European Board of Urology, EBU (Urology section of the UEMS), Netherlands

1. Respondent Profile		
1.1 Please indicate the type of organisation on behalf of which you are		
responding to this consultation:	managers)	
Please indicate level:	European Union umbrella organisation	
Please indicate Member States representation:	Pan European	
Please indicate for what the administration is responsible:		
1.1.1. Other (please specify):		
1.2 Please indicate the name of your organisation or centre:	European Board of Urology, EBU (Urology section of the UEMS)	
1.3 Please indicate the country where your organsation/centre is	NL	
located/has its headquarters or main representative office in Europe:		
1.4 Please indicate the number of EU Member States and EEA countries	28	
(Norway, Iceland, Lichtenstein) and accessing country (Croatia) in		
which your organisation conducts business/is represented:		
1.5 If need be, can we contact you by e-mail to obtain further	Yes	
information on your submission?		
1.5.1 Please provide an e-mail address where we can contact you:	mail@mbrehmer.se	
1.6 Please provide us with a contact person (incl jobtitle and daytime	Marianne Brehmer, Consultant Urologist, Chairman RTPU	
phone number):	committee, EBU, phone number +46 (0)733 79 49 53	
1.7 Please provide additional contact details if needed:		

2.1 How would you describe your organisation's knowledge of CoE and HSHC?	High
2.1.1 Space for further comments:	The EBU has since several years worked on a certification system for reference centres in urological subspecialties. The system, based on peer-reviewing, was launched in December 2012.
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)	Priorities, description and characteristics of CoE and HSHC Management and organisational aspects of highly specialized healthcare Professional performance, clinical practice, quality and safety o specialized healthcare Assessment/evaluation/certification of clinical practice and healthcare providers
2.2.1. Space for further comments:	Standardized assessment would facilitate comparison and may give transparency.
2.3 Is highly specialised healthcare a priority in your organisation's strategies and work plans?	Somewhat
2.3.1 Space for further comments:	Our organization is focused on quality control of education and performance.
2.4. What specific field of healthcare services/specialities are most relevant for your centre/organisation's field of work?	Surgical speciality
Please specify:	Urology

2.5. Has your organisation/centre been directly involved in the design or assessment of professional standards and criteria related with highly specialised healthcare?	
2.5.1 Please describe your role in such actions/projects:	Our organization has designed an advanced system for certification of sub-specialty centres in Urology. The system is up and running.
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:	http://www.ebu.com/certification-training/sub-speciality/ If you would like to have detailed information on the applications and evaluation forms please get in contact.
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	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	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	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:	Education and training, sharing of knowledge
3.1.5. Would you prioritise or suggest any concrete disesase 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:

According to the EBU system, different areas within urology have been identified. Our organisation would rather recommend that system, than to priorities one or a few a certain diseases.

3.2. General criteria of the centres wishing to join a European Reference Network		
3.2.1. Organisation and management	4	
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	3	
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:	Sharing of knowledge (arranging courses, communicating with other health care providers and the public etc)	

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	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:	Our organisation agrees with the criteria mentioned in the survey. The boxes for free text dies, however, not work properly so it is not possible to give good comments.