Health Information Technology Advisory Committee

Annual Report Workgroup Virtual Meeting

Transcript | August 26, 2024, 12 – 1:30 PM ET

Attendance

Members

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

Members Not in Attendance

Sarah DeSilvey, Gravity Project
Anna McCollister, Individual
Kikelomo Oshunkentan, Pegasystems

ASTP Staff

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

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

Seth Pazinski
Good morning, everyone…or close to afternoon, everyone. Welcome to the Annual Report Workgroup meeting for the Fiscal Year (FY) 24 cycle. I am Seth Pazinski. I will be serving as your Designated Federal Officer for today's call. Just a reminder that all workgroup meetings are open to the public and public feedback is welcome throughout. Members of the public can type their feedback in the Zoom chat feature throughout the meeting and we also have time scheduled for any verbal public comments for those interested towards the end of our agenda today. We are going to kick off the call with a roll call of the workgroup members. When I say your name, if you could, indicate that you are present. I will start with our co-chairs. Medell Briggs-Malonson.

Medell Briggs-Malonson
Good morning.

Seth Pazinski
Good morning. Eliel Oliveira.

Eliel Oliveira
Good morning, everyone.

Seth Pazinski
Good morning. Hans Buitendijk.

Hans Buitendijk
Good morning.

Seth Pazinski
Good morning. Hannah Galvin.

Hannah Galvin
Good morning.

Seth Pazinski
Good morning. Jim Jirjis. Anna McCollister? Shila Blend? Sarah DeSilvey? Steven (Ike) Eichner?

Steven (Ike) Eichner
Morning.

Seth Pazinski
Thank you. I did get a message that Kikelomo Oshunkentan will not be able to join today's call. Finally, Rochelle Prosser.

Rochelle Prosser
Good morning. Good afternoon.

Seth Pazinski
Good morning. Thank you all. Now, I will turn it over to Medell and Eliel for their opening remarks.

Opening Remarks (00:01:41)

Medell Briggs-Malonson
Thank you so much, Seth. Good morning. Now, I guess officially good afternoon for those of you on the East Coast. It is always a great pleasure for all of us to get together as the Annual Report Workgroup and I am very excited about all the progress we have made to date. One of the things that we will be doing today, and we will review that a little bit more in our agenda, is we are wrapping up our crosswalk and then we are going to have a very exciting conversation about some of the other what I like to call threads or common strains throughout many of our various different target areas. We are looking forward to another very engaged, as well as very enlightening, Annual Report Workgroup today. I will turn it on over to my wonderful co-chair Eliel.

Update on Workgroup Plans (00:02:27)

Eliel Oliveira
Thank you, Medell, and good morning or afternoon, everyone. It is great to see all of you again here. Like Medell said, we are excited that we are in good shape with the plan and in the final stages of finalizing our crosswalk work. This is exciting. As you will notice, in the beginning we had a full task ahead of us but I think we are making great progress to have a draft report coming up soon. Thank you so much for joining. We are almost there. Really looking forward to the discussion today to address all of the final points we have in our crosswalk.

With that said, I think you see our agenda here. We will eventually, after we discuss our crosswalk, are going to jump into the public comments and then we will define next steps and adjourn for our next meeting. With that said, next slide please.

All right. A little bit of update on our work plan. Here, we are. Today is August 26th. We are in our last step of developing the crosswalk topics. After that, we are going to start developing our draft Annual Report by next meeting, September. Then, a couple of weekends after, we are going to review that report again with comments. In October, have that draft report reviewed at the HITAC meeting, the October meeting. Then, eventually, update the final report for approval. In December, would be sending it to our coordinator and eventually to United States Department of Health and Human Services (HHS) and the federal government, our Congress. That is where we are.

On the next slide, you should see a bit more on the full HITAC committee meeting. Again, we are meeting this September, and by the October 17th meeting, we will review the Annual Report draft, and by November we are going to approve the final report for transmittal. Next slide, please?

Here, we are on the next steps of the Annual Report development. We are going to review the draft report this September and present in October. After any edits, we are going to vote to transmit to the National Coordinator in November and the Assistant Secretary for Technology Policy and Office of the National Coordinator for Health Information Technology (ASTP) forwards the final report to the Secretary of Congress and posts it on healthit.gov. Hopefully, before Christmas we have this posted. Thank you. Next slide, please. Here we are now with the discussion again on draft crosswalk topics where we left off. I will pass it on to Medell to take the lead on that and look forward to hearing your comments. Thanks Medell.

Discussion of Draft Crosswalk of Topics for the HITAC Annual Report for FY24 (00:05:50)

Medell Briggs-Malonson
Thanks, Eliel. As Eliel mentioned, have a wonderful agenda today. Then, after we go back to the crosswalk, we will then go into a discussion about artificial intelligence throughout all of our various different target areas. One thing we do want to do is…our HITAC meeting was incredibly wonderful and we had some great feedback from some of the HITAC committee members that are not a part of the Annual Workgroup. We want to add some visibility to

some of the new changes we have made. Accel, if we can go back into interoperability, privacy and security, and then we are going to start talking about patient access. We want to show the workgroup some of the additional mild changes that we made based off of some of the feedback we received from HITAC as well as there was another bit of feedback we received, especially in the privacy and security area.

Thank you so much. I believe this is underneath our privacy and security. These were all of the various different changes that were made before that we all discussed, including when others were here, such as Deven and all of the different feedback from even we as a workgroup. There is one change that we added. If you look into the proposed recommended HITAC activities, we are going to expand upon this. We did receive some recommendation, I would say, quasi from the public but also from our former co-chair of HITAC and former co-chair of the Annual Report Workgroup, was thinking about neural data. We know there is a lot of neural data coming out with neural links that are being put forth. There are a lot of different entities, and even the industry, discussing the privacy and security of this new neural data.

We decided, because we are a very forward facing workgroup, as well as committee, that as we are thinking about privacy and security of all of our various different health data to also include neural data as some of those sensitive health data elements. Just wanted to bring that in so everybody saw that. We can definitely discuss that a bit more when we do go through all of the various different additional revisions that have been added to the crosswalk from the HITAC full committee as well as from others All right. Any thoughts or questions about that before we move on? Yes, Hans, I see your hand.

Hans Buitendijk
Thank you, Medell. A question that I have. No concerns with including neural data, so I will upfront that. If we are going to enumerate examples, why are we listing this one and not a couple of other examples as well that are forefront on people's minds or otherwise that are also examples of sensitive data? Would it be helpful to list a couple of different ones of which the neural data is included so that people understand what sensitive data could be? I am just trying to understand why we are calling this one out but not others even though others are similarly important **[inaudible – crosstalk] [00:09:02]** perspective.

Medell Briggs-Malonson
I think what you are bringing up is a really good point. I know we have been discussing a little bit about trying not to call out specific areas because it almost seems like it is prioritizing neural data. I think I know some of the other data points but it would be great to see some of the other types of categories you are thinking of. Maybe what we can do is refine this so that it is very inclusive in our crosswalk but then we, of course, expand upon that more in the report. I think those are all really good ideas and let us think about how we can incorporate some of the various different areas we want to be sensitive to while also showing that there are multiple different types of data elements we should be thinking about as we move forward with privacy and security. Yes, Hannah?

Hannah Galvin
Thanks. I will add to that. I cannot remember how neural data specifically came up but historically, and in the Health Data, Technology, and Interoperability: Patient Engagement, Information Sharing, and Public Health Interoperability (HTI-2) Proposed Rule, ASTP focuses on sensitive data that is defined in other legislation. I do not know that neural data…while I think a lot of different types of data can be considered sensitive data, I do not know if that is specifically defined in other legislation, which is why we have tended to start with sensitive data that is previously defined like reproductive health data, substance use disorder data, some of those data elements that are defined in other legislation. Not that other types of data cannot be sensitive data. They certainly can, but starting at a place where these types of data that have previously been defined in legislation seems to be more aligned in terms of what ASTP is doing in policy currently.

Medell Briggs-Malonson
I agree with that, too, Hannah, that there has been some items…the idea behind this…I am looking at all the various different comments. Yes, neural data right now is really being linked to the various different devices that are being inserted. We know that, for instance, there some industries, such as underneath Elon Musk's industry, where they are actually trying to collect various different health data in these various different true biologic neural links. It has not been defined by, to your point, Hannah, by ASTP; however, we as HITAC, as well as the Annual Report Workgroup, have the flexibility to even still bring up various different recommendations to consider. Since we know there is a lot of emerging technologies right now, we are aware of them.

While it is not saying, "This is what ASTP and the other agencies absolutely have to do," part of our charge is thinking about how we support ASTP but also making sure that we are also forward facing as much as possible just for that consideration. That is what I would say about that. This is why wanted to bring this up for us to drill into, to see what we actually wanted to do in that regard. Yes, Hans.

Hans Buitendijk
Thank you. I want to follow up a little bit on Hannah's comments that clearly where privacy rules by jurisdictions we need to have clarity what the scope of the rules are and therefore have a very specific need to define what is the sensitive data that is subject to those rules. What is the data, and then there are sensitivity flags around that if the data is contained in larger datasets. Agreed from that perspective, that it clearly needs to be part of the scope, whether it is neural or not, or other ones as well subject to privacy rules. Then, I think we still want to acknowledge in some fashion that on the other side, patients have opportunity to identify through their consent what data they would or would not like to share. That might not be part of those sensitive datasets subject to privacy rules, but still recognized.

I am not convinced we need to define sets for that but I think in the way that we talk about it we need to recognize there is sensitive data that is subject to privacy rules and there is sensitive data that is subject to patient rules, assuming they have been asked for and accepted. That set we need to understand very specifically the privacy rules, where we want the value sets around. Much more challenging for patients because I may come up with this data is sensitive for XYZ reason that is not a general reason for others but it is for me and it is accepted. It is much harder to predefine a set.

However, there is some work going on around defining templates on how you can get computable patient consents better defined from a piece of paper to computable. While those kinds of templates may not be full encompassing but they would then focus on the typical sensitive data beyond what is in privacy rules. There might still be a way to recognize that number of those things are a part of the scope as well because if we do not capture all of that we still are going to have holes in our ability to manage privacy rules and patient consent rules.

Medell Briggs-Malonson
Absolutely. All great points. All great points. That is why we are capturing all of these different thoughts. Hopefully, we can figure out a way in order to do exactly what you were mentioning, Hans. We have privacy and the consent **[inaudible] [00:15:01]** but then we also have the different types of data elements as well. How do we really define this and communicate this in a way that is very clear so that all understand but then also taking into account all of these various different types of elements that do exist and how we interact with them.

Let us think through that. I know that our colleagues will also help us think through that with the ultimate goal of what we are trying to do is protect sensitive health data, not only the current that is currently defined, but also thinking forward facing because the ecosystem is moving and changing so quickly. How do we ensure the appropriate privacy and security of our patients but then also thinking about that patient autonomy and their

consent of using various different data. All good points. Eliel, we will take your last comment and then we will move on to the other aspect of the crosswalk as well.

Eliel Oliveira
Excellent. I want to take us back a little bit on how we started on this specific topic. I still remember some comments related to the fact that we have Health Insurance Portability and Accountability Act (HIPAA) and then we have 42 Code of Federal Regulations (CFR) Part 2, and then we are clear on how to exchange data under HIPAA across covered entities in particular and whatnot. Then, with 42 CFR Part 2, it becomes tricky and oftentimes we decide not to share anything because we do not know the circumstance, if we are okay or not okay. In that kind of challenge it gets perpetuated with other types of sensitive data, like neural data or genomic data or so on and so forth. I think the idea we have here is how can we define, like Hans was saying, computable ways to be able to parse it out and make decisions on exchange data. This is going to be quite powerful for something like Trusted Exchange Framework and Common Agreement (TEFCA) and Qualified Health Information Networks (QHINs) to be able to feature out what can and cannot be shared at any point in time.

I just wanted to highlight that in view of this specific topic here. The gap is because there are state regulations, federal regulations, and some other levels that it becomes very tricky for anyone that is managing data, like QHINs, to make decisions on what to do. I hope that is helpful in terms of bringing back how we navigate some of the advancements here. Maybe what is proposed here is not a problem that we have there. I do not know that this becomes a priority for everything but I think there is even a way to maybe tier those specific areas to address this management of sensitive data. Do we attack mental health 42 CFR first, or do we want to go to genomic data next, and so on and so forth? That level of prioritization is going to become essential here to make progress.

Medell Briggs-Malonson
Eliel, all fantastic comments. I think those directly align with some of the comments that Hannah put in the chat. Bringing us back to the core and to the origins of how the topic even evolved. To both of your points of really looking at…again, we first started off with sensitive data as defined as this meaning not specifically but the larger categories because we know the importance of the interoperability for provision of clinical care. Then, we also know there is an emerging group of new data that is coming out and how do we actually go about making recommendations for that?

Maybe that is exactly what we can do, is say, “This is the larger domain we are looking at because it is the highest priority because it is here and it is now and it is commonly being used and here are the various different proposed recommendations to fill these gaps of interoperability of this sensitive health data,” while also recognizing there are some other emerging types of technology that are holding Protected Health Information (PHI) that we do also need to think about because of the sensitivity of the data that they may also contain. Maybe we can chat about that and maybe our teams can come back with thoughts and suggestions about that because I think what everybody has said is all very well taken. Thank you so much, everyone. Love the conversation. Let us jump quickly. We are going to go to patient access on the crosswalk.

Now, we will start on the areas that we have not started on yet. We have patient access to information. Hopefully, this is one of our last target areas that we are going to jump into and then we are going to jump into the next session. I will turn it over to Eliel. The next piece here, in terms of the topic itself, we were discussing and identifying patient generated health data. The gap that was identified was accessing patient generated health data (PGHD) requires special effort for providers and patients, including challenges in uploading to electronic health records (EHR) and controlling and directing one's personal data. PGHD devices and software developers are not subject to health IT certification but play a critical role in the ecosystem.

The challenge that is currently at play. Standards are needed to simplify incorporating PGHD data collected from health apps, wearables, devices, and other sources and to providers' existing EHR workflows. In addition, jurisdiction over patient device data spread across multiple federal agencies. More coordination and oversight are needed to prevent data silos. The opportunity we identified was to improve standards and metadata to support the incorporation of personal access and control of clinically relevant PGHD collected from health apps, wearable devices, both consumer and medical, and other sources. At least, right now, the proposed recommendations are to explore opportunities to use PGHD to improve quality measures and also evaluate opportunities to further standardize PGHD. We have discussed PGHD for several different Annual Reports now and it is still a priority for HITAC and the workgroup. Any thoughts, or revisions, or comments on this first topic? All right, Ike? I was like, "Wow, is this perfect? Are we all just moving on?" All right, Ike.

Steven (Ike) Eichner
I had unmuted myself, I just had not raised my hand. A little bit of wordsmithing perhaps, looking at some of the language we have chosen at the moment. We probably want to include interoperability standards. Not just standards, but looking at the concept of interoperability and looking at certification under Digital Analytics Program (DAP), not yet certified or not currently certified for interoperability. There may very well be other certifications, The United States Food and Drug Administration (FDA) licensing for example, or FDA reviews and approvals in that space. I am also not sure we want to constrain ourselves too tightly to wearable devices and apps. For example, a personal ongoing story. Trying to upload a picture of my wound on my left ankle to my primary care physician (PCP). Their patient portal does not include the ability to upload a Joint Photographic Experts Group (JPEG).

It is not there. Being able to do that, even at the invitation of the healthcare provider, would be really useful in coordinating care. I do not need to drive 45 minutes and take two hours off of work to drive to my PCP for them to look at my ankle for 15 seconds. That is not helpful. In this context of patient generated medical information, that counts as patient generated medical information, or should. I think we need to make sure that we have enough scope to include those kinds of elements as well.

Medell Briggs-Malonson
Wonderful points. Absolutely. Do you have a recommendation in terms of how we can modify that language?

Steven (Ike) Eichner
Yes. I think if we are looking at the opportunity piece, if we look at including interoperable standards. Not just standards but focusing on the interoperable. Again, looking at addressing the diversity of technologies that patients use because we also do not want to have a digital gap issue where patients have to have expensive equipment to communicate if there is a simpler, more efficient, and more cost-effective way of doing it. It might not be perfect but sometimes you do have to hit a little bit of that compromise.

Medell Briggs-Malonson
Wonderful. Okay. Thank you for that recommendation and thank you so much for your insight on that. Rochelle, I saw your hand up but then it came down. Any additional comments?

Rochelle Prosser
No. Ike summarized it for me when he hit the second topic. It was more having that flexibility within the language to reduce the patient burden by sharing images so we can use the telehealth option where applicable.

Medell Briggs-Malonson
Excellent. Wonderful. We will modify some of this language so that, again, it is more inclusive of all the various different clinical information and imaging that may be needed to be able to transfer directly to the various different providers. Yes. It is all a good point because oftentimes it may not be through a health app or a wearable but is

just sometimes other clinical information that needs to be uploaded for ease-ability for the providers to see and for the patients to communicate. Thank you for all of those recommendations.

Steven (Ike) Eichner
At some point we will have the better pill container technology to do all our reporting for medication compliance. That is testing in different phases of development today. It is not wearable. It is not an app.

Medell Briggs-Malonson
Correct.

Steven (Ike) Eichner
Or pressure monitoring devices, etcetera, because there are lots of things in that space.

Medell Briggs-Malonson
Great. Thank you, Ike. Any other comments on this topic? Okay. All right. The recommendations? Everyone is okay with this? It says explore opportunities to use PGHD to improve quality measures and evaluate opportunities to further standardize PGHD.

Steven (Ike) Eichner
This is Steve**,** real fast. I think we need to be careful about quality measures in that space because I want to make sure we are careful about putting providers in a space where they might be evaluated on quality measures about patient collected or patient gathered information. I would not want to see providers be responsible for things that are well outside their control. The provider can ask for reporting of blood pressure but they are not in the home with the patient to actually do it and send it in in a timely fashion. I want to be careful that we are not putting an undue burden that would prevent folks from actually using it and being encouraged to participate, if that makes any sense.

Medell Briggs-Malonson
It does. It does, Ike. That is why I brought this up, to make sure we are bringing attention to these two recommended HITAC activities. While it is fantastic to a certain extent, it is a slippery slope if all of a sudden the physicians and the providers are requiring or are going to lean on patient generated health data in order to hit various different quality measures because that is putting more burden back on the patient. I do agree that we have to be very careful about that language, which is why I wanted to bring attention to that. I have additional comments but, Hannah, first I want to get to your comments.

Hannah Galvin
The only other thing, and I am not sure it belongs here. I think we talk about equity and also making the infrastructure, high bandwidth internet available for everyone elsewhere, but I do want to highlight that the tools to collect patient generated health data are not available for everyone currently. Those without high bandwidth internet, who do not have access to that Apple Watch, etcetera, or who are provided devices but do not have the internet capabilities to upload data from those devices, do not have that access right now. I agree with the last comment about not creating quality measures around this because there are still inequities in this space. I do not know if this is the right place to comment on that, to further equitable care and infrastructure, tools needed, and to incentivize these tools for everyone, or if we should handle that elsewhere. I did want to put that out.

Medell Briggs-Malonson
Hannah, you took one of the thoughts that I also had. I think it does need to be here. You bring up those really important pieces because we know it is not accessible to everyone. It is also not accessible due to not one true access. I also think the overall digital literacy sometimes causes additional barriers. I mean, patient portals are still

incredibly confusing. Many of these different devices are still incredibly confusing on how to actually…let alone upload to a system. I think that is an additional opportunity to explore what some of the various different accessibility can be for various different patients, based off of not only true physical accessibility and economic accessibility but also digital literacy of these different items so that the playing field is where it should be in terms of bringing this data into EHRs.

I 100% agree with you and that is one of the reasons why, even for quality measures, that was striking to me that I think we do need to change it. Because if anything, the data collected should help to align with quality measures for the purpose of physicians to think, but we cannot just say that PGHD to improve quality measures because not everybody has the ability to actually submit PGHD and it still places a significant burden on the patients themselves if they are going to be used for quality measures. I do not have the right words but I am with you 100%, Hannah. We need to explore the opportunities to make PGHD more accessible in various different domains so that it is equitable in terms of access and utilization. That is still a huge challenge and a huge opportunity for us. Then, that would actually help, I think, with having a more comprehensive picture of our patients, especially our most vulnerable patient populations. Thank you for that comment.

Hannah Galvin
Absolutely. I can try to put some language in here around that.

Medell Briggs-Malonson
Thank you. Love it. All right. Any other comments on this topic.? Thank you, Rochelle, for the comments there. All right. Hopefully, one of these times we are going to move away from broadband and focus on Wireless Fidelity (Wi-Fi) in general as well. We still need to improve our infrastructures nationwide. Next one is looking at reducing patient burden. Patients continue to face issues in obtaining and using their health information to manage their healthcare. The lack of interoperability between healthcare providers increases patients' workload. Health IT needs to be developed in a more patient centric way, considering the best way for patients to both receive data and participate in their own healthcare. Patients have to spend significant time and effort to coordinate their care across healthcare providers.

Opportunities are to create health IT that is more accessible and inclusive for the patient considering help in digital literacy, multiple languages, and optimal modes of data transport. Consider patient burden implications like in setting priorities for the use of health IT and related to standards to advance efforts that ease burden for patients in managing their health data. The proposed recommendations that we have so far is convene patient advocates and other interested parties to identify use cases and health IT solutions that can advance efforts that ease burden for patients in managing their health data. Request ASTP to consider patient perspectives and impact on reducing patient burden as part of HITAC changes and hearings. Excellent. Thank you so much. We have Ike who has his hand up. Ike, what are your thoughts about this?

Steven (Ike) Eichner
Thank you. I have been spending a lot of time thinking about this particular issue in the last couple of weeks. I think there is one piece to expand on the patient access problem. It is not only access to patient data for particular providers. It is consolidated access to patient information, that I have to go back to every provider, often, and go into their patient portal and extract the information or get the information and then consolidate it on my own. Providers are able to take advantage of Hies and the like to collect the information about me from other healthcare providers. I should be able to do the exact same thing through whatever portal I am using. We need to make sure that we are looking at making recommendations that include that kind of functionality. Going one step further, TEFCA includes, as a part of its base standard, individual access services that are really intended to facilitate individual access to their data.

There is not currently a requirement that every QHINs supports IIS. I think that is something the change between TEFCA agreement version one and version two, but that is still a door that can be leveraged in that space to be able to serve as a gateway to make that access. If you were to change the requirements of certification criterion for EHRs to then utilize those individual access services across TEFCA, it becomes a pretty good chain to at least provide the technical infrastructure to support that integral access across providers and across jurisdictions.

Medell Briggs-Malonson
Wonderful. Thank you for that. If you were to summarize that, Ike, into a thought for a recommended HITAC activity, what are your thoughts about that?

Steven (Ike) Eichner
I think a recommendation is fluency to explore leveraging the TEFCA framework to support individual access services and include, as EHR certification criterion for patient access services, to support the integration of data for multiple providers.

Medell Briggs-Malonson
Thank you for that, Ike. You are absolutely right, even when you said that comment. A lot of the EHRs say, "Please, we want to share all of your different data," but it is oftentimes not standard at all times that all data that you generated throughout various different health systems are pushed back to the patient. I think that is an important piece as we think about reducing patient burden. Thank you for that comment. While we are waiting for more people, if anybody else has any additional items. Even, Hannah, what you were just referring to and what we were just discussing, it is kind of quasi in here but not fully in this topic. I still think that redundancy or repetitiveness is always important for really reinforcing certain ideals and principles but it does nicely dovetail off of reducing patient burden as well. Any other thoughts or comments about reducing patient burden? Yes, Eliel.

Eliel Oliveira
I was just going to highlight here that, just like in the other topics, there is so much here to be done. I completely agree with Ike, on patient portals are still very difficult to manage because they are different with different features, different groups, logins, and whatnot. How do we prioritize advancements here? I think the opportunity, that box has a couple of things that I think are very important. One is language support. If you cannot even understand what language the portal is in, you cannot even get started, right? That could be easily addressed but meanwhile technologies do have to be supportive. The other is literacy as well. How to simplify processes to just get there. Anyway, I think there is an opportunity also to maybe devise a plan on prioritization of what these advancements are to the low hanging fruit ones that can make a big impact to the ones that can be a lot more complicated, like enforcement activities and so on.

Medell Briggs-Malonson
Absolutely.

Seth Pazinski
Eliel, I just wanted to jump in here. Your audio is a little bit hard to hear. It is coming through okay but I do not know if you could maybe switch to a phone or something, if you have the ability to do so?

Eliel Oliveira
I will fix it.

Seth Pazinski
All right. Thanks.

Medell Briggs-Malonson
Thank you, Seth. Thank you, Eliel, for those comments. Yes. We clearly have all of those various different criteria listed as an opportunity but what is the proposed approach in order to address all of those different items. Yes. Really all great points that you bring up, Eliel, in every way. It may even go and coordinate nicely with the recommendation number two, which I do not think that we have done this much. This is the first time, I believe, that in our Annual Report Workgroup we have specifically said we need to gather some of the patient perspectives and really think about what they feel is adding burden. Right now, I will not say that we are in an echo chamber.

We are huge advocates for this but we also know that all of our patients have different perspectives and thinking about bringing together a patient focus group or a patient advisory group in order to help us with thinking through and really helping to provide advice to ASTP in terms of the patient burden and what can potentially be done to help alleviate that and where some of these various different criteria fall into play. All really good points there. Any other items or thoughts about this topic? Yes, Ike. I see your hand.

Steven (Ike) Eichner
I think patient perspective is important. I also think it is important that we recognize that the patients participating in any group need to be diverse and include complex patients as well as simple patients. Someone who is only going to see a PCP once a year, or once every couple of years, for an annual checkup has their experience and they may not need much more data than what their PCP is getting plus couple of lab results versus a more complex patient that is seeing multiple caregivers a week, a month, etcetera. I think it is important that we recognize that there are both generalists and specialists, if you will, from the patient end of it and the diversity of needs really needs to be addressed. I am not sure if it is the lowest common stakeholder or the lowest common denominator but there needs to be a good balance so that folks with more complex situations are benefiting as well and it is not just taking care of 80% of the people by count. We really need to think about the complexity of time.

Medell Briggs-Malonson
A hundred percent. The patients that are providing input need to be diverse on all levels, in multiple different ways. Your point is very well taken. Especially in terms of complexity, the types of conditions, demographics, regions of the country. I mean, diversity in all regards. Thank you for amplifying that. Okay, any other thoughts? If not, we are going to move on to the next topic. The next topic is impact on patients by use of artificial intelligence (AI) in health and healthcare. This is directly along the lines of patients access to information. I believe we just moved this one down here because we are specifically focused on patients. AI data models used for algorithms of predictive analytics may not be representative of diverse populations nor of high quality data raising the risk of harm to patients. Implementation of AI in health and healthcare should be done appropriately, inclusively, and with caution to prevent harm to patients.

The opportunity is to ensure the quality, relevance, safety, and usability of AI data models and algorithms with a proposed recommended activities to coordinate and strategize with ASTP on a framework for AI use in healthcare and other purposes that address patients' concerns and integrate patients' perspectives. Any thoughts on this? Yes, Ike?

Steven (Ike) Eichner
I was making sure other folks have a chance to comment as well. I think it is important that any time a healthcare provider is using AI with a patient, or to help guide choices about a patient's medical care, that there be information provided to the provider about whether there is anything about the particular patient's profile that was not included in the patient population used to generate the AI model. For example, if patient has a rare disease and there was no one with that rare disease included in the analysis that should be a flag to the provider and to the patient that says, "Hey, this model did not include someone reflecting your significant population reflecting your condition so it might not be a perfect model for you."

We are not making assumptions that the model shows that it is a great thing and here you go. Just in the same context we are looking at clinical trials that say we have tried this and are no guarantees but in that same kind of space. Not that we are trying to disrupt the trust of AI but make sure that folks are informed about where it came from.

Medell Briggs-Malonson
Great. Thank you, Ike. You are absolutely right. That is part of the transparency that we are trying to move with all AI, Decision Support Interventions (DSI), and all other types of algorithms such as this. It is clear who was in those models and, who the models were tested on, the outcome those models, and who it was not because that information has to be face up for both providers and patients. Thank you. Michelle --

Steven (Ike) Eichner
Sorry. I just want to add real fast. Payers as well so that we have good clarity there and the patient with a rare condition is not then having to go through a battle with a payer about the AI recommending this as the standard of care when it does not apply because you have a medical exception.

Medell Briggs-Malonson
Absolutely. I hope AI never becomes the standard of care anytime soon. I hope that is still us creating the standard of care but all of your points are well taken.

Steven (Ike) Eichner
Also, it is not AI that is the standard of care. It is a recommendation made by AI as the standard of care, that this is the path you should go and it is easy to envision where that becomes a realistic model about decision-making and we do not need to see that present additional challenges and additional time delays because suddenly you have a rare condition and you have to go through and get another medical appeal because the thing that AI recommends does not work because --

Medell Briggs-Malonson
Yes. That brings us to other different safeguards of AI and those recommendations. All good points. There are a couple of others that I want to get their comments. Rochelle, thank you. You are saying, “Please add the word data between quality and rising.” I think in general we do want to talk about the data quality of it, so we may need to tweak some of those words there. Thank you for that recommendation. Jim, I see your hand as well.

Jim Jirjis
Thank you. Can you hear me?

Medell Briggs-Malonson
We can.

Jim Jirjis
To Ike's point, I want to make a clarification. Some of these AI algorithms, are you suggesting that there be a requirement that in an automated way the electronic medical record (EMR) indicate what aspects of the patient were not part of the population that the model was trained on? The only reason I ask that is there will be some aspects of the patient that are contained within a dataset where that might be feasible but there may be situations where there is information about the patient that is not yet in a data standard, a United States Core Data for Interoperability (USCDI), or whatever. I was just curious. I think we all agree that sharing the aspects of the population that the data was trained on where possible is key for the provider but it sounded like you were saying

then also the requirement being that it key up for the doc aspects of the patient that makes them different. That may be a step too far right now is my only point.

Medell Briggs-Malonson
I think that is a good point, Jim. There have been serious discussions around that. If you do have a data model that is not representative of various different populations, we can even keep it high level saying it does not include any pediatric patients but the model has only been used on adults. There have been serious discussions that that needs to be identified and especially if these are various different models being incorporated into other forms of certified health IT or being used or scaled a wide scale. That is the thought because we know that a lot of our models still are not fully representative. Plus, if you are training and using these models you want to know as much as possible who is in that dataset for transparency because this really does go along with our ethical and just uses of all of those items.

To your point, how can we find exactly who is in those models when sometimes even demographics may not have been part of that initial dataset? I think that is an area we have to pay attention to because this is so incredibly important as we continue to incorporate AI, DSI, and all these other items into our workflows.

Jim Jirjis
No one disagrees about the problem and the notion that that needs to be clear to people. I was just saying if we are recommending making a requirement that the EHR tools, for example, have decision support that actually indicates the ways in which a patient may not match with the population. I am not sure we are ready to say that…to me it seems there is more exploration. It would be great to have a place like that where I as a doctor was notified of all the ways in which the patient may not match the population trained on. I do not know that we are ready from a feasibility standpoint to require that in EMRs, given the breadth of data elements that are used in these studies, in these trainings. That was my only point. Not that none of us believe it is important. It is very important. Just the feasibility in 2024 of expecting all the EMRs to do that was what I was commenting on.

Medell Briggs-Malonson
Absolutely. I think Health Data, Technology, and Interoperability: Certification Program Updates, Algorithm Transparency, and Information Sharing (HTI-1) Final Rule was leaning towards that transparency with all the nutritional labels so we can actually see how the vendors themselves have created some of these different tools.

Jim Jirjis
That is not what I am saying. That just says publish on a baseball card or whatever those aspects of the algorithm. It did not go further to say, “And the EMR must provide decision support on that specific patient to identify where they may or may not match.” It landed with a nice human, consumable set of information about the algorithm but it did not go further than that to require…the decision support literature for important patient safety issues and EMRs have been challenging for Clinical Decision Support (CDS). I am saying we have to be cautious about the next step and make sure we know the scope.

Medell Briggs-Malonson
Of what can be executed. Thank you, Jim. I appreciate that. Hans, you are up.

Hans Buitendijk
Thank you. A couple of comments in part building on Jim’s comments. Generally, I think in this discussion I think it is important not to hone specifically too much on the EHRs but on the HIT. There will be scenarios where the EHR is using another AI capability as a service of sorts and it only provides access to that. It has no clue otherwise. Other parts are that the EHR, on the other side of the spectrum, does include the actual AI capabilities and develops them and has more information about it. I think we need to be very cautious also about the ecosystem

that is going evolve. How much is truly inside of the EHR and how much is going to be actually done outside from either a learning perspective or interactive capabilities where you submit some data outside and it figures something out.

I think there is a lot going on there that we do not know. I think leveling it up to HIT, having general statements on needing to explore this, and tying that into what Jim is indicating on how far we can take a step. I am not looking at, I think, for the report that it would make specific recommendations but it can address that we need to explore not only what data needs to be available on what is used but to the extent possible to what is not used. If we keep that at the high level but not as a requirement of is it the EHR or is it the AI source and training information that is available. In this context of patient access to information the key then seems to be how the patient can get access to that kind of data so they themselves can also be educated and aware of how it applies or not.

I think it is overall on the side of not only what is not used and how you can find out but it will also be hard to figure out what is used. HTI-1 is providing requirements about transparency on the tools that are used, particularly if they are developed by the party. It gets much more problematic if it is not a party that you used, you did not develop it. How can we do that? How can we get those labels? Even in that space, how far can you go in understanding exactly what was used that can help you understand what was not used. I think overall it is a challenging area that we need to explore more and that seems to be more the emphasis for the report than indicating that we are ready to say that any HIT is ready to do a X, Y, or Z. We still need to learn which one is the best place to do that. Is it the EHR with the provider? Is it something that the patient has as an app? Is it the original source? Where do we best provide that capability?

Medell Briggs-Malonson
Thank you for that, Hans. This topic in particular, to your point and to Jim's point, really focuses on patients and the impact directly on patient use and their access to the information. If the various different AI tools, or decision support tools, or whatever that may be was used in their care or available. To your point, this may be more of an exploration of how we ensure that patients are aware and what does that look like and what is that information that is communicated to them as well. It is a special dance between not only our EHR vendors but also our Health IT and how that information is displayed, not only for providers but also patients, and how that truly gets to patients in an appropriate way. It seems like we are all in this exploration point but trying to get it to a point where patients are aware of what is being utilized in their care or not. Thank you for that. Eliel.

Eliel Oliveira
Thanks, Medell. I think we all agree there is a lot of excitement around AI, and fear as well. I think the genie is out of the bottle and there is no putting the genie back in. I think there is a lot of potential, but at the same time I feel like it is a Wild West, where I do not know if anyone would be able to point out exactly today what solution is out there that is reaching our providers and patients and influencing care in one way or the other. I think we cannot necessarily stop progress because there is a lot of opportunity here. At the same time, regulation for anything related to AI is probably going to take a bit of time. I think that maybe one proposed recommendation here to maybe consider policies that would require at least a registry of these tools that in one way the other are being utilized for patient care.

Again, we do not know what the repercussions would be, positive or negative, but if we do not even know they exist it becomes hard to track down in the future when we do have regulations what caused the problem or not for individuals. I think this is the equivalent. I will try to make a comparison here of drug development. Every drug that needs to be developed goes through a process of at least being identified and approved to go to market. Even then, we still find issues later on with drugs that need to be taken out. We do not have anything here that requires vendors that are all over the place to say that they built something and they are going to register it so at least it is

updated and everybody knows that these do exist. Whether we can regulate now or not, that might be something to be done later.

Somehow, we just need a registry of the tools and AIs that are being applied in healthcare that ultimately can affect someone's life. To me, that would be step one in the process of regulating and maintaining some control around AI.

Medell Briggs-Malonson
All right. Thank you. All wonderful insights, Eliel. Jim.

Jim Jirjis
Hey, there. One question I had is that sometimes when we talk about AI we talk about it is as if it has had a deliberate training model. Then, just when we were doing HTI-1 and talking about exposing all of those parameters on a baseball card, if you will, large language models suddenly arose. Large language models, almost by their nature, you do not necessarily have answers to a lot of those questions. How do we address the uniqueness of large language models that may almost categorically not be able to provide some of the information we are saying needs to be exposed?

Medell Briggs-Malonson
Jim, that is a really good question. I think that with this topic, it is interesting that we said specifically in health and healthcare. Healthcare, for instance, in my mind, thinking about the provision of healthcare services or public health services, while health is really more global and universal of all the various different factors we know contribute to one's overall health and wellbeing, which may not be direct healthcare services that are being administered but can be more in the lines of patient engagement, patient education, all of the various different social factors that we know contribute to health, too. I think you bring up a really good point. If you look at the language that we currently have, it seems like it is more slanted towards healthcare services but yet the topic itself is focused on health. You are right. Large language models, as we all know, are really rising quickly and especially to provide triage advice, or general health advice, or whatever that may be.

I do not know if we have captured it right now in this topic. That is something that we should think of and maybe that is part of exploring also how, exactly as you said, large language models come into play, especially as we are advocating for greater health and wellness. If there are some other aspects that need to be there when it comes to patient access because there is no way we can say where all of that information is being gathered. We would be asking what the source is. The sources are going to be very nebulous at times. All I am going to say is just great point. Any other thoughts about Jim's comment or this topic? We can talk for days on AI and on all of these other aspects of it.

Okay. All right, everyone. Thank you. I think we are done with the crosswalk. Let us keep on going. Yes, we are done with the crosswalk. Congratulations, everyone. This is not final but I do want to say a wonderful congratulations to the workgroup. We are done with the crosswalk. We will still be able to go back and refine and we are going to go back and prioritize in terms of the tiers. I do want to thank all of you for providing your thoughts, comments, revisions, of getting through all of these very important and critical topics. Kudos to the entire workgroup on accomplishing this task.

Now, I will turn it over to Eliel. We are going to keep this conversation of artificial intelligence going because, as we can all see, AI and data quality have been the primary threads we are seeing in multiple different areas of our target areas and our topics. Michelle and team put together a wonderful summary of AI in our crosswalk and thinking about it for the Annual Report. Eliel, I will turn it over to you to lead the rest of the discussion.

Eliel Oliveira
Thanks, Medell. We are finally here at this stage where we got close to completing the whole crosswalk but this is such an important topic, as you all know, that is crosscutting across everything that we just went through with the crosswalk that would be important for us to discuss what to do in terms of the use of artificial intelligence in healthcare. We had this topic covered and I will cover it briefly here and would love to hear your comments. AI holds significant promise in solving healthcare challenges, yet research and regulations are necessary to ensure AI is implemented in a safe and unbiased way. Various AI governance, standards, and approaches are being developed but there is a lack of evidence regarding which approaches are best suited to different use cases.

The challenge that we have that AI furthers inequities and bias is a significant concern that must be balanced with the potential benefits as policymakers consider regulating AI. Problems with data quality, representation, inclusion, and usability can contribute to inequities, bias, and safety issues. Finally, in other challenges, there is a need for technical assistance and training to equip clinicians and IT leaders across settings to appropriately use AI in compliance with existing laws, including the Americans with Disabilities Act and tribal laws.

We do have an opportunity to explore how novel data governance approaches, including standards and data guidelines, could be used to improve AI data quality, representation, inclusion, and usability in EHRs and other health technology, and determine which AI governance standards in approaching health and healthcare are best suited to specific use cases. We listed a few proposed recommendations here, activities going forward, which would be explore steps ASTP could take in collaboration with other agencies to establish criteria for what constitutes data quality related to AI models, including both inputs and outputs. This effort should consider the usability and relevance to outputs at the individual, personal level across a spectrum of diverse populations.

Another recommendation is to explore steps ASTP could take to establish additional AI governance standards, including appropriate and ethical uses of AI in healthcare, more ways to leverage industry developed approaches. Finally, explore steps ASTP and other agencies could take to develop evidence generation in support of AI product lifestyle management approaches for different types of AI systems in varying contexts to mitigate bias and inequities. There is quite a bit here. Again, very encompassing across all the things that we covered. I left a comment in the chat here related to this specifically. Where do we even start? We want to make sure that advancements are made in AI in healthcare at the same time all the risks that are related are listed here. With that said, I see, Rochelle, you have your hand up. Any comments or thoughts?

Rochelle Prosser
I think you had just finished off my prior thought as I was typing to say as individuals, as people, as humans, there are limitations for what we can and cannot do. As machine learning or AI develops up and actually takes over teaching and educating itself, the things we would say, “Oh, this is bias,” and we would remove this to the back of our brains, it is not taught that. It would automatically bring these things forward. That is the concern that I have here. Who is training the trainer when the trainer takes over training themselves? As we start to think about as the machine learning, the words context because certain wording or pairings can actually cause disparities between different individual populations or even in the semantics of how we speak. That is the thought that I was thinking. We cannot hold the words or judge the words but we can be mindful in the pairings and groupings and in the context of the words because it is being very lateral, very literal, in what those word groupings are where we, as human beings, can infer, “Hey, let us not go down this road.”

Jim Jirjis
Can you give us examples of what you mean by wording, word pairings?

Rochelle Prosser

Sure. There are two models right now that were released by the National Institute of Health. The first one was in looking at mental health and the differences in word choices that are used between the African American population and the white population in terms of, "I need help," and how they would phrase their words of how they would need help. Depending on the word choices that were used, it would either end with the police being called or someone being shot and unfortunately expired, or it would be an ambulance was called and they would be taken to the appropriate care at a hospital, etcetera. It is simply because of the words that people use culturally in how they explain that they need help.

The second one is in the lung cancer population. Many models were there to predict just looking at the x-ray. All patient PHI was removed but the AI was able to determine the race of the individual presented on the screen even though all demographics, all patient information, including in the metadata, was removed. The AI model had taught itself to determine whether it was an African American, Hispanic American, a white American, etcetera. This is where the machine learning could actually take over learning inferences and we cannot yet determine. It actually generated language that would be punitive. I will hand it over to Medell.

Medell Briggs-Malonson
Rochelle, you are absolutely right. Those of us that are deep within the intersectionality between artifactual intelligence and health equity and justice are really laser focused on these areas where natural language processing, machine learning, all the deep neural connections, all of the various different forms of AI, can not only cause great rewards but also cause great harm. I think that is one of the reasons why…and I was trying to see if it is in here. One of the areas that still needs to be defined and gone deeper into is actually how we train the models to be smart, to be equitable, to really understand where there is already, for instance, systematic biases or institutional biases or practice biases and be aware of those biases so it can be even smarter than humans. Most of the time humans do not pick up the bias that is within all of these various different models as well as even the outcomes.

There does still need to be a large amount of evolution of this work because we have countless numbers of cases where we have clearly identified biased practices that have resulted from the AI but because we know what the AI is doing and why they are doing it, and we are smart enough as humans to understand those nuances, I strongly believe that there is that opportunity to train AI to be more ethical, more equitable, and more just than even humans. We have to add those additional layers on top of it so it still takes the humans driving the training of the models and the models can then take those good trainings and replicate them thousands and millions of times over so hopefully at some point **[inaudible] [01:11:44]** a place where we are not having any forms of biased practices within them.

I think there are some other elements within what we mentioned that meet on this. One of the exercises of what we were trying to do with looking at the AI and all the topics was to go through for the workgroup to see where AI is in each one of the topics and how it all comes together because there were some comments when we first presented it to the full HITAC committee of why is AI in all of these different areas instead of being its own standalone section? I think what we have been trying to do now is show where AI is throughout all of the Annual Report.

Eliel Oliveira
Thank you, Medell. Thank you for those comments. I could not agree more that, as an immigrant, what is appropriate where I come from in Brazil is not necessarily appropriate in many other settings. I learned that the hard way, of course. I think that is also related to what you were saying, Rochelle. I think that we have an opportunity here to actually advance things because that type of communication issue has been around. AI, like Medell is saying, could actually be the differential to address those types of challenges. Rochelle, I see that you have another comment or two.

Rochelle Prosser
Yes. This is the last one. Even in looking between different academic centers, how we speak regionally in California is not how we speak in Boston is not how we speak in the South. In those training models, even though we may put the most advanced guardrails and proper processing, it will work in the region that we reside in but if you take it out of that region and use it in another facility or another area it will break and it will bring in disparities or untoward results that are unexpected. We want to consider that as we go forward and look at the language and the landscape for AI to make sure we incorporate the different regions across the United States.

Eliel Oliveira
Exactly. Great point. That level of granularity would be relevant. Other thoughts or questions here? That is right, Jim. Bless your heart, by the way. Other thoughts or comments?

Jim Jirjis
When I moved to the South I thought I had the most blessed heart until someone told me what they were really saying.

Medell Briggs-Malonson
I was going to say I never knew there was a difference between the South and the North because bless your heart tends to be…I thought that was universal.

Eliel Oliveira
Thoughts or questions? I think one thing we are extracting out of this discussion is that AI is probably coming to our Annual Reporting to stay. in a much larger way probably across all of the themes.

Jim Jirjis
Can I ask one quick question? This is a very stimulating conversation about diversity, equity, and unintended consequences. You pointed out earlier that even humans do not notice it. What is the Gold Standard by which algorithms are judged to not be exclusive or biased, etcetera? Is there something there we can point to? Even humans reviewing it sounds like are flawed.

Medell Briggs-Malonson
This is an area near and dear to my heart, which is what I really focus on in terms of even a large amount of my work. The truth of the matter, as you said and as I mentioned, humans do not understand or oftentimes see when there is bias applications of the various different AI tools or the outcomes. One of the things we have to do is various different simulation and testing of all these models throughout the entire data or algorithm cycle. Number one, with the initial creation of them, assessing the population as much as possible of who that data in which that model is actually utilizing. Rochelle, you bring up a good point. It is also regionally because one model may work in a rural area that has a various different composition but it will not work on someone else.

Ike always brings up the whole item, which is important, about those with rare conditions. That is also various different items that are important. You have to be intentional from the very beginning of having as much as possible a representative model to begin with but after the tools are developed, even after they are deployed, even in the test case, really looking at if there is any variations in outcomes that are unintended. Looking at it from a demographic standpoint, from a medical condition standpoint, or even from a regional standpoint. Then, when it scales up and gets into the real world, that is why it is also important to have checks and balances on how that tool is performing and is it once again performing as expected or not. Are there various different populations that are being more vulnerable or impacted negatively than what is anticipated?

It has to do with the structures and guidelines and we still do not have a definitive source of saying to the developers, “You have to do this.” Even for the providers saying that they have to check this. The thing at least, when it comes to healthcare systems and providers, we know at least that the Office of Civil Rights has clearly stated that if your models, if your technology, is performing in a discriminatory manner that is your responsibility. It is your responsibility to be aware and to correct that. That is going on right now.

Jim Jirjis
Yes. Basically, it is still human review. It is a process but the best we can do is human review and we learn over time how to make sure we do not have blind spots is what I am hearing. There is no Gold Standard to correct human review. It is just being mindful of it and having processes where at each step we are following a process and we are looking for certain differences that might indicate that we need to adjust the training. Is that right?

Medell Briggs-Malonson
That is exactly it. However, I am an optimist. I think we can train other types of AI to do this review. You actually have models that are going to go through the industry, the ecosystem, the organization. Because so much of this is based off of statistics and data and looking at variation and outcomes, which is what we tend to do in quality and research and these other areas, I still strongly feel that we can develop new technology to assess for underlying bias. However, that technology has to be trained by experts on how to assess for negative outcomes or unintended consequences. While right now it has to be human review, I think we as humans can train the next generation of technology to be aware of any unjust or biased outcomes and then help to course correct it. Yes, good robots. **[Inaudible - crosstalk] [01:20:05]** Yes.

Eliel Oliveira
Love the robots comment.

Jim Jirjis
The reason I am asking these questions is if we are still at the humans level then do we want to recommend, or are there already in place, trainings, certifications etcetera, so that the humans that are in positions to actually do this process are trained instead of it just being random? My guess is there are a certain set of dos and do nots that can lead to a certification so that if I am developing an app I am not just randomly relying on somebody to make sure it is not biased. Instead, I have somebody who is certified in AI algorithm and bias or something. Is there an opportunity there?

Medell Briggs-Malonson
I think that is a fantastic opportunity. We have to do it. Our technologies cannot cause harm and there are many different points. Yes. We have not gotten there yet.

Jim Jirjis
I mean, should be recommend it? Should we recommend it in our Annual Report?

Medell Briggs-Malonson
I think we should recommend it. Yes.

Jim Jirjis
That might be nice to add.

Medell Briggs-Malonson
I 100% support it.

Jim Jirjis
Then it builds a community and a tome of knowledge that is centralized. As we learn more best practices as they evolve it could be worked into that certification. Then good people who want to make sure that their algorithms are not biased have a reasonable chance of being successful because we have reduced information asymmetry about who they ought to work with. Right?

Medell Briggs-Malonson
Absolutely. I definitely support adding that as a recommendation.

Eliel Oliveira
Those are good thoughts. I see, Hans, you have your hand up. We only have a couple of minutes left.

Hans Buitendijk
I believe from one of the last comments, the emphasis on the learning system is important. If we are talking about how we have challenges with human beings and challenges with AI then there will be challenges with the AI reviewing the AI. I think that is an ongoing cycle that we are in, no matter where we look at where we are looking at, that maintaining a learning system that we can figure this out and there are components where human beings are clearly involved and we have abilities for technology to help out. Any technology in the end has been trained in some fashion or predisposed in some fashion. I think we need to constantly keep that in mind, that this is a learning environment as we figure these things out and move forward.

Eliel Oliveira
Thank you, Hans. Great thoughts. I agree. I think, like I was saying earlier, it is a topic that is going to be here in our Annual Report Workgroup for a while. Lots of challenges to address but at the same time so much opportunity, right? I can see that good robots can be unchecked but at the same time I have hope that maybe at some point we have such a personable AI that can do better than what we do. As with situations with anyone, we can only dream about that. I think we have **[inaudible - crosstalk] [01:23:32]** --

Jim Jirjis
The only problem is, even with large language models, they are largely training on content that inherently has our biases.

Eliel Oliveira
Right. Correct. That is a problem itself. We do have to go on to public comment now. I will turn back to Seth for that.

Seth Pazinski
Thank you, Eliel. We are going to open up the meeting for public comment. If you are participating on Zoom today, you can use the raise hand function, which is located in your Zoom toolbar at the bottom of your screen. If you are participating by phone only, you can press star nine to raise your hand and then press star six to mute and unmute your line. While we give folks a few seconds to raise their hands for public comments, just a reminder our next Annual Report Workgroup meeting is scheduled for September 9, from 12:00 to 1:30 p.m. Eastern time. I am not seeing any hands raised in the Zoom and we do not have any comments on the phone at this time so I will turn it back to Medell and Eliel to close us out.

Medell Briggs-Malonson
Excellent. Thank you so much, Seth, and thank you so much, everyone. We have had a wonderful meeting again, as always. Once again, congratulations on finishing the crosswalk. When we reconvene, we are going to go back through the crosswalk one last time in order to do small revisions and think about priorities and then we will move

forward to talk about the draft of the report itself. We are moving along very nicely. We are incredibly excited about this and I wish everyone a great end of their summer. I look forward to seeing you all in another two weeks. Eliel, I will let you close us out.

Eliel Oliveira
Thank you, everybody. I am happy we got to this stage. There has been a lot that we covered but I think we have done a great job. Thank you, everyone, for contributing. Thank you, Medell, for summarizing next steps. I think we are in good shape and I wish you all the best with the rest of your day. We will see you soon. Thank you.

Questions and Comments Received Via Zoom Webinar Chat

Rochelle Prosser: +1 on Neural data

Jim Jirjis: neural data?

Steven Eichner: There is also a need to use terminology that is understandable to the broadest audience- Let's include a definition of "neural data"??!!

Jim Jirjis: yes what is neural data?

Rochelle Prosser: +1 Ike

Steven Eichner: I think there is also value in reintroducing the idea of what constitutes "sensitive data." What a health care provider considers to be "sensitive data" may differ substantially from a lawyer, other stakeholders, and the person who the data is about.

Rochelle Prosser: Often implantable devices that connect to the Spine or Brain often do not have security enhancements. Like the current device to stop Parkinson disease. I agree we need to define what is the sensitive data and who is in control of it and How/what does those elements of security and patient data look like.

Steven Eichner: +1 Hans, There needs to be some education for all about why sensitive data needs to be shared, and with whom it needs to be shared for what purposes.

Rochelle Prosser: i.e. programmable devices - pacemakers, Ventroperitonial shunts (VP shunts) ets...

Steven Eichner: Power wheelchairs and any other equipment that collects data. If my wheelchair has a GPS in it, who has rights to that data?

Hannah K. Galvin: It is very difficult to define what constitutes "sensitive data" - this is very subjective and can be very broad. The reason ASTP tries to align with definitions previously set forth in other regulations I believe has to do with their scope. There is a lot to be done in this space. Re: terminologies - Shift is working with the National Association of Community Health Centers to define VSAC value sets for some sensitive data, e.g. reproductive health data, BH, SUD, etc. But this cannot be all-encompassing.

Hans Buitendijk: For privacy rules the sensitive data could and should be well defined, while for patient consents that can include many other data as well/instead, agreed that we cannot defined that beyond "anything else". But for advancing management of computable patient consent rules, we may have an

opportunity to have a list, not complete in any manner, of commonly referenced sensitive data beyond those referenced in jurisdictional privacy rules. E.g., while neural data may not be in privacy rules yet, patient consents may already want consider that data. I.e., we should recognize the existence of other data can be recognized without having to enumerate all of them in a way we need to for jurisdictional privacy rules.

Hannah K. Galvin: Hans, I like this - how do we handle those potentially sensitive data not yet handled by regulation.

Rochelle Prosser: +1 Ike

Eliel Oliveira: Great point Hannah!!

Rochelle Prosser: BEAD program for Broadband don't have the healthcare infrastructure available once the Broad band is there. SOuld we not provide or inquire issues where interoperability does not exist?

Rochelle Prosser: Yes!

Rochelle Prosser: +1 IKE

Rochelle Prosser: and if a QHIN fails what happens next when the QHIN is the holder of patient information data?

Rochelle Prosser: So which path would we focus on since there are currently three vehicles for providing better patient interoperability to reduce patient burden? TEFCA, FHIR or QHINS?

Rochelle Prosser: I agree Ike with using the back door between HTI1 and HTI2

Hannah K. Galvin: I have to jump off - I just sent over the crosswalk with my suggested language. Thanks!

Rochelle Prosser: Thank - you Hanna for you excellent responses

Rochelle Prosser: please add the word data between quality, and rising

Steven Eichner: It may not be possible to consider every factor in a patient record. There should be some baseline comparison's, such as age range, race/ethnicity. and others, and grow from there.

Making the model's population information easily and transparently available to patients and their providers is important.

Pamela Swackhamer: Consider as well if AI is not being used to make/steer a provider but just to help a provider dictate the conversation of the patient visit. Does the patient need to know in writing besides giving their verbal consent at the time of the appt

Rochelle Prosser: +1 Pamela

Rochelle Prosser: Often in media where AI generated images are made there is a disclaimer, shoud there be the same in teh AI generated conversation to the patient wher the MD is present?

Rochelle Prosser: Recently inn AI models, for Lung cancer, patient demographic data or patient identification was able to be discerned using the AI tool...we still cannot determine how this is being done. AS we use AI or NLP to assist healthcare Services and patient interaction

Eliel Oliveira: We can't afford to wait until AI models cause harm to maintain some control. Not knowing what providers and patients are using may be the first step to at least know certain AI is in sure even though we may not be able to regulate just yet. Allowing any AI to continued to be used could lead to issues like in the release of VIOXX t the market: https://en.wikipedia.org/wiki/Rofecoxib

Rochelle Prosser: +1 Eliel

Jim Jirjis: Bless your heart means something different on the south than the north!

Rochelle Prosser: yes Jim!

Rochelle Prosser: ohh no it means something completely different.

Rochelle Prosser: Self aware human review...

Jim Jirjis: Good robots. Scanning for bad robots!

Pamela Swackhamer: We currently have the same thing with using "Dragon Naturally Speaking". Humans have to review what it types out.

Rochelle Prosser: I do not think we can ever remove the Humans out of NLP and AI...my thoughts. we are way too diverse to remove the humanity form it.

Hans Buitendijk: Yet those tools are also trained, thus subject to a the challenges that the primary AI has. I.e., we always have to have multiple approaches to continuously addresses any concerns on any bias.

Rochelle Prosser: +1Jim

Medell K. Briggs-Malonson: AI should always be overseen by humans. We cannot allow technology to go unchecked even if it is a good robot.

Rochelle Prosser: It is often not possible to see what is build witin NLP and AI in private companies until it is published.

Questions and Comments Received Via Email

No comments were received via email.

Resources

AR WG Webpage
AR WG - August 26, 2024, Meeting Webpage

Transcript approved by Seth Pazinski, HITAC DFO, on 10/04/24.