iCONQUERMS

CASE STUDY:

The Power of a Patient Council

How a year-long patient council transformed drug development at EMD Serono

THE SITUATION

Pharmaceutical companies face a persistent challenge in clinical development: how to meaningfully integrate the perspectives of people living with a disease.

While one-off focus groups can offer useful insights, they often lack the depth and continuity needed to inform a multi-year drug development program.

The Partnership & Approach

To embed the perspectives of people affected by MS throughout development, Accelerated Cure Project (ACP) and EMD Serono pioneered a standing Patient-Focused Drug Development (PFDD) council.

ACP leveraged its iConquerMS network to rapidly recruit eight people living with relapsing MS who worked directly with the EMD Serono team for an entire year—building deep trust through workshops, surveys, and in-depth reviews of study plans.

This sustained partnership delivered actionable insights that shaped trial design and development strategy.

Project Highlights

AN INNOVATIVE MODEL
A standing Patient-Focused Drug Development (PFDD) Council, moving beyond transactional feedback.

DEEP ENGAGEMENT
A sustained, year-long partnership that allowed for in-depth collaboration.

TRUE EXPERTISE
A dedicated council of eight people with relapsing MS acting as lived-experience consultants.

DIRECT RESEARCH IMPACT
Actionable insights that directly informed clinical trial design and development strategy.

ACCELERATED Cure PROJECT FOR MULTIPLE SCLEROSIS

Accelerated Cure Project for Multiple Sclerosis (ACP) is a nonprofit founded by a person living with MS, driven by a core belief: research moves faster and has greater impact when the people most affected help shape it. ACP brings together the entire MS community — people affected by MS, researchers, healthcare providers, funders, and partners — in a connected ecosystem built for MS research. That ecosystem includes the ACP Repository, which provides researchers with high-quality biosamples and data; iConquerMS, ACP's people-powered research network; and initiatives that enable more inclusive, equitable, and representative MS research.

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Key Insights & Impact

The patient council embedded input directly into trial design, informing outcome selection, assessment schedules, and definitions of meaningful change. Key achievements included:

Designed and integrated trial endpoints, including patient-reported outcomes (PROs), that captured what was most important to people affected by MS and aligned assessment schedules with their lived experience.

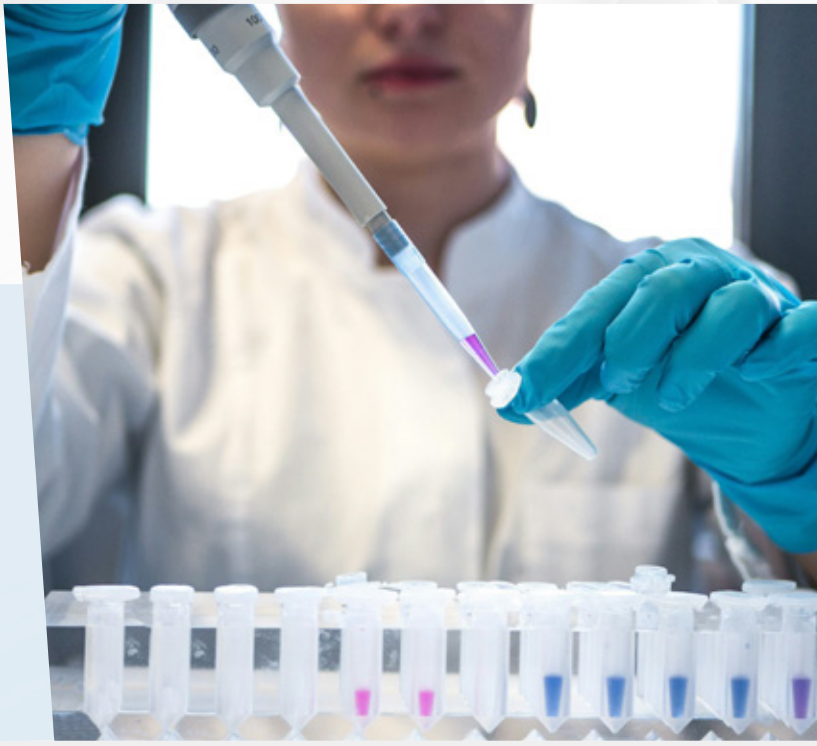
Informed the development of MS PRO instruments by providing critical input throughout the research process, from study design to interpretation of results.

Defined what a 'meaningful change' in symptoms looks like from the patient council's perspective, ensuring the trial measured what truly mattered to people living with MS.

Identified critical gaps in disease-burden evidence, helping to prioritize research questions that reflect patient needs and real-world impact.

The Result

A drug development program designed with the priorities of people affected by MS at its core—improving trial relevance, strengthening recruitment and retention, and delivering therapeutics that address what matters most to people living with MS.



Key Takeaways for Researchers

Sustained engagement delivers better insights. A year-long patient council shaped trial endpoints, assessment schedules, and meaningful change definitions—insights one-off focus groups can't provide.

Start early. Integrate patient input from the beginning to ensure trials measure what matters.

ACP makes it practical. iConquerMS provides the infrastructure to recruit and manage patient councils.

Ready to harness the power of lived experience to guide your research?

To learn how iConquerMS can help you recruit and manage patient advisory councils, contact us at **Partner@AcceleratedCure.org.**

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