

**D6.6 (D34) EuRECa Core Registry Report
January 2021**

Introduction

The EuRECa Core Registry (<https://eurreca.net/core-registry/>) was launched in June 2019 and the platform has been continually improved to include patient access and reporting of patient or clinician reported outcomes, either generic or condition specific. 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. Users can also utilise the ERN information sheets and consent forms. However, the use of the EuRECa consent forms also allows the collection of patient emails that can then be used for providing access to the Registry as well as its self-reporting tools. Both the ERN consent forms and the EuRECa consent forms allow sharing of data with other approved registries. The first group of centres to become registered were the centres of the Project Governing Board (2019-Q3). Thereafter, new centres have joined by completing on-line self-registration (<https://www.mvls.gla.ac.uk/EuRECaAuth/Registration/Create>). So far 16 additional centres have registered. From April 2020, the EuRECa platform was also provided to the EuRR-Bone project for acting as a registry for centres within ERN-BOND.

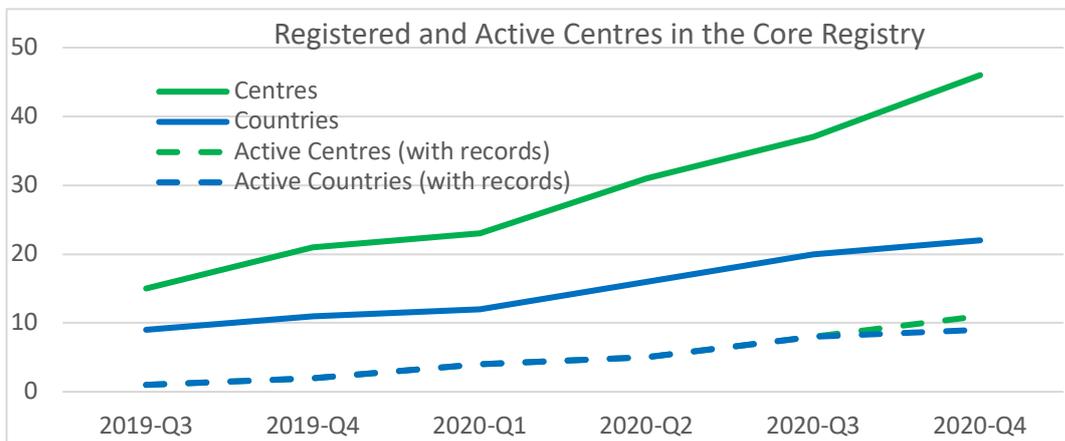
Aim Of This Report

To describe the activity of the EuRECa Core Registry between June 2019 and December 2020.

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. The centres in 2019 Q3 are those who were members of the EuRECa Project Governing Board and these were automatically registered by the EuRECa Project Office. However, the figures from the subsequent quarter represent actual organic growth. Of the 11 active centres which are all based in Europe, 8 are joint Endo-ERN and ERN-BOND centres, 1 is exclusively ERN BOND centre and 2 are neither.

1A



1B

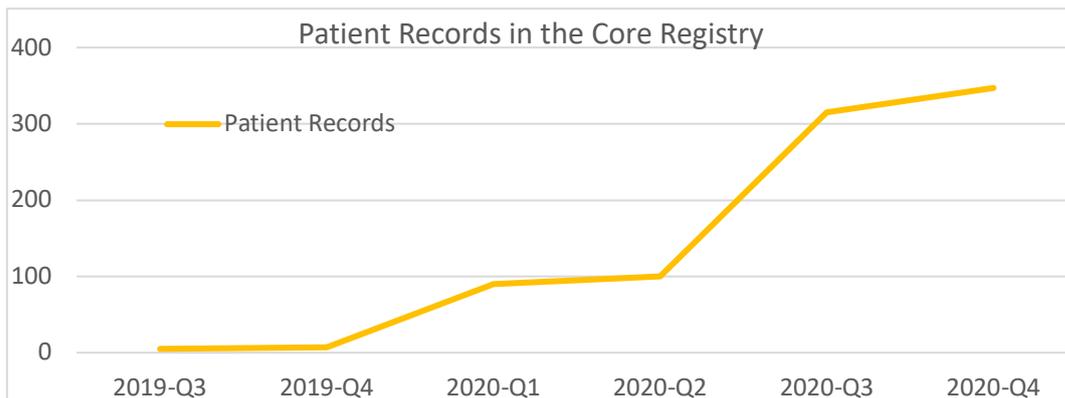


Fig.2 shows the proportion of patients that have been registered with the broad group of conditions or main thematic groups (MTG) within Endo-ERN and ERN-BOND.

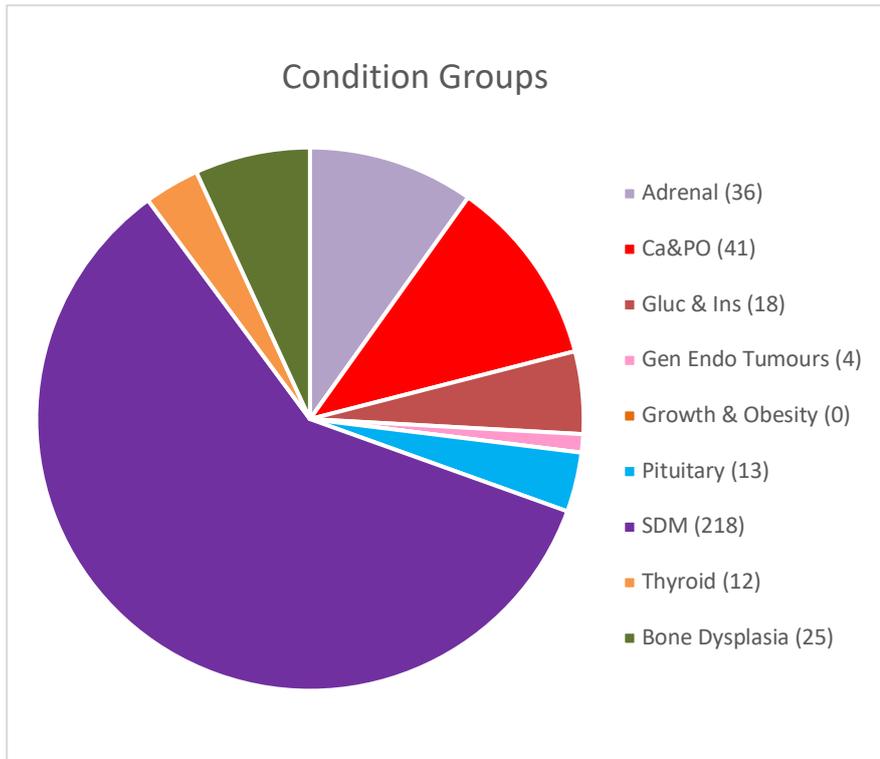


Fig.3 shows the number of patients entered in the Core Registry according to the centres.

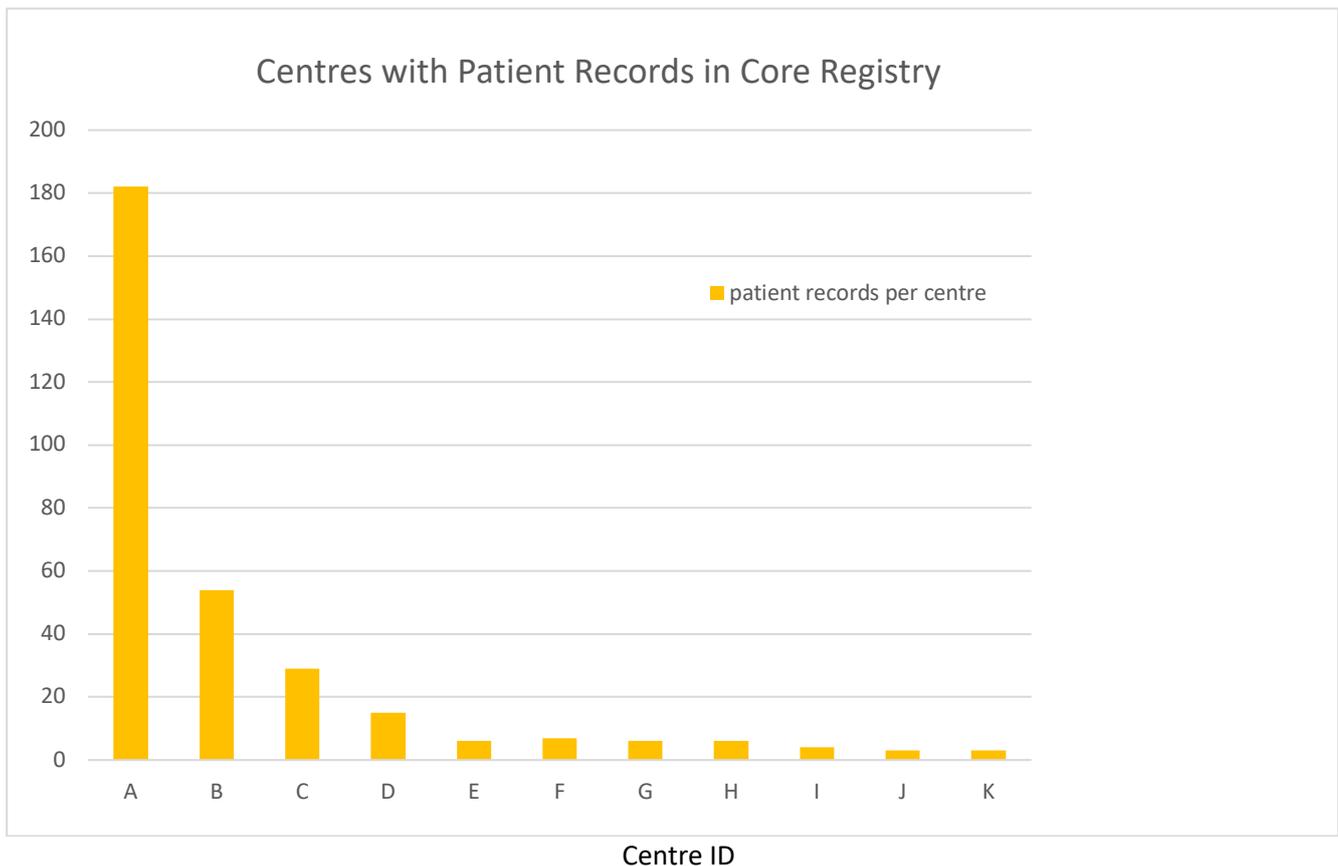


Fig.4 shows further details of the records where access has been provided to patients. Of the 32 patients who have been provided access, one third have activated their account.

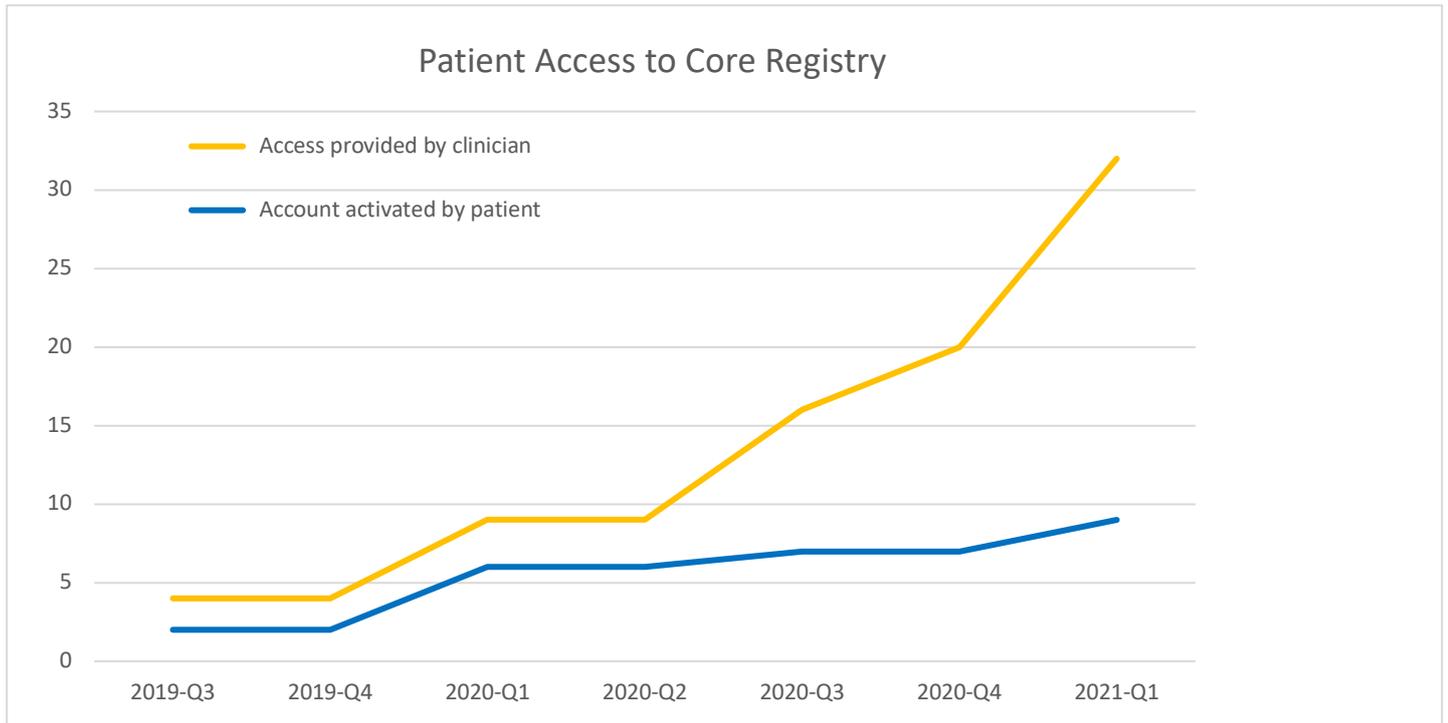


Fig.5 Of the 32 patients provided with access to date, 9 have activated their account, 3 have been invited to complete a PRO and 1 has completed a PRO.

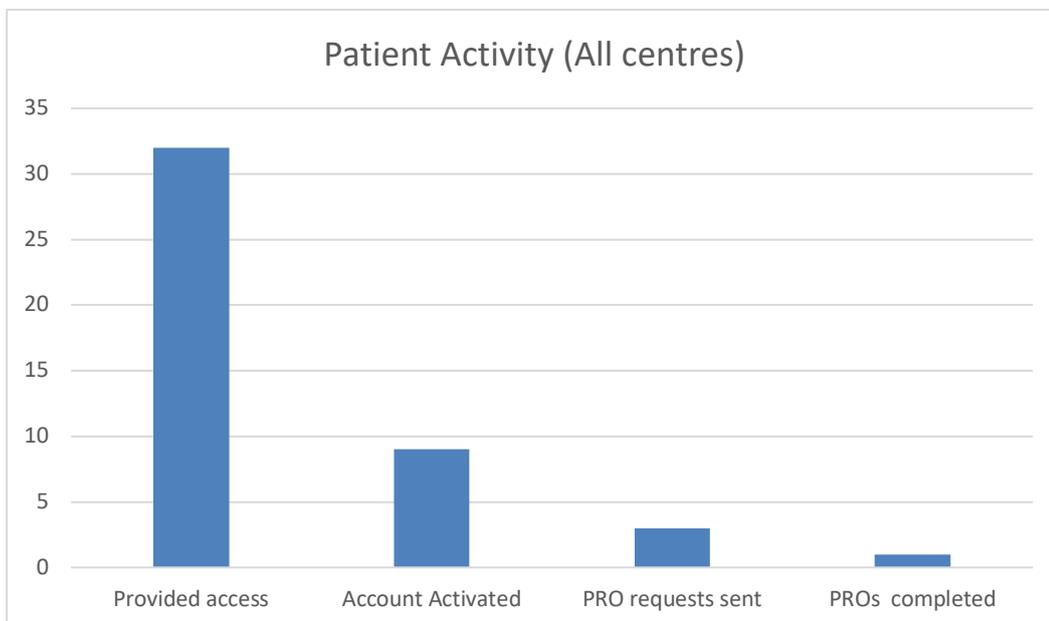
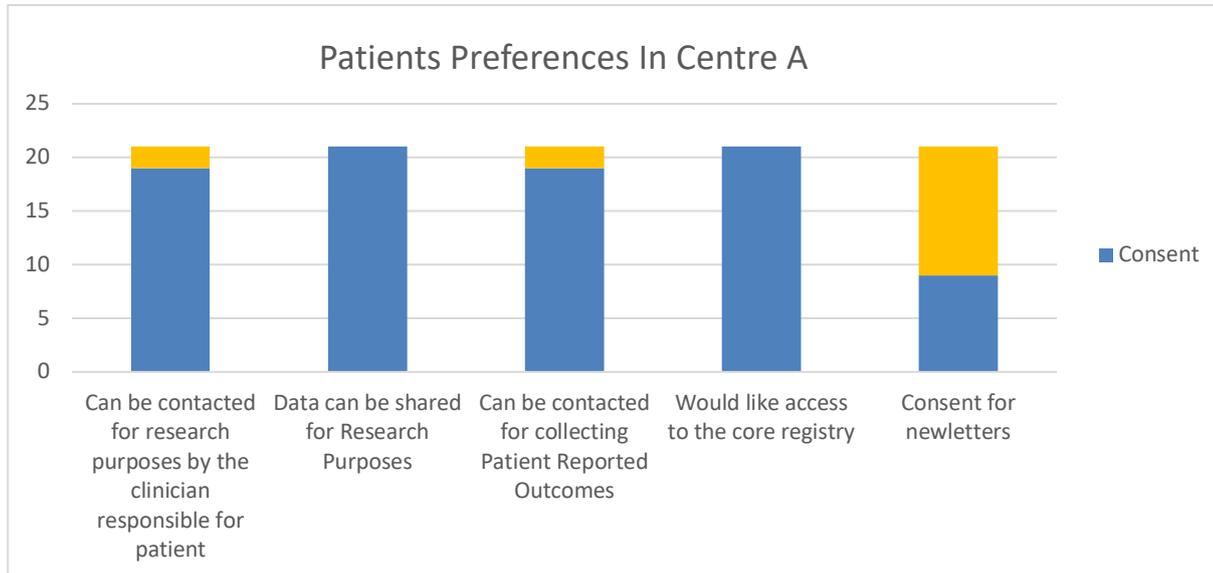


Fig.6 shows the preferences of the 21 patients/parents at the time they consented in Centre A to have their details registered on the EuRRECa Core Registry. Consent for newsletters was an option added after the first cohort of patients were consented in Centre A.



Interpretation of Findings

- An organic increase in the number of centres, users and patients has now started to occur.
- Patients with a wide variety of conditions, except rare conditions affecting growth or obesity, have been registered.
- Currently, registered patients are from a small number of active centres.
- Provision of access to patients is possible. However, of the patients who have been provided with access, a small proportion activate their account.
- When provided a choice, all patients/parents approve the sharing of data for research whilst about 5% of patients/parents are not interested in being contacted for collecting PROs or being contacted for research.

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 prepare 6 monthly reports for the PGB and participating centres.

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