# Let Patients Help.
# We are the ultimate motivated stakeholders.

Testimony before the
Meaningful Use Workgroup, HIT Policy Committee
April 25, 2010

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> "These are exciting and very promising times for the widespread application of information technology to improve the quality of healthcare delivery, while also reducing costs, but there is much yet to do, and in my comments I want to note especially the importance of **the resource that is most often under-utilized** in our information systems – **our patients.**"
>
> – *Charles Safran MD, testimony to the House Ways & Means subcommittee on health* ***in June 2004***

Since Dr. Safran's testimony
US healthcare costs have more than doubled,
quality has not improved,
and virtually nothing has been done
to leverage the engaged patient.

**Let Patients Help!**

"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*

Thank you again to the workgroup for asking for my input. I address you both as a highly engaged cancer survivor and as founding co-chair of the Society for Participatory Medicine:

> "Participatory Medicine is a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners."

We are actively engaged in developing the practices that help patients and physicians be more effective partners. As Stanley Feld MD said in December 2008, "Physicians are coaches. Patients are players." It would be utterly infeasible for patients to excel on the court without access to plans and performance data, and the poor performance of healthcare today is consistent with patients' lack of access to their health data.

I don't have to tell you, the healthcare system is already under stress, and it's about to get a lot worse as 30 million more people gain access to care in a system whose capacity has not increased – on top of the "silver tsunami."

We need **leverage**, some lever that will improve efficiency instead of jacking up costs.

My advice has two simple parts:

**1: Let patients help.**
**We *want* to help.**
**Harness our energy. Give us tools to help ourselves and our beloved elders.**

Toward that end:

**2. Enable innovation through open interfaces.**
**Penalize closed systems.**

Responses to your questions follow. Appendiex A contains responses received on e-patients.net, the blog of the

- ***What I mean when I say "patient"***

N.B.: In all that follows, when I say "patient" I'm including authorized caregivers such as family and friends.

We must stop thinking about care as a binary model in which there are providers (health employees) on one side and "the sick person" on the other. That is an error. Care today has tiers. The only meaningful distinction I can think of is that some people get paid for it and others don't. When I say "patient" I mean all the people who contribute genuine care (including avoiding complications) and aren't getting compensated for it.

## 1. The role of patient-generated data in improving health.

As far as I can tell, people generally don't use PHRs or connected health tools until they have a problem, but then the tools can be vital.

- *Data*

**Patient-generated data can vastly augment what we know** about a patient's condition. I'm including narratives and diaries as well as numeric data. To the extent that better information enables better decisions, that's useful. Example: Once upon a time diabetics could only get their glucose read while in a physician's office; today that seems nuts – or terrifying, if you're the patient.

- *What is the evidence?*

This is a chicken-and-egg problem, and this committee can have a major impact:
**Make studies happen to *create* evidence.**

I endorse the proposal in Eric Dishman's testimony: a Framingham-style longitudinal study.

Gilles Frydman, founder of ACOR and 2010 President of the Society for Participatory Medicine, put it this way: "What ONC should do is to help free funding to do long term studies. Otherwise we'll remain in this insane situation, where we won't be able to direct health professionals and policy makers to evidence-based papers showing the incredible value of patient-generated data. The perfect vicious circle!"

## 2. How can patient-reported data be integrated into EHRs and the clinicians' workflow to improve care management?

EHRs must have an open API, both to submit data to the EHR and to export it.

This will let innovation take its course, without any need for central orchestration by the government or anyone else.

It remains to be seen how this will be integrated into workflows. We should certainly look at the work of systems such as Kaiser, Geisinger, etc etc who have experience at it.

## 3. Future platforms to facilitate patient-centered care, including transparency, coordinated care, patient activation, while protecting patient privacy

- *Encourage "patient as platform" and point of integration*

I believe in the concept proposed by Open Source guru Doc Searls: "patient as platform and point of integration."[1, 2] His view is that the the data should always be where it needs to be: **with the patient.** The matches the concept in Lean workflows that the information any worker needs should already be right there, where it's needed, when it's needed.

This in turn matches the "five Rights" of CDS (clinical decision support),[3] which include the right information at the right time in the workflow. What better place could there be for the information than with the patient? I'm not talking about moment by moment within the hospital – I mean as the patient moves from provider to provider.

- *Enable innovation*

Trying to achieve this through centralized standards would be immense, costly, with great argument at every turn and great risk of getting it wrong, since it's impossible to predict what innovations will arise. Heck, Facebook was formed just six years ago, and the iPhone was introduced in June 2007, less than three years ago! Do we really think we can anticipate what the world will look like in 2013 and 2015?
No: we should set policy to *anticipate* innovation and ride along with it, not be endangered by it.

- *Open APIs*

The central requirement is to make the data readily available to the patient and other tools.

It's all about the ecosystem. Adobe Photoshop became what it is today because of plugins. Twitter became what it is today because of its ecosystem.

Yes, this will require some open architecture, some shared vocabulary. This too should evolve over time, opportunistically, not by centralized orchestration: the government should enable, not dictate, its growth.

There will be complaints from "big iron" vendors about having to adapt to new, open standards. I saw exactly this in the newspaper and typesetting industries decades ago, as they began to automate and move to standards such as PCs and PostScript. Yes, vendors need to develop new interfaces. It's inevitable. Start now.

As some new format *earns* adoption by a substantial population (as PostScript did), current systems will learn to read and write that format in addition to current formats, in the same way that legacy systems learned to speak XML. Ultimately new systems were introduced that natively used the new methods. The temporary discomfort, however real, must be subordinated to our urgent need for a flourishing, organic ecosystem.

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[1] http://e-patients.net/archives/2008/06/doc-searls-patient-as-platform-and-point-of-integration.html

[2] http://www.linuxjournal.com/content/patient-platform

[3] See AHRQ's article on the Five Rights.

- ***Incentives***

Motivational incentives seem important in behavior change. And it seems much more likely that success in this area will evolve through innovation than from figuring it out in advance.

So incentives could be proposed that will reward innovators who produce measurable improvements in health, as is being done in the marketplace today by Dossia and Virgin Health.

Incentives should also be offered for early success (e.g. beta tools) that examine data and correctly predict favorable or unfavorable changes in a person's status. This would incent using smart logic to prevent costs, not just reduce them.

- ***Privacy***

I have nothing to say about privacy, except *please* don't let people die (or get sicker) due to well-meaning but overly zealous thinking that boils down to "privacy at all costs."

The patient ought to control where his or her data goes. I think the real fix for this is to mandate that **the data belongs to the patient,** who is thus legally entitled to do anything with it that s/he wants.

## 4. The role of patients in ensuring EHR data is accurate

This is an urgent issue. The February 25 testimony at this committee's Adoption / Certification Workgroup made all too clear that massive errors exist in many medical records today. We must do everything we can to fix this, not fight about it.

Activated patients are a free, motivated, and readily accessible resource to help with this – and they don't need a penny of stimulus money. Just **Let Patients Help.** This was the focus of my testimony to the February 25 meeting.
My recomendations:

1. To mitigate risk of undetected errors, **mandate consumer viewing** of records, electronic or paper.
2. To accelerate continuous improvement, **mandate that providers log and publish** adverse EHR events.
3. Toward that end, **grant amnesty for all reported errors,** to eliminate providers' liability concerns.

Again: patients are a free, motivated resource. Don't lock them out. Let them help.

## 5. 2013 and 2015

I'm not in a position to say what's achievable by a broad spectrum of providers. I do know two things:

- Nothing blasts through immovable obstacles more powerful than unstoppable market forces. Serious illness creates seriously motivated patients and family. They will become an unstoppable market force, unless policies keep them from getting what they want. We can influence that.
- Data quality can be radically improved by "giving us our damned data" so we can help proofread it.

Here are my requests:

- *2013*

1. **Secure messaging.** Banks have had this nailed for years; so has my hospital, and so have many others. There's nothing to invent here; all we need is to use it.
2. **100% patient read-only visibility into their records.** See my February testimony for details.[4]
3. **Include full access to claims data.** Additional harm can come from errors in one's billing data, as reported by *Consumer Reports* in 2008:[5] a coding error resulting in a cascade of harm for a woman in the Katrina district. Just last month a friend's mother happened to notice a wrong billing

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[4] That testimony urges, by the way, that this apply to both paper and electronic records.

[5] http://e-patients.net/archives/2008/09/whats-in-your-mib.html

code for a prescription; it would have resulting in a wrong diagnosis being on her records.

Some have said that if we can review our billing data we may discover incorrect charges, which could reduce costs, as well. In any case, I adhere to the principle "Nothing about me without me."

4. **A defined process for resolving questions and errors**, per the work of Brandeis professor Ethan Katsh. (He's the acknowledged global guru of online dispute resolution for credit cards etc. On your online American Express statement, where you see "inquire/dispute this item," that's his work. We need the same for health data, and the methodology already exists.)
5. **An export API,** to export the HER's existing data (whatever it may be) in any format. What to *do* with the data (how to parse it etc) will be the responsibility of whoever gets it.

   Keep this simple: just mandate that to qualify for incentives, *you cannot hold onto the data and prevent others (including patients) from leveraging its health benefits.*

- *2015*

I hope that by 2015 some standard structured vocabulary will be available. If so, incentives should require export in that format.

## 6. Conclusion

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:

- **Lives are at stake.** Let's do everything in our power to help people help themselves.
- **Patients are the most underutilized resource.** Let them help themselves.

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

Thank you for the opportunity to testify.

# Appendix A: Comments posted to e-patients.net

## (Blog of the Society for Participatory Medicine)

*Comments received at [http://e-patients.net/archives/2010/04/tell-hhs-whats-the-role-of-patient-generated-data-in-meaningful-use.html#comments](http://e-patients.net/archives/2010/04/tell-hhs-whats-the-role-of-patient-generated-data-in-meaningful-use.html#comments):*

*Gilles Frydman, founder of ACOR and President of the Society for Participatory Medicine:*

Comment 1

There is a certain degree of absurdity in the first question. There has been more than reluctance to spend money to study the impact of patient generated data. In fact there has been very significant pushback for at least 15 years. I had the great luck of working with Barbara Rimer, former director of NCI's Division of Cancer Control and Population Sciences (DCCPS), who was among the first and only scientists ready to risk their reputation doing this kind of research. RWJF funded some very interesting research but the funding did not last long enough for us to be able to really figure out the long term impact of UGC.

What ONC should do is to help free funding to do long term studies. Otherwise we'll remain in this insane situation, where we won't be able to direct health professionals and policy makers to evidence-based papers showing the incredible value of patient-generated data. The perfect vicious circle!

Comment 2

I remember a year ago when we asked about the differences between CCD and CCRs and how each could be dealing with patient narratives.

In other words, now that many people are accepting the rich value of patient narratives and of conversations, what can be done to optimize their archival and potential use in the future? Moving away from the ICD-9 centric EHR world is a good start. Making sure that the CCR of tomorrow is designed with a full section for narrative medicine would be a lot better

*Michelle W:*

I remember going to my university's clinic for a cold and the doctor asking several times if I was pregnant or on drugs. While I sympathized that he often had to deal with hostile patients who wouldn't report such information, I was annoyed that my first responses were assumed to be incorrect.

I have the same issue with any service worker who doesn't take the time to listen to my concerns: don't assume I'm wrong just because I'm not trained the way you are, I may actually have tried what you're about to suggest and it didn't work. But simultaneously, I don't want to be the one totally responsible for a solution: I came to the expert because I couldn't fix it on my own. Such listening and cooperation requires an attitude adjustment and training to work in that way. Studying the long-term uses of such information sounds like a move in the right direction; incorporating patient listening/input into medical education or residency might be another avenue that such studies/evidence would support.

*Mark Boguski MD*

Please see our policy forum published in *Science* last year: [http://www.sciencemag.org/cgi/content/full/324/5933/1394](http://www.sciencemag.org/cgi/content/full/324/5933/1394)

It's a new model of drug discovery that depends on patient-generated data, if the regulatory environment and patent law are modernized.

A particularly pertinent excerpt from above:

> An increasingly important and influential resource is groups of patients who can access medical information on the Internet and see themselves as equal partners with—if not the primary drivers of—the medical profession in managing their health (20). Special online resources, such as Resounding Health, have recently been developed to serve this popula-

tion. In a growing number of cases, patients or their relatives not only initiate, but also design and carry out, research programs that have, for example, advanced understanding and treatment of gastrointestinal stromal tumor, gastroesophageal reflux disease, autism, and the genetic disorder pseudoxanthoma elasticum (20). Most such efforts to date have been carried out as part of a "gift economy," in which patients and their families volunteer time and effort to bypass what they consider the "lethal lag time" of professional research processes and formalisms (20).

*Shaibal Roy:*

In case it is helpful, there are a couple of super-useful papers from the King's Fund from 08 and 09 that describe the factors that best influence the overall experience of care (in primary care) and choice behaviour, i.e. the factors that (most) influence choice of provider.

I use these papers to explain that patient-generated data could focus on the emotional experience of care, which has a solid evidence-based to link to outcomes and safety (apologies if this is an obvious statement for you).

Some of my current work is focused on patient generated data for early warning systems for patient safety, waste identification and continuous quality improvement based on service experience.

If helpful, please don't hesitate to contact me and I'll send the papers and the next level of detail.

*Note from Dave: I have requested the papers from Mr. Roy and will forward them.*

*Janice McCallum, Health Content Avisors:*

Patient-generated data has high value for research purposes and this seems to be the focus of this post and comment stream. But, there's also a need to define what patient information should be embedded in EHRs to be used for clinical decision support at the point-of-care.

I listened to a HIMSS-sponsored webinar this week (4/14) given by Louis Diamond, VP and Medical Director of Thomson Reuters Healthcare. He referenced a 1996 ACP Journal article that defined the three elements of evidence-based medicine as: 1) research evidence 2) clinical experience & judgment and 3) patient preferences. The only hints mentioned in the same article for what constitutes patient preferences are: cultural beliefs, personal values, experience and education.

We're moving toward a health care system where more decisions will be made based on clinical decision support (CDS) systems at the point-of-care. These CDS systems benefit from mining rich data sources, which include traditional medical research and new categories of patient-generated data, including patient reported data and outcomes data generated from EHRs. So, my question is: how do we want to measure and record patient preferences for clinical purposes?

Before figuring out how to measure preferences in a way that can be applied algorithmically in a clinical decision support system, we have to decide what to measure. One obvious item to include in a patient's record is advance directives. What else should we measure? Should we record a patient's preference for lifestyle changes over drug therapies? What about interest in participating in experimental treatments?

The answer to these questions requires market research and the healthcare industry doesn't have a good record for listening to its customers. The current references to patient preferences in meaningful use definitions are vague and focus on language and culture. As we continue to refine methodologies for mining repositories of outcomes data and other patient-generated data to improve targeting of therapies, shouldn't we also be gathering intelligence on patient preferences that extend beyond these externally-defined preferences?

I know I raise a lot of questions here, but I hope I'm offering a slightly different perspective that could be helpful. And I'm always pleased with the feedback I get from posting comments on this site.

*Donna Cryer, Patient Advocate to the FDA:*

Janice, I'm not persuaded that patient preferences are "data" I would find meaningful in the EMR, although meaningful for the development of the treatment plan. I think more of the daily weight, blood pressure, sleep experience, dietary intake, bowel habits, side effect experiences, basal body temperatures, number and quality of headaches, and other measurements that patients have outside of the doctor's office or hospital that can make all the difference to correct diagnosis and assessment of treatment effectiveness.

*Janice replies:*

I agree, patient preferences are helpful for creating treatment plans, not for diagnosis. Although I could imagine a case where data that were classified as "preferences" might be relevant to diagnosis, but I have a way of finding points of connections between things!

# Appendix B: My February 25 testimony

## 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[6] 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.[7]

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

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[6] See blog post, Appendix A.

[7] 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 something went wrong, and prevent recurrence. But if our priority is punishment, it discourages 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 misunderstood a CT scan report and thought a tumor had grown 30% in a week. It turns out I'd misunderstood terms like "craniocaudal," 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[8]:

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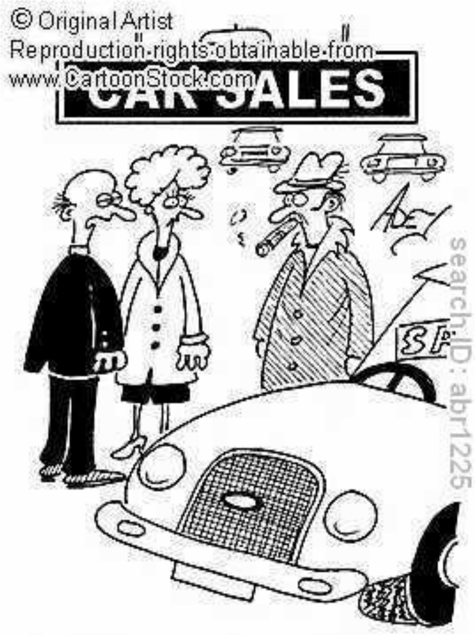
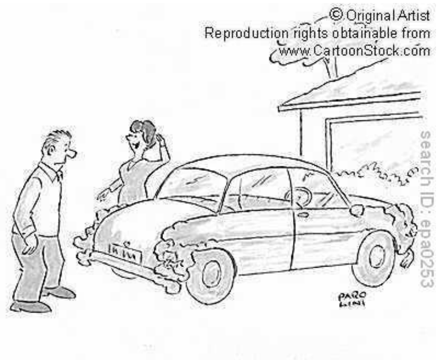
[8] Reproduction rights applied to at CartoonStock.com.



"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? 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.[9]

**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.[10]

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

**Empower people –
enable and train.**

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

In fact to *not* empower 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?

## 5. Recommendations

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

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

[10] Insurance Information Institute's Fact Book 2005

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.[11]
- 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.

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.

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[11] 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.

## 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:

- **Lives are at stake.** Let's do everything in our power to help people help themselves.
- **Punishment is not useful.** 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.