Keynote NOTES

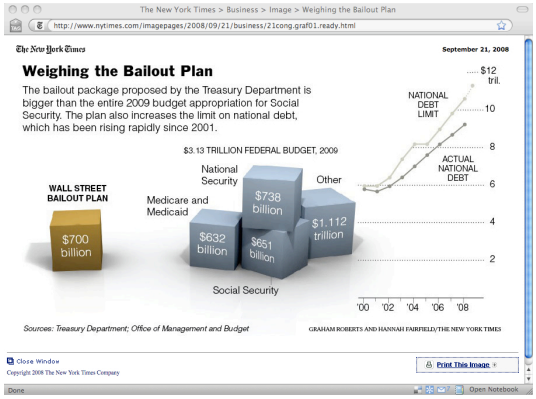
Why "Fear, Greed, Consequences, and our Privacy"?

Simply put: the money is not there to do what we think we should do. Greed (and neglect) got us in this situation). Fear is everywhere, and both fear and greed have consequences.

It's time to get over it and get back to work in a realistic way.

PART 1: HOW BAD ARE THINGS?

Quick answer: bad and getting worse.



The bail-out of our financial system puts our overall debt in perspective (figure from the NY Times). If you want to read more, read Craig Barrett's talks on health care costs or follow the realistic assessments of Jim Cooper, a member from Tennessee of the House of Representatives.

Most of these issues get personal – you and me. For that reason, I looked into the income and health care costs in California.

From 2000 – 2007:

- Salaries increased 19.3%
- Family health care coverage increase 95.8%

Wow! What about this don't people get? This isn't anyone's fault, per se any more than we can blame the collapse of our financial system on any one person. But somehow finance has gotten out of whack. Health care has been out of whack for decades, but somehow the "crash" has not yet happened (unless you are sick).

(And then there's the erosion of a job market; will the California economy someday simply consist of health care workers caring for agricultural workers?)

So, I had to ask:

- Can we afford to have numerous meetings anticipating every nuance of privacy violation?

- Can we marshal the resources we need to enact the right legislation and policies?
- Can we enforce the policies we create?

PART TWO: IT'S ABOUT ME

Here's the funny thing, while we ponder whether or not to "opt out" of things, we forget that just about anything anyone wants to find out about us is out there. At times, it's a matter of knowing where to get it; at times, it's a matter of mathematics – weaving together "de-identified" data sources to re-identify someone. Years back, Governor William Weld found this out the hard way when an MIT grad student named Latanya Sweeney was able to reconstruct his health history from publicly available, often "de-identified" information. She's now at CMU. Governor Weld's current interests can be found from Wikipedia.

Then there is the whole industry of selling health information to enable more effective drug detailing, and the unknown activities of health plans who make information available to each other to bid more effectively on business. It's not clear this is a good or bad thing, but the simple fact is that while people argue about hypotheticals and theoreticals, real companies are doing real things while we aren't paying attention (kind of like the folks who sold credit default swaps – just as arcane, just demonstrably more dangerous at present).

So why do people get so worried about digital health records when the same people – even the so called "consumer advocates" and "privacy advocates" – seem to tolerate quite well the impossibly porous and ineffective paper-based health care system? (You can copy a paper medical record and no one will know.) I think it's in part because the hard trench-level work involved with paper is nowhere near as "cool" as the digital world (try to get the attention of the press about a paper breach when there are so many lost computers out there).

But there are other reasons, and I point them out:

- Digital information can be replicated accurately an infinite number of times
- Aggregated information can often be obtained more easily than disaggregated information. So why steal an apple when you can hijack the entire fruit stand?

There is also the "secondary use" issue. We envision our medical records and correspondence as directed towards our own care (that's not entirely realistic, but that's what we think). This care relationship is about trust – like the relationship you have when you go to your bank and get a home mortgage.

So when all of these artifacts of individual trust relationships can be bundled together and sold for unknown reasons, it should get us upset. Just as in the case of mortgage-backed securities, the

people buying and selling these things simply do not understand the full implications of what they are doing. To me, that's not "markets" and "business" that's "dumb, self-serving, greed" operating under the ruse of market efficiency. We've learned the hard way that we shouldn't sell financial instruments we don't understand. Don't you think we ought to ask the same question about our health information?

PART 3: WHAT IT MEANS

We've got to pay attention to this. The State of California's Security and Privacy Board is so important. A small number of people – working with representatives from all perspectives in the State – can not only improve the lives and economy of Californians, it can focus the vision of the country.

But you have to ask in the current state and national economic climate:

- Do we have the luxury of time?
- Can we enforce what we create?
- Will we even be employed?

My answer is simple: we've got to address these issues and not worry. Franklin Roosevelt didn't give up. Those who struggled to create California didn't give up. Those across the nation who fight in myriad ways to keep us a better place don't give up. We simply cannot retreat to the delusional sanctuary our flat-screen TVs and premium cable channels.

We have to acknowledge that information about our health can be used to embarrass us and even discriminate against us. The economic and psychological consequences of such practices can be damaging if not lethal in rare instances.

But building a completely impractical system can be lethal too! I would argue that consent is very important, but that selective disclosure of health information is both impractical and may kill more people someday than health privacy violations.

At times, I think of many privacy debates are not grounded in the reality of care. They seem to begin with the "what if" hypotheticals of the digital world and never with the "what is" realities of the porous paper world. They pose a selective release reality that precludes knowledge of certain diseases and drugs. As a physician trained in conducting and recording a comprehensive history and physical examination, my "H&P" is by definition violating such barriers. Hence, any such measures to restrict information must, of necessity, ban the use of these documents – even though in Memphis Tennessee's health exchange, at least, these documents are far and away the most valued documents available to emergency department clinicians.

It's like brush fires in California. We can do a lot to prevent them and to contain them, but we cannot prevent them and we must view minimizing harm as a

complex system of housing, behavior, and response.

Medical information is similar. If you want absolute privacy, you had better head to the desert and get off the grid. If you want medical privacy, you had first start looking at what organizations are doing with your information outside of the traditional privacy debate, you should then adopt some principles (like the Markle Foundation principles) and try to apply them. Me? I'd emphasize "audit," "authorization," and "remedy."

PART FOUR: NEW RULES

I end my address with a few ideas.

- Make everyone play by the same rules, including the folks who sell or use "de-identified" data
- Encrypt everything. Why not?
- Treat information like media, not like physical objects
- Understand consent; we don't; we perhaps can't
- Make important legislation uniform. Many of these issues are national. Many important aspects of our privacy "fall between the cracks.
- Don't support practices you don't understand. The surgeon's maxim is applicable to data use and privacy: "when in doubt, cut it out"!
- Be totally and absolutely transparent in all you do. This is a central lesson of markets.
- Make your audits useful. We talk a good fight here, but can we really audit efficiently across the myriad health care transactions as our data bounce from one source to another and yet to a third?
- Prove that you can enforce the regulations you have

I'd also focus on functions like authentication and authorization. With few exceptions, "certifying" emerging and beneficial efforts like RHIOs and PHRs confuses the "mash-up" output of health services with the basic concerns the public has. I don't care what a "RHIO" is (I really don't), but I care a great deal about how confidential information is protected.

FINAL REMARKS

Personally I don't know if I really believe health care is a <u>right</u> that I should have. But I do know that I have an <u>obligation</u> to do everything I can – everything – see that everyone I know and love (and those I don't) have good health care. What kind of person would I be if I didn't have this sense?

I'd suggest we re-frame the privacy debate the same way. Start with the reality that we ought to have an <u>obligation</u> to respect and protect the privacy of each other. This is actually an easier statement to make since it is far easier to argue even to the most staunch libertarian that erosion of privacy means erosion of trust, and without trust there can be no markets, no civilization, and, in my view, no life really worth living.

Thanks to Vicki, Janet, Susan, Gerry, and the many others who were the inspiration for this presentation. And thanks to California for leading the way.