

How to use the Gender Incongruence 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 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.



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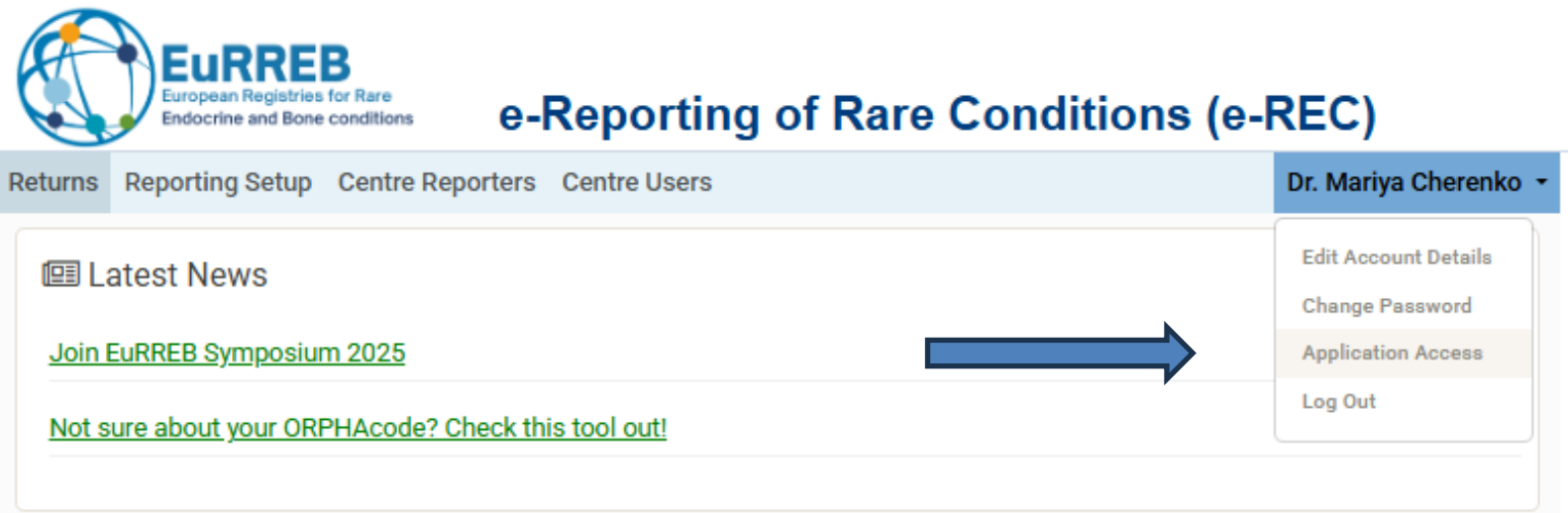


How to change your application role if you already use e-REC

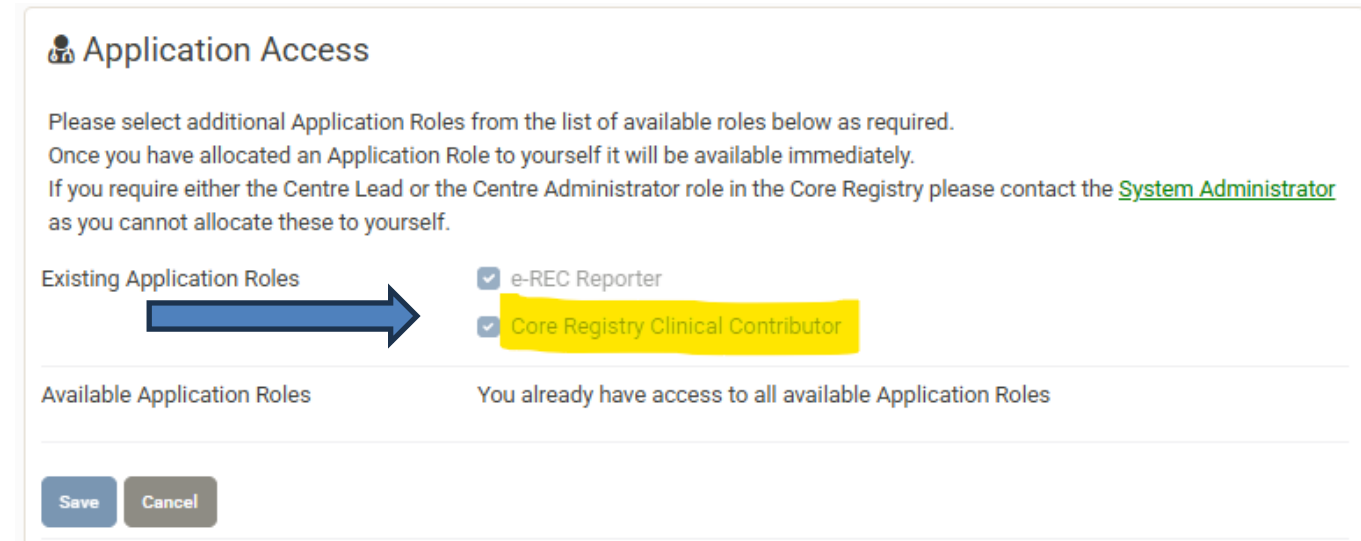
If you are already using e-REC, you can allocate the Core Registry Clinical Contributor role to yourself

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 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", and "Log Out". A blue arrow points from the "Application Access" menu item to the right.

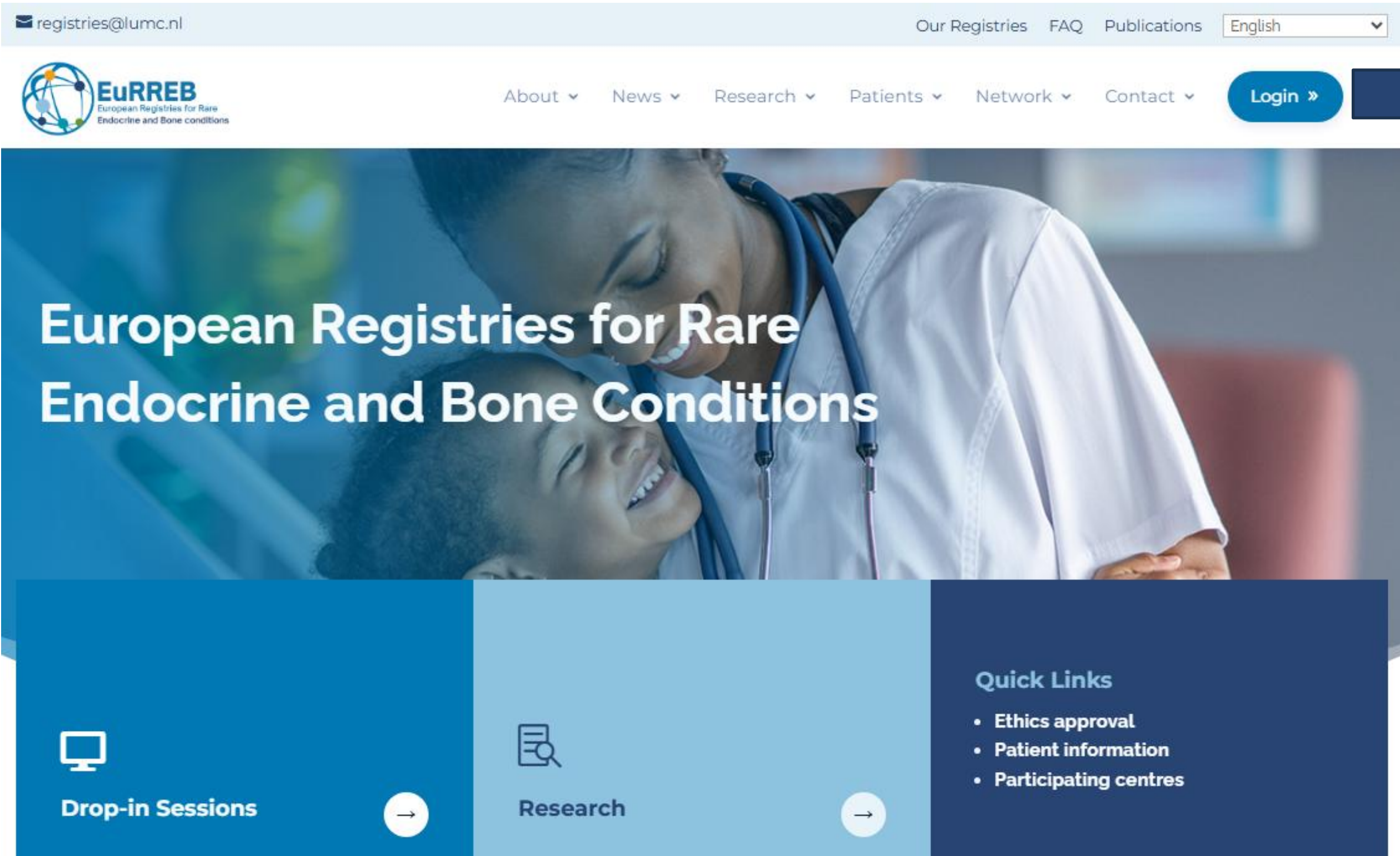


The screenshot shows the "Application Access" configuration page. It includes a title "Application Access" and a user icon. Below the title is a message: "Please select additional Application Roles from the list of available roles below as required. Once you have allocated an Application Role to yourself 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 checkboxes: "e-REC Reporter" and "Core Registry Clinical Contributor". A blue arrow points from the "Existing Application Roles" section to the "Core Registry Clinical Contributor" checkbox. 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.

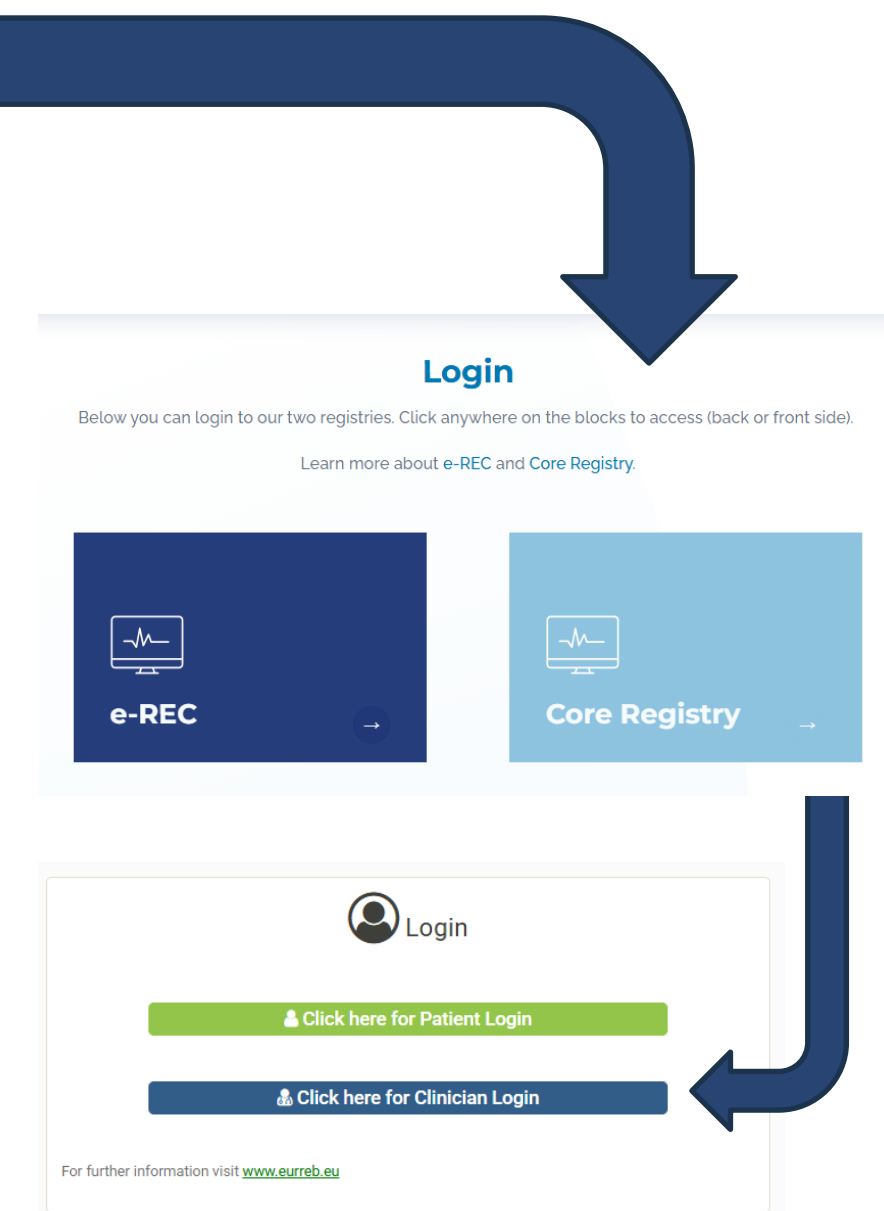


How to log in into the Core Registry

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. 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 a blue "Login" header. Below it is a paragraph: "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" (dark blue) and "Core Registry" (light blue). 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" (dark blue). At the bottom, it says "For further information visit www.eurreb.eu". A large blue arrow points from the "Login" button on the homepage to the "Login" header on this page. Another blue arrow points from the "Click here for Clinician Login" button to the "Core Registry" button on the previous page.



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

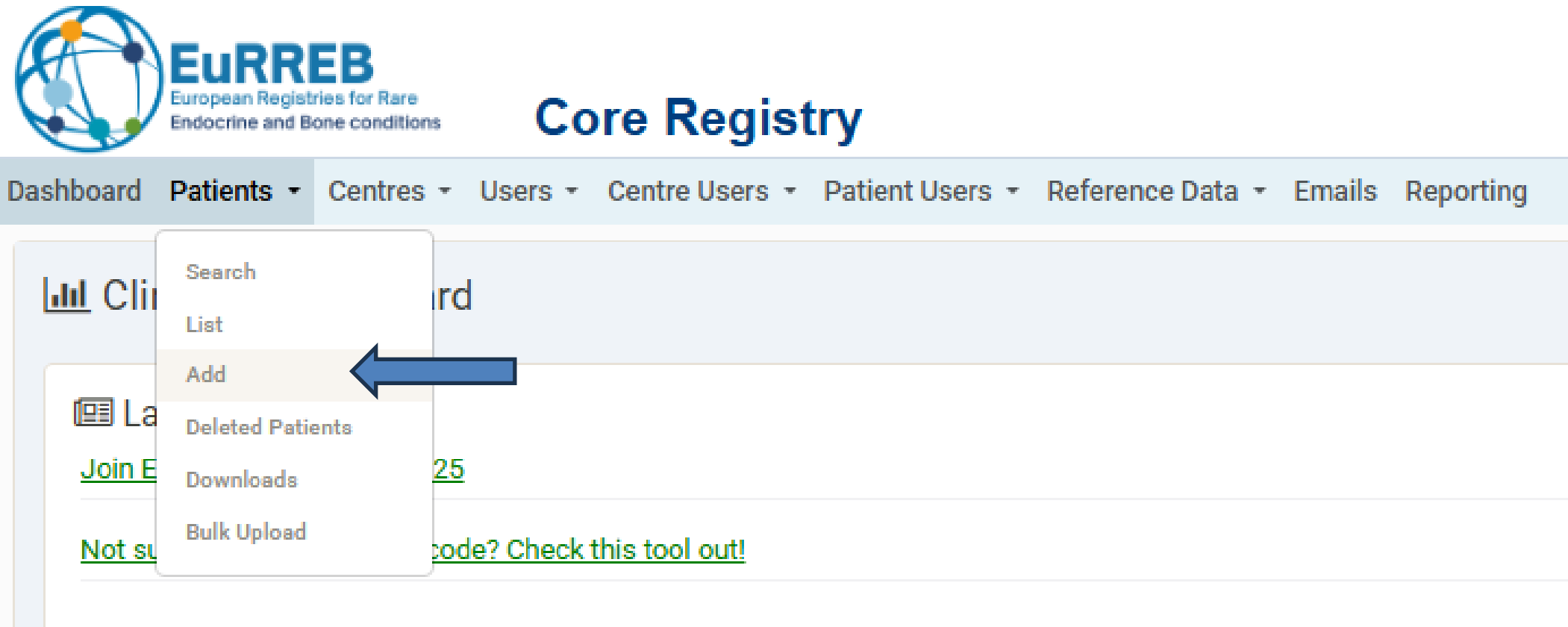


You can explore the different features of the dashboard:

- 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



The screenshot shows the EuRREB Core Registry interface. At the top left is the logo for EuRREB (European Registries for Rare Endocrine and Bone conditions). The main header is 'Core Registry'. Below this is a navigation bar with tabs: Dashboard, Patients, Centres, Users, Centre Users, Patient Users, Reference Data, Emails, and Reporting. The 'Patients' tab is selected, and a dropdown menu is open, showing options: Search, List, Add, Deleted Patients, Downloads, and Bulk Upload. A blue arrow points to the 'Add' option. In the background, there are some charts and text, including 'Join E' and 'Not su'.

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



Fill in the Common Data Elements



Mandatory fields

Fields marked with * are mandatory

* Consent for Core Registry

* Date of Birth

* Condition Group (select all that apply)

Pseudonymised ID (e.g. SPIDER)

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



Save

Opt-in Opt-out

dd-mm-yyyy

ADRENAL CALCIUM & PHOSPHATE GLUCOSE & INSULIN GENETIC ENDOCRINE TUMOURS GROWTH & OBESITY
 HYPOTHAL & PITUITARY SEX DEVELOPMENT THYROID BONE DYSPLASIA

Male Female Other Unknown

Male Female Non-binary Other Asked but unknown

NETHERLANDS

NETHERLANDS

Patient active Patient inactive Patient care suspended Patient care terminated Deceased Unknown

dd-mm-yyyy

- Select -

Yes No Not Known

Yes No Not Known

Yes No Not Known

Yes No Not Known

Yes No Not Known



Select "Sex development and Maturation"



Back to the index

Access the patient condition section

Edit Patient

Patient ID - [REDACTED]

[Edit To Do](#)

Fields marked with * are mandatory

* Consent for Core Registry

* Date of Birth

* Condition Group (select all that apply)

Pseudonymised ID (e.g. SPIDER)

Sex at Birth

Current Gender

Country of Birth

Country of Usual Residence

Patient Follow-up Status

Opt-in [?](#) Opt-out [?](#)

[REDACTED]

ADRENAL [?](#) CALCIUM & PHOSPHATE [?](#) GLUCOSE & INSULIN [?](#) GENETIC ENDOCRINE TUMOURS [?](#)
 GROWTH & OBESITY [?](#) HYPOTHAL & PITUITARY [?](#) SEX DEVELOPMENT [?](#) THYROID [?](#) BONE DYSPLASIA [?](#)

[REDACTED]

Male Female Other Unknown

Male Female Non-binary Other Asked but unknown

NETHERLANDS

NETHERLANDS

Patient active Patient inactive Patient care suspended Patient care terminated Deceased Unknown

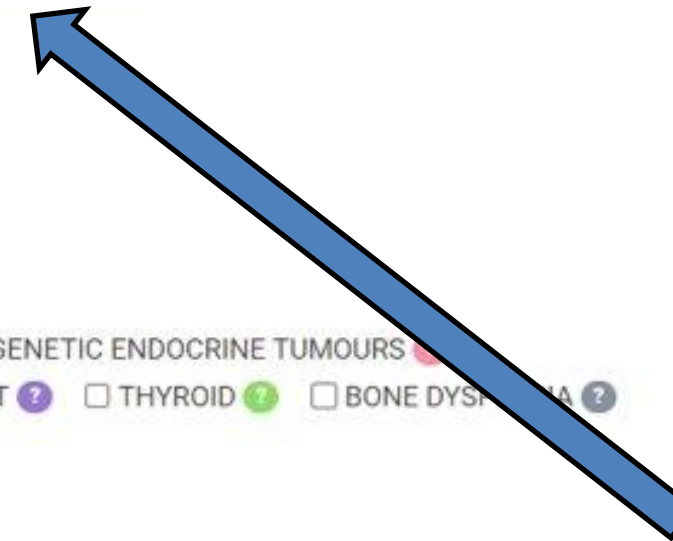
SEX DEVELOPMENT

Generic Outcomes

Documents

Audit

Patient List



Click here to fill in the Sex Development tab



Edit the patient condition section

Edit Patient Condition

Core Data Generic Outcomes Documents Audit Patient List

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

Sex Development and Maturation

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

- XY DSD - Cloacal anomaly
 - XY DSD - Congenital Adrenal Hyperplasia
 - XY DSD - Disorder of androgen action
 - XY DSD - Disorder of androgen excess
 - XY DSD - Disorder of androgen synthesis
 - XY DSD - Disorder of gonadal development
 - XY DSD - Leydig cell defects
 - XY DSD - Non-specific DSD
 - XY DSD - Persistent mullerian duct syndrome
 - XY DSD - Other
 - XX DSD - Cloacal anomaly
 - XX DSD - Congenital Adrenal Hyperplasia
 - XX DSD - Defects of mullerian development
 - XX DSD - Disorder of Androgen Excess
 - XX DSD - Disorder of gonadal development
 - XX DSD - Other
 - Isolated Congenital Anosmic Hypogonadotropic Hypogonadism
 - Isolated Congenital Normosmic Hypogonadotropic Hypogonadism
 - Transgender, male to female**
 - Transgender, female to male
- Select -
- Select -

→ Select a primary condition

Save Cancel



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



Giving patients access to the Core Registry

If your patient consented for access to the Core Registry:

Core Data Patient Access Generic Outcomes Audit Patient List

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

Sex Development and Maturation

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

- XY DSD - Cloacal anomaly
- XY DSD - Congenital Adrenal Hyperplasia
- XY DSD - Disorder of androgen action
- XY DSD - Disorder of androgen excess
- XY DSD - Disorder of androgen synthesis
- XY DSD - Disorder of gonadal development
- XY DSD - Leydig cell defects
- XY DSD - Non-specific DSD
- XY DSD - Persistent mullerian duct syndrome
- XY DSD - Other
- XX DSD - Cloacal anomaly
- XX DSD - Congenital Adrenal Hyperplasia
- XX DSD - Defects of mullerian development
- XX DSD - Disorder of Androgen Excess
- XX DSD - Disorder of gonadal development
- XX DSD - Other
- Isolated Congenital Anosmic Hypogonadotropic Hypogonadism
- Isolated Congenital Normosmic Hypogonadotropic Hypogonadism
- Transgender, male to female**
- Transgender, female to male

- Select -

- Select -

Give access to your patient.
Note: You must know the patient's e-mail for this.

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



The Gender Incongruence Module



Access the condition-specific module

Edit Patient Condition

Patient ID Date of Birth -



Edit To Do

Sex Development and Maturation

Senior Clinician < 18 - N/A

Senior Clinician ≥ 18 - N/A

e-REC ID

First Contact with Centre

mm/dd/yyyy

Clinician Responsible for Patient

Dr. Mariya Cherenko

Date of First Clinical Manifestations

mm/dd/yyyy

Primary Condition

Transgender, male to female

Specific Diagnosis

Transgender, male to female

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

Core Data

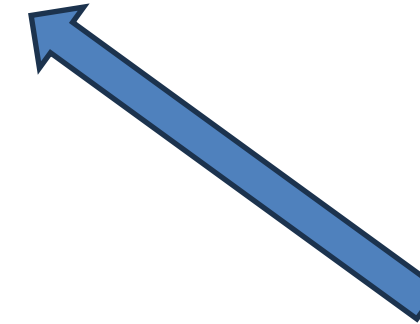
Generic Outcomes

Diagnosis-specific Outcomes

Documents

Audit

Patient List



Click here to fill in the disease-specific module



Back to the index



Fill in a new diagnosis-specific outcome

Diagnosis-specific Outcomes

Core Data **SEX DEVELOPMENT** Generic Outcomes Documents Audit Patient List

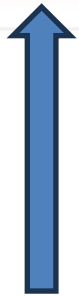
Patient ID Date of Birth -

Sex Development and Maturation

I-DSD Registry

No Outcomes found

New Outcome Language



Click here to fill in the new outcome for the disease-specific module

Note: In case a change occurred, and you need to modify a specific outcome, please click on “new outcome” and fill in the information.



Fill in the data into the module and save

Add Diagnosis-specific Outcome

Patient ID - [redacted] Date of Birth - [redacted] Condition Group - Sex Development and Maturation

Questionnaire: Test version 2 Gender Incongruence - Gender Incongruence

New Outcome

Date of Birth	[redacted]	e-REC ID	
Current Gender		Clinician Responsible for Patient	Mariya Cherenko

General information | Gonada hormonal suppression | Gender affirming medication | Fertility preservation | Surgery

Transition type: - Select -

Detransition: - Select -

First consultation with paediatric endocrinologist concerning Gender Incongruence: mm/dd/yyyy

Age at the earliest memory of Gender Incongruence: - Select -

Mental health comorbidities: - Select -

Specific mental health comorbidities:

- Anxiety
- Autism spectrum disorder
- Depression
- Obsessive-compulsive disorder
- Personality disorder
- Other

Other: [text input]

Has the patient transitioned to the adult care?: - Select -

Date of transition to adult care if applicable: mm/dd/yyyy

If the patient is lost to follow-up please provide date of last examination: mm/dd/yyyy

Fill in all the tabs which are applicable

Save Back



Fill in the data into the module

Diagnosis-specific Outcomes Core Data **SEX DEVELOPMENT** Generic Outcomes Documents Audit Patient List

Patient ID - Date of Birth -

Sex Development and Maturation

I-DSD Registry

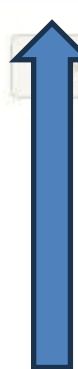
Show entries Search:

Created Date	Latest Assessment Date	Completed By	Questionnaire	Current Specific Diagnosis	Actions
2023-10-20		Dr. Mariya Cherenko	Test version 2 Gender Incongruence - Gender Incongruence	Transgender, male to female	View Amend Delete

New Outcome Language

New Outcome

Previous 1 Next



When reporting a patient in the system, it can happen that at that moment not all the required information is available. You can add new information later by opening the patient's tab and clicking on "amend".



PROMs



Fill in the generic outcomes

Generic Outcomes

Patient ID Date of Birth -

Core Data **SEX DEVELOPMENT** Patient Access Diagnosis-specific Outcomes Audit Patient List

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	1	2	2	74	
2021-03-24	Dr. Ana Priego	EQ-5D-5L	1	2	2	1	1	80	

Previous 1 Next

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

Click here to fill in the new generic outcome for your patient: mobility, FQ-5D or other



Choose the frequency for PROMs

Generic Outcomes

Core Data **SEX DEVELOPMENT** Patient Access Diagnosis-specific Outcomes Audit

Patient ID - [] Date of Birth - []

EQ-5D BPI-SF PROMIS Profile WHO ICF Patient Reported Outcome Request Settings

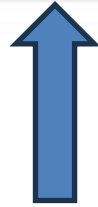
Create or edit requests for the Patient to complete generic questionnaires

Show 10 entries

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

[Add Outcome Request](#)

Previous 1



Click here to choose and add 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





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Ways to contact us:



eurreb.eu



registries@lumc.nl



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