New Technology in the Health Care Industry
Alliance for Health Reform
August 13, 2012
EDWARD F. HOWARD: My name is Ed Howard. I am with the Alliance for Health Reform and on behalf of Senator Rockefeller, our honorary chairman and our board of directors I want to welcome you to this program about patient-generated health information, its potential for making our health system function more efficiently and in a more consumer friendly way. We’ll be hearing about a bunch of, I guess you’d call a gee whiz technology, devices and processes that can transmit your weight or your glucose level to your electronic health record where your physician can use it to monitor your condition and we’ll hear about some of the potential advantages of that technology, challenges that those advances are encountering and what might be done about them.

We’re very pleased to have two partners today in sponsoring this briefing. One is the Robert Wood Johnson Foundation which has been helping Americans enjoy healthier lives and get the care they need for 40 years. Somewhere in my briefcase, I have a little button that I meant to wear and thanks very much to Brian Quinn and Steve Downs and their colleagues at RWJ for their help in thinking this program through and pulling it together. You’re going to hear from Steve in a moment.
The other cosponsor is the Bipartisan Policy Center, a five year old project of four former senate majority leader’s two from each party which is the, I think, only DC based think tank that actively promotes bipartisanship and which has healthcare as one of its main focus areas and we’re very pleased to have co moderating today’s discussion Janet Marchibroda who chairs the BPC Health Information Technology Initiative and I’d like to turn it to Janet at this point.

JANET M. MARCHIBRODA, MBA: Well thank you Ed and it’s a great pleasure to be here today and to be talking about something that is very important to us at the Health IT Initiative over at the Bipartisan Policy Center. As Ed mentioned, we were established back in 2007 by former Senate majority leaders and focused on a broad range of issues, one being healthcare and we’re particularly interested in the discussion today because we’re talking about how one could more effectively engage consumers and patients in their healthcare using electronic tools. Something that we focused a lot on in a recently released report of the Bipartisan Policy Center’s taskforce on delivery system reform in health IT, and we’re experiencing a number of pressures in our healthcare system today between rising healthcare costs, uneven quality, eroding coverage and clearly when you look at all the rapidly emerging initiatives moving across the country whether sponsored by the
federal government, states, or even a number of private sector health plans and providers, all of them have a key goal of activating and engaging at a much higher level consumers and patients in their healthcare and we’ve got a tremendous opportunity to leverage electronic tools, mobile technologies, online tools to make that happen, and in fact, and what we’re going to talk about today, a number of consumers as we’ve found and there’s been a great deal of research in this area, would really like to use a smart phone or a PDA to monitor their health. If they were able to access their medical records and also, not only download information but also push information to their clinicians and care teams and physicians too. Some of the research indicates, there was an article that was published over the last couple of years that while 64-percent of physicians have never used a patient’s electronic health record, 42-percent are willing to try. We’re seeing a lot of interest in this area and in fact, stage two of meaningful use there is a proposed rule that’s out there right now. It actually has a number of key requirements that are proposed around further engaging patients and their health and healthcare using e-health tools like the ones that we’re going to talk about today.

So in teeing up the discussion there are some key areas that we’ll want to explore to make exciting things that we’re
hearing about in this panel today move forward at a more accelerated pace. The first is, and I’m looking forward to hearing some of the presentations around how, between policy and market actions, clinicians this is a new thing for them, how we can continue to support and educate and help them transition to these new ways of providing care and interacting with patients. I know Deven, to my left and Joy is going to talk about any clarification needed to policy issues and privacy, maybe a little about security. One of the key things that we’re hearing and I’m not sure that we’ll get here today, but it is about the need to align incentives further to make sure that this happens and then of course, continuing to build awareness among consumers and assuring that no one gets left behind due to access to some of these technologies and the like. One thing that I did not put on the slide here for folks, there are some technical issues that would also need to be figured out. I know we’ve got a policy audience but something called data providence, what is that? And I think if you’ll talk to the folks that use records as they deliver care, particularly clinicians, figuring out if I have different sets of data where did it come from so I have a better understanding of the source of particular data sets to help me deliver better care. Those are my comments and I look forward to hearing the discussions of the panel.

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EDWARD F. HOWARD: Terrific, thank you very much Janet. Before we introduce the panel let me just go through the logistical checklist if I can. There’ll be a webcast and a podcast available sometime tomorrow on KFF.org which is the website of the Kaiser Family Foundation to whom we are very grateful for providing that service and in a few days you can also view a transcript of today’s discussion at our website, Allhealth.org. C-SPAN is broadcasting this briefing live right now and probably in two AM reruns so you’ll be able to catch it later on this week. If you are watching us on C-SPAN right now and have access to a computer you can go to our website, Allhealth.org and if you punch up this briefing available on our home page you can follow along with the Power Point slide presentations that the speakers will be using. There are green question cards in your packets that you can use to address a question to any or all of our panel and a blue evaluation form which we fervently hope you will fill out before you leave so that we can improve these briefings as we go along. One other announcement, this briefing is being tweeted with the hash tag patient info. It was up on the general slide, it’ll be back up there once the slide presentations are done and you can feel free to re-tweet or whatever it is that one does with tweets.

We have a terrific panel assembled today and as I said I wanted to particularly thank Steve Downs and his colleagues

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at the Foundation for helping to do that and only fittingly turn first to Steve Downs. He’s the Chief Technology and Information officer at RWJ making sure that the Foundation’s technology strategy’s in line with the rest of his programmatic activity. He’s also the co developer of Project Health Design which is going to be front and center in today’s conversation. Steve thanks for being with us.

**STEPHEN J. DOWNS:** Thank you very much and good afternoon. Let’s start with the key development here which is that health is becoming digitized. Notice that I said health and not healthcare. I think we all understand that healthcare when we think of the care that we get in hospitals, doctor’s offices, pharmacies, that’s all becoming digitized as well through the increasing adoption of electronic health records, but we think of health differently. Health is what happens when you’re not at those places. It’s your day-to-day experience and it’s increasingly understood as being a function of the environment in which you live, work, learn, and play and the decisions you make and the behaviors you take on in the context of that environment. Increasingly now, we have technology that can really open a window on to that day-to-day experience that drives your health.

There are two key technological drivers of this and the first is the smart phone and the way I’m going to illustrate...
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this is through an example of a company called GINGER.io that uses data that are held on your smart phone through everyday use; the logs of your calls, your texts, the accelerometer data which shows how you’ve been moving, and your GPS data which shows where you’ve been and they’re able to analyze that data and actually develop what they call a behavioral signature about you and this is really important in the case of mental health because you may have a behavioral signature and then they can start to look at deviations from that and say perhaps if you’re prone to depression you might be sliding back into a depressive episode just by analyzing those data and you have to do nothing. Now I really want to stress for everybody out there, this is not a secret experiment they’re doing on your iPhone right now. We’re talking about consenting patients, controlled studies through which this is being done very carefully but what it does is that it gives you a sense of the power of the data available on your cell phone and increasingly sophisticated things people can do with that.

The second example I’m going to use because the second driver is about sensors and what I show here is a company called Greengoose! which takes tiny wireless sensors, very inexpensive sensors, and actually packages them in little stickers that you can slap on everyday household objects and then start to do things like have competitions in your family

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about whose doing a better job brushing your teeth. This is just an example of the creative and very inexpensive things that you can do with what are going to be increasingly ubiquitous and powerful sensors.

So we’re seeing this played out initially most in the fitness tracking industry. Some examples I’ve got up there are Fitbit which is a really small device, about the size of your thumb. You can slip it into your pocket, it will track your activity throughout the day, the calories you’ve burned, you can put it on a wristband at night and it will tell you how well you slept.

There’s the Withings WiFi scale. You step on it and you will automatically log your weight and God forbid, you can tweet it as well that way.

You can track your runs with RunKeeper. Strap your phone to your arm, go out for a jog and it’ll figure out where you went, how far that was, how fast you did it, and you can also put on a wireless heart monitor while you’re doing it. So the next time you go see your doctor and she asks you if you’re getting any exercise you can say more than I’m trying, in fact, you can actually pull out charts of everywhere you’ve run, how far you’ve gone, how often you do it, how fast you’ve run, and for extra credit how fast your heart beats when you run that far that fast.

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Now don’t try this at home. Right now I don’t recommend that you go to your doctor and do this. The truth is they probably don’t need to know all the gory details. The key point here is what used to be a very vague, imprecise answer to a fairly important question about your health can now be answered with great precision. It’s not just limited to fitness now. You’re increasingly starting to see trackers that will relate to your mood, your diet, your sleep and many indicators and drivers of health.

The big question in all of this is does having access to all of that fine grain data really matter? That’s the question we’ve been trying to answer in Project Health Design which is, as I mentioned, a program of Robert Wood Johnson Foundation’s Pioneer portfolio, it’s run by my colleague Patty [misspelled?] out of the University of Wisconsin and in that program we funded five teams to work with real patients, real clinicians, to collect what we call observations of daily living or ODLs. Think of ODLs as the measurements, of the data associated with your day-to-day health experience. Its data on moods, sleep, diet, exercise, stress level, pain, the meds you actually take as opposed to those that you’re prescribed and so forth. In these studies what we’ve done is the teams have created apps and services for patients to be able to capture and store these ODLs for them to provide feedback to the

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patients on the data within in them and then the tricky part of integrating that into clinical care processes, bringing that data into the doctor’s office and so on. We have five teams working with very different populations, very different conditions.

Breathe Easy, which Steve Rothemich is here to talk about worked with low income, adult populations with asthma and typically mental health challenges like anxiety or depression as well.

Chronology.MD; is a project for people with Chiron’s disease in which they actually use Fitbit for activity and sleep tracking, the wifi scale for weight, and then a special app on iPads for recording things like mood, stress, energy level, and a journal to record subjective thoughts about how you’re feeling. Then what they would do is these data would get charted and then they would bring them into the doctor’s office and discuss them with their doctors and you could see how their condition was developing and how the treatments were progressing.

Dwell Sense [misspelled?] is a project that worked with seniors who are at risk of cognitive decline and it illustrates the power of sensors. They looked at three general, daily, routine tasks; making phone calls, taking medications, and making coffee. They put sensors on them and then they looked

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for patterns that might show that people are starting to have a little bit more confusion about completing those tasks. They’re making more mistakes or they’re taking longer to do them, to see if you could actually start to notice the onset of progression of cognitive decline.

Estrellita is project that worked with infants who were born prematurely who had just spent time in a neonatal intensive care unit to come home and actually have their parents track progress about the babies. Things like the number of diaper changes, weight, also looking at things like are the parents doing bonding activities with those children but then also looking at the parent’s general well being; what’s their mood day-to-day. Anyone who has experienced parenthood for the very first weeks or so know that it’s a pretty intense time. You’ve got to watch your own health during that.

The last one is iN Touch which worked with young women, teens, and young adults who were obese and also suffering from depression and they had a mobile app where they could record information about their diet, their activity, a little bit of their social activity and also their mood as well. Then they would review those data with health coaches who’d give them feedback on how they’re doing.

I want to emphasize a couple of things about these projects. First of all, we’re talking about patients with
serious health challenges. These are all tough diseases and as you see in a number of examples they have coincident conditions as well so it’s not just asthma and depression, for example. These are patients that are very high cost to the system because of the complications of their conditions. These are also not typically affluent, tech-savvy patients. A lot of these folks are from low income backgrounds and had very little familiarity with the technology that they were using the projects.

I also want to emphasize, these projects are just wrapping up. The evaluations have not been completed so we don’t have very hard, clear findings of that but I can share some preliminary observations that we’ve seen in the experiences of those projects. First is the question of would people actually do this? Would people track their mood or track their diet using mobile devices or other ways? The answer is by and large, yes. Certainly not everybody and not everybody who did would track it all the time but we saw a substantial number of people who really did put in enough effort of the tracking that we could gain some value from it. There is definitely examples of where the direct feedback to patients made a difference. For example in the Dwell Sense project, showing somebody their day-to-day medication adherence when they’ve been taking their pills, if they’ve been taking

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their pills brought some real insight to patients who thought they had been doing really well but when they looked at this they found that they had not and they say they needed to adjust their routines a bit. There are cases in the iN Touch project where people who are tracking their diet regularly started to make real changes in those diets and other habit changes as well and in some cases lost quite a lot of weight. There’re definite examples of information making a difference in treatment. Steve’s going to talk about a couple of examples from the Breathe Easy project but there’s one from the Chronology.MD project that I wanted to share because I thought it provided a great example. This is a quote from a patient who first writes, is there any way to extend the study and says “I’m finding this very useful. I have used this data with other doctors outside of the study and as a result of sharing this data with other doctors I’ve changed the meds that I was on. As a result of this med change my quality of life has gone way up. My weight has gone from 112 to 119 pounds and I am not vomiting daily”. And I should say that’s a good thing in this case. This is a really good example of how a little bit of information; this day-to-day information can not only make a difference in treatment but that the change in treatment can actually make a difference in the person’s health.
This also represents a real challenge to the system. I think we all know that doctors are extremely busy and the current mode of practice does not make it easy to add in the extra time to be able to review these data. The second thing is we talk about electronic health records is that they are generally not very well positioned to accept a lot of patient-generated data and particularly the kind of ODLs that we’re talking about. It’s one thing to figure out how to engineer in patient-recorded readings of blood pressure, it’s another to figure out how to record patient-generated readings of mood of which there are very few standards right now.

To summarize, I want to say that technology is creating a new opportunity to practice medicine somewhat differently. The small studies that we’ve done, the early studies that we’ve done are showing there’s real promise in there and not just with typically tech-savvy, affluent patients. As is often the case with technology-led innovations the policy environment, the policy context around which they play out was not developed with innovations in mind and so we’re going to have to take a look at that and I know that Joy’s going to address some of that, Deven will address that and that’s really the conversation that I hope we all have today. Thank you very much.

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EDWARD F. HOWARD: Good, thank you very much Steve.

Indeed, speaking of practicing medicine, we now turn to Dr. Stephen Rothemich who’s an Associate Professor of Family Medicine at Virginia Commonwealth University in Richmond and he’s the co-director of the Breathe Easy project that Steve Downs was talking about which is run with the help of the folks at VCU using advanced technology for caring for patients with asthma. Dr. Rothemich also co-directs VCU’s practice-based research network and Steve, we are very happy to have you with us today.

STEPHEN F. ROTHEMICH, M.D.: Thank you, good afternoon.

I’m the lead clinical investigator on this project but I want to be sure to acknowledge Dr. Masutti who you see over on the right side of the slide. She is the lead investigator of the entire project and she works at RTI and is a leading researcher in user-centered design which was a very important part of developing this app. I also want to reinforce what Steve Downs said about the variety of the different five projects in Project Health Design and encourage you to go look at those because frankly, we have more clinical integration than some of the projects but a lot less with the physical sensors and the electronic passive acquisition of data. Most of our data collection did require a patient step to those. With that, let me go on to the next slide.

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I’m going to talk first about the app and then go back to the patients and what we saw. The patients in our project entered their ODL data through the Breathe Easy app on an Android smart phone. I’ve got a variety of screenshots there for you. If you look at the one there on the left at the top, enter your daily data. This is the place where the subject with asthma would go on a daily basis to answer a series of questions for the ODLs that we negotiated between patients and clinicians as being the ones that we would track for the study. Those included the use of controller medications if they were on one, use of rescue medications and why they had to use it, their peak flow readings which is a measure of how well they’re able to move air, the exposure to asthma triggers, mood, anxiety, sleep, exercise, tobacco use if they smoked, and whether asthma limited their activities, and what symptoms they had. You’ll see that, in terms of the user’s experience, there were checkboxes, radio buttons, places to type in numbers, and this is the basic process that they would do.

The next couple of icons on that left screen; enter rescue meds, enter peak flow data, those were optional ones that the subjects could use during the day if they wanted to report additional ODLs about those things, otherwise they could wait till the next day and enter those.
Another important one is that last one over there where it says dashboard. I’m going to talk about the clinician dashboard in just a minute but this same data was viewable by the patient for the information that had entered in their ODLs.

This is a screenshot of a clinician dashboard. This is what the clinicians used in the practices. It was web-based. They used this on the laptops or desktops that used to access their electronic medical record in their practice and I want to just point out a couple of things to you because I know it’s a little hard to read because it’s not full screen size, but at the top of the screen you’ll notice green, yellow, and red bars across there. Those are where we displayed the peak flow readings and we used the National Asthma guideline numbers of 80-percent or better of your predicted peak flow being green, so that’s good where it should be and if it’s less than 50-percent of what it should be that’s red, that’s the danger zone that definitely requires some action and obviously, yellow is in the middle for that. Below that you’ll see a lot of green and red dots. Let me explain what those are. What we did is the other ODLs that we decided to display on the dashboard, which going down that list are controlling meds, rescue meds, asthma triggers, anxiety, mood, sleep, smoking and asthma symptoms; we tried to make this as easy as we could for the clinicians and say green was good, red’s bad. Green is a desired state.

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example, if you’re on a controller medicine you did use it. You were not exposed to asthma triggers today. You did not have symptoms. Red, those things like you had to use your rescue inhaler today, you had asthma symptoms, or you smoked. That is what the clinicians looked at.

Now I’m going to get back to talking about the setting and the patients. I wanted to be sure to mention that before we did the six months of evaluation, there was a whole series of steps with user-centered design process in terms of having focus groups of patients and clinicians look at mock ups, improve what we had done, go back to them and see if we got it right before we actually fielded it.

With the patients, we actually studied this in 30 patients with moderate to severe asthma and the reason we picked that is the patients with mild asthma might not benefit from the app. There’s not much going on with them that we would actually see. We also did the study in two inner city practices so that influences the patients we work with. Predominantly black women, 24 to 30 at low income, 18 of the 30 had low educational attainment as well. Why that group? This is the group that is more challenging to do this kind of work in so if we can get folks who you might expect would have a harder time doing this than probably anyone to do it successfully, then probably anyone can. They entered their ODL data at a time of

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day of their choice. They got a text message to remind them if they forgot. Each of them was given a smart phone with six months of phone and data service during this evaluation period. I think two of the subjects had a smart phone already and not all of them had cell phones. Those are the patients we worked with. As I mentioned, the practices were two inner city practices in Richmond; the same health system and the same electronic medical record. I work in one of those. Fourteen family physicians, seven nurses and we did this study in nurse-doctor teams which is typically how we practice. Once a week, what the nurses would do is they had a protocol that they would look at the dashboard data that I just showed you a minute ago and determine whether there was actionable information there that needed to be escalated to the physician to address. We focused principally on peak flow, whether or not they were using their controller medicine, whether they had to use their rescue medicine, and whether they were having symptoms because we, as clinicians, knew what to do with that. Some of the other ones we looked at, like sleep, but we weren’t as clear what we should do with those things. The practices were paid $500 per subject to monitor that patient for six months and we modeled that in a way to reimburse them for their time for doing that work the way an insurance company would probably call that
disease management or the way we now talk about medical home payments perhaps.

I have two examples I’m going to show you. The first one here is an exciting one. This is a young, relatively healthy person whose biggest health problem besides their asthma is that they smoke. I’ve actually collapsed this to show you six months of ODL data so you can see the pattern in the peak flows. It makes it very hard to read those nice red and green dots at the bottom but I’m mainly showing you the peak flow here. You notice that this subject, at the beginning of the study, was red and yellow most of the time. The nurse messaged the physician that there was a continued pattern of this. They had not been successful in getting the patient to come in for an office visit. Right before it starts to go into the yellow they decided to start this person on a controller medicine because obviously they needed one. The controller medicine was called in and the nurse talked to the patient about how to use it. They started using the controller medicine and about a week later, up go the peak flows up in to the yellow to green zone, pretty much staying there the rest of the time. Not just these numbers but also, if you look at the second row of rescue meds and the last row of asthma symptoms at the bottom, you’ll see that there’s less rescue med use and fewer days with asthma symptoms in the second three months of

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this study after they got on the controller medicine. Those of you who are looking at the controller med row and noticing that it’s red all the way across, the way we set this up is if you weren’t on a controller medicine at the beginning you didn’t get asked that question so that row is not relevant for this subject. That was exciting. That green dot that’s way up there is probably a spurious reading, either a typo or somebody collected their peak flow with a cough which can make it look much higher than it is. I think it was a typo.

This is the second one I want to talk about. This is a much more challenging patient. This is a subject in their early fifties, comorbid, hypertension, depression, chronic pain; all three of those are very common in this population and something that thank goodness, most of them don’t have lupus as well. This is showing about two months’ worth of data so you can actually see these stars and X’s a little bit better. When we starting collecting data on this patient all of these numbers were actually in the red zone and the reason that they look better than that now is the primary care physician caring for this patient and I made a decision that obviously our predicted peak flow, which is a formula-based on, was not accurate for this subject and we used the actual best readings that they had done to reset the peak flows which moves them up into the green. If you look those, 300 is not a really good number. What
happened with this subject is the nurse observed the lower peak flows, the patterns of meds, they’re using their controller medicine right yet they’ve got to use their rescue medicine every day. They’re having asthma symptoms just about every day and the clinician in this case decided to order a pulmonary function test which is a much fancier test than the peak flow that the patients did and what they found was that this was not reversible and asthma is supposed to be a reversible lung disease. You give the albuterol rescue medicine and you see better numbers and this patient didn’t. The diagnosis of a different lung condition, chronic obstructive pulmonary disease was entertained by this clinician. Even though this patient does not smoke, they were referred to a pulmonology specialist. The pulmonologist did more test and decided this was indeed asthma, just severe refractory asthma and that this was a candidate for monthly immunotherapy drugs that we don’t administer in my practice; it’s only a specialty-based care type situation. This patient had actually not started those at the very beginning.

If you go to the last slide very quickly since I’m running over time, we did separate patient and clinician forms at the end of the study and these are just a few things I want to mention that we’ve learned at this point. Patients found it easy to use. They reported they enjoyed collecting ODLs, they
understood their asthma and their triggers better so we’re very encouraged by that. They could actually do this. Frankly, it surprised me how well they could actually do this. The clinicians were not overwhelmed, and that was good news because we were a little bit worried about how that would go and they reported that it indeed provided clinically useful information. There were educational opportunities. There we a couple of patients who used their controller meds and their rescue meds exactly opposite as they were intended. They misunderstood how to use them and that was corrected by the nurses over the phone. We had patients who had their therapy escalated sometimes between or without visits or at visits and as I mentioned, we had diagnosis changed. We had three subjects were diagnosed with COPD and one changed back to the severe refractory asthma.

**EDWARD F. HOWARD:** Very good, thank you very much Steve. You’ve heard a couple of very interesting presentations about how some of these technologies work in the real world and now we’re going to turn to a couple of folks who know an awful lot about the policy implications of starting to use these technologies and we’re going to start with Deven McGraw who is the Director of the Health Privacy Project at the Center for Democracy and Technology which works on ensuring individual privacy as electronic health information is shared.

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electronically. She’s also on the Health Information and Technology policy committee that was set up by the 2009 stimulus law. We’re very pleased to have Deven McGraw with us this afternoon.

DEVEN MCGRAW, JD, MPH: Thank you Ed. I do a lot of work on policy issues around privacy and security but with respect to Project Health Design, I took on what was really a bit of a new role for me. I teamed up with a law firm, Mannat, Phelps, and Phillips to be part of a legal and regulatory assurance team for the Project Health Design grantees to both assist them in navigating the laws that would apply to the projects as they were doing them and providing them with a path forward for where they wanted to go but also to try to surface some of the bigger policy implications that arose out the projects collectively as well as individually. It’s really exciting to have an opportunity to think about these issues in an on the ground implementation way and see where the rubber meets the road. We started with the grantees by providing them with legal memos and thankfully my colleagues at Mannat, Phillips, and Phelps handled this aspect of it. You’ve got five grantees in three different states and all of them subject to the Health Insurance Portability and Accountability Act rules around privacy and security. Most of you know that as HIPPA. How does HIPPA apply to these projects, how does state law

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apply to these projects in terms of being able to move them forward?

In addition to the concerns about basic compliance with the law, each of the grantees very early on in the projects identified three buckets of concerns that they had from a policy standpoint, one being security for the mobile tools that the patients were going to be using in each of these projects. We won’t go too down in the weeds about security in mobile devices but I think many of you may know that mobile devices often are not as secure as other forms of computer communication. Sometimes you can buy and purchase features that will make your mobile tools more secure but most people don’t tend to use them and it’s often difficult to figure out how to do that.

There were also some concerns raised about potential professional or malpractice liability by the clinicians for the potential to be receiving all of this data from their patients. What if they didn’t see something that was in the data and what if they missed it and what would that mean for them from a professional liability standpoint? Then, as I’ll explain in a minute, HIPAA as a privacy and security policy regime doesn’t apply to all health data and all contexts, it covers some data some of the time but not all health data all of the time and so given that some of the data was going to be collected and

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stored in environments that were not going to be covered by HIPPA what did that mean for the patients? These were all concerns that were primarily surfaced by the project sponsors, but really on behalf of the people that they were going to be asking to participate in these projects.

I think an overarching theme that it’s important to stress from the very beginning is that these arrangements are very unique and innovative but they can be done and these legal and policy concerns that were surfaced from the very beginning, there were plans for managing them and certainly from a legal standpoint all could be done in compliance with the law.

As I mentioned earlier, HIPPA applies to the data in these projects when it’s handled by the healthcare providers. When, for example, the data came into Steve’s dashboard and the clinicians looked at it, that data would be covered by the HIPPA privacy and security rules, but when the patients who were participating in the projects were entering that data into their mobile devices that data was actually not covered by HIPPA. So you had a regime where you had a certain set of rules that would apply to part of the projects like maybe half of the projects or 40-percent of the projects but the other part of the project would not necessarily be covered by clear or, depending on how you felt about them, less than clear rules. If you pick up and start using a mobile device and entering data...
in a mobile app you need to read the privacy policy to determine what the data sharing rules that are going to apply to that data and those promises can be enforced by the Federal Trade Commission but that’s not the same as necessarily having a comprehensive set of rules about how that data can and cannot be used. There may be state laws that apply and again, we had three grantees in California and two of them in two other states, sometimes the application of those state laws is different in terms of who they apply to. Even at the state level there isn’t typically a regime where all health data, no matter who holds it, is subject to some protections. Each grantee was only responsible for complying with its own state law.

We did have a project that involved minors, the iN Touch project and the adolescents and teens struggling with weight issues and sometimes mental health issues and there, state law often provides a very big role in determining who can access data and placing some protections around that data. In the case of that particular project which took place in California, there’re actually strong rights for minors to be able to direct and control their own data when it’s in the healthcare system. Of course those rules are not as applicable outside the healthcare system.
One thing that was incredibly helpful in each of these projects is that all of the institutions involved treated this as a research project which meant that it was subject to internal review and all the participants were consented into the projects and so they really understood what was going on, how their data was going to be used and collected, an environment that is not always present in the private sector when you talk about consumers using off-the-shelf products. It really created moments of transparency and education for the patients that we don’t always have when we’re talking about the purchase and use of tools in a commercial space.

As these projects are wrapping up, we’re trying to take the experience of the Project Health Design grantees and managing these critical policy issues and turn them into papers that can help inform others who might seek to engage in similar projects and the first paper that we did was really about mobile device security and it’s actually been published in The Journal of Health Information Management in the summer issue and there’s a copy of it in your packet and it’s also available online. Here again, remember that the mobile tools are being used by the patients and so many of the security devices and policy recommendations that you might mandate to be used in a provider context, when you’re talking about patients using these tools and making sure that they’re able to utilize them
in a comfortable way and enter the data you might have a
different equation. For example, if you say to a patient, you
have an ability to password protect your device but you can’t
make patients password protect their devices so the extent to
which they use those password protections was really up to
them. Another example was where the grantee really took the
discretion out of the patient’s hand but put in the capability
of being able to remotely wipe the device of data if it were
lost or stolen. That’s something the patient doesn’t feel is
not impactful to them but gives them a level of comfort if the
device was lost or stolen and not surprisingly, in fact, it did
happen in at least one of the projects that there was a device
that was lost and they were able to remotely able to wipe the
data off of the device so that it couldn’t be accessed by
persons who were not authorized to see it. The paper includes a
number of best practices. We looked to the HIPPA security rule
for some guidance but it was really around where the security
rule didn’t necessarily apply and it provides a set of best
practices.

A second paper that we have in draft and that we’re
seeking to have published is how did the professional liability
concerns get managed? Essentially, there are two overarching
themes to this paper. One is that this idea of a never ending
potential stream of data from the patients that the provider

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wouldn’t be able to manage did not happen in any of these projects. They were very carefully thought through. As Dr. Rothemich mentioned, there was a negotiation between the providers and the patients about what data would be collected, who was going to look at it, how often. Not in any project did the data automatically get dumped into the electronic health record without decisions being made about what data, when, how, very careful planning on their part, and so as a result, there really was a level of comfort by the clinicians participating in all of the projects as well as the patients. The expectations were very clear and people stuck to them and we perceived that to be very important. There’s not a lot of case law on this as you can imagine. These are very new types of arrangements, but in terms of looking at ways to manage concerns by providers it is absolutely doable but you have to be willing to put the time in to having those discussions and having those understandings be very clear among both the providers and the patients.

Then the last paper that we’re looking at deals with the issue that we do have privacy protections for one part of this equation and we don’t necessarily have them for the other part of the equation. What does that mean in an environment where we really are trying to encourage patients to use these tools in a more robust way, particularly where they are outside

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of a research project where you have those built in opportunities to talk to people about what this means for them, what the potential benefits are and then they can make decisions accordingly? What does that mean for policy going forward? That’s a paper that we’re actually trying to write as we speak. We’re working on that. I think that’s all I have to say about that, but I’m certainly going to be here to answer questions about how we dealt with those issues in these particular projects. Thank you.

EDWARD F. HOWARD: Thank you so much Deven. Finally we turn to Joy Pritts who is the original Chief Privacy Officer in the office of the HHS Office of National Coordinator for HIT otherwise known as the ONC. She’s been at that post for two-and-a-half years and we’ve asked her today to tell us a bit, not only about privacy concerns, but also about her office’s interest in patient-generated data more generally. Joy, thank you so much for being with us and being part of the event, particularly with the short notice you received.

JOY PRITTS, JD: Thank you for having us. Before I start, I want to explain a little bit for you who are not familiar with our office. It is the Office of the National Coordinator for Health Information Technology. The office was formally created in the HITECH bill which is part of the Economic Recovery Act. Our office is designed to incentivize
people to adopt health information technology and health information exchange. It is a somewhat unique office in the department because it really is totally focused on health information technology and exchange.

HHS as a whole has a real interest in putting the patient at the center. Anybody who has read the Affordable Care Act knows that HHS and the congress when the drafted the Affordable Care Act put the patient in the center. We are going to follow the patient, not just have isolated instances of care and as that it’s essential that the patient be a partner in their care. They are the one who has a lot of the information as everybody has said about what their everyday life is like and how that impacts their care. Most care, as you all know, doesn’t take place within the clinical setting it actually takes place outside of the clinic and so it’s really important that we know what’s happening outside of that environment.

People who are engaged in their own care demonstrate better health outcomes and I think all of these projects that are being run by project health design demonstrate that. It is a challenge sometimes to get people engaged in their own healthcare. People have a lot of other things on their plate to do and they also face a lot of, I would say, cultural challenges in becoming more involved in their healthcare because this is one of those areas is changing even as we
speak. But when people are engaged they can have better health outcomes. As Janet was mentioning earlier, patients now expect to be engaged through IT in everything they do including in their health. The fact that health has been so far behind the ball in this area is somewhat surprising because it is one of those things that is really core into people’s lives every bit as essential as any financial management.

HHS has a number of patient-centered initiatives. One which many of you have probably heard of is Text4Health which involved a lot of different, smaller programs where primarily they were focused on providers generating text messages to patients. Text4Babies was one in which providers generated reminder notices of appointments and things of that to women who were expecting children. This program has greatly expanded and there are a number of projects available. We have a list of resources at the end of my slides so if you’re interested in seeing some more of these projects you can read about them about them on that website and some of the more recent projects are going to be much more interactive.

HHS also, as a whole has shown its interest in giving patients access to more of their own health information by releasing notice of proposed rulemaking a little bit over a year ago now with the CLIA in the HIPPA privacy rule. For those of you who are not familiar with this little piece of lore,  

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when individuals were given access to their health information under HIPPA there is a little carve out for information which was held by clinical laboratories who are subject to the Clinical Laboratories Improvement Act. To make a long story short, the notice of proposed rulemaking is a joint role because there were pieces of HIPPA as well as pieces of CLIA that had to be changed in order to make this happen. It would expand the rights of patients to directly access their lab test results and it’s designed to empower patients to be firm partners with their healthcare providers. As Janet mentioned earlier in more detail than I will go into, there are also provisions in the NPRM for meaningful use stage 2 that also focus on making information more accessible to patients.

ONC, in particular has really taken a focus on this area and has, in fact, created an office of consumer engagement which is currently being run by the acting director, Lygeia Ricciardi who many of you are familiar with and this demonstrates how committed ONC is to not only making sure that providers are meaningfully using health information but also that patients can also do the same thing. The consumer engagement strategy is based on what we fondly refer to as the three A’s; access, action, and attitude. It is very much oriented towards meaningful use for patients. They should have access to their own health information, they should be able to

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easily take action with that information in a meaningful way and that some of these attitudes need to change that have been ingrained in some areas of healthcare for a while, that patients are something that healthcare happens to instead of patients engage in. We are working on all three of these A’s in many projects.

In particular, ONC has a number of patient-generated data initiatives and one of these is a white paper which was commissioned from RTI and it was released in April of this year and it discusses the technical, operational, legal, cultural, and education issues that surround patient-generated data because as Deven mentioned earlier, this is an area that is a little bit different than the way we have thought about health information in the past as being something that’s just generated in a clinical context and flows just one way. The policy committee which was created under HITECH also had a hearing on patient-generated data in June of this year, very recently, and this hearing material is also available on our website for those of you who have more interest in it. There’s also a study on patient access to their health information which looks at the patient getting their access to their information, reviewing it, and giving feedback to their providers and it’s exploring how that patients and the providers are able to engage with this and whether some of the

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challenges which people thought would occur with patient-generated data have occurred in the system, similar to some of the questions that were raised in some of the Project Health Design projects. This project is being conducted by NORK at the Geisenger and the anticipated date of release if the first quarter of 2013.

The point Deven raised earlier, patient-generated data does raise a number of legal issues and in particular privacy and security issues. As you all know, in this country we regulate in a very sector-specific way so we have some rules that apply to this little piece here and other rules that apply to this piece here and a lot of people, particularly consumers that HIPPA protects all of their health information and that is not the case. As Deven mentioned, it does not apply when individuals are entering their own information into a system such as the ones that have been described. We recognize this. As a matter of fact, the Administration has recognized that there are a number of ways in which people interact on the internet where the privacy protections probably do need to be heightened and so there is a White House initiative on internet privacy and it would actually provide what I like to refer to as a safety net protection that would cover some information that’s exchanged on the internet when it is not covered by HIPPA or other federal laws.

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In addition to these large policy issues we have done a lot of work on mHealth and privacy and security in particular in the Office of the Chief Privacy Officer. One of the things that we looked at was the security in mobile devices that was mainly done from a provider perspective but we looked at it from the devices as they came out the box and it is very interesting to look at. There is just a sea of red, even some devices where you could not set a password if you wanted to.

In addition to that we are conducting a focus group research. This came out of the Text4Health recommendations that we look into this issue, in particular, about consumer attitudes to privacy and security on mobile devices and what were the trade outs that they were willing to make and some potential safeguards. In addition to this, we’re also working with the National Strategy for Trusted Identities in Cyberspace which is another acronym called NSTIC which addresses one of the issues that Janet raised when she did her opening about identity proofing patients and authenticating them when they are submitting information on the internet. Those are some of the main things that we are focusing on and we do have this list of websites you can go to for more information on the work that we are doing in this area.

EDWARD F. HOWARD: Terrific, thank you so much Joy. We are now at the opening of the conversation stage in this
program. There are microphones that you can use to go to and verbalize your question. As I mentioned, there are green cards in your packets that you can write your question on. If you will hold that card up, somebody on our staff will pluck it from your fingers and bring it forward.

To get us started, Janet you’ve been scribbling questions as the presentations have gone ahead. Why don’t you get us started?

JANET M. MARCHIBRODA, MBA: Thank you Ed. I’d like to direct my first question to Dr. Rothemich. First of all, thank you for sharing your experiences on the ground with us and it was terrific to hear about all of the positive outcomes that you experienced as a result of using these technologies. Let’s just say, if we were to look at scaling this across the country improving these types of interactions among clinicians and patients which is very exciting, what actions, either policy or otherwise do you believe need to be taken to assist, particularly your fellow clinicians?

STEPHEN F. ROTHEMICH, M.D: This audience is probably more policy expert than I am but one of the things I think saw was that even with 30 patients in two practices this was a sizable amount of additional work that they were taking on to do this and so I think one of the policy implications would be that with any work that gets done at the end of the day

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someone’s got to pay for that time to get it done so whatever the mechanism of payment might be, perhaps it’s something that’s directly reimbursable, perhaps it’s something that is a potential savings to the organization if it’s an accountable care organization or something like that, so I don’t know what the exact solution is, but I do want to acknowledge that it’s a fair amount of work.

From the practice’s perspective I think that we would not have wanted or found it useful to do this with every patient in our practice who had asthma so we’re focusing in on the ones that there was more likelihood of benefit and we did see that for six months the clinicians and the patients both felt this doable and useful but I don’t know that either would necessarily say that after two years. One of the things that I think we’d want to think about is there are probably certain times where certain patients would benefit from looking at this information this intensely. The patients who are having repeated visits to the ER, we can’t get their asthma controlled, and for a time that would need to be looked at very closely. Then obviously, the practices have to figure out how to do this workflow that is work.

JANET M. MARCHIBRODA, MBA: Thank you.

EDWARD F. HOWARD: We have a number of people lined up at the microphones. I would ask you to A, identify yourselves.
and B, keep your questions as brief as you possibly can so we can get through everybody’s inquiries. I don’t know who was first. We’ll start on my right, your left.

**NATHAN DANSKEY:** I’m Nathan Danskey from the HIV Medicine Association. My question is about utilization. If you could talk about two parts of the utilization; one is in terms of increasing the patient’s ability to understand their own healthcare. If there is any resistance from insurers who may not want to detail what might be covered, what might be free, some people’s business model is based on people not utilizing healthcare as much as they could be so if there’s any barriers or resistance or if there needs to be change there. Maybe your insurance provider doesn’t want you to know that you can get a free pair of glasses or whatever it is. On the other side, are there opportunities and do you think this will effect the co-pay structure? For example if you get alerts saying get your free HIV test. It’s that time of year. Get a free flu shot. Get this free preventative visit. What do you see happening as far as utilization goes and what barriers lie ahead?

**EDWARD F. HOWARD:** Steve, everybody seems to be turning to you.

**STEPHEN J. DOWNS:** Great questions. I think the utilization is really probably going to depend very much on the cases of whose using and under what circumstances I think that
Steve detailed. In some ways what I think what Steve was arguing is you need to find the business cases around under what circumstances that it makes sense to do an intensive look at someone’s information. Because you think that’s going to make them healthier in the long run, maybe you reduce utilization and that does point to models like accountable care organizations where realizing those savings makes a difference and is part of the business model. To be honest, we haven’t engaged deeply with the insurance industry other than to have an advisor from that industry and these projects were done off books in that sense.

The co-pay thing is really interesting because this model of practicing care gets you a little bit away from the notion that healthcare is delivered in doses where you show up to an office and receive a treatment. This is saying it’s much more a continuous relationship and the idea of a co-pay starts to make less sense or maybe the co-pay is yes, if you really want to come in and use the office and talk to somebody, that’s a co-pay but in this direction maybe there’s no co-pay at all. I don’t know if others had thoughts on that.

**AL GUIDA:** Hi, my name is Al Guida with Guide Consulting Services. I represent Netsmart Technologies which is a vendor that provides electronic health records to mental health and addiction providers and this is a question to Joy

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Pritts. We have become concerned about confirmed reports that state health information exchanges are not accepting mental health and addiction electronic health records because of conflicting interpretations of state and federal patient confidentiality consent laws particularly related to mental health and addiction records and we know, Joy, that you’re working with the Substance Abuse and Mental Health Services Administration on these issues. I’ve got two questions for you quickly; number one, if you could just tell the audience a bit about how ONC works with SAMSA on the special confidentiality issues related to mental health and addiction records and the second one, is there anything you could say about this pressing HIE matter would be, I think, probably helpful to us. I’ll take your response seated.

JOY PRITTS, JD: In response to your first question, we work very closely with SAMSA on the confidentiality rules. For those of you who are not familiar with those rules there is a set of federal regulations that apply directly to substance and alcohol abuse treatment facilities that receive federal support which is very broadly defined. Those rules are more stringent than the HIPPA privacy rule and they require an individual’s express permission to share their information even for treatment purposes. The purpose behind that rule when it was originated was to make sure that people who had these

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conditions would come in and get treatment without fear of being arrested, frankly, and to our knowledge that last piece has not changed over the years. There is still danger, potential risk of this information falling into the wrong hands. The challenge that has evolved is that the rules were written very much at a time in a paper world and so although the policy may not have changed, the implementation of that policy into an electronic environment has proven to be somewhat challenging. As I was saying we work very closely with SAMSA. We are working with them on trying to find some solutions to this.

We have heard, as you have stated anecdotally, that some of the health information exchange organizations that are forming are hesitant to accept information that is generated from these substance abuse and mental health facilities because it’s one of those areas where the protection actually follows the data because if it’s generated in what we, in shorthand, call 42 CFR part two facility then when the patient consents for it to be shared and the recipient gets it they may not re-disclose that information unless they have the patient’s express permission. We’re working on a number of different fronts on how to tackle this issue because we recognize, and the Administration recognizes how important it is to have these...
substance abuse and mental health facilities really integrated into primary care.

One of the things that my office has been doing for the last year is working on standards development for metadata tagging this information that might help provide a technological solution to this challenge. As you know, because you mentioned that SAMSA has been working with a number of states to try to find ways that they can, not necessarily go back and re-draft all kinds of laws and things but look at the interpretation of things that exist in their states to see if at least they can come up with some common solutions or approaches to some of these issues. One of the keys here the people need to understand is that the way HIPPA treats federal preemption is that a state law which is equal to or more stringent than the privacy protections in HIPPA remain in place so that in itself, it’s not just those two areas that you mentioned. In any state law where state law mandates that an individual’s consent be obtained for these specific purposes, it’s presenting a challenge and I think it’s very important to point out that it’s not just this one little area, it’s a much wider issue.

EDWARD F. HOWARD: Joy, while we have you thinking about the reach of HIPPA there’s a question on a card that I think we can dispose of fairly quickly. The questioner would
like to know whether the health and history information that
they enter into a terminal in their doctor’s office is covered
by HIPPA.

JOY PRITTS, JD: Provided that your healthcare provider
is covered by HIPPA, yes, it should be.

JOHN GREENE: John Greene with the National Association
of Health Underwriters. I wanted to know if the panel shared a
concern that I have relative to apps and a provision in PDUFA
[misspelled?] that would give oversight of approving apps
through the FDA and that whole process which can be very timely
and costly where the shelf life of an app is short and a lot of
these people who develop them are working out of their garage,
for instance, coming up with apps. You’ve got to make it
worthwhile for them so I’m wondering if you had any concerns,
anyone, relative to this oversight. Is the smart phone now a
medical device that has to be approved by the FDA? We’d still
be waiting for Angry Birds if it had to go through FDA.

EDWARD F. HOWARD: Whoever answers that would you take
a moment to explain to some of us PDUFA is. Is it a town in
Illinois?

JOY PRITTS, JD: I think that’s Paducah; Prescription
Drug User Fee Amendments.

STEPHEN F. ROTHEMIC, M.D: It’s a law that was
reauthorized this year. This whole issue of apps was included

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because the FDA now says they’d like to have a peek at apps and whether or not it’s a medical device and the tax aside, how long it takes to get things approved when they don’t have the staff and management now to do the work that they already have now want to take this on.

DEVEN MCGRAW, JD, MPH: Joy, did you want to take that one because I’m happy to talk about it.

JOY PRITTS, JD: I’d prefer not to.

DEVEN MCGRAW, JD, MPH: Since she doesn’t work for the FDA. Yes, it is the case that the Food and Drug Administration is looking at the extent to which it’s congressionally authorized authority to regulate something that is a medical device would extend to certain things that are on your phone like an app. I doubt it’s going to extend to Angry Birds. Those of us who don’t play it might think maybe it should.

STEPHEN J. DOWNS: There aren’t many studies that show that it improves health or decreases it.

DEVEN MCGRAW, JD, MPH: No. I think it’s a difficult line to draw because on one hand if there are two guys in a garage creating an app that a healthcare provider is going to use to make a decision about me clinically where it actually operates like a medical device in terms of saying here’s what that person’s blood pressure is at this moment, here’s what it is after they do a certain thing and somebody makes a medical

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or a clinically relevant decision based on that I want somebody to look at it and make sure that it actually works as its being presented to the world and being sold to the world. On the other hand, if you’ve got a device that’s basically helping you track your fitness level where you may be using it in terms of deciding whether you’re going to run faster the next day and maybe if it’s off by a tenth of a mile or two nobody’s going to die, that doesn’t necessarily need to get through full device regulation procedure. I think that what the FDA is trying to do is draw a line and they’re attempting to do this. What’s a mobile medical app, for example and what’s a wellness app, and what are the types of information that are more on the clinical, medical side generated and collected by an app and used to make a clinical decision versus information that’s used to help your wellness. That is not an easy line to draw. As Steve Downs made the point, information that doesn’t look like healthcare information in one context is, in fact, relevant to your health in other contexts and how you draw that line. From somebody who represents consumers in some of these discussions I don’t know that I want to say FDA go away. To some of these apps that, in fact, are designed to be used to make medically relevant decisions. Would a piece of false information coming out of this device result in somebody getting hurt? Then I do want some sort of standards that are applied. Having said that,

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what does that look like, under what conditions? I don’t think it is all clear to the extent that regulation, when it’s not done appropriately and surgically, correctly, it can be an innovation killer and that’s a problem too. But I don’t think it’s as easy as saying, apps shouldn’t be regulated at all because some of them are actually used for clinical decision making.

**STEPHEN J. DOWNS:** I agree with Deven and if you go back to the example I did earlier of the company that looks at the data on your cell phone and establishes a behavioral signature and then is able to look for changes against that signature, if the output of that was to say, we’ve noticed a change in your behavior. It appears that you may be sliding back into depression, you should double your dose of Prozac immediately in order to stave that off, you would want that regulated. If what they’re doing is just saying we’ve noticed a change in your behavior where you may be concerned about this, you might want to discuss this with your doctor to figure out an appropriate course of action. Those are easy lines to draw but what you hear in the developer community is the most important thing is however they’re drawn they’re drawn and they’re clear because I think that’s the hard thing. If you are the two people in the garage trying to build a company and you’ve got something and it’s really unclear whether or not

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you’re going to need FDA approval, those are hard circumstances to work under.

**EDWARD F. HOWARD:** What you just said, Steve sounds like that whatever the line is might be drawn less on the actual app than on the use to which the information is put.

**STEPHEN J. DOWNS:** It depends on what’s the app and what’s the service. It’s less about the data collected, maybe even less about the analysis of the data but more about any recommendations for action about that. That brings up another point, in the focus group research that was done with the Chronology.MD project after patients had a chance to use that, they talked about being able to see connections among different aspects of their health. For example, Crohn’s patients, when they looked at activity level and sleep and noticed that more activity and more sleep had a real effect on their energy level but their energy level being increased had a real effect on decreasing their pain level. That’s an important insight that you can get from an app, you can get from algorithms and you can make changes in your behavior that help you take advantage of that. I don’t think anything in there necessarily rises to the level of medical treatment or providing medical advice but at the same time its important insight that you can from the data.
JOHN GREENE: I just want to be clear that I didn’t mean to suggest that there should be no oversight. I think oversight is good but it’s got to be reasonable and timely and it’s got to make sense financially.

DEVEN MCGRAW, JD, MPH: Fair points.

UNDINE A. NASH, MS, PHD: My name is Undine Nash, International Journal of Hygiene and Environmental Health. I hope this is farfetched but can you imagine a scenario where it is required or mandatory to provide ODL data in order to be eligible for certain healthcare plans and how could we prevent that?

EDWARD F. HOWARD: An interesting question.

STEPHEN J. DOWNS: I’ll take the first crack at that. The technology infrastructure to make that possible is obviously there, that could happen. That’s where policy comes in and that’s why it’s so important I think when you have technology and the applications of technology emerging that you bring in policies so that you can have discussions about values and what sort of rules you want to put on it. Again, I think this is another example where it’s what you do with the information that ought to be subject to laws and policy and play out in the proper law and policy arenas.

CAROLINE POPLIN, JD, MD: I’m Dr. Caroline Poplin. I’m a primary care physician. In my past life I was an attorney. I

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just wanted to comment on the doctor’s observation that the doctor’s weren’t overwhelmed by the information and that the whole thing went pretty well. Thirty patients in a seven physician setting is a small number over a short time and you picked out one problem, say for instance, in the lupus patient who had five or six problems that could have been followed and monitored. If that were scaled up even limited to sick patients as it should be, that’s a lot of work and a $20 per patient per month management fee is not going to cover that. If you want physicians to use it and do and keep up with the information, which they must, as a lawyer I know a common cause of malpractice lawsuits is something that was missed and then it goes along and turns into something much more serious, so you can’t afford to overlook things. If you want people to do it, it would be a good idea to, until we get to the great ACL in the sky, pay doctors for looking at the information and pay them for telephone calls. There’s already a code for it, it saves everybody money, it’s convenience for the patient, it saves the doctor time and money, it saves the payer time. I don’t understand why CMS can’t pay for phone calls. There is no congressional law forbidding it. They could start the administrative thing going tomorrow.

**STEPHEN F. ROTHEMICH, M.D:** My response would be I don’t disagree with anything you said and I don’t think

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anything I said is counter to what you’re saying either. I said that either we had to find a way to pay for this or it would need to be bucked into those other ones and you are quite right that if we had every patient with asthma and diabetes and you name it collecting this data, that would be impossible. But if we had found that for this small number of 30 that the clinician said no this is too much, that might be a death knell for this kind of work but I think we have to be selective and you’re right, it’s got to be reimbursed because, at the end of the day, it takes somebody’s time.

CAROLINE POPLIN, JD, MD: ACOs will not take it seriously if it’s not reimbursed now. It will just be one more thing to do for the same amount you’re getting paid today.

EDWARD F. HOWARD: Can I just ask has anybody heard of an interest level from ACOs either the private ones or the ones running through CMS in adopting any of the use of ODLs or other kind of data that we’re talking about, the patient-generated data? I would welcome it if people have the answer to that question even though they are not on the panel that would be fine since we don’t have CMS folks on the panel.

EDNA BOONE: [inaudible]

EDWARD F. HOWARD: Since you were out of microphone range I will condense that answer by saying yes, particularly

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in Minnesota. Thank you very much. Do you want to identify yourself?

EDNA BOONE: Edna Boone

EDWARD F. HOWARD: Edna Boone, thank you very much.

MALE SPEAKER 1: [inaudible] I’m an advisor of health information management and strategy for different organizations and small businesses and I was a former FDA fellow so I’m just going to get my two cents in the question asked before about the mobile apps. First of all, I’m going to agree with Deven. What she said is absolutely right. The FDA has been trying to regulate the whole mobile application platform. They are trying to focus on specific high risk applications that have to do with clinical decisions that affect the patient drastically, so always the FDA thinks risks and benefits and they decide if this something we need to regulate so it’s not just the application it may also the mobile device because mobile devices, not just your smart phone, it can be a sensor, it can monitor data, it can be together with other devices so that’s the main concern. The one aspect I want to mention [misspelled?] just to compliment what Deven answered, and then the other aspect is that some people don’t know so well about the definitions of devices according to the FDA and the government. Biomedical software, especially when it’s connected to patient safety is under the regulatory authority of the FDA.

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They haven’t invoked the authority in all these aspects for certain reasons and ONC has also done a lot of good work the last years taking action on that, but they can regulate biomedical software in a lot of areas but of course, for the sake of innovation, we don’t want to make this unaffordable so that’s my other point.

My quick question is this to all of you, I think that we’ve seen the Affordable Care Act ruling already passed and we are looking now for the developments after that and there are certain provisions there, especially in quality reporting that has to do with needs implementation [misspelled?] of information technology. I’m going to mention what states have to do, what hospitals need to collect and report performances and measures. There are standards they’re going to need to implement and other things and other funds that need to be given in the innovators to make this work in the quality reporting. In this part of information technology what do you see as a timeline for the state and federal and also for innovators as we now go to the implementation of the healthcare reform? How can we do this better by what you see in the future?

**EDWARD F. HOWARD:** That’s such a devastatingly complex question that you’ve stumped the panel.
DEVEN MCGRAW, JD, MPH: I would say, again, since we have ways of influencing the healthcare industry and healthcare policy that are nested within a bunch of different agencies within the federal government if you’re even just thinking of the federal government and then you have all of the interesting initiatives that are happening in the private sector it’s not one clear timeline it’s multiple initiatives going on somewhat simultaneously, each one piggy backing off of the other. I can say that at least from the Health IT Policy Committee’s perspective we’re already starting to look at what the criteria would be for the third stage of the EHR incentive program which would include a set of objectives for it being a meaningful user as well as what the technology has to include in order to be certified and then all of that subject to eligibility for federal subsidy. We’re definitely exploring the capability to be able to incorporate patient-generated data from a potentially wide variety of sources with the provider having the option to choose which one works best for his or her particular patient population starting with a relatively low threshold of patients taking into account all of the provider issues that are discussed. There’s one set of initiatives again, being discussed it’s very early stage three discussions but it’s still hearing and looking at where the potential is to
really move the needle on quality and cost issues and trying to drive some incentives in that direction.

**FRANCES CORREA:** Hi, Frances Correa, Family Practice News. I was wondering if you could go into a little bit more detail about some of the incentive structure, how to really encourage physicians to integrate some of these technologies and down the line how that’s really going to affect their meaningful use requirements?

**DEVEN MCGRAW, JD, MPH:** I think we’re really at the start of the incentives that are more aggressively focusing on bringing the patient view into the processes. The focus for state one and much of what we’ve seen of proposals for stage two have been about equipping patients with the data that they might need that they can then use themselves which is a necessary first step. Where the bidirectional flows are concerned that raises additional issues but from a policy and a technology standpoint, that’s why they’re really getting a more meaningful look for stage three which feels like it’s way out there but it’s actually not. It’s just around the corner especially if we have an expectation that the technology vendors who are still busy implementing stages one and two will be able to get the product upgrades in time to be ready for stage three. The first focus being Joy’s three A’s; the access piece of it. Do patients have access to electronic data that

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they can really use? We’ve seen the VA’s Blue Button initiative; we’ve seen CMS do a Blue Button initiative. There’s lots of discussion about how to make that ability for you to get a view and download of your health information and be able to take that elsewhere. Others may want to talk about it. In regard to accountable care organizations, the financial incentives are driven toward outcomes. You can actually realize good outcomes by taking care of patients better when they’re still in their homes. It doesn’t surprise me that there’s at least one ACO that’s exploring it because it’s a very appealing way to leverage resources and get better outcomes.

**STEPHEN J. DOWNS:** I think the way I would think about it is to remind everyone that this is very early days on this kind of work and the studies that were done are very small, not statistically significant claims to make here, but what we’re seeing is promise but we’re also seeing promise not in all patients, not all the time, not all circumstances. For me the question is less about how you provide incentives for people to do this and more, do you create a policy environment where you’re able to do this when it makes sense and when you can find value in it and not be hampered by policy that says don’t do this even it’s a good idea because we’ve structured your payments or we’ve structured the rules to prevent it. In some ways, that’s our purpose of trying to share this work at this
point to say this is coming along. There may be some real
opportunities and you want to make sure that the policy
environment enables those opportunities to be realized but not
necessarily create incentives to say you all need to be doing
this now.

DANEEN GROOMS: Daneen Grooms from the American Academy
of Neurology. I think she pretty much asked the same question I
wanted to ask. I was just thinking, from a provider perspective
with respect to these smart phone apps like Breathe Easy that
was mentioned, it wasn’t clear to me when I was listening to
the discussion exactly how this would be implemented or who
would be the decision maker. Would it come from the physician
who identified the patient and say I think you’d be great for
this or would it be the patient who would have access to the
app and say I think this would be a great way for me to manage
my care? It was a little confusing to me, where is the entry
point? Where does it begin? Is it the physician who
identifies the patient and then they go from there? The reason
I ask that is because it was mentioned that perhaps in the
emergency department, physicians or clinicians there may
identify patients who would be eligible to use the app. If you
could provide some clarification on exactly what’s the intent?
Who’s supposed to use this? Is it the physician that

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identifies the patients or is the patient? I would appreciate that.

**STEPHEN F. ROTHEMICH, M.D:** I think at the end of the day there’s going to have to be some negotiation between those two parties and it’s not a unilateral decision, but in a medical home world it wouldn’t necessarily just be the ER physician who was seeing that this patient was in the ER, I would know that as a primary care doctor, that they’ve been in the ER. I don’t know that there’s a right or wrong answer to it but being a physician, I’m thinking more physician-centrically here and assuming that we would be identifying these people

**DANEEN GROOMS:** Okay, so it would not replace the physician.

**STEPHEN F. ROTHEMICH, M.D:** No, I don’t think so. It would just become another tool that we have.

**DANEEN GROOMS:** Okay, thank you.

**RICHARD D. BRENNAN, JR., MA:** Good afternoon, my name is Richard Brennan; I’m the Executive Director of the Homecare Technology Association of America which is an affiliate of the National Association for Homecare and Hospice. I’ll give credit, maybe to Janet as far as health happens outside the clinic is one the things I heard on the panel that came out today. One of the things that we’re trying to do is align with a group of providers that provided incentives for electronic

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health records along with acute care, those providers with nonacute care and post-acute care providers. We’ve identified this is a huge to make sure that we have alignment across the spectrum of care. I’ve been working in that regards under the SNI framework. It’s a community-led initiative to create a longitudinal care plan. Part of my question in informational just to make sure that you’re looking at that model, the home health plan of care, our use case was just developed through the SNI framework and we’ll go through HL7 balloting that we plan on using and hoping to use across a platform of care providers. In other words, it would be a partnership with physicians but other partners could use this as an electronic means of establishing goals, interventions and also all those being measurable, backed up by clinical data that can be collected either remotely by remote patient monitors or on site by clinicians. As part of my question I just wanted to ask as a more overarching look, I know that we’ve had a very specific look today at specific programs and interventions, but what new models of care coordination are going to be needed in order to better engage patients in their care and have you thought of how this is going to happen in a holistic way? Thank you.

DEVEN MCGRAW, JD, MPH: I can take a stab at that. The Bipartisan Policy Center released a report earlier this year looking at the attributes of high performance, reducing costs
and improving quality in healthcare and the patient activation, engagement piece is huge; a common attribute across a number of organizations that we interviewed. There were two questions around payment. As Steve mentioned, I think looking at specific actions and reimbursing them is very different. We’re very encouraged to see a number of the delivery system models that are being tested by CMMI, a number of states, a number of health plans across our country and providers that are actually providing incentives for better care, coordinated care, accountable care; this is just a piece. Clinicians, doctors working with those who provide financial support for these models working with patients that are heavily involved in governance in a number of these initiatives is the way forward. We applaud your leadership around homecare and this is the wave of the future.

**MALE SPEAKER 2:** My question is about data aggregation. It seems like we’re talking about a patient entering old metrics over a new medium and the physician is the one who aggregates that data instead of, perhaps, a different way of doing things like perhaps, Target, which has more data points than my healthcare provider I’m guessing and who can also figure out when people are pregnant without having to ask them. Are we heading that way? Would such systems that necessitate computerization of healthcare allow people to operate at the
top of their license? Also, are there barriers to it where physicians will feel like they’re Watson technicians? Watson’s the IBM computer which is made to do this sort of thing.

**STEPHEN J. DOWNS:** That brings a whole interesting area and there’re companies like Patients Like Me and Cure Together where people enter a lot of information about themselves, their treatments, their experiences, and then can see in the aggregated crowd how they’re doing relative to others and insight can be done from that. There’re some great stories of patients finding that they were only on 10mg of something because their doctor said that’s all anyone should really take and then they find out that 90-percent of people with similar conditions are actually getting 100mg and so they can go back to their doctor and say, what gives? I think there’s a ton of opportunity there. Again, who’s doing what with those insights is always a good question. In the example of the person who was on an awfully low dose, they can go to their doctor and say I’m not saying that I need 100mg but evidence would suggest that other people are on it so let’s have a conversation about that.

The other thing that I think this does is it really does open up the question of what professional skills are needed to do what tasks associated with providing care in a coordinated team-based fashion. I think the example of Breathe Easy where they had nurses reviewing the data, the dashboards
from the patients, and then triaging escalating to physicians was a good example of saying let’s put the right task with the right person with the right skills and divvy up the work that way. I don’t know if Steve or others have any thoughts on that?

**STEPHEN F. ROTHEMICH, M.D:** I was just going to add that if I’m remembering correctly, Steve, didn’t every project end up with a model like that? In none of these projects did they decide that the physician was going to be the first viewer of the information.

**STEPHEN J. DOWNS:** Yes, absolutely, there was always some element of team going on.

**EDWARD F. HOWARD:** You get the last question.

**Edna Boone:** Good afternoon, Edna Boone. Taking it back to reimbursement, a nice lead in, every model ended up with a different care team, maybe taking a piece of this before it got to that end care provider that might make a decision, but each one of those pieces of the puzzle comes with a salary and a need for reimbursement. A couple of things that came up that the physicians [misspelled?] brought up earlier around telephone visits is the chapter 10 of the Broadband Plan really spoke about e-visits. We are going on four years sitting on components of that plan. How do we, one, move policy forward that keeps up with the technology at hand so we’re looking at e-visits for one? We’re looking to update the antiquated

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reimbursement for telemedicine which is probably five years behind on the books which means 10 to 15 years behind in terms of what the technology can do today. Applaud the ACO model and what’s happening with the Innovation Center but how can we raise that discussion both at ONC and at CMS to look at moving those reimbursement structures forward? Also, how can we look at other industries and what has happened in the microfinance world? We talked a little bit earlier about co-pays but if you look at, for instance, the music industry one of the ways that Apple turned that on its head was you could buy a song for 99 cents. Everybody said well, geez, I can sell an album for $20 or 15, why would I want 99 cents? Because the way that they made it so easy for people to grab that music. Have we looked at other industries in the microfinance is used and being used in other parts of the world, not in the US, and bring that to bear on healthcare? What if it meant that a provider just got very many, many small payments, maybe not out of the insurance industry but directly from patients? I’d be willing to pay, but we don’t have or barely have those financial structures in place at all in the US. We have Square that’s moved in and that’s the beginnings but how could we look at some of the other things that are happening in other industries that might help move us along?

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DEVEN McGRaw, JD, MPH: Edna, I think rather than a question you’ve just thrown out several really important challenges for all of us who are looking to see the needle moved on healthcare both for patients and providers. We didn’t come to the table with any experts on reimbursement but it’s fascinating and it just underscores how we need to be thinking about health information and health differently than the way we’ve historically thought of it. If we really hope to leverage technology better and bring patients more into the center of the conversation and make all of it work far better than it does today. Rather than questions I’ll say good points and good thoughts to follow up on.

Male Speaker: Do you have time for another question?

EDWARD F. Howard: I’m afraid we don’t. I apologize to all of the folks who put questions on cards that we didn’t get to but we have run out of time. I want to come back and thank our friends at the Bipartisan Policy Center, particularly Janet Marchibroda, our colleagues at the Robert Wood Johnson Foundation, particularly Steven Downs. I want to thank you for sticking with an acronym-filled, mind stretching discussion, at least for some of us. I want to take a second to note also and thank Jackie Fitton and Beza Hennock who have labored for the Alliance as interns this summer and this will be Beza’s final day. I don’t know if Jackie is going to be around when we have
our briefing on Friday but when you join me in thanking the panel for a great discussion you will also be thanking Besa and Jackie.

[END RECORDING]