People living with MS are the heart and soul of iConquerMS. A primary objective of the initiative is to enable all people living with MS to participate in research. Network members can not only contribute data about their MS experience, but also steer the direction of research by contributing their ideas. Ideally, tens of thousands of people from all parts of the country, from all backgrounds and ethnic groups, and of all ages and stages of living with MS will participate. This diversity will create a rich, interactive resource for MS research. This innovative program has made significant progress toward realizing this vision. In 2018, the network has grown to over 4,700 registered members living with both relapsing remitting and progressive forms of MS. In February, data was presented at the ACTRIMS Forum 2018 summarizing and comparing the characteristics of participants in the iConquerMS network. These data reveal interesting differences in the ranking of symptoms, functioning and quality of life across the different forms of MS, reinforcing the network’s value as an excellent resource for research.

REAL MS™ (Research Engagement About Life with MS) is an ongoing study of MS that was launched by iConquerMS two years ago. Study participants periodically complete questionnaires about their MS experience through the iConquerMS portal. These data are a growing and powerful resource for MS research, providing investigators and clinicians with real-life information on what living with MS is like.
We’ve learned many interesting things from the data contributed by iConquerMS members, and look forward to learning more in the future! As another year draws to a close, we’d like to say thank you to those who have participated in iConquerMS and REAL MS. Two rounds of surveys were released in the last year (for a total of five rounds), one in March and one in September. To date, more than 60% of the iConquerMS community has completed at least one REAL MS survey (upwards of 2,800 people). The wealth of information provided may be key to unlocking the mysteries of MS and other demyelinating diseases. Let’s keep the momentum going! If you aren’t already a member of iConquerMS, please consider joining this powerful network and start completing your REAL MS surveys today! Already completed yours? Stay tuned for the next round!

iConquerMS has collaborated with researchers and organizations to enable and accelerate 11 research initiatives since its inception. STEP for MS (Supervised versus Telerehab Exercise Program for People with Multiple Sclerosis) is one such initiative, launched in 2018. This four-year study compares the outcomes of a 16-week exercise program conducted either at home, or in an exercise facility. The iConquerMS portal is being used for data collection, and to communicate with participants. The investigators leading STEP for MS hope the evidence generated in the study provides people living with MS information to guide their choice of exercise options. Interested in joining the study? Contact information, as well as criteria for participation, can be found on the STEP for MS website. This study is just one of the many ways iConquerMS is facilitating and accelerating research on topics of importance to people affected by MS.