

A National Web Conference

Personal Health Records: Personal Control of Health Data and Patient-Provider Communications

April 3, 2008

We have two great speakers, Dr. Jonathan Wald and Ken Mandl, who will be talking about personal control of health data and patient provider communications. This is the second of a three-part series of national web conferences on personal health records.

Dr. Jon Wald is associate director of the Clinical Informatics Research and Development or CIR group at Partners HealthCare System. His group provides leadership and expertise in advanced clinical systems development and deployment, including strategy requirements and design, medical practice and evaluation. His main focus is the use of automated systems to improve communication and collaboration in health care, with specific interests in patient or consumer use of computers, physician use of computers, improved medication management, decision support, human computer interaction, confidentiality, and prevention of errors.

Prior to joining Partners in 2000, he was a physician executive at Cerner Corporation, a leading developer of clinical systems. Prior to that, he was on faculty at the Boston Beth Israel Hospital, practicing general psychiatry, doing clinical systems development, and completing the Douglas Porter Fellowship in clinical computing at the Center for Clinical Computing. He received his MD from Brown University, an MPH degree at the Harvard School for Public Health, and a BA from Dartmouth College. And today he will be presenting on Patient Gateway, a secure patient portal of Partner's HealthCare.

Our second speaker for today is Dr. Ken Mandl who is an expert on real time population health monitoring and has published several off-the-groundbreaking journals and articles in the field. He co-directs one of two Centers for Disease Control Prevention Centers of excellence and public health informatics. He is faculty at the Harvard Medical School Center for Biomedical and Informatics. Dr. Mandl also runs the Indivo Health Personally Controlled Health Records or PCHR project. The Indivo PCHR, widely regarded as a transformative technology, is being deployed at Children's Hospital of Boston for all patients, at MIT for students and employees, and for the millions of employees of the Dossia founding companies including Intel, Wal-mart, Cardinal Health, and AT&T.

Currently, Dr. Mandl is working to extend real-time surveillance methods to the area of pharmacovigilance for post approval pharmaceuticals. He received his MD from Harvard Medical School, and his MPH from the Harvard School of Public Health. He also completed graduate work in medical informatics at the Massachusetts Institute of Technology, and he will be presenting on the platform model of personally controlled health records. I would now like to pass this along to Jon Wald who will get us started.

Jon: Thanks, Teresa. I'm going to be talking about Patient Gateway, the secured patient portal that we use at Partners Healthcare. And the other thing I'll talk about at the end is a small piece of the research that we've done as part of the Prepare for Care study, and I'll talk a little bit about our work in diabetes, and that is an AHRQ-sponsored study that has Blackford Middleton as the principal investigator, and I served as Co-PI.

What is Patient Gateway? It's a secure web application that was developed at Partners, and it's currently in use by over 800 providers in 42 practices, both primary care and specialty care practices at four institutions. And there are three institutions where we are primarily in use: Mass General Hospital, Brigham & Women's Hospital, and Dana Farber Cancer Institute. It's a system that's linked to our EMR, our longitudinal medical record that we call the LMR, and it really consists of three main portals.

One is a patient portal, which is available free to the patient, and it contains really three pieces that I'll show you. One is chart information, and so that's information coming primarily from the LMR and the clinical systems at Partners. We display medication lists, allergy lists, immunizations, future and past appointments. We show lab results, currently about 50 results, with expansion to 200 coming very soon.

The second piece is online communication tools, and this is really web messaging that allows a patient to communicate with their practice, and so it's tied to the practice workflow. Patients who send in messages can route them to practice mailboxes, and then those are handled by practice staff. They can be forwarded to physicians. Sometimes they are received directly by physicians by choice of the practice

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and the physician. And the communication also includes reminders and notifications that go directly to e-mail addresses for patients to let them know about new messages or appointment reminders and so on.

And then the third piece of the patient portal is reference information. We license health-wise content to provide information that patients can search and browse. And in addition, there are contextual links from, for example, the immunization's page that go out to other web resources. So that's the first portal.

The second portal that we manage as part of the system is for the practice or the provider, and that offers them a way to view incoming requests and also gives them some integration points with the LMR. For example, they can save a message or a thread of messages, related messages as a note in the chart, or they could open up the chart from the message because there's a link from the patient identifier into the chart.

And the third portal is a support portal that's used to manage the systems, and you'll see that in the presentation as we support requests from patients and have to do configuration and setup of the application for each practice.

The next slide shows a picture of what some people would refer to as a personal health ecosystem. And the idea is that the patient who is shown in the left, in the reddish area, can be using personal health tools, such as applications on their desktop or applications that are managed through a device, whether it be a medical device that manages blood pressure or maybe it's a mobile phone that kind of serves dual purpose as helping them with kind of health-related questions and bringing information and reminders to them. That's on the left of the diagram.

On the right of the diagram, that represents the systems that are offered through healthcare institutions or organizations. For example, a doctor's office or a hospital that offers a web portal like Patient Gateway is shown in red. A health plan can offer a member portal that has health information based on their claims data or other information that they've collected about their members, or maybe a retail pharmacy or a PBM is offering tools that help an individual to manage their medications.

And then in the middle of the diagram are these components that are identified as platforms. And the idea there is that that there could be kind of global Internet brands like Google or Microsoft or Dossia that are connecting information that can be supplied from institutions on the right or supplied from individuals on the left in ways that follow policies and allow patients to control where information can go, how it can get into that platform or how it can leave that platform.

What I'm going to be talking about, at least on this diagram, is an illustration of the patient who is logged into a doctor's office that offers Patient Gateway as their patient portal. And then Ken will be talking, I think, more broadly about platform tools and how data can move really throughout this picture.

The next slide is titled "Why does Partners offer this?" And we've been working on Patient Gateway since about the year 2000, and we first went live in 2002. Our goals were really to offer the patients service convenience and a better way to be able to view and share medical information, better ways to communicate with their practice with the hopes that if they are having a good experience that this will serve to strengthen the engagement between a patient and their doctor's office and sense of ease of interacting with them.

We also have an important set of customers, which are the practices who are striving to be more productive in the work that they do. We're trying to offer them tools to improve their ability to communicate seamlessly with their patients, better ways to receive requests, because the online requests that come in are self-documenting. They're better than phone calls in that respect and always with an eye towards time efficiency.

Often times providers are not being reimbursed directly for using these kinds of tools or offering these kinds of tools. We don't receive any direct reimbursement for doing it here at Partners HealthCare, and

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so making sure that things are time efficient is really critical, otherwise we can't attract physicians and their staff to use these tools.

And then the third area that we are trying to focus on is how do we support quality of care improvements? We've got big programs at Partners around medication safety. And as you can imagine, those focus on core areas like provider-order entry and making sure that we have a single and a very visible medication list and allergy list for all of our patients. But we also see patient portals as a way to strengthen that area through patients who can view and suggest where changes are needed to the medication list that their doctor's office is showing.

In the area of chronic care management, the idea is to use these tools to support diabetes and other conditions that are managed fairly actively. We want patients who are using the Patient Gateway to have tools and information to help them become as engaged and active patients in their care as possible, and ultimately can both drive and also adhere to a joint plan of care.

When you go to the Patient Gateway website, which is at www.patietgateway.org, you see a log-in screen, and on the left-hand side is a place where you can enroll. And when you click on that link, it takes you to several screens, which allow you to identify which providers are yours or the ones that you're interacting with. It also gives you a place to provide some information about yourself, because over the Web we need to know who you are so that we can match you up with a registered patient in our Partners patient lookup. And then there's a place where you can review terms of use and submit a request.

The next slide illustrates that we have enrollment staff who receive that request from the enrollment forms, and they match that up to a patient who's in the Partners patient lookup, and when the match is complete, they create an account which generates a user name that goes back to the requester by e-mail, and a temporary password that gets mailed by postal mail to the registration address on file. The idea here is that security is maintained because the individual who comes back in with the user name and password has had to put these two different pieces of information together in order to log in. The downside of this approach is that it takes a few days for the password to arrive via postal mail. It's also subject to other issues like spam filters that might block the user name e-mail from reaching the user. We have support staff that can help troubleshoot some of those issues.

The other thing we do is on-sight enrollment, which happens in real-time, but of course you have to be at a Partners facility standing in front of somebody in order for that to take place. We're always interested in more efficient ways to do this, and there are obvious trade-offs between making the process quick and very, very easy, versus maintaining security on the account.

On the next screen is an illustration of the welcome screen, so when a user logs in with their user name and password -- and the first time they log in they have to reset their password and answer and set up a secret question later on for password recovery. But then they come to a welcome screen, and this illustrates the main features that are offered through Patient Gateway. There's a mail menu item, there's a requests menu item that offers forms for requesting an appointment, and a prescription, and a referral authorization. The health records screen, which allows them to browse different components of their chart, and this is their doctor's office chart that they're looking at; health library, which allows them to browse the health-wise data; and then some set-up areas where they can add and remove providers. They can look at registration information. And on the front screen are alerts that let them know if they have new messages or if they have appointments coming up. We sometimes alert them about new features, and they can also see some provider information for one or multiple providers, depending on, again, who they have activated in their provider list.

On the next screen, this is an illustration for the proxy feature that is still in pilot, where an individual can log in. In this case they're logged in as BE-11, which is kind of up in the blue top center of the screen, and this individual has the authorization to open up one of several patient records, and this could be a parent with children or it could be an adult who whose parents are patients in the Partners HealthCare

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System. This illustrates one of the areas that we've been working on, which is to expand access beyond just the patient, to family members or care givers who are authorized.

The next screen shows medication and allergies, so you'll notice that we're now looking at the health-record menu, and this is a current medication list that's brought forward from the LMR. The Latin translated to English because the prescriptions are typically written in Latin with Sigs and allergy information. This is in real-time so that as changes are made in the LMR system, any time this data is refreshed you'll see the most current.

The next screen is an immunizations pages that gives a summary of LMR immunization information with information links on the left-hand side that go out to general references about, say, hepatitis A and the disease, the vaccine, and so on.

The next slide is a lab-results screen, which has a similar presentation. In this case it's looking at all the most recent values for lab results that we have across Partners HealthCare on our system in a data store that we call the "Clinical Data Repository." And similarly, there are information links to go to general references, and then there are also hyperlinks. If you drill down on a test name, you'll see all the results for that test. If you drill down on a date, you'll see all the results related to that specimen.

The next slide is titled "online Results Letter," and we have an interface with the LMR that allows physicians or their staff to rather than just print off a results letter that would be mailed to the patient, they can also send them online. Our best practice around this right now is to do both, is to print it, as well as make it available online because we don't have sure ways of knowing right now who has a preference to receive the online letter and stop receiving the printed letter. We're working on some enhancements to be able to collect those preferences and then use them.

The next slide, "Online Journal," is an illustration of a medication journal that we used as part of the Prepare for Care study that we did, the AHRQ-sponsored work, where in this case a patient was invited to review their medication list, and so that's on the left-hand side, and they could select an item like Glucophage, and then in the right-hand panel, answer questions about this medication, such as, are they still taking it as shown above? The dark blue area is information that is coming from the LMR.

In this case the patients are answering questions about how they take the medication and depending on their answers, they get a whole bunch of branching questions, which then can be submitted to the doctor's office in preparation for a visit. I'll talk about this online journal more in the last part of the talk.

The next slide now shows the practice portal, so we've shifted away from the patient portal now to the practice portal where the staff and clinicians are able to see incoming requests from patients. If you look in the subject column you can see there are medication requests and referral requests and other kinds of messages that are coming in that are pre-identified with the patient, they're pre-identified with the provider in this practice, there are workflow tools like the assign column and the task column so that multiple people in the practice can manage basically the completion of tasks associated with these messages. And it's got other conventions that are commonly seen in e-mail applications like sorting and bolding to help people basically manage the messages as they come in. That's the practice portal illustration.

And now I'm going to shift over and talk a little bit about the adoption of Patient Gateway and the current status. As of March of this year, 42 practices are live, a combination of 23 primary care and 19 specialty care. Some of the practices have a lot of their patients who are signed up for this, so the penetration is as high as 63 percent in one of our practices. We've got 680 physicians listed on the enrollment page when you go to sign up, and we've got close to 900 providers when you add in nurse practitioners and social workers and other providers.

We've signed up more than 42,000 patients over the last five years, and we're growing at about 1,000 patients a month who are signing up, and of all the sign-ups about two-thirds who receive that user name and password will go in and log into the site and change that password, and then a third of the patients

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don't. In a single month, we're seeing about 8,100 patients who are logging on, and those are unique individuals who are logging onto the system. You can see the data from this past month, complete month of March where we had 8,157 patients who logged in and then a portion of those, roughly half of them, who sent in online requests. And then on the right-hand side you can see how many sessions and how many individual requests were generated by those patients. And then the charts just show that over the last 18 months we've seen a fair amount of growth.

And that growth is really tied to the practices that are offering Patient Gateway. We've had about 20 new practices added on in the last 12 months, so we've just about doubled the number of practices. And then there's been a similar doubling in the number of providers, whether you look at physicians only or at all licensed providers. So with more practices and providers offering Patient Gateway, there's been an opportunity for more patients to sign up, and that's been sensitive to the marketing that's done in each of the practices to let patients know about it.

The next slide just shows a comparison that the adoption rates are very sensitive to that marketing and to specific efforts that go on at different practices in our different institutions. Mass General has roughly three times the volume as the Brigham, and the Dana Farber is earlier on, but also rising quickly in terms of the number of sessions and requests and patients that they're signing up.

The next slide shows a graph to indicate that our support issues are something that we also pay attention to quite a bit. So the pink line represents how many monthly support issues are coming in from patients. You can see in the recent months where we've grown to about 600 or 650 issues per month. The green line shows how many unique visitors are coming to the site each month, so as I mentioned, that's getting up to the 8,000 mark on the axis on the left. The blue line is the number of new patients that are signing up each month, and you can see that's about a thousand. And so we're trying to manage the demand for support against the use of the app through improving the way that we provide self-service tools to the patients and try to clean up language and focus a lot on usability.

The next slide concerns our lab-results feature. I just wanted to highlight that we've been offering this for about a year and a half. We've got about 89 percent of patients who are able to access labs, and this is just one of the most important features that patients go to the site to use. We've not experienced any increase in workload among physicians or staff associated with this, although that's clearly the concern among practices before they turn this on. The lessons learned, from our experience with Patient Gateway, is very, very, strong enthusiasm from the patients who use it. The types of concerns we hear from providers, typically the ones who are not experienced with this sort of portal, tend to resolve with experience.

People are worried about an avalanche of messages that will arrive on their doorstep as soon as they turn on the Patient Gateway portal. That doesn't happen. They're concerned about other things like patient confusion or concerns, and we just have not seen those in any kind of volume.

The main barriers that we're always working against are making sure that we're continuing to market so that new patients hear about this, helping practices to get past their preconceptions in order to turn on this portal. It's been used on a voluntary basis by all of the 42 practices. We don't yet have an institutional mandate that anybody has to use this. And there aren't really too many incentives, or I should say they're soft incentives not hard ones in terms of why practices would offer this. It's better service, better communication, and some efficiency, but we haven't seen measurable kind of reportable efficiencies, I think largely because we haven't gotten to the kind of volumes that you might need to get to to see those in terms of communication.

I wanted to highlight a randomized control trial in which we have used Patient Gateway with an additional module, this online journal I mentioned earlier, for diabetes. We took 11 clinics and we grouped them and then randomized them into an intervention and control group, and then offered patients who were using Patient Gateway the opportunity to consent into this trial. And if they were patients with diabetes they could basically look at an online diabetes journal two weeks before a visit, fill out some information,

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submit it, and then discuss that at the time of their visit. The outcomes we were monitoring were hemoglobin A1C, cholesterol, blood pressure to see if those changed favorably or differently between the intervention and control groups, as well as medication use and some additional survey and process measures.

The next slide shows a flow diagram, just to point out that we have these 11 practices randomized into the four and seven practices of the intervention arm and the active control arm. The active control arm were patients who were also using Patient Gateway, and they also got Online Journals, but they didn't get diabetes and medication Journals. Their journals had family history and health-maintenance questions. We offered these journals to all the patients with patient Gateway. There were about 655 of those patients with Gateway who had diabetes and could participate in this part of the study, and about 39, or so, percent of those PG users signed up. We ended up with 126 consented enrolled study participants in the intervention group as compared to 118 in the control group, overall only about three to five percent of the overall diabetes population in these practices, so it was a pretty small group. But nevertheless, many of those patients submitted journals, and we analyzed after 12 months of follow up to begin to look at some of these measures.

The next slide shows the diabetes pre-visit journal, and the fact that we were asking patients to review these control areas, these blood sugar and cholesterol and blood pressure, and for each one, they got a series of questions. And so here you can see for blood sugar control we're showing them LMR information, their last hemoglobin A1C pulled out of the record, the fact that they're on Glipizide, the information link so they can find out more about these things, and questions, which basically ask, would you like to improve your blood sugar control, would you like to discuss medications about blood sugar, what about testing for blood sugar. The patients who filled out these journals and submitted them were able to then talk about those in their visits.

This is a sample of the kind of report that a provider would see or a patient, which summarizes the responses that the patient made in these three goal areas, as well as six additional referral and self-care areas, and so this would be brought into the visit. One of the things we found was that many of the patients, as you look at their responses, indicated that they would like to improve their blood sugar, blood pressure, cholesterol control, so over half of the intervention patients indicated this in their electronic journals.

When we looked at the visits that followed submission of these journals, what we found was that in the intervention arm, 53 percent of those visits had medication changes, and in the control arm, only 15 percent of the visits that followed those journals had medication changes. This is one of the positive results that we found that indicates that we've managed to have a positive impact on clinical inertia the inertia that sometimes keeps providers from making changes, and it looks here like the intervention group saw more changes than the control group in terms of medications.

What we did not find was that hemoglobin A1Cs got better between the two groups. And that may be in part because of small numbers and also because the group of patients that consented into the study tended to be some of the best-managed diabetes patients that we have. The average hemoglobin A1C of the group that consented was, I think, about 7.3. It was just a little bit higher than 7. What we found is if we looked at just the group of patients whose hemoglobin A1C started out at greater than 7, that there was a trend, although non significant, towards lower hemoglobin A1Cs among the intervention patients in that group. Some of the caveats around this part of the study are just around the small numbers and the fact that we had kind of a special selected group of patients who participated. This was one-fourth of what we studied. There were also other modules to focus on: health maintenance, family history, and medication safety, and we're in the process of analyzing those results.

Hello, everybody. This is Ken Mandl. And I'm calling in from Boston, where I'm a faculty member at Children's Hospital, and I run an informatics laboratory called the "Intelligent Health Laboratory" at the Children's Hospital and Informatics Program.

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The talk I'm going to give, I think, compliments Jon's talk nicely. Jonathan has been working at the cutting edge of bringing value to patients at Partners HealthCare through the Patient Gateway. And in parallel, we've been working on architectures for ensuring that that kind of value can be delivered on information that is very liquid and flowing across institutional barriers in a way that services people at the point of care in their homes at population levels.

There is a cartoon that I enjoy, where a man arrives in Heaven and is informed by Saint Peter, "We don't know why you died. We can't access your medical records." And here what we'd like to do is actually propose some solutions to that problem, and I'd like to show you how even in that last few months there's been tremendous evolution in this regard.

The fundamental consideration here that I think is driving the work we've been doing for the last ten years is that hospitals and health-care institutions have simply been reluctant to share data with each other, even when it's on behalf of the patient, even when HIPAA gives you, presumably, a strengthened right to your data as a patient. In electronic form, if it is "feasible," most institutions have to date decided that that's not feasible. Health-care institutions -- and I work at a health care institution, so this is a mea culpa for us as well. I'm certainly not pointing any fingers at anyone but ourselves.

But healthcare institutions perceive their data as proprietary. They feel that if their patients' data leaves the institution that their patients will follow their data right out. There are perceived loss of competitive advantage for things like negotiation of payer contracts if too much is revealed about the characteristics of their patient populations, procedures, et cetera. There is the issue of privacy, which is not always handled well, and there's HIPAA, while intended to actually promote this sort of flow of information, has generally been used as an excuse not to make it go. Also, it's well documented that health information exchanges have not been well supported by financial and business models. So there's no data flowing, there's no money flowing, and this has prevented this from happening. So if you have an institution that's reluctant to share data in the first place and then there's no funding, there's no good funding model to make those data flow, it results in data being fairly stale.

I actually chair the medical records committee at our hospital, and I know very well that even though we have an electronic medical records system, when a patient asks for their record, we give them a paper copy. And then this clearly does not promote the idea -- it does not promote data liquidity, which is, I think, a fundamental goal of our work.

The question, then becomes, well what if we give people a tool to access their data from multiple health-care institutions electronically? Okay? So we've developed a tool -- it used to be called "Ping," and this is something I've developed with a colleague here from the informatics program over the last decade: It used to be called "Ping," now it's called "Indivo." Indivo is a personally controlled health record that lets you make this request. It lets you ask for data from each institution in a standard format, and it lets you store it in a repository under your control on the Indivo server.

What this gets you across multiple institutions is a comprehensive record. And the collection of these records is a population database. This provides some very interesting architectural opportunities to construct essentially a RHIO for each person a health information exchange for each person where they use their rights to the data and aggregate the data using those HIPAA-strengthened rights. This means that we don't need to have inter-institutional data sharing agreements in order for the data to flow. We don't need centralized health information exchange authority. And the relationship of personal health records to health information exchange is actually very interesting one, and we've done some thinking about that, although that's going to be beyond the scope of the talk for today.

Here we have a collection of personally-controlled health records. We have each patient's information aggregated. So what is this personally-controlled health record? Well it's a container to store and share your personal health information, and it's essentially, I think of it as a Quicken for health care. People are probably familiar with the Quicken software by Intuit that allows you to download, essentially, information from bank accounts, retirement accounts, other financial accounts, frequent-flyer mile accounts onto your

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computer to use a set of tools on it that adds value. And just aggregating the data together is some value, and then there are analytic tools to add value on top. You could think of this as a health bank account. Health Bank has its own agenda, and you can think of this also as a virtual medical home for patients. This is a place where we can actually establish a whole set of services and opportunities for patients.

We wrote about this in BMJ in 2001. We said a personally controlled health record stores all of an individual's medical history in a container, with patient control, interoperability, open standards, and rules to protect patients.

So what do patients do? They can access the record. They can grant access to other others. They can grant access that's specific to their role. They can grant access of just selected portions of the record. They can store the record in a location of their choice. And they can annotate in the record, and right now we don't have them deleting from these records for medical/legal reasons. That's an interesting conversation in and of itself.

Essentially we've confronting privacy head on by exercising individual rights to information. The patient is the integrator of his or her own medical record.

Right now there are three organizations that are offering this platform model that has been strongly influenced by the Indivo project over the last decade. And we've been working with all these organizations. I'm officially working with the Dossia organization, which is in the middle. That's an organization formed by employers: Wal-Mart, Intel, AT&T, and five other employers who have decided that personally-controlled health-record infrastructure would be a very good thing for beginning to manage information in the health-care system and to begin to get control of processes and therefore costs that these employers are shouldering.

Two other organizations are also offering this recently. Everyone on the call is probably aware that Google has announced a Google Health Initiative, and last fall, Microsoft announced it. Google is doing some work with Cleveland Clinic. Microsoft is doing some work with New York Presbyterian to pilot these ideas. We're doing work with Dossia companies for roll-outs to their employees, and also we have our system implemented at Children's Hospital of Boston.

It's an earlier stage than Jonathan's work. This is our portal, which we're scaling up to provide the personally controlled health records to all patients at Children's. I'm sure we'll have a lot of valuable lessons to learn from the Gateway experience as we go forward with that. The core of this deployment though, is personally controlled health record.

We believe in openness of the approach, and what do we mean? Well, open systems so that essentially we want these systems to be extendable, not just by ourselves, not just by one vendor, but by others, so that new capabilities can be added. Open standards so that the information flow is very clear and that the systems are easily able to exchange the predetermined subset of information that we decide as a community is important for patient care, for research, and for quality, and for public health.

Open application programming interfaces or API, and I'll show you this in a diagram. This allows the building of applications on top of open systems using open standards and open source. I don't think that this is necessarily essential to a model. The Google and Microsoft systems are not open source. They may well succeed. The Indivo system is open source, and what this means is that we are very pleased if another group takes the Indivo software and sets up their own deployment. What we want to see is uniformity of deployment of personally controlled health records so that there is data liquidity, that the data is able to follow the patient no matter where the patient is seeking care, and that vendors out in the community are able to add value to these systems by actually extending them.

I will begin to describe what I mean by a platform, and then we'll see a picture of it. The platform model means the following: At the bottom of the model are the data sources. And we're thinking about data

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sources across a wide variety of data types. So that may be hospital data. It may be clinical data. It may be pharmacy data. It may be payer claims data. And if you can see, it's down at the bottom: hospital or health system, pharmacy, primary care practice claims, laboratory.

What we have here essentially is mechanisms for a patient using a PCHR platform, personally controlled health record platform to create a repository. This is the Quicken for health care. This is the patient exercising their right to this information to get this secure storage of information under their control integrated across sites over time. We give them two interfaces where they can exercise their rights and their will. Down here they can exercise their rights to import data, essentially creating a Quicken for healthcare.

Up here they can do something that's very, very important. =Here we have data, and the data -- in order to make that data sing and dance, we need innovative health applications. So some of those we can imagine. Some of those types of applications, Jonathan showed you very nicely in the last application. Some of those have yet to be thought of. And the case that may exist here would be disease management tools, wellness applications, clinical research management tools, social networking tools. I'll give you some examples, disease management tools. Perhaps we have a big repository. It may be hosted by Dossia. It may be hosted by Google. It may be hosted by Microsoft. There may be new entrants beginning to think about hosting.

And there's an application program interface. What that means is that there's a standard way to connect to the personal health record with the patient's permission. So what happens is let's say the Mayo Clinic, for example, decides we're going to make the best diabetes manager; it's going to download your glucometer data and blue tooth to your insulin pump and put your sliding scale onto your iPhone, and that's a disease management tool.

What we have through this application programming interface is a way for a vendor to just create that value, and then the questions becomes, how do you market that to the patients? . How do you market that to the users of this personally controlled health record? There may be wellness applications; for example, employee health programs. There may be clinical research management tools. There may be, for example, a way for an organization like the Centers for Disease Control or the FDA to ask patients for permission to ask patients to share their data. Maybe they'll share their data for surveillance. Perhaps they'll share their data so that we can track influenza spread in a much more fine-grained way than we do now at the public health level. Perhaps the FDA will ask individuals to share data about the medications they're on and the side effects and adverse events and co-morbidities so that we can conduct better post-marketing surveillance programs.

Perhaps a company like Patients Like Me that provide an extremely successful social networking capability right now to patients with ALS. People may have seen this written up in the Sunday New York Times Magazine. Jamie Haywood has been very successful with this model. Perhaps a social networking tool set like that would actually be a consumer of the application programming interface to a personal health record so we don't rely on patients typing data in in order to share information lessons learned, ideas, symptoms and experiences with other patients who have the same disease.

Essentially the personally controlled health records platform is designed to aggregate data, create this Quicken-for-health-care-like application, and to support an ecosystem, not to create the applications in that ecosystem but to really allow anyone who has an imagination and a business plan, any federal agency that can make a good case and design a good infrastructure for collecting data to be able to actually access very large populations.

It's a very interesting play when a Microsoft healthvault, let's say, working with New York Presbyterian, gives patients control of their health information. If Microsoft actually remains faithful to the personal control model, those patients will be able to share their data with new organizations that may have nothing to do with Columbia and New York Presbyterian Hospital. So those individuals at New York Presbyterian may be presented with opportunities out in this ecosystem to participate in clinical trials, to

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share their data, again, for surveillance, to be given by their health plans or to purchase disease management tools. Very interesting opportunities to connect to devices, to connect to pedometers, cardiac monitors, wellness devices. It really begins to create a very interesting market out there for tools that promote health and organization, like AHRQ, I think, is in a very good position to help set the agenda for evaluating the value of health applications and helping us figure out where we should direct our patients as this ecosystem evolves.

I want to just present briefly how this might work in a research setting. This system could be leveraged. In a paper that I published in Science last spring, a few months ago, we proposed a paradigm that we're actually implementing here at Children's Hospital Boston where we engage patients in research using a personally controlled health record, and I'll just show you here.

Over on the left we've got, essentially, a patient being consented into a study. What are the problems in research that this begins to address? This begins to address the fact that we have trouble following cohorts of patients over time. It's a very labor-intensive process. When we do, we tend to follow them for very restricted research questions, very narrow set of hypotheses. We tend not also to inform patients about what's going on. How can we use the personally controlled health record to shift that paradigm?

So we've got a patient here getting consented with some kind of provider, getting phenotypic data, perhaps getting even genomic data. You can see a little tube of blood there on the desk. And what we do is we store a copy of the standard data in the electronic medical record. They are represented by a filing cabinet. We can also give a copy of this data to the patients because that's what we're doing now. And we also put a copy of the data into the researcher's database. Now researchers tend to get anonymized data. They tend to have to anonymize their data. Is this a good thing or a bad thing? It protects patient privacy, but it also prevents the ability of researchers to offer direct benefit to a patient.

If you've submitted institutional review board proposals you tend to be guided very strongly by your IRB to click off that there is no benefit to the patient from your proposal, and that's because you're really not allowed to share information back with individuals. It turns out that under some circumstances there may be very crucial findings that would be interesting. What IRBs have tended to feel very comfortable about is that since the data are anonymized, even when it would be ethically prudent to share those data back with individuals because the data are anonymized and you can't identify them, you, therefore, can not share the data back with the individuals, and that has been the pact that we have entered into as researchers with IRBs to proceed with our research. It begs the question of whether we're operating in the optimal environment for the outcomes we want to achieve.

So what we do is we've got three copies of the data. In the healthcare record we've got data in personally controlled health records and we've got data in an anonymized research database. Let's say, for example, now that the researchers discover that 14 patients in their cohort have a particular mutation that gives them a high risk of an adverse reaction to a particular drug. It would be very nice to tell those patients that. Unfortunately, the researchers have an anonymized database. What do we do about that? Well, first of all, we've actually created over here on the way right, a set of protocols by a board we call the "Informed Cohort Oversight Board." We refer to this cohort as the informed cohort. What can they do? The Informed Cohort Oversight Board can help decide if this is something that we should communicate back to patients if it has value to them. If so, how do we do it? Are we sure enough about the finding? Does it need to be repeated first or replicated in another setting, and if we do communicate it back to them, how do we do it; what words do we use, how do we bring them into to do this?

We then can actually broadcast back to all the participants of the cohort. What we do is we have a listener built into the personal health record and we broadcast back the information. The information goes to everyone with a personal health record, but the only listeners that actually receive it are the ones that match the criteria. So we send out that if you have mutation X and are on drug Y, we would like to bring you in for a consultation. The personal health record knows who's got mutation X and who's got drug Y. So what happens is, only those patients get the message. We end up with a system where we

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have provided tailored and targeted messaging back to a population of patients while preserving anonymity.

I will just end with what are the big challenges? Well, there's agreement on data standards. For data to be liquid, we've got to send it in a fairly uniform format. The good news is that organizations like HITSP have actually defined those standards. I think they do need to evolve further to actually meet the needs of the health care applications that will be evolving, but we have an excellent starting point.

The data has to be available, so institutions have to make these data available to personal health record platforms so that patients can actually request them electronically. That would be consistent with the spirit of HIPAA. CLIA, which is the laws and regulations pertaining to laboratory data, is interestingly configured in a way that in many states prevents patients from actually getting their own laboratory results back, and there's some work that probably needs to be done there.

Many practices, of course, have data on paper, and that's going to be a barrier to data liquidity, clearly, until we move further along with our penetration of electronic health records. And user authentication, who am I, how can I prove that I am who I am, not only to create a personally controlled health record in the first place but also to get into these other data sources is a societal level challenge. I think there are a number of creative solutions. This has been debated for a long time. My guess is that because there are so many people actually trying to do this now on a large scale that we will come up with some solutions, but we should keep an eye on what those are, whether they're protective ultimately of privacy and patient control.

Q&A:

Jon, the question is primarily directed at you, but I think, Ken, you can speak from your own experience. How has the program, in this case Patient Gateway, and maybe Indivo been marketed? How do patients find out about it? And what do you find has been most successful?

The way that patients find out about Patient Gateway has been centered on activities that are done either at the practice or through the practice. So our general belief is that the best way to market to patients is to let them know about Patient Gateway when they're having kind of a moment of need to engage with the practice. And so telephone messages are used where patients who normally call a practice and they get sometimes a branching telephone menu of choose one for prescription refills, will actually hear on the message something like, "we now offer an online service. Go to www.patientgateway.org and sign up." That gets a lot of the telephone contacts. And then when patients are on the phone with the practice, the staff can mention it, when we've tried direct mailing. And what we found is we've often times got about a ten-percent return. If we mailed a thousand letters out to active patients of a practice, maybe a hundred patients would sign up. Posters in the waiting room, events to have a sign up table or kiosk in the practice.

Those were all examples of marketing directly to the patients, and the other thing I would say about this is that it's incredibly important for the practice physicians and staff to feel comfortable and actually energetic and enthusiastic about marketing it to the patients themselves because if a patient hears from their doctor, "Gee, it's been a pleasure seeing you today, and your lab results will be available on Patient Gateway. I'd like you to sign for that service. It's part of the way that we do business here." That's a powerful message to a patient. And what we found is that there are all kinds of opportunities for staff to communicate that to patients.

We also surface to the staff whether a Patient Gateway account exists or not in the LMR. So they can see an icon that indicates whether a patient is signed up or not. So it's the initial marketing and then also the remarketing, because patients who signed up a few years ago may not be using it today. They may not know about the new features, like the lab results feature, which is fairly recent. And so those are the efforts we've used. We've gotten one example of institutional marketing where the Dana Farber Cancer Institute had a week-long initiative throughout the institute to let patients know, and they used essentially plasma panels in the main lobby, and they had sign up tables and so on. But the other institutions we're

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working with have gotten to that point, in part because they want to see a greater number of practices and providers offering Patient Gateway so that the mass marketing isn't directed at a lot of patients who actually can't yet sign up for the service.

There are a couple of questions regarding patient control. One is directed at you, Ken. I guess you mentioned that patients can control who accesses a portion of the records, the question is, to what extent or to what level? For example, can they control access for some medications like one provider can see some medications but not others? And then there's a similar question to you Jon, if all providers have access to LMR partners, what kind of control do patients have in terms of who sees their information and in particular some of the information they may enter themselves when they annotate their record on Patient Gateway.

Patients using the Indivo system can control at a fine-grained level the sharing as the user interface will allow. The platform is designed to provide extremely fine-grained control with where you can match who sees what at a very fine level. At the same time, that feature is not necessarily going to be desired by the majority of users. The initial user interfaces that we have designed don't support very elaborate schemes to share seven out of eight medicines with one doctor, three out of eight with another, four out of eight with another. But there's no reason that a user interface couldn't support that, and ultimately there will be user access as we understand how people really follow this and what they want through the rapid prototyping and -- stage that we're in now, we'll settle on what is the happy medium for the standard set of features and the applications.

So in responding to the question about basically who can see patient entered information, the model that we used in the Prepare for Care study was that there was a workflow associated with this. The online journal begins under patient control. So the patient can open the journal. They can see the pre-entered LMR data that's visible in the journal. They can see the journal questions. They can start to answer them, and they can stop and start their sessions as often as they wish to complete that electronic journal. Nobody else sees that journal unless the patient presses the submit button. And so if a patient forgets to press the button, that's too bad, nobody can see that. No one else has access to it until they press the submit button.

Once they do press the submit button, that electronic journal is visible in the practice and in our project in the primary care practice that the patient belongs to. And it is not considered yet to be a part of the LMR proper, but it is submitted for the physician and other clinical staff who have rights to see clinical data in the LMR, they can see that journal. They can take that journal and save it off as a note in the LMR if they wish to do that. They can talk about the journal with the patient, and they can edit or modify the LMR record based on those conversations.

There's some automation tools that help them move data into the LMR, but they don't have to use them. It's possible they can look at that journal, and none of that journal information makes it into the chart by clinical judgment. And then we considered the journal sort of intact as it was submitted by the patient to be sort of a secondary piece of information that belongs in the chart. But we -- because it was done as part of a research study, we archived that information off, but we don't make that generally available to everybody who's uses the LMR, just the practices that had access to the journal information as part of the project.

We have a couple of questions regarding user authentication and data integrity. The first one is, what kinds of checks and balances do you have to make sure the individual who is enrolling, whether it be Patient Gateway or Indivo, is who he or she is who he says he is, and how do you handle medical identity theft? And then the second question is, what if there are data errors, whether human or technical in Patient Gateway, or if changes need to be made, how do you handle that? And who bears the burden of legal liability perspective if there are errors?

In terms of authenticating patients, basically when people are doing on-site enrollment then they basically they present some kind of identification and there's a staff person who is selecting the appropriate patient

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from the Partner's patient look up, and then they are collecting an e-mail address for that individual standing in front of them, and then they are printing off a temporary password, handing it to the individual, who then has to put that together with the user name that they get in their e-mail. If it's not an on-site user and the majority of our sign-ups are done remotely, as I showed in my slides, we identify the patient that we think has made the request based on a very, very strong match of information between the enrollment request and the Partners data that we have in our registration database.

If there are discrepancies, the enrollment staff can contact the patient, because they're also the staff who does registration, so they can contact the patient if there are small discrepancies like there's a misspelling or if they've used their winter address and they have a summer address or something like that. And then what we do is we communicate the user name to the requester using their requested e-mail address, and we communicate the password letter to the registration address on file for the Partner's patient. And that's the same address that we use to mail lab results to the patient. And so we then believe that the individual who is able to put together those two pieces of information is a patient.

Every method of authentication has, balances, access, and security, and there's no such thing as perfect protection, and it's also difficult to reach very, very wide levels of access and maintain security. So that's the approach that we use, and so far we feel like it's worked pretty well. There are some organizations that require on-site only, and there are actually many organizations that will do something like we do in terms of remote.

And then just to take the question of what do we do about identity theft. I guess the way I'll interpret that is that if an individual ever feels as if there might be the possibility of unauthorized access to their account, maybe they're going through a divorce or maybe there's some kind of situation where they're afraid that the security is compromised, then what we do is we encourage them to immediately just go and change their password, log in. They can reset the password themselves. They can call us if they would prefer that our support staff handle that request, and we can change the password or we can inactivate the account.

And in terms of data quality and data errors, I'll interpret that question to mean what happens if I, as a patient, see my medication list and it's wrong? Well, what you can do as a patient is you can contact your doctor and say, "my dose changed or I was never on that medication. It's probably on the wrong chart." Or whatever the problem is, you can contact the practice and ask them if they will correct it. And realize that they are making changes in the institutional medical record, the legal record that they maintain. And so that's what patients are doing, not always, but we do get many requests from patients to either add data like immunization data that doesn't exist or medication data or to correct something.

Ken there are a couple of questions for you. One of them is, if a member leaves the Dossia System employer, how do they retain and maintain access to their PHR? And another one is, how concerned are you that primarily healthy and informed patients are enrolled in -- management intervention, could PHRs potentially increase disparities via an amplification of the digital divide?

Ken: At Children's with the Indivo deployment, at Dossia there's commitment to a life-long maintenance of that record. And that marginal cost of providing this to an individual is very low. The employers are committing to making that information available over a lifetime at zero or extremely low cost. When I say extremely low-cost, I'm talking about single-digit dollars potentially. So everyone is very committed to that.

Any time you have a technology that actually improves health to which there is differential access, there's risk of increasing the digital divide. We have to pay a lot of attention to this. There's an obligation on the part of health care institutions using these to make sure that they are pushing out enrollment opportunities and marketing these across the socioeconomic spectrum. There's an obligation on the part of the application vendors to make sure that they are producing applications that can be used by all Americans. There's an obligation on the part of the government to make sure that people who, for example, don't

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have insurance and, therefore, don't have claims data are still enjoying benefit from a rich experience that leveraging other data sources and other forms of access.

I think we're at the part of the learning curve -- certainly at Children's Hospital, the Indivo deployment is designed for everybody. We've had a lot of experience, over a decade, using health information technology in the hands of very low SES patient population. I'm very confident in our ability to continue to do that at the institutional level. At the broader level, as we see use of Microsoft, Google, Dossia, right now we're really at the stage of very early adopters. Those will undoubtedly be an extremely skewed population. I think that's absolutely okay for the first phase, the initial learning phase, and then we're going to have to pay attention to all these issues there as well.

Thanks, Ken, and it sort of segues into another question. Somebody asks about for you to comment on the advantages and disadvantages of tethered PHR like Patient Gateway, versus un-tethered PHR like what you're proposing with Indivo?

The tethered personal health record is clearly very really prominent examples of success with this. And four that come to mind are Patient Gateway, Patient Site at Care Group, The Kaiser deployment of MyChart, which is the tethered portal to the Epic system, and the Veterans Administration Personal Health Record. All of these efforts have between sort of five and eight or so years of experience out there in the real world. And as many people on the call know, many electronic medical record vendors have begun to offer portals that work with the products. These are very successful, and particularly when implemented wisely and thoughtfully, these add a lot of value for the users of those systems.

They don't yet provide data liquidity, but there are clear opportunities to adapt portal functionality to the platform model if that is something that is of interest to individual institutions. I know that that's going to be happening at some places, and I think that there's an opportunity for a nimble health care vendor -- health care information systems vendor, and I think there are many out there, to have a business model that includes portals tethered to EMRs, and also that includes the portal functionality existing as a personal health application out in the ecosystem interfacing with the platform model. I think there's a natural evolution, and I think we're very fortunate that there's been such a good learning curve on patient portals over the last seven or eight years while we've been waiting for the platform model to mature.

Thanks, Ken. You described the platform model and the fact that it opens doors and what are the advantages that others in the community can either take the code and modify it or add their own applications on top of it. This person is curious as to how many people in the community or vendors are actually adding applications to the platform.

There are quite a few vendors who are developing applications for Dossia, for the Google platform, for Microsoft. Many of them actually have press releases every time they have an idea that they're going to do so, so you can follow that out with your Google alerts, and I think that there's been a very strong signal sent that there is a business model even though, for example the Dossia system is a not-for-profit institution and is providing the service for free or for nearly free, Google and Microsoft are providing the personal health record for free, I think there are very interesting business models in the ecosystem for entrepreneurs.

Thanks, Ken. Somebody asked if there is a potential issue with profiling whether it be a government body or an employer group to have access to a PHR. Can you speak to the potential for that risk?

In the personally controlled health record, the only accesses to the record are with patient consent. So there is no government access to the PHR without explicit patient consent. So the risk is minimized or eliminated through the personal control model.

Somebody was trying to follow up on the earlier issue of data inaccuracies and was concerned about what data is incorrect and patients do not realize, whether it be lab results and the health care relies on the inaccurate data. And what happens if the patient is injured as a result of reliance on improper data?

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If you take away this whole conversation about patient portals and just ask that question, I think medical charts for as long as there has been recorded information have suffered from either missing information or wrong or inaccurate information or basically data problems. And so I think the responsibility is unchanged. If a physician has the wrong lab result on the wrong patient that they're using for some other patient's care, then that responsibility would probably fall on the physician to sort of have to answer to that.

I think that the opportunity with these kinds of systems is that overall they can potentially reduce the risk of that happening because essentially it creates a larger set of eyes, so an individual physician, let's say in an ambulatory setting, may have a thousand patients, but a single patient is looking at their own data and can pay attention to that and possibly identify things that they're missing or things that they think should be there or things that they don't understand in a better way using these systems. And actually, the malpractice carrier for many of the Harvard hospitals has started to make statements about the fact that they believe that patient portal technologies, like Patient Gateway, will certainly not increase the chance of successful malpractice cases but actually should reduce risk and should be protective of both patients and their care and also of doctors who might not get sued as much if the data is more transparent.

Thank you, Jon, one other question we had was how you foresee making these platforms affordable for safety net and solo practice providers.

Well right now they're free. I think the real question is whether free is good enough. We'll see whether consumers flock to these things or whether this is the time to see what the uptake is. The zero cost offering does, I think, eliminate that barrier though

Yeah, and I think for something like Patient Gateway, where it really is offered -- the model that we have used is offered by a provider to their patients. And Partner's HealthCare is paying for it, and we do have to deal with the costs. And so a number of institutions at Partners have site licenses to use the system, like the Mass General, and Brigham and Dana Farber. We also have community physicians who are not employed by Partner's HealthCare, and we have to work out pricing for those practices to be able to offer this. We don't have that worked out yet. And so I can't tell you how much it would be, but I can tell you that there are some physicians who, say, are using a product, that's actually quite a different product, so it's kind of apples to oranges. But they're paying anywhere from \$60 to \$90 a month to have a portal that patients can have to use to interact with their doctor's office.

I think that this area is really very immature when you look at kind of the business model side of it. And there's also a lot of vagueness when people are even talking about a PHR. Are they talking about the personally controlled Indivo example, in which case the business model is businesses are supplying money and consumers get to use it for free, or are they talking about a provider sponsored, which has a different business model, and both business models are somewhat immature.