



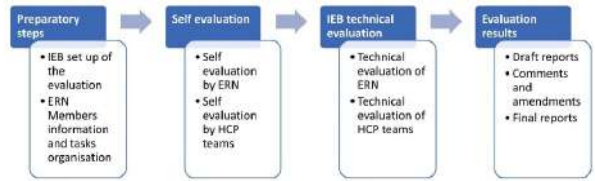
ePAG Steering Committee Annual online meeting

Evaluation of HCP

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ERN GENEURIS



The evaluation process includes some preparatory tasks and 4 main steps



The evaluation of the individual Members of the Network should assess

- If the HCP continues to provide specialized and quality care
- If the HCP team maintains the necessary levels of activity and experience
- What has been the contribution of the HCP team to the Network
- The value of the ERN for the HCP.



Evaluation Criteria for Healthcare Providers

The **evaluation procedure** is mainly based on **verifying** to which extent the HCPs meet **quality requirements** related to the achievement of the objectives for which they were constituted.

Quality requirements are formulated as **criteria**, which describe an "enhanced practice" which is both aspirational and achievable. Each criterion is followed by a list of **measurable elements (ME)**, used to assess the specified aspect or **level of performance**.

Some of the measurable elements are considered "**core**" and **should have been accomplished or implemented** during the evaluation. The other measurable elements refer to important areas in which networks or their members should work and whose level of development indicate their **maturity status**.

The **criteria are grouped** in several areas related to the different goals and objectives included in the evaluation

A set of criteria have been elaborated for the evaluation of the **HCP teams**.



Evaluation Criteria for Healthcare Providers

24 operational criteria with **64 measurable elements**, of which **29 are core**, and classified in **7 areas**, including patient-centred care, organisation and management, research and training, exchange of expertise and e-health, quality and safety, competence and outcomes of care, and human resources.

EVALUATION CRITERIA FOR HCP TEAMS			
AREA	No. CRITERIA	No. ME	No. core ME
Patient centred care	9	19	8
Organisation and management	5	10	4
Research, education, and training	2	11	6
Exchange of expertise, ICT, and eHealth	3	7	3
Quality and safety	2	9	2
Competence, experience, and outcomes of care	1	4	4
Human resources	2	4	2
TOTAL	24	64	29



Evaluation Manual

The Evaluation Manual is the reference handbook, common for all parties involved, that includes both the evaluation of the networks and the healthcare providers.



Evaluation Toolbox

The Evaluation Toolbox is a collection of 18 items including: guidelines, forms, templates, references, and documents. Like the evaluation manual, the toolbox is accessible to everyone to comply with both principles of transparency and fairness to all parties.

Preparatory steps

- IEB set up of the evaluation
- ERN members information and tasks organization



HCP team technical evaluation

The IEB evaluators will review the information and evidence provided through the self-evaluation on the contribution of each Member to the mission of the Network and on the adjustment of their care processes to the required quality levels. Members' evaluation methodology focuses on two sources of information:

Document review:

The following documents will be thoroughly reviewed:

- Initial assessment application and report. *To be provided by the EC*
- Monitoring indicators provided by the Member to the ERN in the last 3 years. To be provided by the Member/ERN as available
- Information and evidence included in the self-evaluation of the Member. Submitted by the Member.

Onsite audit:

The evaluators will visit the HCP Member to perform an onsite audit in order to collect supplementary evidence needed to assess the accomplishment of some measurable elements.



8. SELF-EVALUATION OF HEALTHCARE PROVIDERS: CRITERIA

1 PATIENT CENTRED CARE

1.1 The HCP team has implemented strategies to ensure that care is patient-centred, and that patients' rights, and preferences are respected.

Measurable Elements	0	1	2	Comments
1.1.1 The HCP team provides patients and/or their families with written information about the facility, the organisation, and its specific area of expertise.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
1.1.2 The HCP team gives patients and/or their families written information about their rights and responsibilities in a language they can understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

1.2 The HCP team provides educational activities for patients and their families with the aim of improving knowledge of the disease and the capacity for self-management to face the different aspects of their disease.

Measurable Elements	0	1	2	Comments
1.2.1 Patient and family educational needs are addressed in a defined process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
1.2.2 Education activities are recorded in the medical record	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

List of documents and other evidence suggested to be prepared by the HCP Team

SUGGESTED EVIDENCE/ DOCUMENT	ME		
1 Specific written information provided to the patients.	ME 1.1.1	16	The process followed to identify training needs.
2 Process to identify the educational needs of patients	ME 1.1.1	17	List of training activities within and outside the Healthcare Provider's facility (list and a brief explanation of each)
3 Last year report of patients' complaints and proposed improvement actions if applicable.	ME 1.1.1	18	List of training activities organised by the Network in which you have participated and what has the participation consisted of
4 Results from the last year assessment of the experience or satisfaction of patients and families.	ME 1.1.1	19	List of research activities of the Network in which you have participated (clinical trials and observational prospective studies).
5 Template document of informed consent for research	ME 1.5.2	20	Description of the process followed to involve patients and families included in research studies.
6 HCP policy/protocol regarding disclosure to patients.	ME 1.6.6	21	List of peer-reviewed publications in scientific journals in the framework of the Network in which you have participated
7 Description of process followed for patients' involvement in their care process.	ME 1.8.1	22	List of other professionals and caregivers with whom you maintain an advisory service.
8 Specific information provided about patients' associations (examples)	ME 1.9.1	23	List of procedures in which telemedicine can be used in your HCP team
9 List of patient associations and a brief explanation of the activities carried out	ME 1.9.2	24	List of e-health tools (list and a brief explanation of each)
10 List of affiliated centres in neighbouring countries for cross-border care	ME 2.1.1	25	Telemedicine guidelines used
11 List of policies and procedures established for cross-border patients	ME 2.1.2	26	Inclusion and exclusion criteria for potential telehealth patients.
12 List of centres or highly specialised units outside to which you can refer patients	ME 2.1.1	27	Quality and safety strategies: objectives and actions carried out in the period
13 3 anonymised copies of discharge reports	ME 2.3.1	28	Results of the evaluation of the quality program from last year.
14 Training activities at national level (list and a brief explanation of each)	ME 2.4.1	29	Description of the improvement actions after analysing the reported adverse events.
15 List of educational and training goals aligned with ERN and addressed to staff and other care professionals	ME 3.1.1	30	List of clinical guidelines (developed or adapted by the ERN) that have been implemented in your patients. You can include other good practices recommended by the Network.

List of documents and other evidence suggested to be prepared by the HCP Team

31	Results of the evaluation of adequate compliance with the clinical practice guidelines from last year.	ME 5.2.2
32	Annual data (from the last 5 years), of the number of patients of the group of diseases you serve. Include the reference data agreed by the Network for each of the items.	ME 6.1.1 ¹⁾
33	Annual data (from the last 5 years), of the number of procedures of the group of diseases you serve. Include the reference data agreed by the Network for each of the items.	ME 6.1.2 ¹⁾
34	a) Result of the monitoring indicators reported periodically to the European Commission for the last 3 years b) Result of the clinical indicators established by the Network.	ME 6.1.3 ¹⁾
35	List activities or working groups of the Network in which you have participated (list and a brief explanation of each).	ME 6.1.4

On site audit

- Direct observation
- Meetings/interviews
- Clinical records/document review

On site audit

The onsite visit is carried out in 1 single day, so it requires a good coordination between the evaluation team and the HCP. The contents suggested to be included in the agenda are:

Presentation of the evaluation team and confirmation of the agenda of the day	30 minutes
Presentation of the multidisciplinary team	30 minutes
Interview with professionals	90 minutes
Interview with patients	60 minutes
Review of medical records	120 minutes
Optional: tour of the facilities and review of pending documents (if applicable)	60 minutes
Feedback of the visit to the multidisciplinary team	30 minutes



To obtain a "satisfactory" result, the ERN or the HCP must:

- Get a score of 1 or 2 in 90% of "core" ME. This means that only 3 MEs can be scored "0" for ERNs and for HCPs.
- Get an average score at least 70% of the highest possible score in the group of core ME. This means a score of at least 42 for ERNs and 40 for HCPs:

	No. ME	No. core ME	Maximum no. of core MEs scored "0"	Highest possible score for core ME	70% (satisfactory)
ERN	53	30	3	60	42
HCP	64	29	3	58	40



ERN GENTURIS as a Network received in its final report 100% score with a specific comment from the Evaluation Body:

"ERN GENTURIS was established in March 2017. The need for such a network was driven by the common challenges faced by patients with rare genetic tumour risk syndromes across Europe: delay in diagnosis, lack of prevention for patients and healthy relatives, and therapeutic mismanagement. ERN is working to improve the identification of these syndromes, minimise variation in clinical outcomes, design and implement EU guidelines, develop the GENTURIS registry, support research, and empower patients.

Over the last five years, the ERN has developed a sustainable structure, excellent management, coordination between members, written and approved diagnostic and therapeutic guidelines, active participation in the CPMS, a functioning registry, and several research activities on ERN themes and patient empowerment.

Of particular note is the excellent coordination of the ERN. Coordination is carried out by Radboud University Medical Center in Nijmegen, the Netherlands. The results of the activities and the evaluation of the submitted material reaffirm the smooth coordination process."



Strengths

It should be noted that this evaluation suffers from two limitations: 1) Many of the documents produced are in the national language without English translation; 2) Being a survey on measurable elements, the lack of an on-site audit does not allow detecting the presence and consistency of the same from the direct analysis of randomly selected patient medical records, nor to have direct or indirect confirmations on these topics from verbal confrontation with patients or professionals (as instead specifically provided for by the adopted scoring system). In such cases according to the instructions received, the HCP self-evaluation score was taken as a reference and as valid (which may be sometimes a subjective, non-quantifiable perception). However, the statements of the HCP were compared with the documents sent and in case of non-correspondence, the appropriate corrections were made and justified.

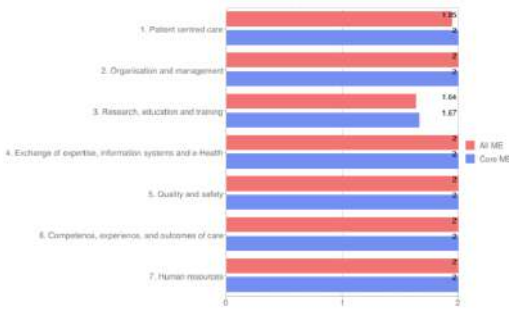
Patient centered care	
The HCP reports maximum efficiency in all parameters in area 1 (patient centered care)	
Organization and management	Organization is strong and management very effective
Research, education and training	Education and training must be identified and great effort is done in this field. Research and scientific production is remarkable. Information to patient organizations of research findings and dissemination of related ERN activities are under progress. Missing patient entries in ERN registries or databases is reviewed.
Exchange of expertise, information systems and e-Health	Telemedicine is implemented
Quality and safety	Quality and safety parameters were fully satisfied.
Competence, experience, and outcomes of care	Competence and experience is fully demonstrated. Number of admitted patients surpasses the ERN requirements. Unfortunately number of procedures are not given. The HCP team regularly collects, and monitors process and outcome indicators as established in the ERN and is actively involved in ERN projects.
Human resources	Adequate performance of specialized tasks is maintained and several multidisciplinary meetings -included in medical records- are performed.



Suggestions for improvement

Patient centered care	
In this area only a greater involvement of patients and their families in care process and decision making is suggested.	
Research, education and training	Collaboration in ERN databases and registries is recommended.
Exchange of expertise, information systems and e-Health	In telemedicine the HCP should better identify the procedures and tools used and satisfaction of patient should be recorded.
Competence, experience, and outcomes of care	Recording the procedures done is requested.

Healthcare Providers' Core MEs Compliance by Area



5. Final Outcome of the Evaluation

The following table shows the total score for all MEs in each area as well as the total score for core MEs and of those MEs that directly "HCP" contribution to the mission of the Network.

Thematic Area	Scoring table		
	Total score	Total possible score	Percentage of total
Patient centered care			
All MEs	27	28	97,37%
Core MEs	16	16	100%
Contribution to the Network MEs	4	4	100%
Organization and management			
All MEs	20	20	100%
Core MEs	8	8	100%
Contribution to the Network MEs	4	4	100%
Research, education and training			
All MEs	18	22	81,82%
Core MEs	16	16	100%
Contribution to the Network MEs	10	14	71,43%
Exchange of expertise, information systems and e-Health			
All MEs	14	14	100%
Core MEs	8	8	100%
Contribution to the Network MEs	4	4	100%
Quality and safety			
All MEs	18	18	100%
Core MEs	4	4	100%
Contribution to the Network MEs	0	0	0%
Competence, experience, and outcomes of care			
All MEs	9	9	100%
Core MEs	9	9	100%
Contribution to the Network MEs	4	4	100%
Human resources			
All MEs	9	9	100%
Core MEs	2	2	100%
Contribution to the Network MEs	0	0	0%
Overall			
Grand Total	121	128	94,53%
Core Total	54	58	93,10%

Personal Opinion on the Evaluation Process of HCPs



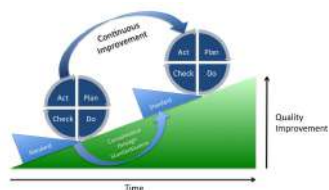
https://www.hapi.com/content/news_publico/2019-10-22/the-doctors-opinion-de-marx-shay/2018



Personal Opinion on the Evaluation Process of HCPs

Firstly, it is important to acknowledge that the **evaluation process is necessary**.

It is **crucial to demonstrate** that HCPs provide specialized and quality care; that the HCP maintains appropriate healthcare activities, **contributing** to the ERN, and that the ERN, in turn, contributes to the HCP.



<https://www.gubator.com/germ/123-online-continuous-improvement-8-report-definition>

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<https://it.aver.com/en/it/and/provide-high-quality-administrative-support>

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It would be beneficial to promote a **continuous evaluation process**, progressively assessing documentation and **expanding on-site evaluation visits**.



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HCPs **lack administrative support** to facilitate the preparation of documents.
Despite the creation of **helpful manuals**, it would have been advisable to **better prepare** HCPs for the process.
It would be beneficial to promote a **continuous evaluation process**, progressively assessing documentation and **expanding on-site evaluation visits**.
Similar to the importance of including **patient experience** evaluations (PREMs) in the assessment of ERNs, it would be crucial to evaluate the **experience of healthcare professionals** who are part of HCPs.

