Agenda for today

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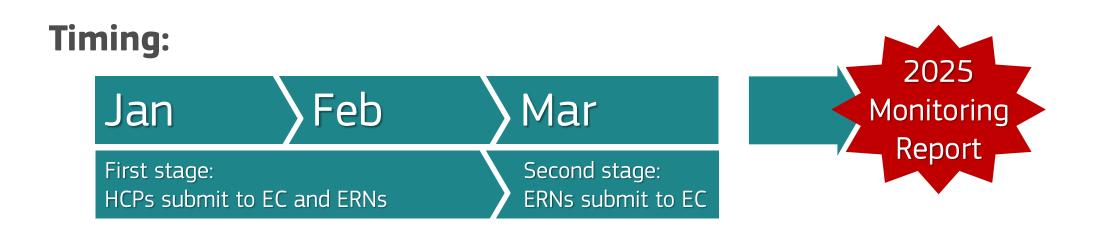4. Questions and answers

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Members and affiliated partners

Expectations

- Participate in all network activities

- Benefit from the network experience and expertise

- Use the correspondent logo

- Participate in the development of the network:

  - By sharing experience and expertise
  - By participating in mandatory activities

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Data collection of 2025

Timing:

Jan	Feb	Mar

First stage:
HCPs submit to EC and ERNs

Second stage:
ERNs submit to EC

2025 Monitoring Report

Indicators reported to EC in the first stage:

- Number of Patients
- Use of Orphacodes

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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).

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Use of Orphacodes

Name:

Does your centre use Orphacodes?

Definition:

Does your centre use Orphacodes for classification of rare clinical cases, (whatever the IT implementation in place at the hospital or at the centre)?

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Accessing the HCP form

1. The HCP designates a person to report – the reporter. It can be the HCP representative to the ERN, the sub-representative or other person.

2. The reporter creates (if not yet done) an EU login account and associates a mobile phone to the account. This process is common to all EU IT platforms. Detailed instructions can be found [here](#).

3. The reporter [submits](#) to the ERN a request to use the monitoring platform.

4. Once the request is approved by the ERN local admin, the reporter can [enter](#) the monitoring platform.

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HCP Form (members and affiliated partners)

European Reference Networks   **ERN Continuous Monitoring and Quality Improvement System**

☐ I am aware of the official definitions of the indicators and that the numbers reported will be validated by the ERN.
I am also aware that I have two months to collect the requested data and submit this form.

(Please choose your ERN)

Official name of CC (in English)	CC code	ERN	CC type

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 center use orphacodes ?	KPI 16

Optional Comment from the clinical centre

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

SAVE   **SUBMIT**

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Thank you!

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