

COVID-19 Survey Frequently Asked Questions

Why is iConquerMS collecting this data?

iConquerMS is conducting this survey to learn more about how people affected by multiple sclerosis (MS) are dealing with the COVID-19 pandemic and what has been their personal experience with COVID-19.

We are interested in learning:

- what people living with MS (PwMS) know about the coronavirus and COVID-19;
- how COVID-19 directly affects PwMS;
- if COVID-19 has resulted in a change in the treatment or quality of life of PwMS; and,
- what factors affect individuals' experience of the COVID-19 pandemic.

We hope that the information gathered through this survey will help people affected by MS and their doctors during the current pandemic and in the case of future viral outbreaks.

How do I take the COVID-19 survey?

If you're already an iConquerMS member, just log into your account at iConquerMS.org. You'll see a new survey called "COVID-19 Survey" in your list of research surveys.

If you're new to iConquerMS, click "Join Now" on our home page to become a member of iConquerMS. You'll be asked to provide your email address on the sign-up page, and then you'll receive an email with a log-in link. Click this link to come back to iConquerMS and set up your password and profile.

Once your account is created, you'll see a list of surveys. Click on "COVID-19 Survey" to get started. Because this is your first iConquerMS survey, you'll be presented with a consent form to read and accept before taking the survey.

How will my privacy be protected if I contribute data to iConquerMS?

iConquerMS takes your privacy very seriously and has policies and processes in place to safeguard your identity and protect your health data. For instance, only authorized staff and data system vendors of Accelerated Cure Project for MS, the non-profit organization that created and manages iConquerMS, will have access to your contact information, and this information will never be attached to the health information that we share with researchers. Before sharing your health information with researchers, all information that identifies you directly will be removed. In terms of data security, iConquerMS takes industry-standard physical and electronic technical precautions to protect the information that you share.

For more information, please review the iConquerMS [privacy policy](#) and [informed consent statement](#).

Will the data I contribute to iConquerMS be shared with others?

Yes, the data you contribute to iConquerMS will be shared in a de-identified manner to enable research. The iConquerMS COVID-19 survey data, in anonymized form, will be shared with an international initiative gathering data from healthcare providers and PwMS across the world. This initiative was created by the Multiple Sclerosis International Federation (<https://www.msif.org>) and the MS Data Alliance (<https://msdataalliance.com>). Pooling COVID-19 data together will help speed up research into COVID-19 and its effects on people with MS worldwide.

Qualified researchers are also able to request health information from iConquerMS for the purpose of conducting research studies. The data collected by the iConquerMS COVID-19 survey could assist companies or other organizations in developing diagnostics, drug treatments, vaccines and other approaches to managing COVID-19 in the context of MS. The [iConquerMS Research Committee](#) oversees the approval process for these requests.

We will also share statistics and summary information as well as study results with iConquerMS participants.

Why do I need to agree to an informed consent statement in order to submit my data?

We want to make sure that you clearly understand how and why the study is being conducted, as well as the ways you will be asked to participate and any risks or benefits there are in doing so.

This [informed consent statement](#), along with other iConquerMS materials, has been reviewed and approved by an Institutional Review Board (ethics board).

What makes iConquerMS different from other MS data-collection initiatives?

iConquerMS is the only MS research initiative that is nonprofit, patient-centered and governed, and part of a nationwide research network. First, it is a nonprofit endeavor governed by people living with MS, and therefore decisions are based on what is in the best interests of PwMS. Second, it is centered on research driven by people living with MS on topics of interest to them. Third, we're part of a national network of people-powered research networks focused on autoimmune diseases. This gives us the power to easily contribute our data to many research efforts and gives MS researchers access to data from a wider group of people.