

# How to use the OI 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/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

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.



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



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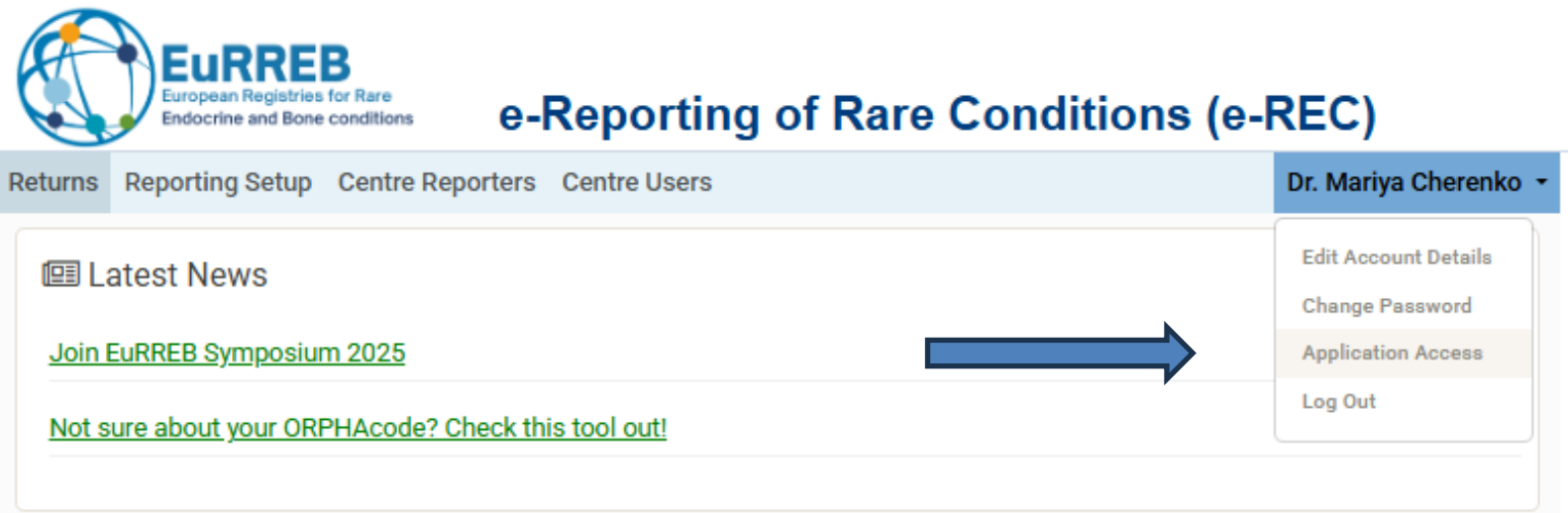


# How to change your application role if you already use e-REC

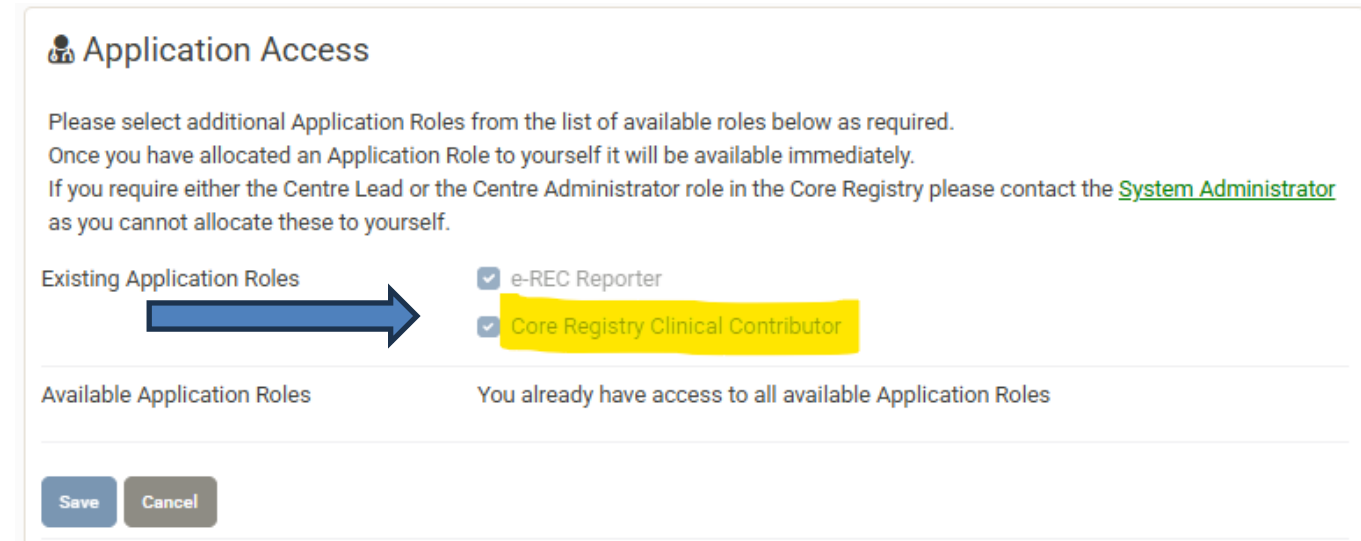
If you are already using e-REC, you can allocate the Core Registry Clinical Contributor role to yourself

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" (highlighted with a blue arrow), and "Log Out". Below the navigation bar, there is a "Latest News" section with two links: "Join EuRREB Symposium 2025" and "Not sure about your ORPHAcode? Check this tool out!".

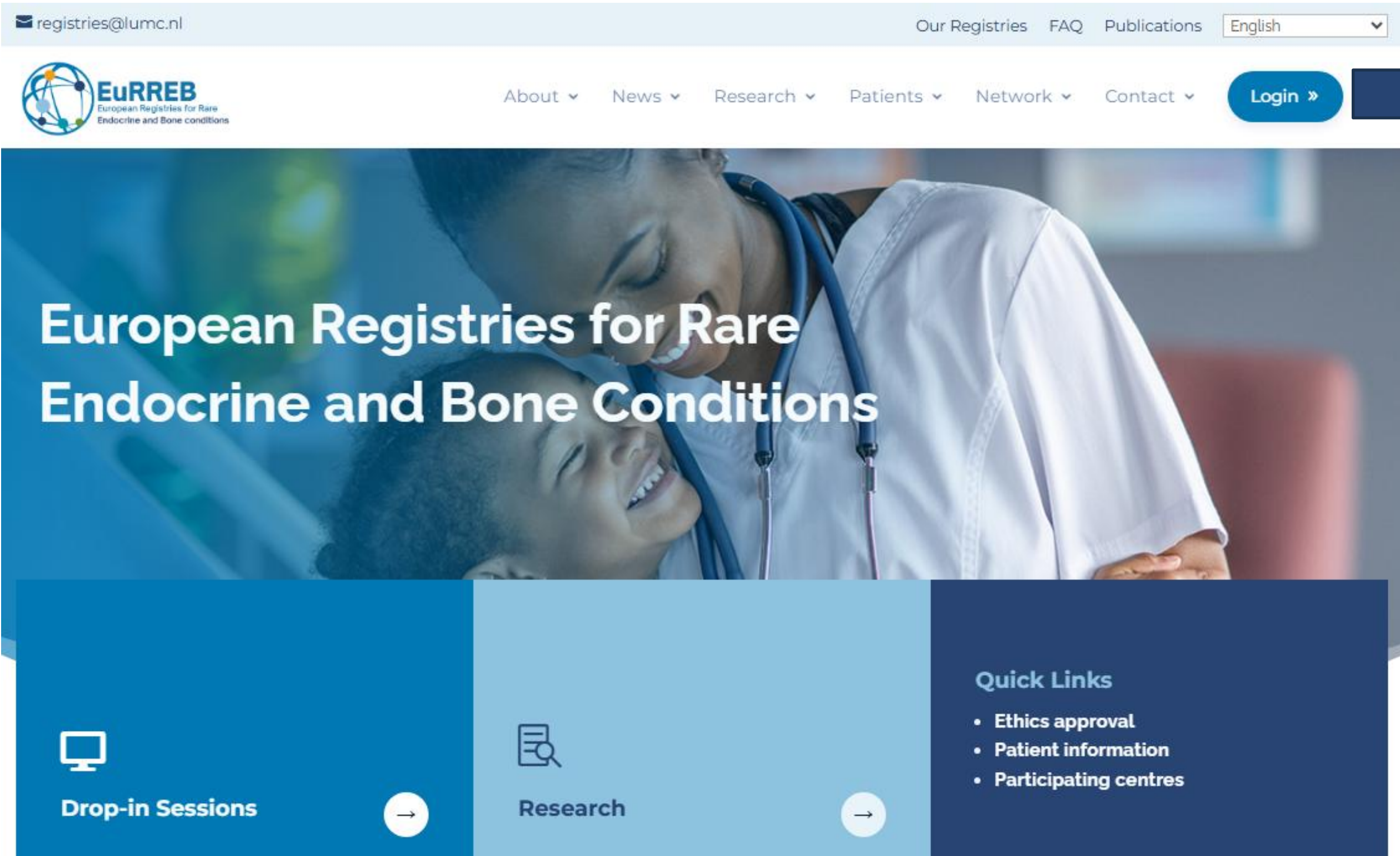


The screenshot shows the "Application Access" configuration page. The title is "Application Access" with a user icon. Below the title is a message: "Please select additional Application Roles from the list of available roles below as required. Once you have allocated an Application Role to yourself it 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." Below this message is a section titled "Existing Application Roles" with a blue arrow pointing to a list of roles: "e-REC Reporter" and "Core Registry Clinical Contributor" (highlighted in yellow). Below this is a section titled "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/> , 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", "Publications", and 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. At the top is the heading "Login". Below it is the text "Below you can login to our two registries. Click anywhere on the blocks to access (back or front side)." and a link "Learn more about e-REC and Core Registry.". There are two main buttons: "e-REC" (dark blue) and "Core Registry" (light blue). Below these is a "Login" section with a user icon and two buttons: "Click here for Patient Login" (green) and "Click here for Clinician Login" (dark blue). At the bottom, it says "For further information visit [www.eurreb.eu](http://www.eurreb.eu)". A large blue arrow points from the "Login" button on the homepage to the "Login" heading on this page. Another blue arrow points from the "Click here for Clinician Login" button to the "Core Registry" button on the previous page.



# 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



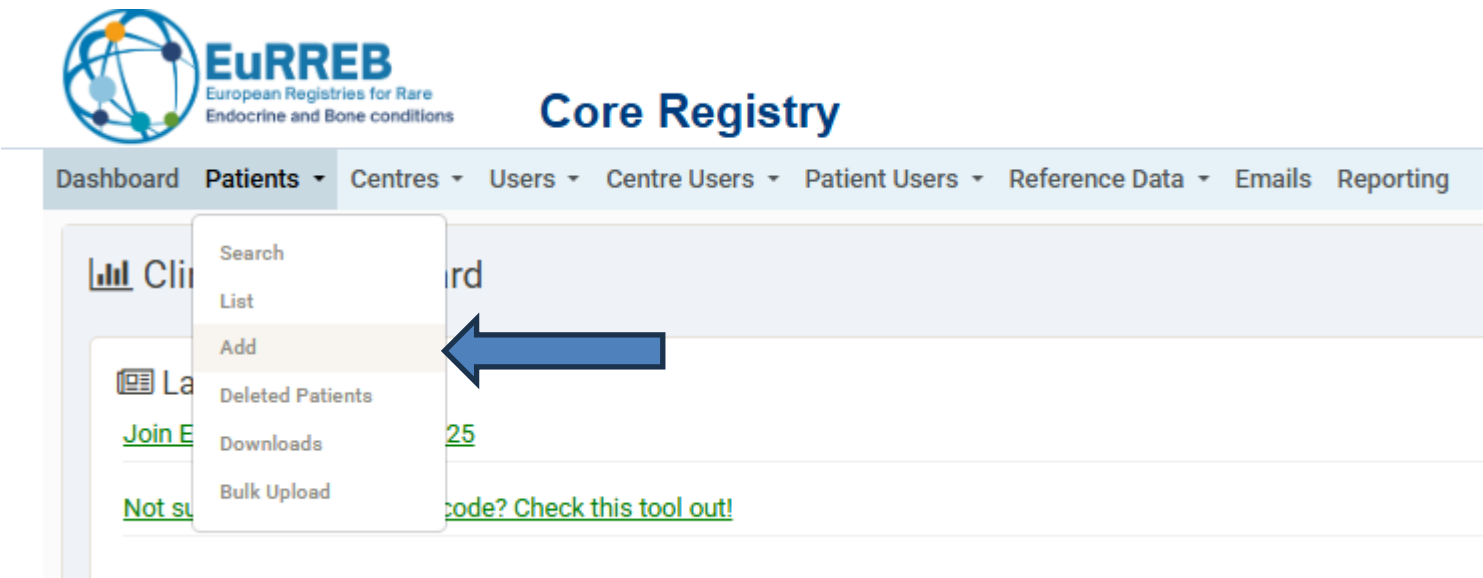
You can explore the different features of the dashboard:

- 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"



Mandatory fields



If applicable



Fill in the Common Data Elements

### 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



# Access the patient condition section

## Edit Patient

Patient ID -  [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

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

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

Male  Female  Other  Unknown

Male  Female  Non-binary  Other  Asked but unknown

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

Yes  No  Not Known

Yes  No  Not Known

Yes  No  Not Known

**BONE DYSPLASIA** Generic Outcomes Audit Patient List

Click here to fill in the bone dysplasia tab




# Edit the patient condition section

## Edit Patient Condition

Core Data Patient Access Generic Outcomes Diagnosis-specific Outcomes Documents Audit

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  
 Not Known

Save Cancel

 If applicable

Fill in all mandatory fields

Select the Primary Condition - "PBD with decreased bone density", for specific diagnosis – choose "OI +/- type" from the list.



# Giving patients access to the Core Registry

If your patient consented for access to the Core Registry:

## Edit Patient Condition

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

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

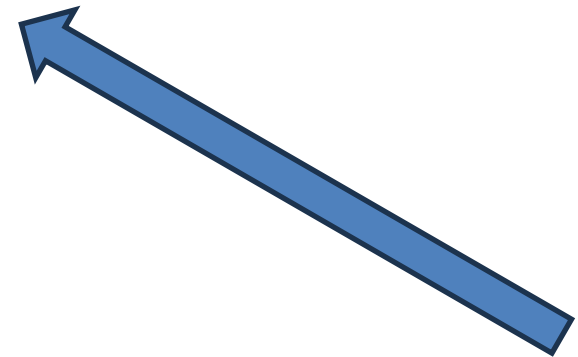
Detailed Disease Registry Patient ID

Biobank Sample Available for Research

Yes  No  Not Known

Biobank Details

Core Data Patient Access Generic Outcomes Audit Patient List



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



# The OI Module



# Go to diagnosis-specific outcome

## Edit Patient Condition

Patient ID - [redacted] Date of Birth

- [redacted]

**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](#)

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

 **Edit To Do**

Use this button to put notes/reminders if needed

Click here to fill in the disease-specific module



# Fill in the new 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: Osteogenesis Imperfecta - Child - Child

### New Outcome

Date of Birth	[redacted]	e-REC ID		Primary Condition
Current Gender	Male	Clinician Responsible for Patient	Mariya Cherenko	Primary bone dysplasia with decreased bone density
				Specific Diagnosis OI type 3
				Date of Diagnosis

Anthropometry | Fractures | Genetic diagnosis | Medication | Spine | Mobility | Lung function | Bone mineral density | Musculoskeletal surgery | Other surgeries

Fill in all the tabs which are applicable

Assessment Date	?	mm/dd/yyyy
Height (cm)	?	
Height SDS	?	
Weight (kg)	?	
Weight SDS	?	
BMI	?	



# 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

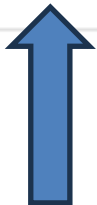
Create or edit requests for the Patient to complete generic questionnaires

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

Core Registry Dashboard Patients Centres

### 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 Questionnaire: WHO-ICF Mobility

Request Frequency: 6 months

Date of Next Request: mm/dd/yyyy

Save Cancel

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





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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](#)



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



# **EuRRREB**

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