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

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.