

Joint Action on integration of ERNs into national health systems

European Reference Networks



https://ec.europa.eu/health/ern_en



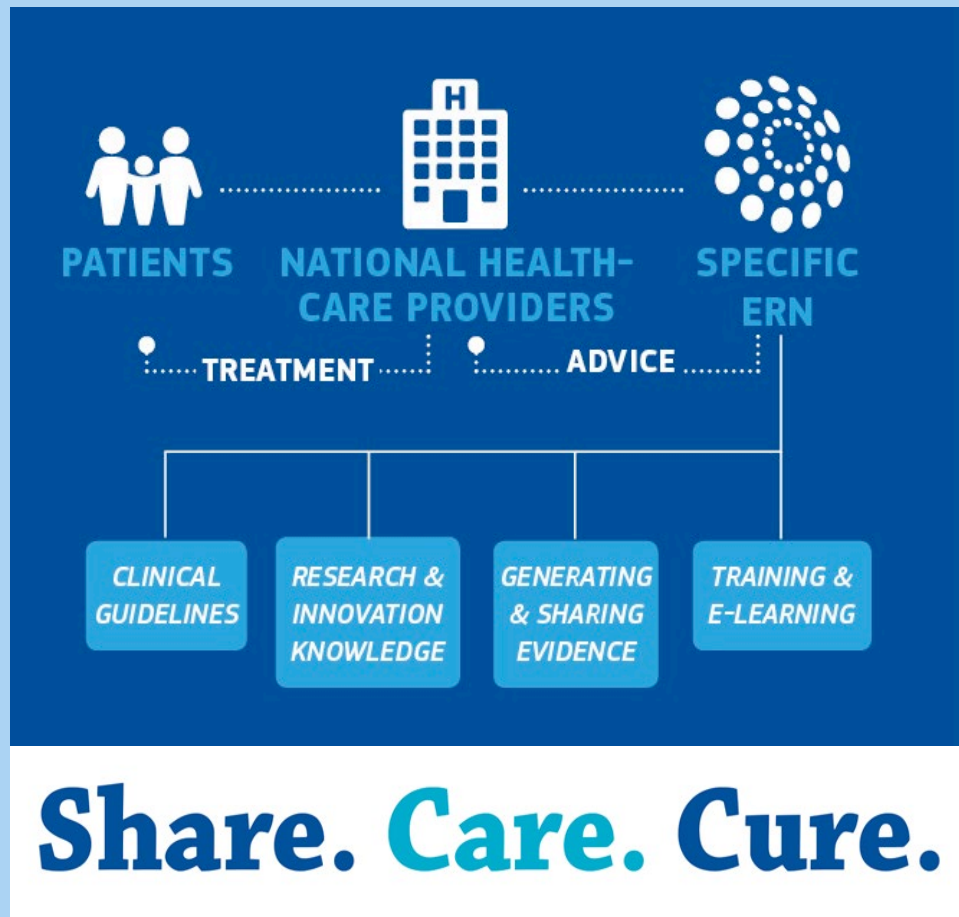
24 European Reference Networks



ERN BOND	Bone Diseases
ERN CRANIO	Craniofacial anomalies and ENT disorders
Endo-ERN	Endocrine Conditions
ERN EpiCARE	Rare and Complex Epilepsies
ERKNet	Kidney Diseases
ERN GENTURIS	Genetic Tumour Risk Syndromes
ERN-EYE	Eye Diseases
ERNICA	inherited and congenital anomalies
ERN-LUNG	Respiratory Diseases
ERN-RND	Neurological Diseases
ERN-Skin	Skin Disorders
ERN EURACAN	Solid Adult Cancers

ERN EuroBloodNet	Onco-Hematological Diseases
ERN EUROGEN	Urogenital Diseases
ERN EURO-NMD	Neuromuscular Diseases
ERN GUARD-HEART	Diseases of the Heart
ERN ITHACA	Congenital Malformations and Intellectual Disability
MetabERN	Hereditary metabolic diseases
ERN PaedCan	Paediatric Cancer
ERN RARE-LIVER	Hepatological Diseases
ERN ReCONNET	Connective Tissue and Musculoskeletal Diseases
ERN RITA	Immunodeficiency, Auto-Inflammatory and Auto Immune Diseases
ERN TRANSPLANT-CHILD	Transplantation in Children
VASCERN	Multisystemic Vascular Diseases

ERN Ecosystem



- ✓ Virtual remote consultations and clinical data on patient cases
- ✓ Knowledge Generation
- ✓ Research on rare diseases
- ✓ Education & professional training

ERN Integration in national systems - Background

- 2019 BoMS Statement on ERN integration:
 - *“To ensure a proper and sustainable functioning of the ERNs and to reap all benefits for patients suffering from rare and low prevalence 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.”*
- Evaluation of Cross-border healthcare Directive – preliminary findings of open public consultation:
 - Better ERN integration into national healthcare systems is one of the challenges for the ERN system
- ERN WG on integration: *“A potential way forward in this area could be through a Joint Action (JA) supported by the European Commission.”*

2022 Work Programme of EU4Health

- **HS-g-22-16.02 Direct grants to Member States' authorities: support ERNs integration to the national healthcare systems of Member States**
- This action supports the integration of the ERNs into the national healthcare systems that will ensure long term sustainability of the ERN system, enable the Member States to strengthen the resilience of their national health system and improve accessibility of the ERN system to rare diseases patients and their health professionals at national, regional, and local level with the aim to enable access to timely diagnosis and appropriate treatment.
- Budget: 11.2 Mill. EUR

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Activities should include:

(a) development of **proposals for national governance models** and practices for rare and complex disease centres and care pathways that are fully interoperable with ERNs and **recommendations to ensure interoperability between national and local data structures and ERN data structures** (including ERN registries and CPMS), taking fully into account the ongoing work on the European Health Data Space and the joint action 'Towards the European Health Data Space' (TEHDAS)

(b) development of a proposal for **national quality assurance models** for rare and complex diseases and **recommendations for the organisation of national care pathways for rare and complex diseases** that interface with ERNs, including processes to recognise at the national level evidence-based resources such as ERN Clinical Practice Guidelines.

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(c) development of a **proposal for the referral systems to the ERNs**, including guidelines for **incorporation of CPMS advice into patients' care** and recommendations on **CPMS reimbursement models**;

(d) preparation of a blueprint for a **national dissemination and communication strategy on the ERNs** and patient empowerment targeted at multi-stakeholder communities at national level;

(e) preparation of an **overview of good practices of mechanisms to provide support to the healthcare providers that participate in the ERNs at the national level** and develop a set of specific recommendations on how the Member States should support their healthcare providers participating in the ERN system;

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(f) support for **capacity building in the Member States**, for national rare disease plans and **setting up of the national networks** on rare disease and their integration with the ERNs.

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Expected results and impact:

- exchange of best practice;
- concrete proposals, guidelines, models and recommendations for better integration of ERNs in the national healthcare systems, including well-defined patient pathways and referral procedures;
- development of national networks on rare disease;
- guidelines for development of national teleconsultation tools interoperable with the ERN CPMS.

For each of the above-mentioned tools developed by the joint action, the joint action should also develop **a mechanism for monitoring the progress and implementation of these proposals**, guidelines, models and recommendations.



European
Commission



**Thank you for
your attention**



Further information:

http://ec.europa.eu/health/ern/policy/index_en.htm