

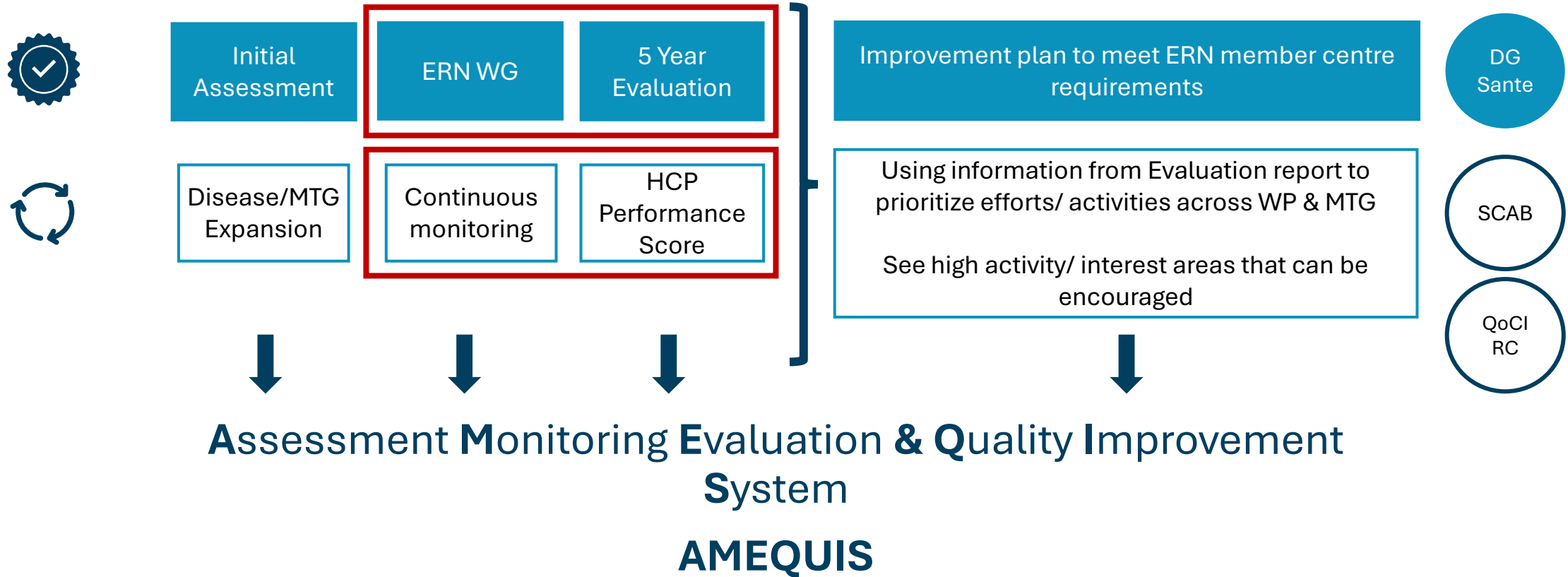
# WP3 Evaluation

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Funded by  
the European Union

## Evaluation in Endo-ERN – QI



# In 2024 Our Members Have....



Seen 21,074 confirmed new cases of rare endocrine patients



Researcher with over 110 active clinical trials and studies



Completed/ hosted over 300 rare disease specific training and educational activities



Used the 67 guidelines and CDSTs endorsed by Endo-ERN and highlighted 6 more worth endorsement



Attended and contributed to 121 congresses, conferences & meetings discussing rare endocrine disease/ care



Worked alongside experts from over 42 countries worldwide

Thank you to the  
102 members who  
completed this  
year's exercise!

A full report is being  
prepared with **final**  
figures in summer...



# Continuous monitoring

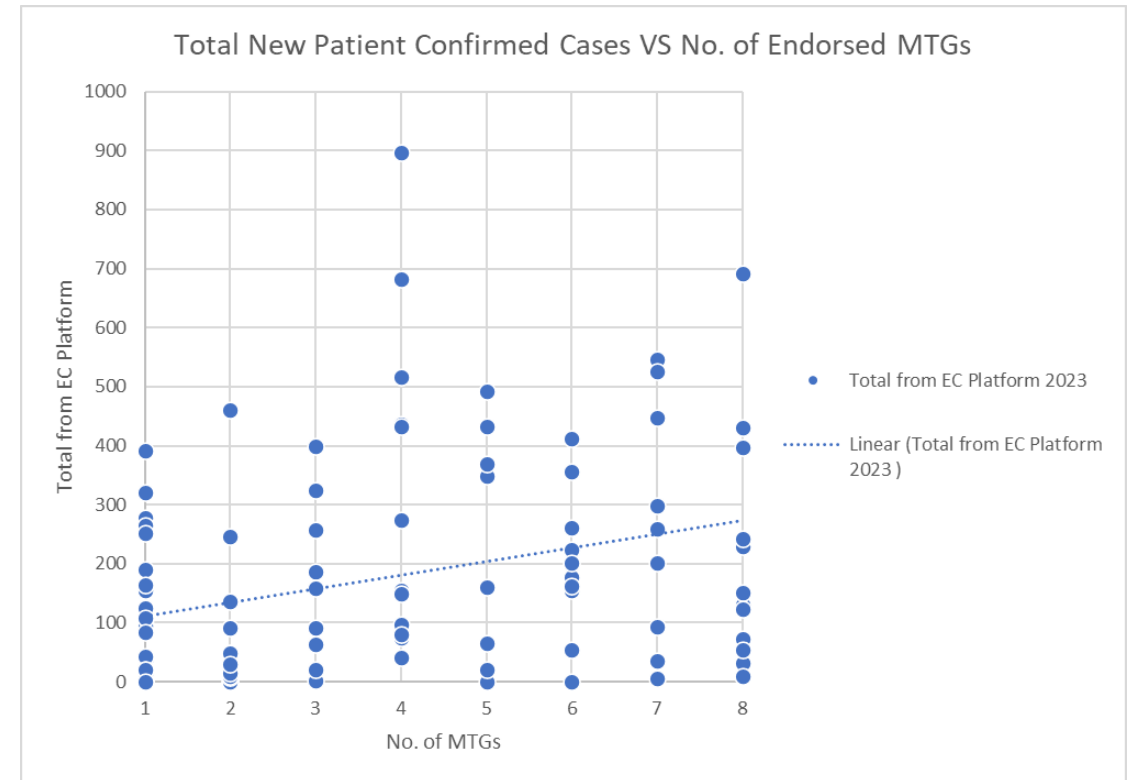
January 1 – February 28, 2025

12 HCPs reported same figures in EC Platform and e-REC

13 HCPs required us to report correct figures to EC during validation

HCPs had differences between e-REC total & EC Platform total

- 14 HCPs had a difference less than 5 patients
- 16 HCPs had a difference more than 100



# HCP Performance System



There are 34 activities that can earn a HCP points, categorized as **Mandatory** , **Expected** and **Bonus**

Mandatory in new grant

Updated annually following data gathering from CM

Scores our members on level of activity within/on behalf of the network

No extra collection from members

## **Mandatory Activities**

that each HCP **has to complete** to retain membership

**7 activities**  
**21 points**

60% of total score

*Ex. Completed Continuous Monitoring exercise*

## **Expected Activities**

that are **not mandated** for membership but expected of contributing member HCPs

**10 activities**  
**20 points**

25% of total Score

*Ex. Attending MTG HCP Meeting*

## **Bonus Activities/roles**

undertaken by HCPs/ individual experts therein that **advances** our mission and seeks to improve the Endo-ERN

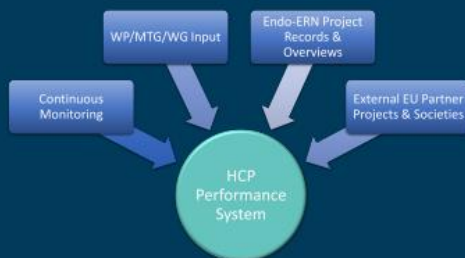
**17 activities**  
**22 points**

15% of total Score

*Ex. Endo-ERN chair*

## Endo-ERN HCP Performance Report 2023

This report is generated within the Endo-ERN HCP Performance system. This mandatory evaluation exercise assesses the activity level of each of our member HCPs based on information from sources shown here.



From our Continuous Monitoring exercise, in 2023 our network members have...

### How do we calculate your score?

There are 34 individual activities a HCP is scored on. These scores are weighted based on their category.

#### Possible Points

21 pts **mandatory** = 60% of total score  
 20 pts **expected** = 25% of total score  
 22 pts **bonus** = 15% of total score

The resulting weighted values are used to calculate the overall Overall Score. Please see [our website](#) for further details.

Mandatory Activities = each HCP has to complete to retain membership (max. 3 points per activity)

Expected Activities = not mandated for membership but expected of contributing member HCPs (max. 2 points per activity)

Bonus Activities = (roles) undertaken by HCPs/ individual experts therein that advances our mission and seeks to improve the Endo-ERN (1-3 points per activity)

## HCP Performance Reports

All HCPs in Endo-ERN received their 1<sup>st</sup> individual reports in August 2024

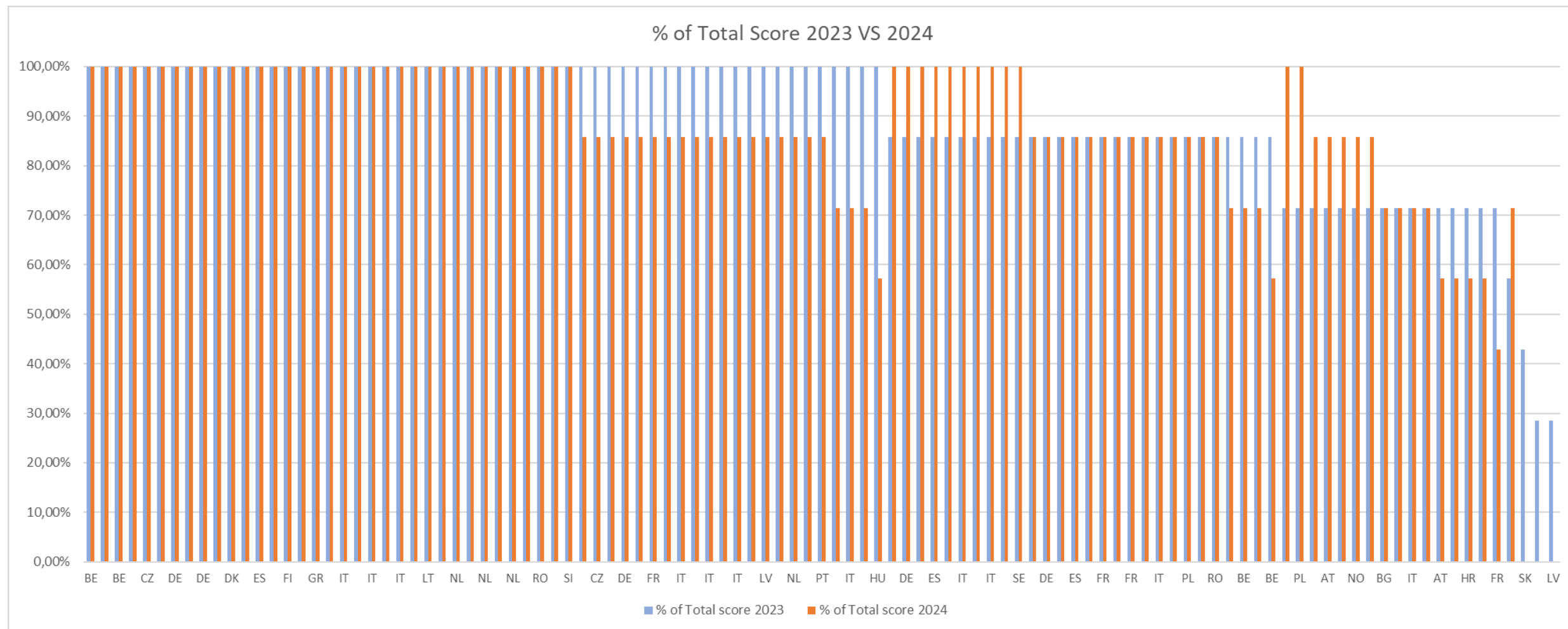
Excellent (100%) = 56 HCPs

Good (60%>) = 46 HCPs

Poor (<60%) = 3 HCPs

Positive reaction to the scoring and receiving feedback!

- Each **WP** will receive personal feedback in a general report
- **MTG** feedback from Continuous Monitoring
- 10 HCPs received updated reports/ scoring



# HCP Performance System



Updates this year:

- Performance Scores 2024 reported by Endo-ERN as part of Continuous Monitoring
- Only based on *Mandatory* activities

Excellent (100%) = 47 HCPs

Good (60%>) = 54 HCPs

Poor (<60%) = 4 HCPs

In 2023 vs 2024:

37 HCPs completed *less* mandatory activities

18 HCPs completed *more* mandatory activities



*Full reports to be released for comments by June 1<sup>st</sup> - we need YOUR feedback*

# ePAG Evaluation



We would like to complement the HCP performance system implemented in 2024. As different activities are assessed for our member hospitals, in parallel we propose to check the activity level of our ePAGs.

## Objectives:

- To identify the key areas of contribution for our ePAGs
- Measuring contribution concretely
- Using this gathered information to inform on the role demands and goals of being an international ePAG for our ERN

## 2024/25 Activities



Each ePAG will receive their personal scoring report:

- Not made public
- Scoring weighted

Mandatory = 60 %

Expected = 25 %

Bonus = 15%

Activities	Details
Mandatory – points per event/ meeting	
1	Attendance at the Endo ERN general assembly
2	Attendance at the SCAB meetings
3	Complete necessary governance documents
4	Attend ePAG regular meeting with coordinator
5	Give input on relevant questions addressed to MTG chairs
6	Include Endo-ERN information/ link/logo at their organisation website
Expected	
7	Participation in patient notebook (submit notebook)
8	Co Chair MTG specific meetings
9	Active contributions WP co-chair role
Bonus	
10	Performed role as rotating Chair for Endo-ERN ePAGs
11	Participated in ePAG Buddy System
12	Endo-ERN representative for other projects/ initiatives/ committees or collaborating with other ERNs
13	Involved in writing/ creating of Endo-ERN resource (CPG, patient material, PJ etc.)
14	Contribute/ present during Endo-ERN webinars
15	Other independent initiatives by ePAGs

# Evaluation WG update



Evaluation WG have reviewed and redrafted the Measurable Elements (MEs) for the 5 year evaluation

- All ERNs coordinators and ePAGs had chance to review proposed redraft
- Next meeting to focus on process of Evaluation:
  - Improvements to be carried out
  - Reduce administrative burden

Next 5 year evaluation for all HCPs based on years **2022-2027**

