

NMO-RG: A Friendly-User Data Platform to Foster Real-World Research and Collaboration

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INTRODUCTION

Patient registries for rare diseases enable the pooling of data to achieve adequate sample sizes, serving as crucial tools for research, clinical trials, and healthcare improvements. Neuromyelitis optica spectrum disorders (NMOSD) are rare conditions whose prevalence, phenotypic features, and outcomes vary by population and geographic region. The Neuromyelitis Optica Registry (NMO-RG) is a newly developed, user-friendly data platform designed to foster cross-border collaborative studies.

MATERIALS AND METHODS

We employed a MySQL-based relational data management system to organize information on NMOSD patients. The platform was developed through HTML, PHP, and JavaScript and features over 250 information fields. Users can add new patients, edit records, generate reports, and export data for statistical analysis. The system includes automatic consistency checks and calculations, indicating when records are incomplete until a standard set of required information is provided.

RESULTS

The platform collects professional user information, ethical statements on patient registration, the patient's unique code, and registration date, along with demographic data, past autoimmune history and comorbidities, family history of autoimmunity, date of disease onset, date of diagnosis, clinical features at disease presentation, treatments, and degree of recovery. It also records characteristics of relapsing attacks, their management, and recovery rates, as well as disease duration, EDSS at the last visit, annualized relapse rate, AQP4-IgG and MOG-IgG serostatus and assay methods, serum systemic autoantibodies, CSF profile, and brain, optic nerve, and spinal cord imaging findings. Previous and current maintenance therapies are noted, and information on optical coherence tomography is currently being incorporated. Presently, the NMO-RG database contains data for more than 1,200 patients from Brazil and Latin America.

CONCLUSION

The NMO-RG provides a structured framework for data collection and analysis, advancing our understanding of NMOSD in diverse racial and environmental contexts. By promoting collaboration and data sharing, it helps overcome the inherent challenges posed by this rare disease.

