Transcript

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

June 3, 2024, 12:00 – 1:30 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
Sarah DeSilvey, Gravity Project, Co-Chair
Steven (Ike) Eichner, Texas Department of State Health Services
Hannah Galvin, Cambridge Health Alliance
Jim Jirjis, Centers for Disease Control and Prevention
Anna McCollister, Individual
Kikelomo Oshunkentan, Pegasystems

MEMBERS NOT IN ATTENDANCE

Rochelle Prosser, Orchid Healthcare Solutions

ONC STAFF

Peter Karras, Acting Designated Federal Officer, ONC
Michelle Murray, Senior Health Policy Analyst, ONC

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

Peter Karras
Good morning, everyone, and welcome to the FY24 cycle of the Annual Report Workgroup. I am Peter Karras with ONC, and I would just like to thank you for joining us today. I will be serving as the designated federal officer for today's call on behalf of Seth Pazinski. A reminder that all workgroup meetings are open to the public and public feedback is welcome. Members of the public can type comments in the Zoom chat feature throughout the meeting or make verbal comments during the public comment period that is scheduled towards the end of the agenda. I will now begin roll call of the workgroup members. When I call your name, please indicate that you are present. Let's start with our co-chairs. Medell Briggs-Malonson?

Medell Briggs-Malonson
Hello. Good afternoon, everyone.

Peter Karras
Eliel Oliveira?

Eliel Oliveira
Good morning, everybody.

Peter Karras
Hans Buitendijk?

Hans Buitendijk
Good afternoon.

Peter Karras

Hannah Galvin?

Hannah Galvin
Hello, good morning.

Peter Karras
Jim Jirjis?

Jim Jirjis
Present.

Peter Karras
Anna McCollister? Shila Blend?

Shila Blend
Good morning, everyone.

Peter Karras
Sarah DeSilvey?

Sarah DeSilvey
Good morning.

Peter Karras
Steve Eichner?

Steven Eichner
Good morning.

Peter Karras
Kikelomo Oshunkentan? Rochelle Prosser? Is there anyone who just joined who did not get a chance to indicate their presence?

Anna McCollister
Anna McCollister just joined.

Peter Karras
Welcome, Anna. Thank you, and now, I would like to turn it over to Medell for her opening remarks.

Opening Remarks, Meeting Schedules, and Next Steps (00:01:58)

Medell Briggs-Malonson
Wonderful. Thank you so much, Peter, and good morning and afternoon to the entire Annual Report Workgroup. We are very excited for this to be our official launch into this year's report workgroup, and especially alongside our brand-new co-chair Eliel. I am very excited to have you as my co-chair of this workgroup. I think all of us are going to have such a fantastic year, and especially bring in a lot of these

relevant as well as pertinent topics that we do want to make sure not only align with the overall focus of ONC, but also, those topics that we all feel are very important to place within this annual report. Eliel, I will turn it on over to you for your opening remarks.

Eliel Oliveira
Thank you, Medell, and good morning and afternoon, everyone. It is great to be here with many of you again. I am very excited about this year's Annual Report Workgroup work that is ahead of us. You are going to see some of the things that we are going to cover. There are quite a few important points, and I do not need to tell you that, based on the previous meeting that we had with you all. We heard quite a bit. You have so many great ideas, and we are excited about incorporating all those in the new annual report. So, thank you, everyone, and I will turn it back to you, Medell.

Medell Briggs-Malonson
Excellent, thank you. And so, what you see in front of you is our meeting agenda. Of course, we have already done the call to order and roll call, as well as the opening remarks. What we are going to then proceed onto is the discussion of our workgroup plans, and then a discussion of potential topics for the HITAC Annual Report for Fiscal Year '24. This is the time period where we really want all of you to bring some of your additional ideas to the table for us to start sorting through what we feel needs to be in this year's annual report. Then we will proceed to public comment, and then adjourn at that moment. Next slide.

Of course, this is our official Annual Report Workgroup membership, as well as the ONC staff. I believe everyone heard when Peter went through the roll call, but we are very excited to have 11 members on the Annual Report Workgroup this year, so we do have one additional slot open, so if there is another HITAC member that would like to join us, then they would be able to be considered for that slot. This is the first time that we have expanded our membership, and we feel like that is so incredibly important due to all the various different insights, as well as perspectives from HITAC membership. We want to make sure we incorporate all of that expertise within that annual report. Also, you see, of course, our outstanding ONC staff below all the various different members. Next slide. Great. Eliel, I will turn it back on over to you for discussion of the workgroup plans.

Eliel Oliveira
That sounds good, Medell. Thank you. Here we go. Next slide, please. So, here is the meeting schedule for the Annual Workgroup that we have. There are quite a few meetings in, as you can see, several months, but I would say it is not long enough for us to cover so many topics of interest that we have so far. So, for this meeting, we are going to develop the list of topics for the annual report in a bit, and then, in July and August, we are going to crosswalk those topics. If acceptable, we are going to develop the draft, and in October, we will actually take it to HITAC for review, and in November, the goal is to get approval and proceed before Christmas to get it transmitted to Congress. That is the plan that we have in front of us. Next slide, please.

This is the full schedule for the committee, so you can see the dates here. I think it has already been coordinated with the members in your calendar, but again, on June 13, we are going to update the status in the report. In July, we will meet again to do the same. In mid-August, hopefully everybody will be back from school at that point, and we will continue on September 12 to update the status of the Annual Report development and go on to finished approval on the final in November after a review in October. That is the

plan that we have ahead of us, and with that, I have one more slide. For the work plan for the Annual Report, we meet in this compressed timeline, as you can see. It seems like a lot, but it is compressed for the amount of work that goes on in this workgroup.

We will transmit that final report to Micky, the national coordinator, at the end of the calendar year. That is the goal. The workgroup develops the topics list and presents it to HITAC in June. The workgroup develops the crosswalk document over the summer and presents it to HITAC in August. The workgroup reviews the draft in September and presents it to HITAC in October, and after further edits, the HITAC votes to approve the report and transmit it to the national coordinator in November. At that point, ONC forwards the final report to the HHS secretary and Congress to post on HealthIT.gov. That is the plan in different flavors, but I hope it gives you a good picture of where we are going. With that, I will turn it back to you, Medell.

Discussion of Workgroup Plans (00:07:52)

Medell Briggs-Malonson
Thank you, Eliel. To amplify what you just mentioned, we are on a shorter timeframe than we have been in the past, and that is why this meeting is so incredibly important, but I would say already that, knowing this group and knowing all the fantastic ideas that come out of this group, if we do not get to discussion of all of the topics, we will still be able to submit some of our proposed topics directly offline as well, and then we can review all of those again at the next meeting, so that is discussion of potential topics for the HITAC Annual Report Workgroup. Next slide, please.

I am going to turn it on over to Peter to provide to us an overview of what we discussed last year in terms of the HITAC 2024 work plan and how our Annual Report directly aligns with some of the ONC priorities. Peter, I will turn it to you on this one.

Peter Karras
Great, thanks so much, Medell. For purposes of this report and just to orient HITAC members, the HITAC evaluates the health IT infrastructure landscape for gaps, opportunities, and recommendations, and the HITAC Annual Report focuses its evaluation on specific topic areas. What we have here is a list of topic areas that tie into our broad priority areas of advancing health equity, interoperability, privacy and security, and patient access. The Cures Act requires the HITAC to develop an annual report to be submitted to the secretary of HHS and to Congress each fiscal year, so this report does comply with that directive by describing a landscape of health IT infrastructure, and that way, that informs ONC's work in support of rulemaking and ONC core activities around standards exchange certification coordination. So, up on this screen is a list of topic areas that tie into our broader priorities across our target areas and what we are looking to leverage the HITAC members to inform in terms of policy and core activities. With that, I will turn it back over to Medell.

Discussion of Potential Topics for the HITAC Annual Report for FY24 (00:10:12)

Medell Briggs-Malonson
Thank you, Peter. The reason why we wanted to reinsert this slide as a reminder is because during our Annual Report Workgroups, we tend to have a fair amount of discussion of what ONC's priorities are and what the potential topics are that we should actually include in the annual report to help to assist and inform ONC, but also, of course, we want to make sure we are bringing additional topics into our Annual Report

Workgroup that may not be on ONC's radar or part of their overall workplan in order to be, again, that forward-facing committee and workgroup as well. And so, we just wanted to just reorient everyone to what ONC has stated are some of their key priorities with the first and the second box, in particular, what they mentioned to us last year, and of course, the third box still being very important, but a little bit farther down on the list of items that they are working on. We just wanted to keep this in mind as we proceed forward for proposing some of the potential topics. Next slide.

So, what do we need to do in order to propose potential topics for the Annual Report Workgroup? The next thing we are going to do is go directly into the draft list of potential topics. The primary discussion questions for all of us as the workgroup members are if there are any questions or comments about the draft list and what other topics should be added to the draft list. Again, these are those that help to support the ONC priorities, but also those that we feel are incredibly important and/or urgent in order to get into the Annual Report for this fiscal year. Also, should any topics be removed from the draft list? Next slide.

Eliel Oliveira
We are switching to the document.

Medell Briggs-Malonson
Oh, we are switching to the document? Okay, great. Thank you, Accel. I appreciate it. So, these are the potential topics for consideration that were sent to all the workgroup members, and I am going to go through the first two target areas, and then Eliel is going to go through the rest of them. Again, what we are going to do, very quickly, is just review these topics and then open it up for full discussion from the entire workgroup to see if any of these are topics that we want to have or if there are some areas that we want to include some additional topics for.

So, the very first one is supporting interoperability standards, laboratories, and pharmacies. This was suggested by Keith Campbell, as well as Hung Luu, for really looking at assuring overall data quality, and so, that is something that has been a theme that has been continued throughout many of our HITAC meetings. As we are thinking about standards and even about new data models that are going to go off and inform artificial intelligence and other forms of technology, we are really making sure that data quality is at the core piece of all the work that we are doing. And so, the description of the issue is as stated, and that data model should contain information about methodology to make sure it is easier for pharmacies and laboratories to adopt the recommended data elements and to share them, as well as with artificial intelligence, and this future recommended activity should be to assess what current data elements are sufficient for this purpose, or if additional data elements are needed.

The second quick item, and then we will pause at the end of this section to go back and really open it up for discussion, is supporting image interoperability. This was brought up by Michael Chiang and Sarah DeSilvey in the interoperability section. Interoperability of radiologic images is increasingly important in medical care. However, radiologic images can play an important role in patient care, yet lack many of the interoperable records and can lead to repeat imaging due to that lack of access to previous images. And so, those are some of the things that we want to start thinking about, and then, we will proceed on from there to where we think this topic should be. Let's pause right now with interoperability and open it up to the workgroup to see if there are any thoughts or ideas on these first two before we move on to privacy and security. Ike, I see that your hand is up.

Steven Eichner
Thank you so much. Looking at the first item, I think it is important to include public health as part of that component so as we are looking at interoperability across laboratories and pharmacies, who are they needing to be interoperable with? It is not just healthcare providers, it is for the entire spectrum of the healthcare community, including hospitals, providers, public health, ambulatory care, long-term care, etc., so I think that is an important part of that capture.

Medell Briggs-Malonson
Absolutely. I agree with you in every single way as well, and Jim, you mentioned something in the chat, which is also very important. Do you want to comment on that?

Jim Jirjis
Yes, thank you, Medell. With one of the questions around lab interoperability, my understanding is it has been a bit of a challenge to try to figure out an appropriate incentive to get the appropriate agents to comply, and so, just keeping in mind… I know the Quad Squad at ONC has assembled, which I am a part of. There are multiple different agencies trying to understand what levers they might have to actually incentivize and influence because if certification standards are developed, there will have to be a lever. I guess one question is how important is an adoption lever in what we recommend for ONC to consider next year?

Medell Briggs-Malonson
That is another great point, and I think that is a challenge that we do need to bring up. Just like what Ike was saying, we need to make sure that this is expanding throughout so many of the different areas, including public health and some of our other entities, but what is the incentive? As you said, what is the adoption lever? That is obviously something that we have to recommend for consideration by ONC, or else all the work that is being done will not be incorporated, so that is another really important point and consideration for that.

Steven Eichner
Medell, to quickly build on that one just a little bit, one of the components that is a little challenging for laboratories in reporting data for public health is that a lot of times, they serve as middlemen or data conveyers for data that they have not actually generated, so there are things like pregnancy status, travel history, or elements like that that are not necessarily relevant to their processing the sample. Part of it is interoperability, and part of it is overall data flow. How do we get the necessary data related to a laboratory report to where it needs to go? It may or may not actually need to get routed as part of a laboratory transaction.

Medell Briggs-Malonson
Those are all very good points. That will be great to synthesize as we are thinking through this report for providing those different thoughts and recommendations to ONC on those solutions for that. Those are all great points. Anna, I see your hand.

Anna McCollister
I have a couple of thoughts. One is that Jim's point about levers that we can use is an important one. Perhaps we need to proactively identify the need for one or make recommendations about what could be

developed. I guess the other thought that I have is really around statutory authority for the agencies to act, whether or not we are asking the agencies to do something that is within their statutory authority as things are currently written, whether it is in Cures or any other piece of legislation, or whether or not we are recommending to Congress that there should be some sort of statutory legislation developed to enable a particular thing.

One of the things that I am thinking about is during the pharmacy workgroup last year, we made a series of recommendations and I was very active in suggesting some recommendations around data transparency related to medication availability, distribution of medication, and basically the amounts of medication that were in different distribution centers because one of the things that we have seen, particularly within the context of drug shortages, but not only drug shortages, is that the amount of work that it takes for patients to be able to locate a pharmacy that has their medication is really challenging, and the ability to be able to reliably trust that when a pharmacy says that they are working on their medication fulfillment, it is actually going to happen.

I am currently waiting on two medications whose prescription has been in process for more than a week. I am completely out of both of them, and it is impossible to actually speak to the pharmacy to find out if they actually have it in stock and are preparing it, if it has been ordered or not, or if there is an outage at the distribution center, and this just creates a remarkable amount of workload on behalf of the patient, as well as the physician. For instance, a doctor was asked to send a prescription to a different pharmacy. Anyway, those kinds of things with regard to information would be super helpful for reducing patient burden that could be fixable through accessible APIs and data that is already there in a structured format that is being shared in one form or another, but for which ONC has no statutory authority.

Medell Briggs-Malonson
What I am hearing, Anna, is that while we are discussing this topic, to your point, we need to ask whether this is within ONC's jurisdiction and authority, and that is an incredibly important question, and maybe we can pose that back to our ONC staff. For instance, in thinking about the data quality and integrity, as well as the expansion across various different organizational entities, but also having the various different levers to ensure accountability and incorporation of this, maybe the ONC staff can come back to us to say if this is within their jurisdiction and statutory responsibilities or authority for this topic. Those are all really good points. Thank you for that.

Anna McCollister
This kind of gets to the crux of the challenge I have in getting my head around exactly what it is we are trying to do. Are we trying to give a report on the status of things that ONC has been working on, are we making recommendations for what we think ONC should be doing within their current statutory authority, or are we making recommendations to Congress about what we think they need to be considering within the context of legislation about what needs to happen to actually support the health data-related objectives that we all have and that they share?

Medell Briggs-Malonson
So, Anna, I would say it is the latter two. We are here to provide direct recommendations to ONC, but we are also here to provide overall recommendations to the secretary and Congress based off of what we as HITAC feel is needed in order to ensure that we have the appropriate standards, policies, and programs

that support that health IT infrastructure to promote greater overall health and wellbeing. I would say the latter two are the primary objectives of what we are doing: Supporting ONC and also giving recommendations to ONC, especially in their overall jurisdiction, but also hopefully being that group that is pushing the envelope a little bit, saying that these are the true recommendations that we also want to provide to all of Congress and all the various different agencies within this domain.

Anna McCollister
Perhaps when we think about how we are going to write this after we choose our topics, maybe we should have a section that specifically denotes things that Congress needs to do if we want to achieve these objectives.

Medell Briggs-Malonson
Absolutely. That is a great point. All of our team, as well as ONC staff and contractors, are on, and there are going to be a lot of changes to the format of the report this year, so we will definitely pin that item. Due to time, I am going to move on to the next one, supporting image interoperability. There are a couple of different things that have come up, and Sarah, I know you mentioned that this came up in the IS WG workgroup. Are there any additional thoughts that anyone has on this topic?

Sarah DeSilvey
Thank you so much, Medell. I am just going to hold up the fact that we went into great depth on it with subject matter experts, so, should we choose to investigate this, a lot of recommendations that came out of that subject matter expert presentation would be relevant. I am by no means an expert in this. Our friend Steven Lane worked with ONC to get a pretty solid presentation last year, but it was identified as a critical gap. I am happy to recenter that and support it, should we consider to go forward with it again.

Medell Briggs-Malonson
That is excellent. If those recommendations are already part of IS WG, one of the things that we have done before is pull recommendations from other workgroups into this workgroup just so there is that full alignment, so it sounds like we need to go a little bit deeper into what was reported out for IS WG. Thank you, Sarah. Are there any other thoughts or items about supporting image interoperability?

Anna McCollister
Just that it is super important.

Medell Briggs-Malonson
Yes, it is.

Eliel Oliveira
I think the point that Ike has made on the bandwidth challenges with moving images around, especially for rural people, is a big consideration. I think we all have heard about the implementation of infrastructure to allow connectivity, but it is still a big issue across the country for many individuals, and even clinics, to be honest. I provided some feedback recently where you would imagine that clinical practices here in Austin, Texas would all be wired and have data access, but that is not necessarily the case. Our behavioral health providers were challenged to have connectivity access. I think that is an important point, Ike, and thank you for pointing that out. I saw a hand come up. Maybe it was Hannah.

Hannah Galvin
It was me, but I put it down because I was jumping the gun.

Medell Briggs-Malonson
Okay, no worries. All right, wonderful. Are there any other comments or thoughts? I think we are all in full agreement that this is a critical gap, this is an area that we need to amplify and elevate, and there are all the additional considerations of image interoperability as well, especially in terms of access, resources, and capacity. All right, there are no other comments. Jim, I do see what you put in the chat, and I do not know the answer to that. I do not know if some of our ONC staff know the answer to Jim's comments, but I think that is an important piece for us to know as the Annual Report Workgroup, but also, in the past, if there have been those true, clear recommendations to ONC/Congress, especially Congress, of needing to support ONC in various different ways. I do not know if Peter or Michelle want to comment on that.

Peter Karras
This is Peter. I will defer to Michelle to see if she has any comments here, but if not, that is something we can definitely note, take back, and get some more information on items that have been recommended and where those items have led to influencing Congress to enact any of those recommendations.

Medell Briggs-Malonson
Michelle, do you have any thoughts there?

Michelle Murray
Sorry, I was double muted. I have been at ONC a long time. I know this has come up before, and I am not going to trust my memory on details of whether it was during HITAC, another advisory committee, or another project. The appetite for going to Congress with that changes a lot because it depends on the Congress, on our leadership, and on the topic, so we will take that back to our leadership and say, "Okay, in this current situation, do we want to go forward with this process, or is there some other way to channel this feedback?" So, we will look into that and get back to you.

Medell Briggs-Malonson
Thank you, Michelle. Thank you so much, Peter. Okay, we are going to go on to the next topic, which is privacy of sensitive health data. This is a topic that we did explore in last year's annual report, but of course, it is a very important topic that continues to come back up, and this was suggested by Michael Chiang and Ike about patient privacy and patient control over their health data as important concepts. The report should acknowledge the variability in how privacy and security practices are currently carried out and how they should be implemented. So, I want to open it up for any thoughts or discussion on this topic, and also how expansive it should be as well. We know that the discussion over sensitive health data comes in many different forms. How should we make sure that we are implementing it almost as if there should be criteria or standards for that? Any thoughts about this?

Eliel Oliveira
I see that Hannah has her hand up.

Medell Briggs-Malonson

Oh, yes, thank you. Sorry. Yes, Hannah?

Hannah Galvin
Thanks so much. This is what I was prematurely raising my hand for previously. Yes, I absolutely echo this. This is an area where I have a lot of thoughts. I agree that privacy and security is an applicable target area. I also think that equity is an applicable target area as well, so if we are thinking about a matrix approach where we think about multiple target areas assigned, interoperability is also a target area, as we often limit interoperability when we put all-or-none controls over sensitive data, and we limit the utility of our exchange of data at this time. In terms of how things should be implemented, I think that is a lot of ongoing work, and I am certainly happy to share that as we move forward some of the work that is being done around this, and we can certainly have some others who are working on with me come and speak to this group, but investing more in understanding this, both from an equity lens and in a furthering of our interoperability infrastructure or ecosystem lens, will be really important. We tend to think of this under privacy and security, but I think there are a lot of other target areas that this impacts as well.

Medell Briggs-Malonson
Thank you, Hannah, for those comments, and I fully agree with you. This actually intersects in many different areas, and in addition to equity and making sure that we are having equitable access, care delivery, and outcome, but also in terms of the interoperability piece, I also want to put something in which is not necessarily underneath one "target area." Privacy of sensitive health data also has taken up clinical-of-care and quality-of-care implications as well across the board, and so, I think that this is something that we need to dive deeper into in terms of what some of those additional recommendations may look like when it comes to the various different forms of sensitive health data, and even that true definition of what we, as HITAC and the Annual Report Workgroup, are referring to as sensitive health data. I think this is a very important topic for us to dive into and expand and flesh out a bit more so it does have the impactful recommendations that we should be providing. Any other thoughts on the privacy of sensitive health data? Okay, excellent. I do not see any more hands or comments, so we will keep going on down to the next page.

All right, these are the last two, and then I will turn it on over to Eliel for the additional potential topics. Patient-generated health data has been something that was also slightly covered in fiscal year 2023. It was brought up by Aaron, but also by Anna, looking at the discussion of integration of electronic health record (EHRs) with medical devices, but maybe it does not go far enough. There is ongoing need for more open and standards-based access to data from these medical devices, and these data are critical for the provision of modern healthcare, yet it continues to be difficult for patients and physicians across the country to access the PGHD from medical devices from their area. So, this falls underneath the target area of patient access to information, but one of the things that we discussed in our last annual report is that this actually impacts, again, providers, being physicians and other healthcare professionals, as well as patients because of lack of interoperability and gaining access to that patient-generated health data specifically from medical devices. So, I wanted to see if there were any additional thoughts, revisions, or additions to that. Anna, I saw your hand go up first.

Anna McCollister
This has been a big issue of mine for 13 years, I would say. I led efforts back when Farzad Mostashari was the head of ONC to get a bunch of patients to try to get ONC to include it in Meaningful Use. Clearly, that did not work. I think it is super important, not just for patient care, which is critical, but also, I have been on

lots of Centers for Medicare & Medicaid Services (CMS) quality measure committees over the years, and we have to have this sort of data, particularly with diabetes, but diabetes is sort of like the canary in the coal mine in terms of the potential utility of using this stuff, but it is absolutely essential to the development of real quality measures that matter far more than some of these incremental biomarkers that are being tested. This is about patient care and about physician access and truly informed physician decision-making, but it is also thinking about how we want to assess what quality health is, what health is, and what disease is. Again, diabetes is an early entrant into this space, but some types of sensors are proliferating, and this stuff needs to be incorporated into the EHR. It has to be a priority.

Medell Briggs-Malonson
Wonderful. Thank you for that, absolutely. Ike?

Steven Eichner
Thank you. I think that interoperability here is a key component, perhaps not patient access to information, at least in the traditional way in terms of patients accessing information from providers. This is a little bit different. I do think that it is important that we figure out or address the quality of the data that is actually generated in terms of what device or what mechanisms are used to generate the data for submission and the conditions under which that data is collected, just from a utility of data from a data quality usability side on the other end, to help ensure or facilitate the collection and forwarding of good quality data that can actually really inform accurately the delivery of healthcare and not be inaccurate data that might lead to false conclusions or inappropriate conclusions. For example, a bad pulse oximeter that does not comply with standards where the numbers are always off feeding in bad data would not be helpful.

Anna McCollister
I agree. I would not categorize this as patient access to information because we have access to the information 24/7. It is more around ensuring appropriate care, and we leave out the development of the quality measures that have any kind of relevance.

Medell Briggs-Malonson
I think all of your points are well taken, and Ike, yes, it seems like this target area should be more about interoperability because we are trying to share the information between various different sources. And then, as you both are saying, quality of the data and standardization of the data, because we know these medical devices are sometimes putting out various different values that may skew things one way or the other, this is a huge area to consider because we are lacking this data, but we have to make sure the data is accurate for it to be actionable as well, so, thank you for those comments. Any other comments? Go ahead, Ike.

Steven Eichner
I do wonder if we should have another magic asterisk, if you will, or another category that tags data quality as a priority item and includes it as a reference source or additional category for these items because there is a lot of focus on data quality or data usability in other spaces, and it might be really helpful to have that as a component in terms of how we are describing things, not only for our own work, but for helping it line up or being utilized by other parties in the Trusted Exchange Framework and Common Agreement (TEFCA) world or other elements further focused on data quality or other components, and if we can use language that is consistent, that might help our report be even more useful at the end of the day.

Medell Briggs-Malonson
That is a brilliant idea, and I love what you said. Jim just put some additional items in the chat as well on quality, but also relevance, without a doubt, and I love that idea of trying now for us to carve out, because so much of what we are talking about is data quality, integrity, and relevance so that it is actionable, so that is something I would say our ONC staff and contractors can help us through because health equity seems to be a very common thread that we are seeing in everything, all the way throughout every target area, throughout all of artificial intelligence, and throughout all of interoperability. Great idea. Jim?

Jim Jirjis
There is one area that may be useful, though maybe I should mention it in another section. We have done a pretty good job as a country of dealing with the pipes the data goes through. For example, TEFCA is live now. We have also done a pretty good job of defining the terminologies and the content format, but what we have not addressed is how much data people send. This kind of piggybacks on the quality road. For example, when I was at HCA, we connected to CommonWell, who is now a Qualified Health Information Network (QHIN), and I had the team look at 180 hospitals and thousands of connections and randomly pick 100 different Consolidated Clinical Document Architectures (C-CDAs) that came across to evaluate what was in them. What we found was that the United States Department of Veterans Affairs (VA) would send two years' worth of data. Some places would send 90 days' worth, but many people interpreted what they were supposed to send in United States Core Data for Interoperability (USCDI) format as just the very last encounter, so we had situations where someone was referred for a heart transplant from another system that had tons of cardiology tests and notes, but unfortunately, the last encounter at that sending institution was a skin tag removal, and so, the only thing that actually came across to the transplant surgeon was the skin tag removal data.

So, we have not yet addressed what expectations are for how far back people should go. That is really important because a whole bunch of use cases when I was at HCA that we were touting evaporated because there was no understanding of how far back someone would send information. And so, I think that is something that has been neglected and affects the value. I like to view it as the water going through the pipes. How much is there? I suggest that we recommend to ONC that they address that so that the receiver has some expectation as to how much information is coming through.

Medell Briggs-Malonson
Jim, I cannot agree with you more. I am in an active project right now of bringing together numerous health systems, federally qualified health centers, and clinics throughout a large region here in California and across the entire state, and it is exactly what you said. We have had this constant conversation of how far back we go in order to pull the data in, and there is so much noise in so much of the data, it is almost not usable at times. So, I think we should have some recommendations on time periods, but gosh, if we are going to be innovative, they should be on how you can even select some of the various different key clinical information that you need to be exchanged for whatever reason. That would be even more fantastic.

Jim Jirjis
Medell, can I make one more quick comment on use case? Even with Fast Healthcare Interoperability Resources (FHIR), we are going to have to define how far back people go. As a public health use case, for example, somebody with a new positive purified protein derivative (PPD) skin test has an abnormality on their chest X-ray. A chest X-ray from six years ago done at some other institution that indicates that there

was an abnormality is the difference between needing to treat for active tuberculosis and realizing that it is okay, it is just an artifact. And so, there are a plethora of clinical situations where… Everyone always talks about recency of data and how the relevance of data decreases as you go back in time, and though that is true, there are still really important use cases where pre-deciding that you are only going to send 90 days is a problem. Even in the FHIR world, where, one day, we can request so we do not just send a giant payload, but instead we request the data that we are looking for, even then, the source institution is going to have to be able to go back, and I think ONC needs to not be silent on how far back. Pick a date. That way, everybody knows, right?

Medell Briggs-Malonson
Right. Thank you for those comments, Jim. They are all really important. Thank you, Hans, for your comments also in the chat. I know we are running short on time, so I am going to speed us up just a bit. Patient burden is the next one. This was suggested by both Anna and me about how patient burden and workflow are not considered enough in regulatory development, and the amount of effort for patients should be lessened when possible. How can health IT help assess this issue? Anna, any additional thoughts about this? This is underneath patient access to information. I also still do not know if that is the right target area for this, but I would love to hear some of your thoughts about when this topic came up, and then I will share some of mine as well.

Anna McCollister
I would say patient access to information, but also interoperability. As I said recently in a Sequoia board meeting, I am not collecting my data because I have some sort of health data scrapbook. I want the data to flow and make it to the doctor so that I do not really have to worry about access. I do access it, but somebody like my mother is not capable of doing that. So, it is really about interoperability and thinking about what we can do from a policy perspective in the context of health data. What can we do to release the amount of workload required for patients?

Medell Briggs-Malonson
Great. I like that as well, and I think where my thoughts were initially with this was as we continue to roll out various different regulations or even various different health IT platforms and infrastructures, we are not really doing it in a patient-centered way, meaning that we are not doing it in an inclusive way of thinking about how best for the patients to receive that information or participate in that information. And so, we are really thinking more about accessibility and inclusivity when it comes directly from, of course, multiple languages, the level of both health and digital literacy involved, and how best in terms of the modes of how that information should be received.

That is one of the things about lessening patient burden so that the patients can take a more active role in all of their health IT and all of their overall patient care and being more engaged, and health IT can truly help to support that. Those were some of my different thoughts when I was talking about patient burden. We have continued to develop our health IT systems from the standpoint of developers and/or oftentimes practitioners, and not from the lens of the patient, which needs to be included.

Anna McCollister
Right, and what we have seen is that as many of these things have been developed, the result has been an increase in patient workload. It is somewhat paradoxical because the number of things you have to do,

the number of portals, the number of documents, the number of suggestions you have to make cumulatively, particularly if you have a complex set of chronic diseases like I do, is just a lot, and the burden has increased and the stress and anxiety has increased rather than decreased over the years.

Medell Briggs-Malonson
Thank you, Anna. Any other thoughts about this topic, about not only streamlining, but also making things much more interoperable, but also accessible and inclusive from the patient perspective? I am not seeing any. Okay, well, Eliel, I am going to turn it on over to you for the other potential topics based on research.

Eliel Oliveira
Thanks, Medell. I know we are running short on time, but those comment in the chat by Hans and Jim are quite important in terms of retention of patient data. I just wanted to highlight those. We agree with Jim. We had specific details about how to do that on paper, but not anymore in the digital world, and it is quite important. These days, if I go to a clinician, I tell them my whole story because it is likely that they cannot find my 50 years of existence in my records. I just want to highlight that point before we start. I think these other topics here, based on research, show that they are covered in the 2023 report, and they cover areas related to health equity, public health, and interoperability as well.

The first one here is very important. I think the summary does not give enough credit to the importance of use of artificial intelligence in healthcare, especially when it relates to health equity, that the organizations and coalitions are increasingly pursuing initiatives to ensure artificial intelligence (AI) is used in a safe and nonbiased way. I think you saw in our AI hearing how much we still are unclear with what to do here, so I just want to highlight how this specific area has so much, just in terms of health equity, trustworthy AI, and many other topics under that umbrella. I will go to the next one, and then I think we have another one on the next page, but maybe I will open it up for comments.

The second one here is optimizing public health data exchange and infrastructure. We covered that a little bit in the previous comments. One thought that I had when we were discussing was the fact that we are talking about labs, standards, and exchanges, and since the pandemic, I do not think we addressed these at-home tests that were being distributed everywhere, and we had no idea what the results were, positive or negative, and there was no way to even share that information to highlight from a public health perspective what was really going on. So, by doing at-home labs, that creates other challenges in terms of data capture as well, but I think you all know that, during the pandemic, we showed a need to have an improvement in public health systems, and the federal government is taking those steps through the CDC data modernization and North Star architecture, and ONC staff will help further advance interoperability in healthcare providers and public health authorities.

And then, on top of that, we are talking about AI increasingly being used in public health to improve public health outcomes, enhance disease surveillance, prevent diseases, and respond to health emergencies, so there is a lot here between AI and all these efforts that are taking place across the country between different agencies, but how do we bring it all together and optimize public health activities? So, before we jump to the next one, I want to pause there for a second and see if there are any comments, and I see that Anna has her hand up, and then Medell.

Anna McCollister

Me or Hannah?

Eliel Oliveira
Anna. Sorry about that.

Anna McCollister
I have one question, and then I will get into the substantive comment. I was wondering if Accel or ONC could add the list of applicable target areas somewhere. I am just looking for it in the slide deck, just because with regard to patient-generated health data and patient burden, I do not think those applicable target areas are completely on. I would also agree that the use of artificial intelligence in health equity… Obviously, health equity is a big issue that needs to be considered, but my hunch at this point, which could be completely misguided, is that one of the things we should do is to think through all of the different ways that we or ONC should think about what potential applications are appropriate for artificial intelligence. For instance, the use of AI to develop composite digital biomarkers could be really helpful. It might be a bad idea, or it might be a great idea. That all depends upon the data quality and the level of whether or not you can trust the quality of the data.

One of many areas that I think is promising in that potential use of AI is the ability to improve data quality because if you look at the data within the EHRs, and when I had my analytics company, I looked at EHR data, it is a mess. When I look at my data through my portal and download it, the idea that that raw data would be fed into AI and somebody would make a decision based off of it is terrifying, but the potential to use AI to actually turn that data into something usable is a very helpful use. It could be helpful, and maybe the shortest road home to get us to where we need to be in terms of exchanging. I think limiting it to health equity is cutting short the potential benefits of artificial intelligence, and I have significant concerns about the misuse of AI. I have concerns about using it as a way of gating access to particular medications. We have seen some horrible case studies of how that is done. We need to be cognizant of those potential harms, but we also need to be really excited, I would hope, about the potential benefits of AI and how that can be used to help us solve some of these other problems. Again, it is less about the topic and more about what the applicable target area is.

Eliel Oliveira
Yes. Great comments, Anna. I could not agree more, and I think that in the hearing that we had on AI, we touched on those steps a little bit. What is the source of data that we are really using, and is it valid? If you remember our Food and Drug Administration (FDA) colleague that was there, I even questioned if we had considered having a similar process as we have had in drug development where there is a design of methods that is done in a contained environment first and then moves on to be tested in a specific population, a specific real setting, and eventually moved to the larger population, but which needs to be monitored in the long run in a surveillance system to see if that algorithm or method is still doing what it is supposed to do. So, there are so many things that need to be addressed in terms of AI that that data quality becomes a central point of it, so I totally agree on that.

Anna McCollister
Again, I am the one that used the term “potentially diabolical” during the HITAC meeting, so I have grave concerns about it with regard to health equity and a variety of other things, but I do not only want us to look at AI through the lens of potential harm because we are also seeing some remarkably compelling case

studies of how consumer-level AI, such as ChatGPT, is providing remarkable insights from a mess of data that made absolutely no sense and has been really helpful in solving some pretty important problems.

Eliel Oliveira
Thank you. Medell, you have your hand up.

Medell Briggs-Malonson
Yes, I do, and while we are looking at these target areas, I have a significant revision that I just caught to design and use of technologies that advance health equity. I would make a strong recommendation to change this language because it can be perceived as incorrect and a little off where it says "for people to reach their full health potential regardless of socially determined circumstances." That is actually very fatalistic and fixed, and that is not how we tend to talk about health equity, and so, I would make a strong recommendation to change this language to "to help all people attain their full health potential." We do not have to put the "regardless of socially determined circumstances" because these circumstances are not determined. The other thing we could say is "full health potential regardless of identity and experiences." That would be perfect, but I would just ask us to change that bottom line, and I am happy to work with you on that.

But now, going back to what I was going to talk about, if we are able to go back to the list of the various different topics, it was talking about all the various different coalitions around AI and what to really do with them, and I think that this is an important piece. I agree with everything that Anna mentioned, that this goes beyond health equity, but we really want to make sure that we are identifying and mitigating any forms of algorithmic bias or underrepresented data sets that we know are going to produce disparate outcomes. So, for this topic in itself, I think we do need to expand out a bit more about what this means. Are we saying for the organizations and the coalitions that are trying to pursue these initiatives that ONC does provide some recommendations or criteria for how they go about it, or, if it is industry that we are leaning on to try to make some of these various different recommendations to promote greater safe, trustworthy, and nonbiased AI, still, what is the goal for ONC? Is ONC going to adopt some of those standards in order to disseminate across the country?

One of the things that we clearly know is that there are organizations that have lots of resources, like my organization, for instance, which has AI governance committees, is going through AI significantly in order to make sure it is safe, trustworthy, and nonbiased, but we have many organizations that are more under resourced, that do not have the expertise, that may not have all the people at the table to do these very extensive evaluations of AI, and in all actuality, going back to the potential benefits of AI, really, it is our more under resourced communities, public health agencies, and healthcare providers that could benefit from truly safe and nonbiased AI to expand their ability to care for individuals and populations. So, I think that is something that is really important where we as the workgroup and HITAC think about what this means in terms of the use of AI to promote, yes, greater health equity, but to promote greater overall health outcomes for all communities and populations.

Eliel Oliveira
Thanks, Medell. Great points. I could not agree more about the fact that different organizations have different capabilities, and it is going to become harder and harder for each one of them to decide what to use and what not to use. Someone needs to be keeping an eye on that and being the unbiased assistant

for organizations like that to be able to use the assistance. I see three hands up. Anna first, and then Hannah.

Anna McCollister
I will go quickly. To the point that I was making previously about the target areas, those are relatively limited target areas, and I understand that we were created by 21st Century Cures, and there is a lot of legislation upon which all of our work rests, but I am just wondering if we need to think beyond those five target areas and perhaps have a separate section or some sort of a section within the annual report that says these are things that are not within the target areas as defined seven years ago by the 21st Century Cures Act, these are ones that are emerging that need to be considered and are outside of those target areas, because those are very limited. There are lots of things that have happened since the 21st Century Cures legislation was developed, and the idea of advising Congress or giving the report to Congress about what is needed that is limited to those five areas sort of limits our utility.

Eliel Oliveira
Thanks, Anna. That is a valid point, and I think the Annual Report's intent is exactly to provide recommendations. I think one area that we probably were not thinking about and that was not clear five or 10 years ago was AI, and as you can see, that is all we talk about these days. I think that could have a place on the report. I think we talked in the last meeting about how most of the recommendations probably will not fall into one of those, but I think there is a space there to say this is a completely new area that we need to consider overall, and AI could be one of those areas. Thank you for that. Hannah?

Hannah Galvin
Thanks, Eliel. Around AI, to Medell's point, there are many organizations, including medium-sized organizations and resource-strapped organizations, which are putting together robust AI governance, but some of the larger organizations are really investing in these AI assurance labs, and I would like to see better definition around what makes an AI assurance lab, what is expected from an AI assurance lab, and how that is different from other AI governance frameworks that are being stood up at lower-resourced organizations. What do we expect to come out of AI assurance labs, and, to Medell's point, is there some expectant standard that needs to go through a standards development or certification process as directed by ONC, not just through an AI assurance lab? I think all of this is evolving right now, but I think that is one area where I would really like to see some better clarification as we address this topic.

Eliel Oliveira
Great point, Hannah. As you were speaking, I was just thinking here that our own Micky Tripathi has been an AI lead as well, but just thinking on that point specifically, there is likely a place where all these need to come together because there is so much information from what you just described, and then, trustworthy AI, regulations around it, and whatnot, that I think all of us are probably getting lost a little bit with how much is being produced out there, how we are going to govern this, and so forth. Great point. I want to move on to Ike because we still have one more topic to cover.

Steven Eichner
Thank you. This may be a parking lot issue, but thinking about the intersection between AI patient burden and patient-generated data, we haven't talked at all about medical research, clinical research, and clinical trial components, and that is probably something that really is a cross-cutting element that impacts an awful

lot of these activities and this information sharing, thinking about sensitive data that I might not want to share for some purposes, but might be interested in sharing as part of a clinical trial that I am participating in. In my particular case, AI helped identify a potential drug that could be used to treat my condition, so I think that is another element that we might want to consider putting in the parking lot for something to be considered. HITAC has really not talked much about the intersection between clinical care research and patient engagement, and I think that is a ripe opportunity.

Eliel Oliveira
Great point, Ike. I think that goes along well with the one that we had in terms of patient consent, which is still a challenge that we need to address in how to allow the patient to have a voice and decide on things like that, but at the same time, there is so much knowledge being generated at AI and identification of individuals that can participate in building to what we call a learning health system and how we uncover new challenges and feed that into practice to be utilized by others. Great point. We have one more section to cover, but before that, are there any other thoughts or questions before I move on to the next page? Hearing none, can you scroll down a bit?

The last topic we have is on interoperability again, and this is very much related to Long-Term and Post-Acute Care (LTPAC), long-term and post-acute care interoperability, and as you can see here, in 2023, the HHS Office of the Assistant Secretary for Planning and Evaluation published a report about the adoption of EHRs by LTPAC settings, noting that 80% of nursing homes and home health organizations had adopted them, but the interoperability exchange of health IT is not widely or routinely used.

The report states that more tracking of the adoption and use of IT is needed to create additional baseline and benchmarks to lead inclusion of LTPAC providers in health IT and interoperability programs and regulations. It also suggests improving LTPAC participations in health information exchanges (HIEs), including easy data sharing barriers and clarifying HIE vendors in profile to their relationships. I will just offer one thought. The LTPAC EHR is not necessarily certified EHR, which means that for HIE connectivity and other communications between EHR vendors, it becomes quite challenging because they might not necessarily have the ability to do so. That includes behavioral health profilers as well. Ike, you have your hand up.

Steven Eichner
Are we going to come back around to the public health element that was the last one on the previous page?

Eliel Oliveira
We can. We had it open for questions, and maybe no one commented on that specifically. I read both at the same time, but yes, we can go back to that, Ike, if you have a comment on that point.

Steven Eichner
If there are no comments, we do not necessarily need to touch it, but it is obviously a subject that is worthy of attention.

Eliel Oliveira
Definitely. Any comments on that, or on this last bullet point related to LTPAC interoperability?

Medell Briggs-Malonson
Eliel, just to make sure, if we go back up, Accel, we want to still make sure, for optimizing public health data exchange and infrastructure to gather, if there are any questions, comments, or additions to this topic as well, correct? Is that what we are doing? Okay.

Eliel Oliveira
That is correct.

Anna McCollister
I do not really have additional comments about these, but I have some thoughts about other things we may want to include. Should I talk about that now, or are we going to be adding things to this document?

Medell Briggs-Malonson
We are absolutely adding things. We are just trying to go through the current topics right now, just to make sure there are no additions, but we absolutely are going to be adding things from the workgroup.

Anna McCollister
Okay.

Steven Eichner
This is Steve. Really quickly, when looking at public health, I think it is important to highlight that it is a collaboration between federal, state, and local governments and healthcare providers. There are lots of actors involved. It is not just a single group with a single set of stakeholders.

Eliel Oliveira
Great point, Ike. I totally agree.

Steven Eichner
I think some of the challenge is that public health may have a lot to contribute to thinking about things. TEFCA is looking at the data quality components and public health's long history of focus on data quality in onboarding, which has been a little bit variable in other spaces, and that is an area that needs to get improved in looking at TEFCA adoption to really be useful to public health. That is, again, a constant focus on ensuring the data that is coming across is of high quality, including timeliness, accuracy, and the other components. I think it is really vital.

Eliel Oliveira
Yes, thanks, Ike. I think your point there on getting the different levels of government aligned is quite important. I see that both you and I are here in Austin, where we have a public health agency, but at the same time, we are at the state level because we are in the capital city, and then, we are collaborating with our Centers for Disease Control and Prevention (CDC) partners and others, so it becomes a real collaboration across several pieces of the government in addition to the organizations on the ground that are providing public health services. Great point on that. Besides that, Ike or others, are there any other points that we need to consider for the public health data exchange and infrastructure? All right, I am making sure that I am giving enough time here this time, but hearing none, maybe we can then proceed to the last

one that I read previously related to our interoperability for LTPAC. Any thoughts, questions, or comments on this one? It is quite important.

I can put my HIE hat on here today and say that it is not very easy to access data from LTPACs. At the same time, they are critical, and we all have seen throughout the pandemic how even more critical and important it was to get access to that data, but we had several challenges there, like the fact that they were not necessarily part of Meaningful Use and do not necessarily have to comply with many of the interoperability requirements that we or other technology vendors have.

Steven Eichner
I would like to call into the group Durable Medical Equipment (DME) providers as a special callout as well.

Eliel Oliveira
Which providers, Ike?

Steven Eichner
Durable medical equipment providers.

Eliel Oliveira
Durable medical equipment, yes.

Steven Eichner
I want that to be included because that becomes really important for many folks in thinking about getting the right equipment to care for a long-term condition, and getting it serviced and coordinated with what your actual needs are would be great. A little wish in the back of my head would be if you had durable medical equipment at home and were going in for a hospital visit, wouldn't it be great if a note could go to the hospital so that the mattress could get rotated out if you had a special need without having to wait three days to get the accommodation in the hospital? That is just an example of where there is that opportunity for that improved coordination.

Eliel Oliveira
Great suggestion, Ike. I could not agree more. In the time and age that we are living through, with global warming, whether you agree or not, and the weather disruptions that we have had, it is quite important for individuals with durable medical equipment that they actually have power, and we are working here in our backyard with Austin Energy to actually address and identify that, and it is quite important for infrastructure services like electricity that we have access to records in some way to identify the individuals that need the most help in terms of a disaster when it strikes, and as you can see, we have many all over the place. Great suggestion.

Steven Eichner
And at that point, would it be a good idea to potentially include social hooks, for lack of a better terminology, or peripheral services that are not necessarily provided by traditional and Health Insurance Portability and Accountability Act (HIPAA) covered entities? I am not quite sure how to capture that from a concept perspective. It is almost a limited extension of HIPAA for special needs when you are thinking about power or other supportive services. That might be too big a reach.

Eliel Oliveira
I think we had that on the list that Medell read earlier about the key priority that came out that there was some mention there about social and other types of organizations that also need to be interoperable with us, and there are so many, as you can imagine, that I think that LTPACs were the first ones that rose to the top, let's say, as ones that have electronic health record systems but are not really communicating with the other clinical providers, and that is one that we want to target first, but I agree with you. There are quite a few others, including social and other types of services, to be integrated. Any other thoughts or questions? I think we are at the 10-minute mark. If there are none left, I will turn it back to you, Medell.

Medell Briggs-Malonson
Thank you so much, Eliel. One of the things we are going to do next is a rapid-fire for you all because we are probably going to have to come back to expand on some of the various different topics, but we just wanted to grab some of your ideas in terms of potential topics for the Annual Report Workgroup. So, does anyone have any additional topics they at least want to put on the table? And then we will likely have to circle back around to it to expand on it a bit more. Any additional topics?

Anna McCollister
I have one.

Medell Briggs-Malonson
Go ahead, Anna.

Anna McCollister
And there may be more. One of the things that we talked about, maybe in the Health Data, Technology, and Interoperability: Certification Program Updates, Algorithm Transparency, and Information Sharing (HTI-1) workgroup, that is important to me and that I think is increasingly important is transparency around use of data. HIPAA gives quite a bit of latitude to data holders about what they can do with data once it has been "deidentified," but there is no compensatory requirement around disclosing what the data has been used for, and I think that is very much needed, and it is an oversight, particularly within the context of the continually deteriorating social trust. I am somebody who thinks that it is really important for data to be deidentified and used for secondary research, but for that to continue, I think it is equally important for there to be disclosures about how that data is used or has been used. I would love to make some sort of proposal. It is probably outside of the statutory authority of ONC or CMS, but I think it is something that needs to be taken very seriously.

Medell Briggs-Malonson
Anna, I agree with you, and I think we should definitely put that on the table and explore what is within ONC's boundaries, but that is such an important topic, and it is an important topic for all patients, but it is definitely also a highly important topic for vulnerable populations or populations that have been historically discriminated against within medicine and in terms of science, since we know the history of our country, so I think that that is such an important piece about transparency of the release of data for other uses, including specifically research and other items, so, absolutely. I have two that I am just going to throw on the table, and then, also, please, from the workgroup, if there are any additional topics.

ONC is currently exploring behavioral health, interoperability, what that means, and what that looks like, so I would like to put that also on the list of potential topics for the annual report to highlight what that looks like in order to ensure that we are having greater access to behavioral health and mental health information in terms of our interoperability. We just have not really focused as much on mental health and behavioral health aspects, and this is such a huge, important topic for our country.

The second topic I would like to put on the table as well is during our last HITAC meeting, of course, we had a discussion about health equity by design. We know that health equity by design is a priority for ONC and definitely a priority for our national coordinator, and I think that, not only through the Annual Report Workgroup, but also hopefully through some other type of task force, we can actually provide recommendations of what health equity by design truly means in health IT and in our health IT infrastructure standards and programs, so I would like to also recommend that potential topic of truly putting action behind what health equity by design means for health IT. Anna, I see that your hand is up, and we have one more minute before we proceed to public comment.

Anna McCollister
The only other thing for now that I would add is, again, something else that came up during the HTI-1 workgroup, and that is accounting of access of who has accessed medical records. It came up in a couple of different sub-workgroups for the HTI-1 task force or whatever the nomenclature is, but I think it should be part of legislation because nobody has figured out how to do it historically, but it has gotten easier to do, that accounting of disclosures or accounting of access. I know it is far more complicated than it sounds, but I think it is something that needs to be considered.

Medell Briggs-Malonson
Excellent. Thank you for that recommendation, Anna. I am now going to turn it back over to Peter for our public comment. Peter, I will turn it over to you.

Public Comment (01:23:48)

Peter Karras
Thanks, Medell. We would like to open the meeting for public comment at this time. If you are on Zoom and would like to make a comment, please use the hand raise function, which is located on the Zoom toolbar at the bottom of your screen. If you are joining by phone only, please press *9 to raise your hand and get in the queue, and once called upon, press *6 to mute and unmute your line. All public comments are limited to three minutes. I do not currently see any comments that have come in through the chat. Excel is noting that there are no public commenters on the phone line at this time. I will give it a few more moments. I am not seeing any public comments, so I will turn it back over to Medell for closing remarks and adjournment of the meeting.

Next Steps and Adjourn (01:24:48)

Medell Briggs-Malonson
Thank you so much, Peter, and thank you so much to all of our Annual Report Workgroup members. This has been a wonderful conversation, the first of many, so let's continue to think about any additional topics we may want to add or if some of the topics we discuss may not be of higher priority. We will then proceed on with trying to figure out what the next steps are for capturing those topics as well, but I just want to

appreciate all of your participation, insights, and perspectives. This is why this workgroup is one of the best ones. Eliel, I will turn it on over to you for your closing comments.

Eliel Oliveira
Thank you, Medell. Thank you, everyone. I think this was a great first meeting. I hope it gives you a taste, and maybe food for thought to start developing additional ideas for us to discuss next. We are looking forward to talking to you again soon. Thank you very much.

Medell Briggs-Malonson
Thanks, everyone. Have a great day.

Anna McCollister
Thank you.

Medell Briggs-Malonson
All right, 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: challenge of the lab interop: what are the incentives for labs to adopt?

Steven Eichner: Accountability of a wider range of disclosures, such as disclosures of patient data to other entities/other EHR systems, to the patient is very much related to the privacy of sensitive data.

Steven Eichner: For imaging interoperability, bandwidth to provide access in rural or other areas where bandwidth may be limited may also be a consideration.

Jim Jirjis: has there been past examples of HITAC recommending to congress items to empower ONC? If so has it led to Congress enacting those recommendations?

Eliel Oliveira: 👍

Hannah K. Galvin: Agreed, Sarah - the need for infrastructure is critical

Eliel Oliveira: I believe we are widening the “digital divide” by not having infrastructure in place. The most in need are getting the least support.

Eliel Oliveira: Making infrastructure a key aspect if Equity First is our mantra!

Hannah K. Galvin: Agreed, Medell.

Jim Jirjis: must not only be quality data, but relevant. 17,000 exercise details, for example, do not belong in the EMR. A summary of exercise patterns might.

Anna McCollister: Completely agree!

Steven Eichner: Or maybe the utility of the data, not necessarily the volume.

Hans Buitendijk: +1 Jim that right-sizing requires still some work to send what is relevant for the question, interaction at hand.

Hans Buitendijk: Particularly with FHIR where the range of data can vary from individual data elements to documents to large data sets.

Hans Buitendijk: Documents contain either too much for the purpose and question at hand, or too little.

Steven Eichner: What if a focus of the data provided is categorized in part by elements on the patient's problem list (both current and historical, depending on the issue at hand)?

In treating my rare condition, going back 40 years may be helpful. For other issues, the last year may be more than sufficient.

Jim Jirjis: +1 Ike though the heuristics for all of those condition rules would have to be managed

Hans Buitendijk: Isn't there a standard medical record retention timeline that should be applied to ePHI? Or should ePHI be retained longer because it can more easily in less space? At what time can my data "disappear"?

Jim Jirjis: Hans: there are recommendations for retention of data. We ignored it because I made the argument that we should not purge clinical data at all. The Tuberculosis example I gave ben just one effective example.

Jim Jirjis: MOst recommendation for retention, I believe were created in the paper world and not readdressed in the digital age

Jim Jirjis: 50 years of existence!? spring chick

Hans Buitendijk: Should my data disappear upon death? By choice by default? De-identified continues? All great questions to figure out. And as more is available, back to the original question, how much needs to be shared for the topic at hand so we don't send everything always, nor last encounter either.

Jim Jirjis: Why should it disappear at death? perhaps family members will want to know genotypic of phenotypic results of their parents for example.

Jim Jirjis: Large Language models are like mansplaining: highly confident, often incorrect and gives you far more information than needed :)

Hans Buitendijk: @Jim: Should not have to, but should not be required to remain either. Interesting question on who owns that data.

Steven Eichner: There are also likely recommendations to be made regarding the absence of data (eg, AI doesn't account for rare conditions).

Medell K. Briggs-Malonson: As an FYI, asking for a new target area or stepping outside of the current target areas requires informing Congress.

Eliel Oliveira: Exactly Medell. Not an easy change.

Anna McCollister: Agree!

Medell K. Briggs-Malonson: Great suggestion, Ike!

Shila Blend: Second behavioral health as a topic

QUESTIONS AND COMMENTS RECEIVED VIA EMAIL

No comments were received via email.

RESOURCES

AR WG Webpage
AR WG - June 3, 2024, Meeting Webpage

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