

Our Questions Have Power

- the iConquerMS Participant-Driven Research Program

If you have multiple sclerosis (MS) or care for someone who does, you probably have questions about MS and its effects. Your questions and insights can help scientists shape research studies to advance knowledge about MS and improve MS care.

Historically, scientists and healthcare professionals have driven research and designed studies to learn and share. Now, through the *Our Questions Have Power* program, iConquerMS participants can play a larger role than ever before in initiating and collaborating with researchers on studies that will expand knowledge in areas that matter most to people affected by MS.

Empowering Solutions Together Partnership | Transparency | Knowledge | Listening | Respect

What Is Participant-Driven Research (PDR)?

PDR is research based on questions proposed and prioritized by people affected by a disease or medical condition. Take part in PDR and drive the direction of MS research by bringing these questions and priorities to the attention of researchers. Together, people affected by MS can weigh in on the importance of different questions or bring to light new questions.

PDR Differs from Other Forms of Research – however, research types can blend

Investigator-Initiated

A researcher proposes an idea and recruits participants affected by the issue.

Participant-Powered

A researcher designs a study and invites people to share their expertise and opinions on the design of the study.

Participant-Driven

People with MS or their care partners share their ideas for a research question and then design and conduct the study with researchers.

Why Take Part?



Have a voice.

Share your ideas, questions, comments, and priorities with the iConquerMS community and the wider MS research world.



Be a trailblazer.

Be among the first to drive and shape research on the topics most important to you and to the MS community.



Take part in research.

Engage with MS researchers, participate in research design, and use your experiences to help others.



Play a continuing role.

Stay informed; stay involved. Play a role in translating research results to impact the care of people living with MS.

Who Is Involved in PDR and What Do They Do?

It takes many different people and roles to design, fund, and conduct a research study. The iConquerMS™ *Our Questions Have Power* program involves people who take part by sharing ideas, raising awareness, offering expertise, making decisions, providing financial support (funders), and conducting the research.



“This is our chance for meaningful change – thanks to iConquerMS we can stop saying no one listens to people affected by MS and contribute our ideas and health data to make a difference. “

– Laura Kolaczowski

How Questions Become New MS Knowledge

1 SHARE QUESTIONS	2 PRIORITIZE TOPICS	3 ENGAGE RESEARCHERS	4 CREATE A RESEARCH PLAN	5 CONDUCT THE RESEARCH	6 SHARE STUDY RESULTS
Questions are proposed on iConquerMS.org. A group of iConquerMS participants, researchers, clinicians, and advocates review, revise, and post the questions.	Participants read the questions and vote for those that matter most to them. The questions, priorities, and comments are available for all MS stakeholders to view.	Participants partner with scientists interested in a particular question and who want to work with iConquerMS to design and undertake the research.	An iConquerMS proposal team partners with researchers to plan the research study and create a plan, with a budget, which is submitted to organizations that fund research.	Once a proposal is approved and funded, a study team, including researchers and iConquerMS participants, recruits people for the study, conducts it and collects data.	The study team delivers updates, progress reports, and results to iConquerMS participants, people who took part in the study, the scientific community, and the public.

How Can You Get Involved?

There are many ways to get involved in the iConquerMS *Our Questions Have Power* participant-driven research program spanning all levels of commitment.



Join and learn. Register with iConquerMS and start learning about MS research and how you can play a role.



Share with others. Tell others affected by MS about the *Our Questions Have Power* program and PDR. Encourage them to join.



Weigh in on ideas. Visit the Research Ideas page. Comment and vote on questions you think are most important.



Submit your questions. Share your questions for research with the iConquerMS community.



Contribute data. Fill out iConquerMS surveys. Researchers use the data on life with MS in their research studies.



Serve on the team. Join an iConquerMS group helping to select and revise research questions or guide studies through to completion.



Participate in a study. Contribute information, health data, biospecimens, or undergo a treatment or a change in behavior.



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