

## FAQ for Continuous Monitoring 2023/2024

### What data do I submit?

- Relevant data from the **period 1st January until 31st December 2023** 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

- 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](mailto:registries@lumc.nl)) for support AND our evaluation manager Emily White ([e.k.white@amsterdamumc.nl](mailto: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/ContinuousMonitoring2024\\_Endo-ERN](https://ec.europa.eu/eusurvey/runner/ContinuousMonitoring2024_Endo-ERN)

### 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](mailto:registries@lumc.nl)