

“Over My Dead Body”: Why reliable, usable systems matter to patients

Testimony before the
Adoption/Certification Workgroup, HIT Policy Committee
April 21, 2011

Dave deBronkart (“e-Patient Dave”)
Blogger, e-patients.net
Volunteer co-chair, Society for Participatory Medicine
<http://www.ePatientDave.com/contact>

4.5 pages plus cover and appendices

Summary

- Data quality matters. It affects care.
- Workflow matters. It affects data quality.
- Usability affects workflow, data quality, and worker productivity.
- In regulating this issue, let us manage expectations wisely.

“e-Patients are Empowered, Engaged,
Equipped, and Enabled.”

*“Doc Tom” Ferguson MD 1943-2006
Founder of e-Patients.net
Precursor of the Society for Participatory Medicine*

“Over My Dead Body”: Why reliable, usable systems matter to patients

“e-Patient Dave” deBronkart
April 21, 2011

Prolog

Last spring a rumor circulated that a health IT executive did not want the company’s systems to be evaluated on usability, as a criterion for Meaningful Use. The executive’s words were reportedly, “Over my dead body.”

If that rumor is true, it’s appalling. Either way, though, the Inspector General’s November report cited that 15,000 elders (Medicare patients) are accidentally killed every month – 500 a day. Whatever the root cause of each of those killings, surely one factor for improvement or decline is the quality of information available to health workers at the bedside.

Data quality matters, and system usability matters.

Last June I spoke at the annual meeting of AHRQ’s grantees and contractors. For my title, I chose those rumored words: “Over My Dead Body: Why reliable systems matter to patients.” In these remarks today, I add usability to my definition of “reliable.” Because as I said then, a system that’s hard to use – when entering data or reading it – will surely affect how well workers can do their job.

I assert that quality matters, workflow matters, and we must have – and enforce with policy – realistic expectations for how good IT can improve care by insisting that systems be usable. Consumers’ / patients’ lives are at stake, and that outweighs business concerns. As I said in that AHRQ talk, “Save lives first. *Then* compete.”

1. Background and Context

The statements submitted by others on this panel have covered the consumer point of view, very much to my satisfaction. Rather than duplicating, I’ll add my perspective as a data-oriented consumer.

Background

I approach this assignment from three perspectives:

- As a practitioner and advocate of participatory medicine, in which “patients shift from being mere passengers to being responsible drivers of their health.”¹
- As someone who has used data and automation throughout his career.
- As someone who experienced, first-hand, the consequences of poorly managed health data. This happened when I moved my hospital data into Google Health two years ago; more on this later. My desire was to encourage innovation; what we saw was that bad data defeats any attempt at automation or analysis.

¹ <http://www.ParticipatoryMedicine.org>

The Society for Participatory Medicine is dedicated to improving healthcare by encouraging doctor-patient collaboration. In conference speeches, blogs, and the Journal of Participatory Medicine, we advocate and develop practices that enable patients and families to be effective partners in their care. As volunteer co-chair of the Society, I testified last year at two ONC workgroup meetings about encouraging consumer participation in health IT.

Professionally, before becoming involved in healthcare I spent most of my career in understanding and developing automated, computerized workflows. Most of that work was in graphic arts, and later in data-driven marketing systems. I understand what data and automation can and cannot do, and how it can go wrong.

An Essential Truth:

If a system supports users in doing things right, things will work better.

That's extremely important when it comes to health data. Systems *must* support the people who must use them to care for patients.

Best practices from other industries must be heeded in health IT.

2. Managing Expectations: What Health IT Can and Can't Do

In media coverage and blogs I've heard many rumors and misconceptions about what automation can achieve. We must set our expectations, and the public's, appropriately. I assert:

Properly implemented,
a medical record system can *store* and *retrieve* information
in ways that make it easier
for staff to care for patients.

Good systems can also
analyze the information, and *display* it,
in ways that make it easier
for staff to care for patients
and for managers and policy makers
to improve care.

All of this depends
on good quality data,
which requires reliable, practical workflows.

Misconceptions and false expectations

Misconceptions abound, sometime explicit, sometimes implicit – even in respected publications.

Two recent articles showed an alarming naivete about what we should expect systems to do. If these go unchecked, we'll make ill-informed decisions.

One post on a respected blog cautioned, **“EMR perpetuates wrong information.”**² Well, of course it does – when you record something wrong, it stays wrong! This has been true since writing was

² <http://www.emrandhipaa.com/emr-and-hipaa/2011/03/15/emr-perpetuates-misinformation> (accessed 4/20/2011)

invented. **It matters what you put in the system.** As with banking, credit cards, and airline reservations, data quality matters.

A foundation principle: You put data into a system so you can read it out. Quality is essential, or you'll read back lies – you'll get automated crap. Workers won't trust the system, and the whole initiative will fail.

The other article said **“EHRs do not impact quality of healthcare”**³. A paper in the *Archives of Internal Medicine* did a retrospective analysis and reached this conclusion. It's an enormous accusation: a key selling point for health IT has been that it *will* improve the care our families get.

But it turns out the researchers' definition of “quality” is not about healthier, better-served patients; they simply evaluated whether the doctor prescribed the right thing! Consumers I've spoken with have been alarmed at the news that doctors often don't, and they've been even more surprised that anyone would expect a computer to fix that.

If the problem is that doctors often don't know what they're doing, do we really expect health IT to fix that? It's an unrealistic expectation. But in a highly politicized environment, we must be conscious of expectations, and we must manage them.

We **should** expect that our systems be reliable. And in the high pressure environment of modern healthcare, that means they must be usable, or they'll get in the way. And then detractors will say “See? Computers aren't useful.”

3. Essential Principle: The “I” in IT stands for Information. Quality is essential.

The next fundamental item to understand is that the entire concept depends on having good *information* in the system, encoded as good *data*. Bad EMR data can be as hazardous as wrong map information in a GPS. This section will discuss the consequences of bad decisions about data and workflow.

Health IT policy decisions are sometimes technically brilliant but naïve technically. For instance, in a modern academic medical center, truly prodigious amounts of data must be moved around reliably, at incredible speeds. That's one part of IT. But for patient medical data, it matters what's *in* the data. It does no good to brilliantly transport massive amounts of bad data.

Said differently, the semantics and workflow must accomplish the mission of conveying knowledge, or things go haywire. My personal experience with this was two years ago, when I tried to move my hospital data into Google Health (Appendix A). What came across was garbage. Why? The answer's not trivial.

- In one sense, **it wasn't Google's fault**: all they did was [trustingly] receive the garbage that my hospital had sent. Two bottom-line factors contributed to it being garbage:
 - An inappropriate data vocabulary had been chosen (billing codes instead of clinical data). The result shows clearly that the vocabulary was never evaluated for fitness for purpose.
 - Just as clearly, the transfer software had never been tested using real-world data, to see if the clinical picture (the information) received at the other end (Google or HealthVault) matched the sending end.

³ See blog discussion on e-patients.net with link to original article and other discussions: <http://e-patients.net/archives/2011/01/electronic-health-records-do-not-impact-the-quality-of-healthcare.html> (accessed 4/20/2011)

- Anyone who's ever developed a production workflow knows this is an essential step. Imagine an automated computer factory where they switched on production without testing the flow.
- Conclusion: It is not acceptable in healthcare to brilliantly move vast quantities of data around, with no concern for whether the data is valid.

There's more to IT than transport; the I stands for *information*. And in health IT, bad information is digital poison.

- **But workflow could have saved the day.** Google could have "architected" some protection against bad incoming data. For instance, when I worked with marketing data I learned the hard way that getting bad data out of the system is messy and costly. So before we imported a big batch, we tested with a small batch. And some systems let the user inspect or preview the incoming data, before it's merged into the system.

Lessons:

- **Quality at the source.** Do what you can to ensure that only reliable data gets into the system. (This is a lesson from Lean and Six Sigma.) Usability helps.
- **Workflow matters.** It matters whether users follow a good process. In my experience, if that's hard to do (e.g. bad usability), people don't do it, and quality suffers predictably.
- **Testing matters.** With real-world data. (More on this later.)

Observations for this project:

- **The individual items we regulate – e.g. usability – must be considered in the context of the whole system.**
 - If we address any one factor in isolation and the system fails, we risk attributing it to the one factor we're evaluating. Naïve or politicized observers may say, "See? We tried using computers, and it stunk." This could torpedo the initiative to modernize health information and innovation. Instead, *we must take a systems view*, including usability.
- **Usability can affect data quality.** A system that's hard to use does not encourage careful, reliable data entry and data read-back. Plus, bad usability can lead to tortuous workflows and workarounds, which in turn affect data quality.

Bottom line:

If our purpose in regulating these systems is to encourage adoption of meaningful, good quality systems, then I assert it's legitimate to **mandate** that systems encourage, not inhibit, getting the job done.

4. Conclusion: We Need Healthcare Workers' Attention on the Patient, not the System.

The questions assigned to us talked about consumer thoughts on usability. Other panelists' statements have addressed that well. I have spoken at an additional level: the impact that usability will have on consumers – patients and their families.

Usability problems get in the way of people doing their job. In any industry that's bad; in healthcare it can be disastrous. When my wife is in a hospital someday, I want workers' attention on her.

And I don't want them overlooking information in paper records, as happened repeatedly with Regina Holliday's husband (Appendix B)!

Ross Koppel's testimony, last year and this year, documents the many ways that obsolete programming creates potholes in the workflow and can even obscure critical warning messages.

On a pragmatic sociological note, the last thing any of us needs is justifiable grumbling next year about stupid bureaucrats who make people use crappy systems. I'm reminded of the major medical center that rejected one costly system, and switched to another that it described as "the cream of the crap."

We can minimize that risk by mandating vendors must make their systems usable. Consumers will surely benefit, and so will the health workers who deliver care.

P.S. – About the need for real-world data...

I've heard repeatedly that we can't test systems using real-world data because it's difficult to get patient's consent on privacy forms. Earlier this year Twitter user @MatthewBrowning brilliantly proposed that we springboard off the VA's "Blue Button" idea – "Download my data" – and create a "Green Button: Donate My Data."

Someone later noted that a "data donor" would be analogous to an organ donor: gladly contributing to others' welfare by donating something very personal. If it ever happens, I'll be among the first.

Appendix A: 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 breakthrough 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?

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.)*

- Acidosis
- Anxiety Disorder
- Aortic Aneurysm
- Arthroplasty - Hip, Total Replacem
- 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

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 scillionth 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.

Appendix B: Regina Holliday's observations at CPeH on reading her husband's medical records

[Blog post](#) on e-patients.net, 12/15/09

Yesterday I attended "How Access to Information Can Empower Patients and their Caregivers," conducted by the Consumer Partnership for eHealth. CPeH is an alliance of stakeholder groups sponsored by the National Partnership for Women and Families. It has no web site of its own - it's just a Partnership for Consumer eHealth, convening to work on accomplishing good health through IT - especially health data.

An incredible moment (and I don't say that often) happened after three physicians presented how their organizations are giving patients access to their medical records online. Their presentations were all encouraging. But during Q&A we got down to the nitty details, and comments from two physicians revealed a well-meaning attitude that I can only describe as protective and paternal:

- Concern about emotional impact of bad news
- Concern about the difficulty of interpreting some reports: "Even I can't understand radiology reports sometimes."

Regina Holliday was there - the "73 Cents" artist whose husband died of kidney cancer in June. Ted Eytan MD, an avid advocate of patient empowerment, asked her thoughts. With a cold clear look in her eye she said:

When I finally got my hands on his medical records - a **month** after I asked for them - I saw that on 3/25, 3/26, 3/27 and 3/28 they mentioned an 8cm tumor in one kidney and 10cm in the other, a large growth in the abdomen, bone mets in the pelvis, sacrum, femur, and skull, and soft tissue mets throughout the lung; at the end the reports say they couldn't get a good image "due to patient's extremely distended bladder." The nurse's notes of 4-7 also mention concern over urine retention.

After another CT on 4-10, *then* the radiologist comes to me to tell me verbally

that the patient's bladder is on the point of rupture.

My husband almost died from a ruptured and infected bladder, while in the care of hospital staff, because nobody **read** the record. I could have read it and known he needed a catheter.

What came next was telling: a physician, meaning well I'm sure, said "Well, we can sit here - we're all college educated ..." and Regina said "I'm not."

What lessons can we take away? I'll start:

- You don't have to be an MD to contribute value from seeing the record.
 - Consider the [Minnesota kidney cancer tragedy](#) two years ago. (A cancer patient awoke to find that the wrong kidney had been removed. It traced back to an error in the first dictated report.) If the family had seen the doctor's notes they could have spotted the wrong-side error.
- As internet visionary Clay Shirky has said, "Giving patients access to their medical records will just naturally improve the quality of what's in there. It's like the way you clean up when you know company's coming."

Regina summed it up in an email today: "Have they met the folks on [ACOR](#)? Might open their eyes."

Perhaps protective paternalism should be inverted: DO show us our data, to help us save our own butts from medical error.

Now that I think of it, who *wouldn't* want to let us help save our own family members?

What a fitting fulfillment of the meeting's title - "How Access to Information Can Empower Patients and their Caregivers." Thanks to CPeH and the National Partnership for an important meeting.