

CASE STUDY HIGHLIGHTS:

Multiple Sclerosis Research Mythbusting Series

How patient advocacy organizations working in a disease area can contribute to diverse clinical trial participation

BACKGROUND

While multiple sclerosis (MS) affects all races and ethnicities, people of color bear an unequal burden from the disease. Genetic, environmental, and social factors may contribute to the development of MS and the treatment received for the disease. Additional disparities relating to access to health services, differing cultural beliefs, and distrust of the medical profession may also contribute to worse outcomes.



- People of color are significantly underrepresented in scientific research in general, and this is true of MS as well.
- Without the participation of people of color in MS research studies, is impossible to understand how the disease manifests and which treatments work best in all people with MS
- People affected by MS from underserved populations may be reluctant to participate in research due to:
 - misconceptions about the risks and demands of participation
 - unclear benefits of research to individuals and their communities
 - lack of trust in research



**MULTI-REGIONAL
CLINICAL TRIALS**

THE MRCT CENTER of
BRIGHAM AND WOMEN'S HOSPITAL
and HARVARD

APPROACH

To address the needs and concerns that lead to underrepresentation in research, two advocacy organizations that serve the MS community, Accelerated Cure Project (ACP) and the Multiple Sclerosis Association of America (MSAA), conducted educational events branded as a “Research Mythbusting Series.”

The events built upon the work of the established MS Minority Research Engagement Partnership Network and focused on providing current, factual information about research participation and study opportunities for individuals with MS and their care partners.

Four in-person educational events and one webinar were held to address the misconceptions (i.e., “myths”) associated with participation in, regulations around, and goals of research.

- The in-person events were held in population centers with significant racial and ethnic diversity.
- The webinar was scheduled to accommodate both the eastern and western parts of the U.S.
- The webinar was recorded for future access by those unable to attend the live event.
- Each event was facilitated by a Black or Latinx MS specialist who used a common set of slides.
- The live events were designed to be interactive and participants were encouraged to ask questions.



<https://mymsaa.org/videos/ms-research-mythbusting>



RESULTS

Most attendees were Black and Latinx people living with MS and their care partners.

Comments from participants on the presentations showed that people with MS, who belong to racially and ethnically diverse groups, support and recognize the value of clinical research but were not aware of the issues caused by the lack of diversity in research studies.

Following their joint Mythbusting series, MSAA and ACP are each continuing to communicate with underrepresented groups about research awareness and participation in order to expand the reach and impact of their message.

CONCLUSION

Learnings from ACP and MSAA's "Research Mythbusting Series" illustrate that patient advocacy organizations can help improve their communities' awareness of the need for all groups to participate in clinical research for the benefits of research to be distributed more fairly.

Additionally, interactive engagement strategies, such as educational events, can help organizations identify gaps in community knowledge about clinical research more broadly.

The engagement of communities from diverse backgrounds requires intentional selection of sites and population demographics, and it works best when organizations commit to sustaining relationships and partnership through continued communication and outreach activities.

For citations and more information on this case, please see the **MRCT Center toolkit**.