

NOMENCLATURE NATIONAL HUBS



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

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 SWEDEN NATIONAL HUB

Orphanet Sweden National Hub is based at Karolinska university hospital and focuses on enhancing the coding and knowledge of rare diseases in Sweden.

We work both regionally and nationally to meet the needs of Orphacoding and the implementation of ORPHACodes in the medical record system of the hospitals. Our goal is to further develop collaboration within the hospital and with the European Reference Networks (ERN).

- ◆ Better data, better care, and a better future for patients with rare diseases!

2025 ACTIVITIES



Trainings:

- *In person trainings*
- *Webinars*
- *Targeted/general trainings*



Networking:

- *RaraSwed*
- *Centers for rare diseases in collaboration*
- *Rare Diseases Sweden*



Helpdesk:

- *Contact point Orphanet Sweden*

CONTACT US



www.orpha.net &
<https://orphanet.site/sweden>



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

orphanet

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OD4RD

Orphanet Data For Rare Diseases