

EURORDIS-Rare Diseases Europe

Job vacancy – Patient Engagement Manager in HTA

Responsible to: Treatment Information and Access Director

Contract type: Permanent, full-time

Salary: 30 – 35 000 euros per annum + one-month performance-based bonus

Location: EURORDIS Barcelona or EURORDIS Paris

Start date: ASAP

Scope of the position

The Patient Engagement Manager in HTA (PEM-HTA) organises the participation (awareness, training, mentoring) of people living with a rare disease and their representatives in the European Cooperation on HTA, including its technical/scientific and political/strategic aspects, and in national HTA procedures. In addition, the position aims at participating in any research activity in the HTA field where EURORDIS is invited to take a role.

The PEM-HTA is supervised by the Treatment Information and Access Director. Whereas the TIAD provides content leadership for all of these initiatives, the PEM-HTA serves as project manager, making the operational link to the Chief Operating Officer and to Finance.

The PEM-HTA works closely with other Patient Engagement Managers; they share common tools (e.g. database, declarations of interest, capacity building programmes). S/He liaises with the Senior Membership manager and the Open Academy team. S/He also connects with the Communication department for the information of EURORDIS' members/stakeholders and for communication to the public.

The PEM-HTA position is focused on the implementation of a programme for the active involvement of people living with a rare disease in HTA procedures, and in the evaluation of policies, both at national and European level. This includes the contribution to discussions on technical and scientific aspects and on the political and strategic vision. The position is meant to build an adequate knowledge on HTA within EURORDIS, to contribute to a meaningful patient engagement and to support EURORDIS' advocacy for access to treatments for persons living with rare diseases.

Main responsibilities

- Coordinate EURORDIS' activities related to the assessment of new health technologies for people living with rare diseases in Europe, orphan medicinal products but also paediatrics, gene and cell therapies, medical devices, diagnostic tests, connected devices, medical applications, tele-monitoring tools (e-health)
- Contribute to EURORDIS advocacy on HTA both at national and European level

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- Manage the process of patient engagement in Health Technology Assessment, in particular with the coordination of an HTA task force composed of EURORDIS volunteers active in HTA at national or European level
- Take action in relevant work packages of the HTx project
HTX project activities represent up to 50% of the position: to coordinate EURORDIS role in the project and report to Finance and Operations, manage involvement and active participation of patients with Head and neck cancer, myelodysplasia, to manage the delivery obligations of partners within the project (including contract management), and project communications with EURORDIS and our stakeholders, ensuring awareness is promoted to a larger group of patient advocates
- Manage documents/bibliography in relation with EURORDIS' action in the field of HTA, and organise workshops with experts in health economy, experts in the organisation of the pharmaceuticals and medical devices markets, - particularly in the context of EUnetHTA, the HTA Network, and other conferences including ERTC.
- Manage EURORDIS' HTA training activity. We are hopeful of securing an HADEA action grant and if this is successful the PEM-HTA will manage the HTA training project, including coordinating EURORDIS's involvement, managing recruitment of patients and allocation of fellowships, managing project reporting. This can represent up to 25% of the PEM's time.

Key tasks

- In the framework of the HTx Project:
 - Meet with key HTx partners with HTA task force volunteers, to understand the progress made and develop information and training tools
 - Attend HTX conferences and workshops
 - Liaise with concerned patient groups (e.g. CABs / disease specific groups selected as pilot in HTx) and communicate to the wider patients' audience (conferences / public fora) about the aims and the methods of the project
 - Supervise subcontractors for the development/production of educational materials
 - Lead all project reporting and make the link to Finance, OA and the COO
- In the framework of EURORDIS' involvement in EUnetHTA21 and the EU Cooperation on HTA:
 - Contribute to EUnetHTA21 public consultations
 - Represent EURORDIS in discussions with EUnetHTA21 and with the European Commission
 - Help EUnetHTA21 and national HTA bodies identify patients (and if applicable to provide support and mentoring on how to participate)
 - Contribute to methodological discussions for HTA, all aspects considered
 - Understand how patients are engaged in HTA at national / regional level
 - Prepare EURORDIS' contribution to the drafting and approval of the delegated and implementing acts of the HTA Regulation
 - When the European Cooperation on HTA will start its activities:
 - Identify patients for the different procedures and to coordinate their training
 - Represent EURORDIS in the Stakeholder Forum
 - Contribute to the work of the working groups
 - Liaise with ERNs when applicable (treatment guidelines)
 - Take part in training (dedicated training on HTA and pricing, EURORDIS's Open Academy etc.)
- Supervise and coordinate the activities of EURORDIS HTA Task Force:

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- Plan meetings and actions of the Task Force, preparing agendas, including logistical aspects
- Prepare the Task Force work plan together with its members, in line with the Task Force mandate
- Report on actions and discussions, checking contributions of volunteers in terms of time spent (economic valuation) and communicate on the task force achievements
- Evaluate the participation of members to the Task Force activities
- Other activities towards EURORDIS members
 - Oversee our training work on HTA (nature will vary depending on HADEA grant discussed above)
 - Inform members on different engagement methods in HTA (both national and European level) and share any other relevant information necessary for their participation in HTA

Experience & skills

- Minimum 5 years' education in science, biology, pharmacy, or medicine
- Understanding of health technology assessment, including economic aspects
- Understanding of Patient Relevant Outcomes Measures, Patient Reported Outcomes Measures, Patient Reported Experience Measures
- Experience in working with volunteers and effective management and coordination of volunteer efforts
- Experience in taking part in European projects, including activity and financial reporting
- Experience working directly with patients, care-givers or patient groups in a support or advocacy setting and knowledge of the Rare Disease environment
- Significant experience working in the communications area and displaying a high level of sophistication in representing an organisation appropriately.
- Ability to organise workshops and training events
- Availability to travel, in particular within Europe.

- Fluent English speaker, knowledge of second European language
- Project management, budgeting and business skills
- Moderating meetings, including diplomatic skills
- International and inter-cultural profile
- Team worker and able to work under pressure
- Graphic design skills (Photoshop, Indesign, Illustrator...)
- Knowledge of Facebook ads and Google Adwords and experience with mass-mailing tools such as Constant Contact, Campaign Monitor, MailChimp etc. desired
- Ability to search for quality medical information on the internet via Pubmed, Orpha.net, Clinical Trials.gov and other sources and source quality RSS feeds (a plus)
- High comfort-level with technology: able to manage online meetings and webinars, taking advantage of zoom functionalities

To apply

Please send your CV and cover letter in English to francois.houyez@eurordis.org

Deadline for applications: 15 July 2022

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