

**European Registries for Rare Endocrine Conditions (EuRECa):  
Results from the Platform for e-Reporting of Rare Endocrine Conditions (e-REC)**

**Introduction**

e-REC (e-Reporting of Rare Endocrine Conditions) is an electronic reporting system which captures activity and allows for a better understanding of the occurrence of rare conditions covered within networks such as Endo-ERN and BOND. It was originally developed to include conditions covered by Endo-ERN and more recently has been adapted to include conditions covered in BOND. For ERNs, the e-REC platform allows continuous reporting of core indicators of activity and enables these clinical networks to objectively map the conditions and related activity. However, the platform is open to all centres that look after people with such conditions and not just limited to those centres that are within ERNs.

**Aim**

This report has been developed to describe the current activity in e-REC.

**Methods**

An electronic reporting ‘card’ was issued on a monthly basis to all clinicians that had registered to participate in e-REC from July 2018 to December 2019. Participants were asked to report any new case of any of the conditions that have been included in Endo-ERN and BOND.

**Results**

- A total of 50 centres from 20 countries registered to participate in e-REC between July 2018 and December 2019.














Country	Centres	Country	Centres
 Austria	1	 Luxembourg	1
 Belgium	5	 Netherlands	6
 Croatia	1	 Poland	1
 Czech Republic	1	 Portugal	1
 Estonia	1	 Romania	1
 France	3	 Slovakia	1
 Germany	9	 Slovenia	1
 Hungary	1	 Spain	2
 Italy	7	 Sweden	1
 Lithuania	1	 United Kingdom	5

Table 1 – Countries and number of centres in each country that registered in participate in e-REC.

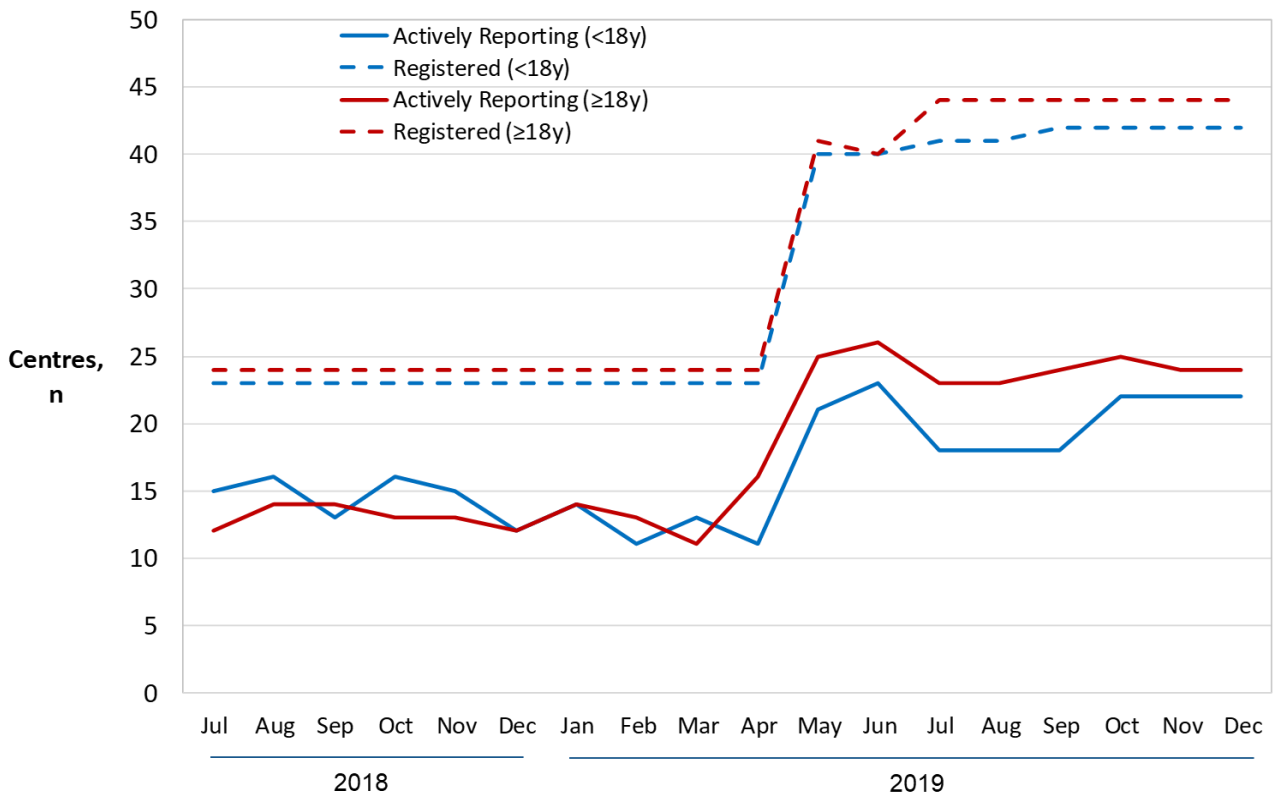


Fig.1 – Change in the number of centres that registered and that were actively reporting between July 2018 and December 2019. Currently, 42 paediatric centres and 44 adult centres have registered to participate in e-REC.

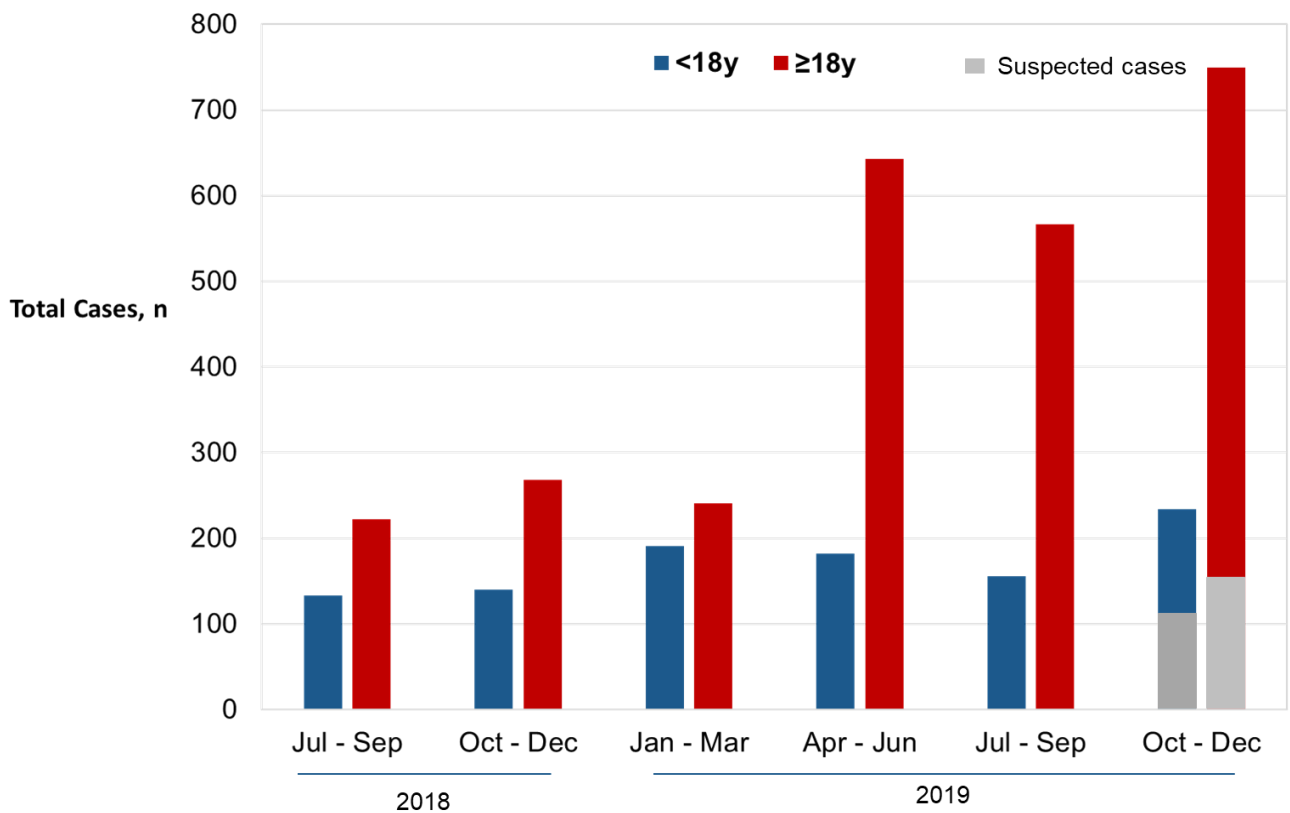


Fig. 2 – The temporal variation in the cases reported between July 2018 and December 2019. For the last quarter of 2019, the platform also collected information on the proportion of cases that were considered to be 'suspected' and the proportion that were 'confirmed'. The latter are identified on the panel as the grey cases.

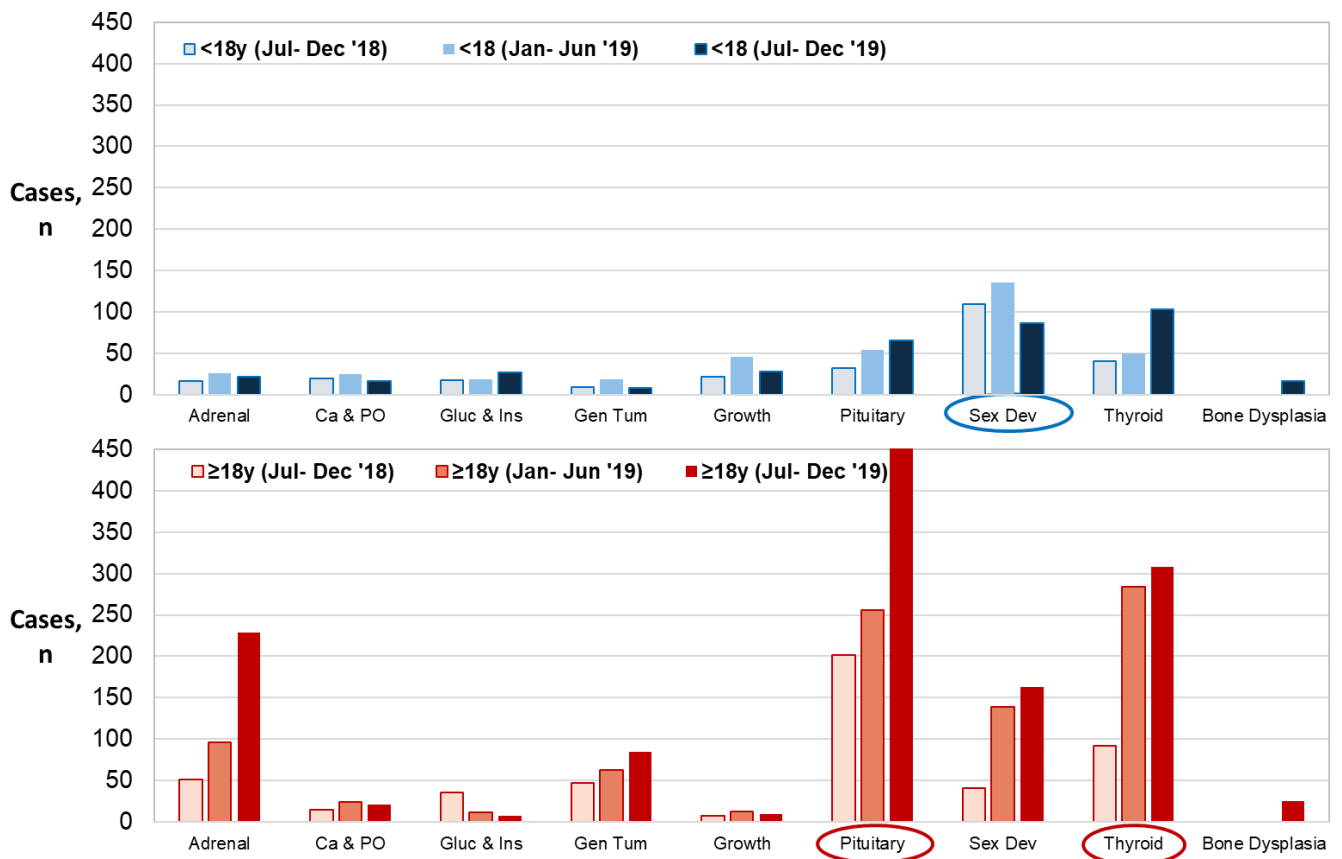


Fig.3 – Cases reported per MTG between July 2018 and December 2019. Conditions within the ‘Sex Development’ and ‘Pituitary’ condition group were most commonly reported amongst children and adults, respectively. For adults, the increase in reported cases over time was evident in several MTGs

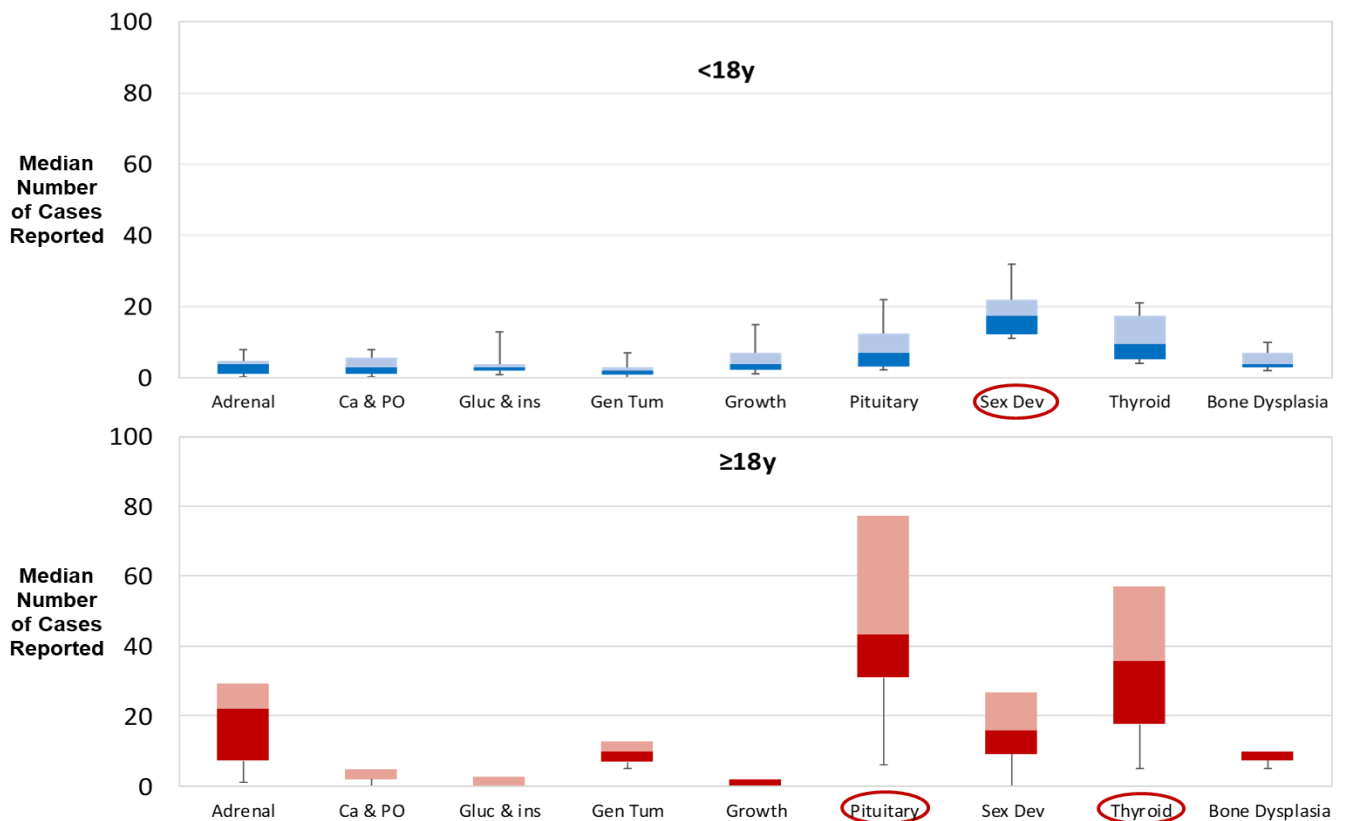
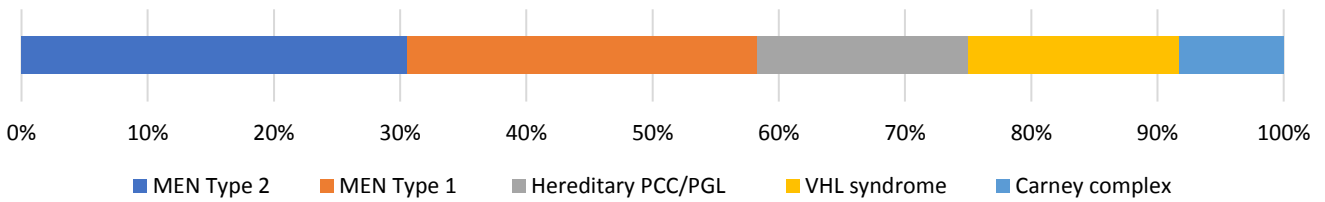


Fig.4 – Cases reported per MTG between July 2018 and December 2019. There is wide variation in the number of cases reported per centre, particularly amongst adults.

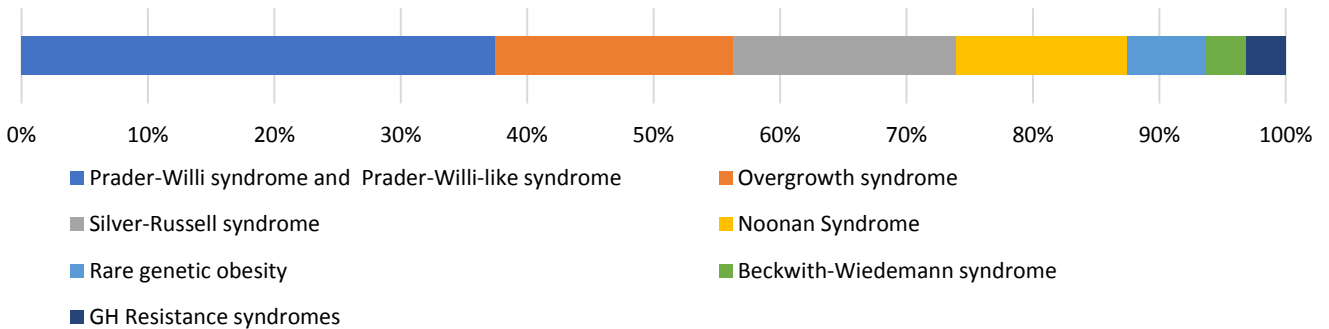
Fig.5 – Commonly reported conditions in children between July 2018 and December 2019; cases, n.



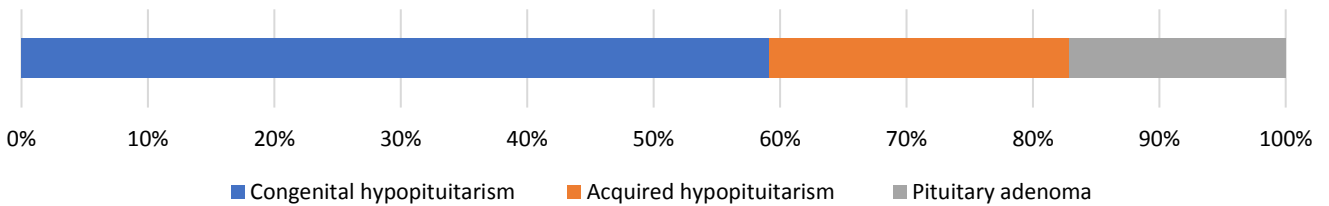
### Children- MTG 4 (Genetic Endocrine Tumours), n= 36



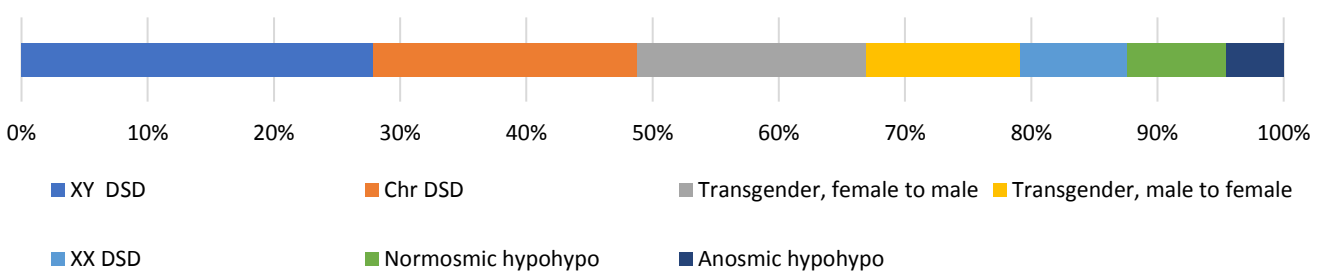
### Children- MTG 5 (Growth), n= 96



### Children- MTG 6 (Pituitary), n= 152



### Children- MTG 7 (Sex Development), n= 330



### Children- MTG 8 (Thyroid), n= 193

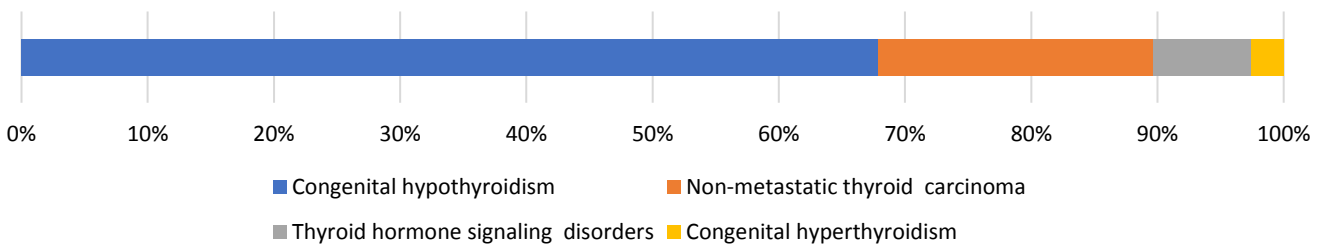
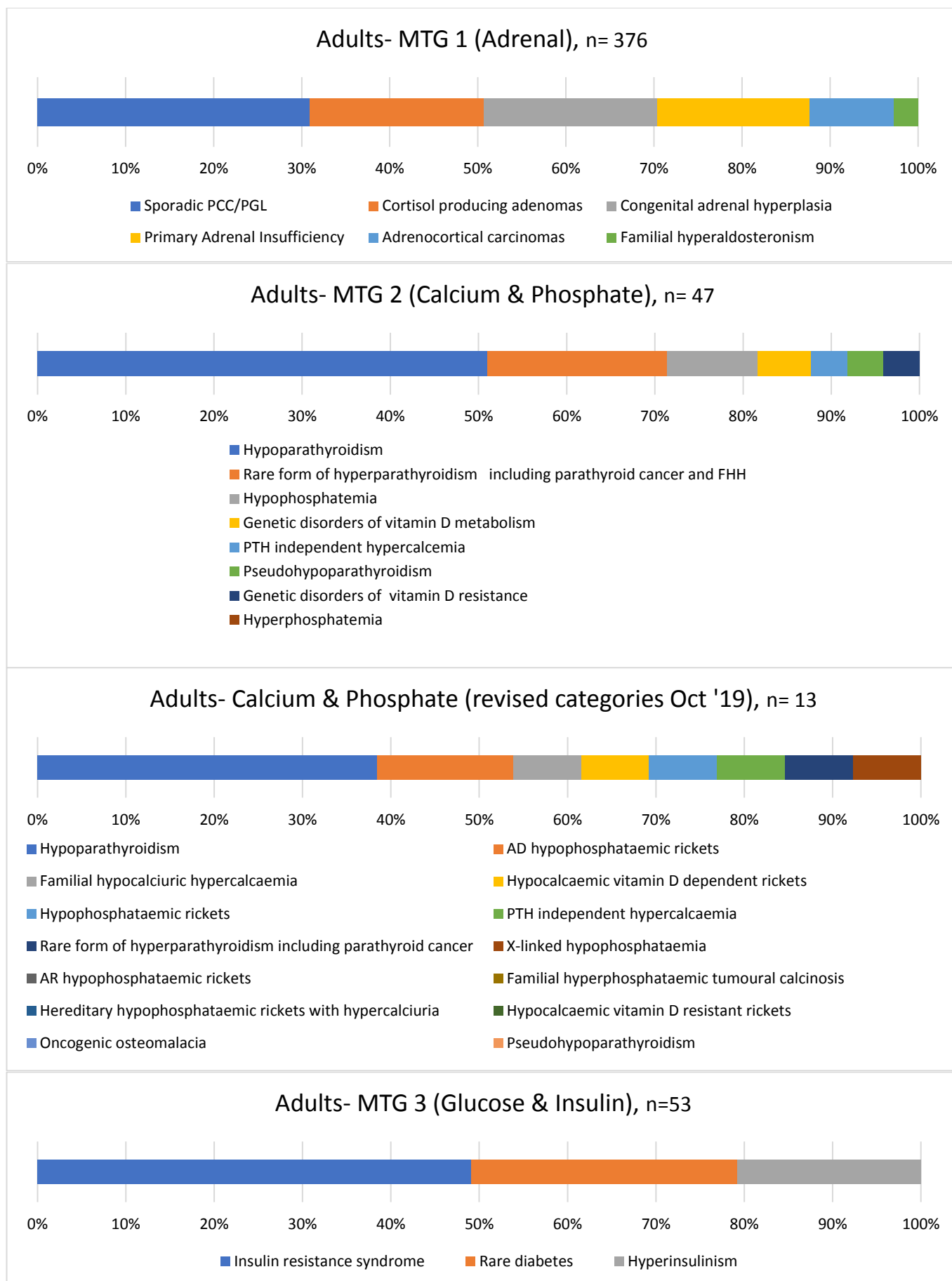
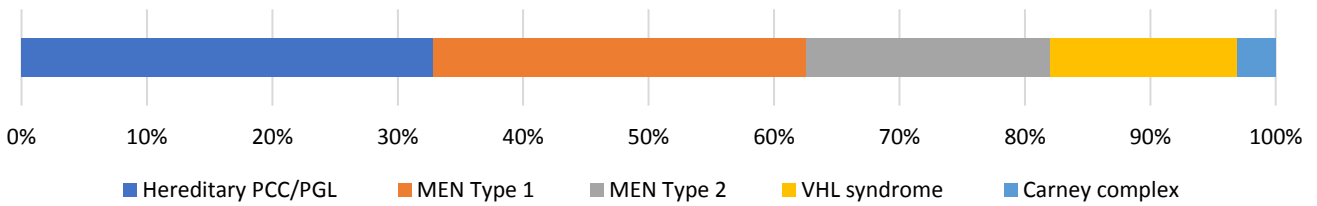


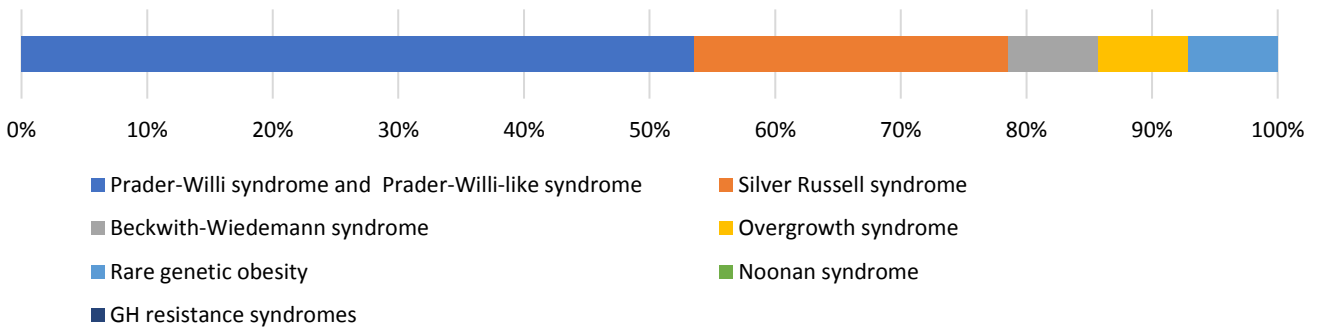
Fig.5 – Commonly reported conditions in adults from July 2018 to December 2019; cases, n



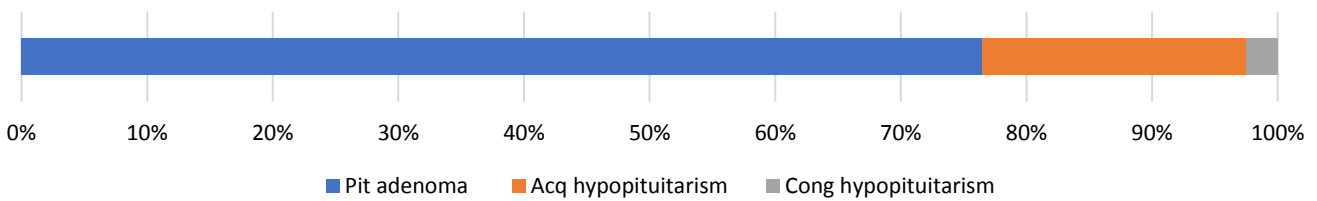
### Adults- MTG 4 (Genetic Endocrine Tumours), n=195



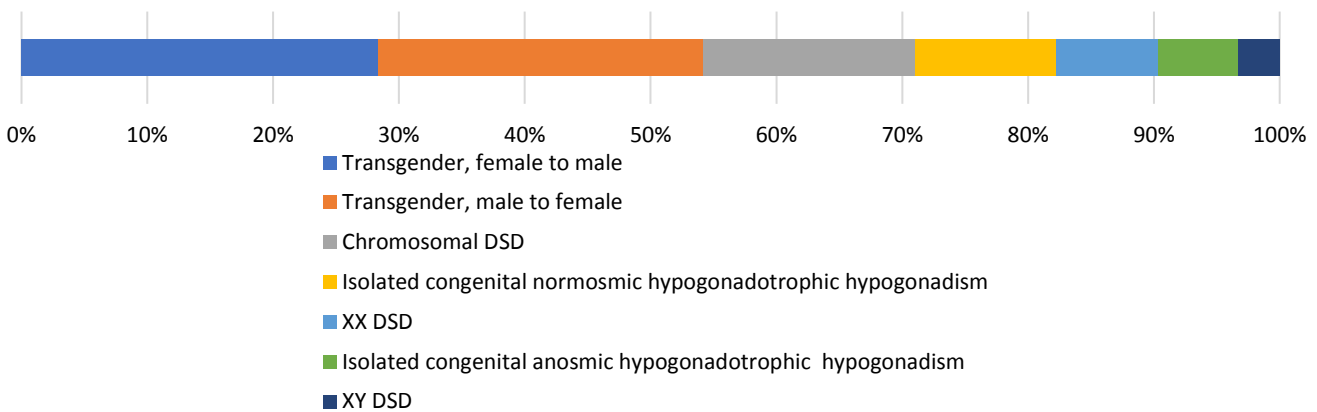
### Adults- MTG 5 (Growth), n=28



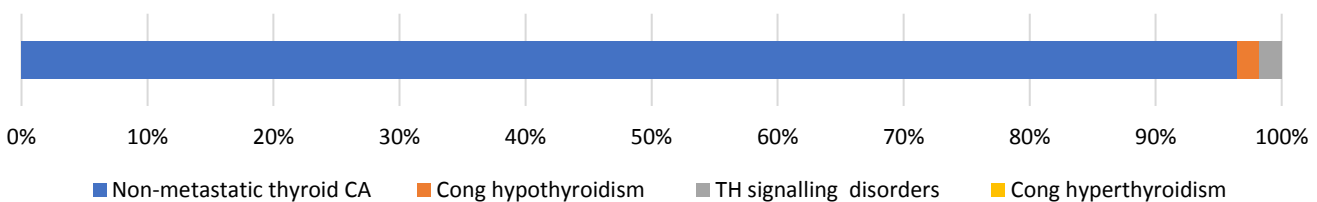
### Adults- MTG 6 (Pituitary), n= 937



### Adults- MTG 7 (Sex Development), n= 343



### Adults- MTG 8 (Thyroid), n= 684



### **Interpretation of Findings**

- The e-REC platform is a simple platform that can be used to capture information on new encounters with patients with rare endocrine conditions.
- There has been an increase in the number of centres registered to use the platform, the number of centres actively reporting cases and the total number of cases that are being reported.
- The increase in number of cases being reported is particularly marked amongst adults with rare conditions
- There is wide variability in the number of cases encountered for different conditions amongst different centres.
- In general, the proportion of cases that are considered to be 'suspected' is much higher in children than adults.
- Amongst children, conditions within the 'Sex Development' condition group were most commonly reported, comprising 33% of all reported conditions. Within adults, conditions within the 'Pituitary' and 'Thyroid' condition groups were most commonly reported, comprising 35% and 25% of all reported conditions, respectively.

### **Recommendations**

- The use of the platform should be disseminated widely.
- Members of ERNs should be able to utilize the platform for continuous reporting.
- Data are available to the EuRRECa Expert Working Groups for further analysis and investigate variations in diagnoses and presentations.
- Subject to the data sharing agreement developed by the EuRRECa Data Access Committee, more detailed data are available to interested parties external to EuRRECa.

Salma Ali, Jillian Bryce, Faisal Ahmed  
EuRRECa Work Package 6  
27<sup>th</sup> February 2020