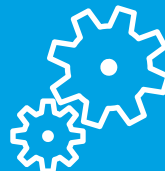


PATIENT GUIDE TO THE 5-YEAR EVALUATION OF THE EUROPEAN REFERENCE NETWORKS

WHAT



HOW



IMPACT



MATURITY



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1. Introduction

This *Patient Guide to the ERN Evaluation* has been developed based on the ERN Evaluation Manual & Toolkit specifically to support patient representatives who are active in the ERNs to understand their role and contribution in the evaluation process of the Networks. The guide aims to empower patients to get involved in the evaluation process by breaking down the rationale, process and supporting methodology of the AMEQUIS¹ Evaluation. The focus of patient representatives' involvement in the evaluation will specifically be to give the patient's perspective on four main elements:

- a. Is the structure of patient involvement in the Networks enable meaningful contribution?
- b. What has been the impact of patient involvement in the strategic discussion and operational activities of the Networks?
- c. What has enabled meaningful involvement of patient representatives and what were the barriers?
- d. Your reflections regarding the whole ERN system, in particular the extent the Network has accomplished the objectives and what have been the achievements of the Network?

Please Note: The role of patients in the evaluation of individual HCPs members is outside the scope of this guide.

The EC commissioned in 2022 the development of the ERNs Evaluation Manual & Toolkit as part of the Assessment, Evaluation & Monitoring Quality Improvement System (AMEQUIS) Framework. As the ERNs are patient-centres networks, the ERN Evaluation Manual and Toolkit, recognises the important role of patients and patient groups in the ERNs. Therefore, the evaluation model has been developed to include patient representatives as key stakeholders to contribute to evaluation of the Networks.

2. Legal Requirement

The European Commission (EC) Delegated Acts on European Reference Networks (ERNs)² mandate that the ERNs are evaluated before the end of the first 5-year contractual period. The expected timeline for the ERN 5-yrd Evaluation is expected to start in September/October 2022 and the evaluation reports completed in August 2023.

All Networks will be evaluated as well as the healthcare providers (HCPs) members of the networks who joined under the first call and at the launch of the Networks in 2017 (c.900). The HCPs that joined the Networks in January 2022, under the second call for applications in 2019 are exempt from this evaluation.

1. AMEQUIS framework has been developed to connect the different activities and elements of the Networks' Assessment, Monitoring, Evaluation into a Quality Improvement System (AMEQUIS)

2. EC Delegated Decision (2014/286/EU & the EC Implementation Decision (2014/287/EU)

3. Legal Mandate of the ERNs

Each ERN identified in their original Network application a minimum of 3 objectives from the 8 objectives listed in the Cross-border Healthcare Directive (2011/24/EU):

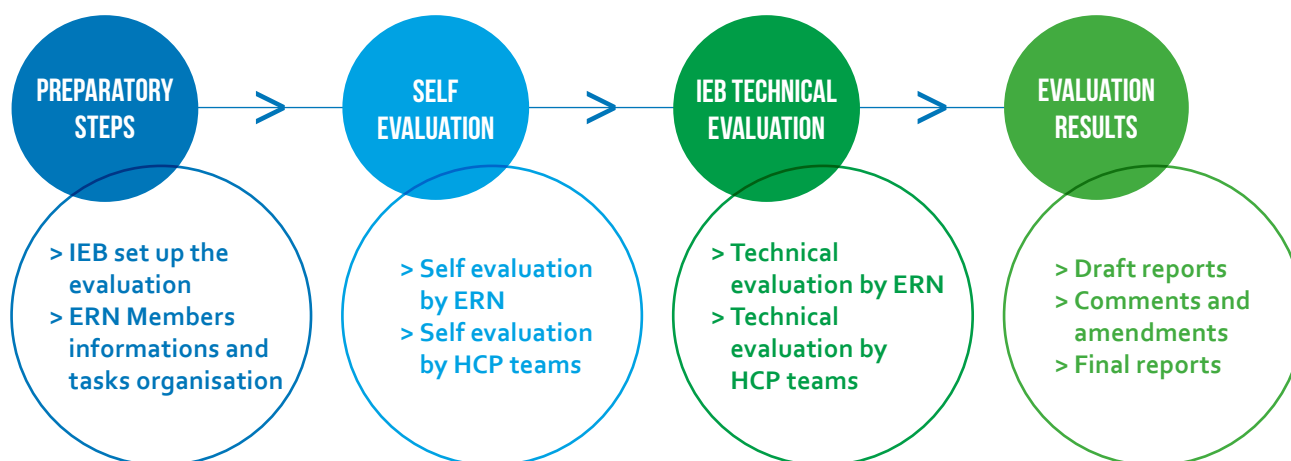
- To help realise the potential of European cooperation regarding highly specialised healthcare for patients and for healthcare systems by exploiting innovations in medical science and health technologies.
- To contribute to the pooling of knowledge regarding sickness prevention.
- To facilitate improvements in diagnosis and the delivery of high-quality, accessible, and cost-effective healthcare for all patients with a medical condition requiring a particular concentration of expertise in medical domains where expertise is rare.
- To maximise the cost-effective use of resources by concentrating them where appropriate.
- To reinforce research, epidemiological surveillance like registries and provide training for health professionals
- To facilitate mobility of expertise, virtually or physically, and to develop, share and spread information, knowledge, and best practice and to foster developments of the diagnosis and treatment of rare diseases, within and outside the networks.
- To encourage the development of quality and safety benchmarks and to help develop and spread best practice within and outside the network.
- To help Member States with an insufficient number of patients with a particular medical condition or lacking technology or expertise to provide highly specialised services of high quality.



4. Evaluation Process & Timeline

According to article 14 & 15 of the [EC ERN Implementation Decision](#), the start of the evaluation process will begin when the ERN Coordinators request the Commission to evaluate their Network. The evaluation process may take between 10 to 12 months, from the appointment of the **Independent Evaluation Body (IEB)** by the European Commission to the issuance of the final evaluation reports.

The diagram below outlines the different phases of the evaluation process:



5. Focus and legal frame of the Evaluation


The evaluation will focus on assessing four key topics:

- a. Continuous fulfilment of the criteria and conditions set out in the [EC ERN Delegated Decision](#) Annex I & II (e.g.: Operational Criteria)
- b. Accomplishment of the objectives set out in the Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare (Article 12.2) chosen by each Network.
- c. Outcomes and performance of the Network and the contribution of each HCP Member
- d. Achievement of the objectives and quality of the deliverables produced with the funding from the Network's Specific Grant Agreement (SGAs).

6. Evaluation Criteria

The Networks will self-evaluate the Networks' continuous fulfilment of the criteria and conditions set out in the EC Delegated Decision, scoring³ themselves using a set of 'evaluation criteria'. Using these criteria, the evaluators will **verify to which extent the Networks meet quality requirements** related to the **achievement of the objectives** for which they were constituted.

Each criterion is broken down into a number of **measurable elements (ME)** to assess a given feature or level of performance. For the purpose of this guide, the term "measurable element" is refer simply as "measures". Each measure is considered either:

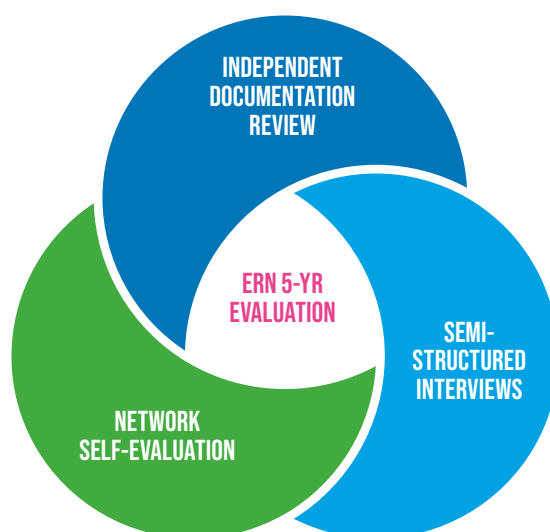
1. **"core"** measures that **should have been implemented at the time of evaluation**. These are identified in the Evaluation Toolbox with a heart symbol 

Or

2. **"enhanced practice"**. These are aspirational measures to drive quality improvement in the Network(s) but they do not need to have been implemented at the time of the evaluation. These measurable elements are important areas as they can serve as an indicator of the maturity status of an ERN.

7. Multiple-Method for Evaluation

All methods for evaluation have strengths and limitations (Beutler L.E. et al. 2001), therefore it is common practice to adopt a multiple methods approach which allows the triangulation of the evidence and validation of the evaluation scoring. The evaluation model for the ERN's 5-Yr adopts a multiple-method approach, using the following methods:



3. Scoring Measures Each measure will receive a score of (0) No activity / not developed. (1) - Partially developed or (2) - Fully developed. The scoring will be used to draw conclusions about the performance of the Network in the last 5 years.

The IEB will evaluate both quantitative evidence, through reviewing indicators and outputs such as deliverables and qualitative evidence, through interviews with the Networks' members and teams including: Coordination Team, HCP Members, Coordinators of Sub-Thematic Networks, work package leaders of EU funded projects and Patient Representatives.

A. SELF-EVALUATION

The purpose of the self-evaluation is to trigger an internal reflection process by the Networks and their Members on the activities performed during these 5 years; and enable the Networks to assess the degree in which they have fulfilled their mission and original objectives.

The Networks will complete this self-evaluation against the evaluation criteria and will need to provide evidence to justify the compliance with the self-scoring.

The self-evaluation also requires the Networks to describe the main accomplishments that the Network has achieved in the past 5 years and appraise the degree in which they have accomplish over this period the objectives identified⁴ in their original application. The self-evaluation including the supporting documents will be submitted through an on-line platform.

B. DOCUMENTATION REVIEW

The IEB evaluation team will complete a **documentation review** of the self-evaluation. The evaluators will review the supporting evidence and reviewing the monitoring indicators collected by the Networks over the past 3 years as well as contractual deliverables submitted to European Health & Digital Executive Agency (HADEA).

C. SEMI-STRUCTURED INTERVIEWS

Interviews with ERN clinical leads

The interviews will be led by the same evaluation team who has completed the documentation review, once they finalise the review. The team will organise an **online meeting / interviews** with the Network clinical leads, including ERN Coordinator, work packages Chairs, Sub-Thematic Network Chairs, etc. to discuss different aspects of emerging from evaluation.

These semi-structured interviews will serve to:

- Respond to questions raised by the ERN about the content of the criteria
- Request clarification by the IEB on the responses and comments provided in the self-evaluation
- Request new documentation or clarifications when the documents by the ERN provided do not allow for proper assessment of the evaluation criteria
- Comment on the most important discrepancies that may exist between the initial evaluation of the IEB and the self-evaluation

4. Each ERN selected at least 3 of the 7 objectives identified in article 12.2 of the Cross-Border Healthcare Directive.

Interviews with Patient Representatives

Separate interviews with patient representatives will be organised. The ERN Coordinators will facilitate communication between the IEB and the patient representatives for the interview. These interviews will last less than 2-hrs and the evaluation team will prepare an interview script. It is expected that the team will evaluate the overall level of participation in the different actions of the Networks; support and barriers to meaningful participation; gather the opinion of the patient representatives on the Networks achievements and progress towards achieving the originally selected objectives.

To prepare for these interviews you may reflect on the following matters:

- What barriers have you encountered to achieve meaningful contribution of patient representatives in the Networks?
- What support have you received (resources) from the Network, Patient Organisation or Member State for your activities related to the Network?
- Your reflections regarding the whole ERN system.
- To what extent do you think that the Network has accomplished the objectives set out in their original application?
- What have been the achievements of the Network?
- Any additional information you would like to provide regarding the evaluation process.

You may also check the Interview Guide in Appendix I to prepare for the interview.

8. Evaluation of patients' involvement in the ERNs

The IEB evaluation team will evaluate the overall level involvement of patient representatives in the Networks, specifically they will assess:

- a. **The "How"** describes the structure and mechanisms for involving patient and patient representatives in the governance (structure).
- b. **The "Maturity"** of the patient-professional collaboration.
- c. **The "What"** describes the involvement of in the Network's activities.
- d. **The "Impact"** of patient participation in the Network.

Some measures have been specifically developed to assess patients' involvement in the Networks while and others, not directly linked to patients' involvement, will also provide to the evaluators with supporting evidence regarding the level of patient participation.

The evaluation team will possibly seek to validate the Networks’ self-evaluation regarding the degree of your involvement in the Network’s strategic, operational and technical activities, by cross-checking the evidence submitted to support the direct measures on patient involvement and the references to patients’ contribution in other measures.

The Evaluation Manual and Toolkit, contains **20 evaluation criteria** for the ERNs that are broken down into **52 measures, 30 of which are “core” measures**. Each measurable element has a code e.g.: ME. 1.1.1 OR 1.1.2.

This Guide summarises the measures that will be used to assess either directly or indirectly the level of patients’ participation in the Network.

9. Overview of evaluation criteria to directly assess patient involvement

The evaluation criteria below will be assessed through specific measures that look at patients’ contribution and involvement. **Please the full list of measures and the supporting evidence that will be required in [Appendix 2](#).**

| AREA | ID | EVALUATION CRITERIA THAT INCLUDE SPECIFIC MEASURES ON PATIENTS' INVOLVEMENT |
|--------------------|-----|---|
| How, What & Impact | 1.3 | The ERN has established mechanisms for the integration of patient organizations in the strategic actions. |
| How | 4.1 | The ERN has implemented mechanisms to empower patients through patient education and engagement (information, training about disease and self-management). Co-creation with patient representatives is an essential issue to be considered. |
| How & Impact | 4.2 | The ERN has developed strategies for patient involvement, as equal partners in care and treatment. Network partnership with patient representatives and organizations in the production of documents and actions related to their care will improve access to information, treatment, care, and support for people living with rare diseases. Acknowledgement of Patients participation and co-authorship, and ePAG assessment framework, if used |
| How & Impact | 4.3 | The ERN has implemented actions to measure and learn from patient experience. The Network have defined a common tool to be used by all Members to collect and analyse data and support the benchmarking of information about patient experience. Different approaches incl. focus groups, satisfaction surveys, patient social networks and, more importantly, PREMs and PROMs questionnaires. Measurement and analysis of results to identify opportunities for improvement. |
| What | 5.1 | The ERN has implemented strategic actions to fill research gaps and promote innovation in medical science. |
| How | 7.1 | The ERN has developed a robust networking system for national and international collaboration and sharing of knowledge, best practices, expertise, and resources. |

10. How can you support your ERN in this exercise?

The PAG may prepare some documents to provide evidence of patient involvement in the Network, such as:

- Description of the patient involvement mechanism ME 1.3.1
- List the issues about the patients and families' input been requested ME 1.3.2
- List of collaborating patient organisations and activities developed with them ME 4.2.1
- Results of ePAG impact assessment measurement, if used.
- List of ERN publications with patients as co-authors
- Description of the tool used for measuring the patient and family experience ME 4.3.1 H-Care report per ERN (only for eUROGEN, ERN Lung, Genturis and ErkNEt) and the general one
- Analysis of needs and barriers to care for patients and families and the improvement actions carried out ME 4.3.2
- Description of the strategies for patients and other stakeholders' involvement in the identification of research gaps ME 5.1.2
- List of collaborative projects and participants ME 5.2.1

11. References

Beutler, L. E. 2001. Comparisons among quality assurance systems: from outcome assessment to clinical utility. *J Consult Clin Psychol*, 69, 197-204.



Appendix 1: Interview Guide

This interview will take place once the evaluation team has performed the documentation review of the Network. The main objective will be to complete the information available (self-evaluation, grant reports and additional documents), and therefore to properly evaluate the work developed by the ERN during the 5 years period.

BEFORE THE VIRTUAL INTERVIEW

The evaluation team will contact the Network coordinator through an email or phone call, to inform about the interview and the recommended attendees. In addition, the evaluation team will propose a period of 1 week for the coordinator to choose the most convenient day and time for the Network and to allow the presence of all the expected attendees.

The coordinator will be informed on the objectives of the interview and the main topics to be discussed, as well as, if necessary, the documentation that at the discretion of the IEB is required to complete the self-evaluation, or any additional information that requires prior preparation by the coordinator and his team. The evaluation team will prepare a previous script of the interview that will be sent to the coordinator of the Network.

EXPECTED DURATION

The duration should not exceed 2 hours, although it will depend on the number of doubts and issues that should be solved. When it is not possible to address all the issues in one meeting, an additional date and time will be agreed for another interview, but this should take place as soon as possible, so as not to delay the evaluation.







DURING THE VIRTUAL INTERVIEW

- Test the technology 15 minutes prior to the call.
- Brief introduction by the evaluation team and the participants themselves.
- Request the feedback of the attendees regarding the self-evaluation.
- If you want to record the session, the permission of the attendees will be requested.
- The evaluation team will ask questions about the topics in which they have doubts or for which they require additional information.
- On the part of the evaluation team, it is important to maintain a relaxed attitude that favours dialogue and allows the free expression of the attendees.
- Before finishing the interview, the evaluation team will make a summary of the topics discussed, confirming with the attendees the information received.



AFTER THE INTERVIEW


The information obtained in the interview will be used by the evaluation team to review the initial assessment of the criteria, introducing the necessary changes.

Appendix 2: Measures to assess direct patient involvement in the ERNs

| AREA | ID | CRITERIA | MEASURES TO DIRECTLY ASSESS PATIENT INVOLVEMENT | EVIDENCE | TYPE OF MEASURE (CORE OR ENHANCED) * |
|--------------|-----|---|--|---|---|
| The "How" | 1.3 | The ERN has established mechanisms for the integration of patient organizations in the strategic actions. | Patient representatives have been included in the governance framework of the ERN, with a specific role (where and how are they involved). 1.3.1 | Describe the specific role of patient representatives in the current governance of the Network (where and how they are involved). |  |
| | | | The ERN monitors and evaluates the involvement of patients in the activities of the ERN (specific methodology to collect information and outcomes) 1.3.4 | Specific methodology to collect information regarding the participation of patient representatives in the ERN activities (i.e., satisfaction surveys; specific monitoring indicators). Outcomes should be submitted. | enhanced |
| The "Impact" | 1.3 | | The Board has incorporated the opinion of patients and families when outlining strategies. 1.3.2 | Explain in which issues the patients and families' input has been requested and which opinions were incorporated. |  |
| The "What"* | | | Patients and support groups are major stakeholders in ERN-related activities. 1.3.3 | a) Is this participation formal and continuous? Provide some examples. b) Acknowledgement of patients' co-authorship in ERN deliverables |  |
| The "How" | 4.1 | The ERN has implemented mechanisms to empower patients through patient education and engagement (information, training about disease and self-management). Co-creation with patient representatives is an essential issue to be considered. | Educational resources for patients addressing disease management, coping skills and other practical skills, have been developed and disseminated. 4.1.1 | <ul style="list-style-type: none"> • Attach all the educational resources developed and explain how they • have been disseminated. Mention which of them have been co-designed with patients. • Specific indicator on patient education, if collected. • The scope of education can include the different resources aimed at patients and patient representatives related to the different activities performed by the Network (navigation of the system, patient pathways, general knowledge about the disease...) |  |
| | | | The ERN produces tailored information on patient safety standards and safety measures for patients and families to reduce or prevent errors. 4.1.2 | Attach the specific information developed (flyers, online information, etc.). | enhanced |
| The "How" | 4.2 | The ERN has developed strategies for patient involvement, as equal partners in care and treatment. Network partnership with patient representatives and organizations in the production of documents and actions related to their care will improve access to information, treatment, care, and support for people living with rare diseases. Acknowledgement of Patients participation and co-authorship, and ePAG assessment framework, if used | The ERN collaborates with patient organisations to develop and implement care pathways, guidelines, protocols, and indicators. 4.2.1 | List of actively involved patient organisations and activities developed with them (i.e., development of clinical guidelines, development, and implementation of clinical indicators...) Acknowledgment of co-authorship in guidelines or other documents produced. Related measurements included in the e-PAG Impact Assessment Framework, if used. |  |
| | | | The ERN has undertaken initiatives to improve the safety and quality of care in collaboration with patient organizations. 4.2.2 | Explain the initiatives carried out to improve safety and quality with the active involvement of patient organizations: i.e., developing the quality and safety strategy; developing the improvement plans at ERN level; developing and piloting the ePAG impact assessment framework; developing PROMs/PREMs... Acknowledgement of patient participation in the activities performed in the network |  |

PATIENT GUIDE TO THE 5-YEAR EVALUATION OF THE EUROPEAN REFERENCE NETWORKS






| AREA | ID | CRITERIA | MEASURES TO DIRECTLY ASSESS PATIENT INVOLVEMENT | EVIDENCE | TYPE OF MEASURE (CORE OR ENHANCED) * |
|----------------------|-----|---|---|--|---|
| The "How" & "Impact" | 4.3 | <ul style="list-style-type: none"> The ERN has implemented actions to measure and learn from patient experience. The Network have defined a common tool to be used by all Members to collect and analyse data and support the benchmarking of information about patient experience. Different approaches incl. focus groups, satisfaction surveys, patient social networks and, more importantly, PREMs and PROMs questionnaires. Measurement and analysis of the results to identify opportunities for improvement (PDSA). | <p>The ERN has established a standardised common tool or methodology for measuring the patient and family experience: i.e., PREMs, patient journeys, patient storytelling. 4.3.1</p> | <p>Describe the tool or any methodology used to collect and improve the patient experience: i.e., PREMs, patient journeys, patient storytelling...</p> | enhanced |
| | | | <p>The ERN periodically evaluates the needs and barriers to care experienced by patients and families and uses this information to implement actions to improve care. The information could be obtained through many ways: workshops, regular calls with e-PAG representatives, surveys, reports. 4.3.2</p> | <p>Include the information collected last year and how it was used for improvement. The information could be obtained through many ways: workshops, regular calls with e-PAG representatives, reports...</p> | enhanced |
| The "How & "What" | 5.1 | <p>The ERN has implemented strategic actions to fill research gaps and promote innovation in medical science.</p> | <p>The ERN has actively involved patients and other stakeholders in identifying research gaps and developing the agenda 5.1.2</p> | <p>Include the strategies/actions used for patient and other stakeholders' involvement in the identification of research gaps and the development of the agenda. Examples: emails asking for patients' feedback, minutes from meetings, participation in the informed consent... Acknowledgement in the authorship of publications.</p> |  |
| The "Maturity" | 7 | <p>The ERN has developed a robust networking system for national and international collaboration and sharing of knowledge, best practices, expertise, and resources.</p> | <p>The ERN has developed partnerships with other stakeholders of interest, such as scientific societies, centres of expertise, diagnostic laboratories, patient organisations, social care providers, industry, affiliated research groups or national healthcare authorities. 7.1.3</p> | <p>Mention any initiative carried out to develop these partnerships. Examples: Establish an expert panel (including scientific societies); mapping patient organisations that are not covered by the ERN (efforts done to find the organisations); any effort done for partnership; any initiative to improve partnership with important stakeholders with the objective of promote the ERN; national alliances; approach to social and psychological providers.</p> |  |

 Core measures: measures that all 24 ERNs should have implemented at the time of evaluation






* Other measures that may allow the evaluators to indirectly assess the involvement of patients in ERNs collaborative activities

Appendix 3: Indirect Measures

* Other measures that may allow the evaluators to indirectly assess the involvement of patients in ERNs collaborative activities:

| ID | MEASURES TO DIRECTLY ASSESS PATIENT INVOLVEMENT | EVIDENCE | TYPE OF MEASURE (CORE OR ENHANCED) * |
|-------|---|--|---|
| 2.1.1 | The ERN has developed or adapted (from other sources) and disseminated clinical guidelines and other types of clinical decision-making tools in collaboration with the HCPs. | <ul style="list-style-type: none"> List of clinical guidelines disseminated. Involved patient organisations in the guideline developed. Acknowledgment of co-authorship in guidelines or other documents produced |  |
| 2.1.2 | The ERN has implemented guidelines and/or protocols to support transition and continuity of care from childhood, through adolescence, and into adulthood, where applicable. | <ul style="list-style-type: none"> List of guidelines/protocols/best practices implemented to support transition and continuity of care from childhood to adulthood. Involved patient organisations in the developed of the guidelines and protocols. |  |
| 2.1.3 | The ERN has developed recommendations for care pathways based on the needs of patients, clinical evidence, and on the available organizational, professional, and technological resources. | <ul style="list-style-type: none"> List of the clinical pathways developed and present a specific example Involved patient organisations in the developed of the care pathways |  |
| 2.1.5 | The ERN follows up the implementation of care pathways to encourage consistent use across its Members. | <ul style="list-style-type: none"> Involved patient organisations in the developed of the care pathways | |
| 2.1.6 | Guidelines, care pathways, and protocols are rechecked and updated if needed at least every three years. | <ul style="list-style-type: none"> Involved patient organisations in the review of the guidelines. | |
| 2.3.1 | The ERN promotes the use of technologies such as telemedicine, e-Health records, remote consultation, health information portals, electronic transfer of prescriptions, multidisciplinary e-Meetings designed according to the needs and requirements of patients and families. | <ul style="list-style-type: none"> Explain the activities carried out to promote it According to the needs and requirements of patients and families. | |
| 3.1.1 | The Quality and safety strategy includes specific objectives and recommended activities for their achievement. | <ul style="list-style-type: none"> Include the strategy or any document including objectives for improvement and the recommended activities to be performed. The strategy should be linked with the actions that emerged from the results of the assessment, monitoring system, evaluation, and the deliverables of the working groups for the grants. | |
| 4.1.1 | Educational resources for patients addressing disease management, coping skills and other practical skills, have been developed and disseminated. | <ul style="list-style-type: none"> Attach all the educational resources developed and explain how they have been disseminated. Mention which of them have been co-designed with patients. Specific indicator on patient education, if collected. The scope of education can include the different resources aimed at patients and patient representatives related to the different activities performed by the Network (navigation of the system, patient pathways, general knowledge about the disease...) |  |
| 4.1.2 | The ERN produces tailored information on patient safety standards and safety measures for patients and families to reduce or prevent errors. | <ul style="list-style-type: none"> Attach the specific information developed (flyers, online information, etc.) |  |

PATIENT GUIDE TO THE 5-YEAR EVALUATION OF THE EUROPEAN REFERENCE NETWORKS

| ID | MEASURES TO DIRECTLY ASSESS PATIENT INVOLVEMENT | EVIDENCE | TYPE OF MEASURE (CORE OR ENHANCED) * |
|-------|--|--|---|
| 5.2.1 | The ERN fosters collaborative instrumental efforts (multicentre trials, participation in EU projects, etc.) amongst its Members, Affiliated Partners and relevant patient (...) organisations. | <ul style="list-style-type: none"> • List of collaborative research projects and participants; joint proposals; papers and reports; trials registration... • Indicators on projects: trials and observational studies |  |
| 6.1.1 | The ERN has identified education, training, and professional development gaps within its area of expertise and defined priority areas for teaching and training. | <ul style="list-style-type: none"> • Involved patient organisations in identifying the gaps in training. |  |
| 6.1.2 | Plans have been implemented to address the priority areas for teaching and training in collaboration with Members, scientific societies, and other partners (patient organisations). | <ul style="list-style-type: none"> • Describe the activities developed during the 5 years. • Involved patient organisations in identifying the priority areas for training. |  |
| 6.1.3 | The plans have been evaluated and the areas of improvement identified have been addressed in the plans for the coming years. | <ul style="list-style-type: none"> • Regular evaluation performed (usefulness, applicability, relevance) according to the plan (i.e., satisfaction surveys) • Survey of patient community on training meeting their needs.. | |
| 6.1.4 | ERN members periodically meet to review and share best practices, and discuss new evidence-based treatments, therapies, and healthcare technologies. | <ul style="list-style-type: none"> • Explain how the Network plans and performs these meetings (webinars, workshops). Provide minutes, agendas, or summaries of the meetings. • Involved patient organisations in learning and sharing best practices. |  |
| 7.3.1 | The ERN has defined and implemented a comprehensive communication and dissemination strategy. | <ul style="list-style-type: none"> • Mention any initiative carried out to develop these partnerships. • Examples: Establish an expert panel (including scientific societies); mapping patient organisations that are not covered by the ERN (efforts done to find the organisations); any effort done for partnership; any initiative to improve partnership with important stakeholders with the objective of promote the ERN; national alliances; approach to social and psychological providers. |  |



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