



RARE  
DISEASES  
INTERNATIONAL

## **Policy on developing, recommending and adopting advocacy initiatives**

This policy applies and details for implementation:

- RDI By-Laws
- RDI Advocacy Committee Terms of Reference

This document was adopted by RDI Council on February 6, 2018



## 1 – Criteria

### **Policy on developing and recommending priorities for Advocacy Initiatives**

The RDI policy on setting advocacy priorities is to focus on areas of potential maximum impact, where there is an opportunity and where we have the capacity. Using the criteria of value for patients and international added value; of coherence with RDI overall priorities; effectiveness in the use of resources to reach the objective.

This policy translates in the following criteria formulated as questions:

- Is it relevant to patients and their families living with a RD? (VALUE)
- Is it an advocacy priority which can only or better be addressed at the international level? (INTERNATIONAL ADDED VALUE)
- Does it help implement the RDI Joint Declaration Recommendations? (CONSISTENCY)
- Is there a potential high impact (IMPACT)
- Is there a Policy opportunity, an open window? (EFFECTIVENESS)
- Is it a priority across a large number of RDs and large number of countries (EFFECTIVENESS)
- Do we have something to say? Do we have a knowledge base (eg. Existing reports, patient-evidence based, testimonies) Is there existing advocacy materials (position papers of our members) (EFFECTIVENESS)
- Do we have the resources to take on this priority? Do we have in-house expertise (ie. staff, volunteers, experts, advisors, partners)? Do we have the financial resources? (CAPACITY)

### Exclusions:

RDI does not advocate on a specific product or treatment for a specific disease (*this does not apply to therapeutic methods like advanced therapies that are relevant to several diseases*)

RDI does not intervene by itself on a specific disease in a specific country, rather RDI can act jointly with or support the actions of the relevant group regarding a specific diseases and a specific country situation, in this case working with at least one local patient group



## 2 – Products

### **RDI Policy on Types of Advocacy Initiatives to be adopted**

RDI will engage in the following types of Advocacy Initiatives:

1. Contribution or Comment and Response to Public Consultation (ie. Written comment with analysis and proposals to a Report produced by a UN institution or major relevant international stakeholder like IRDiRC, IFPMA, ISPOR, IHGS)
2. Statement or Recommendation
3. Position or Concept Paper
4. Declaration or Petition
5. White Paper or Discussion Paper or Reflection Paper
6. State of the Art or Report
7. Policy briefings or Advocacy Tools provided to RDI members and RDI Volunteers
8. Side Meetings in UN system Convention (eg Human Rights, Disability), General Assembly (eg WHO), Sessions (eg ECOSOC)
9. RDI Policy Event (eg on Rare Diseases Day, World Disability Day)

*NB: RDI, in particular through its Advocacy Committee, can decide on an ad hoc basis on engaging in other type of advocacy initiatives*

## 3 – Methods

### **RDI Policy and Modalities for Endorsement of Positions**

1. The Advocacy Committee reviews an existing position, adopt it with or without changes, and recommends it for adoption by the Council.
2. The Advocacy Committee either asks the Advocacy Committee Core Drafting Group or appoints an ad hoc group to initiate the first draft. The Advocacy Committee is responsible for developing and adopting a final draft submitted to the Council with a recommendation for adoption by the Council.

According to the importance of the advocacy initiative (Position, Concept, White Paper, Reflection, Declaration) the Advocacy Committee will organise a consultation of all members by written procedure, at minimum, or ideally by organising a Webinar.

Other types of advocacy initiatives, which are in a specific context and need a quick turnaround (ie. Contributions, Responses to Public Consultations, Comments, Statements or Recommendations) will be presented and adopted directly by the Advocacy Committee. In any case, all positions adopted are conveyed for information to the Council and all members.

In all cases, the Advocacy Committee does its best efforts to seek consensus or robust sound arguments if there are diverging views.



### Types of adoption

For all the different types of advocacy initiatives, there are 3 approaches:

- RDI generates a position paper or statement and **adopts it independently**
- RDI contributes to a position proposed by a member or external stakeholder and **adopts jointly, co-signing**
- RDI **adopts an existing position** without contributing to the content and provide its official support to the producer of this position

### Types of support

Once the decision to support a position has been taken by the Council, the position can be:

- Adopted by **majority of RDI members**

Whenever Members are consulted, if there are diverging views or minority positions, every effort will be made to accommodate and include the minority view in order to deliver a single converging message.

Whenever Members are consulted they will be asked if they wish to adopt it (with an opt out option of 10 days). The lack of opt out automatically indicates support or agreement. RDI will deal with divergences and differences within the organisation and will present to the world, the majority opinion or decision. The names and logos of all the member organisations at the time of the adoption will be explicitly listed.