

SURVEYING THE MS COMMUNITY TO IDENTIFY CRITICAL NEEDS

A use case: The impacts of COVID-19 on people living with multiple sclerosis (MS)

In April 2020, recognizing the critical need for information and support among people with MS in the face of the COVID-19 pandemic, iConquerMS teamed up 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 interested in participating in research, and a streamlined research development and approval processes, the team was able to organize a rapid response that addressed the pressing needs of the MS patient community.

At a glance...



1,019 people with MS
were surveyed



Worry about COVID-19
was higher in female and
non-white PwMS



A majority reported
interruptions to MS
care and **limited access**
to COVID-19 testing



10% reported
changing their disease
modifying therapy as
a result of COVID-19

**The iConquerMS Network allowed
progress to keep pace with the rapidly
evolving nature of COVID-19.**



3/18/2020
Initial discussions



4/3/2020
Joint survey launched



9/19/2020
Initial paper published
on research results



12/1/2020
Follow-up survey



Our engaged and responsive patient community was included at every step from survey development through to results dissemination. Together we efficiently gathered and analyzed the data on topics including:

- **access to COVID-19 information**
- **steps being taken to prevent exposure/infection**
- **adverse impacts on healthcare**

A follow-up survey launched later in the year added additional topics including **mental health** and **attitudes towards vaccination**.

The entire iConquerMS community (5,700 members) was invited to take the survey on the iConquerMS portal. There were 1,145 respondents (response rate: 20%), 1,019 of whom had a diagnosis of MS and fully completed the initial survey.

By complementing physician-reported cases of MS and COVID-19, the data from the iConquerMS surveys gives MS patients, caregivers, doctors, and researchers more knowledge with which to make lifestyle choices, discuss treatment options, and mitigate fears and anxieties within the context of the global pandemic.



PARTNERSHIP AND COLLABORATION

Looking to gather the insights and perspectives of people affected by MS? iConquerMS is an invaluable partner, providing access to a participatory patient population and the expertise and technology needed to gather key data points over time.

Join us in partnership to make MS research efforts more responsive, reliable, and reflective of the needs of PwMS. Together, our data and expertise can improve diagnoses, optimize treatment options, and accelerate the work of finding a cure for MS.

To discuss opportunities for future research collaboration, please reach out to **Hollie Schmidt** at hollie@acceleratedcure.org

To learn more about the iConquerMS people-powered research network, please visit www.iconquerms.org

For information on the Accelerated Cure Project and its biosample repository, please visit www.acceleratedcure.org