EuRRECa Core Registry Report
August 2020

Introduction

The pilot EuRRECa Core Registry (https://eurreca.net/core-registry/) was launched in June 2019 and the platform has been revised further to include patient access and reporting of generic outcome as EQ5D and PROMIS. The registry has ethics approval and information sheets and consent forms in several languages are available at the above website. Users can also utilise the ERN information sheets and consent forms. However, the use of the EuRRECa 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 EuRRECa 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. Thereafter new centres have joined by completing on-line self-registration (https://www.mvls.gla.ac.uk/EuRRECaAuth/Registration/Create). So far 16 additional centres have registered.

There is also now functionality to create and implement any other Generic and Condition-Specific Outcomes.

Aim Of This Report

To describe the activity of the EuRRECa Core Registry between June 2019 and end of June 2020.

Results

Fig.1 shows the number of centres, number of clinical users and the total number of patients that have been registered and those that are actively adding patients. The centres and users in 2019 Q3 are those who were members of the EuRRECa Project Governing Board and these were automatically registered by the EuRRECa Project Office. However, the figures for 2019 Q4, 2020 Q1 and 2020 Q2 represent actual organic growth.

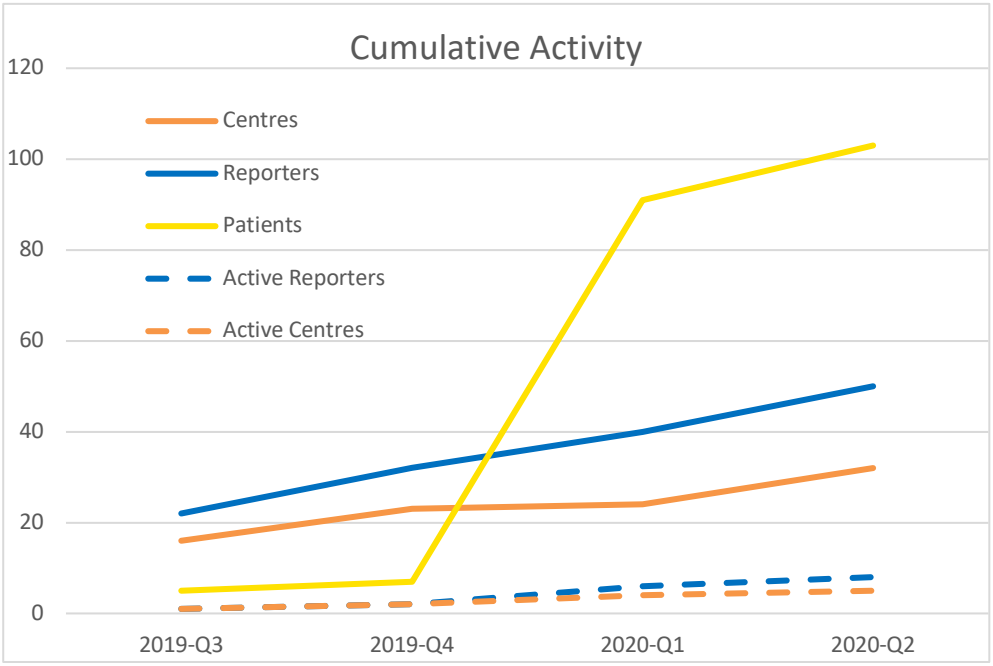


Fig.2 shows the proportion of patients that have been registered with the broad group of conditions or main thematic groups (MTG) within Endo-ERN and ERN-BOND. 6 patients that have been registered under the SDM category have also been shared with the I-DSD Registry.

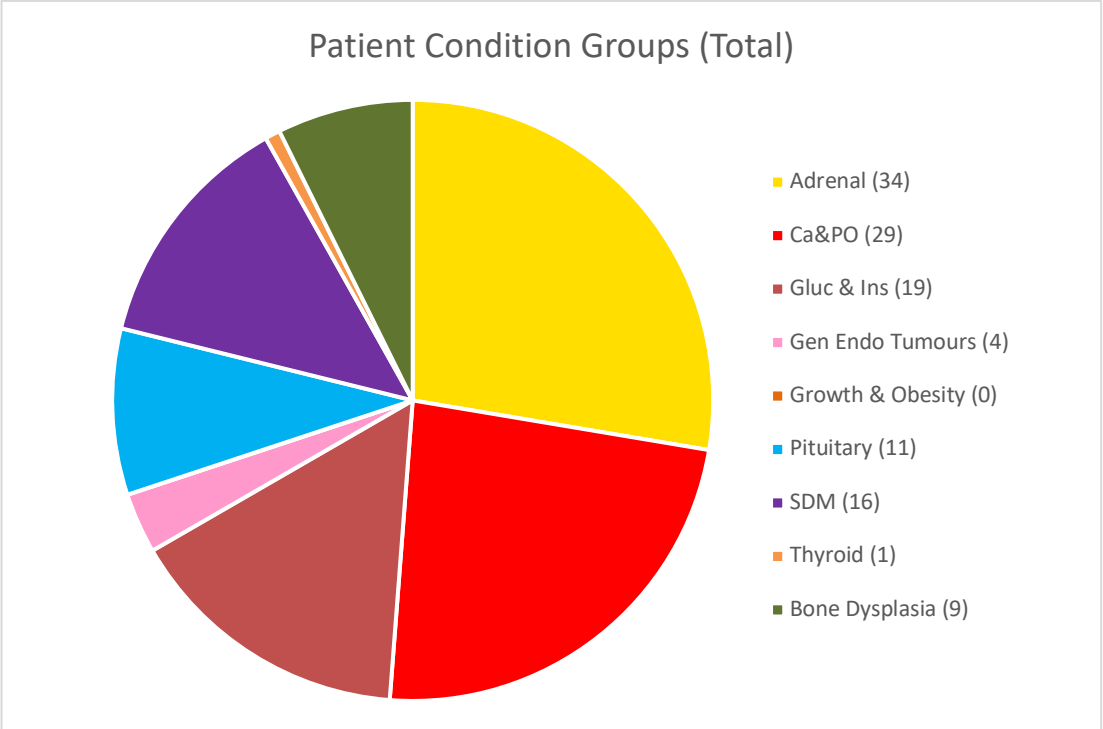


Fig.3 shows centres that have patients in the registry. Only one centre has provided access to the Registry to patients. Of the 11 patients registered, 9 patients wanted access and provided an email address. Of these 9 patients, to date, 5 (56%) have activated their accounts

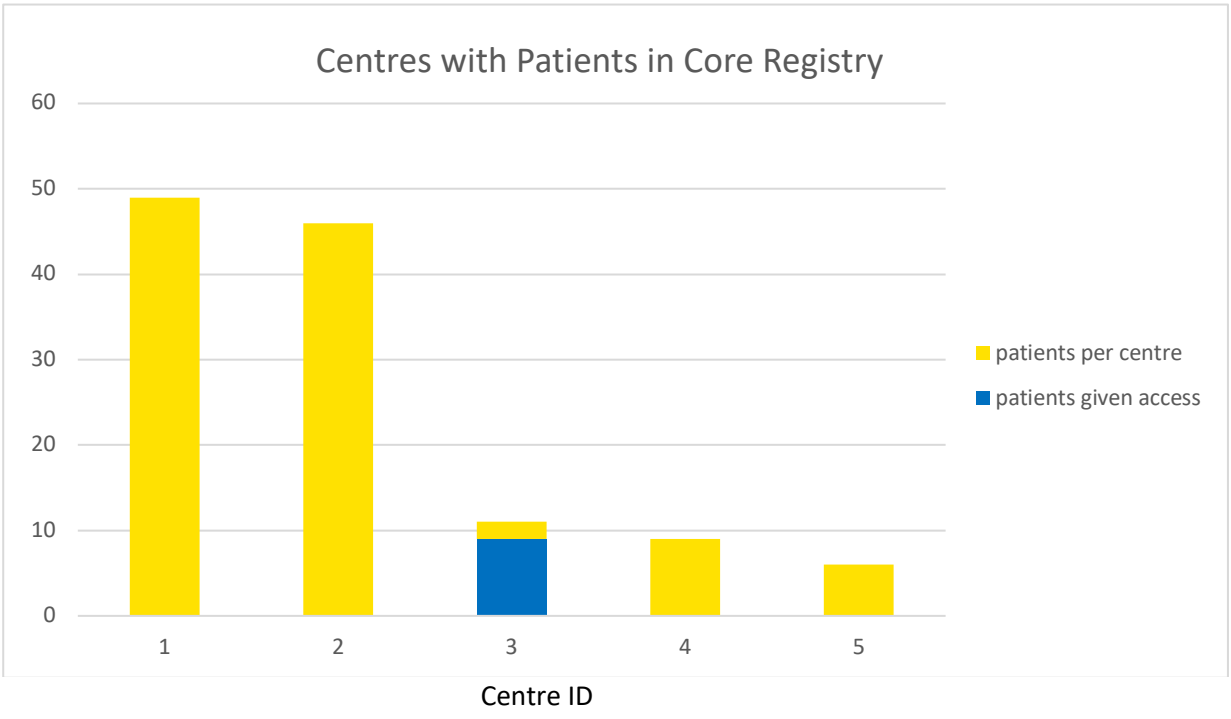
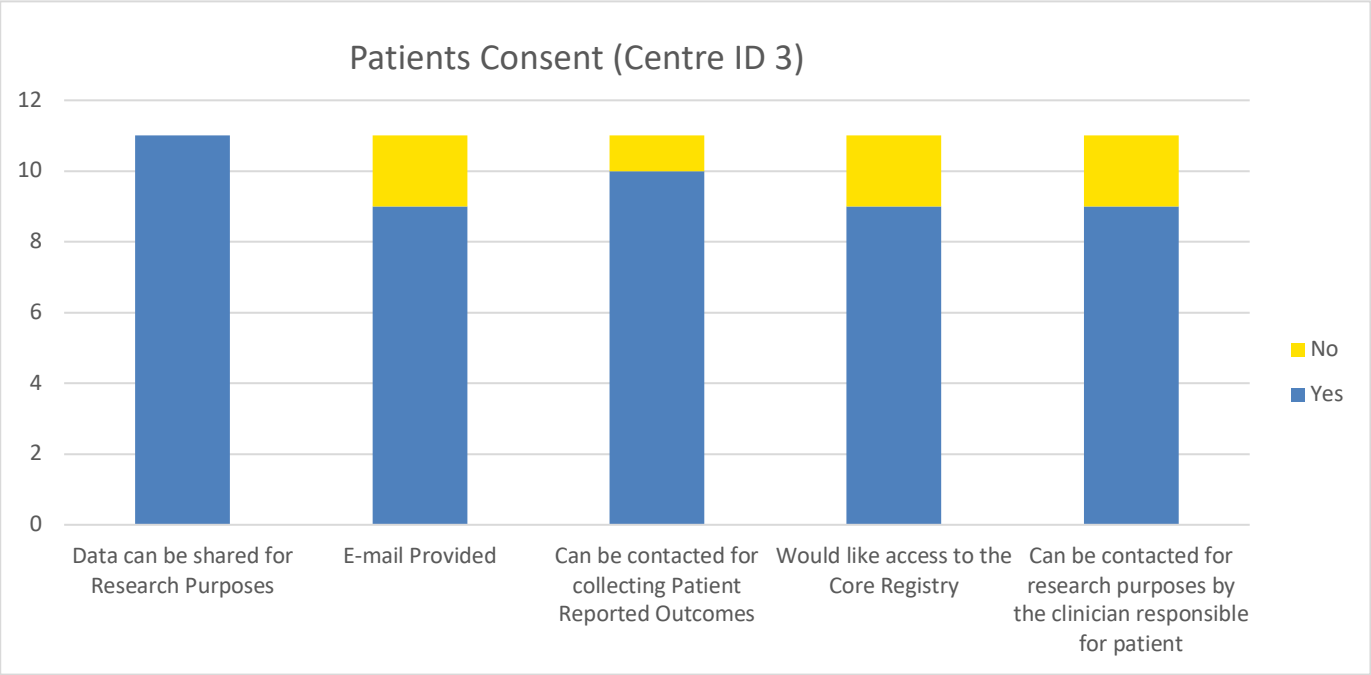


Fig.4 shows the preferences of the 11 patients/parents at the time they consented in Centre ID 3 to have their details registered on the EuRRECa Core Registry.



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 are being registered
- Currently, registered patients are from a small number of active centres
- Provision of access to patients is possible and whilst the majority of patients/parents are interested, the majority do not avail this facility
- Whilst all patients approve the sharing of data, currently, approximately 10-20% of patients/parents are not interested in being contacted for collecting PROs, do not want access to the Registry and are not interested in being contacted for research.

Recommendations

- Disseminate results within Endo-ERN, ERN-BOND and beyond and encourage participation from interested centres
- 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/national ethics requirements.
- Preferable the information sheets and consent form should follow the most recent paperwork in English, but there is flexibility to amend for local requirements.
- The EuRRECa office will prepare 6 monthly reports for the PGB and participating centres.

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