Transcript

HEALTH INFORMATION TECHNOLOGY ADVISORY COMMITTEE (HITAC) ANNUAL REPORT WORKGROUP MEETING

November 30, 2023, 3:00 – 4:30 PM ET

VIRTUAL

MEMBERS IN ATTENDANCE

Medell Briggs-Malonson, UCLA Health, Co-Chair
Hans Buitendijk, Oracle Health
Hannah Galvin, Cambridge Health Alliance
Jim Jirjis, Centers for Disease Control and Prevention
Anna McCollister, Individual
Eliel Oliveira, Harvard Medical School & Harvard Pilgrim Health Care Institute

MEMBERS NOT IN ATTENDANCE

Aaron Miri, Baptist Health, Co-Chair

ONC STAFF

Wendy Noboa, Designated Federal Officer, ONC
Michelle Murray, Senior Health Policy Analyst, ONC

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

Wendy Noboa

Hello, everyone, and thank you for joining the HITAC Annual Report Workgroup. I am Wendy Noboa with ONC, and I am pleased to welcome our cochair Medell Briggs-Malonson along with our workgroup members Hannah Galvin, Jim Jirjis, Anna McCollister, and Eliel Oliveira. Unfortunately, Aaron Miri is not able to join us today, but we are hoping Hans Buitendijk will. Public comments are welcome, which can be typed in the Zoom chat or made verbally during the public comment period. Now, I would like to turn it over to Medell for opening remarks.

Opening Remarks, Meeting Schedules, and Next Steps & Discussion of Draft Crosswalk of Topics for the HITAC Annual Report for FY23: Text Edits and Topic Prioritization (00:00:35)

Medell Briggs-Malonson

Thank you so much, Wendy, and thank you to the rest of the workgroup that is here. As Wendy mentioned, Aaron is actually unable to make it with us today, but he is definitely here in spirit. This is going to be a very packed workgroup meeting. We have several items to go over, including finalizing some pieces on the crosswalk as well as thinking about the structure. Thank you, Hans. It seems that Hans is on as well. If we do have a chance, we are going to get to some of the illustrative cases and topics to highlight the work that we are doing, so why don't we go ahead and jump right on into the meeting agenda?

The first thing we are going to do is go over our meeting schedules, as well as our next steps. As mentioned, we are going to discuss a draft of the crosswalk of topics for the HITAC annual report for fiscal year '23, and we are actually going to start right at the security and privacy tab. Our Accel team is going to tee that up for us so we can jump right on in. If we have time after all those items, we are going to get into discussion of the draft illustrative story ideas, which we have now included for about two or three years now just to highlight what our vision is for each one of the recommendations that we as the Annual Report Workgroup and HITAC are putting forward, and then, as Wendy mentioned, we will open it up for public comment, and then we will convene. Next slide.

All right, let's take a look at the meeting schedules and the next steps. Today is, of course, November 30th, and this is a meeting scheduled for the Annual Report Workgroup. After today, our next meeting will be on December 18th just to finalize some of the various different aspects of the draft for overall HITAC full committee review. You can see the rest of the schedule there, and the goal is for us to actually submit our final report in February and March of next year. Next slide.

This is a meeting scheduled for the full committee, so in January, when we do have our first HITAC meeting of the year, we will go extensively into the review of the draft fiscal year 2023 annual report, and then we will come back to the full committee in February for its final approval. So then, hopefully, it will be nicely refined and cleaned up to be submitted to Micky and then on to the rest of Congress. Next slide.

What are we doing today? So, as mentioned, we are going to continue to review the crosswalk document as well as take a look at the stories across each one of the target areas, and the goal of that is to make sure that the stories match up with what some of our ideas and visions actually are and that they do appropriately illustrate what we want readers to actually step away with. Then, the workgroup is going to start looking a little bit at the draft report, and if we get to that today, that will be fantastic, but there have been some recommended changes to help streamline the report to aligning them more with the ONC goals for next year, so there are some really great recommendations on the table. Then, what we will do is present the draft report for discussion and approval at the HITAC meetings in early 2024, as mentioned. Next slide.

So, we are going to jump right on into the discussion of the draft crosswalk, so I hope everyone was able to do their homework and take a look at some of these different items. We will start here, just because we still have a fair amount of material to cover. I prefer for us to start at the privacy and security section first, finish the crosswalk, and then go back up to the very top of the crosswalk and really quickly go through it to make sure that there are no other changes or revisions. Just to orient everyone back to where we are in some of the different notations of this crosswalk, any of the blue writing is additional recommendations from our previous discussions that are now included, and then, when you get over to the green columns, there are two of them now.

There is the proposed tier, and Hannah's comments are already in there, but we as an overall workgroup will actually determine the proposed tier, whether that should be immediate, meaning we need to execute this in the upcoming 12 months, or long-term of 12 to 18 months, but there is a new column, which is priority for the HITAC 2024 work plan. So, as you all recall, during our last HITAC meeting, ONC did present the HITAC 2024 work plan, as well as the key priorities for those areas. And so, what our ONC colleagues have now done is added an additional column, and they have already prefilled it so that each of our recommendations is actually tracking to that HITAC 2024 work plan that was actually also presented by ONC. So, before we get started, are there any questions about what our plan is for today? All right, not seeing or hearing any, we will jump right on in.

So, the very first topic was privacy of sensitive health data, gender and reproductive health. Remember, we have discussed this before, and we sort of went through and revised some of the language. The gap is that inconsistent legal landscape governing gender and reproductive health data combined with the difficulty in segmenting this data regularly creates barriers to exchange. The challenge is that current health data

privacy laws do not sufficiently protect sensitive health data, particularly gender and reproductive health data, putting it at risk of being compromised.

What we mentioned is that there are opportunities to improve the technical and operational approaches to protecting sensitive health data regarding gender and reproductive health. Our recommendation was to hold a listening session with HHS Office of Civil Rights, especially because this has very much been in the domain of the OCR, and other groups in order to explore the health IT industry's opportunities to improve the protection of this very important, sensitive health data. And so, in terms of the proposed tier, that is where we are here. Are there any other changes or revisions to this particular recommendation? Hans, we see your hand up.

Hans Buitendijk
Yes, I have a question around the challenge in context of the gap and the opportunity for the folks of HITAC. Is the focus here that the health data privacy laws do not sufficiently protect sensitive health data, or is it more that the challenge is that given the variety in the landscape of privacy rules, the technology to enable and support protecting sensitive health data has not advanced sufficiently to do that, which makes it harder and results in people either sharing too much or too little, but the technology to enable support for that is not quite there yet? That is really the challenge, and the opportunity taps into that, looking at the technical and operational approaches to protect that in the context of privacy laws. I am trying to understand which one is the core challenge here that we are trying to address.

Medell Briggs-Malonson
Hans, at least from my interpretation, it is definitely the latter. With the changing landscape, we have to ensure that our technology is up to par in order to protect the data appropriately based off of so much of the changing political and regulatory landscape, and that is where I think some of our proposed recommendations are going, speaking directly and understanding how OCR is positioning so that the industry can be appropriately agile, and we will create those safeguards in order to do so. Those are some of my thoughts, but Hannah, I see your hand up.

Hannah Galvin
I think the way we worded this is a little confusing. As the legal landscape is changing, how do we enact technical protections over data? That is one piece, but I am not sure that just a listening session with HHS and OCR will lead us to answers or solutions on that. I think there are some pieces around the legal landscape that HHS and OCR can help us explore specifically in that with both the changing legal landscape and advancements in technology. Current HIPAA law may need to evolve as part of that if we are going to advance the technology in order to be able to protect the data, and so, I think it is cyclical. You cannot fully advance the technology without addressing current HIPAA law, but I agree with you, Hans, that I do not think we have fleshed that out here, and I think we need to be really crisp about whether we are asking for advancements in technology and understanding of whether the law is advancing, or both.

Hans Buitendijk
In that context, if the challenge is phrased starting with that, given that it is changing and there is a variety across federal and state laws, there is a challenge for the technology to enable users, patients, and otherwise to properly manage it so that data is properly shared or not shared, and in order to advance that, we need to have a conversation, which might be dual. What can be done on the regulatory and legal side

to create parity and consistency where appropriate? On the technology side, what tools do we need to put in place that are not in place yet to help manage it so that we can share the right amount of information and not have a scenario where, because of risk avoidance, people are not sharing enough, or they share too much, which creates a risk of exposing data that should not have been exposed? That is the technology balance. If we can clarify the introduction of the challenge more along those lines, it would be helpful to then set up the opportunity better.

Medell Briggs-Malonson
So, I completely hear and agree with both of you on that, so I think we should just reword it, and I know our ONC team has captured some of that sentiment, so it is really about making sure that the challenge is that our technology is adaptive to the changing legal and regulatory landscape, but what I would also mention is that when we talk about our proposed recommended HITAC activities, we do have to make sure they are clearly defined and within the scope of HITAC as well. I always think we should be advocates, but how much can we do? I see two hands. Anna, then Eliel, and then let's wrap this up because we still have a lot of content, unfortunately, to get through, so I want to make sure we can get through the crosswalk today. Anna?

Anna McCollister
First of all, I think Hannah and Hans's points are spot on. I would add, though, that I think it would be prudent for us to make sure that we recommend that they begin with user experience, either qualitative or quantitative research, about what consumers' and patients' concerns are before we start developing the technology to implement that. I realize that the technology is complicated, especially given the variations in state law, given some of the concerns that have been raised around, for example, what I believe was Georgia's attorney general subpoenaing personal health records and some of those issues. The people who are implementing these EHRs and the EHR developers have significant concerns about how they are going to do this, and as the data starts to flow and the connection starts to happen as TEFCA comes online, that stuff is going to need to be dealt with, but I want to make sure we are beginning with a real understanding of the concerns and needs and how we can incorporate both the user experience of patients and consumers and the developers' perspectives and develop the technology to meet those specific needs.

Medell Briggs-Malonson
So, taking a very informed approach from all of those that are directly impacted. Thank you, Anna. Eliel?

Eliel Oliveira
I will keep it brief, Medell, but I agree with everyone saying that the proposed recommendations may not be sufficient. Gender is a very important piece of data in order to do other things, like record linkage and matching, and one of the things I can share with the team here is that in our pilots, we try to link data for other products. We have USCDI and a definition of gender that is reasonably new, but that is not what is captured in EHRs, so then you find a disconnect with what is being captured in real settings and what you have to comply with in terms of data standards. I guess my point here on the proposed recommendations is that besides this legal aspect and sensitivity, there has to be some broader discussion on how gender gets utilized in so many different ways in electronic exchange, or we are going to face problems later.

Medell Briggs-Malonson

Thank you for that. So then, if we look at the proposed recommendation, since this definitely generated a fair amount of discussion from all of us, it sounds like the proposed recommendation we have now still applies, but there is an "and" situation. First, yes, we should hold a listening session with OCR and others to explore the opportunities that may exist, but that does not get to some of the other items that we discussed. Succinctly, what additional recommendations would we want to add specifically here? We talked about centering the consumer voice as well as the developer voice, we talked about interoperability, and then we talked about looking at the technology itself, as well as advocating for other HIPAA revisions. What would you all say for the next proposed recommendations for this? Hans?

Hans Buitendijk
I think some of the next ones that we have not talked about and want to think about are in the next row. In the first row, I feel comfortable, at least, that the opportunity and proposed recommendation at that level of discussion is a good one to have, where the next row is getting more into the specific details around technology. I do not see a need for additional recommendations. There might be others, but I am not immediately jumping to things that would be added because I already see them in the next rows.

Medell Briggs-Malonson
Okay, great. Hannah?

Hannah Galvin
The only other one I might add is to consider a LEAP grant in order to further work in this area.

Medell Briggs-Malonson
Okay, to consider a LEAP grant there too. Great. Anna?

Hannah Galvin
Is there a LEAP grant in the second one? I did not see a LEAP grant in the second one.

Medell Briggs-Malonson
I do not see that either.

Hannah Galvin
In either one, it would be good as a recommendation for funding to further that area.

Anna McCollister
This feels like a body of work that needs to be **[inaudible – crosstalk] [00:17:54]**.

Medell Briggs-Malonson
Yes, it does. Thank you for all those comments. We will distill that down into the final recommendations with our ONC team. Is the proposed tier immediate or long-term? Right now, it is on the table as immediate. Are there any objections to moving this to long-term? Let me rephrase that. Right now, it is immediate. Are there any votes to actually change this from immediate to long-term, or should this stay immediate?

Anna McCollister
I would keep it immediate.

Medell Briggs-Malonson
Not hearing any changes from immediate, we will keep it there. Let's go on through to the next one, privacy of sensitive health data. Again, very briefly, there is a lack of consensus on key use cases, the definition of sensitive health data, and the path forward to support improved electronic patient consent. The challenge that we have here is the ability to exchange interoperable consent directives across health IT systems, and that is very limited. The opportunity is to implement enabling infrastructure to support the interoperable exchange of consent directives. The proposed recommendations suggest steps towards a terminology value set of sensitive health data elements that can be widely adopted and explore what additional foundational infrastructure needs to be in place to support the interoperable exchange of consent information. Are there any revisions to this topic and the recommendations?

Jim Jirjis
Is this starting from scratch, or is there something we can point to that is a starting point for this kind of work?

Medell Briggs-Malonson
Great question. Any thoughts about that? Anna, did you have some thoughts about that?

Anna McCollister
I am just wondering if we need to be a little bit bolder and say perhaps we need to start looking at moving towards some kind of unified consent or consent process where, if you are going to be exchanging data in your certified health IT, then you need to have your patients' consent using this one standardized consent form or process because consents vary from institution to institution and vendor to vendor. There are all sorts of clauses and things in there that nobody ever reads, but if there was one single type of consent that would be used for all certified health IT as it exchanges information, that would make it a lot easier for consumers or consumer groups to then be able to understand and then share with their constituents.

Jim Jirjis
I completely agree with and support that. I am also wondering about my point about whether anyone has done this, or is it enough just to suggest this, and part of ONC's drill is to figure out if there are people who have already worked on it as a starting point?

Anna McCollister
There are lots of models of consent, and there are really good ones that have tested well.

Jim Jirjis
Maybe I misunderstood your point. Maybe we should be more direct in saying to evaluate the current approaches and terminologies around this and take steps toward identifying a standard, or something like that.

Medell Briggs-Malonson
I think that is great wording, Jim.

Jim Jirjis

Because then they see what we mean. To your point, Anna, there are multiple ways of doing it. What is that quote? “The wonderful thing about standards is there are so many to pick from.”

Medell Briggs-Malonson
Yes, but I think that brings up a really important piece. No. 1, where are we going as an industry, and how do we make this streamlined, but then, what is already out there and what has been successful? We do not need to recreate the wheel. So, that sounds like a great additional proposed recommendation to explore additional models that are out there in order to see if we can potentially progress with one standard. Hans, I see your hand up.

Hans Buitendijk
I want to fully support that suggestion to look at what is already there and what has progressed, and we do not need to literally put this in here, but I want to recognize two barriers that have come up in other discussions, most recently with the pharmacy taskforce as well. First, consent is not expressed in a computable form. It is on paper or a PDF or something, but it is not in a computable form that systems can assist in evaluating. Second, infrastructure is needed to ensure that the right parties have access to that information and that they actually have it.

So, I think No. 2, to explore what additional foundational infrastructure needs to be in place, is getting to that point. To me, at least, it spoke to that part, that it is not only about standards, but the infrastructure to do that. Maybe we can enhance that to indicate that it is the terminology value set, but what we are trying to get to is computable privacy and consent rules. At that point in time, in an HIE context, we will have the opportunity to assist, inform, alert, or whatever may need to be done. As well as it might be organized, from a structural perspective, it is going to be hard for us to say whether plain text can be shared or not.

Medell Briggs-Malonson
Excellent points, absolutely. That was a wonderful discussion on this. Let’s move on. I think our team was able to capture all those additional recommendations there. For the proposed tier, this was directly aligned with the HITAC 2024 work plan, so, right now, the proposed tier is still immediate. Are there any objections to keeping it immediate? All right, it will stay immediate. Great. The next area is lack of accounting of disclosure. The gap is that today’s patients have limited transparency into how their identified and deidentified health data are shared with the growth in exchange and expansion of purposes of use beyond treatment by national networks and the TEFCA program, and it is important to balance increased transparency to consumers.

I think we all agree, especially Anna, with the burden to healthcare organizations in providing accounting of disclosures. The opportunity is to define the metadata that needs to be collected to support the implementation of accounting of disclosures, identify lessons learned from programs and industries, thus successfully providing data use transparency, and learn more about patient preferences for those disclosures about the sharing of their data. Our proposed recommendations so far, which we are just reviewing, were to 1). Explore the metadata needed to implement prioritized use cases that allow patients and healthcare organizations to understand who is accessing patient data and for what purpose, 2). Explore opportunities to encourage healthcare organizations to regularly provide increased transparency into how they use their deidentified data, and 3). Explore patient preferences for disclosures about the sharing of health data. I already see some hands popping up. Hans, you are first.

Hans Buitendijk
My question is around the challenge of the reference to healthcare organizations and where the focus is with burden on healthcare organizations. Is that too limiting for what we are looking at? Are we covering the variety of organizations that capture, receive, and use data about a patient? We might want to recognize whether we are really intended to look at any place where "PHI" is being managed, which may not always be considered a healthcare organization?

Medell Briggs-Malonson
I think that is an excellent point because we know that patient information is actually flowing into many other organizations and entities outside of just healthcare organizations, and this is just as important when they flow into those other areas, so I agree with you. I think that should be broadened. Maybe we can say "a burden on healthcare organizations and other non-healthcare organizations" or just "a burden on organizations" in general, which would be all-encompassing.

Hans Buitendijk
Maybe "organizations that hold patient data or health data" would give us a much wider variety than what is typically thought of as a healthcare organization.

Medell Briggs-Malonson
Correct. Thank you for that. Jim, you are up next.

Jim Jirjis
My question comes from personal experience. Let me give you two sentences on what that is. When I was Vanderbilt, I was the chair of medical records, and we had employees that could look at their own records, but we promised we would do audits to see if inappropriate people were looking at their records. We ended up having to give up because with all the different people who might touch and look at a record, it was not clear who they were, and more often than not, they had a right, but it took an enormous amount of effort to actually find out if they were appropriate or not, so we ended up having to give up on it because it was creating more harm than good. And so, where I am landing is how do we add a literature review or some other way to this to figure out how to balance usefulness to the patient versus creating angst…? I do not know if I am articulating well, but how do we actually study useful ways of presenting it so that we do not suddenly have patients calling hospitals, wondering why Jennifer Smith, who they do not know, accessed their record? In my opinion, there is risk there that we need to evaluate, just having done this.

Medell Briggs-Malonson
That is an excellent point, and it seems like it is twofold. I just dealt with a patient situation in which that patient did not quite understand that health systems can actually see her data, which is completely appropriate if it is in the setting of trying to provide care and other pieces, so she was very concerned about a breach of privacy because she said she did not allow one organization to see her health records in another organizations, so there was that lack of patient education there, similar to what you are saying, but also, what are the best practices in ensuring that there is appropriate use of that data? I think those are all good pieces.

Jim Jirjis

One thing I have to ask about is the level of detail. For example, if we get down to the level of users within systems, which is pretty granular, then somebody covered the nurse at lunch, but the patient knows that is not the nurse. There are enormous amounts of wasted time for the patient and the clinic. I guess what I am saying is how should we be thoughtful about running pilots and understanding what level of information and possible information toxicity is there? Now, that is not to say that we should not do it. I just want patients to have access and understand, but I also want to make sure that we are not wasting their time too. We might put in there something about understanding the usage of information and how to do so in a way that does not waste the time of the patient and the clinic. I do not know how to put that in there, but I strongly think we need to have that as an evaluation so that it is done correctly and we do not find out suddenly that something has been put out there that is bad for patients and institutions.

Medell Briggs-Malonson
Something along the lines of "explore appropriate awareness campaigns that are patient-facing to educate them about the appropriate uses and/or personnel of their data."

Jim Jirjis
I would actually recommend piloting first, having successful pilots that balance the information toxicity versus value before we actually have something that is required in the broad literature. I strongly recommend it. This is not to say that I am for patient privacy and access, but I have been down this road, so I strongly suggest we conduct pilots to make sure we get value and toxicity right.

Medell Briggs-Malonson
Thank you for that, Jim. Anna, you are up next.

Anna McCollister
I have a couple thoughts. First, I completely agree with Hans on the reference to whether we are going to limit this to healthcare institutions or include anybody who uses the data more broadly. The way that I wrote this out in the HTI-1 recommendations was through two distinct things. One is accountability disclosures for individuals. Personally, I am not sure that names are necessarily needed, but perhaps positions in hospitals or hospital systems. Individual data disclosure is critical, and I believe that is part of the HIPAA regulations, or at least part of 21st Century CURES. Deven and I went back and forth about this for a while. There is a specific statute to which this refers.

The second thing, which might be more implementable for organizations that do not deal with identified data, but deidentified data, is to require a listing of the ways that that deidentified data is used. I think that is lacking, and it is critical because if we want data to be interoperable and to be used, then people need to have an understanding of how that data is being used, and I think the vast majority of the uses are things that, broadly speaking, patients would approve of in terms of things like research into cancer, diabetes, or improving public health. There are probably some for which people would not be particularly happy, but it is difficult to know if nobody has any idea of how and when their data is being used.

So, I see accountability and transparency as two distinct types of disclosures, but to Jim's point, this is not going to be a simple and straightforward thing, whether you are talking about it from an information and understanding perspective or from a technical perspective, so maybe this is a separate body of work, again, beginning with user experience and understanding both the recipients of this disclosure information as well

as the people who are inputting the data and accessing the data at the institutions, and then thinking through how you create a system or a standard that meets both of those needs.

Medell Briggs-Malonson
Wonderful. Those are very important points, Anna. Thank you so much for that. Hannah, we have your comments too, so thank you for that, and we are capturing all of your ideas. Eliel?

Eliel Oliveira
I will keep it short as well. I totally agree with Jim. This is a situation that is only addressed when there is a data breach of a celebrity or inadequate access for embryo data and some scandal, and then we have to dig up who exactly had access and when, so it becomes a tough investigative process. At the same time, I think we are talking about technology, meaning there are probably ways to build intelligence systems to track things and warn when there is an issue, and I think I want to suggest here, maybe as part of the recommendation, to look at other parts of the technology specialties to mirror solutions that could work for healthcare.

What I mean specifically is that in data and network security, for instance, the amount of information that goes in and out of every computer through firewalls every minute and second of a day is extensive, but there are still tools that have been built to monitor all that and figure out when something goes wrong, and there are specific data standards on how that is done. To me, that could be an interesting way to leverage other knowledge and computer science that can be utilized here. You do not need to necessarily be digging into all the data, but you need to be able to understand through the logs going through the wire that at some point, something is just not right.

Medell Briggs-Malonson
Absolutely. That is wonderful too. Thank you, Eliel, and thank you, everyone. Let's go on. We are running out of time, so I am going to continue to push us along, and we are really going to focus on if there are any major exclusions that we need to add in and, most importantly, all the prioritization of the tiers. For lack of accounting of disclosures, do we think this is an immediate recommendation that we need to put in place, or is it long-term?

Anna McCollister
I am fine with long-term.

Medell Briggs-Malonson
All right, Hannah and Anna are fine with long-term. Any others?

Anna McCollister
How are we defining it? Is it five years? Is it next year?

Medell Briggs-Malonson
After 18 months. Normally, near-term is anywhere from 12 to 18 months to implementation, making sure we really dive into that, and longer-term is anything longer than 18 months.

Jim Jirjis

Medell, I am just not remembering whether it was in HTI-1 or somewhere else, but isn't ONC requiring EMRs to do this disclosure? I am trying to remember if that was an RFI or if that is already in proposed rules. I am just not remembering. Do you know?

Medell Briggs-Malonson
Jim, I am not 100% sure. At least from ONC's standpoint, I know this piece did not rise to their highest area of priority, but that does not mean it is not important. Does anybody recall anything about the priority of the disclosures?

Jim Jirjis
I just remember making these points because they were going down the path of making this a requirement in our responses, and I do not know if the final included it or not. The reason I say that is because if it is a requirement, then I think we need to giddy-up and this needs to be more immediate, but if it did not rise to the final rule, then I think we ought to have an immediate plan and a long-term plan because in the immediate, if that is where they are headed, they need to do the work of assessing and doing pilots to make sure we understand how to do it, and we might say that within the next 18 months, they ought to evaluate approaches and test them.

Anna McCollister
I completely agree.

Medell Briggs-Malonson
Again, I do not know if we have visibility into the final rules or from where they are thinking about this. At least from what has been communicated so far, it is not rising to the highest level, but still, this is our report, and so, because of some of the other things that are proceeding in other spaces, I agree that we can definitely do this as an immediate approach, and that is just what we list it as right now until we get greater clarity. Hans?

Hans Buitendijk
Just as a note, I am looking at the 2015 certification edition. I need to check what HTI-1 proposed, as it has not been published yet, but that one does have a certification criterion on accounting of disclosure, so there is some requirement on certified software as expressed in certification criteria. I do not know whether that is voluntary or mandatory, but there is a criterion in there.

Anna McCollister
Which one is it in?

Jim Jirjis
HTI-1.

Hans Buitendijk
It is in the 2015 edition. We would have to check whether HTI-1 has advanced additional requirements on it because I have not seen that they have removed it.

Jim Jirjis

I do not know if there is an addition, but I remember this becoming a requirement in HTI-1. I know we do not have the final, but I think it is really important for us to answer that because I think strongly stating that they need to run pilots and not just suddenly make it a requirement to make all this data available to patients…

Medell Briggs-Malonson
Yes. Let's make it immediate because since we do not have the final rule yet, it is better for us to be more proactive than less proactive, and again, just for the ONC team and Michelle, incorporate the language of recommending a pilot of this work prior to the requirement in order to ensure that it works as designed and does not cause any challenges. Excellent. Great. Thanks, everyone. Let's move on and keep on going to the next section, which is patient access to information. Great, we have nothing there. And then, we have our recurring topics. Once again, the recurring topics are still organized into our priority target areas. As you can see, we did have an extensive conversation on several of these areas, which is why there is the green lettering there, so the first one is in terms of interoperability, and this was the standards to support data linking and patient matching. If you all recall, we decided to combine that all into one category versus how they were previously separated out.

Still going back to the gaps, challenges, and opportunities, the main piece was the lack of standardized health data linkage has resulted in disparate interoperability across systems. We also included that patient matching when sharing data needs to be improved as well, especially for vulnerable populations. The challenge is that a national standardized method for linking health data is needed. Patient-matching errors can result in inaccurate record creation, inadvertently merged records, duplication of records, and other patient safety challenges. The opportunity is to explore possibilities for a national strategy on data linkage, especially across QHINs. The efforts are that addressing patient matching should continue, while assuring that solutions meet the needs of vulnerable populations.

The recommendations that we put were to hold a listening session to learn more about how to improve the standardization of data linking that supports interoperability and increases the quality of the data content and the ability for recipients to request needed data, to learn more about the TEFCA QHINs' experience with exchanging data with each other and their recommendations, including how they are implementing cross-QHIN patient matching and supporting vulnerable and diverse populations, and, last but not least, government agencies' experiences when linking clinical and claims data, for instance, CDC, FDA, and other entities. We currently have this rated as immediate right now, something that we need to immediately dive into because of the fact that it really supports our overall interoperability efforts, so I wanted to open it up to any additional revisions and what we think about the priority ranking. First, are there any revisions, or does this seem that it is hitting okay?

Jim Jirjis
I think it being immediate is right on. If I understand this question correctly, when you say "linking," do you mean patient identification methodologies? Is that what we mean by "linkage"? The reason I say that is, as is stated here, TEFCA goes live in two weeks, right? The QHINs are named and operational. I know that CommonWell is a QHIN, and I know from my HEA experience that they had less than a 50% hit rate for proper patient identification because they were looking at a nation's worth of John Smiths, many of whom have the same birthday, and it was abhorrent. From my perspective, if what we are talking about is patient identification methodologies, that is critically important, and it needs to be sooner rather than later because

many of the TEFCA use cases are going to rely on completeness of data, and not matching patients correctly means we have very incomplete data, bad decisions will be made, and the value of TEFCA will plummet. For all those reasons, if that is what we mean, I would endorse it being a high priority in the near term. After all that, am I misunderstanding?

Medell Briggs-Malonson
No, I think you are spot on, because that is how I interpreted it too. It is interesting that you said that because now that you brought that to light, I think all of us were making that assumption, but we do have standards to support data linking and patient matching. It is the appropriate patient identifiers in order to link all that data together for interoperability. So, there is something that may need to be cleaned up here so that there is no confusion, but I think you are spot on. Eliel?

Eliel Oliveira
Jim, I think you are spot on, and I think the reason that we have four bullets here is because there are different use cases that require different linkages and strategies. In the case of QHINs, we are hoping that someday, this is going to be FHIR-enabled. If you do not deduplicate and find out whose identity is whose, you are not going to be able to get live data from the API ecosystem that we are hoping to have at some point. On another point, I specifically dotted the FDA work that we do at Sentinel and the fact that we are using claims data, and we cannot link back to clinical data because there is no way to do so. There are other use cases in addition to real-time clinical use, and programs like Sentinel are a good example. The last bullet there is talking about preserving privacy because there are ways to do that, but nobody has defined how it could be done nationally, where all these big data sets that CDC, FDA, and other agencies have could actually talk, even if identity is not there.

Jim Jirjis
Good point. I think one of the high-level use cases in the CDC is linking data while still having it be deidentified data that is linked.

Eliel Oliveira
Correct.

Jim Jirjis
So, I think that maybe there is a collaboration there on that. The other question I have is that we have been talking about this for years, and I guess one question we have in there is what are the barriers? Are the barriers that are going to prevent us from making progress still real?

Medell Briggs-Malonson
Jim, I think your question is exactly why this is in this recurring topics area, because it has continued to occur for years, and this is one of the reasons why, even outside of this meeting, we have talked about what we are going to do about these recurring topics that the HITAC continues to bring up every single year but that we are not actually gaining momentum on, and that is where some of the new structures came out to play in terms of having some of our tiers of how we are really going to try to start moving this needle, but you are right. This is something that has been on HITAC's list of top priorities for many, many years, and also for the industry for many, many years, so thinking about what we can do and what our

recommendations can be in order to continue to move this work forward is going to be a very important piece of our recommendations. Hans, you are up next, and then Eliel.

Hans Buitendijk
Thank you. I have a couple of thoughts there. Looking at the challenges column, it seems that the first bullet might benefit from stating that a consistent national standards method is lacking because it really indicates what the challenge is, so I would just shift it around a little bit. The thing is, matching varies not only because there are differences in demographics that need to be addressed and that have different characteristics that you need to look for to ensure you get a proper match, but within demographic contexts, we are deploying a variety of different matching techniques, and I think harmonizing so that you have a common reliability so that, when you match, you can indeed trust that it is a proper match is critical. So, I think it is the harmonization of the different methods that are out there.

The biggest barrier that there is our discussion around national identifiers, and in the absence of that, what can you do? If the Trusted Exchange Framework is able to fulfill its promise where QHINs are integral of understanding where patients' records are located, that means that, particularly in that context, other networks have attempted to address that to a greater or lesser extent, but TEFCA has very particularly called that out as a target. I think having the focus that we have here on TEFCA to help figure out how QHINs in particular can do that would be very helpful to ensure that the knowledge that they gain and the mapping that they can achieve is shared across QHINs, and that, therefore, we collectively get a better match from the start, but that still leaves the problem that Jim raised. If you have many people at a national level with the same name and birthday, though not quite the same address, how do you manage that? That is not unique to QHINs, but it just amplifies it in that now you have larger populations together.

It is still the same fundamental on what data you can truly use that creates a good match. That is probably a combination of network-level and local organizations because they are actually in touch with patients. The networks are not. Somehow, we need to address not only the automated and computable version of it, but the processes, registration, administration, and other things that are best practices that can help advance this at the front end. If we only look at the technology, we will continue to have the challenge that we may not have high-quality to match against. US@ address is a part of that, but what else can be done on the process side to get better data up front? I hate to say it, and it is not a great way, but if we do not put high-quality data in, we do not get high-quality matching.

Medell Briggs-Malonson
That is 100% right. Thank you. Those were all very important points in every single way, Hans. Eliel, you will be the last one on this topic, and we are going to continue to move forward.

Eliel Oliveira
It seems like I am always the last one, but I will keep it quick. To the point that we have had this topic for a while, I think it is because of the challenges with it. Before, as you all know, there was a prohibition before, which was lifted, and now we have started evolving certain things. Hans talked about the US@ address project. I mentioned looking at PPIL as an advanced mode on this front, but another one that folks may not even know about is referential matching that is basically using other government sources of data to basically increase accuracy, and it goes without saying that other industries have cracked the code on this as well. When you are trying to get insurance and they ask you three questions, like have you ever had a black

Accord and lived in these addresses, they eventually get to that precision. I think the point here is that to me, this topic is immediate for us to keep bringing it up because we still do not have a solution, but the solution is out there. It is just that we need to get everybody to agree on how to do it.

Medell Briggs-Malonson
I agree, and on what you said in terms of all the other types of industries that actually do match quite well, that is where C comes into play. Maybe we need to expand it beyond government agencies' experience into, as you said, insurance or finance. Financial institutions do this quite well. So, it sounds like we are keeping it immediate. Excellent work, team. We are going to go down to the next topic here. All right, that was the last piece there. Streamlining of health information exchange does not have a recommendation proposed here, so this was a little bit more of a revamp from a prior topic, but just to make sure we go through this, we only have a little while, so I really only want to spend another 10 minutes. Let's do really big revisions, but most importantly, we have to prioritize this because we have to get to the next portion of really thinking about the report itself.

We have been through all of these items before, but if there are any large, glaring gaps we are missing, those are the ones we should pay attention to, and then we have to rank each one of these areas as immediate or long-term. So, with streamlining of health information exchange, gaps in interoperability remain where health organizations rely on multiple methods of electronic data exchange and must coordinate across multiple health systems, health IT systems, and health information networks to enable exchange. The challenge is lack of implementation guidance and varying policies leading to differing implementations and difficulty in exchanging a consistent set of data. For instance, C-CDAs include only data from the previous encounter, while others include data from the past three years.

Our opportunity is to explore the development of implementation guidance that enables increased consistency of the data exchange. Our recommendation right now is to identify priority use cases and develop recommendations on implementation guidance that can be used in the field to increase the consistency of the data shared. Again, are there any big revisions or air gaps that we have lost? Then, we have to talk about where our priorities are. Eliel, you are first this time.

Eliel Oliveira
There are no gaps. For the proposed recommendations, I was going to recommend that this would be a good task for the QHINs and TEFCA to address because they would have to come up with this definition of the basis for these exchanges. That is the only thing I would suggest adding to that column.

Anna McCollister
I agree completely. That was the thought that was going through my head as well.

Medell Briggs-Malonson
Very good. Thank you, Anna. There is a plus one on that recommendation as well. Are there any other pieces, revisions, or additions to the recommendations? Wonderful. Well, where do we want to set this? Is this an immediate goal, meaning coming up within the next 18 months, or long-term, greater than 18 months?

Eliel Oliveira

I think it is long-term. We have lived without it for so long that now, it is better to wait for the QHINs and TEFCA to establish.

Hans Buitendijk
How many immediates do we have right now?

Medell Briggs-Malonson
I think the vast majority are immediate, Hans. Historically, we think everything should happen now, but I do think almost everything so far has been immediate, because we even changed our long-term to an immediate.

Hans Buitendijk
I do not want to totally go down this route and see what TEFCA can do with the QHINs and how much they can put a dent in this, but at the same point in time, given the number of immediates and the other ones that we have, this has been a longstanding challenge. We need to continue to pay attention to it and continue to advance. It is not only going to be TEFCA that can solve the problem. They are part of the potential to solve it, so that indicates to me that it should be longer-term, but we need to look at the different areas. TEFCA can contribute to our networks regardless of whether they are part of the network. There is what you can do in the demographic data to have higher-quality data in there, which then also goes back to what processes can help everybody to do better than how we do today. To me, it is not quite immediate, so longer-term would be okay in light of everything else.

Medell Briggs-Malonson
In context with all of our other immediate priorities, this will be a longer-term, especially given that we want to see at least what the QHINs can do right now, but this is still a priority. Let's say that if we do not get enough momentum over the coming year, because this is a recurring topic, maybe it should change to immediate if there has not been enough forward motion by the time we revisit this area next year. Any objections to long-term? Okay, I am not seeing any, so we will go ahead and move forward to the next one, cybersecurity events across the healthcare infrastructure.

Once again, cybersecurity events continue to block access to health records, which can impede patient care. Cyber attackers' skills and resources are definitely outpacing the ability of cybersecurity professionals in healthcare to prevent cyberattacks. Mitigating the patients' safety risks and financial costs of cybersecurity events is an opportunity for us. Our proposed recommendation right now is to hold a listening session to explore best practices across healthcare and other industries and amplify existing federal and industry initiative to improve cybersecurity. So, once again, cybersecurity is always going to be a priority for all of us. What we are looking for right now is any significant revisions or additions, and then we need to vote on the proposed tier. Hannah?

Hannah Galvin
My only revision would be that in addition to a listening session to explore best practices, a listening session around experiences of those who have had significant cybersecurity events would be incredibly helpful. There was a recent congressional review where health systems who had cybersecurity events came and shared their experiences. Operationally, I and my team have found that incredibly helpful. This is continually

emerging, so, not just the recommended, theoretical, academic best practices, but I think listening sessions with the actual experiential pieces from those who have gone through it would be incredibly helpful.

Medell Briggs-Malonson
That is a great suggestion. That is very helpful. Thank you, Hannah. All right, I do not see any hands raised for revisions, so, as proposed here, is this immediate, or do we think this is long-term?

Anna McCollister
It feels pretty immediate to me, but to your point, it is all immediate and we want it done now.

Eliel Oliveira
I would say this one is immediate because we are already far behind the pace of advancement, and this leaves us further behind.

Anna McCollister
The only thought I have around recommendations relates to the HITRUST framework that is out there, and that seems to work, or at least have a lot of merit. Maybe we could evaluate whether or not that is sufficient to be applied across all hospitals or healthcare institutions. Others are far greater experts on that than I am, so I will just throw that out there.

Medell Briggs-Malonson
Good point. It sounds like immediate is winning, so we will keep it as immediate. The next topic is patient access to information, limited guidance for safety and security, and mobile health applications. Again, this is a topic that we have discussed several times in the Annual Report Group. There is a gap of a uniform public or private approach to overseeing mobile health apps, failed results and inconsistent quality of apps, and widely varying privacy and security protections. Our challenge is the use of apps that are built without an authoritative source and without sound clinical judgment and integrity, and that can produce patient safety issues.

Our opportunity is clinically valid apps vetted by third parties. Specialty societies highlight available guidance and develop certification criteria to support interoperability with other certified health IT modules. Our recommendation is to explore the guidance available in certification criteria needed for apps that have been vetted as clinically valid to support interoperability with other certified health IT modules. Again, are there any large revisions? We should also think about the fact that ONC does not have full jurisdiction over mobile health applications, but of course, that interoperability with certified health IT modules does fall more into ONC's domain. We should keep all of that in context. First, are there any revisions? Then, we will discuss if this is immediate or long-term.

Anna McCollister
In one of the workgroups that I have been on, I know that we talked about this. I do not know if it was the HTI-1 or USCDI group, but I feel like we made a recommendation around this. This is what my dreams are made of these days, but I feel like this is immediate because one of my big issues is patient-generated health data. A lot of that data structured and stored in health apps and phone-based applications, so if it cannot be taken from the phone into the EHR, then it is never going to actually make its way into EHRs, so it feels to me like a pretty important one.

Medell Briggs-Malonson
I definitely hear you in terms of immediacy right now, Anna. Any other thoughts about immediate or long-term?

Eliel Oliveira
Medell, I agree with Anna and Hannah. We talk a lot about patients being involved in their own care, and in my opinion, that means mobile apps along with other things, but they are completely open for exploitation and there is no oversight whatsoever, so I think this is an immediate thing that needs to be addressed.

Medell Briggs-Malonson
Great. Any votes for longer-term? Hans?

Hans Buitendijk
This is not a comment about immediate or long-term, but I think part of it is when the term "incorporation" is used, it has different connotations, where some might interpret it as "part of and equivalent to" and others might interpret it as "accessible, comparable, and reviewable." There is a technological challenge there as to how we do that so that we can be clear on how to meet both those requirements. There is some promising work going on. In that context, I think longer-term would be the better choice, given the work that still needs to be done to make that a reality and put them side by side together in how they truly relate. Is it really incorporation, or is it really accessible as needed?

Medell Briggs-Malonson
Great. So, Hans, you think that our priority for this should be a little more long-term because of that aspect of the incorporation of this.

Hans Buitendijk
Correct. What does that really mean? We need to get everybody on the same page on what that really entails.

Medell Briggs-Malonson
Yes, absolutely. I will tell you that my leaning was more toward long-term for similar reasons, but it was longer-term especially because so many of these mobile apps live within the FDA and FTC incorporation, so I felt like we needed to understand a bit more about that sort of integration, very similar to what you are saying, Hans, about incorporation or not. That is why I was leaning towards long-term, but I think we are the only two who think that, so I think immediate wins and we are going to go on with immediate. All right, let's keep on going to the next areas. Sorry, I am pushing us through. These are the last three, so I am charging us through the course.

Anna McCollister
You are doing great!

Medell Briggs-Malonson
When it comes to patient-reported electronic health record update processes, gaps are that transparency about the accuracy of patient data and an easy electronic mechanism to update incorrect data are still

lacking and that there is no simple technical way to support this and assure that updates are transmitted to downstream providers. The opportunity is to identify best practices to improve existing processes to review and respond to patient-requested changes considering exchange of privacy concerns, and then hold a listening session to identify current processes healthcare providers are using to receive and process patient-requested changes and explore best practices to improve current state. Again, any significant, major revisions or additions?

Hannah Galvin
I put here to evaluate whether or not this is a current priority. This is certainly not something that I… I do not know how much other people are hearing about wanting patients to be able to make these updates with a technical process or a technical standard, but it is something that is not coming to my attention operationally, so I do not know where this recommendation came from, but that was where my comments here came from.

Anna McCollister
There are definitely a lot of concerns within the patient community around the fact that people have raised issues related to accuracy in their records a number of times. I know I certainly have, and I am with it and health literate enough to be able to point it out if inaccurate information is exchanged or makes into a C-CD report, but I have to be able to do that every time, whereas that might be a challenge for others. So, it is an issue. I do not know whether or not it is an issue that has to be mitigated from a technical perspective, but I think some sort of a requirement for mitigation is warranted.

Hannah Galvin
It is covered under HIPAA that the HIM department has to at least hear you or make an addendum. I guess my question is whether or not we need a technical standard to do that or going back and forth with the HIM department can be done over protected email and all of that. I think that is what people are doing today. So, I hear you, Anna. I think it is really important to be able to have that process. I have not heard that we needed a specific technical process to do that, but maybe others have, and maybe that has come up in needing a way to do that.

Medell Briggs-Malonson
Right. Because we do have to set these three priorities and I want to do this, at least coming from ONC's standpoint, it has not been on their highest level of areas that they absolutely want to dive into. Hannah, I agree with you. I think this is an important piece, but I just have not heard about it, saying that we need to have a solution now, so I would vote for longer-term for this. Again, longer-term does not mean that it is not important, it is just that we have other really pressing issues that we want to weigh in on first, so I would vote for longer-term for this one. Are there any other thoughts about the priority?

Hans Buitendijk
This is Hans. I would agree with that. There is still a bit of work to be done. There is some FHIR implementation guidance that has been drafted and that might already be published on how to do this, and there is a need for some technical underpinnings to particularly then go also to how you write that information and from what source, etc., so I think longer-term is a realistic perspective.

Medell Briggs-Malonson

Great. Any other thoughts? It sounds like we are moving more towards long-term.

Anna McCollister
I think that makes sense.

Medell Briggs-Malonson
All right, thank you all. The next one is PGHD, which is very important as well. There is lots of writing here, so I will not go through everything, but the gap is that patient-generated health data can be challenging to transfer into EHRs and time-consuming for providers and patients to access, requiring special effort. The challenge is that standards are needed to simplify incorporating PGHD data from health apps, wearable devices, and other sources. The opportunities that we discussed are to improve standards and metadata to support the inclusion of clinically relevant PGHD collected from health apps, wearable devices, and other sources. The proposed recommendation is to explore collaboration with other relevant federal agencies to define clinically relevant PGHD that could be incorporated into provider clinical workflows and explore best practices for where PGHD is stored securely for the metadata that is required to improve usability of this data. Any changes? All right, let's go towards prioritization. Is this an immediate or long-term action?

Anna McCollister
I think it is immediate.

Medell Briggs-Malonson
Thank you, Anna. All right, we have one immediate, and I also think it is immediate. I think it is going to take a lot of work, but I think we need to explore it. Any other thoughts? Hannah, I know you have long-term here.

Hannah Galvin
I do have long-term, and I will just add context for that. In my particular health system and setting, there has not been a push for patient-generated health data that is reflective of the patient population that I work with, so I just want to set that in context, but I understand that is not every patient population.

Medell Briggs-Malonson
Thank you for that, Hannah. Hans?

Hans Buitendijk
I think the earlier comments around what incorporation really means is one of the challenges that we need to have for alignment. So, there is the interest. The question is how is that data being used? Is just viewing it possible, as some of that is already feasible in certain contexts, or do I need to have it integrated so it becomes, if you will on the other side, part of the same trend line, which then goes to the quality of the data. How do you use it and how can you compare it? Where that balance sits is not very well agreed to. That is why this area remains a bit of a challenge as to how far and what that incorporation means. That makes it a little more challenging to be immediately addressable, but it is an increasing area of interest to figure out how patient-generated data can be part of the data that a clinician has access to as needed and is appropriate to work through. How is that best resolved? Does it truly mean incorporation into the EHR, and does it mean that it is accessible by the clinician from the appropriate trusted source?

Medell Briggs-Malonson
Hans, just to see if you think this is still immediate versus long-term, I think that is where that second bullet came into play. I think it gets to your point of where this data is and if it is truly incorporated or just linked out. I think that is what that second bullet was trying to explore.

Hans Buitendijk
Correct, and I would agree with that. It is just that to me, the balance seems to be a little bit more on the longer-term side than the immediate side. I would not have a concern with starting, as exploration is already under way. I am trying to balance how many immediates we have.

Medell Briggs-Malonson
I know, because everything is a fire we have to put out now. All right, Eliel, unfortunately and fortunately, you are the tiebreaker because we are two and two. Is this immediate or long-term for you?

Eliel Oliveira
I feel the last comments here about how bringing this data inside of EHRs does not make sense and will never make sense. We continue to grow more and more data sources, more sensors. There has to be some way to create that connection in the workflow so that more and more of this data becomes available when needed. I feel it is immediate because there is already so much here, and it is going to continue to grow, and we still do not have a clear way to integrate things alongside the EHR. I do not like that idea of just having it within the EHR because there are so many complexities with doing so, with the thousands of EHRs that are out there, but there are ways to actually do it, and we have done some pilots, where things work alongside each other and you get knowledge of what is going on out there. So, we need a solution for that. I feel that is quite critical.

Medell Briggs-Malonson
So, was that immediate or long-term?

Eliel Oliveira
Immediate.

Medell Briggs-Malonson
Immediate, okay. So, we flipped over to the immediate for that one. Thanks, Eliel, for being the tiebreaker. This is the last one, and then we still have to go through very quickly. I just want you all to see the stories, and then we are going to go to public comment after that. The last one: User-friendly price/cost data transparency. Pricing coverage data provided for transparency can be difficult to understand. There are many different challenges with implementation of and compliance with it. The opportunity is to expand price transparency efforts and further understand patients' experiences, and the recommendation is to invite CMS to provide an update to HITAC on healthcare provider and health plan price transparency initiatives. Is this immediate or long-term? Hannah has voted for long-term.

Hannah Galvin
I will give some context around that, too. We have a lot of immediate things. We want to hear more about what CMS's plans are around that, and that is why I selected long-term, though I know that many patients need to understand this sooner rather than later, and it is very important.

Anna McCollister
I think it is a critical need, but I am just not completely sure it is the ONC's priority.

Discussion of Draft Illustrative Story Ideas for the HITAC Annual Report for FY23 (01:18:22)

Medell Briggs-Malonson
Two for long-term, three for long-term. Any objections to long-term? Good, we have another long-term. Excellent. Thank you all so much for prioritizing and adding some of the different revisions. We have a couple minutes before public comment, so I would ask the Accel team if they could just bring up the various different story. We do not have time yet to go into too much of the draft report. We will do that at another time, but I did want to make sure that we as a workgroup go through the stories visually because when we get together next time, we really do need to revise them. Hopefully, we can do some work before our next meeting to get some of your thoughts and comments.

So, these are the draft illustrative story ideas for the HITAC annual report. For those of you all who are new to HITAC and to the annual report, if we go to the next slide, one of the things that we like to do is that these ideas represent initial options for a set of illustrative stories of the recommended HITAC activities that will occur in the future. So, in the final report, there will be a single story that will be highlighted as a paragraph above each one of our five primary target areas so that someone who is not as familiar with this content will be able to read the story and say, "Oh gosh, that makes sense why HITAC is making these recommendations" and the vision of what HITAC has. Next slide.

We do not have time to go too deeply into it, but I just wanted you all to see this. For instance, for the use of technologies that promote and advance health equity, there are two stories here, one based on a patient who currently lives in a food desert, and also bringing in the incorporation of social drivers of health as well as other community organizations. That is one story. Another story is regarding a senior patient that has low vision needs and how that patient actually navigates in terms of receiving their healthcare. Again, there are two stories for us to look at in order to then revise. Next slide. The next one is use of technologies that support public health. Once again, this is actually a story that has been written about in a sudden surge in cases of gastrointestinal illness, so please take a look at this, make sure that it makes sense, and give us any revisions that you may have. Next slide.

In terms of interoperability, there are two options there, one with a patient with a hyphenated last name and really going back to the idea of that matching and the cardiology practices querying TEFCA in order to learn about the patient's previous diagnoses. We also have information from a skilled nursing facility, and again, we are looking at the interoperability from the skilled nursing facility, their EHR, and other entities. Next slide. Hans, I see your hand, but I am just going to go through these very quickly and then answer your question. For privacy and security, again, there are two different stories for us to take a look at, and our job is to revise them, but also see which story best reflects what our recommendations are trying to contribute to. The last set of stories is patient access to information, and what you have here is one that focuses on endocrinology, the other on neurology, so please take a look at those. Hans, what is your question?

Hans Buitendijk

I have a clarifying question. Are these stories meant to be forward-looking, reflecting on the potential?

Medell Briggs-Malonson
Yes, absolutely. They are the future. So, they are supposed to represent our current recommendations right now. We are trying to get to this forward-facing future state of our systems and healthcare. Excellent question.

Hans Buitendijk
That helps in reviewing them. Thank you.

Medell Briggs-Malonson
Yes, thank you. All right, we are exactly at 4:25 Eastern Time, 1:25 my time, so I will turn it back on over to Wendy for public comment.

Public Comment (01:22:42)

Wendy Noboa
Thank you. Okay, we are going to open the meeting for public comment now. If you are on Zoom and would like to make a comment, please use the hand raise function located on the Zoom toolbar at the bottom of your screen, and if you are on the phone, please press *9 to raise your hand. Once called up, press *6 to mute and unmute your line. Let me take a look here. At this time, there are no public comments, so I will yield the time back to the workgroup. Medell, please proceed.

Next Steps and Adjourn (01:23:10)

Medell Briggs-Malonson
Thank you, Wendy. I want to thank everyone for reviewing the crosswalk. That is by far the largest amount of work that we have to do, and we have now prioritized all of our current themes, as well as our recurrent themes. Our next meeting is scheduled for December 18th. What I would ask is for everyone to actually go through those illustrative stories and, in those target areas that have two stories, select the story that you think is most representative of our vision, but also make any small revisions to those stories. That would be quite helpful because during our next workgroup meeting, we will definitely take a look at the stories, as well as preview one of the initial drafts of the report, and that is what we will do in December in preparation for January to report out to the full committee of HITAC, and of course, hopefully, after the approval of the report in February, there will be review and approval by Micky, and then it will be submitted to Congress.

I just want to thank you all for all of your time, especially over this full year. This has been a fantastic time serving on this workgroup with each one of you. I am happy to see all our collective work finally coming together into one final report, so thank you for that. Any questions from the workgroup?

Anna McCollister
What is the best way to incorporate edits into the stories?

Medell Briggs-Malonson

Wonderful question. What I would recommend is to track changes, since it is a Microsoft Word document, and send it back to us, most importantly to Michelle so that she can see your edits and incorporate them, or so they are at least able to track who is making edits to each one of them. Great question.

Anna McCollister
Where are the stories? I thought they were on the slides.

Medell Briggs-Malonson
They were sent out to the workgroup, and we will resend them as well, but they were sent out in our packet, and in fact, even on this calendar invite, the stories are also there. They are attached to the calendar invite for your review as well. We will make sure to send it back out, especially with any additional instructions for you, too. Any other questions? Well, if there are no other questions, again, thank you, everyone. Enjoy the rest of your day and your evening, and we will see each other in a few weeks.

Eliel Oliveira
Thanks, everyone. Bye.

Anna McCollister
Thank you.

QUESTIONS AND COMMENTS RECEIVED DURING PUBLIC COMMENT

No comments were received during public comment.

QUESTIONS AND COMMENTS RECEIVED VIA ZOOM WEBINAR CHAT

Jim Jirjis: do we need to get through every row today?

Jim Jirjis: ooops I need to respect the handraising

Jim Jirjis: sorry

Hannah K. Galvin: I think Jim made some really good points. Lowering my hand to protect our time, but I agree that significant patient education would be needed - particularly around the intricacies of our health care system. Most individuals don't understand what a pharmacy benefits manager does - so if a user at a PBM accesses their data, it may cause alarm. This requires significant health literacy education and to be done thoughtfully. It may be important to start with non-HIPAA covered entities.

Hannah K. Galvin: Apologies - I'll be right back

Jim Jirjis: Ihave to hop off for a MIcky call at top of the hour

Jim Jirjis: Ann I concur

Jim Jirjis: needs to be strongly stated

Jim Jirjis: Anna then to your point we need to amend the HITAC recommendation to include this evaluation approach and articulate the risks of not doing so

Jim Jirjis: Keep us on task!!! go Medell

Hannah K. Galvin: I think it's probably still worth it to make the recommendation for a national patient identifier - this is the chance to make the recommendation to the Congress.

Anna McCollister: agree w/ hannah

Jim Jirjis: Yes to national identifier. BUt with the caveat that it does not solve all problems

Jim Jirjis: SO sorry I have to hop off

Hans Buitendijk: An QHINs will depend on their participants to make it work.

Hannah K. Galvin: I would add a recommendation that it certification criteria needs to include vetting for 1. clinical validity and 2. privacy/security

QUESTIONS AND COMMENTS RECEIVED VIA EMAIL

No comments were received via email.

RESOURCES

AR WG Webpage
AR WG - November 30, 2023, Meeting Webpage