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Short report

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Mapping myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD) and neuromyelitis optica spectrum disorders (NMOSD): A global review of publicly listed patient disease registries and databases

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Abstract

Background: Real-world data are crucial to improving care for patients with rare diseases.

Objectives: To develop the first global map of myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD) and neuromyelitis optica spectrum disorders (NMOSD) patient registries/databases. Registries/databases were identified through rare disease portals, registry websites, and other sources, and surveyed.

Results: Of the respondents ($N = 26$), the majority were established within the past 15 years and reported being self-funded. Most collect diagnostic, clinical, and laboratory data. Major objectives included supporting scientific research and advancing disease understanding.

Conclusions: Despite cost, time, resource, and data quality challenges, registries/databases provide important insights into addressing unmet needs in MOGAD and NMOSD.

Keywords

patient registry, patient database, real-world data, rare disease, MOGAD, NMOSD

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Introduction

Myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD) and aquaporin-4 (AQP4) antibody-seropositive neuromyelitis optica spectrum disorder (NMOSD) are rare, neuroinflammatory autoimmune diseases of the central nervous system.[1–3] Despite increased disease awareness and research efforts, real-world evidence on both diseases remains limited, particularly regarding natural history, long-term outcomes, and patient characteristics across healthcare settings.[4,5]

Patient registries/databases can address evidence gaps by providing longitudinal data on rare diseases, where randomized clinical trials are challenging to conduct.[6] Although MOGAD and AQP4 antibody-seropositive NMOSD are recognized as distinct entities, their clinical presentations may overlap with each other or with multiple sclerosis and other neuroinflammatory disorders, making differential diagnosis challenging.[2,7] International consensus diagnostic criteria were published in 2015 for NMOSD and in 2023 for MOGAD, underscoring the need for high-quality real-world datasets to refine phenotyping and assessment of outcomes.[1,8] To date, the global landscape of MOGAD and NMOSD registries/databases has not been characterized; this study addresses this gap.

Methods

For the purposes of this exercise, the terms "registry" and "database" describe organized repositories of patient-level information relating to MOGAD and/or NMOSD.

Registries/databases were identified via a structured search of rare disease portals, registry directories, patient advocacy group websites, government agency websites, academic websites, published literature, and consultation with international experts (via the study steering group, collaboration with clinical experts, and direct engagement with registry leaders and patient advocacy organizations). Searches focused on combinations of disease and registry/database terms, including MOGAD, NMOSD, NMO, myelin oligodendrocyte glycoprotein antibody-associated

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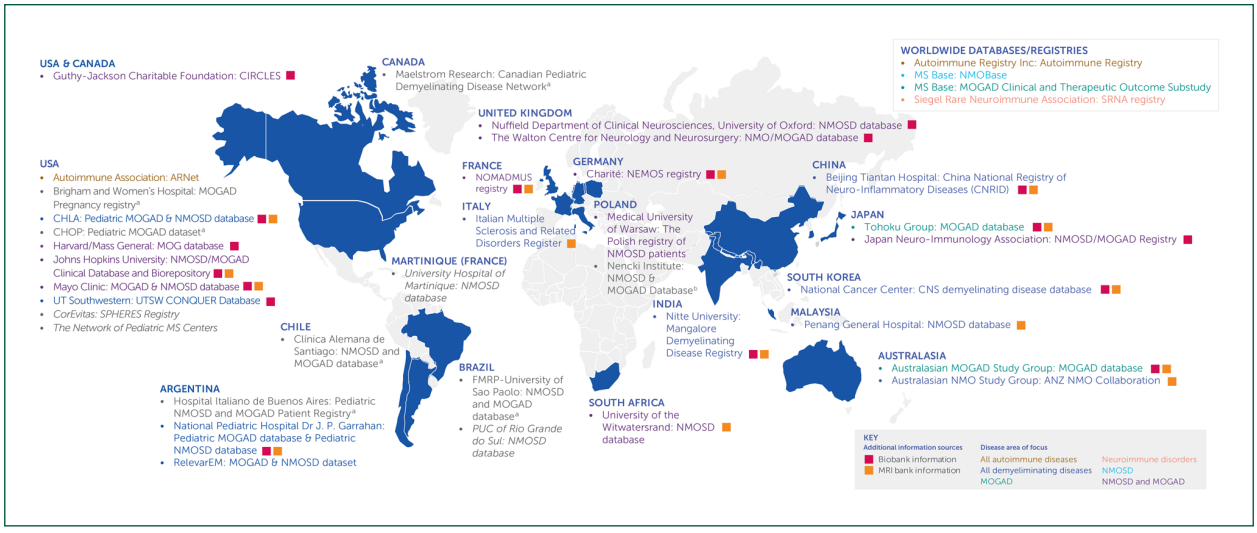


Figure 1. Global map of MOGAD and NMOSD patient registries/databases.
Organizations and databases/registries indicated in *italics* did not respond to the survey or provide any information for this report; they have been included in the map to ensure comprehensiveness. All surveyed databases/registries collect patient demographic and health data.
MOG, myelin oligodendrocyte glycoprotein; MOGAD, myelin oligodendrocyte glycoprotein antibody-associated disease; MRI, magnetic resonance imaging; NMOSD, neuromyelitis optica spectrum disorder.
[a]Agreed to participate but did not complete the survey.
[b]Identified and contacted after survey completion.

disease, neuromyelitis optica, patient registry, patient database, neuroinflammatory disease registry, demyelinating disease registry, and rare disease registry. Where relevant, searches were also refined using country, institution, or known registry names. The included registries/databases collected patient-level information relevant to MOGAD and/or NMOSD; were active or publicly described at the time of mapping; could be verified through publicly available information and/or direct contact with the registry team; and represented either a dedicated MOGAD/NMOSD registry or a broader neuroinflammatory/demyelinating disease registry containing patients with MOGAD and/or NMOSD.

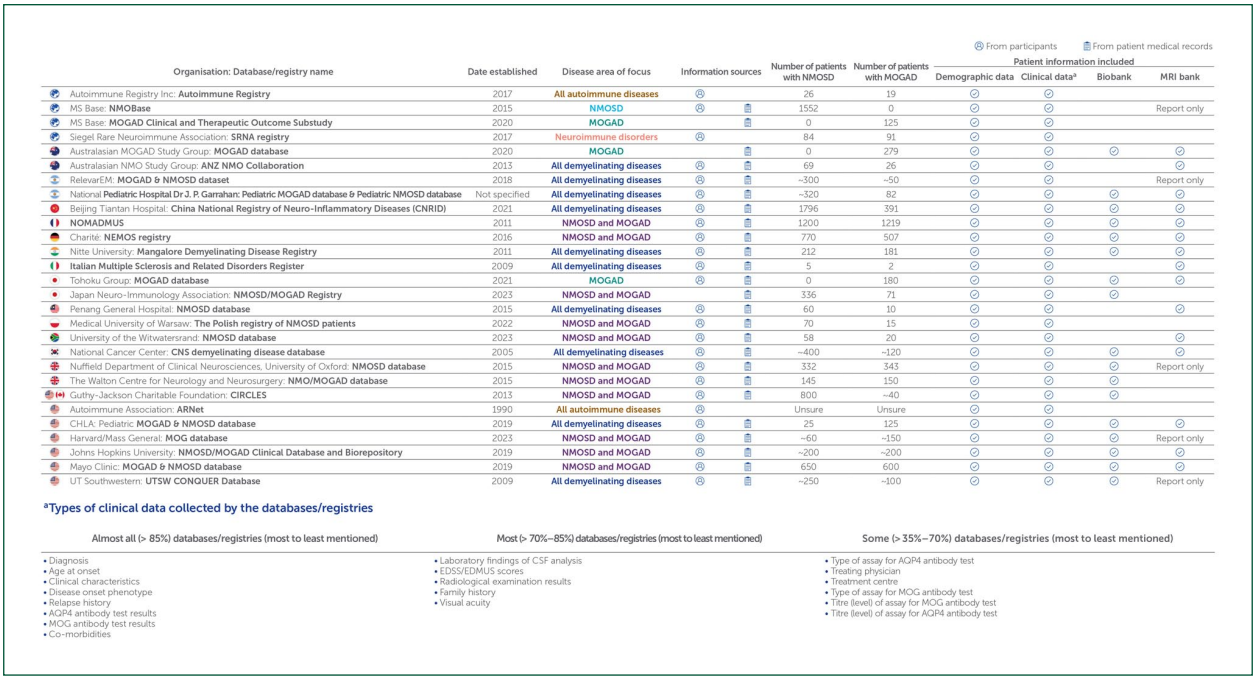
The purpose, number of patients, and types of data collected were recorded for each registry/database. In October 2023, a survey was distributed to contactable registries/databases to collect information on patient numbers, data elements collected, approaches to consent and identifiable information, data-sharing practices, long-term objectives, and operational challenges (Supplemental Table 1). In March 2026, included registries/databases were invited to provide updated patient numbers.

Results

In total, 39 MOGAD and NMOSD registries/databases were identified globally (Figure 1). Survey responses were provided by 26 registries/databases, and an additional three provided information after survey closure. Of these, one (Mayo Clinic MOGAD) was a partner registry to a survey respondent (Mayo Clinic NMOSD), and these were combined, leaving 28 in the final list. In total, 27/28 registries/databases (96%) included patients with MOGAD, and 25/28 (89%) included patients with NMOSD. For the 28 registries/databases, a common dataset was sought; disease area of focus, number of patients, information sources, and types of data recorded are summarized in Figure 2. Below, we report additional survey data collected from the 26 initial respondents.

The majority of the registries/databases (>85%) collected core diagnostic and clinical data, including confirmed diagnosis, age at onset, clinical characteristics, first attack phenotype, relapse history, antibody test results (AQP4 and myelin oligodendrocyte glycoprotein [MOG]), and comorbidities. Most (> 70%–85%) also collected data on laboratory findings of cerebrospinal fluid analysis, Expanded Disability Status Scale/European Database for Multiple Sclerosis scores, radiological examination results, family history, and visual acuity. Fewer (>35%–70%) collected data on assay type and titer for the AQP4 or MOG antibody test, treating physician, and treatment center.

Half of the registries/databases (n=13/26, 50%) collected identifiable patient information that was later deidentified for research purposes. In addition, 8/26 (31%) collected identifiable information with consent from the patient (or their guardian for pediatric patients/those unable to provide consent), while 5/26 (19%) collected only deidentified information. Data-sharing practices varied; 22/26 (85%) and 12/26 (46%) registries/databases shared deidentified information with third-party researchers or industry partners, respectively, for ethics committee-approved projects/collaborations. Self-funding was the primary funding mechanism for most (n=18/26, 69%),



From participants | From patient medical records

Organisation: Database/registry name	Date established	Disease area of focus	Information sources	Number of patients with NMOSD	Number of patients with MOGAD	Patient information included: Demographic data	Clinical data[a]	Biobank	MRI bank
Autoimmune Registry Inc: **Autoimmune Registry**	2017	All autoimmune diseases		26	19	✓	✓		
MS Base: **NMOBase**	2015	NMOSD		1552	0	✓	✓		Report only
MS Base: **MOGAD Clinical and Therapeutic Outcome Substudy**	2020	MOGAD		0	125	✓	✓		
Siegel Rare Neuroimmune Association: **SRNA registry**	2017	Neuroimmune disorders		84	91	✓	✓		
Australasian MOGAD Study Group: **MOGAD database**	2020	MOGAD		0	279	✓	✓	✓	✓
Australasian NMO Study Group: **ANZ NMO Collaboration**	2013	All demyelinating diseases		69	26	✓	✓		✓
RelevarEM: **MOGAD & NMOSD dataset**	2018	All demyelinating diseases		~300	~50	✓	✓		Report only
National **Pediatric Hospital Dr J. P. Garrahan: Pediatric MOGAD database & Pediatric NMOSD database**	Not specified	All demyelinating diseases		~320	82	✓	✓	✓	✓
Beijing Tiantan Hospital: **China National Registry of Neuro-Inflammatory Diseases (CNRID)**	2021	All demyelinating diseases		1796	391	✓	✓	✓	✓
NOMADMUS	2011	NMOSD and MOGAD		1200	1219	✓	✓	✓	✓
Charité: **NEMOS registry**	2016	NMOSD and MOGAD		770	507	✓	✓	✓	✓
Nitte University: **Mangalore Demyelinating Disease Registry**	2011	All demyelinating diseases		212	181	✓	✓	✓	✓
Italian Multiple Sclerosis and Related Disorders Register	2009	All demyelinating diseases		5	2	✓	✓		✓
Tohoku Group: **MOGAD database**	2021	MOGAD		0	180	✓	✓	✓	✓
Japan Neuro-Immunology Association: **NMOSD/MOGAD Registry**	2023	NMOSD and MOGAD		336	71	✓	✓	✓	
Penang General Hospital: **NMOSD database**	2015	All demyelinating diseases		60	10	✓	✓		✓
Medical University of Warsaw: **The Polish registry of NMOSD patients**	2022	NMOSD and MOGAD		70	15	✓	✓		
University of the Witwatersrand: **NMOSD database**	2023	NMOSD and MOGAD		58	20	✓	✓		✓
National Cancer Center: **CNS demyelinating disease database**	2005	All demyelinating diseases		~400	~120	✓	✓	✓	✓
Nuffield Department of Clinical Neurosciences, University of Oxford: **NMOSD database**	2015	NMOSD and MOGAD		332	343	✓	✓	✓	Report only
The Walton Centre for Neurology and Neurosurgery: **NMO/MOGAD database**	2015	NMOSD and MOGAD		145	150	✓	✓	✓	
Guthy-Jackson Charitable Foundation: **CIRCLES**	2013	NMOSD and MOGAD		800	~40	✓	✓	✓	
Autoimmune Association: **ARNet**	1990	All autoimmune diseases		Unsure	Unsure	✓	✓		
CHLA: Pediatric **MOGAD & NMOSD database**	2019	All demyelinating diseases		25	125	✓	✓	✓	✓
Harvard/Mass General: **MOG database**	2023	NMOSD and MOGAD		~60	~150	✓	✓	✓	Report only
Johns Hopkins University: **NMOSD/MOGAD Clinical Database and Biorepository**	2019	NMOSD and MOGAD		~200	~200	✓	✓	✓	✓
Mayo Clinic: **MOGAD & NMOSD database**	2019	NMOSD and MOGAD		650	600	✓	✓	✓	✓
UT Southwestern: **UTSW CONQUER Database**	2009	All demyelinating diseases		~250	~100	✓	✓	✓	Report only

[a]Types of clinical data collected by the databases/registries

Almost all (> 85%) databases/registries (most to least mentioned)

- Diagnosis
- Age at onset
- Clinical characteristics
- Disease onset phenotype
- Relapse history
- AQP4 antibody test results
- MOG antibody test results
- Co-morbidities

Most (> 70%–85%) databases/registries (most to least mentioned)

- Laboratory findings of CSF analysis
- EDSS/EDMUS scores
- Radiological examination results
- Family history
- Visual acuity

Some (> 35%–70%) databases/registries (most to least mentioned)

- Type of assay for AQP4 antibody test
- Treating physician
- Treatment centre
- Type of assay for MOG antibody test
- Titre (level) of assay for MOG antibody test
- Titre (level) of assay for AQP4 antibody test

Figure 2. Summary of MOGAD and NMOSD patient registries/databases who completed the survey/provided information after the survey was closed.

Japan Neuro-Immunology Association: NMOSD/MOGAD registry; Johns Hopkins University: NMOSD/MOGAD Clinical Database and Biorepository; and Mayo Clinic: NMOSD database either did not complete the full survey or were identified and provided some information after the survey was closed. Reported patient counts may reflect cross-registry overlap.

Registries/databases were invited to provide updated patient numbers in March 2026. These were provided by MS Base: NMOBase, Siegel Rare Neuroimmune Association: SRNA registry, Beijing Tiantan Hospital: China National Registry of Neuro-Inflammatory Diseases (CNRID), NOMADMUS, Charité: NEMOS registry, Nitte University: Mangalore Demyelinating Disease Registry, Tohoku Group: MOGAD database, Japan Neuro-Immunology Association: NMOSD/MOGAD Registry, Penang General Hospital: NMOSD database, University of the Witwatersrand: NMOSD database, The Walton Center for Neurology and Neurosurgery: NMO/MOGAD database, Johns Hopkins University: NMOSD/MOGAD Clinical Database and Biorepository, and Mayo Clinic: MOGAD & NMOSD database.

AQP4, aquaporin-4; CSF, cerebrospinal fluid; CNS, central nervous system; EDMUS, European Database for Multiple Sclerosis; EDSS, Expanded Disability Status Scale; MOG, myelin oligodendrocyte glycoprotein; MOGAD, myelin oligodendrocyte glycoprotein antibody–associated disease; MRI, magnetic resonance imaging; MS, multiple sclerosis; NMOSD, neuromyelitis optica spectrum disorder.

followed by grant funding, industry funding, and/or donor support.

Primary objectives articulated were supporting scientific research and advancing disease understanding, facilitating diagnoses and collecting clinical information, providing information and support to patients, supporting clinical trial recruitment, and collecting data for insurance/health provider purposes. Over the next 3–5 years, growth plans involved the inclusion of more data (such as glial/neuronal cell damage biomarkers, genetic data, and magnetic resonance imaging (MRI) results/MRI bank), increasing the number of patients in the registry/database, and maintaining long-term engagement with patients. Registries/databases also reported experiencing challenges such as cost, time, and resource constraints, and issues with data quality (including legal restrictions, selection bias, and challenges tracking deidentified patients).

Discussion

To our knowledge, this study is the first global review of publicly listed and expert-identified MOGAD and NMOSD registries/databases. The identification of 39 registries/databases (including 26 survey respondents) reflects substantial international interest in understanding these rare diseases, although increased disease awareness and education are required to further support establishment of registries/databases globally.

Heterogeneity was a defining characteristic across registries/databases; differences in disease focus, enrollment, data elements, governance structures, and data-sharing practices reflect varied local priorities and resources. Notably, registries in Central America and Africa were limited, reflecting disparities in diagnostic access and research infrastructure.[9] Strengthening international collaborations (e.g. improving access to MOG and AQP-4 antibody testing) may support registry development in these regions. Access to validated AQP4-immunoglobulin G (IgG) and MOG-IgG testing is also important for ensuring the accuracy of registry data, as limited diagnostic capacity can lead to under-recognition or misclassification of cases.[1] In addition, the heterogeneity observed highlights the need for greater harmonization of core data elements and data

collection standards; establishing common data models could facilitate cross-registry analyses and enable larger collaborative studies.[10]

Importantly, registries/databases expressed ambitions to expand and enhance their datasets, including plans for larger cohorts, capturing more granular data, and more frequent updates. However, challenges related to cost, time, data quality, and differences in the types of data collected pose barriers to long-term sustainability and limit opportunities for cross-registry collaboration. In particular, reliance on self-funding highlights the resource constraints many registries/databases face.

This study has several limitations. Firstly, registry/database identification relied on publicly available information, indexed sources, and expert consultation; therefore, some relevant national, institutional, local, or less formal cohorts may not have been identified. Secondly, the survey was voluntary, creating potential response bias as larger, more visible, and better resourced registries/databases may have been more likely to respond than smaller initiatives. As a result, our findings reflect the characteristics of respondents rather than the full MOGAD and NMOSD registry/database landscape. Finally, the reported patient numbers were approximate and may include overlapping populations, highlighting the need for secure, deidentified patient tokens to resolve cross-registry duplication.

Conclusion

MOGAD and NMOSD patient registries/databases have been established in many countries, mostly within the past 15 years; their objectives include advancing disease understanding and supporting scientific research and clinical trial recruitment. This global review of publicly listed and expert-identified registries/databases highlights substantial registry/database activity, while also showing heterogeneity in data collection practices, funding, and governance. Despite financial, operational, and data harmonization challenges, registries/databases are an increasingly important source of real-world data that can be used to address unmet needs in these rare diseases.

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Ethical considerations

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J.L. is executive director and co-founder of The MOG Project; a consultant for UCB; and is on the Roche INSPIRE Council for which she has received travel reimbursement.

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I.N. serves on the scientific advisory boards for Alexion, Biogen Japan, Chugai Pharma, Novartis, and UCB Japan; and receives honoraria for speaking engagements with Alexion, Biogen Japan, Chugai Pharma, Mitsubishi Tanabe Pharma, and Novartis Pharma.

Z.P. is an employee of and stockholder in UCB.

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E.S.S. has served on advisory boards for Alexion, Amgen, and Roche/Genentech; has been involved in non-promotional speaking at meetings for Alexion and Roche/Genentech; site PI for contract research for Ad Scientiam, Alexion, CorEvitas, Roche/Genentech, and UCB; and received research funding from Astoria Biologica.

S.T. has received funding for travel or speaker honoraria from F. Hoffmann-La Roche and Merck S.A; and serves on scientific advisory boards of Alexion Pharmaceuticals Inc. (Chair, NMO Relapse Adjudication Committee) and Genentech-Roche Inc (NMOSD and MOGAD).

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M.R.Y. is chair medical advisor to the Guthy-Jackson Charitable Foundation, which sponsored the CIRCLES study; has received speaker or advisory committee honoraria from Amgen (Horizon), AstraZeneca (Alexion), and Genentech (Roche); and receives research support from the National Institutes of Health and US Department of Defense.

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Data availability statement

Data from non-interventional studies are outside of UCB's data-sharing policy and are unavailable for sharing.

Supplemental material

Supplemental material for this article is available online.

References

1. Banwell B, Bennett JL, Marignier R, et al. Diagnosis of myelin oligodendrocyte glycoprotein antibody-associated disease: International MOGAD Panel proposed criteria. *Lancet Neurol* 2023; 22(3): 268–282.
2. Marignier R, Hacohen Y, Cobo-Calvo A, et al. Myelin-oligodendrocyte glycoprotein antibody-associated disease. *Lancet Neurol* 2021; 20(9): 762–772.
3. Jarius S, Paul F, Weinshenker BG, et al. Neuromyelitis optica. *Nat Rev Dis Primers* 2020; 6(1): 85.
4. Zheng S, Wang Y, Geng J, et al. Global trends in research on MOG antibody-associated disease: bibliometrics and visualization analysis. *Front Immunol* 2024; 15: 1278867.
5. Su Y, Ruan Z, Li S, et al. Emerging trends and research foci of neuromyelitis optica spectrum disorder: a 20-year bibliometric analysis. *Front Immunol* 2023; 14: 1177127.
6. Hageman IC, van Rooij IALM, de Blaauw I, et al. A systematic overview of rare disease patient registries: challenges in design, quality management, and maintenance. *Orphanet J Rare Dis* 2023; 18(1): 106.
7. Gomes ABAGR and Adoni T. Differential diagnosis of demyelinating diseases: what's new? *Arq Neuropsiquiatr* 2022; 80(5 suppl 1): 137–142.
8. Wingerchuk DM, Banwell B, Bennett JL, et al. International consensus diagnostic criteria for neuromyelitis optica spectrum disorders. *Neurology* 2015; 85(2): 177–189.
9. Rojas JI, Gracia F, Patrucco L, et al. Multiple sclerosis and neuromyelitis optica spectrum disorder testing and treatment availability in Latin America. *Neurol Res* 2021; 43(12): 1081–1086.
10. Parciak T, Geys L, Helme A, et al. Introducing a core dataset for real-world data in multiple sclerosis registries and cohorts: recommendations from a global task force. *Mult Scler* 2024; 30(3): 396–418.