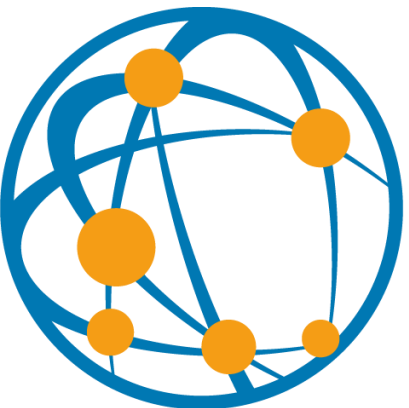
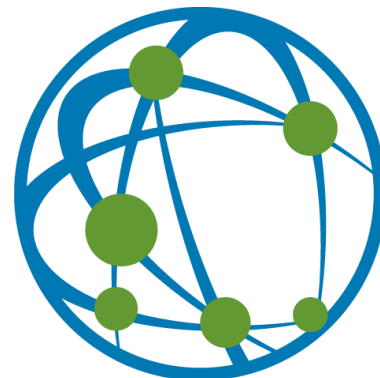


How to use the Parathyroid carcinoma module in Core registry

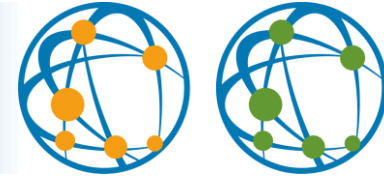


EuRRECa
European Registries for
Rare Endocrine Conditions



EuRR-Bone
European Registries for Rare
Bone and Mineral Conditions

Login in Core registry



Go to <https://eur-bone.com/registries/core/>

HOME STRUCTURE ▾ REGISTRY ▾ PATIENTS NEWS ▾

CORE

The Core Registry collects a core data set for a wide range of rare bone and mineral conditions. The data collected will be used to improve clinical care as well as research and oversight to data access is provided by the [Data Access Committee](#). The Core Registry will also advise participants on other suitable studies and registries. As the Core Registry has been functional within EuRECa since 2019 it has been approved by the National Ethics Service and Information Governance authorities in the UK. This is the reason EuRR-Bone could embark the Core registry quickly and the registry is open for rare bone and mineral conditions.



[Request Access to the Core Registry](#)

[Login to the Core Registry](#)

[Graphic Walkthrough of the Core Registry](#)

If you have no account yet, you can request the access [here](#)

You need an access to Core registry to use the module

  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 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

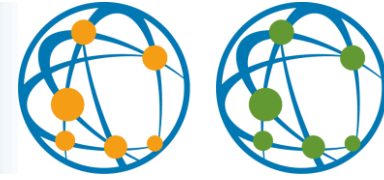
Telephone

I am the Centre Lead for this Centre

Filter Centres by Country (optional)

* Centre

Login in Core registry



Go to <https://eurr-bone.com/registries/core/> and click on “Login to the Core Registry” if you already have an account

HOME STRUCTURE ▾ REGISTRY ▾ PATIENTS NEWS ▾

CORE

The Core Registry collects a core data set for a wide range of rare bone and mineral conditions. The data collected will be used to improve clinical care as well as research and oversight to data access is provided by the [Data Access Committee](#). The Core Registry will also advise participants on other suitable studies and registries. As the Core Registry has been functional within EuRRECa since 2019 it has been approved by the National Ethics Service and Information Governance authorities in the UK. This is the reason EuRR-Bone could embark the Core registry quickly and the registry is open for rare bone and mineral conditions.

[Request Access to the Core Registry](#)

[Login to the Core Registry](#)

[Graphic Walkthrough of the Core Registry](#)

EuRRECa European Registries for Rare Endocrine Conditions

EuRR-Bone European Registries for Rare Bone and Mineral Conditions

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](#)

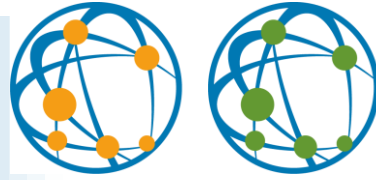
[New Users](#)

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 to download OTP authenticator

Add a new patient



Core Registry

Dashboard Patients Centres Centre Users

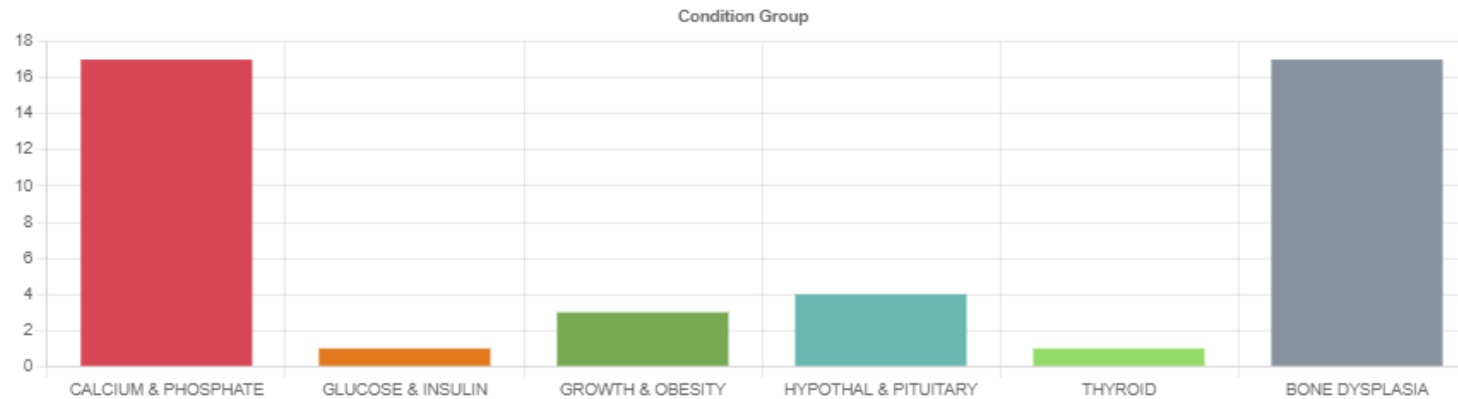
Clinician Dashboard

Patients in Centre: EuRR-Bone-Test

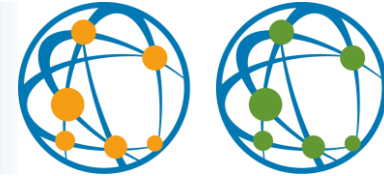
Patients registered by you: 2

Patients registered in your centre: 27

Patients with outstanding actions: 0



Fill in 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)

If applicable

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

Save

Cancel

Choose
"Calcium and
Phosphate"

Opt-in [?] Opt-out [?]

[Redacted]

ADRENAL [?] CALCIUM & PHOSPHATE [?] GLUCOSE & IN:
 BONE DYSPLASIA [?]

[Redacted]

Male Female Other Unknown

Male Female Non-binary Other Asked but unknc

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

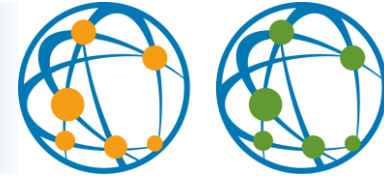
Yes No Not Known

Yes No Not Known

SAVE



Go to condition group section



Edit Patient

Patient ID - 4165



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

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 ? GENETIC ENDOC
 GROWTH & OBESITY ? HYPOTHAL & PITUITARY ? SEX DEVELOPMENT ? THYRC
 BONE DYSPLASIA ?

Male Female Other Unknown

Male Female Non-binary Other Asked but unknown

NETHERLANDS

NETHERLANDS

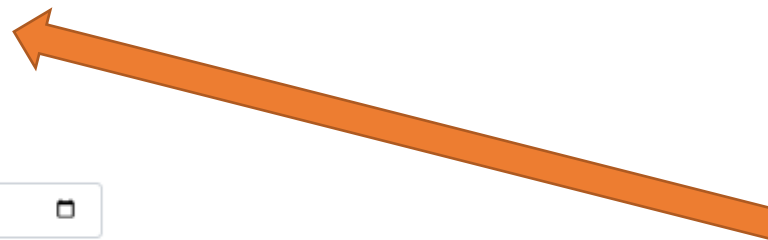
Patient active Patient inactive Patient care suspended Patient care terminated I
 Unknown

mm/dd/yyyy

- Select -

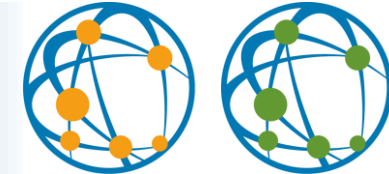
Yes No Not Known

Yes No Not Known



Click here to fill in the
"calcium and
phosphate" tab

Fill in primary condition and specific diagnosis



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference Data Mariya

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

Edit Patient Condition

Patient ID - 4165 Date of Birth

1 Edit To Do

Calcium and Phosphate

Senior Clinician < 18 - N/A

Senior Clinician ≥ 18 - N/A

If applicable

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 Primary condition - "Hyperparathyroidism including parathyroid cancer", for Specific diagnosis - "Parathyroid carcinoma"

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

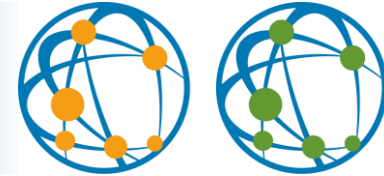
Participation in Detailed Disease Registry

Yes No Not Known

Detailed Disease Registry

Save Cancel

Access the Disease-specific Module



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference Data

Mariya Cherenko - Leiden University Medica

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

Edit Patient Condition

Patient ID - 4167 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

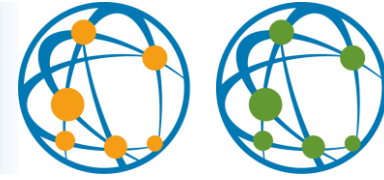
Yes No Not Known

Detailed Disease Registry

Detailed Disease Registry Patient ID

Click here to fill in the disease-specific module

Fill in the new outcome



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference Data

Mariya Cherenko - Leiden University Medical Center

Diagnosis-specific Outcomes

Patient ID - 4167 Date of Birth - [redacted]

Core Data **CALCIUM & PHOSPHATE** Generic Outcomes Audit Patient List

Calcium and Phosphate

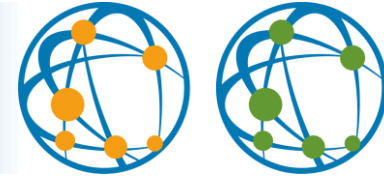
No Outcomes found

Edit Section Options

New Outcome

Click here to fill in the new outcome for disease-specific module

Fill in the data into the module and save



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference

Add Diagnosis-specific Outcome

Patient ID - 4165 Date of Birth - [redacted] Condition Group - Calcium and Phosphate

Questionnaire: Parathyroid cancer

New Outcome

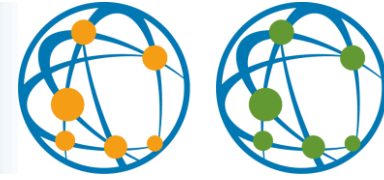
Date of Birth	[redacted]	e-REC ID		Primary Condition	
Current Gender	Male	Clinician Responsible for Patient	Mariya Cherenko	Specific Diagnosis	Hyperparathyroidism including parathyroid cancer Parathyroid carcinoma
				Date of Diagnosis	

General Diagnosis Imaging at time of diagnosis Medical treatment Surgery and histology PHPQoL Recurrence 1 Recurrence 2 Next recurrences PHPQoL recurred

General

Assessment Date	?	mm/dd/yyyy	📅
Smoking habit	?	- Select -	▼
Packyear	?		
Alcohol intake		<input type="radio"/> yes <input type="radio"/> no <input type="radio"/> unknown	
Units of alcohol per week	?		
Height (cm)	?		
Weight (kg)	?		
	?		

Give an access to the platform to your patient



Core Registry

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

CALCIUM & PHOSPHATE

Patient Access

Generic Outcomes

Diagnosis-specific Outcomes

Audit

Patient List

Edit Patient

Patient ID - [redacted] 1 Edit To Do

Fields marked with * are mandatory

* Consent for Core Registry

Opt-in ? Opt-out ?

* Date of Birth

[redacted]

* 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)

test Cherenko2

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

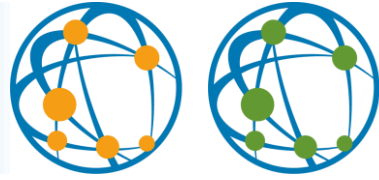
mm/dd/yyyy

Primary Cause of Death

- Select -

Give an access to your patient (in case of consent) - you need to know patient's e-mail for this

Contact us!



Please don't hesitate to contact us by e-mail registries@lumc.nl in case of any questions.

Or join our regularly drop-in sessions <https://eur-bone.com/>

