

# Public Consultation Survey on the Implementation of European Reference Networks (ERN)

Thank you for taking your time in participating in this consultation.

The consultation gives the opportunities to provide your view on the domains and elements to be addressed in the implementation of European Reference Networks (ERN) under the framework of article 12 of 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. It is specifically seeking input in connection with the criteria to be considered in the process of identification and designation of healthcare providers as Centers of Excellence.

This questionnaire should be read along the conceptual paper included in the public consultation website ([link](#))

Overall this consultation consists of 3 sections.

Depending on the detail of your answers, you may want to reserve 15-20 minutes for completing the questionnaire.

The maximum time to complete the questionnaire allowed by the system is 90 minutes. Partial responses will not be saved. This means once you start filling in the questionnaire, you have to answer all compulsory questions to submit your response.

You can, however, preview/print a PDF version of the online questionnaire – (right top corner of the screen) to help you to prepare your response.

Questions marked with an asterisk \* require an answer to be given.

## 1. Respondent Profile

In this section you are asked to provide information to help us build the profile of respondents, such as their background and affiliation. Please be aware that in accordance with Regulation 45/2001, all personal data collected through this survey will be kept securely and ultimately erased.

1.1 Please indicate the type of organisation on behalf of which you are responding to this consultation: \*

- Patient organisation/association
- Health professionals' organisations (e.g. doctors, nurses, managers)
- Healthcare provider organisations (e.g. hospitals association, specialised provider association)
- Healthcare provider
- Academic/public health and healthcare specialised institution/organisation (e.g. Institutes and University Departments of Public Health, Quality, Healthcare, Clinical Excellence)
- Healthcare public administration at national level
- Healthcare public administration at regional level
- Healthcare public administration at local level
- Public authorities and government-appointed bodies responsible or involved in the definition of criteria and the establishment and evaluation of centres of reference/excellence (e.g. highly specialised healthcare, specialised commissioning services)
- Health insurer (e.g. sickness fund)
- Individual respondent

 Please indicate level: \*

- National level organisation
- European Union umbrella organisation

 Please indicate level: \*

- National level
- Regional level

 Please indicate Member States representation: \*

- Less than 10 Member States
- Between 10-20 Member States
- Pan European

 Please indicate what type: \*

- Primary healthcare provider/centre
- Hospital
- In hospital specialised service or unit
- Ambulatory specialised service or unit
- Public/contracted centre unit
- Private not under contract or unit



Please indicate for what the administration is responsible:

\*

- Healthcare planning/organisation     Health Technology Assessment     National/regional health service provider
- Public Health     Quality, patient safety or clinical governance



Please indicate from which sector: \*

- Public     Private

1.1.1. Other (please specify):

1.2 Please indicate the name of your organisation or centre: \*

1.3 Please indicate the country where your organisation/centre is located/has its headquarters or main representative office in Europe: \*

- |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|
| <input type="radio"/> BE | <input type="radio"/> CY | <input type="radio"/> SI |
| <input type="radio"/> BG | <input type="radio"/> LV | <input type="radio"/> SK |
| <input type="radio"/> CZ | <input type="radio"/> LT | <input type="radio"/> FI |
| <input type="radio"/> DK | <input type="radio"/> LU | <input type="radio"/> SE |
| <input type="radio"/> DE | <input type="radio"/> HU | <input type="radio"/> UK |
| <input type="radio"/> EE | <input type="radio"/> MT | <input type="radio"/> LI |
| <input type="radio"/> IE | <input type="radio"/> NL | <input type="radio"/> NO |
| <input type="radio"/> EL | <input type="radio"/> AT | <input type="radio"/> IS |
| <input type="radio"/> ES | <input type="radio"/> PL | <input type="radio"/> HR |
| <input type="radio"/> FR | <input type="radio"/> PT |                          |
| <input type="radio"/> IT | <input type="radio"/> RO |                          |

1.4 Please indicate the number of EU Member States and EEA countries (Norway, Iceland, Lichtenstein) and accessing country (Croatia) in which your organisation conducts business/is represented: \*

- |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|
| <input type="radio"/> 1  | <input type="radio"/> 12 | <input type="radio"/> 23 |
| <input type="radio"/> 2  | <input type="radio"/> 13 | <input type="radio"/> 24 |
| <input type="radio"/> 3  | <input type="radio"/> 14 | <input type="radio"/> 25 |
| <input type="radio"/> 4  | <input type="radio"/> 15 | <input type="radio"/> 26 |
| <input type="radio"/> 5  | <input type="radio"/> 16 | <input type="radio"/> 27 |
| <input type="radio"/> 6  | <input type="radio"/> 17 | <input type="radio"/> 28 |
| <input type="radio"/> 7  | <input type="radio"/> 18 | <input type="radio"/> 29 |
| <input type="radio"/> 8  | <input type="radio"/> 19 | <input type="radio"/> 30 |
| <input type="radio"/> 9  | <input type="radio"/> 20 | <input type="radio"/> 31 |
| <input type="radio"/> 10 | <input type="radio"/> 21 |                          |
| <input type="radio"/> 11 | <input type="radio"/> 22 |                          |

1.5 If need be, can we contact you by e-mail to obtain further information on your submission? \*

- Yes  No



1.5.1 Please provide an e-mail address where we can contact you: \*

1.6 Please provide us with a contact person (incl jobtitle and daytime phone number):

1.7 Please provide additional contact details if needed:

## 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? \*

Very high

Poor

No opinion

High

None

Non applicable

2.1.1 Space for further comments:

(maximum 200 characters)

2.2. What aspects or domains related to the topic of CoE and HSHC would correspond to your organisation's key knowledge? (cross any that applies) \*

- |  |  |
|--|--|
| <input type="checkbox"/> Highly specialised healthcare provision   | <input type="checkbox"/> Costs and economic evaluation |
| <input type="checkbox"/> Priorities, description and characteristics of CoE and HSHC                               | <input type="checkbox"/> Ethical analysis              |
| <input type="checkbox"/> Management and organisational aspects of highly specialized healthcare                    | <input type="checkbox"/> Social aspects                |
| <input type="checkbox"/> Professional performance, clinical practice, quality and safety of specialized healthcare | <input type="checkbox"/> Legal aspects                 |
| <input type="checkbox"/> Assessment/evaluation/certification of clinical practice and healthcare providers         | <input type="checkbox"/> No opinion                    |
| <input type="checkbox"/> Information system, coding  | <input type="checkbox"/> Non applicable                |
| <input type="checkbox"/> Engineering/e-health  |  |

2.2.1. Space for further comments: (maximum 200 characters)

2.3 Is highly specialised healthcare a priority in your organisation's strategies and work plans? \*

- |                                 |                                |                                   |                                      |
|---------------------------------|--------------------------------|-----------------------------------|--------------------------------------|
| <input type="radio"/> Very high | <input type="radio"/> Somewhat | <input type="radio"/> No priority | <input type="radio"/> Non applicable |
| <input type="radio"/> High      | <input type="radio"/> Low      | <input type="radio"/> No opinion  |                                      |

2.3.1 Space for further comments: (maximum 200 characters)

2.4. What specific field of healthcare services/specialities are most relevant for your centre/organisation's field of work? \*

- |   |   |                                      |
|---|---|--------------------------------------|
| <input type="radio"/> Surgical speciality         | <input type="radio"/> High tech diagnostic and treatment services (radiology, nuclear medicine, electrophysiology, radiotherapy etc.) | <input type="radio"/> No opinion     |
| <input type="radio"/> Medical speciality          | <input type="radio"/> Laboratories and central services (e.g. pathology, genetics, biochemistry, pharmacy, microbiology etc.)         | <input type="radio"/> Non applicable |
| <input type="radio"/> Medical/Surgical speciality | <input type="radio"/> Other   |                                      |



Please specify:

\* (maximum 50 characters)

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

- Frequently
- Occasionally
- Never
- No opinion
- Non applicable

2.5.1 Please describe your role in such actions/projects: (maximum 200 characters)


2.6. Has your organisation been involved in projects/activities supported by the Commission in relation with HSHC or professional and technical criteria/standards in highly specialised healthcare? \*

- Yes
- No
- Non applicable

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 (e.g. quality criteria, guidelines, consensus documents)? \*

- Yes
- No
- Non applicable

2.7.1 Space for further comments: (maximum 200 characters)

 2.8. Is your centre or unit directly involved in the management (diagnosis, treatment etc.) of highly specialised diseases or conditions? \*

- Yes
- No
- Non applicable




 2.9. Is your centre or unit designated or recognised as centre of reference/excellence in your country? \*

- Yes
- No
- Non applicable

 2.10. How has your centre been designated/recognised as centre of reference/excellence? \*

- Through a formal institutional process
- Based on professional recognition
- Other


 2.10.1 Space for further comments: (maximum 200 characters)

 2.11. Which is your area of expertise as centre of reference? *(please provide your answer in free text)* \*


(maximum 200 characters)

 2.12 Is your centre participating currently in a network of centres of expertise? \*

- Yes
- No
- Non applicable


 2.13. What is the scope of the network? \*

- Regional
- National
- International


 2.14. Which kind of network? \*

- National
- International
- Founded by the European Commission
- Founded by other sources

 2.14.1 Space for further comments: (maximum 200 characters)

 2.15. Would you be interested in applying to the process to be considered Centre of Excellence of the future European Reference Network? (1 = not interested at all, 5 = very interested) \*

- 1       2       3       4       5

 2.15.1 Space for further comments: (maximum 200 characters)

### 3. Proposed criteria for ERN (scope, general and specific criteria)

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

Characteristics that the condition, disease or technique should fulfil to be considered for inclusion in the scope of the future ERN.

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

a: 1

b: 2

c: 3

d: 4

e: 5

	a	b	c	d	e
<b>3.1.1. Need of highly specialised healthcare*</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.1.1.1. Complexity of the diagnosis and treatment*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.1.1.2. High cost of treatment and resources*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.1.1.3. Need of advanced/highly specialised medical equipment or infrastructures*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>3.1.2. Need of particular concentration of expertise and resources*</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.1.2.1. Rare expertise/need of concentration of cases*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.1.2.2. Low prevalence/incidence/number of cases*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.1.2.3. Evaluated experiences of Member States*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>3.1.3. Based on high-quality, accessible and cost-effective healthcare*</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.1.3.1. Evidence of the safety and favourable risk-benefit analysis*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.1.3.2. Feasibility and evidence of the value and potential positive outcome (clinical)*	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3.1.4. Do you recommend any additional criteria or option that would effectively address the issue?\*

Yes

No



3.1.4.1 Explain your proposal in free text: \* (maximum 200 characters)

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? \*

Yes

No



3.1.5.1 Explain your proposal in free text:

\*

(maximum 200 characters)

## 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 health care provider to be designated as centre of reference (general criteria).

Please cross the option which better reflect your opinion on the importance (value and pertinence) of the proposed domains and elements to be addressed by the criteria and sub-criteria from 1 to 5 (1 = not important at all, 5 = very important).

Sub-criteria and quantitative or qualitative requisites will be further defined for each of the listed criteria:

- a: 1
- b: 2
- c: 3
- d: 4
- e: 5

	a	b	c	d	e
3.2.1. Organisation and management *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.2.2. Patients empowerment and centered care *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.2.3. Patient care, clinical tools and health technology assessment *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.2.4. Quality, patient safety and evaluation framework policies *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.2.5. Business continuity, contingency planning and response capacity *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.2.6. Information systems, technology and e-health tools and applications *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.2.7. Overall framework and capacity for research and training *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.2.8. Specific commitment of the management/direction of the centre/hospital to ensure a full and active participation in the ERN *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

Yes

No

3.2.9.1. Space for further comments: (maximum 200 characters)

### 3.3. Specific criteria regarding the areas of expertise

Specific fields and elements for the assessment of a health care provider wishing to be selected as a centre of reference for a concrete disease or condition (hereafter disease specific criteria).

Please cross the option which better reflect your opinion on the importance (value and pertinence) of the domains and elements to be addressed by the proposed criteria and sub-criteria from 1 to 5 (1 = not important at all, 5 = very important).

Sub-criteria and quantitative or qualitative requisites will be further defined for each of the selected diseases or conditions for each of the following domains:

a: 1

b: 2

c: 3

d: 4

e: 5

	a	b	c	d	e
<b>3.3.1. Competence, experience and good outcomes and care *</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>3.3.2. Specific resources and organisation: *</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.3.2.1. Human resources *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.3.2.2. Team/centre organisation *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.3.2.3. Structural conditions *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.3.2.4. Specific equipment *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.3.2.5. Presence and coordination with other required complementary units or services *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>3.3.3. Patient care pathways, protocols and clinical guidelines in the field of expertise *</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>3.3.4. External coordination, care management and follow-up of patients *</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>3.3.5. Research, training, health technology assessment in the field of expertise *</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>3.3.6. Specific information systems *</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3.3.7. Do you recommend any additional criteria or option that would effectively address the issue? \*

Yes

No



3.3.7.1. Space for further comments: \* (maximum 200 characters)