



madameovary.com

**Live Less and Falter:**  
**A Prognosis for American Health Care As We Approach the Rubicon**

*Oh, look outside the window, there's a woman bein' grabbed  
They've dragged her to the bushes, and now she's bein' stabbed  
Maybe we should call the cops and try to stop the pain  
But Monopoly is so much fun, I'd hate to blow the game  
And I'm sure it wouldn't interest anybody  
Outside of a small circle of friends*

-- from `Outside of a Small Circle of Friends`, by Phil Ochs (1967)

## **Prologue: Why I Left Electronic Medical Recordkeeping**

I was unsure whether to expect the best of times or the worst of times with my introduction to electronic medical records (EMRs). My group practice of obstetrics and gynecology had been considered a premier group in our town for many years, and we were supposed to be excited to have been selected as among the first private offices to join into Yale-New Haven Hospital's conversion to the Epic Systems Corporation (Epic) EMR. For years, I had heard numerous positive comments from colleagues and residents who used VistA, the EMR of the Veterans Health Administration. By all accounts, VistA was quite user-friendly, easy to learn, well-supported, and an overall plus for both physicians and patients. In contrast, more recently, I had heard lots of negatives about academic hospital-based EMRs, that they were dysfunctional, a huge time sink and a pain to use. The benefits of the EMR, for example, that all of your medical information would be instantaneously accessible to of all your care providers, certainly have been prominently trumpeted. So I approached `opening day` with cautious optimism, yet with eyes wide open.

On the very first day of my orientation, a giant red flag immediately emerged. We had been told that `experts` had tailored systems to a physician's particular specialty and needs, which I was quite pleased to hear. A technical specialist was showing my group our `specially designed` order set, which was supposed to streamline the ordering of tests that obstetricians and gynecologists would regularly request. My hopes were smashed, alas, when I saw that the second test item listed on the specialized gynecological order set was for `Bence Jones proteins`. This was like seeing a lobster soufflé as the second menu item at the new McDonalds in town. Bence Jones proteins are a test for multiple myeloma, a hematologic disease of the bone marrow. Now indeed, I had ordered that test once, in 1975, when I was an intern in internal medicine. Not only would no gynecologist in the United States ever natively order such a test, but indeed many would never have even heard of these proteins. Clearly, no meaningful ob/gyn input had been implemented -- so much for `user-centered design` here. I felt both bemused and betrayed, and my antennae went on high alert.

My next enlightenment was in the realm of patient privacy. One of my patients came in for an examination while I was away at a conference. The patient had a fairly minor problem with a vaginal infection, and she felt perfectly comfortable seeing a partner in my group, who treated and cured the vaginitis. My patient had been consulting with me for years about her lack of libido. Indeed, that was the principle reason for her several most recent visits to my office, and the diagnosis of decreased libido was listed as one of her primary diagnoses. My office staff appropriately entered the details of this current visit, along with other recent visits into the Epic system.

Several weeks later, the patient went to visit her dermatologist for a chronic problem with eczema. The dermatologist is one of the most eminent and respected physicians at the Yale School of Medicine. At the end of the appointment, my patient was given a summary printout of the visit, which is standard protocol in this system. Included on the printout was a listing of all of her primary diagnoses, including the diagnosis of "decreased libido." She called our office and yelled at my office manager for 15 minutes, "How dare you write that I have decreased libido? It's none of Dr. So and So's business, and it's all over the chart!"

But if that's your diagnosis, it's in your chart. All culture results and medications are part of the EMR, too. So if you happen to have a positive chlamydia culture for which you were prescribed azithromycin, it's right there in your chart, for all with access to Epic to read. Certainly it is appropriate that other physicians who might prescribe medications be made aware of possible drug interactions, to avoid unwanted side effects. But does a patient want to allow a former partner or a potential employer to learn that she has an STD, either directly or through the grapevine?

Physicians have good reason to dislike the implementation of the EMR as well. Although physicians are mandated to switch to the EMR by many hospital and insurance systems, minimal technical support has been provided, particularly to affiliated private practices. When we were slated to start using the Epic EMR, I tried diligently to enter 30<sup>+</sup> years of chart information for each patient into the computer forms. As I quickly learned, and had been warned, these forms were hardly designed to be user-friendly to physicians, unlike what I would have expected from VistA. It took me anywhere from 30-60 minutes per chart; I was up all night doing this, and none of this time was reimbursed. So I started having our staff technicians enter this chart information into the computer, as did everyone I know. These technicians are certainly well meaning and earnest, but their medical knowledge is very limited. For example, I would find in a chart that a patient carried the diagnosis of osteoporosis. I knew that she did not have osteoporosis; she had been TESTED for osteoporosis, and the bone density test was normal. However, in the computer she was then listed as carrying the diagnosis of HAVING osteoporosis. Of course this is inadequate, but then what were my alternatives? Was I now expected to pull all-nighters for months on end, again without any payment, to convert all of my charts to a non-intuitive and constricted database?

As I wrote up top, a heavily promoted benefit of EMRs is that having your health care data in a computerized system would be terrific, because your data could be instantaneously accessed from anywhere. For example, what if you have chest pain while you are visiting in San Francisco, and your regular care is in New York? Wouldn't it be great to be able to retrieve your baseline cardiogram from the computer? It certainly would be grand! Unfortunately, as I was very disappointed to learn, at present this is a major misconception. Currently it is very unlikely that the computer system that your physician or hospital in San Francisco is using could "speak" to your local New York system. A large and growing number of totally different, discordant EMR systems are in use across the US, so much likelier than not, your cardiogram would be inaccessible from afar. Even the major hospital systems within the small state of Connecticut cannot communicate with each other -- New Haven, Danbury and Hartford are about an hour apart from one another, and are on entirely distinct and incompatible systems.

Along these lines, sometimes even sharing a street address is not necessarily good enough. One of my colleagues recently told me a story about her mother, who had been admitted from the Emergency room of a major metropolitan hospital to the hospital's intensive care unit (ICU). Unfortunately, the ER and the ICU in THAT hospital used different computer systems. The ICU folks thought that her mother had been admitted for a kidney stone, rather than a kidney infection, and they started treating her with pain medication instead of antibiotics. Her mother spent a very sick month recovering from sepsis, which had worsened because of the lack of communication. Ultimately and fortunately, my colleague was able to intervene once she realized the breakdown that had occurred.

The importance of interoperability, this ability to electronically share records at a distance or across systems, powerfully hit home with me a few years ago, when I learned of the death of an eminent colleague whom I had known for a very long time. She was at the peak of her career, by all accounts quite healthy, and on vacation 2000 miles from home, when suddenly she became acutely ill, apparently out of the blue. Within 72 hours, she had died. At her Memorial Service, most of us were still stunned, incredibly sad, and wondering `What if?` It is exactly this type of setting when interoperability would be most utterly crucial, when someone is far from home, unknown to anyone local, and suddenly requires emergency care. The development of a highly functional EMR network that could provide essential health information in this scenario would go a long way towards justifying the premise and promise of EMRs. But again, such a network is certainly not here today, and from what I've both read and heard, won't be in place anytime soon. Full interconnectivity of EMRs needs to be established as an indispensable and highest priority requirement, just as it is for telecommunications.

However, what finally clinched my decision to abandon the EMR is that I really like listening to my patients. I like to look at them when they are telling me their problems; it gives me a lot of information, so that I may be of use to them. But if I were required to use Epic, I would be a servant of *two* masters, with the computer designated as the dominant party. If I were forced to enter data into the computer non-stop, I could not pay my patients nearly the attention that they deserve. And unlike Truffaldino in Goldoni's play, my role as the servant would then lead to a tragic, not a comic ending, according to my value system.

So I have elected to remain a dinosaur, and have exited from the EMR-business complex. I tell my patients that I am maintaining my office charts. What goes into my record stays only in my records, unless my patients tell me otherwise. I'd rather spend that extra time listening, so that I can be their best doctor possible, at least during the next quarter – quarter-century, that is.

---

But I could not go gentle into this good night without trying to be of further use. I felt a moral and a personal obligation to dig into matters somewhat more deeply, on two counts, First, I wanted to connect the dots and clarify to myself and to others how and why the practice of medicine is evolving so rapidly now, and identify the most essential pressing issues. Second, I wanted to foresee how recent systemic changes would more likely than not play out over the longer term if they were left largely unchecked. I am very concerned that a series of short-term directives will lead to many unintended consequences and a badly fissured health care universe within a few years, barring substantial changes in the implementation details of the Affordable Care Act (ACA).

With apologies to Michel de Montaigne, I will try to convey my viewpoints and discoveries as best as possible in a series of essays. The next two pages provide very brief mini-Abstracts for each essay. Some of what I discovered was quite illuminating, and in some instances, shocking to me.

As a sidebar, I've included a short Cheat Sheet that should help to elucidate some core background and related terminology on the HITECH and Affordable Care Acts that underpin much of the recent flux in health care. Part of this includes the `official` word on the distinction between the terms `electronic

medical records` (EMRs) and `electronic health records` (EHRs). Although most physicians whom I know tend to use EMR in a generic sense here, as I do above, the current preferred term for broad context is the electronic health record or EHR, which I adopt in the essays below.

Finally, I do believe that it is still possible to improve the landscape significantly, both for patients and for doctors, without dismantling the core framework and paradigm of the ACA. However, time is very much of the essence, as is substantial political will. So with that optimism in mind, I will also attempt to propose a few suggestions that could potentially be helpful to the cause, or at the very least, kindle or catalyze a couple of new approaches.

## Mini-Abstracts

### **Should I be Human, or a Computer?**

We discuss the effects of EHR record-keeping on the doctor-patient relationship, especially in the face of severe pressures for physicians to constantly interact with a computer during consultations. The relative diminution of face-to-face contact and of careful and layered listening and observation can significantly hinder effective diagnoses, and lessen mutual trust and openness. A reexamination of several important settings, including treatment of ductal carcinoma *in situ* and of prostate cancer, and of discussions on how to maintain a healthy diet and exercise balance, illustrate the issues in play.

### **Franz Kafka, meet Joseph Heller**

A byproduct of EHRs has been the loss of patient privacy and the security of personal health data, with little transparency or accountability. We discuss a number of vast scale transactions, involving many millions of EHR records and in some instances, billions of dollars, among industry, the government, insurers and advertisers. Data analytics companies apply advanced techniques to sift through these huge quantities of very detailed medical records, genetic information, and personal information on behalf of their clients. Promises of data anonymization can be and frequently are readily broken. Finally, we truly live an age of acute cyber vulnerability and require much more data protection, given the numerous, prominent and diverse recent instances of large scale data breaches and theft.

### **Legal Recourse: Slim and None**

Prominent health law experts agree that patients have very limited recourse to protect themselves against violations of privacy.

### **Cheat Sheet**

We clarify the usage of the terms *electronic medical record* (EMR) and *electronic health record* (EHR), what the HITECH Act, Affordable Care Act, and Meaningful Use are and how they relate, and where Epic Systems fits into the big picture.

### **Worse than Russian Roulette**

We quantify the likelihood of interoperability between two different EHR systems – it is small.

### **Life Begins at 60**

Even if we achieve full interoperability among major hospital systems, the extent of a patient's complete **medical history** that exists within the hospital's electronic record may be (and typically is) minimal.

### **Migratory Patterns**

The recent drop in the number of independent primary-care physicians is striking, with 35% independent in 2014, down from 62% in 2008. We describe why this has come about, and what might be lost, particularly continuity of care with a single provider, along with associated consequences. This has accelerated patient interest in alternative solutions such as concierge care.

### **Throw Dr. Kildare from the Train**

In the last few years, I have seen a pronounced increase in the number of retirements and planned retirements among local physicians from both the academic and private community. In large part, this is in response to a profound recent change in the balance of power and authority within nearly all hospitals from a medical-centric to an administrative and business-centric environment, accompanied by a remarkable migration towards incessant bureaucracy, and by a hard push to meet `productivity goals` that are little more than a volume measurement to pursue Meaningful Use dollars. The severe, often

unseemly collateral damage here is that many esteemed colleagues are being treated as commodities or clerks by the hospital staff.

### **Commoditization: The Rise of the Clones**

It appears that physicians have been reduced to generic commodities in the business model of the Affordable Care Act, e.g., independent of competency level or experience. Along similar lines, it is implicitly presumed that there is no consequence to a patient's medical care if one switches insurers, and as a result, switches treating physicians on a yearly basis. I argue that this model will most likely lead to greater long-term system costs, in part due to the loss of continuity of care from a familiar doctor.

### **Turnover – Replacement Parts not Equal**

When I was young, medicine was considered to be the top career choice by many, and a significant percentage of our smartest and most driven students became doctors. Who will replace these physicians upon their (often accelerated) retirement? At present, the job of doctor is still generally well regarded, but the profession no longer seems to attract nearly as many star students, particularly compared to finance, consulting or entrepreneurial ventures. Recent data confirm a compelling shift.

### **EHRs – less Love and more Money**

The depth of doctors' dissatisfaction with EHRs is confirmed by many recent studies. Secondly, we examine a potent 2014 research report by RAND that includes an analysis of the role of EHRs in health care, including a comparison of the VA's VistA and Epic EHRs. RAND concludes that EHRs' principal successes to date relate to billing, not to medical care, and that short-term rewards and procedures are increasingly favored over long-term benefits and prevention.

### **The State of EHR Interconnectivity is `Not Shortly`**

We discuss the current and near-term future status of full interconnectivity of EHRs, plus some of critical behind the scenes issues that frame the debate and the politics.

### **Electronica Britannica**

Two histories from EHR experiences in the United Kingdom provide important cautionary tales for the U.S., given parallelism along several essential lines. First is the recent failure of the nationwide NHS IT program to connect patients' records electronically, *Connecting for Health*, which was “urgently” dismantled in 2011 at a cost \$20 billion following years of well-publicized problems. Second is the history of how the Cambridge University Hospitals NHS Foundation Trust went from being world-renowned centres of excellence and among the safest hospitals in all Britain to a failing enterprise that was placed on “special measures” in a matter of 8 months in 2014-5. An executive report very recently published by the U.K.'s Care Quality Commission detailed, with many specifics, that this drop was to a large extent due to problems the Trust had in implementing its new Epic Systems EHR.

### **Solution Proposals**

We propose several suggestions to potentially help to resolve some of the identified conflicts and concerns, with a view to the long-term. These address patient histories, patient privacy, treatment of physicians, and regulation of EHRs, and more broadly, systemic reform.

### **Final Thoughts**

We discuss who is winning and who is losing in our rapidly changing health care ecosystem. Unchecked, I foresee an acceleration towards two-tier medicine, which probably was not the preferred outcome of recent reforms. There still is time, if we act decisively within the near future, to significantly change yet preserve the system while creating much better long-term outcomes for patients and doctors.

## ***Should I be Human, or a Computer?***

It is hardly news anymore that electronic health records (EHRs) are the bane of many doctor-patient relationships. EHRs are often detested by doctors and viewed at best with mixed feelings by patients, as a necessary evil to achieve the advertised benefits of digitized records. Patients now typically see their physicians spending most of their time interacting with a laptop during consultations, instead of looking at them as they had done previously. Naturally, the patients then often feel like second-class citizens, with the doctor-computer relationship apparently now more important than the doctor-patient relationship. In turn, the doctors are severely pressured to constantly use the EHRs, both to fulfill administrative demands within hospital environments, and to check off scores of boxes on the computer screen to satisfy insurance requirements for payment – moreover, generally at reduced rates. Many of my colleagues tell me that they now spend several extra hours each day on computers, typing while seeing patients, between appointments and late into the evenings. In a recent survey of about 35 interns in several hospitals, Stephen Bergman, Professor of Medicine at N.Y.U. (and author of the novel The House of God under his pen name Samuel Shem) reported that the typical percentage of time spent in front of a computer screen and typing in the data during a shift is 80-90% percent, leaving minimal time for face-to-face doctor patient contact. This is all part of a broader malaise, in which the business and administrative components of healthcare have come to take clear precedence above other needs of doctors and patients, for instance, quality of life issues. On point, last year the American Medical Association called for a major overhaul of EHRs to make usability and high-quality patient care higher priorities.

***The Eyes Have It*** From a strictly diagnostic perspective, much may be lost if a doctor spends only a short amount of time actually looking at his or her patients. About 20 years ago, Irwin Braverman, a nationally prominent (now emeritus) Professor of Dermatology at Yale recognized a critical need to improve observational and diagnostic skills in his medical students. Dr. Braverman then took an unusual means to achieve his goal, developing a course to teach first-year medical students to improve these skills by carefully studying paintings (at the Yale Center for British Art) as if they were surrogate patients. This shortly thereafter became a required course at Yale, and subsequently has been much lauded and emulated by many other prominent medical schools. And the greater attention to visual cues certifiably works -- according to a study published in *JAMA* in 2001, students' abilities to pick up on important medical details significantly improved on the basis of this approach. The students learned that the more time that they spent carefully looking at a patient, the more likely they were to notice something that a cursory glance or tests would have missed.

Indeed, I came to appreciate the importance of careful observation on my very first set of rounds while I was a medical student, a lesson that I never forget. The resident who was leading us diagnosed lupus in a patient who was complaining of severe abdominal pain. What prompted the young doctor to make this remarkable (and correct) diagnosis, which at the time floored me as both miraculous and beyond the reach of any mortal observer? Our resident astutely commented that the beds of the patient's fingernails showed irregular, twisted, and dilated capillaries, or as he said in his regional twang, `linear cuticular telangiectasia`. I surely would never have proposed lupus as a primary differential (diagnosis) based solely on listening to the patient. As I subsequently came to appreciate, the visual appearance of the fingernails can in fact provide clues to a number of underlying systemic diseases. For example, clubbing

(colloquially called `drumstick fingers`), which is often associated with lung or heart disease, was first described by Hippocrates in the fifth century B.C.

What else might be lost in this Brave New World? I am especially concerned about the potential loss of trust and openness, which is paramount in a thriving doctor-patient relationship. As suggested above, EHRs tend to squash any rapport between the doctor and patient, reducing the interaction to pure process. I am sadly reminded of a definition that I learned in college, namely that a *lecture* is the process by which the notes of the professor become the notes of the student without going through the minds of either. However, there are substantial health care benefits in the human interaction between doctor and patient. Studies have shown that patients with close, personal bonds with their doctors and shared engagement with their care are more likely to follow their prescribed treatments. Even placebo effects can be real and strong. The ability to really listen, to pay full attention to tone and cadence, while reading emotions, facial expressions, and body language, is a skill set that is developed throughout medical school and residency, and allows the attuned doctor remarkable insight into a patient's hopes, fears, and expectations. Must this all be forfeited in the name of *productivity*? What about empathy, compassion, comfort, and counsel? I see my role to be a partner in a quest for a patient's best health and quality of life, a coordinator of integrative care, as necessary, and a zealous patient advocate, certainly not an automaton. Good medical care is considerably more than data management.

A reexamination of several important settings should amplify my concerns here.

***In Sickness*** Both ductal carcinoma *in situ* (D.C.I.S.), often referred to as Stage 0 breast cancer, as well as prostate cancer in men, illustrate the issues at play. Screening to detect either of these diagnoses is very controversial, with ongoing debate amidst a large body of equivocal or conflicting evidence of utility, and frequently shifting guidelines. `Do I ever need to test?`, `At what age should I start?`, `How often do I retest?`, and `What to I do with a positive diagnosis?` are all questions that require a personalized response. More acutely, most patients with a fresh, positive diagnosis will be somewhat confused and scared, and should want guidance that is individualized, incorporating both their history and their personal belief structure. Should a woman just diagnosed with DCIS undergo surgery, and if so, is a lumpectomy or a mastectomy the `right` choice? If lumpectomy is chosen, should it be followed by radiation therapy? Is nonsurgical `watchful waiting` (active surveillance) a better option, and if so, what tests should be taken to monitor disease status, and with what frequency? As Siobhan O'Connor recently wrote in a timely and cogent feature article in Time Magazine on this subject, "doctors are learning that a one-size-fits-all approach isn't working." If surgery is elected, most women still have vital concerns regarding body image, sexuality, and attractiveness to their partner, and as always, surgery comes with potential complications, especially if a mastectomy with reconstruction is involved. For men with a recent diagnosis of prostate cancer, the fog of information is particularly problematic because surgery and radiation treatments can have serious side effects like incontinence and erectile dysfunction. Patients receiving either a DCIS or a prostate cancer diagnosis need to explore the options thoroughly before making a decision that depends heavily on the risks that they are willing to take.

Although in the abstract, patients are aware of many of the above issues, let's now reconsider the patient's actual decision-making process in the face of a positive diagnosis. Many patients will prefer to defer to their doctor's recommendations as to how to proceed. But these are life-changing

decisions that we are discussing, and I want this to be a joint (and ongoing) discussion, not a unilateral directive. Most decisions ultimately will be driven by subtle and nuanced personal considerations, balancing programmatic data based on diagnostic findings and medical history with not only my patient's risk tolerance, but also with familial, social and career demands and future expectations, and possibly as well with financial security. I hope to provide some context, experience, judgment and empathy here. This shared decision-making generally requires a significant block of time, not a formulaic resolution. But present incentives tend to go counter to such discussions, especially EHR-based ones that are strongly biased toward billable procedures. And most importantly, this discussion is usually much more likely to be productive in the context of a vibrant, longstanding doctor-patient dynamic, compared to either a truncated or to an unfamiliar relationship.

***And in Health*** On a more upbeat topic, I believe that it is important for all of us to maintain a healthy diet and exercise balance, so I try to incorporate some discussion and positive encouragement on this topic as part of my medical evaluations of patients. However, my approach to motivating patients to come up with a realistic plan that they can and will stick to varies widely from patient to patient. Again, a `one size fits all` glib comment about target weight rarely works, and the best strategies generally spring from a longstanding relationship with the patient. What has worked previously, and what has not? Does my patient prefer solo exercise, or more social workouts, like spinning? Are aerobic exercises best, or ones with less overt sweating, like yoga? Will a Fitbit encourage or frustrate? For joggers with lots of painful wear and tear, what about swimming? Or strength training? Do lifestyle considerations enter into the picture? Is my patient looking to potentially getting involved in a new relationship? Have life stressors derailed the balance, and if so, how can I re-motivate my patient to get going again, or to shift strategies? Does a patient do better with a pat on the back or a poke in the tush? All of these are critical factors to consider in attempting to optimize one's health, among variables that we can control. So I am very concerned that collateral to more commoditized, process-driven care, our patients will be more likely to lapse into and retain a diet-exercise imbalance that will ultimately compromise both their quality of life and their longevity.

***Scribes*** In his eloquent book The Digital Doctor, Robert Wachter makes a strong case for the use of scribes to facilitate EHR management. To paraphrase several sources, `the solution would be to take the doctors off the computer, put them at the bedside, and let the scribe do the transcription.` Indeed, the large number of doctors who now employ medical scribes to record the medical encounter into the EHR confirms the severity of the issue, and the potential utility of this solution. I agree that the scribe model may be both fine and appropriate for some specialties, but alas, not for mine. I can get at most 50% of my patients to allow a Yale resident in the same room to simply observe how I conduct an office visit, given the oftentimes confidential nature of the doctor-patient discussions, so I would expect that most of my patients would balk at the presence of a scribe. Also, I believe that it would often be very challenging for a scribe to properly identify, let alone extract the critical psychological or social observations that I would routinely make, based on longstanding relationships with my patients, that would determine individualized diagnosis and treatment in many cases. Once again, optimal care involves far more than data management and image analysis.

The Turing Test asks, in an Imitation Game, if a computer is sufficiently advanced so that an astute evaluator can no longer distinguish the machine from a human. I optimistically believe that continued

advances in computer hardware and programming will provide ever-increasing complementary and synergistic utility to the practice of medicine. But the profession that I gladly entered, in which the laying on of hands and the heartfelt shared grief of a patient's tears are vital signs as well, should never strive to pass Turing's challenge. □

## Franz Kafka, meet Joseph Heller

***Hold your Enemies Close and your Friends Closer*** In January 2015, Ricardo Alonso-Zaldivar and Jack Gillum of The Associated Press reported that the health insurance site Healthcare.gov had been sharing user data with companies like Google, Twitter and Facebook, as well as with a host of online advertising providers. They wrote that the administration said it had prohibited companies “from using the data to further their own business interests” and that “there is no evidence that personal information has been misused.” However, Cooper Quintin at the Electronic Frontier Foundation, a civil liberties group, wrote that “sending such personal information raises significant privacy concerns.” A company that receives the information, he added, “could match up the personal data provided by Healthcare.gov with an already extensive trove of information” to create an extremely detailed profile of you and your interests. Moreover, he wrote, a company could connect Healthcare.gov data with users’ real identities.

In March 2015, Elizabeth Dwoskin wrote an article in the Wall Street Journal aptly titled ‘The Next Marketing Frontier: Your Medical Records.’ She disclosed that for physicians who utilize EHR software from Practice Fusion, when the physician views patient charts on his or her computer, a *sponsored* alert sometimes pops up to indicate when a patient is due for vaccines (or particular treatment) for influenza or for hepatitis B, among other ailments. Practice Fusion, which gives its software free to doctors, is pioneering a new type of data-driven business, and has built a database of 100 million patient records. Practice Fusion has begun to sell sponsorships for alerts to drug companies, labs and insurance companies, matching preprogrammed alerts to patients in real time based on their health indicators and medical history, letting marketers deliver a crucial pitch at the moment when clinical decisions are being made. Some experts worry that the sponsored alerts blur the line between promoting health and marketing medicines. Practice Fusion, which has raised \$157.5 million from investors, says about 112,000 health professionals, doctors and nurses are using its system and the software logs about 5.5 million office visits a month.

Just this past December, Rebecca Robbins reported in the Boston Globe on some of the new data mining techniques by insurers, in a bid to figure out when you’re likely to get sick, ostensibly to design interventions to keep you healthy (and to save themselves a lot of money in the process). Insurance companies are now paying data analytics companies such as GNS Healthcare and Predilytics to sift through huge quantities of medical records, genetic information, and personal information on everything from what model car you drive to how many hours you sleep, from which magazines you read to where you shop and what you buy. GNS will also rank patients by how much return on investment the insurer can expect if it targets them with particular interventions, such as sending a text message reminding them to refill a prescription or sending a nurse to their home for a checkup. According to Colin Hill, the chief executive of GNS, the algorithm also can tell the insurer not to waste time and money trying to get certain patients to take their pills — but to spend resources on other patients instead. But using an algorithm to determine how and when to intervene raises troubling risks, said Kirsten Martin, an assistant professor at George Washington University who studies business ethics and Big Data. Such analyses are only as good as the underlying data sources, which in numerous instances have exhibited profound inaccuracies, as well as the algorithm used to mine them. Insurers say they don’t deny care to anyone based on algorithms, but just use the data to customize the approach to each patient. Yet surely there are big vested, commercial incentives by insurers to ‘monetize’ this information, either in rate

increases, added constraints or denials. And as always, I worry that insurers are using all this highly personal, often sensitive, possibly inaccurate information without informed consent and with little transparency or accountability.

Finally, IBM just announced the \$2.6 billion purchase of Truven Health Analytics, which has data on the cost and treatment of more than 200 million patients. IBM is looking to enhance the growth of its Watson Health business, and to that end, has now purchased four companies since it created the unit last April, at a total expenditure of more than \$4 billion. Two other acquisitions, Explorys, a spinoff from the Cleveland Clinic, and Phytel, a maker of software to manage patient care based in Dallas, also brought with them significant data assets, mostly data from patients' electronic medical records. The Watson Health business, IBM said, now has health-related data on "approximately 300 million patient lives," mostly in the United States. The goal is to run the patient data through Watson's artificial intelligence (A.I.) software, so that it works as a specialized digital assistant to physicians and health administrators to improve care and curb costs. The \$1 billion purchase of Merge Healthcare, a medical-imaging software company, added expertise in managing health image data. Truven contributes vital payment information on patients, including detailed coding on disease types, diagnosis, drugs prescribed. Now I am optimistic that the vast majority of the IBM *researchers* are interested in the scientific and A.I. opportunities in this project. But look at the dollar values involved here. More crucially, who has allowed the intermediary companies here to obtain and aggregate our medical and health records in such volumes, with such specificity, and trade them like stocks and bonds? Again, I have very serious concerns about data protection, anonymity, and sales of these data to other companies (such as insurers or marketers) with more mercenary or insidious interests. The frank and large scale activity here is in wanton disregard of our privacy rights, especially given the extent of data hacking, the special value of medical data, and the lack of anonymization described below. I could understand the handing off of records between subsystems strictly within a highly secure, closed network, with no outside commercial forces in play. But the present context just described appears to be light years away from such a place.

***Anonymization with Plausible Deniability*** Even when real names and other personal information are deleted from large data sets, it is often possible to use just a few pieces of information to identify a specific person, according to a study published last year in the journal *Science*. A group of data scientists from the M.I.T. Media Lab analyzed credit card transactions made by 1.1 million people over a three-month period. Although the information had been `anonymized` by removing personal details like names and account numbers, knowing just four random pieces of "metadata" information was enough to uniquely re-identify 90 percent of the individuals. The study certainly calls into question the standard methods many companies and systems currently use to anonymize their records. As the authors wrote: "A data set's lack of names, home addresses, phone numbers or other obvious identifiers does not make it anonymous nor safe to release to the public and to third parties." In a 2013 study, Latanya Sweeney similarly demonstrated that researchers were able to re-identify patients by name in a supposedly anonymized hospitalization data set. Frank Pasquale, a law professor at the University of Maryland, has written an important book on the dark side of hidden algorithms, automated judgments and one-way mirrors (corporations watching individuals), entitled The Black Box Society: The Secret Algorithms That Control Money and Information, in which he discusses this issue within a larger context. As he says, we should not necessarily be reassured: "There's a big literature out there on broken promises of anonymization, of efforts where users were assured that the information was anonymized,

but it wasn't really anonymized well." Pasquale is very concerned about "the spillage of data from one context into others," especially commenting that "there's high demand for health data out there." Life insurance companies, for instance, "want to use everything on you to calculate what your life insurance premium should be." Hmm – I think that this links up rather naturally to Rebecca Robbins' report in the Boston Globe on data mining by insurers. Should we be concerned?

***Vulnerability with a King-size "V"*** As we now know, a double-edged byproduct of EHRs has been the loss of patient privacy and the security of personal health information, which of course is in profound contrast to our old-fashioned paper charts that were previously stored in an office or hospital basement. We all appreciate the potentially great advantages that computerization can afford, but much more protection is imperative along this front. Many disclosures within the last couple of years underscore the extent of the concern here, that we truly live an age of acute cyber vulnerability. The long list of both private companies and government organizations that have been hit include Target (70 million), Home Depot (50 million), the health insurer Anthem (80 million), Premera Blue Cross (11 million), and the U.S. Office of Personnel Management (OPM), 4 million federal employees. In many of these breaches, particularly those involving health care data, the stolen files include `huge treasure troves of personal data,` to borrow the phrase used by a Washington Post article last year to characterize the OPM breach. It turns out that in many of the breaches, the affected organizations had failed to take even basic steps to secure its computer networks. This has at times been attributed to `a lack of management focus on the potential problems`. This really means that the organizations did not want to budget funds or time to provide proper protection because profit margins would be lowered, and/or the cost of products might have to be raised slightly, placing them at a `competitive disadvantage`.

Some additional numbers worry me even more. Security experts have warned that further attacks on health care organizations were likely because of the especially high value of medical data on the black market. In black market auctions, complete patient medical records tend to sell at much higher prices than credit card numbers. One security expert said that at one auction credit card records were sold for 33 cents, whereas patient medical records sold for \$251, a factor of nearly 100 times higher. In another `slightly` more cautious estimate, law-enforcement officials gave estimates of credit card numbers sold at \$6 or \$7 versus health care records sold at about \$50, *only* a tenfold increase. A study published last year in the Journal of the American Medical Association found that between 2009 and 2013, more than 29 million medical records were hacked, stolen or otherwise compromised. Chillingly, about 90 percent of health care organizations reported they have had at least one data breach over the last two years, according to a survey of health care providers published last year by the Ponemon Institute, a research concern.

These `bobbles` have real consequence, oftentimes in the form of medical identity theft. According to a survey published last February by Ponemon, such theft affected 2.3 million adult patients in 2014. This could lead to loss of health insurance, collection notices from hospitals, and diminished credit scores. In a twist on identity theft, crooks could then use stolen personal data to get their own health care, prescriptions and medical equipment, which could lead to the thief's health data folded into the victim's own medical charts. Confusion or errors could ensue that could lead to dangerous diagnoses or treatments. Finally, adding insult to injury, a victim often could not fully examine or repair his own

records because the thief's health data, now folded into his, would be protected by federal medical-privacy laws.

I know – just lots of big numbers. Until you or a loved one gets hit, that is.



## **Legal Recourse: Slim and None**

A number of prominent health law experts agree that patients have very limited recourse to protect themselves against violations of privacy. They have concluded that more state and federal legislation is necessary, because there are major holes in the way current health care law is written. Some enlightening and relatively nontechnical details are given in a representative 2007 article in the University of Illinois Law Review entitled `Ensuring the Privacy and Confidentiality of Electronic Health Records`, by Nicolas Terry and Leslie Francis. (Very few primary changes have occurred during the intervening years.) In brief, personal health information has been judged to be under threat either by its collection or its disclosure. The law has parsed these threats separately, expressed as the distinct models of *privacy* and *confidentiality*. When I read this legal splitting of hairs, my antennae quickly went way up. It turns out that contemporary U.S. confidentiality and privacy models are shaped and constrained by several persistent features. First, the regulation of medical records is primarily a creature of state (not federal) law, has a number of exceptions, and is highly qualified. Moreover, and unsurprisingly, there is remarkable variation by state. Second, the law relating to the privacy of medical information is described as underdeveloped and narrowly circumscribed. As a result, common law privacy actions have been successful in only a few extreme cases. Gaps in data protection may be especially apparent if data are transferred across regimes, as when health records are made available to insurers or employers. Any EHR system that transcends state boundaries (including virtually all of the major software providers) thus poses the issue that patient protection is only as strong as the weakest state link. Worse, privacy dispute resolution has been in the hands of the Office for Civil Rights, in the Department of Health and Human Services. Although this may sound benign or neutral, in practice, from a patient's perspective, enforcement has been placed in the hands of an `insider` primarily interested in ensuring the efficiency and continuity of the present system. This is the same agency that enforces the HIPAA Privacy, security and breach notification rules.

The conclusions from this paper come with added *gravitas*, given the stature within the field of the co-authors. Nicolas P. Terry is Professor at the Indiana University McKinney School of Law and Director of the Hall Center for Law and Health, while Professor Francis is the Director of the Center for Law and Biomedical Sciences, Emery Professor of Law and Distinguished Professor of Law and Philosophy at the University of Utah. In particular, Professor Terry is a longstanding authority on the intersection of medicine, law and information technology, and has written extensively on fundamental privacy and confidentiality issues for many years. Remarkably, many of these privacy concerns were already voiced on high more than a decade ago, in expert testimony that Terry was called to give in 2005 before the U.S. Dep't of Health and Human Services, National Committee on Vital and Health Statistics Subcommittee on Privacy. This testimony can be found at <http://www.ncvhs.hhs.gov/wp-content/uploads/2014/05/050816p1.pdf>. Terry's overall concerns and conclusions remain spot on today. Given the specific suggestions for privacy policy reform, both in the aforementioned paper and elsewhere, we can only hope that Terry does not persist as Cassandra to the government's Apollo. □

## **Cheat Sheet**

**EMR or EHR?** The terms “electronic medical record (EMR) and “electronic health record” (EHR) are often used interchangeably, both by many physicians and by the public. I was curious as to the official differentiation between the terms, and after some poking around, found some perspective that should be as definitive as any. In January 2011, Peter Garrett, the Former Director in the Office of Communications and Joshua Seidman, the Director of Meaningful Use at the Office of the National Coordinator for Health Information Technology (ONC), published a memo entitled “EMR vs EHR – What is the Difference?” in the publication Health IT Buzz from the ONC desk. The authors state that at the ONC, electronic health record or EHR is used almost exclusively. They clarify that the EMR term came along first, with most early EMRs “medical” in focus. They viewed EMRs as a digital version of the paper charts in the clinician’s office, containing the medical and treatment history of the patients within one practice (more local). In contrast, EHRs are intended to focus on the “total health” of the patient, and in particular, are designed to reach out beyond the organization that originally collects and compiles the information, to aggregate and share information with other health care providers, such as laboratories and specialists, so they contain information from all the clinicians involved in the patient’s care. So they view EHRs as more global and comprehensive. Still, in practice, most everyone will understand what you are discussing if you use either term.

**EHRs and Meaningful Use** Through the Health Information Technology for Economic and Clinical Health (HITECH) Act, a major provision of the American Recovery and Reinvestment Act of 2009, the federal government injected billions of dollars in financial incentives into the health care system to spur adoption and ***Meaningful Use*** (often abbreviated “MU”) of EHRs. The HITECH law provided for a mix of carrots and sticks to achieve this goal. Doctors and hospitals received \$28 billion (lots of carrots) in federal stimulus money starting in 2011 to install EHRs, with financial penalties (the sticks) if they failed to switch from paper records to EHRs after a suitable time period. However, when Congress created the EHR pool, lawmakers decreed that it was not enough to merely acquire such systems, but that health care providers also would have to make “meaningful use” of these technologies to be eligible for these incentives. Rather than define Meaningful Use in the law, Congress left it up to the Department of Health and Human Services (HHS), in particular the ONC, to do so. In July 2010, HHS released an initial set of regulations defining what constitutes Meaningful Use, although over time, ONC officials plan to expand the definition. Initially, Meaningful Use requirements include a number of clinical functions, such as prescribing medications electronically, as well as measures of clinical quality. Critically, in order to meet the Meaningful Use criteria, providers must adopt certified EHR systems.

**How Did we Get to Now?** The HITECH Act quickly produced dramatic changes in several interrelated directions. First, as intended, the vast incentive pool rapidly accelerated the adoption of EHRs by both hospitals and by private practices. Second, and not surprisingly, federal engagement in promoting EHR development drew in large numbers of private firms and investors. From 2007 to 2012, the EHR market doubled in the intensity of its production, from about \$10 billion to about \$20 billion in yearly activity. As a result, health care institutions and providers found themselves with a large selection of options. Third, the emergence of these HITECH funds served to crystallize the business model of the hospital-medical complex, towards the overwhelmingly dominant goal of obtaining as large a portion of these

MU dollars as possible. Therefore any EHR vendor who could maximize the hospital's potential take would generally become the preferred choice, virtually independent of other implementation attributes.

Now, independent of the HITECH Act, the Affordable Care Act (signed in 2010) led to significant consolidation within medicine in an aim towards synergy, with hospitals buying up many (especially smaller) medical practices as a result of significant financial incentives to both sides. But this system integration into larger, merged hospital systems fed a burgeoning, megalithic beast. Most of these larger systems have now evolved from a previously medical-centric to an administrative and business-centric environment. In retrospect, this should hardly be surprising on two counts: (i) ascendancy within very large-scale organizations is Darwinian; and (ii) many of the new mega-systems are monopolistic within a local area, so that the staff (including newly `acquired` physicians) had no option but to swallow administrative mandates, unless they chose to either move far away or retire. To this more business-centric environment, the HITECH Act basically became a bolus \$28 billion dollar gift (or bomb, depending on which side of the table you sit on). So the last two sentences of the previous paragraph are then reiterated, except now in **BOLD** and in a substantially larger point size.

Incidentally, for you political junkies, while the Affordable Care Act, AKA Obamacare, is an endlessly debated product of the present administration, the HITECH Act in effect was very much a bipartisan effort. Its aim was to achieve nationwide use of health IT by 2014, a goal originally set in 2004 by President George W Bush and reaffirmed by President Obama in 2009.

***Where does Epic Systems Fit In?*** Epic was a solidly regarded EHR vendor prior to the HITECH Act, although hardly the leading company in the business. Their profile initially escalated when in 2003, Kaiser Permanente chose it over two larger companies (IBM and Cerner) to provide the EHR for its 36 hospitals and more than 8 million members. However, the decisive tipping point occurred when the HITECH Act was being formulated. As a 2014 RAND research report (RR-308) clarified, Epic's CEO, Judith Faulkner was selected as the only head of a health IT company to serve on the Obama administration's Federal Health IT Policy Committee. (I will have much more to say from this report, entitled Redirecting Innovation in U.S. Health Care: Options to Decrease Spending and Increase Value, in later essays.) This gave Faulkner and Epic a critical and especially timely edge, as Faulkner was then able to advise the national coordinator for health IT and other federal officials as they crafted a policy framework to develop a nationwide health information infrastructure, including criteria ultimately adopted to satisfy Meaningful Use (MU) in the HITECH Act. Unsurprisingly, then, potential users found that Epic was especially well-suited to help them meet MU criteria and thus get them many millions of dollars in government subsidies once the HITECH Act went live. Word-of-mouth gets around, and major operators often emulate the strategy of other centers that have been highly successful in a similar business endeavor. This has ultimately led to the present state of affairs, in which, as the RAND report describes, "Epic has established itself as the enterprise-wide solution of choice for large private health care systems and academic medical centers, irrespective of ongoing concerns about its limited interoperability and less-than-ideal usability."

So, we reconfirm two key points. First, the particulars of the HITECH Meaningful Use criteria drove most users' selection process of a preferred EHR vendor that best assured certification, and second, in any business-centric (hospital or medical) system, little else counted.

***Is Epic the Main Issue for Physicians?*** In a word, NO. Epic was the best prepared of the business-oriented EHR vendors to meet MU criteria, and therefore to generate lots of revenue for its clients. Epic is the dominant EHR vendor within the most famous academic medical centers, a sound, albeit quasi-monopolistic business strategy. It is the 800 pound gorilla about which many anecdotes are told, and certainly is the system with which I am most familiar, given that it is the system that the Yale-New Haven Hospital uses. And YES, it is a pain to use. But if Epic were not primary, any of its main competitors, such as Cerner or MEDITECH might have become dominant, or alternatively, the EHR market might be even more fragmented than it is today. In any event, from a strictly business vantage-point, the \$28 billion HITECH incentive is driving the focus of all major EHR vendors in this game. Most, if not all of Epic's primary competitors in market share are also strongly billing-centric, and likewise share secondary administrative characteristics. So for a physician who is now part of a major hospital system, a change in EHRs would likely produce negligible change to either their increased patient volume and or to their new, heavily administrative requirements. And most of the issues that I am concerned about here would remain.

No, what I believe is required is balance or counterweight in EHR requirements, beyond the present MU criteria, to ensure that human (providers' and patients') needs are properly fulfilled, as well as business needs. I think that this is achievable by regulating the EHR vendors as public utilities, with health care the underlying public good, and I discuss this in the essay entitled `*Solution Proposals*`. In the absence of such a balance in requirements, although it still might be possible to leverage Epic to be more cooperative in interoperability, little else would likely change at a structural level for physicians.

□

## Worse than Russian Roulette

The ability to review or transfer EHRs from one doctor or hospital to another (interoperability) is one of the major selling points for the adoption of EHRs, and is indeed essential to the smooth functioning of the health care system. However, as I wrote in the Prologue, even within Connecticut, we more resemble the Tower of Babel story, with the three major hospital systems unable to communicate with one another. So I asked myself, ‘How important is this? When is interoperability most critical? And just how bad is the current state of affairs?’ If a patient lives in state, especially in the case of an elective, non-emergency procedure, I often would be able to coordinate with an indicated doctor in a ‘discordant’ system to ensure that they had the essential patient records in advance. In state, I might already know the doctor in question, either directly or through mutual professional connections. But remember the frightening story in the Prologue about my colleague who died in an acute turn of events 2000 miles from home, while on vacation. Again, it is precisely this type of setting that worries me the most, when a patient is far from home, and is unknown to anyone local. In an emergency, especially if there is no luxury of time, late at night or on a weekend, the responsible physician must be able to access the patient’s essential medical records, at the very least.

When I dug into this issue more deeply, I was disturbed to discover the extent of the non-universality of EHRs. Last year, the Office of the National Coordinator for Health Information Technology issued a scathing report that explained how some software developers of EHRs, as well as hospitals and health networks that own physician practices, are intentionally and unreasonably blocking the electronic exchange of health information outside the network as part of a business strategy to “enhance their market dominance.” This is occurring even when the information is required to treat patients, even though a connection is technically feasible and the doctors would be willing to pay for it. The poster child for this criticism has been Epic, although their senior executives have consistently denied participation in any such activities. Similarly, many hospitals and medical practices have made it remarkably difficult for customers and patients to switch to other providers, primarily to gain or retain an edge over competitors. In an Op-Ed piece for the New York Times last year entitled ‘Medical Records: Top Secret’, Elisabeth Rosenthal documented the series of hurdles that had to be cleared in a six week ordeal of a highly informed patient trying to extract his own records from a hospital.

So I did a little digging into the numbers. In the analysis of the most recent (03/15) HealthIT.gov Dashboard data, we see that 10 EHR vendors control more than 90% of the hospital EHR market, with Cerner, MEDITECH and Epic Systems each at about 20% of the market share. In contrast, in the ambulatory care sector, there is much more fragmentation. About 35-40% of the ambulatory EHR market remains in the hands of many small vendors. Epic Systems tops the list at 22%, with Allscript second at 10% of the market share. But five of the market’s top 10 vendors boast a market share of less than 5% each. Moreover, only a very few companies have significant presence in both the hospital sector and the ambulatory sector. The number of EHR products on the market continues to grow, with more than 500 vendors selling systems that generally are not interoperable except within their own product line. We can estimate the likelihood that two systems do not communicate (assuming the norm that systems from distinct vendors are not interoperable). A relatively simple calculation shows that the likelihood of interoperability between two hospital-based systems is about 15%, and about 9% between two ambulatory-based (that is, most medical practice) systems. Furthermore, since different sets of

vendors top the `leaderboards` for hospital-based compared to ambulatory settings, the likelihood of a hospital-based and an ambulatory system successfully sharing information is substantially less than 9%. So overall, if you are far from home, at best you are looking at about a 1 in 7 chance of your local records being readable in a distant hospital or doctor's office system. Not good, and far from universal.

□

## **Life Begins at 60**

Full EHR interoperability has recently received a lot of attention as a core attribute of a smoothly functioning national health care system. This is appropriate. However, interconnection may be of secondary importance compared to a related topic, namely the extent of a patient's complete medical history that exists within the electronic record. Much less attention has been paid to this `extent` -- I think that implicitly, we naturally tend to presume that an extensive prior history is part and parcel of our existing EHR file. So imagine my utter surprise when two months ago I had occasion to check my Epic record on the Yale system. Basically, there is next to nothing in the file, with only my records corresponding to billed procedures within the system after Epic went live, that is, from 2012 forward. This content is comprised of data on a routine colonoscopy, and on a routine minor gynecological procedure. Otherwise, there is an `empty` report from a physician whose name I know, whom I have never seen, plus a (mistakenly placed) mammogram that is not mine, but rather, from a patient of mine. That is the entire record; there is no prior historical data about me prior to March of 2012, except for a few brief comments on my familial history related to colon cancer and/or polyps. From the system's perspective, it was as if I were born at the start of Epic interactions, that is, at age 60. These records provide no mention of my childbearing history, or of an operation to remove my gall bladder many years ago. Most crucially, there was no whiff of history about my two primary medical concerns, namely (i) infrequent but severe episodes of vertigo; (ii) my unusual baseline EKG, with ST segment elevations and flipped T waves. In the absence of comment, this EKG pattern often suggests ischemia and a significantly elevated risk of a heart attack. Indeed, I carry a paper copy of my EKG in my wallet so that in an emergency situation, a treating physician would be apprised that it is my stable, baseline pattern. Again, there is no notation of this anywhere in my Epic electronic record. Now, a relatively complete medical history for me *does* exist -- in my primary physician's office. Alas, my physician uses a separate EHR, entirely outside of any hospital-based system. In fact, my primary physician, like many private practitioners, utilizes an *ambulatory* EHR that is local in the most restrictive way, exclusively used for interoffice documentation only, and adopted primarily to comply with Medicare requirements for reimbursement. So until the day comes when every EHR large and small is interconnected, localized ambulatory records included, I expect that my most critical medical history will be unavailable electronically anywhere outside of my primary physician's office, under present day protocols. For example, if I were on vacation far from home and had a medical emergency, I would be out of luck, unless I carried my own personal records with me.

In retrospect, perhaps I should not have been so surprised to see a scant electronic history on file, given the length of time that I require to satisfactorily abstract my own patients' charts into Epic's system. Yale's EHR, like most commercially available systems, was built to a large extent to avail itself of (cash in on) Meaningful Use (MU) dollars in the Affordable Care Act. It is a direct and inevitable consequence of the MU incentives that nearly all of the large-scale hospital-based EHRs are billing-centric, rather than patient-centric in any broad sense. Since physicians are not reimbursed to abstract and upload histories to non-user friendly computer forms, I expect that scant personal histories exist on electronic files throughout most hospital systems, except for records or data that are directly pertinent to billed procedures performed within the last three years. Unfortunately, I can confirm that minimal personal histories are standard issue in electronic records from outside my office that cross my laptop.

However, I cannot overstate the importance to a physician of a relatively complete patient history, especially if the doctor is unfamiliar with the patient, and particularly in emergency situations. So this issue of largely unpopulated histories for patients in most hospital EHR systems requires our utmost and timely attention and resolution, if we ever want to approach the full potential of interoperability. Finally and furthermore, one of the selling points of the integrated electronic record has been the ultimate potential for big-data analysis of huge caches of medical records of a scope that is presently beyond us, to help us to develop new cures for diseases or to discover new uses for drugs. If we want to do the data-mining effectively to meet the hype and the hope of this promise, we will require strong patient histories to maximize our chances to achieve biologically plausible significant results and greater understanding.

Given that it is unlikely that any EHR will contain even most of your complete health history, the question remains as to how best to ensure that any medical provider has all of your essential background. Last June, Melinda Beck wrote a very nice survey article on this topic in the Wall Street Journal entitled `How to Take Charge of Your Medical Records and Health Information`. A number of her points are quite useful, and bear repeating. You have the right, under federal law, to obtain copies of your medical information from virtually any place you receive health-care services, including doctors and hospitals. By obtaining your records, you can help circumvent “data lock,” serve as your own data hub and give out information when you are consulting specialists, seeking second opinions, or sharing data as you see fit, for example with family members or close friends, to be accessed in an emergency. If you spot errors, you can request changes or add information to make the files more accurate. Also, about half of all Americans, including all Medicare and Veteran’s Administration patients, can access at least some of their health records, free, through the government’s Blue Button program. Several recently developed products allow consumers to create personal health records that are organized in an easy to understand way, often for little or no cost. These encompass apps, software programs and web-based platforms that can help patients manage and integrate their medical and health records, and include iBlueButton (based on the VA’s Blue Button initiative), Microsoft’s HealthVault, and WebMD’s Personal Health Record. To date, relatively few patients have accessed their records; many more of us may want to take advantage of these strategies.

However, I still have some major concerns here. The patients who would be most likely to act on these suggestions generally tend to be those who are already basically healthy, and more computer-facile. My worries here are about the significant segment of patients who are not especially comfortable with technology, those with lower health literacy, and those who are either seriously obese or present with more complex medical regimens. From a public health viewpoint, this sector of our populace is likely the most in need of excellent medical histories, since proper treatment is often more multi-faceted. From a financial perspective, these patients will often accrue the greatest costs to the system. Yet it seems unlikely that many such individuals would routinely go through the effort to obtain accurate, portable computerized personal health records. Furthermore, I am also quite concerned about the possibility of selective editing of one’s electronic records, either to omit records that the patients deems sensitive or embarrassing, or for more `nefarious` reasons. Omitted or altered records could lead to misdiagnosis and improper treatment, with possibly serious health risk to the patient. Finally, more generally, both privacy and hack-proofing must be assured, as best as possible. □

## Migratory Patterns

***Moving Out*** It has become increasingly challenging to stay in business as a private-practice primary-care physician. In recent years, hospitals have purchased large numbers of independent and physician-owned practices. The descent in the numbers is striking. A 2014 Physicians Foundation survey of 20,000 U.S. doctors found that 35% described themselves as independent, down from 49% in 2012 and 62% in 2008. The previously independent doctors typically accepted salaried roles inside larger institutions, often affiliated with a local academic medical center, while retaining their group identity to the outside community. Why has this come about? The first, primary reason is that in the Affordable Care Act (ACA) purposefully provides strong financial incentives to favor hospital ownership of medical practices, ostensibly to improve outcomes, care productivity, and patient experience. Initial evaluations of aggregate changes to outcomes have been mixed and hotly debated, and it would be premature to draw firm conclusions about long-term outcome metrics until the system truly stabilizes from its present state of continuing substantial flux along organizational, payment and legal axes. However, what is not debatable is that doctors now receive substantially better reimbursement rates from health insurers and Medicare for many procedures when performed in a hospital outpatient clinic rather than an independently owned medical office. This differential, coupled with the recognition that private HMOs have aggressively cut back what they pay primary-care physicians in recent years, has compelled many doctors to move on.

Secondly, the implementation costs of EHRs are very high. Although federal incentive payments nominally have helped to defray startup costs, government incentives were capped at about \$44,000 per doctor for systems that cost at least \$100,000 and often closer to \$200,000, presenting financial burdens for doctors, especially in small-to-mid-sized private practices. A report in November 2014 from the Agency for Healthcare Research and Quality found that the average five-physician primary-care practice would spend \$162,000 to implement the system, followed by \$85,000 in first-year maintenance costs, plus subsequent maintenance and upgrade costs. Many private practices often find it difficult to pay such sums, especially if they fear that the new systems are not permanent, thus requiring new significant outlays. So again, they increasingly go under a hospital's umbrella, where an extant EHR is already provided with no further expense to the practice.

Thirdly, although this may be less important to some physicians, technical support for EHRs appears to be significantly more responsive to hospitals, particularly to those affiliated with highly regarded academic centers, than it is to independent practices. This is not a minor point, given that many of the most prominent EHRs do not routinely have a local presence, of course in conjunction with the frustrations and non-usability of EHRs already discussed.

***A Faustian Bargain?*** Nonetheless, many small private practices would still ideally prefer to remain autonomous, even if it meant a modest hit in the pocketbook. Retained independence would allow the physicians to practice in ways that they have adopted over many years, that fits their world view of good doctoring, with a minimum of external influences or burdens. This push-pull tug-of-war between absorption and autonomy has created a golden opportunity for web-based EHR vendors to provide technologic `solutions`, which have become very popular in the last few years. Notable among these companies is Practice Fusion, whose **free** software includes the full EHR package, with charting,

scheduling, e-prescribing, billing, Meaningful Use certification, training, support, and a personal health record for patients. Practice Fusion's blog proudly (and legitimately) notes that their system dramatically reduces the IT burden for practices. This system has recently been named by several well-established ranking organizations as the No. 1 EHR system for value among ambulatory professionals, for customer satisfaction among primary care providers, and for helping doctors achieve Meaningful Use (which of course leads to payments). Moreover, all of this is for free. So, is this the magic bullet for small practices? Well, just perhaps. Think back to the *sponsored* alerts described above – brought to you by the same vendor Practice Fusion as described in the essay *‘Franz Kafka, meet Joseph Heller’*. This is the *quid pro quo* – the EHR vendor that helps most to keep private practices independent, to retain *‘the old ways’* of long-term continuity of care, will pay its bills in part by an interesting model. As a society, do we want to pay for private practices to remain autonomous by this (or similar) means? At the very least, we need to be aware of the present path of least resistance. Some, including Nicolas Terry (the authority on the intersection of medicine, law and information technology featured in the essay *‘Legal Recourse: Slim and None’*), have advocated that we keep third party or commercial interests entirely out of the EHR picture, via legislation. I would wholeheartedly agree, but then many private practices would still require a comparable replacement to what Practice Fusion now provides to stay afloat. Where will – or should – the money come from to pay for this? This screams out to me for attention, discussion, and resolution, by society at large, the sooner the better.

***Lost Horizons*** However, what may be lost in this migration worries me a great deal. Continuity of care with a single provider is gradually being diminished, if not amputated. No matter how excellent an EHR might ever be, it seems highly unlikely that a physician would confidently deduce the interpersonal dynamics of how best to nudge an unfamiliar patient towards helpful behavioral, relationship or lifestyle modifications. Medical care in these newly minted outpatient clinics is becoming more like shift work, more compartmentalized and fragmented. Critically, with the loss of continuity of care by a primary physician (or small group) over an extended time-period, who within the medical profession will be deeply vested in maximizing an individual patient's long-term health? Who will help to fight the system on the behalf of *their* patients? Who will identify well-matched specialists for complicated procedures, and go the extra mile to ensure smoothly coordinated care? And perhaps as importantly to patients, who will be vested to ensure that after procedures, patients will have a minimum of side effects, especially if these occur later or are not routinely quantified? A much smaller percentage of the physicians within large hospital settings, I believe. This recognition by many patients has accelerated the interest in solutions that are entirely out of the present system, a parallel tier, either into concierge care, or a variant in which a physician is identified as a *‘captain of the ship’* overall care coordinator.

Indeed, it was just announced that starting this coming August, Harvard-affiliated Mass General, which was founded more than 200 years ago to treat the poor, plans to open a concierge medicine practice. For \$6,000 a year (and whatever their insurance pays), patients in its new Concierge Medicine Practice will get round-the-clock access to their doctors, as well as personalized nutritional, exercise and wellness counseling. So this evolution by Mass General, one of the nation's top hospitals, vividly confirms a significant pent-up patient demand for a separate track that will allow for more *‘meaningful’* and less administratively-driven patient-physician interaction, even at a substantially elevated price. □

## **Throw Dr. Kildare from the Train**

In the last couple of years, I have seen a substantially increased number of retirements among local physicians, including both senior core academic medical faculty at Yale and `private community` clinicians. Many more of my medical friends and colleagues have told me that they plan to retire shortly, even though until fairly recently, they had no intention of doing so. Some of this is in part a result of the switch from paper records to EHRs, some the loss of face-time with patients, some the loss of revenue, and for many, the loss of continuity of care, of being a meaningful part of their patients' lives. But probably the biggest catalyst for docs to leave the profession has been the profound recent change in the balance of power and authority within nearly all hospitals. The evolution from a medical-centric to an administrative and business-centric environment has rocketed, with little sign of slowing down. The skill-sets to advance in the current environment are organizational acumen and administrative facility, with medical skills of greatly diminished utility and stature. These shifts have been accompanied by a remarkable migration towards incessant bureaucracy, and especially, by a hard push to meet `productivity goals` that are little more than a volume measurement. We receive a seemingly endless flow of changing mandates, protocols and departmental standards as to how now to practice medicine and how to precisely record our proceedings, spelled out down to the finest minutiae. Naturally, there are the required companion meetings in which the changes are presented, so that compliance is ensured. Enthusiasm for and adherence to this brave new world is increasingly rewarded in hiring and promotion criteria and decisions. In a nutshell, the MD as MBA has risen, at the expense of the MD as MD. And Meaningful Use dollars have become `the Precious`, all-consuming and absolute, Tolkien's (or Wagner's) ring, the possession of which ultimately drives nearly all decisions, to the goals of wealth and market dominance.

The collateral damage here is that many of my esteemed (and in my judgment, nearly irreplaceable) colleagues are being treated as commodities or clerks by the hospital staff. I have heard numerous stories of now-salaried physicians being required to see many more patients daily than were their norms for many years, in fact sometimes double the previous volume. What if the numbers were not met? In a number of instances, administrators informed the doctors that there would be either a financial penalty or a cutback in vacation time. And this sometimes was willfully blind to complications or special circumstances that required immediate extra attention, at least by any humane and self-respecting doctor. Some of the physicians involved have been fully autonomous and remarkably productive for four or more decades, and are regarded as among the top specialists in their fields nationally. I can only sympathize with their decision not to put up with such superficial and inflexible edicts anymore, without any available recourse. Yet in an age in which quarterly earning reports drive the business model, within the Medicine as Hospital as Business complex, the ongoing evolution seems ominous, at least within the system. Part of the modern Hippocratic Oath is `I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug.` Where on earth has this gone to?

Dr. Abigail Zuger, an infectious disease specialist in New York City, has written a series of compelling articles in the New York Times in the last two years on a steady and dispiriting beatdown by EHRs. In the aptly titled `Quantifying Tests, Instead of Good Care`, she described a typical work afternoon spent "doing little but ordering tests, far more than I honestly thought any patient needed." Unfortunately,

since she will be evaluated (and probably reimbursed) primarily on the basis of her test-ordering behavior and patients' results, she has little choice in the matter. At first blush, at least the results part of the equation sounded fair. Sadly, yet hardly surprisingly, she wrote a recent follow-up article, in which patients' results are measured on the basis of simplistic metrics that can be used to easily confirm `continuous quality improvement`. In her H.I.V. clinic, a report card was determined simply by the percentage of patients who achieved a benchmark `undetectable level` of the H.I.V. viral load. Her first report card grade was pretty good, hardly great, and was accompanied by a list of her failures by name "and a few generic suggestions for improvement." But most interesting to me was Zuger's descriptions of several of her failures, including a representative `Patient A`. Patient A was graded as a **big** failure, with 11,000 copies of H.I.V. RNA per milliliter of blood. Yet, he came in as a sad loner who trusted nobody, and thrived with her help. His viral load had plunged from several million to 11,000. He had gained 20 pounds, and had rejoined society enough to start to see a dentist. Dr. Zuger considered Patient A as one of her big recent successes, and so would the vast majority of other docs. This grade of failure does not come close to passing the `smell` test.

I have absolutely no problem with performance reviews, which have long been standard not only in the business world, but also are integral in determining promotion to partnership within medical and legal practices. Indeed, some form of merit-based performance evaluation dates to the Roman Empire, which somewhat predates our modern computers. However, if the reviews are based on superficial and often spurious criteria such as Dr. Zuger describes, we will witness some perverse responses. I can foresee two likely outcomes from this type of grading, especially if it actually translates to behavior towards attending physicians and/or salary penalties. First, some of the most mobile (and best) staff will leave. Second, this approach provides strong incentives for hospitals and physicians to skew (`cherry pick`) patient selection, and to select treatment regimens that best achieve a short-term measurement. And again, notice that the quality of the patient's life is nowhere in sight in these calculations. H. Gilbert Welch, Professor of Medicine at Dartmouth, writes in his recent book Less Medicine, More Health, that in medicine, "true quality is extremely hard to measure." "What is easy to measure is whether doctors do things." Although deciding not to do things may generate nothing transparent (or billable), the attentive pass is often the most appropriate, highest quality care.

In a recent Sunday `Week in Review` Op-Ed piece in the New York Times, Theresa Brown elegantly stated "Computer documentation in health care is notoriously inefficient and unwieldy, but an even more serious problem is that it has morphed into more than an account of our work; it has replaced the work itself. Our charting, rather than our care, is increasingly what we are evaluated on." Although Ms. Brown was describing how nursing jobs have evolved in the age of EHRs, this essential observation equally applies to the jobs of most doctors within larger integrated hospital systems. And so long as health care reimbursements are primarily tied to documentation alone, rather than to actual care, this skew towards the increased importance of administrators and coders, away from doctors and nurses, will only accelerate.

As I wrote above, the Affordable Care Act provided strong financial incentives for hospitals to buy up local medical practices. The central premise was to reduce the high aggregate national medical costs while delivering improved quality medicine. The driver behind this is the recognition that larger,

integrated hospital systems can often spend less money on Medicare, by avoiding redundant treatments, and offering a full suite of medical care synergistically. But a study published in December 2015 by the National Bureau of Economic Research casts doubt on the expectation that overall national medical costs will fall as a result of these integrations. The research looked both at Medicare and also at a very large new database drawn from private insurance plans. And it showed that there was very little correlation between total spending on Medicare and spending on the privately insured. In particular, the new findings cast serious doubt on the wisdom of encouraging systematic purchases of local practices and mergers among hospitals. The critical finding was that the merged systems tend to set substantially higher prices in private markets, which often more than offset any savings gained on the Medicare side of the ledger sheet. For instance, the authors found that rates were 15.3 percent higher, on average, in areas with just one hospital, compared to those served by four or more. As Zack Cooper, an assistant professor of health policy at Yale University, and the paper's lead author concluded, the merged systems could charge these elevated prices because they now faced little or no local competition – they now could exhibit monopolistic practice from a position of enhanced market power.

Unfortunately, where does this leave the physicians whose practices have already been bought by hospitals? It would be very difficult to put the genie back into the bottle, as it were, to undo the changes to patient care protocols already rendered within now agglomerated practices. However, the administration can reverse many of the financial incentives that have pushed private practices into hospital mega-systems, and perhaps even provide incentives to preserve some private practices as independent entities, for those practices that have yet to forfeit their autonomy. This could serve to forestall some of the quasi-monopolistic behavior on the part of large hospital systems, while providing patients with more of a choice in the style of medical care that they wish to receive. □

## Commoditization: The Rise of the Clones

I'll start this segment with something that sounds like a sure-fire soporific, guaranteed to put you to sleep. Just hold your eyelids up while you read through the next paragraph – I promise that there is a very important point coming up shortly. While reading some of Nicolas Terry's more recent work on the effectiveness and safety of EHRs, in particular a 2013 article in the Journal of Legal Medicine, I came across part of a paragraph that, although sterile in the academic fashion, startled me. As backdrop, Terry was discussing a 2009 paper by Michael Christensen and Dahlia Remler in the Journal of Health Politics, Policy and Law. In that paper, the authors were discussing market failures as responsible for impeding IT development and adoption. Their primary point is that market failure is due to misaligned incentives, observing that providers (doctors) are the ones who pay for EHRs, although insurers and payers welcome EHRs. Although the point is absolutely correct and astute, the writing did not make my pulse race in the same way that it does when reading F Scott Fitzgerald's The Great Gatsby, for instance. However, then I read:

“Christensen and Remler identify several failures common to general IT adoption, ... However, they argue: “[F]antastic gains of [IT] have outweighed those barriers in most industries and aspects of both public and private life. Why does health care [IT] lag so far behind?” One answer is patient heterogeneity. Going down that imperfect information road also implicates provider heterogeneity.”

**These couple of lines hit me like a ton of bricks.** As in, “Mommy, aren't all doctors the same? They're not?” Yet, once I started to think about it in the context of the Affordable Care Act (ACA), I realized that an implicit presumption of “physician homogeneity” underpins and pervades most, if not all aspects of any associated planning, logistical or economics analysis. This covers costs, competency level, experience, and degree of availability, and a few other criteria that might cause one to differentiate among possible choices. We have been reduced to utterly generic commodities in the business model of the ACA. Thus the first year doc who eked into a mediocre medical school and barely completed his residency program last June is viewed (economically and logistically) as equivalent to a section head or chair at Harvard or Johns Hopkins with 40 years of experience, or to a similarly eminent private practitioner. Sadly, much of the present treatment of physicians within today's hospital environment accurately reflects this viewpoint, as described in the previous essay.

I can only wonder what the response by a hospital president would be when informed that his lunch engagement at Per Se (Thomas Keller's Michelin 3-star gastronomic restaurant in Manhattan) was changed to a meeting at McDonald's, to achieve cost savings based on chef homogeneity.

Along similar lines, and also very important, is the implicit (business) presumption that there is no consequence to a patient's medical care if one switches insurers, and as a result, switches treating physicians on a yearly basis. During the past two years, the ACA has initiated new markets for health insurance, as well as new ways of buying it, via online exchanges. But these new markets have also seen dramatic price variations, or changes in policies, that cause many consumers to switch plans each year. The present administration is actively encouraging comparison shopping and switching as a way to avoid steep increases in premiums, and to promote competition among insurers. Indeed, among states that use HealthCare.gov, about 60% of enrollees had switched to a different plan for 2016. This extent of

switching is being trumpeted as a success, validating the economic model and incentives in play here. And I agree, *from a perspective focused exclusively on near-term cost control*, budgetary objectives may be fulfilled. In a system of identical robot physicians all seamlessly sharing complete information about a patient, this logic would be impeccable.

Unfortunately, in the human world, I believe that this model will most likely lead to greater long-term system costs, particularly for patients with complex medical regimens. Sadly, for these patients, without the continuity of care from a familiar doctor, I would often expect to see a substantial relative decline in their long-term health, and greater complications from medical or surgical interventions. I fear that this would likely be accompanied by a concomitant increase in medical costs that would be significantly larger than the projected systems savings achieved by controlling insurance rates. Why would that be? There are a number of reasons, but the following few points should already voice my concerns. Many doctors will feel less invested in the long-term health of patients if they believe that the patients will be with them only for a short while. There will be fewer incentives for a doctor to develop a master long-term personal health plan for the patient, to push for diet and exercise management and balance, to indicate timely screenings, or to `pull strings` in extenuating circumstances, each of which would be beneficial to both the patient and to the system. And many patients will not have developed the trust in a physician to adopt an `unusual` change in their habits that could be very helpful, and will not feel free to discuss `something minor` or confidential that if properly addressed, could make a world of difference to their health. Moreover, the bottom line change here, I fear, will also often come with a quality of life drop, as well, in addition to the added financial pain.

So we need to be very careful with our budget exercises. If we presume or seek genericity, we may yet achieve mediocrity.

## Turnover – Replacement Parts not Equal

In the essay *‘Throw Dr. Kildare from the Train’*, I wrote that there has been an acceleration in retirements and in retirement planning among local New Haven-area physicians, including both senior members of the Yale Medical school faculty and doctors from the private community. I know from friends and colleagues across the U.S. that this dynamic is playing out in many academic medical centers nationally. Unfortunately, the collateral damage will be severe, with the loss of irreplaceable expertise and experience. The departing muses generally shared a viewpoint of medicine as a calling, and an art, not a corporate infrastructure to be climbed. They also included many of our absolutely best minds and most compelled individuals. Yes, many had alpha-type egos and matching social behavior, but they brought innovation, depths of understanding, fire, and panache to their profession. Who will be left to advise the hard, out-of-the-box, non-formulaic cases that no template protocol can accommodate, once these physicians have left the scene? I do not know. Within modern corporate America, it has become an increasingly common business practice to force out older, often high-functioning senior employees to be replaced by less costly new hires. But this strategy has primary appeal only for short-term accounting. Within medicine, this *de facto* strategy looks to be a recipe for disaster long-term.

When I was young, medicine was considered to be the top career choice by many, and a very significant percentage of our smartest and most driven students became ‘pre-meds’. At present, the job of doctor is still generally well regarded, but the profession no longer seems to attract nearly as many star students, particularly compared to finance, consulting or entrepreneurial ventures. The following data, all obtained from published university sources, tell an interesting tale. I would expect that data from many other colleges and universities would tell a similar story. (1) Yale University. Percentage of graduates who entered Medical School: in 1975, 17%; in 2010, 4% (a remarkable decrease, again consonant with similar observations at other ‘top’ schools). In contrast, going into Business & Finance: in 1975, 8%; in 2014, 21%. (2) Brown University. In 2014, 5% of the graduating class went to medical school. In 2011, of graduates entering the work force, 20% went into consulting or finance, and another 10% went to Silicon Valley or technology companies. (3) MIT. In 2014, 6% of graduates went into health or medicine; 50% went into finance/banking, consulting & computer technologies. (4) Harvard University. In 2014, 5% of grads went into health-related fields; 31% went into finance/consulting (and 70% of the graduating class sent resumes to Wall Street and consulting firms). (5) Princeton University. In 2010, about 3% of graduates went to medical school; 36% of graduates with full time jobs went into finance; if you add management consulting, the figure exceeds 60%.

Even a decade ago, we already perceived a profound shift in the medical talent pool. In a 2004 *Medical Economics* survey, when asked “Do you think the brightest young people are going into medicine today?” 72% of the 7,700 physician responders said No. In my specialty ob/gyn, the percentage was even worse, 82%. Major complaints were a recitative of excessive bureaucracy, not enough reimbursement, medical education debt, and liability. In agreement with the data from the previous paragraph, already by 2004, much of the attrition was due to top students heading to either Silicon Valley or to Wall St, although not yet quite at today’s rates. Why? In a nutshell, they seemed to be following Sutton’s Law for robbing banks, “That’s where the money is.” Charles Lockwood, then chairman of ob/gyn at Yale, felt that nationwide, the quality of candidates had fallen precipitously and that our specialty was “in dire straits.” Lockwood noted that applications and acceptances to ob/gyn

training programs by US medical students have dropped to the lowest level in years, a point subsequently echoed by many chairs and program directors across diverse medical specialties. Based on local evidence, this trend appears to be continuing, if not accelerating.

## **EHRs – less Love and more Money**

There is a lot of unhappiness with electronic health records (EHRs) among nearly all my medical friends and colleagues, and I have heard all flavors of complaints about them. Many of the anecdotes are compelling, in fact at times bordering on the absurd, and given time and license, I can share many horror stories. But here I want to go beyond the anecdotes, in two different directions. First, many recent surveys on EHRs all point to a similar conclusion, from related yet distinct perspectives. I discuss these below as *Sad Numbers*. Second, I found a published 2014 research report by RAND Corporation, Redirecting Innovation in U.S. Health Care: Options to decrease spending and increase value (RR-308), to be very much on point here. As part of the analysis in this report, RAND undertook several case studies, which included an up-to-date analysis of the role of EHRs in health care. The report provides essential background, some executive level conclusions, and policy suggestions. In fact, there are two published `versions` of this report, each of which basically bears the same title. The more executive and slightly glossier version is denoted by RR-308; the second has a subtitle `Case Studies`, and goes into each of the eight studies in somewhat more depth than does the executive version. Nonetheless, they are very similar, and complementary. I found the content of both reports to be illuminating, confirmatory, infuriating, and saddening. Without question, the report is spot on the topic. I will simply refer to RAND or the RAND report below to indicate that the source is one (or both) of these versions. The link to the more executive version is:

[http://www.rand.org/content/dam/rand/pubs/research\\_reports/RR300/RR308/RAND\\_RR308.pdf](http://www.rand.org/content/dam/rand/pubs/research_reports/RR300/RR308/RAND_RR308.pdf) ,

while the link to the more detailed Case Studies version is

[http://www.rand.org/content/dam/rand/pubs/research\\_reports/RR300/RR308/RAND\\_RR308.casestudies.pdf](http://www.rand.org/content/dam/rand/pubs/research_reports/RR300/RR308/RAND_RR308.casestudies.pdf).

I'll discuss the RAND report (in context) below by focusing on their contrast between two major EHR vendors, Epic and VistA, along with their conclusions. One point in RAND's methodology does need to be clarified up top, since their analysis bridges several directions. They synthesized information from peer-reviewed and other literature, from a panel of technical advisors that was convened for the project, and from 50 one-on-one extended expert interviews. These interview subjects included health care industry and/or policy experts, drug and device inventors, regulators, providers, payers and insurers, venture capitalists, and researchers. A few of these interviews provided poignant quotes that pack a powerful, decisive wallop, and I wanted to share them here. So below, when I am quoting from the reports, to clarify who said what, I will indicate RAND commentary by [RAND]:, and commentary or quotations from one of the experts by [EXP]:, along with italicized text.

*Sad Numbers* As Melinda Beck reported last year in the Wall Street Journal, the depth of doctors' dissatisfaction has been confirmed by several recent large-scale studies, with widespread complaints about poor design and usability, incessant needless alerts and poor work flows. 47% of physicians say that EHRs detract from patient care, according to a 2014 survey of 20,000 physicians by the nonprofit Physicians Foundation. In the same study, 46% of respondents indicated that they would give a D or F grade to the Affordable Care Act (ACA); 39% of physicians indicated that they will accelerate their retirement plans due to changes in the healthcare system; and 50% of physicians indicated that implementation of ICD-10 (the new system of narrowly defined and finely detailed medical coding) would cause severe administrative problems in their practices. A 2014 survey by the industry group

Medical Economics discovered that 67% of doctors are “dissatisfied with [EHR] functionality.” In a 2013 AMA/RAND survey, 43% of physicians said that EHRs slowed them down, requiring them to spend too much extra time on data-entry, leaving less time for patients. Moreover, according to the results of a study published by the American Medical Association and the American College of Physicians' American EHR division, physicians have become increasingly dissatisfied with EHRs during the last five years. The survey, “Physician Use of EHR Systems 2014,” found that only 22% indicated they were satisfied, and 12% “very satisfied” with EHRs, a sharp drop from the parallel study conducted five years earlier. An Accenture study in 2012 found that of the eight developed countries surveyed, the U.S. had significantly lower percentages of doctors who believed HIT improves diagnoses, health outcomes or quality of treatment decisions.

An October 2014 survey from the executive suite buttressed these findings. The study from Frost and Sullivan, “EHR Usability-CIOs Weigh in on What's Needed to Improve Information Retrieval,” surveyed about 60 Chief Information Officers (CIOs), primarily from mid to large community hospitals. The CIOs themselves concluded that EHRs are falling down on the job when it comes to finding the information that they hold. The respondents reported that the EHRs were too slow and lacked precision when it came to information retrieval. These problems, as well as the difficulty in finding and reviewing the data, created “significant” productivity losses and increased potential risks to patient safety. Respondents also indicated that rudimentary search functionality and poor usability are more important causes of search problems than lack of end-user training or clinician dislike of technology. Moreover, the principal analyst Nancy Fabozzi predicted that as EHR data expand, the retrieval problem will worsen, and that regulatory response will be forthcoming. So if the experts, who presumably are hardly Luddites, determine that the EHR problems are with the systems and not with the users, there really is a major problem here.

***Epic and VistA*** RAND chose to contrast two of the largest and most influential EHRs in the United States today, Epic Systems and VistA, to illustrate how market forces and public policy actually shape adoption of EHRs by hospital systems and medical practices.

***Epic:*** As RAND describes, Epic is a privately held company that owns its proprietary technology. Among its clients are the vast majority of the United States’ elite academic medical centers, including the Cleveland Clinic, Johns Hopkins, Dartmouth-Hitchcock Medical Center, Kaiser Permanente, nearly the entire University of California system, and Yale-New Haven Health System. Epic has won several awards for both inpatient and outpatient EHRs, as well as for software used in scheduling, billing, and collections. It has been named “The Top EHR Vendor by Number of Meaningful Use Attestations.” Epic has been led by its founding CEO, Judith Faulkner, into a global company with approximately \$1.5 billion in revenue in 2012. As RAND discreetly states it, “Epic does customized installations for each client, allowing health care systems to tailor Epic’s applications and functionality to meet their own needs.” The RAND report quotes from a article in Forbes, “In addition to the software, [Epic] customers pay dearly for hardware, and for an army of Epic-certified technicians that needs to be deployed to get the system up and running.” On point, this past June, Boston-based Partners HealthCare (the Harvard system) launched its Epic system, Partners’ single biggest investment ever, three years in the making at a cost of \$1.2 billion. That’s correct – billion, with a B. The RAND report then continues, “Although Epic is expensive, it works, and in the conservative world of health IT, that’s all that matters.”

This is perhaps more easily understood by distilling some information from the essay *‘Cheat Sheet’*. First, the Health Information Technology (HITECH) Act of 2009 put many billions of dollars in federal incentive payments on the table for medical centers and private practices to adopt certified EHRs that demonstrated ‘Meaningful Use’ (MU). Second, Epic’s CEO, Judith Faulkner was the only head of a health IT company to serve on the Obama administration’s Federal Health IT Policy Committee, when the HITECH Act was being formulated. This gave Faulkner and Epic a critical edge, as Faulkner was then able to advise federal officials as they crafted policy framework, including criteria ultimately adopted to satisfy MU in the HITECH Act. Naturally these official criteria would mesh well with Epic’s existing systems, or with relatively turnkey modifications and additions to their systems. Since the business decision of which EHR vendor to choose almost always reduced to the question of which vendor would max out Meaningful Use revenue, Epic had a very advantageous market position. And indeed, as of mid-2014, more than half of the \$24 billion spent to date by the Meaningful Use program had gone to customers of Epic.

Let’s think about new pressures within the Harvard system, for instance, now that they just invested \$1.2 billion for their spanking new Epic EHR. The business side of the house, which has acquired outsized power within most major academic medical centers, will surely want to recoup this sum ‘in an expedited fashion’. In an age in which 78% of CEO’s say that they will mortgage the future (sell out) to meet the next quarterly earnings report estimate, I am fearful that physicians in the system will feel both implicit and explicit pressures to generate substantial (new) revenue streams. A permanent position versus being let go, tenure, a promotion, a named chair, a piece of the action – all of these incentives seem more tied to new dollars than ever before, entirely apart from the chronic pursuit of NIH grant money. So in the vast numbers of medical settings in which there are a *justifiable* range of possible actions, given the choice between further testing and procedures rather than ‘let’s just sit tight and keep a close eye on this for the moment’, or first trying lifestyle changes (in diet and exercise), I see a heavily tilted see-saw.

There are a couple of other important issues with EHRs as now in place that also require some serious attention. First, although Epic (and many other) EHRs are espoused as powerful tools to advance patient safety, they have inadvertently spawned new types of medical errors. For example, many EHRs impose severe alert fatigue, with very frequent alerts that numb the attending doctors and nurses to the point of tuning them out. In The Digital Doctor, Robert Wachter tells a frightening story about a 39-fold overdose of a common antibiotic given to a teenager, to a large extent the result of this fatigue. The protocol systems for alerts **must** undergo serious revision, and any revised models should be required to be rigorously field-tested by doctors, nurses and pharmacists for approval.

In addition, I experienced several instances of Epic crashes when I was regularly using the EHR, in which the system would be down for hours, paralyzing doctors, staff, and thus indirectly, patient care. In principle, there is a Help Desk, but responses would also be long in coming, and often nonconstructive. To be fair, this problem hardly seems unique to Epic – many friends and colleagues who use other large scale EHR systems have also experienced similar episodes, both in private practice and in hospital-based settings. Apparently this issue still persists today, perhaps with a little less frequency. But in a medical environment, this can be extremely dangerous. More back-up (redundancy) is imperative, in the name of patient safety. We have back-up generators to handle power failures. And some systems, such as

mechanical ventilators, are classified as life-critical, requiring a very high degree of reliability. In an age in which we are becoming exclusively dependent on our electronic records system to function, we must likewise develop (and in fact, require) analogous highly reliable `solutions`.

VistA: As counterpoint to Epic, the RAND report then goes on to describe VistA, from which the following is excerpted. The EHR for the Veterans Health Administration (VA), denoted VistA, provides a sharp contrast to the Epic EHR. Developed in its present form in the mid- to late 1990s, it is very well regarded within the VA health care system for its user-friendliness, interoperability, and impact. VistA has received many accolades for reducing costs, improving both outpatient and inpatient care, and enhancing clinical outcomes in the VA health care system. VistA incorporated, and in some instances pioneered, computerized order entry, electronic prescribing, and bar code medication administration. VistA's success has been attributed in large part to the collaborative nature of its development. Clinicians and information technology (IT) experts worked together to design its user interfaces and patient record system. Equally important, because VistA is built on a standard code, it is fully interoperable within the entire VA. Today, VistA and derivative EHRs, are installed in every Veterans Health Administration (VA) facility in the country. Several recent major independent surveys, including ones by the American Academy of Family Physicians (AAFP) and by Medscape, indicated that physicians are broadly satisfied with VistA, which ranked as one of the very highest systems overall. Notably, VistA significantly outscored nearly all EHRs offered by large vendors, including those by Epic and McKesson. In particular, when the AAFP survey asked respondents to express their level of agreement with the statement, "This EHR enables me to practice higher quality medicine than I could with paper charts," VistA received the top score.

`Higher quality medicine` – now there's a concept worth holding on to.

Yet, as RAND concludes, "despite its known strengths and many favorable reviews by physicians, VistA has not been enthusiastically embraced by the private market. Medsphere, a company created to market a commercial version of VistA, has a modest share in the market, but most hospitals and providers have purchased commercial products that they believe are better designed to meet their needs, particularly billing."

Or perhaps I would prefer to slightly edit the above to read "... , **particularly billing.**" This is hardly surprising, since VistA was not developed with billing (of veterans) as a primary focus. Nonetheless, many doctors, including myself, would very much like to see many of VistA's attributes incorporated into the EHRs that they are required to use. VistA clearly demonstrates that EHRs can be quite beneficial to medicine overall, not only in principle but in practice, at no expense to caregiver morale. However, the ruthlessly `business and billing-centric, all else is extraneous` model of EHRs that has emerged as a natural response to HITECH's financial incentives throw us all under the bus in the name of near-term profit.

***The Short-term is Winning***: Furthermore, the present reimbursement model (via HITECH) does more than `merely` bias towards procedures, as opposed to discussion and watchful waiting. Of at least as much concern to me, it is also accelerating the trend to favor short-term rewards over long-term benefits. Several quotations from the RAND reports strongly reinforce this observation. As one expert reported,

[EXP]: *“Payers tend to have a short-term perspective. A life saved in the future provides no financial value. Payers do not benefit from cancer prevention through screening.”* [RAND]: *“In the context of preventive services, some of which could decrease [long-term] spending,”* another expert reported [EXP]: *“when you look at preventive services, the reason that developers are deterred or discouraged from creating high-value technology that lowers overall spending revolves around reimbursement . . . we can’t set future value to justify the price of preventive services. There’s no market incentive.”* [RAND]: *“In addition, when a health system is siloes [compartmentalized] — few, if any, decisionmakers account for benefits or costs that accrue outside of their silos.”* Then yet a third expert said [EXP]: *“There’s little ability to do longitudinal holistic decisionmaking and evaluation of cost-benefit.”* The RAND authors then conclude that *“Limited time horizons and fragmented decision-making have played substantial roles in the development, adoption, and use of HIT.”*

The RAND report notes that *“EHRs’ principal economic impact to date has been facilitating clinical documentation to support timely and complete billing. . . . Viewed in hindsight, it is not surprising that introducing IT to health care did not immediately generate substantial gains in productivity. . . . When other U.S. industries adopted IT in the 1970s and 1980s, productivity growth initially fell, often significantly. However, when these industries redesigned their IT systems to make them more usable by employees and customers and redesigned work processes to take advantage of IT’s capabilities, productivity soared.”* In the present setting, the *theoretical* argument that EHRs will improve American health care and (probably) the economy is quite sound. However, academic studies have shown that the technology’s promised impact on patient care has been blunted, in likelihood by *elective* limitations in EHR design, usability, and the extent of its interoperability, in the overarching aim to maximize MU receipts. If and when suitable substantive changes are made to EHR design to better serve doctors and patients as well, there remains a strong possibility that EHRs will realize its promise. But that *“If”* must come from the top, not solely based on free market forces, and it must come shortly.

RAND has the last word here. They conclude that *“it is not known how use of EHRs in the United States will evolve, but two points are clear: (1) EHRs are here to stay, and (2) how they are designed and employed will profoundly influence the quality, efficiency, and cost of American health care for decades to come.”*

Indeed – profoundly. This is crucial. Let’s right the ship straight away. □

## The State of EHR Interconnectivity is `Not Shortly`

The ability to review and transfer EHRs from one doctor or hospital to another is one of the major selling points for the adoption of EHRs, and until told otherwise, most patients presume that `of course` this capability is already fully in place. In fact, full interconnectivity and interoperability of EHRs *is* essential to the smooth functioning of the health care system, needs to be a highest priority requirement, yet as we saw in the essay `*Worse than Russian Roulette`*, is very far from the present reality. So what is the current State of the Union on EHRs? And what were and are some of the critical `behind the scenes` issues and dynamics that frame the present state?

The following excerpts from the RAND report RR-308 featured in the previous essay highlight the trade-offs that were made to ensure cooperation from the business world. (Recall from the `*Cheat Sheet`* that the HITECH Act injected billions of dollars into the health care system to spur adoption and *Meaningful Use* of EHRs.) [RAND]: “HITECH’s language clearly indicated that Congress wanted HIT systems to be interconnected and interoperable so that they can readily share data between providers. ... Unfortunately, the rules that the U.S. Department of Health and Human Services (HHS) issued to guide implementation of HITECH watered down the requirement for connectivity.” Then we have the following, directly from the horse’s mouth, in a document just released this past October by The Office of the National Coordinator for Health Information Technology, entitled Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap. Final version 1.0. “Industry response to ONC’s request for information on the topic indicated a general desire for ONC to **refrain from formal governance activity** at that time and to allow nascent and emerging governance efforts in industry to take shape.” In other words, as the RAND report puts it, “The practical effect of this policy change was to promote adoption of existing EHR platforms, rather than to encourage the development of interconnected systems.” I appreciate that some compromise was initially required to entice various segments of the health care industry, particularly large vendors and many health care systems, to come to the dance. But now, we must evolve. As the RAND report goes on to say, “Provisions in the ACA [the Affordable care Act] will enhance interoperability ... **and should substantially increase the value of EHRs to health care providers and their patients**. The shift will be less welcome to large legacy vendors because it will blur the competitive edge they currently enjoy. ... Irrespective of industry ambivalence, the Office of the National Coordinator for Health IT is determined to press ahead.”

This issue has reached a critical threshold. Congress has begun to address the problem of information blocking (interoperability) in a bill denoted the `21<sup>st</sup> Century Cures Act` (HR 6), that was passed last July in the House of Representatives with robust bipartisan support (344 Y, 77 N). One key provision in this bill is that if determined to be noncompliant with interoperability criteria and standards, vendors of EHRs, hospitals and healthcare providers may be found to be `out of compliance`. Then, if bad behavior persists, they can subsequently be decertified (with a minimum exemption of one-year from the Meaningful Use Program, i.e., billing) and possibly subject to a monetary penalty.

As indicated earlier, Epic has been seen as the poster child of information blocking, and has been seen as unwilling to engage in the development of industry-wide communications standards. On the healthcare blog [healthcareit.me](http://healthcareit.me), Colin Rhodes, a prominent expert in health care IT and a Chief Information Officer, wrote an interesting entry last May, entitled `Why Fines for Information Blocking Won’t Work`

that sheds some light on this topic. Rhodes indicates that “The reality is a bit more complicated. Epic products can interoperate with other systems. Epic offers the features and functions that are needed to work with most of the other prominent EHR providers. More importantly, the integrations use standards based protocols.” Rhodes suggests that what’s missing from the equation are powerful enough business incentives that go beyond the `cost of doing business.`

Last March, Niam Yarhagi, a research fellow at the Brookings Institute’s Center for Technology Innovation, wrote an article for the authoritative web-based forum, **The Health Care Blog**, entitled `Congress Can’t Solve the EHR Interoperability Problem`. Yarhagi wrote that “Decertification is not good policy. ... The threat of decertification is a bluff.” He argues that ONC cannot decertify an EHR vendor that has the largest market share [to which I’d like to add, especially at the top academic center hospitals]. At best, if the bill passed unchanged through the Senate and were signed into law, Yarhagi stated that even “in the best case scenario, after Congressional pressure, such vendors may enable data exchange, but will demand very high fees [from competitors] to overcome a plethora of technical barriers, especially if the EHR vendor has a monopoly in the market.” He concludes that “this is a complicated situation which I believe cannot be resolved through regulation.”

Also, the timeline and lack of real urgency here greatly worries me. Although the 21<sup>st</sup> Century Cures Act was passed in the House last July, nothing firm has emerged from the Senate. There seemed to be definite interest within this chamber -- last April, Senate Health Committee (HELP) chairman Lamar Alexander (R-Tenn) and Ranking member Patty Murray (D-Wash) announced a bipartisan working group specifically to address ways to improve EHRs, also notably flagging interoperability as a central focus. "It's a great idea, it holds promise, but it's not working the way it is supposed to," Alexander said of EHRs. So ostensibly we have bipartisan enthusiasm to ensure interoperability, from both houses of Congress. But quite evidently, the issue was not sufficiently `burning` to rapidly progress ahead to a vote, suggesting that the usual jockeying for political credit and primacy between the House and potential Senate versions is very much in play. In this upcoming and especially volatile Presidential election year, I fear that little substantive new legislation will be passed. Further complicating matters, I am concerned that any bipartisan cooperation may be severely compromised by the politics surrounding the filling of the late Antonin Scalia’s seat on the Supreme Court. Thus I will be pleasantly surprised if anything firm on interoperability were to be ready for a Presidential signature before 18 months, at the earliest, and to be clear, I am a bit dubious that any bill will have suitable muscle to change Epic’s present business model of blocking electronic records exchange. Finally, and this is incredibly important, the aforementioned ONC document Connecting Health and Care for the Nation is a **10 year plan**, and full interoperability would not be required until the 2021-2024 time-period. This length delay would cripple the emerging network utility for electronic patient care at a distance for much too long. It would continue to accelerate the attrition of many senior physicians from the core system. And it would also castrate free market competition among EHR vendors, since only a very few competitors to Epic could afford to financially survive this extended time period. Yet, barring a disruption to the present course, it would appear that the Epic’s apparent corporate model to encourage the `slow-walking` of any system-wide changes to EHR protocols will be a decisive and winning business model for them. But at what cost? And with what recourse, what anti-monopolistic protections for patients and doctors?

Several recent government and industry initiatives have been initiated, ostensibly to facilitate interoperability. Among these the CommonWell Health Alliance, which includes Cerner Corporation, McKesson and Athenahealth; Carequality, with whom Epic has aligned, along with some of its existing partners; the Argonaut Project, which is `defining and testing the next generation of interoperability standards`; and the eHealth Initiative, which has released a 2020 Roadmap to broad interoperability. Although in principle these are promising, the evident business conflicts of interests and incentives persist, and more notably, fully realized interoperability outside of any major vendor still lies primarily well into the future. □

## **Electronica Britannica**

***You Can't Always Get What You Want*** The saga of the United Kingdom's *Connecting for Health* EHR program, formally called the National Programme for IT or NPfIT, presents an important cautionary tale for the U.S. Within the U.K., major National Health Service (NHS) IT projects have a history that dates to the late 1960's, with a number of individual NHS Trusts and hospitals introducing their own smaller scale information systems in the 1970s and 1980s. The 1992 NHS Information Management and Technology (IM&T) strategy was the first truly nationwide NHS IT effort. Ultimately this initiative failed, in part due to political battles, in part due to a lack of specificity and sufficient overall objectives and evaluation, plus a need for `better stakeholder communication`, although there were some significant regional successes. This led to a more centralized IM&T strategy, which became known as NPfIT, and launched in 2002 with an expected total cost of about \$3.4 billion. We fast forward, skipping a few nasty bits in the process. In 2011, the U.K. "urgently" dismantled this futile (now) \$20 billion attempt to connect patients' records electronically, following years of well-publicized problems from a system that couldn't even track immunization side effects. A "death knell" for the system began in 2009 because "costs were escalating without evidence of benefits, despite the programme having run for seven years already," as per the Public Accounts Committee. A very interesting 2014 case history report by University of Cambridge researchers provides many further `juicy` details, and can be found online:

<https://www.cl.cam.ac.uk/~rja14/Papers/npfit-mpp-2014-case-history.pdf>.

Although the U.K. setting is hardly identical to our own, there is much to learn from this report, since several major conclusions are broad-stroked and thematic. The authors document a whole series of IT failures, including `no time to engage with users`, `failure to check progress against expectations`, `failure to test systems`, `not providing training`, and `a lack of concern for privacy issues`. We ignore the evident commonalities, and the lessons of history, at our own peril.

***Epic Failure*** In a report very recently published (September, 2015), the United Kingdom's Care Quality Commission (CQC) recommended that the Cambridge University Hospitals NHS Foundation Trust (CUHFT) be put on "special measures," to a large extent because of problems the Trust had in implementing its new Epic EHR, which was implemented in October 2014. (The report is available at [www.cqc.org.uk/sites/default/files/new\\_reports/AAAD0111.pdf](http://www.cqc.org.uk/sites/default/files/new_reports/AAAD0111.pdf)). The report related that the Commission inspected the Trust, which operates Addenbrooke's and the Rosie Hospitals, in April and May 2015, and found its performance rating "**inadequate**" overall, with five elevated risks and four risks on its Intelligent Monitoring system. Just five months prior, the Trust had only two elevated risks and one risk on the same scoring system. The inspection found, among other things, that: **(i, p. 16)** EPIC was the "root cause" of the problems with data collection within maternity and gynaecology (and inferentially, within many other specialties, as well); **(ii, p. 70)** the system was time consuming to use and limited engagement with patients; **(iii, p. 17)** EPIC created significant numbers of delayed discharges that impacted on patients receiving end-of-life care; **(iv, p. 152)** since the implementation of EPIC the trust had seen a serious decline in its referral-to-treatment performance, with 14 of 18 specialties not meeting the required target of 92% of patients waiting no more than 18 weeks from referral; **(v, p. 152)** the system did not produce accurate data; **(vi, pp. 4, 118)** the system generated prescription errors; **(vii, p. 15)** since the introduction of the EHR system, outcomes of patient care and treatment were not robustly collected or monitored; **(viii, p. 124)** some information seemed to disappear from patient records.

As collateral damage, the trust's chief executive Dr Keith McNeil `unexpectedly` quit just prior to the release of the CQC report, as did the chief finance officer, Paul James.

A related article from the BBC noted that the Epic system cost £200m and illustrated one of the Trust's `mistakes.` As the BBC News Analysis team reported, “Perhaps the most worrying aspect of the Addenbrooke's story is not that such a world-renowned hospital has ended up in a predicament like this, but rather that it happened so quickly. A year ago, the trust which runs the hospital - CUHFT- wasn't even on the Care Quality Commission's radar in terms of being a failing centre. In fact, two years ago, [...] it was among the band of hospitals considered to be the safest, according to the risk-rating system at the time. But now a hospital which can boast to being a centre of excellence for major trauma, transplants, cancer, neurosurgery, genetics and paediatrics, has been judged to be a basket case and will join the 12 other failing hospitals already placed in special measures.”

In fact, problems with Epic's Cambridge launch were acknowledged long before this CQC report. In December 2014, just 2 months post-launch, John Naughton reported on this in The Guardian, in an article titled `The NHS's chaotic IT systems show no sign of recovery: Paperless patient records are a necessity, but a new, US-made system at Addenbrooke's in Cambridge is a chronic misreading of patient needs`. Naughton noted that the official hospital announcement of the switch onto EPIC on October 26 trumpeted the new system as being “on *bespoke* software that has been designed by and for clinicians.” He then went on to provide stark contrast given in an email one week post-launch, from a friend who had broken her foot and gone to Addenbrooke's. “From the patients' point of view,” she wrote, “it [the new system] is quite dehumanising. Staff now approach [while] gazing at a mobile device and trying to find you on it; then they check you in with a wrist barcode. There is no time for conversation or even often for eye contact. Some of this might improve as they get more confident with the system but they are deeply unhappy with the change in culture and they say all the real nurses will leave.” □

## **Solution Proposals**

In the essays above, I have attempted to identify and discuss a number of primary issues that have accompanied the recent major changes within health care, with a view to the long-term. Here, I would like to propose a few suggestions that could potentially help to resolve several of these concerns, at least in part. It is my sincere hope that these thoughts trigger productive discussions that either lead to or catalyze some changes in course.

**Patient Histories:** In the essay *'Life Begins at 60'*, I raised a concern that would still greatly compromise the utility of EHRs, even if we achieved full interconnectivity among the major hospital electronic systems. Namely, currently the vast majority of Americans have either no or minimal long-term electronic medical histories in any large hospital EHR system. This is a major limitation, one that I believe must be addressed very shortly as a top priority item. But what can be done? I would propose a WPA type of effort to collect histories on all Americans. This could come from a one-time collection process, done in a similar manner to the collection of census data, with mandatory participation by all, with significant non-compliance penalties. We could recruit and train a small army of recruits to do structured interviews in a systematic way, to obtain standardized 'personal history' entries. The training of interviewers could be done in a similar mode to the training presented in many present coding courses. The interviews would (as best as possible) identify which hospitals, private practice doctors and other medical personnel have records about each individual, either recent or well into the past, and then these sources would then be tapped for the appropriate data entry. As well, the interviews would allow one to indicate recent changes, and/or particular health issues or data of special importance. All these data would be aggregated and entered into a centralized secure, single repository. Routine access to these records would be allowed to individuals or organizations specifically named by each interviewee, such as physicians, hospitals, family members; in emergencies, more flexibility of access would be allowed, on an acute need-to-know basis. The records would be maintained both as a spreadsheet format, as well as a converted file, for instance as a searchable pdf file (so that a doctor could quickly search throughout the history for a key term or attribute). This model would still be imperfect, but much closer to the mark, and in particular, could provide a rich and crucial source of data on the many Americans at highest risk for interventions, yet with modest and very incomplete EHRs at present. At the very least, such a repository would buy time until a universal, totally integrated and updated database were developed (if ever). Of course, the ideal remains a patient with whose records and history are with a single physician, practice or system records, where records could in general be readily accessed, but in a more fractionated and discontinuous world of care, I believe that this could help to fulfill many of the needs for true universality. Finally, it should be easy to recruit and train the requisite army of interviewers -- at 62.5% participation rate, the proportion of Americans in the labor force remains near historic lows, with many white collar workers out of job, and very eager to work.

**Patient Privacy:** I agree in principle with the mission, that long-term, a well-constructed EHR system that balanced privacy and accessibility needs could significantly improve the overall quality of our healthcare. However, the actual roll-out of the Affordable Care Act, particularly of EHRs, to date has primarily facilitated the needs of hospitals, administrators, billing and insurance companies, rather than physicians and patients.

In a 2007 article in the University of Illinois Law Review entitled `Ensuring the Privacy and Confidentiality of Electronic Health Records`, Nicolas Terry and Leslie Francis wrote that what is required is a government-funded independent and apolitical regulatory body and commissioner that will have the power to mediate disputes and publish codes of conduct. (I also referred to this article, with some brief background on both Professors Terry and Francis, in the essay entitled `*Legal Recourse: Slim and None*`). Australia, Canada, New Zealand, and the United Kingdom have all adopted such regulatory review and dispute resolution models as part of their data protection regimes, and most have been particularly active in the health domain.

Frequently, some portions of a patient's records are very sensitive. Many of my patients would strongly prefer that these portions be considered to be `highly confidential` contents, and then classified as unreadable by providers with routine access to the EHR system. Such contents could be accessed only (i) by explicitly named providers; (ii) with a specific additional consent from the patient; or (iii) in the case of an emergency. Obvious examples of sensitive information that might be secured in this way include mental health history; sexual and reproductive history, including abortion, STDs, birth control, pregnancy and sexual dysfunction; and HIV/AIDS history. Other categories should be identified that a patient could routinely wish to tag as highly confidential, such as colorectal cancer. It would be **extremely timely** to address this in the very near future, even if the only categories identified as eligible for high confidentiality classification were the obvious examples just named. There is plenty of precedent for restricting data access based on `need to know` and trustworthiness criteria – the FBI, CIA and NSA have well-established protocols for security clearance, and notably, multiple layers or levels that are commensurate with the degree of sensitivity and the vulnerability if a breach occurs. Indeed, following this theme, there must be meaningful penalties for violations of confidentiality, more than modest fines that amount to `the cost of doing business` that seem so prevalent today. Breaches to NSA or CIA records come with serious consequences, and even disclosures of IRS return information may be subject to felony charges and five years in prison. I feel confident that many of my patients would be less upset by a leak of their taxes than of their sexual history.

Additionally, and perhaps less obviously, some related data must also be protected. For example if I see a prescription for a patient of 250 mg ceftriaxone plus 1g azithromycin, I can infer with virtual certainty that this is for the treatment of gonorrhea. In the paper record world, standard forms for a transfer of a patient's medical records allow for the exclusion of STD, HIV/AIDS and psychiatric histories, including any pertinent drug and prescription information; these same protections must also carry over to the EHR world. It goes without saying that such information could be used for darker purposes such as extortion or other forms of blackmail. Given the extent of data vulnerability and theft that abounds in online databases, in conjunction with the value of and interest in medical-related data, we need to pay special attention to this issue.

Also, we should recognize that much of Western Europe has strict data protection rules that have enshrined an individual's privacy as a fundamental right on a par with freedom of expression. Even Google and Facebook have run into this head on during the past few years. I believe that we should consider some of these protections in rebalancing our own present domestic privacy policies, both for EHRs and well beyond. For instance, a new European data privacy rule finalized last month will have major repercussions for U.S. tech companies that do business there. Among the most prominent aspects

of the new directive are fines of up to 4% of a company's global gross revenue if it misuses people's online data, including obtaining information without people's consent. While companies are unlikely to be hit with the full fine amount except for egregious privacy breaches, the numbers are still staggering. For Google's parent company, for example, the fines could reach \$2.4 billion; for Apple, \$9.3 billion. These kinds of penalties for privacy violations, even if only approached in the U.S., would definitely raise the awareness and responsibility of businesses and agencies that either analyze or pass along our data. Otherwise, the status quo within the U.S. seems quite inadequate. Even when record-setting penalties to major corporations (or banks) for misbehavior are announced with much hoopla, the beat goes on. The penalties are almost always effectively a slap on the wrist, the cost of doing business, and much smaller than the profits gained by pursuing the illegal activities.

***Treatment of Docs:*** In several of the essays, I have tried to point out the degree to which many physicians, especially senior members, are feeling both disheartened and beaten down by systemic changes to medicine within the last 5 years. But what should we make of this, and what can we do to try to ease the pain while moving forward in an electronic world? The bottom line from my perspective has entries in two columns. In the economics column, we must re-align the presently perverse financial incentives, with much more emphasis on long-term health, outcomes and costs. In the personnel column, we must impose some regulations so that physicians are not increasingly treated as `commoditized revenue-generating units to be squeezed`. At a minimum, this should include some mutually agreeable cap on patient volume, with some sane flexibility built in to accommodate unusually complicated cases, emergencies, or atypical patient cohorts. Secondly, significant changes to existing health care software should be mandated towards more doctor- and nurse-centered design, including a very sharp reduction in the number of incessant alerts, with more clearly flagged emphasis on events that require urgent action. Better-tailored order sets to individual specialties would also be a welcome and productive change, and should facilitate improved work-flow. Finally, more reliability and redundancy, that is, system back-up resources should be required of the EHR providers, to significantly reduce the frequency and duration of system down-times, which can paralyze the entire system and endanger patient care.

***Regulation of EHRs:*** In an earlier essay, I mentioned an article by Niam Yarhagi in The Health Care Blog entitled `Congress Can't Solve the EHR Interoperability Problem`. This past April, Ross Koppel, an adjunct professor of Sociology at the University of Pennsylvania (and a leading scholar of healthcare IT and EHRs), and Stephen Soumerai, a Professor of Population Medicine at Harvard Medical School, wrote a response piece. They agreed with Dr. Yarhagi's core points, although they did disagree with his solution. However, my interest here goes beyond their (convincing yet somewhat technical) disagreement, but rather to what they next wrote, which frames the broader issue beautifully: "The more salient question is: why should any HIT vendor be permitted to charge a penny to help share data that is needed to make medical care safer, more efficient, more informed, better? A key feature of HIT is that it allows exchanging information on patients. The government is giving \$30 billion to subsidize purchase and use of these technologies; hospitals and other providers are spending trillions of dollars buying and installing them. It is unconscionable that a vendor would even think about charging clinicians to share data on patients' health. The government need not threaten vendors who don't allow sharing of data. There should be no choice. Data exchange must be required through regulation. We don't negotiate with car drivers about stopping at red lights, and we don't compromise on truck weight limits on certain bridges. Some rules are simply necessary for public safety."

Koppel and Soumerai lead right up to the door of regulating EHRs, at least in part, and I believe that a very strong case can be made here to complete this thought, both on the basis of precedent and of parallelism. Recall the old Bell System telephone network during the 1960's. Prior to divestiture, it was regulated as a public utility, an indispensable part of the national infrastructure, on which we relied constantly. The Bell System gave outstanding service, and established the precedent that identifying a business category as a utility need not compromise the associated product in the slightest. The Federal Communications Commission (FCC) ruled last year to regulate broadband Internet as a public utility, on the basis that it is a public good. This ensured net-neutrality, which means that no content is blocked and that the Internet cannot be divided into pay-to-play fast lanes for some users, and slow lanes for everyone else. Given that universal health care is the signature policy initiative of the last 8 years, we should likewise regulate EHRs as a public utility, on the basis of Common Good, and specifically mandate universal interconnectivity without favoritism. If Comcast and its competitors could work it out, so can EHRs. A public-utility commission (PUC) can ensure that a company neither disadvantages competitors, nor abuses its market power. Every state has a PUC regulating electricity, gas, water, railroads, and telephone service, providing essential consumer protections. PUCs have the power to hold public hearings in response to customer complaints, and critically, have suitable authority to fix problems as they arise, that is, to hold providers' feet to the fire until satisfactory resolution is achieved. Their commissions usually assert their mission is to provide safe, reliable service at reasonable rates. Reasonable rates can be interpreted many ways. Utilities are allowed a fair return, usually calculated as a percentage return to their investments, for example 8%. Indeed, 8% seems a generous incentive, given the present rate of inflation, and should produce a nice profit for the regulated companies. The public benefit would be the assurance of quality service to and treatment of all constituents, here including both the patients and the physician providers. Finally, quality service must include ready access and user-friendliness to all!

Some recent testimony in the context of telephone service provides compelling arguments for the necessity of (existing) regulation in a more familiar, yet in many ways parallel, setting. In 2013, Harold Feld, senior VP of the nonprofit public interest organization Public Knowledge, testified to Congress on 'The Evolution of Wired Communications Networks'. (The testimony can be found online at <https://www.publicknowledge.org/files/Feld%20Testimony%20FINAL%2010.23.13.pdf>).

Feld identifies five "fundamental values" that define our telecommunications network: "service to all Americans (universal access), interconnection and competition, consumer protection, reliability (the system must keep working), and public safety." I believe that these same fundamental values should equally well apply to our EHR network. Feld persuasively argues that free-market incentives cannot and will not ensure that these values are satisfied, but rather, that government oversight is imperative, both on the basis of several convincing case studies, as well as on more conceptual grounds. As one example, in the case study 'The "Market" v. Real People', Feld referred to Superstorm Sandy's impact on Fire Island in New York, in which much of the existing copper network infrastructure was destroyed. The local carrier Verizon faced a choice: rebuild its copper network, deploy the fiber-optic network FIOS, or deploy its fixed wireless product called Voice Link. Verizon made the entirely rational business decision that deploying either a copper or fiber network for the Island's small permanent population was simply not cost effective. Instead, they announced that they would deploy Voice Link, which was much less costly to them, with some well-wrung talking points on the market embrace of wireless, away from

traditional copper. This decision created a firestorm of customer complaints and negative news stories that, combined with regulatory scrutiny from the New York Public Service Commission and the FCC, ultimately forced Verizon to commit to deploying FIOS on Fire Island. Reliability and quality of service (and reception) were concerns about the proposed wireless service. As Feld noted earlier in his testimony, “Given the importance of communications infrastructure to our lives, particularly in an emergency, we will hopefully continue to maintain reliability as a core value and acknowledge that government at all levels have both a keen interest in the safety of their citizens and an important role in ensuring that safety.” A simple substitution of `health care` for `communications` in the previous sentence should highlight the parallelism here.

And notice that regulation hardly means the end of competition or profit – it just mandates reasonable minimum floor levels of service and responsibility by the vendors, in a few essential categories.

Finally, on the crucial line item of interoperability, let’s borrow Mr. Peabody and Sherman’s Wayback time machine, and head backwards in time nearly 50 years, to 1969 and the birth of the Internet. The Internet was actually born as the ARPANET during the 1960s, at the height of the Cold War between the United States and the USSR. Indeed, universality or full interoperability was its initial *raison d’être*, not only during routine operation, but even or especially under severe disruption. US authorities considered ways to communicate without interruption in the aftermath of a nuclear attack, if centralized telecommunications switching facilities were destroyed by enemy weapons. This led to the development of a decentralized (*distributed*) network architecture by Paul Baran with colleagues at RAND, implemented as the ARPANET in 1969 (and renamed the Internet in the late 1980s). The most salient point here, though, is that given enough political will, protocols could be readily established (50 years ago) to establish full interoperability, even among a network of ostensibly very different components. Leonard Kleinrock, a Professor of Computer Science at UCLA and a seminal contributor to both the mathematical theory and early implementation of the ARPANET, succinctly stated the case in his 1976 textbook on Queueing Systems, in which he describes the collection of 100 computers geographically distributed across the United States that were to be connected. “The (HOST) computers are in many ways incompatible with each other, coming from different manufacturers and containing specialized software, data bases, and so on; this in fact presented the challenge of the original network experiment, namely, to provide effective communication among, and utilization of, this collection of incompatible machines.”

And of course, in addition to the Internet, telecommunications and banking, which are likewise essential networks, have been fully interconnected via standardized protocols for many decades.

So for all the reasons stated earlier, a fully realized and interoperable EHR network should be made a topmost, URGENT priority, to be completed shortly. The stars align -- there is an acute need; significant historical precedent; bipartisan support; readily available engineering expertise; and existing software infrastructure either already in place or nearly so. Let’s move!

## **Final Thoughts**

Nearly all of my physician friends and colleagues have entered the EHR world in the past few years, only to report that they just feel as if they are on the short-end of an escalating beat-down. The joy of patient care is being ripped away by increasing administrative demands that are often counterproductive and superficial. Many of my contemporaries who have incorporated their practices into a local academic hospital complex are being treated like titled grocery store clerks, forced to see significantly increased numbers of patients and/or generate specified levels of revenue, regardless of acute patient needs. Doctoring is being forced to become increasingly programmatic and color by number, dehumanizing the doctor-patient dynamic. Non-revenue generating counsel to patients, for example, important discussions of potential side effects or the impact to one's quality of life, are *de facto* being badly punished. Most of my colleagues who are at least 60 years old are actively thinking of getting off of this treadmill in the near future, either by retiring altogether, or at least by leaving the practice or teaching of medicine. Who is winning? The hospitals (as a business); the insurance companies; the associated electronic software and Information Technology industry; and legions of administrative intermediates. Who is losing? Short term, doctors; longer-term, patients, because of the loss of continuity of care, of a doctor truly vested in them for an extended period, and because the incentives play against the doctor getting the care right, so long as the care is administratively plausible or justifiable. Unchecked, I foresee an acceleration towards two-tier medicine, and I do not believe that such a resolution was the intended goal, or in society's best interests.

I certainly recognize the Realpolitik compromises needed on the part of the administration to get the insurers and IT companies (that created the EHRs) to the dance. The very fate of this administration's signature policy initiative rested on this crucial pivot point, with huge political as well as societal ramifications. But although the basic structure of the Affordable Care Act brings both promise and humanity, the initial implementations, if continued for any extended timeframe, will destroy much more of lasting health care worthiness than it will create. There still is time, if we act expeditiously and decisively, to significantly change yet preserve the system while creating much better long-term outcomes for patients and doctors. And we can do this in a way that will still allow quite reasonable profits to be made by the business side of the model. How? Change electronic health records to incorporate the best features of both the VA's VistA and the private EHRs. In particular, mandate a high level of user-friendliness for both doctors and patients, as VistA presently has, as well as significant functionality to broad health care as embodied by the Meaningful Use requirements. Impose a public utility structure on the EHRs, on the basis of Common Good, to **ensure** that these mandates be met, and also to **ensure** full interoperability, ASAP. Facilitate long-term continuity of care, rather than emasculating it by encouraging frequent or yearly changes of insurers (and docs). Impose sensible privacy policies that protect patients, with serious penalties for violations, not the cost of doing business. Record and centralize personal histories on all Americans. And recognize that doctors are not commodities, and that there is much more at stake than a budgetary exercise.

Is this achievable? I believe, or at least hope so, **if** there is enough political will, plus some cross-the-aisle recognition that both sides have much to gain (and much to claim) if the system is extensively altered for the better. So the opportunity still remains open, but the time is now, not in ten years. Bon courage! □