

The Journey from First Symptoms to MS Diagnosis: How Lived Experiences Inform the Work of the MSIN

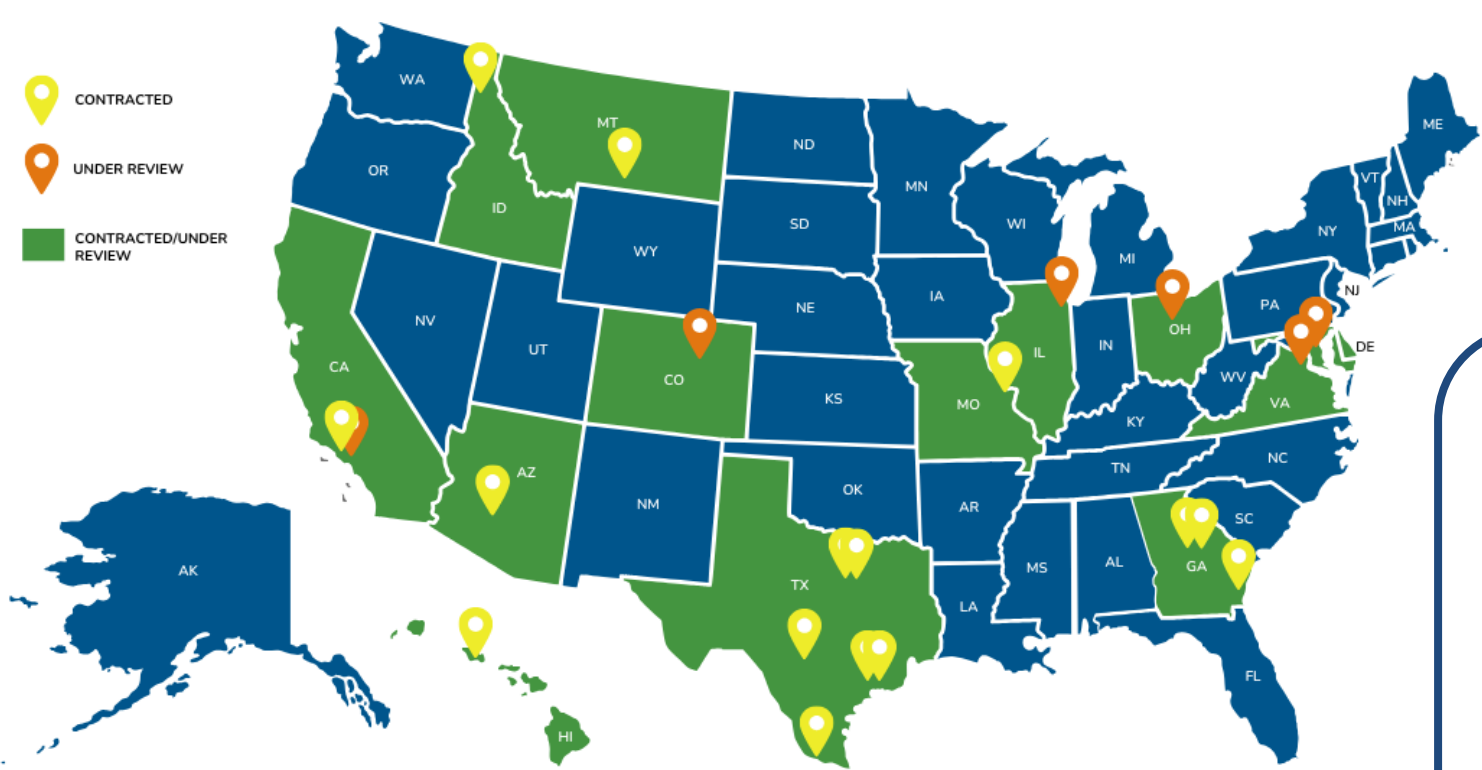
Leorah Freeman [1], Alejandra Gomez [1], Bijal Balasubramanian [2], Amanda English [2], Alexis Kline [3], Kate Durack [3], Li Doggett [1], Claude Pinnock [4], Anita Williams [5], Jason Freeman [6], Maria Fernandez [2], Amanda Montague [3]

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BACKGROUND

A timely MS diagnosis is critical for early treatment and better long-term outcomes, yet delays remain frequent. People with MS often face challenges such as unrecognized or dismissed early symptoms, misdiagnoses, and difficulty accessing knowledgeable providers. Clinicians note additional barriers including atypical presentations, socioeconomic disparities, and gaps in awareness among non-specialists.

The Multiple Sclerosis Implementation Network (MSIN) is a national, patient-centric collaboration of clinicians, people with MS, advocacy organizations, academia, and industry. Its goal is to improve care by developing a practice-based research network and engaging meaningfully with patients, clinicians, and community partners to identify barriers and implement solutions to reduce diagnostic delays and improve outcomes.



OBJECTIVES

Capture the experiences of people with MS (pwMS) from first symptoms to diagnosis.

Identify key challenges contributing to diagnostic delays.

Explore clinician perspectives on barriers and opportunities to improve the diagnostic pathway.

METHODS

Survey of pwMS:

- Online survey distributed to the MS Association of America's database of over 26,000 people living with MS and their care community
- Collected data on time from first symptoms to diagnosis and access to care
- 401 respondents across 43 US states

Clinician Community of Practice (CoP):

- 10 MSIN neurologists invited; 7 participated
- Pre-meeting survey followed by a 60-minute virtual discussion
- Explored barriers to timely diagnosis and potential solutions

OUTCOMES

PwMS survey (n=401, 43 states):

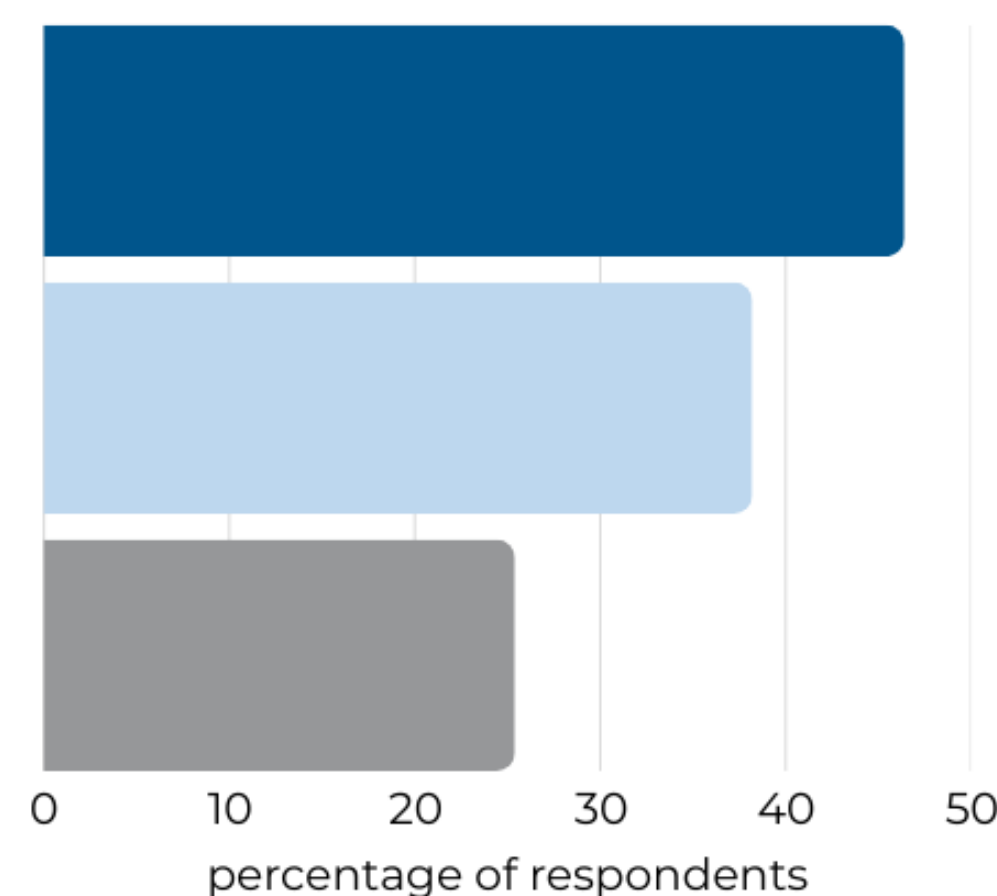
- 78% experienced symptoms ≥ 1 year before diagnosis.
- 40% waited more than 5 years for diagnosis.
- No improvement in diagnostic delays for those diagnosed within the past 10 years.
- Reported barriers:
 - Symptoms not recognized by self (46%).
 - Symptoms dismissed/not recognized by providers (38%).
 - Initial misdiagnosis (25%).

Time from First Symptoms to MS Diagnosis

Under 1 year: 21.7%
1-5 years: 38.3%
Over 5 years: 40%

Top Reported Reasons for Diagnostic Delay

- Unrecognized Symptoms (self)
- Dismissed by Providers
- Initial Misdiagnosis



My diagnosis took so long due to siloed healthcare [and] changes in access over time. If I had 1 champion who believed my symptoms were real or who spent enough time to hear the whole story, it would have saved so much brain and spine.

-Survey Participant

Clinician Community of Practice (n=7):

- Patients at highest risk for delays: rural, lower SES, men, atypical symptoms, outside typical onset age, or lacking primary care access.
- Key needs identified:
 - Broader MS awareness among non-specialists and the public.
 - Better understanding of diverse diagnostic pathways.
 - Targeted strategies for underserved groups.

CONCLUSION

Diagnostic delays remain common in MS, with many people waiting years between first symptoms and diagnosis. Both patient- and system-level barriers contribute, including unrecognized symptoms, misdiagnoses, and disparities in access to care.

Increasing MS awareness among healthcare providers and the community, especially in underserved groups, is essential. The inclusion of people with MS within the MSIN provides a unique opportunity to co-develop and implement solutions that can reduce delays and improve diagnostic pathways across the US.