

# How to use the IPPSD 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

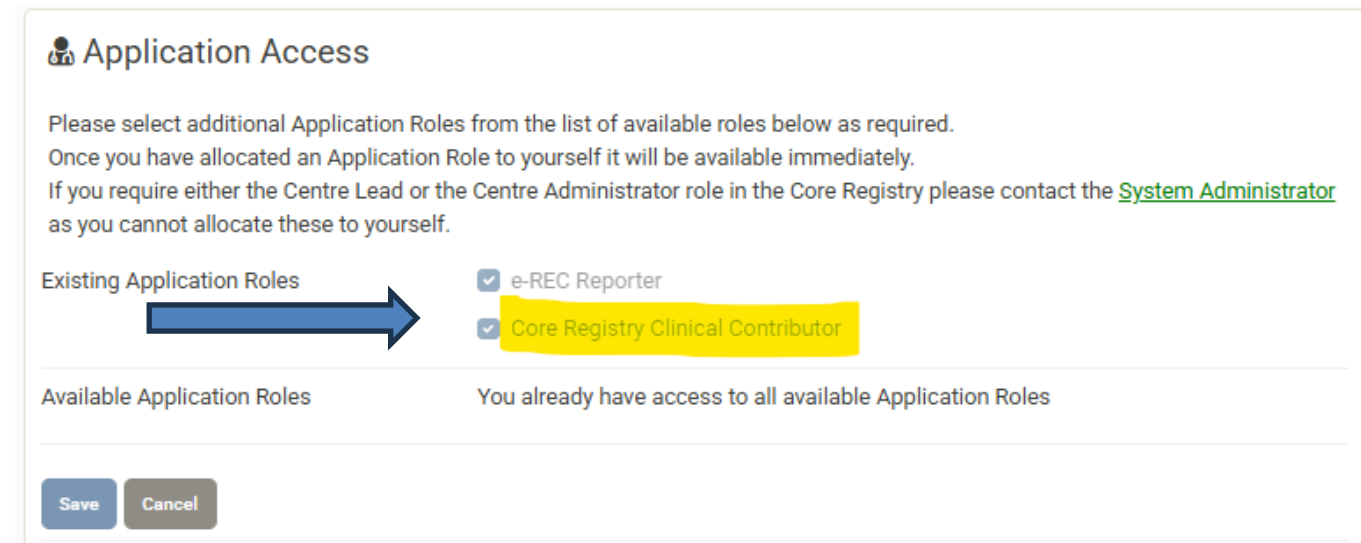
If you are already using e-REC, you can allocate the Core Registry Clinical Contributor role to yourself

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

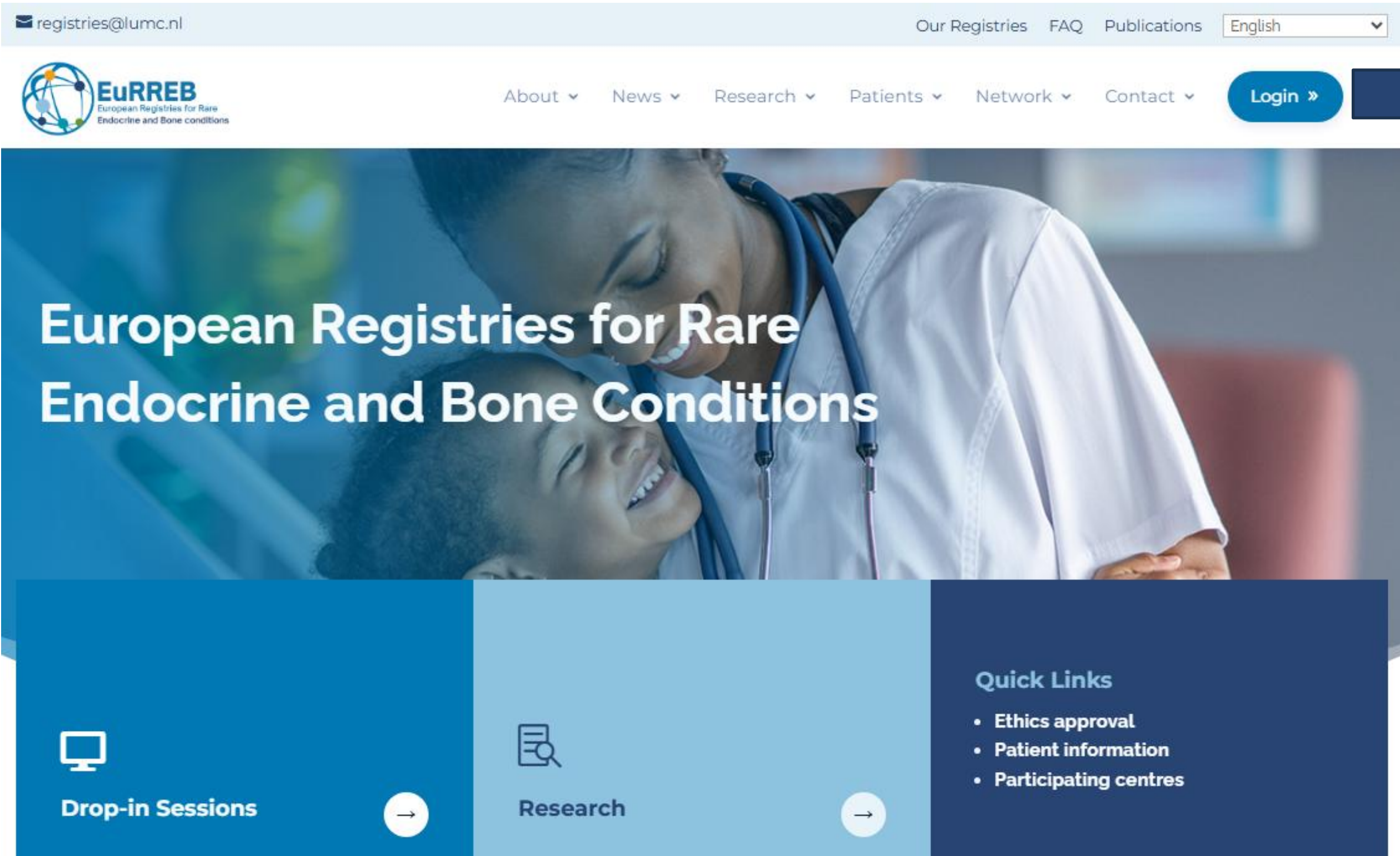


The screenshot shows the "Application Access" configuration page. The title is "Application Access" with a user icon. Below the title is a paragraph: "Please select additional Application Roles from the list of available roles below as required. Once you have allocated an Application Role to yourself 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 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 the roles 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", 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. At the top is a blue "Login" header. Below it is a paragraph: "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." There are two 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" header 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



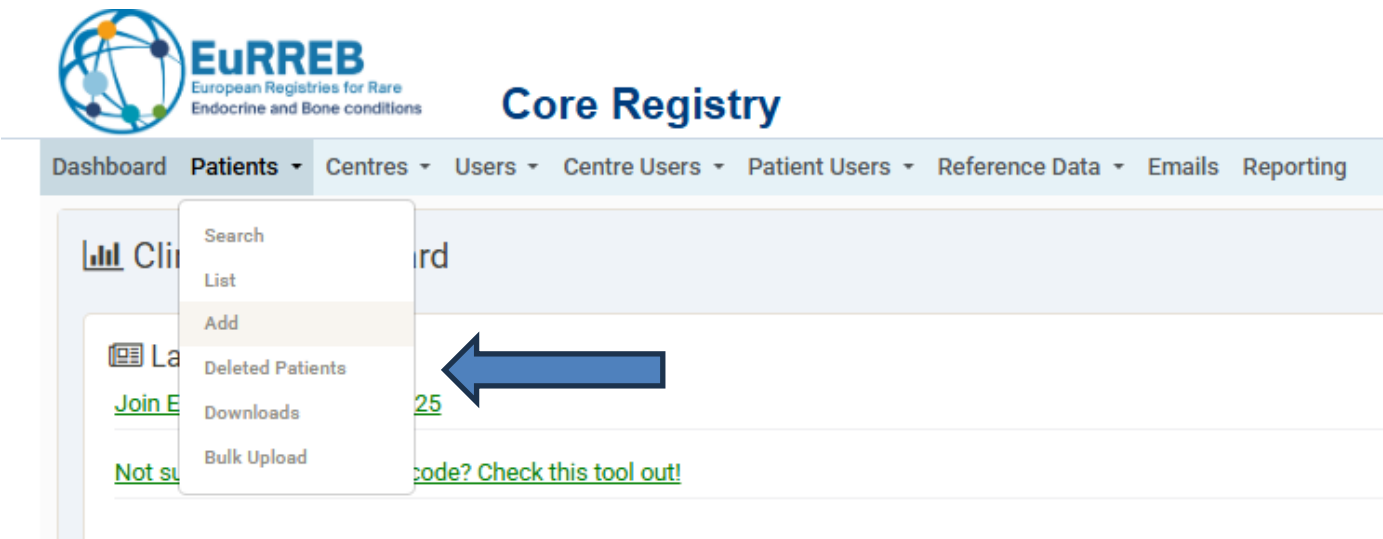
You can explore the different features of the dashboard:

- 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"



Fill in the Common Data Elements

Mandatory fields



## 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

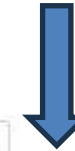
Can be contacted for collecting Patient Reported Outcomes

Patient would like access to Core Registry

Consent for Newsletters

Save Cancel

Select "Calcium & Phosphate"



Opt-in  Opt-out

dd-mm-yyyy

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

NETHERLANDS

NETHERLANDS

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

dd-mm-yyyy

- Select -

Yes  No  Not Known

Yes  No  Not Known

Yes  No  Not Known

Yes  No  Not Known

Yes  No  Not Known



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# 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:  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
- Date of Death:
- Primary Cause of Death:

- 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

Save

- CALCIUM & PHOSPHATE**
- BONE DYSPLASIA
- Patient Access
- Generic Outcomes
- Diagnosis-specific Outcomes
- Audit
- Patient List

- Opt-in  Opt-out
- 
- ADRENAL  CALCIUM & PHOSPHATE  GLUCOSE & INSULIN  GENETIC  BONE TUMOURS
- GROWTH & OBESITY  HYPOTHAL & PITUITARY  SEX DEVELOPMENT  THYROID
- BONE DYSPLASIA



Click here to fill in the Calcium & Phosphate tab



# Fill in primary condition and specific diagnosis

## Edit Patient Condition

Core Data   Generic Outcomes   Documents   Audit   Patient List

Patient ID  Date of Birth -

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 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

Save   Cancel

Select a Clinician Responsible for the Patient

Select the Primary Condition - "Pseudohypoparathyroidism", 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)

EUPID (European Patient ID)

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 Pseudohypoparathyroidism Conditions Module



# Access the disease-specific Module

## Edit Patient Condition

Patient ID - [ ] Date of Birth [ ] 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 First Clinical Manifestations

Primary Condition

Specific Diagnosis

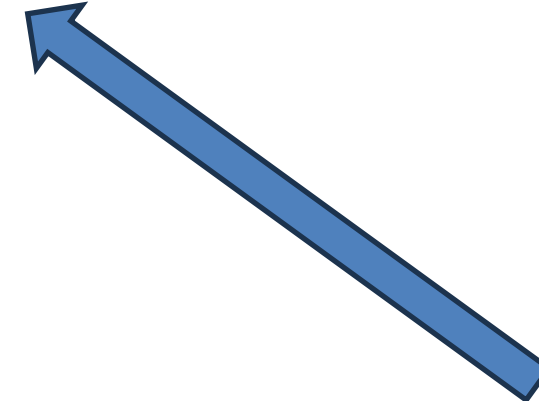
The full hierarchy of Conditions and Specific Diagnoses can be found in the [Core Registry Conditions Dictionary](#)

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

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



Click here to fill in the disease-specific module



# Fill in the new outcome

## Diagnosis-specific Outcomes

Core Data

CALCIUM & PHOSPHATE

Generic Outcomes

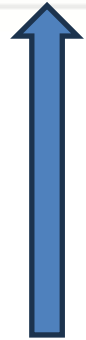
Audit

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



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# Fill in the data into the module and save

Patient ID - [ ] Date of Birth - [ ] Condition Group - Calcium and Phosphate

Questionnaire: iPPSD outcome questionnaire v3 - iPPSD outcome questionnaire v3

New Outcome

Date of Birth	[ ]	e-REC ID		Primary Condition	Pseudohypoparathyroidism
Current Gender		Clinician Responsible for Patient	Aniek Vlasma	Specific Diagnosis	Pseudohypoparathyroidism (IPPSD)
				Date of Diagnosis	

Perinatal features Genetic findings Endocrine Status Auxology parameters Clinical findings Clinical musculoskeletal features Radiological musculoskeletal features Other Radiological findings Therapy Surgical interventions

Assessment Date [?] dd-mm-yyyy

Age at Assessment Date [?] [ ]

Gene variant (cDNA) [?] [ ]

Gene variant (protein) [?] [ ]

Gene

- PTH1R
- GNAS, maternal allele
- GNAS, paternal allele
- GNAS, parental allele not known
- abnormal methylation at least at GNAS A/B DMR
- PRKAR1A
- PDE4D
- PDE3D
- Other
- No genetic analysis
- Unknown

Fill in all the tabs which are applicable



# 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 10 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

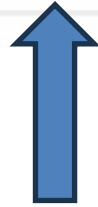
Create or edit requests for the Patient to complete generic questionnaires

Show 10 entries

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

[Add Outcome Request](#)

Previous 1



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

2022-11-01

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





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## 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  
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