

e-Reporting Of Rare Endocrine Conditions (e-REC)

What is EuRRECa

EuRRECa (European Registries for Rare Endocrine Conditions) aims to maximise the opportunity for patients, health care professionals and researchers to participate and use high-quality registries. The project, launched in 2018, includes an e-reporting programme (e-REC) and a core registry that collects a common dataset and clinician and patient reported outcomes. The project will also develop a list of affiliate detailed disease registries that are approved for data sharing. EuRRECa works closely with Endo-ERN, ESPE and ESE and the platforms it has developed have also been adopted by ERN-BOND and its related registry, EuRR-Bone.

What Is e-Reporting Of Rare Conditions (e-REC)

Many clinical and scientific networks for rare conditions operate an electronic reporting system to capture activity as well as to understand the occurrence of these rare conditions. An electronic reporting system that is performed regularly allows doctors to gather more information about these rare conditions and the care received by the people with these conditions. Participation in this project is open to all clinical centres, including those who are not members of Endo-ERN or ERN-BOND.

Who Are We

e-REC is part of the EuRRECa project which is coordinated by Professor Faisal Ahmed who is based at the University of Glasgow and at Leiden University Medical Centre. The EuRR-Bone project is coordinated by Dr Natasha Appelman-Dijkstra who is based at Leiden University Medical Centre. Details of the Project Governing Boards of EuRRECa and EuRR-Bone are available at eurreca.net/project-governing-board/ and eurr-bone.com/project/project-governing-board/.

The e-REC Reporting Process

The electronic reporting platform sends out invitations to doctors each month to enquire whether over the last month they have encountered a new case of any of the conditions that have been included in Endo-ERN (www.endo-ern.eu) or ERN-BOND (ernbond.eu). On receiving the invitation, the doctor will log in go their 'dashboard' and can enter the number of new patients they have encountered in the reporting month for the conditions they have selected to report on. The doctor can report on confirmed or suspected cases in children or in adults. When all encounters have been notified, the doctor can submit their report for the month and the platform will automatically provide unique IDs for each reported case. This ID is stored locally with the reporting doctor to link with the actual case. You can find details of centres that are current participating in e-REC at eurreca.net/e-rec/.

Information Governance

No identifiable or partially identifiable personal information is captured. The reported data are stored on a secure server in the University of Glasgow. The project complies with EU GDPR and is approved by the Information Governance authorities at the NHS Greater Glasgow & Clyde Health Board and the National Research Ethics Service in the UK.

Dissemination Of Results

Data that are generated from this work will be available to all stakeholders following approval by the Data Access Committee of the EuRRECa and EuRR-Bone projects. Reports of the data are available at <https://eurreca.net/reports/>.

Funding

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For Further Information Please Visit

eurreca.net/e-rec, eurr-bone.com