Presenting health data to patients: who's doing what, why, and how well?

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Presenting data: how to convey information most effectively
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Gimme My Damn Data by e-patient Dave deBronkart

The e-patient rap
Huge patient expectations re: processing and leveraging of their health data

- *Gimme My Damn Data* keynote at Medicine 2.0 Congress, Toronto, 2009
- A horror story of bungled medical records on a diagnosis of terminal illness; a happy ending in which our hero demanded better data and saved his own life
- Started a social movement of networked patients aiming to open up clinical care and clinical research
  - [http://e-patients.net/archives/category/medical-records](http://e-patients.net/archives/category/medical-records)
  - [http://participatorymedicine.org](http://participatorymedicine.org)

Local and global power plays are unfolding

- [hic2014](http://www.hic2014.com)
- [The BMJ](http://bmj.com)

Jan 2015

Followings in the path of feminists and civil rights leaders, informed patients are building a progressive social movement to improve medical care.
Doctors’ notes viewable by patients

US experience with doctors and patients sharing clinical notes. BMJ 2015; 350: g7785 (10 February 2015)

A public database of diagnostic reports
Some definitions

And some issues:
- Data creation – confidence in data, caution in interpretation
- Data custodianship – who owns it? who cares?
- Data curation – maintaining structures, applying standards
- Data clouds – from connected information to collective intelligence?

Ten things:
1. How is it different to what I have now?
2. What information will be included?
3. What is a Shared Health Summary?
4. Who can see my MBS & PBS details?
5. Why can’t I see my Pathology and Diagnostic Imaging reports?
6. How can I see info about my medications prescribed and dispensed?
7. Who can see my contact number and what is it for?
8. Who will see information entered via the Child Development function?
9. Can I remove documents?
10. What happens to the information if I stop using my eHealth record?
Worth the effort? evidence on direct patient access to lab test results...

Consumers
- Electronic patient portals are a relatively new technology and the healthcare community has only just begun to engage with this innovation to optimise care delivery, outcomes and patient engagement.
- There are major obstacles which hinder the involvement of consumers. These include a lack of access to clinical information and a lack of appropriate tools, educational aids and decision support aids that can help consumers to understand and engage in their own care.

Providers
- Clinicians’ unease about direct notification of pathology (including abnormal) results often relate to concern about patients’ understanding of, and ability to interpret results, which may lead to unnecessary anxiety and confusion on the part of patients.
- Clinicians’ apprehension may also be related to the impact that direct patient access to test results has on the traditional medical practitioner role as the information gatekeeper.


- RACGP response (N. Pinskier, 14 November 2014): Patients must be appropriately informed about their medical care including understanding what their test results reveal as part of a holistic approach, rather than simply as a set of numbers available online.

Patient portals

Viewing laboratory results = portal function commonly used by patients internationally

Most portals provide links to trusted consumer educational resources from all aspects of data (e.g. web links from each diagnosis or each laboratory test).

“Microsoft HealthVault is truly a wonderful service for long-term health management, and a PCMag Editors’ Choice. Its ability to import data from medical devices, health apps, and consumer health gadgets lets it do a lot of the heavy lifting in the background, without ever asking you to micromanage it.

I love that healthcare providers can email documents right into your account in a secure way. And anyone managing a family’s health needs will find it an excellent service for keeping track of all kinds of records.

Set up an account now, connect a few apps and devices that you use, and return to it every so often to update information that isn’t automatically added.”


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Personal health data hacking and heroics using: social media, self-quantification & citizen sensors

Who plays that outsider role in health care? Patients and caregivers.

For example:

- Hugo Campos, who wants access to his own heart monitor data.
- Ernesto Ramirez, who, along with his Quantified Self compatriots, takes a citizen-scientist approach to helping people understand self-tracking.
- Dana Lewis and Scott Leibrand, who are building an Open Artificial Pancreas, not waiting for the world to catch up to their vision for living with diabetes.
- Erin Moore, whose just-in-time advice to another family in her online community saved a child from unnecessary treatment.
- Emily Kramer-Golinkoff, who believes that her life depends on what she learns online from fellow patients as well as from her clinicians.
- Laura Kolaczkowski, who is helping to create a platform for people living with multiple sclerosis to share their data.
- Matthew Might and Matt Wilson, two rare-disease dads who found each other through a Google search and are helping to create a new model for diagnosing genetic conditions.

More broadly:

- Contributors to PatientsLikeMe, Smart Patients, Quantified Self, Lixon, and other platforms for sharing insights and data.
- Contributors to the RBcom community (and every other disease hashtag) who gather, share, and create a never-ending stream of information and support on Twitter.
Why would you?

**curiosity, performance, control, healing, socialising**


Not so niche …
How good are the data?
JAMA 10 February 2015 313(6).

RESEARCH LETTER

Accuraccy of Smartphone Applications and Wearable Devices for Tracking Physical Activity Data

Despite the potential of pedometers to increase physical activity and improve health, there is little evidence of broad adoption by the general population. In contrast, nearly two-thirds of adults in the United States own a smartphone and technology advancements have enabled these devices to track health behaviors such as physical activity and provide convenient feedback. New wearable devices that may have more consumer appeal have also been developed.

Even though these devices and applications might better engage individuals in their health, for example through workplace wellness programs, there has been little evaluation of their use. The objective of this study was to evaluate the accuracy of smartphone applications and wearable devices compared with direct observation of step counts, a metric successfully used in interventions to improve clinical outcomes.

Methods | This prospective study recruited healthy adults aged 18 years or older through direct verbal outreach at a university. Participants gave verbal informed consent to walk on a treadmill set at 3.0 mph for 500 and 1500 steps, each twice, for no compensation. ANovelObserver (M.A.C.) counted steps using a tally counter in August 2014. This study was approved by the University of Pennsylvania institutional review board.

Figure 1 shows the results for the 500 step trials by device and Figure 2 shows the results for the 1500 step trials. Compared with direct observation, the relative difference in mean step count ranged from -0.3% to 1.6% for the pedometer and accelerometers, -0.7% to 1.5% for the wearable devices, and -6.7% to 6.2% for smartphone applications. Findings were mostly consistent between the 500 and 1500 step trials.

Discussion | We found that most smartphone applications and wearable devices were accurate for tracking step counts. Data from smartphones were only slightly different than observed step counts, but could be higher or lower. Wearable devices differed more and 1 device reported step counts more than 20% lower than observed. Step counts were often used to derive other measures of physical activity, such as distance or calories.

Figure 1. Device Outcomes for the 500 Step Trials

<table>
<thead>
<tr>
<th>Device</th>
<th>No. of Observations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Galaxy S4 Minus App</td>
<td>27</td>
</tr>
<tr>
<td>iPhone 5s Move App</td>
<td>28</td>
</tr>
<tr>
<td>iPhone 5s Health Mate App</td>
<td>28</td>
</tr>
<tr>
<td>iPhone 5s Health Mate app</td>
<td>28</td>
</tr>
<tr>
<td>Nike Fuelband</td>
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<tr>
<td>Jawbone UP24</td>
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<tr>
<td>Fitbit Flex</td>
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<td>Fitbit One</td>
<td>28</td>
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<tr>
<td>Fitbit Zip</td>
<td>28</td>
</tr>
</tbody>
</table>

Log Exercise, Nutrition, Medications, Sleep and More

The power of logarithmic is the ability to quickly identify trends in data. For example, if you log one or two areas of your day, such as fitness, habits, goals, etc., with MySelf, you’re able to log any day or week metrics beyond the basic apps. One of the features you can track using MySelf are your exercise, nutrition, health status, medication, wellness, and prescriptions (including all numbers, doctors and pharmacies). You’ll be able to see the metrics of your activity and how this can impact your day-to-day life. Additionally, you can create your own charts, which express a world of opportunities — any activity can be tracked. Additionally, view your progress with logs, Fitbit, One and data charts and graphs of your activity, wellness, nutrition, and health stats.
Personal health data sharing

The Quantified-Self movement was first developed in...
The smarter way to find the best treatments.
Get access to millions of ratings comparing the real-world performance of treatments across 637 health conditions.

Why you will love CureTogether
1. You’ll learn from people going through the same thing.
2. You won’t see ads or time-wasting content.
3. We’ll work hard to help you achieve better health.

Recognition

Why sharing matters
You’ve been there, and your experience can help someone like you make a better decision. Here’s why you should review your medications on Iodine.

Review any medication you’ve taken—it only takes a minute

Find your medication: Review

When I started this medication, I really felt very calm. It is like when the rain stops, you realize how noisy it was few seconds ago. But I got the ugly side effect of coughing which did not go away until 1 month after I stopped taking.

Looking for other options

How well it worked: How big of a hassle

52 year old male taking Lisinopril.
Citizen science in health

• Citizens crowdsourcing data sets to explore their own biomedical research questions

Citizen science health landscape

Health social networks

Health collaboration communities


Citizen science

Levels of Citizen Science

Level 4 ‘Extreme’
• Collaborative Science – problem definition, data collection and analysis

Level 3 ‘Participatory science’
• Participation in problem definition and data collection

Level 2 ‘Distributed Intelligence’
• Citizens as basic interpreters

Level 1 ‘Crowdsourcing’
• Citizens as sensors

Citizen science is doing some interesting things to research models...
• Google's experimental Google X wing ‘Project Baseline Study’
• Aim: draw genetic and molecular data from large numbers of people, to create a picture of a person in perfect health, as a baseline for [...].
• By using Google’s computational power to identify “biomarkers” in the data that could help people stave off or avoid health issues
• Mid-2014 began harvesting anonymous genetic and molecular information from 175 volunteers using wearable technology,
• Late 2014 announced plan to use magnetic nanoparticles to monitor for signs of cancer and other diseases - you swallow a pill, call it somewhere, trap it, ask it what it saw

• Owano, N. 31 January 2015

Changing designs of health care and health research
Critique: “The use in research of personal fitness or health data shared on social network raises both scientific and ethical concerns.”


- “beyond contribution of genetic and phenotypic information, it is questionable that participants would truly be directing research. They did not have a say in the contours of the research or selection of the investigators who would conduct the studies. … The power to make all these decisions remained in the hands of the research sponsor (in this case, 23andMe and its partners). … it is unclear whether this approach to genetic research is truly democratizing, or is simply an illusion of collective production.”

- “no means of verifying the validity of data uploaded by users … impossible to verify whether users who have uploaded data are actually the sources of that data. This opens the venue to potentially malicious usage, as genotypings from strangers can be uploaded, as well as misinformation about phenotypes can be entered. … users need to be aware of the potential of re-identification through providing metadata along with their genetic information and the genetic discrimination that could follow.”

- “generally healthy people have internalised the notion of the ‘new public health’ and accepted the imperative of personal health responsibility. On the one hand, this bodes well for healthy individuals…. On the other hand, our findings may indicate that other factors, such as social determinants of health, are ignored in health promotion efforts and that those who cannot manage their own health may fall further behind.”
  MacGregor, J. C., & Wathen, C. N. (2014). 'My health is not a job': a qualitative exploration of personal health management and imperatives of the 'new public health'. BMC public health, 14(1), 726.
Thank you!
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