


















Project Governing Board

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EuRRECa (European Registries for Rare Endocrine Conditions) which is funded by EU Health Programme and also supported by the European Society for Paediatric Endocrinology (ESPE) and the European Society of Endocrinology (ESE) is aimed at maximising the opportunity for all patients, health care professionals and researchers to participate and use high-quality, patient-centred registries for rare endocrine conditions that are covered within Endo-ERN – the European Reference Network on Rare Endocrine Conditions. The project was launched in February 2018.



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About the Project

- EuRECa provides registry platforms that allows covering a very wide range of rare conditions
- EuRECa receives guidance from Expert Working Groups that align with broad groups of rare conditions
- This guidance flows through work packages that continue to review the needs of patients, and parents, comply with the highest ethical standards, evaluate the quality and interoperability of datasets and combine them with patient-centred outcomes
- Clear policies that are acceptable to patients, researchers and industry for data governance coupled with widespread dissemination and knowledge exchange through closely affiliated stakeholders will ensure the long-term sustainability of EuRECa

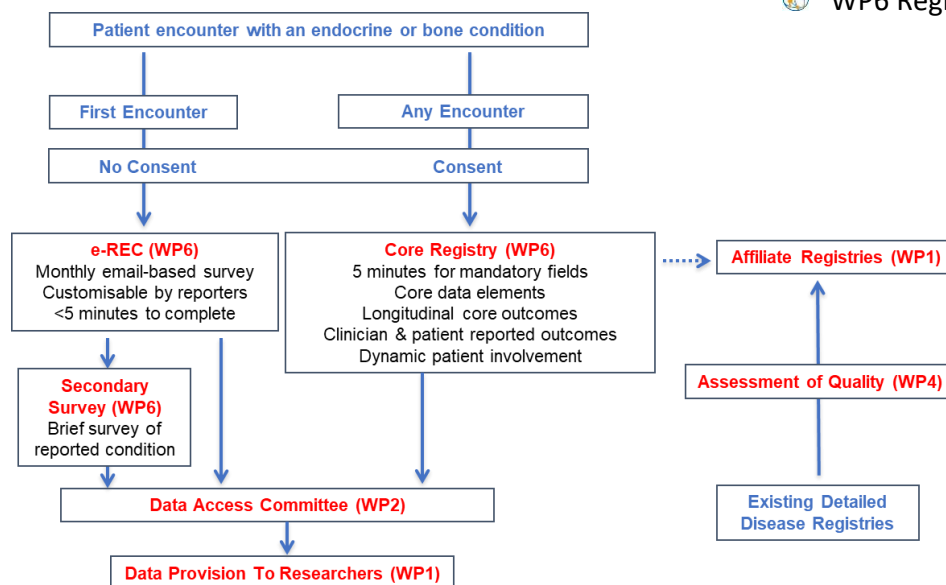
Stakeholders

EuRECa engages with stakeholders beyond the Project Group, including, Patient and Parent Groups, Government Organisations, European Initiatives and Industry

What Does EuRECa Offer

- An e-reporting platform that acts as a surveillance registry for rare conditions (e-REC)
- A core registry that can collect a core dataset for all rare conditions
- A registry that can collect generic or condition specific clinician or patient reported outcomes
- Signpost participants to detailed, disease-specific registries
- Identify conditions where gaps exist for future development of detailed disease registries
- Can offer Reference centres support with ERN Continuous Monitoring

The EuRECa Concept



Expert Working Groups & Leads

- EWG1 Ca/PO & Growth (Netchine/Linglart)
- EWG2 Endocrine Tumours (Patócs)
- EWG3 Pituitary (Katugampola)
- EWG4 Thyroid (Visser)
- EWG5 Adrenal (Reisch)
- EWG6 Sex Dev & Maturation (Nordenström)
- EWG7 Glucose & Insulin (Šumnik)
- EWG8 SWEET Consortium (Danne)

Workpackages & Leads

- WP1 Management & Coordination (Ahmed)
- WP2 Dissemination & Access (Hiort)
- WP3 Quality Assurance & Evaluation (Persani)
- WP4 Core Outcomes (Dekkers)
- WP5 Patients, Parents & Ethics (Cools)
- WP6 Registry & e-Surveillance (Ahmed)