



13TH EHEALTH NETWORK 15 MAY 2018, BRUSSELS, BELGIUM
COVER NOTE BY EHEALTH NETWORK SECRETARIAT

Agenda point 5: Developments in the European Reference Networks

Issue at stake

This agenda point is for information on European Reference Networks (ERNs) achievements, ongoing work and challenges.

European Reference Networks (ERNs) are virtual, cross-border networks bringing together healthcare providers across Europe to tackle rare or complex diseases and conditions that require highly specialised healthcare. A key principle of ERNs is to let the knowledge travel rather than the patient. Since the launch of the European Reference Networks (ERNs) in March 2017 they have moved from the planning phase to the deployment phase.

Summary

Created by the 2011 Directive on Patient Rights¹ in Cross-Border Healthcare, ERNs aim to increase patients' accessibility to the best treatment and advice. ERNs enable specialists in Europe to discuss complex cases, share learnings, and agree on the best treatment and patient pathway. They will lead to economies of scale, more efficient use of costly resources, and make Europe a hub of activity on rare and complex conditions.

The first 24 Networks were launched in March 2017. They include more than 900 healthcare units from over 300 hospitals from 26 countries (25 Member States and Norway), and cover all major rare and complex disease groups.

The ERNs are not directly accessible by individual patients. Instead, healthcare providers refer patients, with their consent and in accordance with the national health system rules, to the relevant Network.

The key achievements in the first year

The patient case panels are operational since November 2017 and thus the first patients have directly benefited from the ERNs.

- The launch of the Clinical Patient Management System (CPMS) took place in November 2017. The IT platform is provided by the Commission and allows the members of the ERNs to carry out virtual panels to discuss complex patient cases and provide the best available clinical advice on diagnoses and treatment.
- So far, 111 virtual panels have been opened, of which 13 have been closed (figures by 31 March 2018).

Ongoing work

- The ERN Coordinators Group created in March 2017 is developing common strategies, guidelines and procedures in areas such as research, knowledge generation, business continuity, monitoring, conflict of interest and data sharing;
- The 24 networks are consolidating their governance and working mechanisms;
- In cooperation with the ERNs, the Commission is also developing a communication and

awareness strategy¹. As sharing the knowledge generated by the ERNs with the healthcare community and patients is a key objective of the ERN system, their clinical and technical deliverables will be made accessible to patients and healthcare professionals through a number of tools like the Europa site², ERNs' own webpages and other communication means.

Challenges for ERNs

Currently the main challenge faced by the ERNs is their Integration in National Healthcare system, notably:

- assessing the changes required in the policy and legal frameworks of each Member State to ensure a smooth integration of the ERNs into its national healthcare system;
- developing patient pathways and deciding how a patient case is referred to an ERN;
- defining how the Member States will support the functioning of the ERNs, notably by financing the activities of the ERNs Coordinators and members.

The Commission is active at technical, strategic and political level with the national health authorities in order to speed up this process of integration.

Format of procedure in the eHN

The Commission co-chair introduces the topic and open the floor for comments and questions.

¹ http://ec.europa.eu/health/ern/toolkit_en

² https://ec.europa.eu/health/ern/networks_en