



# ERN Monitoring Platform Exercise of 2026 for HCPs (data of 2025)

8.01.2026



*European Commission*

*Directorate-General for Health and Food Safety*

# Practical and legal considerations

## 1. Please identify yourself correctly:

**Affiliation – FirstName LastName** (example: DG SANTE – João de Sousa)  
(if necessary: right click on your name and choose “Edit display name”)

## 2. You are muted by default. Please use the chat to raise questions.

This webinar is being recorded for future visioning.  
By attending, you consent to being recorded.

# Agenda for today

1. Calendar
2. Requesting access to the HCP form
3. Reporting to the EC using the HCP form
4. Questions and answers

# Data collection of 2026

## Calendar:



## Indicators reported directly to the EC in the first stage:

- Number of Patients
- Use of Orphacodes

# Number of Patients

## Name:

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

## Definition:

Your ERN may require more detail but the EC only requires the total

The **total number** of patients attending the HCP **for the first time** during the reporting period, whose disease or condition falls within the scope of the ERN, **whatever their age and sex** (includes visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals).

# Use of Orphacodes

## **Name:**

Use of Orphacodes

## **Definition:**

Acknowledgement that a clinical centre uses orphacodes to code/classify patient cases in the local medical record system, regardless of using other types of coding (e.g. for reimbursements).




Applicable to ERNs for which the use of orphacodes is a relevant goal; otherwise, not applicable.

# Accessing the monitoring platform

- If you have already used the platform before – use the same credentials
- If this is your first time – contact your ERN helpdesk

<https://webgate.ec.europa.eu/sante-xmlgate/sdcp-1/#!/forms>



# Accessing the monitoring forms

Collection	Description	
 <b>EC COVID-19 Clearing House</b>	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	▲
 <b>ERN - Application to become a member of a European Reference Network</b>	Directive 2011/24/EU on the application of patients' rights in cross-border healthcare sets out the objectives, principles and criteria of the ERNs	▲
 <b>ERN Continuous Monitoring and Quality Improvement System – Core set of indicators</b>	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	▲





# Accessing the HCP form

Release	Description		Open date	Closed date
 <b>2025 - ERN Members and Affiliated Partners</b>	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	29/09/2026
 <b>2025 - ERN</b>	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	31/12/2026

# Using the HCP form

The screenshot shows the Sante Data Collection Platform (SDCP) web interface. The browser address bar displays the URL: `webgate.acceptance.ec.europa.eu/sante-xmlgate/sdcp-1/#/forms/ern-indicators/2025_form1`. The page header includes the European Commission logo and the text "SANTE DATA COLLECTION PLATFORM". A navigation bar contains links for Home, Forms, About, eTranslation, and Help, along with a user profile for Joao Sousa (sousajl). A blue banner states: "ACCEPTANCE Environment - This is not the production environment and data stored here is not available for analysis or submission."

The main content area features the European Reference Networks logo and the text: "Working for patients with rare, low-prevalence and complex diseases. Share. Care. Cure." Below this, a section titled "Useful documentation" lists three items:

- 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 Specific Privacy Statement.
- 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](mailto:SANTE-ERNSD-ITSUPPORT@ec.europa.eu)

Below the documentation section is a "Select an activity" section with a "Create a new form dossier" subsection. It includes the text: "Fill in a blank form, if you don't see one that you've already started from the list below." and two buttons: "Create new dossier" and "Go to parent data collection".

Further down is a "Select an existing dossier" subsection with the text: "Select an existing dossier to work with. You can edit an existing dossier, or upload a new XML file for an existing dossier. You cannot modify a closed (finalised) dossier."

The footer of the page displays the version number "1.15.2" and a list of links: "SANTE Data Collection Platform - ACCEPTANCE • Help • Data Protection settings • Accessibility • Contact us at Sante-XMLGATE3@ec.europa.eu".

The image shows the cover page of the "Continuous Monitoring of ERNs" document. The title is "Continuous Monitoring of ERNs" with the subtitle "ERN Continuous Monitoring and Quality Improvement System (ERN CMQIS)". Below this, the specific form title "ERN indicators – HCP form" is displayed, followed by the date "November 2025" and the version "Version 9.1". The European Reference Networks logo is centered on the page. At the bottom, it identifies the "ERN Continuous Monitoring Working Group".

# Using the HCP form

Form ID: ⓘ

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

Download PDF of dossier

Finish and exit form

Console Log -> show formData

European Reference Networks

☐

I am aware of the definitions of the current indicators and that the numbers reported must be validated. \*  
I am also aware that a zero value is a valid entry and it means that no activities were accomplished. In some indicators it is perfectly acceptable to report a zero.  
All the required supporting evidence is being uploaded to the website of my network and will be available within 1 month of the closing of this data collection.

Clinical Centre Details

Official name of the Clinical Centre

University Hospital of Padova / BOND unit

Reporting year

2025

Clinical Centre code

IT07 / 1

ERN

BOND

Clinical Centre type

Full Member

# Using the HCP form

Form ID: ⓘ

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 dossier

Finish and exit 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? ⓘ

--- Please select ---


\* KPI 16

Optional comment from the clinical centre.

Number of characters : (0/300)

☐

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



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# Using the HCP form

Form ID: ⓘ

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 dossier

Finish and exit 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 6

5.5

Does your centre use orphacodes to code/classify patient cases? ⓘ

Yes


\* KPI 16

Optional comment from the clinical centre.

Number of characters : (0/300)

☐

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



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# Using the HCP form

Form ID: ⓘ

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.

Save form

Submit and close form

Download PDF of dossier

Finish and exit 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 6

5.5

Does your centre use orphacodes to code/classify patient cases? ⓘ

Yes ▾


\* KPI 16

Optional comment from the clinical centre.

Number of characters : (0/300)

☒

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



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# Live demo

# Questions and Answers



# Thank you!



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