

European Reference Networks



On June 23, the European Commission organised a conference on European Reference Networks (ERN). This conference summary explains the background to ERNs, the process, criteria and timeline for their establishment and membership, and some benefits for EKHA members should they decide to participate.

As one part of the EU Directive on Patients' Rights in Cross-Border Healthcare, the European Commission is seeking to support EU Member States in the development of **European Reference Networks (ERNs)** between Healthcare Providers, Patient Organisations and Centres of Expertise.

The intention of these Networks is to facilitate improvements in access to diagnosis, treatment, and provision of high-quality, accessible and cost-effective healthcare for patients with medical conditions requiring a particular expertise, for instance complex or rare disorders. ERNs are therefore particularly intended to cover medical domains where expertise is scarce. European Reference Networks will also be focal points for medical training and research, information dissemination and evaluation.

The first calls to establish such Networks is expected at the end of 2015, and the Networks are expected to be operational by 2016.

Key Points

- ERNs are a new form of Europe-wide cooperation between healthcare providers of highly specialised services.
- They should improve access to diagnosis, treatment and provision of high-quality healthcare to patients. They could also be focal points for medical training and research, information dissemination, and evaluation.
- Expected benefits for healthcare providers are an improvement in knowledge and capacity, international recognition and leadership in their area of expertise, and better positioning for access to EU funding programmes.
- ERNs will look to build on existing informal thematic peer links, with the expectation that providers will proactively cooperate amongst themselves to establish a Network in a dedicated field of expertise.

Background

While cross-border cooperation in healthcare within the EU has been increasing - primarily through informal clinician-led peer groups, bi-lateral agreements and EU-funded projects - there is currently no formal platform at EU level to construct partnerships on healthcare and take advantage of potential synergies and economies of scale.

ERNs are therefore an attempt to formalise existing arrangements and bring together highly specialised healthcare providers in different Member States to provide affordable, high-quality and cost-effective healthcare to patients with conditions that require a high concentration of resources and expertise. It is expected that this will also improve patient access to the best possible expertise and care available in the EU. The intention is that ERNs will lead to improvements in service delivery, working systems, patient pathways, clinical tools, and the earlier adoption of scientific evidence. They could also be focal points for medical training and research, information dissemination and evaluation, especially for rare diseases.

Establishing European Reference Networks

The European Commission envisages between 20 – 30 ERNs being established in total, which will inevitably involve the clustering of some diseases/conditions (for example, all rare cancers may be joined together into one single Network).

In terms of governance, ERNs can have different organisational models, though they all require one Member as coordinator and an associated governing Board composed of representatives from each Member in the Network. The Board will be responsible for the running of the Network, including rules of procedure, work plans and general activity. All ERNs will have a common EC logo and registered trademark.

Each Network is expected to involve at least 10 hospitals/specialised centres from at least 8 EU Member States. Member States with no Member of a Network may decide to designate healthcare providers with a special link to a given Network. Networks should also be built on **the multidisciplinary team approach and include patient expertise.**

The European Commission will be responsible for leading the process for the establishment of the Networks and their evaluation, largely through its website and a series of conferences and expert meetings.

In particular, the Commission will organise a conference for hospitals/centres interested in applying to understand the process and establish links for the development of applications.

Networks will also be instrumental in harmonisation of guidelines across Member States and will help with the implementation of an eventual EU strategy to assess clinical outcomes. In addition, Patient Registries will be an essential component of ERNs.

Structural funds can be used to help create ERNs however, participating Member States must choose the priorities for their structural fund allocation.

Criteria and conditions for Networks to meet

Have knowledge and expertise to diagnose, follow-up and manage patients with evidence of good practice

1. Follow a multi-disciplinary approach
2. Offer a high level of expertise and have the capacity to produce good practice guidelines and to implement outcome measures and quality control
3. Make a contribution to research
4. Organise teaching and training activities
5. Collaborate closely with other centres of expertise and networks at national and international level

Criteria to be met by healthcare providers to participate in a Network

1. Patient empowerment and patient-centred care
2. Organisational, management and business continuity of the healthcare provider
3. Research and training capacity
4. Exchange of expertise, information systems and eHealth tools
5. Expertise, good practice, quality, patient safety and evaluation
 - Patient Registries will be an essential component of ERNs
 - Each Network will be required to regularly report to the European Commission on its activities and therefore participating organisations should ensure they can dedicate sufficient time and resources to the Network.

An early indication of what an ERN might look like can be found in two pilot networks funded by the Commission's Health Programme in 2013: [ExPO-r-Net](#), the European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment; and [E-Pilepsy](#), a Pilot Network of Reference Centres in refractory epilepsy and epilepsy surgery.

Timeline for the Setting up of an ERN

- **May 2014** Entry into force of the legal acts establishing the ERN
- **July 2014** Call for Assessment Manual
- **2nd half 2015** Call for selection of independent bodies to evaluate ERN
- **End 2015** Call for Networks
- **2nd half 2016** Establishment of ERN
- **Mid 2016** Network is operational
- **2020** Evaluation

Opportunity for Europe's Renal Community

There are opportunities for EKHA's members to participate in an ERN are significant. The actual establishment of ERNs will be dependent on specialised providers

proactively seeking out peers across Europe with which to collaborate. Although no direct EU funding will be attached to being part of an ERN, their profile and status is expected to be considerable across Europe in their particular domain. This will clearly prove an attraction to clinical leaders, and to patients crossing borders, and will put the Networks and their members in a good position to bid for EU research funding going forward.

The Commission is also asking for support and input from the stakeholders on how to identify clusters of diseases/find synergies; define services and ensure that the ERN delivers practical healthcare (not just research).

Recommended Next Steps

- Share ERN information on EKHA Member websites and in EKHA eUpdate
- Map existing renal networks and identify best practice
- Enlist interest and support from National Societies for the development of a European Reference Network on renal care
- Seek opportunities to participate in discussions with the Commission to ensure complex renal care is included in the cluster of the health areas which will form some of the ERNs.