

EURORDIS-Rare Diseases Europe

Job vacancy – Patient Engagement Manager – Healthcare

Responsible to: ERN and Healthcare Director

Contract type: Permanent, full-time

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

Location: EURORDIS Barcelona Office

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 plays a key role to enable sustainable patient-clinician partnership in the ERNs' activities and decision-making process.

S/he will be responsible for the development and implementation of a patient engagement strategy to support effective patient-clinician partnership in the ERNs. The post holder will be the focal point for patient engagement in ERNs. S/he will take the lead role in all patient engagement activities for ERNs, including driving the development of new tools, processes and practices to facilitate patient engagement in the Networks. S/he will ensure that EURORDIS has a strategic approach to patient engagement that is fit for purpose, based on a continuous assessment of the needs of the ePAG advocates.

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 team up on a regular basis with the Patient Engagement Manager - Knowledge Management and Outreach – Healthcare, as well as liaise with relevant EURORDIS staff members, notably other EURORDIS managers supporting patient engagement in the areas of research, access and therapeutic development, to perform the tasks associated with the position.

Job announcement last updated: 25 April 2023

Key tasks & responsibilities

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

Patient engagement tasks:

- Drive the development and implementation of a patient engagement framework for ERNs, taking into account the ERNs' strategic and operational plans.
- Partner with ePAG patient advocates, the Networks' clinical leads and ERN project managers to develop a sustainable approach to structure patient involvement in the ERNs and to ensure good governance of patient representation in the ERNs.
- Provide guidance to individual European Patient Advocacy Groups and ERN project managers, as requested, to conduct effective patient engagement and support patient advocates and clinicians to build and nurture a partnership culture and bridging between both parties when required.
- Support the identification and recruitment of new ePAG advocates, including the regular induction of new ePAG advocates in collaboration with ePAG leads and ERN project managers, and the renewal mandate process each 5 years to ensure optimal patient representation in all ERNs.
- Lead the ePAG Steering Committee and the Patient Partnership WG and work closely with other EURORDIS staff who manage other cross-cutting topic-based ePAG working groups, to have an overall understanding of the work of each group and monitor progress made.
- Adapt examples of best practice in patient partnership from other EURORDIS and non-EURORDIS initiatives and projects to develop common approaches, methods and tools for patient engagement in the ERNs.
- Organise and manage meetings and webinars for peer learning and systematic exchange of good practices on patient partnership in the ERNs and healthcare.
- Support efforts to measure the impact of patient-clinician partnership in the ERNs, liaising with EURORDIS Rare Barometer team.
- Systematically track ePAG-patient engagement related activities for the purposes of regular and annual reporting.

Focal point for patient engagement in the ERNs:

- Represent EURORDIS and support ePAG advocates at ERN Board meetings and other ERN related events/meetings as required.
- Provide advice on patient engagement in ERN issues to EURORDIS Board and the rest of EURORDIS staff.
- Channel information from ePAG advocate leads to EURORDIS, escalating questions and suggestions to the ERN and Healthcare Director and Advisor when needed to get their feedback and reporting back to the interested person.

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- Contact person at EURORDIS for patient organisations (member and non-member) for all activities related to the establishment and coordination of the European Patient Advocacy Groups.

Experience & skills

Required

- Minimum BA degree in public health, public policy (or equivalent).
- Minimum 3 years professional experience in a European or international environment, preferably in the non-profit, humanitarian or health sectors.
- 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.
- Excellent skills writing, speaking and working in English.
- Strong relationship management skills, good communicator and able to listen emphatically to build trust and confidence as well as to prevent and resolve conflicts.

Desirable:

- Experience working in health care delivery sector
- Experience in designing and implementing patient engagement programmes.
- Experience in an international environment in the healthcare sector; knowledge of rare disease patient organisations or advocacy groups will be a plus.
- Demonstrated interest in patient volunteers and understanding of rare diseases or other chronic medical conditions.
- Ability to work 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

Deadline for applications: 19 May 2023

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