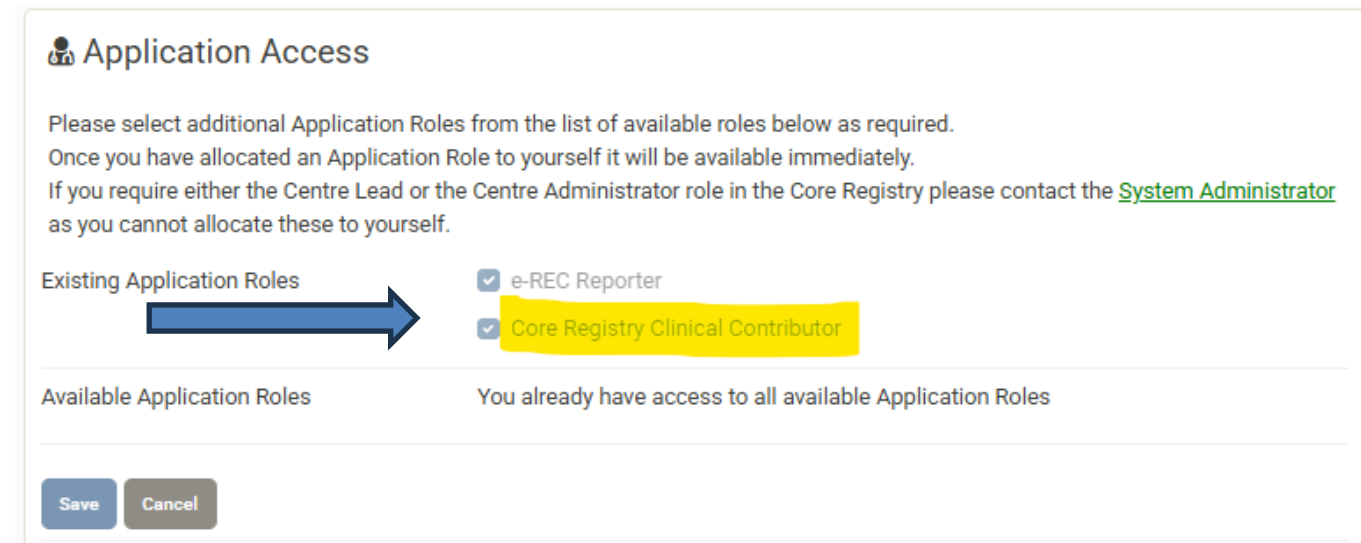
If you are already using e-REC, you can allocate the Core Registry Clinical Contributor role to yourself

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 header is "e-Reporting of Rare Conditions (e-REC)". Below the header 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.

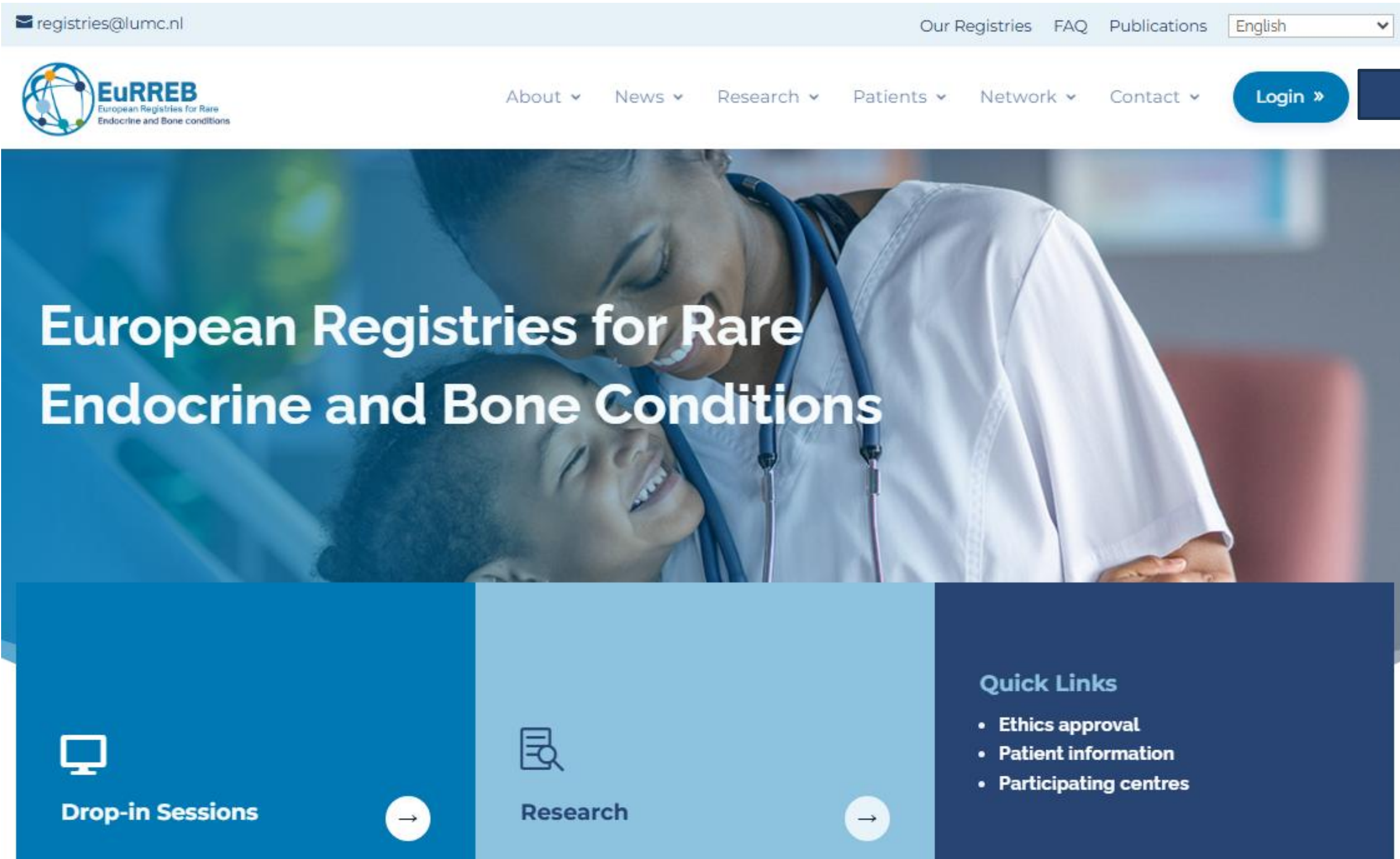


The screenshot shows the "Application Access" configuration page. It includes a title "Application Access" and a user icon. Below the title is a message: "Please select additional Application Roles from the list of available roles below as required. Once you have allocated an Application Role to yourself 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." There are two sections: "Existing Application Roles" and "Available Application Roles". Under "Existing Application Roles", there are two checked items: "e-REC Reporter" and "Core Registry Clinical Contributor". A blue arrow points from the "Existing Application Roles" section to the "Core Registry Clinical Contributor" role. The "Available Application Roles" section contains the text "You already have access to all available Application Roles". At the bottom, there are "Save" and "Cancel" buttons.

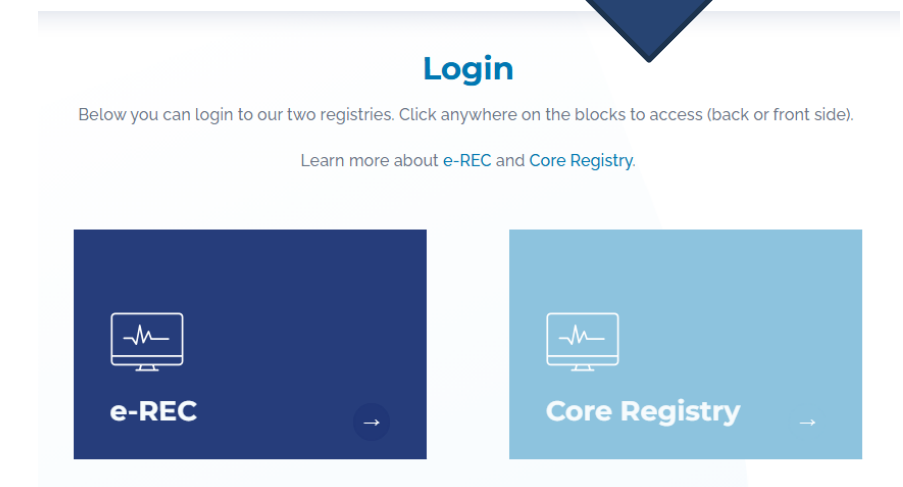
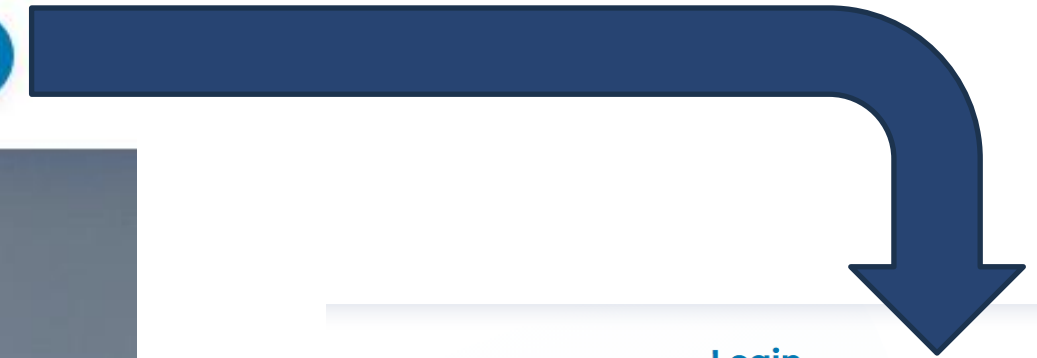


# How to log in into the Core Registry

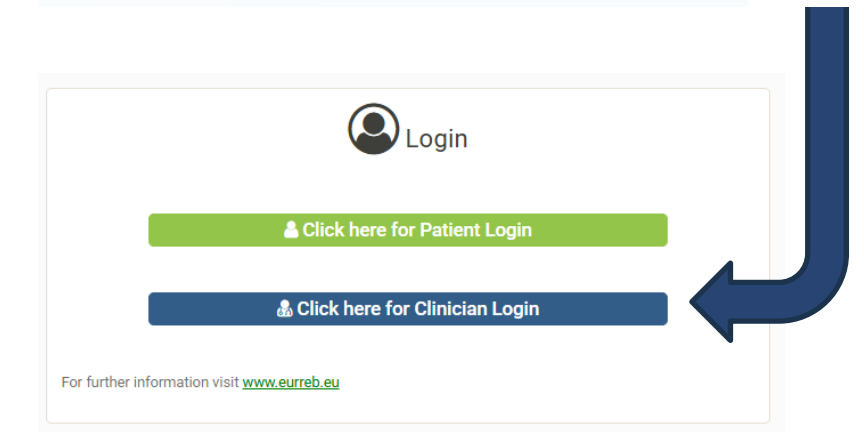
Go to <https://eurreb.eu/>, click on [Login](#), then on Core Registry and choose [Clinician Login](#)



The screenshot shows the EURREB website homepage. At the top left is the email address [registries@lumc.nl](mailto:registries@lumc.nl). To the right are links for "Our Registries", "FAQ", and "Publications", along with a language dropdown menu set to "English". The EURREB logo is on the left, and a navigation menu with "About", "News", "Research", "Patients", "Network", and "Contact" is in the center. A blue "Login »" button is on the right. Below the navigation is a large banner image of a doctor with a stethoscope around a child's neck. The text "European Registries for Rare Endocrine and Bone Conditions" is overlaid on the banner. At the bottom, there are three columns: "Drop-in Sessions" with a monitor icon, "Research" with a magnifying glass icon, and "Quick Links" with a list of "Ethics approval", "Patient information", and "Participating centres".



The screenshot shows the "Login" page. It has a heading "Login" and a sub-heading "Below you can login to our two registries. Click anywhere on the blocks to access (back or front side)." Below this is a link "Learn more about e-REC and Core Registry." There are two main blocks: "e-REC" on the left and "Core Registry" on the right, both with a monitor icon and a right-pointing arrow.



The screenshot shows the login options for the Core Registry. It has a heading "Login" with a person icon. Below are two buttons: a green one labeled "Click here for Patient Login" and a blue one labeled "Click here for Clinician Login". At the bottom, there is a link "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



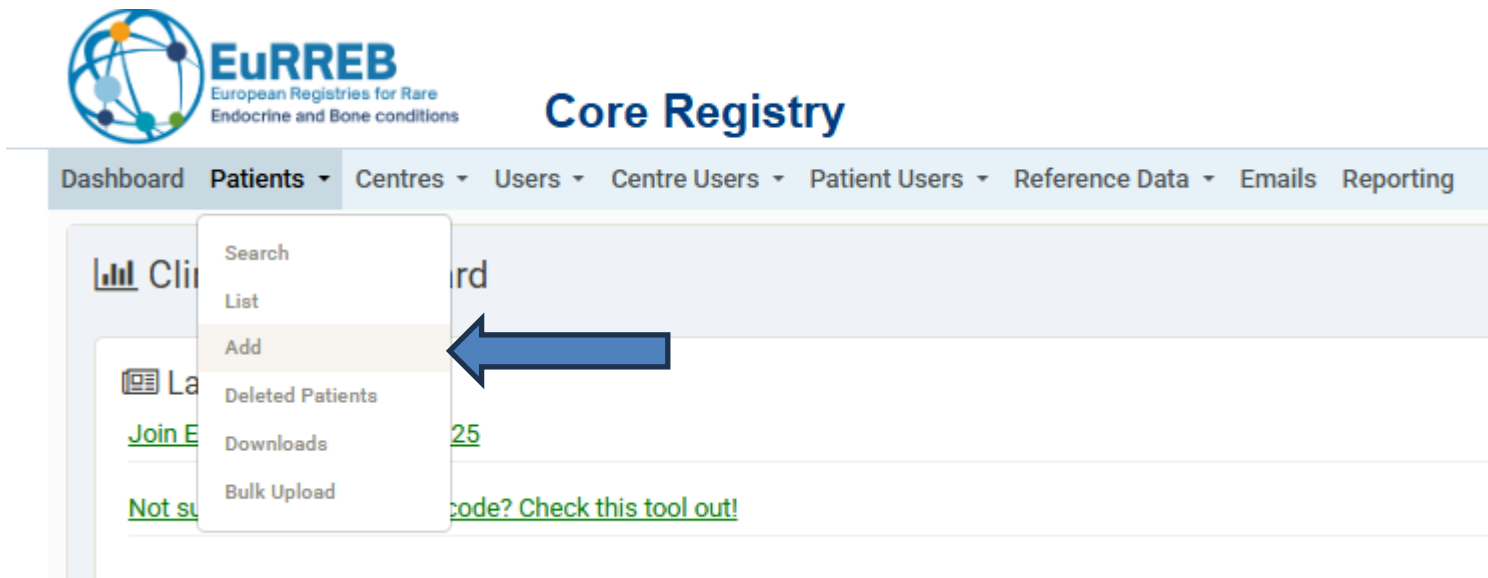
You can explore the different features of the dashboard:

- 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 the Common Data Elements

Mandatory fields



If applicable



## Add Patient

Fields marked with \* are mandatory

\* Consent for Core Registry

\* Date of Birth

\* Condition Group (select all that apply)

Pseudonymised ID (e.g. SPIDER)

Sex at Birth

Current Gender

Country of Birth

Country of Usual Residence

Patient Follow-up Status

Date of Death

Primary Cause of Death

Can be contacted for research purposes by clinician responsible for patient

Data can be shared for research purposes

Can be contacted for collecting Patient Reported Outcomes

Patient would like access to Core Registry

Consent for Newsletters

Choose "Bone  
dysplasia"



Opt-in  Opt-out

ADRENAL  CALCIUM & PHOSPHATE  GLUCOSE & IN:

BONE DYSPLASIA

Male  Female  Other  Unknown

Male  Female  Non-binary  Other  Asked but unkno

NETHERLANDS

NETHERLANDS

Patient active  Patient inactive  Patient care suspended

mm/dd/yyyy

- Select -

Yes  No  Not Known

Yes  No  Not Known

Yes  No  Not Known

Yes  No  Not Known

Yes  No  Not Known

Save and continue

Cancel



Back to the index



# Access the Bone Dysplasia section

## Edit Patient

Patient ID [redacted] [Edit To Do](#)

Fields marked with \* are mandatory

\* Consent for Core Registry

\* Date of Birth

\* Condition Group (select all that apply)

Pseudonymised ID (e.g. SPIDER)

Sex at Birth

Current Gender

Country of Birth

Country of Usual Residence

Patient Follow-up Status

Date of Death

Primary Cause of Death

Can be contacted for research purposes by clinician responsible for patient

Data can be shared for research purposes

Can be contacted for collecting Patient Reported Outcomes

**BONE DYSPLASIA** Generic Outcomes Audit Patient List

Opt-in [?](#)  Opt-out [?](#)

[redacted]

- ADRENAL [?](#)  CALCIUM & PHOSPHATE [?](#)  GLUCOSE & INSULIN [?](#)  
 GENETIC ENDOCRINE TUMOURS [?](#)  GROWTH & OBESITY [?](#)  HYPOTHAL & PITUITARY [?](#)  
 SEX DEVELOPMENT [?](#)  THYROID [?](#)  BONE DYSPLASIA [?](#)

test Cher

Male  Female  Other  Unknown

Male  Female  Non-binary  Other  Asked but unknown

NETHERLANDS

NETHERLANDS

Patient active  Patient inactive  Patient care suspended  Patient care terminated  Deceased  
 Unknown

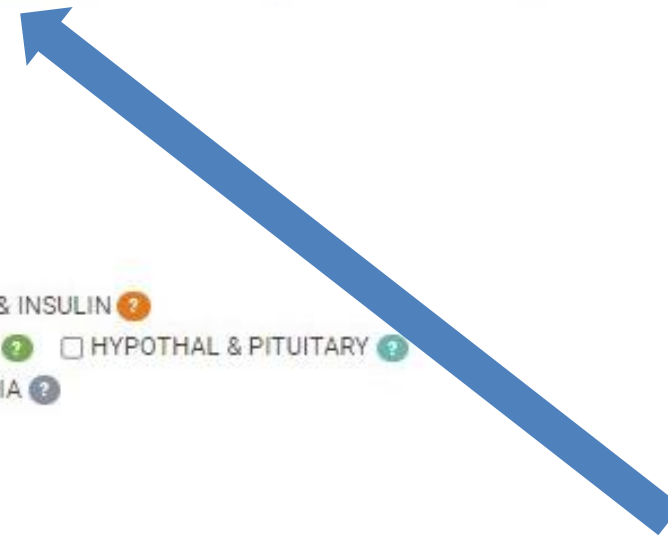
mm/dd/yyyy

- Select -

Yes  No  Not Known

Yes  No  Not Known

Yes  No  Not Known



Click here to fill in the bone dysplasia tab



# Edit the Patient condition section

## Edit Patient Condition

Core Data **BONE DYSPLASIA** Patient Access Generic Outcomes Diagnosis-specific Outcomes Audit Patient List

Patient ID - [redacted] Date of Birth - [redacted]

 Edit To Do

### Bone Dysplasia

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 Detailed Disease Registry  Yes  No  Not Known


Detailed Disease Registry


Detailed Disease Registry Patient ID

Save Cancel

 If applicable

 Fill in all mandatory fields

 Select the Primary Condition - "PBD with increased bone density", for specific diagnosis – choose from the list.





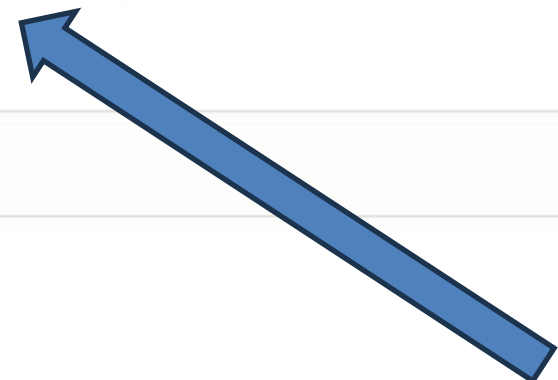
# Giving patients access to the Core Registry

If your patient consented for access to the Core Registry:

Diagnosis-specific Outcomes

Core Data BONE DYSPLASIA Patient Access Generic Outcomes Audit Patient List

Patient ID -  Date of Birth -



Bone Dysplasia

Supplemental material to complete this module

No Outcomes found

New Outcome

Give access to your patient.  
Note: You must know the patient's e-mail for this.



# The Melorheostosis Module



# Access the disease-specific module

## Edit Patient Condition

Core Data Patient Access Generic Outcomes **Diagnosis-specific Outcomes** Audit Patient List

Patient ID - [redacted] Date of Birth  
- [redacted]

 [Edit To Do](#)

### Bone Dysplasia

Senior Clinician < 18 - N/A

Senior Clinician ≥ 18 - N/A

e-REC ID


First Contact with Centre

04/12/2022 


Clinician Responsible for Patient

Natasha Appelman-Dijkstra 


Date of First Clinical Manifestations

01/01/2020 

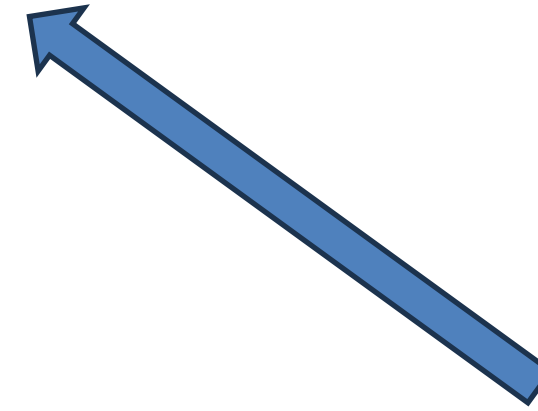
Primary Condition

Primary bone dysplasia with increased bone density 

Specific Diagnosis

Melorheostosis 

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



Click here to fill in the disease-specific module



# Fill in a disease-specific outcome

Diagnosis-specific Outcomes

Core Data **BONE DYSPLASIA** Patient Access Generic Outcomes Audit Patient List

Patient ID -  Date of Birth -

Bone Dysplasia

Supplemental material to complete this module

No Outcomes found

[New Outcome](#)



Click here to fill in the new outcome for the disease-specific module



# Fill in the data into the module and save

## Add Diagnosis-specific Outcome

Patient ID [redacted] Date of Birth - [redacted] Condition Group - Bone Dysplasia

Questionnaire: Melorheostosis, Buschke-Ollendorff syndrome, Isolated osteopoikilosis

### New Outcome

Date of Birth	[redacted]	e-REC ID		Primary Condition	
Current Gender	Male	Clinician Responsible for Patient	Natasha Appelman-Dijkstra	Primary bone dysplasia with increased bone density	
				Specific Diagnosis	Melorheostosis
				Date of Diagnosis	2022-04-12

General Clinical features Genetic analysis Fractures Surgery Medication MSK-HQ BPI

Family ID

Proband  Not Known  Yes  No

Family history  Negative  Positive - Maternal  Positive - Paternal  Positive - Unknown  Unknown

**Fill in all the tabs which are applicable**

Save Back



# PROMs



# Fill in the generic outcomes

[Edit Patient Condition](#) ▶ Patient ID - 427 Date of Birth -

Edit To Do

[Core Data](#) [BONE DYSPLASIA](#) [Generic Outcomes](#) [Diagnosis-specific Outcomes](#) [Life-course Outcomes](#)

**Bone Dysplasia**

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

To fill in PROMs click directly on the buttons from the module or go to the Generic outcomes section to choose from the list of available PROMs

[Generic Outcomes](#) ▶ Patient ID - 427 Date of Birth -

[Core Data](#) [BONE DYSPLASIA](#) [Generic Outcomes](#) [Diagnosis-specific Outcomes](#)

[EQ-5D](#) [BPI-SF](#) [MSK-HQ](#) [NPSI](#) [OHIP-14](#) [WHO ICF](#)

10 entries per page

Created Date	Completed By	Type	Mobility	Self Care	Activity	P
No Patient Reported Outcomes found						

[Create EQ-5D](#)

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

**Core Registry**

[Dashboard](#) [Patients](#) [Centres](#) [Users](#) [Centre Users](#) [Patient Users](#) [Reference Data](#) [Emails](#) [Reporting](#)

### Diagnosis-specific Outcome Details

Patient ID - 427 Date of Birth -  Condition Group - Bone Dysplasia

[Supplemental material to complete this module](#)

Created Date: 2024-06-21  
Completed By: Sophie Huisman

#### Linked Generic Outcomes

[WHO-ICF Mobility](#) [MSK-HQ](#) [BPI-SF](#) [NPSI](#)

Date of Birth	<input type="text"/>	e-REC ID
Current Gender	Female	Clinician Responsible for Patient



# Choose the frequency for PROMs

Generic Outcomes Core Data BONE DYSPLASIA Patient Access Diagnosis-specific Outcomes Audit

Patient ID  Date of Birth -

EQ-5D BPI-SF PROMIS Profile WHO ICF Patient Reported Outcome Request Settings

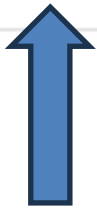
Create or edit requests for the Patient to complete generic questionnaires

Show  entries

Generic Outcome Questionnaire	Request Frequency (months)	Request Start Date	Actions
WHO-ICF Mobility	9	2022-11-01	<span>Edit</span> <span>Delete</span>

Previous 1

Add Outcome Request



Click here to choose the frequency of email requests to the Patient to self-complete a Patient Generic Outcome Questionnaire



# Choose the frequency for PROMs

## Generic Patient Reported Outcome Request Settings



These settings control the frequency of email requests to the Patient to self-complete a Patient Generic Outcome Questionnaire

### Outcome Questionnaires

- × BPI-SF - Brief Pain Inventory Short Form (2)
- × MSK-HQ - MUSCULOSKELETAL HEALTH QUESTIO...
- × NPSI - NEUROPATHIC PAIN SYMPTOM INVENTORY

### Request Frequency

6 months

### Date of Next Request

2026-01-30



Click here to choose the frequency of email requests to the Patient to self-complete PROMs and list of PROMs

Save Cancel





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the European Union



## Ways to contact us:



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



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



[drop-in sessions via Zoom](#)



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# **EuRRREB**

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Back to the index