

## **The ERN Board of Member States decided to pursue the consolidation of the ERNs in its meeting held in Brussels on 26<sup>th</sup> March 2019**

*A Statement of the Board of Member States will be prepared concerning the integration of the ERNs into the national healthcare systems, decided the representatives of Member States. They also discussed relevant aspects related to the strengthening and enlargement of the European Reference Networks and the relationship with industry. The Swedish board member was elected new co-chair for the upcoming two years.*

In order to overcome some geographical gaps and to allow patients from countries lacking membership in certain networks to access the available expertise, Member States have the possibility to designate "Affiliated partners". The Affiliated partners can either be "Associated National Centres" with some degree of clinical expertise or "National Coordination Hubs" which can establish links with several Networks at the same time. Expected benefits of this process would range from strengthening the capacity of affiliated partners by exchanging information with ERN members, to establishing systems for referring patients for virtual consultations within the respective fields of competence. Member States have the possibility to designate Affiliated partners until the launch of the new call for membership, and some Member States already did it. A balance nevertheless needs to be found between the criteria of accessibility and the necessity of ensuring manageability of the networks, and this has been strongly stressed by the Chair of the ERN Coordinators Group. The new call to allow new healthcare providers to become full members of the current networks will be published after the adoption of the amended Implementing Decision, which clarifies several aspects related to the procedure of the networks enlargement as well as data protection aspects deriving from the new European regulation in the field.

The Working group on Ethical and Legal issues proposed an amended version of the 2016 Board Statement on ERNs and Industry at the Coordinators' request, trying to further clarify the areas of activities and conditions for possible collaboration between the ERNs and the industry. Given the divergent positions of Member States in respect to this, further reflection and drafting work is needed and has been requested to the Working group.

The integration of the ERNs into the national health system is one of the current priorities, and the Working group on Integration was mandated to prepare a Board statement with recommendations to the Member States on ways to support the ERNs in their own country and integrate them within their national health system. The French national approach to the ERN integration was presented in details as a good practice. The Commission then presented the Structural Reform Support Service that allows Member States to get a tailored-made support to implement structural reforms as part of their efforts



to support job creation and sustainable growth, including the health sector. Examples comprised the possibility to create or further develop national pathways and referral systems in the field of rare diseases, and for more information is available in an information brochure on [SRSS](#)<sup>1</sup>.

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<sup>1</sup> [https://ec.europa.eu/info/departments/structural-reform-support-service\\_en](https://ec.europa.eu/info/departments/structural-reform-support-service_en)