



*Supporting Rare Diseases codification in  
National Health Information Systems*

### Our Services

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**Assess users' needs** at national level



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



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



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



### **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-koodit-**  
**yhteydenotto**

- 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
- Distributing the e-course about ORPHAcoding created by Norwegian colleagues at the national RD site at Terveystieteiden tutkimuskeskus

## CONTACT US



[www.OD4RD.eu](http://www.OD4RD.eu) /  
[www.orpha.net](http://www.orpha.net)



[harvinaiset@thl.fi](mailto:harvinaiset@thl.fi)



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

orphanet

**KNOW**  
**THE** FOR  
**RARE** BETTER  
CARE



**OD4RD**

Orphanet Data For Rare Diseases