

VSOP, Lupus Netherlands

1. Respondent Profile	
1.1 Please indicate the type of organisation on behalf of which you are	Public authorities and government-appointed bodies
Please indicate level:	National level
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:	VSOP, Lupus Netherlands
1.3 Please indicate the country where your organisation/centre is	NL
1.4 Please indicate the number of EU Member States and EEA countries	3
1.5 If need be, can we contact you by e-mail to obtain further information	Yes
1.5.1 Please provide an e-mail address where we can contact you:	marianne.wiers@casema.nl
1.6 Please provide us with a contact person (incl jobtitle and daytime phone number):	marianne wiers, Netherlands member VSOP Genetic Group member Lupus Netherlands
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?	High

2.1.1 Space for further comments:	I'm a member of the consulted parties for the National Plan for Rare Diseases in the Netherlands
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 Management and organisational aspects of highly specialized
2.2.1. Space for further comments:	I'm a former employee of the National Health Board and thus concerned about the rights of people for the access to good
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:	We seek to improve the national reference network in the Netherlands (NFU) and call for more national and
2.4. What specific field of healthcare services/specialities are most Please specify:	Laboratories and central services (e.g. pathology, genetics, A diagnose for a rare disease takes more than 4 y
2.5. Has your organisation/centre been directly involved in the design or assessment of professional standards and criteria related with highly	Frequently
2.5.1 Please describe your role in such actions/projects:	I already mentioned the National Plan for rare diseases Also the LUMC is developing a care path for the complex disease
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	Yes

2.7.1 Space for further comments:	VSOP is in the EUCERD and LUMC is the centre for contact for ORPHANET Both are developing new brochures and care
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	3
3.1.1.3. Need of advanced/highly specialised medical equipment or	3
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	3
3.1.2.3. Evaluated experiences of Member States	5
3.1.3. Based on high-quality, accessible and cost-effective healthcare	3
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?	Yes
3.1.4.1 Explain your proposal in free text:	Table 1 of the Proposal: - is leading in the newest treatments and laboratory tests, also leading in the tests of new
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	Yes
3.1.5.1 Explain your proposal in free text:	Furthermore: The cross-border expert group needs a member explicitly for rare diseases

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

3.2.1. Organisation and management	3
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	5
3.2.5. Business continuity, contingency planning and response capacity	3
3.2.6. Information systems, technology and e-health tools and applications	3
3.2.7. Overall framework and capacity for research and training	4
3.2.8. Specific commitment of the management/direction of the	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:	National (bio and gen) database exchange and international communication features

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:	3
3.3.2.1. Human resources	4
3.3.2.2. Team/centre organisation	3
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	5
3.3.3. Patient care pathways, protocols and clinical guidelines in the field	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	4
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:	Prevention of regression of the quality of life of patients should be an item!