

HEMOCHROMATOSIS CLINIC AT SANTO ANTÓNIO HOSPITAL, Portugal

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):	
1.2 Please indicate the name of your organisation or centre:	HEMOCHROMATOSIS CLINIC AT SANTO ANTÓNIO HOSPITAL
1.3 Please indicate the country where your organisation/centre is located/has its headquarters or main representative office in Europe:	PT
1.4 Please indicate the number of EU Member States and EEA countries (Norway, Iceland, Lichtenstein) and accession 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:	gporto@ibmc.up.pt
1.6 Please provide us with a contact person (incl jobtitle and daytime phone number):	Graça Porto (Head of the Hemochromatosis Clinic at Santo António Hospital). Mobile phone: 351 913643923

1.7 Please provide additional contact details if needed:

Also: Graça Porto Basic & Clinical Research on Iron Biology (Head)
Institute for Molecular and Cellular Biology Rua Campo Alegre,
823 4150-180, Porto Portugal

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:

Prepared an application for Reference Centre of Hemochromatosis & Iron Overload Disorders in the context of the Portuguese Plan for Rare Diseases but official applications are still not open.

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

2.2.1. Space for further comments:

Expertise in Diagnosis, treatment and research. Social aspects include the participation of a PhD student on social sciences in the activities of the Portuguese Hemochromatosis Association.

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:

This is the main mission of the Centre for Hemochromatosis

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:

Genetic Diagnosis. Imaging (Magnetic Resonance).

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:	Head of the drafting team to update "Guidelines on the Molecular Diagnosis of Hereditary Hemochromatosis" in the frame of EMQN (European Molecular Quality Network)
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)?	No
2.7.1 Space for further comments:	The guidelines are now in the draft form and will be discussed in the frame of a Best Practice Meeting before publication.
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:	Since there is still no official designation, the Centre was inscribed at Orphanet as a self-declared reference centre applying the EUCERD criteria
2.11. Which is your area of expertise as centre of reference? (please provide your answer in free text)	Hemochromatosis and other Rare Disorders of Iron Metabolism
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:	A network of Expertise Centers in Iron Overload Disorders is being planned with the support of the Federation of the Associations of Patients with Hemochromatosis (EFAPH). Still in development.
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:	

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	1
3.1.1.1. Complexity of the diagnosis and treatment	3
3.1.1.2. High cost of treatment and resources	3

3.1.1.3. Need of advanced/highly specialised medical equipment or infrastructures	3
3.1.2. Need of particular concentration of expertise and resources	1
3.1.2.1. Rare expertise/need of concentration of cases	1
3.1.2.2. Low prevalence/incidence/number of cases	3
3.1.2.3. Evaluated experiences of Member States	2
3.1.3. Based on high-quality, accessible and cost-effective healthcare	1
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:	Develop Research on the area of expertise
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:	Hereditary Hemochromatosis: a high number of subjects at risk but very low awareness; Other Rare Disorders of Iron Metabolism (overload or deficiency): needs highly specialised diagnosis

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

3.2.1. Organisation and management	1
3.2.2. Patients empowerment and centered care	1
3.2.3. Patient care, clinical tools and health technology assessment	1
3.2.4. Quality, patient safety and evaluation framework policies	1
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	1
3.2.8. Specific commitment of the management/direction of the centre/hospital to ensure a full and active participation in the ERN	3
3.2.9. Do you recommend any additional option that would effectively address the issue?	No
3.2.9.1. Space for further comments:	

3.3. Specific criteria regarding the areas of expertise

3.3.1. Competence, experience and good outcomes and care	1
3.3.2. Specific resources and organisation:	1
3.3.2.1. Human resources	2
3.3.2.2. Team/centre organisation	2

3.3.2.3. Structural conditions	3
3.3.2.4. Specific equipment	4
3.3.2.5. Presence and coordination with other required complementary units or services	1
3.3.3. Patient care pathways, protocols and clinical guidelines in the field of expertise	1
3.3.4. External coordination, care management and follow-up of patients	3
3.3.5. Research, training, health technology assessment in the field of expertise	1
3.3.6. Specific information systems	1
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:	link to Patients Associations