



BOARD OF MEMBER STATES ON ERNS

18 JUNE 2020, 9:00-12:30

VIDEO-CONFERENCING VIA WEBEX

MINUTES

CO-CHAIRS: ANDRZEJ RYS (CHAIR) & LENNART CHRISTIANSSON (CO-CHAIR)

1. Welcome, approval of the agenda and minutes of past meeting

The Co-Chair, DG SANTE B Director welcomed all participants and opened the meeting. The minutes of last meeting were then approved and have been made publically available on SANTE's website¹. The Board considered the agenda prepared by the Secretariat and approved it as proposed.

The Commission thanked the Board for their support expressed in the Board Statement on COVID-19 Communication Support System adopted on 31 March 2020.

2.

i. Introduction, general scene setter

The Commission in its general introduction underlined that the ERNs model represents an extraordinary EU collaborative effort. Also, the COVID-19 pandemic has shown a clear value of the ERNs model as a unique way to connect expertise, generate and disseminate knowledge. Nonetheless, ERNs are still in their initial deployment phase and are facing the logical challenges of being operative and functional. They will be able to bring benefits to patients once we will manage to consolidate what has been achieved so far, with a vision towards better and shared sustainability among all actors.

At present, not everyone can access ERNs, funding of the system relies mainly on EU funding. Healthcare professionals often do not have access to the appropriate expertise related to rare disease management as knowledge is still scattered. Not all Networks are clearly linked to national health systems and the increasing number of members can make managing the Networks more challenging in the future. Moreover, there is a lot of potential to be exploited in the fields of research and innovation.

Now with the proposed new EU4Health programme new opportunities are emerging on the horizon. Among the many activities, with this Programme the EU will intend to expand initiatives like the European Reference Networks system which is seen as a successful cross-border cooperation.

¹ https://ec.europa.eu/health/ern/events_en#anchor0

On ERNs the Commission Proposal for the EU4Health underlines that *“European Reference Networks 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.”*

New opportunities may arise, however challenges related to budget, to coverage (over- and underrepresentation), or to integration need to be addressed one-by-one in cooperation among the Commission, Member States, the ERN Coordinators and by taking into account the views of patient organisations.

The lessons learned through the ERNs implementation will help to identify other health related areas where such a network approach could be applied. This new way of cooperation, which overcomes the traditional barriers in the area of EU healthcare cooperation, can represent a unique opportunity through EU solidarity to help reduce inequalities in the access to healthcare.

ii. ERNs and COVID-19

The Commission presented some of the conclusions drawn during the COVID-19 crisis. The pandemic showed the vulnerability of the healthcare systems in all Member States. ERNs system has shown its capacity to be flexible and reactive to such a major crisis, by bringing clinicians together at European level to exchange clinical knowledge.

The European Commission created the “COVID-19 Clinical Management Support System” to support the clinicians and put them in contact with one another for the sharing of knowledge. Clinicians across Europe were given access to supporting tools like the CPMS and web conferences. Interested clinicians could decide to register themselves to participate and receive assistance. The project was not addressing any strategic epidemiological or surveillance issue but was a mean to support the clinicians with their clinical work. The communication system was based on the knowledge of the ERNs and on the experience of the ERNs system.

Further, the Commission organised a series of webinars focusing on COVID-19 and its possible impact on rare diseases patients. Between April and June 2020, 14 webinars were delivered and published in the webpage and were followed by more than 2000 participants. The Commission received very good feedback on the webinars with regards to their quality and usefulness. All the presentations and recordings are publicly available in the EUROPA webpage.

Coordinator of ERN EPICARE shared his experience on the COVID-19 crisis and the lessons they have learned. It was confirmed that the ERNs, although still very young, were able to fill deficits in information, awareness and care at both local and EU levels. This included support in diffusing knowledge to doctors, smaller hospitals and patients’ organisations. The process was possible because the ERNs had developed prior to the crisis a degree of mutual trust between specialists’ teams.

The crisis highlighted the need to develop telemedicine tools further across Europe. As regards how to mitigate the impact of similar crisis in the future, the need to reinforce the national reference networks was underlined.

Some Member States also briefly updated the Board on what they have done at national level to spread and share knowledge on COVID-19.

iii. Enlargement of the Networks (on-going call and affiliated partners)

The Board adopted with minor changes the 24 integration strategy for affiliated partners prepared by the ERNs.

An update was given on the advancement of the bilateral cooperation agreements between the ERNs and the affiliated partners. As regards the bilateral agreements for National Coordination Hubs, a lot of agreements still needed to be finalised. Thanks to an update of the Commission's Service Directory, it was now possible to grant access to the CPMS to the Hubs individually once the agreements were signed.

By now overall 81% of the agreements have been completed. The Board also fixed a deadline (31 August 2020) to complete the process (establishing bilateral cooperation agreements).

On the call for new members the Board was informed on the timeline to be followed after the suspension of the assessment process for new applicants due to the Covid-19 crises. The call was closed on 30 November 2019 and an eligibility check was performed between the 15 of December 2019 and the 31 of January 2020. Afterwards the applications were sent to the concerned ERNs for review by the Boards of the Networks. At present, due to the COVID-19 crisis, the review process was suspended and would start again on the 1 September 2020.

In total 841 applications were received, 623 of which were eligible. 92 applications already received positive reviews. 45 applications were resent to the healthcare providers with negative reviews. Details were given on the role of the Board in the assessment process.

iv. CMPS update and discussion on the sustainability of the system

The Commission presented the recent adaptations of the system in response to the COVID-19 crises to facilitate the transfer of clinical data. It was decided to use the CPMS to facilitate clinical data transfers between hospitals. The CPMS was adapted in March and April to make room for the function and it was deployed mid-May. There were no impacts on the normal use of the CPMS, but it put all other developments on hold due to the urgency of the request.

The current suboptimal use of CPMS, with less than one panel per healthcare provider per year was put forward by the Commission together with the question if the CPMS usage should be included in the criteria for termination of membership. Some Member States agreed to that proposal, others were against it. Some other Member States inquired further on the obstacles which prevent the ERNs to use the system. Further, questions were raised on the interoperability of the CPMS with the European Health Record and with patients' data on rare diseases. To support integration, some Member States argued in favour of using it at national level and/or interoperability should be ensured with other telemedicine systems at national level.

v. Integration of ERNs into the health systems of the Member States

The Commission underlined that it was essential to have a structured overview on how integration was evolving in each Member State. Further, there is also a need to better identify what is concretely needed in terms of integration, what are concrete objectives that need to be achieved and how the Commission can support Member States in their integration process.

Several Member States confirmed the importance of continuing working on integration at nation level. They expressed their interest in exchanging knowledge on how integration is implemented, what actions/initiatives are done at national level. One Member State underlined that integration cannot be limited to "ERN integration" as it might end up in an isolated type of decision, but setting up the system of care for rare disease patients is a major and much more complex issue as it involves all levels of care.

The Chair of the Integration Working Group referred to a collection of “references” in a 100 pages document, and to the necessity to organise national workshops on integration. Other countries reported on their ongoing reforms with the introduction of referral systems and their link with the ERNs, for example. The Commission proposed the option of promoting trainings and peer-to-peer coaching between Member States, from the more advanced countries to the ones that wish to learn. The inclusion of an indicator(s) on integration into the monitoring was also projected by the Commission. The importance of setting-up national networks as one of the essential pre-conditions for efficient and sustainable ERNs was emphasised by several Member States.

vi. Monitoring

The Commission presented the summary of the work of the Monitoring Working Group and the outcomes of the data collection exercise for 2019. The core set of 18 key performance, structure and outcomes indicators represents one of the four strands of the future ERN Continuous Monitoring and Quality Improvement System.

Regarding the 2019 data collection exercise it was emphasised that even though the data collection has improved there are still some issues related with double counting or inconsistency of the data. The total patients’ population for the ERNs was estimated at 1,5 million patients. The number did not represent the number of patients being currently treated but the total population recorded in the system. Around 85% of healthcare providers have participated to the 2019 data collection. Certain indicators had been identified as problematic such as the indicator regarding the number of educational activities and webinars and the indicator on research activities.

Administrative and IT support of the Hospitals to ensure adequate and valid data collection for some indicators is of major importance. The performance of the ERNs measured through the monitoring system needs to be made public in the upcoming weeks as it would represent a key element for the decision process and to support to the ERNs. The Working Group on monitoring will address the establishment of a new indicator (most probably qualitative) to monitor the ERNs integration at national level. MS were invited to join the WG for this new task.

3. Communication

The Commission updated the ERN BoMS on ERNs communication activities.

In January 2020, an ERN interactive map was published on the EUROPA Website. The map allows patients to identify where to find full members and affiliated partners part of each Network.

In April 2020, the Commission published the third Newsletter. Add-on sections on the COVID-19 were included.

A new webpage was created on the EUROPA website where people can see what the Commission and the ERNs did in relation to the COVID-19 crisis.

In July 2020 the dubbed and subtitled versions of the ERN animation clip addressed to the patients will be released.

4. Vision for ERNs

The Commission presented a vision matrix prepared to stimulate a brainstorming on how the ERNs should look like in 10 years' time. One Member State called to make this a multi-stakeholder brainstorming, and that other contributions should be taken into account like the project called "Rare2030". Due to lack of time, the Commission proposed to set up a follow-up webinar end June/early July to allow a longer brainstorming.

5. AOB

The Chair of the LES Working Group briefly informed the Board on the ongoing written procedure on the finalised 'Managing Conflicts of Interests' and 'Disclosure Form' documents.

The Board was informed on the next tentative meeting date (25 November 2020).

END OF THE MEETING