

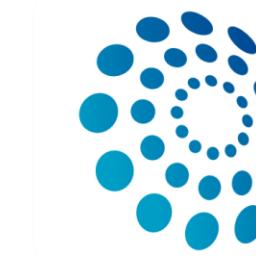


HCP Continuous Monitoring

2025-2026

Emily White
Evaluation Manager





Contents

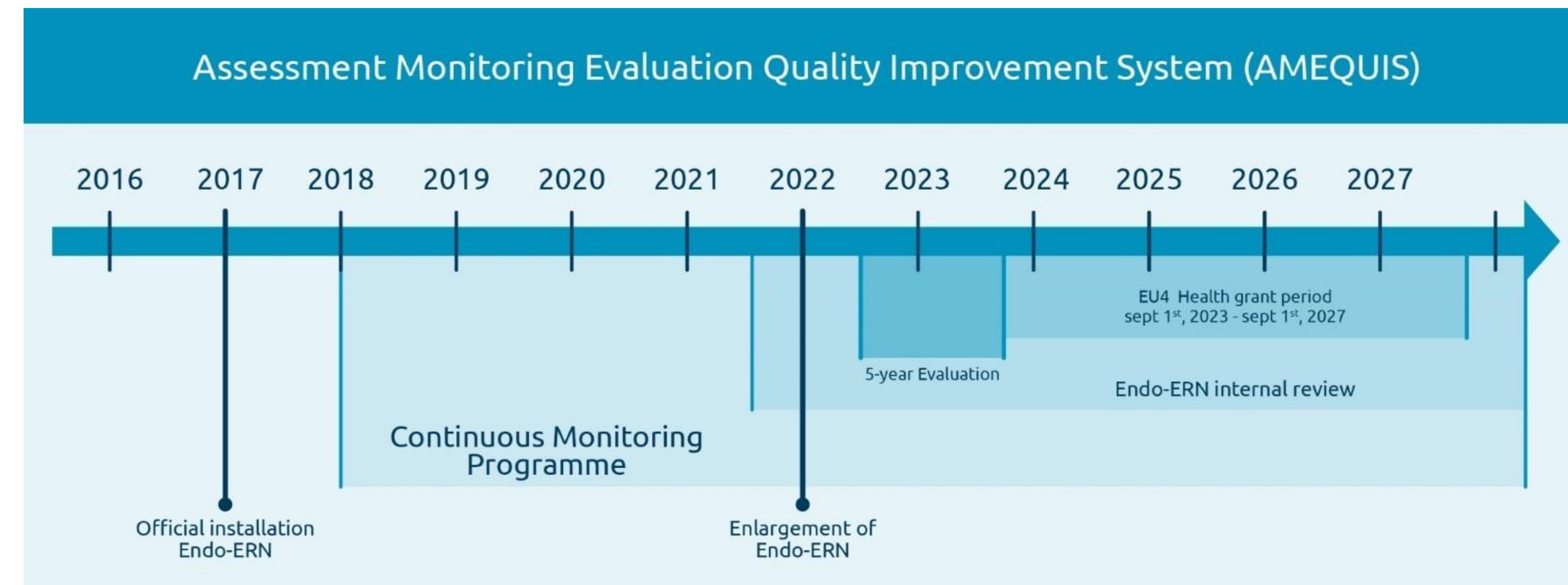
- Brief explanation of Continuous Monitoring
 - What, why, when, how, outcomes
- Instructions
 - Step 1
 - Step 2
 - Endo-ERN Survey
 - Timeline
- FAQ

Background



European Commission

- 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







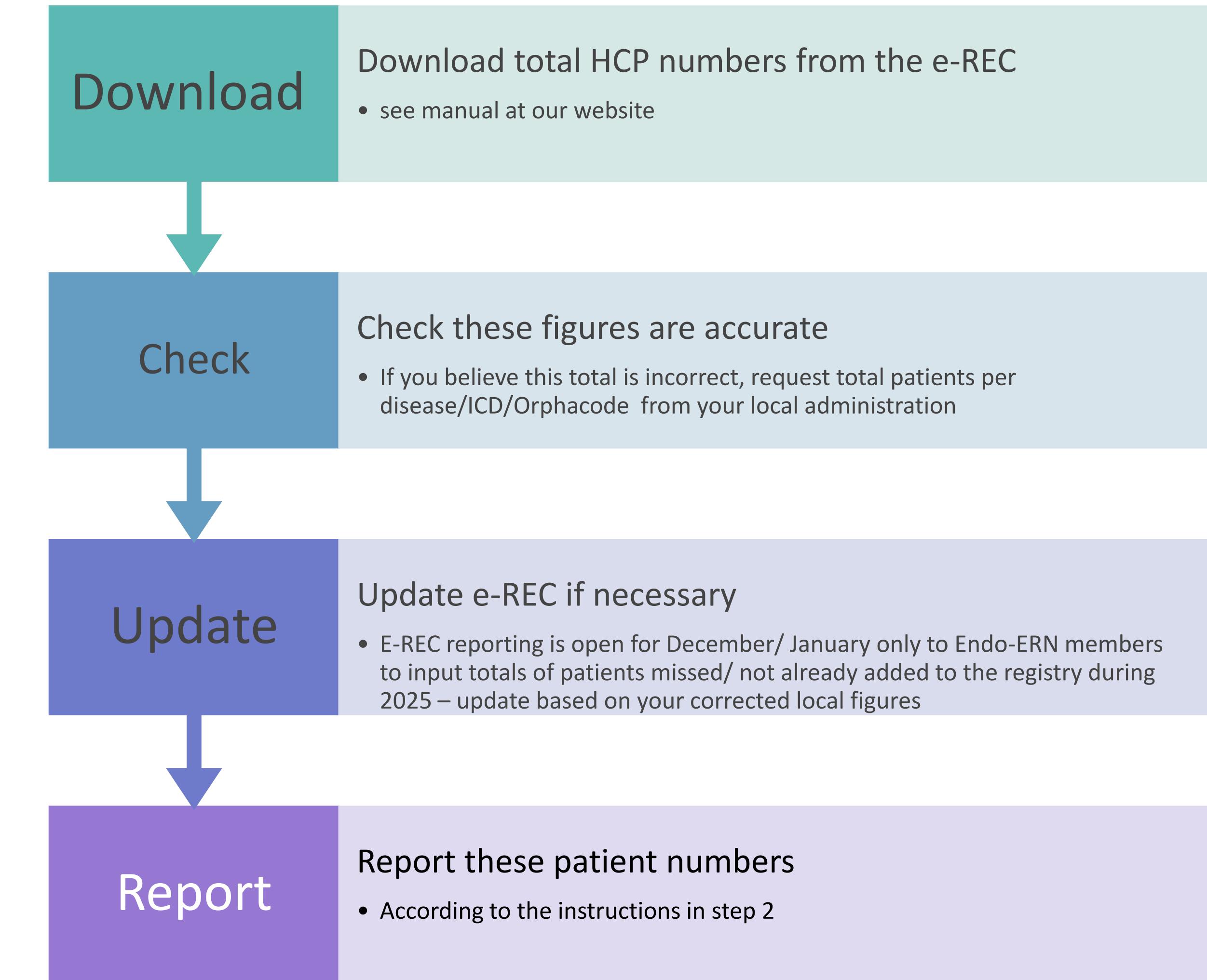
Instructions for January 2026

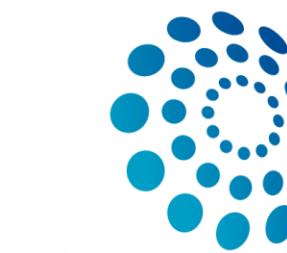


Step 1: e-REC numbers

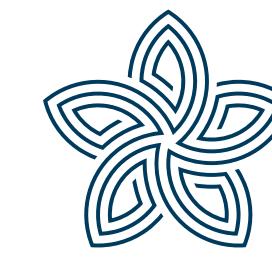
Gather your centre's new
Patient Numbers for rare
endocrine diseases in 2025

Deadline 31st January to
update e-REC for year
2025>>>





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Step 2 - Completing submission

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 28th 2026**

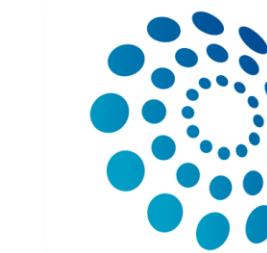
1. [Link from Endo-ERN](#)

- A survey to respond on remaining indicators
- 1 report from each HCP (consortia will be combined by us)

2. [Link from European commission \(DG Sante\)](#)

- 1 reporter for each HCP – this is the main representative by default
- Reporter needs EU Login to enter form
- Give details on 2 indicators:
 - Report total new Patient Numbers seen in 2025 at the centre for all endorsed MTGs
 - If you use Orphacodes at the centre/hospital in patient coding/ records

Step 2 - Options



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1. Link from Endo-ERN

- A survey to respond on remaining indicators
- 1 report from each HCP (consortia will be combined by us)



Less materials requested this year as indicators are focused on ERN funded activities

2. Link from European commission (DG Sante)

- 1 reporter for each HCP – this is the main representative by default
- Reporter needs EU Login to enter form
- Give details on 2 indicators:
 - Report total new Patient Numbers seen in 2025 at the centre for all endorsed MTGs
 - If you use Orphacodes at the centre/hospital in patient coding/ records

Option: If preferred you can email your orphacode use to e.k.white@amsterdamumc.nl and she will submit this and your e-REC numbers



EC platform – IF you are same reporter as January 2025



1. Use your EU login at this link : [SANTE Data Collection Platform](#)
2. Create a new dossier – images contain next steps

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The Commission is in the process of updating some of the content on this website in light of the withdrawal of the United Kingdom from the European Union. If the site contains content that does not yet reflect the withdrawal of the United Kingdom, it is unintentional and will be addressed.

Collection	Description
EC COVID-19 Clearing House	Following the rapid development and transmission of the SARS-CoV-2 virus, EU Member States are facing shortages of products. This form collects the needs of Mem
ERN - Application to become a member of a European Reference Network	Directive 2011/24/EU on the application of patients' rights in cross-border healthcare sets out the objectives, principles and criteria of the ERNs
ERN Continuous Monitoring and Quality Improvement System – Core set of indicators	According to Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, setting out the objectives, principles and criteria of the

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ERN Continuous Monitoring and Quality Improvement System – Core set of indicators

Yearly continuous monitoring and assessment system of the ERNs to allow for closer follow up of the activities performed by the networks.

Release	Description	Open date	Closed date
2025 - ERN Members and Affiliated Partners	According to Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, setting out the objectives, principles and criteria of the	01/01/2026	28/02/2026
2025 - ERN	According to Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, setting out the objectives, principles and criteria of the	01/01/2025	31/03/2026



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Networks

Working for patients with rare, low-prevalence and complex diseases.

Share.Care.Cure.

Useful documentation

Full indicators text from DG Sante



Indicators' definitions:

[ERN Indicators V9.1 - HCP Form.pdf](#)

Privacy statement:

[SDCP ERN Indicators Privacy Statement V2.pdf](#)

To request deletion of your personal data in relation to this data collection only, please contact the data controller listed in this

SANTE-ERNSD-ITSUPPORT@ec.europa.eu



Technical support:

For technical questions related to the use of this form, please send an email to the following address : SANTE-ERNSD-ITSUPPORT@ec.europa.eu

Select an activity

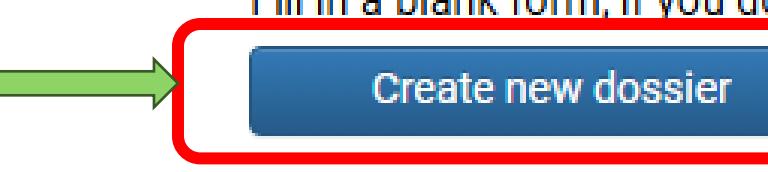
Create a new form dossier

Fill in a blank form, if you don't see one that you've already started from the list below.

[Create new dossier](#)

[← Go to parent data collection](#)

Click here to start your submission



Using the HCP form

Form ID: 1 This form is not valid for submission.
The content can be saved, but not submitted until all required fields have been correctly completed.

[Save form](#) [Download PDF of dataset](#) [Finish and !\[\]\(ecec84f6abef68045d94a9e318e4e7dc_img.jpg\) form](#)

KPI Indicators

2.1 Number of new patients referred to your clinical centre, with the diagnosis of a disease or condition that falls within the scope of your ERN   * KPI 6

5.5 Does your centre use orphacodes to code/classify patient cases?   * KPI 16

Optional comment from the clinical centre:

Number of observations: (0/800)

I confirm that these values are correct and all the supporting evidence requested by the ERN was provided. *

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Connecting Europe Facility

Colour coded –
cannot submit the final
version if anything is
RED



Using the HCP form



This form is valid for submission.
You can submit but please note that there is at least one empty field or comment in your form.
You can save your form if you want to modify it later.

Form ID: 1

Save form **Submit and close form** Download PDF of document Print and edit form

KPI Indicators

2.1 Number of new patients referred to your clinical centre, with the diagnosis of a disease or condition that falls within the scope of your ERN * 5 * KPI 5

5.6 Does your centre use orphacodes to code/classify patient cases? * Yes * KPI 16

Optional comment from the clinical centre.

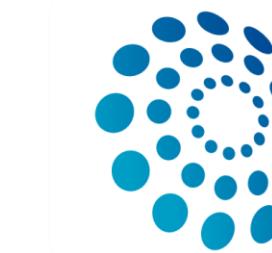
Number of characters: (2000)

I confirm that these values are correct and all the supporting evidence requested by the ERN was provided. *

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Colour coded –
cannot submit the final
version if anything is
RED

Only when **GREEN**
the submit option
appears



Endo-ERN Survey

- The indicators to be reported on are based on these objectives and 18 measures from the EU commission AND data to inform the HCP Performance Scores
- There are some additional matters the survey will ask you to report on this year from our Work Packages
- Key new topics:
 - Number of referred/cross border rare endocrine patients from EU countries
 - Number of Ukrainian patients referred/ treated in your HCP in 2025
 - Crisis protocols/ management e.g. extreme weather, power disruptions, epidemic, war

Timeline & Events



1st: EC platform opens & Endo-ERN survey opens
8th: Instruction webinar from DG Sante
9th: Endo-ERN Q&A session @12:00
21st: Endo-ERN Q&A session @16:00

Endo-ERN validate data and submit final figures

January 2024

February 2024

March 2024

April

13th: Endo-ERN Q&A session @15:00
28th: Submission Deadline - Submission close

20th: Report on CM exercise presented at General Assembly

FAQ



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

- Endo-ERN will submit your figures from e-REC AND contact you for answers on orphacode use
- If you do not have figures in e-REC, this will be marked as non-compliance with Endo-ERN 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 for our SURVEY (not the EC reporting platform).
- The survey pdf can be downloaded by our members to use to collaborate offline between colleagues/ gather input

Can individual centres in a consortium submit separate answers?

- For EC report , NO
 - As consortium is counted as 1 member of the network and must report as this. The consortium needs to communicate with each other and elect 1 person who will be provided the data to report (ideally the main/substitute representative).
- For Endo-ERN Survey, YES
 - As the survey involves a greater amount of information and data there is the option to submit from each consortium centre (as stated in previous FAQ). This should be agreed by those coordinating the consortium

'I need support in e-REC entering patients'

- Join a drop in session for support from the registries team [Inloop sessies - EuRRECa en EuRR-Bone \(eurreb.eu\)](https://eurreb.eu)



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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

HCP Main Representative /
Substitute Representative



What each role needs/ does

- 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

Recommended process



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1. Decide whom you need for this task
 - e.g. fellow experts, (different MTGs, pediatric & adult), local rare disease office, health informatics/ ICT team to request numbers from etc.
2. Check with your team how they report their rare patient cases (in e-REC already, in the local patient file, own records etc.)
3. Decide how you submit the Endo-ERN survey – 1 submission OR multiple
4. Decide deadlines for following:
 - when you will have the patient numbers (and survey data) provided to you from all team members
 - If relevant, when numbers from central system will be available and be checked if necessary by team members
5. Before January 31st - upload totals to e-REC per disease, adult & paediatric, suspected or confirmed
6. Before February 28th - Report the total confirmed cases to the EC & complete Endo-ERN survey