

EURORDIS-Rare Diseases Europe

Job vacancy – Survey project manager

Responsible to: Rare Barometer Lead

Contract type: Permanent, full-time

Salary: 34 – 40 000 euros per annum + one-month performance-based bonus, if based in France

Location: EURORDIS Paris preferred but Brussels/Barcelona/Working remotely can be envisaged

Start date: As soon as possible

About EURORDIS-Rare Diseases Europe

[EURORDIS](#) is a non-governmental patient-driven alliance of patient organisations representing 1000 rare disease patient organisations in 74 countries. We are the voice of 30 million people affected by rare diseases throughout 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, policies and patient services.



Main scope of the position

At the core of this role is the Rare Barometer programme. This survey programme collects rare disease patients' perspectives and opinions through **qualitative and quantitative data collection methods** on important topics for the rare disease community. These data contribute to feeding EURORDIS' evidence-based advocacy work to improve the lives of people living with a rare disease in Europe. Survey results are disseminated among patient organisations, European and International institutions and various networks and conferences.

Under the supervision of the Rare Barometer Senior Manager, the Survey Project Manager oversees the design, dissemination and analysis of international surveys gathering the experience and perspective of rare disease patients.

Key tasks & responsibilities

- Managing quantitative surveys including drafting questionnaires, implementing the survey in the software, supervising survey fieldwork, drafting reports;
- Managing qualitative research projects, including drafting interview guide, conducting qualitative interviews or focus groups, analysing qualitative material, drafting reports;
- Answering patients' and carers' requests regarding the survey;
- Ensuring the integrity of data and reviewing data for anomalies and resolving issues around data;

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- Conducting basic and advanced statistical analysis using Sphinx software or another relevant software (SPSS, R, SAS);
- Analysing and codifying open questions from quantitative surveys;
- Drafting reports about the results of the survey;
- Organising and facilitating online or face to face focus groups;
- Facilitate group discussions with patient organisations and other stakeholders around the survey results;
- Maintaining data quality, both in the context of responses to individual surveys as well as for the Rare Barometer survey database
- Conducting literature reviews;
- Transform survey results into key messages that will be used for EURORDIS advocacy;
- Delivering oral presentations of the survey results.

Education and experience

- Master's degree or Ph.D in quantitative sociology, health sociology, medical/social statistics, epidemiology, medical statistics, economics, psychology, demography.
- At least 2 years' experience in quantitative research, preferably health-related, data collection methods, and advanced statistical analysis;
- Background and experience in qualitative research;
- Experience working in advocacy and public communication; or experience working with patient organisations preferred.

Skills and capabilities

- Knowledge of Sphinx software that is used within the Rare Barometer programme would be highly desirable;
- Working knowledge of statistical software, such as Statistical Analysis System (SAS) and Statistical Package for the Social Sciences (SPSS);
- Very high level of proficiency in English; additional languages desirable.

To apply

Please send your CV and cover letter in English to jessie.dubief@eurordis.org

Deadline for applications: 31 March 2023

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