

**Meaningful Use Workgroup**  
**Draft Transcript**  
**May 4, 2010**

**Presentation**

**Operator**

You're now joined with the public.

**Josh Seidman - ONC**

Great, thanks. Paul, do you want me to do the roll call?

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Yes, please.

**Josh Seidman - ONC**

Art?

**Art Davidson – Public Health Informatics at Denver Public Health - Director**

Present.

**Josh Seidman - ONC**

George Hripcsak? David Bates?

**David Bates – Brigham and Women's Hospital – Chief, Div. Internal Medicine**

I'm here.

**Josh Seidman - ONC**

Christine Bechtel?

**Christine Bechtel – National Partnership for Women & Families – VP**

I'm here.

**Josh Seidman - ONC**

Calman, I know is here. Art, you said you were here. David Lansky?

**David Lansky – Pacific Business Group on Health – President & CEO**

I'm here.

**Josh Seidman - ONC**

Deven McGraw?

**Deven McGraw – Center for Democracy & Technology – Director**

Here.

**Josh Seidman - ONC**

Latanya Sweeney? Linda Fischetti? Charlene Underwood?

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

I'm here.

**Josh Seidman - ONC**

Michael Barr? Jim Figge?

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

I think you're breaking up. I think somebody's typing and that's causing the mike, are you on a conference phone perhaps?

**Josh Seidman - ONC**

Yes, there is someone else typing and I'm not sure who that is, but if you can mute your phone that'd be great.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Did you finish all the names?

**Josh Seidman - ONC**

Yes.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay, great. Thanks, and welcome, everyone. We have a couple major agenda items for today, one is to debrief on the patient engagement hearing. And come up, not with recommendations, as you know, we've been having a series of hearings on the various categories of meaningful use as we build up and reconsider what the 2013 and 2015 criteria, and perhaps even as reshaping of the framework might be called for. So, we're accumulating some our takeaway messages and lessons learned from these hearings and we plan to sit down and pull it all together as we work towards recommendations for 2013 and 2015. In fact, perhaps one of the ways I could start this out is to give a little bit of some of the timeline. Is Jodi on the call as well?

**Josh Seidman - ONC**

I don't think so.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay, that we've discussed with ONC as far as just a preliminary draft, kind of a guiding timeline and this is not cast in concrete. We just want to sort of plan out the work. And more to come from ONC on the work plans for this and the other workgroups.

We have three more hearings that we've scheduled or hearing topics at least. One is on health disparities that we'll talk about later on in this call, another has to do with chronic coordination of care, and the third has to do with population in public health. And these are the other categories. We have three more hearings, then we would probably break into, that would be June, July, and August, and then planning to get together in a face-to-face meeting in September to try to get all of this information together and start working on the formative recommendations for 2013 and 2015. Then we'd bring that forward to the full committee, HIT policy committee, get some more feedback, and then return to our corner and try to incorporate that feedback before returning with final recommendations. So that would put us into the November/December timeframe where we could get information about draft recommendations from the committee out.

One of the ideas we're thinking about is to use what's just been posted for one of the privacy areas, which is sort of an RFI approach. If you'll recall last time, I'm not sure what we called it, but we did open up for

our draft recommendations for public comment, and took that into consideration as we produced our final metrics in the meaningful use workgroup back in June/July of last year. We want to find a way of getting access to more public comment as we form the 2013/2015 criteria as well. That gives us a bit of an additional ability to hear from the public and from the industry and providers as we go into the next round.

Any comments on that before we move on? We can return to that subject as we plan for the next hearing on disparities, but that's sort of just a draft of milestones for our work the rest of the year.

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

Paul, this is Charlene, is there a picture of this timeline somewhere?

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

I think this is something that the office is actually working on. Josh, do you have any further information about that?

**Josh Seidman – ONC**

Yes. There is something that we're working on, some more comprehensive timeline. And yes, we can try to develop something that is sort of internal and has a bunch of internal steps that don't mean much to everybody. But we could probably design something simplified for distribution.

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

The reason I ask is I think it would be valuable especially if you're trying to gather or get ready for testimony to get people thinking about it and if you could advertise it a little bit. I think that would be valuable in helping what the goal is to try and accelerate this, but be prepared and think about it. So I think that might be helpful to see what that timeline is.

**Josh Seidman - ONC**

Okay, great.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

It's a fair comment, Charlene. As you know the office and the factor committees are trying to respond to the interest in having more information sooner. And you already know that the tension is you don't want to pre-cast decisions or recommendations without getting some feedback for how this one is working. So that's the twisting between the kind of situation we're in now. But that's exactly why the office is working on sort of an overall timeline for the committee and the workgroups.

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

I guess my concern is I just don't translate it correctly based on what you said.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Right. I understand. Okay, so as I mentioned the two major topics we have for today are to debrief on the patient engagement hearing and then proceed with our planning for the disparities hearing that we'd like to propose for June the 3<sup>rd</sup>. I think we put that out as part of our announcement for the meeting.

The first one is the patient engagement hearing. If you'd like I'm happy to summarize what I presented in front of the main committee and the day after our hearing to start us off, would that be useful?

**David Lansky – Pacific Business Group on Health – President & CEO**

Sure.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Or does everybody recall the hearing and we can start discussions?

**David Lansky – Pacific Business Group on Health – President & CEO**

Sure.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Sure.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

I'm not sure which?

**David Lansky – Pacific Business Group on Health – President & CEO**

Sure, summarize.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay. We talked about how the patient played an important role in what we described as the learning health system. So not only are they gleaned information and knowledge from the system itself, but we really wanted to rely more and more on information from them and the people who support them, informally called the informal caregivers.

We heard loud and clear, particularly from the first panel, that particularly the consumer groups feel that the time for incremental change is over. That they need this information to become more active participants and we need to move beyond the status quo, which mainly sequesters information on the professional side of the equation.

We heard a need for and a demand for universal and immediate access to this data as the beginning point in their engagement in the learning health systems. Like the privacy and security foundational plank to our learning health system, the patients needs really wraps around all of the other categories as well. We keep talking about privacy and security be important to each one of the clinical on health objectives. Well, the patients needs have that same sort of wrap around little function.

So thinking of that, one of the questions that was raised was should we perhaps somewhat redirect our focus of meaningful use criteria to what's meaningful to patients to their experience, to their quality of life, to their mortality? One of the examples that was given, is it really my A1C that I as a patient am worried about or is it making it to my granddaughter's wedding? That kind of health goals. How do we incorporate that into how the professional team interacts with the EHR and makes meaningful use of that? One of the panelists talked about the goal of having three E's, engagement, education, and empowerment, which you can almost think of different kinds of steps in truly active participation.

In stage one, we were fairly prescriptive on what kinds of functions needed to be in the EHR, and what kinds of use should the providers be making of the EHRs? A thought was raised maybe in 2013 and 2015, it's less prescriptive and more flexible on patient outcomes focused, which was always one of our goals. Somebody gave the analogy of like Y2K was ... maybe we need that kind of attention, but it's sort of a Y2K plus 20. As an example, he was saying, well maybe we should have 50% of the care be delivered at home as part of our goal. Another suggestion was to create a meaningful use video to help explain to the public what are our goals, as well as how can you use this technology that we're incentivizing providers to purchase and make meaningful use of to improve their health?

There was a suggestion that we should create the community between patients and their professional healthcare team. That we support the community's ability to support patients in their health. That patient outcome measures like we might be striving more towards measures that are directed toward patient outcomes rather than the more traditional NQF measures of professional performance.

So those are some of the ones at least that come to mind, and certainly welcome anybody else to contribute other things that are not on that list that should be mentioned as we begin the discussion.

### **Josh Seidman - ONC**

This is Josh. I'll just mention that we also have held open the ... blog, the federal budget committee blog. We've gotten about 40 comments through that and there's been some very thoughtful input. I think a couple things that came out in addition, a lot of those things came out in the blog discussion.

There also were some things around the needs as we think about patient family engagement, to think about the needs of a diverse population and are there different kinds of electronic health record formats that might be needed to meet those needs? So things like simple ways with the issue of a children's format for an electronic health record or things of that nature.

And then also in addition to that meeting, the needs of the population. The issue of user center design and thinking about physical space design and so forth, which was actually something that was discussed in the hearing as well, but has also come out on the blog. So I just wanted to bring those to people's attention.

### **Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay, thank you. Other comments, other additions to the summary?

### **Christine Bechtel – National Partnership for Women & Families - VP**

Paul, it's Christine. I think you did a great job summarizing it. And I think particularly the focus on the orientation of the criteria overall, and beginning to orient them around patient outcomes and patient goals is definitely the way to go. What I struggled with is how we begin to operationalize those themes. So I did some thinking that I can throw out in terms of how we might translate that, if that's helpful. Is that helpful at this point?

### **Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

I think that'd be a perfect kickoff to exactly that discussion. How do we translate what we heard, what we learned into the meaningful use framework?

### **Christine Bechtel – National Partnership for Women & Families - VP**

I think first it would be helpful to go back and look at the criteria specifically, and think about their orientation and think about if we have patient outcomes, patient goals, and patient experience as our three kind of lenses. Then have we chosen the right criteria? How do they fit in? How do they all play together? And I don't know the answer to that, I just think that that's something that would be worth doing.

I did do a blog, as Josh just talked about, that'll I think go up this week, and that was where I started to translate some of this. And so I came up with three areas just as food for thought. The first is communication. And I think Neil did a good job in the hearing talking about the need to really open up communication and find less restrictive ways to facilitate that communication and real collaboration between patients and their care teams.

I thought of the things that I heard mentioned were E-visits, ways that we might leverage alternative media, certainly patient experience, and ways in the future, and I don't know that this 2013, but ways in the future that we can lay the ground work for platforms for collaboration and that sense of community, Paul, that you mentioned. And I'm thinking about how do we apply social networking constructs to the care team relationship?

The second area that came up was the data component. We heard about the secure download button. And I think actually that is hugely key to laying the ground work for the platforms for collaboration that I just mentioned, as well as accepting patient reported data. I heard a need to start thinking about how we could put information kiosks at the site of care so that as people are like in the hospital for example, a caregiver could access health information electronically. And then I also heard a real need for delivering information upon service instead of upon request, which is an orientation issue I think we have in the current criteria.

And then the third bucket that I thought about was what Eric Dishman talked about how do we focus more on care in the home and community and connecting that to care sites? So I heard remote monitoring. I heard uploads of patient generated data. I also heard online patient and caregiver assessments, whether that's functional status or health outcomes or something like the FF36, and that that ought to be the basis for care planning. And I think we could beef up care planning certainly. And then I also thought about bidirectional mobile applications.

So again, those are some of the things I think we could think about seriously for 2013, and other things as we think about them for 2015 would require us to lay some ground work. But those are the three kind of areas that I've thought about.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Thanks, Christine. You had community, you had data, and how did you label the third category?

**Christine Bechtel – National Partnership for Women & Families - VP**

Communication, data, and home, home and community.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Home, okay. Reactions?

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

It's definitely the right direction. It's wonderful. What's feasible for 20 for stage two is what we'll have to actually sort out.

**David Bates – Brigham and Women's Hospital – Chief, Div. Internal Medicine**

This is David Bates, that's my reaction too. I think we should try and avoid being too prescriptive about what specific things people have to do. And they might want to kind of choose from things within those areas.

**Christine Bechtel – National Partnership for Women & Families - VP**

I think that makes sense, and I heard Deven at the hearing talk about the need to be flexible, and I agree with that. And I think it's again, this is going to be the issue that we always struggle to find the balance point on. It occurred to me that if we start with patient outcomes, functional status, and care planning, that that might allow some flexibility around meeting patient goals and improving patient health outcomes.

And that points us to the measurement criteria, which should be a combination of the kinds of quality measures that levers electronic clinical data along with patient outcome improvements and status improvements. And then to me it also again points back to the need for measuring by asking patients themselves, "Okay, your providers have these flexible criteria to meet based on your health status and your goals, are they actually doing that and how's that going?" And so back to patient experience.

**David Bates – Brigham and Women's Hospital – Chief, Div. Internal Medicine**

It seems to me like the very first thing is to show that you're doing substantially more in terms of communication even if you can't measure changes and outcomes, functional status, or even care planning. But those three areas are where we want to go.

**Neil Calman – Institute for Family Health – President & CEO**

This is Neil. I think that we shouldn't underestimate the extent to which the stuff we're talking about here really flies in the face of everything that exists in traditional medical practice. More than almost anything else we've talked about in this HIT discussion, we're really transforming the relationship between providers and patients in a way that's fundamental through this process.

I think that's got such incredible power and it's something we need to do, but I don't think we should minimize the push back that'll come from things like this. Just a concept, Dave deBronkart said in his testimony, he said, "Let's just start with the principle that patients own their own data and records." So just try to put that through the current system.

It's not the way we teach people. It could be true legally, but it's not in any way the way the system functions. It's why I think we should really try to signal what it is we're demanding that people do, but maybe target one or two things in each area that we think are really doable. Like the download button, to me, that's like such a concrete thing and it really signals in a very simple way. We believe that people should have a right to just get a download of their medical records in a particular format, at anytime they want it, anywhere they want it, inpatient, outpatient, whatever. To me that's a great concept, and it's simple, and it signals exactly what we're trying to accomplish. And we need some more things like that.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Christine, if I look at and heard what Neil just said, I totally agree. This is really the transformative piece is to get really engaged and bring patients on their health team. And what David Bates and George Hripcsak said, which is we want not to be prescript to say, you must have this particular thing because this is the way we look at the world in 2010.

If I were to sort of give you little tag lines for the three categories you described, one might be access to my data anytime, anywhere, immediately. That's sort of what Dave deBronkart said and that's Neil just summarized. The next piece might be your category one, which is how can I be in continuous communication with the rest of the members or my health team? And the third one is how can I incorporate all of this out of the office, out of the hospital information into my record in meaningful way? You have to balance it, like Patti Brennan was saying, you have to balance. It's not that we anyone can make an effective use of up from a ... or a volume of information.

Part of incorporating information is to make sure we have some kind of filter that says, while this is going to be useful to your entire team versus this may be useful to me as a patient, etc. Which you should have the ability to put somewhere, but we want to make it in a meaningful format, so that's part of it. But anyway, those were three great categories you had and maybe we can start there.

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

This is Charlene. I just wanted to actually challenge that just a bit because they tend to get at the tactical level, not that I don't think they won't work, but I spent some time talking with some providers and actually the EHR software developers. It was surprising, because in talking with the providers, I got reaction like Neil said, "Oh, my gosh," like, "What? It's going to make patients want to do this," that kind of thing. So I got a range of reactions.

I asked them about demand for the information and they said it kind of wasn't there. But then someone piped up and said, "Oh, by the way, number one, we don't have a lot of time in hospitals today to educate patients. So what we do is while they're there, we print out their document and share with them their medications and their list of information. And it's in patient friendly terms and the patients love it, and it helps them when they go home."

So I think Neil's exactly right, but it brings me back, Paul, to your original concept. It's about the engaged, the educate, and the empower piece that needs to happen throughout their care process. And I don't want to lose that concept how you categorize because that's really what's happening in those processes to make it work.

**Art Davidson – Public Health Informatics at Denver Public Health - Director**

This is Art. I think that James Ralston had a really good example of the power capacity to transform healthcare as it happens in group health with the way that they redesigned. And just based on Charlene's comments, there was all this concern by the docs about the secure e-mail going back and forth between providers and patients, and now the docs like it. And what did he say, 30% of their care is provided through this service? That to me is the transformation we're looking for and it gets back to your three E's.

I hear what George and David Bates are saying about let's not go too far and let's not be prescriptive. I agree with that. But I think we should allow for sufficient flexibility to reach some transformation, not to let this be without a good signal where we think we're trying to head.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Art, I think the key thing is to figure out which of these things, one, two, three, whatever number of them lead to all the others. Do you know what I mean? What lever is the strongest if we can only pick one that we can fight with people on. I think that downloading the data, for me right this second, I think I'm leaning towards that as the one that would lead to the most of everything else on the list.

**Art Davidson – Public Health Informatics at Denver Public Health - Director**

But I think again that that empower is about the real opportunity for the bidirectional communication. And going back to Christine's comments about the home and community being able to contribute.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Well we definitely want, so yes, so that's—

**Art Davidson – Public Health Informatics at Denver Public Health - Director**

So that's where I mean—

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

I'm not arguing against it.

**Art Davidson – Public Health Informatics at Denver Public Health - Director**

Yes.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

But I was just thinking, yes, I guess so.

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

One of the things the provider said was focus first on making sure there's exchange among the stakeholders, because that's crucial. But in the case the stakeholders don't have the information, having the patient have the information is good too. So again, there's a sequence here to some extent.

**Christine Bechtel – National Partnership for Women & Families - VP**

Yes, but Charlene, I'm not sure if you're saying that patients should get sequence later after other stakeholders, which I would—

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

They don't think that. Or use that same dataset. Standardize and use that same dataset so that you see that, but I just felt it was really important to get to the healthcare goals that the providers also were really focused on in terms of sharing data.

**Christine Bechtel – National Partnership for Women & Families - VP**

I just don't think there is a dataset right now and I don't think waiting for the perfect dataset is going to be good. Patients are not all the same. And I think when I hear providers say there is a demand, yes, well that's because it's not easy, you're shelved in nine different places.

If we can start to free up the information, it becomes a balancing act between not wanting to create like the sneaker net where the patient is the one responsible person for moving their data. But at the other hand, not sequencing them so late in the game that they're just not engaged and all their data is just falling and they don't have access to it. They will use it. We hear over and over again from families who have real and acute needs in this area.

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

Yes, I don't disagree with what you just said, Christine.

**David Bates – Brigham and Women's Hospital – Chief, Div. Internal Medicine**

Right. So this is David Bates. From my perspective, the very first thing is the communication. And much of the evidence that we have about the benefits around this are that if you can communicate with the practice that patients like that, that a lot of things improve, that it's good for both providers and patients. I'm in favor of allowing people to download the data too, but we don't really have so much evidence that that works. And there's just a lot of practical issues with operationalizing, and I think we ought to include that pretty soon. But from my perspective, the first is ensuring that everybody can communicate with the practice electronically.

**David Lansky – Pacific Business Group on Health – President & CEO**

This is David Lansky. I echo David Bates earlier suggestion. It seems to me that in terms of how we, not be too prescriptive, but it seems to me, coming back to Christine's structure, that there are three half ways we could try to implement criteria around. One, I do support the download button. I think we heard pretty much all the witnesses say giving people access to their data is a priority and it's a piece of innovation infrastructure that we have to enable. So I think coming up with a measure around download is important.

The second area, I was surprised, but impressed that we heard a lot of discussion about patient experience as one of the tests that affected the EHR implemented from the patient's point of view. And I

think if we can come back to a measure, that would capture several of the dimensions around communication for example. If we could test from the patient, whether they feel that they're now better. And Paul, in your language, continuously in a relationship now with their providers because of the mediating technology.

And the third area I would go back to is going back to the Ralston point. And maybe the way to start rethinking the quality of measurement category in general is to have in each panel of quality measures that we come back to this issue of how the specialties are going to deal with quality measures and so on. But within each panel of quality measures there should be an outcome measure, which is likely to be affected by comprehensive team based information rich care, whatever you want to call it.

And the examples that group health used to blood pressure control and diabetes control were good examples where having a metric of that kind, if it helped. If achievement on that goal is helped by better communication and home monitoring and home testing and all that, then great, and if it's not, that's fine. But the challenge to the practice is to improve the outcome of those chronic disease indicators using whatever technology is helpful.

To me, those three buckets of the download button, patient experience, and an outcome measure appropriate to some kind of either specialty or a setting or a condition would cover most of what we heard. And I don't think it's too prescriptive, but I guess the prescriptive part would be you've got to download data and you have to know if patients are in good communication with you using this technology. And the third bucket is more flexible to the particular category that CMS is already working on structuring.

**Christine Bechtel – National Partnership for Women & Families - VP**

David, it's Christine. What I liked about that is that the third category of flexible outcome measures would start to drive some of the things we want to see around care planning and assessments as the starting point. That's the only thing that I wanted to make sure we also capture is this idea that if you start with the patient's goals around what's important to them in their health outcomes, you may actually get to a very different place; and it's going to require engagement, education, and empowerment in a much larger way than what we currently see.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

If I could just comment on David's comment about communication versus data. I think David, you're right from an evidence point of view and a practical point of view, and so I'm easily convinced. However, my instinct is that communication is an incremental change that's going to happen anyway versus the data is one that may have much larger unexpected positive affects that we're not thinking of. And that's kind of why I was favoring it.

On the other hand, meaningful use is not supposed to be the place where we're doing the risk taking and that would lean towards the communication based on evidence rather than the data and hoping that that leads to something. For example, the quality may be driven by the patient. There may be a swell, a push for patient based quality based on just making the data available.

**David Bates – Brigham and Women's Hospital – Chief, Div. Internal Medicine**

My train of thought is, it's easiest to make the case for things where the evidence is available.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Yes.

**David Bates – Brigham and Women's Hospital – Chief, Div. Internal Medicine**

There is cadre of providers that are still thinking that they are not going to need to communicate with patients this way, and this would send them the signal that they got to get over that. Everybody finds it works really well once they start doing it, but they're just some laggards. So I think it would send a really important signal.

I do think we also absolutely have to do the download thing, but the effects of that really just are not so clear, and it is clear that there are all kinds of problems once you do that. Particularly if you take the data and dump it into somebody's personal health record, you end up with all sorts of duplication and problems, and it's going to be tricky working that out.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

I agree a hundred percent with everything you've said, but it's just some instinct that says the data will be transformative and that's an opportunity we should take advantage of, but I understand everything you said. It's exactly right.

**Neil Calman – Institute for Family Health – President & CEO**

This is Neil. I'll just give you an anecdotal example of ways that we didn't predict. But what's really transformative even if people don't even look at the data, is that it deals with this whole issue of trust. There's something about people knowing that they have access to all of the information, that it's not secretive, that there's not information being passed. Remember nothing about me without me. People just knowing that information is not being passed around this system without them having access to it themselves.

From our perspective, I can tell you when we were printing copies of progress notes and stuff like that for people, at the time of every visit that included what the providers were writing about them, I don't even think that half the patients read them. But they would still ask for them at every single visit if you forgot to give it to them, they would start asking you where's my summary. And I think there is something transformative about that, that even beyond the use of the data itself.

**Christine Bechtel – National Partnership for Women & Families - VP**

It's Christine, I agree. And I think there is evidence that certainly that this is what patients want. And we published a piece in *Health Affairs*, and I think it came out today, that just based on our own focus groups and research with consumers, and the two things they told us they wanted more than anything in the healthcare system were more communication and better coordination, which are inextricably linked.

The communication channels and opening them up I think is really critical. And I don't think we can underestimate the way that opening up the data itself will begin to facilitate a lot more communication. And if we design some criteria well, then I think there's going to be a natural incentive for providers to want to offer alternative ways to interpret and understand and use that information from their own self-interested perspective of needing to improve patient health outcome; and also needing to avoid getting cluttered with calls because patients don't understand what kind of data is there. But there's ample evidence that opening up the data is something that patients really, really want.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Paul, let's just—

**Deven McGraw – Center for Democracy & Technology - Director**

I agree, this Deven. I'm not so sure that I agree that there are lots and lots of problems with doing this, sort of picking up on David's comment. I think there's certainly some issues to resolve, but I don't see any of them as necessarily being obstacles to pushing this forward.

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

Actually, this is Charlene, I've got some comments on that. I think we've got a again look at the experience there. This is on the download. Again, the kind of feedback I work and I think, Neil had actually referenced this in his comment, the data that's available to providers is in provider E. In some cases, like for instance, the medications where it's valuable is if you list the meds and you say, okay, this is to reduce blood pressure. So there's some translation that maybe necessary to get to where you want to go.

Again, if you start, you can just say, let's just download the information, but at the end of the day it's probably not going to be sufficient to get to what you want to accomplish, and there's going to have to be some work to make it more consumable by consumers and patients. I think at the end that's what, so there's going to be work to really make this work well.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Absolutely, and I think to answer that—

**Christine Bechtel – National Partnership for Women & Families - VP**

I think that's a fair point, and I agree, and I think it will happen. If you look at TF and ... and some of the other folks who can already do some of that, I think the market has a role to play. This can't all be on the providers baskets to somehow program and code their own PHR. I think the issue is that they're serving as the central source of data at this point, and then the way that patients will get access to market has innovated in the past. And I think it will do it again here to make it more consumable and useable by patients and providers.

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

Yes, and that's where there's going to need to be some degree of standardization underlying it so that can happen. Back to that standard point, Christine, we were debating on before, not everything, but some on the key elements.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Any other comments?

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Paul, can I just say, is ONC commissioning studies at this point, and if we ever have question, can we feed into that to answer a question. It would take a little while, but for a literature review wouldn't take too long. I'm just wondering if a question comes up, does ONC have a mechanism to answer it?

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Are you talking about issues around the evidence base for things or—

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Yes, presumably, yes.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Regarding the evidence base, I think that is something that we want to do a good job of for stage two is actually compiling evidence to support recommendations and so forth. Recognizing that the evidence needs to be taken into account that things are changing very quickly, so it's that piece of it.

There are also some additional studies and research projects that ONC is doing that are related. There are two surveys that are going to be going out. In terms of consumer surveys, one is around privacy and security, and the other is more around general values and preferences around electronic health information.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Okay, thanks.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

I wonder if I could try to summarize some of this discussion and add a little bit of a twist to it or additional points. One is I think we want to make sure that we, just as our framework does, are targeted towards the health objectives and not the technology objectives. So with that in mind, we might want to consider the three E's. And I've added a fourth as our objective in the sense that the patient engagement objectives, and those were engage, educate, and empower. And I might add a fourth E, which would be enable, and that really just brings the patient on the team.

So with those as our objectives from this conversation, I think Christine gave us a great start in terms of what are three categories of HIT enablers to accomplishing patient engagement objectives. So one is communication, two is data, and three is incorporation out of office, out of hospital kind of data into the record. And then maybe close with some of what David Lansky was saying in terms of let's measure the outcome from the patients perspective. Let's re-orient some of our traditional thinking about quality measures and patient performance kind of outcomes, and take a patient perspective view of that.

Is that a fair sort of summary of what this discussion has been and what we would bring into our meeting when we talk about, what are we going to do in the patient and family engagement category in 2013 and 2015?

**Christine Bechtel – National Partnership for Women & Families - VP**

I like it.

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

Yes.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Yes.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay. Alright, good. Okay, so we'll make sure that we keep that and we bring it into our meeting. As I said that was tentatively targeted for September.

The next topic is to plan our hearing on disparities. Now we threw out a date of June the 3<sup>rd</sup>, which works for a bunch of folks in the office, as well as the contractor, and the hotel availability, and the interacting with other workgroup meetings, etc., etc. How does that work for folks on this call for the meaningful use workgroup?

**David Lansky – Pacific Business Group on Health – President & CEO**

Paul, just note that the Markle has an all-day meeting the same day, and I don't know what the overlap might be, but it's worth checking.

**Neil Calman – Institute for Family Health – President & CEO**

Yes, and this is Neil, I cannot make it that day. I'm speaking at a cancer summit and there's also a big community health center meeting for all of region two that day.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay.

**Neil Calman – Institute for Family Health – President & CEO**

And the 2<sup>nd</sup>, and it goes from the 2<sup>nd</sup> through the 4<sup>th</sup>. There seems to be a lot of conflict.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay.

**Neil Calman – Institute for Family Health – President & CEO**

Are there any other days that are optional?

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

The 2<sup>nd</sup> through the 4<sup>th</sup>, for example, is the 4<sup>th</sup> a possibility, Neil?

**Neil Calman – Institute for Family Health – President & CEO**

Yes, the 4<sup>th</sup> would be fine.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

And David, then that would help also with the Markle meeting?

**David Lansky – Pacific Business Group on Health – President & CEO**

Yes, no, I couldn't make the 4<sup>th</sup>, but otherwise, I don't know that there's a conflict for people in general.

**Christine Bechtel – National Partnership for Women & Families - VP**

I think we already have a meaningful use workgroup scheduled for the 4<sup>th</sup>, so that would work for me.

**Neil Calman – Institute for Family Health – President & CEO**

Yes, we have a conference call scheduled that morning.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Correct. So how does the 4<sup>th</sup> work for folks? Who's here, 15, Neil? Neil said it—

**W**

Yes, it works for them.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

So with everyone besides David Lansky unfortunately?

**W**

Yes, that's good.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

And Josh, do you have any idea or is there anybody from Altarum that has any idea what the calendars look like, whether that could be done?

**Josh Seidman - ONC**

I don't know about in terms of the location and everything, but I think we can certainly do it.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay, so we'll work on that.

**W**

Yes, we at Altarum can assist you.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Great. The faster we can turn that around, the better. Okay, Neil, would you like to lead us off on some of your thoughts in terms of how to organize the hearing?

**Neil Calman – Institute for Family Health – President & CEO**

I guess I'm not sure how to organize it, but my thought was that there are a number of different ways in which the disparities issue is going to play out. First of all, if you just play back the discussion we just had and think about the extent to which we're beginning to depend upon our thinking; not who we are, but we're thinking about HIT as a major tool over the next decade to transform the patient experience, the way they engage in their care, the way they communicate with their providers, the way they have access to their own information. Then the concern becomes like other technologies, is this something, if we don't explicitly pay attention to this, it's something that's going to leave the most vulnerable folks in our society behind.

Who are the most vulnerable folks? There's different ways of organizing this. One would be to say let's organize it around the groups of people that we're concerned about. So we're concerned about people with limited English proficiency. To me that's at the very, very top of the list. If you want to add health literacy and numeric literacy and things like that, you can really think about that at the top of the list because it affects tens of millions of people in our country.

And the fact that we're developing this capability, I think there's actually, not being a lawyer, but I think there's actually a legal issue here. Because when you think about what we're doing, there's a civil rights protection around language access. There's been suits around that. There's been lots of settlements around limited language access. And here we're creating like a whole part of the delivery system where we haven't dealt with language access. So people have to have translators when they go to an emergency room or a hospital, but we haven't really dealt with what that means.

Do they not have to have translation available when we hand them a piece of paper in English with discharge instructions or with a copy of their medical record? So I think that this is just right for some really serious problems if we don't take advantage of the opportunity we have now. So for me I think there's a whole piece around language and I'd like to think about this in a positive way. So what tools are available now that can help us sort of deal with this?

What are the health education materials that are out there now that are available in multiple languages? What about translation engines? What's the state-of-the-art in terms of translation engines that might be available to help people translate things? What are people doing about literacy, language assessments, and things like that to make sure that information is available in reasonable literacy? What are people

doing about abbreviations? A huge problem I think in starting to give people access to health information is abbreviations, and the idea that any abbreviations are allowable.

What are we doing around use of medical terminology? The ability to translate those medical terms into lay language. So I think there's a whole, you can practically do days on that, but to me that's like a whole area of concern.

I think a second area of concern would be around culture. I think technology means different things to people in different cultures. The way that technology is used in communication has different implications in different cultures. And being in New York, we see this. There are people who just don't relate to the technology piece at all and are very suspicious of the technology, and there are others who jump at it and see its benefit immediately.

I think there's the issue of people with disabilities and I'm very concerned that we're sort of creating a whole structure again. And if you think about people who are getting care at home, people who are homebound, people who have physical disabilities that limit their use of computers and information, whether they have visual disabilities or others, people with mental disabilities for whom this kind of information and the way we're talking about presenting it may not make sense. I just feel like as we're moving in this direction, not everybody is going to be able to move with us and that will create an opportunity for increasing disparity.

I think that the third category for me would be special settings. The homeless, the folks who are homeless, folks who are homebound, folks in prisons, what are the special settings in which a lack of access to this information could potentially increase disparities. Folks living on Native American reservations, folks living in other institutionalized settings, so to me those are kind of the only way that I thought of maybe sensibly breaking this down. And I'm surely open to lots of other suggestions.

**David Bates – Brigham and Women's Hospital – Chief, Div. Internal Medicine**

This is David Bates. We just did a study that looked at some of these issues empirically, which was fun and interesting. And that to just summarize what we found very briefly is we found that there were pretty substantial disparities as other people have found, just in uptick of a personal health record. But interestingly, once people started using it, minorities and those at lower SES, really liked it a lot, and did not appear to have too many issues with using it. People with multiple comorbidity were actually a little more likely to use, which I was surprised about.

I agree with everything Neil said about literacy and language, that's largely not been addressed so as best I can tell. From the disability side of things, it seems to me like it's imperative that we focus a lot on making sure that the proxy functions are really good, because there are just many people for whom it'll be hard to do this themselves and they'll need to be able to use a proxy and that has to work reasonably well.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Other comments?

**Christine Bechtel – National Partnership for Women & Families - VP**

It's Christine. I like the frame. I think as Neil, is it right to say, it's three areas language and literacy and culture, and then maybe the third is really access; which could be people with disabilities or the homeless or people who are in institutions or even people who are more sick than the average. Does that make sense to think about it in terms of access?

**Neil Calman – Institute for Family Health – President & CEO**

Yes. I was thinking of it in I guess three categories, the language, literacy, culture piece. The piece on disabilities, which I agree, I think the proxy access stuff is an important part of that. And then sort of the special settings where care takes place as sort of a separate piece because there's lots of non-traditional care settings or I wouldn't say non-traditional. There's lots of care settings other than physician offices in homes where we have to think about how people are going to get access to information and how they're going to become better engaged in their healthcare.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Can I throw in perhaps a little edits to your classification, which I thought was really good? So maybe your first category is sort of health literacy, and that's very cross-cutting, really against across the entire population, so that might stand on its own.

The second area you had was culture. And perhaps one way of classifying these or reporting on these groups is the race ethnicity and language, because those will all tie in a lot to the culture and can be orthogonal in some respects to the health literacy.

And then third, I'm sort of with Christine, is there a way to lump this into limited access situations? So whether it's some physical limitations and some kinds of disability, whether it's your access to computers, whether it's your access to, well I guess that the computers would be the homeless, the prisons, and long-term care, etc. Does that fit very well, Neil?

**Neil Calman – Institute for Family Health – President & CEO**

Yes, would you put the language piece with literacy or with culture?

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

I moved it a little bit down to culture, because health literacy is so cross-cutting. And language tends to break people up, because you can't even have health literacy issues in any language and in any culture. Yet, language is a part of, helps define the culture that you were raised in, etc.

**Neil Calman – Institute for Family Health – President & CEO**

Yes.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

It's the REL kind of a thing.

**Neil Calman – Institute for Family Health – President & CEO**

I think with the language culture piece, just my own opinion as related to HIT, I think this is 90% language and 10% culture.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

I see, okay.

**Neil Calman – Institute for Family Health – President & CEO**

Which I would agree with David based, I think the culture piece is largely defected, people are excluded based upon their language. So I would put the language piece in there. If you want to keep that as a separate category, I think that would be the primary issue. And then also because it's so technologically driven, both the solutions to it and the problem.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

So I might have one response to that. And I think what happens if you put language as a separate, some folks might think I solved the language problem, which you could even use a Google translator, I've solved the problem. And for me, there are two separate orthogonal problems, one is the language, which is one of the manifestations of a culture that you were raised in and to which your thought processes are shaped, and literacy and health domain, which as I said is a cross-cutting kind of issue. That was my own, but either way is fine.

So we seem to have three, which is nice, so we have three topical areas, and we can build three panels around those. Is that—

**David Lansky – Pacific Business Group on Health – President & CEO**

This is David. There's one other kind of angle, another orthogonal angle, I can't quite make sense of, but I'll just throw it out. If we start with the health disparities outcomes as the goal or the challenge, and we'll think less about the technology distribution and the current data settings of care and so on, and going back to our health outcomes paradigm. And we ask ourselves about the populations and settings that are associated with disparity outcomes, it might take us in another direction.

And I'm just thinking for example about mobile technologies and community farm worker clinics and all kinds of other distributional systems for health information being shared, other media, and where EHR or HIE fit into those is another question. I guess I'm trying to think if whether we could frame this more in terms of outcomes and less in terms of our perceived pattern.

Another category we haven't talked about so much is children, and the children in different settings, which has multi-layers for policy issues, as well as technical infrastructure issues. And I'm a little, I guess the challenge we always have is not too much limiting our horizon to the current state of technology distribution, but thinking more about the pathways we have to address the underlying problem.

Certainly, especially in terms of the technology platform, we know that a lot of the population is with limited access. EHR and even the desktop Internet, won't be the way to do health services to them. It'll be through other technology platforms.

**Neil Calman – Institute for Family Health – President & CEO**

Yes. I think it's going to be really important to focus on the solutions. The one thing you worry about when people start talking about this is that, people say it's going to increase disparities here. And I think the whole frame for our hearing ought to be, what do we do in the process of this rollout to make sure that this does not increase disparities? And in fact, addresses some of the issues you just raised, David.

**Christine Bechtel – National Partnership for Women & Families - VP**

Yes, Neil, I like that, or even how can we leverage this opportunity to put us on the path for eliminating disparities. I like the idea of focusing on solutions.

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

That's a great assessment.

**Neil Calman – Institute for Family Health – President & CEO**

Otherwise we just give ammunition I think to people who are not necessarily thinking about the same things we are.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

So maybe the way to accomplish that, we have our topical areas where we want to bring up the outcome oriented needs. But one of the questions we pose to people, like we've done in past panels, is identify the needs but also bring with you what are your proposed solutions? How do we overcome that, not just what are the problems?

**Neil Calman – Institute for Family Health – President & CEO**

But I think also looking for people who are developing solutions—

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Yes.

**Neil Calman – Institute for Family Health – President & CEO**

There are people working in this space. There's a lot of work going on around translation stuff. And I think we should really try to find people who are doing that and find people who are working with IT in special kinds of settings that we might not know about.

**David Lansky – Pacific Business Group on Health – President & CEO**

I would add, Paul, one theme that's not totally clear, maybe it's cross-cutting or maybe we should bracket it out as the policy category. And there are certainly some stakeholder groups if you like who see this whole issue through the lens of inadequate policy that's going to come up in the privacy area. In the area of segregating sensitive information that may be perceived to disadvantage people, mental health information obviously. And it'll come up in terms of there's some other policy categories that we'll have to address.

I don't know if you want to take that as a separate, have some witnesses who can talk specifically to those questions or if it's better to weave them through. I'm definitely worried about it because it's very volatile. And depending on how it goes, there could be interested parties who have very strong feelings about the policy environment that they believe contribute to disparate outcomes, including digital divide issues. And we have to at least anticipate there will be some public comment along those lines, kind of like the whole patient consent and control and segregation of data will come up.

Oh, Deven's happy.

**Deven McGraw – Center for Democracy & Technology - Director**

I'm just laughing, because you can't avoid it, but you're right that it's so messy. And it's enough that one group has to take it on. We do need to, and creeping up in this space too. But maybe actually as I'm thinking about it that that provides us with, there are a certain subset of these issues that the privacy and security workgroup arguably ought to be taking on. And that might give us at least with respect to meaningful use recommendations some cover for not directly addressing them. Ultimately you can't take it all on in this one set of recommendations. We'll never get to draw conclusions if we attempt to do that.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

What I'm not hearing so much is what is it we need to learn? And I guess I heard from Neil, we want to hear about solutions that we don't otherwise know about. Because our taxonomy is not intended to solve it, yet, it's to learn what we're missing.

**Art Davidson – Public Health Informatics at Denver Public Health - Director**

This is Art. I thought I heard from David that in addition to the focus on solutions that you just described, George, that we include someone who has a policy perspective on this, hopefully with some sort of policy solutions as well.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

So what does the mind feels when we try to do this or something or that's getting exaggerating there, but someone who can look at those policy issues?

**Art Davidson – Public Health Informatics at Denver Public Health - Director**

What do you mean by the policy solutions, I'm sorry, I don't really—

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Policy issues, not solutions.

**Art Davidson – Public Health Informatics at Denver Public Health - Director**

What I was thinking that based on what we know so far, have there been any progress in these health literacy, culture, and limited access? How have people with limited access whether it'd be physical or computer, how are policies developed in these areas to try to promote better access through some mobile technology or something? I don't know. I don't have an answer to this, but I think what we're trying to do is put a positive spin that we're looking for solutions, both in a technical and in a policy framework or presentation.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Can I express a concern with at least the choice of words. When we say focus on solutions, that's a bit different from the way we've been doing everything else in terms of trying to understand the issues and trying to create enabling policy through our criteria that would not stifle innovation by pre-casting such and such a technical approach as the answer. So when you say focus on solutions, certainly it's useful to be exposed to some of the approaches in solutions that are out there, but when you say focus, I hope we're not talking about something very prescriptive?

**Art Davidson – Public Health Informatics at Denver Public Health - Director**

Not at all. A positive experience.

**Neil Calman – Institute for Family Health – President & CEO**

Yes, our hearings are just that. We bring people together who are experts, and who are addressing these problems, not people who are sort of complaining about them.

**Art Davidson – Public Health Informatics at Denver Public Health - Director**

Right.

**Neil Calman – Institute for Family Health – President & CEO**

For the most part, think about the patient engagement. Aside from the two consumer folks who I think did an incredible job of just framing what the issues were, other people were people who were working in this space and trying to develop technologies and things like that and mechanisms of addressing the issues. I don't think we're trying to say that there's a solution. I think we're trying to say instead of having four people testify about how language is a barrier, to start thinking about who's out there that's trying to address these issues.

**Art Davidson – Public Health Informatics at Denver Public Health – Director**

Right.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

And maybe be more focused on and who's out there that's been successfully addressing them.

**Art Davidson – Public Health Informatics at Denver Public Health – Director**

Exactly.

**Neil Calman – Institute for Family Health – President & CEO**

Maybe that's a better word, Paul.

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

And I would just suggest maybe, this is Charlene, we want to include successfully or just addressing the issues, because if you look, Indian Health Service has a pretty powerful system. The recent study that came still shows lots of disparities there, so it'd be great to have them share their experience about what they've done with their system and how its helped or not.

**Neil Calman – Institute for Family Health – President & CEO**

I just wanted to go back to sort of the policy question again. I think there are some policy issues that we need to address. One of them, what do we expect of ONC as time rolls out to be able to sort of evaluate whether or not the rollout of HIT is addressing disparities in our healthcare system or not or perhaps worsening them?

One thing that I think I mentioned previously and also in the stuff that I sent around was just the ability to do something like evaluating the implementation rate. The adoption rate of people in safety net hospitals and community health centers, prisons, places that are very much care for disparities populations. Looking at the adoption rates of those institutions compared to the population at large. That would be sort of a policy issue I think that we would need to deal with in terms of whether or not we're serious about really monitoring this impact.

Another thing would be try to think about mechanisms for a community participation in the way that policy is being set and even the way meaningful use criteria are being set. I know that we have hearings that are open to the public and stuff and available for public comment in a real public process, but you can't deny the fact that the majority of the decisions are being made by us who are basically technologically oriented, which is why we're in the positions we're in. And to make sure that we're getting adequate community participation is another sort of policy issue.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

We probably should start working on narrowing the panels and starting to get names if we're going to have this in June.

**Jim Figge – NY State DoH – Medical Director**

Can I give one suggestion?

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Yes.

**Jim Figge – NY State DoH – Medical Director**

This is Jim Figge from New York. We're actually working on this type of project right now with New York Presbyterian Hospital. We're working with them on a 50% Medicaid population in Washington Heights, which is largely Hispanic. We're working on providing personal health records with their medication history. And already what we're learning is that it's not good enough to translate into Spanish. There are dozens of dialects and if you don't get down to the dialect level, you have miscommunications. So you've got to really understand how to provide the data in a culturally competent way.

And the folks at NYP are really working on this and coming up with solutions. So I would just probably pose that as one example of a group that's actually making some progress in terms of how do you present this technical data through HIT tools in a culturally competent way to a Medicaid population that's largely foreign speaking, not English speaking. It's much more complex in the implementation than you might think. And I think if you bring in a group like that, you would get some really good perspectives on it.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Hold onto that thought, Jim, and we'll ask you for some names actually in just a minute.

**Jim Figge – NY State DoH – Medical Director**

Yes.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

To recap, Neil, do you want to have language with the health literacy or with the culture?

**Neil Calman – Institute for Family Health – President & CEO**

I guess with the culture.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay.

**Neil Calman – Institute for Family Health – President & CEO**

But I would put language/culture.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay. So that speaks a little bit to the point that Jim just raised. Okay, so far I think we have health literacy, we have culture/language, and we have limited access situations.

**Neil Calman – Institute for Family Health – President & CEO**

I think that limited access situations thing is pretty broad.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Yes.

**Neil Calman – Institute for Family Health – President & CEO**

And it's going to be hard to make any kind of coherent sense out of it if you're looking at people with disabilities. You're looking at people who are being cared for in alternative settings. You're also looking at people with limited access to broadband, both in urban and in rural settings. I think you got a handful of stuff there that's going to be hard to kind of create any kind of a coherent message about, but we could try it, maybe we'll leave that for the afternoon and break that up into two.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Yes, that could be possible. And it's surprisingly, we had a panel of I think six on this last hearing and that still worked out okay, so it may work. Alright, so are people happy with that grouping and the last one might turn into two?

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

I think we have to just see how many people we want in each area. Do we need as much on literacy as limited access. I don't know.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Right.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Let's come up with the people and then we'll—

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Exactly right. So let's move onto the people. So in health literacy—

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Neil, who would be the person, the primary person that you know, is it Maxine or is it someone at NYU or something that's done all this EHR literacy work?

**Neil Calman – Institute for Family Health – President & CEO**

Maxine has, but I would need to do some investigation to figure out who the best people are. I wouldn't just, I don't want to just throw out a name, maybe I should have thought about this before.

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

Yes, and I think we've lost Christine. Is Christine still on?

**Christine Bechtel – National Partnership for Women & Families - VP**

I am, but you must be psychic, because I do have to go. I was about to hang up.

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

I was like, I was trying to think if there was somebody that the National Partnership knew.

**Christine Bechtel – National Partnership for Women & Families - VP**

Yes.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Christine, before you, you might want to throw out any names in any of these categories.

**Christine Bechtel – National Partnership for Women & Families - VP**

Yes, that's a good thought, and I have them, but now they're in my e-mail, because I did think of a couple folks. But we do lots of work with the National Collaborative for the underserved, but Neil, I know you do as well. But they're less on language and literacy. So let me give some thought to that and maybe we can e-mail in some names.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Great.

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

I do think on the language side that it might be helpful to hear a little bit about what are the current legal requirements with respect to making information available in languages other than English. It's not my legal area of expertise, but I think there are some laws that apply that the Office of Civil Rights, which also enforces HIPAA, their primary responsibility is also to enforce that set of requirements. And it would be helpful to know what those are and who they apply to and where the gaps are.

**Christine Bechtel – National Partnership for Women & Families - VP**

Yes. We can do some outreach to in house, the National Health Law Program, Emily Spitzer is there head, and they certainly do a lot of work in this area.

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

Yes, ...

**Christine Bechtel – National Partnership for Women & Families - VP**

Yes.

**Neil Calman – Institute for Family Health – President & CEO**

I think that would be great, because if in fact, there's some legal impetus to this, it could put some real fuel behind getting some energy into this issue.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

So it's—

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

It's just an Office of Minority something or other, so we could clearly go there. There's a woman at Brookings, Kaylan ... who's done a lot of this, at least in the race ethnicity area.

**David Bates – Brigham and Women's Hospital – Chief, Div. Internal Medicine**

Alisha Scott Wright, she's did her PhD with me, focusing in this area.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay, if you could send that name in.

**David Bates – Brigham and Women's Hospital – Chief, Div. Internal Medicine**

Sure. Who are we sending them to?

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Josh, do you want to take lead in Judy's absence?

**Josh Seidman - ONC**

Yes, sorry, what was that last comment?

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Do you want to take some of these names down as we get them and then people can forward in names to you and Judy?

**Josh Seidman - ONC**

Yes.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay.

**Tom – ONC**

Paul, this is Tom at ONC. Francesca Gany, NYU, has done a lot of work on simultaneous language translation during the point of visit. But she's using technologies other than the EHR, if you want to focus on that.

**Neil Calman – Institute for Family Health – President & CEO**

They're doing stuff mostly with telephone, right?

**Tom - ONC**

Yes.

**Neil Calman – Institute for Family Health – President & CEO**

Yes, it's about simultaneously telephone translation.

**Tom - ONC**

Yes, it's pretty innovative. And then, there are, Neil, Jeff Caballero knows a lot of the Community Health Center folks within AAPCHO that are doing patient education materials that have different types of languages, especially API languages. Some folks in Hawaii and then even Charles B. Wang has been producing a lot of different types of patient brochures and stuff that print directly from the EHRs.

**Neil Calman – Institute for Family Health – President & CEO**

Does anybody know anything about people that are working on like computer translation?

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Yes.

**Deven McGraw – Center for Democracy & Technology - Director**

Yes, I could find, this is Deven, I could ask around CDT as well. It seems like there was an NPR story on that very issue just like a few days ago.

**Neil Calman – Institute for Family Health – President & CEO**

...

**Deven McGraw – Center for Democracy & Technology – Director**

...

**Neil Calman – Institute for Family Health – President & CEO**

—on stuff. And there are different methods like replacing the words ... and stuff ...

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

It's great for people to be submitting names. I think it would make the process even more efficient if you wouldn't mind when you submit a name, if you could just put a little annotation about what's the particular expertise or contribution this person would make; that will help the rest of us as we look at a list of names, understand what their background is.

**Neil Calman – Institute for Family Health – President & CEO**

I thought we were starting with the health literacy piece, but it seems like we've kind of morphed into the language area. Is there anybody who knows about the use of technologies to help with promoting health literacy or numeracy or methods to help people get past that?

**Charlene Underwood – Siemens Medical – Director, Gov. & Industry Affairs**

Yes, I think Don Kemper at Health Lives. They just won an award and I'd have to go look at what it is, but it is related to this issue. So let me, and Josh, you may know about that because you worked a lot with Don, but I can forward the information in an e-mail.

**Deven McGraw – Center for Democracy & Technology - Director**

David Lansky, is he still on?

**David Lansky – Pacific Business Group on Health – President & CEO**

Yes, I'm here.

**Deven McGraw – Center for Democracy & Technology - Director**

From the payer view, is there any experience. There is clearly a lot of diversity the payers had to deal with, any experience in that space? I know it's a little off track.

**David Lansky – Pacific Business Group on Health – President & CEO**

You mean payers or purchasers in this case? You mean a health plan particularly?

**Deven McGraw – Center for Democracy & Technology - Director**

The health plans.

**David Lansky – Pacific Business Group on Health – President & CEO**

Well, I'm sure. We could certainly get one of the Medicaid plans, which have a huge diverse populations would be worth involving.

**Deven McGraw – Center for Democracy & Technology - Director**

Yes, because they've been doing, again, they vary, but a lot of outreach too with their technologies too to get patients engaged.

**David Lansky – Pacific Business Group on Health – President & CEO**

Yes, we can certainly ask Charles Kennedy to point us in the right direction among the plans. And some of the big Medicaid plans like in Los Angeles County might have some interesting things to report.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Other suggestion in either of these areas, health literacy, language/culture?

**Deven McGraw – Center for Democracy & Technology - Director**

Again, I think we should use the opportunity to see if either the VA or Health Indian Services has experience in this space because of their culture. They've got a lot of diversity they deal with. I know Linda is not on the call, but I think she'd be a good resource to find out from.

**David Bates – Brigham and Women's Hospital – Chief, Div. Internal Medicine**

Sure. Yes, Tom Sequist has done a lot of work with the Indian Health Service.

**Neil Calman – Institute for Family Health – President & CEO**

Yes, he's good.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Who's the woman who did the BVIA?

**David Lansky – Pacific Business Group on Health – President & CEO**

Cynthia Soloman.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Yes, that's correct. I think she might be able to help us there too.

**David Lansky – Pacific Business Group on Health – President & CEO**

Yes.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay, what about the mega group of the limited access situations, whether it's disability or special settings or children, that's a limited access situation?

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

There is a research project that CMS and ARC are doing right now on the development of a model EHR format, and they have started that work. So they may have collected a lot of information and I can get feedback on that.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay.

**Neil Calman – Institute for Family Health – President & CEO**

I think maybe we should reach out to some of the patient advocacy groups. Folks that represent people who are visually handicapped, disability advocates, and see if anybody is doing anything in those areas. I guess we need to try to identify what some of those organizations would be. And definitely should try to find people, do we know of people who are doing innovative work with HIT in prisons or with the homeless population or anything like that?

**Deven McGraw – Center for Democracy & Technology - Director**

No, again, I don't know if the public health system might have some of this. I know there's an overarching organization. But I certainly know, and Art, I know you see this, there's certainly a lot, the safety net hospitals deal with a lot of what you just talked about.

**Art Davidson – Public Health Informatics at Denver Public Health - Director**

Right. There have been some tests with some mobile technology with the homeless populations. I could try to search around for some of those contacts. The prison populations, I don't know that the individuals in prison have access, but there are prison healthcare services that use technology. I can ask some questions of that group as well.

**Neil Calman – Institute for Family Health – President & CEO**

I think one of the keys here is the transfer of information between people that are incarcerated and the community when they leave and back and forth.

**Art Davidson – Public Health Informatics at Denver Public Health - Director**

Right.

**Neil Calman – Institute for Family Health – President & CEO**

So people that go into prison, it's like they were just born that day. They come in with no information, and there's no, I've never ever seen in the 30 years of practice, a request from a prison health system for somebody's past medical records, ever.

**Art Davidson – Public Health Informatics at Denver Public Health - Director**

Yes, and—

**Neil Calman – Institute for Family Health – President & CEO**

They come in with nothing and they leave with nothing, and that whole period of time that they're incarcerated, there's no communication. So I know that there's some attempt in the city health department in New York City to try to do some work to try to bridge that information back and forth to the community. But there must be other people thinking about this issue.

**David Lansky – Pacific Business Group on Health – President & CEO**

In California, because of this huge receivership problem and we've spent a billion dollars on the prison IT system, and they've done a lot. It's a big federated HIE model, so we could find someone. And they've really wrestled with this huge complex prison environment and a lot of cross traffic to the community health system.

**Neil Calman – Institute for Family Health – President & CEO**

Yes, that's exactly what we should look at.

**David Lansky – Pacific Business Group on Health – President & CEO**

They've probably done a lot, at least the analysis and some of the building of how to solve that.

**Art Davidson – Public Health Informatics at Denver Public Health - Director**

Yes, we have some of that in Denver as well. And there's also some work going on in the Denver Metro area about the homeless and people with mental and substance abuse problems, and trying to avoid having them cycle back into the prison system. There may be some contacts I can find and I can pass them along to Josh.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Another area we should not forget about is foster care, that suffers from the same kind of problem.

**David Lansky – Pacific Business Group on Health – President & CEO**

Yes, yes.

**David Lansky – Pacific Business Group on Health – President & CEO**

...

**Neil Calman – Institute for Family Health – President & CEO**

We should look at the people who are homeless, the homeless advocates, and see if there's anything going on in that space.

**Jim Figge – NY State DoH – Medical Director**

I know that there is a project in Boston, health record for the homeless project that's been going on for several years, and I could try to find out. David Bates, if you know anything about that?

**David Bates – Brigham and Women's Hospital – Chief, Div. Internal Medicine**

I'm sorry, which project?

**Jim Figge – NY State DoH – Medical Director**

It's a health record for the homeless project.

**David Bates – Brigham and Women's Hospital – Chief, Div. Internal Medicine**

Yes. So that's at MGH and it's been actually very successful. It makes sense that if you keep track of people and they show up at various locations, that's worked really well. It's run out of healthcare for the homeless. I don't know who the current contact is.

**Jim Figge – NY State DoH – Medical Director**

Okay.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay, so I think if people wouldn't mind either jogging some of their memories or their contacts and forwarding names onto Josh and Judy Sparrow. Hopefully with as much information that you can provide, the name, contact information, and just a little annotation on what the topic where you think they'd be appropriate. We'll try to accumulate that. Let's see today is Tuesday, and I guess try to re-post that to the group by the end of the week. Does that make sense, Josh?

**Josh Seidman - ONC**

Yes, I think we really should try to get something and—

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Yes.

**Josh Seidman - ONC**

—get a lot done by the end of the week, because we don't have a lot of time, one month from yesterday, right?

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

So if people could get their responses in today and tomorrow. Perhaps we could get it out Thursday, get some comments back in by Friday, and start messaging this to see what kind of panels we might have, and see whether we need three or four. So where we have a limited let's say a panel of three people, we could do that in an hour instead of an hour and a half, and all of a sudden that buys us some time to have a fourth group if that helps.

**Neil Calman – Institute for Family Health – President & CEO**

So I think in the early discussion, Paul, I think it was David Bates who said something about limited access in a physical versus a computer sense. Were we thinking in terms of the physical or David maybe you could comment on this, are you thinking people who were physically disabled? And have we got a group that would represent that, some sort of assisted technology? How would we ... that perspective?

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

I think he was referring to processes as well, which is another—

**David Bates – Brigham and Women's Hospital – Chief, Div. Internal Medicine**

Neil really brought this up and I think did a nice job discussing it. I think that reaching out to some of the support groups in this area would be helpful.

**Neil Calman – Institute for Family Health – President & CEO**

Okay. I'll try to get some information on that.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay, so does that sound like a good plan? We're really going to have to try to get the list turned around let's say Thursday and then try to re-post the final comments, and start clustering by Friday/Monday, so we can get invitations out.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Sounds good.

**David Bates – Brigham and Women's Hospital – Chief, Div. Internal Medicine**

That sounds good.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Alright, thank you. Any other thoughts on, okay, so let's go back to the first agenda, which was that sort of draft timeline now that you've heard about the patient engagement hearing and the disparities hearing that kind of rough plan. We have three more hearing days, a time for a face-to-face working on the 2013/2015 criteria, and move it to the full committee, get back information, and sort of finalize information for a broader public comment.

Does it still sound like a good plan? And as the plan gets finalized or firmed up a bit more, per Charlene's request, we'll certainly be getting information from the office.

**George Hripcsak – Dept. of Biomedical Informatics Columbia University - Chair**

Yes.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay, ready for public comment.

**Josh Seidman - ONC**

Yes.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay.

**Josh Seidman - ONC**

Operator, Altarum, can you call us up for public comment?

**Neil Calman – Institute for Family Health – President & CEO**

So while we're waiting, Paul, this June 4<sup>th</sup> meeting, we have scheduled the phone conversation, this would be a face-to-face?

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Correct, so this would be the actual hearing.

**Neil Calman – Institute for Family Health – President & CEO**

Okay.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

The actual disparities panels.

**Operator**

We do not have any questions at this time.

**Paul Tang – Palo Alto Medical Foundation – Internist, VP & CMIO**

Okay. Well, thank you very much to the workgroup members and to ONC staff for helping us with another call. And we have some good information and look forward to a good hearing. Thanks, everyone.

**Public Comment Received During the Meeting**

1. Has there been any discussion about incorporating a measure of SES into the EMR in order to track disparities?