If it doesn't directly help patients, it ain't meaningful.
We should mandate 100% patient access, including ability to export.

Testimony before the National Committee on Vital and Health Statistics
Subcommittee on Privacy, Confidentiality and Security
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1. Preface

Most readers are aware of my cancer story. Short version: in January 2007 a routine shoulder x-ray incidentally revealed that Stage IV, grade 4 kidney cancer was in the process of killing me; were it not for that lucky x-ray I'd be dead today because I had no symptoms for another six weeks. As it was, my median survival time was rated at 24 weeks. I got great surgery and treatment at Beth Israel Deaconess Medical Center in Boston, and am completely well today.

In the process I used the internet in every way imaginable: I viewed my medical records online, shared the login info with medically knowledge-able family and friends, found a kidney cancer peer community on ACOR.org, created a support community on CaringBridge, and even emailed a photo of a leg infection to my orthopedist post-surgery.

In essence, with my life at stake, I used every tool at my disposal. As with much of the world today, that included a lot of internet use.

Four months after the crisis had passed, I discovered the e-patient movement, founded by Tom Ferguson MD in the 1990s. He said "e-patients are Empowered, Equipped, Engaged and Enabled." I read the white paper that's posted on the e-patients.net blog, and my life changed: I knew what I would do with my "free replay in the game of life."

In early 2009, as a natural next step in being an e-patient, I moved my data from my hospital's patient portal into Google Health. This produced some extraordinary surprises (errors), which led to important realizations about the data in today's medical records systems.

The blog post I wrote about the experience is Appendix B; it became front page news in the Boston *Globe* on April 13, 2009, producing a vigorous discussion about data quality in medical records (over 100 comments), over 1,000 articles and blog posts, and leading within days to policy changes by both the hospital and Google Health.

The balance of this document talks about the lessons learned from these experiences, and from the many ensuing conversations with people around the world who've become involved with the story.[1]

2. Lives can depend on the data in medical records.

While ill, I experienced the value of reading my medical data online and sharing it with others. In my case, since I was already at one of the best hospitals in the world for my disease, I didn't need to move my data to another hospital. I now know that was lucky, because if I'd needed to move quickly, I'd have been out of luck.

In 2009 while researching the errors that arose in my data transfer I learned more than I'd wanted about the realities of our medical data.

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[1] Note that those conversations and connections took place through social media – mostly blogs and Twitter, not email. Ten years ago that would not have been so. The world is changing.

I was surprised to learn that most patients don't *have* online access to their data, as I did. (You probably don't have access to yours). I've learned that this lack can make life miserable for families in stress, and in some cases it's made it difficult for patients to seek care where they want, even when they're desperate.

The need to view our records is heightened by the realization that our records *often* contain errors, which can be serious. Humans (even healthcare providers) make mistakes, which is not "a hangin' offense" in itself. But if a provider resists a patient's efforts to help their own cause by reading the data, *that* would be intolerable to me. After all, it's the patient's life that's at stake.

All this spotlights the question:

3. Whose data is it, anyway?

My May 10, 2009 post on meaningful use said:

> "**It's my data.** It's my life that's at stake. I have a right to seek the best care in the world, and if that means exporting a copy of my data from your system and taking it somewhere else, I have a right to do that."

The full body of that post is in Appendix A.

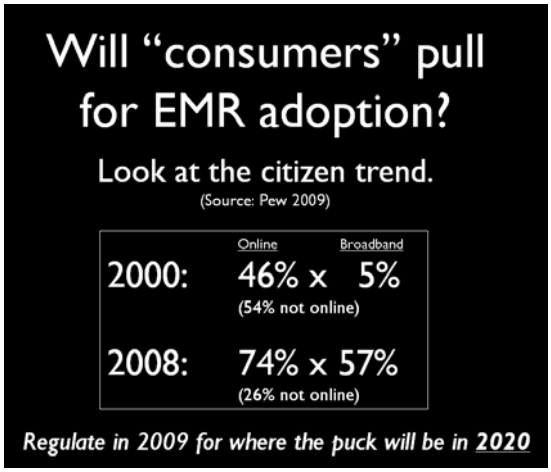
4. We should plan for use in 2020.

Appendix A contains additional thoughts about the world of 2020, which we'll impact with the rules we write in 2009.

Year after year, data from the Pew Internet and American Life project show increasing adoption of everything online. This includes accessing medical information, which I imagine will increase more rapidly as another decade of internet-savvy boomers enters the high consumption era of their healthcare lives[2], and today's graduates become new parents caring for their children.

[2] Here's something to watch for. I took two plane flights this week, and on one of them when I debarked, a line of seven wheelchairs were awaiting passengers; on the return flight, five wheelchairs boarded. Boomers are entering the wheelchair years.

I presented this slide at a June 2 meeting of the board of the National eHealth Collaborative:



The regulations we write today will be with us for at least a decade, just as HIPAA and similar regulations govern what we can and cannot do. Let us regulate wisely for the predictable future.

5. We must, must, must hold fundamental human rights in our minds and our hearts as we regulate.

In recent weeks my thinking has evolved to realize these rights, which I now hold close based on my own near-fatal cancer experience:

- The right of a desperate person to try to save themselves
- The right to know what your options are
- The right to pick up your data and pursue a treatment option elsewhere. Promptly.

I've learned that patients do not always hear about all treatment options from their own physicians. For my own disease, the laparoscopic surgery I had involves immensely less pain and faster recovery than the "open surgery" alternative but I've learned it's common for patients not to be told the option exists. (My surgeon knows of cases where a surgeon didn't even tell a patient that *his own partner* offered laparoscopy.)

Similarly, on the medical front, I had the only near-curative treatment for kidney cancer (high-dosage Interleukin-2, aka HDIL-2), but on my ACOR patient listerve every month we have

new patients show up whose oncologists didn't tell them the option exists. Sometimes this is because the doctor's information is out of date; we also know of cases where a hospital has a policy of not telling patients about treatments they don't offer. In either case, the patient isn't aware of all their options, and I believe they should.

This is aided greatly by patient communities, and as patient communities grow (as all other forms of social networks have grown), we will surely see more cases where people in desperate trouble want to go elsewhere in a hurry. We can improve outcomes by helping with our policies.

Taking our data with us can be made quick and reliable if we mandate it. People export data from computer systems all the time. There is no justifiable reason for hospitals to continue to be any different in export capability.

6. Automation initiatives can fail if they're not designed with the primary objective of helping the ultimate consumer – in this case, the patient.

I want the EMR initiative to succeed. I believe in automation; I've seen the improvements and reliability that automation can create when it genuinely gets the job done better.

But I've also seen automation initiatives fail when they were "all about the technology" and nobody had identified *concretely* how the consumer will benefit. (It's not sufficient to mouth a generic, such as "things will cost less." That's a self-delusion, avoiding the work of identifying concretely how it will happen.) And I'm petrified of the long-term consequences if we invest billions in an initiative that fails, so that for decades afterward enemies of change point to it.

It's hard for me to imagine any use of EMR systems being "meaningful" if benefits don't accrue directly – and promptly – to the patient / consumer. That's why I say "If it doesn't directly help patients, it ain't meaningful." I say promptly because many businesses have failed by pursuing a "hockey stick" business plan requiring years of investment with the promise that at some point, years out, the bottom line will suddenly inflect upward, like a hockey stick. We need to be able to point to benefits early on, and we must not fall prey to assurances that things will be better sometime.

7. The fastest, surest, least complicated way to benefit consumer/patients is to give them/us 100% access to our medical records.

This is an easy one. As I myself saw two years ago, **sharing is easy: all I had to do was give friends my password.** *Believe* me, I was glad to do it. And nobody has to do it; it's optional.

Why does this matter? Patient access to medical records empowers being actively engaged in one's care, aka participatory medicine. Patients sometimes spot errors, which can avoid harm. And access to records can enable moving to another facility more reliably.

We can even achieve this goal and benefit before we automate: we could mandate that providers must give patients access to all their data, starting *now*, with existing paper records. Not every consumer/patient will want to look, and that's fine. But for patients who are motivated, and especially for those who are desperate, we certainly should not stand in the way.

8. Include access to claims data and charts, as well as clinical data such as radiology reports and labs.

My PatientSite / Google Health experience showed that our medical data is quite likely not subject to the information quality standards and best practices observed in most industries. And this was at one of the nation's most IT-enabled hospitals.

Indeed, the data professionals blog Information Quality Trainwrecks wrote about the PatientSite / Google story, saying "To say that the quality of the information that was transferred was poor is an understatement." [3]

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[3] http://www.iqtrainwrecks.com/2009/04/15/google-health-dead-on-arrival-due-to-duff-data-quality captured June 3, 2009

We should do what we can to clean up errors in our existing records *before we automate*. The author of that post later commented, "Throwing more automation at bad processes and crummy data just leads to faster arrival at a trainwreck scenario."

I include **claims data** partly because many people have told me their claims data is in good shape and they *want* to be able to use it, and partly because it can be used by a future insurer to deny coverage based on pre-existing conditions. In both cases the data is about us, and in both cases we have a direct stake in reviewing it and weeding out errors.

Erroneous billing codes can also be submitted to the MIB. In 2008 Consumer Reports Health told of a woman who suffered significant financial harm because of a coding error that had propagated into the MIB.[4] This led me to obtain my own MIB report, and to blog about the opacity of their reporting: the source of an entry disappears after a period of time, although the entry itself persists.[5]

Meanwhile, **our charts** (our providers' notes about each case) can contain errors that don't show up in a patient portal such as PatientSite. (PatientSite only shows me specific facts and reports, not all the information providers shared behind the scenes.) The recent case of D.C. resident Fred Holliday has been publicized by his wife Regina on several health blogs. His chart contains many incorrect statements about an advance directive, equipment orders that were never filled, and so on. She didn't learn of these errors until she'd left the hospital and went back to get the data, because many important items were not in the transfer notes. She then discovered that the hundreds of pages she needed took hours to output and were only available at a cost of 73 cents per page, and only then did she discover the errors and unfulfilled orders.

All of this can be substantially improved, today, without installing any new systems, by mandating patient access to their records, both online and off. We can then carry this policy forward to the new generation of online systems.

9. Summary

My own case in 2007 was remarkable in several ways: the severity of the diagnosis, the rapidity of my turnaround, and the wide range of ways my friends, family and I used the internet to help our cause. We were leading edge in that regard, but as the Pew data shows, the world is already moving in our direction.

Demographic data also shows that the people entering each phase of life are increasingly online and expect their data to be online.

As my blog post about 2020 suggests, the regulations we write today should "skate to where the puck will be."

In summary:

- As all of today's age ranges grow older, **the public will be increasingly motivated and able to participate** in their care.
- **Whose data is it, anyway? It's ours.** And it's our lives that are at stake. Mandate that providers must help us help ourselves.
- In my view **"meaningful use" requires complete patient access.** Many benefits can accrue from this simple declaration of policy, both online and off.

We have a golden opportunity to do the right thing, at the outset of a new wave of system purchases and installations.

Thank you for the opportunity to testify.

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[4] http://blogs.consumerreports.org/health/2008/08/denied-insuranc.html, accessed June 3, 2009.

[5] http://patientdave.blogspot.com/2008/09/whats-in-your-mib.html, accessed June 3, 2009.

Appendix A: My blog post about "meaningful use"

"Meaningful Use": a pivotal definition for new-wave medical records systems

by e-Patient Dave on May 10, 2009

I've struggled with what to say about this subject for two weeks, because I want to "get it right" but it's vast. So I'm giving up any hope of being comprehensive, and I'm just going to say what little I know, and what I think, and let any discussion happen from there.

The issue

We (the US, and probably the world) are at a pivotal moment in healthcare, a turning point. The direction we choose now can have a lasting effect on how well healthcare works in the coming years – even for the next decade, I suspect. So as we consider this, I suggest that we think not in 2010 terms, but 2020 terms.

The issue at hand is the definition of "meaningful use." You've probably heard of the $19B in the US "ARRA" economic stimulus package that's set aside to encourage adoption of electronic medical records systems. (A Google search for "HIT stimulus ARRA billion" produces 25,700 hits.) Medical practices that have EMRs and put them to "meaningful use" will get higher reimbursement from the government.

When the stimulus package was passed by Congress, the term "meaningful use" was intentionally left to be clarified later. *See David Kibbe's comment here for three items that were specified.* And here we are: the work is now underway to define and clarify that term. Many meetings are happening in Washington to get this done.

I believe, and many basically agree, that meaningful use should be defined to include **full patient access to their data** in EMR systems. Here's why.

First, let's look at the world for which we're designing: 2020.

2020: The world for which we're planning

The systems we design today will be in use a long time from now, so I suggest we look at the world as it will be in 2020, and how we'll be using these systems then. What does that world look like?

- **We will all be ten years older.** You will be ten years older; your children will be ten years old; your parents will be ten years older.
- **The internet will be ten years more advanced.** If you think back to the dial-up world of ten years ago (1999), when browsers were just five years old, there's been a huge amount of progress … and, significantly for this discussion, a lot of it's related to having more access to our personal data online: banking, plane reservations, shopping, and more. Think how that will change in the next decade.
- **Handheld computers (smartphones)** will be ten years more advanced. (*More* advanced? Heck, the iPhone was only introduced 28 months ago.)
- **Connected e-health devices** will be out of their infancy: WiFi blood pressure monitors, bathroom scales, glucose monitors, you name it. It's fairly certain that by then we'll be able to use cheap devices that send routine data to some central storage place, where smart software (your *choice* of smart software) can send out alarms or reminders, your care team can view it … and you should be able to view it, too. And make notes on it.

- **Doctors will be ten years older.** *Fast Company* magazine's Doctor of the Future **Jay Parkinson will be middle aged** (Ha!). Our oldest doctors will be retired (or dead). Today's youngest doctors will be well into their careers and owning practices; a new generation of providers will be practicing who were *born after Amazon.com* (1994). They have never known a world without household email. They expect *everything* to be online.

In this world, what kind of data access do we want? We need to build that into our design choices now. Why?

The product development cycle

It takes time to plan, design, code, test, install, and train on systems. And once that's done, the decisions that are made will be with us for a long time – until vendors decide to go through that whole process again.

Sure, a lot of code gets written and updated fast. But if I've learned one thing about healthcare IT since I got in the e-patient game, it's that healthcare systems are big, complex, and slow to change. These are not things that get re-engineered frequently.

Docs/nurses etc: how old are the systems you use today? Some are new, but many of you are using systems designed in 2000, right?

And here's where regulatory requirements come in.

The impact of regulatory requirements

Some regulatory requirements profoundly affect product design. If a law is passed saying you can get a tax credit for a computer where the "Q" key is colored orange, vendors will offer that, because customers will buy it. Similarly, if a law *requires* that a system have a particular feature, people will only buy that, so vendors put it in the product plan, right from the get-go.

That's the case with HIPAA. Many systems are required by the government to be HIPAA compliant. So vendors design accordingly.

And so it is today with the definition of "meaningful use." Providers will only receive stimulus money if the system they choose meets the definition of meaningful use. So the definition we choose today can have a profound impact on *what you can do with your data* far into the future.

My principles

- **Patient is a first-person word.** Your time will come: someday it will be you, your child, your mother, your spouse on that hospital bed or at that roadside being tended by an EMT. The way to think about this is in the first person: when that time comes, what should be possible with "my data," not "patients' data."

- Corollary: **No more captive data.** We must put an end to the era where a system provider thinks the data they collect is their property. *Lives are at stake.* Whose data is it, anyway?

  Vendors must adapt to a world where they earn their margins by creating on-going value, not by holding data captive. This includes images (CT scans, MRIs, etc, at full diagnostic resolution) as well as lab results and everything else.

  My opinion is that "whose data is it" applies to healthcare providers as well as system vendors. If you haven't yet, consider what happened to Web guru Doc Searls last year when he couldn't share his scan data with another MD.

- **Enable participatory medicine** – doctor-patient collaboration. Make it possible for each party to view the same data. (Ideally, I'd like to enable collaboration tools such as online discussion of my medical records – but that's beyond the scope of this post.)

- **Let each constituency say what works for them.** Patients shouldn't say what doctors need, and doctors shouldn't mandate how patients should and shouldn't describe things.

  Warning: experts on both sides *should* be able to comment on / warn the other about apparent errors. Docs must be able to say "Whoops, you overlooked this," and

patients must be able to say "Whoops, you overlooked this." (See related discussion of "who will vet the vetters" in "Medpedia: who gets to say what info is reliable?")

Recommendations

These are my personal recommendations, not necessarily those of e-patients.net or the Society for Participatory Medicine. (Hey you out there - what do you think? Participate in the comments! You count!)

- **Grant patients full access to their medical records.**

  Exception: the best minds I know have said doctors need the ability to store private notes, and I can grant that. But I want full access to all my data: all the numbers, all the test results, all the radiology reports, everything.

  Among other things, the records might contain errors, and we can help clean them up.

- **Let me export my data and take it elsewhere.** I have a right to seek the best care anywhere, even if it means going somewhere else. Systems must be designed to allow exporting data (and, of course, importing data). I know there are lots of details to be worked out. Let's just start with this principle: *it's my data*.

- **Enable the most able.** Don't dumb down the data. Allow different levels of viewing – simple, medium, expert. (Hint: let each group participate in creating the language, and let users vote it up or down.)

This is our golden moment. It's not fundamentally hard to give patients access to their data, not any more than it's hard for banks to give us access to our banking information. It took banks two or three generations to get it right, but the technology exists, and now it's widespread. Let's encourage EMR vendors to get it right on the first try, by defining meaningful use to include giving us full access to all our medical data.

Appendix B: E-Patients.net blog post about exporting my data from PatientSite to Google Health

Imagine someone had been managing your data, and then you looked.

by e-Patient Dave on April 1, 2009

This is a complex post, so don't jump to any conclusions.

Two weeks ago (gad, was it that long?) I asked you to think about something for a few days:

> Imagine that for all your life, and your parents' lives, your money had been managed by other people who had extensive training and licensing. Imagine that all your records were in their possession, and you could occasionally see parts of them, but you just figured the pros had it under control.
>
> Imagine that you knew you weren't a financial planner but you wanted to take as much responsibility as you could – to participate. Imagine that some money managers (not all, but many) attacked people who wanted to make their own decisions, saying "Who's the financial planner here?"

Then imagine that one day you were allowed to see the records, and you found out there were a whole lot of errors, and the people carefully guarding your data were not as on top of things as everyone thought.

Two weeks before that post, I'd had a personal breakthough in my thinking. For a year I'd been a rabid enemy of Google Health, but now I said: **I'm putting my data in Google and HealthVault**: "I'm concluding that **we can do more good by aggregating our data** into large, anonymized databanks that **smart software can analyze** to look for patterns. Early detection means early intervention means fewer crises."

And I observed that the power of Web 2.0 "mash-ups" …

> …lets people *create software gadgets* without knowing how they'll be used, it lets *people build tools* that use data without knowing where the data will come from, and it lets *people build big new systems* just by assembling them out of "software Legos."

So, I said, "I'm in." I decided to punch the big red button and copy my personal health data into Google Health.

What happened is the result of PatientSite's "version 1" implementation, not their eventual full implementation, of the interface. To my knowledge, zero or one other hospitals have any interface at all, and as I'll say later, I'm not even sure how much of the Google Health side of the connection is complete. Nonetheless, what I learned about my own data was quite informative, and quite surprising.

(I've discussed what follows with hospital staff; this isn't gossip behind anyone's back. IMO, empowered people don't gossip, they communicate clearly and directly with the people involved.)

When Google Health launched last May, my hospital's CIO blog said "we have enhanced our hospital and ambulatory systems such that a patient, with their consent and control, can upload their BIDMC records to Google Health in a few keystrokes. There is no need to manually enter this health data into Google's personal health record, unlike earlier PHRs from Dr. Koop, HealthCentral and Revolution Health."

So I went into my patient portal, PatientSite, and clicked the button to do it. I checked the boxes for all the options and clicked Upload. It was pretty quick.

But what the heck?

Requires immediate attention Discuss with your doctor soon

Hydrochlorothiazide and **Low Amount of Potassium in the Blood**

Medications given to people who have certain conditions can lead to an increase in side effects and/or worsening of the condition. Hydrochlorothiazide Oral generally should not be given to people with Hypokalemia. This health profile includes this condition.

An alarm**:** "! Requires immediate attention"

Okay, yes, HCTz is my blood pressure medication. But low potassium? That was true when I was hospitalized two years ago, not now. What's going on?

Then I saw the list of "conditions" it told Google I have. Below is a partial screen grab, followed by the complete condition list that PatientSite transmitted: *(Spoiler alert; this stuff is biological and might seem gross.)*

Profile summary Print

Conditions

- Acidosis More info »
- Anxiety Disorder More info »
- Aortic Aneurysm
- Arthroplasty - Hip, Total Replacement
- Bone Disease
- CANCER
- Cancer Metastasis to Bone
- Cardiac Impairment
- CHEST MASS
- Chronic Lung Disease
- Depressed Mood More info »
- DEPRESSION More info »
- Diarrhea
- Elevated Blood Pressure More info »
- Hair Follicle Inflammation with Abscess in Sweat Gland Areas
- HEALTH MAINTENANCE
- HYDRADENITIS
- HYPERTENSION More info »
- Inflammation of the Large Intestine More info »
- Intestinal Parasitic Infection

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Acidosis
Anxiety Disorder
Aortic Aneurysm
Arthroplasty - Hip, Total Replacemt
Bone Disease
CANCER
Cancer Metastasis to Bone
Cardiac Impairment
 CHEST MASS
 Chronic Lung Disease
 Depressed Mood
 DEPRESSION
 Diarrhea
Elevated Blood Pressure
Hair Follicle Inflammation w Abscess in
  Sweat Gland Areas
HEALTH MAINTENANCE
HYDRADENITIS
HYPERTENSION
Inflammation of the Large Intestine
Intestinal Parasitic Infection
Kidney Problems Causing a Decreased
 Amount of Urine to be Passed
Lightheaded
Low Amount of Calcium in the Blood
Low Amount of Potassium in the Blood
Malignant Neoplastic Disease
Migraine Headache
MIGRAINES
Nausea and Vomiting
Nephrosis
PSYCH
Rash
Spread of Cancer to Brain or
  Spinal Cord
Swollen Lymph Nodes
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Yes, ladies and germs, it transmitted **everything I've ever had. With almost no dates attached.** (It did have the correct date for my very first visit, and for Chest Mass, the x-ray that first found the undiagnosed lesion that turned out to be cancer. But the date for CANCER itself, the big one, was 5/25/07 – four months after the diagnosis. And no other line item had any date. For instance, the "anxiety" diagnosis was when I was puking my guts out during my cancer treatment. I got medicated for that, justified by the intelligent observation (diagnosis) that I was anxious. But you wouldn't know *that* from looking at this.)

See how some of the listed conditions have links for More Info? Let's see, I was diagnosed with optical migraine. *(I diagnosed myself, actually, by researching my symptoms and finding this illustrated site. That's what e-patients do;* **it saves time in the doctor's office…** *I brought a printout, with a dated list of episodes.)* But optical migraine is not the impression you'd get from reading my Conditions list – in fact during my cancer workup one resident said "But you have headaches, right?" "No," I said – "optical migraines, but without pain." *(The illustration shows the dazzling pattern that an optical migraine produces.)*

So for that item in the conditions list, I clicked More Info. I didn't get more info (i.e. accurate info) about my diagnosis, just Google's encyclopedia-style article about migraines in general. (An optical migraine has little in common with migraines in general.)

The really fun stuff, though, is that **some of the conditions transmitted are things I've never had:** aortic aneurysm and mets to the brain or spine.

So what the heck??

I've been discussing this with the docs in the back room here, and they quickly figured out what was going on before I confirmed it: **the system transmitted insurance billing codes** to Google Health, **not doctors' diagnoses.** And as those in the know are well aware, in our system today, insurance billing codes bear no resemblance to reality.

(I don't want to get into the whole thing right now, but basically if a doc needs to bill insurance for something and the list of billing codes doesn't happen to include exactly what your condition is, they cram it into something else so the stupid system will accept it.) (And, btw, everyone in the business is apparently accustomed to the system being stupid, so it's no surprise that nobody can tell whether things are making any sense: nobody counts on the data to be meaningful in the first place.)

It was around this time that I commented on Ted Eytan's blog, "**when you're exporting to a new system, the rule is, Garbage Out, Garbage In. (Hint: visibility into the data in your old system may leave you aghast.)**"

We could (and will someday) have a nice big discussion about why the hell the most expensive healthcare system in the world (America's) STILL doesn't have an accurate data model, but that's not my point. We'll get to that.

And now we get to why I said, at the outset, don't jump to conclusions. I'm mildly bitching about PatientSite, but that alone wouldn't justify staying up to 3 in the morning writing a 2800 word post; that one system isn't a big deal for e-patients everywhere. (And besides, although PatientSite is old and clunky, a 1999 system if I ever saw one, it beats what most hospitals offer, and it did the job very well for me during my illness. And this is just version 1 of the interface; the current folly is not a permanent situation.)

The BIG question is, **do you know what's in your medical record?** And THAT is a question worth answering. For every one of you.

See, every time I speak at a conference I point out that my 12/6/2003 x-ray identified me as a 53 year old woman. I admit I have the man-boob thing going on, but not THAT much. And here's the next thing: it took me months to get that error corrected, because **nobody's in the habit of actually fixing errors.**

Think about THAT. I mean, some EMR pontificators are saying "Online data in the hospital won't do any good at the scene of a car crash." Well, GOOD: you think I'd want the EMTs to think I have an aneurysm, anxiety, migraines and brain mets?? Yet if I hadn't punched that button, I never would have known my data in the system was erroneous.

And **this isn't just academic:** remember the Minnesota kidney cancer tragedy just a year ago, which arose at least partly out of an error that ended up in the hospital's EMR system. Their patient portal allowed patients and family to view some radiology reports, but not the one that contained the fateful error.

The punch line came when I got over my surprise about what had been transmitted, and realized what had not: my history. Weight, BP, and lab data were all still in PatientSite, and not in Google Health.

So I went back and looked at the boxes I'd checked for what data to send, and son of a gun, there were only three boxes: diagnoses, medications, and allergies. **Nothing about lab data, nothing about vital signs.**
(So much for "no need to manually enter this

health data into Google's personal health record.")

And of the three things it did transmit:

- what they transmitted for diagnoses was actually **billing codes**
- the one item of medication data they sent was correct, but it was only my current BP med. (Which, btw, Google Health said had an urgent conflict with my two-years-ago potassium condition, which had been sent without a date). **It sent no medication history,** not even the fact that I'd had four weeks of high dosage Interleukin-2, which just MIGHT be useful to have in my personal health record, eh?
- the allergies data did NOT include the one thing I must not ever, ever violate: **no steroids ever again** (e.g. cortisone) (they suppress the immune system), because it'll interfere with the immune treatment that saved my life and is still active within me. (I am well, but my type of cancer normally recurs.)

In other words, the data that arrived in Google Health was essentially unusable.

And now I'm seeing why, on every visit, they make me re-state all my current medications and allergies: maybe they know the data in their system might not be reliable. Hey wait, a new article in the *Archives of Internal Medicine* (co-authored by our own Danny Sands, my very own primary) says **Clinicians override most medication alerts**. Could it be they've been through this exercise themselves, and *they* consider the data unreliable? (Or do they just not trust computers?) (Hey Pew Internet, wanna check for generational differences?)

Who knows, perhaps the resident in the migraine story has learned early on that the data in his system is not to be taken at face value – I don't know.

In any case, my hospital is very proactive and empowering to staff about root cause analysis for failures, with its "SPIRIT" program, and they'll add any process or form that can catch potential errors. That's good.

But wait: On numerous visits, I've restated on those forms "no steroids." But evidently what I write on the forms never gets entered into the system. Hm.

I work with data in my day job. (I do marketing analytics for a software company. We import and export data all the time.) I understand what it takes to make sure you've got clean data, and make sure the data models line up on both sides of a transfer. I know what it's like to look at a transfer gone bad, and hunt down where the errors arose, so they don't happen again. And I'm fairly good at sniffing out how something went wobbly.

And you know what I suspect? **I suspect processes for data integrity in healthcare are largely absent, by ordinary business standards.** I suspect there are few, if any, processes in place to prevent wrong data from entering the system, or tracking down the cause when things do go awry.

And here's the real kicker: **my hospital is one of the more advanced in the US in the use of electronic medical records.** So I suspect that most healthcare institutions don't even know what it means to have processes in place to ensure that data doesn't get screwed up in the system, or if it does, to trace how it happened.

Consider the article in *Fast Company* last fall, about an innovative program at Geisinger. Anecdotally, it ended with this chiller:

> … a list of everybody that accessed the medical record from the time he was seen in the clinic to two weeks post-op.'There were **113 people** listed — and every one had an appropriate reason to be in that chart. It shocked all of us. We all knew this was a team sport, but to recognize it was that big a team, **every one of whom is empowered to screw it up** — that makes me toss and turn in my sleep."

In my day job, our sales and marketing system (Salesforce.com) has very granular authorizations for who can change what, and we can switch on a feature (at no extra cost) to track every change that's made on any data field. Why? Because in some business situations it's important to know where errors arose – an

error might cause business damage, or an employee might sue over a missed quota.

So I'm thinking, **why on earth don't medical records systems have these protections?** If a popular-priced sales management system has audit traces, to prevent an occasional lawsuit over a sales rep's missed commission, why isn't this a standard feature in high-priced medical records systems?

In any case, in the several weeks since these discoveries started, as far as I know they haven't figured out how my wrong data got in there. And without knowing how the wrong data got in, there's not a prayer of identifying what process failed.

BUT AS I SAID, this is not about my hospital; a problem at my hospital affects only one scrillionth of patients in the US, not to mention the rest of the world. And please don't blame my hospital's CIO; I think what he wrote about the Google Health interface was overzealous, but I believe he's a good man, committed to helping us own our own data (his work on the Google Health advisory board was unpaid), and this post isn't about him: as far as I know, **this hospital is farther along than anyone else:** hardly anyone else has implemented a Google Health interface. (Perhaps for good reason.)

Nor is this a slam on Google Health. I haven't probed yet into whether there are limitations in what it does; might be fine, might not. Heck, neither PatientSite nor I have put any good data into it yet. (And I haven't even touched HealthVault.) None of that is my point.

Rather, my point is about the data that was already in my PHR, uninspected. For that, let's return to my previous post:

Then imagine that one day you were allowed to see the records, and you found out there were a whole lot of errors, and the people carefully guarding your data were not as on top of things as everyone thought.

In my day job, when we discover that a data set has not been well managed, we have to make a decision: do we go back and clean up the data (which takes time and money), or do we decide to just start "living clean" from now on?

My point, my advice to e-patients, is:

Find out what's in your medical record. What's in *your* wallet, medically speaking? Better find out, and correct what's wrong.

Get started, manually, moving your data into Google Health, HealthVault, or some such system. I've heard there are similar PHR systems (personal health records), not free but modestly priced, that can reportedly make this easier. I'm sure their friends will show up here in the comments. (Feel free to post product info links in the comments, everyone.)

Let's start working, now, on a reliable interoperable data model. I know the policy wonks are going to scream "Not possible!" and I know there are lots of good reasons why it's impossibly complex. But y'know what else? I've talked to enough e-patients to be confident that **we patients *want* working, interoperable data.** And if you-all in the vendor community can't work it out, we will start growing one. It won't be as sophisticated as yours, but as with all disruptive technologies, **it will be what we want.** And we'll add features to ours, faster than you can hold meetings to discuss us.

I have to say, while researching this post I was quite surprised at how very, very far the industry has to go before reaching a viable universal data model. New standards are in development, but I'm certain that it will take years and years and gazillions of dollars before any of that is a reality. (What, like costs aren't high enough already?) In the meantime, your data is probably not going to flow very easily from system to system. Far, far harder than (for instance) downloading your data to Quicken from different credit card companies and banks.

(Wizards and geeks refer to this "flow" issue as "data liquidity." We'll talk about that in the future.)

Let's start working, now, on an open source EMR/PHR system. The open

source community creates functionality faster, and more bug-free, than commercial vendors do – and nobody can latch onto proprietary data in such systems to milk more margin out of us… because it *ain't* proprietary.The great limitation of open source is that it's generally not well funded. But you know what? Every person in America (including software engineers) is motivated to have good reliable healthcare systems, and I assert that the industry ain't getting' it done on their own. As I said in my Thousand Points of Pain post (cross-posted on IBM's Smarter Planet blog as **A business thinker asks, what will it take to get traction?**), it's fine with me if industry vendors come along too – but I would not stake my life on their moving fast enough for my needs. Or your mother's.

Want a case study with real consequences? Recall what happened last year to famed **Linux guru Doc Searls** when he couldn't read his own scan data, because good cross-platform image viewing tools weren't available. (His prescription: the patient should be the platform and "the point of integration.")

Well, okay, so Doc was a year ahead of me. I'm catching on. This illustrates why I think people from outside the profession may be our greatest asset in building what *patients* really need: patients tend to build what they want. And we who work with data all day know that these problems are not unsolvable.

My bottom line: I think **we ought to get our data into secure online systems,** and we shouldn't expect it to happen with the push of a button. It'll take work. **So let's get to work.**

You know the work will be good for you, and heaven only knows what you'll learn in the process. You'll certainly end up more aware of your health data than when you started. And that's a good thing.