EuRRECa (European Registries for Rare Endocrine Conditions, eurreca.net) is a new project that includes the development of a core endocrine registry and the development of an e-reporting programme for rare endocrine conditions (e-REC) that are covered within Endo-ERN (endo-ern.eu).

METHOD

- 46 endocrine centres within 18 countries volunteered to participate between July 2018 and June 2019 (Fig 1).
- Electronic reporting ‘card’ developed through REDCap was issued monthly to enquire whether clinicians had encountered a new case of any condition within the 8 Endo-ERN main thematic groups (MTGs).
- Unique IDs were generated for reported cases and these were stored locally at centre.

RESULTS

- On a monthly basis, from July 2018 to June 2019, a median of 14 paediatric centres (range 11, 21) and 13 (11, 25) adult centres actively reported cases (Fig 2).

Fig 1. Centres participating in e-REC (Jul ’18 - Jun ’19)

Fig 2. Number of actively reporting centres

RESULTS

- In children, conditions within the Sex Development & Maturation theme were most commonly reported (38% of all conditions). In adults, Pituitary and Thyroid conditions were most commonly reported (34% and 26% of all conditions) (Fig 3).

Fig 3. Cases reported per main thematic group

- In children, over a 12 month period, the median number of cases reported per centre was 21 (9, 32) for conditions affecting Sex Development & Maturation. In adults, 37 (6, 75) Pituitary and 22 (5, 80) Thyroid cases were reported per centre (Fig 4 & 5).

Fig 4. Cases reported per centre per main thematic group

SUMMARY

- e-REC is a simple platform that can be used effectively to capture information on new patients with rare conditions presenting within a clinical network.
- Year 1 results show wide variability in the number of patients encountered for different conditions.
- The platform is now open for all centres to participate and increase richness of data.
- Data are available to all interested stakeholders.

FURTHER INFORMATION

- eurreca.net/e-rec/