

How to use the Rare Hypophosphataemic Conditions 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

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.



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

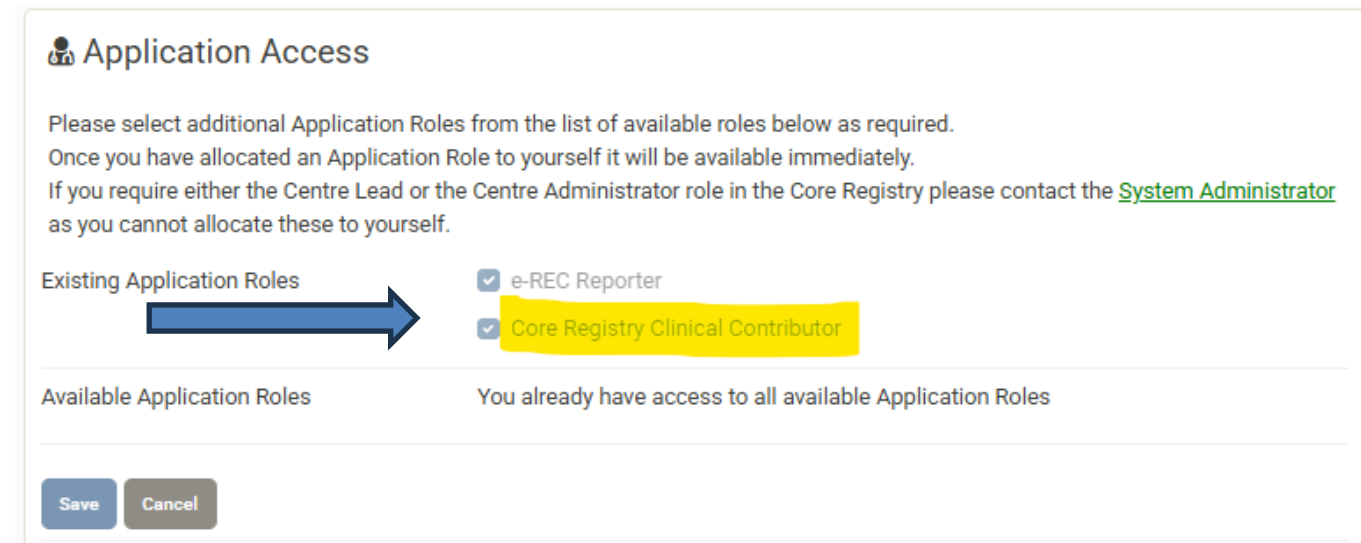
If you are already using e-REC, you can allocate the Core Registry Clinical Contributor role to yourself

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", and "Log Out". A blue arrow points from the "Application Access" menu item to the right.

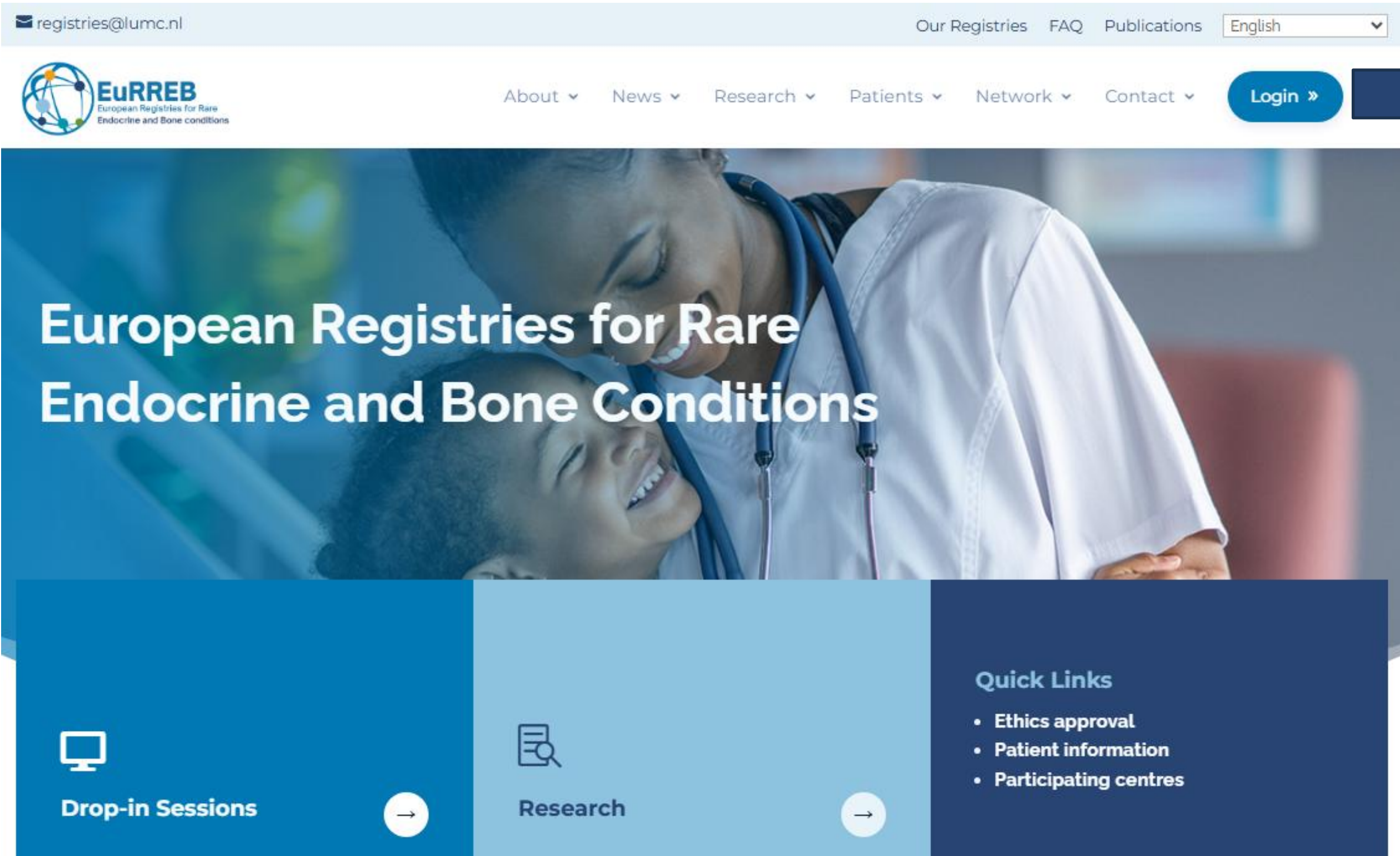


The screenshot shows the "Application Access" configuration page. It includes a title "Application Access" with a user icon. Below the title is a paragraph: "Please select additional Application Roles from the list of available roles below as required. Once you have allocated an Application Role to yourself 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 a blue arrow pointing to a list of roles: "e-REC Reporter" and "Core Registry Clinical Contributor". The "Core Registry Clinical Contributor" role is highlighted in yellow. Below this 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.

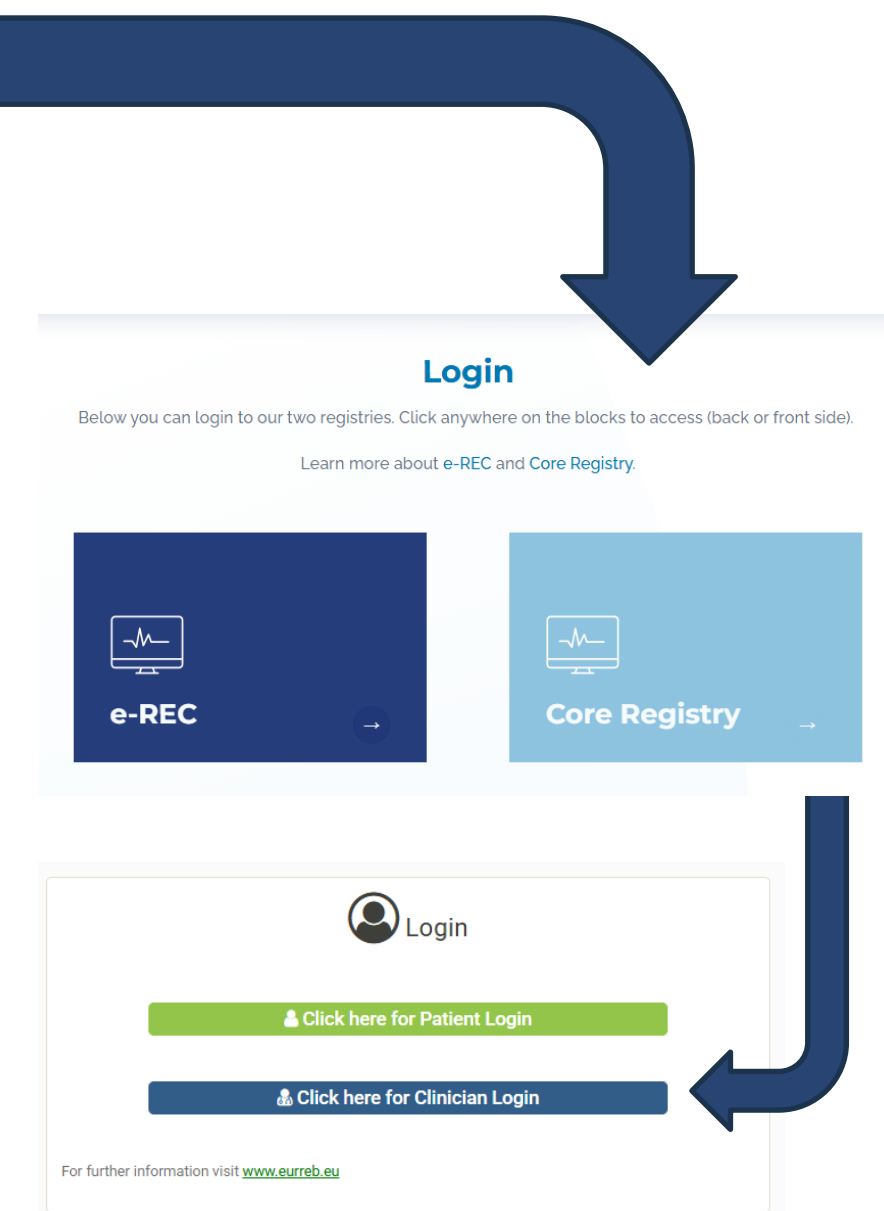


How to log in into the Core Registry

Go to <https://eurreb.eu/> , 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. 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, with the text "European Registries for Rare Endocrine and Bone Conditions". 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".



This section shows the login process. A large blue arrow points from the "Login »" button on the homepage to the "Login" page. The "Login" page has the heading "Login" and the text "Below you can login to our two registries. Click anywhere on the blocks to access (back or front side). Learn more about e-REC and Core Registry." Below this are two buttons: "e-REC" and "Core Registry". A second blue arrow points from the "Core Registry" button to a login form. The login form has a "Login" heading and two buttons: "Click here for Patient Login" (highlighted in green) and "Click here for Clinician Login". A third blue arrow points from the "Click here for Clinician Login" button to the right. At the bottom of the login form, it says "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](#)

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



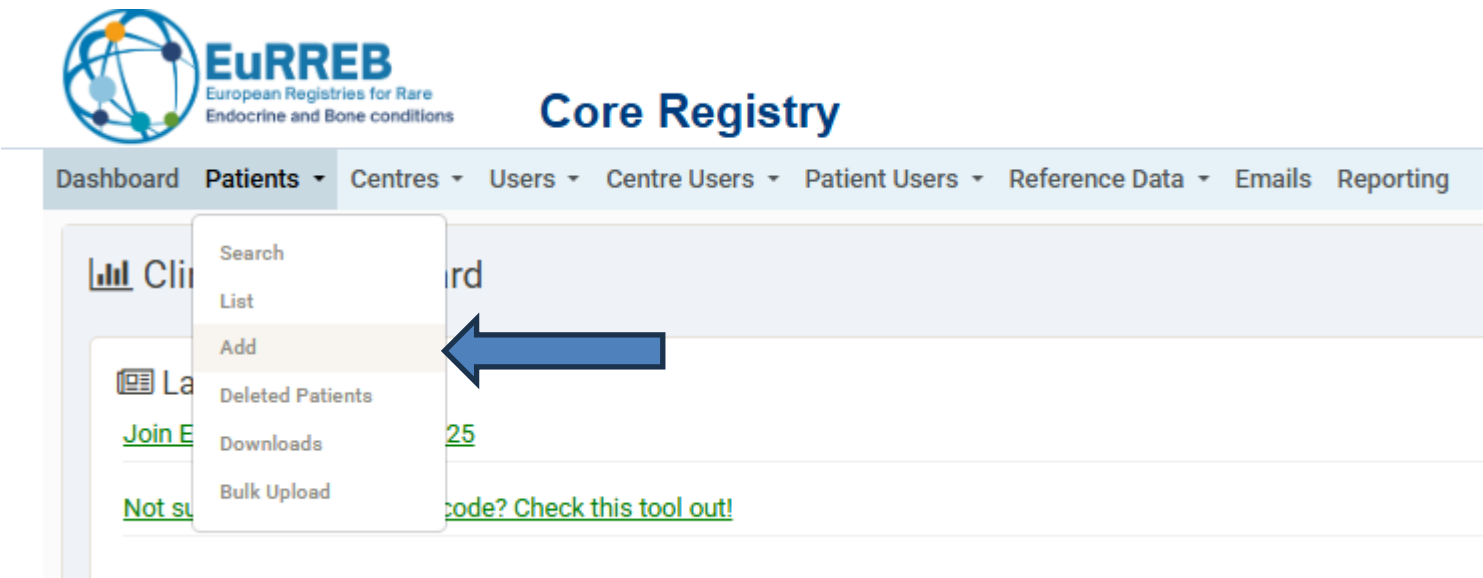
You can explore the different features of the dashboard:

- 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

Opt-in Opt-out

ADRENAL CALCIUM & PHOSPHATE GLUCOSE & INI
 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

Choose "Calcium & Phosphate"



Save and continue Cancel



Access the patient condition section

Edit Patient

Patient ID - 1 [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

CALCIUM & PHOSPHATE Patient Access Generic Outcomes Diagnosis-specific Outcomes

Opt-in ? Opt-out ?

ADRENAL ? CALCIUM & PHOSPHATE ? GLUCOSE & INSULIN ? METABOLIC ENDOCRINE ?
 GROWTH & OBESITY ? HYPOTHAL & PITUITARY ? SEX DEVELOPMENT ? OTHER ?
 BONE DYSPLASIA ?

Male Female Other Unknown

Male Female Non-binary Other Asked but unknown

NETHERLANDS

NETHERLANDS

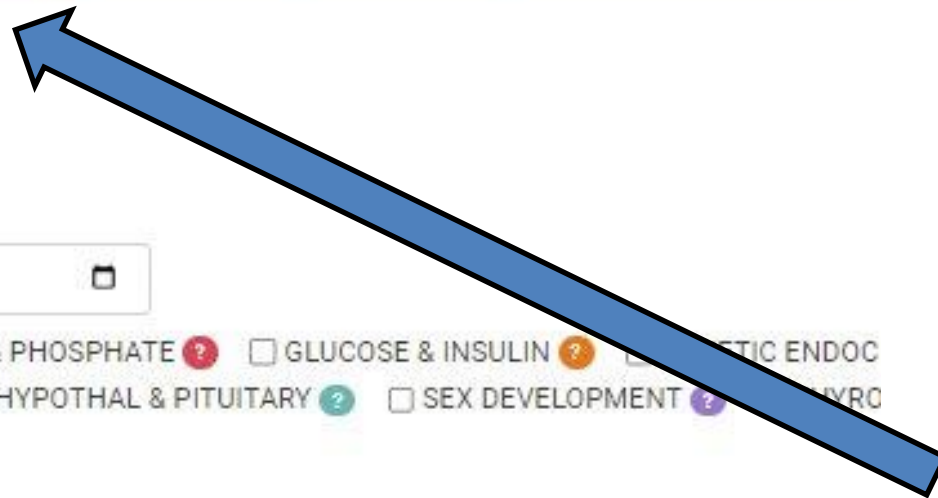
Patient active Patient inactive Patient care suspended Patient care terminated I
 Unknown

mm/dd/yyyy

- Select -

Yes No Not Known

Yes No Not Known



Click here to fill in the "Calcium & Phosphate" tab



Fill in primary condition and specific diagnosis

Edit Patient Condition

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

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

Edit To Do

Calcium and Phosphate

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

Save Cancel

If applicable

Fill in all mandatory fields

Select the Primary Condition - "Hypophosphatemia", for specific diagnosis – choose from the list.




Giving patients access to the Core Registry

If your patient consented for access to the Core Registry:

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

CALCIUM & PHOSPHATE Patient Access Generic Outcomes Diagnosis-specific 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 Cherenko2

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 -

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



The Rare Hypophosphataemic Conditions Module




Access the disease-specific module

Edit Patient Condition

Patient ID - [redacted] Date of Birth

[redacted]

 [Edit To Do](#)

[Core Data](#) [Generic Outcomes](#) [Diagnosis-specific Outcomes](#) [Audit](#) [Patient List](#)

Calcium and Phosphate

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

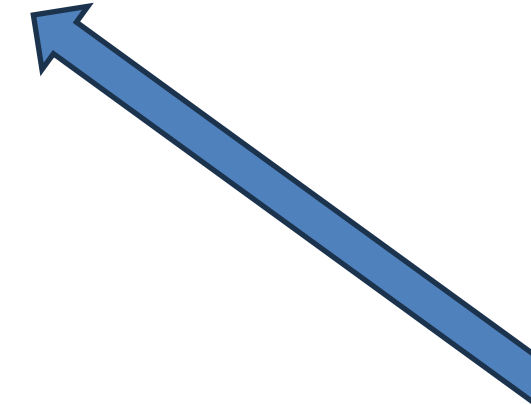
Date of Diagnosis

Participation in Detailed Disease Registry

Yes No Not Known

Detailed Disease Registry



Click here to fill in the disease-specific module



Fill in the new outcome

Diagnosis-specific Outcomes

Core Data

CALCIUM & PHOSPHATE

Generic Outcomes

Audit

Patient ID - Date of Birth -

Calcium and Phosphate

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 · Date of Birth Condition Group - Calcium and Phosphate

Questionnaire: Test version 3 Rare hypophosphataemia - Adult

New Outcome

Date of Birth	<input type="text"/>	e-REC ID	<input type="text"/>	Primary Condition	Hypophosphataemia
Current Gender	Male	Clinician Responsible for Patient	<input type="text"/>	Specific Diagnosis	X-linked hypophosphataemia
				Date of Diagnosis	

Basic disease module Genetic findings Family and perinatal history Clinical outcomes Clinical musculoskeletal findings Radiological musculoskeletal findings Other investigations Biochemical findings Therapy

Surgical intervention

Fill in all the tabs which are applicable

Assessment Date

Age at Assessment Date

Gene variant (cDNA)

Gene variant (protein)

Gene **Collecting information on mosaicisms**

Mosaicism

- Select -
- Select -
- Not Known
- Yes
- No

Back



PROMs



Fill in the generic outcomes

Generic Outcomes

- Core Data
- CALCIUM & PHOSPHATE**
- Patient Access
- Diagnosis-specific Outcomes
- Audit
- Patient List

Patient ID Date of Birth -

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

← Click here to fill in the new generic outcome for your patient: mobility, FQ-5D or other

Show entries Search:

Created Date	Completed By	Type	Mobility	Self Care	Activity	Pain	Anxiety	EQ VAS	Actions
2022-11-02	Dr. Ana Priego	EQ-5D-5L	2	2	2	2	1	71	
2021-03-24	Dr. Ana Priego	EQ-5D-Y	1	1	1	2	2	74	
2021-03-24	Dr. Ana Priego	EQ-5D-5L	1	2	2	1	1	80	

Previous 1 Next

Current Patient EQ-5D Request Settings: EQ-5D-5L every 3 months, starting on 2022-06-30

[Patient EQ-5D Request Settings](#) [Create EQ-5D](#)



Choose the frequency for PROMs

Generic Outcomes

Core Data **CALCIUM & PHOSPHATE** Patient Access Diagnosis-specific Outcomes Audit

Patient ID [] Date of Birth - []

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

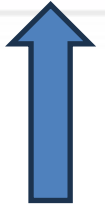
Create or edit requests for the Patient to complete generic questionnaires

Show 10 entries

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

Previous 1

Add Outcome Request



Click here to choose and add 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





Funded by
the European Union



Ways to contact us:



eurreb.eu



registries@lumc.nl



[drop-in sessions via Zoom](#)



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