

# Participants

**Population-based registries:** Institute of Rare Diseases Research (IIER, ISCIII) and the 17 Health Departments of the Autonomous Communities of Spain

**Patient organizations:** FEDER, Teletón FEDER Foundation

**National RD Center:** CREER

**Industry:** ASEBIO, AELMHU, Farmaindustria

**Patient registries:** Differentiation Sexual Disorders (DSD), Alveolar proteinosis, Alpha-1 antitrypsin deficiency, Histiocytosis X, Lymphangiomas, Rare hereditary ataxia and hereditary spastic paraparesis, Epidermolysis Bullosa, Interstitial Lung disease specific to childhood, Bradikinin mediated angioedema, Rare and congenital anemias, Sarcoidosis, Tracheal stenosis

**Patient registries in process:** Fragile X Syndrome, Congenital Malformations, Tumor Adrenocortical tumor (Cushing), McArdle disease, Ano-rectal malformations and Hirschsprung disease, Xeroderma Pigmentosum, All rare diseases included in the neonatal screening national program, Congenital Adrenal Hyperplasia (CAH)




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Instituto de Investigación de Enfermedades Raras

# SpainRDR Spanish Rare Diseases Registries Research Network



SpainRDR

<https://spainrdr.isciii.es>



Membership:

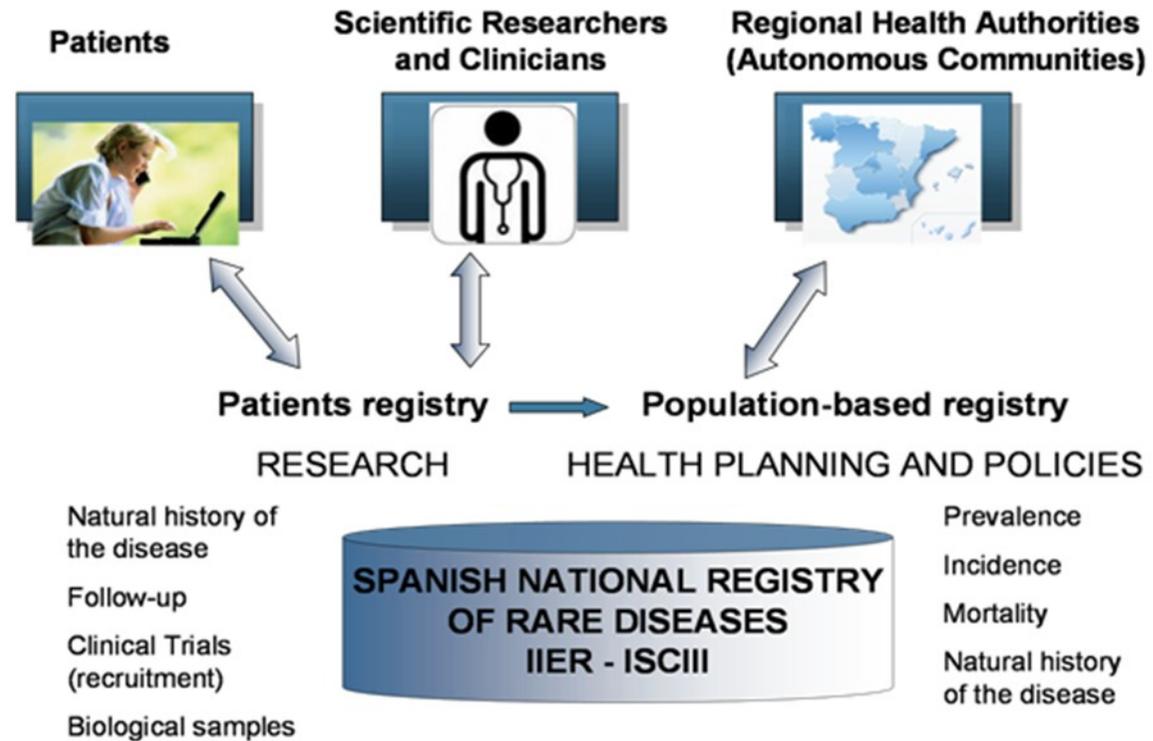


# SpainRDR Spanish Rare Diseases Registries Research Network

**The Spanish Rare Diseases Registries Research Network-** SpainRDR is a project financed by the Institute of Health Carlos III (ISCIII) within the scope of the IRDiRC for the years 2012 to 2014 with 2.4 M €.

**SpainRDR aims to build the National Rare Diseases Registry in Spain** based on the input of two different strategies: patient registries oriented to patient outcome research and population-based registries oriented to epidemiologic research and social and health systems planning.

**The National Rare Diseases Registry** will provide the necessary information to contribute to the development of new treatments to the improvement of prevention, diagnosis, prognosis and quality of life of rare diseases patients and their families



Source: ISCIII / Instituto de Investigación de Enfermedades Raras

National Rare Diseases Registry <https://registroraras.isciii.es/>

