

Health Information Technology Advisory Committee

Annual Report Workgroup Virtual Meeting

Transcript | April 13, 2026, 3 – 4:30 PM ET

Attendance

Members

Eliel Oliveira, Connexus, Co-Chair
Shila Blend, North Dakota Health Information Network, Co-Chair
Hans Buitendijk, Oracle Health
Michael Chiang, National Institutes of Health
Steven Eichner, Texas Department of State Health Services
Hannah Galvin, Cambridge Health Alliance
Anna McCollister, Individual
Kikelomo Oshunkentan, Humana
Naresh Sundar Rajan, Neantix.Inc

Members Not in Attendance

Bryant Thomas Karras, Washington State Dept. of Health
Rochelle Prosser, Orchid Healthcare Solutions
Mark Sendak, Vega Health

ONC Staff

Tara Porter, Designated Federal Officer
Peter Karras, HITAC Support Team
Maggie Zeng, HITAC Support Team

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

Tara Porter

Thank you. Hello, good afternoon, everybody. Welcome to the first Annual Report Workgroup meeting for the FY 2026 cycle. I am Tara Porter with The Office of the National Coordinator for Health Information Technology (ONC), and I will be serving as the designated federal officer for today's meeting. I want to note 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 toward the end of today's agenda. You could go to the next slide, please. Today's agenda will begin with a quick roll call to see who is on the line with us today, and then I will transition to the co-chairs to provide a few opening remarks before shifting to a discussion of the workgroup plans as well as a discussion of draft topics for the HITAC annual report for fiscal year 2026. We will then shift to a public comment portion before discussing next steps and adjourning today's meeting.

Next slide, please. We will now begin with a roll call of the workgroup members. When I call your name, if you could just please indicate that you are present. We will start with our co-chairs, Eliel Olivera.

Eliel Oliveira

Good afternoon. I am here.

Tara Porter

Good afternoon. Shila Blend.

Shila Blend

Good afternoon.

Tara Porter

Good afternoon. Hans Buitendijk. Michael Chiang.

Michael Chiang

Good afternoon. I am here, and I am going to turn my camera off now.

Tara Porter

Good afternoon. Steve Eichner.

Steven Eichner

Good afternoon. Present.

Tara Porter

Hannah Galvin. Bryant Thomas Karras. Anna McCollister.

Anna McCollister

Hi there. I am here.

Tara Porter

Hi. Good afternoon. Kikelomo Oshunkentan.

Kikelomo Oshunkentan

Feel free to call me Dayo Oshunkentan. I am here. Good afternoon.

Tara Porter

Good afternoon. Thank you. Rochelle Prosser. Mark Sendak. Naresh Sundar Rajan.

Naresh Sundar Rajan

Good afternoon. I am here.

Tara Porter

Good afternoon. All right. Thank you. I will now turn it over to Eliel and Shila for their opening remarks.

Opening Remarks (00:02:42)

Eliei Oliveira

Thank you, Tara, and thank you, everyone, for joining today. It is great to see this group starting again in full force. We are going to go over a few things today, and there is quite a bit of work ahead. If you have been on the Annual Report Workgroup, we do quite a bit here. Thank you for your time and for providing us with the support that we need. Shila?

Shila Blend

Yes. Thank you, everybody. It is exciting to be back after our hiatus to continue on with this important work. I agree with Eliei. We are very excited about our focus areas for this year, and we look forward to the fruitful discussion in the coming months as we put together this annual report. I believe this [slide] was mine. We are going to go over a few slides here reviewing the workgroup and a few things about what our charge exactly is to refresh everybody's memory. As you can see, the overarching charge will be to inform, contribute, and review the draft and final versions of the HITAC annual report, which are going to be submitted to the Secretary of Health and Human Services and Congress each fiscal year. As a part of that, our workgroup helps track the ongoing HITAC progress. The specific charge with that is to provide feedback on the context of the report as required by the 21st Century Cures Act.

This includes the following: analysis of HITAC progress related to the priority target areas outlined in Cures, assessment of health IT infrastructure and advancements for the priority target areas, which we will be talking about a little bit later, analysis of existing gaps in policies and resources for the priority target areas, and ideas for potential HITAC activities to address the identified gaps. Next slide, please. These are our group priority target areas that were in the 21st Century Cures Act. As you can see, a main focus is interoperability, where the goal of that is achieving a health information technology infrastructure that allows for the electronic access, exchange, and use of health information. Secondly, we have privacy and security, which is the promotion and protection and privacy and security of health information and health IT. Finally, we have patient access to information, which is the facilitation of secure access by an individual and their caregiver to such individuals' protected health information. Next slide.

Discussion of Workgroup Plans & Discussion for Potential Topics for HITAC Annual Report for FY 26 (00:05:56)

Eliei Oliveira

Thank you, Shila. Let me go over a little bit the work plan that we have for the year, so if we can go to the next slide, please. We have a business timeline here, as you can see. Usually, it is very common for this workgroup if you have not been here before. We did kick off to validate the topics, as you remember. We are going to update the status on the annual report by next month, discuss the target areas in July and August, and then have a discussion and review the draft annual report by August, where we then, with that draft report, can present that report to ONC to receive feedback to the rest of the HITAC and finalize the draft report in October, aiming for a vote in early November so that we can then submit the report to Congress and to the Secretary. That is the timeline we have at this point. We can answer questions in a bit, but if we can go to the next slide. This is the format of the outline for the report.

If you are not familiar with it, we are going to have a foreword letter from the chairs, the co-chairs, and then we have to talk a little bit about the outline. The ONC HITAC support team here, Accel, would help us put that together, including Tara and her team. We will talk about the 2026 progress in the priority target areas in the Cures Act, the federal activities across the target areas, and then we will have the specific content for the year on the annual report workgroup. We basically go over the gaps and recommendations across the priority targets. If you have been in a group before, that is what is going to happen in the coming calls. We are going to talk about the gaps and recommendations for, in this case, interoperability, privacy and security, and patient access. Then, to close the report, we have an appendix with the objectives and benchmarks, and an acknowledgment for the group. That is also done by the HITAC support team and the ONC support team. Next, I will pass it on to you, Shila.

I think we are going to open the report and talk a little bit about, in plain language, how the reports are going to be organized this year. I think if you saw last year, this is pretty much aligned with the last, is less text-intensive, more graphical and visual, and utilizes plain language. In some cases in the last year, we even used some use cases to demonstrate the situations that the report was conveying. We are going to go ahead and jump to the topic areas right now, with that, and the specific drafted topics that we have. I will pass it on to you, Shila, for us to read that.

Shila Blend

Next slide, please. Referring back, do we have the list of the annual report topics we can pull up, the draft list?

Accel Solutions

Yes, we are pulling it up.

Shila Blend

As you can see here, these are our draft annual report topics list. On the left side, you can see the three main topics are the priority target areas that I had discussed earlier, and on the right, the subtopics I am going through. Tara can keep me in line. If not, I think we wanted to go through and look at the subtopics and verify that these are our focus areas and that we do not have any additional areas that we need to add, correct?

Tara Porter

Yes. Just to summarize, as Shila mentioned, the priority target areas are the themes that are mentioned in the Cures Act that the report is framed by. This topic list is just really a draft that we proposed based on some prior conversations to have you all start discussing. You do not need to keep all topics on this list, and you can certainly feel free to edit what is here as well as propose different topics. If you have reviewed prior reports, once we validate this topic list, the subsequent meetings will be doing deeper dives within these topics, discussing the gaps and challenges surrounding these topics, and then coming up with opportunities and recommendations to advance each of these topics. Hopefully, that helps with framing the discussion.

Shila Blend

Yes, thank you very much, Tara. It was very helpful. To start off, let us talk a little bit about interoperability. The suggested topics that were brought on were advantage, and I know some of these we discussed on a pass as we were setting up the meeting, advancing image interoperability, lab interoperability, pharmacy interoperability, and payer interoperability, improving public health data exchange, improving data quality standardization, improving data sharing for research, reducing administrative burden, and use of artificial intelligence (AI) to support access, exchange, or use of electronic health information. I see we have a hand up by Hans.

Hans Buitendijk

Hello, Shila. Thank you, and again, apologies for joining a little bit later. Just a quick question on this, and it is a clarifying question. The topics of public health and research are separated out as improving, and the first four are advancing interoperability topics. I am just trying to figure out, is there an intentional difference in what we are trying to achieve, or are we just generally, for the six topics, looking at what it would take to advance/improve interoperability? The other ones, I understand why they are separated out, but those ones, I am not sure whether there was an intention behind separating them.

Shila Blend

I will look to Tara. I do not know that there was an intention. I think these were suggested topics to do deeper dives in. Obviously, there is going to be some overlap, I believe, but Tara, you are welcome to jump on if anybody from your team has additional feedback on that.

Tara Porter

Sure. Yes, I do not think it was an intentional separation. You could certainly say advance public health, interoperability, and data exchange, or parse them out any way that you might want to frame it differently than what is proposed there.

Hans Buitendijk

Thank you. That helps clarify. I was trying to figure out whether there was something different about them.

Shila Blend

If we do have that suggestion, we can definitely do that.

Hans Buitendijk

Yes, it seems like we want to advance and improve on all six, and whatever it might be for each of the topics, whatever the overlap might be.

Shila Blend

Yes, so maybe take that down as a note. Advance and improve might be a good suggestion to add. Steve Eichner.

Steven Eichner

Thank you. Yes, I have the same question as Hans for the public health reporting or data exchange as well. I just have a couple of other questions. 1) Looking at an advanced category, we currently have one content topic listed, but the rest are more along provider types. That is an important distinction that images could be cross-cutting and affect many different types of providers or other entities involved in exchanging information. However, the others listed are more along the lines of provider types. I know things that are of interest across the board are things like access to laboratory results across multiple provider types or multiple user types, the same thing for pharmacy information. We might want to consider that as how we are describing what we are advancing.

The other missing element here, I think, is looking at patient applications or patient resources and tools, looking at interoperability. It may not be just about patients accessing information in a provider portal or something, but how are we improving interoperability between provider-managed systems and patient systems or patient access systems, getting to a point where a patient can have all of their data consolidated or accessible in a single portal and not have to go multiple places to get all the information about them.

Shila Blend

Thank you. That is a very helpful suggestion, Steve. All right, Dayo.

Kikelomo Oshunkentan

Hi. Thank you, Shila. I just have a question. It is more logistical, really, in truth, in regard to looking at these topics. Should we cut it down to a set number of topics as we are looking to identify these priority target areas? Are we limited, or is it completely up to us how many topics we decide to delve into?

Shila Blend

I believe it is up to us. Tara can jump in. We are verifying the list and adding any additional ones. As she said, this is what they are going to use to bring in subject matter or focus our future discussions as we plan out the coming months. I would think if we have more, it limits our time a little bit on each topic, but Tara or somebody can jump in if you have any additional thoughts.

Tara Porter

Yes, great questions. No, this list is not limited. It can be as long as you would like or as short as you would like, but just, I guess, keep in mind, the longer the list, obviously, it might be a little bit harder to have robust conversations about each. You might want to consider coming up with some sort of number of what might be feasible to make sure that you are able to do a deep dive into those topics and really come up with strong recommendations. No, you are not limited. You can choose as many topics as you would like to dive into with the report.

Kikelomo Oshunkentan

Thank you.

Shila Blend

Eliel, did you have something to say?

Eliel Oliveira

Yes, I can wait, Shila, for the other ones that are in line. I feel that there are a couple of great comments here, but I will wait for my turn.

Shila Blend

Michael.

Michael Chiang

Tara, I have a comment about interoperability and one about privacy, but maybe I will talk about interoperability for right now because it seems to be what we are focused on. I do not know enough about each of them to really know where we are compared to where we want to be for each of these bullet points, but I feel like one common thread is what is the combination of carrots and sticks that ONC could or should be using to drive the community toward interoperability in each of these areas? I just hope that can be something that crosscuts all of these other things that we could be doing, maybe with other agencies, other parts of government, to push the community forward.

Shila Blend

Great comments. Thank you, Michael. I am going to go to Anna next, but just quickly, we do have some comments in the comment chat. There was a comment regarding the idea of changing it to lab test orders, enabling and sharing across all relevant parties, talking about that for pharmacy and payer, and also, potential value with describing the content areas and then user creation or user categories, and how the content areas apply to each user category. This is a great discussion, thinking about how best to format this and the most efficient way of going forward. Anna.

Anna McCollister

There are a number of things I would like to bring up as potential topics that I think need to be pursued. I was going to bring up some of these under the patient access to information, but I want to concur with Ike's statement about individual access and what are the things that have become increasingly apparent as somebody who is a patient, works as a consultant with different companies who are trying to use Individual Access Services (IAS) and is embedded deeply in the Centers for Medicare & Medicaid Services (CMS) health ecosystem is that IAS is not working and we need to figure out why IAS is not working. Everybody is focused on patient matching. I think that is part of it. The reality is, we do not really have any benchmarks. We do not really have any metrics around what the specific roadblocks are, but we are pretending that this is an exchange purpose that exists, and then we are just waiting for fairy dust to happen to make it work. The reality is, it is just not working, which is one of the reasons that a lot of different apps and tools are trying to put everything through the treatment exchange purpose. I also believe very strongly we need to create a lane for research as an exchange purpose and define exactly what that means.

I have voiced that on HITAC meetings over the past couple of years, but it has become more and more apparent to me that IAS is a lovely thing that was written into the Trusted Exchange Framework and Common Agreement (TEFCA) process, but it is not something that has been taken seriously in terms of implementation. We need to find a way to make it work because right now, providers are just not allowing apps to have access to the data.

Shila Blend

Thank you, Anna. Great comments. Eliel, we will move to you.

Eliel Oliveira

Yes, thanks, Anna. I totally agree on the matching and record linkage process, which I think, yes, the IAS is a great new advancement for us to be able to identify someone, which I think is well developed, but the process of actually linking someone to many different types of data sources is tricky. I say that coming from a health information exchange that uses mass-to-patient index technologies to match, and it is not something that we rely on 100% of the time. We have to have high levels of controls to be able to make sure that the matches are accurate, right? I know CMS released a guide on how to do that linkage and matching, but I agree with Anna. That is something that we should probably have a definition for. To be honest, I think you all know that we had a prohibition for a long time on creating a national patient ID, so we do not have one. Now that prohibition has been lifted. It did not create anything, but I think it is maybe part of our group here to discuss what we need then, so that we are not having this challenge of matching records forever and ever.

Anna McCollister

Has the prohibition been lifted? I guess I missed that one.

Eliel Oliveira

It was a few years back, but it did not provide any solutions. The prohibition does not exist anymore. Now, that was just a comment back to you, and I think I want to highlight also a comment from Steve Eichner related to different types of providers, right? I know we are simplifying the requirements for certification, which I think is great, but at the same time, so two things that come out of that, right? One is the types of providers, maybe we want to be more specific about the types of providers that we want to require certification because as you guys know, we only have hospitals and primary care providers under the Meaningful Use and many other types of electronic health record (EHR) vendors that are used by other types of providers do not fall under that, and it is very hard to then integrate. Many of them do, they work well, but I think it might be important to highlight that, for instance, behavioral health, post-acute care providers, and other types similarly do not necessarily have EHR vendors that can interoperate as we would want them to, like the other hospitals and primary care providers.

I think maybe we want to not in discussion be that specific. Finally, I think another point here that I think we talked quite a bit on the CMS side that I think for privacy and security might be important, and which also I think in the

new revisions of our Health Data, Technology, and Interoperability (HTI) rules that it is logging, which I think we need some national standard to define how logs are created by electronic systems, and how they can be mined so that we can find out who uses what and when, and I think that could fall under the privacy and security aspect. I will stop there, and I think, Hans, you have your hands up.

Hans Buitendijk

Yes, I want to respond a little bit further or add to the conversation around IAS provider matching, etc. I think it would be a good topic on interoperability to have that perspective that cuts across all the interoperability, particularly where the party involved is the consumer, the patient, the caregivers, and what is still needed to make that a seamless experience. I think it would be a good topic to add and contemplate, where some of the considerations are consistency, whether it is CMS, TEFCA, Health Information Exchange (HIE), or otherwise, point-to-point, how can that all work in a consistent fashion, because not everything will be immediately connected in the same place in the same manner, but the approach should be the same. I think that would be helpful to discuss and recognize the roles of identity management all the way through matching, the ability to validate whether the information that was received is indeed accurate per the source.

There are a number of things that can be put in there. Whether it sits under interoperability or privacy, security, they all are going to be dependent on that and patient access. It is all going to sit around that, but we need to look at it across the board. As far as that, I had the same reaction as Anna: Is the prohibition lifted? I believe that it was reduced in that some money can be spent on research, but not on the actual implementation of a singular identifier, but that would be interesting as to what that would be. Either way, identity management cannot live separately from matching and vice versa, so it would be a great topic to include here explicitly.

Shila Blend

We will do one more comment here. Ike?

Steven Eichner

I think in relation to access control or identity management, we really need to think about it in terms of access control, as we look at the potential for multiple people affiliated with a particular patient to have access in different ways to data, whether you are looking at a parent of a child or looking at an adult providing support services for their parents. What does that mean as we are looking at expanded access to data? I think about it, my mother is in her 80s and was in town for the last couple of days, but it made me recognize that I need to be more engaged in some of the care that she is getting, since she lives 1,000 miles from here. How do I get access and maintain access appropriately to some of her data without creating an additional burden on her or her care providers? I think that part of that identity management needs to be access control and access management to patients and their caregivers. It might be a way of looking at it or framing it, or patients and their families.

Shila Blend

Thank you. The team will take this back as feedback, and we do have another meeting where we will discuss more with the updated feedback, but in the interest of time, I am going to move on to the privacy and security portion. Moving down to there, as you can see under the privacy and security on priority target area, the three topics we currently have are improving transparency and responsible secondary uses of health data to secondarily improve privacy consent and patient control of health data, and finally, the governance of AI and emerging technologies. Do we have any feedback from the group or any additional thoughts for additional comments, Ike?

Steven Eichner

Yes, I think it is important that we recognize that order becomes really relevant here, as we just were talking about access control and access to limits or control of data. I think it is really important to discuss patient control of data before you start talking about increased transparency and responsible secondary uses of data, which are really tied at the hip, I think, as to who is controlling the release of data for what circumstance.

Shila Blend

Do you think the first topic on there should be patient control of data?

Steven Eichner

Or broader control of data because it is great to provide increased transparency and secondary uses, but all those uses and things should be managed in the context of what the patients want their data to be used for, because it really is their data, and that should be part of the framing conversation.

Shila Blend

We have noted that. Thank you. Any other thoughts on privacy and security? Anna?

Anna McCollister

Again, I just want to concur with Ike. This was on my list of things to bring up. I mean, we are now at a point where we do have technological capabilities to do much more granular levels of consent and transparency about who actually does have access to providing transparency to patients, but actually, who is accessing their data and how that data is being used, whether it is identifiable data or it is de-identified data. We give a lot of latitude to the data holders under the Health Insurance Portability and Accountability Act (HIPAA) to de-identify the data, and once it is de-identified, you can do whatever you want. The reality is, it is never really de-identified. It is super easy to knit it back together with tokenization and create an incredibly impressive dossier of health and consumer tracking data, so that the only people who cannot get access to those dossiers are the patients. Anyway, so I think the fallacy, the computable consent through technical means at a more granular level, we have moved beyond that as a sticking point.

I am not saying it is easy, but I am saying it is doable, and it needs to be prioritized. Secondly, one of the things that has really come to my attention and I have been focusing on lately within the context of privacy and consent, a couple of things, but one is that the consent that patients sign with providers is a legal document meant to protect providers. It is not real consent for patients. It is not presented in a way that you are actually able to read it and cohere it before you sign it. It is given to you as you are signing up for an appointment, and maybe you are running late, or the doctor just needs to get you in. You just sign everything so that you can make it to the appointment. I have experienced this recently. Again, through the CMS health tech ecosystem, there are all these discussions about how patients cannot trust these apps to be able to access their data because they do not know what is going to be done with it.

They have to be driven back through the provider portal in some way, shape, or form to actually give more granular consent through the provider. The reality is that patients are never really given any kind of trustworthy consent processes with their providers. That is something I feel like we need to provide some leadership on and say, "Enough already with the legal CYA. If you say you are concerned about patient privacy and security, give us some evidence that you actually are, because right now, I am not seeing a lot of it. Just a private pet peeve and just based on very recent personal experience, I go to MedStar, and a lot of my providers at MedStar, I have a lot of data there. I was notified, I do not know, like a month ago, that there was a data breach in October that included my Social Security number, date of birth, phone number, home address, and my medical information.

All of that is now on the dark web. I actually already knew that because I have a credit monitoring service that has been telling me that since October. It waits, what, four months, five, six months, whatever, before I hear anything from the provider whatsoever. Their response to it is to give me free credit monitoring services, but that's not going to do anything. I am already getting credit monitoring services that are informing me of how completely inadequate their notification is. We have to come up with far more serious penalties for providers when they get hacked and when it is released into the dark web, because it is just this whole, "We are going to provide you with free credit monitoring services," which is absurd. It is insulting. When you couple that with concerns about providers wanting to protect patients from other people having access to their data discussions, there is just so much kabuki theater happening. It is ridiculous. Anyway, I will stop.

Shila Blend

Thank you, Anna. Very, very important details. I am sure we will be delving into them further as we discuss how to improve privacy, consent, and control. Michael?

Michael Chiang

Tara, I think my comment is very similar in spirit to Anna's and Ike's, which is that I think a lot of health data that are being used right now in the real world are actually not consented to at all because they are de-identified. They are de-identified legally and used for whatever they are used for: treatment, payment operations, research, and administrative stuff. I think that is something that is confusing for the communities that I work with because people are always wondering, "Well, is creating this dataset okay?" Sometimes, different institutions have different decisions about whether it is okay or not when presented with the exact same data. Is this thing de-identified or not? I think that is a real barrier right now. Everything that is happening right now is all completely legal, but it is just different. Everyone is interpreting the rules differently about whether it is okay to build this dataset. It would be really tough to get some guidance to the community about what the rules are for what constitutes de-identified data in 2026, and whether patient consent is required for using a piece of data in 2026.

Last thing I will mention is I was literally just in a meeting about United States Core Data for Interoperability (USCDI)+ with some folks from the ONC USCDI team. This topic came up. That may be an avenue for collaboration within different sectors of the United States Department of Health and Human Services (HHS).

Shila Blend

All right. Thank you. I know we are going to start getting low on time here. Hans.

Hans Buitendijk

Thank you. On the topic of privacy and security, and particularly privacy and consent, I really appreciate that the topic is on the list. What I think we could benefit from is understanding, as part of the discussion that we are going to go into, what is actually there and what is actually not there. What are we missing? The need for granular controls is increasing, but the ability to do so consistently across all the data holders so that, from a patient perspective, the data is consistently shared or not shared where it should be, according to the privacy and consent rules, there are still a fair number of gaps in what is needed before that can be fully done. I think having that part of the conversation when we go through it, recognizing where the missing parts are, where the gaps are, how much can be achieved before they are filled, and what cannot be done until they are filled, would be very informative in providing recommendations on where to go with this, what is next to make this work.

Shila Blend

Thank you. Eliel, I guess we are at you.

Eliel Oliveira

Yes. I wanted to offer one suggestion, I think, on privacy and security, and we can have a bit more discussion on that. I think you all know about some of the situations of misuse of data for treatment within TEFCA. I think that relates a lot to a few things that we have here, including what I was talking about in terms of standardized logging. I think those cases are going to probably take years in terms of how those class action lawsuits are going to run. I think, yes, ways to track down and log who is using whom for what purpose is one thing that becomes quite important. How to frame that specifically in the case of TEFCA or others, that might be a discussion point for us to extend when we start talking about the topics. Steve, you have a comment as well?

Steven Eichner

Yes. I was just going to say, the other piece of disclosing data is really looking at the potential for including accountability for those data disclosures, so that patients understand to whom their data has been disclosed for what purpose. I just put a kind of human touch on it. I always like to point myself as an example of re-identification. I am the only male in Texas above the age of 45 with my particular rare condition, which makes it really, really difficult to de-identify me. I am perfectly happy in most circumstances to be identified, but it does provide a real-world example that identification really can be a challenging thing, or de-identification can really be a challenging thing that can affect people's lives. How do we manage it?

Shila Blend

Yes. I will add on yours before moving on to the next topic. One thing I see when looking at rural health research and the things we deal with in North Dakota for de-identifying is that it can be a challenge, especially in rural, very small populations. When you get into very rural areas and certain things, it is very easy, even if you de-identify, to be able to identify, so it is definitely something that needs to be considered, as well as the example you mentioned. In the interest of time, I think we have about maybe 10 minutes before I give it back to Tara to wrap up, we will go to the patient access information and get some feedback on that. The first topic on there is improving the use and sharing of patient-generated health data. Secondly, improving the usability of health data. Third, improving price transparency and consumer-driven affordability. Fourth, to address information blocking and enforcement. Finally, to improve access to clinical and device data. Open to comments on patient access to information from anyone. Anna?

Anna McCollister

Yes. One of the things that has become more and more of a concern for me as I get access to more and more of my data through different apps that are getting me data through, like TEFCA or Care Quality, etc., is the prevalence of errors. Sometimes they are not even errors. They are coding choices that a clinician has made because it is easier to get something reimbursed if you put down a code. I have seen diagnoses that I have never been given, but if I trace it back to the physician who gave that diagnosis, I have seen it in my data; it is like, "Oh, that is interesting." If I trace it back to the physician who actually made that "diagnosis" or entered that ICD-10

code, I understand they were trying to get this particular imaging test covered. It is a lot easier to do that if you gave me this particular ICD-10 code. There are others that are more overt errors. I have heard so many different stories from patients.

Somebody's a mother who was not able to get transitioned into care because she was diagnosed with a case of Methicillin-resistant Staphylococcus aureus (MRSA), and it was not. It was an old thing, but the way that they coded, something about her situation, so if they put it as having MRSA, they were better able to get access to a particular treatment. I do not remember the specifics of it, but it made it difficult for this person to get access to her assisted living facility. I have seen others that are funny where men are coded with menopausal related symptoms, etc., because it helped them get access to something. It can create serious issues. Sometimes it is humorous if it is a human doctor who is actually reading it and taking a look at it. As we move towards the institution of AI in the clinical setting, these types of errors in data or specifically chosen ICD-10 codes to justify treatment justify access to a particular treatment or diagnostic can cause real issues.

There needs to be some degree of standard, a fidelity of data, before it actually gets incorporated into some sort of AI system. Otherwise, we are going to end up with more errors than we are preventing. Secondly, one of the easiest ways to do that is to make it really easy for patients to access, review, and fix their data. The processes that are currently in place do not work. I have done it with my providers. I never get any feedback. I never get any response to my request for an error correction. That is one thing that is a significant issue that needs to be addressed. It is not taken seriously. I know it is not easy, but the reality is that it is not just a human who is going to be reading this data. We are moving very quickly into a situation where this is all going to be read by a machine or an algorithm that will not be given the ability to make decisions or make recommendations that may not represent what is in the best interest of the patients.

One of the things that I have become more and more aware of, or more and more sensitive to, is the fact that I feel like ONC and HHS need to do much more investment in incorporating patient input into these kinds of decisions. It has not been something historically that has been prioritized by ONC, by CMS, by other things. They make rules or Requests for Information (RFIs) available for anybody to be able to comment. The reality is that most of those comments are done by industry, by people who are paid to pore over these extensive documents and to give their expert opinions. "Patients" do not have time to do that. Some of us do it anyway as a volunteer, but we are not getting paid for the substantial amount of time and expertise that it requires to be able to read it, understand it, and get input. The idea that we are making it possible for patients to give input into regulatory decision-making at any level, I would argue, but particularly when it comes to things like health IT and health technology, is absurd.

It is window dressing. As we get into more and more sensitive discussions around privacy, security, consent, AI, etc., there needs to be a much more concerted, deliberate, and thoughtful approach to getting patient input in a way that makes it accessible to enough patients that you can get a diversity of perspectives.

Shila Blend

Thank you, Anna. Those are very helpful comments. I agree with the AI comment because, as they have said, "Garbage in, garbage out." If the data is not clean, we have wrong codes, it is going to snowball and lead to more and more issues as more of that is incorporated. That was a great comment to bring up. Eliel?

Eliel Oliveira

Yes, I agree as well. If it is not complete data, that is another big issue, right? We need to get all the data of one individual to be combined so that you can actually have intelligent AI use the complete data. That is where I had a point. Here is the last bullet we had on patient access to information. It says, "Improve access to clinical and device data." My personal opinion is that it could be expanded to improve access to health-related data of all types, not just clinical and device data. We could have social data. We can have all the types of health-related data that affect someone's life, which I think would be important. Maybe we want to consider some reorder, which we do not need to discuss here today, because I think access is the key first step. Then usability might be another one, which Anna touched on, and then we can reorder them by priority and importance. Steve, I know we are running out of time quickly.

Shila Blend

Eliel, we are okay on time. I checked with them, and they told me we are okay to keep discussing for a bit yet.

Steven Eichner

I will also keep it short. I think another aspect of AI and patient use or patient access data is including patients in the loop about both AI development and its utilization. As I mentioned earlier, I have got this really rare condition. One of my concerns personally is how that information is being incorporated into AI so that, as we look to AI decision-making about making recommendations about treatments, is AI including the diversity of health information that is out there to recognize conditions like what I have and lots of other ones, and accounting for that as it is making a recommendation about a care plan?

Shila Blend

Thank you. I am going to have Michael go real quick, Anna, since he has not talked about this one yet. Michael?

Michael Chiang

Shila, my comment was actually in follow-up to a comment from Anna's, ironically, which is one of her comments, that stuff ends up in the medical record that is not exactly true because it was selected, for example, in Anna's example, for billing rather than for medical care. I do agree that that happens quite often. I just wanted to make the comment that under interoperability, one of the topics is improving data quality and standardization. To me, that is where that really belongs. Having said that, that bullet point, to me, in a way, covers that topic. What I am going with that is that I think improving the quality of data is really hard. I am not sure how to go about doing that. If there are cases where we need additional research to figure out how to improve data quality or, for example, whether there are automatic ways to review and identify mistakes, and if NIH can play a role in doing some of that research, if that is an avenue of collaboration, I would love it if that ends up somewhere in the report. That is basically my comment.

Shila Blend

Thank you. Anna?

Anna McCollister

I will try to make this quick because I have talked about it a lot in prior report workgroups and quite a bit over the past 15 years. We have to be able to get sensor-based data into the EHR, particularly within the context of AI. Whether the issue is data quality and accuracy or deliberate miscoding to support reimbursement, that to me is terrifying when you think about incorporating that into an AI system and what might come out of it, particularly if I am unconscious. The idea of somebody making a decision that does not include my continuous glucose monitor or my Continuous Glucose Monitor (CGM) monitor data or my insulin pump data, to me, if that is not incorporated into some sort of automated decision-making process with AI, I do not have the slightest idea what might come up. I have been in a situation like in the ER, where I have been in diabetic ketoacidosis because of a device failure. I overheard the ER doc giving insulin dosing recommendations.

Fortunately, I was still conscious enough at that point to be able to stop them and say, "If you give that to me, it will either kill me because of super insulin sensitivity, or it is going to make my blood glucose drop so dangerously low that you are going to have to pull me out of a coma. Also, that could cause brain damage, cardiac arrest, etc." If that data, which is freely available on my phone or in the cloud in any other way, could be incorporated into a decision-making matrix, if those sorts of decisions are going to be automated, then it needs to have the most granular data available. Right now, the idea of just doing AI based on basic Randomized Controlled Trial (RCT)-based clinical standards is terrifying because there is so much variability in the Type 1 diabetes community, and that is just with the disease that I live with. I am sure it is the case with lots of other things, too. It has to be prioritized, again, as we are moving more and more breathlessly toward incorporating AI into the clinical setting. Maybe not as brief as I thought.

Shila Blend

It is fine. You are good. All the details because the Accel team did tell me that they expect us to have time. We can discuss up to 4:25 if we need to. We can go back if anybody has additional comments. Now that we have made it through everything, if anybody has additional comments that they have thought of, some of the other ones. Hannah has a comment. You have arrived. Do you want to jump on and talk about that interoperability suggestion you have?

Hannah Galvin

Thanks, Shila. I apologize for being late. I am hearing across the industry right now concerns regarding trust in interoperability in the various frameworks, in TEFCA, and in care quality. I think restoring that trust, restoring the T in TEFCA as it were, is really important. Actors are not going to join these frameworks if they do not trust them. I would suggest a priority target area, not just stating that we want to advance these many areas of interoperability,

but improving the overall public trust in interoperability, as I think that is an area that is a prerequisite for achieving the type of nationwide interoperability that we envision. I will just put that up for everyone else's consideration as well.

Kikelomo Oshunkentan

Just if I can piggyback off of you, Hannah, is the lack of trust there in solely residing within the patient aspect, or is it in the provider aspect as well? Can you speak more about the distrust and what you are seeing and hearing, because it may be in line with what I am seeing on my side? I am curious as to what that looks like for you, what you are hearing.

Hannah Galvin

I think there is a lot of distrust on the provider side after some of the issues that have happened with particle health and others. As the frameworks are scaling, as TEFCA is scaling quickly, I think there is a lot of concern about whether this is being done thoughtfully, and providers trying to be advocates for their patients and making sure that data is being exchanged thoughtfully in a way, but also that actors are representing themselves appropriately and using the data appropriately. I am not saying that everybody's a bad actor or that there are bad actors necessarily, but sometimes everybody's moving so fast that they are getting access to some data that they may not need access to or should not have access to because everything is moving so quickly and scaling so quickly. I think there is concern about that. The TEFCA Standard Operating Procedures (SOPs) are coming fast and furiously. I think that is of concern. We want to provide patients access to their data.

We want to be scaling, but I think there is concern when we see some of the issues that are happening about whether we are scaling in the right way. This is all contractual. Then, what happens when the contract is broken? Who is adjudicating that? Do they have the teeth to adjudicate that well? I think all of that is up for consideration, especially when the new actors are considering joining the framework as well.

Shila Blend

Great discussion. Hans?

Hans Buitendijk

Yes. I would like to make some supporting comments on the term scalable, which trust is frequently attained in one-on-one relationships. What we are now trying to do and we have been working in a variety of different ways. This is not new. Any HIE that you start to connect with, the general term HIE, the more you start to scale, be a network, be part of it, you build on the trust that you establish, what it can be used for and with a larger mix of purpose of use or actually the absence of purposes of use where perhaps the parties may have, generally, a right to access, but not necessarily through the access purpose that they would like to get it through, is not available yet. What do you do? I think the scalable aspect of the topic is critically important to look at it that way and understand what is there, what can be further done to enhance that, so that we can rapidly work on that. There are certainly elements progressing in that space. Some of the SOPs being talked about would relate to vetting. How do you do that better?

How do I establish that upfront so that you can work with it, but it is then also the other side, what if that still is broken? How do you deal with that? It is a very complex area. If there are comments to be made, good topic, very specifically around the scalable part of it, what can make that work better that we can rely on there?

Shila Blend

Before I go to Anna, I am just going to jump on your comments that I agree with, especially as the health information exchanges are evolving into more of the health data utility models, going from exchange of information, of utilized information. A lot of these topics with interoperability, privacy, and different things are very important as we move forward. Anna?

Anna McCollister

Yes, I just wanted to concur with the discussion and thank Hannah for raising it. It is a significant concern, and I do think that both you and what Hans emphasized are really part of the problem. I have not been involved in the governance of TEFCA at all. I have a little bit of insight into it as a member of the board of Sequoia, but it is very limited. I do not have time to sit in on all the monthly TEFCA meetings. There are many things that are happening of which I am not aware. My sense is that so much of the effort around TEFCA was really focused on standing it up and getting it up and going and becoming a functional thing. Now, we are at this natural point in development

where it is like, “Okay, so it is operational. How is it working? What are the holes? What are the things that need to be fixed? What are the things that need to be addressed?”

I feel like ONC really needs to focus on contributing resources and devoting resources to making sure that there are processes to validate the participation. Also, to ensure that data is actually being exchanged, that there are not broad blocks placed by providers to stop data from going to any kind of third-party apps, because there are third-party apps that are using IAL2 and AAL2, and they are still not able to access data. That is ridiculous. Anyway, there needs to be some degree of enforcement in both of those directions, which is part of the whole let us make IAS real discussion that I brought up earlier. If providers have concerns about who is getting access to their patient’s data, we can talk about having real provider consents instead of just a legal CYA document and coming up with ways and metrics of assessing how the data is being exchanged, what is being exchanged at what rate, who is not letting data go through, and then what is happening to it once it does go to these apps and tools and third-party technologies.

Shila Blend

Thank you, Anna. A lot of great discussion. We still have another 10 minutes or so. If anybody has any more thoughts on interoperability or anything on privacy and security or patient access to information, again, the Accel team and HITAC are going to take this back and update this. We will have another chance to validate it and discuss it also at the next meeting. Any other thoughts or discussion?

Eliel Oliveira

I would love to share a couple of thoughts there, Shila. I really appreciate the comments around trust because I believe that it is something that is hard to acquire, but when it is lost, it is even harder to recover from. I think the example that comes to mind here is for human subjects in research. I think if you are familiar with the Belmont Report, which is available at the HHS website, on how I think the background, the history here, the Tuskegee syphilis study that basically targeted individuals inappropriately, it was a terrible example of abuse of trust that then led to the creation of the report and the regulations that we have today to protect human subjects in research. We still have not recovered. Even though that report was written in 1979, we still have a very hard issue recruiting African-American subjects in research because of the loss of trust in the Tuskegee study. All that to say that it is a good time for us to address trust in data sharing because I think, just like in research, we could see situations here that are very high abuse that would then be much harder to recover from in the future.

Thank you, everyone, for your comments on that front. Steve, I think you had your hand up.

Steven Eichner

Yes, I was just thinking about the mechanics of interoperability and ensuring that we are continuing to build a world where we are using things like USCDI and other frameworks, so that we are looking at terms in common and ensuring data is both semantic and functionally interoperable.

Shila Blend

Yes, thank you for that. If there are no other comments, I thank you all for the great discussion. You brought a lot up that definitely I know the team will take back to Justin, as I said, for further discussion. I will hand it back to you, Tara.

Public Comments (01:07:09)

Tara Porter

Perfect. Thank you. Can we go to the next slide, please? While we are waiting, we will now be opening up the call for public comment. 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 on the phone only, you can press star nine to raise your hand. Once called upon, you can press star six to mute or unmute your line. I am not seeing any raised hands. Do we have anybody on the phone only who would like to make a comment?

Accel Solutions

No comments at this time.

Next Steps and Adjourn (01:08:06)

Tara Porter

Thank you. If you could please go to the next slide, just as next steps, just to refresh everybody on the work plan, as Shila mentioned, we do have one more meeting devoted to continuing the discussion on this topic list and validating the list. Just going back to a question that we had early on about the number of topics to be discussed, just from a framing perspective, there are two meetings dedicated to each target priority area for a total of six meetings. You can just consider that when framing the discussion, once you identify those topics, you will have two meetings to do a deep dive on each of those topics to come up with those gaps and opportunities for each of those. We look forward to seeing you all at our next meeting, which is currently scheduled for April 27 from 3:00 to 4:30 p.m. Thanks, everybody. We can adjourn.

Questions and Comments Received Via Zoom Webinar Chat

Hans Buitendijk: Would it help to change "Laboratory interoperability" to "Lab tests/orders/results interoperability" to enable sharing of kind of data across all relevant parties?

Hans Buitendijk: And if so, do the same for Pharmacy and Payer?

Hans Buitendijk: +1 Steve

Hannah K. Galvin: I was late - I apologize. I would like to suggest adding a piece to interoperability of Improving public trust in data exchange. This is something I've talked with Sequoia about and is one of their strategic goals as well.

Elieel Oliveira: <https://www.tc.columbia.edu/institutional-review-board/irb-blog/2020/the-history-of-the-belmont-report/>

Questions and Comments Received Via Email

No comments were received via email.

Resources

[AR WG Webpage](#)

[AR WG - April 13, 2026, Meeting Webpage](#)

Transcript approved by Tara Porter, HITAC DFO, on 4/17/26.