

How to use Hypoparathyroidism module in the Core Registry



EuRREB

European Registries for Rare
Endocrine and Bone conditions

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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 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

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.

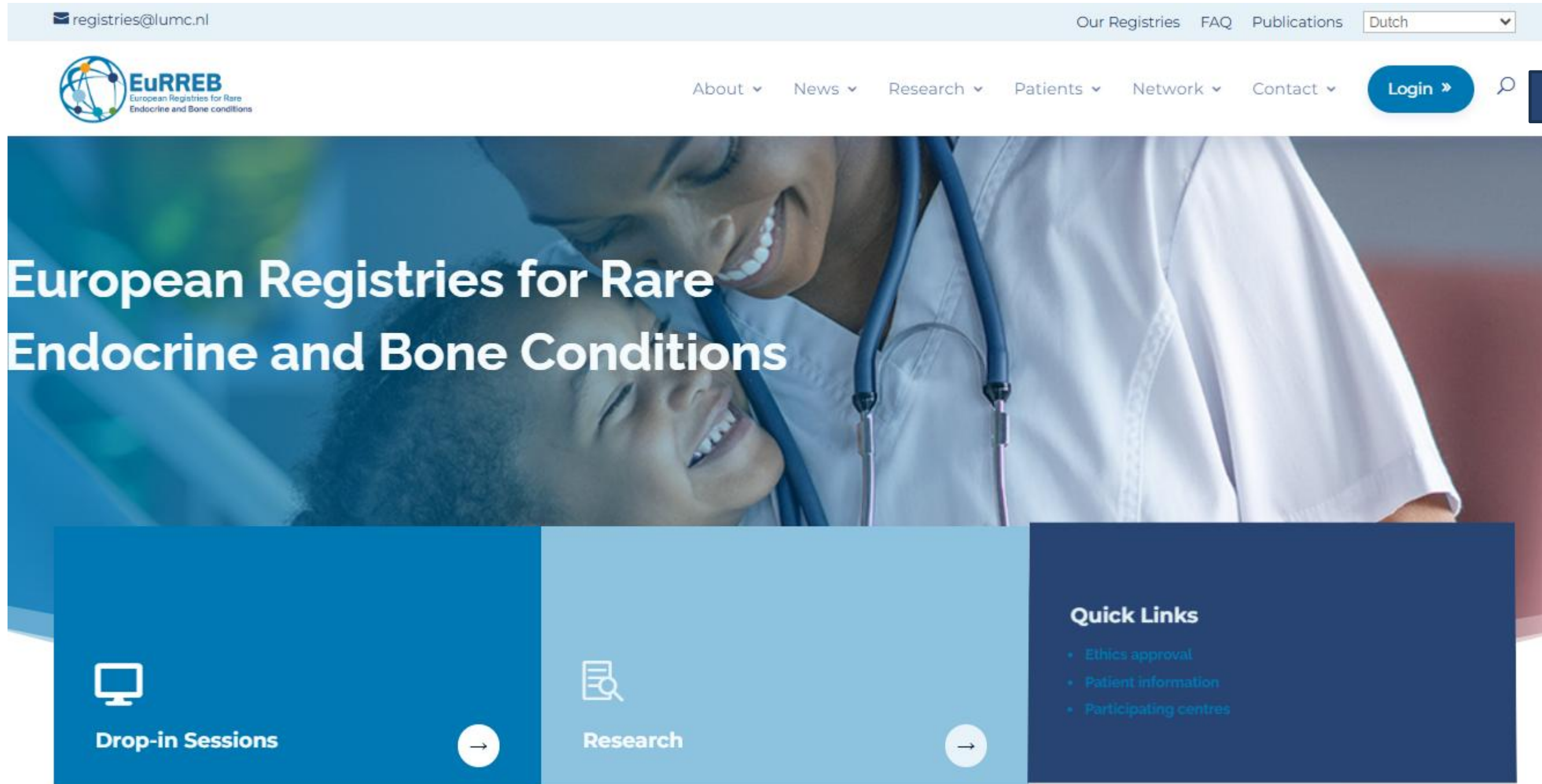


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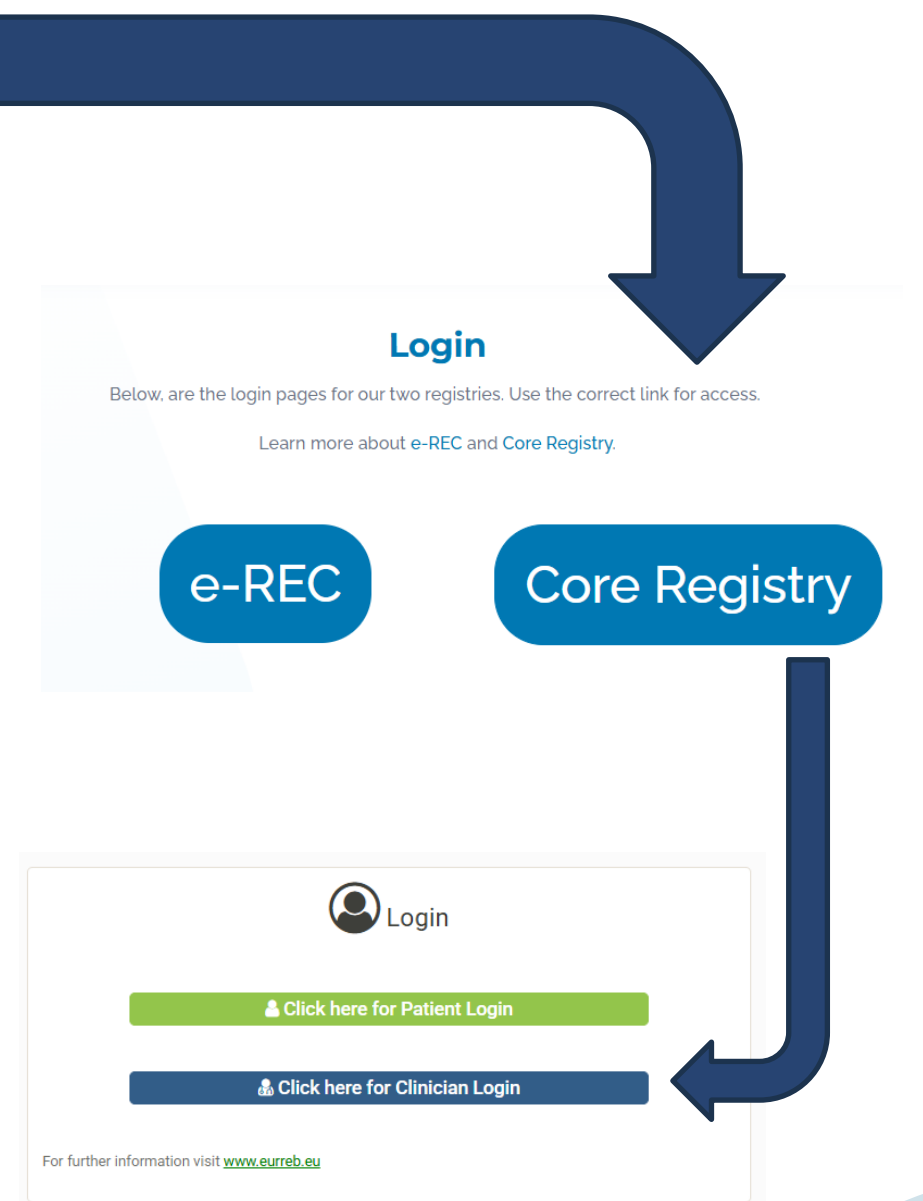


How to login into the Core Registry

Go to <https://eurreb.eu/> and use [Login button](#) and go to the Core Registry and choose [Clinician Login page](#)



The screenshot shows the homepage of the European Registries for Rare Endocrine and Bone Conditions (EURREB). The header includes the email address registries@lumc.nl, navigation links for Our Registries, FAQ, and Publications, and a language dropdown menu set to Dutch. The main navigation menu contains links for About, News, Research, Patients, Network, and Contact, along with a prominent blue Login button. The main banner features a photograph of a smiling doctor with a stethoscope around a young child's neck, with the text "European Registries for Rare Endocrine and Bone Conditions". Below the banner are three navigation cards: "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 screenshot shows the Login page of the EURREB website. It features a "Login" heading and a sub-heading: "Below, are the login pages for our two registries. Use the correct link for access." Below this, there is a link to "Learn more about e-REC and Core Registry." Two large blue buttons are displayed: "e-REC" and "Core Registry". A blue arrow points from the "Login" button on the homepage to the "Login" heading. Another blue arrow points from the "Core Registry" button to the "Login" section below. The "Login" section contains a "Login" heading with a user icon, a green button labeled "Click here for Patient Login", and a blue button labeled "Click here for Clinician Login". A blue arrow points from the "Click here for Clinician Login" button to the "Click here for Clinician Login" button in the previous screenshot. At the bottom, there is a link for further information: "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

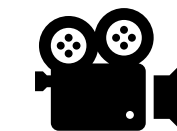
 6 digit PIN from your mobile device 

[→ 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](#)



You can also watch a short video on how to use the CR on [our website](#)



The Core Registry



Dashboard



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference Data Emails Reporting Leiden University Medical Center

Clinician Dashboard

Latest News

[Join EuRREB Symposium 2025](#)

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

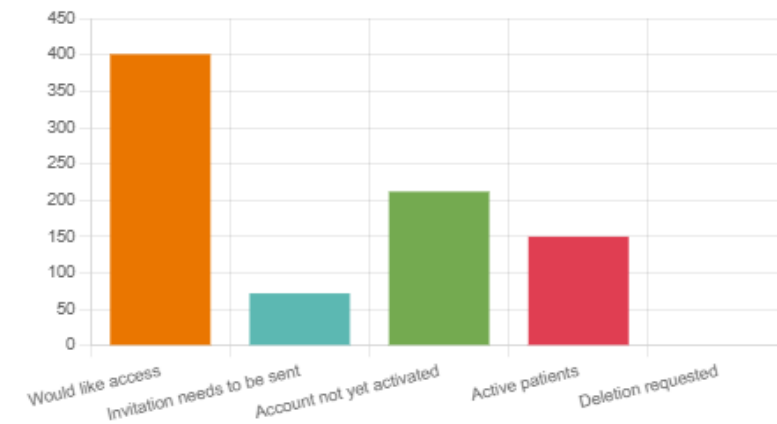
Patients in Centre: Leiden University Medical Center

[Patients registered by you: 19](#)

Patients registered in your centre: 839

[Patients with outstanding actions: 50](#)

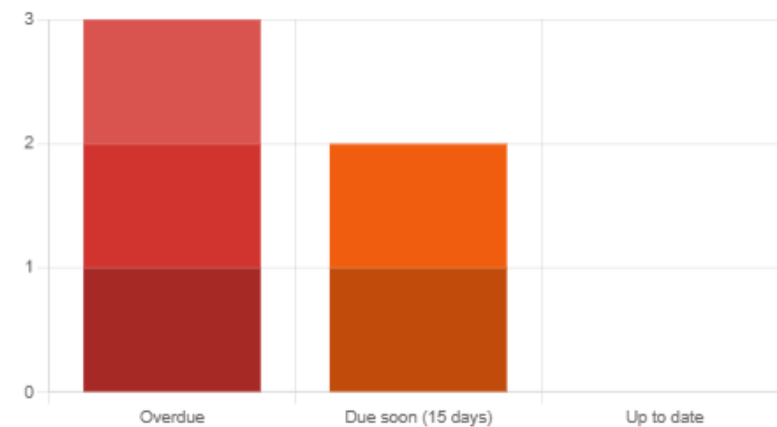
Patient Access



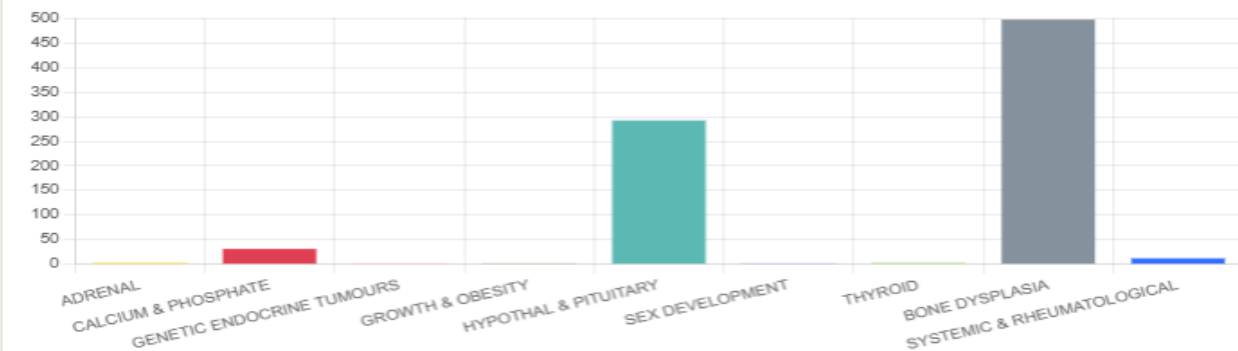
My Diagnosis-specific Outcomes Status



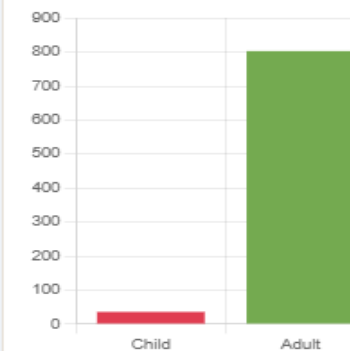
Patient Outcomes Status



Condition Groups



Age Groups



You can explore different features of the dashboard:

- you have access to all patients, registered in your centre,
- you are able to see the latest news
- you can see the distribution of cases by MTG and Age groups,
- you can check patient access status, patient and clinician outcomes status.

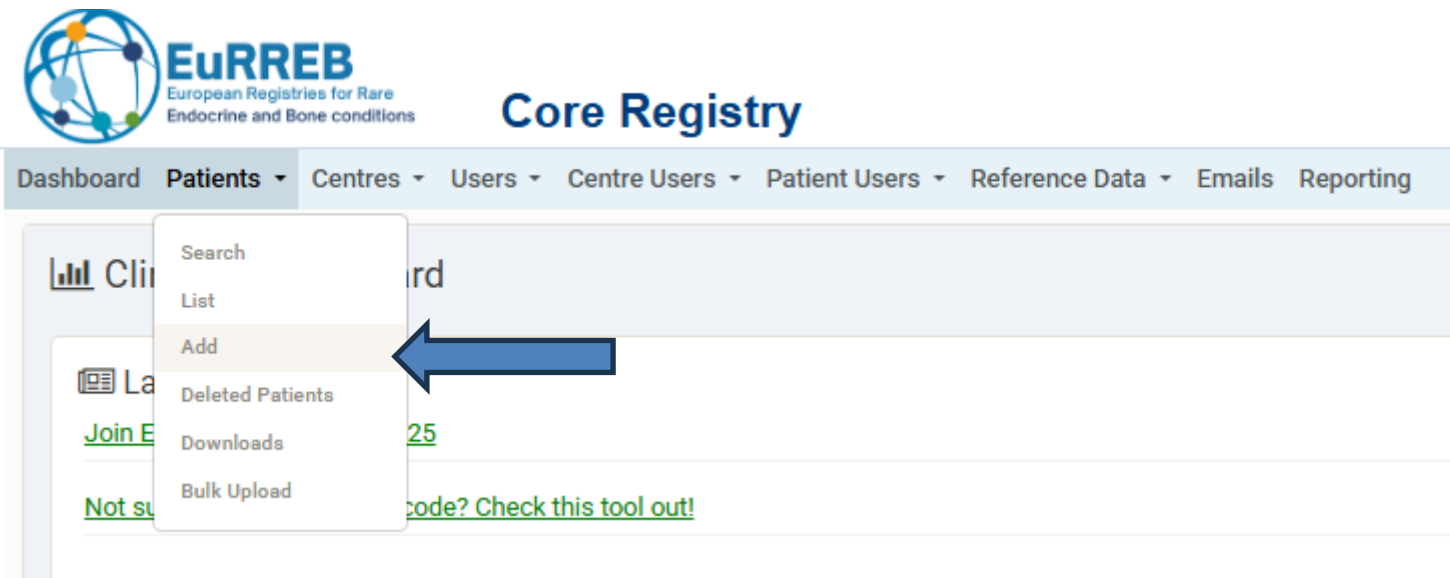


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How to add a new patient

Choose "Add" button from the menu tab "Patients".



Fill in all mandatory fields in the Common Data Elements and select "CALCIUM & PHOSPHATE"



The screenshot shows the 'Add Patient' form. The 'Is Test Case' checkbox is checked, with a blue arrow pointing to it and a text box that says 'Tick this box only if you want to test the platform'. The 'Condition Group' section has 'CALCIUM & PHOSPHATE' selected, with a blue arrow pointing to it. The 'Save and continue' button is highlighted with a blue arrow. The form includes fields for 'Consent for Core Registry', 'Date of Birth', 'Condition Group', 'Pseudonymised ID', 'Sex at Birth', 'Current Gender', 'Country of Birth', 'Country of Usual Residence', and 'Patient Follow-up Status'. A note states 'Fields marked with * are mandatory'.



Fill in the mandatory fields in the condition group section

Edit To Do

Core Data **CALCIUM & PHOSPHATE** Patient Access Generic Outcomes **Diagnosis-specific Outcomes** Documents 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 First Clinical Manifestations

* Primary Condition

* Specific Diagnosis

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

Save

After the completion of the mandatory fields and saving, "Diagnosis-specific Outcomes" button will appear in the menu



The Hypoparathyroidism Module



How to fill in the module

If you added the patient with hypoparathyroidism to the Core Registry, “Diagnosis-specific Outcomes” button will appear in the menu, click there to create a 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.

Diagnosis-specific Outcomes ▶ Patient ID **5106** 📅 Date of Birth -

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

Calcium and Phosphate - Dr. Mariya Cherenko

10 entries per page Search:

Created Date	Comments	Latest Assessment Date	Completed By	Questionnaire	Current Specific Diagnosis	Actions
2025-10-28	<input type="text" value="Comments"/>		Mariya Cherenko	Hypoparathyroidism - adults_beta_version2	Secondary hypoparathyroidism due to impaired parathormone secretion	<input type="button" value="View"/> <input type="button" value="Amend"/> <input type="button" value="Delete"/>
2025-10-28	<input type="text" value="Comments"/>		Mariya Cherenko	Hypoparathyroidism - adults_beta_version2	Secondary hypoparathyroidism due to impaired parathormone secretion	<input type="button" value="View"/> <input type="button" value="Amend"/> <input type="button" value="Delete"/>

« 1 »

New Outcome Language

You can amend, view or delete the outcomes when needed. Next outcome will be automatically prefilled with the data from previous outcome.



Fill in the data into the module

👉 Note: Some questions are hidden and will only appear based on the answers you choose.
Explore all the tabs and the tooltips.

Disease summary | Comorbidities | Lab results | Treatment | Admissions

Disease summary at baseline

Assessment Date

Height (cm)

Weight (kg)

BMI

Age at menarche

Menopause? Not Known Yes No

Educational level

Hypoparathyroidism type Post-surgical Non-surgical

Disease summary at follow-up

Assessment Date

Height (cm)

Weight (kg)

BMI

Menopause? Not Known Yes No

Sick leave from education or work?

Pregnancy after Hypoparathyroidism diagnosis? Not Known Yes No

Changes in diagnosis since the last assessment? No Yes

Systematic assessment of the quality of life? Not Known Yes No

For the subsequent follow-ups – create a new outcome and fill in only follow-up data.
Note, the outcome will be already prefilled with a previous data.



PROMs



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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

CALCIUM & PHOSPHATE Patient Access Generic Outcomes Diagnosis-specific Outcomes Audit

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

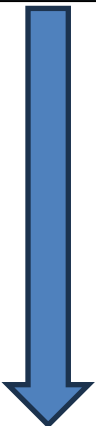
Grant Access

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.



How to fill in PROMs for this 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 this module we are currently collecting EQ-5D and HPQ-28



Generic Outcomes ▶ Patient ID - 5106 📅 Date of Birth -

* - Condition sections marked with * contain mandatory fields that require your attention!

Core Data * HYPOTHAL & PITUITARY Patient Access **Generic Outcomes** Diagnosis-specific Outcomes Documents Audit Patient List

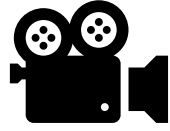
EQ-5D BPI-SF MSK-HQ NPSI OHIP-14 Transition WHO ICF Patient Reported Outcome Request Settings

10 entries per page Search:

Created Date	Completed By	Type	Mobility	Self Care	Activity	Pain	Anxiety	EQ VAS	Actions
No Patient Reported Outcomes found									

Current Patient EQ-5D Request Settings: EQ-5D-5L every 3 months, starting on 2023-09-30

Patient EQ-5D Request Settings Create EQ-5D



You can also watch a short video on how to assign PROMs on [our website](#)





Funded by
the European Union



Ways to contact us:



eurreb.eu



registries@lumc.nl



[drop-in sessions via Zoom](#)



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