



Working Group on Research Terms of Reference

To fulfil RDI's mission to be the voice of people living with rare diseases worldwide and in line with RDI's Joint Declaration that includes Research as a policy priority with international value-added; it is deemed necessary to constitute a Working Group to work specifically on promoting rare disease research at the international level.

General Objectives

The Working Group on Research will be responsible for feeding RDI's position on research and steering all research-related activities of the Organisation, by:

- (a) providing expert opinion on and input on research or topics related to research, produce or endorse existing position papers
- (b) providing expert opinion and input on policies, projects, campaigns relevant to rare disease research that RDI decides to develop and promote
- (c) elevating rare disease research to the status of global public health priority by encouraging and supporting actions through the World Health Organization and the rest of the United Nations system
- (d) being an active link and developer of partnership with relevant scientific and learned societies
- (e) highlighting current or potential opportunities for improved and more integrated international collaborations or public-private partnerships amongst research teams, internationally
- (f) being the reference on Rare Disease Research for the RDI Council and members

Specific Objectives / Deliverables

1. Develop and elaborate on the two recommendations on Research of the *Joint Declaration Rare Diseases: An International Public Health Priority*
2. Provide intelligence on the status of rare disease research worldwide, in view of including non- European countries in the *RareDiseasePlatform (RDPlatform): report on rare disease research in Europe*
3. Support and guide the #RAREvolution Project's awareness and advocacy activities, in particular the Petition to support Rare Disease Research and the *Rare Disease Day 2017* Policy Event. (cf. Letter of Agreement with BLACKSWAN Foundation)
4. Support and guide RDI's representation in *International Rare Disease Research Consortium (IRDiRC)*, in particular in the Consortium Assembly, the Group of Constituents of Patient Organisations and Scientific Committees or Task Forces.

5. Support and guide RDI's representation in the *United Nations NGO Committee for Rare Diseases* on research-related matters

Composition & Selection Criteria

Working Group Members may be full or associate members of RDI or external scientific experts from research and academia.

The Members of the Working Group are appointed based on a Call for Expression of Interest. Additionally, the Council may appoint individuals or organisations to be a Member of the Working Group. Preference will be given to organisations funding research or directly involved in research activities.

The Working Group will also seek to appoint temporary scientific experts of the research community who bring ad-hoc field experience and are knowledgeable in public policy.

The Chair will be a Member of the Council of RDI and the Coordinator will be a full or associate Member of RDI appointed by the Council.

The Chair is responsible for ensuring that the Working Group operates in accordance with its terms of reference and the applicable procedures.

The Coordinator is responsible for presenting and disseminating draft documents, coordinating and consolidating the feedback received from the other members and experts of the Working Group and producing a final version for adoption by the Group. The Coordinator is also responsible for calling actions, meetings and/or elections when needed.

Duration

Members of the Working Group will be appointed by the RDI Council for a mandate of 3 years, renewable at the discretion of the Council and the continued interest of the members and external experts.

Organisation and Communication

The members of the Working Groups are accountable to the Council and shall report back to the Council through the Chair and the Coordinator about their activities and decisions, including participation in relevant Conferences.

Meetings and Voting- A Working Group meeting may be called by its Coordinator or by at least two members with prior notice. Meetings should run according to an announced agenda. Written short minutes shall be kept of all meetings and made available to the RDI Secretariat. The Secretariat can also be invited to attend the meetings and take notes to report back to the Council.

The members' interactions will be mostly performed by email and other electronic means as well as video conferences. The Coordinator with the support of the RDI

Secretariat will organise at least one face-to-face meeting, as a satellite meeting of other relevant events, such as the RDI Annual Meeting, the RE(ACT) Congress, IRDiRC Conference, European Conference on Rare Diseases and Orphan Products or ICORD. The travel expenses of the Chair and Coordinator to prepare and attend the meeting will be paid with RDI Budget.

A private on-line discussion group on the RareConnect (rareconnect.org) platform will support collective exchange and decision-making. A Google drive specifically created for this purpose will be used to work on papers and positions.

The Working Groups shall strive to achieve consensus. If a vote is necessary a simple majority vote shall constitute the decision the Committee. On-line voting is accepted within 7 days.

Members of the RDI Council cannot receive payment for their duties. Only reimbursement of certain expenses incurred for the Working Group will be reimbursed if approved by the Chair of the Working Group.

The purpose and the list of members of the Working Group are listed on RDI website. Members of the Working Group may also publicise their participation in the Working Group.

The external experts are a highly valuable resource to RDI and will be valued for their significant in-kind support.

Conflict of Interest

All candidates to Working Group, shall disclose their potential competing interest. A form for the Declaration of Potential Competing Interest will be provided by the RDI Secretariat. The fact of not providing a filled form will be a reason for not accepting the candidacy or to invalidate it.