Information Blocking (IB) Workgroup 1

Transcript
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Virtual Meeting

SPEAKERS

Name	Organization	Title
Michael Adcock	Individual	Co-Chair
Cynthia A. Fisher	WaterRev LLC	Member
John Kansky	Indiana Health Information Exchange	Member
Lauren Thompson	DoD/VA Interagency Program Office	Member
Sheryl Turney	Anthem Blue Cross Blue Shield	Member
Mark Knee	Office of the National Coordinator	Staff Lead

Guide Transcript

Operator
Thank you. All lines are now bridged.

Lauren Richie – Office of the National Coordinator for Health Information Technology – Designated Federal Officer
Good morning, everyone. Welcome to the HITAC information Blocking Task Force Workgroup One looking at statutory terms and provisions. A quick roll call and we will get started with a cONCinued discussion on health information networks and exchanges. Andy Truscott? I don't think he's on the line yet. Michael will be absent. Sheryl Turney?

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
Sheryl Turney is on.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer
Thank you. John Kansky?

John Kansky – Indiana Health Information Exchange - Member
Here.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer
Denni McColm? Not yet? Okay. Cynthia Fisher?

Cynthia Fisher – WaterRev LLC - Member
Yes, I'm here. Thank you.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer
Great. Okay. I hope that Andy is going to be able to join us, but in the meantime, I'm gonna turn it over to Mark to get us started.

Mark Knee – Office of the National Coordinator – Staff Lead
Hey, great. Hey everyone. And Lauren, I actually just remembered I think Andy might not be able to join this call, but if you wanna reach out to him and speak, you're welcome to you. So, I guess...do we have...oh, yes. There's the agenda for today. And with this group I can share my screen momentarily, but I think we probably...and you all as members can guide the conversation as you like, but I was hoping to maybe try to work to get some more clarity on our definitions of health information networking exchanges, and electronic health information, and price information because I think where we left off on the last call there were some different opinions about the direction we should take. And I know Andy had kind of asked that everyone in the meantime go on to the Google Doc and try to put

pen to paper for some of the suggestions that the folks were throwing out there last time. So, I'm pulling up the Google Doc now and I guess, before we proceed, does that sound like a good place to focus today? Or does anyone have any other issues they'd like to shift to before we do that?

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
I think that's a good place to start. This is Sheryl.

Mark Knee – Office of the National Coordinator – Staff Lead
Great. Great. Thanks, Sheryl. Okay, Lauren or others, can you see my screen now? I need to zoom in, I know. But I just shared the screen.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer
Yup. We can see it. Just waiting for you to zoom in.

Mark Knee – Office of the National Coordinator – Staff Lead
Great. Okay. Well, does...I guess...do you guys wanna...have any thoughts since the last time? Maybe we'll start with health information...well, would you like to start with health information network or EHI? What's your preference?

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
I think we should start with EHI. And just so you know, I have some trouble getting in the Google Doc. I actually have to do it outside of my company computer because for some reason it's blocking it. So...and I was having some issues with my home computer this week because I had no Internet, but I apologize for that.

Mark Knee – Office of the National Coordinator – Staff Lead
Oh, yeah. No problem. And I've actually heard from the other work groups...I think they're having some other issues when you try to open it on your work computer. There's some security blocking, ironically, going on. So, Yeah. No problem. Sorry about that. And I definitely understand.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
Okay.

Mark Knee – Office of the National Coordinator – Staff Lead
Well, I have pulled up as Andy kind of talked about last time, he broke...I believe he and Michael worked on this and it broke it down by discussion, and then regulatory text recommendation, and preamble recommendation, but if I recall, especially the reg text recommendation may be different or there might be multiple directions we want to go. So, I don't know. Do you folks have thoughts after having some time to think about this?

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
I know that after we have a meeting and then we had a follow-up conversation regarding the definition, we all have a better understanding of where this definition came from. So, I think there's

less ambiguity about that. I know Cynthia, you had some points that you had made in a previous meeting, but where we are... I'm happy with the definition the way it currently stands.

Mark Knee – Office of the National Coordinator – Staff Lead
Cynthia, do you have any thoughts or...

Cynthia Fisher -– WaterRev LLC
Yes. I am in transit, so I apologize. I'm trying to pull up the app on my phone as I am in transit.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay.

Cynthia Fisher – WaterRev LLC - Member
I'll be able to speak better once I'm able to pull it all up. I apologize.

[Crosstalk]

Mark Knee – Office of the National Coordinator – Staff Lead
No problem. But yeah, I do want to note...I'm sorry. Go ahead.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
The last time where we got bogged down was where we were talking about should there be some additional wording that talks about information being electronic as well as other. And where that got us into a little bit of trouble is that information could be a tumor sample or a blood sample. Not just data. And so, that's where we got bogged down on that particular point. And so, by clarifying it we could be essentially making it more complicated because again, we're talking about information being electronic, but information...are we only talking about data? That's kind of where that got bogged down. That refers to Andy's notes underneath.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay. And so, this one you're talking about, Sheryl, is...or not Sheryl. Sorry...

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
Yeah. This is Sheryl.

Mark Knee – Office of the National Coordinator – Staff Lead
It is Sheryl. Okay. Great. Are you talking about the preamble? We have the preamble recommendation that talks about applying both to human readable and machine readable. So, I think that recommendation...it seemed like everyone was on board with that, but you're saying that the preamble clarification would be okay, but you're not thinking that a reg text amendment is necessary in that regard?

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
Right. Right. Exactly.

Mark Knee – Office of the National Coordinator – Staff Lead

Okay. Great. And while Cindy as pulling up the stuff on a computer, I did want to note that he did e-mail me. And I'm not sure if you all listened in on the Help Committee meeting yesterday, but he wanted to say that he thought there was interesting commentary about audit trails. He's been thinking about it and he thought there might be some kind of modification the group should consider to the EHI definition to add either audit trail, which might be too vague, or including something like, "Including records of who has access to that data" to the definition in some capacity. Back to the group for discussion as well. I'm not sure how you all think it would fit in or whether it's more implementation than actual definition, but I just wanted to throw it out there.

Cynthia Fisher – WaterRev LLC - Member

Well, the thing of it is in today's world under HIPAA a patient has the right to ask who that data has been shared with anyway. So, I don't know if this came up related to the data provenance discussion that we had. I wasn't in the meeting yesterday that you're talking about so I don't know what the frame of reference was that was around it, but certainly we do need data provenance, but again, I think the guidance we got from ONC was simpler, is better, and lets it evolve. Because essentially, an audit trail, which I consider to be metadata about the data, could become bigger than the data itself. And then, what kind of burden are we putting on the sharing of that? I mean, at the end of the day, what we need to really focus on is to have the ability for the data to be shared and to have a good record of where that data came from so that you will be able to provide that information upon request.

And again, I've been focusing on let's focus it at the organization or source ID rather than an individual because again, that then becomes...once you go back to a provider or facility, they should have records of all the people that have updated it. I don't know if I as a payer would need to know that. All I would need to know is that Hospital ABC is the source.

Mark Knee – Office of the National Coordinator – Staff Lead

Yeah. And just as far as cONCacts, I think there was a health committee hearing yesterday with some different experts testifying about their reaction to our rule and CMS rule and I think it came up in that cONCext. But that was just the background.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member

And I think the data provenance discussion we've had under the USCDI takes care of that. I don't know if it really needs to be in the preamble.

Cynthia Fisher – WaterRev LLC - Member

This is Cynthia. Just from the patient perspective, if you look... I mean the whole emphasis of CURES is to really get...I mean we all know... let's not kid ourselves, that there's big data all behind us and outside of HIPAA connected to our financial system and connected to payment is a substantial amount of health information and there really is no privacy. But if we look at it within a provider system and HIPAA and the definition of health information, the patient isn't getting access. And so, the whole goal of this entire effort is to put it in the hands of the patient. And I think as we look at this definition, we

just want to make sure that broad enough tools can be delivered to the patient, so the patient has access to their record longitudinally and readily. So, much like going to a restaurant you see what's on the menu. The patient should be able to see pricing.

Now pricing is going to be broader. It's going to be broader and outside of the individual record, but as the patient gets care and the choices of medicines and the choices of therapeutic modalities our price differential around the surrounding geography of the patient, the patient, and the position can work together in making that decision when we electronically disclose that for the patient. And if we go back to the health information definition of HIPAA, it includes aspects of future mental health and clinical health as well as past present and future payment. So, you can look at when I'm a patient, I'd like to know the price just like any other industry. I'd like to know my choices. I get to choose my provider based on access and availability and then I also want my health record of my own personal clinical and professional care.

Then, the other part of it is as part of my health record would be also my payment record which is part of health information. So, I should be able to have all at one time the itemized list of what was price quoted to me and what my payment is so that I have negotiating leverage when I've been charged for something erroneously or egregiously. And just like in a restaurant or in the grocery store we can compare the price to the actual bill. Because we do know of patients being charged and going to debt collection with charge back to prices even though they have insurance coverage and they are covered in other ways.

So, empowerment is just beyond the individually identifiable traceable to the clinical information. It's actually that we need to look at changing the game for the really consumer-driven care as we're in this moment of time of great transition of empowering patients with actually being able to cONCrol their health and their wealth. So, I think as we look at the definition, we want to look at both and think of how we use Uber and think of how we use our phone apps for our banking. This can all be done and applied, and we want to make sure that we're not entangling ourselves and entangling the organization to state status quo because the status quo is broken.

John Kansky – Indiana Health Information Exchange - Member
Mark, this is John. I've had my hand up for a while.

Mark Knee – Office of the National Coordinator – Staff Lead
Oh, yeah. Sorry John, I didn't see the hand up. I feel like I usually...people can just chime in whenever. But yeah, what's on your mind?

John Kansky – Indiana Health Information Exchange - Member
Because I was failing to chime in, I decided to try raising my hand. It's all right. So, getting back to Sheryl's point about... I'm sorry. The Andy question about audit trails and the point that Sheryl raised about the fact that consumers already have Federal rights. Was the cONCext...or do you know if the cONCext of the Help Committee was that people are blocking access to audit trails? Because I've never heard that one before. And then I'm inclined to not...consistent with my earlier comments and the ones I've made in the Google Docs, I'm inclined not to make the definition any longer with more

prepositional phrases, harder to interpret and enforce. I think cleanliness and clarity should rule. So, if there is a compelling reason to start talking about audit trails, then I wouldn't be in favor of adding anything.

Mark Knee – Office of the National Coordinator – Staff Lead

I listened in on the committee meeting, but I can't say I was listening. I was doing other things during it. So, I can't really speak necessarily...I think what they were talking about was not that audit trails are being blocked, but more generally speaking that data provenance is important and it's really essential that patients and others understand where the information has been and who has touched it, and that's an essential aspect of all of this. But I don't believe there was a specific issue of blocking audit trails. No. And my take is that when Andy emailed me it was just a brief email. I think that it's a really important issue. I don't know that it would necessarily fit in the definition of EHI in my opinion. If you all have other recommendations that's fine. But I think as Sheryl said, it might be addressed in other capacities in the role or just as implementation goes...how we're trying to do this. But I don't know if in the scope of an EHI definition for info blocking whether it fits. That's just me.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member

Yeah. I would agree with you on that, but I do think it might have room for addressing in the preamble because it is helpful for the patient to know where the data is shared and in other avenues of their digital life with Google and Facebook, you can see the trail through a click and be able to pull up the history. So, I think it's totally traceable and do-able without extra effort and perhaps we cover it in a preamble.

Mark Knee – Office of the National Coordinator – Staff Lead

Okay. I guess if folks have...if you're able to...not necessarily right now. I know this is a new issue. Not to put you on the spot, but if you have thoughts on those recommendations forthe preamble, you're definitely welcome. I guess maybe bringing it –

Sheryl Turney – Anthem Blue Cross Blue Shield - Member

I'm sorry, but I have to weigh in here because to say that that would be done without burden is not accurate. I mean the way that Google or someone else has created their ability to show you the bread crumbs, is not the way any of the payers have built their systems because they weren't built initially for user facing. So, it's not that it can't be done, but it isn't going to be automatic and it would be time required in order to produce that type of result. I don't know any payer, and I've worked with multiple, that could do that today.

Mark Knee – Office of the National Coordinator – Staff Lead

Yeah. I guess also another consideration...I think that's a really good point, Sheryl, is just also the presentation that LO1C did...we kind of based our definition of EHI on this construct of previous laws and trying to look at what Congress was trying to do and what EHI would mean and it just seems to me that audit trails...again, maybe there's a clarification in preamble that could be made. It sounds like we're all on the same page, it's just the definition shouldn't be changed for audit trails. But we just have to be careful I think is what you're saying, Sheryl, how far we go because we have to look at what the scope of what we're trying to do here would be.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
Right. And we are within the USCDI Task Force indicating that data provenance is going to be a requirement. So, at the end of the day, that ability to do that...I don't know if it will necessarily be a bread crumb, but to identify where the data came from and where it went will be a requirement in the future. But to what level of granularity, I think all of that needs to be discussed. But it's already a right in HIPAA and I don't know if it merits us having to call it out again is my point.

Cynthia Fisher – WaterRev LLC - Member
Well, I think the issue is information blocking. It's not being provided to the patients today and they don't know how to even get access to where their data is being shared. And so, they have a right to know where their providers and payers are maybe sharing the data.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay, well, just to keep us moving, I know John...do you have any other thoughts? I think you're pretty clear in what you were thinking about that. No. So, maybe Cynthia, you might...think about if there are any preamble clarifications he wants to propose for the group and feel free to add them to the Google Doc and we can talk about them next time. Again, I don't want to put you on the spot since this is a new issue.

I guess...so going back to the definition of electronic health information, the screen right now...so, I think where we were last time is, Andy and Michael had come up with some pretty minor proposed updates. I think they're all underlined and highlighted in the one on the screen. If you can't see the screen, it was just including "as defined in HIPAA" to talk about EHI just as a clarification and I think they changed 'can' to 'could' which, in my perspective, it really doesn't change the meaning at all of the definition. And then also I think there's this clause that "or derived from identifiable patient data." I don't know. Do you guys have thoughts? I know that before we...ONC didn't the presentation there were different views about the breadth of this definition. And I know, John, you had ideas about maybe ways to make it less confusing. Do you guys have thoughts on that?

John Kansky – Indiana Health Information Exchange - Member
Yeah. This is John. In general, I think I may be in the minority in trying to simplify the definition. I think the perception of the other side of the argument was that we didn't want to risk in any way narrowing the definition. I'm much more focused on having it be something that those organizations that have to comply with can easily understand and don't have to hire attorneys to just understand the words, which we have now lost on the screen.

Mark Knee – Office of the National Coordinator – Staff Lead
Oh, yeah. Let me...sorry. I'll put that up there.

John Kansky – Indiana Health Information Exchange - Member
I'd rather look at the lake, but...

Mark Knee – Office of the National Coordinator – Staff Lead

Yeah. I don't know if I told you the background. That's actually right where I got married a couple of years ago. It's in North Carolina. But it makes me feel happy looking at it.

John Kansky – Indiana Health Information Exchange - Member
Good. It's good that you think of your marriage and you're still happy. That's nice.

Mark Knee – Office of the National Coordinator – Staff Lead
Yeah. I definitely do. Anyway, not to interrupt, so go on with what you were saying.

John Kansky – Indiana Health Information Exchange - Member
So, the...and I'm trying to remember the rationale behind the highlighted "or as derived from identifiable patient data" because I feel like if it's no longer identified, then I'm not sure those trying to comply with the regulation would even know to include it in a request such that they wouldn't be accused of or guilty of information blocking. So, again, when you include things for...I'm a bit of a 90/10 or maybe 95/5 suggesting that kind of approach in this regulation that if we eliminate it 95% of all information blocking that would be awesome. And I think trying to sweep out the corners with the last half a percent is going to dramatically increase the confusion, cost, and burden of complying with the regulations. So, that's basically the whole basis of my argument.

Mark Knee – Office of the National Coordinator – Staff Lead
Yeah. And I think

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
So –

Mark Knee – Office of the National Coordinator – Staff Lead
Oh, sorry Sheryl. I was just gonna say I think that because...like that addition had to do with the conversation we were having about de-identifiable information and how we are not including the de-identifiable information. I think that was supposed to be a point of clarification and a definition, but it might make it more confusing. Anyway, Sheryl. I'm sorry to interrupt.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
No. I was just saying by including this...and maybe originally this...I'm not sure who brought this into it, but if a patient said, "All right. Where is our data being used? Where is my data being used?" by including this comment, then that would mean any research that is being done or in some cases, we have vendors that gather data on behalf of employer groups. And as a part of doing business with that vendor, the vendor requires that they are able to de-identify the data and use it in a benchmarking database. So, the individual then...we would provide data to a vendor on behalf of an employer group and that data then goes into multiple scenarios. Well, then that vendor then sells that de-identified data to hundreds of customers. This requirement would then make that...when we identified that vender as the data that recipient would then have to provide the hundreds of customers that actually get that de-identified data in that benchmarking database. And is that really going to be meaningful to the patient? And is that what was intended? And I think that's the same use case I brought up when

this was first brought up. I'm not saying one over the other, but that's what would have to happen if this wording stays in there.

Mark Knee – Office of the National Coordinator – Staff Lead
So, would you prefer it not be in there?

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
It depends on who the burden is on. If the burden is on the receiving organization and not the covered entity, then I don't have a dog in that fight. If the burden is on the covered entity, which would be me as a payer, then I would rather that data not be in there because I don't know all the hundreds of people that that vendor who is not even our vendor, is gonna give that the data to.

John Kansky – Indiana Health Information Exchange - Member
Mark, this is John. I'm trying to respond to your question and I'm leaning towards agreeing. Yes, I think I'm in favor of leaving it out. Can anyone articulate the argument...what information blocking scenarios are we preventing by speaking about formerly identified data?

[Crosstalk]

John Kansky – Indiana Health Information Exchange - Member
Go ahead.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
The only information blocking I can see in this case though is that the patient never knows their data is being used by those hundreds of other players. And there's no way that I would know that it's being used. Because again, in this use case that I presented its a vendor of our employer group and it was an ASO group so they own the responsibility of maintaining that data as a covered entity and they have allowed the vendor to use it in a deidentified database that then gets sold to thousands of customers. So, the patient never knows that basically, their claim data is going to all those places.

John Kansky – Indiana Health Information Exchange - Member
Well, and there's a difference between...I mean, we absolutely want patients to have the right to know what the patient should have a right to know. But this is an information blocking regulation so this is...my understanding the Intimus blocking regulation is to prevent the circumstances where organizations have refused to share information intentionally or through neglect or misunderstanding, but information hasn't been shared in a way that would have been beneficial to the healthcare system or the patient. And so, I don't think we're trying to create new rights to know stuff. We're trying to prevent the circumstances where information has been blocked, right?

Cynthia Fisher – WaterRev LLC - Member
Right. This is Cynthia. And so, the patient.... many...most patients today don't even know that their information is being resold. And this is the information blocking to the patient. And so, having the comprehension and the choice to say yea or nay...isn't that real privacy protection in some ways? And then aren't we also wanting to empower the patient to actually have transparency into what's really

going on with their health data. And you know, one can argue that it gets deidentified and can easily be re-identified. So, the real issue here is to empower the patient with being able to drive better health and wealth management.

John Kansky – Indiana Health Information Exchange - Member
But we've occasionally called on examples from retail and financial Industries and I assert that none of us have a clear understanding nor could gain one in terms of how our deidentified data is being used in retail or finance.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay. So, I guess...does the group want to leave this "order that is derived from identifiable patient data" in there? Or should I maybe take it...is anyone in favor of having it in there? I think it was something that Andy was just kind of spit-balling on potentially.

John Kansky – Indiana Health Information Exchange - Member
I'm in favor of taking it out on the basis that I don't know what bad thing it prevents, and it seems to have great potential for unintended consequences.

Mark Knee – Office of the National Coordinator – Staff Lead
Is anyone opposed to taking it out?

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
I'm not opposed because I don't think it provides any clarity. I think it makes it more confusing.

Michael Adcock – Individual – Co-Chair
And this is Michael. I'm sorry...sorry for being late. I'll talk when I can. I can't talk much, but I agree. I think it...I don't know that it prevents anything, and I don't know that it does anything to make it more confusing. So, I'm all in favor of taking it out.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay. Great. Thanks, Michael.

Cynthia Fisher – WaterRev LLC - Member
I find it interesting because last week when we were on the call I was looking at a broad definition but I thought that HHS...ONC had put that in because they wanted to...now I can't... the phrase is out and I can't remember what it said. It was just...can you just click it someplace else or put it underneath it?

Mark Knee – Office of the National Coordinator – Staff Lead
Yeah.

Cynthia Fisher – WaterRev LLC - Member
It is derived from identifiable patient data. So, is the concern here that you don't want the patients to know where their identifiable patient data is being utilized or re-brokered?

John Kansky – Indiana Health Information Exchange - Member
No. The concern is that we've rewritten...we're trying to write a regulation that allows patients to have access to their data and to allow the healthcare system to freely share data that's in the interest of health and healthcare. Once the data has been...I mean, again, calling on my examples of retail, internet retail, bricks and mortar retail, or the finance industry, once data has been identified, it gets reused in lots and lots of ways. I would say most of which are not nefarious, but it's deidentified data. And it's not the intent of this regulation to require the sharing of the data that's deidentified. And the consequences of trying to broaden the definition to include what's essentially deidentified data that's been derived from data that used to be identified data. I think the interpretation, implementation, and enforceability of that is utterly impossible.

Cynthia Fisher – WaterRev LLC - Member
Okay. So, I understand your point about your concern is that it's de-identified and then it's reidentified by other industries in many, many ways. For market research or other avenues. And so, basically, you're saying that if it's derived from deidentified and re-identified and it's now in another industry, then you don't want that to be trailed ONCo the patient. So, I understand what you're saying, but I also understand that I do believe it's important that the patient is made fully aware to whom that is brokered from their health provider and payers to whom that information is going to be shared, deidentified, and possibly reidentified.

John Kansky – Indiana Health Information Exchange - Member
Well, that's a HIPAA right to know where your data has been disclosed from covered entities. That right already exists under Federal law. It only applies to –

Cynthia Fisher – WaterRev LLC - Member
Patients don't really get that today. So, we want to make sure that's given to patients. And then, I can agree with this because I understand it if big data is all behind –

John Kansky – Indiana Health Information Exchange - Member
Hang on, Cynthia. If a covered entity is not granting a patient a federally guaranteed right, there in violation of HIPAA and can be penalized and there is a process for that.

Cynthia Fisher – WaterRev LLC - Member
That's a subject for another matter, but routinely it's not identified to the patients.

John Kansky – Indiana Health Information Exchange - Member
Well, what you just told me is that people violate Federal law.

Cynthia Fisher – WaterRev LLC - Member
Yeah. It is ambiguously provided to the patients, but specifically, it would be a good thing for patients to actually know with transparency. Secondly, I do understand how you all would like to have it out and why and I can agree with that. However, I do also believe that the patient should be made fully aware and be very transparent as to how their data is being used.

Michael Adcock – Individual – Co-Chair
This is Michael. I think we're all on the same page. We agree that whether it's a law that currently exists, or whether it's something that we're writing a regulation for we agree that enforcement should be happening. The rights should be honored. And if it's not, then that again is an important issue. I don't know that that one little statement did anything other than confuse the issue to achieve what we're trying to accomplish which is the sharing of that and what we're trying to do and get this definition together. So, I don't know that anybody is in disagreement on this. What I heard is that we're all in agreement to take it out and the definition was fine the way it was. Is that correct?

Cynthia Fisher – WaterRev LLC - Member
And so, could we...yeah. Could you...yeah, you're gonna put it there. Great. Thanks a lot. It helps to have that language.

Mark Knee – Office of the National Coordinator – Staff Lead
Sure. No problem. And definitely, I think like Michael said, we're trying to move forward, but Cynthia and others, look it over and if you have any further thoughts on that clause... I do think that having it in there...basically, in my opinion, what it was doing was making a point that we already are making about deidentified information not being included so I do think it was a bit confusing the way it was written. So, just to keep on the definition of electronic health information, it looks like the only other changes, and Mike will correct me if I'm wrong, that Michael and Andy had included are after EHI including a parenthetical about 'as defined in HIPAA', and then changing 'can' to 'could' be used. So, what are people's thoughts on those additions and whether...is there anything else that should be changed?

John Kansky – Indiana Health Information Exchange - Member
Mark, this is John. I'm on record as lobbying for deleting that entire 'or' phrase, but I understand I'm in the minority. So, I have nothing further to –

Mark Knee – Office of the National Coordinator – Staff Lead
Yeah. Let me note just so I'm clear. So, you want all of –

John Kansky – Indiana Health Information Exchange - Member
Through the word 'identify'...oh, no, no, no. Through the word 'individual'. So, if they read, "Any other information that identifies the individual and is transmitted or maintained in Electronic Media" I just think it's much easier and clearer to understand. That's just Kansky's opinion and I'm just one guy here.

Mark Knee – Office of the National Coordinator – Staff Lead
How about I'll make a note, John, because like I said throughout this process, if you really feel strongly about that, I think we can have...and Michael, correct me if I'm wrong, we can have multiple opinions and you can kind of make known that that is your feeling. So, I'll just make a note on that. Oh, shoot. Not that. Sorry, that's not it.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member

Oh, I got reconnected. I don't know what happened to my phone. That was the weirdest thing. Hello?

[Crosstalk]

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
Okay. So, I'm back on. I didn't even dial a number so all of a sudden, I got a busy signal. I was just gonna say with what John said, I would prefer we leave in the 'or' statement because this is referenced in HIPAA and I don't think it's anything that people are commonly aware of, but even with Safe Harbor methods for de-identification, if you have someone with a rare medical condition there's always the opportunity that you can easily identify the person even though the 16 elements or 18 elements have been eliminated. Especially in rural areas or with a very specific health concern. So, I do think we need to keep that 'or' in there. That's the first 'or' when you were with "or with respect to which there's a reasonable basis to believe the information could be used to identify the individual."

John Kansky – Indiana Health Information Exchange - Member
Yup. Got it.

Cynthia Fisher – WaterRev LLC - Member
So, you're saying to keep the first 'or'?

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
Yes, I am.

Cynthia Fisher – WaterRev LLC - Member
Okay, I'm going back to your previous point is 'or is there identifiable patient data'. If there is information derived by identifiable patient's data for that patient and it's not shared with the patient, that could negatively impact that patient's health. So, I just want to flag that that if the patient is information blocked from synthesis of their identifiable patient data that could affect their care, then we are information blocking on something that could provide improved quality and improved diagnosis. So, I just want to flag that too from a patient standpoint that as you look at the removed proposed addition that we just did, we may be negatively impacting the future of patient care.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
How could that happen, Cynthia? I'm not following your point because if it's not identifiable and it's a dataset that derives from the identifiable patient data, how would it be used that it could negatively impact the patient's healthcare?

Cynthia Fisher – WaterRev LLC - Member
If there's a synthesis of data from identifiable data that say...even charge trends, and it's derived from identifiable patient's data and its electronic and it provides information of that patient versus a norm or an average or median...it could be a data analytical factor that is derived that would be helpful as a part of that patient record. So, it ultimately could be the result of an analysis of that identifiable patient information compared to a broader group and charted and provided into the hands of the patient. In the EHR or in an app for instance that comes out of that provider or EHR vendor or

developer. I just put that...I would like to add that in as a consideration of you might be wiping out a whole new fraud industry for better and improved care management. That might be for diabetics, that might be for a broad range of diseased patients, compared to a norm or a trend.

So, I think we just need to not box ourselves in that we're able to withhold information for patients that would not improve their care and care decisions. So, I just would like to have that in there so if you could add my comments, please underneath the 'remove revision'. And then secondly, I just want to ask the group how you all see that getting access to pricing versus as part of the electronic health information that gives us the right to pricing as well as the rights to payment history. How do you foresee this definition ensuring that the patient in the future will have readily available digital access of that information along with their clinical?

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
Well, Cynthia, two things. First, I think the second question you asked we have to leave for another day because right now we're charged with a specific responsibility here to come up with these definitions. And if we keep going down these rabbit holes were never gonna get this done. But the first one is, in the example you just gave, is exactly the same use case that I just described 10 minutes ago regarding third parties that do data analytics on identifiable patient data.

I understand what your intent is, but again, and the example that I provided to you, we have hundreds of employer groups who own their data or cONCrol that data. They allow a vendor to use it and that vendor gives it to...sells it to hundreds of people for normative databases which are doing exactly what you just said. And we are unaware of who any of those customers are. So, how can we potentially ever provide that data to the patient? And what's the benefit the patient is going to get out of it? Are you basically saying now that you're wanting to block the ability to use that data that way? Because if that's the case then I think we need to do more than just refine this definition.

Cynthia Fisher – WaterRev LLC - Member
I'm not saying to block any data. That's a misstatement. I'm just flagging from the page in perspective getting access to trends and equip chart analysis of them against a norm that might be part of their care service. But I'm just throwing that out there and throw it in as a flag and wanted you to provide that in your case as we consider that. And I do understand your concern, Sheryl, for the broad folks that you sell that data to and –

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
So, any data, Cynthia? That's what I was trying to say. Our employer groups as part of their cONCracts with vendors give the vendor the right to sell the data. We don't sell any data at all. Other payers do. Blues do not.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay. I think that was really a good conversation. Cynthia, were there any notes you wanted me to make? You had mentioned...I wanted to make sure I capture everything. So –

Cynthia Fisher – WaterRev LLC - Member

Yeah. Just get the flag on the use. Under that it's just gonna say there's a use case where the patient having access to electronic access should not be blocked from having access to analytics that may be part of the software tools used by the provider and use by the application of where they are receiving their care that compares their identifiable data trends, for instance, against a broader population base and helps them in their care management. And so, we want to make sure that we're not excluding relevant portions of electronic health record that is patient data compared to a broader population norm for better healthcare diagnoses and management. So, I think that would be what...just on the other side of the flip of the coin. I understand Sheryl's concerns and that this is just the other flip of the coin.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay. I tried to document that, but feel free to go in and update it. I'm just gonna say that you're considering recommendations for the preamble. Is that fair?

Cynthia Fisher – WaterRev LLC - Member
I just think this is just here as a note.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay. Great.

Cynthia Fisher – WaterRev LLC - Member
And then I think I disagree with Sheryl because I don't think it's radical for a patient to try and make care decisions by part of their electronic health record in both the price and the payment. And just like when we go get our car repaired, you get the price and you get the payment and you get the itemized listing. Or you get it in a grocery store or in restaurants. So, that's part of their record.

And so, as we look at electronic health information as it applies to the broader definition in HIPAA, how are we as a committee here looking at this definition that we can provide those tools in the future to patients and physicians as they look at the appropriate modality. And the example I give you is a real crisis concern for many pre-diabetics and diabetics on the substantial change in a new medicine that many had no idea it was going to cost them $1,000 to $1,500 dollars more per mONCh until after the fact. And then they have to go back to their doctors and ask for their old diabetes regimen. So, these types of things can be prevented that put patient's' health at risk and pocketbooks in duress. So, how do we have this definition to make sure that if it's not patient identifiable, the patient can get that broad access to price choices?

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
But this is the thing that I think...I don't think we're actually disagreeing, Cynthia. I think you're actually asking for something completely different. And what you're looking for are benchmarks, risk analysis, socially determinants of health, and other factors that are used in order to determine healthcare decisions. That's not ever derived from identifiable patient data. The problem of trying to present on that is that most of the covered entities are not the ones selling that data so we wouldn't know who it's been sold to.

That's the problem I was trying to present. What you're talking about is that you're looking for more of the risk analysis, the scores, the benchmark, the underwriting that goes into how those pricing decisions are made. That's a completely different thing and a completely different set of data and I don't know if the definition is where that belongs. To me, some of those things are things that need to be brought up in the USCDI if you're looking for that's to be data that should be shared with a patient in terms of what is included because the definition and sell can't cover that really mountain of activity that's going on today. And I think that's where the wording is getting confused.

Cynthia Fisher – WaterRev LLC - Member
Sheryl, this is looking at price and payment so that when they get the bill, if it doesn't match the price in the future, they have the tools in their hand to negotiate and resolve and fix just like we do in any other industry. And not as a flag of keeping that as a flag because the HIPAA definition of health information includes payment information and price along with the electronic –

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
And that's all...we didn't take that out. You'll see it's still on the paper. I know you're not in a place where you can see it, but it's still there.

Cynthia Fisher – WaterRev LLC - Member
No, I see it. I see it. I just want to make sure that it addresses that. If you all feel that it addresses that as long as it's identified to the individuals, that's the conflict. To say if it's identified to the individual. There might be pricing information that's not identified to the individual. But if you all think it can be accomplished where you can see pricing information that's not identified to the individual, that might be cheaper. But you might be able to see pricing that's a tenth the price of the identifiable to the individual, but the other plan might be 10 times more. Do you see what I'm saying? So, it might make sense for you to get the same thing for a tenth of the price versus your negotiated rate which might be 10 times higher that's identified to you as the individual.

Mark Knee – Office of the National Coordinator – Staff Lead
So, just as a bit of a segue, I think that's really helpful. It seems like we're trying to maybe shift into the price information conversation, which is very relevant and, on the agenda, but I just want to make sure that we've dotted all the 'i's on this issue here before we move on to the price information. So, and anyone chime in, but what I'm understanding is that everyone seems to be in favor of this addition to clarify the DPHI as defined in HIPAA. Does anyone have any thoughts on this change that I believe Andy and Michael made from 'can' to 'could'? Again, I don't think, in my opinion, legally it makes any difference in the definition. So, I might lean toward not changing it, but if you all think it's a good change that would be fine. I'm happy to leave it. Do people have thoughts on that?

John Kansky – Indiana Health Information Exchange - Member
I'm where you're at in that I'm not sure it changes anything. So, leave well enough alone if you're not accomplishing anything with the change.

Cynthia Fisher – WaterRev LLC - Member
Are you calling out anything specific, Mark?

Mark Knee – Office of the National Coordinator – Staff Lead
I think Andy and Michael...right here it says, "There's a reasonable basis to believe the information" and it used to say in the definition, "can be used" and they changed it to "could be used". And what I'm saying is in the regulatory text it's really important...these words, but I don't believe 'can' and 'could' are really interpreted any differently in this cONCext. At least I wouldn't think so.

Cynthia Fisher – WaterRev LLC - Member
So, I'm not a lawyer but I think it's probably worth your ask of your lawyers to see if it does because the only thing I would say is does it allow for ambiguity? And is 'could' subjective when 'can' is determinative? I don't know if determinative is a word, guys. I might have just made up a new word.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
It's present and 'could' is past. So, I think...I don't know if that was his intent, but typically 'can' is present and 'could' is past.

Mark Knee – Office of the National Coordinator – Staff Lead
Michael? I know you can't talk too much with your voice. Can you give any cONCext for what you and Andy were thinking with this one?

Michael Adcock – Individual – Co-Chair
Honestly, that was all Andy. That wasn't me. And I'm thrown him under the bus. He's not here.

Mark Knee – Office of the National Coordinator – Staff Lead
And I had talked with him and I think he wouldn't really mind changing it back. So, how about I'll make a note of it. I'm gonna change it back. And again, Cynthia, I'll just go back to you. If you think that 'can' doesn't get at the right meaning, feel free to propose it differently. But the interpretation of 'can' and 'could', like Sheryl mentioned, I think it's just the tense really. One of them is not prescriptive and the other nonprescriptive. They're both kind of... I think have the same effect. So, I'll make a note as far as another removed proposed addition right here.

Cynthia Fisher – WaterRev LLC - Member
I wasn't **[inaudible] [00:57:16]**

Mark Knee – Office of the National Coordinator – Staff Lead
Neither was I by any means. So, I definitely understand. Okay. So, it sounds like, and again, with the caveat that I know, John, that your position is 'or with respect to' should be pulled out and I guess maybe you'll consider whether you want to write out a little rationale and include it in our final recommendations as to why your position is it should be out even if the group leaves it in. But beyond that, it seems like we're all in agreement on this definition. Is that fair to say?

John Kansky – Indiana Health Information Exchange - Member
Fair.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
Agreed.

Michael Adcock – Individual – Co-Chair
Yes.

Mark Knee – Office of the National Coordinator – Staff Lead
Great. Well, and Cynthia, is that accurate? Does that sound all right to you?

Cynthia Fisher – WaterRev LLC - Member
Yeah...I don't know. You'd have to ask a legal if it even makes a difference. I don't know, so I have to say I don't know.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay, but beyond that issue...it might just be a British thing, who knows.

Cynthia Fisher – WaterRev LLC - Member
I don't know.

Michael Adcock – Individual – Co-Chair
Maybe it's a Texas thing.

Mark Knee – Office of the National Coordinator – Staff Lead
Yeah. It's a combination there.

Cynthia Fisher – WaterRev LLC - Member
I think you spent a lot more time in England.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay. So, but Cynthia, speaking more broadly beyond the 'can' or 'could' issue, are you okay moving forward with this definition as we have it with the only change being that we say, "as defined in HIPAA for EHI"?

Cynthia Fisher – WaterRev LLC - Member
Yes.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay. Perfect. Do you all want to shift to the price information discussion then? Does that make sense now?

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
I think it does.

John Kansky – Indiana Health Information Exchange - Member

Yes.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
Also, unfortunately, I have to leave at 1:30 p.m. for another meeting I couldn't get out of.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay. Well, thanks for the heads up. We'll try to get much done between now and 1:30 p.m. then. Okay. So, just again, as a little bit of background, in the rule we say, we have both a request for comment and a request for information, I believe, with respect to price information. We say, "To be clear that definition provides for an inexpensive set of EHI which could include information of an individual's health insurance eligibility and benefit, billing for healthcare services, and payment information for services to be provided or already provided which may include price information." So, for the conversation you are just having, we do say that the definition of EHI currently includes price information.

And then we have the request for comment...sorry. The request for information that is both on a departmental level at HHS and also ONC level here. And I can pull up that language, but that's just to set the stage. Let's see what we've said already. Let me scroll down here. We have quite a bit. So, does anyone want to jump in on where you're falling with price information or any proposed recommendations that should be made? Or price transparency? If not, I can read over...I know, John, you've said that you like hearing stuff. I can read what we have currently in the discussion section if that would be helpful.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
I just need a minute to process it.

Mark Knee – Office of the National Coordinator – Staff Lead
Yeah. Take your time.

John Kansky – Indiana Health Information Exchange - Member
Mark, you've got a 'to' there that should be a 'too'.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay. Where is that? Sorry.

John Kansky – Indiana Health Information Exchange - Member
Third line...to tightly.

Mark Knee – Office of the National Coordinator – Staff Lead
Ah ha. Not to blame Andy, but I'll blame Andy.

John Kansky – Indiana Health Information Exchange - Member
He's from another country.

Michael Adcock – Individual – Co-Chair
I think that's the proper **[inaudible] [01:02:15]** Blame Andy whenever we can.

Mark Knee – Office of the National Coordinator – Staff Lead
Yeah. If he's not on the call, it's fair game. But whenever you all are done reading this, it might be helpful...I'd be happy to pull ONCo the screen the page or two we have in the rule about price information just to read it over for the cONCext of this conversation. If that would be helpful, I'm happy to do that.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member
I think that would be helpful.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay. Should I do that now?

Cynthia Fisher – WaterRev LLC - Member
So, did you say you're gonna read it?

Mark Knee – Office of the National Coordinator – Staff Lead
I was gonna pull over the specific language we have in the rule. So, here is where it starts. And this is at the end of the discussion about electronic health information. So, I'll give you a minute to read that line...or those four lines. Okay. And then we have the section and I'll scroll down slowly, but it's a request for information –

Cynthia Fisher – WaterRev LLC - Member
I'm a slow reader. Sorry about that. I'll pull it up on my phone and read it.

Mark Knee – Office of the National Coordinator – Staff Lead
Take your time. All right. So, here's this...and I'll keep going down slowly. And as I'm scrolling, we're getting close now to the actual request for comment that we have in here.

John Kansky – Indiana Health Information Exchange - Member
Mark, this is John. Not to break the silence here, but the questions in the preamble...that's a good six hours of discussion, right?

Mark Knee – Office of the National Coordinator – Staff Lead
Yup.

John Kansky – Indiana Health Information Exchange - Member
And this is what ONC is asking for feedback on through...so what would be a constructive use of our time today? And let that question be in the parking lot for a second. I like the comments that...I think they are in the Google Doc that you showed earlier, that my understanding is that those comments assert the following: that pricing information is currently included in the definition of electronic health information that we've written, and that regulation is cONCemplated by ONC that will target

specifically price transparency. And therefore the information blocking rule, having pricing information defined within EHI in that it's related to the past, future, or present... whatever the words are...payment for healthcare being the pricing information is included in the definition of EHI, then information blocking assures that when a future price transparency rule is written, that information blocking regulations will prevent that information from being blocked. So, the two worked in tandem. That's how I interpreted those comments and I think that's appropriate.

Mark Knee – Office of the National Coordinator – Staff Lead
Yeah. I think that's right, and I think you're absolutely right that if this group wanted to get through all of the bulleted questions I just flagged, it would take a while. And I guess the amount of detail that you all want to get into...and it really depends on the group, but I think what you're saying is right. As I pointed out, currently as written pricing information is included in the definition of electronic health information and we do say as such in the preamble.

I think what we're looking for, and it seems that everyone is in agreement based on past conversations, that that should be the case. I think maybe what we're asking for is, not to regurgitate the language, but the parameters and implications of including price information within the scope of EHI for the purpose of information blocking on the ONC level. So, that's like for all these purposes, but also on the departmental level, if you all have thoughts on the operational, legal, cultural, environmental and other challenges in creating price transparency within healthcare. I know that's broad, but just thinking prospectively we wanna think through all the implications of what we might be doing whether it's in this rule or future rules.

Cynthia Fisher – WaterRev LLC - Member
Mark?

Mark Knee – Office of the National Coordinator – Staff Lead
Yes?

Cynthia Fisher – WaterRev LLC - Member
It's Mark, right? Yes. Thank you. And I'd like to commend ONC and CMS for their leadership in asking for the request for information on pricing because it's a bold move and it's a much-needed move. And we are at a moment in time where this information blocking rule and the administration can actually deliver the best care at the lowest possible price for both the consumer, the employer, our government, and our economy. So, thank you.

Secondly, I would like to note on the third sentence that I disagree with the third sentence in the first paragraph of the workgroup...thank you... where you just highlighted in blue. I believe that this information blocking and these information blocking tools that John just alluded to do support the definition of the electronic health information and the patient getting access to past, present, and future pricing. I am concerned about the words that, "signed information blocking regulations, through tying it to the regulations, may have unintended consequences of slowing down information blocking regulation." I disagree with that. I believe that if we don't treat past, present, and future

payment information in conjunction with the rest of the electronic health record, that we're actually gonna slow down drastically changing the lives of our American public for the better.

John Kansky – Indiana Health Information Exchange - Member
I'm sorry, I'm confused. I thought the pricing –

Cynthia Fisher – WaterRev LLC - Member
So, I would like to flip that on its head that we have this moment of time where it's really easy to hold back that cloak because those cONCract negotiated terms and those prices have been baked into the system so that EHR's were originally...the whole system was built originally on billing and pricing and cONCracted terms. So, then the records came after that...the clinical records and notes in the history of digitization. So, now we're in a place where we can open the kimono and actually deliver to the patient really consumer-driven healthcare. And so, I think that we...I would like to see our workgroup encouraged that the information blocking regulations are utilized to provide pricing and payment information to the patient. And we do it timely along with the other rulemaking on this rule.

John Kansky – Indiana Health Information Exchange - Member
I'm confused in that the second...the very next paragraph says that it's clear that pricing information is part of the definition.

Cynthia Fisher – WaterRev LLC - Member
Yes, but I don't agree with the sentence above where tying information blocking reg to pricing...I think it's part of it and we then just agreeing that we're using the information blocking that if providers and payers do not provide the prices, that they are information blocking for the patient. We have patients that have come to us that have hundreds of thousands of dollars of unknown surprise billings. That devastates their lives. They get divorced over it and they go bankrupt over it. And thanks to this administration, we are at this moment of time where...that this rulemaking can hold players accountable to deliver that pricing.

John Kansky – Indiana Health Information Exchange - Member
I violently agree. The question is, what is the efficient, effective regulatory path to solve that problem?

Mark Knee – Office of the National Coordinator – Staff Lead
And John, I can't remember what you said at the last meeting when we talked about this, but I think he said essentially...you framed it really well. So, if you could remember what you said, I would encourage you to do so. But I think what you were getting at was that...like it says here, "The price information is included currently in the definition of EHI." So, as written, our rule would not preclude in any way including price information when we're looking at information blocking. However, to what extent should this regulation that we're really getting into a price transparency issue I think is what we're getting at.

John Kansky – Indiana Health Information Exchange - Member
I think this regulation helps dramatically in moving towards price transparency because it has a very broad definition of actors that goes well beyond HIPAA covered entities. It has a broad information of

electronic health information which as it states right there, is included in the definition of health information and it's a Federal law that says you can't not share it. So, if that doesn't help with price transparency...well, it does. And so, I can't repeat exactly what I said last time because I've slept since then, but I think it's a matter of just trying to use...I mean, the info blocking regulation accomplishes a lot in terms of making that information...it literally will be against Federal law not to share it. So, good.

I think the question is, do you try and...I think the metaphor I may have used last time is use a hammer to drive nails and a screwdriver to put in screws is I cONCend that to accomplish price transparency further, after having defined what information blocking is including that the definition of the EHI includes that information, to go further in trying to get the industry to be price transparent will require a more precise take at that regulation. We just don't have the...we've got a hammer here and not a screwdriver and the screwdriver will be needed to go with the hammer.

Cynthia Fisher – WaterRev LLC - Member

I can support future regulation and see the intent... I mean, it is an RFI. And we have the opportunity to utilize this regulation for the enforcement of compliance. So, I think we're at a moment in time where we can do the work and if you look in the tech industry across the spectrum having transparency gives a simple aggregated ability to 'uberize' the patient's tools to determine where to go and get their care that's affordable to their wallet. So, I think the sooner we...my concern is the third sentence and I just think if we eliminate that, we're fine and we can do our job and answer the questions that ONC has asked of us on the RFI. I just would be concerned that that's not our job to slow it down. I think it's our job to help HHS deliver real-time transparency to the marketplace as soon as they can.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member

This is Sheryl. I don't think, Cynthia, that the intent of that sentence is to slow anything down. I think the concern that was being expressed was that if you tie the two regulations together too tightly, one could hold up the other. That's all that Andy was trying to communicate. And it seems that that's being taken a different way depending on how the receivers of the information process it. Just look at how long Teska has taken. They're...I do think that's a real concern and I do think it's something that can be called out. It doesn't mean one is any less important than the other. It just means that whatever we do, we should try to keep them, I think, as independently as possible so that one does not hold up the other. We wouldn't want to hold up information blocking for the price transparency rule to come out. And likewise, we wouldn't want information blocking to hold up the price transparency rule.

Mark Knee – Office of the National Coordinator – Staff Lead

And while people are thinking that over, I just want to make a point that there is a request in a request for information in the role of price information. So, I just wanted to be clear on that because I know Cynthia said Request for Information.

Cynthia Fisher – WaterRev LLC - Member

I'm sorry. Could you say that again, Mark?

Mark Knee – Office of the National Coordinator – Staff Lead
There was a request for comment, so we have the request for comment in a request for information regarding price transparency. So, basically, all I'm saying is that your request for comment on I think the definition of EHI and the inclusion of price information, but also the request for information more broadly about future role making. I just wanted to make that point.

Cynthia Fisher – WaterRev LLC - Member
Thank you for your clarifications and I apologize for misspeaking.

Mark Knee – Office of the National Coordinator – Staff Lead
Oh, no! No. It 's a very...yeah. That's one of those complexities of rulemaking. So, I just wanted to be clear. But anyway, back to Sheryl's point. Does anyone have any thoughts on that?

Cynthia Fisher – WaterRev LLC - Member
Well, I know there's a request for comment that I believe that even behooves us more so to comment and lead the path and the conduit to get this done. So, I would support our working on those questions to get it in.

Mark Knee – Office of the National Coordinator – Staff Lead
So, I guess...maybe what I'm hearing is that perhaps Andy and Michael with input from the group might want to consider restructuring the sentence I have highlighted. But generally speaking, it sounds like just to paraphrase the whole group... the group believes that price information should be included in the definition of EHI as we have it. Price transparency should be addressed on some level just kind of different views about maybe how much it should be addressed and with what specificity in this regulation versus future rulemaking. Is that accurate?

Cynthia Fisher – WaterRev LLC - Member
Well, I just disagree with it. So, I just think that we need to comment and enable it. And to me, this sentence looks for us as a group to ask for a delay of gain and I don't think that's fair to the American public or American employers. And I just think that we can respond to the comment that you're asking us to. And should there be future rule-making on pricing, then we've done the work utilizing the information blocking Cures Act to help support future rule-making in addition to this one.

Michael Adcock – Individual – Co-Chair
Okay. So, this is Michael. I don't think that anybody is trying to throw a delayed game flag of not putting this in there. I think it's just the recognition of the fact that tying them too tightly could cause delays either way with both, just like Mark said. The thing that I would recommend so that we don't keep going back and forth on this point is that if there are other...if that's the one sentence in there that people don't agree with, this document is live and can be typed into. I would recommend that we type into there what we want to. This is comments, not recommendations. So, if you have comments, just initially type it and put your name there and let's add to it.

I hear what you are saying, Cynthia. We're not trying to kick the can down the road, but I think we would be...quite frankly I think that we would be naive to think that tying these two issues too closely

and not going into the entire depth of what information blocking... I mean price transparency could cause delays. That's all this is saying. That it could cause delay. I mean we've already –

Cynthia Fisher – WaterRev LLC - Member
Okay. I have to argue with you on this one. That's what it says.

Michael Adcock – Individual – Co-Chair
Well, hold on...let me...can I finish my point first? Hold on just a second.

Cynthia Fisher – WaterRev LLC - Member
Yeah. Sorry. I didn't mean to be rude. I apologize.

Michael Adcock – Individual – Co-Chair
No, that's okay. What I was saying is I don't think that we shouldn't address it. I'm not saying that we shouldn't address it. All I'm saying is that there was a sentence put in there to state...and we can reword the statement that tying these together to try and address all of the price transparency in a workgroup where we haven't been able to get through the definitions completely yet have the potential of delaying either one of these. Either one or both. That's all that statement was meant to say.

Cynthia Fisher – WaterRev LLC - Member
Okay. That was Michael?

Michael Adcock – Individual – Co-Chair
Yes.

Cynthia Fisher – WaterRev LLC - Member
So, Michael? Let me point out to you in that sentence...it says that," slowing down information blocking, that price transparency...that it's an already daunting task." That's an opinion. That's one person. The issue is is that I'm looking at price transparency and consulting with companies on what if they were transparent in whatever the format...like chargemaster prices...list pricing goes out into the atmosphere. How long would it take these tech companies to aggregate and having surveyed five different tech companies, they're salivating to do it. And they told me they could do it on average each one of them said three mONChs...that they could have it into an app and aggregated in a utilizable tool for patients within three mONChs. So, I think it behooves us to not say that it's a daunting task.

And I think the reason we've spent this amount of time is, gosh, you know, we can change the game of healthcare! I mean, I don't know about you, but I know people who have filed bankruptcy because they got breast cancer. We can change that because there are these egregious charges with no understanding of what it's going to cost us. So, this is a moment in time where it's not daunting. It's absolutely necessary. And I'm sorry I've been a dog with a bone on this, but when you file bankruptcy and you help people out it's devastating out there. Twenty percent of our population is in medical debt. It behooves us to do the right thing and I just think we don't want to put opinions in to delay the game.

Michael Adcock – Individual – Co-Chair
Cynthia, we've... I feel like I've agreed with you so many times that we agree that is a serious national problem. So, can we just agree that we agree with you? It's just a question of the correct regulatory path to get that thing that we all want.

Cynthia Fisher – WaterRev LLC - Member
Okay, but I sit on this committee and I just view that third sentence as subjective. And the others that we have are more factual. So, I guess that's where I land is saying that we're putting something in that to me looks like a flag to delay the game. And its objective. It's not a daunting task.

Michael Adcock – Individual – Co-Chair
Well, the daunting task that we're talking about, if you read the way the sentence is written, the daunting task is the information blocking regulations finalization. I know you've been on these calls and the task force calls. That part is a daunting task. It's not saying that price transparency is a daunting task. It's saying that if you tie the two closely together, it could have intended consequences. That's all its saying. The information blocking rule finalization is a daunting task. That's why we spent on average 12 hours a week for the last three weeks on calls just trying to...in this workgroup only trying to get through the definitions. That is a fact. It is a daunting task. It's not saying that price transparency is a daunting task.

That's all the time reading in that they certainly would welcome anyone...again, this is just comments. It's not meant to be right or wrong. I think that we are all in agreement that price transparency is a huge issue that has to be solved. And Cynthia, the only thing I wanna say is I have witnessed firsthand with my parents how medical bills through the death of my brother when he was a child with cancer, through my father's disability, through my mother's chronic diseases and strokes I have seen the bankruptcies. I've seen the bills come in. I have seen all of that. Believe me, I want it to be solved just as much as anyone else. I'm not... I think everybody on the workgroup is...and I haven' heard anybody dissenting yet, is in agreement that that needs to happen. I think that what that one statement is only saying that we agree it needs to happen, that it could have unintended consequences of slowing things down. And it could. I'm not saying that it will, it could. But I certainly...as you're looking at the Google Doc and not driving, if you want to type some things in or change something or voice that you don't think that one statement is correct, I certainly think that's perfectly appropriate. I think we're all in agreement with you that pricing transparency is important.

Mark Knee – Office of the National Coordinator – Staff Lead
Well, just to piggyback on you, Michael, and I agree with everything you all are saying, not that it matters because I'm not part...I'm not coming up with these recommendations, but I would say I don't think we should necessarily dwell too much on this one sentence. I think that sentence could easily be tweaked to more accurately reflect the sentiment of the group. I think what we need to be thinking about more is big picture, what are the recommendations that you all want to make if you are in agreement? Do you want to go through the questions that I had on the screen earlier? And there, do you want to come up with specific recommendations that you might want to float by the group about how you think this rule should address price transparency or how future rules should address price

transparency? Because I think that the level of specificity that would be helpful for everyone to see at HHS at the departmental level.

Cynthia Fisher – WaterRev LLC - Member

Okay. So, I think perhaps we could all look at then each of us on this task force looking at drafting question by question. I think Andy suggested this in a previous call, is how we answer the questions one by one on the issue. And then we come together on those. So, let's move forward and we can't just tweak that. And thank you for supporting patients here. I'm really passionate about what we've seen and witnessed. So, thank you. Do others agree that it would be helpful to add comments into each of these? A breakdown to look at transparency?

Michael Adcock – Individual – Co-Chair

I was giving John a chance to respond. I do. I think that looking at this off-line and entering our comments is probably the most effective way of going forward. I think there is a lot of passion around this issue and this certainly think that anybody that's involved with healthcare and isn't focused on the patients is focused on the wrong things. So, I agree with you completely. I do think that we should do as much of this off-line as we can and come back to those things add up to refine because we are getting... I'm not saying that we're out of time, but we are getting limited on time in our recommendations. And that is the one piece...our portion of the workgroup with definitions is what we were tasked with doing and I want to make sure that at the very least we get finished with all of that. The required work and then all the work that we can get done in addition to that. So, I think that's a great suggestion, Cynthia.

Cynthia Fisher – WaterRev LLC - Member

I was just gonna say that for Sheryl and others that are on the payer side of the equation, it would be really helpful to understand how...where we could see price transparency, how will we see where the prices might be at the individual level, the net negotiated price, posted, so that we prevent situations where a primary care doc sends a patient...I mean, this happened to my whole family within the hospital system, for a blood test that charged master rate was $4,300. The negotiated rate by our TPA was $3,300. If we went three blocks down the street and could see the price it would have been $200. So, it's $700 out-of-pocket versus a $20 out-of-pocket and $200. So, by the same negotiated care cONCexts terms so I think, within the same insurance and stuff with no visibility to it.

So, those things add up to families and I think if we could get from their perspective at the individual basis, but also seeing well, heck, if there's even a $100 test and the patient can pay $100 out-of-pocket versus $3,300 plus $700 out-of-pocket... or $3,300 from the insurer the self-employed employer and $700 from the patient, I mean we should be able to have visibility into those offsets. And so, how do we do this? I think as we approach this problem it would be really helpful to say, okay, we're in a moment of time where the consumer can drive their choices. And just from your perspective, it's gonna change game and how that competitive marketplace can enable good decisions to keep people from bankruptcy and keep people from debt.

Michael Adcock – Individual – Co-Chair

Well, I know Sheryl... Sheryl sent a note that she had to drop off, so, I know that she had mentioned that she had to drop off at 1:30 p.m. So, she was not able to hear that.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay. So, it sounds like what we're gonna do then is that everyone in this group and maybe Michael...you and Andy can send out something just for the folks that aren't on the call right now, just as a bit of homework may be to go through for the specific request for comments and information in the rule and bring back either through comments in the Google Doc, or just commentary on our next call thoughts on how to answer or address some of those questions. You all don't have to necessarily answer every question if you don't want to, but the types of things, Cynthia, that you just mentioned would be helpful to clarify as a group what would be included in the price information that we're talking about and how we would define those parameters and scope. I think that would be really helpful.

Michael Adcock – Individual – Co-Chair
That's correct, Mark. I really I think that's exactly what we need to do and I prefer, and I'll send this out...I'll talk to Andy and then I'll send it out as well as I would prefer for us to put it in the Google Doc so that we can look at it. And again, I don't know that I have comments about every question, but the ones that I do, I'm gonna put comments down just so we can have something to look at and people can see it as they're looking at the Google Doc. I know that it may seem like additional work, but if we can go in and everybody agrees with the statements, it's a lot easier for us to be in there and it is to try to dictate your typing as we're going.

Cynthia Fisher – WaterRev LLC - Member
Mark, when would you want that information in?

Michael Adcock – Individual – Co-Chair
Mark, I don't have my calendar pulled up. I'm sorry. When is our next meeting?

Mark Knee – Office of the National Coordinator – Staff Lead
So, our next meeting with this group is tomorrow, I believe. So, I think we're running short on time today. We didn't get quite to the other big topic which it's connected so I think you'd wanna try and think about this between now and tomorrow which is health information networks and exchanges. So, maybe do some homework on that. We'll bring that up on the agenda of the first thing tomorrow. But to your question, Cynthia, for the next call we have definitely, which would be a week from today, I believe. So, maybe have your thoughts and ideas about those questions that ONC poses maybe in the Google Doc to set a time frame by, I don't know...by Monday, maybe so people can have a day or two to react? Does that seem reasonable?

Michael Adcock – Individual – Co-Chair
I think that's reasonable, yes. I don't think we should spend time focusing on –

Cynthia Fisher – WaterRev LLC - Member
So, tomorrow we do HIE's and HIM's? And then we get all of our comments in by Monday?

Michael Adcock – Individual – Co-Chair
Yes. That would be great.

Mark Knee – Office of the National Coordinator – Staff Lead
Yup.

Cynthia Fisher – WaterRev LLC - Member
Yeah. I think that makes sense.

Mark Knee – Office of the National Coordinator – Staff Lead
Great. And I think that will really be a good conversation. I think we've made a lot of really good headway on this, but I think having people's thoughts on paper just to look at and I can pull it up on the screen will be really helpful to keep it moving. So, that would be great.

Michael Adcock – Individual – Co-Chair
Agreed.

Cynthia Fisher – WaterRev LLC - Member
Thank you all.

John Kansky – Indiana Health Information Exchange - Member
Are we gonna talk at all about HIE/HIN before we get off today? Because I have one really quick thing that might help to get us up for the next call.

Mark Knee – Office of the National Coordinator – Staff Lead
Yeah. So, if the group is...is the group ready to move on to that for the last seven or so minutes of this call?

John Kansky – Indiana Health Information Exchange - Member
Yes.

Cynthia Fisher – WaterRev LLC - Member
Yes.

Mark Knee – Office of the National Coordinator – Staff Lead
Great. Go ahead, John.

John Kansky – Indiana Health Information Exchange - Member
Yes. So, at the bottom of the...let me make sure it's the bottom of the Google Doc. Well, it's not really even at the bottom. On the bottom of Page...oh, I just had it up here. Andy says, "Another suggested approach" ...oh, it's on the bottom of Page Nine. He asked me about this when we were out in DC and I just wanted to call it out as I think something worth considering is the definitions of HIE and HIM are not that different and the distinction...I don't want to put words in his mouth, but I think I'm trying to

agree with his proposed approach here which is it's not helpful to separate the two and it is clearer to just smush them together into one definition. So, I'm just calling out the suggested approach on the bottom of Page Nine for consideration.

Mark Knee – Office of the National Coordinator – Staff Lead
And I pulled it up on the screen, but just thinking it through, if you did make that recommendation, would you use one of the existing definitions? Or would you all want to come up with a hybrid definition of some sort?

John Kansky – Indiana Health Information Exchange - Member
I'm trying to read and see if his...if he gets so far as to answer that question in his comment. Do you know?

Mark Knee – Office of the National Coordinator – Staff Lead
I'm not sure. It's a lot...that something may be to think about. We don't have too much time today, so we could think about for the next call. Do others have thoughts about that? About grouping HIEs and HINs together in one definition?

Cynthia Fisher – WaterRev LLC - Member
Well, I think that acts as a whole other level of potential confusion. I think CURES was the first to network the exchanges separately. ONC is gonna... we just spent the last meeting going through the individual definitions of HIE and HIN and I just think that there's been a lot of folks that put a lot of thought into the two categories. So, now for us to go into a new frONCier of combining them may be exhaustive.

Mark Knee – Office of the National Coordinator – Staff Lead
Yeah. And I... oh, sorry. Go ahead.

John Kansky – Indiana Health Information Exchange - Member
No, you go first.

Mark Knee – Office of the National Coordinator – Staff Lead
I was just gonna say just to back up what Cynthia said, I do think it's somewhat problematic from our perspective. Again, not to direct your recommendations in any way, but from our perspective, when we write CURES, it does lay out those for actor groups and it seems to me that the Congress is pretty clear that those were two different groups of actors. That's why we defined them separately. So, just a note that from my perspective, it would be problematic.

John Kansky – Indiana Health Information Exchange - Member
And one of my comments that we discussed on an earlier call was can you provide examples in the preamble that would help those organizations know what ONC was thinking of them because if I could...maybe it would help for the next call if you could offer an example of an organization that met the definition of a health information network that did not meet the definition of an HIE and vice versa...offer the definition of a health information exchange that does not meet the definition of an

HIN, then I think that would help me understand the separation. Because right now, the definitions...I think, and this is Andy's point and I'm trying to echo him and agree, is that as written, it's a lot less confusing...because I can't think of one organization that isn't both that's in either category.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay. I'm happy to look. I mean I know I say a lot. I think we do have that...quite a bit of discussion about this in the preamble, but I'm happy to re-read that and come back with hopefully some examples or cases to discuss. And maybe just as far as additional homework for our discussion tomorrow, if you all could reread the preamble discussion about HIEs and HINs. I think that would be helpful to inform our conversation.

John Kansky – Indiana Health Information Exchange - Member
I'm looking at...that's 339 to 44?

Mark Knee – Office of the National Coordinator – Staff Lead
Let me see. It's in the Google Doc, but let me see. It's...yeah. So, 339...

John Kansky – Indiana Health Information Exchange - Member
Yeah. That's what I was reading off of.

Mark Knee – Office of the National Coordinator – Staff Lead
Yeah. That's right. But yeah, John, I think it's a great point and I think it's definitely something we should talk about tomorrow because you're right. If we do say that they're different groups, then there should be a clear distinction. And that was our goal. So, if that's not clear then it should be.

Michael Adcock – Individual – Co-Chair
Yeah. I hope that everyone can come ready tomorrow. I'm hoping that we can make some good headway with that HIE/HIN and those definitions tomorrow. It's maybe one minute before time to go to public comments, so, I think that unless somebody has a brief statement that we should go ahead and move to public comment if at all possible. Hearing none, can we go to public comment?

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer
Sure. Thanks, Michael. Can we open the public line?

Operator
If you'd like to make a public comment, please press *1 on your telephone keypad. A confirmation tone will indicate your line is in the queue. You may press *2 if you'd like to remove your comment from the queue. For participants using speaker equipment, it may be necessary to pick up your handset before pressing the * keys.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer
And do we have any comments at this time?

Operator
None at this time.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer
All right. We have the number open for a few minutes so hopefully, that gave folks time to dial in, but I will hand it back to you Mark and Michael for any last-minute remarks.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay. Michael, what do you want to do here?

Michael Adcock – Individual – Co-Chair
No, I just wanted to say that I appreciate all the comments and all the points of view and the discussion. I hope nobody gets the wrong idea by my pushing that I'm trying to stifle any of that discussion. I'm really not. I'm just trying to get the point where we can have some solid recommendations moving forward. Not that they'd be the wrong recommendations, but that we get to a point where we have recommendations even if that means that we have to have multiple recommendations. I just wanted to remind everybody that we are...we need to be looking at those questions for the meeting. We need to look at the questions around price transparency and have those into the Google Docs by Monday close of business.

And also, be prepared via looking at the HIE/HIN comments that Andy put on there, anything in the preamble, and be ready to have a discussion tomorrow. And hopefully we'll be able to close out the majority of that discussion tomorrow and come up with some recommendations on how we think that should look around HIEs and HINs or HIE/HIN together however, we're gonna go about that, but if at all possible wherever possible, go ahead and put comments into the Google Doc. That helps...I know that I pull it up quite often look and see what people have written. If you get that opportunity, that would be great.

Mark Knee – Office of the National Coordinator – Staff Lead
All right. And Michael, do you want to end early today and maybe get people a few more minutes to do that homework? Does that sound good?

Michael Adcock – Individual – Co-Chair
Sure, unless John or Cynthia, if you all have something you want to add at the end, go ahead. If not, we'll end a few minutes early knowing that we're gonna have another spirited conversation tomorrow and probably a couple of next week as well. So, if you have something to say, certainly say it. I don't want to block anybody or do any information blocking here by blocking anyone from saying what they want to say, but I know most people could use eight or nine minutes back to the end of the day.

John Kansky – Indiana Health Information Exchange - Member
I'm already reading the preamble so I'm good to let it go.

Cynthia Fisher – WaterRev LLC - Member
Likewise. All right. We'll do our homework.

Michael Adcock – Individual – Co-Chair
All right. Thank you.

Mark Knee – Office of the National Coordinator – Staff Lead
Thanks everyone. Talk to you tomorrow. Bye.

[Event Concluded]