



# Data Collection, Warehousing, Governance, and Sharing

*NHC CMO/CSO Meeting  
October 16, 2018*

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CEO, ACP & Co-PI iConquerMS™



*Accelerating MS Research*

## Background on Accelerated Cure Project

Founded in 2001

*Focus on accelerating research efforts to improve diagnosis, to optimize treatment and to advance cures for multiple sclerosis*

- ACP Repository program - since 2005
  - iConquerMS™ PPRN - since 2014
- } Resources for accelerating MS research



Feinstein Kean Healthcare  
An Ogilvy Company



iConquer MS™

## The MS People-Powered Research Network

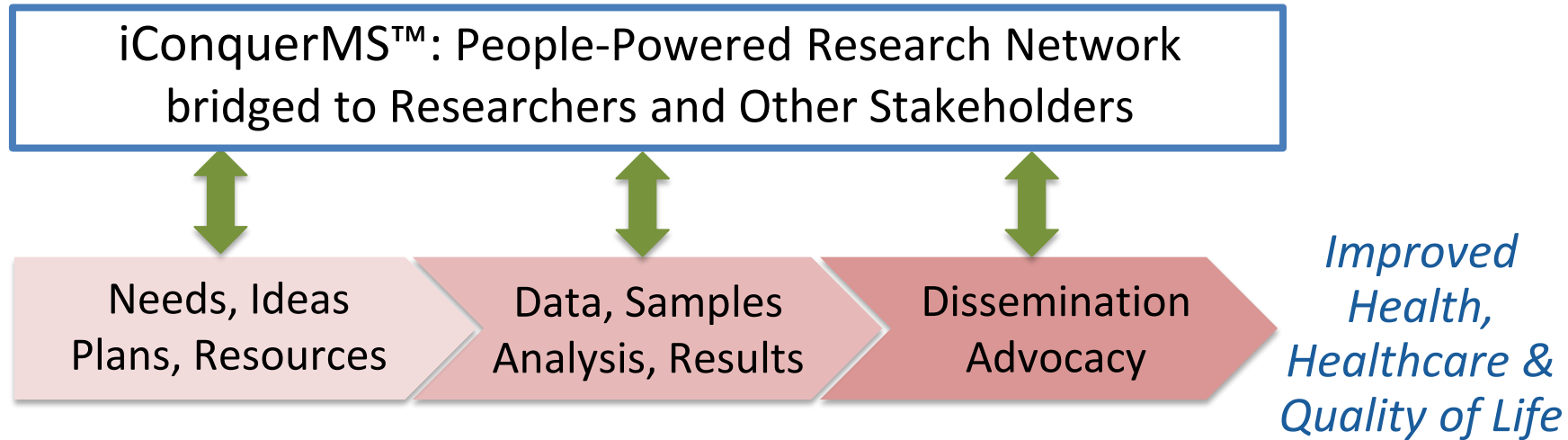
*To improve health, healthcare, and quality of life for people with MS by connecting those affected by MS, caregivers, clinicians, and researchers, and to work together to accelerate innovation, research, and the application of new knowledge.*

YOU?



## *iConquerMS™* - [www.iConquerMS.org](http://www.iConquerMS.org)

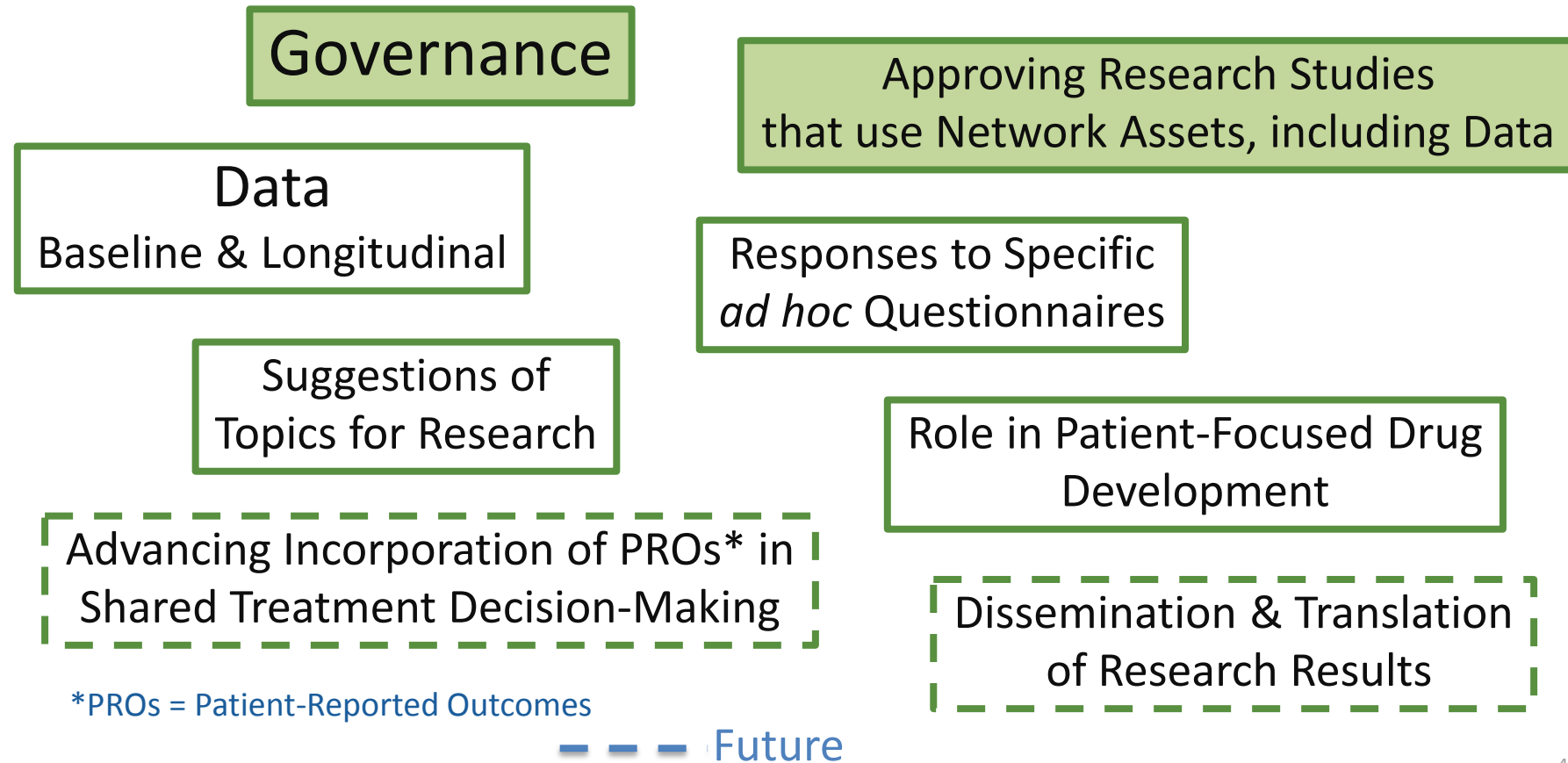
**Launched  
in Nov 2014**



- >4,600 registered participants, growing daily
- Established with funding from PCORI (PCORnet1.0)
- Governed by majority of PwMS - the experts
- Research portfolio developing rapidly

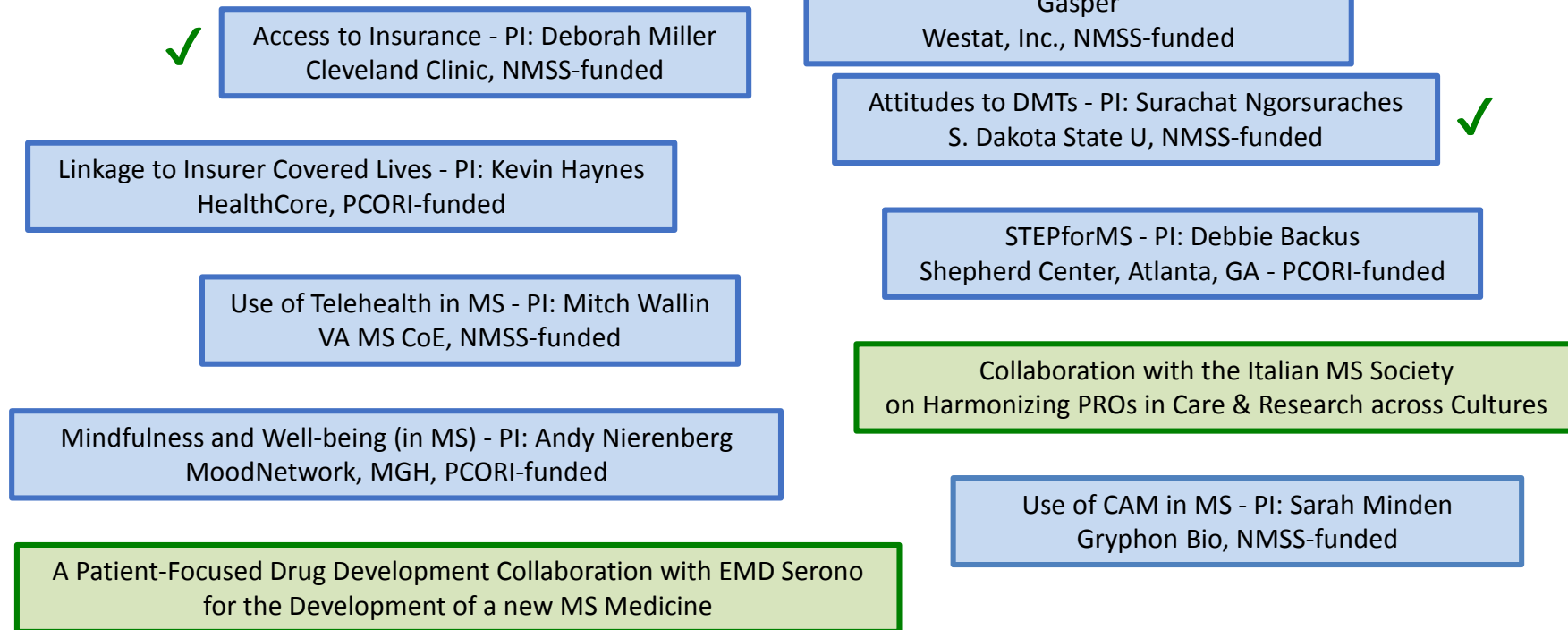
***OPEN SCIENCE  
driven by  
People with MS  
to accelerate MS research***

## A Unique Platform for the “Voice” of People with MS



## Collaborative Projects Achieve the PPRN's Purpose

✓ = completed



## *iConquerMS™ Participants Contribute Data Regularly (REAL MS™)\**

Survey	REAL MS™ Status
Demographics	Initial, S* 2016, W*&S 2017, W&S 2018
MS Characteristics	Initial, S 2016, W&S 2017, W&S 2018
Neuro-QoL Adult Short Form + 3 <sup>+</sup> (now called “Quality of Life”)	Initial, S 2016, W <sup>+</sup> &S 2017, W&S 2018
PROMIS® Global Health Survey (now called “Overall Health”)	Initial, S 2016, W&S 2017, W&S 2018
Physical Activity	S 2016, W& S 2017, W&S 2018
Other (Medical) Conditions	S 2016, W&S 2017, W&S 2018
Wellness & Diet	S 2017, W&S 2018
Patient Determined Disease Steps	W&S 2018

<sup>+</sup> added Bowel, Bladder and Vision from MSQLI

\* S=Summer, W=Winter

Ordinal Data’s  
CURE Platform:  
Cloud-based,  
open-source, data  
collection system  
developed first  
for NIH-NCI

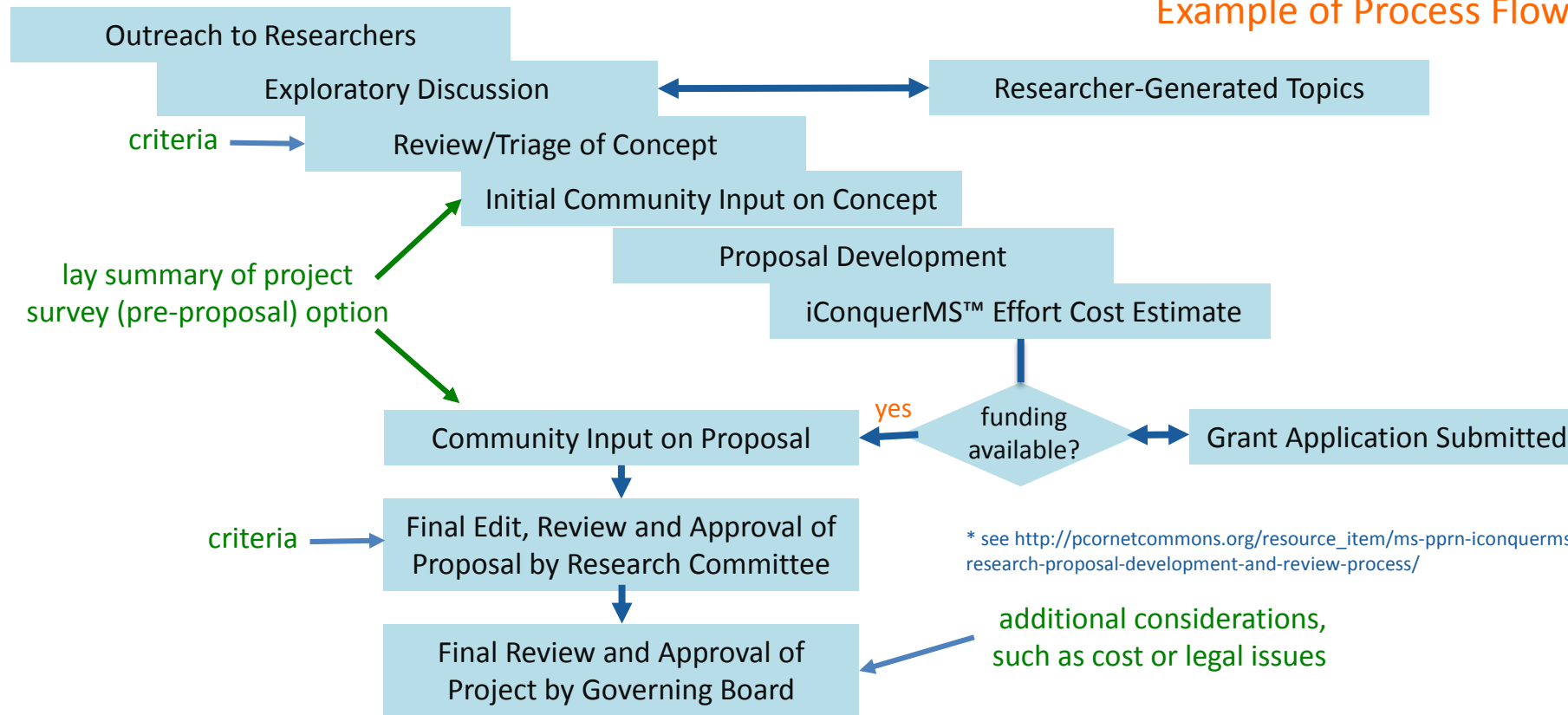
Utilizes Apache  
Fdn

CouchDB open  
source tools for  
dB management

\*Research Engagement  
About Life with MS

# Research Project Development, Review & Approval Process\*

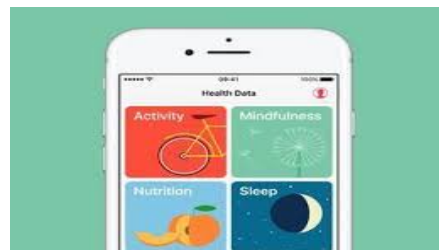
Example of Process Flow



\* see [http://pcornetcommons.org/resource\\_item/ms-pprn-iconquerms-research-proposal-development-and-review-process/](http://pcornetcommons.org/resource_item/ms-pprn-iconquerms-research-proposal-development-and-review-process/)

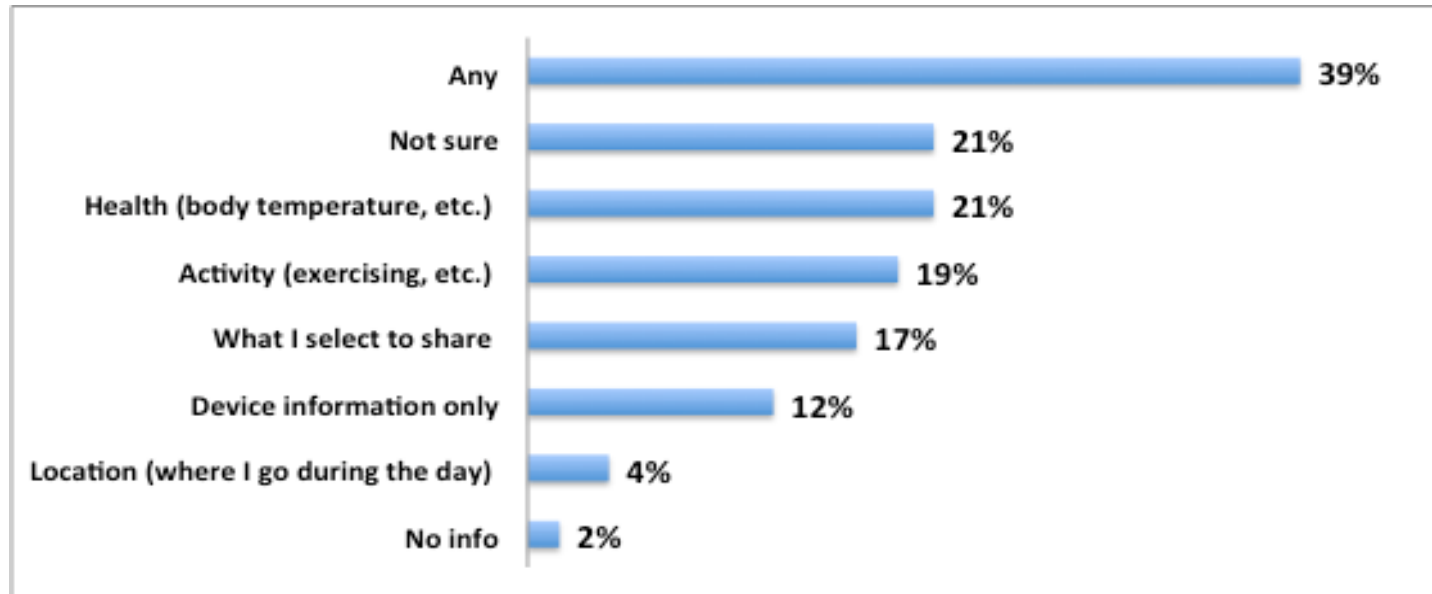


## *iConquerMS Survey: Sharing of Health Data (including sensor data)*

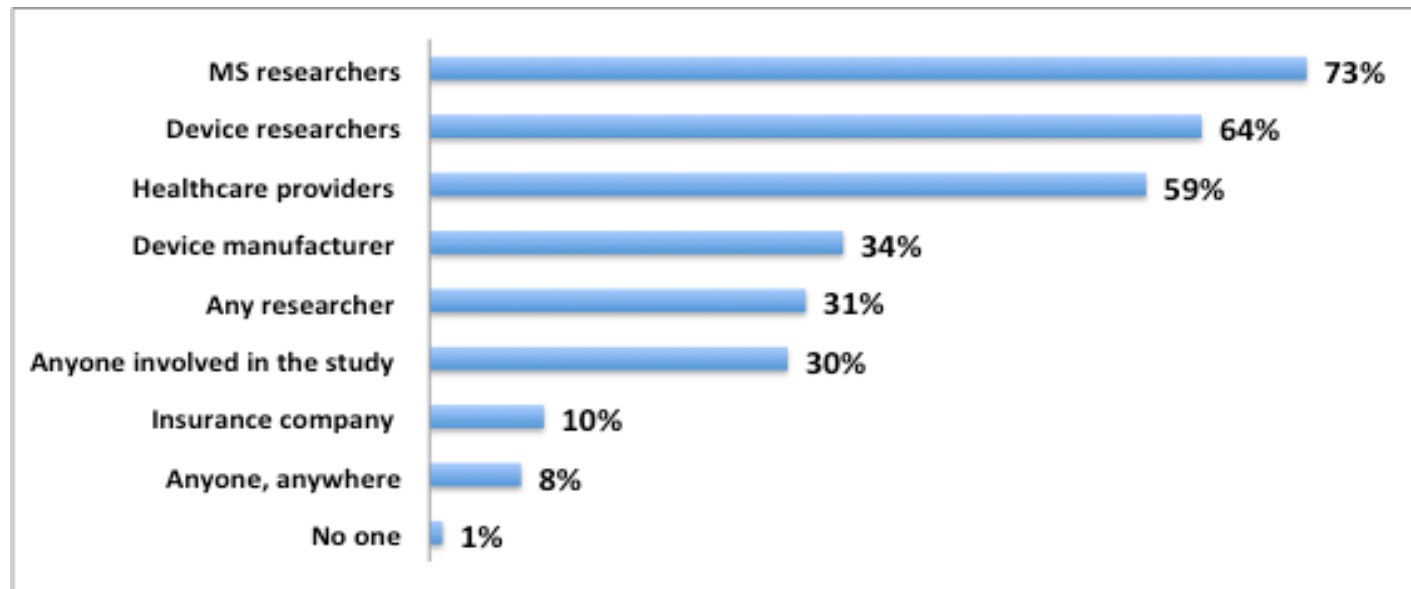


- 645 Respondents
- 3:1 Female:Male
- Ages 17 – 83, skewed slightly older than MS population
- Subtype:
  - 63% RRMS
  - 22% SPMS
  - 12% PPMS

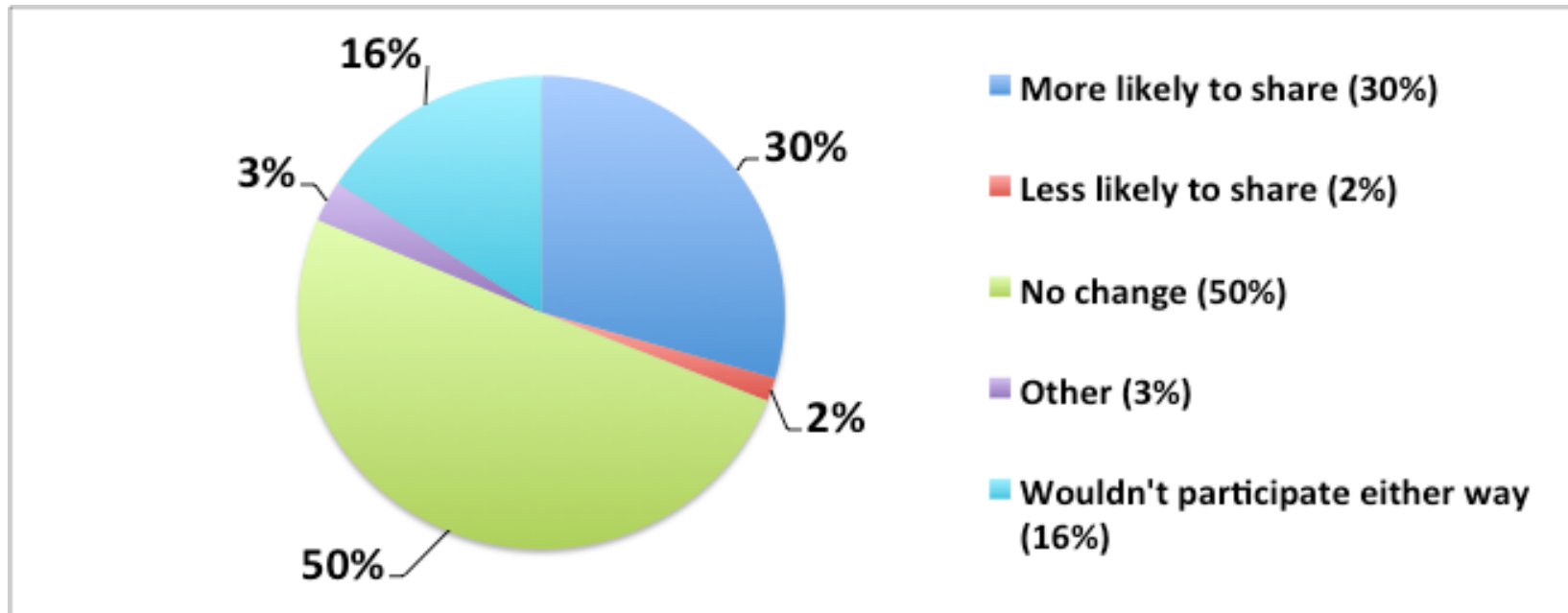
## 39% Ready to Share **Any** Data



# Who Are They Willing To Share With?



## *What If: Data Returned to Participant*



*What If: Data Returned to Participant - Selected Free Text Comments*

I would not agree to the device unless  
I had all available data from my  
device at my disposal. ALL DATA.

# Thank You

## iConquerMS™ Project Team

L. Kolaczowski (Co-PI)  
S. Loud  
H. Siefers  
H. Schmidt  
K. Buetow, ASU  
W. Tulsie, Ordinal Data  
L. Santiago  
M. Kean, FKH/Ogilvy  
K. Mulligan, FKH/Ogilvy  
R. McBurney



+ iConquerMS™ Governance

+ >4,600 MS Conquerors

## Research Project Review & Approval Process - Criteria\*

Criterion	Criterion Met Yes/No
<b>All Proposals</b>	
1. The research focuses on issues and concerns that are considered important by people with MS.	
2. The research proposal has been developed with input from people with MS. (If the original proposal from the researcher was not developed with input from people with MS, the researcher agreed to, and did, adequately incorporate the ideas and suggestions from people with MS into the final proposal.)	
3. The research has the potential to definitively answer an important question because the aims of the research and technical plan are scientifically rigorous.	
4. The required data is available or the required new data is feasible to collect.	
<b>Additional Special Consideration</b>	
5. Where the research leverages data from, or involvement of, other PCORnet partners, PCORnet partners have approved the research plan.	

\* see [http://pcorcommons.org/resource\\_item/ms-pprn-iconquerms-research-proposal-development-and-review-process/](http://pcorcommons.org/resource_item/ms-pprn-iconquerms-research-proposal-development-and-review-process/)