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## **TERMS OF REFERENCE FOR THE EURORDIS DIGITAL ADVISORY GROUP**

The EURORDIS Board of Directors endorsed, on 6 July 2019, the creation of a Digital advisory group (DAG) and approved the Terms of Reference describing the strategy and rules of procedure for the EURORDIS DAG.

### **Objectives, Mandates, and Rules of Procedures**

#### **1. MISSION**

To recognise the opportunities for people living with a rare disease and to understand that EURORDIS can play a role in bringing the voice of patients/ patient input into this area/activity.

To pursue opportunities for influence, strategic decision making, helping EURORDIS to assess and bring views of patients to highest level. To access funding opportunities.

#### **2. GENERAL OBJECTIVES**

The Advisory Group advises EURORDIS on all aspects regarding digital policies and procedures. Its role is:

- to inform EURORDIS on developments in the digital space and raise awareness within EURORDIS staff, members and volunteers of digital developments;
- to draw EURORDIS' attention to specific opportunities to bring the view of patients living with rare diseases to any relevant decision-making forum;
- to facilitate the participation of patients in relevant consultations by sharing and collecting contributions from patients and their organisations, comparing different methods for the involvement of patients;
- to contribute to EURORDIS consultations by the European Commission or other relevant EU and international institutions;
- to provide advice and where appropriate help pursue collaboration with the Global Commission to End the Diagnostic Odyssey for Children with a Rare Disease
- to help EURORDIS draft advocacy positions on digital issues, for ultimate consideration by the EURORDIS European Public Affairs Committee or the Board where necessary;
- to horizon scan with a view to help identify opportunities to participate in digital projects, or access grants either as EURORDIS or on behalf of our members; and to make recommendations on which opportunities are the most promising.

#### **3. ACTIVITIES**

Specific activities for the DAG will be regularly defined by the Advisory Group itself. This should be a blend of proactive goals as well as reacting to opportunities and issues that emerge. The review of the value of this group and its ways of working will be reviewed after one full year of activity.



The responsibilities of the DAG include a commitment to participate actively in the work of the group and to adhere to all relevant policies. (see section 10).

#### 4. COMPOSITION of the DIGITAL ADVISORY GROUP

The DAG will be composed of a **MAXIMUM of 14 representatives**, including the following:

- EURORDIS volunteers from Full and Associate Members of EURORDIS who fulfil the following criteria:
  - availability for a minimum of four to six e-meetings and up to two face-to-face meetings per year;
  - strong interest in digital health as evidenced by relevant professional or volunteer experience or relevant training;
  - Previous participation/willingness to participate in EURORDIS Summer School / EURORDIS Digital Academy subject to availability;
  - English language skills and the ability to work in English;
- The Advisory Group will also include a maximum of 4 members of EURORDIS staff serving in an ex officio capacity
- The Advisory Group will include external digital experts from EURORDIS partner organisations acting in the field. External representatives cannot exceed 50% of the group.
- The composition of the group will be reviewed after one full year of its establishment.

As representatives, staff, and volunteers are acting in their individual capacity, it is their responsibility to liaise with their organisation as necessary. It is also their responsibility to inform their organisation about the activities of the Advisory Group and their own membership.

Members of the DAG will be nominated for a term of 3 years; however, membership will be confirmed on a yearly basis based on participation and commitment.

On occasion discussion within the DAG may be subject to confidentiality, and when this is specified confidentiality must be respected by all participants.

#### 5. MEETINGS

EURORDIS aims to organise a one-day face-face session at least once per year. The meeting place and date will be decided on a case by case basis, with a view to minimising cost and maximising convenience for all participants. Other meetings will be conducted by webinar.

Expenses will be covered for EURORDIS volunteers where possible.

All meetings will be held in English.

#### 6. EURORDIS' RESPONSIBILITIES

EURORDIS shall:

- Co-ordinate the work of the Advisory Group;
- Organise meetings (face to face, conference call, video conferences) of the DAG, ensuring timely circulation of meeting documents;



- Ensure adequate co-ordination of the work carried out within the DAG;
- In relation with a DAG member, assist in the preparation of the agenda and minutes of the meetings of the DAG;
- Cover expenses of attendance of meetings for volunteers;
- Contribute to the identification of experts;
- Review existing communication tools and evaluate possibilities for new ones;
- Review adherence to the Code of Conduct and annual declarations on conflict of interest.

## 7. CONTACT

- The DAG will be co-ordinated by Denis Costello, [denis.costello@eurordis.org](mailto:denis.costello@eurordis.org).

## 8. CONFERENCES

8.1. When participating in international or other forums not specifically on behalf of the DAG, members shall make clear that the views expressed are their own views and not those of the DAG.

8.2. When being invited as a EURORDIS' representative, member of the EURORDIS DAG must inform the EURORDIS contact person who will appreciate whether it is appropriate for a member to participate and represent the DAG.

In this case the DAG member:

- Shall ensure that the views expressed are those of the DAG;
- Will identify her/himself with its affiliations to her/his patient groups as well as to EURORDIS;
- Will report back to the DAG on the outcomes and relevant aspects of the meeting.

## 9. GUARANTEES of INDEPENDENCE and PREVENTION OF POTENTIAL CONFLICTS OF INTEREST

Any direct interests in the digital sector must be declared and, where necessary, volunteers and professionals with an interest must recuse themselves. They shall undertake to act in the public interest and in an independent manner, and shall make an annual declaration of potential conflicts of interest. These declarations will be made on a EURORDIS template document.

## 10. CODE OF CONDUCT

The members of the EURORDIS DAG shall comply with the Charter of the EURORDIS Volunteers, which has been adopted by the EURORDIS General Assembly on 8 May 2014 in Berlin. All DAG members will be asked to sign a copy of this code.