

The 2007 American Medical Informatics Association (AMIA) Spring Congress:
“Informatics Across the Spectrum”
Orlando, Florida
May, 22, 2007

Putting Health into the Patient's Hands - Consumerism and Health Care

Keynote by Adam Bosworth, VP, Google, Inc.

This is an attempt to articulate a vision of what consumers should expect over the next decade out of the health care system.

I want to start by articulating a vision about the future of health care. It sounds simple and obvious, but it is very far from our current reality. Then I want, briefly, to outline an example of how this vision can come together to deliver huge value to the consumer. Lastly I want to talk about what the prerequisites that can and will enable this vision to slowly and painfully become a reality. It is really the second part of the talk that is important. Visions are cheap. Anyone can dream. But turning dreams into reality requires hard work and persistence and sweat and deep reserves of energy.

This vision for the future of health care starts with the premise that consumers should own their own total personal health and wellness data (I'll call it PHW for short) and that only consumers, not insurers, not government, not employers, and not even doctors, but only consumers, should have complete control over how it is used. As an additional premise, we believe consumers should have the right to all data that is about their personal health and wellness in electronic form. People often misunderstand this point and argue that HIPAA gives them this right, but in fact, if your doctor has no electronic medical record (EMR) and 85% of them do not, then the labs you take and the prescriptions you fill out and even the images of your body are usually not available to you in electronic form even though they flow through the net speeding their way to insurers and Pharmacy Benefit Managers (PBMs) and formularies so that, in the end, people can get paid. We believe that consumers have the right to demand that if this information is flowing, it should also flow to them.

Given this control over information and this access to it, we then believe that in a good health system, consumers will have three core abilities:

- Discovery - Consumers should be able to discover the most relevant health information possible
- Action - Consumers should have direct access to personalized services to help them get the best and most convenient possible health support
- Community - Consumers should be able to learn from and educate those in similar health circumstances and from their health practitioners

Let's examine each of these abilities in more detail.

Discovery: What consumers need to know and where or to whom they should go taking into account their personal health and wellness information as they see fit. In general, we think consumers should easily be able to discover:

- What might be wrong with them

- All relevant online information about who can treat them, including available institutions and physicians and other health and wellness practitioners such as chiropractors, nursing homes, home health aides and all relevant and public information about these people, places, and institutions. Centers for Medicare and Medicaid Services (CMS) data, for example, should be public and transparent, and people should be able to learn what has been the experience of others when treated by these institutions or health and wellness practitioners
- What is the relevant, current, and generally accepted level of care for them given their unique PHW and, for that matter, what are the various alternative wellness choices that are recommended for them given their unique health and wellness issues
- All relevant online expertise available to help to them manage their ongoing illnesses and chronic diseases
- All insurance information and costs relevant to them and their health needs and which institutions and doctors can treat them under their insurance and how those doctors and institutions compare to those overall
- What evidence actually underlies a given diagnostic or treatment decision

Action: What activities can consumers perform using the Internet taking into account their PHW as they see fit? In general, we think consumers should be able to:

- Decide in a controlled and personalized manner how to share their PHW with those who can assist them. This means more than HIPAA which simply says that any health practitioner caring for you has the right to access all other health data about you. This means that the consumer can decide, case by case, what the practitioner can see. Perhaps there was a teenage episode with anorexia or Planned Parenthood. The consumer should be able to decide who has access to such information and with whom they share what portion of it.
- Access all online health data about them in a standardized and computable form, including information such as prescriptions, labs, images, coded conditions and procedures and, under their control, decide how to incorporate this data into their PHW even if this information isn't in an EMR. I alluded to this early in this talk. This doesn't just mean that the consumer can walk into their doctor's office and demand a faxed copy of their medical records. It means that where the information has been coded and is being used electronically, they can demand that a copy be sent to their online PHW, something that elsewhere I've called a Health URL.
- Manage their health issues needs where possible online, including time saving activities such as managing refills, scheduling visits, e-consulting, care management guidance, and service oriented activities such as requesting second opinions, getting online coaching or diet or exercise advice or getting assistance with insurance claims. As we all know 80% of our medical costs come from 20% of the population, the more chronically ill. What we sometimes lose sight of is that we make life very hard for this population because coordinating with doctors is a terrible time sink for a population that is already debilitated. What we sometimes lose sight of is that this group can be helped the most with ongoing monitoring and coaching and can both experience the most gain and often save the system the most money with such online care guidance, but that they don't get it.

Community: When you are trying to learn more, how can you learn from people who are walking in your shoes and experiencing what you are experiencing?

- Consumers can organize into communities which are protected from inappropriate commercial exploitation but allow consumers to share their experiences with others whose medical situations are similar, to rate the value of resources such as sites and health practitioners, and even to answer questions of each other in real time. Anyone who has ever watched a group of similarly sick people in a waiting room has experienced the shock of realizing that they want to talk to each other about what is going on. They want to compare notes. They want comfort that they aren't alone in this. They want to know how others are coping with the problems. I sometimes marvel that the industry loses sight of the human condition and the need people have to share their experience with others. But they want to share it with people who are truly in the same boat and not exploiting them. Accordingly they need some way to know that this is true. This doesn't necessarily mean exposing their identity, but interestingly, often, if the situation is dire, people want to. I used to watch my mother share notes with others while waiting for chemo at Sloan Kettering and soon they came to know each other, their kids, their life stories, and so on. Clearly here their identity was known. Sloan Kettering and the room in which one waited was clearly authenticating that the others were facing similar issues and had similar conditions. But for tens of millions trying to find others online this is a much harder problem and yet, a most basic need and one that will doubtless lead to many discoveries about what works for people.

All this is the vision: That consumers can discover the information they need, that they can act upon it with guided assistance, and that they can find others like them and share their stories and learn from each other and then learn from them if they so choose.

Let me pick a concrete example of all this in action. Let's talk about how these three core consumer capabilities, discovery, action, and community can come together to deliver value to the consumer. This example is motivated by a true story documented in a book, *Coronary*, written by Stephen Klaidman, about how a huge number of people in Redding, California received unnecessary heart surgery to at the very least, great cost to them, and to some the far worse costs of permanent damage or even death. Most of this happened because the patients were too scared to get second opinions, but some did and when they did, they were typically told that they didn't have any signs of coronary disease or certainly not enough to warrant the treatment being proposed.

Now imagine that when looking up by condition and doctor and procedure or medicine or both, you could see how others had fared. Then most of these people would have seen this, the evidence would have quickly mounted and been overwhelming, and this terrible tragedy would have been nipped in the bud. More to the point, scared cancer patients could find out how others were tolerating the same medicines they were on for the same conditions and so on and how the doctor was. People really care about how they are treated by the doctors. Are they listened to? Is the doctor actually treating them as an adult and understanding their needs? All this could surface. Customers searching for information about doctors or conditions would discover this.

But how does one know that these reviews really came from people who were really treated by the doctors they say they were for the condition they say they have with the procedure or medicines they say? Well, as a thought experiment let's limit the world to Medicare and imagine the CMS suddenly decides to help here. Imagine if patients can come to a "Reviews" website and the site asks them to prove that all these things they say about their review are true. The "Reviews" site redirects them to their friendly new CMS personal health record (PHR) where they have to authenticate themselves to CMS. CMS then returns back to the "Reviews" site a signed document authenticating that this reviewer was indeed treated by the doctor for the

condition and with the procedure and/or medicines claimed. As I'll explain in a moment, this doesn't compromise their anonymity at the "Reviews" site. Only CMS knows who they are, not the "Reviews" site.

All this can have enormous implications. Suddenly you have the core material for consumer driven communication about health. The trust and confidence that all can have in such reviews is such that it will inevitably lead to actions like requesting online second opinions, to communities forming of people who suffer from similar conditions and are going through similar treatments because, and this is the key thing, they can all trust that the other members are in the same boat.

What is required to make this vision a reality?

We need two core changes in electronic medicine.

Discovery, Actions, and Community rest on a dual foundation of trust, authentication, and shared standardized online computable health data. Online services cannot help consumers discover the information that is truly relevant to them unless their health conditions can be understood. Nor can people trust such services to guard their privacy unless they can trust that no one can access this information without their approval and even then, they can control who can access what, which requires knowing the identity of those seeking to access it.

Online services cannot reliably enable the actions that help a consumer to manage their health needs or get online guidance and advice unless the health data is computable and unambiguously encoded for drugs, for conditions, for diagnoses, for test results from labs, for procedures, for allergies and for immunizations. Communities cannot be sure that the others in the community are truly going through the same ordeal they are unless the medical record is well defined and can be authenticated to ensure that those in the community really belong there.

When it comes to computable health data, much of this is now almost at our fingertips. With the advent of standards such as the Continuity of Care Record (CCR) and Continuity of Care Document (CCD) to follow shortly, we are almost there when it comes to computable health data. There is a single hole in these formats today. That hole is in describing precisely how drugs, conditions, procedures, allergies, and test results from labs should be encoded so that any system can unambiguously understand the medical data. The current standards deferred this decision with the goal of supporting flexibility and evolving standards. It is all very well to build an extensible model, but what is required right now is a precise description. Accordingly, as Google looks at these standards and we will, undoubtedly, over time want to support both so that we can help search intelligently for phenotypic information and connect people with the information, places, people, and online expertise that they need, we are likely to endorse these standards, but with the caveat that we will all need precise encodings and precise dosages or quantities to be spelled out. So this is practically a reality.

When it comes to authentication and trust, we at Google may be able to help. We face this issue every day. For example, people want to expose one of their Google calendars to some time management service or to Salesforce.com, but not all their calendars, let alone their email, their personal Google Documents (spreadsheets, text documents, and presentations) or their other personal data. Thus, giving up their user name and password to the service is totally inappropriate. And it is important that not only are access rights constrained, but that they can be revoked because the customer may end up losing trust in the individual or online service with whom the data is shared. To us, trust does not mean a national identity since as far as we can see

this flies in the face of the very human need to compartmentalize and maintain privacy. We have come up and are shipping a solution known as Account Authentication Proxy for Web-Based Applications, also known as Auth/Sub. For more information see <http://code.google.com/apis/accounts/AuthForWebApps.html>.

How does this technology work? When two parties on the web want to give rights to each other, both of them share what are called “public keys,” which is tech talk for a way to be sure that the other side is who they say they are. The first site authenticates the user (think of my example of CMS’s PHR). It then redirects to the second site with the URL to redirect back to. The second site then separately authenticates the user (think the review site), makes sure that the rights are clear in terms of what the first site can do with respect to the second, and then returns to the first site. There is then an exchange between the two web servers just to make sure no one intercepted some web traffic and tried to spoof this. Then a long magic number known as an authsub token is shared between them that permits the first site (and only the first site) limited rights to data in the second site for a given patient/consumer. If a different site tries to access the consumer’s calendar using this number, they will fail. This model has the advantage that sites can share information with other sites without the consumer ever compromising his or her identity to either of them. This model is battle hardened now and would allow the sort of authentication of medical data I described above.

It is Google’s vision that these two core capabilities, reliable unambiguous computable medical data and safe systems for trust and authentication and controlled access will dovetail with the consumer needs for discovery about everything in their health arena. As this rolls out and consumers truly can discover what is the state of the art and what they should know about their treatments, where they are being treated, how they are being treated, and how they will manage their diseases or recovery, this consumer awareness will lead to far greater consumer control, far better health data, and inevitably, to a very different health world than the current one.