

Título del Proyecto	European Joint Programme on Rare Diseases — EJP RD
Nº de expediente asignado	GA: 825575
Abstract	<p>As recognized by the Council Recommendation 2009/C 151/02, rare diseases (RD) are a prime example of a research area that can strongly profit from coordination on a European and international scale. RD research should be improved to overcome fragmentation, leading to efficacious use of data and resources, faster scientific progress and competitiveness, and most importantly to decrease unnecessary hardship and prolonged suffering of RD patients. In the specific context of the massive generation, need for reuse and efficient interpretation of data, introduction of omics into care practice and the structuration of RD care centers in European Reference Networks, it appears crucial and timely to maximize the potential of already funded tools and programmes by supporting them further, scaling up, linking, and most importantly, adapting them to the needs of end-users through implementation tests in real settings. Such a concerted effort is necessary to develop a sustainable ecosystem allowing a virtuous circle between RD care, research and medical innovation. To achieve this goal, the European Joint Programme on RD (EJP RD) has two major objectives: (i) To improve the integration, the efficacy, the production and the social impact of research on RD through the development, demonstration and promotion of Europe/world-wide sharing of research and clinical data, materials, processes, knowledge and know-how; (ii) To implement and further develop an efficient model of financial support for all types of research on RD (fundamental, clinical, epidemiological, social, economic, health service) coupled with accelerated exploitation of research results for benefit of patients. To this end, the EJP RD actions will be organized within four major Pillars assisted by the central coordination: (P1): Funding of research; (P2): Coordinated access to data and services; (P3) Capacity building; (P4): Accelerated translation of research projects and improvement outcomes of clinical studies.</p>
Entidad Financiadora	Unión Europea (Comisión Europea)

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Enlaces:	http://www.ejprarediseases.org/