

Introduction

The pilot EuRECa 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. 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 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.

Aim Of This Report

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

Results

Fig.1 shows the number of centres, number of clinical users and the total number of patients that have been registered. The centres and users 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 for 2019 Q4 and 2020 Q1 represent actual organic growth. Given that 2020 Q1 will end in March, it is expected that the current figures will be an underestimation of the actual figures for this quarter.

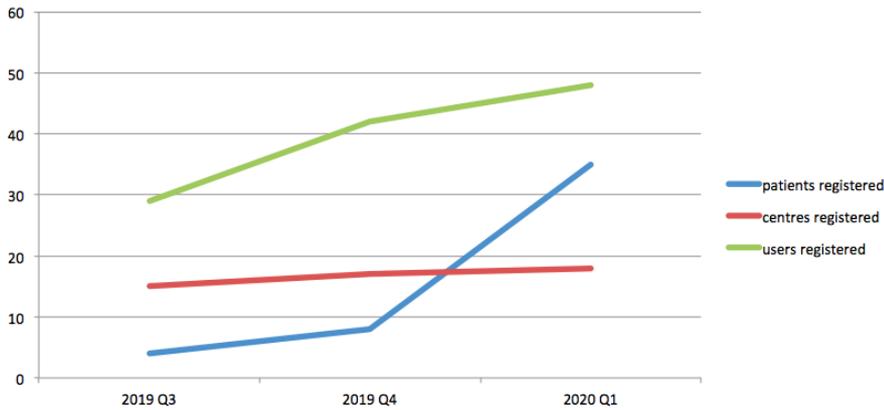


Fig.2 shows the number of users and patients that have been registered for each registered centre. The centres marked with an asterisk (*) are those that are not represented in the Project Governing Board of EuRECa and were not automatically registered by the EuRECa Project Office

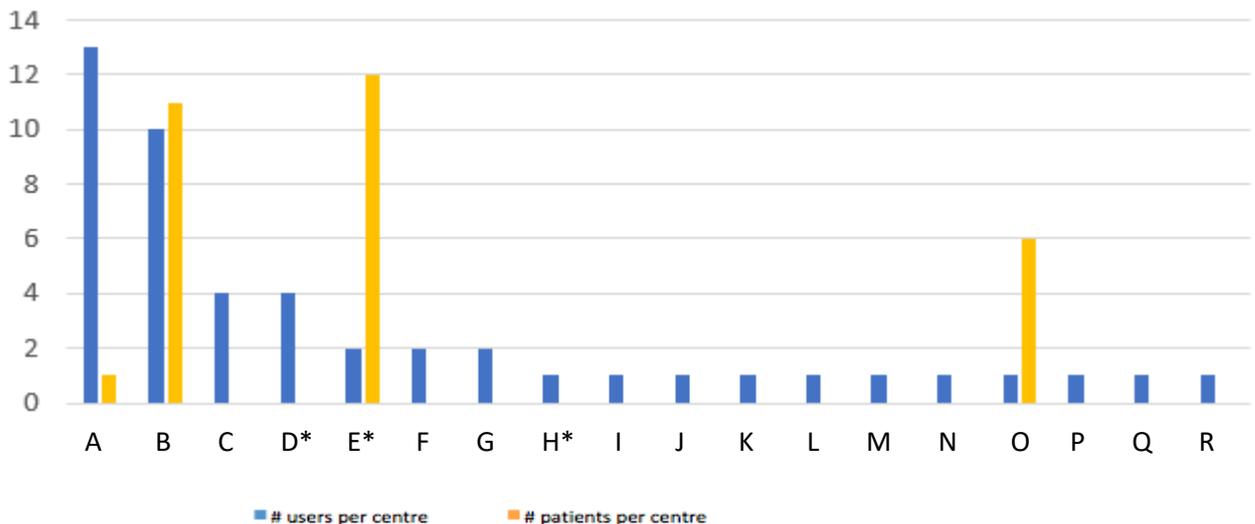


Fig.3 shows the proportion of patients that have been registered with the broad group of conditions or main thematic groups (MTG) within Endo-ERN. All 6 patients that have been registered under the SDM category have also been shared with the I-DSD Registry.

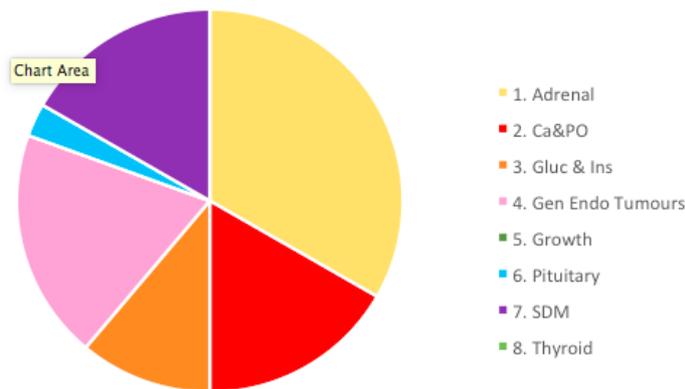


Fig.4 shows the proportion of patients that have been provided access to their data in the Registry according to the centres that have registered patients. Only one centre has provided access to the Registry to patients. Of the 11 patients registered, 8 patients wanted access and provided an email address. Of these 8 patients, to date, 3 (38%) have activated their accounts

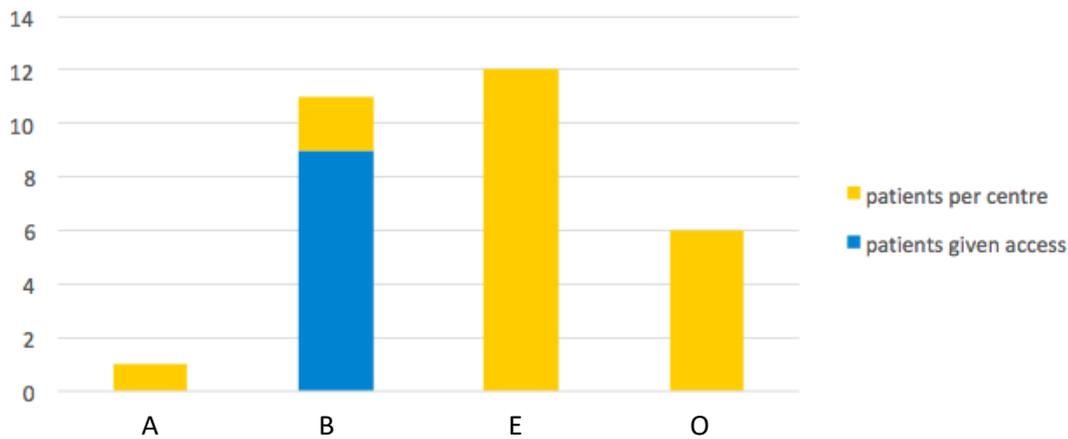
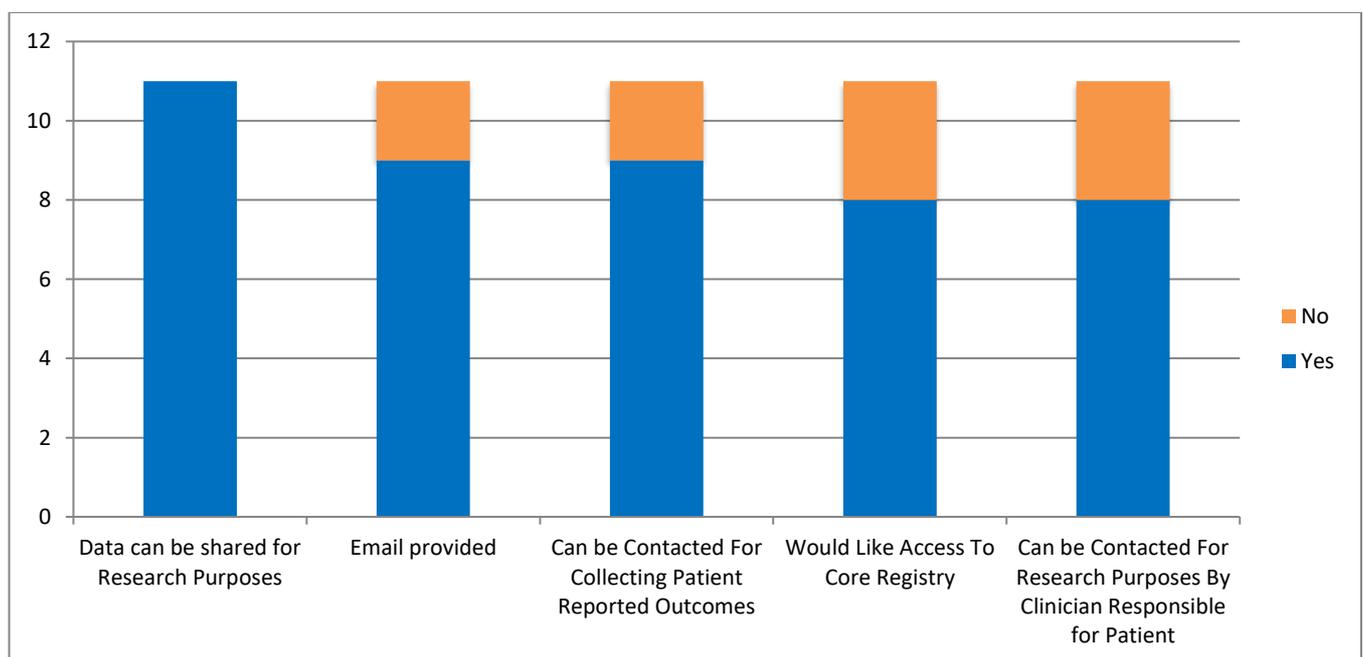


Fig.5 shows the preferences of the 11 patients/parents at the time they consented in Centre B to have their details registered on the EurRECa Core Registry



Interpretation of Findings

- After a slow start, 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 20-25% 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 and beyond and encourage participation from interested centres
- Participating centres should look at the information sheets and consent forms. These have been professionally translated but it would be better if they are checked by local health care staff.
- The information sheets and consent form need to be updated so that they are the same as the recently updated paperwork in English.
- The EuRRECa office will prepare quarterly reports for the PGB and participating centres.
- Develop a process for seeking approval from the Data Access Committee to share data with other registries.

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