

# NETWORK OF *orphanet* NOMENCLATURE NATIONAL HUBS 2024

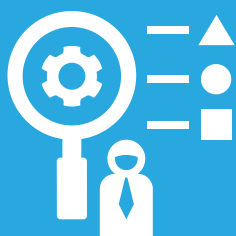


Set up by the OD4RD/OD4RD2 project

**Supporting Rare Diseases codification in National Health Information Systems**

## Our Services

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**Assess users' needs** at national level

**State of Play in 19 countries & A Survey to evaluate the current situation of ORPHAcodes usage by HCPs linked to ERNs (1523 units from 16 countries)**



**Organise capacity building** around the Orphanet Nomenclature and tools

**95 trainings with 1883 participants & 230 ad Hoc meetings or awareness events in national language in 19 countries**



**Support and advice** implementation and use of ORPHAcodes

**200+ demands received via the national HELPDESKs feeding a shared FAQ & Best practice**



**Coordinate partners** to mutualise knowledge and build capacity across the network

**Annual Train for trainers  
Monthly ad Hoc sessions  
Bi-monthly progress meetings**