

# EURORDIS-Rare Diseases Europe

## Job vacancy – Patient Data Director

**Responsible to:** Chief Operating Officer

**Contract type:** Permanent, full-time

**Salary:** To be confirmed depending on experience and location

**Location:** EURORDIS Barcelona / Brussels

**Start date:** 3 January 2022

### About EURORDIS-Rare Diseases Europe

[EURORDIS](#) is a unique, non-profit alliance of 974 rare disease patient organisations from 74 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research and policies.



### Main scope of the position

The Patient Data Director (PDD) is responsible for shaping EURORDIS' vision in the field of health data sharing for rare diseases. Working with the Digital & Data Patient Engagement Manager, s/he ensures EURORDIS captures and brings the views of people living with rare diseases to the myriad multi-stakeholder efforts working to build an integrated European framework for the collection, use, and reuse of data of relevance to rare diseases.

The PDD will monitor the European landscape and the overall data ecosystem relevant to RDs from a policy and advocacy perspective, managing all related activities, and help us to prioritise the most impactful initiatives. S/he also contributes to building capacities of members and people living with rare diseases and their engagement in relevant data governance structures and networks. S/he will liaise and coordinate with other EURORDIS directors and managers to ensure a consistent and coherent approach to health data protection and data sharing in the different areas.

S/he will reinforce the operational data capacity across the whole of the EURORDIS team by contributing to the development of new EU projects and grant funding related to data and digital for rare diseases.

The post holder will help to develop and implement a comprehensive programme to strengthen the ecosystem for Rare Disease patient health data. This post is in the context of a foundation grant, and the postholder will partner with the COO and the Development Relations Senior Manager to manage the grant and develop the programme's financial resources.

Job announcement last updated: 22 October 2021

## Key tasks & responsibilities

- Monitor legislation and policy activities in the field of EU health data policy, lead analysis and determine the potential impact on people living with a rare disease, developing appropriate responses.
- Drive EURORDIS' cross-cutting work on data by ensuring that the organisation aligns its activities with those messages, liaising across teams and areas, promoting cohesiveness, and help EURORDIS advance with a coherent health data agenda.
- Bring and accept responsibility to maintain expertise on all legal, ethical and policy matters in the fields of digital health and health data, including data protection and privacy, mobile apps, wearables and AI.
- Guides the development of the organisation's capacities in understanding health data.
- Co-ordinate and support the work of the Digital & Data Patient Engagement Manager, providing guidance to develop the Digital & Data Advisory Group (DAG).
- Play a hands-on role in developing projects and pursuing consortiums that will help us put our data strategy into practice and expand our competencies around data and potentially digital technologies.
- Help EURORDIS and its network of patient groups to build on its previous 3 years of published qualitative and quantitative studies of patient perspective on data sharing and data protection, to encourage and scale up the safe sharing of data.
- Help EURORDIS and its network of patient groups to map and make the most of opportunities for improved approaches to patient registries.
- Support EURORDIS' CEO and the wider team on high profile digital technology projects and activities, such as the Global Commission on Diagnostics and the World Economic Forum's Health Digital activities in the 4th Industrial Revolution.

## Experience & skills

### Education/ experience

- Minimum Master's degree in law, public health, or public policy (or equivalent)
- Minimum 10 years professional experience in senior level positions in non-profit organisations or equivalent business setting with a demonstrable track record in analysis of legal and ethical issues with patient data.

### Required

- Fluent English speaker with excellent written and verbal communication skills
- Excellent understanding of patient data and health ecosystem
- Deep understanding of the EU legal and policy framework around data and data sharing and awareness of initiatives in place to facilitate data sharing whilst protecting the rights of patients
- Experience with project development
- Experience working with multidisciplinary teams, with the ability to demonstrate examples of successful teamwork in her/his professional work
- Willingness to travel, particularly within Europe.

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## Preferred

- Knowledge of the rare disease environment
- Experience in working with volunteers and effective management and coordination of volunteer efforts
- Familiarity with research into patient expectations around data sharing and data protection
- Advanced knowledge of a second language
- Understanding of medicines development, issues with access to treatment, and regulation around medical devices
- Broad understanding of digital technologies

## To apply

Please send your CV and cover letter **in English** to [PDD@eurordis.org](mailto:PDD@eurordis.org)

**Deadline for applications: 21 November 2021**

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