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NOTE

From: General Secretariat of the Council
To: Council

Subject: **Employment, Social Policy, Health and Consumer Affairs Council**
meeting on 8 December 2016
European Reference Networks
– *Information from the Commission*
(Any Other Business item)

Delegations will find attached an information note from the Commission services on the above mentioned subject.

European Reference Networks

The European Reference Networks (ERN) bring together healthcare providers across Europe to tackle complex or rare medical conditions, and more patients will have access to highly specialised quality treatment for their disease through the pooling of knowledge and resources.

ERNs are being set up under the Directive on patients' rights in cross-border healthcare, which not only enables patients to be reimbursed for treatment in another EU Member State, but also makes it easier for patients to access information on healthcare through National Contact Points and healthcare providers and thus increase their treatment options.

Benefits for the patients

Many rare and complex diseases cause chronic health problems and are often life-threatening. Around 5 000 to 8 000 rare diseases affect the daily lives of around 30 million people - many of whom are children - in the EU. For example, there are almost 200 different types of rare cancers alone and each year more than half a million people in Europe are diagnosed with one.

Many of those affected by a rare disease or condition do not have access to the diagnosis and to high quality treatment as expertise and specialist knowledge may be scarce, particularly in smaller Member States. Many patients start scouring the internet for knowledge and trying to find doctors and centres with the expertise to give them the best possible chance of surviving with a good quality of life. Many may not find what they are looking for. The chances of getting the best treatment and advice will considerably improve through the pooling of the knowledge and expertise of the specialist healthcare centres who will be members of the ERNs. Raising awareness about the existence of ERNs among health professionals and patients as well as putting in place necessary patient pathways will be crucial to fully exploit the potential of ERNs.

Functioning of the European Reference Networks

Member States keep the lead in the ERN process as they are responsible for the recognition of centres at national level and the endorsement of their applications.

Connected through a dedicated IT platform, a network coordinator will convene a "virtual" advisory board of medical specialists across different disciplines, using telemedicine tools to review the patient's condition for diagnosis and treatment. So the medical knowledge and expertise will travel instead of the patients, keeping them in their supportive family and language environment (with the exception of a few cases where the patient may need to be referred for treatment in another country).

The ERN initiative will receive support from several EU funding programmes, for instance the Health Programme, the Connecting European Facility and Horizon 2020.

Added value for the European economy and health systems

For the first time, a formal structure of voluntary collaboration between healthcare providers across the EU is being created for the direct benefit of the patient. As a result there is a strong feeling of ownership of the ERN model, a high level of commitment and recognition of its EU added value, all of which are crucial for the success of the Networks.

Innovation in healthcare delivery is the cornerstone of the ERNs. The Networks will help developing innovative care models, eHealth and telemedicine tools, medical solutions and devices, influencing the way in which treatment itself is delivered.

The ERNs will stimulate digital provision of healthcare, such as online health platforms and telemedicine. They will contribute to bring down obstacles and enable patients and healthcare providers to access healthcare services, wherever they live, in the EU.

Boosting research: there is still no effective treatment for the majority of rare diseases

By gathering and analysing a large pool of patient cases, ERNs will help developing large clinical studies and trials for better knowledge of diseases and new drugs development, and more effective diagnosis and treatments with potentially far-reaching benefits for patients.

Capacity building and dissemination of state-of-the-art knowledge for health professionals and patients will improve the expertise across all EU Member States and improve standards of care, quality of life and prognosis for the wide spectrum of rare and complex diseases.

ERNs will help to boost economies of scale and ensure a more efficient use of costly resources, ultimately having an impact also on the sustainability of healthcare systems. They will improve the access to and the quality of care of many EU citizens, and help to strengthen the capacity and efficiency of EU healthcare systems.

Expected outcome

In response to the call for proposals in 2016, 24 networks applied, including 960 highly specialised healthcare units of 370 hospitals located in 26 Member States and covering a high number of disease groups. The ERNs will be designated by the Board of Member States, following an independent technical assessment of candidate networks, and will become operational in 2017. Over the next five years, they are expected to reinforce their capacities to benefit thousands of EU patients suffering from a rare or complex condition.

A major conference organised by the Commission, hosted by Lithuania and under the auspices of the incoming Maltese Presidency of the Council will be held on 9 March 2017 in Vilnius to mark the official launch of ERN activities. Over 600 ERN members, health authorities and other involved stakeholders will take part in the conference.