

Catalonia's Care Model for Rare Diseases (RD) (Spain)

Roser Francisco, Pilar Magrinyà, Diana Altabella, Josefa Rivera, Josep Jiménez, Lluís Franch, Àlex Guarga, Josep Torrent and Cristina Nadal
 Servei Català de la Salut, Departament de Salut. Generalitat de Catalunya (Ministry of Health of Catalonia)

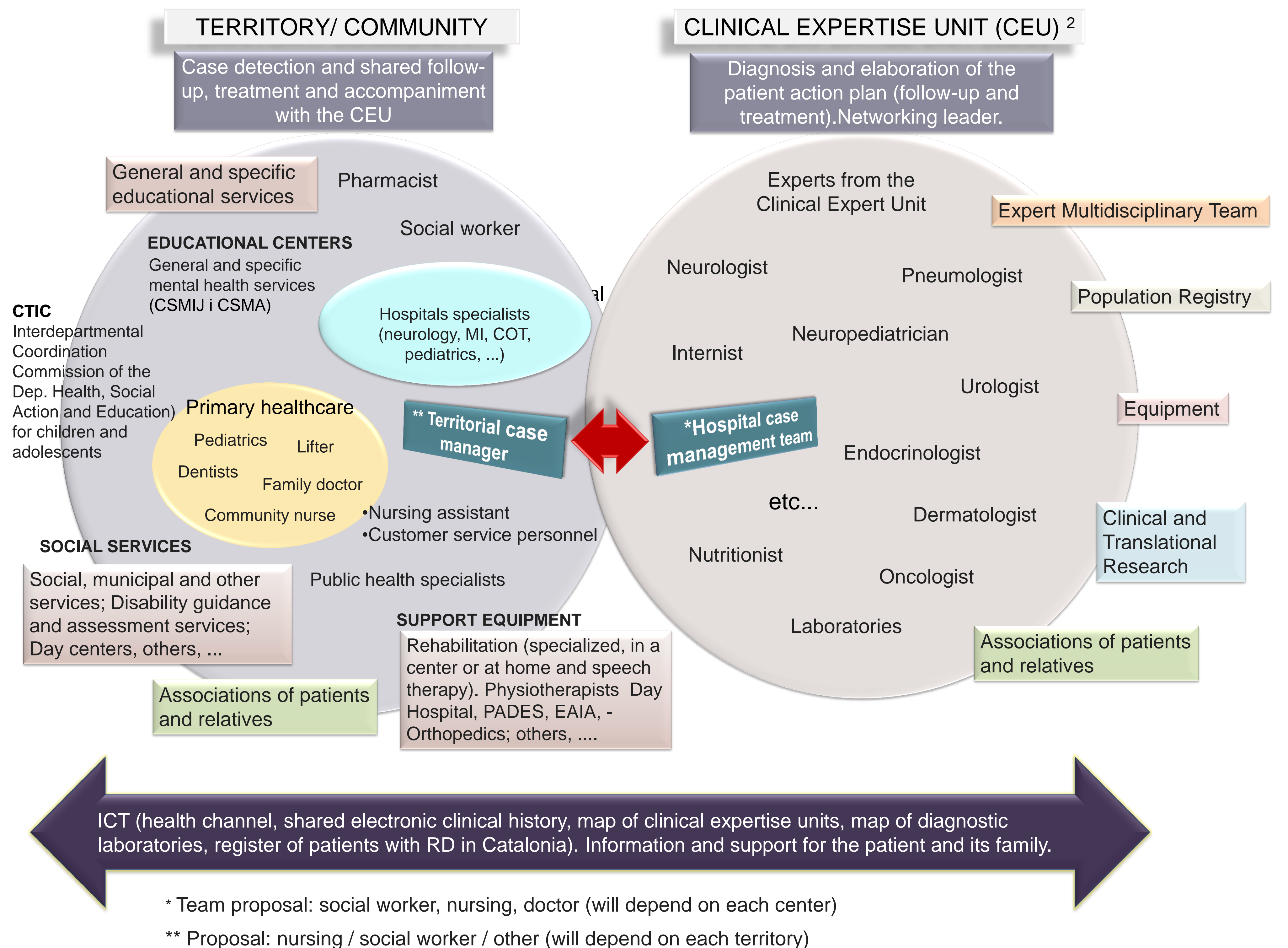
In 2010, the Catalan Ministry of Health defined a Care Model for Rare Diseases (RD) in Catalonia.

The model was defined taking into account the viewpoint of people affected by RD, clinicians, professionals of different administration bodies and the recommendations published by EUCERD¹. It aims to optimise the resources available and to improve care quality, establishing patient care levels and circuits that guarantee access to expertise units, optimal outcomes, efficiency, continuity of care, and accompaniment of patients and their families during the different episodes of the illness.

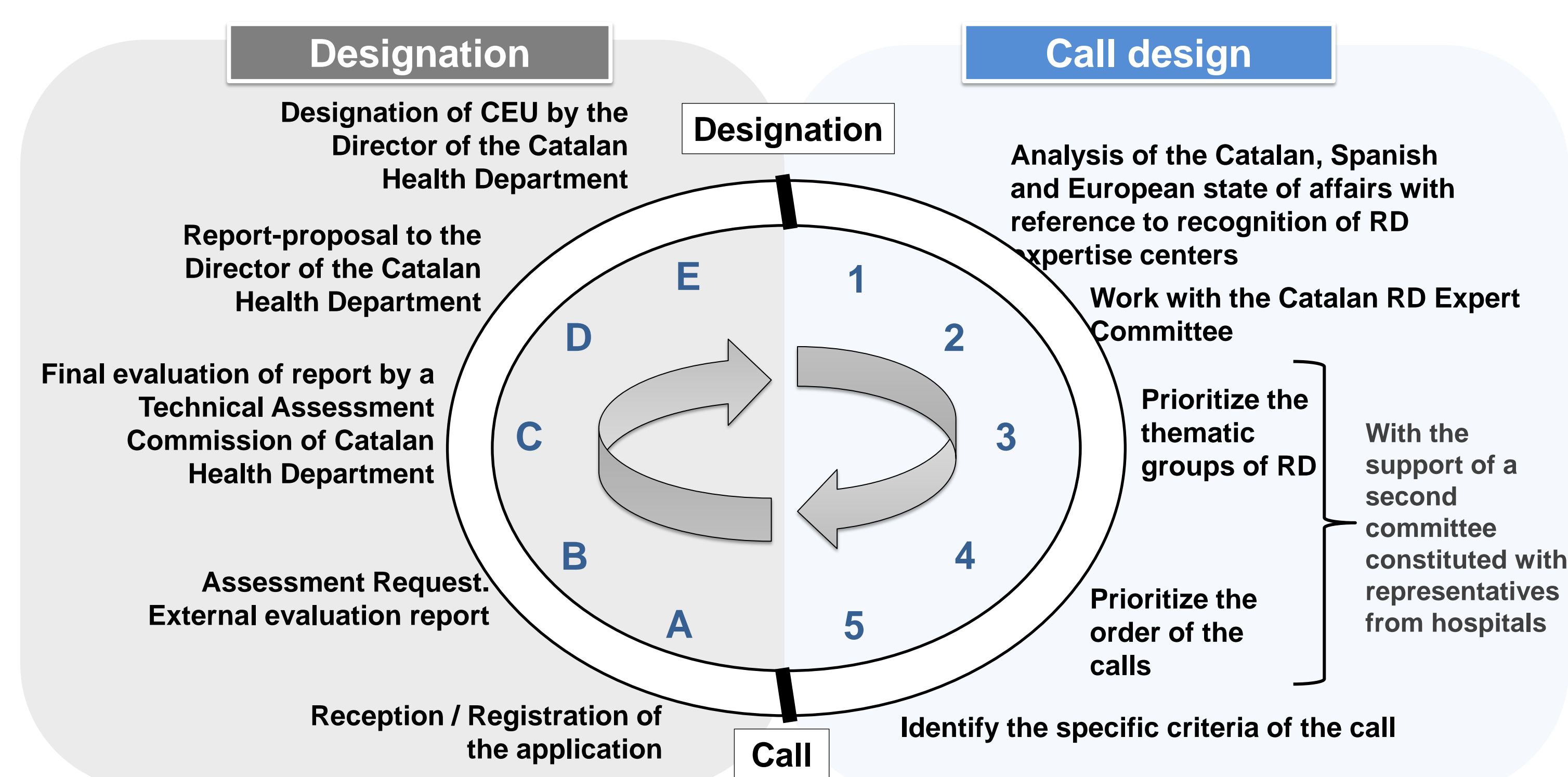
Model of RD Attention

✓ 2 levels of care:

- an **expert care level** (based on clinical expertise units for a thematic group of RD that work as a network), and
 - a **territorial or community level**, close to the home of the person affected by a RD (includes primary healthcare, territorial reference specialised care and other territorial health services, as well as social, educational and labour resources of the territory).
- ✓ It is an **integrated care network** where all the different resources involved in the patient care participate. This implies a collaborative attitude and the use of eHealth tools.
- ✓ It guarantees **equity of access**; every person living in Catalonia affected by a RD must have fast access to a CEU
- ✓ The care is provided by a **multidisciplinary care team**, integrated by the set of professionals intervening in the diagnostic, and therapeutic and monitoring process.
- ✓ Every person with a suspected or confirmed RD living in Catalonia must have guaranteed a **definitive diagnosis and a care plan**, which includes the therapeutic strategy as well as the monitoring strategy shared by the two levels of attention.



Process of Implementation



- ✓ **The 7.000 RD are grouped in thematic groups** (similar to the ERN³ grouping)
- ✓ **The model implementation is done by phases**; beta limited number of RD thematic groups will be prioritized and work per year (2-4 calls for CEU networks/year)
- ✓ The **RD thematic grouping** for which CEU networks will be designated are **prioritized with the collaboration of the Catalan RD Expert Committee**; the committee is integrated by patients, professional experts, and three Catalan ministries (health, welfare, education)
- ✓ The specific criteria used to identified CEU for each specific group is establish with the collaboration of hospitals an expert professionals on the field of rare diseases
- ✓ Once the CEU are designated and the network is underway, quality and follow up indicators are fixed, and a reevaluation is done at the end of the 3rd year of accreditation.

Key Concepts

Person Focused Care	Organize the care around the affected person and its family
Expertise Identification	Identify CEU networks for thematic grouping of RD: multidisciplinary teams, visit planning, transition from paediatric to adult
Equity of Access	Assure equity of access to CEU networks in the Catalan territory
Excellence of Care	Diagnosis, personal care plan, therapeutic strategy, monitoring process
Integrate Care Network	Leadership, knowledge sharing, teamwork, shared monitoring between the more specialised level and the territory level
Population Registry	Obtain high quality data of RD prevalence and incidence in Catalonia
Collaborative Implementation	Collaborative approach; the thematic group call's are prioritized by the Catalan RD Expert Committee, with the support of a second committee constituted with representatives from 11 Catalan hospitals, guided by technicians from the Catalan Health Department
Professionals participation	Assure criteria that can recognize expertise in our territory; for each thematic grouping a group of experts is created. During 2017-2018 more than 100 professionals have participated in the implementation process defining criteria
Continuous Improvement	Promote professional development, resources, regulatory standards of practice and guidelines and clinical, organizational & research ethics
Constant Evaluation	Assure a dynamic model that guaranties expertise by establishing a quality framework and periodic evaluations
ERN Alignment	Guaranty coherence and consistency between the Catalan expert network and the ERNs ³ of rare and complex diseases

¹ European Union Committee of experts on rare diseases, ² Clinical Expertise Unit, ³ European Reference Networks