

## **ERN Board of Member States**

### **Statement on the Timeline for the designation of Associated National Centres and Coordination Hubs (Affiliated Partners) by the Member States**

**FINAL**

**June 2018**

The ERN Board of Member States,

#### TAKING INTO ACCOUNT THAT

As indicated in the Board Statement of 10 October 2017<sup>1</sup>, "*the main aim of ERNs is to pool and disseminate expertise for the benefit of patients and Member States*". Therefore, it is of great importance to ensure a high level of inclusion for the ERNs and to broaden their geographical coverage, while respecting the fact that "*identification and selection of affiliated partners remains in the exclusive competence of the Member States taking into account their individual situation and planning*".

Currently, ERNs do not count among their members at least one healthcare provider from each Member State, which could thus refer patients from the Member State to the ERN: this may represent an obstacle to ERNs accessibility. Affiliated Partners (for the purposes of this document, Associated National Centres<sup>2</sup> and National Coordination Hubs<sup>3</sup>) may effectively address this accessibility problem and allow for the establishment of "*a special link*"<sup>4</sup> between the Member States and the Networks. National Coordination Hubs may notably represent a useful solution for those Member States that need to establish such links with many ERNs at once.

#### INVITES

the Member States to designate **in the next months and possibly at the latest by December 2018:**

- **Associated National Centres** for those ERNs where they do not have a healthcare provider established in their territory as member;

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<sup>1</sup> Statement adopted by the Board of Member States on the definition and minimum recommended criteria for Associated National Centres and Coordination Hubs designated by Member States and their link to European Reference Networks, 10 October 2017, accessible at [https://ec.europa.eu/health/sites/health/files/ern/docs/boms\\_affiliated\\_partners\\_en.pdf](https://ec.europa.eu/health/sites/health/files/ern/docs/boms_affiliated_partners_en.pdf).

<sup>2</sup> As defined in the Board Statement of 10 October 2017, an Associated National Centres is "*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".

<sup>3</sup> As indicated in the Board Statement of 10 October 2017, 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*".

<sup>4</sup> See recital 14 of Commission Delegated Decision 2014/286/EU of 10 March 2014 setting out criteria and conditions that European Reference Networks and healthcare providers wishing to join a European Reference Network must fulfil (OJ L 147, 17.5.2014, p. 71).

and / or

- a **National Coordination Hub** which will establish a link with all Networks in which the Member State does not have a healthcare provider as member or as Associated National Centre and with which the Member State wishes to establish such link.

In line with the Board Statement of 20 May 2016<sup>5</sup>, each Member States shall address to the European Commission and to the relevant Coordinators as well as to the Board, for information, the **official national designation letters** of their Affiliated Partners.

As indicated in the Board Statement of 10 October 2017, the affiliation process "*should be executed in an as flexible as possible manner with regard to the exact timing of affiliation for each Member State in order to account for any kind of country-specific factors and conditions, in particular for the time required to identify and designate the different subtypes of affiliated partners in each Member State*" (Associated National Centre and National Coordination Hubs).

## REQUESTS

the ERNs, in line with the Board Statement of 10 October 2017, to develop **by end of February 2019**:

- "*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*";
- "*a **clear strategy** which includes detailed pathways regarding the integration and participation of affiliated partners in the networks*". These strategies will need to be presented to, discussed with and approved by the Board of Member States prior to implementation" in the first Board meeting of **2019**.

As stated by the Board on 10 October 2017, "*in the event of a disagreement on the integration of a designated Affiliated Partner into an ERN between the Member State and the Coordinator of the given Network, the Board shall be contacted by both parties*", **possibly at the latest two weeks before the first Board meeting of 2019**, "*and provided with all necessary information on the nationally designated candidate in question, as well as the reasons identified by the ERN why it might not be advisable to include this specific candidate into the Network. Based on the information and evidence provided, the Board will take the final decision on the inclusion or non-inclusion of this candidate into the network*".

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<sup>5</sup> Statement adopted by the Board of Member States on Affiliated Partners, 20 May 2016, accessible at: [https://ec.europa.eu/health/sites/health/files/ern/docs/boms\\_strategicview\\_affiliatedpartners\\_en.pdf](https://ec.europa.eu/health/sites/health/files/ern/docs/boms_strategicview_affiliatedpartners_en.pdf)

Once the integration strategies are approved by the Board and **at the latest after the first Board meeting of 2019**, the ERNs will start the inclusion process of the designated Affiliated Partners, in line with the inclusion strategies approved by the Board.

As stated by the Board on 10 October 2017, "*the inclusion of further new affiliated partners (after the enrolment of this first group) should be planned and operated in tandem with the inclusion of new full members*".