



Minority Engagement in MS Research

Patient Recruitment Toolkit for Research Professionals



**MS Minority
Research
Engagement**

PARTNERSHIP NETWORK

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Thank you for your interest in bringing MS research opportunities to a wider, more inclusive, and diverse population of patients and communities who may be at risk for multiple sclerosis (MS)!

Racial and ethnic minorities are underrepresented in MS research, resulting in a lack of evidence about their disease characteristics and optimal treatment. As a research professional, you can play a vital role in correcting this imbalance by working to include members of minority groups in the studies you conduct or support.

This toolkit is designed to help you learn more about what is currently known about MS in different racial and ethnic minorities, offer insights into the perceptions and concerns patients from different ethnic and racial backgrounds may have when it comes to research, and help you reach out to these communities and work with them in ways that are culturally appropriate, effective, and mutually beneficial.

On the following pages, you'll find tools and discussion guides, evidence-based research on patient perceptions, resources for identifying community leaders and reaching out to different groups, and educational materials to download for your patients and volunteers. We recognize that reaching recruitment goals can be time-consuming and challenging. These tools are intended to help you to better reach those in minority populations without slowing down the timeline of the study.

This toolkit has been developed by the **MS Minority Research Engagement Partnership Network** (MS MREPN), a multi-stakeholder group dedicated to increasing research participation and inclusion among different ethnic and racial groups so that treatment can be best tailored to each group. We are doing this by understanding the barriers that may prevent people from different communities from participating in medical research, and by developing messages and materials that help to overcome these barriers. We are also working to help health care providers and researchers better understand how to encourage MS patients from ethnically diverse backgrounds to participate in research activities so that every community benefits from the work that is being done.

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Why Focus on MS among Minorities?

MS affects people of many races and ethnicities and recent studies indicate it may have a disproportionate impact on some minority populations. For example, African Americans may have a higher risk of developing MS¹⁻³ and several studies suggest it can be more aggressive in this group, causing greater retinal damage,⁴ larger brain lesion volumes,^{5,6} and more rapid disease progression.^{1,7-9} Among Hispanic/Latino communities, the risk of developing MS may be lower, but studies indicate it may present earlier and pose a higher risk of disability earlier in the disease.^{10,11}

People from different ethnic and racial minority groups may have significantly different responses to medical treatments, due to intrinsic factors such as genetics and metabolism, and extrinsic factors such as diet, environment, and sociocultural issues.¹²⁻¹⁵ In addition, many minority populations are adversely affected by disparities in access to and utilization of health services.^{16,17}

Knowledge of MS risk, presentation, progression, and response to treatment for ethnic and racial minorities is still limited. Traditionally, MS was largely viewed as a young White woman's disease, affecting primarily those living at high latitudes. This misperception led researchers to believe minorities were at lower risk and that there was little need to include these populations in MS research. At the same time, the perceived low risk meant many minority patients were diagnosed late and might be eligible for fewer studies or have less access to researchers.²

Reviews of published MS studies indicate that interest in ethnic and racial minorities has only become more prevalent in the last decade or so,¹ and cohorts for subgroup analyses in major clinical trials are generally small.^{1,18,19} The **MS Minority Research Engagement Partnership Network** is studying how to better reach minority communities in a culturally appropriate, respectful, and empowering way and encourage people with MS to engage in research that will improve MS treatment.

Minority Participation in MS Research

Multiple social and general factors, including past abuses, have left minority populations underrepresented in scientific research. This hampers efforts to uncover key insights into how the pathophysiology and progression of disease occurs and better understand how well treatments work for various populations.¹⁸

The ideal clinical trial population should be proportionately representative of the real-world population of patients with the disease who will eventually have access to the resulting medical treatment.²⁰ This is often not the case.^{19,21–25} Due to a combination of historical and demographic factors, racial and ethnic minorities are underrepresented in clinical research. In fact, while African Americans represent 12 percent of the U.S. population, they make up only 5 percent of clinical trial participants, while Hispanics, who make up 16 percent of the population, represent only 1 percent of clinical trial participants.¹⁸

This is concerning because response to medical interventions may vary based on gender, age, race, and ethnicity.^{14,15} Additionally, these factors may affect susceptibility to disease.^{14,15}

The Impact of Race and Ethnic Experiences on Research Participation

Historically, African Americans have expressed concerns about distrust of medical research as a result of past abuses, such as the Tuskegee Syphilis Study^{18,26} and patterns of actual and implicit bias in the health care system.^{26,27}

Among Hispanics, place of birth (U.S. vs. other countries), social and economic factors, and cultural perceptions of illness may strongly impact trust and participation in medical research.²⁸ Studies have shown that certain Hispanic communities hold beliefs that diseases, including MS, may have been caused by environmental factors such as excessive stress or poor diet and/or emotional factors such as depression or a traumatic event. This may affect outcomes, coping strategies, and treatment adherence and preferences.²⁸

However, these attitudes seem to be changing.^{29,30} In fact, a 2013 study found that 91 percent of African American research participants would be willing to take part in medical research again,³¹ while a survey of 50 Asian and Pacific Islanders found 88 percent would consider joining a study.³² Similarly, a 2017 survey of 2,600 people

with MS conducted by the MS MREPN ³³ found that African Americans and Hispanics were highly supportive of clinical research and almost all of the respondents expressed a willingness to consider participating in some type of research.

Patients Want to Talk with Their Clinicians about Research

Patients report wanting to hear about research opportunities from their specialist or primary care doctor. Yet, many say their physician doesn't bring it up. In fact, the Center for Information and Study on Clinical Research Participants found 51 percent of survey respondents listed their health care provider as their preferred information source, but only 23 percent reported it was their actual information source.³⁴ **Because of their trusted position, clinicians can play a vital role in correcting the racial/ethnic imbalance in research participation by helping to recruit their minority patients into studies and pointing them to available opportunities.**

Why People with MS Do – and Don't – Participate in MS Research

When discussing research opportunities with patients, it's good to be aware of the reasons why people choose to participate in MS clinical research and factors that may hold them back. Some are fairly universal, while others are more prominent among communities of different racial and ethnic backgrounds.^{26,33,35,36} Of course, it's important to recognize that each patient is an individual with specific interests and concerns, and that belonging to a minority group doesn't mean that an individual will have the same preferences as the group in general.

Barriers	Facilitators
<ul style="list-style-type: none"> ● Lack of Awareness of Research Opportunities ● Lack of Clear and Thorough Information about the Study and Consent ● Concerns for Safety ● Lack of Trust ● Legal and Financial Risk ● Competing Time and Cost Demands ● Different Cultural Beliefs 	<ul style="list-style-type: none"> ● Altruism ● Benefits to and Accommodations for the Participant ● Cultural Congruence ● Credibility and Low Risk ● Less Invasive Options

Barriers

Certain concerns about participating in MS research are prevalent among all groups (African American, Hispanic/Latino, Asian, White, and others). These include fears of side effects, receiving incomplete study information, and disruption of treatments and relationships with their health care professional.^{26,30,33} In addition, the MS MREPN survey, along with other minority engagement research studies, indicates common barriers for minority groups. Below are common barriers to study participation that might affect people's willingness to volunteer for research studies:

- **Lack of Awareness / Information**^{26,30}
 - Lack of information about research participation in general, especially about how to get involved
 - Lack of connection between minority communities and researchers and recruiters, limiting understanding of community needs, interests, and concerns and causing them to be overlooked
 - Less familiarity among minority communities with the idea of research participation
- **Lack of Clear and Thorough Information**^{26,30,37}
 - Study materials that are written at an advanced level and not user friendly
 - Unclear informed consent process and language
 - Lack of culturally competent, language-appropriate research staff and written materials
 - Lack of information about study results, causing participants to feel used
 - Lack of follow through for those aren't eligible, including explanation of why and options for other studies³⁸
- **Concerns for Safety**^{26,36}
 - Fears of unknown long- and short-term side effects
 - Interference with current treatments
 - Uncertainty about the effectiveness of the treatment being studied
 - Lack of access to necessary care should something go wrong
 - Concern about receiving poor quality medical care

- **Lack of Trust**^{26,27,29,33}
 - Overt, structural, and implicit bias
 - Fears that institutions and pharmaceutical companies may put own interests/profits ahead of the patients' best interests
 - Concerns that study findings will only benefit Whites
 - Doubt that research staff will have an adequate understanding of their community's needs and concerns.
 - Perception that researchers are using a community, rather than building a long-term partnership concerned with their health
- **Legal and Financial Risk**^{26,36}
 - Concerns about loss of insurance coverage
 - Fear of discrimination by insurance companies
 - Concerns about risks to jobs or legal status, particularly among Hispanics
 - Fear of disclosure of genetic or other medical information, especially among African Americans
- **Competing Time and Cost Demands**²⁶
 - Time, transportation, and financial constraints
 - Competing responsibilities such as work and child and elder care
- **Different Cultural Beliefs**²⁸
 - Reluctance to talk about illnesses
 - Beliefs about causes and treatments of illness
 - Preferences for types of treatment

Facilitators

Facilitators are aspects of the research experience that make participation easier or more appealing. Like barriers, many facilitators are universal across races and ethnicities,³³ while some are stronger motivators for particular communities.

- **Altruism**^{26,33}
 - Knowledge that the results may contribute to improved health and knowledge
 - Benefits to people in one's own racial or ethnic group (in the MREPN survey, this was expressed by 86 percent of African Americans and 77 percent of Hispanics)³³
- **Benefits to and Accommodations for the Participant**²⁶
 - Monetary incentives and other benefits such as free health care, food, etc.
 - Ability to address logistical issues such as transportation, child care, and schedules
- **Cultural Congruence**²⁶
 - Availability of information about the research study and informed consent in clear lay language in English and participants' native languages
 - Encouragement from family members
- **Credibility and Low Risk**^{26,33}
 - An established sense of trust in the doctor and research center
 - Inclusion of diverse ethnic and racial groups (knowing Whites are included helps alleviate fears of harm among minority groups)
 - Representation within the research team by members of one's own race/ethnicity who are able to speak their own language
 - Demonstrated long-term engagement with a community of interest, i.e., involving people in advisory boards, incorporating community input into research agendas and study design, and consistently reporting back results
- **Less Invasive Options**^{26,33}
 - Knowledge of and access to studies that are less risky or burdensome, such as nutrition and exercise, or cognitive studies

Benefits of Including a Diverse Population in Your Study

Including a diverse, representative cohort of study participants that reflects the population you are trying to help can be a challenging goal to reach, but the benefits are clear:

- With a more diverse group of participants, research results will be applicable to a broader spectrum of people with MS.
- Including large enough samples of specific ethnic and racial minorities may make it possible to uncover differences in biology, genetics, disease progression and presentation, and treatment responses that underlie the heterogeneity of MS, and enable personalized health care.
- Today more funders are including requirements for diverse recruitment in research design.³⁹

Suggested Practices for Successful Recruiting

Recruitment practices that work well in one community may not be as effective in another. Tailoring outreach and recruitment efforts can help. Here are some insights and suggestions for greater success in recruiting study volunteers from diverse communities:

- **Work with the Communities.** Take the time to identify the community or communities you would like to engage in your research. Reach out early in the study process to the trusted individuals and organizations that represent these communities. They can often help you understand the priorities, motivations, and concerns of the people you want to reach, help you find people who may be a good match for your study, and become a partner for sharing resources.^{20,40,41}
 - MS organization chapters and support groups, as well as organizations that work with patients and health care professionals from minority communities can help you better understand and reach different communities. The local chapters of some of these organizations may also help you identify community leaders who can advise your team and help with outreach.
 - Reach out to MS organizations, including our Network Partners, the Accelerated Cure Project for MS (www.acceleratedcure.org), the National MS

Society (www.nationalmssociety.org) and the MS Society of America (www.mymsaa.org), as well as other MS organizations such as the Consortium of MS Centers (www.mscares.org), and the International Organization of Multiple Sclerosis Nurses (<http://iomsn.org>).

- Our Network Partners, the National Hispanic Medical Association (www.nhmamd.org), the National Black Nurses Association (www.nbna.org), MANA, a National Latina Organization (www.hermana.org), and National Minority Quality Forum (www.nmqf.org), as well as other organizations such as the Black Women’s Health Imperative (www.bwhi.org), and the National Medical Association (www.nmanet.org) are good places to begin.
- Local community advocates, churches, local policymakers, and business leaders may also be helpful resources for advice and outreach. Holding community meetings has been identified as a useful and preferred method for learning about research.³⁰
- **Be There for the Long Haul.** Once you have established foundational connections with the relevant communities, invest the time and effort in maintaining these relationships and demonstrate your commitment to improving health.
 - Engage in regular, two-way dialogue with these communities to continue understanding their needs and desires. Share your ideas, and identify where your interests overlap with theirs.
 - Build partnerships focused on addressing the disease area and overall health (within which your study – and future studies – would be included) rather than a “one-off” interaction built around a single study.
- **Design Studies with Participants in Mind.** It is becoming common practice to involve patient and consumer advocates in the study design process, as well as inviting them to participate on Institutional Review Boards (IRBs) and panels that make funding decisions.
 - Consider including minority community members in the study design and planning process, including study focus, design, recruitment materials, and dissemination plans. The study will be more attractive to that community and the individuals may be able to promote or assist with recruitment into your study as an ambassador or navigator.
 - Be flexible and respectful of study participants’ schedules, mobility and transportation issues, and responsibilities. For people with financial

constraints and/or multiple obligations, evening and weekend visits, telephone and online check-ins, and reimbursement for travel, accommodation, food, and time can go a long way to making the commitment easier to keep.⁴²

- **Speak the Right Language.** A commonly reported concern among potential research participants is that they have trouble understanding the study, its goals, the consent forms, and what is expected of them.
 - **Health literacy & Lay Language.** For most people, science and medicine are foreign languages. Not only are the words unfamiliar, but some of the concepts around the scientific method and research design may be new, or at least long forgotten. It is important to prepare recruitment, informed consent, and informational materials that are understandable and relatable to your potential participants. Use terms they can understand and images that look like them.^{34,37}
 - **Translation and Cultural Competence.** To reach more diverse participants, such as people from Hispanic/Latino and Asian groups, creating accurate, culturally relevant materials is key. Even if they speak English, many people may feel more comfortable and more confident listening to or reading recruitment materials, screening questionnaires, consent forms, and other study materials in their native language. Enlist a professional translator or bilingual research coordinator to help communicate with participants for whom English is not their first language.⁴³
 - **Use the Teach-Back Method.** To ensure your patients understand the information presented, have them state it back to you in their own words.⁴⁴ Find information on the method on the Agency for Healthcare Resources and Quality [website](#).
- **Set and Meet Expectations.** Building trust is vital to recruitment and retention success for clinical trials, and transparency is an important component. Avoiding misunderstandings by ensuring that volunteers have a realistic understanding of what will happen in the study can help build and maintain trust.
 - Explain the study questions, goals, and what will be involved, using plain, easy-to-understand language. Communicate why the study matters, and how it may contribute to our understanding of MS and help people with MS.
 - Help participants understand what results (if any) they can expect to receive, and approximately when they would receive these results.

- Describe any benefits that the study may provide to racial and ethnic minority communities or other subgroups of participants. For example, “We want to include people of different races and ethnicities in this study so we can understand whether the treatment works differently in different groups.”
- Encourage volunteers to ask questions and address any possible concerns or challenges up front. Be ready with answers about side effects and long-term risks, treatment in the control group if there is one, funding and financial conflicts (especially related to pharmaceutical companies), and who else might be participating as both researchers and volunteers.
- Explain the reasoning when a volunteer cannot be accepted in a study and, if possible, direct them to other options. Being disqualified for a study without being told the reason why can deter a volunteer from seeking other research opportunities.³⁸
- **Seek Truly Informed Consent.**
 - Use the consent document as a communication tool when talking to potential volunteers about the study. Provide copies to read and refer to sections in the document during your meeting.
 - Explore alternative models of informed consent, such as electronic consent options that present the required information in a more user-friendly format than a lengthy paper document. Companies such as Sage Bionetworks have developed mobile-friendly, modular consent platforms that allow the participant to consent to specific parts of the study, but not to others. Consider splitting up the informed consent process into two meetings so people have time to read the materials, think about them, and ask questions before enrolling.
 - Make absolutely clear that participation is voluntary and they can leave the study at any time.
 - Understand that in some communities, such as the Hispanic community, family members are often included in decisions concerning medical care and research participation. Be available and prepared for an informed consent process that includes a wider family group.

- **Choose the Right Channel.**
 - **Health Care Professionals.** Patients report a preference for hearing about research opportunities from their physicians. However, information about studies isn't always easy to find for busy clinicians. Reach out and supply informational materials – patient flyers, brochures, fact sheets, and contact information – directly to the MS clinics, neurologists, and pharmacists in the areas where you want to reach patients. National and state medical societies for MS health care professionals and minority health care professionals may be another good conduit. See [here](#) for a list of specialty and minority professional organizations.
 - **MS Organizations.** Organizations for people with MS are another source of information about clinical trials that people with MS trust.³³ These organizations may post links to current research opportunities, share information about them in newsletters, emails, and social media, and even be able to recommend people to serve your research team as an advisor. See [here](#) for a list of MS patient advocacy organizations.
 - **Institutions, Centers, and Clinics.** Reach out to health care professionals in your institution and/or other MS centers, clinics, and pharmacies.
 - Talk with physicians, nurses, and other health professionals about the study and the patients you are looking to recruit. Consider hosting a meeting or grand rounds on the topic.
 - Post information about your study in institutional newsletters, emails, updates, and the like, as well as flyers and waiting rooms
 - If available, work with your Institution's programs or offices that are aimed at increasing minority research recruitment and/or patient advocates.
 - **Websites, blogs, and social media.** Look for websites, bloggers, and social media groups that cater to people with MS from different racial and ethnic backgrounds.
 - Contact the site or group owner and ask to share information with their audience or followers or, if the group allows public posts, upload an appealing message. Social posts with an image are more likely to be read.

- **Keep Participants in the Loop.**

- Offer to share information that will help participants. In a study conducted among patients with MS, patients noted that they would like to receive useful information about MS as part of their participation in the study. They also noted that they would like receive information about the research they participated in when the study is complete. Some noted that this was a factor as to whether they would participate at all, as they don't want to feel like the benefit of their participation is a one-way value proposition.
- When people volunteer for clinical research, they care about their contribution and want to know what was learned. In fact, learning the outcomes of a study generally ranks as a top reason people participate.^{45,46}
- Yet very few actually do learn the results, and fewer still in language that is meaningful to them.^{45,47} This can make participants feel undervalued and used, and can create a barrier against future participation.⁴⁸
- The Declaration of Helsinki⁴⁹ considers dissemination of study results to participants a moral obligation, and the FDA requires researchers to enter data into the ClinicalTrials.gov registry.⁴⁷ However, professional tools such as registries, even though publicly available, are often not easily understood by the lay public.
- Developing a summary of the relevant findings in clear lay language is an effective way to communicate results to study participants.

Useful Resources for Further Information

Researcher Experiences

- A Research Professional Learns First-Hand What Matters Most to Patients CISCRP. Available at <https://www.ciscrp.org/download/a-research-professional-learns-firsthand-what-matters-most-to-patients/?wpdmdl=5162>

Strategies & Tools for Recruitment

- **Enhancing Minority Participation in Clinical Trials (EMPaCT) Consortium Website** <http://empactconsortium.com/> (tailored toward cancer but much of the content is also applicable to MS)
Free online [training](http://empactconsortium.com/training-courses/) available at <http://empactconsortium.com/training-courses/>
Links to curated [resources](http://empactconsortium.com/resource-reviews/) available at <http://empactconsortium.com/resource-reviews/>
- **CISCRP – Lay Language Summaries/Communicating Trial Results** <https://www.ciscrp.org/services/communicating-trial-results/>
- **Strategies to Build Trust and Recruit African American and Latino Community Residents for Health Research: A Cohort Study** <http://onlinelibrary.wiley.com/doi/10.1111/cts.12273/full>
Ibrahima C. Sankaré, Rachelle Bross, Arleen F. Brown, Homero E. del Pino, Loretta F. Jones, D'Ann M. Morris, Courtney Porter, Aziza Lucas-Wright, Roberto Vargas, Nell Forge, Keith C. Norris, Katherine L. Kahn. Clinical and Translational Science (June 2015)
- **Culturally Competent Strategies for Recruitment and Retention of African American Populations into Clinical Trials** <http://onlinelibrary.wiley.com/doi/10.1111/cts.12285/full>
Jane Otado, John Kwagyan, Diane Edwards, Alice Ukaegbu, Faun Rockcliffe, Nana Osafo. Clinical and Translational Science (October 2015)
- **Strategies to Increase Inclusiveness (Infographic) PCORNET Commons** http://pcornetcommons.org/resource_item/strategies-to-increase-inclusiveness/
- **Health Literacy Universal Precautions Toolkit, 2nd Edition.** Agency for Healthcare Research and Quality. <https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthlittoolkit2-tool5.html>

Tools for Informed Consent

- **Sage Bionetworks**

<http://www.sagebionetworks.org>

This site offers an extensive set of tools for innovative forms of modular informed consent, lay language consent documents, and mobile-friendly consents.

- **Bridge**

<https://developer.sagebridge.org/index.html>

Developed by Sage Bionetworks, this app can be used to support mobile registration and consent to participate in research studies, design and scheduling of surveys, and mobile sensor-driven activities.

Surveys & Data

- **Center for Information & Study on Clinical Research Participation Survey**

<https://www.ciscrp.org/services/research-services/public-and-patient-perceptions-insights-study/>

Building on prior studies conducted in 2013 and 2015, this online survey of 12,427 respondents around the world was conducted between May and July 2017 to monitor trends and identify opportunities to better inform and engage the public and patients as stakeholders and partners in clinical research.

- **2017 Perceptions & Insights Study: The Participation Experience**

<https://www.ciscrp.org/download/2017-perceptions-insights-study-the-participation-experience/?wpdmdl=8770>

CISCRP report on aspects of the clinical research participation experience and opportunities to enhance the experience and achieve more study volunteer engagement.

- **2017 Perceptions & Insights Study: The Participant Decision-Making Process**

<https://www.ciscrp.org/services/research-services/public-and-patient-perceptions-insights-study/#>

CISCRP report on the participation decision-making process and opportunities for stakeholders to support prospective study volunteers.

- **2017 Perceptions & Insights Study: General Perceptions and Knowledge on Clinical Research**

<https://www.ciscrp.org/download/2017-perceptions-insights-study-general-perceptions-and-knowledge-on-clinical-research/?wpdmdl=8773>

CISCRP report on general perceptions and knowledge of clinical research by participants; opportunities for stakeholders to develop targeted educational initiatives to meet the unique needs of various populations.

Professional Societies and Patient Advocacy Organizations

Multiple Sclerosis Organizations

- **Accelerated Cure Project for MS (ACP)**
www.acceleratedcure.org
- **American Academy of Neurology (AAN)**
www.aan.com
- **American Association of Neuroscience Nurses (AANN)**
<http://aann.org/>
- **Can Do MS**
www.cando-ms.org
- **Consortium of MS Centers (CMSC)**
www.ms-care.org
- **International Organization of Multiple Sclerosis Nurses (IOMSN)**
<http://iomsn.org/>
- **MS News & Views**
www.msviews.org
- **Multiple Sclerosis Association of America (MSAA)**
www.mysaa.org
- **Multiple Sclerosis Foundation (MSF)**
<https://msfocus.org>
- **National Multiple Sclerosis Society (NMSS)**
www.nationalmssociety.org
To request your study be listed on their Participate in Research Study page, a site for people with MS to find open research opportunities, send an email to studies@nmss.org.
- **United Spinal Association**
www.unitedspinal.org

Minority Health Professionals Organizations

- **National Association of Hispanic Nurses (NAHN)**
www.nahnnet.org
- **National Black Nurses Association (NBNA)**
www.nbna.org
- **National Hispanic Medical Association (NHMA)**
www.nhmamd.org
- **National Medical Association (NMA)**
www.nmanet.org
- **National Association of Black Social Workers (NABSW)**
<http://nabsw.org/>

Minority Patient Advocacy Organizations

- **Black Women's Health Imperative**
www.bwhi.org
- **Health Power for Minorities**
<http://healthpowerforminorities.com/>
- **MANA, A National Latina Organization**
www.hermana.org
- **National Alliance for Hispanic Health**
www.healthyamericas.org/
- **National Latina Health Network**
www.nlhn.net

About the MS Minority Research Engagement Partnership Network

The **MS Minority Research Engagement Partnership Network** (MS MREPN) is a group dedicated to increasing research participation and inclusion among different ethnic and racial groups so that diagnosis and treatment can be best tailored to each group. It is doing this by understanding the barriers that may prevent people from different communities from participating in medical research, and by developing messages and materials that help to overcome these barriers. It is also helping health care providers and researchers better understand how they can include MS patients from different backgrounds in research activities, and build durable partnerships with minority communities to maximize the benefits of research for all involved.

Funding for the MS Minority Research Engagement Partnership Network is provided through a Eugene Washington Award from the Patient-Centered Outcomes Research Institute.

The MS MREPN is conducting primary and secondary research to understand the barriers and facilitators that affect different minorities regarding participation in clinical research for MS, as well as better understanding the factors that affect health care professionals' and researchers' efforts to engage patients from minority communities in that research. The Network began its efforts by focusing on African Americans and Hispanic/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 will 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.

This toolkit is part of a multi-tiered effort to understand the issue and develop an educational and outreach model, as well as tools and resources to address barriers and encourage greater involvement. Components of the project include:

- A national survey of people with MS to understand their knowledge and perceptions about MS clinical research and openness to participating in different types of studies.
- Primary and secondary research into existing practices, materials, and methods for recruiting members of minority communities specifically for MS research.
- A review of literature and existing educational tools to understand members of different minority groups' perceptions and attitudes toward research participation in general and MS research in particular.
- Development of educational materials and a website to aid people with MS in better understanding the breadth and depth of clinical MS research, their rights and protections, and the benefits and risks involved, as well as tools for learning about current research opportunities and volunteering to participate for those who are interested.
- Development of tools and resources to help health care professionals have open conversations with their patients about participating in clinical research and address their own and their patients' concerns.
- Development of tools and resources to assist researchers and research recruiters in reaching and engaging more diverse communities and designing studies and protocols that encourage greater participation and retention in studies.
- Creation of a model and tools that can be adapted for use by other organizations, health care professionals, and researchers working with other diseases and populations.

How to Get Involved with the Network

Your support is critical to increasing minority representation in MS research and pushing the understanding of the disease forward. This toolkit is intended to help facilitate conversations with patients and potential study volunteers in a manner that takes into account different cultural expectations and perceptions. Here are some suggestions for how to use the information and tools in this toolkit and how to share it with staff and colleagues.

- **Conversation Guides.** This toolkit contains several guides for bringing up studies with patients, preparing for questions they may have, and resources for answering their questions. Use the tools to guide conversations with patients and research volunteers.
- **Participant Outreach.** Finding potential research volunteers – both those with MS and healthy volunteers – from different communities can be time-consuming and difficult. This toolkit contains suggestions for additional avenues for recruitment, guides for culturally sensitive outreach, and resources for organizations that can help.
- **Educational Materials.** Printable educational handouts, as well as links to respected resources by other organizations are included to share with patients in your practice or clinic and volunteers for research studies at your institution. They can also be used at community events such as health fairs and presentations, and shared with patient advocacy and community organizations to help raise awareness and engage more potential study participants.
- **Share This Toolkit.** Please consider sharing this toolkit with colleagues and staff. Use our **drop-in PowerPoint slides** [www.acceleratedcure.org/DropInSlides.pptx] to share information about it at meetings or grand rounds. Use the **template announcement** [www.acceleratedcure.org/researcher-toolkit-newsletter-text] in emails and newsletters, and the sample **social media posts** [www.acceleratedcure.org/researcher-toolkit-social-media], for more easy ways to share.

Did you find this toolkit helpful? Please tell us what you think by filling out this short survey at:

<https://www.surveymzmo.com/s3/4575570/Researchers-Toolkit-Feedback>

If you are interested in working with the network, please contact Hollie Schmidt at mminorityresearch@acceleratedcure.org or call 781-487-0099.

MS Minority Research Engagement Partnership Network

Organization Members: Accelerated Cure Project | Ogilvy | FKH
National Multiple Sclerosis Society | Multiple Sclerosis Association of America
National Black Nurses Association | National Hispanic Medical Association
MANA, A National Latina Organization | National Minority Quality Forum
Biogen | Genentech

Individual Members: Shawn Feliciano | Anita Williams | Mitzi Williams, MD
Lilyana Amezcua, MD | Daniela Pimentel Maldonado, MD | April Moreno, PhD

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Contact Us: Read more about the MS Minority Research Engagement Partnership Network at www.acceleratedcure.org/MinorityNetwork or contact us at mminorityresearch@acceleratedcure.org.

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