EuRREB
European Registries for Rare
Endocrine and Bone conditions

Core Registry
Annual Activity Report

February 2026

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Introduction

The Core Registry (https://eurreb.eu/core-registry/) was launched in June 2019 as part of the EuRRECa project, and since April 2020, it has also supported the EuRR-Bone project. Since March 2025, EuRRECa and EuRR-Bone have merged into a single project: the European Registries for Rare Endocrine and Bone conditions (EuRREB). EuRREB supports the needs of both the European Reference Networks on Rare Endocrine and Bone Disorders.

The platform includes patient access and reporting of patient or clinician-reported generic or condition-specific outcomes. Reporting by patients can occur in their preferred language. The Registry has ethics approval, and information sheets and consent forms are available in multiple languages on its website. (https://eurreb.eu/ethics-approval/).

Aim of this Report

To describe the activity of the Core Registry between June 2019 and January 2026, with a particular focus on developments since our last annual report.

Results

Since January 2025, an additional 19 centres have joined the platform, bringing the total to 154 registered centres, supported by 396 registered users. Of these, 70 centres (45%) have actively contributed data to the Core Registry and are therefore classified as 'Active Centres'.

Of these 70 centres, 19 operate as joint Endo-ERN and ERN BOND centres, 25 are exclusively affiliated with Endo-ERN, five are exclusively affiliated with ERN BOND, and 21 are not associated with any European Reference Network.

These centres are distributed across 22 countries, including four that are not members of the European Union. Italy hosts the largest number of participating centres (13), followed by the Netherlands (7), and France and Greece (5 each). The overall distribution of participating centres and the number of cases entered per country is illustrated in Figure 1.

By January 1st 2026, a total of 5,225 records had been registered in the platform. The number of patient records increased by more than 30 percent compared with 2024 (Fig. 2). The highest volume of cases was contributed by the Netherlands (1,695 cases), followed by Italy (783 cases) and France (653 cases).

Thirty-nine centres (56%) have submitted ten or more cases, accounting collectively for 5,124 records (98% of all entries). The median number of reported cases per centre is 11, with a range from one to 901. The distribution of cases across condition groups varies substantially, from ten cases in 'Genetic Disorders of Glucose & Insulin Homeostasis' to 1,795 cases in 'Hypothalamic & Pituitary Conditions'. The 'Bone dysplasia' group represents the second-largest MTG by case volume (Fig. 3). Reporting trends by MTG are presented in Figure 4.

The Core Registry enables patients to create and manage their own accounts. To date, 1,688 of the 5,225 registered patients (32%) have expressed interest in accessing the platform. Among them, 460 patients (27%) have activated their accounts. A total of 127 patients (27%) have independently completed PROMs within the Core Registry platform.

Patient-reported outcome measures (PROMs) have been filled in on the Core Registry platform by both clinicians and patients (Fig 5). The most frequently used are EQ-5D for the assessment of quality of life, Brief Pain Inventory Short Form (BPI-SF) and WHO-ICF mobility questionnaire. Several other questionnaires (in multiple languages) are also available on the platform such as MSK-HQ (Musculoskeletal Health Questionnaire), OHIP-14 (Oral health impact profile), PHQoL (Quality-of-Life Questionnaire for Patients with Primary Hyperparathyroidism) and NPSI (Neuropathic Pain Symptom Inventory).

Fig. 1 – The number of centres and cases per country

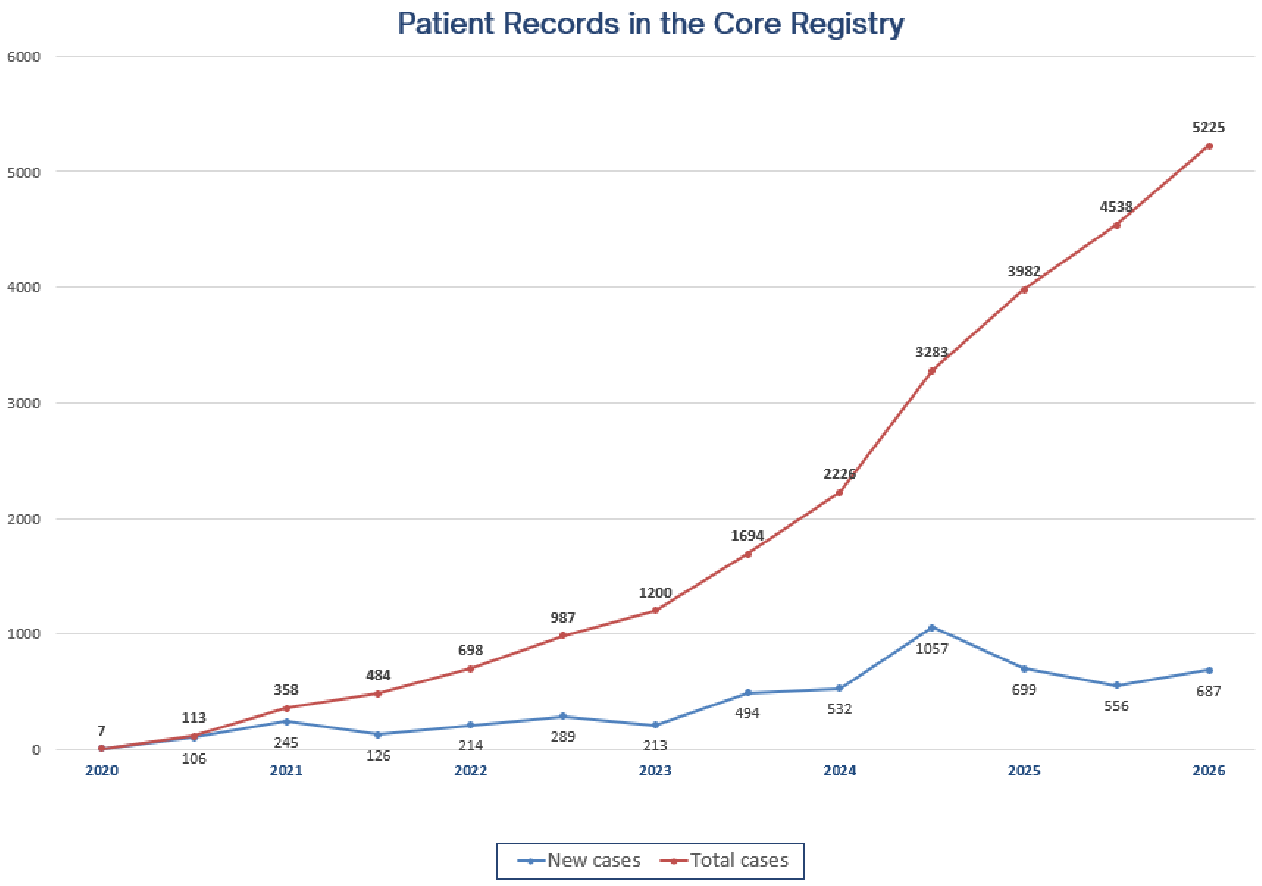


Fig. 2 – The number of patient records in the registry over time

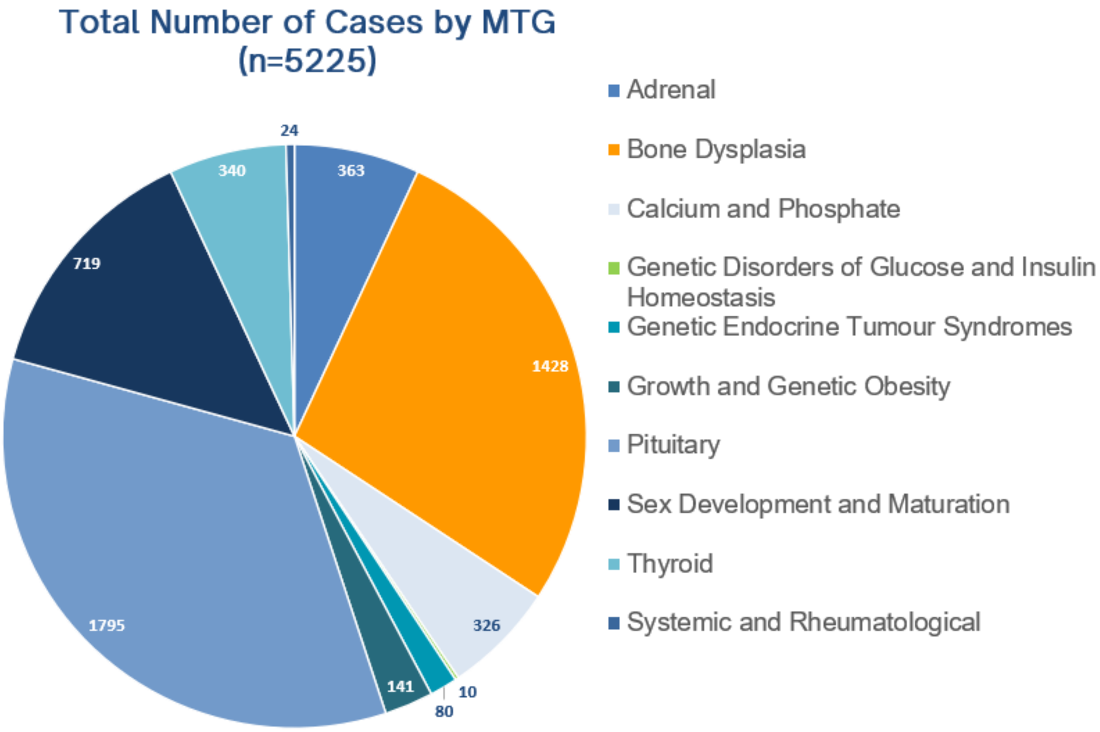


Fig. 3 - The proportion of patients that have been registered with the broad group of conditions or main thematic groups (MTGs) within Endo-ERN and ERN BOND

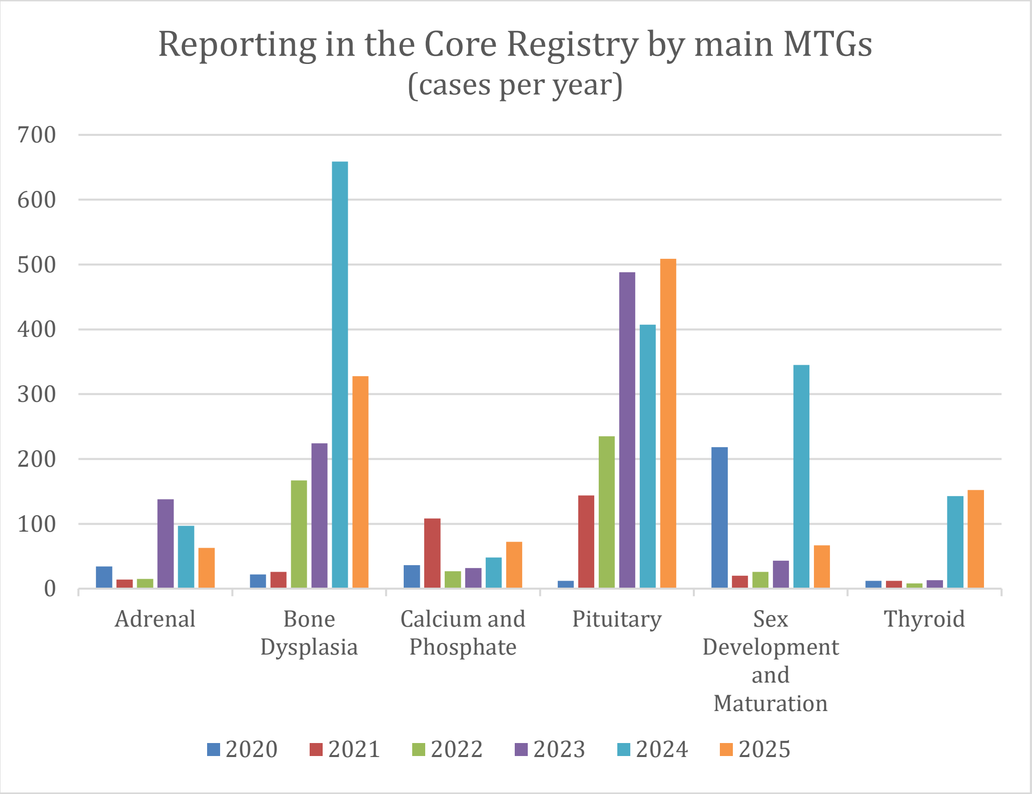


Fig. 4 – The number of patient records by main MTGs over time

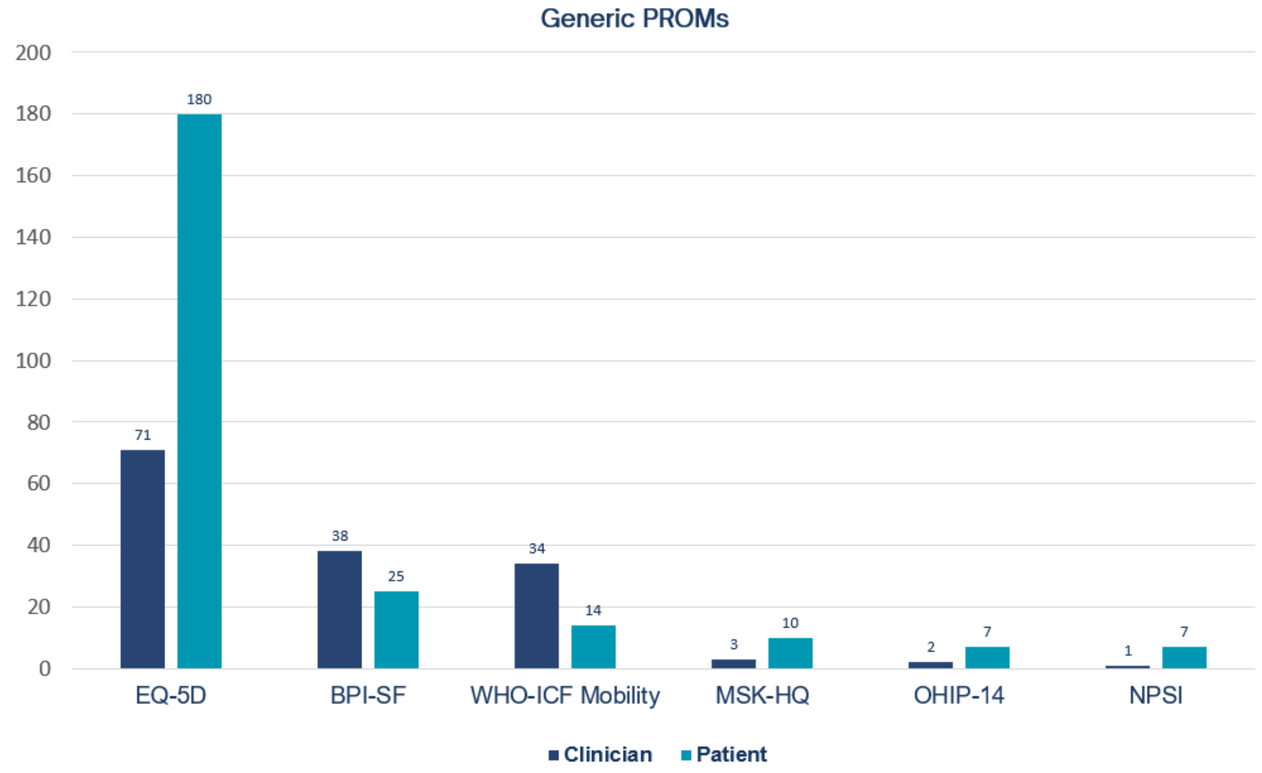
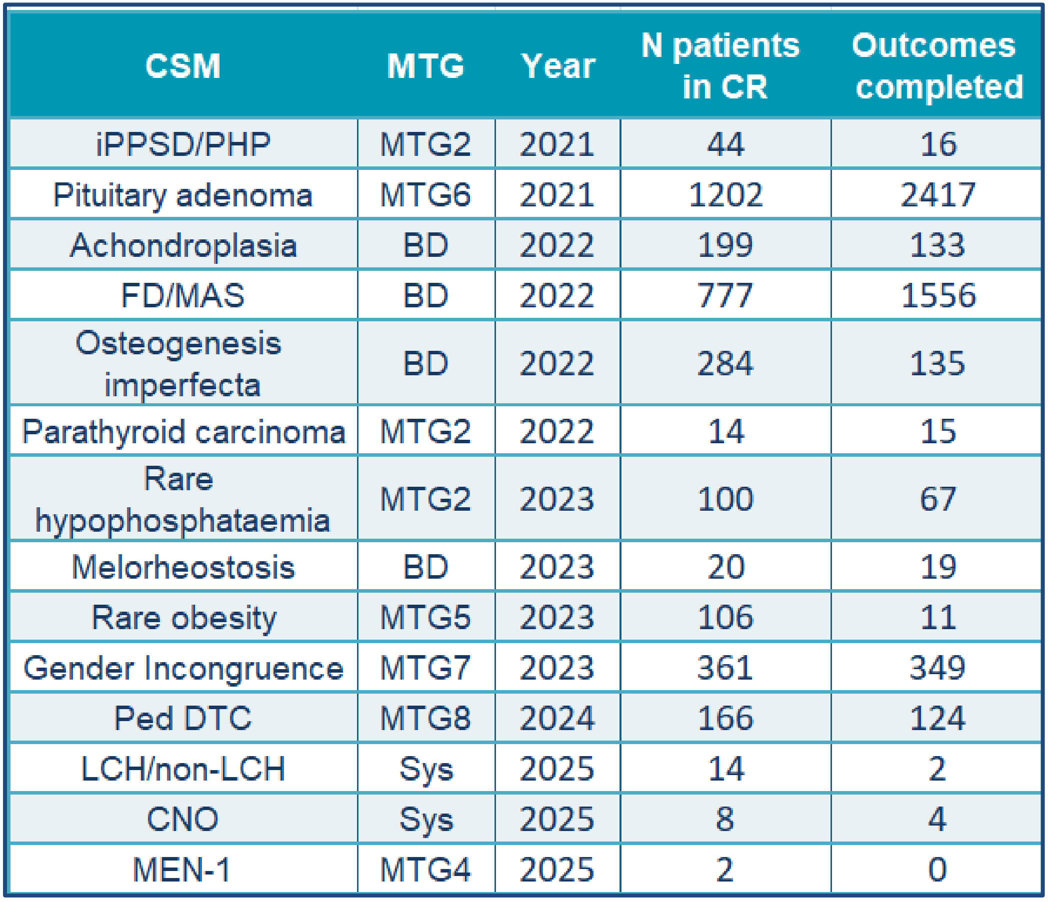


Fig. 5 - Patient-reported outcome measures (PROMs), filled in by clinician or patient

During the past year, four additional condition-specific modules were deployed, increasing the total to 15 and extending coverage to eight of the ten MTGs. By January 2026, the platform had registered 1,584 new outcomes—an increase of 30% compared with 2024 – bringing the cumulative total to 4,848 outcomes. The number of patients enrolled across all CSMs reached 2,096, reflecting the fact that multiple outcomes are collected for many individuals at various time points.
Currently, the most active modules are those dedicated to Pituitary Tumours, Fibrous Dysplasia/McCune-Albright Syndrome (FD/MAS), and Gender Incongruence (Fig. 6). In 2024, a new condition group – Systemic and Rheumatological – was introduced to the platform. Since 2025, this group has incorporated three additional modules focused on endocrine and skeletal complications associated with Langerhans and non-Langerhans Cell Histiocytosis, as well as Chronic Nonbacterial Osteitis. Furthermore, the MEN1 (Multiple Endocrine Neoplasia type 1) module was launched in December 2025. Three further modules are scheduled for release in 2026: hypoparathyroidism, hypophosphatasia, ROHHAD syndrome and a crosscutting women's health module, which will include pregnancy related data.

The registry continues to expand, with an increasing number of centres, users, and patients. A wide range of conditions across all ten main thematic groups are now represented, with patients registered from 70 active centres, 49 of which are within the related ERNs and 21 outside them. The Core Registry platform also provides a means for patients to complete Patient-Reported Outcomes (PROs), further enhancing the value of the data collected. To date, 15 condition-specific modules have been developed within six MTGs, supporting improved understanding and management of these rare conditions.



CSM	MTG	Year	N patients in CR	Outcomes completed
iPPSD/PHP	MTG2	2021	44	16
Pituitary adenoma	MTG6	2021	1202	2417
Achondroplasia	BD	2022	199	133
FD/MAS	BD	2022	777	1556
Osteogenesis imperfecta	BD	2022	284	135
Parathyroid carcinoma	MTG2	2022	14	15
Rare hypophosphataemia	MTG2	2023	100	67
Melorheostosis	BD	2023	20	19
Rare obesity	MTG5	2023	106	11
Gender Incongruence	MTG7	2023	361	349
Ped DTC	MTG8	2024	166	124
LCH/non-LCH	Sys	2025	14	2
CNO	Sys	2025	8	4
MEN-1	MTG4	2025	2	0

Fig 6. Condition-specific modules developed within the platform, year of release, total number of patients with this specific condition in the Core registry and number of completed outcomes per module. For one patient more than one outcome could be created.
(iPPSD/PHP – pseudohypoparathyroidism, FD/MAS - Fibrous Dysplasia/McCune-Albright Syndrome, Ped DTC – Paediatric Differentiated Thyroid Carcinoma, LCH/non-LCH – Langerhans Cell Histiocytosis/non- Langerhans Cell Histiocytosis, CNO –Chronic Non-bacterial Osteitis, MEN-1 - Multiple Endocrine Neoplasia type 1)

Recommendations for 2026

- The dissemination of results within Endo-ERN, ERN BOND, and beyond remains a priority, with efforts to encourage participation from additional interested centres.
- The Registries project management team will explore the possibilities to facilitate data entry by participating centres.
- Data cleaning and module updates are planned for 2026.

The registries project management team: Mariya Cherenko, Ana Priego Zurita, Charlotte van Beuzekom, Jacqueline van der Blom, Faisal Ahmed, Natasha Appelman-Dijkstra

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