

EURORDIS-Rare Diseases Europe

Job vacancy – Patient Experience Survey Research Executive

Position: Patient Experience Survey Research Executive

Responsible to: Rare Barometer survey program Senior Manager

Contract type: Short-term, full-time – to April 2020

Salary: 37 – 41 000 euros per annum

Location: EURORDIS Paris/Barcelona/Brussels – possibility to work remotely

Start date: ASAP

The **Patient Experience Survey Research Executive (PESRE)** will be in charge of managing a large-scale pilot survey aiming to collect rare disease patients' experience within hospitals affiliated to a European Reference Networks (ERNs), with the objective of designing a data collection and analysis model.

EURORDIS is a non-governmental patient-driven alliance of patient organisations representing 860 rare disease patient organisations in 70 countries. We are the voice of 30 million people affected by rare diseases throughout Europe. EURORDIS is supporting 4 European Reference Networks to develop a pilot survey. ERNs are virtual networks that aim to tackle complex or rare diseases that require highly specialised treatment and a concentration of knowledge and resources. There are 24 ERNs that bring together more than 900 expert centres on complex and rare diseases across 25 European countries. The overall goal with this pilot is to prove that patients' experience within the ERN project is both an important and viable metric.



The project is carried out within the framework of the EURORDIS Rare Barometer programme. This survey programme aims to collect rare disease patients' opinions and experiences through validated methods on topics that directly affect them. Results of the surveys are used to develop an evidence-based approach to our advocacy work. Rare disease patients participating in this pilot will join [the Rare Barometer Voices panel](#), a group of patients who are willing to take part in surveys. The patient experience survey research executive will report to the Rare Barometer survey program Senior Manager.

A working group composed by patient advocates, clinicians, ERN project managers working in the 4 ERNs has been set up to steer the pilot. EURORDIS' ERN and Healthcare Director and the Rare Barometer survey program Senior Manager are also part of this working group and will define the general approach of the pilot survey.

Key tasks & responsibilities

The main scope of this post includes:

- Carrying out a literature review on validated scales that will be used to collect patients' experience
- Defining and collecting other background information needed (official statistics, scientific publications on how to measure patient satisfaction) for the data collection model

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- Establishing survey data collection systems: designing survey questionnaires, questionnaire translation processes, etc.
- Managing the survey fieldwork: implementing the survey, developing a dashboard to follow the fieldwork, answering patients' and care providers' requests, reporting on survey fieldwork to the manager of the programme
- Ensuring the integrity of data and reviewing data for anomalies and resolving issues around data
- Generating survey reports and graphical analysis
- Carrying out basic and advanced statistical analysis using Sphinx software or another relevant software (SPSS, R, SAS) and analysing the data
- Communicating with the pilot working group as well as healthcare providers involved in the project to maintain an optimal level of engagement
- Drafting reports about the results of the survey and a feedback report on the pilot experience
- Contributing to identifying funding opportunities for future development of the project

The PESRE will also provide occasional support to the Rare Barometer team for other survey projects as and when required.

Experience & skills

- Preferably Ph.D or Master's degree in quantitative social science discipline, such as medical/social statistics epidemiology, medical statistics, sociology, economics, psychology, demography.
- PHD or at least 5 years' experience in health-related quantitative research, data collection methods, and advanced statistical analysis. Working knowledge of statistical software, such as Statistical Analysis System (SAS) and Statistical Package for the Social Sciences (SPSS)
- Written and spoken proficiency in English, an additional language such as French in particular would be highly appreciated

To apply

Please send your CV and cover letter in English to Sandra.courbier@eurordis.org

Deadline for applications: 31 July 2019

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