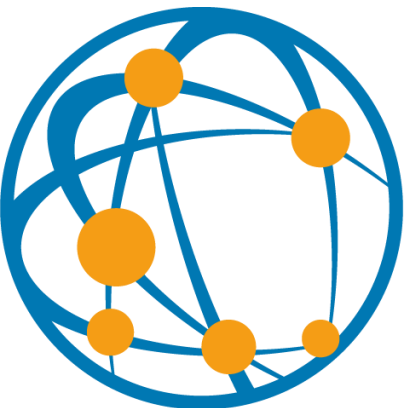
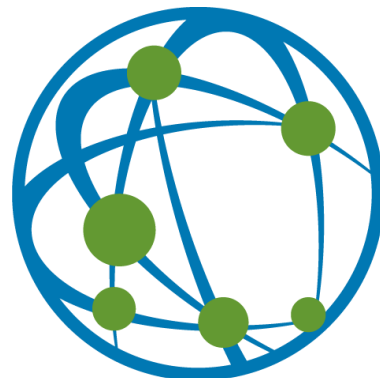


# Using the Rare Hypophosphataemic Conditions module in the Core registry



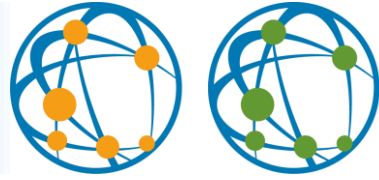
**EuRRECa**

European Registries for  
Rare Endocrine Conditions



**EuRR-Bone**

European Registries for Rare  
Bone and Mineral Conditions

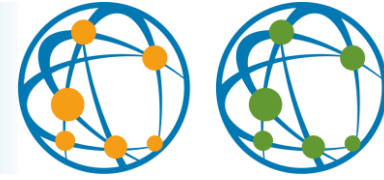


This condition-specific module is open for the following diagnoses

- X- linked hypophosphataemia **ORPHA:89936**
- Autosomal dominant hypophosphataemic rickets **ORPHA:89937**
- Autosomal recessive hypophosphataemic rickets **ORPHA:289176**
- Dominant hypophosphataemia with nephrolithiasis or osteoporosis **ORPHA:244305**
- Hereditary hypophosphataemic rickets with hypercalciuria **ORPHA:157215**
- Dent disease **ORPHA:1652**

In this guide, we will show you how to access the module step by step

# Log in to the Core Registry



Go to <https://eurreca.lumc.nl/CoreRegistry/Account/Login>

If you don't have an account, please request access via the [Self-Registration link](#)



Core Registry

## Clinician Login

User Name

Password

Forgotten password? To reset your password please click on the following [Reset Password link](#)

6 digit PIN from your mobile device

Click on the following link for further information about OTP authentication: [OTP Authentication](#)

Log in

## New Users

To request access to the system please click on the following [Self-Registration link](#)



e-Reporting of Rare Conditions (e-REC) and 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

\* Confirm Password

Telephone

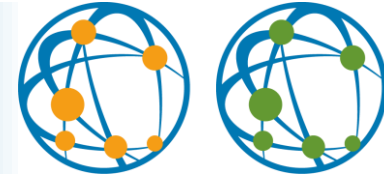
I am the Centre Lead for this Centre

Filter Centres by Country (optional)

\* Centre

Save

# Log in to the Core Registry



To log in go to

<https://eurreca.lumc.nl/CoreRegistry/Account/Login>



Core Registry

## Clinician Login

User Name

Password

Forgotten password? To reset your password please click on the following [Reset Password](#) link

6 digit PIN from your mobile device ?

Click on the following link for further information about OTP authentication: [OTP Authentication](#)

Log in

New Users

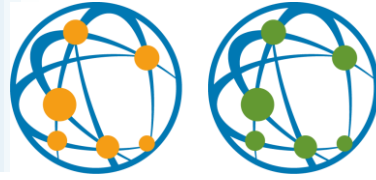
To request access to the system please click on the following [Self-Registration](#) link

Provide your credentials and [6 digit PIN](#)

If needed, [reset your password](#)

You will need an [authentication app](#) on your mobile phone

# Add a new patient



Core Registry

Dashboard Patients Centres Centre Users

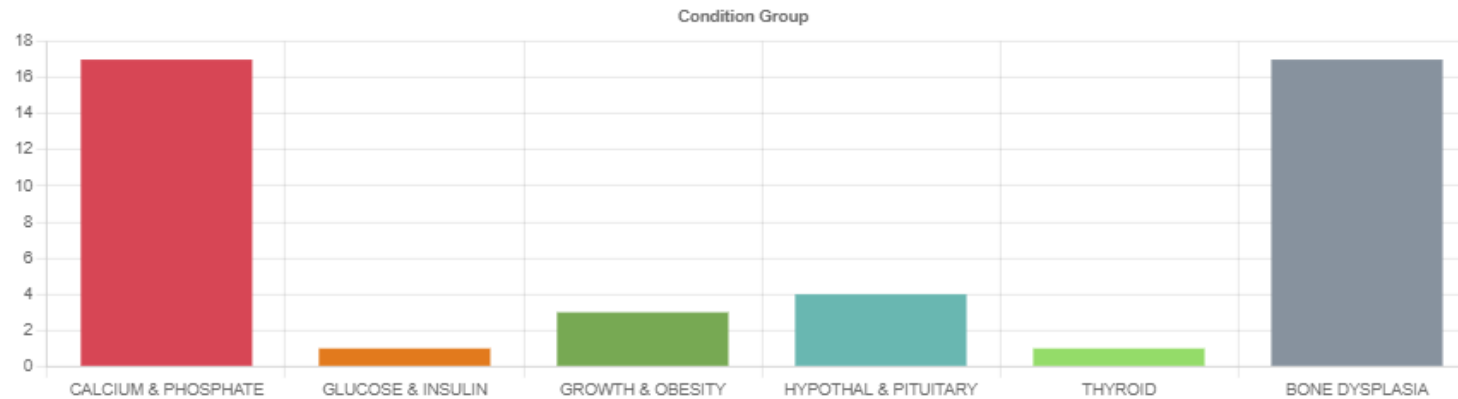
## Clinician Dashboard

Patients in Centre: EuRR-Bone-Test

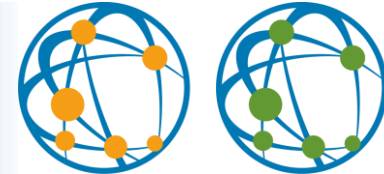
Patients registered by you: 2

Patients registered in your centre: 27

Patients with outstanding actions: 0



# 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)

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

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 <sup>?</sup>  Opt-out <sup>?</sup>

dd-mm-yyyy

- ADRENAL <sup>?</sup>  CALCIUM & PHOSPHATE <sup>?</sup>  GLUCOSE & INSULIN <sup>?</sup>  
 GENETIC ENDOCRINE TUMOURS <sup>?</sup>  GROWTH & OBESITY <sup>?</sup>  HYPOTHAL & PITUITARY <sup>?</sup>  
 SEX DEVELOPMENT <sup>?</sup>  THYROID <sup>?</sup>  BONE DYSPLASIA <sup>?</sup>

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

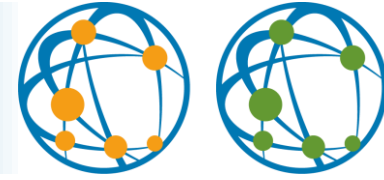
Select "Calcium & Phosphate"

SAVE

Save

Cancel

# Go to the Patient Condition section



## Edit Patient

Patient ID - 2647



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

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

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

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

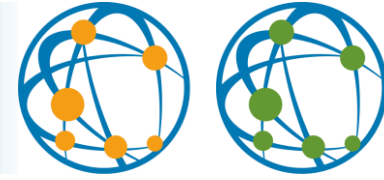
dd-mm-yyyy

- Select -

Save

A navigation menu will appear, click on "Calcium & Phosphate"

# Edit the Patient Condition section



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference Data Mariya Cherenko - Lei

## Edit Patient Condition

Core Data Generic Outcomes Diagnosis-specific Outcomes 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 Condition Onset

Select a Clinician Responsible for the patient



Primary Condition

Specific Diagnosis

- Select the "Hypophosphataemia" as Primary Condition
- Select a Specific Diagnosis from the list



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

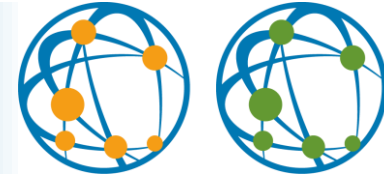
Save



Save



# Access the Disease-specific Module



Core Registry

Dashboard

Patients

Centres

Users

Centre Users

Patient Users

Reference Data

Mariya Cherenko - Lei

## Edit Patient Condition

Patient ID      ! Date of Birth



Edit To Do

Core Data

Generic Outcomes

Diagnosis-specific Outcomes

Audit

Patient List



Click here to fill in the disease-specific module

### 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

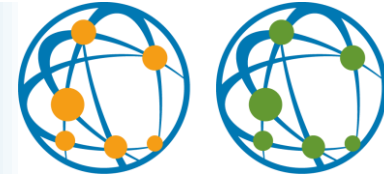
Participation in Detailed Disease Registry

Yes    No    Not Known

Save

Cancel

# Fill in a Disease-specific outcome



Core Registry

Dashboard

Patients ▾

Centres ▾

Users ▾

Centre Users ▾

Patient Users ▾

Reference Data ▾

Mariya Cherenko - Li

Diagnosis-specific Outcomes

Core Data

**CALCIUM & PHOSPHATE**

Generic Outcomes

Audit

Patient ID

Date of Birth -

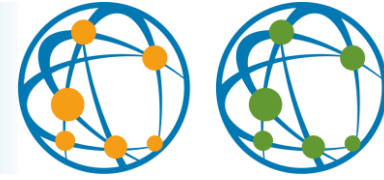
Calcium and Phosphate

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



Core Registry

Dashboard Patients Centres Centre Users Patient Users

Dr. Ana Priego - EuRR-Bone-Test

## 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	Primary Condition	Hypophosphataemia
Current Gender	Male	Clinician Responsible for Patient	Specific Diagnosis	X-linked hypophosphataemia
			Date of Diagnosis	

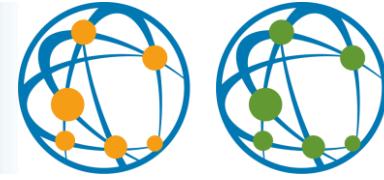
Basic disease module Genetic findings Family and perinatal history Clinical outcomes Clinical musculoskeletal findings Radiological musculoskeletal findings Other investigations Biochemical findings Therapy

Surgical intervention

Assessment Date	?	dd-mm-yyyy
Age at Assessment Date	?	<input type="text"/>
Gene variant (cDNA)	?	<input type="text"/>
Gene variant (protein)	?	<input type="text"/>
Gene	Collecting information on mosaicisms	<input type="text"/>
Mosaicism		- Select - - Select - Not Known Yes No

Back

# Give the Patient access to the Core Registry



## Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference Data

CALCIUM & PHOSPHATE

Patient Access

Generic Outcomes

Diagnosis-specific Outcomes

Audit

Patient List

### Edit Patient

Patient ID -



Edit To Do

Fields marked with \* are mandatory

\* Consent for Core Registry

Opt-in  Opt-out

\* Date of Birth

\* Condition Group (select all that apply)

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

EUPID (European Patient ID)

Sex at Birth

Male  Female  Other  Unknown

Current Gender

Male  Female  Non-binary  Other  Asked but unknown

Country of Birth

NETHERLANDS

Country of Usual Residence

NETHERLANDS

Patient Follow-up Status

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

Date of Death

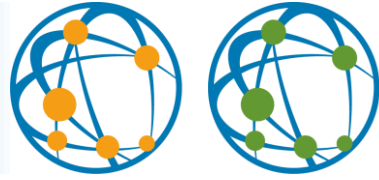
mm/dd/yyyy

Primary Cause of Death

- Select -

Give access to your patient  
\*if consent was given in the Common  
Data Elements section

# Contact us!



Please do not hesitate to contact us by e-mail at [registries@lumc.nl](mailto:registries@lumc.nl) in case of any questions

We invite you to join our regularly drop-in sessions <https://eurr-bone.com/>

