

The iConquerMS™ informed consent statement can be found below. This is the information you are asked to agree to, while registering for iConquerMS™.

It is necessary for you to provide informed consent before participating in any research.

The policy below describes iConquerMS™ and what your role will be. Please read carefully to ensure you fully understand the initiative before joining.

Name of Research Study:	A Multiple Sclerosis Patient-Powered Research Network (MS-PPRN), iConquerMS™
Study #:	ACP-MS-PPRN-001
Sponsor:	Accelerated Cure Project for Multiple Sclerosis
Principal Investigator:	Robert McBurney
Research Site Address(es):	460 Totten Pond Road, Suite 420, Waltham, MA 02451
Daytime telephone number(s):	844-897-1211
24-hour contact number(s):	844-897-1211

A copy of this form will be accessible via your iConquerMS™ account. If you have any questions or problems during the study, please contact [Accelerated Cure Project for Multiple Sclerosis \(ACP\)](#) at 844-897-1211.

What is the purpose of this participant information and the consent form?

The purpose of this form is to tell you about a research study, the Multiple Sclerosis Patient-Powered Research Network (MS-PPRN) (or iConquerMS™) data collection study.

Taking part in this study is your choice. You should take part in this study only if you want to. You can choose whether to take part and you can leave at any time. You do not have to give a reason. There will be no penalty or loss of benefits to you if you decide not to take part or if you leave the study early. Before you decide if you want to take part, it is important that you read the information below. This form may use words you do not understand. Please contact ACP at 844-897-1211 to explain any words that you do not clearly understand.

Why is this study being done?

The purpose of this study is to create a Multiple Sclerosis Patient-Powered Research Network (MS-PPRN) that includes at least 20,000 people with multiple sclerosis (MS) who contribute data on their health and other topics. Survey data will be made available to research scientists who are studying MS and similar diseases. Our goal is to use this data to answer questions that researchers and people with MS have regarding the disease, including its causes, treatments, and other topics.

The MS-PPRN will be part of a national network for conducting research called PCORnet, the National Patient-Centered Clinical Research Network. PCORnet is supported by the Patient-Centered Outcomes Research Institute (PCORI). As the MS-PPRN is part of PCORnet, the data collected in surveys you complete may also be shared with researchers studying other diseases within the PCORnet network.

While the MS-PPRN is focused on enrolling people with MS, people without MS are also welcome to participate in this research study.

This study will be conducted online via the iConquerMS.org website. This is an ongoing study and will last for an indefinite period of time. It is possible your involvement in the research could last a period of years.

Who is sponsoring this study?

The Sponsor of this study is Accelerated Cure Project for Multiple Sclerosis (ACP), a national nonprofit organization dedicated to accelerating research efforts to improve diagnosis, to optimize treatment, and to cure MS. The Sponsor is responsible for all collected information and how it will be used.

What will happen during the study?

If you consent to take part in the study, we give you access to the registered-member section of the iConquerMS™ website. You create your username and password to keep your account private. Through iConquerMS™, we give you access to a series of online surveys. Each survey focuses on a specific topic, such as medical history, reproductive health history, diet and exercise, and other areas of health and well-being. We repeat some questions over time to track changes. We will add new surveys in the future. The answers you provide are your “research data.”

In iConquerMS™, you may also elect to provide input on ideas for MS research, post comments in a web-based forum with other participants, or monitor your own health history in comparison to the aggregate iConquerMS™ membership. Data obtained through these activities will also become your “research data.”

ACP provides the information you and others enter to investigators conducting research on MS and other diseases. Researchers who want access to this information will be asked to submit a written request. Before providing the data to researchers, a Research Committee reviews the request. We assess requests based on many factors, including the scientific merit of the research, the ability of the researcher to increase the knowledge of MS and similar diseases, and its adherence to this consent. Before releasing data, we remove information that identifies you directly.

We may contact you periodically to complete additional surveys, to update your contact information, or for other reasons associated with the research study.

What are the risks or discomforts of the study?

You may not feel comfortable answering some of the survey questions. You may decide to not complete a survey if it contains questions that you do not wish to answer.

There is a risk of loss of confidentiality in research studies. Commercially reasonable efforts will be made to protect you and your health information to the extent possible. Absolute confidentiality cannot be guaranteed. Your identity may become known in conjunction with your medical or research data. ACP and the company developing the iConquerMS™ website and computer systems will take reasonable technical precautions to keep your data secure.

The iConquerMS.org website will allow for participants to communicate with each other through forum functionality. Information you choose to share about yourself in this optional forum might enable another participant to identify you. Information shared by other participants in the forum may make you uncomfortable.

Who will have access to my information?

Only ACP will have authorized access to your contact information and information related to non-survey activities in iConquerMS™. This information will be used to contact you to keep you informed of study-related activities.

Your research data may be reviewed by:

- ACP, the study sponsor
- People who work with ACP on the study
- Government agencies, such as the FDA

- Copernicus Group Independent Review Board (CGIRB). The IRB is a group of scientists and non-scientists who review the ethics of research. The goal of the IRB is to protect the rights and welfare of study subjects.

These people may look at your data to make sure the study has been done the right way. They also want to make sure that your health information has been collected the right way, or for other reasons that are allowed under the law.

Are there any benefits?

You will not likely receive direct benefits in this study, but the information you provide may help current and future generations better understand MS and other diseases.

Will I be paid to take part?

You will not receive any payment for taking part in this research study.

Are there any costs?

There are no costs to participating in this research study.

What are the alternatives?

Your alternative is to not participate in the study.

How can I leave the study?

To withdraw from participation, you must access your iConquerMS™ account online and follow the instructions for withdrawal. Withdrawing from the study means that you will no longer receive correspondence about this study and will no longer be asked to complete surveys. Any data you had submitted prior to withdrawal will be kept by ACP, but will no longer be distributed to researchers. Any data that had previously been shared for research purposes cannot be retrieved from the researcher.

If you have any questions or concerns related to withdrawal from the study, please contact the investigator for this study at 844-897-1211.

Who do I call if I have questions?

If you have any questions, concerns, or complaints about this research study or if you think you have been harmed as a result of joining this research, contact [ACP](#) at 844-897-1211.

Please call Copernicus Group IRB at 1-888-303-2224 if:

- You want to talk to someone other than the study staff about research-related questions, concerns, or complaints
- You have a hard time reaching the study staff
- You have questions about your rights as a research subject

Please visit the Copernicus Group IRB website www.cgirb.com for more information about research studies and the role of a research subject.

I consent to take part in this research study.