How to use the OI disease specific module in the Core registry

EuRRECa
European Registries for Rare Endocrine Conditions

EuRR-Bone
European Registries for Rare Bone and Mineral Conditions

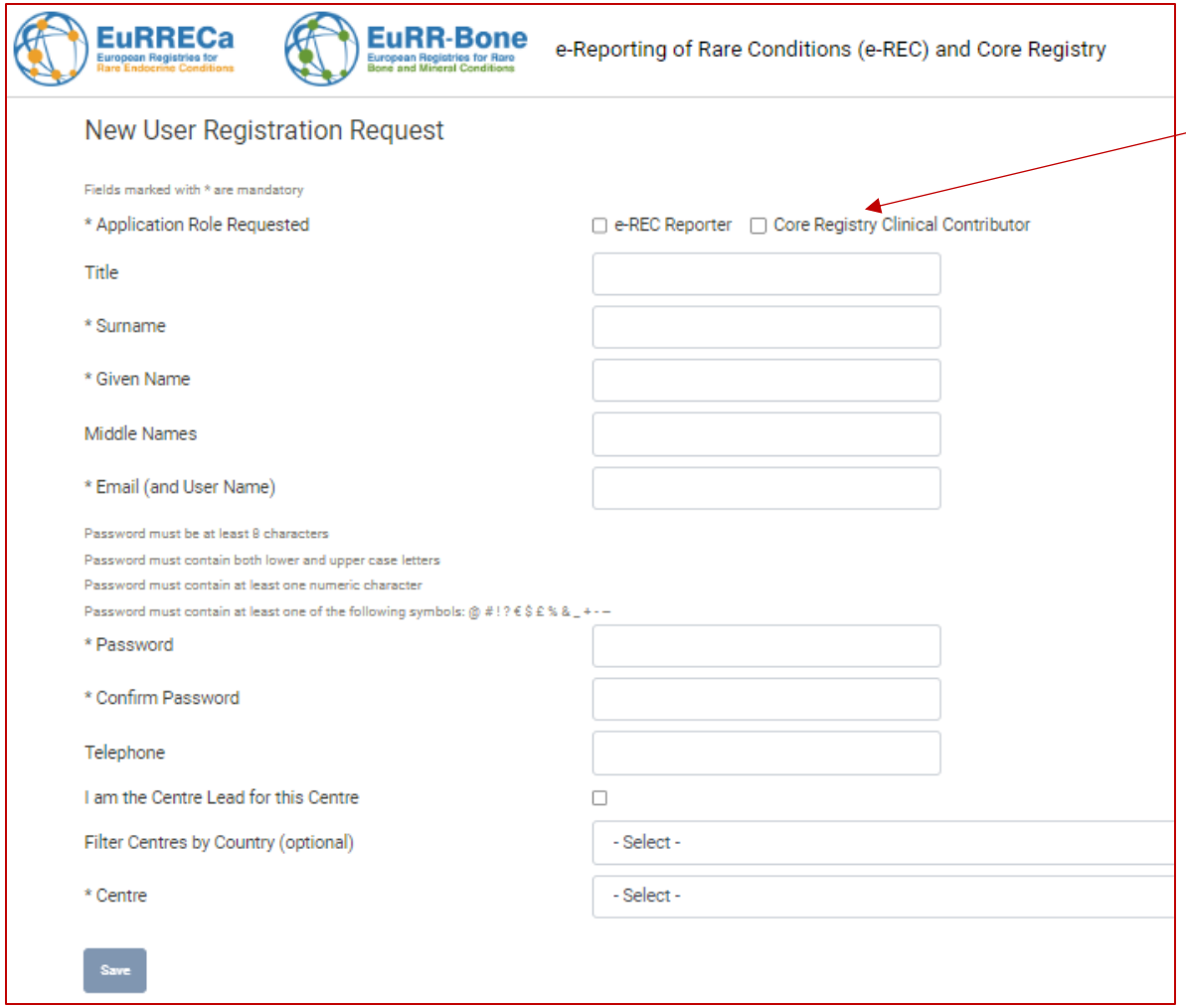
Register in the Core registry

Go to https://eurreb.eu/

If you have no account yet, you can request the access here or choose "information" from the "access" button

Register in the Core registry

Follow the self-registration link:



You need an access to Core registry to use the module

Fill in the mandatory information.
Your request will be approved as soon as possible.

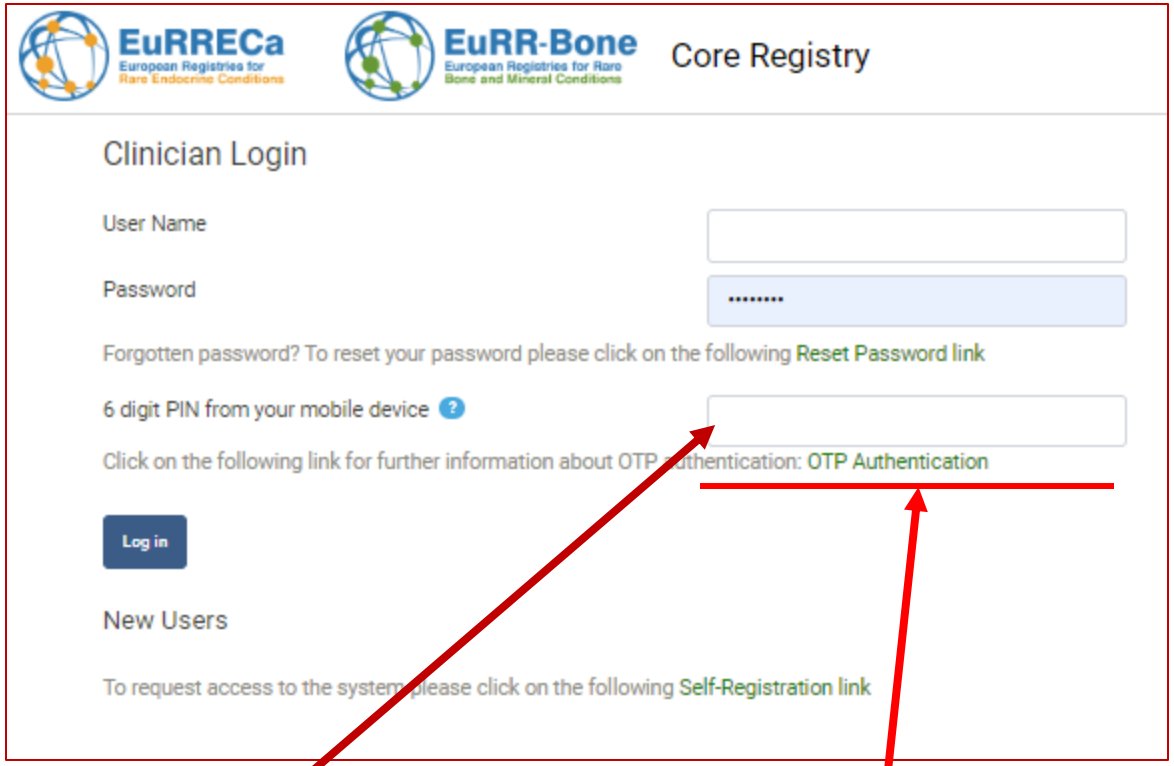
Login to the Core registry

Go to https://eurreb.eu/

Login to Core registry using this button and your credentials

Login to the Core registry

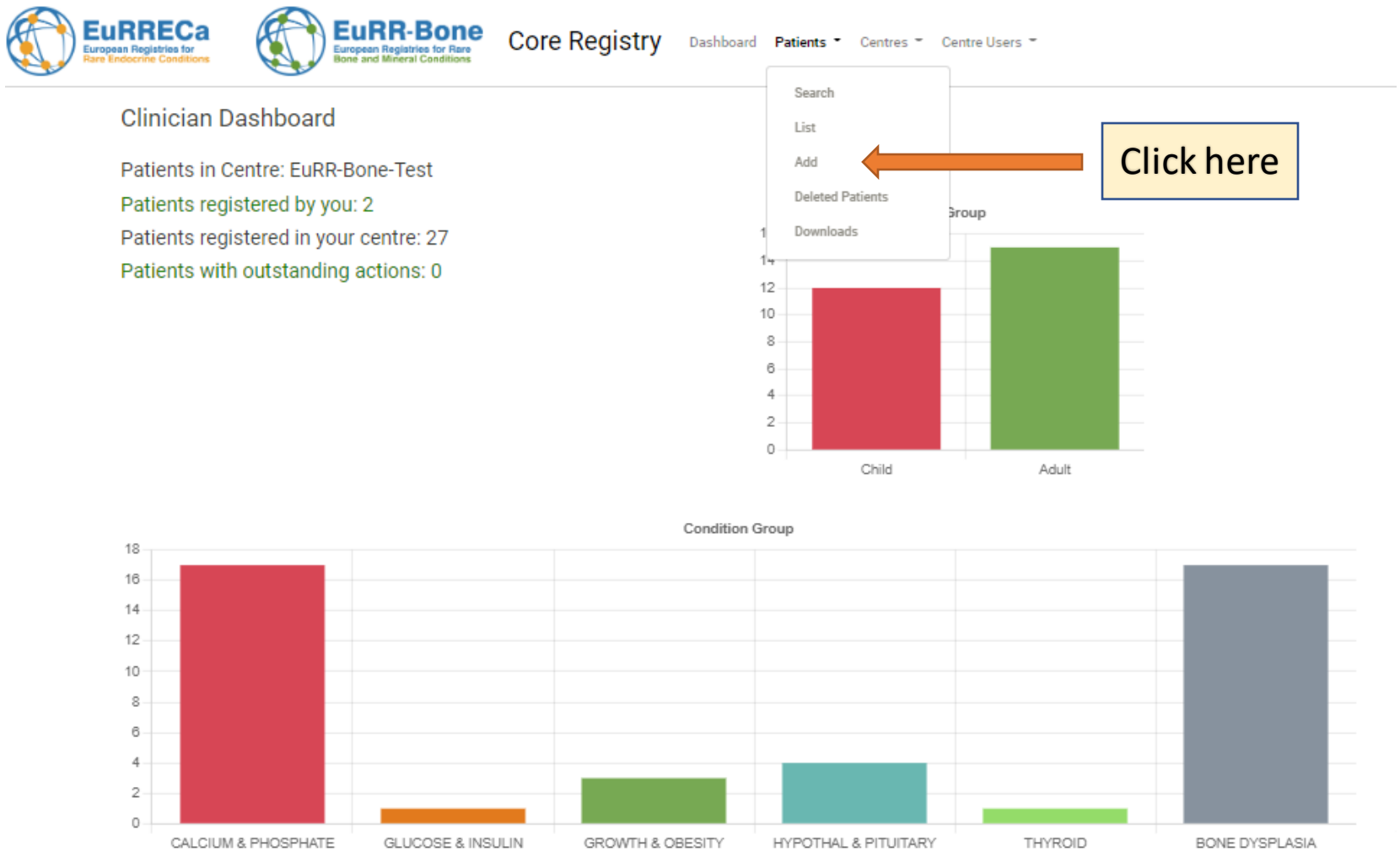
Choose clinician login and then provide your credentials:



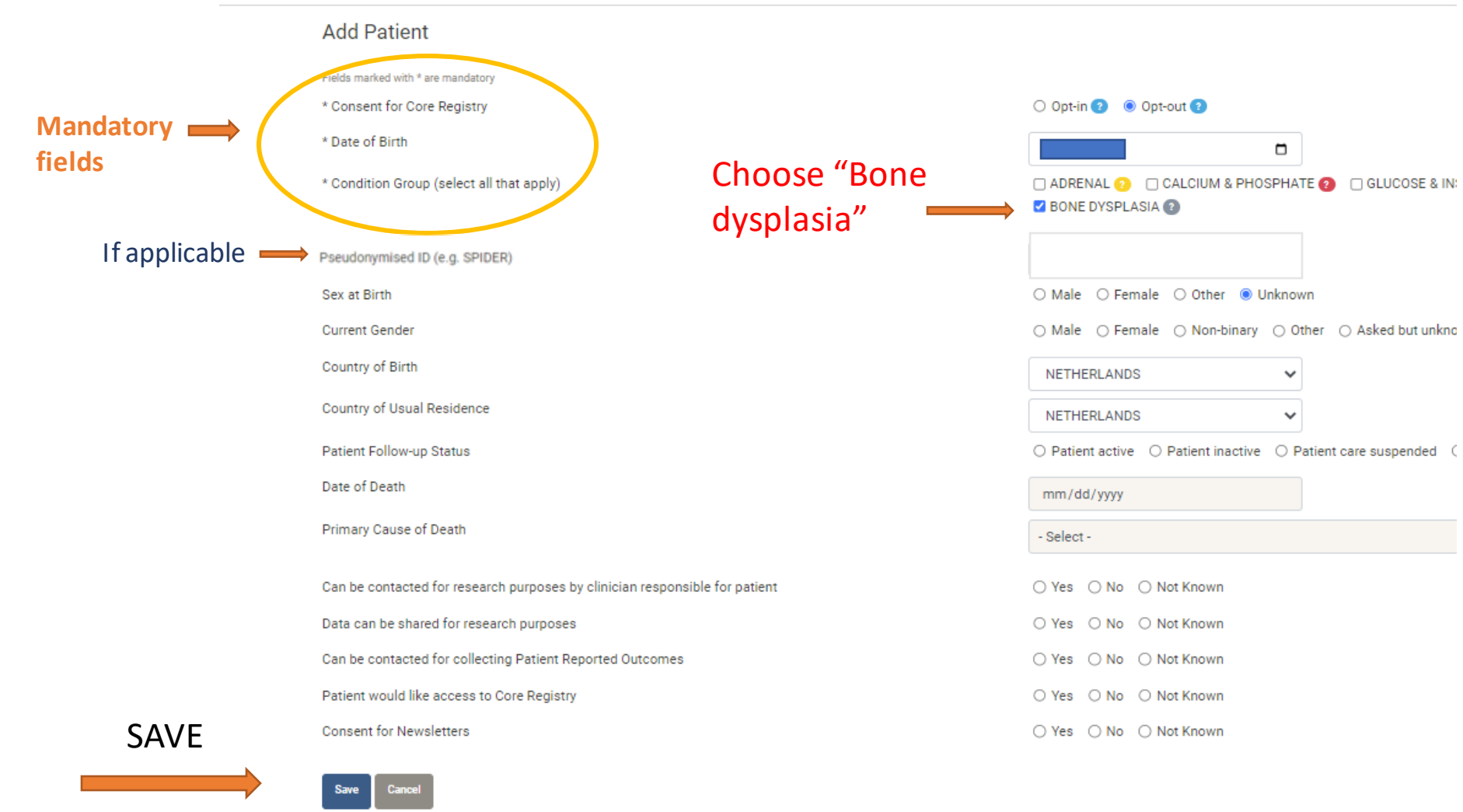
Provide your credentials and 6 digit PIN, if needed, reset your password

You will need to download OTP authenticator

Add a new patient



Fill in the Common Data Elements



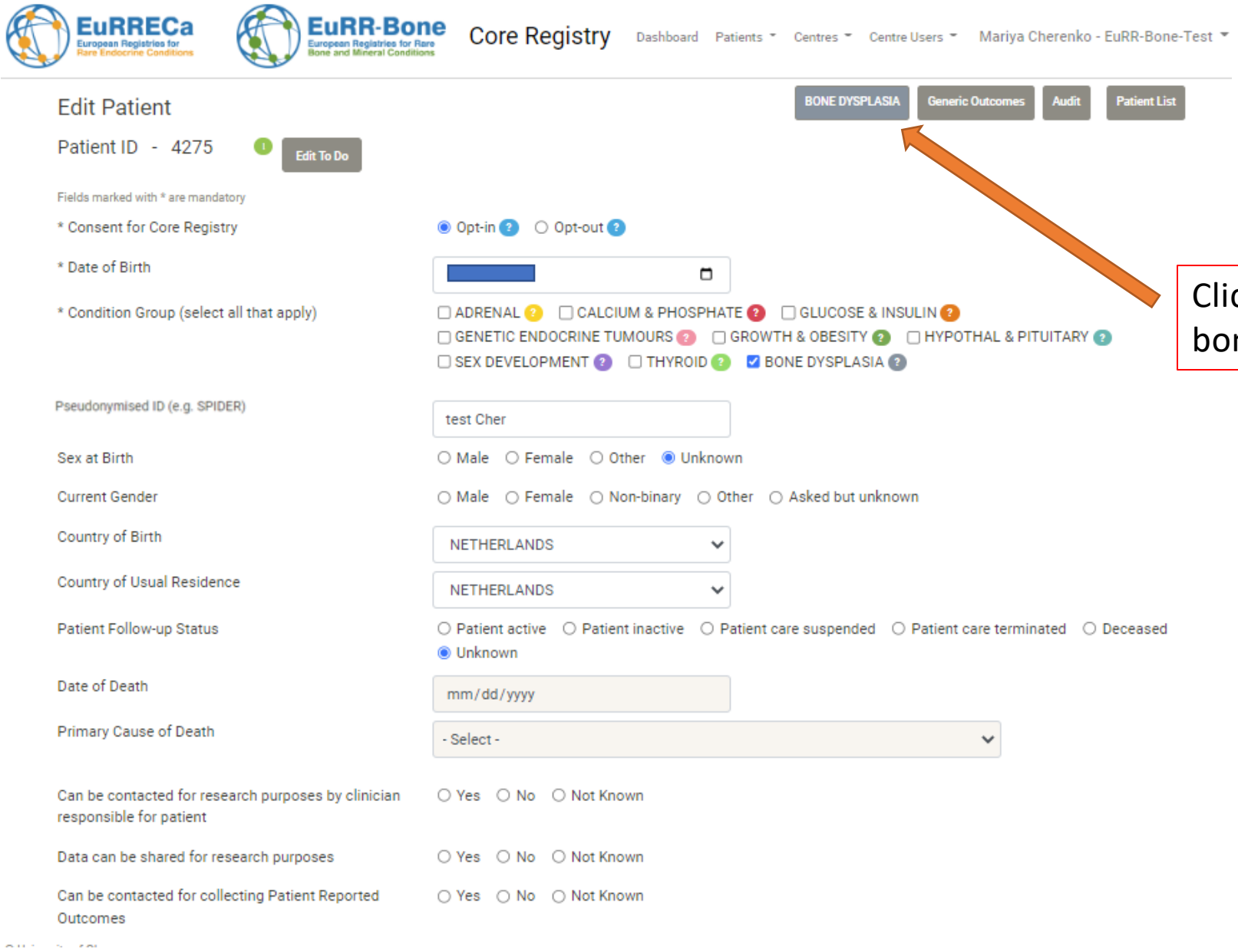
Mandatory fields

If applicable

Choose "Bone dysplasia"

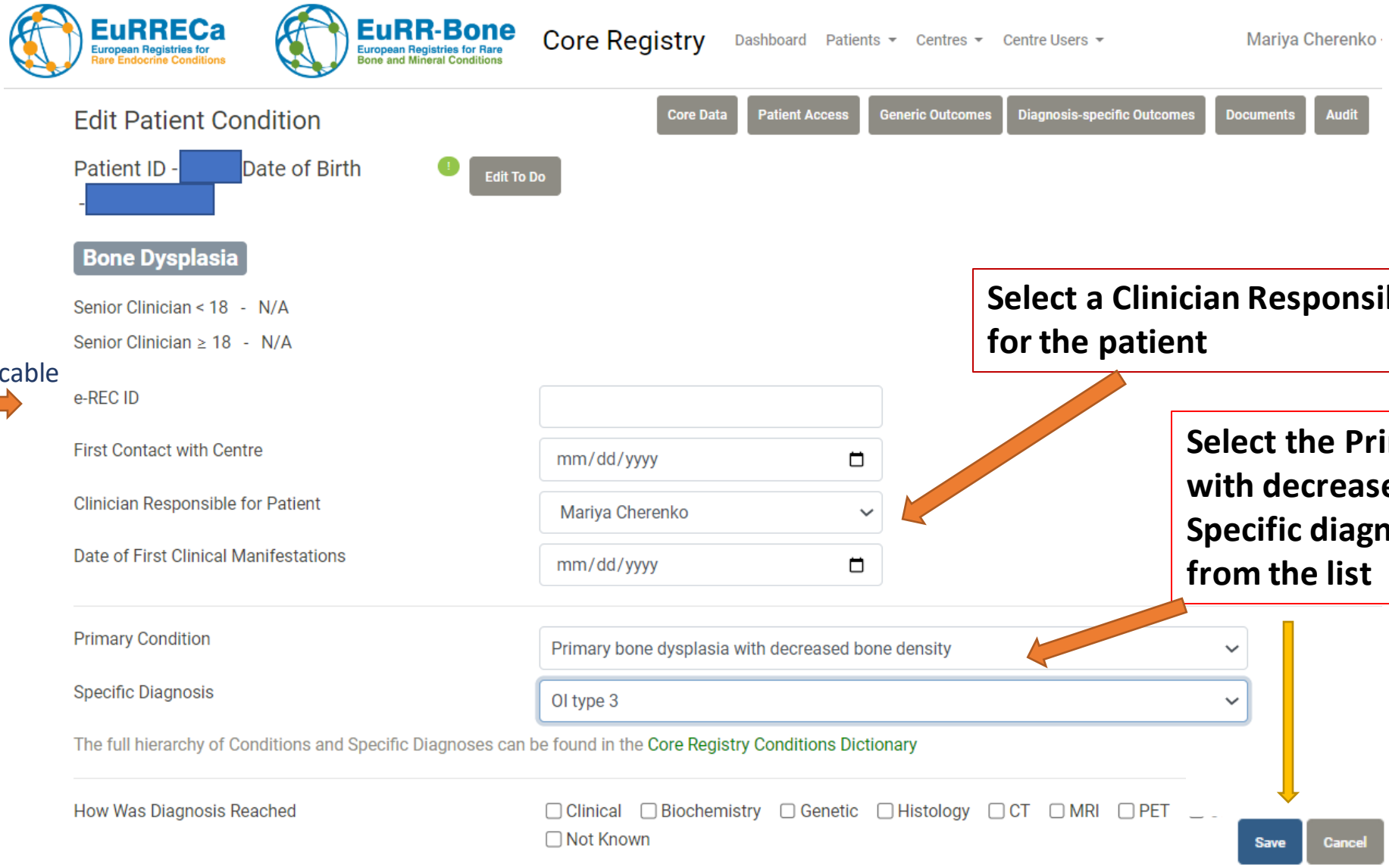
SAVE

Go to condition group section



Click here to fill in the bone dysplasia tab

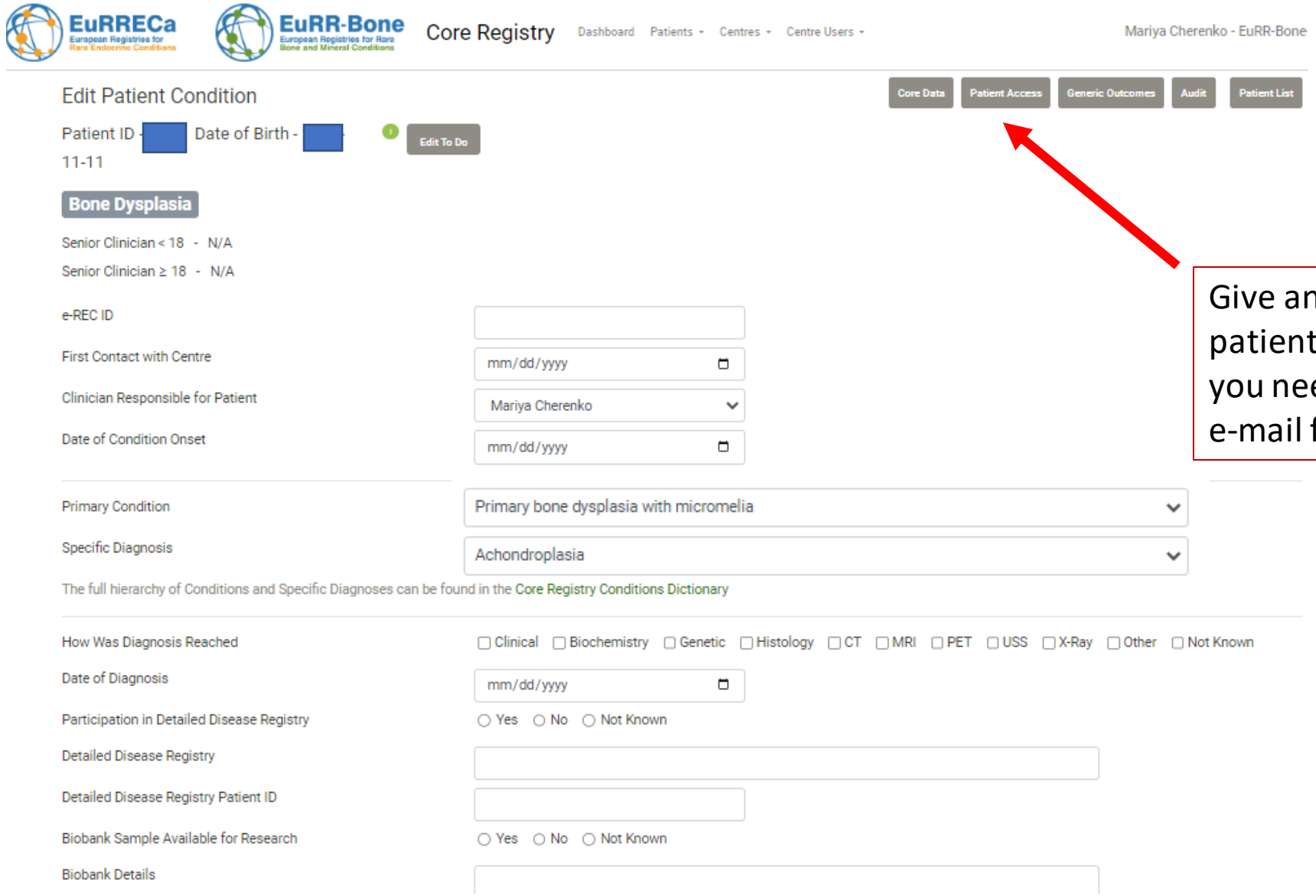
Edit the Patient Condition section



Select a Clinician Responsible for the patient

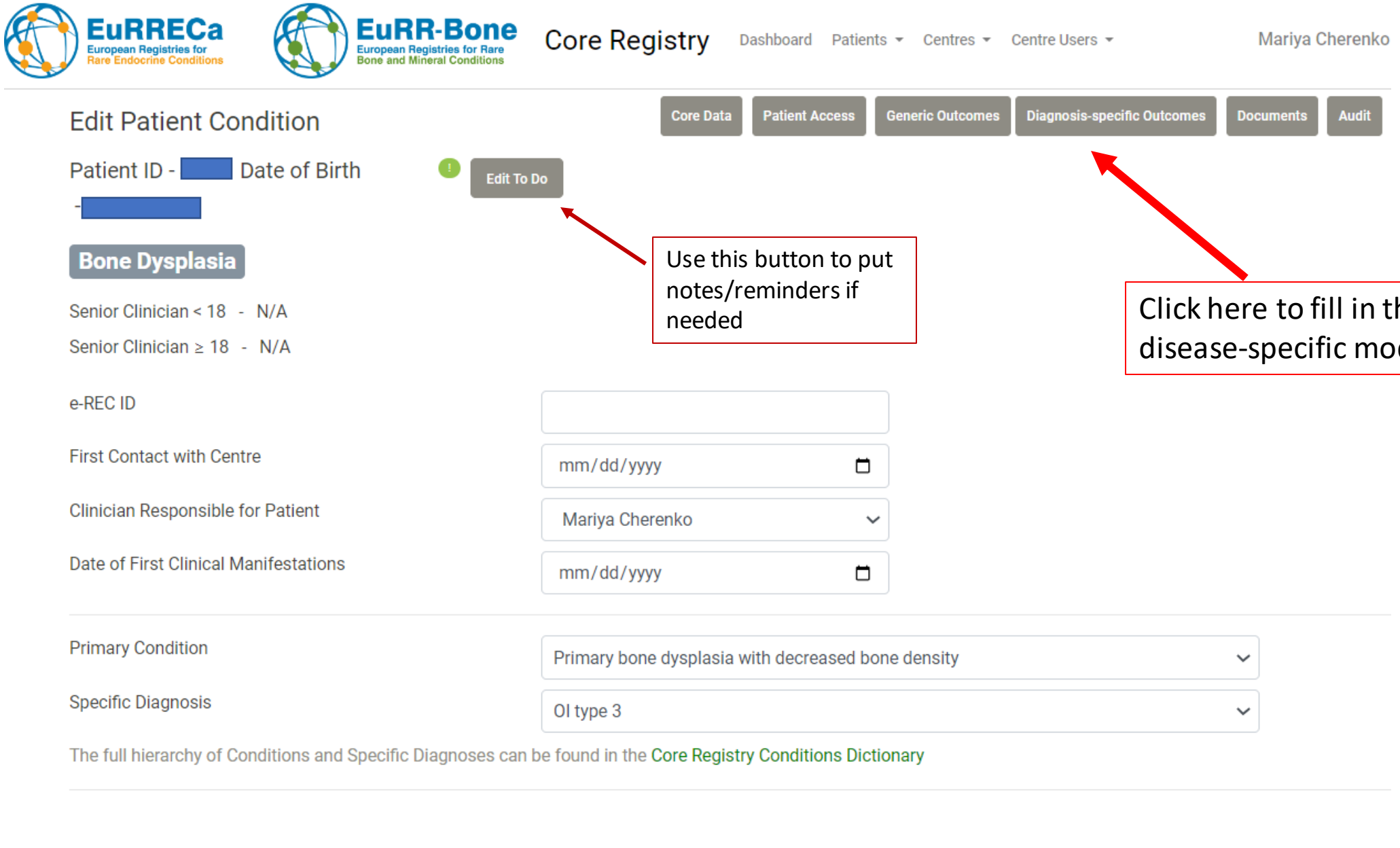
Select the Primary condition - "PBD with decreased bone density", for Specific diagnosis – choose "OI +/- type" from the list

Give an access to the platform to your patient

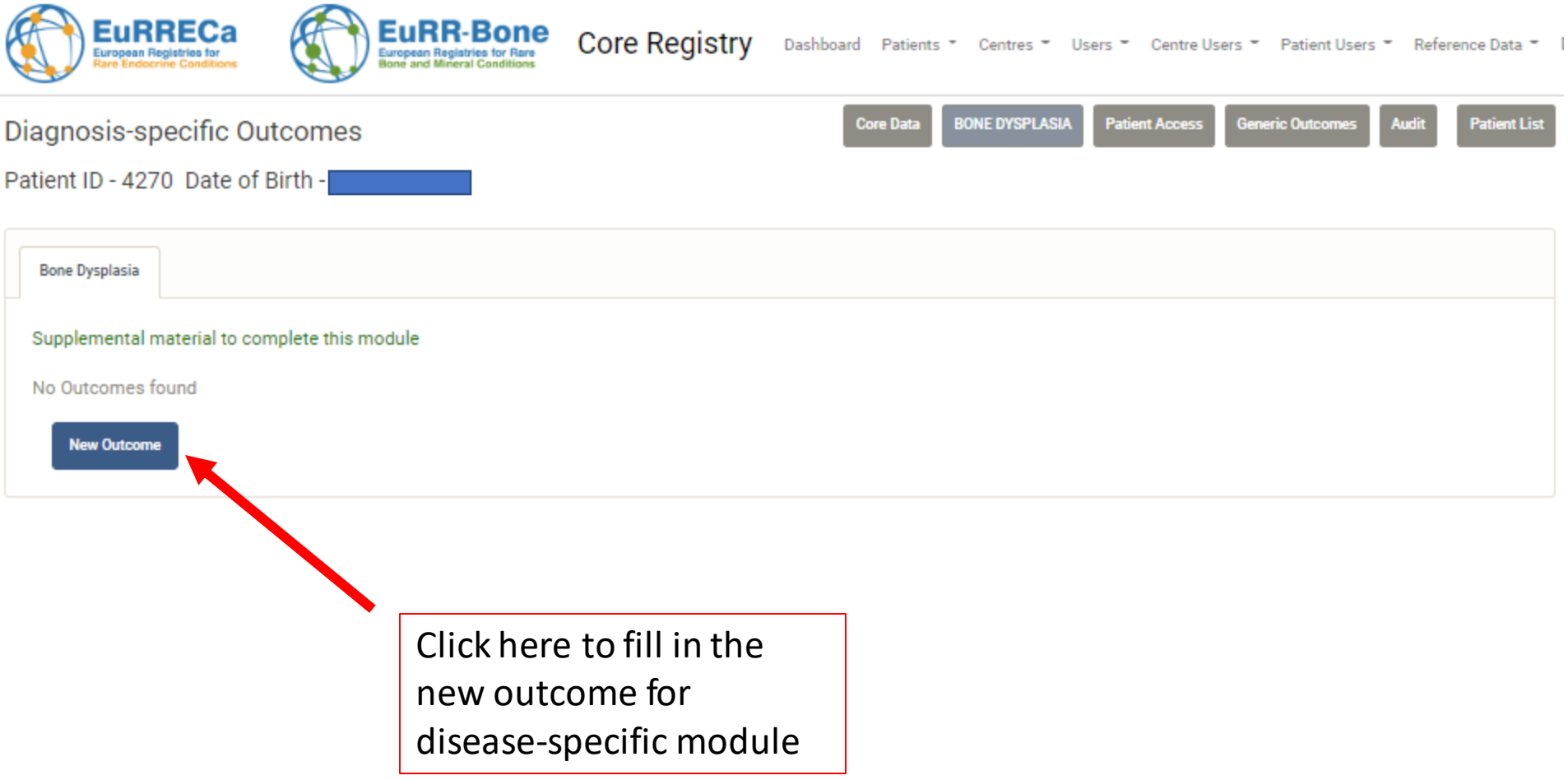


Give an access to your patient (in case of consent) – you need to know patient's e-mail for this

Go to diagnosis-specific outcome



Fill in the new outcome



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

Fill in the data into the module and save

Add Diagnosis-specific Outcome

Patient ID - [redacted] Date of Birth - [redacted] Condition Group - Bone Dysplasia

Questionnaire: Osteogenesis Imperfecta - Child - Child

New Outcome

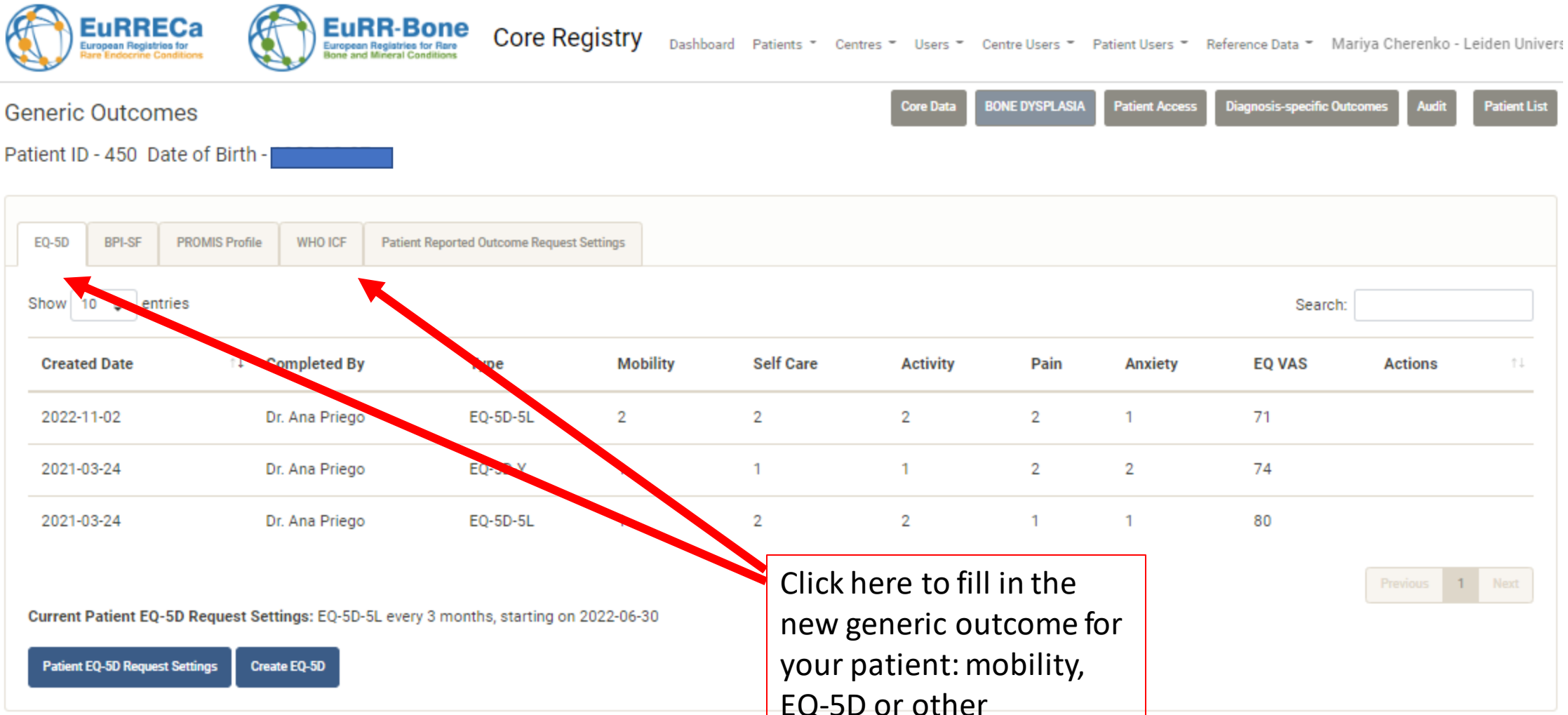
Date of Birth	[redacted]	e-REC ID		Primary Condition	
Current Gender	Male	Clinician Responsible for Patient	Mariya Cherenko	Primary bone dysplasia with decreased bone density	
				Specific Diagnosis	OI type 3
				Date of Diagnosis	

Anthropometry | Fractures | Genetic diagnosis | Medication | Spine | Mobility | Lung function | Bone mineral density | Musculoskeletal surgery | Other surgeries

Assessment Date	mm/dd/yyyy
Height (cm)	
Height SDS	
Weight (kg)	
Weight SDS	
BMI	

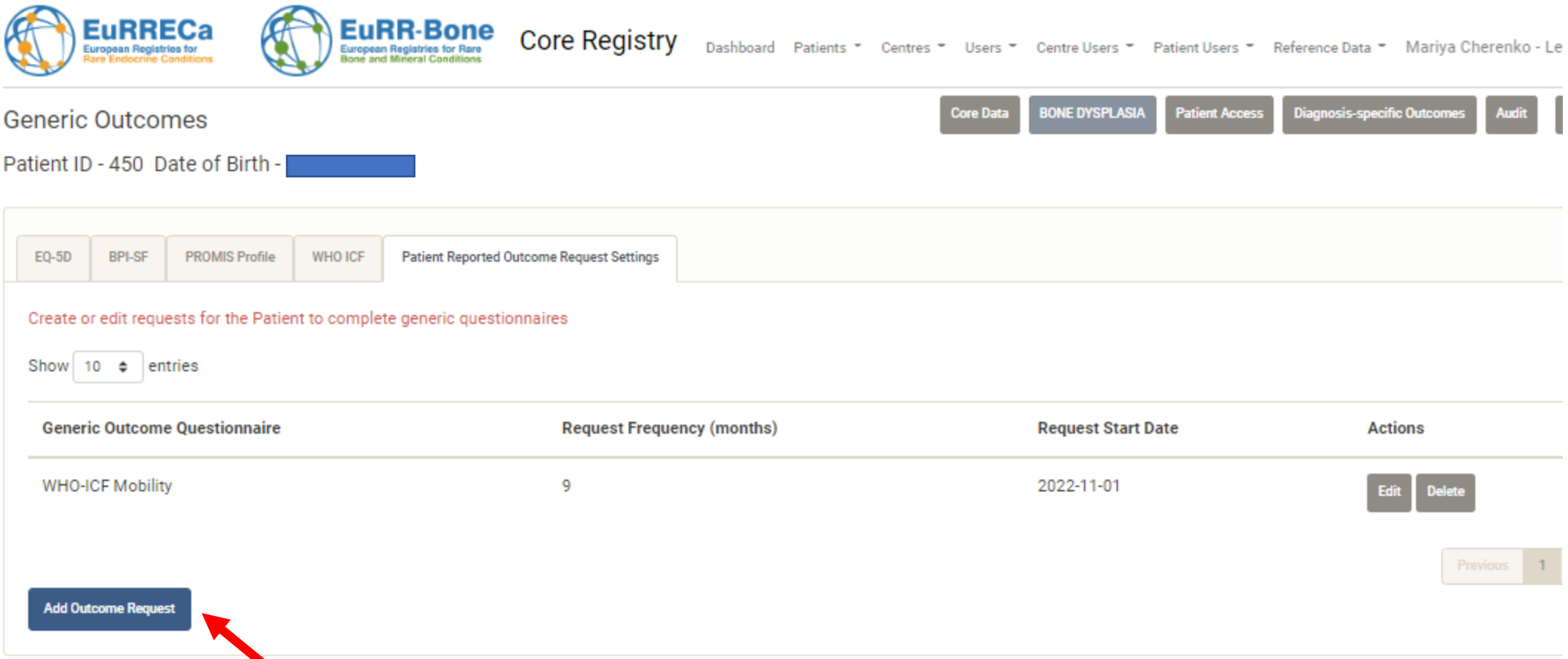
Fill in all the tabs which are applicable

Fill in the generic outcomes



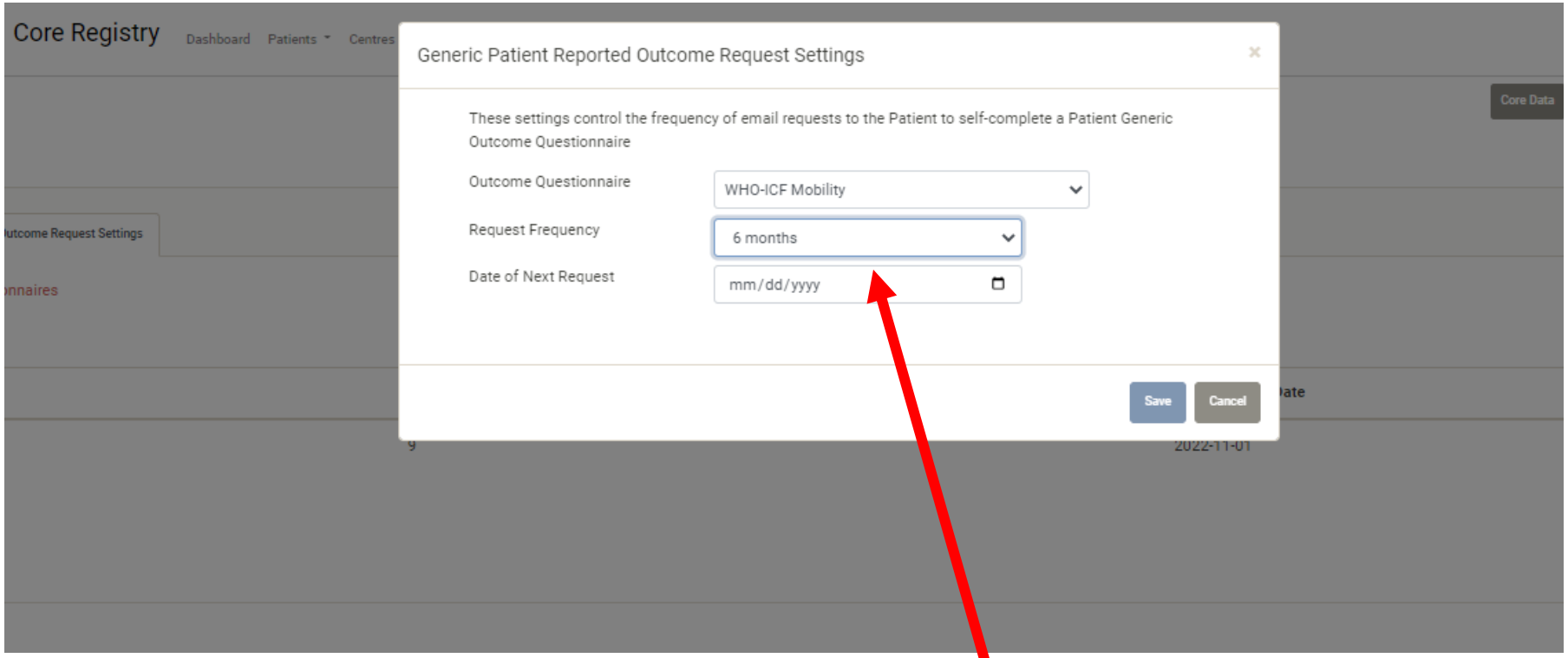
Click here to fill in the new generic outcome for your patient: mobility, EQ-5D or other

Choose the frequency for PROMs



Click here to choose the frequency of email requests to the Patient to self-complete a Patient Generic Outcome Questionnaire

Choose the frequency for PROMs



Click here to choose the frequency of email requests to the Patient to self-complete a Patient Generic Outcome Questionnaire

Contact us!

Please don’t hesitate to contact us by e-mail registries@lumc.nl in case of any questions.

Or join our regularly drop-in sessions https://eurreb.eu/