

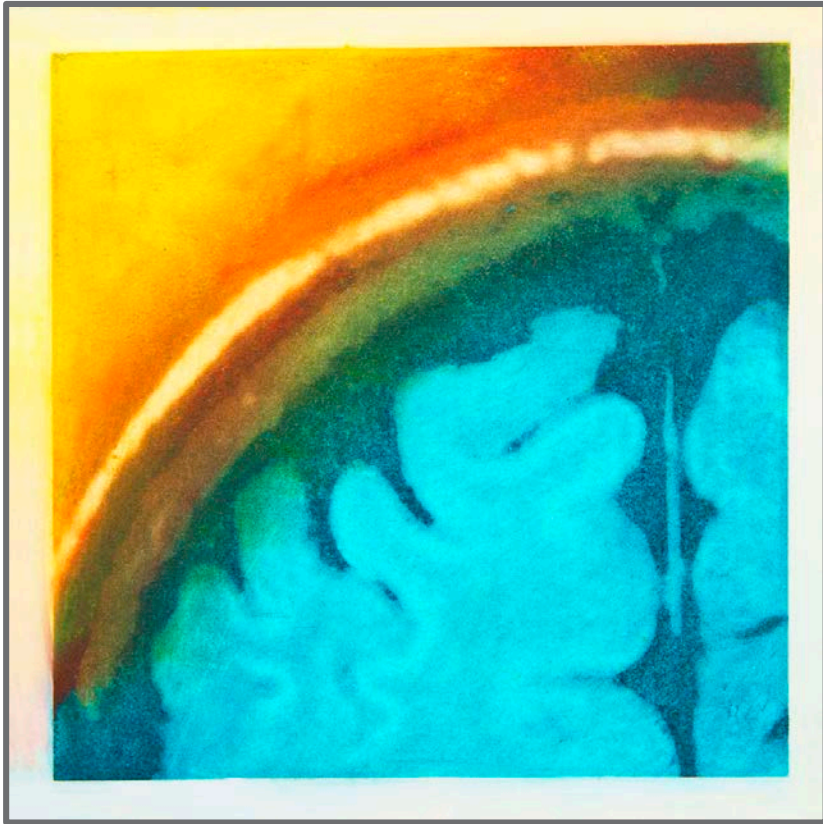
Breakthrough or Big Brother? Thoughts on Advanced Technologies and Data Sharing from the Multiple Sclerosis Community

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COO, Accelerated Cure Project*

Harnessing Mobile Technology to Predict, Diagnose, Monitor, and Develop Treatments for Nervous System Disorders

The National Academies of Sciences, Engineering, and Medicine
June 6, 2018

Multiple Sclerosis



Emerging by Elizabeth Jameson

- › Chronic neurological disorder
- › Most diagnosed ages 20-40
- › Subtypes:
 - Relapsing/Remitting
 - Secondary Progressive
 - Primary Progressive
- › Abundant Tx options, no guidance on selection

Accelerated Cure Project for MS

- › Patient-founded nonprofit
- › Mission: Accelerate research in MS to better diagnose, treat, and cure MS
- › Open-access resources available to researchers
- › ACP Repository: Biospecimens annotated with patient and clinical data



Carousel by Elizabeth Jameson

iConquerMS™: People-Powered Research



Celebration by Elizabeth Jameson

- › 4,600+ members
- › Open for research
 - REAL MS™ data
 - Prospective data/samples
- › Community engagement
 - Study design
 - Product design
 - Opinion/Experience/Perspective

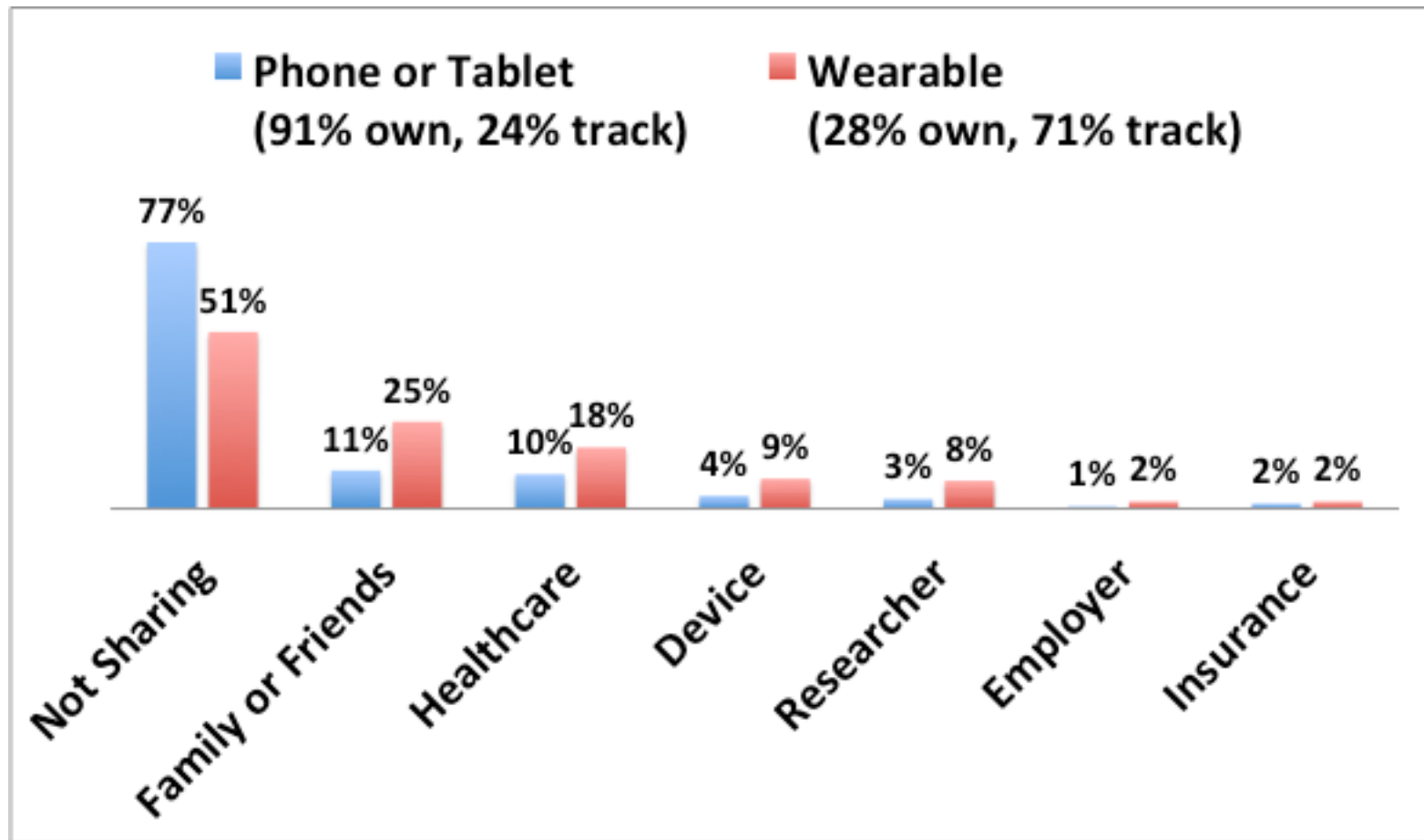
Survey: Sharing of Health Data



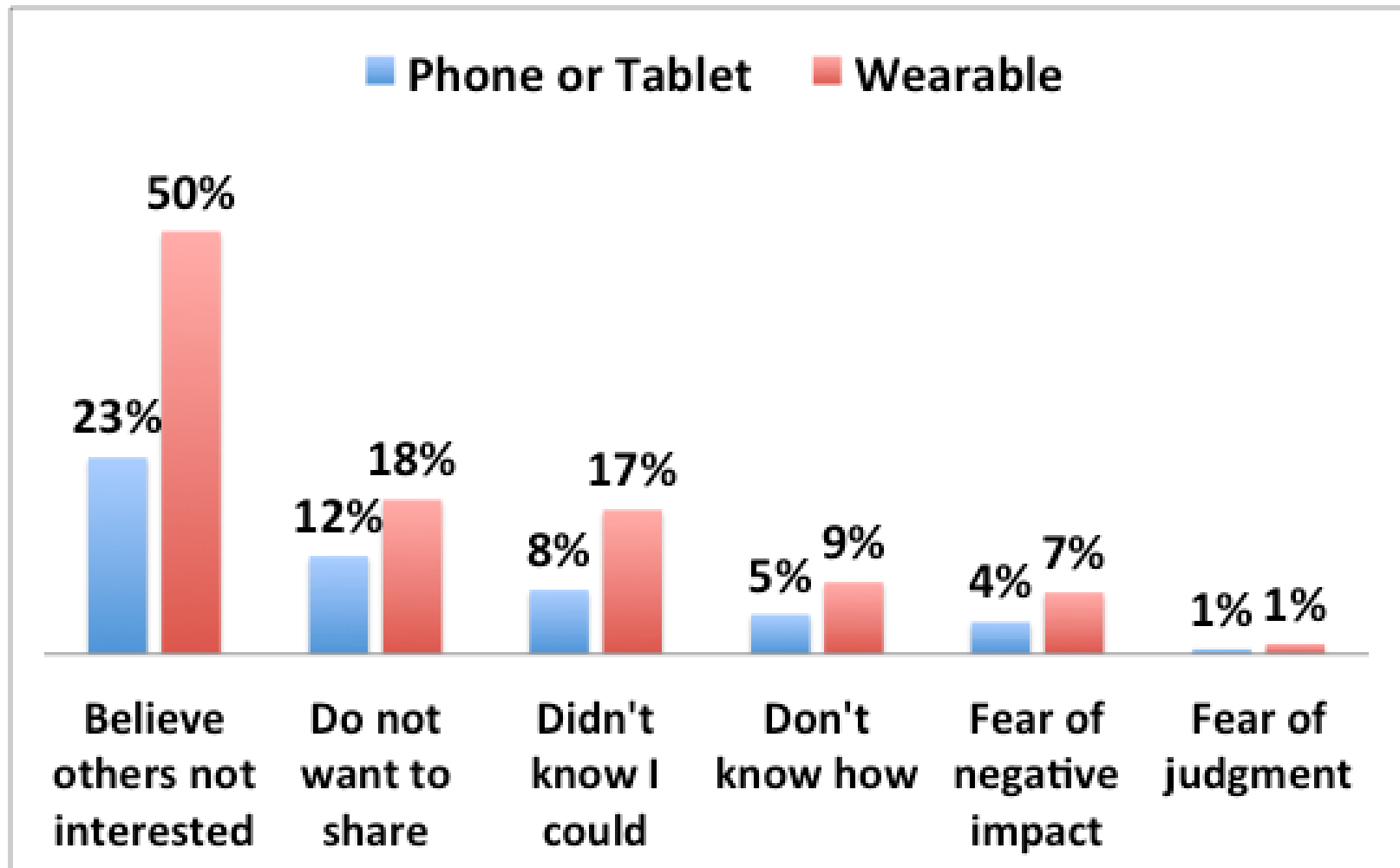
- 645 Respondents
- 3:1 Female:Male
- Ages 17 – 83, skewed slightly older than MS population
- Subtype:
 - 63% RRMS
 - 22% SPMS
 - 12% PPMS



Smartphones, Tablets and Wearables

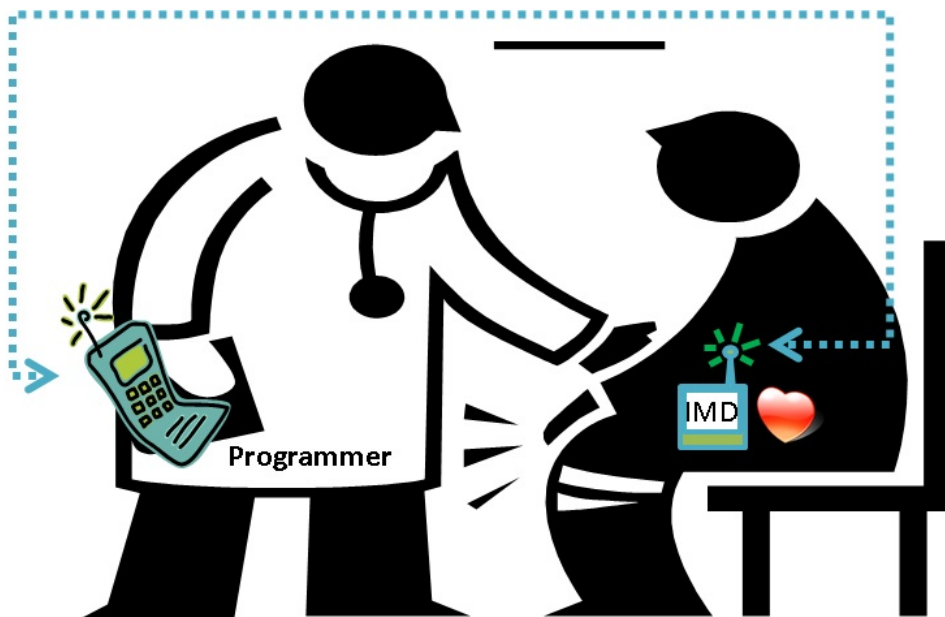


Why Not Share?



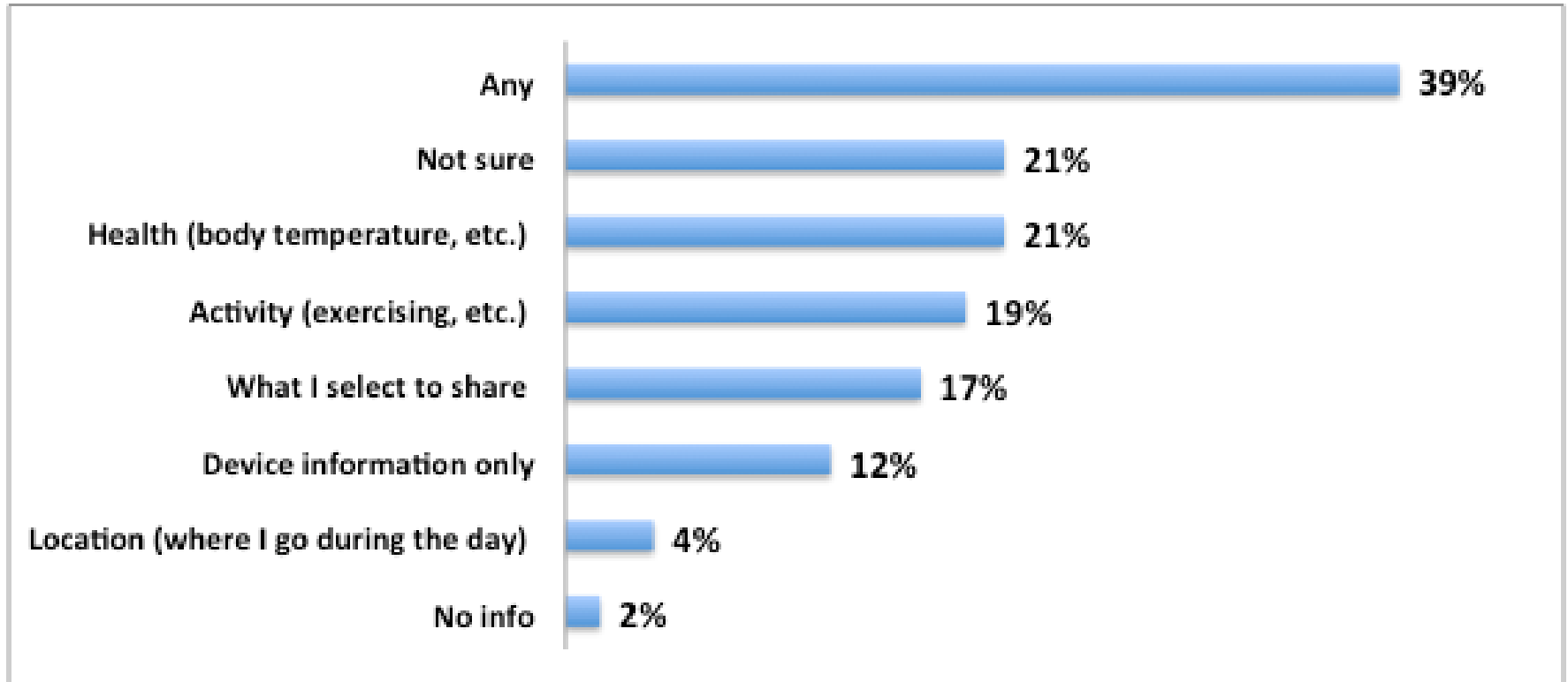
Implantable Device Scenario

- › Clinical trial
- › Implantable device that may help symptoms
- › Device would gather information beyond functionality (symptoms, health, activity, location, etc.)

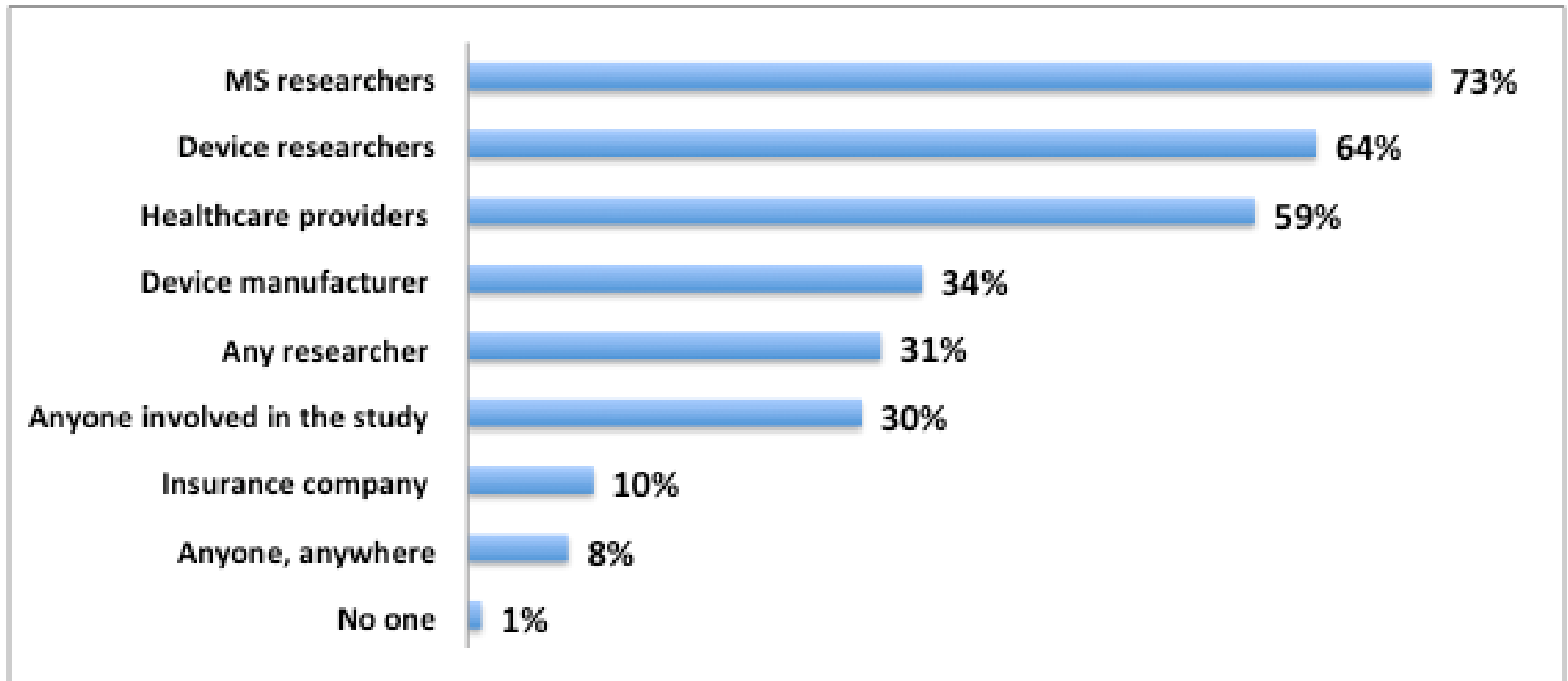


85% would consider

39% Ready to Share **Any** Data

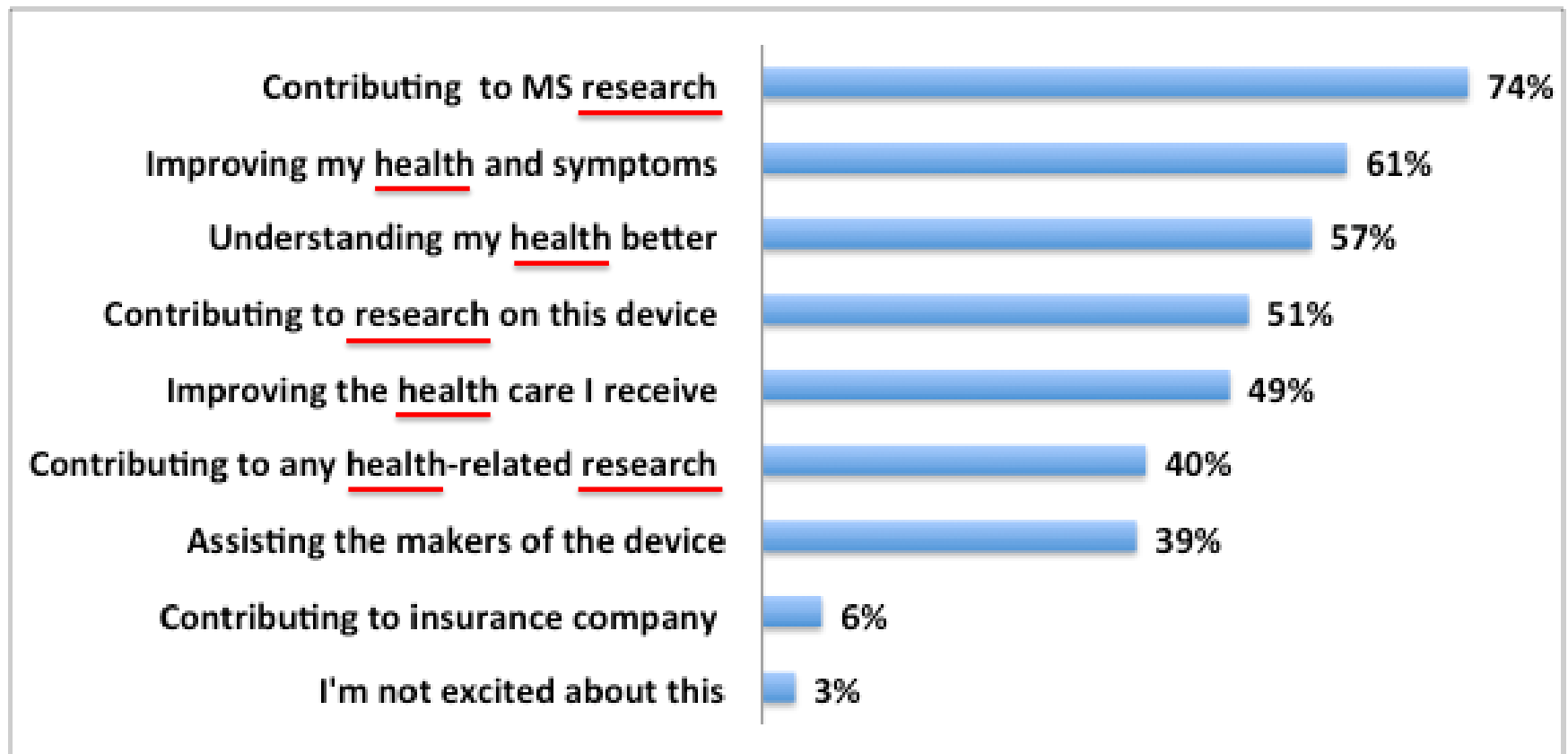


Who Are They Willing To Share With?

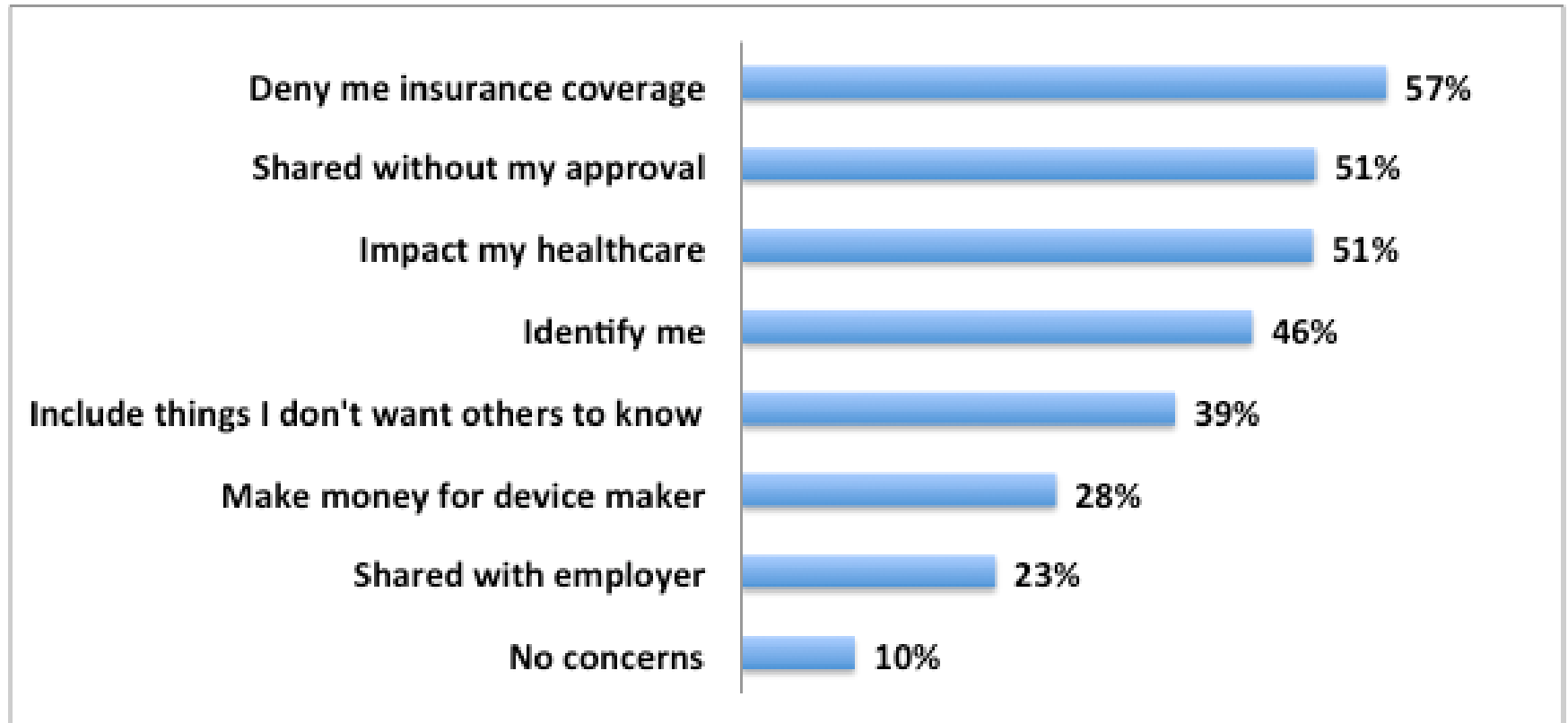


Share to drive research, improve health

What's **Exciting** About This?

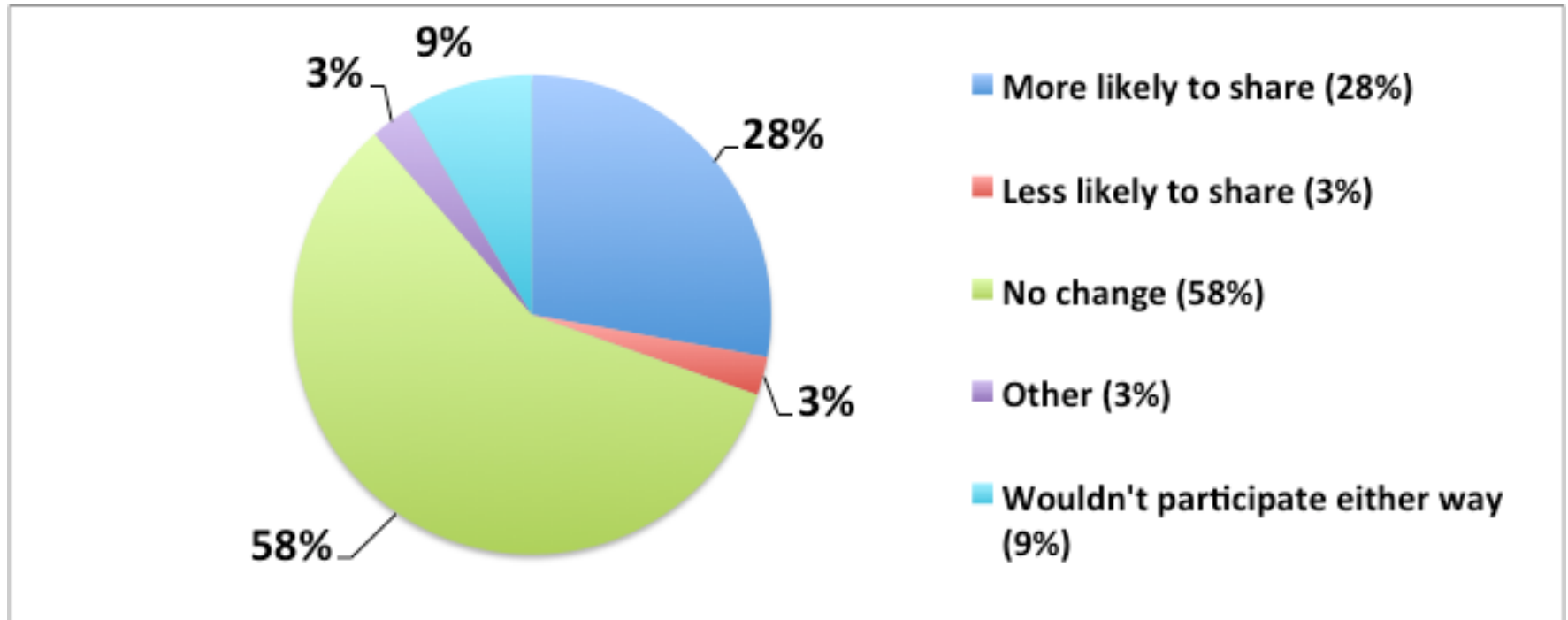


What's **Concerning** About This?



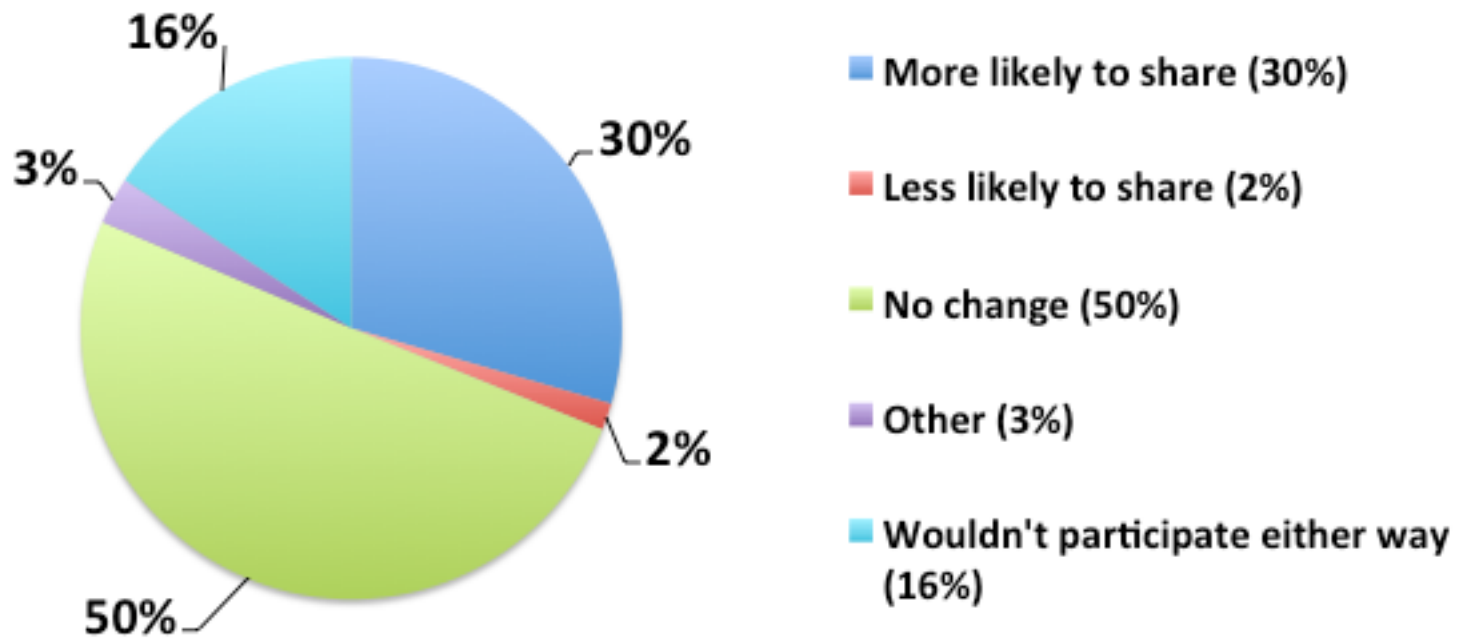
**Loss of coverage (insurance, healthcare) and
privacy**

What Ifs: Wearable not Implant



Concerns: Reliability of device; accuracy of data

What Ifs: Data Return to Participant



What Ifs: Data Return to Participant

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

Protection, Selection, Access

- › Majority ready and willing to share at least some of **their** data
 - Remember who it belongs to
 - Protect it from misuse
- › Participants want
 - their data **protected**
 - to **have a say** in who receives it
 - to have **meaningful access** to it themselves

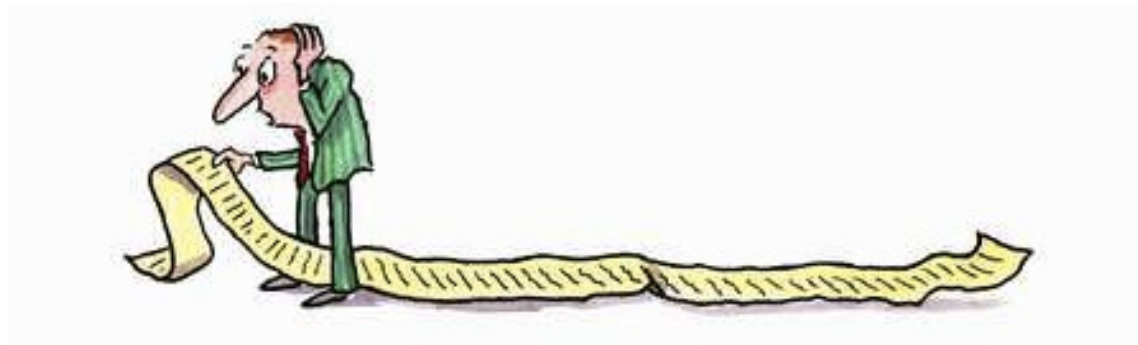


- › Motivations
 - Disease specific and general research
 - Improving own health

Study Design: Communications and Tools

› Study design

- Consent:
 - Clear language
 - Tiered approval
- Technology:
 - eConsent
 - Selective sharing
 - Data return to participant



Data Return – Participant & Provider

- › Understandable
- › Meaningful
- › Actionable
- › Accessible



Some Questions

- › Co-design/study design
- › Communications
- › Technology
- › Engagement – participant and provider
- › Data return



iConquerMS: How Can We Help?

- › Bridge to the MS community
- › Accelerate research
- › Engagement model for other diseases



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iConquerMS™