

North German Epilepsy Center Hamburg

1. Respondent Profile	
1.1 Please indicate the type of organisation on behalf of which you are responding to this consultation:	Healthcare provider
Please indicate what type:	In hospital specialised service or unit
Please indicate for what the administration is responsible:	
1.1.1. Other (please specify):	Specialized ambulatory services are integrated with in-hospital service
1.2 Please indicate the name of your organisation or centre:	North German Epilepsy Center Hamburg
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 accessing country (Croatia) in which your organisation conducts business/is represented:	6
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:	s.stodieck@alsterdorf.de
1.6 Please provide us with a contact person (incl jobtitle and daytime phone number):	Stefan R.G. Stodieck, MD PhD Head North German Epilepsy Center Hamburg Bodelschwinghstr. 24 22337 Hamburg Tel: +49 40 5077 3507 Fax: +49 40 5077 3471

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: Highest level (IV) Epilepsy Reference Center for northern Germany. Formal network with different health service providers (private & public). Comprehensive longterm care in-hospital & ambulatory.

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
Social aspects
Professional performance, clinical practice, quality and safety of specialized healthcare
Engineering/e-health

2.2.1. Space for further comments: Development of high-level Epilepsy-Monitoring hard- & software and patient interaction system via smartphone. Special emphasis on employability and social inclusion of mentally retarded patients.

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

2.3.1 Space for further comments: Since 1999 our organisation is supported by the state health authorities to provide and develop highly specialized healthcare for seizure patients in northern Germany.

2.4. What specific field of healthcare services/specialities are most relevant for your centre/organisation's field of work?	High tech diagnostic and treatment services (radiology, nuclear medicine, electrophysiology, radiotherapy etc.)
Please specify:	brain imaging, epilepsy surgery, neuromodulation
2.5. Has your organisation/centre been directly involved in the design or assessment of professional standards and criteria related with highly specialised healthcare?	Occasionally
2.5.1 Please describe your role in such actions/projects:	Development of criteria for national Epilepsy Centers. Development of standards of care for women with epilepsy. Contribution to European standards development .
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?	No
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:	Essential services, personnel, and facilities in specialized epilepsy centers - revised 2010 guidelines. National Association of Epilepsy centers. Epilepsia 51:2322-2333, Nov 2010
2.8. Is your centre or unit directly involved in the management (diagnosis, treatment etc.) of highly specialised diseases or conditions?	Yes

2.9. Is your centre or unit designated or recognised as centre of reference/excellence in your country?	Yes
2.10. How has your centre been designated/recognised as centre of reference/excellence?	Based on professional recognition
2.10.1 Space for further comments:	Formal recognition as Grade IV Epilepsy Center by the German Chapter of ILAE (International League Against Epilepsy) is pending
2.11. Which is your area of expertise as centre of reference? (please provide your answer in free text)	Diagnostics & care of pts. w. Epilepsy or other Seizure Disorders. Highest level Referral Center. Video-EEG-Monitoring, Epilepsy Surgery, Neurostimulation. Expertise in pregnancy & mental retardation.
2.12 Is your centre participating currently in a network of centres of expertise?	Yes
2.13. What is the scope of the network?	International
2.14. Which kind of network?	International
2.14.1 Space for further comments:	Task Group Presurgical Epilepsy Diagnostics and Epilepsy Surgery of the German Chapter of the ILAE. Association of European Epilepsy Centers.
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)	5

2.15.1 Space for further comments:

We are very interested because we plan the continuous further development of high-tech diagnostics at our center and we already treat a relevant number of international patients from EU countries.

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	2
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	2
3.1.3. Based on high-quality, accessible and cost-effective healthcare	2
3.1.3.1. Evidence of the safety and favourable risk-benefit analysis	2

3.1.3.2. Feasibility and evidence of the value and potential positive outcome (clinical)	3
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:	Chronic condition with need of continuous interdisciplinary comprehensive health care, in-hospital & ambulatory, manifesting in different age groups with need of optimal transition between age groups.
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:	Epilepsy and other Seizure Disorders that are - chronic diseases of high psychosocial impact - often (1/3) difficult to diagnose and to treat Many rare diseases manifest primarily by epilepsy.

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

3.2.1. Organisation and management	2
3.2.2. Patients empowerment and centered care	4
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	2

3.2.6. Information systems, technology and e-health tools and applications	5
3.2.7. Overall framework and capacity for research and training	3
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:	Cross-cultural communication and foreign language competences.

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	4
3.3.2.2. Team/centre organisation	4
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	4

3.3.4. External coordination, care management and follow-up of patients	2
3.3.5. Research, training, health technology assessment in the field of expertise	2
3.3.6. Specific information systems	3
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:	Development of standards and protocols of care with special emphasis on follow-up assessment and longterm care management.