

## **Statement of the ERN Board of Member States on Integration of the European Reference Networks to the healthcare systems of Member States**

(adopted Statement on 25 June 2019)

European Reference Networks (ERNs) were created under the 2011 Directive on Patient Rights' in Cross-Border Healthcare. They are based on the voluntary cooperation of Member States that contribute to the ERNs' activities in accordance with their national legislation. ERNs are operational since March 2017. To ensure a proper and sustainable functioning of the ERNs and to reap all benefits for patients suffering from rare and low prevalence complex diseases across the EU, the ERNs need to be linked in a clear and stable way to the healthcare systems of the Member States. These are issues of key importance and demand tangible actions.

This Statement aims to give incentives to Member States to further enhance the integration process based on the input provided by the Working Group on Integration<sup>1</sup>.

Member States are encouraged to facilitate the integration of ERNs to their healthcare systems by:

- (a) assessing and if needed adapting or updating the national policy and/or legal framework to ensure a smooth integration of the ERNs into the national healthcare systems of the Member States, including e.g. the national rare diseases plans or strategies and national cancer control plans;
- (b) creating appropriate (clear and well-defined) patients' pathways in order to improve the care and management of patients with complex or rare diseases. The objective is to build on existing pathways, where possible, and link them to the ERNs where they have not hitherto been foreseen. Member States that have no defined pathways for complex or rare disease patients are encouraged to build these along current best practices and in accordance with the disease-specific pathways being developed by the ERNs;
- (c) developing clear systems for referral to ERNs to be used by the healthcare providers. Referral procedures shall be transparent, seamless and effective. The referral is relatively easier when a Member State has one or more healthcare provider that are Members or Affiliated Partners<sup>2</sup> of an ERN. It is also important that Member States identify the link between any healthcare providers that provide care for patients with rare or complex diseases and healthcare providers that are the Members or Affiliated Partners of an ERN. Rules on cooperation at national level are needed in case of multiple Members or Affiliated Partners;
- (d) developing a clear strategy for communicating and disseminating information about ERNs towards all levels of healthcare providers in their territory and by facilitating access for healthcare professionals to the knowledge generated by the ERNs (clinical guidelines, training materials etc.);
- (e) reflecting on the means to best support (administrative, financial, organisational, informational, etc.) Coordinators, ERN Members and Affiliated Partners to ensure patients will have access to the best available expertise. Strengthening the coordination role of national authorities shall be pursued.

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<sup>1</sup> Working Group set up by the ERN Board of Member States in October 2017.

<sup>2</sup> For definitions of Affiliated Partners see the Board Statement of 10 October 2017:  
[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)

The underlying objective of the ERN Board of Member States for issuing these recommendations is to facilitate access to timely diagnosis and delivery of high quality, accessible and cost-effective healthcare for all patients with rare or complex diseases that require highly specialised treatment and a particular concentration of expertise and resources through the application of the opportunities made available by the ERNs and in accordance with each Member State's national legislation.

Annexed to this Statement is a list of prioritised potential actions that were considered by the Members of the Working Group to be relevant for the planning and implementation of sustainable integration processes.