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

We can empower healthcare organizations, providers and payers to unify the capture, analysis, and use of data to drive smarter care and business.

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.
miracle 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

<table>
<thead>
<tr>
<th>Sources of Data</th>
<th>Hypothesis Generation</th>
<th>Hypothesis Testing</th>
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</thead>
<tbody>
<tr>
<td>Profile Data – breadcrumbs of site usage</td>
<td></td>
<td></td>
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<tr>
<td>➢ Structured – condition history, symptoms, treatment evaluations, PROs,</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>➢ Unstructured – Journal feeds, Forum posts, annotations</td>
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<td>x</td>
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<tr>
<td>Survey Data – developed to answer specific research questions</td>
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<tr>
<td>➢ Multiple choice</td>
<td></td>
<td>x</td>
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<tr>
<td>➢ Open text fields</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>➢ Profile pull through (i.e. basic demographics)</td>
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<td>x</td>
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<tr>
<td>➢ External pull through (i.e. EQ5D)</td>
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Personas add context, perspective, nuance...

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

Site-wide personas

Audrey
Activated patient

Tracy
Tweaker/Tracker

Sam
Newly diagnosed, slow decision possible

Carl
Contented

Layla
Leader/Connector

Frank
New cancer diagnosis, fast decision required

Lorraine
Undiagnosed & in limbo

Karen
Caregiver

The 6 most common questions patients ask

What is this thing I have?

What will this (Dx, Rx, Tx) do to me?

Am I crazy/alone?

What might help me get better?

What might help me live with it?

How do I deal with problems caused by my illness (life, work, money)?

Patient & caregiver journey

Experiencing a change
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 assessment of physician performance of epilepsy quality-of-care measures

Paul Wicks, PhD
Nathan B. Fountain, MD
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
Patient insights about sleep variation by condition
Patient insights on measurement

Floor effect of measure excluded PALS using assistive technology

- 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

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:

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

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

Patients with Parkinson’s Disease

Voice Analysis

Patient-Reported Outcome

Cloud-Based Analysis Competition

DARPA

patientslikeme®
Patients track and assess impact of wearables

Device selection

“Out of box” experience

Research protocol design

IRB review

Tailored communications

Informed consent

Device procurement

Study participant selection

Product enhancements

Data architecture design

Study execution

Insight generation
### 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

Examples of biomedical data:
- Pharmacy data
- Health care center (electronic health record) data
- Claims data
- Registry or clinical trial data
- Data outside of health care system

Ability to link data to an individual:
- Easier to link to individuals
- Harder to link to individuals
- Only aggregate data exists

Data quantity:
- More
- Less
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

Your experience counts.

It is the key to the next discovery, the missing ingredient for better treatments, the future of health care.

When it comes to changing medicine, every experience matters. Will you share yours?

Be counted
To learn listen well to impressions voiced by patients first.

~ okun 2010 ~