

## Background document

**The European Reference Networks (ERNs)** were established in 2017 in accordance with Article 12 of Directive 2011/24/EU.<sup>1</sup> Currently, there are **24 virtual networks** involving 1613 individual healthcare units and 380 hospitals across the Union, all **focussing on rare and complex diseases**. The governance body of the ERNs system is the Board of the Member States for ERNs (BoMS), whose members are nominated by the Health Competent Authorities of the EU Member States and Norway.

In 2019, the BoMS performed a first internal analysis about the interaction between ERNs and the national healthcare systems and highlighted in the related statement that **'the ERNs need to be linked in a clear and stable way to the healthcare systems of the Member States 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'**. Moreover, an evaluation was conducted in 2021 on the implementation of the Cross Border Healthcare Directive, and one point for improvement was 'to set out, in consultation with the Member States, ways forward to address the challenges faced by the European Reference Networks (including **integration** of the European Reference Networks into **national healthcare systems**, and patients' registries)'.<sup>2</sup>



To address these concerns and help the Member States achieve these objectives, the Commission launched under the Annual **EU4Health Work Programme 2022** a **Joint Action** for a 3-year duration from 2024-2027 to **support ERNs integration into the national healthcare systems of Member States**, with a final co-funding budget of almost EUR 19.000.000,00.



[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. 45–65.

[2] REPORT FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT AND THE COUNCIL on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare. COM/2022/210 final.



## Main areas

**Raising awareness about ERNs activity:** elaboration of targeted information material on ERNs and design of comprehensive information campaigns to disseminate this information to **two target groups:** (1) **patients and their relatives** and (2) **medical personnel**, in particular from the **primary care level**.

**WP2. Lead institution:** Foundation for Biomedical Research of La Paz University Hospital (FIBHULP), Spain.

Elaboration of proposals for **national governance models for rare diseases** and quality assurance systems adapted to the different types of national healthcare systems in Europe.

**WP5. Co-lead institutions:** Rizzoli Orthopedic Institute (IOR) and Pisan University Hospital (AOUP), Italy; and Medical University of Vienna (MUW), Austria.

Elaboration of a compendium of **model care pathways for rare diseases** or groups of rare diseases and of recommendations for the organisation of national care pathways, referral systems to ERNs and incorporation of CPMS advice for rare and complex diseases.

**WP6. Co-lead institutions:** Vilnius University Hospital Santaros Klinikos (VULSK), Lithuania; Health Service Executive (HSE), Ireland; and Medical University of Vienna (MUW), Austria.

Elaboration of **models** and **recommendations** for (a) **National Reference Networks**, or equivalent strategies for rare and complex diseases, and (b) **National Undiagnosed Disease Programs** or equivalent strategies, both times connected with their integration with ERNs.

**WP7. Co-lead institutions:** University Hospital Tübingen (UKT), Germany; and Medical University of Vienna (MUW), Austria.

Proposal and development of implementable solutions for **data sharing in the field of rare diseases** overcoming organisational, technical, and legal barriers, in particular supporting the integration of national health systems and ERN data management.

**WP8. Co-lead institutions:** Ministry of Labour, Health, Solidarity, and Families (DGOS), France; and Leiden University Medical Centre (LUMC), The Netherlands.

**Support of ERN healthcare providers and ERN centres:** Analysis of good practices and mechanisms to provide support to ERN-hosting healthcare providers at national level as well as to individual ERN centres at the hospital level and development of corresponding recommendations.

**WP9. Lead institution:** General University Hospital in Prague (GUH), Czech Republic.

## Expected key results and their potential impact

Identifying, promoting and upscaling best practices for the integration of the ERNs into the national healthcare systems and ensuring their sustainability



Achieving economies of scale for providing better services in a more efficient way



Facilitating evidence-based decision making regarding the organisation of healthcare for people with rare and complex conditions



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