

Título del Proyecto	Orphanet Network
Nº de expediente asignado	GA: 831390
Abstract	<p>Rare diseases (RD) have been considered a challenge for Europe, for they have been identified as one of the paradigmatic fields in which actions conducted at the European level constitute the adequate response to their specific problems: poor recognition leading to diagnostic delay and inappropriate management including adapted social services, poor health outcomes, social burden, limited knowledge on natural history and pathophysiology leading to an insufficient development of new therapies. Amongst the key actions the European Commission (EC) has contributed to develop so far in order to address key priorities in the field of RD there is Orphanet, a European Knowledge base dedicated to RD and orphan drugs, accessible from the portal www.orpha.net, and providing re-usable data through the platform www.orphadata.org. Orphanet has also be recognised, by the EC, as having a de facto monopoly in its field. The objectives of the project are:</p> <ol style="list-style-type: none"> 1. To provide the RD community with interoperability tools, in particular around an inventory of RD, to allow for semantic interoperability between countries and between domains (health, research). 2. To provide high-quality information on RD, in particular through an encyclopedia in several languages. 3. To provide a directory of expert services in order to help patients, physicians and stakeholders finding the expertise on a particular disease in Europe and beyond, and to produce data needed to support policy actions. 4. To further develop and sustain Orphanet as the reference knowledge base on RD, by establishing and consolidating collaboration within the Orphanet pan-European network and with European Reference Networks (ERNs) for the production, improvement and dissemination of knowledge on rare diseases. It will allow for the creation of a consistent expertise ecosystem for rare diseases in Europe. <p>The overall outcome is the consolidation of Orphanet as the reference source of information on RD for European citizens.</p>
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Enlaces:	https://www.orpha.net/consor/cgi-bin/Clinics_ERN.php?Ing=EN https://www.orpha.net/consor/cgi-bin/ResearchTrials_Networks.php?Ing=EN