Information Blocking (IB) Workgroup 1

Transcript
March 7, 2019
Virtual Meeting

SPEAKERS

Name	Organization	Title
Michael Adcock	Individual	Co-Chair
Andrew Truscott	Accenture	Co-Chair
Cynthia A. Fisher	WaterRev LLC	Member
Valerie Grey	New York eHealth Collaborative	Member
Anil K. Jain	IBM Watson Health	Member
John Kansky	Indiana Health Information Exchange	Member
Steven Lane	Sutter Health	Member
Arien Malec	Change Healthcare	Member
Denni McColm	Citizens Memorial Healthcare	Member
Aaron Miri	The University of Texas at Austin, Dell Medical School and UT Health Austin	Member
Sasha TerMaat	Epic	Member
Lauren Thompson	DoD/VA Interagency Program Office	Member
Sheryl Turney	Anthem Blue Cross Blue Shield	Member
Denise Webb	Individual	Member
Mark Knee	Office of the National Coordinator	Staff Lead
Morris Landau	Office of the National Coordinator	Back Up/ Support
Penelope Hughes	Office of the National Coordinator	Back Up/ Support

Operator
Thank you. All lines are now bridged.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer
Good afternoon, everyone. Welcome to the HITAC's Workgroup 1 under the Information Blocking Taskforce. We will jump right in, starting with a brief roll call. Andrew Truscott?

Andrew Truscott – Accenture – Co-Chair
Here.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer
Michael Adcock?

Michael Adcock – Individual – Co-Chair
Present.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer
Sheryl Turney will be a little bit late. John Kansky.

John Kansky – Indiana Health Information Exchange - Member
I'm here.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer
Denni McColm and Cynthia Fisher. He's on as well.

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

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer
Okay. Great. All right. So, I will hand it over to Andy and/or Mike to get us started.

Andrew Truscott – Accenture – Co-Chair
Well, thanks. Andy. Hey, guys. Thanks ever so much for joining this second session in this workgroup we're on, one, so the Information Blocking Taskforce. We've got two particular areas to focus upon today, following on from our immensely successful session yesterday. The first of those is to request a comment regarding price information. Cynthia, are you able to see your screen, even though you're not able to type in comments?

Cynthia A. Fisher – WaterRev LLC - Member

I see the old one from the other day, and my assistant's just gonna send my comments now. So, yes. All on my phone.

Andrew Truscott – Accenture – Co-Chair
Okay. Okay, that's cool, because – okay, so we're going to the request for comment regarding pricing information. And I'm pretty sure that you've probably got some opening thoughts on this one. Do you want me to read the actual regulation? Oh, no, there are your comments actually going in right now.

Michael Adcock – Individual – Co-Chair
Oh wow. There they are.

Andrew Truscott – Accenture – Co-Chair
Wow. How many pages did you write, Cynthia?

Cynthia A. Fisher – WaterRev LLC – Member
I know. Well, I was multitasking, so forgive the random thoughts and the verboseness of it all.

Andrew Truscott – Accenture – Co-Chair
Okay. Well, we'll add them onto my comments too. Go ahead, then, I'm sorry.

Michael Adcock – Individual – Co-Chair
Yeah. I'm glad I didn't have to be the scribe for that. That would have taken a while, so that was good.

Cynthia A. Fisher – WaterRev LLC - Member
Well, God bless my assistant.

Andrew Truscott – Accenture – Co-Chair
Okie-dokie. So, Cynthia, you've obviously put some thinking into this. Do you want to give us the high-level view of where you're coming from?

Cynthia A. Fisher – WaterRev LLC – Member
Yeah. Yeah, so the high-level view is, I think that both Congress's intent, as stated with 21st Century Cures and also the President's in the White House's intent, as noted from a White House release document on their healthcare priorities, included system-wide pricing transparency. And they have been trying to get at how do you do that? And we all kind of know experientially, and we could all tell our own stories, which I've been collecting. Our collaborators have been collecting both patient and physician stories about the trends in healthcare, and the runaway costs, and the egregious out-of-network and surprise billings of both facility fees and out-of-network fees. And even at the negotiated rates, may be 11 to 23 times the Medicare rate.

So, knowing that everybody's trying to figure out how to get there, I think we are in this moment of time where we're on this committee where we see the intent. And I believe that

we have a societal fiduciary role in our role to say let's make it happen, because we know that a free and competitive marketplace in grocery or gasoline prices, or any other entity can be trusted because they're transparent. So, anyway, I just think we have, through this data access, and also, if you go back to the definition in step one of both the HIPAA and the public access of health information, if you take note – if you go back to HIPAA in 1996, HIPAA states that we are to have access. It was portability that he – it was really intended for portability to the individual and the patient to have access to our clinical, our physical and mental health, and our care coordinated – our care, past, present, and future, along with the second part of the HIPAA definition, which is our payment information, which includes past, present, and future payment.

So, if you look at what – HIPAA has been in law since 1996 and promulgated since 2000. One could argue that future payment is a price. And so, to get down off my soapbox here about how strongly I feel that we would all benefit to see prices and see the real prices, and that it can be done, I think it behooves us as a committee to figure out what we can do to make that easy and accessible industry-wide. And yes, one could say it could be highly disruptive, but if you think about it, we could plow the runway free and clear of the opacity of the mountains and the moguls of opacity intentionally built in for sort of a baked-in greed that's been running rampant across the system to allow for a technological revolution to show transparency and really get to the consumer-driven care.

And then finally, I'll close with saying in Massachusetts, there was a newspaper article last week by the Small Business Association saying how the small businesses are penalized with the highest high plans – among the highest health plans in the country, almost $31,000.00, and then the high deductibles. And yet, deductibles ranging from $3,000.00 to $6,000.00. And yet, being built out of network that aren't even covered by those high health plans. So, the small businesses and the American workers are getting hosed. And if you think about it, we just have this opportunity to really change the game – empower the employer and empower the consumer to drive down the cost of care, and basically Uber-ize healthcare.

I mean, wouldn't it be nice if we could all Uber-ize and pick and choose, like we can when we choose our Uber driver or Uber Share, and then you could see once we get to pick our Uber driver and pay the price we can afford to pay, then we can also rate our Uber driver on quality, and we could even comment on whether we got a hospital-based interaction or what the outcomes would be, so that we would eventually be able to buy the best quality of care at the lowest possible price. So, okay, now I'm gonna get off my soapbox. Thank you.

Andrew Truscott – Accenture – Co-Chair
Thanks, Cynthia. I think that's pretty clear, and I think that's a very good expression of a lot of the sentiments that have got us to these decision points that we're in right now. I think that's good. I'm not sure I agree necessarily with Uber-ization. I think more, in my mind, democratization. With Uber, I'm never quite sure what's gonna turn up till it gets here. But okay, I get what you're saying.

Cynthia A. Fisher – WaterRev LLC – Member
Okay, well said. Maybe I need to find another word choice.

Andrew Truscott – Accenture – Co-Chair
Well, so what do the other members of the workgroup think?

Denni McColm – Citizens Memorial Healthcare – Member
This is Denni. I'm sorry, I was a little bit late. I don't know who all is on. I just feel like price transparency is really out of scope for this rule. This is a rule about sharing individual's health information, electronic health information, and pricing transparency is just something totally different, besides the fact that we already have some requirements to publish our prices. And it's just not helpful without context of what is my insurance plan, what's my insurance contract, what's my individual situation with regard to my deductible. I just think it dilutes the rest of what this proposal is supposed to – this rule is supposed to be about, to introduce price transparency. Price transparency is great. I'm all for it. I just don't think this is the place for it.

Andrew Truscott – Accenture – Co-Chair
Okay. Thanks. Thanks, Denni. Sheryl? John?

John Kansky – Indiana Health Information Exchange - Member
This is John. I, as luck would have it, was at a price transparency summit – there was a bunch of states represented – earlier this week. It's absolutely a goal. I have to admit that that isn't really – health information exchanges tend not to deal in financial or pricing information. And so, my expertise and experience gets a little shallow there. So, I think I'm in the camp of philosophically agree with it. Certainly am not focusing on it as the primary goal of this information blocking rule. So, a little bit noncommittal, and all I can say is I could think a little bit more about it. But I'm definitely thinking about the information blocking rule as focusing on making health data more fluid.

Andrew Truscott – Accenture – Co-Chair
Thanks. Thanks, then, John. Has Sheryl joined us? Okay. Mike?

Michael Adcock – Individual – Co-Chair
Hey, I happen to agree. Of course, I am all for transparency in any type of pricing – drug pricing, whatever the type of pricing might be. I do think that it's a stretch for the role that we've been tasked with in this committee and this taskforce. I think that the information that we're trying to define, the information we're trying to make sure flows freely, is an individual's information, their health information, not necessarily the information about pricing drugs.

Andrew Truscott – Accenture – Co-Chair
Okay. So, if I look at the chart we've got here, given that price information impacts the ability of patients to shop for or make decisions about their care, we seek comments on the parameters and implications of including price information within the scope of EHI for the purposes of information blocking. Okay, so that's the first question that we're asked. Should price information be within the scope of EHI for information blocking purposes?

Secondly, we've been asked for this much broader overall Department of **[inaudible] [00:10:42]** comments on the technical operation or legal, cultural, environmental, and other challenges to creating price transparency within healthcare. So, there are technically to what we've been asked.

Mark Knee – Office of the National Coordinator – Staff Lead

And just to jump on that, Andy, it's a bit more in detail. If you all have the rule open, it's on page 345, and I can pull it onto the shared screen as well. We give a little background about what we're talking about, and then there's a list of specific questions that we ask about pricing. So, that might help guide the conversation with a little more detail, if you want.

Andrew Truscott – Accenture – Co-Chair

Well, this – yeah, the bottom of page 346 going to 347 has the first part of this. Should prices be included in EHI, and then you've got some comments around that and some parameters around that. But I think I'd like to treat this, with your permission, as almost two separate questions.

Mark Knee – Office of the National Coordinator – Staff Lead

Sure, yeah. I mean, however you want to do it is fine.

Andrew Truscott – Accenture – Co-Chair

Well, no, with – as much as I love you, Mike, not just you, the group. So, Cynthia, Denni, John, Mike, what do you think? Is that okay with you?

Cynthia A. Fisher – WaterRev LLC - Member

Yes, I'm fine with addressing them as two separate questions.

Andrew Truscott – Accenture – Co-Chair

Okay, yeah. Everyone was scrabbling for their mute button then, weren't they? Okay, so if we split this, I think, Cynthia, a lot of the excellent input that you've given us, I think is in the second part of this. But I think I'd like us to talk through – and those of you who are online can see some of my notes already around the implications of including price information within the scope of EHI for the purposes of information blocking. So, this is basically saying the definition of what is electronic health information, which we touched upon in our first meeting, is going to be augmented to included price information as well.

John Kansky – Indiana Health Information Exchange - Member

So, ready for a reaction?

Andrew Truscott – Accenture – Co-Chair

Absolutely. Go for it.

John Kansky – Indiana Health Information Exchange - Member

Okay. So, keeping in mind the philosophical support for the position that I understood

Cynthia to be taking earlier, I made the observation a moment ago that health information exchanges tend not to deal in financial information. And the experience that I have is that we have one of, if not the largest, multi-organizational clinical data repositories. And the reason it does not include any financial information is it would have never gotten off the ground if a condition of participating was sharing not only your clinical data, but the associated financial data that goes with it – meaning it dramatically impacts – it's not quite a third rail, but it makes the data-sharing equation a lot more tenuous for a whole series of other reasons, and I wouldn't want to see that getting in the way of progress on healthcare and clinical data-sharing.

So, one might argue, well, but John, this is the whole point. We want transparency of healthcare data, but we also want transparency of pricing data. So, I guess I'm being a little bit of a practical realist, and wanting the industry to accept the regulation and not fight it for all it's worth. So, for that reason, I'm very careful – that's not the right word. I would probably argue against broadening it to include pricing.

Andrew Truscott – Accenture – Co-Chair
Okay, thanks, John.

Cynthia A. Fisher – WaterRev LLC - Member
This is Cynthia. I started in my career – I'm old, so it was a long time ago – but it was in medical billing, electronic sharing of information through networking between hospitals and insurers. And I go back to the beginnings of the networking happening in the early '80s, late '70s, early '80s, that sharing of information between hospital and payers. And we do know that the EHR system, sort of the backbone, was also from where medical billing was first conducted.

So, I think that we can also look then back to the HIPAA definition that I referred to earlier, which is the patient's aggregated data on their billing and claims – let's be real. Behind the scenes, I don't know about you all, but I've seen the software programs that aggregate all of that data, both payment connected to our credit cards, connected to our insurance payment, connected to our cash payment, behind the scenes for big data AI and even to prevent fraud, to comply with the Medicare/Medicaid ruling for organizations and companies. So, what we're asking here is to have the same be able to be delivered to the patient to make choices. And we have been surveying, across the country, patients and physicians alike that have received bills from surgeons or caregivers up to $100,000.00, well beyond what the average rate would be for that surgery. Maybe it's $2,500.00 for the actual surgery, and patients have been billed out-of-network for $101,000.00. We have many, many cases like that. So, if you can't –

Andrew Truscott – Accenture – Co-Chair
So, Cynthia. I've got a question.

Cynthia A. Fisher – WaterRev LLC - Member
Why can't we work in the direction that we've been asked on price?

Andrew Truscott – Accenture – Co-Chair

Okay, so Cynthia, here's a question. Do we think that mandating pricing information into the scope of EHI is going to aid creating price transparency?

Cynthia A. Fisher – WaterRev LLC - Member

Well, I think it goes back to what we discussed yesterday about the definition of network and exchanges, because you know – we all know that that data gets exchanged, and it's networked, and it's linked to the individual patient.

Andrew Truscott – Accenture – Co-Chair

That's absolutely true. But mandating it – because, we're being asked a very discrete question here. There are two questions, as I said earlier. But the first part of it is do we think that actually including price information within the definition of electronic health information just for the purposes of information blocking – yes, I think we all agree that exchanging price information is very important, and we should be doing it. I think we all agree that having – this is in my notes – some kind of centralized registry of **[inaudible] [00:18:07]** related procedures with a generic set of patient situations providing a single point of reference for comparison of costs would be a good thing. That would enable price transparency. But should we mandate to every provider and every payer that every time you pass any insight about a patient, there is the cost to that patient – at that point in time is expressed with that data? And I must confess, I'm not sure that that – I think there'd be an adverse consequence of doing that, an unintended consequence, in that the actual – the overhead of doing it is really hard.

Cynthia A. Fisher – WaterRev LLC - Member

Well, actually, not really, because you think about this data is shared. It's shared per individual. And it's known in advance, and it's negotiated in advance of care on the contract negotiated terms. So –

Andrew Truscott – Accenture – Co-Chair

Some prices, it is. But not all. Remember, this is a law that would touch everybody equally. We don't – **[crosstalk] [00:19:12]** can say it only goes to some people more than others, and yes, if you want to contact them, then that would have to be said. But if it's out-of-pocket, it wouldn't. We don't get that opportunity. So, it's one law that serves everybody.

Cynthia A. Fisher – WaterRev LLC - Member

And it serves everybody well to know that in advance of care. I mean, if you post it and you have it, then you can compare, and we can compare both on the plan level, and we can compare both on the provider-specificity level. I think especially as we have, like I talked yesterday, about the oligopolies – there's consolidation, and then you've got the vertical integration. You can be sure that the businesses that are vertically integrating between hospitals and insurers and GPOs and pharmacies that all of this is – they know the numbers, and then contractually between entities are being negotiated to optimize profitability, whether it's a nonprofit or a for profit.

Andrew Truscott – Accenture – Co-Chair

Absolutely. No, you're absolutely right. And I agree with every point you're making. I'm just going back to the, does the group think that we should be recommending that there's a mandate that price information is included inside the EHI definition, which is 102, the first thing we've been charged with, the information blocking purposes? Which means if you don't share it, you're information blocking.

Cynthia A. Fisher – WaterRev LLC - Member

Well, how do you justify to the patients who are suffering substantial medical debt from not having any optics into price choices in their care?

Andrew Truscott – Accenture – Co-Chair

Absolutely. No, you're right. You can't justify it. It's impossible.

Cynthia A. Fisher – WaterRev LLC - Member

How do we justify that we're in this moment of time – and if you read the definition right now, it says past, present, and future payments. And that's been in place since 1996. So, why don't we honor it?

Andrew Truscott – Accenture – Co-Chair

I agree with you. I agree with you.

Cynthia A. Fisher – WaterRev LLC - Member

Why don't we honor it? And guess what? Information blocking is the only teeth that we have to hold for accountability.

Andrew Truscott – Accenture – Co-Chair

Okay. So, I think that's another of your points, which is we don't have any other way of forcing this to happen, so this is the right way of doing it.

Cynthia A. Fisher – WaterRev LLC - Member

Well, it just holds everybody to the same set of rules to say we have accountability. And it's good behavior. It's like when groceries put unit pricing and prices on groceries. Can you imagine if we went grocery shopping and we didn't know what was going to be charged? But in today's world, we can know that we're gonna probably pay a little bit more at Whole Foods than we are at Costco. But they're gonna be in the range, you know?

Andrew Truscott – Accenture – Co-Chair

Okay. So, let's open this out to the rest of the group. Given the background, of course, you just heard between Cynthia and I, what do you guys think?

Denni McColm – Citizens Memorial Healthcare – Member

This is Denni. I still think it's out of scope. I think it doesn't belong here. We already have other mandates. We have a mandate already to publish the pricing. It dilutes the effect of

what we're really trying to do, which is prevent information blocking of electronic health information, not the price of what some entity charged for or will charge, which is even – I don't even think you guys are talking exactly about the same thing. I think Cynthia's discussing price transparency by here's our pricing and here's what you're gonna have to pay before you have this service, versus having it as part of the set of information about the service I did receive when my record is shared.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Yes, I think I agree with you. This is Sheryl. And there are also many state laws that make conflict with whatever we recommend here, because currently, the states believe they have the right to regulate cost transparency under what they were provided with the ACA. So, then we're going to have developing that dilemma of something here that conflicts with a state rule regarding cost transparency as well. And what the research has shown is it has to be meaningful data that makes sense to the person receiving it. And so, giving them unit cost information is not meaningful, because they don't really know how to use that. And most members and residents don't even use the cost transparency data that's available to them today, which is unfortunate. But at the end of the day, there are a lot of movements payers are making to create something similar to a retail claim experience. But that's not gonna work for a complex procedure. Those work for simple office visits and simple procedures that can be more clearly defined in terms of all of the diagnosis and service codes.

Cynthia A. Fisher – WaterRev LLC - Member

I disagree. Go ahead. Go ahead. I'll come back to that. I was just gonna disagree with you on the states. We've investigated very heavily the states and state laws. I mean, really – I mean, what this is looking at is honoring the definition of patient information and patient data, and giving patients access to their health information. Look at the definition. We have this opportunity in this moment of time, and I know that there are a lot of special interests out there that want to protect the opacity. But I think we as a fiduciary role to the citizens of our country, these are government funds. This is our government setting a regulatory path to affect one, individuals; and two, our economy; and three, our deficit. And if you can look at having transparency, we can actually empower that consumer.

But now, consumers have $6,000.00, $9,000.00 deductibles, and they have no transparency into choice. So, take the simple MRI or lab. They have no alternative to see. We even had a case where someone came to us with having stitches removed from around an orbital of an eye for $6,500.00, when they could have gone and gotten it for probably $150.00.

John Kansky – Indiana Health Information Exchange - Member

This is John.

Cynthia A. Fisher – WaterRev LLC - Member

This is crazy. It's crazy making out there today.

John Kansky – Indiana Health Information Exchange - Member

This is John. I'm just trying to jump in and respond to Andy's invitation to comment in general. Well, I think we all agree with – well, conceptually agree with the need for price

transparency in healthcare. My philosophy is that policy is a fairly blunt instrument to begin with. And so, we should make it as clear and focused as is possible. And so, consistent with my arguments yesterday on definition, I don't think vagueness is good, and I don't think pulling in – trying to broaden what's already a blunt instrument just makes it more blunt. So, while we want price transparency, I think, and I'm trying to be consistent in my feedback from point to point – I think I agree with, I think, the end of Denni's comment, which is that it dilutes our attempt to achieve liquidity of healthcare information if we broaden this and weigh it down with a bunch of industry pushback. So, I think narrow focused policy is good.

Andrew Truscott – Accenture – Co-Chair

But John, Cynthia's point is that a blunt instrument is what's required, because it's the only way to get any movement.

John Kansky – Indiana Health Information Exchange - Member

I think policy is a blunt instrument. You can't make it not a blunt instrument. And so, taking a club that's six inches wide and making it 10 inches wide, when what you're trying to do is crack a walnut – that's a terrible metaphor. But there's gonna be more collateral damage the blunter you make the instrument.

Andrew Truscott – Accenture – Co-Chair

Okay. So, is there any kind of middle ground? And I'm still talking about this first part of this question, where the – well, we've been asked to comment on the parameters and implications of including price information within the scope. So, could we come up with some parameters around that pricing information? I think that everyone's made some pretty good points here. And the point that I think I heard was that simply, price information isn't available all the time. So, it's not reasonable to say that it always has to be transferred, and your information blocking is not – would that be a point that everyone could get behind?

Cynthia A. Fisher – WaterRev LLC - Member

Andy, could you restate what you were saying, please?

Andrew Truscott – Accenture – Co-Chair

I'm just saying that I'm not sure that every interaction of electronic health information is legitimate to have a price associated with it, because it may or may not be a procedure. You may or may not have sufficient information to even put a price to something. I've never, ever seen financial information included in a definition of PHI, EHI, or anything of the same.

Cynthia A. Fisher – WaterRev LLC - Member

Okay, but if we go back to the 21st Century Cures Act and the discussion of yesterday, that information that's electronic, and it's individualized about the patient, the patient should have access to that information. And usually, what we see is patients don't get access to it until months later and fragmented in pieces.

Andrew Truscott – Accenture – Co-Chair

Yup. Agreed.

Cynthia A. Fisher – WaterRev LLC - Member

And we know that it's digitally shared among the players. And it's digitally shared real-time, and it's digitally shared, contractually negotiated prior to receiving care based upon planned, contract negotiated rate. So, our citizenry is blindfolded, and they have negotiating power. And I can tell you case after case where it's like, too bad, that's what your plan negotiated. You have no negotiating power. And then you're expected to write with a blank check. And we have this opportunity, because if we pay attention to both what that definition says today, and we also look at the small N and small E about patient data sharing, why would we not want to know a price of our care? Not the cost – the price . . . when we can see it **[crosstalk] [00:30:49]**. I would not want to enable that as a committee here, looking at using the one tool Congress had intended, as well as the White House.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

I don't think any of us are saying that we wouldn't want to share that data. I think that what we have to be careful about is how the words in this rule can be understood. And in the example in the rule, it's actually describing how the benefit to insurers by having price information would drive the prices down. The example isn't even from a patient's perspective, because I'm reading it right now. So, I think there are a lot of interpretations to it. And to me, I do think it would be beneficial that all folks that are insured or not insured should be able to go in and say, what is the price of a knee replacement? Tell me what it would cost and who the providers in my areas are. Most states require that tool today, and having something of that nature available through an API would be beneficial to a member or a patient. So, I don't think any of us are saying that that's not the case. I just think caution needs to be applied to how we express it here so that an unintended consequence doesn't occur.

Andrew Truscott – Accenture – Co-Chair

I think Cynthia's point is we don't have any other vehicle in this. And I think Cynthia's point is that this was the intended vehicle.

Cynthia A. Fisher – WaterRev LLC - Member

That's right. Both Congress and the White House administration asked us to look at this because it's the intended vehicle to do it. And I disagree with you. We do not know one state that effectively can tell you the price before care. You can get some cost estimators, but even within the own plans that have their own cost estimator tools, they're not accurate, because they may have one larger employer have a far less charged rate, or their reference billing may be far less than what the cost estimator is, and they may charge another entity covered by their same plan or the same TPA 11 times a Medicare rate that –

John Kansky – Indiana Health Information Exchange - Member

So, I think that –

Cynthia A. Fisher – WaterRev LLC - Member

They go the gamut. And people don't know, and they can't see. We just had – in

Massachusetts, we just had an article about the discrepancies in MRIs and non-visibility into it, and lab tests, and also in insurance plans. This is a crisis of our country, and we know healthcare pricing and issues are the number one in the last election, and it will be in the next election. And we are in this moment of time to really provide for our citizenry. And they're paying for all this work through their tax dollars. They deserve better. And I think it's our fiduciary role to support them.

John Kansky – Indiana Health Information Exchange - Member

So, this is John, and I keep agreeing over and over again with the philosophy. When we turn back to the regulation itself that needs to be implementable and needs to achieve, as narrowly as possible, what the blunt instrument is designed to achieve, what I'm trying to wrap my head around – the patient is a convenient example because we all agree that the patient should have access to their health data and transparency around the prices of their services. My God, of course they should. What I'm trying to wrap my head around is the fact that this regulation requires information sharing between lots of entities that aren't the patient. And I'm thinking about the implications – I mean, the free market economy outside healthcare, whether you're selling automobiles or whatever, you're not expected to share pricing and cost information across the competitive marketplace. So, can anybody help me think through what the ramifications would be of requiring pricing information to be shared not just with the patient, but across the continuum?

Cynthia A. Fisher – WaterRev LLC - Member

Well, but prices are shared in every other industry across the continuum. We're not asking for the cost or the revenue, the profitability. We're asking for the price, the actual price that that consumer will play, the actual price the employer will pay. So, that's done in every other industry. And in fact, the patients we survey, they can buy a car and trust buying a car and getting the real prices of their car, rather than their doctor. There's so much fear in going to a doctor. And you can interview them, that a working class person believes that they're one hospital visit away from financial ruin if they have to go to the hospital. It is out of control. And some of these hospitals aren't even transparent. We have video, and I'm happy to share it with the group, of a certain specific hospital – some states actually, the hospitals are suing their patients for their medical bills. And each one of those medical bills broken down into each fit is a separate day in court, okay? And each court fee costs $75.00.

So, if you have a $57.00 delinquent lab test, you have a $75.00 court fee and a day in court. And people are – it's out of control. People have no visibility into what their lives ahead may be with a medical bill or a delinquent medical bill that they have no negotiating leverage to go back to that hospital to say, you overpriced me, you overcharged me. I have nothing to compare.

Andrew Truscott – Accenture – Co-Chair

So, Cynthia, what would you propose we recommend?

Cynthia A. Fisher – WaterRev LLC - Member

I think the question asks us if we would use information blocking as a tool to say that entities across the healthcare system that transact and share, if they get a piece or share a fee based

upon that patient's misfortune, whether it's a lab test or a rotator cuff MRI, whatever it is, that if they are anybody and they're sharing that contract negotiated term across the system, that's a net price that's gonna be to that individual. And that should be delivered to the patient, and we should utilize these tools that Congress gave us to deliver a free and competitive marketplace to the patients and our citizenry. That's what I believe firmly, and I apologize for being on my soapbox.

Andrew Truscott – Accenture – Co-Chair

No, no, it's okay. I just want to think this through to what does it mean actually as a patient? How would I experience this access to information?

Cynthia A. Fisher – WaterRev LLC - Member

Andy, you could imagine just like anything else. If the payers and the providers and the middle players just post publicly their negotiated rates, then the posted negotiated rates, we would enable the runway to be cleared for a technological revolution for the Amazons, the Googles, the Yelps, the entities to be able to aggregate that data and be able to show, differentiate and show pricing. And we would start to create a competitive marketplace. And you could imagine that the Costcos of the world may be able in the future, once we show these things – why couldn't you buy your health insurance from Costco in the future? Why wouldn't we buy it online? And why wouldn't we use the welfare part of our wages with choice, so that HSAs and high deductibles can really work? So, I think we are in this inflection point of this moment in time where we could be as high tech, folks – I mean, look how long this council's worked, for 10 years, just to get standards. But if you think about it, this tech revolution could happen and transform it for the better for our country.

John Kansky – Indiana Health Information Exchange - Member

Okay, Andy, can I sneak in a – I'm trying to –

Andrew Truscott – Accenture – Co-Chair

No, go for it. Go for it.

John Kansky – Indiana Health Information Exchange - Member

– understand the same question. So, if there's a patient, and they go to a new physician, or they're referred outside a system where they've gotten care, we want to make sure that the health information regarding their previous care must be exchanged by their previous providers. And so, I'm asking myself is this now EHI includes pricing information, does that require – and I'm not saying it necessarily creates a business problem. I'm just trying to go through scenarios in my head. Does it require the referring provider to send not only the health information but the pricing information of the services they provided, or am I really distorting things?

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

I think what's Cynthia's describing, though, is that she wants the pricing information before the service has been rendered, and that's where I see the dilemma here. I see why we need it, but it's like the way I frame it, it's analogous to I buy an insurance policy for my car. I get in

a car accident. If the car manufacturer gives me money to correct the collision, but it's not until I bring the car in that they may give me an estimate. Then I bring it back, and all of a sudden, it's $1,000.00 more because there's something they didn't see. Although that's a simple example, this is the same scenario we're talking about here. We can give people price information, but it's not until the doctor sees you and you're on the table that they realize, oh, I have to fix this too and do that. How do you give people all those variables upfront to satisfy the need and give that information for a variety of providers and hospitals so they can make a decision? That's different than giving them EHI information for something that already happened.

John Kansky – Indiana Health Information Exchange - Member

Yeah, and I think you're making a good point, and we absolutely should talk about that. I'm trying to make a separate point, which is becoming a little clearer in my head, is that – and this is what I mean about trying to focus the regulation. If the regulation says, if it's EHI, you have to share it, and when anybody asks for it, there's no holding back, and we put in the definition of EHI pricing information, then we're telling providers that when they share information for a clinical purpose, they have to include pricing information, which probably comes from an entirely different system. And we've doubled, if not tripled, the cost of complying with the regulation, which is kind of one of the things I'm also concerned about.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

I agree with you 100 percent.

Andrew Truscott – Accenture – Co-Chair

I think the point we're trying to get to is so that patients understand –

Denni McColm – Citizens Memorial Healthcare – Member

This Denni. I just agree too.

Andrew Truscott – Accenture – Co-Chair

Go on, Denni. Go on.

Denni McColm – Citizens Memorial Healthcare – Member

Sorry, I didn't mean to interrupt. I just wanted to say I agree too. I just think it's out of scope. Price transparency at the point where you provide prices to patients isn't even specifically related to the patients, and there is no way that I know of to attach price information to health information that we might share with the next provider of care for the patient.

Andrew Truscott – Accenture – Co-Chair

Well, it would mean augmentation of the existing standards to do it. But I think for billing purposes, I get how to do it as well. But as **[inaudible] [00:43:21]** said, it would mean some agile **[inaudible]** and augmentation.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

And let me add, though, from a claim perspective as a payer, we would provide cost

information about what they paid and what their portion is with a claims inquiry. So, if they came to us and then we were providing that data via an API, we can provide what was submitted, what we paid, and what their portion is. So, in that scenario, price information makes sense. But it doesn't make sense in the clinical scenario.

Cynthia A. Fisher – WaterRev LLC - Member

I disagree with you on that, because let's take this example. And I went to Blue Cross Blue Shield to try to get price information. It took two of us about six weeks. We got the cost estimator, but the reality was it was 11 times more than the cost estimator, and the out of pocket was $700.00 versus $21.00 of the cost estimator for a series of blood tests. So, looking at how long it was and how hard it was for the consumer, think about this scenario, where people over the age of 50 are told they should get colonoscopies every so often, just as a well visit. But you don't know whether you're gonna go to Mass General and have a colonoscopy and have an out-of-network radiologist – or not radiologist, a pathologist, anesthesiologist. You don't know if you're gonna get a facility fee. And how do you compare that to Steward Hospital, or the Brigham, or the BI? So, you don't have any way to see that.

But if I knew that a colonoscopy, I could have all in one, and I'd have a certain number of co-pay, and I have a $9,000.00 deductible, I would rather do that than have a surprise bill out-of-network of $6,000.00. And there's just no visibility. There's no transparency. And so, we have the opportunity because you, the payer, actually have that contract negotiated term. And you have it before we get coverage, before we get care. It's already done. And according to Blue Cross Blue Shield, even though they pay the Brigham 11 times more than they would pay Steward Hospital, and we're self-insured, I ask, why would you do that? Our employees, if they go to the Brigham, are gonna be charged 11 times more, and you negotiated that of our TPA. And even as an employer, I have no power because I have no visibility to shop.

So, both as an employer with 1,600 employees, I have no visibility to know what my TPA negotiated or why they would pay the Brigham 11 times more. So, it's all done in advance. I think we have to – that's why I'm like, why don't we do the right thing? And this is the moment in time. And that was the intent of Congress, because information blocking, remember why they did it. It's because of the anticompetitive practices in healthcare that is devastating our people and our economy.

Andrew Truscott – Accenture – Co-Chair

So, ONC staff, those of you that were involved in the drafting of the rule and have spoken to the people who drafted the actual original 21st Century Cures, what's your perception on this?

Mark Knee – Office of the National Coordinator – Staff Lead

Well, so I'd say we have to be careful what we could say. I'd point you to the definitions. I know it's getting old, probably. But really, to get the intent of, I guess, what we're trying to do, you've got to look at the definition of electronic health information and see if within that definition, whether you land one way or the other, whether you think as a group or individually that pricing information should be included in the definition, you have to assess whether, based on the definition we currently have, it would be included or it wouldn't be

included. And I think what it says is it is included, but there's a bunch of questions as to how far we want to go and how it would be implemented. I know that's kind of punting. I just can't get into the details of – I think you all know. You've been listening. I was just gonna say that – yeah.

Andrew Truscott – Accenture – Co-Chair
Why have we been asked to comment on this in the rule?

Mark Knee – Office of the National Coordinator – Staff Lead
Because I think it's become a very big issue within the administration. You all have probably heard about CMS price transparency. And it's an issue that is very important to this administration, and it could, as you guys are talking about this, it could fall within the scope of information blocking to different degrees, or – I guess we're trying to assess to what extent, as we say in the questions, price transparency and pricing information should be included in the information blocking, and how we would go about including what are the parameters of that. So, we're trying to get more information.

Because as you all are talking about, pricing is very complicated. As we show in these questions, if it's decided that price information is included, what exactly are we talking about there? Amount to be charged and paid for by the patient's health plan? Charged master price, negotiated price? So, there are a lot of follow-up questions. I think that's what we're trying to get at.

Andrew Truscott – Accenture – Co-Chair
Okay. Thank you.

Morris- Office of the National Coordinator - Back Up/ Support
And I agree with everything Mark is saying – and this is Morris again. I would just say that the Cures Act does not specifically define EHI, and the Cures Act or High Tech or other statutes, and the definition of health information does come from the Sole Security Act, which is where the definition came from in HIPAA. So, that's why we're asking these questions.

Andrew Truscott – Accenture – Co-Chair
And the definition that's in HIPAA is what?

Morris- Office of the National Coordinator - Back Up/ Support
The definition from the Health Insurance Portability and Accountability Act, as someone said, the definition of health information, that's where that definition came from, it came from the Sole Security Act, which is derived from the HIPAA statute. That health information, that definition came from the HIPAA statute in 1996. **[Crosstalk] [00:50:28]**

Andrew Truscott – Accenture – Co-Chair
Yeah, and what was that definition? Does it include price information?

John Kansky – Indiana Health Information Exchange - Member

Well, so, Morris, what you're talking about – you're not talking about electronic health information, though, I don't think.

Morris- Office of the National Coordinator - Back Up/ Support
Correct. Just health information. Yeah.

Cynthia A. Fisher – WaterRev LLC - Member
It does include past. It includes clinical. It includes physical and mental health, and past, present, and future. And it includes payment information, both past payment, present, and future payment information. And it is consistent.

John Kansky – Indiana Health Information Exchange - Member
And I believe that's correct, as I have some depth of knowledge on HIPAA. And the only thing I'm turning over in my head is that the purpose of HIPAA was to define what should be protected. And the purpose of the information blocking rule is to define what absolutely should be shared. And I don't know that that necessarily makes a difference. But it seems worthy of noting.

Cynthia A. Fisher – WaterRev LLC - Member
Well, I would also like to note that the P in HIPAA is portability. And the intent of HIPAA was also to have that portability for the individual to have access to their health information back in 1996. So, the Health Information Portability Act.

John Kansky – Indiana Health Information Exchange - Member
Well, the portability in the HIPAA law was related to the portability of health insurance, not of information. But I don't think that argues against the philosophy.

Andrew Truscott – Accenture – Co-Chair
Okay. I think that we've got lots of opinions on the table. I'm gonna suggest that we pause at this point on this particular item. Obviously, we're gonna come back to it. I know I have a bunch of thinking to do around it. I'm sure others do as well. With the permission of the group, I'd like to move into something that's gonna be just about as contentious as well, I think. Would actually the group be okay to move on, and we'd come back to this? Seeing as this is supposed to be our first ask.

Denni McColm – Citizens Memorial Healthcare – Member
Yeah, this is Denni. Do we actually have multiple views, or do we just have two?

Andrew Truscott – Accenture – Co-Chair
We have two. Well, no. Actually, I think we have – we probably have three. I think definitely Cynthia has expressed a particular view, which I think we all understand. I think I've heard another view from yourself around this doesn't belong. I must confess, I think me personally, if I step out of chairing, I think I'm probably somewhere in the middle. Though I think this is a good act and a good opportunity to engender some kind of transparency, but I'm just not sure that adding price to the definition of EHI for the purpose of information blocking is the

right way to do it. And I'm trying to work out what I think a better way would be. And as you can see from my notes, I'm trying to think through kind of the actual ramifications of what this would mean to – well, I've just called them prices, no matter who they are, what entity is actually doing the pricing. So, I think maybe at least three views. If anyone – John, Mike, you've got other views as well, just to add more color to the rainbow?

John Kansky – Indiana Health Information Exchange - Member

This is John. I think I'd either be in the camp of leaving it out in the sake of focus and narrowness, or with an asterisk of alternatively – and Cynthia's calling up HIPAA has helped me in my thinking. The problem is, I need time to think about the unintended consequences of how this definition is applied in the rest of the regulation, because I have no problem with – for example, HIPAA included all this stuff in the definition of health information so that it could be protected. And then it goes on for hundreds of pages to use that definition to state rules. So, I'm okay with considering putting payment – or, I'm sorry, pricing information into the definition if and only if the way definition is applied elsewhere in the regulation doesn't have these unintended consequences. So, that isn't my primary point of view. I think the way to defend against the unintended consequences is to leave it out.

Cynthia A. Fisher – WaterRev LLC - Member

Well, I just put this out here because I'm probably the only one that represents the patients, families, and caregivers unconflicted. And if you think about from each entity, by having the opacity and not having to reveal price, as "actors" or "players" in the system, then entities can charge whatever they want. And that's what is happening. And I'm happy to share with you what we have on the pulse of the marketplace of information of the harm. If we're in healthcare, we're to do no harm. And we're in an inflection point. Medicare goes bankrupt, as Seema Verma said the other day, in what, 2026? It's not funded anymore, and that's means the tax base will have to pay for it. But we don't have the long-term planning.

But the bigger issue is the insured, and the small business, and the American worker – if you're on Medicaid, you're okay. If you're on Medicare, you're okay. But the American worker and the insured community out there is really suffering. And we're seeing people file bankruptcy because they get cancer. And when a new drug – when you look at your cancer care, whether it's in the hospital system or not, people are having to pay what's worth a new car a month for their care. So, it's across the system. And so, not having transparency into that is a real issue. And I just think that we have this opportunity – there's the intent there. You saw it from the White House that I put up. You saw it from the administration, but also from this whole 21st Century Cures, to create a competitive and trusted marketplace. And the opacity does not serve that.

And I guess I just call to each one of us, just as – what is the right thing to do? And it might not be perfect at what we try to do, but isn't done better than perfect? And can't we work toward that goal by really removing the cloak of opacity?

Andrew Truscott – Accenture – Co-Chair

Okay. I'm gonna time box this one now and say, look, we're gonna park this. We're gonna move on to the other section we have got to discuss today, and we will come back to this in a

future meeting. Okay?

Michael Adcock – Individual – Co-Chair
Sounds good.

Andrew Truscott – Accenture – Co-Chair
Okay. In fact, guys, thank you ever so much for all your contributions. I know that not all of these discussions we're having are gonna be ones where we're coming from the same viewpoint. And I think all of us have got a lot of food for thought coming out of that particular discussion, so thank you.

The second session we have to talk about today is the request for comment regarding practices that may implicate the information blocking provision. Okay, so, we request comment regarding our proposals about practices that may implicate the information blocking provision. Specifically, we seek comment on the circumstances described and other circumstances that may present an especially high likelihood that a practice will interfere with access exchange or use of EHI within the meaning of the information blocking provision.

Michael Adcock – Individual – Co-Chair
Hey, Andy, is it just me, or can we get that pulled up on the screen?

Andrew Truscott – Accenture – Co-Chair
Yeah. So, Mark, could you pull that up on the screen, sir?

Mark Knee – Office of the National Coordinator – Staff Lead
Yeah. Are you seeing it now?

Andrew Truscott – Accenture – Co-Chair
No. We've got a slide.

Mark Knee – Office of the National Coordinator – Staff Lead
Oh. Really?

Andrew Truscott – Accenture – Co-Chair
Yeah.

Mark Knee – Office of the National Coordinator – Staff Lead
Huh. Oh, I have to share the screen. Let me see. Hold on one second. Oh yeah. There we go. All right. Yeah. Give me one second. There you go. Can you see it now?

Andrew Truscott – Accenture – Co-Chair
Well, you need to make it larger. There we go.

Mark Knee – Office of the National Coordinator – Staff Lead
Oh yeah.

Andrew Truscott – Accenture – Co-Chair
Zoom in a bit.

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

Andrew Truscott – Accenture – Co-Chair
Okay, there we go. It's onscreen, guys.

Michael Adcock – Individual – Co-Chair
Thank you, guys.

Mark Knee – Office of the National Coordinator – Staff Lead
Sure. Sorry about that. I should have had it up earlier.

Andrew Truscott – Accenture – Co-Chair
No that's . . . So, I'll actually start it off with one of my comments, which is I think there is a clear disincentive to providing access via patient or open exchange of EHI where there is a competitive landscape between providers. And information retention is a mechanism for de-incentivizing a patient moving between providers. I think, Cynthia, this sounds like you and I would agree completely on this. And providers can be medical services or other ancillaries, such as pharmacies, labs, etc. So, something which came to my mind when I was thinking through this point.

Cynthia A. Fisher – WaterRev LLC - Member
Well, let me just comment on some specific examples that are in the proposed rule. Could we have those pulled up?

Mark Knee – Office of the National Coordinator – Staff Lead
Yeah, I can pull those up. And Andy, I mean, I think to your comment, I think that everything in the rule, we're in agreement of that. That is one of the reasons – one of the many reasons why we're doing this, is that we want the free flow of information. But let me –

Andrew Truscott – Accenture – Co-Chair
Oh yeah, I agree. I don't think it's a contentious point. It's just not being stated clearly. But I think that my point is actually that providers can actually be a very broad church here. Providers can be actual physicians or physicians groups, hospitals, etc., but also pharmacies, retail pharmacies, labs, blablabla.

Mark Knee – Office of the National Coordinator – Staff Lead
Yeah. I mean, that ties into kind of our discussion the other day, is that that's true. And again,

broken record, we have to look at the definition of provider provided, that the Public Health Service Act definition.

Andrew Truscott – Accenture – Co-Chair
We know. That's why we've said – I think we've said repeatedly, we need to look at that definition, because that definition isn't broad or clear.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay. Yeah. Sorry, just finding the text for this.

Andrew Truscott – Accenture – Co-Chair
It's page 364.

Mark Knee – Office of the National Coordinator – Staff Lead
Yeah. Yup, yup. Give me one second. All right. So, there's a number of – it starts on, I think, 353 here. But when we break it down – I'll just scroll through, try not to give you guys a headache. Break it up into different categories. There's prevention material, discouragement, other interference. And then we talk about the likelihood of interference. Then we discuss observational health, which is the primary type of electronic health information that we focus on. It has to do with medical care. And we have a discussion of that. And then we get into purposes – why information may be needed. Anyway, so there's a lengthy discussion and lots of examples.

So, I think to Andy's point, what are we getting at here, I think we just want to make sure that we are accurate and exhaustive in our – and you can't be totally exhaustive, but we cover all of the really important scenarios that would explain what information blocking is and make sure that the examples provided are accurate and on point as far as the type of conduct you would expect to be included as information blocking.

Andrew Truscott – Accenture – Co-Chair
So, is your suggestion, Mark, we actually work through the preamble?

Mark Knee – Office of the National Coordinator – Staff Lead
I mean, again, I don't know that – this is just my opinion. I don't know that there's – I mean, we have a request for comment, but it's really a general one. And I don't know that I have specific issues about this topic that need to be discussed. If you would like to go through each example, we can. But I guess I don't have a focused idea of any issues to raise here. It's more just a general request for comment.

Denni McColm – Citizens Memorial Healthcare – Member
This is Denni. I thought you showed some specific examples, which I see at the bottom – on yesterday's call, which I see at the bottom of a page farther down, 365, that you . . .

Mark Knee – Office of the National Coordinator – Staff Lead
Sorry to interrupt. Yeah, you're right. I mean, we do provide different examples. I think they

start here. Yeah. I'll scroll down. So, here are examples on 364, and then that's where we break it up into the categories, restrictions on access, exchange, or use. And then we have these bulleted examples. Would you all like to kind of walk through those?

Andrew Truscott – Accenture – Co-Chair
I think the bottom of 365 onwards.

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

Michael Adcock – Individual – Co-Chair
I would.

Andrew Truscott – Accenture – Co-Chair
Yeah.

Mark Knee – Office of the National Coordinator – Staff Lead
Okay. Yeah, it's up on the screen. And I can just scroll through as we go through, if that's helpful.

Andrew Truscott – Accenture – Co-Chair
So, let's walk through these together on the screen. Can you zoom in?

Mark Knee – Office of the National Coordinator – Staff Lead
Zoom in more? Yeah, yup. Let me zoom in.

Andrew Truscott – Accenture – Co-Chair
It seems we're all sitting there with you as a subset of our screen. Okay, got it.

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

Andrew Truscott – Accenture – Co-Chair
Is that the first one? Yeah. Okay. So, health system's internal policies or procedures require staff to obtain an individual's written consent before sharing of any patient EHI **[inaudible] [01:06:25]** even obtaining an individual's consent is not required by state or federal law.

Mark Knee – Office of the National Coordinator – Staff Lead
And just to put a finer point on our position, I don't think that, from our perspective, we're really asking whether these – we feel strongly these are situations that implicate the information blocking provision. I think it's more – I can pull up the exact request for comment – but other situations, maybe, that could be added. I mean, we can kind of talk about these fact patterns. But from our perspective, these are things that would implicate the information blocking provision.

Denni McColm – Citizens Memorial Healthcare – Member
So, this one by itself is a little weird, now that I have read these through. The health system's policies require staff to obtain written consent before sharing the patient's EHI with any affiliate providers, even though obtaining an individual's consent is not required by state or federal law. Where is it? I mean, there's certain exchanges of information, I guess for care, that don't require an individual's consent. But what else would not require an individual's consent?

Mark Knee – Office of the National Coordinator – Staff Lead
Well, so, without getting into – I mean, and Morris is the expert on HIPAA and things like that, so I'll let him chime in. But the purpose of these examples is to show when an actor might be creating an extra burden that would – as I kind of explained in the last call, these are situations that would implicate the information blocking provision, meaning that there's an actor who's defined as one of the four – a provider, a developer, an exchange, or network; there's an interference with access exchange or use of electronic health information as defined in Cures. And then that's kind of the basis here. There could still be a requirement by law or an exception that would apply. So, this is just –

Andrew Truscott – Accenture – Co-Chair
But Mark, I think the point that was being made was that this might not be a realistic illustration because there isn't a situation where individual consent is not required.

John Kansky – Indiana Health Information Exchange - Member
That's not how – I think –

Mark Knee – Office of the National Coordinator – Staff Lead
No.

John Kansky – Indiana Health Information Exchange - Member
I think this is a good – well, let me make sure I understand it. I think this is a fine example. It's basically saying, okay, you're in a state where there's no additional requirement to get a patient's consent to share their data, assuming it's for treatment – and it says it's for treatment purposes. So, under HIPAA, there's no requirement that the patient consent to their sharing of this data with another covered entity. So, if the health system has an internal policy that says, nope, nope, nope, you can't do that without getting an individual's written consent, do we think that's a fair – do we think that practice should trigger information blocking? That's my interpretation of the question.

Andrew Truscott – Accenture – Co-Chair
Well, it does say "unaffiliated providers."

Denni McColm – Citizens Memorial Healthcare – Member
Okay, this is Denni. I get it. I get it now. I wasn't reading the "for treatment purposes." Okay.

John Kansky – Indiana Health Information Exchange - Member
The thing is – I mean, I'm reading down to the next example and moving on, and it's kind of like, wow, this is gonna get interesting, because – this isn't a particularly intelligent comment. It's just to say that, yeah, this stuff happens all the time. And when I – waiting for this rule to drop and thinking about the kinds of situations that we were trying to prevent, I was thinking of more egregious examples. But that's of no particular use, except to say that I'm sure these happen all the time.

Andrew Truscott – Accenture – Co-Chair
Actually, guys, just so you know, coming out of another one of the workgroups yesterday, there was a comment that if we do this, this is an impact to everybody. And I think we're seeing a bit of that right now. We're asking that this stuff happens all the time.

Cynthia A. Fisher – WaterRev LLC - Member
That's right. And we've been told of examples where the quality of healthcare and the risk to the patient was very high when they couldn't represent themselves, and the institutional parameters of how HIPAA was used egregiously prevented the ability to share information that, even in life-threatening situations for the patient, caused a duress in care and a duress in physicians having to advocate and dial and get whomever they can to try to get access to patient information. So, I think the intent here, and maybe the agency can help us – but isn't the intent to prevent information blocking and provide for the patient readily available access within state law, and not have egregious rules and procedures that create, essentially, information blocking?

Mark Knee – Office of the National Coordinator – Staff Lead
Sure, yeah. I mean, and these examples are based off of stakeholder feedback. We've been meeting with stakeholders on this issue for quite some time. And like you all are saying, this stuff happens all the time, and this is our reaction to it. And yes, patients should have their information, and information should be flowing freely, or with a reasonable cost, or one of the exceptions applies, or it's required by law. So, yes, the intention is make the information flow and allow folks to get access, exchange, or use to their health information.

Cynthia A. Fisher – WaterRev LLC - Member
And I mean, the intent is really – we're looking at this digital world. Once it's electronically available, it has de minimis cost, and it's already been paid for. And so, we're looking at real-time and free, ultimately for the patient, so that it's part of their longitudinal record. And then, when you have an infection from a hip surgery, for instance, whether you would know the microorganism because you could have the actual past report pushed to your aggregated place, versus literally seeing six weeks and snail mail and a check to try to get something that's well beyond the timeframe that you need it. So, this is our opportunity and our moment in time to get the patients their data.

Mark Knee – Office of the National Coordinator – Staff Lead
Exactly. I agree.

John Kansky – Indiana Health Information Exchange - Member

Andy, can I weigh in on one of the examples in the preamble?

Andrew Truscott – Accenture – Co-Chair
Please do.

John Kansky – Indiana Health Information Exchange - Member
So, the third example, which is the second one on the top of page 366. So, let me, with the caveat that I've been assuming that the Indiana Health Information Exchange fits the definition of a health information exchange. I have not considered whether the Indian Health Information Exchange meets the definition of a health information network. But using us as a case study, this basically says that an HIN's participation agreement prohibits entities that receive EHI through the HIN from transmitting EHI to entities that are not participants of the HIN. So, the participation community, the Indiana Health Information Exchange works like a co-op. So, you join it, you share your data. Others can view your data. You get access to their data. And there's obviously a participation agreement, and there's fees, and it works great. And under circumstances like SHIEC Patient Centered Data Home or eHealth Exchange, we're certainly sharing data beyond through the exchange under different data use agreements, etc., etc.

But the participation agreement certainly defines who is in and outside of the co-op, and would definitely prohibit data-sharing outside the co-op, because those are the rules of participation, and that's the only reason people are comfortable sharing their data. So, as I read this, I'm kind of like, well, I think I understand the intent of that. It's to avoid creating walled gardens that are like, neener, neener, you can't have our data. But I'm not sure how that doesn't fly in the face of having participation agreements that define anything.

Mark Knee – Office of the National Coordinator – Staff Lead
Yeah. So, I see your point. I mean, I think in that situation, the HIN would need to look at whether there's – or we would have to look at whether the HIN claimed that it was covered by an exception, like security; whether the reason that they're not sharing or transmitting the EHI to entities outside of the HIN is because there's a security risk, or privacy, or something like that. I think that what we're saying is that this is a problematic situation because there's an interference with access, exchange, or use of EHI, and in order for it to be okay, there would need to be a reason that we lay out in the exceptions.

John Kansky – Indiana Health Information Exchange - Member
Well, and not assuming that any exception would necessarily apply to that, if I could just give you a quick example, I think it's fair to say IHIE is a successful and sustainable health information exchange, and the federal government likes there to be those things, in the best interests of healthcare, etc. But we have hospitals on the Indiana side of the state line five miles from hospitals that are in South Chicago. And the participant from Indiana pays us a not insignificant sum of money to participate in and benefit from the sharing of data. And the hospital on the Illinois side of the line that does not participate currently does not share the data and isn't a member, and doesn't pay fees. So, if we were required by information blocking to share that data, regardless of whether that organization had agreed to the rules of sharing or had paid any fees, etc., etc., I mean, that blows a hole through our entire

business model and probably puts us out of business.

Denni McColm – Citizens Memorial Healthcare – Member

So, I have a question about that. If a patient goes to that Indiana hospital, and then they decide to transfer their care to Illinois Hospital, can the Indiana hospital release the information they got from the health exchange that's sort of part of their record now that they used to care for that patient?

John Kansky – Indiana Health Information Exchange - Member

Yes, absolutely. **[Crosstalk] [01:17:35]**

Cynthia A. Fisher – WaterRev LLC - Member

But isn't information blocking intent to just open up the pipes so that you let it flow freely, and if you belong to a certain exchange, or you have a way to exchange, remember, there will be the future, and we want to lay the pipe for the future so that we have conduit. And so, I think it's a matter of enabling the pipe flow. And the "you need to be a member and pay us fees," I don't think is in our realm. It's about opening the pipes.

Andrew Truscott – Accenture – Co-Chair

Okay, guys. Let's just park this one for the time being. I think it's time to open up for public comment. Could we quickly do that?

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer

Sure. Operator, can you please open the line?

Operator

If you would 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 would 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

Great. Okay. So, we've had the number up for a few minutes, hopefully give folks time to dial in. Do we have any comments in the queue at this time?

Operator

Not at this time.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer

Okay. Andy, I'll hand it back to you.

Andrew Truscott – Accenture – Co-Chair
Thanks, Lauren. So, Cynthia, do you want to finish off your point?

Cynthia A. Fisher – WaterRev LLC - Member
Oh, I was finished, thank you.

Andrew Truscott – Accenture – Co-Chair
Okay. So, I hear what you're saying. Again, this is another set of ones I think we're gonna have to go away and think about. I've just made a comment on the dark board, maybe more to myself, but if you look at the – Mark, can you quickly scroll to the one that's at the bottom of page 368?

Mark Knee – Office of the National Coordinator – Staff Lead
Yup, sure. Give me one second here. And –

Andrew Truscott – Accenture – Co-Chair
Oh, go on.

Mark Knee – Office of the National Coordinator – Staff Lead
And I just wanted to make a note to John, just because what I said, we're very open, as I think you're noting in your comment, if you think it's an example that maybe isn't as clear or is problematic, we definitely want to hear about that. So, I didn't want to . . .

John Kansky – Indiana Health Information Exchange - Member
No, thank you. Absolutely. I'll put something in there. And key to my comment, which I need to go back and assess whether the health information network even applies. So, I'll be careful.

Mark Knee – Office of the National Coordinator – Staff Lead
Great. Here you go, Andy. I think this is the one you're talking about.

Andrew Truscott – Accenture – Co-Chair
Yeah. And thanks, John. And yeah, as we go back to it, the definition of HIE and HIN, we're gonna need to come and visit, I think, this example as a useful case point. So, guys, have a quick look at this one. And you need to scroll on to the next page slightly as well, if you can. A health system implements locally hosted EHR technology. Okay. And it has a series of APIs associated with it. And the technology develops or provides a health system with the capability to publish those endpoints. So, we can say to the outside world, okay, here are the APIs. Come and get at them to get access to patient data. The health system chooses not to enable the capability, however, and provides the endpoint information only to actors specifically approved. Okay. This prevents other applications that patients use from accessing data that be made readily available by **[inaudible] [01:21:08]** APIs.

I get that principle and I get that point. But my concern is, I don't think the intent is to have free, uncontrolled, unregulated access to patient information. I think, isn't there an onus to a

provider that they need to be confident that the people accessing their data are authorized to do so?

Mark Knee – Office of the National Coordinator – Staff Lead

Yeah. I mean, so there is an exception for costs reasonably incurred and for licensing on RAND terms. And also, on the API section, it's kind of a bit of a cross-reference, there are certain costs that are allowable, because we want to promote innovation for APIs and app developers, all that. So, we do address that. It shouldn't all be free except for the patient, so.

Andrew Truscott – Accenture – Co-Chair

Oh, no, no, sorry. By free there, I mean unregulated and uncontrolled.

John Kansky – Indiana Health Information Exchange - Member

Yeah, and Andy, I see – the example that I was thinking about, which I think I've heard some of the EHR vendors comment on, is does the security exception allow a health system to say, well, my EHR vendor has certified these five products that we're giving access to via API, but there's 36 other products out there that we either haven't had a chance to assess whether they're secure or not, or have deemed that they're not secure. Is that gonna be okay? I mean, you can see a bunch of places we could get tripped up. But it also seems reasonable that a hospital shouldn't have to share its data with any application that was just rolled out yesterday.

Andrew Truscott – Accenture – Co-Chair

Yeah, I agree with you. And I'm sure that there's some intricacy somewhere else inside here that says, oh no, you wouldn't have to do that, which is why I think these illustrations should be a little bit more – well, should be mindful about. Mark, Morris, do you want to – since you guys were authors of these, do you want to comment?

Mark Knee – Office of the National Coordinator – Staff Lead

Sorry, I didn't realize that was a question. Can you say it one more time? I guess what the question is –

Andrew Truscott – Accenture – Co-Chair

Well, the question is, do you agree with where John and I are coming from, that there has to be some control? No one's an authorized individual just because they've got an app, getting access to patient data.

Mark Knee – Office of the National Coordinator – Staff Lead

No. I mean, I think as far as controls go, the exceptions are supposed to act as controls for – we want responsible sharing of information. But you start with the default that information should be shared, unless it's required by law or there's an exception that applies.

Andrew Truscott – Accenture – Co-Chair

Yeah. And this particular example is saying that when the health system won't actually allow you to access unless they approve the app that you're using.

Mark Knee – Office of the National Coordinator – Staff Lead
Right. I think what we're getting at there is that it's an unnecessary restriction. Let me read the example one more time, but . . . So, the technology provides the health system with the capability to automatically publish its production endpoints. So, there is the capability, but the health system chooses not to, and there's no reason for us to believe that that's for a security reason or any other reason. It could be, but I guess the facts don't provide that.

John Kansky – Indiana Health Information Exchange - Member
I guess, yeah. So, that seems reasonable. What I'm just pointing out is that there's gonna be hospitals that have vendors that say, here's our list of products that –

Andrew Truscott – Accenture – Co-Chair
Approved actors, yeah.

John Kansky – Indiana Health Information Exchange - Member
Yeah, that we approve. And others need to apply here and go through this process. And if they can say security exception, and the federal government doesn't get them in trouble, then that's fine.

Andrew Truscott – Accenture – Co-Chair
John, I think this is the one on page 371, first bullet point.

John Kansky – Indiana Health Information Exchange - Member
Yeah?

Andrew Truscott – Accenture – Co-Chair
Yeah. An EHI developer of certified health IT requires third party applications to be vetted for security before use, but does not properly conduct the vetting or conducts the vetting in a discriminatory or exclusionary manner.

John Kansky – Indiana Health Information Exchange - Member
But then it's okay or that's not okay?

Mark Knee – Office of the National Coordinator – Staff Lead
No, that's another one that's not okay. This is a whole section of – this would fall into the category of impeding innovation. And one of the other driving forces behind information blocking provision and our exceptions is that competition is really important. And a lot of – based on stakeholder feedback, we've seen that there are situations where interoperability elements or information is not shared because it has to do with a competitor. And I think that's what we're getting at with some of these, is that you can have a legitimate reason. But if you're just saying, "I'm not gonna share for my own business purposes; it doesn't help me," that's not a good enough reason.

Andrew Truscott – Accenture – Co-Chair

Ooh, I'll tell you, look at the third bullet point on this page. Those of you that work across the – phew!

Mark Knee – Office of the National Coordinator – Staff Lead

What page? 371, or where are we at?

Andrew Truscott – Accenture – Co-Chair

371. An EHR developer of certified health IT maintains an app store through which other developers can have apps listed that run natively on the EHI developer's platform. However, if an app competes with the EHI developer's apps or apps it plans to develop, the developer requires that the app developer grant the developer the right to use the app source code. What? Okay. **[Crosstalk] [01:27:08]** I'm just thinking of developers who **[inaudible] [01:27:11]**. So, yes. That's a big one.

Mark Knee – Office of the National Coordinator – Staff Lead

Yeah. And if that kind of example – and I mean, Andy, I know you're involved in all of this. But the exception for licensing on RAND terms will probably interest you, because it gets into that type – and we talk about competition in the reg text, and preamble, that you can't limit access, exchange, or use based on competition.

Andrew Truscott – Accenture – Co-Chair

Okay, team.

John Kansky – Indiana Health Information Exchange - Member

There's such an opportunity for subjectivity and fights. Oh, my God.

Andrew Truscott – Accenture – Co-Chair

John, you should apply for a job with OIG. The OIG's gonna be insanely busy with this. Okay. It's 2:00. We're gonna meet again next week as a work group, and we're gonna meet again tomorrow as a taskforce. We're gonna just quickly touch upon the fact that literally, the objective – this is the progress we're making. This is how far we've got so far. That's it. Does anybody on this workgroup have any issues that they want to raise with the core taskforce?

Okay, that's great. Well, for that, it's top of the hour. Thank you ever so much for your time. I look forward to speaking to you tomorrow and next week.

Cynthia A. Fisher – WaterRev LLC - Member

Great. Thanks, everybody.

John Kansky – Indiana Health Information Exchange - Member

Thanks.

Mark Knee – Office of the National Coordinator – Staff Lead

Thank you.

Denni McColm – Citizens Memorial Healthcare – Member
Bye-bye, everyone.

Andrew Truscott – Accenture – Co-Chair
All right, bye. Thanks, team. Bye-bye.

Duration : 89 Minutes