

How to use CNO module in the Core Registry



EuRREB

European Registries for Rare
Endocrine and Bone conditions

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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 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 as soon as possible.



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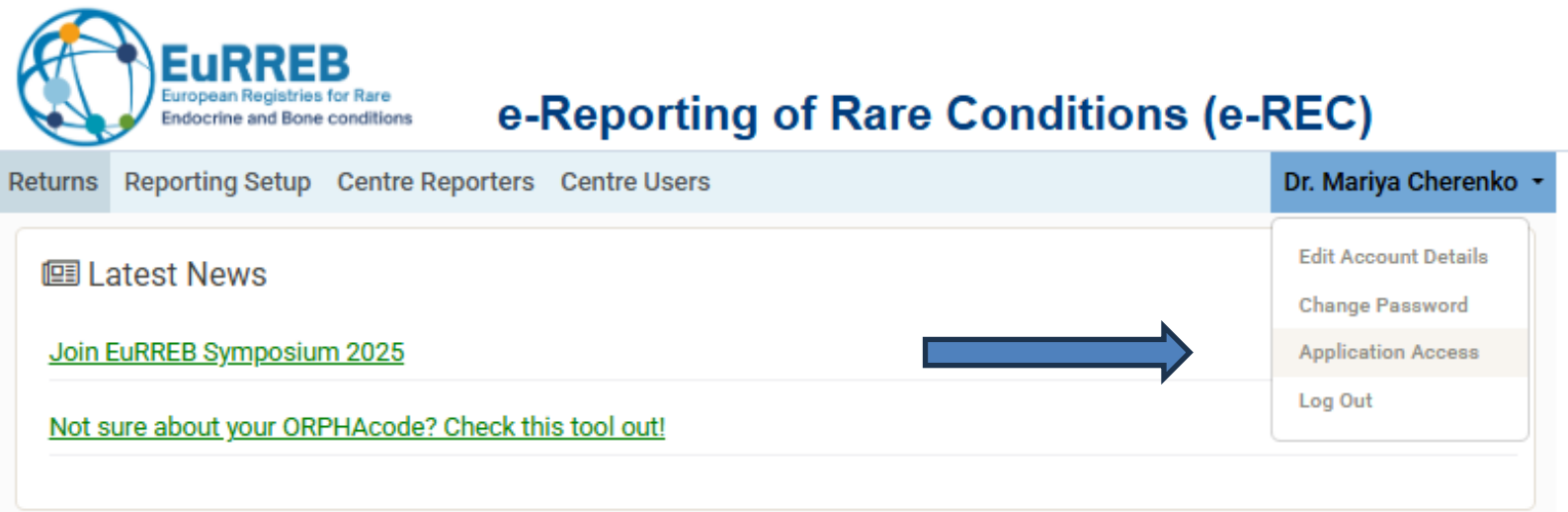


How to change your application role if you already use e-REC

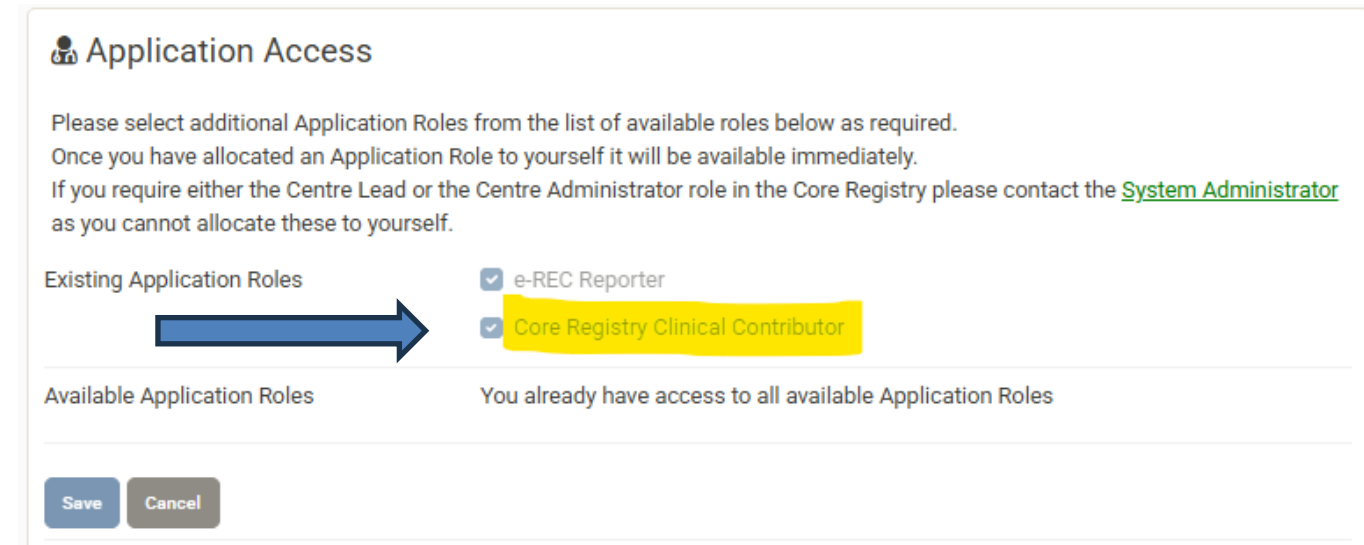
If you are already using e-REC, you can easily allocate the Core Registry Clinical Contributor role to yourself

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 title is "e-Reporting of Rare Conditions (e-REC)". Below the title 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", and "Log Out". A blue arrow points from the "Application Access" menu item to the right.



The screenshot shows the "Application Access" configuration page. It includes a title "Application Access" and 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 "Existing Application Roles" with two items: "e-REC Reporter" (checked) and "Core Registry Clinical Contributor" (checked and highlighted in yellow). A blue arrow points from the "Application Access" menu in the previous screenshot to this section. Below "Existing Application Roles" is a section "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 login into the Core Registry

Go to <https://eurreb.eu/> and use [Login button](#) and go to the Core Registry and choose [Clinician Login page](#)

The screenshot shows the EURREB website homepage. At the top left is the email address registries@lumc.nl. The top right navigation bar includes links for "Our Registries", "FAQ", "Publications", and a language dropdown menu set to "Dutch". Below this is the EURREB logo and a main navigation menu with "About", "News", "Research", "Patients", "Network", and "Contact". A prominent blue "Login" button is located to the right of the navigation menu. The main banner features a photograph of a doctor smiling at a young girl, with the text "European Registries for Rare Endocrine and Bone Conditions". At the bottom, there are three sections: "Drop-in Sessions" with a monitor icon, "Research" with a magnifying glass icon, and "Quick Links" with a list of links: "Ethics approval", "Patient information", and "Participating centres".

The screenshot shows the EURREB login page. It has a "Login" heading and a sub-heading: "Below, are the login pages for our two registries. Use the correct link for access." Below this is a link to "Learn more about e-REC and Core Registry." There are two large blue buttons: "e-REC" and "Core Registry". A blue arrow points from the "Login" button on the homepage to the "Login" heading on this page. Another blue arrow points from the "Core Registry" button to the "Login" section below. The "Login" section contains a "Login" heading with a person icon, a green button labeled "Click here for Patient Login", and a blue button labeled "Click here for Clinician Login". At the bottom, it says "For further information visit www.eurreb.eu".



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



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference Data Emails Reporting Mariya Cherenko - Leiden University Medical Center

Clinician Dashboard

Latest News

[Join EuRREB Symposium 2025](#)

[Not sure about your ORPHAcode? Check this tool out!](#)

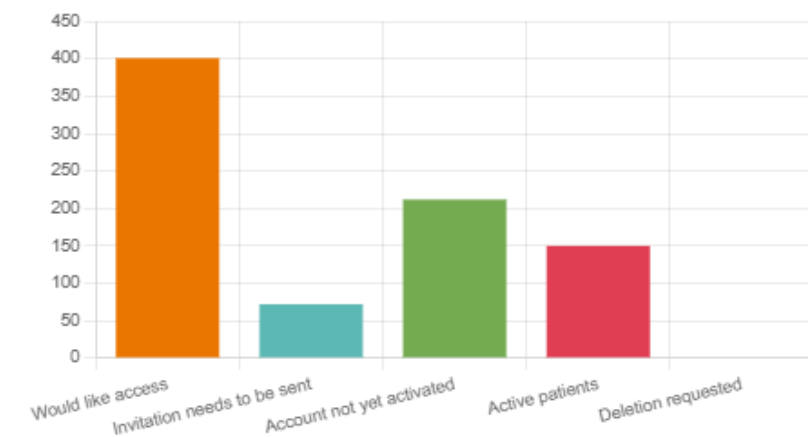
Patients in Centre: Leiden University Medical Center

[Patients registered by you: 19](#)

Patients registered in your centre: 839

[Patients with outstanding actions: 50](#)

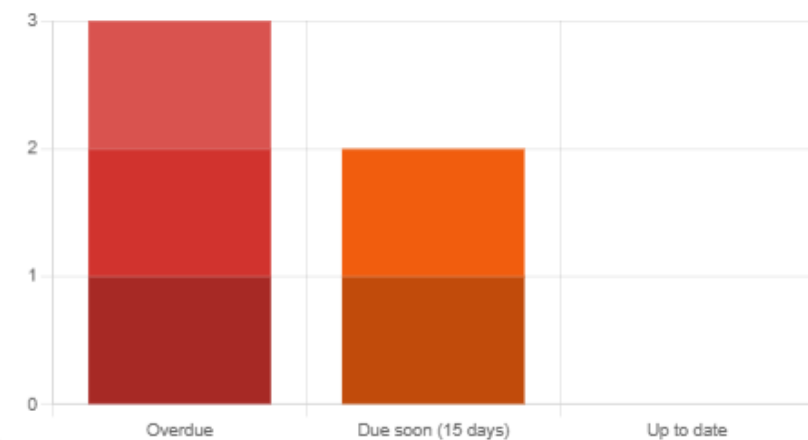
Patient Access



My Diagnosis-specific Outcomes Status



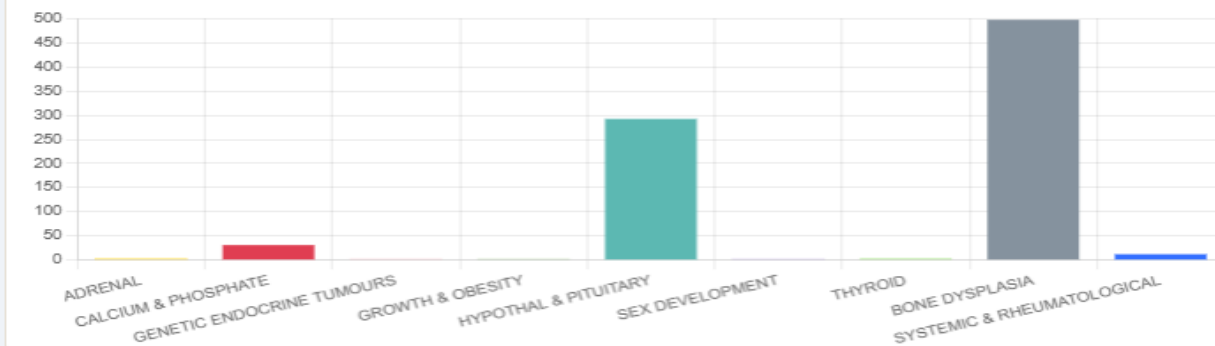
Patient Outcomes Status



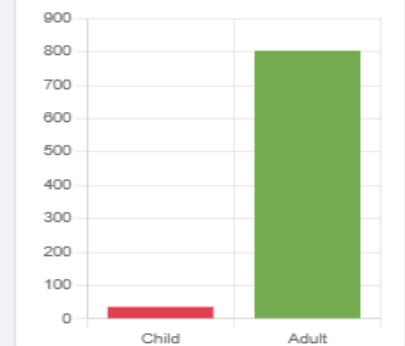
You can explore different features of the dashboard:

- you have access to all patients, registered in your centre,
- you are able to see the latest news
- you can see the distribution of cases by MTG and Age groups,
- you can check patient access status, patient and clinician outcomes status.

Condition Groups

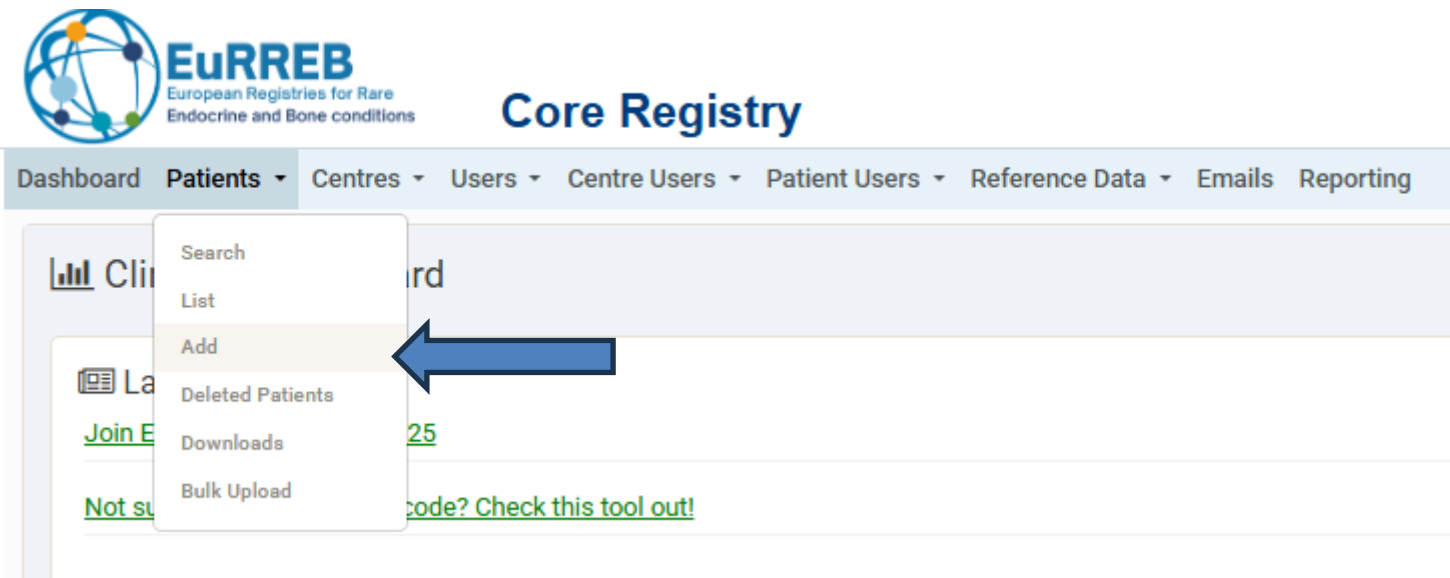


Age Groups



How to add a new patient

Choose "Add" button from the menu tab "Patients".



Fill in all mandatory fields in the Common Data Elements, choose "SYSTEMIC & RHEUMATOLOGICAL" to use CNO module

The 'Add Patient' form contains the following fields and options:

- Is Test Case ?
- Fields marked with * are mandatory
- * Consent for Core Registry: Opt-in ? Opt-out ?
- * Date of Birth ? : yyyy-mm-dd
- * Condition Group (select all that apply):
 - ADRENAL ?
 - CALCIUM & PHOSPHATE ?
 - GLUCOSE & INSULIN ?
 - GENETIC ENDOCRINE TUMOURS ?
 - GROWTH & OBESITY ?
 - HYPOTHAL & PITUITARY ?
 - SEX DEVELOPMENT ?
 - THYROID ?
 - BONE DYSPLASIA ?
 - SYSTEMIC & RHEUMATOLOGICAL ?
- Pseudonymised ID (e.g. SPIDER): [Text input field]
- * Sex at Birth: Male Female Other Unknown
- Current Gender: Male Female Non-binary Other Asked but unknown
- * Country of Birth: [Dropdown menu: NETHERLANDS]
- * Country of Usual Residence: [Dropdown menu: NETHERLANDS]
- * Patient Follow-up Status: Patient active Patient inactive Patient care suspended Patient care terminated Deceased Unknown

Buttons: **Save and continue** (blue), **Cancel** (grey)



Fill in the mandatory fields in the condition group section

Edit To Do Core Data **SYSTEMIC & RHEUMATOLOGICAL** Generic Outcomes **Diagnosis-specific Outcomes** Documents Audit Patient List

Systemic & Rheumatological

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](#).

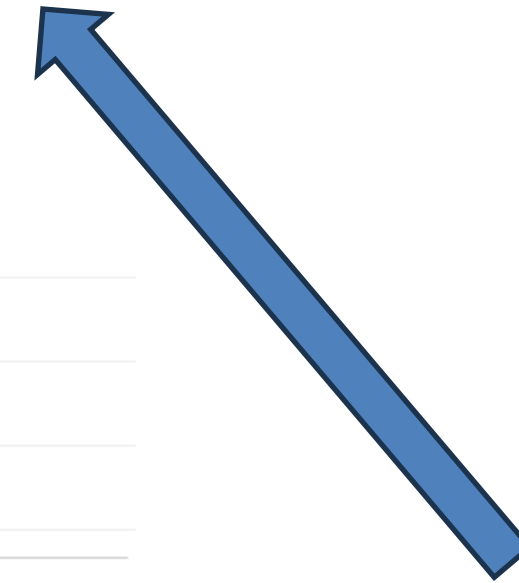
How Was Diagnosis Reached [?] Clinical Biochemistry Genetic Histology CT MRI PET USS
 X-Ray Other Not Known

* Date of Diagnosis [?]

Participation in another Detailed Disease Registry Yes No Not Known

Name of Detailed Disease Registry

Save



After the completion of the mandatory fields and saving, "Diagnosis-specific Outcomes" button will appear in the menu



Access for a patient to the Core Registry

If your patient consented for the access to the Core Registry:

* 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

After ticking the correspondent answer, 'Patient Access' button will appear automatically in the menu

Patient Access

Core Data SYSTEMIC & RHEUMATOLOGICAL Patient Access Generic Outcomes Diagnosis-specific Outcomes Documents Audit Patient List

This is a preview of the data the Patient will see if you approve this access. The Patient will also have the facility to change consents and to request data deletion.

Patient Core	GENETIC ENDOCRINE TUMOURS	Centre
Patient Registry ID	7890	
Consent Type for Registry	Opt-out	
Date added to Registry	2025-07-14	
Date of Birth	1966-02-28	
Pseudonymised ID (e.g. SPIDER)		
Sex at Birth	Female	
Current Gender	Female	
Country of Birth	GERMANY	
Country of Usual Residence	GERMANY	
Patient Follow-up Status	Patient active	

Enter the Patient's Email Address, edit your default Patient Invitation Message if required and click on Grant Access to approve access to this data. The patient will need to enter a Date of Birth that matches the one entered by you in this Registry to successfully activate the account. If you didn't enter the actual date of birth, please provide this information in the invitation below.

* Patient Email

Additional Message to Patient

Patient Preferred Language

You need to know your patient's e-mail address. The system will send the invitation link. You can write an additional message and choose preferred language. On the platform patient can see the information about him and fill in the PROMs.



The CNO Module



EuRREB
European Registries for Rare
Endocrine and Bone conditions

How to fill in the CNO module

If you added the patient with CNO to the Core Registry, “Diagnosis-specific Outcomes” button will appear in the menu, click there to create a new outcome

The screenshot shows the 'Diagnosis-specific Outcomes' interface for Patient ID 7599. The breadcrumb trail is 'Diagnosis-specific Outcomes > Patient ID - 7599 > Date of Birth - [redacted]'. A horizontal menu contains several items: 'Core Data', 'SYSTEMIC & RHEUMATOLOGICAL', 'Generic Outcomes', 'Diagnosis-specific Outcomes', 'Documents', 'Audit', and 'Patient List'. The 'Diagnosis-specific Outcomes' item is highlighted with a dark background. Below the menu, there is a section titled 'Systemic & Rheumatological' which displays 'No Outcomes found'. Underneath, there is a 'New Outcome Language' dropdown menu set to 'English'. A blue button labeled 'New Outcome' is located at the bottom left of this section. Two blue arrows are overlaid on the image: one points from the text box above to the 'Diagnosis-specific Outcomes' menu item, and another points from below to the 'New Outcome' button.



Fill in the data into the module

👉 Note: Some questions are hidden and will only appear based on the answers you choose. Explore all the tabs and the tooltips.

Basic module Follow-up

Clinical picture at diagnosis (in your center)

Assessment Date ?

Does this case meet ASAS criteria? ? Not Known Yes No

Does this case meet CASPAR criteria? ? Not Known Yes No

Was the diagnosis made based on typical clinical picture + radiology? ? No Yes

Was the alternative diagnosis made before? ? No Yes

Focal inflammatory signs at physical examination ? Not Known Yes No

Bone pain at CNO lesion site Not Known Yes No

Onset of complaints after trauma or tonsillitis or infection? Not Known Yes No

Weight ?

Height ?

C-reactive protein ?

Erythrocyte sedimentation rate ?

Bone biopsy performed? Not Known Yes No

Patient history

Positive family history ? No Yes

Smoking status Non smoker Active smoker Ceased smoker Not known

Work participation Full absence from paid/unpaid work due to CNO Partial absence from paid/unpaid work due to CNO No absence from paid/unpaid work due to CNO Not known

Type of work

Is the patient able to fulfil daily routine? No Yes

Educational level ?

Pregnancy



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General instructions for the CNO module

1. At the first data entry - fill in only the basic module tab.
2. At the next follow-up – fill in only the follow-up tab.
3. For the subsequent follow-ups – create a new outcome and fill in only follow-up tab.
Note, the outcome will be already prefilled with a previous data.
4. The ‘Treatment history’ in the follow-up tab refers only to changes since the last data entry.
5. The ‘Current treatment for CNO’ – refers to the treatment as on the day of the last visit.

For your convenience – you can name (create comments) on your list of outcomes



Diagnosis-specific Outcomes ▶ Patient ID - 7599 📅 Date of Birth - 1966-02-16

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

Created Date	Comments	Latest Assessment Date	Completed By	Questionnaire	Current Specific Diagnosis	Actions
2025-10-16	1 st visit		Mariya Cherenko	CNO_beta_version6	Chronic nonbacterial osteomyelitis (CNO)	View Amend Delete
2025-10-16	visit on 20.09.2025		Mariya Cherenko	CNO_beta_version6	Chronic nonbacterial osteomyelitis (CNO)	View Amend Delete

New Outcome Language: English

New Outcome

Export Outcomes to Excel



PROMs



How to fill in PROMs for this module

You can fill in PROMs for your patient or the patient can do it himself after activating his access to the Core Registry platform.
Choose 'Generic Outcomes' to see which PROMs are available.
For this module we are currently collecting EQ-5D and Brief pain inventory (BPI-SF).

Core Data SYSTEMIC & RHEUMATOLOGICAL Patient Access Generic Outcomes Diagnosis-specific Outcomes Documents Audit Patient List

EQ-5D BPI-SF MSK-HQ NPSI OHIP-14 Transition WHO ICF Patient Reported Outcome Request Settings

10 entries per page Search:

Created Date	Completed By	Type	Mobility	Self Care	Activity	Pain	Anxiety	EQ VAS	Actions
No Patient Reported Outcomes found									

Current Patient EQ-5D Request Settings: EQ-5D-5L every 3 months, starting on 2025-07-14

Patient EQ-5D Request Settings Create EQ-5D

EQ-5D Request Settings

These settings control the EQ-5D type which will be provided to the Patient for self-completion and the frequency of email requests to the Patient to self-complete the EQ-5D

EQ-5D Type EQ-5D-5L ? EQ-5D-Y ?

EQ-5D Request Frequency 3 months

Date of Next EQ-5D Request 2025-07-14

Save Cancel

Use this button to decide on the frequency of PROMs. Patient will receive notification via e-mail.





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the European Union



Ways to contact us:



eurreb.eu



registries@lumc.nl



[drop-in sessions via Zoom](#)



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