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Strategy of attention to rare diseases in Catalonia

People living with rare diseases (RD) are vulnerable to healthcare systems because standard procedures are not adequate for these patients. Catalonia's Health Ministry has been working since 2009 on different health policies that seek to improve awareness, diagnosis and treatment of people affected by RD.

One of these policies defines the Catalan RD Care Model. This model aims to achieve a person-centred care and to guarantee equity of access to specialized care; it integrates the different patient care levels and optimizes the resources available by identifying and guaranteeing the access to clinical reference units (UEC) which are responsible for leading an integrated care network in collaboration with the territorial/community level (XUEC).

The model has been designed with the advice of a RD Advisory Committee (CAMM) and takes into account the viewpoint of patients, clinicians and professionals of different administration bodies (health, welfare and education). Furthermore it is aligned with the RD national and European strategies (Estrategia nacional de Enfermedades raras and European Reference Networks -ERNs-), and follows the recommendations published by EUCERD and the Ministry of Health of Spain.

The model implementation process has been designed by phases; RDs are grouped in thematic groups (similar to ERN grouping) which are prioritized and worked in collaboration with professional experts of our territory. In 2017, the first integrated care network was designated, it addresses genetic cognitive behavioural diseases. At least two more networks will be designated during 2018.

Other key aspects of the model are its quality assessment workplan, and its vinculation to a Catalan RD population registry

Biography

Roser Francisco is a registered nurse and a biologist, and has completed her PhD on Biomedicine from the University of Barcelona. She is the Head of the rare diseases program of the Catalan Health Service (CatSalut), a public health administration. Her work has always been related to rare diseases, from research to health planning. Thanks to her experience she has an holistic knowledge of RD's needs: doctoral thesis on the rare paediatric oncologic disease neuroblastoma (basic research), advice and monitoring of clinical trials in rare diseases (translational research), participation in the wording and implementation of the Catalan Rare Diseases' Care Model (health planning).

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