

Endo-ERN

European Reference Network
on Rare Endocrine Conditions

HCP Continuous Monitoring

2022 - 2023



European
Commission

Endo-ERN is an European Reference Network funded
by the European Union's Health Programme



European
Reference
Network

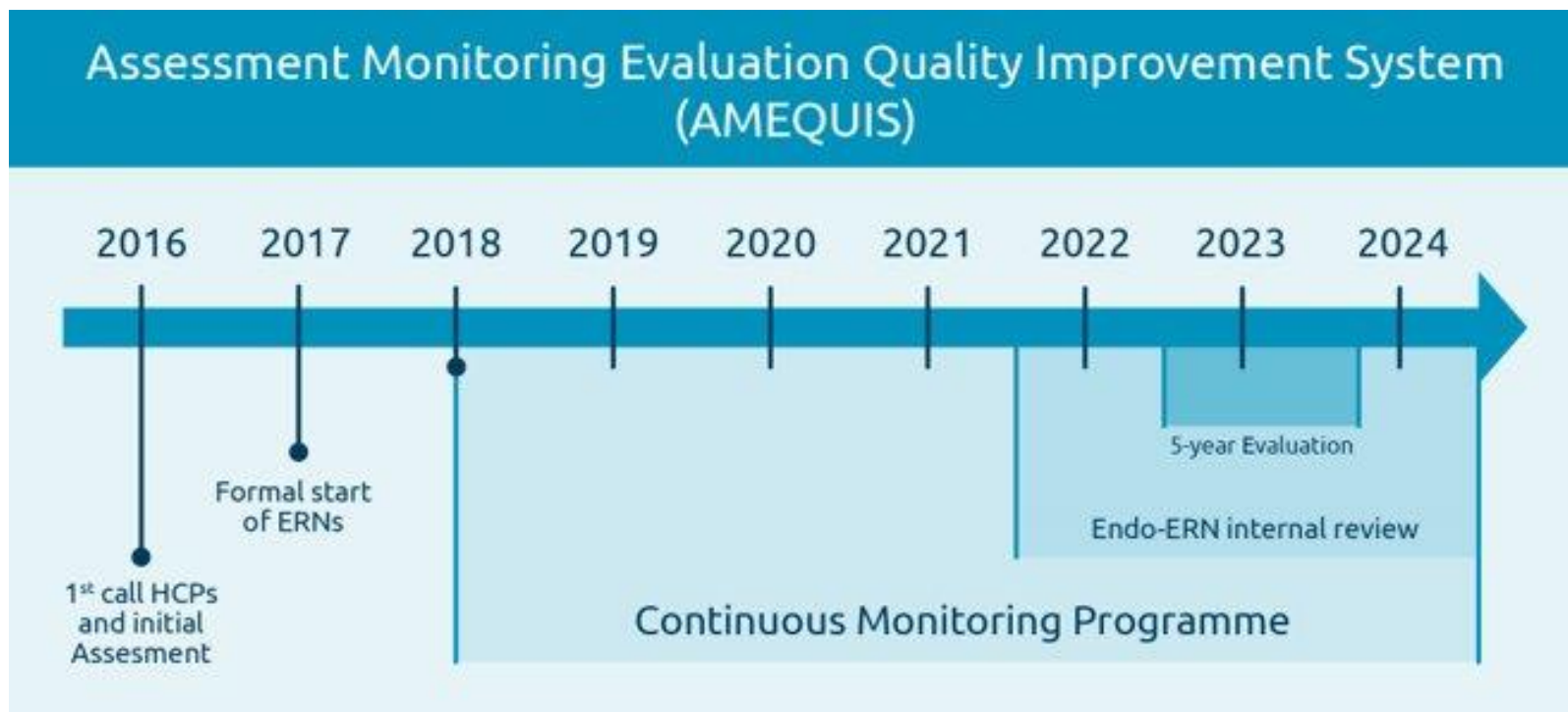


Agenda

- Brief explanation of Continuous Monitoring
 - What, why , when, how , outcomes
 - List of indicators measured
- Survey walk through
- Questions – direct from members
- Website information



Endo-ERN Evaluation Roadmap - AMEQUIS





Background

- European Commission devised a set of **18 core performance indicators** that gathers data annually from all Full Member HCPs
- As part of the monitoring program, we have created a database of [Clinical Trials](#) and [registered studies](#) our members are running or partaking in across our various rare endocrine disease [MTGs](#).
- All data:
 - Gathered via a survey
 - Subjected to a validation SOP devised by Endo-ERN
 - Our website databases are updated accordingly
- Submission of validated data to European Commission



European Commission

- Initial [assessment](#) of networks (Delegated Decision 2014/286/EU)
- **Periodic [evaluation](#) of performance of the networks and their members, five years after their approval or last evaluation (Implementing Decision 2014/287/EU)**

Continuous Monitoring headlines



Who

- All Endo-ERN member HCPs

What

- Measure of impact ERN has in our member HCPs
- HCP team membership activities to Endo-ERN
- **Mandatory** exercise from European Commission

How

- Record data based on 18 Indicators via Survey
- Regular E-REC data submission

When

- Annually - once a year during month of March
- 2022 data collected in April due to 5 yr Eval. timeline

Outcomes

- Internal Review Score
- Changes to evaluation processes
- Map & Showcase ongoing efforts of our HCPs

Changes this year ...



- ERN submission deadline = **14th April**
- 1st Call Members have just completed 5 year evaluation – to help reduce the burden of another evaluation exercise:
 - **main priority**
 - track the **patient numbers admitted to your centre in 2022** for relevant rare conditions
 - confirming if you **implement any of the CPGs/ CDSTs** currently suggested by the network
 - If you do not have time to fill in the full extent of the survey, please prioritize the patient numbers for 2022
 - If easier, you may **send us a raw data file** of the patient numbers for the specific MTG conditions rather than filling this into the survey?
 - If you **report in e-REC regularly** and these numbers are accurate we can extract these, and you will not need to fill in the numbers once again in the survey - this option is built into our survey this year.
 - If you use any of our CPGs or CDSTs , **there's a full overview list in each MTG section** of our website that you can quickly look through to see if there are any you are implementing
- Please note:
 - survey shorter this year
 - process of reporting on research activities is a data check rather than gathering exercise for the clinical trials and observational studies



Important moving forward

- E-REC will be the only method used to gather patient numbers next year
 - Start using this now!
- To report patient numbers in e-REC
 - It is a number report only i.e. submit the condition diagnosed and the hospital
 - Report every month
 - No patient consent required – no direct patient details required
 - [e-REC – EuRRECa](#)





Next Steps....

- What to do ?
 - Complete Survey
 - Inform your HCP administration of need to use e-REC registry (EuRRECa) moving forward

What to use at our [website](#)?

- Continuous Monitoring page
- These slides
- Manual of Indicators

