

Título del Proyecto	<b>Codification for Rare Diseases — RDCODE</b>
Nº de expediente asignado	GA: 826607
Abstract	<p>The objective of this project is to support Member States in improving gathering information on rare diseases by implementation of Orphacodes (rare diseases specific codification system). The implementation process will be guided by the "Standard procedure and guide for the coding with Orphacodes" and the "Specification and implementation manual of the Master file" both developed in the frame of the current RD-ACTION. The aim of the Orphacode project is to promote the use of the Orphanet nomenclature for implementation into routine coding systems. This enables a standardised and consistent level of information to be shared at European level. Starting with countries that have no systematic implementation of the Orpha codification yet, but that are actively committed already in doing so, this project will provide a sufficient real-world implementation experience to be captured by other countries in the future. Outcomes are:</p> <ul style="list-style-type: none"> <li>• Development of comprehensive rules of use and meta-data documentation for Orphacodes use in clinical health information and other applications that has been developed and rigorously tested in health care systems from EC countries of varying sizes, health information systems, and languages.</li> <li>• An electronic repository will be created to house this information at the Orphanet website, linking to Orphadata, to include: guidance for use of Orphacodes; teaching and training documents used in health care systems; tools for export of Orphacodes to federated data exploitation at the EC level.</li> <li>• Through collaboration of RDCODE partners and invited collaboration with key stakeholders at workshops, effective implementation will be achieved at implementing countries as well as momentum will be developed in other</li> </ul>

	jurisdictions to implement Orphacodes in widespread use to accurately measure the impact of rare diseases in the EC.
Entidad Financiadora	Unión Europea (Comisión Europea)
Convocatoria:	HP-PJ-2018
Importe de la ayuda	54.966€
Fechas de ejecución del proyecto	01/01/2019-30/06/2021
	“This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 826607 ”.
	
Enlaces:	<a href="http://www.rd-code.eu/">http://www.rd-code.eu/</a>