



iConquerMS™

*A Platform for Patient-Powered Research
in Multiple Sclerosis*

*Overview Presentation
September 2015*

Overview of iConquerMS™

Highlights of iConquerMS™

- An initiative ***by and for*** people living with MS who understand the need to contribute their ideas & health data to fuel research
 - Focused on research topics of interest to people living with MS
 - Governed by people with MS
- Funded by PCORI, iConquerMS™ serves nationally as the MS Patient-Power Research Network (MS-PPRN) within PCORnet
- Participation occurs through the iConquerMS.org portal
- Current enrollment is 2,600 in September 2015; ultimate goal is up to 20,000 members, representative of the US MS population in all its diversity

iConquerMS.org: Information and activity portal for iConquerMS™

iConquerMS™

[Home](#) | [Contact Us](#)

search



Need to increase text size? [A](#) [A](#) [A](#) [A](#)

[ABOUT](#)

[WHY JOIN](#)

[JOIN iConquerMS™](#)

[FOR RESEARCHERS](#)

[NEWS & INSIGHTS](#)

Welcome to iConquerMS™!

Where people living with multiple sclerosis can help conquer this disease by safely and securely contributing their health information and submitting ideas for research on topics important to them.

 [Play video](#)

[JOIN NOW >](#)



iConquerMS™

People join iConquerMS™ by consenting and registering

JOIN
iConquerMS™ >

Other Ways to
Participate >

View Informed
Consent
Statement >

Invite a friend

email >

Sign up for updates

email >

JOIN iConquerMS™

By joining iConquerMS™, you help advance MS research in new and exciting ways. By sharing your health data and ideas, you can help researchers better understand MS, develop better treatments, and ultimately cure MS. This section will guide you through the iConquerMS™ registration process.

Registration is easy. Just 3 simple steps...

- 1 Agree to Informed Consent**
You should fully understand the initiative before joining. Here, you can read about the informed consent and privacy policy of iConquerMS™ and learn exactly what your role will be.
- 2 Enter and Submit Your Email Address**
You will receive a confirmation link after you submit your email address. Clicking on this link lets you continue the registration process.
- 3 Complete Your Profile**
You can enter the iConquerMS™ member section after you create a password, and provide a few quick personal details.

It only takes a few minutes.

GET STARTED >

The iConquerMS™ Pledge

When you sign up for the study, here's what you can expect of us - and what we expect of you.

We promise to....



Make things
easy for you.



Respect your
time and
privacy.



Give you
updates.

You promise to....



Tell us about
your health.



Check in
regularly.



Stay involved.

Participants visit their dashboard for data contribution and other interactions

MY DATA

NETWORK DATA

CONNECT WITH RESEARCH

NEWS & INSIGHTS




Welcome to Your Dashboard

This is your personal iConquerMS™ dashboard, where you can share and access your personal health information and connect with the MS research community by submitting ideas for research. In the future, it will also offer a place to further engage with others. We invite you to visit often as part of conquering MS, as well as to provide feedback about this portal.

My Research Surveys

[View All >](#)

These surveys are research tools, developed by researchers specifically to provide information of value in the fight against MS. Your answers will be used in a variety of ways, along with answers from thousands of others living with MS. This approach enables researchers to gain new insights into MS, leading to better diagnoses, improved treatment results, and eventually cures.

 NEW	 IN PROGRESS	 COMPLETED
	MS History	Demographics
		Overall Health (PROMIS Global Health Scale)
		Quality of Life (Neuro-QoL)

My Electronic Health Records (EHRs)

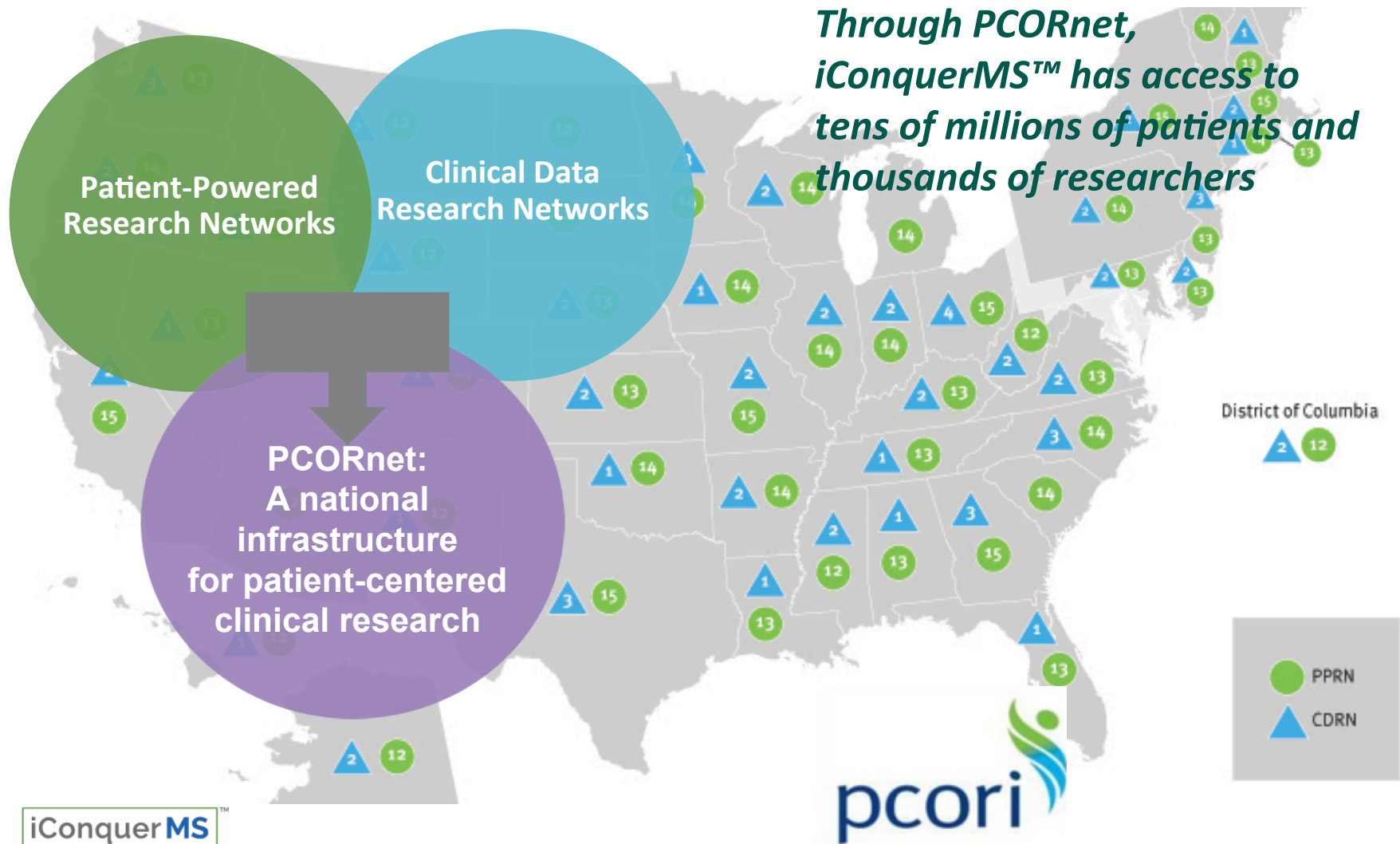
Electronic health records (EHRs) provide a digital snapshot of your health status and medical history. iConquerMS™ will help you obtain and share your records for research.

[VIEW PRIVACY POLICY >](#)

[FREQUENTLY ASKED QUESTIONS >](#)

[REQUEST my EHR >](#)

iConquerMS™ is part of the PCORnet national research network



iConquerMS™ Project Team

Accelerated Cure for MS

- Unique provider of research resources to the community
- Biosamples/data for >3200 participants have enabled 90 research studies worldwide and generated >1 trillion returned datapoints

Arizona State University

- Computational Science & Informatics Program (since 2012) led by Ken Buetow, former Director of Biomedical Informatics and Information Technology, NCI
- Created open-source tools for healthcare information technology

Feinstein Kean Healthcare

- Leading healthcare communications firm with 27+ year track record of innovation

iConquerMS™ Research Capabilities

iConquerMS™ delivers research solutions

- ▶ iConquerMS™ is a working example of **patient-centric, data-driven** research
- ▶ iConquerMS™ applies **highly interactive, social media-based** tools and approaches
- ▶ iConquerMS™ can collect **diverse data** (clinical, experiential, genomic, personal monitoring, imaging)
- ▶ iConquerMS™ has extensive computational capabilities for **integration/analysis of complex data**
- ▶ iConquerMS™ can catalyze **multi-stakeholder collaborations**
- ▶ iConquerMS™ is **a model** for other patient-centric disease research

Perfect timing for patient-driven research

- ▶ National dialogue and resources (PCORI) driving new patient-centric, data-driven approaches
- ▶ Greater patient engagement in care and treatment decisions
- ▶ Increasing demand for personalization of treatment choices
- ▶ Digital consumer tools available for tracking and self-management of disease
- ▶ Widespread recognition of importance of Big Data in research, including patient-reported outcomes
- ▶ Availability of huge computing power
- ▶ Greater willingness among biomedical silos to collaborate

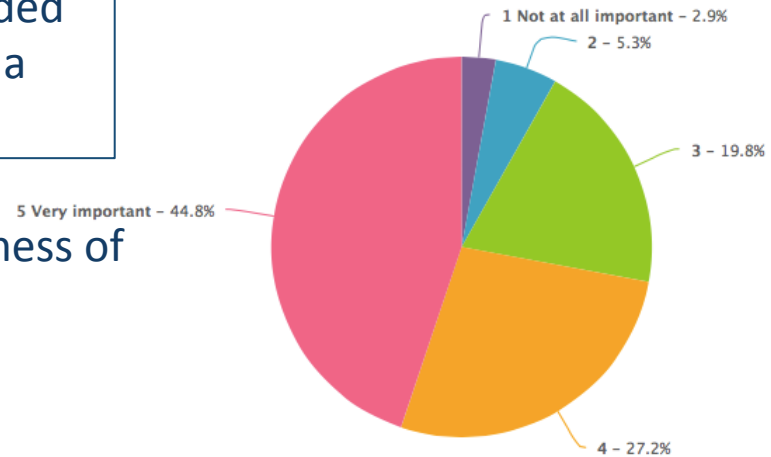
How iConquerMS™ participants power research

- Contributing ideas and personal experiences that can be developed into research topics
- Setting the research agenda with other stakeholders
- Commenting on individual studies to improve their design and likelihood of success
- Contributing data (online queries/surveys, EHRs, apps) and biological samples for research
- Participating in results analysis and dissemination
- Encouraging others in the MS community to get involved

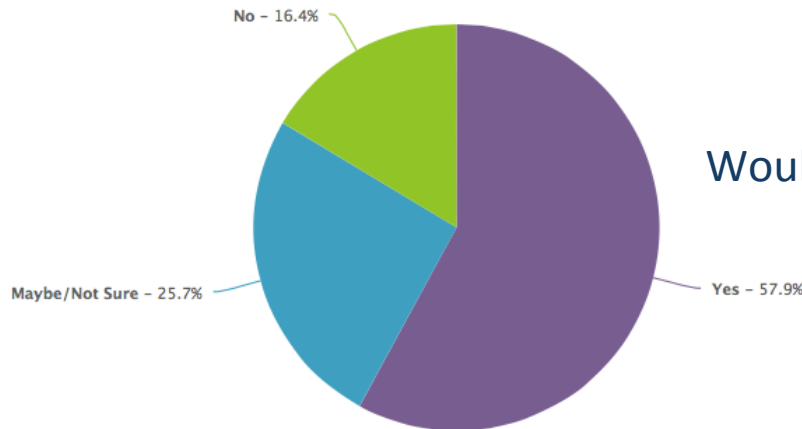
Example: iConquerMS™ mood study

Over 400 iConquerMS™ participants responded to a survey asking for input on the design of a new depression study

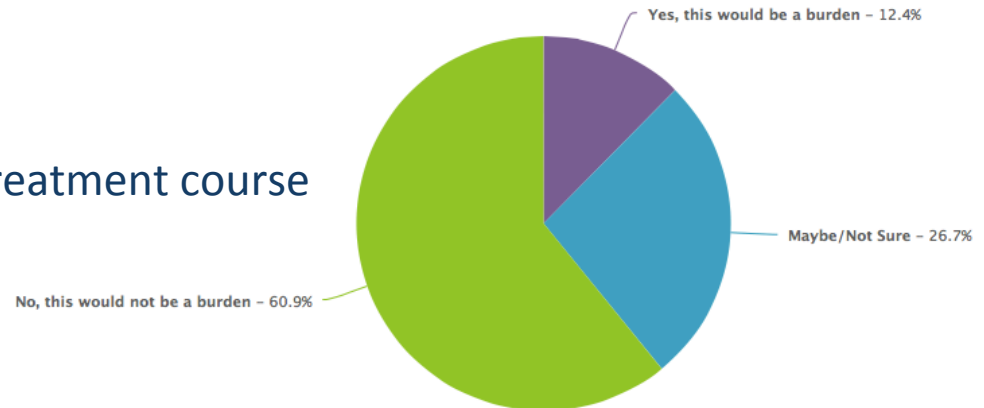
How important is it to compare effectiveness of 2 online therapies?



Would you want to participate in this study?



Would participating in an 8-week treatment course be a burden?



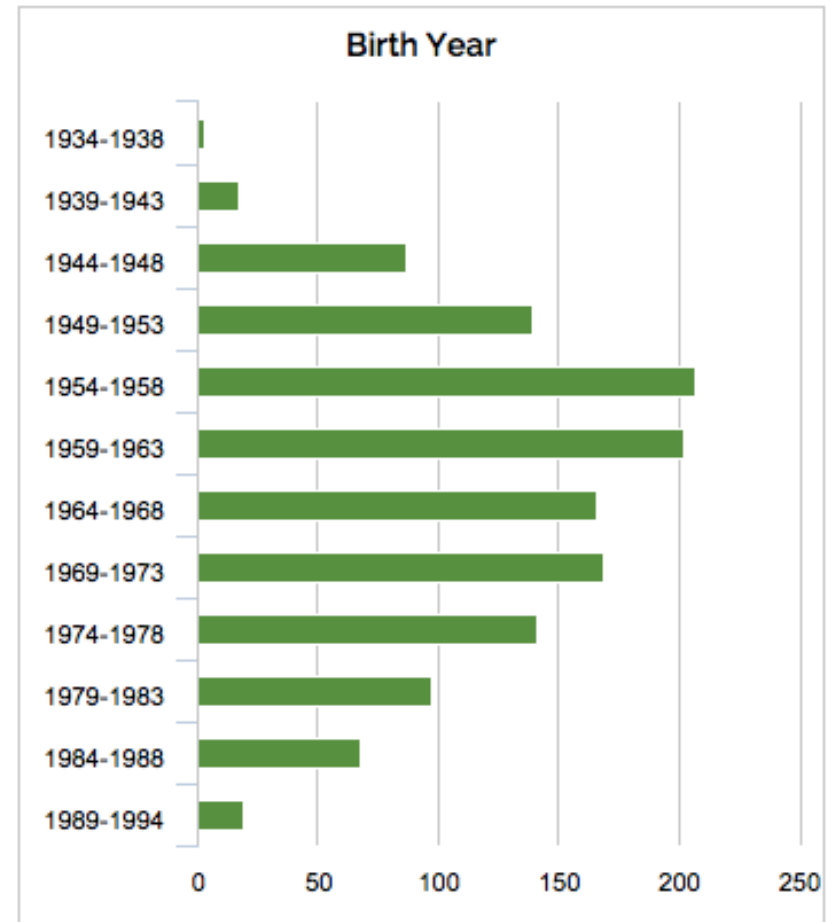
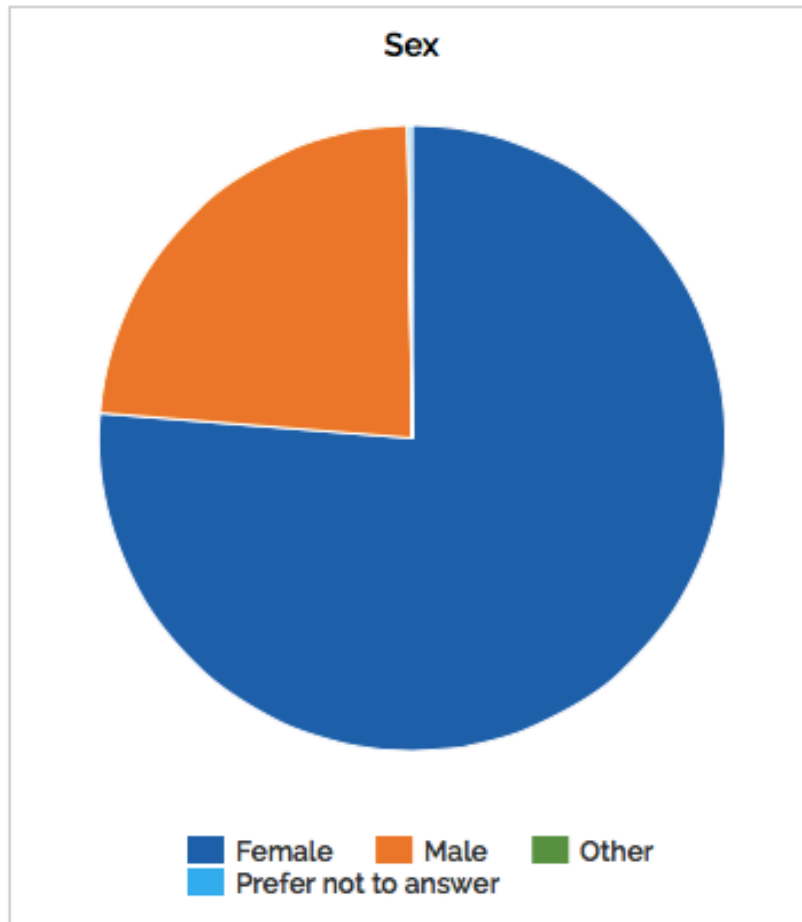
How iConquerMS™ supports research

- Providing “core” longitudinal research data (MS history, demographics, Neuro-QoL, PROMIS Global Health Scale)
- Conducting custom data collections (cross-sectional or longitudinal, via Web or other platforms)
- Providing biosamples (home- or lab-based collections)
- Providing EHRs contributed for research studies
- Facilitating access to PCORnet data
- Helping recruit subjects for existing studies
- Providing feedback from people with MS on study designs

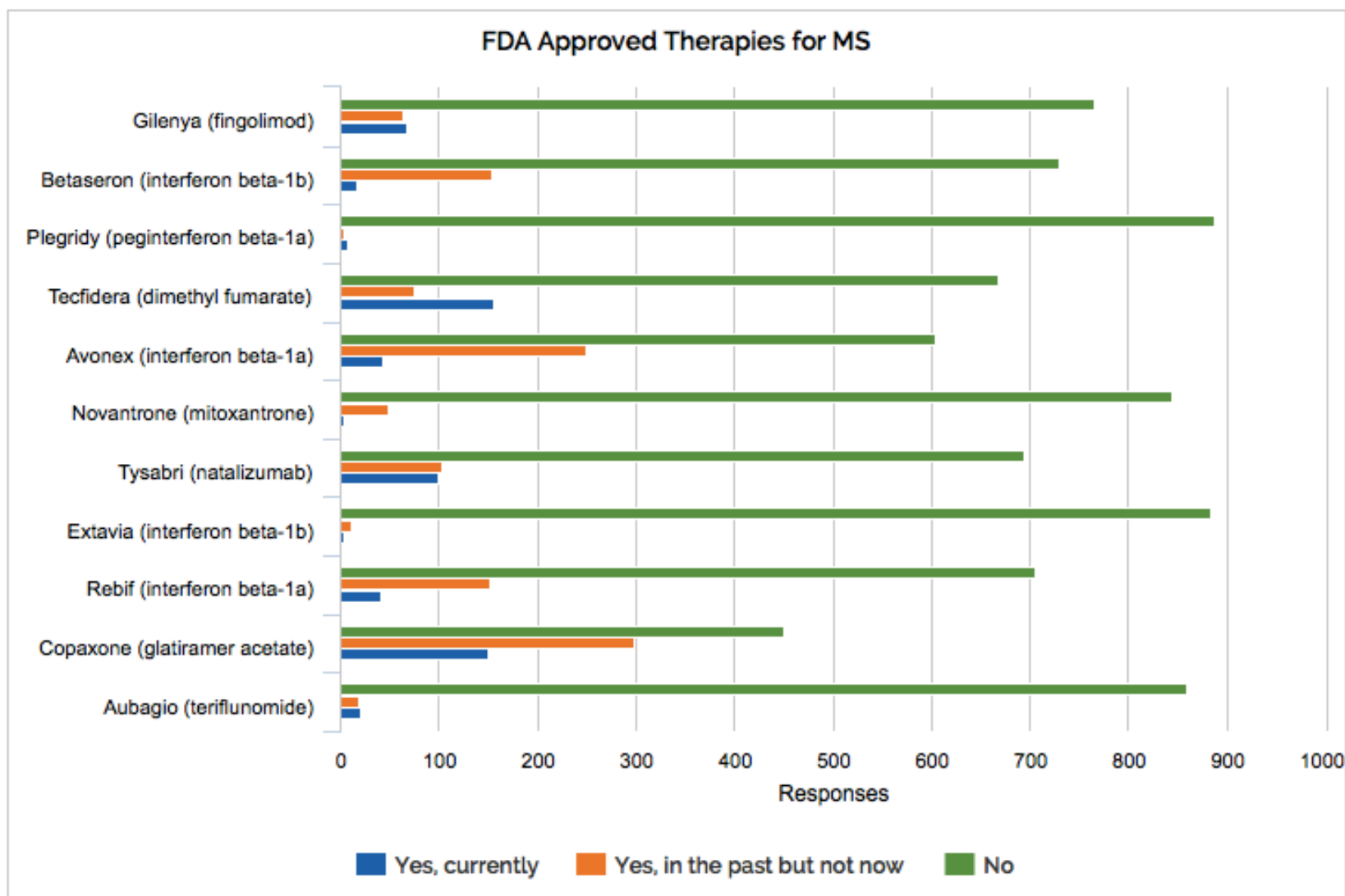
Characteristics of the iConquerMS™ Community

As of September 2015

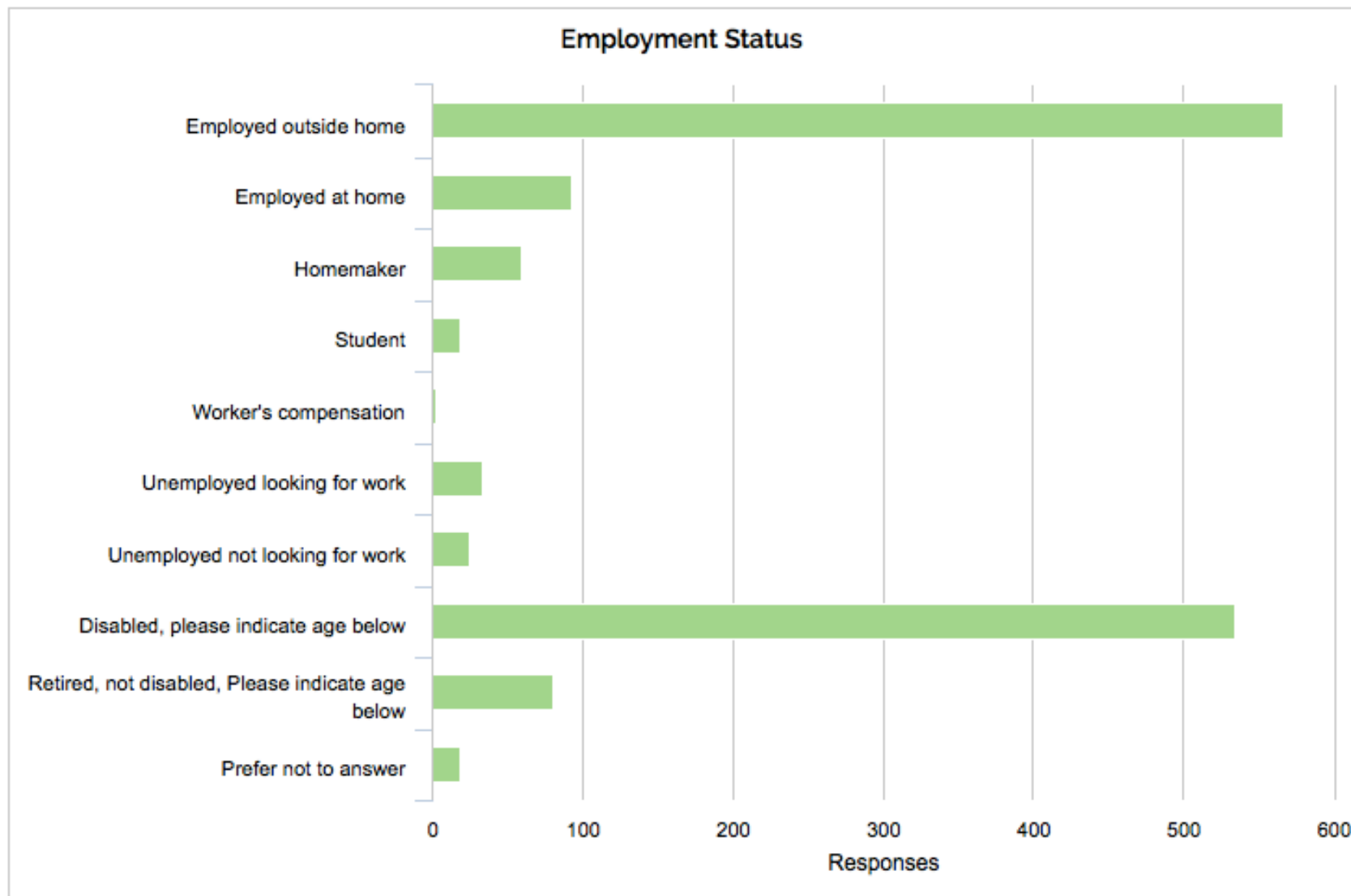
Snapshots of the iConquerMS™ community



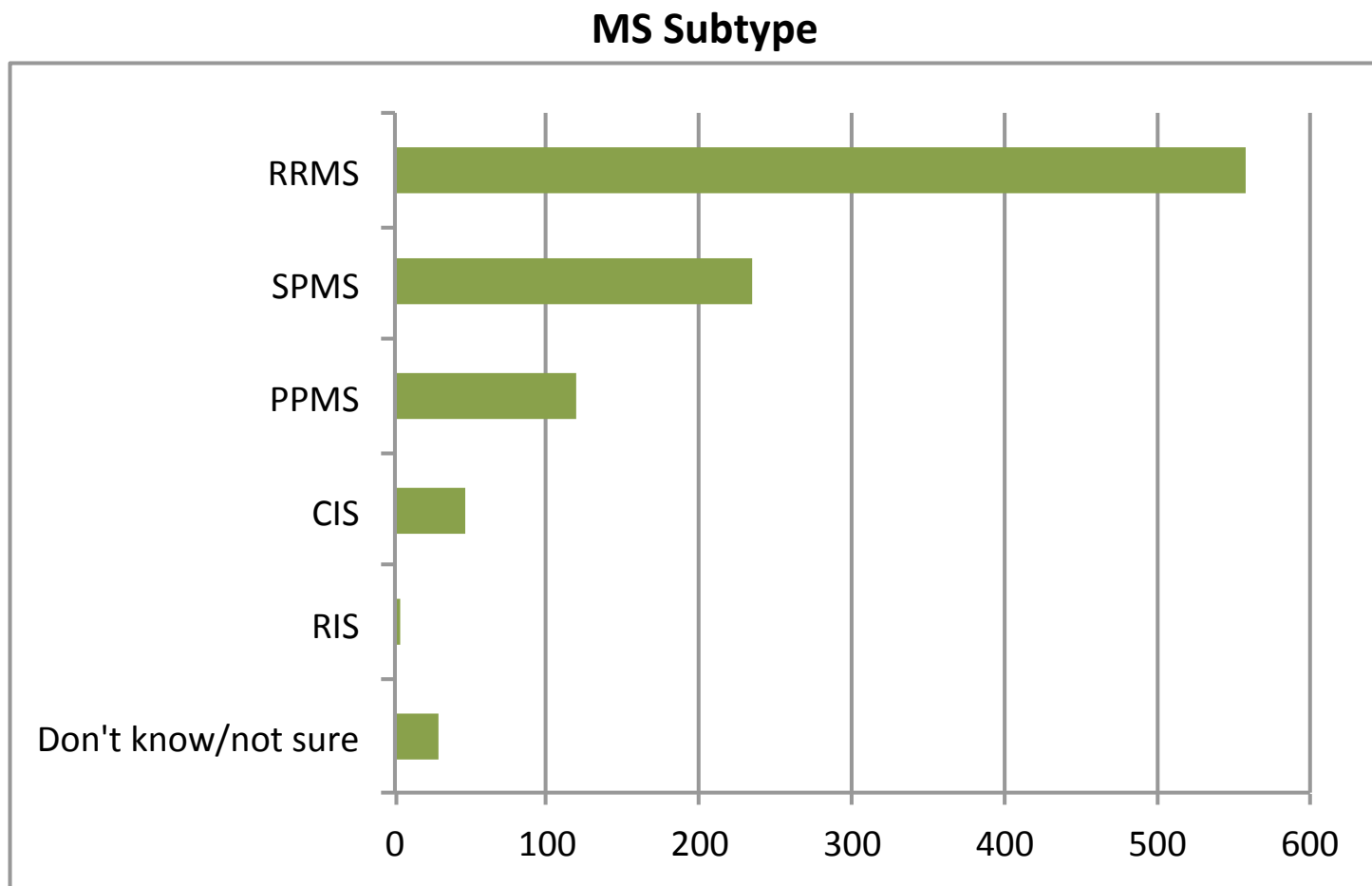
Snapshots of the iConquerMS™ community



Snapshots of the iConquerMS™ community



Snapshots of the iConquerMS™ community



What's Ahead for iConquerMS™?

What to expect in 2016 and beyond

- ▶ Growing numbers (2,500 -> 20,000) of patients
- ▶ More face-to-face events bringing patients and researchers together
- ▶ Increased number of collaborations with PCORnet partner networks (recruitment, research)
- ▶ Systematic biosample collection (pilot collection to be performed in 2015)

What to expect in 2016 and beyond

- ▶ Integration of digital monitoring data
- ▶ Linkage to providers for more facile EHR access
- ▶ Analysis of iConquerMS™ data integrated with data from other public/proprietary sources

iConquerMS™ welcomes collaborations

- ▶ To explore and join iConquerMS™, visit iConquerMS.org
- ▶ To contact us:
 - Email research@iConquerMS.org
 - Call 1-844-897-1211