

**Core Registry Report
July 2021**

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 January 2021 an additional 22 centres have registered bringing the total to 58 centres (91 registered users). Since April 2020, the EuRRECa platform has also been supporting the EuRR-Bone project.

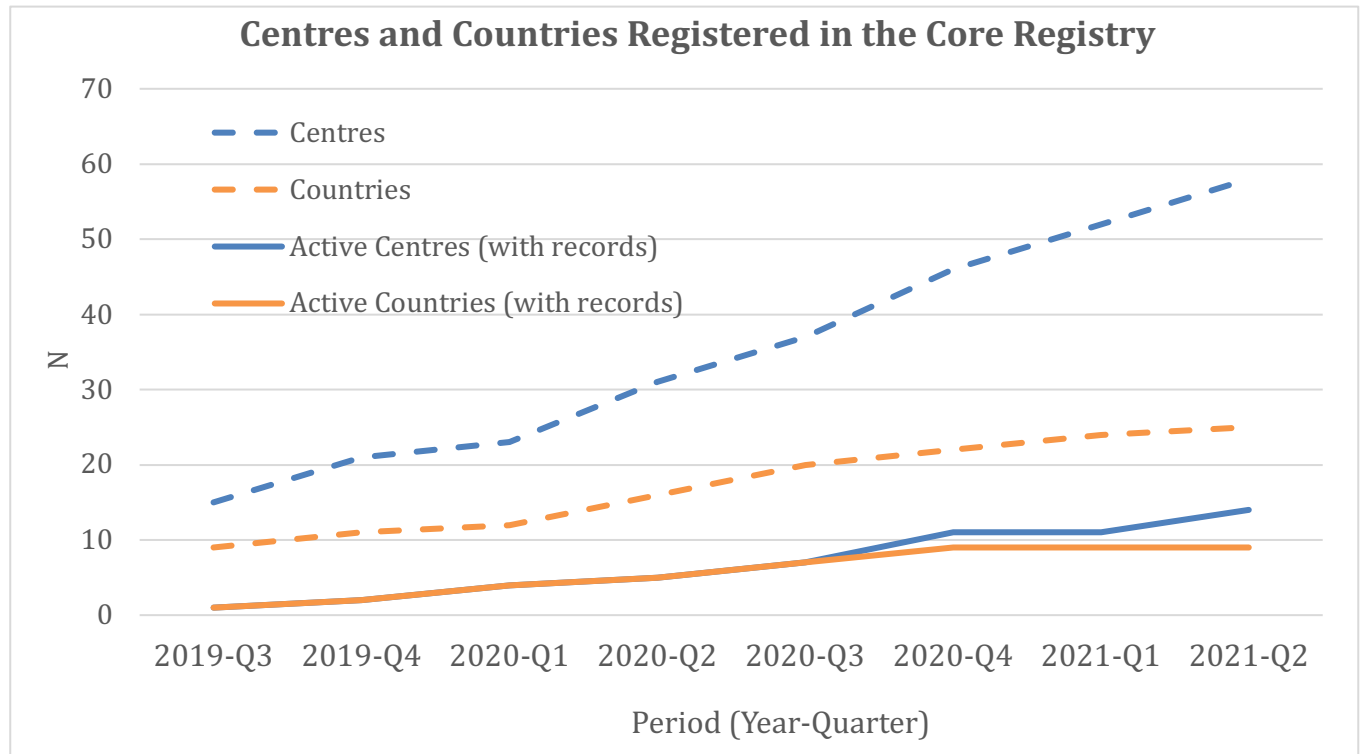
Aim Of This Report

To describe the activity of the EuRRECa Core Registry between June 2019 and July 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 14 active centres which are all based in Europe, 7 are joint Endo-ERN and ERN-BOND centres, 2 are exclusively Endo-ERN centres, 1 is exclusively ERN BOND and 4 are neither.

1A



1B

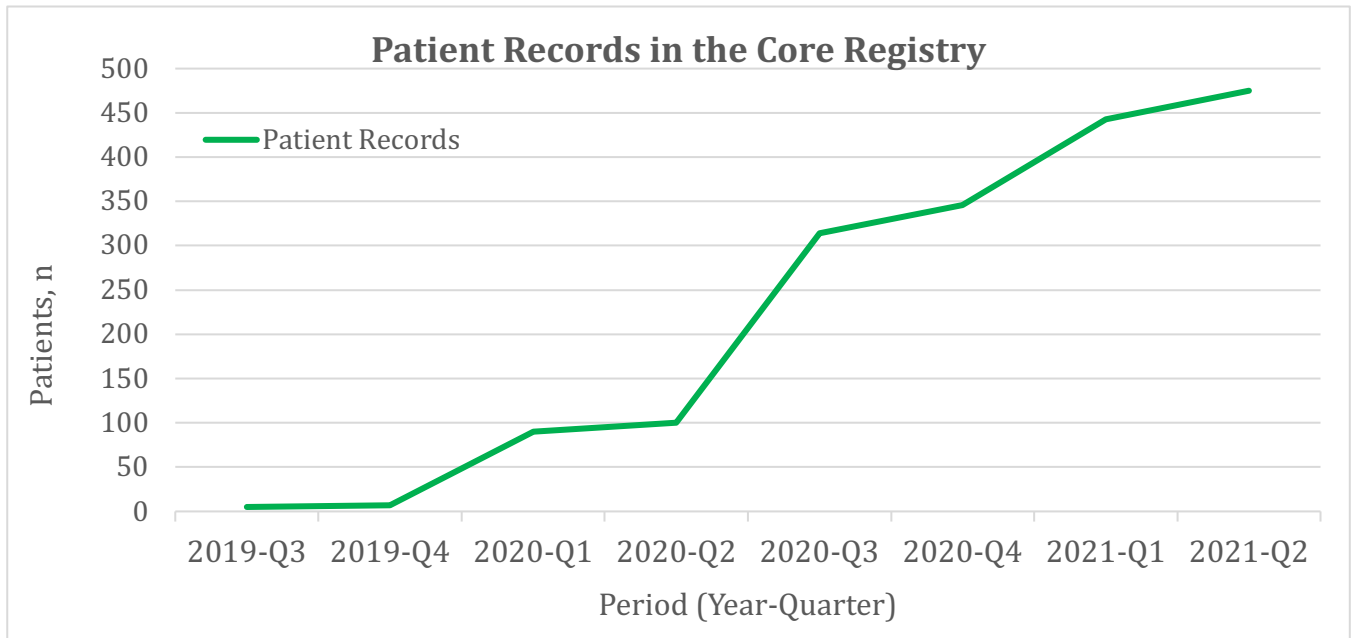


Fig.2 shows the proportion of patients that have been registered with the broad group of conditions or main thematic groups (MTG) within Endo-ERN and ERN-BOND.

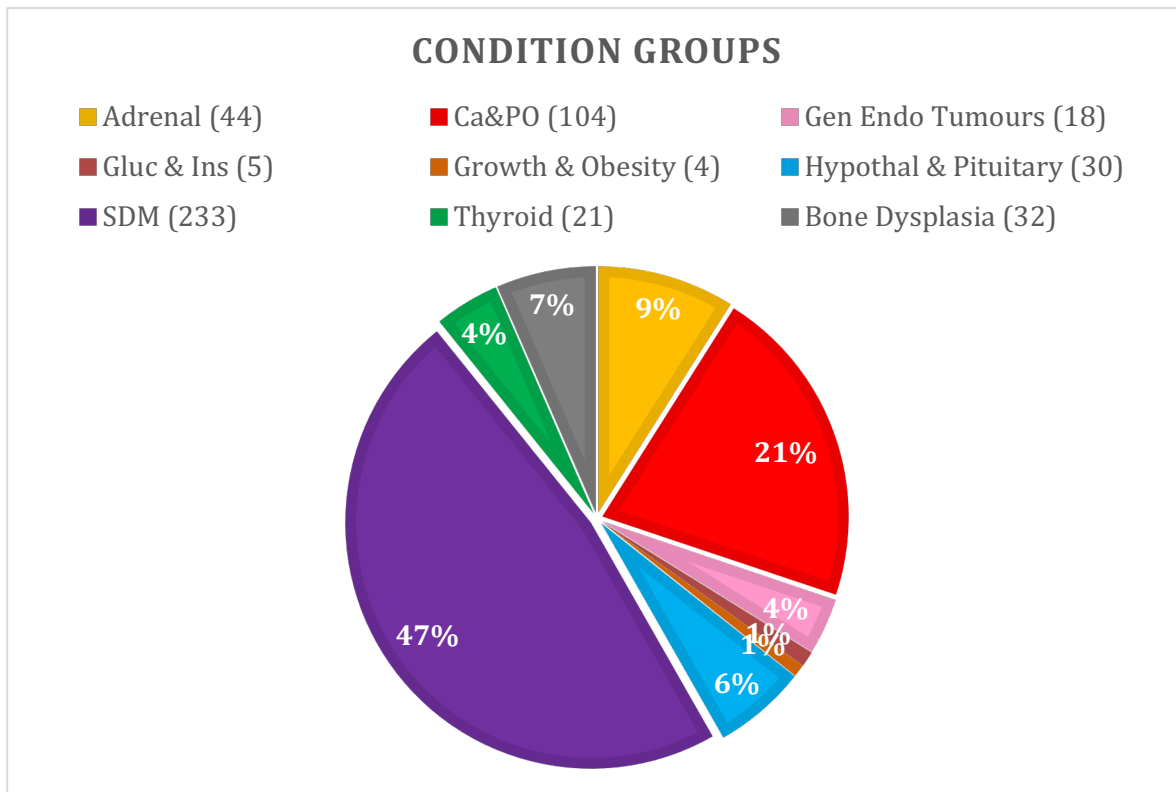


Fig.3 shows the number of patients entered in the Core Registry according to the centres.

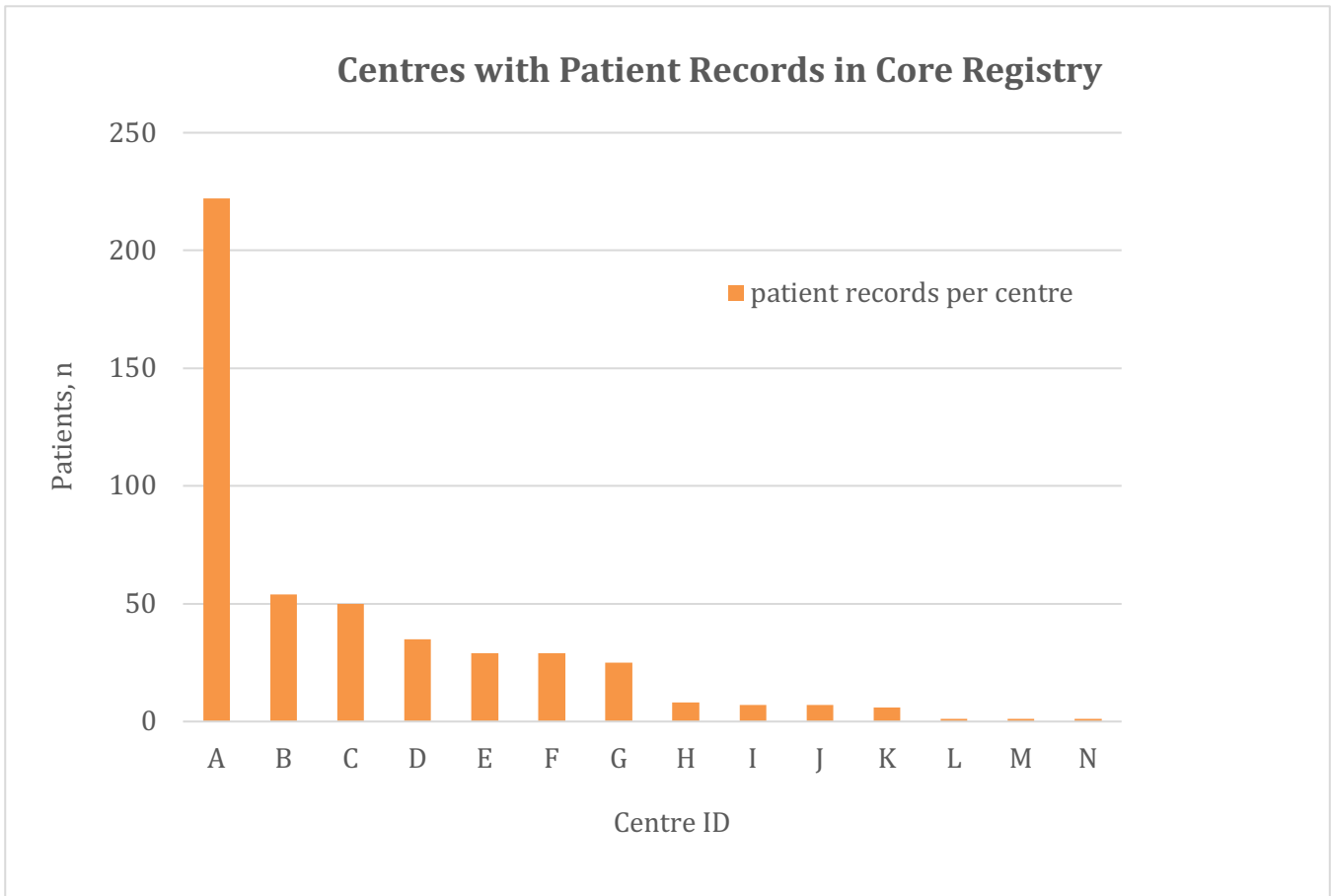


Fig.4 shows further details of the records where access has been provided to patients. Of the 65 patients who have been provided access, one third have activated their account.

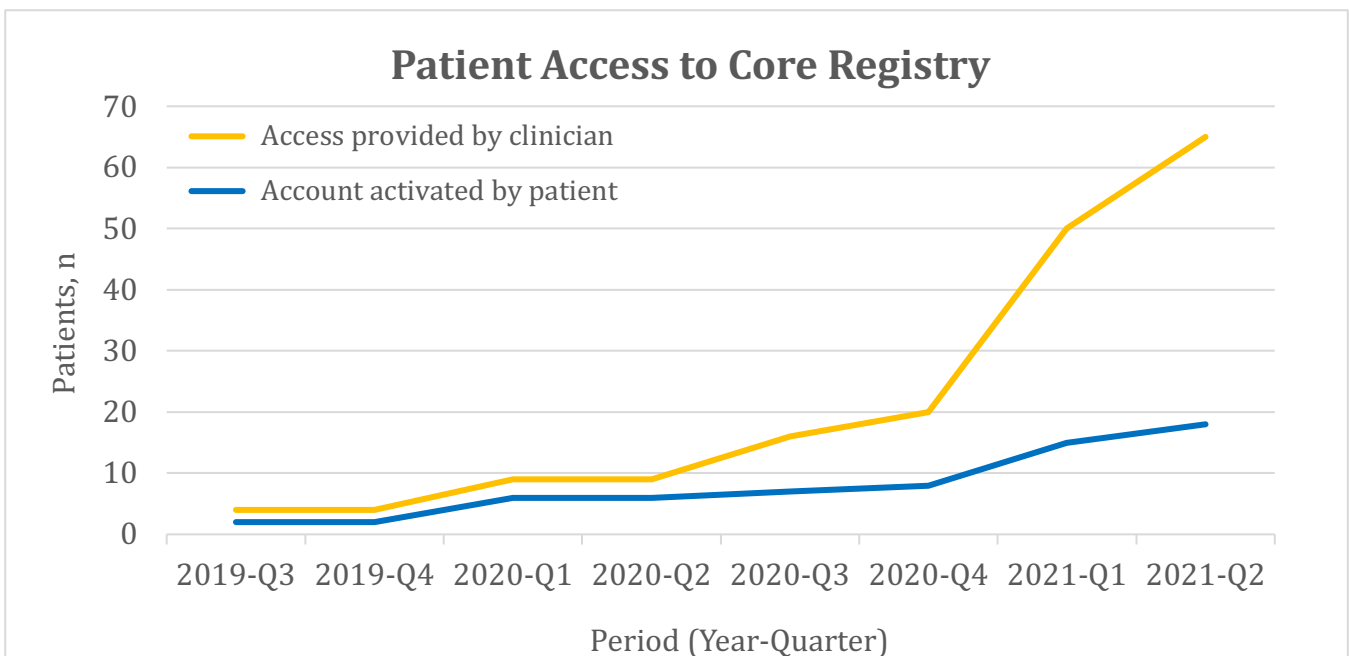


Fig.5 Of the 472 patients in the Core Registry, 65 patients from 6 centres were provided with access to their record. Of the 65, 18 (28%) patients have activated their account, 7 have been invited to complete a PRO and 2 have completed a PRO to date.

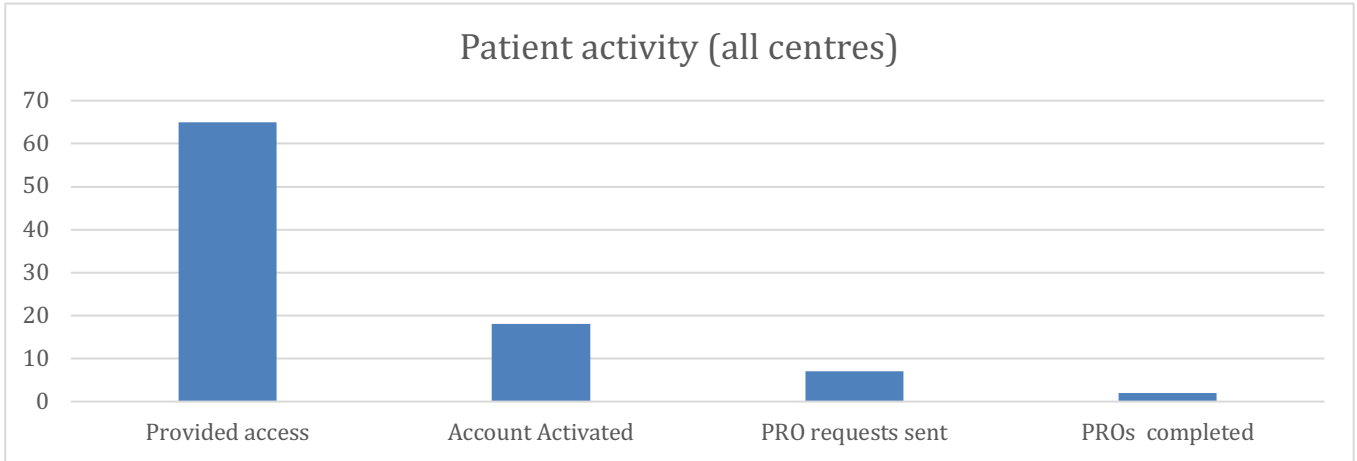
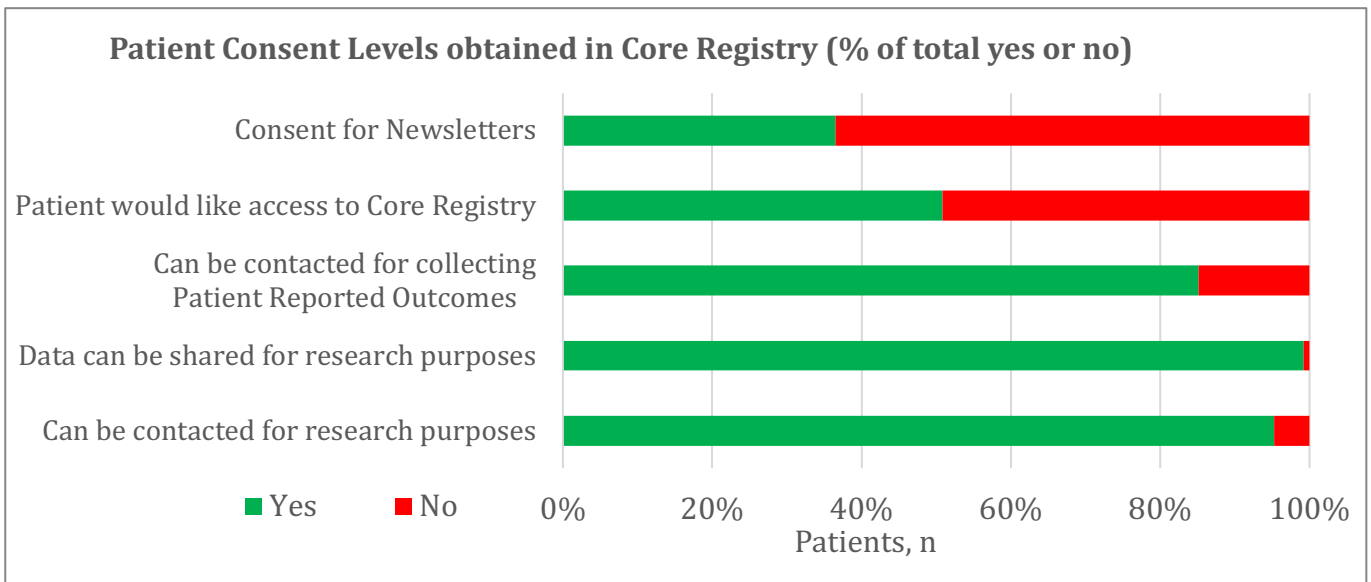


Fig 6 shows the individual preferences of patients for their level of interaction with the project.



6th October 2021



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