

RD-Action Consultative Group

Terms of Reference

1. To support and inform the policy work of RD-Action WP6, a Consultative Group (CG) shall be established.
2. The RD-Action CG is comprised of representatives from Beneficiaries and Collaborating partners and is chaired by UNEW (Kate Bushby). UNEW will also provide the secretariat support to the CG.
3. The membership of the CG has been confirmed via expressions of interest and a mailing distribution list established for regular communication. There are currently 30 members of the CG.
4. The CG will participate in conference calls every 2 months, which will be organised by UNEW. The dates for these calls will be provided at least 2 months in advance (6 months in advance from 2016 onwards). All documents and agendas will be distributed by UNEW at least 5 working days ahead of the conference call. CG members will be required to familiarise themselves with any preparatory documents disseminated in advance of the conference calls.
5. CG members will be asked to provide feedback on proposals relating to the current or any new Thematic Priorities, either on the conference calls themselves, or via email.
6. CG members will act as dissemination point for their institution/stakeholders in their Member State. This responsibility will be to cascade relevant messages and updates – and this should include close interactions with the relevant national Orphanet team.
7. CG members will review documents and provide feedback where appropriate (which will include, but not limited to, agendas for workshops, preparatory documents for workshops, and draft documents for the Expert Group, etc.)
8. CG members can request to host workshops funded by WP6, where workshops are required to support policy work on any of the Thematic Priorities. As the budget for all WP6 workshops is held by UNEW as the WP leader, each hosting CG member institution will be required to enter into a contract with UNEW to agree the budget for the workshop, what local support will be provided for the workshop and their contribution to workshop outcomes.
9. CG members may be asked to provide expert support on Thematic Priorities related to their area of speciality/expertise and/ or to provide the links to other relevant experts within their Member State or area of expertise.