

The ERN Coordinators are getting ready for the challenges of enlarging the European Reference Networks

The ERN coordinators met in Brussels on the 25th March 2019 and addressed several key aspects of the networks' development. The main discussions focussed on the on-going designation by Member States of Affiliated partners, both from a procedural point of view and concerning the practical implication for the ERNs. Several topics were then addressed which are related to the growing operational activities and development of the networks: the use of the IT platforms (CPMS and ECP), the communication activities, the relations with industry, the monitoring, the research activities, education and training, and the support from different financial instruments.

In order to strengthen access to the networks in the countries which are under-represented in the ERNs, Member States can designate "**Affiliated partners**", which act as "entrance doors" for patients and in some cases can also upgrade their own expertise capacities through their collaboration with the networks. With more than 130 designations already received from a few Member States and the process still ongoing, the Coordinators raised their concerns regarding the practical implications of this enlargement, which will soon be followed by the inclusion of new members after the publication of a new call by the Commission. Aspects related to financial implications, manageability of the networks and sustainability were also underlined. The Chair of the Coordinators was asked to flag these aspects to the Member States at the meeting of the Board of Member States scheduled the following day. The Commission informed the group about the state of play of the adoption of the Implementing decision, which is required for the publication of the new call to incorporate new members.

The state of play of several ongoing ERN activities was shared among the participants. The **Working Group on Ethical and Legal Issues** informed the Coordinators about the latest updates on the Board statement on ERNs and industry, which was expected to be discussed the day after the meeting by the Board of Member States. It also reported on the workshop organised with industry and patient organisations in January to explore possibilities of collaboration.

The **Working Group on Research** provided an update of its work to define the definition and boundaries of the so-called "ERN research", and informed about possible synergies with other initiatives, in particular with the European Joint Programme (EJP) Co-Fund on Rare Diseases launched in January 2019.

The **Working Group on Knowledge generation** referred to its different tasks concerning the ongoing work with the contractor of the Taxonomy project, the choice of priority areas related to the Clinical Practice Guidelines (CPG) and Clinical Decision Support Tools (CDST), the basis of a future ERN strategy on training and education.



The **Working Group on monitoring** reported on the current data processing by the ERNs based on the core set of 18 indicators that was approved by the ERN Board of Member States in September 2018 and the IT platform developed by the Commission.

Statistics on the use of the IT tool developed for the ERNS (CPMS and ECP) and further information on the use of the systems were then illustrated. The Coordinators were also invited to share their best practices and their concerns or requests for improvement with the Commission, particularly at the occasion of the ITAG meeting scheduled on the 2nd of April and exceptionally open to all ERNs.

The Coordinators were also informed of the latest communication activities deployed and the ones planned for 2019. Amongst others the Commission raised attention to the strict data protection rules that need to be followed when communicating about patients.

Finally, several new financial instruments to support the work of the ERNs were announced.