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EFN answer to the Public Consultation on the Implementation of European Reference Networks (ERN)

1. Respondent Profile

- Health professional's organisations
- European Union umbrella organisation
- Pan European
- The EFN was established in 1971, to represent the nursing profession and its interests to the European Institutions, on the nursing education and free movement Directives, being drafted by the European Commission at that moment, and is the independent voice of the nursing profession, representing more than one million nurses at European Level. The EFN members are drawn from the National Nurses Associations from **34 European countries**. The EFN aims to bring to the attention of the EU the current and potential collaboration of nurses and nursing to meeting the health needs of the population throughout the Union. Key priorities orient the daily work of the EFN: nurse education, health workforce, quality and safety, and eHealth.

2. Involvement of your organisation in the matter of centres of excellence/reference (COE) and healthcare networks in highly specialised healthcare (HSHC).

2.1. How would you describe your organisation's knowledge of CoE and HSHC?

High

2.2. What aspects or domains related to the topic of CoE and HSHC would correspond to your organisations' key knowledge?

(selected options are **in red**)

- **Highly specialised healthcare provision**
- **Priorities, description and characteristics of CoE and HSHC**
- **Management and organisational aspects of highly specialised healthcare**
- **Professional performance, clinical practice , quality and safety of specialised healthcare**
- **Assessment/evaluation/certification of clinical practice and healthcare providers**
- Information system, coding.
- Engineering/eHealth
- Costs and economic evaluation

- Ethical analysis
- Social aspects
- Legal aspects

2.2.1 Space for further comments

The EFN members are engaged in the development and implementation of Advanced Nurse Practitioner roles across community and acute care settings. Nurses working in advanced practice have clinical expertise and specialist knowledge that enables them to deliver effective, efficient and patient-centred care, especially when caring for patients with long-term conditions. Furthermore, the EFN and EFN members are involved in several initiatives (Thematic Networks and European Partnerships) aiming to pull together evidenced based knowledge that supports the definition of priorities, criteria and characteristics of Centres of Excellence across the EU. Some initiatives like the development of innovative nursing models of care that are founded on strong clinical leadership and management, and optimal skill mix ratios have been instrumental in delivering high quality healthcare and improving patient outcomes within CoEs. At national level, EFN members are involved in assessing, evaluating and certifying professional practice. They participate actively to develop and share clinical best practices in order to promote excellence in healthcare through equitable access, improving quality of care and ensuring patient safety.

2.3. Is highly specialised healthcare a priority in your organisation's strategies and workplans?

High

2.3.1. Space for further comments:

The EFN looks at highly specialised healthcare from the perspective of what is needed to achieve it. One of the fundamental pillars to promote excellence is through a highly educated, dedicated and skilled workforce.

Key priorities for EFN are:

- Advocating for a highly qualified and competent nursing workforce;
- Investing in the education and training of this skilled workforce. It is also important to support nurses with their continued professional development;
- Ensuring development of robust definitions of necessary skills and competencies to deliver highly quality healthcare;
- Promoting safe staffing levels and optimal skill mix;
- Developing strong clinical leadership at management level to drive up quality and link provision of care services with patient outcomes;
- Promotion of advanced roles for nurses, which are proven to boost quality, safety and cost effectiveness of the healthcare delivered.

2.4. What specific field of healthcare services/specialities are most relevant for your organisations' field of work?

Other

2.4.1. Please specify

The EFN is taking particular action on the governance and management of healthcare, and how different models of care can improve efficiency, enhance patient care, improve health outcomes and contribute to the sustainability of health systems.

2.5. Has your organisation been directly involved in the design or assessment of professional standards and criteria related with highly specialised healthcare?

Frequently

2.5.1. Please describe your role in such actions

The EFN members are involved at national level in the design and assessment of professional standards related to education and training, continued professional development, workflows, staffing level ratios and skill mix, and quality and safety monitoring and evaluation.

2.7. Do you have concrete examples based on your own organisation's experience or could you provide us with references or links to documents related with professional criteria and standards in highly specialised healthcare/CoE or HSHC (quality criteria, guidelines or consensus documents)?

2.7.1. Space for further comments:

Key organisational values and guiding principles include:

- **Always put our patients first:** by ensuring that the patient is at the heart of everything we do.
- **Focus on pioneering research:** by rapidly and efficiently translating new discoveries into practical actions and benefits for patients locally, nationally and internationally.
- **Provide innovative learning opportunities:** by bringing together educational, academic and clinical expertise to deliver a world-class learning experience for students and the entire workforce.
- **Work in partnership:** by building on and extending clinical and academic collaborations and links locally and globally.
- **Transform the nature of healthcare:** by moving from treatment towards population screening and disease prevention.
- **Deliver excellence:** by setting new standards of achievement in patient care, research, and education and training.
- **Disseminate knowledge:** by ensuring benefits from our innovations are widely adopted.
- **Exercise scholarship in everything we do:** by being enquiring, thoughtful, reflective and challenging to ensure that everything we do adds value.

- **Be inclusive:** by designing systems and procedures so that everyone is actively encouraged to become involved and has the opportunity to do so.”

3.1. Criteria related with diseases or conditions in order to be considered under the scope of the ERN.

Please select the option which better reflect your opinion on the importance of the proposed criteria from 1 to 5 (1 not important and 5 very important).

3.1.1. Need of highly specialised healthcare: 5

3.1.1.1. complexity of the diagnosis and treatment: 5

3.1.1.2. high cost of treatment and resources: 5

3.1.1.3. need of advanced/highly specialised equipment or infrastructures: 5

3.1.2. Need of particular concentration of expertise and resources: 5

3.1.2.1. Rare expertise/need of concentration of cases: 5.

3.1.2.2. Low prevalence/incidence/number of cases: 5.

3.1.2.3. Evaluated experiences of Member States: 5.

3.1.3. Based on high-quality, accessible and cost-effective healthcare: 5

3.1.3.1. Evidence of the safety and favourable risk-benefit analysis: 5.

3.1.3.2. Feasibility and evidence of the value and potential positive outcome: 5.

3.1.4. Do you recommend any additional criteria that would effectively address this issue?

The criteria presented above focuses on the clinical process and diagnosis of diseases and conditions. The EFN agrees on focusing on very specific conditions when talking about a centre of excellence however, we would like the Commission to also highlight the importance of a whole-system approach in delivering excellence in health care. The EFN also believes in the need to include indicators that comprises the whole care pathway, including the diagnosis and clinical process, but also the complexity of the care, the needed monitoring and the rehabilitation from such a condition. Furthermore, there is need to facilitate integration of evidenced based research, education and training, and clinical care (both basic and advanced care) in order to deliver top quality care within these centres.

One of the major difficulties that arise in the cross border mobility debate is the lack of continuity of care provision across hospital and community settings and health and social care sectors. If the focus is predominately on diagnosis and clinical process, there is an increased likelihood that proper discharge planning and follow-up care (in outpatient or GP clinics) might be neglected. This neglect could result in a possible patient readmission to hospital due to a relapse episode, inadvertently costing the healthcare system more money in the long-term. Continuity of care must also be organised and encouraged within the national and regional health systems of the EU to make a broad collaboration in cross border healthcare possible. Therefore, it is necessary to implement care pathways within and across

organisational, disciplinary and country boundaries to ensure continuity in the healthcare process.

Nurses are often the first contact for patients accessing hospital or emergency care services and as such they play a central role in the delivery of safe, evidence based, effective and patient-centred care. A healthcare provider attempting to create a centre of excellence needs to develop and support its clinical nursing workforce in order to deliver evidenced based care, measure outcomes against care practices and develop clinical nurse leaders. As an example, in the United States, the Magnet status is awarded to hospitals that comply with a set of criteria designed to measure the strength and quality of their nursing workforce and its impact on patient care. According to Linda Aiken et al research in 2011 on hospitals with a magnet recognition from the American Nurses Credentialing Center (ANCC) in the US, it is known that these hospitals have better work environments, a more highly educated nursing workforce, superior nurse-to-patient staffing ratios, and higher nurse satisfaction rates.

Reference:

- *EFN Position on Continuity of Care.*

- *Magnet Hospitals:*

http://journals.lww.com/jonajournal/Abstract/2011/10000/Nurse_Outcomes_in_Magnet_and_Non_Magnet_Hospitals.9.aspx

3.1.5. Would you prioritise or suggest any concrete disease or group of diseases to be addressed by the future ERN according to the above criteria?

From an EFN's perspective, therefore nursing perspective, we believe that the focus should not only be on a particular disease or group of diseases but we believe that special attention to addressing Non-Communicable Diseases is needed, due to the burden that they represent and the complexity in their care. The EFN is of the opinion that no single disease should lead to the creation of an ERN but there need to be a complex process of care where a highly qualified and advanced healthcare workforce is needed. Nursing is a cross-cutting and holistic profession that embraces indicators that are often forgotten when a disease-specific approach is taken in healthcare.

3.2. General criteria of the centres wishing to join a European Reference Network

General and common fields and elements required for the assessment of any type of healthcare provider to be designated as centre of reference (1=Not important; 5= Very important).

3.2.1. Organisation and management: 5

3.2.2. Patient empowerment and centred care: 5

3.2.3. Patient care, clinical tools and health technology assessment: 5

3.2.4. Quality, patient safety and evaluation framework policies: 5

3.2.5. Business continuity, contingency planning and response capacity: 4

- 3.2.6. Information systems, technology and eHealth tools and applications: 5.
- 3.2.7. Overall framework and capacity for research and training: 5
- 3.2.8. Specific commitment of the management of the centre to ensure a full and active participation in the ERN: 3.

3.2.9. Do you recommend any additional option that would effectively address the issue?

Yes. The EFN would like to see the below criteria included under the general criteria of the centres:

- The centres need to include in their workplace policies criteria that support **continuity of care**; this will ensure that healthcare services and care management guidelines are based on holistic approaches tailored to the individual's needs. A **holistic and integrated approach** will help to empower patients.
- Establish systems to **measure outcomes** pertaining to continuity of care, quality of care and patient safety.
- Accurate, comprehensive, up to date, clear, user friendly, standardised, accessible, integrated and secure patient records.
- Interoperable systems of information and eHealth services to support channels of communication among healthcare professionals with clear mechanism for information sharing.
- Promotion of advanced nurse practitioners.
- Nursing terminology, such as the International Classification for Nursing Practise (ICNP^R) should be integrated in patient records, in order to ensure quality of care, patient safety and nursing sensitive outcomes.
- Evaluation and improvement of assessment systems; standardised systems put in place to measure patient sensitive quality nursing indicators and assess the continuity and quality of the healthcare provided.

3.3. Specific criteria regarding the areas of expertise

Specific fields and elements for the assessment of a healthcare provider wishing to be selected as a centre of reference for a concrete disease or condition (1=Not important; 5= Very important).

- 3.3.1 Competence, experience and good outcomes and care: 5
- 3.3.2. Specific resources and organisation: 5
 - 3.3.2.1. Human resources: 5
 - 3.3.2.2. Team/centre organisation: 5
 - 3.3.2.3. Structural conditions: 4
 - 3.3.2.4. Specific equipment: 3
 - 3.3.2.5. Presence and coordination with other required complementary units or services: 5
- 3.3.3. Patient care pathways, protocols and clinical guidelines in the field of expertise: 5
- 3.3.4. External coordination, care management and follow up of patients: 5
- 3.3.5. Research, training, health technology assessment in the field of expertise: 5

3.3.6. Specific information systems: 5.

3.3.7. Additional criteria? Yes

3.3.7.1. The development of evidence based care pathways and guidelines are of utmost importance for a centre of excellence, as their expertise must be able to be evaluated and shared. To that end, the centre must promote nursing leadership and research opportunities and should encourage professional autonomy that is strengthened by a well-developed and routinely evaluated Continuous Professional Development system.

Centres of excellence should be underpinned on principles like high standards of cooperation, active flows of communication and knowledge sharing, partnership working, robust workforce planning, strong clinical leadership and multidisciplinary approaches. The centre must use integrated approach to service planning, financing, organisational restructuring and implementation. It is also important that local integration plans are designed in partnership with other service providers and outputs are clearly defined.

Workloads and shift work should be monitored, ensuring optimal staffing skill mix ratios. Safe staffing levels are instrumental in delivering positive health outcomes, driving up quality and promoting safety. Staffing shortages can compromise care both directly and indirectly. During times of economic austerity, we have witnessed numerous nursing jobs being cut which can have a direct impact on patient safety and quality of care. Having a robust workforce plan is needed to mitigate the risk and continue to deliver a quality service that puts the patient first.

