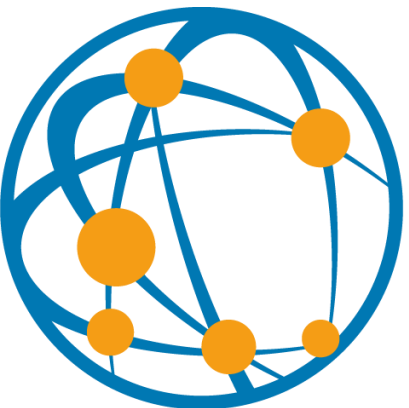
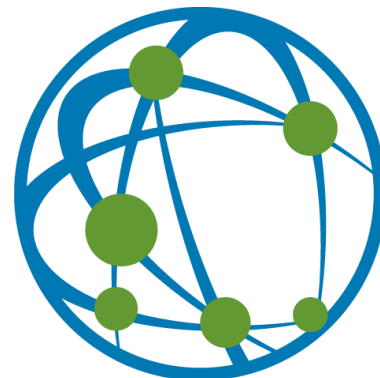


# How to use the disease specific module in Core registry

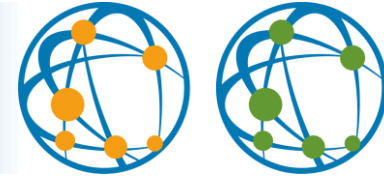


**EuRRECa**  
European Registries for  
Rare Endocrine Conditions



**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

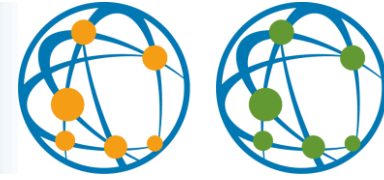
Telephone

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](#)

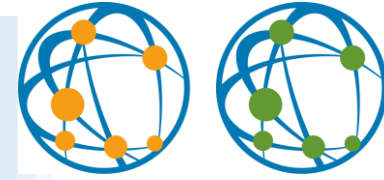
[New Users](#)

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

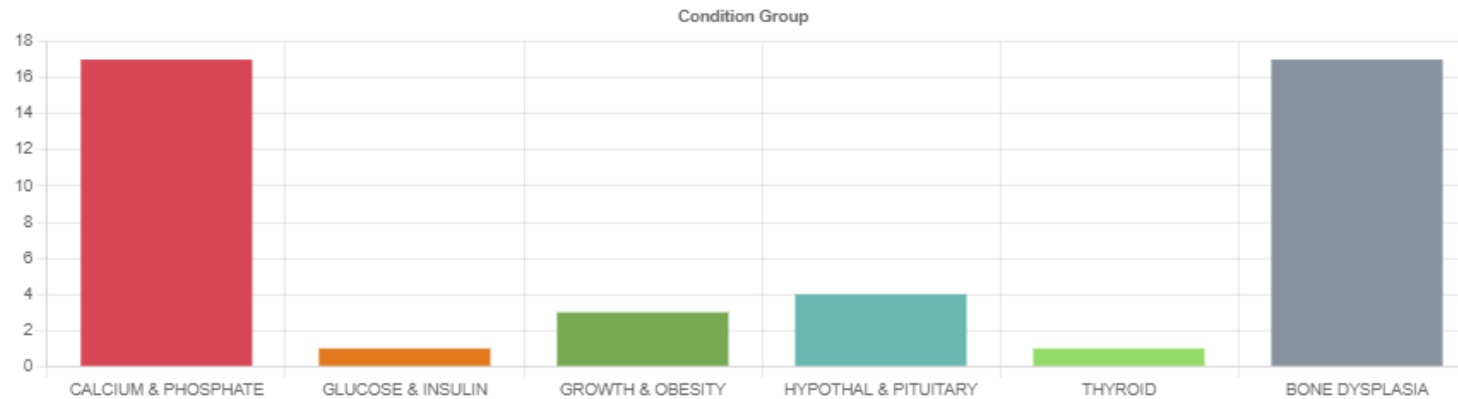
## Clinician Dashboard

Patients in Centre: EuRR-Bone-Test

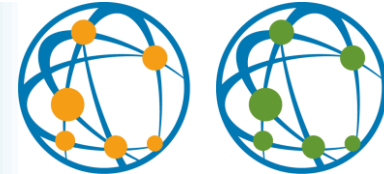
Patients registered by you: 2

Patients registered in your centre: 27

Patients with outstanding actions: 0



# Fill in 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)

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

Choose "Bone dysplasia" →

Opt-in  Opt-out

ADRENAL  CALCIUM & PHOSPHATE  GLUCOSE & IN:  
 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

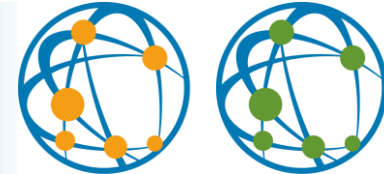
Yes  No  Not Known

Yes  No  Not Known

Yes  No  Not Known

SAVE →

# Go to condition group section



Core Registry

Dashboard Patients Centres Centre Users Mariya Cherenko - EuRR-Bone-Test

## Edit Patient

Patient ID - 4275

1 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

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

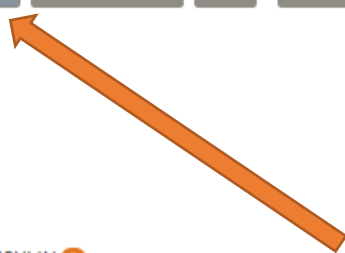
Data can be shared for research purposes

Yes  No  Not Known

Can be contacted for collecting Patient Reported Outcomes

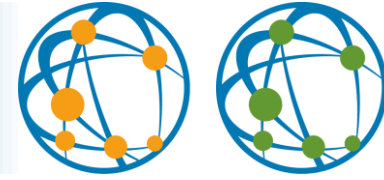
Yes  No  Not Known

BONE DYSPLASIA Generic Outcomes Audit Patient List



Click here to fill in the bone dysplasia tab

# Edit the Patient Condition section



Core Registry

Dashboard

Patients

Centres

Centre Users

Mariya Cherenko

## Edit Patient Condition

Core Data

Patient Access

Generic Outcomes

Diagnosis-specific Outcomes

Documents

Audit

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

! Edit To Do

### Bone Dysplasia

Senior Clinician < 18 - N/A

Senior Clinician ≥ 18 - N/A

If applicable



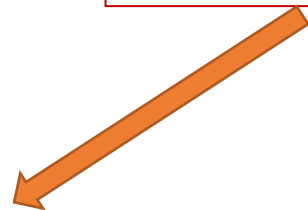
e-REC ID

First Contact with Centre

Clinician Responsible for Patient

Date of First Clinical Manifestations

Select a Clinician Responsible for the patient



Select the Primary condition - "PBD with decreased bone density", for Specific diagnosis – choose "OI +/- type" from the list



Primary Condition

Specific Diagnosis

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

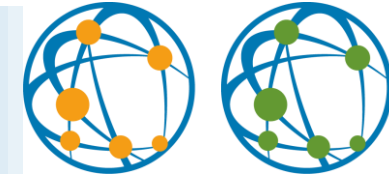
How Was Diagnosis Reached

- Clinical
- Biochemistry
- Genetic
- Histology
- CT
- MRI
- PET
- Not Known

Save Cancel



# Give an access to the platform to your patient



Core Registry

Dashboard Patients - Centres - Centre Users -

Mariya Cherenko - EuRR-Bone

## Edit Patient Condition

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

### Bone Dysplasia

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

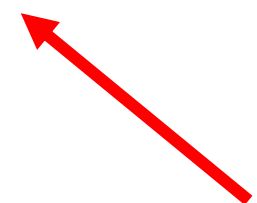
Participation in Detailed Disease Registry  Yes  No  Not Known

Detailed Disease Registry

Detailed Disease Registry Patient ID

Biobank Sample Available for Research  Yes  No  Not Known

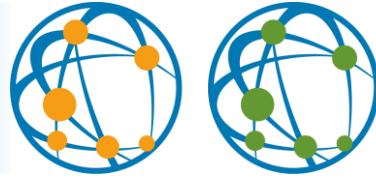
Biobank Details



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



# Go to diagnosis-specific outcome



Core Registry

Dashboard Patients ▾ Centres ▾ Centre Users ▾


Mariya Cherenko

## Edit Patient Condition

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

Patient ID - [redacted] Date of Birth

[redacted]

 **Edit To Do**

Use this button to put notes/reminders if needed

Click here to fill in the disease-specific module

**Bone Dysplasia**

Senior Clinician < 18 - N/A

Senior Clinician ≥ 18 - N/A

e-REC ID

First Contact with Centre

mm/dd/yyyy



Clinician Responsible for Patient

Mariya Cherenko



Date of First Clinical Manifestations

mm/dd/yyyy



Primary Condition

Primary bone dysplasia with decreased bone density



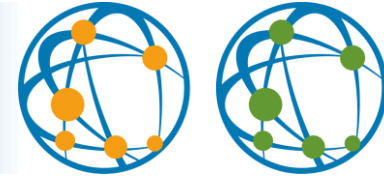
Specific Diagnosis

OI type 3



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

# Fill in the new outcome



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference Data

## Diagnosis-specific Outcomes

Core Data **BONE DYSPLASIA** Patient Access Generic Outcomes Audit Patient List

Patient ID - 4270 Date of Birth - [REDACTED]

Bone Dysplasia

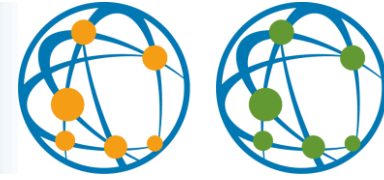
Supplemental material to complete this module

No Outcomes found

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 ▾

Centre Users ▾

Mariya Cherenko -

## Add Diagnosis-specific Outcome

Patient ID - [redacted] Date of Birth - [redacted] Condition Group - Bone Dysplasia

Questionnaire: Osteogenesis Imperfecta - Child - Child

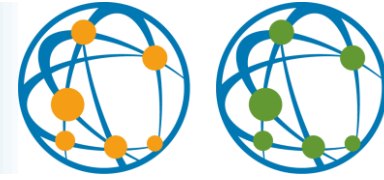
### New Outcome

Date of Birth	[redacted]	e-REC ID		Primary Condition
Current Gender	Male	Clinician Responsible for Patient	Mariya Cherenko	Primary bone dysplasia with decreased bone density
				Specific Diagnosis OI type 3
				Date of Diagnosis

Anthropometry	Fractures	Genetic diagnosis	Medication	Spine	Mobility	Lung function	Bone mineral density	Musculoskeletal surgery	Other surgeries
Assessment Date	?	mm/dd/yyyy							
Height (cm)	?								
Height SDS	?								
Weight (kg)	?								
Weight SDS	?								
BMI	?								

Fill in all the tabs which are applicable

# Fill in the generic outcomes



Core Registry

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

## Generic Outcomes

Core Data BONE DYSPLASIA Patient Access Diagnosis-specific Outcomes Audit Patient List

Patient ID - 450 Date of Birth -

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

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	2	2	74	
2021-03-24	Dr. Ana Priego	EQ-5D-5L		2	2	1	1	80	

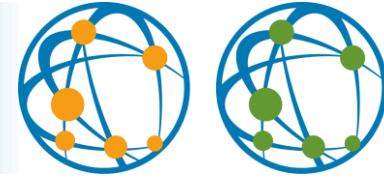
Current Patient EQ-5D Request Settings: EQ-5D-5L every 3 months, starting on 2022-06-30

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

Previous 1 Next

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

# Choose the frequency for PROMs



Core Registry

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

## Generic Outcomes

Core Data BONE DYSPLASIA Patient Access Diagnosis-specific Outcomes Audit

Patient ID - 450 Date of Birth - [REDACTED]

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

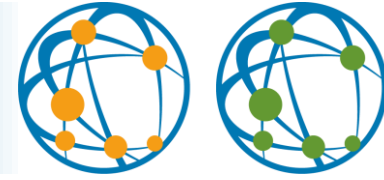
Generic Outcome Questionnaire	Request Frequency (months)	Request Start Date	Actions
WHO-ICF Mobility	9	2022-11-01	Edit Delete

Previous 1

Add Outcome Request

Click here to choose 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

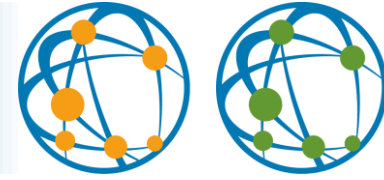
Date of Next Request mm/dd/yyyy

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

# Contact us!



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

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

