

European Registries for Rare Endocrine Conditions (EuRRECa): Results From The Platform For e-Reporting of Rare Endocrine Conditions (e-REC)

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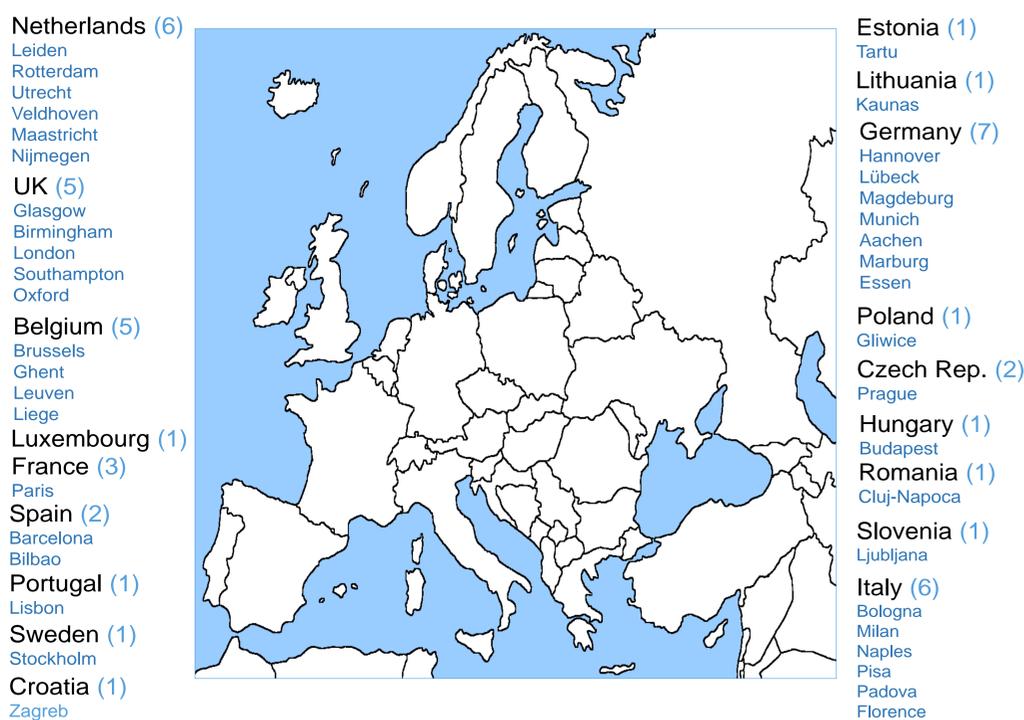
BACKGROUND

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.

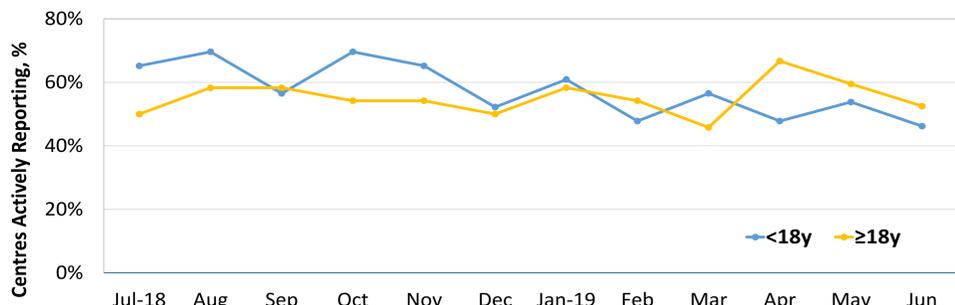
Fig 1. Centres participating in e-REC (Jul '18 - Jun '19)



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 2. Number of actively reporting centres

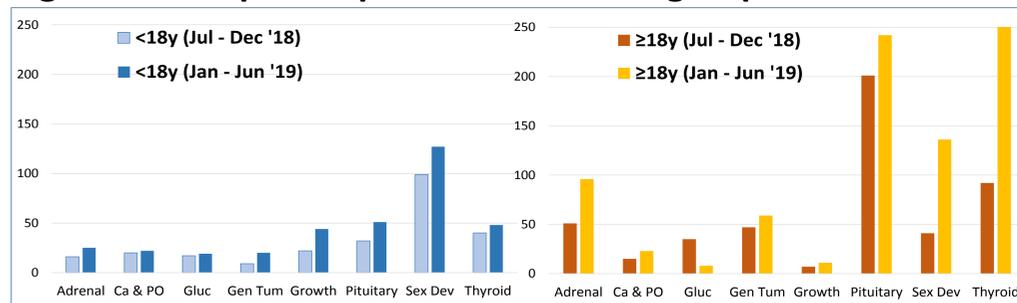


Total Number of Participating Centres	Paediatric	Adult
Pilot Phase (Jul-18 to Apr-19)	23	24
Current	39	40

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

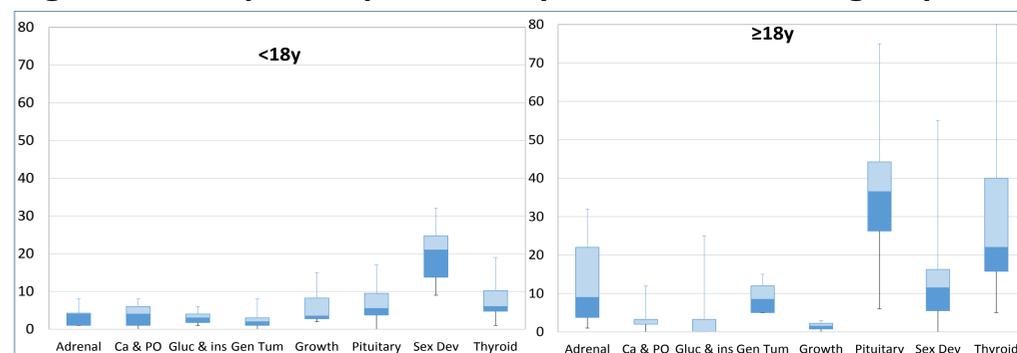
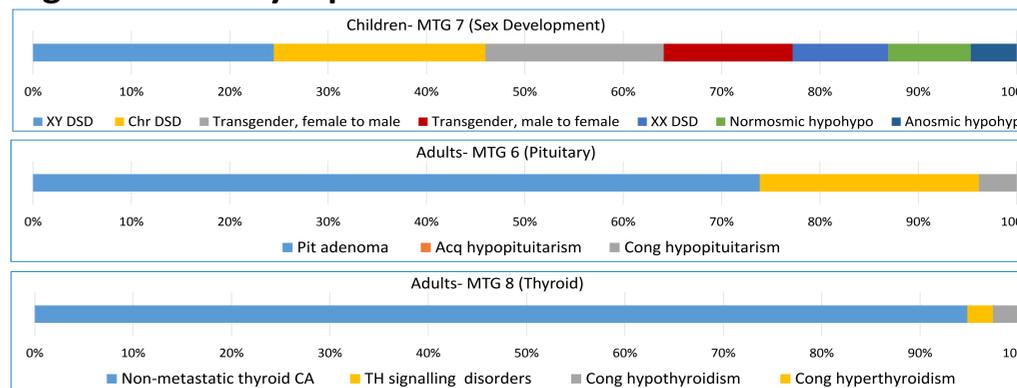


Fig 5. Commonly reported conditions



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/