

How to use the Pituitary tumour module in the Core Registry



Table of contents

1	How to create an account in the Core Registry?
2	How to login if you have an account?
3	How to add a new patient in the Core Registry?
4	How to give patients access to the Core Registry?
5	How to use the Pituitary tumour module?
6	How to fill in PROMs?
7	How to contact us?



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 the 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 shortly.

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.



Back to the index



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

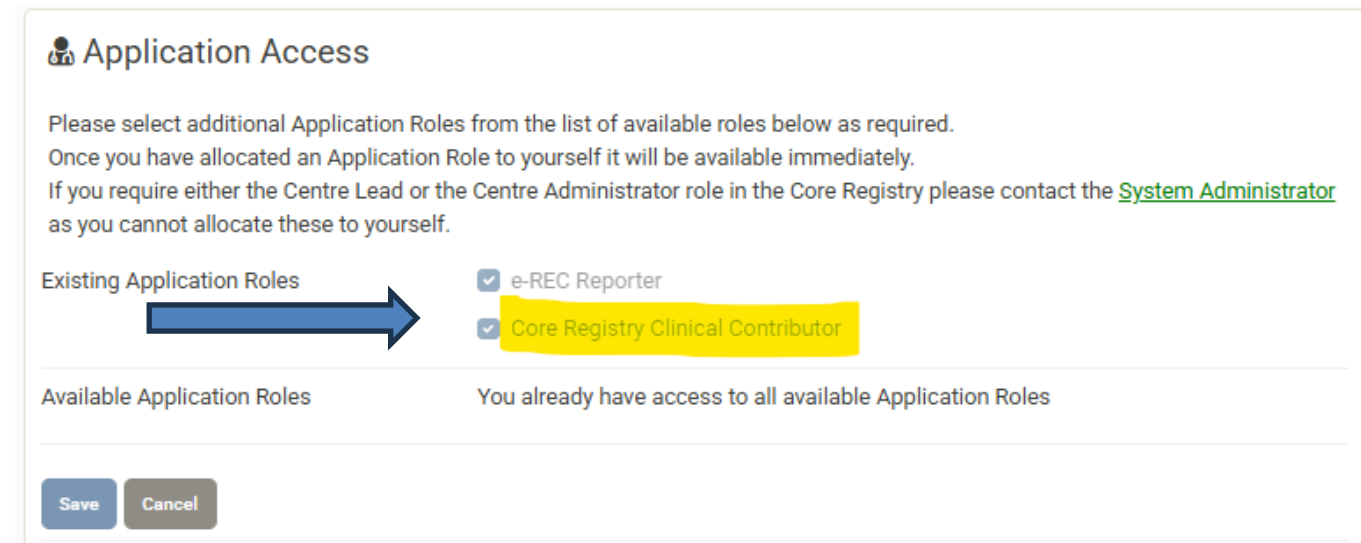
If you are already using e-REC, you can allocate the Core Registry Clinical Contributor role to yourself

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 header is "e-Reporting of Rare Conditions (e-REC)". Below the header 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!".

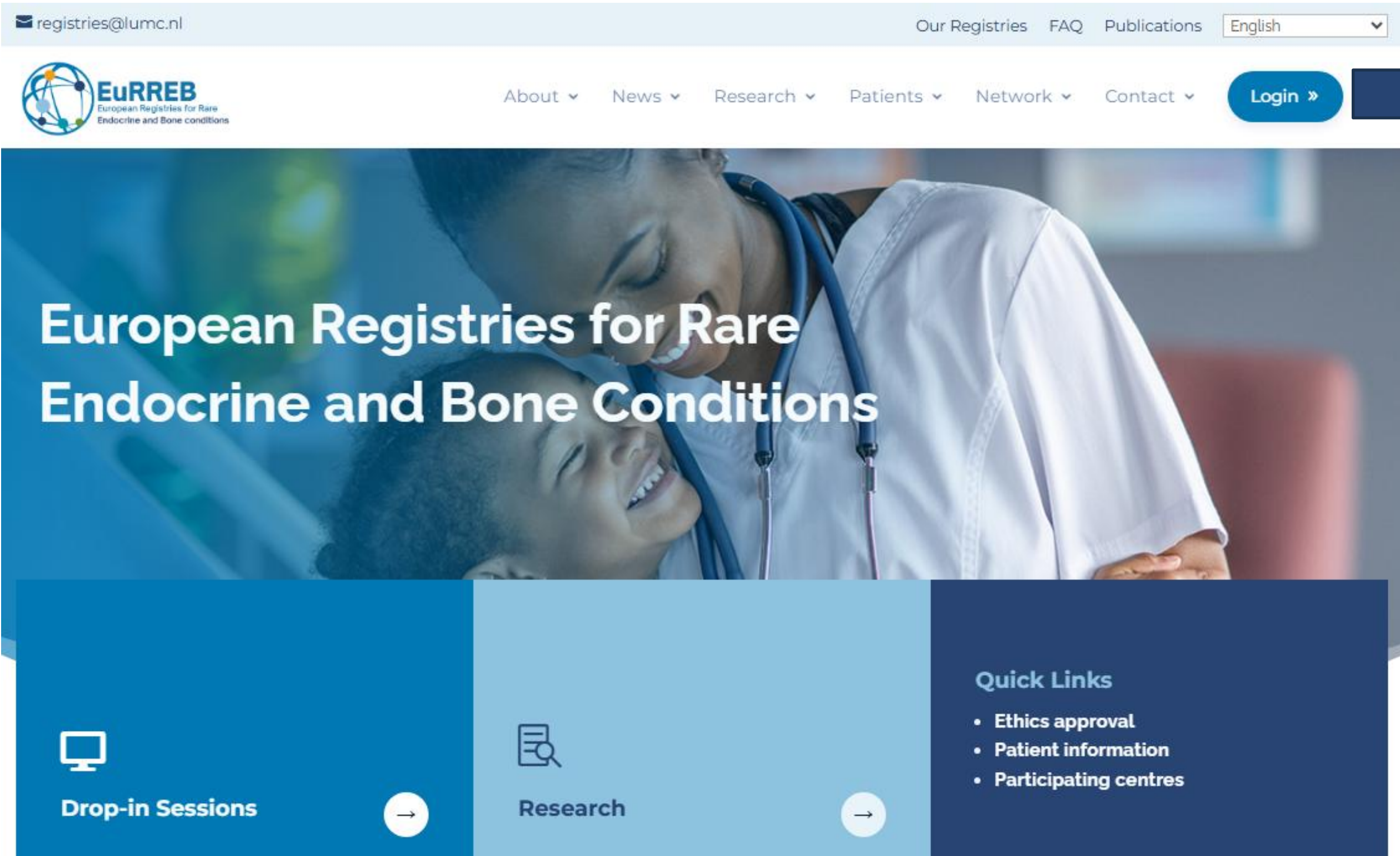


The screenshot shows the "Application Access" configuration page. The title is "Application Access" with a user icon. Below the title is a message: "Please select additional Application Roles from the list of available roles below as required. Once you have allocated an Application Role to yourself it 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." Below this is a section for "Existing Application Roles" with a blue arrow pointing to a list of roles: "e-REC Reporter" and "Core Registry Clinical Contributor" (highlighted in yellow). Below that is a section for "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 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. 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. Below the navigation is a large banner image of a doctor with a stethoscope around a child's neck. The text "European Registries for Rare Endocrine and Bone Conditions" is overlaid on the banner. At the bottom, there are three columns: "Drop-in Sessions" with a monitor icon, "Research" with a magnifying glass icon, and "Quick Links" with a list of "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)." and a link "Learn more about e-REC and Core Registry.". There are two main buttons: "e-REC" and "Core Registry", both with a monitor icon and a right-pointing arrow. Below these is a "Login" section with a user icon and the word "Login". There are two buttons: a green one labeled "Click here for Patient Login" and a blue one labeled "Click here for Clinician Login". At the bottom, there is a link "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



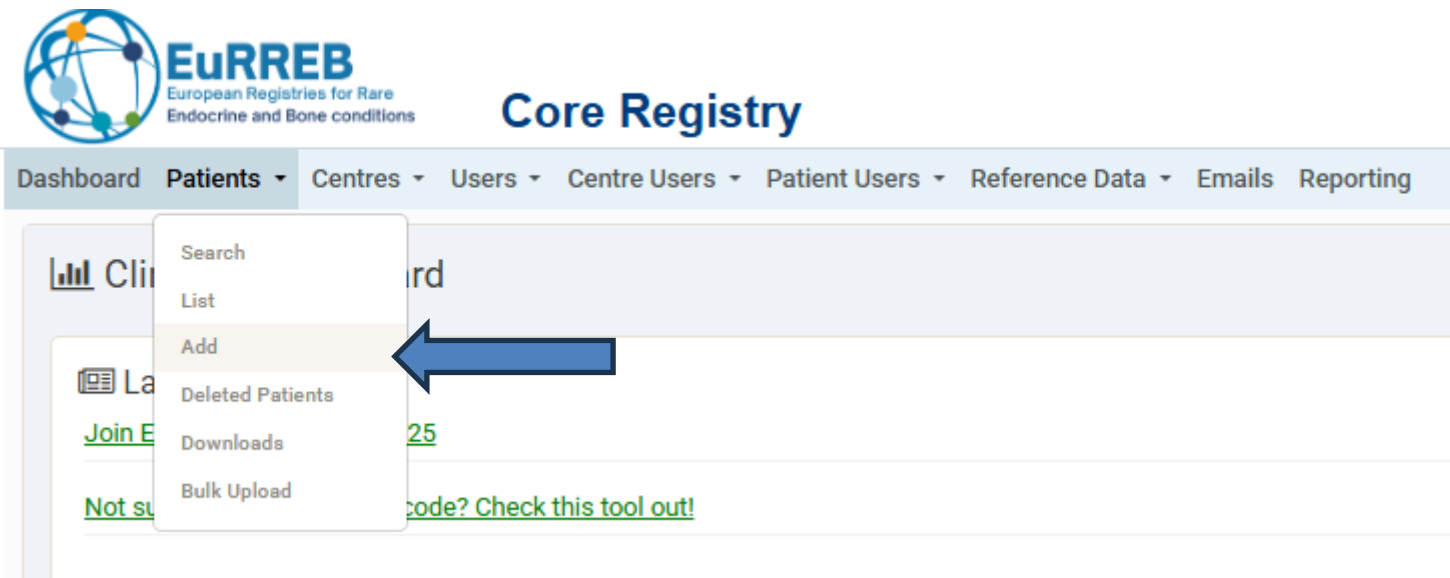
You can explore the different features of the dashboard:

- 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 the Common Data Elements, and select "Hypothal & Pituitary"

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

- Is Test Case [?](#) (Annotation: Tick this box only if you want to test the module)
- Fields marked with * are mandatory
- * Consent for Core Registry: Opt-in [?](#) Opt-out [?](#)
- * Date of Birth [?](#): Input field with placeholder 'yyyy-mm-dd' and a calendar icon.
- * 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): Input field.
- * Sex at Birth: Male Female Other Unknown
- Current Gender: Male Female Non-binary Other Asked but unknown
- * Country of Birth: Dropdown menu with 'NETHERLANDS' selected.
- * Country of Usual Residence: Dropdown menu with 'NETHERLANDS' selected.
- * Patient Follow-up Status: Patient active Patient inactive Patient care suspended Patient care terminated Deceased Unknown

At the bottom, there are two buttons: 'Save and continue' and 'Cancel'. A blue arrow points to the 'Save and continue' button.



Go to the patient condition section

Dashboard Patients Centres Users Centre Users Patient Users Reference Data Emails Reporting

[Edit Patient Condition](#) ▶ Patient ID - 467 [Date of Birth](#) - [REDACTED]

Edit To Do

Core Data **HYPOTHAL & PITUITARY** Generic Outcomes Diagnosis-specific Outcomes

Pituitary

Senior Clinician < 18 - N/A
Senior Clinician ≥ 18 - N/A

e-REC ID ?

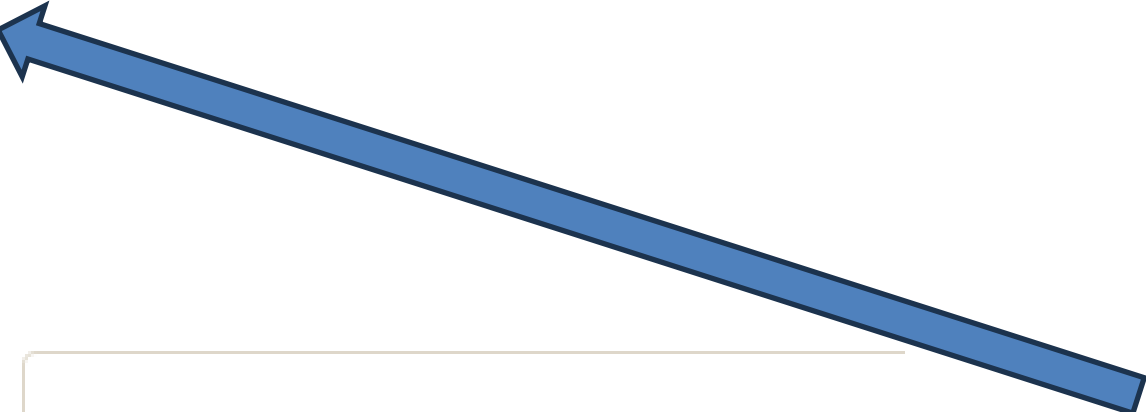
* First Contact with Centre ? 2017-07-25

* Clinician Responsible for Patient ? Prof Nienke Biermasz

* Date of First Clinical Manifestations ? 2017-01-01

* Primary Condition Pituitary Adenoma

* Specific Diagnosis Non-functioning pituitary adenoma



A navigation menu will appear, click on **'Hypothal & Pituitary'**



Edit the patient condition section

Edit Patient Condition

Core Data Generic Outcomes Documents Audit Patient List

Patient ID [] Date of Birth [] Edit To Do

Pituitary

Senior Clinician < 18 - N/A
Senior Clinician ≥ 18 - N/A

e-REC ID []
First Contact with Centre [dd-mm-iiii]
Clinician Responsible for Patient [Dr. Ana Priego]
Date of First Clinical Manifestations [dd-mm-iiii]

Primary Condition [Pituitary Adenoma]
Specific Diagnosis [- Select -]
The full hierarchy of Conditions and Specific Diagnoses can be found in the Core Re
How Was Diagnosis Reached []
Date of Diagnosis []
Participation in Detailed Disease Registry []
Detailed Disease Registry []
Detailed Disease Registry Patient ID []
Biobank Sample Available for Research []
Biobank Details []
Biobank Patient ID []

- Select -
- Select -
- Pituitary adenoma
- Cushing disease
- Familial isolated pituitary adenoma
- Functioning gonadotropic adenoma
- Functioning pituitary adenoma
- Mixed functioning pituitary adenoma
- Non-functioning pituitary adenoma
- Null pituitary adenoma
- Prolactinoma
- Silent pituitary adenoma
- Somatomammotropinoma
- TSH-secreting pituitary adenoma
- Acromegaly
- Pituitary gigantism
- X-linked acrogigantism
- Pituitary carcinoma

Fill in all mandatory fields

Select "Pituitary Adenoma" as Primary Condition, and for Specific Diagnosis - choose from the list

Save



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

Core Data **+ HYPOTHAL & PITUITARY** **Patient Access** Generic Outcomes Diagnosis-specific Outcomes Documents

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	
SYSTEMIC & RHEUMATOLOGICAL Centre	
Patient Registry ID	7474
Consent Type for Registry	Opt-in
Date added to Registry	2025-03-26
Date of Birth	1969-09-24
Pseudonymised ID (e.g. SPIDER)	
Sex at Birth	Female
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

Additional Message to Patient

Patient Preferred Language

Grant Access

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 Pituitary Tumour Module



EuRREB

European Registries for Rare
Endocrine and Bone conditions

How to fill in the module

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

Diagnosis-specific Outcomes ▶ Patient ID 5106 📅 Date of Birth -

* - Condition sections marked with * contain mandatory fields that require your attention!

Core Data * HYPOTHAL & PITUITARY Patient Access Generic Outcomes **Diagnosis-specific Outcomes** Documents Audit Patient List

Pituitary

[Check Pituitary Tumour Module Manual](#)

No Outcomes found

New Outcome Language English

New Outcome

When a patient is registered in the system, a **unique code** is generated and must be stored locally by the healthcare provider, who will be the only one able to retrieve which patient is associated with a specific code.

For this module we ask you to create a new outcome for different time-points. In comments you can leave a remark for yourself to facilitate your work.

Created Date	Comments	Latest Assessment Date	Completed By	Questionnaire	Current Specific Diagnosis	Actions
2025-07-10	first visit		Mariya Cherenko	Pituitary tumour module - Pituitary tumour	Cushing disease	View Amend Delete
2025-07-10	radiation		Mariya Cherenko	Pituitary tumour module - Pituitary tumour	Cushing disease	View Amend Delete

You can amend, view or delete the outcomes when needed. Next outcome will be automatically prefilled with the data from previous outcome.



Fill in the data into the module and save

👉 Note: Some questions are hidden and will only appear based on the answers you choose. Explore all the tabs and the tooltips. Read the manual about this module and conducted studies.

Add Diagnosis-specific Outcome

Patient ID - 5106 Date of Birth - Pituitary Condition Group - Pituitary
Questionnaire: Pituitary module_v4_2024
New Outcome

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	Pituitary Adenoma
Current Gender	Female	Clinician Responsible for Patient	Mariya Cherenko
		Specific Diagnosis	Acromegaly
		Date of Diagnosis	

Basic disease module | Auxology parameters | Manifestations | Imaging | Genetics | Histopathology | Radiation | Medical therapy | Surgery | VTE

Patient status

To be filled in at every outcome ?
(see Manual Pituitary Tumour Module)

Assessment date ? yyyy-mm-dd

Comorbidities

Which of the following comorbidities/medical history were present at the time of diagnosis of the pituitary adenoma? ?

- Osteopenia/osteoporosis (DXA scan T-score ≤ 2.5 OR T-score ≤ 1.0 and vertebral fractures)
- Hypertension
- Diabetes type 2
- Diabetes type 1
- Cerebrovascular accident

Add Reminder

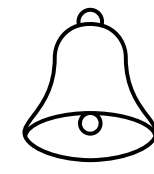
1 month 2 months 3 months 6 months 1 year 2 years 3 years 4 years 5 years 10 years

* Name 1 year

* Reminder Date 2026-07-14

Details To complete follow-up

Cancel Save



You can use this reminders and define their frequency.



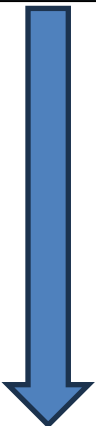
PROMs



EuRREB
European Registries for Rare
Endocrine and Bone conditions

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.



Generic Outcomes ▶ Patient ID - 5106 📅 Date of Birth -

* - Condition sections marked with * contain mandatory fields that require your attention!

Core Data * HYPOTHAL & PITUITARY 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 2023-09-30

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





Funded by
the European Union



Ways to contact us:



eurreb.eu



registries@lumc.nl



[drop-in sessions via Zoom](#)



[European Registries for Rare
Endocrine and Bone Conditions](#)



EuRRREB

European Registries for Rare
Endocrine and Bone conditions



Back to the index