

FAQ for Continuous Monitoring

What data do I submit?

- Relevant data from the **reporting year 1st January until 31st December** for our 18 indicators.
- Details about the indicators being asked about are available in the [Manual at our website](#). Specific data is asked for in different survey sections or sections of the reporting form.

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

- DG Sante will track this in their system and your HCP will be marked non-compliant in their 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 Endo-ERN mandatory evaluation activity

My centre does not use Orphacodes, only ICD-10 – how do I add these to e-REC?

The registries team uses the following [data dictionary](#) (e-REC) to map Orphacodes onto [various other coding system](#) (core registry) but not ICD-10 as the direct link between single codes is less clear and therefore this needs further evaluation by our experts. There is a draft file with relevant ICD10s mapped onto Orphacodes available on request to support your reporting.

- Please decide in your HCP team which conditions you will report on for your continuous monitoring, based on those you used previous years for reporting
- Report any conditions in e-REC that are clear to your team e.g. all pituitary adenoma's should be reported under 'Pituitary Adenoma, ORPHA99408'
- If uncertain how to categorize please contact the registries team (registries@lumc.nl) for support AND our evaluation manager Emily White (e.k.white@amsterdamumc.nl)

I cannot find the link to enter the European Commission reporting platform:

- Link here: <https://webgate.ec.europa.eu/sante-xmlgate/#!/forms/ern-indicators>

I cannot find the link to the Endo-ERN survey

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

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).
- A template document/ form is available at our Endo-ERN website created by our members to use to collaborate 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 [Inloopsessies - EuRRECa en EuRR-Bone \(eurreb.eu\)](#)
- Contact the registries team at registries@lumc.nl

'I have missed cases in specific months e-REC'

- For the purpose of continuous monitoring please add these missed cases to the open December report (called returns) in your e-REC account.
- If your e-REC returns are already reported and closed for December contact the registries team at registries@lumc.nl