

Tiger Team
Draft Transcript
August 3, 2010

Presentation

Judy Sparrow – Office of the National Coordinator – Executive Director

Good morning, everybody, and welcome to the Privacy and Security Tiger Team call. Just a reminder that there will be opportunity at the end of the meeting for the public to make comment and also workgroup members, if you could remember to identify yourselves when speaking. 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 – eScription – CEO

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Latanya Sweeney? Gayle Harrell?

Gayle Harrell – Florida – Former State Legislator

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Carol Diamond?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Judy Faulkner?

Judy Faulkner – Epic Systems – Founder

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Dave McCallie?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Present.

Judy Sparrow – Office of the National Coordinator – Executive Director

David Lansky? Dixie Baker?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I'm here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Micky Tripathi? I think he's on holiday.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Judy Sparrow – Office of the National Coordinator – Executive Director

Rachel Block?

Rachel Block – New York eHealth Collaborative – Executive Director

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Christine Bechtel?

Christine Bechtel - National Partnership for Women & Families – VP

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

John Houston? Wes Rishel?

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

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Leslie Francis? Adam Greene?

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

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 anybody off? With that, I'll turn it over to Deven and Paul.

Paul Egerman – eScription – CEO

Good morning. I happen to be this morning in San Francisco, and so this gives me an opportunity to show extra appreciation for our West Coast members, Dixie and Wes, to realize that it's not that easy to get up early in the morning and do a 7:00 a.m. phone call, so I appreciate your dedication and, of course, appreciate everybody's dedication in participating in these calls.

We are having an interesting discussion on the entire topic of consent, and we are again to remind everybody a tiger team that was established by ONC for the purpose of answering some very specific questions about privacy and security, predominantly over the summer months. And we report to the HIT

Policy Committee that has to approve any recommendations that we make. This is, of course, a public call, and we very much appreciate any members of the public who are listening this morning and look forward to hearing your comments during the period at the end that we have for our public comment.

Since our last tiger team meeting, a number of things have happened. Deven and I have made presentations in front of both the policy committee and the standards committee. When we met with the standards committee, had lunch with some of the standards committee members who are members of the tiger team who suggested that we start each meeting by sort of like doing a little bit better job of trying to frame the question, review where we are in our entire process, and we felt that was a great suggestion. So we're going to start out today by really just sort of doing a quick review of where we are in terms of the decisions and recommendations we've made on a number of topics, and then we're going to launch into a continued discussion about various issues related to consent.

Having made those comments, Deven, do you want to take us through these slides, the first part of these slides? I don't know if you have any other comments you want to make.

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

This is John Houston. If you already did roll call, I just signed in.

Deven McGraw - Center for Democracy & Technology – Director

I don't have anything to add other than, again, it's our continuing hope. I mean, it's our plan, actually. Hope is the wrong verb. For several of these recommendations that we have made in the past, it has always been our plan to sort of pull them together into a single document, review them, and refine them before finalizing them, so keeping in mind. I know there's been a little bit of e-mail traffic about some issues that we have put before the policy and standards committee in the past, and so I just want to remind folks that while we have been proceeding with putting our recommendations to date before the policy and standards committee for feedback, we have always done so with the proviso that we would look at them as a whole in a sort of much more comprehensive fashion before and see if we need to refine them in some ways before we would put the final stamp on them.

Paul, do you want add anything to that before I—?

Paul Egerman – eScription – CEO

No, I think that's correct. And so what we were planning to do was to go through some these slides, and I think the first part, Deven, you were going to do, and then I was going to do the second part.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Paul Egerman – eScription – CEO

It's sort of a reduced version of what we did for the policy committee and standards committee.

Deven McGraw - Center for Democracy & Technology – Director

Right, that's right. Okay. So without further ado, I can go to the next slide. This slide reminds everybody that we have already been dealing in our conversations with a more narrow scope of data access, use, and disclosure, and we've been focusing on exchange of patient identifiable health information to meet stage one of meaningful use. So there are many important questions to be resolved in privacy and security that are not sort of part of the dark purple bubbles on this slide that are in the gray area and that we do know need to get resolved, but we deliberately narrowed the scope of our discussions in order to be better focused and enable us to come to some recommendations that can help up, sort of provide us

with a jumping off point for tackling some of the issues that are not necessarily triggered by stage one of meaningful use, but are important uses of information and for which there needs to be a privacy and security policy framework in place.

So within that overall framing, here are some of the recommendations that we have put before that the policy committee has accepted and that we have made to date. The relationship between the patient and his or her healthcare provider is the foundation for trust and ... information exchange, which means providers hold the trust and are ultimately responsible for maintaining privacy and security of their records. It doesn't mean they can't delegate certain decisions that they would need to make related to exchange. They can do this as long as the delegation is done in a way that maintains that trust.

Some examples of this, which we sort of tossed up and talked about in some of our very first meetings involve issuing digital credentials or verifying provider identity. Where we also noted that notwithstanding that provider's have the ultimate responsibility here, that federal and state governments have a role to play in assuring that there are policies in place with respect to this credentialing and identification and authentication to make sure that this gets done in a trustworthy manner.

All entities involved in health information exchange, including providers and third party service providers like HIOs and intermediaries, should follow the full complement of fair information practices when handling patient information. These include transparency, data integrity, and quality ... specification, collection, and use limitations, data minimizations, security safeguards, individual access or control, and oversight and accountability. And we know that these have been articulated in many places, but in particular for our purposes, ONC has articulated them in a nationwide framework for exchange, which was actually expressed ... by the policy committee into the strategic document.

Then we used those principles, and particularly those related to purpose specification, collection, and use limitation, and data minimization for which we tinkered around with some potential definitions to answer some very specific questions about exchange, and we're not going to go through them today on the call, but they are in the appendix to your slide, both the questions and the answers that we came up with. Again, we need to find a way to wrap all of this, including the questions and the answers, into an understandable sort of document that can be useful, both to ONC, as well as to the outside world.

With that, Paul, I'm going to turn it over to you for what we've said specifically on individual choice, which is just one of the fair information practices.

Paul Egerman – eScripton – CEO

What you see here is a slide talking about the concept of what we called general consent, and basically we've framed this discussion by saying the discussion on consent would have two parts. One is this discussion about consent from a standpoint of like all in or all out, and then there'd be a second part of the discussion, which would be about whether or not you consent, but not all in or all out, whether or not there was something that was like a middle ground, and also whether or not once you did consent, whether a patient could assert some control over what happened afterwards. That's the framing. This part of the discussion was all in or all out.

And basically the discussion you're going to see in the second bullet and very important was we reemphasized the foundation of the provider/patient relationship. So when I presented before both the policy committee and the standards committee, we actually repeated the slide that Deven had showed earlier. We talked about that. But it also assumes that all participants are following the laws, following everything that we said about policy and safety safeguards. And you also see the added principle at the

bottom that's very important. It's a very simple principle to consider patient expectations, that patients should not be surprised, is the basic concept.

As you see on the next slide, we also reviewed a previous recommendation that we had made, which is directed exchange. When directed exchange occurs for the purposes of treating a patient, it does not create an additional requirement for consent beyond which might be already required by law. Then you see this little parenthetical note. See later slide 13 for a suggestion, so that's sort of like a hint to tell you that something very exciting is going to happen in slide 13. I don't want to ruin that slide by telling you that, but anyway, that was our previous recommendation on directed exchange, which is no additional required consent.

Then we had this discussion about what factors triggered the need by a provider to obtain the patient's consent. So again, we pictured this in the environment. The patient provider relationship that that's the starting point for the discussion, and then to remind everyone, then we listed off these various triggers, so this is triggers about patient's health information is no longer under control. The health information is retained for future use.

I won't go through all the items on this, but this is what we had decided and discussed before. This information was well received by the policy committee. However, there were some concerns that some aspects of this were unclear, so there was a request that we reword some of these like the issue of control was a concern. And there was also about a million questions about aggregated data, so that I think the concepts have all been approved, but there is an outstanding issue that we need to clarify what is written here.

The next aspect of what we have presented is what we call the recommendations for the choice model. This is the whole discussion. First, it's the discussion that says ONC needs to use all of its policy levers to implement what we say about a patient's consent or patient's choice. And that by itself, incidentally, is an extremely strong statement. Then we have this description of this concept of meaningful choice, which really came from Carol and the Markle Foundation, but this is really an excellent description, and this was extremely well received. People feel very good about what is written here, and so this whole discussion of consent went really well.

Then there was an additional slide that's not in this deck, I don't think, where I described how we did not come to a consensus on this business of opt in or opt out. That there was one group that believed that basically providers should choose their consent models based on the circumstances as long as they're referring to what you see on this screen for meaningful choice. And there was another group who believed that this clearly had to be an opt in kind of choice whenever these triggers that were on the previous slide occur. And I did describe that there was like heartfelt expressions that feel very passionate about these issues. In both the policy committee and standards committee, there were a fair amount of debate or discussion of this very topic.

One observation I would make about that discussion that's not written in this deck and it's just an observation, which is that a lot of the people who wanted to make sure that basically providers could choose whatever model they wanted seemed to be people who were very concerned about patients' health or healthcare. They wanted to make sure that we didn't do something that would prevent, become an obstacle for patients being able to benefit from a service that could be helpful to them. The people who seemed to be very focused on opt in as a solution seemed to frequently be very much motivated by issues related to individual autonomy. There were even arguments about individual rights. In saying that, though, I know that may be way oversimplifying the discussion, and that may not fit into anybody's own

views, but those seem to be things that I notice because that might be helpful to understand where people are coming from in this entire debate.

The third question that we answered so far in this all in or all out discussion about consent or choice was whether or not providers should have a choice about participating, and we said yes to that, and that, I think, was accepted also. And then we made this other summary comment that I think people seemed to accept, which is to be successful, we need to earn the trust of both consumers and physicians. Here it just says to be successful. I think we really meant to be successful with health information exchange, but it's probably true with everything that we're doing with the standards committee and policy committee that we have to earn that trust.

This was our presentation. The policy committee accepted and endorsed the entire presentation, which they did though with the understanding that we were going to come back with the sort of completed package that Deven just referred to, and that they would have another chance to look at it as a whole, and also with the understanding that when we came back with the completed package, we ourselves might be making some adjustments besides the wordsmithing changes that we clearly have to do to the triggers, we also might be coming back and saying, well, based on some additional understanding, we're altering something so that that was also clearly stated.

The information we presented did sort of make the national press or at least the national press in terms of trade journals, although they seemed to primarily talk about the opt in/opt out discussion, but it does seem like people are following our work, which means that people view it as very important. Again, the purpose of presenting this is to be responsive to people's requests that we sort of frame where we are so that people understand and the tiger team members can understand where we are and where we're heading.

Where we are is we've completed a very important discussion about all in, all out consent. And what we want to do today is to transition to say, well, what about is there something in the middle between all in and all out? Can you give consent and transmit a part of your medical record based on one of these triggers or based on some other lawful requirement to give consent? Is there a middle ground? And, actually, whether or not there's a middle ground, to what extent do patients have any ability to exercise any control after they've given consent as to who can access the record? Those are the questions we want to ask.

We have about, I think, five or six questions specifically around them. We do the first question, I think Deven is going to lead us, but the first question is actually a little bit of cleanup work because when we presented everything, somebody, I think it was actually Judy Faulkner pointed out. One slide we said directed exchange does not require consent. And on another slide, we said since the sensitive data could be a trigger for consent, and so somebody that we needed to reconcile it. So the first question relates to that, then the subsequent questions relate to the sort of middle ground.

Did you want to add anything, Deven, or perhaps take us through this first question?

Deven McGraw - Center for Democracy & Technology – Director

No, I don't think I have anything to add, although I actually think it would be helpful, Paul, if we lay out what all of the questions are we hope to get to today, and then start to tackle them one-by-one.

Paul Egerman – eScription – CEO

Okay.

Deven McGraw - Center for Democracy & Technology – Director

So we've got sort of, as Paul mentioned, we've got this question about sort of reconciling some previous statements that we made, particularly with respect to whether direct exchange would require obtaining, giving the patient some choice when there's sensitive data involved, since sensitive data were the trigger. Then we move on to another question that notes that, again, as Paul mentioned, our previous recommendations on consent were based on sort of an all or nothing or all in or all out approach. To what extent does current technology support the ability for patients to make more granular decisions on consent? And, in particular, and we've got sort of this technology question bifurcated into two pieces. This first one really deals with what I'll call the what. To what extent does the technology support the ability for patients to make more granular decisions, i.e. to transmit only certain parts of their medical record when it's on the amount or type of data sent, limits on what data gets sent.

And then the next question is, to what extent does current EHR or even HIO technology support the ability of patients to control who can access their health information per their preferences, so this is about who receives the data, limits on potential recipients. And then the fourth question is what actions should ONC take to enable patients to make more granular consent decisions such as pilot projects or establishing certification criteria for a future stage of meaningful use? And then the final question that we hope to get to today, and since we have four hours, we should, are these technical capabilities – as the technical capabilities are being developed, and there are certainly some assumptions built into this that the technology probably isn't as far along as some might hope, what options are available to honor patient preferences in the meantime? That's the sort of constellation of questions we have as a goal of tackling today.

And so going back to the first question, for directed exchange, is the presence of sensitive data and the information being exchanged a trigger for requiring consent? Now we acknowledge that the term sensitive data is one that might be subjective to the individual, but we also know that certainly there are some both federal and state laws that provide additional protections on certain types of data like substance abuse, treatment records on the federal side, as well as the state, or mental health records or HIV records just as examples.

On the next slide, what we have here is a straw proposal. It's a lot of words, another slide with a lot of words on it, and we thank Wes Rishel for getting us started with this language. It's not verbatim from an e-mail that he offered last week, but it's fairly close. And it starts off that all health information is sensitive, quite frankly, and what patients deem to be sensitive is likely to be dependent on their own circumstances. However, some federal and state law recognizes some categories of data as being more sensitive than others. Unless otherwise required by law, and we do know there is law in this area that does provide patients with some rights with respect to access, use, and disclosure.

But with respect to direct exchange for treatment, the presence of sensitive data in the information being exchanged doesn't trigger a requirement to obtain the patient's consent in the course of treating a patient. However, the absence of one of the factors triggering consent does not change the patient/provider relationship. When information is transmitted by a provider as a direct exchange for specific treatment purpose, clinicians should take into account and honor to the extent possible patient's expressed or likely concerns to privacy and also insure the patient understands the information that the receiving clinician will likely need in order to provide safe and effective care.

The use of direct exchange does not materially change the considerations that would be undertaken in exchanging such information by non-electronic means. As always, clinicians should be prepared and willing to discuss with their patients how their information is disclosed. So I think, in essence here, and these are the two surprise provisions that Paul alluded to earlier, not that they are necessarily surprising

in their content. I think they flow very well from the fundamental doctor/patient relationship as the foundation principle that we have been operating from. But these are starred because we think they might actually fit better in the wrap up of all of these recommendations as part of the set of recommendations that we make for direct exchange where the treating provider is in control of decisions with respect to disclosures of information from his or her record. Let me pause there and open the floor for discussion.

Gayle Harrell – Florida – Former State Legislator

Deven, this is Gayle. First of all, I do want to acknowledge that there are very stringent state laws, and they vary state-to-state as to what can be disclosed and what permission is required of a physician. For instance, in Florida, any STD, HIV status, any kind of sexually transmitted diseases or anything of that nature, abortions, for instance, as well as mental health and substance abuse records, do by statute require specific permission to do that. And in a non-electronic world, physicians evaluate records before they're sent, and they only send those records that are available, that they feel are necessary, that limited set of data necessary for patient treatment.

However, in an electronic world, when you electronically send a record, the whole record goes at that point. So there really needs to be that same level of physician oversight as to what goes when you're faxing a record, when you're sending a record in the mail and making a copy of it. You specifically evaluate what parts of that record you're going to send. So I think we need to be very clear that there's that physician involvement in evaluating what sections of that record are sent. This does, to some degree, but I don't know you could differentiate that or make it even a little stronger that that physician involvement in sending that sensitive data needs – is a very significant responsibility of the physician.

Deven McGraw - Center for Democracy & Technology – Director

Okay. I mean, I think it's a good point, Gayle. I think it's a matter of maybe strengthening the language, but I'm not sure that the intent is all together different from what we've got here. But I'm not disagreeing with the point you're making at all.

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

My view has evolved on this over the course of the discussion with respect to the specific issue of the demands on physician time for maintaining the privacy relationship. It comes in two categories. One is, in some of the language I've proposed, I've changed the physician obligation with regards to counseling the patient on privacy from proactively doing it to being available and prepared to do it.

But in this case, I think we have to consider that given the burdens that are on physician's time, the benefit we expect to get from electronic health interchange will be circumscribed to the degree that that exchange is not a computerized process, but requires an active physician review of the case and information in order to transmit the information. I'm not saying that that argues for send it all, all the time. I am saying, however, that we are in a kind of a triangle of constraints here between the capabilities of technology today, the availability of physician time to prepare information for transmission, and the privacy requirements of the patient.

Where there is an active referral, where a patient is being referred and, in effect, there's a directed exchange going on, I am thinking it is more likely that there will continue to be, at least at that point there is an act. That is, the physician is involved in considering the case at the time. And, in addition, we know that where there is an act of referral, there is a different set of constraints on privacy. And as Judy outlined in her e-mail, the ability to select patients meaningfully is a limit, so we may recognize a different case for active referral than providing the patient data on a pro forma basis as a part of – in a way that we're attempting to enhance information flow.

Deven McGraw - Center for Democracy & Technology – Director

Wes, I think I want to understand when in the sort of universe of stage one meaningful use What do you mean when you say pro forma versus a sort of more active or proactive sending of data?

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

We have directed exchange and we have other exchange, and this is not directly— I think you can correlate some of it to meaningful use, but it's more around the question of is the information being sent on the basis of a specific, anticipated use for treatment or is it being made available for pull by another physician for a purpose, which is as yet unknown or unstated?

Paul Egerman – eScription – CEO

Wes, this question is directed exchange for treatment. You actually see that in the third bullet. Maybe we need to emphasize that.

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

I'm sorry. I forgot we were going back. Right.

Paul Egerman – eScription – CEO

Yes. In other words, this question is sort of a cleanup question.

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

Right.

Paul Egerman – eScription – CEO

This is directed exchange for treatment.

Judy Faulkner – Epic Systems – Founder

I think that the paragraph that begins with a double star, however, may end up in many, many cases negating what we said previously in that. See, the knowledge I have about the healthcare organization lawyers and compliance offices, they are very – as reasonable – they're very conservative. And if they read that the clinician should take into account and honor that information and make sure that the patient understands, I think they're going to have to make certain requirements of everyone that will negate that there's a trust and the physician should send the information.

Deven McGraw - Center for Democracy & Technology – Director

All right. Judy, I mean, first of all, I'm not immune to what overly conservative lawyers will do. I'm not immune to it at all, and I may be was one in a previous life. But I will say that I think it's a mistake for us to sort of use that as a jumping off point for making what we think are the right set of policy recommendations, but will have to be extra clear that we're not imposing another legal requirement beyond what's in law.

But if our recommendation is the foundation of trust is in the doctor/patient relationship, and those discussions and the doctor knowing his or her patient, and in a direct exchange environment where the provider is in control of disclosure decisions from his or her record, I think we have to acknowledge that the conversation is desirable. And certainly with transparency, patients at least have to understand what's going on with their data and be very clear that we're not suggesting that ONC pursue a HIPAA ammendment that would change the law in this regard, but certainly we don't want to also have our recommendations, I don't think, be interpreted to mean that the physician could, over a patient's known objection, that they would want to or should disclose data that is known to be sensitive to the patient.

Judy Faulkner – Epic Systems – Founder

I agree with you with everything you said. I don't read this that way, and I'm wondering whether this can be— Because I absolutely agree. The physician should not over a patient's known or objections do anything like that. I also think that it could be perhaps rewritten in a way that talks more about education of the patients in general rather than each time the patient requests information that has to be done, because it can be interpreted that way too. I'm wondering, in order that we don't have some healthcare organizations take it a different way, which I think is also plausible, can we clarify it and still retain what you just said, but clarify it so that people will not misinterpret it, because I think it's just amazing how people misinterpret these things.

Paul Egerman – eScription – CEO

Yes

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I think we are misinterpreting what's on the page as well. We have here the patient/provider relationship, and I keep hearing people refer to as the physician. Jim Walker made a really good point at the standards committee meeting and in his followup e-mails that the relationship is not a patient/physician relationship. In fact, that's not what we have here. We have the relationship between the patient and the provider entity. But his recommendation was that we really acknowledge that in today's world and increasingly in tomorrow's world, the relationship is between the patient and their care team and not a physician. If we really want to avoid sounding like we're placing another requirement on the physician, then I suggest we consider referring to the care team, which in the future would apply to the continuity of accountability as well.

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

I'd like to respond, but I wonder if the chair wants to sequence these issues separately.

Deven McGraw - Center for Democracy & Technology – Director

Dixie, I think your point is well taken. It's one, we also sort of interchangeably use clinician, provider, physician. I think we can and should pay a little attention to that in our wordsmithing and wrap up. I'm not sure that it necessarily changes the content or the basis substance of what we're trying to convey here. It almost sounded like we're sort of circling the same set of issues, but not of us wholly satisfied that we have pegged it right in the wording. Am I wrong about that or, Wes, what ...?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

No, I wasn't talking about wording. I'm really talking about the concept that we keep talking about overburdening these physicians. And that's not a matter of wording. That's a matter of acknowledging how care is provided in this day and age.

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

Well, let me say that I think there are a couple of substantive issues going here. One, as a rule, we don't want to say anything that precludes care teams being a way medicine is delivered. I think, however, that we also have to consider small physician offices where the care team still is the physician largely, and we can't ignore that situation at least. The second substantive issue is, is directed transmission a dump of the record, or is it selected information specific to the event that causes the directed exchange?

Paul Egerman – eScription – CEO

It's a good question, Wes. ... I also want to say there's actually a third question here that Judy Faulkner is raising, which is sort of like the scope of what we're suggesting with these asterisk issues. But to first

respond to your question, Wes, because it's also something that Gayle referenced. The directed exchange, in my opinion, does not necessarily mean a dump of the record. If you look at the examples, there was a healthy e-mail exchange on this where I wrote out a couple of examples that Neil Calman wrote two examples also. Neil's examples were much more sophisticated or complex and probably more realistic too than mine.

But the directed exchange examples, at least two or three of them, involved ordering tests. When you order tests electronically, you know, you don't dump the entire record. There's a specific format. In fact, people get annoyed if you dump the record if you wanted to order a laboratory test. You know, there's a specific format for that. And the other example happened to be a patient getting discharged from an acute care setting, from a hospital, and being transferred into an extended care facility, but even then you don't dump the whole record. What you do is you transmit a discharge summary, which is a fairly structured document that summarizes things. I don't think that directed exchange necessarily means that the entire record is transmitted. It could mean that, but it doesn't necessarily mean that.

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

The problem is, based upon what that exchange needs to be and the case of like a discharge to a long-term care facility, it might one thing. It might be another in another circumstance. However, there are so many nuances, and there are very many cases where much of the record does need to be transferred or made accessible for some period of time. And so we're dealing with this right now in my institution as it relates to discharge and discharge planning to long-term care facilities, and there is a dramatic difference in what type of information needs to be made available based upon the patient circumstances and the setting of care. So it is very difficult because, unfortunately, it's not mechanical, and sometimes you almost have to over-communicate information and allow because you're not necessarily sure with precision what really needs to be transmitted.

Paul Egerman – eScription – CEO

That's right. In the example of that transition of care from an acute care setting to extended care setting is an interesting situation because there are a lot of people who are advocating to transmit more information in order to try to help avoid or reduce readmissions rates that the next facility needs to understand as much as they can about the patient. But the sum total here was the idea was those situations don't trigger a requirement for consent. And that just because if you're transferring a patient from the acute care setting to the extended care setting, and let's say the patient is taking an antidepressant medication. Well, the reasonable expectation of everybody is that they continue to have to take that medicine, and the new facility is going to know the same thing that the previous facility knew about the patient, and it's a reasonable expectation.

Deven McGraw - Center for Democracy & Technology – Director

Right.

Paul Egerman – eScription – CEO

And so how it's implemented, John, is difficult. My point was it's not necessarily the case that the entire record is always sent.

Deven McGraw - Center for Democracy & Technology – Director

No.

Paul Egerman – eScription – CEO

In other words, if you order a laboratory result test

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

Right.

Deven McGraw - Center for Democracy & Technology – Director

Right. That's right, but I think we're straying a little bit far from the question. I don't think we should try to create sort of one size fits all policy and say that directed exchange is only when parts of the record are sent versus the whole record being sent. I mean, obviously when you've got the elements of direct exchange that have been consistent throughout all of our discussions is that the provider or the record holder, whether it's a small doc or a large institution, has the control over the decision about both whether to release information and how much information to release based on the purpose for which the data is being disclosed or for which the data is being sought. And so there's a judgment call sort of built into that and acknowledging that we don't want to overload those judgment calls in the name of privacy, but also acknowledge that when there is particularly sensitive information in what's being disclosed, there's that much more need for some way to assure that the patient understands what's going on and that if the patient doesn't want their data being sent, or if in fact there's a state or federal law that requires consent to be obtained, that that law will operate and the doctor may actually have to get consent.

I'm saying more than intended to. I want to get us back to the basic question that we're trying to answer here, which is that we have said in the past that when it's direct exchange, when the provider has the control over what gets disclosed from the record, and there isn't— We're not suggesting that ONC place additional requirements for obtaining specific patient consent absent what the law might already require. Then we came up with some triggers for when we think in fact ONC ought to set national policy and require that patients have some choice. One of the triggers we at least identified in our initial use, in our initial list was sensitive data. So getting back to the simple question of when you have direct exchange, and there is sensitive data in what is being exchanged, whether that's the whole record or just the lab result, does that require consent?

What we've got in the straw proposal is, no, we're not suggesting that ONC place—that the presence of sensitive data is a trigger in a direct exchange context where the provider already has control, but it doesn't mean that there isn't one, sometimes law, that needs to be complied with, which may require consent. And second, that that information, if the patient has an issue and would prefer that it not to go, that that's a conversation between the doctor and his or her care team if that's the applicable term there, or his or her doctor if it's a smaller practice ... from the foundation of trust sort of principle that we've got there.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think we've kind of positioned all of these to lie under the general rubric of the fair information practices, which would be consistent with what's written here that its purpose specific exchange necessary for the task at hand.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I'm fine with what's on this slide.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes. I think it's pretty good. I agree.

Judy Faulkner – Epic Systems – Founder

I'm worried about several things. I'm worried about, it says clinicians should take into account ... and I think the point that was made earlier that we should replace that with providers because people will take it literally, and it says clinicians. That will help. And I think that there should be something that says this

does not mean that every patient has to be asked every time when information is shared with a receiving provider. Something that explains what you're intent is because I'm afraid it's too easy to misread it.

Paul Egerman – eScription – CEO

Yes. It's interesting. Your comments, Judy, are interesting because the two sort of asterisk bullets were put at the bottom because some people were concerned by saying there was no concern, no requirement for trigger would mean that the physicians and providers would start to do less than what they're currently doing. Now you're concerned that by putting what we said in here that it's going to have the opposite affect.

Judy Faulkner – Epic Systems – Founder

I didn't get what you first said. The concern was when there was no requirement, what?

Paul Egerman – eScription – CEO

In other words, the last two bullets were added because I think somebody was concerned that if all we did was say no requirement for consent, that would somehow be interpreted that physicians don't ever have to talk to patients about anything.

Judy Faulkner – Epic Systems – Founder

Yes.

Paul Egerman – eScription – CEO

But if you look at the first sentence of each of the last two bullets, I think they accomplish what you're looking for, Judy. It's just the subsequent sentences. The first sentence on the next to the last bullet says the absence of one of the factors triggering consent does not change the patient provider relationship. And the next bullet says, the use of directed exchange does not materially change the considerations that should be undertaken in exchange of information by non-electronic means. In other words, I interpret those two sentences to say is there's no requirement for consent. But by making a requirement by consent, we didn't mean to disturb whatever the existing responsibilities are.

Judy Faulkner – Epic Systems – Founder

Then

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

It's the last phrase, right, that's Judy's issue?

Judy Faulkner – Epic Systems – Founder

I'm worried about clinicians should take into account and honor to the extent possible patient's expressed or likely concerns for privacy. My worry is not only the word —"clinicians", but how is the patient supposed to, the physician supposed to anticipate the patient's likely concern for privacy. I don't know how a physician is going to do that.

Paul Egerman – eScription – CEO

They talk to them. That's the essence of the relationship, isn't it?

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

Don't they do that now? Don't they leave out non-pertinent information when they think it's—I mean.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes.

Paul Egerman – eScription – CEO

Absolutely.

Judy Faulkner – Epic Systems – Founder

They do that on their own, but I think that this is going to— Boy, I like it saying that it doesn't materially change. I wonder if you could take out that last sentence in the however, and just make it the first sentence or reword it

Gayle Harrell – Florida – Former State Legislator

... agree with that.

Judy Faulkner – Epic Systems – Founder

You do or don't?

Deven McGraw - Center for Democracy & Technology – Director

Judy, what if we take the ... stuff out, making this not be interpreted by some overly conservative folks as creating a requirement and provide just some examples of what we mean.

Judy Faulkner – Epic Systems – Founder

That might be

Deven McGraw - Center for Democracy & Technology – Director

Document that we put together.

Paul Egerman – eScription – CEO

Yes.

Judy Faulkner – Epic Systems – Founder

That might be just fine, and I'm coming from, well, I guess I'm thinking years because it's been years of sitting with the compliance offices and lawyers on subtle things like this that just get them very perturbed and feel that they can't do interoperability.

Paul Egerman – eScription – CEO

Yes. I wonder if another way to respond to this, besides the examples, is to use the same formula as used in the bottom bullet in the one that's troubling you, Judy, when it says information is transmitted. We have some preamble that says, you know, as already exists in the patient/provider relationships whenever information is transmitted electronically. In other words, all we're trying to do is say they have to have the same considerations electronically that they're doing with paper.

Judy Faulkner – Epic Systems – Founder

I think that's fine.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes. I just want to make a comment. I've been listening to this conversation, and I know I've made this comment before. I think the places where technology gets in trouble is when it tries to override the way things actually work in the real world today. I just want everybody to also appreciate the fact that anyone

who has seen patients as a clinician of any kind knows that patients very often with new clinicians, they've very selective about what they disclose and what they don't until they've established a relationship with that physician. So this is not just a question of the provider being a filter. It's the question of the way things work from the patient standpoint and their expectations today.

I guess I'm raising this because I think these last two bullets are critically important to make it clear that there are things that need to be taken into account that honor the patient's expectations for how their information will be shared, and that anything less than that or saying you don't have to think about those things unless it's "something that falls into a sensitive category", is a huge mistake.

Gayle Harrell – Florida – Former State Legislator

I absolutely agree with you, Carol, and I want to make sure that we don't water this down. I was looking to even make it a little stronger in saying that you really need to reiterate the minimal necessary information for the specific problems that needs to be sent, and you raise. It comes down to patient expectations, and they expect things to work just like it did in the paper world, and with the minimum necessary being sent for their specific problem.

You can't discount that trust relationship, whether it's a team approach, an individual physician approach, a provider approach, or whatever. Patients need to have that trust. The further you get away from that and, yes, there are overaggressive lawyers out there who may interpret this one way, and so be it. I think that trust is so, so important.

Paul Egerman – eScription – CEO

So then picking up on what you just said, Gayle, and what Judy said, and to make sure I got what Carol said too, the main emphasis here is that because it's electronic, we don't want to change, disturb sort of that trust relationship.

Judy Faulkner – Epic Systems – Founder

I think if we say it that way, we're fine. I think, if we say they must send over the minimal information required, that is not fine because then you're almost going to have to go test by test through everything and say what is the minimal to be compliant with what the requirement is. The other thing is, you don't always know what the minimal is, and you could harm the patient by deciding wrongly what the minimal is, and so I think that what you said is just right. And that is that ... that is that it has to stay like it was, and we shouldn't be describing what we think it's like it was. We should just say it's like it was.

Paul Egerman – eScription – CEO

Yes, and it's an interesting issue, Judy, too because my concern, you had like the opposite concern I had when I read this. My concern was, well, no one is going to pay any attention to what we write and what the physician should be or clinician should be doing. Everyone is going to be paying attention to whether or not consent is required, and that's all they're going to read. ... to hear that my assumption was wrong, but it's the tone. If I understand the tone, the tone of the discussion is the absence of a requirement for consent is not intended to sort of alter that existing patient/provider relationship in terms of what the provider does and how the provider interacts with the patient. It's not intended to alter that.

Judy Faulkner – Epic Systems – Founder

I think that that's much better than trying to say what it should be, and then I agree with you.

Paul Egerman – eScription – CEO

If I understand, are people in agreement with that so that we just have to wordsmith that a little bit?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I'm not clear what you mean exactly, so I got lost.

Paul Egerman – eScription – CEO

I'm just saying providers are already doing this somehow with patients ... sensitive data when they don't do things electronically. They're making decisions about what to transmit. They're making decisions about how to communicate with patients. They're already taking patients' viewpoints into consideration. So we're just saying we don't want to alter whatever that process is ... electronically.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

But I don't think, I mean, I think I agree with the spirit of that, but I'm not sure that it makes sense to put into our recommendation that you don't change what you did with paper. I mean, I think we're trying to state the goal here in a positive way with this language that the provider is obligated with the trust relationship to be thoughtful about what they share for the specific treatment purpose. That's what they did in paper. That's what they should keep doing.

Paul Egerman – eScription – CEO

Yes.

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

Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

... paper.

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

I kind of, I mean, this would be a nice way to do the down the canal treaty approach, which is to leave ambiguity, kick, kick, kick the decision down the road. But I think that we may consider the following statement, which itself has an awful lot of impact on health information exchange, but I think this is the crux of what we're talking about here is that the use of electronic exchange should not be carte blanche for sending the whole record.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Right.

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

That as has been the case in patient records. There's still an obligation to be sensitive to the possibility of sensitive data, pardon the wording there, and to send pertinent data. I agree with Judy. I don't think we want to get to this minimal data necessary because that sort of creates a razor edge, and we're more asking the physicians and the systems they use to support the physicians in selecting the data the physician thinks is appropriate.

Deven McGraw - Center for Democracy & Technology – Director

Yes. I would agree with you, Wes. I think we want to stay away from the term minimum necessary in part because minimum necessary actually does not apply to treatment disclosures under HIPAA for the very reason that Judy expressed is that there was, I think, a fear that people would use it as a shield for not sending data when in fact, you know, but it wasn't intended to mean that data holders would not exercise good judgment in the interest of caring for the patient about what data needs to be sent. That's always been the case, and should remain the case, and be unchanged by the fact that having the data electronically might make it easier to send more than you would have sent on paper.

Paul Egerman – eScription – CEO

I guess I hear in this comments, I think the comments that I hear, I don't get a sense that anybody is advocating for anything different about the consent issue. There's just a lot of concern about how we worded the last two bullets.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Paul Egerman – eScription – CEO

Maybe what Deven and I could do is to do our best to draft something. Rather than hanging everybody on the phone, Dixie, to discuss this, is we send it out and get people to respond with e-mails. Sooner or later, Wes writes something that everybody agrees.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

That sounds good to me.

Paul Egerman – eScription – CEO

Okay. But I think we had

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

The important part is everybody has to be really tired. Everybody has to be really tired before

Paul Egerman – eScription – CEO

... Wes rights something and everyone thinks ... somehow nailed it.

Deven McGraw - Center for Democracy & Technology – Director

Yes. I totally agree, Paul, and I actually, you know, normally would have been trying to edit these as we were talking, but there's just too many words on the slide to have it make sense, but I have been taking some notes.

Paul Egerman – eScription – CEO

That's right. And also, we should explain to everybody, unfortunately, there's still a staffing issue where Deven and I are suffering from a situation we call miter deficiency. That's why some of this is a little bit rough, but we'll put this together for you. If everybody is okay, are we ready to move on to the next question?

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

I just want to

Joy Pritts – ONC – Chief Privacy Officer

Paul, before you move on, I wanted to

Deven McGraw - Center for Democracy & Technology – Director

Joy, can you pick up the phone? It's hard to hear you on the speaker.

Joy Pritts – ONC – Chief Privacy Officer

I'm going to have to move closer because if I pick up, you're going to get feedback. While you've been having this discussion, I've been frantically doing research because I remembered something in the

privacy rule preamble from 2000 that dealt with the disclosure of an entire medical record. And indeed there is guidance in that that is pertinent to the discussion you just had.

Deven McGraw - Center for Democracy & Technology – Director

Okay.

Joy Pritts – ONC – Chief Privacy Officer

Can you hear me still?

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Joy Pritts – ONC – Chief Privacy Officer

I'm looking at— I can send you the citation. I'll spare you for the moment. But it basically says a covered entity's policies and procedures must provide the disclosure of an entire medical record will not be made except for this policy, which specifically justifies why the entire medical record is needed.

Paul Egerman – eScription – CEO

That's very helpful. Maybe, if you don't mind, if you could e-mail it to Deven and me or e-mail it to the whole team, so we can make sure it's part of how we write this up.

Joy Pritts – ONC – Chief Privacy Officer

Okay.

Judy Faulkner – Epic Systems – Founder

I'm going to go into the technical question. If in fact—

Deven McGraw - Center for Democracy & Technology – Director

Well, hold on a second, Judy. That's the next set of questions. I just want to ... before we get there that we

Judy Faulkner – Epic Systems – Founder

Sure.

Paul Egerman – eScription – CEO

Yes. I think, because I think we've had a good discussion of this question, so if Joy could e-mail us that information, Deven and I will take it upon ourselves to put that together and some redrafted wording, and we will do our best to phrase this so that people are comfortable with it.

Joy Pritts – ONC – Chief Privacy Officer

Yes, but what it says is, you know, providers can use the entire medical record, but for sending it around, you just have to be able to say, yes, this is why we would do this.

Paul Egerman – eScription – CEO

Yes, and so that could be very helpful in terms of answering that aspect of this issue, so that's terrific, Joy.

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

I had one minor concern. There are many different ways in which electronic medical records information is shared, various models, and they all have their own idiosyncracies and technology constraints. I just

want to make sure, whatever we come up with is something that doesn't put us behind two, three, or four years from a technology perspective. Again, a lot of these solutions are limited in granularity in which information can be, I don't want say segregated. That's the wrong word. But how much control we have over what information can be sent, and so I just think we also have to be very practical about our expectations here in terms of the technology supporting this, at least in the short-term.

Paul Egerman – eScription – CEO

That's an excellent comment, John, because it's a good segue into our second question. That's exactly what we want to start talking about.

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

Paul, one thing before we—

Deven McGraw - Center for Democracy & Technology – Director

Adam, is this you?

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

Yes. The language regarding not using the entire medical record unless absolutely necessary, that pertains to minimum necessary.

Joy Pritts – ONC – Chief Privacy Officer

I'm sorry. I found it doing a word search, so I didn't get the whole context. I was going to go back and look at it. So it doesn't pertain for medical uses for treatment purposes?

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

No, it would only apply where minimum necessary is applicable.

Joy Pritts – ONC – Chief Privacy Officer

Sorry.

Deven McGraw - Center for Democracy & Technology – Director

We'll work without that then, but we'll still

Paul Egerman – eScription – CEO

We'll still put something together. I think this has been a very good discussion. Now let's move on to the second question. The previous question was sort of like a cleanup question because we had to clean up and reconcile two of our own recommendations. This question gets to some of the issues that John Houston just referenced. In other words, it's a practical question.

The issue still is to sort of reframe this issue. What we've been talking about, about consent so far has been sort of like an all in or all out situation. It's an all or nothing approach. If you think back to the slide that had the triggers, if you think about a situation where one has a consent situation because it's, say, a statewide HIE organization that is a centralized model, so the data will be sent to the statewide organization, and it will be retained in a statewide organization. Right now, that's a centralized model, and so far we've talked about that as all in or all out. The patient could either choose to participate or choose not to participate.

This question is really a very practical question. It says, to what extent does current EHR technology support the ability for patients to make more granular decisions on consent, in particular, to give consent

to the providers to transmit only certain parts of their record. This is, as Deven said, a discussion about to what extent there can be limits on what amount of data is.... This is really about what is being sent.

Deven McGraw - Center for Democracy & Technology – Director

Right and, Paul, it would apply in a trigger situation, but also the question is arguably relevant to giving providers some technical means to honor state consent requirements, for example.

Paul Egerman – eScription – CEO

That's correct. It's whenever. It applies to trigger, but it applies to other places too where consent for one reason or another is requested.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Just a clarification question: Are you specifically referring to the provider's legal medical record, or are you referring to an HIE or some other means for sharing that information to a broader community because I think those are quite different.

Paul Egerman – eScription – CEO

Yes. In this question, it's the provider's record. So again, we're sort of returning. I'm glad you asked that David because it's very important, returning the patient/provider relationship, so you have this picture. The patient is sitting with his or her clinician, and they're about to make a decision as to whether or not to send the data from the provider's computer into something else, and so it's the patient provider relationship. It's starting with the patient/provider's record, and the question is, can they decide? To what extent they can currently decide not to send everything.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I have a clarification question too because I'm either not understanding or not agreeing with the context that you said about our previous recommendations being all or nothing based on, I think you said, a state wide database. I made this comment at the standards committee meeting and I'll make it here again, which is to say that if every technical approach is on the table, including ones that we feel raise the stakes in terms of privacy and security, consent on its own is a very inadequate means to try to offer the patient the protections that I think could be offered, and it puts the burden on the patient to understand, well, how is the information collected? Where it is being collected? How is it being secured? And I just think that makes consent a very sort of weak option. We should be using ever policy and technology approach at our disposal to try to create a constellation of what we feel will both enable information to move when it needs to, to protect the patient, and also provide the patient with some other means of protection other than just, well, do you consent or not.

Paul Egerman – eScription – CEO

Those are excellent comments, Carol. The purpose of this question is not to imply that this is the only protection the patient will get. But this question is simply a question of is there a middle ground.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

My comment wasn't about the question. It was about the context that you established, really the first sentence about our previous recommendations. I just want to make sure that that context is something I understand.

Deven McGraw - Center for Democracy & Technology – Director

Right. It was shorthand, and it left out all of the recommendations that we made on fair information practices with full acknowledgement that I think there are many of us that would want to explore those aspects in a lot more detail on subsequent calls when we are able to beyond saying it should apply

across the board and answering some discrete questions, largely related to third parties and intermediaries. Having said that, trying to provide some assistance to ONC on some consent questions that are arising from state grantees while also acknowledging that focusing exclusively on consent is wrong and places too much burden on the patient, this question should be in the context of all of the recommendations that we've made with respect to fair information practices applying.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I'd like to make a comment about that, and this relates to our previous discussion and Joy is pointing out about not sending the entire record. If you look back into our fair information practices, one of those is specifically number three that it includes transparency, etc., collection and use limitations, data minimization, etc. We have made a recommendation as a fair information practice that even if it's a directed exchange that the physician should adhere to fair information practices and should be sending everything that's available.

The second point I wanted to make is that although I recognize our topic is consent, I would argue that the technology that is needed to enforce any kind of consent decision that a patient may say regarding limitation of what he sent is the same technology that is needed by a physician to enable the physician or provider to send only what is necessary for the purpose at hand.

The third comment, now that I have the floor, is that these questions, I think this refers to questions two, three, the next three, at least two and three. The patient, if we're talking EHR technology, the patient doesn't have any control over the information. I think that these should be worded to make it clear, as David McCallie pointed out, that it is the provider that ultimately makes that decision, and we're talking about technology that will enable a provider to enforce a preference that the consumer has made.

Paul Egerman – eScription – CEO

That's a helpful clarification, and that's a fair point because it is the case, so this is—to what extent does current EHA technology support the ability for providers to honor patients' requests to make more granular decisions on consent.

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

... ask the question because I've been wondering about a point here, which is that the a lot of what has been done so far in health information exchange puts the burden on the health information exchange, particularly if it keeps a repository to enforce rules. As long as the question of that capability of the health information is not on the table right now, I'm fine with limiting the scope of the discussion, but ... to be sure.

Paul Egerman – eScription – CEO

It's not. You're right, Wes. It's not on the table right now. I think we put it on the table in the next question.

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

Okay.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think a phrase that might be useful is release of information or control, release of information because that's how hospitals and provider organizations currently think about this is you have to acknowledge certain release of information requests, and I think most EHR vendors have tools to allow someone in the facility to do that, to manage the release of information, to manage and track it.

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

Yes, but

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I agree

Paul Egerman – eScription – CEO

Yes, but that's not quite what we're talking about.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

That's what I was trying to get clarification over. Are we talking about the ability to control what gets released or the ability to capture the patient's request?

Paul Egerman – eScription – CEO

What we're really talking about is the ability to, in response to a patient concern about some aspect of the data to not transmit that data.

Deven McGraw - Center for Democracy & Technology – Director

Controlled release.

Paul Egerman – eScription – CEO

... a portion.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

So that is control the release.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

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

Yes, I agree.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, so the answer is yes. Technologies can do that. It may not be incredibly easy or sophisticated, but it's doable.

Paul Egerman – eScription – CEO

Okay.

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

But then I

David McCallie – Cerner Corporation – Vice President of Medical Informatics

They have to legally today.

Paul Egerman – eScription – CEO

But the more

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

No, they don't.

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

Well, no, they don't. They have to enable the person in the HIM department to do it.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, that's what I mean. They enable someone to do that.

Paul Egerman – eScription – CEO

But the real issue that this question is trying to get to is sort of like not just to control the release, but rather, to limit what data is included in the release.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes.

Paul Egerman – eScription – CEO

In other words, this is so controlling the release is a little bit of a, I don't know how to describe it. It's a procedural issue.

Deven McGraw - Center for Democracy & Technology – Director

It's control what data gets released.

Paul Egerman – eScription – CEO

That's right. This is exactly what Deven said. This is what data is getting released.

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

It's categorically control as opposed to enable someone to click yes/no boxes on the screen. Right.

Paul Egerman – eScription – CEO

So what this question is all about is actually just prior to the meeting, Judy Faulkner sent out an interesting e-mail. I think she sent it to the entire tiger team, but she talked about, for example, behavioral health notes, I mean, which is narrative descriptions. The current technology is such that that is frequently data that is somehow separated from the record when the record is transmitted. That's an example.

What this question is all about is, well, to what extent can you do that. In other words, behavioral health free text is one area that you can face the limit on the record and not transmit. My question is what other limits currently exist.

Judy Faulkner – Epic Systems – Founder

Can you place a limit on the record, Paul, or can you place a limit on the notes? Because if behavior health has added things to orders, test results, medications, they go all over to different files.

Paul Egerman – eScription – CEO

Again, Judy, according to your messages, the limits that can be—the current technology limit, in other words, this is just a question of what is currently being done. Going over your note, which I agree with, what is currently being done is the behavioral health free text only is the part that is sort like redacted, is removed from the record.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

But, Paul, getting back to my discussion with you earlier, even though we use the term sent and transmit, etc., this question also applies to an architecture that's really allowed a view as well, right?

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

That is a huge issue, but great question.

Paul Egerman – eScription – CEO

I didn't follow the question. Could you say it again?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

We keep implying that all of these are information flows from place one ... a real copy, a flow of a copy of a portion of a record from place one to place two. In earlier discussions, I believe we've said that this policy also needs to apply in cases where you grant access to a view and data don't literally flow or are not literally transmitted from point A to point B.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think those are both important, but they're very different.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I know. I know. They are very different. But I think we're saying the policy applies to both.

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

I thought David's use of release of information nicely covered both cases. The release might happen at the time of a specific flow, or the release might happen at the time of a specific request that leads to a specific flow.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes. I think there's a different between access control and release of information. I mean, just practically speaking, they're different. Someone in the HIM department, for example, has access to the full record, but exercising their duties, they may release only a certain subset to an external party.

Paul Egerman – eScription – CEO

But I think the extent, what I hope, Dixie, is to the extent we're talking about views, we're talking about views by other organizations. We're really not talking right now at all about sharing within an organization.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes.

Paul Egerman – eScription – CEO

And so I think Wes' comment is correct that what David said about release of information is a better word than transmit. In other words, whether the information is actually transmitted, say, from provider A to provider B, they are separate entity providers, or if provider B simply is able to look something up is not necessarily relevant to the process, and there might even be some middle ground between those.

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

But wait. I have a problem with all of this because the idea that the notion that HIM is sitting in the middle like the Wizard of Oz and magically saying yes and no to all of these different information requests I just don't think is really the environment we're dealing with, especially

Paul Egerman – eScription – CEO

Yes. And, John, that's not the environment that we're talking about here. Again, we're talking about an environment where consent has been triggered for some reason. It's not an information request. Consent has been triggered for some reason. So the trigger, the example I gave was a patient's opt in decision to participate in this centralized HIO, so consent has been triggered.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

But we're not talking about an HIO, I thought.

Paul Egerman – eScription – CEO

Well, we're talking about the patient/provider relationship, and consent has been triggered. Now the question is can the patient give consent to transmit parts of the record? What ability exists to say to the patient, listen? You want to participate in this health information exchange. That's great. You're worried about your notes with your psychiatrist. We're not going to send that information. It's sort of like what limits can be placed on the type of data that is released.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes.

Paul Egerman – eScription – CEO

That is what we're talking about. We're not talking about John responding to requests or putting burdens on the HIM department.

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

But when I keep hearing people talk about the HIM department magically being in the middle of all this

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

Well, no. I think that that's one model for how information is released, but I think it would be— There was no intent by anyone, I think, to mean that's the only model.

Deven McGraw - Center for Democracy & Technology – Director

... require that, John.

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

Say what?

Deven McGraw - Center for Democracy & Technology – Director

I don't think we're talking about sending a policy requirement that the HIM department review every request.

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

I just continue to hear that, and I just think, in this model, HIM is going to be further and further out of the loop, I think, is the general rule.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right.

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

Yes.

Paul Egerman – eScription – CEO

It's an interesting issue, but the issue here is just a very pragmatic issue. I mean, it's an issue of trying to understand what is currently happening with these requests because what is currently happening is, I think, what Judy Faulkner wrote up, which is, there are some things that are currently happening in order to transmit only certain parts of the record. So one thing that's currently happening is behavioral health notes, psychiatric, I think some people call it psychotherapy notes are frequently not released.

Another thing that is currently happening is for some, you know, for some protected areas like abortions or like substance abuse. The entire record is kept completely separate and is sort of like never released. And so the issue is to simply walk through ... we're more interested in this question of what the current practice is for types of data. The issue is to walk through and understand what is currently happening.

Deven McGraw - Center for Democracy & Technology – Director

Right.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

The current technology is capable of more granular separation than what is currently happening.

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

I disagree. I think Judy's leaky e-mail is the operant issue here.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

But leaking of information and control of what gets released are separate issues. I certainly agree that a leak

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

And the ... issue, if you can't identify the implications of information, you can't control on any granular basis how it's released.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Sure you can. I mean, leakage occurs, but you can manage that. It's not going to be perfect, but that doesn't mean you don't try.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

You can sub-select what lab results go out, for example. You can sub-select that you only send a chest x-ray report or a CT scan report that's necessary for some purpose. There's not going to be any leakage occurring there in an average case.

Judy Faulkner – Epic Systems – Founder

I agree that you can do that if in fact the human being sits in front of it.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right, and that's why I was bringing it up.

Judy Faulkner – Epic Systems – Founder

But you can't do it automatically.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

You can't do it automatically. The technology is there. You can do deep packet inspection and the intelligence community does that all the time.

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

We're not worried about detecting it by a bad guy here. We're worried about what information the EHR can automatically select from the data it has on a patient that gives respect to granular consent.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

So we're looking

Judy Faulkner – Epic Systems – Founder

And I'm going to add to that, Wes, that it keeps the patient's trust, and the patient has no surprises. That's part of what we said earlier, and it's those two together.

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

The point I'm trying to make here is, and we've had a lot of business trying to nail down what we mean by segmentation. But what I think Paul has described it to mean this time is what I just said, that it has to do with the ability of the EHR to systematically or automatically or algorithmically honor granular consent. And what are the limitations in terms of how granular we can be. And I think, based on this discussion, how we need to recognize that there is a lot of value in being partly effective in algorithmically enforcing granular consent.

So for example, we know states where consensus committees have gotten together and said, well, we consider these tests to be AIDS sensitive, or we consider these other codes. I doubt if anyone in that consensus group felt that excluding those tests completely disguised, the fact that the patient had AIDS, but there was value to society, at least to society that includes state legislatures in performing that level of redaction.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

We are talking about unintended, algorithmic controls. Is that correct?

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

I believe that's the only way we can make sense out of this discussion and narrow it down to the

David McCallie – Cerner Corporation – Vice President of Medical Informatics

That's not how it's worded. Is that what the question is? No human intervention?

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

Let's check with Paul and Deven.

Deven McGraw - Center for Democracy & Technology – Director

We don't have to. I don't think, I mean, Paul may disagree with me, but we come up with these questions as best we can. I don't think we need to necessarily be ... massaging them. I do think we were talking. You know, at my policy level, which is not that well technologically informed always. At the policy level, it's the basic question of we know that from a policy standpoint, we want to be able to honor patient preferences and, in some cases, we legally have to do so. To what extent can the technology help us do this?

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

Yes. We're really focusing on a definition of the phrase ... does the technology support. All right? And I took an approach that I thought, the way I read it, was consistent with at least some of the e-mail traffic. But I would say that we could also answer this question in terms of automated processes and manual processes if we wanted to do it that way. But I think we have to at least decide which issue we're talking about and talk about them serially rather than in parallel.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

But I also think, I mean, I would totally agree with you that EHRs themselves don't do this. But every healthcare organization I know has an interface engine that can do a lot of this type of thing. And I think that we really should be talking about the typical health information technology environment.

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

I think the definition of EHR technology currently in the regulations is pretty broad to include the ability to prepare outgoing information.

Paul Egerman – eScription – CEO

Yes, I agree with that, Wes. The definition of EHR technology, interface engines are considered a component of EHR technology, so that's not an issue. What there is between what Deven said and what you said, Wes, is almost the response to this question because Deven gave some very clear and articular discussion about patient consent. And then what you said, Wes, as well.

But here's the reality of how it all works. The reality of how it all works is sort of what's in Judy's message, which is, there are some things you can do with progress notes. There are some things you could do with suppressing certain tests. And that, in one sense, is beneficial and goes a certain length of a ways to respond to this issue. But in another sense, it's kind of limited. It's doesn't really do what ... you know, it's just plain limited. In other words

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

So I think a conclusion we can draw is that if we really want to maintain the patient's sense of trust, we shouldn't let them conclude that they have more protection. I mean, they're not so much concerned about does this test go over or does this drug go over. They're concerned about what someone infers on the other end from the information they get that the patient has this problem or had this procedure.

Paul Egerman – eScription – CEO

Right.

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

And if we're going to maintain the patient trust, whatever partial solutions we describe that are consistent with the current EHR technology need to be characterized as partial solutions, as incomplete solutions, and that characterization has to get all the way to the patient.

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

I want to add one thing too. I think, although Dixie is correct, most healthcare organizations have an interface engine, I've really never seen one with the ability to parse out medical data with the kind of precision required for care. So I think maybe someday we'll achieve that level of natural language processing.

But I think there's a difference between what the NSA does scanning for certain words, and they have a process to flag them raise them up to levels where other people examine them for intension. I think we still have to be careful to not presume there's some magic layer of technology that can carry the medical precision and do all these things that we're contemplating here because it just doesn't really exist today.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Well ... depends on, you know, they do inspect HL-7 messages, and depending on the version of the HL-7 messages, they can identify certain segments and certain codes, you know, tags

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

The other

Paul Egerman – eScription – CEO

(Inaudible.)

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

... where this function happens for now.

Paul Egerman – eScription – CEO

Yes.

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

We're focusing in, I think, on three levels of specificity with regards to granularity.

Deven McGraw - Center for Democracy & Technology – Director

Right.

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

One is specific codes for medications, procedures, problems, allergies, whatever, can be identified and used as automatic criterion.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Right.

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

The other is the implications of specific codes on that downstream inference. In my opinion, we can discuss it, but in my opinion, that's beyond the state of the art right now. And the third is the implications of plain text. Again, unless you can talk about the inference of codes, you can't talk about the inference of data in plain text.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I would agree with that. I would add the additional constraint that in practical implementations, the kind of filtering that you described there, Wes, accurately, is typically not patient specific, but is rather contract specific or interface specific, which is not to say it couldn't be made patient specific, but it typically isn't.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

But it could filter out, just to filter out, say, a particular type of data like all the HIV.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes.

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

No, I don't think it can do that. I think we've got plenty of evidence that there's no – there're filters that are used now in other circumstances that could easily be employed to select data out by a specific list. These codes are prohibited. In fact, if you look at the implementations that are created according to state law in some states now, that is the level at which those implementations work.

Paul Egerman – eScription – CEO

So the comments that I'm getting from Wes and also from Judy is that you have these capabilities that the technology currently has, which are things that you listed, which is

Deven McGraw - Center for Democracy & Technology – Director

Paul, do you want me to do the screen share and try to write some of this down?

Paul Egerman – eScription – CEO

Sure, if you could do that.

Deven McGraw - Center for Democracy & Technology – Director

Okay.

Paul Egerman – eScription – CEO

But you listed specific codes that could be suppressed. You listed free text that could be suppressed. What was the third thing you listed? Was there a third one?

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

Inference from codes about the underlying issue that the patient really is concerned about.

Paul Egerman – eScription – CEO

Well, the fundamental issue is while you could do these things, to use Judy's phrase, it's leaky. In other words, we don't have a way to

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

I believe that the leakiness comes from the fact that the second and third cases are not handable with current EHR technology.

Joy Pritts – ONC – Chief Privacy Officer

I have a question here, which is, in the rest of our discussion, we focused primarily on meaningful use stage one. I believe, in meaningful use, stage one, we're looking primarily at the exchange of, I think, their continuity of care records, their continuity of care documents. I'd like to know how limiting exchange in that matter would impact this discussion.

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

I don't think it does. The continuity of care documents have a list of coded and textual information in them, so

Joy Pritts – ONC – Chief Privacy Officer

They have both.

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

So it's back to the same issues.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, I think you could read

Joy Pritts – ONC – Chief Privacy Officer

That's what I'm asking. What are the fields there?

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

The CCD is interpreted very widely according to different use cases, but it could be effectively all the data about an encounter or all the data relevant about the patient.

Joy Pritts – ONC – Chief Privacy Officer

Some of the information is structured, and some of the information is in free text. Is that right?

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

That's true, and furthermore, even when the data is structured, we have this problem about we know that creating a specific list of prohibited codes doesn't really prevent the inference that patients are concerned about.

Paul Egerman – eScription – CEO

Yes. To give a specific example, or maybe it's not such a great example, but, Joy, it would be the CCD. You could suppress a patient's test result indicating that they had a sexually transmitted disease. But the CCD might also show some medication for a large amount of antibiotics that would be a clear indication that that's what was suppressed.

Joy Pritts – ONC – Chief Privacy Officer

Right. But I understand also that having read many of the state laws that some of the state laws require that the individual's consent to share an HIV test result.

Paul Egerman – eScription – CEO

That's correct.

Joy Pritts – ONC – Chief Privacy Officer

But that is where the law stops.

Paul Egerman – eScription – CEO

And that's a good example, Joy, because what Wes is laying out here is that it's fundamentally that the technology could suppress, could choose to show or not show the test result. But you could clearly see from elsewhere in the CCD that the patient must have HIV.

Joy Pritts – ONC – Chief Privacy Officer

From your inferences.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Paul Egerman – eScription – CEO

From inferences, just based on what was the medication that was ordered, based on even sometimes other test results.

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

I would just complicate this a little further. People will make inferences that aren't entirely justified by logic. No, seriously. A pattern of medications or visits or other things might lead someone to surmise that the patient has HIV even though all of the specific prohibited codes weren't sent, particularly in an environment where we know this code prohibition is going on, that the leakiness extends to the mind of the beholder actually.

Joy Pritts – ONC – Chief Privacy Officer

That's really a very good point because we have encountered circumstances where individuals have been precluded from getting health insurance because it was a menopausal woman who was being prescribed antidepressants, and the conclusion was that she was depressed. And she might have been, but that wasn't why she was getting the antidepressants. But just what you just said there, I think that we should not gloss over, based on what the needs are for implementing some of the state laws, just what you said, which is that there is at least now some ability to restrict based on code that would restrict, that would help, potentially help, implement some of these state laws that are limited in how ... disclosure of test results.

Deven McGraw - Center for Democracy & Technology – Director

Can I ask a question? This is back to the point about how, in practice, the kind of code filtering that's possible with structured data is done not so much based on honoring a request of the patient, but more often on a sort of contract or interface basis. Do we know why? Is there ...?

Paul Egerman – eScription – CEO

I think we do know why. I think right now patients actually have very little access to the electronic health record. Very few patients really have access. And to the extent they have access, the really don't have a vehicle.

Deven McGraw - Center for Democracy & Technology – Director

But I'm not suggesting that the patient actually take advantage of the tool, but that the exercise of that point that David McCallie made that

Paul Egerman – eScription – CEO

No, I interpreted—

Deven McGraw - Center for Democracy & Technology – Director

...filtered at some patient's request, but

Paul Egerman – eScription – CEO

I interpreted David's point to mean that this filtering, to the extent that it exists is not really occurring at the patient's request. It's just occurring.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Let me just clarify. I was answering the question along the lines of current EHR technology and kind of inferring from that current practice with the current EHR technology.

Paul Egerman – eScription – CEO

That's correct.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

And I was suggesting that, in some of the cases that I've been involved with, there may be a state constraint or a contractual constraint that filters generically certain coded values. Typically what we do, at least in the case that I'm thinking of, is we put the data into a— This was headed to a PHR where the consumer then had the ability to do additional filtering, so the consumer could go in and express additional constraints as to who could see the data. But generically, we filtered across the board, and that's just an example of current technology and current constraints. We could do deeper per patient filtering if the technology is available. It's cumbersome, and no one I'm aware of is currently doing it. We typically put that burden onto the consumer to go and manage their own record.

Paul Egerman – eScription – CEO

And that's an interesting approach that we might want to talk a little bit more about later, but you're correct, David. This question is sort of about current technology and current practices.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, and I certainly agree with the leakiness point. I mean, absolutely even with careful, thought out code filtering, there's leakiness, and certainly if documents are going across, there's huge leakiness. That doesn't mean it's not worth considering filtering codes because some of the abuses of the data could be in fact limited to SQL queries where you can't see the content of the document. I'm just saying that leakiness is, and it happens, but that doesn't mean we throw the baby out with the bathwater and say filtering of codes is, therefore, unjustified.

Deven McGraw - Center for Democracy & Technology – Director

Right.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes. I agree.

Paul Egerman – eScription – CEO

So we've got this list of four items. I believe there's one other capability that currently occurs, which again I think Judy referenced in her e-mail, which is for some situations, actually separate records are maintained and simply never released, so that's what happens with a case of abortions. It's also what happens with substance abuse situations where sometimes just a completely separate record is maintained and not released.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes. I think that certainly was common in the past, particularly when automation hadn't percolated to every corner of an institution. It's less and less true today.

Paul Egerman – eScription – CEO

I think it has to do with substance abuse. You're notes say psychotherapy notes. It's actually not a separate record for psychotherapy notes, Deven.

Deven McGraw - Center for Democracy & Technology – Director

Are you sure because ...?

Paul Egerman – eScription – CEO

Yes.

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

That was the basic premise that Bill Brafely always used in describing that restriction in HIPAA is that psychotherapy notes are specifically the notes taken by the psychotherapist during a discussion.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

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

And are not normally stored with the automated record.

Deven McGraw - Center for Democracy & Technology – Director

Right, or not shared generally.

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

Yes. The definition in HIPAA includes that they are separated from the rest of the individual's medical record. So if you don't keep that wall between the psychotherapy notes and the medical record then, under HIPAA at least, they're no longer considered to be psychotherapy notes.

Paul Egerman – eScription – CEO

Okay. So that's fine the way it's written. The question is, is this a good or we're simply trying to describe what is currently happening. Is this a good description of what is currently happening?

Joy Pritts – ONC – Chief Privacy Officer

I have another question before you go there, which is, we had heard at the technology hearing, I believe, that there was also some ability based on episode of care. Is that accurate or not?

Deven McGraw - Center for Democracy & Technology – Director

Joy, I'm trying to— Who in particular talked about that?

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

I think there were certain EMRs that provided the ability to segment information based upon an episode of care.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes. I mean, I'm sure this is common in EMRs, but we can set up a variety of, at least with respect to the provider users of the EHR, a variety of access control restrictions, which can take into account the encounter and the location of the encounter, amongst a variety of other filter settings to restrict access to subsets of the record. That's for internal use of the record. I'm not talking about controlling the flow of information out of the record. That's a different set of controls.

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

But the "but" to that though is that even where certain EMRs today will allow you to make a sensitive encounter, if we want to call it that, certain information, even within the sensitive encounter, would still be part of the general medical record. And I'll give you an example. If there's a sensitive encounter, psych encounter that involves a prescription of a medication, even though the psych encounter itself, even outside of a psychotherapy note, but even though the sensitive encounter might be considered, might be segregated as part of that sensitive encounter, the meds that were prescribed or given would not be and potentially would be part of the medical record. I know of at least one vendor that does it that way.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes. I'm sure that there are some that do it that way and some that would give you the ability to restrict it and just flag that some were not visible to the current user.

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

Right.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

The other thing that was pointed out at that same hearing is some kind of forward thinking work that the VA is doing with HL-7 and OASIS on information redaction. But I would consider that preliminary. It certainly isn't common practice at this point. But we maybe should mention that we know about it anyway.

Deven McGraw - Center for Democracy & Technology – Director

What was that again, Dixie?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

It's work that the VA is doing with OASIS and HL-7 information redaction.

Deven McGraw - Center for Democracy & Technology – Director

Is that related to the specific code redaction point?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I believe they even do—well, certainly related to patient consent. VA has a very advanced

Deven McGraw - Center for Democracy & Technology – Director

No, no, but I thought. I'm just trying to distinguish how that's different from the point that we've already got on the slide about specific codes being able to be identified and suppressed.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Right. No, I think this is beyond just codes. I think this is entire note sections and that, but I could get you some further information on exactly where they are if you're interested.

Deven McGraw - Center for Democracy & Technology – Director

Is it being used?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

It's a pilot, yes. It's an active pilot. It was reported to us in the hearing.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, we saw it.

Deven McGraw - Center for Democracy & Technology – Director

No

Joy Pritts – ONC – Chief Privacy Officer

...it's in San Diego, isn't it, Dixie?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes. I think it's part of ... in the Beacon community pilot.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right. We saw it demonstrated during that day of hearings.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Exactly.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I asked—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Duane Dekoto.

Deven McGraw - Center for Democracy & Technology – Director

Yes. No, I know. Go ahead, David.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Well, I asked him specifically after the hearings were over whether or not the controls that they demonstrated were intended for only use in gaining external exposure through, say, an HIE or whether they intended to implement them on the EHR itself, and he said initially the former, but eventually both. So they were envisioning these controls that they had demonstrated as becoming part and parcel of the EHR itself.

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

I'd like to suggest we carefully distinguish what we saw from a conclusion that this is an accepted technology that has been proven out. I think, as of the time of the hearing, the number of records that had been transferred under this regimen was in the low thousands.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes. Yes, it absolutely is a pilot. But I think we should acknowledge that it exists, or else I think somebody else will.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, and there's been substantial work by the standardizing committees to try to make it more real, but I agree with you, Wes. It's absolutely still pilot level or lower work.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes.

Paul Egerman – eScription – CEO

So let's get back to the question. We had the description. We just added the pilot. Do we think we've answered this question with the addition? We listed off a number of items, and it's actually a richer list than I expected, and so is this a complete answer to this question?

The other thing I wanted to ask is I still come to the conclusion looking at this as this is somewhat limited. This is certainly not patient preference oriented, and we talk about implications and leakiness problems. This is right for a more perfect solution.

Deven McGraw - Center for Democracy & Technology – Director

I think that's right, Paul. I've been doing the same sort of, what's the overall picture here? And that is, it might be brighter than some of us expected, but there's still room for improvement.

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

I think this goes back to the prior discussion that we recognize that in maintaining patient trust, we have to not over sell what is available. In fact, we have to describe it carefully. But that we believe that even with the limitations, adopting measures along these lines are better than just throwing up our hands and saying nothing is possible.

Deven McGraw - Center for Democracy & Technology – Director

Right.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think that the distinction between what happens in an EHR where usage is controlled; access control is mandatory and is implemented versus what happens in downstream sharing arrangements, let's call them HIOs, HIEs, are really two separate questions.

Paul Egerman – eScription – CEO

I agree with that, and that might be a good segue to question number three.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

You can thank me later.

Deven McGraw - Center for Democracy & Technology – Director

You guys are good with this.

Paul Egerman – eScription – CEO

...that was like perfect timing there, David.

Judy Faulkner – Epic Systems – Founder

Can I ask a question about this just before you go on, and that is, when you have the first one there specific codes can be done, is that going to end up with a recommendation to do that, which I think would be wrong, and then we should discuss it? Or is this just a comment on, sure, any vendor can program in, delete the diagnosis of HIV. We can all program that in. But making it meaningful is a very different thing because of everything else. They may have multiple codes for HIV, and maybe they missed some, for example. So I don't know whether it's going to be recommendations.

Paul Egerman – eScription – CEO

It's not a recommendation. This is just an answer to the question. This is what's currently happening.

Judy Faulkner – Epic Systems – Founder

Thanks.

Paul Egerman – eScription – CEO

It's like Gayle pointed out in Florida has a law about HIV tests, something about disclosing it. So you can put in, you know, I'm sure the EHR vendors in Florida just somehow do something with that specific code so that it doesn't show up in records under some circumstances, so that something could be done exactly as you've already suggested, Judy, questionable as to the value associated with it, and that's why we're trying to put in some comment about caution not to oversell this to patients because they need to understand that it doesn't necessarily – we're not where they want us to be.

Judy Faulkner – Epic Systems – Founder

Yes, and the other thing that I have found, I mentioned this a long time ago was that the more complex you make this, the more the media gets it all mixed up and states it wrongly, and over – makes it overly positive, and that's going to mislead patients.

Paul Egerman – eScription – CEO

I think that's—

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

By the way, I don't think every vendor necessarily is in the same boat here regarding suppressing automatically information by code, so I think that this is not necessarily a uniform technology that might exist.

Paul Egerman – eScription – CEO

Yes. It's probably good that we put for some of these things some vendors or something.

Judy Faulkner – Epic Systems – Founder

I don't. I think that I agree with you entirely, John, that it isn't something that exists, but that it's something that probably, I don't know ... Carl, can it be written throughout the system that everywhere it would suppress that, or ...?

Paul Egerman – eScription – CEO

Well, Judy, it's not really written throughout the system. This part of the question really relates to information exchange.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right. I was referring to transfer out through an interface.

Paul Egerman – eScription – CEO

This is some transfer or release of information outside the organization.

Judy Faulkner – Epic Systems – Founder

Right, so all we have to do is ... so we would have to program it. I think the vendors could program it. I don't think it exists.

Paul Egerman – eScription – CEO

Yes, well, the issue there is, again, responding to what Joy said. You look at the CCD document. It's not that big a deal since they were never going to send an HIV test in the CCD document.

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

It is. I mean, it again depends on the degree to which it's identified by structured data.

Paul Egerman – eScription – CEO

That's right. You're not going to give a test result, but you could still end up with a document that says ... end up with a comment that says

Carl Dvorak – Epic Systems – EVP

As you think about those things, you have to also think about the safety and that you can't just zap a code out arbitrarily. You have to construct the model that tells you what all needs to go with it and how not to mess up the other data. Then you've got this signaling problem, as you're taking things out, that somebody may have assumed you would be able to factor in.

So the sender may assume you're going to factor something into your decision making process ... interface engine chops out. Somehow you've got to signal back to the sender that what they thought they transferred may not actually be what transferred, and they have to take appropriate steps with their patient or the other provider to deal with it.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

But just in a real world setting here in Kansas City, that's exactly what we do, and it is doable. It's cumbersome. It's expensive. It's not standardizable, but it can be done.

Paul Egerman – eScription – CEO

I think that what we're coming to agreement on is this is what's currently happening, and it's problematic, but it is what's happening. That's sort of the statement

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I don't think any of us would argue that it's optimum, but it does happen.

Paul Egerman – eScription – CEO

So having said that, if it's okay with everybody, I'd like to move on to question number three because I think that was in response to David's segue. Deven, are you going to walk us through this one?

Deven McGraw - Center for Democracy & Technology – Director

Yes. We focused in our last conversation on the –what” and, I think, here we're talking about the ability to control who can receive the data. So I think one example that is that I'm okay with my primary care provider getting all this information, but I don't want the institution where my husband works to get all this information because it includes some treatment that I sought that he's not aware of.

Paul Egerman – eScription – CEO

Deven, this question also does broaden beyond the EHR, so this is

Deven McGraw - Center for Democracy & Technology – Director

I mean, we put HIO in here as well in part because I assume, and I'm sure you guys will correct me if this is not the right assumption, but I assume that in a case where the provider is actually in control of the disclosure decision that there's a greater ability for him or her to say, oh, well, I'm directing the sending of this information, so I have some ability to control that. In a trigger situation where the provider doesn't have that control, to what extent can the data, I don't know whether it's tagging data and here I'm sort of getting into technology, and this is a dangerous place for me to be. But to what extent does the technology exist to sort of control who can receive it in sort of trigger type situations like a central database.

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

I'd like to suggest that this is the kind of issue that really scares the heck out of me and has turned me into a bit of a Luddite about technology. The concern is not so much with an individual transmission from the original source. It's the fact that information that has been transmitted might be retransmitted in another context or might be stored. I guess that's the concern.

We've seen; we saw people testify about technology that would permit the consent to follow the data. The specific rules by which this data was constrained to travel with the data and, thus, be interpretable by each step in the link. But in the discussion of that technology, it became clear that while the SAML standards and engines to interpret the SAML standards existed, the universal or widespread use of the

codes necessary to populate the SAML rules was essentially nonexistent at this point. Even if we were to implement that technology, we would find that as patient data is absorbed into the thought process of a clinician and then reconceptualized into a report ... this patient is a 37-year-old woman, Deven, I'm guessing, with these conditions. You know, then we've lost that implied thought that you ever had the ability to control whether this got back to the practice where your husband worked.

Deven McGraw - Center for Democracy & Technology – Director

Right.

Paul Egerman – eScription – CEO

Wes, are you saying your Ludditism leads you to say that since it's difficult, we shouldn't do it? Where are you headed?

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

I think that we need ... there's a number of different ways that we think patients might like to constrain how their data is shared, and then there's interactions among them. I want no data to ever go to the place where my practice works, or I don't want the data about this particular condition to go to the practice where my husband works would be two examples.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

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

And I'm concerned that we not take – the short answer to your question is I don't know. Frankly, it may be, and I don't think because of Ludditism, but just because of a recognition of the state of the technology today and the ability to implement this notion of the consent accompanies the data.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

But I don't think we have to assume consent accompanies the data. I mean, that's an option that is appealing in some ways and has been explored in some industries aggressively like content protection of songs and movies. But we don't have to assume that that's the only choice. I would say....

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

But, David, I would just say that I don't actually think it's been successfully implemented in any other sector. The CRM promise is a failure at the end of the day. It largely coupled content to hardware, but it didn't serve the other purpose.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Carol, I said experimented with extensively. I didn't say successful.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes, so I just raise it because it's hard to point to another sector that's been able to implement successfully the permissions follow the data model.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Okay. That's fine. My point in response to Wes was I don't think that we have to assume that's the only choice that gives us some value. I'm hesitant to bring up Facebook because it has complexities, but I think that's actually the point is a tool like Facebook or pick any other place where people can take their personal data and upload it and aggregate it, there are controls that are possible. So I can choose to include you in my list of friends or not, and that's not going to stop somebody from passing a rumor about

me outside of that Facebook context, but it certainly allows me within that Facebook context to at least have some control over who can and can't see the stuff that I've uploaded.

Paul Egerman – eScription – CEO

But, David, what you just described for Facebook is sort of like a vision as to how some people would like this all to work.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right.

Paul Egerman – eScription – CEO

That's not what current technology does.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Okay. Well, I think it does to some degree in the PHR space. There are PHRs, which give you a modicum of that kind of control, choosing which data to expose and choosing to whom it can be exposed. There are a number of vendors that support that today.

Paul Egerman – eScription – CEO

That's outside the EHR, but that's probably a valid thing to write down is some PHRs provide

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right. Absolutely, outside the EHR.

Paul Egerman – eScription – CEO

Some PHRs provide patient—

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

Well, in fact, that's probably a principle, a characteristic of PHRs is the patient mediated, and to the extent we're agreeing that there are other models that may assist in this regard, I think we should acknowledge that.

Paul Egerman – eScription – CEO

Yes.

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

I say medical record banks.

Paul Egerman – eScription – CEO

You didn't hear it from me, but I'll endorse that.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I think we need to reword that first sub-bullet because you will recall that in our hearing, we heard a model where the data, consent data are not transmitted with the information, but rather, are contained in a permission database and access as a service. So I think we should change that to the ability of patient preference to be bound to the information because it doesn't necessarily have to be transmitted with it, but the information has to know to go to this repository and get the permission.

Paul Egerman – eScription – CEO

A very helpful comment, Dixie. So far, as I look at this list, the only capabilities we're saying that are like operational right now are in the PHR world.

Deven McGraw - Center for Democracy & Technology – Director

And even those are limited. I mean, that's really just an initial disclosure, right?

Paul Egerman – eScription – CEO

Right.

Deven McGraw - Center for Democracy & Technology – Director

Like I decide to share it, but what happens after that is less in my control.

Paul Egerman – eScription – CEO

What about HIOs themselves? Don't they have some capabilities to do this, or do they?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think we saw it in the demonstration that we saw a couple of months ago. There were a couple of companies that demonstrated the ability to add those filters in front of an HIO. I don't know that any of them had been deployed in production, but they demonstrated it. And it's the technology involves what's called a policy enforcement point where someone who has expressed what their desires are, that is communicated to a tool, which acts as a filter, gating all access to the data. And so the technologies are out there to do that. The problems, as Wes pointed out, are as much in the lack of agreement on how to name the things that should be restricted, what we call the taxonomy of the sensitive data, and how to name the individuals and/or their organizations who should be restricted. How do you identify a particular provider or a particular organization? It's almost a reference data problem is the barrier.

Paul Egerman – eScription – CEO

Interesting.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I think, for those that we saw at the hearing, the one that has been deployed the most is private access. They have like three customers, and they're all pharmaceutical customers. So even they don't have EHRs are not integrated with any EHR to this point.

Deven McGraw - Center for Democracy & Technology – Director

Right. That's for research consents, right?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

No.

Paul Egerman – eScription – CEO

No.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

The technology is not, but the implementations to date are.

Deven McGraw - Center for Democracy & Technology – Director

Okay.

Paul Egerman – eScription – CEO

Yes, and that's part of their business model is enabling researchers, enabling consumers to grant access to researchers.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

No. No, their business model is to enable consumers to grant, to essentially manage all the permissions, including health and banking. I mean, their business model is much broader than even health.

Paul Egerman – eScription – CEO

Okay. I'm not in a position to explain their business model, but they have an optional tool available to HIEs to use, so the HIE would have to agree to use them as a policy enforcement point, and that's true of all of the approaches. Somebody has to agree to put this tool in place, whichever tool you use, whichever policy enforcement tool you choose. But notwithstanding which tool you use, there is still a problem of how does one describe your preferences in a generic language that everyone would understand what it means.

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

I'd also add on the list of problems is the authentication of the patient. I've heard anecdotal evidence from HIOs that they just do not have that ability right now.

Paul Egerman – eScription – CEO

Yes. There's the parallel issue of authentication of the providers and/or the provider staff, and it's generally the staff who would do the access is not an unsolvable problem, but it is a very real problem.

Deven McGraw - Center for Democracy & Technology – Director

Yes. I also. This is another one, Adam, where I don't, well, I guess we have strayed into the PHR space where the patient does have that kind of direct control, but we've sort of been looking at the EHRs where the provider or the HIO would be trying to exercise that level of control based on some preference that the patient has expressed, but is less of an identity issue.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

So we should reword this one as well.

Deven McGraw - Center for Democracy & Technology – Director

Yes, or just make it

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

...HIOs ... control, who can access the information based on patient preference.

Deven McGraw - Center for Democracy & Technology – Director

This sounds like one where, you know, it's another area where there are some indications of innovation going on, but even less in widespread use than the technology that we identified in our answers to question two.

Joy Pritts – ONC – Chief Privacy Officer

I would like to know a little bit more. We don't have this information before us, but the e-health initiative released their survey recently as in, I think, last week, where they had the survey that says that searching initiatives, health information exchange type initiatives have individual data element opt in, opt out policies, 14 have emergency care opt in/opt out policies. I think you sent this around earlier today, Deven, or yesterday.

Deven McGraw - Center for Democracy & Technology – Director

No, I didn't send it around yet. I can send it around to people, but I did have a conversation with folks from e-HI yesterday. For those of you who don't know, the e-health initiative does a survey, self-reported survey of health information exchanges every year, and they've done it for the past seven years. And they did ask a question about patient preferences that was phrased in terms of opt in or opt out. At least 13 of them allow opt in or opt out at what they identify as the individual data element level. But the other thing that's interesting is that this is with respect to whether the information is or is not available in the exchange, not necessarily once it's in the exchange, whether there's some additional filtering that goes on because according to e-HI, they don't think any of their exchanges retain any – are sort of database models or retain data.

Joy Pritts – ONC – Chief Privacy Officer

I guess a question that we have not addressed at this point is at what juncture these choices are being made.

Deven McGraw - Center for Democracy & Technology – Director

Well, that's right, and they would have to go back and contact the survey respondents to try to get additional information, which they are more than willing to do if we would like them to. You know, of interest is that a lot of the type of data that they report exchanging and those who said that they give patients choice at the individual data element level report exchanging the type of data that is more often to be found in structured content like lab results and medication data. But it's not limited to that type of data.

They also say they exchange allergy information, cardiology information, and radiology results. But I think there are a lot of unanswered questions about when they self-report that they're allowing choice to be made at an individual data element level, what that really means. But I definitely, after conversation, took it to be much more pertinent to question number two than number three, but they'd be happy to follow up, I guess, if we want them to do that. And I'll circulate the letter. It's not very long.

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

It would be good to have some pretty specific questions to go back with. Many technologists will say that the text of a report is a single data element, which is this blob of text.

Joy Pritts – ONC – Chief Privacy Officer

Wes, doesn't ... encounter level then that you have ...?

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

No, it could very well be that where they have structured data, they can. I think data element is one of those words, one of those phrases that just gets defined according to rule of it means what I need it to mean when I make this statement.

Joy Pritts – ONC – Chief Privacy Officer

I found when I looked at this issue that data element could mean anything from an entire document to a specific test result.

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

Yes, I agree. Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Just when we ask the question, we need to be specific about lab results, medications, diagnoses, documents, and so forth. Just don't use a phrase like data element. It's too vague. I want to make a couple of comments, Deven, in relation to something I think that you passed over earlier. One of which was that the use of some kind of a policy enforcement point to filter access to the data applies regardless of whether the data is centralized or whether it's federated. You know, the policy access point would be the final step that would filter the data regardless of where it came from. You could push it upstream in some settings, but the net effect is logically the same.

And the second point on a different subject is you used the word market exploration or something like that about these technologies to enforce policy. I want to point out that there isn't a longstanding and fairly sophisticated effort in the standards bodies, in particular, HL-7, IHE, and OASIS that have been wrestling with this issue for quite some time. It's not something that's just an entrepreneurial activity. There is a substantial standards basis for it.

Paul Egerman – eScription – CEO

Substantial standards basis doesn't mean it's in operation.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Correct. It's not finished, but I don't want to leave the impression that nobody has thought about this in the informatics community. It's been being worked on aggressively for some time, and that was the basis for the demonstrations that we had a month ago. They were all using the tools that have come out of the combination of HL-7, IHE, and OASIS.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes.

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

My understanding, though, is that that's still a fairly long time horizon, even in the best of circumstances. Is that what you understand it to be too?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think it's a question of what level of granularity you wish to implement and where you wish to do it, so you could define. I mean, sort of like our meaningful use things. It's a long process to get to where we eventually want to be, but you do it in stages, and you can make the steps not too steep, and I think that was the point of those demos is to show the applicability with the tools that we have today to do meaningful filtering if we desire to do that.

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

I would just suggest that until we have feedback from physicians at Kaiser on what was the impact of these redacted notes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

That's a different question, Wes. That's a completely different question.

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

No, I don't think it's a completely different question. I think there's some overlap in the two issues, which is that if in fact redaction or—if you're saying it's a different question because it has to do with who gets it rather than whether the note is redacted?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

No, I think this question is focusing on what are the current capabilities to do this. I'm not trying to raise the value judgment on whether we ought to do it or not or whether there are more negative consequences than positive.

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

I would argue that if we have a capability and, at the end of the pilot, the conclusion is that the operation was a success, but the patient died, then we don't have a capability yet. All I'm suggesting is that

David McCallie – Cerner Corporation – Vice President of Medical Informatics

We don't know the answer to that.

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

Right, so any assessment of this has to be, I mean, the difference between records being transferred and the patient living, I think, is still – makes this a very tentative conclusion. I would say that this, by the way, is quite consistent with the last message we had from Latanya, which is that in other fields, there's a lot of endeavor going on to figure out how to make this work, but she didn't, in that message, she specifically didn't characterize it as being a done deal.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

It's been an issue forever, but I believe what David was talking about has a higher level of work that's being done with SAML, XACML, and not specifically the redaction of pieces of information, but rather, managed consent across organizations.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes. And I think that, in a practical sense, the decision that a consumer might wish to exercise about who can access their data may be more relevant and practical than the question about what subset of the data is exposed.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I agree with you.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

My expectation is that consumers would wish to say these doctors I want to have access to my complete record, and these doctors, who I don't know, haven't met, and do not have a treatment relationship with, I do not wish to have access to my record. I think that will be a reasonable and common expectation.

Paul Egerman – eScription – CEO

In terms of that expectation that you just talked about, David, would you agree that it's fair to say, based on the answers to questions two and three, that the current technology don't support that expectation?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I don't think that the technology is widely deployed to support that. I think that their technology exists to enable that, and it's mostly been deployed to date in PHR settings, not in HIE settings.

Paul Egerman – eScription – CEO

Yes. So there may be some personal record capabilities, but there are not EHR capabilities to do this.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right.

Judy Faulkner – Epic Systems – Founder

And I think

David McCallie – Cerner Corporation – Vice President of Medical Informatics

In an EHR, definitely not.

Judy Faulkner – Epic Systems – Founder

And I think the EHR has a much bigger, broader problem in that the record can go lots of different places, and identification of who the physician is, as people said earlier, is going to be extremely difficult. The other thing too is that I don't think this is commonly in EHRs, but a level that would be easier would be to say it can't go. We're still playing back and forth with the word provider, but it can't go to a provider organization at the request of a patient given that the NHIN gets to the step of a simple, computerized, phonebook service that can translate clinic names to Internet addresses that EMRs can use to talk to each other.

At that point, then that's identifiable. At this point, it's not yet, and so when that becomes identifiable, then the EHRs can write the code, and it's not there yet because, unless it's within the EHR's own circle of customers, they can begin to write it outside that circle, and I don't even know if it's available within the circles either.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

But I think that, in general, there would be an assumption that access to any kind of HIE sharing model would require knowledge of who the user is that's making that access. I don't think we have anonymous access to these systems. It's not an easy problem. It's not a universal identifier necessarily, but it will be known who is accessing it, right?

Judy Faulkner – Epic Systems – Founder

No. I think what I'm saying is that the patient in advance will be able to say, I don't want my record to go to the East Clinic Organization. I don't want it to go to St. Elsewhere, and I don't want it to go to someplace else. But they can't really put that into the system very well until they have a way to identify that when they put that in.

Paul Egerman – eScription – CEO

... directory service.

Judy Faulkner – Epic Systems – Founder

Prospectively being able to say that.

Paul Egerman – eScription – CEO

That's a helpful comment, Judy. It does say, until we get some directory service to identify these various entities, there's no vehicle to do this.

Judy Faulkner – Epic Systems – Founder

Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

But one could imagine that an HIO has a list of authorized accessors that could be presented, ideally, to a consumer to say, which of these are you comfortable with?

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

Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

It could be done.

Paul Egerman – eScription – CEO

That's true.

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

I would say that in the context of an HIO, rather than the NHIN, there is an assumption that they understand their endpoints, so we have to be careful to describe our answer in terms of the globalness of reference. But I also think, and I'm just looking at the slide to try to refresh my memory of where we are in the discussion. I also think that we have – we're considering right now a single instance of the transfer of information. We're not, I mean, you know, when we begin to talk about data that is stored in a repository and then later retrieved. Then we get into issues of has the coding of the identifiers of the legal recipients changed between the time it was put in the repository and the time it came out? We've got just all kinds of conceptual issues yet.

Paul Egerman – eScription – CEO

The sum total is, as I'm listening to this, our response to question three is sort of similar to our response to question two, except there's less here that we like. I mean, for question two, there were some things that were positive. It seems like there's a lot less here in terms of controlling the who.

Deven McGraw - Center for Democracy & Technology – Director

Maybe the glass is half full for number two and half empty for number three.

Paul Egerman – eScription – CEO

Yes, I think it's more than half empty for number three.

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

As long as we also add, in order to try to be on the right side of half full or half empty, just add the comment that there are other models that would give the patient more control or something like that.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think that the potential for satisfactory solutions is actually higher in the glass half empty case, in the HIE case. And the reason for that, I think, is that the HIE is fundamentally not having to implement complex workflow. It is a repository, either direct or federated. And, as such, is performing a much simpler set of operations and, therefore, is much more amendable to making it feasible to implement these controls.

Paul Egerman – eScription – CEO

That's true, although I've got to say, David, some people could say that doing workflow and doing access control, that it might be possible to do both.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes. In an ideal world, it's possible to do both, but in the EHR world, it is incredibly complicated, the number of ... users.

Paul Egerman – eScription – CEO

I agree.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

And HIE is starting out with a simpler problem. It'll get complicated eventually.

Paul Egerman – eScription – CEO

Are we comfortable with our answers to number three?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Paul, the only other thing I think we need to capture, which we've sort of started, is the lack of agreed upon vocabulary on consent.

Deven McGraw - Center for Democracy & Technology – Director

What do you mean?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

The taxonomy of items that could be managed and the identities of the people who would manage them.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Not the identities so much, but if you look at even ... down to the

Paul Egerman – eScription – CEO

Let me make an observation. I don't mean to interrupt. Our job here is not to engineer a solution to this problem.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I'm not. I'm identifying another. It goes with another limitation we have in this area.

Deven McGraw - Center for Democracy & Technology – Director

Adam, when you say taxonomy, Dixie, are you talking about a way for a computer to interpret it? Because my legal brain can't wrap my mind around what do you mean we don't have a taxonomy...?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I didn't say taxonomy. Somebody else did.

Deven McGraw - Center for Democracy & Technology – Director

Okay. I didn't mean to put words in your mouth.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

It's standard vocabulary for describing the consent.

Deven McGraw - Center for Democracy & Technology – Director

Like in a standardized vocabulary.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Exactly. If you look at two forms between two organizations, they will even define the same conceptual consent in different ways. So we need a common vocabulary among consent.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I have a real issue with the way you've worded the third sub-bullet on the first bullet: PHRs and medical record banks provide greater level of control ... initial disclosure. I would say this. I think PHRs and

medical record banks provide controls to patients, not greater level. They provide control to patients over the copy of the information that's in them. They do not provide any level of control greater or less than on either the source of that information, in other words the place where the copy came from or was made from, or whether the sources may choose to share information. PHRs provide control of the copy of information that's in them, and we shouldn't write this in a way that sounds like somehow that control extends into all the other places that the copies of that information may exist.

Paul Egerman – eScription – CEO

Excellent point.

Deven McGraw - Center for Democracy & Technology – Director

Thanks, Carol. I think I got it.

Paul Egerman – eScription – CEO

Are we ready to move onto the next one?

Gayle Harrell – Florida – Former State Legislator

I'm at a little bit of a disadvantage in that I am not in front of a computer, so I'm not seeing what's going up. When the site is complete or whatever, could somebody mail it to me?

Deven McGraw - Center for Democracy & Technology – Director

Yes. We'll e-mail it to everybody.

Paul Egerman – eScription – CEO

Yes, not a problem.

Gayle Harrell – Florida – Former State Legislator

Now I'm at the gbh@gayleharrell.com. I'm sorry to be complicated, but we're in ... of moving offices.

Paul Egerman – eScription – CEO

You're a moving target.

Deven McGraw - Center for Democracy & Technology – Director

Gayle, I'll mail to you what we've got right now.

Gayle Harrell – Florida – Former State Legislator

Thank you.

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

Your identifier has changed.

Paul Egerman – eScription – CEO

Absolutely. Are we ready to move on to number four? Great. Thank you.

Question number four is a really interesting and difficult question. Given what we've just seen for questions two and three, question number four is what should ONC do to enable patients to be able to make more granular consent decisions. It's not listed here, but one conclusion we've come to is that we're completely happy with our answers in two and three, and ONC doesn't have to do anything. It says maybe they need to do grants for pilot projects. It does seem this area is a thorny area. There are a lot

of issues with concerns about patient safety. There are a lot of issues. What advice should we be telling ONC that they should do next?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I'll put one option on the table just to have a straw man to beat up, which is the lever arm that will be of intense interest in the next year is what is in meaningful use stage two and stage three. If ONC defined or recommended meaningful use constraints that suggested the implementation of granular consent as being a requirement, then that would be the pressure that would drive various entities like the standards bodies to produce such capabilities.

Paul Egerman – eScription – CEO

Do you think ...?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Be a forcing function is where I guess I'm saying.

Paul Egerman – eScription – CEO

Yes, but let's be clear. You can't make it a requirement in meaningful use as a vehicle to motivate standards bodies to do something because if it's in meaningful use stage two or stage three, all the necessary certification criteria also has to be published at the same time. Otherwise people won't be able to meet the criteria.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right, so it would

Paul Egerman – eScription – CEO

So the standards and everything has to happen first.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

But I think it would force and prioritize the definition of what could be certified.

Paul Egerman – eScription – CEO

Well

Deven McGraw - Center for Democracy & Technology – Director

Well, no

David McCallie – Cerner Corporation – Vice President of Medical Informatics

In other words

Paul Egerman – eScription – CEO

No, no. It has to be certified at the same time, David.

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

I'd like to suggest that we, I mean, I agree with David that nothing makes people focus like a deadline, but particularly if they're already past it. But I'd like to suggest that our appreciation of the problem right now includes a lot of recognition of ambiguity about even what the questions are, and it would be difficult to get the standards community to move that far that fast, even given the good basis they have already. I'd suggest that ONC establish grants for creating concrete models in determining their feasibility perhaps leading to pilot projects. In other words, until we get to the point where we say this is what we want, you

know, either that or the policy committee creates those models. I don't know, but fundamentally I think we're missing a step even before pilot projects at this point.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes. That's the spirit in which I was headed is that we need to have a target and work backwards from that target to cause the missing pieces of technology and nomenclature and taxonomies, etc. to be made concrete.

Paul Egerman – eScription – CEO

Yes, but I just want to pick up on what you're saying, Wes. What I'm picturing based on what you're saying is like a two- or three-step process. One is we need to create these things you called models. The second step is to create some pilot projects to see if it works. And the third step would be to put this in the form of meaningful use standards, certification, and all of that stuff after you've got some successful pilots. Does that sound right?

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

Yes. Yes, I would say that at the level of these recommendations, that's fine. I would probably want to add, at least in commentary, that the models should include some gedanken evaluation of their feasibility and that we probably want to have some sort of comments on a goal of creating of finding specific models that are more implementable rather than sort of doing an academic job of systematically exploring all of the models.

Paul Egerman – eScription – CEO

That sounds good. Now how does ONC create these concrete models?

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

I think it's a grant usually or they do it through NIEM. I mean, I honestly don't. I think somewhere there needs to be a focus of work. Could it be work done by volunteers through the FACA? I'm not sure. I think there needs to be some kind of a contract or grants or something involved, plus guidance at the volunteer level.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I too am a little worried about this turning into largely an academic exercise, and one thing I would say is that the metric that matters here at the end of the day is whether or not these —models” can be used by patients to successfully manage their desires or their requests, and not whether a standard could be developed or a file could be exchanged or any of those things. I really think the ultimate metric here, if this is really about trying to get to an understanding of what patients want and how they will use it, they have to sort of zero in on that.

Judy Faulkner – Epic Systems – Founder

I'm wondering whether the third one makes sense, if we have a model. First we have to create the grants. Then we have to do the models. Then the models have to be evaluated, I think, by objective third parties. Then you've got to create the pilot. Then that has to be evaluated, and see if it's really expandable to multiple EHR vendors. Then the EHR vendors have to program it. I don't—

Paul Egerman – eScription – CEO

It would seem to me that the earliest you could possibly do item number three might be stage three.

Judy Faulkner – Epic Systems – Founder

And I don't even think that if C3 is 2014, and we're halfway through 2010, I don't—

Paul Egerman – eScription – CEO

You'd have to be real lucky to make it in stage three.

Judy Faulkner – Epic Systems – Founder

Yes, I don't think the vendors can make it. That's number one. Number two, and this is something that's come up occasionally. Are we going the wrong direction? Are we going the direction of looking through the entire record and seeing how we can make a basically segmentable and know that there are inferences that are probably going to leak through anyway? Should we instead be looking at the patient can create his or her own version of a record, which is more what the PHRs do, which is why they can do more?

Paul Egerman – eScription – CEO

It's an interesting—

Judy Faulkner – Epic Systems – Founder

And go that direction instead so that patient can create—

Paul Egerman – eScription – CEO

It's a very interesting suggestion.

Judy Faulkner – Epic Systems – Founder

Yes.

Paul Egerman – eScription – CEO

I mean, especially since if you look at what we said for our answers for questions two and three, it seems like the patient record side was where the most flexibility exists.

Judy Faulkner – Epic Systems – Founder

Well, and I think that the good thing about that is if you are a doctor, and you get a record, say, from Cleveland Clinic, do you trust it or not? If things are hidden and they're not there, you've got to start over with the patient and basically not trust the record. If it says there are things hidden, at least it gives you a hint. And then you know that otherwise you can trust it. But if you get the patient summary, the patient may try to figure out ahead of time, for this doctor, I want this. For that doctor, I want that. And use some different judgment, then all sorts of stuff is hidden.

Paul Egerman – eScription – CEO

It's interesting, Judy, because the way I'm thinking about this a little bit is, on the one hand, we have healthcare providers who are very concerned about patient safety and concerned about inferences and want to do the right thing. But just feel that, gee, their hands are tied, and they have to release this information. So they get the healthcare people on one side. On the other side, you have the people who are very interested in individual autonomy who feel the patients should have this flexibility.

Judy Faulkner – Epic Systems – Founder

Right, and this gives them—

Paul Egerman – eScription – CEO

What we're trying to do is we're trying to thread a needle and make everybody happy.

Deven McGraw - Center for Democracy & Technology – Director

Yes. It does. Judy, it doesn't accomplish what you think it does because all, I mean, and I'm a big fan of personal health records, and I would include health record banks as a model of PHR. But it is just a copy. Even if it's of a record for the patient to use and disclose at her discretion, once she makes that disclosure to the physician and it's part of the physician's record, she loses control over that if we look to the PHR to be the resolver of all of these

Judy Faulkner – Epic Systems – Founder

No, I'm not saying the PHR. I'm saying that the patient works with the physician or works with her HIM department and creates a face sheet type record that is the only thing she has approved to go out to be sent out when information is requested. That way there is no misunderstanding. There's no lack of trust. She has what she wants on it, and if she decides she wants to tell the provider anything in addition, she can. The provider knows that he or she can trust records that come from that healthcare organization that are complete because the records aren't going to be. Some are fully there, and some aren't, so they don't know where they have to begin. They know that for the record from this patient, that's what the patient has chosen to share with them.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I'm not sure I follow your concern as being one that would affect what Judy is proposing or Paul had proposed. Any time you disclose health information to a provider, you run the risk that that provider could inadvertently disclose it to other people.

Deven McGraw - Center for Democracy & Technology – Director

Well, that's right. I'm saying it's an incomplete solution, David, for more granular choices with respect to how their data is shared even among their providers. That's all I'm saying. I have not heard Judy's face sheet solution before, and I'm not sure why that's not just another technical model for granular consent.

Judy Faulkner – Epic Systems – Founder

In a sense, it is. It's a technical model for granular consent that really gives control to the patient to say what she wants and doesn't want on there.

Paul Egerman – eScription – CEO

Yes. What's interesting about what Judy is saying, as I think about it, you've got this basic conflict. You have the electronic health record, electronic medical record, which at least right now is completely under the control of providers, and providers are concerned about giving up that control. Then you have the patients who want to have control over how their record is described or displayed. And so one way to sort of thread the needle is to say, well, there's a provider record, and providers can control that. Patients have access to it, but providers control what's in it. And there is a patient face sheet or patient summary document or something that patients can control. And if they don't like what the provider is submitting, they can submit their own document. But it's clearly not coming from the provider.

Judy Faulkner – Epic Systems – Founder

I think the provider organization submits it for the patient, so it still comes from the provider organization, but that's what they send, so they look at it two ways. Either they send the record, or they send with or without the sensitive notes from certain departments, probably can be hidden, hidden. They send the record or they send the patient's version of the record. That's their only two choices.

Paul Egerman – eScription – CEO

What Judy has described is an alternate way to accomplish this.

Deven McGraw - Center for Democracy & Technology – Director

Yes. I mean, why is that not one of the concrete models?

Gayle Harrell – Florida – Former State Legislator

Judy, I am amazed. That is just wonderful. That gives the patient ultimate control, which is really what a lot of people are very concerned about, and puts the trust back in the relationship. I think that's a marvelous idea. It should certainly be one of the options out there.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think the health bank model is fairly close to what Judy has suggested, albeit it could include more than the face sheet. It includes potentially a copy of all of the relevant data that the patient has accumulated through a lifetime of receiving care. The difference between a PHR and a health bank is subtle and there's not, I don't think, a formal distinction. But those of us who talk about health banks a lot would probably say that a health bank has some compliance with standards so that it would be feasible and easy for a standard compliant EHR to access it as opposed to PHRs, which tend to be completely idiosyncratic. And, number two, the health bank follows some rules that are just part of the agreement when you become a health bank that would allow the provider to be told what that data has been withheld.

Paul Egerman – eScription – CEO

Yes. Those are good comments, David. Let me suggest though to sort of keep the discussion at a high level and to respond also to what Deven said is that maybe we review what Judy put forward as one model that ONC should consider, which is a model in which there's some patient control over a separate sort of patient document, and not really talk necessarily right now as to whether that's a health bank or even a PHR.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I just think that a single face sheet summary won't be adequate for, I mean, it's certainly a great

Paul Egerman – eScription – CEO

Well, is there a way we can just describe Judy's thing where it's, you know a separate patient controlled, patient generated document that is separate from the provider's record?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

You mean document as opposed to anything broader than a document ... record of some kind?

Paul Egerman – eScription – CEO

I'm searching for the right word.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes. I think it's a record. I mean, if you can control a document, you can control a record.

Paul Egerman – eScription – CEO

Right.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I guess I'm confused. Are you implying that this is way to have patient exercise control over what providers exchange?

Judy Faulkner – Epic Systems – Founder

Yes. Yes, so the patient would basically write what the provider is to see, and then there's no misunderstandings.

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

However, you know, in the abstract, great, the patient can say I want them to see X, Y, and Z. But when there's a very specific circumstance that requires very detailed information and maybe that the patient is not even capable of, you know, is unconscious or is not lucid, additional information may be required in order to treat them. How do we deal with that situation, especially when ...?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Well, that would have to be worked out through the model, but I think you would work that out through the arguments about directed exchange.

Judy Faulkner – Epic Systems – Founder

That's either break the glass, or it's a phone call.

Paul Egerman – eScription – CEO

Yes.

Judy Faulkner – Epic Systems – Founder

To say I have an unconscious patient in front of me, and this isn't sufficient, and this is life threatening.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, and the models that have been explored all support some form of break the glass for that capability. I think that's common.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

...glass.

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

We need to make it clear that that's part of this then.

Deven McGraw - Center for Democracy & Technology – Director

We are not making the recommendation that that be adopted as a solution. It's not my impression.

Paul Egerman – eScription – CEO

That's correct. We're just saying this is a model to consider.

Deven McGraw - Center for Democracy & Technology – Director

And the

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Well, but how do we know that? Who has actually managed this kind of sort of authorization table where patients can change on a Wednesday what information they want shared with whom and whether or not it's effective. I mean, I guess I just think from an administrative standpoint, even for large enterprises, with their own employees, this is a very challenging, complex issue. And I'm just wondering where we think the sort of big implementation of this indicates that this can actually be managed in a way that satisfies patients' needs and that can be sort of handled at an administrative level.

Paul Egerman – eScription – CEO

Those are good comments, Carol, and you're showing some skepticism that it might work. But again, it's being written down simply as a model. What do you think should happen here?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Look. My sense of this is that the simplicity of thinking that there could be a place to manage very granular authorizations over data for every patient in the country and the changes to that and the updates to the that and the sort of need to redact those permissions could all be managed. It's a really good aspiration, but I don't know of a place where something like that can actually or has been implemented. And my perspective has always been that we go back to where we started, which is to say that the closer the patient and the provider are to controlling how and where information is shared, the closer we're going to come to meeting the expectations of patients and consumers. And the more sort of infrastructure and administrative overhead we put in the middle of it doesn't exist today, and that is questionable in terms of how it would be managed and who would manage it and how successful it can be managed, I think the farther we get from something that can really be, if we're really focused on stage one meaningful use over the next couple of years that can really provide sort of meaningful guidance for what's possible now.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

But, Carol, are you saying it's easier to put controls in place at every possible source of information.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes. I'm saying that at every place the patient has a relationship with a provider, that is a place for the patient to have that conversation and to make, with that provider, decisions about what and how their information is shared, whether it's one shot at a time or whether or not the patient and provider agree they want to participate in something longer I am worried that recommendations that say, you know, those decisions and those interactions can happen somewhere else other than between the patient and the provider is a big, big challenge, at least in today's environment. And I am just asking that we stay true to the principles that we have around keeping the relationship between the patient and the provider the place where those decisions get made.

Paul Egerman – eScription – CEO

I'm just trying to understand what you're saying. I'm the patient, and I meet with my physician, and I say, "I want you to transmit my record, but I don't want the record to indicate that I'm depressed." And my physician says, "I'm sorry. I don't have any way of doing that." So then what happens next?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

The physician may or may not have a way of doing that, Paul. We don't know. Right? So if the physician feels they can adhere to that request, the physician can do it. We heard testimony on technologies and ways that people are trying to do some of these things. But if the physician can't do that, if the physician says, "You know what? I can transfer your record in a way that I can reasonably assure you that no one looking at this information could infer that you're depressed," that's a decision that has to be made between the patient and the provider, and that we can't intuit. We're not all knowing of every situation that's going to come up. We can't sort of at the middle say, well, don't worry. There'll be some Wizard of Oz in the middle that's going to manage all of the sorts of nuances of what needs to be done.

I think there is opportunity for innovation and for technology to sort of catch up with these kinds of desires, and we should be indicating that in our recommendations. In other words, the more that technology can accommodate these things, the better. But I worry when we start sort of dreaming up administrative functions that don't exist in today's healthcare system because

David McCallie – Cerner Corporation – Vice President of Medical Informatics

But, Carol, I think we're proposing the wizard in the middle is the engaged consumer. I mean, how can a provider manage downstream control of the data when the consumer at the time of the provider encounter doesn't even know the future providers that they may wish or wish not to share with.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

But, David, I guess I'm saying, I don't think the patient can manage that either, and this goes back to our, you know, how is the patient supposed to know....

Paul Egerman – eScription – CEO

Carol, let me just ask you something. How would you answer this question then? Would you answer this question that ONC should do nothing and leave it at the patient/provider discussion level? In other words, how would you answer this question?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I'm reacting to the way that we're proposing to answer it, which is to say that there's some new infrastructure that gets created that has the ability to administer this kind of thing. I am all for some sort of a recommendation that says this is the direction and need on the part of patients that needs to be accommodated. But I am worried about saying here's the model that should be used. You know, somebody should develop a table that has the atomic data elements of every element in a medical record and then the permissions that go with every element of that record and....

Judy Faulkner – Epic Systems – Founder

Carol, this is Judy, and I don't see it – I see it as technologically much simpler than perhaps you're seeing it. And I actually think that administratively it would

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

...doing it ... just to be clear, Judy, I'm not saying it's a technological challenge. I'm saying it's an administrative challenge.

Judy Faulkner – Epic Systems – Founder

Yes. I'm going to go with that also, but

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

What answer would you put in here?

Judy Faulkner – Epic Systems – Founder

But I see it more looking like perhaps the CCR record looks like right now, which is, it's a simple record. It doesn't take a long time to do, and it might be a whole lot quicker than talking with each physician about the details since there are so many details, as you say. In the complete electronic record, I think this would be quicker and simpler.

Deven McGraw - Center for Democracy & Technology – Director

I think we're spending way too much time talking about one or two particular potential solutions where, where we started with this recommendation was to encourage ONC to explore the feasibility of certain models and pursue those that appear to be the most promising through pilot projects and go from there. I don't think that we have enough information among those of us on the call to say to ONC at this point, you should pursue X, or you should pursue Y. But to at least have a recommendation that says, explore some technological models to try to do this better than what we've got today is definitely pushing the envelope. I don't want to get into an extended discussion of whether Judy's particular model is the right

one. It doesn't mean that it's not something that ONC shouldn't explore, in addition to help record banking.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I agree with that, Deven, and I would say that I think one thing ... to stimulate innovation. And, quite frankly, this group isn't going to come up with all the ways to solve this problem. We should, in this recommendation, try to find a way to stimulate innovation to meet the challenge rather than finding

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

How would you reword the recommendation, Carol?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I don't see the wording of the previous recommendation. It's already changed.

Deven McGraw - Center for Democracy & Technology – Director

Yes, I just took off the example of the face sheet.

Paul Egerman – eScription – CEO

Are you okay with what it says now: concrete models to determine feasibility and stimulate ...?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

How does ONC do that?

Paul Egerman – eScription – CEO

And the second question that I think ONC might likely ask is, is that not what the NHIN is and has been? How does this relate to their support of that?

Deven McGraw - Center for Democracy & Technology – Director

Well, I think the NHIN has been very much focused on simulating exchange between providers for at least stage one of meaningful use, depending on what NHIN project you're talking about.

Paul Egerman – eScription – CEO

That's NHIN Direct, I think.

Deven McGraw - Center for Democracy & Technology – Director

There are some functions beyond that, but, David, you've paid more attention to this stuff, but I don't see any NHIN models out there that are directly interfacing with health record banks, for example. That stuff is going on at the state level. I mean, I think that ONC has got, what, a hundred some odd staff people working for it now? We don't have to be the only source for which they get recommendations on this stuff.

Paul Egerman – eScription – CEO

I would agree, certainly. We would be essentially saying we think that additional models are worth exploring.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

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

Yes. Carol has raised an issue that I think resonates well with me, which is that we want to put the charge or make the suggestion to ONC in a way that stimulates their thinking beyond the notion of the control models associated with an HIO to solve this problem.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Right.

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

And I'd like to make sure that we don't accidentally imply something different in this wording, which is why I was trying to push her to suggest some wording for us.

Paul Egerman – eScription – CEO

Say that again then, or what's the correct wording?

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

I don't know. I was asking Carol.

Deven McGraw - Center for Democracy & Technology – Director

He's trying to give you a better prompt. Would it be, create and explore concrete models beyond those already in existence?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

It's really to create new models.

Paul Egerman – eScription – CEO

Additional.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I think the answer we want here is for them to explore some combination of EHR sharing and health record banks to achieve different purposes, use of health information for different purposes. Today we have a single model, and every single secondary use of data somehow comes out of this single model EHR. There are definitely, in my opinion, purposes, secondary purposes of data that would be better suited for a PHR model. My preference would be to recommend that the ONC explore the use of some combination of EHR, EHR exchanges, and health record banks to give patients greater control over the exchange and secondary use of their information.

Judy Faulkner – Epic Systems – Founder

I'm going to push back on that one because I'm really nervous about us maybe because for so many of the PHRs, they don't come under some of the confidentiality and privacy rules, and because there are concerns about them. I think it's fine to say let the EHR vendors do something similar to, I mean, what you would have to do was present the patient with a CCR record ... edit. But I think it's fine for the EHRs, but I would not bring the PHRs into this.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Well, I—

Paul Egerman – eScription – CEO

Wait a second.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

...let me respond.

Paul Egerman – eScription – CEO

Let me interrupt. Maybe, again, I want to make sure we keep this discussion at the right level. We don't necessarily have to talk about whether it's a PHR or even a health data bank. There ought to be some way to say that this exploration should also include new roles for patient data structures. So we give it some name. I don't know if patient data structure is the right word. I don't want to engineer it now and say, yes, it's a PHR. Yes, it's a health databank. We'll just say it's a patient data structure and figure it out.

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

I guess, what I hear is that all we really can say so far to answer this question is do something.

Paul Egerman – eScription – CEO

Well, that's right. It's a good comment because, again, the question I'm asking is, this actually comes back to what you suggested, Wes. The very first thing was to create these new models. Can ONC do that?

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

Well, I think—

Paul Egerman – eScription – CEO

...ONC can ... we have to tell ONC something more before they can create the models?

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

I think where we are is that we, in answers to previous questions, we've identified both conceptual fuzziness and practical, technological challenges to enabling patients to make more granular consent decisions. And the question we're now asking ourselves is what actions should ONC take. I don't know that we're going to get much more than to say that this is an area that needs to be explored with a wide vision for possible approaches and that we believe. Now when it gets to advising ONC how to accomplish that, I don't know that I have the competence to talk about what's done by staff versus what's done by contract or things like that. So I'm trying, what I'm trying to do is find some way to say, A, this is important. B, there's not a clear path. C, do something.

Paul Egerman – eScription – CEO

Okay.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Paul Egerman – eScription – CEO

Now when we say do something, should we be capturing some of these things like what Judy mentioned?

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

We might want to include those on a supplementary basis as a list of for instances, but

Deven McGraw - Center for Democracy & Technology – Director

Yes. I don't mind providing them as possible examples that have been suggested by individual tiger team members, but I think we need to be careful not to present it as a consensus of we think

Paul Egerman – eScription – CEO

That's right because there's not a consensus

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

Not unless we want to spend another couple hours.

Paul Egerman – eScription – CEO

It's just that Judy suggested something. Gayle liked it. Carol didn't like it, but

Deven McGraw - Center for Democracy & Technology – Director

Well, she raised some questions that

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

If we want to discuss it, I'll put my two cents in, but I think I will say that I think there are some benefits to that approach, but I also see some issues that concern me substantially, so I would not, despite recognizing the benefits, I wouldn't sign up to saying it was a consensus at this point.

Paul Egerman – eScription – CEO

Yes, I agree. What I'm hearing is that we could list Judy's concept as a for example after the

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

As long as it's positioned in the document, probably not on the slide, but somewhere in a way that says these are ideas that were discussed as opposed to these are ideas the group agreed on.

Judy Faulkner – Epic Systems – Founder

Yes, and I think

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes, and I don't think we should be in the position of providing the solution to things that aren't widely used or understood right now. The best approach for me would be to say that there are opportunities that ONC has not in sort of saying here's a solution; build it. But in saying in grant making or in requirements, preference will be given to solutions that explore patient's more granular control, whatever. There are ways to simulate people to find ways to achieve this objective that are not about let's procure the solution. I think it's a very complex issue, and I think we're just not going to be in a good place if we think we can think up the answer amongst ourselves and say....

Paul Egerman – eScription – CEO

I appreciate those comments, Carol. I'm trying to understand. Is what Deven wrote on this screen, are you okay with that?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Well, I don't know. We've got MU and certification stage three granular consensus is a requirement. I am assuming that we're going to learn something before we get to stage three about this, and know what it is that might be certifiable, but I don't know that we know, even this discussion amongst ourselves between PHRs and EHRs and the authorization table. I mean, I think this has to be – there's more that needs to be learned about this. There are some very promising sorts of things that are happening out in the technology space that we need to track. But I guess I want to make sure that the levers that ONC has

are used to motivate that kind of further implementation and learning and understanding of how to do this rather than say the way you're going to get this done is to create a certification requirement for something even we can't really articulate.

Paul Egerman – eScription – CEO

So are you okay with everything except that MU and certification stage three?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes.

Paul Egerman – eScription – CEO

Now for the MU and certification stage three, before we delete it—

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I just want you to know, the slide is changing as we speak.

Paul Egerman – eScription – CEO

I know. It's like Gayle. It's a moving target. You never know where she is, and we never know what the slide is. This is hard, but this is the way life works.

Deven McGraw - Center for Democracy & Technology – Director

...isn't doing it. It's me, so you can tell me to stop.

Paul Egerman – eScription – CEO

No, this is just great. It adds unbelievable element of excitement to this discussion. Let's look at that number three, MU and certification stage three. One possibility is to drop it. Another possibility ... something to say something that that would be the earliest that we would imagine that the material could be available, and I think it might be helpful to provide— Would it be helpful to provide some reasonable expectation that this is going to take time? This is not a stage two thing. I think we'd be lucky to get it done by stage three, so is it valuable to say something like that possibly the earliest is going to be stage three, or would you just suggest we drop that all together?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I didn't pay close enough attention. I probably should have listened more carefully, but in the so-called telegraphing of stage two and stage three, my memory is that health information exchange beyond the directed exchange of stage one will be a requirement of some kind, right?

Paul Egerman – eScription – CEO

Correct. I suspect so.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

So some of this is going to be on the table regardless.

Paul Egerman – eScription – CEO

Well, I don't know if that's the case. I don't know.

Deven McGraw - Center for Democracy & Technology – Director

Yes. I mean, there's more robust exchange. I don't think it's entirely clear that it's at all model dependent.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

But it would be more robust exchange, and given the funding to the states, one assumes that state HIEs, HIOs will be involved in that. I'm just saying that some of these issues are going to be on the table regardless of what we write here in this timeframe.

Deven McGraw - Center for Democracy & Technology – Director

Absolutely.

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

Yes. I'd like to say, I don't think we should prejudge. In prejudging the timeframe, we are assuming that there is no sort of conceptual breakthrough that hacks off the specific part of the problem and say, you know what? This part is doable. I agree that almost anything that gets introduced has a four-year introduction cycle. If there's a need for standards, a need for changes to systems, and there's a need to those systems to roll out three years at the most. But I'd rather not prejudge that there isn't some way to advance this cause incrementally, you know, in the timeframe of – well, certainly not in the timeframe of meaningful use because that goes on beyond 2015, but not in the timeframe of the incentives.

Paul Egerman – eScription – CEO

Based on that comment, Wes, are you suggesting we just drop that item number three all together?

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

I've got to look at it here.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I suggest we just drop

Paul Egerman – eScription – CEO

I want to hear Wes.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Excuse me.

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

I would say that, yes, I think that's, you know, if you wanted, you might be able to say achieving something suitable for meaningful use criteria by stage three. Yes, I think drop it.

Paul Egerman – eScription – CEO

Okay. Dixie, you were about to say something.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes. I would suggest we drop all of those sub-bullets and just clarify the first one, which was Wes' statement up there that this in an area should be a priority for ONC to explore further with a wide vision for possible approaches to enabling – to providing patients greater control over the exchange and use of their information, period.

Paul Egerman – eScription – CEO

I guess I would challenge that a little bit. I think the idea of models and pilot projects is important. I'm just even picking up on what Carol said. We've got to make sure that something that's done here is really practical.

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

Can I say, rather than greater, we say appropriate control?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Appropriate, exactly. Good.

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

We may find that that solves your problem.

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

No, we're not going to get to a national consensus on what appropriate control is. I mean, we're going to have this continued balance between informing the clinical process and patient concerns about protecting their data, and I don't believe there is a brilliant solution that's going to solve both of those needs. This is not one of those issues.

Deven McGraw - Center for Democracy & Technology – Director

And keep in mind that the question is just about – is a question that we have focused our entire discussion on, which is granularity, more granular than all in or all out.

Paul Egerman – eScription – CEO

Yes. We want to say more – instead of approach, it's more granular control.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I think somewhere we should capture what Wes just said about balancing achievement and effective balance between informing the clinical process and providing and protecting individual privacy. That's really what this whole exercise should be focused on.

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

Well, see, what I was saying is there is no chance in the world of achieving that balance.

Deven McGraw - Center for Democracy & Technology – Director

In a way that's going to satisfy everyone, yes.

Paul Egerman – eScription – CEO

Right, which is—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

That's what we should be— It shouldn't be just, for example, targeted at determining feasibility. You know, whatever they came up with is, you know, you make it feasible. But it should not only be feasible, but it should be safe for the patient and protect their privacy.

Paul Egerman – eScription – CEO

Determine feasibility and patient safety.

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

You know, I don't mean to speak like I play a doctor on TV or something, but we don't – the best I can tell, we have a hard time determining when a medication absolutely is safe or not safe, much less when sharing information is safe or not safe.

Paul Egerman – eScription – CEO

Yes.

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

This is a gray area.

Paul Egerman – eScription – CEO

That's a good comment, Wes. I also wonder if we're just starting to wordsmith our question. I think we've got an answer to this question, right?

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Paul Egerman – eScription – CEO

Our answer to this question is there's a lot of work that needs to be done, and ONC is going to do some evaluation, do some pilots, and find out what can really work.

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

Given the nature of committees and the tiger team, I think it's important that we feel we are moving the ball down the field, and I think we are here. We might have hoped to have moved it farther, but I think, after a fair amount of rather illuminating discussion, we've decided to go for a short run over the center here.

Paul Egerman – eScription – CEO

I think this is very good. If people are okay, then we will have to wordsmith this a little bit. Are we ready to go on to question number five?

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

My God. There's another question?

Paul Egerman – eScription – CEO

Yes, there are another 35 questions.

Deven McGraw - Center for Democracy & Technology – Director

No, there's one. Thanks, Paul.

Paul Egerman – eScription – CEO

I know it feels like

Deven McGraw - Center for Democracy & Technology – Director

I'm waiting for all the hang up buttons to start.

Paul Egerman – eScription – CEO

Before, I just want to say, we've made really great progress, even with these first four questions. This is really impressive.

Deven McGraw - Center for Democracy & Technology – Director

We have. Here, I think we developed this last question just as a vehicle for whether ... eliciting whether there's something that we want to recommend be done when we understand that the technical capabilities are not as far along as we would like. And so one of the things that has come out in our discussions is the concept of data that leaks or has implied qualities to it and whether, you know sort of

one clear option is that the patients need to understand that when they ask for some more, you know, make a request that their data be restricted in some way, shape, or form, they need to sort of understand that if the technology has limits with respect to being able to honor it, I think they need to understand that.

Gayle Harrell – Florida – Former State Legislator

I'd like to address the whole issue ... four-hour discussion, and I want to thank everybody for hanging in there. I know it's a long day for me. I'm sure it is for everybody. But I can tell you; this to me says two things. Number one, we've got to educate patients as to what the realities of the system are and what they can really expect, and it also, I'm going to have to make my plug one more time, really very strongly for the.... You have to combine the education and then given the inability of the system right now to really honor the requests of the patients, especially on sensitive data, the only option is opt in and educated opt in.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I'll second the notion. Whether it's opt in or opt out, the only solution to these problems in the long run is going to be an engaged consumer who wishes to take charge. You can't delegate this complexity to other entities or individuals.

Judy Faulkner – Epic Systems – Founder

Our experience has been, it's about 2%.

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

I agree with Judy.

Judy Faulkner – Epic Systems – Founder

...opt out, so the burden would be huge on the opt in side. I would be for the opt out side.

Paul Egerman – eScription – CEO

Let's not—

Judy Faulkner – Epic Systems – Founder

Let's not go into that now.

Paul Egerman – eScription – CEO

Let's not go into that one now because—

Deven McGraw - Center for Democracy & Technology – Director

In 20 minutes....

Paul Egerman – eScription – CEO

...time for another four-hour meeting at some point, we'll do it then. But I'm picking up on what you said, Judy.

Deven McGraw - Center for Democracy & Technology – Director

I have to give you credit, Gayle, for squeezing that one in though.

Paul Egerman – eScription – CEO

Yes, absolutely.

Gayle Harrell – Florida – Former State Legislator

I missed the opportunity.

Paul Egerman – eScription – CEO

That's right. Getting back to what Judy just said, are you suggesting that there be something here about encouraging patient engagement with the electronic health record?

Judy Faulkner – Epic Systems – Founder

I'm not sure what your question is, Paul.

Paul Egerman – eScription – CEO

Well, I'm saying, based on where we are right now, the question is what should happen in the short term? Is there something that ONC should do in the short term? You're saying only 2% of the patients are involved.

Judy Faulkner – Epic Systems – Founder

Yes. We're finding 2% of the patients, approximately, don't send their record back and forth, and the other 98% just say send the whole thing.

Paul Egerman – eScription – CEO

So is that an argument then that, in the short term, ONC doesn't really have to do anything?

Judy Faulkner – Epic Systems – Founder

No, it's just an argument to keep this in perspective, as we talk about things and make decisions because we have to keep balancing what is the good for everyone, and we don't want to harm the 98% for the 2%. We don't want to harm the 2% for the 98%. But we have to keep those percentages in mind.

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

I agree. I mean, our experience is that patients far more are concerned when their data is not available even though we do absolutely have to worry about privacy. I think Judy expresses what—

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

Are we going to capture that? I think the general statement that we're dealing with two distinct populations in roughly those ratios and that the things – I guess I missed part of— Do you know from the data that you have, Judy, that if they had the option for more granular consent, they would exercise it?

Judy Faulkner – Epic Systems – Founder

No. All we know is that they are asked if they want to send the entire record over, and—

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

So they're given an all or nothing, and....

Judy Faulkner – Epic Systems – Founder

Yes, and 98% say yes.

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

Right.

Gayle Harrell – Florida – Former State Legislator

...they're asked. That's an opt in. They're asked.

Judy Faulkner – Epic Systems – Founder

Well, when they are asked, and that's why we're making those generalizations. What we have found is a number of our customers, after seeing those percentages, and found opt in to be very burdensome, switched to opt out.

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

How did we get to opt in and opt out?

Deven McGraw - Center for Democracy & Technology – Director

It's not. We are not. The co-chairs, and I'm assuming Paul agrees with me, have affirmatively said that that is out of order.

Paul Egerman – eScription – CEO

That's right.

Joy Pritts – ONC – Chief Privacy Officer

Here, here.

Deven McGraw - Center for Democracy & Technology – Director

Now, having said that, beyond making sure that patients are aware that things that requests that they make when there is not a technical ability to honor it well, that they understand that. I think maybe the other option is, you know, certainly where there's choice. You know, you have a trigger for choice and if it cannot be exercised more granularly, in part, because the technology may not be able to support what the patient asks for. Certainly they still have the general consent option. It's a lousy choice, but it's there.

Gayle Harrell – Florida – Former State Legislator

I'd like to bring up another aspect of this. I think this, the fact that the technology is not there also puts an additional burden on HIOs, and we need to talk about governance of HIOs and how and the security of HIOs. The security and the privacy relationships between the provider and the HIO, I think that whole governance thing needs to be addressed.

Deven McGraw - Center for Democracy & Technology – Director

Gayle, it's good to remind us that we've got a set of recommendations on the table that say that all entities involved in health information exchange have to follow good security practices and all of the fair information practices. I think we've got some further work to do to refine basic aspects of that, but—

Gayle Harrell – Florida – Former State Legislator

Not so much the security aspects, but going back to the privacy aspects and who uses that information. I think there needs to be some further work done on that.

Deven McGraw - Center for Democracy & Technology – Director

Yes. I don't disagree. Maybe there's just nothing else to say here.

Paul Egerman – eScription – CEO

I don't know how to say it. The only other thing to say is there should be an expectation that there's not going to be something happening very fast on this.

Deven McGraw - Center for Democracy & Technology – Director

Right.

Paul Egerman – eScription – CEO

I mean, I liked what Wes said about a four-year lead time between when you get started and when something is in the marketplace, and so somehow there needs to be a realistic expectation that's set that there's a lot of work that needs to be done. And maybe within that realistic expectation, there's an opportunity for the HIOs or for private enterprise or somebody to come up with something creative.

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

I would say that at a minimum, we have said that the solutions that have come to mind are in at least that four-year timeframe. I don't want to rule out the possibility that, I mean, the best innovation is often – isn't a clever way to build exactly the same bridge you thought you wanted. It's a way to figure out where you're going to build a different bridge, and I just want us to leave the possibility that there's going to be a solution open.

Paul Egerman – eScription – CEO

Sure. Because it's like as an entrepreneur, I always feel that my customers' problem is my business opportunity to come up with a solution.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Right.

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

Yes, but I want to also add—

Paul Egerman – eScription – CEO

...not only ... for these HIOs.

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

Right. We have to be careful that we don't phrase this in a way that it's only a business opportunity for EHR vendors. The whole part about innovation, my metaphor of building a bridge in a different place is about leaving us open to whose opportunity it is.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Sort of emphasizing the first half of this and not the second, I think, as these technical capabilities are being developed, I think another thing that can be done to honor patient's rights is to make sharing more transparent. It doesn't give them more, you know, more preference, but at least it gives them more visibility.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I certainly second that. I don't know if it's on topic, but I like that idea.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Gayle Harrell – Florida – Former State Legislator

I think the education of patients needs to be emphasized, that they know exactly what's happening and whether it's ONC, there's a role for ONC in the bully pulpit that they have. There's a role for the physician, the provider to play in this, and there's a role for the HIOs to play in this. And it needs to be very much discussed publicly.

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

Yes. Gayle, you managed to quiet the room, or did I go offline? Am I here?

Deven McGraw - Center for Democracy & Technology – Director

No, you're here.

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

Okay. I haven't heard this call be that quiet in so long, I figured the phone died.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think we're hungry and tired.

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

Yes, that could be it.

Deven McGraw - Center for Democracy & Technology – Director

Bio break.

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

I would say that there's another factor to consider, which is that year-by-year, physicians and patients will be getting more experienced with information interchange and better able to appreciate the concerns. They'll be less hypothetical and more real to them, so that in addition to patient education, just recognizing that the whole, there's a whole maturing process going on in its regard is important.

Paul Egerman – eScription – CEO

Does the silence mean either that everyone is exhausted, or does it mean that everyone is completely happy with what's written on the screen?

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

Let's vote for somewhere in the middle.

Paul Egerman – eScription – CEO

If the technology will allow us to give a middle response.

Deven McGraw - Center for Democracy & Technology – Director

We've squeezed enough blood from the turnip.

Joy Pritts – ONC – Chief Privacy Officer

We are comfortably numb.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

We all have fanny fatigue.

Deven McGraw - Center for Democracy & Technology – Director

Right. I can't feel my toes anymore. All right. Well, I think we've got some good stuff on these slides, and we can continue to do a little work on wordsmithing them. I think of the things that we want to accomplish in our next meeting is to take a look at the triggers in light of the discussion that we've had lately and some of the issues that have been raised by members of the policy and standards committees, and make sure that we've got them, that they're still the right ones, the consent triggers. And I'll go back there, but then I think I'm going to turn slide control back to Altarum We want to spend some time refining those on our call on Friday.

Paul Egerman – eScription – CEO

We want to refine this and fix this.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Paul Egerman – eScription – CEO

Do we also want to take another shot at this opt in business?

Deven McGraw - Center for Democracy & Technology – Director

Can I suggest that we spend a lot more time getting the language right on when choice is triggered and what meaningful choice ought to look like and these triggers. And if the triggers lead us to a more clear vision of opt in or opt out, then we can go there. But I'm hard pressed to see how we're going to get any farther than we were able to get absent a little bit more clarity on some of these other issues.

Paul Egerman – eScription – CEO

Okay, well—

Deven McGraw - Center for Democracy & Technology – Director

I don't want to suggest that, like we ruled it out of order for this discussion today. Maybe we don't have to be quite so draconian in the future, but I too am dismayed by the fact that very few people picked up on what I think was some of the most valuable work that we did on patient choice and instead focused on the fact that we were conflicted over the defaults about whether it should be opt in or opt out. And I'd hate to continue to perpetuate that versus doing some work that will really continue to move the ball forward, as Wes said, but we don't have to rule it out.

Paul Egerman – eScription – CEO

I guess our next meeting is on Friday.

Deven McGraw - Center for Democracy & Technology – Director

Yes.

Paul Egerman – eScription – CEO

And our overall intension though is to wrap up consent, to package that as a recommendation overall, which would be a really terrific accomplishment for this group.

Joy Pritts – ONC – Chief Privacy Officer

It really would be.

Paul Egerman – eScription – CEO

It's a complicated issue, and so I think we're almost there, so that's very exciting. And somewhere over the next few days, it's possible we'll send you an e-mail about starting two subgroups. One is a subgroup on provider authentication. The other one is on patient identity matching. This is really probably more of a technical discussion to see how we can write a scope document and who is interested in working on those issues.

Joy Pritts – ONC – Chief Privacy Officer

Paul, I'd like to jump in here because I just heard about something on that issue this morning, which is, they might also be addressing some of these issues in the enrollment workgroup that I think you're involved with also.

Paul Egerman – eScripton – CEO

Yes.

Joy Pritts – ONC – Chief Privacy Officer

So we might be trying to combine some of these people from our workgroup with their workgroup so that it's only addressed once.

Paul Egerman – eScripton – CEO

Yes, Joy. I am involved with that. Actually, we did say that we were going to combine it. They sort of are asking us to put it together.

Joy Pritts – ONC – Chief Privacy Officer

Okay. Wonderful.

Paul Egerman – eScripton – CEO

This will be combined with the enrollment side, but I'm just trying to say, and we need some help from ONC on this issue in order to coordinate that with the enrollment people.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Paul, but you raise an issue that's actually been a question in my mind. I might have missed it in some of the earlier plans, but we're called the privacy and security tiger team, yet we haven't really done much on, as you said, some of the technical issues or the security issues. Are we charged to get to that? Is that going to be a part of our work, or is that happening elsewhere?

Paul Egerman – eScripton – CEO

Well, it is. I mean, again, our work is to do what ONC asks us to do. At least the last I understand, this is part of our scope. And the reason I'm suggesting the subgroup is because some of these things about authentication, it's a bit technical, and I'm not sure everybody wants to be involved with it.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I'm asking about other aspects of what we would call security also.

Paul Egerman – eScripton – CEO

Yes.

Joy Pritts – ONC – Chief Privacy Officer

We have yet to develop a long-term plan on that, Carol. There are lots of issues that we have to develop here, and I'm trying to get some help onboard in order for us to get a really good, long-term plan going on as to who is addressing what issues.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Okay.

Deven McGraw - Center for Democracy & Technology – Director

Okay.

Paul Egerman – eScription – CEO

The only reason I made the comment is just to tell you that that e-mail might be coming up, and to think about it, as some people might be very interested in these issues, and some people might view it as the worst punishment in the world to participate in those calls. And so that was my other comment, but I think we've done great work here, Deven.

Deven McGraw - Center for Democracy & Technology – Director

I think so too, and much credit goes to all of you who have taken up so much of your time to hang with us on these. We've got a few more, two more, actually, of these long calls before we have the package of recommendations to put before the policy committee, and we will have gone through the tiger team ambitious schedule. And, as Joy said, we need more of a long-term plan, and we'll get one. But, in the meantime, we wouldn't be where we are today if everyone hadn't been willing to spend so much time on the phone, sitting in a chair, and engaging your brains in some really difficult conversations.

Joy Pritts – ONC – Chief Privacy Officer

It really has been an amazing concentration of effort over the summer, and we can't begin to express our appreciation for this because it really, I should save this until we get all the recommendations in, so we don't jinx any of it.

Deven McGraw - Center for Democracy & Technology – Director

I know. I was going to say, we're not quite over the finish line.

Joy Pritts – ONC – Chief Privacy Officer

Okay, but up to today, we really appreciate everything everybody has done, and we're looking forward to getting all of those recommendations.

Paul Egerman – eScription – CEO

That's great. Before we throw this open for public comments, do people have something else they want to say?

Judy Faulkner – Epic Systems – Founder

What are we doing with the slide on the screen right – there are two questions.

Deven McGraw - Center for Democracy & Technology – Director

Sorry, we're going to try to refine these in our next call because people's brains are fried. We still arguable have five minutes, but—

Judy Faulkner – Epic Systems – Founder

Okay. Then the second question that I have is when you said recommendations, did I miss something? Are we supposed to be sending in something?

Deven McGraw - Center for Democracy & Technology – Director

No. Keep an eye out for your e-mail, as usual. There'll be, well, number one, the preparation documents for Friday are coming, but also, as Paul mentioned, that we're setting up some sort of special workgroups to tease out some issues on provider authentication and patient matching that have some fairly technical components to them that we might want to have a subgroup.

Judy Faulkner – Epic Systems – Founder

I just didn't want to miss the homework assignment.

Deven McGraw - Center for Democracy & Technology – Director

Yes. No, I think you're good right now.

Judy Faulkner – Epic Systems – Founder

Okay. Great.

Gayle Harrell – Florida – Former State Legislator

Would you send me the slides?

Deven McGraw - Center for Democracy & Technology – Director

Yes. Everybody is going to get the slides. Yes.

Paul Egerman – eScription – CEO

Any other comments or questions? If not, Judy Sparrow, could you open the lines for public comment?

Judy Sparrow – Office of the National Coordinator – Executive Director

Yes. Let's see how many stayed with us. Operator, can you see if anybody wants to comment from the public, please?

Operator

You don't have any comments at this time.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thank you, everybody. What a great call.

Deven McGraw - Center for Democracy & Technology – Director

The team hung in there, but we lost the public.

Paul Egerman – eScription – CEO

Well, I guess we answered all the questions.

Operator

We do have a comment that just came in.

Judy Sparrow – Office of the National Coordinator – Executive Director

Good. Could you please identify yourself?

Les Kepper

Yes. This is Les Kepper. As you know, I'm an old-timer and been at this for years and continue to be impressed with the leadership and the participation. It's fantastic. The reason I feel this is because you have not lost the essence of our entire healthcare community, and that is the relationship between the patient and the physician. And if we keep up the spirit of what you're talking about, this will be successful. Thank you.

Paul Egerman – eScription – CEO

Thank you, Les. We really appreciate that.

Judy Sparrow – Office of the National Coordinator – Executive Director

Okay. Well, thank you, Deven and Paul. Great job.

Paul Egerman – eScription – CEO

Thank you. And thank you, Judy Sparrow and Joy.

Deven McGraw - Center for Democracy & Technology – Director

And Joy and Jamie.

Paul Egerman – eScription – CEO

And Jamie, and the entire Altarum team, and I guess we'll talk to you again on Friday.

Deven McGraw - Center for Democracy & Technology – Director

Yes. Thanks, everyone.

Judy Sparrow – Office of the National Coordinator – Executive Director

Bye-bye.

Public Comment Received During the Meeting

1. If that data that is to be w/held is disclosed, then the consumer/patient should have given consent to same.
2. We need to be careful that we are defining this as a workflow process as EHR interfaces are designed for the purpose of delivering care; any deviation from those workflows will only harm the process and adoption. And each office works differently, so be careful with assumptions as to what information is and is not appropriate in a clinical setting. Only the patient and doctor can make that determination. It is less of detection and more of context-appropriate. How can this be defined without patient involvement? "Line-item veto" access to patient records? And how does treatment planning work into this? How can we categorically define what information is and is not appropriate for HIE data? This is something that can be completely subjective to the patient's perspective and the practitioner? What is the assumption of the "current architecture" and "technology"? That all have access to encrypted RDB? What are the min tech specs assumed? My concern is that we are defining for today and the current processes; we are not allowing for future technology and medical delivery changes. If we can define the intent and goals, we will not create a process that will be outdated as soon as the technology changes. Can these "rules" be restructured as "goals" with rewards rather than penalties? That will encourage the right and positive activity rather than browbeat others into compliance.
3. Agree with the sentiment that tech has to follow paper processes; what can be done to encourage innovation without stifling with too many requirements?