



ERNS BOARD TERMS of REFERENCE

Purpose and objectives of the board

The ERNs Board is in charge of providing advice on the strategy addressing the ORPHAcodification and implementation needs, and of facilitating the collaboration between ERN groups and Orphanet team in improving the Orphanet nomenclature and the production of RD information.

The ERN Board will act as the forum in which different kinds of Orphanet-ERNs collaboration will be presented to promote synergies across ERNs.

Mandate

Board members will be invited to :

- Facilitate the connexions with national HCPs in OD4RD participating countries
- Facilitating the application of the ORPHAcodes revision methodology in their networks
- Facilitating the development and validation of information related with RD (i.e. abstracts and definitions) within their networks

Membership

The members are nominated by the Executive Committee. The membership should cover ideally all ERNs.

Rules of procedures

The members are not compensated for the work they dedicate to the project. Members accept their names and affiliations displayed on the OD4RD website.

Expenses related to attending physical meetings (1/y) will be covered by the OD4RD project.

The Board will be regularly provided with all the material necessary to achieve its mission, Responsibilities consist in:

- Responding to Doodle polls and attending virtual meetings
- Read correspondence and documentation ahead of the meetings
- Revising documents
- Providing feedback when requested on specific questions