

A. SELF EVALUATION OF HEALTHCARE PROVIDERS: GENERAL INFORMATION

7 Types of services covered by the Healthcare Provider within the Network’s area of expertise. Please select all that apply.

- | | | |
|---|--|--|
| <input type="checkbox"/> Prevention | <input type="checkbox"/> Acute Care | <input type="checkbox"/> Ambulatory services |
| <input type="checkbox"/> Diagnostic services | <input type="checkbox"/> Interventional therapeutic services | <input type="checkbox"/> Rehabilitation |
| <input type="checkbox"/> Social care services | <input type="checkbox"/> Palliative care services | <input type="checkbox"/> Others |

III. ACTIVITY OF THE HEALTHCARE PROVIDER

8 Number of patients with the rare or complex disease (s), condition (s) or highly specialised intervention (s) seen by the Healthcare Provider each year

Specific condition	Measure	2019	2020	2021	Minimum number established by the Network ⁷
Specific condition 1	Number of patients/year				
	Number of new patients/year				
	Number of procedures/year				
Specific condition 2	Number of patients/year				
	Number of new patients/year				
	Number of procedures/year				
Specific condition 3	Number of patients/year				
	Number of new patients/year				
	Number of procedures/year				
Specific condition 4	Number of patients/year				
	Number of new patients/year				
	Number of procedures/year				
Specific condition 5	Number of patients/year				
	Number of new patients/year				

⁷ According to the specific criteria set by the ERN for the assessment process

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	Number of procedures/year				
Specific condition 6	Number of patients/year				
	Number of new patients/year				
	Number of procedures/year				
Specific condition 7	Number of patients/year				
	Number of new patients/year				
	Number of procedures/year				
9	Please indicate the research activities and clinical trials, at both national and international level, within the Network's area of expertise in which the HCP has participated in the framework of the Network				
10	Please indicate the results of the <i>monitoring indicators</i> ⁸ provided to the Network in the last 3 years				
	Name of indicator	2019	2020	2021	

⁸ ERN Continuous Monitoring and Quality Improvement System (ERN CMQIS)


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11	Please indicate the results of the <i>clinical indicators</i> ⁹ agreed in the framework of your Network for last year.		
	Name of indicator	2021	
IV. ADDITIONAL INFORMATION			
12	Have you received any type of support (resources) from your hospital, Health Administration or Member State for your activities related to the Network? Please explain		
13	Mention what aspects have hindered your participation in the Network or have prevented a more active participation.		
14	Any additional information you would like to provide regarding the evaluation process.		

⁹ Specific indicators for the ERN, if any


B. 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	 10
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"/>		


¹⁰ The Symbol  indicates the requirement to have ready at the time of application a specific document as evidence of compliance. These documents are to be submitted at the request of the IEB

1.3 The HCP team provides patients with clear and transparent information about the complaints' procedures and remedies and ways of redress available for both domestic and foreign patients.					
Measurable Elements	0	1	2	Comments	
1.3.1 The information about complaints, violation of the rights, and concern of the care and/or safety of patients and their families is periodically analysed and integrated into a continuous quality improvement process. An annual report is made on the complaints and the improvement actions carried out.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
1.4 The HCP team regularly collects information on patient satisfaction within the ERN's area of expertise and uses this information to make ongoing improvements.					
Measurable Elements	0	1	2	Comments	
1.4.1 The HCP team routinely measures patient and family satisfaction using the ERN common tool.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
1.5 The HCP team obtains the patient informed consent to provide clinical risk treatments and procedures.					
Measurable Elements	0	1	2	Comments	
1.5.1 The Informed Consent (IC) is documented in the patient's medical record, including the risks, benefits, and alternatives of the procedure to be performed, and must be understandable to patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
1.5.2 The document to obtain IC for research must contain information on the risks, benefits, and alternatives of the procedure to be performed, and conflicts of interest (financial or not financial)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
1.5.3 The patients' medical records included in a clinical trial contain information about their participation in it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		


1.6 The HCP team maintains transparency by providing information to patients about clinical outcomes, treatment options, and quality and safety standards that are in place.

Measurable Elements	0	1	2	Comments	
1.6.1 The HCP team provides comprehensive diagnostic and treatment information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
1.6.2 Information is provided in the language of the different populations being served.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
1.6.3 The information necessary for the follow-up of the patient after the treatment is provided	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
1.6.4 The HCP team provides information on coordinating care with other levels from care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
1.6.5 The information provided to the patient and the family on the follow up and coordinating care with other levels of care.is included in the clinical record.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
1.6.6 Unanticipated outcomes and complications are disclosed to patients and their families as established in the HCP policy/procedure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		


1.7 The HCP implements a pain identification and management protocol.

Measurable Elements	0	1	2	Comments	
1.7.1 In hospitalised patients with rare diseases or complex patients, pain is regularly identified with a standardised scale as established in the hospital`s protocol.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

1.8 Professionals encourage the participation of the patient and their family, based on their interests, in the care process and in decision-making.


Measurable Elements	0	1	2	Comments	
1.8.1 Professionals encourage the participation of the patient and their family, based on their interests, in the care process and in decision-making.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

1.9 The HCP team collaborates and carries out activities with patient associations.


Measurable Elements	0	1	2	Comments	
1.9.1 The HCP team provides information on patients' associations that can support the patient and family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
1.9.2 The HCP team collaborates and carries out activities with patients' associations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

2 ORGANISATION AND MANAGEMENT


2.1 The HCP team follows policies and procedures to manage the services offered to cross-border patients, including an easy access to information regarding any tariffs that may be in place.

Measurable Elements	0	1	2	Comments	
2.1.1 The HCP team establishes collaboration with affiliated centres in neighbouring countries for cross-border care or for training / dissemination of information for professionals and patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
2.1.2 The HCP team establishes and maintains a set of policies and procedures addressing aspects for the management and health care services of cross border patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
2.1.3 The HCP team shares information with patients and their families about any tariffs that may be in place for the reimbursement of care, as well as services provided and expected benefits.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		


2.2 The HCP team implements procedures and/or inter-agency or shared care agreements to support ease of access and coordination with other resources, specific units, or services necessary for managing patients.

Measurable Elements	0	1	2	Comments	
2.2.1 When necessary, the HCP team has easy access to other centres or highly specialised units outside its own facilities necessary for diagnosis, treatment, and delivery of care to patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
2.2.2 The HCP team sends the receiving organization a written summary about the patient's clinical condition and the interventions carried out in the hospital from which he/she is referred. The process is recorded in the medical record	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		



2.3 The HCP team has policies and procedures implemented to communicate post discharge with clinicians, including cross border.

Measurable Elements	0	1	2	Comments	
2.3.1 Discharge reports contain at a minimum: diagnoses, significant physical findings; diagnostic, surgical and medical procedures performed, medication received at discharge, and follow-up instructions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
2.3.2 The HCP team provides clinicians post discharge with complete discharge summaries in English for all cross-border patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		



2.4 The HCP team is integrated into national networks.

Measurable Elements	0	1	2	Comments	
2.4.1 The HCP team collaborates in training or dissemination activities with centres which are not members of the ERN	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

2.5 The HCP team uses CPMS and includes all the information required.


Measurable Elements	0	1	2	Comments	
The HCP team shares patient information or participates in panels of complex cases through the CPMS with other members of the ERN.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
The CPMS of each patient includes: a) physical needs b) social needs c) psychological needs d) treatment and care plan e) sign off completed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
3 RESEARCH, EDUCATION AND TRAINING					
3.1 The HCP team participates in education and training activities, such as continuing medical education and distance learning, aimed at staff, students, and other care professionals.					
Measurable Elements	0	1	2	Comments	
3.1.1 The HCP team has a defined set of objectives for its education and training activities aligned with ERN	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
3.1.2 The HCP team regularly detects the training needs of the staff members.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
3.1.3 Education and training activities are delivered to providers involved in the same chain of care within and outside the HCP's facility.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
3.1.4 The HCP team participates in the training activities organised by the ERN.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		



3.2 The HCP team has the capacity to carry out research activities and demonstrated research experience in the framework of the ERN.						
Measurable Elements	0	1	2	Comments		
3.2.1 The HCP team leads and/or participates in research activities and clinical trials, at both national and international level, within the ERN's area of expertise.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
3.2.2 The HCP team ensures that records from research activities and clinical trials are safely stored.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
3.2.3 The HCP team involves patients and / or their representatives in the most relevant aspects of the research process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
3.2.4 The HCP team shares the results, in a timely manner, from its research activities and clinical trials through scientific publications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
3.2.5 The results should be disseminated to patient associations in lay language.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
3.2.6 The HCP team provides patients' information for the registries or databases promoted by the ERN.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
3.2.7 The HCP team is contributing to disseminate the ERN activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
4. EXCHANGE OF EXPERTISE, INFORMATION SYSTEMS, AND e-HEALTH						
4.1 The HCP team is able to exchange expertise with other providers and provide support to them.						
Measurable Elements	0	1	2	Comments		
4.1.1 The HCP team offers an advisory service to exchange expertise with other professionals and caregivers involved in the patients'	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			

treatment.					
4.2 The HCP team fosters the use of telemedicine and other e-health tools within and outside its facility.					
Measurable Elements	0	1	2	Comments	
4.2.1 The HCP team uses telemedicine and other e-health tools.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
4.2.2 Professional telemedicine guidelines available are used to guarantee the homogeneity of its use.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
4.2.3 The HCP team should identify inclusion and exclusion criteria for potential telehealth patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
4.2.4 Patients and family members who access telehealth have the right to have their privacy guaranteed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
4.2.5 When surveying patient and family satisfaction, satisfaction with the services provided by telehealth should be included, when appropriate.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
4.3 The HCP team codes the information, and the information system is aligned with nationally and internationally recognised systems when appropriate in the framework of the ERN.					
Measurable Elements	0	1	2	Comments	
4.3.1 The HCP team uses a standardised information and coding system for rare or low prevalence complex disease(s) or conditions(s), agreed within the ERN.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

5 QUALITY AND SAFETY


5.1 The HCP team regularly monitors and improves the quality and safety of the care provided to patients with rare or low prevalence complex diseases or conditions.

Measurable Elements	0	1	2	Comments	
5.1.1 The HCP team applies a strategy of quality and safety improvement, which includes specific objectives and recommended activities for the achievement of the objectives.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
5.1.2 The main objectives of the strategy of quality and safety improvement include: a) Hand hygiene b) Prevention and control of healthcare related infection c) Prevention of medication errors (completed medical orders, process of administration, identified high-risk medications) d) Ensure safe surgery (verification, time out and sign out) e) Unequivocal identification of patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
5.1.3 The quality and safety strategies are implemented, and the results obtained are evaluated.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
5.1.4 There is a procedure in place to report, document, investigate, and learn from adverse events and complications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
5.1.5 The HCP team uses this information to make ongoing improvements.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
5.1.6 All healthcare personnel are familiar with the system for reporting safety incidents and adverse events.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
5.1.7 A procedure is implemented to provide information on adverse events with patient damage to patients and their families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		


5.2 The HCP team adopts and uses clinical practice guidelines in their area of expertise.					
Measurable Elements	0	1	2	Comments	
5.2.1 The HCP team adopts and implements clinical practice guidelines and decision-making tools developed or adapted by the ERN.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
5.2.3 An annual evaluation on adequate compliance of the clinical practice guidelines is carried out using the indicators agreed in the ERN.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
6 COMPETENCE, EXPERTISE AND OUTCOMES OF CARE					
6.1 The HCP team maintains its clinical competence in the ERN's area of expertise.					
Measurable Elements	0	1	2	Comments	
6.1.1 To maintain its competency and expertise, the HCP team serves the minimum/optimal number of patients per year as defined by the ERN based on professional/technical standards or recommendations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
6.1.2 To maintain its competency and expertise, the HCP team serves the minimum/optimal number of procedures per year as defined by the ERN based on professional/technical standards or recommendations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
6.1.3 The HCP team regularly collects, and monitors process and outcome indicators as established in the ERN.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
6.1.4 The HCP team is actively involved in the activities organized for the development of the ERN.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

7 HUMAN RESOURCES

7.1 The HCP has a team of trained professionals with the required competencies within the ERN's area of expertise.

Measurable Elements	0	1	2	Comments	
7.1.1 The HCP team identifies and documents the skills and professional qualifications required for the new staff in the multidisciplinary team performing activities critical to the quality of patient care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
7.1.2 There is a process to routinely assess staff skill to ensure adequate performance of specialized tasks.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

7.2 The HCP team delivers a comprehensive care by a multidisciplinary and specialised team.

Measurable Elements	0	1	2	Comments	
7.2.1 There are regular structured meetings between multidisciplinary team members.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
7.2.2 The decisions of the multidisciplinary clinical sessions on a determined patient are recorded in their medical record.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		