

Privacy & Security Tiger Team
Draft Transcript
December 10, 2010

Presentation

Judy Sparrow – Office of the National Coordinator – Executive Director

Good morning, everybody, and welcome to the Privacy and Security Tiger Team. This call will run from 10:00 until noon Eastern Time. This is a Federal Advisory Committee, so there will be opportunity at the end of the call for the public to make comment.

Let me do a quick roll call. Deven McGraw?

Deven McGraw – Center for Democracy & Technology – Director

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Paul Egerman?

Paul Egerman – Software Entrepreneur

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Latanya Sweeney? Gayle Harrell? Carol Diamond? Judy Faulkner?

Judy Faulkner – Epic Systems – Founder

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Carl Dvorak is on. David McCallie? Neil Calman?

Neil Calman – Institute for Family Health – President & Cofounder

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

David Lansky? Dixie Baker? Micky Tripathi? Rachel Block? Alice Brown is on for Christine Bechtel. John Houston?

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

I'm on, yes.

Judy Sparrow – Office of the National Coordinator – Executive Director

Wes Rishel? Leslie Francis? Adam Greene?

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

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Did I leave anyone off?

Joy Pritts – ONC – Chief Privacy Officer

Joy.

Judy Sparrow – Office of the National Coordinator – Executive Director

Alright, I'll turn it over to Deven.

Deven McGraw – Center for Democracy & Technology – Director

Nice that we're all together two days in a row: once in person and once on the phone. Thanks for all of you who were able to attend the hearing that we had yesterday on patient matching. It was very interesting. We had some great testimony from the witnesses, and good opportunities to ask some questions and tease out even more of their thoughts and recommendations.

What we want to do with our two-hour call today and in preparation for the Policy Committee meeting on Monday is go through a set of slides that tried to summarize some of the key themes both in terms of the issues, as well as potential solutions that we heard. So we can talk about them and think about which ones we want to emphasize to the Policy Committee at the meeting on Monday. We only have the two hours today and not a lot of time before the Policy Committee meeting on Monday. So we did not think that there was likely time for us to come up with consensus recommendations and specific answers to the some of the questions that we specifically asked the testifiers.

But of course, certainly, if our conversations are going well and heading in a common or consensus direction, I think that at a minimum that will help us to tease up with a little bit more specificity for the Policy Committee where our current thinking is. That will of course make it more likely that we can more quickly come to a final set of recommendations and maybe even be able to present them at the January Policy Committee meeting. Although that one comes up quite quickly as well, January 13th, and we have really only one meeting on the schedule between now and then, but we will always try to do our best to push this as much as we can to get to some conclusions and conclusive recommendations. I think ideally by January, but given the holidays in the schedule, it may take us a little longer, but I think that's the goal.

Paul, do you want to add anything to that?

Paul Egerman – Software Entrepreneur

No, I think that that's an excellent summary. I want to echo your comment, Deven, that I want to thank everyone. I wanted to thank the members of the tiger team for showing great continued dedication. I also want to thank any members of the public, who might be listening to our phone call, but I think you did a good summary, Deven.

Deven McGraw – Center for Democracy & Technology – Director

Our trustee MITRE team pulled some slides together for us, and we have some background, just to set the frame for the discussion. We'll go through them pretty quickly.

Just to remind folks about what our overall objective is. It's to provide policy recommendations on privacy and security issues associated with linking or matching patients to their information within healthcare entities in order to support information exchange. Obviously, the ability to match patients with their appropriate data is important. It's a vital step in quality healthcare. Accuracy, integrity, and quality of the data are important. I think we heard this loud and clear yesterday; we've got to get the internal data issues resolved before you can think about exchange.

Paul kicked us off by reading the law, which currently constrains—

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

Deven, can we go back to that last slide for a second?

Deven McGraw – Center for Democracy & Technology – Director

Okay, really, John? This is background.

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

I know, but is this what we're going to be presenting?

Deven McGraw – Center for Democracy & Technology – Director

No, not necessarily.

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

Okay, then I don't need to talk about, never mind.

Paul Egerman – Software Entrepreneur

John, we have no clue yet what we're presenting on Monday, but hopefully, by the end of this call, we'll have an idea.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

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

I was just trying to think, there's an issue I want to make sure that this makes for better privacy if you get this stuff right.

Deven McGraw – Center for Democracy & Technology – Director

Right, absolutely. Actually, it's interesting, I thought you were going to say that some of these matching issues are not just about privacy and security. I think some of the comments that came up were data quality related, whether it's more related to healthcare quality than privacy, but nevertheless, it has a bigger scope I think. That's what I thought you were going to say.

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

It does, but I want to make sure, if you're going to present this to the Policy Committee, that we certainly want to pick and tie it back to privacy as being an end goal.

Deven McGraw – Center for Democracy & Technology – Director

Right, absolutely.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Deven, I just wanted to let you know I'm on the line. Also, I'm going to send you and Paul just a note about some of the wording in slide three is out.

Paul Egerman – Software Entrepreneur

Yes. Thank you for that comment, Carol. One observation I want to make sure we understand is we really appreciate the way MITRE and Lisa put this together on short notice. We got it quite late last night, and Deven and I looked at it very briefly. So there is, especially on the slides that I'm going to be doing, a fair amount of wording issues that we probably want to work on. But the way that you're approaching, Carol, is exactly— What we would like for you to simply send us an e-mail, but this is not ready for prime time in front of the Policy Committee. So it's very much a working document.

Gayle Harrell – Florida – State Representative

I wanted to let you know I'm onboard too and also you might want to mention patient safety as part of the importance of the linking.

Paul Egerman – Software Entrepreneur

Yes. Actually, a great observation, although we do get to that.

Deven McGraw – Center for Democracy & Technology – Director

Yes, okay, so just a reminder to folks about the law that's currently in effect and has been since 1999 that constrains the solutions here. HHS is prohibited from using any of its funds to promulgate or adopt any final standard providing for or providing for the assignment of a unique health identifier of an individual until legislation is enacted specifically approving the standard.

Other applicable laws that are relevant here include the HIPAA privacy and security rules. There's a minimum necessary standard in HIPAA that applies to disclosures. It doesn't apply to treatment disclosures, but it applies to other access uses and disclosures within HIPAA, which is to access, use, and disclose only what's the minimum necessary in order to accomplish the purpose. Then similarly, there are provisions that are fairly generically, generally worded about assuring that the right data is associated with the right person. So there is a legal baseline and a set of obligations that entities covered by HIPAA need to meet—

Adam, I don't know if you have anything that you wanted to add?

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

No, I think that covers it.

Deven McGraw – Center for Democracy & Technology – Director

Okay, great. Then just a reminder of the questions that we posed to the witnesses, which are the rough guides I think for our discussion today; which is what level of accuracy should be established for patient matching, i.e., matching patients to their data? What standards if any might need to be established in order to assist with patient matching? Are their best practices that should be recommended to assist with patient matching? So again, what we're trying to do is to tease out some of the common themes that emerged during the hearing that are likely to influence how we as a tiger team would answer those questions.

Now I'm going to turn it over to Paul to begin the discussion of some of those issues and themes.

Paul Egerman – Software Entrepreneur

Before I start, I also just want to re-emphasize what Deven just said, to ask everyone to keep in mind these three questions. Because basically, that's the way we framed the hearing for the people who participated, who testified in front of us. So hopefully in our response, eventually we will come up with our answers to these three questions. In terms of the first one, the level of accuracy, the second is, what standards, if any, do we want to recommend, and the third is, are the best practices that we want to recommend. We can say anything else in addition, but I think we should at a minimum answer those three questions.

Now we have the slides also that Lisa put together. As we go through this, I have to confess, as a former vendor, I have this bad habit, if you put a PowerPoint presentation in front of me, I start to sell whatever it says in the PowerPoint, and this is a working document. So the right way to do this is rather than me trying to sell what it says here is to say this is being put in front of you to stimulate discussion. What we should be doing here is asking you to say, is this right or wrong? Other than wordsmithing, what should it say?

The first question is, why is the patient linking important? This is where the comment that Gayle made comes up, at least what's important, because it's a patient safety concern. There's other things written here, what do people think about what is written here?

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

Again, the fact that we should put privacy as a bullet point here.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Paul Egerman – Software Entrepreneur

So this is where you would like to see, I like the way you phrased it, improves privacy as opposed to create privacy concerns, but if we do it right, it improves privacy.

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

Yes.

Paul Egerman – Software Entrepreneur

I think so.

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

The question should be, why is patient linking important, you say why is accurate patient linking important?

Paul Egerman – Software Entrepreneur

Yes, that's correct.

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

Which is the question?

Paul Egerman – Software Entrepreneur

It's what John just said.

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

So we're not concerned with justifying patient linking at all, we're only concerned with

Deven McGraw – Center for Democracy & Technology – Director

Who's speaking, please?

Paul Egerman – Software Entrepreneur

It sounds like Wes.

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

This is Wes, I'm sorry.

Deven McGraw – Center for Democracy & Technology – Director

Oh, thanks.

Paul Egerman – Software Entrepreneur

So you think the question should be what's originally here, why is patient linking important?

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

Yes, the question that is says, right.

Paul Egerman – Software Entrepreneur

Okay.

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

There's no qualitative component to that. There's bad patient linking and good patient linking, and I think what we want to try to do is improve or make sure that we have maximized the quality of patient linking.

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

Okay, I haven't heard anything conclusive that improving the quality includes either patient linking or improved quality of patient linking is the net positive for privacy. I've only heard that there are aspects of it that may improve privacy.

Joy Pritts – ONC – Chief Privacy Officer

This team is also looking at security, and data integrity is one of the elements of security. So perhaps you want to expand the perspective a little bit.

Paul Egerman – Software Entrepreneur

Explain that a little bit, like when you say expand perspective?

Joy Pritts – ONC – Chief Privacy Officer

You don't need to just focus on privacy, it's the Privacy and Security Workgroup, and so we can also focus on the security aspects of it, which includes ensuring data integrity.

Deven McGraw – Center for Democracy & Technology – Director

Yes, I mean, that all sounds great to me. Wes, do you not think that that's a legitimate aim? I'm trying to understand the point.

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

All I'm saying is that we really as the group need to be careful that what we say is consistent with what we hear. On the one hand, by the way, I have other reasons why it's important. I'm just questioning sort of the bald-faced statement that it improves privacy.

Paul Egerman – Software Entrepreneur

Well, suppose we do, Wes, what Joy said, which is it ensures data integrity. It's sort of like a bullet by itself if that makes sense.

Deven McGraw – Center for Democracy & Technology – Director

I don't think it ensures that, I think it promotes it.

Paul Egerman – Software Entrepreneur

Promotes integrity.

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

No, it doesn't even promote data integrity. I mean, we know that there's going to be an error rate associated with linking. Unlinked data doesn't lack integrity, it just lacks connection.

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

I think there was some discussion about the fact, this is John Houston, that it could result in bad integrity. You could in theory link inappropriate patients, the two patients records together.

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

So better patient link and this is back to what question are we answering? If it's the sense of the committee that we're answering why is good patient linking important, and let's change the title of the slide and say that, and then answer that question.

Paul Egerman – Software Entrepreneur

Okay, so let's do that. So let's change it to why is good patient linking important, okay? For now, that's the question. Are you okay with promoting data integrity?

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

Yes.

Paul Egerman – Software Entrepreneur

Okay. Also improve security and privacy?

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

I'm fine with it, but there are those who will say that any kind of linking threatens privacy.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

It might be one where it's better said of the negative is that it avoids inappropriate exposure by mismatches.

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

Good, yes, avoids inappropriate exposure of patient data, right, yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Because the harm is unequivocal if there's a mismatch. The good is not so clear if you avoid the actual match. If someone is trying to segregate their data by ensuring that there's not a match, then that's not so clear.

Paul Egerman – Software Entrepreneur

Okay. So we have promotes data integrity, avoid inappropriate exposure through mismatches.

Deven McGraw – Center for Democracy & Technology – Director

Through a mismatch, right.

Paul Egerman – Software Entrepreneur

Through mismatches.

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

I think as far as why put patient linking as important, that the ability through population studies and research is almost nonexistent without some point of patient linking.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

So really this slide, this is the benefits of accurate patient linking.

Paul Egerman – Software Entrepreneur

Right.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

And it is possible that we may have some downsides. Well, maybe the downsides of inaccurate patient linking. There's a law of the excluded middle, I'm not sure.

Paul Egerman – Software Entrepreneur

Okay, promoting data integrity, avoids inappropriate exposure, impact on population studies and research. Do we agree also patient safety?

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

Absolutely.

Paul Egerman – Software Entrepreneur

As the benefit?

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Paul Egerman – Software Entrepreneur

Okay. What about some of these other things that are written here, improved outcomes? We agree with that or disagree with that?

Deven McGraw – Center for Democracy & Technology – Director

I would agree because if the data, both in terms of— I think we heard loud and clear during the hearing that this is ultimately a data quality issue. So data quality and integrity certainly has implications for improved care. If the data in your record is incorrect and action is taken in reliance on it, that could be both a safety and a quality problem.

Paul Egerman – Software Entrepreneur

Okay.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

If we want it—

Gayle Harrell – Florida – State Representative

I would also add improve care coordination.

Paul Egerman – Software Entrepreneur

Okay.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

And if we want to be really picky about it, it's really the potential for improved outcomes and better care coordination.

Gayle Harrell – Florida – State Representative

Yes, I think that would be more appropriate, because you can't guarantee it will be better outcome.

Paul Egerman – Software Entrepreneur

But the care coordination, I personally like that, because it's correct. It's a benefit really of doing the right thing with information exchange.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, I agree.

Paul Egerman – Software Entrepreneur

So we've got the improved outcomes, we've got the patient safety. The other thing that's written on this slide is basically operational efficiency, impact on the efficiency of operations.

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

I understand a component of that is cost, but even if you have efficient operations, there's also cost reduction here as well. I think from an insurance perspective, people would find that that might be in addition to efficiency of operations.

Paul Egerman – Software Entrepreneur

Okay. So first, do we agree on efficiency of operations?

Gayle Harrell – Florida – State Representative

I think you may want to also put down, avoid potential for duplication of services.

Paul Egerman – Software Entrepreneur

Is that the same thing as efficiency of operations?

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

Not necessarily.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think it depends on whose operations you're talking about.

Gayle Harrell – Florida – State Representative

Correct.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

The HIEs operations, the payer, the provider, the consumer.

Paul Egerman – Software Entrepreneur

Okay.

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

I think the question is, is it worth singling out all of the things that fall under this broad net of efficiency of operations to make it clear what we mean by it.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

....

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

Yes.

Paul Egerman – Software Entrepreneur

Okay. Then I just want to get back to what you said, John Houston, on costs. Is that an aspect of efficiency of operations?

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

No, efficiency of operations in my mind is a provider issue. If I'm going to ensure though, if I can avoid duplicate costs, I'm going to reduce my sentence or what I have to pay out. I guess it's a different part of this that's affected by it, provider versus payer or payer versus provider.

Paul Egerman – Software Entrepreneur

Okay.

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

I think that the term implies equally to payers and providers, efficiency of operations.

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

I think reduced costs would be a valuable thing to add. Because that's also one of the reasons why you're seeing your meaningful use and why NHIN is being formed, which is the results to try to reduce the cost and the burdens of healthcare; which ... not able to put in here explicitly.

Paul Egerman – Software Entrepreneur

Okay. Let's also go on to the next bullet that's here, reduction of fraud. Do we agree with that? Does that one fit in?

Deven McGraw – Center for Democracy & Technology – Director

I thought we definitely heard that, at least from the Paul Oates from Cigna, if not from others.

Gayle Harrell – Florida – State Representative

I think that's an important aspect of it. I think we definitely should include that.

Paul Egerman – Software Entrepreneur

Okay. This is one of these things where we've got like a lot of reasons why patient linking is important

Gayle Harrell – Florida – State Representative

Yes, I'm starting to call this the apple pie list.

Paul Egerman – Software Entrepreneur

That's right. It's sort of like—

Neil Calman – Institute for Family Health – President & Cofounder

I mean it's sort of anything that has to do with patients that we've been talking about since the beginning, it's supported by this. It sounds like, we're trying to make a subset, but there is no subset. It's really everything that we're doing in the Policy Committee that requires any kind of certain patient identification is supported by this.

Paul Egerman – Software Entrepreneur

That's correct.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Neil Calman – Institute for Family Health – President & Cofounder

So maybe this slide is really redundant in terms of just stating the obvious.

Paul Egerman – Software Entrepreneur

That could be.

Gayle Harrell – Florida – State Representative

At times I believe you need to state the obvious so that you can really establish the premise upon which you're working.

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

I think also there's this sort of background need to justify linking versus the implicit threat to privacy. So it's well worth stating the obvious.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I wonder if the obvious is obvious, is it worth focusing a slide on the downsides or the potential negatives of patient linking?

Paul Egerman – Software Entrepreneur

Let me suggest this, these are good comments, but let's make sure that we don't get too far into starting to design our presentation. The goal of our discussion this morning is to try to understand the themes that came from yesterday's hearing, and see if we have a consensus about that. Because what I'd like to do is proceed with the next slide, and then hopefully we'll have another opportunity to polish the presentation. If this is okay with everybody, I'd like to go ahead and go on to the next one.

This next one is to try to understand what are the challenges that exist in patient linking? This is what Lisa wrote down in her notes that I'd like to see if people agree why this is not necessarily an easy thing to do. She wrote that there's technology challenges, and she wrote human processes and workflows. I'm not sure I know the difference between those two, but maybe there is a difference. She wrote different geographic settings pose different challenges. She made a comment about data quality. She made a comment that there's multiple algorithms.

She made a comment that, this came I think from Scott Whyte' testimony, that there's an increased margin of error or likelihood of error, to further remove from the original source of data. I think what that refers to is Scott seemed to suggest that the larger the organizations, the further away you got from the physician, the more people involved, the greater the likelihood of a problem. Then there was also a comment about data linking challenges in HIEs.

So this is an important issue, which is what of these things, what do we agree with, what's missing, what's people response to what's written here?

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

I think that there was a comment, I'm trying to find it in my notes, it was more than data quality, it was missing data as well. I forget who tried to differentiate the two or at least indicate that there was a difference between data quality and missing data.

Deven McGraw – Center for Democracy & Technology – Director

It's not that there's a difference, but that the issue of data quality is both about inaccurate data, mismatched data, as well as missing data.

Gayle Harrell – Florida – State Representative

Yes, and it is here.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

This is on the missing data, being the worst of the worst.

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

It was Scott Schumacher, it seem like he said, you cannot compensate for data completeness, only data quality, that's what he said. I don't know whether that's worthwhile bringing up in this slide or whether it's too detailed.

Paul Egerman – Software Entrepreneur

It's an interesting issue. The basic question, data quality and data completeness are two separate issues that are both challenges.

Deven McGraw – Center for Democracy & Technology – Director

I'm not sure I disagree with the wording of that. To me, the quality of the record that the completeness of the data is an issue that's quality related.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes, I don't think Scott Schumacher's comment should be taken to mean the data quality doesn't matter and you can compensate for it. That answer was given specifically in the context of whether having more data can allow you to compensate for data quality issues, but the theme of data quality came through every person who spoke yesterday.

Paul Egerman – Software Entrepreneur

Okay. These are comments really about the third bullet, where it talks about poor data quality. So it is the consensus of this group that data quality includes data completeness and that's not something that we need to call out separately?

Deven McGraw – Center for Democracy & Technology – Director

I do think we should mention data completeness as an issue in data, as well as—

Paul Egerman – Software Entrepreneur

It's really poor data quality and completeness significantly in this.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes. How about just something like poor data quality or missing data, maybe that's the same thing?

Paul Egerman – Software Entrepreneur

Okay. We'll pass to the third bullet, I just wanted to make sure that we didn't pass through the first two bullets too fast. The first bullet, we may need to wordsmith it, but I think that was an important theme that we've called a lot of places. It's not just technology, there's other things. There are human processes. This is a complicated thing.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes.

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

I think that a very common theme was that collection of data and having people that were willing to, who had the discipline to collect accurate data was incredibly important.

Paul Egerman – Software Entrepreneur

Yes.

Deven McGraw – Center for Democracy & Technology – Director

Yes, I absolutely heard that. I think we can wordsmith this, but I think the important point is that it isn't just about the technology.

Paul Egerman – Software Entrepreneur

Yes, that's right.

Deven McGraw – Center for Democracy & Technology – Director

It's a human factors problem.

Paul Egerman – Software Entrepreneur

Yes, I see that—the fact, again, I think it was Scott Whyte that somebody said, there is no technology silver bullet to solve this problem. You can't just use technology to fix it.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, if the registration part doesn't care when they take the patient information, then you're going to have bad data in the system.

Paul Egerman – Software Entrepreneur

That's true, although, part of my philosophy, you can't just blame the registration clerk, there's workflow processes, sometimes that person is under pressure, because there's ten people in line that lot of things can happen.

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

Right.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Or you have uncooperative patients even.

Paul Egerman – Software Entrepreneur

Well right, patients in discomfort, whatever.

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

I'd like to suggest that most care organizations are pretty good at fixing workflow problems that interfere with them getting paid. In fact, one of the ways they do that is just accept the data from the payer without even, let it override the data they have in their own system. So that it really gets down to a combination of variability in training to do this job correctly and variability and definition of what the correct job is.

So for example, we've heard that different VA hospitals had different policies on whether to use the nickname that the veteran presented or the legal name in collecting data. Presumably those represent an actual difference of opinion about which does a better job of identifying a patient of making it able to identify the patient the next time he shows up. I think that it's important that we recognize that there are these two sources of errors, one is simply not doing a job as well as defined, and the other is inconsistent definition of what the job is.

Paul Egerman – Software Entrepreneur

That's helpful.

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

I also think that we heard very strongly that there is no best case—well first, we heard very strongly that all matching algorithms deal with false positives and false matches and are tuned according to how they're used. For epidemiology, there's a different tuning then for assembling clinical notes on a patient. The important thing to recognize is that means there is no best way of doing it, it depends entirely on how it's being used.

Paul Egerman – Software Entrepreneur

Okay. So returning to the first bullet, we're going to have to do some wordsmithing. But it seems like there's an agreement that this is complicated, and there's a lot of workflows and human factors involved in management factors.

The second bullet is, it says pick the geographic settings opposed to challenges.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes, and I think that is a minimum should be expanded to address, not only geographic settings, but different objectives. Wes was just articulating—

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

—in all the different populations.

Paul Egerman – Software Entrepreneur

Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think it has no graphics.

Paul Egerman – Software Entrepreneur

Well, it's populations, and it's the settings themselves.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

It has no graphics.

Paul Egerman – Software Entrepreneur

That's different, I mean Wes just talked about the VA, but does the VA have the different challenge than people challenged. And is somebody who runs like a two-person medical group practice, because they have fewer people. So the management challenges are very different.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Right, but the issue Wes raised was also that for different purposes—

Paul Egerman – Software Entrepreneur

That's true.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

—there are different challenges.

Deven McGraw – Center for Democracy & Technology – Director

Well that's right. I think we heard pretty loud and clear that the margin of error, whether you error on the side of more false positives or false negatives, what is the algorithmic approach that you use? All is going to vary based on a number of factors, including what's your purpose, what's population are you studying, what's your setting, etc. So I think it's much bigger than just the geographic setting issue.

Paul Egerman – Software Entrepreneur

So it's like different populations, purposes, settings, and size. It's like a whole combination of factors created.

Deven McGraw – Center for Democracy & Technology – Director

Right, although, I think the size issue is related to what is the likelihood of an error challenge?

Paul Egerman – Software Entrepreneur

Okay, so the size perhaps is the—

Deven McGraw – Center for Democracy & Technology – Director

What kind of algorithmic match do you use?

Paul Egerman – Software Entrepreneur

Yes, so it's different purposes, populations, and settings.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Paul Egerman – Software Entrepreneur

Okay. So that's just the expansion of the second bullet. The third one we've already discussed. The fourth one says a variety of algorithms are used, and then it says, these algorithms vary in their design, no formal testing or acceptance process.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think that might be better read, limited formal.

Paul Egerman – Software Entrepreneur

I'm sorry, David?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I was saying limited formal testing, because there has been certainly testing of these, it's just limited, not enough.

Gayle Harrell – Florida – State Representative

I think it's not formal, it's standard, testing may be the better word. I would also say that I think the variability in the design of algorithms is actually important. In other words, it's a positive.

Deven McGraw – Center for Democracy & Technology – Director

Yes, I do too.

Gayle Harrell – Florida – State Representative

So we should say something like the algorithms need to be tuned to the specifics of how they're applied in some of the issues we just discussed earlier. In other words, that variability is in fact what makes them work.

Paul Egerman – Software Entrepreneur

Right.

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

I'd like to suggest this, a, first of all that we agree that we're in the phase of this technology, innovation is still favored over the standardizations, but that there are no ways to judge the output. That is there are no known consensus ways to say this algorithm is or is not better than that.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Paul Egerman – Software Entrepreneur

So Wes, when you say formal standardization, do you mean like formal evaluation?

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

Yes, there's no methodology for comparative effectiveness research on

Paul Egerman – Software Entrepreneur

That's right. So it's really, that's the real issue, there's no comparative effectiveness.

Gayle Harrell – Florida – State Representative

Also there's little transparency on what, not the algorithm itself, but the level of false positives that are accepted within that algorithm; and therefore, the impact on the reliability of what the data you're pulling in.

Paul Egerman – Software Entrepreneur

Okay, those are good observations.

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

Yes, I think that there was really a concern expressed that if you knew that you were using data that was a result of a match, you would want to know what the tuning was in that data. I think on several of the early testers are trying to imply there ought to be a way to carry that information forward out of the match.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes, I do think that starts to get to the issue of the accuracy rate that the different algorithms provide. What I heard them say is there's no common way that they each would measure that. In other words—

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

Measured it, yes.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

—the work is very different data sets and very different organizations with very different outcomes potentially that they're looking at. But that an accuracy rate, and honestly, this is something that we've said for a very long time, an accuracy rate that is trustworthy is really important for the network to function. In other words, being able to say that you can accurately link to a certain level I think is an important attribute of trust.

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

Yes, I agree. I think it's careful, they were advising us very carefully not to confuse tuning the algorithm between false positives and false negatives and accuracy.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes, I agree with you, Wes.

Gayle Harrell – Florida – State Representative

Therefore, the transparency issue becomes very important so that you know what they are, but the purpose for which they have their accuracy level.

Paul Egerman – Software Entrepreneur

The issues we have is that, so like the concept, there's a variety of algorithms which we think are very good. We have a concept that there is not like a formal effectiveness evaluations of these things. We have an issue of—

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

Measurement.

Paul Egerman – Software Entrepreneur

—measurement, that that's important, and we have an issue of transparency.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Wes, I want to come back to what you and Carol were saying that you didn't think accuracy was related to true positive and false positive rates. It's defined in terms of those.

Paul Egerman – Software Entrepreneur

We're going to get to that issue actually in the next slide. We'll still have a chance to discuss that issue.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Okay, I mean, that's just a matter of definition and I didn't follow the point they were trying to make.

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

All I was saying was that I don't think that saying that this algorithm is tuned towards false positives or tuned towards false negatives in a given setting is saying anything about the accuracy of the algorithm.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Right. Also that you may need a higher rate of false positives or a lower rate of false positives or false negatives depending on the application that they're using the algorithm for. Again, it's not a statement about the accuracy of the algorithm.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Well, it is though. If you are accepting a higher proportion of false positives, you have a less accurate algorithm by definition.

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

No.

Paul Egerman – Software Entrepreneur

Wait, let me just interrupt the discussion, let's figure out, what we're trying to do is understand the challenges in patient linking. What we're simply saying is, the variety of algorithms exist, and there's no formal evaluation process. We're saying that measurement is important and that there's a challenge with the transparency. So from the standpoint of the challenges in patient linking, do we need to go into this level of detail that's being described right now?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

No, I don't necessarily think so. Although I think at some point we'll have to be more careful about how we define these terms in which we use under the word accuracy and multiple different meanings.

Paul Egerman – Software Entrepreneur

Which we're going to do on the next slide, I agree. If you don't mind, I'd like to go on. The next bullet that's here, the increased margin of error further removed from the original source of data. Which when I read it, I think that relates to the larger and more complex organizations tend to have greater challenges in patient linking. I don't know if that's increased margin of error. But what do people think about that as an important theme that we should be calling out and agreeing on?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I agree with the underlying message here. The basic point that was made at the hearing is that in an environment where there's a relationship with the patient, and the patient is known on a personal level, there is the ability to reduce the errors because there's that relationship and people know the person. The farther you get from that relationship, the harder it is to communicate that or picking it up in the data.

Paul Egerman – Software Entrepreneur

That's correct. Carol, you made a good comment, because even some of the examples were, like the HEMS report, and they talk about problems with medical devices. It's almost by definition, the medical devices, sort of like getting farther removed from the initial contact between the patient and the physician. So that in a lot of ways, the farther removed you are, the more likely than of a problem.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes, I think—

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

You also lose context, maybe this is what you're saying, if the provider, the one example about the laboratory that does the lab tests for a provider, and they making data upon one particular item, which might be a specific number that's used for the transactions between the two. For them that's perfectly acceptable and sufficient, because they know exactly what they're keying their match on, which is a single number. But as you go further and further away from that relationship, other providers lose that context associated with that particular transaction, that lab test that was performed. So that's also I think a component of it as well.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes, and I just want to say that I think this very issue influenced our discussions on information sharing in HIEs. As well in terms of the farther you get from the person who has a relationship with the individual whose data it is; the harder it is to make some of these determinations and adjudicate quite frankly, adjudicate the situations where the data may be wrong.

Paul Egerman – Software Entrepreneur

The sense I'm getting from this discussion is that there's an agreement about this, the farther away from this source that this is the important concept. We'll probably have to wordsmith it, but it's an important concept. We might even promote it in terms of the order of the bullets and put it a little bit higher up that this is an important thing. Is that correct? Okay, I'll assume silence means it is correct.

Then the next bullet and the last one on this page is the issue that you just raised, Carol, which is HIEs. So maybe we need to change that to HIOs, but data linking challenges may be magnified due to the complexities from multiple data sources. Do we agree with that comment?

Deven McGraw – Center for Democracy & Technology – Director

I think generally, yes. Although it might be worth noting that for some, I recall Shaun Grannis saying that they have very rigorous data quality standards for their participants. So it might be worth mentioning that while certainly those challenges are present, I'm not suggesting that that negates the statement. But in some cases, you might look to HIEs to be enforcers of data quality.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

He did say that they had a role of enforcing the quality, but I do think the point we just discussed is the results of even this point, which is the farther away you get from the person who's creating the data and has the relationship with a patient, the more complexities there are.

Deven McGraw – Center for Democracy & Technology – Director

Yes, that's absolutely true. I don't think that Shaun's point at all negates that principle that we heard from many witnesses, absolutely.

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

Can we maybe suggest that data linkage challenges increase as the number of data sources increase, and get the discussion of HIEs out of the bullet point?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I like that. I think it's a number of sources, as well as distance from source.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Well, I just want to say that some challenges increase, and sometimes the more data you have, and we heard this point too, some challenges decrease. So I think if we're going to say this, we have to say it very carefully.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

And Carol, I mean, when I say a number of sources, I mean number of different feeds of information that have to be reconciled, not number of elements. I didn't mean to be unclear about that.

Paul Egerman – Software Entrepreneur

Right.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

....

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I mean, it's just a truism really, but the more number of sources that you have to match accurately, the harder your job is.

Paul Egerman – Software Entrepreneur

So I just want to make sure I understand the discussion that's going on right now. We all agree the farther you get from the data, the harder it is, and the more sources you have, the harder it is. The only topic of discussion that we're talking about right now is whether or not we want to call out HIEs specifically.

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

I think we want to avoid that, because I really think as one individual stated, HIEs will often be able to provide better data quality as it relates to those who participate in the HIE.

Gayle Harrell – Florida – State Representative

One of the—

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I don't know how that's possible. I don't remember—

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

Because we're dealing with standards.

Gayle Harrell – Florida – State Representative

Excuse me, this—

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

That's not an accuracy statement standards. If the HIE gets data of poor quality that it has errors in it, the HIE, as we've just said, is in a difficult position to try to correct those.

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

But the HIE can enforce a certain amount rigor in terms of data quality and that can be improved, that's my only point.

Paul Egerman – Software Entrepreneur

Okay, let me suggest this, let's right now put this part of the discussion sort of like on the parking lot, because we agree on the fundamental principle about multiple sources creates challenges, and the farther you get away from the source of the data, that also creates challenges. So we're really only talking about whether or not we want to say anything specifically about HIEs, which I think is sort of a wordsmithing kind of an issue. If it's okay with everybody, I'd like to move on to the next slide. Is that okay?

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

We don't think we necessarily agree on the things you said we agreed on, but

Paul Egerman – Software Entrepreneur

Okay, so maybe we don't. So if that's the case then we need to go back to that part.

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

I'm willing to support moving on anyway, because I think we could resolve that with a couple of e-mails.

Paul Egerman – Software Entrepreneur

Okay. Is that okay with everybody? Great, so on the next slide, what we tried to do was simply through definitions. So the first one is the definition of this concept of accuracy, which we defined as a number of patients correctly identified, divided by a total number of patients. Which is interesting, because actually it seems like people really when we use statistics, it was inaccuracy ... 8% to 12%

Deven McGraw – Center for Democracy & Technology – Director

Right.

Paul Egerman – Software Entrepreneur

This is what we've defined as accuracy, and actually it's a very important issue. I think you, Wes, was the one who asked this question, what does this mean? I'm not sure everybody was using exactly this definition, but before we go on to the next part, do we agree with that?

Deven McGraw – Center for Democracy & Technology – Director

I think it skews a little bit. It's not that the patients are correctly identified, but that the patients are correctly linked to the right data that is in their file.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, if you want to be precise about it, accuracy is a parameter that describes the effectiveness of the test. The test in this case is whether the match was correct or not and it's independent of the population. I mean it's the measure of test, and you'll get different results with different populations. It's true positives plus true negatives, divided by the total number of true and false positives and negatives.

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

I don't know that anybody testified to this definition. I like the slides, because it's implying accuracy not as false positives or false negatives. It doesn't say one is better than the other somehow, they're both inaccurate.

Paul Egerman – Software Entrepreneur

You broke up a bit, Wes, could you just try and say that again, please?

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

I don't think anybody testified to this slide, but I like the definitions primarily because it makes it clear that we're trading off two kinds of inaccuracies. False positives, some people say all false negatives are much less problem than false positives, so that depends. And this slide makes it clear that both false negatives and false positives are inaccuracies.

Paul Egerman – Software Entrepreneur

Okay.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Correct, and it's a statistical definition. If we want to use that word in this context, we should use I think the accurate definition. I don't think the testimony is relevant one way or the other. This is just a formal definition.

Deven McGraw – Center for Democracy & Technology – Director

I don't know that we need to wrap ourselves up in defining these terms, but I do think that it's helpful to demonstrate to the Policy Committee what is meant by a false positive or a false negative. So I like the graphic, I don't think we need to get hung up on what is the exact definition of accuracy, because ultimately what we're trying to achieve here is the right data matched to the right patient.

Neil Calman – Institute for Family Health – President & Cofounder

Right, the implications of false positives and false negatives in different settings, I think speaks to why we have to deal with them separately. So for example, if I'm querying an HIE for a patient information, to me, having a false positive is less of a problem. Having a false negative means I don't get the information

that's out there. Having a false positive because the patient might be in front of me, gives me an opportunity to say, "So let me be clear, you had your kidney removed last year," and they say, "No, that's not me." But at least you've gotten an opportunity to look at a match to identify something. I think there's a difference, and the context makes a difference. It makes it important to call out the slide, because I haven't seen the subsequent slide, but they have different implications for sure.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

That came out totally clear in the testimony of all of the participants, so I think we'll cover that. I just think that if you had a one hundred percent accurate measure, sensitivity and specificity tradeoffs, true positives, false positives, the false negative tradeoffs would be irrelevant. The point is that none of these matches are a hundred percent accurate, so now you have to deal with the tradeoffs.

Neil Calman – Institute for Family Health – President & Cofounder

Right.

Paul Egerman – Software Entrepreneur

And the purpose of this slide I think would be simply perhaps to be beneficial for us internally to make sure we use the same terminology. The false positive and false negative terminology was used by several of the people who testified. It wasn't used universally. A couple people had used different words. Lisa asked me afterwards is that standard terminology in the industry? My answer was I don't think so, I don't know, but a lot of people used it, and I think that's probably why we just thought it would be helpful to write it down.

The accuracy concept that people were throwing around accuracy numbers. I thought it was Wes who asked the question what's the definition of accuracy? But it just seems helpful if we wrote down the definition. People—

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

I don't know that anybody testified to that particular, I don't think it matters, I think you could take this top bullet off the slide—

Deven McGraw – Center for Democracy & Technology – Director

Yes.

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

—and increase the value of the slide, because I think there can be argument about whether what's the right divisor and things like that statisticians will have, but for the most part we don't care about.

Deven McGraw – Center for Democracy & Technology – Director

Right, I agree.

Paul Egerman – Software Entrepreneur

Okay, so maybe the thing to do is to remove the accuracy thing, because that's less important, but the false positive and false negative, there was some consistent testimony about that, and it's good that we have common terminology.

Deven McGraw – Center for Democracy & Technology – Director

But the box that says most systems are designed around the false positives, I think negates the very point that we heard strongly that whether you error on the side of false positives or false negatives depends on the purpose of the data, the objectives that you're trying to meet. I didn't hear—

Paul Egerman – Software Entrepreneur

Maybe we should just remove that.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Well, no, I—

Paul Egerman – Software Entrepreneur

So is there a chance we can move that box?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

But no, I think, I did hear that, and that that is the number that most people start with because it's such an important number on the safety side. So I mean I—

Deven McGraw – Center for Democracy & Technology – Director

I guess I wouldn't mind mentioning it, that aspect of it, David, but I think it's got to be in the context of the choices that get made about the level of inaccuracy that's acceptable and which end of that you error on is going to depend on what you're doing.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right, but I think the testimony of several people was that they start by specifying the desired false positive rate. I don't mind it getting removed, but I do think that the slide is consistent with what we've heard.

Judy Faulkner – Epic Systems – Founder

I have a question for you about that meeting, when they talked about false positive and false negatives, and we just heard Neil say that he thinks that he can deal better with false positives. I think it depends on the context, because where I have seen really bad things with false positives is when surgery is involved. Well, no, that's not funny.

Deven McGraw – Center for Democracy & Technology – Director

I know, Judy, I know.

Judy Faulkner – Epic Systems – Founder

Yes, but there have been too many stories about false positives with surgery where the wrong person had something removed and the right person did not, and both were in terrible shape.

Paul Egerman – Software Entrepreneur

Right, and so what happens is—

David McCallie – Cerner Corporation – Vice President of Medical Informatics

That came through.

Judy Faulkner – Epic Systems – Founder

Okay

Paul Egerman – Software Entrepreneur

That did come through, and what I got as an impression from listening to the hearing was that people try very hard to avoid the false positive, and as a result, there's a tendency to increase the number of false negatives.

Judy Faulkner – Epic Systems – Founder

Okay.

Paul Egerman – Software Entrepreneur

And people are so afraid of exactly the situation that you just described.

Judy Faulkner – Epic Systems – Founder

Yes.

Paul Egerman – Software Entrepreneur

That it increases the likelihood that you create duplicate patients. The duplicate patients, which is the false negative, has its own set of patient safety issues, even if you look at the exact issue that you just raised, which is a surgery. If you have a situation where the surgeon is performing a procedure not knowing of a particular lab result that may exist, because it was put into a duplicate record, and that that lab result may have been important for that surgeon to know prior to the surgery.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

What I heard was that people typically start by thinking about the acceptable rate of false positives and then that determines the settings and the tuning for the rest of the system.

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

I'd like to suggest that what we heard was that in a care giving setting most people start, consider it much more important to avoid false positives and false negatives, not that either is good—

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Correct.

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

—that there are other settings that are served in health information exchange where that may not be the case, such as epidemiology.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

And research.

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

Yes, and I think what we want to do is first educate not only the Policy Committee, but also the people out there in the listening audience that there is such a thing as false positive and false negative, that there are people who are just naive on that point. Then we want to make the points that say for most care giving situations, false positives are believed to be more threatening, but that in the case of health information exchange, that's not something that can be predetermined, the preference for false negatives.

Neil Calman – Institute for Family Health – President & Cofounder

I think that this has to be looked at in the context of the workflow and what information is being exchanged and in what context. I don't think you can make a broad statement that says positives are worse than negatives or whatever. I think it depends upon the type of data you're talking about, the situation in which that takes place, and the workflow that gives you an opportunity to potentially identify a mismatch.

Gayle Harrell – Florida – State Representative

I would absolutely agree that that came through loud and clear in the testimony.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

And I think that's what Wes just said.

Deven McGraw – Center for Democracy & Technology – Director

Well, he did, but—

Neil Calman – Institute for Family Health – President & Cofounder

But I think he was basically weighing the two and saying false positives are worse than false negatives.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Only for certain settings.

Deven McGraw – Center for Democracy & Technology – Director

Yes, we don't need to be that specific I think with the Policy Committee about whether it's in the clinical context, more false positives, they're more of a problem. I don't think we need to go there because nobody at this hearing called on us to do accuracy standards that differ based on false positives or false negatives. So it's not really relevant to the set of recommendations that we're likely to come up with.

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

I agree.

Judy Faulkner – Epic Systems – Founder

I agree too. I'd like to make more comment and that is, if data is merged it is harder to separate two records pulled together and merged than it is to take separate records and later on determine they're the same person.

Paul Egerman – Software Entrepreneur

Right. What you just said, Judy, is very important about merging. I want to discuss that, so I want to put that aside for a minute. I just want to stay focused right now on this slide. The sense I'm getting from what Deven has proposed is that what we ought to do with this slide is just stick with the definition. So to get rid of the box that says something about designed around false positive and false negative, simply is this, we do good if we just define it rather than make some subjective comment about how systems are designed.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I agree.

Judy Faulkner – Epic Systems – Founder

Yes, I agree.

Paul Egerman – Software Entrepreneur

And so also the other thing I just want to make sure I got it right, where also on this slide, we're dropping the definition of the ... statement.

Judy Faulkner – Epic Systems – Founder

Yes.

Paul Egerman – Software Entrepreneur

Okay?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I'm not happy with that, but I'll tolerate it.

Paul Egerman – Software Entrepreneur

Okay. Now to get to Judy's comment about merging—

Judy Faulkner – Epic Systems – Founder

Oh, yes.

Paul Egerman – Software Entrepreneur

Judy, just made a comment about merging. Actually a few participants in the hearing made a similar comment saying something like merging is evil.

Judy Faulkner – Epic Systems – Founder

Yes.

Paul Egerman – Software Entrepreneur

And somebody said it's like the most evil thing that you could do, which caused me to think of possibly other things I could do that might be more evil than a merge. But I should confess that that's what I was

thinking of. But my observation is in the slide presentation, we didn't put that any place. Is that something that's valuable that we need to capture somewhere along the way?

Judy Faulkner – Epic Systems – Founder

What is the if, is it in your—?

Paul Egerman – Software Entrepreneur

Well, the comment that you just made about once you merge it—

Deven McGraw – Center for Democracy & Technology – Director

How bad merging is.

Paul Egerman – Software Entrepreneur

—it's difficult to unmerge the data.

Judy Faulkner – Epic Systems – Founder

Right.

Paul Egerman – Software Entrepreneur

And that was just an observation that was made in the hearing. Some people were saying never merge the data, only link to it. Is that important that we have, this is sort of like one of the things that we learned from this hearing is what I'm asking?

Judy Faulkner – Epic Systems – Founder

I disagree with that, never merge the data, because I think in the end if it is the same patient, either you're going to merge it or someone's left hand is going to enter that stuff and mix them up.

Paul Egerman – Software Entrepreneur

Well—

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

Really, I think we're talking here now, not about the linking, they were talking about how you handle the linking system.

Judy Faulkner – Epic Systems – Founder

Right.

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

I think there are two—

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

... the discussion about what you do downstream when you discover a possible link. So if you build a linking system that once someone proposed that these two patients were the same, it lost all evidence that they had been separate, that would be evil. What you do in your medical record system when you decide has got to do with whether you have the ability to pull up patients with separate linkages and merge the data or not. It's a different question.

Carl Dvorak – Epic Systems – EVP

Yes, Wes, I think there's an issue of the mechanics of it; most modern systems when they merge a patient preserve both the original and then they create a third patient that's the composite. If they ever need to unmerge, you can go back to the original. I think there's a mechanics issue. But the real insidious issue though is not the mechanics of it, the real issue is that once a provider treats a patient on a merged record, you can no longer tell what they did not personally add to the record because they thought it was already there, which may come undone later as the result of a merge.

So any unmerged generally needs direct clinician involvement and a review of the patients involved to determine if there is anything now on one of those patients that would need to be there that would not be there due to the unmerged. Because what the provider sees as they treat that patient the next three times, will not actually be there going forward in all cases. So there's a

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

How would you recommend that HIE handle that law, would you recommend that they not accept the one merge unless it's signed by a clinician?

Carl Dvorak – Epic Systems – EVP

Well, I don't know the mechanics that I'd specifically recommend for that, that could be that false positives are harder to deal with than false negatives.

Paul Egerman – Software Entrepreneur

Let me ask a different question, do we need to address this issue? I like your comment, Carl, that this is about the mechanics of how you handle the situation when you re-link or try to alter the linking that was initially established. Is that an issue that we should be diving into?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I don't think so.

Carl Dvorak – Epic Systems – EVP

I don't think so.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

No, Paul, I would say everything that Carl said applies mostly to how the application handles the information, and this is the point that Wes was making as well. The testimony that we heard was purely about the linking system, the system that says these two records potentially belong to the same person. That's where I think our recommendation should end, and not get into what happens now when those are served up to the application or the provider or the EHR.

Paul Egerman – Software Entrepreneur

Okay, that makes sense. So I think—

Judy Faulkner – Epic Systems – Founder

But as we make whatever recommendations we make, we have to have in our minds an understanding of what it really means so that we don't make a recommendation that downstream will cause some bad effects—

Paul Egerman – Software Entrepreneur

Absolutely.

Judy Faulkner – Epic Systems – Founder

—number one; number two, there are rules on redistribution. So in general, people will not merge the data because of the rules of redistribution.

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

I'm going to channel Paul here and say, we're not doing recommendations today, we're doing a summary of the testimony.

Paul Egerman – Software Entrepreneur

Right.

Deven McGraw – Center for Democracy & Technology – Director

That's absolutely right. And where actually we have less than an hour left in this call to get through the rest of the summary.

Paul Egerman – Software Entrepreneur

That's right. Okay, so on this slide, this is helpful, we've got a definition of false positive and false negative. We're dropping accuracy and we're dropping the extra red box, it's not a definition. Let's move on to the next slide. Again, and I appreciate your comment, Wes, to reground us on what we're trying to accomplish. We're trying to make sure we have some sense of consensus as to what we heard at the hearings, because then we'll have a foundation to make recommendations.

So here is what was written about what was said about accuracy and standards, and tell us if this is right. The first bullet says, required levels of matching accuracy vary based on the situation. That may be redundant with something we already said. The next bullet says organizations should measure their matching accuracy as part of their internal improvement or learning process. The next bullet says, who is responsible for measuring errors? That may have been a question that Gayle asked, and the answer was whoever owns the database, who establishes the database. But there was a statement that entities in the middle of the HIEs can play a role.

So what do we think about this slide and what it says here?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think that first bullet is really not the required levels of matching accuracy, it's the tradeoff between false positives and false negatives varies. Then you set your threshold, and that's what varies, you're not changing the accuracy. It's not about accuracy, it's about what your tradeoff between true and false is.

Paul Egerman – Software Entrepreneur

Okay.

Deven McGraw – Center for Democracy & Technology – Director

Okay.

Carl Dvorak – Epic Systems – EVP

That goes with the second bullet point as well, the organizations need to decide that balance rather than measure they're accuracy.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, yes. Nobody willfully makes the system less accurate, they just accept tradeoffs that reflect what they think the risks are of the errors.

Paul Egerman – Software Entrepreneur

Although, I thought I heard some of the speakers saying, this was predominantly Scott Schumacher say, organizations should be tracking this and should be establishing like goals as to what they want to do. That was what I thought I heard, did I hear it wrong?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

No, I think they do, I just think that the goal is not actually usually measured in terms of overall accuracy, it's measured in terms of what are we willing to tolerate on the false positive or false negative. Again, depending upon the use case, patient care versus research has different sets of tradeoffs. That they think of it in terms of where they make that tradeoff rather than in the absolute accuracy, because the accuracy doesn't tell you where your errors are occurring, which side of the curve your errors are on.

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

Yes, I'd like to suggest that we change the wording, this is Wes, change the wording to required balance between false positives and false negatives, varies based on the situation.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, that's well said, Wes, that's what I was trying to say, you always say it better.

Carl Dvorak – Epic Systems – EVP

By the way, what Scott Schumacher said I think in response to the questioning was, is that, the question was what error rates are acceptable? He said, somebody has to define what error rates are acceptable and let industry determine how to get there is I think what he said.

Paul Egerman – Software Entrepreneur

That is correct. Although, I also got the sense, maybe it was from Scott Whyte's testimony is that there really needs to be processes where organizations keep track of this and try to learn things from it and improve themselves from it too.

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

Well, I think that gets to the other issue, I think which is back to comparative effectiveness in a way. That right now if you have an HIE, you don't have any idea whether the one hospital is investing heavily in technology and training to improve the accuracy of the way they collect data about patients and the way they internally link patients versus the other.

He's saying that therefore, when you effectively create at least a virtually combined database from the outputs from these multiple hospitals that you don't know what the composite accuracy of the HIE is. This is not false positives and false negatives now, this is really about the accuracy of the data that goes into the thing. I think Sean went a step further and said, we actually have standards for the accuracy of the data and apply them differently to small practices and large data sources. I think it has to do with something whether, I forget the specifics, but he did say that much I know.

Paul Egerman – Software Entrepreneur

Okay, that's helpful, although, I'm trying to pull this all together. In terms of organization, you should measure their accuracy. We're saying organization should determine the balance between the false positives and the false negatives, is that right?

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

No, that's the problem is that other than the first bullet, that we're really talking, the second and third bullet shift from the balance to the issue of the processes that create the data that goes into downstream matching. First of all, it's a very hard thing to measure. But secondly, there is no requirement to measure it. There is no knowledge.

Now it happens that IBM would sell a lot more products if there were, because that's what they do, that's what they sell.

Paul Egerman – Software Entrepreneur

Sure.

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

But nonetheless, I think his point is well taken, back in the '80s I thought the same thing that we had a higher false negative rate than we needed, because every time the patient came in, they got to be a new patient.

Paul Egerman – Software Entrepreneur

What should we say if anything for this second bullet?

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

Well, I think as organizations should measure their patient identification accuracy as part of the internal improvement learning process. I guess I don't have any problem with the third bullet the way it's written if we change the second bullet.

Deven McGraw – Center for Democracy & Technology – Director

Yes, likewise, I agree.

Paul Egerman – Software Entrepreneur

Okay.

Deven McGraw – Center for Democracy & Technology – Director

Other than to say, instead of saying owners of data, I think we should say stewards, and this is a knit picky point—

Paul Egerman – Software Entrepreneur

Yes.

Deven McGraw – Center for Democracy & Technology – Director

—so if you don't want to deal with it, we don't have to, but in some states patients own the data.

Paul Egerman – Software Entrepreneur

Yes, I understand, that's fine.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

What was the rewording for the second bullet, Wes or Paul?

Deven McGraw – Center for Democracy & Technology – Director

Organizations should measure their patient identification accuracy.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Okay, which organizations? Are we talking about the source organizations or the ones that are doing matching?

Deven McGraw – Center for Democracy & Technology – Director

Source.

Paul Egerman – Software Entrepreneur

Source organizations.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Okay, you may want to call that out.

Deven McGraw – Center for Democracy & Technology – Director

Yes, we got it.

Paul Egerman – Software Entrepreneur

Okay. Any other comments on this before we go to the next slide?

Gayle Harrell – Florida – State Representative

Are we eliminating the third point?

Deven McGraw – Center for Democracy & Technology – Director

No.

Paul Egerman – Software Entrepreneur

No, I think it's still there.

Gayle Harrell – Florida – State Representative

Great, okay.

Paul Egerman – Software Entrepreneur

It's just we're wordsmithing a little bit, instead of owners of the data, we're going to call it something like stewards of the data or something.

Gayle Harrell – Florida – State Representative

Sure, got it.

Paul Egerman – Software Entrepreneur

The issue about the concept of data ownership.

Deven McGraw – Center for Democracy & Technology – Director

Okay.

Paul Egerman – Software Entrepreneur

Okay. The next slide is very interesting, it says where standards might be helpful. So this is not us recommending standards, this is us that you see this concept of strengths of the theme on the left, sort of like rating where we heard the people who testified say where it might be helpful, more important to do. So the top is like stronger, and it is like, yes, we should do it, and the bottom is, weaker, and that there was a lot less enthusiasm.

What's listed here are four concepts, the first one is, it relates to demographic data, and it specifically calls out name, date of birth, zip code, address, gender, and basically says common formats were named. There was also a discussion about, it says accuracy and verification. I think we might need to wordsmith that a little bit, but really normalization of the address according to the postal service probably standards, but also accuracy that the address exist. So that was one area.

The second one was standards for data fields and formats. I guess that's sort of like completeness. The third one was matching algorithms. The fourth one that's rated lowest is matching accuracy.

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

I would flip three and four, because what I heard was, at least in the Schumacher statement was that somebody needs to set the standard for accuracy, then let organizations determine how to get there. Then I thought I heard that really the least important was trying to ... algorithms, because that's something that people are, there's a lot of maturity with regards to different algorithms that exist for one; and secondly, it sounds like some of those algorithms are frankly patented. I'm not sure you can set a standard for an algorithm that's already patented. So I think that's how vendors will try to differentiate themselves is maybe what their algorithms are.

Paul Egerman – Software Entrepreneur

And that's fine. Although, I personally don't have any objection to flipping three and four, but what I personally heard at the hearing was, there was very little enthusiasm for standardizing either one of those two.

Gayle Harrell – Florida – State Representative

Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I agree that there wasn't a whole lot of enthusiasm for either one, but I think the question of whether or not there should be more open approach to algorithm design and validation was we got certainly very strong support from that from Shaun Grannis.

Paul Egerman – Software Entrepreneur

Yes, but that's not a standardization.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

No. Yes, from a point of view of a formal standard, I agree, but from the point of view of making this what is now an opaque trade secret process more open and subject to validation, we had at least two panelists make very strong statements in favor of that.

Paul Egerman – Software Entrepreneur

What you just said, David, is correct, but we need to talk about that as a separate category. I agree with you 100%, but these two here is what standards. If you remember, to ground this discussion, there was like these three questions that were asked going to the hearing.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Correct.

Paul Egerman – Software Entrepreneur

The first one was accuracy levels, question two was what standards might ONC create or might we recommend that ONC create.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes.

Paul Egerman – Software Entrepreneur

So this is trying to see which list of things that we talk about. Let's mark ourselves through this, the first one, the demographic data. The people agree that that seemed to agree that where there was the strongest statement, yes, that there would be some benefit if we could standardize things like name formats, normalization of the address, etc.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

We got some testimony that it didn't matter at all, but I think we got more testimony that it would in fact be helpful, and for no other reason it forces the capture of the data to be more careful.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

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

Yes, I think that we all understand from having been there, but that others may not understand that by consistent data fields, and first of all, I don't think there's any problem with standardization of formats for any of these data elements. I didn't hear anybody say there was a problem. I like the requirements to use standards for data fields from the second bullet.

But I think that the first sub-bullet should be establishing consistent requirements for data content for a minimum set of patient demographics. Because the problem wasn't that two people were representing date of birth differently or zip code differently, gender might be a problem dealing with transgender and so forth, but generally it's administrative gender. But that the problem was, are they filling out the middle name or not, are they using partial dates, age 81, as opposed to January 5, 1981 or whatever the right year is for age 81?

Are they getting the current address, are they taking a default just to make their system edits work, but does the address to the emergency department or what are they doing? So it's really established consistent, I can't even remember what I said now, but it was about getting the practices for how the data is collected comparable.

Paul Egerman – Software Entrepreneur

Okay.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

So there's two issues is how it's collected and what is collected. So should systems be held to a standard to capture a full middle name for example is somewhat different than how do you format name fields.

Paul Egerman – Software Entrepreneur

Yes, although—

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

There is no problem for standard formats, the name fields, date of birth, zip, address, and gender, with the possible exception of the number of values of gender. I didn't hear any of them say that there is. I did hear some people say what's addressed in the second sub-bullet, which is that the requirement to use standards for data fields and formats may be an issue. But there hasn't been anybody who said, we having trouble with HL-7 because we can't represent a data field.

Paul Egerman – Software Entrepreneur

So basically, if I'm hearing you right, Wes, what you're saying is you would kind of like to merge one and two together

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

No, no, no, what I'm saying is—

Deven McGraw – Center for Democracy & Technology – Director

No.

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

—don't interpret number one in terms of data format standards, you've got the ... formats from the first sub-bullet. Then add practices and collection of data or something like that.

Paul Egerman – Software Entrepreneur

Right. Well, it's interesting you're talking about that, the collection of the data, but let me put forward the idea that another way to approach this, our focus is really on interoperability and information exchange. Another way to approach this would be to establish requirements for the data when exchange occurs.

Deven McGraw – Center for Democracy & Technology – Director

Yes, but that's something we've always done, Paul, that it was garbage in and garbage out. It's got to get collected right at the source.

Paul Egerman – Software Entrepreneur

I understand that, but I'm saying by establishing the requirements for the data exchange, it has an upstream effect. In other words—

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

I agree with Paul. If a given entity decides to capture its post admission rather than add admission, that's none of our business, but that if they send it out incorrect, that is our business. I just don't want to, and linking is to when it's sent, I don't want to link it to the standard for the format. I think that message solved this year, we're going to need to raise it.

Paul Egerman – Software Entrepreneur

Yes, so I think I understand what you're saying, Wes, but to clarify also what I'm saying is that one possible benefit of what I'm saying too is you've got to realize when we do something to the requirements there's an issue of transition. But if we say until you establish the requirements on the exchange process itself, then you do have a way that people who may have data that already exist have two choices, like name and address field, you either run through ten million records and normalize all the addresses. Or if you choose to, you could normalize them at the point in which the exchange occurs. From the standpoint of interoperability, I don't think you really care as long as you get the data.

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

That's right. In fact, we really explicitly considered the way data is formatted inside the EHR as being a third rail that we don't want to touch. So I agree with you completely, I don't want the first bullet to be anything about format whatsoever.

Deven McGraw – Center for Democracy & Technology – Director

Right.

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

I want the second bullet to be about format, I want the first bullet to be about what data is available at the time it's transmitted to the HIE.

Paul Egerman – Software Entrepreneur

Right.

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

Because the biggest problem we have, one of the big problems is not implementing standards, is to get the format right, if they don't get, this system is cutting off the last name of ten characters, that system is cutting off the last name of 15 characters. So all kinds of issues like that come up.

Paul Egerman – Software Entrepreneur

Okay, so you're really suggesting, I just want to make sure I'm getting it right, Wes, flipping the first and the second one.

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

I didn't suggest that, but I don't have any problem with it.

Paul Egerman – Software Entrepreneur

Okay. Now if we do that though, I want to make sure that we don't lose the comments about the importance of getting the name and normalization on the name, and the normalization and validation on the address. So in my opinion that perhaps goes on this revised first bullet. That just seemed like that was an important theme that was discussed, do people agree with that?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Paul Egerman – Software Entrepreneur

Okay.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, and Wes, just when you talk about the format, what do you mean by that, the transmission format or the data entry format or the validation edit checks?

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

All we care about is the transmission format, right?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

No. It seems to me that that's the least of our worries.

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

That's my point, it's the least of our worries.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right.

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

But what I'm saying is that there's a standard that says how, if you don't add an address, will it work in every darn country in the world including the U.S.? So we don't need a new standard for how to format that.

Deven McGraw – Center for Democracy & Technology – Director

I agree.

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

But we do need people to stop putting the street name in the city field.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right, so what do we call that, edit checks?

Paul Egerman – Software Entrepreneur

Well, but Wes, the way I understood the testimony for example on address was that people were interested in making sure that there was consistent format. So the postal service has a format that does the persons, and it's apartment number 3, you write something, you write apt 3 or something, you don't write apartment, then a number sign. So that was something that people were saying, at least that's what I heard, what would be a helpful thing is that if everybody complied with it, and also used the postal service system to make sure that you had a valid address.

Judy Faulkner – Epic Systems – Founder

Yes.

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

Okay, it's possible that we have conflicting standards around address, that the HL-7 one and the postal one, although they represent the same data, they represent it differently.

Paul Egerman – Software Entrepreneur

Right.

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

No.

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

That's certainly worthy of investigating. But the main thing I think is that most of the problems that exist now are not about whether name, date of birth, zip, address, and gender are sent in a common format. They are whether they are being collected consistently, and therefore, are consistent in the transmission. I'm willing to leave out collected consistently as long as we understand that what we're talking about here is not, is there a place to put the middle name or is the last name the family name or the last name in the person's language. But are they collecting the last name, is it the family name, are they putting the family name in there instead of the last name?

Paul Egerman – Software Entrepreneur

I understand now what you're saying. Wes, what you're saying is a problem is not an absence of standards around these things, our problem is in absence of enforcement of those standards around those things.

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

I would say, the problem is not standards for format, the problem is standards for content. Yes, it's enforcement of standards for content, right.

Paul Egerman – Software Entrepreneur

Okay.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

So one test case, and I'm going out on a limb here, but just to try to understand, you could imagine for example a recommendation that emerges that says systems should be certified as to whether they validate address fields against the post office standard. Is that the direction that we're heading in?

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

Yes, that would be a good start, but it's not enough. I mean, it would have to be to get to how the data, what the decisions they make in the admitting department are, in terms of how they put data in a field. You'd have to go on and say meaningful use is 80% of all patients have, and I don't know how to phrase it right now, but what they're saying is more than just what the system can do, it is what does the user do with the system?

Paul Egerman – Software Entrepreneur

Let's get back to this slide, should the first bullet be requirements to use content standards or demographic data fields during information exchange?

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

How about to accurately use.

Judy Faulkner – Epic Systems – Founder

Yes.

Paul Egerman – Software Entrepreneur

Requirements for accurate demographic data content standards.

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

Paul, I'm sorry, Paul, I thought you finished the first two bullets, so I was answering about what the second bullet that we're looking at.

Paul Egerman – Software Entrepreneur

You thought I did what?

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

You just asked what's the first bullet? But previously you said you were going to flip the two bullets.

Paul Egerman – Software Entrepreneur

Yes, that's the first bullet, right. So what's now the second bullet becomes the first bullet. So it's the requirements to use accurate content standards—

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

No, no, what is now the second bullet is about data fields and formats.

Paul Egerman – Software Entrepreneur

Right.

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

Okay, what is now the first bullet is about data content. Paul, I'd be happy to write an e-mail and suggest how

Paul Egerman – Software Entrepreneur

Okay, why don't we do that.

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

Yes, okay.

Paul Egerman – Software Entrepreneur

I was trying to respond to what I thought I heard, so I must have gotten confused.

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

... that we're having, it's hard to carry this off in a group on the phone under a time limit. So I'd be happy to write an e-mail.

Paul Egerman – Software Entrepreneur

Okay, so let's do that. But the basic concept, I'm afraid to even try to summarize the basic concept, but the basic concept though is that the content of the demographic data, it needs to be compliant around the standards, just sort of the content of the demographic data. It needs to be accurate during information exchange, which hopefully creates an upstream requirement for how the data gets collected. Is that close?

Deven McGraw – Center for Democracy & Technology – Director

Upstream requirement for how the data gets collected?

Paul Egerman – Software Entrepreneur

Well has an impact.

Deven McGraw – Center for Democracy & Technology – Director

I mean, that's where it starts.

Paul Egerman – Software Entrepreneur

Yes.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

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

Yes, I think we want to sort of hint that that's the underlying problem—

Deven McGraw – Center for Democracy & Technology – Director

Yes.

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

—where they're not saying we're trying to standardize what their admission process is.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Paul Egerman – Software Entrepreneur

Okay.

Gayle Harrell – Florida – State Representative

I think we're getting a little too boxed in making specific recommendations, because this is supposed to be an overview. I think that we're kind of down in the weeds where we probably want to be on our next call.

Paul Egerman – Software Entrepreneur

I think that's an absolute good observation. So then let's just take a step back and see, are there other standards that should be listed here? We had algorithms and accuracy, which—

Deven McGraw – Center for Democracy & Technology – Director

Can I actually, Paul, I'm going to interrupt you, only because it's 11:35, and we still have three more slides to get through, and we're just trying to get a top of the tree summary for the Policy Committee. I don't know that we have to be in excruciating detail here.

Paul Egerman – Software Entrepreneur

Okay. So do you want to move on to the next slide then?

Deven McGraw – Center for Democracy & Technology – Director

I do.

Paul Egerman – Software Entrepreneur

Okay.

Deven McGraw – Center for Democracy & Technology – Director

Thank you. Alright, so what we have left just to give you an overview, this slide number 12, where I think we've heard loud and clear from many of the testifiers about the need to disseminate and share best practices, as well as adopt them. Because again, this is not just about the technology, it's also about the human factors. Then some recommendations about what the role of ONC could be in encouraging improvement in data quality and matching. Then we had some additional thoughts at the end that hopefully we will get to. But I think hopefully we'll at least get through the best practices and what the role of ONC is.

On best practices, there were a number of things mentioned here and some of it is a repeat of some points that we've made earlier, conducting evaluations of algorithm efficacy, encouraging documentation, testing, and transparency, maybe creating some common test data sets. I think Brad Malin mentioned that.

Soliciting best practices on how organizations that do this right, do it effectively, recommending that organizations measure and track accuracy for performance improvement, that we probably had this better worded on the earlier slide. Transparency and algorithms again, this is the repeat point I think, creating a learning system, community of interest to facilitate best practices. Then enhancing matching capabilities through the use of additional data points like biometrics or knowledge attributes, and maybe at least as the potential research opportunity, if not something affirmative to proceed with.

Paul Egerman – Software Entrepreneur

Okay.

Deven McGraw – Center for Democracy & Technology – Director

What do folks think about this generally, if there's something that strikes you in the language as being not quite right? Did we miss a best practice? I think there's a sort of overall theme of, there's just not enough information out there for organizations to use and rely on in order to get better at what they do, as well, too few of them probably focus on this and measure it regularly, pay attention to it.

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

Again, back to Scott Schumacher's point, which was give me a standard or an acceptable iterate, and let the industry decide how to get there. I don't know if that's a best practice or that's an ONC recommendation, but should we think about making a recommendation that ONC should sort of establish benchmark standards in terms of error rates?

Deven McGraw – Center for Democracy & Technology – Director

I think I would like to have that discussion when we actually get to the recommendations.

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

Okay.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Because I thought we sort of downplayed the notion of standardizing for an error rate.

Deven McGraw – Center for Democracy & Technology – Director

Yes, that's what I thought too. So I think that is worthy of additional conversation, but I think that's part of our recommendations discussion.

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

Yes, I'd like to suggest that recommending transparency and algorithms was not a universal, that it was an issue whether it was some debate among the testifiers.

Deven McGraw – Center for Democracy & Technology – Director

So—

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, maybe it's consider or—

Deven McGraw – Center for Democracy & Technology – Director

Right, maybe all of these are really consider, because these were, again, if this is a summary of what we heard in testimony, it's really about potential best practices. And these are all things to consider.

Gayle Harrell – Florida – State Representative

In fact, that's what you may want to be your top—

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

Just say at the top, the potential of best practices.

Deven McGraw – Center for Democracy & Technology – Director

Yes, well, that's what I thought. Gayle, I thought I heard you, but it—

Gayle Harrell – Florida – State Representative

Yes, I would say a potential best practices or best practices to be considered.

Deven McGraw – Center for Democracy & Technology – Director

Okay, great.

Gayle Harrell – Florida – State Representative

Thank you.

Deven McGraw – Center for Democracy & Technology – Director

Anything else on here that sort of struck people? Again, assuming that this is sort of a list of things to consider, not necessarily an exclusive list, but anything that's missing? Okay, well, then I'm going to go ahead and move on, if folks have additional thoughts after the call, please e-mail to let us know.

The next set of issues that were raised by our testifiers were in direct response to questions that we posed to them about why you recommend that ONC do? What would be the role of ONC in promoting improvements in this space? Some of the suggestions include that the discussion be broadened so that it's not focused narrowly on patient matching, but to cover data quality more broadly. Supporting a conversation about the development of standards for a minimum data set. This is related to the conversation that we just had. Clearly, this is a little bit of a follow on that if we came up with specific recommendations with respect to standards, there would be a role clearly that ONC could play there.

Promoting transparency and consumer education and communication; the process for sharing how patient matching is conducted, how accurate. Here's that accuracy word again; challenges in health information exchange, transparency to the consumer, developing a testing process, making sure that consumers understand that matching systems are never going to be perfect, that that's a goal that's not possible to achieve, but we certainly can be doing better; and developing some accountability mechanisms.

What do folks think about this? Maybe we should give a moment for people to actually read it. I read through it, but I didn't stop. The other thing that occurs to me as I'm reading through this is that rather than address what ONC's potential role is in just this hearing summary that we're trying to give on Monday, is that we hold off on making any recommendations about what role ONC would play until we get a little bit more definitive about what the recommendations are.

Joy Pritts – ONC – Chief Privacy Officer

I agree with that, Deven, I was also going to say in the second bullet here, the term minimum data set has a lot of connotations, so we just should be careful about these things.

Deven McGraw – Center for Democracy & Technology – Director

Yes. What do other folks think about, that we not begin to engage in a discussion about what ONC's role would be until we figure out exactly what it is we want to see done?

Judy Faulkner – Epic Systems – Founder

If it's not a conversation tomorrow, Monday, about what we heard, and we heard a lot of this in the meeting.

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

Agreed.

Deven McGraw – Center for Democracy & Technology – Director

That's absolutely true. But I guess I feel like that there would be a role for ONC to play in the multiple fixes that we heard might be needed in this state, sort of the multiple levers to push to fix this. I think it's sort of both implied and expected, given that we're a tiger team that makes recommendations to ONC. So I sort of feel like some of these bullets are a repeat of substance that we've already talked about. In some respect, I just trying to make sure that, it's given that we have a really short amount of time with the Policy Committee on Monday that we probably emphasize the substance, the what versus the how.

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

Agreed.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I agree. One minor point on slide 13, the liability concerns, I think maybe is more than just a sub-bullet. I think there were quite a few people who brought that up.

Gayle Harrell – Florida – State Representative

I think that was a major point that was discussed many times.

Deven McGraw – Center for Democracy & Technology – Director

Okay. Maybe we can see if there's a substantive place for that in one of the other slides, because I wouldn't want to miss raising it.

Gayle Harrell – Florida – State Representative

Yes, that was more a substantive than just what the role of the ONC should be, that was actually much more of a discussion at the substantive level.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think in some of these transparency things go forward, they have to be matched against that.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

The California example was raised a couple of times.

Gayle Harrell – Florida – State Representative

Yes.

Deven McGraw – Center for Democracy & Technology – Director

Anybody else want to make a point on this before we move on and pick up the last slide with Paul.

Gayle Harrell – Florida – State Representative

I think the accountability mechanism, that kind of discussion was more substantive than the role of ONC. So I think that needs to be put somewhere within the substantive area, maybe you can eliminate this slide. It was definitely more than just the role of the ONC.

Deven McGraw – Center for Democracy & Technology – Director

The need for some accountability infrastructure?

Gayle Harrell – Florida – State Representative

Yes.

Deven McGraw – Center for Democracy & Technology – Director

Okay. Alright, okay, Paul, you want to take us through the last slide?

Paul Egerman – Software Entrepreneur

The last slide is just other thoughts, it's just sort of observations I think that weren't on the previous slides. So the first one, it actually came from Alice, was that to consider at some point perhaps in the future to change the context from patient identity linking to consumer identity linkage, but that was also perhaps an issue for the payers.

The second bullet says, user centric identity of raising concerns based on variability experienced in other domains. I actually don't know what that means.

Deven McGraw – Center for Democracy & Technology – Director

I think that this was, and certainly Lisa from MITRE can correct me if I'm wrong, but I think this was in response to the question that I raised about whether there was any possibility for a sort of user sense, a more consumer centered approach to identity and what points are used for identity matching. I got pretty well shut down by Paul Oates from Cigna, who said that they didn't trust the information that patients gave them. So I don't know that this needs to be mentioned, but I think that's why it was on the slide.

Paul Egerman – Software Entrepreneur

Okay. The third is also sort of the catch all about this universal patient identifier stuff, which is, could voluntary identifiers, it says, they were talked about, but they were not consistently described as an important part of the matching process.

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

I think that the way you've worded that is that you word in the negatives. Some people said that if you were to provide a universal patient identifier, even on a voluntary basis, that it could improve the quality. It's not that we hear it virtually described as it absolutely being necessary, but the thing marked consistently. It makes it sound like people didn't think it was all that important. What I think I heard was, that there were people that said that that could be of value. I think we should express this in that way.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes.

Judy Faulkner – Epic Systems – Founder

But not everyone said that.

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

I doubt that not everybody said any of these things, about anything in this presentation.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

The people that were testifying were people that basically exist because we don't have a universal identifier. So they were pretty bias. I don't think we consider this testimony—

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

David, can I—

Deven McGraw – Center for Democracy & Technology – Director

I totally disagree with that, David. They don't exist just because we don't have a universal identifier. The one thing that was consistent is that everyone said that a number would not by itself be sufficient. So you would always need matching techniques of which an additional number would be another data point that could be used.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Deven, that's not what I said. There was no one in there testifying as an advocate of the voluntary universal patient ID.

Paul Egerman – Software Entrepreneur

Would it be easier—

David McCallie – Cerner Corporation – Vice President of Medical Informatics

And groups that were testifying, don't have a particular vested interest in seeing that approach succeed, so we shouldn't expect them to be real enthusiastic about it.

Paul Egerman – Software Entrepreneur

Should we just drop the whole bullet?

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

No, I think that bullet is important to have in there, but I don't think you say, use words like not consistently described. I think what you say is some people identified that as being something of value.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, a potential value worthy of study is what I think one of the groups said.

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

I must had a number of opportunities to consider the voluntary identifier. One of my conclusions is similar to what we heard from some of the testimony, which is that the process of converting will enable us the identifier would be a very long-term process at best. That we know from other centuries that simply giving out a number is not adequate particularly in terms of depending against

Judy Faulkner – Epic Systems – Founder

That's right. I think the example of other countries was very important and not including that folks felt one way about this issue.

Paul Egerman – Software Entrepreneur

So perhaps another way to say this is, to pick up on what John said was, some people expressed an interest in this area, but that there is not a consensus about moving in this direction except to the extent that there is a belief that moving towards a universal patient identifier would be a long-term process.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, I think I would accept that wording. I think the—

Judy Faulkner – Epic Systems – Founder

It would not obviate the need for linking.

Paul Egerman – Software Entrepreneur

Yes, it's a long-term process, that's right, it would not obviate the need for linking, certainly, that's correct.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Right. The view on a proposal does not obviate the need for linking. It merely manages the distribution of guaranteed unique numbers. So it doesn't eliminate linking at all. But the linking companies that were testifying are not particularly interested in additional infrastructure linking.

Paul Egerman – Software Entrepreneur

No, we're—

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

What was summarized in the testimony, and we know it's clear who was testifying.

Paul Egerman – Software Entrepreneur

Yes. So again, the purpose of this is to try to get all of us on the same page. Because in our next conference call, we're going to try to see if we can fine tune this into what we want to have for any specific recommendations. I think on Monday, I suspect what we'll do is we're going to try to just summarize the major themes that perhaps explain the false positives and false negatives. And show you there was some interest in this one area of standardization, and that we will be coming back later with more specific recommendations.

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

There was one other point I think that you may want to add to this slide. I know Ken Tarkoff has spoken to this, which is the role of the patient or consumer.

Paul Egerman – Software Entrepreneur

Patient access?

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

Well not just patient access, but accountability for ensuring that information is accurate.

Deven McGraw – Center for Democracy & Technology – Director

That patients can have a role in making sure.

Paul Egerman – Software Entrepreneur

Yes, that's correct. That's an important concept, so I'm glad you raised that, John.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I would add that it may not have been a very major subject of conversation, but we did have some conversation about the need for more investigation on authentication of the consumer's data at the time it's captured. So that you know that the consumers data being presented matches the actual consumer. So we talk about biometrics, photo IDs, challenge questions.

Gayle Harrell – Florida – State Representative

And that was definitely a point that was discussed by several.

Deven McGraw – Center for Democracy & Technology – Director

Yes, I think that was on the best practices slide.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Oh, was it, I'm sorry.

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

Yes, I was just going to say, if that's what that point was meant to convey, maybe we can make it a little bit more specific, because I had the same thought that it didn't quite get at, this notion of patient or consumer accountability.

Deven McGraw – Center for Democracy & Technology – Director

Okay. Actually, Alice, we'd love it if you'd suggest some wording.

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

Sure.

Deven McGraw – Center for Democracy & Technology – Director

Thank you.

Paul Egerman – Software Entrepreneur

That's right, Alice, we really appreciate your participation yesterday too.

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

Oh, no problem, thanks, guys.

Paul Egerman – Software Entrepreneur

Terrific, so before we throw ourselves open for public comment, which we're always eager to do, are there any other comments that anybody from the tiger team want to make?

Deven McGraw – Center for Democracy & Technology – Director

One more request I'll make for folks who agreed to give us some language, if you can do that today, since the Policy Committee meeting is Monday, that would be great.

Paul Egerman – Software Entrepreneur

Yes, Deven and I are actually going to meet, have a conference call in a few minutes and try to figure out what we're going to say on Monday. So as soon as you can put that together for us that would be very helpful. So Judy, can we open the lines for public comment?

Judy Sparrow – Office of the National Coordinator – Executive Director

Operator, if you can give the dial in number in case they need that?

Operator

We do have a comment.

Judy Sparrow – Office of the National Coordinator – Executive Director

Okay, speaker, please identify yourself. Hello, is somebody there for a comment? Operator?

Moderator

We lost them, sorry.

Judy Sparrow – Office of the National Coordinator – Executive Director

Okay.

Deven McGraw – Center for Democracy & Technology – Director

Okay.

Judy Sparrow – Office of the National Coordinator – Executive Director

Alright, well, thank you.

Paul Egerman – Software Entrepreneur

Thank you very much. Let me take a minute to again thank Judy Sparrow, and especially the people at MITRE, Lisa, I can never pronounce your last name correctly, tutter—

Deven McGraw – Center for Democracy & Technology – Director

Tutterow.

Paul Egerman – Software Entrepreneur

Tutterow, thank you very much for unbelievable work and putting together the slide deck so fast. Of course, thanks to all the tiger team members, and Joy Pritts, we very much appreciate your dedication being on the call today, being on the hearing yesterday. Let me wish everybody Happy Holidays.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

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

You too, thank you very much.

Deven McGraw – Center for Democracy & Technology – Director

Thank you to you too.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Thanks, everyone.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thank you, goodbye.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Goodbye.

Deven McGraw – Center for Democracy & Technology – Director

Goodbye.