

**Core Registry Activity Report  
January 2022**

**Introduction**

The EuRRECa Core Registry (<https://eurreca.net/core-registry/>) was launched in June 2019 and is open to all health care providers. 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/>). Since the last report in July 2021 an additional 7 centres have registered bringing the total to 65 centres (107 registered users). Since April 2020, the EuRRECa platform has also been supporting the EuRR-Bone project.

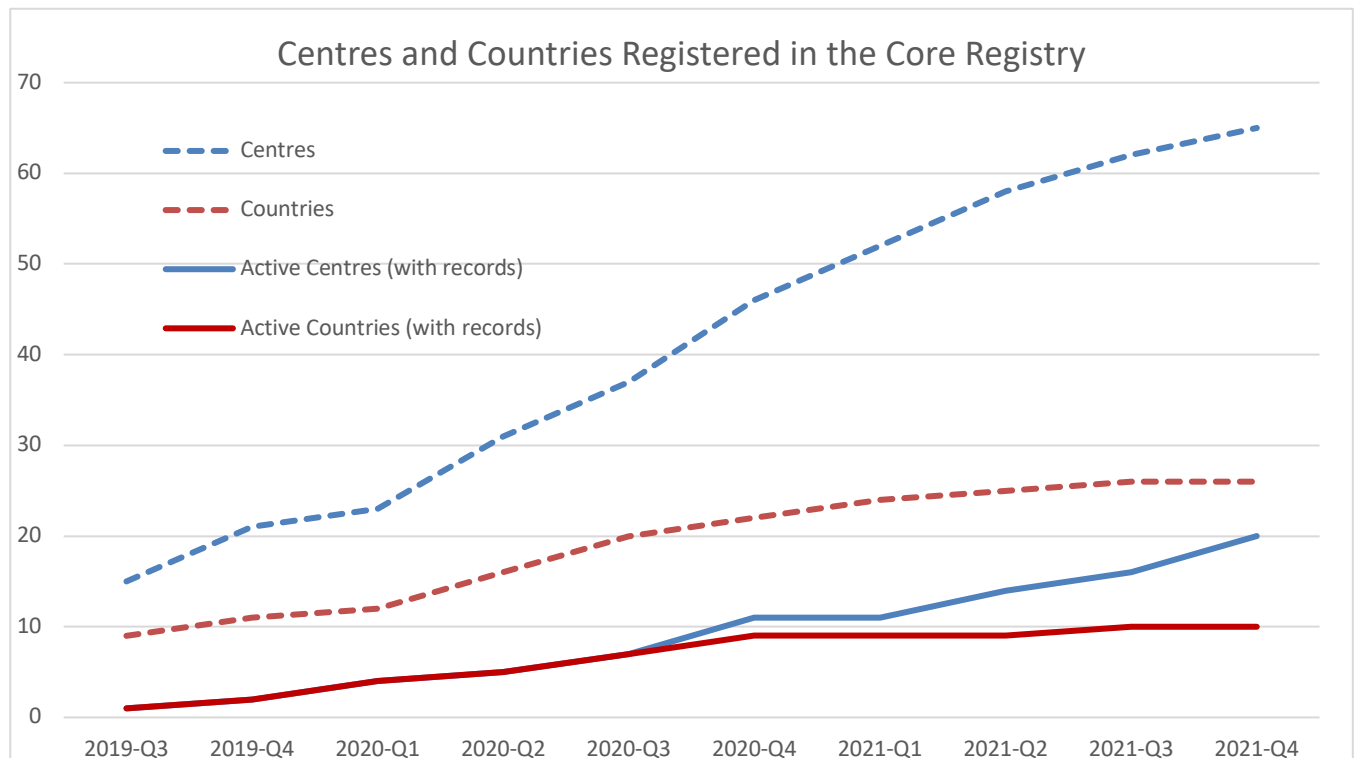
**Aim Of This Report**

To describe the activity of the EuRRECa Core Registry between June 2019 and December 2021.

**Results**

Fig.1A shows the number of countries and centres registered over time and those that are actively adding patients. Fig.1B shows the numbers of patient records in the registry over time. Of the 19 active centres, of which 17 are based in Europe, 8 are joint Endo-ERN and ERN-BOND centres, 4 are exclusively Endo-ERN centres, 1 is exclusively ERN BOND and 6 are neither. To date, 712 records have been registered.

1A



1B

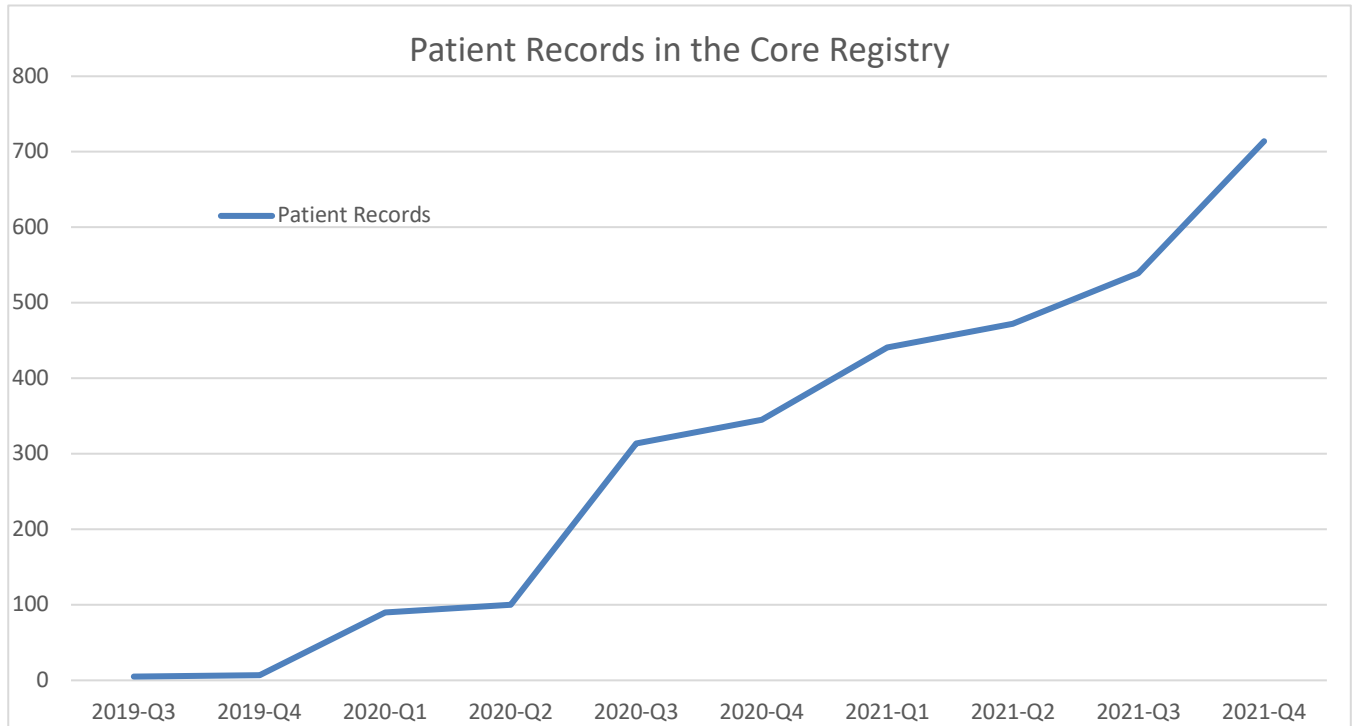


Fig.2 shows the proportion of patients that have been registered with the broad group of conditions or main thematic groups (MTG) within Endo-ERN and ERN-BOND.

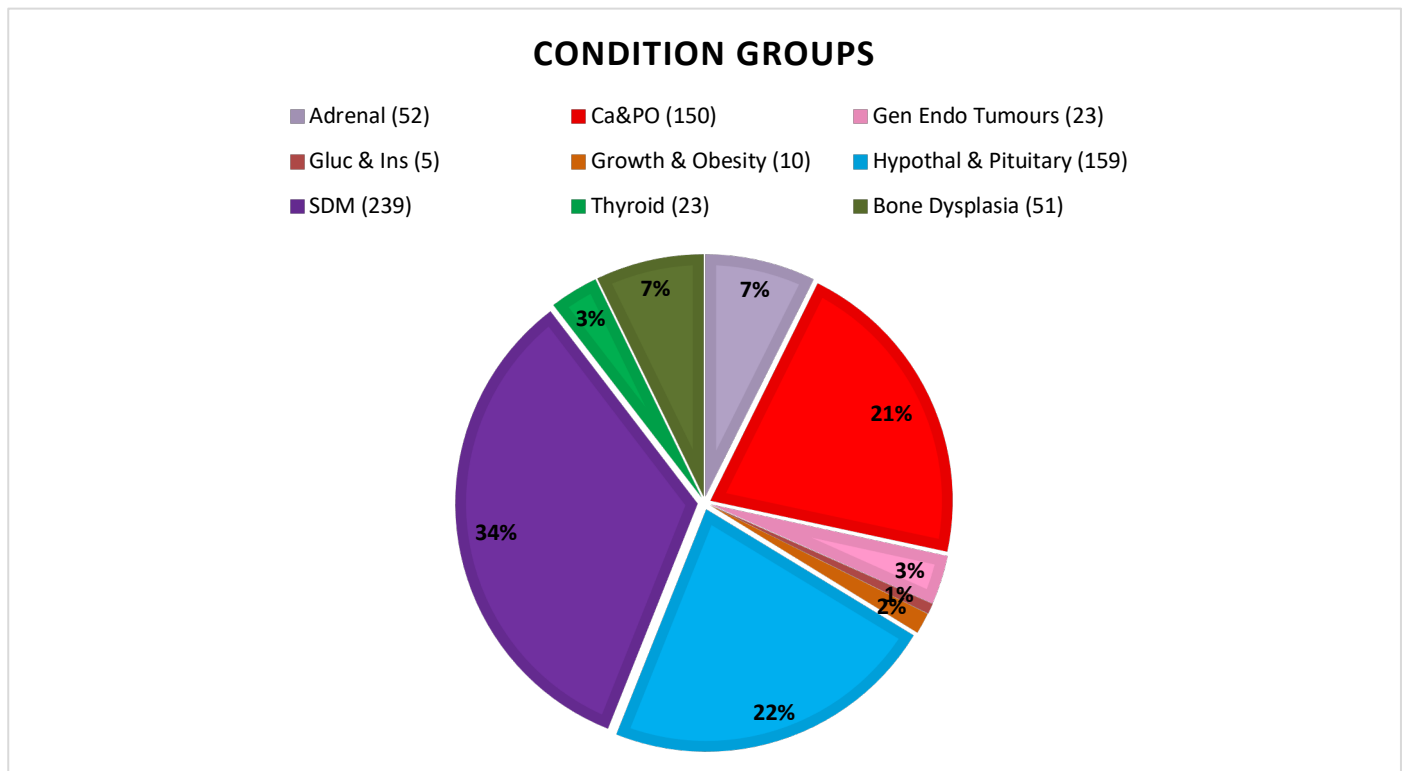


Fig.3 shows the number of patients entered in the Core Registry according to the centres.

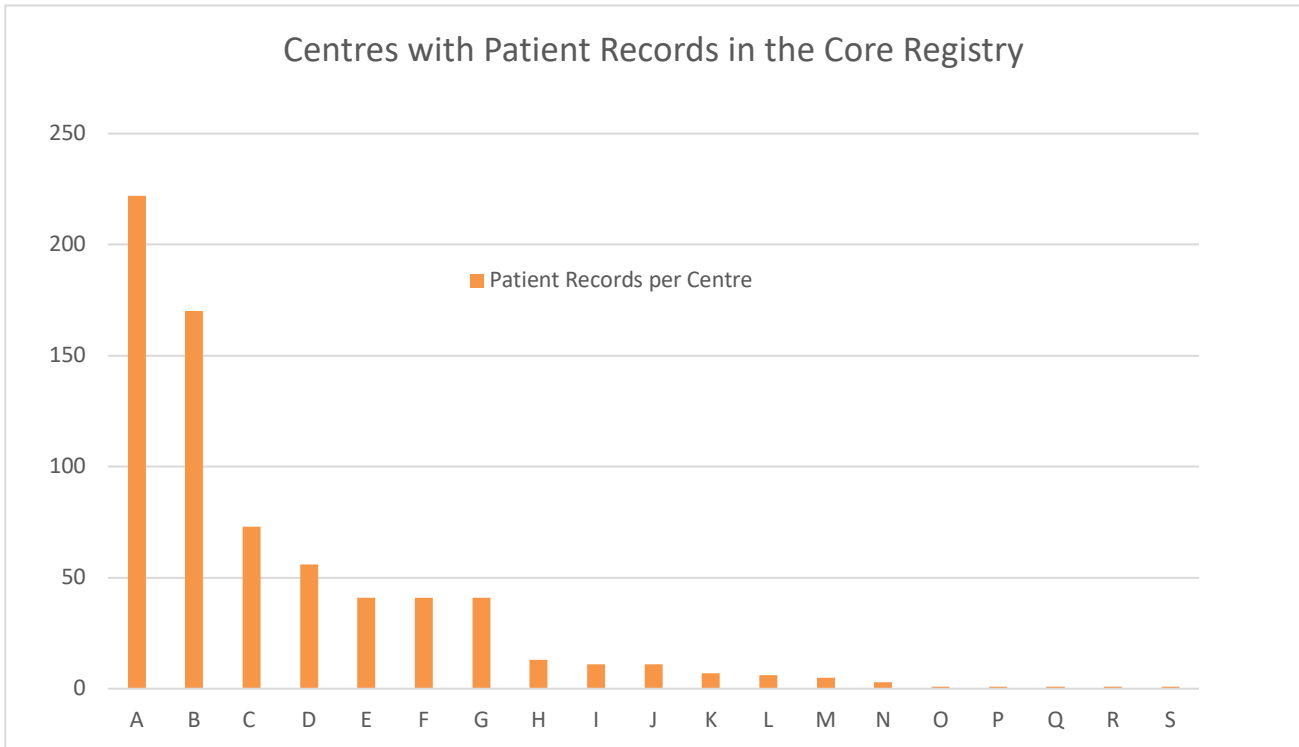


Fig 4 shows the individual preferences of patients for their level of interaction with the project.

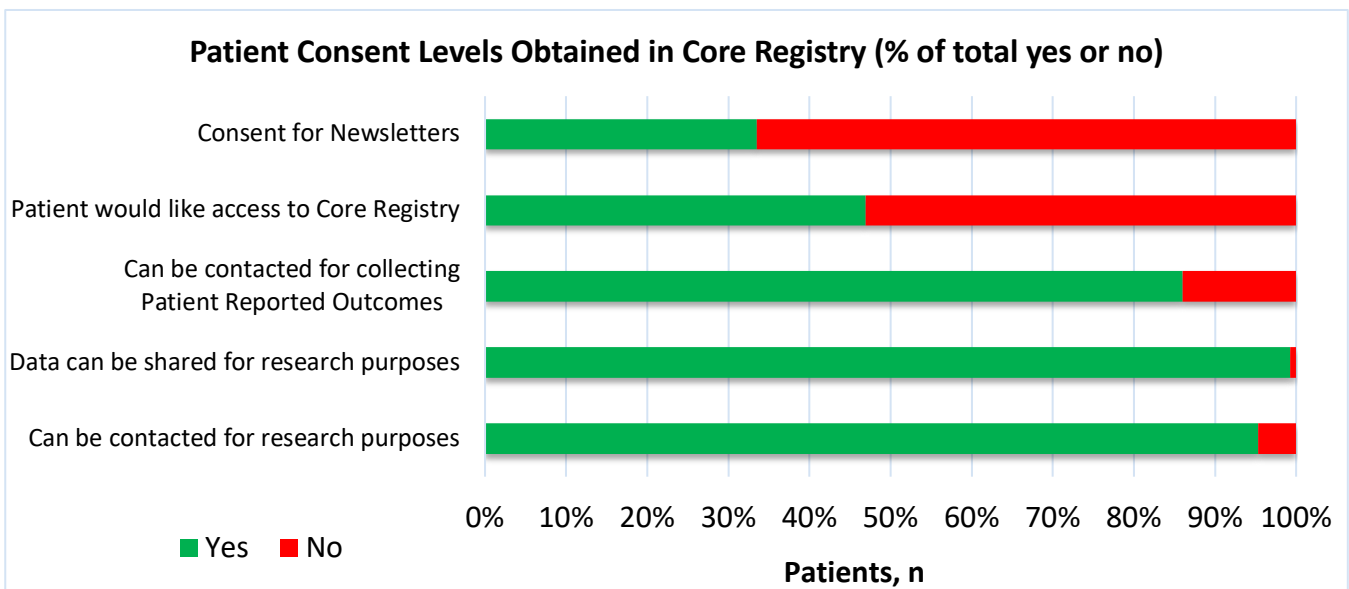
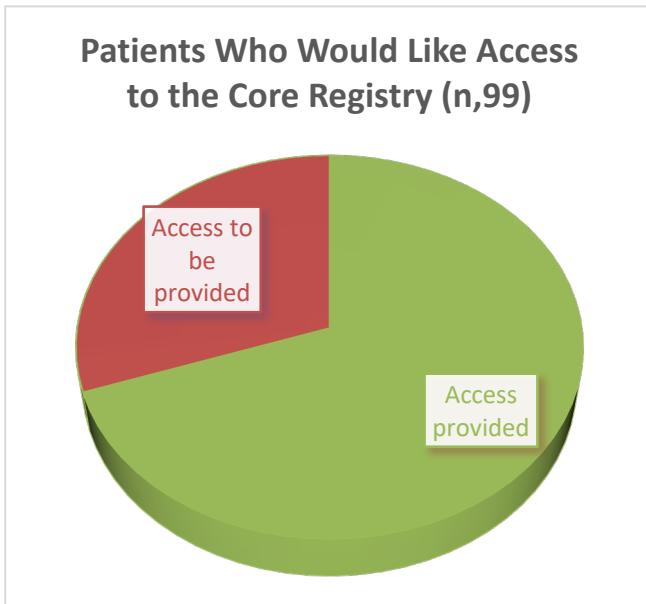


Fig.5A shows further details of the patients who expressed their wish to have access to the platform. Fig.5B shows further details of the records where access has been provided to patients. Of the 69 patients who have been provided access, a quarter have activated their account.

5A



5B

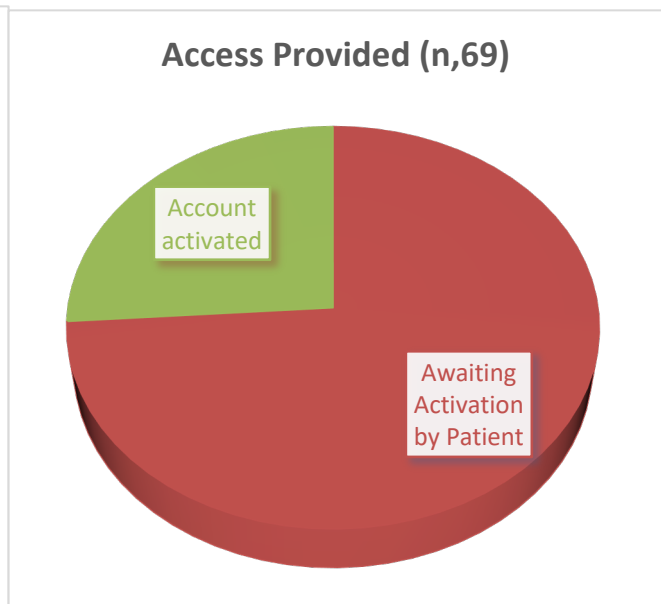
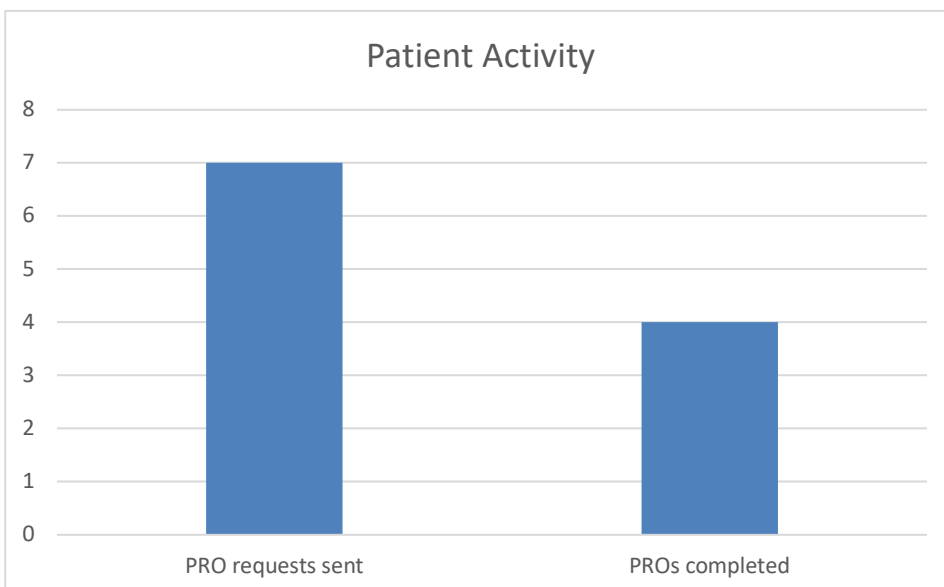


Fig.6 Of the 18 patients with an active account in the Core Registry, 7 have received a request to complete a patient reported outcome and 4 have completed an outcome.



### 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 19 active centres of which 11 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

### 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 office will continue to prepare yearly reports for the PGB and participating centres

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