

## Phakomatoses Centre, Hospital of the Lithuanian University of Health Sciences Kauno klinikos, Lithuania

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):	University hospital
1.2 Please indicate the name of your organisation or centre:	Phakomatoses Centre, Hospital of the Lithuanian University of Health Sciences Kauno klinikos
1.3 Please indicate the country where your organisation/centre is located/has its headquarters or main representative office in Europe:	LT
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:	15
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:	endziniene@gmail.com
1.6 Please provide us with a contact person (incl jobtitle and daytime phone number):	Prof. Milda Endziniene, M.D., Ph.D. Tel:+370 37 326 811; mob: +370 686 64662
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?	Poor
2.1.1 Space for further comments:	Networking has just started: final preparations for international registry on tuberous sclerosis (TOSCA). Regular comprehensive care of TSC patients informally since 1999.
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 Priorities, description and characteristics of CoE and HSHC Management and organisational aspects of highly specialized healthcare Professional performance, clinical practice, quality and safety of specialized healthcare
2.2.1. Space for further comments:	
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:	
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:	Multidisciplinary service (both pediatric/adult)
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:	Working group membership in building up strategies for rare disorders in Lithuania. Working on preparations of guidelines in the management of tuberous sclerosis in Lithuania
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:	For patients and caregivers, also general practitioners: I. Adomaitienė, Milda Endzinienė. "Tuberozinė sklerozė", Kaunas, 2001. Under preparation - for professionals (planned for 2013).
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?	Through a formal institutional process
2.10.1 Space for further comments:	Experience in management of tuberous sclerosis for around 15 years, formally registered as a CoE at the University Hospital level in 2012, going to apply for country-wide recognition in 2013.

2.11. Which is your area of expertise as centre of reference? (please provide your answer in free text)	Diagnosis, multidisciplinary follow-up, conservative and surgical management of tuberous sclerosis, neurofibromatosis (epilepsy, tumours in brain, kidneys and other organs), patient education.
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?	Founded by other sources
2.14.1 Space for further comments:	Final stage of preparations for joining the International registry for tuberous sclerosis
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:	Would be interested for the purpose of gaining and sharing experience, contribution to scientific research.

### 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	5

3.1.1.3. Need of advanced/highly specialised medical equipment or infrastructures	4
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	4
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 (clinical)	5
3.1.4. Do you recommend any additional criteria or option that would effectively address the issue?	No
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:	Phakomatoses (Tuberous sclerosis, Neurofibromatosis type I-II), Myelomeningocele, Neuromuscular disorders, Childhood multiple sclerosis.

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

3.2.1. Organisation and management	5
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3.2.2. Patients empowerment and centered 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	5
3.2.6. Information systems, technology and e-health tools and applications	5
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?	No
3.2.9.1. Space for further comments:	Setting the limits for the minimum number of patients for the CoE as a criteria is not appropriate as this would not allow small countries to join the network - the ones that badly need networking!

### 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	5
3.3.2.4. Specific equipment	4
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	4
3.3.7. Do you recommend any additional criteria or option that would effectively address the issue?	No
3.3.7.1. Space for further comments:	No