

## EURORDIS-Rare Diseases Europe

# Job vacancy – Patient Engagement Manager - Knowledge Management & Outreach – Healthcare

**Responsible to:** ERN and Healthcare Director

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

**Salary:** 34,00 – 38,000 euros per annum + one-month performance-based bonus

**Location:** EURORDIS Barcelona

**Start date:** ASAP

### Main scope of the position

Following the transposition of the EU Cross-Border Healthcare Directive into domestic EU Member State law, Member States and the European Commission established the first 24 European Reference Networks (ERNs) in 2016. European Reference Networks connect scattered expertise, rare disease patients and data to improve access to high quality and safe highly specialised healthcare. EURORDIS created 24 European Patient Advocacy Groups (ePAGs) in 2016 to support structured patient engagement in the ERNs. Today all ERNs have integrated into their governance structures patient representatives following slightly different approaches.

The Patient Engagement Manager - Knowledge Management and Outreach – Healthcare, plays a key role supporting the ERN and Healthcare team to enable sustainable patient-clinician partnership in the ERNs' activities and decision-making process.

The position will play a vital role in helping to identify synergies and facilitate knowledge sharing and access to information on emerging best practices on patient-clinician partnership generated in the ERNs, create new content and curating the body of knowledge and experiences in this area. S/he will be also responsible to lead and manage the ERN & Healthcare team communication activities in close collaboration with EURORDIS Communications team.

S/he will work within the ERN & Healthcare team that is part of EURORDIS Operations Unit. S/he will partner with the ERN & Healthcare Director and Healthcare Advisor, and with the Patient Engagement Manager – Healthcare to support effective patient-clinician partnership in the ERNs, as well as liaise with relevant EURORDIS staff members, notably EURORDIS Communications team to perform the tasks associated with the position.

Job announcement last updated: 25 April 2023

## Key tasks & responsibilities

Support the involvement of ePAG advocates in the ERNs collaborative activities and strategic planning including but not limited to:

### **Knowledge management and Communication tasks:**

- Develop and implement a knowledge management strategy for patient-clinician partnership in close collaboration with the ERN and Healthcare team members.
- Lead on the identification, development and dissemination of knowledge products and lessons learned on patient-clinician partnership in healthcare.
- Develop new content and re-use the content created by the ERN and Healthcare team, including webinars, peer learning sessions and other activities.
- Publish and disseminate knowledge products on patient-clinician partnership in healthcare to enable wide access and use for ePAG patient advocates, EURORDIS staff and ERNs, making it easily accessible and re-usable in close cooperation with EURORDIS Communications Team.
- Draft papers, factsheets and reports and other materials to synthesize existing knowledge and expertise on patient partnership in healthcare.
- Organise and manage meetings and webinars for peer learning and systematic exchange of good practices on patient partnership in the ERNs and healthcare.
- Coordinate and manage the ERN and Healthcare team dissemination activities and conducting communications needs assessment for the team, in close cooperation with EURORDIS Communications Team including dissemination of webinars and other team activities.
- Manage and support of the “Connecting patients to ERNs” working groups including organisation of regular calls and managing the group’s work that focuses on the development of comms materials, such as podcast episodes, factsheets, videos, etc. to connect the patient community with the ERNs.
- Develop communication materials for external communication. (e.g. ePAG newsletter, posters, briefings, articles, social media posts, etc.) and updating the ERN and ePAG sections of EURORDIS website.
- Systematically track the ERN and Healthcare team knowledge management and comms related activities for the purposes of regular and annual reporting.

### **Focal point for knowledge management and communications:**

- Serve as the ERN and Healthcare team focal point for knowledge management and communications, working closely with the Communications team and other EURORDIS teams as required.
- Provide timely and effective responses to inquiries for information on best practices and on patient partnership in healthcare.

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## Experience & skills

### Required

- Minimum BA degree in public health, public policy (or equivalent).
- Minimum 3 years professional experience in non-profit organisations or equivalent business setting with a demonstrable track record in programme and/or project development.
- Excellent written and spoken English, able to independently write complex reports in English for a lay audience.
- Strong planning and organisational skills.
- Strong analytical skills, data analysis skills and reporting using Excel and other tools and strong working knowledge of Word and PowerPoint.
- Experience using digital tools for collaboration and knowledge sharing.

### Desirable:

- Experience in an international environment in the healthcare sector; knowledge of rare disease patient organisations or advocacy groups will be a plus.
- Previous experience in the development and implementation of information/knowledge management strategies
- Previous experience in the development and implementation of communication strategies and tools
- Demonstrated interest in patient needs and by rare diseases or chronic medical conditions.
- Experience working with patient advocacy groups and to support the work of volunteers (patients, carers, professionals) to empower them.

## To apply

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

**Deadline for applications: 19 May 2023**