



Making a Difference in MS through Research

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

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.

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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?

MS Minority Research Engagement Partnership Network Members:

Organizations: Accelerated Cure Project | Ogilvy | FKH | National Multiple Sclerosis Society
Multiple Sclerosis Association of America | National Black Nurses Association
National Hispanic Medical Association | National Minority Quality Forum
MANA, A National Latina Organization | Biogen | Genentech
Individual Members: Lilyana Amezcua, MD | Shawn Feliciano | April Moreno, PhD
Daniela Pimentel Maldonado, MD | Mitzi Williams, MD | Anita Williams



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