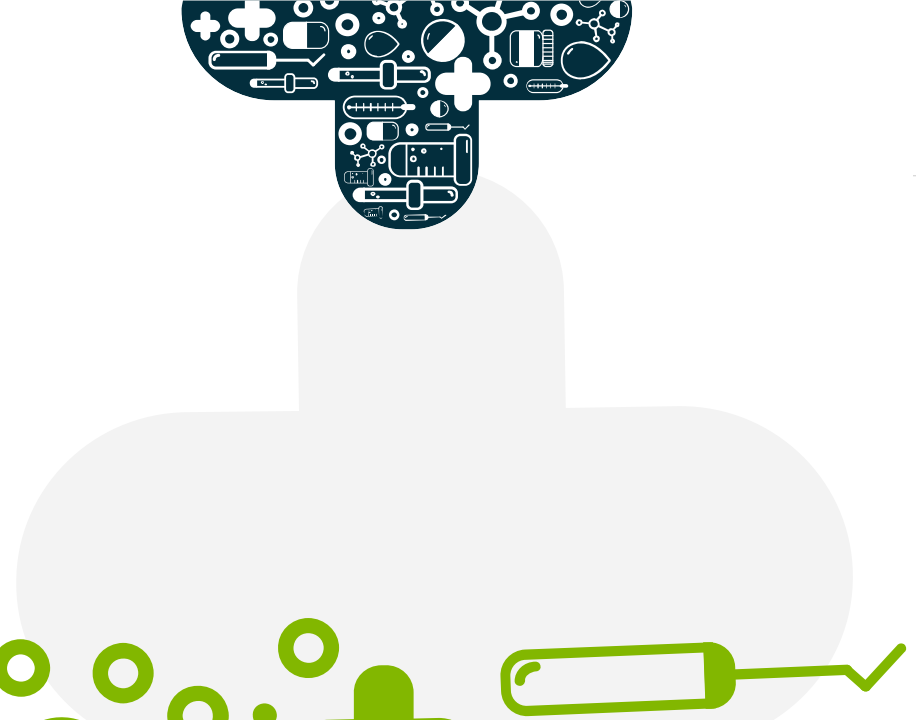
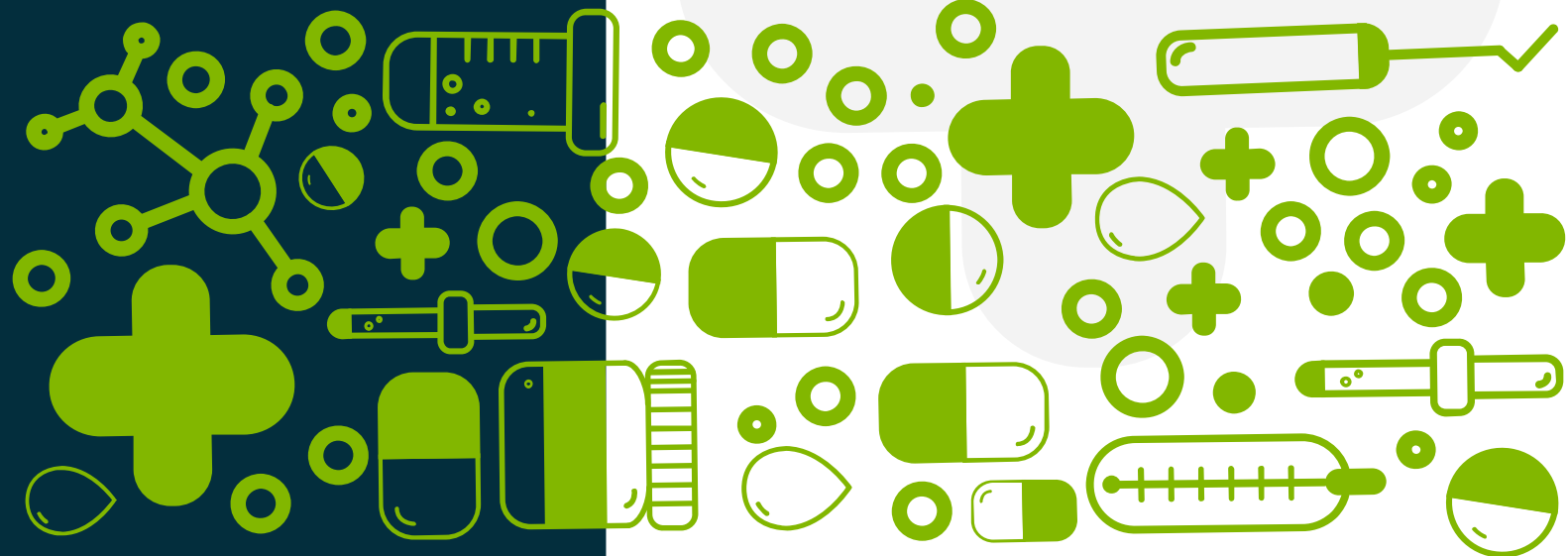
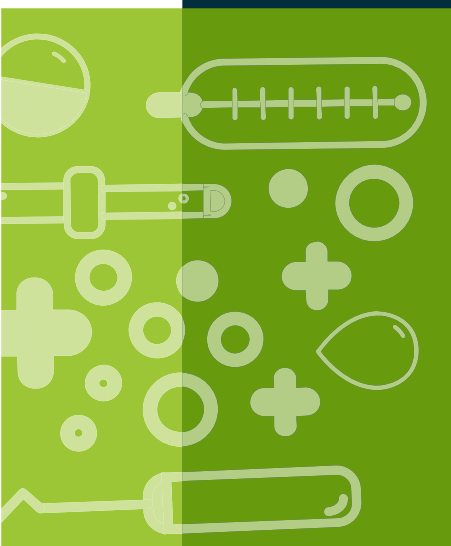


European Reference Network evaluation: the way forward

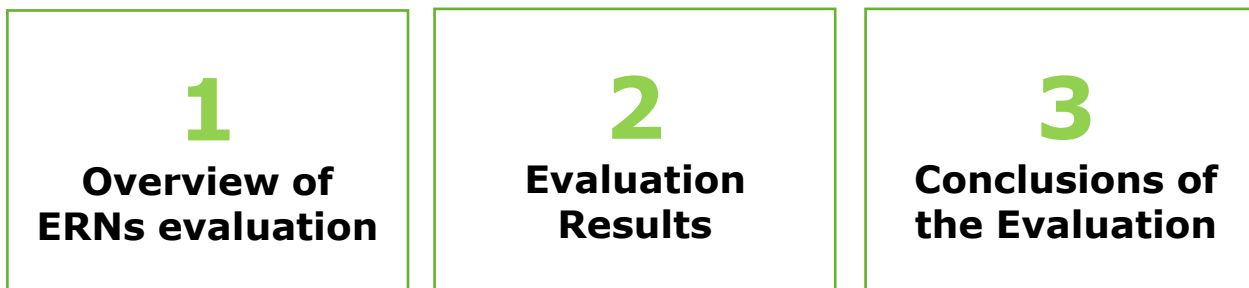
ERN evaluation report

4th December 2024







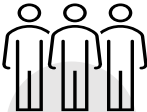
■ Agenda



1. Overview of the ERNs Evaluation (1/3)

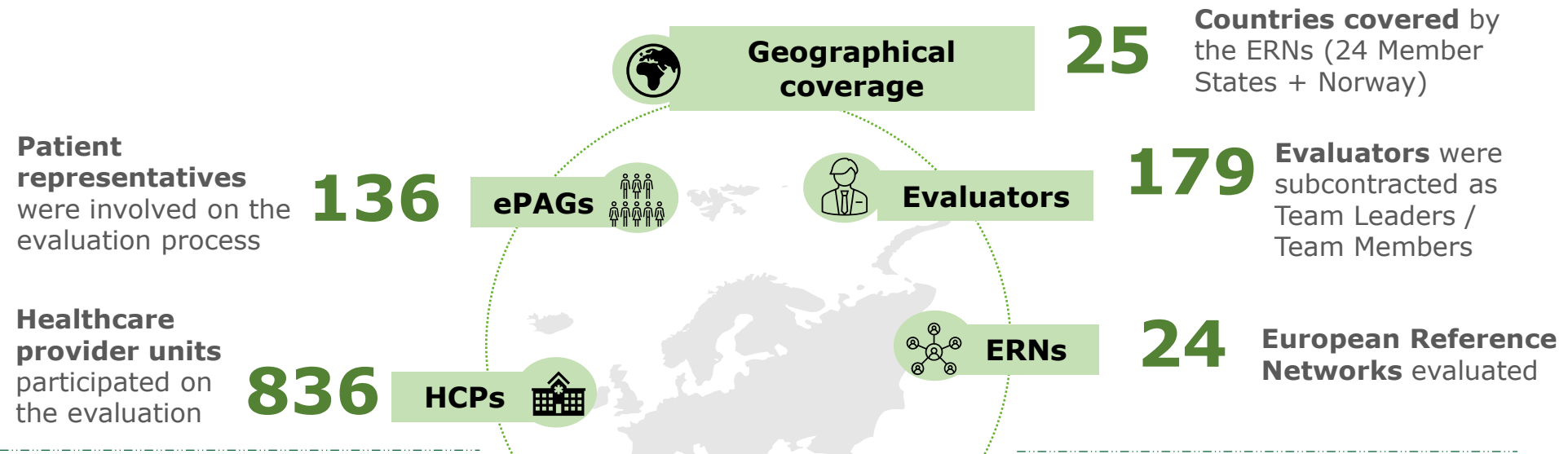
The 1st evaluation exercise has been performed to determine the worth or significance of the work and actions developed by the 24 ERNs and their 836 HCPs during the first 5 years of activity (2017-2021)

Activities

 <p>DOCUMENT REVIEWS</p>	<p>24 ERNs</p>	<p>836 HCPs</p>
 <p>VIRTUAL INTERVIEWS</p>	<p>24 ERNs teams</p>	<p>24 ePAGs</p>
 <p>AUDITS TO HCPs</p>	<p>192 Onsite visits</p>	<p>1 On-line interview</p>

1. Overview of the ERNs Evaluation (2/3)

The evaluation has involved a large number of stakeholders of the ERN System, covering 25 European countries



PEOPLE INVOLVED

-  **845** Healthcare Provider Representatives
-  **464** Healthcare Provider Sub-Representatives

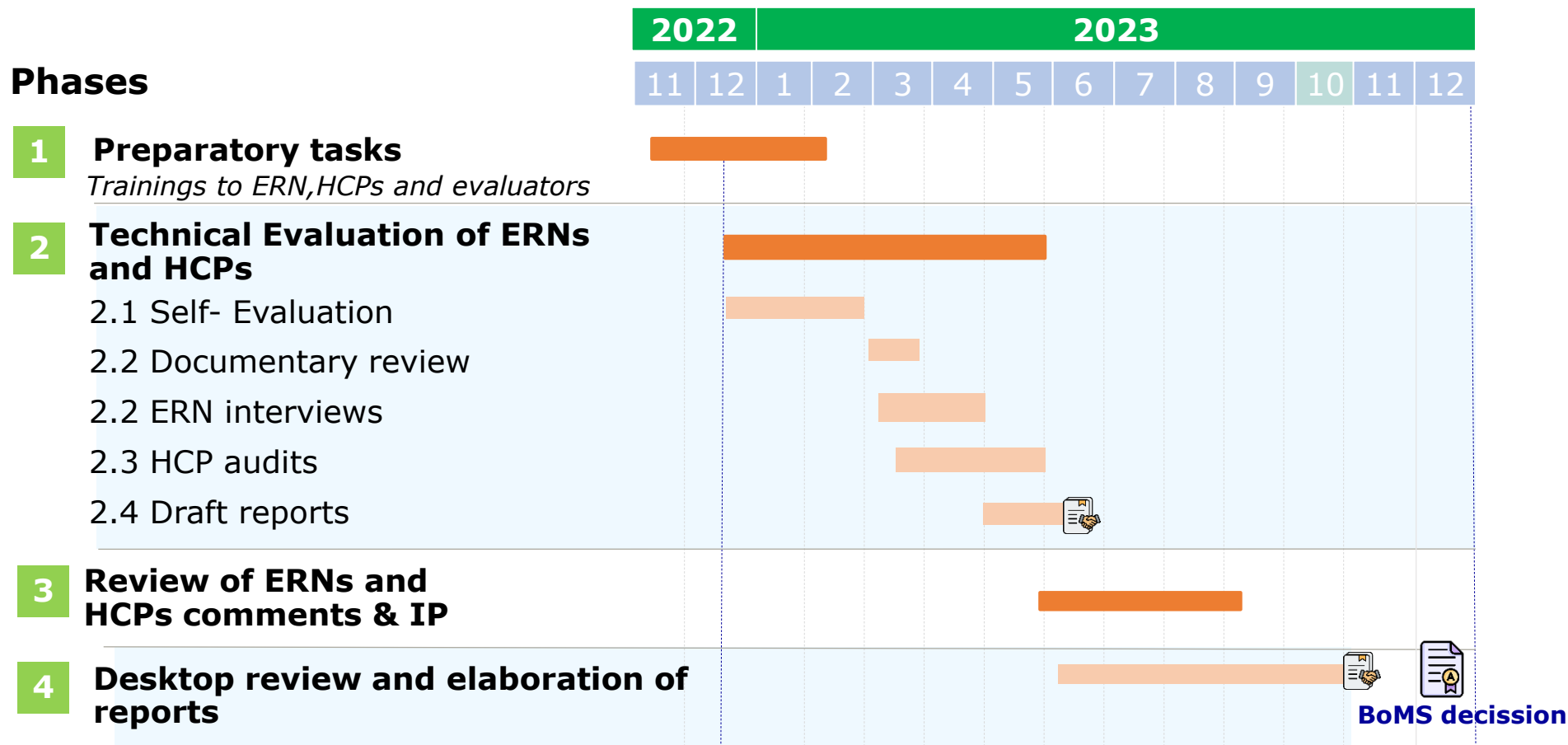
- 24**  Network Coordinators
- 42**  Network Project Managers
- 12**  CPMS Managers



1. Overview of the ERNs Evaluation (3/3)

The evaluation was conducted in 11 months, starting in December 2022 and finishing in October 2023 with presentation of the evaluation results to the BoMs

Phases





2. Evaluation results (1/3)

The high level of participation and successful evaluation results have demonstrated the commitment and relevance of the networks and their members.

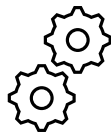
The following are the main points highlighted:



High Commitment to Evaluation: 100% of ERNs and 97.61% of HCPs completed the self-evaluation, showing strong dedication.



Satisfactory Results: 100% of ERNs and 87.68% of HCPs met the criteria, reflecting high standards.



Improvement Plans: 72 out of the 84 HCPs with unsatisfactory results submitted improvement plans, representing 8.61% of the total HCPs.



Membership Terminations: 31 HCPs (3.71%) had their membership terminated for various reasons, including non-completion of self-evaluation and non-submission of improvement plans.

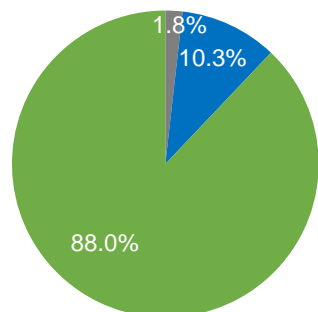


2. Evaluation results (2/3)

100% of the Networks obtained a satisfactory result. The area with the highest score is *Networking and dissemination* and the least developed one is *Quality and Patient safety*

Performance

Global Compliance with the Criteria



- 0: Not activity/Not developed
- 1: Partially developed
- 2: Fully developed



Areas for improvement

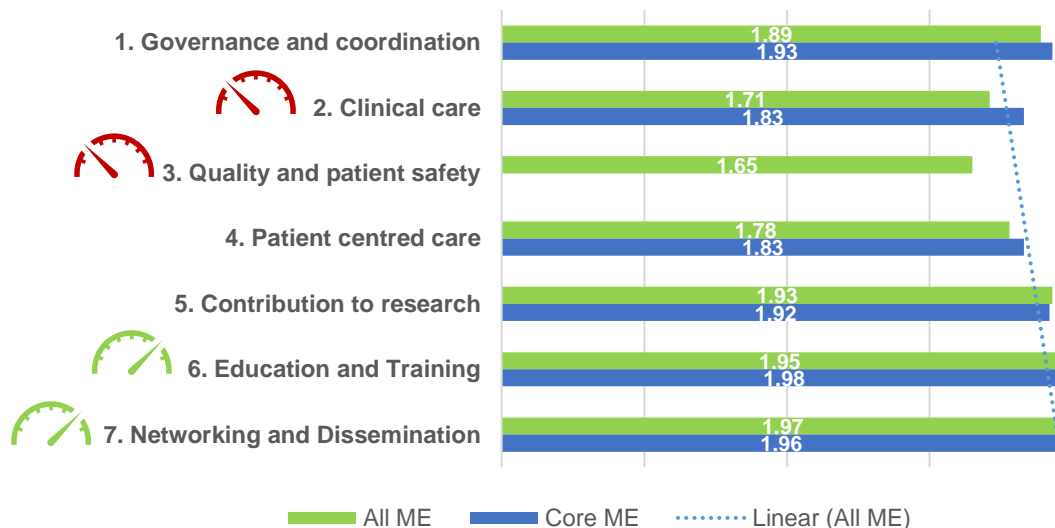
Clinical Care

- Measure Clinical Practice Guidelines implementation

Quality and Patient safety

- Analyse indicators to monitor clinical processes, performance, and outcomes of care

Average rating for all the MEs and the core ones in the same thematic area

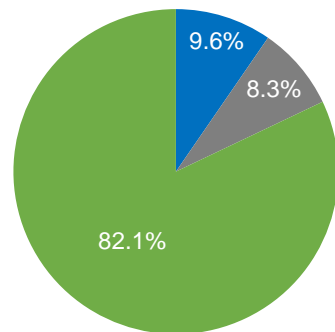


2. Evaluation results (3/3)

733 (89,70%) HCPs received a satisfactory result. The most developed area is *Exchange of expertise* and the least developed is *Organisation and management*

Performance

Global Compliance with the Criteria



- 0: Not activity/Not developed
- 1: Partially developed
- 2: Fully developed



Areas for improvement

Organisation and management

- Use of the CPMS

Quality and safety

- Clinical Practice Guidelines implementation










Average rating for all the MEs and the core ones in the same thematic area



■ Core ME ■ All ME

3. Conclusions of the Evaluation (1/7)

The conclusions and recommendations of the ERN system are based on the results of the technical evaluation, complemented with the information collected through surveys and interviews with a selection of stakeholders

	 Networks	 ePAGs	 HCPs	 Evaluators	 BoMS
 Technical evaluations	24	136	836	179	
 Survey response rate	50%	25.7%	57.4%	68%	
 Interviews with stakeholders	4		5	8	5

Conclusions and recommendations on the ERN system

Recommendations to improve the evaluation methodology

3. Conclusions of the Evaluation (2/7)

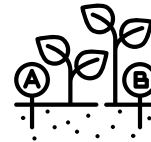
The ERN system is well represented in terms of geographical coverage and diseases. Most of their objectives have been achieved, however the integration of their activities in national healthcare systems should be improved

Structure



- **Broad geographical representation**
- Wide **disease range**
- **Regional disparities**: East-West differences
- Need to strengthen communication with national healthcare systems

Maturity



- ERN system's **objectives** are **correctly pursued**
- There is an urgent need to **support and motivate HCPs** for their continued involvement in the ERNs

Activity



- ERNs have **successfully developed most planned activities**
- Some activities, like the development of **Clinical Practice Guidelines or Pathways** and **CPMS usage**, are still in progress

Impact

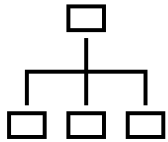


- Increase **visibility of rare and complex diseases**
- European trainings and registries have enhanced the **exchange of specialised knowledge** and **comprehensive research** data
- There is a need to promote tools for analysing this impact

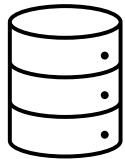


■ 3. Conclusions of the Evaluation (3/7)

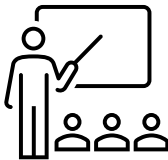
Strengths have been highlighted in different thematic areas based on the highest scores obtained during the evaluation of ERNs



Governance and Coordination: The establishment of a **clear governance framework** that enables the collaboration between HCPs within the same ERN and allows the involvement of patients' organisations in the ERNs' activities



Contribution to research: Enabling **data-sharing** between different HCPs and creating **registries and databases at EU level** to contribute to rare disease epidemiology and inform future research directions.



Education and training: Setting in motion various **educational and training activities** for professionals involved in the care of rare diseases throughout Europe (integrated into the network or not).



Networking and dissemination: Properly identifying the target groups that require **information** and adapting the content to suit their needs.

3. Conclusions of the Evaluation (4/7)

Based on the results of the 1st evaluation, 8 areas for improvement of the ERN system have been identified



Coordination within the ERN System

- Increase **hospitals' management involvement**
- Alling **national** rare disease **plans**
- Address **cross-cutting issues** within the ERNs



Visibility and recognition for ERNs and HCPs

- Increase the **ERNs' visibility**
- Foster **National Support**
- **Long-term Funding** Structure
- Establish a **legal entity for ERNs**



Legal issues

- Integrate **patient registration**
- Unify cross-border data exchange (**EHDS**)



Lack of resources

- Secure **financial support** from **Member States**
- Increase **recognition** and support to **healthcare professionals**

3. Conclusions of the Evaluation (5/7)

Based on the results of the 1st evaluation, 8 areas for improvement of the ERN system have been identified



Patient Empowerment

- **Recognise** patient representatives as **ERN members**
- **Allocate of ERN resources** to support patient representatives



Revision of the CPMS

- Solve **technical difficulties** to make it more **user-friendly**
- Implement a **payment system** for **CPMS usage**



Geographical distribution

- Include more expert **centres** from **underrepresented countries**
- Implement shared **learning activities** across **Europe**



Revision of the monitoring indicators

- Establish a **common system** to measure the impact of ERN contributions
- Strengthen the **monitoring system**
- Define a common **methodology for result analysis**



3. Conclusions of the Evaluation (6/7)

A working group is currently focused on reviewing the evaluation methodology from the lesson learned gained after the first evaluation of ERNs

Guide principles on the evaluation review



Promote **ongoing** quality **improvement**



Foster organizational change or adjustments in **strategy**



Show that the **ERNs** are producing useful **results**



Request the further **support of hospital managers**



Allow for timely identification of **areas for improvement** and **best practises** to share



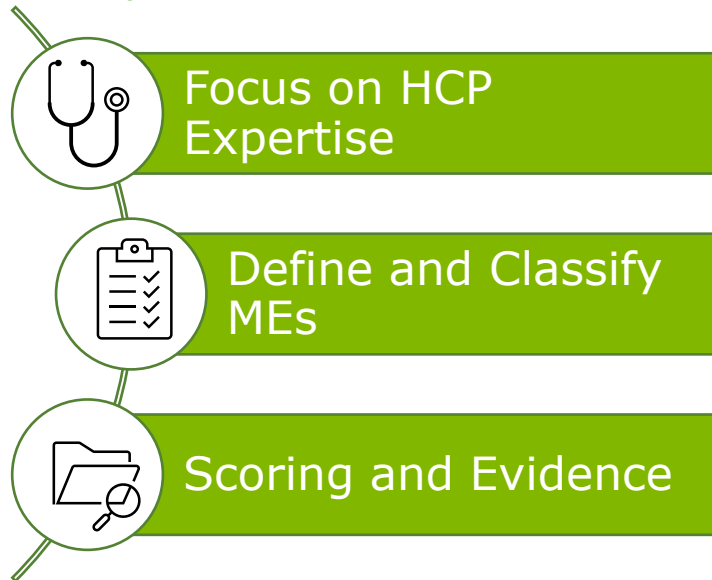
Contribute to creating a **culture quality improvement** and **patient oriented** healthcare services in Europe



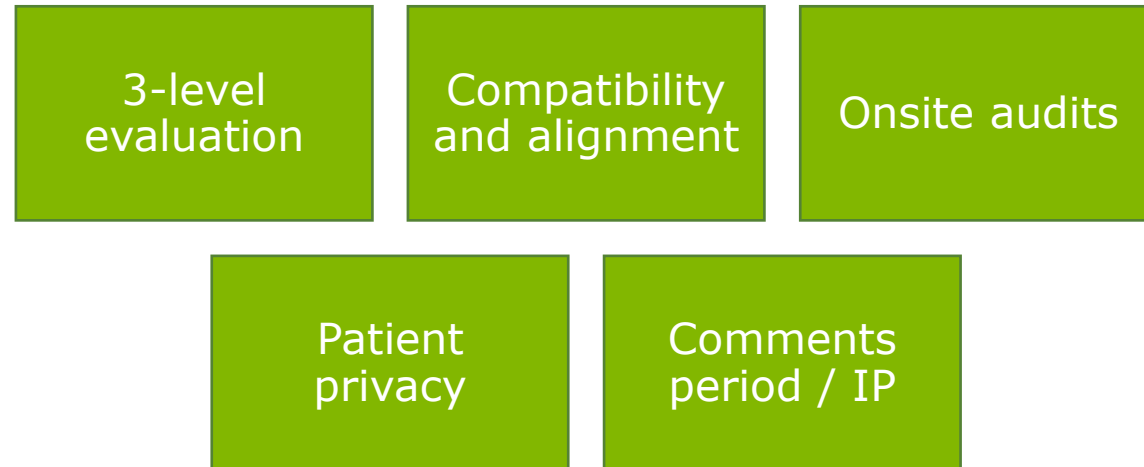
3. Conclusions of the Evaluation (7/7)

The rationale of the evaluation methodology and process needs to be adapted to focus on the HCP expertise and its participation in ERN activities and help reduce the workload of the process

Evaluation approach



Evaluation process



**Thank you very
much for your
attention**

