ACCELERATED CURE PROJECT

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YOUR PARTNER FOR PATIENT-CENTERED MS RESEARCH

Does your organization’s mission include improving the health and well-being of people diagnosed with multiple sclerosis? Would collaborating with patients and caregivers to gain access to their perspectives and data accelerate progress toward your mission?

Accelerated Cure Project can support your efforts in fulfilling your mission by providing efficient access to high-value information and insights from people affected by multiple sclerosis (MS) through its iConquerMS™ initiative.

About ACP and iConquerMS

iConquerMS is a network of over 8,500 people affected by MS who are interested in accelerating research including the development of products and services. iConquerMS was launched in 2015 by the Accelerated Cure Project, a nonprofit organization with proven experience in developing and sharing resources with MS researchers worldwide. iConquerMS participants are located across the US and in over 50 other countries, come from all backgrounds and ethnic groups, and represent all ages and stages of living with MS.

iConquerMS is a patient-centered initiative, with people affected by MS serving in key leadership roles and with all decisions and activities shaped by patient and caregiver priorities. This patient-centered orientation enhances the impact and authenticity of patient insight collaborations and enables our research partners, both commercial and academic, to more effectively understand and address the most pressing needs of people affected by MS.

We can provide you with a variety of collaboration options for leveraging patient and caregiver perspectives and data in all stages of research, product and service development. Read on to learn how partnering with Accelerated Cure Project and iConquerMS can help you achieve your mission.

How we work with industry and researchers

Meaningful research relationships with patient and caregiver communities are built on trust and consistent engagement. We make this our priority, so that our partners can benefit from collaborating with people affected by MS, allowing them to accomplish goals such as:

- Understanding the impact of MS on key aspects of health and well-being
- Understanding the diversity of perspectives in the MS community
- Obtaining input on new products entering the pipeline
- Understanding how people affected by MS view and prioritize new product features
- Effectively designing clinical trials that will recruit and retain participants
- Selecting outcome measures that are meaningful to people with MS
- Testing new technologies for use by the MS community
- Receiving regular and meaningful feedback on educational materials and approaches
- Disseminating research evidence and other information of value in accessible ways
- Prospectively collecting bio-samples and data from a real-world population

Our collaborations typically involve one or more of the following activities:

Providing access to iConquerMS patient data

Our existing and constantly growing database contains information from iConquerMS members including demographics, MS history, the Neuro-QOL short form, the PROMIS Global Health Questionnaire, diet, wellness, physical activity, and comorbidities. New surveys are launched every six months to collect updated information from our members.

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Collecting new data from iConquerMS participants

Through the iConquerMS portal, we can efficiently conduct surveys that help you understand the community's needs, interests, and experiences of living with MS, on a cross-sectional or longitudinal basis. Our platform includes a full range of survey hosting features. We support a range of survey types and can collect data from the broader iConquerMS community or from a subsection based on your criteria. We use a variety of techniques to encourage participation in surveys.

Forming and facilitating focus groups and councils

We can convene and facilitate focus groups and patient councils to gather perspectives and insights on a wide variety of topics. Whether you're looking for a one-time conversation or a longer-term engagement, the diversity of our community, including both demographics and disease characteristics, allows us to recruit individuals matching your target audience.

Recruiting for your studies or other research activities

Through outreach to our network via targeted email lists and our monthly newsletter, we can help you find, communicate with, and recruit participants for studies and activities outside of iConquerMS.

Supporting your research and innovation activities

Our network and data collection platform are perfectly poised to provide research services that test the usability and efficacy of new interventions, technologies, online tools, and virtual products. We can help with all aspects of conducting research including recruitment, consenting, data and trial management, collection of patient-reported and clinical outcome measures, administration of incentive payments, and participant support.

Disseminating evidence from your studies or other research activities

We can assist in the dissemination of research evidence to the patient and caregiver communities in a variety of formats (lay summaries, infographics, etc.) and channels, providing the MS community with valuable health related information in understandable and accessible ways.

Collecting biosamples from iConquerMS participants

We can facilitate the collection of samples such as saliva, cheek cells, skin swabs, urine, or fecal samples, and can also coordinate with mobile phlebotomy services for in-home blood sample collection. The collected samples can be sent directly to your lab or to an external lab for processing and can be annotated with data collected from the participant via the iConquerMS platform.

Facilitating diversity, equity, and inclusion initiatives

iConquerMS hosts multiple diversity, equity, and inclusion-focused initiatives geared towards making MS research participation more representative and equitable. Our Research Inclusion, Diversity, and Equity (RIDE) Council brings together people with MS from a variety of backgrounds who can advise you on approaches to diversify your research and other initiatives.

How to work with us

Engaging with Accelerated Cure Project is easy!

1. Send a message briefly outlining your needs to info@iConquerMS.org.
2. Join us for an introductory call to discuss the request. During this call we will go over your specific needs so that we are able to provide potential options for collaboration and a general cost estimate. If your needs and our offerings align, we will jointly develop a project description, budget and timeline.
3. Our iConquerMS research committee, comprised of researchers and people with MS, will review the project to provide valuable guidance and ensure patient-centricity.
4. We'll finalize the project, execute agreements as needed, and get started!

Costing Model

The following page details starting costs for various types of collaborations. Please note that due to the wide range of patient-centered offerings Accelerated Cure Project can provide, costs are highly variable. A detailed written estimate of costs relevant to your unique needs will be shared following an initial consultation call.

Providing access to existing iConquerMS patient data

Factors affecting cost include complexity of data request, quantity of data, number of time points

Starting cost from $5,000

Forming and facilitating focus groups and patient councils

Factors affecting cost include length of engagement, level of facilitation, setting (virtual v. in-person), group size and specificity, participant incentives

Starting cost from $20,000

Supporting research activities through trial management and/or data collection

Factors affecting cost include type of initiative and services required, length of engagement, size of population, participant incentives

Custom pricing provided after initial call

Facilitating successful Diversity, Equity, and Inclusion initiatives

Factors affecting cost include type of initiative and services required, outputs/goals, length of engagement, timeline, participant incentives

Custom pricing provided after initial call

Collecting new data from iConquerMS members

Factors affecting cost include survey complexity, sample size, duration of study, participant incentives

Starting cost from $10,000

Assisting with recruitment for non-iConquerMS studies

Factors affecting cost include distribution channel (email and/or newsletter) and specificity of target population

Starting cost from $1,500

Collecting biosamples from iConquerMS members

Factors affecting cost include sample type, timeline, cohort size, accompanying data, accessibility of target population

Starting cost from $125/sample

Disseminating evidence from research studies

Factors affecting cost include type of initiative and services required, number and type of formats and channels desired, timeline

Custom pricing after initial call

Example Activities

Patient-Focused Drug Development Council with EMD Serono

In 2018, EMD Serono and Accelerated Cure Project launched a Patient Focused Drug Development (PFDD) collaboration to solicit and integrate perspectives of people with relapsing MS into a drug development program. The collaboration centered on the formation of a standing council consisting of iConquerMS members who worked with EMD Serono over the course of a year.

Project phases included initial project definition and scoping; recruitment of 8 council members meeting EMD Serono's criteria; meeting facilitation; council engagement and communication; and development and review of project materials and reports. Various channels were used including face-to-face workshops, teleconferences, structured surveys, and review of study plans and reports. Working with this group of participants over time created the level of trust and mutual understanding necessary to elicit meaningful and actionable feedback. It also allowed participants to build on past discussions creating depth and connection between topic areas.

For more information, click here

Focus Group and Survey Delivery Combinations

A successful model supported by Accelerated Cure Project is the facilitation of a series of focus groups combined with one or more iConquerMS community surveys. Focus group members are selected based on agreed upon criteria with an eye towards diversity of opinions and voices. These small groups enable deep conversation that highlight important aspects of the patient experience. This information can then be validated and expanded upon with a broader iConquerMS-wide survey. Alternatively, we can support focus groups or interviews following an initial survey to explore specific aspects of the survey results in more detail.

Accelerated Cure Project has collaborated with both academic and industry partners on focus group and survey-based projects. Sample topics include use of telemedicine, valuation of disease-modifying therapies, the impact of COVID-19 on people with MS, perspectives on drug administration, views of patient assistance programs offered by pharmaceutical companies, and living with progressive MS.

Our partners often have questions that exist outside of formal research projects. They may want to know things such as how their materials are perceived by patients, whether or not educational tools are clear and accessible, and what gaps exist in patient knowledge of potential treatment options. Accelerated Cure Project is perfectly organized to collect feedback on these and many other topics through iConquerMS.

COVID-19 Surveys and Sample Analysis

In April 2020, recognizing the critical need for information and support among people with MS in the face of the COVID-19 pandemic, Accelerated Cure Project partnered with Dr. Farrah Mateen from Massachusetts General Hospital to conduct a survey of people with MS (PwMS). Through the iConquerMS portal that supports both cross-sectional and longitudinal survey administration, its existing cohort of people with MS, and streamlined research development and approval processes, the team organized a rapid response that addressed the pressing needs of the MS patient community. Within a month, the survey was launched and more than 1,108 iConquerMS members responded. An initial paper of research results was published approximately five months after survey launch. For more information, click here.

Once COVID-19 vaccines because available, ACP launched the COVER-MS study in collaboration with Quest Diagnostics and the National MS Society to assess the immune response to the vaccines in people with MS taking different MS therapies. Over 1,660 participants completed surveys about their vaccine experiences, and over 200 enrolled in a substudy to analyze antibody and T-cell responses in blood samples. For more information, click here.

To learn more...

Please email info@iConquerMS.org to tell us more about your initiative. We look forward to partnering with you and assisting as you integrate the patient and caregiver voice into your research, products and services.