

Accelerated Cure Project for MS

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Accelerating research towards a cure for multiple sclerosis

Diversity is Lacking in Clinical Trials – and it’s a Problem

Clinical trials are studies that test whether drugs work, and provide information for doctors regarding how to treat their patients. Fewer than 10 percent of patients enrolled in clinical trials today are minorities. As discussed in the [September 2017 newsletter](#), this could partly be due to past injustices that



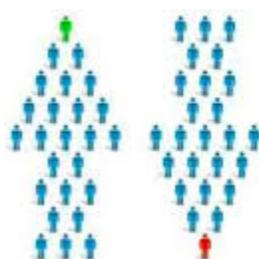
have led people in minority communities to have less trust in clinical research than they otherwise might have. However, it’s important for participants in clinical trials to “look like” the patients who could end up taking the treatments. People of all genders, ages, races and ethnicities require medical treatment. When research involves a group of people who are too much alike, the findings may not apply to or benefit everyone.

The [MS Minority Research Engagement Partnership Network](#) is a team led by ACP that is dedicated to understanding the barriers that prevent minorities from participating in MS research, with the ultimate goal of overcoming them. The team consists of advocacy partners, clinicians and researchers, industry representatives, as well as people with MS belonging to minority communities (both African American and Hispanic American). Anita Williams is an African American woman participating as an advisor in the Network. Anita was diagnosed with MS when she was 44 years old. In her words, “It’s a cross section of people who care. Everything the committee does is fueled by passion, commitment and



caring. When I was first diagnosed with MS I had so many treatment choices because people before me participated in research. Everyone on the committee cares about getting more People of Color into studies. As a Black woman I feel an obligation to my community to let them know that we welcome you, we want your voice and participation. We need you.”

Much work has already been done to investigate ways to increase diversity in clinical research. The Minority Research Engagement Partnership Network’s program is specifically focused on MS research. Historically, MS was believed to be a disease of young white women, with the incidence of MS being less common in African Americans than Caucasian Americans. However, results of [recent studies](#) show the



incidence of MS is higher in African Americans than in Caucasian, Hispanic, or Asian Americans, and their disease course tends to be more progressive and less responsive to certain disease-modifying therapies. In addition, study results indicate that Hispanic Americans may have an earlier age of onset and, as a result, develop increased disability at an earlier age than other populations. Yet these groups are consistently underrepresented in MS clinical trials. This makes it difficult to learn how MS affects people in minority groups, and to determine which treatments are most effective for

them. While talking about these new data, Anita Williams said, “This turns everything upside down in terms of assumptions. The research information for minority groups isn’t there, not at rates that would be comparable to the studies that have been done with white subjects. We must bring in the voice of People of Color with MS. This will give us a chance to compare answers.”

In an effort to understand why this disparity exists, members of the Network designed a survey asking about people’s attitudes and concerns about research, and other research related topics. English and Spanish versions of the survey were offered online to people with MS over a period of 2 months. In all, more than 2,600 people with MS responded to the survey. Information from people in different racial and ethnic groups that had more than 150 responses (African Americans, Caucasians, Hispanics and non-Hispanics) was compared.



An overview of the survey results can be found in the report [Opinions and Experiences about Research](#), which was released in January. In summary, people with MS across all groups generally agreed that medical research has led to better MS treatments (and, therefore, needs to continue). Forty percent of respondents had participated in a research study. Most of them thought it was a good experience and would participate again. They also want to be kept up to date on the results of studies they participate in. The sources



that most people would consult for information about research studies were MS organizations and MS websites or blogs. The most trusted sources of this information were MS organizations, doctors, and nurses.

Across all groups, the biggest concern about participating in research was not being fully informed about the study. African Americans were more concerned about being taken advantage of by the research team, or about having their personal information released without approval. From Anita Williams' perspective, "Considering what happened with [Henrietta Lacks](#), I think it's a trust issue and I believe this is also true for other People of Color. It's a cultural feeling. As time goes on more and more atrocities are dug up. But this is not something that can't be overcome."

Inclusion of minorities in clinical trials is key to ensuring that discoveries, treatments, and prevention strategies are relevant to those populations. The MS Minority Research Engagement Partnership Network will make recommendations based on survey results to researchers on their study procedures and recruitment methods in hopes of helping them include more minority participants in their studies. These recommendations will be shared with scientists at meetings and on the Network [web site](#). The team plans to continue learning about how people with MS feel about research, and striving to ensure that MS research helps all people.



In Anita Williams' words, "What we're doing is bigger than MS, we can extrapolate the information. Other diseases can use this as a model. We must dive deeply into how to make systemic changes that will bring people in. We must work with both researchers and clinicians. Our efforts have to be targeted, and they have to be sensitive. This is new and groundbreaking, and can be mined for so many different things. This is the beginning of a great journey and I am excited to be involved."

