e-Patients Can Help. Let Us.
Our Families' Lives Are At Stake.

Testimony before the
Adoption/Certification Workgroup, HIT Policy Committee
February 25, 2010

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- Let our foremost commitment be: To do healthcare better.

- Improvements that happen "now" make a big difference.
  There are people in hospitals *now* who are at risk from errors
  and bad data. Let us be compassionate, caring and creative now,
  in addition to building better "future nows."

- Let us work together. Let us do what encourages improvement.

"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

1. Preface

One of my first career mentors told me "All software has bugs. Any complex system has unintended behaviors. There's no use arguing about this; what works is to manage it thoughtfully."

Let us hold certain fundamental human rights in our hearts and our minds as we regulate.

In the past year I've come 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 – not in the 30-60 days allowed today by our 1996 HIPAA law.

I often say "Patient is not a third person word. Your time will come." This will likely matter to you sooner than you expect, and surely before we've finished implementing all our plans for great new health IT systems. A useful question: what can we do now, to help each other now, while we work on creating the future?

I am no physician, nor a policy wonk, nor a health IT guru. But three real-life stories informed my thinking as I prepared these notes.

Three anecdotes

- *My PHR data transfer*

A year ago I famously[1] tried to transfer my cliinical records from my hospital to Google Health. What came across instead was billing data, which, it turns out is not a good representation of clinical reality.

There was a media and blogging firestorm. As often happens in such cases, the original message got lost. Some people now think I claim IT will solve everything. No; what I said was "**Find out what's in your medical record.** What's in your wallet, medically speaking? Better find out, and correct what's wrong."

The root cause of the errors turned out to be that an inappropriate data vocabulary had been chosen (ICD-9 billing codes), not suitable to the task of modeling clinical reality, and had not been sufficiently testedbefore public release. These are IT policy errors, easy to understand once the resulting data was seen.

- *Cancer patient wakes up to find wrong kidney has been removed.*

A year after my own nephrectomy, in a hospital near where I used to live, a surgeon removed the wrong kidney, leaving the cancerous one in place. The root cause turned out to be an error in the surgeon's original dictated notes.

The hospital's patient portal lets patients and families see some records but not the one containing the fateful error. If the family had reviewed the notes they could have prevented this tragedy.

- *Soon-to-be-widow discovers orders and information in her husband's medical record that staff had overlooked*

Regina Holliday, now famous as the "73 cents" artist whose mural covers a wall in Northwest DC, labored to get her husband's medical records out of the previous hospital. The sole provider for two small children in a one bedroom apartment, she paid 73 cents a page for hundreds of pages of printout. Among other things she found an unfilled order for a walker (her husband had painful bone metastases) and weeks-old radiology reports indicating that his bladder was in danger of rupture.[2]

A catheter was immediately inserted, averting another disaster, because the family reviewed the records.

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[1] See blog post, Appendix A.

[2] See blog post, Appendix B

2. The case for safety, compassion and collaboration

These anecdotes drive home several points:

- **Human enterprises involve frailty.** With or without I.T., mistakes happen.

- In healthcare more than most places, **mistakes can have tragic consequences.**

- **Workload can outstrip staff capacity.** This is a vital reality to accept. To the person whose parent is in a hospital bed *now*, it doesn't matter whether an overload is due to short staff, a peak in workload, or suboptimal skills. What matters is the gap: being aware of it and doing everything we can to "manage it thoughtfully," as my mentor said.

- **It is not helpful to focus on punishment.** Like the black box in airliners, root cause analysis can help understand how some-thing went wrong, and prevent recurrence. But if our priority is punishment, it dis-courages open collaboration toward continuous improvement.

- **Patients can help.** You don't have be an oncologist to notice "Wait a minute, the cancer's in the *left* kidney" or "Hey, the doctor ordered a walker to reduce Fred's pain. Where is it?"

3. A second set of eyes

Others will speak of the many risks introduced by poorly managed EHR data or software bugs, not to mention clinicians being forced to use systems that can make life hard. How can we "manage it thoughtfully," without adding vast complexity that will take years to achieve?

A second set of eyes can help.

Workgroup co-chair Paul Egerman told me that when he worked on Mass General's first EMR, he would let the patient see what he was typing, to reduce errors. And I thought back to my early career, in typesetting, where it's axiomatic that you can't proofread your own work.

Heck, even drive-through restaurants do this: your order is displayed on a sign as it's entered. Why do they spend money on all that technology? **Because it reduces errors.**

4. Yes, we can handle it.

When advocates propose giving patients full access to 100% of their records, a commonly cited concern is whether patients can "handle it." Physicians have earnestly shared first-hand experiences with me:

- A patient sees a lab number highlighted in red and is worried.

- Worse, there's the possible emotional impact of truly bad news.

- There's concern about the difficulty of interpreting some reports: "Even I can't understand radiology reports sometimes," said one doctor.

- Concern about patients flooding the physician's office or email with questions.

Been there, done that. Early in my disease I mis-understood a CT scan report and thought a tumor had grown 30% in a week. It turns out I'd misunderstood terms like "craniocaudad," identifying different axes (x, y, or z) in different scans. I emailed my oncologist, Dr. David McDermott. I was worried but kept the email short. He explained. I apologized.

And he responded "I am happy to field your questions." This, from one of the greatest oncologists in the field.

If a great physician can happily field questions, how is it that other physicans fear our naivete?

Whenever a new population enters a field, there are concerns about competence and stories of failure.

When I was young, women often didn't drive, and women drivers (usually portrayed as airheads) were the butt of jokes by comedians and cartoonists[3]:

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[3] Reproduction rights applied to at CartoonStock.com.

CAR SALES

"It's for her- Do you have one with a bumper all the way around?"
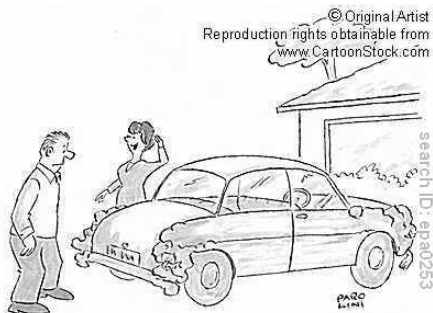
"TALK ABOUT LUCK! THREE FENDER BENDERS AND MY HAIR IS STILL IN MINT CONDITION!"

Why this contempt? Because a simple truth is often forgotten: **Until people gain experience, they're inexperienced.**

My own mother (no airhead) didn't learn to drive until she had three kids and a salesman husband who was often away. She was remorseful when she had her first fender-bender (backing into a lamppole), but her husband said "I'm glad. Now you know how easily it can happen." That's empowering.[4]

It is an error to construe early ineptitude as inherent unfitness. Today we know women have 1/3 fewer accidents than the men who used to insult them.[5]

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**The solution is not
to withhold and constrain.**

**Empower the people –
enable and train.**

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Or as my primary physician Danny Sands, MD, MPH says, "Embrace knowledge symmetry."

In fact, to *not* empower and train competent new eyes will inhibit better safety in the future. Who wants that? **Let patients help.**

Yes, that includes the scary stuff.

The December 2009 meeting of the Consumer Partnership for eHealth was titled "How Access to Information Can Empower Patients and their Caregivers." A telling moment occurred as physician presenters candidly discussed their concerns about whether patients can "handle it," and Regina Holliday had just recited the areas where she'd been plenty capable of identifying ways to help her husband – even reading the most gruesome details.

What came next was telling: a physician said "Well, we can sit here and think that - we're all college educated ..."

And Regina said, "I'm not."

Regina is an example of an e-patient: an empowered, engaged family member who will help in any way she can. Who *insists* on helping any way she can.

Please: **Let e-patients help.**

Not all families want to get involved; but why deny the ones who do?

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[4] A punishing attitude would not have been useful. (And guess whose career had more violations.)

[5] Insurance Information Institute's Fact Book 2005

5. Recommendations

1. To mitigate risk of undetected errors, mandate consumer viewing of records, electronic or paper. A second set of eyes.

One rapidly achievable way to mitigate risk is "while you wait" visibility into existing medical records, either electronic or paper.

- In this regard HIPAA is outdated. There is no technical reason why families shouldn't be allowed to see records on request.[6]

- For EMRs, put a terminal in the hall or a private room. (Perhaps provide glossaries at different levels of complexity.)
  - Mandate that no provider shall qualify for meaningful use incentives unless they, by policy, allow patients and families to view the record on demand – perhaps within an hour or two.
  - Move toward exposing the data via browser. That will take work, but it's achievable: it's a well understood process from other industries.

2. To accelerate continuous improvement, mandate that providers log and publish adverse EHR events.

 This too can be part of MU eligibility. To me this is no different from the FAA requiring collection of data about airline adverse events, from near misses to actual crashes.

I also urge that this requirement apply to system vendors. I'm new to this subject but today's "hold harmless" clause seems to fail to encourage "managing thoughtfully," i.e. collecting information that would help us identify the best opportunities to improve safety.

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[6] An important non-technical reason is embarrassment about messy records. Internet visionary Clay Shirky told me, "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." We'll have to get past this – including telling patients to just deal with it, not explode, in the interest of working together to improve quality.

Note that I didn't say "identify the biggest culprits"! As I said, it's not useful to focus on punishment. In my experience patients want safety far more than they want to find fault.

BUT, endless cries for tort reform make clear that wishful thinking won't do any good. So:

3. Toward that end, grant amnesty for all reported errors, to eliminate providers' liability concerns.

Wherever the source of the error is, let us help find it so we can prevent recurring harm.

Today's "hold harmless" clause apparently works to put 100% of the burden on the hospital and clinicians as "learned intermediaries." I understand this logic to some extent but as a patient with computer system experience, I think it's absurd, unfair, unrealistic and unworkable.

Do we truly want our priority to be avoiding punishment, or shall we regulate to encourage innovation and improvement? I say the latter.

Plus, reports from the patient safety field show that where there are "apology laws" allowing physicans to apologize for errors, it helps.

So I believe we must grant amnesty to all for reporting problems: vendors, institutions and employees. This is a well established practice across all quality improvement disciplines, and we should encourage improvement by codifying it for health IT.

The millions of patients in care *now* will appreciate it. And the patients you and I will know (or will become) in the coming years will be even more grateful.

4. Mandate strong privacy / security.

I didn't discuss this above, and I'm not qualified to offer details on implementation, but I hear this clearly from a broad minority of patients across the country. Some consider it a vital concern about medical records: that which is online can be snooped and abused.

I know there are those who say "You have no privacy. Get over it." I know USA Patriot allows unprecedented types of data collection. And I've talked to people who say co-workers at their

companies actively sought private medical information about employees so they could get target those people for termination for some other reason.

In any case, a lot of patients are concerned about privacy. It's a concern we need to listen to and address.

6. Conclusion

Throughout my career I've worked at making automation succeed. In the 1970s and 80s I was part of automating the newspaper industry; it's not quite as life and death an industry as healthcare, but they have very low tolerance for coverups: a daily newspaper system *must* get the job done *every day*, and if there's a bug, they just want to know about it so they can deal with it.

That is, so they can manage it thoughtfully.

In the two years since I began learning about healthcare I've developed wonderful relationships with visionary thinkers and many people who work hard to deliver great care and devise new delivery systems. I've become an advocate for my own hospital, publishing podcasts with my physicians, and appearing in a video on their site. I *love* good healthcare. I'm alive because of it, and I used my hospital's personal health portal in every way I could – even in ways that surprised them.

Please, let us remember these key points:

- **<u>Lives are at stake.</u>** Let's do everything in our power to help people help themselves.

- **<u>Punishment is not useful.</u>** Partnership is.

I believe in technology. I believe in the value of good quality data, well managed.

I also know what can happen when automation is applied to bad data.

Throughout all these thoughts, what calls to me most is what I put at the top of this paper.

Thank you for the opportunity to testify.

- Let our foremost commitment be this: To do healthcare better.

- Improvements that happen "now" make a big difference. There are people in hospitals *now* who are at risk from errors and bad data. Let us be compassionate, caring and creative now, in addition to building better "future nows."

- Let us work together. Let us do what encourages improvement.

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 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?

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.)*


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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
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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 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.

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

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.