Título del Proyecto	**Orphanet Data for Rare Diseases II (OD4RDII)**
Nº de expediente asignado	GA 101110100
Abstract	The proposed project, following a pilot phase in 2022, wants to contribute to meet the ambitions set by rare 2030 concerning data. Despite the fact that the Orphanet nomenclature already exists and is freely available in computable formats, the real-life implementation in health information systems is challenging due to the heterogeneity of coding systems and practices, and tools. The experience from the RD-CODE project , supporting diverse implementation models in four MS, taught us that local support in local language for coders and technical teams is necessary to achieve proper implementation in compliance with good practice guidelines for coding and to therefore increase data quality and comparability. To address those needs, it is important to maintain the Orphanet nomenclature of rare diseases, and to improve it building on the well organised and structured rare disease expertise laying in ERNs, to increase its interoperability with other terminologies in use in different countries and in registries, and to contribute to the adoption and implementation, starting by the hospitals involved in ERNs by setting up a Network of National Orphanet Nomenclature Hubs in 19 MS and finally facilitate evidence based decision through exploitation of the Orphanet Knowledge base linked to the ORPHAcodes.

Entidad Financiadora	European Health and Digital Executive Agency (HADEA)
Convocatoria:	EU4H-2022-DGA-IO1-IBA-01
Importe de la ayuda	94 350.25€
Fechas de ejecución del proyecto	01/04/2023-31/12/2025
	“This project has received funding from the European “EU4H Project Grants” under grant agreement No 101110100”. *“Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or HADEA. Neither the European Union nor the granting authority can be held responsible for them.”*
	 Funded by the European Union
Enlaces:	