

The MS Minority Research Engagement Partnership Network

The *MS Minority Research Engagement Partnership Network* is an inclusive, comprehensive, and far-reaching program designed to bring together diverse stakeholder groups to identify and characterize current barriers to minority participation in MS research and develop community-endorsed, culturally appropriate strategies and solutions to overcome these barriers. The Network is spearheaded by Accelerated Cure Project, a patient-founded, non-profit organization that focuses on meeting the research needs and interests of people with multiple sclerosis and research communities. Expertise and support is provided by Feinstein Kean Healthcare, a leading strategy and communications firm.

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.
- Minority populations, particularly African Americans, may have a higher risk of developing MS and several studies show it can be more aggressive in this group, causing greater retinal damage, larger brain lesions, and higher rates of disease progression.
- Many minority populations are adversely affected by disparities in use and receipt of health services.
- Minority populations are severely underrepresented in scientific research, making it difficult to uncover key insights into how the disease works and how well treatments work for people in different groups.
- In its initial phase, the Network effort will focus on African Americans and Latino Americans because they represent the two largest racial/ethnic minorities in the U.S. In the future, the model and methods developed and used by this group can be generalized and applied to other minority communities with additional input and insight from those populations. These models and methods will also be applicable for use in outreach efforts for other diseases.

Together We Can Understand the Obstacles and Find Solutions

- Partners in the Network represent a wide range of stakeholders involved in overcoming MS, including minority health organizations, MS patient advocacy organizations, researchers in the field, biopharmaceutical companies developing treatments, policymakers and community organizers, business leaders, educators, faith institutions, and individuals affected by the disease, including members of the Accelerated Cure Project's patient-powered research network, iConquerMS™.
- Many brains are better than one – and the Partnership 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.
- This initiative is funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington Engagement Award. These awards are intended to increase engagement in research, i.e., the meaningful involvement of patients, caregivers, clinicians, and other [healthcare stakeholders](#) throughout the research process.

The MS Engagement Toolkit

- An important focus of the Network will be to develop strategies, programs, and materials to overcome the key obstacles we uncover that prevent people in minority groups from participating in MS research.

- Together, the Partnership Network will collect and develop important tools and resources to equip network members, other organizations, and communities to address minority underrepresentation in health research.
- The tools and resources that make up the MS Engagement Toolkit will be used by the Network to carry out its mission and will also be made publicly available for other groups to use in their research engagement efforts.

How to Get Involved

The Partnership Network includes representatives from diverse stakeholder groups with strong relationships to minority and MS communities, including:

- Members of iConquerMS™ (people with MS) who represent minority racial/ethnic groups
- Minority health organizations
- MS patient advocacy organizations
- MS biopharmaceutical companies
- Investigators who belong to minority groups and/or are conducting research on issues relevant to MS minority groups
- Non-traditional stakeholders who are trusted community leaders, such as pastors, educators, business owners, policymakers and/or community organizers.

If you are interested in joining the network, please contact: msminorityresearch@acceleratedcure.org.