

# How to use the ped-DTC module in the Core Registry



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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

Choose your centre from the list or add your centre's details if not listed yet. We will approve the centre addition along with your registration.



Fill in the mandatory information.  
Your request will be approved shortly.



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

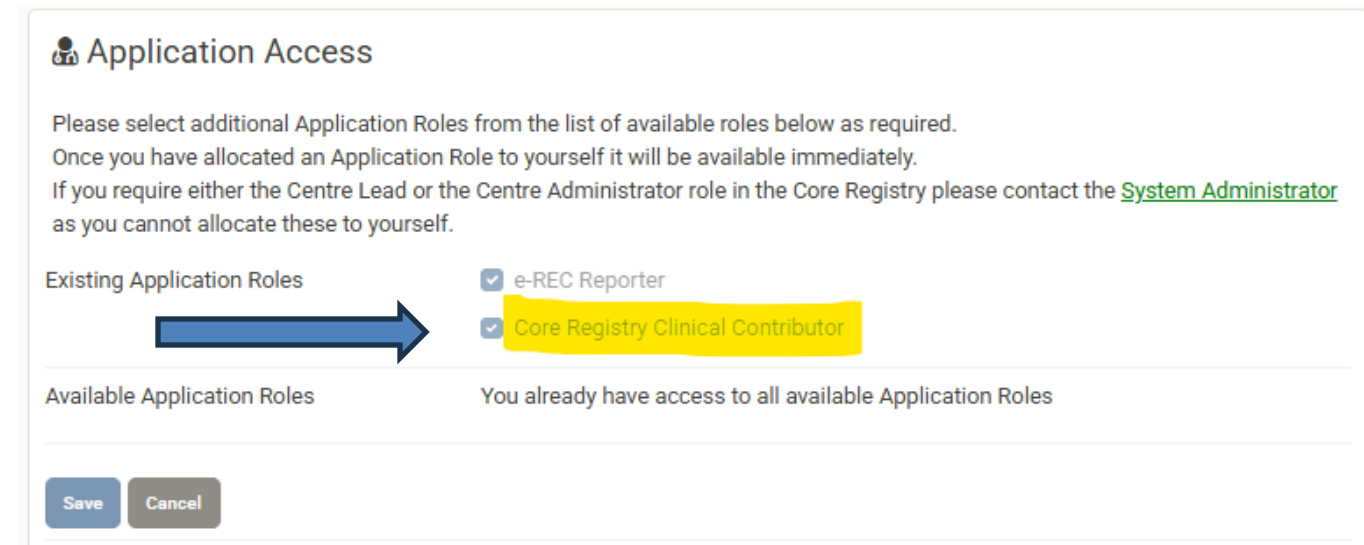
If you are already using e-REC, you can allocate the Core Registry Clinical Contributor role to yourself

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" (highlighted with a blue arrow), and "Log Out". Below the navigation bar is a "Latest News" section with two links: "Join EuRREB Symposium 2025" and "Not sure about your ORPHAcode? Check this tool out!".

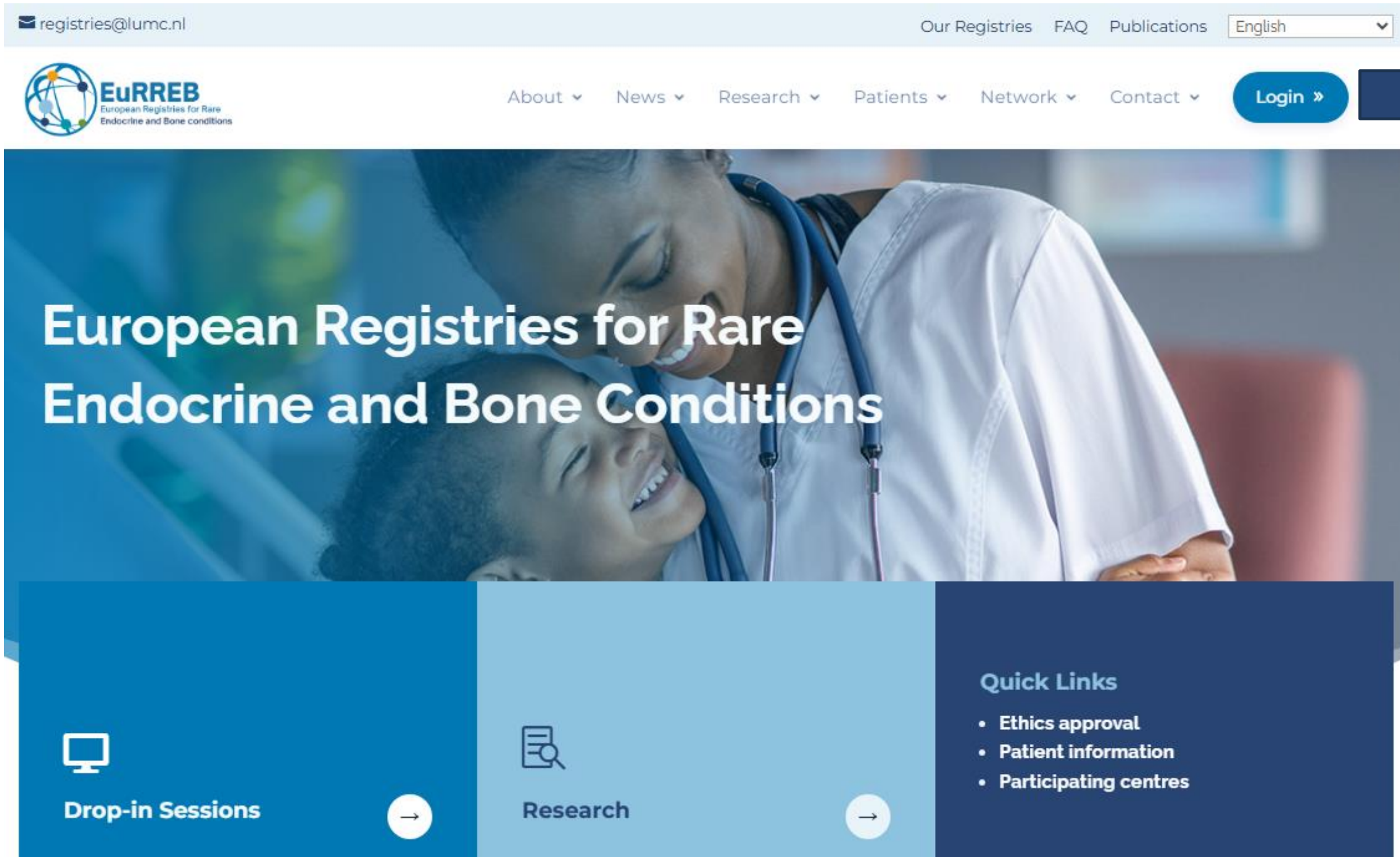


The screenshot shows the "Application Access" configuration page. It includes a heading "Application Access" and a user icon. Below the heading is a message: "Please select additional Application Roles from the list of available roles below as required. Once you have allocated an Application Role to 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." There are two sections: "Existing Application Roles" and "Available Application Roles". Under "Existing Application Roles", there are two checked items: "e-REC Reporter" and "Core Registry Clinical Contributor" (highlighted in yellow). A blue arrow points from the "Application Access" option in the previous screenshot to this page. Under "Available Application Roles", the text says "You already have access to all available Application Roles". At the bottom, there are "Save" and "Cancel" buttons.

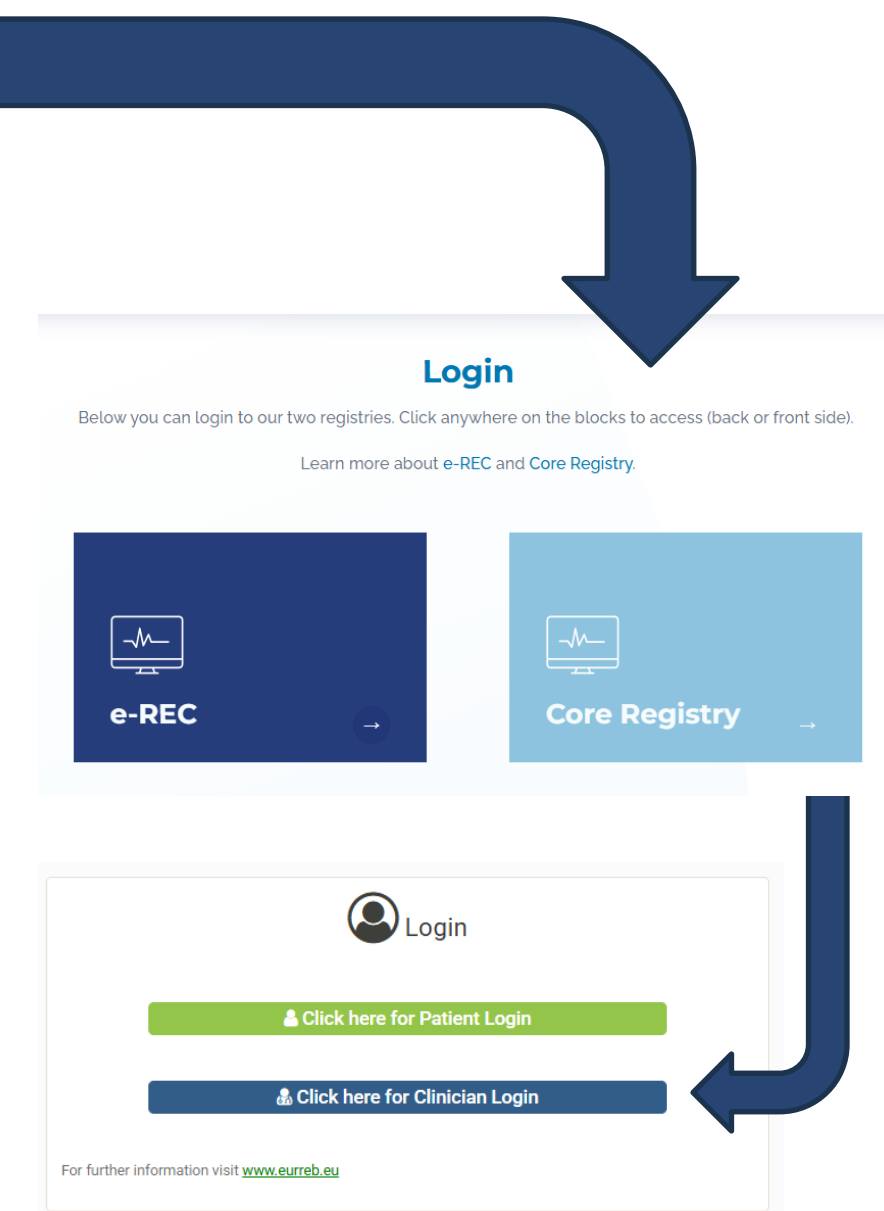


# How to log in into the Core Registry

Go to <https://eurreb.eu/>, click on [Login](#), then on Core Registry and choose [Clinician Login](#)



The screenshot shows the EURREB website homepage. At the top left is the email address [registries@lumc.nl](mailto:registries@lumc.nl). To the right are links for "Our Registries", "FAQ", and "Publications", along with a language dropdown menu set to "English". The EURREB logo is on the left, and a navigation menu with "About", "News", "Research", "Patients", "Network", and "Contact" is in the center. A blue "Login »" button is on the right. The main banner features a photo of a doctor with a stethoscope and a child, with the text "European Registries for Rare Endocrine and Bone Conditions". Below the banner are three sections: "Drop-in Sessions" with a monitor icon, "Research" with a magnifying glass icon, and "Quick Links" with a list: "Ethics approval", "Patient information", and "Participating centres".



The screenshot shows the login page. At the top is the heading "Login". Below it is the text: "Below you can login to our two registries. Click anywhere on the blocks to access (back or front side). Learn more about e-REC and Core Registry." There are two buttons: "e-REC" and "Core Registry". Below these is a "Login" section with a user icon and two buttons: "Click here for Patient Login" (green) and "Click here for Clinician Login" (blue). At the bottom, it says "For further information visit [www.eurreb.eu](http://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

## Clinician Dashboard

### Latest News

[Updates in achondroplasia module](#)

[Join EuREB Symposium 2025](#)

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

### Patients in Centre: EuRR-Bone-Test

[Patients registered by you: 40](#)

Patients registered in your centre: 55

[Patients with outstanding actions: 1](#)

### Patient Outcomes Notifications

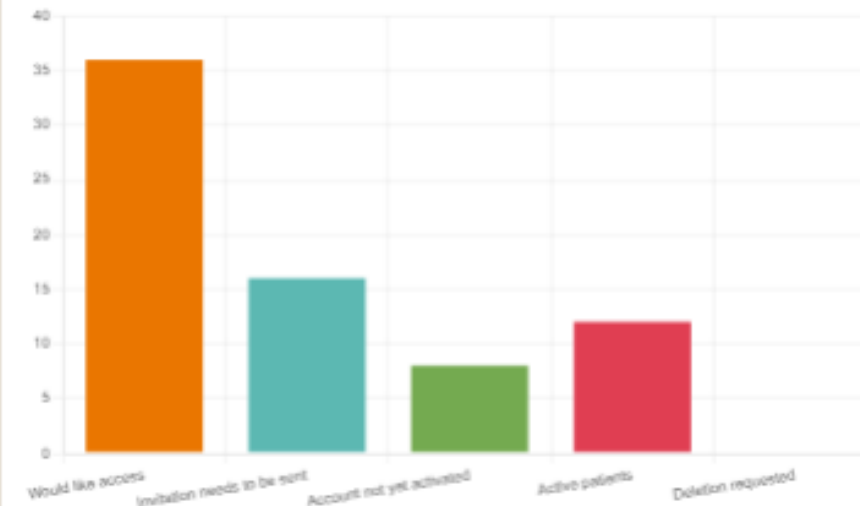
[2025-04-07, Patient ID:450, Create - EQ-5D-5L](#)

[Dismiss](#)

[2024-12-11, Patient ID:450, Create - EQ-5D-5L](#)

[Dismiss](#)

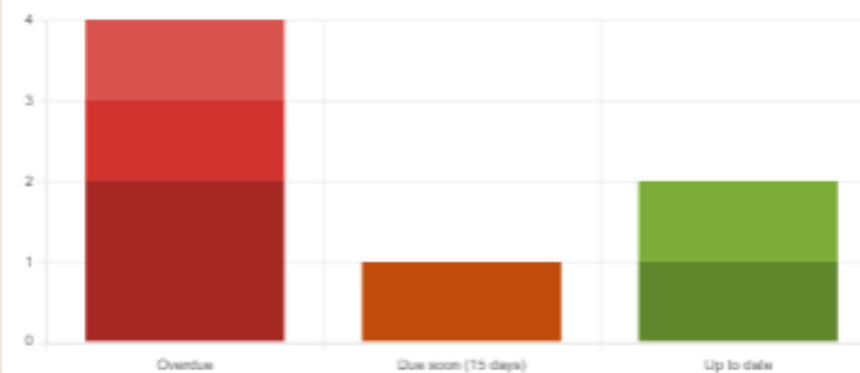
### Patient Access



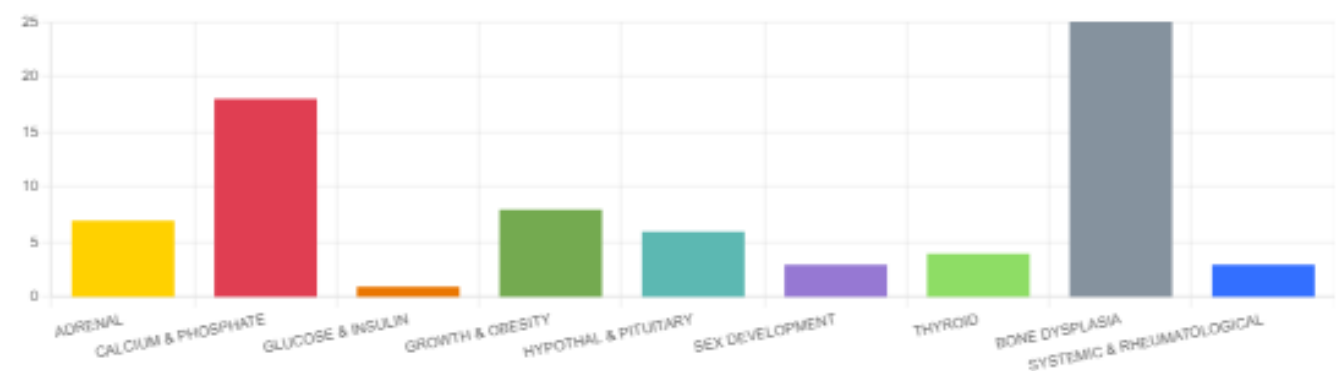
### My Diagnosis-specific Outcomes Status



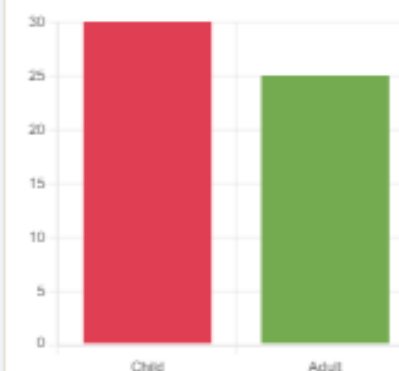
### Patient Outcomes Status



### Condition Groups



### Age Groups



You can explore the different features of the dashboard:

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

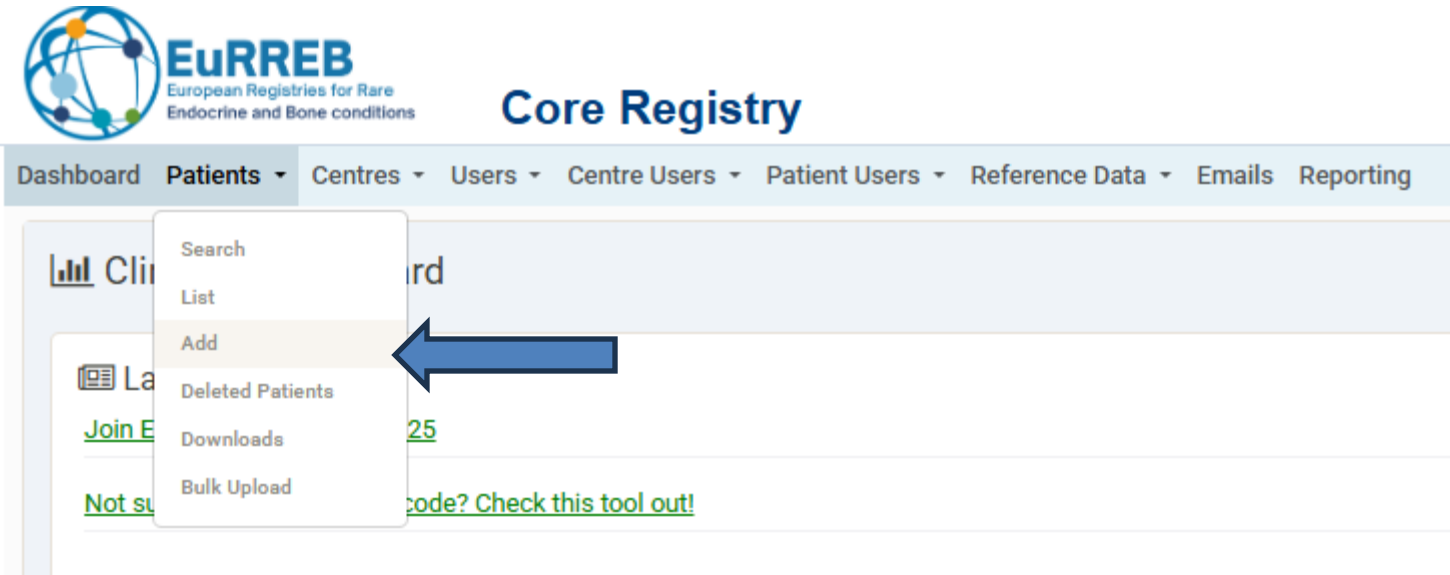


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# How to add a new patient

Click on "Add" from the menu tab "Patients"



Fill in all mandatory fields in the Common Data Elements

Tick this box if you want to test the module



## + Add Patient

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)

\* 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



Save and continue

Cancel

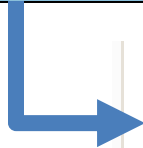


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# Fill in the mandatory fields in the condition group section

You can use this field to add notes



**Edit To Do**

- Core Data
- THYROID**
- Patient Access
- Generic Outcomes
- Diagnosis-specific Outcomes**
- Documents

## Thyroid

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](#)

After completing the mandatory fields and saving the changes, a "Diagnosis-specific Outcomes" button will appear in the menu

**Save**



# Giving patients access to the Core Registry

If your patient consented for 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

The 'Patient Access' button will appear automatically in the menu

**Patient Access**

Core Data **THYROID** **Patient Access** Generic Outcomes Diagnosis-specific Outcomes Comments 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 Registry ID	7842
Consent Type for Registry	Opt-in
Date added to Registry	2025-06-30
Date of Birth	2005-10-12
Pseudonymised ID (e.g. SPIDER)	
Sex at Birth	Male
Current Gender	
Country of Birth	NETHERLANDS
Country of Usual Residence	NETHERLANDS
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

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 a preferred language. On the platform, patients can see the information you have added and fill in PROMs



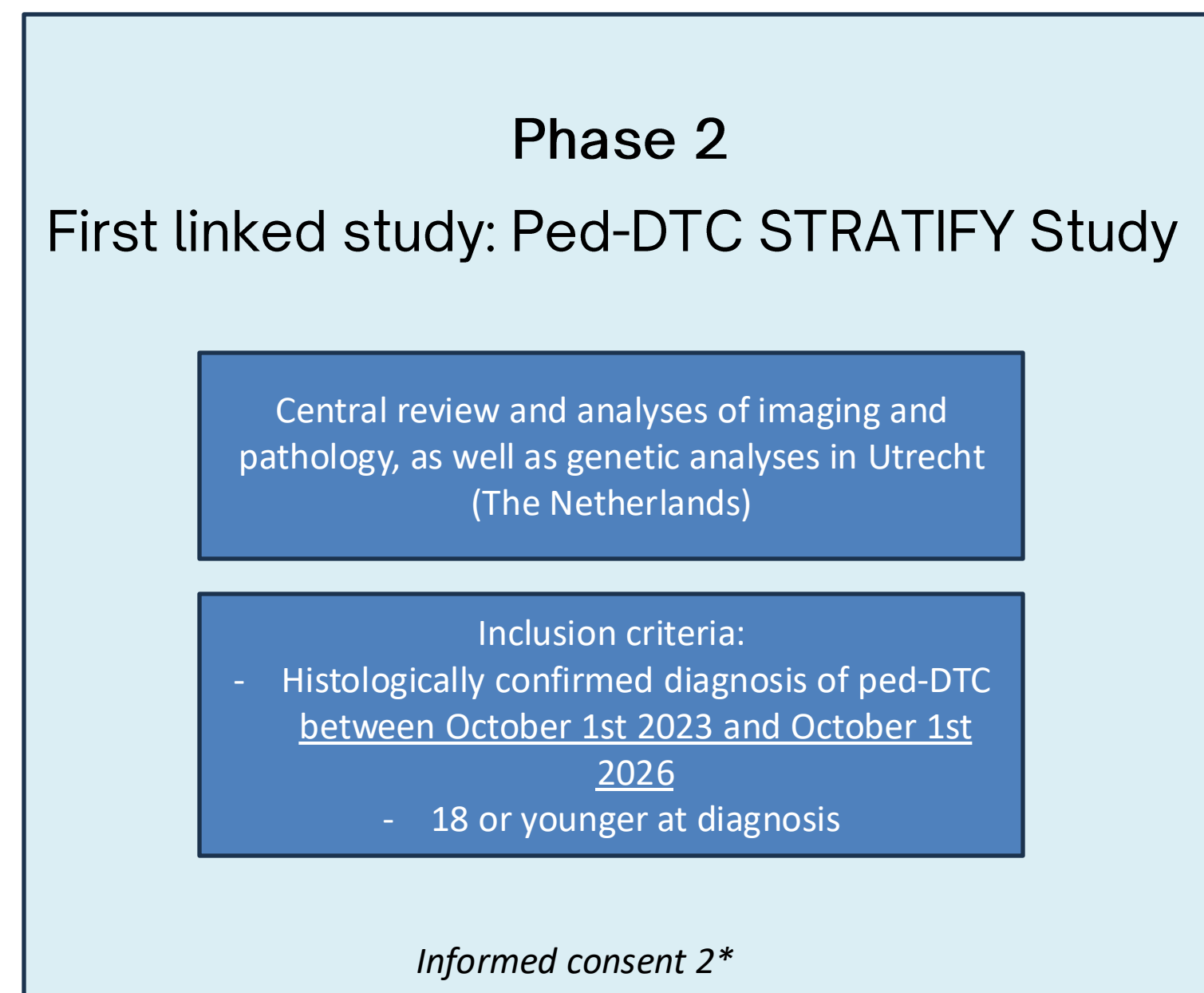
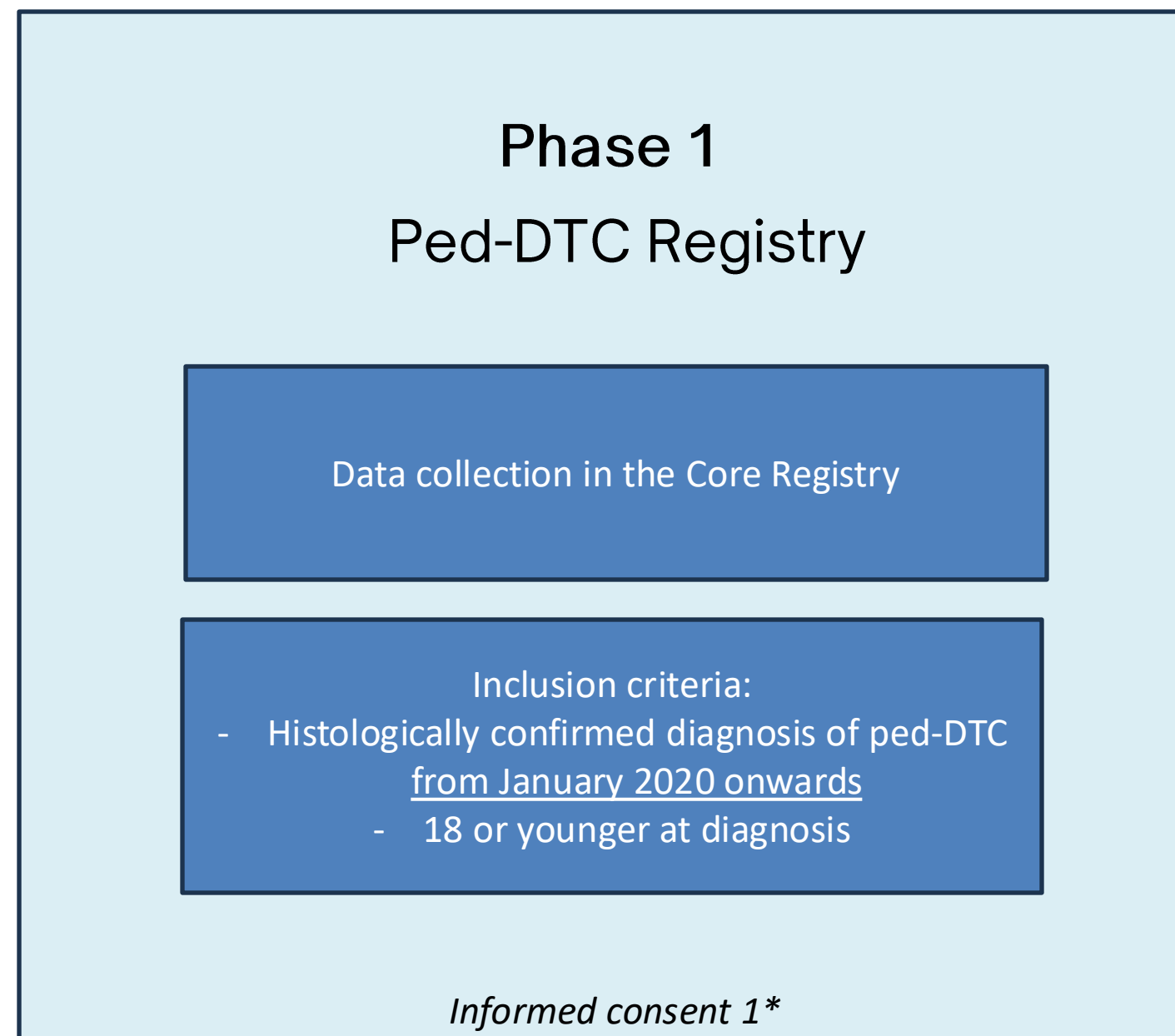
# The Ped-DTC Module



## Ped-DTC STRATIFY Study

### Primary Objective:

To develop a predictive model for risk stratification into high- vs low-risk groups among children ( $\leq 18$  years) diagnosed with pediatric DTC, for recurrent or persistent disease after 2 years of follow-up (n = 200).



# How to get started with the Ped-DTC module

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

The screenshot displays the user interface for the Ped-DTC module. At the top, there is a breadcrumb trail: "Diagnosis-specific Outcomes" followed by "Patient ID - 7842" and "Date of Birth - [redacted]". Below this is a horizontal menu with several items: "Core Data", "THYROID", "Patient Access", "Generic Outcomes", "Diagnosis-specific Outcomes", "Documents", "Audit", and "Patient List". The "Diagnosis-specific Outcomes" item is highlighted with a dark background. A blue arrow points from the text box above to this menu item. Below the menu is a content area with a "Thyroid" tab, the text "No Outcomes found", and a "New Outcome Language" dropdown menu set to "English". A blue arrow points from the text box above to the "Diagnosis-specific Outcomes" menu item, and another blue arrow points from the bottom left to the "New Outcome" button.




# Fill in the data into the module and save

 Note: For this module only one outcome is needed


## Edit Diagnosis-specific Outcome

Patient ID - 7842 Date of Birth -  Condition Group - Thyroid

Questionnaire: Pediatric differentiated thyroid carcinoma - V5  
Created Date: 2025-07-01

Reminders for Responsible Clinician - Dr. Mariya Cherenko 

Name	Reminder Date	Details	Created On	Created By	Actions
No reminders found					





Date of Birth	<input type="text"/>	e-REC ID	<input type="text"/>	Primary Condition	Thyroid carcinoma
Current Gender	<input type="text"/>	Clinician Responsible	Mariya Cherenko for Patient	Specific Diagnosis	Papillary thyroid carcinoma
		Date of Diagnosis	2025-01-06		

Linked studies: Preoperative data T0 | T0 Surgical outcomes | T1 6 months 131I therapy | T1 6 months Outcomes | T2 12 months Outcomes | T3 2 years Outcomes | T5 5 years Outcomes | T10 10 years Outcomes | Transition | Remarks


Is the patient participating in a linked study of the ped-DTC module within EuRREB?

Which linked study is the patient participating in?

Please enter the patient study number in the ped-DTC STRATIFY study here



Once you have saved an outcome, the 'Add reminder' feature will become available. Use it to set up reminders to enter data. The responsible clinician will receive a notification via e-mail


Add Reminder 






\* Name

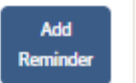
\* Reminder Date  

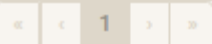
Details

Reminders for Responsible Clinician - Dr. Mariya Cherenko 

Name	Reminder Date	Details	Created On	Created By	Actions
6 months	2026-01-01		2025-07-01	Dr. Mariya Cherenko	 
1 year	2026-07-01 to fill in		2025-07-01	Dr. Mariya Cherenko	 
2 years	2027-07-01		2025-07-01	Dr. Mariya Cherenko	 







# Fill in the data into the module and save

👉 Note: For this module only one outcome is needed. To add data to the different timepoints, amend the existing outcome to add new information

📍 Diagnosis-specific Outcomes ▶ Patient ID - 7842 📅 Date of Birth -

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

Thyroid

10 entries per page Search:

Created Date	Latest Assessment Date	Completed By	Questionnaire	Current Specific Diagnosis	Actions
2025-07-01		Dr. Mariya Cherenko	Pediatric differentiated thyroid carcinoma - V5	Papillary thyroid carcinoma	<a href="#">View</a> <a href="#">Amend</a> <a href="#">Delete</a>

New Outcome Language:

[New Outcome](#)

Click on 'amend' to edit an outcome, e.g. to add new data



[Export Outcomes to Excel](#)





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## Ways to contact us:



[eurreb.eu](http://eurreb.eu)



[registries@lumc.nl](mailto:registries@lumc.nl)



[drop-in sessions via Zoom](#)



European Registries for Rare  
Endocrine and Bone Conditions



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