

Central Registry for ground-breaking research

What exactly is the Core Registry? And why would you participate in this? MD and PhD Candidate Loren van der Hoeven explains.

One of the ways to improve care is by conducting scientific research. It is important to collect data from as large a group of patients as possible. Especially in the case of rare conditions. Much more research is possible by working together in an international network.

“
We collect data from larger groups of patients throughout Europe
”

Core Registry

This need to increase data collection for rare endocrine conditions from a larger group of patients led to **Endo-ERN** developing the central **European Registry: the Core Registry** in partnership with the **European Registry for Rare Endocrine Conditions (EuRECa)**. Doctors can enter data about their patients not just in the Netherlands, but throughout Europe and beyond.

The Core Registry has different sections for the different rare endocrine conditions. In the Netherlands, three hospitals already participate in the pituitary section of the **Core Registry**:

- Amsterdam University Medical Center
- Leiden University Medical Center
- Radboudumc (Nijmegen)

Condition Specific Modules

For every patient who participates, first the confirmed diagnosis is registered. In the Condition Specific Modules of the **Core Registry** additional data is collected. Examples of Condition Specific Modules are the modules on Gender Incongruence, Pediatric Differentiated Thyroid Carcinoma, Rare Obesity and Pituitary Tumours. The module on pituitary tumours, for example, includes data collection on:

- the functioning of the different hormone axes
- Is there overproduction of one hormone? Or are one or more hormones not produced? Or are not enough hormones produced?
- MRI images – such as the character and size of the condition
 - the treatments and their results – such as medication, surgery or radiotherapy

There are unique questions and datapoints for collection in the other Condition Specific Modules of the **Core Registry**.

How does it work?

Your caregivers at your hospital can ask you if you want to participate in the **Core Registry**. They will ask you this during or after your visit, but if they don't you can also tell your doctor that you want to participate. If your hospital is not yet participating in the Core Registry then you can contact the EuRECa Registry Team. The registry collects data on all patients with a rare endocrine conditions including children.

Core registry participation

When you participate in the **Core Registry** you will not have to come to the hospital more frequently or have additional tests. Your doctor enters the results of your usual examinations and treatments in the **Core Registry**. The aim of the registry is to gather real-world data from as many patients as possible and make it as simple as possible. It should be noted that your treatment will not change either.

What is a registry?

A registry is a collection of data. This is also called a database. Medical information about patients can be entered here. This data can be used for scientific research and to improve care.

Your data is protected

It is important that the **Core Registry** handles your data properly and therefore the **Core Registry** adheres to all laws and regulations regarding privacy. The data is coded and personal data such as your name and address will not be included in the registry. We also do not share data that can be traced back to you with other researchers or hospitals.

We ensure your privacy with this process:

- Every patient receives a code.
- Only the hospital that treats you has the key to this code.
- The data that research teams receive cannot be traced back to you.

If a research team wants to receive data from the **Core Registry** it has to be approved by a special committee of the **Core Registry** that includes a patient representative. The committee will assess the application, and if everything is in order, the committee gives the research team permission to receive and use the data.

Actively involved

Patients will always remain the owner of their data. If you want, you can have an account for the Core Registry.



Loren van der Hoeven

With your **Core Registry** account you are able to:

- see which data has been entered for you
- complete questionnaires
- receive newsletters with results of research

This way you as a patient remain actively involved in the research. And you contribute to the collection of data yourself.

Participation in the **Core Registry** is always voluntary. You can stop your participation at any time and have your data removed from the registry. If a research team has already received your data it is not possible to remove the data. Only that team will still use your data for their research.

Want to know more or have questions?

More information and frequently asked questions about the Core Registry can be found at www.eurreb.eu and www.endo-ern.eu. The registry team can be contacted via registries@lumc.nl.

