



Minority Engagement in MS Research

Patient Recruitment Toolkit for Health Care Professionals



PARTNERSHIP NETWORK

Minority Engagement in MS Research Patient Recruitment Toolkit for Health Care Professionals

Thank you for your interest in helping your patients learn about opportunities to volunteer for multiple sclerosis (MS) research! This toolkit is designed to help you learn more about current MS research opportunities, talk to your MS patients about them, and offer insights into the perceptions and concerns patients from different ethnic and racial backgrounds may have when it comes to research.

Racial and ethnic minorities are underrepresented in MS research, resulting in a lack of evidence about their disease characteristics and optimal treatment. As a clinician, you can play a vital role in correcting this imbalance by bringing up research participation with your minority patients and pointing them to available opportunities.

On the following pages, you'll find tools and discussion guides, evidence-based research on patient perceptions, resources for identifying current opportunities, and educational materials to download for your patients.

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 identifying the barriers that may prevent people in various 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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IN THIS TOOLKIT

Why Focus on MS among Minorities?	4
Minority Participation in MS Research	5
The Impact of Race and Ethnic Experiences on Research Participation	5
Patients Want to Talk with their Clinicians about Research	6
Why People with MS Do – and Don’t – Participate in MS Research	6
Barriers.....	7
Facilitators	9
Information and Tools for Health Care Professionals	10
The Benefits of Talking to Patients about Research Participation	10
Common Concerns among Health Care Professionals	11
Current MS Research Opportunity Resources	12
Suggestions for Talking to Patients about MS Research Participation	14
Resources for Talking with Your Patients about MS Clinical Research	16
Types of MS Clinical Research Studies	16
Questions to Guide Conversations	17
Educational Materials to Share with Your Patients.....	18
Learning More about Medical Research	18
Patient Protections.....	18
Talking about MS.....	19
Professional Societies and Patient Advocacy Organizations.....	20
Multiple Sclerosis Organizations	20
Minority Health Professionals Organizations	21
Minority Patient Advocacy Organizations	21
About the MS Minority Research Engagement Partnership Network	22
How to Get Involved with the Network	24
References	26

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 become more prevalent only 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 nutrition 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 MREPN³³ 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 bringing up the topic with their minority patients 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 your patients' 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

Information and Tools for Health Care Professionals

The following information and conversation guides are designed to address common concerns and questions health care professionals may have about approaching patients about taking part in a research study. This section also includes fact sheets and resources to share with patients and answer their questions.

The Benefits of Talking to Patients about Research Participation

- Many people with MS are interested in learning about clinical research opportunities and believe it can benefit themselves and others with MS.^{33,39}
- People trust their health care providers and generally look to you first for medical information and information and advice on joining studies.³³ In fact, a survey by Sood et al., found 76 percent of 400 patients expected their physician to tell them about current clinical trials.⁴⁰
- As a health care provider, you know your patients' medical histories, so you can help them determine if a study is a good match for them.
- A clinical trial may provide access to treatments that would otherwise not be available, or that you cannot provide.
- Some studies, such as ones that address nutrition, physical fitness, or complementary medicine, may provide a good adjunct to the treatment you are providing.
- Participation means greater knowledge about new treatments, and which ones work best for different groups of patients—contributing to the greater good and to your ability to provide personalized medicine to your patients in the future.

Common Concerns among Health Care Professionals

- **If I refer a patient, will I still be able to provide treatment to him or her?**
 - Many healthcare providers are concerned that a patient referred to a research study will decide to transfer to the study center for their regular healthcare. This does happen on occasion, but patients may also prefer to stay with their original provider for ongoing care. Consider what is in the best interest of your patients – it may be that referring them to an outside study would be best for them even though there is a risk of their switching practices.
- **How will participation in a trial affect the way I deliver care to my patient?**
 - For studies that involve activities such as surveys, brain-training exercises, or biomarker research, your patient’s participation will have little or no effect on the care you deliver. Drug studies, on the other hand, may require them to switch treatments or may restrict them from changing their current regimen for a period of time. If they participate in a blinded study, neither you nor they will know which study treatment they are receiving.
- **Will my patient feel exploited or pressured to participate if I bring it up?**
 - Studies show that patients—across different ethnic and racial groups—are generally interested in taking part in research. However, they report that their physicians and nurses never bring it up, and they have difficulty finding information on their own.⁴¹⁻⁴³ When you suggest research opportunities to your patients, you can avoid any feelings of pressure or coercion by being transparent about the pros and cons, and making clear that participation is entirely up to them and if they do join, they can withdraw consent and drop out for any reason at any time.
- **What happens if my patient is assigned to the control group?**
 - In any controlled interventional study there is a chance of receiving the control treatment instead of the treatment under investigation. If the study involves an MS indication for which there is an existing treatment, the control arm will likely be an active treatment instead of placebo. When no safe, effective alternative exists, then a placebo may be used, and it is necessary to determine the effects of the study treatment. Many studies offer control participants the option of switching to the test treatment at the end, and they can feel good about their important contribution to the study.

- **Will my patient be able to participate in the trial if they have already demonstrated difficulties with adhering to their treatment?**
 - If your patient is having difficulty adhering to treatment because of side effects or it because doesn't seem to be working, a trial may be a good alternative. They may find that the new treatment is more acceptable. However, if they simply have trouble complying with treatment, for non-medical reasons, they may not be a good fit.
- **How do I determine whether a patient is eligible or a good candidate for a trial?**
 - The trial protocol should describe, in detail, the factors that make a patient eligible or ineligible for a particular study. With this information, you can evaluate your patient to see if they meet the criteria. You can then talk to them to see if it's a good fit in terms of their health goals, factors that could make participation easier or more difficult, and the patients' own interests.

Current MS Research Opportunity Resources

These MS studies are currently recruiting people with MS and may be of particular interest to minority patients because of their focus, their convenience, and/or their benefits to specific communities. iConquerMS™ and NARCOMS are open to all people with MS, regardless of race or ethnicity.

- **iConquerMS™**
<https://www.iconquerms.org/>
 iConquerMS™ is an online community of people with MS who share health information, connect with researchers, and participate in studies. Enrollment is open to anyone who wants to help shape and contribute to MS research.
- **North American Research Committee on MS (NARCOMS)**
<https://www.narcoms.org/>
 NARCOMS is a global registry of more than 38,000 people with MS that is focused on MS research, treatment, and patient education. It has supported past research analyses on MS in African-Americans and Hispanics/Latinos.
- **The Multiple Sclerosis Genetics Project**
<http://www.nationalmssociety.org/About-the-Society/News/Researchers-Recruiting-African-Americans-with-MS-a>The University of California San Francisco is inviting African Americans to participate in a national study of the genes that affect the risk of MS. Participation involves providing information and medical records, and having blood drawn at a lab site near you.

- **Alliance for Research in Hispanic Multiple Sclerosis**

<http://www.arhms.org/contact>

Collaborators in California and Florida are inviting Hispanic Americans to participate in a study about factors that affect MS risk and experience. Participation involves an office visit and donating information and blood samples.

- **Study of Genetics and Culture in Hispanics/Latinos with MS**

<https://www.nationalmssociety.org/About-the-Society/News/Investigators-Recruiting-Hispanics-Latinos-with-MS>

Investigators in California, Florida, New Mexico, and Puerto Rico are inviting Hispanics/Latinos who have been diagnosed with MS within the last two years to participate in a study about the impact of genetics and culture on disease severity. Participants will have a clinic visit to fill out questionnaires, watch a short film about MS, and provide blood samples.

In addition to these studies, you and your patients can find many other research opportunities by visiting these sites:

- **NMSS Participate in Research Studies**

<http://www.nationalmssociety.org/Research/Participate-in-Research-Studies>

The National Multiple Sclerosis Society provides a list of research study opportunities on its website. These include clinical trials, surveys, genetic studies, and tissue banks.

- **Clinical Trials Search**

<https://mymsaa.org/ms-information/clinical-trials-search/>

The Multiple Sclerosis Association of America, in partnership with a company called Antidote, hosts a clinical trial search tool on their website.

- **ClinicalTrials.gov**

<https://clinicaltrials.gov/>

You can search for MS research studies at ClinicalTrials.gov. This site contains information about clinical studies with human volunteers around the world.

- **CenterWatch.com**

<http://www.centerwatch.com/clinical-trials/listings/condition/102/multiple-sclerosis>

This website offers information on clinical trials for both patients and researchers, and puts out a variety of newsletters, books, and databases. You can search it for open MS clinical trials.

- **ResearchMatch.org**

<https://www.researchmatch.org/>

This is a membership organization that matches people who are looking for research studies related to their condition and researchers looking for study participants. It was developed by major universities across the U.S. and is free to join.

Suggestions for Talking to Patients about MS Research Participation

If you have patients who are good candidates for joining a clinical trial, there are several ways to raise the subject in a safe, comfortable, and trusting environment.

- **Raise the Topic.**
 - Talk to your patients about enrolling in clinical trials. Often, the biggest barrier to participation is that health care providers rarely bring it up.
 - Identify an appropriate trial, or address a trial your patient brings up, in a clear, concrete way.⁴³
- **Ensure a Trusting and Comfortable Atmosphere.**
 - Invite your patient to bring along a friend or loved one who can provide moral support and an extra set of ears.
 - Provide paper and pencil and encourage questions. Check that you have answered any questions to their satisfaction.
 - Break the discussion down over more than one appointment so they have time to think about the decision and ask additional questions.
- **Explain What the Study Is and What Its Goals Are.**
 - Explain concepts such as the different types and phases of clinical trials and the randomization process so that your patient has realistic expectations about the trial. Be sure to explain how randomization works and what will happen if they are assigned to the control group.
 - Talk about what the researchers are trying to learn, and how it fits in with your patient's treatment and the body of knowledge about MS.
 - Discuss why you believe the trial may be a good option and what they may hope to gain as a result of participating. Is the treatment under study their best option to manage their symptoms? Is it something that can be used alongside their current treatment to improve quality of life? Or will the study have little effect on your patient's status but will benefit people like them in the future?
 - Use the Teach-Back Method to ensure your patients understand the information presented by having them state it back to you in their own words.⁴⁴ Find information on this method on the Agency for Healthcare Resources and Quality [website](#).

- **Present the Options.**
 - Describe the current treatments and the benefits and drawbacks of the clinical trial and how it compares to what they are doing now.
 - Make sure it is clear that participation is voluntary, and they can withdraw consent and drop out at any time.
 - If you have other patients who have taken part in clinical trials, consider asking if they would consent to meeting with your patient to talk about their experiences.
- **Address Your Relationship.**
 - Talk about how your involvement may or may not change if they become part of a study. Will you continue to see them while they are participating? Will you receive reports and updates to your medical charts from the researchers to their medical chart? Will they see you for treatment when the study is over?
- **Explain how Participants' Rights and Interests Are Protected.**
 - Acknowledge that taking part in medical research can increase the risk of harm, and that there have been serious abuses in the past that we must always guard against.
 - Talk about how ethical protections have been put in place to ensure that research participants are not exploited or put at undue risk. These protections include:
 - Ensuring that participants are appropriately informed about what to expect and are given the choice to participate or not.
 - Requiring researchers to ensure that their studies treat individuals and groups fairly and maximize the benefits to participants while minimizing the risks.
 - Having all study plans reviewed and approved by ethics boards (Institutional Review Boards) that make sure that the welfare, rights and privacy of participants are protected.
 - Clarify that specific regulations are in place to protect the rights of vulnerable groups of people such as prisoners or children.

Resources for Talking with Your Patients about MS Clinical Research

Patients may be interested in taking part in MS research – some may bring it up, but others may need their health care professional to raise the possibility, and they will likely have different perceptions of what MS research actually entails. Below are some questions to guide the discussion, along with information and resources for further information.

Types of MS Clinical Research Studies

While many people think of drug trials when they think about MS clinical research, there are numerous other study topics and formats that may benefit your patients. In fact, the MS MREPN study showed African Americans were particularly interested in studies on lifestyle interventions, such as diet and exercise.³³ Similar preferences have also been reported in Hispanics with MS as well.²⁸ Research studies can include:

- Clinical drug trials
- Non-drug treatment trials, such as physical therapy, yoga, biofeedback, or other practices that may help reduce symptoms
- Biospecimen tests and collections for biorepositories
- Surveys
- Journals and logs
- Brain training games
- Usability testing
- Interviews and focus groups
- Patient or consumer advocacy for engagement in research design, funding, and other aspects of research

Questions to Guide Conversations

Here are some common questions patients may have about participating in research, although some people may not articulate them. Of course, the answers will vary with each patient. However, these questions can help prepare you and guide the conversation over how a particular research opportunity may impact each individual patient's treatment plan, health, and health care professional relationship.

- Are there clinical studies going on that could potentially be beneficial to me?
- Why do you think this trial would benefit me?
- What is the goal of the study? Is this something that will treat my MS, or is it designed to help scientists learn more about the disease?
- Is the treatment intended to cure the disease or suppress symptoms?
- How would it differ from my current treatment?
- Will I continue to see you for treatment and monitoring?
- How will the treatment be given to me? Will I be able to continue it after the study?
- I read about a study that is recruiting patients who sound a lot like me. I would like to discuss whether this would be a good option for me.

Educational Materials to Share with Your Patients

Share these links and materials with your patients to help them learn more about medical research, patient protections, and MS.

Learning More about Medical Research

- **For People with MS – What Should I Expect as a Research Participant?**
<https://www.acceleratedcure.org/people-ms>
A description of different study experiences and what to expect as a volunteer.
- The Center for Information & Study on Clinical Research Participation (CISCRP)
Patient Perspective
<https://www.ciscrp.org/download/3-women-share-their-perspectives/?wpdmdl=5168/public-and-patient-perceptions-insights-study/>
Three women explain why they participated in clinical research as patients.
- **HHS Office for Human Research Protections: Videos about Participation**
English: <https://www.hhs.gov/ohrp/education-and-outreach/about-research-participation/informational-videos/index.html>
Spanish: <https://www.hhs.gov/ohrp/education-and-outreach/about-research-participation/videos-informativos/index.html>
These videos are intended to help potential participants understand how research works, what questions they should consider asking, and what things to think about when deciding whether to participate in a study.

Patient Protections

- **Regulations to Protect Volunteers in Research (HHS, Office of Human Research Protections)**
<https://www.hhs.gov/ohrp/education-and-outreach/about-research-participation/protecting-research-volunteers/index.html>
An explanation of the protections in place for research volunteers from the HHS Office of Human Research Protections.
- **CISCRP Participant Bill of Rights** [PDF, 69KB]
<https://www.ciscrp.org/wp-content/uploads/2017/08/Participant-Bill-of-Rights.pdf>
A list of rights study volunteers are entitled to when considering enrolling in a trial.

Talking about MS

- **Talking to Your Doctor about MS/Questions to Ask Your Doctor about MS**
[PDF 239 KB]
<https://www.acceleratedcure.org/sites/default/files/images/TalkToYourDoctor.pdf>
A two-page handout for patients with information about being an active participant in their MS care and suggested questions to better understand MS and its treatments.
- **Making a Difference in MS through Research/Questions to Ask Before Joining a Research Study** [PDF, 232KB]
<https://www.acceleratedcure.org/sites/default/files/images/MakingDifference.pdf>
A two-page handout that describes the importance of having a diverse representation of patients in MS clinical research and suggested questions your patients may want to ask the researchers or recruiters involved in the study.
- **Information for People with MS**
<https://www.acceleratedcure.org/people-ms>
The MS Minority Research Engagement Partnership Network has pulled together information and resources for people with MS.
- **Research Opportunities** [PDF 238 KB]
<https://www.acceleratedcure.org/MSResearch>
Find descriptions and links to studies that are currently recruiting people with MS as well as searchable databases of ongoing research projects.
- **African Americans and Clinical Research** [PDF 1.9 MB]
<https://www.cisgrp.org/wp-content/uploads/2017/08/African-Americans-and-Clinical-Research.pdf>
CISCRP developed a six-page booklet about clinical trials, what to ask, and what to expect, specifically for the African American community.
- **Los Hispanos y la Investigacion Clinica (Hispanics and Clinical Research)**
[PDF 2.3 MB]
<https://www.cisgrp.org/wp-content/uploads/2017/12/Hispanics-and-Clinical-Research.pdf>
CISCRP created a five-page booklet about clinical trials, what to ask, and what to expect, specifically for Spanish speakers.

Professional Societies and Patient Advocacy Organizations

Multiple Sclerosis Organizations

- **Accelerated Cure Project for MS (ACP)**
www.acceleratedcure.org
- **American Academy of Neurology (AAN)**
<http://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 Views & News**
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**
<https://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 working to help health care providers and researchers better understand how they can include MS patients from different backgrounds in research activities so that every community benefits from the work that is being done.

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The MS MREPN is conducting primary and secondary research to understand the barriers and motivators 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 trials.
- 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 clinical trials with patients, guidance on 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.** If you also conduct research, you may have found that recruiting 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.** Links to printable educational handouts developed by the network, 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/clinician-toolkit-newsletter-text] in emails and newsletters, and the sample **social media posts** [www.acceleratedcure.org/clinician-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.surveygizmo.com/s3/4573658/HCP-Toolkit-Feedback>.

If you are interested in working with the network, please contact Hollie Schmidt at msminorityresearch@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.

References

1. Khan O, Williams MJ, Amezcua L, Javed A, Larsen KE, Smrtka JM. Multiple sclerosis in US minority populations: Clinical practice insights. *Neurol Clin Pract*. 2015;5(2):132-142. doi:10.1212/CPJ.0000000000000112
2. Langer-Gould A, Brara SM, Beaber BE, Zhang JL. Incidence of multiple sclerosis in multiple racial and ethnic groups. *Neurology*. 2013;80(19):1734-1739. doi:10.1212/WNL.0b013e3182918cc2
3. Wallin MT, Culpepper WJ, Coffman P, et al. The Gulf War era multiple sclerosis cohort: Age and incidence rates by race, sex and service. *Brain*. 2012;135(6):1778-1785. doi:10.1093/brain/aws099
4. Kimbrough DJ, Sotirchos ES, Wilson JA, et al. Retinal damage and vision loss in African American multiple sclerosis patients. *Ann Neurol*. 2016;77(2):228-236. doi:10.1002/ana.24308
5. Howard J, Battaglini M, Babb JS, et al. MRI correlates of disability in African-Americans with multiple sclerosis. *PLoS One*. 2012;7(8):8-11. doi:10.1371/journal.pone.0043061
6. Naismith RT, Trinkaus K, Cross AH. Phenotype and prognosis in African-Americans with multiple sclerosis: A retrospective chart review. *Mult Scler*. 2006;12(6):775-781. doi:10.1177/1352458506070923
7. Kister I, Chamot E, Bacon JH, et al. Rapid disease course in African Americans with multiple sclerosis. *Neurology*. 2010;75(3):217-223. doi:10.1212/WNL.0b013e3181e8e72a
8. Ventura RE, Antezana AO, Bacon T, Kister I. Hispanic Americans and African Americans with multiple sclerosis have more severe disease course than Caucasian Americans. *Mult Scler*. 2017;23(11):1554-1557. doi:10.1177/1352458516679894
9. Weinstock-Guttman B, Ramanathan M, Hashmi K, et al. Increased tissue damage and lesion volumes in African Americans with multiple sclerosis. *Neurology*. 2010;74(7):538-544. doi:10.1212/WNL.0b013e3181c96fb
10. Amezcua L, Oksenberg JR, McCauley JL. MS in self-identified Hispanic/Latino individuals living in the US. *Mult Scler J - Exp Transl Clin*. 2017;3(3):205521731772510. doi:10.1177/2055217317725103
11. Rivas-Rodríguez E, Amezcua L. Ethnic considerations and multiple sclerosis disease variability in the United States. *Neurol Clin*. 2018;36(1):151-162. doi:10.1016/j.ncl.2017.08.007
12. Cree BAC, Stuart WH, Tornatore CS, Jeffery DR, Pace AL, Cha CH. Efficacy of Natalizumab therapy in patients of African descent with relapsing multiple sclerosis: Analysis of AFFIRM and SENTINEL data. *Arch Neurol*. 2011;68(4):464-468. doi:10.1001/archneurol.2011.45
13. Cree BAC, Al-Sabbagh A, Bennett R, Goodin D. Response to interferon beta-1a treatment in African American multiple sclerosis patients. *Arch Neurol*. 2005;62(11):1681. doi:10.1001/archneur.62.11.1681
14. Huang SM, Temple R. Is this the drug or dose for you?: Impact and consideration of ethnic factors in global drug development, regulatory review, and clinical practice. *Clin Pharmacol Ther*. 2008;84(3):287-294. doi:10.1038/clpt.2008.144
15. Ramamoorthy A, Pacanowski MA, Bull J ZL. Racial/ethnic differences in drug disposition and response: review of recently approved drugs. *Clin Pharmacol Ther*. 2015;97(3):263-273. <https://doi.org/10.1002/cpt.61>
16. Fiscella K, Sanders MR. Racial and ethnic disparities in the quality of health care. *Annu Rev Public Health*. 2016;37(1):375-394. doi:10.1146/annurev-publhealth-032315-021439
17. Shabas D, Heffner M. Multiple sclerosis management for low-income minorities. *Mult Scler*. 2005;11(6):635-640. doi:10.1191/1352458505ms1215oa

18. U.S. Food and Drug Administration. Clinical Trials Shed Light on Minority Health. U.S. Food and Drug Administration Website. <https://www.fda.gov/ForConsumers/ConsumerUpdates/ucm349063.htm>. Published 2018
19. Levine, D, Greenberg R. More Minorities Needed in Clinical Trials to Make Research Relevant to All. *AAMC News*. 2016. <https://news.aamc.org/diversity/article/more-minorities-needed-clinical-trials-research/>
20. Kauffman KS, dosReis S, Ross M, Barnet B, Onukwugha E, Mullins CD. Engaging hard-to-reach patients in patient-centered outcomes research. *J Comp Eff Res*. 2013;2(3):313-324. doi:10.2217/cer.13.11
21. Burke JF, Brown DL, et al. Participation of women and minorities in NINDS stroke trials. *Stroke*. 2010;41(4):e253. <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed9&NEWS=N&AN=70429317>
22. Oh SS, Galanter J, Thakur N, et al. Diversity in clinical and biomedical research: A promise yet to be fulfilled. *PLoS Med*. 2015;12(12):1-9. doi:10.1371/journal.pmed.1001918
23. Powell JH, Fleming Y, Walker-McGill CL, Lenoir M. Awareness of clinical trials. *Clin Trials*. 2008;100(2):14-18
24. Scalici J, Finan MA, Black J, et al. Minority participation in Gynecologic Oncology Group (GOG) studies. *Gynecol Oncol*. 2015;138(2):441-444. doi:10.1016/j.ygyno.2015.05.014
25. Williams, M, Powers, M, Yun, Y-G. Minority participation in randomized controlled trials for obsessive-compulsive disorder. *J Anxiety Disord*. 2010;24(2):171-177. doi:10.1016/j.janxdis.2009.11.004
26. George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *Am J Public Health*. 2014;104(2):16-31. doi:10.2105/AJPH.2013.301706
27. Byrd WM, Clayton L a. Race, medicine, and health care in the United States: a historical survey. *J Natl Med Assoc*. 2001;93(3 Suppl):11S-34S. <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2593958&tool=pmcentrez&rendertype=abstract>
28. Obiwuru O, Joseph S, Liu L, et al. Perceptions of multiple sclerosis in Hispanic Americans: Need for targeted messaging. *Int J MS Care*. 2017;19(3):131-139. doi:10.7224/1537-2073.2015-081
29. Crawley LM. African-American participation in clinical trials: situating trust and trustworthiness. *J Natl Med Assoc*. 2001;93(12 Suppl):14S-17S
30. Erves JC, Mayo-Gamble TL, Malin-Fair A, et al. Needs, priorities, and recommendations for engaging underrepresented populations in clinical research: A community perspective. *J Community Health*. 2017;42(3):472-480. doi:10.1007/s10900-016-0279-2
31. Lang R, Kelkar VA, Byrd JR, Edwards CL, Pericak-Vance M, Byrd GS. African American participation in health-related research studies: Indicators for effective recruitment. *J Public Heal Manag Pract*. 2013;19(2):110-118. doi:10.1097/PHH.0b013e31825717ef
32. Gollin LX, Harrigan RC, Calderón JL, Perez J, Easa D. Improving Hawaiian and Filipino involvement in clinical research opportunities: Qualitative findings from Hawai'i. *Ethn Dis*. 2005;15(4 SUPPL. 5)
33. Pimentel Maldonado D, Moreno Arellano A, Williams A, et al. Preferences regarding research study attributes among people with MS belonging to different racial and ethnic groups. 2018. (ms in preparation)
34. CISCRP. *Charts and Statistics: Useful Information about Clinical Research before Participating in a Trial* CISCRP. <https://www.ciscrp.org/education-center/charts-and-statistics/before-participation/>

35. Anderson, Karen M., and Steve Olson, eds. 2016. *Strategies for Ensuring Diversity, Inclusion, and Meaningful Participation in Clinical Trials*. Washington, D.C.: National Academies Press. doi:10.17226/23530
36. Kurt A, Semler L, Jacoby JL, et al. Racial differences among factors associated with participation in clinical research trials. *J Racial Ethn Heal Disparities*. 2017;4(5):827-836. doi:10.1007/s40615-016-0285-1
37. Friedman DB, Kim SH, Tanner A, Bergeron CD, Foster C, General K. How are we communicating about clinical trials? An assessment of the content and readability of recruitment resources. *Contemp Clin Trials*. 2014;38(2):275-283. doi:10.1016/j.cct.2014.05.004
38. Schmidt HK, Williams A, Williams MJ, Flockhart N, LaRoque M. (2018, May). Presentation: *Discussion on Diversity and Inclusion in MS Clinical Research*. MS Center of Atlanta. Atlanta
39. Wilkins CH. Precision medicine for everyone. *NEJM Catal*. February 2018. <https://catalyst.nejm.org/precision-medicine-initiative-everyone/>
40. Sood A, Prasad K, Chhatwani L, et al. Patients' attitudes and preferences about participation and recruitment strategies in clinical trials. *Mayo Clin Proc*. 2009;84(3):243-247. doi:10.4065/84.3.243
41. Getz BK, Hallinan Z. Creating a standard practice for communicating trial results to study volunteers. *Res Pract*. 2016:10-15
42. Albrecht TL, Eggly SS, Gleason MEJ, et al. Influence of clinical communication on patients' decision making on participation in clinical trials. *J Clin Oncol*. 2008;26(16):2666-2673. doi:10.1200/JCO.2007.14.8114
43. Albrecht TL, Eggly SS, Gleason MEJ, et al. Influence of clinical communication on patients' decision making on participation in clinical trials. 2013;26(16):1-15. doi:10.1200/JCO.2007.14.8114
44. Agency for Healthcare Quality and Research. *Health Literacy Universal Precautions Toolkit, 2nd Edition*. 2015. <https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthlittoolkit2-tool5.html>