Health Information Technology Advisory Committee Annual Report Workgroup Meeting

Transcript
February 12, 2020
Virtual Meeting

SPEAKERS

Name	Organization	
Aaron Miri	The University of Texas at Austin, Dell Medical School and UT Health Austin	Co-Chair
Carolyn Petersen	Individual	Co-Chair
Christina Caraballo	Audacious Inquiry	Member
Brett Oliver	Baptist Health	Member
Lauren Richie	Office of the National Coordinator	Designated Federal Officer
Michelle Murray	Office of the National Coordinator	Staff Lead
Cassandra Hadley	Office of the National Coordinator	HITAC Back Up/ Support

Call to Order/Roll Call (0:00:11)

Operator
All lines are now bridged.

Lauren Richie
Hello, everyone. Welcome to the HITAC annual report workgroup meeting. We have Carolyn Petersen, and I believe Aaron Miri will be joining us shortly. They're joined by our other workgroup members Christina Caraballo and Brett Oliver. We are nearing the finish line for our fiscal year '19 annual report, so we're looking to hopefully wrap that up in the next call or so, and with that, I will turn it over to our co-chair Carolyn Petersen to get us started.

Opening Remarks and Meeting Schedules (0:00:44)

Carolyn Petersen
Thanks, Lauren. Good morning, everyone. As Lauren mentioned, we are in the home stretch. Hopefully, this will be the last significant meeting we have where we have things to discuss and changes to look at for the annual report. We have 90 minutes blocked for this time, but Aaron and I had the intention of going through as efficiently as possible, so perhaps we can give some of that back to you. Could we have the next slide, please? Here's our agenda. Again, we'll review our meeting schedule, get right into the comments that we discussed, have a public comment period, and then establish our next steps and adjourn. Next slide, please.

So, here's the meeting schedule that I think we're all pretty familiar with right now. We have today's meeting, and nothing scheduled beyond that pending the outcome of the presentation of the report at next week's full HITAC meeting. Next slide, please. Here is an acknowledgement of the date, February 19, for that call. Next slide, please.

Discussion of Revised Draft HITAC Annual Report for FY19 (0:02:02)

So, now, we'll head into the discussion of the comments we've received from HITAC members, and make whatever revisions we think are necessary for the annual report that we will present and hopefully get approval of at next week's HITAC meeting. Next slide, please.

So, Aaron and I have gone through all the comments that were received, along with the ONC SL report preparation team, and where there were changes, suggestions for things like typos, or correcting the proper name of something, we've gone ahead and just made those. They are noted in the large table of comments and how those were handled that you received prior to the meeting. We didn't anticipate a need to discuss those things today. We have what we have. On the slides are a number of things that we felt would be best addressed by discussion of the working group, and our goal is to try to work through all these slides today and be able to get those changes made in the next day or so so that the revised draft can go out to the HITAC members hopefully Friday, and that we can get a resolution on that next Wednesday.

I know in the past, we've sometimes gone through several slides, and then started back through them individually, but we were thinking it might be easiest for us if we just started with a slide and dealt with what's on it and just kept working straight through to minimize the back-and-forth. So, if you'll open your list of member comments that we received from HITAC, this first issue has to do with making some changes to where we placed potential actions in the tiering system. You'll recall we had the immediate tier, and then the longer-term tier. We did get some feedback from some members that some of those should be placed in a different tier, and that's what we'll review right now.

So, for the opportunity related to improved patient matching, there was the thought we should move this opportunity from the longer-term to the immediate because ONC has to submit a report to Congress about patient ID methods in 2020, so it seemed that it would be a good opportunity for HITAC to have some role in that. Are there any thoughts about that movement?

Aaron Miri
This is Aaron. I think the tiering makes sense. I think that there was some clarity, I believe, that the public gave to HITAC to show how we put things into what tier, but other than that, I thought most people found it pretty interesting and understandable.

Christina Caraballo
Yeah, I would agree that this is a good edit.

Brett Oliver
I was just going to agree as well.

Carolyn Petersen
Okay. And then, in a similar vein, the opportunity then creates transparency of EHR-related adverse patient safety events – move that from the longer-term to the immediate because the HITAC has included discussion of the EHR reporting program in the 2020 plan. Any concerns about making this shift?

Aaron Miri
None for me. This makes sense. I think we should.

Carolyn Petersen
Brett or Christina?

Brett Oliver
Yeah, I don't mind making the shift. The opportunity seems vague to me, unlike the opportunity for patient matching. That's a specific opportunity. What do we mean by "increased transparency of EHR-related safety events"?

Aaron Miri

Well, if I remember correctly, Brett, it was about trying to start getting visibility on some of the issues there, like around UDI and other things, and start connecting the dots for folks as to how to move these things forward. That's what I recall the conversation was about, and how we can leverage the information-blocking final rules – again, we don't know what it says, but potentially to help get more data out of the system to say what we can do to make it better for patient safety. At least, that's what I recall.

Christina Caraballo
I think it shows some support for going down that road of if there is potentially some work that HITAC could do related to the info-blocking rule. I don't think it means that we're absolutely going to approach this topic in terms of what we know today about the work plan, but it certainly would signal that we recognize the synergy and potentially could be involved.

Brett Oliver
Yeah, I think it probably is sooner rather than later. Really, the only way you have to do that right now is through a patient safety organization, a PSO, right? When you're talking about safety events, there's that hesitation to share anything because you're going to become liable. I agree with what you all are saying.

Carolyn Petersen
Okay, then. I think we're good with making these changes. Let's go to the next slide. So, again, these are more changes to the tiers in the SDOH topic. We have a longer-term opportunity in interoperability about developing and adopting standards for SDOH data activities, and also, an immediate opportunity in the privacy and security target area to facilitate more exchange of SDOH data between providers and community service organizations, and also raising patient awareness about consent. The comment was to better align the timeframes for these two things that have to do with SDOH data, and the potential action would be to shift the first opportunity to the immediate tier as well. Michelle, did you have any thoughts about the way that that aligns in the report? I know when I looked at it, it seemed like there may have been something else driving it that we needed to be sure was aligned.

Michelle Murray
Yeah, it was just that one that we had that had a gap, and then, three opportunities and three recommendations. We ended up having to split apart, and you'll get to it later. That meant pulling consent out separately, which was easy to do in the report. The audacious inquiry team helped us look at that, so it didn't really affect the report deeply, it just meant visually splitting apart into two gaps of opportunities – or, three opportunities and two gaps. So, SDH is still linked in that section to PGHD, patient-generated health data, so when we get to that, we'll see if we still agree with that, but that was the main gist that occurred because of this comment and the comment about consent.

Aaron Miri
I guess I agree. I do go back to – There's obviously a major concern when it comes to what consent is and how that – that's a whole other track for us to look at in terms of consent, but in terms of alignment of timelines, that makes sense for me, so this change does make sense, but I do think this is a very deep subject. So, I look at this, and I wonder if we're doing it justice with this, but I understand

the point of it because around privacy and security, a priority target area, but this is a giant thing in itself, right?

Carolyn Petersen
Yeah, absolutely.

Aaron Miri
Brett, what do you think? Do you think this is important – this level of granularity and timing for SDOH – as a provider?

Brett Oliver
I might be a little contrary to the popular belief among the committee, not to mention this workgroup. There are so many other things that I would rather get right now to move the needle from a patient care standpoint. I understand there's all this excitement about social determinants of health. I know that if you live in a different ZIP code, you do better. I don't know what I'd do about that. I get that there's some feedback data out there, but the data seem kind of sparse. It seems like the enthusiasm has exceeded reality right now, and maybe that's because we don't have the data, and maybe that's what we're here to talk about, but I will go along with this workgroup's consensus and support it; I would typically put both these things as longer-term opportunities, but I'm not going to buck what you guys want as far as that consensus goes.

Aaron Miri
Being in the thick of it, I have the data warehouse team here at the University of Texas, and we're doing a lot with SDOH. Just getting access to the data is half the battle. Getting access to figure out where there are food deserts, what the climate weather is, and all this other stuff – getting that, normalizing it, and making it part of the calculus, per se, to be able to draw out inferences and other dynamics – it's hard just to get ahold of the data, much less do anything with it. So, I think your comment about whether this opens up the water taps per se to allow us to begin to actually leverage SDOH – that's how I'm looking at this and saying, "Okay, if we take these considerations into play and move it up to immediate, once the data is there, then we can actually start doing value-based care the way we're supposed to be doing it because now, we have the data to make meaningful choices and decisions." So, that's how I'm reading this.

Brett Oliver
Yeah, I follow you, and I think that would bridge my current gap with what you're saying.

Michelle Murray
I'll just add one point. Sorry, I just want to get to a technical point. I think the HITAC member pointing this out was wondering why standards came after exchange. They were just saying we should either put them together or sequence them differently, so that was the comment that was coming forward from the HITAC, not really which tier it should be in, so it is up to you guys to recommend that part, but this is why they were trying to get them aligned together.

Aaron Miri

Right. Michelle, I took that in terms of urgency – don't lollygag on sharing the data; do both, and do it immediately. So, I could buy that if it's because I want to start doing more meaningful stuff down the road. I get why the comment was made, but I'm taking it one step further. If we do that, then the promise should be we can now do stuff with SDOH in future reports or activities that we couldn't do before, assuming we were able to accomplish that goal. Christina, were you saying something?

Christina Caraballo
I was just going to take what Brett said into consideration and agree with you, Aaron, on the fact that this is setting the framework. So, we're talking about facilitating exchange in our target area that we've designed here, and I think that we're not pushing it completely, but considering all the excitement around social determinants of health and the fact that there's so much acceleration in the standard work to support social determinants of health, I think focusing on the privacy and security aspects in tandem is really important, and I do think that this pushed up to a tier 1, and that doesn't mean that we're going to make all provides start incorporating social determinants of health. To me, it's saying we should lay a foundation and start thinking about what that looks like from an IT perspective for those organizations like yours, Aaron, that are already pushing forward, and they can better inform those that will come next.

Carolyn Petersen
It's not just the IT perspective. I think it's also the workflow perspective because providers are going to need to see that it's relevant in how it actually fits into what they do, and that it's not just another requirement to mess with or something else to document in the EHR, but also to get a sense of how they can be meaningfully used, and not in the "meaningful use" kind of way, but how they can be effectively implemented so that they actually make a difference in the care and the outcomes. I think people are really on board with doing different things or harder things when they see that there's value in it. We need to start thinking about how to demonstrate the value.

Brett Oliver
Yeah, and I'm coming from a provider's perspective and CMIO perspective, so it's very helpful to hear from you guys and from other views because it may not involve the provider at all where the benefit may come from. But, to Carolyn's point, if you can show me – we've been asked to do what end up being so many silly, time-wasting things from the government and other people that unless you start showing me the value behind it, you're going to struggle.

For instance, I may have mentioned this before, but for telehealth services, Medicaid in the state of Kentucky wanted us to add an ambulance code modifier so they could find out where the service originated from and where it was being given from, and we never utilized that, but it was going to be on the backs of providers to learn this code and provide it, and they didn't know what they were going to do. They thought it was interesting information, and probably something we're going to want to know. So, when you hear stories of that, I guess I get a little prickly when there's something else that we're going to do, and everybody's excited about it, and five years from now, we're not doing it anymore, and we're onto the next thing, yet we continue to have this burden added to the end user. So, that's probably more background than you all wanted – a little background on why social determinants of health have not fallen on rich ears at my end at this point.

Carolyn Petersen
Absolutely, that is very valid in light of ONC's efforts to reduce provider burden. I think that's a very appropriate point, and we need to keep that in mind so we're dovetailing with that initiative as well, just as a general desire to address the SDOH thing.

Brett Oliver
Well, thank you for indulging me. I'll get off my soapbox.

Carolyn Petersen
No, it's important feedback. It's good to have. So, are we feeling like we can make an action or decision on this?

Aaron Miri
I'm good with it. I think we go.

Carolyn Petersen
Okay. Let's move onto the next slide, then, Michelle. Do you want to lead this one, Aaron?

Aaron Miri
Sure. So, on this one, the topic is restricting the scope of data shared with third parties. The new gap that was there was limited support for restricting scope of data shared with third parties. We have FHIR, and the opportunity was increase capacity to reasonably restrict the scope of data via FHIR. The new recommended HITAC activity was to convene a HITAC workgroup to review and provide recommendations on how federal agencies and standards development works could improve and maybe offer reasonable restrictions that are placed on scope of data shared via FHIR. Potential actions may include clarifying any ONC certification criteria that enabling restrictions are allowed and encouraged, and updating underlying standards support such reasonable restrictions in a standard manner. If I remember right, this was hand in hand with patients being able to restrict sensitive data and working through how we could allow people to have that granular choice of what to share and what not to share. Is that right?

Brett Oliver
That's what I remember. Was that Ken's –?

Aaron Miri
Yeah, I think so. I'm stretching my memory here.

Christina Caraballo
I think so, yeah.

Carolyn Petersen
It was.

Aaron Miri
Okay. If that's the case, for me, that absolutely makes sense, but this is a huge ask because to my knowledge, there's not a normal known method for doing that. Discrete elements within an HL7 feed – in this case, FHIR standard – how do you exclude certain fields, notate them, or whatever? Besides mainly concatenating a string, which is what that is, I don't know how to do that. So, this is a big thing for either USCDI or something else.

Brett Oliver
Do we support convening that workgroup or adding it to USCDI? Is that the question?

Aaron Miri
Yeah, that's the question, but I want folks to understand that this is not an easy – we're going to have to really dig into it, and it'll be a lot of chopping up to understand – personally, I think it's important, but I just want us to understand this is not an easy one.

Carolyn Petersen
Is it something we could put in as a longer-term opportunity so that it surfaces and we don't forget about it, but we also recognize it's not something we can just start on in May or June?

Aaron Miri
To me, that's smart. Christina, I'm curious about your take since that you co-chaired some of those technical standards committees.

Christina Caraballo
When I read this, my initial reaction was that it made a lot of sense, and I was going to support it. I thought it was a really excellent point when Ken brought it up during our HITAC meeting, and I think the full committee was really receptive to it. When I think about some of our workgroup work, my point of view is that we take on some of the bigger challenges and start to identify what we need to do. It doesn't mean that we are necessarily coming up with every single solution, but we're starting the conversation, so I do think this is an important one, but I also recognize that it's a lot of work, so I'm a little divided. When I think long-term, I think we're tabling that. When I think immediate, we're getting started. So, I think USCDI – that was phased, and this could be something that ONC looks at, and if they agree this is important for the HITAC to take on, then they can come up with different charges to get us started, but –

Aaron Miri
That's fair. So, you're saying let's get Sarah to assess what the work is, and then, based upon that, we can chop it up into appropriate chunks and divvy it out to the right subgroups to go get that done, and then also figure out what a reasonable length of time is. I want to be cautious because look at TEFCA. We've been talking about TEFCA for two years, but we had to extend it because there was some great feedback from the public we wanted to take into account, and we wanted to assess and reconvene, and at the beginning, we were hopeful that we could just charge through it and get it done. Well, that was a whole lot to really think about or really work through. I look at this one, and I can see this being the same thing. It's not that we don't do it now, but I just want to set the expectation for the folks –

especially the public – that it will take us some time to go through this. So, I support it. I just want everybody to have eyes wide open. That's what I'm trying to say.

Carolyn Petersen
I think that it's good to put it out there so that there is awareness of it, and it doesn't wind up being something that lives in the parking lot on a permanent basis because that's another hazard. You hear about something, you think, "Oh, that's great, we're not quite ready, let's put it in the parking lot for next year," and then, when next year rolls around, there are five other things that have suddenly become shinier and more important, and the parking lot becomes the permanent refugee camp instead of the parking lot.

Aaron Miri
Fair point, and that's the last thing any of us want. We don't want inaction on anything. You're exactly right. I just don't want people thinking this is something really simple and we should just do it. Every day, I hear, "It's just IT. How hard can it be?" Yeah, okay.

Brett Oliver
Exactly.

Carolyn Petersen
Okay. So, do we take this conversation that we will add this? Is that our feedback to the team?

Aaron Miri
I'm supportive.

Brett Oliver
I am as well.

Carolyn Petersen
Okay. Let's move onto the next slide. Suggested addition in the topic of price transparency and the landscape analysis under the federal activities. The suggestion is to update the price transparency subsection to reflect CMS rulemaking, and in the interoperability, priority target area section to add miscellaneous mentions of financial information. The gap analysis under the access to patient data remains highly fragmented from the patient perspective. Adding some text to that, integration of clinical and financial data in the description of the gap, the opportunity would be changing the language of that opportunity from the clinical information that's less dependent on providers, and also, noting clinical information in the recommended HITAC activity. Michelle, can you tell us the page that we would find more information about these suggested changes in our Word doc?

Michelle Murray
Yeah, they're across multiple pages, so it's not that simple, unfortunately, but is there a particular one you want to focus on?

Carolyn Petersen

I was hoping we could easily start at the top, but if we can't – I'm just thinking it's a little easier to talk about it if we can look at it or find it.

Michelle Murray
I agree. I'm looking myself. So, page 19 in the current draft is where we added more information in the federal activities. The comment there was correct that since we started the draft in December, there have been updates to the final rule for CMS, so it was correct to update that, so we made some accurate updates based on their suggestion and added some footnotes – endnotes, actually – so, that's on page 19.

Carolyn Petersen
Good. That sounds like the right thing to do, being that that was accurate.

Michelle Murray
Yeah, and I think the discussion that you and I have had was there are a few places where we mentioned health information, and that's not clearly defined yet, even industry-wide, and it may become more so after the rule is published, but right now, it's hard to put a definition around that, so we decided to leave that phrase as is without being very specific about what it includes. The assumption of this workgroup was that it includes price information as appropriate, but that may not always be the case, so I think the commenter was trying to get clarification around that, which we may or may not be able to offer at the moment. I think there are spots where you asked that we not add that comment, but in other places, it seemed okay to say "clinical and financial information" to be very specific. That was the gist of that.

Carolyn Petersen
Right. Yeah, that was the situation, where in some uses, terms are defined and known, and in some, they're not. Also, the recognition that there are all kinds of data. There's financial data, there are clinical notes, there's patient-generated data that people just collect and try to use, like tracker information, there are patient-reported outcomes that could be part of a clinical trial or daily care, and my thought was if we start naming particular types of information when we wind up with a list of 17 types of information, I think just in terms of readability of the report, if we can keep it very general, we'll do better, and then by naming individual types of data, but that's something I'm interested in getting feedback on.

Christina Caraballo
Yeah, I agree with that, and I stopped on this slide because this is under price transparency – and, Michelle, keep me honest on this – the recommendation is to hold the listening sessions with experts on access, right? And then, we have an addition of the clinical information, but to me, this seems like a larger recommendation that we had in general, updating the roadmap for patient access, which would include price transparency and other things. So, I would vote to take off "clinical information," supporting what Carolyn just said, but I want to make sure that I'm reading this recommendation and where it belongs in the report correctly, since this is specifically under price transparency.

Carolyn Petersen

Yeah, that is an accurate read. I went back and forth on it a few times myself, particularly as I got further into the report, where there were similar references of this type, trying to be sure that I was framing it accurately in my mind. It seems to me that we want to try to keep things fairly broad, and also to target the recommendations that we were –not to make them so broad that they could refer to anything. It's broad within its category, but then, relatively targeted. So, I'm fine with what you suggest, Christina, but interested to hear others' feedback.

Aaron Miri
Christina, I'm trying to make sure I'm hearing you correctly. You're saying strike the word "clinical information" and just leave it as "access to their data." Is that right?

Christina Caraballo
No, I actually was thinking that we might want to add a different phrase. If we think about patient access, we've got access through portals, but we know that we haven't completely solved the problem of meaningful access, of a good user experience, so maybe we should change the recommendation to something like "At the end, identify ideas for an updated roadmap for patient access that is a more streamlined experience for patients." I think that's what we were getting at originally with this recommendation.

Aaron Miri
Oh, I see, so that you don't end up with what happened when CMS had that voluntary post of your chargemaster, and some people posted a machine-readable-only format that was totally worthless to the patient. You want something that's functional as well as useful.

Christina Caraballo
Yeah, I would say that's fair.

Aaron Miri
Okay, that makes sense.

Carolyn Petersen
That's a good point.

Aaron Miri
In that context, yes. First of all, we don't want to say inadvertently in any way that we think both are just as important. We want full transparency. People are going to have their data regardless of whether it's financial or clinical. But, your point is to make sure that people can do something with it, that it means something to them. I like that. That's a really nice way of articulating it. "Don't just be an engineer, be a human. Solve it like a human." Any feelings, Brett?

Carolyn Petersen
How does that – sorry.

Brett Oliver

No, that's fine. I have nothing to add. Thanks.

Carolyn Petersen
So, how do we want to apply that in terms of changing or not changing the text? Do you have a suggestion, Christina, or do we have it on the table and I'm getting lost in the details?

Christina Caraballo
I can probably make a suggestion really quickly. I also want to incorporate the opportunity. I like how in the opportunity, we state that this is less dependent on providers and the EHR developers because our goal is to also reduce burden for providers. So, when you think of consumer access, I would say as we convene with the sessions, as we update at the end, we should identify ideas for an updated roadmap for patient access that is a more streamlined experience for patients while reducing burden on providers. I think that incorporates the full opportunity, and it's not just telling providers to make a great user experience, but it's speaking to how we create it as an industry.

Carolyn Petersen
Does that sound good to you, Brett?

Brett Oliver
I got a little lost on that last part. Could you say it again?

Christina Caraballo
Yes. So, just replace "clinical information" with "patient access that is a more streamlined experience for patients, while reducing burden on providers." I don't know if we need all that, but –

Brett Oliver
I like it.

Carolyn Petersen
I think it's good to reinforce the goals that we started previously elsewhere in terms of reducing the provider burden and doing something that supports provider experience as well as patient experience. Is that what you needed, Michelle, or do you need more from us?

Michelle Murray
I think it's good. I'm a little stuck on the word "streamlined" because that could be a very narrow thing. It could just mean "less data," and that might not be what we intend. I like the word "meaningful," but it's so overused now that it doesn't have meaning anymore.

Carolyn Petersen
"Efficient"?

Michelle Murray
Is efficiency what we're trying to get at? I also like the word "useful."

Aaron Miri
Let's play with it, Michelle, and just get the intent out there. Everybody agrees with the intent, and we can wordsmith it just to keep us on time.

Michelle Murray
I only have a day after this to turn around the final, so –

Christina Caraballo
So, things to think about – I started – I had put a couple. I haven't gotten the perfect word, but "meaningful," "interactive," "digestible" information – we can play with some of those words. I like "useful" too.

Michelle Murray
Okay. That's enough to work with for now, I think. Thank you.

Carolyn Petersen
Okay, let's move onto the next. Now, the topic is consent, and we're looking at the existing gap, lack of control over sharing and disclosure of information. The comment is that there are several concerns related to this, either for fiscal year '19 – this report – or next year. To wit, reuse of data after release by patient without clarity around implications of sharing data – and, that brings up the point of if it's really consent if it's not clear. Regulations to control reuse, clarity around who has authority to consent to release, part of the issue of who has the authority to consent to treatment. Of course, how are these different types of consent capture, shared, and enforced, and what happens if they are not? That's the enforcement piece.

My 35,000-foot look at this is that there's a lot here to unpack, and I would honestly prefer to move it forward to the '20 version because then we could spend some time researching it and talking about it ourselves, and perhaps getting some time on a full HITAC agenda to tease out people's thoughts about that more so that we covered it well, and it was truly a group recommendation, and not just something that one person had brought up without the full committee thinking, but I'm interested to hear what others have to say.

Michelle Murray
Let me put out here that there are actually three sides that go together. Do we want to tackle each one separately or all of them together? This was the one I mentioned earlier that we split out as a new gap to cover the existing opportunity and recommended activity, but also agreed that some of these questions could go towards the FY '20 report. So, it's up to you how to cover this right now, but there are three sides that go together.

Carolyn Petersen
Well, let's look at it all at once, and hopefully, we can deal with it as one discussion. So, the next slide – This is the existing gap about the lack of control over sharing and disclosure, getting to the recommended activity, identifying it, and suggesting how consent should be captured under TEFCA. The comments are that further complexity arises from the intersection of consent from clinical,

administrative, and research data, including for highly sensitive data, and also, reidentification – should there be a more uniform baseline, process, and standard for consent that allows the individual to opt in for further restrictions, and what would be the role for a HITAC task force in considering these concerns?

And then, if we go to the third slide – which, again, still gets at more consent – create a new gap for the topic with related existing opportunity and recommended activity, that the new gap would be the lack of clarity about the parameters of data-sharing and disclosure, and their implications for consent. An existing opportunity would be to improve the capabilities of health IT to electronically capture, store, and share consent information, and there's an existing recommended HITAC activity to identify and suggest how consent should be captured under TEFCA. So, there are lots of things that are interconnected and brought out in different ways by different people and comments, but perhaps we can do a better job by trying to do it more broadly. We can kick it to next year; we can note that this is an emerging concern in the text someplace and set ourselves up for discussion next year. I'm open to any of those. I think we probably all see this as important. The question is how we best integrate it into the work product and set it up to have some activity next year.

Brett Oliver
I like it being set up for next year, just simply because the final rules aren't out, and I'm sure that's going to change some perspective on this.

Aaron Miri
Right. I was actually going to say that, Brett. I'm actually curious about some of the interesting public opposition that's happening right now, and I want to better understand the arguments and the retorts, and just understand the data behind it so that as we go into this, we're going into it with eyes wide open and taking all public feedback into account, which includes those public hesitations on moving forward with the final rules.

Carolyn Petersen
Yeah, that's an excellent point, Aaron. It's certainly a contentious issue right now. I don't think we would hurt ourselves or anybody else by setting this up for 2020.

Christina Caraballo
I agree with that.

Michelle Murray
To clarify, we're not saying either/or; we're clarifying our current gap in activity and adding it to our list for 2020. Is that what we're saying?

Aaron Miri
Yes. We would push all of it to the 2020.

Michelle Murray
So, I should take out the current gap, opportunity, and recommended activity completely?

Carolyn Petersen
I like leaving it in there as it is now because I think it does help to keep us on target that it's something on the table. We don't want to put it so far out in the parking lot that we forget it there.

Aaron Miri
Right.

Carolyn Petersen
It also does signal that this is an ongoing topic of interest for readers of the report after it comes out, but perhaps before some of those things are addressed, because even though we all keep hearing that we're right around the corner for the final rules coming out, we don't actually know that.

Aaron Miri
Once it's final, I'm sure there are going to be challenges in court. That's been stated publicly. Again, all that will be really helpful for us to look at and disseminate. All right. Any other feedback?

Carolyn Petersen
Does that get at your concern, Michelle?

Michelle Murray
Yeah, it sounds like you're comfortable with the proposal that's in blue at the top. We have two actions here. One is to add a new gap and split out the opportunity/recommended activity with that, and also add it to the list for next year.

Carolyn Petersen
Yup. Going once? Going twice? Okay, let's do that and move onto the next. Do you want to tee this one up, Aaron?

Aaron Miri
Sure. So, on the topic of consequences of reidentification, the gap – new technological capabilities to reidentify/deidentify data. Say that three times fast. The opportunity is to increase awareness of technological capabilities, to reidentify/deidentify data, and then, our recommended activity is to convene a listening session to assess the development of technologies that prevent reidentification and notify individuals of reidentification as it occurs. The comment – should the focus of the activity be prevention or punishment? Interesting. To address comments, the above text about informing individuals could be added to the activity.

So, this one was our discussion about now, essentially, with machine learning, you can pretty much ascertain a whole lot about a deidentified dataset, and the gaps that exist with current law and coverage about that, because obviously, this wasn't contemplated in '96 or anytime before. But then, we didn't know that we wouldn't know. How far along is this type of technology? Is it readily available? What is the real risk? So, it was kind of like, "Let's figure out how bad this is. We knew it could be done, but how bad is it?" And then, further ongoing – so, to me, it's about awareness and appropriate

safeguards. I think "punishment" is an interesting word to use, but what's the recourse if safeguards are breached versus punishment? That's my take.

Carolyn Petersen
I think it's about enforcement rather than punishment and consequences. Is that a financial penalty? Is that some kind of being barred from the market for some period?

Aaron Miri
Right, or is it additional regulatory powers in the beginning to, say – I'm making this up – the FTC so they can enforce this if a third-party app tries to do this when they gobble up data from my health system and there was no proper permission or consent to do that from the patients. What does that look like? I have a whole litany of questions on this. I just think we don't know what we don't know.

Christina Caraballo
Aaron, like you just said, we don't know what we don't know, but our recommendation was to convene a listening session to better understand, but then, this additional text is a specific recommendation, should this happen. So, while I think being transparent to patients is important, and I support that, it doesn't make sense to me in the recommendation. I feel like that would come out of the recommendation, but –

Aaron Miri
Yeah, you're right. We would hope a goal would be that now that we know how bad it is, we can tell patients if said technique or technology was used to reidentify your data, but how do we even know that's a thing?

Brett Oliver
I would agree. I don't think it's necessary.

Aaron Miri
But, let's play devil's advocate. I don't want to lose the fact that we're all saying we want to be transparent. We do want to be transparent, so is there a way to word this with a hopeful objective of being able to identify individuals when reidentification has occurred? I'm not a wordsmith, but I'm saying this is an idealistic objective versus a hard recommendation for that part in blue. Is that worth doing, or should we strike it altogether?

Brett Oliver
I just think you can have probably seven or eight different statements. We just don't know yet. It could be that one, but that would include something else. We would box ourselves in.

Carolyn Petersen
Can we put this in the parking lot and revisit it next year to determine if we have enough information to say something about it that we actually contribute to the conversation?

Brett Oliver

We could leave the recommendation but take the –

Aaron Miri
– blue and put the – yeah.

Carolyn Petersen
I feel like we could spend a lot of time wordsmithing, and it might all be for nothing anyway, which isn't necessarily helpful, given that it just increases the length of the report without saying more.

Aaron Miri
I'm good with that. Again, I just don't want us to lose the intent. We are trying to be transparent. We are absolutely 100 percent on board with that, it's just that we don't know. I honestly don't know. I know this technology is floating out there in academia, but I haven't seen it in the mainstream.

Christina Caraballo
I'm fine if we want to move on. We could consider the easy fix of moving that text into the opportunity, so if it's adding those as an opportunity to better understand how individuals will be notified, and then we could add to the recommendation something along the lines of –just something simple like "and consider how individuals will be made aware." Or, we can move on. That's fine. Did I lose you guys?

Brett Oliver
I'm still here.

Aaron Miri
I'm thinking, actually. I'm good either way. I think we're all saying the same thing, to be honest with you.

Carolyn Petersen
Okay. So, do we want to retain the blue text in the bolded recommended HITAC activity, or do we just want to set that aside for now and look at it next year?

Aaron Miri
Yeah, I'd say put the blue aside for next year.

Carolyn Petersen
Okay, I'm good with that.

Christina Caraballo
Sounds good.

Brett Oliver
No issue.

Carolyn Petersen
Okay, let's head to the next slide. Ah, a short one. In the other topic area in the conclusion, a suggestion to finish the section by adding a few items from the HITAC 2020 plan. It doesn't strike me as controversial per se. I don't think that would hurt the report either way. The question is do we want to invest time in this, do we have project team time, or do we just want to tee it up with a one- or two-sentence intro and a bullet list of items that are in the 2020 plan?

Michelle Murray
If you look at page 46 of the draft, we went ahead and proposed some texts, so we're at that step already. Do you want me to read the sentence?

Carolyn Petersen
Sure.

Michelle Murray
I'll just read the whole paragraph. It's only five lines. "The HITAC made significant progress in advancing interoperability, privacy and security, and patient-accessed information in 2019; however, work remains in this priority target areas to achieve the full potential using health IT tools to help transform the healthcare sector. In FY '20, ONC and the HITAC will continue to" – this is where it starts the new text – "focus on advancing the implementation of the health IT provisions of the CURES Act, including the EHR reporting program and the Trusted Exchange Framework and Common Agreement, as well as address emerging issues, including the intersection of clinical and administrative data standards." So, those were a few items that were on the FY '20 work plan as happening this year that's already under way in their planning, so that's where we pulled from.

Brett Oliver
Nothing controversial from me.

Christina Caraballo
I'm good with it.

Aaron Miri
I'm good.

Carolyn Petersen
Next slide. So, we have some suggested additions to the list of potential topics for fiscal year 2020. One topic would be price transparency, likely increased coverage of improving patient access to financial information, including showing any progress made by the HITAC while discussing the intersection of clinical and administrative data. At least one recommendation should be made for the "patient access to information" priority target area. Any thoughts about that? Personally, I'm a bit uncomfortable saying that we have to make recommendations about anything. I think it's valuable to say this is an important topic that we might choose to make recommendations about depending on what happens during the year and what activity HITAC does, but I feel like there's just way too much flux to be saying

we have to make recommendations about anything given that we don't even know what the full work plan will turn out to be.

Aaron Miri
Yeah, or what the final rules will be. I don't even know what the final rules say yet – no one does.

Carolyn Petersen
Yeah, and if they're tied up in appeal, then that kicks everything down the road.

Aaron Miri
Can we put these in a future parking lot item? I think they're important. Everybody wants price transparency. Everybody wants to be able to give patients everything they ask for. We just don't know what we don't know.

Carolyn Petersen
I'd be comfortable with the parking lot.

Christina Caraballo
Sounds good.

Brett Oliver
Yeah, I like what you said, Carolyn, about making specific recommendations or not, I suppose – being a little more general in that. But, I agree with you guys, too. We need to wait on the rules.

Aaron Miri
We do.

Carolyn Petersen
And then, there was a topic suggested for updates to the USCDI consideration of additional data elements that may include images, care plans, and price and payment information. Do you have thoughts about that, Christina? I know you were involved in that work.

Brett Oliver
I don't mean to butt in here, but that's the whole point of the task force – to develop the process to get additional data elements. I didn't understand why would add this consideration, basically.

Christina Caraballo
I would agree with that. I got stuck.

Aaron Miri
You have a whole process, Christina, that was proposed to add additional elements, and the timing to do so, and the escalation matrix. It was good work that was done that was readily applauded, so why wouldn't this just follow that?

Christina Caraballo
I don't see where this adds value anywhere. I don't know where it would fit, and in our recommendations, there already is an annual review of the on-cue data elements from the HITAC. I think we can just remove this one.

Carolyn Petersen
I'm fine with that.

Aaron Miri
I'm fine with that.

Carolyn Petersen
Okay. And then, the third item on the slide – recommended HITAC activities for "patient access to information" priority target area – add more activities for increased balance across the priority target areas. Personally, on the one hand, I appreciate that it's a value that we should be thinking about all of the priority target areas, but given that a lot of our work is driven by legislation, SRM, and other things, I feel like it's hard to say we should have the same amount of stuff going on in every area. In some cases, everything would be driven by external events, and we wouldn't be able to do anything ourselves that we thought was important. In other areas, you'd be struggling to find something to do that wasn't very important, so you could say we have parity among the amount of activity.

Christina Caraballo
I would agree with that, and I think in our process, we go through the sections, but they come up to the top based on need and things that are important, not filling certain bubbles under each.

Aaron Miri
I would also go back to what we've been saying. We don't know what kind of activities will bubble up because of the final rules, right? There may be a priority matrix based upon that alone. Brett, were you saying something?

Brett Oliver
No, I just was going to say in general, just because you have more activities doesn't mean there's less balance. Does that make sense? You can have one activity that takes up 80% of your time. I just didn't understand the concept we were getting into here.

Aaron Miri
More labs, Brett. Do more labs, more CBCs.

Carolyn Petersen
I think it's a call for remembering all the priority areas, but I don't know that that's really a problem that we've had, so I'm fine with bypassing this one as well. All right, let's hit the next slide. Again, this is still in the potential topics for fiscal year '20. The new topic is metadata, the new gap is standards for metadata, the new opportunity is to establish common nomenclature and use, and a new recommended HITAC activity is to convene a HITAC workgroup to review and provide

recommendations regarding metadata standards and potential additions to USCDI. Okay, I see we are all really engaged in talking about metadata. I think it's potentially an area that we might want to do something with in 2020, but seeing that it's not something that's had significant discussion in HITAC meetings, I'm feeling more like it's a parking-lot thing than something that we give equal visibility to in the report itself, but I'm open if you guys are supportive of elevating this one.

Aaron Miri
I am. I think this is like the other one. In my mind, it just needs to go through that process that Christina mentioned.

Brett Oliver
I would agree. Prove that process doesn't work and that there's a reason for a different approach.

Carolyn Petersen
Do we want to leave this one out of the report, then, or drop it in the parking lot?

Aaron Miri
I think this is going to come out in that process. I don't know why we need to recommend this. I thought this was part of the whole USCDI, proposing these standards, that whole thing. In my mind, this will come out in that, unless I'm misunderstanding.

Carolyn Petersen
No, I'm fine with leaving it out of the report, I just don't want to jump in and say we should do it if someone else has a reason to keep it in somewhere. Okay, it's out. Metadata goes.

Michelle Murray
When you say it's out completely, does that mean it's not on next year's list?

Carolyn Petersen
I don't think it hurts to put it on next year's list, but I wouldn't put it on many pages of next year's list.

Christina Caraballo
Yeah, I would just capture it quickly. I'm hesitant to say anything on the phone because I'm just not sure – I would agree with what everybody said, but I think we should capture it in the report so we can potentially bring it up next year as an identified area to tick through the process. I know in our USCDI calls, metadata came up multiple times, but I don't feel versed enough to have an opinion on escalating it, so I think capturing it for further discussion is a good idea. I support Carolyn and Aaron.

Carolyn Petersen
I'm good with that. Let's move onto the next slide. Do you want to take this one, Aaron?

Aaron Miri
Sure. The topic is synthetic data. That's such a fun buzzword. That'll be a new buzzword for next year, just watch. All right, new gaps – use of synthetic data raises concerns. Comment – there are several

concerns to consider. 1). Synthetic data is a dataset that is derived from real data, statistically identical to real data, but completely a new dataset that does not relate to any actual humans. What security and privacy considerations are driven by the emergence of synthetic data, would this fall under HIPAA, and to what extent have the validity of claims for the benefits of this type of data been tested and validated? There are only five on this one. So, again, being a large academic medical center, I see all kinds of data. I see all kinds of synthetic data that are created for test purposes. To be quite honest, I'm not certain why we're going to call this out in this report. I think this is an important topic, but I don't know why this is any different than any of the other security or privacy items, or any other kinds of data, be it FERPA or whatever. Why is this any different?

Brett Oliver
I don't think there is any difference as well, Aaron. I think we could end up parsing out dozens of these.

Carolyn Petersen
I feel like I'm not close enough to it to be able to say whether this is important or not, but I'm fine with the notion that we can't call out everything specially, and we should just leave the report where it was without this.

Aaron Miri
If anything, if the HITAC feels strongly about this, we could just use commentary, Carolyn – something to consider – we could always ask for one of those updated FAQs about data types from the ONC because the ONC does those little briefs that collaborate with OCR to answer the question of whether HIPAA covers synthetic data. Wouldn't that answer that?

Carolyn Petersen
Yup, that's an opportunity.

Aaron Miri
Not that it's not an important topic, but if it's felt strongly that we need to address it, well, here's a brief on whether HIPAA covers it or not – just have the OCR weigh in.

Carolyn Petersen
Yeah, and it might be something that would be considered a relevant activity by the agencies anyway, given that there's more buzz around synthetic data these days. So, parking lot?

Aaron Miri
I think so.

Brett Oliver
Yeah, I think that makes the most sense.

Christina Caraballo
Okay.

Carolyn Petersen
Let's go onto the next slide. So, the changes that we've discussed today will be implemented into the current draft of the report, and that will be sent out for the HITAC members to review ahead of next Wednesday's meeting, and we will present this revised draft and entertain whatever discussion there may be. Hopefully, it will be brought forth for a vote of approval, and then, from that point, you're ready to document, and it goes to the national coordinator, who can send it on to Congress. Potentially, there might be other changes discussed, and then we would go from there, depending on what those might be and whether those are deemed to be something we can put in the parking lot at the meeting, or if it looks like we won't need to do more activity on it.

But hopefully, we're just about at the end of this. We've had several presentations to the HITAC and a number of our own meetings where we've had public discussion about these things, and we've captured all of the comments from HITAC members in the document that you received for this meeting, so you can see that everything has been addressed in one way or another. I think we're pretty much good. Does anyone else have any questions, thoughts, comments, or concerns about those things we might need to do?

Aaron Miri
I don't. I think this has been great. We've built upon last year's work for this one, and I give credit to Michelle and the entire team there. I think it's a lot of easier this year – I say "easier" in quotes. At least there was a framework we could follow.

Carolyn Petersen
I agree.

Public Comment (1:08:15)

Carolyn Petersen
So, if our workgroup doesn't have any further comments or thoughts, are we able to go to public comment now, Cassandra?

Cassandra Hadley
Sure, no problem. Operator, can you open the line?

Operator
Yes. If you'd like to make a public comment, press *1 on your telephone keypad. A confirmation tone will indicate your line is in the queue. You may press *2 if you'd like to remove your comment from the queue, and for participants using speaker equipment, it may be necessary to pick up your handset before pressing the star key. We'll pause for a brief moment to poll for comments.

Cassandra Hadley
Thank you. Are there any comments in the queue yet?

Operator

There are no comments in the queue at this time.

Cassandra Hadley
Okay. Carolyn?

Carolyn Petersen
Why don't we leave the slide up on the screen in case somebody is trying to dial in and having a little trouble, and I'll poll the workgroup members one more time on if we have any other thoughts or items to discuss or comments we want to make while we're waiting.

Next Steps and Adjourn (1:09:28)

Aaron Miri
This an observation of last year to this year. I really appreciate how much diligence we took to make sure that every comment we got from the HITAC and from the public was documented, noted, discussed, put in a parking lot, added, or whatever we did with it. I think that was really well done, so I give a lot of credit to Michelle, Carolyn, and the whole team working that to make sure that – and then, you verified. You sent out the whole list of whatever we had to everybody – the whole HITAC – to see if we missed anybody. We captured it, we documented it, and we evaluated it again so that everybody felt heard. I think that's so important because this is a culmination of public work.

Carolyn Petersen
Thanks, Aaron. Just speaking for Robert Wah as well as myself as a HITAC co-chair, we really wanted to have a very transparent process where everyone felt like whatever the outcome was, they were listened to, heard, and really had a chance to bring forth their concern or their consideration. I felt like this year, I was much more confident that we really captured everything. I think last year, we tried really hard, but in the first year, you always wonder if there's something you've missed that you don't know you've missed, but this year, we really had the tracking down, and were able to keep tabs on everything, and be sure it was all involved and included.

Christina Caraballo
I'm just chiming in to say thank you to Carolyn, Aaron, and Michelle. As a workgroup member, it was really easy to follow along and be prepared ahead of discussions. This time, I think we were extremely organized. We learned a lot in the first year, and I think the second year was really well run, so thank you all. That made it easier to participate. I think we've got a pretty good report, so kudos.

Brett Oliver
I would agree as well. I love the fact that we have a smaller group, too. We don't have electronic hand-raising. It's more of a dialogue, and I think that really helps contribute to a better endpoint, but Michelle's framework in teeing it up has just been fabulous.

Carolyn Petersen
I agree. Michelle has really been helpful and great to work with in terms of being able to get the product to you and have meetings with a clear purpose and goals.

Michelle Murray
Thanks, everybody. I want to extend thanks to everybody else.

Cassandra Hadley
There are no comments in the queue, Carolyn.

Carolyn Petersen
Okay. Then, unless any of the members have anything else to bring up, we can take back 14 minutes.

Aaron Miri
Groovy. Thank you, everybody.

Christina Caraballo
Thanks, everyone.

Brett Oliver
Have a good rest of your day.