

**Core Registry Activity Report
March 2023**

Introduction

The Core Registry (<https://eurr-bone.com/registries/core/>) was launched in 2019 and is open to all health care providers. The platform is open for EuRR-Bone since April 2020 including 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://eurr-bone.com/core-registry-protocols/>).

Aim Of This Report

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

Results

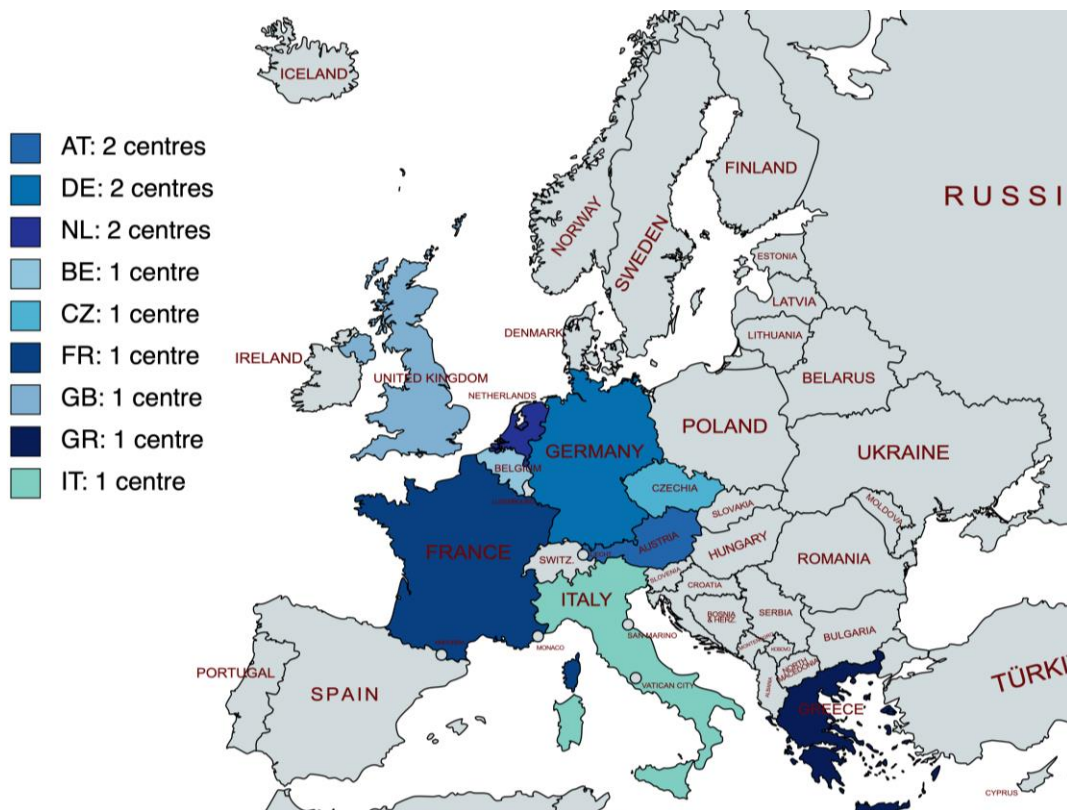


Fig.1 Centres actively adding patients per country. Of the 13 active centres, of which 12 are based in Europe, 7 are joint Endo-ERN and ERN-BOND centres, 1 is exclusively Endo-ERN centre and 5 are neither.

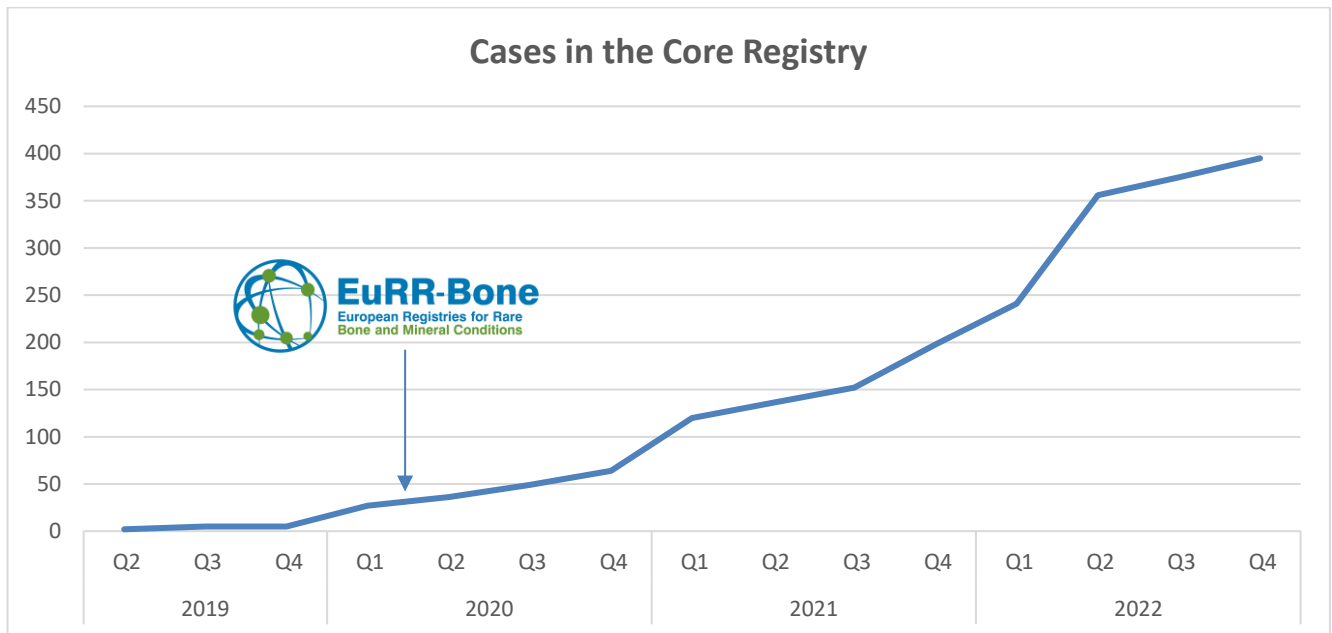


Fig.2 Number of patient records in the registry over time. Until December 2022, 401 records were registered.

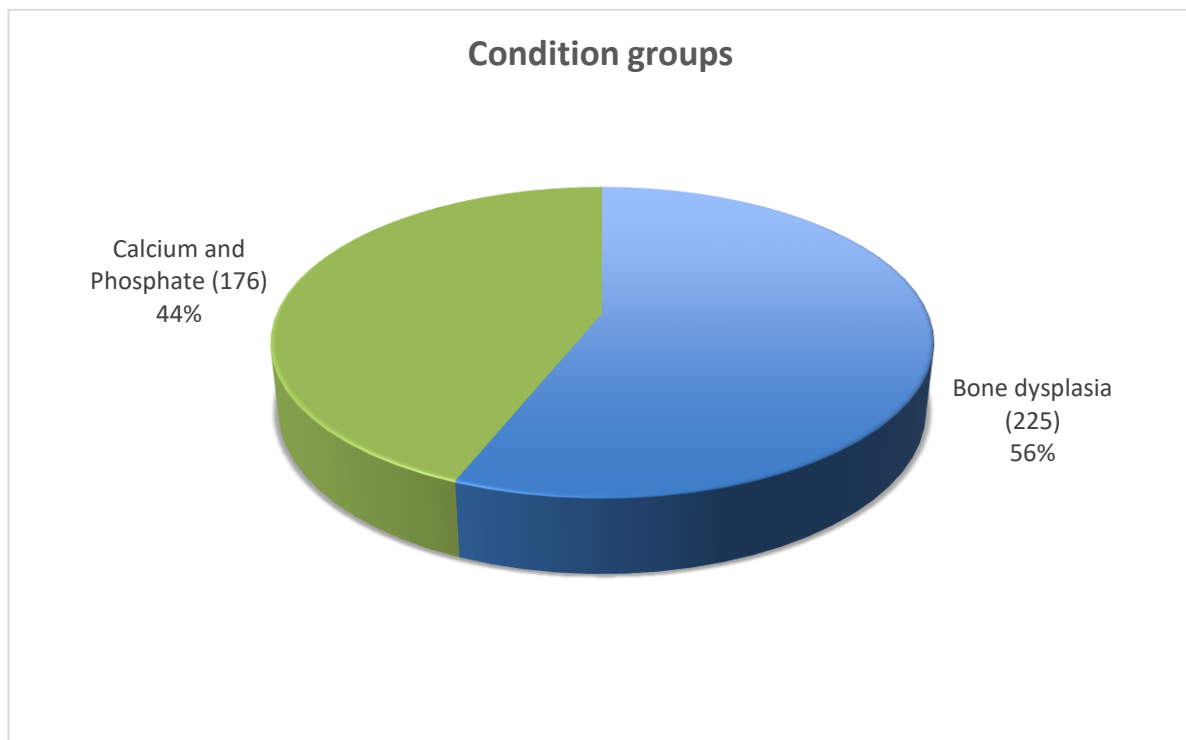


Fig.3 Distribution of patients that have been registered with the 2 broad group of conditions or main thematic groups (MTG) within Endo-ERN and ERN-BOND.

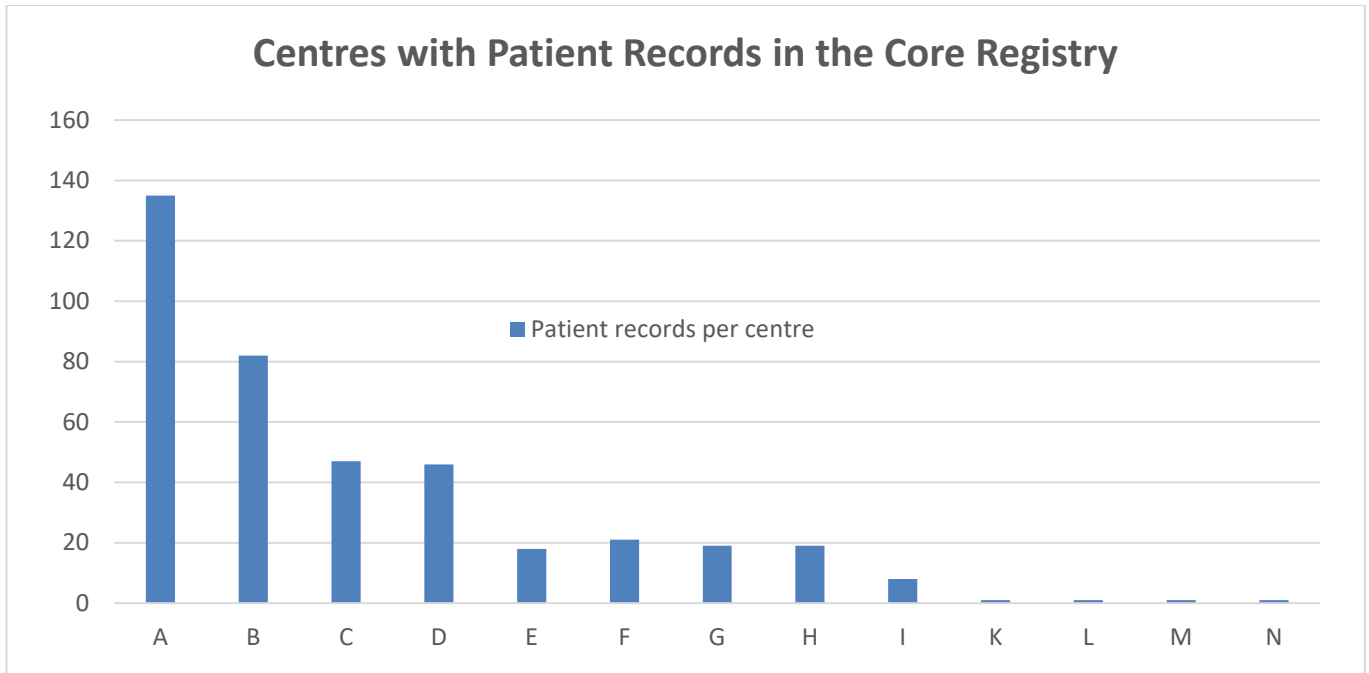


Fig.4 Number of patients entered in the Core Registry according to the active centres.

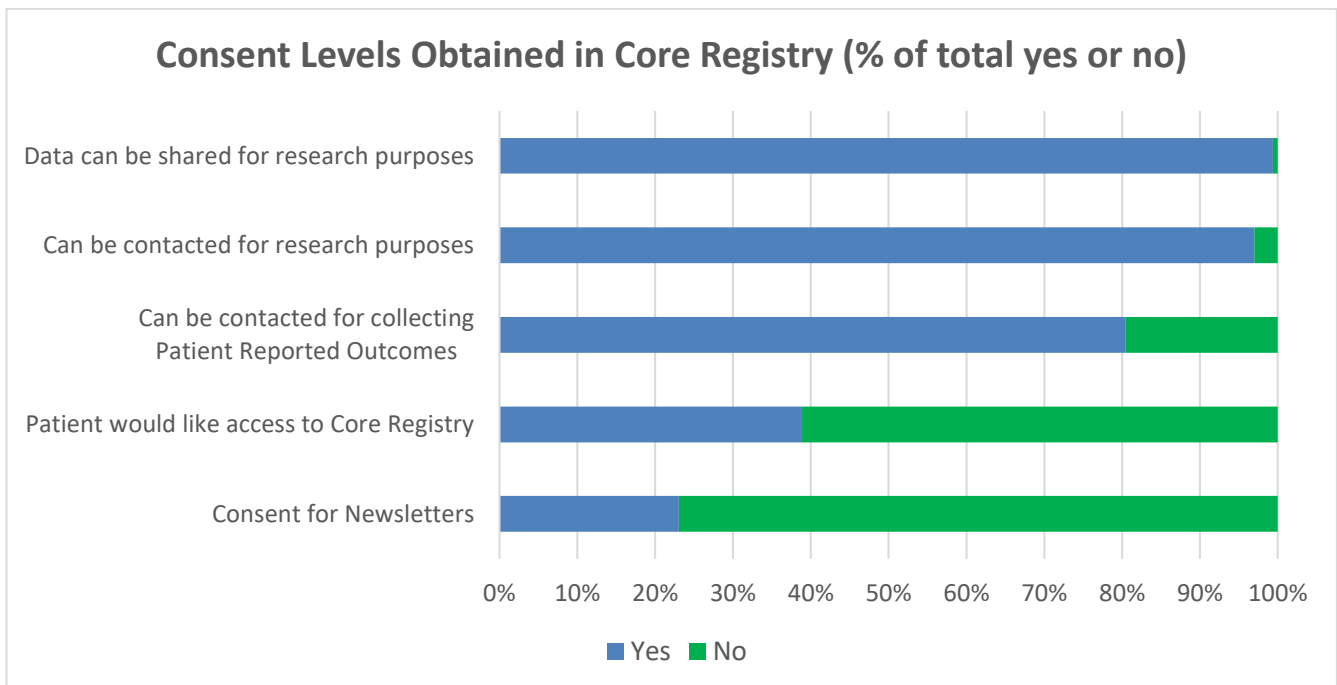


Fig.5 Individual preferences of patients for their level of interaction with the project.

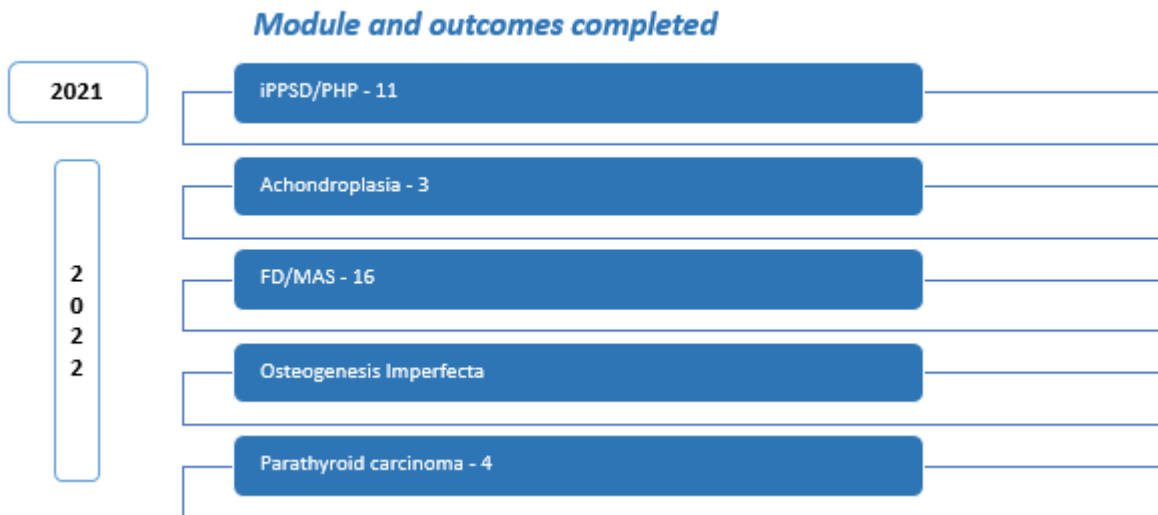


Fig 6. Condition-specific modules developed within the platform and year of release. The number next to the name of the condition-specific module indicates the outcomes completed per module until December 2022.

Interpretation of Findings

- An increase in the number of centres, users and patients continues to occur
- Currently, registered patients are from 13 active centres of which 8 are in ERNs and 5 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 both MTGs

Recommendations

- Disseminate results within ERN-BOND, Endo-ERN 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

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