Transcript

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

June 17, 2024, 3:00 – 4:30 PM ET

VIRTUAL

MEMBERS IN ATTENDANCE

Medell Briggs-Malonson, UCLA Health, Co-Chair
Eliel Oliveira, Harvard Medical School & Harvard Pilgrim Health Care Institute, Co-Chair
Shila Blend, North Dakota Health Information Network
Hans Buitendijk, Oracle Health
Steven (Ike) Eichner, Texas Department of State Health Services
Jim Jirjis, Centers for Disease Control and Prevention
Anna McCollister, Individual
Kikelomo Oshunkentan, Pegasystems
Rochelle Prosser, Orchid Healthcare Solutions

MEMBERS NOT IN ATTENDANCE

Hannah Galvin, Cambridge Health Alliance
Sarah DeSilvey, Gravity Project, Co-Chair

ONC STAFF

Seth Pazinski, Designated Federal Officer, ONC
Michelle Murray, Senior Health Policy Analyst, ONC

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

Seth Pazinski
All right. Good afternoon, everyone. Welcome to the Annual Report Workgroup meeting for the fiscal year 2024 cycle. I am Seth Pazinski. I am the ONC Designated Federal Officer for the HITAC. I want to remind all of the workgroup members that the meetings are open to the public and that public feedback is welcome throughout. Members of the public can type comments in the Zoom chat feature throughout the meeting and we have time at the end of the agenda to make verbal public comments as well. I am going to begin the call with a roll call of the workgroup members. When I call your name, if you could indicate you're present and I will start with our co-chairs. Medell Briggs-Malonson.

Medell Briggs-Malonson
Good afternoon, everyone.

Seth Pazinski
Eliel Oliveira.

Eliel Oliveira
Good afternoon.

Seth Pazinski
Hans Buitendijk.

Hans Buitendijk
Good afternoon.

Seth Pazinski
Hannah Galvin. Jim Jirjis.

Jim Jirjis
Present.

Seth Pazinski
Anna McCollister.

Anna McCollister
I am here. I was on mute.

Seth Pazinski
Shila Blend.

Shila Blend
Good afternoon.

Seth Pazinski

Sarah DeSilvey, unfortunately, could not make today's call. Steve Eichner.

Steven Eichner
Good afternoon.

Seth Pazinski
Kikelomo Oshunkentan.

Kikelomo Oshunkentan
Good afternoon.

Seth Pazinski
Rochelle Prosser.

Rochelle Prosser
Good afternoon.

Seth Pazinski
Is there anyone I missed or who joined a few minutes late? Thank you. Now, let us turn it back over to Medell and Eliel for their opening remarks.

Opening Remarks (00:02:00)

Medell Briggs-Malonson
Thank you so much, Seth. And it is such a pleasure as always to be with the Annual Report Workgroup. This is going to be another exciting meeting because we get to dive even more into the potential topics for the annual report. I am really looking forward to having a very concise yet highly informative meeting today. Eliel, I will turn it over to you.

Eliel Oliveira
Thank you, Medell and thanks, Seth, everyone for joining. We are excited about moving forward with a workgroup and for the topics you raised last time. It was a great discussion. There is so much to talk about so let us dive into it.

Medell Briggs-Malonson
Thank you. And what we will do right now is quickly go over the meeting agenda, as well as some of the various different aspects of our Annual Report Workgroup. So, one of the things we will move into is communicating and using HITAC Annual Reports. There was a large amount of discussion about our prior reports and how we were able to effectively use them to influence and guide some of the additional charges and discussions that have taken place, not only in ONC but in other areas as well. Then, we will talk about discussion of workgroup plans, discussion of potential topics for the HITAC Annual Report work for fiscal year 2024. We did go over some of the ones recommended previously from the HITAC. But we also want to make sure that we are incorporating all of the various different ideas and voice from our workgroup here today. And then, we will end by public comment and then talk about the next steps and adjourn from there. This is just the overall membership as well as ONC staff, as was mentioned. And thank you, Seth, already for all of our roll call.

And Seth, I think we will turn it back to you to give an update on communicating and using the HITAC annual reports.

Communicating and Using HITAC Annual Reports (00:04:05)

Seth Pazinski
Thank you, Medell. I wanted to just respond to a few of the items that Medell highlighted that were discussed in the prior call. I just wanted to clarify one scoping question and then, talk about ways that ONC communicates the HITAC annual report and then, also pose for discussion how we can really maximize the use of the HITAC annual report as well. I am going to give a few remarks and then, we will have potentially a few minutes for questions. To start off, one of the questions that came up at the kickoff meeting was around the ability for HITAC through the annual report to make recommendations to Congress on legislation and funding gaps. I did want to clarify that, yes, that is in scope. The HITAC annual report can identify existing gaps in policies and resources and provide recommendations to address those gaps. The one caveat on that is that those gaps must be connected to either furthering interoperability or achieving the ONC objective and benchmarks.

This is specifically called out both to address gaps in policies and resources and related recommendations, and then aligning those to the advancing interoperability and achieving ONC objectives and benchmarks in the legislative requirements for the HITAC annual report. Hopefully, that provides some clarity on one of the discussion questions that came up at the kickoff meeting. Next, I wanted to give a background into how the HITAC annual report gets delivered to the Secretary and to Congress. By statute the HITAC annual reports are required to go to Congress and Secretary of Health and Human Services. That happens in a few steps. HITAC votes and approves the annual report and then, the HITAC co-chairs through a signed transmittal memo submit the annual report to the national coordinator. Once that happens, ONC staff, so folks like myself and Michelle Murry who you are familiar with, on behalf of the HITAC will submit the annual report to the Secretary of the U.S. Department of Health and Human Services (HHS).

Then, there is an official correspondence for submitting things to the secretary so we use that process. And then, we also on behalf of the HITAC facilitate the submission of the annual report to Congress. HHS has an executive secretariat or Exec Sec as I like to call it for short. Exec Sec manages HHS development and review of regulations and correspondence, as well as reports to Congress. Exec Sec directly supports the Secretary and the Deputy Secretary of HHS and works across all of the divisions of HHS and with other federal agencies. ONC staff work with the HHS executive secretariat as well as the HHS Assistant Secretary for Legislation. The Assistant Secretary for Legislation is the one who formally submits the annual report via a signed memo to Congress. On the Congress side, the memo is delivered specifically to the Senate Committee on Finance, the Senate Health, Education, Labor, and Pensions or HELP Committee, the House Ways and Means Committee, the House Committee on Science-Based and Technology, and House Energy and Commerce Committee.

And once that occurs, there is an ONC legislative team that coordinates legislative matters within the agency, as well as with the Assistant Secretary for Legislation. And that team helps confirm that the HITAC annual reports have been received by those congressional committees that I previously mentioned and also helps point to the annual report as relevant in supporting communications between Congress and HHS. Jim, I see you have your hand raised.

Jim Jirjis
With any report like this, one of the questions is who actually reads it. Is it mostly the health committees? Do you have evidence that by submitting this report, who responds to it? Do we get questions? And who is the main audience? I know it is a broad group we are sending it to, but I have to believe that senators that are not involved in the health committee might not have time to read. Who is our usual customer for this report? And then, what ends up happening to it? Because from my perch, we submit it and I am not sure we hear much. And then, the next year we submit another one. Can you give us a little taste of that?

Seth Pazinski
Yes, sure. We at times through reports to Congress that ONC submits will get questions from Congress or meeting requests. Those are all managed through the HHS Assistant Secretary for Legislation. That is the formal group within the Department of Health and Human Services on behalf of ONC who will coordinate the communications between ONC and the Hill. Typically in my experience, it will be a health policy lead within the congressional members' office who will be engaging on substantive matters that ONC is communicating on. Medell?

Medell Briggs-Malonson
Thank you. Thank you for all of these explanations, Seth. And Jim, I know that you have served on this Annual Report Workgroup for several years and we are so appreciative. Seth, would you say that still our primary customer is still ONC by far, just because of the fact that we are an advisory committee for ONC and for health information technology? Would you say that we have primary customers and then, we also have the secondary as you are just mentioning?

Seth Pazinski
Yes. Maybe this will help to differentiate a few different ways that the committee can leverage the annual report and focus the content. Definitely ONC is the primary customer for the HITAC annual report and one of the ways that in particular I would say is we use the annual report as our primary driver for developing the annual HITAC work plans. Typically, we will present the ONC objectives and benchmarks. That is the statutorily required steps. We present those to the HITAC in the fall timeframe. And those get incorporated into the HITAC Annual Report. That is ONC's perspective on what our priorities are in the coming years. And then, the remainder of the HITAC Annual Report is the committee's perspective on the different topics and what the potential is for the committee to take on the topics. It is the primary resource we use in agenda setting for the committee. And I can put a link in the chat, too, that breaks down.

We have the historical record of each of task forces and workgroups that happen each year and that includes all of the HITAC Annual Report. Generally, you will see that there is about three to four subcommittees of HITAC that occur each year. Some of those are where ONC is putting something forward like a proposed rule or a draft United States Core Data for Interoperability (USCDI) version and the committee is responding to those. And some are more open topics like public health data systems, for example, where the committee is kind of broadly looking at a segment of the health value chain and providing feedback to ONC. We really leverage the annual reports to figure out what are the topics that we want to charge the committee to dig into. We also use it as a source for emerging issues. One of the things that the annual reports lay out is these are the things that are pressing right now.

These are the things that the HITAC sees as items that are coming down the line to address in a few years. That helps inform us on what are the potential issues that ONC needs to be aware of that are emerging within industry and what are the things where we may want to take some action on, what are the things that we are more in a monitor posture on to track along with the committee, or what are the things that maybe ONC is taking a position on to help provide clarity to industry? Agenda-setting for both our own work as an agency and for the HITAC, as well as having an understanding of what those key issues **[inaudible] [00:14:02]** come to the table in the next few years. Those are really how we as ONC as a primary recipient of the document use it each year.

Medell Briggs-Malonson
Excellent. Thank you so much, Seth. Are there any other questions regarding the communication as well as the utilization of our HITAC annual report and how best that we can leverage this report in the future? Are there any additional questions for Seth?

Seth Pazinski
I am going to highlight one example to show how that life cycle can start with an annual report and, ultimately, come back to the HITAC later. Public health data systems is a great example where the committee and the HITAC annual report elevated public health as a priority target area. And that subsequently led to two different task forces that were focused on public health that informed HHS as it was coordinating internally on its plans for public health data systems modernization. Last week that came full circle where we are having a conversation around USCDI public health initiatives and getting the committee's feedback. That is one example to just show you how something being elevated through the annual report can inform subsequent work of the HITAC and, ultimately, lead to action on behalf of ONC as an agency or the department as a whole. I did want to share that example.

Medell Briggs-Malonson
Excellent example. Thank you so much, Seth. Are there any additional questions? Well, thank you, Seth. This was very informative because we did have a robust conversation. I think you were able to provide some additional insight into how these reports do go forward and influence change. We appreciate you. Eliel, I will turn it over to you.

Discussion of Workgroup Plans (00:16:20)

Eliel Oliveira
Thank you, Medell. Can we move to the next slide, please? Let us dive in on the discussion of our workgroup plans. This is the calendar of our schedule of meetings coming up for the month. As you see today, we are moving forward with developing our topics. And then early in July, we will start working on the crosswalk topics for the annual report all the way to the end of August. And you will see in a minute how those relate very well to the HITAC meetings where we present to the HITAC and receive feedback and make adjustments to develop a draft of the annual report in September and October and then, update that final draft for approval. And we may be ready to submit at that point to Congress. And here are the full HITAC committee meetings. As you can see in July, we update the status of the report development with the discussion topic list.

And then by August after we have discussed the crosswalk, we update again the team where we are in September. We go through the updated status of the report, review the draft with the feedback in October

in front of the HITAC, the whole group. And then in November, we approve the final version of the annual report, again, to summarize the work plan for the Annual Report Workgroup. We have a compressed timeline, as you can see to the end of the year. In previous years for those of you that have been here before, usually we are submitting to Congress in February. Now, we want to make sure that this is in our yearly calendar. We are going to try to have this completed before December. There a lot of topics and less time. As you saw in the list, we developed the potential topics to present HITAC in July, which we have been working on.

Then, we will work on the crosswalk document over the summer and present to the HITAC in August. And I think you all have seen the crosswalk document so far. Then, we will review the draft report in September and present it to HITAC in October. And after those edits and HITAC votes to approve the report and transmit it to the coordinator in November. At that point after the final review, the ONC forwards the report to the Secretary and Congress and posts that by the end of the year. And that is our plan. I will turn it back to you, Medell, to walk us through the topics now. Thank you.

Discussion of Potential Topics for the HITAC Annual Report for FY24 (00:19:30)

Medell Briggs-Malonson
Great. Thank you so much, Eliel. I think we will tag team on this a little bit as well because we really want to make sure that there is a large amount of robust conversation. We will go directly into the potential topics for the annual report for fiscal year 2024. Once again, remember the workgroup's insight, as well as their recommendations are so incredibly important. We want to hear some of your thoughts on these topics. This was a little bit of a quick overview of the prioritization that came directly from ONC. You all remember it was almost three different tiers with the true focus of really thinking more about health equity data, Long-Term and Post-Acute Care (LTPAC)’s community-based and social drivers of health data exchange, consent management and sensitive data as well as laboratory and pharmacy standards with the second tier of ONC's priorities, really thinking of the algorithmic bias and transparency, information blocking impact and infeasibility exception, third party apps beyond Health Insurance Portability and Accountability Act (HIPAA), and safety and security of mobile health apps.

And we can include data integrity and quality into some of those areas but we know data integrity and quality have been across many different domains. And then, the third area which is here as well for everyone to see in terms of improvements in patient-matching methodologies, interoperability, as well as patient-reported electronic health record (EHR) update processes and also some additional pieces on data.

And potential topics for the HITAC annual report. We are going to finish up with the next list of those potential topics that were provided to us directly from HITAC. However, we really want to use the vast majority of today's meeting in order to see if are there any questions or comments about those topics that have already been proposed. But most importantly, are there topics that we should add that are currently not on the list? That was also a question that was asked to the HITAC. And we did get one or two additional recommendations. But we also want to know directly from everyone here as who is part of the Annual Report Workgroup.

I believe this is the last slide so maybe we can bring up the topics and, Eliel, I will turn it over to you to start going back through some of those topics. Thank you so much.

Eliel Oliveira
Thank you. I think maybe if the members have had a chance to walk through the topic list, great. If not, we are going to have a little bit of time to go through those right now. As you can see here, we are considering interoperability standards, labs and pharmacy data aspects, supporting image and interoperability, and privacy of sensitive health data consent. I believe that we covered some of those overviews last time. My thinking is that we go quickly over all of them so everybody refreshes their memory and come back to see what are the topics recommended and suggested to be added or removed.

Medell Briggs-Malonson
Correct, Eliel. I believe the red is what Michelle and the rest of the team added from our conversation from our last meeting. And then, farther down is where we stopped last meeting. So to your point, to go over those new areas and then, we can see if there are additional topics as well.

Eliel Oliveira
With that said, maybe if you can scroll down briefly to the rest of the list to just see what else we have for the team to be aware and a refresher. We had PGD, patient-generated data, and quite a bit added here with some of the comments we heard last time. Patient burden and workflow and occupational intelligence as you all know. And if we can keep it scrolling down. Optimizing public health data exchange and infrastructure, long term and post-acute interoperability, health equity by design. And can you keep going? We will come back to the top again in a second. Health equity as well. Behavioral health, further improvement of data quality and sharing, lack of accounting of the disclosures. And as you can see, some of those are the topics that were in our list of wishful topics to add to this year. And transparency in use of deidentified data. That is it. I thought so.

Just high level, that is what we covered. We, of course, can go over the specific edits that we made last time but that is the topic list. And I see Rochelle has a question or a comment. We cannot hear you.

Medell Briggs-Malonson
Rochelle, we cannot hear you. Now, we can.

Rochelle Prosser
I am sorry about that. I will have to speak up louder. I have been having some technical issues since the heavy flooding in Miami all last week. Hopefully, it will get better. Just let me know if you cannot hear me. In the HITAC meeting last week, I mentioned issues that did not get transcribed yet. I was not able to add them to the list. You had not mentioned if I should bring them up here. That is what I am trying to do today.

Medell Briggs-Malonson
And Rochelle, you are 100% correct because they were broader, sweeping recommendations. And do you mind recapping for us?

Rochelle Prosser
I think we were talking about Artificial Intelligence (AI) and its use in women's health and how it can be used punitively depending on where we are in the states and how we can address this federally. Although, we have been able to put some privacies in place around certain aspects of women's health that would equate to the equivalence of privacy with human immunodeficiency virus (HIV). But we need to go further because

of certain specific use case scenarios of what is going on politically in the country. There is such a divergence between where you are depending on access and what is collected that can pose real potential health disparities in use of the data, how that is structured, the consent, the lack of transparency, etc. And I was bringing up how other entities are using our data as data grabs in ways unimaginable. I am not going to mention them here. But it was specifically targeting certain sectors of the community just to do a proposed study. But it does not actually resolve a clinical issue.

And they are not fully being transparent on what they are trying to do with our data, who is the owners, how is that structured, and how we can go forward in preventing the use of our healthcare data in ways that are not harmful but promotes the advancement for all.

Medell Briggs-Malonson
Thank you so much, Rochelle, for summarizing that. And it almost is like two separate topics. I am wondering, in terms of privacy of sensitive health data, one of the things we also included in our annual report last year is privacy of sensitive health and reproductive data. We actually kind of broadened that and even right now on the screen, we have privacy of sensitive health data. And I am wondering, and this is for the workgroup and also for you, that this is another time because that was one of the comments and changes we made last year because of some of the concerns that you are bringing up right now were concerns that we also had last year, which were incorporated into the Annual Report Workgroup. It would be interesting to cross-reference what we also discussed last year and kind of refine it and re-iterate it maybe, especially with some of those additional points that you are bringing up around the privacy and the consent of this data as well.

And also, what you are referring to about overall consent and privacy of our data is even outside of sensitive data and the importance of making sure that there is full transparency of that as well. I think those are two really good points to add up. And whether we expand upon one of these current topics to incorporate it or actually add an additional topic to those as well.

Rochelle Prosser
That is what you would recommend for me to do. I am fully on board with that. I see additional hands so I will defer.

Steven Eichner
Medell, this is Steve. I think it is both health and personal data, not just reproductive health, which is a subset of health data but really looking at personal data, which means health data or things that are not necessarily health data but are considered to be personal or pseudo health data, depending on your circumstance.

Rochelle Prosser
I agree.

Medell Briggs-Malonson
That is a great way of putting that. And that is more comprehensive. I know last year we were focused specifically on the legislation that had just came out but that makes sense. I like that very comprehensively.

Eliel Oliveira
Hans?

Hans Buitendijk
Thank you. A question that I have for comment on the topic and it is twofold, to what extent do we need to consider the difference between privacy rules established by jurisdictions and challenges with that? The consent rules defined by the patient assuming they have been accepted as appropriate to be followed and how to manage that? There seems to be two parts. They come together because the combination will tell us what we can share or not share. But there seems to be two sides of that coin of understanding the rules and which one apply from jurisdictional perspective and what are the rules that apply from a patient perspective once agreed to. That is one part I am trying to figure out is if it is relevant to include that in here from an interoperability perspective and from an evaluation perspective. We always recognize there are two parts to that story.

And what they have in common clearly is that in order to make that more computable so that we can manage that more easily rather than a written narrative that needs to be interpreted, is the question of what constitutes sensitive health data or sensitive data in light of the other comments just made. What is that? I think it is partly that we want to recognize there in the solution direction that there is an aspect of specific codes, diagnosis, medications on their own or in combination, as well as categorization of data because it is inside a document. It is inside a data set that you need to have a sense of does it contain any sensitive data because you do not necessarily have immediate access to the content but you can mark the set of laws. When we talk about sensitive health data, I think we need to recognize there are specific codes that we can assess and evaluate and include as part of a rule one way or another or categorization of certain data because you do not have access to that individual data yet.

Eliel Oliveira
Those are excellent points, Hans. I think one specific owned jurisdiction almost makes me think that we need a specific structure for consent that defined things like the boundaries of what that content allows from a jurisdictional perspective. If it is county level or state level or federal level that you are authorizing that consent, that becomes very helpful. I think, for instance, we worked on the mental health consent in California and everybody is wondering, can we replicate that in other states. And if someone consents in one, that applies elsewhere. I think that is a very important aspect. And I think on the imaging, the same goes for notes where there is a lot of data buried in the notes as they are in images. It is really hard to detach the two. And research has shown us that it is very difficult sometimes to just do that. We can learn a little bit there how machine learning research is trying to do that work of extracting pieces of information out of notes.

I feel like it might be a bit off, given we still have not started a consent model and one that is across regions like you described. Anyway, I am repeating a bit here to say these are excellent points. Thank you so much for those.

Steven Eichner
We have it identified later on disclosure practices and disclosure information or communicating disclosures recurred are tied hand in hand. It is one thing to have a security practice about the technical aspects of

disclosing data and another thing to talk about the disclosure practices about when data is actually just being disclosed and what is the accountability of those disclosures.

Eliel Oliveira
Thanks, Steven. I will make a comment on that. I do not remember who in this group was in the previous workgroup last year, this Annual Report Workgroup. But we talked extensively about that specific topic. And just realize how hard it is it already to track account of disclosure in current EHR systems and whatnot. And so it does not change the challenge here with the consent aspect. It adds to it. Very important.

Steven Eichner
Well, you don't undertake task because they're easy, you undertake tasks because they need to get done. And we might not have a perfect model or looking at accountability and disclosures but I would think that even at a minimum, looking at disclosures going out of the entity where there is already tracking about the disclosure for other purposes would not be a terribly difficult bottom rung to provide patients some understanding about where that data is actually being disclosed.

Eliel Oliveira
Exactly.

Medell Briggs-Malonson
I was going to say I think it is worth taking a look at that as another potential topic. And this year since I have just seen what we as HITAC can recommend in that space, it may definitely be worth doing that from what Ike was mentioning.

Eliel Oliveira
I see Rochelle have your hand up.

Rochelle Prosser
Thank you, Hans, for saying what I was inarticulate in saying without full disclosure but if anyone wants to go on Linked In, they can see what I am talking about. I really thank you for bringing up those topics because I think that there is a lot of devil in the details on how this is being used. Yes, we can put algorithms together and try to do our best to prevent it in certain aspects but encourage it in others. At the end of the day, we want to know how it is going to impact the patient and/or the end user. And what we do not want is that it becomes so onerous for the patient that they have to do this self-reporting in multiple surveys or having to constantly repeat something that is already in there. And then, you really lose the sense of who is responsible at the end of it and who do you contact in order to turn that pipeline off. I know Anna is probably going to talk about a lot of these aspects. I see her hand up. I know that you started talking about some of it in the annual report lower down.

But Hans, thank you so much. I applaud you because these are some of the things that keep me up at night. And I really was not able to articulate the future use and all of the interoperability that comes with that. Thank you.

Hans Buitendijk

Thanks, Rochelle. That already is the case in other situations as well. We will continue to ask of individuals to provide data information and patient-reported outcomes and social determinants of health (SDOH) needs assessments that we ask, basically, everywhere we go as opposed to having a unified approach that once someone provides some information whether it is a consent or details about a survey that you guys know this well, family history and those medical details you have to provide to every provider you go. There is a paper and you fill out those forms pretty much everywhere you go again and again. That becomes very taxing on patients. I saw that we have Jim, and Anna, I still wanted to see if you have any comments.

Anna McCollister
I took my hand down because there was a point I wanted to raise but I am not sure if this is the right time in the meeting to raise it. I will just say what it is and you can tell me if we should pick it up at a different time. One of the things that I have been pushing for years and mentioned and we talked through in a couple of different context on HITAC last year and I believe in the annual report but I cannot remember, was giving ONC or asking ONC to require or incentivize some sort of disclosure of how data is used. I am all for data to be used, how it is going to be identified for research of all different types. I think it is good. I think it is helpful. I think for that to be done in a way where patients really understand the benefit of that, we need to be told what is happening with that data and what types of research is being done. I have been able to convince one of my clients to do this and it was an incredibly positive experience. Patients loved it with all the uses of de-identified data.

And patients were very excited to see it. Even patients that are a little skeptical of the use of de-identified data and the commercialization of data were very excited to see how their data had been used to support research. And I think this would be a healthy addition to building out this ecosystem. I do not know what kind of ONC jurisdiction or what kind of jurisdiction I would see one having this case, but I do think it is something that if we are serious about building data resources out not just for treatment but also treatment flowing into research that it is important for everybody to be able to have a sense of what is happening. I guess I did raise it now.

Eliel Oliveira
Excellent. Thank you, Anna. I think as you are speaking it, I am thinking about Institutional Review Board (IRB) and how they have systemic processes to validate and make sure the patients know exactly what should not be done when they are part of a specific research project. It seems to me that maybe a lot of that could be leveraged with those experiences with patient consent as well.

Anna McCollister
If we get into consenting everybody to do secondary research, research in secondary uses of data, it is never going to happen. I do not necessarily think that is a constructive way of thinking about it. I think disclosing and letting people know what is being done with it is important because there is a lot of really good stuff that is being done with this. And for people to really have a sense and a trust that this is something that needs to happen, they need to be able to see what that is.

Eliel Oliveira
Jim, I see your hand up.

Jim Jirjis

On the same topic, it seems like disclosure often ties really closely to consent because as the patient sees how their data is being used, it leads to questions. Why are they using it for that? One question is are there models? It seems like it is easier said than done. If you are just a single electronic medical record (EMR) and it is one thing to tell your patients as a practice what you are doing with their data if anything. As the data jumps from place to place, are there simplified models that 1) are actually doable from an operation and technical perspective and 2) generate information to the patient that they can understand. I did this at a big medical center, just a single, Vanderbilt. And we encouraged people to look at their own records. If their job required they got an EMR, our stance was you have the right to look at your own record. But we were worried that others would look at their record that should not.

And so, we tried to audit it. But the terminologies, even understanding where the data is going, came back such gibberish that we could not even understand what was happening let alone translate it for the patient. One question is if there something HITAC can recommend about the development of simplified models that are operational, define the right level of disclosure and how data may be used in a secondary manner that is understandable to patients and operationalize this new world of interoperability because it seems like there is a big challenge. Is that something that HITAC could recommend?

Medell Briggs-Malonson
Eliel, my comment is directly to both Anna and Jim. I think that this is a fantastic theme to add to HITAC and, of course, you all know that I am going to put on my health services research, public health, and health equity hat with this. I think, Jim, to your point, one thing that I actually did implement within my health system which has been adopted by others, it is very simple but we have now started to use this model in many different ways is that, for instance, even when we were collecting all of the self-reported to various different forms of data, especially demographic data and other information, which people may consider to be protected sensitive data, we did and still do have a disclaimer of saying this is why we are collecting this data. And the whole purpose of the data is to provide you better care, as well as to help to provide better care to all of the different populations and communities.

We had a disclaimer that was created and vetted by many of our patient and family advisory committees to make sure the language was always at a Grade Level 6 or below but also, that it was just clear and made sure to communicate what it needed to communicate in a way that was acceptable to various different patients throughout.

We actually have had a very successful uptake and also reaction to these disclaimers like with collecting data and using the data for various different reasons, we had an uptake of over 90%, especially from our new patients and then established patients. And we started to use those same disclaimers in other areas saying this data may be shared, but if this data is shared, this is what it is shared for. I do think if we are able to develop more disclaimers that are very concise, at the appropriate literacy level for everyone, which is why it should be at Grade 6 regardless of the population it is used in. And then, also just in a way that we make sure our patients are involved in the process, I think it could be very meaningful and it could actually increase our ability to do so much more in terms of patient care, public health efforts, and research.

Anna McCollister
In terms of models, I would be more than happy to share the report that my client did as a publicly traded genetic testing company. They issued a report and we have done two reports. Unfortunately, the company

just declared bankruptcy and was purchased. I am no longer working with them. But it was a great report. And, again, basically what they did with all of the aggregated de-identified data, this company did not give patients the ability to choose not to have their data used as part of the aggregate data, which I think is a gold standard practice. Whether or not we want to go there with ONC is a different question as opposed to what this company chose to do when we were working through data governance. The report in and of itself was incredibly impressive in terms of how they de-identified secondary use of data, had been used to develop a science of genetics and medical genomics. Again, patients who were very active in the patient groups whose data were represented were excited about it.

I am happy to send it out. I do not know if ONC wants to create models. I will let ONC figure that out. But at least to encourage or incentivize in some way if that is possible the disclosure of how data is used because there is a lot of data that is being used. And a lot of companies are making a lot of money based off the fact of once it has been de-identified through HIPAA. I am all for that. I just want to know what it is. If there is a market for it, the data will be better quality. I am all for that, but I just want to know what is being done with it. That is my personal opinion.

Eliel Oliveira
I see Jim's comments on the chat. And I agree with Medell is that we are talking about quite a bit here. We started with consent and now disclosures and data level. Go ahead, Jim.

Jim Jirjis
I have one quick question to make sure we are all talking about the same thing. We say disclosure but what is being done with my data? There are different levels of it. The announcement that this might be done for research to further knowledge and improve treatments. And then, there is specifically Dr. John Smith's research center is going to be looking at breast cancer attitudes and opinions. And that is just the research side. Then there is treatment, payment, operations. Are we saying what does it mean to disclose how the data is going to be used for treatment? That is what I meant is by if it is general or if the patient wants to know exactly which nurses and doctors look at it. If we are talking the latter that implies a unified terminology. For someone to know that Billy Jones looked at their record, well, why did Billy Jones look at their record? Maybe Billy Jones is not a nurse in their primary care practice but was a float nurse who usually works somewhere else and that confuses the patient.

Is it appropriate for us to make recommendations around Version 1? What level of granularity is doable because if you get real granular within each of these permissible uses, you end up with a lot of data problems and translation to patients sixth grade level challenges.

Medell Briggs-Malonson
I was going to say very quickly that I fully agree with you but I look at this as like a larger ecosystem universe and then, there are subsets within each one of those universes. However, I think if we have clear principles that are recommended. For instance, I am thinking more about the process versus the exact content, if that makes sense, and the principles of disclosures. When we do disclose to the patients, it should have certain recommendations in terms of the appropriate literacy status or the translation to specific languages. It should also include, in general, what that data should be used for and then, of course, if we are going more into that very subset-specific forms of data where there is truly going to be real research for a specific cause, I feel that that data should not only incorporate those same general principles but then, yes, there will need

to be some additional information for that patient to be able to understand how their data may be used for that particular study.

I think, in general, even having the principles of how to write appropriate patient-directed disclosures is an area that Elise and I know that Seth just put something in terms of privacy and practices but something is that a little bit more applicable and will be more impactful when it comes to educating our patients.

Steven Eichner
From a patient perspective, I am often less interested in a specific person that may have looked at a piece of data but knowing that they are a person that is a member of my care team and understanding who is a member of my care team and the data being accessed for my personal care is usually sufficient. To think about it from a tiered perspective, is the data being used for my personal care by my care team? Is it being shared more broadly for research purposes? Is it shared more broadly for customer service improvement purposes at the hospital? There is a fairly broad mix that can be in most cases. Try not to look at data ad infinitum at a super granular level. I think there are some general thrusts or general direction that may be sufficient for almost every use case.

Jim Jirjis
Can I make a quick comment? There when you said is it being looked at and used by someone on my care team. I do not know that we have a definition of care team. And there are different levels of abstraction. For example, where we run into problems trying to create this disclosure was if the member of the care team is Dr. Jirjis, his nurse, his secretary, and other staff that work, does it include other staff that might cover at lunch? Does it include the traveling nurse that comes in? The logistics of defining that I wonder if HITAC can weigh in on how to define what is my care team? What happens is they see a name on there and it is not someone on their care team and that generates a bunch of angst and work only to find out it was a nurse that is not typically on my care team who was covering that day. I know it sounds like an edge case but it turns out it was not.

We had to stop the program because that level of granularity, the computers could not explain and understand well. I am not being negative. I am saying there might be an opportunity for HITAC to define an appropriate level that does not create those unintended confusion consequences.

Steven Eichner
I agree. There is probably a happy balance if we can figure out what it is.

Jim Jirjis
Basically, do not get too granular too quickly until you learn more and until the computers can categorize everything correctly.

Eliel Oliveira
Thank you both. Those are some great points and highlight how complex this is between disclaimers and disclosures and consent management and whatnot for different purposes. I think we have certain things already. We have established like we were saying for research, what can be done or not done. And on the HIPAA as well, with TPO regulations. I think we all have the same thing that we also have a lot of challenges on how to capture the report efficiently. I want to pass it on. I see that Hannah has a hand up. I do want to

see also if we have other topics we want to discuss. We spent quite a bit of time here. That is fine. It is that important. But maybe we wanted to talk about other things as well. Anna, go ahead.

Anna McCollister
Well, I just wanted to make one final statement. We are talking about two different things. In my mind, they are two different things. One is disclosure of access to my personal data. And I think that is important and there were two different task force groups as part of the HTI-1 workgroup that came up with the recommendations for the fact that we need to find a way to have some sort of auditing or revelation of disclosures or listing of disclosures. Deven went into some detail about how that was incredibly difficult and the last time that the HIT Policy Committee took a look at this. What I was talking about, I think that is important. But as a separate topic, I am talking about aggregated data and the fact that we have given hospital institutions and companies a lot of latitude to be able to do whatever they want with de-identified data and to be able to use it for other sorts of things.

By and large, that is probably a good thing. But I think those uses and the specific research and activities that come out of those uses are something that should be disclosed. We have given them, again, a lot of latitude and they are making a lot of money. They are spending a lot of time and resources to make the data work and make it usable so that is fine. But the data is generated by an individual and we have a right to know how that data is being used.

Eliel Oliveira
Thanks. I think one challenge that I am having with that comment, Anna, is that let us say we generate a de-identified data set that is going to be used by some research. If we then notify the individuals where that data came from about the use, it is almost like we are re-identifying that data, which leads to other challenges. I do not know if that makes sense but that is the issue I am thinking is once you de-identify, you should not let anyone know that their data has been used for specific research purposes.

Steven Eichner
The difficulty with not sharing that information is that you are then putting the patient in the position of not knowing if their data was misused. It goes back to that accountability and not sharing any information about disclosures in the first place. If I do not know where my data was shared, it makes it very difficult for me to determine whether it was misused or not. And in my particular case, if you have got my full medical record, it is not going to be de-identified if you got two pieces of information because I am a huge outlier with respect to this identifiable criterion. That is a whole different story.

Medell Briggs-Malonson
This is an amazing conversation. Obviously, it is something we need to walk through a bit more. I believe Michelle and team have captured the various different perspectives and we can see how they distill it down. We are talking about a range of items here as well. And so, it will be really great to see how they distill it. And once it goes into the crosswalk, we can build upon each one of these areas and see if they have their own streams of recommendations and activities from each one of these topics as well. We only have about maybe 22 more minutes. We do want to make sure that if there are any additional topics that anyone wants to put on and especially we do have some members that have not mentioned anything yet. I do not want to put you on the spot but your voice and insights and ideas are so incredibly important. If there are any additional topics that are top of mind for anyone, this will be a wonderful time to share them as well.

Steven Eichner
Medell, we have talked a little bit about special populations and looking at health equity cases. I think we might want to call some special attention to individuals with disabilities, especially from a public health perspective thinking about what are special data needs in that space to help those public health and care providers across a broad spectrum of use cases and information whether you are talking about emergency response, emergency evacuation, emergency plans for things like de-contaminating individuals, rapid use wheelchairs, special planning and that space because you cannot just use necessarily a regular de-contamination approach if you have someone in a power wheelchair as an example or looking at a broad spectrum of other pieces. Our data standards do not necessarily do a great job of collecting relevant data.

Medell Briggs-Malonson
Ike, I will give you plus five on that if not more. This is actually another one of my topics on my list. You came at it from a public health standpoint, which I fully agree with everything that you said. You mentioned at the very end even with looking at standards. One of the things that even within my organization that we have really are doing laser focus on in trying to prioritize is the appropriate capture of information for our patients that are living with diverse abilities and making sure that we even are capturing the additional accommodations that they may need in order to provide the most appropriate and equitable care so that when they come into a healthcare facility that we are already anticipating what they may need so that they can actually take part in the same level of engagement with their providers as someone else may. And so, I think all of the different pieces that you brought up about that exchange of information from a public health standpoint and emergency preparation standpoint is key.

I would also say, and I know we do not have Sarah on as the co-chair, but you are definitely on from the IS WG, and forgive me about my lack of knowledge because I have been looking into this, even the key standards of what information we need to collect in our systems for appropriate interoperability between care settings is another area because I think all of us throughout the country and globally can do a much better job thinking and caring and anticipating the various different needs of all of our patients in communities that are living with diverse abilities both cognitive as well as mental as well as physical.

Steven Eichner
Absolutely. Thank you. I would add on it is not just access to care once at a healthcare facility. It is access to potentially the healthcare facility in and of itself thinking about transportation or **[inaudible] [01:04:05]** might be a better tool, depending what your particular needs are of the moment.

Medell Briggs-Malonson
Absolutely. And we can expand that even further into now we are getting into thinking about all of those social drivers of health. But one of the other pieces that I had for my list as well is making still more inclusive health technology. As we are thinking about telemedicine, and we spoke about this a little bit in our annual report group last year, I do not think we went as deep into it, especially when it came to the ability status, but making sure that we do not have any winding divides between our emerging technologies when it comes to AI or telemedicine or virtual health with those that do have diverse abilities. Again, as you know, I am always concerned about us having advances but then, leaving people or populations behind because we are not inclusive with what we are thinking about when it comes to our new advances. Yes, I agree with you in totality. I think that it is a very important topic to really spell out in our annual report.

Steven Eichner
Also, thinking about it in the context of AI computer decision support tools that the decision support tools need to accommodate individuals with disabilities as they are looking at their data so they are not making recommendations that may not be a good fit for the patient, that cannot follow the recommendation of the clinical decision support (CDS) or some other contraindicated kind of factor that the CDS is based on but does not work or has bad data because there is a background factor based on individuals' disability or other condition.

Medell Briggs-Malonson
Correct. Our full underrepresentation in the training models to begin with so, therefore, incorrect recommendations. I fully agree. Thank you.

Eliel Oliveira
I love this topic. Thank you. Jim?

Jim Jirjis
I have one other topic that looped into a different topic that to me is an opportunity is sort of a next step of what we are seeing with Trusted Exchange Framework and Common Agreement (TEFCA). You may have heard me talk about before I came over to CDC at HCA last year or the year before, I had the team look at all of these CCDs that are being sent. We signed up for CommonWell so we received all of these CCDs. And so, I had the team look at it and many of you heard me say that there is no guidance for what the expectations are in the source. If we look at the value of TEFCA, it is the recipient who is trying to care for the patient and needs enough information to make it useful. The sender, the source of information in information exchange with TEFCA, for example, knows that they are supposed to submit it in a format of USCDI. They know the transport mechanism. Many centers were just defining what they had to send as the last encounter.

Maybe it was a skin tag removal? The Veterans Affairs (VA) goes two years back and sends USCDI anything from the past two years. Many places do 90 days. Nowhere do I see anyone addressing expectations around how far back people need to be able to go when they are sending a USCDI payload through TEFCA, for example. I think it is important because then there is unpredictability on the part of the receiver. And the value of TEFCA goes down because you may be getting a bunch of CCDs but if each of the senders is interpreting it differently, the last encounter versus two years of info, you have no idea whether you are getting complete information or not. This is a suggestion that maybe we amend that ONC address the expectations around the amount of data that is being sent.

Medell Briggs-Malonson
Eliel, is it okay if I ask Jim a quick question?

Eliel Oliveira
Of course.

Medell Briggs-Malonson

Jim, I fully agree. I think this is a fascinating, important topic for us to address. I know you mentioned that this was your experience through CommonWell. Do we know if that is the same experience with, for instance, Care Quality and others? And the only reason I mention that is because I am currently working, and I think I mentioned this before, with creating a very special system that is linking several academic medical centers and other large health systems with a federally qualified health center. We are using full interoperability through all of our diverse EHRs through Care Quality. And we have that conversation about how far back that we should go in terms of being able to pull records. And we were able to actually set it. And there are a lot of different discussions exactly as you were mentioning about going much further back. And some people are like, "No, we do not want that large amount of data and we just need to go back two or three years."

My question is do we know if there is differences based off of CommonWell or Care Quality or now thinking about everything through TEFCA if there are built-in limits or, to your point, we need to make sure we have clarity and standards?

Jim Jirjis
In my opinion, CommonWell would say those are just conduits. Those are just pipes sending the info. It is really back at the EMR level. We met with Epic two or three months ago. And they had built capabilities for 90 days back. Based on what? And what is Oracle doing? A lot has to do with the source system. Some source systems purge their data into a data warehouse and the EMR only has a limited amount of data. I think that maybe one of the recommendations is to do an analysis or identify what the current state is on request for information (RFI) as part of that ONC should explore the content and the amount of data because I do not think that it is based on the Qualified Health Information Network (QHIN). I think it is based on the source.

Medell Briggs-Malonson
And I agree with some type of analysis because I can tell you we have been able to pull data from definitely much larger, much farther out than 90 days into the CCDs that are coming through.

Jim Jirjis
Those are academic centers, probably, too, right?

Medell Briggs-Malonson
No. There are some federally qualified health centers as well.

Jim Jirjis
I have no doubt that they can. I remember even at HCA, we were trying to figure out how do we arbitrarily decide how much to send and we just decided. The idea that everyone would decide exactly the same thing is pretty low. Even if the whole country knew it is 90 days right now, at least everyone would know what to expect. If I am looking for a chest x-ray from five years ago to compare my new tuberculosis chest x-ray to, I know it is not going to be in the last 90 days versus trying to guess. I guess I say all of that to say that doing an analysis and coming up with a set of recommendations may be useful. I do not know if Fast Healthcare Interoperability Resources (FHIR) will fix it. These FHIR converters, they only have access to the data available in the EMR. You think FHIR means that the requester of the data can indicate how far

back. That is only true if the IT system on the source side are set up to have the FHIR converters have access to data that far back.

I think even in this push world today of CCDs, and in the future world, it is probably worth setting expectations and defining how far back. That is just my opinion on what maybe this annual report group could recommend that might be new but adjacent to TEFCA.

Eliel Oliveira
I am thinking here, Jim, that this might be an interesting topic for the standards workgroup to consider, maybe the possibility of making adjustments to standards in such a way that the requester can determine what should that range be, nine days, a year or two, whatnot. But that also implies that systems would have to be flexible to be adaptable to the request coming in. I can see where it can go in all kinds of directions on what the load should look like. I think it is a great topic but I am also thinking here that since we have another workgroup, there are only, as you know, in HITAC is the annual reports and the standards one. That might be a great topic on that front. Definitely you could put it in the report. Steve?

Steven Eichner
It is important at a base level because without the data requester, any useful information back is not really going to do them a whole lot of good for continuity of care. There does need to be some kind of frame in that space. It may not be in the annual workgroup's purview necessarily to go in and dig deep on what that standard might be. But I do think that it is a broad enough issue that probably needs to get recognized here and then perhaps pushed. A companion tool would be a set of regulators, not from a legal regulation standpoint, but from a volume perspective just to help manage traffic on the size of information so that a person or entity sending data was not sending too much data and the receiver was not going to end up receiving too much data to overwhelm either of their systems. I think there is opportunity for modifying standards to accommodate both of those tools. I think the fundamental element is ensuring that the data being sent is sufficient enough to meet the requester's need.

Eliel Oliveira
Thanks, Steve. That makes sense along the lines of what I was saying. Medell, do you have your hand up?

Medell Briggs-Malonson
I did. I think that these are such important topics for us to discuss. And, yes, as we put them on the crosswalk, we are going to look at the various different recommendations and then, also prioritize them as well. And so, what I was thinking was exactly what Ike and Jim were, and Jim put something in. There may be some opportunities for us to suggest new innovative approaches because while it could be a push and then you filter through receiving, it may be also just be I want to query X number or X years of data for my purposes because in Jim's situation, for instance, of trying to understand a patient and seeing if they need treatment for tuberculosis, he absolutely may need to go back five or seven years while there may be another reason to start pulling through some of that data for another case use, which they only need to have the past six months.

There are just a lot of various different things we can recommend as the Annual Report Workgroup, as well as overall HITAC. And we would be able to flush out that a bit more with the crosswalk.

As a time check, we have six more minutes until we have to go to public comment. Any new topics that anyone, especially for those we have not heard from. Yes, Jim, you as well. I do want to give a chance to anyone who we may not have heard from during this meeting as well. Are there any other topics from our workgroup members?

Jim Jirjis
Just one adjacent new topic and one suggestion. TEFCA has been about the pipes and USCDI+, etc., have been about the data format. What I am suggesting is that we recommend ONC pursue data content how far back. And another one I put in the chat is data segmentation. You have the ability to actually identify subsets of data that either should not be shared or should be. And so, maybe that falls under the bigger rubric of, ONC, instead of just format and transport standards, let us talk about content standards.

Medell Briggs-Malonson
And then, we add quality on top of that.

Jim Jirjis
Yes, that is right.

Medell Briggs-Malonson
I agree. I think we now have the bones and now, we have to fill in the bones with all of the true content that is going to be relevant and actionable. Great, great points there.

Jim Jirjis
Not a vegan friendly example, but yes.

Medell Briggs-Malonson
I just said bones. You notice I did not say meat. I said bones only. We will call it pescatarian approach. Are there any other comments from anyone that we have not heard from? Eliel, I am looking as well.

Eliel Oliveira
I do not see any. I would emphasize for the team to do take a look at this list of topics and send anything else that comes up. I think that we actually have a very good list already based on the things that we kind of left off from last year's report. And it is not here showing on this one. I think if we scroll down, you will see details about healthy support and other things that are quite important. I do want to suggest that everybody take another look at this list and think about and suggest additional topics. This is the time for it because then when we start working on the content and suggestions of recommendations, we may be limited on what we can do with the time that we have.

Medell Briggs-Malonson
First, are there any other topics? Are there any other comments or suggestions? I am not seeing any either. And if there are no other topics to address or any other comments or questions, it seems like we may be able to move to our public comment. Seth, is it possible for us to do so now?

Public Comment (01:19:38)

Seth Pazinski

Yes. We can move to open the meeting for public comment. If you can open us up for public comment, please. And for folks on the Zoom, if you would like to make a comment, please use the hand raise function, which is located in the Zoom toolbar at the bottom of your screen. If you are participating by phone only today, you can press star nine to raise your hand. Once called upon, press star six to mute and unmute your line. We will give folks a chance to tee up with any questions or comments. I see no hands were raised. Do we have comments from the line? No comments. Medell and Eliel, back to you to close us out.

Next Steps and Adjourn (01:20:38)

Medell Briggs-Malonson
Awesome. Well, thank you so much, Seth. And thank you also to our public for being here. And please if you ever do have any suggestions or comments, we appreciate your insights and we would definitely welcome them at all times. Once again, everyone, thank you for coming and participating in our Annual Report Workgroup meeting today. I think we have been able to expand our topic list to really cover a wide variety of issues and concerns and recommendations. I am very much looking forward to creating our crosswalk together so we can truly solidify our recommendations for our workgroups. Thank you all. Eliel, I will turn it to you.

Eliel Oliveira
Thank you, Medell. Thank you, everybody. I think that was a good discussion. If those were easy topics, we would not be here. I know they are hard but I think we moved to a next phase now talking about what are some ideas to address these specific topics. Like I said, if anything comes up, consider sending to us because the next meeting, we will be looking deeper into the specific topics that we just selected and went over. Thank you so much and hope to see you again soon.

Medell Briggs-Malonson
Have a good afternoon, everyone. Bye-bye.

QUESTIONS AND COMMENTS RECEIVED DURING PUBLIC COMMENT

No comments were received during public comment.

QUESTIONS AND COMMENTS RECEIVED VIA ZOOM WEBINAR CHAT

Jim Jirjis: thank you. That was helpful

Rochelle Prosser: +1 Hans

Medell K. Briggs-Malonson: Agree with Anna. Transparency is key when using patients' data to build trust and engagement.

Rochelle Prosser: Anna +1 I completely agree

Rochelle Prosser: Great example Eliel

Rochelle Prosser: Well said

Jim Jirjis: Are we talking about a general disclaimer? Or are we talking about dat lament or data set level disclosure?

Medell K. Briggs-Malonson: I believe both.

Jim Jirjis: The latter is pretty tough

Seth Pazinski: FYI, Model Notices of Privacy Practices https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/model-notices-privacy-practices/index.html

Rochelle Prosser: Exactly! +1 Medell

Hans Buitendijk: There are patient directed consent directives as to who to share with, but also who not to share with, that either way need to be in some computable fashion based on specific codes where they can be evaluated, and/or categorize where either a user or a system can tag the relevant data (individual note, document, data set, etc.). That then also includes understanding who, as the receiver, that applies to that opens the challenges that Jim is raising on persons, teams, roles, organizations, replacements, etc.

Jim Jirjis: It created information toxicity as patients wasted their time and staff time questioning why a stranger who is not on their care team was looking at their chart. Only to find out it was a phlebotomy tech or covering nurse traveler erc

Eliel Oliveira: Thanks Hans!

Rochelle Prosser: Understood Hans. Also, there are safe guards within facilities and IT departments to identify whether the correct person is within the correct charts.

Medell K. Briggs-Malonson: @Rochelle, yes there are often safeguards to flag unusual and/or inappropriate activity within a specific patient's chart.

Anna McCollister: Here's a link to the report I did with my client on the prior year's use of de-identified, aggregate testing data. https://view.publitas.com/invitae/r102-patient-trust-data-transparency-report-2021/page/1https://view.publitas.com/invitae/r102-patient-trust-data-transparency-report-2021/page/1https://view.publitas.com/invitae/r102-patient-trust-data-transparency-report-2021/page/1https://view.publitas.com/invitae/r102-patient-trust-data-transparency-report-2021/page/1

Eliel Oliveira: Thanks Anna!

Rochelle Prosser: Thank - you Anna

Rochelle Prosser: this is the proper link from Anna

Rochelle Prosser: https://view.publitas.com/invitae/r102-patient-trust-data-transparency-report-2021/page/1

Steven Eichner: +1 Jim!

Steven Eichner: A companion tool would be a set of regulators to limit the volume of the return to no more than the sender can send and the receiver can manage on receipt.

Jim Jirjis: What about data segmentation as part of recommendations

Rochelle Prosser: Thank you Jim and Ike for brining up all of these great data segments. I am +1 on both of your comments

Eliel Oliveira: Me too!

QUESTIONS AND COMMENTS RECEIVED VIA EMAIL

No comments were received via email.

RESOURCES

AR WG Webpage
AR WG - June 17, 2024, Meeting Webpage

Transcript approved by Seth Pazinski, HITAC DFO on 8/1/2024.