

University Medical Center Hamburg-Eppendorf, Germany

1. Respondent Profile	
1.1 Please indicate the type of organisation on behalf of which you are responding to this consultation:	Academic/public health and healthcare specialised institution/organisation (e.g. Institutes and University Departments of Public Health, Quality, Healthcare, Clinical Excellence)
Please indicate level:	National level organisation
Please indicate for what the administration is responsible:	
1.1.1. Other (please specify):	Highest Level of Healthcare
1.2 Please indicate the name of your organisation or centre:	University Medical Center Hamburg-Eppendorf
1.3 Please indicate the country where your organisation/centre is located/has its headquarters or main representative office in Europe:	DE
1.4 Please indicate the number of EU Member States and EEA countries (Norway, Iceland, Lichtenstein) and accession country (Croatia) in which your organisation conducts business/is represented:	25
1.5 If need be, can we contact you by e-mail to obtain further information on your submission?	Yes
1.5.1 Please provide an e-mail address where we can contact you:	zeitz@uke.de

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

Professor Dr.med. Martin Zeitz Medical Director, CEO
University Medical Center Hamburg-Eppendorf Martinistr.52,
20246 Hamburg Germany, Building Ost 35 Tel: +49 (0)407410
55000

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

2.1.1 Space for further comments:

Highly specialized healthcare, centers of excellence, eg, stroke, cancer, autoimmune liver and metabolic disorders, rare diseases. Multiprofessional training site for students, MD, nurses, therapists

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)

Highly specialised healthcare provision
Costs and economic evaluation
Ethical analysis
Management and organisational aspects of highly specialized healthcare
Social aspects
Professional performance, clinical practice, quality and safety of specialized healthcare
Assessment/evaluation/certification of clinical practice and healthcare providers
Information system, coding
Engineering/e-health

2.2.1. Space for further comments:	HIMSS level-7 certified electronic clinical info. system (Soarian) funded by German Research Council. International trials, eg, WAKE-UP stroke trial (EU FP7), EU-project DEM Child (ceroidlipofusc.)
2.3 Is highly specialised healthcare a priority in your organisation's strategies and work plans?	Very high
2.3.1 Space for further comments:	Development and implementation of individualized therapies; bringing forward specialized "personalized medicine", eg, individually adapted immunomodulation in autoimmune diseases or tumor therapy
2.4. What specific field of healthcare services/specialities are most relevant for your centre/organisation's field of work?	Medical/Surgical speciality
Please specify:	High-tech diagnostics/interventional services
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
2.5.1 Please describe your role in such actions/projects:	
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

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
2.7.1 Space for further comments:	eg, German Diagnosis and Treatment Guidelines in Neurology, European Association for the Study of the Liver (EASL) Clinical Practice Guidelines, National guidelines for different Diseases
2.13. What is the scope of the network?	
2.14. Which kind of network?	
2.14.1 Space for further comments:	
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)	
2.15.1 Space for further comments:	

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

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	4
3.1.1.3. Need of advanced/highly specialised medical 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	4
3.1.2.3. Evaluated experiences of Member States	3
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	4
3.1.3.2. Feasibility and evidence of the value and potential positive outcome (clinical)	5
3.1.4. Do you recommend any additional criteria or option that would effectively address the issue?	Yes
3.1.4.1 Explain your proposal in free text:	Focus is transitional medicine as several complex diseases requiring highly specialized healthcare impose interdisciplinary challenges to both pediatric and adult medicine specialties
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
3.1.5.1 Explain your proposal in free text:	Advancing novel diagnostics/treatment of, eg, autoimmune liver diseases, pediatric lysosomal and metabolic diseases, complex neurovascular and neuroimmunological disorders, neurofibromatosis

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

3.2.1. Organisation and management	5
3.2.2. Patients empowerment and centered care	5
3.2.3. Patient care, clinical tools and health technology assessment	4
3.2.4. Quality, patient safety and evaluation framework policies	4
3.2.5. Business continuity, contingency planning and response capacity	4
3.2.6. Information systems, technology and e-health tools and applications	4
3.2.7. Overall framework and capacity for research and training	5
3.2.8. Specific commitment of the management/direction of the centre/hospital to ensure a full and active participation in the ERN	5
3.2.9. Do you recommend any additional option that would effectively address the issue?	Yes
3.2.9.1. Space for further comments:	Structured follow-up care programs für HSHC patients warranting quality management and evaluation of clinical pathways, transcultural patient care and foreign language competence for cross-border care

3.3. Specific criteria regarding the areas of expertise

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	5
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. Do you recommend any additional criteria or option that would effectively address the issue?	Yes
3.3.7.1. Space for further comments:	Integration of follow-up programs in clinical pathways, evaluation/quality management to achieve treatment and research goals, bridging the gap between children and adults (transitional medicine)