

Privacy & Security Tiger Team
Draft Transcript
January 4, 2011

Presentation

Judy Sparrow – Office of the National Coordinator – Executive Director

Good afternoon, everybody and welcome to the Privacy and Security Tiger Team. This is a Federal Advisory Committee so there will be opportunity at the end of the call for the public to make comments. Just a reminder, workgroup members please identify yourselves when speaking. The call will go from 2:00 p.m. to 4:00 p.m. today. A quick roll call, Deven McGraw?

Deven McGraw – Center for Democracy & Technology – Director

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Paul Egerman?

Paul Egerman – Software Entrepreneur

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Latanya Sweeney? Gayle Harrell? Carol Diamond?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Peter Duvall, in for Judy Faulkner?

Peter Duvall – Independent Health – Wellness and Fitness Professional

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

David McCallie?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Neil Calman?

Neil Calman – Institute for Family Health – President & Cofounder

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

David Lansky? Dixie Baker? Micky Tripathi?

Micky Tripathi – Massachusetts eHealth Collaborative – President & CEO

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Rachel Block? Christine Bechtel?

Alice Brown – National Partnership for Women & Families – Director HITP

This is Alice, on for Christine.

Judy Sparrow – Office of the National Coordinator – Executive Director

Alice, thank you. John Houston?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Wes Rishel? Leslie Francis?

Leslie Francis – NCVHS – Co-Chair

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Adam Greene?

Adam Greene – Office of Civil Rights – Senior HIT & Privacy Specialist

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Lisa Tetero?

Lisa Tetero

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Joy Pritts?

Joy Pritts – ONC – Chief Privacy Officer

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Did I leave anyone off? Okay, thank you. I'll turn it over to Paul and Deven.

Paul Egerman – Software Entrepreneur

Yes, good afternoon. I want to start by saying, Happy New Year. Welcome to our first tiger team call of 2011. The 2010 tiger team did excellent work. I have heard that people are listening very intently to everything that we say.

Deven McGraw – Center for Democracy & Technology – Director

It's a little scary.

Paul Egerman – Software Entrepreneur

It is actually a little bit frightening that that is the case; that we appear to be having a fair amount of influence, but I think that's a reflection of the excellent work of this group. So I'm very excited as to what we're going to be able to accomplish in 2011. I think our best discussions are definitely ahead of us and that we've done great work so far and even better work is going to come.

What we want to accomplish on today's call is to see if we can come up with recommendations and wrap up our discussion on the patient matching topic. To very quickly refresh everyone's memory on this topic, we held a hearing in December and we had some discussions afterwards about what we learned. I'd probably make a big mistake if I tried to summarize very briefly what we learned, but we learned that it's a complicated issue and that it's not an issue where there is like a single technical solution to it; that there are some technical aspects to it, there's a lot of human factors. There were just a lot of interesting aspects to the entire issue.

What Deven and I tried to do to try to help to focus this discussion was to break down recommendations that we might make into four areas. The four areas are, first, any standards about demographic data. The second area is the role, if any, that a patient portal or patient access might have. The third is what policies or how do we want to respond to the various human factors issues. The fourth was just are there best practices? In other words, instead of like standards, but best practices that ONC should be somehow promoting. Those are the four topics that we'd like to try to cover today and then when we get through all of that then we'll also have a quick discussion about the agenda for the rest of 2011, or at least for the next few months of 2011.

Before I launch into the first topic, the first of those four, which is the demographic standards, did you have anything to add to that, Deven?

Deven McGraw – Center for Democracy & Technology – Director

Yes, I think the only thing that I would add—it was a great introduction, Paul—is to say that we had a discussion in December where we sort of talked about the hearing themes and conclusions and we did go into a fair amount of detail. When Paul and I worked up these four broad categories of recommendations, we took all of that into consideration. But also thinking about how those issues might sort of be grouped into bigger categories and also what was feasible as a set of sort of good first steps to tackling what, as Paul stated and I think we all understand, is a very complicated problem. So, that's all I'll say. I think we can move right into the discussion, unless folks have other questions, into the first set of recommendations.

Paul Egerman – Software Entrepreneur

Are there any other comments or questions before we move into it? Okay. The first of these four relate to demographic data standardization and what is written here— Unfortunately, he's not on the call, but Wes Rishel made a number of comments in our December conference call and sent out an e-mail to everybody that was extremely helpful. So what's written here was influenced by what Wes said and, again, this is alike a strawman proposal, but what Wes seemed to be saying is, well, in terms of the demographic data there really are standards that already exist, with one possible exception, the standards really do exist. It's just a matter of enforcing the standards and he seemed to say you've really got to enforce the standards, but that's all you can do. You can't really enforce standards for how patient matching occurs. You can really just do standardization on what are the content and structures of the data elements.

So, what is written here as the strawman is there are two letter As. One is that the Standards Committee should select an existing format and content standards for a minimum set of demographic data elements and then additionally that such standards should be really required for certification and for data entry validation for EHR systems. There's another alternative that's written here, which is intended to be the same thing with the first part, it's the same thing with fewer words. "The Standards Committee should select existing format and content standards, which would be required for certification, for information exchange transactions."

The difference between these two is the first one is about data entry into the EHR and the second one is, well, just apply the standards on the information exchange side, possibly thinking that has an upstream impact on how the rest of the EHR is going to be constructed anyway. Let me pause and say what are people's reactions to this?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

The recommendation is we can leave the and/or in there or are we really going to pick between A or A,B, and C?

Paul Egerman – Software Entrepreneur

It's whatever this group wants. In other words, I think this was written as a strawman so that you could say—I guess there are three choices. You could choose the first A or you could choose the second A or you could choose both of them. I guess there is a fourth choice, so you can say, "It's awful. I don't want any of these. I want something different," so there are four choices here.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

Can I ask a question then of Wes?

Deven McGraw – Center for Democracy & Technology – Director

He's not on the call.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

Because I was wondering, how mature would the second A be in terms of what— Are the existing formats and content standards sufficient to do what we want to do? Because I'd hate to remake the wheel if it already exists, but I don't have any expertise to say whether we have sufficient standards that we should try and select from them.

Paul Egerman – Software Entrepreneur

Wes isn't on the call. I have to tell you my impression.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Paul, I just joined the call just this minute. So, if you can refresh the question—I mean, as a general rule I say there are always sufficient standards, but it helps to know the question sometimes.

Paul Egerman – Software Entrepreneur

John, why don't you repeat your question?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

Sure. It really is just that, are the existing standards that we're talking about here sufficiently mature that we could make a selection from one of the existing standards in lieu of picking the first A, which was to develop, in essence, a new format and standard.

Deven McGraw – Center for Democracy & Technology – Director

Well, actually, I don't think we intended for A to be directing the Standards Committee to come up with new standards. I think what we're asking here is for the Standards Committee to select, or maybe recognize existing standards for the minimum set of demographic data—Wes, we really were trying to capture what was in your e-mail here—and those would be required for certification. The real distinction between the first A and the second A is do those get tested just with respect to validating data entry into an EHR system or do you test them just at the Exchange level or do you have them be tested at both?

Is that, Paul, an accurate statement of what we were trying to achieve here? Not that we're telling Standards make up a standard, but it is their job to select the ones that they think make sense and we're essentially telling them this should be a priority.

Paul Egerman – Software Entrepreneur

That's correct.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

Sorry, I sort of took the first A to be, yes, we might have existing formats, but then we're going to come up with this minimum set that would become a standard for identity grouping or whatever you want

to call it and so, thank you for the clarification.

Paul Egerman – Software Entrepreneur

Yes, the minimum set is just the idea that we, the Policy Committee, the tiger team wouldn't define the minimum set, but the Standards Committee would in terms of what's required for patient matching. So, that's probably like—I'd take a guess what it is—it's name, date of birth, gender, maybe address. We'll let the Standards Committee select that minimum set.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

So, just because I have a re-training problem today, we're saying what is the— First of all, it's a given that there will be a format standard that covers many more data elements than the minimum. The question at hand here is what is the level of minimality, if you will, where we shouldn't even bother to try to match patient?

Paul Egerman – Software Entrepreneur

That's a good question, but I don't think it was the question that we were asking. At a high level, the question that we're asking is what does the tiger team want to do on the issue of standardization, if anything? The strawman would be to direct the Standards Committee to define the minimum set of demographic data and the standards and then to have certification criteria to test EHR's systems around data entry validation for that minimum set. That's one strawman.

Another strawman is the Standards Committee selects the minimum set, the Standards Committee selects the standards and you apply the certification testing on information exchange transactions, not on data entry. Another strawman is you do both of them.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

So, I'm hung up on the word minimum because the way I interpret the word it's implying that if you don't do that many you don't do. As you said, that's an interesting question, but if I'm understanding what you're telling me, if we would just take out the word minimum and say an appropriate set of data elements for patient identity matching.

Peter Duvall – Independent Health – Wellness and Fitness Professional

I think maybe we're confusing system capability with what you need for some particular concrete transaction and if I'm understanding this correctly we're talking about what a system has to minimally be able to allow the entry of in the one case or be able to send as part of a patient matching transaction. As opposed to talking about what a user might actually be putting in the demographics record of a patient or using to try to match a patient, which I think is down in B more than it is in A.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Yes, I would say that we are at this point, according to the way I interpreted Paul, we're talking about the capabilities that will be certified in a system.

Deven McGraw – Center for Democracy & Technology – Director

That's right.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

We're discussing the two possibilities of what data can be entered by a user and what data can be sent out in some standard format because there is no real way to test the sending of data unless there is a format associated with it.

My own sense is that we should be targeting a variety of data elements that are known to be effective in patient matching, including many that may not be transmitted in a given situation, such as driver's license numbers, former phone numbers, things like that, and that we should expect there to be two sets of data

elements. One is the set that can be transmitted in a standard format and the second is the set that will be required by a system for data entry where that data entry subsequently supports patient matching through a health information exchange.

Paul Egerman – Software Entrepreneur

Correct. I don't want to get hung up on the word minimum and if you want to use the word appropriate instead, that's fine. Although, I have to tell you I think we got the word minimum from your e-mail, Wes.

Deven McGraw – Center for Democracy & Technology – Director

We did, but I have it pulled up and I realize that, Wes, you were using the term minimum with respect to a requirement for users to enter a minimum—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Yes.

Paul Egerman – Software Entrepreneur

Maybe we misunderstood it, okay. Because we're sort of like trained by ONC to do minimum any place we can.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

That's another reason to be careful here because minimum has a whole different set of implications around minimum use.

Paul Egerman – Software Entrepreneur

Okay, but to make sure we're all grounded in this discussion, the problem we're trying to solve or address or mitigate is the patient matching issue. The information from the hearing was if we standardized some of the data elements and formats, that would help a bit. At least that's the sense I had, so it's not like this is a silver bullet solution. The idea is that perhaps this will help a bit.

Peter Duvall – Independent Health – Wellness and Fitness Professional

I agree with Wes that we're really talking about two different sets. On the one hand, there is the set of—probably a larger set, well, it definitely is a larger set of—elements that have standard representations and those, perhaps, should be enforced and that are useful in patient matching. That's a different set of elements then—I also agree that minimum doesn't make sense in that context. Then the other set we're talking about is what should be required or strived for, I guess, at the user entry level and that does make sense as a minimum.

Gayle Harrell – Florida – Former State Legislator

For our recommendation, though, aren't we really just taking the very basic element of the patient matching and it would be up to the Standards Committee to set what those elements and formats would be? I think our recommendation should basically be that we have to have some standards in place to facilitate data exchange and for patient matching. Do we need to get into that much of a technical detail as to it? Is that not the role of the Standards Committee?

Paul Egerman – Software Entrepreneur

I think you're right, Gayle, it is the role of the Standards Committee to choose the data elements and choose the formats, but we just need to give some direction as to what we want them to be doing.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Speaking as a member of the Standards Committee—

Gayle Harrell – Florida – Former State Legislator

... give them that mandate.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Speaking as a member of the Standards Committee, I would say that I would be very concerned that we could do a lot of work and then have the Policy Committee simply say, “Well, you never spoke to us about whether this data element was acceptable for the patient matching.”

Paul Egerman – Software Entrepreneur

We’re not going to ask the Standards Committee to do anything without approval first from the Policy Committee.

Deven McGraw – Center for Democracy & Technology – Director

Well, that’s right, but to date the Policy Committee has not gone back to look at Standards Committee recommendations and said, “You didn’t ask us about this particular standard.” I think that is the essence of the division of labor here. What I want to make sure we do is to give the folks on Standards a clear enough set of—not instructions necessarily because those sound too detailed, but an indication that this is a priority in order to allow you to do the work that’s necessary to select the format and content standards that the committee thinks is appropriate.

Paul Egerman – Software Entrepreneur

That makes sense. I’m wondering, Peter, you said something before, could you repeat it? Can you say—? What direction should Policy Committee be giving Standards Committee on this issue?

Peter Duvall – Independent Health – Wellness and Fitness Professional

Well, specifically regarding A because we haven’t really gotten to B yet and I think that’s going to be slightly different. But regarding A, I think we should recommend to the Standards Committee that they choose a set of demographic elements that are useful in patient matching and choose the standard formats that systems must be capable of representing those elements in.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I thought we had a bunch of testimony and had agreed that we are not and the Standards Committee is not the right place to determine what’s useful in patient matching because very often the matching has to be tuned to the purpose and the population. I’m a little leery about making assumptions about what everybody needs to standardize because we know from the testimony we heard that there’s a high degree of variability here.

Peter Duvall – Independent Health – Wellness and Fitness Professional

I think that the issue of standardizing the formats for almost all of the data elements we can think of as maybe being useful in some situations for patient matching is one of the easier questions that will ever get put to the Standards Committee. The question of when to use which one or how much to certify inside an EHR are the ones that are more prone to have the kind of discussions we’re just opening up right now.

Paul Egerman – Software Entrepreneur

Yes, which is not we’re asking Standards to do. You raise a good issue, Carol, but the main concept is we’re not trying to standardize how the patient matching occurs. We’re trying to do something very simple, which is let’s try to get everyone to do the date of birth in the same format. Let’s try to get everyone to do patient’s gender in the same format.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Not have a 20 character limit on the last name, for example.

Paul Egerman – Software Entrepreneur

Yes, let's clarify that stuff and it's just like foundational and that will—it's not like a solution, but it's at least a baby step forward in trying to help with this problem. It's low hanging fruit.

Deven McGraw – Center for Democracy & Technology – Director

Yes, and in addition, Carol, my recollection from the hearing was that folks were pretty aligned around standardization with respect to common demographic data fields. That the issue of attempting to standardize algorithms or set a level of accuracy was the one where it would definitely vary with respect to purpose, etc., and that we could not set a standard that would be sort of a one size fits all solution.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I'm a little confused in the way this is being discussed because when you say standard demographic fields and then say the algorithm would be different, there's a disconnect for me. The algorithm is determined by which fields have the best predictability, which fields when used serve the purpose best and deliver the highest degree of accuracy. They may be different in different scenarios. So, if we're saying there's a general standard that covers all demographic fields, that's one thing, but I don't think we can be saying these are the standard ways of expressing these demographic fields and that's what you need to use.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Here's why I think we're having this discussion. I think we're finally agreeing with each other actually, but the way I was interpreting your words—and I know you didn't mean it that way—you said what we should do and what we shouldn't do are the same thing. So, let me say I think we know that there are a number of data elements that might be useful in a lot of use cases and we should have a standard format for sending all of those. Is that okay, Carol?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes, a standard format that is not specific to a certain pre-selected number of fields.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Right. So, it may be in a given transaction the use of the standard may allow for sending fewer or more data elements. The specific data elements that are sent may be different in different applications of the standard, but every output that goes out will have every element that it has in the same format and every system that receives that will be able to receive any of the elements and interpret them properly. It may not be able to use them in an algorithm, but it can at least receive them.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think we should be careful not to drift into specifying message formats. Wes, I don't know if that's what you were aiming for.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I was actually assuming—I don't know how to specify data formats without specifying message formats.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Well, I mean you can name the fields and name the characteristics of the fields without specifying how those fields are moved from place to place.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

If the purpose that we're leading towards is to certify a system for interoperability, it is helpful, but not sufficient to say what the data content should be and to describe the data elements in great detail.

Paul Egerman – Software Entrepreneur

Let me just interrupt. Let's try to make sure we're going through this step-by-step. So, the first step, just to make sure we're in sync, is instead of what's written here, what we're saying is what we want Standards Committee to do is to choose a set of data elements that are frequently used for patient

matching and then to create standardization and to choose an existing standard format. As an example, date of birth is frequently used for patient matching.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I don't agree with this. I don't think the Standards Committee should choose the data fields.

Peter Duvall – Independent Health – Wellness and Fitness Professional

So, Carol, I don't think we're suggesting that they should choose fields that, in combination, get used for a particular patient matching use case. I think we're suggesting that they choose sort of a universe, a small universe, but a universe of data fields that do get used in combination in various use cases in different combinations for patient matching and to standardize the formats for those when they do get used.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

That is if you are going to certify, meaning to test, then somebody is going to write a definition of what the screen should capture to pass the test and that will be a de facto minimum.

Paul Egerman – Software Entrepreneur

Yes, the issue is—what we heard in the hearing is—among the problems we have is some people truncate the patient name after a certain number of characters and some vendors give you dates of birth that aren't valid dates of birth. Even on gender, you have multiple different responses that you're getting and if we could just get some of these to be consistent. Because remember, we're talking about patient matching in this context from a standpoint of information exchange. You get a transaction on a patient; you'd like to match it up from another system.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

So, Paul, I agree with the idea that this is about data exchange and I don't think this is about making sure that whatever we do fixes every hospital's or doctor's system's idiosyncrasies with how they store patient data. Our primary objective is to improve the accuracy of patient matching and not to improve the accuracy of data storage within the walls of an organization. I guess I want to go back to the question that was asked, which was if we're talking about data format standards I don't know how to separate that completely either. I'm sitting here thinking about HL7 or CCD or CCR and thinking what level exactly are we talking about standardizing?

Peter Duvall – Independent Health – Wellness and Fitness Professional

I think what we're saying is that when a name is captured or when a name is sent as part of an interoperability transaction this is the format it should be in and with these constraints. When a date of birth is captured or sent as part of a transaction this is the format and with these constraints, for example, that it has to be a four-digit year.

Paul Egerman – Software Entrepreneur

Yes, and I think we're making this harder than we need to. When we do any kind of information exchange, we have to establish some standards. If you're talking about laboratory stuff, you choose vocabulary standards, you choose stuff and you go with it.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I'd like to suggest that one of the reasons it's confusing is that some of the stuff has been done for so long that it's almost like why are we talking about it? But, what we heard in a committee meeting was what some people like to call the boundary cases or the edge cases; they are ways in which the data is not being sent. Either the spec is ambiguous or the data is typically not following the spec.

An example is, is there a valid date of birth known? Okay, if not some systems are sending all nines, which is an invalid format. Some systems are sending the data as just not present. This issue about how long should a name be kept, we have three options. One is to say all names should be kept in their full length. One option is to say there is a specific length that everyone must keep names to so that two people that collected the same long name end up sending out the same string, which is shorter. The third

is to say there is a minimum number of characters that should be kept in a long name and the matching systems have to deal with the fact that some of the identity sending systems will send more data than the others. In fact, the good ones are built to do that now.

The question on minimum is can we learn that 15 characters matters a lot more than ten or not? If we learn that there is some critical number of characters that really makes a difference in identity matching, then we might want to set that as a minimum.

Paul Egerman – Software Entrepreneur

Right and I think what you just said, Wes, is like a great summary. Because what we're looking to do, what's being proposed at least, is the idea of saying in the examples you gave for date of birth, one of the things we're hoping the Standards Committee would do is well, you've got to have a valid date. If the date is unknown, this is what you're supposed to write. For length of the patient's name, here are the rules. I don't really care what the rules are, but it would be great if we all played by the same rules when we exchange those data elements.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Let me try to give an example of why I think we're going a little too far. There are some examples where some level of patient matching is required, but it's not required to this degree. So, there may be a public health purpose, for instance, where there's a need to collect information about people in a certain age group, but the date of birth is not necessary. Age will suffice, as long as it can be accurately reported.

Paul Egerman – Software Entrepreneur

Yes, but in that example, Carol, I shrug my shoulders and say, "Well, that's okay." I mean if you don't have to report date of birth, you don't care how it's formatted, but in a lot of other transactions, date of birth is important.

Peter Duvall – Independent Health – Wellness and Fitness Professional

Yes, and that's not EHR certification question either.

Paul Egerman – Software Entrepreneur

Yes, that's not any of the transactions that we have done so far for meaningful use.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

The point I'm trying to make, if I could just finish, is that there is always a tendency to send more than is necessary if the specific data elements get specified. If our recommendation comes with the notion that only what's necessary is used and these fields are not necessary for patient matching in every instance, I'm more comfortable. What I'm worried about is that our guidance may sound like we're saying all of these fields are what people should be using.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

That's why I think we need to separate the how and the what very carefully in our proposals and I think it particularly chases a great subject because what we learned is that depending on the situation, a given data may be more or less important, but almost no data element is absolutely mandatory.

Paul Egerman – Software Entrepreneur

So, I think we can be clear, in response to what you're saying, Carol, that by requesting this we're not suggesting that these data elements are necessarily to be used. We're simply saying that if they are used this standardization would be helpful and if they are used this is what the format needs to be.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I'm fundamentally trying to get to the issue of the idea that the identity may or may not need to be disclosed at any level. In fact, there is a lot of research going on right now of seeing patients without including any of the identifiers.

Paul Egerman – Software Entrepreneur

Yes, I understand that, but that's not the topic that we're discussing. We're discussing a situation where you have information exchange and you need to do patient matching.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

That's the topic I'm discussing, too. I just want to be clear that there is more than one way to do patient matching and there—

Paul Egerman – Software Entrepreneur

Well, let me put the question differently, then. Do you think that we should not do any standardization of data elements? Should we not make any recommendation on that?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Well, like I said, I'm trying to understand what level we're talking about standardization because I'm going to go back to the question Wes raised earlier, many of these standards already specify a format that are already in the standards that have been specified by ONC. If we are saying ... want to offer guidance on the accuracy of the collection and use of those data elements, that's one thing. But I don't want to go to a place where we are saying, "These are the identifiers you must exchange and you must use inpatient matching."

Peter Duvall – Independent Health – Wellness and Fitness Professional

I think we're all in agreement on that.

Deven McGraw – Center for Democracy & Technology – Director

Yes, I do, too.

W

I think so, too.

Deven McGraw – Center for Democracy & Technology – Director

I think Carol is right, that we're going to very carefully word this to avoid sending the wrong message about what we're trying to do here. Be very clear that when we're asking for standards for certain demographic data fields, we are not making a recommendation that those data fields always would need to be exchanged and that the choice of which data field gets exchanged will be appropriate depending on the circumstances.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

In fact, the data fields may not need to be exchanged at all.

Deven McGraw – Center for Democracy & Technology – Director

Right, good point.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Just to zoom back out a little bit, one of the things I remember from the hearing, maybe filtered by a month or so of forgetting the details was that the complaint was not so much that the systems that were capturing primary data didn't have the right fields, but that the data was being captured poorly.

Paul Egerman – Software Entrepreneur

That's correct. Actually, David, we're going to get to that issue on subsequent slides.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

On validation points?

Paul Egerman – Software Entrepreneur

Yes, when we start talking about some of the human factors and best practices and patient portal kinds of things.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Well, I think the degree to which it might be relevant here is if we were—and maybe it's the Standards Committee's work if we turf it to them, but—if you were to, for example, specify that a street address was a required field or a suggested field or whatever word we're going to use, that you could say that it should be validated against an online dictionary of valid street addresses. That was one of the suggestions.

Paul Egerman – Software Entrepreneur

In fact, that's one of the things that's listed on the strawman and since you raised it, Dave, that's letter C. That's written as a question because that was in the hearing.

Deven McGraw – Center for Democracy & Technology – Director

But wait, before we get to that, Paul, there was one thing in what David said, if I heard it correctly, that sounded like it was in contradiction to what we had just concluded, which is that we are not going to require the exchange of any particular data field.

Paul Egerman – Software Entrepreneur

Let me respond to that. We're saying we're not required as a part of our recommendation, but when you get to the actual transaction, it's very possible the Standards Committee will require something, right? In other words, the Standards Committee might say, "Well, when you do a CCD, you have to have these fields."

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I think that they already do that.

Paul Egerman – Software Entrepreneur

Yes, and so I don't want to say—sometimes you just have to have certain data.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

So, actually although our purpose is to make sure that interoperability transactions match patients correctly, the testimony we heard is the difficulty is actually in how the data is captured. So, that's what my point was about was capture.

Deven McGraw – Center for Democracy & Technology – Director

I agree.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I do think we can suggest that in EHR system specifically, we are talking about EHRs here, for certification purposes anyway, that an EHR system needs to be able to capture, when it's available, a certain set of data and when a user does enter data into those fields that it gets captured according to certain constraints and formats.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think that was well said. That was the point I was trying to make, not about exchange, but about capture. The plea that we heard was to make sure it's captured accurately and as completely as is needed for the use case.

Paul Egerman – Software Entrepreneur

Right, and the comments that I'm hearing from Carol and everybody is we're not making any recommendations about what will be specifically required for patient matching. We're not making any recommendations about patient-matching algorithms. The question is, though, is it helpful if we ask Standards Committee to make format recommendations for some data elements that are frequently used

as part of the patient matching process so that when information exchange is used and if it is appropriate to use those data elements the format is established basically on a national basis.

Gayle Harrell – Florida – Former State Legislator

I think that's essentially what we need to do. We're kind of beating a dead horse to some degree. That sounds very logical and very simple to me, to make that in the form of a recommendation, making sure that we're not specifying what those are and leave that up to the Standards Committee.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I want to just make sure what you meant by leave that up to the Standards Committee, leave the set of data elements that will be used up to the Standards, or leave the way data elements will be described and collected.

Deven McGraw – Center for Democracy & Technology – Director

The latter.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

The latter, okay, that's fine. I want to just back up a little bit on a response I made today earlier in the call. He said, "We shouldn't necessarily be describing the message, only the format," and I said, "Well, we can't test the interoperability of an EHR unless we describe the message." I think that's true, but I also think that we should ask the Standards Committee to layer the standards into those things that are the same across all formats and those things that aren't. For example, we know that some of the data items we are describing might be used in the header of a CCD as well as in an HL7 version two message in different use cases. It ought to be that all of these things about the number of characters and how to send non-existent dates and so forth and specifically not to use all nine for non-existent dates and so forth, it should be the same across the different standards.

Paul Egerman – Software Entrepreneur

I think what you're saying there, Wes, sort of leads to what this sort of choice was when it says and/or on the slides because it does strike me that there are a couple of ways to accomplish this. One way would be to simply ask Standards Committee for the existing transactions to sort of tighten up on some of these things, like the date of birth and so you have the existing transactions, but the benefit of that is you can test it. The other way you could do this would be to try to do the testing on the EHR system at the point of data entry, although I'm not sure that accomplishes the second thing because you could enter the data.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Any good interoperability testing should be for outgoing data, it should be from the point of entry to the outgoing data. That is, it should check both of those characteristics.

Paul Egerman – Software Entrepreneur

So, for the and/or piece you would do and.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, I think we can put it in one.

Deven McGraw – Center for Democracy & Technology – Director

Yes, I think we could probably combine into one.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

We just say interoperability testing from data entry through to— It's a little tougher for incoming data, but I don't think we have to test—for the most part, I don't know that we have to test EHRs for that.

Paul Egerman – Software Entrepreneur

So, I get the sense that we have an agreement. I'm afraid to say it out loud, though.

Deven McGraw – Center for Democracy & Technology – Director

Yes, I know. I do think this is one of those where we're going to have to probably do some offline work by e-mail to make sure we're getting the wording.

Paul Egerman – Software Entrepreneur

Yes, but I like what you said, Wes, that it's from data entry to the output. It's that we'll be careful to be clear, that we are not determining what data elements are used in patient matching or what algorithms are used for patient matching. That we're asking the Standards Committee to choose a set that we think would be frequently and possibly used, without us saying they have to be used, and to be clear, very clear on what the formats are and specifically, also be very clear as to what should be transmitted if the data element is unknown. In other words, what do you say when there is an unknown date of birth and you're expected to transmit a date of birth.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Yes, we're going to wordsmith because I want to look at the words to make sure that the issue of how to handle minimum name length is in there, too. But fundamentally, it's one thing about minimum name; it's another thing about minimum length for social security number and getting the first five doesn't help that much.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

And you could get into details, and I assume that some of the existing standards do this, about whether there should be dashes in the social security number and parentheses.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

That's the format, I think that should be all—

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Standards Committee stuff. Right. My concern, Wes, was that you not tell me that it has to be in an XML structure of a certain size and shape or That's somebody else's decision.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Yes, I think so.

Paul Egerman – Software Entrepreneur

I think we've got an agreement because we're really just talking about the data on this. I think we've got an agreement on that topic. I'd like to keep, because we're running considerably behind the schedule. There is a letter B written on this slide, "Eligible providers, institutions and ONC grantees should be required to meaningful use in ONC grant programs to active reviews or promote the use of the data standards for patient identity."

Deven McGraw – Center for Democracy & Technology – Director

So, this is one that I'm realizing based on our subsequent discussion I want to explain what I think we were trying to get at here. It was not to require people to use certain data fields in exchange, but rather to say when you use them that you use the standards for which the EHRs will be certified and you use them accurately. It's getting at the accurate capture from the user side of it versus just thinking about this in some capabilities. Maybe it's not appropriately or carefully worded, but I think that's what we were trying to get at here.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

That makes sense, and the clarification helps. So, for example, not to put all nines in a date if the date of birth is not known, that kind of thing.

Deven McGraw – Center for Democracy & Technology – Director

Yes, I think that's part of it. I'm not quite sure off the top of my head how to reformat, reword this. We'll have to do that because I think the point we were trying to make here is the certification only takes care of

the system capabilities. Is there an additional step we need to take, such as what we've done with respect to the requirement to use lab coats, for example, for certain lab transactions that we want to say here to make sure that when those data fields are appropriate to use, people are using them.

Gayle Harrell – Florida – Former State Legislator

How do you evaluate that, though? What is the mechanism for evaluation?

Deven McGraw – Center for Democracy & Technology – Director

Well, I think that's a good question, Gayle. So, if you think about the way that it's done on the lab side with respect to the expression of lab values using the vocabulary and content standards, my recollection is that it's largely through attestation at this stage, but people can correct me if I'm wrong.

Gayle Harrell – Florida – Former State Legislator

Because for instance if someone misspells a word, if you have not used it accurately, the last name field or they put a dash if you have a hyphenated name as opposed to whatever else might be put there, a space or whatever, and you definitely don't get a match. Are you not getting a match because it's a different person or because there was an error? So, how do you determine why the match didn't happen? Who is going to count the matches?

Deven McGraw – Center for Democracy & Technology – Director

Those are all good questions, Gayle, and it makes me wonder whether—we have another human factors set of recommendations that I think get to much of what you're expressing and that maybe those are better taken care of in that.

Paul Egerman – Software Entrepreneur

Well, another possibility, I'm thinking about what Gayle just said, Deven, would another possibility for your letter B, so this is an issues that also needs to be part of the NHIN governance function. We have this other enforcement concept, which is the NHIN governance process and maybe that's how you could handle this issue.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

But I do think Gayle's question begs the question of what problem are we trying to solve. If an EHR is certified to have certain field lengths, for instance, or a certain standard in the way it captures a certain field, that doesn't mean the operator uses it correctly. So I think the question really is how far upstream do we think we need to go in order to make an incremental improvement? Just saying, you know, you need to use a standard, like it's an easy thing to do, it rolls off the tongue, but I really think we have to ask ourselves what is the objective we have? What is the problem we're trying to solve that will materially improve the accuracy of patient information?

Deven McGraw – Center for Democracy & Technology – Director

Right.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Or patient matching.

Deven McGraw – Center for Democracy & Technology – Director

Right. I mean, it's a really good question, Carol. I think ultimately, what we're trying to get at here and maybe it's not the right hammer for this particular nail, but we were getting at the user side of appropriately capturing data that is frequently used in patient matching. The idea that you can get the systems to be certified to have the capability of capturing those fields, but at the end of the day, we need people to use them when it's appropriate to do so.

Paul Egerman – Software Entrepreneur

If I understand your comment, Deven, it's sort of like a situation, to use David's example, of unknown date of birth. You could have a healthcare organization that records all dates of birth as unknown because

they just don't bother to record it and maybe that causes a huge problem if that's what they do because they just never sent it through information exchange. But doesn't that become, my question is isn't that a governance issue, isn't that a NHIN governance issue that they're just not playing by the right rules? Is that the vehicle to handle that?

Gayle Harrell – Florida – Former State Legislator

Or is it a measurement issue that you set meaningful use criteria on and that you then do not get paid, you don't meet meaningful use criteria? That's pretty Draconian.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

But I think, Gayle, you are going down the right path in the sense that the motivation for having the ability to accurately identify a patient needs to exist in the system. Nobody adopts a standard for the sake of adopting a standard, right? I mean the standard gets adopted because it needs to be used in order to accomplish something and presumably there is value in accomplishing that something.

So, my sense is that we don't need to go all the way into how to implement and enforce the accuracy of information collection down to every last detail in every organization in order to accomplish the task. We have this axiom in Connecting for Health where we talk about cleaning up for company. When data gets used for a purpose that has value, people tend to pay more attention to the quality and accuracy of that data. I think setting accuracy standards and performance standards gets us far along that road and maybe more quickly than trying to specify how everybody best achieves that standard.

Gayle Harrell – Florida – Former State Legislator

The question then becomes, Carol, is how do you measure that?

Peter Duvall – Independent Health – Wellness and Fitness Professional

So, I've got an idea. I'm not sure it's a good idea yet, I'm sure you'll tell me right way if it's not. But one of the things that we heard in the testimony that rang quite true to me, which is that when we try to micromanage the way that systems get used, it often doesn't have exactly the intent that we're trying to have, or it doesn't solve the problem that we're trying to solve. That instead we should have some kind of goal to be reached and one of the things that I'm thinking about is when there is inaccuracy in data collection or incomplete data collection.

One of the things that will result is duplicate patient records in the system. That's also a source for mismatching of patient data and there are ways of measuring in EHR system the number of probable duplicates in the system. I wonder whether we might use that as a proxy variable for a whole set of processes that we leave it up to the institution to try to optimize and say that for meaningful use you have to have your probably duplicate patient count below a certain threshold.

Paul Egerman – Software Entrepreneur

I have two comments to what you said, Peter. It's very helpful, but the comments are, and the one comment is, if I heard correctly from the hearing, there's not a one size fits all for these metrics, that in different environments the number of duplicates might be different.

Peter Duvall – Independent Health – Wellness and Fitness Professional

I think that's true.

Paul Egerman – Software Entrepreneur

And you can't, even speaking to what Carol said about an accuracy level, you think about the environment of, say, Associated Catholic Hospitals West has, which is this huge, multiple hospitals, multiple environments. That's very different than a small group practice that does a single specialty in Florida in terms of what one could ask for and expect for accuracy numbers.

M

The other argument, too, is that the people that end up not being on a matched data aren't the ones that are providing the bad data. It's like if a hospital gets bad data and can't do the matching, it's not their bad data that caused the mismatch.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I'd like to suggest that we have one experience base to look at here, which is there is one incentive that I know of that has real dollar value for creating matchable patient data and that's getting paid. What most healthcare institutions do is if they do eligibility checking they take the demographic data that they payer says and that's the demographic data they're going to use, because that way they get paid.

Now, if we, as a matter of policy, if the federal government wants to set another requirement that is different than that, then it has a number of things, I supposed, and it has to find a lever. If we want to recommend to ONC that the government do that, that's a policy discussion we can have. I think it's a very complex discussion, though, and it doesn't need to be done before we set this charge to the Standards Committee.

Paul Egerman – Software Entrepreneur

I agree, because it sounds to me like we don't have a consensus as to how to do this letter B.

Deven McGraw – Center for Democracy & Technology – Director

Yes. I would say that we—

Gayle Harrell – Florida – Former State Legislator

It's very complicated.

Deven McGraw – Center for Democracy & Technology – Director

— at this point. When we get to the discussion of how to handle some of these human factors we sort of open it up a little bit more broadly and think about sort of what's the right set of kind of policy levers that we ought to recommend be tweaked or utilized in order to encourage the right behavior here.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Let me say that I understood B entirely differently, however. I understood it to be that A says we should have a standard; B says we should encourage people to use that standard. I didn't even interpret B as meaning that we should interpret them to type in that many characters. I mean I thought it was more what are you doing about that date, so what are you doing about other violations of the standard. In other words, I thought of B as more of enforcing the standards in A as opposed to imposing new standards on the operation of EHRs.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I had the same interpretation, by the way, so we may need to rework this, but I do want to make a comment about something that Paul said. When we did the common framework, we actually identified accuracy as a requirement for trust in a network. Which is to say that if you can't accurately identify a patient as both a privacy risk and it is potentially a care risk and to say that we can accept different levels of accuracy from different institutions I think doesn't play out in the real world. What ends up happening if someone sends you the wrong or bad data is that you don't trust them and you don't exchange information with them anymore.

My sense that one of the elements in getting toward an accuracy goal is to think about whether or not there are ways in creating more transparency around some of these systematic errors that may be occurring, either in reporting mechanisms or, I don't know, some other way. But I do think that in terms of a trust framework accuracy is a critical element and neither patients, nor doctors will trust these systems unless they can accurately respond with the appropriate information and not respond with the wrong information.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

But to your point earlier, Carol, I think there are use cases where the accuracy that is acceptable would be different, not necessarily institution to institution, but use case to use case. I believe that one of the testifiers talked about public health aggregation having different thresholds for false positives than HIE patient matching and that the context was that people will adjust their thresholds to fit the use case and then do—

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

—as absolutely as best they can for their use case.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes. I agree.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

We shouldn't try to set a standard for that other than to encourage that people think of it that way. It's the right way to think of the problem.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I like Carol's notion of creating transparency and accuracy. I think another comment that's derived from the general notion of it being use case specific and also from Carol's comment on trust is that it's a governance issue. As Carol says, if I am building a health information exchange I have certain rules for who I let play. If one of those rules ... that implements the notion that I can't trust their data, I can't trust their patient identification, I can't afford to let them play in the network because the whole network takes a hit for credibility.

Paul Egerman – Software Entrepreneur

What are you suggesting?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

That we should recommend measures for achieving transparency on the quality of patient matching—

Paul Egerman – Software Entrepreneur

What does that mean, measures for achieving transparency?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Well, I don't know exactly, but Peter talked about an algorithm for estimating duplicates at the level of the EHR. Maybe there is something like that at the HIE. Maybe there is just simply a requirement to report adverse incidents associated with bad matching, but it seems to be that like almost every other kind of thing that happens bad, if we don't sweep it under the rug or we move the rug anyways, then things improve.

Paul Egerman – Software Entrepreneur

Well, that's an interesting issue. Here's what I want to do with this issue, because part of what I want to do is move on to the next slide, because we want to talk about patient access as possibly one way to find out about inaccuracies. I think that that would be a useful thing to do, so part of me wants to sort of like put this in the parking lot for a little bit. Before I do that let me just ask is there a specific suggestion that you have, Wes, or you have, Carol, about this? I mean are you saying that as part of meaningful use eligible providers and hospitals should have to report some accuracy number? Is that what you're suggesting?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

On themselves or others?

Paul Egerman – Software Entrepreneur

Well, I don't know how you could do that on others. You could do that on yourself.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

But if it's your accuracy numbers and you're dependent upon that data coming from some third party your accuracy could be lower, but it is not your fault.

Paul Egerman – Software Entrepreneur

I know. Well—

Deven McGraw – Center for Democracy & Technology – Director

I'm not even sure we have enough internal measurement of accuracy going on to get necessarily to the level of a recommendation to requiring people to publicly report on it. But I do think it's worth discussing whether sort of some of the stuff that we heard and maybe not at this particular juncture, because we sort of hint at it on this human factors of strawman slide, which is the third sort of bucket of recommendations. But this issue of getting organizations and all of the way down to solo practitioners to start paying attention to this and looking at how well they are doing this, as well as their peers.

With respect to HIEs, we heard some good testimony from ... about how they do set a certain level of expectations for the participants in their network. So I think there is great potential of the role for some policy levers that we have at our disposal, but I think there is a sort of walk before we can run aspect to this that I think we also need to talk about.

Paul Egerman – Software Entrepreneur

So what should we do? Should we put this to the side for now and go on to the next slide? Is that the right thing, Deven?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

As long as we make a note—

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Paul Egerman – Software Entrepreneur

That we want to return to this.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Right. Yes.

Deven McGraw – Center for Democracy & Technology – Director

That we're not leaving this discussion permanently, but just I sort of feel like we're starting to bleed into another big category that I know, Paul, you and I had slated for the third discussion.

Paul Egerman – Software Entrepreneur

Yes, so let's—

Deven McGraw – Center for Democracy & Technology – Director

The second set might be a little easier, although I'm always wrong when I think that things are going to be easy. They're always more complicated than you expect them to be, but I agree that we should parking lot that; not eliminate it; and see what we can do with the consumer role in patient matching aspect of it.

Paul Egerman – Software Entrepreneur

Okay.

Deven McGraw – Center for Democracy & Technology – Director

Does that sound good? Okay.

Paul Egerman – Software Entrepreneur

So let's move to the concept of the role of consumers in this. Do you want to take us through this, Deven?

Deven McGraw – Center for Democracy & Technology – Director

Yes, sure. So another thing that we heard at the hearing was that there is a role that consumers and patients can play in contributing to improved accuracy in patient linking, patient matching. One of the things that had come up in our Policy Committee discussions in December with respect to patient access to data is the value of a patient portal. This is with respect to meaningful use and certification for stage two of the financial incentive program. Certainly, we're not at the stage of finalizing the sort of patient access recommendations. There's going to be a public comment period that will be launched this month on the initial set of recommendations that came from the Meaningful Use Workgroup that the Policy Committee had some discussion about at its December meeting. But one of the suggestions that received a high degree of enthusiasm—we didn't vote on it, but it was warmly received—was the idea of patient portals as a mechanism for allowing consumers and patients to check data that's in the record.

One of the questions that we ask here is should we recommend and/or support, given that this may be sort of something that is also part of the Meaningful Use Workgroup's recommendations, the use of a patient portal that allows consumers to verify the accuracy of information that is collected? Keeping in mind that patient access to date, we already have a number of policy initiatives in the works to support this, one being the changes to the HIPAA rule regarding patient access data that make it clear that when the data is kept electronically the patient should be able to get an electronic copy of it. That's in proposed rule format, but we hope will be finalized soon and then also, the meaningful use requirements with respect to patient access to data. So we've got a couple of suggestions here, again, one being the portal.

Another thought that Paul and I wanted to put on the table is the idea of giving people an easy mechanism through the portal, for example, to report errors in the data that they see. Then sort of a third area that we thought might be helpful to think about is best practice or guidance on how to handle requests for corrections.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I want to just go back for a minute to the accuracy issue and just say that I'm not satisfied with where we left that conversation. I don't think it's true that we can't measure accuracy at all and I do think it's an important area to drill down on. I would propose maybe that we try to put together a small group on this, something where we can work in parallel so we don't hold up the timeline, but I think there's more here. Even in 2005 when we did the common ... work we made more progress on this issue of accuracy. I think it merits a discussion.

But the other issue I want to raise is that there is a policy area that's missing to me here as we talk about this issue of accuracy, which is what happens when the wrong information is disclosed. That is an area we spent a lot of time on back then. I think it's worth a conversation or it's worth adding it to the list, because accuracy is never perfect.

Then finally, on this consumer question, this set of slides, I would just say that I think again we're getting into the how, which is the portal, and that maybe the appropriate place for us to be is that when a consumer has a mechanism to check and correct their own information is a requirement, however that mechanism is implemented. It could be a portal. It could be when they come in and they come in for a visit they are asked to review and look at their demographic information and correct anything that's inaccurate. It doesn't happen nearly enough in my opinion, but I'm reluctant to say everybody needs to have a portal for patients to correct their demographic information. That's not the way other sectors operate. The credit bureaus largely, as you all know, do that as a service, but it's not something that every offerer of on-line services necessarily is required to do.

Paul Egerman – Software Entrepreneur

Those are good comments, Carol, and I agree with you that if we look at this demographic data issue in isolation it's sort of not necessarily the right solution to recommend a portal. I think the reason that we put a portal on this slide was that in the most recent Policy Committee meeting there was a fair amount of enthusiasm for a patient portal being part of stage two of meaningful use as a vehicle for patients to determine, to help make sure that like medications lists and problems lists are being maintained properly and kept up to date. So the idea of mentioning patient portal here was sort of, I think, to help support that concept.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes and it's really one way to accomplish it. Don't get me wrong. It's great if it exists, but I guess what's important is that the policy direction that we give is in service of this objective and there maybe more than one way to accomplish it.

Paul Egerman – Software Entrepreneur

Sure. So you just need patient access as opposed to a patient portal?

Deven McGraw – Center for Democracy & Technology – Director

Yes. Well, actually, I mean I think the way that Carol framed it was that a requirement along the lines of consumer eligible providers and institutions and maybe even other ONC grantees, the infrastructure grantees, be required to have a mechanism for allowing consumers to access and request corrections to their data.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes, which I want to remind everyone is one of the Fair Information principles. So it very much is aligned with FIPS and with sort of the policy principles we started with.

Deven McGraw – Center for Democracy & Technology – Director

Right. So it's a little more generally stated, but with the backing of you have to provide this mechanism.

Neil Calman – Institute for Family Health – President & Cofounder

You've got to remember that a patient portal is tied to a particular provider and a particular EHR, so if there are inaccurate information floating out there somebody is going to have to access every specialist and every hospital they've been to to make sure that all of this stuff gets fixed.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

That's right.

Neil Calman – Institute for Family Health – President & Cofounder

And that's not really realistic. So I think that it's much more realistic that somebody would have an opportunity to do that while they're in an office, an opportunity to verify information and stuff like that. But I do agree that the portal is important for the other purpose that we stated last time, which is to give people an opportunity to correct their basic health information with whoever their primary caregiver is, but that's different than what we're talking about here.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think there are two questions that we could be talking about and maybe in light of what Carol said and what Neil just said that we should be careful to distinguish. Are we talking about correcting data at these source systems, giving the consumer a right to do that and are we talking about correcting it at systems where data from different sources has been merged, like in an HIE, which is where the patient match errors tend to occur? In other words—

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I'm not sure that's necessarily true, David, when we did our work, there are some entities, who have such matching problems just internal to their own enterprise that we used to say, "You're not tall enough to get

on this ride. You're not ready for health information exchange, because you have an accuracy problem that needs to be solved internally."

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right, but to run with Neil's example, let's say for example an HIE has matched up my data. I change my address; I change my name and correct it at one of the institutions. The HIE now is broken, because they're treating me as a new person and I'm not really a new person. I can be completely accurate in both of the contributor systems, but at the HIE I might never know if I don't have a way to request how are you matching my records together. I might never know that I've now been split into two people inappropriately.

Neil Calman – Institute for Family Health – President & Cofounder

Well, this actually gets to one of the most complicated things I've ever tried to do with exchange and this just has to do with the whole operation of starting to load enrollee information for managed care companies into our system. That is you get into this and you have to then figure out who's got the most accurate information and the most up-to-date information when their things don't match. I don't see any way of doing that without involving the consumer themselves.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Neil Calman – Institute for Family Health – President & Cofounder

Because otherwise it's just a crap shoot, you know. We had so many mismatches in just a single situation like that and you never knew which one was right.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I agree. I do think we need to add a footnote anyway. Remember what the representative from the insurance industry told us about people willingly obfuscating the match for purposes of fraud or for whatever other reason that drives them. So it needs consumer input, but it has to be validated somehow.

Deven McGraw – Center for Democracy & Technology – Director

Don, I heard you trying to get in earlier. Did we bypass your point or is it still—?

Don

The only comment I would make is I think this is an incredibly complex issue and we also have to be aware of the fact that there is a possibility that two patients are matched incorrectly so; going back to the source system may not even be relevant, because it's not that the data is bad at the source system. It's the match that went bad—

Deven McGraw – Center for Democracy & Technology – Director

Right.

Don

The source system is still good; it's just the wrong patient.

Deven McGraw – Center for Democracy & Technology – Director

Right and I don't know that we should put on patients – well, I know that I don't want to put on patients the responsibility of figuring out what the source was. I think the point, what I was trying to get at with the sort of more general recommendation, using the policy levers, which are the grantees and the meaningful use incentive recipients, to require that there be some mechanism for consumers being able to both, access, as well as request corrections to their data. Once they do that, certainly, for those entities that are covered by HIPAA, which is the covered entities and the business associates, there is a set of requirements with respect to how those requests get handled and then corrections propagated out of them. Am I right about that?

Don

Agreed.

Paul Egerman – Software Entrepreneur

Wes.

M

By the way, just so people know too, I think a lot of providers today are looking at the requirements of providing electronic copy of the medical record to the patient and deciding that that portal strategy is the most effective way to do that. I understand we don't want to necessarily recommend a portal strategy, but I think already that's what people are looking to.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I'd just like to one minor adaptation that we've been talking here: I think it's important that we enable patients to be able to see their data and correct it or request corrections to it, but that we can't rely on that as our only mechanism for worrying about correctness of data.

Deven McGraw – Center for Democracy & Technology – Director

Oh, absolutely.

M

Yes. Agreed.

Paul Egerman – Software Entrepreneur

That's right. I like what you just said, Wes, from two standpoints. One is it's just like the previous discussion on standardization. I'll use the statement baby-step forward. This is a step forward. This is not the solution. There is no single solution enabling patients to have access and to facilitate or make it easier for them to request corrections. It just seems that that would be another step forward.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

But it does raise— I mean I disagree with the idea that this can't be addressed at the HIE level, because it does raise performance standards there. Again, I think there are some policy issues on how an HIE goes about returning information for a query, what their threshold is for possible false positives or false negatives.

Gayle Harrell – Florida – Former State Legislator

I totally agree with what Carol is saying. I think that here again we may need to push this back down to the HIE governance level and say what kinds of accuracy level accessing is the HIE going to require from its providers, who are giving that information.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I agree that accuracy is an important discussion, but Carol's point as I heard it was that the requirement, if you would put that word in quotes, would be that the HIE provide some mechanism whereby the consumer can participate in improving the accuracy of their patient match. You have to do it in a way that doesn't expose data.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

No, I'm not actually saying that. I'm saying that the consumer should have the opportunity to correct their information at the source—

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

But the HIE is not off the hook as saying, “Well, we got it wrong because we had two sources with two different last names and so we took our best shot.”

David McCallie – Cerner Corporation – Vice President of Medical Informatics

No. I agree. I’m saying the HIE must provide the consumer a way to fix that.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Well, I do think there are ways of managing an HIE where there are always going to be uncertainties and there are policy decisions to be made for how you deal with those uncertainties.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Do you think the HIE has no duty to the consumer to report out in some way whether they’re accurate or not? I mean that would be less of a standard than the credit bureaus have.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

It depends on the HIE but, David, my more important point is that the HIE, there are a set of policies around accuracy that the HIE will set that no matter what happens at the source system and no matter how much there is the opportunity for the consumer to correct their own data they won’t be able to resolve. I think it’s important to set policies for those situations.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right, but even a perfectly functioning system may make mistakes. I wouldn’t even call them mistakes. They may make misclassifications of a match based on changes that they haven’t been made aware of. If so, they haven’t failed. Their algorithms are working as designed, but the consumer I think still needs some recourse to say fix my data.

Deven McGraw – Center for Democracy & Technology – Director

Wait. I think we’re starting to merge a couple of discussions here, one being the issue that we want to get to about accountability for accuracy, which we will get to. We probably won’t finish that discussion on this call and we’ll have to do more work on that, but I think on the issue of just the more narrow issue of what is the role of consumers and who should bear the responsibility of making sure that consumers are enabled to access their data and correct it. I think I’m hearing a clear consensus that certainly with respect to the sources of data that’s clear. I would say that HIEs could play that role as well, whether or not we want to require it or not seems like a bit of an unsettled issue.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I think we can require it and I think many of our other recommendations went to the notion of the entity that has the relationship with the patient. If an entity gets a report of an updated or changed set of demographic information there are ways to address that in terms of the way the HIE is notified and its data is updated between the provider and the HIE. That doesn’t have to have the consumer reporting their information to 12 places.

Deven McGraw – Center for Democracy & Technology – Director

Right.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right.

M

Do consumers have access to these HIE organizations?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

No, typically not.

M

Unless the HIE develops a portal of its own.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Right or some kind of a process or a report, and so my experience with the credit bureau was when I first checked after they passed the law that gave you the right to get an answer from the credit bureaus as to what your credit rating was. I discovered that they were confusing; they had been for years confusing me and my father, who shared a common name and for a long time, a common address. It's good news for me. His credit rating was better than mine, but nonetheless, it was wrong and when I asked them to fix it they fixed it.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Right.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I think we need something similar if we are not going to have a more formal mechanism of identifying patients for a consumer to say, "How are you identifying me in your system? Because I think there must be a mistake. I'm getting messages that suggest I'm pregnant and I'm not," or whatever.

Paul Egerman – Software Entrepreneur

The example you gave is interesting. It seems to me there could probably be nothing more frustrating than an organization that you don't know who they are, somehow doesn't know who you are but somehow has data on you.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Has very sensitive data on you.

Paul Egerman – Software Entrepreneur

Yes. If you think about what you just said and that's got to be what the HIEs are to patients. They don't know who these organizations are and they have data on the patients and there is no way for the consumers to check to see if it's accurate. I'm not sure how we can address that.

Neil Calman – Institute for Family Health – President & Cofounder

The thing that concerns me the most is if you correct that data at the HIE and the HIE doesn't have a way of finding all of the other places that have data on that patient. Then actually what you've done is you've made it almost impossible to match that data back with anything unless the HIE is a repository for all of this stuff. But if it's really just an index in a federated kind of system you correct it in the HIE and basically all you've done is you've now made it impossible for it to match against anything, because that's the only place that's got the corrected data potentially.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I mean I think that opens the door to challenges for HIEs to figure out how to increase their accuracy. It may be that their answer to the consumer, "You must go back to that source. Here's the phone number," and, "Get it corrected there," but that's a service in and of itself.

W

Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

But to put them off the hook and say, "You're going to be matching up this very sensitive data and you have no obligation of transparency seems wrong to me."

(Overlapping voices.)

W

... issues for the HIE.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes. I—

W

I don't—

(Overlapping voices.)

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

It's an issue of letting the HIE off the hook. The place where an inaccuracy would be discovered is the source—

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Exactly.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

—goes in for care. It's not going to be because they're randomly checking the HIE.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

No, it can be. I mean the consumer won't know what all of the sources are and the only way they might find out is to check the HIE. If you go to the hospital and you have an episode of care, data will flow to that HIE, some from Surescripts, some RxHub, some from your insurance company, some from a claims clearinghouse. Who knows? You don't know about those sources. Every one of those could distort the data along the way and this happens. I mean these are real world problems. It happened in the HIE that we built here in Kansas City. The data was getting corrupted along the way through the payer.

Paul Egerman – Software Entrepreneur

So I understand this description of the problem, which is that the HIE could possibly be, using David's expression, distorting data. I also understand there are a lot of different models of how these HIE organizations work, federated, centralized and so on—

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right.

Paul Egerman – Software Entrepreneur

So my question is what should we do about it.

Deven McGraw – Center for Democracy & Technology – Director

Here's my suggestion, given that we sort of have less than half an hour on this. I think in some respects we may be able to address the issue of the responsibilities of HIEs to consumers after we've had a more complete discussion about accountability for errors and transparency and measurement that we need to have and want to have and where that accountability lies. Then I think we can take it back, because otherwise I think we're trying to solve this myriad of problems where we want the HIEs to play an accountable role, but we're looking at it only through this consumer lens and that I think is not the sole answer.

So I guess what I'm suggesting here is that we parking lot the role of HIEs in sharing data with consumers for error correction purposes. Get back to it when we've had a more robust discussion on the accountability side and some consensus around how we want to hold the multiplicity of actors here—the

institutions, the providers, the infrastructure grantees, whether they're HIEs, Beacon grants, however we want to sort of bucket those, and come back to it. Because I feel like we're looking at this to bear the whole weight of a discussion that has a lot of pieces to it.

Okay. So that is the sort of third prong of the discussion where we, where Paul and I did not have, that we've already started to have some discussion about with Carol suggesting potentially a subgroup to look at the measurement. I think we want to get some suggestions, because we didn't necessarily have some hard and fast recommendations on this one, but we called it human factors. Whether there is a difference between thinking about an accountability infrastructure and what the human factors are, then we should talk about that too. But we heard very clearly in the hearing that it's not just an issue of technology; that it's an issue of both, internal processes, staff training, as well as accountability at both the front and the back-end, both for processes and outcomes. So I think what's probably most useful for the time that we have remaining is to think about directions that we want to explore in more detail in this big category.

So, for example, Carol, I'm going to go back to you again to talk to resurface the idea about measurement. Was it a measurement idea, hitting transparency of accuracy? Are you still on the line?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes. It's an issue of accuracy and how to measure it and I suggested that one way to implement an accuracy requirement is to create some level of transparency around success or failure. In other words, if there's a way to have people report or identify errors consistently then there's both, a transparency about their ability or lack of ability to participate in the exchange and also there is motivation for them to improve whatever internal processes need to get improved in order to achieve a certain level of accuracy.

Paul Egerman – Software Entrepreneur

Carol, I have a couple of questions about what you just said. One is how do they measure their own accuracy. The second one is do you think healthcare organizations are really good about reporting their errors, self-reporting errors?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

No, I don't think the reporting can necessarily happen in the healthcare organizations, but I do think—and Peter alluded to some of this—there are a variety of methods is why I suggested maybe we get a small group with some people, maybe who testified. Talk to them about their variety of methods, such as completeness of data fields, such as duplicate records, such as test data sets that you can work with. We talked about postal software. There are a variety of methods to kind of improve accuracy or measure accuracy. I don't think we should leave it as it's hard to do because it is a critical requirement for trusted exchange. There is just no way that you can have trusted exchange if you think that there is a level of inaccuracy that either exposes data inadvertently or provides the wrong data for clinical decision making. It's just such a fundamental issue.

W

Yes. I have a question for you, Carol. If you're going to have that transparency and you're going to have reporting, who are you going to report to and how do you make that transparent?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes. So the reason that this was triggered for me was because, gosh, I don't even know what workgroup it was, but wherever we were talking about certificates for providers for exchange we suggested that whatever body is providing the provider organization the certificate— Was that us?

W

It was governance.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Governance, okay. So whatever body is providing the certificate, if they inadvertently provide a certificate to a fraudulent user that that be made known, that there is some level of transparency around that

because the whole network, the whole sort of trust in the network falls apart once that starts to happen, because people just inherently don't want to use it. We were suggesting this also because the one time "accreditation" or certification doesn't really provide the users of a network with the kind of real-time or timely understanding of any problems that may exist.

So this is a really complicated issue. Don't me wrong. I don't think there's a completely simple answer, but what I'm proposing is that we try to pull together a small subgroup with some people, who have expertise in this area and see if we can make some directional recommendations that speak to a level of accuracy. Also I am suggesting that in addition, in this committee, we put on the list policies for getting to the issue of policies for what happens when it goes wrong, when people don't get it right. I think that's also critical.

Paul Egerman – Software Entrepreneur

Let me ask you, Carol; I was trying to understand the concept of this small group. Are you suggesting this small group will define the metric, I mean how you measure accuracy?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes. I'm saying this small group should bring this question of accuracy since we heard it in a lot of the testimony. You know we heard don't tell us how to do it, just tell us what bar we need to achieve. I'm suggesting we put a small group together to try to make some more refined recommendations on this issue of accuracy and—

Paul Egerman – Software Entrepreneur

... national standard on accuracy?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes.

Paul Egerman – Software Entrepreneur

Carol, are you referring to accuracy of the initial capture of the source system?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

No. No, of linking.

Paul Egerman – Software Entrepreneur

Of linking. How would that deal with the potentially inaccurate data from the source system? Would you just assume the source system is accurate and then measure from there?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

No. You can never assume the source system is accurate. I think there are multiple layers here and this is why I'm suggesting that we tease it apart. I do think that part of the issue of source systems and what to return in a query in information exchange can be and should be addressed through policies that get to the issues of false positives and false negatives and level of certainty in matching that most current master patient indices that people use have and make assumptions around.

Paul Egerman – Software Entrepreneur

Yes, but you also have an assumption that there is a master patient index. I mean think about like an acute care hospital, a community hospital. Their requirements around that area might be very different than a site that has a robust ambulatory environment.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

It doesn't have to be in a master patient index, Paul, but it's however they will identify a patient for information exchange, whatever that mechanism is has to meet a certain set of accuracy requirements. We're not going to say here is how everybody has to do it, but if someone is unable to adjudicate. You know, in some communities there are 500 patients with the same first and last name—

Deven McGraw – Center for Democracy & Technology – Director

Right.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

If somebody is unable to adjudicate that inside of their own system maybe we simply make a policy statement and say until you can do that you're not ready to exchange information outside the organization. It's not going to be improved at an HIE.

Paul Egerman – Software Entrepreneur

That's why I keep thinking that you're describing the source system accuracy.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I'm saying there are issues at both levels.

Paul Egerman – Software Entrepreneur

Yes. I like your suggestion. This is just one vote that says yes. It's really complicated and is worth teasing apart in more detail. I think you could devise measures that would be an approximation or a score of how well a system appears to be doing that are fairly objective. That's an interesting thought.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I'd also like to suggest that we keep in mind that, unless I missed a transition, our goal is towards transparency of accuracy and finding ways to measure and describe transparency as opposed to immediately setting performance standards.

Paul Egerman – Software Entrepreneur

Yes. I agree with what you just said. I think that was Wes. In other words, I think if you talk about transparencies or publishing or improvement programs and you help people by defining metrics they can use—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Yes.

Paul Egerman – Software Entrepreneur

That's good, but if you say everyone has got to be at this standard and the standard is you've got to be 94.5% pure—

M

That might be more of a—

Paul Egerman – Software Entrepreneur

I think we would have to set the bar so low that we could actually do harm, right?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

No. My point in transparency is—

Paul Egerman – Software Entrepreneur

... to include those people.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

My point around transparency was that it would have that effect; that by being transparent there would be a motivation—

Deven McGraw – Center for Democracy & Technology – Director

Right, to improve.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

—to improve the accuracy. Right.

Paul Egerman – Software Entrepreneur

That's right, but as long as it's transparency as opposed to setting an absolute standard.

Neil Calman – Institute for Family Health – President & Cofounder

I'm not sure that that motivation actually exists. I mean remember the motivation to collect payment is a good one. There are still huge inaccuracies in people being able to deal with those transactions and I just think it's important to remember that when you exclude somebody from this system because they don't meet a particular threshold the people that suffer are their patients, not them. I mean unless we're imposing some severe financial penalty or something or we can get this in time for 2015 meaningful use dollars or something then the only people that suffer are the other people in the practice, who've now been denied the opportunity to have their information available to them. But the provider, at least at this point, doesn't really suffer any significant consequence.

So I just think it's really important that we not— I've been worried about this issue every time we talk about if you screw up as part of the trusted framework then you just get excluded from the process. Well, that's great if you exclude me, but when you exclude the 100,000 patients that we take care of too the people who are being penalized are not the people who are responsible for the errors.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

So, Neil, they don't necessarily have to be excluded. There are other ways to get the information that you need. The question is when you go out on the network to retrieve a medication list for a patient that you're seeing you need a certain level of confidence that the medications that you're looking at are for that patient. If you find out that every time you go to the system you're kind of getting the wrong patient's information, not the wrong medications in the list, but the wrong patient's information you just won't use it. There's no way around it. It's not an exclusionary thing. If the system can tell you the patient's been seen somewhere else and you know where that somewhere else is, you still have other ways to get that information or retrieve that information. The question is really about when it automatically is retrievable.

Neil Calman – Institute for Family Health – President & Cofounder

Right. Well, right now I mean, again, this gets back to the discussion we had about the context in which that takes place and right now even when we get information now there's still a verification process—

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Absolutely.

Neil Calman – Institute for Family Health – President & Cofounder

You're still not going to just, say, have it automatically dump into your electronic health record. You're still going to say, "Are you the person that had your appendix taken out last year?"

"What? What are you talking about? I didn't." Well, that must be the wrong Mary Jones. There is still a verification process in the context of most care environments that could take place and that got to I think it was Wes, who was saying before there is all kinds of additional information that could be used in that verification process that's not necessarily exchanged in a standardized format.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

That's right.

Neil Calman – Institute for Family Health – President & Cofounder

But I think the point is that we want to give people the greatest chances for a match and then the greatest chances to verify that that match is exactly who the person is that they're collecting the information on. That process should be our primary way of kind of verifying accuracy at this point. I just worry about

every time we keep talking about exclusions and stuff like that that we're really just hurting the very people that we're trying to help here.

Paul Egerman – Software Entrepreneur

Those are good comments, Neil. I'd also add that you don't always get a chance, even if you'd like to exclude somebody, to really exclude them. You could have some entity in your community, I don't know, maybe an imaging center or something that does a bad job of sending you data and your patients still go there. Maybe it's the only place they can go in your community and so you've just got to do your best with it. You don't really necessarily always get a choice. You wish you had one.

Deven McGraw – Center for Democracy & Technology – Director

Right. So let me just interject here, because we have ten minutes left in the call and we want to open it up for public comment. This is clearly something that we want to have additional discussion on, both in terms of this transparency point that we've spent the last ten minutes talking about, as well as some finalizing of specific language on some of the recommendations we talked about before, so we're definitely not done with this. I think I like the idea of sort of pulling together a small group to tee up some more fully baked ideas on how to deal with this transparency issue. Those would, of course, be brought to the tiger team for further discussion, but it's helpful to have some additional heads, including some of the folks who testified at our hearing, to help us flesh this out some more.

Carol, it sounds like you're interested.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Now, I don't know that I would conclude that, Deven.

Deven McGraw – Center for Democracy & Technology – Director

I was hoping you would say yes. At any rate, we can work off-line to put together a process for teeing up some more specifics on this issue, but suffice it to say we'll have some more time to deal with this. We do have some other work.

Paul and I are also trying to work on a schedule for the meetings over the next several months. I think for some of these issues that take a little more time to develop we may be able to be working on a couple of issues at once, which we have never yet tried to do. But in order for us to continue to make progress on some issues that take a little bit of extra time and development that may be one way to do it. So, for example, one of the issues that we had teed up on an earlier agenda was the patient access and patient identity proofing, which we didn't get to in our authentication identity proofing discussion on the provider entity side. We had always said we were going to get to it, so that's one that we want to start to get to, but I want us to put together— This topic of matching is very important. I think we have a great opportunity to put together a solid set of recommendations that really move the ball forward in this area, but we're going to need to take some time to do it.

Paul, do you have anything you want to add before we—?

Paul Egerman – Software Entrepreneur

No. I think that's a great summary. The only other comment that I'd make is we are, as Deven said, reviewing the schedule. I suspect that ONC is going to also ask us in the near future to review our previous recommendations in light of the PCAST Report, so we might spend some time in our next meeting doing that in addition to continuing to work on the patient matching issue.

Leslie Francis – NCVHS – Co-Chair

You just said what I was sitting here thinking, which is that even what came out of the discussion today might have looked different in light of the PCAST Report.

Paul Egerman – Software Entrepreneur

Yes, so I think part of the discussion would be just looking at from that perspective, change, what we've already done and what we're planning to do.

Deven McGraw – Center for Democracy & Technology – Director

Well, right. I understand that there's also a PCAST Working Group being created, so—

Leslie Francis – NCVHS – Co-Chair

Do you mean by ONC?

Deven McGraw – Center for Democracy & Technology – Director

Yes. There are a lot of balls in the air on that one.

Leslie Francis – NCVHS – Co-Chair

Do we have—as you guys are coming up with a schedule maybe I missed it—a set of topics or areas that you could send around? It might have already been sent around, but—

Deven McGraw – Center for Democracy & Technology – Director

We haven't yet.

Paul Egerman – Software Entrepreneur

We haven't yet.

Deven McGraw – Center for Democracy & Technology – Director

We haven't yet, but we actually will do.

Paul Egerman – Software Entrepreneur

We will be developing that.

Deven McGraw – Center for Democracy & Technology – Director

Yes, the MITRE Team had teed one up for us, but we didn't think we'd have time to talk about it on this call and we were right about that. There are some further things that we need to discuss in light of the conversations that we've had today and we need to refine it, but we definitely want to get input on it. As is always the case, we're trying to flesh out the framework of policies that implement the principles, the data sharing principles that ONC has adopted and so we need to always be mindful of where the most important holes are; that there is an overarching goal here and we're not just cherry picking issues.

Leslie Francis – NCVHS – Co-Chair

Have we got a copy of the PCAST recommendations and conclusions? Because I don't know if I've seen that if it has been circulated to us.

Deven McGraw – Center for Democracy & Technology – Director

I'm happy to circulate the link. It came out in December.

Judy Sparrow – Office of the National Coordinator – Executive Director

I can send that on, Deven.

Deven McGraw – Center for Democracy & Technology – Director

Thank you, Judy.

Paul Egerman – Software Entrepreneur

So, excellent discussion. I didn't mean to take us astray in mentioning PCAST, because that's opening a whole, interesting, significant discussion. The only reason I mentioned it is I think at our next call we're going to try to continue to make some progress on patient matching to possibly consider having some discussion about PCAST, but maybe not. We will work that out.

I think we're about out of time and we really need to do the public comment.

Deven McGraw – Center for Democracy & Technology – Director

Yes, we have to do public comments.

Judy Sparrow – Office of the National Coordinator – Executive Director

Right. Okay. Operator, can you check with the public and see if anybody wishes to make a comment?

Operator

We do not have any public comment.

Judy Sparrow – Office of the National Coordinator – Executive Director

Okay. Thank you. Thank you, Deven and Paul.

Deven McGraw – Center for Democracy & Technology – Director

Thank you, everyone.

Paul Egerman – Software Entrepreneur

Thank you, everybody, for the spirited discussion. Thank you.

Public Comment Received During the Meeting

1. I find it difficult to follow the idea of measuring data accuracy and counting duplicates. If, within your system you can recognize duplicates, then there must be enough data in the records to have made a match. If you did not make a match then there is not enough concordance in the data to recognize multiple records as duplicates.