



Next steps to enhance the system of ERNs

European Commission

Health Monitoring and Cooperation, Health Networks – DG SANTE

Enhance the system of European Reference Network and their evaluation

- **Improvement of the evaluation process (Working group)**
- **Consolidate the ERN network and integrate them into the national healthcare systems (Joint Action JARDIN)**
- **Work on data management (CPMS 2.0, ERN registries, EHDS)**

European Reference Networks - Evaluations

- **24** European Reference Networks and **836** members completed their first evaluation.
- The evaluation concluded that **the ERN ecosystem is functioning well:** delivering on highly specialist work for rare disease patients such as consultations for diagnosis and therapies, the production of clinical guidelines and specialised trainings, registration of patients
 - 100% of the ERNs obtained satisfactory results
 - 88% of their healthcare providers obtained satisfactory results
 - 4% of their healthcare providers saw their membership terminated
 - 72 Clinical centres will be re-evaluated after implementing their improvement plans

WG on the improvement of ERN evaluation

- Established in February 2024 to improve the evaluation methodology starting from the next round of the evaluation process.
- Objective: Simplification and better alignment of measurable elements to ERN legislation and monitoring process.
- WG report will be used to redraft the evaluation manual and the toolbox.

Joint Action JARDIN



- Participation: 27 MS, NO and UA;
- EU-funding: EUR almost 15 million, + the 20% national co-funding (so EUR 18 653 330 in total);
- Duration: 2024- 2026 (3 years)

<https://jardin-ern.eu/>



Joint Action JARDIN



- **Better integrate ERNs into national health systems of EU MS and Norway;**
- **Sustainability of ERN ecosystem beyond duration of JARDIN**
- **Propose national governance structure to improve accessibility of ERNs to RD patients**



Joint Action JARDIN

- **WP 1: Coordination**
- **WP 2: Dissemination**
- **WP 3: Evaluation**
- **WP 4: Sustainability of outcomes of JARDIN**
- **WP 5: National governance and quality assurance models**
- **WP 6: National care pathways and ERN referral systems**
- **WP 7: National reference networks and undiagnosed disease programmes**
- **WP 8: Data management**
- **WP 9: National support options for ERN-HCP**

Data management

- **Migration to CPMS 2.0**
- **Work on ERN registries**
- **The European Health Data Space (EHDS)**

Thank you

https://health.ec.europa.eu/rare-diseases-and-european-reference-networks_en



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