

## Summary ERN BoMS Statement on Affiliated Members (Nov 17)

Document outlines timeline, criteria and instructions about the identification, designation and affiliation procedure.

### **3 subtypes:**

- **Associated National Centres**
- **Coordination Hubs**
- Collaborative National Centers (not included in this guidelines, separate document)
- ➔ **Designated only by their MS**

**Purpose of designation of Affiliated Partners:** in order to achieve the widest possible geographical coverage, exchange of knowledge and best practice throughout Europe.

### **General principles for the affiliation process of Healthcare Providers to the ERNs**

- **Priority to identify and select affiliated partners for Member States with no full member in a given ERN**
- **Inclusiveness of the affiliation process**
- **Assurance of a fruitful relationship between the affiliated partners and ERNs: a “win-win” situation**
- **Development of bilateral cooperation agreements between affiliated partners and related ERNs**
- **Consensus to allow newly established ERNs a period of initial operational preparation prior to the first enrolment of affiliated partners**
- **Open time frame for the further enrolment of affiliated partners**

### **Definition and minimum criteria**

- the minimum criteria are designed as a conceptual framework and guideline only

### **Associated National Centers:**

- focus on the provision of healthcare
- is defined as a healthcare provider with at least some special expertise matching the global thematic domain of a given reference network that concentrates primarily on the provision of healthcare directly related to the activities and services of this specific network, including any type of diagnostic contribution supporting this provision of healthcare.

### **Associated National Centres can therefore comprise any of the following institutions:**

- Clinics and departments/clinical units providing direct outpatient and/or inpatient services to patients;
- Medical and genetic diagnostic laboratories;
- Pathological laboratories;
- Specific facilities for instrument-based diagnostics.

### **Criteria:**

- Similar but not equal to full members (BoMS recommends applicants to complete the applications forms for full members as exhaustively as possible)
- Details see document

- Should pave the way to full membership for clinics and departments/clinical units offering direct services to patients
- This does not include laboratories and mere facilities for instrument-based diagnostics

### **National Coordination Hubs**

National Coordination Hubs are an option for MS to link "with all types of Networks". Thus, National Coordination Hubs comprise any type of institution with the appropriate knowledge and the legal and organizational capacity to link the national healthcare system to a number or all European Reference Networks. National Coordination Hubs function as interfaces between the national healthcare system and those networks where a given Member State is neither represented by a full member nor by an Associated National Centre. National Coordination Hubs do not need any specific medical expertise or knowledge and their composition might range from:

- A major national healthcare provider offering the necessary organisational support (such as management, infrastructure and resources) to specialised units that can join different ERNs and that operate within its organisational structure;
- A network of healthcare providers coordinated at national level;
- A non-hospital-based, specifically assigned institution as contact and coordination point, linking ERNs with the national healthcare system, like, for instance, an administrative authority such as a national and/or regional ministry of health or other health authority, or a national or regional focal contact point such as those established by the Directive 2011/24/EU on the application of patients' rights in cross-border healthcare.

### **Criteria:**

- Details see document

### **Timeline**

- Once started (when network is running and working well/after preparation period), procedure to integrate affiliated partners should be possible at any time
- should take place at regular time intervals (in combination with acceptance of new full members)
- exact timing for first enrollment to be defined by BoMS and will be updated later

### **Procedure:**

- 1. Development of an affiliation strategy** (by ERNs and Member States) and identification of affiliated partners (by Member States)
- 2. Integration of affiliated partners** identified and designated on the national level into their respective ERNs

### **Termination of the affiliation:**

Possible and comparable procedure with full members

### **To do ERNs:**

- ➔ each ERN must develop a clear policy objective for the active engagement and participation of affiliated partners, underpinned by transparent rules and strategies that describe how affiliated partners can interact, participate and contribute to the specific ERN

### **Before Affiliation Process can start:**

- ➔ bilateral cooperation agreement between the two parties should be developed (work plan agreement), defining the rules of engagement, areas of collaboration, objectives, commitment and active involvement