

Patient voice: from anecdote to valued data source

- Historically, patient input was largely viewed as non-essential to discovery, research and care delivery
- Today, the demand for patient voice is accelerating rapidly across all sectors of the health system
- In 2004 PatientsLikeMe set out to improve the lives of patients through new knowledge derived from shared real-world experiences and outcomes.
 - We've shown that patient voice can be meaningfully collected, aggregated, and measured...and then methodologically analyzed, understood and used for research, safety and care
 - We've translated more than 30 million structured patient generated data points into clinically relevant concepts
 - We've created a repository of 90 open access literature and scientific posters sourced directly from patient generated data

Creating value with standards, methods, give back

- Study patient data characteristics to better understand how it compares to other sources
- Identify and elevate best practices for patient-centric data collection models
- Socialize a patient-centric 'give-back' strategy into research protocols
- Convert data into actionable information useful as complimentary source of real world evidence
- Publish in literature to advance knowledge base
- Establish patient data as contributor to learning health system

Social Networking Sites and the Continuously Learning Health System: A Survey

U.S. Adult Social Media Users:

Willing to Share Health Data, Despite Potential Risks ...

94%

agree with sharing their health data to help doctors improve care.

94%

with a medical condition would be willing to share their health data to help doctors improve care, with appropriate anonymity. The same proportion (94%) would be willing to do this to help other patients like them.

92%

with a medical condition agree with sharing their health data to help research.

92%

with a medical condition would be willing to anonymously share health data for researchers to learn more about their disease. **84%** would be willing to share such information with drug companies to help them make safer products, and **78%** would do so to let drug companies learn more about their disease.

94%

agree with sharing their health data to help patients like themselves.

94%

believe that their health data should be used to improve the care of future patients who may have the same or similar condition.

76%

worry that health data that they share may be used in detrimental ways.

76%

with a medical condition believe that data from their personal health record could potentially be used without their knowledge, **72%** to deny them health care benefits, and **66%** to deny them job opportunities.

Discussion Paper

Authored by members from IOM Evidence Communication Innovation Collaborative*

Survey of 2,125 PLM members:

- 94% willing to share health data to help doctors improve care
- 94% willing to help other patients like them
- 92% willing to help researchers learn more about their disease
- Yet, despite worries that their health data may be used without their knowledge 94% still believed that their health data *should* be used to improve care of future patients who might have the same or similar condition.

*Grajales, F., D. Clifford, P. Loupos, S. Okun, S. Quattrone, M. Simon, P. Wicks, and D. Henderson. 2014. Social networking sites and the continuously learning health system: A survey. Discussion Paper, Institute of Medicine, Washington, DC.