

**European Registry for Rare Bone and Mineral Conditions (EuRR-Bone):
Results from the Platform for e-Reporting of Rare Conditions (e-REC).**

Introduction

e-REC is an electronic reporting system which captures activity and allows for a better understanding of the occurrence of the rare conditions covered within networks such as **ERN BOND** and **Endo-ERN**. This is a joint platform originally set up by **EuRRECa** and has been specifically adapted for **EuRR-Bone**.

The platform is open to all centres that look after people with rare bone and mineral conditions. It allows continuous reporting of core indicators of activity and enables clinical networks to objectively map the conditions and related activities

Aim

This report has been developed to describe the current activity in e-REC during the period of April to December 2020.

Methods

The e-REC platform issues invitations to clinicians who have participated in e-REC from April to December 2020 to ask them to complete a monthly return. Participants can create a reporting set up and report any newly encountered cases of any of the conditions that have been included in Endo-ERN, ERN-BOND and more recently, COVID-19 infections.

Results

By December 2020, a total of 35 centres from 17 countries had reported on e-REC. Of these 23 are Endo-ERN affiliated centres, 12 are joint Endo-ERN and ERN-BOND and 12 are neither.

Country	Centers	Country	Centers
 Austria	1	 Italy	7
 Belgium	2	 Latvia	1
 Croatia	1	 Lithuania	1
 Czech Republic	1	 Netherlands	3
 Estonia	1	 Romania	1
 France	1	 Spain	2
 Germany	6	 Sweden	1
 Hungary	1	 United Kingdom	4
 Israel	1		

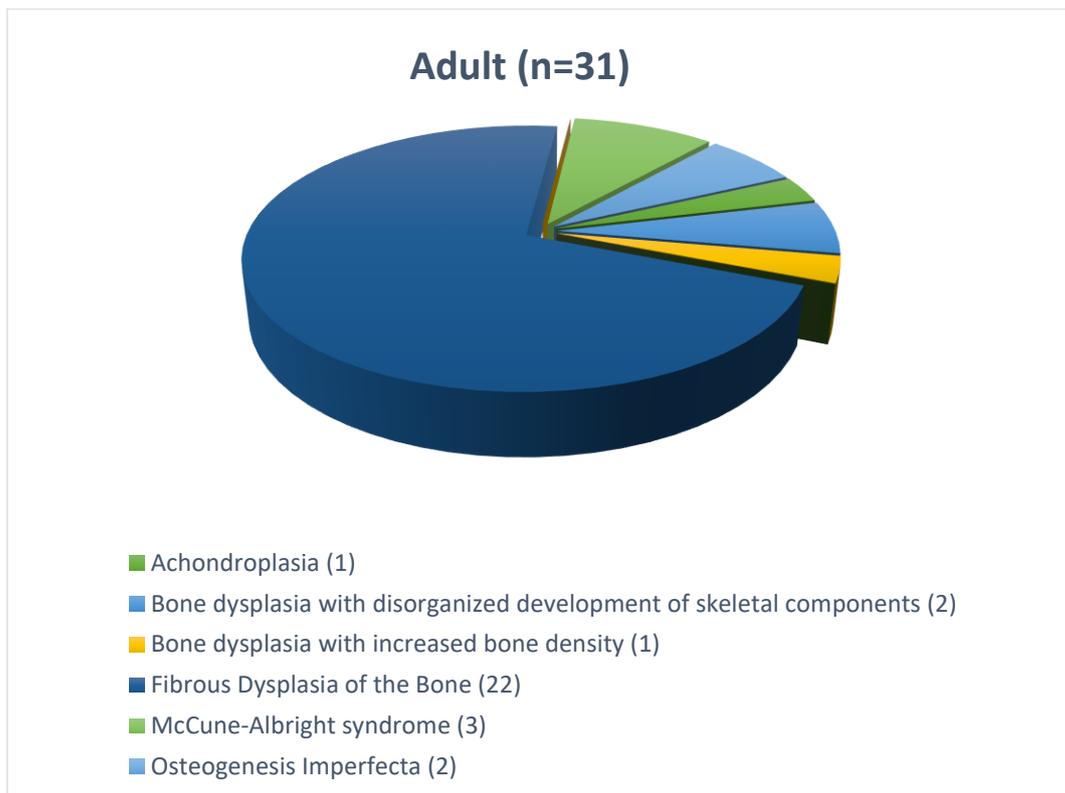


Fig.2 - Bone dysplasia cases reported in e-REC per condition in adults.

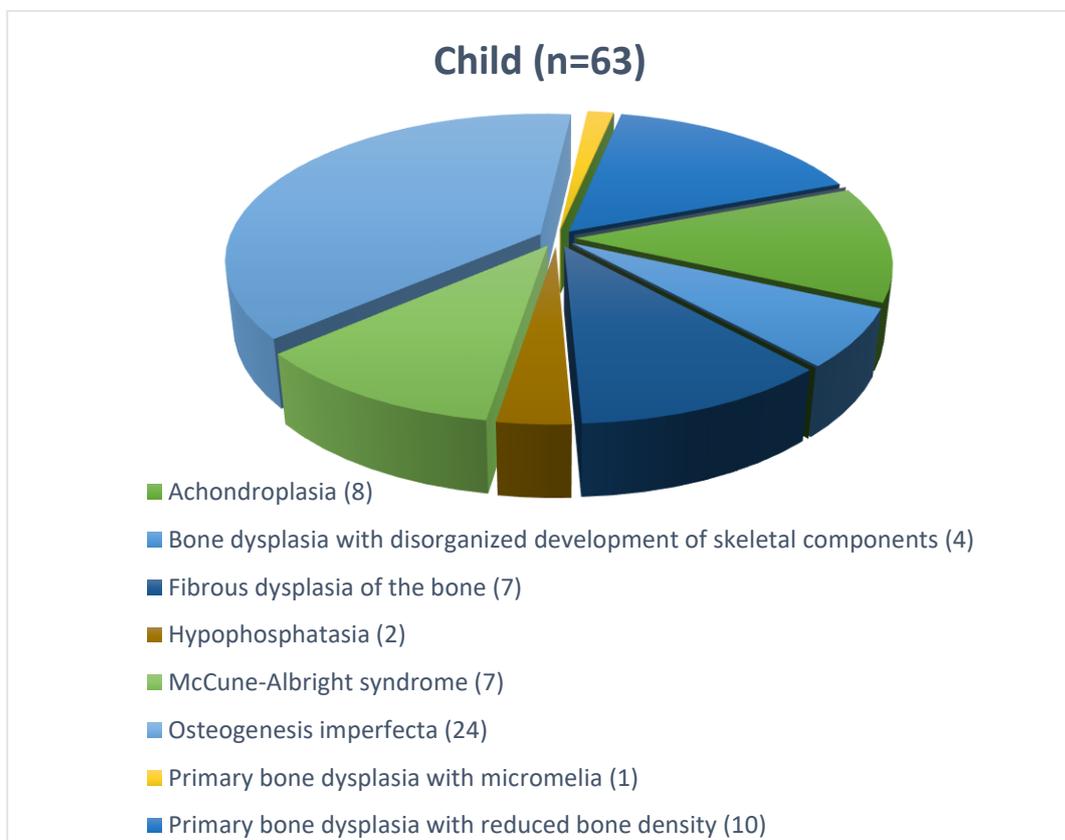


Fig.3 - Bone dysplasia cases reported in e-REC per condition in children.

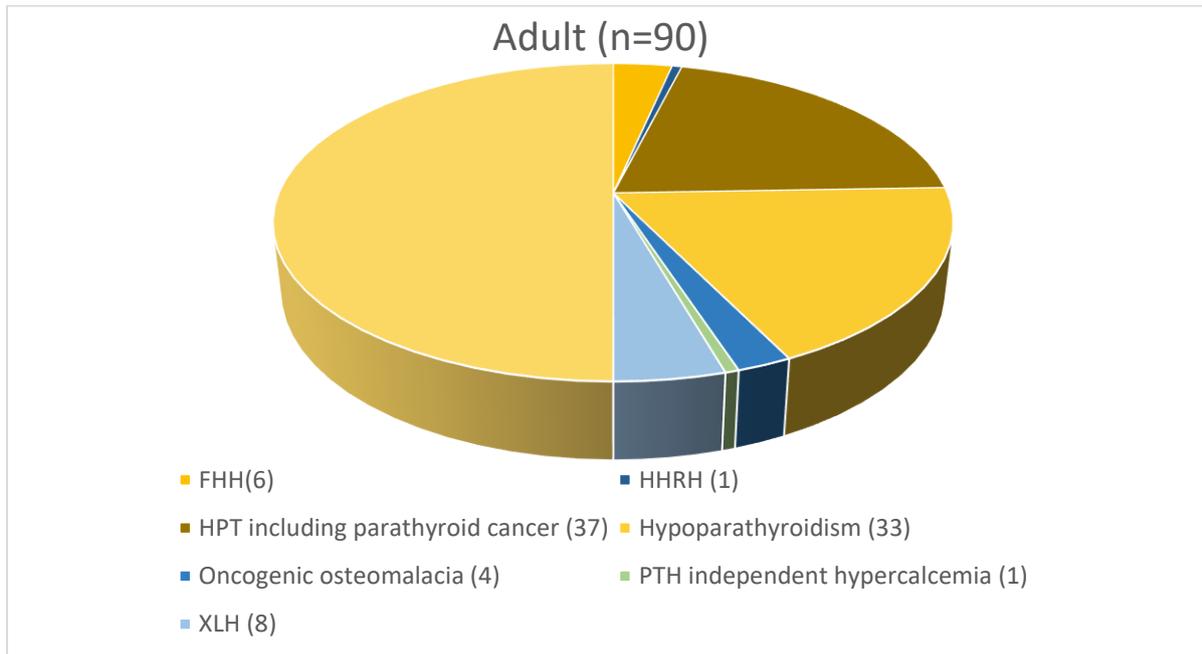


Fig.4 - Calcium and Phosphate cases reported in e-REC per condition in adults.

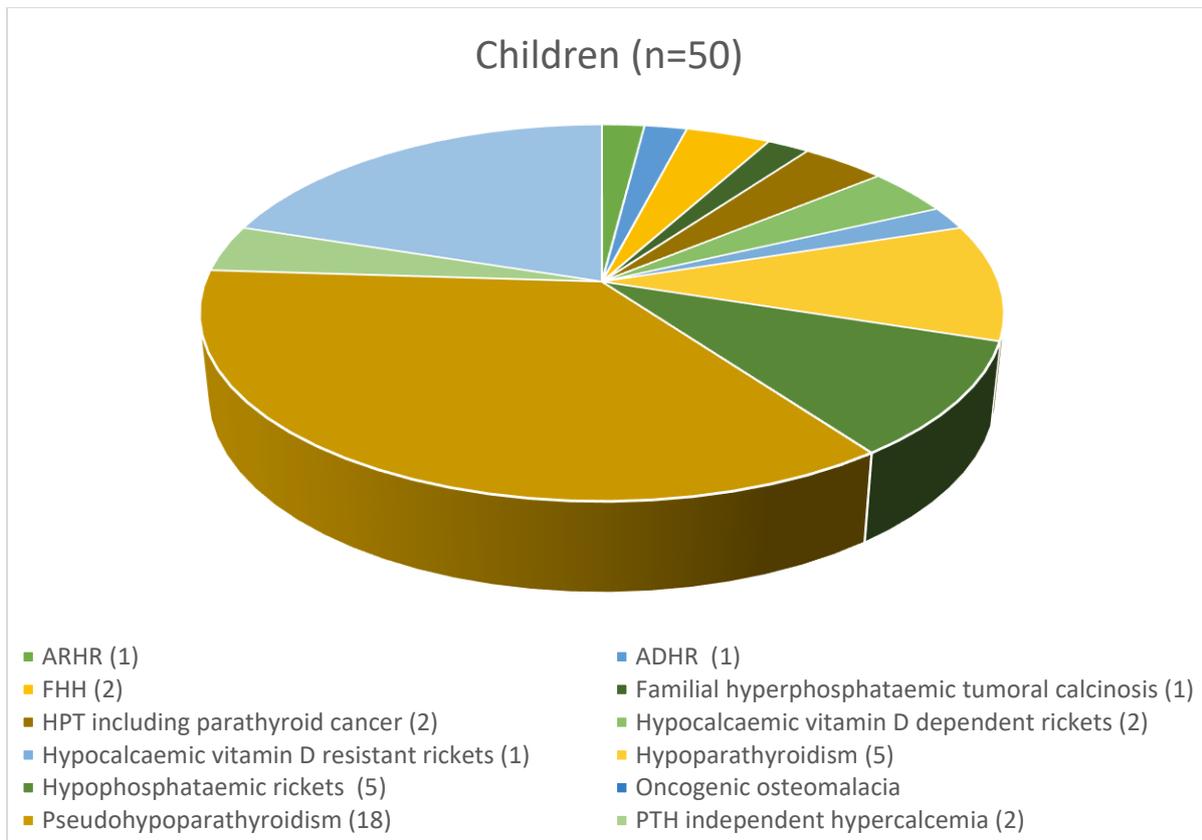


Fig.5 - Calcium and Phosphate cases reported in e-REC per condition in children.

Findings

e-REC is a simple platform that can be used to capture new encounters with patients with bone and mineral conditions.

Reporting centres have slowly increased since the EuRR-Bone project was launch in April 2020. More centres are reporting on the pediatric group than on the adult group.

A total of 234 cases were reported from April to December 2020. For the bone dysplasia group the most reported condition in adults was fibrous dysplasia of the bone while in children osteogenesis imperfecta was the most reported. For the calcium and phosphate group the most reported conditions in adults were hyperparathyroidism including parathyroid cancer and hypoparathyroidism while in children pseudohypoparathyroidism and XLH were the most reported.

There is wide variability in the number of cases encountered for different conditions amongst different centres.

Recommendations

The use of the platform should continue to be disseminated widely.

Members of ERNs should be able to utilize the platform for continuous reporting.

ERN-BOND members could consider using e-REC for continuous reporting.

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Find full report at <https://eurr-bone.com/report-e-rec-april-dec-2020/>