

MS Minority Research Engagement Partnership Network Frequently Asked Questions

What is the MS Minority Research Engagement Partnership Network?

The Network is a multi-stakeholder network coming together to better define and address the issue of racial/ethnic minority underrepresentation in multiple sclerosis (MS) research.

What are the goals of the Network?

Our goals are to:

- Develop a shared understanding of the specific barriers to participation in research for minority community members with MS;
- Develop an action plan with specific outreach efforts to counteract those barriers;
- Implement the action plan, measure outcomes, and adjust activities based on results; and
- Openly disseminate the resources and materials we develop for the benefit of other efforts working to achieve similar aims.

Why focus on MS in Minority Populations?

Multiple sclerosis (MS) affects people of many races and ethnicities and we are learning that it may have an especially heavy impact on minority populations. As with many other diseases, minority populations are severely underrepresented in MS research, making it difficult to uncover key insights into how the disease works and how well treatments work for people in different groups.

Why should I or my organization join the Network as a partner?

We need your voice as a stakeholder to better understand and address barriers to minority participation in MS research. By joining the Network, your knowledge and resources with respect to MS, medical research, minority health, and/or community engagement will help shape the research, insights, and outreach needed for a successful program. The Network will use the collective knowledge, research, and insights of member organizations to dig deeper into the issues, aim higher for innovative solutions, and reach wider communities for engagement.

How is the Network funded?

Funding for the network's initial 2 years is provided by Patient-Centered Outcomes Research Institute (PCORI) through an award (contract) to Accelerated Cure Project (ACP). Other funding may be sought to support additional activities of the Network or to extend its timeframe.

Who are the members of the Network?

- People with MS belonging to racial/ethnic minority groups

- Organizations dedicated to reducing disparities in health
- MS patient advocacy organizations
- MS biopharmaceutical companies
- MS clinicians and investigators
- MS community leaders

Who are the Network leaders?

Hollie Schmidt (ACP) and Monique LaRocque (Feinstein Kean Healthcare, a leading strategy and communication firm) will be providing leadership. Anita Williams and Shawn Feliciano are MS patient advocates who will help guide the work of the Network as MS Advisors. Support staff from FKH will assist with and facilitate the work of the Network. Each partner organization will also appoint a lead person to represent the organization at Network activities such as calls and meetings.

How does the Network perform its work?

Network members will work together to achieve the Network's goals through the following activities:

- Share information, knowledge and resources that each member has available to contribute;
- Collectively discuss and plan the work of the Network;
- Execute plans working collaboratively or individually, as appropriate;;
- Communicate by conference calls/web meetings and one face-to-face meeting in the first year; and
- Document and share our resources and knowledge with the wider world.

What are Network members expected to contribute?

Network members are expected to contribute any knowledge, information and resources, relevant to the topic of minority participation in MS research, that is available to be shared openly. They will also participate in monthly telephone meetings and one in-person meeting for the purpose of sharing information, setting goals, and developing and implementing action plans. To the extent appropriate, Network members will also be directly involved in carrying out the activities of the Network.

What kinds of activities will the Network conduct?

The first set of activities for the Network involves sharing available information and gathering additional data needed to assess the key factors contributing to minority underrepresentation in MS research. Based on this information, the Network will determine the best methods for engaging minority populations with MS. While the exact methods will be determined collaboratively, at a general level we expect these activities to include:

- Development and dissemination of educational materials aimed at removing barriers to participation in research;
- Outreach to organizations and community leaders;
- Planning and execution of in-person outreach events and meetings with local partners; and
- Use of networks, including social media, to share messaging.

Are Network members expected to contribute financially?

There is no membership fee or contribution for Network Partners. However, partner organizations will be expected to cover the cost of staff time and/or travel needed for Network participation.

How do organizations join the Network?

If you are interested in joining the network, please contact:

mminorityresearch@acceleratedcure.org.

Are there other ways to be involved?

Yes! As we move forward, the Network will work with many organizations to reach key audiences around the country.

Where can I find more information about the MS Minority Research Engagement Partnership Network?

Visit our website at <https://www.acceleratedcure.org/ms-minority-research-network>.