

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 and will run for 36 months.



This leaflet is part of the project '777215 / EuRRECa' which has received funding from the European Union's Health Programme (2014-2020).

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About the Project

- EuRRECa is closely linked to Endo-ERN but is open to all professionals providing endocrine care and who would like to participate
- EuRRECa receives guidance from Expert Working Groups that align with the Main Thematic Groups of Endo-ERN
- This guidance will flow through work packages that will 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 that EuRRECa is sustained beyond the current lifetime of the project

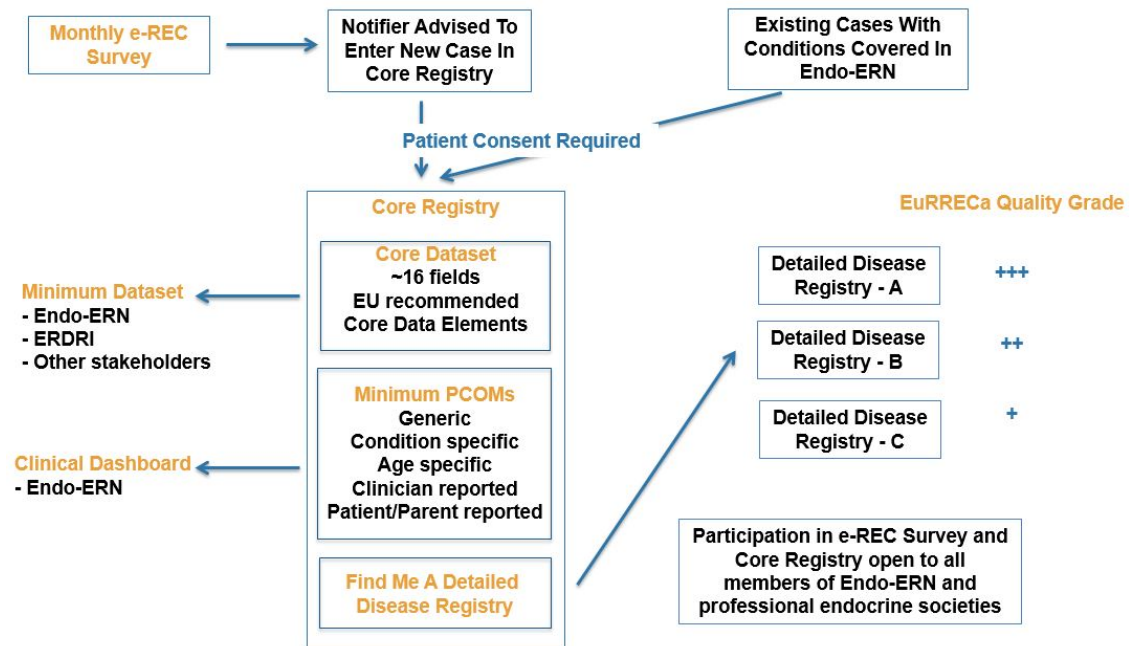
Stakeholders

EuRRECa will engage with stakeholders beyond the Project Group, including, Patient and Parent Groups, Government Organisations, European Initiatives and Industry

Aims of EuRRECa

- e-REC: e-reporting programme of Rare Endocrine Conditions
- Develop a new core registry that collects a core dataset for all rare endocrine conditions in Endo-ERN
- Incorporate clinician and patient reported markers of clinical outcome in core endocrine registry
- Signpost participants to detailed, disease-specific registries that have been endorsed by EuRRECa
- Identify conditions that require new high-quality detailed disease registries

The EuRRECa Concept



Expert Working Groups & Leads

- EWG1 Ca/PO & Growth (Netchine/Linglart)
- EWG2 Endocrine Tumours (Patócs)
- EWG3 Pituitary (Dattani)
- EWG4 Thyroid (Visser)
- EWG5 Adrenal (Beuschlein)
- 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)