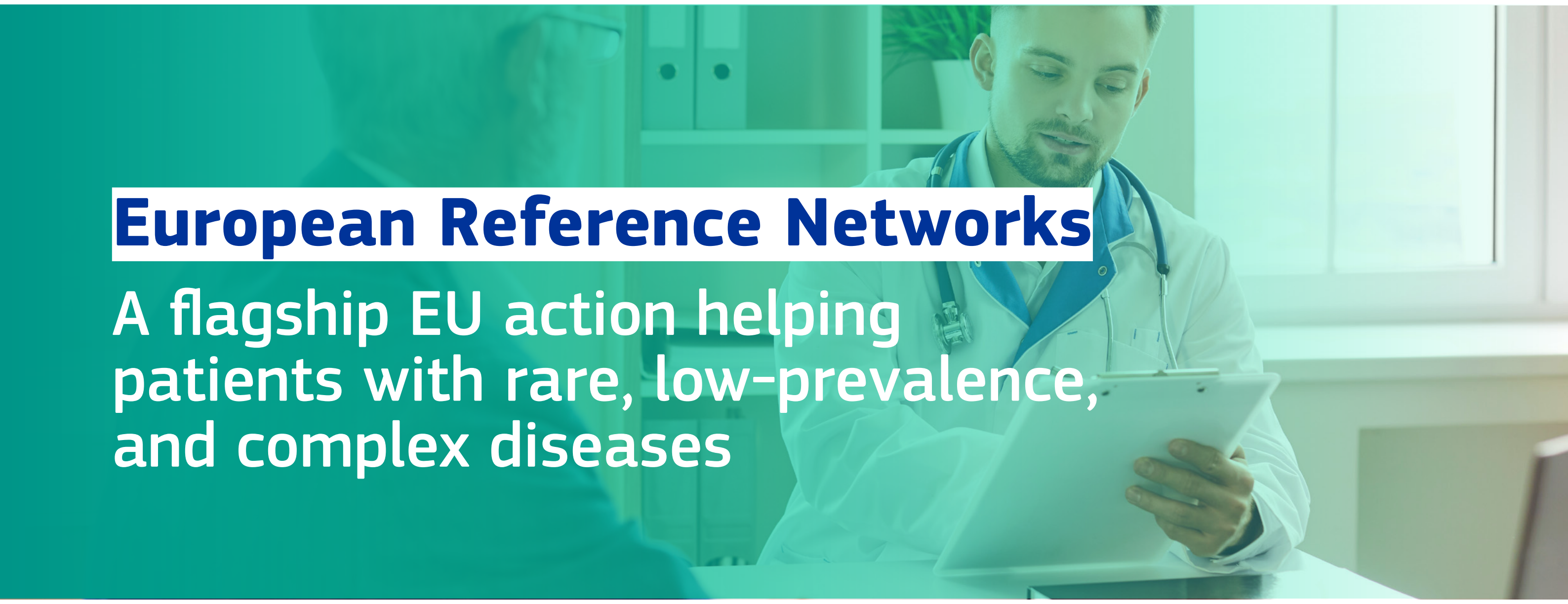


# European Reference Networks

## A flagship EU action helping patients with rare, low-prevalence, and complex diseases

## What are European Reference Networks (ERNs)?

Established under Directive 2011/24/EU on patients'rights in cross-border healthcare, the European Reference Networks (ERNs) are virtual networks of healthcare providers established in the European Union (EU) and Norway specialised in treating patients with rare, low-prevalence and complex diseases.

**European Reference Networks gather knowledge, experience, and expertise, and support individual health professionals to provide a more accurate diagnosis and the best available treatment.**

More than **6 000 rare diseases** affect the daily life of up to 36 million people in the EU.

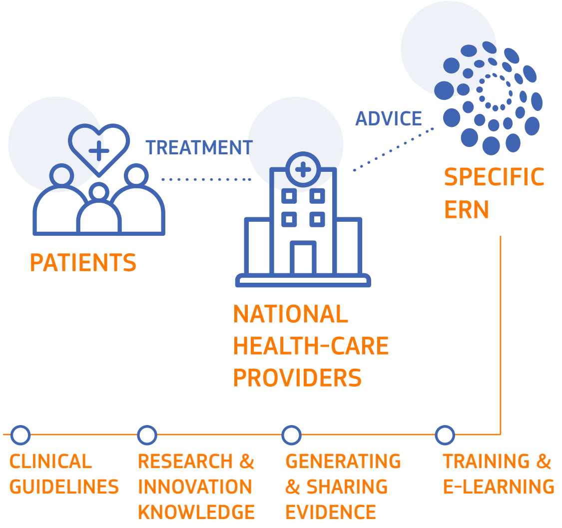
A rare disease is defined in the EU as one that affects fewer than **5 persons out of 10 000**

Using a dedicated, secure IT platform, patient cases can be evaluated by a team of European experts without requiring patients to leave their own country.

**Knowledge travels so that patients don't have to.**

## European Reference Networks:

- **review individual patient cases** (more than 3 800 to date) by convening virtual discussions among experts belonging to healthcare providers supported by a dedicated, secure IT platform funded by the European Commission. The experts discuss clinical cases to agree on diagnoses and treatments.
- **develop clinical practice guidelines and other clinical decision support tools for a specific rare disease to guide clinicians, and training courses for healthcare providers.**
- **facilitate networking and large clinical studies** that would otherwise be impossible, pooling data across the EU to better understand rare and complex diseases and help develop treatments.
- **develop and maintain rare disease registries** with the data of patients referred to them.
- **involve patients** though European Patient Advocacy Groups, **bringing their voice to the heart of the ERNs' activities.**



These 24 ERNs were launched in 2017, comprising more than 900 specialised clinical centres located in more than 300 hospitals in 26 Member States.

In 2024, they comprise 1 619 specialised clinical centres located in 382 hospitals across all 27 EU Member States and Norway.

The 24 ERNs established so far cover many rare diseases, including rare bone disorders, rare cancers, rare endocrine conditions, rare neurological and neuromuscular diseases, to name a few.

## How are ERNs approved and evaluated?

To join an ERN, healthcare providers respond to a call from the European Commission, following which an Independent Evaluation Body (IEB) assesses their application and prepares a report for the Board of Member States (BoMS).

The BoMS decides whether to approve a proposal to establish a network and the following applications for membership.

The ERNs are periodically evaluated. The first round of external evaluations was in 2022, five years after the establishment of the 24 ERNs and 836 members. The results showed that 100 % of the ERNs achieved 'satisfactory' results, as did 88 % of the members. A small fraction of the members, 8 %, needed improvement and 4 % of memberships were terminated. The results of the evaluation confirm that the ERNs are an EU success story, and they will remain a powerful instrument in the work to tackle rare diseases in the years ahead.

## ERNs must:

① be patient-centred and clinically led

② have at least 10 members in at least 8 countries

③ undergo a strong, independent assessment

④ fulfil Network and Member criteria

⑤ obtain endorsement and approval by national authorities

## How is the EU supporting the ERNs?

The Commission is investing heavily to further reinforce the ERNs. In addition to the funding provided in previous years, the Commission is offering new direct grants, worth EUR 77 million, to consolidate these networks in the coming years (until 30 September 2027).

Furthermore, the Commission is providing another EUR 15 million (18 million in total) through a Joint Action aimed at integrating ERNs into national health systems.

## Useful links

European Reference Networks (Europa website)

ERN Brochure (Publications Office of the EU, 2023)

Luxembourg: Publications Office of the European Union, 2026

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