

## orphanet

# NOMENCLATURE NATIONAL HUBS

## **Our Services**



Assess users' needs at national level



Organise
capacity
building around
the Orphanet
Nomenclature
and tools

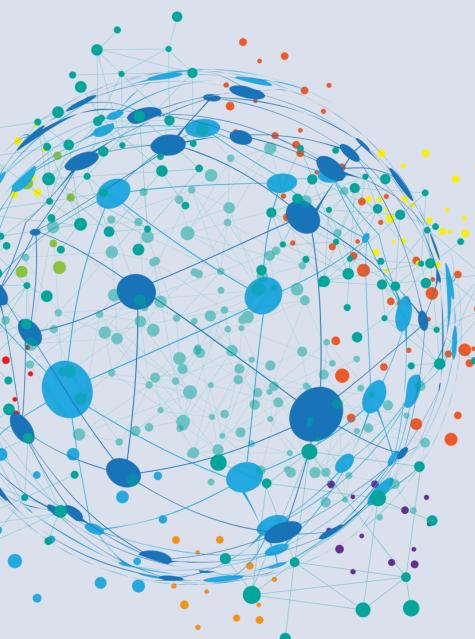


Support and advice mplementation and use of ORPHAcodes



partners to
mutualise
knowledge and
build capacity
across the network

Supporting Rare Diseases codification in National Health Information Systems



#### **About us:**

The OD4RD and OD4RD2 projects have set up a Network of 20 Orphanet Nomenclature National Hubs across EU

## **ORPHANET FINLAND NATIONAL HUB**

The Orphanet Finland National Hub has been established in 2022 and it is hosted by the Finnish institute for health and welfare (THL).

The National Hub is supported by an expert working group on rare diseases, which includes representatives of both the authorities and professionals. Patient organisations are also represented.

## **2023-2025 ACTIVITIES**



**Trainings** 



Networking National expert working group



Helpdesk thl.fi/orpha-koodityhteydenotto

- Increasing knowledge of ORPHAcodes through the national expert group of RD
- Building up an e-course of rare diseases and ORPHAcodes, together with Oppiportti/ Duodecim
- Implementing ORPHAcodes as part of 2/5 University Hospitals' electronic patient files
- Distrubuting the e-course about ORPHAcoding created by Norwegian colleagues at the national RD site at Terveyskylä

### **CONTACT US**







https://github.com/OD4RD/Main-Help-Desk







