

**European Registries for Rare Endocrine and Bone Conditions (EuREB):
Core Registry Activity Report
March 2024**

Introduction

The EuRECa Core Registry (<https://eureb.eu/registries/core-registry/>) was launched in June 2019 and since April 2020, it has also been supporting the EuRR-Bone project. 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 in several languages are available at its website (<https://eureb.eu/registries/ethics-approval/>).

Aim Of This Report

To describe the activity of the EuRECa Core Registry between June 2019 and January 2024.

Results

Since January 2023 an additional 32 centres have registered bringing the total to 114 centres (249 registered users). Of the 114 centres, 34 (30%) have entered data and are described as 'Active Centres'. Of these 34, 30 are based in Europe, 13 are a combination of Endo-ERN and ERN-BOND centres, 11 are exclusively Endo-ERN centres, 2 exclusively ERN BOND and 8 are neither (Fig. 1). To date, 2576 records have been registered. The increase in registration is more than 100% in 2023 (Fig. 2).

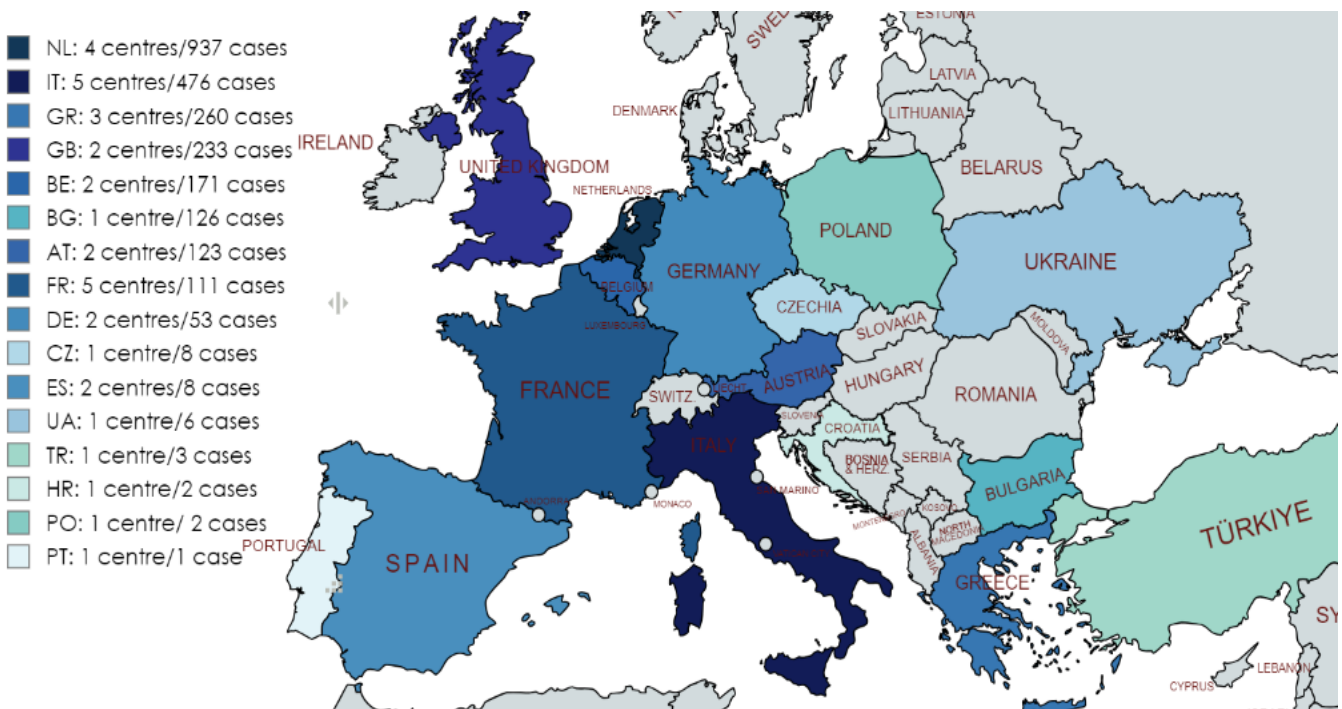


Fig. 1 – The number of cases and centres per country.

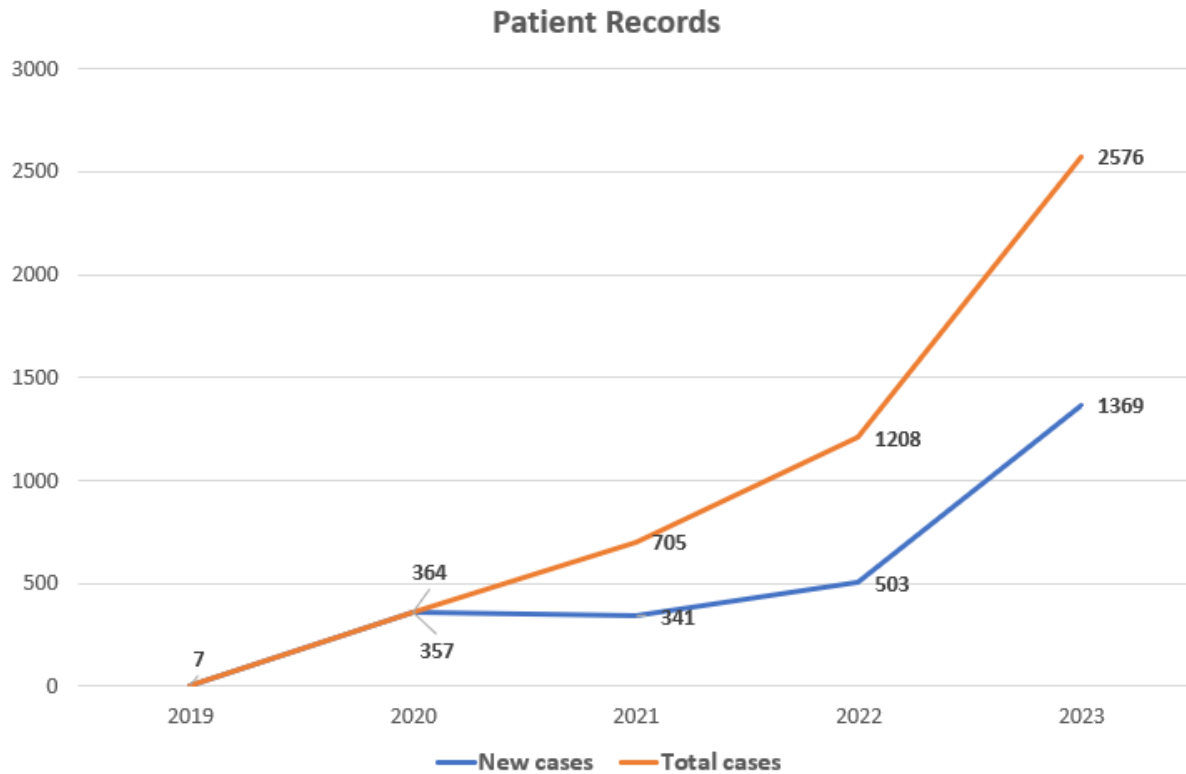


Fig. 2 – The number of patient records in the registry over time.

Condition groups (n=2576 cases)

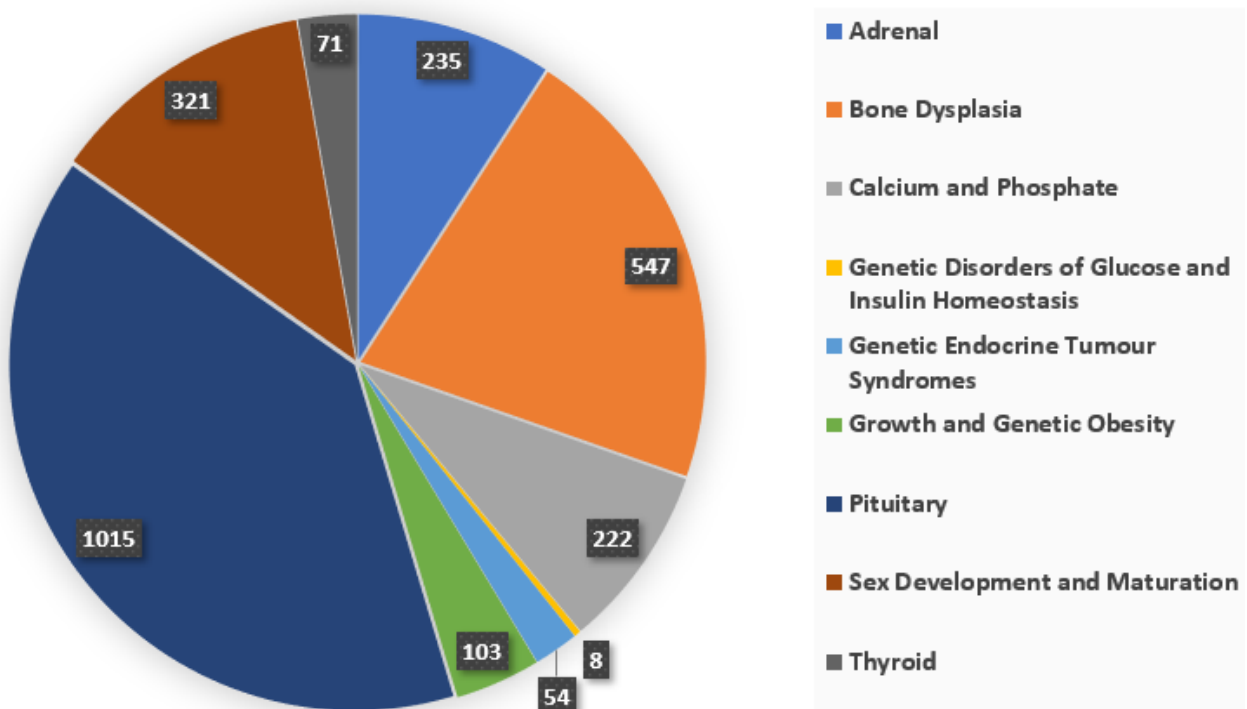


Fig. 3 - The proportion of patients that have been registered with the broad group of conditions or main thematic groups (MTG) within Endo-ERN and ERN-BOND.

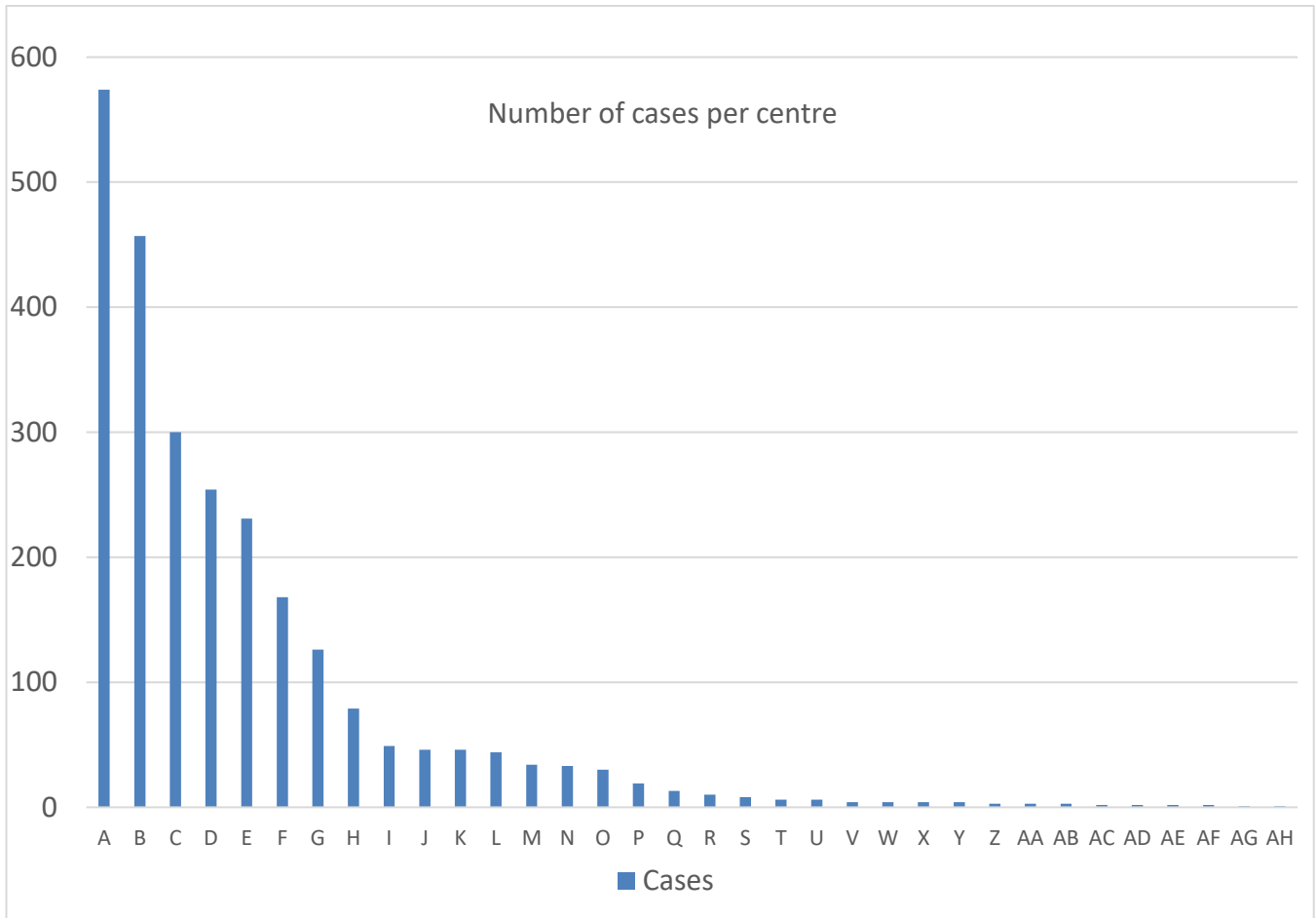


Fig. 4 - The number of patients entered in the Core Registry according to the centres.

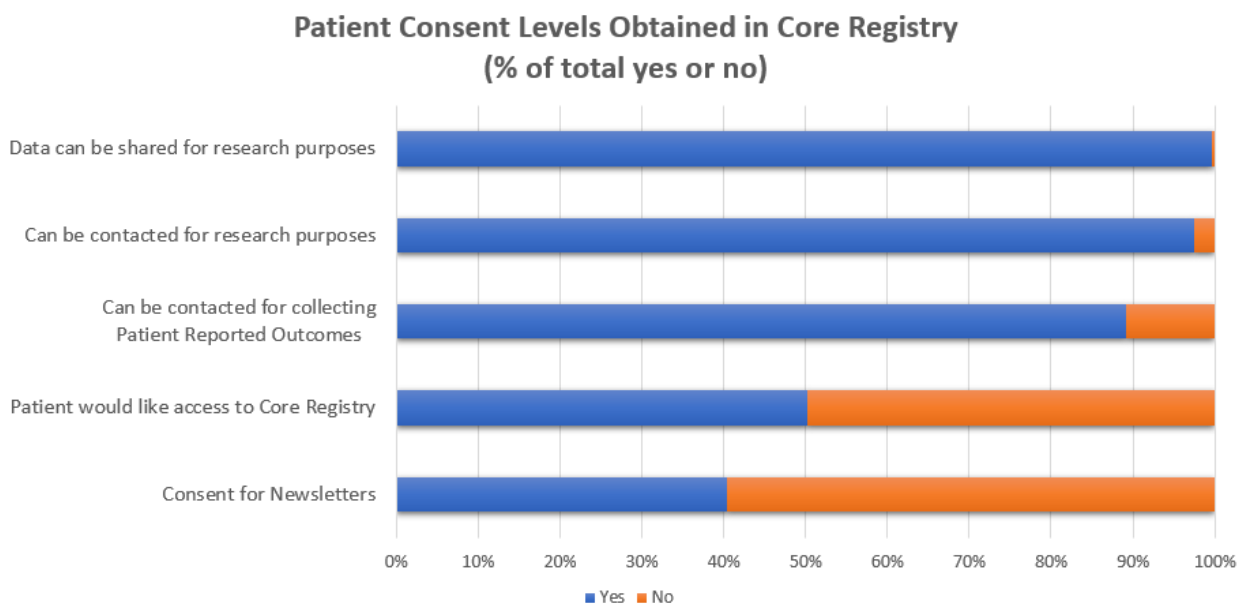


Fig. 5 - The individual preferences of patients for their level of interaction with the project. In total 244 (9.5%) of patients have activated their account on the Core Registry platform.

Patient reported outcome measures (PROMs) have been filled in on the Core Registry platform by both – clinicians and patients (Fig 6). The most 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, as MSK-HQ, OHIP-14 and PHQoL.

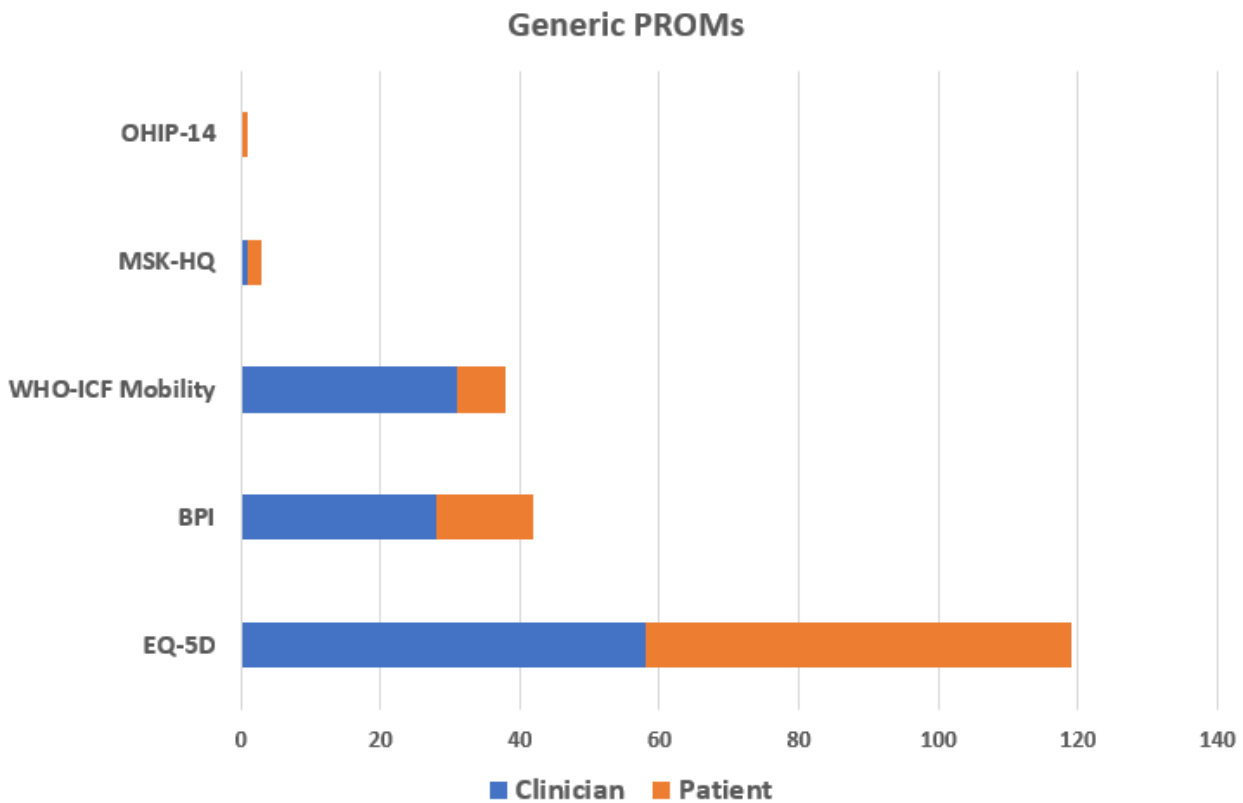


Fig 6. Patient reported outcome measures (PROMs)

From 2021 till the end of 2023, 11 condition-specific modules have been launched on the Core Registry platform, covering 6 out of 9 MTGs (4 of them in Bone Dysplasia group). Five new modules have been launched in 2023. Until December 2023, 1249 outcomes were completed. The most active modules currently are Pituitary Tumour, Fibrous Dysplasia / McCune Albright Syndrome (FD/MAS) and Achondroplasia. (Fig. 7).

Interpretation of Findings

- An increase in the number of centres, users and patients continues to occur
- Patients with a wide variety of conditions across all 9 main thematic groups have been registered
- Currently, registered patients are from 34 active centres of which 26 are in ERNs and 8 are not in ERNs
- The Core Registry platform can provide access to patients to complete PROs but this functionality requires further exploration over time
- 11 condition-specific outcomes have been developed within 6 MTGs

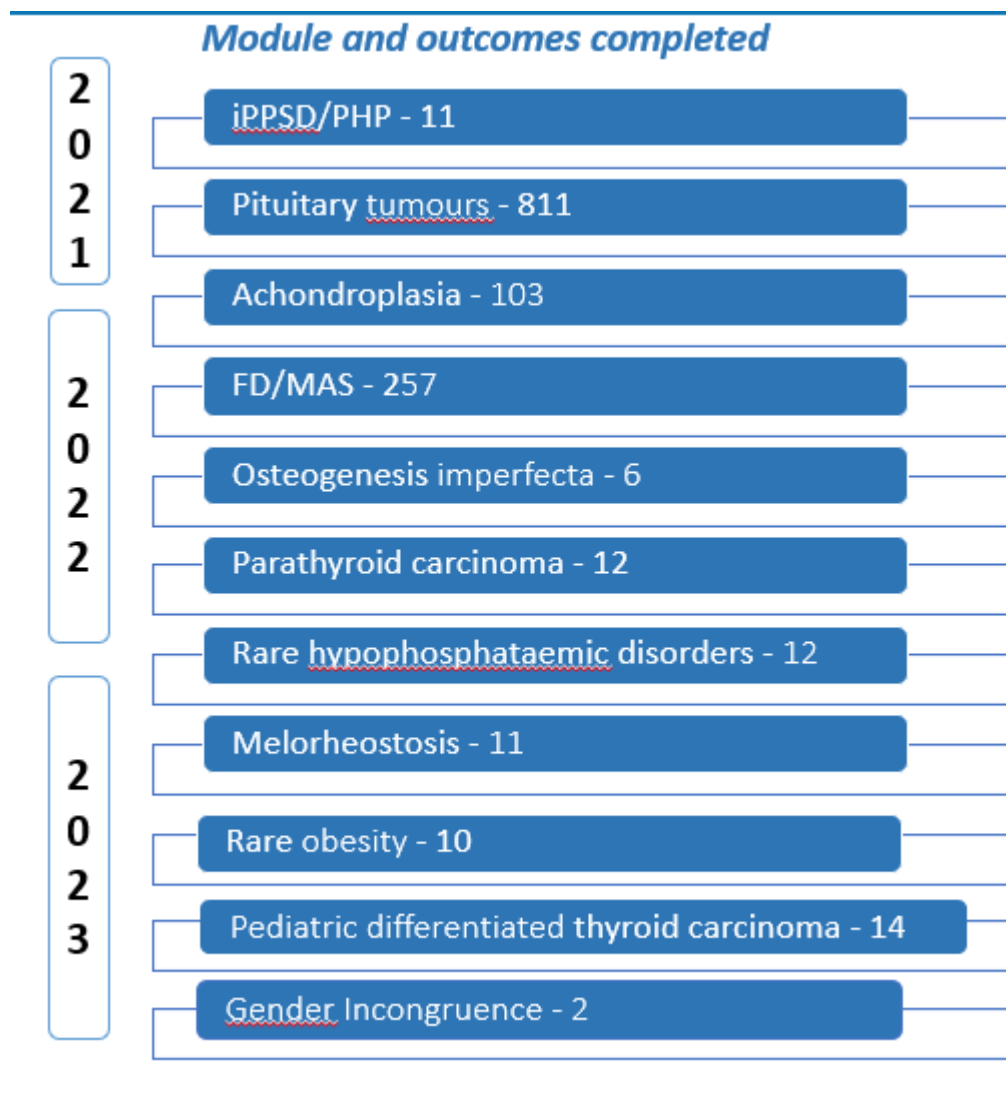


Fig 7. Condition-specific modules developed within the platform, year of release and number of completed outcomes. The number next to the name of the condition-specific module indicates the outcomes completed per module.

Recommendations

- Disseminate results within Endo-ERN, ERN-BOND and beyond and encourage participation from interested centres
- New participating centres should look at the information sheets and consent forms. These have been translated by centres actively using the Core Registry but should be checked locally to ensure compliance with local institutional policies
- The EuRRECa/EuRR-Bone (EuRREB) office will continue to prepare yearly reports
- Researchers are encouraged to contact the Registries team to obtain data that are being collected.

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29th March, 2024



Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or HaDEA. Neither the European Union nor the granting authority can be held responsible for them. Project: 101156495 (Endo-ERN), Project: 101157116 (ERN BOND); EU4H-2023-ERN2-IBA-01.