Incorporating Patient Voice into Real-World Evidence Generation in the Canadian Neuromuscular Disease Registry.


Registry Goals
- Support therapy development
- Improve patient outcomes
- Improve understanding of disease

Registry Utility

Current Successes: Clinic-based data
- 4415 registrants
- 136 projects: Clinical Trial Inquiries, Data Analyses, Patient and Practitioner Surveys.
- 94 project partners: Pharma, Government, Patient Organizations, Academics.

Filling the gap: Patient Voice

Patient Preferences Survey
Collect patient preferences for engagement and participation in patient-generated health data to inform registry methods and data collection
- Participation motivators and barriers
- Time commitment and frequency
- Methods of engagement
- Research topics
- Technology preferences

Analysis:
- Adult vs. pediatric, gender
- Disease-specific & severity
- Urban vs. Rural/ Provincial

Patient Voice in Registry Research

Objectives
Patient Voice incorporated into clinical registry

Methods
Patient-reported Outcome Measures
Datasets tailored by diseases

Data Collection
Real-time monitoring

Results & Analysis
Quality-of-life Activities of daily living
Wearables

The CNDR provides a nationwide platform for quantifying the burden of illness and describing clinical care across a diverse country. The addition of patient-generated data in combination with clinical data will improve the scope and impact of the registry. For collaboration opportunities, contact us at: admin@cndr.org.