EuroBloodNet
European Reference Network in Rare Hematological Diseases

Criteria defined by the Network for Rare bleeding-coagulation disorders

The following information defines the specific criteria for our proposal for a European Reference Network (ERN) for Rare Hematological Diseases, EuroBloodNet. Each health care provider willing to be member of our ERN has to fulfil these criteria. These evidence based criteria intend to be realistic while ensuring a high level patient care.

The following information corresponds to the following points in the HCP application form:

1) Point 7_Table in Page 6 Diseases, conditions and highly specialized interventions: it includes not only diseases but also highly specialized interventions, treatments eg bone marrow transplantation

2) Point 11_Table in Page 9 10 of the 16 "Diseases, conditions and highly specialized interventions" defined in point 7 needs to be quantified

3) Point 12_Table in page 11 "Multidisciplinary team"Up to 16 Health care professionals have to be defined: position, training and number of patients/procedures by year (for assure expertise)

4) Point 13_Table in page 12 "Specialised equipment, infrastructure and IT" Up to 16 Specialised equipment, infrastructure and IT used by the HCP to support diagnosis, care and treatment

5) Point 21_Table in page 18 "Clinical outcome data" Up to 22 relevant clinical outcomes related to the Rare or complex disease, condition or highly specialized interventions defined

- Subthematic area of expertise:
  - Rare red blood cell disorders and allied defects
  - Bone marrow failures and rare haematopoietic disorders
  - Hemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis
  - X **Rare bleeding-coagulation disorders**
  - Myeloid malignancies
  - Lymphoid malignancies

1) Point 7_Table in Page 6 Diseases, conditions and highly specialized interventions: it includes not only diseases but also highly specialized interventions, treatments eg bone marrow transplantation Up to 16

Subthematic area of expertise	Rare or complex disease, condition or highly specialized interventions	ICD / Orphanet Code
Rare bleeding-coagulation disorders	Haemophilia A and B (including female carriers)	ICD 10 D66, D67 / ORPHA 98878, ORPHA 98879
Rare bleeding-coagulation disorders	The rarer congenital deficiencies of other coagulation factors (such as fibrinogen and factors II, V, VII, X, XI and XIII)	ICD 10 D68.1, D68.2 / ORPHA 248315
Rare bleeding-coagulation disorders	Von Willebrand disease	ICD 10 D68.0 ORPHA 903
Rare bleeding-coagulation disorders	Inherited platelet defects.	ICD 10 D69.1 / ORPHA 248326
Rare bleeding-coagulation disorders	Special care for patients with inhibitors, including surgery.	
Rare bleeding - coagulation disorders	Acute events management for Haemophilia A and B	

2) Point 11_Table in Page 9 10 of the 16 "Diseases, conditions and highly specialized interventions" defined in point 7 needs to be quantified

Specific diseases, conditions and highly specialized interventions	Measure	Evidence
Haemophilia A and B (including female carriers)	Number of patients per year	40
Haemophilia A and B (including female carriers)	Number of new patients per year	5

3) Point 12_Table in page 11 "Multidisciplinary team" "Up to 16 Health care professionals have to be defined: position, training and number of patients/procedures by year (for assure expertise)

Healthcare professional	Training and qualifications	Nº procedures/patients per year
Hematologist / medical staff	Expertise in carrying out routine and emergency treatment and follow-up	40

	clinical reviews of Haemophilia patients	
Nurses	Experience in co-ordinating much of the day to day treatment and supplies of coagulation factor concentrates	40
Laboratory specialists	Experience in providing a diagnostic and factor replacement monitoring service.	40
Physiotherapy and orthopaedics	Expertise in carrying out routine and emergency treatment and follow-up clinical reviews of Haemophilia patients	40
Orthopaedic Surgeon	Expertise in carrying out routine and emergency treatment and follow-up clinical reviews of Haemophilia patients	40
Dental care	Expertise in carrying out routine and emergency treatment and follow-up clinical reviews of Haemophilia patients	40
Paediatrics	Expertise in carrying out routine and emergency treatment and follow-up clinical reviews of Haemophilia patients	40
Hepatology, Infectious diseases	Expertise in carrying out routine and emergency treatment and follow-up clinical reviews of Haemophilia patients	20
Obstetrics and Gynaecology	Expertise in carrying out routine and emergency treatment and follow-up clinical reviews of women with pregnancies at risk of bleeding disorders	20

4) Point 13_Table in page 12 "Specialised equipment, infrastructure and IT" Up to 16 Specialised equipment, infrastructure and IT used by the HCP to support diagnosis, care and treatment

NOTE: ERN HCP for inherited bleeding disorders should provide a level of care that is at least as good as that provided by the European Haemophilia Comprehensive Care Centres (EHCCC) as defined by the EUHANET network.

Specific diseases, conditions and highly specialized interventions	Specific equipment, infrastructure and information technology (IT)
Special care for patients with inhibitors, including surgery.	Provides specialist care for patients with inhibitors, including surgery. Has access to orthopaedic and/or rheumatological service with provision of surgery.
Acute events management for Haemophilia A and B	Provides a 24 hour advisory service for patients, families, hospital doctors, general practitioners and affiliated EHTCs health care professionals. Provides a 24 hour laboratory service for clotting factor assays and inhibitors screens.

5) Point 21_Table in page 18 "Clinical outcome data" Up to 22 relevant clinical outcomes related to the Rare or complex disease, condition or highly specialized interventions defined

Rare or complex disease, condition or highly specialized interventions	Clinical outcome	Evidence (quantifier)
Rare bleeding-coagulation disorders	Documentation of the coagulation factor concentrate used by each patient per year	>90%