

**Core Registry Activity Report
March 2023**

Introduction

The Core Registry (<https://eurreca.net/core-registry/>) was launched in June 2019 by EuRRECa 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://eurreca.net/core-registry-information-sheets/>).

Aim Of This Report

To describe the activity of the Core Registry between June 2019 and December 2022.

Results

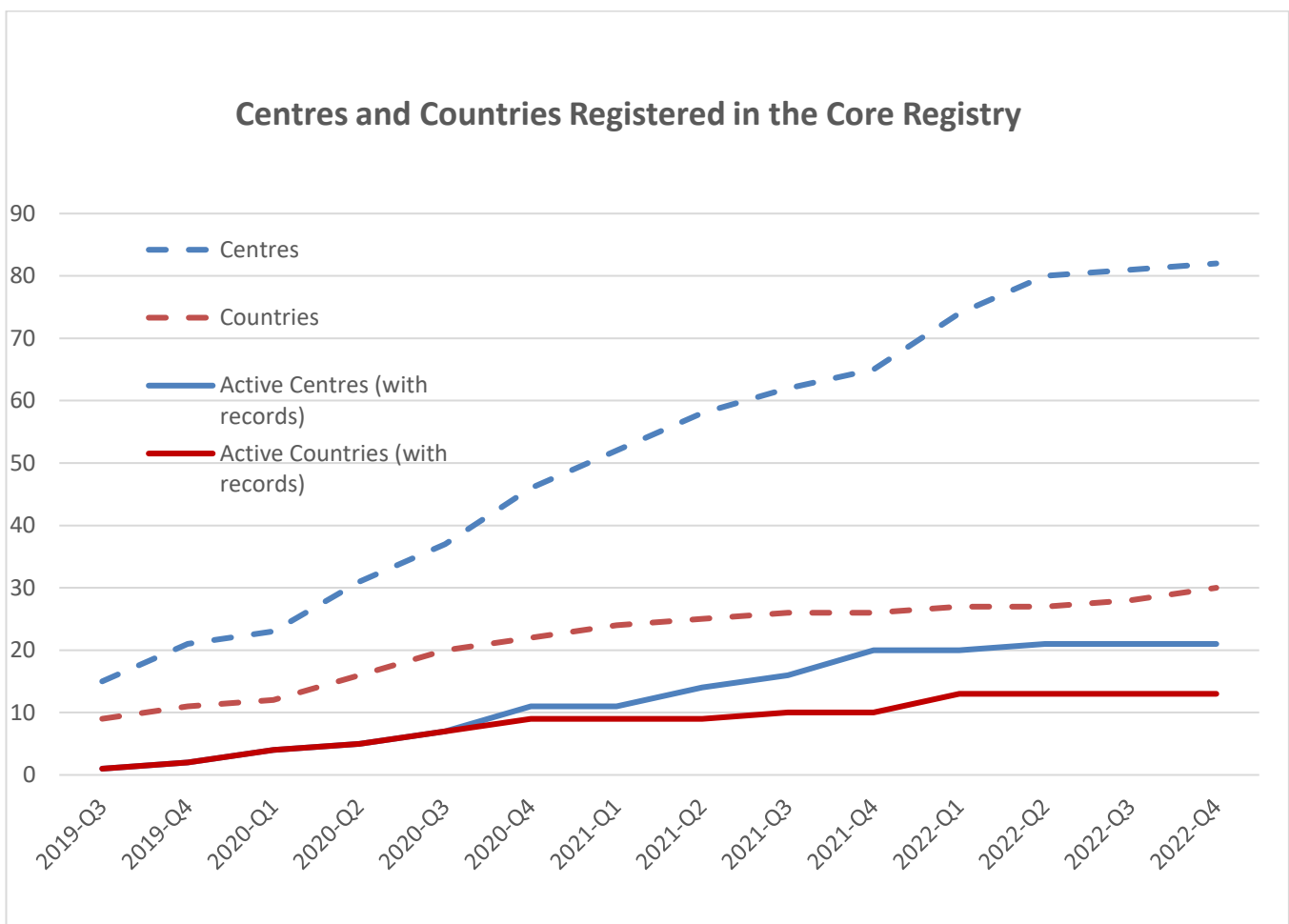


Fig.1A - The number of countries and centres registered over time and those that are actively adding patients. Since January 2022 an additional 17 centres have registered bringing the total to 82 centres (163 registered users). Of the 82 centres, 21 (26%) have entered data and are described as ‘Active Centres’. Of these 21, 18 are based in Europe, 10 are a combination of Endo-ERN and ERN-BOND centres, 4 are exclusively Endo-ERN centres and 7 are neither.

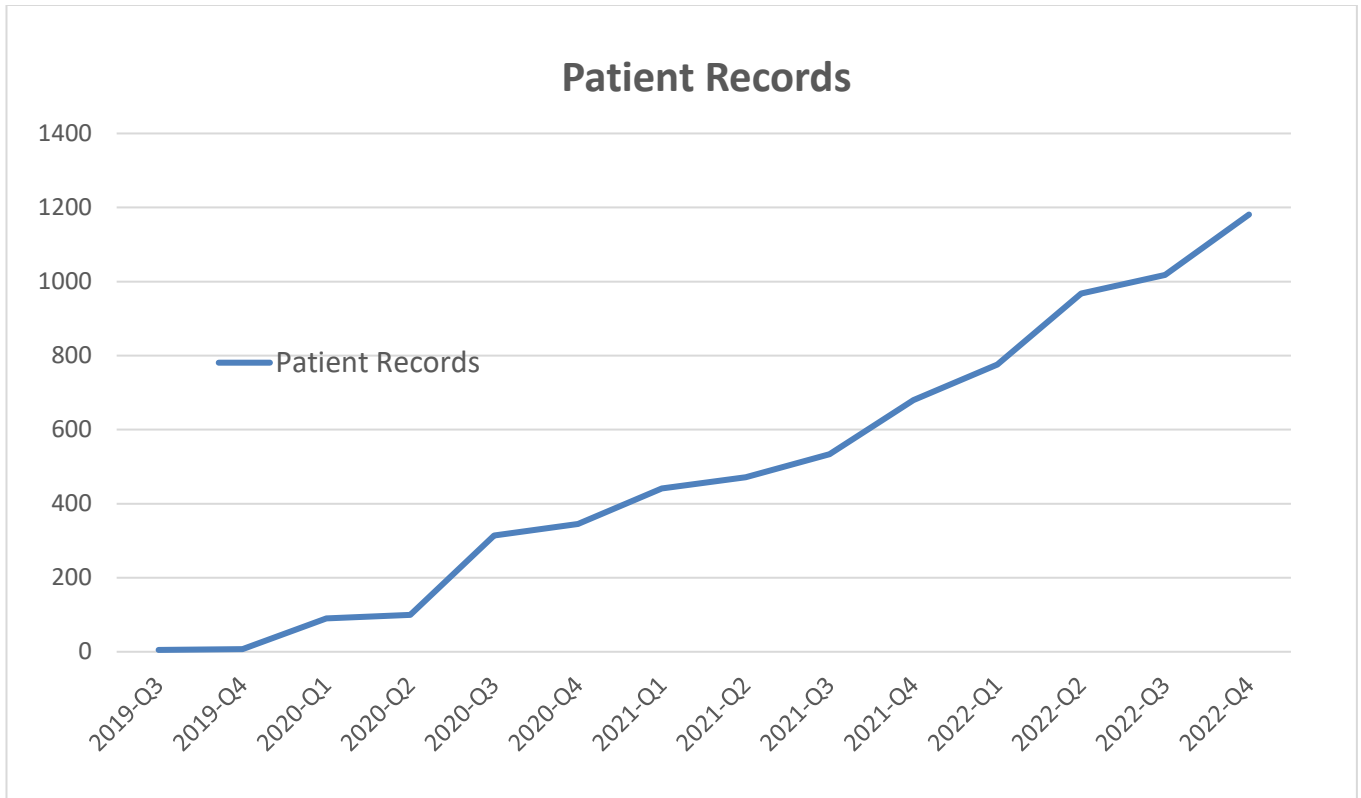


Fig.1B – The number of patient records in the registry over time. To date, 1,181 records have been registered.

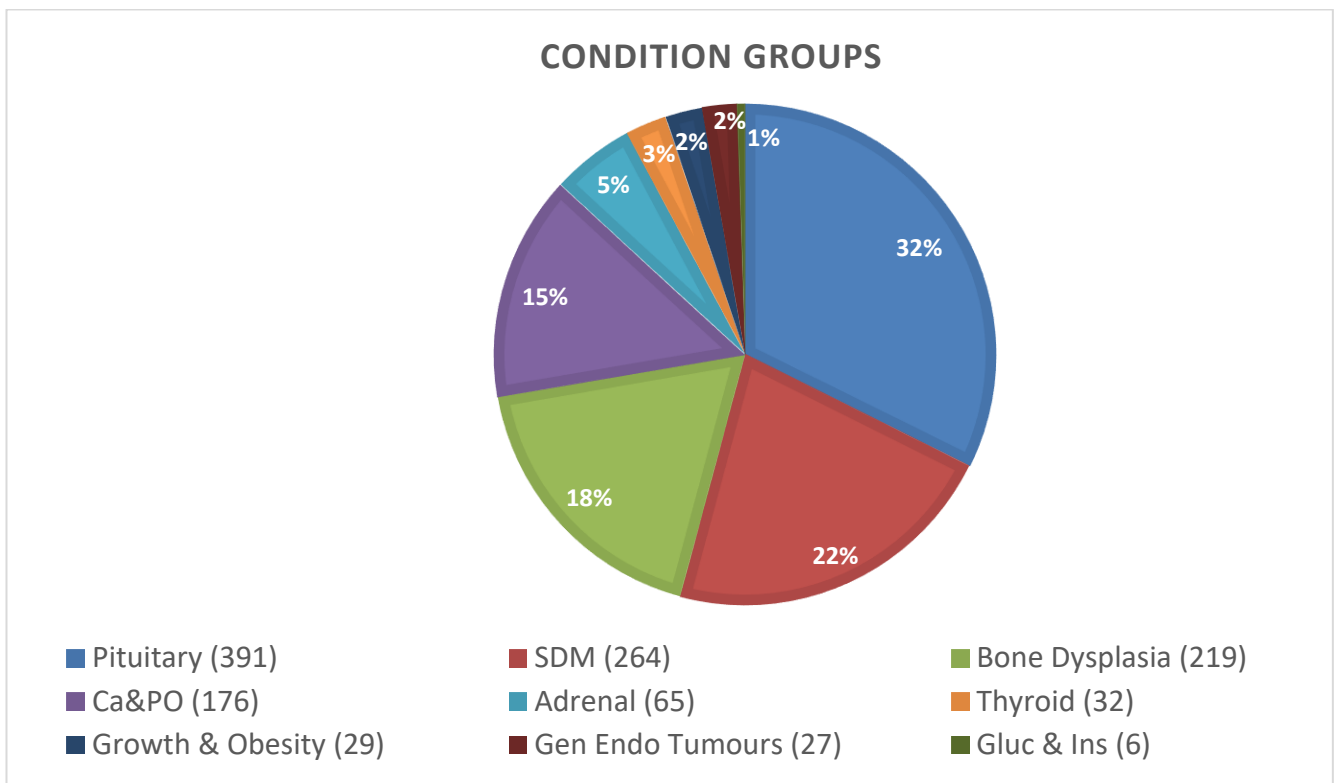


Fig.2 - The proportion of patients that have been registered with the broad group of conditions or main thematic groups (MTG) within Endo-ERN and ERN-BOND.

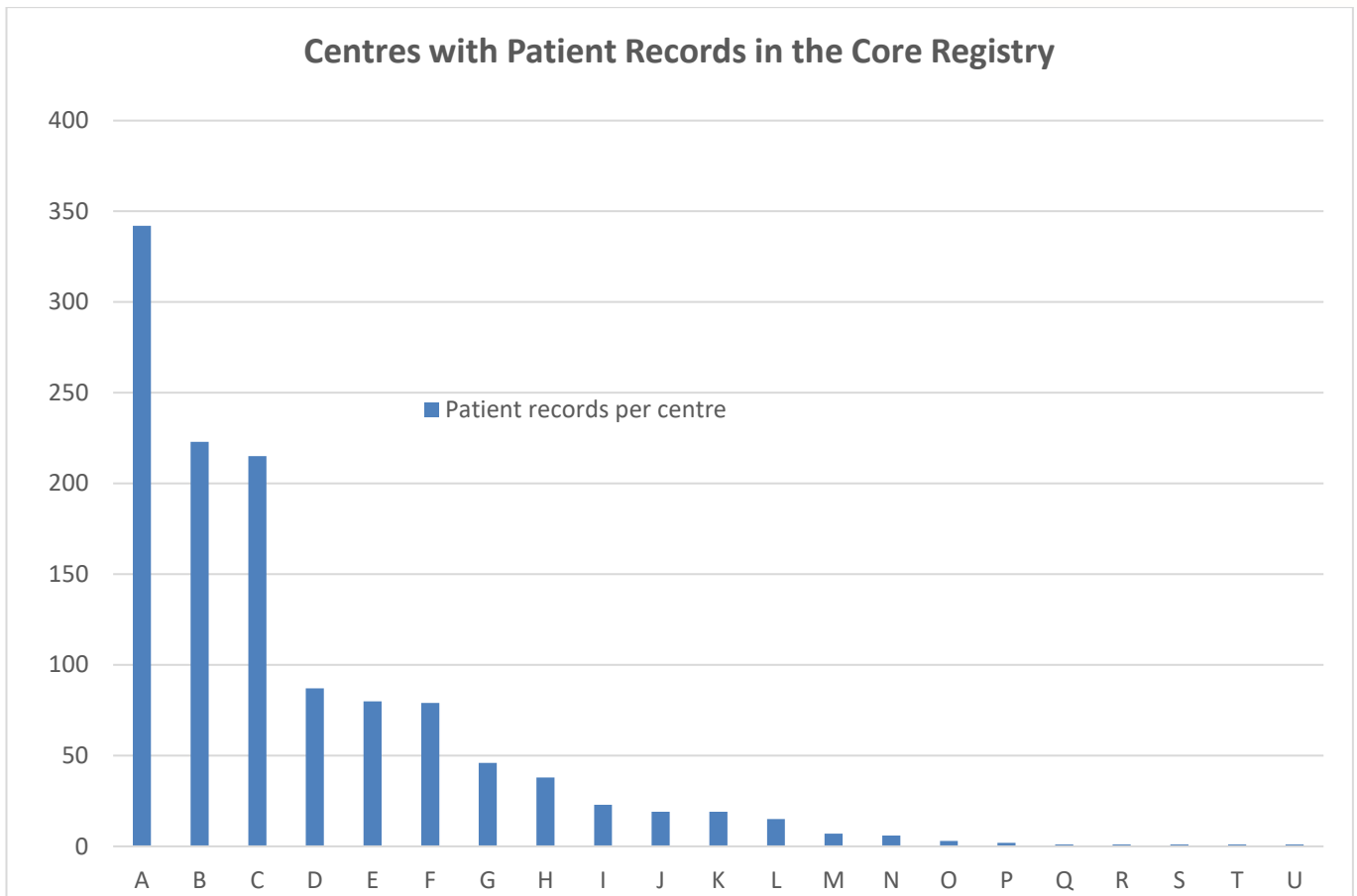


Fig.3 - The number of patients entered in the Core Registry according to the centres.

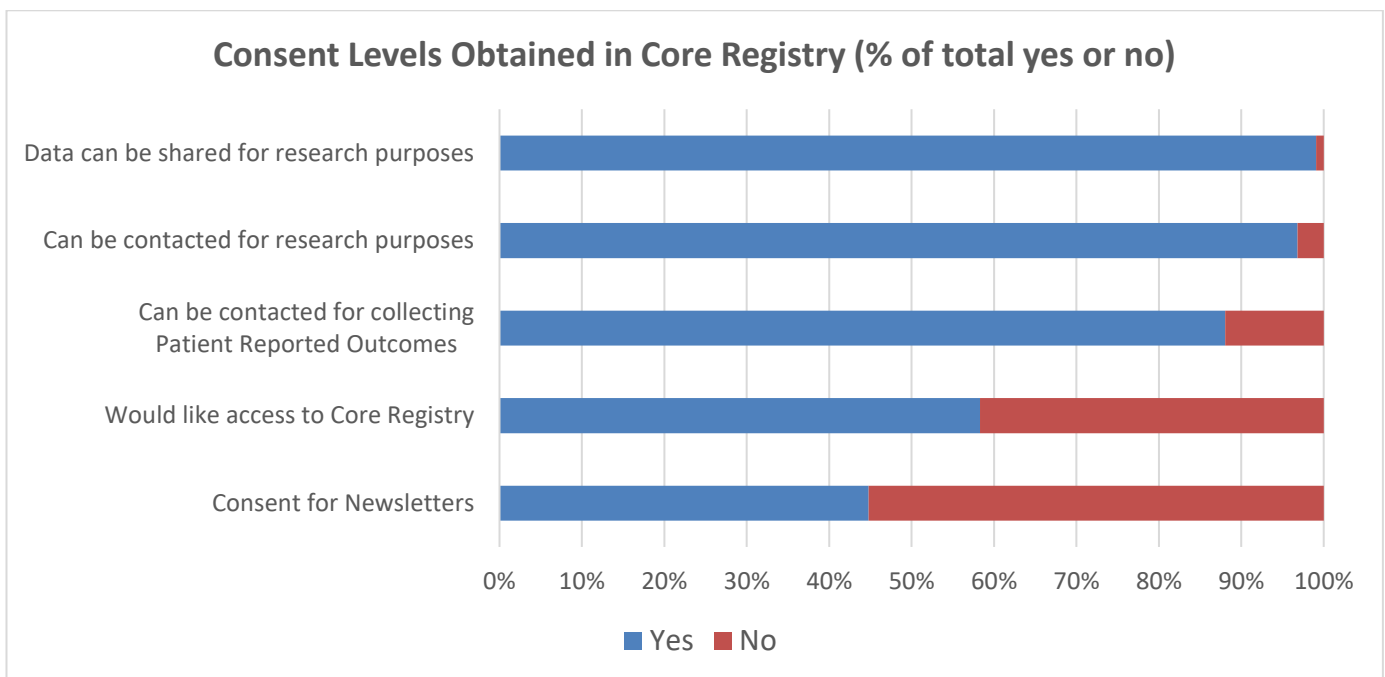


Fig.4 - The individual preferences of patients for their level of interaction with the project.

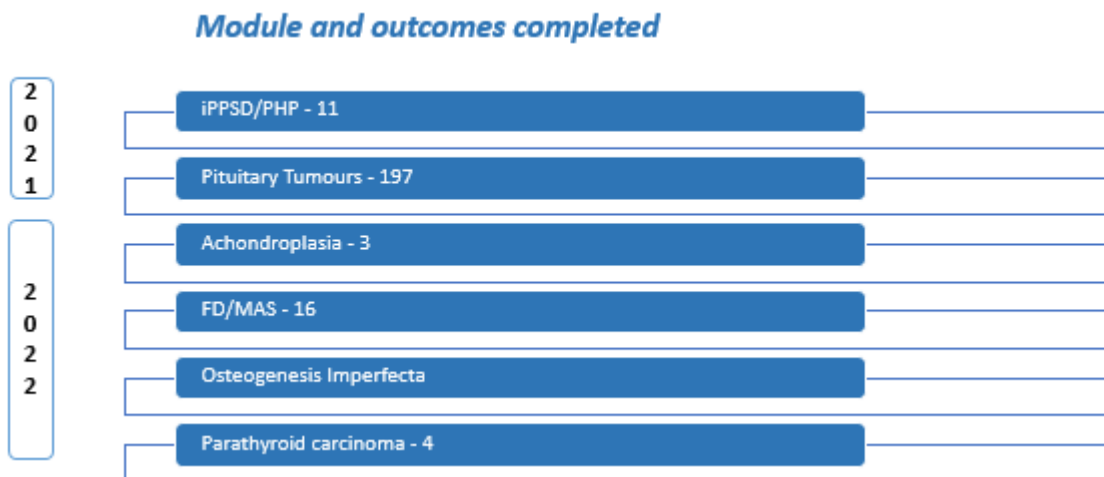


Fig 5. Condition-specific modules developed within the platform and year of release. The number next to the name of the condition-specific module indicates the outcomes completed per module. Until December 2022 238 outcomes were completed.

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 21 active centres of which 14 are in ERNs and 7 are not in ERNs
- The Core Registry platform can provide access to patients to complete PROs but this functionality requires further exploration over time
- Condition-specific outcomes have been developed within 4 MTGs

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 Registries office will continue to prepare yearly reports
- Researchers are encouraged to contact the Registries team to obtain data that are being collected

Ana Priego Zurita, Mariya Cherenko, Tess de Rooij, Natasha Appelman-Dijkstra, Faisal Ahmed

26th March, 2023



This report is part of the project '777215 / EuRRECa' which has received funding from the European Union's Health Programme (2014-2020) and is part of the project '946831 / EuRR-Bone' which has received funding from the European Union's Health Programme (2020-2023). The content of this report represents the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.