WORKSHOP TITLE: Preliminary outcomes of the survey on centres of expertise

DATE: 31 March - 1 April 2014

PLACE: Madrid

WORK THEME: Quality of care/centres of expertise


CONTEXT:

The European Union Committee of Experts on Rare Diseases (EUCERD) Joint Action: Working for Rare Diseases (N° 2011 22 01) started on 1 March 2012 and will support for a three-year duration the activities and mandate of the EUCERD. From 2014 it supports the activities of the European Commission Expert Group on Rare Diseases which replaces the EUCERD.

This workshop was organised in the scope of Work Package 7 of the EUCERD Joint Action. This work package aims to identify actions which could improve access to higher-quality healthcare in rare diseases (RD), enhancing quality of life for patients. Healthcare here is defined very broadly and includes the entire continuum of services, from diagnosis to care and rehabilitation. Various initiatives across the EU Member States (MS), which address the quality of care for rare diseases, have been explored, with the aim of identifying and sharing good practices in healthcare. Special emphasis has been placed on activities relating to the Centres of Expertise. Furthermore, the factors influencing policy decisions pertaining to quality of care for RD have been examined, as well as assessing how healthcare systems organise themselves to accommodate RD policies and patients.

Case studies have been collected and examined in order to draw comparisons between the current provisions for RD healthcare in different MS. Data has been gathered from in-depth interviews with experts in the field, selected from across the MS and stakeholder groups.

WORKSHOP AIMS:

This workshop aimed to gather experts to discuss centres of expertise for rare diseases, an area where the EUCERD has already elaborated recommendations. In particular the objectives and the preliminary results of the survey undertaken by Work Package 7 of the EUCERD Joint Action (see context above) were presented and discussed amongst stakeholders. This workshop also aimed to
raise awareness of EC-supported initiatives in the field of rare diseases supporting the improvement of quality of care.

FURTHER INFORMATION

EUCERD Joint Action website: www.eucerd.eu

CONTACT INFORMATION

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