

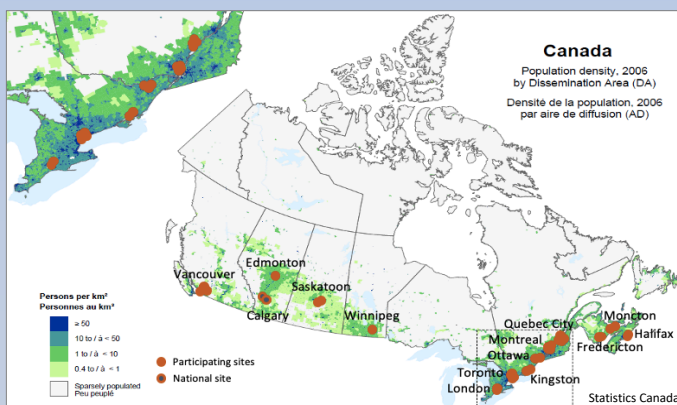
Incorporating Patient Voice into Real-World Evidence Generation in the Canadian Neuromuscular Disease Registry.

Vu L, Hodgkinson V, M'Dahoma S, Lounsberry J, Brais B, Campbell C, Johnston W, Lochmüller H, McCormick A, Nguyen CT, O'Ferrall E, Oskoui M, Korngut L, and the CNDR Investigator Network.



Registry Goals

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



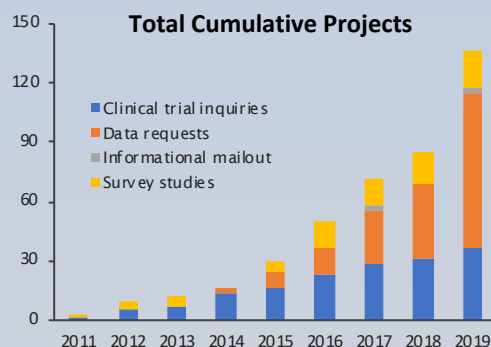
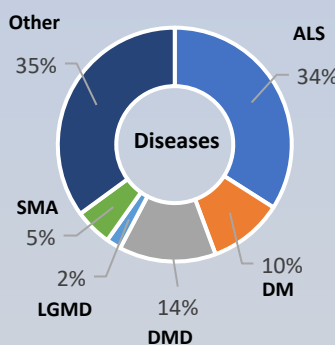
CNDR Overview

- Clinic-based data collection
- Launched **2011**
- **32 neuromuscular and ALS clinics**
- Network of **57 investigators**

Registry Utility

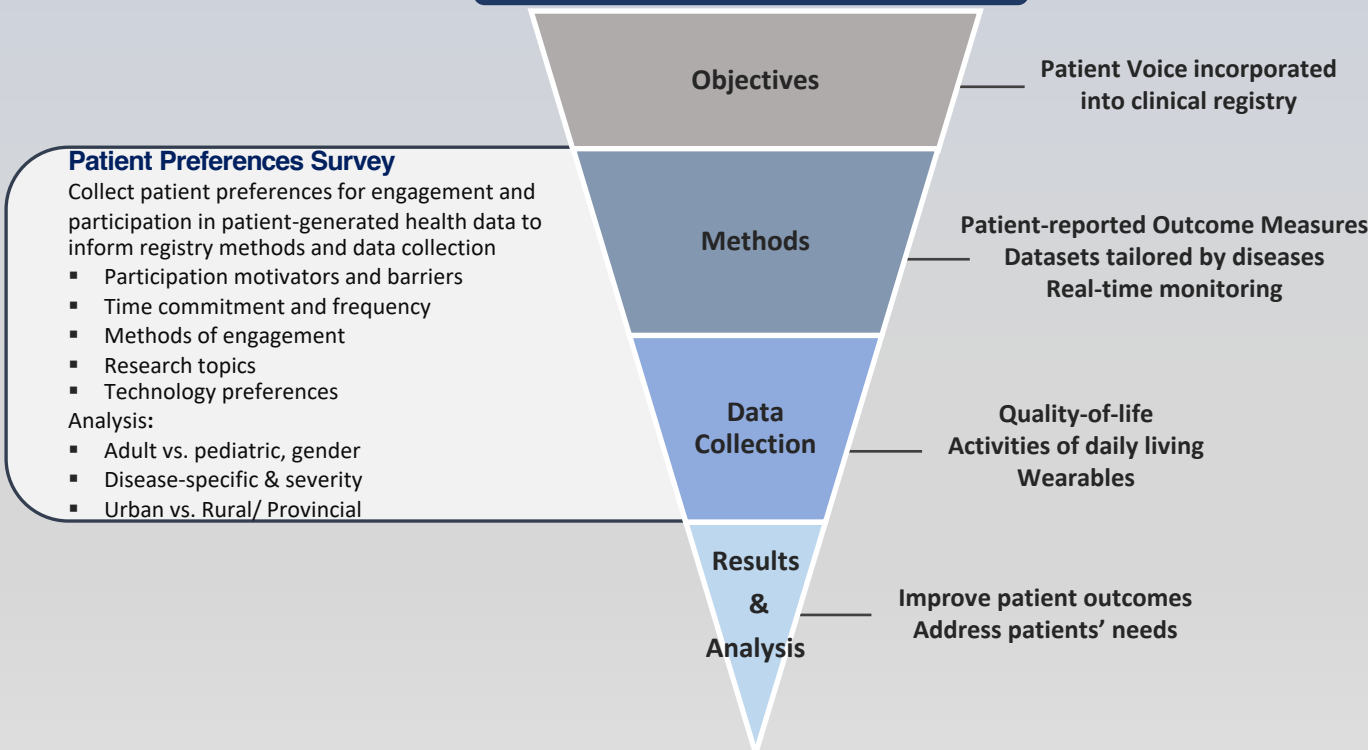
Current Successes: Clinic-based data

- **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 Voice in Registry Research



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.