



EUCERD Recommendations on European Reference Networks for Rare Diseases

On the 31 January 2013, during the seventh meeting of the European Union Committee of Experts on Rare Diseases, the EUCERD Recommendations on European Reference Networks for Rare Diseases (RD ERNs) were unanimously adopted by the 51-member EUCERD. This Recommendation is complementary to the EUCERD Recommendations on Quality Criteria for Centres of Expertise for Rare Diseases in Member States, adopted on 24 October 2011.

There are around 6000 rare diseases and most are unknown to healthcare professionals so rare diseases patients suffer from not knowing where to consult. To overcome this, some Member States have established centres specialised in some rare diseases/groups of rare diseases which have proven to be very efficient in improving quality of care. Now the European Commission is planning to link these centres together through European Reference Networks (ERNs) in order to gather expertise and improve healthcare for rare disease patients.

The development of centres of expertise and European Reference Networks in the field of rare diseases is encouraged in the Council Recommendation on an Action in the Field of Rare Diseases (2009/C 151/02) (8 June 2009) and in the Directive on the application of patients' rights in cross-border healthcare (2011/24/EU) (9 March 2011) as a means of organising care for the thousands of heterogeneous rare conditions affecting scattered patient populations across Europe.

European Reference Networks (ERNs) are one of the structures foreseen by the aforementioned Cross-Border Healthcare Directive to share knowledge, facilitate the mobility of expertise, and to allow Member States to provide highly specialised services of high quality for patients where this would have been impossible without European networking, such as in the case of rare diseases.

The EUCERD Recommendation for RD ERNs cover a range of points including the mission, vision and scope of ERNs, their governance, their composition, their funding and evaluation, as well as their designation. The overall vision of RD ERNs is that they will provide the framework for healthcare pathways for RD patients through a high level of integrated expertise. Due to the complexity of rare diseases, these networks will link Centres of Expertise as well as other stakeholders involved in the care management of the patients such as specialised health and social care providers, patient groups, research groups and diagnostic laboratories.

In addition, in order to improve the delivery of care in an efficient manner while reducing costs, RD ERNs need to facilitate the sharing of information and tools amongst Centres of Expertise and other care providers, for instance disease registries, communication of



guidelines/ best standards of diagnosis and care, training, quality assurance schemes, telemedicine, cross-border referral mechanisms.

The objective in the next decade is that RD ERNs will cover, within a step-wise approach, all rare diseases grouped by diagnostic and systemic areas.

The 21 recommendations on RD ERNs build upon these previous achievements and will serve both to inform the Commission services and Expert Group working on criteria for the creation and designation of ERNs in the context of the Cross-Border Healthcare Directive on the specificities of RD, as well as the Member States who are developing their healthcare pathways at both the national and EU levels in the field of rare diseases in the context of national plans/strategies for rare diseases which the Council has urged all Member States to elaborate by 2013.

The recommendations have been presented to the Cross-Border Healthcare Expert Group at the European Commission to inform their work on the designation criteria for ERNs on 6 February 2013.

The Recommendations are available on www.eucerd.eu here:

http://www.eucerd.eu/?post_type=document&p=2207