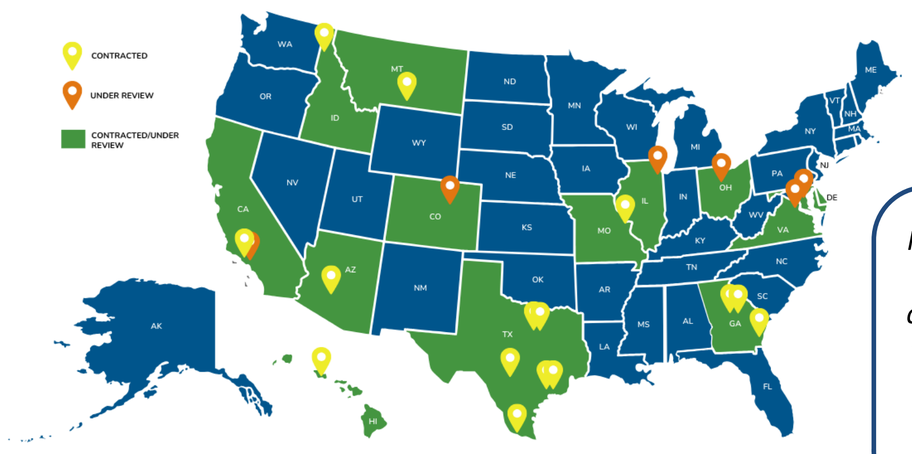
The Journey from First Symptoms to MS Diagnosis: How Lived Experiences Inform the Work of the MSIN

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

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):

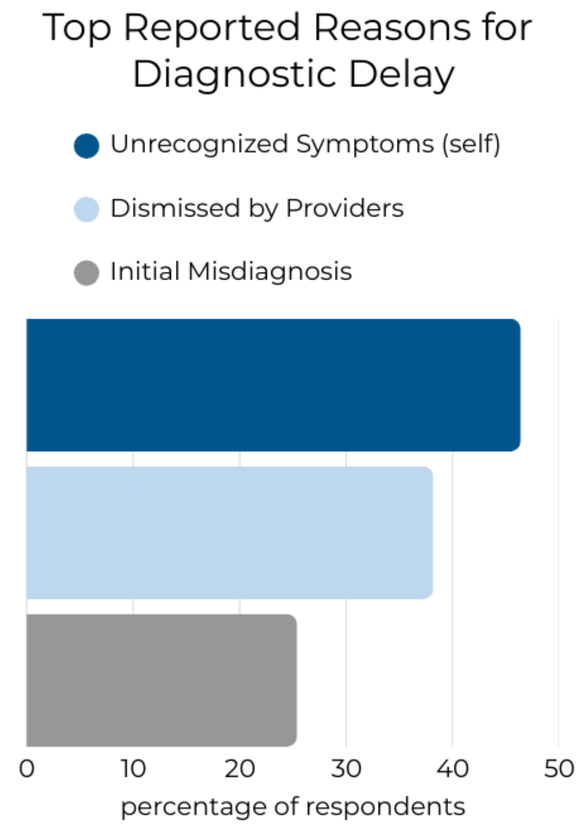
- 78% experienced symptoms ≥1 year before diagnosis.
- 40% waited more than 5 years for diagnosis.
- No improvement in diagnostic delays for those diagnosed within the past 10 years.
- Reported barriers:
  - Symptoms not recognized by self (46%).
  - Symptoms dismissed/not recognized by providers (38%).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

Time from First Symptoms to MS Diagnosis

Under 1 year: 21.7%

1-5 years: 38.3%

Over 5 years: 40%



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.

THIS RESEARCH WOULD NOT HAVE BEEN POSSIBLE WITHOUT THE INVALUABLE CONTRIBUTIONS OF PEOPLE LIVING WITH MULTIPLE SCLEROSIS. THEIR WILLINGNESS TO SHARE THEIR EXPERIENCES HAS BEEN CRUCIAL IN SHAPING THIS WORK.

THE CONTENT IS SOLELY THE RESPONSIBILITY OF THE AUTHORS AND DOES NOT NECESSARILY REPRESENT THE OFFICIAL VIEWS OF NOVARTIS, MSAA, UTHEALTH, OR OTHER MSIN PARTNERS.

1 DELL MEDICAL SCHOOL, THE UNIVERSITY OF TEXAS AT AUSTIN, AUSTIN, TX, USA
2 UTHEALTH HOUSTON INSTITUTE FOR IMPLEMENTATION SCIENCE, UNIVERSITY OF TEXAS HEALTH SCIENCE CENTER AT HOUSTON, HOUSTON, TX, USA
3 MULTIPLE SCLEROSIS ASSOCIATION OF AMERICA, CHERRY HILL, NJ, USA
4 MSIN Steering & Oversight Committee Board Member, New York, NY, USA
5 MSIN Steering & Oversight Committee Board Member, Denver, CO, USA
6 NOVARTIS PHARMACEUTICALS CORPORATION, EAST HANOVER, NJ, USA

Desarrollo del MSIN: Una Red para la Implementación de Innovaciones en Esclerosis Múltiple

FERNANDEZ, ME, PhD[1,6]; OBEKPA, EO, DrPH[1]; SILVEIRA, SL, PhD[1,2]; GHOSH, S, PhD[1,3]; BLAKELY, ML, MD, MS, MMHC[1,4]; BALASUBRAMANIAN, BA, MBBS, PhD[1,5]; WALKER, T, PhD[1,6]; GUTIERREZ, L, MPH[1]; MERKITCH, D, BS[3]; KWIATKOWSKI, E, PhD[3]; CAO, T, PhD[3]; SWARTZ, M, PhD[3]; ALLEN, C, MPH, MA[1]; KLINE, A, MPH[7]; PINNOCK, C, MD, MPH[7]; DURACK, K, MPS[7]; MONTAGUE, A, EdM[7]; GOMEZ, A, BSA, BA[8]; FREEMAN, L, MD, PhD[8]; YAMAL, JM, PhD[1,3]

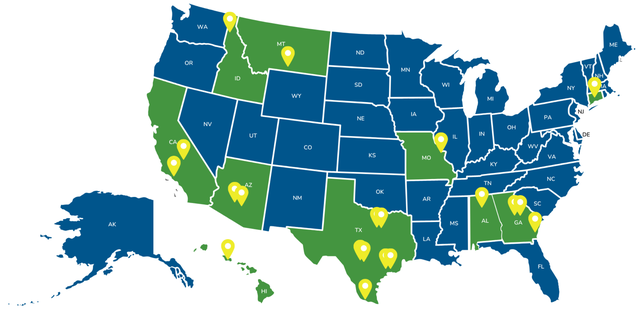
ANTECEDENTES

- La Red de Implementación de Esclerosis Múltiple (MSIN, por sus siglas en inglés) es una red de investigación basada en la práctica (Practice-Based Research Network – PBRN, en Ingles) que reúne a profesionales clínicos, sistemas de salud y pacientes para cerrar la brecha entre la investigación y la práctica, con el fin de mejorar la atención y los resultados en la esclerosis múltiple.
- Socios: Multiple Sclerosis Association of America (MSAA), UTHealth Houston, Dell Medical School at UT Austin, Novartis

MÉTODOS

- MSIN está dirigido por un Comité de Supervisión Estratégica, una Junta Asesora Clínica y un Grupo Asesor Comunitario.
- Convocamos una comunidad de práctica (CoP) de proveedores de EM dentro de la PBRN de MSIN para
  - desarrollar una agenda de investigación y práctica.
  - facilitar el intercambio de información, mejores prácticas y experiencias para mejorar la atención y los resultados en la esclerosis múltiple.
  - co-diseñar y evaluar estrategias de implementación diseñadas para mejorar la práctica.
- Se envía una encuesta de opinión a los proveedores antes de cada reunión para facilitar la discusión.
- Los facilitadores de la CoP conducen las conversaciones utilizando preguntas abiertas.
- El registro integra datos del EHR con encuestas de resultados reportados por los pacientes (PDDS, SymptoMScreen, PROMIS Fatigue, PRAPARE).

FIG. 1. CLÍNICAS DE MSIN (N=20)

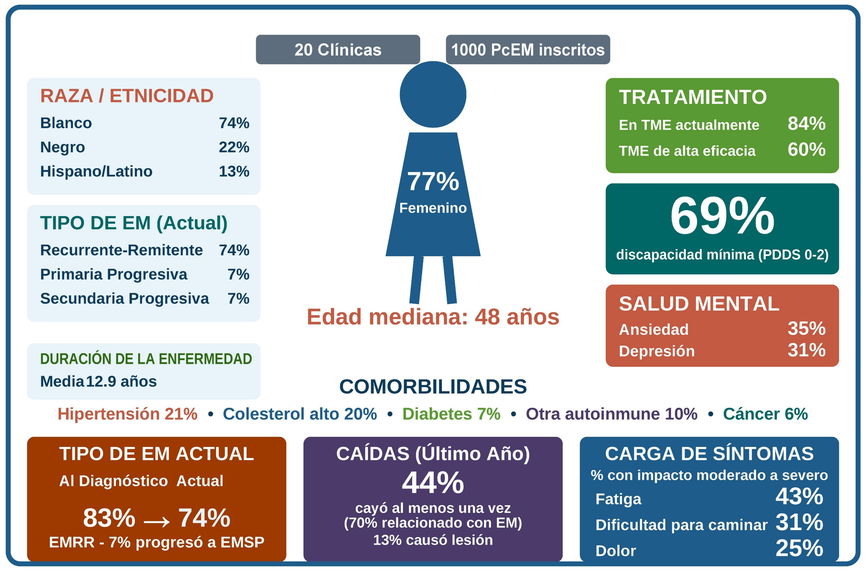


RESULTADOS

- Después de su lanzamiento en abril de 2025, MSIN se ha expandido a 20 sitios clínicos en 11 estados de los EE. UU. (Fig. 1).
- Se han inscrito mas de 1000 personas con EM en 44 semanas.
- Los datos se recopilan cuando el paciente se inscribe y cada 3 meses durante 3 años.
- La CoP se ha reunido 8 veces en 7 meses, identificando los siguientes desafíos: demoras en el diagnóstico, acceso limitado a tratamientos de alta eficacia y barreras para el manejo a largo plazo.

FIG. 2. RECLUTAMIENTO DE CLÍNICAS Y RECOPILACIÓN DE DATOS

FIG. 3. CARACTERÍSTICAS DE LOS PACIENTES



TME: Tratamientos modificadores de la enfermedad

- La CoP ha identificado las siguientes soluciones: mejorar el acceso a la resonancia magnética, optimizar las derivaciones y desarrollar modelos de atención multidisciplinaria.
- Realizamos una revisión exploratoria e identificamos 250. intervenciones de promoción de la salud y atención de apoyo basadas en evidencia.
- La CoP priorizará estas intervenciones basadas en evidencia (EBIs) para su implementación en los sitios de MSIN.

ETEPAS PRÓXIMAS

1) **MSDA Biomarker Trial:** Actualmente estamos planficando un estudio híbrido de efectividad-implementación para evaluar estrategias destinadas a aumentar el uso de la prueba de biomarcador MSDA de Octave para monitorear la actividad de la enfermedad en clíseleccionados de MSIN. nicas
2) **Expansión a América Latina:** Estamos explorando alianzas con sitios clínicos en América Latina.

AFFILIATIONS:
[1] Institute of Implementation Science, UTHealth Houston School of Public Health
[2] Department of Management, Policy, and Community Health, UTHealth Houston School of Public Health
[3] Department of Biostatistics and Data Science, Coordinating Center for Clinical Trials, UTHealth Houston School of Public Health
[4] Department of Pediatric Surgery, McGovern Medical School at UTHealth Houston
[5] Department of Epidemiology, UTHealth Houston School of Public Health in Dallas
[6] Department of Health Promotion and Behavioral Sciences, UTHealth Houston School of Public Health
[7] Multiple Sclerosis Association of America
[8] Department of Neurology, UTHealth Austin Dell Medical School

This research would not have been possible without the invaluable contributions of people living with multiple sclerosis. Their willingness to share their experiences has been crucial in shaping this work.

Evidence-Based Health Promotion, Symptom Management, and Supportive Care Interventions for People with Multiple Sclerosis: A Scoping Review

AUTHORS: Elizabeth O. Obekpa[1], Stephanie L. Silveira[1,2], Jose-Miguel Yamal[1,3], Amanda Montague[4], Leorah Freeman[5], Martin L. Blakely[1,6], Bijal A. Balasubramanian[1,7], Maria E. Fernandez[1,8]

BACKGROUND

- Despite significant medical advances in MS care, evidence-based health promotion and supportive care interventions (EBIs) remain underutilized in clinical practice.
- The Multiple Sclerosis Implementation Network (MSIN), a national practice-based research network, aims to bridge this gap by identifying and implementing high-impact EBIs for people living with MS (PLwMS).
- We conducted a scoping review to identify health promotion, symptom management, and supportive care interventions for PLwMS.

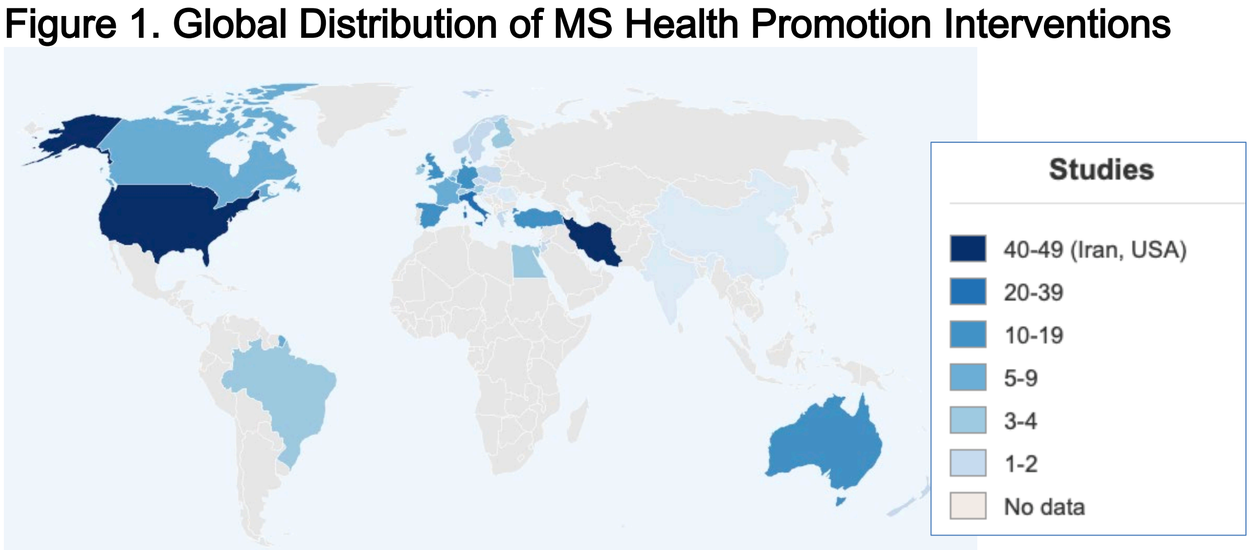
METHODS

- **Databases:** 1,049 articles identified from PubMed, Web of Science, CINAHL, and Cochrane Library.
- **Inclusion criteria**: Peer-reviewed studies (Jan. 2014–Aug. 2025) in English, evaluating health promotion and supportive care interventions for adults with MS, with meaningful clinical or statistical outcomes, identified through randomized controlled trials (RCTs) or systematic reviews & meta-analyses (SR/MA).

RESULTS

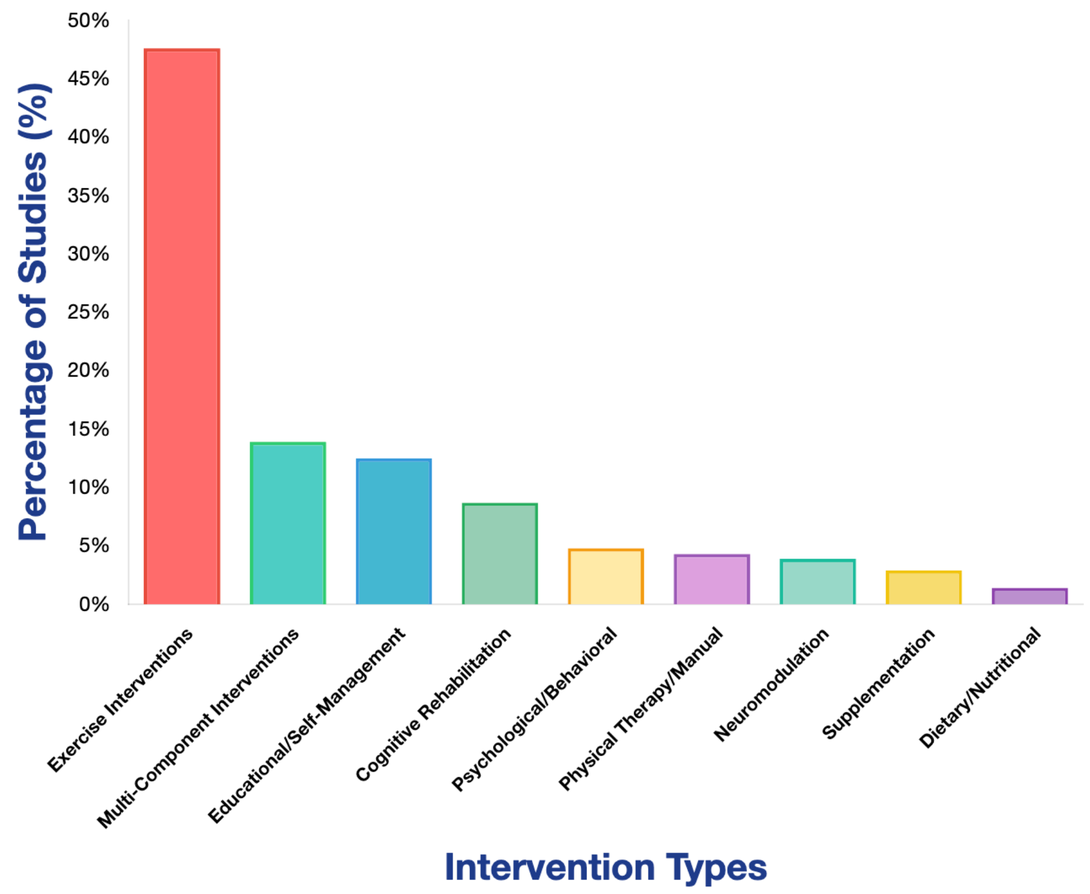
- 208 studies (168 RCTs & 40 SR/MA) met the inclusion criteria.
- Research spanned 33 countries, with the USA, Iran, Italy, Turkey, and Spain accounting for 69% of studies (Figure 1). Limited research from Africa (Egypt), Asia (China, India), & Latin America (Brazil).

Figure 1. Global Distribution of MS Health Promotion Interventions



- **Study settings (n=135):** Most were home-based or virtual (27.4%), multiple (24.4%), and university-based (15.6%; academic hospitals or facilities, e.g., hospitals, labs, research, or sport centers) settings.
- **Outcome categories:** Symptom management (53.8%), motor function & disability (44.2%), functioning (29.3%), cognitive function (21.2%), psychological (20.2%), biomarkers & physiology (14.9%), physical fitness (9.6%), decision-making & self-management (5.3%), and diet & nutrition (1.4%).
- Exercise interventions dominated research (47.6%), including aerobic and resistance training, aquatic therapy, and balance and technology-enhanced exercises.
- Multi-component EBIs (13.9%) were the second most common, combining education, rehab, exercise, and brain stimulation.
- Only one Phase III intervention was identified - Behavioral Intervention for Physical Activity in MS (BIPAMS).
- Dietary/Nutritional interventions represent the most understudied area (1.4% of studies), followed by Supplementation (2.9%) and Neuromodulation (3.9%), highlighting significant research gaps in MS care.

Figure 2: Distribution of MS Health Promotion Interventions (n = 208)



CONCLUSION

- Most EBIs were developed by single research teams without independent replication, creating evidence validation gaps.
- Geographic concentration and critical gaps in methodology reporting and intervention replication present challenges for evidence synthesis and implementation planning in diverse healthcare settings.

MSIN OPPORTUNITIES

- MSIN provides a venue for interdisciplinary implementation research that could improve health outcomes for PLwMS.
- Each intervention will be prioritized based on the strength of evidence, potential impact on patient outcomes, alignment with patient and stakeholder priorities, and feasibility of adoption and implementation across MSIN sites.

THIS RESEARCH WOULD NOT HAVE BEEN POSSIBLE WITHOUT THE INVALUABLE CONTRIBUTIONS OF PEOPLE LIVING WITH MULTIPLE SCLEROSIS. THEIR WILLINGNESS TO SHARE THEIR EXPERIENCES HAS BEEN CRUCIAL IN SHAPING THIS WORK.

AFFILIATIONS: [1]Institute of Implementation Science, UTHealth Houston School of Public Health, [2]Department of Management, Policy, and Community Health, UTHealth Houston School of Public Health, [3]Department of Biostatistics and Data Science, UTHealth Houston School of Public Health, [4]Multiple Sclerosis Association of America, Cherry Hill, [5]Dell Medical School, The University of Texas at Austin, [6]Department of Pediatric Surgery, McGovern Medical School at UTHealth Houston, [7]Department of Epidemiology, UTHealth Houston School of Public Health, Dallas, United States, [8]Department of Health Promotion and Behavioral Sciences, UTHealth Houston School of Public Health, United States.
DISCLOSURES:The content is solely the responsibility of the authors and does not necessarily represent the official views of Novartis, MS AA, UTHealth, or other MSIN partners

The Multiple Sclerosis Implementation Network (MSIN): Barriers to Optimal Care for People Living with MS

Amanda Montague Ed.M.[1], Maria Fernandez PhD[2], Leorah Freeman, MD, PhD[3], Jason Freeman, MD, MBA[4], Claude Pinnock, MD, MPH[5], Anita Williams, MSW[6], Alexis Kline, MPH[1]

Funding for MSIN has been provided by Novartis Pharmaceuticals Corporation.

INTRODUCTION

The Multiple Sclerosis Implementation Network (MSIN) is a multi-stakeholder clinical research study led by the Multiple Sclerosis Association of America (MSAA), a national nonprofit organization. MSIN connects people with MS, clinicians, researchers, and industry leaders to address pressing questions and promote evidence-based practices in MS care. The study has established two advisory councils: a Community Council, including people living with MS, patient advocates, and representatives from advocacy organizations across chronic disease communities; and a Scientific & Clinical Council, comprising neurologists, specialists, researchers, pharmacists, nurse practitioners, and other healthcare professionals. MSAA also conducts pulse surveys and community surveys to capture perspectives from the broader MS community.

The MSIN incorporates community-based participatory research (CBPR) frameworks in several aspects of the network's activities including disseminating community pulse surveys and convening community advisory councils. CBPR is a validated framework that emphasizes equitable collaboration between researchers and community members and is known to improve the value, trustworthiness, and impact of research findings (Newman, 2011; Baccar, 2012).

AIMS

To ensure that research and planning efforts are aligned with the needs and priorities of the multiple sclerosis (MS) community, the MSIN engages diverse stakeholders, including people living with MS, patient advocates, clinicians, and researchers. By combining insights from community surveys, group discussions, and expert council input, MSIN seeks to capture contemporary themes of importance and apply them to guide future research agendas. The following aims outline how these efforts translate into actionable objectives for advancing the MS field.

AIM 1

Identify and contextualize key, contemporary themes of interest to the MS community through community surveys, group discussions, and input from MSIN expert councils and MSAA's lived-experience experts (PlwMS).

AIM 2

Apply these insights to establish shared perspectives on research agendas, inform future planning in areas important to the MS community, and elevate contributions from diverse stakeholders.

METHODS

A deductive approach for analysis of the council meeting transcripts and open-ended responses from the pre-meeting survey were analyzed for key topics (n=19). These data sources explored perceptions of what barriers to MS care are experienced from dynamic and diverse lived experience, clinical, academic, and other stakeholders. Findings from the advisory council were then compared to responses from the broader MS community captured from a separate pulse survey, which included a question on challenges in accessing care.

RESULTS

Key themes from the advisory council were then compared with responses from the broader MS community collected through a separate pulse survey, which included a question on challenges in accessing care. This step allowed us to assess whether the themes identified by the council aligned with or diverged from the experiences reported by the wider community.

THEMES

- **Access to a disease-modifying therapy (DMT)**
- **Access to an MS specialist**
- **Integration of shared decision-making**
- **Need for comprehensive care**
- **Access to routine MRI monitoring**

CONCLUSION

The intersection between community and council identified minimum adequate care key themes and barriers to care could indicate important systemic and environmental relationships influencing how and why some people living with MS may or may not be seeking basic treatment or care in the management of their MS. This information can be used to deepen the contextualize evidence available about how SDOH are impact MS care outcomes.

ACKNOWLEDGEMENTS

This research would not have been made possible without the invaluable contributions of people living with multiple sclerosis. Their willingness to share their perspectives has been crucial to shaping this work.

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1Multiple Sclerosis Association of America, Cherry Hill, NJ, USA. Nothing to disclose.

2UTHealth Houston Institute for Implementation Science, University of Texas Health Science Center at Houston, Houston, TX, US A. Nothing to disclose.

3The Dell Medical School, The University of Texas at Austin, Austin, TX, USA. LF: Has received fees for consultancy and/or ad visory board participation from Bristol Myers Squibb, EMD Serono, Genentech, Horizon Therapeutics, Novartis, Sanofi, and TG Therapeutics; has received speaker fees from EMD Serono, the MS Association of America, and Sanofi; has received honorarium for participation in educati onal programs from Medscape, Inc and the MS Association of America; has received program sponsorship from EMD Serono; and grant support from EMD Serono, Genentech, NIH/NINDS, and PCORI through her institution.

4Novartis Pharmaceuticals, East Hanover, NJ, USA. Dr. Freeman is a Medical Director at Novartis Pharmaceuticals.

5MSIN Steering & Oversight Committee Board Member, New York, NY, USA. Nothing to disclose.

6MSIN Steering & Oversight Committee Board Member, Denver, CO, USA. Nothing to disclose.

Developing a Community of Practice to Bridge the Research-to-Practice Gap in Multiple Sclerosis

AUTHORS: Bijal Balasubramanian[1,2], Amanda S. English[1], Lizette Gutierrez[1], Stephanie L. Silveira[1,3], Amanda Montague[4], Leorah Freeman[5], Maria E. Fernandez[1,6]

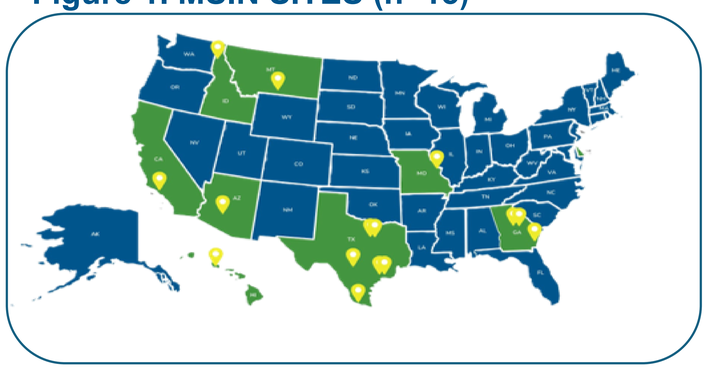
BACKGROUND

- The Multiple Sclerosis Implementation Network (MSIN) is
  - a unique collaboration between academic, industry, and advocacy organizations focused on improving outcomes for people living with multiple sclerosis (PwMS).
  - an innovative, patient-centered, practice-based research network (PBRN)[1] of clinicians, health systems, and patients across the U.S. focused on bridging the research-to-practice gap to improve care quality, value, and outcomes for PwMS.
- We developed a Community of Practice (CoP)[2] of MS providers and clinics within the MSIN PBRN to
  - develop a research and practice agenda
  - facilitate the exchange of information, best practices, and experiences to improve MS care and outcomes
  - co-design implementation strategies to test through new D&I hybrid trials

METHODS

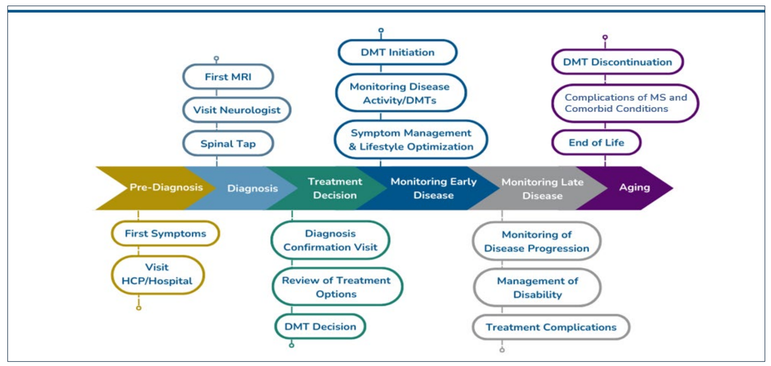
- We recruited 15 MS clinics across the U.S. (Figure 1).

Figure 1. MSIN SITES (n=15)



- Eight 1-hour virtual meetings were conducted over 7 months.
  - A kick-off meeting was held to confirm goals and gather feedback on the proposed approach.
  - A framework delineating the phases of the journey of a PwMS guided the sessions (Figure 2).

Figure 2. MS Journey Map



- Before each meeting, a brief provider insight survey was sent to participants to facilitate discussion.
- Facilitators led discussions using focus group techniques, open-ended questioning, and consensus building.
- Meeting transcripts were summarized using MS CoPilot, and investigators reviewed summaries to identify care gaps, potential solutions, and implementation research questions.

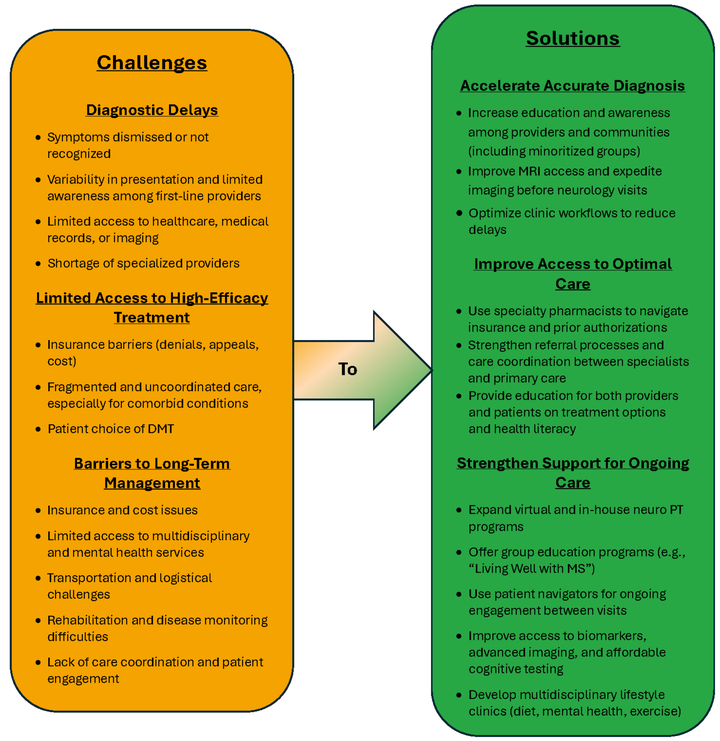
FINDINGS

- About 40% of the clinical sites were represented at each meeting.
- Data from the analysis showed that providers identified several challenges to MS care as well as several solutions (Figure 3).

IMPLICATIONS FOR D&I RESEARCH

- Developing a CoP within the MSIN PBRN enhanced engagement with diverse health systems and clinic sites, identified practice challenges in MS care delivery, and identified promising, pragmatic practice-based solutions.
- CoPs offers a promising way to develop a research and practice agenda to advance MS care and provide a platform to co-develop implementation strategies with clinicians, researchers, and advocacy and industry professionals focused on enhancing MS care.
- This scalable, adaptable model encourages learning and supports innovation across diverse healthcare settings.

Figure 3. CoP-Identified Challenges and Solutions



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AFFILIATIONS:
[1] UTHealth Houston Institute for Implementation Science
[2] Department of Epidemiology, UTHealth Houston School of Public Health in Dallas
[3] Department of Management, Policy, and Community Health, UTHealth Houston School of Public Health
[4] Multiple Sclerosis Association of America
[5] UT Health Austin Dell Medical School
[6] Department of Health Promotion and Behavioral Sciences, UTHealth Houston School of Public Health

THE MS IMPLEMENTATION NETWORK (MSIN)

An Innovative, Patient-Driven Research Network and Implementation Research Study

Introduction

The Multiple Sclerosis Implementation Network (MSIN) is a patient-centric, innovative collaboration between industry, academia and patient advocacy aimed at improving MS care and practice through the development of a practice-based learning research network.

The vision is for people living with MS to be informed leaders of their care team through the sharing of treatment data and outcomes generated in a practice-based research network.

People living with MS will be included in all aspects of the research collaborative including MSIN Advisory Boards and governance structure and will help to guide the direction of the study.

Methods

MSIN is an innovative collaborative research study, uniting key partners in the field of MS care. Led by the MSAA, the MSIN Steering and Oversight Committee (SOC) includes the University of Texas Health Science Center at Houston, the University of Texas at Austin Dell Medical School, Novartis Pharmaceuticals Corporation and people living with MS.

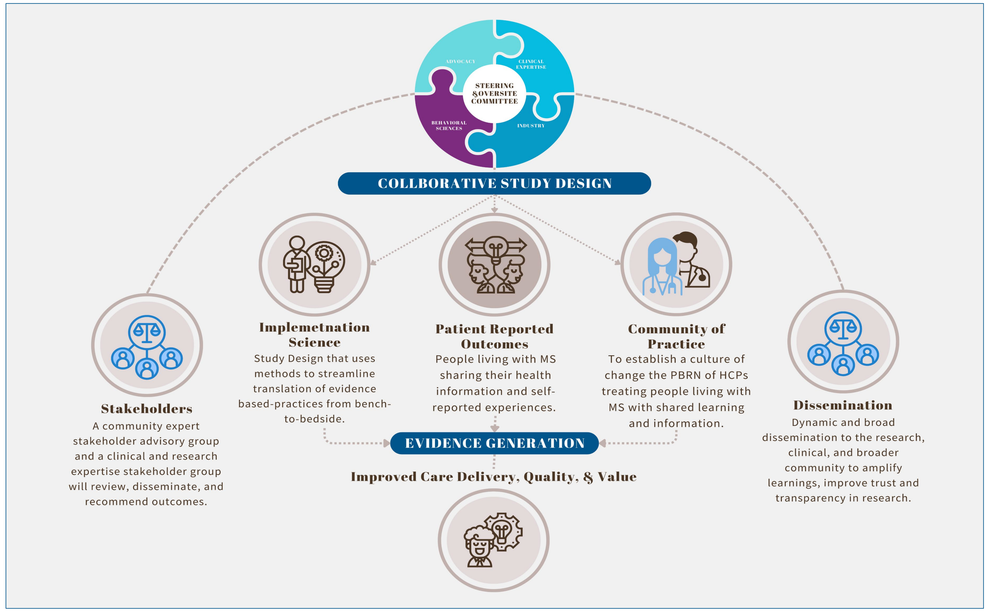
Under the direction of the SOC, MSIN has six collaborative work groups:

1) data management and analytics;
2) community engagement and partnerships;
3) outcomes and measures;
4) evidence-based intervention identification;
5) implementation strategy planning; and
6) Practice-based research network, research and agenda.

Aims

The initial aim for the study is to establish a practice-based research network of a diverse group of clinicians who provide care for people living with MS. **MSIN will establish a patient registry while simultaneously supporting and improving the practice of the MS clinicians in the network.**

The secondary aim for the study is to establish **an implementation research program capable of conducting rapid-cycle implementation research** that will enable the study to implement, evaluate and improve evidence-based interventions for MS care.



Conclusion

MSIN's patient-centered approach in developing an implementation science research network will accelerate the translation of best MS practices into clinical practices, improving care and outcomes for people living with MS equitably.

Discussion

The MSIN is properly situated and strategically designed to inform the necessary evidence generation to address sustained gaps in how multiple sclerosis is treated.

The PBRN framing of the MSIN is intended to streamline information sharing and knowledge transfer between clinical practitioners across the country, using implementation science quality improvement strategies.

The MSIN stakeholder convening groups complement PBRN activities while simultaneously elevating the study to a community of practice.

Instead of the customary siloed collaborations of clinicians and patients, or industry and researchers, or industry and patients, the MSIN convening groups bridge these traditionally dispersed system influencers to incorporate all perspectives. In the same way that the MSIN preparatory work was conducted,

MSAA, as the strategic lead, will identify opportunities to evaluate and synthesize knowledge and disseminate outcomes through concept papers and publications.

Montague A [1], Freeman L [2], Fernandez ME [3], Freeman J [4], Kline A [1]

1.Multiple Sclerosis Association of America, Cherry Hill, NJ, USA
2.University of Texas at Austin Clinical Practice of Dell Medical, Austin, TX
3.University of Texas at Houston Health Science Center, Houston, TX
4.Novartis Pharmaceuticals Corporation, East Hanover, NJ

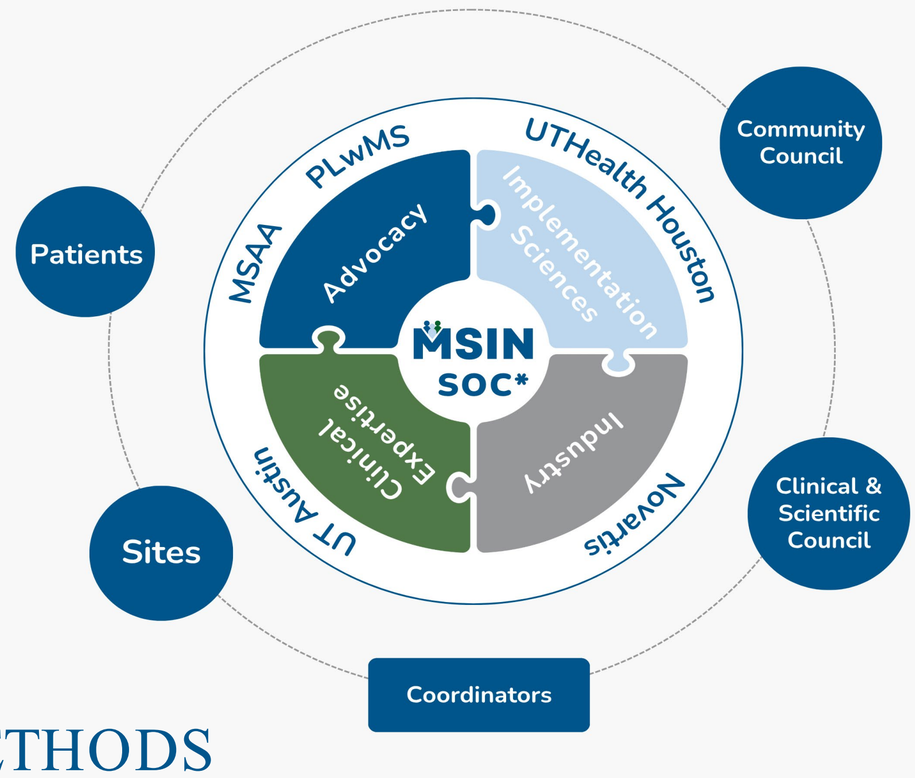
Disclosures: A. Montague, A. Kline and M. Fernandez: nothing to disclose. L. Freeman has received fees for consultancy and/or advisory board participation from Hoffmann-La Roche, Genentech, Novartis, Bristol Myers Squibb, EMD Serono, Sanofi, Horizon Therapeutics, and TG Therapeutics; has received honoraria for participation in educational programs from Medscape, Inc. and the MS Association of America; has received program sponsorship from EMD Serono; and has received grant support from NIH/NINDS, PCORI, the MS Association of America, Genentech, Sanofi, and EMD Serono through her institution. J. Freeman has received personal compensation for serving as a Medical Director at Novartis.

Shaping the Future of MS Care: Meaningful Patient Engagement in the Multiple Sclerosis Implementation Network (MSIN)

MONTAGUE A, ED.M [1], FERNANDEZ M, PHD [2], FREEMAN L, MD, PHD [3], FREEMAN J, MD, MBA [4], PINNOCK C, MD, MPH [5], WILLIAMS A, MSC [6], KLINE A [1], DURACK K, MPS [1]

BACKGROUND

The Multiple Sclerosis Implementation Network (MSIN) is an innovative patient-driven research network that connects participating multiple sclerosis care centers. In sharing data and experiences, MS healthcare professionals can learn from each other with the goal of improving care for people living with MS. The MSIN aims to transform how cutting-edge discoveries are translated into real-world practice that improve outcomes and reduce disparities across the healthcare continuum. Central to MSIN's mission is the active engagement of people living with MS, who are integral in shaping the network's priorities and represent over 30% of MSIN's Steering and Oversight Committee (SOC), MSIN's governance structure. The unique structure of the study is outlined below:



METHODS

MSIN convened a Community Insights and a Clinical Insights Advisory Board to provide strategic input and expertise to MSIN leadership from a wide range of stakeholders. The Advisory Boards are comprised of people living with MS, care partners, patient advocacy organizations, MS clinicians, researchers, and payers. At the first meetings held in January 2025, the Advisory Board members (n=16) discussed the MSIN research agenda and were asked to define what makes research and care patient- centered. These insights were then gathered and reviewed to identify key components of meaningful patient engagement.

"Patient-centered research means integrating patients at every step-from defining research questions to sharing results. Their perspective must guide every decision."

"MS care must reflect the intersectionality of each patient's lived experience. Diversity isn't optional, it's essential to achieving equity and relevance."

"Patient-centered care means listening to what matter most. Awareness, advocacy, and cultural competence are essential, especially in underserved communities."

"Truly patient-centered research hardwires patient voice into care delivery. Data must reflect lived experience-not just clinical outcomes."

"Patient-centered care means the individual is at the center of every decision. I strongly advocate for shared decision-making and collaborative care with neurologists."

OUTCOMES

The key themes that emerged around patient-centered care and research included:

- Empowerment & Leadership: Patients as co-creators, not just participants.
- Collaboration & Partnership: Equal contribution from stakeholders across all sectors.
- Trust & Communication: Clear, transparent, and ongoing dialogue.
- Systemic Change: Disrupting traditional research hierarchies
- Impact-Driven: Focus on real-world outcomes like function, quality of life, and access.
- Inclusivity: Importance of including a diverse group of people living with MS and care partners.

EMERGING THEMES ON WHAT MAKES RESEARCH PATIENT-CENTERED

CONCLUSION

The insights from MSIN Council members reinforce that engagement must be empowering, collaborative, personalized, and equity-driven to create lasting, real-world impact in MS care. During their initial meeting, the two distinct councils, each bringing different areas of expertise, focused on the same topics: exploring meaningful approaches to measurement and identifying potential evidence-based interventions for the network to study. This shared focus enabled us to understand both the diversity and the alignment of perspectives across the councils.

THIS RESEARCH WOULD NOT HAVE BEEN POSSIBLE WITHOUT THE INVALUABLE CONTRIBUTIONS OF PEOPLE LIVING WITH MULTIPLE SCLEROSIS. THEIR WILLINGNESS TO SHARE THEIR EXPERIENCES HAS BEEN CRUCIAL IN SHAPING THIS WORK.

1 MULTIPLE SCLEROSIS ASSOCIATION OF AMERICA, CHERRY HILL, NJ, USA
2 UTHEALTH HOUSTON INSTITUTE FOR IMPLEMENTATION SCIENCE, UNIVERSITY OF TEXAS HEALTH SCIENCE CENTER AT HOUSTON, HOUSTON, TX, USA
3 THE DELL MEDICAL SCHOOL, THE UNIVERSITY OF TEXAS AT AUSTIN, AUSTIN, TX, USA
4 NOVARTIS PHARMACEUTICALS CORPORATION, EAST HANOVER, NJ, USA
5 THE BETA POND
6 WIDER CIRCLE

Mapping the Multiple Sclerosis Care Journey: Integrating Lived Experience and Clinician Insight to Drive Implementation through the Multiple Sclerosis Implementation Network (MSIN)

LEORAH FREEMAN, MD, PHD1, BIJAL BALASUBRAMANIAN, MBBS, PHD2, AMANDA S ENGLISH, DRPH, MCHES2, LIZETTE GUTIERREZ, MPH, CHES2, S TEPHANIE SILVEIRA, PHD2, ALEXIS KLINE, MPH3, CLAUDE PINNOCK, MD MPH3, KATE DURACK, MA3, AMANDA MONTAGUE, EDM3, AND MARIA E FERNANDEZ, PHD2
,

BACKGROUND

The Multiple Sclerosis Implementation Network (MSIN) is a patient-driven practice-based research network (PBRN) designed to bridge the research-to-practice gap for people living with multiple sclerosis (pwMS). MSIN brings together MS clinicians, patient advocacy organizations, clinical and implementation science researchers, and industry partners to improve care quality and outcomes across the MS care continuum.

A central component of MSIN is its Community of Practice (CoP), which connects MS healthcare professionals and clinics to share best practices, collaborate on solutions, and address challenges in MS care delivery.

METHODS

Fifteen MSIN clinical sites participated in a Community of Practice (CoP) consisting of eight one-hour virtual meetings. Facilitators used focus group techniques to guide discussions among MS clinicians and care teams. Prior to each session, participants completed brief clinician insight surveys to capture perspectives on challenges across the MS care continuum.

To complement CoP discussions, two online pulse surveys were conducted among pwMS to assess experiences related to diagnostic delays and access to care. Survey responses were analyzed using descriptive statistics, and findings were shared with CoP members to inform discussions, identify gaps in care, and prioritize implementation-focused strategies.

If I had one champion who believed my symptoms were real, it would have saved so much brain and spine.

Always be your own advocate for your health.

I wish more doctors were proactive in preventing damage — once a new lesion occurs, you're stuck with the new symptoms.

PERSPECTIVE OF PEOPLE LIVING WITH MS

401 people living with MS across 43 U.S. states completed the online pulse surveys.

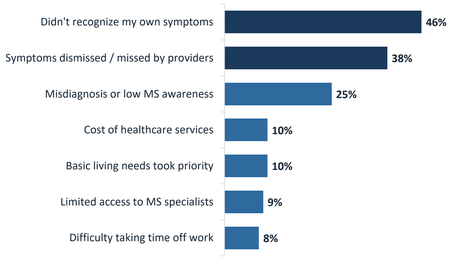
The diagnostic journey is long for most people with MS

78% had symptoms for ≥1 year before being diagnosed

>40% waited more than 5 years for a diagnosis

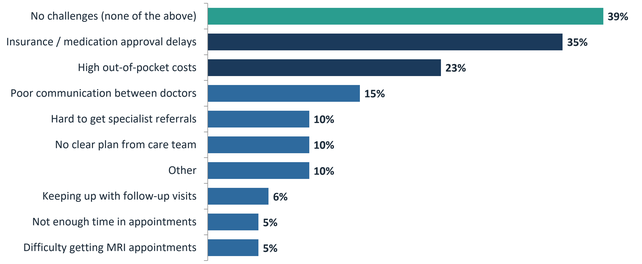
Patient-reported barriers to a timely MS diagnosis

Respondents could select up to 3 barriers · n = 401



Challenges in getting good MS care after starting treatment

Select all that apply



KEY INSIGHTS FROM MSIN CLINICIANS

Clinician-identified drivers of diagnostic delay

Perspectives from MSIN clinicians · Community of Practice

WHO is most at risk of delayed diagnosis

- Lower socioeconomic status
- Rural residence
- Men (male sex)
- Atypical or mild symptoms
- Presentation outside typical age ranges
- Limited primary care access

WHAT drives the delay

- Limited MS awareness among first-line providers
- Difficulty obtaining medical or imaging records
- Limited appointment availability

CONVERGENCE

Where patient and clinician priorities converge

Integrating lived experience and clinician insight to drive implementation

People living with MS + **MS clinicians**

1. **Earlier use of high-efficacy therapy**
2. **Stronger care navigation & clinician education**
3. **Expanded multidisciplinary care**
4. **Biomarker-guided treatment & monitoring**

Proposed implementation strategies

- **Provider & community education**
  Encourage referring clinicians to order MRI before the neurology visit
- **Clinic workflow redesign**
  Urgent new-patient slots, referral triage, and APPs for stable patients to improve access
  Increase access to biomarkers
- **Multidisciplinary care clinics**
  With dieticians, exercise specialists, mental health specialists, cognitive health specialists
  Group education

CONCLUSION

Diagnostic delays and systemic barriers to optimal MS care remain common across the United States. Findings from both patient surveys and clinician discussions identified significant challenges related to symptom recognition, access to specialty care, insurance restrictions, care coordination, and disease monitoring.

Integrating patient and clinician perspectives through a Community of Practice enabled MSIN to identify actionable, implementation-focused strategies to improve MS care delivery. This collaborative, stakeholder-driven approach within a practice-based research network highlights opportunities for scalable and equitable interventions across real-world MS care settings.

THIS RESEARCH WOULD NOT HAVE BEEN POSSIBLE WITHOUT THE INVALUABLE CONTRIBUTIONS OF PEOPLE LIVING WITH MULTIPLE SCLEROSIS. THEIR WILLINGNESS TO SHARE THEIR EXPERIENCES HAS BEEN CRUCIAL IN SHAPING THIS WORK

THIS POSTER WAS SUPPORTED THROUGH COLLABORATION WITH NOVARTIS PHARMACEUTICALS AND GENENTECH.

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3 MULTIPLE SCLEROSIS ASSOCIATION OF AMERICA, CHERRY HILL, NJ, USA5

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Leorah Freeman: has received fees for consultancy and/or advisory board participation from Hoffmann La Roche, Genentech, EMD Therapeutics, Amgen and Octave Bioscience; has received honoraria for participation in educational programs from Can Do MS, M MS Association of America; has received speaking honoraria from the MS Association of America, Genentech, Sanofi and Merck; h support from NIH/NINDS, PCORI, Genentech, TG Therapeutics, Sanofi, EMD Serono, Novartis, and MS Association of America throug
Jason Freeman: is a medical director at Novartis Pharmaceuticals
All other authors: Nothing to disclose.

Ser ono, Sanofi, TG eds cape, Inc and the as received grant h h er institution.

THE MS IMPLEMENTATION NETWORK (MSIN)

DEVELOPING A LEARNING HEALTH SYSTEM COLLABORATIVE AND COMMUNITY OF PRACTICE FOR IMPROVEMENT, INNOVATION AND IMPLEMENTATION RESEARCH TO IMPROVE OUTCOMES IN MS

Montague A [1], Kline A [1], Mehta F [2], Ahmad J [2], Durack K [1], and Oliver BJ [2-5], on behalf of the Investigators and People Living with MS participating in the MSIN

1. Multiple Sclerosis Association of America, Cherry Hill, NJ, USA
2. Chronic Health Improvement Research Program (CHIRP), Department of Community & Family Medicine, Dartmouth Health, Lebanon, NH, USA
3. The Dartmouth Institute for Health Policy & Clinical Practice, Geisel School of Medicine at Dartmouth, Hanover, NH, USA
4. Department of Psychiatry, Geisel School of Medicine at Dartmouth, Hanover, NH, USA
5. Care Experience, Value Institute, Dartmouth Health, Lebanon, NH, USA

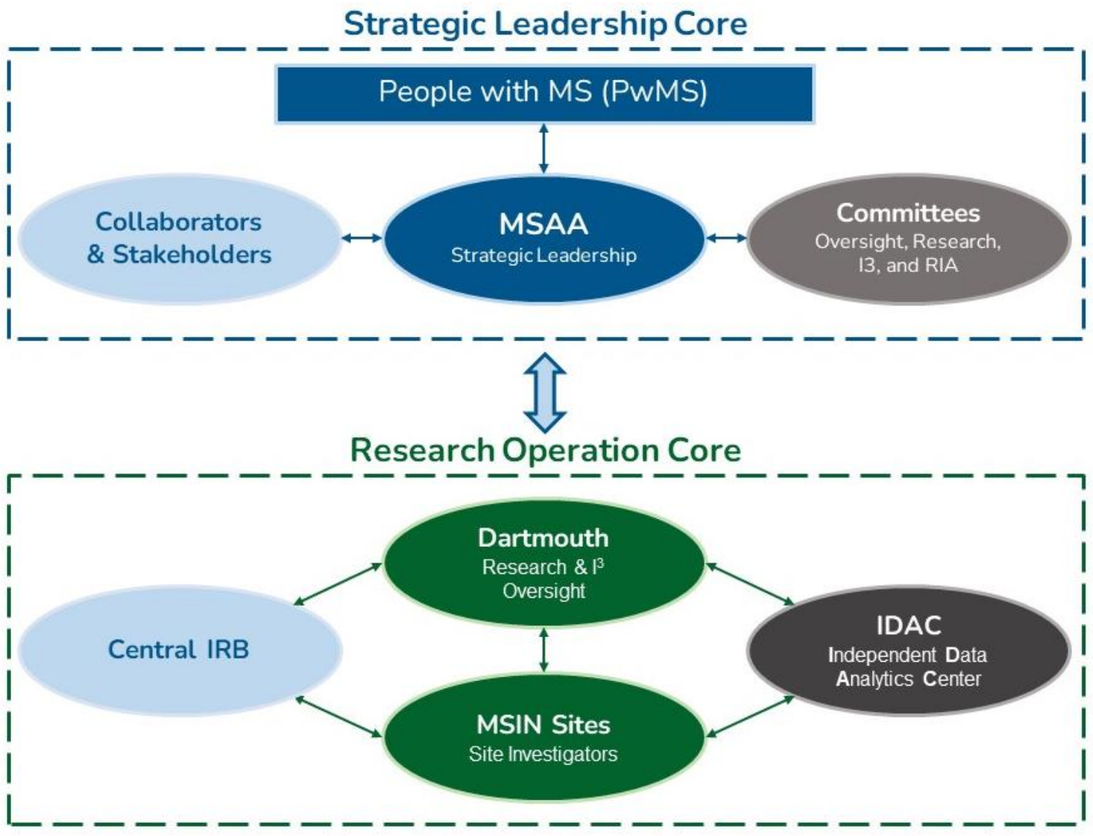
Abstract

The MS Implementation Network (MSIN) is a learning health system collaborative and community of practice for improvement, innovation and implementation research to optimize health outcomes for people living with MS (PwMS). Co-designed by the Multiple Sclerosis Association and Dartmouth University, MSIN seeks to establish the first implementation science research network for multiple sclerosis.

MS is a complex, chronic and costly ("3C") condition that is among the most common and disabling neurological disease in adults.[i] MS affects nearly one million Americans with a prevalence of 309 per 100,000 adults[ii] and generates substantial burden on PwMS, the healthcare system, and society as a whole,[iii] with an estimated annual individual cost to a PwMS of $8,528-$54,244.[iv, v, vi] While MS has been investigated at the basic science, individual and population levels of analysis, including large data registry initiatives, this study will establish the fist multi-center implementation science research network for MS to evaluate system and population-level variation in process and outcomes, evaluate implementation feasibility, acceptability, utility and effectiveness while also informing best practices in how patient advocacy organizations, healthcare centers, and research institutes can work collaboratively to improve outcomes and quality of life for PwMS.

Introduction

The MSIN is founded in partnership between the Multiple Sclerosis Association of America (MSAA) and the Chronic Health Improvement Research Program (CHIRP) at Dartmouth. Founded in 1970, MSAA is a leading MS patient advocacy organization dedicated to improving lives through vital services and support and driving a patient centric-future for MS care and research. CHIRP at Dartmouth is an academic leader in improvement, implementation and innovation science. MSAA and CHIRP at Dartmouth have come together to develop a patient-centric implementation research collaborative for multiple sclerosis. The MSIN is a multi-stakeholder collaborative, leveraging all partners who are part of the MS care continuum and community while keeping the patient at the center of all that we do.



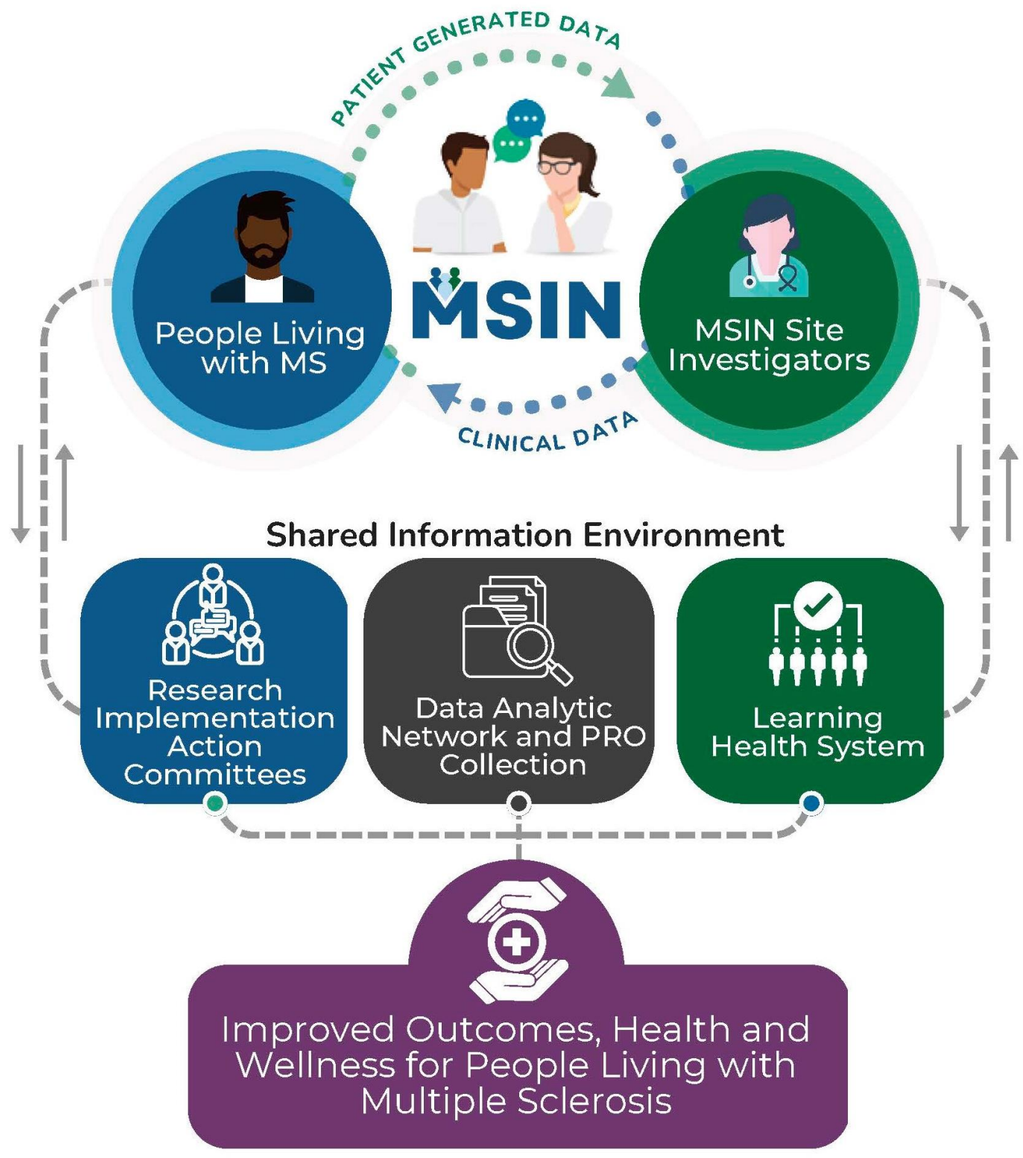
Objectives

The MSIN will establish a multi-center learning health network that incorporates a community of practice, a learning collaborative, a learning health system data infrastructure, and an improvement and implementation training academy.

Specific MSIN Aims include:

- Use improvement, co-design and agile design methods to establish and develop a scalable registry-enabled MS implementation Learning Health System collaborative and stakeholder-driven community of practice network
- Study the current state and experience of MS treatment patterns, and outcomes across participating MS centers, and use data transparency, visualization, and benchmarking approaches to help demonstrate practice variation and identify opportunities for improvement and standardization
- Facilitate a prospective cluster randomized system-level study to evaluate the implementation of an intervention to improve DMT treatment decision support and decision quality to improve patient activation, increase appropriate utilization of high efficacy DMT treatment, and optimize related health, experience, and wellness outcomes

Methods & Design



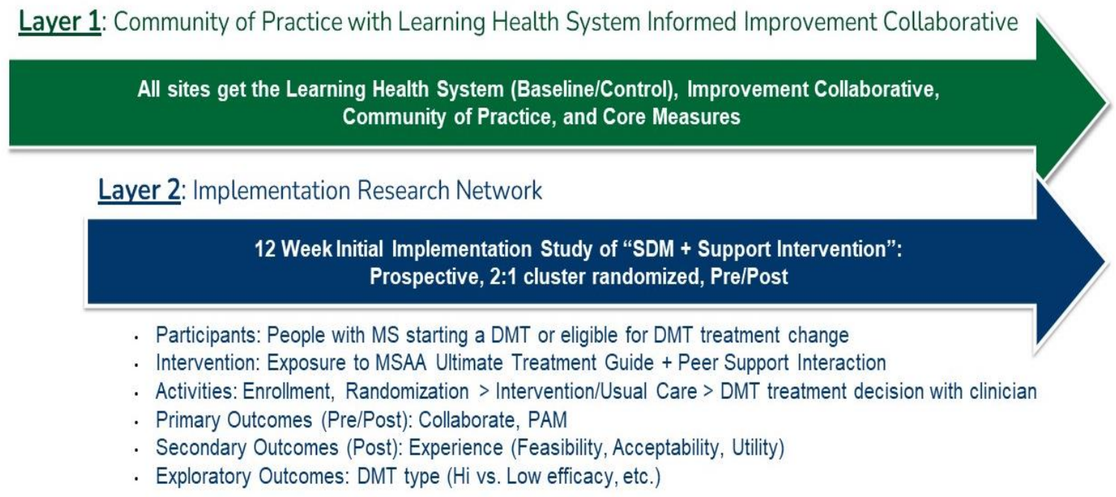
Adapted with permission from the Dartmouth coproduction LHS model: https://sites.dartmouth.edu/coproduction/our-model/

The MSIN design is based on the Dartmouth Institute for Health Policy & Clinical Practice (TDI) Coproduction Learning Health System model and a prior multicenter pilot study (MS-CQI, 2017-2020), and includes:

- Feed-forward clinical and patient reported data
- Feedback data for transparency, benchmarking, informing improvement, and hypothesis generation
- Data visualization: Dashboards and reporting
- Aggregated data for implementation and population health research
- Learning collaborative, community of practice structure

The study will enroll twelve sites in Year 1, with sites selected to represent diversity in the following areas: 1) geographic diversity; 2) the diversity of practice (i.e., general neurologist vs comprehensive MS center with an MS specialist); and 3) demographic diversity of PwMS served at a site.

Clinical trial sites will be responsible for recruiting PwMS and will be involved in implementation interventions and participate in improvement measures through coaching. Sites will also be part of the MSIN Learning Collaborative and expected to attend monthly webinar meetings and periodic MSIN community of practice meetings and can also be included in MSIN Advisory Boards and play an essential role in how the research is disseminated within the broader MS community.



Key Outcomes

Information sources will include:

- Longitudinal data registry including clinical data
- Patient reported outcomes
- Claims data
- Qualitative data

Anticipated outcomes include:

- Improved quality of care and clinical outcomes for people with MS.
- Improved levels of resilience (lower burnout) and improved processes and outcomes performance for clinical trial sites as compared to the 'usual care' control group

Conclusions

By developing a multi-center system-level registry-enabled learning health system for MS, then we can create a patient-centric implementation science research network for MS that can study variation in system-level performance and related population outcomes.

Through this work, we will then be able to test the implementation of evidence-based interventions and in real time work to improve the quality of MS care and outcomes for PwMS. This research may also lead to improvements in healthcare systems and better inform policy makers and best practices in MS care and treatment.

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