



European
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Network



Endo-ERN

HCP Continuous Monitoring

2024-2025

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Continuous Monitoring Overview

Who

- All Endo-ERN member HCPs
- All Affiliated Partners

What

- Measure of impact ERN has in our member HCPs
- Check HCPs complete membership activities for Endo-ERN
- **Mandatory** exercise from European Commission
- Signature Annual Conflict of Interest

New feature 2025

How

- Record data based on 18 Indicators via Survey from Endo-ERN
- Regular E-REC data submission
- Report totals to European commission directly

Same as January 2024

When

- Annually – once a year in the first quarter
- 2023 data collected starting from January 2024

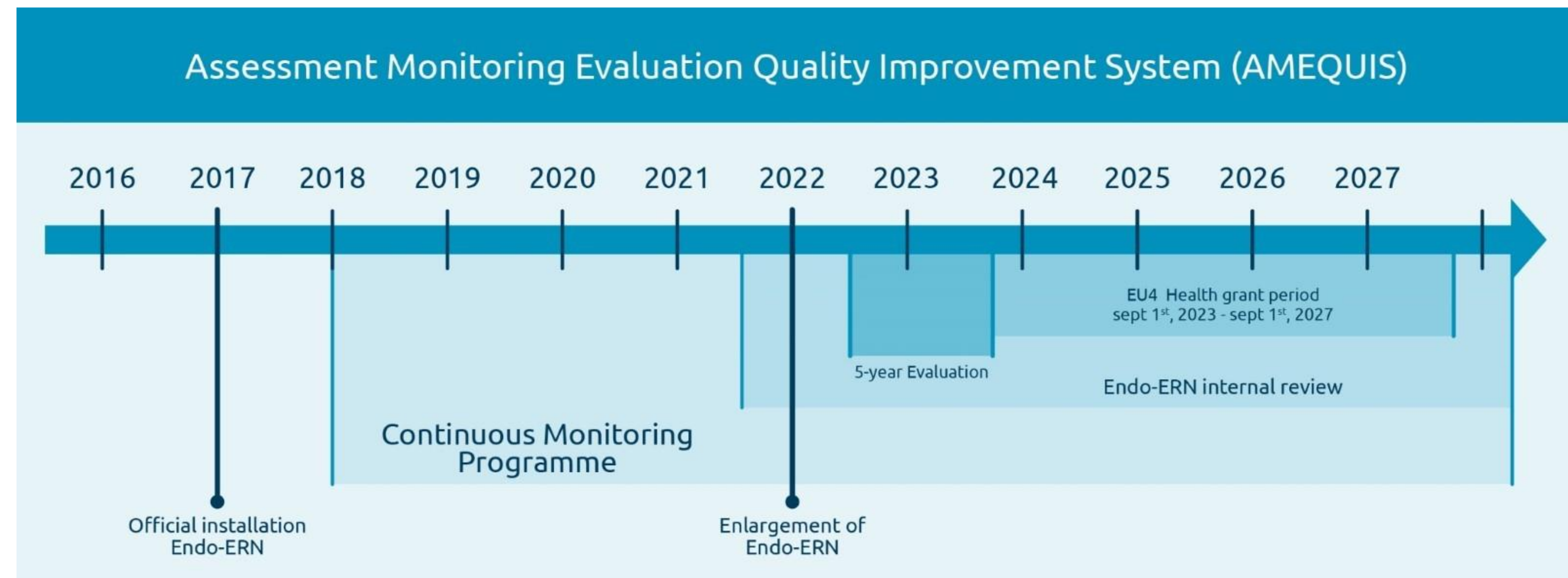
Outcomes

- HCP performance system – internal scoring
- Changes to evaluation processes
- Map & Showcase ongoing efforts of our HCPs

Background



- European Commission devised a set of **18 core performance indicators** that gathers data annually from all Member HCPs
- All data:
 - Gathered via a survey, e-REC registry and European commission platforms
 - Subjected to validation by Endo-ERN
 - Our website databases are updated accordingly



Who does what in my HCP



This exercise has 2 main steps, as detailed in the next instructions section.
Please note that the gathering of data takes varied amounts of time per centre, so please start step 1 early in January.

Roles/ People

What each role needs/ does

HCP Main Representative /
Substitute Representative



- Needs an EU Login – [obtain here if you do not have](#) one
- Fills in EC platform
- Fills in Endo-ERN Survey

Care Team in your centre



- Provides details on Endo-ERN survey activities
 - Replies to survey directly if team decides to do so
- Checks patient numbers they reported in e-REC



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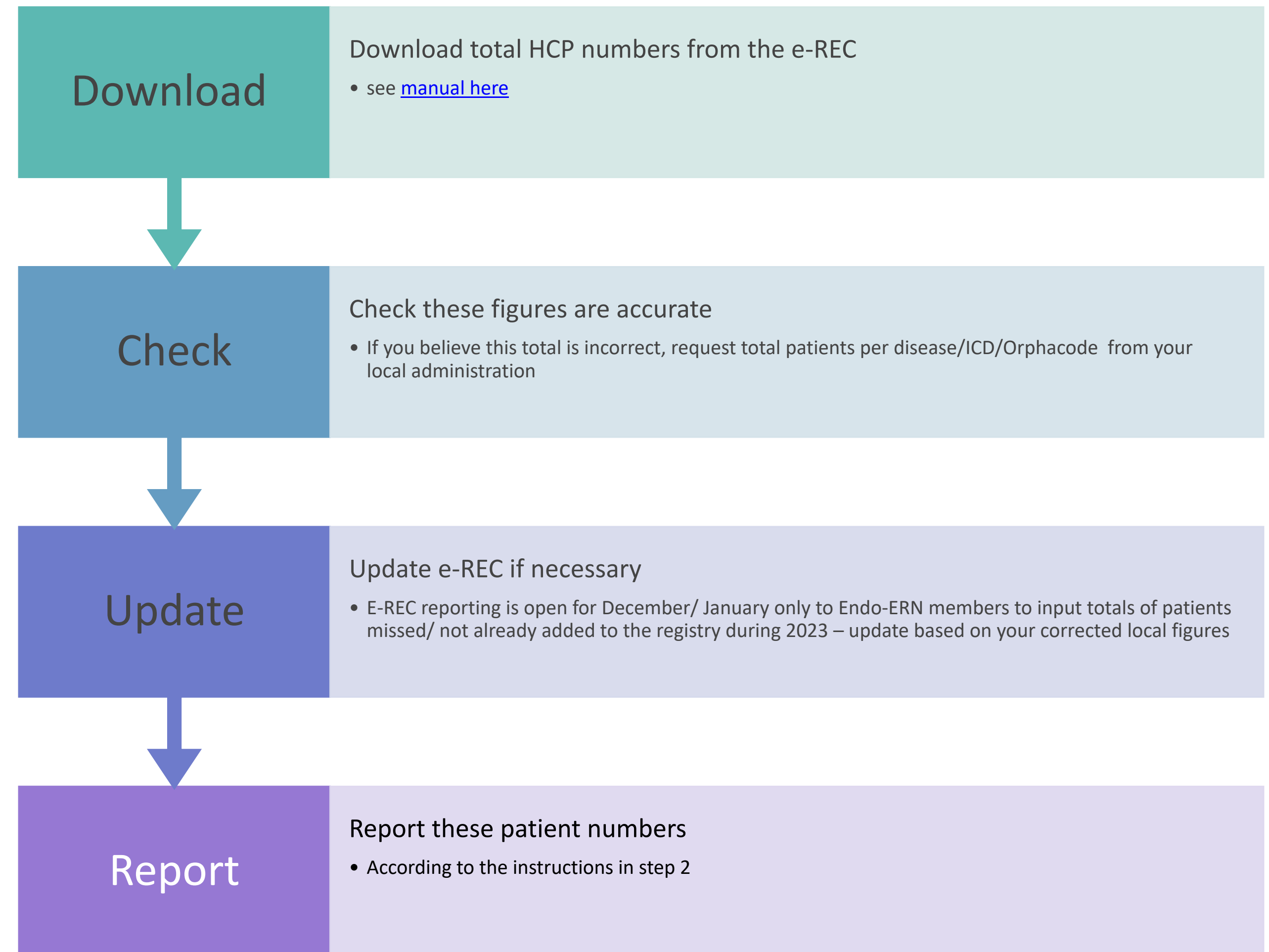
Instructions for January 2025



Instructions for 2024: Step 1



Update & gather your centre's new **Patient Numbers** for rare endocrine diseases in 2023



Instructions for this year: Step 2

HCPs must report to both Endo-ERN and European Commission (DG Sante) directly, therefore there are 2 reporting links that are open to response from **January 1st until February 29th 2025**

1. Link from Endo-ERN

- A survey to respond on remaining indicators
- 1 report from each HCP (consortia will be combined by us)
 - Get input from your team on these indicators
 - Option for multiple reporters
- Here you can report new patient numbers per individual disease in pediatric / adult patients to Endo-ERN Survey

2. Link from European commission (DG Sante)

- 1 reporter for each HCP – this is the main representative by default
 - Request change of reporter [via email](#)
 - Reporter needs EU Login to enter form
- Give details on 2 indicators:
 - Report total new Patient Numbers seen in 2023 at the centre for all endorsed MTGs
 - State if/how you use Orphacodes at the centre/hospital

Endo-ERN Survey

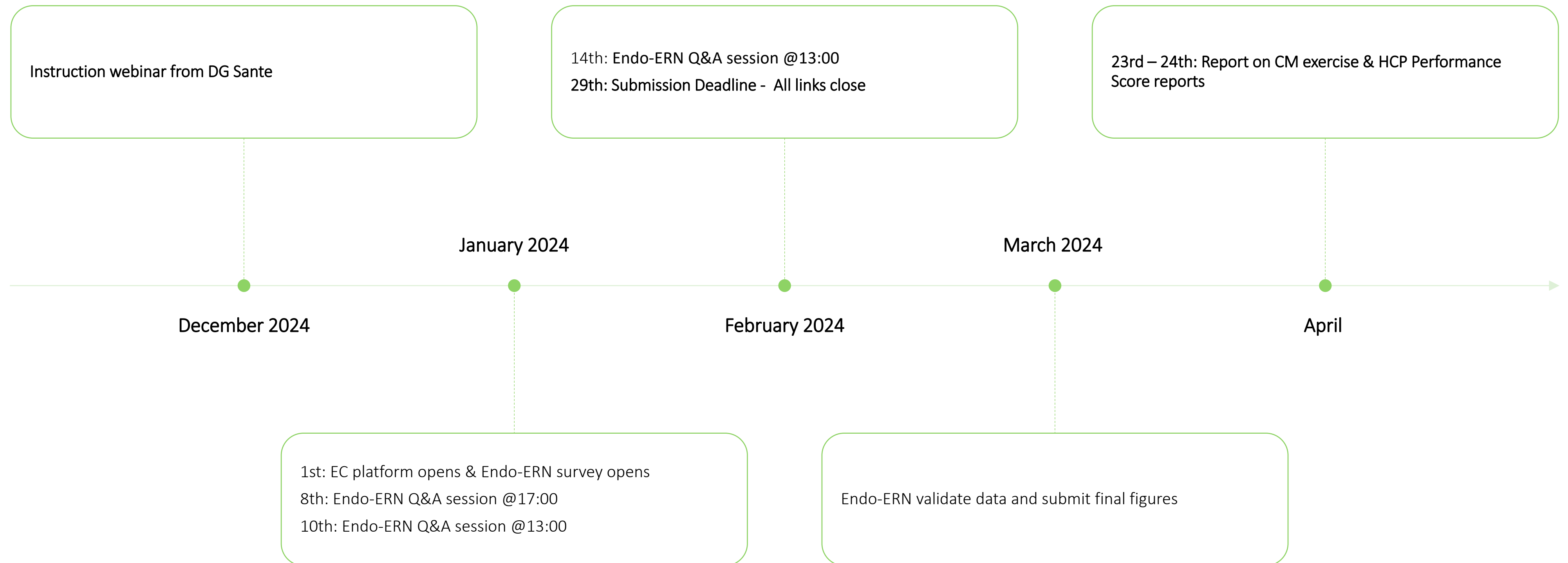
The indicators to be reported on are based on these objectives and 18 measures in addition to the [HCP Performance System activities](#).

Link available from January 1st 2025

https://ec.europa.eu/eusurvey/runner/CM_Endo-ERN_2025

	Objective 1: To ensure that ERNs are operational and successfully carry out their activities	Source
1.1	Number of Member States represented in the ERN	EC
1.2	Number of full members of the ERN	EC
1.3	Number of affiliated partners of the ERN	EC
1.4	Number of patient organisations represented in the ERN	ERN
	Objective 2: To improve access to clinical advice, diagnosis, treatment, and follow-up of patients	
2.1	Number of new patients referred to the Health Care Providers of the ERN, with the diagnosis of a disease or condition that falls within the scope of the ERN	ERN
2.2	Number of patient cases discussed in the CPMS	EC
	Objective 3: To optimise patient outcomes by combining healthcare professionals' skills & resources used	
3.1	Number of CPMS outcome reports produced during the reporting period	EC
3.2	Days between enrolment in the CPMS and multidisciplinary clinical advice 3.2.a) non-urgent cases 3.2.b) urgent cases	EC
	Objective 4: To increase the capacity of professionals to recognize and manage cases of rare and complex conditions and diseases within the scope of the ERN	
4.1	Number of education/training activities not accruing higher education credits aimed at healthcare professionals delivered by the coordination teams or HCP members of the ERN	ERN
4.2	Number of formal educational activities that are accruing higher educational credits aimed at healthcare professionals delivered by the coordination teams or HCP members of the ERN	ERN
	Objective 5: To reinforce clinical research in the field of rare and complex conditions and diseases by collecting data and carrying out research activities	
5.1	5.1.a) Number of Clinical Trials involving ERN members in at least two Member States 5.1.b) Number of Observational prospective studies / Observational cohort or case-control studies / Case-series studies involving ERN members in at least two Member States	ERN
5.2	Number of accepted peer-reviewed publications in accredited scientific journals falling within the scope of the ERN and acknowledging the ERN.	ERN
	Objective 6: To ensure that patients referred to ERNs have equal access to high and quality healthcare services	
6.1	Number of Clinical Practice Guidelines and other types of Clinical Decision-making Tools, adopted for diseases within the scope of the ERN	ERN
6.2.	6.2.a) Number of new Clinical Practice Guidelines written by the ERN and released during the reporting period 6.2.b) Number of other types of new Clinical Decision-making Tools (clinical consensus statements or consensus recommendations), written by the ERN and released during the reporting period	ERN
	Objective 7: To guarantee that knowledge, expertise and awareness is spread outside the ERN so that more people can benefit from the ERN activities	
7.1	Number of congresses/conferences/meetings at which the ERN activities and results were presented	ERN
7.2	Number of individual ERN website hits	ERN
	Objective 8: Complex and long-term indicators which need further development	
8.1	Level of patient satisfaction (still to be developed)	
8.2	Integration in the national health systems of Member States (still to be developed)	

Timeline & Events



FAQ



What if I do not report my patient figures directly to DG Sante?

- DG Sante will track this in their system and include it in the annual report. Endo-ERN will submit your figures from e-REC
- If you do not have figures in e-REC, this will be marked as non-compliance with mandatory evaluation activity

Can more than one submission be made from my HCP for Endo-ERN e.g. if two departments want to respond separately?

- This is possible ONLY if you have informed Endo-ERN via the survey to expect multiple submissions to be combined
- A template document/ form is available at our Endo-ERN website created by Erasmus UMC centre to use to collaborate between colleagues/ gather input

'I need support in e-REC entering patients'

- Join a drop in session for support from the registries team [Inloopsessies - EuRRECa en EuRR-Bone \(eurreb.eu\)](#)



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