



Trusted Exchange Framework and Common Agreement Task Force

Transcript
June 13, 2019
Virtual Meeting

SPEAKERS

Name	Organization	Role
Arien Malec	Change Healthcare	Co-Chair
John Kansky	Indiana Health Information Exchange	Co-Chair
Noam Arzt	HLN Consulting, LLC	Public Member
Laura Conn	Centers for Disease Control and Prevention (CDC)	Member
Cynthia A. Fisher	WaterRev, LLC	Member
Anil K. Jain	IBM Watson Health	Member
David McCallie, Jr.	Individual	Public Member
Aaron Miri	The University of Texas at Austin, Dell Medical School and UT Health Austin	Member
Carolyn Petersen	Individual	Member
Steve L. Ready	Norton Healthcare	Member
Mark Roche	Centers for Medicare and Medicaid Services (CMS)	Member
Mark Savage	UCSF Center for Digital Health Innovation	Public Member
Sasha TerMaat	Epic	Member
Grace Terrell	Envision Genomics	Public Member
Andrew Truscott	Accenture	Member
Sheryl Turney	Anthem Blue Cross Blue Shield	Member
Denise Webb	Individual	Member
Lauren Richie	Office of the National Coordinator	Designated Federal Officer
Cassandra Hadley	Office of the National Coordinator	HITAC Back Up/Support
Zoe Barber	Office of the National Coordinator	Staff Lead
Kim Tavernia	Office of the National Coordinator	Back Up/Support
Alex Kontur	Office of the National Coordinator	SME
Morris Landau	Office of the National Coordinator	Back-up/Support

Michael Berry	Office of the National Coordinator	SME
Debbie Bucci	Office of the National Coordinator	SME
Kathryn Marchesini	Office of the National Coordinator	Chief Privacy Officer

Operator

Thank you. All lines are now bridged.

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

Good afternoon or good morning, everyone. Welcome to the TEFCA task force. We'll get started with a roll call. John Kansky.

John Kansky - Indiana Health Information Exchange - Co-Chair

I'm here.

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

Arien Malec. Carolyn Petersen. I believe she's joining. Aaron Miri. Sheryl Turney.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Here.

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

Hi, Sheryl. Was that Aaron as well? Okay. Sasha TerMaat.

Sasha TerMaat - Epic - Member

Here.

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

Steve Ready. Cynthia Fisher.

Cynthia Fisher - WaterRev, LLC - Member

Present.

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

Anil Jain. Mark Roche. Andy Truscott. Denise Webb.

Denise Webb - Individual - Member

Here.

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

David McCallie.

David McCallie, Jr. - Individual - Public Member

Here.

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

Mark Savage.

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

Good morning.

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

Noam Arzt.

Noam Arzt - HLN Consulting, LLC - Public Member

I'm here.

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

Grace Terrell. And Laura Conn.

Laura Conn - Centers for Disease Control and Prevention - Member

Here.

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

Okay. John, it's all you.

John Kansky - Indiana Health Information Exchange - Co-Chair

Thanks. And welcome again. We are picking up where we left off from Tuesday. And we're going through the draft transmittal letter with the recommendations. For those who were not on the call last time, I don't know if there is anyone in that category, we're picking up with individual access services, which is 4.1. A little bit of an explanation of where we are in terms of process is there was a request for – let me start that sentence over again. We've made edits to the document based on the feedback we got on the call on Tuesday to everything prior to 4.1 in this document.

We're optimistic that we're going to get to the end of this document today and we'll turn another round of edit to get to the bottom of the document and get that out by the weekend, including a clean and red lined version depending on your preference for those that want to see how it was edited. And then, we'll be looking for you to read that and be ready to feedback on our next call. Is anybody willing to tell me that that made sense, what I just said?

David McCallie, Jr. - Individual - Public Member

That made sense.

Denise Webb - Individual - Member

Yeah.

John Kansky - Indiana Health Information Exchange - Co-Chair

Thank you. I need validation sometimes.

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

And just a reminder that our next call is actually going to be our presentation of the draft recommendations to the committee. So, I think it stands to reason this will definitely be draft. We're going to have to do more discussion afterward. So, I think we have four calls right now scheduled between the 19th and July 11. And we can always add on more if we feel it necessary.

John Kansky - Indiana Health Information Exchange - Co-Chair

So, Zoe, consistent with the rules, are we going to go into that HITAC meeting presentation with the draft as it exists after that last round of edits? And what I mean by that is what opportunity, if any, is there to take feedback from the task force and make edits between them and the HITAC meeting?

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

Yeah. So, Lauren and Cassandra if you're on, I'm going to ask you guys to jump in here a little bit. What I think is we can probably make edits based on feedback we get from the task force Monday and Tuesday. When do we need to send in the draft letter to the full committee prior to Wednesday's call and, I guess, how baked does the letter have to be? Can it have place holders and highlights and redlines or should it be as close to clean as it can be?

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

This is Lauren. We're shooting to get everything through the full committee by Monday. We do want to give them at least a couple of days to review everything ahead of the meeting. It doesn't have to be completely baked. I think if you want to or need to leave your redline edits in there, you can but as clean as possible so they get a sense of where the recommendations are. And I would say Wednesday morning at the latest.

David McCallie, Jr. - Individual - Public Member

Does the committee get the document that we've been editing over or do they get it put into a PowerPoint? Can you just remind us?

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

Designated Federal Officer

It will be both. The PowerPoint is mostly for the public and for the Adobe display. But we, typically, send the actual document. Again, it doesn't have to be completely final.

John Kansky - Indiana Health Information Exchange - Co-Chair

So, what I heard is that it will go out over the weekend. If there are any ambitious task force members who want to read and send suggested edits, who would they do that over the weekend? Or should we not put that on the table?

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

I think the latest we can get everything out is Tuesday morning. So, if you want to iterate over the weekend, I'd say that's fine. But you'd have to wrap it up by end of the day Monday.

John Kansky - Indiana Health Information Exchange - Co-Chair

Yeah. No, I'm not trying to push your timeline. So, then let me start that over. It sounds like whatever draft we have after the round of edits after this call will be the drafts that we're going into the HITAC presentation with because it will be sent out Monday. Just my preference or my suggestion would be that I'd rather say that we're still editing and this isn't final than it is to make people read through redlines on the PowerPoint. So, just as a HITAC member and trying to follow the work of other task forces that I'm not on, I'd prefer to be reading something as clean as possible, even if there's a big red thing at the bottom that says this isn't final.

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

Yes, and I think that's perfectly fine.

John Kansky - Indiana Health Information Exchange - Co-Chair

Okay, thank you.

David McCallie, Jr. - Individual - Public Member

And the whole point of presenting it to the task force is to get additional feedback for us to take into consideration, right? So, we want them to think of it as a draft that seeks their input in the discussion.

John Kansky - Indiana Health Information Exchange - Co-Chair

That's my understanding as well.

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

Yeah. John, quick question. Do you want any time on today's agenda to discuss priorities for the presentation since we're not meeting again before you're actually making it or just do it yourself? Different task forces, in my experience, have approached that question differently.

John Kansky - Indiana Health Information Exchange - Co-Chair

Yeah. I'm not sure I either A) understand the question or B) have given it any thought because going into this, I'm going to be happy to clearly explain our work and our recommendations. So, can you clarify what you mean by priority?

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

In the past, we've sometimes picked issues to instead of just going through something from A to Z, we sometimes said here are the most important things for you to focus on. Now, we're going to go to Z. That's been a task force discussion ahead of time just to help the presenters if they had any questions. I don't see time for that on today's agenda. That's why I was asking the question.

John Kansky - Indiana Health Information Exchange - Co-Chair

Yeah. I'll admit we hadn't planned for that. So, why don't we –

David McCallie, Jr. - Individual - Public Member

Well, we did identify a prioritization. I think that our discussions have been gated by that list that you and Arien put together early on. Maybe you could share that just as a backdrop of where we focused our energies.

John Kansky - Indiana Health Information Exchange - Co-Chair

Good point. That's probably where the presentation will start is with that framing before we dive into recommendations. I would offer that if we're extremely lucky and we have an extra five or ten minutes in the end – was that Mark's suggestion or question?

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

That was Mark, yes.

John Kansky - Indiana Health Information Exchange - Co-Chair

Wow, I'm learning voices. If we have a few minutes in the end and you feel strongly about some aspects of priority, we'll try and take that on at the end. And if we don't get to that, we'll leave on the approach that David just suggested.

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

Okay. If we do have time in the end, it will help me if somebody can throw up whatever that prioritization was because it's not committed to my short term memory.

John Kansky - Indiana Health Information Exchange - Co-Chair

Yeah, same here. It was more of a framing of the charge, I think if I'm remembering correctly. Okay. Let's dive in because the sooner we work through these recommendations, the more likely it is we'll have time to prepare for the HITAC presentation. Okay. We left off on individual access services. By the way, disclaimer and apology in advance are that I'm slightly less prepared today than I have been for previous calls. So, I may end up having to read these to you to get them back in my RAM as well. This one is focused on, I think, Recommendation

7A, an alternative recommendation, represent slightly different points of view.

And I think we want to have a focused discussion to find out if there's a consensus among the group. On Recommendation 7 and, again, tell me if I'm wrong, I think, Mark, you may have been championing this on a prior call –

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

I was.

John Kansky - Indiana Health Information Exchange - Co-Chair

Thank you. So, I may impose on you to speak to this after framing. So, the observation was that individual access services as defined in draft TEFCA have a certain constrained focus and that ONC should consider building a broader set of capabilities for individuals, not just limited to access a copy of their EHI. An alternative recommendation was that we are suggesting ONC should walk first then, run suggesting that the capability of IAS in TEFCA is already a huge step forward. If ONC adds write capabilities into TEFCA, they would also need to include in the rule. Okay. So, I think, if I'm not misinterpreting, it's two alternative points of view. One that the IAS draft TEFCA isn't broad enough and the other is that it's fine, don't put any more in there right now. With that, where do we stand? Carolyn Petersen is fastest to the draw.

David McCallie, Jr. - Individual - Public Member

David here.

John Kansky - Indiana Health Information Exchange - Co-Chair

Okay. David, you're after Carolyn.

David McCallie, Jr. - Individual - Public Member

Oh, okay. I didn't hear you. Go ahead. I'm sorry. I just lost the sound for a second there. Go ahead, Carolyn.

Carolyn Petersen - Individual - Member

Yeah. I just wanted to express my support for Recommendation 7A. I think that a broader approach is important because, certainly, this is something that consumers are starting to do and have demonstrated an interest in. It may be very important for patients to be able to have this capability as more mobile health apps are built out and there is greater reliance on patient-reported outcomes and other interactive measures. I think saying we don't need to worry about this just kicks the can down the road and creates a problem in a few years where we have technology that doesn't support the capabilities that providers and patients want to use.

John Kansky - Indiana Health Information Exchange - Co-Chair

Thank you. David?

David McCallie, Jr. - Individual - Public Member

So, I'll take a compromise point of view. I don't think these need to be alternatives. I think you could say, basically, start first with the described read capabilities that leverage existing networks and then, incrementally advance from there. Don't limit yourself to read. ONC should not limit the TEF to read access but you should start there. The technical complexity to add better-rated write access directly to clinical data repository's electronic health records is a gigantic technical step of complexity, risk, security, etc. And it would be, I think, ill-advised to start with that as an immediate goal. Start with the goal that's currently expressed and then, incrementally advance. So, I'm in favor of mentioning the expansion to write capability. But I think 7B is the starting point. So, I would just merge those two into a single thought.

John Kansky - Indiana Health Information Exchange - Co-Chair

Thank you. Noam has his hand raised.

Noam Arzt - HLN Consulting, LLC - Public Member

Yeah, just real quick. I actually support what David is saying. To me, 7B provides the answer to the when of expanding 7A. So, 7A doesn't say sort of when that capacity should be broader. But 7B sort of says you do read first and then, you worry about other capabilities. So, I would also support sort of munching them together.

John Kansky - Indiana Health Information Exchange - Co-Chair

Thank you. Mark and then, Denise.

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

I think we should keep – there are two issues here and they are, in some ways, connected but in other ways, separate. The read/write is a question. But expanding individual access services beyond merely exercising two writes under the HIPAA privacy rule doesn't depend on whether you've got write access or not. And so, I would disconnect those two in people's thinking. I think whatever we say on read and write, I think we also should expand individual access services beyond just getting a copy under 524 or directing under Section 164.524 or directly a copy be transmitted to a third party.

David McCallie, Jr. - Individual - Public Member

Mark, what do you have in your mind's eye just to help me understand the use case?

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

So, previous ones that do involve writing, things like PGHG, patient-reported outcomes but imagine the kinds of things that people are already trying to do on their portal around lab results, prescriptions, contacting their doctors, shared care planning in its current nascent forms. There's a third HIPAA right, actually, that if we're just focused on rights, it definitely should be in there, which is the right to correct or amend your record when there are errors or omissions. Those are all things that should be a part – those are core uses cases. That's not the stuff around the periphery that I think should be a part of individual access services. So, I wouldn't even be defining it around exercising these rights under HIPAA.

David McCallie, Jr. - Individual - Public Member

My concern would be whether –

John Kansky - Indiana Health Information Exchange - Co-Chair

Go ahead, David.

David McCallie, Jr. - Individual - Public Member

I'm sorry. I just think those are laudable goals. I'm not sure that TEF is a framework to achieve them. The complexity to do so compared to doing it with consumers directly interacting with the people that are helping manage their care is not necessarily worth the risks, it would seem to me. That's something that should be carefully thought out.

John Kansky - Indiana Health Information Exchange - Co-Chair

So, we've got a lot of people wanting to weigh in on this one. I'm going to put myself in line behind Denise, Cynthia, and Carolyn. So, Denise, you're up.

Denise Webb - Individual - Member

So, I see Mark's point on this about the differentiation and the two issues of read/write versus read versus the particular use cases that individual access services is limited to or expanded to. But I, generally, think that these issues all need to be combined and addressed in one recommendation and that there should not be a cap or a limit on the individual access services exchange purpose. That we should start with a place that's achievable but not limit what potential there is.

John Kansky - Indiana Health Information Exchange - Co-Chair

So, I understand that comment to be somewhat consistent with the walk first then, run. Sort of what Noam was saying a few minutes ago. And I think I feel maybe an edit to this recommendation emerging as advising ONC that there are lots of other things individuals are going to want and need to do but some understanding that they can't all be done immediately within the first implementation of TEF. Cynthia.

Denise Webb - Individual - Member

That's a good point. Thank you. And I was just going to say that whether it's read or write, it depends on the use case. And we shouldn't restrict things to just being read.

John Kansky - Indiana Health Information Exchange - Co-Chair

Got it. And, again, I'm going to respect those with their hands raised and not offer my opinion until we get through. Cynthia and then, Carolyn.

Cynthia Fisher - WaterRev, LLC - Member

Yes, hi. I support what Mark was bringing up and Denise. It really needs to be read/write access for the patients. And this is really about delivering patient individual access to their data. And I think the restrictive based upon limited capabilities of today's software is also a

problem. And I think needing to open it up that even in patients wanting access to open notes, for instance, and being able to correct those notes where they're erroneous and then, also being able to share to a third party. These things are going to be imminently important in allowing for fluidity and also across systems. And also, I think we have to be really cognizant of how disruptive innovation can be to allow for superior convenience, efficiency, and reduced cost to the individual.

So, by them getting the highest level of access and fluidity across systems and read/write ability for correcting errors, having that access is going to be really, really important. I think in this week's *Boston Globe*, there was a report on the hospital misdiagnoses and error rates in the hospital up in Massachusetts. And we saw nearly 20 percent. If we can prevent that and bring that number down through patient engagement in actively engaged data into their results, that's a critically important factor to improve healthcare and also reduce the price. Thanks.

John Kansky - Indiana Health Information Exchange - Co-Chair

Thank you. And a key question from me, which I think I'm going to – there are three people with their hands raised so let me just kind of park this one but a question I have for Mark, Carolyn, Cynthia who seem to be in the same camp is – are you insisting or feeling strongly that this broader capability for individual access services needs to be defined in the exchange purpose that's required from Day 1? And Carolyn is next up with her hand raised, not to put you on the spot.

Carolyn Petersen - Individual - Member

As you ask the question that way and frame it that way, given that you're looking for an either/or yes or no answer, I'd have to say yes. I appreciate that there are technical difficulties with all of this and it's hard and it costs money but if we don't think broadly and look down the road to the future to all of the things that the system currently expects patients and providers to do and will expect them to do more and more going forward, we will always be in this position of the technology not keeping up with the needs, waste, safety issues, problems that never get solved because we're not looking far enough down the road. I'd say yeah, it needs to be in the broad from the beginning. Thank you.

John Kansky - Indiana Health Information Exchange - Co-Chair

So, defining a phased, and I'm arbitrarily going to say three phases, of first this then, that then, that and building that into the path of TEFCA wouldn't address your concern that it would be forgotten.

Carolyn Petersen - Individual - Member

Well, that depends on what the language is. If you have very vague language that says when we have achieved X then, we'll think about Y then, you are left forever arguing about whether we've achieved X and what X actually was and what anybody agreed to in the first place. And you never get down the road. So, I'm happy to look at the language and to try to help craft something that I think addresses where Cynthia and Mark and I and perhaps others are looking. But we need to be careful about what we're actually saying and make sure we're saying something.

John Kansky - Indiana Health Information Exchange - Co-Chair

Thank you. David and Aaron and waiting patiently so I'm going to withhold interjecting my opinion. David, keep going.

David McCallie, Jr. - Individual - Public Member

Yeah. I've got a million things I could react to but I want to zoom out a tiny bit and maybe it's a Zoe question, which is over time, how does TEF change the permitted purposes and use cases? Does it require new rule making if that's something that can be delegated to the RCE? Is there an RCE ONC back channel path that will allow for expansion of use cases? In other words, we're talking about, essentially, adding a new use case here. That could happen now in the recommendations that we're making or it could happen a year from now if we talk about the go slow, do it later approach. But either way, it's expanding the current list of I'm calling them use cases because I think it's a mix of permitted purpose and modality. So, the question in a wordy way is how do those things get expanded over time? Does that require new rule making or is that built into the TEF definition?

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

Yeah. So, we do anticipate that the use cases will be expanded over time and that the RCE will be responsible for figuring out a process for how to do that and how to kind of come to consensus along with the industry that a use case is ready for widespread adoption and can be adopted into the TEFCA. It would require a new version of the common agreement so just to differentiate between rule making. This is not a rule. So, ideally, we would be able to update the common agreement a little bit faster without having to go through the entire rule making process but it would still require an update to the agreement. And then, we said that any time there is an update to the common agreement that participating entities would have 18 months to implement those updates.

So, if there is a process also that we want to recommend to the RCE for how to determine whether a use case is ready for adoption that would be something that we would consider in the recommendation as well.

David McCallie, Jr. - Individual - Public Member

Yeah. I think the fact that that's how you anticipate it working is worth calling out because it means that we're not fixed in stone with the list of use cases on Day 1 with cohort 1. So, regardless of how we land on the wording of Recommendation 7A and B, it's probably worth calling out that this is not a static set of capabilities. It can be expanded. I'll make my second point, which is, remember, this is a voluntary network. So, you have to convince the stakeholders that it's worth doing. And I say start with stuff that they already comfortable doing.

John Kansky - Indiana Health Information Exchange - Co-Chair

And Aaron is next in line. But Aaron, I'm going to sneak in a quick point on I think, David, I think of TEFCA as a big basket that we're going to ask the industry to voluntarily pick up. And the more we put in that basket, the heavier it's going to be and undeniable that we want

individuals to have more and better access and better capabilities. I'm concerned about how big this brick is that we're suggesting putting in the basket. So, Aaron, you're up.

Aaron Miri - The University of Texas at Austin, Dell Medical School, and UT Health Austin - Member

Thanks. So, two things. 1) I think as an industry CIO, I still remember the large push to get portal adoption and then, we dropped it from the threshold of 20 percent down to one patient being able to leverage a patient portal. I think back to the view download transmit requirements that were eventually whittled back. I am in agreement that up front, we do need to state up front more capabilities beyond just walk and run. We need to be able to write. And users should have the ability. Patients should have the ability to write into TEFCA and request things if for nothing else for privacy requests such as Title 10 and other things people need to consider and think about. How else will a patient notify respective nodes on the network to remove their information and so forth? So, for me, I don't think that we should restrict ourselves because it's more difficult.

And I understand the concern about the brick being too big to lift. However, I think we're doing ourselves a disservice and the industry a disservice if we don't state that up front.

John Kansky - Indiana Health Information Exchange - Co-Chair

Thank you. Mark has his hand raised.

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

Just an observation. This came up for me because we have all of these exchange purposes, treatment, benefits, determination, quality, public health. Individual access services were the one that was actually limited to those two things. There aren't limits on the other exchange purposes that I've discovered so far. So, I don't actually feel like we're trying to add big use cases in. The thing that has been done differently for individual access is to actually put a bottle neck around it.

John Kansky - Indiana Health Information Exchange - Co-Chair

Yeah. I think I'm detecting that we may have a minority and a majority recommendation here. I'm trying to fathom what are they writing to because if you're asking – so I'm just offering an example of where my head is going in terms of technologically, if we add a broader set of capabilities around individual access services then, giving the patient the opportunity to get their healthcare information via individual access services, we're broadening those to capabilities that include writing. I'm not sure are they writing to every EHR and every participant member across every QHIN or what are they writing to?

Aaron Miri - The University of Texas at Austin, Dell Medical School, and UT Health Austin - Member

But more importantly, is can they write. Don't even worry about that. That's what I'm saying is let them be able to write and then, we can determine what the right vehicle modality is.

John Kansky - Indiana Health Information Exchange - Co-Chair

But if I can't answer the question of what are we talking about them writing to then, I don't know what letting them write means.

Aaron Miri - The University of Texas at Austin, Dell Medical School, and UT Health Austin - Member

Well, case and point and I don't want a solution design here on the phone. But if I'm a patient and I want to restrict my information because of Title 10, for whatever reason, I should be able to send out some sort of broadcast message to everybody saying please remove my records for Title 10 purposes and whatnot. And that's noted so that folks can comply with that from a Title 10 perspective and show that they're making that requirement just for that item. So, again, we could solution design all day. But at some point, you've got to be able to write back.

John Kansky - Indiana Health Information Exchange - Co-Chair

And we're going to talk about meaningful choice in a minute. And I know what you just said goes beyond that but I think it's in the context of I don't know that I need to ask ONC to comment but invite them to the idea behind the meaningful choice was to give individuals the opportunity to express that restriction and have it communicated across TEFCA ecosystem.

Aaron Miri - The University of Texas at Austin, Dell Medical School, and UT Health Austin - Member

Awesome. Okay.

John Kansky - Indiana Health Information Exchange - Co-Chair

Okay. A bunch of people with their hands in line. Mark, David, Cynthia, Noam. So, please keep your comments as pointed as possible.

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

So, you may still have my hand up but I do have an answer to your question. And I would suggest starting with the simplest one that's been around for 20 years, which is you want to make a correction or amendment to your record. That's in the HIPAA privacy rule. That would be an example of write that's been around.

John Kansky - Indiana Health Information Exchange - Co-Chair

Thank you. David.

David McCallie, Jr. - Individual - Public Member

Yeah. I like enumerating some of these goals as for examples but defer to the RCE to come up with a technical scheme that's actually feasible. And I'll make an analogy. It's dangerous sometimes to make analogies. But in banking and personal finance, there are nice services like Mint and others that allow you to create an aggregated very detailed view of your financial situation. But those services almost never and maybe never allow you to directly perform transactions against the native participants and against the bank or the financial exchange. You go through their process to do that. And I don't think healthcare data is any

less sensitive than financial data. So, this is a really big step to go from aggregating a view of your record, aggregating all of the data in your record, which is the current state of the proposal to one where you can go and modify data at each of the nodes on the network.

It's aspirational, yes. It's practically extremely difficult. So, listed as an aspirational goal, let people figure it out. As APIs proliferate, it may get easier to do this but you have to deal with patient identity in a way that's much stronger than our current model. You have to deal with the fact that your record is spread and copied over and over again. If you make a correction, do the corrections propagate all across the network? It just gets really complicated. I can't imagine doing it actually. Better than me trying to list them. I agree.

John Kansky - Indiana Health Information Exchange - Co-Chair

And I guess this is a comment and a question. The HIPAA right is to request a correction to your record, not to correct your record. Is that legally accurate?

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

This is Mark. That's right. You don't actually write the correction directly into the record. It's moderated by the provider.

John Kansky - Indiana Health Information Exchange - Co-Chair

What you're asking is to give the individual the right to submit to that request for correction, not make a correction.

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

In that particular instance, that's the usual form. At UCSF, we've done some interviewing of people using write APIs. And there are different models. So, sometimes, there is write directly into the record. Sometimes, you're actually writing into a separate data warehouse and then, somebody else is making a decision about what to incorporate from the data warehouse into the electronic health record. I know we're not solving those kinds of things in this task force. But there are different ways of doing this. Some of them may have raised fears and others may not.

John Kansky - Indiana Health Information Exchange - Co-Chair

Okay. Thank you. I'll admit that it's a bit of a mind blower for me. I'm kind of with David on thinking about how that would happen. But what you just said helped me. Cynthia and then, Noam and then, I think we – go on.

David McCallie, Jr. - Individual - Public Member

I'm in favor of listing some of these goals. I'm not opposed. Don't get me wrong. I think these are great ideas. I just want to respect the fact that they may be awfully heavy bricks to start with. That's my main concern.

John Kansky - Indiana Health Information Exchange - Co-Chair

That's where I'm at. Good ideas. I'm worried about putting them in the basket initially. Okay. Noam and then, we need to move on, I think.

Cynthia Fisher - WaterRev, LLC - Member

This is Cynthia. I was in there.

Noam Arzt - HLN Consulting, LLC - Public Member

No, there was someone ahead of me.

John Kansky - Indiana Health Information Exchange - Co-Chair

I'm sorry. You're right. Cynthia and then, Noam.

Cynthia Fisher - WaterRev, LLC - Member

Thank you. Yeah. I go back to what Aaron was saying earlier with Mark and Carolyn and me with real empowerment. The whole Cures Act, TEFCOA, this whole enterprise and all of this work is really to empower the patient with their information. And I just want to make sure that we're not looking to solve how the coding is done or what the design is today. But the reality is there are so many amazing API's out there that exist in other ways and management that can be flipped to be utilized in the healthcare arena as well. And I just think that we have to not be paternalistic here to the individual and the individual's right to access. And we are in a moment in time where the technology, the data, and the design is out there to employer the consumer to have a two-way read/write ability to do significant 1) correction where it's feasible. And we're not talking about banking because we're not talking about the financial part and changing numbers.

We're actually allowing the patient who is the best person and most knowledgeable person of their actual health. And they really have to have a role of empowerment on the accuracy of managing their own healthcare. So, I think they're a very missing player at this table. And I just would support what some of the others have said about really putting it in there as our objective and the design will happen. So, I think it's our role to open the pipes and make it happen.

John Kansky - Indiana Health Information Exchange - Co-Chair

Thank you. Noam and then, we'll move on to Recommendation 8.

Noam Arzt - HLN Consulting, LLC - Public Member

Yeah. Just real quick. There was a comment a bit earlier that this is the only exchange purpose that seems to have some kind of throttle on its capability. But to me, it's the modalities that really define what you can actually do within the exchange purposes. And, frankly, it's the modality that constrains all of them. We have two query mode modalities. They're not going to help a patient write anything and a message delivery modality. That might help a patient submit a correction. But to me, those are really the throttling effects and they throttle all of the exchange purposes because if there isn't a modality to do something you conceive of doing, you can't do it. Right?

John Kansky - Indiana Health Information Exchange - Co-Chair

Thank you.

David McCallie, Jr. - Individual - Public Member

Are the modalities limited? That's a Zoe question.

Noam Arzt - HLN Consulting, LLC - Public Member

The modalities say what they are, right. It's targeted query, broadcast query, message delivery. And the first two say this is about, essentially, receiving EHI. The third one says this is about pushing EHI and not receiving it.

John Kansky - Indiana Health Information Exchange - Co-Chair

I think David is trying to ask a question about the latitude.

David McCallie, Jr. - Individual - Public Member

Yeah. It's the same question I asked about the use cases before to Zoe and my understanding based on her former answer, her current answer, the prior answer is that the RCE could expand on those things, including modalities. But maybe I got that wrong.

Noam Arzt - HLN Consulting, LLC - Public Member

Sure. That could expand on anything but we have to decide what we want to comment on. But the point is we can't push about patient writing unless we address the modality that would support that, right. We can't make recommendations overall that are inconsistent with each other. So, if there isn't a modality, as I'll say, to support patient rights then, to me, that's a structural problem with our recommendation.

John Kansky - Indiana Health Information Exchange - Co-Chair

Yeah. I have to give that some thought because my assumption without thinking about individual access services but thinking about the other modalities is whether I query for some information or whether I am pushed some information, I can incorporate that in my system in the appropriate patient record, etc. So, I, ultimately, am writing to the system based on the information I got back from a query or information that was pushed to me. So, I have to think about your point.

Noam Arzt - HLN Consulting, LLC - Public Member

Right. But would you be expected to query a patient?

John Kansky - Indiana Health Information Exchange - Co-Chair

Well, you made the point that perhaps the patients, to accomplish this capability, you're suggesting would use the messaging modality. Again, I have to think about it but that's kind of an unsolicited here is something you need to know. We have a ton of feedback. Clearly, we'll have a dramatically different version of Recommendation 7, whether that ends up being a primary and possibly minority view or whether we just note that we have some more work to do. Related, I'm going to take us through Recommendation 8, which I think is perhaps a Noam memorial recommendation. And I have a question that goes along with it. Public health authorities as defined under HIPAA shouldn't be required to respond to individual access services.

And, initially, my comment giving myself the opportunity to go first here was, initially, that seems to make sense to me. And then, I thought what about are there any exceptions to that like – let me explain myself. Exceptions like immunization registries. Wow, it sure seems like an individual might want to be able to query their record from a public health information registry. What also seems true knowing what I know about public health and the capabilities of, for example, local health departments technology, which is, in some cases, almost none is that we shouldn't require them to be able to produce anything they have as we're requiring of other actors in this equation because I just think they can't. And I don't want my tax dollars to be allocated to creating that burden on local health departments. So, my comment would be it sounds like it makes sense.

There might be some exceptions like immunization registry. I must have said something to tweak curiosity because I've got four people in line. But Noam, did you want to comment? I'll give you first shot.

Noam Arzt - HLN Consulting, LLC - Public Member

I think the key word there is required. So, there is some concern that public health collects clinical data through its public health function under HIPAA and under state and local law. It isn't typically funded and doesn't typically have a mandate to provide any of that data back. It doesn't mean it doesn't or couldn't. And you're right. Immunization registries where they're funded and where they're legally permitted to, in fact, provide data back. But data from electronic lab reporting is typically never provided back to the patient in part because identifying the patient can be sometimes problematic. So, for me, I certainly support this recommendation.

And the key word there is required. So, public health folks are concerned that they're going to get sort of caught up in this TEFCA thing and be required to respond to a patient's request or desire.

John Kansky - Indiana Health Information Exchange - Co-Chair

And as written, I believe that's accurate that they would be required. ONC, is that correct?

Noam Arzt - HLN Consulting, LLC - Public Member

I'm not actually so sure about that because there's this notion of direct relationship. So, if an immunization registry, even one that's capable of responding to a patient query, doesn't establish a direct relationship with the patient, it's not clear to me how they actually would be required.

John Kansky - Indiana Health Information Exchange - Co-Chair

Okay. So, let's explore that so we're starting from the right place because here's my understanding is that no, public health is not required to enable individuals to come to them and say I want to establish a direct relationship. But if somewhere in the TEFCA ecosystem, the individual establishes a direct relationship and then, queries for their information, if that local or county or state health department is in the TEFCA ecosystem as a participant or participant member, they would be required to respond. And I'm asking ONC if that interpretation is correct.

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

I think that Noam has pointed out a discrepancy in the way it's currently drafted. So, I do think the intention is that everybody would have to respond to individual access services queries. But he is correct that the language also does say with a direct relationship. So, I think if the task force could help with the recommendation on that discrepancy that would be really helpful.

John Kansky - Indiana Health Information Exchange - Co-Chair

So, I'm not sure –

Noam Arzt - HLN Consulting, LLC - Public Member

And that – Recommendation 8 should stand. Just say no.

John Kansky - Indiana Health Information Exchange - Co-Chair

And we're going to get to the folks in line here in a second. But I'm not sure I understood your answer, Zoe. So, I was going to say if I'm an individual, well, I'm an individual. And so, I declare a direct relationship with someone in the TEFCA ecosystem who is a participant. And I request my information from a state health department or local health department that's a participant, whether they're on another QHIN or not, where is the ambiguity or where is the discrepancy? The draft says that they would currently have to respond to that, even if that patient didn't have a direct relationship with them. Is that wrong?

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

Let me find it. So, I think in –

Noam Arzt - HLN Consulting, LLC - Public Member

While she's looking, I don't think any one party can declare unilaterally a direct relationship, right. That's a mutual thing. So, one answer would say well, public health just doesn't establish direct relationships. It just says no. No, patient, you can't establish a direct relationship with me. It's a bilateral thing, isn't it?

John Kansky - Indiana Health Information Exchange - Co-Chair

Or this gets to the definition of direct relationship and it's important in this conversation that we have a clear understanding. Here's how I understand it. If there's an individual that wants to participate in TEFCA, they can go to a QHIN, a participant, or a participant member that offers individual access services. And they can say I want my direct relationship to be with you. They have chosen their on ramp for the TEFCA ecosystem. But if you're in the TEFCA ecosystem somewhere else in another state, in another place, under another QHIN, you're still in the TEFCA ecosystem. And when an individual makes a request for information, you have a duty to respond. And I'm asking if that's wrong because that's my understanding.

Noam Arzt - HLN Consulting, LLC - Public Member

But look at that definition on the screen. It says that the participant has to offer the services.

John Kansky - Indiana Health Information Exchange - Co-Chair

Correct.

Noam Arzt - HLN Consulting, LLC - Public Member

So, if a public health registry simply – so, the question is what does offer the services mean?

John Kansky - Indiana Health Information Exchange - Co-Chair

Okay. So, you're assumption, Noam, and I'm not saying mine is correct, I'm trying to clarify, is your assumption is that if I want information from a participant, participant member, or QHIN, I have to have a direct relationship with them. And, therefore, as an individual, I would have to declare a direct relationship with anybody in TEFCFA that I wanted their information from. And I'm assuming that as an individual, I only need to declare a direct relationship with anybody who is in TEFCFA and they'll be my on ramp to the rest of the ecosystem.

Noam Arzt - HLN Consulting, LLC - Public Member

Okay. I see the difference but the ultimate source of the information still has to offer the service.

John Kansky - Indiana Health Information Exchange - Co-Chair

And that's the point that I thought that was clear is that when we say that these are the exchange purposes in TEFCFA and we're saying that QHIN's need to be able to do all of them and any participant that signs on with them need to be able to do all of them. And any participant member that signs on needs to be able to do all of them. So, when that local health department chooses to participate in TEFCFA as drafted, they're basically saying yes, we will respond to individual access services as well as the other exchange purposes.

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

I think the problem is, my interpretation, it's drafted both ways, which is where I appreciate you guys pointing out this discrepancy because, in the 2.2.1 section, it does say the way John just said that everybody has to respond to all requests for individual access services. But then, in the individual access services language, it specifies the direct relationship.

David McCallie, Jr. - Individual - Public Member

So, you could argue, I think, that public health, you have a direct relationship if you're in the public covered by a particular public health entity. It's not a choice kind of relationship. It's mandated by your local laws. You do have a direct relationship.

John Kansky - Indiana Health Information Exchange - Co-Chair

But this is a capital "D", capital "R" direction relationship as defined in TEFCFA. It's something an individual would have to declare.

David McCallie, Jr. - Individual - Public Member

But I think it needs to be broadened to include those relationships that are implicit by other laws like public health. You don't have a choice about whether your provider submits your immunization data to a registry.

Noam Arzt - HLN Consulting, LLC - Public Member

Oh, yes, you do.

David McCallie, Jr. - Individual - Public Member

It's required by law. Well, it's required by law in most settings, right? And you can't withhold it.

Noam Arzt - HLN Consulting, LLC - Public Member

No, it's required by law in some states.

David McCallie, Jr. - Individual - Public Member

In some states, okay. So, I'm just saying –

Noam Arzt - HLN Consulting, LLC - Public Member

It's not required by law in many states and there are opt out provisions in many states.

David McCallie, Jr. - Individual - Public Member

So, if you've opted out and you don't have your data in the registry then, the query will return nothing because it's not there. So, if it's there, it's there because you either allowed it to be there or your state required it to be there. So, you have a relationship with public health based on whether public health has your data.

John Kansky - Indiana Health Information Exchange - Co-Chair

Who is trying to get in, please?

Denise Webb - Individual - Member

It's Denise. I had my hand raised it was just that –

John Kansky - Indiana Health Information Exchange - Co-Chair

Yes, you have been very patient and Mark as well.

Denise Webb - Individual - Member

So, I have some background from having worked in public health. And as I'm listening to this conversation, first of all, most data that we received in public health, we were not the source of the data. We received the data from providers that do have a direct relationship with the patient. And so, patients can get their information from those entities they have a direct relationship with such as their providers. Does public health provide information to patients? Yes, they may like with an immunization registry, which you can query and get your

information in some states.

The other point I wanted to make is that there are situations where public health does have a direct relationship from a care perspective with patients such as through a public health nurse or if you go to a public health department to receive your immunization if they run an immunization clinic or if they run some other sort of clinic, which some public health departments do. And then, they would be the original source of the information. So, I really do think we need a recommendation here stating that public health authorities are not required. They may but they're not required to respond to IAS unless they provide direct patient care and hold that patient's information. But they're the source of the information and they participate in the TEF ecosystem.

Noam Arzt - HLN Consulting, LLC - Public Member

If public health agencies provide services like any other clinical site, I believe that looking Recommendation 8, they're then a hybrid entity and they're not functioning in that public health role in that clinical service role.

Denise Webb - Individual - Member

I totally agree.

Noam Arzt - HLN Consulting, LLC - Public Member

So, I respect what you say –

Denise Webb - Individual - Member

They're more or less covered entities.

Noam Arzt - HLN Consulting, LLC - Public Member

Right, right, right. And that's what a hybrid entity is. So, I would support what Denise said. I'm not even sure that the second half is necessary to say because that's already the public health agency not functioning as a public health agency but functioning as a regular clinical site.

David McCallie, Jr. - Individual - Public Member

Comments or are you going to go through the hands?

John Kansky - Indiana Health Information Exchange - Co-Chair

Sure. Mark is next.

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

I liked that sure. So, Denise, I think, picked up on one of the questions I wanted to raise, which is I don't know the definitions in HIPAA but I am aware that public health is sometimes providing care to individuals, treatment to individuals. And I don't know if that's called public health for purposes of HIPAA or otherwise. But it seems to be a situation that we need to figure out the answer for that whether they have to or not under the current draft. And if

not, we should be making a recommendation that allows individuals to get their information from them. I also want to support the notion that there may be registry data where individuals ought to be able to get the information, too. And I know from nationwide consumer surveys, including one that I oversaw that immunizations are a huge deal.

And if it requires saying an exception for immunizations, that's definitely worth considering because it affects all of the people who are trying to get their kids into school and summer camps and all of that kind of thing and have to fill out the forms. It's a huge use case. And there are others but just to affirm the notion that immunizations need to be looked at. Thank you.

John Kansky - Indiana Health Information Exchange - Co-Chair

Well, thinking about the fact that this recommendation is going to go in front of HITAC next week, I would offer to whoever is taking notes that the recommendation needs to include three things. 1) Kind of what it says now as drafted plus 2) except when acting as a provider as defined by HIPAA. Oh, there are four of them. And 3) is we probably need to discuss an exception for immunization registries. And then, 4) is that we need to ask ONC to clarify the Noam interpretation, John interpretation because there is ambiguity about whether all participants and participant members are required to respond to individual access service queries or not. I hope you're a fast typist. Okay.

So, while that's getting documented, moving on to 4.2, which is related to public health and we have to decide, I guess, ultimately, where we're going to put Recommendation 8 because it could go either place but I wanted to just have a place holder. Did we exhaust our public health specific recommendations with that discussion or is there anything else admitting that I'm tempting fate?

David McCallie, Jr. - Individual - Public Member

I have more that's a broader principle that public health falls under.

John Kansky - Indiana Health Information Exchange - Co-Chair

David, go ahead.

David McCallie, Jr. - Individual - Public Member

Yeah. So, the success of the current exchange networks like Common Well and Care Quality E-Health Exchange is based heavily on the notion of reciprocity, which is that if you query others for data, you have to be willing to share data. And I worry about the slippery slope of creating carve outs where that reciprocity no longer applies, particularly if the carve out is based on some concern like Noam's initial concern, public health entities aren't technically equipped to respond. Would we also extend the carve out to say that small EHR vendors that have limited technical staff don't have to respond or that skilled nursing facilities that have no IT Department don't have to respond? Where do you draw the line of who you carve out of reciprocity?

And I think there probably are legitimate places where you would carve out an exception to

reciprocity. But they have to be really carefully scoped. And I would say, probably, that's an RCE function in their enumeration of use cases where they carefully limit the carve outs to reciprocity. Just because you're a small entity and can't afford to do it and don't have appropriate funding, I don't think that automatically gives you a right to, basically, not share patient data that you have. You have to deal with that problem.

John Kansky - Indiana Health Information Exchange - Co-Chair

I think I would actually offer my opinion. I'd second that line of thinking. With that, can we move on to privacy and meaningful choice or are there other comments related to public health? I don't want to force anything. We just wanted to make sure we didn't skip over that.

Laura Conn - Centers for Disease Control and Prevention - Member

Hi, this is Laura Conn. I have my hand up. Can you hear me?

John Kansky - Indiana Health Information Exchange - Co-Chair

Yes, I'm sorry. You absolutely do have your hand up. I apologize.

Laura Conn - Centers for Disease Control and Prevention - Member

Okay. No problem. And I'm not sure if it goes here but I wanted to raise the issue of fees and the change from TEACA 1 to TEACA 2. TEACA 1 had public health exception for fees and TEACA 2 does not. And I think that could be a real issue for public health if public health is going to be required to participate in fees related to queries and push messages. I'm not sure if it goes under this public health specific section or if there's something about the fee somewhere else in the letter?

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

Laura, just to clarify, this is Zoe, the fees are strictly QHIN to QHIN. There's also no requirement that there are fees. It's the case that fees are put on the QHIN. It would be the QHIN who has to pay the fee to receive the data. Now, the QHIN could pass that fee down to their participants but I just wanted to be clear about that.

Laura Conn - Centers for Disease Control and Prevention - Member

So, can you say more about why it was changed and why it was in the first one and not the second one?

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

We received feedback that we should leave the majority of any policies around fees up to the RCE to develop aside from these individual acts of services use case because I think the policy aim that we had in mind is that individuals have already paid enough into the health system. And they want to ensure that that access is as easy as possible for them. But otherwise, many of the public comments asked us to leave the rest of the fee schedule to the RCE.

Laura Conn - Centers for Disease Control and Prevention - Member

Okay. So, the RCE would have the ability to make a statement around public health exchanges that would apply to all QHIN's?

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

That would apply to QHIN's, yeah. And then, in terms of fees lowered down, the RCE could make requirements around the fees that QHIN's may to the RCE. But beyond that, QHIN's would be in charge of their own internal fee schedule so what participant members and participants have to pay to join if anything.

Laura Conn - Centers for Disease Control and Prevention - Member

Okay. Thank you.

John Kansky - Indiana Health Information Exchange - Co-Chair

Zoe, I'm going to note, and there are a couple of hands raised, but I'm going to note that it's 1:06. We, eventually, have to go to public comment. And we are not even on Recommendation 9 of 18. So, we're clearly not going to get through this document before the HITAC meeting. And I wanted to pause and note that and ask if you have any suggestions.

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

I think we should try to get through meaningful choice because I think there was the most discussion around that. And then, I guess, the only thing to do is really present the remainder of the recommendations either as we haven't had a chance to follow up on these and we need to have more discussion or, Lauren, if you think it's okay for us to say we're only going to present our recommendations up to meaningful choice and we're still working on the others.

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

Yeah. I think it probably makes sense to present what's final or as close to final as possible before moving on beyond the meaningful choice recommendations.

John Kansky - Indiana Health Information Exchange - Co-Chair

Thank you. I just wanted to note that. So, we have Noam and Mark and then, let's make sure we get on to meaningful choice quickly. Noam.

Noam Arzt - HLN Consulting, LLC - Public Member

Yeah. Just a quick comment. I think there may be some traction behind David's comment about exceptions or reciprocity. But I just don't want to let it go without, again, saying that public health is not in control of its own funding usually. And to put mandates on it that it simply cannot fulfill would be a real problem even with immunization registries. Very strong use case, very strong will. But if there just isn't the funding to do it, you just can't require public health to do that.

John Kansky - Indiana Health Information Exchange - Co-Chair

I feel like this is analogous to your saying don't put a brick in the basket that places this requirement on public health. And I feel like it's analogous to the brick in the basket argument I was making with regard to the rest of the industry so it's tough. Mark, you put your hand down, is that correct? Okay. I'm going to assume silence means okay to move on. So, we're on to meaningful choice. A nice easy one. So, we have three recommendations under this category. And I am going to read these to put these in RAM for myself and everybody else. Recommendation 9, ONC should clarify the policy goals around meaningful choice and leave the granular technical requirements to the RCE. ONC should require the RCE to establish appropriate flow down terms that require participants and participant members to allow for meaningful choice.

Any comments on that – was the idea behind this recommendation, I'm trying to remember where we left off, was there lack of clarity around when one made a request for meaningful choice whether that was to trickle through to the whole TEFCA ecosystem or was that not the basis of this recommendation? Does anyone remember?

David McCallie, Jr. - Individual - Public Member

The granular technical requirement part I remember. And that's just, basically, what it says. The current document is pretty specific about the notion of broadcasting choice decisions and that might not make a lot of sense whether that's a technical means of achieving the policy goal of having choice. I don't recall the flow-down argument. I don't recall what that was about.

John Kansky - Indiana Health Information Exchange - Co-Chair

So, David, and I'm just asking to try and get the task force all back on the same page, you support the first half of that recommendation? It's not a question of whether the meaningful choice should or shouldn't be communicated across the whole TEF ecosystem. It's a question of whether the RCE should be allowed to specify how it's done versus having it in the QTF?

David McCallie, Jr. - Individual - Public Member

Yeah. I'm in agreement with that notion that the technical details should be left to the RCE. I think I now understand that second sentence. I think it's just there must have been some concern that participants could somehow opt out of being required to grant meaningful choice. And they're saying the RCE contract language should require them to grant meaningful choice. And I don't know that that means to be said because I think that's already in there. But that makes sense, certainly. You shouldn't be able to sidestep it just because you don't want to do it.

John Kansky - Indiana Health Information Exchange - Co-Chair

Question to ONC, and I apologize because I think we answered this one before. When an individual exercises their meaningful choice, is it currently in the draft specified that that meaningful choice needs to be communicated up through their chain through their QHIN to the other QHIN's and down? Or oh, it's all coming back to me now. I think what we discussed is that it needs to be communicated up to their QHIN and across to the other QHIN's but isn't required to be communicated throughout the whole network. That's my recollection. Is

anybody from ONC able to tell me that's right?

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

That's correct, right. It goes up to the QHIN and then, across to the other QHIN's but doesn't need to go all the way down the chain.

John Kansky - Indiana Health Information Exchange - Co-Chair

Okay.

David McCallie, Jr. - Individual - Public Member

What would that mean? You could meaningfully opt out of QHIN to QHIN exchange but that wouldn't affect what the QHIN is doing internally with its participants? You couldn't opt out of that because it's inside of the QHIN?

John Kansky - Indiana Health Information Exchange - Co-Chair

David, I think that means that let's pretend there are four QHIN's and you're an individual that's under one of them. If you exercise your meaningful choice then, that meaningful choice is going to apply across all participants and participant members of that QHIN. Your QHIN is also going to communicate that to the other QHIN's so that they're, I don't know, my clear view of this is breaking down a little bit, but they'll be aware of it but that doesn't mean that if you sought care with another participant member under another QHIN that they wouldn't have that meaningful choice knowledge necessarily. That they wouldn't have that meaningful choice knowledge.

David McCallie, Jr. - Individual - Public Member

Yeah. I that's what's being said. This is why this is so complicated. What on earth would that mean?

John Kansky - Indiana Health Information Exchange - Co-Chair

So, it sounds like part of this recommendation or Recommendation 9B should be our understanding is as described but that needs to be clarified and it's a little confusing.

David McCallie, Jr. - Individual - Public Member

So, maybe the question is clarifying whether meaningful choice only applies to TEF mediated exchange or whether it propagates into non TEF exchange. And it seems pretty clear that it doesn't propagate. Maybe we need to get clarity on that. I guess TEF has no authority anyway so you can't make it propagate.

John Kansky - Indiana Health Information Exchange - Co-Chair

My assumption was that by definition, meaningful choice only applied to TEF transactions.

David McCallie, Jr. - Individual - Public Member

Yeah.

John Kansky - Indiana Health Information Exchange - Co-Chair

Okay.

David McCallie, Jr. - Individual - Public Member

That makes sense.

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

This is Mark. Can I just jump in to say when we ask for clarification, I don't know that we're going to ever get an opportunity to do anything with the clarification? So, we should perhaps put in the request but also put in the parameters of our thinking because this is our one opportunity.

John Kansky - Indiana Health Information Exchange - Co-Chair

Keep going. I'm just trying to understand. Do you mean make the request for clarification as clear as possible?

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

Yes, but also do our best to say what we think the answer should be because we don't know that we're going to be asked to come up with Version 2 or Version 3 of recommendations. This is the letter that's going to the national coordinator.

John Kansky - Indiana Health Information Exchange - Co-Chair

I agree that's better. That sounds a lot harder, too.

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

Understood.

John Kansky - Indiana Health Information Exchange - Co-Chair

I would suggest that for now, if you want, we can make a note in the draft recommendation that says that we're going to try and give some thought to how it should be and then, circle back to it after the HITAC meeting without making a commitment that we necessarily can. And I would welcome any thoughts. I think that's a different discussion and debate entirely on now that we know what it says, how should it be.

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

Right. I'm saying this because I remember we've made statements above that just say we need clarification here, we need clarification there. I think this is an observation that applies to each of those points. Not to take any more time right now.

John Kansky - Indiana Health Information Exchange - Co-Chair

No, fair point. And we will aspire to, whenever possible, make – my sense is that up to this point if we think we know how it should be and we can agree, we've already said that. But we also have some time after the HITAC meeting to add clarify where we can, add

suggestions where we can. Okay. No. 10 is somewhat easier, I think, to recall. It's ONC should ensure that meaningful choice is not just a check the box exercise but that it provides meaningful information about where and how an individual's EHI will be used and disclosed. I'm going to argue with those words a little bit. I thought the intent of those that brought this up said if this is buried in process in a way that the individual doesn't really understand it, that's bad. We should make sure that isn't the case. And I'm not sure that that's what the second half of the sentence says.

No, I think it does. Sorry, I apologize. So, to me, it's easy for me to agree with this recommendation but I feel like kind of the cousin of the suggestion Mark just made is so, what do we suggest.

David McCallie, Jr. - Individual - Public Member

Well, doesn't the current draft require, what do they call it, the minimum information that you have to communicate around this privacy policy and choice policy? It seems like my memory is that it's already addressed in somewhat specific language. Zoe, is it not?

John Kansky - Indiana Health Information Exchange - Co-Chair

I think – go ahead, Zoe.

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

So, minimum information is a different concept. But what we say about meaningful choice is that instructions for how to exercise your meaningful choice need to be included in the written privacy summary that the entity publishes to the individual. So, we do address it but we can be more clear about making sure that it's prominent within that written privacy summary or that the written privacy summary is made more prominent or something on the website so the individual sees it.

John Kansky - Indiana Health Information Exchange - Co-Chair

Yeah, the list that you're remembering, David, I think is related to if you're asking the individual to give authorization for another purpose of use, there are a minimum amount of things you need to tell them about what you're going to do.

David McCallie, Jr. - Individual - Public Member

Yeah. That's what I was remembering. You're right.

John Kansky - Indiana Health Information Exchange - Co-Chair

Noam and then, Mark. So, Noam, you're up.

Noam Arzt - HLN Consulting, LLC - Public Member

Yeah. Just real quick, what this whole section on meaningful use doesn't address or comment on and it may have to do with this second half of the sentence, my reading of TEFCA is that meaningful choice is a sort of all or nothing from the patient standpoint, right. It's not selective granular consent for this data, not that data. So, we haven't really talked about

whether we support that sort of all or nothing aspect of this. And my concern is that a patient will make a meaningful choice not to share data and an unintended consequence, unintended, would be that their public health data where they're permitted to make such a choice, in some states you can and some you can't, would then also be restricted. And the patient might not even realize it.

John Kansky - Indiana Health Information Exchange - Co-Chair

Fair concern. So, let's pause for a moment because we're coming up on public comment. Mark, noting that you're in – Mark, do you have a quick comment that you want to get in or can I come back to you after public comment?

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

Either way.

John Kansky - Indiana Health Information Exchange - Co-Chair

Why don't you go?

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

Just channeling what Arien was saying earlier about the work of the privacy and security tiger team. I've been searching for the definition. They did talk – there's good language out there about what this recommendation is trying to do. And I'm looking for it so I can drop it into the chat box.

David McCallie, Jr. - Individual - Public Member

It was circulated that I think she circulated the recommendation from the tiger team in an email a couple of days ago.

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

Oh, you are right. I will look there.

John Kansky - Indiana Health Information Exchange - Co-Chair

So, we're going to go to public comment and I'm just going to note for the ONC team that I suddenly lost connection to the view so I'm going to try and get back connected during public comment.

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

That's okay, John. We'll go to public comment. So, operator, can we open the line?

Operator

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

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

Thank you. And do we have any comments in the cue?

Operator

Our first comment comes from Mary Savikus, Woodchime. Please proceed with your comment.

Mary Savikus - Woodchime

Hi. Thanks, everyone. I joined the call late but I did want to make one comment surrounding the feedback we've been receiving from our members. We largely represent CIOs, CMIOs, and others in the C suite who purchase and deploy the technology. And one of the concerns that they have with this and acknowledging all of the hard work that's gone into this by the committee and by ONC is how to manage the HIPAA standard with the new TEFCFA standard. So, there seems to be a lot of complexities and things that need to be ironed out [audio interference] consent. We have a lot of questions about how that would be managed.

And one of the things that we're going to recommend in our comment letter on Monday is that there be some sort of crosswalk between how this will interplay with other existing rules. So, thank you for the opportunity to comment.

John Kansky - Indiana Health Information Exchange - Co-Chair

Thank you. And I actually think we have a recommendation that comes pretty close to saying we agree. And I believe that was based on comments that we got on the last call. So, thank you for your input. And I think we're making a recommendation that supports what you just said.

Mary Savikus - Woodchime

Yeah. We totally appreciate that. Thank you so much.

John Kansky - Indiana Health Information Exchange - Co-Chair

Sure.

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

Operator, do we have any other comments?

Operator

There are no further comments at this time.

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

Okay. John, I'll let you know if any others come through.

John Kansky - Indiana Health Information Exchange - Co-Chair

Thank you. In the meantime, I will note that I cannot connect but I've got my file in front of me. So, if we can push through the discussion of Recommendation 11A and B, we will have met our compromised target for the day. So, 11A was that ONC should clarify the meaning of perspective as it relates to the definition of meaningful choice and how such choice would be implemented and enforced. We had a lively debate and now, I'm trying to channel Mark's suggestion that, great, you're asking for clarification but how should it be. I think we started thinking through what does it mean if you say that my data shouldn't be used in the future but the data that you've transacted in the past can be used. The implementation of that seemed to be a little unclear.

It was unclear what ONC intended to have happen and, therefore, it was difficult to extrapolate whether that was technologically easy, hard, or impossible. Are there comments because I cannot see raised hands anymore?

David McCallie, Jr. - Individual - Public Member

This is David. I've got one. Surprise!

John Kansky - Indiana Health Information Exchange - Co-Chair

Okay. You're my best customer. Keep going.

David McCallie, Jr. - Individual - Public Member

Well, I think a proposed clarification might be, to Mark's request, that we do not just ask for clarification but we actually make a proposal is that they clarify that this can only apply to the prospective flow of information through entities governed by the contract they have with TEF. It cannot legally apply to data that's already been collected because the authority of the TEF doesn't apply to that as well as, of course, the clinical difficulty of unseeing something in an electronic medical record. So, I would propose that we clarify that it's prospective only, if not equivalent to right to be forgotten because there's no authority to do that I don't think.

Noam Arzt - HLN Consulting, LLC - Public Member

And that's how I read this all along. So, I'm not sure what clarification, frankly, is really necessary.

John Kansky - Indiana Health Information Exchange - Co-Chair

Does anybody remember – yeah, Noam, I'm trying to help you there? I remember some specific examples of if I've got data that was transacted on this patient before they exercised meaningful choice, I guess maybe is there any lack of clarity around that means that I can use their data for anything that – there was some issue of have I opted out of only exchange purposes or can I use it for anything that's allowed in the future uses. I'm just trying to ping people's brains. I'm not trying to make a problem where there isn't one.

David McCallie, Jr. - Individual - Public Member

Someone raised the question about the fact that it wasn't clear. So, I think I agree with Noam

that it is fairly clear but maybe we can just say make it more clear that it's a prospective with respect to flow.

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

I think what wasn't – with the comment that was confusing about the need for second was more about how it's going to be implemented.

John Kansky - Indiana Health Information Exchange - Co-Chair

Does anyone recall an example? Because I know there were some good examples raised where I kind of went yeah, wow, that's going to be hard. And those are not coming back to mind today.

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

This is Mark.

David McCallie, Jr. - Individual - Public Member

Go ahead, Mark. You've thought about this more.

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

I've been doing some research on something else for this and so I'm not sure I picked up on the conversation just before. I may have been the one that put this in and there was a concern on my part that yes, you cannot delete information from a record once it's put in. But the language that said you could continue to use it and disclose it that was what was giving me heartburn then and now. And I don't think folks should be able to continue to use and disclose information once the choice has been made.

John Kansky - Indiana Health Information Exchange - Co-Chair

Okay. So, there isn't a lack of clarity because I think you're saying there should be a right to be forgotten. Is that what that translates to?

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

Forgotten, yes, but I wasn't going so far as to say delete all of the information from the prior records because that's not the practice.

John Kansky - Indiana Health Information Exchange - Co-Chair

Okay. So, it's not right to be forgotten. You're saying the request to –

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

Stop using it, stop disclosing it.

John Kansky - Indiana Health Information Exchange - Co-Chair

But you don't have to stop having it.

Mark Savage - UCSF Center for Digital Health Innovation- Public Member

Correct because it's already a part of your business records.

David McCallie, Jr. - Individual - Public Member

I don't know how you stop using something that you have in your record. I think that would be quite a legal challenge to a provider to not act on something that's in his or her record. I can see non-provider cases where that would be straight forward.

John Kansky - Indiana Health Information Exchange - Co-Chair

I remember from the prior call that was, I believe, ONC's rationale was they were trying to make this meaningful choice implementable.

Noam Arzt - HLN Consulting, LLC - Public Member

I think you have a provenance problem where you have to sort of stick where everything came from and then, filter it based on those meaningful choices.

David McCallie, Jr. - Individual - Public Member

Very much that's the technical approach, which is not well supported today, unfortunately.

John Kansky - Indiana Health Information Exchange - Co-Chair

Okay. So, there's a good clarification to Recommendation A. Let me see if I can bring this in under the wire on Recommendation B. It was just an issue that meaningful choice should be revocable. Individuals should have the ability to change their meaningful choice preferences at any time. However, there was some lack of clarity on whether such changes should apply retrospectively or prospectively. I think we can probably mush these two together because it's the same question. It's going to get complicated if an individual turns their access off and then, back on again or their permission to use their data on and back off again or the other way. It's going to get confusing but we're saying that they should have that right. It's the same issue.

Noam Arzt - HLN Consulting, LLC - Public Member

Right. But that's not a lack of clarity. That's just disagreement, right. For me, there isn't a lack of clarity. Some folks are just disagreeing. There's a difference.

John Kansky - Indiana Health Information Exchange - Co-Chair

No, I agree. So, Recommendation 11 A and B should be, I'm noting this for whoever is taking notes, should probably be written to not be requesting clarification. It should be to point out that we understand that the – and this may be one where we have a disagreement that, on the one hand, we understand the intent of ONC as saying the prospective use is constrained but the use of data retrospectively shared can be continued to be used. But there are some who don't think that's a good idea. And acknowledging that we do still agree that meaningful choice should be revocable and the draft says that it is I believe.

David McCallie, Jr. - Individual - Public Member

Yeah. That's what choice implies.

John Kansky - Indiana Health Information Exchange - Co-Chair

Okay. So, with that, we are a little bit past time. Zoe, Lauren, is that a good stopping point?

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

Yeah. It works from our perspective. Zoe, do you have anything else before we wrap up?

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

No. I guess I will ask practice wise, John, do we want folks to send feedback over the weekend and then, we can attempt to incorporate it on Monday? Or do we –

John Kansky - Indiana Health Information Exchange - Co-Chair

So, to whom would they send it? And the second half of that question is should we constrain that just to make a task doable to say if you have input on, this is probably terrible, Recommendations 12 through 18, send us feedback? Or is that exactly what we shouldn't try to do?

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

I would say that my recommendation would be for now to limit the feedback to Recommendations 1 through 11 and to try as hard as possible if you do to do redline inline edits that can be easily accepted just to make life easier. And then, I'll offer that we can either use the Google doc or people can just send me their feedback directly and I can reconcile it all.

David McCallie, Jr. - Individual - Public Member

Would we be reacting to the current draft in front of us or to what is going to reflect today's discussion?

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

What's going to reflect today's discussion. So, we'll edit this draft and we'll do a redline comparison so you have a redline copy and a clean copy.

John Kansky - Indiana Health Information Exchange - Co-Chair

So, we're giving the task force the opportunity to react to the next version, which will be sent out. And, Zoe, I believe you're committing to midnight Friday or what are we committing to?

Zoe Barber - Office of the National Coordinator for Health Information Technology - Staff Lead

Yeah. To the end of the day Friday.

John Kansky - Indiana Health Information Exchange - Co-Chair

Okay. And then, just for simplicity sake, I'm going to say task force members send any edits using track changes to Zoe and copy Arien and myself so we can see what's going on.

David McCallie, Jr. - Individual - Public Member

Sounds good.

John Kansky - Indiana Health Information Exchange - Co-Chair

Okay. Thank you. Good catch, Zoe. With that, I apologize for going over and thanks for everybody. And we'll do our best to present this work at the HITAC meeting.