

iConquerMS™: A Patient-Powered Research Network for Multiple Sclerosis



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Background

iConquerMS™ is a new research resource that brings together the health data, biosamples, experiences, and ideas from thousands of people with MS for use in research on topics that matter most to them. It is sponsored by the nonprofit organization Accelerated Cure Project (ACP) in collaboration with Feinstein Kean Healthcare (FKH) and Arizona State University (ASU). Initial funding for iConquerMS™ has been provided by the Patient Centered Outcomes Research Institute (PCORI).



The home page of the iConquerMS.org web portal

Mission

The mission of iConquerMS™ is to drive research on topics that are most important to people with MS. We are creating a large virtual cohort of people with MS who provide their health data and biosamples for use in research studies, and who contribute their experience and ideas for shaping the activities and research agenda of the initiative.

Infrastructure and Governance

Recruitment of iConquerMS™ members, collection of health data including survey instruments and electronic health records, and provision of information about iConquerMS™ are all supported by the iConquerMS.org Web portal. Based on a Drupal platform, iConquerMS.org supports the hosting of research survey instruments, discussion forums, and infographics generated in real-time describing the composition of the cohort. A clean, user-friendly design with appealing graphics facilitates recruitment and engagement of members.

The governance of iConquerMS™ is carried out by a Governing Board and committees focused on Membership, Communications, and Research. **People with MS constitute a majority of the members of the iConquerMS™ governance structure.** Administration of iConquerMS™ is conducted by Accelerated Cure Project, Feinstein Kean Healthcare, Arizona State University, and Life Data Systems, Inc.

Building the iConquerMS™ Cohort

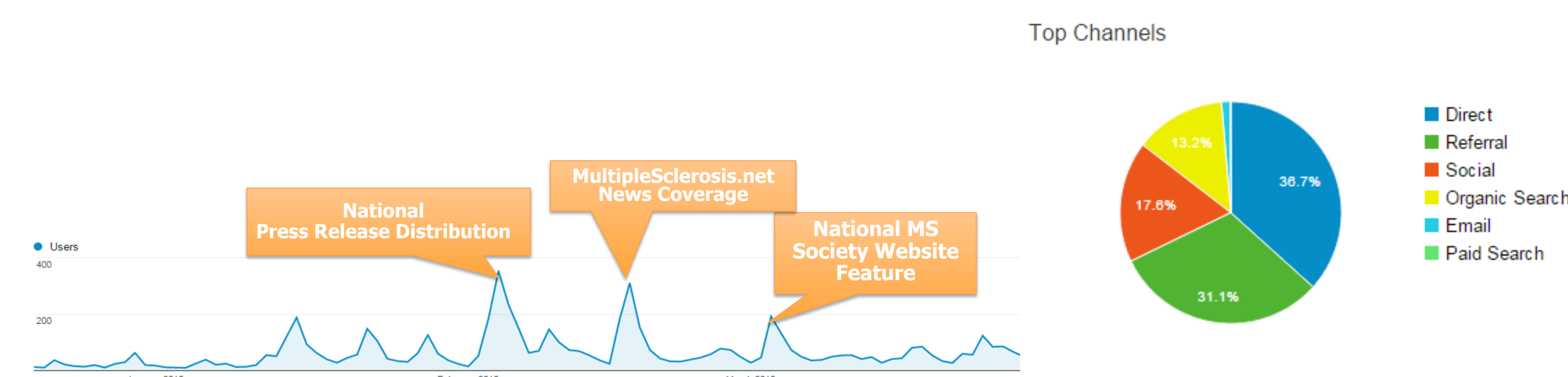
Our goal is to build a cohort of 20,000 iConquerMS™ members, totaling 5% of the estimated total US MS population, representative of the diversity of people with MS in the US. As of May 2015, approximately 2,000 members have joined iConquerMS™.

iConquerMS.org was made available to an initial group of supporters in November 2014. A comprehensive national communications campaign was launched in February 2015 to introduce iConquerMS™ to the wider MS community. Awareness methods used to encourage enrollment include:

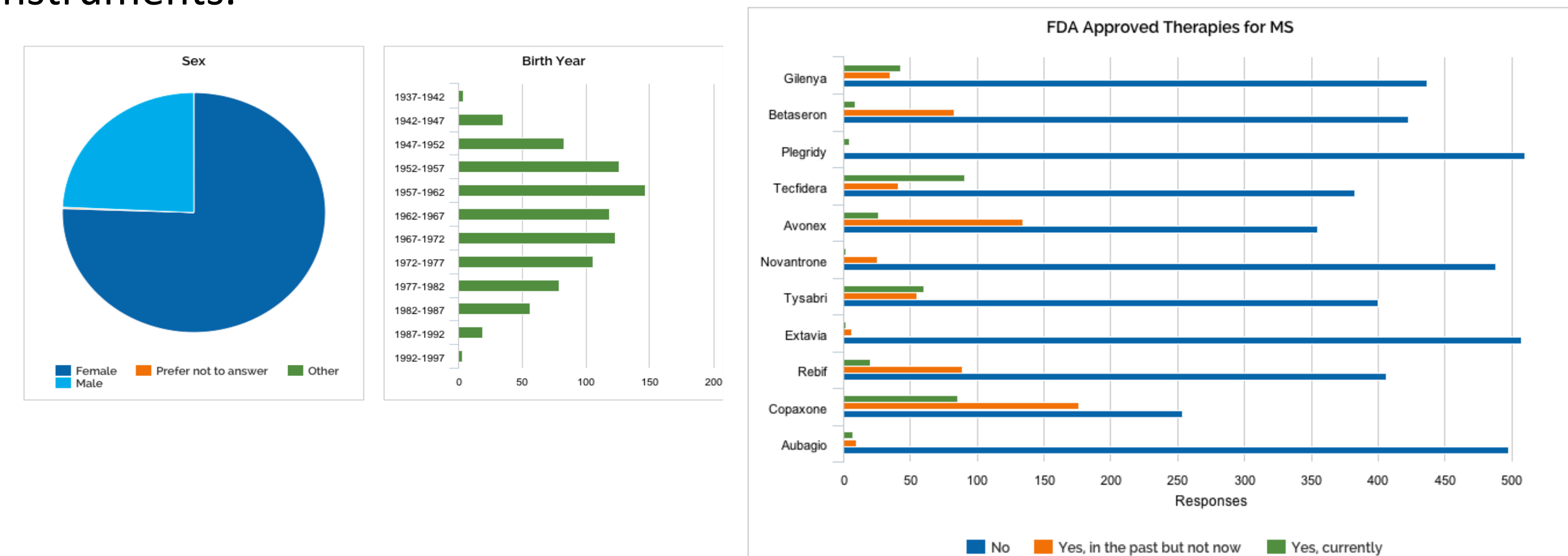
- Use of social media and outreach to key MS bloggers and influencers
- Promotion through traditional media organizations (digital, print, TV/ radio) including mainstream and health-focused outlets
- Messages to ACP mailing lists
- Assistance from collaborating partner organizations:



We are tracking visits to iConquerMS.org via a variety of Google Analytics tools in order to evaluate the effectiveness of each outreach method.



We are also tracking the overall composition of the iConquerMS™ cohort as it grows using data obtained from the Demographics and MS History instruments.



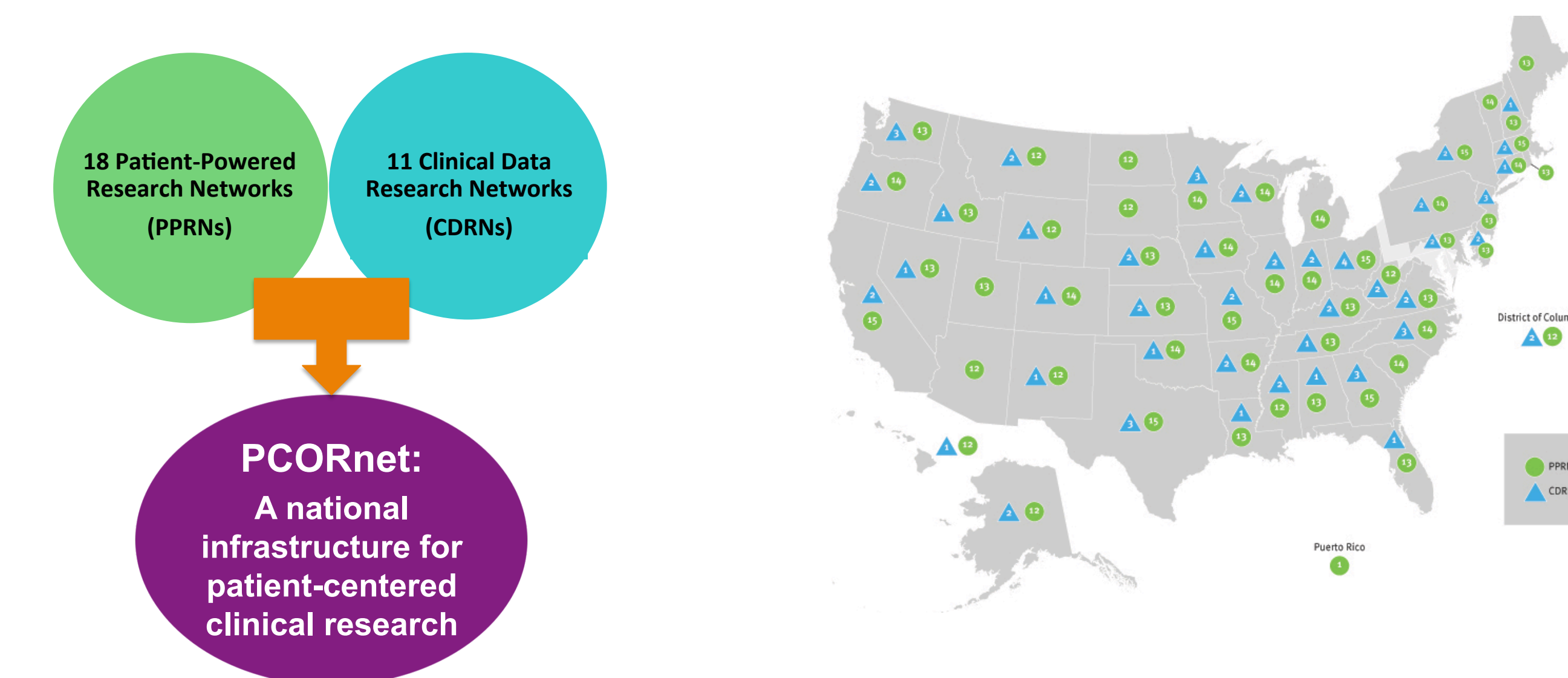
Conducting research with iConquerMS™

We welcome collaboration with US and international researchers with an interest in MS. Opportunities include but are not limited to the following:

- Analysis of biannual survey data (Demographics, MS History, Neuro-QoL, and PROMIS Global Health)
- Collection of cross-sectional or longitudinal research data via surveys, EHRs, mobile apps or fitness devices on topics of special interest, such as:
 - Research to capture the total patient experience for developing new MS outcome measures for regulatory clinical trials
 - Assessment of patient risk tolerance for MS therapeutics
 - Assessment of factors affecting initiation and switching of DMTs and adherence to medication regimens
 - Lifestyle factors and their effect on health outcomes
- Analysis of biological samples linked to data
- Assistance with recruiting iConquerMS™ subjects into existing studies

Interested researchers are invited to contact us to learn about the process for proposing and initiating studies with iConquerMS™. All study proposals receive review and valuable feedback from the iConquerMS™ Research Committee and iConquerMS™ participants.

iConquerMS™ is a Patient-Powered Research Network member of PCORnet, a new national research network providing access to data from tens of millions of patients. Researchers interested in conducting “Big Data” studies through access to PCORnet resources can contact iConquerMS™ to learn more.



For more information

Please visit iConquerMS.org to learn more about this initiative and contact us with further questions.

For general information about iConquerMS™: Sara Loud, sloud@acceleratedcure.org, 781-487-0032

For information about research collaborations: Hollie Schmidt, hollie@acceleratedcure.org, 781-487-0099

