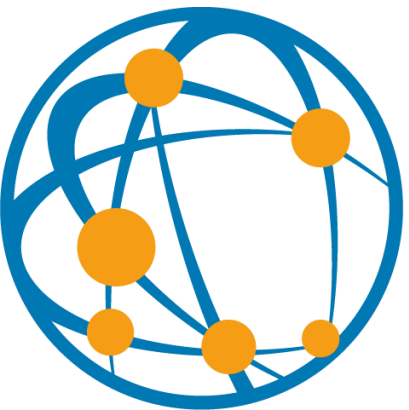
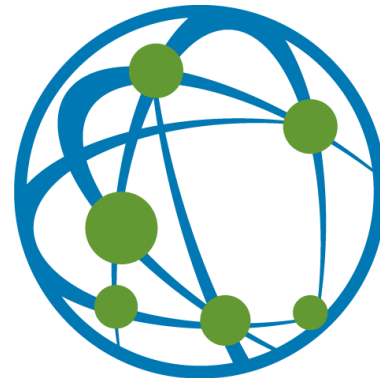


How to use Melorheostosis module in Core registry



EuRRECa

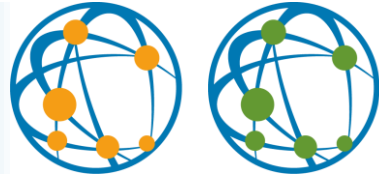
European Registries for
Rare Endocrine Conditions



EuRR-Bone

European Registries for Rare
Bone and Mineral Conditions

Melorheostosis module

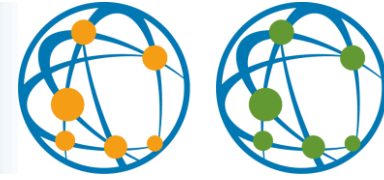


This condition-specific module is open for the following diagnoses:

- Melorheostosis (ORPHA2485),
- Melorheostosis with osteopoikilosis (ORPHA1879),
- Buschke-Ollendorff syndrome (ORPHA1306)
- Isolated osteopoikilosis (ORPHA166119)

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

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

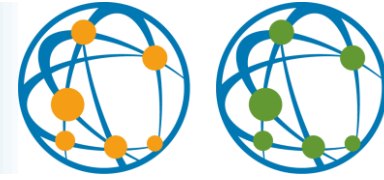
Telephone

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](#)

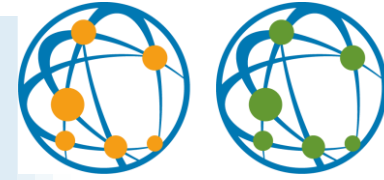
[New Users](#)

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

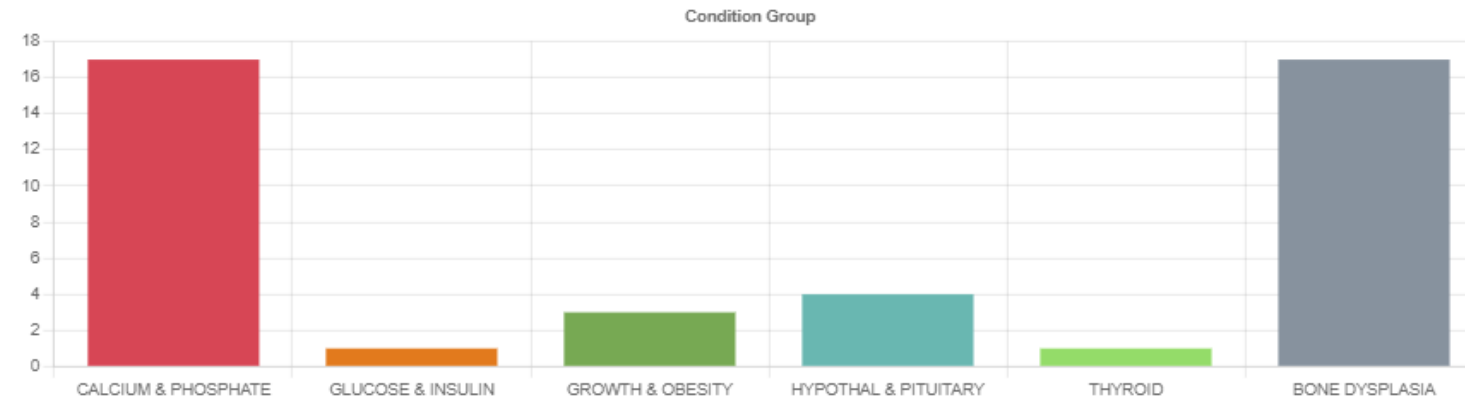
Clinician Dashboard

Patients in Centre: EuRR-Bone-Test

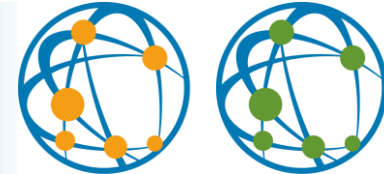
Patients registered by you: 2

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

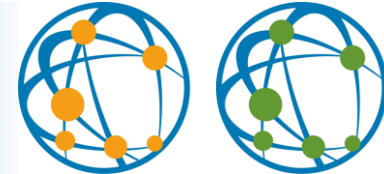
Yes No Not Known

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



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

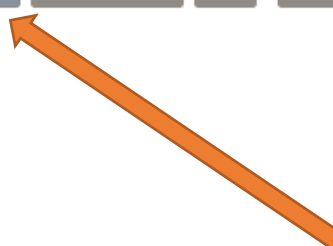
Data can be shared for research purposes

Yes No Not Known

Can be contacted for collecting Patient Reported Outcomes

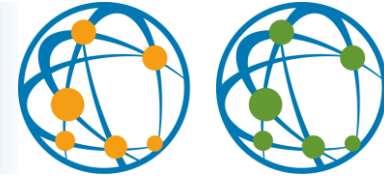
Yes No Not Known

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 - EuRR-Bone-Test

Edit Patient Condition

Core Data

CALCIUM & PHOSPHATE

Patient Access

Generic Outcomes

Diagnosis-specific Outcomes

Audit

Patient List

Patient ID - 551 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

mm/dd/yyyy



Clinician Responsible for Patient

Dr. Ana Priego



Date of Condition Onset

mm/dd/yyyy



Select a Clinician Responsible for the patient

Primary Condition

Primary bone dysplasia with increased bone density

Specific Diagnosis

Melorheostosis with osteopoikilosis

Select the Primary condition - "PBD with increased bone density", for Specific diagnosis – choose from the list

How Was Diagnosis Reached

Clinical Biochemistry Genetic Histology CT MRI PET USS X-Ray
 Other Not Known

Date of Diagnosis

mm/dd/yyyy



Participation in Detailed Disease Registry

Yes No Not Known

Detailed Disease Registry

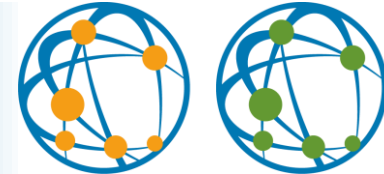
Detailed Disease Registry Patient ID



Save

Cancel

Access the Disease-specific Module



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference

Edit Patient Condition

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

Patient ID - 4270 Date of Birth

- [Redacted]



Edit To Do

Bone Dysplasia

Senior Clinician < 18 - N/A

Senior Clinician ≥ 18 - N/A

e-REC ID

First Contact with Centre

04/12/2022



Clinician Responsible for Patient

Natasha Appelman-Dijkstra



Date of Condition Onset

01/01/2020



Primary Condition

Primary bone dysplasia with increased bone density

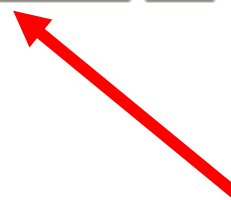


Specific Diagnosis

Melorheostosis

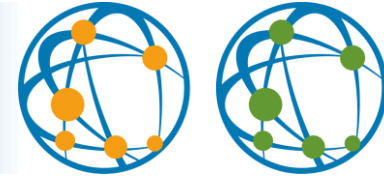


The full hierarchy of Conditions and Specific Diagnoses can be found in the [Core Registry Conditions Dictionary](#)



Click here to fill in the disease-specific module

Fill in a Disease-specific 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 -

Bone Dysplasia

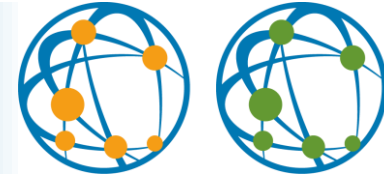
Supplemental material to complete this module

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



Add Diagnosis-specific Outcome

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

Questionnaire: Melorheostosis, Buschke-Ollendorff syndrome, Isolated osteopoikilosis

New Outcome

Date of Birth	[redacted]	e-REC ID		Primary Condition	
Current Gender	Male	Clinician Responsible for Patient	Natasha Appelman-Dijkstra	Primary bone dysplasia with increased bone density	
				Specific Diagnosis	Melorheostosis
				Date of Diagnosis	2022-04-12

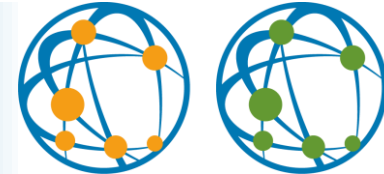
General Clinical features Genetic analysis Fractures Surgery Medication MSK-HQ BPI

Family ID ?

Proband Not Known Yes No

Family history Negative Positive - Maternal Positive - Paternal Positive - Unknown Unknown

Give an access to the platform to your patient



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 -

Bone Dysplasia

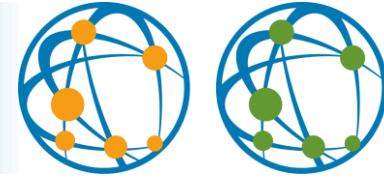
Supplemental material to complete this module

No Outcomes found

New Outcome

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

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	

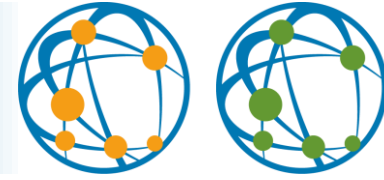
Current Patient EQ-5D Request Settings: EQ-5D-5L every 3 months, starting on 2022-06-30

[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

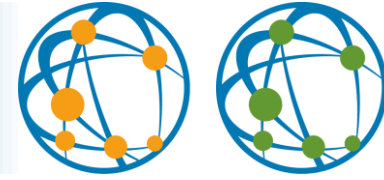
Generic Outcome Questionnaire	Request Frequency (months)	Request Start Date	Actions
WHO-ICF Mobility	9	2022-11-01	Edit Delete

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

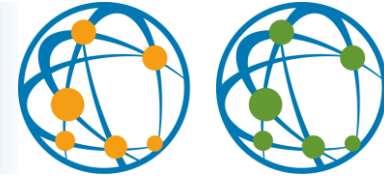
Date of Next Request mm/dd/yyyy

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 in case of any questions.

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

