

# 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)

- Select -

\* Centre

- Select -

Save

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.



# 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.



**e-Reporting of Rare Conditions (e-REC)**

ReturnsReporting SetupCentre ReportersCentre Users

Dr. Mariya Cherenko

Latest News

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

Edit Account Details

Change Password

Application Access

Log Out

Application Access

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.

Existing Application Roles

☒ e-REC Reporter

☒ Core Registry Clinical Contributor

Available Application Roles

You already have access to all available Application Roles

Save

Cancel



# How to log in into the Core Registry

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

 registries@lumc.nl

Our Registries   FAQ   Publications   

English ▾



About ▾   News ▾   Research ▾   Patients ▾   Network ▾   Contact ▾   

Login »

European Registries for Rare Endocrine and Bone Conditions



Drop-in Sessions

→



Research

→

Quick Links

- Ethics approval
- Patient information
- Participating centres

Login

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](#).



e-REC

→



Core Registry

→

 Login

Click here for Patient Login

Click here for Clinician Login

For further information visit [www.eurreb.eu](https://www.eurreb.eu)

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# 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

Choose how you want to receive your authentication code: mobile device or email

 Clinician Login

User Name

Password

Forgotten password? To reset your password please click on the following [Reset Password link](#)

Log in

Back

 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](#)

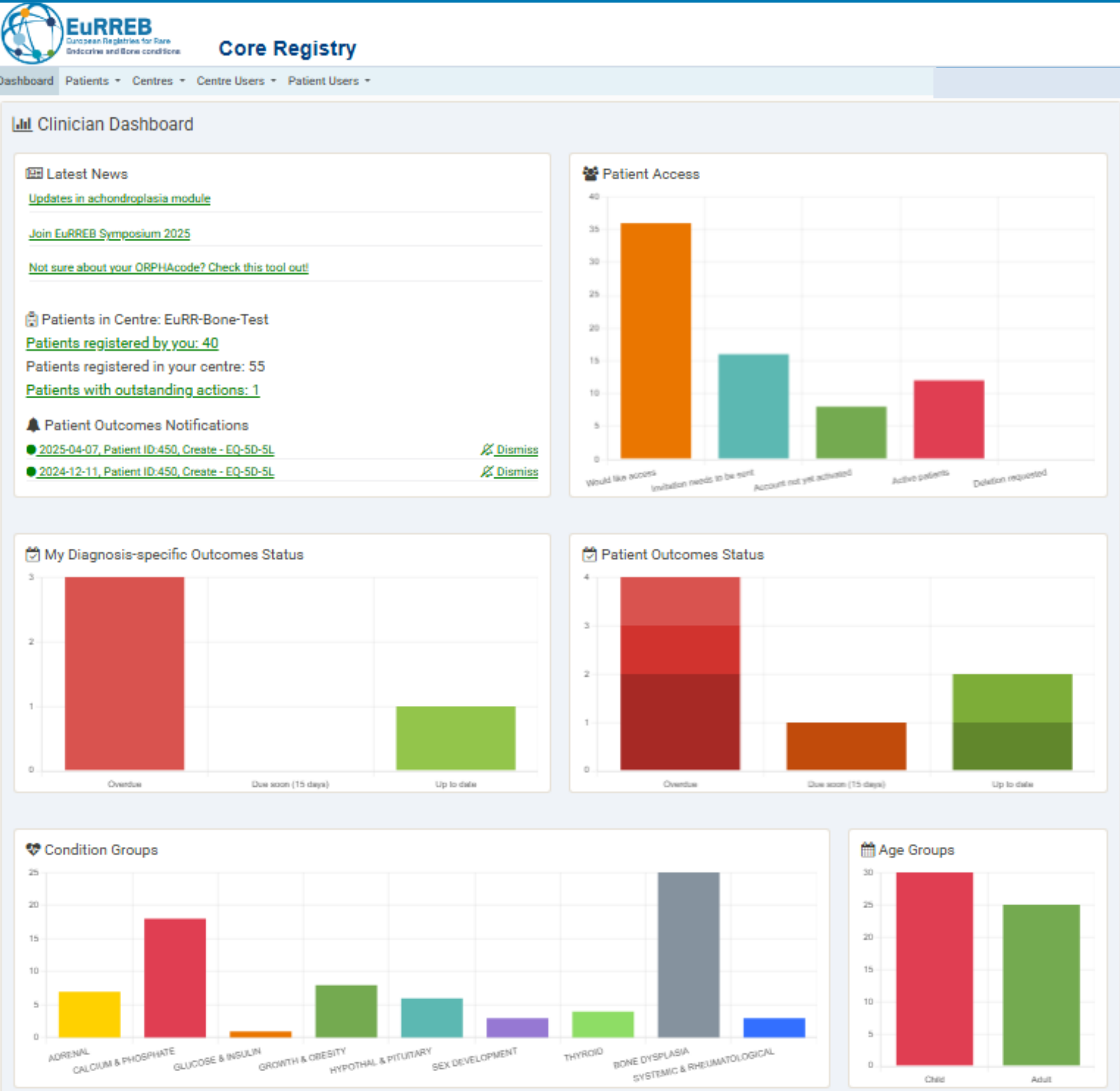




# The Core Registry



# Dashboard



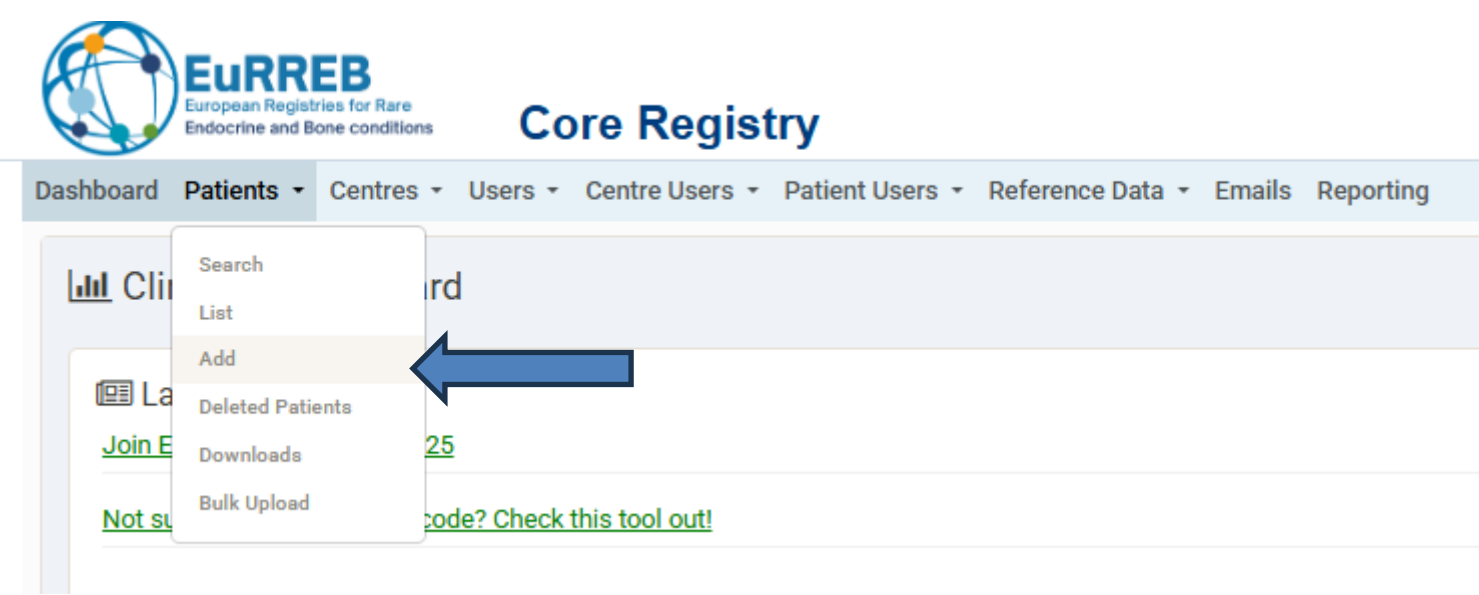
- You can explore the different features of the dashboard:
- you have access to all patients registered in your centre
  - you can see the latest news
  - you can see the distribution of cases by MTG and age groups
  - you can check patient access status and patient and clinician outcomes status





# 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 ?

\* 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

\* Country of Usual Residence

\* Patient Follow-up Status ☐ Patient active ☐ Patient inactive ☐ Patient care suspended ☐ Patient care terminated ☐ Deceased ☐ Unknown



# 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 

2024-02-06



\* Clinician Responsible for Patient 

Dr. Mariya Cherenko



\* Date of First Clinical Manifestations 

2024-01-01



\* Primary Condition

Thyroid carcinoma

\* Specific Diagnosis

Papillary thyroid carcinoma



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

Save

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



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# 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

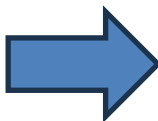
☐ Yes ☐ No ☒ Not Known

\* 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 Core

THYROID

Centre

|                                |                |
|--------------------------------|----------------|
| 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

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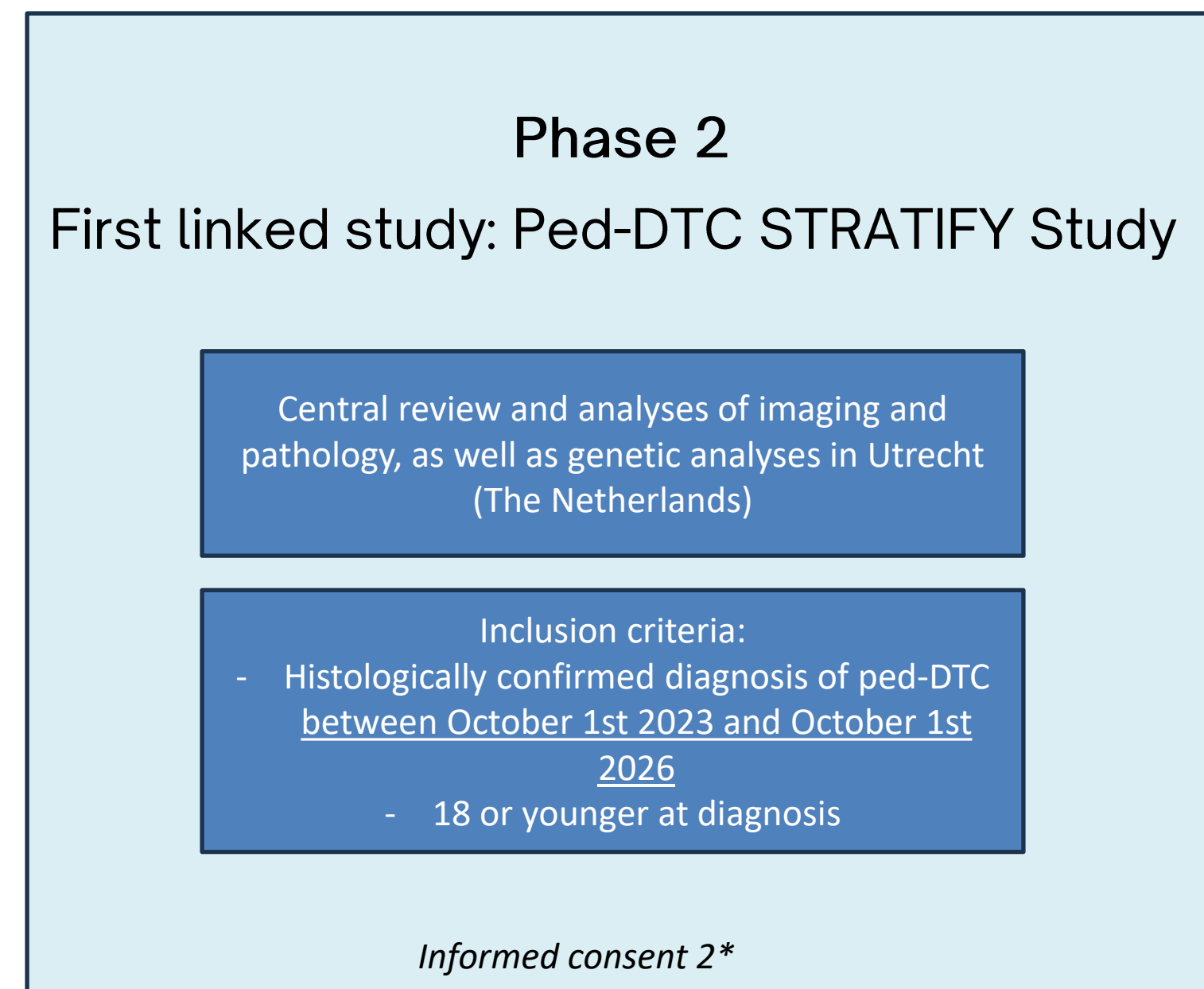
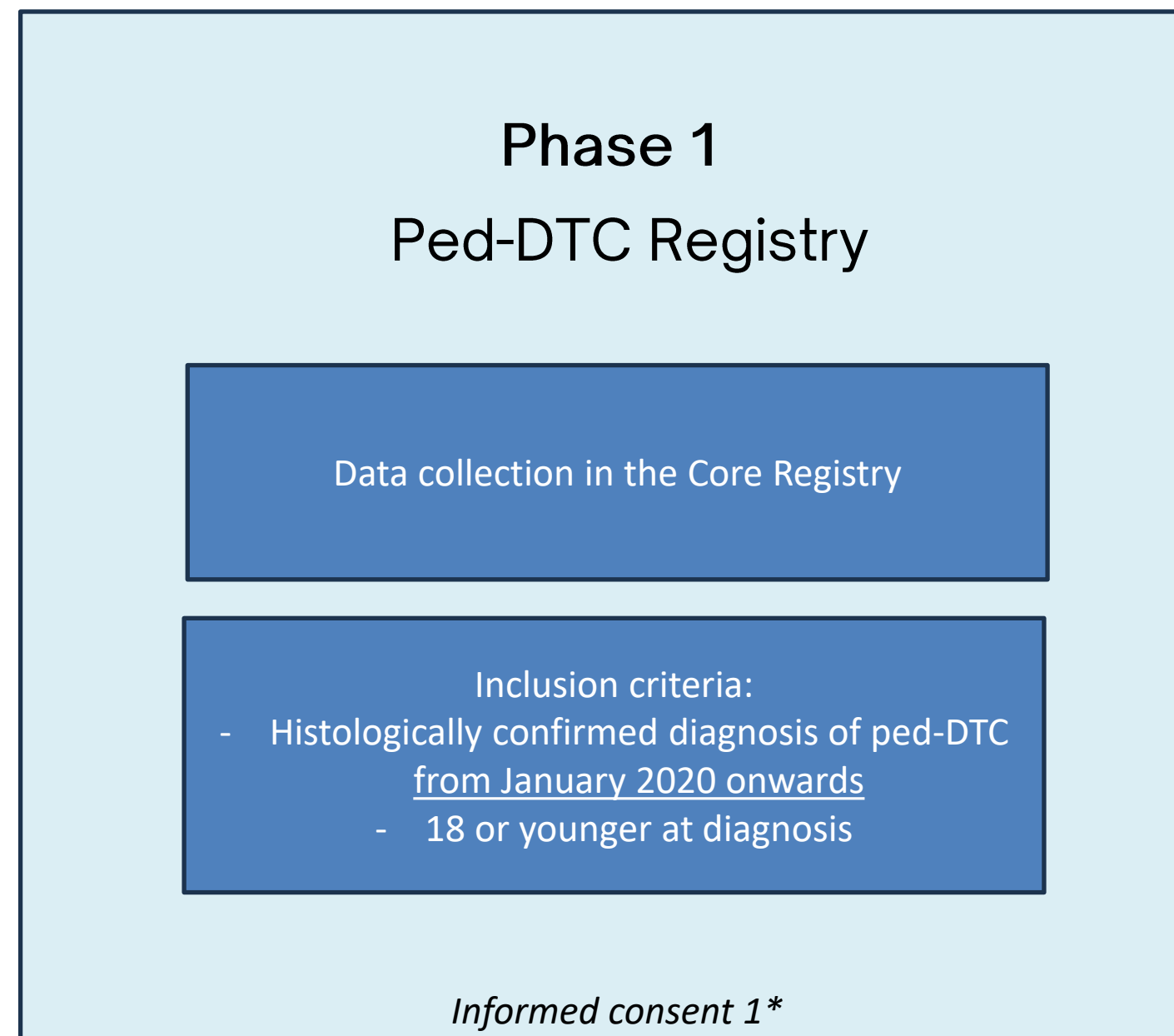
# The Ped-DTC Module



## 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

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

Core Data

THYROID

Patient Access

Generic Outcomes

Diagnosis-specific Outcomes

Documents

Audit

Patient List

Thyroid

No Outcomes found

New Outcome Language 

English

New Outcome





# 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 ?

Add Reminder

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

|                |  |                       |                             |                    |                             |
|----------------|--|-----------------------|-----------------------------|--------------------|-----------------------------|
| Date of Birth  |  | e-REC ID              |                             | Primary Condition  | Thyroid carcinoma           |
| Current Gender |  | 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 EuREB?

Yes

Which linked study is the patient participating in?

ped-DTC STRATIFY

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

Save

Back

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

1 month

2 months

3 months

6 months

1 year

2 years

3 years

4 years

5 years

10 years

\* Name

1 year

\* Reminder Date

2026-07-01

Details

to be filled in

Cancel

Save

🔔Reminders for Responsible Clinician - Dr. Mariya Cherenko ?

Add Reminder

| Name     | Reminder Date         | Details | Created On | Created By          | Actions                           |
|----------|-----------------------|---------|------------|---------------------|-----------------------------------|
| 6 months | 2026-01-01            |         | 2025-07-01 | Dr. Mariya Cherenko | <div>Edit</div> <div>Delete</div> |
| 1 year   | 2026-07-01 to fill in |         | 2025-07-01 | Dr. Mariya Cherenko | <div>Edit</div> <div>Delete</div> |
| 2 years  | 2027-07-01            |         | 2025-07-01 | Dr. Mariya Cherenko | <div>Edit</div> <div>Delete</div> |

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# 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 | <div>View</div> <div>Amend</div> <div>Delete</div> |

New Outcome Language

English

New Outcome

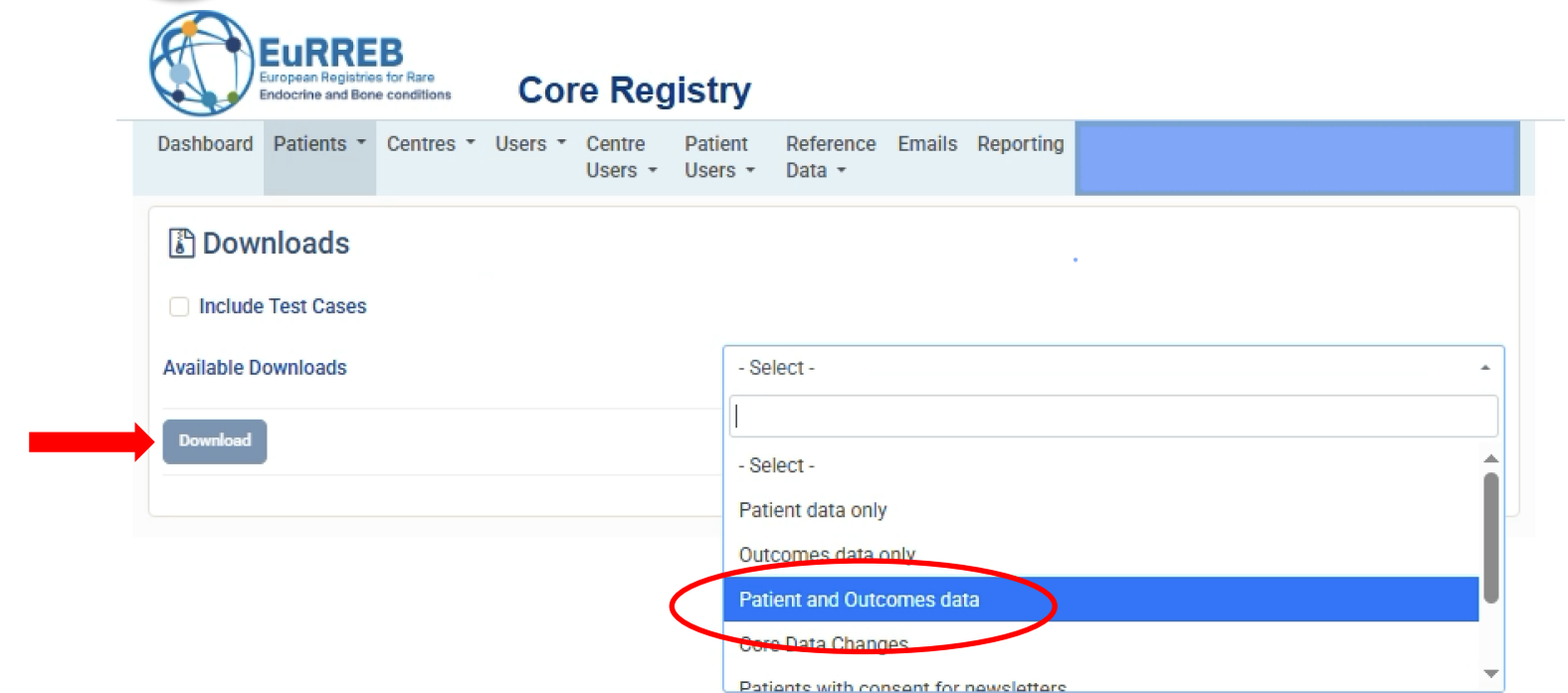
Export Outcomes to Excel

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



**Note:** Centre Leads can download data for the entire centre, while Contributors can only download data for their own patients.

2



3

|    | A                                              | B                                  | C                    | D              | E                    | F              | G               | H                                                                         | I            | J                   |
|----|------------------------------------------------|------------------------------------|----------------------|----------------|----------------------|----------------|-----------------|---------------------------------------------------------------------------|--------------|---------------------|
| 1  | <b>Core Registry Patient and Outcomes Data</b> |                                    |                      |                |                      |                |                 |                                                                           |              |                     |
| 2  | Generated at 00:12 on 09 Mar 2026              |                                    |                      |                |                      |                |                 |                                                                           |              |                     |
| 3  |                                                |                                    |                      |                |                      |                |                 |                                                                           |              |                     |
| 4  | <b>Patient ID</b>                              | <b>Patient Record Created Date</b> | <b>Date of Birth</b> | <b>Country</b> | <b>Centre Number</b> | <b>Centre</b>  | <b>Uploader</b> | <b>Consent for Core Registry</b>                                          | <b>EUPID</b> | <b>Sex at Birth</b> |
| 5  | ✓                                              | 2021-01-13                         |                      | NETHERLANDS    | EuRR-Bone-Test       | EuRR-Bone-Test | Dr. Ana Priego  | Opt-in consent – informed consent is obtained in writing from the patient |              | Female              |
| 6  | ✓                                              | 2021-01-13                         |                      | NETHERLANDS    | EuRR-Bone-Test       | EuRR-Bone-Test | Dr. Ana Priego  | Opt-in consent – informed consent is obtained in writing from the patient |              | Female              |
| 7  | ✓                                              | 2021-01-13                         |                      | NETHERLANDS    | EuRR-Bone-Test       | EuRR-Bone-Test | Dr. Ana Priego  | Opt-in consent – informed consent is obtained in writing from the patient |              | Female              |
| 8  | ✓                                              | 2021-01-13                         |                      | NETHERLANDS    | EuRR-Bone-Test       | EuRR-Bone-Test | Dr. Ana Priego  | Opt-in consent – informed consent is obtained in writing from the patient |              | Female              |
| 9  | ✓                                              | 2021-01-19                         |                      | NETHERLANDS    | EuRR-Bone-Test       | EuRR-Bone-Test | Dr. Ana Priego  | Opt-in consent – informed consent is obtained in writing from the patient |              | Male                |
| 10 | ✓                                              | 2021-01-19                         |                      | NETHERLANDS    | EuRR-Bone-Test       | EuRR-Bone-Test | Dr. Ana Priego  | Opt-in consent – informed consent is obtained in writing from the patient |              | Male                |
| 11 | ✓                                              | 2021-01-19                         |                      | NETHERLANDS    | EuRR-Bone-Test       | EuRR-Bone-Test | Dr. Ana Priego  | Opt-in consent – informed consent is obtained in writing from the patient |              | Male                |
| 12 | ✓                                              | 2021-01-20                         |                      | NETHERLANDS    | EuRR-Bone-Test       | EuRR-Bone-Test | Dr. Ana Priego  | Opt-in consent – informed consent is obtained in writing from the patient |              | Female              |
| 13 | ✓                                              | 2021-01-20                         |                      | NETHERLANDS    | EuRR-Bone-Test       | EuRR-Bone-Test | Dr. Ana Priego  | Opt-in consent – informed consent is obtained in writing from the patient |              | Female              |
| 14 | ✓                                              | 2021-01-20                         |                      | NETHERLANDS    | EuRR-Bone-Test       | EuRR-Bone-Test | Dr. Ana Priego  | Opt-in consent – informed consent is obtained in writing from the patient |              | Male                |
| 15 | ✓                                              | 2021-01-20                         |                      | NETHERLANDS    | EuRR-Bone-Test       | EuRR-Bone-Test | Dr. Ana Priego  | Opt-in consent – informed consent is obtained in writing from the patient |              | Male                |

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Patient Core and Condition data

EQ-5D-5L

EQ-5D-Y

Condition Specific Outcomes 1

Condition

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+

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the European Union



## Ways to contact us:



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



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



[drop-in sessions via Zoom](#)



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Endocrine and Bone Conditions



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