Board of Member States for the
European Reference Networks
on rare diseases

27th April 2022

Dear Sir, / Dear Madam,

The European Reference Networks (ERNs) were established in 2017 in accordance with Article 12 of Directive 2011/24/EU of the European Parliament and of the Council[1] in the field of rare and complex diseases. Currently there are 24 virtual networks involving healthcare providers across the Union specialised in various areas of medicine. The governance body of the ERNs system is the Board of the Member States for ERNs (BoMS), which is composed of national authorities nominated by each Member State.

As recognised by the **BoMS in its statement from 2019**[2], to **ensure a proper and sustainable functioning of the ERNs** and to reap all benefits for patients suffering from rare and 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**.

A dedicated ERN Working group on ERN integration into national health systems was established in 2018 to steer the process of ERN integration and propose solutions to the BoMS and Members States.

To address these concerns and help the Member States achieve these objectives, the Commission included in the Annual EU4Health Work Programme 2022[3], adopted on 14 January 2022, the following **Joint Action:**

> ***EU4H-2022-JA-05: Direct grants to Member States' authorities: support ERNs integration to the national healthcare systems of Member States (AWP Ref: HS-g-22-16.02) – EUR 11 200 000 EU co-funding.***

On **16 March 2022, the Commission sent a formal letter to the Member States** Permanent Representations to the EU (Ref. Ares(2022)1885690) **inviting them to nominate, by 1**

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[1] Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare (OJ L 88, 4.4.2011, p. 45).

[2] https://ec.europa.eu/health/system/files/2019-07/integration_healthcaresystems_en_0.pdf

[3] C(2022) 317 final and its Annex: https://ec.europa.eu/assets/sante/health/funding/wp2022_en.pdf

September 2022, one competent authority to participate on behalf of their country on **this Joint Action** (and other Joint Actions included in the 2022 Work Programme). The nominated competent authority may involve other participants such as affiliated entities and subcontractors in the grant under its responsibility.

The BoMS would like to stress the importance of the Member States' engagement in this Joint Action for the long-term sustainability of the ERN system and for bringing concrete benefits to rare diseases patients and health professionals across the EU Member States. It is of outmost importance that competent authorities from as many Member States as possible are nominated for the participation in this Joint Action within the set deadline.

The expected results of this Joint Action are exchange of best practice and concrete proposals, guidelines, models, and recommendations for better integration of ERNs into national healthcare systems, including well-defined patient pathways, referral procedures, development of national networks on rare diseases, and **guidelines for development of national teleconsultation tools** interoperable with the ERN IT tool ("CPMS").

For each of the above-mentioned tools developed by the Joint Action, a mechanism for monitoring their progress and implementation should be established.

A multistakeholder composition is a prerequisite for this Joint Action to achieve the expected results, including not only respective health authorities, but also ERN coordinators or ERN members, hospital managers, patient representatives, and experts in the field. These stakeholders may be directly nominated as competent authorities or participate as affiliated entities or subcontractors. Furthermore, integration of the dedicated ERN Working group would provide a necessary bridge between the BoMS and the Joint Action and ensure the long-term sustainability of the Joint Action results.

The BoMS, therefore, strongly encourages Member States to actively follow up on the above-mentioned Commission's invitation letter of 16 March 2022 and to **ensure participation of their competent authorities in the Joint Action on the ERN integration into national healthcare systems** for the benefits of the rare and complex diseases community in the EU. Furthermore, the BoMS strongly recommends involving the respective national stakeholders in the Joint Action.

Yours faithfully,

Board of Member States for the
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