

HIT Policy Committee Meeting Final Transcript August 19, 2010

Presentation

Judy Sparrow – Office of the National Coordinator – Executive Director

Good morning, everybody, and welcome to the 15th meeting of the HIT Policy Committee. This is a federal advisory committee, which means there will be opportunity at the end of the meeting for the public to make comment. It's also a virtual meeting, so just to remind members of the committee to please not put your call on hold or we will be hearing your music and also, please use your mute button when not speaking and finally, to please identify yourself when talking.

Let me do a roll call of the members. Paul Tang?

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

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

David Bates?

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

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Christine Bechtel?

Christine Bechtel – National Partnership for Women & Families – VP

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Jim Borland?

Jim Borland – SSA – Special Advisor for Health IT, Office of the Commissioner

I'm here, Judy.

Judy Sparrow – Office of the National Coordinator – Executive Director

Neil Calman? Rick Chapman?

Rick Chapman – Kindred Healthcare – Chief Administrative Officer/CIO/EVP

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Adam Clark? Art Davidson?

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

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Connie Delaney?

Connie Delaney – University of Minnesota School of Nursing – Dean

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Paul Egerman?

Paul Egerman – eScription – CEO

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Judy Faulkner?

Judy Faulkner – Epic Systems – Founder

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Gayle Harrell?

Gayle Harrell – Florida – Former State Legislator

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Charles Kennedy? Michael Klag?

Michael Klag – Johns Hopkins University, Bloomberg School of Public Health

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

David Lansky?

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

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Deven McGraw?

Deven McGraw – Center for Democracy & Technology – Director

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Frank Nemeč? Stephen Ondra?

Stephen Ondra – NeHC – Senior Policy Advisor

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Marc Probst?

Marc Probst – Intermountain Healthcare – CIO

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

LaTanya Sweeney? Tony Trenkle? Michael Weiner? Scott White?

Scott White – 1199 SEIU – Assistant Director & Technology Project Director

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

With that I'll turn it over to Dr. Tang.

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

Well, good morning and thank you, everyone, for participating in this sort of WebEx call; this virtual call. We're trying to help give you a little relief at least from the travel part of the committee meeting. We will have a lunch break in the middle. We have some report out from some of the workgroups. We'll start out with the Meaningful Use Workgroup and then move on to the Privacy & Security Tiger Team, which is delivering some of their final recommendations from work they've been asked to do over the summer. We'll then break for an hour for lunch and then resume with an update from the Enrollment Workgroup and some concluding comments from the Information Exchange Workgroup, at which point we'll conclude with opening the session for public comment.

Any other agenda items that I've missed?

Judy Sparrow – Office of the National Coordinator – Executive Director

The minutes, Paul.

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

Yes. I'm going to that next. So, I'd like to entertain a motion for approving the minutes or any changes.

Deven McGraw – Center for Democracy & Technology – Director

I move we approve the minutes.

W

Second.

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

And all in favor?

Participants

Aye.

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

And is there any opposed? Any abstentions? Thank you.

Well, then why don't we begin with a report out from a couple of very interesting hearings we had in the Meaningful Use Workgroup and Art Davidson is going to talk about the Population Health Hearing.

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

Paul, this is George Hripcsak. I am going to give Art's report. So, we actually had a great hearing. It was held on July 29th on Population and Public Health. The first thing we did was go over what is the definition of population and public health. Public health often conjures the image of governmental infrastructure. Population health is a broader term, which encompasses really what we're trying to achieve in meaningful use, not just health for individual patients, but health across the population.

We had three panels: The first one hearing input from three levels of public health—that is federal, state and county level—on their view of meaningful use and where we're headed. That was our first panel shown there. Our second panel gave us specific examples of concrete projects going on that were kind of meaningful use like as kind of prototypes of what we could do with meaningful use and public health and population health. Our third panel looked forward to the future, calling on people familiar with population and public health and where they see, A, the future and, B, specifically how we could help out in that.

So here is a summary of what we found. First of all, we noted the concept of one health. One health: That is it's not there are patients doing personalized health and then doctors doing their individual workflow and then public health workers doing their thing, but there is one health across the population that needs to be linked. That's kind of a guiding principle for what we're doing here.

Then I'm going to explain a couple of specific meaningful use criteria that was suggested. I like these suggestions. I don't want this to be taken as the Workgroup or the Committee's proposal for stage two and stage three yet. This is what just came out of the hearing. First was a send-it-to-public-health button. That is case reporting. When a doctor is seeing a case, say, a sexually transmitted disease, it's reportable. It should be easy, given health information technology, to send that to public health, not have to find the right form, fill it out by hand, mail it with a stamp, but actually have these things linked.

Second, going back—remember, this is not just a narrow view of public health, but a broad view of population health—are the dashboards for providers, including the quality indicators we've talked about, preventive healthcare status and environmental factors. Environmental factors were interesting suggestions, for example, what fast food is around that person's location. Do they have access to fresh foods that we're suggesting that they eat? Is the advice that we're giving them feasible in their neighborhood, given their environmental factors?

The third suggestion was the clinical decision support that includes information from public health. In other words, if you're seeing a patient with a dire illness you'd like to know what outbreaks have gone on in your community and that should be coming from public health.

Fourth, reporting on the ability to download immunization data, that's closing the link. In other words, we already have a provision for being able to upload immunization data, but now, can that doctor when they're seeing a patient, download the immunization information to act on it appropriately. Of course, that's contingent on both, the doctor doing it and the infrastructure being there on the public health side. We recognize that.

We heard about the population health record or popHR that informs healthcare workers and clinicians about local disease rates. That was a wonderful presentation. Quality metrics with allowances for patient co-morbidities and tracking trends; the concept of bi-directional flow, which I just mentioned, like for immunizations. By the way, we consider an early win of linking public health and primary care might be something like newborn screening. We talked about that a little while.

We talked about the need for national data standards, especially the use of CCD as a common medium and the use of LOINC for vocabulary. It was pointed out during the panel that the standards for public health reporting really need to be vetted with the public health community. In other words, we shouldn't be going forward blindly since there is work going on that side.

We talked about how to create a truly longitudinal record, including clinical care, vital records and care delivered from within public health departments. Remember, we want the whole record. What the providers provide is one part, but public health provides another statement of that for certain populations.

We talked about occupation as a key risk variable to assess risk. We talked about the importance of addressing both privacy and maintaining public trust and on patient identification, as they go from a newborn on through their life. We talked about a next generation healthcare system that pulls together personal health records and public health and that goes back to the concept of one health.

And finally, although it's not within our mandate exactly, we heard over and over again a plea for public health informatics funding and for a move away from ... funding. In other words, now a days a lot of the way that public health funding comes about, it's for a specific disease. So you get an IT solution for this disease and an IT solution for that problem and an IT solution for that other problem and those may not link. If we have a coordinated funding we could have an IT infrastructure that serves all of the needs.

So that's my summary of the panel. Is Art on the phone?

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

Yes. Hello, George.

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

Do you want to add to that?

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

Well, I think you did a nice job. The main thing right now is that we are trying to review everything and come up with some concrete ideas, going back to some of the panelists and some of the others in the public health community to help give us a good set of proposed criteria for us to work on for stage two, but I think you did a nice job.

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

Any comments from the committees or questions?

Michael Klag – Johns Hopkins University, Bloomberg School of Public Health

I wasn't at the meeting, but I too like the summary. Just one caveat; that the concept of one health, that's a term that's used a lot to describe emerging diseases and the link between animal health and human health. The AVMA has a whole one-health initiative, so as the Committee moves forward they might want to think of another term that might not create confusion to describe that link between clinical care and personal wellness and public health.

Christine Bechtel – National Partnership for Women & Families – VP

I see the discussion around the population health record to inform health workers and clinicians about local disease rates and then I'm also looking at the ... one around dashboards for providers, quality indicators and I ... if the population health record is something that is separate from that EHR as people are envisioning it or if it should really be a function within—

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

Maybe I'll take a crack at that, George. So I think the way that Gib Parrish, who made the presentation about the popHR in his recent article in *JAMA*, it's more about a record that serves the public health worker rather than the professional, who's seeing a patient at the moment. That discussion kind of led into what would a professional seeing a patient want to know and how might that popHR help allow that clinician to see what's going on in their community. So one of them is directed more to the public health worker and the other is directed more to the clinician, who's seeing patients in his or her office.

Christine Bechtel – National Partnership for Women & Families – VP

That's great, Art. Thank you. That's very helpful.

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

Other questions or comments? Well, thank you to both, Art and George in terms of the Workgroup report out.

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

Also, Paul, thank you to Jim Figge and Laura Cohen, who were co-organizers of that hearing I should have mentioned.

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

Yes. Thank you. It was a rich hearing and all of this information is going in as input into the development of a draft for stage two and three on meaningful use criteria.

The next hearing we had was on care coordination and David Bates led that one.

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

So the hearing that we had was also a really rich hearing and there was a diverse array of perspectives that were presented. We had three panels. The first one focused on current support of care coordination by health information technology. The second one focused on transition in care coordination and all of the issues that relate to that. Then the third focused on care coordination in the ambulatory environment.

The overall assessment of the current status was that there were major gaps between what the electronic records today support and the key needs of practices and that was especially true for those focusing on practices, which are working on enabling team care, especially medical homes. But there is also enormous evolution that's going on today in how these practices are being managed, so vendors can't really be expected to support things that are not even well defined at this point.

We have reports from several groups that are leaders in this area, including a very innovative practice from Delaware, another practice from Mayo, another report from Geisinger and that information was really helpful. It came out that there are a number of minor issues with the electronic records of today, which people felt can be addressed soon, but this is, as noted above, going to be an area in which additional change will occur and so what we ask for will have to evolve over time.

The key functions of electronic records for care coordination were proposed by Ann O'Malley, et. al from the Center for Studying Health Care Systems Change based on a study that they did of about 15 electronic records to be reconciling medications, tracking laboratory tests, communicating across settings and mediating care plans between disciplines. All of those issues presented a problem given today's records. Namely, many of the records don't have good tools for helping providers do medication reconciliation, tracking of lab tests can be a challenge.

Often, the links between settings are not present or could be better and there was not even often a place to put care plans so that they could be shared between disciplines. So the key domains in electronic records were proposed to be medication based care, problem lists, the progress of the patient over time and then population oriented tools and all of these areas had room for improvement as well, as will come out in a minute. Some of the other key activities in care coordination that came up throughout the hearing included referrals, which are very important, consultations and then care transitions.

There were a number of recommendations that were made that, again, as I would frame things in the way that George just did on the population health hearing, not that these are ready to be stage two or stage three criteria, but these are some initial thoughts. One that came out and was put forward by multiple panelists was that we need to have the ability to support an interactive and longitudinal care plan. Many records don't have a way to do that other than to post something as a note and it's not obvious what it is or that it really should be a key organizing tool.

Second is that we need to be able to track who is on a care team and then share that information with the patient. Again, the current ability of records today to do that is somewhat variable. A particularly important part of that is to display and record for all patients who is the primary care provider and to share that with the patient so that that can be kept up to date, because it's so important for coordinating care. Second was tools to aggregate either data or messages and then be able to send them to all who need it.

The next sets of overarching recommendations were the need to support medication reconciliation, including at least the four following main functions: First, the ability to import medication data from other sources, like fill data. Second: to be able to display and to compare medication lists. Again, it's really hard to compare medication lists today. Third: to be able to order medications. Fourth: to be able to document the information.

In addition, a key need is to improve the information that's exchanged at transfers and one external standard that we might be able to point towards is something called the transfer summary document, which includes roughly 9 to 11 elements, which are in the care transitions performance set. This has been developed for discharges. The recommendation was that we support that and in addition, that we not only provide the summary, but also make sure that we can confirm that it was actually received by someone. There was also strong support to ensure that this include advanced care directives, which are often not passed across settings.

Then there were a number of specific recommendations. Included in this list was, first, the need to support longitudinal views. Most of the records today really do not make it easy to figure out what

happened to the patient over the course of things, like admissions and that should include the discharge diagnosis.

A second issue we came up with was many records today don't support the ability of multiple providers on a team to write notes and document simultaneously and that is just an enormous practical issue. That's something that we should probably think about making our requirement reasonably soon.

Another was to support the ability to designate who ordered a medication and who is allowed to refill it. That can be complicated and many records don't do that today. Another issue that came up was that referrals should include the question to the consultant. About half of referrals today do not in some evaluations.

Another thing that was felt to be an important value-add would be to make problem lists sortable and searchable. Many, again, today are not. Similarly there was a request to make the medication list sortable by organ system. It turns out to be very useful, for example, to be able to see what cardiac drugs the patient was on before and afterwards.

So, to wrap up, the conclusions were that the electronic records today do not support needed care coordination activities well, but as I noted before, this really varies an enormous amount among practices, so it's not something that vendors can be expected to do. That being said, there are some specific things that can be helpful. Doing well in this area broadly we believe will be central to improving efficiency, safety and quality and really getting to where we want to go with meaningful use. As I've noted, a number of specific items can be targeted for 2013, but evolution will be needed and this does, we believe, represent an important area for further research because there is so much evolution that has to occur.

I'll stop there. George or Paul, do you have additional comments?

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

No. I think both of these hearings were eye opening in the sense of even through our professional training, whether it's physicians or nurses or all clinicians. We've been trained to focus on individual encounters, almost individual days in the hospital or individual encounters in the out patient setting and when you think about the broader ramifications that can happen, the implications of having an electronic infrastructure and ability to share your eyes open wide with respect to whether its population or what David just talked about, which is this whole care coordination and all of these things are so obvious and of such obvious importance it seems like we really could benefit from moving the country and the products and the ways we think, down to the professional training, in this direction.

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

Agreed. Very good.

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

So are there comments and questions?

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

My question, I guess, for David first is this is an ongoing challenge and probably will be a greater one in stage two and three, but as we think about the purpose of the meaningful use criteria and the care coordination goals— For example, it seems to me that we're learning a lot as we do these kinds of hearings about the specific functions, which would improve care coordination like how we sort the medication list, for example. But also, that's the kind of thing that you probably wouldn't want to prescribe to vendors. It's the kind of thing you would expect the market to do innovation and continuous improvement around usability and features and functions.

So I think it will be important for us to sort of distill out of these hearings what are the quality and safety enabling functions at an almost generic level that we might want to incorporate in as a criterion for meaningful use or as a quality measure, for example, medication error avoidance, that we might want to measure and have reporting on for meaningful use, which would trigger vendor and market and workflow

innovation, like how we display and sort medication lists that support better care coordination. I guess I'd ask our Committee to think about sort of inferring from these hearings what those higher level metrics are that we can instantiate to drive continuous improvement in the provision of EHRs.

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

Yes. I think it's challenging to sort out how granular we should be and I agree that we shouldn't be too prescriptive. I do think that it might send a helpful signal to the market to say that medication lists should be sortable by condition rather than how you do it. I certainly wouldn't want to get to that level of granularity.

Similarly, the thing about multiple providers being able to write things at the same time that may seem like a fairly basic thing, but it was a real problem for some of the practices that were trying to do this sort of work.

M

And also, let's say this shared care plan, I think as David mentioned, actually, I doubt just because physicians don't think of a care plan the way nurses do, I don't know that I've seen a "care plan" that crossed in the ambulatory care setting that even for a patient, let alone shared across to multiple practitioners who work with a patient. So that concept seems very eye opening and how you implement it, of course, is up to the individual vendor, but that seems like one of those overarching things that really underpins good care coordination.

Would you agree with that or where do you think that fits in terms of the granularity of functional specifications? I guess I was responding to David Lansky's—

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

Let me go first. I was thinking the shared care plan and the ... health work ... the tool and the issue raised for me actually was in our hearings so far how are we looking at the patient, family and caregiver support for care coordination. I think David mentioned the opportunity to provide some of the same tools to the patient so that they're an agent of their own care coordination. I guess I hope they'll factor that in. That seems to me that is kind of the level of granularity I think we do want to address in our proposal going forward.

Rick Chapman – Kindred Healthcare – Chief Administrative Officer/CIO/EVP

I'd just like to comment along the same lines as David Lansky. I think the longitudinal aspect of the record has similar characteristics to what we're talking about that may lend themselves to not being meaningful use specific, but vendor differentiators and specific provider approach to how they practice differentiation. So I think all I would ask is that the meaningful use group just consider as we listen to these various recommendations, which should be specific to meaningful use and which should be optional or differentiators by vendor.

Gayle Harrell – Florida – Former State Legislator

Well, again, I want to reiterate the need of specialists in this whole thing. Most of what we've discussed this morning has certainly talked more in the lines of internal medicine, general medicine, public health departments, things of that sort, but if we're talking about how we're going to really design an electronic health record and push vendors in that direction, which is, I think, what I'm hearing through the definition of meaningful use, please, let's remember that we want everyone to have electronic health records from all of their providers. Let's not get too specific or let's not just consider general practice. Let's make sure that we don't push and continue to push specialists out of the realm of electronic health records.

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

First of all, David Bates, thank you for the summary. I do think these specific recommendations that you have, and we understand they're all sort of informal at present, represent some important steps that would be helpful to any health professional, specialist, primary care, nurse. This is about care coordination. I think the meeting that we had allowed us to hear how that would help across all of the

transitions of care. I don't know where the Committee should be precisely in terms of the granularity, but right now I think this is on a good track, at least I believe what David Bates has presented is on that track.

M

Let me drill down a little bit on this just to make sure we're at least understanding each other, if not on the exact same page, the notion of granularity. So let's look at the shared care plan. Gayle, would you say that the specialists should both, have access to and contribute to a shared care plan? That's the first question.

Gayle Harrell – Florida – Former State Legislator

Oh, I would absolutely agree they need to have access to a shared care plan. They need to have some knowledge about what else is going on with the patient. However, what we've done and the core recommendations that's ... in this definition of meaningful use certainly make it very difficult for many of our specialties to participate and as we go down, as we're moving down the list, every discussion in the direction seems to be, again, down that primary care road, which absolutely is important, but we need to have some conversations in how we do this to make sure that all aspects, so we do have a shared plan and that all of the other specialties come into play on this. I didn't hear that in any of the conversation.

Charles Kennedy – WellPoint – VP for Health IT

I want to also support the notion of a shared care plan. I think when we look at how medicine is practiced we see lots of opportunity for ..., resolution and conflict, the very things that physicians are doing, who are not sharing information currently. So I look at sharing a care plan as a next, very compelling step even beyond just sharing basic information. I do worry though that if we stay too high level in our recommendations there may be a lot of issues. For instance, where might that shared care plan sit? I'm challenged to see how multiple EMRs all operating independently could share a care plan or at least I'd say there are lots of issues in trying to figure that piece of it out versus maybe having it held centrally at a health information exchange. So I think at some level we're going to have to be cognizant of what the implications are of that recommendation.

Then the second point I'd like to make is when we look at the recommendation around sorting medications by condition; you all know this; multiple indications for many particular medications and so sorting that out will require many of these vendors to get much more sophisticated in the data management space, which most of them are not too sophisticated in at this particular point in time.

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

Regarding the latter point, it's not trivial to do it, but we've been able to do it, for example. It took some time and effort, but it's enormously useful. We don't always get it right either, because many drugs do have multiple indications.

Charles Kennedy – WellPoint – VP for Health IT

Yes. Yes.

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

Other comments, either on the hearing and the recommendations or specifically on the level of granularity for meaningful use criteria and objectives?

Neil Calman – Institute for Family Health – President & Cofounder

I guess I have a concern that we're like trying to train for a marathon before we've learned to walk. Clearly, shared coordination around patients is a critical issue, but I mean as we're going to hear, I think shortly, the issues of just how to get information from one point to another is sort of where we're at at this point. We don't really have a general model for what a care coordination plan even looks like that's accepted on paper or that's used broadly. I think this is something that's done differently every place you go.

I guess I just want to remind us all that what we're looking for, the tool we have at hand really is a tool around meaningful use, is a tool of providing incentives for providers. We've used that to signal what we

think the vendors should be working on, but we got a lot of push back in the last round by people saying there is lots of stuff that we either don't, can't do now or that the vendors don't provide for us.

So I think on the issue of granularity, I think it's really important. I mean I love these kinds of discussions about what we should be doing and all of the great things that IT could enable us to do, but I think we sort of learned the last time that what we should think about is what are the very specific things that we're going to signal for providers so that we can start signaling those things to vendors. I think we need to get very granular about what specific recommendations we might want to make.

I also just want to remind us that we should look at things for which we know that there is some real payback, where at least we think we're generating dozens of ideas, where we think that there's real opportunity to improve patient safety or quality of care.

Stephen Ondra – NeHC – Senior Policy Advisor

Yes. I want to echo that we should not only signal a long-term vision, but have near-term deliverables and achievable targets defined in a very granular way.

Neil Calman – Institute for Family Health – President & Cofounder

We have a very short period of time in which to put those out and start to get people giving us feedback, even informally on that. That's why I'm suggesting that we get pretty granular pretty quickly and say here are some of the things we're thinking about, like we did in public health, that we could actually ask people to do that we think have real impact and that we should be moving towards.

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

Good comments. Other comments or questions?

Scott White – 1199 SEIU – Assistant Director & Technology Project Director

David, just a quick one: You mentioned that there is enormous variation. What would account for that? Is it the difference in the EHRs themselves or best practices? Can we learn from some of those variations or the positive variations, I should say?

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

I think it's really more the latter. I mean it kind of gets back to what Neil was just saying in that practices are doing this in very different ways today and there hasn't been convergence on sort of one standard best way of doing it.

Scott White – 1199 SEIU – Assistant Director & Technology Project Director

Can we collect some of those or do we have an ability to get that information out? I don't know if it's a ... or whatever, but can we learn from others' experiences?

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

Well, I think we got some good information in this hearing actually about some of the organizations that are doing this reasonably well. We can certainly draw from that, but even amongst the very best places there is still a good bit of variation in the way that we do it, so I don't think we want to be, on the one hand, too prescriptive, but I do think we need to send some signals. For example, everybody talked about the importance of supporting an interactive and longitudinal care plan, even though I agree with Neil that we don't know exactly what that should look like.

Scott White – 1199 SEIU – Assistant Director & Technology Project Director

Thank you.

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

If I am digesting the comments correctly, I think people are saying that there are some areas where functionality does not currently exist and that in the context of this program, the meaningful use incentives, we would like to make sure that gets covered by the 2015 criteria, as an example, not that ONC, as they signaled, can't have other future phases, but that we should also have very concrete and

granular short-term criteria to make sure that we can be very specific about what needs to be done in the shorter-term, which in our frame, is 2013. A couple of the things that have come up that seem to me that they're longer-term, but we do want to get in by 2015 have to do with this longitudinal shared care plan that's primary care and specialists and patients and medication reconciliation.

Have I captured that correctly in terms of a sense of the group? Because I want to use this to go into our September meeting for the Meaningful Use Workgroup to come out with a draft that we will be placing before you the next meeting.

Neil Calman – Institute for Family Health – President & Cofounder

Just one more thought about the care coordination: I mean I think in real integrated systems there's probably a first order approach to this in real integrated systems where the majority of prescriptions are filled in the same place, where most of the people that a patient is seeing are all working for the same organization, multi-specialty groups and other stuff. I think then when you bring it up to the next level where those folks are all working in independent practices in different locations then we're sort of in a totally different realm.

So I guess my sense would be that if we're going to approach this in a way to signal something we ought to sort of look first at the real integrated systems where we're not dealing with all of the issues about how we get information, issues that we haven't even solved in the simplest sort of how do you get a consult from one place to another. If we're going to start looking at that, why don't we try to look at that within systems that are really substantially integrated and where the issues of health information exchange don't complicate it and then see if there's some good models there that maybe we could then bring to the next level and say now let's look at how those things work when all of the folks are not working within an integrated delivery system.

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

It's a good point.

Christine Bechtel – National Partnership for Women & Families – VP

I guess I agree with Neil at first, but I would also then suggest that the Workgroup back it off of there. My concern about putting too much stock in 2015 is that, as we all know, the incentive money in 2015 is negligible compared to the earlier years and so I'm thinking about ways that we can, as Gayle suggested, be realistic about capabilities, but also drive some forward progress.

So I think we ought to know ahead of time. There are some quality measures around the documentation of the presence of a care plan that I believe are NQF endorsed and we ought to look at the range of those, but also I think what are the key elements of the care plan and what standards might exist and whether we need to pull in the Standards Committee and ask that they do some work on this as well, but I'd rather really focus on how we can sort of carve out some concrete elements of some of these most important things and use some key drivers today to build some focus into the 2013 criteria.

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

Good point and I think it is possible to strike a balance in terms of what a provider in different kinds of settings, as described, has to comply with. We also remember that when we have a meaningful use criteria that translates into some standards that translate into certification requirements. For example, the more separated groups that Neil talked about in the second group can potentially be virtually linked if the EHRs are using support for that kind of function and so that's part of the benefits of creating some kind of meaningful use objective in some criteria that gets translated into EHR certification, so it makes it available if you

Anyway, this has been a very rich discussion. I'll ask for any final ones, but I'll point out that this information, both from the hearing and from the comments from the committee as sort of signals for the Workgroup will be used in our September 22nd meeting when we meet face-to-face to try to start working on the drafts for the 2013 and some of the 2015 objectives and criteria. We'll be bringing that forward to the full committee again in September and our longer-term plan is to go out with an RFI towards the end

of this calendar year so that the public has more opportunity, somewhat like we did with the very original framework to give public comment.

We'll digest that, as well as start getting information from CMS and ONC on what the activity and response to the 2011 phase one, stage one criteria and enrollment, the registration process and how they're responding. We'll try to put all of that together in an anticipating more like a springtime final recommendation to the full committee for its endorsement. We're sort of trying to lead, get information to ONC from its advisory committee as it prepares its NPRM for the stage two criteria.

Christine Bechtel – National Partnership for Women & Families – VP

Do you think it would be possible before our September 22nd face-to-face for staff to begin exploring if we take all of the key lessons that we've learned across all of the hearings and some of the functions and objectives and measures that we've identified to do some of that homework around where the quality measures exist, what's realistic, what needs to happen, sort of environmental analysis around those key elements?

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

Yes. Part of our briefing will be a summary of our previous hearings and you mentioned quality measures and actually, NQF working with ONC is preparing exactly that kind of document going in, so what exists, what's in the pipeline, what could be retooled, what are the kinds of measures we could draw from, at least as they exist today. So that will be all part of your reading material. Any other final comments on the two hearings from the Meaningful Use Workgroup?

Charles Kennedy – WellPoint – VP for Health IT

I have one last comment, which is there was a comment made earlier about looking for some low-hanging fruit or quick wins. One thing I didn't see is the health plan industry has invested billions of dollars in ... based disease management, largely not as effective as it should be, in part because of the specific information sharing issue, so in terms of looking for a quick win, including the health plan and I recognize the privacy and security issues, but assuming we get over that, including some of those disease management opportunities, I think, could offer some very tangible quick wins in the short-term.

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

I think we're ready to move on to the Privacy and Security Tiger Team report. They're going to be presenting a letter that they would like to have our input on and if all goes well, with some edits, would actually like an approval for the letter, a draft of which—and by the way, that is a draft—you received to be forwarded on to the National Coordinator. Deven and Paul Egerman are going to present.

Deven McGraw – Center for Democracy & Technology – Director

Yes, all of you should have received that letter. I'll be optimistic and say that it is our hope that you accept these recommendations that we have in the letter today. So this is more than just a presentation of a draft for input, in fact, many of these recommendations are ones you've seen that we've tweaked a little in response to previous comments that you all have given us that have been really helpful. There is a bit of new material that you haven't seen yet that we will talk about, but all in all, our end game here is to get an acceptance of recommendations, either as written or if there are modifications that we need to make in order to get them approved then so be it, but that's our goal just to lay the ground work there.

I want to say at the outset that we want to thank our Tiger Team members, which are up here on the slide. We've talked about this before and the schedule that we asked each one of these people to commit to. Quite often there were two phone calls a week at three to four hours a pop. This is difficult material to get through, so I don't think it's an over statement to say that these recommendations have a bit of blood, sweat and tears on them, but nevertheless, I think that we did an excellent job under the constraints that we had and we are very eager to be presenting them to you today.

I also want to thank Adam Greene and Joy Pritts and Judy Sparrow, Joy and Judy from ONC and Adam Greene, who is with the Office of Civil Rights, for their extraordinary support and help, assistance to the Tiger Team in our deliberations. There were, quite frankly, lots of times when we were conflicted over an

issue and either Adam or Joy would come to the rescue with an answer that was already something in the law and it just allowed us to move forward and that was incredibly helpful. Of course, Judy is the glue that holds all of us together and we wouldn't be sitting here today without her, so I just want to provide those thanks.

Paul, I don't know if you want to add anything before we get right to the substance of the letter.

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

No. On behalf of David, who—

Deven McGraw – Center for Democracy & Technology – Director

Wait, Paul. Different Paul. Paul Egerman. Then you can talk, Paul Tang.

Paul Egerman – eScription – CEO

I think she meant me, Paul.

Deven McGraw – Center for Democracy & Technology – Director

Paul E.

Paul Egerman – eScription – CEO

I just want to echo what Deven said. I mean we asked an awful lot during the summer from this group of people and they really delivered. Literally hundreds of e-mails and a lot of very good thoughts; we're most appreciative of everybody's efforts, especially, as Deven said, Adam Greene, Joy Pritts and Judy Sparrow. Really excellent.

Deven McGraw – Center for Democracy & Technology – Director

Paul Tang, if you want—

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

Go ahead. I mean I just wanted to echo the thanks because I just know how much time this was and how hard of issues these are. There are a lot of states in the rest of the country interested in having some of these issues dealt with, so thank you for your time.

Deven McGraw – Center for Democracy & Technology – Director

So here is a little agenda of what we're going to highlight in the presentation that Paul Egerman and I are making today. As I noted, we put together an extensive letter of recommendations. It's 18 pages and it's really the culmination of all of our work over the summer. We focused in particular on questions that had been raised by ONC that needed to be addressed over the summer and that was the rationale for the intensity of the schedule.

Most of the recommendations in the letter are ones that you have seen in previous meetings. In some cases the letter refines the recommendation in response to some suggestions that you all had made and overall it presents the recommendations as really a coherent package, so we're going to review the high points of the recommendation letter with a particular focus on items that you haven't seen before or areas where you raised a fair number of questions or issues in the past.

Just to give you an overview of the layout of this presentation, we'll talk a bit about the scope of what our recommendations cover; a core overarching recommendation, which is really more overall to exchange within the scope of disclosures that we were focusing on; a set of core values that are really the foundation for our recommendations, in particular the ones with respect to patient consent; triggers in meaningful consent and the extent to which we distinguish directed exchange and the circumstances where we recommend that patients' meaningful consent be obtained for health information exchange; granular consent and in particular, where we are from a technology standpoint with respect to the ability of electronic health record technology to support patient consent at a more granular level and then some conclusions to put it all into perspective. So that's the layout of what you're going to see today.

To start with we want to make it very clear and we've made it very clear in the letter that the recommendations of the Tiger Team from this summer's worth of work apply to electronic exchange of patient identifiable health information among known entities to meet stage one of meaningful use. You've seen this diagram before. It's the most graphic that we get on these slides, quite frankly, and it underscores that we're focusing again on the exchange for stage one and there's a lot of exchange of information that we just haven't gotten to yet. It includes patient access, access to information for research purposes, claims and payment processing. It's not that we don't believe that there are issues that need to be discussed in those categories of exchange, but we focused on stage one because that is, quite frankly, the focus of ONC with respect to the incentive dollars and it's a good place to start if you're going to lay down some foundational recommendations that you can then build on to address some of the questions that come up in these other areas of exchange.

Here are the specifics of issues and questions that we addressed in our letter. The use of intermediaries or third party service providers in identifiable health information exchange; the trust framework to allow exchange among providers for the purpose of treating patients; the ability of a patient to consent to participation in identifiable health information exchange at a general level, i.e., yes or no; and how this consent should be implemented; the ability of technology to support more granular patient consent, such as the authorization of exchange of specific pieces of information while excluding other records and then a set of additional recommendations with respect to exchange for stage one of meaningful use. That is treatment, again, quality reporting and public health reporting. Again, as you'll see, the recommendations actually in one, two and five are all ones that you have seen before and we'll spend less time on them in our presentation today.

Starting with our core Tiger Team recommendation— And this one should look familiar to the committee, because we've presented it before, but it bears repeating. We think it's a very important, over arching, general recommendation that all entities involved in health information exchange should follow the full complement of fair information practices when handling personally identifiable health information. For those of you who read the letter, you noticed that for each set of recommendations that we make we actually map them to the applicable start information practice principle that we think that set of recommendations aims to at least partially address.

The formulation of the Fair Information Practices, sometimes known as FIP, comes from ONC's nation wide privacy and security framework for electronic exchange of individually identifiable health information. ONC released this late in 2008, but it was also more recently adopted by the Policy Committee as part of the strategic framework document that we all remember discussing.

Now I want to talk about the core values that, again, are the foundation for our recommendations in this letter and particularly those related to consent. The first is that the relationship between the patient and his or her healthcare provider is the foundation for trust in health information exchange. This is particularly true with respect to protecting the confidentiality of personal health information, so no matter what you say about whether that trust relationship holds up in all contexts in healthcare it certainly is the most true when you talk about what the patient expects with respect to protecting confidentiality for health information.

The second core value is that as key agents—and it really follows from the first core value—as key agents of trust for patients providers are responsible for maintaining the privacy and security of their patients' records. We must consider patient needs and expectations. At one point in our deliberations, you all may remember, we called this the Paul Tang principle and we added to it in the Tiger Team, so maybe this is the Tiger Team corollary. Patients should not be surprised about or harmed by collections, uses or disclosures of their information.

The last core value is that ultimately to be successful in the use of health information exchange to improve health and healthcare we need to earn the trust of both consumers and physicians.

Moving on: Addressing recommendations one and two, which involves the use of intermediaries or what are commonly called third party service providers or we used the term third party service organization in

the letter to distinguish it from providers; of course, we all know who they are; and the trust framework to allow exchange among providers for the purpose of treating patients. Those are recommendations that we have previously presented to you that have not been substantially modified and so we have included them in the appendix to the slides. Of course, they are in your letter on pages six through nine, so if folks have specific questions or issues to raise with those recommendations we can certainly and should talk about them in this meeting so we can put the final stamp on them, but we don't intend to spend time during this presentation that Paul Egerman and I are making going through them in detail.

With that, the set of recommendations that we do want to spend some time on is consent and I'm going to turn it over to my Co-Chair, Paul Egerman, to talk about this next set of recommendations.

Paul Egerman – eScripton – CEO

I'm going to take you through the first part of recommendation three, which deals with consent. This is material that Deven and I did present to the Policy Committee for the most part previously and was previously accepted, but we made a number of changes to what we previously presented at your suggestion and also responded to some suggestions from the Standards Committee, so I wanted to explain what we did and what's a little bit different.

Recommendation 3.1 deals with consent and directed exchange. To refresh everyone's memory, directed exchange means information goes from provider A directly to provider B with sort of no organization or entity in the middle, sort of like faxing information except electronically transmitting. An example might be ordering a laboratory result or ordering a radiology exam or getting a referral or a consultation report.

Basically, what we said here, assuming FIPs, assuming Fair Information Practices are followed, directed exchange does not create an additional requirement for patient consent, additional beyond what may already be required in law. We realize in some states there are some laws about some situations or what has been customary practice, the concept of customary practice has been added because we also came to understand that there are some organizations that have established their own rules that are basically stronger or more stringed that require consent where we are not requiring it. Certainly, there is no intention of disrupting that, so the two bullets you see here, we're saying we are not trying to make any changes to the patient/provider relationship as a result of this recommendation and also, we're not trying to change the considerations that already exist that people might be using when they do fax exchange. So that's the concept of consent in directed exchange, so directed exchange does not require consent.

We had a few questions of what does require consent and that's what's included in our next recommendation, recommendation 3.2, which we called the trigger, as to what would create a situation where consent is required. This recommendation does not involve directed exchange. This involves other exchange processes that are possibly more complicated. When we presented this information to you before, when we presented this before, I presented six different triggers and there were a lot of questions about the triggers. You asked us to simplify it and reword it. We did that. We were actually able to simplify it into a single trigger.

In understanding this trigger one should go back to the core value that Deven just referenced of the patient/provider relationship as being the foundation of the relationship where confidentiality and trust is maintained. Basically, what we're saying is that the trigger then for requiring consent from the patient is when the electronic records are moved out of that provider's control, out of the patient/provider's control to some other entity. So here is what we wrote. I'll read it. It's on the slide. ~~When~~ the decision to disclose or exchange the patient's identifiable health information from the provider's record is not in the control of the provider or that provider's organized healthcare arrangement, OHCA," and we'll talk about that in a minute, ~~Patients~~ should be able to exercise meaningful consent through their participation."

So, if I was presenting this in person I'd be using like a laser pointer and I'd point to this thing that says, ~~Organized healthcare arrangement, OHCA,"~~ and say, ~~What is that all about?"~~ Sort of an example of one of the places where Adam Greene at OCR helped us a lot, but it's not an acronym that our Tiger Team made up. It exists within HIPAA. An organized healthcare arrangement is an expression that

relates to the various combinations of providers that work together for various reasons to offer services to patients, so integrated delivery networks, accountable care organizations, the medical home, community records; all of those things are OHCA or organized healthcare arrangements.

The reason why this is a major change, the reason why we put this into the trigger is we want to make it clear that this trigger doesn't really relate to healthcare relationships. We're not trying to talk about how the radiology department works with the cardiology department at an institution. This really relates to sort of like the non-healthcare delivery systems, the people that we all the HIOs that do the healthcare information exchange or perhaps some vendors who facilitate the exchange. This is not relating to the organized healthcare arrangement.

So this is a significant change to simplify it, to place the decision to disclose or exchange information and to clarify that this concept of OHCA does not relate to the OHCA. To try to give you some examples of how this looks and works we have three examples on this slide.

The first example is the centralized HIO model. That's a model, which is, I'm sure everybody knows, where identifiable patient data is actually retained by the organization, in HIOs, in healthcare information organizations, sort of like the entity that does healthcare information exchange. So if you have a centralized HIO model it's retaining data. It's making that information available to other parties other than the patient and the source provider. We say for that to occur that's a trigger for consent.

A second example is a federated HIO model, which exercises control. The way it exercises control is actually it may not have storage of the data, but it has linkages to where the data is located. Through those linkages it makes the data available to other providers or other entities and so it's similarly, a federated HIO model participating and that triggers consent.

The third example is sort of like a mouthful; I'll do my best to read it. It is, —Information is aggregated outside the auspices of the provider or OHCA and co-mingled with information about the patient from other sources.” So, to give you an example of that, there are companies that I would call them e-prescribing gateways, so when you do an electronic prescription you send it through that gateway company. The gateway company perhaps reformats the transaction and sends it to a retail pharmacy, but some of those companies may, for example, create a medications profile on the patient and keep track of every medication ordered from every single separate provider for the purpose of assisting with drug interactions, for example. Well, if that occurs they're maintaining a profile and making data available on the patient to other parties and so that would trigger consent.

Those are examples of what I said in the previous slide. I also wanted to make it clear when I say something triggers consent it's not to say that there's anything negative about it. All of these things offer significant value. They're very important. We're just saying from the standpoint of the patient not being surprised about what is happening the patient needs to be informed.

As you can see on the next slide, we say they need to be informed and they need to be informed in advance. So on this slide we talk about how the consent is actually applied and we say that the patient must be provided with an opportunity to give meaningful consent before the provider releases control over exchanged information. So we've got the word before in Italics and that's the main emphasis. That's the headline of this process is that consent has to happen in advance, before, for example, data can be sent into a centralized HIO.

You see the words meaningful consent underlined. We have meaningful use and now we have meaningful consent. We'll be talking about that a little bit more in a minute in terms of the actual definition of consent.

I want to explain a little bit more about what happens if the patient decides not to give consent, which is if the patient does not consent to participate in addition to the fact that you can't make the information available in a centralized HIO or a federated model HIO, the provider should alternatively exchange

information through directed exchange or with whatever other mechanism he or she wants to use, but probably directed exchange.

Then there is the third concept that's in the letter. It might be a little confusing, but I can explain it. There are some HIOs that offer multiple services and so to use the example I gave before of the e-prescription gateway, if a patient declines to give consent, decides, —I don't want my medication profile handled in that way,” you can still use that e-prescription gateway; you just can't allow that gateway to accumulate data on that patient. Similarly, some HIOs, in fact, the way a lot of these get started is they'll start sending and receiving laboratory data and as they send and receive the laboratory data they may retain the laboratory results in order to establish a database to make available to other providers.

The way advanced consent works is before they can retain any data on patients consent needs to be established. If a patient says no a provider can still use that same HIO to send and receive the data; it's just that that organization cannot retain any of the data. The purpose of doing it this way was to make it as administratively simple as possible for the provider.

Now Deven will talk a little bit more about meaningful consent attributes.

Deven McGraw – Center for Democracy & Technology – Director

As Paul mentioned, we've coined our own meaningful term, although I actually don't think we can claim complete ownership of it, but what do we mean when we say that individuals should have the opportunity to provide meaningful consent in a trigger situation before their information becomes part of a model that is a trigger model? That is, as Paul underscored in his presentation, it's time to make it in advance; that you have knowledge about what is being proposed with respect to your information and you have some time to make a decision before anything happens. Ideally it should be outside of an urgent need for care.

Not compelled or used for discriminatory purposes, again, ideally what this means here is that it's not a condition of medical services. Because we have specifically said that this does not apply to models of healthcare delivery that actually provide the care, whether it's an OHCA or an integrated delivery system or a centrally controlled provider with multiple locations, we are not suggesting that in that case the patient could say, —Well, I don't want my data to be part of a shared record system,” and then the provider would still have to treat the patient in order for consent to be meaningful.

We're really talking about the types of models where, again, these are ones that are not necessarily what the patient expects based on the traditional doctor/patient model that's the ... of trust and so it wouldn't be meaningful for consent to be applied and then for the provider to say, —Well, if you don't allow me to put your data in a centralized HIO I don't want to treat you,” so just to be clear about what we mean there.

Obviously, full transparency and education commensurate with the circumstances. What we mean here is the amount of education and the degree of time that's provided for people to make a decision, for example, should be commensurate with the degree to which the model that's on the table is different from what people expect. One could foresee a model that's pretty basic and maybe you wouldn't have to go the full mile to make sure that people fully understand it, but this is a common, meaningful consent principle, again, consistent with patient expectations and revocable.

People should be able to revoke it and it should be very clear what the consequences are of a revocation, whether it can be retrospectively applied or whether, if it's prospective only, that should be made very clear to the patient. Just to underscore, we talk about these in a little bit more detail in the appendix slides and similarly, of course, there is more discussion in the letter. We did not invent these on our own. We actually looked to some work that had been done by the Markle Foundation's multi-stakeholder, Connecting for Health initiative, which has laid out these elements of meaningful consent in health information exchange. Again, the details are in the appendix if you want to see them.

Paul, do you want to—?

Paul Egerman – eScription – CEO

Sure. Yes. Our Tiger Team was a full-service Tiger Team, so we also looked at consent implementation guidance and so we have the following guidance about how to implement consent:

First of all, we say the provider is the entity. The provider has the responsibility to educate and discuss with patients how their information is shared. That comes really entirely from the core values of the patient/provider relationship, so from our standpoint it's sort of like, of course the provider is the one who is responsible. But as we looked at this we were also influenced considerably by Neil Calman's comment at the previous Tiger Team meeting where he talked about the administrative burden on healthcare and especially on small physician groups. So what we also say is the federal government, as well as regional extension centers and HIOs and vendors also have responsibility to educate the public.

It's written out in more detail in the letter, but the federal government we think, through ONC, should establish Web sites and marketing campaigns or outreach campaigns to make sure people understand how all of this works. The regional extension centers should be helping physicians and medical groups implement all of this. The HIOs can also help in providing booklets and materials. Among all of those groups they can be establishing common formats for the consent arrangement. So the idea is to provide assistance to the providers to do this.

The third bullet here is that the question is really who has to administer all of this in addition to educating patients? Because Deven, for example, just talked about the ability of patients to revoke their consent. Well, somebody has to keep track that a patient gave consent on a certain date and then revoked it on a certain date. People can make these changes however they want and so we again said it's the provider's responsibility for keeping track of all of that. However, we're saying they can delegate their consent management administrative functions to a third party, such as an HIO. In saying it that way we're hopeful that the HIOs will provide tools or other capabilities to help.

Ultimately, what we're saying in this slide here is that the provider's responsibility is to educate and administer the consent for their patients, but at the same time, all of these other entities should be working together to reduce the burden to make it as easy as possible for the providers. That's particularly important when you look at what Deven is going to present on the very next slide.

Deven McGraw – Center for Democracy & Technology – Director

So here it is and you've all seen it before. We have spent a lot of time talking about whether the patient should have opportunity to consent for certain types of exchange and so we thought it was important to also address whether providers should have a choice about participating in exchange models. We presented this response and we thought that the answer should be yes, at least with respect to ONC's policies with respect to information exchange.

Paul Egerman – eScription – CEO

So what we did in recommendation number three was responded to, actually, question number three that ONC gave us, which had to do with consent, but it was consent from a standpoint of all or nothing, a zero or a one. It was consent from a standpoint of either I'm going to participate in the HIO or I'm not going to participate.

So question number four is can you give consent, but can you do something between the zero and the one, between the all or the nothing. Can you say I want some of my record to be exchanged? If I'm a patient can I say I want some of my record exchanged, but not all of it?

The reason a patient might want to do that is because of this concept of sensitive data. There are some issues about sensitive data and, as we say in our letter, I mean recognize that all data in an electronic health record is sensitive, but again, there are some areas that either state laws or society uses particularly sensitive areas. These are things like issues related to reproductive health, sexually transmitted diseases, domestic violence, mental health; there is a whole series of issues. So maybe patients have some of those issues in their record or maybe they have some other issues and they just don't want people to know about it.

What we did with this is, first, as you see on June 29th, we had a technology hearing and we have a fair amount of detail describing that in the letter, but the purpose of the technology hearing was to try to understand what technology currently exists that allow patients to make these determinations, to sort of say I want to have parts of my record transmitted.

We also reviewed the prior NCVHS recommendations in the prior letters and, as you can see in the third bullet, the co-chairs of the current NCVHS Confidentiality and Privacy Workgroup made a presentation to us. We also had an NCVHS representative on our Tiger Team so that we could be sure that we were coordinating all of our work with NCVHS, which we did. So we took in all of that information and here's what we saw.

The first thing you see is we saw that there is some very promising technology and as part of the promising technology I want to acknowledge that a lot of the EHR systems have capabilities to do things like suppress behavioral health or mental health progress notes; this is the narrative notes. They have capabilities to suppress specific test results, so you can say if an HIV test is positive you can suppress that. What we are again focusing on though is really on the patient's ability to sort of manipulate what is going to be distributed. What we saw there was a lot of promising technology, a lot of people with really excellent ideas, but we thought everything was still in a very early stage of development and adoption.

As a result, you see in the second bullet we say that we think further experience is needed and ONC should be involved in stimulating innovation. Also, we say it should be an area that's a priority for ONC. This is actually an extremely important area for ONC to address. As a result, here are our recommendations as it relates to this issue of granular consent, the ability to again consent to a part of the record.

We think that it's important that ONC find evidence, such as through pilots, for successful models and not rely on theoretical possibilities. In other words, we don't see that the current state of the technology is such that we could recommend to ONC that they should be writing certification criteria for something and that this should be part of stage two of meaningful use. We just don't see that it's quite ready for that.

We also don't think ONC should do any theoretical acceptance and say if something works for a social network site like, say, Facebook, maybe it will work with healthcare and we should adopt that approach. We think that is not the right approach. We think that ONC needs to do piloting. It needs to see models in operation before it starts to move towards a wider spread adoption.

Then we make this other comment that's very important though in the interim while that is occurring: Patient education is paramount and we also say realistic expectations about privacy need to be established, which is critically important as far as the whole process.

Deven McGraw – Center for Democracy & Technology – Director

Wrapping this up, the fifth question that we addressed is just really a bucket of additional recommendations with respect to exchange for stage one of meaningful use involving treatment and quality reporting and public health reporting. All of these were presented at a previous meeting and so we have, again, included more detail in the appendix and, of course, the letter has more detail as well on page 17 to 18, but we did not want to spend the little bit of time that we have on the call to discuss them in detail unless someone had a particular question or an issue to raise.

So, in conclusion, again, these recommendations were targeted to address a set of questions raised by ONC. As we noted at the outset they were already focused on just a particular subset of exchange and not the full gamut of exchange that, in fact, is already going on in many places and for which we do need to address the privacy and security issues that are raised; so therefore, they're recommendations. These are not a definitive and final word on privacy and security and health IT and health information exchange, but they are a first step.

More work is going to be necessary because we have said multiple times and have talked about this at length in committee deliberations throughout the many months that we've all been together, only a

systemic and comprehensive approach privacy and security can really achieve public confidence. So we've put the first steps. We've laid out a foundation here with these recommendations and we're eager to hear your questions and feedback, but we wanted to also identify issues that we know need further work and we're also happy to take suggestions along those lines too.

Exchange beyond stage one: What are provider credentialing and assurance levels? We had hoped to get to that this summer, but we just didn't have the time, given the scope of other questions that we needed to resolve. Individual access to information, transparency, security safeguards and de-identified data are among the wish list for the future, for the near future.

With that, again, there is this appendix of slides that we didn't go over because they had been presented at previous meetings, but I just wanted to remind you that they're there. Of course, everything is in detail in the letter.

We'll stop now and, Paul Egerman, I don't know if you have further thoughts that you want to provide before we open it up to questions.

Paul Egerman – eScription – CEO

My only further thought would be to return back to the core values that we tried to maintain the concept of the confidentiality, the patient/provider relationship, the concept that patients should not be surprised. Finally, the final core value that you see on this screen is it says, ultimately, to be successful we're reminded our entire program is a voluntary program, so we're saying, "To be successful in the use of health information exchange, to improve health and healthcare we," and we is everybody, all of us who are working in the industry ... consumers and physicians.

With that, Dr. Tang, hopefully there is some discussion, but we're asking for the Policy Committee to approve our letter.

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

Thank you very much. I just have to, after listening to this and knowing how much work has gone into it, thank Deven and Paul Egerman and really, the entire Tiger Team for spending that amount of time. It's not just the time; it's a personal commitment to trying to do the best thing possible with this critical and foundational issue.

I can't speak on behalf of California, but I can speak from California: We all need these kinds of guidelines, this kind of guidance, because as your final slides talk about, this is a systemic issue. If we deal with it like we were dealing with data in the past, in silos, we've completely undermined the privacy and the trust that patients and consumers need to have in the system; that it's supposed to be built for improving their care and their health. So this is totally important work and was so critical to all of the organizations, all of the HIE and HIO organizations, to advance the cause, so thank you so much for doing this in such a short time frame.

I know there will be discussion, but let's have discussion and further clarification if needed for some of these recommendations and concepts.

Neil Calman – Institute for Family Health – President & Cofounder

First of all, I cannot believe how much progress people made in such a short time frame. This is just an amazing document and I hope that you don't take any of the tweaks or other things that folks are going to comment on as anything other than the fact that I think there are still a few problems that need to be solved.

The one from a provider point of view that hits me the most is the issue about the phrase not compelled to do stuff. The way I read this, unless I'm reading it wrong, which is possible, if I, as a provider, decide to use a regional exchange or a health information exchange as the major way that my system is going to communicate with other people in my community that I need to have an alternative mechanism in place as well. So basically, I need to develop two different systems, one for the folks who consent to that, but in

order to not be sort of compelling people to do it is saying, “Look, I can’t exchange your information if you don’t consent to this.” I need to have an alternative model. I need to have a directed exchange model as well.

To me that might mean that the regional exchanges, we’re actually signaling them to say you folks all need to have two different models, one in which you can add value, aggregate information, put information together from different sources for those who consent to have that done. But if that’s going to be my exclusive way of sort of exchanging information I also need to compel that organization and say, “You also have to give me an alternative model for the people who choose not to have their data handled that way.”

I think we’re sending out two signals; one to those organizations that say, “We want you, Dr. Calman, to be using us as your model for exchange,” and I have to go back to them and say but you now need to have two different ways of doing that, one that allows that more robust value added kind of context for those that will do that and one that doesn’t for people who consent not to do that. I don’t know whether the exchanges are all— I think they’re having enough problems trying to figure out one way of doing this and I’m not sure that that’s going to be realistic. So I want to make sure that that I’m understanding that issue right.

The second thing that I think is related is the issue of that one slide that you had five words on. It says, “Can the providers opt out? Yes.” So I can opt out of any kind of exchange, but I can’t say to a patient, “Look, if you come to my practice this is the way we do business. If you don’t want your information handled or aggregated in this way this is what happens in our practice.”

Now, I can do that for every other possible thing about the way I run my practice. If you don’t like the fact that I’m only open mornings you have to go some place else. If you don’t like the fact that I use that call group you can go somewhere else, but if you don’t like the fact that I use an exchange that aggregates information I still have to take care of you. So I think we just need to rethink that one piece.

I think it’s unrealistic to ask practices to be all things to all people and I don’t think this is an important enough issue to say every single practice has to have multiple ways of doing this. I think a patient should be informed of how the practice operates, but the way they ultimately decide about whether to use a practice or a provider or not is by accepting that way of practice or not.

I’ll end my comments there. I think it’s just an incredible move forward from where you all were the last time I heard about this.

Paul Egerman – eScription – CEO

Thank you for those comments. If you look at the slide that I put up, the third bullet on this slide addresses the major portion of your concern, which is we did set it up so that you, as a provider, do not have to have two ways of doing everything in case a patient opts out—that’s the wrong term—in case a patient decides not to consent to participate. The concept here is that the regional health information organizations, the HIOs, can do this. They can offer whatever exchange services they already offer without retaining the data. That is something that they can do.

Let’s say we’re talking about laboratory results. You can order your laboratory results, your laboratory tests, get your results back from a HIO if you choose to do so. You can tell the HIO through a process that they give you that says patient John Smith doesn’t want their data retained and the HIO then has to abide by that process.

These are mechanisms that the HIOs have in one form or another already. This is doable and you don’t have to have two systems do this.

Deven McGraw – Center for Democracy & Technology – Director

What I heard in Neil’s question I thought got more to the issue of when the trigger triggers, for lack of a better way to put it. Which is to say, and maybe there’s a distinction that we can make more clear in our

examples, but when you have a provider, who is deciding to, is part of like an organized healthcare arrangement where their record is part of a shared record set of circumstances and the letter has the definition of an organized healthcare arrangement or the record is part of sort of a centralized system record, again, from an integrated delivery system where the provider actually would be significantly burdened if a patient said, “Well, I don’t want my record as part of this.” The truth is that’s where the record is.

We were trying to distinguish between those circumstances and ones where the HIO essentially facilitates access to that record or has a copy of the record that can then be accessed by multiple providers. I’ll let Paul Egerman weigh in on whether I’m making a correct distinction, but we had a lot of discussion about the very issue that you raised, Neil, about compelled consent. We’re trying very hard to make a distinction between circumstances where if a patient said no the provider would be significantly inconvenienced because they’d have to create a separate record for that patient. That’s not what’s intended here.

We’re trying to create a line between those sorts of situations where the record sharing aspect that is facilitated by the HIO is in addition to what the provider keeps in his or her own record so that if the patient says, “No, I’m not really comfortable that my record is available in this HIO repository,” the provider still has the patient’s record and has control over those decisions. It’s not like the provider has to keep a separate paper copy.

I don’t know if that’s—

Neil Calman – Institute for Family Health – President & Cofounder
Right.

Deven McGraw – Center for Democracy & Technology – Director

We tried very hard to draw those lines. We’re not talking about centralized or community records where there’s an organized delivery arrangement.

Neil Calman – Institute for Family Health – President & Cofounder

Right. I understand that. I guess the point that I was making inarticulately is that the real value that we’re looking for out of these HIOs is not that they just become a switchboard, but that they actually become an organizing framework for communities to work together around the care of patients. So it’s just I think we’re asking for people to separate the switchboard function from the value added function and be able to provide either. So you either provide me just a highway to get my information from one place to the other and people have a way of opting out of that added value function, so I think that there is some down side to that, because I think that that’s what we’re looking for from people. We’re looking for that sort of coordination function. That’s what we were hoping that those exchanges would add to quality and safety.

Paul Egerman – eScription – CEO

I agree with that, Neil. Actually, you are quite articulate in saying there’s a switchboard function and there’s a value added function. We’re saying most of these HIOs already have the ability to separate those.

We’re also saying our expectation is the majority, hopefully the vast majority of people will want the value added process, but we’re saying it can’t be compelled on everybody. It’s okay for somebody to say I don’t want to do value added.

It’s particularly important when we’re also saying that the state of the technology is such that you can’t hard for patients to do granular consent, so patients may have a lot of reasons why they don’t necessarily want to participate in the value added function. The way we set it up is a patient makes that decision. That’s not a burden, not intended to be a burden on the provider. That’s something that the patient can do. It’s nothing more than a patient right now can decide to see you as his or her provider and for whatever reason, not tell you everything that ever happened to the patient or tell you every drug that they’re taking. That’s their decision and so we want to provider that same capability if people want to exercise that right.

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

I have a couple of more questions on this particular recommendation, unless other people also want to chime in? So, my two questions on this: One is the phrase not in control. If you use a business associate to do this function is that considered in the control of the covered entity or not?

Paul Egerman – eScription – CEO

Well, the issue is, first of all, this is intended to be a business associate arrangement. When I made the statement we were looking at recommendation 3.2. I made the statement this does not involve healthcare organizations. That sort of implies that this is a business associate arrangement, but a business associate agreement by itself we're saying is not enough to say it's in control.

Again, if you think about the centralized model there has been a transition that the patient's data has ... at least a summary of the data or some of the data has transitioned from the control of the provider, so under the control of the provider when the provider basically has it on his or her computer system and knows who can access it. It becomes no longer under the provider's control when the record is at some entity and they're deciding who can access the data. That's not a business associate agreement. That's an issue of how the flow works.

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

So in your bullet two example where it's federated but this, now, business associate can actually access the individual patient data even though that's not their specific function, if I interpret that correctly you say someone in the federated model, who does have the ability to access your data, that would require an additional consent?

Paul Egerman – eScription – CEO

That's correct. That's pretty much what I said. It's not the business associate themselves that can access the data. It's the other providers or entities that an access it through the federated model. So if you. at Sutter, register me as a patient in a federated model and then let's say I go across the street and get care at Kaiser, if Kaiser then can access that data through the federated model that's the change in control.

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

That's a very good example and that leads to my second question. There is a vendor that is acting as an HIO in a sense for its customers and the contract says that no one can restrict access from another one of these organizations when you participate in this vendor's network, is that acceptable?

Paul Egerman – eScription – CEO

I don't understand your analogy.

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

Yes. So healthcare organizations subscribe to this vendor's HIO in a sense. It is federated, but in the contract that you have to sign to be part of this HIO, this federated model, no healthcare entity can restrict the exchange of health information at the request of another entity as part of this network unless that patient has opted out. So, in a sense, organization A cannot say, "Wow, organization B has been fined a number of times, prosecuted a number of times for privacy violation. I would like to restrict access by organization B to any of the patients that we serve." But the contract to be a part of that network says you can't do that.

Paul Egerman – eScription – CEO

Neil, your description of it; it's always hard to do this, but it sounds to me like that triggers patient consent.

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

It triggers patient consent, but did you consider whether that is an allowable, trustworthy relationship?

Paul Egerman – eScription – CEO

No.

Deven McGraw – Center for Democracy & Technology – Director

No.

Paul Egerman – eScription – CEO

No. That was not in the scope of what we were looking at. We were simply looking at what are the circumstances that trigger consent.

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

So could you see where—?

Paul Egerman – eScription – CEO

In other words, we looked at all of these. We weren't commenting in ... comment on centralized versus federated versus directed exchange. We simply looked at the models and said, "Look, what were the situations that triggered consent?" Also, I realize that your example shows, Paul, there are lots of models. Everything doesn't just fit neatly into two or three categories.

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

So do you think this is the kind of thing that needs to be considered at a policy level versus letting every HIO decide their own policies?

Paul Egerman – eScription – CEO

Well, I think it could be. I mean one of the challenges we had as the Tiger Team was to create policy around an environment where there are so many architectures of how the data and how these things all work. So at some point it would be good to limit the number of possible architectures, but that's not what we're doing in this letter.

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

Okay. Thank you.

Deven McGraw – Center for Democracy & Technology – Director

We definitely didn't take it up. I think we think that that is a fruitful direction to go from a policy standpoint. I think it's worth a further conversation with ONC, because certainly, my impression has been with respect to ONC programs that there seems to be a desire not to dictate particular models but to create a policy infrastructure under which all of them must find a way to operate. But having said that; LaTanya is not on; I don't know if she's joined us on the phone since the roll call; but this is a point that she raises every single meeting; that technology architecture in fact has policy implications and we ought to think about that, but it's not for this letter. It wasn't part of these questions that we tried to address.

Gayle Harrell – Florida – Former State Legislator

If I could a little bit to that, I think what we need to realize too is that governance has a roll to play in issues such as that as well. When you talk about HIEs or HIOs and we had kind of parking lotted a lot of that conversation and certainly, the use of a business associate agreement when you have a powerful entity and a less powerful entity, usually the physician or the group dealing with a large vendor there's a ... of power relationship there. I think those are issues that need to be discussed in governance and how things, what mechanisms you can put into place for ... of HIEs or whatever that allow for those disparities of power to be considered.

Judy Faulkner – Epic Systems – Founder

I think that this is an interesting question. If you have to figure out if a patient shows up at site B and requests information to go there does site A say, "We don't send your data to B. We just send it to C and D, but we don't send it to B." Or is it the patient's choice?

There is another issue too and that is sometimes what I have observed is the most frequent reason that organizations want to work, organization A wants to work with C and D, but not B is for competitive reasons. It's not been for patient care reasons.

Paul Egerman – eScription – CEO

Those are excellent comments, but sending information from organization A to B or to C are all examples of directed exchange.

Judy Faulkner – Epic Systems – Founder

Yes, I know but I think that's what Paul was talking about though.

Paul Egerman – eScription – CEO

Okay. So our recommendations really don't put any requirement on that and Gayle's observation is a very good one; that some of this also could be some governance issues, but that's also something that we didn't address, although I understand that it will be addressed, I think by the NHIN Group, starting in September.

M

... one more on the example I gave. When you had that one word recommendation, i.e., yes, whether a provider should be able to opt out, is that saying that an HIO should not require exchange between two parties, A and B, let's say in that example.

Paul Egerman – eScription – CEO

No. The provider consent to participate in exchange; I guess we had considered this more as part of the recommendation for 3.2. But the observation I would give you is the provider can always decide they don't want to participate by simply having a paper record. Right? If they don't have a computer system they can't exchange data electronically. It's sort of like they don't have to have a fax machine. They don't have to send and receive faxes if they don't want to. We're just making the point that this is a voluntary system and that we ... this way and it was another way to respond to some of the concerns that Neil is raising to say we've got to make it as easy as we can for providers to participate, otherwise they won't.

Neil Calman – Institute for Family Health – President & Cofounder

I don't think that that response to my concern; my concern is different than that. My concern is that we don't want to do anything that discourages providers from using electronic means to facilitate communication. What I'm concerned about is will you require them to participate in this whole consenting process and then you say, "Not only do you have to do that, but you have to have ways, potentially have two ways of delivering this." I know you're not requiring two ways, but in reality that's what we are signaling, that for the things that we really want to do in my own organization to improve quality, working with the regional exchanges that we're doing and things that require some value add, if that's what I want I am going to come to depend on those as things that provide safety and improved quality for my patients. But I also have to have a mechanism to do exactly those same functions if my patients choose not to have that done through the exchange.

I guess what I'm saying is I would like to see very explicitly a statement that says that a provider establish a model for doing business and patients, who don't want to participate in that model can opt out of that practice and that's not considered compelling a patient to participate. It basically is the way I practice. I need to inform my patients of that, but I shouldn't be required—

Christine Bechtel – National Partnership for Women & Families – VP

Neil, I'm completely with you. I mean I'm following you. I'm not sure that I'm with you. So I have a question for you, which is as I'm thinking about this, if you want to share my data for the purpose of treatment and I don't want you to do it through the exchange you can do a directed exchange. You can do fax. You can do, as Paul said, sort of lots of other options. You don't have to have two models. But I want to make sure I'm understanding what you're saying, which is if you use these exchange to do other things, like quality improvement or performance reporting and things like that—

Neil Calman – Institute for Family Health – President & Cofounder

Yes.

Christine Bechtel – National Partnership for Women & Families – VP

But in that case I mean aren't we talking about a relatively small number of patients, who you wouldn't have in your pool, but otherwise you've got enough to get the point basically of what you're trying to do?

Neil Calman – Institute for Family Health – President & Cofounder

Yes, but you need a mechanism. You can't just say, "For this patient I can't do med reconciliation because I don't have any other information from anybody, so I'm just going to like forget about it." You need a process for it that doesn't require the information you otherwise get through an exchange and so you can't also say, "Well, I'm not going to worry about the diabetics who didn't give me permission to work with the regional exchange on diabetes improvement and not do outreach to them for education and not do all of the other things that we're developing as part of this regional information. I need an alternative mechanism to go after those people in my practice, who have chosen not to consent.

What I'm saying is if I inform people that's how we do business that people make all kinds of decisions about what kinds of providers and who they're going to go to. Why are we separating this one out and saying that this is not a legitimate reason for a patient to just say, "I don't want to be part of that practice because that practice participates in this method of exchange and I don't want my data out there."

Christine Bechtel – National Partnership for Women & Families – VP

But I think that's part of the issue. If I don't want my data shared in a trigger situation because the provider loses control and I decide I don't want to consent to that I'm not sure that that's cause to like boot me out of the practice, you know?

Neil Calman – Institute for Family Health – President & Cofounder

I'm not booting you out. I'm just—

Christine Bechtel – National Partnership for Women & Families – VP

Isn't that what you're saying though?

Neil Calman – Institute for Family Health – President & Cofounder

Well, any more than I'm saying, look, we have nurse practitioners in my practice. There are all kinds of other things about ways practices are structured, the way emergency calls are handled, everything else. I mean we don't use that as a way, we don't tell people you have to have multiple systems of all of those other things. I guess I just don't want this to be one of those things that makes it so difficult for providers that they basically say this is ridiculous. Why would I go through this whole model with the exchange when only half the people in my practice I've managed to get to consent to this.

Paul Egerman – eScription – CEO

Neil, that's why I was saying what shows on this screen is related to this issue. We need to make it easy for providers to participate; otherwise, they won't.

Neil Calman – Institute for Family Health – President & Cofounder

Right, but I don't want to opt out of all exchanges.

Paul Egerman – eScription – CEO

I understand, so that's why we want to do it this way. To pick up on what Christine is saying, the issue that you're starting to get as a debate here is like at the core of a lot of the discussions we had. On the one hand you would have people approach this from the healthcare standpoint and say, "This is good for patients. This is good for patients. We need to do everything we can to get everybody in on the whole system."

Then you have people, who are into individual autonomy that say, "Well, hold everything. Before you take a patient's data and put it into an organization that patients would perceive to be related to the

government, some sort of government agency or supported by the government, patients need to not only know about it; they have a right to say I don't want my data moved around."

So it's an issue between a patient's autonomy and the desires to do the best we can for our patients. That's not a debate that has like a natural resolution because they're both very, very valid viewpoints—

Christine Bechtel – National Partnership for Women & Families – VP

But I think, Paul, that's the point of the kind of meaningful choice that we've outlined, which is we have in the letter a number of references to the kind of genuine conversation that needs to happen between patient and provider so that if I come to the practice and I say, —~~L~~ok, I'm not comfortable because I have a lot of sensitive health information. It's been breached before. It's been used against me. I want to make sure that it's only you because I trust you looking at this and that you don't drop it into this particular model."

That's when the provider can come back and say, —~~O~~ay. I understand what you're saying, but let me tell you what that means based on the way we practice is you wouldn't get reminders and follow-up. I wouldn't be able to ...," and it's a conversation about how this happens and therefore, it's much more of a meaningful choice than the current HIPAA forms today.

Paul Eggerman – eScription – CEO

That's right. And if providers feel ... the way Neil feels about it, my guess is after that conversation 99% of their patients will participate—

Christine Bechtel – National Partnership for Women & Families – VP

Right.

Paul Eggerman – eScription – CEO

But they'll know what they're doing.

W

Right. I agree.

Deven McGraw – Center for Democracy & Technology – Director

I think it is helpful to understand that in many cases when patients have an opportunity to make a choice they say yes way more often than they say no. I know that probably feels like slim consolation, but I think we need to understand what's at the core of why we're offering these recommendations, which strains of it have been picked up in lots of people's comments. It's just the people who are nervous about their privacy, which isn't everybody, but a number of people that we don't want to leave out of the system, when they trust their own doctors, but these new entities that are being created where the data can be accessed without their provider vetting whether it should flow and what should flow; that we ought to give people some choice. If the choice is you participate or you have to leave the doctor you like it's not a very good choice.

So if we're talking about trying to build the trust in these infrastructures that we are trying to create, even if we recognize that these are very valuable in healthcare ultimately, but we won't get there if people can't evolve to the same place where we are in thinking that these are very good for patients.

Gayle Harrell – Florida – Former State Legislator

I'd like to add to that. I think, Deven, you make a very valid point. We need to go back to the very foundation of this whole discussion in that privacy is paramount to what we're doing here and is absolutely essential for the patient. If we don't have that trust we're not going to be able to move this whole endeavor forward.

I go back to the basic constitutional ... that everyone has and your health information is absolutely the most sacred thing you have. As I've said many, many times, that this is a core value of what we're doing and if we just put that aside, a convenience or health provider preference is paramount over that we've

lost that trust. This is a core element and I really want us to understand that and make sure that as we move forward that it stays at that core value.

I want to commend Paul and Deven, having been, perhaps, the lone voice or one of the voices out here on that real strong privacy element, the need to have this transparency and foreknowledge of what's happening and ... opt-in; I'm still there on opt-in; but I think really this is absolutely essential in what we are doing. I think Paul and Deven ..., thank you for all of your hard work on this.

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

Other comments and questions?

Charles Kennedy – WellPoint – VP for Health IT

I think I know the answer to this, but I just want to confirm that none of these recommendations would apply to the claims processing, the clearinghouses associated with them, as well as the clinical data embedded and required for those processes.

Paul Egerman – eScription – CEO

That's correct. It doesn't involve payment situations at all.

W

You're next, Charles.

Charles Kennedy – WellPoint – VP for Health IT

Yes. I'm trying to lay low.

Paul Egerman – eScription – CEO

It's a good question, Charles. It goes back to what Christine was saying. I think patients would be surprised if they realized how many people have to see their data. It's something they really ought to know about.

Charles Kennedy – WellPoint – VP for Health IT

Absolutely, but I just worry about ... if we don't want to break the hundreds of millions of transactions that are flowing through the

Paul Egerman – eScription – CEO

No. It doesn't affect that. The claims clearinghouses play important and valuable roles and that's not what this is aimed towards.

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

Other comments, questions? Is the Committee ready to take a vote for approval on this letter? If so, would somebody like to file a motion?

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

I move that we approve this letter as a recommendation.

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

Is there a second?

Paul Egerman – eScription – CEO

I'll second it.

Christine Bechtel – National Partnership for Women & Families – VP

There is a second. Can you hear me? I'm working the mute function.

Scott White – 1199 SEIU – Assistant Director & Technology Project Director

This is Scott. I second it too.

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

Is there any further discussion? Okay. So I didn't hear an amendment. Is that true, Neil, in terms of 3.2?

Neil Calman – Institute for Family Health – President & Cofounder

Well, I don't want to dominate the discussion. I'm still concerned about the issues that I raised and I'm specifically concerned about the requirement for practices to have multiple mechanisms of doing things. Right now the last thing I'll say is a patient that comes into my office that says, "I'm afraid somebody is going to hack into your office system and steal my information," does not have an opportunity right now to say, "I want my records kept on paper."

Deven McGraw – Center for Democracy & Technology – Director

Right. Well—

Neil Calman – Institute for Family Health – President & Cofounder

We don't do paper records.

Deven McGraw – Center for Democracy & Technology – Director

No. That's right.

Neil Calman – Institute for Family Health – President & Cofounder

The same way all of the other mechanisms that we're going to create to care for our patients, improve quality, coordinate care with other people, I don't want to be setting up systems so that every time somebody says I don't want to participate in that or this or have the information shared that we need an alternative mechanism. This is the future of medical practice.

I want to inform people about that. I want to convince them that they should remain our patients, but ultimately, I don't want to be compelled to create a second mechanism of care for people that don't want that. So just from my own perspective, if that's not changed I would abstain from voting on the letter.

Christine Bechtel – National Partnership for Women & Families – VP

Can I just say I think the distinction between those two analogies is the concept that when it's your electronic health record then the data and the information and the security practices and processes and protections, as you've said, of those things are largely within your control and your decisions. The distinction is when you choose to use a model where the movement of the data is really no longer under your control that's really the trigger here. It's not generally you will participate in an exchange where you still maintain control and it's for treatment purposes. Then there's no issue. You don't have to set up separate ... because this is really—

Neil Calman – Institute for Family Health – President & Cofounder

That's a false distinction because from a patient's point of view they don't know what those security systems are within my organization –

Deven McGraw – Center for Democracy & Technology – Director

It's not security, Neil. It's about whether when there is a decision to release information that's in your record do you make it.

Christine Bechtel – National Partnership for Women & Families – VP

Right.

Judy Faulkner – Epic Systems – Founder

This is the one section that says is compelled that, as we discussed it on the committee I was most concerned about. My acceptance of it was based on will the providers feel that it is very difficult for them or will they feel that it is okay for them? I think if Neil has significant concerns this is an area that we should be talking to providers about to see whether it makes it difficult for them, because I hate for those of us who aren't providers to make that judgment and harm the providers.

Michael Klag – Johns Hopkins University, Bloomberg School of Public Health

As a former provider I share Neil's concerns. Having worked in academic medical centers these decisions about how this will be interpreted will be made by the general counsel and they are incredibly conservative. Their whole mindset is to prevent risk to the institution, so I think Neil raises good points.

Paul Eggerman – eScription – CEO

I think Neil raises good points, but I think we addressed it, because you do not need to methodologies to order tests or two methodologies to do everything because, as Neil said, these HIOs can offer switchboard functions, as well as these value added functions. So I think we did address it.

I would also make the observation that patients actually do have choices all of the time that they make their settings on. I can go to my physician and my physician can say you've got to have this vaccination because you're over 60 and everybody over 60 gets this vaccination. I can say, "No, I read about that. I don't want that vaccination." It's then the physician's job to talk me into it. If he can't talk me into it I can walk out the door and he can be thinking I made the stupidest decision in the world, but that's my decision and we live in a time period where patients can choose.

Michael Klag – Johns Hopkins University, Bloomberg School of Public Health

Paul, that doesn't address the fundamental way the practice is organized in delivered—

Deven McGraw – Center for Democracy & Technology – Director

But we exempted that, Mike. We tried to make very clear that in no way were we saying that a patient could say to a provider, "You have to leave my record in paper." This has to do with when copies of information flow to models and then are made available to people where the provider can no longer exercise control over who gets data that are from their records and how much and to whom it goes, because it's all part of it's an entity where the terms of participation allow people to freely use it, even for a limited set of purposes. That, to us, is significantly different from the traditional doctor/patient relationship where the doctor has the record and makes the decisions about how it's share and to whom it's shared with.

There ought to be some choice that patients are provided. We think that there are enough additional mechanisms in place that if it's in an electronic record that that data can still be shared, albeit, admittedly, there will be some value adds that the patient might miss, but if the patient makes that choice fully informed then so be it. Again, we're talking about the foundation of trust that has to be built for both, providers and patients—

(Overlapping voices.)

Christine Bechtel – National Partnership for Women & Families – VP

I think the only thing I would add to what Deven just said, which I think is absolutely right on, is the fact that if meaningful choice is really exercised and there is a genuine conversation about what happens when I put your data somewhere where I can no longer control it, then I think we're talking about a very, very small portion of patients, who will actually opt-out, but the choice is really meaningful in building and maintaining trust, again, outside the context of day-to-day care.

Judy Faulkner – Epic Systems – Founder

Even if one patient opts out it creates for the provider a responsibility to create a different way. Underneath it all is really still the question there is an assumption that we're making here that it's really just triggered on, triggered off; the patient will either go this direction or that direction. It's not a huge burden on the provider. That's the underlying assumption that we're making separate from it should be the patient's right.

The problem that we haven't answered yet is is that a correct assumption. Is it really true? Paul, Neil, I'll ask you this: Is it really true that in your mind it will be just a right/left switch or an on/off switch and you

can put the patient in one or the other? Even one makes you create another path. Or do you feel that it will be a burden? If so, where is the burden?

Paul Egerman – eScription – CEO

I'm sorry, Judy. Who are you asking? Are you asking Neil or are you asking me?

Judy Faulkner – Epic Systems – Founder

Neil. My gut feel is that we are taking a risk as a committee in not being really clear that there isn't some burden because we've had two physicians now speak up and say they think there may very well be. If there is, we're in trouble with that phrase.

Neil Calman – Institute for Family Health – President & Cofounder

Let me just give you an example. We're working collaboratively with three other health centers, a bunch of hospitals, to develop a program in the mid-Hudson Valley that would consolidate information on diabetic patients. And we are not doing other quality improvement work because all of our quality improvement work is based on this shared model of diabetes information with lots of centralized resources to improve the care of diabetics in the community. So now, if I have a bunch of people who are, first of all, the whole opt-in thing to me is like now I have to reach out to 5,000 diabetic patients to say, —“Do you want to participate in this,” instead of having the centralized outreach team first—

Paul Egerman – eScription – CEO

Neil—

Neil Calman – Institute for Family Health – President & Cofounder

Let me just finish, Paul. Just instead of having that team do the outreach, now what we're saying is I, as an individual provider, have to reach out to them first to say before I even have this team call you I need to get your consent because it's happening through a place where we're taking diabetes information and putting it sort of centrally. Even though I feel totally in control of it, I'm on the board of that operation, I control it, it doesn't matter because it's now in a different space. I just think we're adding a level of complexity to this that doesn't need to be added.

So I'm just going to make a very specific recommendation. Since there's dissent on this issue, why can't we just park this issue like you've parked a bunch of other things right now and let's at least just have an opportunity to ask a broader range of providers. I don't want to represent the entire provider world. Let's ask a broader range of people whether people feel this is an issue or not. If it's not, I'm glad to back off, but if it is I think we should know that before we come out with a major recommendation in this area.

Paul Egerman – eScription – CEO

Well, again, certainly the fact that if we decide not to do this it's going to be a lot of people see that as very interesting. I just want to understand. What you're suggesting is providers should be able to simply say to their patients, —“I'm going to send to the government all of your medical records information. They can use it for whatever purpose they want and if you don't like it you can go elsewhere.”

Neil Calman – Institute for Family Health – President & Cofounder

The government?

Paul Egerman – eScription – CEO

Well, yes.

Neil Calman – Institute for Family Health – President & Cofounder

Why are we talking about the government?

Paul Egerman – eScription – CEO

A lot of the HIOs are organized as public/private partnerships. A lot of them give information to public health agencies. They give information to all kinds of different places. What you're saying is providers should be able to give that data to the patients, to these entities and then patients have no say.

Neil Calman – Institute for Family Health – President & Cofounder

No. They do have a say. I am not saying that at all. I'm saying that I want to be able to say to my patients that coming to my practice has these parameters; we're open these hours; we're organized these ways; we handle emergencies these ways; and we handle your data in these ways. I don't want to have to create a second mechanism of doing those things. I don't want to have to say somebody can't say, "Well, that's great, Dr. Calman, but I want my calls answered by my individual primary care provider." I can't turn around to that person and say that's a legitimate thing.

I think that the idea of saying this is how you have to organize your practice to be able to handle these two categories of patients is unrealistic for most practices. Most people, we're going to be happy if most people find a single mechanism to handle the things that we're asking people to do. I don't think we want people to have to think about, have to create systems that differentiate patients. If their systems can do that, great—

Paul Egerman – eScription – CEO

We're not asking you to have systems—

Deven McGraw – Center for Democracy & Technology – Director

Paul, can I interrupt here? I just want to say that most of the examples that I have heard are ones, Neil, as well as from Mike Klag, I mean to me your description of what you were trying to do in the Hudson Valley is an OHCA, because you're doing quality assurance through it. We have tried to address the very issues that you raised and there hasn't been a single example that's been put forth that I don't think we've already covered in the letter and we can certainly clarify it again. These sort of organized arrangements for quality assurance purposes, for utilization review, those are OHCA's and they are expressly not triggers for consent.

Neil Calman – Institute for Family Health – President & Cofounder

Okay. First of all, that's a new term for me, so I apologize. If you're saying that all of the things that we are talking about are considered part of these organized arrangements then to me I think that's going to cover all of these kinds of reporting things, because all of these are going to be organized by these entities to improve care or to improve safety. Why else would people be organizing this?

Paul Egerman – eScription – CEO

Well, I think what Deven is saying is your example is a really good example of this organized healthcare arrangement. IPAs do this as well. What they're saying is you would need a separate consent if you wanted to, say, give it to someone who's not participating in this arrangement you just described—

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Paul Egerman – eScription – CEO

Because you've created a formal organization; it's virtual in a sense, but it's a formal organization. You all have some way of even talking about a board. That's not what they're talking about. They're talking about if it's going to go somewhere else you should give the patients a choice. That's what they mean by not compelled.

Joy Pritts – ONC – Chief Privacy Officer

Can I read the definition of an organized healthcare arrangement from the role so that everybody is on the same page?

Paul Egerman – eScription – CEO

Sure.

Joy Pritts – ONC – Chief Privacy Officer

Organized healthcare arrangement means, one: A clinically integrated care setting in which individuals typically receive healthcare from more than one healthcare provider.

Two: This is a separate category. An organized system of healthcare in which more than one covered entity participates in which the participating covered entities fold themselves out to the public as participating in a joint arrangement and participate in joint activities that include at least one of the following—

I don't think I'm going to read all of this to you, because it's really long, but it includes utilization review, quality assessment and improvement activities in which treatment provided by participating covered entities is assessed by other participating covered entities or by third party or certain payment activities. Is that helpful?

Paul Egerman – eScription – CEO

It is. I think Neil, particularly since you have a board, you definitely represent to the public that you are a group of collaborating organizations—

Neil Calman – Institute for Family Health – President & Cofounder

So if you're a member then of an exchange and that exchange's purpose, one of purposes of that health information exchange is to improve quality; that would be covered. Is that the way you're explaining this? I guess I'm addressing that to Deven.

Deven McGraw – Center for Democracy & Technology – Director

Yes. That was our intent. Again, what I know I like about the concept of an organized healthcare arrangement is it's not just a bunch of people dumping data into a repository so that it can be accessed. I mean it would be totally open accessed, but they're gathering the data together for a specific purpose of working together to improve quality, working together to make utilization more efficient or working together to share financial risk.

Neil Calman – Institute for Family Health – President & Cofounder

I'm satisfied.

Gayle Harrell – Florida – Former State Legislator

I'd like to address that. We had this whole conversation in the committee on OHCAs and I have great fear and here again I think we need—as a committee and as the ONC—to look into perhaps in the future need legislation on making sure that we are not making all HIOs and HIEs focused. I have a great fear of that and I think we need to be very careful and very specific on how we expand or utilize OHCAs; that's every HIO, who wants to do whatever with healthcare information, become focused.

Paul Egerman – eScription – CEO

Gayle, I think the distinction is that an HIO is a business associate.

Deven McGraw – Center for Democracy & Technology – Director

I'm not sure that that's a totally accurate—

M

Yes. I don't think that's—

Deven McGraw – Center for Democracy & Technology – Director

They're not one healthcare organization. They are, by definition, a collection of ... that agree to work together.

Paul Egerman – eScription – CEO

But they're covered entities.

Deven McGraw – Center for Democracy & Technology – Director

Right. That's right.

Paul Egerman – eScription – CEO

And an HIO is a business. It's not a covered entity.

Joy Pritts – ONC – Chief Privacy Officer

I'm reading from frequently asked questions from the Web site of the Office of Civil Rights. Is Adam on the phone, by any chance? No. Okay. So I will jump in here.

There is a question and an answer on OCR's Web site that's directly applicable to the question that you have raised. The question is, —“On a health information organization, HIO, participate as part of an organized healthcare arrangement, an OHCA?”

The answer is a HIO, by definition, cannot participate as part of an OHCA because the HIPAA privacy rule defines an OHCA as an arrangement involving only healthcare providers or health plans, neither of which a HIO qualifies as. However, a HIO may be a business associate of an OHCA if that HIO performs functions or activities on behalf of the OHCA. For example, a hospital and healthcare providers with staff privileges at the hospital are an OHCA and to the extent such an arrangement uses a HIO for electronic health information exchange the HIO would be a business associate of the OHCA.

Does that just raise more questions?

Deven McGraw – Center for Democracy & Technology – Director

Yes, it did, Joy.

Joy Pritts – ONC – Chief Privacy Officer

I'm sorry. I apologize, but I think that if there is a question and answer on it from ... that is available that we should at least be aware of it.

Deven McGraw – Center for Democracy & Technology – Director

Well, I just think it's a little bit of a form over function—

Joy Pritts – ONC – Chief Privacy Officer

It may be a little bit of that.

Deven McGraw – Center for Democracy & Technology – Director

And it's not something that we talked a lot in our Tiger Team deliberations. I mean we deliberately put OHCA's and said those types of arrangements are not triggers because of our understanding of what an OHCA was, not necessarily because an OHCA is a covered entity and something else is a BA. We understand that there are business associate agreements required for HIOs, but to me that doesn't address the question.

The issue is whether there is a purpose for which the data is being shared by covered entities, for which that's what an OHCA does, versus the concept of a HIO, which to us is different and admittedly, not very well universally defined, but we were trying to draw that line and that's why the recommendation is phrased in the way that it is. But it's not about OHCA's or providers. It's about when the patient's data is moved into a setting where it isn't under the control of either the provider or the OHCA or the provider is in an OHCA. So we tried very hard to make that distinction to understand that we were trying to talk about two different things here.

Judy Faulkner – Epic Systems – Founder

Deven, maybe you can help me understand this a little bit better. Maybe ... the definition of OHCA, the definition of provider. I saw the provider, as we use it, as primarily the healthcare organization or in some cases, for example ... but would a provider be, for example, the Lance Armstrong Organization, where they want to do research on cancer and come up with specific decision support criteria to help the

organizations that they're sharing the data with, which reminds me a little bit of Neil's board. When is that considered a provider and therefore, could be part of an OHCA and when is it not really a provider?

Deven McGraw – Center for Democracy & Technology – Director

Judy, just keep in mind that all of these recommendations are limited to the stage one meaningful use characteristics and that sounds a bit more like sharing for research purposes. So I think we can presume that the term provider in our letter means the HIPAA term provider and providers under the meaningful use program.

Judy Faulkner – Epic Systems – Founder

But isn't Neil's example kind of research for the diabetic example he gave?

Neil Calman – Institute for Family Health – President & Cofounder

No.

Deven McGraw – Center for Democracy & Technology – Director

No.

Neil Calman – Institute for Family Health – President & Cofounder

It wasn't meant to be. It was really meant to be quality improvement, outreach in quality improvement.

Deven McGraw – Center for Democracy & Technology – Director

Yes. Statement and care coordination, quality improvement.

Judy Faulkner – Epic Systems – Founder

Okay.

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

Okay. The last I heard Neil said he was satisfied.

Neil Calman – Institute for Family Health – President & Cofounder

Yes, but now I think we're more confused because I think we're using this term OHCA, which, from what I'm hearing, doesn't really cover what we're trying to accomplish, right? We're really talking about two concepts that one is what's the data used for and the other is who's in control of it.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Neil Calman – Institute for Family Health – President & Cofounder

Those are the two things that I hear you talking about. What's the data being used or and who's in control of it? Then you're sort of using this OHCA definition to kind of handle that, but I'm not sure it really does that.

Marc Probst – Intermountain Healthcare – CIO

I was pretty comfortable right up until the point of I think we got way more liberal with what OHCA is and that makes me far less comfortable. It sounds like we're being way more open with what is required, when meaningful consent is required.

Deven McGraw – Center for Democracy & Technology – Director

Okay.

Marc Probst – Intermountain Healthcare – CIO

Okay like you didn't understand what I just said?

Deven McGraw – Center for Democracy & Technology – Director

Well, I guess I want you to be more specific about what then you would want the recommendation to say to address your concerns.

Marc Probst – Intermountain Healthcare – CIO

My concern is we talked about HIOs and that if I go back to page ten and it's considered an OHCA then you don't require meaningful consent to be part of an HIO or an HIE.

Paul Egerman – eScription – CEO

No. An HIO is not an OHCA.

Neil Calman – Institute for Family Health – President & Cofounder

That would be a problem for me.

Paul Egerman – eScription – CEO

But, Marc, an HIO is not an OHCA.

Neil Calman – Institute for Family Health – President & Cofounder

I wasn't sure in what we were just talking about that that's true. If that's true, if an HIO is not an OHCA and that's what we're defining it as that's better.

Marc Probst – Intermountain Healthcare – CIO

Now, an HIO that wanted to do other things with the data would require consent. It would trigger this?

Paul Egerman – eScription – CEO

Yes, especially the comment they want to do other things with the data.

Marc Probst – Intermountain Healthcare – CIO

Right.

Paul Egerman – eScription – CEO

That's very different than a collection, a group of healthcare providers that has a board that is trying to improve the healthcare of diabetics. The HIO wants to do other things with the data. What do they want to do? Do they want to sell it to a pharmaceutical company to generate money?

Neil Calman – Institute for Family Health – President & Cofounder

But I think you're also now raising another issue, which is the governance of the HIO, so the way I understand it now is if the HIO is really governed exclusively by a board of healthcare providers you're basically going to be okay, because it's still within the control of that group, but if the HIO governance includes now other entities or other kinds of people or whatever then it's no longer in the control of the healthcare provider, of the OHCA.

Deven McGraw – Center for Democracy & Technology – Director

That's right.

Neil Calman – Institute for Family Health – President & Cofounder

So we're into a whole area now about the HIO governance and we're going to be signaling something that says to providers let's think about what the governance model is for the HIOs, because if you want to be able to participate in this without getting individual consent from all of your patients, make sure that the HIO is governed exclusively by the providers in the community, as opposed to having other people in governance.

I'm just trying to spin out what the implications are of what we're doing. I think there are still unanswered questions, but I'm not going to be ... I mean you guys have put so many hours of work into this; I just think there's a lot of detail that needs to be worked out.

Marc Probst – Intermountain Healthcare – CIO

But, Deven, what Neil just said—

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Marc Probst – Intermountain Healthcare – CIO

It's part of where we're exchanging information, even with known participants, so a physician that is affiliated with Intermountain Healthcare, I don't need any kind of meaningful consent to do that?

Deven McGraw – Center for Democracy & Technology – Director

Correct.

Marc Probst – Intermountain Healthcare – CIO

Okay, but I do need that if I'm going to go put it out on the Utah Health Information Exchange where a provider in a far away city in an emergency department might access that data, but I don't really have a formal relationship, nor does the patient?

Deven McGraw – Center for Democracy & Technology – Director

That's right. While the patient is in the emergency room, presumably, but right. That's right.

Marc Probst – Intermountain Healthcare – CIO

Okay.

Deven McGraw – Center for Democracy & Technology – Director

That's what we were trying to get at is this notion, again, keeping in mind that where this emanates from is the patient's relationship with the physician. I don't know too many patients who think of themselves as having a relationship with an OHCA, but nevertheless, there are some requirements to be an OHCA and it involves the participation by the patient's providers and they've got to be working together for certain purposes. It's not just a way to make data available.

(Overlapping voices.)

M

A whole lot of technical issues there—

Deven McGraw – Center for Democracy & Technology – Director

Yes.

M

... some of these exchanges work, because once you expose it, whether they have permission or not, a lot of people can access that data.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

M

Well, that's the issue.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

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

That's the issue. So I think we have revisited some of the things that the Tiger Team has done. I think it's clarified it for some. I think part of what Deven said in terms of they're really working on a function of reform and the reason is some of the definitions, particularly HIOs, is not at all set in concrete. We do

have the NHIN Workgroup that's looking at the governance issues, so a lot of these issues are inter-related.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

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

But for the spirit and the function that they've talked about; and I think they really have had this discussion that includes this discussion; I think they've produced a really good output, any objection to calling the vote for this approval? So all in favor?

Participants

Aye.

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

Is there any opposed? Are there any abstentions? Okay. Deven and Paul, thank you so much for putting together the work product and thank you to the Tiger Team for participating in this and really hammering out a very good letter.

You did mention in a couple of paragraphs some of the work you were planning to do in the future. Is that work you plan to do or do you need further direction from ONC or this Committee?

Deven McGraw – Center for Democracy & Technology – Director

I think we need some further direction from ONC. I also would welcome suggestions from the Policy Committee on future directions. I think that would be helpful. People know where to find me and Paul by e-mail.

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

There was a list of things, de-identification and so on and so forth that you had in some of these.

Deven McGraw – Center for Democracy & Technology – Director

Yes. There is a list on the slides, but then Joy and I spoke to the folks from the NHIN Direct Working Group and they had a long list too and we can't take it all on or else we'll be working at the pace that we were over the summer for months and I think people are ready to deal with these in a more regular twice a month meeting manner.

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

Okay. Fair enough. Okay. We were scheduled for an hour lunch. Given the virtual nature of this call, would it be helpful for people to have a shorter break, that is a half hour lunch since you're in your home environment, and resume earlier so that we can finish earlier? Also, I think the Enrollment Workgroup could use a little bit more time. If we got back together at 1:00 Eastern Time would that be okay with the committee members?

Participants

That's fine. Yes.

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

Okay.

Judy Sparrow – Office of the National Coordinator – Executive Director

One other thing, I am going to be sending around a revised slide deck for the Enrollment Workgroup and a letter. I'll do it right now.

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

Okay. Very good. We'll see you all at 1:00 Eastern back on this ... line. Thank you.

(Lunch break.)

Judy Sparrow – Office of the National Coordinator – Executive Director

Aneesh Chopra or Sam Karp, are you on yet? Okay, Paul, I guess we have to wait for them.

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

Okay.

Judy Sparrow – Office of the National Coordinator – Executive Director

Sam if you want to open it up, he'll (Aneesh) be along.

Sam Karp – California HealthCare Foundation – VP of Programs

Okay. That's great. Are you ready, Paul?

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

Yes, sir.

Sam Karp – California HealthCare Foundation – VP of Programs

Good morning, good afternoon, everyone, depending on what time zone you're in. I guess I want to say that we're pleased to report that the Workgroup has made significant progress since we last presented to you. We have developed ten recommendations based on the work of four Tiger Teams and also NIEM work that was conducted by ONC. While we are still refining these recommendations, given the timeline constraints in the statutes and also the time required for the federal clearance process, we are going to ask that you approve these recommendations today. We don't expect that there will be any substantial, at least any major changes to them. I know that's a process issue for you to discuss.

You have the recommendations before you there, but we envision the final document to be three to five pages, prefaced with a preamble about the importance of consumer usability and consumer mediation, which is consistent with the Affordability Care Act, focus on making enrollment much more efficient and consumer friendly. We also will include a series of appendices with much more detailed information that supports each of the ten recommendations.

I am going to walk you through the first three recommendations with respect to core data and verification and then Aneesh, when he gets on, will walk you through the remaining recommendations, which have to do with business rules, transmission of enrollment information and privacy and security, so there are five different sections where we have recommendations under each of those sections and you have those in a revised— Judy, I assume the revised deck got out to everybody.

Judy Sparrow – Office of the National Coordinator – Executive Director

Yes it did.

Sam Karp – California HealthCare Foundation – VP of Programs

So let me start with the core data recommendations. At the last meeting Doug had given you an overview of the work that he and his team were doing. They had done NIEM analysis, essentially of core data elements across 34 different programs in 10 states, a sampling to get a sense of what was involved in the complexity of data harmonization and trying to get a handle on exactly what was the depth of data harmonization that would be necessary. Their work is still in process, but it will be completed before these recommendations are made public, I understand, on September 17th.

They will ensure that the data elements are as close to operational as possible and in particular, they're going to look at the four or five core data elements that are required to do the electronic verifications that are specified in the ACA. The ACA requires that income be verified with the IRS, that citizenship be verified with the Social Security Administration and that legal status be verified with the Department of Homeland Security. Each of those federal agencies require a certain number of core data elements to be used to match individuals and so we're really going to focus on down to data format those core data elements so that we can get a higher match rate.

For the recommendation on core data is that—you can turn to your recommendation page—that federal and state entities administering Health and Human Service programs use the NIEM guidelines to develop, disseminate and support standards and processes that enable the consistent, transparent exchange of data elements between programs and states. I want to be clear that we aren't recommending or even requiring or suggesting that states should change their core data elements or the way they collect and display those data elements within their own systems. What we are suggesting through this recommendation is that the data elements that we already know are common across many programs that can be transmitted between programs so that the receiving program is able to easily identify and incorporate the data element in its system.

Let me stop with that and see if there are any questions. Doug, I believe you're on the line as well?

Doug Fridsma – Arizona State – Assoc. Prof. Dept. Biomedical Informatics

I'm here.

Sam Karp – California HealthCare Foundation – VP of Programs

Is that a fair representation of where we are with this recommendation?

Doug Fridsma – Arizona State – Assoc. Prof. Dept. Biomedical Informatics

Yes. I think that's a good summary.

Sam Karp – California HealthCare Foundation – VP of Programs

So we'll take any questions or clarifications that you all need.

Gayle Harrell – Florida – Former State Legislator

I know different states have many different programs, many different databases that are run. Are you suggesting that there be an interface built that connects all of these or how do you anticipate this working?

Sam Karp – California HealthCare Foundation – VP of Programs

Doug, do you want to start?

Doug Fridsma – Arizona State – Assoc. Prof. Dept. Biomedical Informatics

Well, I think you're absolutely right. There are a lot of different kinds of interfaces. There will be the need to try to connect those pieces together. The reason for the recommendation to use the NIEM process is that it provides sort of a standard to which those programs can be mapped rather than trying to map all of them, every single program to every other single program and all of the complexity that's involved with that. It provides a standard that people can sort of map to once to help the legacy systems work and then as new systems are constructed there is a way that they can then follow those standards to assure that interoperability.

Gayle Harrell – Florida – Former State Legislator

I'd like to clarify that. If they map to that standard is this a requirement that they do it or is this a recommendation that they do it?

Farzad Mostashari - ONC

Sam, maybe you might want to clarify: We have to be clear that the work of the Health IT Policy and Standards Committees and ONC making these recommendations is around the standards and not around what policy should be used with respect to how states choose to implement the various enrollment eligibility programs that are envisioned as part of the ACA. So I think we've tried to be pretty careful not to have the technology standards kind of be forcing any policy decisions—

Sam Karp – California HealthCare Foundation – VP of Programs

Let me also be clear while Section 1561, which has authorized in a sense the work of this workgroup is broad to cover all Health and Human Service programs, we have focused largely, as Farzad mentioned,

on the requirements of ACA. And that is that the programs that we're primarily talking about are Medicaid, CHIP and the subsidy programs connected with the health insurance exchanges. While our Workgroup has looked at what might be possible to extend eligibility using the eligibility data submitted for the exchange to help qualify people for Medicaid, for food stamps or for earned income tax credit, we are largely talking about the data set involved in those, the health insurance exchange, the subsidy programs, Medicaid and CHIP, so while 1561 does address something broader, our focus really is on the ACA.

Gayle Harrell – Florida – Former State Legislator

Okay. And what you're doing is you're establishing those standards to which states are going to be required to map to? Does ACA require that the mapping take place?

Sam Karp – California HealthCare Foundation – VP of Programs

I think, as Farzad was suggesting, this is a policy decision that's going to need to be made by HHS, but these are recommendations that are going to the secretary.

Farzad Mostashari - ONC

What the legislation says is that the secretary may—and that's a separate policy decision from what we're talking today—make conformance to those standards a condition of grants that would go to the states. Does that clarify it, Gayle?

Gayle Harrell – Florida – Former State Legislator

Well, does that provide funding for the states to do that?

Sam Karp – California HealthCare Foundation – VP of Programs

There is a grant program associated with this statute, but no funds were authorized for it, which is not to say that HHS or CMS may not provide funds to the states to do this work. That certainly is something that's being discussed between the states and HHS.

Gayle Harrell – Florida – Former State Legislator

So the work of this committee essentially is to establish that standard and then whether or not it becomes a requirement does the legislation provide that in order to receive CHIP or Medicaid funding that you must do this? I'm not sure in the 3,000 pages of that bill, which I have to admit I haven't read all of it, although I've made some dents in it, I don't know what exactly that provided. Does it require, as a premise of funding for S-CHIP or a premise of participation that you must do this?

Sam Karp – California HealthCare Foundation – VP of Programs

As far as I know it does not. Again, as Farzad said, the secretary may require these along with funding.

Gayle Harrell – Florida – Former State Legislator

So if the secretary makes the determination that yes, he will require that any participant in Medicaid—that any state that participates in Medicaid must do this then he can do that by rule and that becomes law then?

Sam Karp – California HealthCare Foundation – VP of Programs

I assume so. Is that correct, Farzad?

Farzad Mostashari - ONC

If we may, I would suggest that I'm concerned that we address what was asked of the Policy and Standards Committee and ONC to do rather than—

Sam Karp – California HealthCare Foundation – VP of Programs

Speculate on—

Farzad Mostashari - ONC

Yes.

Gayle Harrell – Florida – Former State Legislator

Agreed, but there's a lot of potential once the standards are set off and the whole ... goes down.

Sam Karp – California HealthCare Foundation – VP of Programs

Well, but I think we have a very specific charge from the law.

Gayle Harrell – Florida – Former State Legislator

Thank you.

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

Okay. Go ahead, Sam.

Sam Karp – California HealthCare Foundation – VP of Programs

I'm going to move to the Verification Interface recommendations. There are two recommendations here. The first recommendation is that we recommend that federal agencies required by Section 1411 of the Affordable Care Act share data with states and other entities for verification of an individual's initial eligibility, recertification and any change in circumstances for health insurance coverage, options under ACA that the federal agencies and the states use a Web service approach that could also be used to support such eligibility determinations in other Health and Human Service programs, including Medicaid, CHIP, SNAP and TANF.

This is what I was speaking to a minute ago; that the Section 1411 of ACA requires a minimum use of three verification sources, from the IRS for income, from the Department of Homeland Security for legal status, the Social Security Administration for citizenship. We've had testimony from all three of those federal agencies that they are in the process of developing the mechanism to be able to provide real-time and they believe they can provide a Web services capability for states to verify those three different sets of information with these federal agencies. We're recommending that a Web services approach, which we believe is most efficient and could operate in real-time.

Our second recommendation is that the federal government develop a Reference at Implementation software tool that contains the standard for obtaining verification of an individual's eligibility to ensure a consistent, cost effective, streamlined approach. So we're recommending that an actual reference verification service be developed that potentially could be used by all states rather than the states having to build separate verification services, one-off in each state.

What we're suggesting in the second bullet under recommendation 2.2 is that in order to ensure a comprehensive and timely verification process, additional information, additional sources may be needed to fully determine eligibility for Medicaid, as ACA requires and then for the various subsidy programs and that the list of other verification sources on this page may be required to come up with a comprehensive and a timely eligibility determination. So first is that Web services be used as the vehicle for these required electronic verifications and second, that a reference application be developed by the federal government that potentially could be used by all states.

I'll stop there with the set of second recommendations, second and third recommendations. Questions?

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

Any questions or comments? It sounds like you're a go.

Sam Karp – California HealthCare Foundation – VP of Programs

Let me just mention one other thing, this is a really critically important component of simplifying eligibility and enrollment. Currently, in most systems applicants are asked for a lot of information that verifies their income, their citizenship and so on and they have to provide written documentation. If this can be done through a set of core data elements a lot of questions don't have to be asked and the paper documentation doesn't have to be provided in many cases. There will still be instances where there will have to be manual intervention and so on, but an 80/20 rule here can greatly simplify the process.

Aneesh, are you on?

Aneesh Chopra – White House – CTO

I am.

Sam Karp – California HealthCare Foundation – VP of Programs

Terrific. I hand it over to you.

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

Before you go on there's a question.

Gayle Harrell – Florida – Former State Legislator

What is the mechanism for authentication of the individual? Are they going to be doing this on-line? How are we going to authenticate or is this in person? What's the process?

Sam Karp – California HealthCare Foundation – VP of Programs

Authentication is actually done by the agency, by the state agency or the exchange or the Medicaid department. The authentication, the verification is not done by the individual. We are going to talk about authentication of the individual in our Privacy and Security recommendations in a few minutes.

Gayle Harrell – Florida – Former State Legislator

Okay. Also, this is happening, presumably at the individual who is applying for these benefits would then, of course, you're assuming that they have the consent to access this information.

Sam Karp – California HealthCare Foundation – VP of Programs

They would give their consent as part of the process. They would be asked to give their consent as part of the process. There would be use agreement, limitation of use agreement, as there are now between the state agencies and the federal department.

Gayle Harrell – Florida – Former State Legislator

Okay.

Neil Calman – Institute for Family Health – President & Cofounder

I just have a couple of questions about operationalizing this. So if somebody enters a hospital and the hospital seeks to obtain coverage for the person through an emergency Medicaid provision or something, the hospital hands the person a piece of paper and says, "We're going to apply for insurance coverage for you," what happens? Can the person refuse to do that knowing that there is information in one of these things that shows that they're not documented or something like that? What would happen in a circumstance like that?

Sam Karp – California HealthCare Foundation – VP of Programs

I'm not sure I can answer that question.

Neil Calman – Institute for Family Health – President & Cofounder

I mean I'm just thinking about what the implications are of what we're doing as opposed to the—maybe that's outside the scope.

Sam Karp – California HealthCare Foundation – VP of Programs

Yes. That is most certainly outside of the scope. I mean the core question, the charge that we have is to understand in a very simple and practice manner for state and local agencies looking to enroll recipients that there are certain required verifications. Those verifications sit, as referenced in this document, in federal agencies.

The question is what is the technical method by which those state and local entities access federal agency data. As you might imagine, we have a variety of technical models, depending on the agency at hand. So in some models there's a batch query; in others there is the chance for real-time data checking.

The recommendations here are explicitly around the technical model or how we stand up a referenced implementation, software tool to make the process of connecting to the federal government cost effective and simple. That is the scope of this particular group and the nature with which we've been doing our work.

Neil Calman – Institute for Family Health – President & Cofounder

So I guess I would address this to Farzad. Where are the policy implications and the healthcare implications of this connectivity going to be discussed or is that—

Farzad Mostashari - ONC

Well, certainly not with the health IT. Agency, ONC or Policy Committee ... this is really something that we all have to be very careful to resist is to get into where there is really critical policy decisions that will be made through the health reform and Affordable Care Act implementation process.

Gayle Harrell – Florida – Former State Legislator

Does the legislation provide where that discussion is going to take place?

Sam Karp – California HealthCare Foundation – VP of Programs

That's out of my scope.

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

This is a huge program, everything in the ACA, and so we've been asked the specific task, to provide recommendations, so I think we probably should focus our discussion on that task if that's okay.

Sam Karp – California HealthCare Foundation – VP of Programs

In every single circumstance where we've talked about technology we've always been able to have a discussion about what the implications of simplifying this stuff are. For example, what does it mean when these data sources that are coming from different places have different information in them and so people are actually impeded in getting coverage because there are three different addresses and three different data sources and how that stuff gets reconciled. There are policy implications behind using the way in which information is passed also creates completely new workflows and impact on patients that are seeking care and people seeking coverage. So it would just be nice to be able to figure out, at least know that that discussion is taking place somewhere.

Aneesh Chopra – White House – CTO

Absolutely, that's a conversation that's being run out of the secretary's office in conjunction with the White House Office of Health Reform. They're on a plan and a timeline to make the policy decisions as we gear up towards 2014. I'm highly confident there will be plenty of opportunities for public input on the whole range of policy issues around the issues you've just outlined. But the particular question we've been tasked with, if people need to verify their data by submitting a batch query to the Social Security administration as opposed to a real-time Web service what's the model? What's the option? What's the recommendation? On that very specific and narrowly defined question we have a recommendation and that's what you see in front of you.

Sam Karp – California HealthCare Foundation – VP of Programs

That was

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

I have a question. Maybe I missed a little bit of this at the beginning when Sam was talking I think. Were there four data elements that were going to be used or four core elements that were going to be passed? Did I get that right?

Sam Karp – California HealthCare Foundation – VP of Programs

We've looked at ten core elements. I was referring specifically there to the core data elements for the verification service. What we heard in testimony from the Social Security Administration, for example, is that of those ten core data elements I can't remember if it was four or five that they use that are very

specific just for the match of the individual for verification purposes, so not all of the core data elements that Doug was looking at, but a subset of those that are used for verification. We're going to go a little deeper on those, particularly looking at the format. So, for example, we might specify the number of characters in a last name field so that the last names aren't truncated which makes doing matches much more difficult.

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

Yes. I think that gets at it a little bit. I don't know if Neil was headed in this direction. I just wanted to be sure that we understand if we're proposing a standard how accurate is that standard, what sort of duplicates there were, issues of matching and how those get resolved and how efficient the process really can be. I understand we're really focused on the technical stuff here and want to keep that as the core comment, but it's important if you're trying to do this verification that you have some sense of reliability in the process.

Sam Karp – California HealthCare Foundation – VP of Programs

That's right.

Aneesh Chopra – White House – CTO

Without much further ado, in the same spirit of these technical recommendations I'd like to provide the final three categories that we tackled. The first of those is in the expression of business rules. If you flip to the next slide we have two recommendations that I'd like to share with the group.

The first of those recommendations—and perhaps the most relevant—is that as we proceed the recommendation explicitly calls for the expression of business rules using a consistent and technology neutral standard. More to the point, we encourage the federal and state agencies should clearly and unambiguously express those business rules outside of the transactional systems to provide maximum transparency to the end user. The mechanical challenge we face is that today the overwhelming share of those business rules are not transparent or in a manner that is easily accessible.

So our second recommendation is to allow for an open and collaborative exchange of information and the ability to innovate. In order to do that we're recommending that the federal government maintain a repository of business rules that are needed to administer the Affordable Care Act and Medicaid health insurance programs. That may include an open source forum for documenting and displaying eligibility, entitlement and enrollment business rules to the public in a standards based format.

Reactions to this topic?

W

Can you give us some examples of what you're talking about in business rules?

Aneesh Chopra – White House – CTO

There are so many, but I'll give you an example of a given rule. A particular state might have a rule that says you're eligible for Medicaid if you are under a certain amount of the federal poverty level with some exceptions by adding back in child support or whatever, other financial sources that they would use in their calculations. So in order for that business rule to be understood and if there is transparency in the rule, the goal is to have the rule itself expressed in a manner that is outside of their underlying operational system that is made available. The purpose of that is that one of the requirements of the Affordable Care Act is to simplify the consumer experience such that if they are applying for health insurance, for example, through the exchange how easy is it for them to proceed with evaluating options in other Health and Human Services programs.

Well, in order to do that one needs to understand what the eligibility business rules are so that they can evaluate what verified data sources we matched up against those rules in order to make some progress in determining whether or not that individual is eligible for those additional programs.

So today it isn't exactly transparent at the technical level for us to understand how state program A, B, C or D calculates or renders its judgments about whether you are or you're not eligible for that program. This just moves us on a path of transparency so that more and more of the technical solutions can connect and render judgments based on the verified data that we've outlined on the interface discussion that preceded.

Other questions?

Paul Egerman – eScription – CEO

I like all of the recommendations, but this one about business rules I think is really extremely good.

Aneesh Chopra – White House – CTO

Is that an Amen, Paul?

Paul Egerman – eScription – CEO

Absolutely. From the standpoint of transparency and also building these systems in the future, to build them on a rules basis instead of the way they're built right now, this is actually a very important step forward. One of the things that was interesting attending some of the meetings were people from different states really wanted to know how other states are doing things to understand the differences. Maybe they don't need to be as different as they are. Each state doesn't necessarily need to be as different as they are. This recommendation is very, very good.

Aneesh Chopra – White House – CTO

Thank you, Paul. Others?

Gayle Harrell – Florida – Former State Legislator

Are you proposing that basically that each state maintain a Web site with their individual rules or the federal government has a Web site and it's by state so you know what, for instance, eligibility requirements in Florida for Medicaid are or S-CHIP versus, say, Georgia or another state?

Aneesh Chopra – White House – CTO

Well, the recommendation is actually much more optional in its nature, which is to say the open and collaborative forum, which we are encouraging the federal government to maintain, has as its core principle in the spirit of open source that organization may or may not participate in this program. I mean in a sense the spirit of this is the role of government as convener and there is benefit and transparency and those who'd like to participate—

I came out of the state government and I understand personally how difficult it is. Our public health, social services database is written in Unisys Mapper back in the '70s. There isn't a human being on the planet that actually knows how to go into the underlying code and pull out all of the individual rules that have been hard coded into that software over the years. It's a product that's now been sunset, so states all over the country are in a very difficult task, because there's no transparency in their IT around what those rules are.

So our simple recommendation is that there be an open collaborative that would encourage and invite folks, who wish to share their rules to be able to do so and benefit from each other. I think the states and locals from the testimony we've heard would find this to be a very welcomed and encouraging tool. It's an open collaboration, which means it's not mandated. It's not suggested. It's an availability that I believe will be value added to those who participate.

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

I'd almost like to build on Paul Egerman's comment. I may be opening more nests, but I almost think we need these kinds of rules for privacy. In other words, the whole notion that it is transparent and open and can be shared may move a lot of things forward and you're saying it's enrollment and eligibility, but any, that's a side comment.

Aneesh Chopra – White House – CTO

Well, you're previewing my recommendations on privacy and security that are coming up.

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

Okay. Go ahead.

Aneesh Chopra – White House – CTO

Other reactions to this? Gayle, did I answer your question?

Gayle Harrell – Florida – Former State Legislator

I want to know when you're talking about the open source kind of thing, are consumers going to have access to this and know what's in there and be able to see the differences, bring those rules one state to another or are we talking about sharing code for states to build their databases on.

Aneesh Chopra – White House – CTO

Well, my presumption is that this will evolve over time and it will be simpler and easier to use as it goes. My gut instinct is that this information will be made available and that by being an open platform third parties could consume it and retransmit the information in a way that is plain English for folks to know what those rules are. That software programmers will find value in this by being able to reuse components for their own judgments, state and local government decision makers will be able to see in a transparent manner how they benchmark on some of these things to judge tradeoffs between whether or not a particular rule that creates an administrative cost burden that may be higher or lower relative to other states might see in a transparent manner the other options. The beauty of a collaborative forum like this is that it's, frankly, open to the end users to do with it what they wish, so we're not recommending any restrictions on who can see this information and how it's used. We're simply suggesting that there be a platform available, which, today does not exist.

Farzad Mostashari - ONC

Gayle, I do think that transparency to the consumer is an important goal as we call out in the first recommendation.

Gayle Harrell – Florida – Former State Legislator

I would like to see us go even stronger in the idea that ... knowledge be done in a way that it is understandable to consumers.

Aneesh Chopra – White House – CTO

Yes. So our language around clearly and unambiguously expressing the business rules to provide maximum transparency to the consumer I think was the spirit of that comment. We would certainly welcome your feedback on how maybe, if that is not exactly clear, to make it clearer.

Farzad Mostashari - ONC

Gayle, it maybe is something that goes beyond standards based format to human readable as well.

Gayle Harrell – Florida – Former State Legislator

Yes.

Aneesh Chopra – White House – CTO

That's very helpful. Thank you. Other reactions to business rules?

The next set of recommendations are in the area of transmission of the enrollment information. It's one of the key, obvious points that came out of our working group. There are moments and handoffs between once your eligible you then have to be enrolled and to be enrolled we have to transfer information from party A to party B. In this case, either the insurance plans or the state and local health programs or human service programs. So we dove into the technical toolbox and we identified a couple of recommendations.

The first is that we use the existing HIPAA standards and specifically called out 834, 270 and 271 to facilitate the transfer of applicant eligibility, enrollment and disenrollment information between ACA, health insurance programs and the various others that I just described. That is basically an existing standard that's been in use and so we sort of encourage that that be a critical component of this program, but; and that's important but; the second recommendation.

We did believe there needed to be further investigation of whether these existing standards actually acknowledge the receipt of an 834 transaction and if not, perhaps consider the development of new standards. So it's not so much as just saying here's the information on the applicant. Good luck. The notion is we were not privy to, nor did we believe there exists a basic standard in acknowledging receipt of that transaction, so with that one caveat we felt these were important recommendations to ensure that the end-to-end experience for the consumer would be met.

Reactions to this one? All right. That was pretty straightforward, so I figured that was fine.

Now the last set of recommendations and there are three that govern privacy and security, so let's take a few minutes on each of these. The first recommendation is to make sure that consumers have timely, electronic access to their eligibility and enrollment data in a format that they can use and, frankly, reuse.

Second, the knowledge of how their eligibility enrollment information will be used, including the sharing of that information across programs to facilitate additional enrollments and, frankly, we recommend to the extent practical, allow for the control over such use.

Third in this recommendation is the ability to request a correction or update to that data. The key insight here was to bring the great work that's been done in privacy and security in the clinical realm, building on the work that's been done under the HITECH Act, which actually specifically gave consumers the right to obtain an electronic copy of their protected health information from HIPAA covered entities to basically, now that that's also been including health plans and clearinghouses, that we should take a look at the format and the content of those disclosures as needed. So basically, we are transferring or benefiting from the great work that's been done in the clinical realm and encouraging further evaluation about format and content provisions as we move to expanding the number of those covered entities to include the administrative side in terms of the health plans and the clearinghouses.

Any questions on this particular recommendation? There are two more in privacy and security.

Gayle Harrell – Florida – Former State Legislator

Am I reading this to say that basically a consumer would have the right to know who has apps for eligibility, who has access to their information or to know what, for instance, the health insurance plan perhaps may have denied them, why and they would know exactly what has gone on with their eligibility information and they would have the ability to access that and find out all of that information?

Aneesh Chopra – White House – CTO

The first of your comments was an absolute yes. I want to be slightly careful about how you said the second half. I mean we are acknowledging how their eligibility enrollment information will be used. It basically says in very practical terms that we've just verified that you are, in fact, a citizen. We verified your income based on whatever data source we've chosen. That that information is going to be shared with program X, Y or Z or the exchange or whatever, that that information, the knowledge of how your eligibility enrollment information will be used, in addition to giving you transparency over how it will be used. We're also proposing, again, to be impracticable, control over that use, so if you do not wish for that information to be reusable in the context of looking at other programs, our suggestion is that you should have control over that use.

Now, what happens in the agency rendering its judgments based on the data that you know has been used to render that judgment is not specifically called for in this recommendation.

Deven McGraw – Center for Democracy & Technology – Director

Depending on the program there might be some other laws that would apply that would give consumers access to that data.

Aneesh Chopra – White House – CTO

Yes. This is just narrowly scoped on the technical data elements that are called for in 1561 that you should have as much transparency and control over the use of that data as possible is basically the recommendation.

Deven McGraw – Center for Democracy & Technology – Director

Which is a good one, I just have one question though. Say I'm at the beginning of an implementation, noted that there would be limitation of use agreement among the participating agencies, something to the effect of were using this data to determine your eligibility and that's our sole use of it. We're not using it for any other purpose. We won't let anybody else touch it, etc.

I think that needs to go in here because I know it's a policy statement, but it's also everything on this slide one could argue is policy. So I don't think it's totally out of bounds and without mentioning that specifically in these recommendations one could read that recommendation 5.1 is suggesting that it's really all up to the consumer to control how their data is used.

M

Could you comment on part two of this that sort of alludes to the notion of knowledge and how it will be used?

Deven McGraw – Center for Democracy & Technology – Director

Yes.

M

Could you think of an amended sentence, a word or two that kind of gets at that? Sam, do you want to react to that?

(Overlapping voices.)

Sam Karp – California HealthCare Foundation – VP of Programs

... make a comment. I mean, Deven, your comment is correct. If you read the letter it is referenced in the letter in the appendix on privacy and security. What it describes in the appendix is that there is going to be a privacy notice that is actually given before any information is entered. It tells the consumer basically what all of the uses are for the consumer's data and the notice. That it says in the letter that if there's any uses of the data, other than what's in the privacy noticed, basically, consent has to be obtained—

Deven McGraw – Center for Democracy & Technology – Director

Yes, but what I'm talking about is an application of fair information practice, collection, use and disclosure limitation, such as you customarily find between state agencies that have a grief to share data in order to administer a program. It's simple language and it says, "We're only going to use this data to implement this program and that's different from just sticking it in. It's a commitment of the entities participating in this program. It's not just that you provide notice to the consumer, who is going to have a limited ability to control what the agencies do with it unless clear limitations are put on the data.

Farzad Mostashari - ONC

One thing to maybe just make you think about though is that explicitly the goal of all of this is that different agencies and different programs ... the consumer not have to apply separately for each of them, so I—

Deven McGraw – Center for Democracy & Technology – Director

I totally get that, Farzad, and I'm not suggesting that the uses of the data that are contemplated by this program that there's anything untoward or inappropriate about it, but there isn't any reason why the

agency should not, in participating this, commit themselves to when we get this data to do your eligibility that's what we're using it for. We're not going to use it for something else.

Farzad Mostashari - ONC

My point is just that if we draft, if we revise this then we should just be careful that the recommendation doesn't subvert the intent of this, which is that information collected for one program can be reused for ... for food stamps—

Deven McGraw – Center for Democracy & Technology – Director

That's right, but even accepting the sort of scope of uses that we intend to promote through this program, that just ought to be specified and uses beyond those should be limited. That's all.

Farzad Mostashari - ONC

That's exactly the intent of the second one, so that they have knowledge over how it's going to be used—

Deven McGraw – Center for Democracy & Technology – Director

Right, but it's not framed in terms of commitment among the participants and that's different than just providing knowledge to a consumer.

Gayle Harrell – Florida – Former State Legislator

I totally agree with what Deven is saying. I think this can get very out of hand if you're not very, very careful.

Jim Borland – SSA – Special Advisor for Health IT, Office of the Commissioner

I want to address Deven's point. First of all, that kind of language and those kinds of requirements are in every data use agreement that we have with states.

Deven McGraw – Center for Democracy & Technology – Director

That's what I thought.

Jim Borland – SSA – Special Advisor for Health IT, Office of the Commissioner

I can assure you that they're also in every agreement that the IRS and DHS has as well. I think the real issue here and maybe this is what you were getting at, Deven, is that the agreements between the health insurance exchanges and the providers, the health insurance providers that they work with have to contain that kind of language as well. We would certainly make it a requirement of the state in our data use agreements.

Aneesh Chopra – White House – CTO

Jim, my presumption is that that's clearly a policy judgment that you obviously will be doing. Is there a technical aspect of this that needs referencing in this set of recommendations that data under this shall abide by the constraining principles as outlined or what have you? I'm not entirely sure—

Jim Borland – SSA – Special Advisor for Health IT, Office of the Commissioner

Well, certainly we could get legal ease in there in terms of talking about the Computer Matching Act and things like that, but I think it's really a relatively narrow issue of data use governance between the state insurance exchanges and their participating insurers. So I think it's a policy issue. It's certainly not a standards issue.

Deven McGraw – Center for Democracy & Technology – Director

It is. It's absolutely a policy issue, but I suggest that everything on this slide that's up on the screen now is policy. I felt like you kicked a door open, so I walked right into it.

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

I too see this as a slide full of policy. Going back to maybe what I thought I heard, but I wasn't sure, when there was a question maybe from Aneesh to Deven, are you saying that maybe we should change from control over the appropriate use to knowledge of?

Deven McGraw – Center for Democracy & Technology – Director

No. I'm not suggesting any change to number two. It's a completely different, but related concept of the participants and the agency and the health insurance exchange and the health insurance participants in here be subject to some contractual limitations on their use of the data, consistent with the purpose of the program.

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

Okay. So then let me go back then to something that I think Neil was alluding to earlier: Someone gets into a hospital, goes through some verification and then they say, —don't want you to go out and check with the IRS or Homeland Security or whatever else. Does that word control there mean that that person has that right and even though the law says an appropriate use is to do this they can interfere or somehow prohibit that sharing of knowledge or sharing of their verification data?

M

I'll take that one. The reason we wrote the words to the extent practicable, the required in law verifications are obviously there for required in law and therefore, if you are suggesting that you have a certain income or you're suggesting that you are of a certain status, those are to be verified. That's in statute.

The control question here is whether or not after you've completed that transaction you allow for or have control over whether or not that data can be made available in a manner that allows you to be evaluated for other additional programs. So the individual transaction by which you're coming in for, this is not to say that you can control the terms of that transaction. It's to say, as you are to include sharing across the other programs that would like to reuse that data that you have control. That's what that's about.

M

Deven, I understand, I think, the impetus. I do wonder though in terms of these recommendations are all clustered around the point of the enrollment process that is prior to the relationship that you're describing and the recommendation to have the consumer centric approach to the enrollment process is still clustered around the enrollment, the needed enrollment process.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

M

I'm not sure. We'll have to take a look at whether the 1561 statute really brings to bear on what you're talking about, which is the relationship between, for example, the state and the health plan and the relationship—

Paul Egerman – eScription – CEO

That's true. What you just said was true although, again, if you read the letter of recommendation there's an Appendix E or Exhibit E that does describe fair information practices and it says collections and limitation. I think we can accommodate what Deven is asking for by just adding collections, limitations and use limitations; it's collections and use limitations; just add a sentence there.

All we're doing in Appendix E is saying here are best practices for fair information practices that the state should consider.

Deven McGraw – Center for Democracy & Technology – Director

Yes. I mean I didn't have a chance to read the appendix, but that's exactly what I'm asking for.

Aneesh Chopra – White House – CTO

Perfect.

Paul Egerman – eScription – CEO

Where it says collection and limitation I think we can address it if it said collection and use limitation and I think it takes care of that entire issue. It's a very legitimate issue.

Aneesh Chopra – White House – CTO

Excellent. Okay. So let me quickly run down the last two privacy and security recommendations. The next one has to deal with the consumer's ability to designate a proxy or a third party to be able to actually have certain authorities on the data; that is whether or not the third party can read the data, write to the data, read and write to the data or read, write and even edit to the data. Therefore, the recommendation is that there should be the ability for a consumer to designate a proxy and if so, here are the subjects that we wish to recommend.

One: that they should be subject to the granting of separate authentication and/or log-in processes for proxies. What we don't want to have is someone saying, —by, Deven, I'm going to log in as you and I'm going to do this work for you.”

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Aneesh Chopra – White House – CTO

What we want is I authenticate myself as a proxy. There are rules governing how and what manner I have rights to serve as a proxy. The great news is there are technical methods by which we can authenticate the proxy separate from the user name, if you will, for the individual. There should be absolute tracking and immutable audit logs designated to each specific proxy access and major activities and those should be time limited and very easily revocable, so if we had a network of proxies and we learn of that action, that there is a technical methodology for basically cutting you off for bad behavior, if you will.

So that's the second recommendation; it's governing how to address proxies. Again, it's a policy decision if a state or local wishes to allow for proxies, but if they were to choose to do so there is a technical path that gives us the authority to separately authenticate and so forth.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Aneesh Chopra – White House – CTO

Reactions? Questions to this one?

Gayle Harrell – Florida – Former State Legislator

Can you give us an example of a proxy? Who would you assume would be a proxy?

Aneesh Chopra – White House – CTO

So this is a fun one that came out of our hearing last week. I don't know if you have Netflix—

Gayle Harrell – Florida – Former State Legislator

Yes.

Aneesh Chopra – White House – CTO

Okay. So Netflix—I don't know if you have an iPhone or an iPad or an Android device, but assuming, let's just for the sake of discussion, say that you have an iPad. There is a third party proxy called PhoneFlix that has the right to present to you information and help manage your account, change what movies you rent and adjust your queue and so forth. That application is a proxy that has the authority on your behalf to manage your queue.

When you register, first, the software product had to register as a proxy with Netflix and under its own authentication rules when, Gayle, if you were to use that product before you could get to use that product you are given a set of controls. Would you like this third party to be able to adjust your queue? Would

you like them only to let you see what's in the queue and not change it? You have those controls. So that was sort of a non-healthcare example of the use of technical proxies that are in the mainstream today.

Sam Karp – California HealthCare Foundation – VP of Programs

And the example of who it might be given to is a family member, a community based organization that's assisting an applicant through the actual enrollment process and so on.

Aneesh Chopra – White House – CTO

Does that answer your question?

Gayle Harrell – Florida – Former State Legislator

Yes. I'm just concerned about how you authenticate the proxies.

Aneesh Chopra – White House – CTO

That's the whole point. You have to separately authenticate them from the individuals and that's exactly what that recommendation speaks to.

Gayle Harrell – Florida – Former State Legislator

I can see in this era of identity fraud and especially Medicaid fraud that we face in Florida I can see tremendous abuse potential.

Aneesh Chopra – White House – CTO

Yes, which is why the third bullet says, —Easily revocable.”

Gayle Harrell – Florida – Former State Legislator

Well, I think the authentication element is extremely important. We face huge Medicaid fraud here and Medicare fraud. This has tremendous potential for abuse if it's not done very carefully.

M

So it's revocable if the primary party knows that they have a proxy—

Gayle Harrell – Florida – Former State Legislator

Yes. Right. What happens, this is a pay and chase system. These people disappear very easily and they have built—the state of Florida and the federal government—millions and millions of dollars before they ever are found out.

M

But, Gayle, it's up to the states to decide how they're going to implement this. I mean what we're doing is setting up some standards to help the states do this.

Aneesh Chopra – White House – CTO

Right. Florida may choose not to. Yes.

M

... methodology to offset the ... proxies and that might be helpful to the state of Florida. The whole discussion that Aneesh just gave about Netflix, the technical discussion was actually fascinating, how that there is technology that's available to do this. So that's how we might be helpful to the states in showing them how to do it, how they do it is up to the state of Florida.

Aneesh Chopra – White House – CTO

For example, in my tenure in Virginia we had software that allowed community health organizations to enroll young children in the CHIP program. That software, under this recommendation, would have much greater control today than it did when that program was launched in the sense that it would be registered as a proxy. You would know who has the authority over it. You would have all of the immutable audit laws and you'd have the ability to track and revoke privileges if it's a violation, but it's extraordinarily

customer friendly if a young person walks into a federally qualified health center and learns that they can enroll in S-CHIP, that process being more made accessible. So, Virginia allowed that to happen and other states may choose not to or do and that's obviously a judgment that they make.

The last recommendation: We believe that the state or other entities that are administering the various programs have very strong security safeguards that will ensure the privacy and security of the personally identifiable information. So we said very specifically data in motion should be encrypted. We recommend specifically the NIST standards for how one does that and that the eligibility systems, the automated ones specifically, should have the capability to record their actions related to the PII for determining eligibility, including the date, the time and all of the information associated with how and when they rendered such judgment and that they have an audit log that is accessible. That's just to make sure that we have clarity, so, for example, if you are in fact transmitting your data from system A to system B that data in motion must now be encrypted.

Any reactions to this recommendation?

Gayle Harrell – Florida – Former State Legislator

Good.

M

Great job.

Aneesh Chopra – White House – CTO

All right. This is where we are, team.

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

You need an approval of this, correct, Aneesh?

Aneesh Chopra – White House – CTO

Yes. We, as a society, need approval.

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

We as a society. No pressure. So would anyone like to move that we approve this recommendation?

M

Just a note, Paul, that we had, I think, one line edit that we talked about making it human readable format for the rules. If there any other edits like that then we can vote and then with the understanding that those line items would be included.

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

Yes. There was an issue that Deven brought up in Appendix E where it says collections and limitations; it should be collections and use limitations.

M

Motion to approve with those line edits—

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

Is there a second?

M

Second.

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

Any further discussion? Okay. All in favor?

Participants

Aye.

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

Is there any opposed? Are there any abstentions? Okay, Aneesh.

W

Woohoo. Woohoo.

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

First, thank you very much for your time flexibility. I knew that this was something you needed to get a final approval, so I wanted to make sure you had time and we snuck in the time; we created the extra time for you.

Aneesh Chopra – White House – CTO

Well done. Terrific. Thank you, Paul. Have a great day.

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

Thank you.

Aneesh Chopra – White House – CTO

Good-bye.

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

Now we'll have an update from the Information Exchange Workgroup with Micky and David.

Micky Tripathi – Massachusetts eHealth Collaborative – President & CEO

Hello. I'm here. Is David on?

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

I'm here.

Micky Tripathi – Massachusetts eHealth Collaborative – President & CEO

Thank you and good afternoon, everyone. We'll do a pretty quick update. I think, as everyone knows, we've been sort of spending the summer thinking about the refocus of the Information Exchange Workgroup and reconstituting it to correspond with that focus and then once we sort of got through all of the vacation issues and all of that we've now sort of put our heads together and have the group up and running and are moving forward with the development of the agenda, a couple of taskforces that we're launching now and some more stuff to come, so we want to give the Policy Committee a quick update on that.

So this is the newly constituted Workgroup. We basically had a couple of changes and these are very quick. David Lansky is now Co-Chair. We were able to co-op him into coming over and being the Co-Chair, which I'm delighted about. We have added some new members of the Workgroup, which I think I've described before. I won't go down in detail because we have talked about this before, but it was really to get a broader array and more diverse array of folks from the state, so state ... coordinators or folks involved in state level activities with an eye towards being able to understand more of the emergent issues coming up from state implementations as they happen. Also, wanting to get more representation from Medicaid and public health as two critical areas that require a lot of coordination at the state level as the implementations are under way.

Neither of those kinds of activities were really fully represented or even adequately represented on the Workgroup before. So we've reached out and tried to get more representation along all three of those dimensions, which is the Workgroup that you have here. We've graduated in size so that we now have to be on two calls as opposed to one.

So the basic charge—the next few slides are just review—just to remind the committee of where we left off when we last discussed the changes to the Information Exchange Workgroup. First is we're going to focus on breakthrough areas where there are policy barriers that may be preventing providers and/or states from being effective enablers of broader and deeper health exchange. Those are specific clinical transactions that are already identified as important or critical issues that are likely to get unearthed as we move forward with all of the various activities under way related to information exchange at every level you can pick up.

The second charge to the group is to really be sort of a conduit with an ear to the round of the state level activities. As we know from the experience that we've had to date with information exchange and interoperability, a lot of the issues that end up being policy issues aren't obvious from the beginning and they actually emerge from implementation activities once people really start to get into the nuts and bolts of things, so the idea being that we want to be able to have this be a place where we can stay, keep the pulse of that at the state level and then be able to distill issues as they start to arise and as they seem to be appearing in a number of places that are policy relevant and may lend themselves to actionable policy solutions and then be able to investigate those, dive into them and bring them to the committee as the Workgroup sees fit. So those are really sort of the two charges that I think we've already talked about and that the committee, I think, was very supportive of in the May meeting.

So, this is a slide that, again, another background slide, that you have seen. Just sort of think about the overall framework here; what we don't want to do is just start to boil the ocean around every type of interoperability issue that one can imagine because there's a whole host of issues and there's no end to that. The idea here is to look very specifically at the key meaningful use transactions and try to identify breakthrough areas where they were maybe able to see that those will be helpful and then, as I said, kind of emerging issues as well. Some of the ones that have already presented themselves as being possible barriers are barriers to directed exchange, in particular, provider directories being an area that almost every state or reasonable activity is focusing on now as it relates to directed exchange. That's one area that David will describe when he talks about taskforces that we're going to be focusing on and then these coordination issues with public health and Medicaid as well.

We want to go through a framework to identify where, in which areas do we think that they may lend themselves, the issues may lend themselves to actionable policy recommendations and then try to make some recommendations related to specific levers that the government may be able to use to facilitate a more robust health exchange.

So in the next few slides I'm going to turn it over to David Lansky, who is going to describe the two taskforces that we've put together to really just hit the ground right now on provider directories and public health. Then I'll come back with next steps and a preview of what we want to present at the next set of Policy Committee meetings.

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

I think this may be very small print on your screen, so let me just quickly summarize the main themes here. Essentially, we've asked two subgroups to form and we have several members on each and a few who are on both. They're addressing the two topics Micky just introduced, the need for some kind of interoperability nationally among the provider directories and the need for those directories, therefore, to be interoperable and have some kind of common standards to their content and layout, but also implicit in that are some kinds of agreements about what the expectations or rules will be for the entities that are registered with these provider directories.

As you see on this list, there are a number of questions that have surfaced in a preliminary way. This is really kind of a laundry list still that will be pared down and prioritized once the group starts to meet, which is next week. So this group hasn't even met yet. Our first ... issues that surface on provider directories, how do we assure interoperability across provider directories that different states and other entities may be creating. As you recall, about a year ago we had an initial hearing on provider directories, so we want to move forward with that preliminary information and start talking about how do we leverage the existing directories that many entities maintain to take advantage of them in what we do here, including

immunization registries, the private commercial registries and so on and then have some kind of authoritative directory, whatever that might mean.

How do we promote economies in directory development so that every state isn't reinventing the design work and legal work and business work around these things? Who is going to be responsible for maintaining and managing directories that are accessible to the HIE? What is the governance model for state-wide or other directories? What policies are needed, particularly as the different directory models, whether they're central or federated, come into play? Are there any different requirements for the policies that govern these, much as the Tiger Team talked about this morning? Many of the same issues may apply to the provider directory side as well.

What business models will, in the long-term, sustain the operation of these things? Are we comfortable with those business models? Do we need any controls over those business models? A lot of people have an interest, an economic interest, in accessing provider directories and how do we feel about that? How do we maintain currency of information on providers in these directories and what motivates providers to maintain their own, self manage and maintain their own entries versus having some third party be responsible for maintaining accurate, current information. Then how do the public health and Medicaid applications affect the design of the directory that we envision for HIE?

That may not be the end of our list, but it's a starter set for some of the topics the provider directory group wants to take up. I'll say parenthetically, and I think Micky will come back to this, that there is some sense of time urgency on this one; that a number of the states in particular, under their cooperative agreement are feeling the need to stand up or at least identify a provider directory infrastructure in order to support information exchange and given that they all want to get going in the next year, over the next three to nine months they have to address some of these questions. So to the extent we can help ONC provide guidance to the states in support of their cooperative agreements we think that's a fairly urgent priority.

The next slide is on the public health domain and here you'll see another long set of issues, some of which overlap with the provider directory topics, so we'll sort out how to take advantage of our expertise in that area. How do we leverage provider directories through public health purchases? How do they interact with the HIE uses of provider directories? There is more.

This is from how do we respect the fact the state's public health agencies are under tremendous economic pressure, yet they want to be supportive of helping to meet the meaningful use requirements? How do we implement the meaningful use public health reporting and daily exchange requirements and have that be a harmonious process where existing state public health reporting requirements and now the meaningful use and other federal requirements? How do we harmonize and implement those? The NHIN Direct standards and the public health reporting standards; are those going to be interacting successfully?

Noting that the public health agencies don't have a lot of money to update the daily collection systems, but meaningful use is going to encourage more public health reporting can we help address that in some efficient, national way? The ONC standards for EHRs, can they help to facilitate an efficient adoption process across the state? And then what policies and resources can help uniformity and public health data platforms so we can minimize either duplication or proliferation of public health reporting systems. Again, this group hasn't yet met. I'm sure when they do they'll start with this list and then begin to prioritize and probably add to it, but these are the kinds of topics that have so far surfaced.

With that, let me go back to Micky.

Micky Tripathi – Massachusetts eHealth Collaborative – President & CEO

Let me pause here and see if anyone from the committee has any questions. I mean the origins of these two and, as I said, we're trying to start somewhere with the things that seem to be the highest priority. The origins of these two are one, as David noted, the provider directory issue is front and center with many, many states as they think about their cooperative agreements and in particular as directed exchange and NHIN Direct have taken a huge focus after the issuance of the PIN and its requirement that

they focus on summary exchange. So that's a front and center issue and the ONC staff has asked that we try to provide any help and support there that we can.

The public health one is more along the lines of one of the critical use transaction areas. I'm sorry, the meaningful use transaction items that, as we tick down the list of what are the key stage one meaningful use transactions public health, we did labs. Not that the labs are done, but we had a focus on labs. We had a set of hearings on e-prescribing and public health was sort of the next one on the list as we started to work our way down there.

Gayle Harrell – Florida – Former State Legislator

I'd just like to comment on the provider directories as far as the states go. I think it's the sooner the better that we get the recommendations out there and not have each state reinvent the wheel. I think if giving guidance to states and of course, they may tweak things. They may do things, but we're going to have a lot of duplication. States, of course, are the ones that have control of licensure and things of that sort, so they're the ideal place to do this, but I think that some assistance to the states on how to do it would be very helpful.

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

Yes. I think this is coming at a critical time, so the good news is that it is something that's on everyone's mind. The bad news is that we need to act fast if we're going to provide any guidance, but there are two regional efforts that I'm aware of, one up in the northeast with New England and New York and one in the southeast where a group of states have gotten together to think about directories, so some of that collaboration and sort of thinking about joint approaches is already there, so there is certainly something to build on.

Micky Tripathi – Massachusetts eHealth Collaborative – President & CEO

Why don't we move to the last slide here? So in terms of next steps, what we want to do is for the September 14th Policy Committee meeting is we're going to work with these taskforces, which are really sort of at the formative stages now in terms of having cast the net widely to say what we think the issues are. Now let's start to prioritize and drill down into them.

We'll come back with a detailed work plan and deliverables for each of the taskforces and also some identification of what might be the next set of focus areas, so that we're always sort of forward-looking and thinking about what's next and what do we think is on the horizon so that we get people moving forward in a way that sort of matches up with where we think the needs are and where they're going to arise. Obviously, one big part of that, I think, is coordinating with the other workgroups, in particular, the Meaningful Use Workgroup, so we want to be able to coordinate with them and be sure that we're tracking their focus on stage two and stage three meaningful use definitions and supporting their efforts as much as possible.

For the October 20th Policy Committee meeting what we're going to aim for is recommendations on provider directories and then some perspectives on key public health issues that could be in the form of recommendations. I think there's an alignment that we want to make sure that we're doing with the Meaningful Use Workgroup, who are also doing some work on public health as well, so we don't want to be crossing wires there, so that's why I put it as perspectives. It could be in the form of recommendations as well, but we can work off-line with Paul and the Meaningful Use Workgroup to make sure that we're coordinated on that.

Then identification of emerging state level implementation issues; we had I think in the May Policy Committee meeting talked about the possibility of standing up sort of a standing advisory group of HIT coordinators. In talking more with ONC staff, some of the complexities of doing that arose and there is already, as everyone knows, sort of a robust programmatic approach with communities of practice and a program to support those activities and we wanted to be sure that we weren't creating something that would be duplicative or potentially just sort of conflicting in some ways. So I think we'll think about some other ways to be able to identify emerging issues, whether it's through more ad hoc hearing kinds of settings.

As I said, we also have more members from the states on the working group itself already, so I think it's just a way of our being able to periodically, but formally, reach out and try to understand what issues may be there and then crystallize those. We'll have the first set of those for the October 20th Policy Committee meeting.

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

Any questions or comments from members? That's great. Before we invite the public in I just wanted to thank the members for participating on this call. It's sometimes harder to work in a call format, but it seems like everyone was engaged and we had certainly very robust discussions. We did approve a couple of important letters from a time and issue of importance it was critical that we deal with and so I just wanted to express my appreciation for everybody's contribution to the participation.

I also wanted to let you know the reason David Blumenthal is not on the call is because even the National Coordinator gets a vacation.

Why don't we open up the call to the public, please, Judy?

Judy Sparrow – Office of the National Coordinator – Executive Director

Sure. Yes. It is time for public comment. We'll pause for a minute to see if anybody wants to make a comment.

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

I think there are no comments then. I want to thank everybody for their time. I look forward to, as they say, seeing you in September.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thank you, Paul. Thank you, everybody.

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

Thank you.

Public Comment Received During the Meeting

1. Victoria Prescott: question for Tiger Team from morning: are you recommending that the provider obtain written consent at every encounter or just once (assuming the patient can revoke consent at any time)?
2. How would these consent requirements impact existing large data stores that were collected under different models (e.g., without consent or with an opt out approach)? Would all that data now be NOT able to be used for how it is used now (e.g., treatment, quality, de-identified research)?
3. Victoria Prescott: Did you consider medical emergency situations, which usually fall under an exception to requiring consent?