

## Landsbond van Onafhankelijke Ziekenfondsen - Union Nationale des Mutualités Libres, Belgium

1. Respondent Profile	
1.1 Please indicate the type of organisation on behalf of which you are responding to this consultation:	Health insurer (e.g. sickness fund)
Please indicate for what the administration is responsible:	
Please indicate from which sector:	Public
1.1.1. Other (please specify):	Our organisation has legal structure "sui generis". It is a private organisation but with a responsibility of general public interest, as we are responsible for executing and managing the compulsory health insurance and the national health care system.
1.2 Please indicate the name of your organisation or centre:	Landsbond van Onafhankelijke Ziekenfondsen - Union Nationale des Mutualités Libres
1.3 Please indicate the country where your organisation/centre is located/has its headquarters or main representative office in Europe:	BE
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:	1
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:	christian.horemans@mloz.be
1.6 Please provide us with a contact person (incl jobtitle and daytime phone number):	Christian Horemans International affairs Manager + 32 (0)2 778 94 18
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:	Our organisation is involved in CoE /HSHC, as we are f. e. implicated in the concertation concerning the organisation of health care for chronic patients (chronic pain, deep brain stimulation, ...)
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)	Costs and economic evaluation Management and organisational aspects of highly specialized healthcare Assessment/evaluation/certification of clinical practice and healthcare providers Information system, coding
2.2.1. Space for further comments:	The health insurance funds also develop and co-sign agreements with care centres We participate in the negotiations on the objectifs, prices,necessary infrastructure (f.e. for hadrontherapy abroad)
2.3 Is highly specialised healthcare a priority in your organisation's strategies and work plans?	Somewhat
2.3.1 Space for further comments:	Improtant because: - its financial impact and question of cost efficiency - looking for ballance bewteen: CoE and HSHC are often exceptions vs Affordable care for everybody - necessity of more HTA
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:	Co-responsible for creation/monitoring of centres
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:	see previous answers

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:	- Study on Hadrontherapy: <a href="https://kce.fgov.be/publication/report/hadrontherapy">https://kce.fgov.be/publication/report/hadrontherapy</a> - Recommendations on Rare diseases: <a href="http://www.kbs-frb.be/publication.aspx?id=295101&amp;langtype=1033&amp;src=true">www.kbs-frb.be/publication.aspx?id=295101&amp;langtype=1033&amp;src=true</a>
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	5
3.1.2.3. Evaluated experiences of Member States	3
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	3
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:	- testing of new drugs/treatment for rare diseases => better if same centres do this - when treatment has to start within certain time limit (f.e. stroke unit) => faster in hospital other side border
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:	Apart from rare diseases: - burns => for capacity issues - stroke units in cross border areas - cancer treatment (f.e. hadrontherapy)

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

3.2.1. Organisation and management	4
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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	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:	- the key ambition should be: share expertise and give/get coaching/training - once a patient is back in home: the belgian specialist must be able to ask info to foreign provider , ERN as back office

### 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	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	4
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:	Need for evaluation by independant entity (no auto-proclamation) Need for objective criteria for selection (no political criteria) Hospitals need to be accredited.