



**MS Minority
Research
Engagement**

PARTNERSHIP NETWORK



Minority Engagement in
MS Research
Community Partner Toolkit

Minority Engagement in MS Research Community Partner Toolkit

Thank you for your interest in raising awareness about multiple sclerosis (MS) in your community. The MS Minority Research Engagement Toolkit is designed to help increase awareness of why it is so important for people from all different racial and ethnic backgrounds to take part in MS research studies and give them the confidence and knowledge to explore the available study opportunities.

Why Focus on MS Among Minorities?

For a long time, doctors thought MS most commonly affected non-Hispanic white people. However, as more people are diagnosed and more research is done to see who is affected, we are learning that MS may actually occur more frequently in African-Americans than in other racial and ethnic groups. In addition, African Americans and Hispanics may be more severely affected by the disease. Genetic and biological differences as well as cultural norms and health system usage may all contribute to poorer MS outcomes in racial and ethnic minority groups.

Clinical research is paramount to the development of new treatments and interventions. However, medical studies have historically had underrepresented participation among women, racial and ethnic minorities, and children. There are many systemic, socio-economic, and historic contributors to this. In MS as in other diseases, African Americans and Hispanics make up a small fraction of people who take part in clinical trials even though they represent a quarter of the U.S. population. For example, in the Phase 3 trials for a recently-approved MS drug, over 90% of the combined participants were white, while the remaining 10% were African-American or another racial minority.

Without participation in research studies, it is impossible to fully understand important aspects of MS including which treatments work best in specific groups or individuals. The more we know about how MS affects minority communities, the better scientists and clinicians can improve diagnosis and tailor treatments to keep all people with MS as healthy as possible.

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Get Involved: Suggested Activities for Your Community

Your support is critical to increasing minority representation in MS research and pushing the understanding of the disease forward.

The MS Minority Research Engagement Toolkit contains educational materials and resources to help people understand how clinical research can benefit individuals and communities, and why diversity in research is so important. You can use the toolkit's educational and media tools on your website, in your communications to members, and at conferences and events – any place where you connect with people who have MS.

Help is needed to:

- 1) Increase awareness about MS and ensure people with MS have access to the care they need
- 2) Increase awareness about the importance of participating in clinical studies among health professionals, people with MS, and caregivers

Here are some ways to share the information in this toolkit:

- **Spread the word.** Publish a newsletter article or blog post, or send an email alert using our sample text on pages 13 and 14 below.
- **Start Sharing on Social.** Share our sample social media posts on page 14 below through your network with the hashtag #MSResearch4All.
- **Raise your voices.** Maybe you work with people who have taken part in research already. Help and encourage them to share their experiences with their peers through a blog post, or an interview in writing or on camera. We hope you'll share their stories with us!
- **Get personal.** If your organization hosts meetings, conference calls, support groups, or other events, make MS research participation part of the discussion. Consider bringing in experts – local researchers, health care providers, and especially people with MS who have taken part in research – to talk about their experiences.
- **Learn together.** Host or participate in an educational event. Hospitals, community centers, and churches often host health fairs and educational programs for their communities. Make minority participation in MS research part of the agenda at one of these events – or host a virtual event online or on a conference call.
- **Open the lab.** Hold a “Meet a Researcher” open house at a university or hospital or online using social media and connect people with MS with researchers who are active in MS trials.

Join the Network: If you are interested in joining the network, please contact:

msminorityresearch@acceleratedcure.org or call 781-487-0099 to discuss collaboration.

Please access the resources in this toolkit to help engage others in your community.

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

Resources to Educate Patients and Caregivers

Understanding Multiple Sclerosis

What Is MS?

Multiple sclerosis (MS) is a chronic or long-lasting disease that affects the central nervous system, which are the nerves that process information and send signals throughout your brain and spinal cord. When someone has MS, their immune system, which normally protects the body from disease, attacks the protective coating around the body's own nerve fibers. The nerves themselves are also damaged in the process. This damage interrupts the flow of information through the nervous system, resulting in symptoms throughout the body.

MS Symptoms

MS affects people of all ages, but symptoms often begin between the ages of 20 and 40. MS symptoms can range from mild to very severe. Some common symptoms may include:

- Fatigue
- Pain, numbness, tingling or itchy feelings around your body
- Muscle weakness and lack of coordination
- Dizziness or trouble with balance
- Trouble walking
- Vision problems, such as blurry or double vision
- Difficulty concentrating or remembering things
- Bladder and bowel problems
- Depression and emotional changes
- Sexual problems

The symptoms can get worse over time or may vary between more and less severe symptoms. There is no cure for MS, but there are treatments that help reduce existing symptoms, prevent new attacks (relapses) and slow the pace of disability.

The symptoms of MS tend to be wide ranging and are often associated with other disorders. As a result, many people are not diagnosed with it right away.

MS Diagnosis

People with MS-like symptoms are often diagnosed by a neurologist, a type of doctor who specializes in treating the brain and nervous system. Different tests are used to diagnose MS, including:

- Blood tests to rule out other diseases with similar symptoms
- Physical tests of balance, muscle coordination, vision, and other functions
- An MRI imaging test to look for signs of lesions (damaged tissue) on the brain
- An analysis of the fluid that cushions your brain and spinal cord
- Tests to measure electrical activity in your nervous system

For information on MS treatments, visit the National Multiple Sclerosis Society's Treating MS section at <https://www.nationalmssociety.org/Treating-MS>.

MS in Minorities

MS can be found in people of all different races and ethnicities. Several famous African-Americans have been diagnosed with MS, including Montel Williams, Barbara Jordan, Richard Pryor, and Lena Horne.

MS may occur in some racial and ethnic groups more often than others. Recent [studies](#) of people in the U.S. military and members of the Kaiser Permanente health system indicate that the risk of developing MS may be highest in African Americans. Studies have also shown that MS may also be more aggressive and cause more disability at a faster pace in African Americans. Other studies have shown that people from racial and ethnic minorities, particularly African Americans and Hispanics, may use or have access to fewer health services. This can result in getting diagnosed later, missing out on treatments that could be helpful, and having worse health.

While much is already known about MS, there are still many questions that need to be answered. These include:

- Why does MS affect some people and not others, and why is the risk of MS higher in African-Americans?
- Why is it more severe in some people compared to others?
- Which MS treatments are best for which people?
- What role does diet and exercise play in MS?

There are many research studies underway to answer these and other questions. People from **all races and ethnicities** are needed to participate in these studies. That way everyone can benefit from the answers that are found and the new treatments that are developed.

Resources to Educate Patients and Caregivers

Talking to Your Doctor about MS

You are the most important member of your health care team. Managing MS – whether you have just been diagnosed or have had it for a long time – can be overwhelming at times. Taking an active role in your treatment can help you feel more in control and more satisfied with your care. Coming to medical appointments prepared is an important way to participate in your care because you will be better able to make decisions about what treatments are best for you.

Five Steps for a Better Medical Visit

- **Make a list.** Write down all the questions you want to ask during your appointment, starting with the ones that are most important to you.
- **Record your health history.** Put together a record of your personal health history, including current conditions and symptoms, and all past surgeries and significant or long-term illnesses.
- **Know your meds.** Gather all your medications in a bag to bring them the appointment or take pictures of the labels with your cell phone so you have a precise record of names and dosages.
- **Learn your family health history.** Write down your family's health history, especially that of your parents, grandparents, and aunts and uncles.
- **Bring a witness.** Ask a family member or friend to come with you who can help you remember and understand what the health care provider said. If no one can come along, bring along a voice recorder so you can listen again later.

Questions to Ask Your Doctor about MS

Diagnosis and Treatment

- What kind of MS do I have? What is the typical course for this kind of MS?
- Will I need more tests? What should I expect during these tests and how should I prepare?
- What are the different treatment options? What are the risks and benefits of each option?
- What are disease-modifying therapies and would any work for me? If so, how do I choose from among the different options?
- Why is the one you are recommending best for me?
- Will you recommend a different treatment if I have a relapse (flare up)?

Side Effects

- What complications of MS should I watch for?
- Can you spell out the name of the drug you are prescribing? Will it interact with other medicines or over-the-counter drugs or supplements that I take?
- What kinds of side effects should I expect?
- What should I do if they occur or my symptoms get worse?
- Who should I call if I have questions?

Clinical Trials

- Are there clinical studies going on that could potentially be beneficial to me?
- Why do you think this trial would benefit me?
- How would it differ from my current treatment?
- 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. (Bring a printed description of the study.)

Daily Life and Support

- How will MS affect my daily life? Will I need to change my daily routine?
- Will I need to change the way I exercise or what I eat?
- If I need physical therapy or rehabilitation services, what do you provide and/or recommend?
- Where can I find help and advice for help with personal and business issues? Are there support services or groups for counseling, insurance, employment issues, and financial concerns?

Additional Resources

For more information and resources in English and Spanish, please visit our resource page *For People with MS* at <https://www.acceleratedcure.org/people-ms>.

For more information about finding the right MS treatment for you, download the MS Association of America's "How to S.E.A.R.C.H.™ for the Right MS Therapy for You!" <https://mymsaa.org/publications/search/>.

[Download a printable version of this handout to share](#)

Resources to Educate Patients and Caregivers

MS Research: Making a Difference in MS by Contributing to Future Breakthroughs

What Is Medical Research?

Medical research aims to generate knowledge that improves the health and well-being of people. It takes many forms. It is used to learn about all aspects of health and illness, from whether a drug is safe and effective to whether an educational brochure is useful and easy to understand. Medical research has enabled a wide range of MS treatments to be made available, it has led to improvements in the diagnosis of MS, and it is helping create new breakthroughs for the future treatment of MS.

Medical research studies often need human volunteers to participate in study activities. As a person with MS, you may decide to volunteer for a study that will generate new knowledge about this disease. Research studies can take place at a clinic, at your doctor's office, online or by phone, or in your own home. Some involve very simple activities, such as completing a survey. Other studies involve things like visiting a clinic, receiving a treatment, and having lab tests done. There are a variety of study opportunities available, depending on your preferences and interests. Learn more about the different types of research at <https://www.acceleratedcure.org/people-ms>.

What to Expect as a Research Participant?

If you are considering participating in a research study, you'll want to know what to expect about the study activities involved, the time and cost to you to participate, how you will benefit, and what might be the risks of participating. If the study is being conducted in a clinic, a member of the research team, usually a doctor, nurse, or study coordinator, will talk to you about the study and what to expect. The details of the study will be outlined in an informed consent form, which you will be asked to sign if you decide to participate in the study. Informed consent is not a contract, so you are free to withdraw from a study at any time. If the study is being conducted over the phone, on the internet, or by mail, you should still be provided with information about the study, but you may not have a conversation with the research team or be asked to sign an informed consent form.

How are Research Participants' Rights Protected?

When people take part in medical research, they may undertake some risk of harm for the good of others. In response to serious abuses that took place in the past, ethical protections have been put in place to ensure that research participants are not exploited or put at unneeded risk. These protections ensure that participants know what to expect and are given the choice to participate or not. They also require researchers to treat individuals and groups fairly, and provide the greatest benefits to participants while making the risks as small as possible.

One protection that has been put in place is the informed consent process described above. Another is the creation of ethics boards that review research to make sure that the welfare, rights and privacy of participants are protected. Specific rules are in place to protect the rights of vulnerable groups of people such as prisoners or children.

Questions to Ask Before Joining a Research Study

If you decide entering a research study might be the right choice for you, it's important to ask the researcher or person who recruits volunteers certain questions to make sure you know exactly what will happen. Here are some of the important questions and topics to ask about when deciding whether to take part in a research study:

- **Purpose of the study.**
 - What is the specific goal of this study? What questions does the team hope to answer?
 - What happens to the information that is collected and how will it be used?
 - How is the study funded? Who is funding it?
- **Treatments and participation.**
 - What treatments or drugs will I receive, if any?
 - Is there a chance I won't receive the drug or treatment you will be studying?
 - What happens if I want to stop participating in the study?
- **Study activities.**
 - What activities, tests, or treatments will the study include?
 - Where will these be performed? Will I need to stay overnight in a clinic or hospital?
 - What information will be collected?
 - How often will I need to see or contact the research team?
- **Risks and benefits.**
 - What are the short- and long-term risks of participating in this study?
 - What are the short- and long-term benefits?
 - How do these risks and benefits compare with my options for care outside of the study?
 - Who can see my personal information and how will it be used?
- **Effects on daily life and responsibilities.**
 - How will taking part in this study affect my daily life? Will it affect my schedule?
 - Will it interfere with my ability to go to work as normal or hurt my ability to do my job?
 - Will I need to get child or elder care?
 - Will it affect transportation? For instance, will I have to arrange rides or take public transportation? Will I have to travel far?
- **Costs and payments.**
 - What costs should I expect for medical care, tests, treatments, or other aspects of the study? What is covered by the study and what will I have to pay?
 - What costs should I expect for transportation, hotel, and meals? Will any of these costs be paid for by the study?
 - Is there any compensation, such as a gift card or money, for participating? When would I receive it?

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How to Find Research Opportunities

Taking part in MS research studies is one way to give back to your community. The information learned through research studies may lead to better understanding of how MS affects individuals like you. It may also lead to better health care for people in your community. See below to find studies that are currently recruiting volunteers and talk to your health care provider about whether any of these or another study is right for you.

- **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 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 donation of 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 where they will fill out questionnaires, watch a short film about MS, and provide blood samples.

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

- **Participate in Research Studies (from the NMSS)**
<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 of human participants conducted 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 member 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.

Additional Resources

For more information about clinical trials, as well as resources in English and Spanish, please visit our resource page *For People with MS* at <https://www.acceleratedcure.org/people-ms>.

[Download a printable version of this handout to share](#)

Template Newsletter Text and Social Media Posts

Adapt the text below for your newsletter, emails, blogs, or website. Long and short versions are available to suit your needs.

Long Version

You Can Make a Difference in MS Research

MS affects African Americans and Hispanics in different ways compared with other ethnic groups. Symptoms may differ, the disease may progress faster, and treatments may have different effects.

Yet, African Americans and Hispanic/Latinos are underrepresented in research studies. That makes it difficult to tell which treatments are best for them, or how to reduce the risk of MS in these groups.

The [*insert your organization's name*] is working with MS Minority Research Engagement Partnership Network, a group of a group of non-profit organizations, health care professionals, researchers, MS biopharmaceutical companies, and people with MS, that is addressing the problem of minority underrepresentation in MS research.

Together we are learning why racial and ethnic minorities aren't fully represented in MS research, and developing solutions to help increase research opportunities for these communities. Without you, it is more difficult to develop insights and solutions for all people with MS. Help us increase minority representation in MS research.

How Can You Help?

- Learn why participation in research is important, and find out how you can help educate others: www.acceleratedcure.org/MinorityNetwork.
- If you or a loved one are have MS, talk to your health care provider about participating in a clinical trial or other types of research.
- Join iConquerMS.org, a research network open to all people with MS, and learn about other research studies at www.acceleratedcure.org/MSResearch.

www.acceleratedcure.org/MinorityNetwork

msminorityresearch@acceleratedcure.org

Find Twitter posts on this topic: #MSResearch4All

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

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Short Version

Help Make a Difference in MS Research

MS affects African Americans and Hispanics in different ways compared with other ethnic groups. Symptoms may differ, the disease may progress faster, and treatments may have different effects. Yet African Americans and Hispanics are underrepresented in clinical research, making it difficult to identify the best treatments or wellness activities to help them.

The [*insert your organization's name*] is working with the MS Minority Research Engagement Partnership Network, a group of non-profit organizations, health care professionals, researchers, MS biopharmaceutical companies, and people with MS, to better understand why racial and ethnic minorities aren't fully represented in research and to develop solutions to encourage participation. Learn more about the project at www.acceleratedcure.org/MinorityNetwork and follow Twitter posts on this topic with #MSResearch4All.

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Sample Posts for Facebook & Twitter

Consider sharing the following text through your social media channels.

- Learn why it's so important for people of all racial and ethnic groups to participate in #MSResearch and how to get involved educating others. www.acceleratedcure.org/MinorityNetwork #MSResearch4All
- African-Americans with #MultipleSclerosis may have different symptoms and respond differently to treatments. Learn more at www.acceleratedcure.org/MinorityNetwork #MSResearch4All
- Hispanic Americans are underrepresented in #MultipleSclerosis clinical trials, making it harder to understand how it affects them. Learn how to get involved in #MSResearch at www.acceleratedcure.org/MinorityNetwork #MSResearch4All
- #MultipleSclerosis can affect people of different racial and ethnic minorities very differently. www.acceleratedcure.org/MinorityNetwork #MSResearch4All

About the MS Minority Research Engagement Partner Network

The MS Minority Research Engagement Partnership Network 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. 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 they can include MS patients from different backgrounds in research activities so that every community benefits from the work that is being done.

The Network is spearheaded by Accelerated Cure Project, a patient-founded, non-profit organization that focuses on meeting the research needs and interests of people with MS and research communities. Its members include the MS Association of America, National MS Society; MANA, a National Latina Organization, National Black Nurses Association, National Hispanic Medical Association, National Minority Quality Forum; patient advocates Anita Williams and Shawn Feliciano; clinicians/researchers Dr. Lilyana Amezcua, Dr. Mitzi Williams, Dr. Daniela Pimentel Maldonado, and Dr. April Moreno; Feinstein Kean Healthcare; Biogen; and Genentech. Funding is provided by a Eugene Washington PCORI Engagement Award made by the Patient-Centered Outcomes Research Institute (PCORI).

www.acceleratedcure.org

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