

22 June 2020

## **Covid19 crisis management, enlargement and sustainability of the ERNs at the heart of discussions by the ERNs Coordinators and the ERN Board of Member States**

*In two respective meetings organized remotely on 17 and 18 June, the Coordinators and the Board of Member States shared information on initiatives put in place during the outbreak to support patients affected by rare diseases and to draw lessons for a potential second wave. They discussed the questions related to the on-going enlargement process of the ERNs through the recent inclusion of Affiliated partners and the forthcoming new members in 2021, while addressing the implications in terms of financing, use of the virtual consultation platform CPMS, integration of the ERNs within national systems. Besides the consolidation of the current system, the discussion kick-started a brainstorming concerning a more long term vision of the whole ERN ecosystem by horizon 2030, that will continue in other meetings.*

Both meetings' participants discussed on how the COVID19 crises highlighted the vulnerability of the health systems across Europe. Nonetheless, the ERNs showed how they have been able to cope with the current crisis, and how such adaptation strategy could even guide some future reforms of health systems, for instance through the strengthening of telemedicine's services. Most ERNs have offered specific services to patients and health professionals on how to support rare diseases patients in a crisis sanitarian context, ensuring continuity of care and adequate treatments. Some national authorities also referred to their own initiatives to coordinate and support the action of health care in the field of rare diseases during the pandemic. The Commission organized 14 webinars through the [COVID-19 Clinical Management Support System](#) to support the clinicians across Europe working with rare diseases patients.

As far as the enlargement is concerned, the Networks include now around 250 designated Affiliated partners, whose role is to ease access to the ERNs expertise especially from countries or regions where the expertise is scarce. They come from 18 different Member States and all ERNs are welcoming one or more Affiliated partners. 81% of the Affiliated partners have finalized their bilateral agreement with the ERN they belong to, and all ERNs are working on defining an "integration strategy" to fully involve the newcomers. As far as the 2019 call for new membership is concerned, the current on-going assessment of the 841 applications has been suspended until the 1st September, due to the Covid19 outbreak. In the dynamic of enlargement, the Commission informed the participants that it explores the set up of 3 new ERNs in the upcoming years in order to cover some existing gaps, namely



rare and low incidence or new threatening infectious diseases, rare gynaecologic-obstetric diseases and conditions and rare and complex mental health diseases or conditions.

Both ERNs Coordinators and ERN Board of Member States acknowledged the necessity to deepen the integration of the ERNs within the national health systems. The exchange of knowledge among Member States can be of support to inspire national initiative, through for instance dedicated webinars, the collection of information, the organisation of national workshops or the setting up of indicators for benchmarking. The setting-up of referral national pathways for patients and of national reference networks would help link the ERNs structure and the European level.

To ensure sustainability of the ERN system, the Clinical Patient Management System (CPMS) used by healthcare professionals to discuss patients' cases with colleagues in Europe in a remote way could be further simplified, linked to national telemedicine systems or made interoperable with patients' data and health records. The monitoring system is also progressing and will soon be able to deliver outcomes to give an overview of the activities conducted by the ERNs and the patients benefiting from their action.

Participants were informed on the Commission Proposal for the EU4Health Programme. It has been underlined that ERNs are examples of areas where integrated work among Member States has shown to have strong added value and great potential to increase the efficiency of health systems and thus health in general.

The participants in both meetings had then an exchange on the vision of the ERNs systems by 2030, which is a first step for a brainstorming exercise which will follow up in the coming months.