Research Data Analyst

Position Description:
Are you passionate about the power of data to transform biomedical disease understanding, research, and medicine development? Are you an organized individual who has a scientific mind who excels at process implementation? Are you detail and process-oriented with the ability to think creatively and be flexible to stakeholder needs? We seek a Research Data Analyst to contribute to our efforts to integrate and align internal and external data to support open science research in rare disease.

RARE-X is a 501(c)(3) patient advocacy organization focused on supporting the acceleration and development of life-altering treatments and future cures for patients impacted by rare diseases. Enabled by best-in-class technology, patients, researchers, and partners, RARE-X will support patients and advocates to gather structured, high-quality, standardized data to share broadly, benefitting from 21st-century governance, consent, and federated data sharing platform technology. RARE-X intends to build the largest collaborative patient-driven, open-data access platform for rare diseases globally.

The Research Data Analyst will work closely with RARE-X’s platform team and Principal Investigator to integrate data from a variety of systems and sources, both external and internal. The Data Analyst will implement quality control programs and monitor the quality of internal data stores and flows. This individual will also meet regularly with our platform partners to ensure that both the original data and user interface effectively meet the needs of RARE-X’s research users.

RESPONSIBILITIES

- Develop and implement integration of new data structures within RARE-X’s data collection platform.
- Investigate, troubleshoot and document data discrepancies from internal and external data sources. Develop processes to identify and resolve quality control issues, and communicate opportunities for process improvement.
- Support data movement throughout the RARE-X data ecosystem from data collection, aggregation/federation through access.
- Develop familiarity with established data models for the systematic analysis of internal and external biomedical data sets. Work with RARE-X’s Principal Investigator to ensure that data collected and incorporated into the open research platform enable efficient analyses by research partners.
- Align data points for new surveys and patient-reported outcome measures (PROs) to existing data models for integration onto the RARE-X platform.
- Support alignment of clinical research data collection from RARE-X collaborative clinics and integration medical record data source partners.
- Work with key external stakeholder partners to review data structure and support the governance of data sharing and alignment.
- Support open science data challenge initiatives by conducting queries and determining feasibility of challenge questions.
REQUIREMENTS

- BA or BS in biology related field with preference for bioinformatics and computational biology
- Bioinformatics/biostatistics and coding experience (proficiency with R and Python preferred)
- Knowledge of research methods, statistical methods, and cloud-based data analytics
- Strong analytical/problem solving and decision-making skills
- Familiarity with medical coding, terminology, and ontologies a plus
- Excellent written, verbal, and interpersonal skills
- Flexibility and responsiveness in a fast-paced, rapid growth environment
- Detail-oriented, with demonstrated ability to follow Standard Operating Procedures (SOP) and maintain detailed records

COMPENSATION AND HOURS REQUIRED

- Full-time employee
- Hours: 40 hours per week, The daily schedule can vary based on project priorities and organizational needs.
- Remote: The RARE-X team is located across the United States and all meetings are remote. Occasional travel may be required. Compensation: Competitive pay for services