



Health Information Technology Advisory Committee Annual Report Workgroup Meeting

Transcript
December 13, 2019
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

Call to Order/Roll Call (0:00:10)

Operator

Thank you, all lines are now bridged.

Lauren Richie

Good morning, everyone, welcome to the Annual Report Workgroup meeting. Happy Friday. We have the full group accounted for: our two co-chairs, Carolyn Peterson, and Aaron Miri, and Christina Caraballo, and Brett Oliver is on as well. With that, I will turn it over to Carolyn and Aaron to get us started.

Opening Remarks and Meeting Schedules (0:00:32)

Carolyn Petersen

Good afternoon, everyone and welcome to our last meeting, well just about the end, before we present a draft to the full HITAC. I know some really good stuff came out this week to look at, and I am looking forward to good discussion today, so we can finalize some of that. And I'll hand it over to Aaron.

Aaron Miri

Yeah, Happy Friday 13, everybody listening. Thanks for this group getting together today to talk through some of these things. We're getting into throes of getting ready for some phenomenal work from our ONC partners as we tighten up the report and whatnot, so today is an important discussion, as we look at the content, and look at the meat of kinda what we want to be thinking about for the report. For our group, it's particularly important to look at these concepts, these topics, these issues, these items, things we're proposing, and make sure that it makes sense, that it's relevant, that we're not missing anything, that we ask some specific questions of ourselves, and making sure that this is how we want to represent items and issues and whatnot, and address anything that maybe gapped. So, Carolyn, do you want to take us forward?

Carolyn Petersen

Sure. Here is our agenda. We will go through our usual schedules, and then get into discussion of the draft. We'll have a time for public comment and then decide what next steps we have, and then adjourn. If we could have the next slide, please. We are all pretty familiar with the schedule by now. The good news is we are at the point where we can review a draft, and look to present that to the full HITAC next month, and hopefully get approval in February and move it forward to the national coordinator. Next slide, please. So, here we've got our dates for the HITAC meeting, the in person meeting on January 15, and then a virtual meeting on February 19. Next slide, please. So, we've done, in the past few months, we've looked at the landscape analysis, the progress report, on what HITAC has done, the GAP analysis and recommendations section, and this month, next month we're ready to look at the draft of the annual report as a whole. Next slide, please. Getting into the discussion. Next.

Discussion of Draft HITAC Annual Report for FY19 (0:03:05)

Carolyn Petersen

So, here's the outline for the draft. I think we have covered pretty much all of these areas, and discussion about potential future activities for HITAC is ongoing, as always. We will probably get into that somewhat in January, and perhaps February as well. Next slide, please. Getting into the discussion for today, we have a couple of specific questions. First, looking at general impressions, suggestions or concerns. Length and focus, of course, are things we should take a look at, given that we are somewhat longer than last year. Of course we have this year the HITAC progress section as well that we didn't have last year. And then more specifics about what we might want to talk about, the tiering of topics and potential activities and any edits to opportunities or other things that we are bringing forward. Then, our next step to take, we all have until December 17th, that would be next Tuesday to submit our written comments. I know it's quite a long report and your comments may benefit from multiple reviews, so we've given some extension to do that, and then, we'll be bringing the full draft to the full HITAC on January 15. So, we're about one month out. It's very exciting to see our work coming to fruition. So, do you want to get the discussion started, Aaron?

Aaron Miri

Yeah, I think it is time to get into the meat of it. This is important, because again, last time we met, I want to say it was last time we met as in person HITAC, the report workgroup discussion took some time, and that was more of a topical discussion. This time the HITAC will have something substantive in front of them, and so I can imagine the discussion very robust, which will be fun, and I'm eager to hear that. So I think this workgroup really giving this document a once over, really thinking it through, and then thinking it over the next couple of weeks, sending feedback to Michelle will be critical, because it will inform, I could imagine, a robust discussion during the January 15th HITAC. What that, let's get into it. Next slide.

Michelle Murray

Did you want to walk through the... Sorry, this is Michelle, the summary table? I think that's what we had discussed because the crosswalk is slightly less pertinent to the report at this point. It's got the same information but has extra information that we don't need, but the summary table does show concisely the gaps in opportunities, and the recommendations.

Aaron Miri

Yes, that's a document I had, thank you. That's the word I was looking for in my head, because that's what I have open on my screen, yes, that.

Michelle Murray

Okay, yeah, that's correct, thank you.

Christina Caraballo

Hey, Aaron, before we get started on that, can I just make a general comment? The last slide had a question on length. What are the concerns with the length? I know it's long, but to me, this is a really well-written summary, that touches a lot of things, so it's a great reference on kind of the landscape of the health IT in general, and what the gaps are, I mean, all our focus areas. And then, we did do quite a

bit of work this past year, and I think having it all in one place, and to send the report to Congress, is not a bad thing. So, I was just curious what the concerns were with the length.

Aaron Miri

And Carolyn and Michelle, feel free to jump in, but in a nutshell, Christina, it was if we continue to add this list, it may get very wordy and very robust and we may miss the meat of what this document, what these topics are. The additional thing was, we talked about this last time, that we should combine or we need to split them up. But really it's how do we get this tight and concise, and get the topics that are very relevant across that are timely to be addressed. We did not talk about, or I have not heard any concerns, rather, about if this needs to be trimmed up, but rather, let's not add to it unless we absolutely have to, so we don't lose substance of what this document is. And Christine or Carolyn or Michelle, do you want to add to that?

Carolyn Petersen

Yes, I would say that is accurate. I'm not in favor of trimming it at all, but I think we have to be mindful that, at a certain point, it becomes so long people find it less useful or can't find things in it, or it's hard to tell what we think is most important. Yeah, I think we just want to be sure we don't come up with some great ideas and add another 10 or 15 pages to it.

Christina Caraballo

That's really helpful. I was planning on doing like a deeper read this weekend, so I just want to make sure I was on the same page as everybody else, so thank you.

Aaron Miri

Any other general questions? All right, if not, let's go into it, then. We've talked about these as a group already, a lot of these, but we'll go section by section, I think, is the better way to do that, and just a way to think about it. So, let's start with the first section with the immediate opportunities in interoperability, and 4 topics there. So, we'll start with the first one, there: challenges with incorporation and reconciliation of data. I'm not going to read the document back to you, but just in general, I mean, as we are looking at that, it's all around enabling easier integration, and from our perspective as a HITAC, we're really trying to make a recommendations on best practice. Is there anything with that one that you guys go, "Gosh, we are missing the boat on?"

Michelle Murray

Aaron, this is Michelle, jumping here to some ONC perspective. What we're hoping, since we're more familiar, obviously, with the text, and you guys are still just reading it, we are hoping to be able to refer back and decide what's written. We're trying to make sure we're explaining the topic well and that it's the right amount of text to do that. Is it too much, is it too little? So, I think we're pretty solid on what we're saying so far, but we want to know, did we explain it well in the report itself? That's the transition I'm hoping to see today. But if there are other things you want to accomplish, you know, go ahead.

Aaron Miri

That is what I'm asking; does this make sense to everybody, right? Are we saying this right?

Carolyn Petersen

It made sense to me when I read through it, and I think the simplified version the table was really helpful for me, from the cross that we looked at previously.

Aaron Miri

Yes.

Brett Oliver

This is Brett, where would it fit in, in terms of, if you have incorrect data that you have sent out, through interoperability, and subsequently figure out, "Wait a minute, this is the wrong patient?" Would that be included here, under best practices, on not just how to incorporate and reconcile the data but then practices on correcting data that is in error?

Aaron Miri

That's a good question. I thought we had talked about that with another section. I'm trying to look. That's crosswalk. But it could be here too. Or we had also talked about sections that sort of reference each other because they are similar in topic, but yet it crosses multiple domains. So I do know, Michelle, if you could point to what section you think that would be best under, or is it here?

Michelle Murray

In the GAP analysis, there's a discussion of the patient safety topic, and the role of EHRs in that, and it's mentioned briefly again in patient matching, also in the GAP analysis. Yeah, it is further down in the report.

Brett Oliver

Yes, thank you. I apologize for not being a little more knowledgeable about the report at this point.

Aaron Miri

Yeah, us, too, Brett.

Michelle Murray

As you read through, if you notice, we tried really hard, except for the crosswalk exercise, to make sure the landscape topics, like everything shows up there to explain what the topic is, and then, the GAPs refer back to that. They don't explicitly refer back, they are built on what's in the landscape analysis. And then, on down, a topic should flow from the landscape to the GAP to the recommendations. So, that's another thing to look for as you read, to make sure the flow is clear. So, if we're not saying enough about errors up front in the landscape analysis, we might need to add more text about that.

Aaron Miri

Yep, okay. That's something we can look at and see if we want to highlight some more, once we read the full document. With lack of price transparency, or the UDI, I'm gonna just take the whole top section there, those top 4 under immediate: so, price transparency, UDI and then the clarification of the use on clinical data and research. If you will take a minute just to read those and offer any feedback.

Carolyn Petersen

I thought they were pretty well done. They're tightly written, it's really clear, and you can get through them and quickly and know exactly what the possible activities are. I like this format.

Aaron Miri

Yeah, I do too.

Brett Oliver

I do Carolyn.

Christina Caraballo

I agree.

Aaron Miri

The only question I came up with when I read this was on the research item. I know Clem and several others had made a focus on this, and I can appreciate it being here, over a large economic medical center with the University of Texas. There is a thing for review or recommendations and guidelines but there may be, also, a play here related to a lot of work that is been going on that was cures mandated for the FDA, related to human subjects. And I believe it's CFR 46, I want to say, or 46 CFR, rather, I believe that's right. But there are a number of initiatives that the FDA, related to research and human subjects that we may want to link to, but that is really all I came up with and that was perhaps something we need to expand upon. Okay. No comments about that.

Christina Caraballo

Wait, Aaron, what was that? You were saying the linking to like people to do... Can you repeat that, I'm sorry?

Aaron Miri

That's no problem at all. So, under the human subjects rules, human research rules, the FDA was required to basically harmonize with what they're doing and how the human subject regulations correlate together with what FDA does and what HHS does under the common role. So, there's gotta be some harmony that is given for how you handle human subjects and even today there was some inquiries to the FDA from the Senate, asking this question publicly: where has the FDA stood on this? It has mandated by cures, and all around research. You know, how do you deal with human subjects? And this is all research related, so my point was, do we need to footnote that and tie back to some of the work that FDA has been doing, because they came out publicly and said, "Hey we are doing things." So, how does HITAC help educate and give recommendations, in conjunction with what other requirements are given for other agencies that are HHS? Does that make better sense?

Christina Caraballo

Yeah, I think that's a really good point. And I'm sorry when you were talking, I was thinking and reading at the same time. So, I agree, and I was trying to read this and make sure it was captured correctly and I think it's beyond just the framework for clinical data use in research. I think it is really what is the framework for collecting this information, that's needed for research? I think things like social

determinants of health and things such as environment are important and may or may not be collected in the clinical system. So, it's really establishing a whole framework and ecosystem that is going to enable research to be better through data information, and I think it's beyond just linking to the clinical system.

Carolyn Petersen

It may be an opportunity, also, to call out collaboration with FDA, which is something that some of the HITAC members have brought up in previous conversations.

Michelle Murray

I agree, and I think CDC, as well, is doing research-focused initiatives and there have been a couple, but do you think this could be a little broader?

Aaron Miri

Mm-hmm, okay. Good feedback. If no other comments, then we can go to longer-term opportunities here to keep on time. Let's look at the rest of the first page here, so these 4 items: PDMP's, improve patient matching, capture social determinants and EHR-related adverse patient safety events. Take a second to read this, please. Okay, feedback or thoughts?

Carolyn Petersen

I like the idea of holding hearings to get educated on new and emerging technologies as approaches to things and I think that, individually, we may use that in the news if it is not something that happens to be well-connected to our personal areas as informatics and the kinds of work we do. So, I think that would be very useful for the HITAC, both in understanding what is on the landscape as well as thinking about future activities.

Aaron Miri

Brett, you were saying something?

Brett Oliver

I was going to add, on the PDMP's, I think there needs to be analysis of current business practices that may lead to interoperability challenges for PDMP's. It may well be answered with information blocking rules that emerge, but I think that is a stumbling block right now. You've got one company that monopolizes this and really dictates a lot of the exchange.

Aaron Miri

That's a fair comment.

Brett Oliver

So, as an action item, an analysis of the current business practices that might hinder PDMP exchange.

Aaron Miri

Okay.

Christina Caraballo

So, I know we have to draw the line somewhere, but considering the priority how they are addressing the opioid crisis on the points of patient matching, I'm wondering why these are long-term. I guess, when I read these specific recommendations, around PDMP and what it can help, it makes sense that it's in this bucket, but the patient matching one is standing out a little bit to me. I would just like to discuss why that is long-term as opposed to the nearer-term.

Michelle Murray

It's Michelle, just as a reminder, we all agreed at the last meeting that, at least temporarily, we would use the draft HITAC 2020 plan from October to guide immediate versus longer-term. So, I think the next year or two on the plan were immediate, and then I think further out, as a possibility that's not defined yet as something that HITAC would take on in 2020 or 2021 would be longer-term. So, that's what we're letting guide us at the moment. That could shift, I guess, in January, when it's presented again, and I'm not sure. I don't have insight because I'm not part of that subcommittee within ONC, but things could shift category just based on that plan alone. But also, I think the workgroup has a chance to say that we strongly believe this should be done sooner.

Aaron Miri

Yeah, that's a fair point.

Christina Caraballo

Then it was from ONC priority then not HITAC priority.

Michelle Murray

Well, it was a joint effort with the cochairs of the HITAC, so far, and ONC planning like Elise and Seth and Lauren.

Aaron Miri

But we could asterisk this and say, "Let's talk about it as a committee in January and see if there is consensus there," Christina, that the committee could highlight, if we should consider... I want to say elevating the urgency, but there's already urgency so just making this a near-term or immediate opportunity versus longer-term opportunity.

Michelle Murray

Absolutely.

Christina Caraballo

Yeah, I think when I read through the report, one of the things I want to see if it's in there and not is, with the patient matching, maybe it's identified as something that is a big challenge, but a lot of work, I know, is being done right now, and maybe it is not immediate because we just don't think we can solve it in two years. I don't know if that's correct or not, but as we are reading through the report, we should think through things like that as well, like what is tangible and what is not, and where we keep moving along, and where others in industry kind of taking a lead that is in the HITAC.

Aaron Miri

That's fair. Or what's difficult because of regulatory challenges, case and point in patient matching, what's allowed or not allowed, and what's permissible or not permissible under law, right?

Christina Caraballo

Yeah, exactly, and I think we can kind of have that story together when we present these to the HITAC with the rationale, it would make for better discussion the whole group.

Aaron Miri

Interesting, so you're suggested a companion document to go to this, maybe an appendix to the report, that gives the logic for why we elected to go immediate versus longer-term, for various items here.

Christina Caraballo

That would be nice for the record I did not just add a task. I think I would just challenge us as we are reading through this, before our December 17th deadline, to think about it, and then maybe we can decide the best approach after. Some of this language might already exist in the report, and we've kind of been working in this grid and less in the report, so just kind of a thought.

Aaron Miri

It's a fair thought. I could see a lot of it happening because of a lack of understanding, or lack of insight from the committee, not for any other reason. So, it would help expedite conversation to be more substantive, versus immediate versus long-term decisions.

Christina Caraballo

Exactly.

Aaron Miri

Carolyn, what you think about that?

Carolyn Petersen

I was just looking at this chart, thinking, "Is there a way to do like a little footnote that, at the end of each one there is an asterisk or hanging cross or something, and at the bottom of the page, the reference, this comes from X document, this comes from Y document." Then we wouldn't have to create additional sections or additional text and people wouldn't be flipping around, they could just see it was categorized that way and some other document. Would that be workable, do you think?

Michelle Murray

Can I ask what documents you were thinking of, because right now I just know the HITAC planning draft? Is there some other document that you're referring to?

Carolyn Petersen

Well, whatever the other logic is for how things get put into one category or another.

Aaron Miri

Yeah, let is play with it. I think let's play with it and talk about it off-line and what makes sense, and what does not put too much on Michelle's team to help us tease out.

Christina Caraballo

And for usability, too, because if we have an appendix and people have to refer back and forth and that is kind of cumbersome also. But we can work on this more.

Aaron Miri

Okay, good comment, Christina. Those are good comments. What else? Brett, what are you thinking?

Brett Oliver

I am just still analyzing. I think what Carolyn said, I like that approach. Nothing else to add right now.

Aaron Miri

Okay. All right, should we go to the next page, Carolyn?

Carolyn Petersen

Sure.

Aaron Miri

Okay, let's go to page two. So, very top of page 2 you have the last bullet item from the previous section so let is include that, please, in terms of reviewing, but let's take a minute to look at the first there, immediate opportunities in privacy and security, including the one bullet at the top from the previous section, please. Okay, thoughts, questions?

Christina Caraballo

I thought this was really well-written and clear.

Carolyn Petersen

Yeah, it's a nice tight way of convey the many, many things that we talk about when we talk about privacy and security.

Brett Oliver

Agree, can't think of anything to add.

Aaron Miri

I think it's very well done. The only question I have is, and I know we covered in the text of the report, or will cover it in the text of the report, really point out that section number four, under the first immediate opportunity with third-party access. My only question in this is, as time goes on, about how much focus is being given or now to third-party access, does that merit its own section? I'm not trying to encourage us to keep adding and adding bullets, but is that something so important that we want to make it its own thing? Because I do think third-party access is going to become one of the key issues

that will eventually drive future legislation. It's inevitable, there's just too much ambiguity. That's just my two cents though.

Brett Oliver

I think you're right, Aaron, the structure of the report need it to be separate, or are you saying it's gonna be less important if it's identified as number 4 in this section versus calling it out?

Aaron Miri

Yeah, I don't know if I would say less important, as much I don't want folks to just let it get buried in the text, right?

Brett Oliver

Got you.

Christina Caraballo

Aaron, would you phrase the gap in opportunity differently, that would match this recommendation?

Aaron Miri

I think, yeah, I think it would match. I'm just saying should we tease it out and make it its own separate thing?

Christina Caraballo

That's what I'm saying in the structure they put, if it is the same, how would we call it out differently?

Aaron Miri

Well pull it out a section and call it, you know, privacy and cyber security rules for third-party access. So you would have lack of clear privacy rules not subject to HIPAA protections, boom, boom, boom, and then we'd have something specific on third-party access, and right of access, and the disparity between state law and federal law, and all the things that are there that adding contribute to this, and lack of a clear agency of jurisdiction, that sort of thing. But again we do talk about it here, but I just want to make sure if anybody feels like there isn't enough spotlight on this issue. If it's number 4, are we okay? That's my question.

Brett Oliver

Think it's a fair point that you make. I agree with you that it's only going to gather steam going forward. I just don't have enough experience with a report like this to know if it's left as it is, does that make it less apparent or not?

Michelle Murray

Would you like it better, Aaron, if it was number 1 rather than number 4? A

Aaron Miri

I think that would be helpful, yes, just something to, again, I'm not trying to elevate or escalate it, but we need to make sure that people do not lose sight that we recognize, as a committee, the importance

of clarifying some of the ambiguity out there in the industry, which I know a lot of folks are working on thicken about and mulling over how to do this, but I think it should match. That's my two cents.

Carolyn Petersen

Yes, I think it's a higher priority than some of the other activities. I thinking making it number 1 would be helpful.

Christina Caraballo

Agreed. So, on this, the other thing I want to point out is the second one, with social determinants of health, I think we should add PGHD to that, as well.

Carolyn Petersen

Yep, there is talk of PGHD in another section so decide if we want to combine these somehow.

Christina Caraballo

Well I just think it's different like social determinants of health, it's data that can come from a patient to provider, but patient-generated health data is data that's generated by the patient and I think they're both important. In here, I think you could just do a slash.

Carolyn Petersen

There's a Houston sharing PGHD section in the landscape analysis that we carried over from last year. I'm just trying to find the matching gap. The gap, we still have barriers to use and sharing of PGHD as a separate section. And it should show up in your summary chart as well. I think it's down in the patient access area, but it's up here.

Aaron Miri

But I see and I think I see your point, Christina, you are saying that it's both, social determinants as well as patient-generated data and that fit into this category, under the facilitate the exchange safely, all that sort of thing like that. Would the recommendation be the same though for both? I don't think so, right?

Christina Caraballo

It just disappeared, okay, there.

Aaron Miri

And I see your point. I think they are both important, right? So how do you do that, how do you do like a 1A and 1B?

Christina Caraballo

Yeah, I'm not really...

Aaron Miri

You just bullet it like we did that first one there? You're right, we do need to think about that. All right, let's highlight that and we can discuss that over the email. Let's just keep the time here. But I think

that's a fair point, first does PGHD need to be there and then, two, how do we or how would we work through that, on this one?

Christina Caraballo

Yeah, and I will pay attention when I read the section dedicated to PGHD. But I'm thinking that probably it needs the space in the privacy and security section.

Aaron Miri

Okay. All right, any other comments on this top section? Go ahead.

Carolyn Petersen

I said I didn't have any.

Aaron Miri

All right, moving to the long-term opportunities, starting with the variability of information sharing policies and then that kind of goes over to the next page. It's three items. Just take a minute to read those. All right, I'll start first with comment I have when I read the section. Under de-identified data, the more I talked to folks, the more I realize how varying the definition of de-identified data actually means. While I realize there's HIPAA definition, right, how do you de-identified data to meet HIPAA? I think everybody accepts the premise, now, that it's not as difficult to be used to be to reconstruct de-identified data and find specific correlations and data or even potentially specific patients in de-identified data, due to uniqueness of data sets and data promenades. So, I was going to ask, should there be a bullet in that number 2 section there, under new technology capabilities re-identified, de-identified data, that we talk about what does de-identified data actually mean, and help level set that across the industry or something to that effect.

Brett Oliver

A definition of sorts, Aaron?

Aaron Miri

A definition, a method to actually de-identify, or we call it something different, maybe obfuscation, you know, some degree of obfuscation of data because de-identified means I cannot really tell who is this at all, when that's not really the case anymore depending on the data set, and depending on the definition to follow.

Carolyn Petersen

Well, that gets the debate that I have been hearing more in the avian space, where there's a recognition that de-identification is an administrative process, that involves removing certain pieces of information as a process, but that individuals, because the term de-identify is used, assume that it means that you can't figure out who that data relates to, or identify me, as a result of what you've done and that is really not the case. It's an unfortunate choice of word in the current age we live in, you know, which is of course much different from when HIPAA was different or written.

Aaron Miri

Right, you hit the nail on the head, and my question is, should there be like a number 3 here, that says something to that effect, that we need to really look at that and help the industry understand how to truly de-identify and/or re-term it, and/or rework with the various powers that be in helping to re-coin this or reconstitute it or re-implement across the industry? Because, particularly as it relates to research, you try to do as much as you can with the identify data, unless it's a specific cohort where you have consent, and it concerns me every single day just how we have these data sets that, once upon a time to your point, Carolyn, we're as secure as we can possibly be, there's no way to reconstitute them. Now with the power of computing, I mean, it's not that difficult as it used to be, if you truly have that intent.

Carolyn Petersen

Well, and that gets at the question of do we have a parallel activity, similar to others in the draft, getting at patient education about what de-identification means, what it does and doesn't do, and the fact that it's an administrative process, not an actual event that protects you, necessarily.

Aaron Miri

Right, right. Exactly right. Brett, Carolyn or Christina, what do you think?

Brett Oliver

I agree.

Christina Caraballo

Yeah, I agree with what you said about it.

Brett Oliver

Yeah, I think defining terms and current capabilities are helpful.

Aaron Miri

I mean, we could even hold a hearing to talk to some of these folks that of been publishing their work about re-identification. I mean, I remember seeing a study out of Australia with an organization that had done that, and several others reading about, so people have been publishing some great work on it, and I'm sure they would be more than helpful to help educate the committee, and help us come up with ways to appropriately and inform the public and organizations and research organizations. I mean, I'm sure folks like all of us and others will be helpful to come in and talk to us so that's a potential activity.

Michelle Murray

So, this is Michelle. These recommendations, what would we change about them? We do have education and community listening session but are they not focused quite right? Is that what you're saying?

Aaron Miri

That's exactly right. I think there is one thing about sort of general education about this is what it's and this is how you use it, versus this is what the identified means in this day and age, and this is what you

need to do in order to appropriately protect your patients or protect the data set or however. I just think it needs to be a little more focused on the fact that de-identified doesn't mean de-identified anymore, at least in the sense that it used to be. So my proposal, Michelle, to be specific, is to add another bullet on here, where we as a HITAC define what de-identified really means, and/or any other terminology that needs to be start being used, and then help propagate that or help educate the industry on that, and the ramifications of not following recommended principles.

Michelle Murray

Okay, and I'll just read as you review. Let me finish one thing, and then I'll get to Brett. On page 27 of landscape analysis, it does have a definition under HIPAA regulations, of what de-identified means so if we want to change that or de-emphasize that definition, we can do that. We just want you to look at the page, page 27.

Aaron Miri

Absolutely, absolutely, and as I was saying earlier, the definition of de-identified, from a HIPAA perspective, I understand clearly, but even a de-identified data set under HIPAA is still identifiable, with using today's technology, and so that's point I'm making is that gap, whatever you call that, we need to at some point I like, educate, address in some form or fashion. And then Brett, you are saying something sir.

Brett Oliver

That's fine, I was agreeing with you that I think yes, there's a definition of HIPAA but it's not a practical definition any longer.

Aaron Miri

Right.

Brett Oliver

So, that's part of the listening session or education that needs to happen is what's the definition for de-identified, and perhaps even in different settings: for research purposes, for patients understanding if they are giving consent for an MRI. If I give consent for an MRI it's de-identified, if you're still getting a picture of my face, there are recent studies showing we can identify who you are by your MRI.

Aaron Miri

That's right.

Brett Oliver

So, you know, there's some fascinating things going on, and I think we can educate the public on the HIPAA definition of de-identified. I'm not sure that, with current technology, I think that's what you are getting at, Aaron.

Aaron Miri

That's exactly right, no, nail on the head. Any other comments on this section?

Carolyn Petersen

It kind of feels like everything ought to be a short-term issue, but I know that, by the way we've decided to break them out, that that's not the case. But just thinking about the cyber security situation, of course de-identification. It's all important, right?

Aaron Miri

It's all important, we need to do it all.

Carolyn Petersen

Some things are more important than anything but it's still all important.

Aaron Miri

It's all important. That's the hardest part of this is it's literally 1A and 1B, I mean they're all critical. These are all issues, but we would be doing a disservice to ourselves if we try to bite more often than we could chew, and then we don't get anything of the high-quality that we have been producing for the past year and a half. We water it down. So, we have to figure out where the line is, right? Okay. Let's go to the next section there under, if there are no other comments, patient access to information. Take a minute to read the immediate opportunity section, please. All right, thoughts or questions?

Aaron Miri

The only thought I had on the first one there was limited accessibility. From a perspective of being the University of Texas, one of the things that we do is make sure that everything is also ADA compliant. And that's everything from color schemes to what we develop and what we use and everything, right? We try to make sure of that as a conscious thought process. I know we talk about accessibility and usability and other things like that, but is it important to call out the importance of ADA conformance, particularly as development moves offshores, as we develop more software, engage with many more partners in the community, I've realized a lack of understanding, not for negligence, but just because they don't know, a lot of major development partners, particularly offshore, particularly as it is cheaper to develop in other countries. They do great work, they just don't know, and so I spend a lot of time educating, and I'm wondering how many other organizations face that, and I think this is a critical component for patient access.

Carolyn Petersen

When I was reading the accessibility term in the document, I was assuming that it was ADA disability accessibility, but certainly we could change the language to make that clearer.

Aaron Miri

Right, I would think like you would just put kind of brackets beside accessibility and put ADA compliance, you know, multi-language compliance, kind of give a few bulleted examples there, so folks know that accessibility means a lot of things, not just being able to pull it off on the smart device of any sort. I don't know, Christina or Brett?

Brett Oliver

Yeah, under the plan, would part of that we evaluate why there's been low adoption of patient portals as well? Are we just assuming because it's usability? I would argue that and something else going on besides just usability.

Aaron Miri

That's fair.

Brett Oliver

I mean, I know Dr. Rucker at ONC wants everybody to have all their medical information on the phone, and probably most of the HITAC gets that, but I'll be honest, our organization, we got maybe... I mean, we have 35% signed up for our portal, but the usage is still pretty limited, and certainly something like Apple health that we have, it's even lower than that and so hard and it's no more difficult.

Aaron Miri

Right, no, I agree with you. I totally agree.

Brett Oliver

Yeah, so just investigating that, are we not providing information that they need? Or if isn't usable that's one thing, but I'm not convinced that's it.

Aaron Miri

Yeah, we, too, rolled out Apple Health, and I mean, we blasted it out all of our televisions in all of our clinics and we have signs posted and we have people who will help you, and I mean, the adoption rate has been very slow, unfortunately. People still want it all printed up or emailed to them securely or something like that. I don't know what the deal is. We tried. But I do think some of it is awareness. I mean, a lot of people remark to us, because we capture why people... there's low adoption. We talk to our patients, and especially when doing MPS and promoter score when they leave, and the feedback we get is a lot of people do not even realize their phone has that capability. So, maybe you're right, Brett, education. So, accessibility is compliance with all these things, but also, how do we get to get the word out better or smarter or whatever else?

Brett Oliver

I suppose as I reread this, Michelle, that I guess you could include what I insane in evaluating the patient portals and patient facing mobile app's operational effectiveness patient engagement, and/or patient understanding. That's potentially part of that.

Christina Caraballo

I really like number 2. I think a lot of this conversation can tie into what is learned from that one, pulling the roadmap.

Brett Oliver

Who's defining the roadmap there? Quote, experts, is that what we're...?

Christina Caraballo

Good question.

Brett Oliver

Or is that an event that we would create after listening?

Christina Caraballo

Me, I read it like a deep dive of kind of the whole framework around patient engagement. Like, what are the gaps, what are the challenges, and what is happening now? And we had discussed, in one of our workgroups, taking a look at the patient engagement framework that was already done by ONC, and kind of doing or review and revamp of it, and address some of these issues to patient access that we've uncovered over the last few years. And like understanding why aren't patients using their portals like you just said, Aaron. It would be kind of a whole market assessment, with recommendations on how to make it better. But I could be reading that because I would like that.

Aaron Miri

I mean, the bottom line is, people will post on social media every facet of their life, yet somehow, there's a lack of engagement with their own medical record, generally speaking, no matter what we do, same modality, same everything. But what is the sticky we are missing, right? There's got to be something more to it.

Carolyn Petersen

Well I think that some of the mobile interfaces leave something to be desired, just in the sense of it being a very small screen where you're trying to absorb complex information. That's not always a good fit. And, you know, people hear also about how you need to protect her information, and not say or do certain things in public settings. That can work against people's willingness to look at stuff, unless they're in their house, and if you're in your house, why wouldn't you look at it on another computer where the usability is better, et cetera. I think that the smart phone is not the best way to do a lot of the things that you technically can do on the smart phone, and I think sometimes people have some reluctance there without really appreciating it.

Aaron Miri

That's true.

Carolyn Petersen

My idea of a good display is sort of like the Johnson space Center, the wall of monitors. I would have six monitors if I could figure out a way to hook them all up to my computer. So, when I look at the smart phone, it's like, "Nah.". But that's just me. All right, are we ready to move on to the longer-term?

Aaron Miri

Yeah, let's do it. So, it's really just the PGHD one that's on there, right? It goes over to the next page, right?

Carolyn Petersen

So Christina, looking at this placed here, what are you thinking about the place above where we talked about PGHD and noting that?

Christina Caraballo

Yeah, I still think that this bullet, the second recommendation, is related privacy and security so it would make sense that that's in that section.

Carolyn Petersen

In this section or above?

Christina Caraballo

In the privacy and security section.

Carolyn Petersen

Okay.

Christina Caraballo

Just my opinion.

Carolyn Petersen

That make sense to me too but I just want to be sure what you meant.

Christina Caraballo

Yeah, and since this is all by itself, let's just bump it up.

Carolyn Petersen

What gap in opportunity would we tie it to? Would be the determinants of health? Well, actually, it was lack of control, up above.

Christina Caraballo

If you go back up to the privacy and security section, I think it's almost, might need a little editing, but a copy and paste of the bullet with social determinants of health, and then just insert PGHD. Does that work?

Carolyn Petersen

Yeah, I'm trying to find where you are exactly. If you are on page 2 of the summary, is it the lack of control over sharing and disclosing information gap that you are talking about?

Christina Caraballo

Yeah.

Carolyn Petersen

Okay, and then under opportunity is that linked to either existing opportunity or do we need to create another one?

Christina Caraballo

I think, based on the discussion we just had, they're different, so creating a new one.

Carolyn Petersen

Yeah, I think that number 1, can stay where it is in this last section on longer-term opportunities, and the number 2 probably needs to get moved up with its own gap in opportunity text.

Michelle Murray

So that's not part of the gap about lack of control and sharing and disclosing information? That's what I thought I heard Christina say, and that might be part of the gap, but it needs that opportunity.

Carolyn Petersen

Well, I just don't want to see the whole item go up to privacy and security and be taken out of this part of the report. I think it needs to be in both, in some iteration.

Christina Caraballo

I think it's number 2, review actions already underway, regarding privacy and security breaches involving PGHD, right?

Michelle Murray

Right, that would go up and get its own gap in opportunity. So, I'm trying to pin down, so we could work on it, what that gap in opportunity might be. Is it not the existing gap that we were talking about before, on page 2, about lack of control? Is it a new kind of gap, or is it more just a separate opportunity within that gap?

Christina Caraballo

So, this privacy and security breaches, can we go back up? Or I can just see it on my computer, I've got it up.

Michelle Murray

In the reports on page 35, the gap description.

Christina Caraballo

I think they're two different areas, so maybe... It's lack of control or sharing of information. I'm thinking out loud. I don't mind trying to play with this one when I write some of my edits back.

Michelle Murray

Okay. Do you have thoughts on how to phrase the opportunity? Is it similar to the social determinants of health, or is it something different?

Christina Caraballo

That's what I want to give some thought to, because this one has a privacy and security breaches, which is one thing, and then the other one, it was more about facilitating the exchange. So, there's a

difference between breaches and feeling safe to exchange and share the data. So, I think they're two separate things. So, I'd almost put it like... add another one. So, if you look at the lack of control over sharing and disclosing information, then you do another item that kind of almost swaps out social determinants of health for PGHD and adds that there are two sub-bullets under that. So, you'd have a third under that loss of control over sharing and disclosing information, and then this might be an actual separate one, because it's on part of the security breaches.

Michelle Murray

Right, yeah, I think I'm following what you are saying.

Christina Caraballo

But we should probably think that out a little bit. I want to read it and play with it, because I'm not sure that's the best approach. But I think my point is they're kind of three isolated thoughts, and I'm not sure we should consolidate or not. Other thoughts?

Carolyn Petersen

It feels like keeping them separate helped to express the various dimensions, but if the weight of the opinion of others was different, I wouldn't argue or push back.

Christina Caraballo

That's kind of how I feel. I want to look at the text and how it's written to see how best it best fits but again, I don't mind thinking through that as I'm doing my more deep review, and making a suggestion for everyone to react to.

Aaron Miri

Yeah, that's fair. Let's go that route.

Brett Oliver

Agreed.

Aaron Miri

Okay. Any other comments or questions? That's the end of this document.

Carolyn Petersen

I don't have any.

Aaron Miri

Okay. Michelle, did we answer everything that you needed to be answered?

Michelle Murray

Yeah, I think at a general level, yes, especially, you know, is a length okay? Because I know the co-chairs in ONC talked about options, that we had not come to agreement of what is the right length so there was not really a guideline for that, but I think getting that feedback today that it's actually looking okay to all of you, and as you read it, you'll think through that again and see if there are places

that it's still too long, or maybe even we need more text. Just let us know. I think you did cover the concept of getting a little closer on the actual language, and then as you read it think about that again. Are there ways to make it easier for HITAC to tackle some things? And I want to put out, too, that the HITAC 2020 plan, the way we link to it was saying it might start in those years, rather than it has to be completed in that time period. So, we have some things that could take several years. So, it's really just what should we get started on in the next year or two as far as immediate opportunities?

Aaron Miri

Right. All right, Carolyn, let me turn it back over to you.

Carolyn Petersen

Okay. So, we have covered length of focus and we have gone through crosswalk. We've talked about tiers, in terms of what is in the crosswalk, summary table... Let me think what else we can do today, what else we want to do, given that we really haven't had a lot of time to look at the larger draft.

Aaron Miri

I mean, I feel good, Carolyn, I think we have substantively looked at this, talked about it, considered it, worked through it, given great feedback. I mean, I feel good about let's take some time and over the next week or two and review really thoughtfully and really think about some things, and then we talk about it some more after the new year, but I feel really good with today's progress.

Carolyn Petersen

Okay, how about you, Brett and Christina?

Brett Oliver

Yeah, I would like a little more time to dig into that, dig into the text itself. I just haven't yet, but so far I feel good about where we are.

Michelle Murray

So, do you want a little insight on our timeline in the next couple of weeks?

Carolyn Petersen

Sure.

Michelle Murray

Okay, we're crunched, in a nutshell, because we took our time to do the crosswalk and get our alignment right, so it does mean we are shorter on the amount of time edit the draft that we had hoped for, so that's why we are pushing for comments from you by the 17th, because ONC has a couple of days to work with our contactor to do any writing and research that we need, get another draft together, and by the end of that week, we need to get it to our senior leadership, because they really haven't had a chance to look at this. They wanted to look at it pretty soon, before it went to the HITAC in January. But then the government, a lot of us have leave, so we're off, mostly, the last week or so of December and we regroup when we get back in January. Then it's quick then, too, because the HITAC needs a week or so to review. So, we need to turn it around by about the seventh or eighth, to finalize

the document to get it ready to send out and probably on the ninth. I do have a co-chair call set up now on the morning of the ninth to finalize it. So, there's really only a small window, you know, a few days before the holidays and a few days after, that ONC can help you make changes.

Carolyn Petersen

I think if, with the 17th being a date that we need to get our written comments to you, I think that's fine. That's giving us a week to do that, and I would think if there was any – when I looked at it I didn't have a sense that there was anything that might jump out and that would require a major rework. I think it's probably a lot of small-track changes kind of stuff. But if there is, we can certainly, by email, try to figure out how to touch base about that, any small items.

Brett Oliver

I agree with you, Carolyn, I don't think there will be any large substantive changes.

Carolyn Petersen

It seems to me to be in pretty good shape. It's minor tweaks at this point, if there's really much to do and all.

Aaron Miri

Yep.

Carolyn Petersen

All right, seeing that we feel that we completed what we do today, are we able to go to public comment, Lauren?

Public Comment (1:05:22)

Lauren Richie

Sure, we're just a little bit ahead, but let's go ahead to public comment and see if there's anyone on the line. Operator, can we open the line?

Operator

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

Lauren Richie

Thank you, and do we have any comments from the queue?

Operator

There are no comments at this time.

Lauren Richie

Okay, Michelle, anything else from your end that we should cover?

Next Steps and Adjourn (1:06:04)

Michelle Murray

No, I think we are in a good place, and I'm looking forward to hearing your comments.

Lauren Richie

Okay, it sounds like we'll give you guys some time back to review the report, and thank you for your time today and we'll see you all in January.

Aaron Miri

Thank you.

Brett Oliver

Thank you, have a good holiday.

Aaron Miri

Happy holidays.

Christina Caraballo

Thank you, happy holidays, take care, bye-bye.