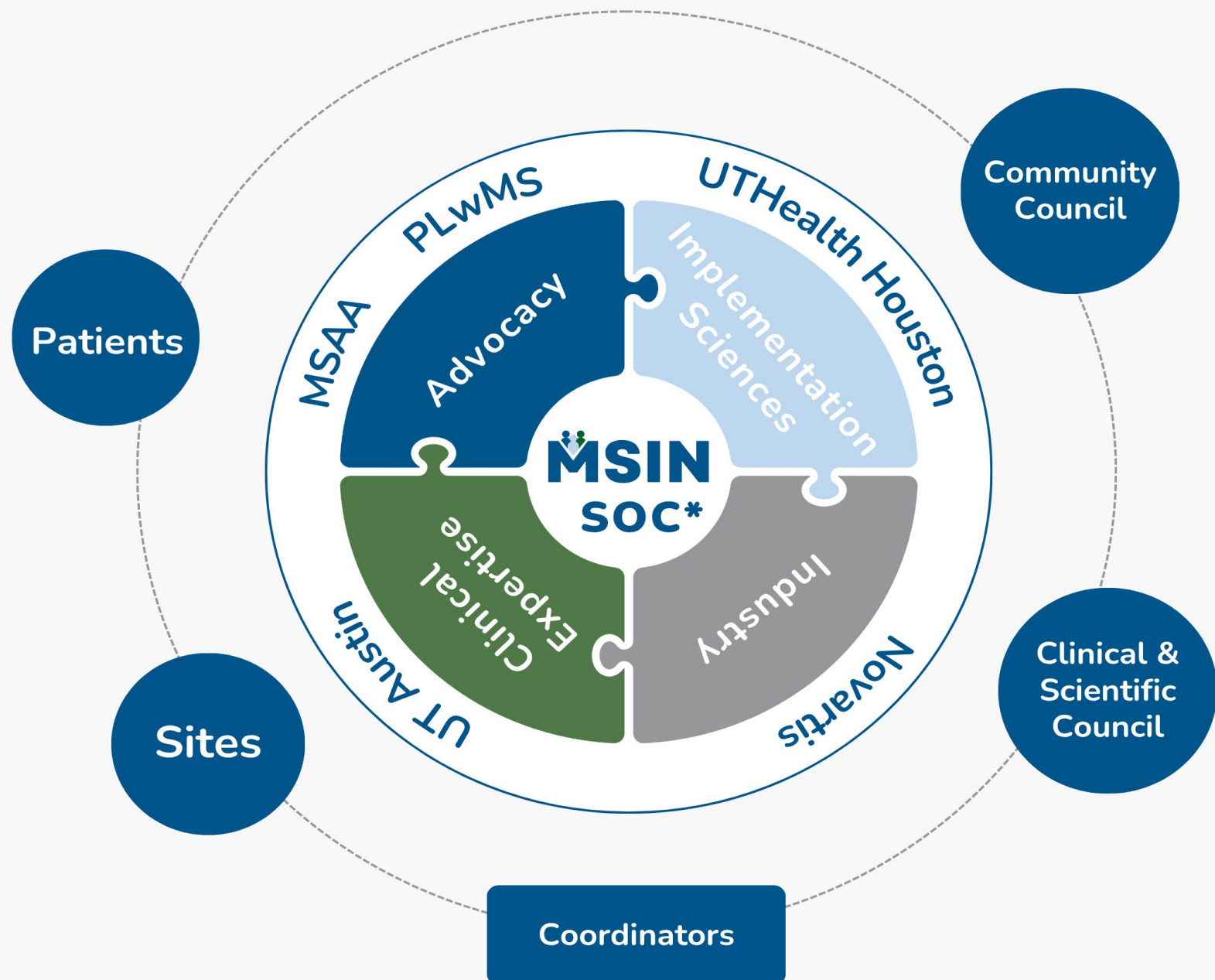


# Shaping the Future of MS Care: Meaningful Patient Engagement in the Multiple Sclerosis Implementation Network (MSIN)

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.