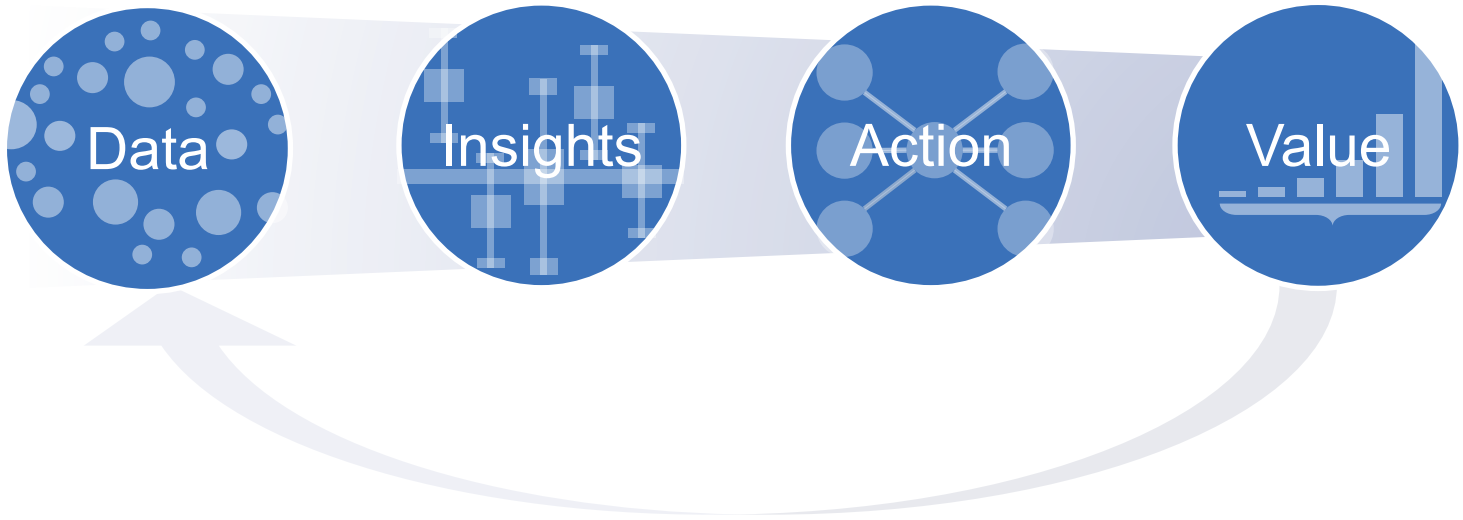
Bedside to Bench…

From *My Data* to *Our Data* to *Big Data*



March 23, 2015

Harvard Catalyst: ReSourcing Big Data

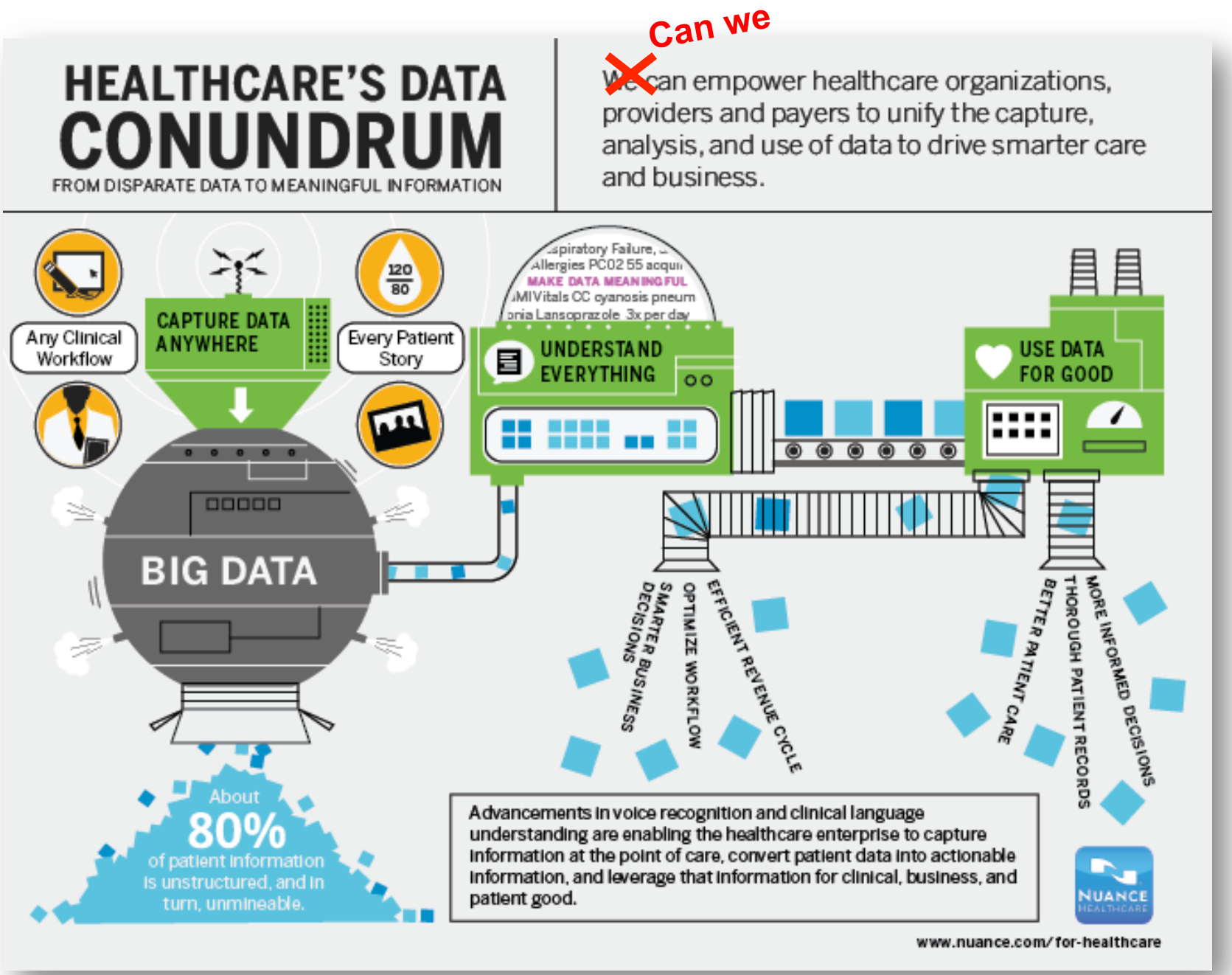
While the stethoscope was in common use in 1918 many doctors still relied on traditional methods to diagnose their patients.

Credit: National Library of Medicine

What a difference a century makes…

Health 2.0 's Worldview

Source: http://www.health2con.com/news/2014/08/07/the-old-world-the-new-empire-of-enterprise-health-it/

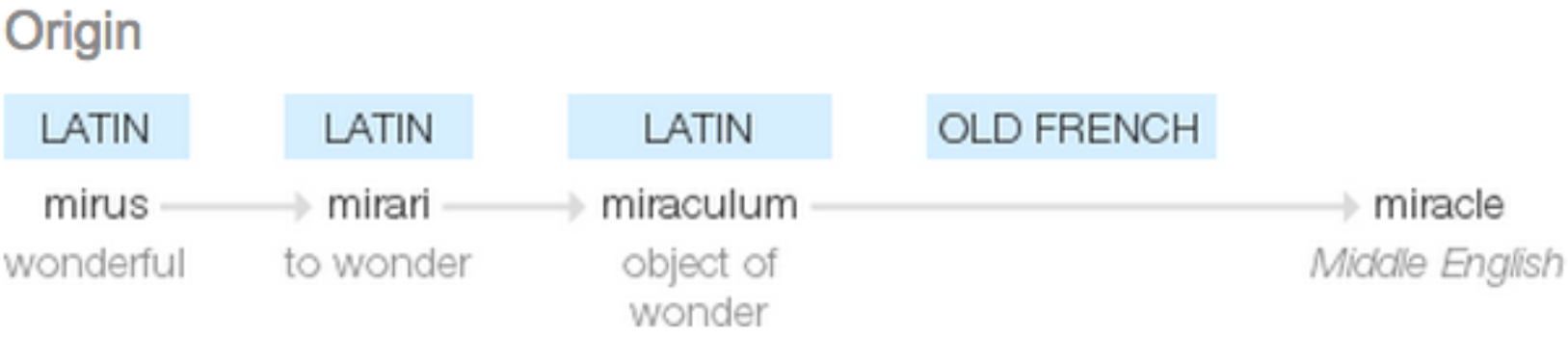

HEALTHCARE'S DATA
CONUNDRUM
FROM DISPARATE DATA TO MEANINGFUL INFORMATION
Can we
We can empower healthcare organizations, providers and payers to unify the capture, analysis, and use of data to drive smarter care and business.
Any Clinical Workflow
CAPTURE DATA ANYWHERE
120
80
Every Patient Story
MAKE DATA MEANINGFUL
UNDERSTAND EVERYTHING
USE DATA FOR GOOD
BIG DATA
SMARTER BUSINESS DECISIONS
OPTIMIZE WORKFLOW
EFFICIENT REVENUE CYCLE
BETTER PATIENT CARE
THOROUGH PATIENT RECORDS
MORE INFORMED DECISIONS
About 80% of patient information is unstructured, and in turn, unmineable.
Advancements in voice recognition and clinical language understanding are enabling the healthcare enterprise to capture information at the point of care, convert patient data into actionable information, and leverage that information for clinical, business, and patient good.
NUANCE HEALTHCARE
www.nuance.com/for-healthcare

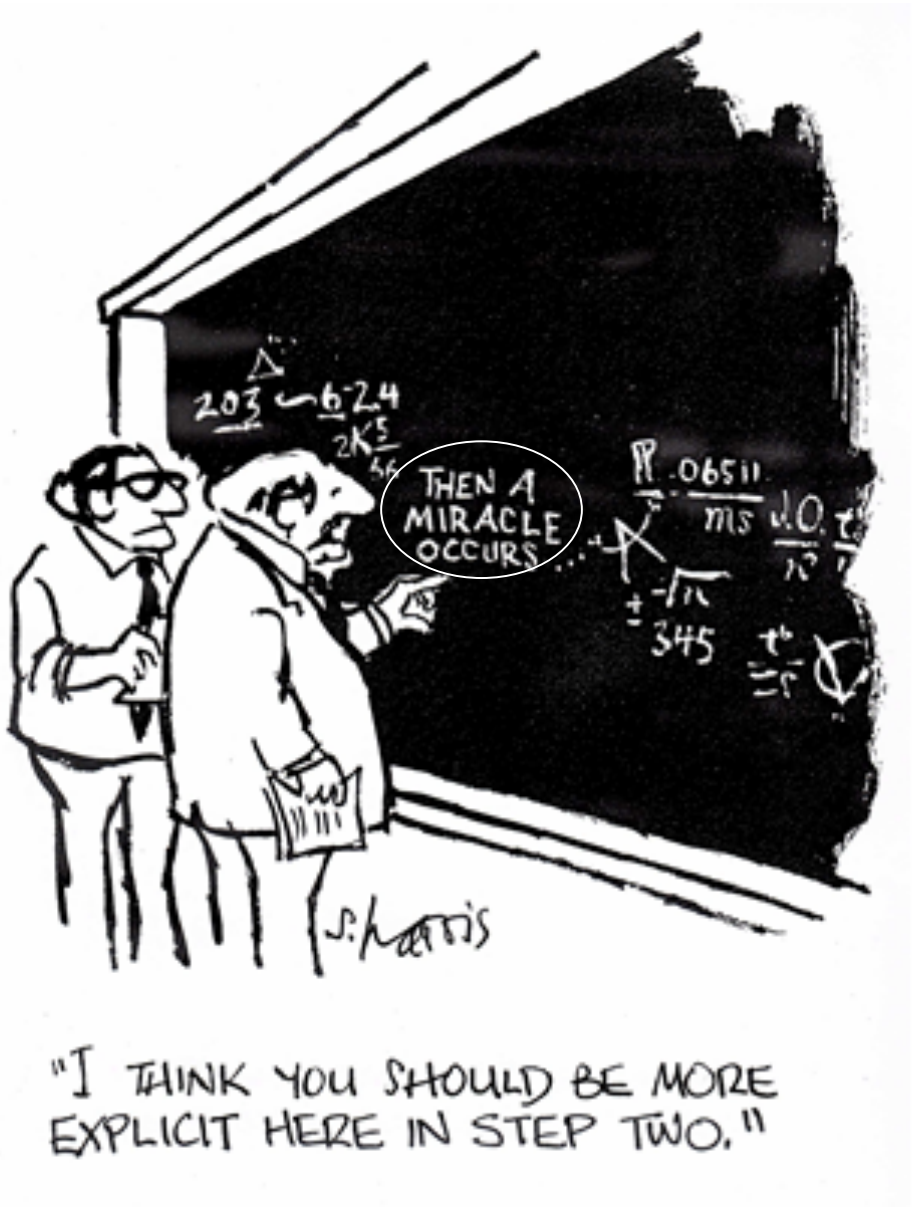
Google
facebook
FINANCIAL TIMES

mir·a·cle *n.*

1. a surprising and welcome event that is not explicable by natural or scientific laws

2. a highly improbable or extraordinary event, development, or accomplishment that brings welcome consequences



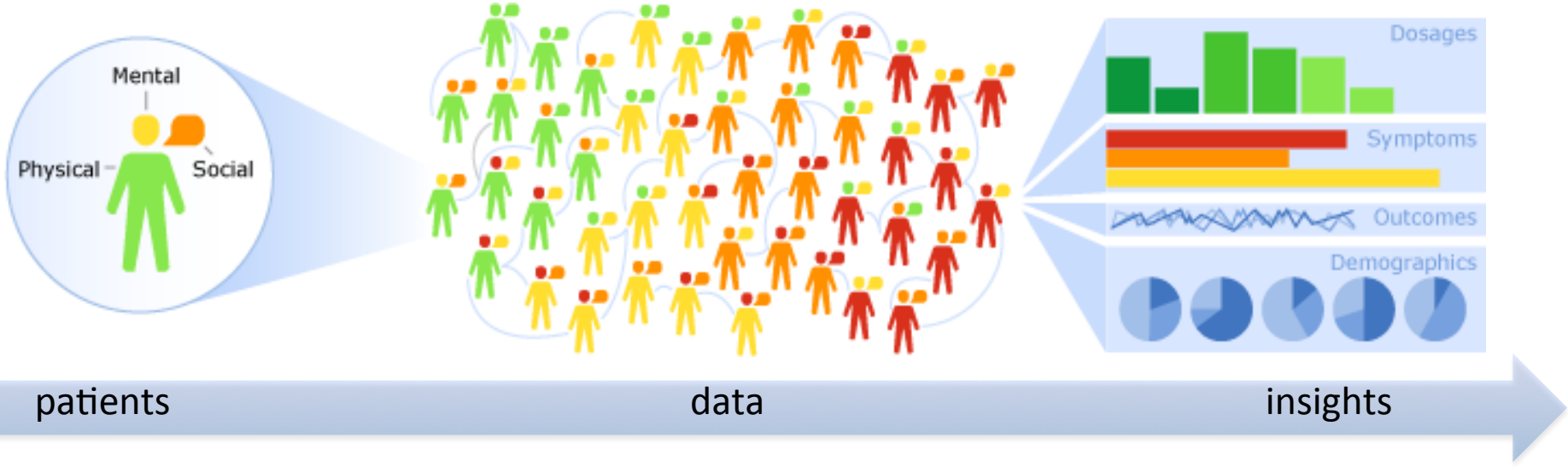


Moving knowledge from bedside to bench…

…behind every bit of data is a person's story

From “my story, my data” to “our data, our insights”

Given my status what’s the best outcome I can hope to achieve & how do I get there?



- 320,000 + Patients
- 2300 + Diseases

- Every minute a patient adds data
- 25 million structured data points
- 2 million free text fields

- 50+ peer-reviewed papers
- Patient vocabulary
- Drug safety monitoring
- PRO creation platform

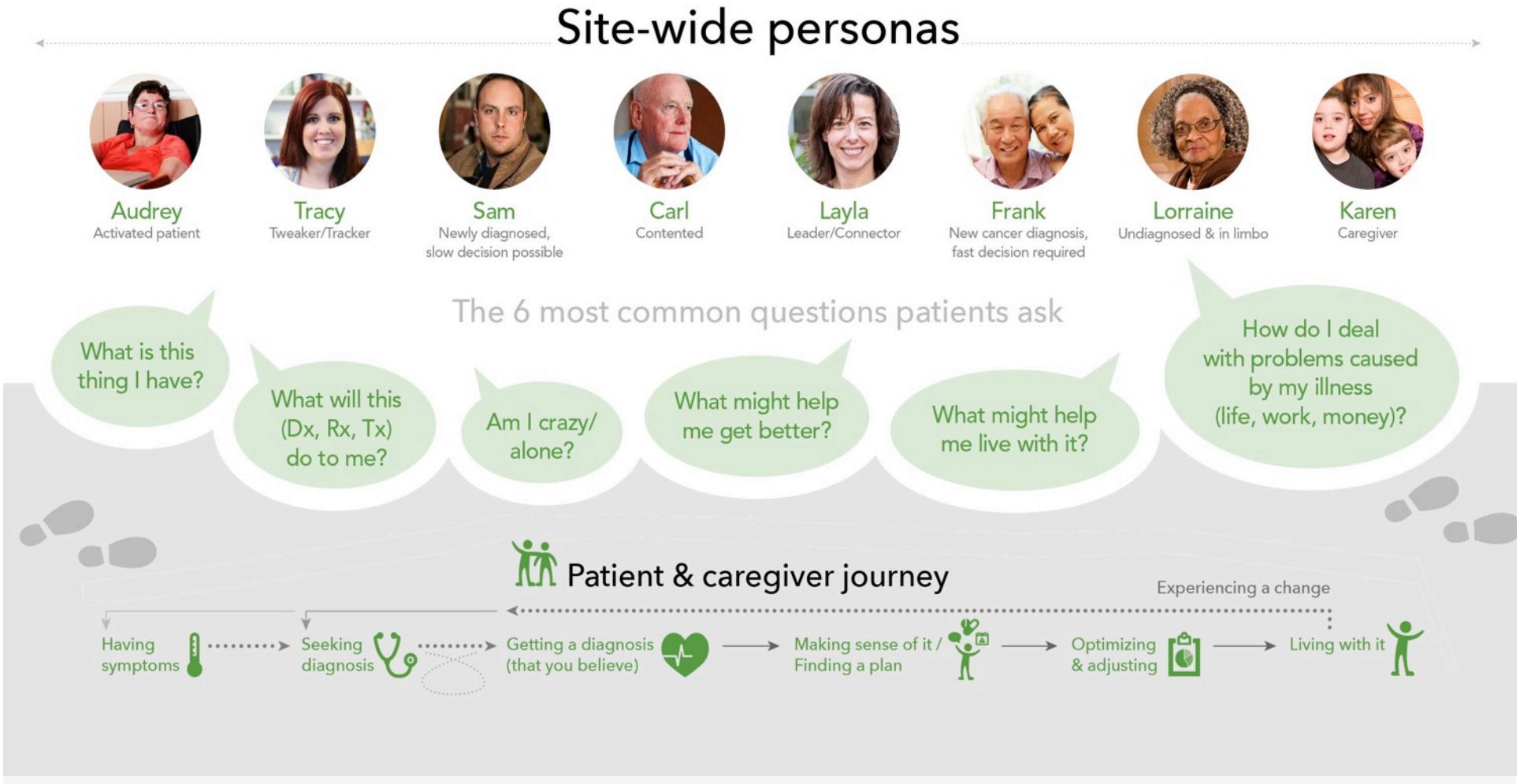
Transforming “my” story into “our” data…

Different collection methods provide different opportunities

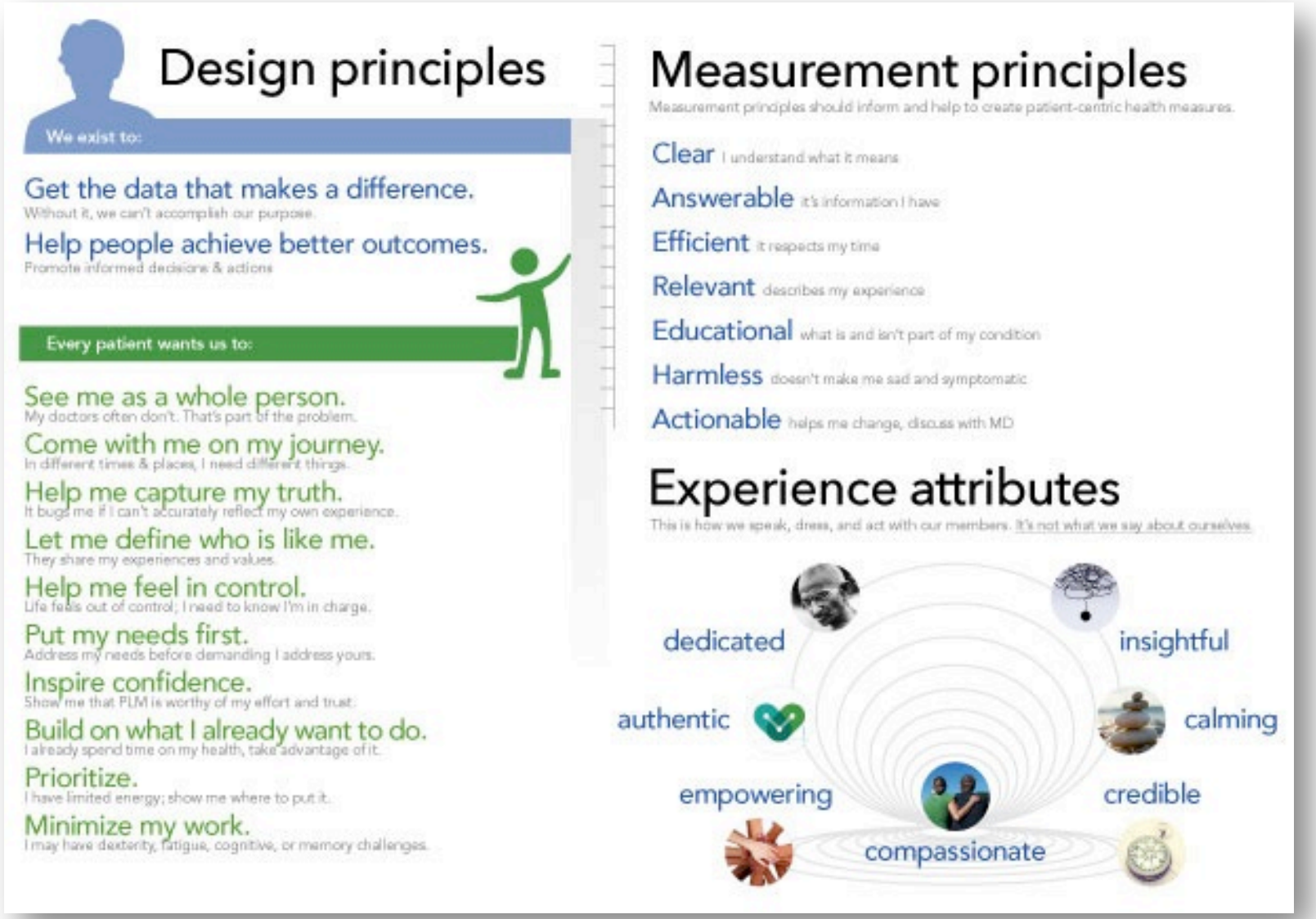
Sources of Data	Hypothesis Generation	Hypothesis Testing
Profile Data – breadcrumbs of site usage		
➢ Structured – condition history, symptoms, treatment evaluations, PROs,	✖	
➢ Unstructured – Journal feeds, Forum posts, annotations	✖	
Survey Data – developed to answer specific research questions		
➢ Multiple choice		✖
➢ Open text fields		✖
➢ Profile pull through (i.e. basic demographics)		✖
➢ External pull through (i.e. EQ5D		✖

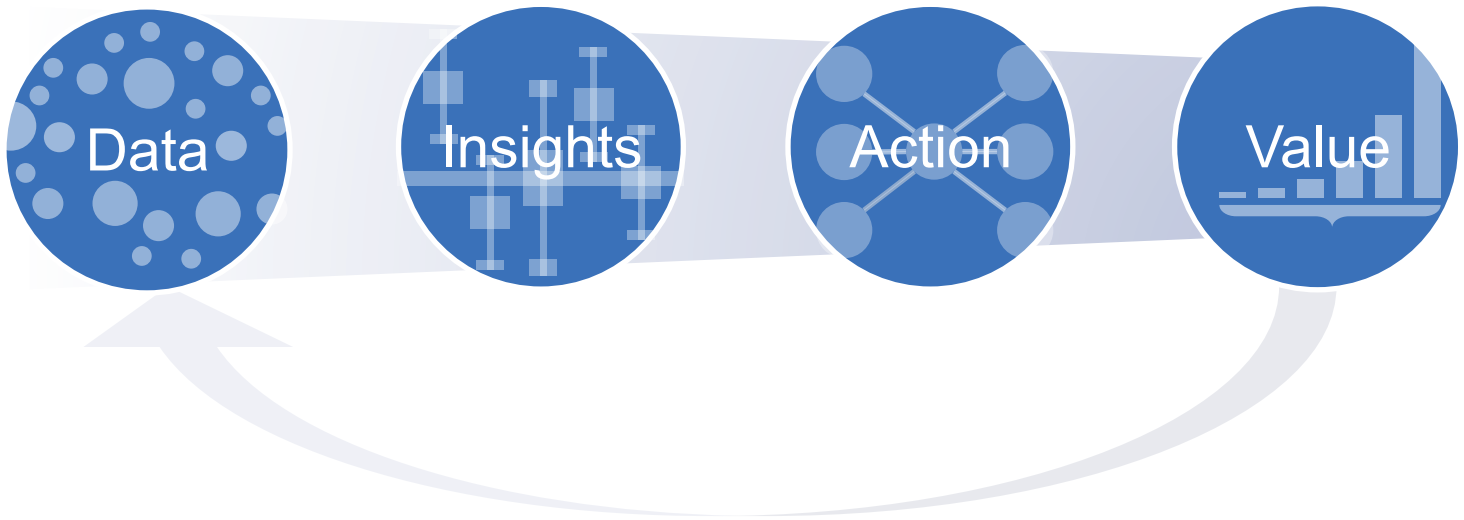
Personas add context, perspective, nuance…

We mapped the patient / caregiver journey to identify key personas, including their characteristics and most commonly asked questions



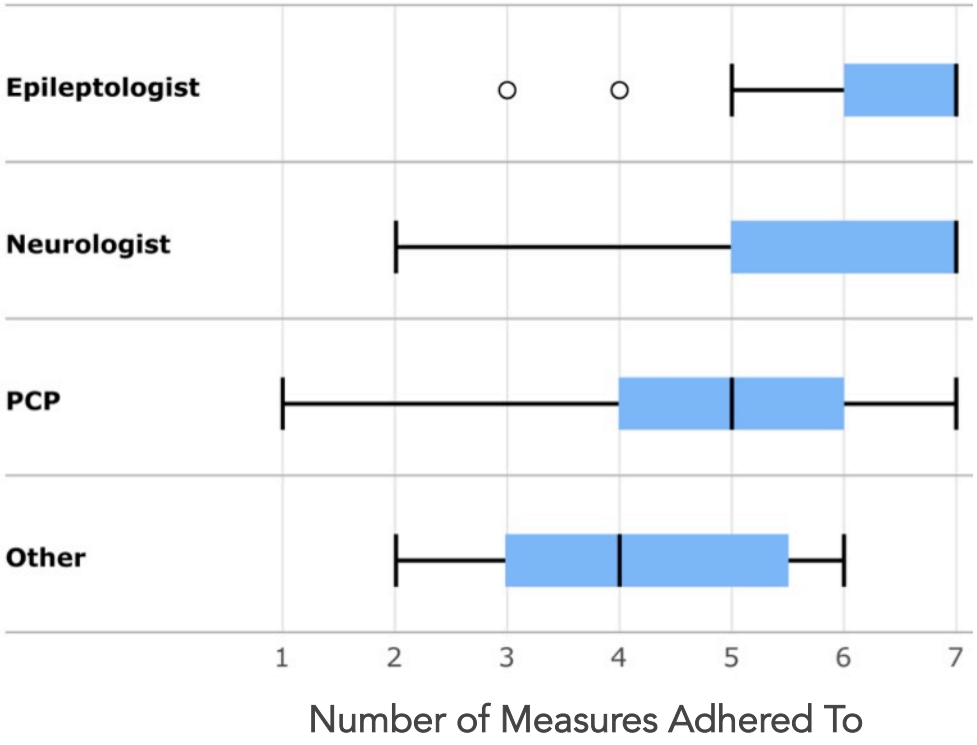
Patient-centric function, form and fit for purpose…





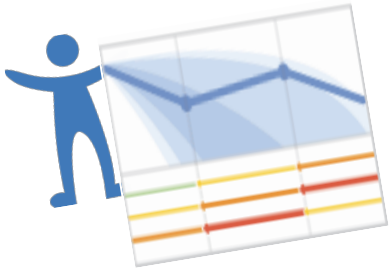
Continuous learning from bedside to bench…

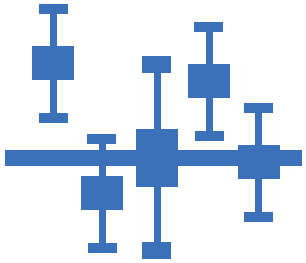
Patient insights on care quality



- Adapted AAN's epilepsy quality measures to self-report instrument
- Significant differences between MD types
- Identified gaps around side effect management, surgery referral, reproductive issues in women
- Fed into NQF, lead to changes in neurology training
- Letitia's story: n of 1 life changing results

Patient insights on sleep





Core dataset:

225,000+ total members with **~16MM+** data points

63,000+ reported on insomnia as a symptom **184K+** reports

70%+ have had moderate/ severe insomnia

~83K forum posts – free text mentioning sleep/insomnia

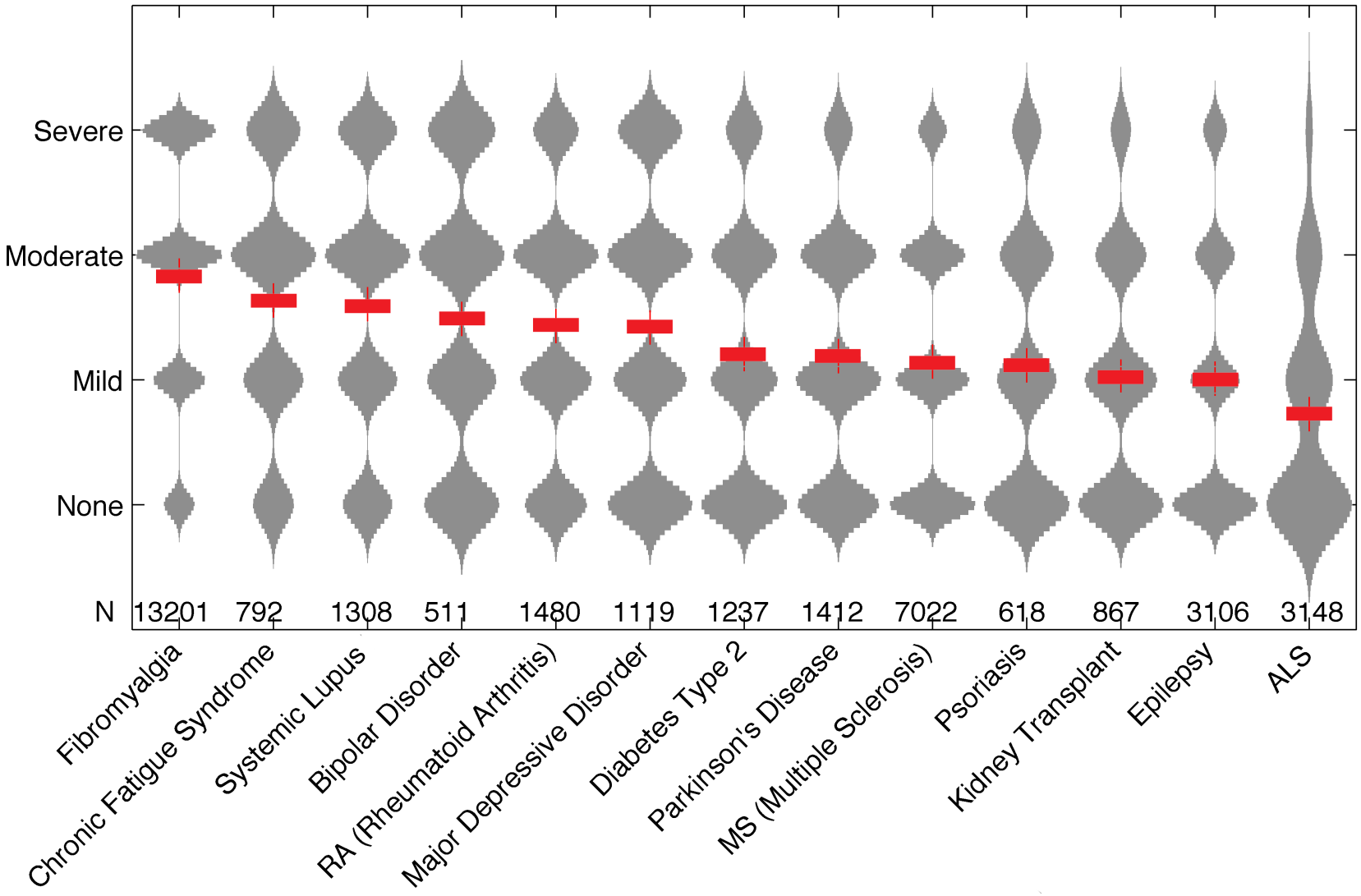
Rapid Research:

90 question survey taken by **5256** members in 2 weeks

Patient insights compared to general population

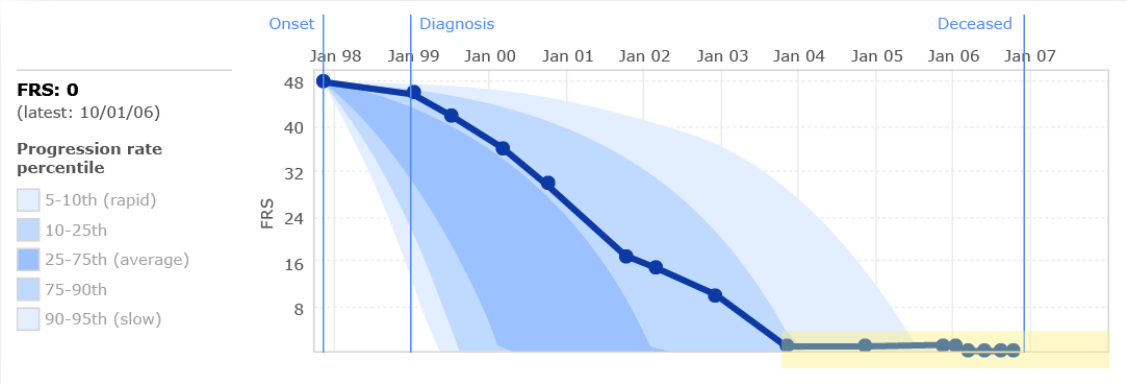
* National Sleep Foundation 2005 Sleep in America Poll
** PatientsLikeMe 2013 Sleep Survey US Population only

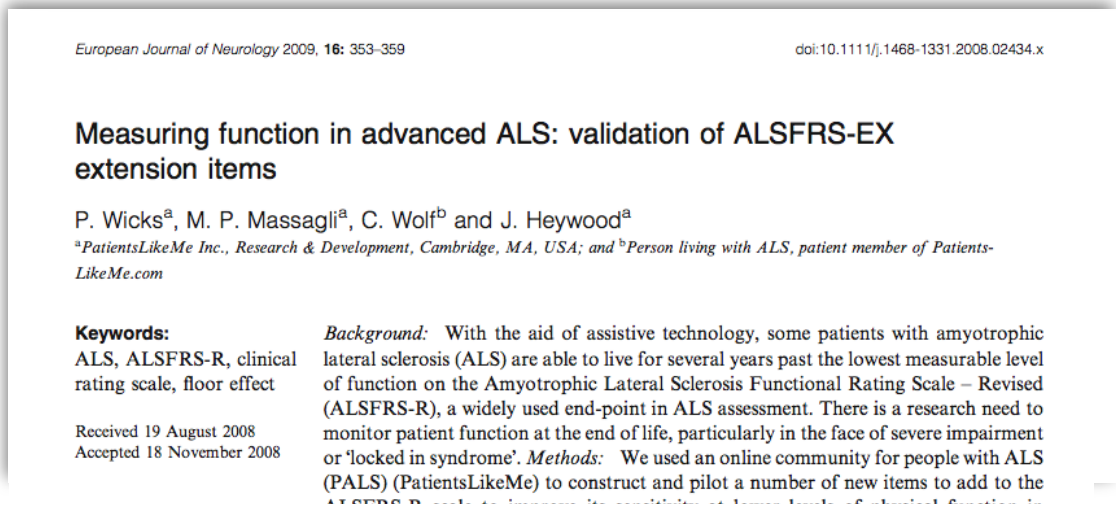
Patient insights about sleep variation by condition



Patient insights on measurement

Floor effect of measure excluded PALS using assistive technology





European Journal of Neurology 2009, **16:** 353–359 doi:10.1111/j.1468-1331.2008.02434.x

Measuring function in advanced ALS: validation of ALSFRS-EX extension items

P. Wicks[a], M. P. Massagli[a], C. Wolf[b] and J. Heywood[a]

[a]*PatientsLikeMe Inc., Research & Development, Cambridge, MA, USA; and* [b]*Person living with ALS, patient member of PatientsLikeMe.com*

Keywords:
ALS, ALSFRS-R, clinical rating scale, floor effect

Received 19 August 2008
Accepted 18 November 2008

Background: With the aid of assistive technology, some patients with amyotrophic lateral sclerosis (ALS) are able to live for several years past the lowest measurable level of function on the Amyotrophic Lateral Sclerosis Functional Rating Scale – Revised (ALSFRS-R), a widely used end-point in ALS assessment. There is a research need to monitor patient function at the end of life, particularly in the face of severe impairment or 'locked in syndrome'. *Methods:* We used an online community for people with ALS (PALS) (PatientsLikeMe) to construct and pilot a number of new items to add to the

- ALSFRS-R not sensitive enough to capture function in advanced ALS
- 200+ patients engaged in study to construct and pilot a new, more sensitive instrument
- 3 new items selected to be included in the new ALSFRS-EX measure
- In use by VA biobank and academic studies

Patient actions and insights challenge trial results

_computational BIOLOGY ANALYSIS

Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm

Paul Wicks, Timothy E Vaughan, Michael P Massagli & James Heywood

Mathematical description of algorithm. We developed an algorithm to minimize the area between the FRS progression curves of patients and controls over the entire course of the disease (before lithium start). The area is illustrated in **Figure 1c**.

1. Define t_0 as the lithium start date of the patient who took lithium.
2. Determine the patient's FRS at twice-monthly intervals t_i before their study start date (linearly interpolating if necessary), back to time of onset. These are FRS_i.
3. For each control, define their t_0 as one of their reported FRS dates, and determine FRS_i as above.
4. For each patient-control pair, calculate the area:

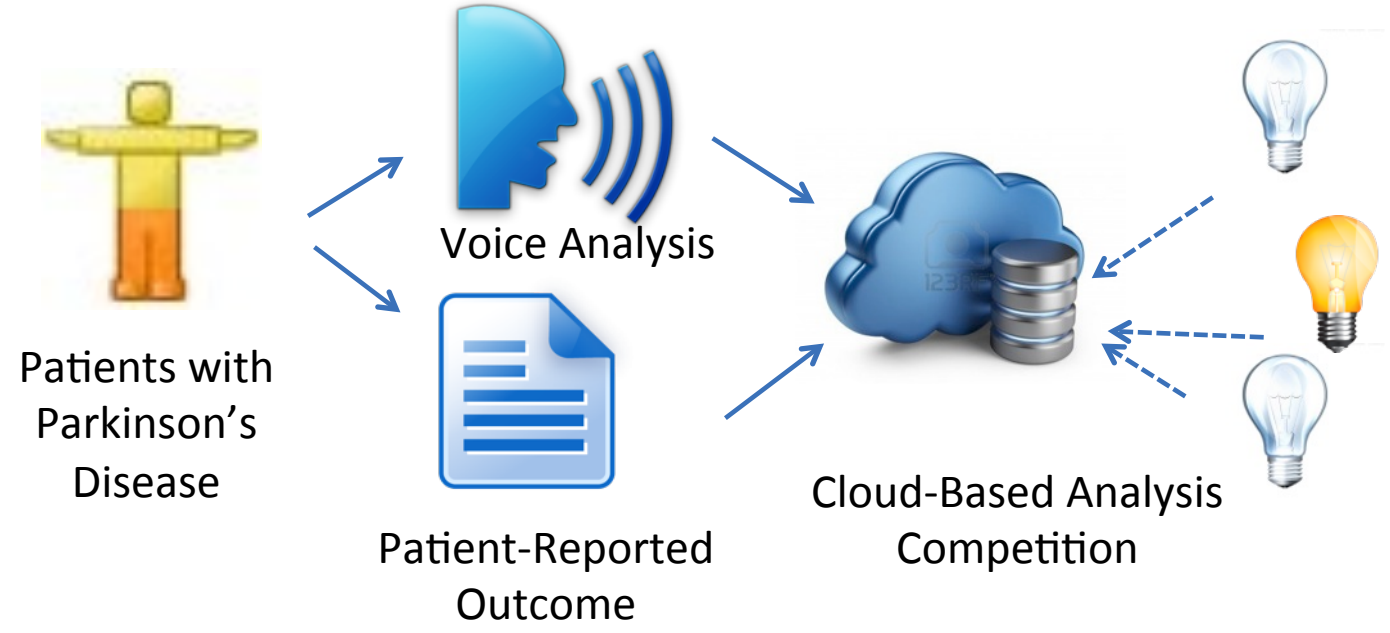
$$\text{i.Area} = \sum_i abs(FRS_i^{treated} - FRS_i^{control}) \times (t_i - t_{i-1})$$

5. For each patient, choose the control that minimizes this area.

Published alongside matching algorithm and full de-identified dataset for replication

Patients activated in crowd-sourced voice validation

Community engagement and collaborative data interpretation



DARPA

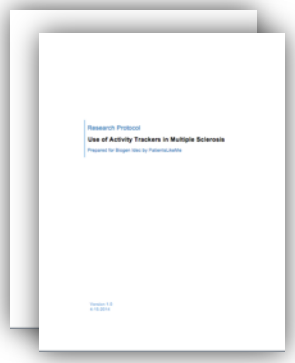
Sage BIONETWORKS

Patients track and assess impact of wearables

Device selection

"Out of box" experience

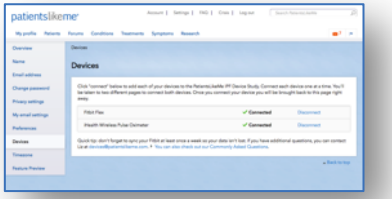
Tailored communications



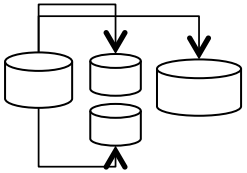
Research protocol design

IRB review

Informed consent



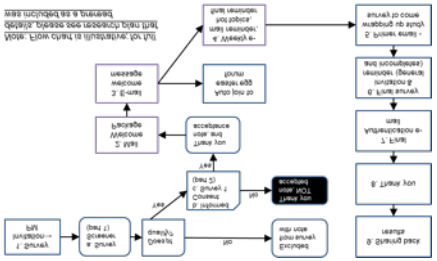
Product enhancements



Data architecture design

Device procurement

Study participant selection



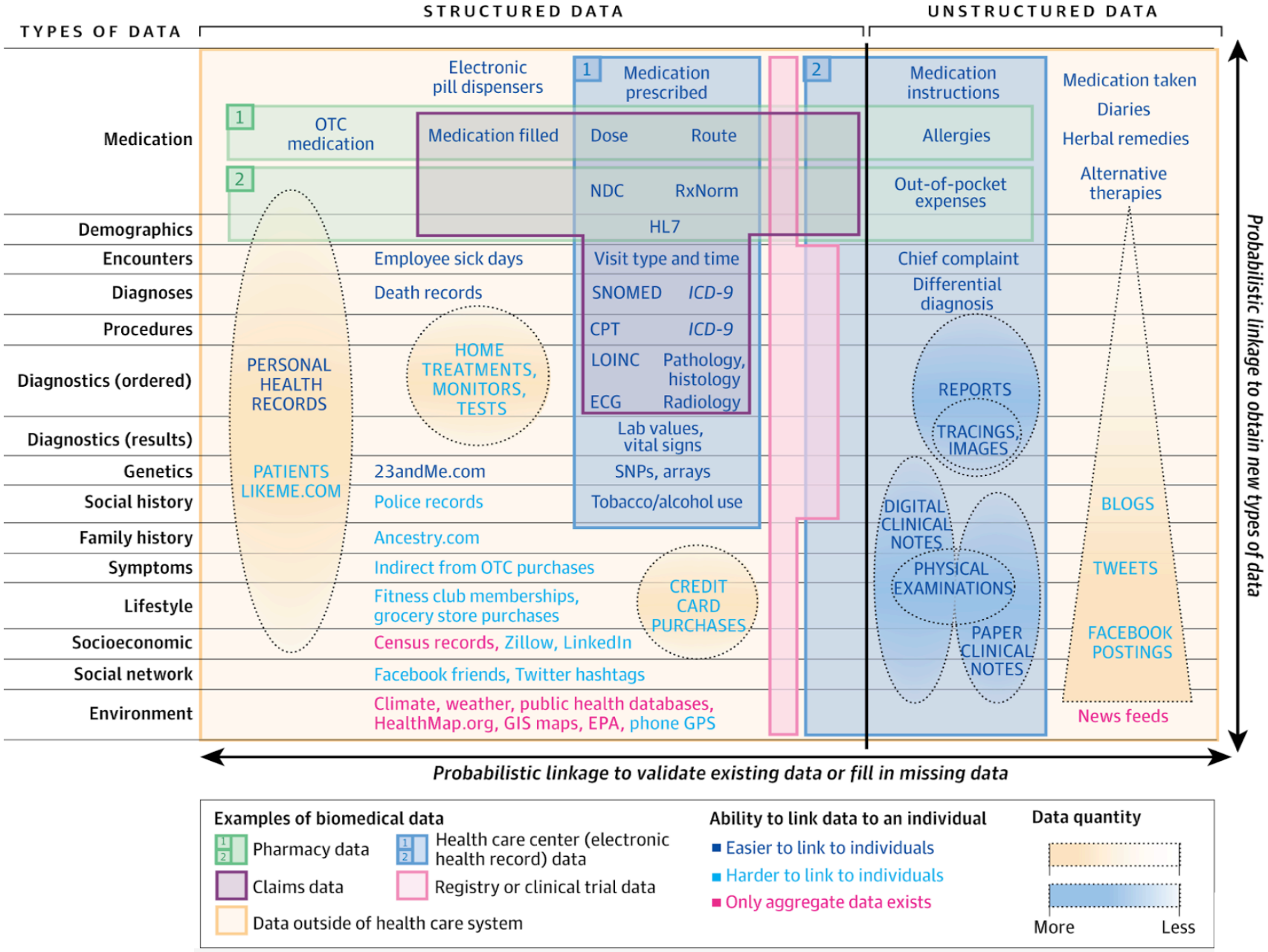
Study execution

Insight generation

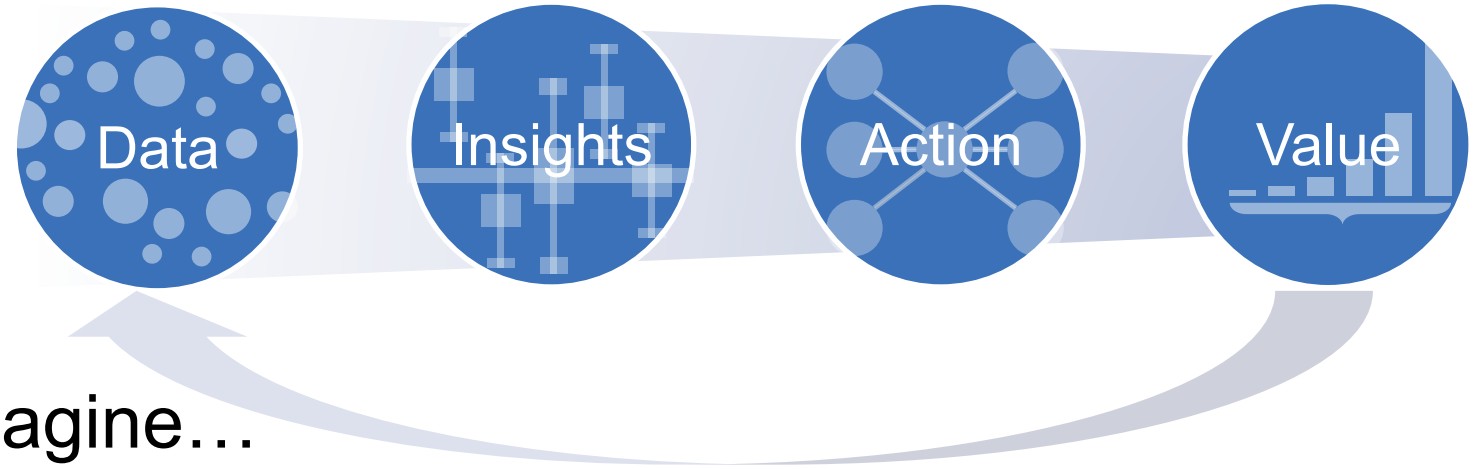
Patient engaged in generating value proposition

Observations	Patient engagement and interest	• 248 study participants were recruited in less than 24 hours • 90% of participants that connected devices to PLM did so within 7 days • High engagement during study. E.g. a member initiated discussion forum • 237 touch-points with participants outside of planned messaging; significant unsolicited positive feedback • Larger (77%) than expected final survey completion rate
	Device deployment and uptake	• 213 participants connected devices to PLM against a target of 70 • 92% participants provided positive feedback on PLM guides and support • The average step count was ~4400; participants used both the website and the mobile app to access Fitbit data multiple times a day • 56 fields of Fitbit data captured for 203 participants • Participants shared data with friends, family, and even physicians
Findings		• Large majority (92%) of participants believe physical activity is important but nearly half (47%) had never tracked it before the study • 84% would recommend such a device to other MS patients • Larger than expected recruitment enabled preliminary data analysis • Study confirmed that higher-severity MS patients showed lower activity • A minority of participants expressed frustration in setting up the device

The Tapestry of Potentially High-Value Information Sources That May be Linked to an Individual for Use in Health Care



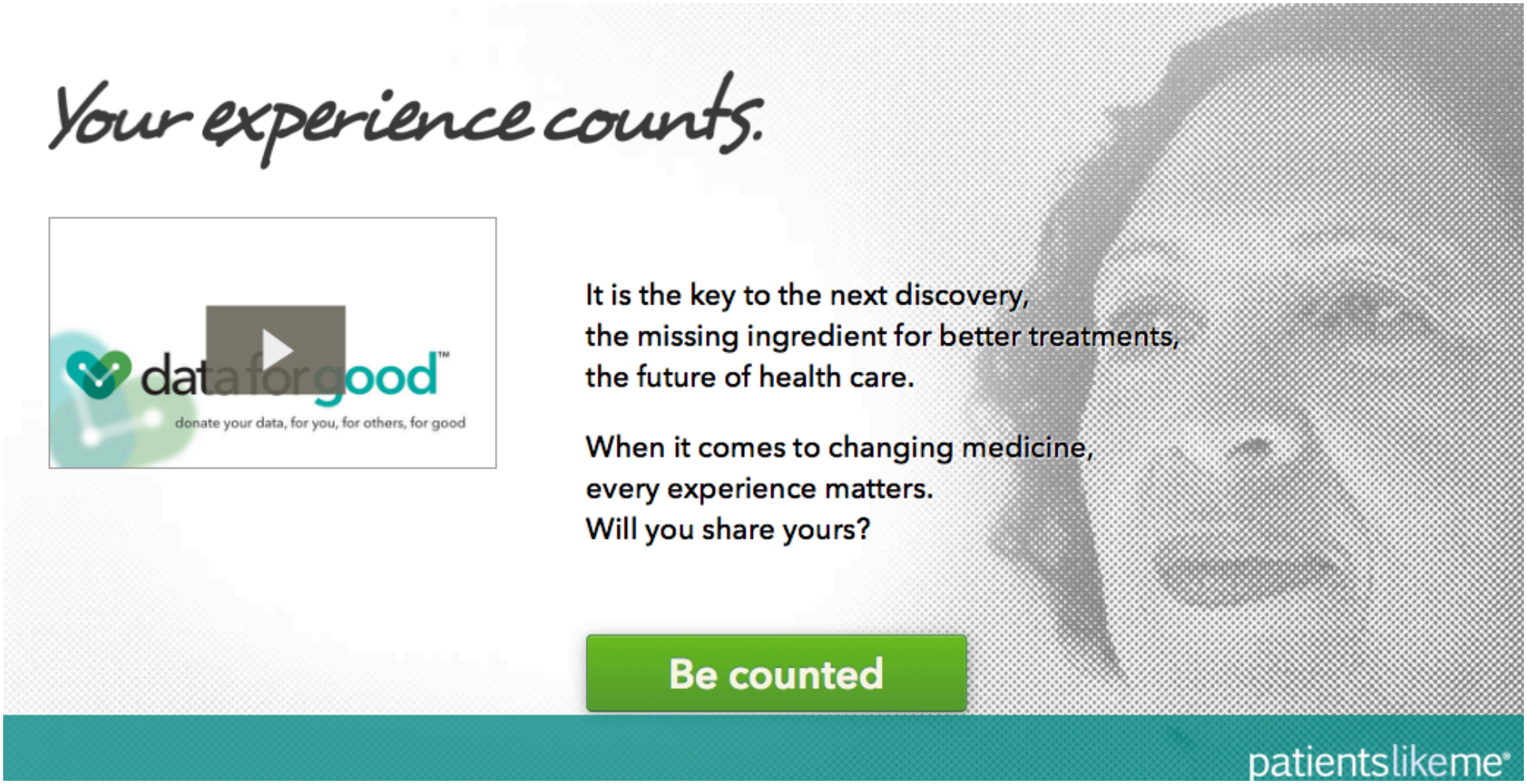
Weber GM, Mandl KD, Kohane IS. Finding the Missing Link for Big Biomedical Data. JAMA. Published online May 22, 2014. doi:10.1001/jama.2014.4228.

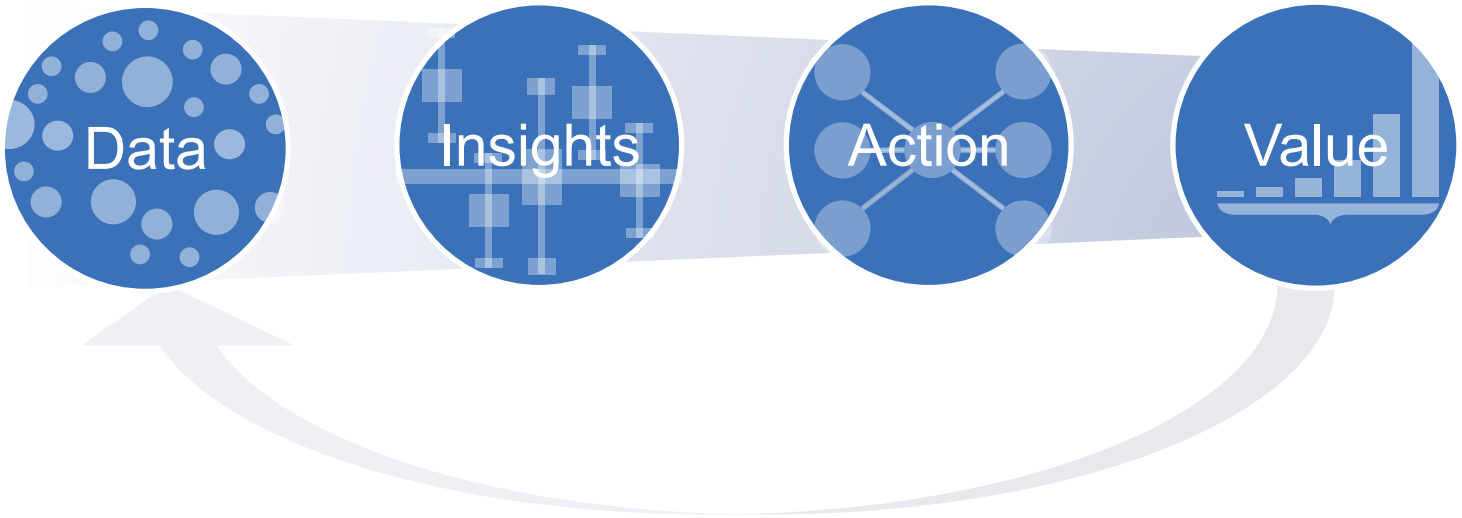


Imagine…

- Knowing for all patients in a truly patient centered way the meaningful measures that impact individuals' health outcomes.
- Illuminating insights in real time about the best path forward from continually updated predictive models.
- Discovering, rewarding, reinforcing the best models…learning when models are wrong and finding out why.
- Interfacing with emerging data and a patient's reality…together affirming, coaching, healing, verifying, acting.
- A networked model where every shared decision made in partnership with patients creates continuous learning and value.

Every story counts…data for you, for others, for good





To learn listen well

to impressions voiced by

patients first.

~ okun 2010 ~