

## **Clinical Outcome Assessment Methodology Lead**

RARE-X is reimagining the role of patient-powered data collection and sharing to drive research. We believe that there is an opportunity to radically impact how we work to support patients and the rare disease ecosystem to be more efficient, supportive and open. We imagine:

- A world in which the only barrier to solving for rare diseases is the pace of science
- An organization that applies health technology and data sciences coupled with patient driven data, to one of the biggest and most solvable challenges in rare disease therapeutic development: *data access*
- A team that thinks creatively, works collaboratively with and for patient communities, and operates with accountability to establish a shared and trusted environment for rare disease data access

RARE-X believes that by enabling rare patient communities to more easily gather, structure and securely share data through a common platform, in collaboration with researchers, drug developers and clinicians anywhere in the world, we will accelerate diagnosis, disease understanding, and development of future treatments and cures across rare diseases.

## **Job Description**

As the RARE-X Clinical Outcome Assessment Methodology Lead, you will drive RARE-X data structure and standardization efforts for patient-reported data across multiple domains, while supporting the development and implementation of processes for standardized data collection and utilization of natural history data for downstream analysis.

### **Responsibilities**

- Develop high quality, efficient processes to reproducibly identify and integrate new data domains to the RARE-X platform that are disease relevant and meet the highest scientific standards
- Identify existing survey data standards, gaps in existing data standards and develop new data elements where applicable
- Lead development of data elements, surveys, and data dictionaries



- Work cross-functionally on robust, quality implementation of surveys in RARE-X platform
- Develop and manage multi-stakeholder working groups to develop standards-based domains and data elements, including content experts, patient advocates, and industry advisors and researchers, with the overarching goal of developing patient-centered outcomes
- Recruit and manage survey methods team
- Develop data quality/surveillance Standard Operating Procedures Overseeing data quality in new data collection projects
- Support efforts to link standardized data elements to electronic health record data
- Support data federation efforts to integrate existing natural history or registry databases, allowing for integrated analysis through the RARE-X platform.
- Evaluate retrospective data collection from previous registries or other data collection efforts
- Represent RARE-X in meetings, conferences, presentations, and education efforts
- Present research findings at industry conferences and via publications in high-quality journals and other appropriate media
- Serve as an expert scientific/technical resource across the company

### **Experience**

- Advanced degree (PhD or Masters) or equivalent experience in Survey Methodology, Biostatistics or related fields of analytics, social science or health research
- 10+ years' experience in survey methodology, data collection and related work
- Experience working in rare disease research highly desirable
- Experience developing clinical outcome assessments to support regulatory filings highly desirable
- Proven ability to work collaboratively across multiple disciplines within an organization
- Highly motivated with the ability to work independently and in a dynamic team environment
- Excellent problem solving, project management, communication and presentation skills
- Personal qualities of integrity, accountability, credibility, empathy and passionate commitment to the mission of RARE-X

Please email your resume and cover letter to [jobs@rare-x.org](mailto:jobs@rare-x.org).



RARE-X values diversity and is committed to equal opportunity employment. All qualified applicants will receive consideration for employment without regard to race, color, religion, sex, sexual orientation, gender identity, national origin, disability or protected veteran status.