



**11<sup>TH</sup> eHEALTH NETWORK 9 MAY 2017, ST. JULIAN'S, MALTA**  
**COVER NOTE BY eHEALTH NETWORK SECRETARIAT**

**Topic 2: Implementation of the eHealth DSI (agenda point 8)**

**– State-of-play on European Reference Networks –**

**Issue at stake**

European Reference Networks (ERN) are virtual networks bringing together healthcare providers across Europe to tackle rare or complex diseases and conditions that require highly specialised healthcare and a concentration of knowledge and resources. The Networks give healthcare providers access to a much larger pool of expertise and knowledge, increasing the chances of patients suffering from such conditions and diseases to receive the best advice to treat and diagnose their condition.

24 European Reference Networks (ERNs), which cover more than 950 highly specialised healthcare units located in 313 hospitals of 25 Member States and Norway, were formally launched on 9 March 2017. Representatives from the networks and Member States, along with patients and policymakers, gathered in Vilnius, Lithuania, for the 3rd ERN Conference and kick-off meetings (9 & 10 March). There was strong political support for the ERNs which were hailed as an important European success story with the potential to change millions of lives. A key principle of ERNs is to let the knowledge travel rather than the patient (with the exception of a few cases where the patient may be referred for treatment in another country). There is now a strong feeling of ownership, a high level of commitment and recognition of EU added value in ERN cooperation. This should be sustained for a successful implementation.

The Core Services for ERN consist of ERN Collaborative Platform, Clinical Patient Management System (CPMS), and other modules like a public website, and e-Training tools. Work is also under way to address and support the development of interoperable registries for the ERNs.

By using the CPMS specialist will be able to review a patient's diagnosis and treatment. Healthcare providers/members of an ERN will consult, exchange information and share knowledge with other members of the network. Coordinators of a specific ERN will have a possibility to convene inter-ERN 'virtual' advisory panels composed of medical specialists across different disciplines.

ERNs are not directly accessible to individual patients. However, with the patients' consent, and in accordance with the rules of their national health system, a patient's case can be referred to the relevant ERN member in their country by their healthcare provider.

**Format of procedure in the eHN**

The Commission co-chair will introduce the topic and gives the floor to Tapani Piha who will present the update on European Reference Networks.