SPRU Friday Seminar

Date 28 February 2014
Speaker Richard Wooley (Ingenio, CSIC-Universidad Poiltècnica de València)
Title Mobilising knowledge and expertise for Rare Diseases in Europe

Abstract

Rare Diseases (RD) present a range of challenges for organising and delivering health interventions to improve quality of care for RD patients. Often it is the scarcity or inaccessibility of expertise regarding RDs that is the biggest obstacle to improving quality of care. This presentation describes and discusses efforts to institutionalise an effective Europe-wide approach to improving the way RDs are managed. In particular, it outlines progress in designating Centres of Expertise (CEs) for RD across EU Member States utilising harmonised criteria, and the further goal of establishing European Reference Networks (ERNs) for diseases or groups of diseases. The objectives guiding this process are summarised and a number of institutional, organisational, political and social challenges to the fulfilment of these objectives are identified. The remainder of the presentation deals with work-in-progress in an innovative study investigating the capacity of the CE organisational form as a platform for resolving knowledge and expertise-based problems that can contribute to the provision of enhanced quality of care for RD patients.